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CONTEXTUALISATION OF PHYSIOTHERAPY CLINICAL PRACTICE GUIDELINES FOR HOSPITALISED PREMATURELY BORN INFANTS IN SOUTH AFRICA

BY

PETRONELLA J. VAN DER WALT

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Supervisors

Prof. C.A. Eksteen

Prof. C. Maree

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DECLARATION OF ORIGINALITY

I declare that this thesis titled 'Contextualisation of Physiotherapy Clinical Practice Guidelines for hospitalised prematurely born infants in South Africa', which I hereby submit to the University of Pretoria for the degree PhD (Physiotherapy), is my own work and has not been previously submitted by me for a degree at this or any other tertiary institution.

29 August 2019

SIGNATURE **DATE**

PETRONELLA J. VAN DER WALT

STATEMENT FROM LANGUAGE EDITOR

EDITOR'S STATEMENT

FJ Opper – Translator and Language Editor

6 Birkenhead Avenue
CAPE ST FRANCIS
6312

Tel 042 298 0330 / 082 5326 015

TO WHOM IT MAY CONCERN

Herewith I, FJ OPPER, confirm that I undertook the language editing of Mrs PJ van der Walt's thesis titled:

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20 August 2019

DEDICATED TO:

My husband

Thank you that we can be a team. You are my true inspiration and I love you very much.

My children, Adriaan and Petroné

Thank you for supporting Mommy and believing that I could do this!

My family

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SUMMARY

Background:

The incidence of premature infant births in South Africa (SA) is estimated at 168 000 per year. Current concern is that premature birth may be associated with lower educational achievement, greater need for social grants in adulthood and lower rates of employment due to the increased risk of disability caused by post-birth complications. Physiotherapists working in neonatal intensive care units (NICUs), high care units (HCUs) or kangaroo mother care (KMC) wards have a unique window of opportunity to influence the infants' neuromusculoskeletal systems and motor organisation and monitor respiratory function to decrease the risk of impairment. Physiotherapists working in NICUs, HCUs or KMC wards in high-income countries have well-defined clinical practice guidelines (CPGs) to guide the standard of practice, such guidelines are not available in SA.

Ethical approval to conduct this study was obtained from the Research Ethics Committee of the Faculty of Health Sciences, University of Pretoria (99/2014).

Purpose:

The primary aim of the study was to contextualise a CPG for physiotherapists treating prematurely born infants in NICUs, HCUs or KMC wards.

Methods:

An exploratory sequential mixed methods research approach was followed. Phase 1 was qualitative in nature and consisted of focus group discussions / interviews / online survey with consenting multidisciplinary team (MDT) members and parents or caregivers to gain information on the current patient journeys of prematurely born infants in SA. An integrative literature search was undertaken to identify current CPGs for physiotherapists on the management of prematurely born infants in NICUs, HCUs or KMC wards. Phase 2 entailed the compilation of a questionnaire consisting of the statements identified during the focus group discussions / interviews and recommendations from the identified literature. The statements and recommendations were validated in Phase 3 by using a Delphi method (quantitative research approach)

Results:

In Phase 1, four possible patient journeys for prematurely born infants in SA were identified. Seven CPGs or position statements were identified and critically appraised by three appraisers using the AGREE II instrument. Three CPGs / position statements were found to be valid for inclusion in this study and permission for inclusion was obtained from the authors of the selected CPGs / position statements. A list of evidence-based recommendations (from the literature) and statements derived from the patient journey that were appropriate for the SA health care context were validated by expert physiotherapists working in clinical and/or academic settings in NICUs, HCUs or KMC wards in SA. The statements were included in the contextualised CPG if they were graded 60% (and above) by participants.

Conclusion:

A clinical practice guideline was contextualised for use by physiotherapists working in NICUs, HCUs or KMC wards in SA. It is recommended that future research be undertaken to determine the application of the CPG in physiotherapy practice in SA.

Implication:

The implication is that physiotherapy management of prematurely born infants in NICUs, HCUs and KMC wards in SA could potentially be standardised, and may result in the standardisation of infant care while reducing unwarranted health care cost and outcomes.

Key words:

Prematurely born infants, physiotherapy, clinical practice guidelines, contextualisation

PUBLICATIONS AND PRESENTATIONS IN SUPPORT OF THIS THESIS

The researcher presented a paper titled '*Current patient pathways for prematurely born infants in Gauteng Province: Implications for physiotherapy service providers'* at the 2nd Gauteng Health Early Childhood Intervention (ECI) Conference, held on 4 and 5 September 2017.

- The researcher presented a paper titled '*Patient journeys of prematurely born infants in the public and private health sectors in South Africa*' at the South African Society of Physiotherapy (SASP) Congress held on 15 September 2018.

- The abstract titled *'Contextualisation of physiotherapy clinical practice guidelines for hospitalised prematurely born infants in South Africa'* was accepted for a poster presentation at the World Confederation for Physical Therapy (WCPT) Congress held in May 2019.

- The researcher presented a paper titled 'Contextualisation of physiotherapy clinical practice guidelines for hospitalised prematurely born infants in South Africa' at the University of Pretoria Faculty of Health Sciences' Research day held on 20 August 2019.

- The researcher and her supervisor, Prof Eksteen, are in the process of writing an article titled *'Patient journeys of prematurely born infants in South Africa'*, which will be submitted to the SASP journal for publication.

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LIST OF ABBREVIATIONS AND ACRONYMS

ADHD	attention deficit / hyperactivity disorder
AGREE	Appraisal of Guidelines for Research and Evaluation
AHRQ	Agency for Healthcare Research and Quality
APCP	Association of Paediatric Chartered Physiotherapists
ATVV	auditory tactile visual vestibular
BIIP	Initial Validation of the Behavioral Indicators of Infant Pain
BPD	bronchopulmonary dysplasia
CEOs	chief executive officers
CER	comparative effectiveness research
CP	cerebral palsy
CPD	continuing professional development
CPG	clinical practice guideline
CPR	cardiopulmonary resuscitation
CSF	cerebrospinal fluid
CT	computerised tomography
DECIDE	Developing and Evaluating Communication Strategies to Support Informed Decisions and Practice Based on Evidence
FORM	Formulating Recommendations Matrix
GIN	Guidelines International Network
GMA	General Movement Assessment
GRADE	Grading of Recommendations Assessment, Development and Evaluation
GUIDE-M	Guideline Implementability for Decision Excellence Model
HCU	high care unit
HIV	human immunodeficiency virus
HPA	hypothalamic-pituitary-adrenal
HR	heart rate
iCAHE	International Centre for Allied Health Evidence
ICF	International Classification of Functioning, Disability and Health

ICH	intracranial haemorrhage
ICSI	Institute for Clinical Systems Improvement
ICU	intensive care unit
IHME	Institute for Health Metrics and Evaluation
IOM	Institute of Medicine
IP	internet protocol
IVH	intraventricular haemorrhage
KMC	kangaroo mother care
LBW	low birth weight
MDT	multidisciplinary team
MeSH	medical subject headings
MRI	magnetic resonance imaging
MRSA	Methicillin-resistant staphylococcus aureus
NANI	Neurologic Assessment of the Preterm and Full Term Newborn Infant
NAPI	Neurobehavioral Assessment of the Preterm Infant
NBO	Newborn Behavioral Observations
NCAFS	Nursing Child Assessment Feeding Scale
NDT	neurodevelopmental techniques
NEC	necrotising enterocolitis
NG	nasogastric
NGO	non-governmental organisation
NHI	National Health Insurance
NHMRC	(Australian) National Health and Medical Research Council
NICE	(United Kingdom) National Institute for Health and Clinical Excellence
NICU	neonatal intensive care unit
NIDCAP	Newborn Individualised Developmental Care and Assessment Programme
NIH	National Institutes of Health
NNS	non-nutritive sucking
NOMAS	Neonatal Oral-Motor Assessment Scale
NZGG	New Zealand Guidelines Group

PARM	Philippines Academy of Rehabilitation Medicine
PDA	patent ductus arteriosus
PhD	Doctor of Philosophy
PIPP	Premature Infant Pain Profile
PIBBS	Preterm Infant Breastfeeding Behaviour Scale
PMA	postmenstrual age
PMT	patient management tool
PNICU	paediatric / neonatal intensive care unit
PTSD	posttraumatic stress disorder
PVL	periventricular leukomalacia
RCT	randomised controlled trial
RDS	respiratory distress syndrome
ROP	retinopathy of prematurity
RSV	respiratory syncytial virus
SA	South Africa
SAGE	South African Guidelines Excellence
SASP	South African Society of Physiotherapy
SIDS	sudden infant death syndrome
SIGN	Scottish Intercollegiate Guidelines
TDF	Theoretical Domains Framework
TIMP	Test of Infant Motor Performance
TIMPSI	Test of Infant Motor Performance Screening Items
UK	United Kingdom
UP	University of Pretoria
USA	United States of America
US NGC	United States National Guideline Clearinghouse
VP	ventriculoperitoneal
WCPT	World Confederation for Physical Therapy
WHO	World Health Organization

CLARIFICATION OF CONCEPTS

Prematurely born infant: The World Health Organization (2019) defines prematurely born infants as infants born alive before 37 weeks gestational age and divide this patient population into three sub-categories:

- Extremely preterm (less than 28 weeks gestational age)
- Very preterm (28 to 32 weeks gestational age)
- Moderate to late preterm (32 to 37 weeks gestational age)

In this study, the researcher does not distinguish between the abovementioned three subcategories. The term prematurely born infant is used for any infant born before 37 weeks gestational age and does not include prematurely born infants with congenital defects, any medical condition, or who had undergone surgery to correct congenital defects. The term prematurely born infants, as used in this thesis, refers to 'healthy' infants who might have complications such as cerebral palsy or other neurological conditions due to their premature birth. The term prematurely born infant also includes infants with low birth weight (LBW), but the researcher distinguishes between infants based on their gestational age and not on their weight. Throughout this study the terms prematurely born infant and premature infant will be used to refer to the same patient population.

Clinical practice guidelines (CPGs): 'Clinical practice guidelines are statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options'(Institute of Medicine, 2011:4).

In this study the term clinical practice guidelines (CPGs) refers to the document that contains recommendations for best practice that professionals such as physiotherapists can use to guide their clinical practice during the management of a specific patient population, for example prematurely born infants, as in this study.

Contextualisation: The word context refers to 'the situation within which something exists or happens, and that can help explain it', according to the Cambridge Dictionary (2019).

To contextualise something therefore means that general information about the time when, and the place and situation in which something occurs is provided to promote understanding. In this study the process of contextualisation refers to the process of changing an existing CPG to include the local context in which it will be used / can be implemented.

Patient journeys: The term patient journey refers to the journey of a specific patient within the health care sector.

A patient journey includes all the steps and processes that patients (in this study prematurely born infants and parents / caregivers) go through from the initial contact with the health care provider until eventual discharge from the health care services (Gonzalez-Suarez, Dizon, King, Lorenzo, Valdecanas, Gambito et al., 2012).

In this study a patient journey refers to the period that starts at the moment an infant is born prematurely and comes into contact with health care providers and continues through all the steps the infant and his / her parents or caregivers will follow until discharge from all health care services. The following is an example of such a journey: A prematurely born infant born at a tertiary hospital is first admitted to the Neonatal Intensive Care Unit (NICU), from where he / she is transferred to the High Care Unit (HCU) and eventually to the Kangaroo Mother Care (KMC) ward at the same hospital. After discharge, three-monthly follow-up examinations will be carried out by the multidisciplinary team (MDT) at a clinic. The infant is usually discharged from the clinic at the post-corrected age of two years.

CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

As clinical science developed, the quality of care in neonatal intensive care units (NICUs) and the ability to resuscitate very low birth weight (LBW) and / or prematurely born infants improved and the mortality rate of infants born prematurely (before 37 weeks gestational age) and infants with LBW declined (Pietsch and Isic, 2007). This has led to an increase in the number of prematurely born infants (±25 to 36 weeks gestational age) needing care in NICUs, high care units (HCUs) or kangaroo mother care (KMC) wards. These infants have a higher risk of developing morbidities due to their premature birth (Glass, Costarino, Stayer, Brett, Cladis and Davis, 2015). As members of multidisciplinary teams (MDTs), physiotherapists have an opportunity to reduce these morbidities as they are regarded as specialists in respiratory care, movement and postural control in an infant–family context (Barbosa, 2013; Umphred, 2013). In the NICU or HCU, physiotherapists have a unique window of opportunity to influence the prematurely born infant's musculoskeletal system and motor organisation (Sweeney, Heriza, Blanchard and Dusing, 2010). Morita, Bito, Kurihara and Uchitomi (2005) explain that a clinical practice guideline (CPG) can assist clinicians in their decision-making to adequately and holistically evaluate and treat a patient in order to improve the quality of care and patient outcomes.

In addition to the definition under the heading 'Clarification of concepts', clinical practice guidelines (CPGs) can also be defined as systematically developed statements and recommendations that could assist a practitioner, patient and / or their parents / caregivers in making decisions about the appropriate health care for specific clinical circumstances (Kredo, Bernhardsson, Machingaidze, Young, Louw, Ochodo et al., 2016). The World Confederation for Physical Therapy (WCPT) has prioritised the development and implementation of CPGs in its policy at the international level (Van der Wees, Moore, Powers, Stewart, Nijhuis-van der Sanden and De Bie, 2011) since the physiotherapy profession has rapidly increased its body of knowledge and a CPG will assist therapists to put research into practice.

1.2 BACKGROUND

The World Health Organization (WHO) reports that globally the incidence of premature births is estimated at 15 million infants annually, which is more than one in every 10 infants born (World Health Organization 2019). In the United States of America (USA), the prevalence of premature birth is estimated to have increased by 31% between 1981 and 2005 (Brecht, Shaw, Horwitz and John, 2012). It is estimated that the incidence of premature infant births in South Africa (SA) is about 168 000 per year (Brits, Adriaanse, Rall, Van Biljon, Van der Walt, Wasserman et al., 2015).

According to the Institute for Health Metrics and Evaluation (IHME), neonatal disorders was one of the top three causes of premature deaths in SA in 2017, as shown in Figure 1.1 (The Institute for Health Metrics and Evaluation 2017). The causes of premature death as shown in Figure 1.1 are not applicable to infants and children only, but to the entire South African population.

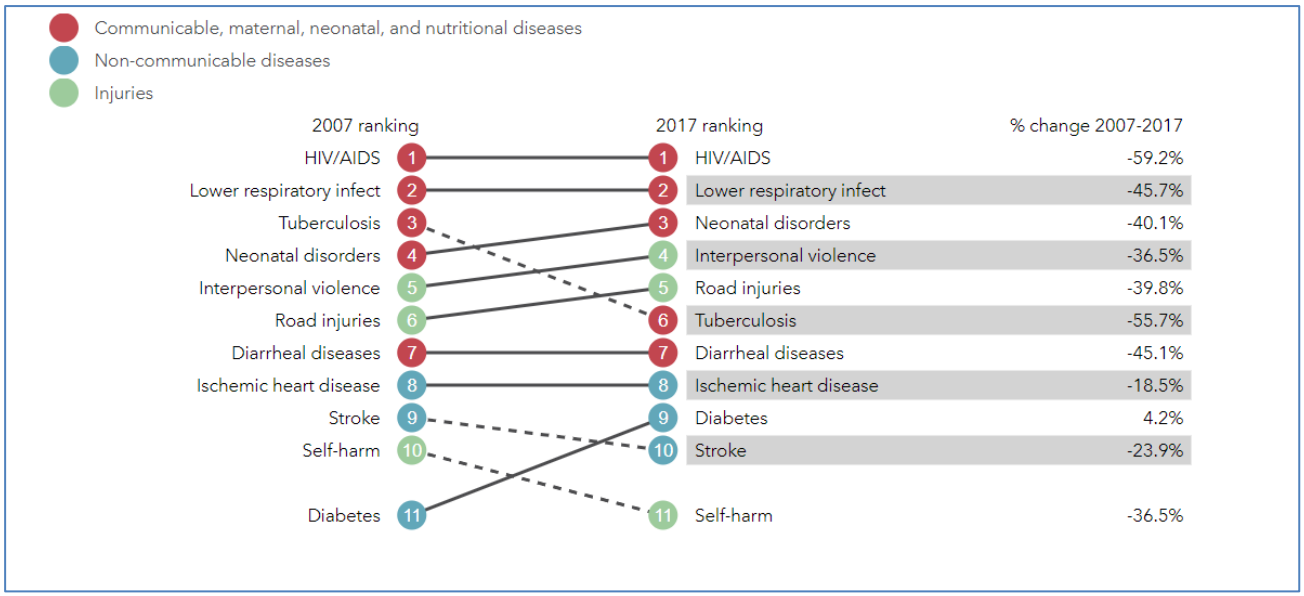


FIGURE 1.1 TOP 10 CAUSES OF PREMATURE DEATH IN SOUTH AFRICA, ACCORDING TO THE IHME (2017)

Causes related specifically to premature birth are discussed in more detail in the literature review (Chapter 2, Section 2.2.1). With regard to the mortality rate among newborn infants, SA ranks 24th out of 184 countries (Mongale, 2012; Pietsch et al., 2007). According to Lloyd and de Witt (2013), neonatal deaths account for approximately 40% of all deaths in children under the age of five years in SA.

The Institute for Health Metrics and Evaluation (2017) also compared the causes of premature death applicable to the entire SA population to other high- and upper-middle-income countries. As can be seen in Figure 1.2, compared to other countries on the list, SA clearly has a very high number of premature deaths due to neonatal disorders.

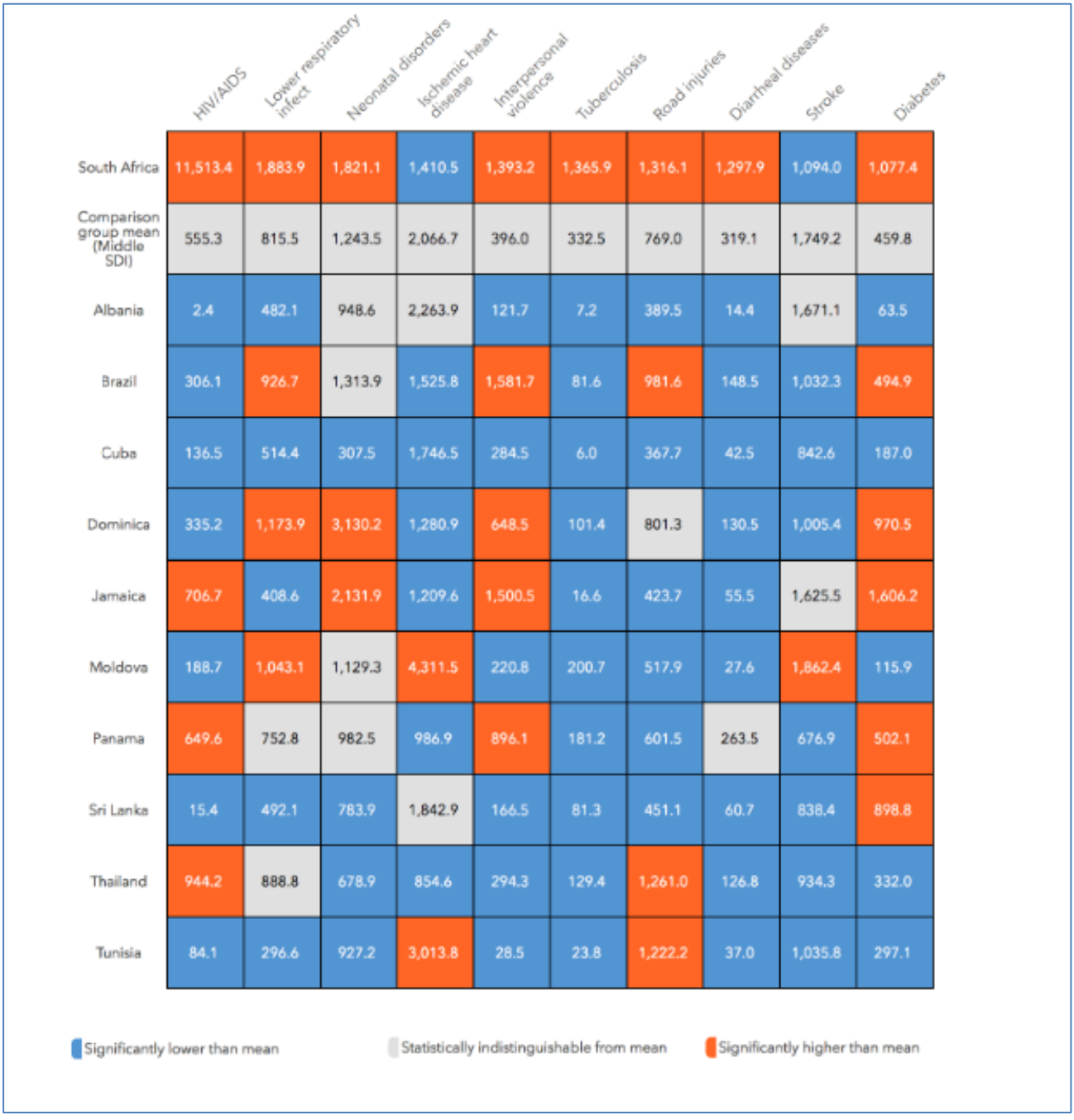


FIGURE 1.2 CAUSES OF PREMATURE DEATH COMPARED TO OTHER HIGH AND UPPER-MIDDLE INCOME COUNTRIES (IHME, 2017)

The World Health Organization (2019) furthermore estimated that approximately 75% of the prematurely born infants that die each year could be saved without high-technology care. Lloyd et al. (2013) discuss some cost-effective interventions that could drastically reduce the number of deaths, especially in resource-limited settings, including resuscitation of the newborn infant, breastfeeding, KMC and prevention of hypothermia.

Prematurely born infants are vulnerable to post-birth complications due to the fact that rapid brain and special sensory organ development takes place between 20 to 32 weeks gestation. Illness or infection and malnutrition can compromise the development of the neural system and other special sensory organs such as vision and hearing (Peng, Bachman, Jenkins, Chen, Chang, Chang et al., 2009; Pietsch et al., 2007). Prematurely born infants are therefore at greater risk for developing neuro-sensory-motor disorders. These disorders may result in co-ordination development disorders cerebral palsy (CP), visual and hearing impairments, learning disabilities, social / behavioural problems and also respiratory conditions (Beck, Wojdyla, Say, Betran, Merialdi, Requejo et al., 2010; Brecht et al., 2012; Javier, 2012; Marlow, Wolke, Bracewell and Samara, 2005; Mangham, Petrou, Doyle, Draper and Marlow, 2009; Pietsch et al., 2007). Developmental disorders or disability can also be caused by stressors to which the prematurely born infant is exposed in the NICU or HCU. These stressors may include environmental stressors (e.g. fluctuations in noise levels, temperature, light, noxious stimuli and handling), chemical stressors (e.g. exposure to pharmacological agents) and social or family stressors (e.g. limited family bonding) (Peng et al., 2009). Some of the typical procedures that the infant will undergo during the hospital stay include up to 62 procedures per day that cause pain or discomfort (Perlman, 2012; Oberlander, Grunau, Whitfield, Fitzgerald, Pitfield and Saul, 2000). More than 90% of these procedures causing unexpected nociceptive activation of the prematurely born infant's immature central nervous system are conducted without pre-procedural analgesia and can significantly alter the infant's long-term sensory processing as they inhibit the development of the neuronal pathways and interfere with the full differentiation of sensory input (Oberlander et al., 2000; Pietsch et al., 2007).

Deep sleep is important for these infants as it promotes the development of the neurosensory system and the maturation of the brain (McGrath, 2007) and unexpected painful stimuli disturb the prematurely born infant's sleep pattern.

If the effect of environmental stressors on the prematurely born infant could be decreased, it may shorten the infant's stay in hospital and therefore decrease the financial cost of hospitalisation (Peng et al., 2009). The exposure of prematurely born infants to environmental stressors in the NICU or HCU during their final developmental phases, which should have happened in utero, results in extended hospitalisation and an increase in the cost of post-birth health care, compared to the cost of post-birth care for full-term infants (Peng et al., 2009; Shahheidari and Homer, 2012). In some cases, the increase in health care costs is not limited to the cost of a longer stay in hospital (NICU, HCU or KMC ward) and the specialised care needed, but can persist throughout childhood into adulthood if the child developed complications due to premature birth.

There is an association between premature birth and lower educational qualifications, a lower rate of employment and a greater need for social grants in adulthood due to the increased risk of disability as a result of possible post-birth complications (Bilgin, Mendonca and Wolke, 2018; Mathiasen, Hansen, Nybo Anderson and Greisen, 2009; Moster, Lie and Markestad, 2008)

The prematurely born infant has to be seen as part of a family unit that includes parents or caregivers. It was found that family involvement is essential to a positive developmental outcome for infants in the NCIU (Goldstein, 2013). The author explains that it is important for the multidisciplinary team (MDT) to consider the possibility that, with regard to the care of an infant in the NICU, HCU or KMC ward, the parents / caregivers might have priorities and concerns that differ from those of the medical professionals, and mentions the following factors that might influence the parents / caregivers of prematurely born infants:

(i) Stress due to the premature birth of their infant. Additional stress could include stress regarding the mother's recovery from a high-risk pregnancy and uncertainty about the infant's survival or outcome.
(ii) Anxiety due to parents' or caregivers' perception that they are not adequately prepared or sufficiently competent to care for the infant at home after discharge from the hospital.
(iii) Socio-economic concerns regarding the infant's care and the management of the cost of the hospital stay or continued care after discharge.

As part of the MDT, physiotherapists could play an important role in supporting parents or caregivers in managing the abovementioned concerns during the hospitalisation of the infant. Furthermore, therapists could influence the facilitation of positive outcomes for infants and their families by incorporating an individualised support and educational programme that focuses on specific exercises that parents or caregivers can do with their infants, rather than on facts or principles (Goldstein, 2013). In order to provide the prematurely born infant with holistic care that includes the parents or caregivers in the NICU, HCU or KMC ward, a MDT team needs to be involved in the management of the infant. Barbosa (2013) describes the MDT members in the NICU as the medical / specialist, developmental and support teams (Table 1.1).

TABLE 1.1 THE DIFFERENT MULTIDISCIPLINARY PROFESSIONALS WORKING IN THE NEONATAL INTENSIVE CARE OR HIGH CARE UNIT

Type of team	Members of the team
Medical team	Physicians (paediatricians / neonatologists); registered nurses; nutritionists / dieticians
Developmental care team	Physiotherapists; occupational therapists; psychologists; speech and language therapists; social workers; lactation consultants
Support team	Secretarial and clerical staff; housekeeping personnel

Barbosa (2013) further mentions that the composition of the MDT (medical, developmental and support teams) will differ at different hospitals or health care facilities, depending on their policies, organisational culture and resource allocation. The nature of a health care facility will also determine the diversity of staff, and therefore the different MDT members available to treat prematurely born infants (Barbosa, 2013). Compared to district or secondary hospitals in the public health care sector, academic or tertiary hospitals (public sector) and private hospitals (institutions) may, for example, be more likely to appoint different developmental team professionals to work in their NICUs, HCUs or KMC wards. According to Barbosa (2013), information on the current roles and responsibilities of specific MDT members is limited. The researcher found that hospitals in the greater Tswane Metropole are making use of the ‘traditional MDT approach’ within the NICU, HCU or KMC ward.

According to this approach, each health care professional manages the infant according to the standards stipulated by each discipline's professional organisation.

Other approaches that could be implemented include the inter-professional collaborative or transdisciplinary approach, in which case information, knowledge and skills are deliberately pooled and exchanged by various team members across traditional disciplinary boundaries (Barbosa, 2013). The researcher was unable to find a good example of this in current practice while conducting this research, but feels that this is a goal to which the MDT should aspire. Regardless of whether a hospital has a well-functioning MDT or makes use of the interprofessional collaborative approach, a lack of role delineation might cause frustration and conflict between team members. Role clarification and role assignment are therefore important and are recommended to ensure that each member's role is clearly defined and costly duplication of treatment that may be to the detriment of the infant is prevented (Barbosa, 2013).

In this study the researcher referred to the different team members as the MDT and was of the opinion that it was important for physiotherapists to be aware of the delineation of the roles of the MDT members in the management of prematurely born infants in the NICU, HCU or KMC ward.

To ensure that prematurely born infants have the best potential for growth and development, these infants need to receive standardised nutrition and evidence-based clinical care (Bhutta, Giuliani, Haroon, Knight, Albernaz, Batra et al., 2013). The successful implementation of a CPG could benefit MDT member in gaining knowledge and awareness of the risks that prematurely born infants face (Bahtsevani Rn, Willman Rn, Stoltz Rn and Östman Dr Med Sc, 2010). Successful implementation could further improve patient outcomes through the improvement of quality of care because CPGs could reduce practice / treatment variation, the length of hospitalisation, cost and could improve the referral to indicated MDT members which could lead to early detection of complications (Bahtsevani Rn et al., 2010; Almazrou Mazrou, 2013). Physiotherapists working with prematurely born infants in high-income countries have a well-defined CPG to guide their standard of practice (Sweeney et al., 2010).

Other authors also used this CPG as a basis for developing competency frameworks or position statements to guide the standard of practice for physiotherapists working with prematurely born infants in NICUs or HCUs (Byrne and Campbell, 2013a; Byrne and Garber, 2013b; Brady and Smith, 2015; Price and Ronan, 2014). The CPG, competency frameworks and position statements are linked to information regarding the physiotherapist's role within the MDT, as well as to the support and health education that should be provided to the parents or caregivers of prematurely born infants.

The current scope and practice of physiotherapists according to the Health Professions Counsil of South Africa (1974) includes physiotherapists working in intensive care units (ICUs), but specific reference to the NICU is not made. Physiotherapists' scope and practice does include the care and handling of children and infants, as well as education for those responsible for their care. Physiotherapists are allowed to provide rehabilitation and respiratory care to all patient populations (Health Professions Counsil of South Africa 1974). The researcher found that it was a matter for concern that a literature search on various databases (described in Chapter 3, Section 3.3.3) found no indication of the existence of a CPG to guide physiotherapists' management of prematurely born infants in upper-middle-income countries such as SA. The CPG used in high-income countries cannot be implemented directly in a country like SA, which has a unique health care setting and problems that a CPG from a high-income country could not effectively address. Van der Wees et al. (2011) suggest that guideline development in low- and middle-income countries (such as SA) relies on international guidelines, but that local adaptations should be included to provide local context to guidelines that will be implemented in the 'new' health care setting. Guindon, Lavis, Boupha, Shi, Sidibe, Turdaliyeva et al. (2010) found that health care providers in low- and middle-income countries are more willing to implement CPGs in their clinical practice if they have been adapted to their own countries' local settings.

The different CPG development processes will be discussed in Chapter 2, Section 2.4. One CPG development process that does incorporate local context into and existing international CPG is the contextualisation process described by Gonzalez-Suarez et al. (2012), who found that it is more efficient to contextualise existing high-income countries' guideline recommendations for middle-income countries' environmental, social, economic and political contexts.

For this reason the researcher decided to use the contextualisation process as the process of choice to develop a CPG for physiotherapists treating prematurely born infant NICUs, HCUs and KMC wards in SA. The complete process of contextualisation that the researcher used in this study is discussed in Chapter 3: Methodology.

According to Gonzalez-Suarez et al. (2012), the main steps in the contextualisation process must include:

i. The construction of a 'typical' patient journey (for prematurely born infants in SA in this study). The 'typical' patient journey includes all the steps and processes that an infant and his / her parents or caregivers follow from the initial presentation to a health care provider up to discharge from the health care services.
ii. The identification and critically appraisal of relevant CPGs that will be included in the contextualised CPG (end product).
iii. The incorporation of the patient journey with the CPGs identified in Step (ii).

From the preceding discussion it is clear that the development of premature infants is influenced by various factors, such as the environment of the NICU, HCU or KMC ward, the policies and practices of the MDT working in these units and wards, parental education, the expectations and cultural beliefs of the parents and the MDT. The researcher identified the Bronfenbrenner (1979) eco-systemic model, which describes the influence of the different systems (referred to as levels throughout this document) on a child's development as a model of care. The original eco-systemic model consisted of four levels, namely the *micro level,* which represents the child itself, the *meso level,* which represents the child's environment, the *exo level,* which represents the local policies and services within which the child (infant) is treated and lastly, the *macro level,* which represents the attitudes and ideologies of the culture (of the parents or socio-economic group) within which the child is born. Bronfenbrenner's eco-systemic model was adapted as the model of care for this study. The researcher adapted this model to explain the factors that influence the health and development of prematurely born infants hospitalised in NICUs, HCUs or KMC wards.

The adapted Bronfenbrenner model consists of the micro level, which represents the anatomical and physiological development of the premature infant, the meso level, which represents the environment of the NICU, HCU and KMC ward, the exo level, which represents the practices and policies within which the MDT functions, and the *macro level*, which represents the cultural beliefs and expectations of the parents and caregivers, as well as those of the MDT members treating the infant. This model is also used as a premise for the contextualisation of a CPG for holistic intervention in cases of premature birth. Furthermore, the eco-systemic model of care is used to indicate the roles of the physiotherapist, the rest of the MDT and the parents or caregivers in ensuring the optimisation of the infant's health and development in the NICU, HCU or KMC ward. The adaptation of the model for the purpose of this study is illustrated in Figure 1.3.

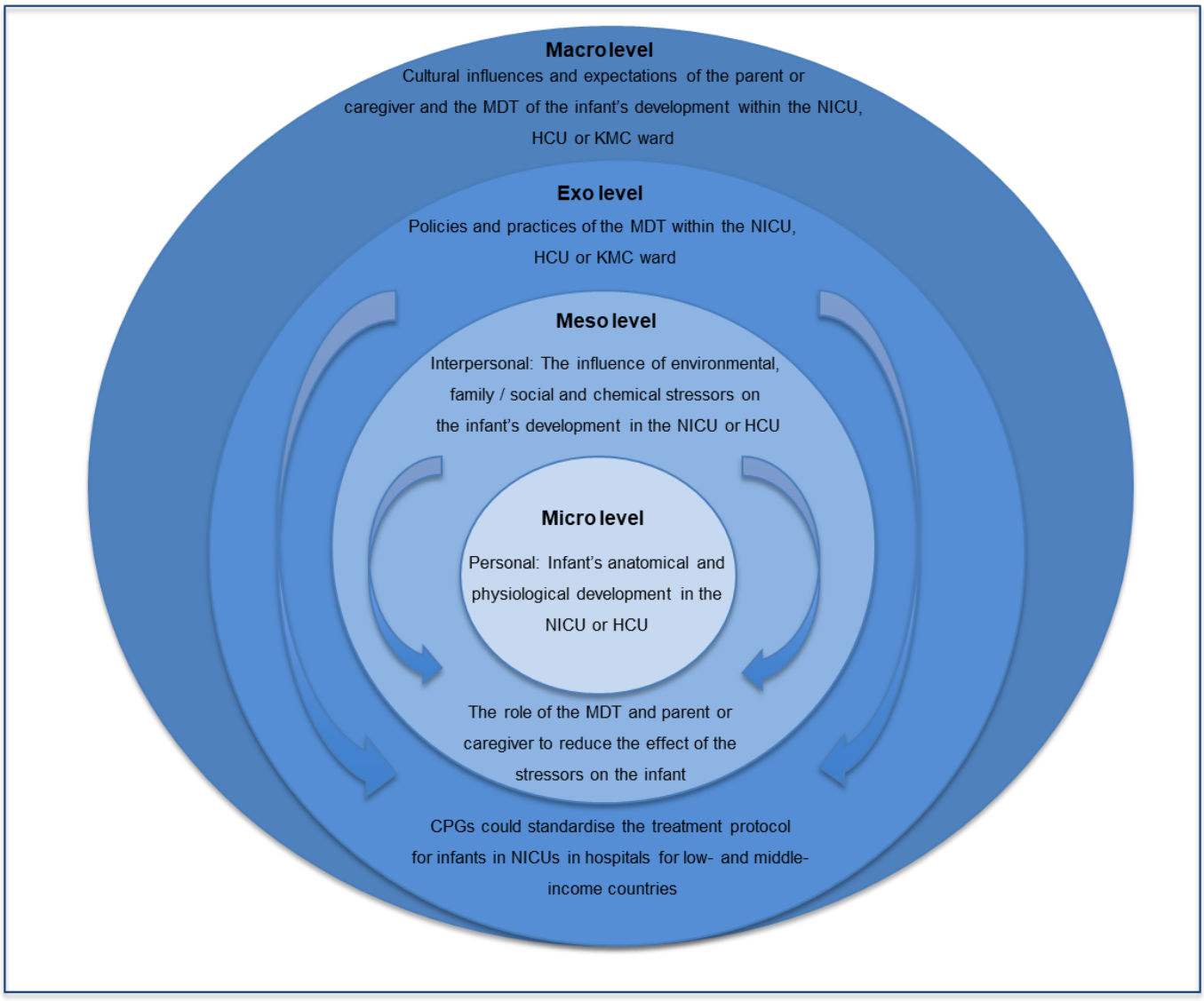


FIGURE 1.3 ECO-SYSTEMIC MODEL OF INFLUENCES (ADAPTED FROM BRONFENBRENNER, 1979)

The adapted Bronfenbrenner model enabled the researcher to identify and address the factors that influence the holistic health and development of infants in the NICU, HCU or KMC ward.

1.3 PROBLEM STATEMENT

No *exo-level* CPG exist for physiotherapists as an integral part of the MDT's approach to guide evidence-based practice and management of prematurely born infants in NICUs, HCUs or KMC wards in SA.

Based on Sweeney et al. (2010), unless a CPG is implemented in NICUs, HCUs or KMC wards in SA, it will be very difficult to deliver standardised, high-quality, cost-effective, transparent and parental- or caregiver-focused treatment (*meso level*) to potentially improve the health and developmental outcome of prematurely born infants on the *micro level*. The fact that no CPG exists for physiotherapists managing prematurely born infants in SA (*exo level*) limits the role delineation of the physiotherapist as a member of the MDT. A thorough understanding of the role of the physiotherapist could be very valuable when therapists rely on the referral of infants by other team members, as is currently the practice in the South African private health care sector. A CPG that delineates the role of the physiotherapist could also limit duplication of treatment by different professionals, and thereby decrease the stress placed on the infant by unnecessary handling in the NICU, HCU or KMC ward (*meso level*). Parents or caregivers can assist the MDT in the management of the infant on the *meso level*. The researcher could not identify any literature (on the *exo level*) on the information or education physiotherapists should provide to parents or caregivers of prematurely born infants in NICUs, HCUs or KMC wards in SA. The fact that no CPG exists to guide the physiotherapist's management of the infant (as part of the MDT) could negatively influence development, which could affect the infant's ability to reach his / her full potential (on the *macro level*). A CPG that could guide the standardised management of infants (*exo level*) could possibly improve the health and developmental outcome of prematurely born infants (*micro level*), and could potentially meet the parents or caregivers' expectations for the development of their infant (on the *macro level*) and limit the potential burden of disability on SA.

The identified problems gave rise to the formulation of the research question, aims and objectives, which are discussed in the following section.

1.4 RESEARCH QUESTIONS, AIMS AND OBJECTIVES

Once the problem areas that physiotherapists face in their management of prematurely born infants in SA had been identified (see section 1.3), the researcher was able to formulate the following research question, aims and objectives to guide this study.

Research question:

What should the CPG for physiotherapists, in the context of the MDT management of prematurely born infants in the NICUs, HCUs or KMC wards in public and private health care sectors in SA entail?

The primary aim of the current study was therefore to contextualise a CPG for physiotherapists treating prematurely born infants in NICUs, HCUs or KMC wards in South African public and private health care sectors.

The secondary aims related to the contextualisation of the existing CPGs for physiotherapists treating prematurely born infants in the South African health care context were:

1. Identify and describe the care pathways (patient journeys) of prematurely born infants and their parents or caregivers in NICUs, HCUs or KMC wards so as to:
    - ascertain the perspectives of the MDT members involved in the care and management of prematurely born infants in NICUs, HCUs or KMC wards and their parents or caregivers on what the patient journey for these infants and their parents or caregivers entailed;
    - obtain the perspectives of the parents or caregivers on what the patient journey in the NICU, HCU or KMC entailed for themselves and their infants, and how the physiotherapist and MDT could support and empower them to be prepared for their discharge;
    - to conduct a literature search to identify relevant literature on the current role of physiotherapists / physiotherapy practice during the patient journey of hospitalised prematurely born infants.
2. Formulate the evidence-based statements based on the first secondary aim. The objectives for the second secondary aim were, among other things:

- to compare the patient journeys in the South African health care context to the evidence-based statements included in the identified CPGs (secondary aim 1); and
- to formulate evidence-based statements that could potentially be part of a CPG for physiotherapists in SA.

3. Validate the evidence-based statements based on the SA health care context. The objectives of the third secondary aim included:

- obtaining input on the relevance of the evidence-based statements from physiotherapists treating prematurely born infants in NICUs, HCUs or KMC wards in the public and private health care sectors in SA; and
- formulating the list of statements and recommendations that forms the basis for writing up the final CPG document for physiotherapists treating prematurely born infants in NICUs, HCUs or KMC wards in the public and private health care sectors in SA.

1.5 SIGNIFICANCE OF THE PROPOSED STUDY

Since the CPG might enhance the standardisation, quality of treatment and cost-effectiveness of physiotherapy practice for prematurely born infants (and their parents or caregivers) in NICUs, HCUs or KMC wards in the public and private health care sectors in SA, the results of this study may potentially ensure the achievement of the best health outcome for this vulnerable patient group. Clinical practice guidelines (CPGs) consist of evidence-based statements, and if physiotherapists implement these statements in practice it could result in a decrease in the potential long-term complications or impairments from which prematurely born infants may suffer, which should in turn bring about a decrease in the economic burden placed on the health care system, the family and society (Bilgin et al., 2018).

The CPG may also give the physiotherapists treating prematurely born infants an overview of the role of each member of the MDT in the NICU, HCU or KMC ward, which could lead to improved collaboration between the team members and the optimisation of the management of the infants in their care (Barbosa, 2013). The clarification regarding the needs of parents or caregivers and the health information and education that the physiotherapist as a member of the MDT could provide to them may empower them to manage their infant in the NICU, HCU or KMC ward more confidently (Goldstein, 2013). Information on the role of the MDT in the NICU, HCU or KMC ward could improve the collaboration between the parents or caregivers and the MDT, and ideally may have a positive impact on the health and developmental outcomes of prematurely born infants (Goldstein, 2013; Byrne et al., 2013b).

The significance of the outcome of the study is also further addressed in Chapter 8. The opportunities and challenges relevant to the significance of this study as it emerged from the current study is further discussed in section 8.2.2 (Chapter 8).

1.6 RESEARCH APPROACH, DELINEATION AND ASSUMPTIONS OF THE STUDY

1.6.1 Research approach

The researcher decided to use an exploratory sequential mixed methods research design for this study, which was completed in three phases. The approach is explained in Chapter 3, Section 3.2.

Phase 1 consisted of qualitative research conducted in three parts. In the first part the researcher endeavoured to determine the course of the patient journey of prematurely born infants and their parents or caregivers in the SA health care context, which plays out mainly in NICUs, HCUs or KMC wards. To obtain the necessary information, the researcher conducted focus group discussions and key informant interviews with MDT members who were experienced in the management of these infants in order to gain insight into their perspectives on the journey of the infants and their parents / caregivers in the SA public and private health care sectors. In the second part of Phase 1, the researcher aimed to develop an understanding of the patient journey from the perspective of parents or caregivers who previously, or at the time of the study, had prematurely born infants in NICUs, HCUs or KMC wards in one of the SA health care sectors. Information from the parents or caregivers was obtained by conducting structured interviews and by posting an online survey. In the third part of Phase 1, the researcher conducted an integrative literature review to determine the physiotherapy procedures followed during the management of prematurely born infants. The systematically identified literature was critically appraised and the recommendations for best practice were obtained.

In Phase 2 of the study, the recommendations in Part 3 of Phase 1 were integrated with the information obtained from the patient journeys (Parts 1 and 2 of Phase 1). This was done through the completion of the following four steps:

(1) Comparison of supporting evidence (references) linked to the recommendations identified in the appraised CPG or literature found during the integrative literature search

(2) Comparison of phrasing of the recommendations identified in the appraised CPG or literature found during the integrative literature search

(3) The integration of the recommendations (mentioned in Steps 1 and 2) with the patient journeys

(4) Formulation of statements and recommendations to be used in Phase 3. This phase was mainly qualitative in nature.

The aim of Phase 3 of the study was to validate the statements and recommendations formulated in Phase 2 by way of consultation with physiotherapists experienced in the management of prematurely born infants in the public and private health care sectors in SA. The researcher implemented the Delphi method in two rounds to invite participants to complete questionnaires online. This phase of the study was mainly quantitative in nature.

A full discussion of the methodology of each phase is presented in Chapter 3.

1.6.2 Delineation of the study

The main purpose of the study was to contextualise an existing CPG for physiotherapists treating prematurely born infants in NICUs, HCUs and KMC wards in SA. Since prematurely born infants and their parents or caregivers are treated as 'functional or family units', the CPG should include the health education provided to parents or caregivers. In order to determine what knowledge would be valuable to the parents or caregivers, information was gathered from consenting MDT members, parents or caregivers whose prematurely born infants had been treated in NICUs, HCUs or KMC wards, and physiotherapists who treated prematurely born infants in those facilities to obtain information regarding the patient journeys of prematurely born infants and their parents or caregivers. The end product of the study could guide the practice of physiotherapists in the treatment of prematurely born infants and their parents or caregivers, but could also serve to inform MDT members on the role of the physiotherapist in the management of those infants.

An analysis was done of the data collected in the greater Tshwane Metropole during Parts 1 and 2 of Phase 1.

The researcher assumed that the patient journeys of prematurely born infants and their parents or caregivers in other SA provinces would be similar to those compiled from the information obtained in the Greater Tshwane Metropole. To validate the results from the data analysis, the list of evidence-based statements was subjected to the input of physiotherapists treating prematurely born infants in NICUs, HCUs and KMC wards across SA.

The literature included in Phase 1 was limited to CPGs, conceptual frameworks in articles and position statements used by physiotherapists working in NICUs or HCUs in high-income countries. The researcher assumed that unpublished literature from middle- or low-income countries could exist, but failed to find any such literature despite an extensive literature search in four databases and hand searches undertaken by her. Such potential literature was therefore not included in this study. The literature search was conducted to include CPGs, competency frameworks and position statements on prematurely born infants who had no congenital defects or did not need surgical interventions to address congenital defects or conditions.

During the validation process (Phase 3) of the study, the researcher included consenting academic and clinical experts in physiotherapy working in the NICUs, HCUs or KMC wards in SA, as well as members of the paediatric and cardiopulmonary special-interest groups of the South African Society of Physiotherapy (SASP). The validation process was initiated by asking the expert panel to participate in the Delphi method. The researcher concedes that there might be experts in the field of neonatology who were not included due to the fact that their contact information was not available, or to their failure to respond.

The aim of this research study was to contextualise a CPG for physiotherapists who treat hospitalised prematurely born infants in NICUs, HCUs or KMC wards in both the private and public health care sectors, and not for the period after discharge. However, the patient journeys described in Chapter 4 included both the hospitalisation phase and the short- and long-term follow-up of these infants. The reason for this was that aspects of the short- and long-term follow-up visits were influenced by the actions of, and the health education provided by the physiotherapist and other members of the MDT during the hospitalisation phase.

Although the researcher acknowledges the short- and long-term follow-up phases in the patient journeys, the focus of this study remains on the hospitalisation phase.

This study focused mainly on the contextualisation of the CPG, and not on the implementation of the CPG in physiotherapy practice in SA, which will be recommended as a topic for future investigation.

1.6.3 Assumptions

This section contains a discussion of the ontological, epistemological and methodological assumptions of the current study, which was conducted within the comparative effectiveness research (CER) paradigm (Marko and Weil, 2012). Comparative effectiveness research is commonly defined as 'the generation and synthesis of evidence that compares the benefits and harms of alternative methods to prevent, diagnose, treat, and monitor a clinical condition or to improve delivery of care' (Marko et al., 2012:425). The CER approach has been used in various research activities, including the application of evidence in guideline development (Brouwers, Thabane, Moher and Straus, 2012). Comparative effectiveness research focuses primarily on the generation and synthesis of evidence and the results contribute to the development of guidelines. It was therefore appropriate for the researcher to use this approach for this research study. The primary interest of CER investigators is to determine whether a specific care option works for a specific patient population, in other words, to determine whether the evaluation or treatment is effective (Brouwers et al., 2012). In the current study, the recommendations formulated in Phase 2 of the study, which described the care options (evaluation and treatment) for prematurely born infants, were tested for effectiveness and relevancy in Phase 3 by applying the Delphi method.

1.6.3.1 Ontological assumptions

The ontological assumptions of a study discuss the 'nature of reality' (Polit and Beck, 2012). In the context of the definition of the CER model this research was conducted in the 'real-world' setting. The contextualisation process included the formulation of patient journeys to determine what the 'real-world' setting (environment) entails for prematurely born infants and their parents or caregivers in the context of the South African health care environment.

In Phase 1 of this research study, the researcher studied the health care environment of prematurely born infants and their parents or caregivers from the perspectives of both the MDT and the parents or caregivers. The perspectives of the MDT members and the parents or caregivers were based on each participant's personal perception of prematurely born infants' health care journeys in the different health care sectors in SA. The researcher acknowledges that these perspectives were limited as they were collected only in the greater Tshwane Metropole. In Phase 3 of the study, the researcher also obtained the perspectives of physiotherapists who participated in the management of prematurely born infants across SA. The participants in the first round of the Delphi method confirmed that the perspectives obtained during Phase 1 constituted a true representation of the patient journeys of prematurely born infants across SA.

The ontological assumption on which the current study was based, was that CPGs (on the exo level of the eco-systemic model adapted from the Bronfenbrenner's eco-systemic model, as discussed in Section 1.3 of this chapter) may potentially assist physiotherapists in SA, as members of the MDT, in delivering standardised and cost-effective management (on the micro- and meso levels of the eco-systemic model) to prematurely born infants in NICUs, HCUs or KMC wards.

The contextualised CPG included recommendations on the information and education that a physiotherapist (in collaboration with other members of the MDT) should provide to parents or caregivers of prematurely born infants in NICUs, HCUs or KMC wards in SA. The information could potentially empower parents or caregivers to collaborate with the members of the MDT in optimising the management of their prematurely born infants while hospitalised. The optimised and standardised physiotherapy / MDT management of prematurely born infants in NICUs, HCUs or KMC wards could impact the parents or caregivers' expectations regarding the development of their prematurely born infants on the macro level of the eco-systemic model.

1.6.3.2 Epistemological assumptions

Epistemological assumptions address the question relating to the nature of the relationship between the inquirer and those being studied (Polit et al., 2012).

In discussing the epistemological assumptions, the researcher therefore declared her viewpoint and philosophy on the research topic. The discussion should answer the question: What is the relationship between the researcher and the prematurely born infants and their parents or caregivers being studied in this research study?

I (the researcher) am a qualified physiotherapist with a background in the rehabilitation of patients with neurological impairments. My husband and I had twins, prematurely born at 36 weeks gestational age, who were admitted to the NICU in a private hospital in Johannesburg, SA. My prematurely born infants remained in the NICU / HCU for three weeks. I therefore personally experienced the stressors experienced by parents or caregivers whose infants are being treated in NICUs, HCUs or KMC wards due to prematurity or critical illness while recovering from a complicated pregnancy. The hospital in which the researcher's infants were treated did not have a dedicated KMC ward, but intermittent KMC was encouraged while the infants were being fed. The nursing staff also encouraged my husband to practise intermittent KMC during the feedings with a nasogastric tube. This provided us, as new parents, with opportunities to bond with the infants, which felt very limited due to the fact that parents were only allowed inside the NICU during the infants' feeding times.

My husband and I felt emotionally overwhelmed when the infants were discharged from the NICU and we could take them home. We lived in the North-West Province, which was far from the support system provided by the nursing staff at the hospital. The feeling of isolation that we experienced continued throughout the first year of the twins' life when delayed complications that could be ascribed to their premature birth became evident. During this time I realised that the information we had received during the infants' hospital stay on how to care for them and what we should expect regarding their development was insufficient. We were not adequately prepared to manage the complications that occurred and did not have access to medical support system in our hometown. None of the MDT members involved in the management of our infants (which included a paediatrician, nursing staff and an audiologist) had suggested follow-up evaluations of the twins. During visits to the Well-baby Clinic, the nursing practitioner focused on weight gain and growth, and the infants were never monitored for any developmental delays or complications. At that stage I realised the advantage I had being a physiotherapist with a background in neurology.

I was able to identify developmental delays early and could consult and collaborate with the relevant MDT members.

Realising the need I felt to consult another MDT member made me aware of the responsibility that we as medical professionals have towards prematurely born infants and their parents or caregivers. During our twins' hospitalisation, the MDT responsible for managing their condition did not include a physiotherapist, and this personal experience led me to seriously think about the role a physiotherapist might fulfil in a NICU, an HCU, or a KMC ward.

No information on the management of developmental problems were shared by the MDT members and parents or caregivers were consequently not able to identify and/or manage developmental complications or delays. No follow-up system other than a scheduled follow-up appointment with the paediatrician six weeks after discharge was in place. My purpose with this study was therefore to determine how other parents or caregivers experienced their prematurely born infants' stay in NICUs, ICUs and KMC wards, and how they thought physiotherapy could be helpful and assist in the future management of such infants.

My experience contributed to my understanding of how the MDT functions within the NICU and HCU, as well as what the holistic management of prematurely born infants should include. I was also better equipped to interpret findings in literature with regard to this topic.

The researcher acted independently from any stakeholders that may have an interest in the outcome of the study and therefore has no conflict of interest to declare.

To avoid bias during the research study, the researcher gathered information from different MDT members who manage prematurely born infants and their parents or caregivers, as well as from parents or caregivers from different socio-economic and cultural backgrounds. The information was triangulated with published research results obtained through an integrated literature search and review (triangulation is discussed in Chapter 3, Section 3.3.5).

The researcher ensured transparency in the research process by creating an audit trail (integrative literature search and audio recordings made during focus group discussions and key informant interviews). Transparency was further ensured by obtaining expert opinions on the validity and reliability of the final list of evidence-based statements in the contextualisation of the CPG.

1.6.3.3 Methodological assumptions

According to Bradshaw, Atkinson and Doody (2017), the methodological assumptions ask how the best research methodology can be identified to obtain the research evidence needed to answer the research question / achieve the research goal. The researcher decided to implement the exploratory sequential mixed methods approach or design for this study, as mentioned in Section 1.6.1.

The researcher made the assumption that the use of focus group discussions and key informant interviews in Phase 1 of the study would enable the relevant MDT members to disclose the procedures they followed for the management of prematurely born infants in NICUs, HCUs or KMC wards in the private and public health care sectors in the Greater Tshwane Metropole in SA. The researcher also assumed that structured interviews with, and an online survey for parents or caregivers from different socio-economic and cultural backgrounds would provide information on what specific information on / training in the management of their prematurely born infant in the NICU / HCU / KMC ward they regarded as necessary.

A further methodological assumption was that, based on the integrative literature review, recommendations could be formulated that reflected the roles and management strategies of physiotherapists, specifically in relation to the roles of the MDT members. In respect of the CER paradigm, the integrative literature search was used to identify the benefits of the different treatment strategies used to manage the health and developmental outcomes of prematurely born infants in NICUs, HCUs or KMC wards.

The researcher also assumed that by using the Delphi method, the recommendations that reflected the role and management strategies of physiotherapists in the Greater Tshwane Metropole could be validated by physiotherapists who are in experts treating prematurely born infants in NICUs, HCUs or KMC wards in both South African health care sectors.

1.7 OUTLINE OF THE STUDY

Chapter 1 provides an overview of the study. In Chapter 2, the researcher discusses the review of existing literature dealing with the definition, mortality and morbidity rates of prematurely born infants, and what their management in the NICU entails. The literature review undertaken to determine the different methods available for the development of a CPG is also discussed in Chapter 2 and is followed by a discussion of the methodology applied for this study in Chapter 3.

Chapters 4 contain a discussion of the results of Part 1 – the focus group discussions and key informant interviews with the MDT members – and Part 2 – the structured interviews and online survey involving parents or caregivers to gather information on the patient journey of prematurely born infants (Phase 1 of the study). In Chapter 5 the results of Part 3 of Phase 1, the integrative literature search, are discussed. Literature that addresses the current physiotherapy practice regarding the management of prematurely born infants and the critical appraisal process are presented in this chapter.

The results and discussion of Phase 2 – the integration of current CPG recommendations with South African patient journeys – is presented in Chapter 6, while in Chapter 7 the results of Phase 3, the discussion on the Delphi method and the contextualisation of the CPG are discussed.

The study concludes with Chapter 8, in which the researcher reviews the aims and objectives of the study and discusses the challenges, limitations and opportunities identified. Recommendations are also made for future research and the implementation of the contextualised CPG.

1.8 CONCLUSION OF CHAPTER 1

In this chapter the researcher provided background information on the current management of prematurely born infants and highlighted the main challenges faced by MDT members, including physiotherapists. The eco-systemic model of influences and the CER model of the study were discussed and the research question, aims and objectives were stated.

The researcher's reason for undertaking this study was discussed, along with the assumptions on which the study was based. A brief outline of the rest of this dissertation was also provided. The literature review in the next chapter aims to deepen the reader's understanding of the background to the research topic.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In the previous chapter the research question, aims and objectives of the study (Section 1.4) were presented and the significance of the proposed study was briefly discussed (Section 1.5). This chapter contains a detailed discussion of the literature that provided the background to the study of the physiotherapy management of prematurely born infants in NICUs, HCUs or KMC wards. The need to standardise the physiotherapy management of prematurely born infants through the development of CPGs is also discussed.

The objectives of the literature review are to:

- define the term prematurely born infant;
- discuss the incidence of premature births and the morbidity and mortality associated with prematurely born infants;
- determine the factors that influence morbidity and mortality in order to determine the extent of the problem in SA;
- discuss hospitalised prematurely born infants according to the eco-systemic model, as discussed in Section 1.3;
- define clinical practice guidelines;
- identify the different methods used to develop a clinical practice guideline; and
- discuss the factors that influence the development of a CPG in SA. Some factors include the health care sector in which the NICUs, HCUs or KMC wards are functioning, and the most appropriate method to use when developing a CPG for physiotherapists working in NICUs, HCUs or KMC wards in the SA health care sectors.

With the literature review the researcher aimed to create an understanding of the patient population (prematurely born infants) and justify the methodological decisions that were made with regard to the process chosen to develop a CPG in this study.

2.2 PREMATURELY BORN INFANTS

The researcher acknowledges that prematurely born infants can be classified / defined in different ways and will now discuss some of the definitions used in the relevant literature. Premature birth is usually defined as 'spontaneous' or 'indicated' premature birth (Frey and Klebanoff, 2016). 'Spontaneous' premature birth occurs in women who present with preterm rupture of membranes or preterm labour with cervical dilation. 'Indicated' premature birth is initiated by a health care provider by the early induction of labour or caesarean birth (for either medical or non-medical reasons). The common maternal risk factors that may lead to the premature birth of an infant include:

- genitourinary or extragenital infections of the mother;
- low socio-economic status associated with poor nutrition and limited access to health care;
- smoking and use of substances by the mother;
- older or very young maternal age;
- chronic maternal conditions such as diabetes mellitus Type I or II, or hypertension;
- maternal stress or depression;
- genetic influences;
- maternal uterine anomalies;
- greater prevalence of infertility treatment (leading to increased rate of multiple pregnancies);
- multiple pregnancies;
- preterm inductions and caesarean deliveries; and
- previous preterm deliveries (World Health Organization 2019; Koullali, Oudijk, Nijman, Mol and Pajkrt, 2016; Frey et al., 2016; Steer, 2005; Nosarti, Murray and Hack, 2010).

Engle (2006) mentions that the World Health Assembly provided the first international definition of a premature or immature infant in 1948. This definition stated that a premature / immature infant is a live-born infant with a birth weight of 2 500 g or less, and / or an infant with a gestational age of less than 38 completed weeks. The problem with this definition was that infants born with a birth weight above 2 500 g, but a gestational age of 35 weeks, for example, were then incorrectly classified as term infants.

Another problem was that term infants (with a gestational age of at least 38 weeks) who weighed less than 2 500 g were incorrectly classified as premature infants. In order to address these problems, Battaglia and Lubchenco (1967) developed the first classification system for newborn infants based on birth weight and gestational age. The World Health Organization (2019) has refined their definition and defines a 'preterm' infant as an infant born alive before 37 weeks gestational age, and divides this patient population into three subcategories:

- Extremely preterm (less than 28 weeks gestational age)
- Very preterm (28 to 32 weeks gestational age)
- Moderate to late preterm (32 to 37 weeks gestational age)

The WHO and the International Federation of Gynecology and Obstetrics define spontaneous preterm labour as labour resulting in the birth of an infant before 37 completed weeks gestational age. Steer (2005) notes that the concept 'completed weeks' is still misunderstood. The weeks and days should be truncated together to whole weeks and not rounded up to the nearest whole week, e.g. 35 weeks and six days should be truncated to 35 weeks and not rounded up to 36 weeks. As a result of health care practitioners' tendency of rounding when calculating gestational age, the number of infants being incorrectly classified as prematurely born infants increased by as much as 10% at a hospital in England (Steer, 2005).

Every infant's developmental maturity should also be carefully determined as some moderately premature infants (e.g. born at 32 weeks gestational age) could show more signs of maturity than some late premature infants (e.g. born at 36 weeks gestational age), and the late premature infants' needs may differ from those of the moderately premature infants (Morgan and Boyle, 2018). Steer (2005) also notes that the proportion of prematurely born infants who were transferred to special care baby units (such as NICUs or HCUs) was more than 90% for infants born before 33 completed weeks, 83% at 34 completed weeks, 58% at 35 completed weeks and 31% at 36 completed weeks. He further notes that 14% of infants born at 37 completed weeks gestational age, 7% born at 38 completed weeks and 5% born at 39 completed weeks were admitted to special care units.

Another definition that needs to be clarified is low birth weight infants.

Low birth weight refers to infants born with a birth weight of 2 500 g or less; very low birth weight refers to a birth weight of 1 500 g or less, and extremely low birth weight refers to infants with a birth weight of 1 000 g or less (Nosarti et al., 2010). Low birth weight can be due to either prematurity or intrauterine growth retardation. Not all infants with a low birth weight are therefore born prematurely.

Based on the discussion in the preceding paragraphs, in the current study the physiotherapy management of 'prematurely born infants' includes all infants born before 37 weeks completed gestational age, regardless of their birth weights. The CPG for the physiotherapy management of prematurely born infants that is contextualised in the current study will therefore be relevant only for infants classified as premature infants based on completed weeks of gestational age, and not infants with low birth weight or those diagnosed as high-risk full-term infants who may also be admitted to NICUs or HCUs for medical management.

To determine the extent of the problem of prematurely born infants in SA in order to develop a CPG for their physiotherapy management, the researcher further undertook a literature review on the incidence of prematurely born infants in SA and the rate of morbidity and mortality among them. Details of the morbidity rate assisted the researcher in addressing the problem areas identified in the physiotherapy management of these infants with a view to determining where physiotherapists could play a role. The incidence of premature births and the morbidity and mortality rates among prematurely born infants are discussed below.

2.2.1 Incidence of premature births and mortality and morbidity among prematurely born infants

In this section the researcher attempts to answer the following two questions: (1) What is the incidence of premature births and mortality and morbidity among prematurely born infants in SA? (2) Which factors influence the incidence of premature births and mortality and morbidity among prematurely born infants in SA?

2.2.1.1 Incidence of premature births and mortality among prematurely born infants

In order to answer the above questions, a literature search was carried out on the Medline, PubMed and CINAHL databases by using the keywords premature infant, mortality OR mortality rate, and South Africa. The searches were limited to articles published in English during the past fifteen years that dealt with human subjects. A hand search was conducted on Google Scholar, making use of different combinations of the keywords. The hand search also included searches in the Health Sciences library of the University of Pretoria (UP), where the researcher identified possible books for inclusion.

Although the literature search did not specifically include the phrase 'incidence of prematurely born infants', the literature listed in Table 2.2 provided the information that was required. The search process is illustrated in Figure 2.1.

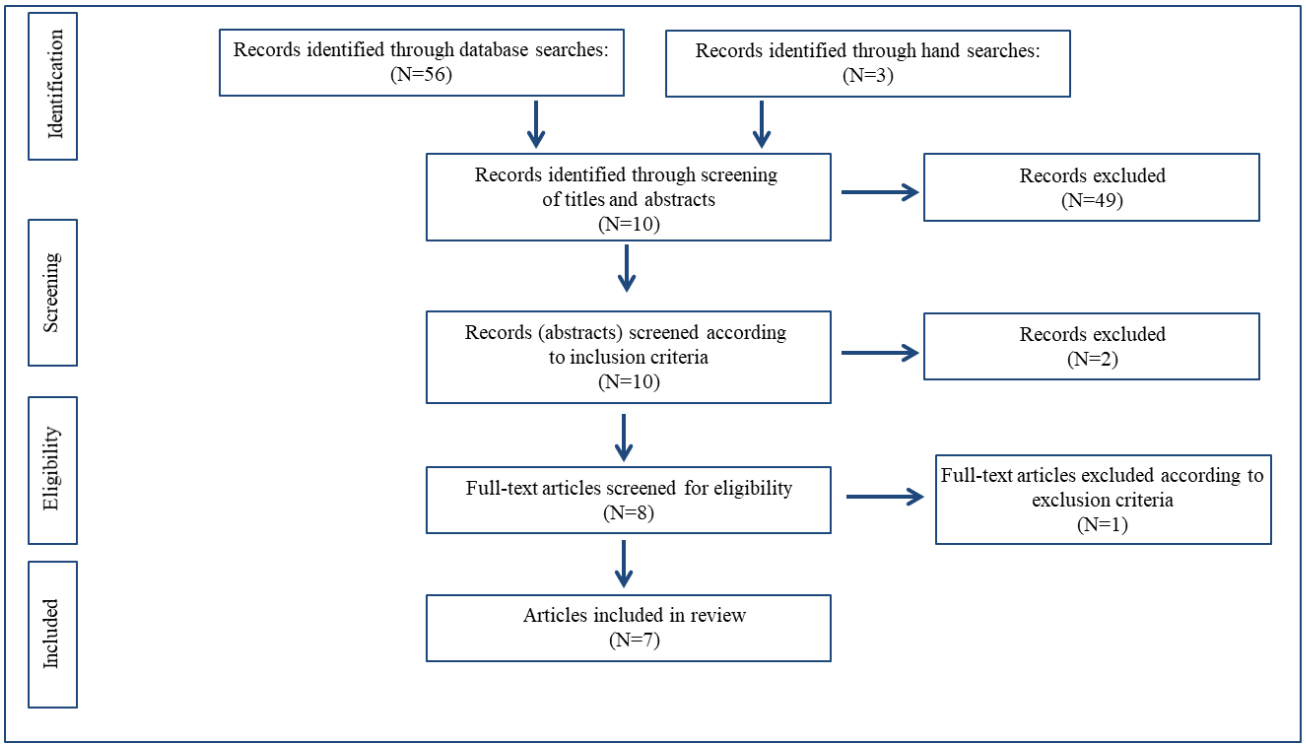


FIGURE 2.1 LITERATURE SEARCH PROCESS TO IDENTIFY THE MORTALITY RATE OF PREMATURELY BORN INFANTS IN SOUTH AFRICA

The researcher used the hierarchy of evidence (Table 2.1) as explained by Sweeney et al. (2010), which was based on the levels of evidence as described by Oxford Centre for Evidence-Based Medicine (2009) to determine the level of evidence for the seven articles included in the review. This hierarchy was also used in Phase 2 of the study when the researcher had to determine the level of evidence linked to the recommendations made in the identified CPG and position statements (Chapter 3, section 3.4.1).

TABLE 2.1 HIERARCHY OF THE RESEARCH EVIDENCE DESCRIBED BY SWEENEY ET AL. (2010)

Level of evidence	***Description***
Level I	Randomised controlled trials (RCTs) or systematic reviews of RCTs
Level II	Small RCTs, cohort studies, or systematic reviews of cohort studies
Level III	Case-control studies or systematic reviews of case-control studies
Level IV	Case series (no control group)
Level V	Opinion of experts or authorities

The level of evidence for the seven articles on which the literature review was based is shown in Table 2.2.

TABLE 2.2 LEVELS OF EVIDENCE OF THE ARTICLES INCLUDED IN THE REVIEW ON THE MORTALITY RATE OF PREMATURELY BORN INFANTS IN SOUTH AFRICA

Article	***Level of evidence***
Brits et al. (2015)	Level III
Allanson, Muller and Pattinson (2015)	Level IV
Griffin, McClure, Kamath-Rayne, Hepler, Rouse, Jobe et al. (2017)	Level IV
Pattinson (2004)	Level IV
Wagura, Wasunna, Laving, Wamalwa and Ng'ang'a (2018)	Level IV
Koullali et al. (2016)	Level V
Lehtonen, Gimeno, Parra-Llorca and Vento (2017)	Level V

Relevant information identified in a book by Nosarti et al. (2010) was also included.

- ***Incidence amongst prematurely born infants***

The WHO reported that approximately 15 million of the 130 million infants born globally each year are born premature and that in most countries for which reliable data is available, the premature birth rate increased over the past 20 years (World Health Organization 2019; Koullali et al., 2016; Wagura et al., 2018). Sub-Saharan Africa and Asia have the highest incidence of premature births and account for more than 60% of the world's prematurely born infants (Wagura et al., 2018). Brits et al. (2015) report that approximately 14% of the 1.2 million infants born annually in SA (168 000 infants) are born prematurely, which is much higher than the 84 000 infants that was reported by Mongale (2012).

- ***Mortality among prematurely born infants***

The risk of neonatal mortality due to complications after premature birth is 12 times higher for African infants than for European infants (Wagura et al., 2018). Among the possible reasons for this statistic is that a large number of infants born prematurely in Africa are in greater need of standardised care than those born prematurely in Europe.

Another factor could be that Africa has fewer hospitals equipped to manage these large numbers of prematurely born infants. Pattinson (2004) and Nosarti et al. (2010) explain that in SA and other middle-income or low-income counties, infants born prematurely in the metropolitan areas with well-equipped NICUs have a better chance of survival than those born in hospitals in the rural areas. The mortality rate of prematurely born infants is therefore determined in part by the socio-economic status of the population (country) in which they are born. According to Nosarti et al. (2010), 90% of extremely preterm infants born in low-income countries die within the first few days, compared to 10% in high-income countries. Griffin et al. (2017) suggests that in order to reduce the mortality rate of prematurely born infants in sub-Saharan African countries, these countries will have to improve the infrastructure for higher levels of institutional care, which suggests better equipped hospitals with NICUs or HCUs and improved obstetrical management by better trained health care professionals.

In 2013, complications due to premature birth were listed as one of the leading causes of neonatal death (death of an infant within the first 28 days of life) globally (Lehtonen et al., 2017). Other causes included birth-related complications such as birth asphyxia or trauma, infections such as pneumonia, tetanus and neonatal sepsis, and diarrhoea. Allanson et al. (2015) agree that these complications are frequently cited as the most common contributors to perinatal mortality (death of an infant during the period between 22 weeks gestational age and one week post birth) in low- and middle-income countries. Brits et al. (2015) state that the most common causes of mortality in prematurely born infants in SA are respiratory distress syndrome, intra-ventricular haemorrhage and sepsis.

Prematurity of newborn infants can therefore still be considered as a major obstacle in achieving the WHO Sustainable Development Goal Number 3, which is to reduce child mortality (Wagura et al., 2018). From the discussion it is clear that if premature births could be avoided or better managed by MDTs, neonatal mortality could be significantly reduced.

The World Health Organization (2019) states that three quarters of the 15 million infants that are annually born prematurely worldwide could be saved with practical, cost-effective care of the mother and infant during childbirth and the postnatal period, and suggests that the following principles of care could positively impact the outcome of premature birth:

- Provision of antenatal steroid injections (which, following a predetermined set of criteria, is given to mothers at risk of preterm labour to optimise the infant's lung function post birth)
- Kangaroo mother care (KMC) (this includes skin-to-skin contact and frequent breastfeeding)
- Antibiotics to treat infections contracted by newborn infants

The World Health Organization (2019) also emphasises that the prevention of neonatal complications in prematurely born infants that could lead to premature infant mortality starts with a healthy pregnancy. The WHO's antenatal care guidelines incorporate key interventions that could assist in reducing or preventing premature birth. These antenatal care guidelines include:

- Counselling of the mother on healthy diet / optimal nutrition and avoidance of tobacco and substance use
- Advising the mother to ensure that foetal measurement and ultrasounds are carried out to determine gestational age and detect multiple pregnancies
- Advising the mother to have a minimum of eight appointments with health professionals during the pregnancy so that potential risk factors (e.g. infections) for premature birth can be identified and managed
- Improved access to contraceptives and the empowerment of women could also assist in reducing premature births

2.2.1.2 Morbidities amongst prematurely born infants

Since the researcher wanted to determine the morbidities that may potentially affect prematurely born infants during the hospitalisation phase in NICUs, HCUs or KMC wards, she conducted a literature search (Figure 2.2) on the Medline, PubMed and CINAHL databases using the keywords premature infant and morbidity. The search was limited to articles published in English in the past five years and studies conducted on human subjects. A hand search included searches in the Health Sciences library of UP, where possible books for inclusion were identified.

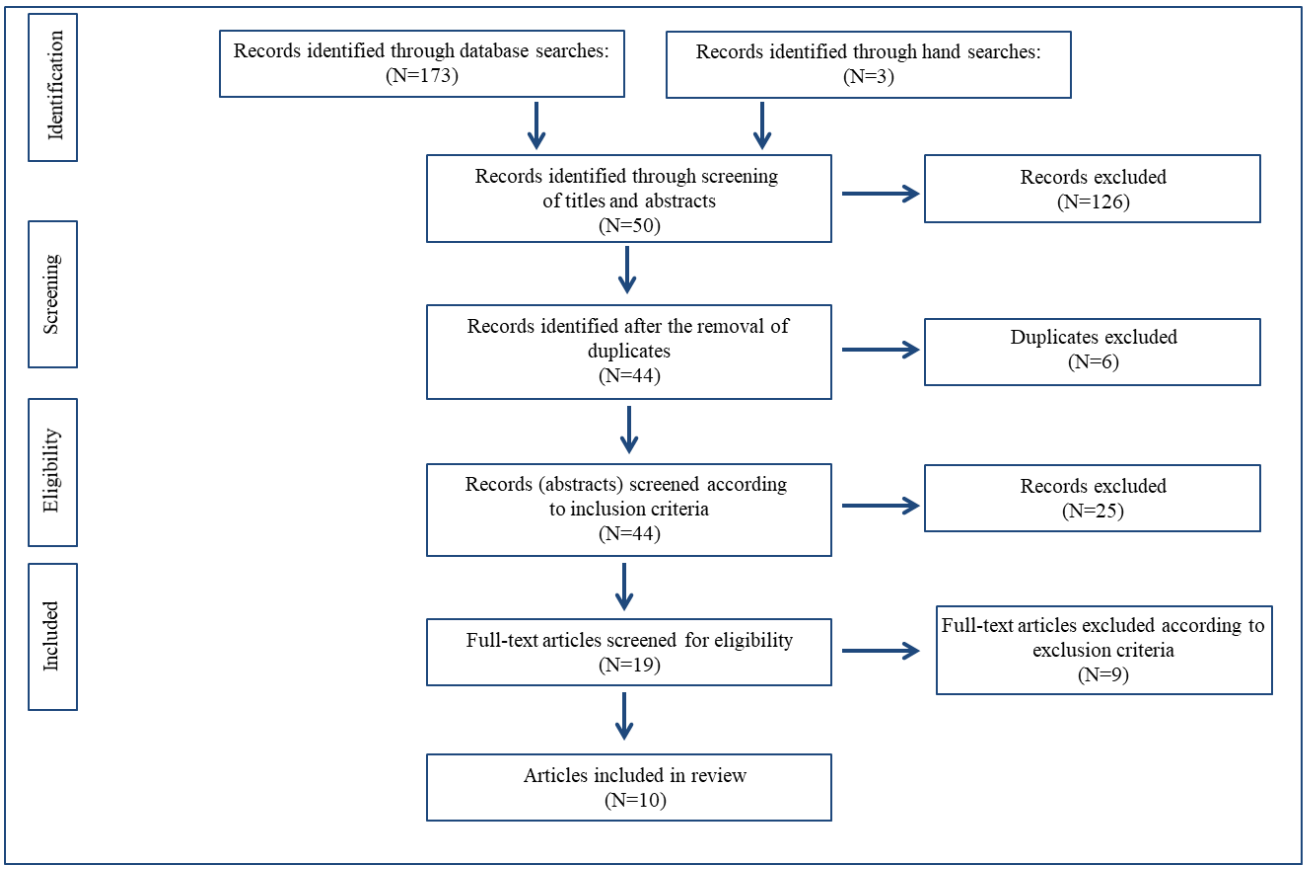


FIGURE 2.2 LITERATURE SEARCH FOR INFORMATION ON MORBIDITIES ASSOCIATED WITH PREMATURELY BORN INFANTS

The level of evidence of the articles identified for inclusion in the review, as determined by using the hierarchy of evidence described by Sweeney et al. (2010), is shown in Table 2.3.

TABLE 2.3 LEVELS OF EVIDENCE OF THE ARTICLES INCLUDED IN THE REVIEW TO DETERMINE THE POTENTIAL MORBIDITIES ASSOCIATED WITH PREMATURELY BORN INFANTS

Article	***Level of evidence***
Anderson, Baer, Partridge, Kuppermann, Franck, Rand et al. (2016)	Level II
Gupta, Mital, Kumar, Yadav, Jain and Upadhyay (2017)	Level II
Martinez-Nadal, Demestre, Schonhaut, Munoz and Sala (2018)	Level II
Natarajan and Shankaran (2016)	Level II
Patra and Greene (2018)	Level II
Bulut, Gürsoy and Ovalı (2016)	Level IV
Reichman, Teitler, Moullin, Ostfeld and Hegyi (2015)	Level IV
Frey et al. (2016)	Level V
Koullali et al. (2016)	Level V
Williams and Pugh (2018)	Level V

The morbidity and mortality rates of prematurely born infants increase with lower gestational ages (Anderson et al., 2016; Koullali et al., 2016). The global incidence of extremely premature (less than 28 weeks gestational age) and very premature infants (28–32 weeks gestational age) account for about 16% of all premature births (Koullali et al., 2016). According to Nosarti et al. (2010), this means that 1–2% of all pregnancies end in a very preterm birth. Although survival rates for very and extremely prematurely born infants have improved, the morbidity and mortality rate is still the highest for these infants, especially in low-income countries (Koullali et al., 2016). Infants born at 23 to 25 weeks gestational age (therefore extremely premature) have extremely immature organs that are ill equipped for the transition from intrauterine to extrauterine life in the NICU (Nosarti et al., 2010). Anderson et al. (2016) report that their study found that only half of the prematurely born infants born at the lowest gestational ages (22-23 weeks) survived after attempted resuscitation, and that two-thirds of the surviving infants had more than one major morbidity. Nosarti et al. (2010) further explain that infants born very and extremely prematurely commonly experience multiple and interacting morbidities.

Late gestational age (34–36 weeks) and moderately premature infants (32–33 weeks gestational age) constitute approximately 84% of all premature infants (Natarajan et al., 2016). The morbidity and mortality rates are lower for infants with a moderate to late gestational age than for extremely and very premature infants, but still significantly higher than for term infants (Koullali et al., 2016). Williams et al. (2018) found that although prematurely born infants with a late gestational age may be close to term, the loss of the six weeks' gestation in utero is crucial to their metabolic and physiological maturity and the authors are therefore of the opinion that the higher morbidity rate among infants in this group can be ascribed to their metabolic and physiological immaturity. Prematurely born infants with a late gestational age are at risk for short-term complications such as feeding difficulties, fluctuating temperatures, infections, respiratory complications, hypoglycaemia, hyperbilirubinemia and neurodevelopmental delays (Nosarti et al., 2010; Williams et al., 2018; Bulut et al., 2016). These short-term complications could explain why, compared to term infants, prematurely born infants with a late gestational age have higher health care utilisation and re-hospitalisation rates during their first year of life (Gupta et al., 2017; Natarajan et al., 2016).

Martinez-Nadal et al. (2018) found that prematurely born infants with a late gestational age are also at risk for long-term morbidities such as adverse neurological development and learning difficulties up to the age of seven. Long-term morbidities for preterm infants with a late gestational age further include asthma, attention deficit disorder and emotional / behavioural problems in childhood. In adulthood they may be at risk for higher rates of insulin resistance and hypertension than term infants (Frey et al., 2016; Reichman et al., 2015). Possible complications or disabilities for which the prematurely born infant is at risk and in respect of which a physiotherapist could play a role in reducing the impairment are discussed in Section 2.2.2.

In the short term, premature birth places a financial burden on the parents or caregivers of the infants and could possibly impact their financial situation in the long term. In the short term there are out-of-pocket costs, such as transportation, accommodation, childcare for siblings during the hospitalisation phase and out-patient visits (Frey et al., 2016). Premature birth can also affect the mother's ability to continue working.

Frey et al. (2016) found that only 52% of mothers who had been employed during pregnancy and whose babies were born prematurely were able to return to work by six months post birth. Some of those who did return to work had to limit their working hours to care for their prematurely born infants. In the long term, prematurely born infants who grow up with some form of disability may also place a financial burden on their parents / caregivers due to loss of income, as well as on the health services due to their need for on-going medical and education care (Patra et al., 2018). In adulthood a disabled person might also be financially constrained as a result of loss of income or limited income. To give an indication of the long term financial impact of prematurely born infants, Frey et al. (2016) provide an estimate of the annual cost to society of premature births in the USA, which they calculate at approximately $26 billion. The authors explain that although the information on which they based their estimate dated back more than 10 years, no more recent information was available. The estimated annual societal cost of raising a disabled child includes medical care up to the age of five years for children born prematurely, the maternal delivery cost and the cost of early intervention, which may include care in a NICU or an HCU. The annual cost to society also included disability-specific lifetime medical and special education costs, as well as the loss of productivity (income) of adults with CP, mental retardation, or visual and / or hearing impairment associated with premature birth (Frey et al., 2016). The authors also acknowledge the fact that the cost to society of a large number of disabled adults could not be taken into account because the impairments listed above are not the only impairments for which prematurely born infants are at risk, and babies born full term can also become disabled adults.

From the discussion it is clear that health care providers should aim to reduce the number of premature births and optimise the care of prematurely born infants to reduce the morbidities that these infants may face in order to help them to develop to their full potential and become economically independent participants in society when they reach adulthood.

In the next section, the role of the physiotherapist in the management of prematurely born infants during the hospitalisation period is discussed.

2.2.2 Physiotherapy for the hospitalised prematurely born infant

In this section the researcher discusses the context of the hospitalised prematurely born infant based on the eco-systemic model of influences (Bronfenbrenner, 1979), as discussed in Chapter 1, section 1.2. The model, as shown in Figure 1.3, has four layers. In the centre we find the *micro level*, which represents the prematurely born infant's anatomical and physiological development in the NICU, HCU or KMC ward. The next level is the *meso level*, which is the interpersonal level where the environmental and family / social stressors can influence the prematurely born infant's development in the NICU, HCU or KMC ward. The hospitalised infant is also exposed to chemical stressors, which include medication that might be indicated and needed, but could have negative side effects, such as drowsiness. The *meso level* may impact the *micro level* either positively or negatively, depending on the number and combination of stressors to which the infant is subjected. The *exo level*, which is the third level, refers to the influence of policies and practices on the MDT's management of prematurely born infants in NICUs, HCUs or KMC wards. The policies and practices of the MDT, which includes a physiotherapist, should be standardised. By standardising the physiotherapist's policies and practices, it might be possible to optimise the current physiotherapy management of prematurely born infants. An MDT that includes a physiotherapist can also impact an infant's *macro level* by forming a relationship with the parents or caregivers and providing support and possibly relevant education to them during the infant's hospital stay. To appropriately influence the *macro level*, the relevant health education should take into consideration the cultural influences to which parents or caregivers and families are subjected by the communities in which they live. In NICUs, HCUs and KMC wards, MDTs must ensure that, regardless of their own expectations, they strive to meet the parents or caregivers' expectations for their infants' well-being and development.

The role of the physiotherapist at the *micro*, *meso*, *exo* and *macro levels* is discussed in the following sections.

2.2.2.1 Micro level – The infant's anatomical and physiological development in the neonatal intensive care unit, high care unit or kangaroo mother care ward

Information regarding the effect of premature birth on a prematurely born infant's physiological and anatomical development is important to guide the way in which the infant should be approached in the NICU, HCU or KMC ward, and to assist in the physiotherapist's clinical decision-making during assessment and treatment. The question that guided this part of the literature search was: What is the effect of premature birth and physiological stress on the development of the prematurely born infant in the NICU, HCU or KMC ward? A search (Figure 2.3) was undertaken in the Medline, PubMed and CINAHL databases by using the keywords premature infant, intensive care units, neonatal AND stress, physiological. The search was limited to articles published in English in the past five years that dealt with research involving human subjects. The hand search also included searches in the Health Sciences library of UP, where the researcher identified books for possible inclusion.

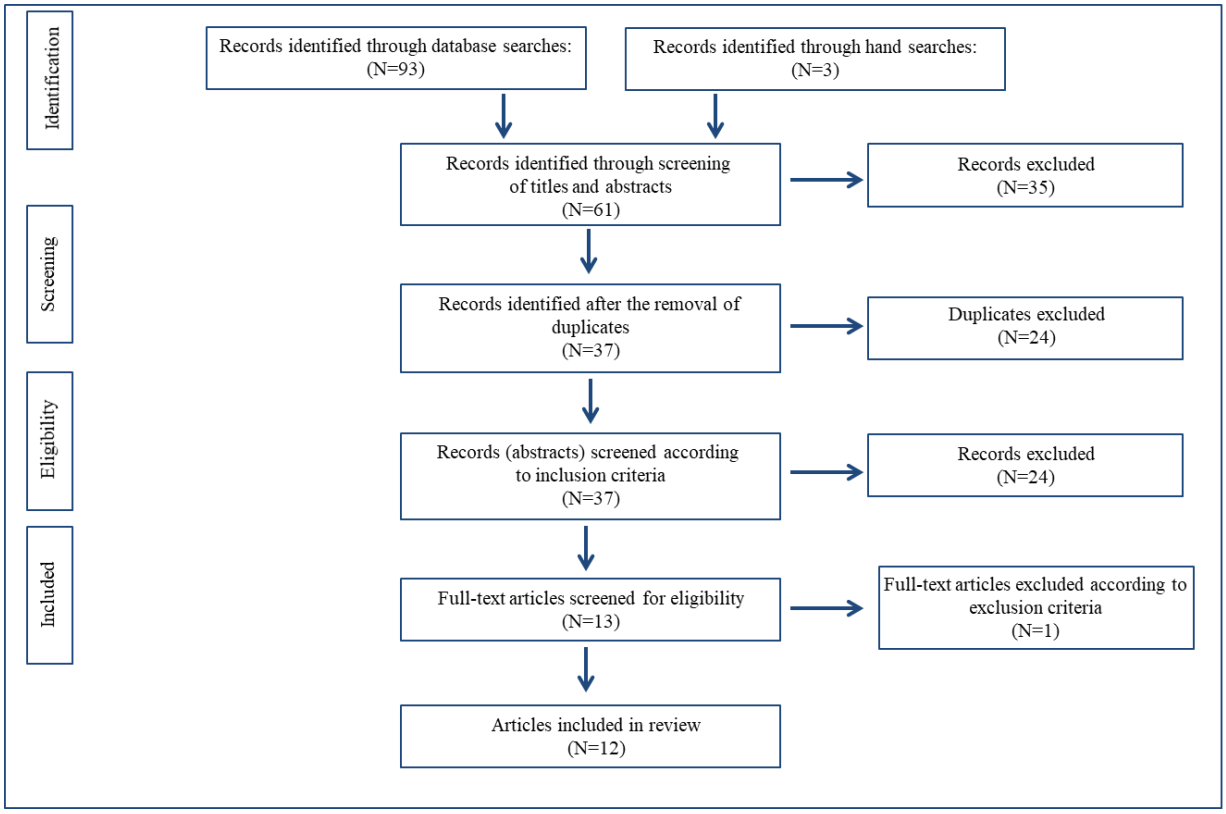


FIGURE 2.3 LITERATURE SEARCH TO DETERMINE INFLUENCES ON THE PREMATURELY BORN INFANT'S MICRO-LEVEL DEVELOPMENT

The level of evidence of the articles identified for inclusion in the review is shown in Table 2.4. The hierarchy of evidence described by Sweeney et al. (2010) was used to determine the level of evidence. The researcher also gathered information from three books identified during the hand search, namely those written by Ratliffe (1998), Nosarti et al. (2010) and Umphred (2013).

TABLE 2.4 LEVELS OF EVIDENCE OF THE ARTICLES INCLUDED IN THE REVIEW TO DETERMINE INFLUENCE ON THE PREMATURELY BORN INFANT'S MICRO-LEVEL DEVELOPMENT

Article	***Level of evidence***
Moore, Schmid, Anderson-Berry and Berger (2016)	Level II
Zeiner, Storm and Doheny (2016)	Level II
Calikusu Incekar and Balci (2017)	Level III
Morelius, He and Shorey (2016)	Level III
Gorzilio, Garrido, Gaspardo, Martinez and Linhares (2015)	Level IV
Lin, Huang, Li, Chen, Bachman and Peng (2014)	Level IV
Peng, Bachman, Chen, Huang, Lin and Li (2014)	Level IV
Byrne et al. (2013b)	Level V
Byrne et al. (2013a)	Level V
Maroney (2003)	Level V
Montirosso and Provenzi (2015)	Level V
Rakhetla and Lubbe (2016)	Level V

It is important for the physiotherapist to be able to recognise the differences between prematurely born and term infants as the management of prematurely born infants differs from that of term infants due to the former's immature development at the time of birth (Morelius et al., 2016). In-utero development of the sensory system of the infant takes place sequentially: the development of each sensory system is dependent on the maturation of the preceding system (Rakhetla et al., 2016). The order in which neurosensory system development takes place is: limbic, hippocampal, chemosensory, somatosensory, kinesthetics proprioception, auditory and, lastly, visual development.

This is known as 'the synactive model of infant behavioural organisation' and is shown in Figure 2.4 (Rakhetla et al., 2016; Umphred, 2013). Umphred (2013) explain that this model is a neonatal dynamic system model, suggesting that physiological stability is the foundation for the organisation of the infant's motor development, behavioural state and attention, or interactive behaviours between an infant and the MDT / parents / caregivers. If the infant is physiologically stable, self-regulation becomes possible. In the case of prematurely born infants, this development has to take place outside of the uterus in the hospital environment (NICU / HCU / KMC ward).

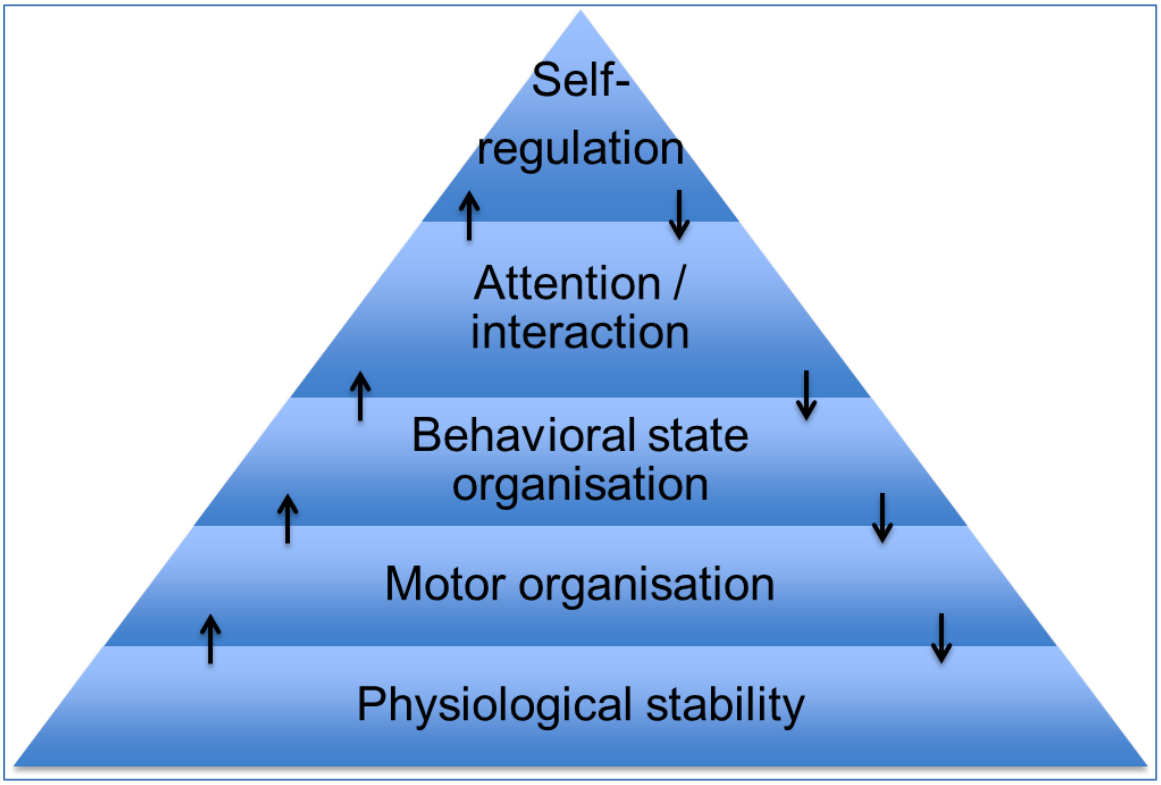


FIGURE 2.4 PYRAMID OF SYNACTIVE MODEL OF INFANT BEHAVIOURAL ORGANISATION (UMPHRED, 2013:272)

Physiological stability after birth, which forms the basis of the synactive model for the infant's behavioural organisation, is first assessed within one and five minutes after birth with the Apgar score (Ratliffe, 1998). The Apgar score assesses heart rate, respiratory effort / rate / oxygen saturation, muscle tone, reflex irritability (response to nasal suctioning or foot slap) and the infant's skin colouration.

The physical appearance of the prematurely born infant differs from that of the term infant. The appearance of the prematurely born infant is influenced by a number of factors, such as being physically small due to the infant's gestational age and appearing lethargic and unresponsive due to illness. Prematurely born infants may also have genetic or other disorders. The most appropriate reason for the smaller size of the prematurely born infant is that, compared to a term infant, the infant may have less body fat and decreased muscle tone. Prematurely born infants are less able to regulate their behavioural organisation (Figure 2.7), which is characterised by sleeping, crying, quiet spells and fussy or alert states (Ratliffe, 1998). The characteristics of the prematurely born infant are listed in Table 2.5.

TABLE 2.5 CHARACTERISTICS OF PREMATURELY BORN INFANTS (RATLIFFE, 1998:360)

Factor	**Extremely and very premature (25–30 weeks)**	**Moderately premature (31–36 weeks)**	**Almost term (37–38 weeks)**	**Term (39–40 weeks)**
Muscle tone	Extremely hypotonic, floppy	Hypotonic; some beginning flexor tone can be felt and seen at rest	Moderate flexor tone at rest	Strong physiological flexion
Posture	Lies with all extremities in full extension	Lies with all extremities in moderate extension	Lies with some flexion of extremities	Strong flexion of all extremities
Facial features	Well defined, but ears have no cartilage formation and can be folded	Well defined; ear cartilage is beginning to form	Well defined	Well defined
Hair and nails	Early hair, called lanugo, forms over most of body; healthy scalp hair	Has fingernails and toenails	Lanugo and much of scalp hair may fall out; fingernails and toenails may need trimming	Lanugo and much of scalp hair may fall out; fingernails and toenails may need trimming
Genitals	Poorly developed Females: outer labia do not cover inner labia and clitoris Male: scrotum small and smooth; testicles undescended	Still undeveloped Females: outer labia do not cover inner labia and clitoris Male: scrotum small and smooth; testicles undescended	More fully developed Female: outer labia cover inner tissues Male: testicles may descend to fill scrotum	Fully developed
Skin	Thin, translucent with wrinkles; veins apparent; dusky red colour at birth	Still thin but more opaque; more fat under skin but still somewhat wrinkled	Opaque, healthy layer of fat under skin	Opaque, chubby appearance

Head shape	Skull bones thin and malleable; exposed to gravity and uneven pressure, head often becomes elongated and flattened	Skull bones thin and malleable; exposed to gravity and uneven pressure, head often becomes elongated and flattened	Skull bones thicker in older premature infant; head shaping not as typical as that of earlier premature infant	Skull bones shaped by more even pressure of uterus, so are relatively round
Movements	Jerky, unorganised	Jerky and unorganised, but better controlled than in very premature infants	Movements more controlled; less excursion than in premature infants	Movements mostly smooth
Behaviour	Poor state control; overwhelmed by sensory stimuli	Poor state control; beginning habituation to aversive or repetitive stimuli	Emerging state control; can sometimes calm him/herself	Variable state control; may be able to calm him/herself
Sleep	Sleeps most of the time; sleep characterised by restlessness	More quiet sleep; still sleeps most of the time	Brief periods of wakefulness; sleep mostly quiet	Periods of alert wakefulness; sleep mostly quiet

Apart from having to be aware of the physical differences, the physiotherapist also has to understand how difficult it is for the prematurely born infant to maintain homeostasis in the NICU, HCU or KMC ward environment. Peng et al. (2014) explain that infants in NICUs, HCUs or KMC wards may experience increased energy requirements for maintaining physiological homeostasis and promoting growth to overcome the stress caused by the overstimulation of their immature neurological systems. The authors also state that prematurely born infants require more energy for their normal growth than for maintaining homeostasis.

It is well known that the NICU, HCU or KMC ward environment is stressful for the prematurely born infant (Gorzilio et al., 2015). The noise in a NICU or an HCU, caused by alarms from monitors or people speaking, result in auditory stress, while physical stressors are caused by invasive procedures like a heel prick, or by handling procedures (e.g. bathing and diaper changes).

Morelius et al. (2016) state that the hypothalamic-pituitary-adrenal (HPA) axis regulates cortisol production in each person. At the beginning of the second trimester (around 13 weeks gestational age), the HPA axis regulates cortisol production in order to organise the infant in response to the in-utero environment. Cortisol is essential for ensuring lung maturation at birth, which is why an increased level of cortisol is found from 13 weeks gestational age onwards (Morelius et al., 2016). Prematurely born infants' developmental immaturity and / or the impact of critical illness could lead to insufficient cortisol production, which makes it difficult for the infant to maintain homeostasis when exposed to stressors (Gorzilio et al., 2015; Morelius et al., 2016). It is therefore important to monitor the infants' recovery from stressful stimuli in order to provide them with optimal support to handle the stressors in the NICU, HCU or KMC ward. Prematurely born infants are at a greater risk of short-term effects of stress than term infants (Morelius et al., 2016). The short-term consequences of stress could include fluctuations in intracranial blood pressure, which puts the infants at risk of intraventricular haemorrhage. The prematurely born infant is also at risk of long-term consequences of stress, which could include an inability to respond appropriately to an auditory, environmental or physiological stressor. Signs and symptoms of stress in a prematurely born infant could include an increased heart rate, skin conductance (changes in the palmar and plantar sweat glands due to reaction to stress) (Zeiner et al., 2016) and decreased oxygen saturation. To reduce stressors, the MDT could implement methods such as family-centred care and KMC (Zeiner et al., 2016). The authors further suggest that gentle touch, positioning in a flexed position, non-nutritive sucking, hands-on containment (by supportively cradling the infant in your hands) and nesting could help the prematurely born infant to maintain neurobehavioral stability and to optimally reduce stress.

It is important for physiotherapists to evaluate the type of intervention that they perform in NICUs, HCUs or KMC wards in order to prevent unnecessary stress that could result in enduring high levels of cortisol build-up, or an unnecessary increase in energy expenditure in prematurely born infants (Morelius et al., 2016; Burger, Frieg and Louw, 2011; Peng et al., 2014; Lin et al., 2014). Apart from stressors to which prematurely born infants may be subjected, the physiotherapist should be able to identify the most common conditions that these infants could experience due to premature birth.

Identification / knowledge of such conditions could enable physiotherapists to follow a holistic approach to the treatment of prematurely born infants, who could suffer from one, or a combination of two or more of these conditions. These conditions, as explained by Maroney (2003), Ratliffe (1998), Nosarti et al. (2010) and Byrne et al. (2013a), include:

- *Respiratory impairment,* for example respiratory distress syndrome (RDS), also known as hyaline membrane disease. Ventilated infants may be at risk of developing bronchopulmonary dysplasia (BPD). Both RDS and BPD can cause long-term complications lasting into childhood, when they might recover more slowly from chest infections and might even be regularly re-admitted to hospital.
- *Cardiac impairment,* for example patent ductus arteriosus (PDA), which results in decreased blood circulation to the lungs and tissue and therefore places strain on both the heart and lungs.
- *Intracranial haemorrhage (ICH),* which could occur in different areas of the infant's brain. An example of this is intraventricular haemorrhage (IVH) with bleeding in the ventricles of the brain or a subarachnoid haemorrhage. The resulting brain damage may lead to the diagnosis of a neurological deficit such as CP. IVH may lead to hydrocephalus due to impaired cerebrospinal fluid (CSF) circulation.
- *Periventricular leukomalacia (PVL)* is related to hypoxia and inflammation that causes damage to the white matter. The initial insult may occur shortly after birth or when a sudden clinical deterioration in the infant's general condition occurs. Periventricular leukomalacia develops over the following weeks. Some forms of PVL are strongly associated with CP.
- *Necrotizing enterocolitis (NEC)* is unique to prematurely born infants and is due to poor circulation to the intestinal wall, which may become inflamed and necrotic. Poor circulation to the intestines could be due to immaturity of the internal organs or specifically the intestines, environmental or internal / emotional stress, or other factors. This condition results in pain, poor nutrition and intestinal infection.
- *Retinopathy of prematurity (ROP),* which occurs in infants who have been exposed to high levels of oxygen for prolonged periods without protection of their eyes. Due to the immature vascularisation of the infant's eyes, the oxygen causes a proliferation of blood vessels in the retina, which can cause visual impairment or blindness in one or both eyes.

- *Hyperbilirubinemia,* which may result in jaundice. Prematurely born infants are especially susceptible to hyperbilirubinemia due to the immaturity of their livers, and the liver's inability to process the high concentration of bilirubin (a breakdown product of red blood cells). If bilirubin increases to toxic levels it may be deposited in the infant's brain, leading to neurological conditions such as athetoid CP, mental retardation or sensorineural hearing loss.
- *Apnoea* and *bradycardia,* which occur in infants with immature respiratory regulation centres. If this condition continues in infants after discharge, the parents or caregivers might make use of a monitor that sounds an alarm when the infant stops breathing or heart arrest occurs. If the parents / caregivers act quickly enough, sudden infant death syndrome (SIDS) may be prevented.
- *Poor growth and feeding problems*, which could cause long-term developmental problems.
- *Attention deficits* or *hyperactivity disorder (ADHD),* which may be diagnosed at a later stage due to the fact that prematurely born infants are at a significantly greater risk for being diagnosed with ADHD and generalised anxiety, and symptoms of depression. These conditions may eventually lead to learning disabilities and social problems.

Knowing how prematurely born infants (on the *micro level*) can be negatively affected by the environment, it is now important to take a closer look at the NICU, HCU or KMC ward environment (*meso level*) to determine what role the physiotherapist should play to diminish the impact of the *meso level* on the infant at the *micro level*.

2.2.2.2 Meso level – the influence of environmental stressors on the development of infants in neonatal intensive care units, high care units or kangaroo mother care wards

The literature search conducted to find information on the effect of the *meso level* on the prematurely born infant was guided by the question: What are the factors that influence the prematurely born infant's development in the NICU, HCU or KMC ward? A literature search (shown in Figure 2.5) was done in the Medline, PubMed and CINAHL databases by using the key words premature infant AND environment AND intensive care units, neonatal OR high care unit OR Kangaroo Mother Care.

The search was limited to articles that were published in English in the past five years and dealt with research involving human subjects. The hand search included searches in the Health Sciences library of UP, where books for possible inclusion were identified.

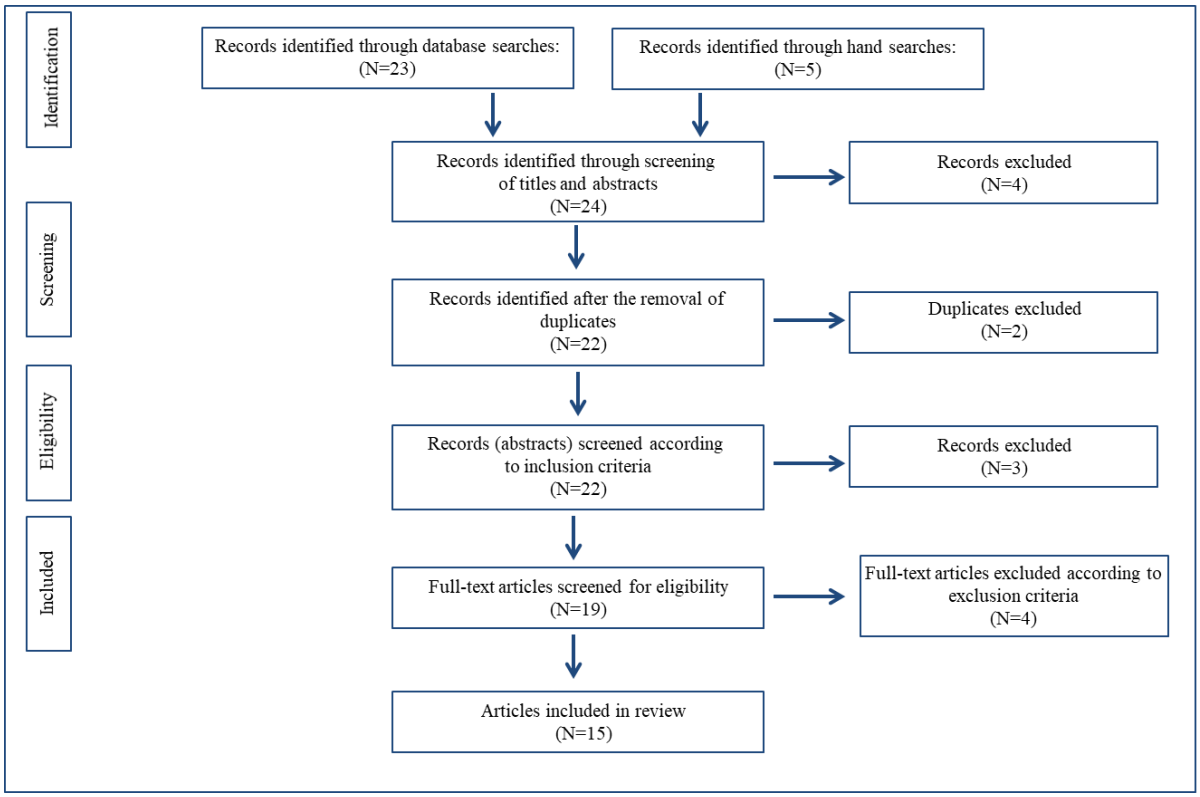


FIGURE 2.5 LITERATURE SEARCH TO DETERMINE INFLUENCES ON PREMATURELY BORN INFANTS' MESO LEVEL OF DEVELOPMENT

Since no literature dealing with the environment of HCU or KMC units could be found during the literature search, this review includes only literature on the NICU environment. The researcher acknowledges that the NICU environment might differ from the HCU and KMC ward environments. The level of evidence of the articles identified for inclusion was determined by using the hierarchy of evidence described by Sweeney et al. (2010) and is shown in Table 2.6. The researcher also gathered information from the book by Campbell, Palisano and Vander Linden (2006b).

TABLE 2.6 LEVELS OF EVIDENCE OF THE ARTICLES INCLUDED IN THE REVIEW TO DETERMINE INFLUENCES ON PREMATURELY BORN INFANTS' MESO LEVEL OF DEVELOPMENT

Article	***Level of evidence***
Almadhoob and Ohlsson (2015)	Level I
Casavant, Bernier, Andrews and Bourgoin (2017)	Level I
Khalesi, Khosravi, Ranjbar, Godarzi and Karimi (2017)	Level III
Best, Bogossian and New (2018)	Level IV
Chang, Lin and Lin (2001)	Level IV
Chawla, Barach, Dwaihy, Kamat, Shankaran, Panaitescu et al. (2017)	Level IV
Lejeune, Parra, Berne-Audéoud, Marcus, Barisnikov, Gentaz et al. (2016)	Level IV
Philpott-Robinson, Lane, Korostenski and Lane (2017)	Level IV
Pineda, Durant, Mathur, Inder, Wallendorf and Schlaggar (2017)	Level IV
Shimizu and Matsuo (2016)	Level IV
Thomas and Uran (2007)	Level IV
Als and McAnulty (2011)	Level V
Byrne et al. (2013b)	Level V
Nair, Gupta and Jatana (2003)	Level V
Rand and Lahav (2014)	Level V

Approximately 70% of prematurely born infants require hospitalisation in the NICU (Khalesi et al., 2017). Premature birth results in a sudden change for an infant whose environment had previously been protected, with minimal tactile stimulation, muffled sound and soft lighting (Lejeune et al., 2016). The NICUs and HCUs are noisy, bright and busy, with the emphasis on the medical assessment and treatment of prematurely born infants, which can include painful tactile stimulation (Ratliffe, 1998; Lejeune et al., 2016).

As discussed in section 2.2.2.1 and shown in Figure. 2.6, the NICU environment may contribute to prematurely born infants' levels of stress, which could lead to short- and long-term impairment and could also place infants at risk of developing medical complications due to the immaturity of their organs and systems (Rakhetla et al., 2016; Morelius et al., 2016).

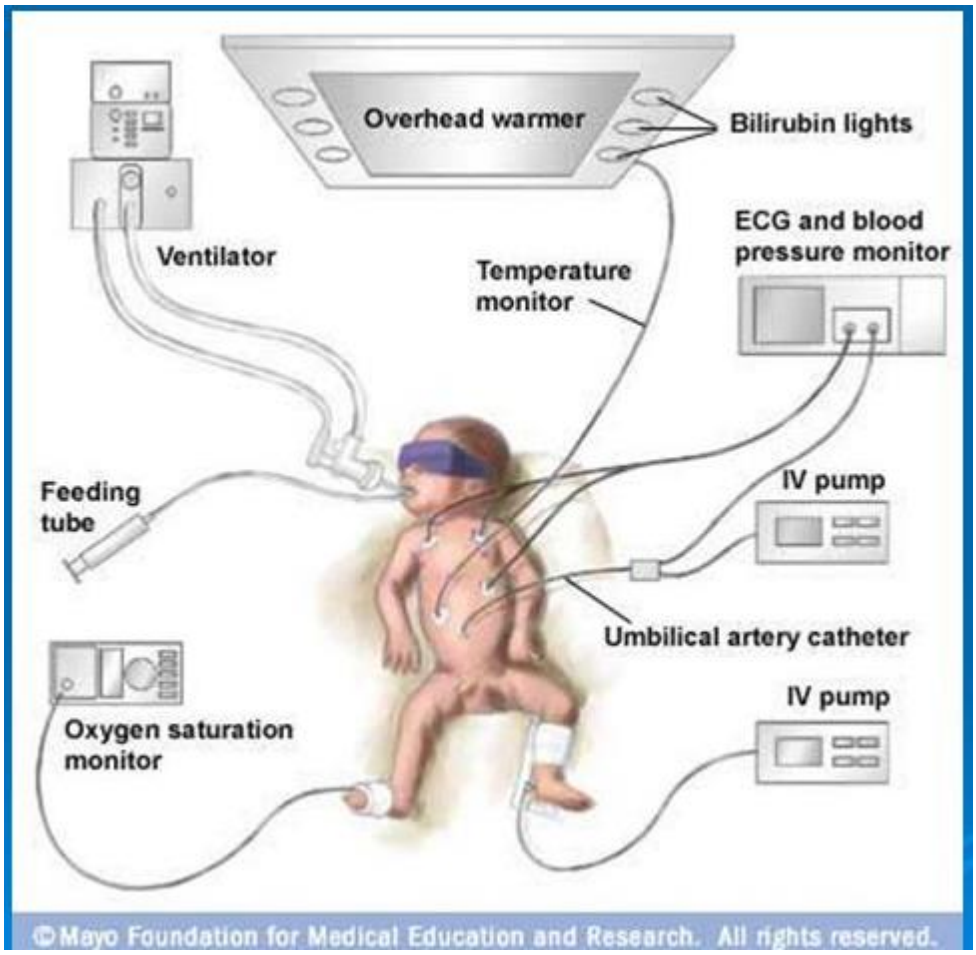


FIGURE 2.6 AN EXAMPLE OF A NEONATAL INTENSIVE CARE OR HIGH CARE UNIT ENVIRONMENT

SOURCE: MAYO FOUNDATION FOR MEDICAL EDUCATION AND RESEARCH

The environmental characteristics of the NICU mentioned in the literature are discussed in the following paragraphs. Although infants are also exposed to chemical substances (medication) that may act as chemical stressors, Philpott-Robinson et al. (2017) suggest that the chemical exposure of these infants needs to be further investigated to understand the long-term association between their exposure to chemical stressors and their neurobehavioural outcomes.

(1) Visual characteristics

According to Best et al. (2018), prematurely born infants below the gestational age of 32 weeks have very thin eyelids and lack adequate pupillary constriction, which prevents them from minimising the effect of bright light. Pupillary constriction only becomes more responsive between 34 and 36 weeks gestational age (Best et al., 2018). Precautionary practice in NICUs, HCUs or KMC wards could be to cover infants' eyes when they receive phototherapy in order to protect their developing retinas (Rakhetla et al., 2016; Nair et al., 2003). Constant light or darkness might inhibit prematurely born infants' ability to generate circadian entrainment (interaction between circadian rhythms and the environment), which leads to the infants being unable to settle in routine sleep-wake cycles (Nair et al., 2003; Campbell et al., 2006b; Best et al., 2018). Circadian rhythms are essential for prematurely born infants' hormonal control and the maintenance of homeostasis of the physiological processes, including cardiorespiratory function, sleep and temperature regulation (Best et al., 2018). If NICUs, HCUs or KMC wards regulate the use of light so that there is sufficient light during the day, but lights are dimmed at night, this might help infants to settle in a day / night sleep routine that might be helpful to parents or caregivers when infants are discharged.

Byrne et al. (2013b) suggest that the physiotherapist should take the light in the environment into consideration when handling the infant outside of the isolette. They recommend that lights be dimmed, especially when the physiotherapist facilitates visual interaction, as this might facilitate infants' success in accomplishing visual interaction as a developmental task.

(2) Sensory / Tactile characteristics

Nair et al. (2003) mention that the sense of touch develops early on in foetal life. An infant's kinesthetic proprioception develops before the auditory and visual systems, during the development of the neurosensory system (Best et al., 2018). While, according to Nair et al. (2003), prematurely born infants of less than 30 weeks gestational age may experience touch as painful, stressful and not soothing, moderate to late prematurely born infants may find touch to be helpful in calming them and assisting in state regulation.

Facilitation of behavioural state regulation includes interventions to promote a calm state, and motor organisation in prematurely born infants should be a priority for physiotherapists (Byrne et al., 2013b). Interventions that could assist infants in the process of reaching a calm state and motor organisation include non-nutritive sucking, containment and positioning to foster flexion and midline placement of the infant's extremities. The positioning of the infant in a flexed posture, which mimics what the infant would have experienced in-utero, can reduce exposure to an extension posture when gravity and the flat surface of the incubator / isolette promotes the extension position (Ratliffe, 1998).

Containment and positioning of the infants could also be applied in the KMC ward and have been found to be beneficial to both the prematurely born infants and their parents or caregivers (Byrne et al., 2013b). Calm state and motor organisation are only possible if the infant is physiologically stable, and in the case of prematurely born infants this requires a heart rate of 120 to 180 beats per minute, oxygen saturation approaching 100% and a respiratory rate of 20 to 50 breaths per minute (Byrne et al., 2013b). Each infant should be individually assessed to determine whether he / she would be able to tolerate handling (intervention), and the assessment should be made in the context of the type of interventions the infant has already experienced earlier in the day and the infant's response to those intervention(s). The timing of handling / interventions by the physiotherapist should also be carefully planned so as not to disturb the infant's sleeping pattern, since it is estimated that in-utero infants of between 28-32 weeks gestational age sleep up to 80% of the time (Campbell et al., 2006b). In the NICU / HCU, prematurely born infants could be disturbed on average 23 times in 24 hours (Campbell et al., 2006b), which disturbs their resting periods and could negatively impact their development.

However, resting periods are not disrupted only by daily handling care or medical procedures in the NICU or HCU; Nosarti et al. (2010) report that infants in the NICU could be subjected to an average of 14 painful procedures per day. These painful stimuli may lead to the abnormal development of nociceptive circuits and permanent alteration in the brain pathways due to the infants' responses to pain. It could also be associated with abnormalities in the infants' stress behaviour responses later in life.

Other abnormal sensory experiences that a prematurely born infant could possibly experience in the NICU or HCU include different types of respiratory assistance and feeding procedures required by the infant (e.g. ventilator and naso-gastric tube feeding) (Philpott-Robinson et al., 2017).

(3) Auditory characteristics

The auditory system develops at approximately 23 to 24 weeks gestational age, which is the viable age for the survival of extremely prematurely born infants (Khalesi et al., 2017). Since this is the gestational age at which the auditory system develops, it is possible that the extremely / very premature infant's auditory system may develop while s/he is being cared for in the NICU or HCU. Pineda et al. (2017) explain that the neural connections between the cochlea and the brainstem are established by 24 to 25 weeks gestation, and the neural connections between the temporal lobe and the auditory cortex as early as at 30 to 31 weeks gestational age. The American Academy of Pediatrics recommends that sound levels in the NICU or HCU should not exceed 45 decibels to ensure that infants are in an environment in which they are not exposed to a noise level that exceeds what they would have experienced in-utero (Pineda et al., 2017). This recommendation was put in place to protect prematurely born infants from unnecessary stress and potential long-term hearing impairment. Almadhoob et al. (2015) report that hearing impairment is diagnosed in between 2% and 10% of prematurely born infants, whereas the corresponding figure for the general paediatric population is 0,1%.

Chang et al. (2001) studied the nature of the noises and reported that an infant in an NICU can be exposed to up to 4 994 peak noises during a 48-hour observation period. Of the 4 994 peak noises, 90% are of human-related origin (MDT, parents / caregivers, other hospital personnel). Chawla et al. (2017) report that the noise in the NICU, especially during the morning shift, can be as loud and noisy as in a restaurant, which exceeds the recommended NICU and HCU sound levels. Some of the sources of negative auditory exposure of prematurely born infants in NICUs or HCUs include alarms, ventilators (mechanical ventilation, high-frequency oscillatory ventilators, oxygen via nasal cannula), telephones, staff / parents or caregivers' conversations, types of beds (incubator, isolette) and heating / air-conditioning systems (Casavant et al., 2017; Pineda et al., 2017; Shimizu et al., 2016).

With regard to the type of bed used, Thomas et al. (2007) found that even if the noise levels in the NICU environment were to be reduced, the noise that an infant may experience inside an incubator is just as loud (if not louder) than the noise outside the incubator.

Excessive auditory stimuli, including loud, sharp and unpredictable sounds, could create negative developmental and physiological responses in the prematurely born infant (Khalesi et al., 2017). Lejeune et al. (2016) found that intermittent auditory stimulation (loud / sharp sounds) in the NICU or HCU can provoke a pain-like stress response in the prematurely born infant that can cause behavioural inhibition and decreased ability to adjust to environmental stimuli.

Some of the preventative measures that the MDT could implement to decrease the negative impact of auditory exposure in the NICU or HCU entail that they should become more aware or conscious of the sources of noise in the unit so that they can be removed. Other strategies to limit the noise levels to which the infants are exposed include using private rooms to care for an infant if rooms are available, using incubators in which the sound can be controlled, or intermittently using earmuffs / earplugs for infants (Almadhoob et al., 2015). It should, however, be noted that Pineda et al. (2017) found greater impairment in language outcomes, as well as differences in early brain development, among prematurely born infants hospitalised in private rooms in NICUs with low parent or caregiver visitation and holding rates. The fact that a lack of sufficient opportunities to perceive maternal speech sounds during a prolonged NICU stay can alter language development in prematurely born infants was also documented by Rand et al. (2014). Pineda et al. (2017) further demonstrated a positive correlation between parents or caregivers being present and holding and talking to their infants in NICUs or HCUs and the infants' language development later in life.

Byrne et al. (2013b) suggest that NICUs and HCUs could institute 'quiet times' in their routines during which the MDT should consciously limit the noise level to the best of their ability. A reduction of the noise levels in NICUs and HCUs is possible, but would require a change in the manner in which the MDT operates.

Casavant et al. (2017) state that if the MDT buys into the process of limiting noise levels and implements it diligently, it could make a significant difference to the infants' exposure to noise, which could lead to a decrease in auditory stress. The authors further suggest that parents / caregivers should be educated to understand the infants' need for 'quiet time'.

Positive auditory exposure also exists within the NICU or HCU in the sense that if noise attenuation is decreased to within recommended levels, it may improve the infants' physiological stability for vital signs, growth, neurosensory maturation, parent-infant interaction and speech and language development (Chawla et al., 2017). Research has demonstrated that auditory exposure during the final trimester of pregnancy (28 to 40 weeks gestational age) may be essential for brain development (including language development) and is therefore equally important for the prematurely born infant during the weeks spent in a NICU or HCU (Pineda et al., 2017). The physiotherapist should be aware of the importance of the negative and positive effects of noise levels and language exposure in the NICU or HCU and could assist other members of the MDT with the provision of parent / caregiver education. Byrne et al. (2013b) suggest that physiotherapists should also plan their intervention timing, as far as possible, to incorporate the facilitation of the prematurely born infant's self-regulation outside the incubator / isolette during 'quiet time'. The quiet environment could have a positive effect on the infant and could support participation in interaction with the physiotherapist or the parents / caregivers if the therapist includes them in the treatment session.

(4) Preventative care in the neonatal intensive care unit

Overstimulation of an infant at the *meso level* could impact the prematurely born infant in the *micro level* and result in de-saturation, fluctuations in heart and respiratory rates (tachycardia, tachypnoea, or apnoea) and a possible increase in intracranial pressure due to crying (Ratliffe, 1998; Nair et al., 2003). The MDT's awareness of the harmful effects of overstimulation caused by various stimuli has led to changes in care activities in many hospitals where an effort was made to control the environment in the NICU or HCU in order to reduce the environmental stress on the infants. Different approaches to the care of infants in NICUs or HCUs have been developed, such as the individualised, comprehensive, family-focused, developmentally supportive care that originated in the 1980s (Als et al., 2011).

The shift in the focus to supportive care led to the development of the Newborn Individualised Developmental Care and Assessment Program (NIDCAP) in the USA (Als et al., 2011). This programme focuses on identifying and interpreting each individual prematurely born infant's behavioural cues in order to adapt the environmental and care interventions to best support the infant. One of the aims of the NIDCAP is to protect the prematurely born infant's neurodevelopment in a stressor-filled NICU or HCU environment.

The following factors were found to assist in the optimal maturation and development of infants (Ratliffe, 1998; Campbell et al., 2006b):

- Promoting a night / day schedule (lights dimmed at night), as discussed in section (1) above
- Facilitating infant-parent bonding with KMC
- Decreasing the noise levels at all times, as discussed in section (3) above
- Grouping or clustering care or handling during MDT procedures to maximise periods of sleep, as discussed in section (4) above
- Changing the environment by (i) placing the mother's scent on clothing; (ii) the odour of breastmilk on the pacifier to sooth the infant; (iii) co-bedding of multiple-birth neonates to provide emotional support.

The abovementioned methods could lead to improvements in weight gain, number of days on a ventilator, saturation of the infant, duration of hospitalisation, neuromotor behaviour of the infant, as well as perceptual and cognitive abilities at a later stage in the infant's life (Campbell et al., 2006b). The challenge for the physiotherapist as a member of the MDT working in a NICU, an HCU or a KMC ward is to contribute towards the standardisation of care for prematurely born infants in any hospital setting. Physiotherapists should always be aware of how their interaction with these infants could affect the infant's physiological homeostasis and development, and should incorporate neuroprotective practice into their assessment and intervention plans (Byrne et al., 2013b). A CPG could guide the practice of physiotherapists treating prematurely born infants. The CPG should, however, not replace the therapist's clinical reasoning and each infant should be assessed individually to determine which recommendations in the guideline apply to that infant's specific physiological homeostasis and circumstances.

In high-income countries, CPGs are implemented to standardise physiotherapy practice in NICUs, HCUs or KMC wards, but the researcher was unable to identify any guidelines for physiotherapists in SA, which led her to undertake the current study (see Chapter 1, section 1.4). Clinical practice and approaches to the management of infants in NICUs, HCUs or KMC wards, as discussed above, are influenced by the policies and practices (*exo level*) of a hospital / professional approaches. As member of the MDT, the physiotherapist could influence the management of prematurely born infants on the *meso level*, which could then indirectly influence the infants' physiological homeostasis and development on the *micro level*.

2.2.2.3 Exo level – policies and practices that influence the management of prematurely born infants in a neonatal intensive care unit, high care unit or kangaroo mother care ward by the physiotherapist as a member of the multidisciplinary team

The question that guided the literature search in this section was: What are the policies and practices that guide the physiotherapy management of prematurely born infants in a NICU, HCU or KMC ward? A literature search (shown in Figure 2.7) was undertaken in the Medline, PubMed and CINAHL databases by using the key words intensive care units, neonatal AND physiotherapy OR physical therapy, policies. The search was limited to articles that were published in English in the past 10 years and dealt with human subjects. A hand search was also conducted in the Health Sciences library of UP, where books for possible inclusion were identified.

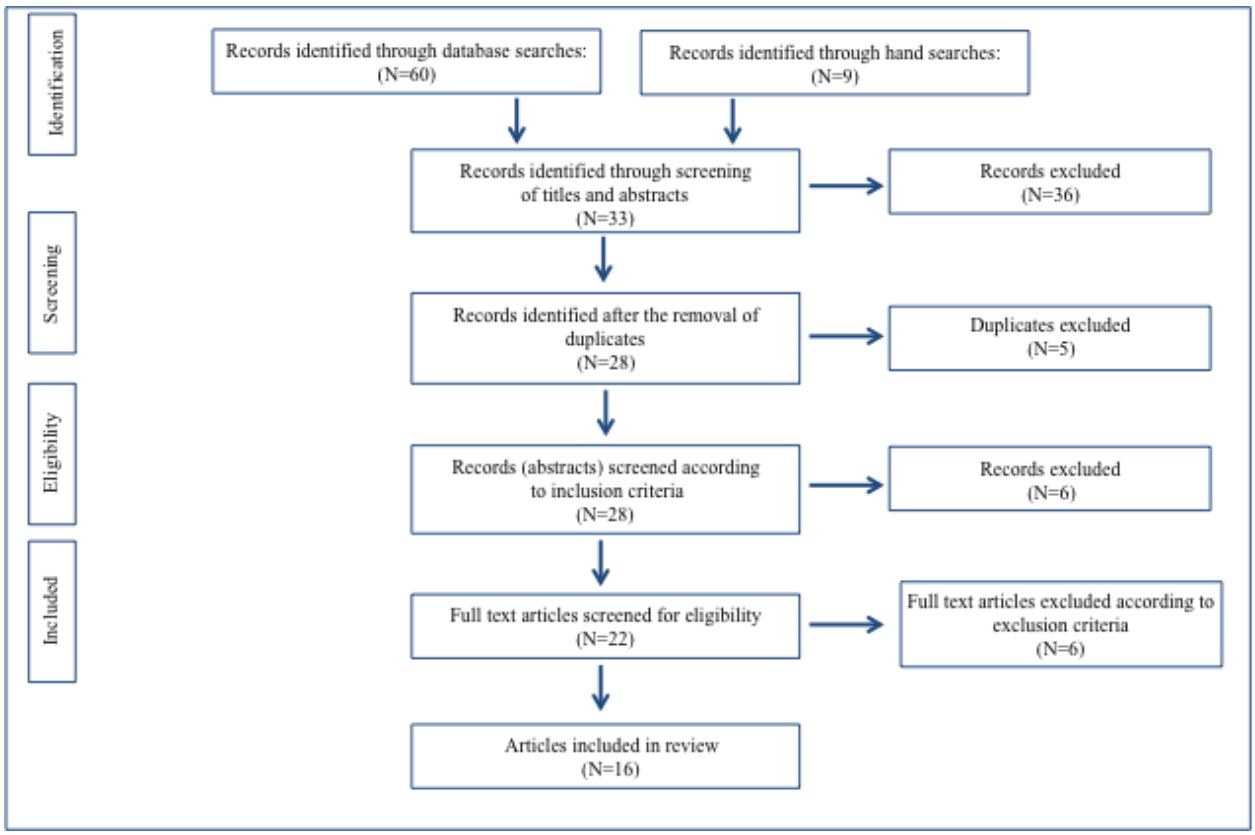


FIGURE 2.7 LITERATURE SEARCH UNDERTAKEN TO DETERMINE THE INFLUENCES ON PREMATURELY BORN INFANTS' EXO LEVEL OF DEVELOPMENT

The level of evidence of the articles identified for inclusion in the review is shown in Table 2.7. The hierarchy of evidence described by Sweeney et al. (2010) was used to determine the level of evidence.

TABLE 2.7 LEVELS OF EVIDENCE OF THE ARTICLES INCLUDED IN THE REVIEW TO DETERMINE INFLUENCES ON PREMATURELY BORN INFANTS' EXO LEVEL OF DEVELOPMENT

Article	***Level of evidence***
Allinson, Doyle, Denehy and Spittle (2017)	Level IV
Ballot, Davies, Cooper, Chirwa, Argent and Mer (2016)	Level IV
Borges Nery, Snider, Camelo, Zachary, Fatima, Jessica et al. (2019)	Level IV
Burger et al. (2011)	Level IV
Ranchod, Ballot, Martinez, Cory, Davies and Partridge (2004)	Level IV
Roets, Rowe-Rowe and Nel (2012)	Level IV
Ross, Heiny, Conner, Spener and Pineda (2017)	Level IV
Barbosa (2013)	Level V
Brady et al. (2015)	Level V
Byrne et al. (2013a)	Level V
Byrne et al. (2013b)	Level V
Lloyd et al. (2013)	Level V
Price et al. (2014)	Level V
Sweeney et al. (2010)	Level V
Sweeney, Heriza and Blanchard (2009)	Level V
Van Sant (2009)	Level V

The current study found that physiotherapists in SA are involved in the management of prematurely born infants in the NICUs, HCUs or KMC wards in the private or public health care sectors. Due to the highly specialised nature of NICUs and HCUs in private hospitals, the private hospitals that render these services can be regarded as tertiary care hospitals / tertiary health care units. Although NICUs or HCUs are found in selected private hospitals in the private health care sector throughout the country, there are no dedicated KMC wards in these hospitals. In the public health care sector, NICUs, HCUs or KMC wards are found at tertiary / academic hospitals or district / secondary hospitals. Since caring for prematurely born infants is a specialised field that requires specialised equipment, the care of these infants in the public and private health care sectors will not take place at any hospitals / institutions other than tertiary / academic or district / secondary hospitals.

According to Ranchod et al. (2004), there is a shortage of beds in the NICUs in the public health care sector and in some areas in SA hospitals do not have NICUs or HCUs. Approximately two thirds of infants born in the public sector lack access to NICUs or HCUs. Lloyd et al. (2013) report similar findings and state that infant mortality is linked to the lack of access to tertiary or specialised secondary services or inadequate facilities available to care for prematurely born infants (e.g. unavailability of NICU beds with ventilators), a lack of staff to care for prematurely born infants, a lack of transport between health care facilities and inadequate resuscitation equipment available at hospitals. Prematurely born infants who are unable to enter the health care system often do not survive (Lloyd et al., 2013). Physiotherapists should take note of the fact that infants who survived premature birth even though they could not enter the health care system might later present with disabilities at follow-up clinics. The patient journeys of prematurely born infants in different hospitals and those born at home are discussed in more detail in section 4.4 of Chapter 4.

Although the researcher did not come across any combined paediatric and neonatal ICUs during her research, she is aware of the fact that some hospitals in SA do treat prematurely born infants in paediatric ICUs. One example of such a hospital is an academic hospital in Gauteng Province, where there is a paediatric/neonatal ICU (PNICU), which is a single ICU for the treatment of paediatric patients and neonatal (premature) infants (Ballot et al., 2016). This PNICU is responsible for caring for prematurely born infants, paediatric patients suffering from general conditions and paediatric patients who had undergone surgery. Ballot et al. (2016) report that this PNICU also experiences a shortage of beds and raised the issue of the lack of consideration for children's right to access to health care. These authors explain that the unit struggles to balance the rights of the prematurely born infants with those of paediatric patients (when a decision has to be made on who should be admitted to the unit). The authors further highlight a report from 2007 that showed that only 19.6% of the ICU beds in SA are dedicated to the care of children / infants. Throughout the rest of this report, the researcher will refer to NICUs only, and not to PNICUs, as the same principles regarding the management of prematurely born infants that apply to NICUs apply to PNICUs.

Physiotherapists will have to familiarise themselves with the policies of the NICU, HCU or KMC ward before becoming involved in the management of prematurely born infants.

The functioning of the health care providers (MDT members) in each hospital's NICU, HCU or KMC ward may differ, depending on the availability of staff and the financial ability of the hospital to employ different health care providers. The value system (culture) of the hospital or unit with regard to the priorities of the health care staff's (MDT's) decision-making structure or procedures, approach to the treatment of prematurely born infants, collaboration between the MDT members and between the MDT and parents or caregivers, etc. might also differ (Barbosa, 2013). Physiotherapists should be able to adapt their management approaches to the needs of the prematurely born infants, depending on the policies, decision-making structure and values that are adopted by the MDT in the unit / ward. The two main types of service-delivery models encountered in the literature that was reviewed are (i) the multidisciplinary or interprofessional collaborative approach and (ii) the transdisciplinary approach (Barbosa, 2013).

(i) Multidisciplinary or interprofessional collaborative approach

When a multidisciplinary or interprofessional collaborative approach is implemented in a NICU, an HCU or a KMC ward, a variety of the health care providers, such as a physiotherapist, occupational therapist, speech therapist and dietician are involved in the management of prematurely born infants (Barbosa, 2013). Ross et al. (2017) explain that by understanding how therapy is structured in the NICU, HCU or KMC ward and how the MDT members operate successfully as a team could be a positive step towards the improved integration of therapists in NICUs, HCUs or KMCs. Improved integration of therapists into the policies and procedures of NICUs, HCUs or KMC wards may lead to improved management of the unique developmental needs of prematurely born infants in an effort to reverse the high rates of morbidity. Although there may be overlaps in the interventions provided by the different therapists included in the MDT, each therapist also provides a unique contribution to the infants' physiological homeostasis / health / development, or to the health education provided to the parents or caregivers from the perspective of the specific profession (Ross et al., 2017; Borges Nery et al., 2019). The different disciplines included in the MDT should therefore communicate very clearly with each other, as well as with the parents or caregivers of the infants, to plan and formulate goals for the benefit of the infants and their parents or caregivers, and to guide each professional to individually and collectively work towards achieving those goals (Borges Nery et al., 2019; Allinson et al., 2017).

(ii) Transdisciplinary approach

If the transdisciplinary approach is followed in the NICU, HCU or KMC ward, fewer MDT members are involved in the management of the prematurely born infants (Barbosa, 2013). This approach enables therapists to cross and re-cross traditional disciplinary boundaries to manage the infants in a holistic manner. If, for example, a physiotherapist is the only professional available in a NICU (apart from the nursing staff or doctors), interventions such as splinting / strapping for asymmetrical limbs or ankles, which are traditionally done by occupational therapists, would be carried out by the physiotherapist. The positive outcome of the transdisciplinary approach could be that the number of therapy interventions for an infant will decrease, which leads to fewer handling episodes during the infant's hospital stay (Barbosa, 2013). A negative of the transdisciplinary approach could be that therapists are working outside of their scope of practice and might lack the experience required for certain specialised interventions. This approach was not discussed in the studies included in the literature search.

In section 1.2 of Chapter 1, the researcher mentioned that the multidisciplinary approach was identified as the approach most commonly used in hospitals in the greater Tshwane Metropole, which is why, throughout the study, reference is made to MDTs rather than to interprofessional or transdisciplinary teams.

Multidisciplinary team members working in NICUs, HCUs or KMC wards (making use of either the MDT / interprofessional or transdisciplinary approach) need advanced knowledge and skills to optimise the treatment / intervention outcome of prematurely born infants (Ross et al., 2017; Allinson et al., 2017). The MDT members need to adapt their intervention based on their knowledge and understanding of an infant's concomitant medical condition and interventions that may occur simultaneously with physiotherapy (Ross et al., 2017). An example could be that the physiotherapist should still focus on the positioning of the infant to optimise the regulation of homeostasis, even while the infant is receiving oxygen via a nasal cannula. It is therefore essential that physiotherapists working in NICUs, HCUs or KMC wards should have the knowledge and experience needed to manage vulnerable prematurely born infants with complex medical, behavioural and physiological conditions.

Sweeney et al. (2009) state that the NICU / HCU is not an appropriate environment for physiotherapists who are generalists, physiotherapy assistants or students, and highlight areas of knowledge that should have been included in the training of a physiotherapist working in a NICU or an HCU, as well as the clinical competencies that physiotherapists should acquire. The Association of Paediatric Chartered Physiotherapists in the United Kingdom (UK) adopted the areas of knowledge and clinical competencies listed by Sweeney et al. (2009) and developed them into a competence framework for physiotherapists working in NICUs or HCUs (Brady et al., 2015). More information regarding the development of the competency framework by Brady et al. (2015) will be provided in section 2.2.2.3. The areas of knowledge and clinical competencies are listed in Tables 2.8 and 2.9.

TABLE 2.8 AREAS OF KNOWLEDGE FOR PHYSIOTHERAPISTS MANAGING PREMATURELY BORN INFANTS IN NEONATAL INTENSIVE CARE UNITS (BRADY ET AL., 2015:18-9)

Knowledge base for physiotherapists working in NICUs / HCUs	*Foundation Sciences*	• Genetics • Embryology • Developmental anatomy • Foetal and neonatal physiology • Pathophysiology of the premature infant • Neuroanatomy / neurophysiology of the premature infant • Histology • Epidemiology • Socio-emotional development of the foetus, newborn and infant • Scientific enquiry • Management science • Cultural anthropology • Knowledge of highly technical NICU environment and equipment, depending of the level of care delivered by individual units
	Behavioural Sciences	• Infant neuro-behavioural organisation • Reading behavioural cues • Developmental psychology • Neuro-behaviour and neuro-behavioural assessment tools • Parent-infant attachment • Parental stresses in the NICU • Grief and the bereavement process • Counselling skills • Family systems • Interpersonal collaboration • Medical / legal issues • Medical ethics

	Clinical Sciences	• Knowledge of normal growth and development of term and prematurely born infants • Atypical foetal, newborn and infant development • Analysis of developmental movement patterns • Individualised Development Care • Family-Centred Care • Aetiology, prognosis and clinical alterations in premature infants' postural control related to each of the body systems: (i) musculoskeletal; (ii) appropriateness of early physiotherapy intervention for prematurely born infants; (iii) neuromuscular; (iv) cardiovascular and pulmonary assessment and treatment; (v) endocrine and metabolic; (vi) integumentary; and (vii) gastrointestinal and genito-urinary. • Oral-motor development • Use of adaptive equipment, positioning aids and splints • Infection control • Developmental science – functional variables of growth, age, developmental level and interaction of the body systems

	Movement Sciences	• Knowledge of theoretical frameworks of motor development including: (i) Neuro-maturational theory; (ii) Dynamic system model; (iii) Synactive theory of development; and (iv) Theory of neuronal group selection. • Developmental biomechanics • Developmental kinesiology and pathokinesiology • Developmental assessment tools for term and prematurely born infants • Developmental physiotherapy assessment and treatment • Motor control • Motor learning • Motor development • Comparison between the posture and movement of prematurely born and full-term infants • Parent education in the NICU: to reduce parental stress and improve parental mental health so as to attune parents to their infant's capabilities

	Other Required Skills	• A holistic approach to assessment and treatment of the prematurely born infant in the NICU and after discharge • Provide consultation with professional staff in assessment, intervention and evaluation • Be able to work collaboratively with a wide range of professionals and family as a member of the team (MDT) • Work within a developmental framework • Show flexibility • Show excellent communication skills • Leadership skills to become a catalyst for change • Foster respect and autonomy

TABLE 2.9 SUMMARY OF COMPETENCIES OF PHYSIOTHERAPISTS MANAGING PREMATURELY BORN INFANTS IN NEONATAL INTENSIVE CARE UNITS

Competencies	***Role of the physiotherapist***
Screening, primary prevention and risk management	• Screen infants in the NICU to determine the need for physiotherapy services based on referral or diagnostic criteria. • Develop and implement a management plan for each neonate to prevent neurobehavioural disorganisation (physiological, motor and state systems) and secondary complications in musculoskeletal, neuromuscular and integumentary systems, and to maximise neurodevelopmental function.
Examination and evaluation	• Examine infants and interpret findings.
Planning and implementing neonatal interventions	• Design, implement and evaluate intervention plans and strategies in collaboration with the family and the neonatal team. • Develop and implement discharge plans in collaboration with caregivers and community staff.
Consultation	• Consult and collaborate with health professionals, families, professional and community organisations or agencies.
Scientific inquiry	• Incorporate evidence-based literature into neonatal practice. • Support or participate in research involving infants and parents or caregivers in NICUs.
Education and self-learning / professional development	• Communicate, demonstrate and evaluate neonatal physiotherapy care processes with other NICU professionals and caregivers. • Pursue active commitment to continuous education in practice topics related to neonatology.

Administration	• Plan and administer a neonatal physiotherapy programme. • Develop a physiotherapy risk management programme. • Evaluate the effectiveness of a neonatal physiotherapy programme.

In Table 2.9, only the competencies and roles of the physiotherapist are summarised. Further information regarding the clinical proficiencies and knowledge areas linked to each role is available from Brady and Smith (2015:20-32) or Sweeney et al. (2009:298-301). If physiotherapists managing prematurely born infants in NICUs, HCUs or KMC wards familiarise themselves with the knowledge areas, competencies and roles listed in Tables 2.9 and 2.10, they should be able to incorporate this information into their practice and possibly into the policies of the unit in which they work. The incorporation of the information into practice could influence the management of the infants on the *meso level* (and therefore indirectly on the *micro level*).

Each person representing a discipline in the MDT (especially the nurse, occupational therapist, physiotherapist and speech therapist) should have guidelines or frameworks that delineate their roles and indicate each discipline's unique areas of competence in the management of prematurely born infants in NICUs, HCUs or KMC wards (Ross et al., 2017; Borges Nery et al., 2019; Barbosa, 2013; Byrne et al., 2013a; Sweeney et al., 2010). The CPG for physiotherapists was developed by Sweeney et al. (2010), who recognised the need for a CPG for physiotherapists working in NICUs to guide practice in this advanced area. The CPG developed by Sweeney et al. (2010) has been used as a basis for the NICU Care Path developed by Byrne et al. (2013a), and Byrne et al. (2013b) for the assessment and treatment of prematurely born infants. The Association of Paediatric Chartered Physiotherapists (Brady et al., 2015) also based their Competence Framework and Evidence-Based Practice Guidance for Physiotherapists Working in the NICU or Special Care Unit on the CPG developed by Sweeney et al. (2010). The competence framework was compiled to encourage physiotherapists working in NICUs in the UK to work towards a standardised model of good practice.

The CPG developed by Sweeney et al. (2010) therefore formed the basis for other frameworks (the NICU Care Path and Competence Framework used in the UK) and also for the contextualised CPG of this study. It is therefore important to describe the basis used by Sweeney et al. (2010) for the CPG that they developed.

The three theoretical concepts that formed the foundation for their CPG are shown in Figure 2.8.

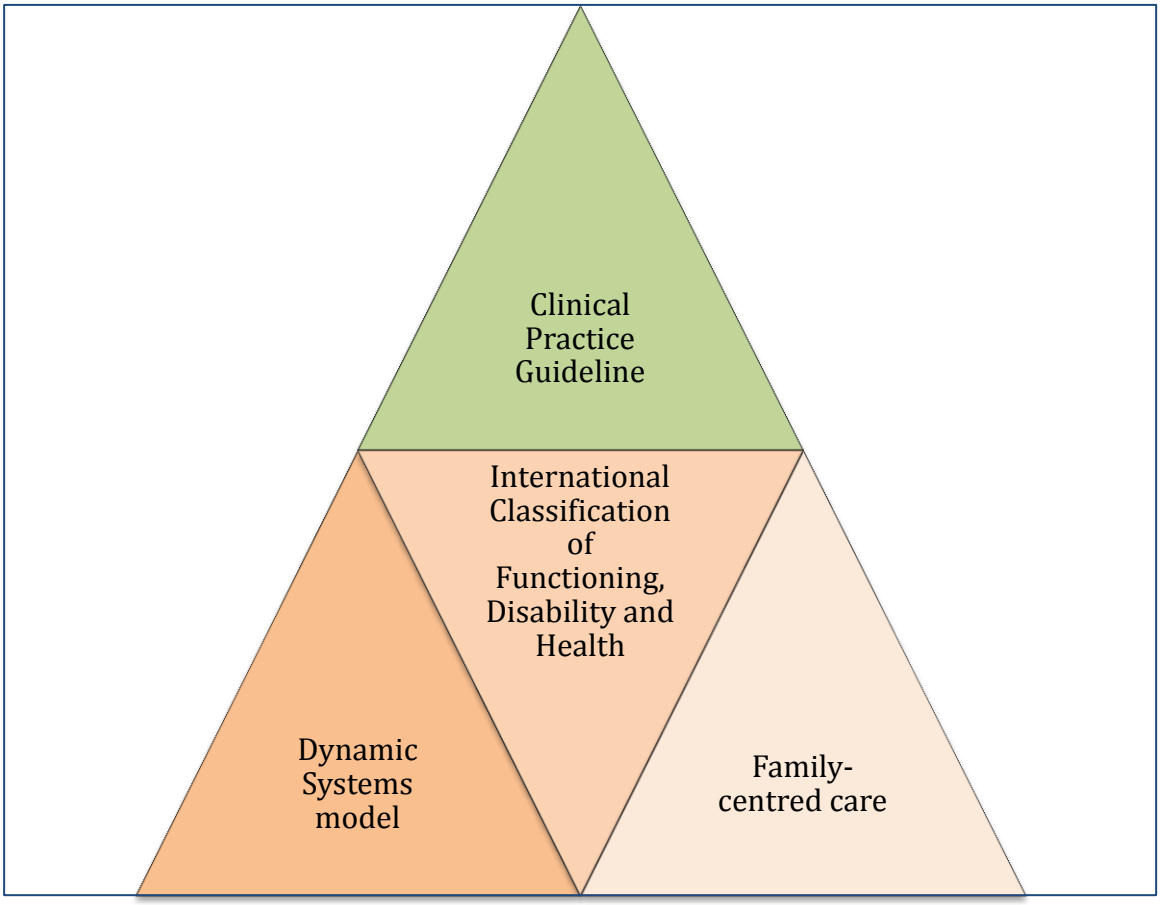


FIGURE 2.8 THE THREE THEORETICAL CONCEPTS ON WHICH SWEENEY ET AL.'S (2010) CLINICAL PRACTICE GUIDELINES WAS BASED

- ***The Dynamic System model***

From the perspective of the Dynamic System model, the prematurely born infant's developing systems are viewed as interacting with each other, as well as with the environment (the NICU, HCU or KMC ward).

The purpose of the MDT in those environments should be to enhance the interaction between the multiple systems in the environment and the infant's physiological systems in order to enhance the infant's functional performance (Sweeney et al., 2010). In the NICU, the components of the Dynamic System model include (i) the prematurely born infant's biological 'makeup', which includes the physiological, physical, behavioural, social and psychological systems; (ii) the environmental system, which includes the physical and sociocultural components (family and MDT members) in which the prematurely born infant's movements and postural control develop; (iii) the task / goal (activity-level action) of the prematurely born infant, such as maintaining self-regulation of physiological processes or maintaining attention for interaction with family / caregivers. An example provided by Sweeney et al. (2010) is that of the infant 'deciding' to self-regulate by non-nutritive sucking of the fingers (the task). If the infant is, for example, placed in a supine lying position in which gravity affects motor performance and is unable to raise his / her arms in order to bring the hands to the mouth, the task cannot be successfully performed. If the infant's position is changed to supported side-lying, the task can be facilitated by the physiotherapist (or another MDT member) and a successful completion of the task is possible. The infant's initiation of movement, or attempts at initiating movement, provides an opportunity to practise and learn motor tasks. The periods of learning in the context of the dynamic system theory are also known as periods of transition. It is during the periods of transition that the prematurely born infant's systems are most responsive to change and the optimisation of motor learning is possible (Sweeney et al., 2010). An example of the Dynamic System model is the synactive theory of development described in section 2.2.2.1.

- ***International Classification of Functioning, Disability and Health***

Sweeney et al. (2010) describe the International Classification of Functioning, Disability and Health (ICF) as a model that represents the complex interaction between the patient's health and environmental and personal factors. As such, the ICF model provides an understanding and coherent view of the integration of the different perspectives of health, namely biological, individual and social (the biopsychosocial model) (World Health Organization 2002).

The complex integration of the factors influencing the health and well-being of prematurely born infants in NICUs / HCUs or KMC wards can be explained by the ICF, which is the 'conceptual basis for the definition, measurement and policy formulation for disability and health' (World Health Organization 2002:19). The ICF is also compatible with the dynamic system model and the eco-systemic model (Bronfenbrenner, 1979), and an integration of the models is shown in Figure 2.9.

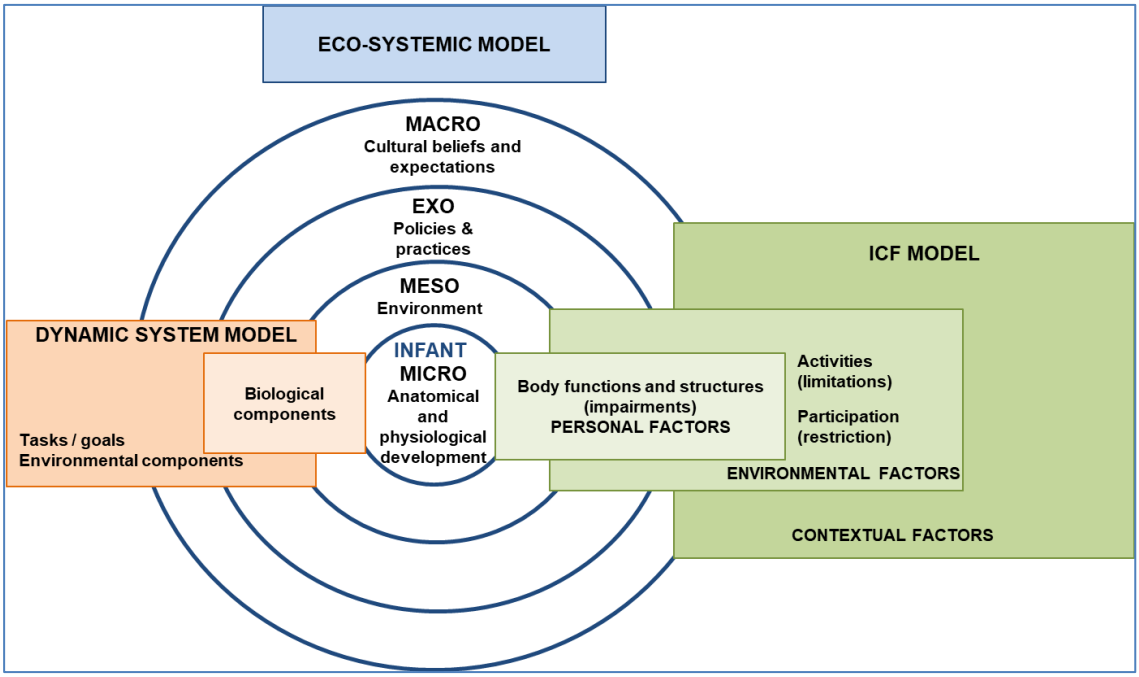


FIGURE 2.9 INTEGRATION OF THE DYNAMIC SYSTEM MODEL, ECO-SYSTEMIC MODEL AND THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH MODEL

All three models shown in Figure 2.9 address the prematurely born infant in the centre (*micro level*) and the environmental factors or components that affect the infant's development (on the *meso level*). The three models are relevant to the current study as this research study aims to standardise the policies and practices of physiotherapists (*exo level*) working in the NICU, HCU or KMC environments (*meso level*), with a view to optimising the development of the prematurely born infant (*micro level*).

Physiotherapy for the management of the prematurely born infant in the NICU / HCU / KMC ward, within the ICF model (which addresses the *micro*, *meso* and *macro levels*) should address the following aspects:

1) The functional and structural integrity of the infant's body parts and systems, and any impairments that the infant might experience on this level, e.g. inability to control physiological system that could lead to apnoea (*micro level*).
2) The promotion of age-appropriate postural and movement activities, also any limitations to activities, e.g. the infant's inability to raise the arms against gravity to bring the hands to the mouth for self-regulating purposes (*meso level*).
3) The appropriate interaction between infants and their parents or caregivers (infant-parental bonding) and MDT members. Encouraging visual focus / interaction with parents or caregivers, for example during feeding, may decrease any participation restrictions that the infant might experience during the activity. It could also address the parents or caregivers' expectations of their infant's development on the *macro level*.

The ICF model, used in combination with the dynamic system model and eco-systemic model, could be useful to physiotherapists managing prematurely born infants in NICUs, HCUs or KMC wards for the identification of factors that directly influence their management approach or the development of infants in the units or wards. The physiotherapist (as well as other MDT members) could potentially address the factors that have been identified in the model to reduce the stress on the infant and to potentially optimise the infant's care and environment.

- ***Family-centred care***

The MDT members, including the physiotherapist, should view prematurely born infants and their parents or caregivers (family) as a unit, and should not focus only on the well-being of the infants in their care. The MDT members should therefore treat the parents or caregivers with understanding and empathy (Sweeney et al., 2010). Roets et al. (2012) identified a gap between the concept family-centred care and the practical implementation of such care in clinical practice.

Strategies for family-centred care that could be implemented by the physiotherapist, as a member of the MDT, include:

- Collaboration and support, which the physiotherapist could achieve through communication with the parents or caregivers during their infant's stay in the NICU, HCU or KMC ward (Sweeney et al., 2010). An example could be to arrange family meetings to enable the MDT members to familiarise themselves with the parents or caregivers' expectations for their infant and the infant's care.
- Encouraging parents or caregivers to join support groups to help them cope with the traumatic experience of having a prematurely born infant in the NICU, HCU or KMC ward (Roets et al., 2012).
- Appropriate education could also alleviate some of the parents or caregiver's stress and anxiety.

  For example, by teaching the parents or caregivers to understand and respond to their infant's behavioural cues, parent-infant bonding could be encouraged (Sweeney et al., 2010).

The theoretical concepts that provided the basis for the development of Sweeney et al. (2010) CPG were discussed in previous sections. The method used to develop the CPG will be discussed next. Sweeney et al. (2010) conducted a systematic literature review during which they identified relevant literature to support the recommendations included in the CPG. The literature was appraised according to the hierarchy of evidence (as shown in Table 2.1). Each recommendation was linked to the references and the level of evidence. The CPG is shown in Figure 3.8 in Chapter 3, section 3.4.1, and the type of recommendations contained in the CPG are listed in Table 2.10. The references and level of evidence are not listed in this table.

TABLE 2.10 EXAMPLE OF THE TYPE OF RECOMMENDATIONS INCLUDED IN THE CLINICAL PRACTICE GUIDELINE DEVELOPED BY SWEENEY ET AL. (2010:13)

Type of recommendation	***Recommendation***
Prevention	Collaborate with caregivers to reduce risk for skull deformity, torticollis, and extremity malalignment through diligent positioning for symmetry and neutral alignment.
Examination	Conduct baseline observation to determine physiologic and behavioural stability (readiness) for evaluative handling.
	Provide continuous physiologic and behavioural monitoring during and after evaluative handling to determine adaptation to evaluative handling and to signal the need for modification of pace and sequence, given expected physiologic changes, particularly during neuromotor test procedures.
Intervention	Collaborate with caregivers to create a developmentally supportive environment with modulated stimulation from light, noise, and handling.
	Support body position and extremity movement (1) supine position: semiflexed, midline alignment using blanket for swaddling containment or "nest" of positioning rolls; and (2) prone position: vertical roll under thorax; horizontal roll under hips.
	In selected neonates with movement impairment or disorganisation, consider therapeutic handling carefully graded in intensity and paced to facilitate head and trunk control, antigravity movement, and midline orientation.
	Consider gradual exposure to multimodal stimuli for stable neonates approaching hospital discharge.
	Provide opportunities for independent oral exploration through positioning with hands to face, and for nonnutritive sucking to improve state organisation and readiness to feed.
	Determine readiness for and advancement of oral feeding trials using infant behavioural cues.
	Encourage parental involvement with feeding and provide interventions for physiologic stability (pacing and slowed flow rate).
	Consider hydrotherapy before feeding for stable infants with movement impairment.
Education	Educate parents on behavioural cues and developmental status to mitigate parental stress and to improve parental mental health outcomes.

	Implement multiple methods of instruction for parents and caregivers (demonstration, discussion, video, and written materials).

Physiotherapists managing prematurely born infants in NICUs, HCUs or KMC wards should be able to apply the principles described in the CPG to guide their practice and could use the CPG to guide the policy followed in the unit. Sweeney et al. (2010) CPG was developed in a high-income country where the health care system differs from that in SA. Physiotherapists in SA can therefore not apply the CPG developed by Sweeney et al. (2010) in clinical practice; therefore the current study aims to contextualise a CPG specifically for use by physiotherapists treating prematurely born infants in NICUs, HCUs or KMC wards in SA. Various methods for the development of CPGs are described in the literature reviewed (Grimmer, Machingaidze, Dizon, Kredo, Louw and Young, 2016; Kredo et al., 2016; Machingaidze, Grimmer, Louw, Kredo, Young and Volmink, 2018). These methods are discussed in Section 2.3.

In summary, the physiotherapist (as a member of the MDT) should be aware of the influence of the NICU, HCU or KMC environment (*meso level*) on the development of prematurely born infants (*micro level*). Factors that should be considered when planning assessments or interventions include the type of unit (NICU, PNICU, HCU or KMC ward) to which the prematurely born infant is admitted. Each unit might have its own policies for practice, with which physiotherapists should acquaint themselves. Physiotherapists should also determine what type of service delivery approach the unit has adopted, e.g. a multidisciplinary / interprofessional collaborative approach or a transdisciplinary approach. Furthermore, they should be aware of the areas of knowledge and the clinical competencies they should comply with to be able to practise in any of those particular environments. Lastly, physiotherapists could make use of a CPG to guide their practice and management of prematurely born infants. It should, however, be clear that the CPG is only a tool to guide practice and that physiotherapists should be able to apply clinical reasoning to determine which recommendations are applicable to each patient. If a physiotherapist applied the family-centred approach on the *meso level*, a relationship should be fostered and this could influence the *macro level* of the eco-systemic model.

In the section that follows, the researcher will discuss the influences of the *macro level* on the prematurely born infant's development in the NICU, HCU or KMC ward.

2.2.2.4 Macro level – cultural influences and expectations of parents or caregivers with prematurely born infants in a neonatal intensive care unit, high care unit or kangaroo mother care ward

In the previous section the importance of family-centred care was highlighted, and this led to the questions: How does having a prematurely born infant in the NICU impact parents or caregivers' expectations or beliefs with regard to their infant? and What role does the physiotherapist as a member of the MDT play in supporting the parents or caregivers? A literature search (shown in Figure 2.10) was undertaken in the Medline, PubMed and CINAHL databases by using the following key words: intensive care units, neonatal AND parent-infant relations OR parental expectations AND cultural beliefs. The search was limited to articles published in English in the past five years that dealt with research involving human subjects. The same key words were used for the hand search in Google Scholar.

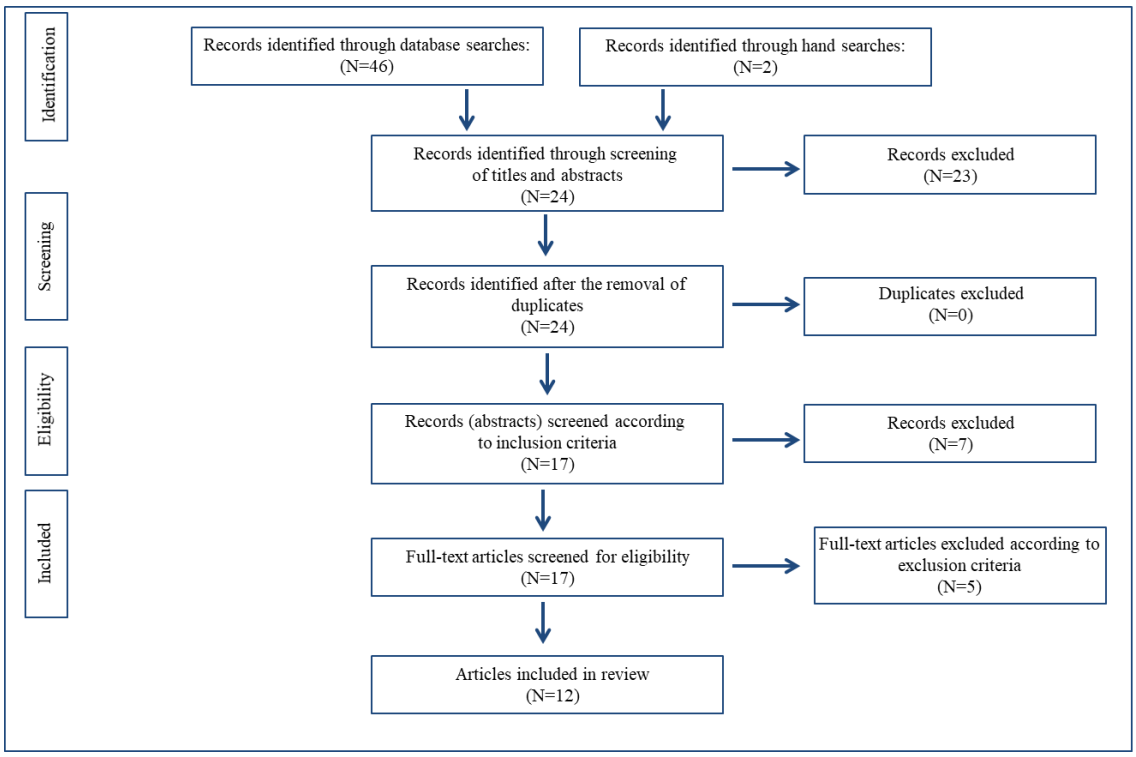


FIGURE 2.10 LITERATURE SEARCH TO ESTABLISH INFLUENCES ON PREMATURELY BORN INFANTS' MACRO LEVEL OF DEVELOPMENT

The level of evidence of the articles identified for inclusion in the review is shown in Table 2.11. The hierarchy of evidence described by Sweeney et al. (2010) was used to determine the level of evidence.

TABLE 2.11 LEVELS OF EVIDENCE OF THE ARTICLES INCLUDED IN THE REVIEW TO ESTABLISH INFLUENCES ON PREMATURELY BORN INFANTS' MACRO LEVEL OF DEVELOPMENT

Article	***Level of evidence***
Ding, Zhu, Zhang, Wang, Wang and Latour (2019)	Level I
Petteys and Adoumie (2018)	Level I
Grunberg, Geller, Bonacquisti and Patterson (2019)	Level III
Vittner, McGrath, Robinson, Lawhon, Cusson, Eisenfeld et al. (2018)	Level III
Barr (2015)	Level IV
Butt, McGrath, Samra and Gupta (2013)	Level IV
Byrne, Sweeney, Schwartz, Umphred and Constantinou (2019)	Level IV
Fernandez Medina, Granero-Molina, Fernandez-Sola, Hernandez-Padilla, Camacho Avila and Lopez Rodriguez (2018)	Level IV
Kawafha (2018)	Level IV
Shaw, Suonpera, Gallagher, Aladangady, Stokoe and Marlow (2019)	Level IV
Rakhetla et al. (2016)	Level V
Skene, Gerrish, Price, Pilling and Bayliss (2016)	Level V

In the past, neonatal care was focused primarily on the reduction of prematurely born infants' mortality and morbidity, and to a lesser extent on the psychosocial needs of the infants' families (Shaw et al., 2019). Parents or caregivers who were anticipating the birth of a healthy, full-term infant are forced to deal with the anxiety and stress of a NICU admission and a potentially prolonged hospital stay, with some parents or caregivers even facing the possibility that their infant might not survive (Petteys et al., 2018). Barr (2015) found that the parents or caregivers of prematurely born infants being cared for in a NICU reported that they experienced the unit as being 'overwhelming' because of all the equipment needed to keep their infants alive. Some were upset by the physical appearance of their infants, especially in cases of extremely or very premature birth.

Other parents stated that they did not feel like parents as they were not able to interact with their infants in a 'normal' way, i.e. in the way parents of full-term infants can (Barr, 2015; Kawafha, 2018). Petteys et al. (2018) listed some of the feelings that parents or caregivers expressed while observing their infants in the NICU, which included shock, uncertainty, fear, guilt, anger, failure, grief, depression, loss of control, blame, helplessness and anxiety.

It is important for physiotherapists and the rest of the MDT to remember that prematurely born infants are born into social (cultural) environments that include all religions, nationalities, cultural backgrounds and races (Kawafha, 2018), and that each infant and his / her parents or caregivers should be managed individually, based on the social environmental factors. Kawafha (2018) also mentions other factors that influence the stress levels of parents or caregivers, such as financial stress (e.g. the cost of care for the infant and the additional costs of transportation to and from the hospital). The educational levels of parents or caregivers could also play a role in their stress levels. Well-educated parents, for example, may experience higher stress levels as they have a better basic knowledge of the implications of the situation in which the infant finds him / herself and can more readily access information on the internet or from other health information sources. Parents with a lower educational level may find it stressful because they do not fully understand the medical team's explanations with regard to their infant's condition (Kawafha, 2018). Another factor that influences parental or caregiver stress could be the medical diagnosis / condition of the infant, especially if it is linked to a poor prognosis. Parents or caregivers with a history of infertility might find it very stressful to have their first-born infant in the NICU after having lived with the stress of not being able to conceive and possible infertility treatment (Kawafha, 2018). It is also important to consider the possibility that parents or caregivers with infants in the NICU may experience psychological distress even after their infant has survived and has been discharged from the hospital. Parents or caregivers may even be at risk for developing posttraumatic stress disorder (Petteys et al., 2018). Skene et al. (2016) explain that the period of hospitalisation of a prematurely born infant in the NICU or HCU can also be extremely stressful for the infant, who is denied contact with his / her parents or caregivers for long periods (due to rules regarding visits). A lack of mother-infant interaction in early postnatal life could impair an infant's emotional and cognitive development (Skene et al., 2016).

Health care professionals realised that care in the NICU, HCU or KMC ward should not focus on the infants only, but should include the parents or caregivers (family unit). According to Shaw et al. (2019), neonatal care has evolved to support parents or caregivers by helping them to manage or alleviate their feelings of stress or anxiety. Family-centred care, which is defined as MDTs collaborating with and supporting parents or caregivers of prematurely born infants by including them early on in the team's developmental interventions with the infant in the NICU or HCU, is now often included in neonatal care (Sweeney et al., 2010). The CPG for physiotherapists developed by Sweeney et al. (2010) to guide the management of prematurely born infants in NICUs or HCUs were based on the principles of family-centred care (Section 2.2.2.3). Skene et al. (2016) are of the opinion that family-centred care has unfortunately not yet been sufficiently implemented by MDTs working in NICUs, HCUs or KMC wards, and that there is room for improvement. The authors argue that family-centred care should be implemented as substantial evidence exists that parent or caregiver involvement in the care of prematurely born infants in NICUs could result in improved neonatal outcomes as it will reduce parental / caregiver stress and facilitate parent-infant bonding. Some of the reported positive effects on parents or caregivers who are included in family-centred care include the enhancement of their role in the care of their infants. By spending time close to their infants, they learn how to provide comforting care under the supervision of the nursing staff and other MDT members (Skene et al., 2016). Parents or caregivers who are included in a family-centred care approach not only improve their skills in the care of their infants, but also become less anxious, depressed and stressed (Ding et al., 2019). Another benefit of family-centred care is a reduction in the length of the time prematurely born infants are hospitalised, which could result in decreases costs and an unquantifiable decrease in emotional and psychological stress for parents or caregivers (Petteys et al., 2018; Skene et al., 2016).

Kangaroo mother care (KMC) is a form of family-centred care during which the mother or caregiver is in constant skin-to-skin contact with the infant and hands-on care of the infant occurs under supervision and in collaboration with the nursing staff and medical doctors. Some of the reported positive effects of family-centred care on the prematurely born infant receiving KMC include an acceleration of the 'healthy' prematurely born infant's brain maturation, accompanied by improved motor and mental development and behavioural responses (Skene et al., 2016; Vittner et al., 2018).

Other positive effects are improved cognitive development, reduced pain and increased weight gain and breast-feeding rates (Skene et al., 2016; Ding et al., 2019), as well as an improvement in the prematurely born infant's autonomic regulation, with a more stable heart rate and improved respiratory status and temperature regulation than is generally achieved by the care provided in an incubator / isolette (Vittner et al., 2018). Kangaroo mother care can therefore be regarded as a family-centred approach or strategy.

Other strategies for family-centred care could include sessions between the parents or caregivers and the MDT or a team member to improve their understanding of the prematurely born infant's behaviour and to encourage responsiveness during caregiving activities. These sessions can be viewed as parental or caregiver education (Skene et al., 2016; Ding et al., 2019). The formation of support groups (e.g. parent-to-parent support) in which the parents / caregivers are included in decision-making with regard to their infants' care and supported in managing the transition to the home environment (e.g. discharge planning) could also be seen as a family-centred strategy (Skene et al., 2016).

Physiotherapists could further educate parents or caregivers on handling techniques and activities that will enhance motor development, which could be performed with their infants during the hospital stay, but also after discharge (Byrne et al., 2019). Byrne et al. (2019) caution that physiotherapists should be sensitive to the parents or caregivers' readiness to receive and apply the knowledge and skills transferred to them. Parents or caregivers who are too emotionally overwhelmed by the NICU or HCU environment, or by their responsibilities in the KMC ward, will not be optimally empowered to participate in the management of their infants. Educational sessions on selected topics should therefore be planned so that the right topic can be addressed at the right time, taking into consideration that it can be challenging due to the parents or caregiver's experience of the NICU or HCU as unpredictable and variable.

Vittner et al. (2018) and Fernandez Medina et al. (2018) recommend that in family-centred care, MDT members should prioritise the engagement of fathers with their prematurely born infants in order to enhance the father-infant relationships.

Mothers are traditionally more involved in the care (e.g. feeding) of infants in the NICU or HCU, and fathers may initially not understand their role, or that it is essential that they too should form a bond with the infants. Physiotherapists should realise that effective partnerships between themselves and the parents or caregivers are necessary to successfully implement family-centred care in the NICU, HCU or KMC ward. Effective partnerships are based on mutual respect, valuing family expertise / habits / cultural views, sharing all information, and informed joint decision making (Butt et al., 2013).

The physiotherapist as a member of the MDT should realise the importance of communication with other MDT members, as well as with the parents or caregivers of prematurely born infants in the NICU, HCU or KMC ward, and should manage communication effectively. Shaw et al. (2019) suggest that by documenting parent or caregiver experiences and participation, the physiotherapist could tailor the care of an infant to the specific needs of the family. They recommend that MDT members should document their care / management of prematurely born infants and the support / education they provided to the parents or caregivers in a way that reflects professional accountability. Details of parents or caregivers' expectations or beliefs regarding their participation in the care of their infants are rarely recorded in the clinical records (Shaw et al., 2019). This lack of information shared with regard to expectations or beliefs could hamper the implementation of effective collaboration between MDT members, and therefore also family-centred care. If, for instance, a physiotherapist had a discussion with parents or caregivers about their beliefs or expectations, but failed to record this information in detail in the clinical records, other team members will not be aware of it and will be unable to incorporate the parents or caregiver's expectations in their treatment approach, or may have to duplicate the aforementioned discussion.

Effective communication between MDT members and the physiotherapist is important, but it is equally important for the therapist to find an effective way to communicate information to the parents or caregivers (parent / caregiver education). Byrne et al. (2019) suggest three methods of instruction that the physiotherapist could use when teaching parents or caregivers how to handle or position their prematurely born infants, namely a written-pictorial method, direct instruction and a video / DVD instruction method.

Although parents or caregivers reacted positively to all three methods, the authors found that as a teaching method the written instruction was less effective than the other two methods. The same authors report that written instructions may be less effective because direct and video / DVD instruction emphasise the clinical importance of the correct handling of prematurely born infants. Another reason may be that physiotherapists are sometimes expected to leave the instructional material at the infant's bedside for perusal by the parents or caregivers, without any further instruction. A better method would therefore be to directly demonstrate the information to the parents or caregivers or to show them a video / DVD recording to illustrate to them how their infants should be handled. Byrne et al. (2019) further found that parents or caregivers with a more formal education were better able than those with less formal education to interpret the written pictorial instructions. If possible, it is therefore advisable to provide parents or caregivers with less formal education with direct or video / DVD instructions.

In summary, the literature highlighted the expectations, emotions and beliefs of parents or caregivers as revealed during the hospitalisation of their prematurely born infants in NICUs, HCUs or KMC wards, as well as the need for physiotherapists to implement the family-centred approach in the NICUs, HCUs or KMC wards to support parents or caregivers as part of their management of the infant. It was shown that, in addition to improving the prematurely born infant's outcome, the family-centred approach could possibly decrease the stress / anxiety experienced by parents or caregivers. Physiotherapists in high-income countries where the CPG developed by Sweeney et al. (2010) has been implemented should base their interventions on the family-centred approach to care. This CPG formed the basis for the contextualised CPG suggested in this study and the research approach. The methodology applied for conducting the contextualisation is discussed in more detail in Chapter 3. The same principles and approaches that formed the basis of the CPG developed by Sweeney et al. (2010) will have to be adopted in the CPG that is contextualised in this study.

The implementation of a family-centred approach to care in clinical practice could lead to physiotherapists supporting parents or caregivers' beliefs and expectations with regard to the care of their infant in the NICU, HCU or KMC ward on the *macro level*, which could ultimately impact the infant indirectly on the *meso* and *micro levels* of development.

The definition of a CPG and the various processes by which CPGs can be developed, as well as how CPG development evolved over time and how, according to the literature, they are currently developed in SA, will be discussed in the section that follows.

2.3 DEVELOPMENT OF CLINICAL PRACTICE GUIDELINES

The literature search in this section was guided by the following questions:

- How does the literature define a CPG?
- What are the different methods used to develop a CPG?
- Which method should be applied in this study in order to develop a CPG for physiotherapists working in NICUs, HCUs or KMC wards in SA?
- What are the factors that influence the development or implementation of a CPG in SA?

Searches in the Medline, CINAHL and PubMed databases to identify relevant literature were unsuccessful. Based on the presentation by Grimmer, Dizon, Louw and Berhardsson at the World Confederation for Physical Therapy's Congress in 2017, which addressed the topic of CPG development, uptake, implementation, barriers and enablers in CPG activities in physiotherapy, the researcher performed a Google Scholar search. Professors Karen Grimmer and Quinette Louw were identified as presenters who were involved in CPG development in SA. Their names were used as key words in the Google Scholar search, which was limited to literature published in English between 2014 and 2019. The search results are shown in Figure 2.11.

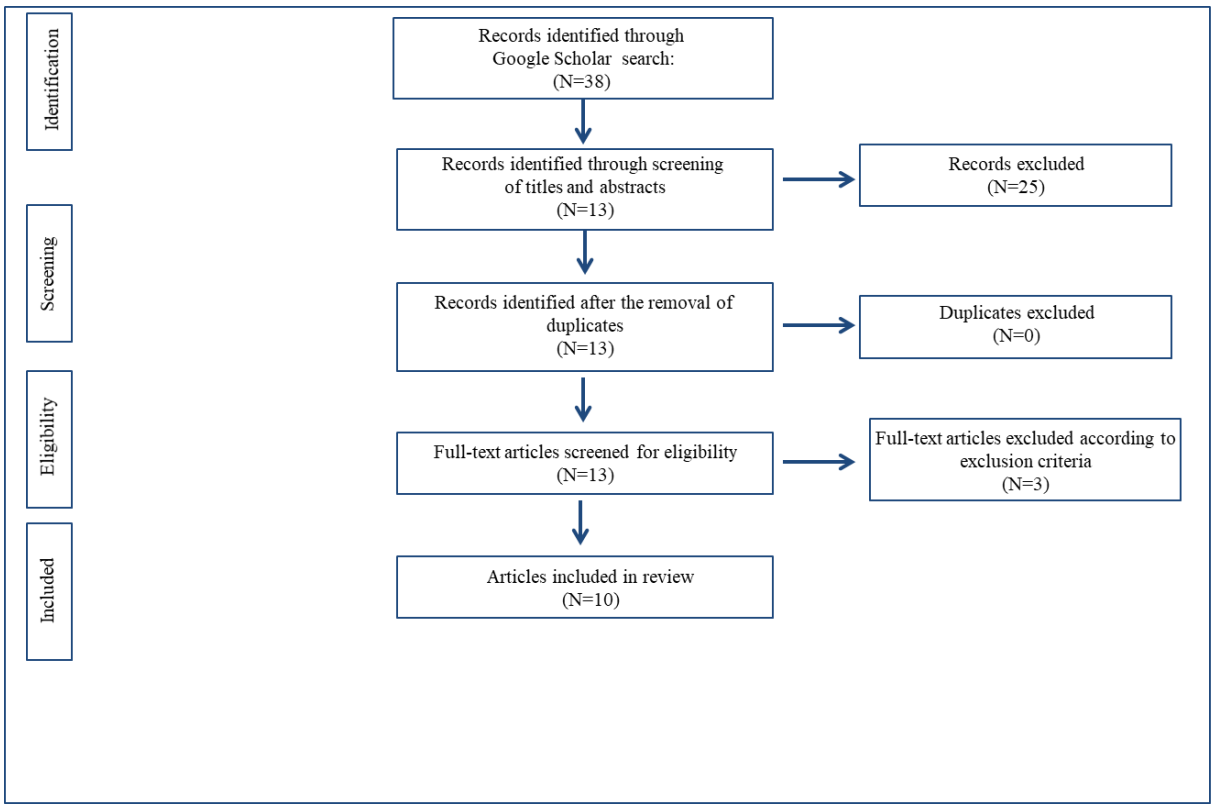


FIGURE 2.11 LITERATURE SEARCH FOR DEFINITIONS AND METHODS OF DEVELOPMENT OF CLINICAL PRACTICE GUIDELINES

The level of evidence of the articles identified for inclusion in the review is shown in Table 2.12. The hierarchy of evidence described by Sweeney et al. (2010) was used to determine the level of evidence.

TABLE 2.12 LEVELS OF EVIDENCE OF THE ARTICLES INCLUDED IN THE REVIEW TO DETERMINE THE DEFINITION AND METHODS OF DEVELOPMENT OF CLINICAL PRACTICE GUIDELINES IN SOUTH AFRICA

Article	***Level of evidence***
Dizon, Machingaidze and Grimmer (2016a)	Level V
Dizon, Grimmer, Machingaidze, McLaren and Louw (2016b)	Level V
Grimmer et al. (2016)	Level V
Kredo, Cooper, Abrams, Daniels, Volmink and Atkins (2018)	Level V
Kredo, Abrams, Young, Louw, Volmink and Daniels (2017)	Level V
Kredo et al. (2016)	Level V
Kredo, Machingaidze, Louw, Young and Grimmer (2015)	Level V
Machingaidze et al. (2018)	Level V
Machingaidze, Zani, Abrams, Durao, Louw, Kredo et al. (2017)	Level V
Machingaidze, Kredo, Louw, Young and Grimmer (2015)	Level V

2.3.1 Defining clinical practice guidelines

According to Machingaidze et al. (2018), the knowledge base of theory and practice in CPG development has evolved over the past 35 years. This evolving process indicates the increase in the complexity of clinical epidemiology, new methods of evidence synthesis and the writing / documentation of CPGs, and has led to the progression of the definition of a CPG. Three main definitions were identified in the literature. An early definition by the Institute of Medicine (IOM) in 1990 described a CPG as 'systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstance' (Kredo et al., 2016:122). The goal of the IOM's report in 1990 was to encourage the standardisation of, and consistency in guideline development. The IOM appointed a committee to provide technical assistance and advice on definitions, the key attributes of a good guideline, and how to address certain aspects of planning the implementation and evaluation of a CPG.

The initial definition was updated in 2011 to strongly emphasise the need for CPG developers to include rigorous methodology in the guideline development processes. In 2011, the IOM defined a CPG as: 'Clinical guidelines are statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options'(Kredo et al., 2016:122; Kredo et al., 2015; Machingaidze et al., 2017).

The Developing and Evaluating Communication Strategies to Support Informed Decisions and Practice Based on Evidence (DECIDE) project was launched to evaluate and improve the communication of evidence-based recommendations (CPG) to the end users (e.g. health care decision makers / clinicians) in order to improve the implementation of evidence-based research in practice (Treweek, Oxman, Alderson, Bossuyt, Brandt, Brożek et al., 2013). The end users of CPGs are those who put CPG recommendations into practice, such as service or health managers, health care providers or clinicians, policy makers, funders / insurers, regulatory authorities and / or the patients themselves (Grimmer et al., 2016; Kredo et al., 2016; Machingaidze et al., 2018). Treweek et al. (2013:6) suggest the following definition for a CPG: 'Guidelines are a convenient way of packaging evidence and presenting recommendations to healthcare decision makers.' The definition therefore evolved as the focus of developers of CPGs shifted from standardisation and consistency of development towards emphasising the importance of using a rigorous and transparent methodological process, and towards a focus on the implementation of the CPGs (Machingaidze et al., 2018; Kredo et al., 2016).

In the section under the heading Concept clarification (page xvii of the current document), the researcher mentioned that in this study a CPG is viewed as a document that contains recommendations for best practice for implementation by professionals, for example physiotherapists, to guide their practice in a specific patient population – in this case prematurely born infants.

The general consensus is that CPGs are quality-improvement tools (Machingaidze et al., 2015).

High-quality, evidence-based CPGs may be useful in bridging the gap between the policy followed in a specific ward / unit / hospital (e.g. a NICU), local contexts applicable to the country or province (e.g. SA), what, based on evidence indicate best practice should be for the management of a specific patient population (e.g. prematurely born infants) and the patient's choice (e.g. incorporating the parents or caregivers' inputs) (Kredo et al., 2016; Machingaidze et al., 2017; Kredo et al., 2015; Kredo et al., 2018; Machingaidze et al., 2015). These authors further indicated that CPGs could possibly:

- improve the effectiveness and quality of care;
- standardise, and therefore decrease variations in clinical practice;
- decrease costly and preventable mistakes;
- improve the safety of clinical practice;
- provide a benchmark or gold standard of care against which individuals or units could be audited or audit themselves;
- improve patients' access to care; and
- improve patient outcomes.

In the section that follows, the definition of CPGs and their possible uses will be clarified and the different methods of development will be discussed.

2.3.2 Methods of developing clinical practice guidelines

When planning the development of a CPG, it is important to determine who the end users will be. In the current study, the end users are physiotherapists working in NICUs, HCUs and KMC wards in SA.

In the past decade, much information has been published on how CPGs should be developed; how they should report best practice; the development process per se (for instance through adoption, contextualisation or adaptation of existing CPGs); how the quality of the CPG should be evaluated; and how it should be implemented (Kredo et al., 2016).

During this time the processes for developing CPGs have also shifted from CPGs being written by experts (based on expert opinion) to being written mainly by methodologists who make use of transparent, evidence-based approaches that integrate expert opinion with patient values (Machingaidze et al., 2015; Kredo et al., 2015).

The development of CPGs has also improved in respect of the accessibility of CPGs for end users; evaluation (critical appraisal) instruments for the assessment of the quality of a CPG; adaptation or contextualisation processes for developing a CPG; and the implementation of CPGs (Machingaidze et al., 2017).

If a rigorous methodological approach is not followed when writing CPGs, there are three possible pitfalls. First, poor-quality CPGs may be adopted by their end users, which could lead to poor quality service delivery and poor patient outcomes. Second, the lack of well-developed, easily accessible CPGs may undermine the commitment made by end users to ensure that current best evidence is put into practice, especially in low- and middle-income countries where there is a shortage of health care providers and time and human resources are limited (Machingaidze et al., 2017). Third, Machingaidze et al. (2015) suggest that without adherence to rigorous guideline development and reporting standards, the considerable time and effort put into developing CPGs might be wasted as the intended end users may lack confidence in the CPG recommendations.

The factors that are important in identifying / selecting an appropriate method for developing a CPG are discussed in the following sections.

2.3.2.1 Regulation of quality when developing clinical practice guidelines

There is no internationally agreed-upon standard approach for developing or constructing CPGs (Machingaidze et al., 2017). However, there is a general expectation that the recommendations included in a CPG should be transparent and based on current best evidence (Grimmer et al., 2016).

Due to the increased interest in CPG development shown by different developmental groups, such as the Scottish Intercollegiate Guidelines Network (SIGN), the Guidelines International Network (GIN) and the National Institute for Health and Care Excellence (NICE), evidence is reported in different ways, which makes it difficult to compare the guidelines (Machingaidze et al., 2018). If CPGs are compared internationally, one would not only find differences in the CPG writing processes and terminology, but also in the ways in which information is reported or presented to the end users. These differences highlight the fact that CPG development should be standardised internationally (Machingaidze et al., 2018). Standardised criteria would enable future CPG developers to identify research gaps in the CPG process for updating evidence and successfully transferring existing evidence developed in one setting to a different setting (Machingaidze et al., 2018). Between 2011 and 2013, the IOM group, the GIN group and McMaster University (Machingaidze et al., 2017; Machingaidze et al., 2015; Kredo et al., 2015) independently developed three sets of standards to assist CPG developers in addressing key quality issues (Kredo et al., 2018).

Developers of CPGs have a choice between two instruments / checklists for the critical appraisal of a CPG, namely the Appraisal of Guidelines for Research & Evaluation II (AGREE II) instrument and the International Centre for Allied Health Evidence (iCAHE) guideline quality checklist (Kredo et al., 2018; Kredo et al., 2016; Grimmer et al., 2016). Both checklists were developed for use in the critical appraisal of the quality of a CPG and to encourage developers to follow a transparent, evidence-based approach to develop CPGs for clearly defined purposes (scope) in consultation with stakeholders (patients or health care professionals) (Kredo et al., 2018).

When using the AGREE II instrument for the critical appraisal of a CPG, more than one scorer is required, while critical appraisal of a CPG with the iCAHE checklist requires only one scorer (Kredo et al., 2016). The same authors further explain that both instruments / checklists include criteria for the CPG development process, i.e., for the methods to be used by CPG developers to establish what the body of evidence used to support the recommendations listed in the CPG entail, and to report on the findings. The AGREE II instrument is internationally recognised for its effectiveness for the critical appraisal of a CPG and has also been endorsed by the South African Medical Journal as the instrument of choice for assessing the quality of a CPG developed in SA (Machingaidze et al., 2017).

The iCAHE guideline quality checklist is viewed as a simpler, more user-friendly checklist. Grimmer et al. (2016) state that, depending on the complexity of the CPG layout, scoring by using the iCAHE checklist takes between 5 and 10 minutes. The AGREE II instrument requires up to an hour per scorer for the appraisal of a CPG. The authors further state that the choice of instrument depends on the purpose of the appraisal, the time available and whether appropriate additional people are available to implement the AGREE II instrument. The researcher decided to use the AGREE II instrument for this study as it is nationally and internationally recognised as the instrument of choice. Table 2.13 lists the domains or question groups for both the AGREE II instrument and the iCAHE checklist.

TABLE 2.13 DOMAINS AND QUESTION GROUPS LISTED IN THE AGREE II INSTRUMENT AND THE iCAHE CHECKLIST

AGREE II instrument	iCAHE checklist
Scope and purpose	Availability
Stakeholder involvement	Dates
Rigour of development	Underlying evidence
Clarity of presentation	Guideline developers
Applicability	Guideline purpose and users
Editorial independence	Ease of use
Overall assessment	

The two abovementioned instruments share the following four domains or question groups (Grimmer et al., 2016):

(1) Scope and purpose (AGREE II instrument); Guideline purpose and users (iCAHE checklist)
(2) Stakeholder involvement (AGREE II instrument); Guideline purpose and users (iCAHE checklist)
(3) Rigour of development (AGREE II instrument); Underlying evidence (iCAHE checklist)
(4) Clarity of presentation (AGREE II instrument); Ease of use (iCAHE checklist)

These shared domains or question groups will be discussed in the following section.

(1) Scope and purpose or guideline purpose

The purpose of a CPG intrinsically links with the end users (physiotherapists in the current study) and the target population (prematurely born infants and their parents or caregivers).

The scope of the CPG underpins the formulation of the research question(s), which determines what the CPG should address (the scope) (Machingaidze et al., 2015). These authors further suggest that CPG developers should define the scope and purpose of the CPG early on in the development process to facilitate the selection of the methodological approach to be followed. The methodological approach may be influenced by factors such as deciding which stakeholders need to be engaged (patients or health care professionals), how they should be incorporated, and whether interviews or surveys should be used (Machingaidze et al., 2015).

(2) Stakeholder involvement or guideline users

Stakeholders can be seen as the group that will benefit from the CPG to be developed. In the case of this study, the stakeholders included the physiotherapists who were likely to implement the CPG in their clinical practice and could also include parents or caregivers and prematurely born infants. Developers of CPGs should incorporate the stakeholders in the CPG development process, either by eliciting their opinions on the health care area that the CPG aims to address, or by involving them in the development of recommendations to be included in the CPG. When end users of the CPG recognise the involvement of relevant stakeholders in the development process, they may more readily implement the CPG in their practice (Machingaidze et al., 2015). A reason for this could be that the stakeholders who were part of the development process represented the end-user population (and their opinions or concerns) in the consultation process. Unless end users have confidence in the quality of the evidence underpinning CPG recommendations and the process of CPG development followed, they are unlikely to adopt the CPG in their practice (Grimmer et al., 2016). Stakeholder engagement can either involve individuals, in which case they act as ‘experts’ in consultation with the methodology team / CPG developers on a one-on-one basis, or groups of stakeholders who are asked to collectively provide feedback on CPG drafts (Machingaidze et al., 2015).

(3) Rigour of development or underlying evidence

Machingaidze et al. (2015) suggest that CPG developers should include a comprehensive discussion on the methodology used to develop the CPG and should state the research question(s), discuss the methods used to identify relevant literature, and explain how it was accessed. The method used for the critical appraisal of the literature and the appropriateness of the data extracted have to be explained, as well as how the strength of the body of evidence was established and reported. The CPG developers should further include a comprehensive reference list that can be accessed by the CPG users who would like to identify the literature that was included. Two main approaches were highlighted by the literature to support CPG developers in the systematic and comprehensive process of synthesising the evidence, namely the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach and the Formulating Recommendations Matrix (FORM) approach (Kredo et al., 2016). By following one of these two approaches, CPG developers may be able to summarise the body of evidence in systematic reviews and formulate recommendations that might be relevant to the local context in a standardised, transparent manner.

The AGREE II instrument and the iCAHE checklist (in the question group 'Dates') further highlight the importance of updating a CPG after the completion of the initial implementation. Very little research or evidence is available on the CPG updating process (Kredo et al., 2016). The CPG developers should ensure that the CPG is based on the best current evidence, since maintaining the currency or relevance of the evidence of the CPG has proven to be a constant challenge (Machingaidze et al., 2015). The CPG has to be regularly updated, but not before the developers have informed themselves on the most recent evidence on the specific health topic being addressed (found in the literature / through a new literature search). Second, the developers should determine whether, in the light of new evidence, the research questions addressed in the original CPG are still relevant. Relevant new findings should then be included in the CPG's previous recommendations by making use of a standardised approach (Machingaidze et al., 2015). During the updating process, the CPG developers should follow a rigorous, transparent process, which should be well documented to improve the trustworthiness of the updated version (Kredo et al., 2016). The updating process is not addressed in the current study, but the researcher acknowledges the importance of this process and will refer to it in her recommendations for future research.

(4) Clarity of presentation or ease of use

While there is international consensus regarding the key quality components that should be included in CPGs (as described by the AGREE II instrument and iCAHE checklist), there is no standardised layout prescribing what the actual document or CPG should 'look' like (Machingaidze et al., 2018). A lack of standardisation in the layout of a CPG leads to major differences in its presentation. Examples are given in section 2.3.2.2. Developers of CPGs should ensure that the end product is a clearly formulated document with comprehensive supporting documentation (Machingaidze et al., 2015). A clearly written document with a standardised layout should assist end users to implement the recommendations into clinical practice (Kredo et al., 2016; Machingaidze et al., 2017). In the current study, the researcher used the AGREE II instrument to guide the formulation of a user-friendly end product.

Domains that are specifically addressed in the AGREE II instrument, but not in the iCAHE checklist, are discussed in the following sections.

(1) Applicability

This study did not focus on the implementation of the CPG, but a further investigation in this regard will be recommended for future research. Nevertheless, the implementation of the CPG is vital and should be addressed specifically. The AGREE II instrument has a specific domain for the implementation of the CPG, which includes the assessment of possible barriers or facilitators for implementation, advice on how the CPG should be implemented, tools to be used for this purpose, potential resource implications of the implementation of the CPG, and how the implementation of the CPG should be monitored based on auditing criteria. On the whole the relevant literature offers little in the line of decisive guidance or recommendations on how CPGs could be successfully implemented (Kredo et al., 2016).

The successful implementation of a CPG may require a behavioural change by its end users as it may require the implementation of evaluation or intervention practices not previously used by them. For behavioural change to be successful, CPG developers should consider the context in which the CPG may be used. The recommendations included in the CPG should therefore be relevant to the end user's place of work / patients being treated (Kredo et al., 2016).

Other barriers that could negatively affect the implementation of the CPG include a lack of time on the part of the end users, inadequate financial resources if new equipment is needed or suggested (by the clinician or hospitals), and a lack of knowledge if techniques are suggested that the end users are not qualified to perform (Grimmer et al., 2016). Dizon et al. (2016a) state that to improve the chances for the successful implementation of the CPG, the developers should highlight the comprehensiveness and relevance of the evidence base included in the CPG and aim to obtain the acceptance of the CPG by local policy makers, clinicians and / or patients. The authors also mention other factors that should be considered when assessing whether the CPG could be successfully implemented, which are to determine (i) whether the CPG has cultural relevance (for end users and the patient population); (ii) whether the CPG is relevant to the local health care context in which it will be implemented, for example, whether the health care availability, equity and the patient population's access to care were addressed; and (iii) whether the implementation of the CPG is affordable. Machingaidze et al. (2018) are of the opinion that barriers to the implementation of a CPG could be identified and effectively addressed with expert input and consideration of local contexts.

The models and frameworks available to assist CPG developers with the process of implementing a CPG include the Guideline Implementability for Decision Excellence Model (GUIDE-M), the Promoting Action on Research Implementation in Health Services Framework, and the Consolidated Framework for Implementation Research and the Theoretical Domains Framework (TDF) (Kredo et al., 2016). However, these authors found that only 20% of the 235 CPGs evaluated in a study had made use of a specific implementation theory / model / framework (Kredo et al., 2016).

(2) Editorial independence

The CPG developers should declare potential conflicts of interest and the views of the body from which funding was received to develop the CPG, and must explicitly state that the CPG developers acted as independent researchers in the process followed to identify and critically appraise the body of evidence included in the CPG.

The search strategies for appropriate literature and research evidence (the search trail) should be clearly and comprehensively described so that they can be repeated by other researchers. This will limit bias during the research / CPG development and avoid competing interests of participants (Machingaidze et al., 2015).

After identifying the factors that influence the quality of a CPG and need to be taken into consideration during its development, the focus now shifts to the CPG development processes in SA, as described in the literature reviewed.

2.3.2.2 Approaches to the development of clinical practice guidelines in South Africa

The improvement of guideline development processes to better serve the South African health care system (primary care) requires an understanding of the current practices of guideline development and reporting (Machingaidze et al., 2017). If all CPG developers could consistently make use of established methodological processes when they develop CPGs, it would be possible to standardise the development of CPGs. A CPG based on the best research evidence could help to make the end users more confident about the application of the recommendations in practice, and could therefore improve the implementation of the CPG (Machingaidze et al., 2017). The literature consulted (Kredo et al., 2015; Machingaidze et al., 2018; Kredo et al., 2017) indicates that in SA CPGs for primary health care have been developed at the national, provincial and local health care levels by the Departments of Health and at facilities (hospitals), as well as by non-governmental organisations (NGOs). Academic departments at universities and professional societies also develop CPGs to address areas in fields of practice for which the National Department of Health has not yet provided CPGs (Kredo et al., 2018). Medical / health insurers also play a role in guideline development in SA (Kredo et al., 2015).When compared to global standards, it is clear that the CPGs developed in SA do not yet include all the aspects of the expected guideline quality indicators (as described in section 2.3.2.1) (Kredo et al., 2015).

According to Kredo et al. (2015), CPGs developers in SA should: (i) improve their knowledge of the overall context and processes of guideline development; (ii) undertake the implementation of the CPG and ensure the end user's adherence to its recommendations; and (iii) be aware of factors that could improve the accessibility of CPGs in the local health care context and should, for instance, make health care providers aware of the availability of CPGs and where they can be accessed.

In 2014, the South African Medical Journal, recognising the need for the improvement of the quality of CPGs, appointed an editorial subcommittee with the specific mandate to review CPGs submitted for publication (Machingaidze et al., 2015). Another initiative to improve the quality of CPGs developed in SA was the South African Guidelines Excellence (SAGE) project (Machingaidze et al., 2015; Kredo et al., 2015; Kredo et al., 2017). SAGE is a partnership between Cochrane South Africa, the Centre for Evidence-based Health Care in the Department of Physiotherapy in the Faculty of Medicine and Health Sciences, Stellenbosch University and the International Centre for Allied Health Evidence, University of South Australia (Kredo et al., 2015). The SAGE team's goals were to understand the guideline development arena in SA, to provide tools to improve the standard of CPG development, and to assist CPG developers in SA to effectively make use of the CPG development methodology according to which they have to develop, adapt, adopt or contextualise and implement primary care CPGs (Machingaidze et al., 2015; Kredo et al., 2015; Kredo et al., 2017).

SAGE introduced a Clinical Practice Guideline Development Framework that is based on a transparent evidence-synthesis processes (Tier 1) and the inclusion of clinical contexts (Tier 2), which support the end product(s) that are tailored specifically for different contexts, purposes and users (Tier 3) (Dizon et al., 2016a; Machingaidze et al., 2018). The three-tier framework or model is shown in Figure 2.12.

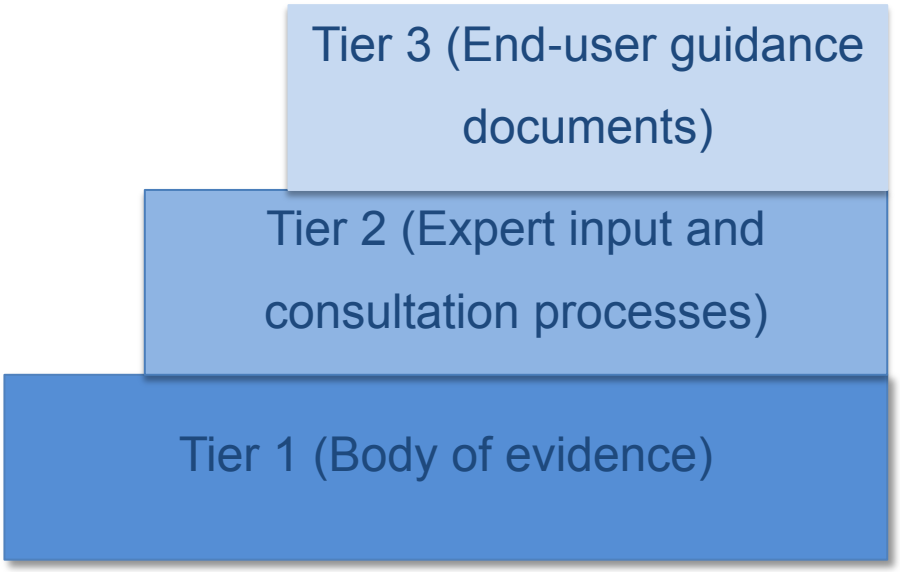


FIGURE 2.12 THE CONCEPTUAL MODEL, AS DESCRIBED BY MACHINGAIDZE (2018:9)

- ***Tier 1 (body of evidence)***

The body of evidence provides the foundation for the CPG and should include literature that answers the research question formulated by the CPG developers during the initial stages of development (Dizon et al., 2016a). The evidence included in Tier 1 should be based on transparent, comprehensive and systematic literature searches and reviews. A CPG without a credible and robust body of evidence cannot be viewed as a document of high quality, with the result that the end users might not trust its recommendations and might therefore refrain from implementing them (Machingaidze et al., 2018).

- ***Tier 2 (expert opinion and consultation process)***

CPG developers cannot rely on expert opinion alone when developing a CPG, due to the risk that the experts might present selective, non-current, misleading or biased views of the available evidence (Dizon et al., 2016a). Expert opinion could, however, assist CPG developers in establishing the relevance and applicability of the body of evidence (identified in Tier 1) to local contexts (Machingaidze et al., 2018), which may include a variety of issues that are often not addressed or reported in the body of evidence.

Experts could provide information regarding these issues, such as local health care systems, the names of available health care providers (MDT members), the training health care providers receive or should receive, available infrastructure and resources, the burden of disease for a specific patient population, and patient needs (Dizon et al., 2016a). The information received from local experts could assist CPG developers to formulate recommendations (identified in Tier 1) in a way that could address end user needs, take health care culture into account and address implementation barriers. The formulation of relevant recommendations in Tier 2 (using information received from local experts) could make the CPG relevant to the local (SA) health care system. The CPG developers could further use different methods to obtain expert opinions, for example by making use of a robust research method such as the Delphi method (Dizon et al., 2016a).

- ***Tier 3 (end-user guidance documents)***

The end user guidance documents or CPGs are the end products of CPG development processes. A CPG should include the developers' recommendations (Tier 1) based on their systematic literature search and presented in a way that includes the information obtained from local experts (Tier 2) (Machingaidze et al., 2018). The CPG as the end product should comply with the list of factors that determine the quality of a CPG, as discussed in section 2.3.2.1. A high-quality CPG that is transparent and based on a sound methodological process should be accepted as trustworthy by the end users, who should be able to implement the recommendations in their practice (Machingaidze et al., 2018). The SAGE group states that the Tier 3 document can be one of three types of documents, namely (i) an evidence-based summary of recommendations; (ii) a patient management tool; or (iii) a protocol (Machingaidze et al., 2018). These three types of documents are described as follows:

(i) An evidence-based document contains a summary of the recommendations based on the literature (evidence) that was identified by way of a systematic literature review during which an identified body of evidence was critically appraised and the recommendations for best practice relevant to the research question were included. The information relating to local content obtained from local experts must be included in the recommendations. The evidence-based summary of the recommendations document may include prompts for health care providers, for example pictures, a summary of the recommendations linked to references from the body of evidence, checklists and / or resource material.

(ii) Patient management tools (PMTs) are intended for the use of frontline health care professionals who have to make decisions about diagnoses, immediate treatment and the long-term management of patients. These decision-support tools could include pictures, algorithms, management checklists, lists of symptoms, treatment options and referral pathways.

(iii) Protocols provide step-by-step guidance on how to carry out specific health care tasks (e.g. drawing blood). Protocols are used when there is only one correct way to carry out a specific task and could be illustrated by using a step-by-step diagram. Protocols could be included in the evidence-based document containing a summary of recommendations, or in the PMT.

In the current study the CPG / end product is described as an evidence-based summary of recommendations since the researcher completed a literature search to obtain recommendations for best practice. The researcher included expert opinions to ensure that the recommendations were relevant to physiotherapists' practice in NICUs, HCUs or KMC wards. A detailed description of the methodological process followed in this study is provided in Chapter 3, section 3.2.

The SAGE group suggested that CPG developers in SA should determine which CPG development approach they should follow to best satisfy their needs, namely to adopt, adapt or contextualise CPGs from another country / health care facility. These three approaches make use of the existing high-quality evidence base of international guidelines (identified in the systematic literature search in Tier 1) developed in other countries for similar target patient populations and end users (Dizon et al., 2016a). The three approaches (adopt, adapt and contextualise) therefore do not develop a 'new' Tier 1, but focus on the incorporation of expert opinion and local context (Tier 2) to produce a document that is relevant to the health care environment and the end user population (Tier 3). The CPGs developed by using these three approaches should be appropriate for the clinical settings for which they were developed (Dizon et al., 2016a). The SAGE group acknowledges the value of taking a developed CPG in one country and applying it to other countries by adopting, adapting or contextualising it. The development of a different / new CPG (starting from scratch) by using the De Novo approach should be avoided (Kredo et al., 2016) as it is an expensive, time-consuming approach that requires a dedicated team of developers.

More information about the De Novo approach is discussed in section (1) below. Considering the cost, time and human resource implications of the De Novo approach, CPG developers in SA would be well advised to rather use an alternative approach, i.e. adopt, adapt or contextualise (Dizon et al., 2016a).

The terminology relating to the different CPG development approaches is not clearly described in the literature and lends itself to different interpretations. The terms contextualisation and adaptation, for example, were found to be used interchangeably even though they refer to different approaches requiring different CPG development procedures (Dizon et al., 2016a). Internationally there is no consensus regarding the appropriate terminology for describing the process of adapting CPGs used in one health system or setting for use in another (Kredo et al., 2016). It is therefore important to clarify the approaches to the development of CPGs, such as the De Novo, contextualisation, adaptation and adoption approaches, before selecting an approach for developing a CPG.

(1) De Novo approach

As mentioned in the preceding section, the De Novo approach is expensive and time consuming and requires a dedicated team of methodologists and experts to complete systematic literature searches, appraise the literature, and debate the usefulness and relevance of the body of evidence that could provide relevant clinical guidance to the end users of the developed CPG (Dizon et al., 2016a). A large volume of literature and guidelines is available to support the De Novo approach. The guidelines include those developed by the IOM group, the GIN group and McMaster University (section 2.3.2.1). The De Novo approach has been the preferred approach internationally, especially in high-income countries where resources are readily available (Dizon et al., 2016a).

The SAGE group determined that CPG developers in SA should use this approach only if a true gap exists in the available guidance on a specific health care topic. However, before the De Novo approach is applied, the gap should be verified by a comprehensive literature search to identify any CPGs that might answer the research questions (Kredo et al., 2016).

Making use of existing CPGs that were developed elsewhere and implementing a structured, transparent process to make recommendations relevant to local contexts might not only be a valuable alternative for CPG developers in SA, but may also provide a way of breaking down barriers to implementation (Dizon et al., 2016a).

(2) Contextualisation approach

The Philippines Academy of Rehabilitation Medicine (PARM) group proposed an innovative contextualisation approach for identifying relevant best-practice guideline recommendations and integrating the recommendations into a typical Filipino patient pathway (Dizon et al., 2016a; Gonzalez-Suarez et al., 2012). The PARM group identified local 'context points' relevant to Filipino health care settings and incorporated this information in the recommendations. The contextualisation process supported the implementation of the CPG (Gonzalez-Suarez et al., 2012). The International Society of Physical and Rehabilitation Medicine view the contextualisation approach as the best alternative to the De Novo development approach for low- and middle-income countries (Dizon et al., 2016a; Kredo et al., 2016; Kredo et al., 2018).

The SAGE group explained the contextualisation process by referring to the three-tier framework or model (Figure 2.12). The evidence base (Tier 1) and the resultant recommendations (Tier 3) remain the same as in the original 'borrowed' CPG and are therefore adopted. There are, however, additional Tier 2 processes (expert input) that assist in making the recommendations in Tier 3 more relevant to the local health care context, which in turn assists with the implementation of the CPG by the end users (Dizon et al., 2016a). The local context points that should be considered by CPG developers in Tier 2 of the CPG development process include obtaining information from the local stakeholders, for instance the health care professionals (end users) that might implement the CPG in their clinical practice. In the current study, the researcher included the opinions and information provided by the physiotherapists who are likely to be the end users of the CPG developed in this study. The CPG developers should take the training of the health care professionals (end users) into consideration. If a CPG includes recommendations for which the local professionals have not been trained, or with which they are not familiar, it would make the recommendations irrelevant to the particular end-user group.

The CPG developers should also consider the patient population for which the CPG is developed and should determine whether these patients have access to health care, and how access to health care services could differ from that of the original target population (Dizon et al., 2016a).

The researcher decided to implement this approach in the current study. A detailed description of the methodology followed in the contextualisation approach will follow in Chapter 3, section 3.2.

(3) The adapt approach

The ADAPTE collaboration started the process of defining an adaptation approach that allows for the implementation of guidelines from one health care setting in another. The ADAPTE collaboration created a manual and resource toolkit to assist CPG developers in the adaptation process (Dizon et al., 2016a). The SAGE group identified areas in the ADAPTE manual that lacked detail in the explanations of how recommendations in the guidelines developed in high-income country settings should be transferred to low- or middle-income country settings (Kredo et al., 2016).

The SAGE group described this approach according to the three-tier framework or model (Figure 2.12). In Tier 1, the CPG developers may base their CPG on the body of evidence of the original CPG, or they may choose to change / expand the body of evidence depending on whether the guideline questions remain relevant in the new health care setting. Adaptation may occur within the Tier 2 process where the CPG developers may revise the way in which the recommendations are formulated / worded or presented in the Tier 3 document. In summary, to adapt a CPG requires a permanent change to the original CPG document where additional literature searches identify and include local information to support substitution, or a change in the original recommendations. The adaptation process ensures that the adapted CPG recommendations are relevant to local contexts (Dizon et al., 2016a).

(4) The adopt approach

Clinical practice guideline developers who decide to implement the adopt approach should commit to implementing the identified CPG's recommendations exactly as proposed and written into the new health care setting (Dizon et al., 2016a). A high-quality CPG, developed by applying the De Novo approach, should be based on a comprehensive, systematic literature search that developed based on evidence for Tier 1 (as previously mentioned). The comprehensive literature search would have identified all the relevant research evidence and not only the research evidence from the country where the CPG is being developed. Clinical practice guideline developers could therefore adopt a CPG developed in a country with a similar health care system, patient population and burden of disease (Dizon et al., 2016a). In such a case the developers could expect that the adopted recommendations will be as applicable, relevant and effective in their local health care context as they are in the country (health care system) in which they were developed. In the case of countries like Australia and the UK, which have developed market economies and similar patient populations, health care systems and resources, it should be possible to successfully adopt and implement a high-quality CPG developed for one for use in the other (Dizon, Grimmer, Louw, Kredo, Young and Machingaidze, 2016c).

After discussing the quality aspects with which the development of CPGs should comply (see section 2.3.2.1) and the methods or approaches recommended by the SAGE group for use by developers of CPGs for SA, the problems areas identified in the literature with regard to the existing CPGs used / implemented in SA were summarised in the following section.

Machingaidze et al. (2018) state that, in order to be able to manage the increasing prevalence of communicable and non-communicable diseases in SA, standardised CPGs that are based on the best evidence are needed. These authors further report that human and financial resources for developing and implementing CPGs have been constrained for about three decades (Machingaidze et al., 2018).

Problems identified when the quality of the CPGs currently used in SA was appraised using the AGREE II instrument included:

- Many of the CPGs did not report on the development process, i.e., they failed to describe the literature search, the inclusion or exclusion criteria for literature to be used, or how the evidence was used in order to make the recommendations in the CPG. The strength of the body of evidence was not linked to the recommendations (Machingaidze et al., 2017; Kredo et al., 2017). The CPGs therefore score poorly in the rigour and development domain. Machingaidze et al. (2018) explain that the focus of CPG developers in SA might not have been on comprehensive reporting of the CPG methodology, but rather on developing a user-friendly guidance document for the end users. The documents should therefore not have been called CPGs, but rather guidance documents. The quality of currently used CPGs could have been improved if developers had made use of the AGREE II principles as a development framework (Machingaidze et al., 2018).

- Kredo et al. (2017), who identified poor reporting of editorial independence in the CPGs, also found that end users believe that developers or other stakeholders (who have an interest in the development of the CPG) might in some instances manipulate CPG development. Clinical practice guideline developers have to describe the methodology they used in a transparent way and should clearly describe their own involvement in the development process. If developers fail to declare their involvement in the development process, end users will find it difficult to trust the CPG and could then prefer to not implement the recommendations in their practices.

- Limited stakeholder involvement was identified as a limitation in the CPGs developed in SA. The views of end users or patient populations were not included in the process of development or described in the documents. Clinical practice guideline developers should also incorporate a description of the local context in the recommendations, and if stakeholders (end users or the patient population) are not consulted during the development process, implementation may be limited (Machingaidze et al., 2017; Kredo et al., 2018).

- A lack of adequate human resources (e.g. if not all the MDT members are available to provide a service) for health care, as well as a fragmented health care system, are commonly reported problems in SA, particularly in rural districts (Kredo et al., 2017; Kredo et al., 2018). The fragmentation of government programmes and the disparity between the public and private sectors also contribute to problems relating to who should take ownership of the CPG development process (Kredo et al., 2018). For example, the values for addressing inequitable service delivery that are commonly shared by CPG developers representing the different development groups, such as the Department of Health, professional organisations and hospitals, might motivate them to improve the quality of the CPGs that they develop (Kredo et al., 2017).

A frequent recommendation throughout the literature reviewed was that a central, nationally recognised and accepted CPG development unit should be established in SA. The existence of such a unit should increase opportunities for CPG developers to communicate with one another and to possibly standardise the process of CPG development (Machingaidze et al., 2017; Machingaidze et al., 2015; Machingaidze et al., 2018; Kredo et al., 2017). The CPG development unit should advocate for transparent methodological development procedures, as well as for the documentation and management of developers' independence or potential conflict of interests, and make provision for financial relationships and sources (Kredo et al., 2018). A central, nationally recognised and accepted CPG development unit could limit or prevent possible duplication due to the improvement of communication between national CPG development groups (Kredo et al., 2017; Kredo et al., 2018).

The identification of the limitations in the current CPGs used in SA enabled the researcher to formulate the methodological approach used in this study. The discussion of the approach chosen for the development of a CPG, namely the contextualisation approach, raised the researcher's awareness of potential problems that should be avoided during development of a CPG for use in SA. In the following section, the SA health care context will be described.

2.3.2.3 The South African health care system in which clinical practice guidelines are developed or implemented

When developing a CPG, it is essential to consider the South African health care system in which it will be implemented once it has been approved and adopted by the South African Society of Physiotherapy (SASP).

Primary health care is the current main framework used in SA, and by making use of this framework health care providers aim to provide effective, efficient, integrated and accessible care to the greatest possible number of people living in SA (Dizon et al., 2016b). General practitioners, nurses or other rehabilitative health care professionals (such as physiotherapists) provide primary health care services and are regarded as the first point of entry into the health care system. The goals of primary care are to promote health and prevent disease through early diagnosis, management and referral to secondary and tertiary care, thereby providing the potential for continuity of care for each patient (Dizon et al., 2016b; Machingaidze et al., 2018).

The management of prematurely born infants in SA takes place in both the public and private health care sectors and on both the secondary and tertiary levels of care. Prematurely born infants and their parents or caregivers can follow a patient journey in either of the health care sectors. The differences between the public and private health care sectors and the different levels of care formed part of the research process for the current study and are described in detail in Chapter 4.

It is the responsibility of the National Department of Health to ensure that all patients have access to standardised public health care (Machingaidze et al., 2017). The contextualised CPG that was developed in the current study was developed for the dual health care system currently in place in SA.

Physiotherapists as members of MDTs or the rehabilitative health professionals work in different sectors of the health care system.

Physiotherapy is taught in eight South African universities located in seven of the nine provinces and physiotherapy services are rendered in the private health care sector, mostly at community-based private practices funded by patients with or without private medical health insurance (Dizon et al., 2016b). Physiotherapy services are also rendered at hospitals / clinics and practices on the national, provincial and district levels in the public health care sector. The clinical structures where physiotherapists were found to be working in the public health care sector differed between provinces, particularly with reference to primary care and disability portfolios, since each province approaches rehabilitation and physiotherapy-specific activities differently (Dizon et al., 2016b). The clinical structures were found to rely on the specific patient population's needs, workforce availability (how many physiotherapists were available at the hospital) and local resource constraints (e.g. financial or equipment constraints) (Dizon et al., 2016b).

The primary health care re-engineering strategy that is currently being implemented in SA aims to strengthen the district health care system through the establishment and efficient functioning of district and sub-district management teams (Machingaidze et al., 2017; Kredo et al., 2015). These teams include a professional nurse, environmental health and health promotion practitioners and community health workers. Physiotherapists are not members of these teams, but patients can be referred to them, and if needed to tertiary / academic hospitals, by the district / secondary hospitals.

Inequalities in health care delivery and outcomes in the public health care sector between urban and rural settings, as well as in and between provinces, persist and have led to the re-engineering strategy for the health care system (Kredo et al., 2017).

The plans for universal health coverage announced by the Minister of Health are described in the National Health Insurance (NHI) White Paper (Kredo et al., 2017). The primary goal of the NHI system is the delivery of quality health service to ensure that all South African citizens are provided with essential health care, regardless of their employment status and ability to make a direct monetary contribution to the NHI Fund (DOH, 2018; Kredo et al., 2017). The NHI initiative therefore is aimed at reducing the inequality of health care provision and will require new approaches to health care delivery focused on health promotion and preventative activities (Kredo et al., 2015).

The CPG contextualised in the current study was aligned with health promotion and preventative care for prematurely born infants. Kredo et al. (2015) explain that health care providers (including physiotherapists) in a changing health care system need clear and trustworthy guidance (in the form of CPGs) in order to provide the best care possible to their patients. When the NHI system is implemented, current CPGs may have to be updated to address possible new challenges in the health care system (Kredo et al., 2017). The researcher therefore included the recommendation that the CPG contextualised in this study be updated to ensure that the CPG remains relevant in the new NHI health care system that is being envisaged.

2.4 SUMMARY OF THE CHAPTER

In this chapter the researcher discussed prematurely born infants and their parents or caregivers as a vulnerable patient group that could benefit from physiotherapy intervention in NICUs, HCUs or KMC wards. Such intervention offers the benefit of, for example, reducing the possibility and impact of the *meso level* (environment) on infants' morbidities that could potentially have a negative impact on infants' lives. Physiotherapists have a role in all four layers of the eco-systemic model of influences that affects the management of hospitalised prematurely born infants (Figure 1.3, Chapter 1, section 1.2). The researcher also indicated how the eco-systemic model, the dynamic systems model and the ICF integrate with each other. To ensure an optimal family-centred care approach, the focus of physiotherapy intervention should not be aimed only at the infant, but also at their parents or caregivers.

It was established that a need existed for transparent, high-quality CPGs to guide physiotherapy practice in a changing health care environment. The methodology followed by the researcher in contextualising the CPG will be discussed in the Chapter 3.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

In the previous chapter, the literature dealing with the process of contextualising CPGs and the reasons for choosing this process for this study, as well as the potential impact of the contextualised CPG resulting from this study on the care of prematurely born infants in SA were discussed. In this chapter the methodology followed in each of the three phases of the current study will be described. Due to the nature of the research question that the current study attempts to answer (Chapter 1, section 1.4), a mixed methods study approach was followed to answer the question and achieve the aims and objectives of this study. The research design will now be discussed in more detail.

3.2 THE RESEARCH DESIGN

The phases in which the qualitative research paradigm was mainly used were Phases 1 and 2 of the current study. These two phases consisted of MDT focus group discussions, parent / caregiver interviews / an online survey and an integrative literature search. From the data collected in Phase 1, four different patient journeys were 'compiled', which represented the pathways of care for prematurely born infants in SA. These patient journeys were integrated with the literature selected during the integrative literature search in Phase 2 of the study to compile a questionnaire to gather information on the current physiotherapy management of infants in NICUs, HCUs and KMC wards. The questionnaire was compiled in preparation for Phase 3, in which the Delphi method was used to validate and finalise the statements and evidence-based recommendations for inclusion in the contextualised CPG. The Delphi method falls within the quantitative research paradigm. The research design used for this study was therefore a mixed methods design.

The combination of qualitative and quantitative approaches throughout the study is demonstrated in Figure 3.1.

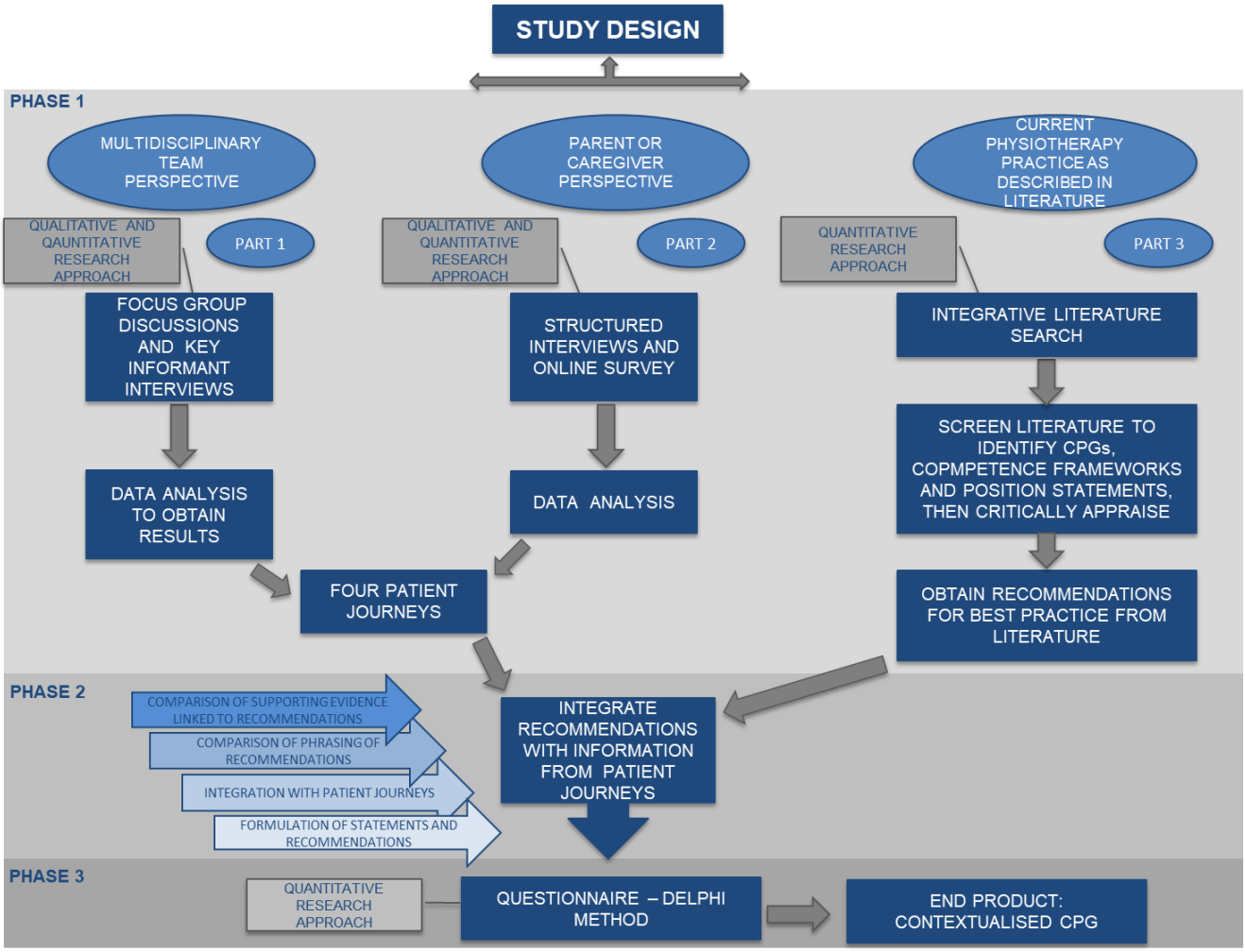


FIGURE 3.1 STUDY DESIGN: PROCESS TO CONTEXTUALISE A CLINICAL PRACTICE GUIDELINE FOR PHYSIOTHERAPISTS TREATING PREMATURELY BORN INFANTS IN NEONATAL INTENSIVE CARE UNITS, HIGH CARE UNITS AND KANGAROO MOTHER CARE WARDS IN SOUTH AFRICA

Creswell (2002) defines a mixed methods research design as a procedure for first collecting, second analysing, and third 'mixing' both quantitative and qualitative methods in a single study or a series of studies to better understand a research problem. The author further mentions that when combining quantitative and qualitative methods, the basic assumption is that the combination could provide a more in-depth understanding of the research problem than either method could provide on its own. The researcher found this to be true for the current study as the MDT's perspective of the health care system and the management of prematurely born infants could not have been obtained by way of a purely qualitative research method. Qualitative research in the form of group discussions and interviews enhanced the researcher's understanding of what the current management of prematurely born infants entails.

The use of the Delphi method (a qualitative research method) was necessary to establish which evidence-based recommendations and statements should be included in the contextualised CPG. Physiotherapy experts who are currently involved in the management of prematurely born infants gave their input. If the researcher had not used the qualitative Delphi method, she would have had to rely on subjective reasoning to select recommendations and statements for inclusion.

The mixed methods research approach has been established as one of three major research approaches or paradigms (Johnson, Onwuegbuzie and Turner, 2007), which also include qualitative and quantitative research paradigms. Since two of the three phases in the current study were based mainly on the qualitative paradigm, it can be regarded as a qualitative-dominant mixed methods research study. There are also several other mixed methods designs that could be applied to research, for example the convergent parallel design, embedded design or transformative design (Creswell, 2002). For this study, the researcher decided on the exploratory sequential design, as shown in Figure 3.2.

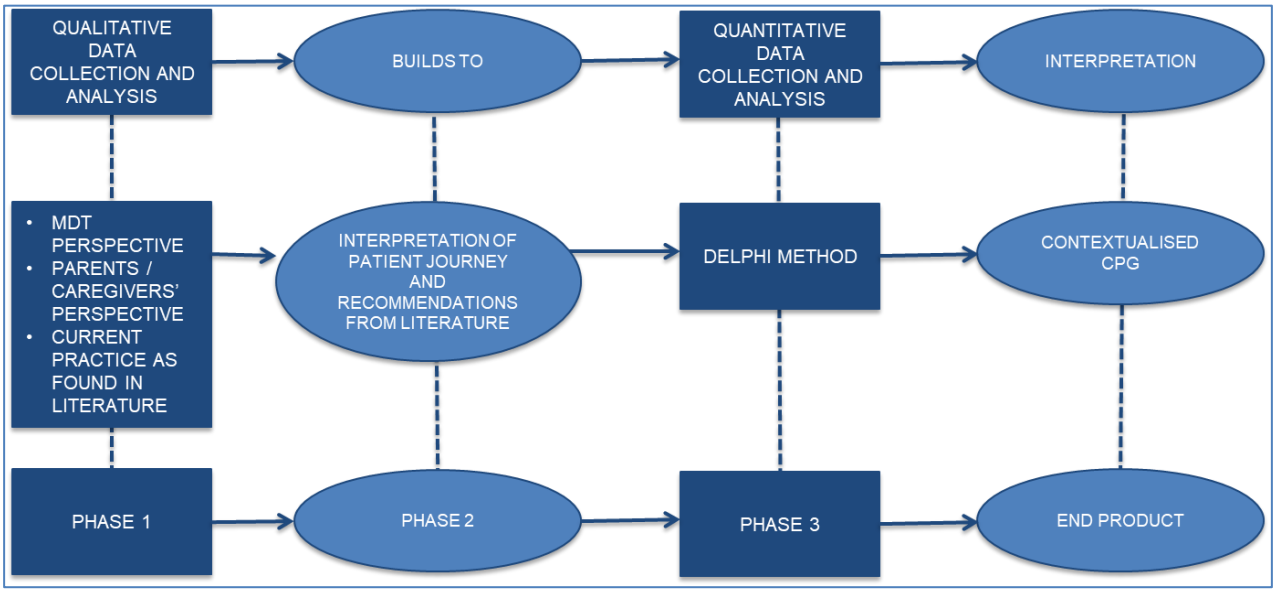


FIGURE 3.2 EXPLORATORY SEQUENTIAL DESIGN AS ADAPTED FROM CRESWELL (2002)

Johnson et al. (2007) describe mixed methods research as an approach to knowledge generation that can include both theory and practice.

Researchers using the mixed methods approach consider multiple viewpoints, perspectives and positions to better understand the research problem, as was also done in the current study. The researcher relied on experienced and knowledgeable MDT members to provide their views on the patient journeys of prematurely born infants in the South African health care context. The MDT's viewpoints or opinions regarding the role of physiotherapists in the current patient journey also added value to the study. The researcher relied on the parents or caregivers of prematurely born infants to share their experiences and their views on the care that their infants received in the NICUs, HCUs or KMC wards. Their opinions regarding the support they received during this period were also valuable to the researcher.

The researcher conducted an integrative literature review to gain a theoretical perspective on the physiotherapist's role in the management of prematurely born infants during their patient journey. The literature sources reviewed that described the physiotherapists' clinical practice or the competency frameworks used by them during the hospitalisation of prematurely born infants related only to physiotherapists working in high-income countries. Since it could not be assumed that the practice would be the same in SA, which is an upper-middle-income country, the perspectives provided by MDT members and parents or caregivers were valuable to this study and helped the researcher to bridge the gap in the literature.

The contextualisation process embedded in the study design entailed that the existing CPGs (identified in the literature) be contextualised to fit the South African health care context. The researcher adapted the contextualisation guidelines as described by Gonzalez-Suarez et al. (2012) to address all the facets of the contextualisation process that were relevant to this study. The adapted guideline is presented in Table 3.1.

TABLE 3.1 GUIDELINES FOR THE CONTEXTUALISATION PROCESS OF A CLINICAL PRACTICE GUIDELINE (ADAPTED FROM GONZALEZ-SUAREZ ET AL. 2012)

Process	***Steps in process***	***Phase in study that addressed the step***
Initial steps in the contextualisation process	Construct 'typical' patient journeys for the specific patient population	Phase 1
	Establish purpose, scope and end users of guidelines	Phase 1
Systematic search, appraisal and synthesis of the evidence	Search for clinical practice guidelines in the literature	Phase 1
	Screen guidelines for relevance to scope, purpose and the patient journeys	Phase 1
	Critically appraise guideline quality and currency, and retain recent, high-quality guidelines	Phase 1
	Contact developers for permission to use guidelines	Phase 1
	Identify and describe differences between guidelines in respect of phrasing of recommendations, ways of reporting underpinning evidence and strength of the evidence	Phase 2
Final steps in the contextualisation process	Identify recommendations relevant to the patient journey	Phase 2
	Collate a table of recommendations for validation	Phase 2
	Validate the recommendations for generalisability and applicability to the current practice of physiotherapists in the SA health care sector	Phase 3
	Collate and edit the end product, namely the contextualised CPG	Phase 3

The methodology followed in each of the three phases of the study is discussed in sequence.

3.3 METHODOLOGY OF PHASE 1: MULTIDISCIPLINARY TEAM AND PARENT OR CAREGIVER PERSPECTIVES REGARDING THE PREMATURELY BORN INFANT'S PATIENT JOURNEY AND CURRENT PHYSIOTHERAPY PRACTICE AS DESCRIBED IN THE RELEVANT LITERATURE

The first phase of the contextualisation process of the CPG for the physiotherapy management of prematurely born infants in the current study consisted of three parts, which dealt with the objectives set out for the first secondary aim of the study as described in Chapter 1, Section 1.4. The three parts are outlined in Figure 3.3 below.

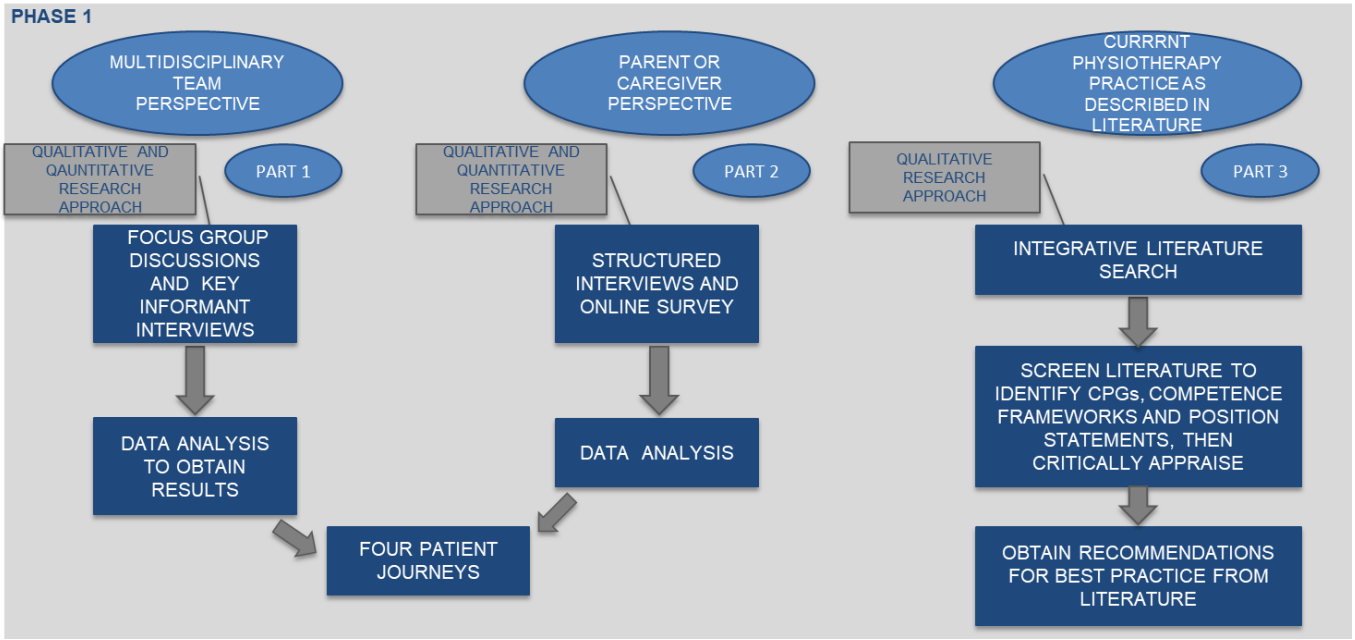


FIGURE 3.3 STUDY DESIGN FOR PHASE 1 OF THE STUDY

Parts 1 and 2 were completed in order to identify the patient journeys of prematurely born infants in SA. In Part 3 the researcher established the nature of current practice for physiotherapists working in NICUs, HCUs or KMC wards according to CPGs, competence frameworks or position statements identified during an integrative literature review.

The methodology followed for these three parts of Phase 1 will now be discussed.

3.3.1 Methodology for Part 1: Obtaining the multidisciplinary team perspective on the patient journey of prematurely born infants and their parents or caregivers

Part 1 deals with the perspectives on the patient journey of infants and their parents / caregivers as shared by MDT members who were involved in the management of prematurely born infants in NICUs, HCUs and KMC wards. Their opinions on the role of the physiotherapist in the current management of hospitalised prematurely infants were also obtained.

3.3.1.1 Data collection procedure

Gill, Stewart, Treasure and Chadwick (2008) describe different ways of collecting qualitative data and the researcher decided to use focus group discussions and key informant interviews. Krueger and Casey (2014) confirm that participants' perspectives could be gained by conducting focus group discussions and key informant interviews at their places of work. The inclusion criteria for participants who participated in the focus group discussions and key informant interviews were that they had to be members of MDTs who were, at the time of this study, involved in the management of prematurely born infants and their parents or caregivers. Specific information about the participants will be provided in section 3.3.1.2 of this chapter.

The researcher and research assistant, who are both experienced in the field of paediatric physiotherapy and qualitative research methodology, contacted the Chief Executive Officers (CEOs) of various private, academic or tertiary and district or secondary hospitals and clinics in the greater Tshwane Metropole to obtain written consent to conduct focus group discussions / interviews at these institutions (Annexure A). Before the discussion and interviews commenced, written informed consent was also obtained from each participant (Annexure B).

The researcher identified pre-existing MDT teams working together at a hospital / practice / clinic with the assumption that the communication, comfort and familiarity between team members would contribute to practice-based discussions and that they would challenge each other on key points discussed. The researcher followed the advice given by Gill et al. (2008), which is that the number of participants in the focus group discussions should vary between six and eight.

Prior to the focus group discussions and interviews, which were held between May 2014 and January 2017, appointments were made with the teams and individuals who participated. The five focus group discussions and seven interviews took place during the participants' workday and did not exceed one hour each, which was also the time frame previously agreed upon. The discussions and interviews were audio-recorded and the research assistant took field notes during discussions between participants at the end of the sessions, when they were reflecting on the discussions once audio-recording had stopped.

To focus the content of the focus group discussions and the interviews, the researcher compiled a semi-structured question guide (Table 3.2), which was used to guide the discussions, but also to allow the researcher and participants to elaborate or diverge on certain aspects of the discussion. The questions in the guide were formulated according to the information that the researcher wanted to obtain from the focus group discussions and key informant interviews. Unlike structured interviews, semi-structured interviews allow for a more natural form of discussion and for new topics to emerge (Gill et al. (2008). This question guide was firstly piloted with a group of MDT members that were similar to the participants of the focus group discussions to validate that the questions in the question guide did indeed guide a discussion. The question guide was adapted as discussions progressed and new topics that required consideration emerged. The focus group discussions generated valuable information on the groups' collective views and beliefs.

TABLE 3.2 QUESTION GUIDE FOR FOCUS GROUP DISCUSSIONS AND KEY INFORMANT INTERVIEWS

No.	Question
1.	Explain your treatment approach to premature infants.
2.	From where / whom do you receive your referral to treat a prematurely born infant?
3.	Do you experience a difference between the various public and private health care systems?
4.	Are other members of the multidisciplinary team involved in the care of the infant in the (a) Neonatal Intensive Care Unit; (b) High Care Unit; (c) Kangaroo Mother Care ward; (d) after discharge up to one year post-corrected age?
5.	Is screening of the infants done by the physiotherapist in the Neonatal Intensive Care Unit? Do any of the other multidisciplinary team members screen the infant?
6.	Which outcome measures do you mostly use to screen / assess the infants?
7.	What complications or conditions do you mostly treat (a) during the infant's stay in the Neonatal Intensive Care Unit; (b) post discharge up to one year post-corrected age?
8.	Which treatment modalities / approaches are used to treat prematurely born infants?
9.	Does the multidisciplinary team collaborate in the treatment plan for the infant(s) during their hospital stay and after discharge?
10.	Are the parents or caregivers involved in the collaboration process?
11.	Do you schedule a follow-up appointment for the infant after discharge? Are follow-up appointments made only by the paediatrician, or also by the other members of the multidisciplinary team?
12.	Up to what age are post-discharge follow-up appointments arranged for prematurely born infants?
13.	What are the criteria for infants to be discharged from (a) the Neonatal Intensive Care Unit; (b) the hospital; (c) follow-up care?
14.	Do the parents or caregivers receive information or education on the post-discharge care of the infant?
15.	Who provides them with information / education?
16.	In what format do they receive the information, e.g. practical demonstrations, leaflets?

The participants in both the focus group discussions and the key informant interviews completed a questionnaire requiring biographical and demographical information.

The questionnaire also included questions designed to better understand the participants' opinions regarding the qualifications required by MDT member working in NICUs, HCUs or KMC wards, and how they experienced working with the infants' parents or caregivers (Annexure C).

The focus group discussions and interviews were transcribed verbatim and analysed (section 3.3.1.3). The construction of the conceptual frameworks for the patient journeys for prematurely born infants and their parents / caregivers was based on the analysis of the transcribed data. The conceptual frameworks describing the patient journeys of the infants and their parents / caregivers were subjected to an audit trail process. The researcher and the research assistant re-introduced the patient journeys to three of the initial focus groups, namely a focus group at an academic hospital (public health care sector), one at a private practice (private health care sector) and one at an academic institution. This gave the participants an opportunity to determine whether the researcher had correctly interpreted the information provided in the first focus group discussions / interviews. Participants were also asked to elaborate on aspects of the patient journey that they felt needed to be clarified, included or elaborated on. These discussions were also audio-recorded and transcribed.

3.3.1.2 Population

The participants in the focus group discussions and key informant interviews included 30 MDT members (n=30) managing prematurely born infants at private, academic or tertiary and district or secondary hospitals and clinics in the greater Tshwane Metropole. The recruitment of participants was terminated once data saturation was reached, as described by Mason (2010). Demographic details, including details of the professions that were included, are shown in Table 3.3.

TABLE 3.3 DEMOGRAPHIC DETAILS OF THE PARTICIPANTS (N=30) IN PART 1 OF PHASE 1

Participant's profession	**Number of participants from this profession in *focus group discussions***	**Health care sector represented by participants**	**Number of participants from this profession in *key informant interviews***	**Health care sector represented by participants**
Professional nurse	3	Private; public; academic (university); clinics (private sector)	6	Private; public; academic (university); clinics (public sector)
Physiotherapist	8	Private; public; academic (university); non-governmental organisation	-	-
Speech and language therapist / Audiologist	3	Public; private; non-governmental organisation	-	-
Occupational therapist	5	Public; non-governmental organisation	-	-
Art therapist – music therapy	1	Private; non-governmental organisation	-	-
Paediatrician	1	Public	-	-
Dietician	2	Public; private	-	-
Advanced midwife	-	-	1	Public

3.3.1.3 Data analysis

The data analysis was a process of refinement and the researcher's attempt to gain a better and deeper understanding of the research topic and the information that was gathered (Basit, 2003). The researcher transcribed the audio-recordings of all the focus group discussions and key informant interviews.

The researcher and research assistant familiarised themselves with the content before open-coding the transcripts as advised by Basit (2003). The line-by-line approach of open coding, as explained by Khandkar (2009), was chosen for this study. Khandkar (2009) explains that codes can be assigned to concepts by going through the transcript line by line. An example is shown in Figure 3.4. All the transcripts were electronically stored and can be made available on request. The primary goal with open coding was to conceptualise and categorise the constructs, and to label the individual concepts (Brown, Stevens Jr, Troiano and Schneider, 2002). Seventeen initial codes or labels emerged from the open coding (Table 3.4.).

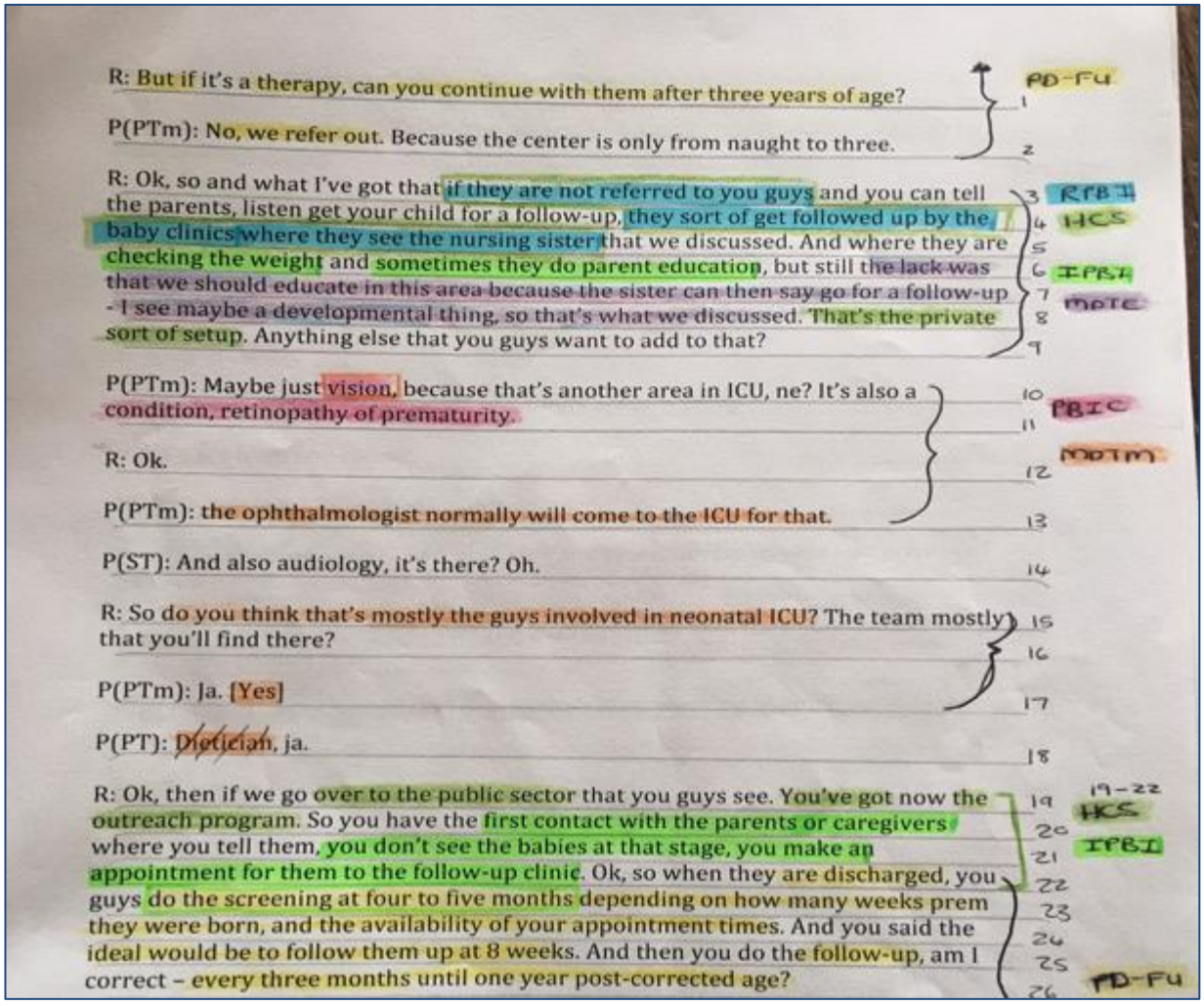


FIGURE 3.4 EXAMPLE OF OPEN-CODING TRANSCRIPTS

TABLE 3.4 INITIAL CODES IDENTIFIED DURING OPEN CODING

Codes	Description
IPBI	Intervention for prematurely born infant
HE	Hospital environment
PD-FU	Post-discharge follow-up
RPBI	Referral of prematurely born infant
MDTM	Multidisciplinary team members
Problem@MDTM	Problem with multidisciplinary team member
PBIC	Prematurely born infant condition
MDTE	Multidisciplinary team education
Problem@RPBI	Problem with referral of prematurely born infant
MDT-R-PC	Multidisciplinary team relationship with parent / caregiver
FI	Financial implications
PCE	Parent / caregiver education
HCS	Health care system
EC	Ethical consideration
PC-PBI	Parent / caregiver and prematurely born infant
CPG-PT	Clinical practice guideline for physiotherapists
LI	Legal issues

Open coding was followed by the second stage of data analysis, namely axial coding. Axial coding comprised of the following four analytical processes: (1) continuously linking subcategories to a main category; (2) verifying the categories with the transcripts; (3) developing the density of the categories by specifying the properties and dimensions identified in the data; and (4) exploring the variations found in the phenomena (Brown et al., 2002).

From the initial codes, the researcher deducted concepts of which an example is shown in Table 3.5. These concepts were then classified into categories and themes, as shown in Table 3.6.

TABLE 3.5 EXAMPLE OF CONCEPT FORMULATION

Code	Line and page number in transcript	Quotation	Concepts
IPBI	**FGD 1**		
	L 6,7 -p1	'child weighs 500 g, usually they will be intubated; monitor their lungs; monitor their positioning'	In public health care sector infants with complications or LBW will go to NICU for intubation, monitoring of respiratory function and monitoring of positioning.
	L 10-p1	'look after them until extubation'	In the public health care sector the physiotherapist manages the intubated infant in the NICU until extubation.
	L 11-p1	'then to kangaroo mother care'	In the public health care sector the infant will be transferred from the NICU to the HCU, and finally to the KMC ward.
	L 12-p1	'keep them there until the child is 1,7 kg.'	The infants remain in KMC until a weight of 1,7 kg is reached (public health care sector).
	L 14-p1	'we see, problem'	(In the public health care sector) After discharge the infant attends a monthly baby clinic and if the physiotherapist identifies a problem the infant is referred to paediatric neurology.
	L 16,17-p1	'We see them on an out-patient base'	(In the public health care sector) Due to a possible long waiting list at the paediatric neurology department, the physiotherapist, occupational therapist and speech therapist treat the infant until an appointment can be made and an official diagnosis is received.

TABLE 3.6 DEDUCTION OF CATEGORIES AND THEMES FROM IDENTIFIED CONCEPTS

Themes	Categories	Frequency of concepts in transcripts
Admission to or transfers within the hospital	Admission or transfers to NICU / HCU / KMC/ Baby room – public health care sector	14
(19 concepts)	Admission or transfers to NICU / HCU / Baby room – private health care sector	5
Prematurely born infants not entering the HCS in hospitalisation phase	Prematurely born infants not entering health care sector	2
(2 concepts)		
Hospitalisation of prematurely born infant	Hospitalisation in tertiary / academic hospital – public health care sector	4
(43 concepts)	Hospitalisation Secondary / District hospital - public health care sector	6
	Hospitalisation public health care sector	7
	Hospitalisation private health care sector	26
NICU environment	Professionalism	1
(19 concepts)	Sterile environment	2
	NICU environmental stressors	12
	NICU environment – private health care sector	3
	Maintenance of equipment – public health care sector	1
Ethical conduct of MDT in NICU	Ethical conduct	2
(7 concepts)	Knowledge and training of MDT in NICU	3
	Unnecessary treatment of prematurely born infant	2

All the identified themes related to one of the three stages of the prematurely born infant's patient journey, namely the hospitalisation (birth to discharge from hospital), short-term follow-up (discharge from hospital up to discharge from follow-up clinic) and long-term follow-up (any period between short- and long-term follow-up) stages. This process resulted in four initial conceptual frameworks that represented the patient journeys of prematurely born infants and their parents or caregivers. Although the hospitalisation, short-term follow-up and long-term follow-up stages are a continuous process, the focus of the current study was the conceptualisation of the hospitalisation stage of infants and their parents or caregivers. The current study therefore does not include the short- and long-term follow-up stages. The initial conceptual frameworks describing the processes of the patient journeys of the infants and their parents or caregivers were subject to an audit trail process, as described in section 3.3.1.1 of this chapter. Following the audit trail, the researcher adapted the initial conceptual frameworks based on the participants' comments.

The four patient journeys could only be completed after Part 2 of Phase 1, when the perspectives of the parents and caregivers were obtained and included. The methodology for Part 2 will now be discussed.

3.3.2 Methodology of Part 2: Obtaining the parents or caregivers' perspectives on their prematurely born infants' patient journeys

It was important to obtain the perspective of the parents or caregivers of prematurely born infants in NICUs, HCUs or KMC wards on what the patient journeys entailed for them and their infants. Their perspectives could differ from those of the MDT, which the researcher had already obtained during Part 1 of Phase 1. The parents or caregivers' perspectives obtained in Part 2 of Phase 1 enhanced the researcher's understanding of the patient journey and what the parents or caregivers perceived the role of the physiotherapist to be in current practice.

3.3.2.1 Data collection procedure

The researcher decided to use structured interviews as part of the data collection procedure for this part of the research study.

Gill et al. (2008) describe the structured interview as being essentially a verbally administered questionnaire, which is quick and easy to administer and can be used to clarify specific research questions. The question for Part 2 was aimed at obtaining parents or caregivers' views regarding the 'reality' of their infants' management in NICUs, HCUs or KMC wards. The researcher was of the opinion that structured interviews alone would limit the perspectives obtained to those of parents or caregivers who, at the time when the study was conducted, had infants at hospitals in the private or public health care sector, which were the environments in which the researcher had access to parents or caregivers with prematurely born infants. It was therefore decided to also include an online survey, using the same questionnaire as the one used during the structured interviews. This allowed the researcher to reach a larger demographic of parents or caregivers, which would potentially strengthen the diversity of the participating parents or caregivers. The structured interviews provided the researcher with information on the parents or caregivers' current experience, and the online survey provided a retrospective view on how parents or caregivers experienced the health care system and their infants' journeys. Fielding (2012) found that several previous mixed methods design studies had combined survey and interview data, as is the case with this study.

A questionnaire was compiled, which was used for data collection in both the structured interviews and the online survey (Annexure D). The questions were designed to obtain the following information:

(i) Biographical information about the parent or caregiver completing the questionnaire
(ii) Information regarding the premature birth, e.g. the gestational age at which the infant was born and whether it was the mother's first premature infant
(iii) Information about the infant's hospitalisation stage (team involved in care, units or wards to which the infant was admitted, what medical conditions the infant had been diagnosed with)
(iv) Information about whether the parents or caregivers received information or education during the hospitalisation stage, and what their recommendations were regarding the improvement of the MDT's service delivery
(v) Information about their infant's short-term follow-up stage.

A pilot study was conducted with the online questionnaire using LimeSurvey software on license from UP.

The survey was sent to five pre-selected parents / caregivers who had agreed to participate in the pilot study and had agreed verbally and online to complete the questionnaire. All five participants (n=5) who were contacted were parents of prematurely born infants who had previously been admitted to a NICU, an HCU or a KMC ward. Three of the participants responded immediately and two were sent reminders before they completed the questionnaire. The researcher asked the participants to give feedback on the clarity of the questionnaire and whether all aspects relevant to an infant's patient journey were covered. Lastly, they were asked to comment on the user-friendliness of the questionnaire. The feedback suggested the adjustment of some technical aspects of the questionnaire, e.g. to include more options for a question regarding the admission of the infant, or to provide a space in which they could elaborate on their answers. Participants found the questionnaire easy and quick to complete, but wanted fewer open-ended questions and more questions with options to choose from. The questionnaire was adjusted accordingly.

The researcher and research assistant (as mentioned in section 3.3.1.1 of this chapter) contacted the CEOs of two academic hospitals, two district hospitals and private Well-baby clinics in the greater Tshwane Metropole to obtain written consent for the structured interviews to be conducted at those institutions (Annexure E). Structured interviews were conducted with consenting parents or caregivers who attended the short-term follow-up clinics at the two academic hospitals (n=17) with their prematurely born infants, and with parents or caregivers whose infants were still hospitalised in KMC wards at the two district hospitals (n=6). More details regarding the participants will be provided in section 3.3.2.2.

The interviews were conducted between February and March 2016. Although an interpreter was available to assist parents or caregivers who were not able to understand or answer the questions in English, none of the parents or caregivers requested such assistance.

The researcher and research assistant conducted a one-on-one structured interview with each participating parent or caregiver. The participants did not complete the questionnaire on their own as the researcher was of the opinion that individual structured interviews offered the opportunity to immediately clarify any uncertainties about the questions.

Another reason for deciding to conduct the structured interviews in person was that the researcher wanted to minimise the impact that illiteracy could have on the participants' answers. The structured interviews conducted at the short-term follow-up clinics at the two academic hospitals (n=17) were completed while the parents or caregivers were waiting for their appointments with the various MDT members. The fact that the researcher chose the short-term follow-up clinics as a venue meant that only parents or caregivers who made use of the follow-up service were included in the study. The advantage of the chosen venues was that there were no additional travel costs for the participants as they had to be at the venues anyway for their infants' follow-ups. Each interview lasted approximately 15 to 20 minutes. The participants were offered the opportunity to be interviewed in a more private adjacent space, but did not make use of this offer. The same principles were applied to the structured interviews that were completed in the KMC wards at the two district hospitals (n=6), except that these interviews were completed at the participants' bedsides in the ward. Informed consent was obtained from all the parents or caregivers who participated in the structured interviews (Annexure F).

The link to the online survey was sent to MDT members (participants in Part 1 of Phase 1 of the study), as well as to nursing staff working at out-patient clinics or Well-baby clinics. These clinic sisters, who had access to the parents or caregivers who brought their prematurely born infants to the clinic for immunisations, were asked to provide the link with information on what the online questionnaire entailed to these parents or caregivers. The parents or caregivers who chose to activate the link had to provide informed consent online before they could answer the questions. The link was active from 11/08/2016 until 15/10/2016 and a total of 64 parents or caregivers (n=64) who had previously had prematurely born infants completed the survey.

3.3.2.2 Population

The researcher included parents or caregivers who at the time of the study (i) had prematurely born infants in a KMC ward; or (ii) were attending short-term follow-up clinics with their infants; or (iii) had previously had prematurely born infants in NICUs, HCUs or KMC wards and were attending Well-baby or out-patient clinics for immunisations. All the participants were recruited in the greater Tshwane Metropole. Purposive sampling was used to identify parents or caregivers for participation in the structured interviews and online survey.

Purposive sampling is used primarily in qualitative studies as participants are deliberately selected based on the important information that they can provide and which would not be obtained if another sampling method was chosen (Teddlie and Yu, 2007).

The questionnaire that was used in the structured interviews and online survey was piloted with five parents or caregivers who had prematurely born infants in NICUs, HCUs or KMC wards. Of the five participants (n=5), four were female (n=4) and one was male (n=1). Informed written consent was obtained from the parents or caregivers who participated in the structured interviews. The researcher conducted structured interviews with 24 parents or caregivers (n=24). One participant was excluded from the study after giving unreliable answers during the structured interview, therefore 23 structured interviews (n=23) were included in the data analysis. All the participants in the structured interviews were female.

The parents or caregivers who completed the online survey had to provide written (online) consent before the questionnaire was activated in LimeSurvey. Sixty-four parents or caregivers (n=64) participated in the online survey. Of the 64 participants, one was male (n=1) and 62 were female (n=62). One participant did not specify gender (n=1).

3.3.2.3 Data analysis

The researcher consulted with a statistician regarding the analysis of the data obtained through the structured interviews and online survey, and it was found that the data was more qualitative in nature. The data obtained through the structured interviews was uploaded together with the responses from the online survey in the LimeSurvey software, which provided the researcher with a total of n=87 responses. All the data was exported to a Microsoft Excel spreadsheet for analysis. The LimeSurvey software offers a function for creating statistics from the responses to the questions. The frequencies were calculated for the questions that provided quantitative data and the qualitative data was open-coded.

The researcher incorporated the relevant information from Part 2 of Phase 1 (parent or caregiver perspective on the infant's patient journey) into the initial conceptual frameworks that were formulated in Part 1 of Phase 1 (MDT perspective on the infants' patient journeys). The four completed patient journeys will be described in Chapter 4, section 4.4.

The methodology followed for Part 3 of Phase 1 will now be discussed.

3.3.3 Methodology for Part 3: Current physiotherapy practice as described in the literature

In Part 3, the researcher had to complete an integrative literature search in order to determine what the current physiotherapy practice in the management of prematurely born infants entails. An integrative literature search or review assists the researcher to identify gaps in the current research, it also assist in identifying areas for future research (Russell, 2005; Lubbe, Van der Walt and Klopper, 2012). The integrative literature search comprises of five steps, namely (i) formulating a research question, (ii) formulating a search strategy, (iii) critically appraising the literature, (iv) data analysis and synthesis and (v) interpretation and presentation of results (Lubbe et al., 2012; Russell, 2005). In the next phase, namely Phase 2 of this study, the suitable literature was integrated in the patient journeys (constructed in Parts 1 and 2 of Phase 1). The participants and the methodology of the processes followed in Part 3 of Phase1 will now be discussed.

3.3.3.1 Participants in the integrative literature search and appraisal of literature

The integrative literature search was conducted by the researcher and a co-literature searcher (referred to as co-searcher), a senior information specialist for Physiotherapy in the Faculty Library on the medical campus of UP. The process will be discussed in the section that follows.

The researcher and research assistant (as mentioned in sections 3.3.1.1 and 3.3.2.1 of this chapter) screened the titles of literature identified to allocate CPGs, competence frameworks or position statements for critical appraisal.

The researcher and two assistant appraisers (an academic staff member and an expert clinician) critically appraised the selected literature sources. The process will be discussed in section 3.3.3.3 below.

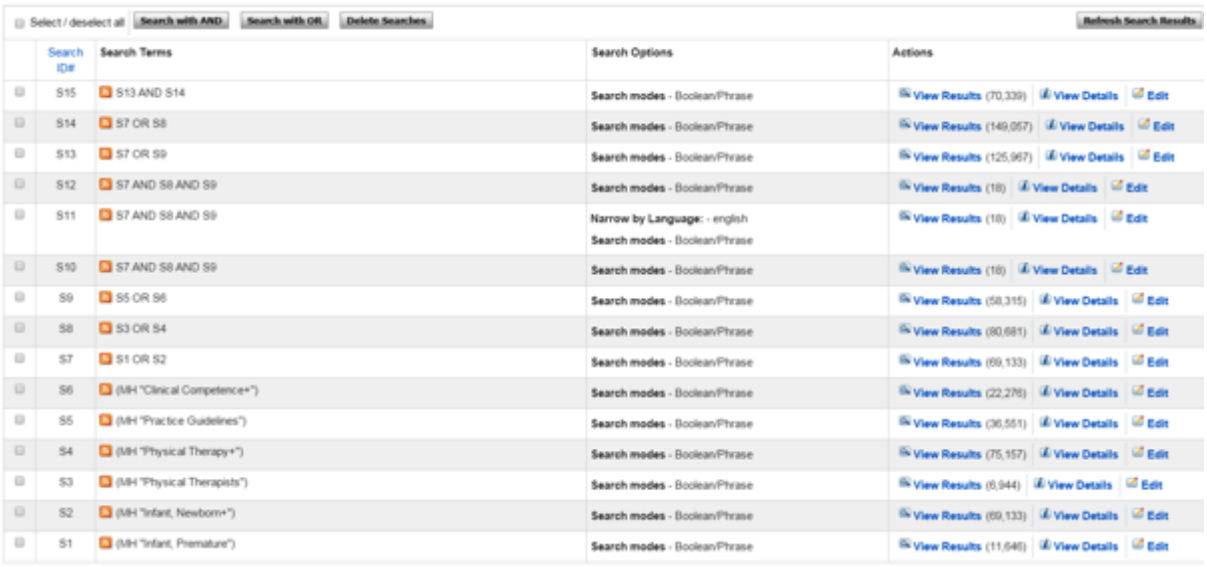
3.3.3.2 The integrative literature search process

The researcher decided on an integrative literature search approach rather than a systematic review as the integrative approach allows for a wider range of literature to be included, while the systematic review is limited to the inclusion of clinically controlled trials only (Lubbe et al., 2012). Lubbe et al. (2012) also found that, similar to the aim of this study, the integrative literature review has the potential to build a body of knowledge on a specific topic that could inform research, practice and policy initiatives. The researcher and co-searcher conducted the integrative literature search between 17 and 27 November 2015.

After several discussions on the search strategies to be followed, the researcher received training in how to conduct searches in the selected databases, i.e. CINAHL, Medline, Cochrane and PubMed. The search terms (MeSH term (medical subject headings)) decided upon included Infant premature; Infant newborn; Premature birth; Physical therapist; Physical therapy modalities; Modalities / Physical therapist specialties; Guideline; Guidelines (as topic); Practice guidelines; Clinical competence; Competence framework; and Intensive care unit neonatal. The advanced search option was chosen (when available on the database) and the search was limited to literature dealing with human subjects that was published in English between 1 January 2005 and 31 December 2015. The researcher and co-searcher piloted and refined the search strategies. Since differences were detected in the results in the different search browsers, the researcher decided that the co-searcher would conduct literature searches in Internet Explorer and Chrome, while she herself would conduct searches in the search browser Firefox and Safari to ensure that all the relevant literature would be identified, regardless of which search browser were used.

It was also decided that the literature searches would be carried out separately by the researcher and the co-searcher. The reason for this was that the researcher wanted to identify as many relevant literature sources as possible.

Therefore, even though the strategies used by the researcher and the co-searcher might have differed slightly, their chances of identifying more relevant literature were increased. An example of the search strategies followed is shown in Figure 3.5. All strategies were stored electronically and are available from either the researcher or the co-searcher on request.



Select / deselect all | Search with AND | Search with OR | Delete Searches | Refresh Search Results

Search ID#	Search Terms	Search Options	Actions
S15	S13 AND S14	Search modes - Boolean/Phrase	View Results (70,339) | View Details | Edit
S14	S7 OR S8	Search modes - Boolean/Phrase	View Results (149,057) | View Details | Edit
S13	S7 OR S9	Search modes - Boolean/Phrase	View Results (125,967) | View Details | Edit
S12	S7 AND S8 AND S9	Search modes - Boolean/Phrase	View Results (18) | View Details | Edit
S11	S7 AND S8 AND S9	Narrow by Language: - english Search modes - Boolean/Phrase	View Results (18) | View Details | Edit
S10	S7 AND S8 AND S9	Search modes - Boolean/Phrase	View Results (18) | View Details | Edit
S9	S5 OR S6	Search modes - Boolean/Phrase	View Results (58,315) | View Details | Edit
S8	S3 OR S4	Search modes - Boolean/Phrase	View Results (80,681) | View Details | Edit
S7	S1 OR S2	Search modes - Boolean/Phrase	View Results (69,133) | View Details | Edit
S6	(MH "Clinical Competence+")	Search modes - Boolean/Phrase	View Results (22,276) | View Details | Edit
S5	(MH "Practice Guidelines")	Search modes - Boolean/Phrase	View Results (36,551) | View Details | Edit
S4	(MH "Physical Therapy+")	Search modes - Boolean/Phrase	View Results (75,157) | View Details | Edit
S3	(MH "Physical Therapists")	Search modes - Boolean/Phrase	View Results (6,944) | View Details | Edit
S2	(MH "Infant, Newborn+")	Search modes - Boolean/Phrase	View Results (69,133) | View Details | Edit
S1	(MH "Infant, Premature")	Search modes - Boolean/Phrase	View Results (11,646) | View Details | Edit

FIGURE 3.5 CO-SEARCHER'S SEARCH STRATEGY FOR THE CINAHL DATABASE

The co-searcher identified five CPGs, competence frameworks or position statements (n=5) and the researcher identified 23 (n=23). The researcher also conducted a search in the electronic databases of the following guideline clearinghouses: the US National Guideline Clearinghouse (US NGC); the Agency for Healthcare Research and Quality (AHRQ); the Guidelines International Network (G-I-N); the New Zealand Guidelines Group (NZGG); the WHO guidelines; the National Institutes of Health (NIH); Australia's National Health and Medical Research Council (NHMRC); the Canadian Medical Association Clinical Practice Guidelines Infobase and the Institute for Clinical Systems Improvement (ICSI); the Scottish Intercollegiate Guidelines (SIGN); the United Kingdom's National Institute for Health and Clinical Excellence (NICE); and the Association of Paediatric Chartered Physiotherapists (APCP) in the UK. This search identified two more competency frameworks used in the UK, which brought the total number of CPGs, competence frameworks or position statements identified by the researcher to 25 (n=25).

The researcher and research assistant checked the titles and abstracts of the identified literature against the criteria for inclusion to identify the literature appropriate for appraisal. This process will be discussed in Chapter 5, section 5.2.

The integrative literature search was repeated in August 2018 to ensure that all CPGs, competency frameworks and position statements published since 31 December 2015 were also included in the study. No other CPGs, competency frameworks or position statements were identified during the second search.

3.3.3.3 Critical appraisal of identified literature

The researcher and two assistant appraisers critically appraised the identified literature by using the AGREE II instrument. The AGREE instrument was found to be reliable for the critical appraisal of CPGs by physiotherapists (MacDermid, Brooks, Solway, Switzer-McIntyre, Brosseau and Graham (2005). The researcher and the two assistant appraisers piloted the implementation of the AGREE II instrument. A couple of CPGs (not included in the study) were appraised to ensure that the appraisers understood the use of the instrument. Discussions were held between the researcher and two appraisers to confirm the process of appraisal to be followed, and how decisions around the scoring of publications on the items of the AGREE II instrument were to be made. The researcher consulted with Professor Karen Grimmer from the University of South Australia, who is an expert in many areas of the development and implementation of CPGs, regarding the use of the AGREE II instrument for competency frameworks or position statements. A decision was made to use the AGREE II instrument for all three types of literature, namely CPGs, competency frameworks and position statements. The reason for this decision was that by using a single tool to critically appraise evidence, the literature could be compared. The use of more than one appraisal instrument would have made such comparison impossible. By using the AGREE II instrument, the researcher was able to highlight the positives and negatives of each CPG, competency framework or position statement and was subsequently able to form a literature base that could be included in the contextualisation process.

The AGREE II instrument consists of six domains. These domains and the items that fall under each domain are shown in Table 3.7.

TABLE 3.7 SUMMARY OF DOMAINS AND ITEMS INCLUDED IN THE AGREE II INSTRUMENT AS DESCRIBED BY BROUWERS (2010)

Domain	***Items included in the domain***
Domain 1: Scope and purpose	1. The overall objective(s) of the guideline is (are) specifically described. 2. The health question(s) covered by the guideline is (are) specifically described. 3. The population (patients, public, etc.) to whom the guideline is meant to apply is specifically described.
Domain 2: Stakeholder involvement	4. The guideline development group includes individuals from all relevant professional groups. 5. The views and preferences of the target population (patients, public, etc.) were sought. 6. The target users of the guideline are clearly defined.
Domain 3: Rigour of development	7. Systematic methods were used to search for evidence. 8. The criteria for selecting the evidence are clearly described. 9. The strengths and limitations of the body of evidence are clearly described. 10. The methods for formulating the recommendations are clearly described. 11. Health benefits, side effects and risks were considered in formulating the recommendations. 12. There is an explicit link between the recommendations and the supporting evidence. 13. Prior to its publication, the guideline was externally reviewed by experts. 14. A procedure for updating the guideline is provided.
Domain 4: Clarity of presentation	15. The recommendations are specific and unambiguous. 16. The different options for the management of the condition or health issue are clearly presented. 17. Key recommendations are easily identifiable.
Domain 5: Applicability	18. The guideline describes facilitators and barriers to its application. 19. The guideline provides tools and / or advice on how the recommendations can be put into practice. 20. The potential resource implications of applying the recommendations were considered. 21. The guideline presents monitoring and / or auditing criteria.
Domain 6: Editorial independence	22. The views of the funding body did not influence the content of the guideline. 23. Competing interests of guideline development group members were recorded and addressed.
Overall guideline assessment	1. Rate the overall quality of this guideline. 2. I would recommend this guideline for use: Yes / Yes with modifications / No.

As the researcher became familiar with the literature it was noted that the position statements by Byrne et al. (2013a) and (Byrne et al., 2013b) formed a unit that together described the NICU Care Path instrument. It was therefore decided to appraise these two position statements together.

The seven CPGs, competence frameworks or position statements that were identified in the integrative literature search were critically appraised by the researcher and two appraisers, and the appraisal were compared. A discussion of the items for which the scores differed by more than three points took place after each appraisal. A difference of three points or more for an item indicated a notable difference between appraisers' opinions and the discussions allowed them to explain how they had arrived at a specific score, after which the researcher and the appraisers together decided on a suitable score. An example of the results of the appraised publications is shown in Table 3.8. The rest of the results are available in electronic form.

TABLE 3.8 EXAMPLE OF AGREE II SCORING SHEET

Title of CPG: Neonatal Physical Therapy Part II: Practice Frameworks and Evidence-based Practice Guidelines

Item number	Appraiser 1	Appraiser 2	Appraiser 3	After discussion – final value
1	*(4)	7	7	6
2	*(2)	6	6	5
3	6	6	6	6
4	2	3	1	2
5	1	2	2	2
6	5	7	5	6
7	1	1	1	1
8	1	1	1	1
9	*(6)	3	2	3
10	2	1	1	1
11	3	4	3	3
12	7	6	*(4)	5
13	2	2	1	2
14	1	2	1	1
15	6	6	4	5
16	7	7	*(4)	6
17	7	7	7	7
18	3	2	1	2
19	*(1)	4	5	3
20	2	1	2	2
21	*(1)	3	3	3
22	1	1	2	1
23	1	1	1	1
Overall 1	4	4	4	4
Overall 2	2 – Yes with modifications	2 – Yes with modifications	2 – Yes with modifications	2 – Yes with modifications

*If the value between appraisers differed by more than three, the scoring was discussed to reach consensus.

Each item was scored on a seven-point scale on which 1 indicated strongly disagree and 7 indicated strongly agree. The combined scores of the items listed in each domain constituted the domain score. The three appraisers' domain scores were combined and an average percentage was calculated. An example of the calculation of the domain percentage, as described by Brouwers (2010) in the user's manual, which is an appendix to the article, is shown in Table 3.9 (which includes the calculations that follow the table).

TABLE 3.9 AN EXAMPLE OF THE SCORES FOR DOMAIN 1

Item	**Appraiser 1**	**Appraiser 2**	**Appraiser 3**	**Total:**
Item 1	6	7	7	20
Item 2	5	6	6	17
Item 3	6	6	6	18
				55

Example of how the researcher calculated the domain percentage for Domain 1:

Maximum possible score for Domain 1: (3 items x 7, the maximum score on the seven-point scale) x 3 appraisers) 63

Minimum possible score for domain 1: (3 items x 1, the minimum score on the seven-point scale) x 3 appraisers) 9

$\frac{55-9\ (=46)}{63-9\ (=54)} = 0{,}851 \times 100$

= 85,18%

= 85% is the domain percentage for Domain 1 in this example

The SASP has a Professional Development Portfolio Committee that focuses on improving service delivery in all fields of physiotherapy in SA. This Committee has prioritised the development of CPGs to standardise the treatment / management protocols for physiotherapists.

The Committee discussed the domain percentages that have to be obtained by CPGs for inclusion in a CPG contextualisation or other development process. The scores decided upon were as follows:

- Domain 1: Scope and purpose (70%)
- Domain 2: Stakeholder involvement (50%)
- Domain 3: Rigour of development (70%)
- Domain 4: Clarity of presentation (60%)
- Domain 5: Applicability (50%)
- Domain 6: Editorial independence (50%)

Bearing in mind the guidance provided by the SASP's Professional Development Portfolio Committee regarding domain percentages, the researcher and two appraisers decided which literature to include in the contextualisation process in Phase 2 of the study. Phase 2 included the CPG developed by Sweeney et al. (2010) and the position statements by Byrne et al. (2013a) and Byrne et al. (2013b). The researcher refers to the position statements as the NICU Care Path developed by these authors.

3.3.4 Ethical considerations for phase one of the study

The researcher obtained ethical approval for this study from the Research Ethics Committee of the Faculty Health Sciences of the University of Pretoria (nr. 99/2014). Written informed consent was obtained from the CEOs of the hospitals / clinics (Annexures A and E) and all participants in Parts 1 and 2 of Phase 1 (Annexures B and F). The aims and objectives were explained to the MDT members and parents or caregivers and they participated voluntarily and were not coerced to participate. All participants were assured that there would be no negative consequences if they decided not to participate in the study at any time, and that even if they decided not participate any further that participants would still have access to the CPG contextualised in this study. Parents or caregivers were also assured that the treatment of their prematurely born infant by the MDT would in no way be affected by their participation or non-participation. Consent was not a once off, but rather an ongoing process where the researcher obtained and retained consent from participants (Ensign, 2003). Since very few males were unfortunately available, the majority of the participants were female.

Permission to make audio recordings was obtained from the MDT participants in the focus group discussions and interviews. During the transcription of the audio recordings, the researcher assigned a code to each participant to ensure anonymity and confidentiality. Confidentiality of data, demographic information and information of participants were maintained at all times throughout the study.

Original data was and will continued to be stored in electronic format as well as hard copies for a period of 15 years in compliance with university regulations.

The researcher contacted the authors / developers of the relevant CPGs, concept frameworks or position statements identified in Part 3 of Phase 1 to obtain permission to include their work in this study.

3.3.5 Rigour of Phase 1 of the study

Triangulation can be viewed as a qualitative research strategy to test the validity of data obtained through the convergence of information / data from different sources (Carter, Bryant-Lukosius, DiCenso, Blythe and Neville, 2014). By obtaining the perspectives of the MDT members and parents or caregivers, as well as information on current physiotherapy practice in NICUs, HCUs or KMC wards obtained from literature, it was possible to do a methodological triangulation, which was important to ensure the rigour of Phase 1. The methodological triangulation is shown in Figure. 3.6. Methodological triangulation was achieved as three independent processes confirmed the prematurely born infant's patient journey, which included the journey of the parents or caregivers, and the physiotherapists' role in the management of the infants. The three processes included the focus group discussions / key informant interviews (MDT members), structured interviews and online survey (parents or caregivers), and the integrative literature search (theory) (Johnson et al., 2007). Carter et al. (2014) further explained that it was best to make use of both focus group discussions and informant interviews, because different types of information would emerge from the two methods due to the difference in the nature of the data collection procedures. Triangulation of data improved the trustworthiness or validity of the results obtained for Phase 1, and therefore its rigour.

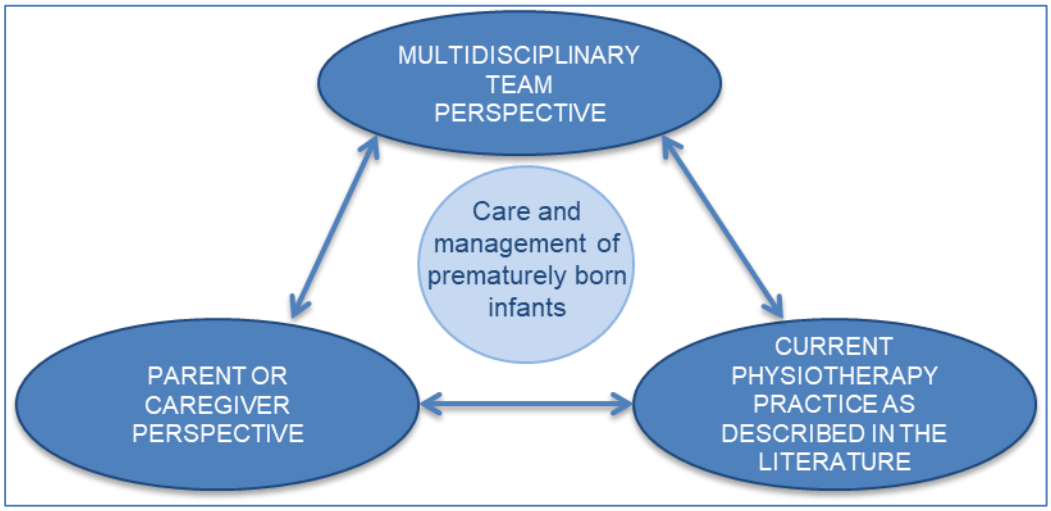


FIGURE 3.6 METHODOLOGICAL TRIANGULATION IN PHASE 1 OF THE STUDY

In Part 1 of Phase 1, the researcher included MDT members from both the private and the public sectors of the SA health care system. This enabled the researcher to obtain a true representation of what the patient journey entails throughout the South African health context.

By making field notes after each focus group discussion, the data obtained during the discussions were enriched. The field notes included the reflections of the participants after the discussions, when they felt that they could speak freely.

The researcher transcribed the recorded interviews. This required that the audio recordings be listened to repeatedly, which familiarised the researcher with the content and improved her understanding of what the participants meant when they made a statement as the context was clear to her. The researcher made use of reflexivity which is a strategy used when generating knowledge in qualitative research (Berger, 2015). The author further explains that reflexivity is commonly viewed as a process of continual internal dialogue and critical self-evaluation where the researcher acknowledges how her position and opinions might affect the research process and outcome. The researcher also chose to open-code the transcripts line by line, rather than use a computer program to do the coding.

She found that after transcribing the interviews and discussions and becoming familiar with the content, the coding and identification of codes and categories were easier and a natural progression of the coding process. All data collected and analysed was electronically stored and will be made available on request. This forms part of the paper trail and the researcher's thought process.

In Part 2 of Phase 1, the researcher piloted the questionnaire used in the structured interviews and the online survey. The participants in the pilot study assisted the researcher in making the questionnaire more user friendly for future participants. Since the researcher and research assistant completed the structured interview with the participants, they were able to ask questions immediately as the need arose and the participants could provide more exact answers without having to write them down. This ensured that illiterate participants would not feel self-conscious.

In Part 3 of Phase 1 the researcher received very helpful training in how to conduct searches in different databases. Anyone who does not do searches on a regular basis could find it difficult to understand the correct procedure. The fact that the researcher and co-searcher piloted the search strategies improved the search terms as well as the researcher's confidence in carrying out the searches. The researcher and co-searcher also conducted the literature searches in different search engines, namely Internet Explorer, Chrome, Firefox and Safari, to improve the rigour of the results obtained during the integrative literature search.

Making use of three appraisers in the process of appraising the identified literature also improved the rigour of the results. Discussions about results (when the difference in scores were three or more) improved the appraisers' ability to reason about when a particular score would be appropriate for a specific item in each domain.

3.4 METHODOLOGY OF PHASE 2: INTEGRATION OF CURRENT CPG RECOMMENDATIONS WITH THE SOUTH AFRICAN PATIENT JOURNEYS

In Phase 2 of the study, the researcher integrated the description of the patient journeys (South African health care context for prematurely born infants), based on the results of Parts 1 and 2 of Phase 1, with the identified and appraised CPG and NICU Care Path (Part 3 of Phase 1). Figure 3.7 shows the four steps that the researcher completed during Phase 2.

The end product of Phase 2 was the evidence-based recommendations and statements that formed the basis for the questionnaire used in the first-round Delphi method in Phase 3. Evidence-based recommendations are the recommendations found in the CPG and NICU Care Path that were relevant to the SA health care system, according to the patient journeys. The term 'statements' refers to the statements derived from the focus group discussions, key informant interviews and the parental interviews and online survey. These statements were based on the experience of the MDT members and parents or caregivers on the current patient journey for prematurely born infants in the greater Tshwane Metropole. The researcher needed to confirm whether physiotherapists from other areas in SA had a similar experience.

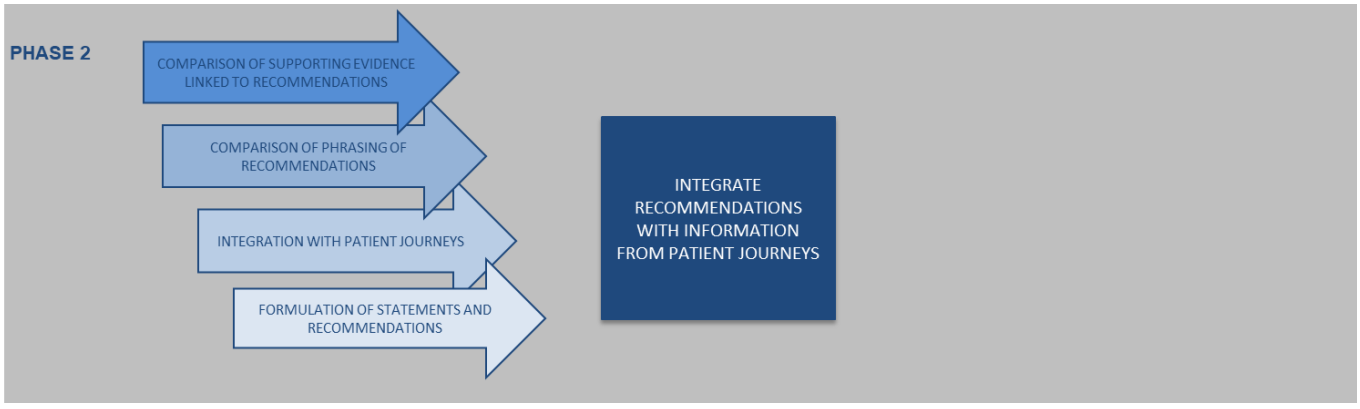


FIGURE 3.7 STUDY DESIGN FOR PHASE 2 OF THE STUDY

3.4.1 Comparison of supporting evidence linked to recommendations in the clinical practice guideline and NICU Care Path

The way in which Sweeney et al. (2010) linked the supporting evidence to the recommendations in the CPG that they developed differed from how Byrne et al. (2013a) and Byrne et al. (2013b) presented the evidence for the NICU Care Path. The CPG is shown in Figure 3.8 and the NICU Care Path is shown in Figures 3.9 and 3.10.

Evidence-Based Recommendations for Neonatal Physical Therapy

Type	Recommendations	Level of Evidence	References
Prevention	• Collaborate with caregivers to reduce risk for skull deformity, torticollis, and extremity malalignment through diligent positioning for symmetry and neutral alignment	Level II Level II Level II	Van Vlimmeren et al[63] Vaivre-Douret et al[65] Monterosso et al[67]
Examination	• Conduct baseline observation to determine physiologic and behavioral stability (readiness) for evaluative handling	Level II	Sweeney[32]
	• Provide continuous physiologic and behavioral monitoring during and after evaluative handling to determine adaptation to evaluative handling and to signal the need for modification of pace and sequence, given expected physiologic changes, particularly during neuromotor test procedures	Level II	Sweeney[33]
Intervention	• Collaborate with caregivers to create a developmentally supportive environment with modulated stimulation from light, noise, and handling	Level I Level II Level I	Symington et al[34] Westrup et al[35] Peters et al[13]
	• Support body position and extremity movement (1) supine position: semiflexed, midline alignment using blanket for swaddling containment or "nest" of positioning rolls; and (2) prone position: vertical roll under thorax; horizontal roll under hips	Level II Level II Level II Level II	Vaivre-Doure et al[65] Monterosso et al[69] Short et al[70] Ferrari et al[62]
	• In selected neonates with movement impairment or disorganization, consider therapeutic handling carefully graded in intensity and paced to facilitate head and trunk control, antigravity movement, and midline orientation	Level II	Girolami et al[73]
	• Consider gradual exposure to multimodal stimuli for stable neonates approaching hospital discharge	Level I	Symington et al[34]
	• Provide opportunities for independent oral exploration through positioning with hands to face, and for nonnutritive sucking to improve state organization and readiness to feed	Level I	Pinelli et al[80]
	• Determine readiness for and advancement of oral feeding trials using infant behavioral cues	Level II Level II	Kirk et al[83] McGrath et al[85]
	• Encourage parental involvement with feeding and provide interventions for physiologic stability (pacing and slowed flow rate)	Level III Level II	Law-Morstatt et al[81] Chang et al[82]
	• Consider hydrotherapy before feeding for stable infants with movement impairment	Level IV	Sweeney[93]
Education	• Educate parents on behavioral cues and developmental status to mitigate parental stress and to improve parental mental health outcomes	Level II Level I	Kaaresen et al[94] Melnyk et al[95]
	• Implement multiple methods of instruction for parents and caregivers (demonstration, discussion, video, and written materials)	Level V	Dusing et al[100]

FIGURE 3.8 CLINICAL PRACTICE GUIDELINE DEVELOPED BY SWEENEY ET AL. (2010:13)

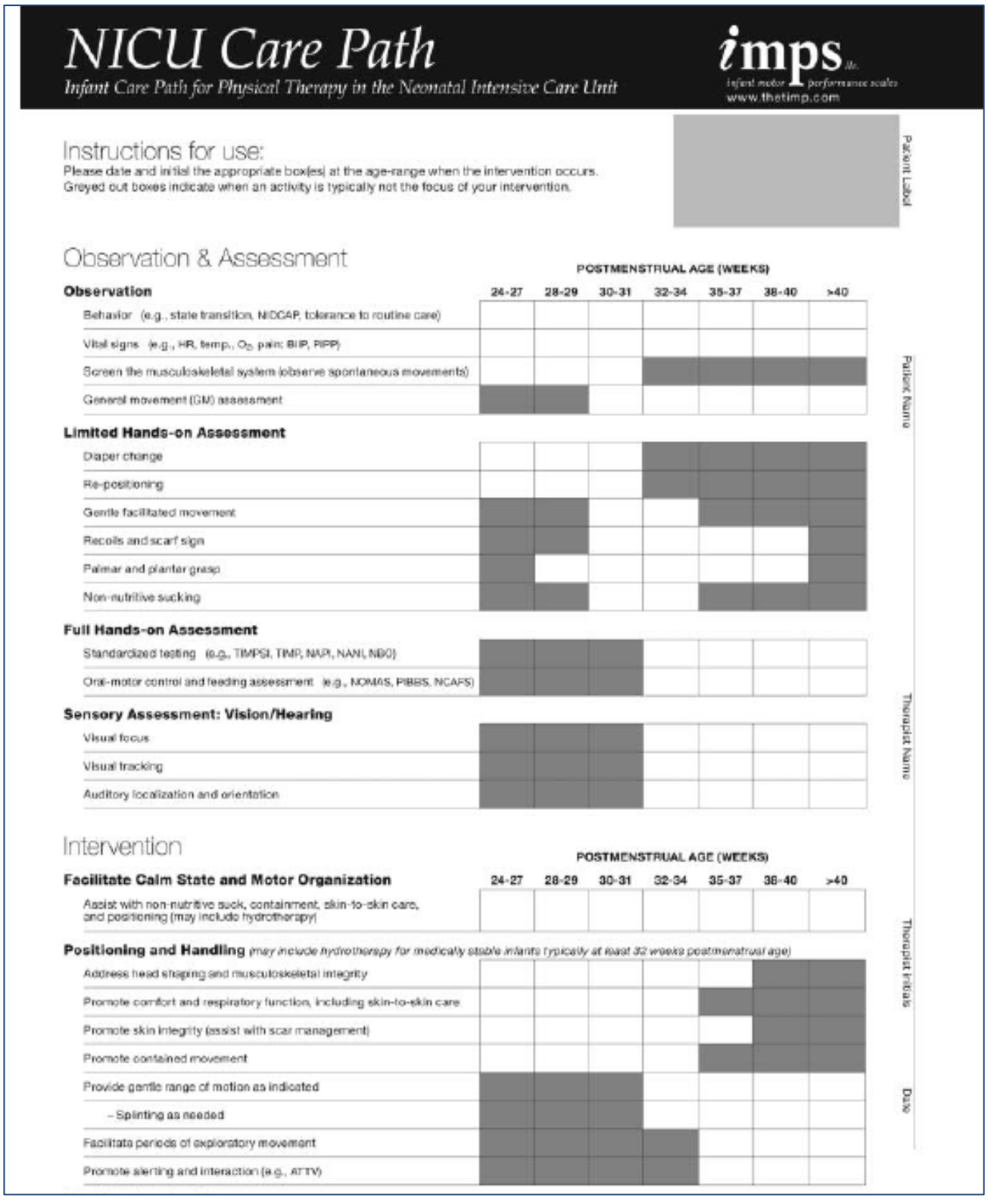


FIGURE 3.9 PART 1 OF THE NICU CARE PATH DEVELOPED BY BYRNE ET AL. (2013A) AND BYRNE ET AL. (2013B:76)

FIGURE 3.10 PART 2 OF THE NICU CARE PATH DEVELOPED BY BYRNE ET AL. (2013A) AND BYRNE ET AL. (2013B:77)

In the CPG (Sweeney et al., 2010), the supporting evidence was linked to each recommendation, as can be seen in Figure 3.8. Figure 3.8 further shows how the level of evidence was provided by making use of a hierarchy of evidence as (shown in Table 2.1 in Chapter 2, section 2.2.1.1) where:

- Level I consisted of randomised control trials (RCTs) or systematic reviews of RCTs
- Level II consisted of small RCTs, cohort studies or systematic reviews on cohort studies
- Level III consisted of case-control studies or systematic reviews of case-control studies

- Level IV consisted of case series that did not have a control group in the study
- Level V consisted of the opinions of experts or authorities

The NICU Care Path (Byrne et al., 2013a; Byrne et al., 2013b), as shown in Figures 3.9 and 3.10, was presented in the form of two articles. The figures show that the supporting evidence was not directly linked to the recommendations, but was rather discussed in the text. The researcher therefore identified the evidence that was specific to each recommendation in the text and listed the evidence mentioned in table format, as shown in Table 6.2 in Chapter 6. The authors do not indicate that they determined the level of evidence for the evidence that they included in the articles. The researcher therefore determined the level of evidence by making use of the hierarchy of evidence used by Sweeney et al. (2010) in their CPG. The level of evidence linked to each recommendation by the researcher is also dealt with in Chapter 6, Table 6.2.

3.4.2 Comparison of phrasing of recommendations in the clinical practice guideline and NICU Care Path

The researcher compared the phrasing of the recommendations listed by Sweeney et al. (2010) in their CPG with the phrasing of the recommendations found in the NICU Care Path (Byrne et al., 2013a; Byrne et al., 2013b). The authors of the NICU Care Path did mention that their work was based on the CPG developed by Sweeney et al. (2010), but a comparison between Figure 3.8 and Figures 3.9 and 3.10 clearly shows that Byrne et al. (2013a) and Byrne et al. (2013b) greatly expanded their NICU Care Path. The NICU Care Path includes a wider variety of observation / assessment and intervention options that physiotherapists could use when managing the prematurely born infant in the NICU.

The recommendations from the CPG and NICU Care Path that addressed the same issues were grouped together by the researcher, e.g. observation and assessment (NICU Care Path) with examination (CPG), under the following headings:

- Assessment
- Prevention
- Intervention
- Parental / caregiver education

These headings with the recommendations listed under each were integrated with the information derived from the patient journeys (as described in the following section) and then became part of the questionnaire that the researcher used in the first round of the Delphi method in Phase 3 of the study. The final editing of the combination of phrasing of the recommendations (CPG and NICU Care Path) was done by the researcher before the second round of the Delphi method in Phase 3. This process is described in Chapter 7, section 7.4.

3.4.3 Integration of recommendations from the clinical practice guideline and NICU Care Path with the patient journeys developed in Phase 1

The list of evidence-based recommendations made in the CPG and NICU Care Path, which the researcher grouped and placed under the headings listed in section 3.4.2, was then collated with the statements relevant to the hospitalisation phase of the patient journeys (developed in Phase 1). The collation was done by comparing each evidence-based recommendation to the concepts derived from the transcripts of the focus group discussions and key informant interviews (Part 1 of Phase 2), as listed in tables such as Table 3.3 in Section 3.3.1.3 of this chapter. If the researcher identified concepts that were relevant to a specific recommendation from the CPG or NICU Care Path, an additional statement was added with the recommendations under the specific heading, and was included in the questionnaire used in the first-round Delphi method (Phase 3). An example of this process is shown in Table 3.10.

TABLE 3.10 EXAMPLE OF THE COLLATION PROCESS COMBINING RECOMMENDATIONS IDENTIFIED IN THE CLINICAL PRACTICE GUIDELINE AND NICU CARE PATH WITH CONCEPTS FROM THE PATIENT JOURNEY

Heading selected by researcher	***Relevant CPG recommendation***	***Relevant NICU Care Path recommendation***	***Relevant concepts from hospitalisation phase of the patient journey that will be included as a statement***
Prevention	Collaborate with caregivers to reduce risk for skull deformity, torticollis and extremity malalignment through diligent positioning for symmetry and neutral alignment.	None	The physiotherapist as a member of the MDT will monitor the respiratory function of the intubated or non-intubated infant in the NICU or HCU.
			The physiotherapist as a member of the MDT should monitor the effect of the environmental, social and chemical stressors on the infant in the NICU or HCU to avoid overstimulation and other complications.
			The physiotherapist observes feeding assessments done by nursing practitioners or speech therapists in order to do respiratory care (e.g. suction of the infant) in case the infant aspirates.
			The physiotherapist takes special care to implement sterile procedures in the NICU or HCU to prevent cross-infection to infants with underdeveloped immune systems.

The process shown in Table 3.10 was then repeated for all recommendations under the selected headings.

3.4.4 Formulation of statements and recommendations to be included in the questionnaire for Phase 3

The researcher, in consultation with her supervisors, constructed a questionnaire that was tested in the first-round Delphi method in Phase 3 (Annexure G). The questionnaire consisted of an informed consent section, where the participants were provided with information on the background of the study and informed consent was required before they could complete the questionnaire. This was followed by a biographic information section. The rest of the questionnaire was divided into three parts. The first part dealt with the hospital setting of the prematurely born infant as perceived by the MDT and parents or caregivers of prematurely born infants in the greater Tshwane Metropole. All the concepts from the patient journey that were found to be relevant to the hospital setting were changed into statements by the researcher and were grouped here. The second part of the questionnaire dealt with the scope and practice of the MDT members with whom the physiotherapist collaborates in the NICU, HCU or KMC ward. All the concepts from the patient journey that were found to be relevant to the MDT were changed into statements by the researcher and were grouped here. The collated evidence-based recommendations and statements, as described in section 3.4.3, formed part of the third part of the questionnaire, which dealt with the role and scope of practice of the physiotherapist working in the NICU, HCU or KMC ward in SA and also included a section on holistic family care, the professional ethical conduct of the physiotherapist and the education and knowledge of the physiotherapist working in a NICU, an HCUs or a KMC ward. These sections included only those statements from the concepts identified in the patient journey that did not occur in the CPG or NICU Care Path.

3.4.5 Ethical considerations for Phase 2 of the study

The researcher contacted the authors / developers, namely Sweeney et al. (2010), as well as Byrne et al. (2013a) and Byrne et al. (2013b) to obtain permission to include their work in this study.

They were contacted via email and the researcher provided them with the protocol of the study to inform them on what she planned to do with their developed CPG and NICU Care Path. They had no objection to the inclusion of their work in this study (Annexure H).

3.4.6 Rigour for Phase 2 of the study

The researcher improved the rigour of the recommendations made in the CPG and NICU Care Path by comparing the evidence linked to the recommendations or, as in the case of the NICU Care Path, by linking the evidence to the specific section of the recommendations. The rigour was further strengthened when the researcher added the relevant statements derived from the data on the patient journeys to the recommendations from the CPG or NICU Care Path, which formed part of the contextualisation process described by Gonzalez-Suarez et al. (2012). This provided the South African health care context that was needed for the contextualisation process. The data analysis was electronically saved and is available on request. This forms part of the paper trail and the researcher's thought process.

The methodological triangulation, as described in Section 3.3.5 of this chapter, continued in Phase 2.

3.5 METHODOLOGY OF PHASE 3 DELPHI METHOD AND CONTEXTUALISATION OF THE CLINICAL PRACTICE GUIDELINE

In Phase 3 of the study, physiotherapists who were managing prematurely born infants in NICUs, HCUs or KMC wards in SA provided input on the relevance of the recommendation and statements formulated in Phase 2. This was an important step in the contextualisation process as those physiotherapists were the potential end users of the contextualised CPG, which was the end product of this study. The researcher decided to use the 'typical' Delphi method to obtain information from participants online. This method, as described by Skulmoski, Hartman and Krahn (2007), is illustrated in Figure 3.11.

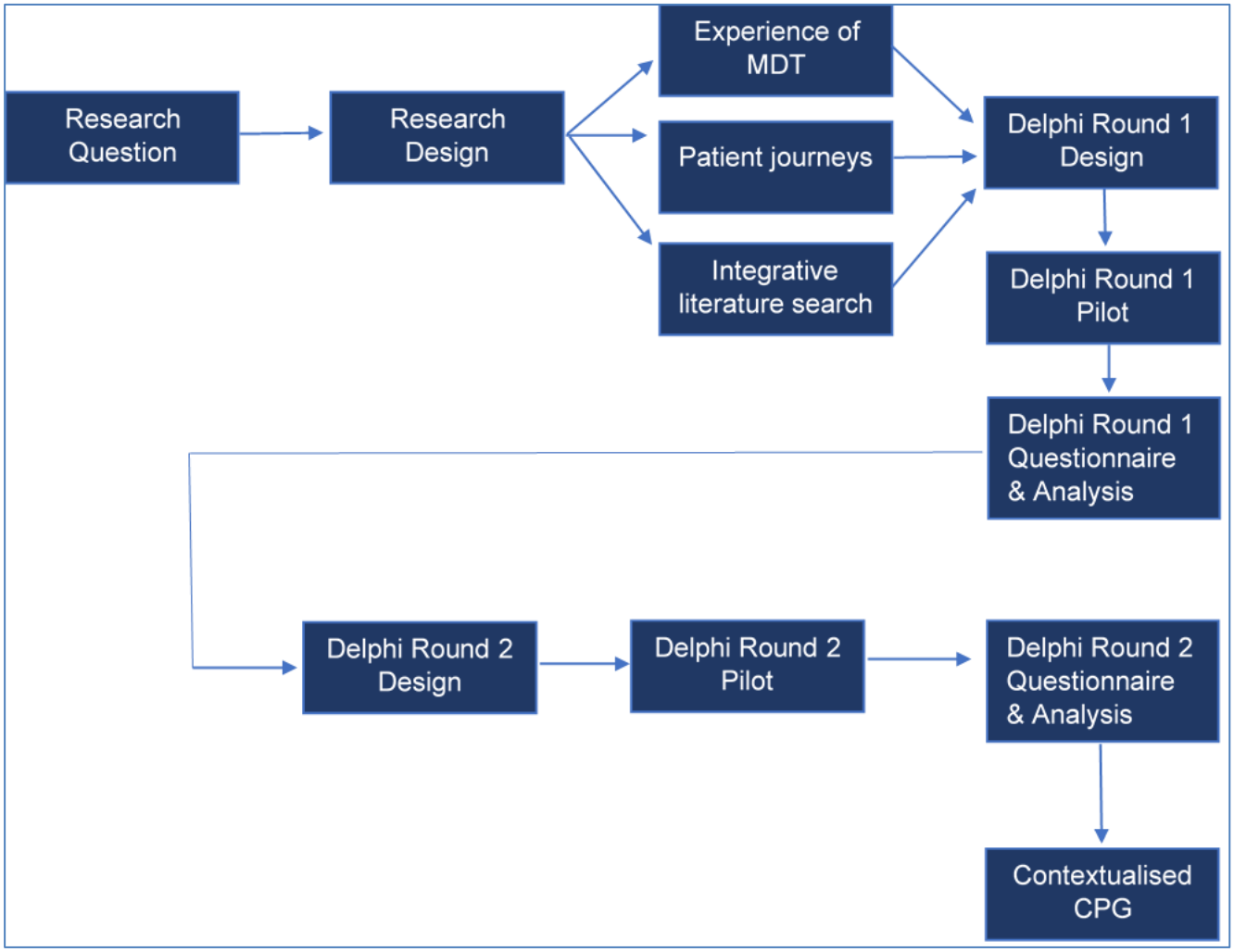


FIGURE 3.11 EXPLANATION OF THE 'TYPICAL' DELPHI METHOD USED IN THIS STUDY

It was found that the Delphi method is useful when the issue under investigation—in this case the physiotherapy management of prematurely born infants in NICUs, HCUs or KMC wards—does not lend itself to precise analytical techniques. The issue under investigation can then benefit more from subjective input from identified experts on a collective basis (Grisham, 2009). Vaughan-Graham and Cott (2016) state that the Delphi method is a popular research method that has been successfully used by health care professionals in order to access the opinions of a geographically diverse group of experts. In this phase of the study, the researcher wanted to include the opinions of physiotherapy experts working across SA and in various health care settings.

Yeung, Woods, Dubrowski, Hodges and Carnahan (2015) define the Delphi method as a 'consensus-seeking method that utilises a sequential set of questionnaires (rounds) to systematically gather opinions on a topic from a panel of experts.

In this iterative process the experts have an opportunity to refine or re-evaluate their input in the sequential rounds of the process (Plenge, Nortje, Marais, Jordaan, Parker, van der Westhuizen et al., 2018).

Phase 3 of this study consisted of two rounds. Diamond, Grant, Feldman, Pencharz, Ling, Moore et al. (2014) mention that a key feature of the Delphi method is that the participants remain anonymous, which may lead to participants being more willing to freely share their opinions on the questions posed. The researcher regards this as a positive element of the Delphi method. Grisham (2009) also confirms that the Delphi method was developed with the intention of removing the bias that could occur when a diverse group of experts meet. The anonymity means that participants or experts cannot influence each other's answers to questions relating to what their management of prematurely born infants entails.

Figure 3.12 shows the study design for Phase 3. The Delphi method is typically used as a quantitative technique (Skulmoski et al., 2007), but the researcher incorporated qualitative aspects by asking the experts / participants to give their opinions regarding the recommendations or statements, which were then integrated with the statements or recommendations included in the questionnaire that was used in the following round.

FIGURE 3.12 STUDY DESIGN FOR PHASE 3 OF THE STUDY

The methodology followed in Phase 3 will be discussed next.

3.5.1 Data collection procedure

The structured questionnaire formulated in Phase 2 (as discussed in section 3.4.4) was used in the first-round Delphi method. Hsu and Sandford (2007) found that a structured questionnaire is suitable for use in a Delphi method.

The questionnaire was uploaded to the LimeSurvey software licenced to UP with the assistance of the manager of the Digital Scholarship and MakerSpace Centre in the Department of Library Services – Strategic Innovation, who is experienced in the use of the LimeSurvey software. The researcher and two study supervisors piloted the questionnaire to ensure that all the questions were activated correctly and that the questionnaire was user friendly.

The software generated a link to the questionnaire that was made available to participants via email. The researcher provided the link to the SASP, which in turn made it available to the members of the SASP paediatric and cardiopulmonary special interest groups. The reason for this will be discussed in section 3.5.4, which deals with ethical considerations. The researcher also made the link available to clinical and academic physiotherapy experts who were working at different universities in SA. Participants were asked to provide the researcher with the contact information of physiotherapists known to them who managed prematurely born infants and the link was subsequently also forwarded to them. The link was active from 30 July 2018 until 14 September 2018.

The shortcomings or weaknesses of the Delphi method include the potential of a low response rate and a time constraint (Hsu et al., 2007). To increase the response rate, the researcher and SASP followed Dillman (2011) suggestion to have three points of contact with the participants. These contact points were the initial email containing the link to the questionnaire, a follow-up thank you / reminder email three weeks after the initial email, and lastly a final reminder six weeks after the initial email.

After opening the link, participants were prompted to provide informed consent before they were given access to the recommendations and statements.

Each recommendation and statement in the questionnaire had to be graded on a 6-point Likert scale, on which 1 (one) meant strongly disagree and 6 (six) meant strongly agree. Each recommendation and statement also provided an optional number 7 (seven), which could be chosen if the answer was 'I don't know'. Each recommendation and statement was followed by an 'open section' in which participants could comment on the recommendations or statements or add information on their experiences in practice, or suggestion for effective physiotherapy practice in SA.

After completing the data analysis for the first-round Delphi method (which will be discussed in section 3.5.3), the researcher compiled a questionnaire for use in the second round. This questionnaire differed from that used in the first round in that the researcher did not include Parts 1 and 2 (as discussed in section 3.4.4). The reason for excluding those two parts was that the hospital setting (Part 1 of the first-round questionnaire) and the scope and practice of the MDT working with the physiotherapist (Part 2 of the first-round questionnaire) were confirmed by the participants in the first round of the Delphi method. The focus of the questionnaire for the second-round Delphi method was therefore only on the physiotherapy management of prematurely born infants and their parents or caregivers.

The same procedure was followed to load the second-round questionnaire into the LimeSurvey Software for piloting by the researcher and the two study supervisors before making the link available to the participants. The link to the second-round Delphi questionnaires was again made available to the SASP, the academic and clinical experts from the universities, and the physiotherapists managing prematurely born infants who had been identified by the participants.

3.5.2 Population

The population consisted of physiotherapy members of the SASP paediatric and cardiopulmonary special interest groups. The researcher acknowledges the limitations of selecting members of the SASP as some physiotherapists involved in the management of prematurely born infants might not be members of this society. It was for this reason that participants who had provided informed consent were asked to provide the researcher with the contact details of other physiotherapists known to be managing prematurely born infants (word of mouth).

The researcher aimed to include as many suitable participants as possible. The participants provided the researcher with 18 additional names (n=18) and contact details of possible participants in the first round. The researcher further identified 49 clinical and academic physiotherapy experts (n=49) who, at the time of the study, were working at different universities in SA. These participants were found on university websites and by word of mouth.

The LimeSurvey software logged each reply under the participant's internet protocol (IP) address in order to preserve anonymity. The only information about the participants was given in the biographical section of the questionnaire, which will be discussed in Chapter 7, section 7.2.

A total of 43 (n=43) participants who had provided informed consent and had completed the questionnaire participated in the first-round Delphi method, but not all of them completed the entire questionnaire. The number of participants who had answered each specific question is indicated in Chapter 7, section 7.2. The researcher found the number of participants to be adequate. According to Eubank, Mohtadi, Lafave, Wiley, Bois, Boorman et al. (2016), who also used the Delphi method to obtain consensus for statements / recommendations to be included in a CPG, five to ten experts are considered adequate for content validation. They had included 14 participants in their study.

The participants for the second-round Delphi method were the same as for the first round, namely the SASP paediatric and cardiopulmonary special interest group members and the 49 clinical and academic physiotherapy experts (n=49) who were, at the time of this study, working at different universities in SA. The participants provided the researcher with four more names (n=4) and contact details of possible participants. Participant details will be discussed in Chapter 7, section 7.5. The second-round Delphi method had 25 participants (n=25) who provided informed consent and completed the questionnaire (although not all answered all the questions). The number of participants who had answered each specific question is indicated in Chapter 7, section 7.5 and was found to be adequate for content validation (Eubank et al., 2016).

3.5.3 Data analysis

The LimeSurvey software provided the option to export the data set to Microsoft Excel. The researcher was able to calculate the response frequencies for each item in the questionnaire. A score of between 1 and 3 on the 6-point Likert scale was considered to indicate that participants disagreed with the statement or recommendation, and a score of between 4 and 6 was considered to indicate agreement with the statement or recommendation. Consensus was defined *a priori* as above 80%. Eubank et al. (2016) recommended that, when there are at least 10 experts participating in the Delphi method, at least 80% should agree on an item in order to achieve content validity. Statements or recommendations that obtained consensus of at least 80% in the first-round Delphi method were included in the questionnaire for the second round. Statements or recommendations that obtained consensus of between 60% and 79% were also included, but were edited to include the participants' opinions. Those that scored below 60% were removed from the questionnaire for the second-round Delphi. The statements and recommendations, and the scores achieved, are listed in Chapter 7, section 7.2.

The analysis of the data was the same as for the data set obtained through the second-round Delphi method. The tables listing the statements and recommendations and the scores achieved can be found in Chapter 7, section 7.5. The statements or recommendations that achieved a consensus rating of 80% and higher were included in the contextualised CPG and were listed as statements or recommendations with high relevance to the physiotherapy management of prematurely born infants. Statements or recommendations that scored between 60% and 79% were listed for the end users of the CPG as statements or recommendations with a moderate level of relevance to the physiotherapy management of the infants. The users' own discretion should be used when considering these statements or recommendations.

A formulation of the contextualised CPG concluded this research study.

3.5.4 Ethical considerations for Phase 3

The SASP made the link to the questionnaires in rounds one (Annexure G) and two of the Delphi method available to the members of the paediatric and cardiopulmonary special-interest groups as information about them was confidential and could not be shared with the researcher.

All the participants had to provide informed consent before completing the questionnaires in rounds one and two of the Delphi method. Participation was voluntary and participants were not coerced to participate. Participants were informed that they reserve the right to withdraw from the study at any given time and were assured that there would be no negative consequences for those who decided not to take part, and that access to the contextualised CPG would still be granted to them at the end of the study. Consent was therefore not a once off, but a process of retaining the participants' consent (Ensign, 2003).

The LimeSurvey software ensured the anonymity of the participants as each completed entry was logged under the participant's IP address. Confidentiality of the data provided by the participants, including demographical data, were maintained throughout the study. Original data was and will continued to be stored in an electronic format as well as hard copies for a period of 15 years in compliance with university regulations.

3.5.5 Rigour for Phase 3

Since it is impossible to change data captured by the LimeSurvey software, the data was exactly as provided by the participants, and their anonymity throughout the Delphi methods ensured that they could not be influenced. Both data sets and the data analysis (for rounds one and two of the Delphi method) were electronically saved by the researcher and are available on request.

The final statements or recommendations included in the contextualised CPG were based on the findings / input of the participants, namely the consensus scores that the statements or recommendations achieved in the second-round Delphi method. That means that the contextualised CPG is not based on the researcher's opinion regarding what should be included in the physiotherapist's management of prematurely born infants and their parents or caregivers.

3.6 SUMMARY OF THE CHAPTER

In this chapter the researcher explained the exploratory sequential mixed methods design and the methodology followed in each of the three phases of the current study. The exploratory sequential mixed methods design was chosen to contextualise a CPG for physiotherapists working in NICUs, HCUs or KMC wards. The results of Phase 1 will be discussed in Chapters 4 and 5.

CHAPTER 4

RESULTS OF PHASE 1: MULTIDISCIPLINARY TEAM AND PARENT OR CAREGIVER PERSPECTIVES REGARDING THE PATIENT JOURNEY OF THE PREMATURELY BORN INFANT

4.1 INTRODUCTION

The results of Phase 1 of the current study are presented in Chapters 4 and 5. Figure 4.1 below outlines their content.

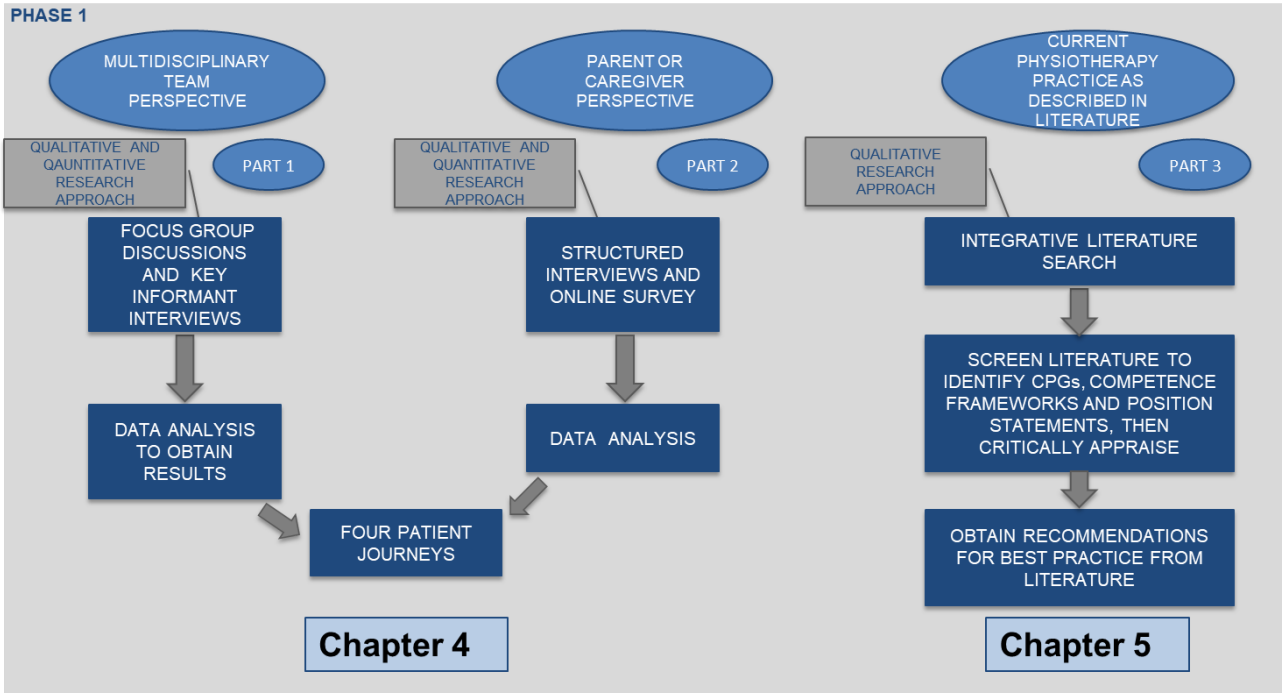


FIGURE 4.1 CONTENT OF CHAPTERS 4 AND 5 OUTLINED

In this chapter, the results obtained with regard to the *multidisciplinary team's perspective* on the patient journey of prematurely born infants (and their parents or caregivers) in the South African health care system, as well as the *parents or caregivers' perspectives* on the (patient) journey of their infant(s), as they had experienced it, are discussed. Since parents or caregivers are intimately involved in their infant's health care process, they share the infant's journey in the health care system. Flow diagrams that illustrate the four patient journeys that were developed based on the perspectives of the MDT and the parents or caregivers are given at the end of this chapter. The purpose of the construction of the patient journeys was to provide the context of the health care system in which prematurely born infants receive health care. Developing the patient journey was the first step in the contextualisation process, as described by Gonzalez-Suarez et al. (2012). The patient journeys included the role of the physiotherapist as a member of the MDT in the holistic management of prematurely born infants in the South African health care system.

The results obtained regarding the MDT and parents or caregivers' perspectives are presented and discussed below.

4.2 MULTIDISCIPLINARY TEAM PERSPECTIVE

Thirty MDT members (n=30) participated in the focus group discussions and key informant interviews conducted in Phase 1 of the study (Chapter 3, Section 3.3.1.2). The demographic information of these MDT members was derived from the questionnaire (Annexure C) that they completed (see section 4.2.1). The description of the themes and categories relating to the hospitalisation phase of the prematurely born infants was derived from the coded data in the transcriptions of the focus group discussions and key informant interviews. The hospitalisation phase of the infant is described in section 4.2.2.

4.2.1 Demographic information

A list indicating the participants' professions and the health care sectors in which they were employed is provided in Table 3.3 (Chapter 3, section 3.3.1.2).

4.2.1.1 Highest qualification

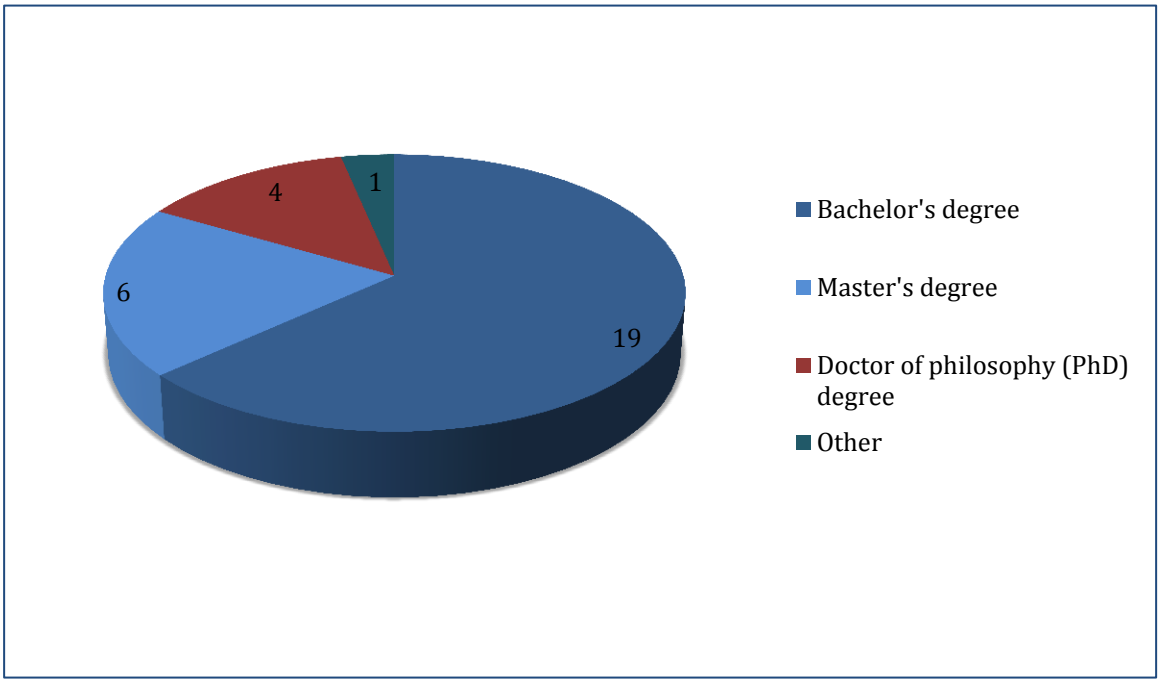


FIGURE 4.2 HIGHEST QUALIFICATIONS OF PARTICIPANTS (N=30)

Figure 4.2 indicates the participants' highest qualifications. The single participant who indicated 'other' was a nursing practitioner who specialised in neonatal nursing and paediatrics. Thirty-seven percent (37%) of participants had postgraduate qualifications.

4.2.1.2 Employment

Figure 4.3 indicates the health care sectors of SA in which the participants were employed at the time when they participated in the focus group discussions or key informant interviews.

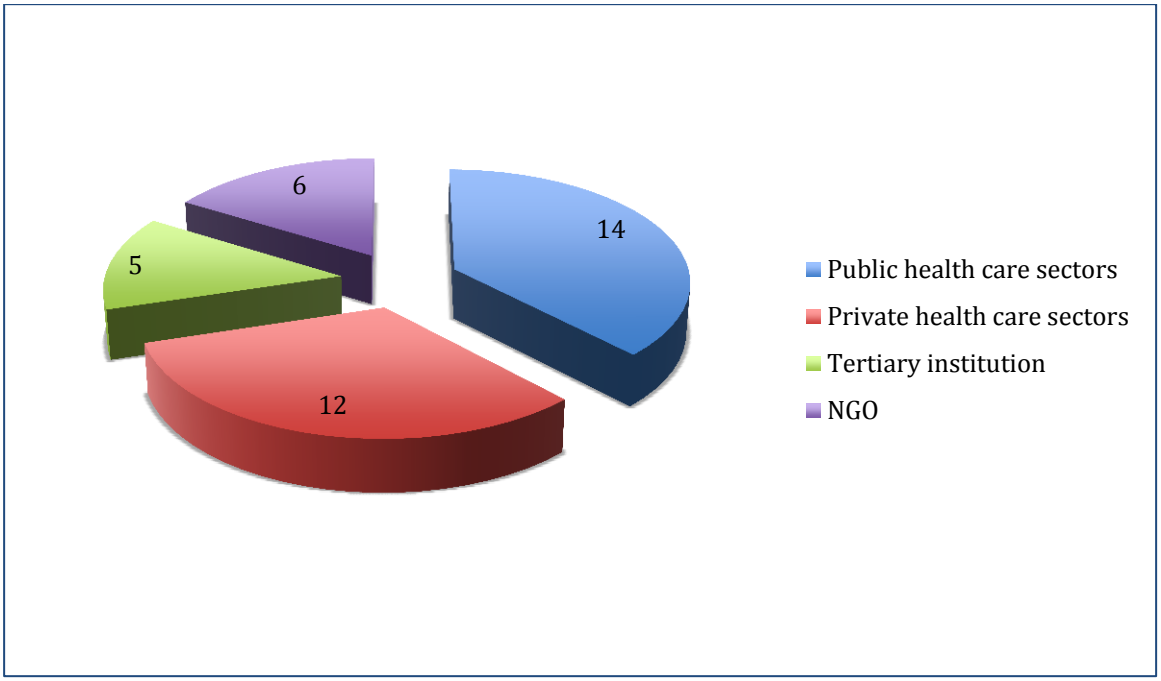


FIGURE 4.3 EMPLOYMENT OF PARTICIPANTS (N=30) IN THE VARIOUS SOUTH AFRICAN HEALTH CARE SECTORS

Participants could indicate whether they were employed in more than one sector at the time as some worked in both the public and the private health care sectors. Five participants (n=5) indicated that they were employed in the private health care sector, but also worked at NGOs, and two (n=2) were employed in both the private and public health care sectors.

The number of years that participants had been employed in the various sectors is shown in Figure 4.4.

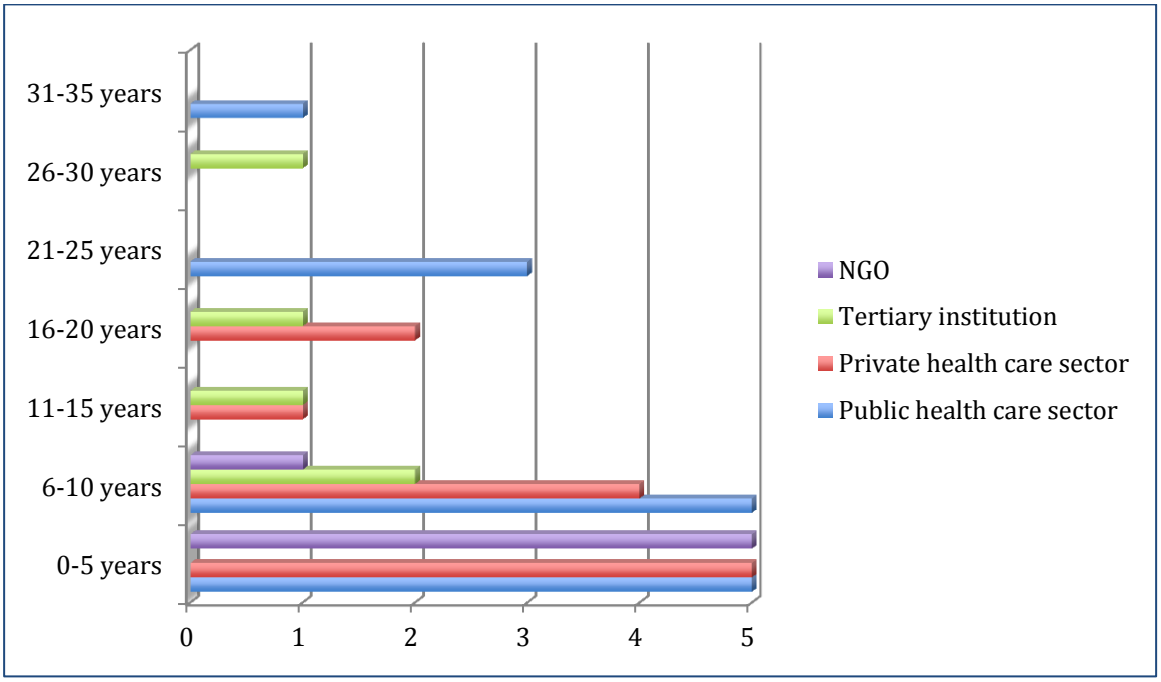


FIGURE 4.4 NUMBER OF YEARS PARTICIPANTS HAD BEEN EMPLOYED IN DIFFERENT SECTORS

The number of years that participants had been employed in the different health care sectors varied, but was well balanced as some had less than five years' and others more than twenty years' experience.

Half of the participants (n=15) had previously been employed in other health care sectors in SA. Of these:

- nine (n=9) had previously been employed in the public health care sector;
- three (n=3) had previously been employed in the private health care sector;
- one (n=1) had previously been employed in both the public and private health care sectors;
- one (n=1) had previously been employed at a school for disabled children; and
- one (n=1) indicated that (s)he had been employed in a different sector, but did not indicate which sector.

4.2.1.3 Multidisciplinary involvement with prematurely born infants and their parents or caregivers

Twenty-four of the participants (n=24) indicated that they were involved in the care and management of prematurely born infants either during the hospitalisation phase or during follow-up services post discharge. These participants could indicate in which areas of the patient journey they were involved, and also whether they were involved in many different areas, as shown in Figure 4.5.

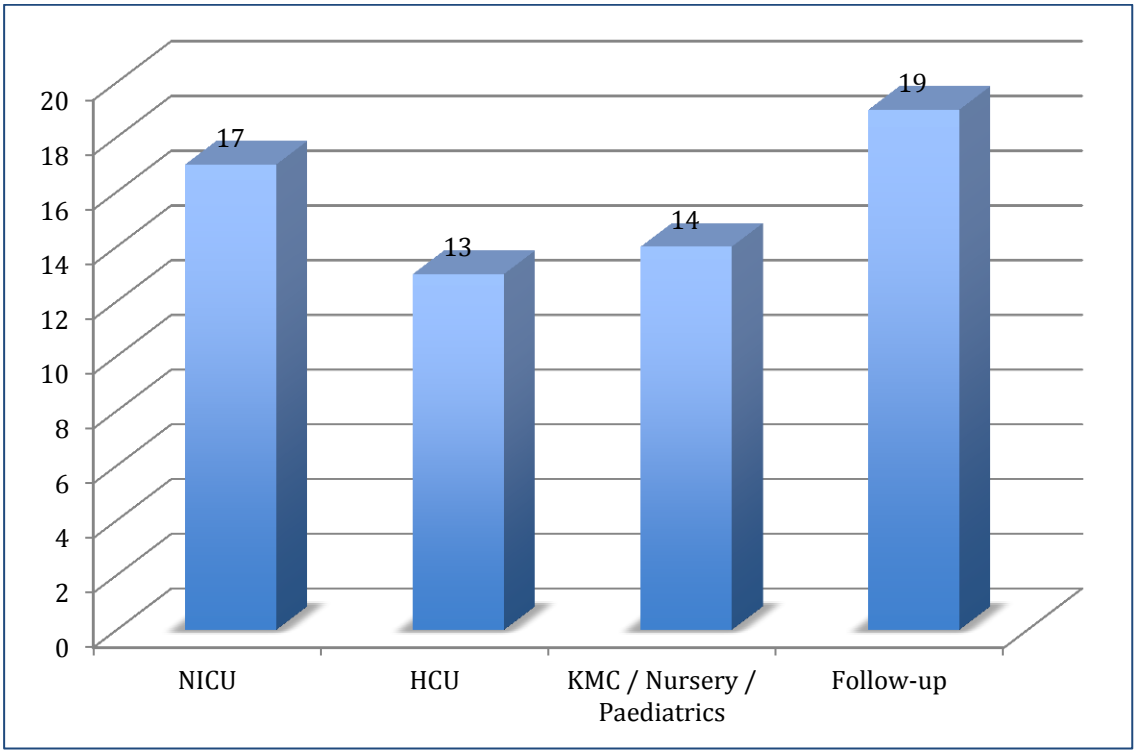


FIGURE 4.5 AREAS OF INVOLVEMENT IN PATIENT JOURNEYS

The majority of the participants indicated that they were involved with the care of prematurely born infants during the NICU phase and the follow-up care. Seventy per cent (70%) indicated that they did not think that the parents or caregivers of prematurely born infants were adequately equipped to manage their infants after discharge, or were sufficiently knowledgeable about what to expect during the first year post corrected age.

Twenty-eight participants (n=28) indicated the MDT members who, in their experience, were involved in parent or caregiver education (Figure 4.6). Two participants (n=2) did not answer this question.

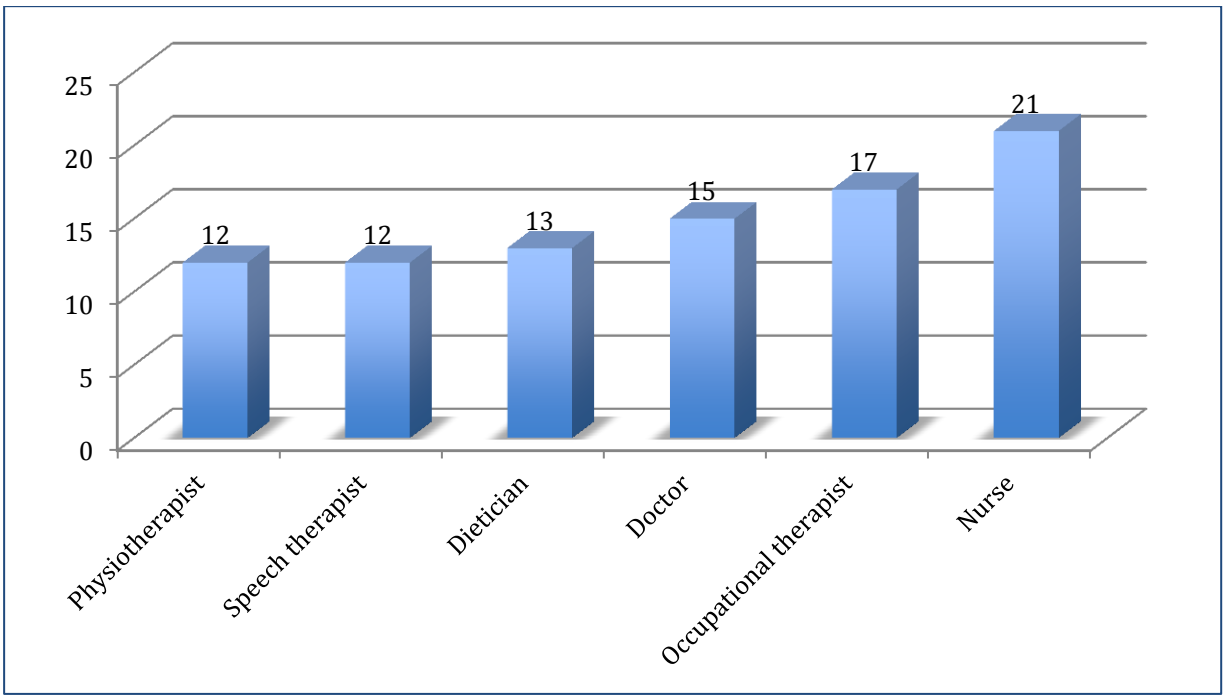


FIGURE 4.6 MULTIDISCIPLINARY TEAM MEMBERS' INVOLVEMENT IN PARENT / CAREGIVER EDUCATION

Nursing practitioners and occupational therapists were found to be the MDT members most involved in the education of parents or caregivers of prematurely born infants, while physiotherapists and speech therapists were shown to be the least involved in this respect. Ninety-seven percent (97%) of participants agreed that parents or caregivers of prematurely born infants could benefit from information or relevant health education, especially if parents or caregivers were able to provide input on what their needs entailed.

Seventy-three per cent (73%) of the participants indicated that their pre- or postgraduate continuing professional development (CPD) courses covered the principles of evidence-based practice, and six (n=6 or 20%) indicated that their courses did not cover those principles. Two participants (n=2) did not answer the question.

4.2.1.4 Multidisciplinary team's fields of interest or specialisation

The participants (n=30) indicated their fields of special interest, which included:

- Paediatrics (n=12)
- Neonatology / NICU (n=11)
- Neurodevelopmental supportive care and development (n=5)
- Early intervention (n=4)
- Breastfeeding (n=4)
- Paediatrics ICU (n=2)
- Primary health care services (n=2)
- KMC (n=2)
- Dysphagia (n=1)
- Hand therapy (n=1)
- Treatment of human immunodeficiency virus (HIV) (n=1)
- Midwifery (n=1)
- Vocational rehabilitation (n=1)
- Orthopaedic rehabilitation (n=1)
- Pulmonology (n=1)
- Treatment of allergies (n=1)

The participants (n=30) were asked to explain how they had obtained their clinical expertise and provided the following information:

- *Further studies or additional qualifications* were indicated by most participants (n=21). The additional studies or qualifications could include courses completed nationally and / or internationally, postgraduate courses or informal education through workshops. It could also include activities for CPD, which were mentioned by three participants (n=3).
- *Work experience,* which included experience in both the private and public health care sectors (n=20).
- *Communication or training with colleagues.* Nine participants (n=9) included the sharing of experiences, mentoring and consultation with peers.
- *The study of literature and evidence-based practice* were listed by six participants (n=6) as important ways of obtaining expertise in a field of interest.
- *Participation in research* as a way to develop expertise in a field of interest was listed by four (n=4) participants.
- *Lecturing or involvement in student training* was listed by three participants (n=3).
- Participating in *academic ward rounds* with fellow MDT members was listed by two participants (n=2).

In response to the question regarding the requirements for a clinician to be regarded as an expert in the clinical management of prematurely born infants, the following aspects were highlighted by the participants:

- Obtaining *additional qualifications* through postgraduate courses, which could include a master's degree or PhD in the specific field (n=23)
- *Work experience* in the field of neonatology or paediatrics (Work experience could include experience in different areas within the health care sectors, e.g. hospitals or clinics. Some participants (n=16) suggested that work experience should be gained under the guidance of a mentor, and that the therapist should gain experience in the treatment or management of different conditions that could occur in the specific patient population, i.e., prematurely born infants in the NICU)
- Consulting *literature and evidence-based practice guidelines* (n=7)

- *A passion* for working with infants and specialisation in the field of either neonatology or paediatrics (n=4)
- *Regular MDT interaction* (n=3)
- *Attending CPD workshops* (n=3)
- *Conducting research* in the field (n=2)
- The participants also mentioned that a clinician should have knowledge in the following areas:
    - ✓ Treatment indications and contra-indications
    - ✓ Assessment and various intervention options
    - ✓ The role of the physiotherapist in the care of prematurely born infants
    - ✓ The care routine of the infant in the NICU, HCU or KMC ward
    - ✓ Understanding of the pathway of care for these infants
    - ✓ The developmental care of infants and support of the parents or caregivers

Two of the participants, a physiotherapist and an occupational therapist who is a health manager (n=2), felt that basic or undergraduate training was adequate for a therapist to be involved in the care / management of prematurely born infants. The physiotherapist recommended the attendance of additional courses to keep abreast of new developments in their fields.

4.2.1.5 The need for a clinical practice guideline for the management of prematurely born infants

Ninety-seven percent (97%) of the participants agreed that a CPG that includes the delineation of the role of the physiotherapist in an MDT in SA is necessary. One participant (n=1) did not answer the question. The participants' reasons for regarding the availability of a CPG for physiotherapists as important are listed below:

A CPG would offer the following advantages:

- It could provide guidance on best practice and what the management of prematurely born infants should entail. It could also clarify physiotherapists' scope of practice and their role within the MDT, which was considered to be important, especially for a newly qualified therapist. Participants felt that a CPG could standardise the quality of practice and could contribute towards physiotherapists' ethical practise (n=13).
- It has the potential to improve the care and outcome of the infants and could possibly assist in the prevention of long-term complications due to premature birth (n=11).
- It could improve physiotherapists' involvement in MDTs and could assist them in aligning their interventions with the goals and aims set by the team for each individual infant (n=7).
- It could potentially assist the physiotherapist in providing support and training to the infant's parents or caregivers, which may promote the parent-infant bonding process (n=3).
- It could provide guidance to the paediatrician and the nursing staff on the nature of the physiotherapist's role in the care and management of prematurely born infants (n=3).
- It could increase MDT members' awareness of the role of the physiotherapist, which may lead to more referrals of infants for physiotherapy (n=2).
- It could assist physiotherapists in the standardisation of follow-up examinations of prematurely born infants as it might highlight the importance of follow-up care and assessments, especially for high-risk infants (n=1).

4.2.1.6 Parent or caregiver education in practice

The MDT's perspectives on the health care education given to the parents / caregivers during the infants' hospitalisation phase were categorised into positive and negative comments (Table 4.1).

TABLE 4.1 MULTIDISCIPLINARY TEAM'S POSITIVE AND NEGATIVE COMMENTS REGARDING PARENT / CAREGIVER EDUCATION IN THE CURRENT HEALTH CARE SECTORS

Positive comments about parent / caregiver education	Negative comments about parent / caregiver education
The parents or caregivers receive information regarding KMC, handling, positioning and feeding of the infant.	The parents or caregivers usually have limited knowledge and experience in the management of the infants after discharge, or what the prognosis of high-risk infants could include. The parents or caregivers therefore lack adequate MDT input before discharge.
If therapists discover that an infant present with neurological complications, the parents are informed of the condition and possible interventions.	Parents or caregivers might identify problems at home as they occur, and might not know that intervention is needed or who to contact if they are worried about something. By the time they eventually contact MDT members, it is possible that the delayed intervention might no longer achieve the optimal outcome.
If parents or caregivers start the journey with the physiotherapist in the NICU, they will be provided with information for care during hospitalisation and post-discharge care.	Parents or caregivers might not receive information on possible developmental delays, how the infant should develop (expected developmental milestones), or the benefits of KMC.
Information is provided to parents or caregivers by the therapists, but will vary from one hospital to the next.	Parents or caregivers have to rely on social media groups for information.
Compared to parents or caregivers with infants in the private health care sector, those with infants in the public health care sector are better informed and equipped for the transition from the hospital to their homes.	A standardised parental education protocol does not exist in current practice.

There are weekly education sessions for parents or caregivers, during which nursing staff from the KMC wards provide support and booklets on a variety of health-related topics, e.g. resuscitation or what to do if an infant has a fever (public health care sector).	Parents or caregivers are not educated on the infant's physiological cues and how they should be interpreted without monitors, which can be very stressful to parents or caregivers once the infant has been discharged.
The infants undergo regular follow-up evaluations during which the parents or caregivers receive further education. (public health care sector).	Parents or caregivers are unaware that early screening and intervention and follow-up with the MDT, including the physiotherapist, are necessary. No standardised follow-up programmes exist in the private health care sector. Parents or caregivers who are referred to an MDT might not be well informed regarding their infant's condition, or might not know why they are being referred. This could be due to poor communication between the paediatrician and the parents or caregivers.
	Parents or caregivers are not educated on important terminology, e.g. corrected age.
	The parents or caregivers might not be the primary carers after discharge. The grandmother or other family member who takes over the responsibility for an infant's care might not have received the necessary education and might therefore lack the knowledge needed to care for the infant at home.

The results based on the demographic information will be discussed in section 4.2.3. The hospitalisation phase of prematurely born infants, as derived from the transcriptions of the focus group discussions and key informant interviews, will be discussed next.

4.2.2 Description of the hospitalisation phase of prematurely born infants

During the open and axial coding of the transcripts of the focus group discussions and key informant interviews (Chapter 3, section 3.3.1.3), the researcher identified three main themes for the hospitalisation phase of the patient journey. The complete list of themes and categories linked to the identified codes of the hospitalisation phase is provided in Annexure J.

The three main themes derived from the concepts identified during the coding process are:

1) The prematurely born infant entering the health care sectors (private or public)
2) The journey of the prematurely born infant's parent or caregivers
3) The hospital (NICU, HCU or KMC ward) environment

Figures 4.7 to 4.11 summarise the concepts and themes (identified during the coding process) linked to each main theme.

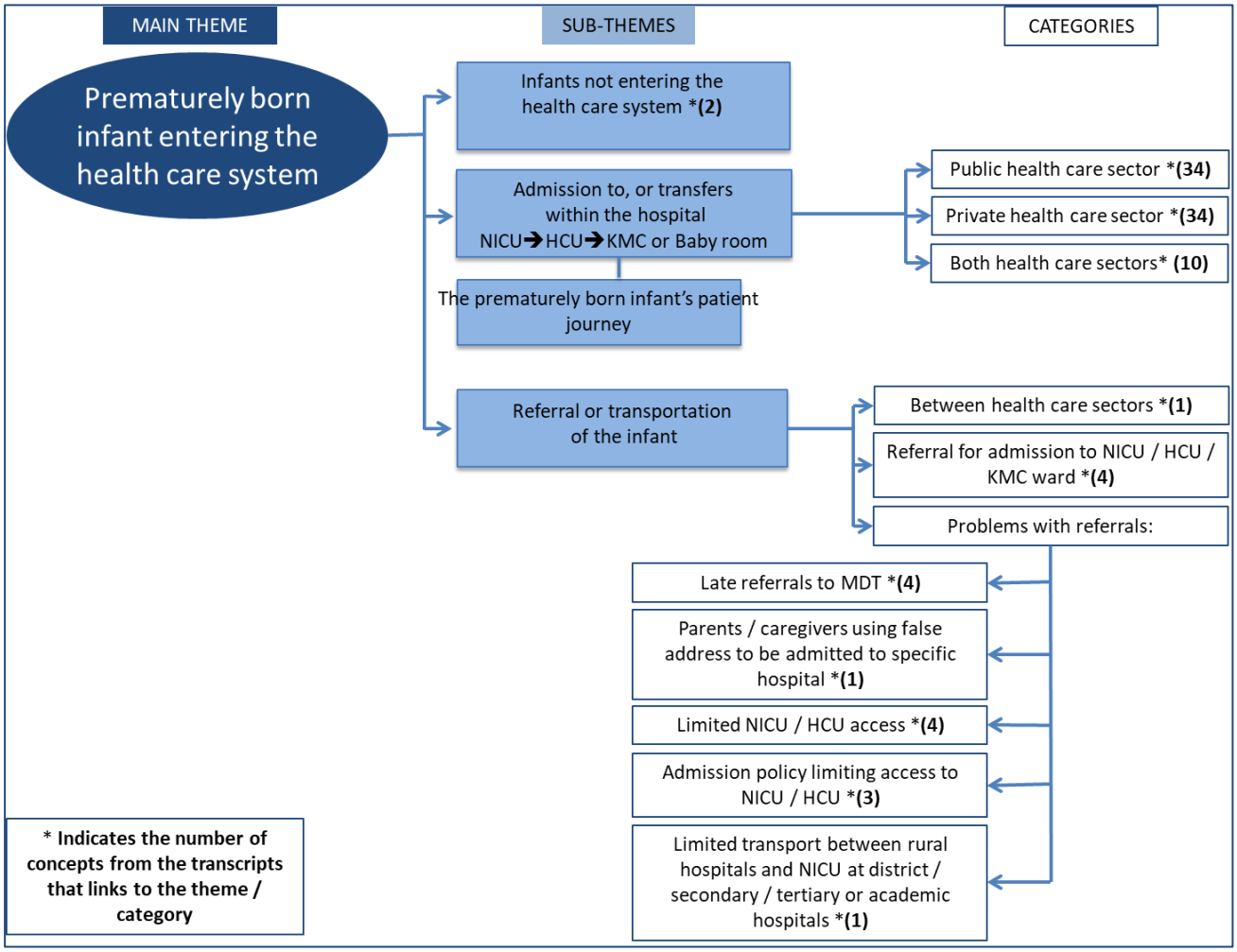


FIGURE 4.7 THE PREMATURELY BORN INFANT ENTERING THE HEALTH CARE SYSTEM

As mentioned earlier, the parents or caregivers of the prematurely born infant form part of the infant's patient journey. Their journey in the hospital is illustrated in Figure 4.8.

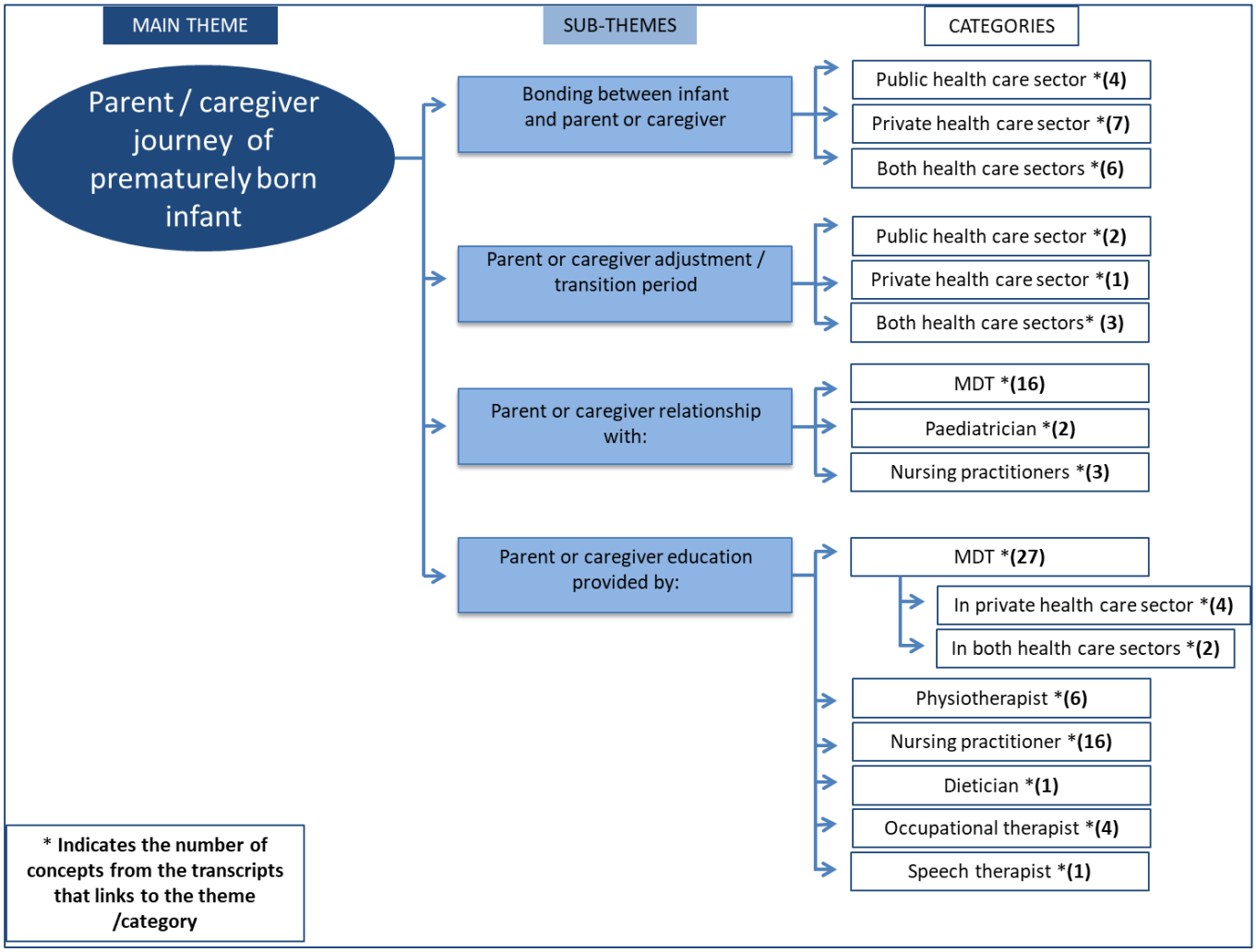


FIGURE 4.8 THE JOURNEY OF THE PARENTS OR CAREGIVERS OF THE PREMATURELY BORN INFANT

The third main theme, namely the hospital (NICU, HCU or KMC ward) environment, relates to the perspectives of the MDT members in this regard and the sub-themes they indicated as being important in respect of the hospital environment, is shown in Figures 4.9 and 4.10 below.

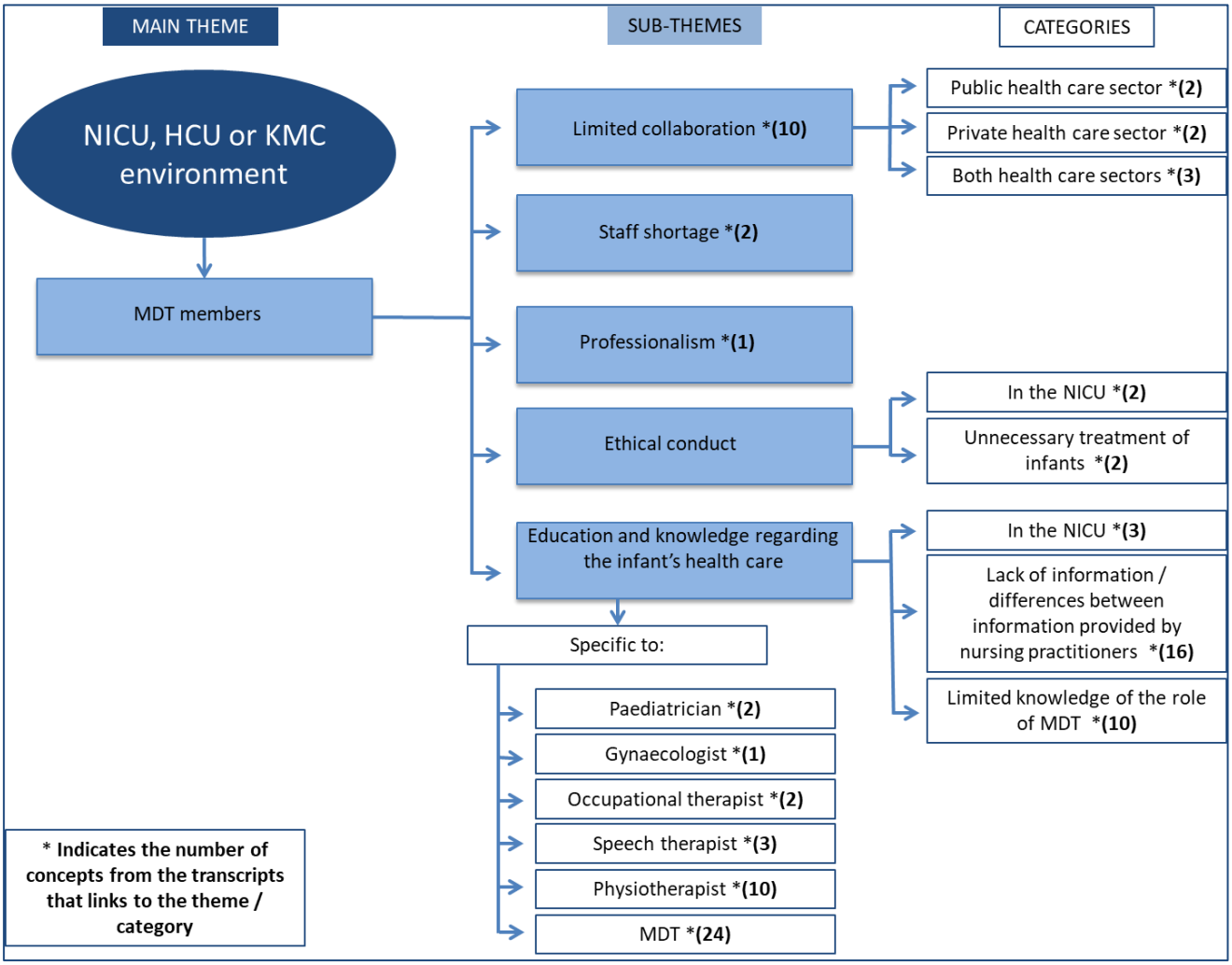


FIGURE 4.9 THE HOSPITAL (NICU, HCU OR KMC WARD) ENVIRONMENT

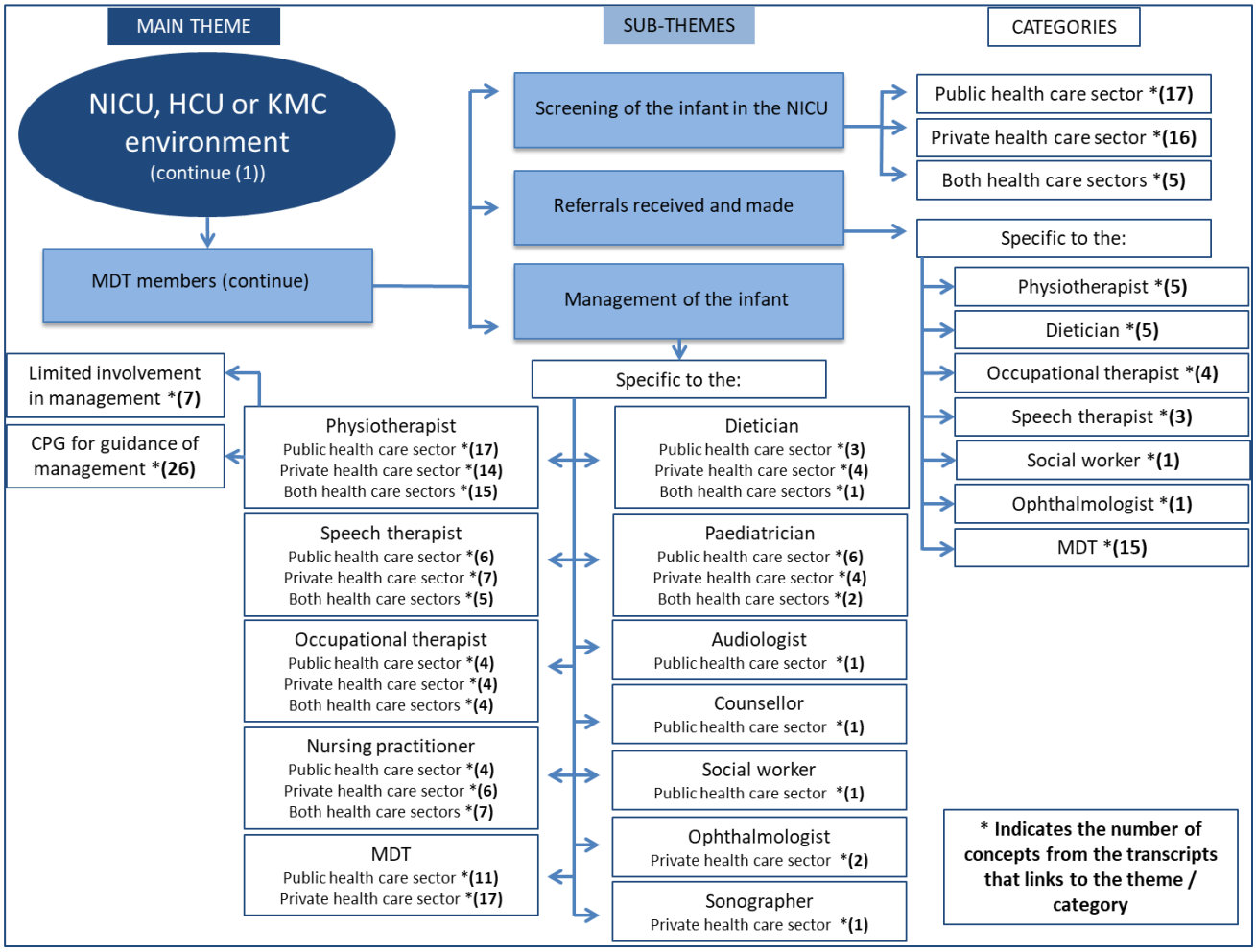


FIGURE 4.10 THE HOSPITAL (NICU, HCU OR KMC WARD) ENVIRONMENT (CONTINUED (1))

Figure 4.11 lists other sub-themes and categories mentioned by the MDT members that relate to the main theme, namely the hospital (NICU, HCU or KMC ward) environment.

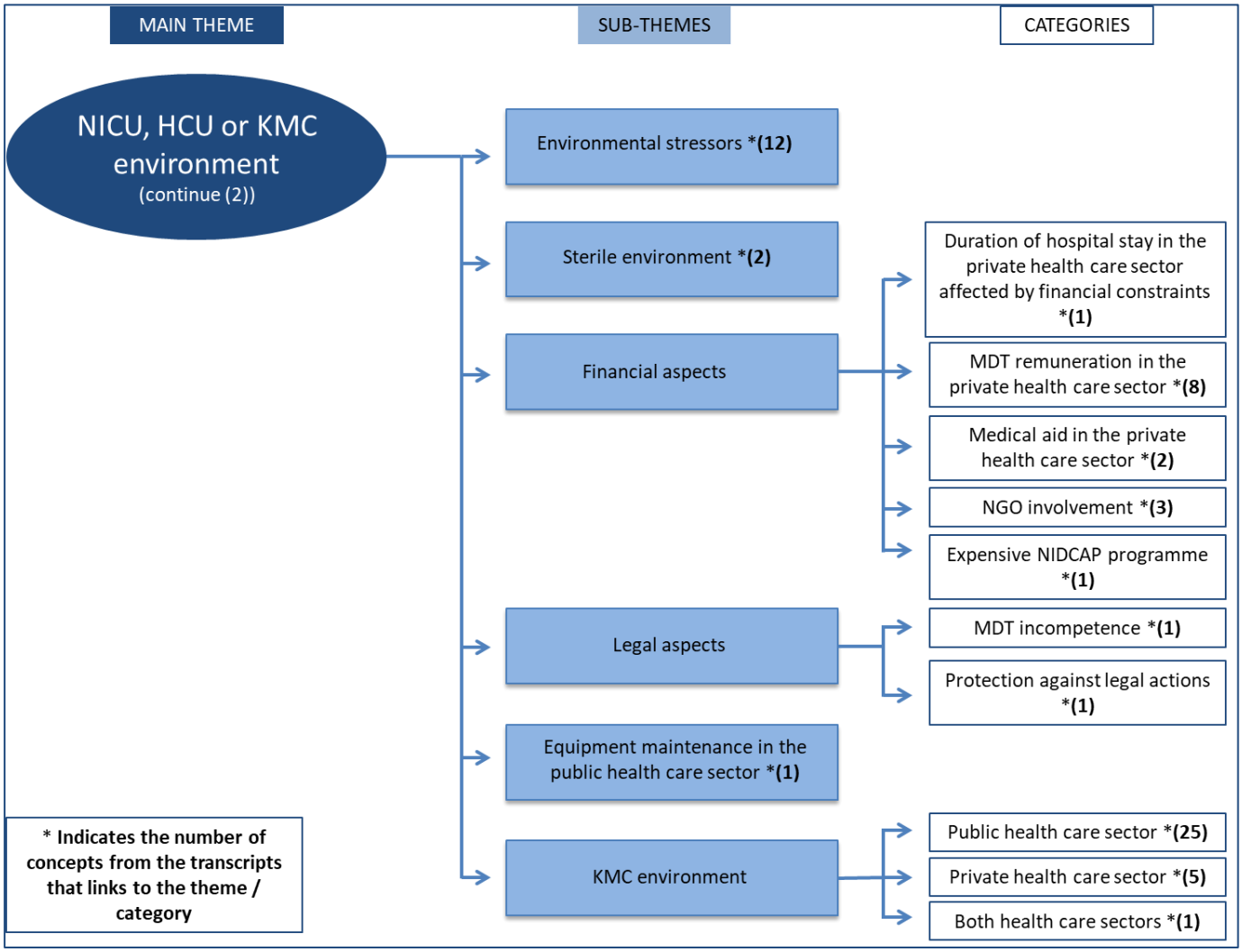


FIGURE 4.11 THE HOSPITAL (NICU, HCU OR KMC WARD) ENVIRONMENT (CONTINUE (2))

The results presented in Figures 4.7, 4.8, 4.9, 4.10 and 4.11 will be discussed in the next section.

4.2.3 Discussion of results

The discussion will be divided into the following main topics:

- Demographic information of participants who were members of MDTs

- The MDT members' opinions regarding the prematurely born infant's entry into the health care system
- The MDT members' opinions regarding the journey of prematurely born infants' parents or caregivers
- The MDT members' opinion regarding factors in the hospital environment that influence the care of prematurely born infants and their parents or caregivers
- The MDT members' knowledge of evidence-based practice and requirements for being considered a clinical expert in a specific field

4.2.3.1 Demographic information provided by multidisciplinary team participants (n=30)

The participants who participated in the focus group discussions and key informant interviews were experienced professionals of whom 37% (n=11) had postgraduate qualifications. This meant that more than a third of the participants were familiar with principles of research, which made their input especially valuable to this study. The fields of special interest indicated by the majority of the participants included paediatrics, neonatology / NICU, neurodevelopmental supportive care / development, early intervention and breastfeeding. These fields of interest suggested that the participants shared an interest in the care of prematurely born infants during the hospitalisation and short-term follow-up phases, which correlates with the interest of this study.

Both the private and public health care sectors in SA were well represented by the participants, half of whom indicated that they had experience in both the private and public health care sectors. This was important as the researcher wanted to map the patient journeys of prematurely born infants in both health care sectors. The participants were therefore able to provide valuable insight regarding all possible patient journeys.

The participants' years of experience were also well balanced as the group included both newly qualified professionals and participants with up to 35 years' experience.

Eighty percent (80%) of participants were involved in the care and management of prematurely born infants at the time of their participation in the current study, and the majority was working in the NICU environment and was involved with the follow-up care of the infants.

Information was therefore obtained from participants who were familiar with the current patient journeys of prematurely born infants in SA.

4.2.3.2 Opinions of multidisciplinary team members regarding prematurely born infants entering the health care system

The themes and categories relating to the MDT members' opinion regarding prematurely born infants' entry into the health care system are listed in Figure 4.7. Various themes or categories will now be discussed:

- *Prematurely born infants who do not enter the health care system for hospitalisation*
  Participants stated that not all prematurely born infants enter the health care system (especially in the public health care sector), and that infants born prematurely (but not admitted to hospital at birth) were often referred to them with health care concerns or complications during the follow-up phase of care. Participants explained that infants might also be referred for follow-up consultations with the MDT, but that the parents or caregivers often did not understand the reason for the referral and consequently unfortunately delayed their visits to health care services.

- *Admission to, or transfers within the hospital*
  Participants mentioned that infants could be transferred within the public health care sector, depending on their medical / physiological stability. An infant born at a secondary / district hospital who is not medically or physiologically stable enough to be cared for in the HCU at that hospital, could be transferred to a NICU at a tertiary / academic hospital. Generally infants who are transferred to a tertiary / academic hospital are transferred back to the secondary / district hospital, from where they are then discharged. The follow-up will then take place at the secondary / district hospital.

- *Problems with referrals of infants in the health care sectors*

  Participants who worked at tertiary / academic hospitals explained that infants are admitted to public hospitals in the area or province closest to where they live. If there are no tertiary or academic hospital nearby, the parents might provide a false address close to those hospitals to ensure that the infant is admitted there. Parents or caregivers might provide false addresses because they believe that their infants will receive better care at a tertiary / academic hospital than at a district / secondary hospital.

  According to the participants, transfers of infants between the public and private health care sectors were also possible, but was not a simple process. A transfer from a private to a public hospital could, for instance, occur when the parents / caregivers' medical aid is depleted and the infant's care has to continue. In such a case the infant has to be transferred to the public health care NICU. The opposite could also happen, i.e., the parents / caregivers of an infant admitted to a hospital in the public health care sector could decide to privately fund their infant's care and request a transfer to the private health care sector.

4.2.3.3 The opinion of members of the multidisciplinary team regarding the journey of a prematurely born infant's parents or caregivers

In Figure 4.8, the researcher listed the themes and categories relating to the MDT members' opinions regarding parents or caregivers' journey during the hospitalisation phase of their infants. The following themes or categories will now be discussed:

- *Parent or caregiver education*

  The majority of participants (70%) felt that parents or caregivers of prematurely born infants are not well equipped with knowledge of what to expect in the first year post-corrected age, or the skills needed to deal with possible problems. Almost all the participants (97%) agreed that there is a need for parental or caregiver health education and stated that the three MDT members who currently take responsibility for providing health education to the parents or caregiver are the nurses, occupational therapists and doctors (e.g. paediatricians or neonatologists).

The MDT members who participated in the study indicated that they were uncertain about what the exact nature of the physiotherapist's role in the patient journey of the prematurely born infants and their parents or caregivers should be. The following statement was made by one MDT member: 'I must honestly say that physiotherapy is the only group that we don't really include because in neonatal we don't know what the role is.' Based on the literature discussed in Chapter 2 (section 2.2.2.3), it was clear that the physiotherapist does have a definite role as a member of the MDT in the management of prematurely born infants in the NICU, HCU or KMC ward. The literature further indicated that the role of the physiotherapist does not include only the management of the infant, but also support and education of the parents or caregivers (Goldstein, 2013). According to Goldstein (2013), the most important aspects of the physiotherapist's role in parental / caregiver health education include:

- How the parent or caregiver should recognise or respond to infant behavioural cues
- How to hold and interact with the infant during awake periods, and which activities to do when providing sensory stimulation
- How to handle the infant during feeding
- Guidance on the transition from the hospital to the home and the provision of information on community resources, should the parents or caregivers need to consult with someone after their infant has been discharged
- How to facilitate the infant's developmental progress with a home programme

- *Parents or caregivers' relationship with multidisciplinary team members*

  The participants highlighted some negative factors that affect the relationship between the MDT and the parents or caregivers of prematurely born infants, one of which was that in the private health care sector, the physiotherapist and other MDT members are not allowed inside the NICU or HCU without a referral from a doctor. The MDT's access to the parents or caregivers of the infant in the private sector is therefore limited, and consequently team members cannot provide them with the necessary health education or information about the necessity of follow-up appointments during the first year post-corrected age.

The MDTs working in the public health care sector have easier access to parents or caregivers (without referrals, but based on a mutual understanding between team members) and can therefore provide parents or caregivers with the necessary education and information during the hospitalisation period. Another negative factor that influence the MDT's relationship with the parents or caregivers was that the private and public health care sectors followed different follow-up processes after the infants' discharge from hospital. The public health care sector had a structured follow-up system that enabled parents or caregivers to communicate with the different MDT members at the follow-up clinics, so that their education could continue as complications occurred. The participants indicated that there was no structured follow-up process in the private health care sector and that parents or caregivers therefore did not receive on-going support.

- *Bonding between infants and parents or caregivers*

  Participants found that in the public health care sector where KMC wards are available, parents or caregivers have the opportunity to bond with their infants whilst being supported by the MDT members. In the KMC ward, the nursing staff conducted daily or weekly information sessions with the parents or caregivers during which different aspects of the care of the infants were addressed. Participants felt that the education sessions promoted parents or caregivers' understanding of the infants' needs and assisted in the bonding process. Participants who were working in the private health care sector reported that intermitted KMC was encouraged at some hospitals.

4.2.3.4 The multidisciplinary team's opinion regarding the hospital environment for prematurely born infants and their parents or caregivers

Figures 4.9, 4.10 and 4.11 indicate themes identified by MDT members who participated in the focus group discussions and key informant interviews relating to the hospital environment of prematurely born infants and their parents or caregivers.

Different issues raised by them are discussed below:

- *Equipment maintenance in the public health care sector*

  Participants who worked in the public health care sector mentioned that equipment was not well maintained and that they were often unable to perform certain evaluations or screening procedures with infants due to equipment that was out of order, which was detrimental to the care of the prematurely born infants at those hospitals. A participant said: “at the moment our screening program isn’t running because or machine isn’t working, but we do try”. Another participant working in the public health care sector said: “There are no audiologists, they don’t have equipment”.

- *Legal aspects*

  The participants were aware of the possibility of legal actions that could be taken by parents or caregivers who felt that the management of their infant by a particular MDT member was inadequate. This possibly contributed to the exercising of greater caution by team members when deciding on the treatment modality / approaches to be used for the management of infants in order to protect themselves against legal action. A participant commented: “It is such a bad situation at the moment, and I think it will get worse and then there will be court cases”.

- *Financial aspects*

  Participants mentioned that financial aspects could also impact the MDT members’ management of prematurely born infants. In the private health care sector, therapists are allowed to treat patients (including prematurely born infants) in the ICU or HCU twice a day, which will be covered by medical aids schemes / insurance companies. Participants (who were physiotherapists) felt that physiotherapists should be aware that treatment of infants in NICUs or HCUs should take place only if definitely indicated and should not become routine, in other words, the therapist should evaluate the infant’s physiological and medical status to determine whether treatment is needed. The submission of unnecessary claims to medical aid schemes is unethical and should therefore be avoided. One participant said: “It is shocking to say but it is about that, because the baby is easy money, nobody checks you”.

The NIDCAP programme has been proven to be effective in the management of prematurely born infants (Chapter 2, Section 2.2.2.2.4). It impacts the management of environmental stressors in NICUs and HCUs and could help to reduce the length of hospital stays. However, due to the high cost involved, the NIDCAP programme can unfortunately not be implemented in local NICUs or HCUs, which is another financial aspect that could possibly affect the management of prematurely born infants in SA.

- *Sterile environment*

  The participants mentioned that a sterile environment should be maintained to support / protect prematurely born infants, whose immune systems are already compromised. They felt that all MDT members who handle these infants should take special precautions to ensure that a sterile environment is maintained.

  It was reported by some participants that not all MDT members working with more than one infant in NICUs, HCUs or KMC wards washed their hands between procedures with different infants, which could lead to cross- infections.

- *Limited collaboration*

  Participants reported that collaboration between MDT members did occur in some NICUs, HCUs or KMC wards, but varied from one hospital to the next. They regarded referrals in the public health care sector as being less important as team members have access to the units and the screening of infants by the different team members is possible. Referral / collaboration in the private health care sector was found to be extremely difficult as team members needed referrals from medical practitioners to gain access to units for routine screenings of infants. A participant said: “In private practice it is a challenge, you cannot as a physio or OT or speech therapist go to the unit, the doctor has to ask you to come”.

- *Staff shortages*

  Some participants mentioned that staff shortages affected their ability to effectively manage prematurely born infants in NICUs, HCUs or KMC wards, or at the follow-up clinic. In some departments the MDT had to prioritise the area of care on which they would focus.

Where the staff is inadequate therapists might, for example, focus on short-term follow-up care rather than on delivering a (routine) service in the NICU, HCU or KMC ward. A participant working in the public health care sector said: "But now with the staff shortage, I have neonatal and peads ICU. So we have decided to rather work on therapy, but if we have enough staff, I must do fulltime neonatal".

- *Professionalism*

  Participants emphasised the importance of professional conduct by MDT members in NICUs, HCUs or KMC wards. This included ethical conduct and members' commitment to their own continued professional education and development. A participant mentioned: "I know where this thing comes from of therapists thinking it's cool to work in a neonatal ICU, if not necessary it's actually extremely dangerous if you do not know what you're doing or if you do not have proper training to do so".

  The following section focuses on these components.

4.2.3.5 The multidisciplinary team's knowledge of evidence-based practice and requirements to qualify as a clinical expert in a particular field

The themes and categories relating to the MDT's professional education and knowledge concerning the health care and management of prematurely born infants listed in Figure 4.9 are discussed below. The questionnaire completed by the participants also contained information on the MDT's education and knowledge.

- *Evidence-based practice*

  The majority of participants (73%) reported that they were familiar with the principles of evidence-based practice as they had been educated / trained in the use of evidence-based practice during their pre- or postgraduate courses. Only 20% of the participants indicated that they had received no such training in either their undergraduate or post-basic / postgraduate courses.

To ensure that every participant understood the principles of evidence-based practice, the researcher provided the necessary explanation of what evidence-based practice is and its relevance to the current study process, as well as the need to contextualise a CPG for physiotherapists. The participants reported that they regularly consulted relevant literature to keep abreast of new developments in the field of neonatology / the management of prematurely born infants so as to be able to implement evidence-based practice into their daily practice. They further mentioned that evidence-based practice, obtaining an additional qualification in the field and work experience were important requirements for anyone wanting to practise as a clinical expert. The researcher confirmed these statements by participants in the first round of the Delphi method in Phase 3, which will be further discussed under the Phase 3 results (Chapter 7, section 7.2).

- *Necessity of a clinical practice guideline to guide the physiotherapy management of prematurely born infants*

  The majority of the participants (97%) agreed that there was an urgent need for a CPG for physiotherapists in SA, and the reasons they gave aligned well with literature regarding the possible benefits of a CPG. As discussed in Chapter 2, section 2.3.1, a CPG could assist policymakers, managers, clinicians and patients to make evidence-informed health care decisions (Dizon et al., 2016c).

  In SA, it could guide physiotherapists' management of prematurely born infants, but could also assist in making other MDT members, such as the paediatricians, aware of physiotherapists' role and improve the referral rate to physiotherapists in particular. Other benefits that were mentioned and are supported by the literature included the improvement of the standard of care and health outcomes for the infants and better support for, and empowerment of parents or caregivers to prepare them for discharge (Sweeney et al., 2010). Participants further mentioned that a CPG could assist all MDT members, for example when an interprofessional collaborative / transdisciplinary approach was needed in a specific situation and the MDT at the hospital was incomplete.

If a hospital does not employ a physiotherapist and another MDT member has to apply the specific treatment principles in the NICU, HCU or KMC ward, the CPG will provide the necessary information to assist the responsible person. One participant stated, 'Because you not only have to know your own field, but I also have to understand the physio ...'. This indicated that it is important to have a sound knowledge of other MDT members' functions in the management of prematurely born infants in NICUs, HCUs or KMC wards.

4.2.4 Conclusion of the multidisciplinary team's perspective on the patient journeys of prematurely born infants and their parents or caregivers in the South African health care sectors

The researcher used the information gathered during the focus group discussions and key informant interviews, and from the questionnaire completed by the MDT participants on their perspectives on the patient journeys of prematurely born infants and their parents or caregivers. The information was combined to formulate four possible patient journeys, which are presented in Figures 4.24 to 4.27 at the end of this chapter. After establishing what the MDT members' perspectives were, the researcher wanted to obtain the parents or caregivers' perspectives on both their own and their infants' journeys in the SA health care sectors. The parents or caregivers' perspectives are discussed in the following section.

4.3 PARENT OR CAREGIVER PERSPECTIVES

The parent or caregiver perspectives were obtained by means of structured interviews and an online survey. Parents or caregivers who participated in the structured interviews did so after having given their written informed consent (n=23). They all had infants admitted to NICUs, HCUs or KMC wards at the time of the study, or were attending the follow-up clinic with their infants after discharge. These participants were therefore able to provide a 'current perspective' on their and their infants' journeys.

Parents or caregivers who participated in an online survey provided informed consent before completing the same questionnaire (n=64). They did not have infants in NICUs, HCUs or KMC wards at the time of this study, but were able to provide retrospective information of their and their prematurely born infants' journeys through the health care system. In total, 87 parents or caregivers (n=87) participated in this phase of the study. The process of data capturing and analysis was discussed in Chapter 3, section 3.3.2.

The structured interviews and online survey contained both quantitative and qualitative results. The interviews and survey were divided into the following three main themes:

i. Hospitalisation phase
ii. Short-term follow-up phase
iii. Long-term follow-up phase

The reason for the inclusion of information on the short- and long-term follow-up phases was that the health education provided to parents or caregivers formed part of the patient journeys of prematurely born infants in NICUs / HCUs or KMC wards. The short- and long-term phases were included in the data collection so as to be able to compile the patient journey diagrams, but were not the focus of the current study. The results of the structured interviews and online survey are discussed in the following sections with reference to these three main themes.

4.3.1 Hospitalisation phase

The hospitalisation phase of prematurely born infants from the perspectives of parents or caregivers will now be discussed.

4.3.1.1 Information regarding prematurely born infants and care received during hospitalisation

The gestational ages at which prematurely born infants were born are shown in Figure 4.12. Two participants (n=2) did not answer the question and one (n=1) indicated the age for two infants (twins). The gestational ages of 86 infants (n=86) are therefore shown in Figure 4.12.

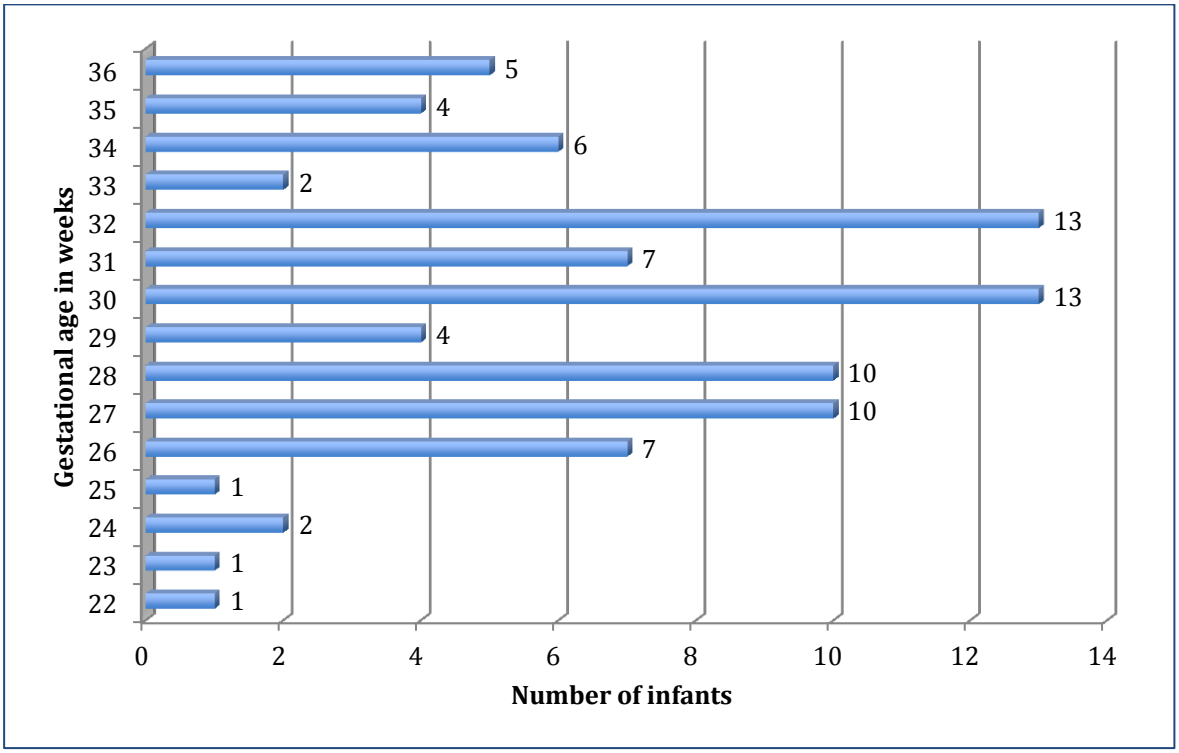


FIGURE 4.12 GESTATIONAL AGES OF PREMATURELY BORN INFANTS

In order to interpret Figure 4.12, the researcher divided the infants (n=86) into the following three categories of prematurity, as described by the World Health Organization (2019): (i) extremely preterm (born at less than 28 weeks gestational age); (ii) very preterm (born between 28 and 32 weeks gestational age); and (iii) moderate to late preterm (born between 33 and 37 weeks gestational age).

Figure 4.13 illustrates the number of infants in each of the three categories of prematurity.

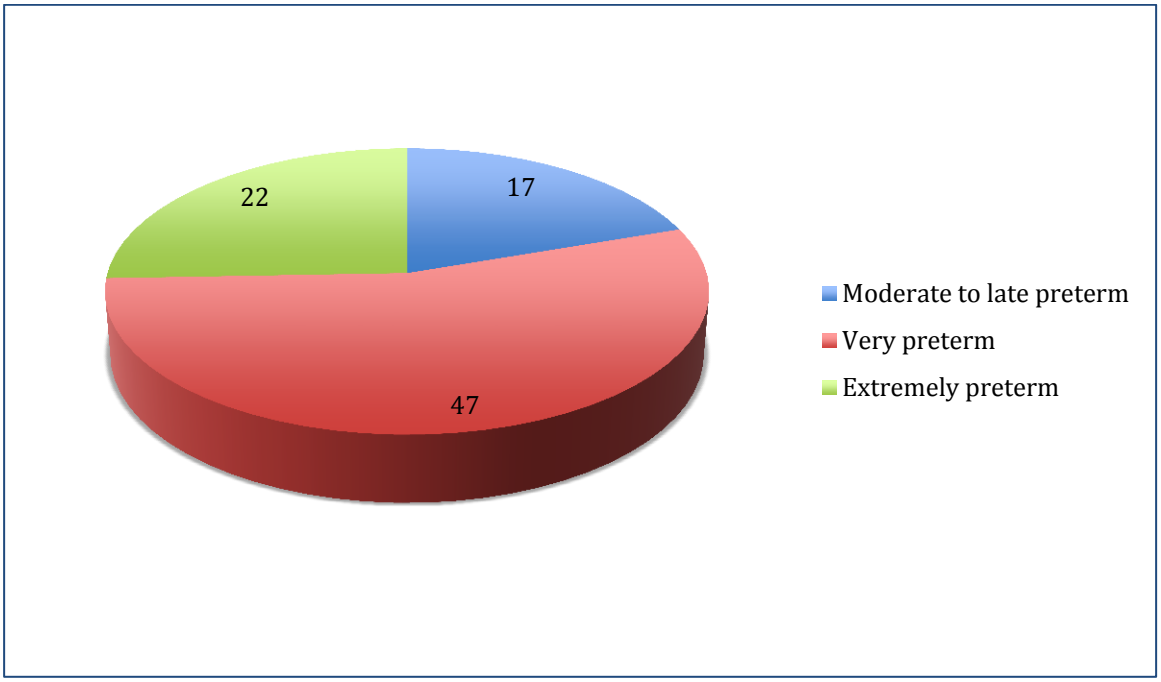


FIGURE 4.13 CATEGORIES OF PREMATURITY

Fifty five percent of the prematurely born infants were categorised as infants born very preterm and were followed by infants born extremely preterm (25%). Only 20% of infants were born moderate to late preterm.

Of the 85 participants (n=85) who answered the question regarding multiple pregnancies, 22% (n=19) indicated that they had had a multiple pregnancy. Of the 85 participants, 20% had twins (n=17), 1% had triplets (n=1) and 1% had quadruplets (n=1).

In the case of 77 of the participants (n=77; 89%) the pregnancy reported on was their first prematurely born infant(s). Eight participants (n=8; 9%) had previously given birth prematurely, and two (n=2) did not answer the question. Forty-four participants (n=44; 51%) had not previously given birth.

The hospital sections in which the infants were treated are indicated in Figure 4.14. All transfers of infants between NICUs, HCUs, KMC wards or Baby rooms in maternity wards were included in Figure 4.14, i.e., the same infant may be recorded as having received care in the NICU, and afterwards in the KMC ward. Four participants (n=4) indicated that their infants had been: (i) admitted to other wards / facilities, which included admission to the paediatric ward (n=1); (ii) transferred from a KMC ward to a KMC ward at another hospital (n=1); (iii) transferred from a district hospital to an academic hospital (n=1); and (iv) born at a clinic and was subsequently transferred to a district hospital (n=1).

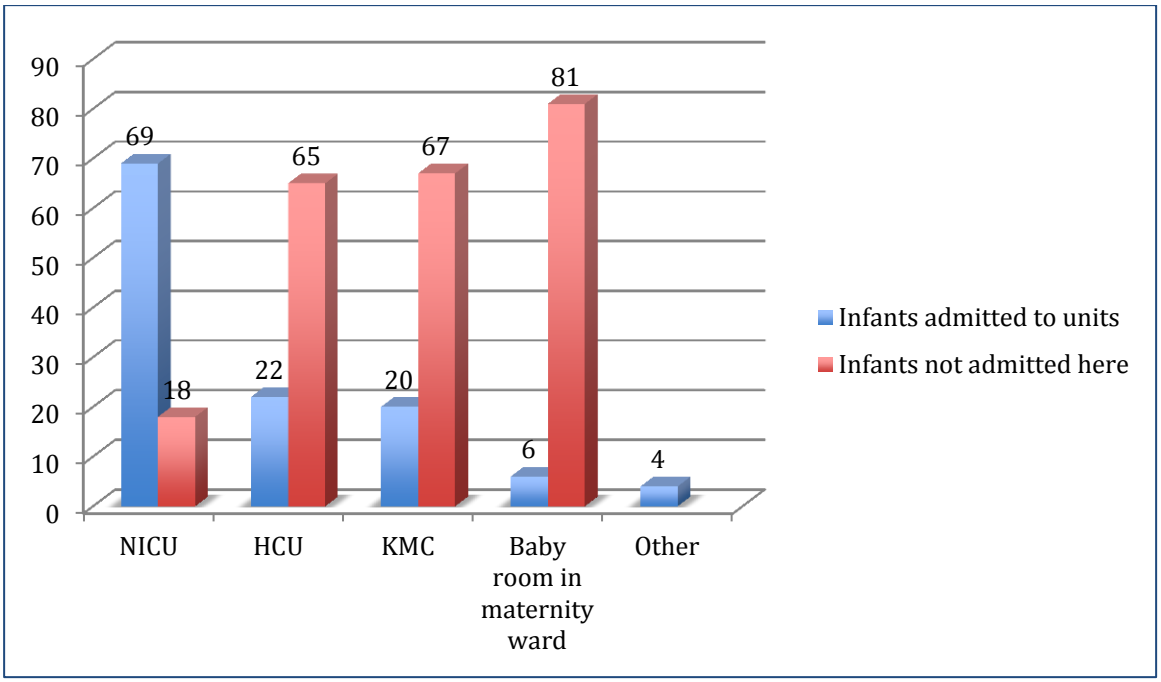


FIGURE 4.14 PREMATURELY BORN INFANTS' ADMISSION TO UNITS OR WARDS

A large number of prematurely born infants (n=69) received care in NICUs, with only a few (n=6) being cared for in baby rooms.

The average time that infants spent in NICUs, HCUs, KMC wards or baby rooms is shown in Figure 4.15 and provides an indication of how long the hospital stay of prematurely born infants could be.

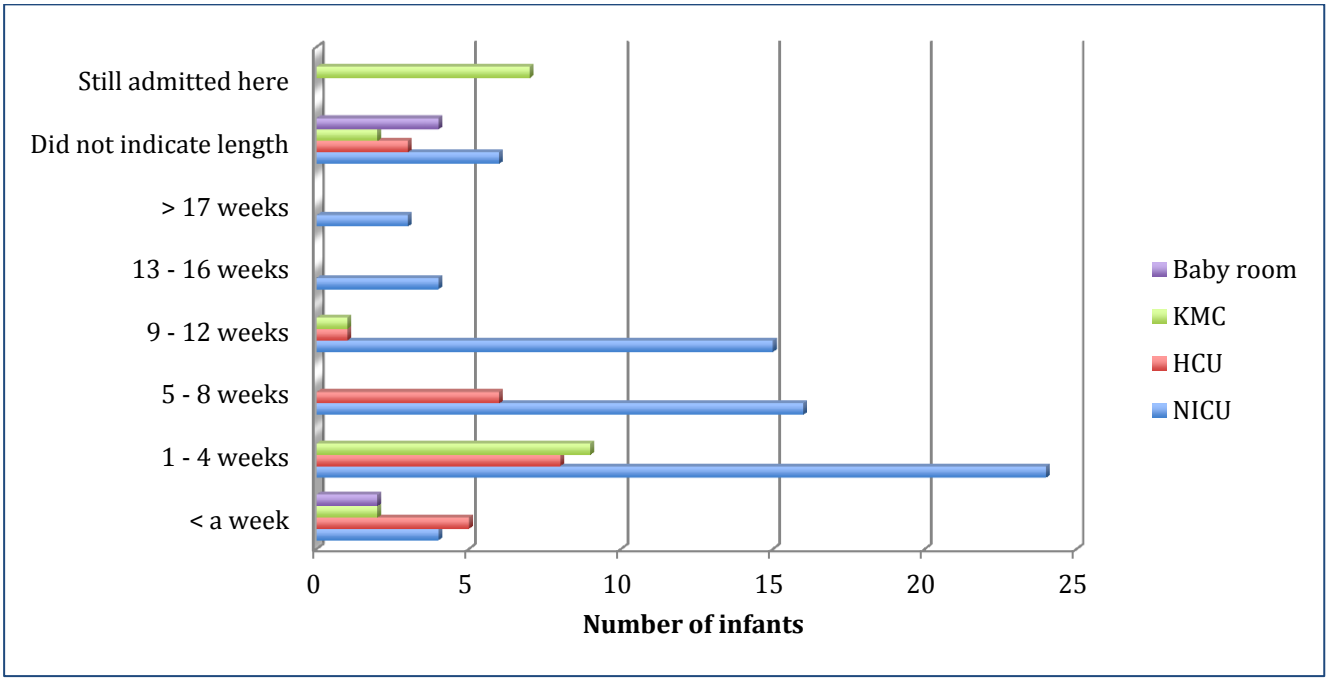


FIGURE 4.15 LENGTH OF STAY IN UNIT OR WARD

The majority of the infants (n=24) required a NICU stay of between one and four weeks and very few infants were admitted to the baby room.

Figure 4.16 shows which MDT members were involved in the treatment of the prematurely born infants during the time of admission / hospitalisation.

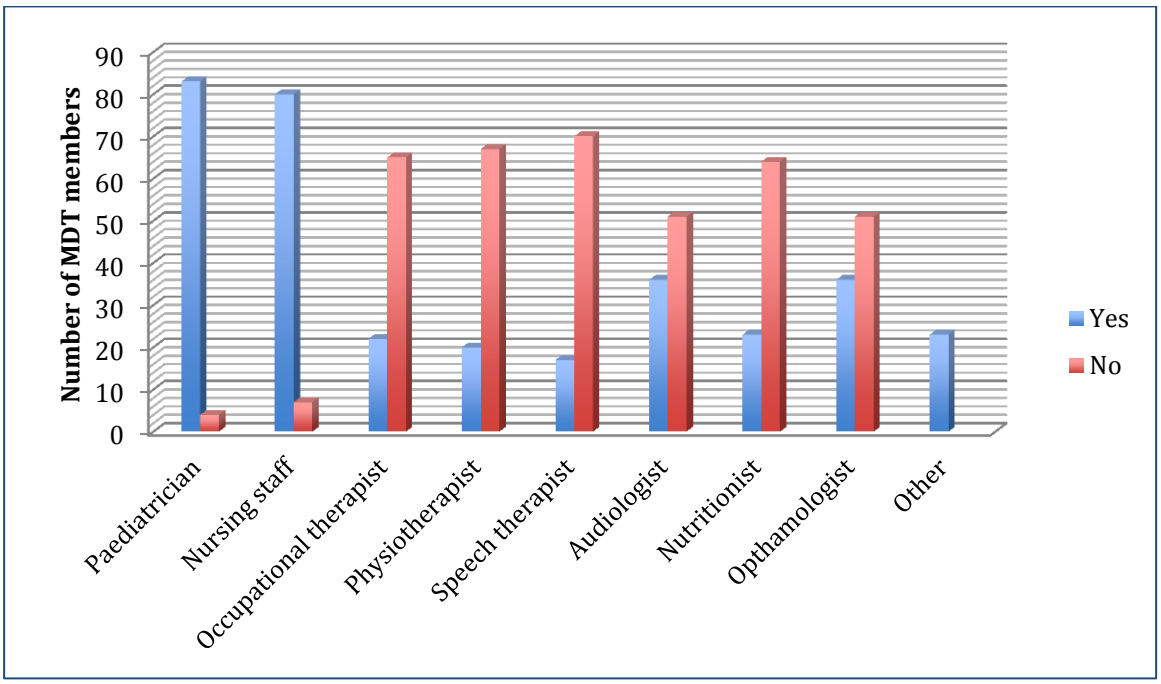


FIGURE 4.16 MULTIDISCIPLINARY TEAM MEMBERS INVOLVED IN THE CARE OF INFANTS DURING HOSPITALISATION

The following team members were not listed in the questionnaire, but were mentioned by parents or caregivers under the heading 'Other':

- Neurosurgeon (n=1)
- Pulmonologist (n=1)
- Cardiologist (n=2)
- Educational psychologist (n=1)
- Neurologist (n=1)
- Nephrologist (n=1)
- Developmental specialist (n=1)
- Neonatologist (n=5)
- Urologist (n=1)
- Members who might still become involved (still hospitalised) (n=5)
- Not sure (n=4)

In order to identify the complications that prematurely born infants experienced during their hospitalisation, the parents or caregivers were asked about the types of tests that had been carried out during this time. The special tests or evaluations that the infants had undergone while hospitalised are listed in Figure 4.17.

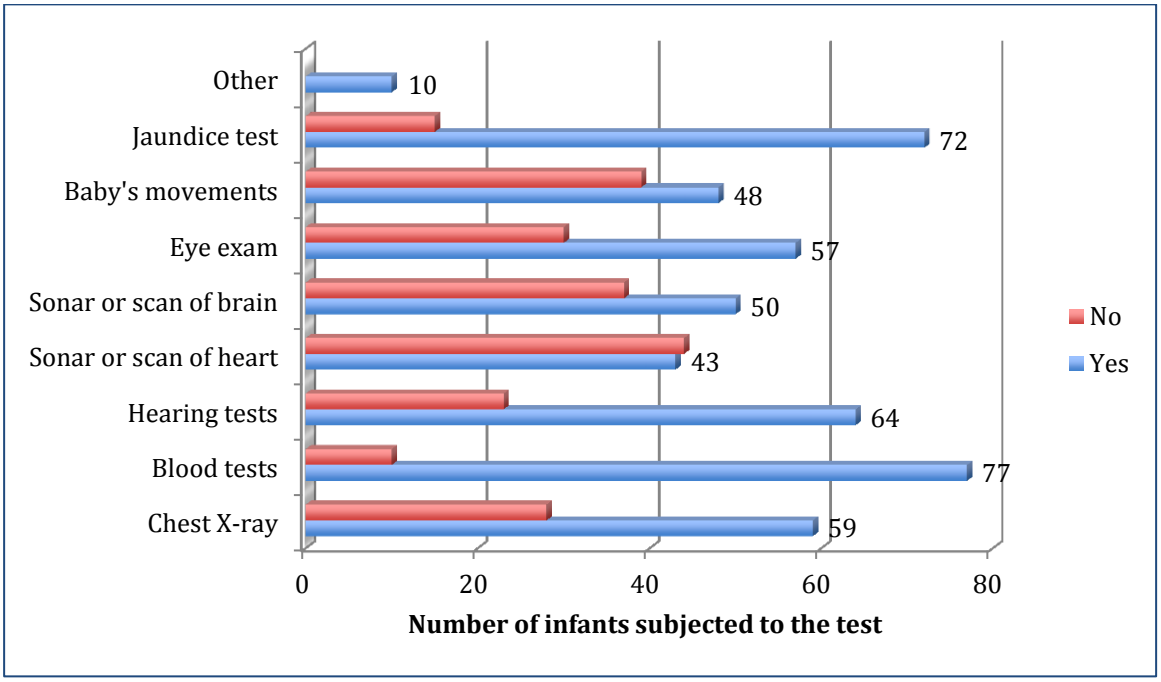


FIGURE 4.17 TESTS OR EVALUATIONS PERFORMED ON INFANTS DURING HOSPITALISATION

The tests that were mentioned by the participants in addition to those on the list provided (under 'other') included the following:

- Brain test (n=1)
- Laser on eyes (n=1)
- Kidney tests (sonar, x-ray) (n=3)
- Cardiology tests (n=1)
- Tests done by students from universities (n=1)
- Don't know which tests (n=3)

- Infant/s is/are currently still hospitalised and tests might still be done (n=3)
- Parents or caregivers were not informed on which tests were done (n=1)

In an open-ended question, the researcher asked the parents or caregivers to discuss the results or outcomes of the evaluations or tests that had been performed on their infants during the hospitalisation phase. The responses are listed in Table 4.2.

TABLE 4.2 RESULTS OR OUTCOMES OF THE EVALUATIONS OR TESTS PERFORMED DURING HOSPITALISATION OF THE INFANT

Results or outcomes of the evaluations or tests performed	Number of participants
All results good considering the infant's prematurity	2
Not sure which tests or evaluations were performed, no results received	3
Identified conditions that affect the infant's pulmonary system:	
• Chronic lung condition	1
• Pulmonary stenosis	1
• Underdeveloped lungs	1
• Chronic lung disease due to ventilator use	1
• Long period of time on oxygen	1
• Apnoea	2
• Low saturation levels	1
• Infant was intubated	1
• Chest infection	1
Identified conditions that affect the cardio system:	
• Patent ductus arteriosus	4
• Bradycardia	1
• Low blood pressure	1
Identified conditions that affect the neurological system:	
• Brain bleed (not specific)	2
• Grade I brain bleed	1
• Dilated brain ventricles	1
Identified conditions that affect the intestines:	
• Bowel obstruction	1
• Infection in the stomach	1
Identified conditions that affect hearing:	
• Auditory neuropathy	1
Identified conditions that affect vision:	
• Squint eye	2
Identified conditions that affect the blood count:	
• Anaemia	1
• Low haemoglobin levels	1
• Needed blood transfusion	1
Identified conditions that affect the feeding of the infant:	
• Needed a nasogastric tube for feeding	1
• Unsatisfactory weight gain	1
Identified conditions that affect the sensory processing:	
• Sensory processing problems	1
• Sensitivity to touch	1
Jaundice	5

Forms / Types of infection:	
• Septicaemia	1
• Meningitis	1
• Methicillin-resistant staphylococcus aureus (MRSA) infection	1

The results for the short-term follow-up phase are discussed and graphically presented in the following section.

4.3.2 Short-term follow-up phase

The short-term follow-up phase is the period of one to two years post-corrected age following the prematurely born infant's discharge from hospital. The duration of the follow-up phase is determined by the needs of individual infants.

4.3.2.1 Follow-up information

Seventy-nine participants (n=79; 91%) indicated that a follow-up appointment with one of the MDT members had been scheduled for them at the time of their infants' discharge from hospital. Five (n=5) did not have scheduled appointments and three (n=3) did not answer the question.

The MDT members with whom the participants and their infants had follow-up appointments after discharge are shown in Figure 4.18. Six participants (n=6) indicated that their infants were still being hospitalised and that the question therefore did not apply to them.

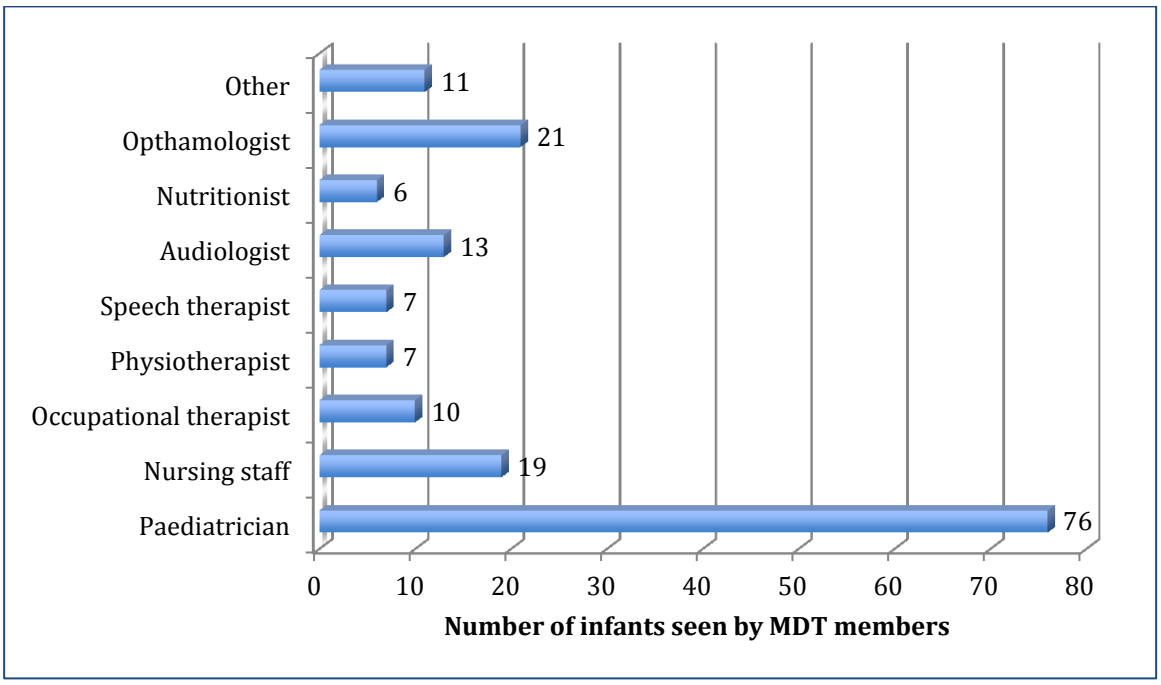


FIGURE 4.18 MULTIDISCIPLINARY TEAM MEMBERS INVOLVED IN SHORT-TERM FOLLOW-UP

Other MDT members mentioned by the participants (under 'Other') in addition to those on the list that was provided were:

- Pulmonologist
- Nephrologist
- Neurologist
- Developmental specialist
- Neonatologist

The first follow-up appointments and the period between the discharge of prematurely born infants and the first follow-up appointments are shown in Figure 4.19.

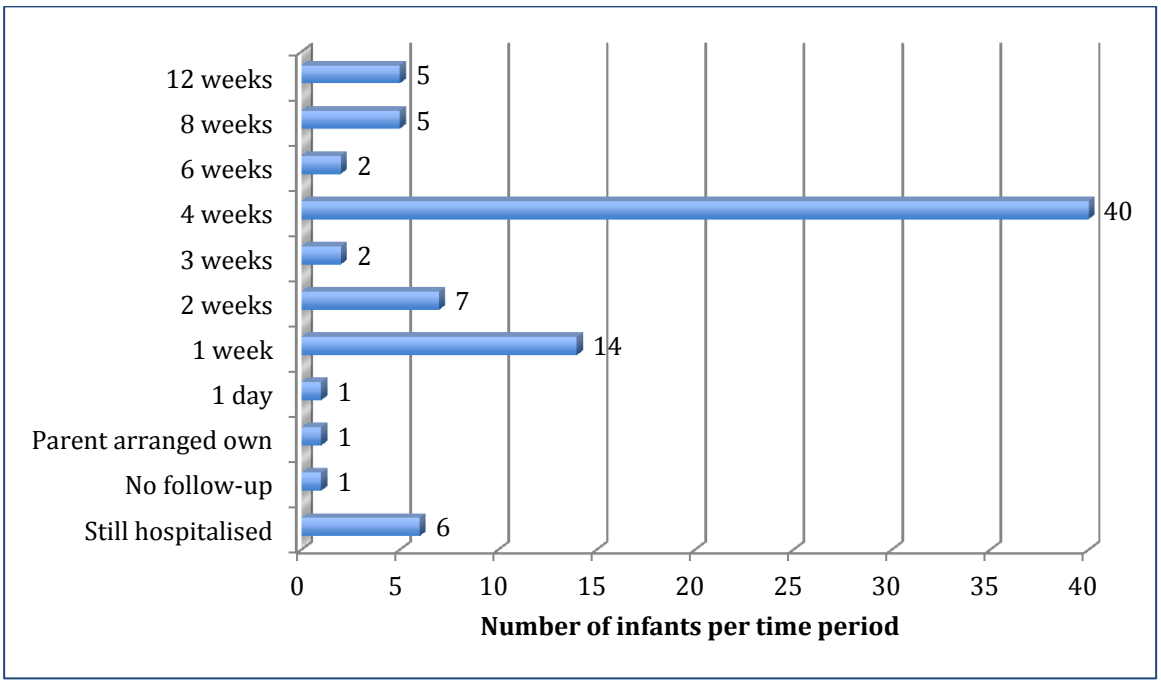


FIGURE 4.19 TIME PERIOD BETWEEN DISCHARGE FROM HOSPITAL AND FIRST FOLLOW-UP APPOINTMENT

Three participants (n=3) did not answer the question. The majority of the infants (n=40) had attended the follow-up clinic one month after their discharge from hospital. Fourteen infants had attended a follow-up clinic a week after discharge, as arranged by the paediatrician in order to monitor their growth and to ensure that the parents or caregivers were coping with the infants' care at home.

The participants were asked to indicate how often / regularly the follow-up appointments were made with MDT members. The information provided is shown in Figure 4.20.

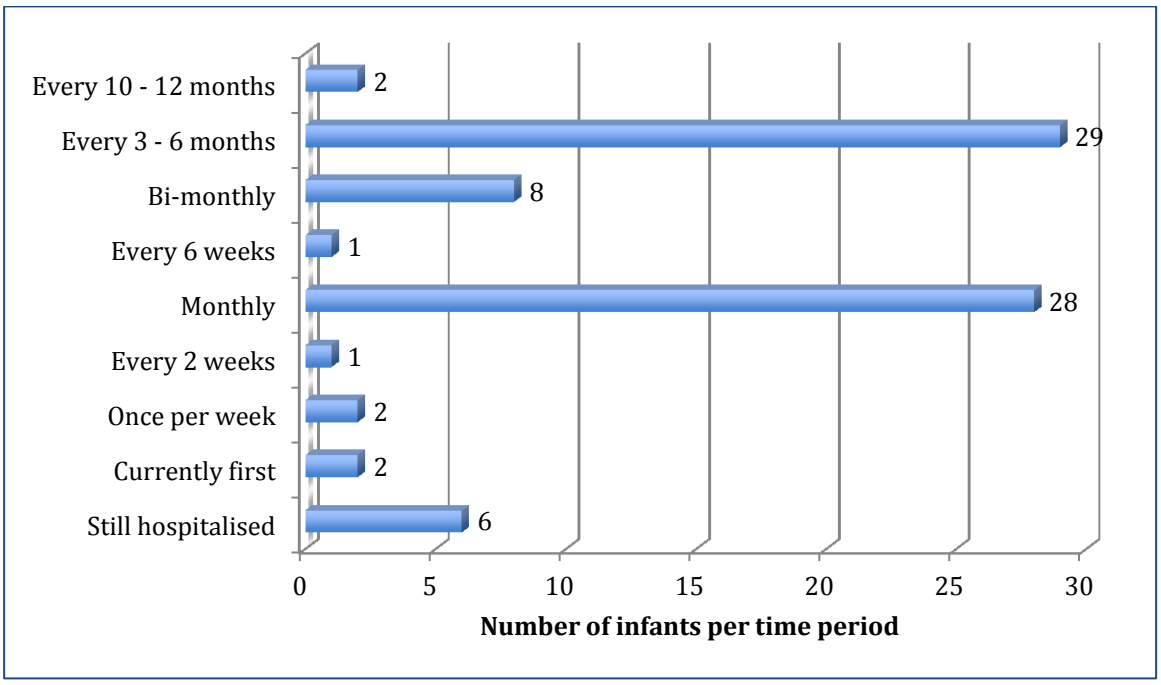


FIGURE 4.20 FREQUENCY OF INFANT'S FOLLOW-UP APPOINTMENTS

Three participants (n=3) did not answer the question. One (n=1) said that they had not been informed on how often the follow-up appointments would take place, and one (n=1) said that the periods between follow-up appointments varied. Two participants (n=2) stated that they never had follow-up appointments for their infants.

The ages at which the infants were discharged from the follow-up appointments are indicated in Figure 4.21.

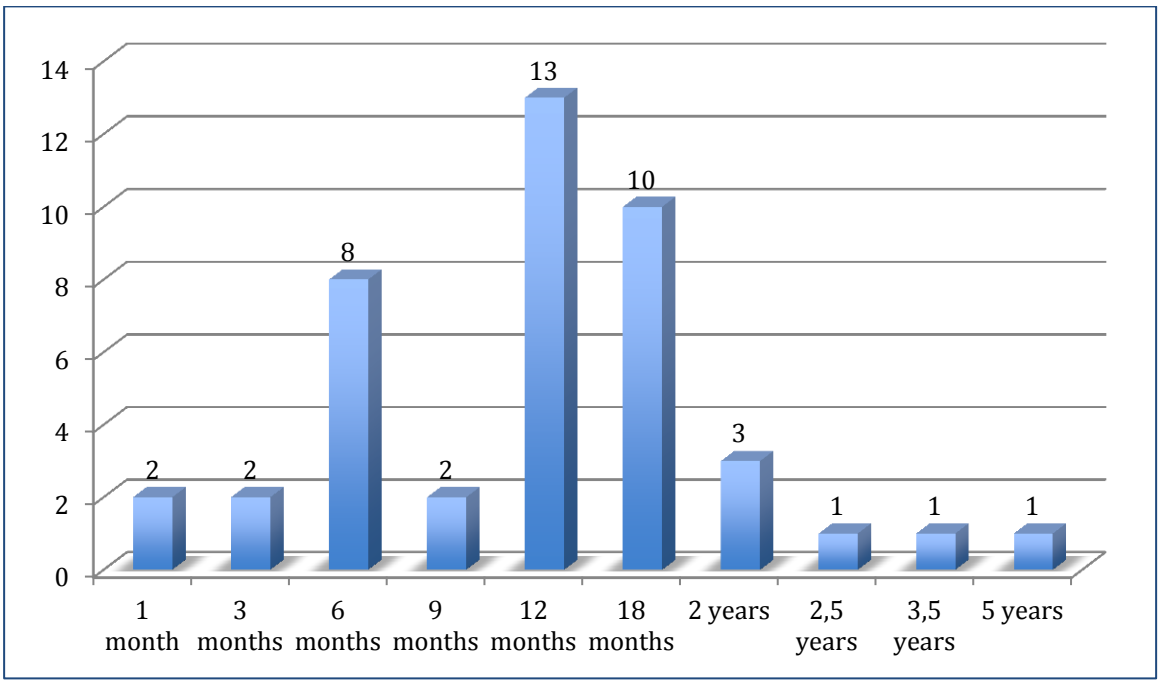


FIGURE 4.21 INFANT'S AGES AT THE TIME OF DISCHARGE FROM FOLLOW-UP SERVICES

Forty-three participants (n=43) indicated the age of their infants at the time of discharge from the follow-up services. The largest number (n=13) was discharged at the age of one year.

The remaining participants (n=43) provided the following answers:

- Three participants (n=3) did not answer the question.
- One participant (n=1) said that they never had a follow-up appointment.
- One participant (n=1) stated that, due to complications, their infant had passed away at the age of 11 months.
- One participant (n=1) said that they had only one follow-up session, with none scheduled after that.
- Six participants (n=6) indicated that as their infants were still hospitalised, the question was not applicable to them.
- Twenty-seven participants (n=27) indicated that they were not sure, or had not been informed of the age up to which follow-up visits would continue, but that the follow-up appointments were still continuing.

- One participant (n=1) indicated that annual follow-up appointments were still continuing, and two (n=2) stated that they attended follow-up appointments every six months.
- Two participants (n=2) said that they were only continuing with follow-up appointments with the ophthalmologist.

4.3.2.2 Parental or caregiver education at the time of the infant's discharge from hospital

Of the 87 participants, six (n=6) indicated that their infants were still being hospitalised and therefore they did not comment on the education received. Of the remaining 81 participants, 90% stated that they had received the necessary education from the MDT with regard to the handling / management of their infants' transition to their homes after discharge. When asked whether they had received any information regarding problems that might occur during the first year after discharge, only 57% confirmed having received this type of health education / information.

In response to the question that required participants to indicate the format in which the information or education had been provided to them, they could select more than one answer. They were also asked in which format they would prefer to receive information or education. Their responses are summarised in Table 4.3.

TABLE 4.3 FORMAT IN WHICH PARENTS OR CAREGIVERS RECEIVED OR WOULD PREFER TO RECEIVE INFORMATION OR EDUCATION

Format of information or education	***In which format did parents or caregivers receive information or education?***	***The format in which parents or caregivers preferred to receive the information or education***
Practical demonstrations	47% of participants	43% of participants preferred practical demonstrations
Group classes	18% of participants	23% of participants
Booklet	34% of participants	53% of participants
Link to a website (electronic)	2% of participants	30% of participants
Other	23% of participants ○ Video material ○ Meetings ○ Personal contact with the paediatrician or MDT members ○ Discussions ○ Verbal instructions only ○ Practical demonstrations that include the father	8% of participants ○ Any format ○ One-on-one sessions ○ Information on support systems or contact details of parents or caregivers who had made successful transitions from the hospital to their home ○ Verbal instructions ○ Discussions between professionals (MDT members) and parents or caregivers in the NICU ○ Parents or caregivers should feel free to ask questions

The MDT team members who were indicated as having provided the parents or caregivers with information or education are listed in Figure 4.22.

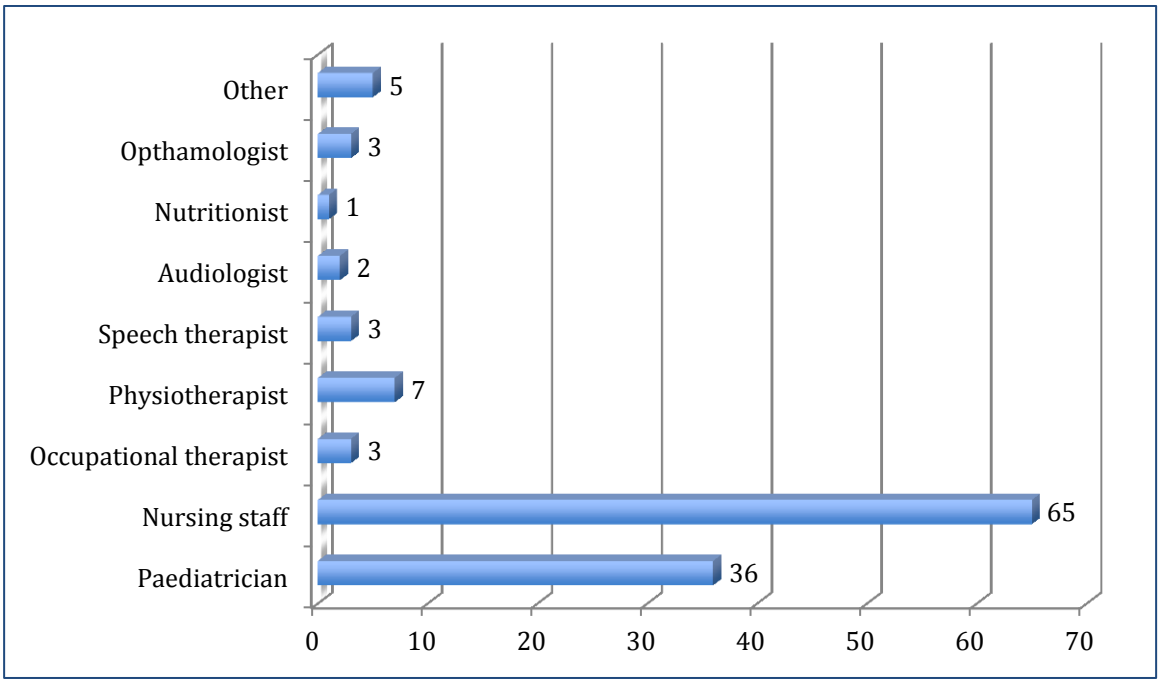


FIGURE 4.22 MULTIDISCIPLINARY TEAM MEMBERS WHO HAD PROVIDED PARENTS OR CAREGIVERS WITH INFORMATION OR EDUCATION

The members listed under the heading 'Other' included the developmental specialist and the neonatologist. One participant (n=1) said that (s)he had not received any information, and another (n=1) stated that all the disciplines had provided education.

The type of education provided at the infants' discharge from hospital, as indicated by the participants, included:

- ✓ *Medical advice and information with regard to:*
  - feeding difficulty, volume and frequency of feeding, monitoring of weight gain and the use of a cup or bottle instead of breastfeeding;
  - possible reflux problems;

- the management of a ventriculoperitoneal (VP) shunt, e.g. how to monitor constant flow / signs or symptoms indication poor drainage, or how to clean incisions;
- the use of Synagis, a medication that helps to prevent serious lung disease caused by the respiratory syncytial virus (RSV) in infants or children;
- a list of medication and dosages to be administered to the infant at home;
- the danger of using Lennon products and the importance of making sure that the ingredients of medication are safe before giving it to your infant;
- vaccination cards and vaccination dates;
- how to monitor jaundice;
- the possibility of developmental delays and reasons why prematurely born infants should not be compared to term infants;
- the possibility of hearing, visual or movement problems that may present;
- how to apply cardiopulmonary resuscitation (CPR) and manage apnoea, and what to do when the infant chokes;
- attending the nearest clinic if complications develop at home; and
- follow-ups, which were recommended at four months post corrected age.

✓ *Advice on the home environment with regard to:*

- Noise management
- Positioning / swaddling of infant
- Sleeping patterns and positions
- How to handle the infant during activities of daily living, e.g. bathing
- How to perform KMC with the infant
- How to manage the infant in a sterile, hygienic environment and avoid people who might have colds or infections during the first months of the infant's life and during the winter months

✓ *Advice on the use of equipment at home:*

- How to use an oxygen monitor
- How to use an apnoea monitor

The participants were then asked to indicate the type of health education they would prefer to receive from MDT members. Their answers included:

- ✓ *Medical advice and information with regard to:*
    - Reflux (why and how it occurs)
    - Bowel movements (how often they should occur) and the treatment of colic
    - The types of delays that might occur and the possibility of neurological conditions such as CP
    - How to assist with developmental aspects
    - The provision of a growth chart or milestone checklist so that the parents or caregivers can monitor the infant's progress
    - The possibility of follow-up evaluations that could include computerised tomography (CT) or magnetic resonance imaging (MRI) scans
    - The possibility that the infant could be vulnerable to chest infections during the winter months and during the first year after discharge, which might result in hospital visits
    - The growth, weight gain and nutrition of the infant at home
    - Alternatives to breastfeeding
    - Information on the transition from three-hourly breastfeeding in the NICU to feeding with a cup, and feeding on demand at home
    - First aid, e.g. CPR and how to manage apnoea or choking
    - Warning signs to look out for – indications of possible common complications or other problems
    - How to administer medication, especially without a nasogastric (NG) tube
    - Immunisation and its importance for the infant
    - How to interpret test results
- ✓ *Advice on the home environment with regard to information on:*
    - Managing the infant during activities of daily living
    - 'Normal' sleeping patterns
    - How to work hygienically to maintain a sterile environment for the infant at home

- ✓ *Advice and emotional support suggested by the parents or caregivers:*
    - The MDT should contact parents or caregivers after discharge, even if it is only by telephone, to ensure that they are coping
    - Parents or caregivers should be given information on local support groups consisting of other parents of prematurely born infants who have also had to deal with the transition from hospital to home
    - The MDT should ask the parents or caregivers what information they need / require
    - Information on the importance of follow-up with the paediatrician, physiotherapist or occupational therapist
    - Information on the father's role in the care of the infant
    - Information on the benefits of therapy for postpartum depression / posttraumatic stress disorder (PTSD) due to the trauma of premature birth

The researcher asked the participants to make recommendations regarding the best care for their infants in their environments. During the coding of the answers, two main themes emerged. One theme revolved around the support received by parents or caregivers during the hospitalisation of their infants and after discharge. The second emphasised the knowledge that the parents or caregivers would like to receive. The main concepts are highlighted in Tables 4.4 and 4.5.

TABLE 4.4 SUPPORT NEEDED FROM THE MULTIDISCIPLINARY TEAM AS INDICATED BY PARENTS OR CAREGIVERS

Theme	***Statements by participants (direct quotes)***
Support	Better support of parents / caregivers after discharge of their infants.
	Find a support group, it is easier to not be alone.
	The MDT should engage the parents or caregivers with positivity – put the parents or caregivers at ease.
	Parents or caregivers need love and support from the MDT, be careful not to be rude.
	The medical staff feels like family and it is hard to lose that contact after discharge of the infant.
	Mothers need counselling to manage their trauma of birth and what follows.
	Do the necessary tests while the infant is in hospital and the medical aid will cover the costs. It is extremely expensive as an out-patient.
	Do not provide too much information and scare parents or caregivers because their infant might be fine.
	Parents or caregivers need KMC units in the private health care sector.
	There is limited bonding in the NICU between parents or caregivers and their infant(s), parents or caregivers therefore need support from the MDT to assist in bonding.
	Some units are short-staffed and there is a need for more staff at night.

TABLE 4.5 ESSENTIAL KNOWLEDGE, AS INDICATED BY THE PARENTS OR CAREGIVERS

Theme	***Statements by participants (direct quotes)***
Knowledge	On signs of complications.
	On infant behavioural cues because understanding your infant makes the adjustment easier.
	On the benefits of follow-up appointments with the MDT, and to know what therapy is available and that the team could monitor the progress of the infant.
	To know not to compare the prematurely born infant to term infants.
	To understand the diagnosis. Parents or caregivers should trust their own instinct and question the doctor, do not assume that the infant will catch up on developmental aspects. The doctors should refer to the therapists.
	Information on early intervention.
	Parents or caregivers want a holistic approach and do not want each team member to only focus on their own part in the care and management of the infant.
	To be aware of a sterile environment when the infant is vulnerable, e.g. avoid crowds and limit exposure to germs.
	Benefits of breastfeeding for as long as possible.
	Benefits of KMC and bonding with the infant.
	How to monitor the environment to reduce stressors like noise and lights.
	Information on first aid, e.g. CPR.
	On how to interpret the results of tests done so that the parents or caregivers can understand it.
	Information on equipment, e.g. oxygen tanks / machines, apnoea monitors.
	Information on feeding, e.g. when to start introducing solids into the infant's diet.
	Information on stimulation guidelines, e.g. baby gym, how to improve the physical and cognitive development.
	Information on long-term *[sensory-motor] development.
	Information on how to follow medical instructions.
	How to boost the infant's immune system.
	Knowledge specific to your infant and not general information that might not apply to your infant.

*[Added by the researcher]

4.3.3 Long-term follow-up phase

When asked their opinion on whether their prematurely born infant has any long-term effects due to the premature birth, 37 participants (43%) agreed that they felt that there were long-term effects. The complications, as perceived by the participants, are listed in Figure 4.23.

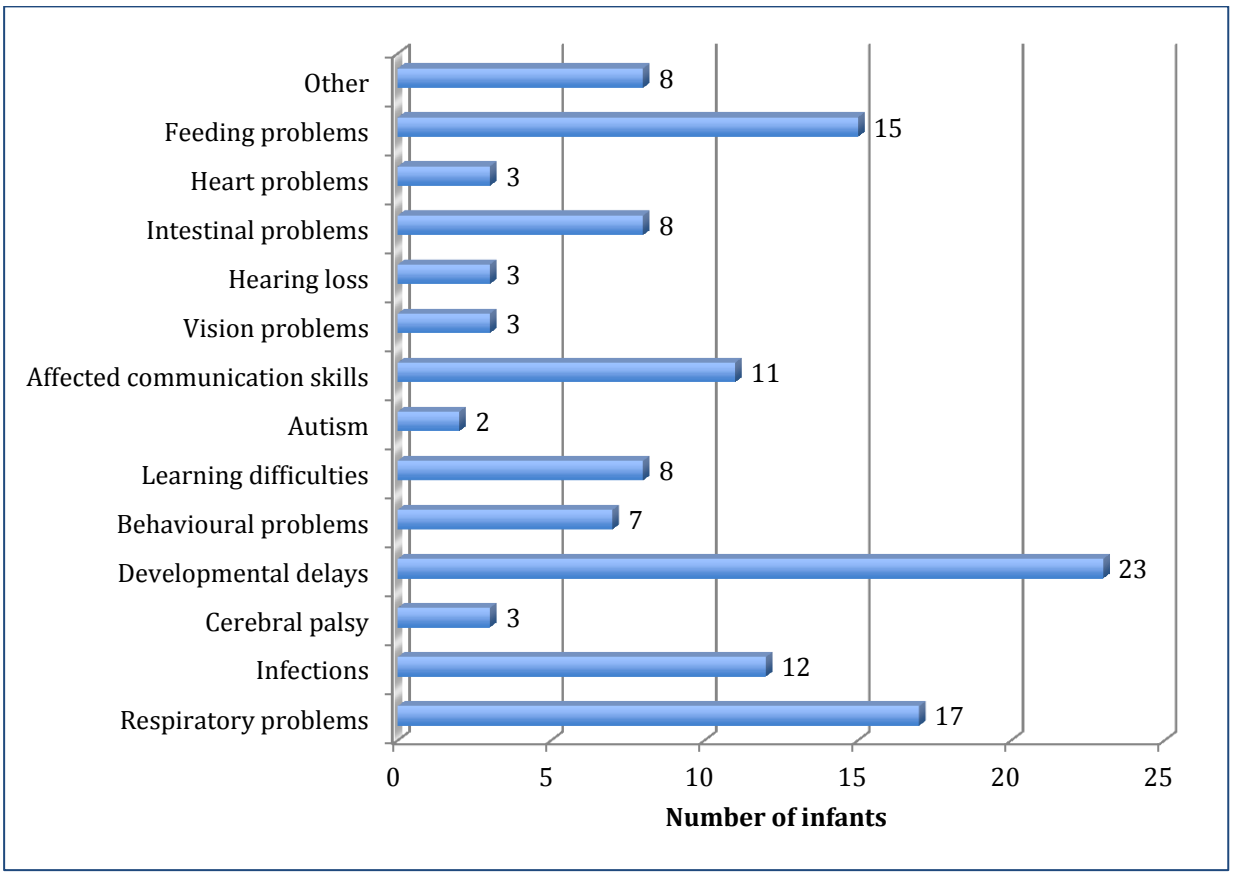


FIGURE 4.23 LONG-TERM EFFECTS ON PREMATURELY BORN INFANTS

Conditions listed in addition to those listed above (n=8) included:

- Hydrocephalus with VP shunt
- Low motor skills
- Kidney problems
- Hemiplegia
- Severe allergies
- Sensory integration dysfunction
- Very low immunity, low IgA and T cells
- Sensory processing difficulties due to very early exposure to pain and noise

In the following section the researcher discusses the quantitative and qualitative results of the structured interviews with parents or caregivers and the online survey.

4.3.4 Discussion of results

The three main themes covered by the structured interviews and the online survey will be addressed here.

4.3.4.1 Hospitalisation phase

The participating parents and caregivers indicated that 80% of their infants had been born extremely or very preterm. This number is much higher than the number reported by Koullali et al. (2016), according to whose findings extremely and very premature births account for approximately 16% of all premature births globally. Nosarti et al. (2010) also reported that approximately 15% of all preterm births were very preterm (birth before 32 completed gestational weeks). The importance of the higher rate of extremely and very preterm births recorded for the population involved in this study is that these infants are more at risk for morbidity and mortality than moderate to late preterm infants (Koullali et al., 2016).

Multiple pregnancies have been identified by various researchers (Koullali et al., 2016; Frey et al., 2016; Steer, 2005; Nosarti et al., 2010) as a risk factor for premature birth. In this study, 19 participants (n=19 or 22%) indicated that they had had multiple pregnancies, most commonly with twins. A woman who has previously given birth to a prematurely born infant is at risk for a second premature birth (Koullali et al., 2016; World Health Organization 2019; Frey et al., 2016; Steer, 2005). Nine percent (9%) of participants indicated that had previously had a prematurely born infant.

The participants indicated that the majority (79%) of their prematurely born infants had been admitted to the NICU for care and management, which was confirmed by the fact that the majority of the infants included in the current study had been born extremely or very prematurely. Extremely or very premature born infants have vulnerable immune systems and organs (Chapter 2, section 2.2.1), and therefore initially need to be cared for in NICUs where they can be closely monitored. The admission of the majority of infants included in this study to NICUs means that they were exposed to the NICU environment, and therefore to environmental stressors (Chapter 2, Section 2.2.2.2). The parents or caregivers who participated in this study reported that their infants had been exposed to the NICU environment for periods varying from less than a week to as long as 17 weeks. The participants indicated that the ideal time for physiotherapists or other MDT members to start supporting the parents or caregivers would be while the prematurely born infant is in the NICU. Most of the participants indicated the paediatricians and nursing staff as the MDT members who were involved in the care and management of their infants, followed by the audiologists and ophthalmologists. Participants indicated that the MDT members involved in the neurodevelopmental aspects of their infants' development, such as the physiotherapist (23%), occupational therapist (25%) and speech therapists (20%), were less involved in the care of the infants during the hospitalisation phase. Physiotherapists could therefore focus on improving their support of parents or caregivers of hospitalised prematurely born infants. Physiotherapists should also make a special effort to make parents or caregivers and other MDT members aware of their specific role during the hospitalisation and short-term follow-up phases.

The participants stated that the most common tests done on the infants during the hospitalisation phase were blood tests (n=77), tests for jaundice (n=72), hearing tests (n=64), chest x-rays (n=59) and eye examinations (n=57). The information they provided on the results of the tests or examinations were in line with what the researcher found in the literature, as discussed in Chapter 2, section 2.2.2.1.

Conditions listed by the participants and to which references were also found in the literature included chronic lung conditions due to the ventilation of the infants, apnoea and bradycardia, patent ductus arteriosus, intracranial haemorrhage, necrotising enterocolitis, feeding problems and jaundice (Maroney, 2003; Nosarti et al., 2010; Byrne et al., 2013a).

Participants reported that they were not sure of which tests or evaluations had been done due to poor communication by the MDT with regard to the need for testing and the results of tests. The parents or caregivers were not allowed to spend whole days or nights in the NICU or HCU, which could have contributed to their ignorance regarding the tests to which their infants had been subjected.

During the structured interviews, the researcher observed that some parents or caregivers were uncertain about the roles of the different MDT members. They referred to all MDT members as 'doctor'. This observation is not supported by any specific data as the structured interview guide did not include questions to determine the parents or caregivers' understanding of the different MDT roles. A recommendation for future research will therefore be to determine parents or caregivers' perception of what the roles of the different MDT members entail. A lack of communication during their infants' stay in the NICU, and also during the rest of their hospitalisation phase, adds to the parents or caregivers' burden of uncertainty (Wigert, Blom and Bry, 2014). This lack of communication can leave parents or caregivers feeling lonely and abandoned and could have a negative effect on their experience when spending time with their infants. The MDT should be encouraged to be attentive and compassionate when communicating with the parents or caregivers of prematurely born infants so as to provide them with a sense of relief or respite from the reality of their situation (Wigert et al., 2014).

Participants also indicated that it was difficult for them to bond with their infants in the NICU.

Some whose infants had been hospitalised in the private health care sector felt that this sector has a need for KMC units such as those found in the public health care sector, which would offer better opportunities for bonding with their infants and would assist with their adjustment in the home environment after the infant's discharge from hospital.

4.3.4.2 Short-term follow-up phase

Seventy-nine participants (91%) indicated that post-discharge follow-up appointments had been scheduled for their infants. The majority (87%) of follow-up appointments were with a paediatrician. Only 8% of the participants indicated that they had had follow-up appointments with a physiotherapist. For most of the infants the first follow-up appointment was within the first month post discharge, after which follow-ups continued monthly or every three to six months.

The majority of infants were discharged from follow-up services between the ages of 12 and 18 months, which was found to be in line with the NICE guidelines for short-term follow-up of prematurely born infants at risk of developmental delays. The short-term follow-up guidelines in the NICE were not applicable to the current study, which focused on the hospitalisation phase whereas the NICE guidelines address the follow-up monitoring of prematurely born infants. Kallioinen, Eadon, Murphy and Baird (2017) summarised the NICE recommendations, which suggest that all prematurely born infants who are at a higher risk of experiencing developmental problems or disorders should be considered for enhanced support for up to two years corrected age and should be monitored for developmental progress. Risk factors for infants at high risk include a developmental problem or disorder, Grade 2 or 3 hypoxic ischaemic encephalopathy, a significant brain lesion, bacterial meningitis or herpes simplex encephalitis. The enhanced support and monitoring should include two face-to-face follow-up visits during the first year (corrected age), during which the focus should be on the infant's development (Kallioinen et al., 2017). The same authors further suggested that a detailed developmental assessment should take place at two years corrected age to identify children at risk of developmental delays.

The evaluation should include physical, emotional and educational development and the MDT team responsible for this assessment should include a neonatologist or paediatrician and at least one of the rehabilitation professionals, i.e. an occupational therapist, a physiotherapist or a speech and language therapist (Kallioinen et al., 2017).

- ***Parental or caregiver education at discharge of the infant from hospital***

Ninety percent (90%) of the participants indicated that the MDT had provided them with information to assist them with the transition to their homes, but only 57% had been informed on possible difficulties during the first year post-corrected age. Unfortunately they did not specify the type of information they were given regarding the possible difficulties. The NICE's recommendations also identified the parents or caregivers' need for support during the first two years (corrected age) and recommended that they be advised with regard to developmental concerns and the care of the infant (or child) at home (feeding, sleeping and interaction). Their need for psychological and emotional support was also emphasised (Kallioinen et al., 2017). The advice recommended by the NICE group aligns with some of the medical advice or information with regard to their infants' development that the participants in this study indicated they would find helpful. For future practice, the participants recommended the inclusion of information on the types of delays that could occur, what the warning signs are, and how the parents or caregivers can support the infant and evaluate development. This should include information on normal growth, weight gain and feeding / nutrition. The participants also felt that information was needed on the benefits of follow-up appointments with the MDT to monitor the infants' developmental progress. It was evident from the responses that the participants felt a great need for emotional support, especially after their infants' discharge from hospital. They stated that they wanted information or education specific to their individual situations and did not want to be overwhelmed by information that is either not relevant to their infant or might only serve to increase their anxiety about possible future complications.

The NICE guideline recommends that parental or caregiver support should be provided by the MDT in a variety of approaches according to individual needs and could include face-to-face meetings, a telephone helpline or electronic messages (Kallioinen et al., 2017). More than half (53%) of the participants in this study indicated (Table 4.3) that they would prefer a booklet with information; 43% were interested in practical demonstrations; and 30% said that a link to a website (electronically) would be useful to them. Participants also indicated a need for support groups or telephonic follow-ups from the MDT once their infants had been discharged to monitor the transition home and establish whether the parents or caregivers are coping, both physically and emotionally, with the management of the infant.

It was reported that health education or information for parents or caregivers was provide mainly by the nursing staff and the paediatrician, with only seven participants (n=7) indicating that the physiotherapist was also involved. There is therefore room for improvement in the service provided by physiotherapists to support the parents or caregivers of prematurely born infants in SA.

4.3.4.3 Long-term follow-up

As previously stated, long-term follow-up is not the focus of the current study, but should be briefly discussed as the MDT should form a relationship with parents or caregivers during the hospitalisation phase and should ensure that they are aware of the availability of long-term follow-up care if a need for further care is indicated. In the opinion of 43% of the participants, their infants did have some form of long-term impairment or activity limitation due to premature birth. This is a significant percentage if it is taken into account that some infants were still hospitalised and some were seen for their first follow-up during this study. The most common complications listed were developmental delays, followed by respiratory and feeding problems (Figure 4.23).

The NICE recommends that infants born before 28 weeks gestational age, as well as infants who demonstrate developmental delay at two years corrected age, should receive further developmental assessments (long-term follow-up) at four years of age (uncorrected) as they are more likely to have special educational needs (Kallioinen et al., 2017).

4.4 CONCLUSION BASED ON THE MULTIDISCIPLINARY TEAM AND PARENTS OR CAREGIVERS' PERSPECTIVES ON THE PATIENT JOURNEY OF A PREMATURELY BORN INFANT

The researcher combined the information provided by MDT members and parents or caregivers regarding their perspectives on the patient journeys of prematurely born infants in the South African health care sectors, which are summarised in the following four diagrams (Figure 4.24 to 4.27). The different patient journeys included a journey for infants born at home, infants born in the private health care sector, and two possible journeys in the public health care sector, i.e. for infants born at either a district / secondary hospital or a tertiary / academic hospital. The patient journeys (Figures 4.24 to 4.27) were further divided into the three phases identified in this study: the hospitalisation phase; the short-term follow-up phase; and the long-term follow-up phase.

In the abovementioned figures, the researcher distinguishes between the three phases by indicating the hospitalisation phase against a green background, the short-term follow-up phase against a blue background and the long-term follow-up phase against an orange background. The MDT members who were involved in each journey are also indicated.

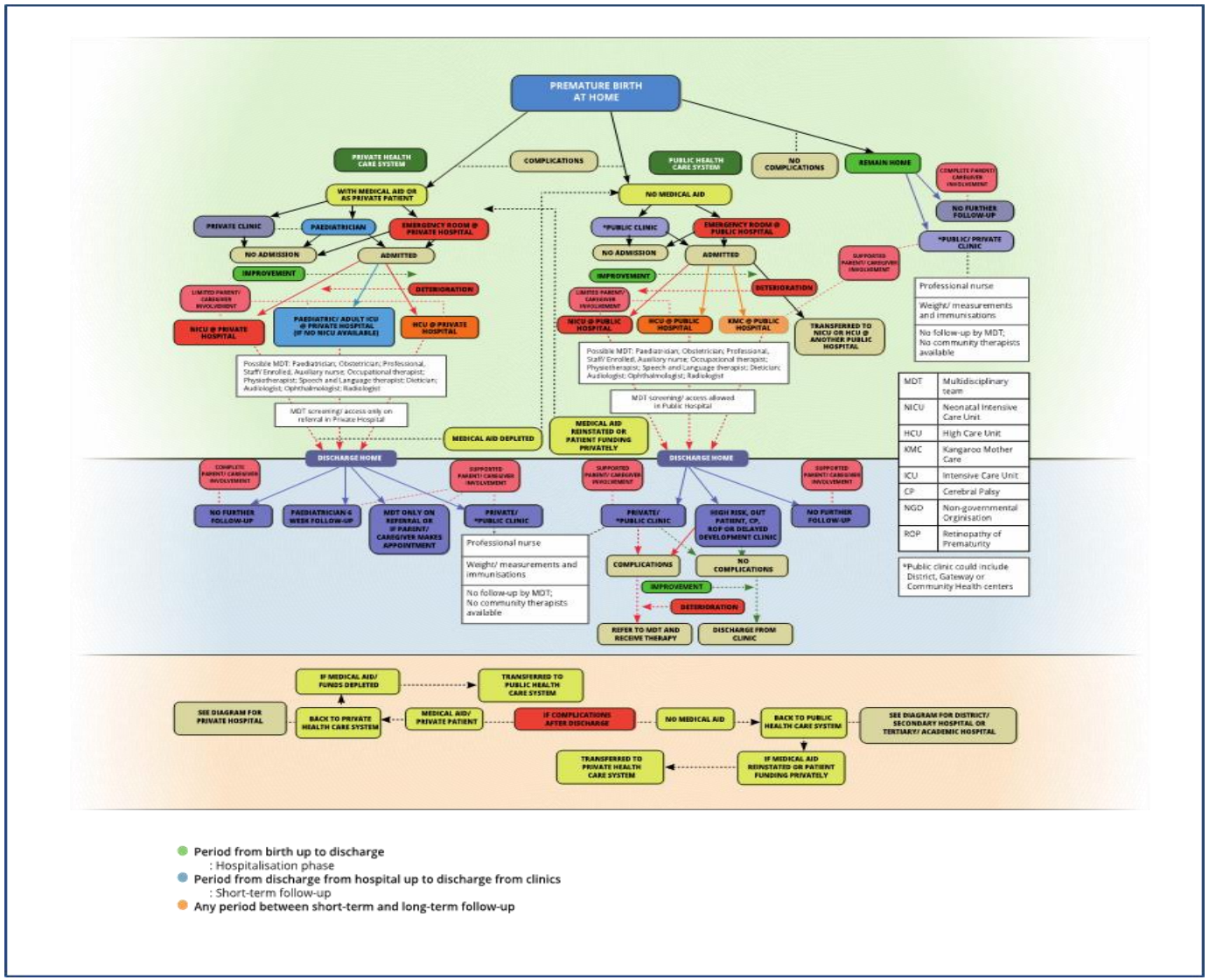


FIGURE 4.24 PATIENT JOURNEY OF INFANTS BORN AT HOME

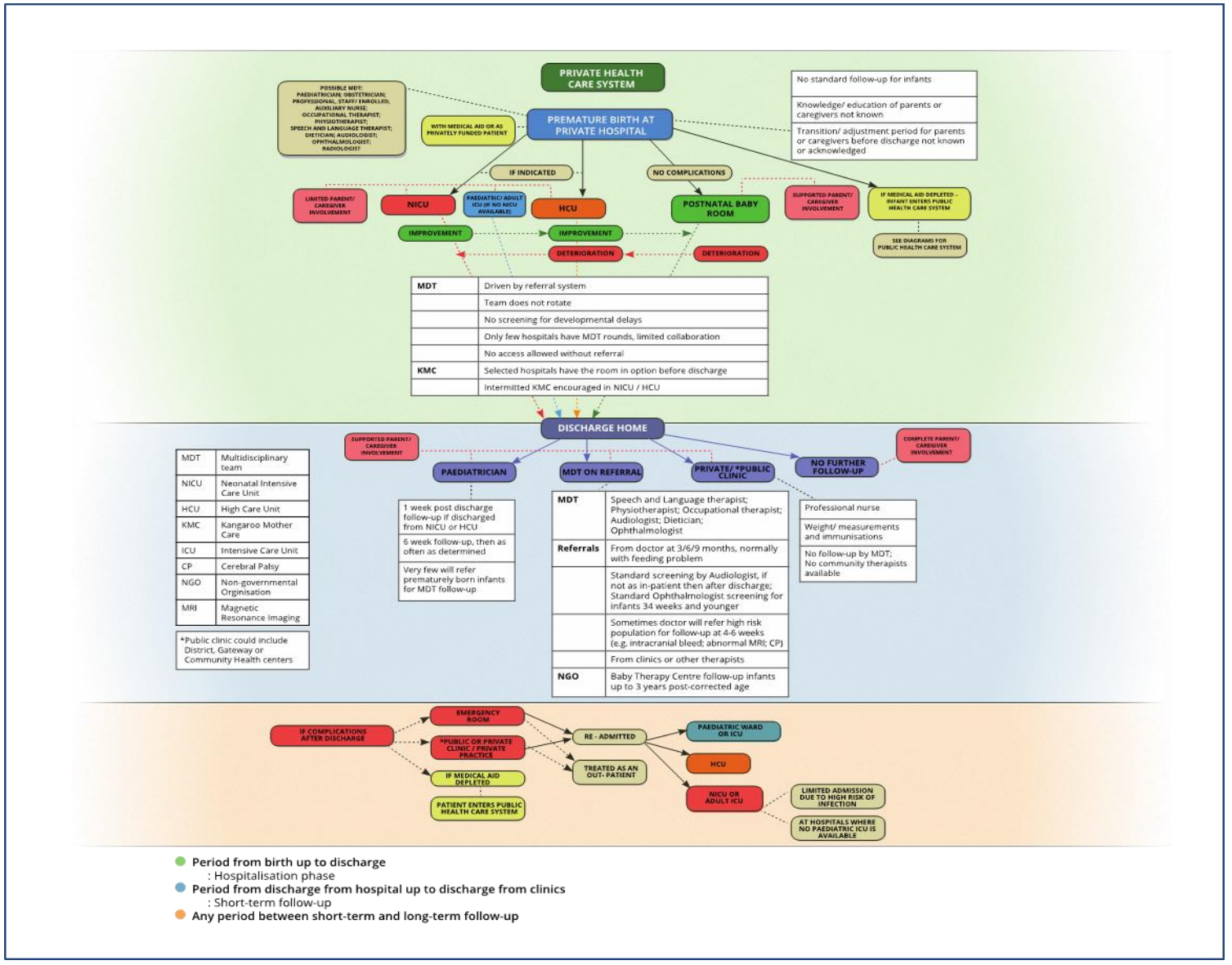


FIGURE 4.25 PATIENT JOURNEY FOR INFANTS BORN AT A PRIVATE HOSPITAL

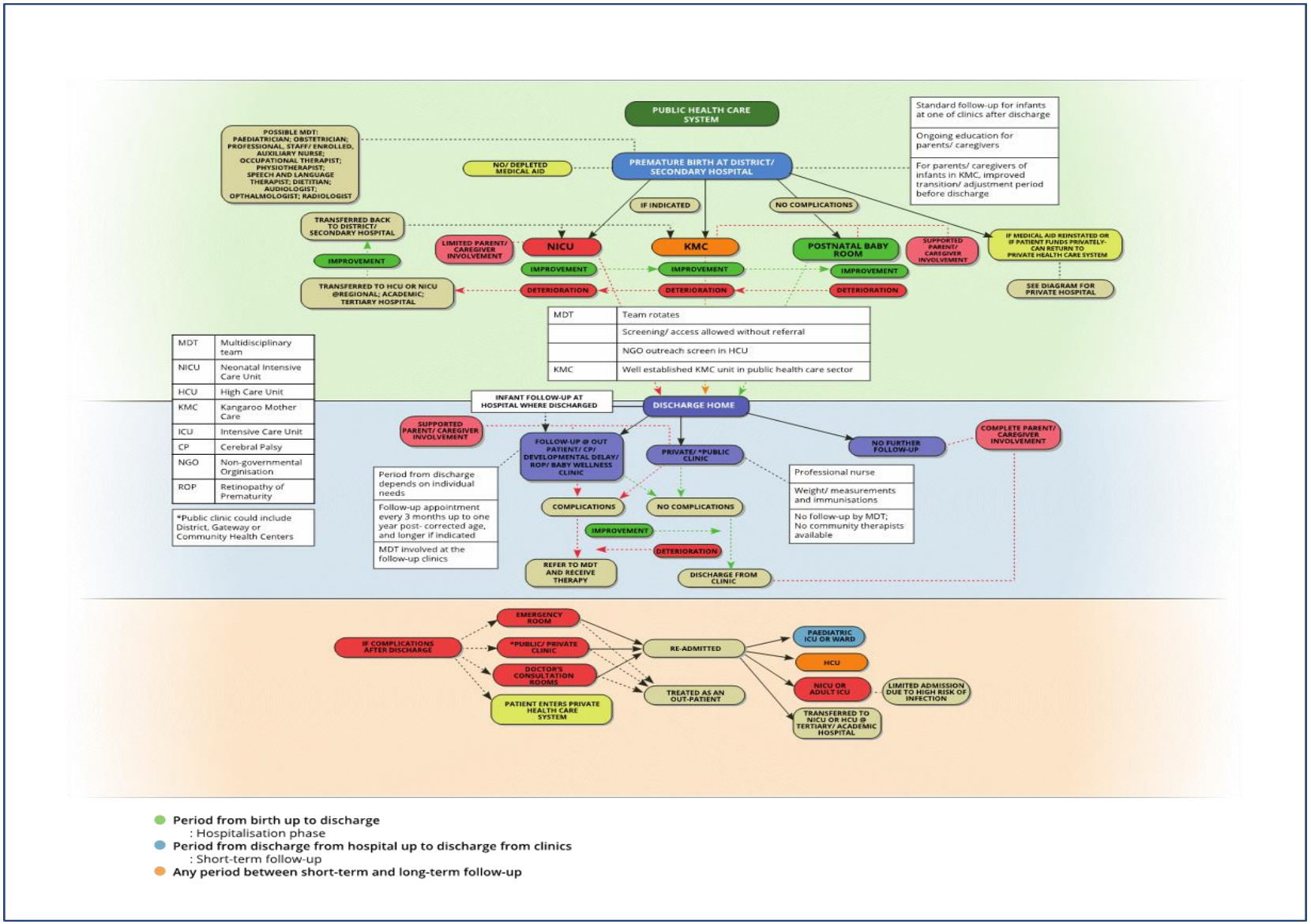


FIGURE 4.26 PATIENT JOURNEY FOR INFANTS BORN AT A DISTRICT OR SECONDARY HOSPITAL

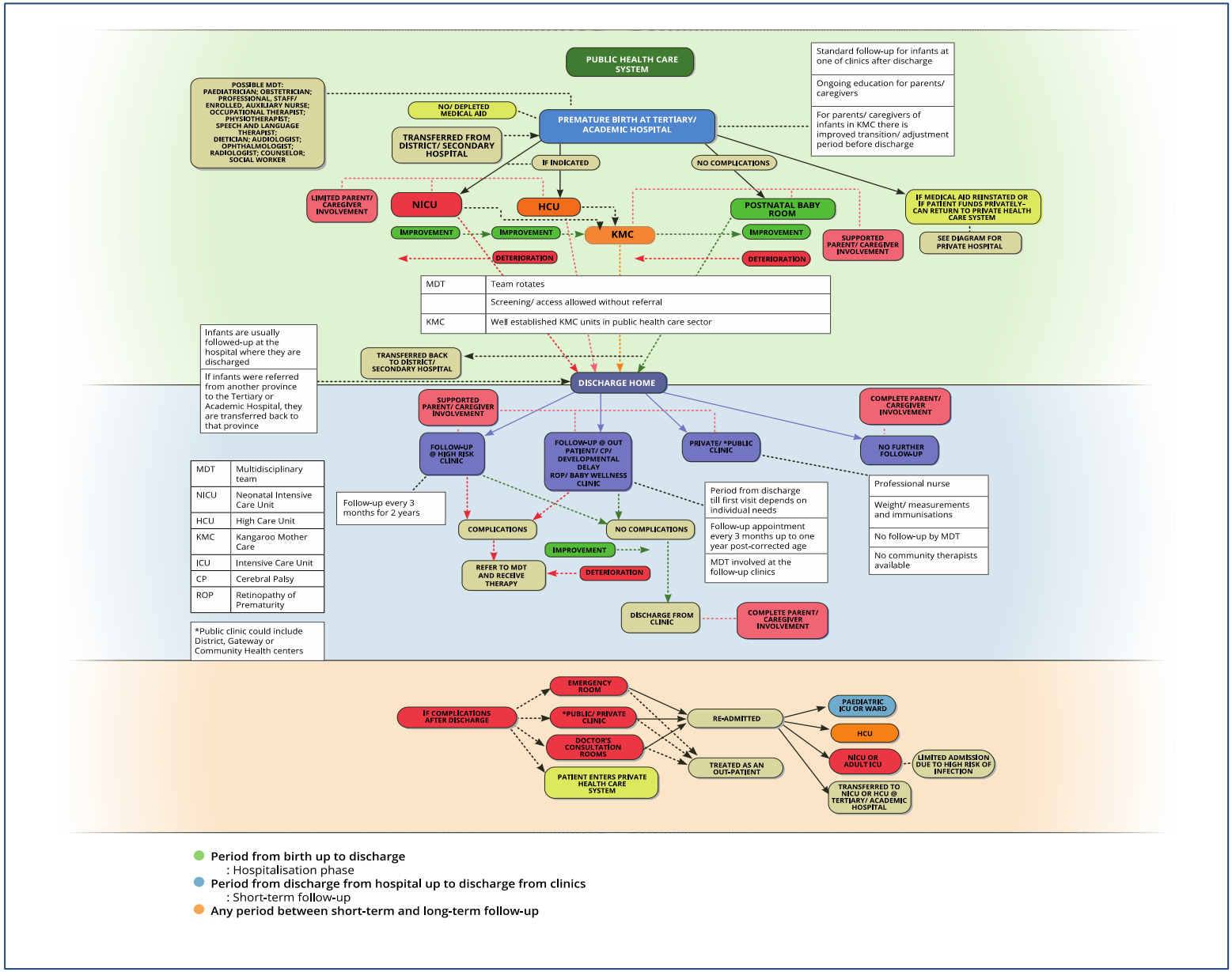


FIGURE 4.27 PATIENT JOURNEY FOR INFANTS BORN AT A TERTIARY OR ACADEMIC HOSPITAL

In the next chapter (Chapter 5) the researcher will describe the integrative literature search that was conducted to identify the available CPGs, competency frameworks and position statements that guide the physiotherapy treatment / management of prematurely born infants in NICUs or HCUs. The identified CPGs, competency frameworks and position statements were all developed in the USA and UK, which are both categorised as high-income countries. The CPGs, competency frameworks and position statements were critically appraised and, together with the patient journeys described in this chapter, form the basis for Phase 2 of the study (see Chapter 6).

CHAPTER 5

RESULTS OF PHASE 1: LITERATURE SEARCH STRATEGIES AND CRITICAL APPRAISAL OF LITERATURE

5.1 INTRODUCTION

In this chapter the researcher discusses the results of the integrative literature search strategy that was used to identify relevant existing literature that guides physiotherapy practice in NICUs, HCUs or KMC wards. According to Torraco (2005), an integrative literature search and review could address 'new' topics not yet addressed in a health care sector, for example the physiotherapy management of prematurely born infants in SA. The 'new' topic (a CPG for the physiotherapy management of prematurely born infants in NICUs, HCUs and KMC wards in SA) warranted a holistic, integrated literature search strategy and critical appraisal and synthesis of all relevant literature published to date (Torraco, 2005). Appropriate literature identified by way of an integrative literature search strategy constitutes one of the pillars of the contextualisation process of developing a CPG for prematurely born infants in the SA health care system.

5.2 RESULTS OF THE INTEGRATIVE LITERATURE SEARCH

The question that guided the integrative literature search was: What guidelines, competency frameworks or position statements are available to physiotherapists for treating prematurely born infants in the NICU, HCU or KMC ward? The strategy followed to conduct the literature search, the databases included in the search and the key words used to identify relevant literature were discussed in Chapter 3, section 3.3.3. The literature search was conducted by the researcher and an information specialist (referred to as the co-searcher) and the results obtained by both are provided in Tables 5.1 and 5.2 respectively.

TABLE 5.1 LITERATURE SEARCH RESULTS FOR CO-SEARCHER (NOVEMBER 2015)

Databases	Co-searcher	Not applicable to neonatal	Applicable to neonatal, but not to this study	Applicable to this study, but not to a CPG, competency framework or position statement	Applicable to this study, as well as to a CPG, competency framework or position statement
CINAHL	18 records	8	6	2	2
Cochrane	15 records	12	1	2	0
Medline	33 records	5	13	13	2
PubMed	221 records	220	0	0	1
Total:	**287 records**	**245**	**20**	**17**	**5**

TABLE 5.2 LITERATURE SEARCH RESULTS FOR RESEARCHER (NOVEMBER 2015)

Databases	Researcher	Not applicable to neonatal	Applicable to neonatal, but not to this study	Applicable to this study, but not a CPG, competency framework or position statement	Applicable to this study, as well as to a CPG, competency framework or position statement
CINAHL	15 records	0	3	9	3
Cochrane	85 records	66	7	12	0
Medline	105 records	3	21	71	10
PubMed	16 records	1	1	4	10
Total:	**221 records**	**70**	**32**	**96**	**23**

Conducting a hand search, the researcher identified two more relevant competency frameworks in the Health Sciences library of UP and in Google Scholar. These were included and increased the total number of documents identified by the researcher to 25 (n=25).

The researcher and a colleague who is familiar with the current research, literature search strategies and research methodology, examined the titles and abstracts / summaries of the identified literature to determine whether they complied with the criteria for inclusion in this study, which were:

- Literature applicable to prematurely born infants' treatment in NICUs, HCUs or KMC wards
- Literature that provides information on CPGs or competency frameworks for physiotherapists' protocol for the treatment (management) of prematurely born infants in NICUs, HCUs or KMC wards
- Literature containing position statements or expert opinions on the treatment of prematurely born infants in NICUs, HCUs or KMC wards by physiotherapists
- Recent literature published between 1 January 2005 and the date of the search strategy
- Literature published in English

The process of elimination that was followed to identify the relevant literature, which could contain CPGs, competency frameworks or position statements that were eligible for inclusion in the next step, namely the critical appraisal of the literature, is illustrated in Figure 5.1.

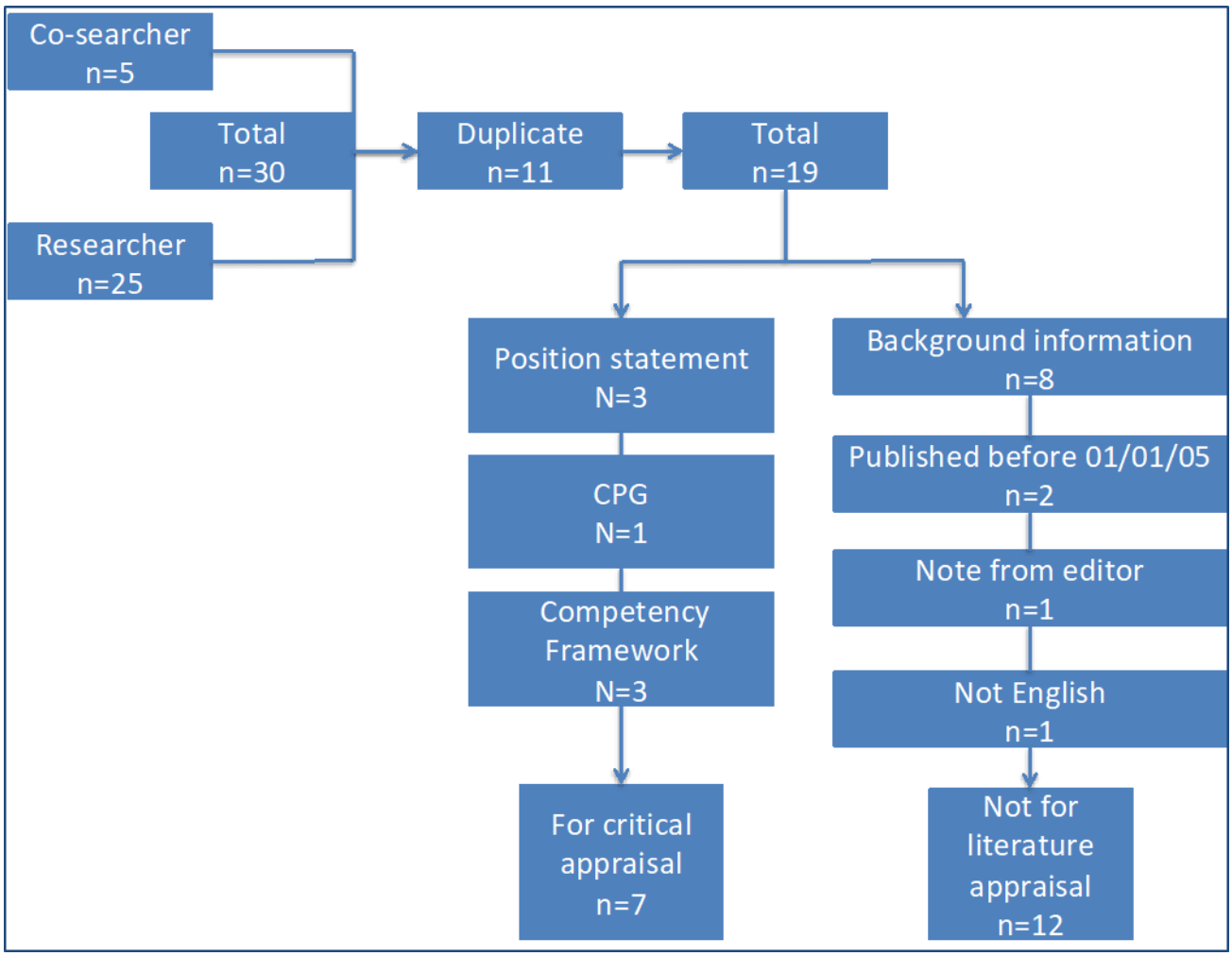


FIGURE 5.1 THE PROCESS OF ELIMINATION FOLLOWED TO IDENTIFY LITERATURE FOR APPRAISAL

Following the identification of the literature that met all the criteria for inclusion, the documents were divided into three categories, namely CPGs, competency frameworks and positions statements (Table 5.3), and were then critically appraised.

TABLE 5.3 LITERATURE SELECTED FOR CRITICAL APPRAISAL

Clinical practice guideline	*Competency framework*	*Position statement*
Neonatal Physical Therapy. Part II: Practice Frameworks and Evidence-based Practice Guidelines (Sweeney et al., 2010)	Neonatal Physical Therapy. Part I: Clinical Competencies and Neonatal Intensive Care Unit Clinical Training Models (Sweeney et al., 2009)	Physical Therapy Observation and Assessment in the Neonatal Intensive Care Unit (Byrne et al., 2013a)
	A Competence Framework and Evidence-based Practice Guidance for the Physiotherapist working in the Neonatal Intensive Care and Special Care Unit in the United Kingdom (Brady et al., 2015)	Physical Therapy Intervention in the Neonatal Intensive Care Unit (Byrne et al., 2013b)
	A Competence Framework and Evidence-Based Practice Guidance for Physiotherapists providing Respiratory Interventions for Preterm Infants in the United Kingdom (Price et al., 2014)	Family Support and Education (Goldstein, 2013)

5.3 APPRAISAL OF THE CLINICAL PRACTICE GUIDELINE, COMPETENCY FRAMEWORKS AND POSITION STATEMENTS

The researcher and two assistant appraisers, trained in the critical appraisal of literature, used the AGREE II instrument to appraise the documents listed in Table 5.3 (see Chapter 3, section 3.3.3.3). The method of scoring the documents on the rating scale of the sub-sections of the AGREE II was also discussed in Chapter 3, Section 3.3.3.3. The scoring involved establishing the extent to which the CPG, competency frameworks and position statements met the criteria in each domain of the AGREE II and rating the relevant aspects on a 7-point scale. The numerical total score for each document was calculated by adding up the score for each domain so that each document was allocated an AGREE II percentage. These percentages were compared to the minimum percentages approved by the SASP's Professional Development Portfolio Committee (2014).

The two position statements by Byrne et al. (2013a) and Byrne et al. (2013b) were appraised as one document as the researcher found that the two position statements together described the complete NICU Care Path. Table 5.4 contains a summary of the AGREE II percentages allocated to the CPG, competency frameworks and position statements in each domain.

TABLE 5.4 AGREE II SCORES FOR THE CLINICAL PRACTICE GUIDELINE, COMPETENCY FRAMEWORKS AND POSITION STATEMENTS

AGREE II domains	**Neonatal Physical Therapy. Part I: Clinical Competencies and Neonatal Intensive Care Unit Clinical Training Models (Sweeney et al., 2009)**	**Neonatal Physical Therapy. Part II: Practice Frameworks and Evidence-Based Practice Guidelines (Sweeney et al., 2010)**	**NICU Care Path (Byrne et al., 2013a; Byrne et al., 2013b)**	**Family Support and Education (Goldstein, 2013)**	**A Competence Framework and Evidence-Based Practice Guidance for the Physiotherapist working in the Neonatal Intensive Care and Special Care Unit in the United Kingdom (Brady et al., 2015)**	**A Competence Framework and Evidence-Based Practice Guidance for Physiotherapists providing Respiratory Interventions for Preterm Infants in the United Kingdom (Price et al., 2014)**	**SASP's Professional Development Portfolio Committee recommendation**
Domain 1: Scope and purpose							
Overall objectives	Appraiser 1: 6/7 Appraiser 2: 7/7 Appraiser 3: 6/7	Appraiser 1: 6/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 7/7 Appraiser 2: 6/7 Appraiser 3: 7/7	Appraiser 1: 6/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 7/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 7/7 Appraiser 2: 7/7 Appraiser 3: 7/7	
Health questions	Appraiser 1: 5/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 5/7 Appraiser 2: 6/7 Appraiser 3: 6/7	Appraiser 1: 5/7 Appraiser 2: 4/7 Appraiser 3: 5/7	Appraiser 1: 5/7 Appraiser 2: 7/7 Appraiser 3: 6/7	Appraiser 1: 6/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 7/7 Appraiser 2: 7/7 Appraiser 3: 7/7	

Target population	Appraiser 1: 5/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 6/7 Appraiser 2: 6/7 Appraiser 3: 6/7	Appraiser 1: 7/7 Appraiser 2: 6/7 Appraiser 3: 7/7	Appraiser 1: 6/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 5/7 Appraiser 2: 7/7 Appraiser 3: 6/7	Appraiser 1: 7/7 Appraiser 2: 6/7 Appraiser 3: 7/7	
Combined total:	**89%**	**85%**	**83%**	**91%**	**93%**	**98%**	**70%**
Domain 2: Stakeholder involvement							
Guideline development group	Appraiser 1: 7/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 2/7 Appraiser 2: 3/7 Appraiser 3: 1/7	Appraiser 1: 7/7 Appraiser 2: 6/7 Appraiser 3: 5/7	Appraiser 1: 4/7 Appraiser 2: 5/7 Appraiser 3: 4/7	Appraiser 1: 5/7 Appraiser 2: 4/7 Appraiser 3: 5/7	Appraiser 1: 5/7 Appraiser 2: 5/7 Appraiser 3: 5/7	
Views / preferences of target population	Appraiser 1: 2/7 Appraiser 2: 1/7 Appraiser 3: 2/7	Appraiser 1: 1/7 Appraiser 2: 2/7 Appraiser 3: 2/7	Appraiser 1: 1/7 Appraiser 2: 2/7 Appraiser 3: 3/7	Appraiser 1: 4/7 Appraiser 2: 5/7 Appraiser 3: 4/7	Appraiser 1: 3/7 Appraiser 2: 2/7 Appraiser 3: 4/7	Appraiser 1: 1/7 Appraiser 2: 2/7 Appraiser 3: 2/7	
Target users	Appraiser 1: 5/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 5/7 Appraiser 2: 7/7 Appraiser 3: 5/7	Appraiser 1: 7/7 Appraiser 2: 6/7 Appraiser 3: 7/7	Appraiser 1: 5/7 Appraiser 2: 7/7 Appraiser 3: 5/7	Appraiser 1: 7/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 7/7 Appraiser 2: 7/7 Appraiser 3: 7/7	
Combined total:	**67%**	**35%**	**65%**	**63%**	**65%**	**59%**	**50%**
Domain 3: Rigour of development							

Systematic methods	Appraiser 1: 1/7 Appraiser 2: 2/7 Appraiser 3: 2/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 2/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 2/7 Appraiser 2: 2/7 Appraiser 3: 2/7	
Criteria for selecting evidence	Appraiser 1: 1/7 Appraiser 2: 2/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 2/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 2/7 Appraiser 2: 2/7 Appraiser 3: 2/7	
Strengths and limitations of body of evidence	Appraiser 1: 3/7 Appraiser 2: 5/7 Appraiser 3: 2/7	Appraiser 1: 3/7 Appraiser 2: 3/7 Appraiser 3: 2/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 2/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 2/7 Appraiser 2: 1/7 Appraiser 3: 2/7	Appraiser 1: 3/7 Appraiser 2: 4/7 Appraiser 3: 2/7	
Formulation of recommendations	Appraiser 1: 2/7 Appraiser 2: 2/7 Appraiser 3: 1/7	Appraiser 1: 2/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 2/7 Appraiser 3: 2/7	Appraiser 1: 1/7 Appraiser 2: 2/7 Appraiser 3: 2/7	Appraiser 1: 2/7 Appraiser 2: 3/7 Appraiser 3: 3/7	Appraiser 1: 4/7 Appraiser 2: 3/7 Appraiser 3: 2/7	
Health benefits, side effects and risks	Appraiser 1: 5/7 Appraiser 2: 6/7 Appraiser 3: 5/7	Appraiser 1: 3/7 Appraiser 2: 4/7 Appraiser 3: 3/7	Appraiser 1: 6/7 Appraiser 2: 6/7 Appraiser 3: 7/7	Appraiser 1: 3/7 Appraiser 2: 4/7 Appraiser 3: 4/7	Appraiser 1: 2/7 Appraiser 2: 2/7 Appraiser 3: 2/7	Appraiser 1: 7/7 Appraiser 2: 6/7 Appraiser 3: 5/7	

Link between evidence and recommendations	Appraiser 1: 6/7 Appraiser 2: 5/7 Appraiser 3: 4/7	Appraiser 1: 7/7 Appraiser 2: 6/7 Appraiser 3: 5/7	Appraiser 1: 4/7 Appraiser 2: 4/7 Appraiser 3: 5/7	Appraiser 1: 4/7 Appraiser 2: 5/7 Appraiser 3: 4/7	Appraiser 1: 1/7 Appraiser 2: 3/7 Appraiser 3: 3/7	Appraiser 1: 5/7 Appraiser 2: 4/7 Appraiser 3: 3/7	
Externally reviewed	Appraiser 1: 3/7 Appraiser 2: 3/7 Appraiser 3: 3/7	Appraiser 1: 2/7 Appraiser 2: 2/7 Appraiser 3: 1/7	Appraiser 1: 2/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 3/7 Appraiser 2: 3/7 Appraiser 3: 3/7	Appraiser 1: 5/7 Appraiser 2: 4/7 Appraiser 3: 4/7	
Procedure for updating	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 2/7 Appraiser 3: 1/7	Appraiser 1: 2/7 Appraiser 2: 3/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 2/7 Appraiser 3: 2/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 2/7 Appraiser 2: 2/7 Appraiser 3: 2/7	
Combined total:	**30%**	**22%**	**24%**	**15%**	**15%**	**38%**	**70%**
Domain 4: Clarity of presentation							
Recommendations specific and unambiguous	Appraiser 1: 6/7 Appraiser 2: 5/7 Appraiser 3: 4/7	Appraiser 1: 6/7 Appraiser 2: 6/7 Appraiser 3: 4/7	Appraiser 1: 6/7 Appraiser 2: 6/7 Appraiser 3: 7/7	Appraiser 1: 5/7 Appraiser 2: 5/7 Appraiser 3: 5/7	Appraiser 1: 4/7 Appraiser 2: 5/7 Appraiser 3: 4/7	Appraiser 1: 7/7 Appraiser 2: 6/7 Appraiser 3: 5/7	
Different options for management of health issue	Appraiser 1: 4/7 Appraiser 2: 4/7 Appraiser 3: 4/7	Appraiser 1: 7/7 Appraiser 2: 7/7 Appraiser 3: 6/7	Appraiser 1: 5/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 2/7 Appraiser 2: 3/7 Appraiser 3: 2/7	Appraiser 1: 4/7 Appraiser 2: 5/7 Appraiser 3: 4/7	Appraiser 1: 7/7 Appraiser 2: 6/7 Appraiser 3: 6/7	

Easily identifiable recommendations	Appraiser 1: 5/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 7/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 6/7 Appraiser 2: 6/7 Appraiser 3: 5/7	Appraiser 1: 6/7 Appraiser 2: 7/7 Appraiser 3: 6/7	Appraiser 1: 4/7 Appraiser 2: 6/7 Appraiser 3: 6/7	Appraiser 1: 7/7 Appraiser 2: 6/7 Appraiser 3: 6/7	
Combined total:	**69%**	**89%**	**85%**	**59%**	**61%**	**87%**	**60%**
Domain 5: Applicability							
Facilitators and barriers to application	Appraiser 1: 2/7 Appraiser 2: 2/7 Appraiser 3: 2/7	Appraiser 1: 3/7 Appraiser 2: 2/7 Appraiser 3: 1/7	Appraiser 1: 2/7 Appraiser 2: 2/7 Appraiser 3: 1/7	Appraiser 1: 4/7 Appraiser 2: 4/7 Appraiser 3: 4/7	Appraiser 1: 3/7 Appraiser 2: 1/7 Appraiser 3: 3/7	Appraiser 1: 2/7 Appraiser 2: 2/7 Appraiser 3: 3/7	
Advice and / or tools to assist in the implementation of the recommendations	Appraiser 1: 2/7 Appraiser 2: 4/7 Appraiser 3: 3/7	Appraiser 1: 3/7 Appraiser 2: 4/7 Appraiser 3: 5/7	Appraiser 1: 6/7 Appraiser 2: 6/7 Appraiser 3: 7/7	Appraiser 1: 6/7 Appraiser 2: 7/7 Appraiser 3: 6/7	Appraiser 1: 3/7 Appraiser 2: 4/7 Appraiser 3: 4/7	Appraiser 1: 7/7 Appraiser 2: 6/7 Appraiser 3: 5/7	
Resource implications	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 2/7 Appraiser 2: 1/7 Appraiser 3: 2/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 2/7 Appraiser 2: 1/7 Appraiser 3: 2/7	Appraiser 1: 2/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 2/7	
Monitoring and / or auditing criteria	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 3/7 Appraiser 2: 3/7 Appraiser 3: 3/7	Appraiser 1: 6/7 Appraiser 2: 6/7 Appraiser 3: 5/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 2/7 Appraiser 2: 1/7 Appraiser 3: 2/7	Appraiser 1: 5/7 Appraiser 2: 4/7 Appraiser 3: 3/7	
Combined total:	**13%**	**28%**	**44%**	**38%**	**21%**	**40%**	**50%**

Domain 6: Editorial independence							
Views of funding body	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 2/7	Appraiser 1: 6/7 Appraiser 2: 7/7 Appraiser 3: 6/7	Appraiser 1: 7/7 Appraiser 2: 7/7 Appraiser 3: 7/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	
Competing interests of guideline development group	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 4/7 Appraiser 2: 5/7 Appraiser 3: 6/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	Appraiser 1: 1/7 Appraiser 2: 1/7 Appraiser 3: 1/7	
Combined total:	**0%**	**3%**	**78%**	**50%**	**0%**	**0%**	**50%**
Overall guideline assessment							
Overall quality	Appraiser 1: 3/7 Appraiser 2: 5/7 Appraiser 3: 4/7	Appraiser 1: 4/7 Appraiser 2: 4/7 Appraiser 3: 4/7	Appraiser 1: 4/7 Appraiser 2: 5/7 Appraiser 3: 6/7	Appraiser 1: 4/7 Appraiser 2: 6/7 Appraiser 3: 4/7	Appraiser 1: 4/7 Appraiser 2: 4/7 Appraiser 3: 4/7	Appraiser 1: 6/7 Appraiser 2: 5/7 Appraiser 3: 5/7	
Recommend the guideline for use	Appraiser 1: Yes, with modifications Appraiser 2: Yes Appraiser 3: Yes, with modifications	Appraiser 1: Yes, with modifications Appraiser 2: Yes, with modifications Appraiser 3: Yes, with modifications	Appraiser 1: Yes, with modifications Appraiser 2: Yes, with modifications Appraiser 3: Yes	Appraiser 1: Yes, with modifications Appraiser 2: Yes, with modifications Appraiser 3: Yes, with modifications	Appraiser 1: Yes, with modifications Appraiser 2: Yes, with modifications Appraiser 3: Yes, with modifications	Appraiser 1: Yes Appraiser 2: Yes, with modifications Appraiser 3: Yes, with modifications	

Overall score:	**50%** **Appraisers recommended this guideline with modification**	**50%** **Appraisers recommended this guideline with modification**	**67%** **Appraisers recommended this guideline with modification**	**61%** **Appraisers recommended this guideline with modification**	**50%** **Appraisers recommended this guideline with modification**	**72%** **Appraisers recommended this guideline with modification**	

5.4 DISCUSSION OF RESULTS

The AGREE II instrument is used to (i) assess the quality of guidelines; (ii) provide a methodological strategy for the development of guidelines; and (iii) inform on the content to be included in a CPG and the format in which a guideline ought to be written and published (Brouwers, 2010). The researcher therefore used the AGREE II instrument to guide the appraisal of the quality of the CPG, competency frameworks or position statements in this study (Chapter 3, section 3.3.3.3).

It became apparent that the authors of the identified literature (Sweeney et al., 2010; Byrne et al., 2013a; Byrne et al., 2013b; Sweeney et al., 2009; Goldstein, 2013; Brady et al., 2015; Price et al., 2014) that was critically appraised in this phase of the study had not covered all the criteria required in the domains of the AGREE II instrument in their published documents. The results of the critical appraisal scores of the CPG, competency frameworks and position statements (Table 5.4) are discussed in the following sections.

5.4.1 Domain 1: Scope and purpose

One area in which all six documents, namely the CPG, competency frameworks and position papers, scored above the recommendations made by the SASP's Professional Development Portfolio Committee was *the scope and purpose domain*. In this domain, the researcher and two assistant appraisers scored the documents according to the following criteria:

(i) Whether the overall objective(s) of the guideline were specifically described
(ii) Whether the health question(s) covered by the guideline were specifically described
(iii) Whether the population for which the guideline was developed was specifically described

It was important for the scope and purpose of the CPG, competency frameworks and position statements included in the contextualised CPG for this study to correspond with the scope and purpose of the current study.

The scope and purpose of the CPG, competency frameworks and position statements address the end users, which in this case are the physiotherapists who might implement the recommendations contained in these documents in their management of prematurely born infants in NICUs, HCUs or KMC wards.

The scope and purpose of the CPG, competency frameworks and position statements also address the target population, which includes prematurely born infants in NICUs, HCUs and their parents or caregivers. In Chapter 2, section 2.3.2.1 the importance of the links between the end users, target populations and the scope and purpose of a guideline / competency framework / position statement were highlighted. It was mentioned that the scope and purpose assist researchers in the selection of the methodological approach that they should follow to develop the CPG, competency frameworks or position statements (Machingaidze et al., 2015).

5.4.2 Domain 2: Stakeholder involvement

The stakeholder involvement domain was scored by the researcher and two assistant appraisers according to information provided by the authors of the CPG, competency framework or position statement in respect of whether:

(i) the guideline development group described in the CPG, competency frameworks or position statements included individuals from all relevant professions;
(ii) the views and preferences of members of the target population have been sought; and
(iii) the target users of the guideline were clearly defined.

The CPG by Sweeney et al. (2010) scored below the SASP's Professional Development Portfolio Committee recommendation of 50% for the total percentage in Domain 2. Since the published document did not contain details regarding the guideline development group, the identities and affiliations or positions of those involved are not known.

Information on the views or preferences of the target population (prematurely born infants and their parents or caregivers) was not included in the published document. The developers of the CPG / competency frameworks / position statements could have improved the likelihood of the document's incorporation into practice by the target users (i.e. physiotherapists) if the information regarding stakeholder involvement in the development process had been adequately described (Chapter 2, section 2.3.2.1). The reason for this is that the target users could identify with the development group if they recognise the individuals involved in the development of the CPG, which might lead to the target users having confidence in the quality of the document (Grimmer et al., 2016).

5.4.3 Domain 3: Rigour of development

The CPG developed by Sweeney et al. (2010) was included in a published article, while the other papers were either written as competency frameworks or position statements for possible use by physiotherapists working in NICUs in the USA and UK (Sweeney et al., 2009; Widen, Folsom, Cone-Wesson, Carty, Dunnell, Koebsell et al., 2000; Brady et al., 2015; Price et al., 2014; Byrne et al., 2013a; Byrne et al., 2013b; Goldstein, 2013). For this reason all six documents—the CPG, the competency frameworks and the position statements– scored well below the minimum requirement of 70% recommended by the SASP's Professional Development Portfolio Committee in the domain *Rigour of development.*

The scores allocated by the researcher and two assistant appraisers in the domain *Rigour of development* were based on:

(i) the systematic methods that the authors used to search for evidence;
(ii) the criteria used for selecting the evidence;
(iii) the strengths and limitations of the body of evidence;
(iv) the methods for formulating the recommendations;
(v) the health benefits, side effects and risks that they considered in formulating the recommendations;
(vi) whether there was an explicit link between the recommendations and the supporting evidence;

(vii) whether the guideline had been externally reviewed by experts prior to its publication; and

(viii) a procedure for updating the guideline.

The CPG, competency frameworks and position statements received low scores in respect of 'systematic methods', 'criteria for selecting evidence', 'strengths and limitations of body of evidence' and 'formulation of recommendations'. The researcher and assistant appraisers were unable to identify the search strategies, databases or key words used by the developers. Fellow researchers who might want to repeat the literature search could therefore not carry out a duplication of the literature searches done by the developers of the CPG, competency frameworks and position statements. The development groups of the CPG, competency frameworks and position statements could have improved the reporting of their process of synthesis of the evidence if they made use of either the GRADE or FORM approaches (Kredo et al., 2016). The authors explained that these two approaches assist developers to summarise the body of evidence as well as to formulate the recommendations in a standardised and transparent manner. The developers of the CPG, competency frameworks and position statements did not clarify the process used to formulate the recommendations, which might lead to the end users (physiotherapists) managing prematurely born infants in NICUs, HCUs or KMC wards questioning the recommendations' trustworthiness.

The scores for the 'procedure for updating' the guideline, competency framework or position statement were also low. Although developers did recommend that the documents be updated after a period of time, no structured plans for the updating process were provided as recommended in literature (see Chapter 2, section 2.3.2.1). Both the AGREE II instrument and the iCAHE checklist highlight the importance of updating a guideline due to the fact that new research might become available after the guideline, competency framework or position statements were formulated. It is therefore an important procedure that developers should incorporate to ensure that the CPG, competency framework or position statement stays relevant for the use of the end users (Machingaidze et al., 2015).

However, the appraisers found that the developers of the CPG, competency frameworks and position statements did address the health benefits, side effects of treatment and risks involved in the treatment of prematurely born infants and could link the evidence found during the literature search to the recommendations made in the documents. The literature could therefore be included in the current study.

5.4.4 Domain 4: Clarity of presentation

With the exception of Goldstein's (2013) position statement on Family Support and Education, which obtained a score of 59% in the domain *clarity of presentation*, the CPG, competency frameworks and position statements scored above the SASP's Professional Development Portfolio Committee's recommended score of 60%.

The scores for the domain *clarity of presentation* were determined by the researcher and two assistant appraisers according to information provided by the authors of the CPG, competency framework or position statement in respect of:

(i) the recommendations included in the guideline (which require recommendations to be specific and unambiguous);
(ii) the different options for the management of the condition (premature birth) or health issue (which must be clearly presented); and
(iii) the need for key recommendations to be easily identifiable.

The recommendations included in the CPG, competency frameworks and position statements had to be clearly presented as this was an important requirement for the researcher to be able to assess them for potential inclusion in Phase 2 of the current study (integration of current CPG recommendations with the South African patient journeys).

5.4.5 Domain 5: Applicability

In the domain *applicability,* all six of the documents scored below the SASP's Professional Development Portfolio Committee's recommended score of 50%.

The domain *applicability* was scored by the researcher and two assistant appraisers on the basis of how the authors of the CPG, competency frameworks or position statements had addressed:

(i) facilitators and barriers to the application of the guideline;
(ii) advice regarding (or tools for) the practical application of the recommendations in the guideline;
(iii) the potential resource implications of applying the recommendations; and
(iv) how the guideline presents monitoring and / or auditing criteria.

It is possible that the authors had addressed these domains in their research, but since their findings were not documented in the CPG, competency frameworks or position statements, no score could be allocated for this criterion. The appraisers were unable to find any descriptions by the developers of these documents of factors that facilitated, or barriers that impeded the end users' (physiotherapists') practical implementation of the recommendations. The developers of a guideline, competency framework or position statement should consider the local context in which the document might be implemented and the recommendations should therefore be relevant to the end user's work environment (Kredo et al., 2016)

The developers of the CPG, competency frameworks or position statements further neglected to address the potential resource implications if physiotherapists were to implement the recommendations listed in the documents in practice. Inadequate financial resources, a lack of available time on the part of the end users and a lack of knowledge if new techniques are suggested are implementation barriers that developers of guidelines, competency frameworks or position statements should consider (Grimmer et al., 2016). Resource implications could arise if a recommendation required additional resources, such as specialised therapists or new equipment, which may not be available in a hospital and may result in additional costs to the hospital or the parents or caregivers of prematurely born infants.

There are models and frameworks available to assist guideline, competency framework or position statement developers with the process of implementation, like the GUIDE-M model, but Kredo et al. (2016) reported that less than a quarter of guideline, competency framework or position statement developers made use of an implementation theory / model / framework.

5.4.6 Domain 6: Editorial independence

In the domain *Editorial independence,* the two position statements, namely the NICU Care Path by Byrne et al. (2013a) and Byrne et al. (2013b), and Family Support and Education by Goldstein (2013) scored above the SASP's Professional Development Portfolio Committee's recommendation of 50%.

The CPG and three competency frameworks scored between 0% and 3% in this domain, making it the domain in which the developers obtained the lowest scores.

The domain *Editorial independence* was scored by the researcher and two assistant appraisers on the basis of how the developers of the CPG, competency frameworks or position statements dealt with the following:

(i) that the content of the CPG, competency framework or position statement had not been influenced by the views of any funding body; and
(ii) that the development group members stated that there were no competing interests, or provided information on how competing interests were addressed.

The developers of the CPG and three of the competency frameworks did not report on any potential influences that funding bodies may have had on the development of those documents, or on any competing interests. Consequently, since these aspects were not explicitly mentioned in the documents, they could not be scored. By providing the information regarding potential conflicts of interest, as well as information regarding the audit / search trail the developers of the CPG or competency frameworks could have limited their bias during the development process (Machingaidze et al., 2015).

5.4.7 Overall guideline assessment

The percentage scores that the CPG, competency frameworks and position statements received were based on the researcher and two assistant appraisers' rating of the overall quality of the document. The SASP's Professional Development Portfolio Committee did not make recommendations for this section of the AGREE II instrument.

The researcher and two assistant appraisers agreed that they would recommend the CPG, competency frameworks and position papers for physiotherapists working in NICUs, HCUs or KMC wards if modifications were made, such as the inclusion of information that was highlighted and recommended in the AGREE II domains.

Based on consultation about the domain scores of the AGREE II instrument that took place between the researcher and the two assistant appraisers, consensus was reached regarding the CPG, competency frameworks and position papers that would be included in Phase 2 of the current study. The documents that were included—despite the low score allocated to especially Sweeney et al.'s (2010) CPG—and those that were excluded, as well as the reasons for their inclusion or exclusion are shown in Table 5.5.

TABLE 5.5 LITERATURE INCLUDED IN PHASE 2 OF THE CURRENT STUDY

CPG, competency framework or position statement included	***Reason for inclusion***	***CPG, competency framework or position statement excluded***	***Reason for exclusion***
Neonatal Physical Therapy. Part II: Practice Frameworks and Evidence-Based Practice Guidelines (Sweeney et al., 2010)	✓ The CPG developers included well-defined / presented recommendation relevant to the scope and purpose of the current study.	Neonatal Physical Therapy Part I: Clinical Competencies and Neonatal Intensive Care Unit Clinical Training Models (Sweeney et al., 2009)	× The competency framework was well written, but focused on the competencies of the physiotherapist, rather than on recommendations for the management of prematurely born infants and their parents or caregivers.
Physical Therapy Observation and Assessment in the Neonatal Intensive Care Unit (Byrne et al., 2013a) Physical Therapy Intervention in the Neonatal Intensive Care Unit (Byrne et al., 2013b)	✓ The position paper developers based their research on the CPG developed by Sweeney et al. (2010), but continued with a literature search of their own to formulate the NICU Care Path. ✓ The recommendations are clearly stated and the developers linked a time frame in gestational age to each recommendation.	A Competence Framework and Evidence-based Practice Guidance for the Physiotherapist working in the Neonatal Intensive Care and Special Care Unit in the United Kingdom by (Brady et al., 2015)	× The competency framework was well written, but focused on the competencies of the physiotherapist. × The recommendations included in the competency framework were similar to those included in the CPG by Sweeney et al. (2010) since the competency framework was based on the research of Sweeney et al. (2010).

		A Competence Framework and Evidence-based Practice Guidance for Physiotherapists providing Respiratory Interventions for Preterm Infants in the United Kingdom (Price et al., 2014)	× The competency framework was well written, but focused on the competencies of the physiotherapist. × The recommendations included in the competency framework were similar to those in the CPG developed by Sweeney et al. (2010), on whose research it was based.
		Family Support and Education (Goldstein, 2013)	× The position statement was well written and included a NICU discharge path, but the researcher and assistant appraisers found that this document provides valuable additional information to the NICU care path, and should be used as a source of information rather than for formulating recommendations .

Based on the consensus between the researcher and the two assistant appraisers, the CPG developed by Sweeney et al. (2010) and the NICU Care Path instrument developed by Byrne et al. (2013a) and Byrne et al. (2013b) were included in Phase 2 (Integration of current CPG recommendations with the South African patient journeys) of the current study.

5.5 CONCLUSION REGARDING THE INTEGRATIVE LITERATURE SEARCH

In this chapter the researcher explained the literature search strategies followed to identify the CPG, competency frameworks and position statements relevant to the management of prematurely born infants in NICUs, HCUs or KMC wards. Three independent appraisers appraised these documents by using the AGREE II instrument. The scores allocated by each of the appraisers for each domain of the AGREE II instrument were presented in Table 5.5, and the areas in which the documents scored adequately or below the criteria recommended by the SASP's Professional Development Portfolio Committee were discussed. Based on the results of the critical appraisal and the consensus decision reached by the appraisers, the researcher could decide which documents should be included in Phase 2 of the current study, which deals with the integration of current CPG / position statement / competency framework recommendations with South African patient journeys (described in Chapter 4). The documents included in Phase 2 were the CPG developed by Sweeney et al. (2010) and the NICU Care Path developed by Byrne et al. (2013a) and Byrne et al. (2013b).

The results of Phase 2 will be discussed in Chapter 6.

CHAPTER 6

PHASE 2: COMPARISON AND INTEGRATION OF CURRENT CPG / NICU CARE PATH RECOMMENDATIONS WITH THE SOUTH AFRICAN PATIENT JOURNEY

6.1 INTRODUCTION

In this chapter the researcher explains how the evidence-based recommendations of the CPG developed by Sweeney et al. (2010) and the NICU Care Path developed by Byrne et al. (2013a) and Byrne et al. (2013b) were integrated with the patient journeys of prematurely born infants in the South African health care system. It is important to first compare the level of evidence linked to the recommendations made in the CPG and the NICU Care Path, and then to compare the phrasing of the recommendations in those two documents. The integration of the SA patient journeys and the CPG / NICU Care Path forms part of the contextualisation process of formulating a CPG for physiotherapists in SA.

The purpose of Phase 2 was to compile a list of recommendations (from the CPG and NICU Care Path) and statements (from the coded focus group transcripts and responses to the questionnaire completed by the parents / caregivers) that were tested in Phase 3 of the study by implementing the Delphi method.

6.2 COMPARISON OF SUPPORTING EVIDENCE USED FOR MAKING RECOMMENDATIONS

Sweeney et al. (2010) included the level of evidence on which the formulation of the recommendations in the CPG was based. The researcher made use of the same hierarchy of evidence as that used by Sweeney et al. (2010), which was described in Chapter 2, section 2.2.1.1 (Table 2.1) .

The NICU Care Path (Byrne et al., 2013a; Byrne et al., 2013b) does not indicate the level of evidence for the recommendations, but does discuss the information on the basis of which the recommendations were formulated in the position statement, which enabled the researcher to identify references. The references were then linked to the recommendations, and the level of evidence for each recommendation was subsequently determined by using the hierarchy of evidence used by Sweeney et al. (2010). Some of the literature on which the NICU Care Path recommendations regarding oral-motor function and feeding were based was found in Garber's (2013) article. References made in this article were also linked to recommendations in the NICU Care Path (Byrne et al., 2013a; Byrne et al., 2013b).

The recommendations made by Sweeney et al. (2010) and references to support the recommendations, as well as the level of evidence of each reference, are presented in Table 6.1.

TABLE 6.1 RECOMMENDATIONS, REFERENCES AND LEVEL OF EVIDENCE OF REFERENCES AS DESCRIBED BY SWEENEY ET AL. (2010:13)

Type of recommendation	***Recommendation***	***Level of evidence***	***Reference***
Prevention	Collaborate with caregivers to reduce risk for skull deformity, torticollis and extremity malalignment through diligent positioning for symmetry and neutral alignment	Level II	van Vlimmeren, van der Graaf, Boere-Boonekamp, L'Hoir, Helders and Engelbert (2008)
		Level II	Vaivre-Douret, Ennouri, Jrad, Garrec and Papiernik (2004)
		Level II	Monterosso, Kristjanson, Cole and Evans (2003)
Examination	Conduct baseline observation to determine physiologic and behavioural stability (readiness) for evaluative handling	Level II	Sweeney (1986)
	Provide continuous physiologic and behavioural monitoring during and after evaluative handling to determine adaption to evaluative handling and to signal the nee for modification of pace and sequence, given expected physiologic changes, particularly during neuromotor test procedures	Level II	Sweeney (1987)
Intervention	Collaborate with caregivers to create a developmentally supportive environment with modulated stimulation from light, noise, and handling	Level I	Symington and Pinelli (2006)
		Level II	Westrup, Bohm, Lagercrantz and Stjernqvist (2004)
		Level I	Peters, Rosychuk, Hendson, Coté, McPherson and Tyebkhan (2009)
	Support body position and extremity movement in (1) supine position: semiflexed, midline alignment using blanket for swaddling containment or "nest" of positioning rolls; and (2) prone position: vertical roll under thorax; horizontal roll under hips	Level II	Vaivre-Douret et al. (2004)
		Level II	Monterosso, Kristjanson and Cole (2002)
		Level II	Short, Brooks-Brunn, Reeves, Yeager and Thorpe (1996)

		Level II	Ferrari, Bertoncelli, Gallo, Roversi, Guerra, Ranzi et al. (2007)
	In selected neonates with movement impairment or disorganisation, consider therapeutic handling carefully graded in intensity and paced to facilitate head and trunk control, antigravity movement, and midline orientation	Level II	Girolami and Campbell (1994)
	Consider gradual exposure to multimodal stimuli for stable neonates approaching hospital discharge	Level I	Symington et al. (2006)
	Provide opportunities for independent oral exploration through positioning with hands to face, and for non-nutritive sucking to improve state organisation and readiness to feed	Level I	Pinelli and Symington (2005)
	Determine readiness for and advancement of oral feeding trials using infant behavioral cues	Level II	Kirk, Alder and King (2007)
		Level II	McGrath and Medoff-Cooper (2002)
	Encourage parental involvement with feeding and provide interventions for physiologic stability (pacing and slowed flow rate)	Level III	Law-Morstatt, Judd, Snyder, Baier and Dhanireddy (2003)
		Level II	Chang, Lin, Lin and Lin (2007)
	Consider hydrotherapy before feeding for stable infants with movement impairment	Level IV	Sweeney (2003)
Education	Educate parents on behavioral cues and developmental status to mitigate parental stress and to improve parental mental health outcomes	Level II	Kaaresen, Rønning, Ulvund and Dahl (2006)
		Level I	Melnyk, Feinstein, Alpert-Gillis, Fairbanks, Crean, Sinkin et al. (2006)
	Implement multiple methods of instruction for parents and caregivers (demonstration, discussion, video, and written materials)	Level V	Dusing, Murray and Stern (2008)

See Table 6.2 below for the NICU Care Path recommendations by Byrne et al. (2013a) and Byrne et al. (2013b), with references to support the recommendations, as well as the level or evidence (determined by using the hierarchy of evidence described by Sweeney et al. (2010)).

TABLE 6.2 RECOMMENDATIONS, REFERENCES AND LEVELS OF EVIDENCE OR REFERENCES AS DESCRIBED BY BYRNE ET AL. (2013A) AND BYRNE ET AL. (2013B)

Type of recommendation	***Recommendation***	***Level of evidence***	***Reference***
Observation and assessment *Observation:*	Behavior (e.g. state transition, NIDCAP, tolerance or routine care) (24–>40 weeks) (Postmenstrual age (PMA))	Level V	Campbell (1999)
		NIDCAP:	
		Level I	Als, Duffy, McAnulty, Rivkin, Vajapeyam, Mulkern et al. (2004)
	Vital signs (e.g. HR, temp, O_2, pain: BIIP, PIPP) (24–>40 weeks PMA)	Level V	Duhn and Medves (2004)
		Pain:	
		Level I	Holsti, Grunau, Oberlander, Whitfield and Weinberg (2005)
		Level V	Holsti, Grunau and Shany (2011)
		Level IV	Grunau, Whitfield, Fay, Holsti, Oberlander and Rogers (2006)
		Level II	Holsti and Grunau (2007)
		Level IV	Ahn and Jun (2007)
		Level IV	Morison, Holsti, Grunau, Whitfield, Oberlander, Chan et al. (2003)
		Pain & KMC:	
		Level II	Johnston, Stevens, Pinelli, Gibbins, Filion, Jack et al. (2003)
	Screen the musculoskeletal system by observing the infants' spontaneous movements (24–31 weeks PMA)	Level V	Byrne et al. (2013a)
		Level V	Sweeney and Gutierrez (2002)
	General movement assessment (GMA) (30–>40 weeks PMA)	Level V	Einspieler and Prechtl (2004)
		Level II	Snider, Majnemer, Mazer, Campbell and Bos (2008)
		Level V	Noble and Boyd (2012)
		Level IV	Prechtl, Einspieler, Cioni, Bos, Ferrari and Sontheimer (1997)

		Level IV	Ferrari, Cioni, Einspieler, Roversi, Bos, Paolicelli et al. (2002)
		Level V	Cioni, Einspieler and Paolicelli (2007)
Limited hands-on assessment:	Diaper change (24–31 weeks PMA)	Level V	Byrne et al. (2013a)
	Re-positioning (24–31 weeks PMA)	Level IV	Heimler, Langlois, Hodel, Nelin and Sasidharan (1992)
		Level IV	Levy, Habib, Liptsen, Singh, Kahn, Steele et al. (2006)
		Level V	Sweeney et al. (2002)
		Level IV	Grenier, Bigsby, Vergara and Lester (2003)
		Level V	Najarian (1999)
		Level V	Neufeld and Birkett (2000)
	Gentle facilitated movement (30–34 weeks PMA)	Level V	Byrne et al. (2013a)
	Recoils and scarf sign (30–40 weeks PMA)	Level IV	Dubowitz, Dubowitz and Goldberg (1970)
		Level V	Dubowitz, Dubowitz and Mercuri (1999)
		Level IV	Allen and Capute (1990)
		Level V	Amiel-Tison (1968)
		Level IV	Lekskulchai and Cole (2000)
		Level IV	Cole and Lekskulchai (2000)
	Palmar and plantar grasp (28–40 weeks PMA)	Level IV	Futagi, Suzuki and Goto (1999)
		Level IV	Zafeiriou (2000)
		Level V	Schott and Rossor (2003)
	Non-nutritive sucking (30–34 weeks PMA)	Level II	Neiva, Leone and Leone (2008)
		Level I	Elserafy, Alsaedi, Louwrens, Sadiq and Mersale (2009)
		Level V	Garber (2013)

Full hands-on assessment:	Standardised testing (e.g. TIMPSI, TIMP, NAPI, NANI, NBO) (32–>40 weeks PMA)	Level IV	Barbosa, Campbell, Smith and Berbaum (2005)
		Level IV	Campbell, Swanlund, Smith, Liao and Zawacki (2008)
		Level IV	Campbell, Levy, Zawacki and Liao (2006a)
		Level II	Girolami et al. (1994)
		Level I	Lekskulchai and Cole (2001)
		Level IV	Kolobe, Bulanda and Susman (2004)
		Level V	Dubowitz et al. (1999)
		Level IV	Dubowitz, Dubowitz, Palmer, Miller, Fawer and Levene (1984)
		Level IV	Molteno, Grosz, Wallace and Jones (1995)
		Level V	Korner (2000)
		Level IV	Korner, Guilleminault, Van den Hoed and Baldwin (1978)
		Level V	Majnemer and Snider (2005a)
		Level II	Snider, Tremblay, Limperopoulos, Majnemer, Filion and Johnston (2005)
		Level V	Nugent (2007)
		Level V	Sanders and Buckner (2006)
		Level V	Noble et al. (2012)
	Oral-motor control and feeding assessment (e.g. NOMAS, PIBBS, NCAFS) (32–>40 weeks PMA)	Level V	Sheppard and Fletcher (2007)
		Level IV	Vice and Gewolb (2008)
		Level IV	Howe, Sheu, Hinojosa, Lin and Holzman (2007b)
		Level IV	Howe, Sheu, Hsieh and Hsieh (2007a)

		Level II	da Costa and van der Schans (2008)
		Level IV	DeMatteo, Matovich and Hjartarson (2005)
		Level IV	Mizuno and Ueda (2005)
		Level IV	Nyqvist (2008)
		Level V	Nyqvist, Rubertsson, Ewald and Sjödén (1996)
		Level V	Scanlon, Alexander, Serdula, Davis and Bowman (2002)
		Level V	Palmer, Crawley and Blanco (1993)
		Level IV	Hodges, Houck and Kindermann (2007)
		Level IV	Case-Smith, Cooper and Scala (1989)
		Level V	Palmer and Heyman (1999)
		Level V	Sumner and Spietz (1995)
		Level I	Badr, Garg and Kamath (2006)
Sensory assessment: Vision / Hearing	Visual focus (32–>40 weeks PMA)	Level II	White-Traut, Nelson, Silvestri, Vasan, Littau, Meleedy-Rey et al. (2002)
		Level V	Graven (2004)
	Visual tracking (32–>40 weeks PMA)	Level V	Avery, MacDonald, Seshia and Mullett (2005)
	Auditory localisation and orientation (32–>40 weeks PMA)	Level V	Hall (2000)
		Level V	Avery et al. (2005)
		Level V	Graven (2000)
		Level II	Caskey, Stephens, Tucker and Vohr (2011)
Intervention *Facilitate calm state and motor organisation*	Assist with non-nutritive sucking (NNS), containment, skin-to-skin care, and positioning (may include hydrotherapy) (24–>40 weeks PMA)	*Physiological stability*:	
		Level II	Buehler, Als, Duffy, McAnulty and Liederman (1995)
		Organised state:	
		Level I	Als (1994)
		NNS:	

		Level II	Kirk et al. (2007)
		Level II	Boiron, Nobrega, Roux, Henrot and Saliba (2007)
		Positioning:	
		Level I	Axelin, Salanterä, Kirjavainen and Lehtonen (2009)
		Level IV	Neu and Browne (1997)
		Level II	Short et al. (1996)
		Level IV	Heimler et al. (1992)
		Level IV	Corvaglia, Rotatori, Ferlini, Aceti, Ancora and Faldella (2007)
		Level IV	Grenier et al. (2003)
		Level II	Ferrari et al. (2007)
		Skin-to-skin (KMC):	
		Level IV	Föhe, Kropf and Avenarius (2000)
		Level II	Bier, Ferguson, Morales, Liebling, Archer, Oh et al. (1996)
		Level II	Wahlberg, Affonso and Persson (1992)
		Level II	Feldman, Weller, Eidelman and Sirota (2002)
		Hydrotherapy:	
		Level V	Tinti, Somera, Valente and Domingos (2010)
		Level V	Pechter, Maaroos, Mesikepp, Veraksits and Ots (2003)
		Level II	Pechter, Ots, Mesikepp, Zilmer, Kullissaar, Vihalemm et al. (2003)
		Level IV	Sweeney (1983)
		Level IV	Sweeney (2003)
Positioning and handling	* Evidence supporting '*Positioning and Handling* (may include hydrotherapy for medically stable infants typically at least 32 weeks postmenstrual age)'	*Supportive positioning:*	
		Level V	Campbell, Palisano and Orlin (2012)
		Level II	Grant-Beuttler, Reddien, Miller, Palisano, Heriza, Shewokis et al. (2006)

		Tone development:	
		Level IV	Allen et al. (1990)
		Position:	
		Level V	Sweeney et al. (2002)
	Address head shaping and musculoskeletal integrity (24–37 weeks PMA)	Level V	Sweeney et al. (2002)
		Level II	Vaivre-Douret et al. (2004)
		Level V	Najarian (1999)
		Level V	Neufeld et al. (2000)
		Level II	van Vlimmeren et al. (2008)
		Level V	McManus and Capistran (2008)
	Promote comfort and respiratory function, including skin-to-skin care (24–34 weeks PMA)	*Skin-to-skin benefits respiratory function:*	
		Level V	Cleary, Spinner, Gibson and Greenspan (1997)
		Respiratory function:	
		Level IV	Heimler et al. (1992)
		Level IV	Levy et al. (2006)
		Level I	Axelin et al. (2009)
	Promote skin integrity (assist with scar management) (24–37 weeks PMA)	*Skin integrity:*	
		Level IV	Marcellus (2004)
		Scar management:	
		Level I	O'Brien and Pandit (2006)
		Level IV	Karagoz, Yuksel, Ulkur and Evinc (2009)
		Level IV	Sakuraba, Takahashi, Akahoshi, Miyasaka and Suzuki (2011)
		Level IV	Wigger-Albert, Kuhlmann, Wilhelm, Mrowietz, Eichhorn, Ortega et al. (2009)
		Level IV	Engrav, Heimbach, Rivara, Moore, Wang, Carrougher et al. (2010)
		Level I	Li-Tsang, Zheng and Lau (2010)
	Promote contained movement (24–34 weeks PMA)	*Contained movement*:	
		Level IV	de Vries and Bos (2010)
		Level V	Prechtl (1990)
		Nested support:	
		Level II	Ferrari et al. (2007)

	Provide gentle range of motion as indicated (splinting as needed) (32–>40 weeks PMA)	*Contra-indications*:	
		Level IV	Dabezies and Warren (1997)
		Level V	Weinstein (1994)
	Facilitate periods of exploratory movement (35–>40 weeks)	Level V	Byrne et al. (2013b)
		Benefits:	
		Level IV	van Wijk, Benninga, Dent, Lontis, Goodchild, McCall et al. (2007)
		Level IV	Bhat, Leipälä, Singh, Rafferty, Hannam and Greenough (2003)
	Promote alerting and interaction (e.g. Auditory Tactile Visual Vestibular (ATVV)) (35–>40 weeks PMA)	*Calm alert state:*	
		Level V	Brazelton and Nugent (1995)
		ATVV program:	
		Level IV	White-Traut, Nelson, Silvestri, Cunningham and Patel (1997)
		Level II	White-Traut, Nelson, Silvestri, Patel and Kilgallon (1993)
		Level II	White-Traut et al. (2002)
Movement therapy Facilitate development and strength through:	Guided extremity movements (allow infant to push against you) (32–>40 weeks PMA)	*Joint molding (as normally occurs in utero):*	
		Level V	Sweeney et al. (2002)
		Decrease bone demineralisation:	
		Level I	Litmanovitz, Dolfin, Friedland, Arnon, Regev, Shainkin-Kestenbaum et al. (2003)
		Level I	Moyer-Mileur, Brunstetter, McNaught, Gill and Chan (2000)
	Increased time in upright position (35–>40 weeks PMA)	*Supported sitting:*	
		Level V	Tecklin (1994)
		Level V	Byrne et al. (2013b)
		Positions after discharge:	
		Level IV	Bartlett and Kneale Fanning (2003)
	Varied developmental positions	*Varied holding positions:*	

	(32–>40 weeks PMA)	Level V	Hummel and Fortado (2005)
		Level V	Byrne et al. (2013b)
		Varied play positions:	
		Level IV	Majnemer and Barr (2005b)
		Level IV	Dudek-Shriber and Zelazny (2007)
		Level IV	Fetters and Huang (2007)
		Infrequent prone position:	
		Level IV	Murney and Campbell (1998)
		Level IV	Kennedy, Majnemer, Farmer, Barr and Platt (2009)
	Enhancement of trunk mobility and diaphragmatic breathing (35–>40 weeks PMA)	*Support lung function*:	
		Level II	Friedrich, Stein, Pitrez, Corso and Jones (2006)
		Level II	Hutten, van Eykern, Latzin, Thamrin, van Aalderen and Frey (2010)
		Level V	Byrne et al. (2013b)
		Level IV	Dimitriou, Greenough, Pink, McGhee, Hickey and Rafferty (2002)
		Positioning effect on gastric emptying and reflux:	
		Level IV	van Wijk et al. (2007)
	Promotion of antigravity movements (35–>40 weeks PMA)	*Antigravity movements:*	
		Level II	Green, Mulcahy and Pountney (1995)
		Level II	Fallang, Saugstad, Grogaard and Hadders-Algra (2003b)
		Level II	Heathcock, Bhat, Lobo and Galloway (2004)
		Level IV	Heathcock, Bhat, Lobo and Galloway (2005)
		Level II	Dusing, Mercer, Yu, Reilly and Thorpe (2005)
		Level I	Fallang, Saugstad and Hadders-Algra (2003a)

		Level I	Heathcock and Galloway (2009)
		Level II	Heathcock, Lobo and Galloway (2008)
		Level II	Jeng, Chen, Tsou, Chen and Luo (2004)
		Level IV	Luo, Chen, Hsieh, Lin, Lu, Chen et al. (2009)
		Supine, prone and supported sitting antigravity movement:	
		Level I	Heathcock et al. (2009)
		Level V	Bly (1999)
		Level V	Boehme and Boehme (1990)
	Neurodevelopmental techniques (e.g. NDT) (35–>40 weeks PMA)	Level II	Girolami et al. (1994)
		Level V	Sweeney et al. (2010)
Oral motor Facilitate oral-motor organisation and functional oral feeding through:	Oral stimulation and non-nutritive sucking during gavage feedings (30–34 weeks PMA)	Level I	Fucile, Gisel and Lau (2005)
		Level II	Hill (2005)
		Level II	White-Traut et al. (2002)
		Level II	Bernbaum, Pereira, Watkins and Peckham (1983)
		Level II	Boiron et al. (2007)
		Level IV	De Curtis, McIntosh, Ventura and Brooke (1986)
		Level I	Ernst, Rickard, Neal, Yu, Oei and Lemons (1989)
		Level I	Field, Ignatoff, Stringer, Brennan, Greenberg, Widmayer et al. (1982)
		Level IV	Woodson and Hamilton (1988)
		Level V	Dougherty and Luther (2008)
		Level II	Kirk et al. (2007)
		Level I	Pinelli et al. (2005)
		Level V	Arvedson, Clark, Lazarus, Schooling and Frymark (2010)

		Level I	Howard, Howard, Lanphear, Eberly, deBlieck, Oakes et al. (2003)
		Level I	Jenik, Vain, Gorestein, Jacobi, Pacifier and Breastfeeding Trial (2009)
		Level I	Collins, Ryan, Crowther, McPhee, Paterson and Hiller (2004)
	Initiate nutritive sucking with small amounts of breast milk or formula (30–34 weeks PMA)	Level II	Pickler and Reyna (2003)
		Level I	Simpson, Schanler and Lau (2002)
		Level V	Byrne et al. (2013a)
		Level IV	Pickler, Best, Reyna, Wetzel and Gutcher (2005)
			Characteristics of nutritive sucking as opposed to non-nutritive sucking:
		Level I	Wolff (1968)
		Level V	Mathew (1991)
		Level V	Miller and Kang (2007)
		Level V	Lau and Kusnierczyk (2001)
		Level IV	Amaizu, Shulman, Schanler and Lau (2008)
		Level IV	Lau, Alagugurusamy, Schanler, Smith and Shulman (2000b)
		Level V	Arvedson et al. (2010)
		Level IV	Pickler and Reyna (2004)
	Nutritive sucking and small volume nipple feeding 1-2x/day (32–37 weeks PMA)	Level I	Fucile et al. (2005)
		Level I	Pickler, Best, Reyna, Gutcher and Wetzel (2006)
		Level II	Pickler et al. (2003)

			Evidence supporting benefits of early introduction of nutritive sucking:
		Level I	Bragelien, Røkke and Markestad (2007)
		Level IV	Pickler, Mauck and Geldmaker (1997)
		Level IV	Blackwell, Eichenwald, McAlmon, Petit, Linton, McCormick et al. (2005)
		Level IV	Dodrill, Donovan, Cleghorn, McMahon and Davies (2008)
		Level IV	Pickler et al. (2006)
		Level I	Simpson et al. (2002)
		Level II	Pickler et al. (2003)
			Feeding readiness behaviours:
		Level V	McGrath and Braescu (2004)
		Level I	Simpson et al. (2002)
		Level I	Fucile et al. (2005)
		Level II	Kirk et al. (2007)
		Level V	Reyna, Pickler and Thompson (2006)
		Level I	White-Traut, Berbaum, Lessen, McFarlin and Cardenas (2005)
		Level V	Byrne et al. (2013a)
		Level II	da Costa et al. (2008)
		Level IV	Howe et al. (2007a)
			Techniques for introduction of small-volume nutritive sucking:
		Level III	Law-Morstatt et al. (2003)
		Level V	Premji, McNeil and Scotland (2004)
		Level IV	Bu'Lock, Woolridge and Baum (1990)
		Level IV	Gryboski (1969)
		Level IV	Mathew (1988)

		Level IV	Palmer et al. (1993)
		Level IV	Thoyre and Carlson (2003)
		Level IV	Clark, Kennedy, Pring and Hird (2007)
		Level V	McGrath et al. (2004)
		Level V	Updike, Schmidt, Macke, Cahoon and Miller (1986)
		Level V	Dougherty et al. (2008)
		Level II	Marinelli, Burke and Dodd (2001)
		Level IV	Mizuno and Kani (2005)
		Level I	Collins, Makrides, Gillis and McPhee (2008)
		Level I	Hawes, McEwan and McGuire (2004)
		Level V	Peter, Wiechers, Bohnhorst, Silny and Poets (2002)
		Level IV	Shiao and DiFiore (1996)
			Differences between breastfeeding and bottle feeding:
		Level IV	Mizuno and Ueda (2006)
		Level IV	Furman and Minich (2004)
		Level V	Nyqvist et al. (1996)
		Level V	Byrne et al. (2013a)
	Gradual increase in frequency, volume and duration of nipple feedings (32–37 weeks PMA)	Level IV	Howe et al. (2007b)
		Level V	McGrath et al. (2004)
		Level V	Ross and Browne (2002)
			Characteristics of nipples and bottles:
		Level II	Schrank, Al-Sayed, Beahm and Thach (1998)
		Level II	Chang et al. (2007)
		Level IV	Lau and Schanler (2000a)
		Level V	Dougherty et al. (2008)

		Level IV	Scheel, Schanler and Lau (2005)
		Level IV	Mizuno, Ueda and Takeuchi (2002)
		Level V	Vandenplas, Rudolph, Di Lorenzo, Hassall, Liptak, Mazur et al. (2009)
			Evidence supporting benefits of intervention measures to assist nipple feeding:
		Level II	Boiron et al. (2007)
		Level II	Einarsson-Backes, Deitz, Price, Glass and Hays (1994)
		Level IV	Hill, Kurkowski and Garcia (2000)
		Level IV	Lau et al. (2000a)
		Level III	Law-Morstatt et al. (2003)
		Level V	Medoff-Cooper (2005)
		Level IV	Amaizu et al. (2008)
		Level V	McGrath et al. (2004)
		Level V	Ross et al. (2002)
		Level I	Bragelien et al. (2007)
		Level V	Garber (2013)
		Level V	Byrne et al. (2013a)
		Level IV	Hodges et al. (2007)
	Progression to autonomous breast or nipple feeding (35–40 weeks PMA)	Level IV	Bakewell-Sachs, Medoff-Cooper, Escobar, Silber and Lorch (2009)
			Evidence supporting the benefits of a gradual transition from gavage to nipple feeding:
		Level IV	Pickler et al. (2005)
		Level I	Simpson et al. (2002)
		Level I	McCain, Gartside, Greenberg and Lott (2001)
		Level IV	Lucas, King and Bishop (1992)
		Level II	Kirk et al. (2007)

		Level I	McCormick, Tosh and McGuire (2010)
Family support and education	* Evidence supporting all recommendations for 'Family Support and Education'	*Level V *Level V	Byrne et al. (2013b) Blauw-Hospers and Hadders-Algra (2007)
	Infant behaviour and cues (parent facilitates transition between states and recognises infant's readiness for feeding and play) (24–40 weeks PMA)	*Level I *Level I	Heathcock et al. (2009) Heathcock et al. (2008)
	Promote skin-to-skin holding and parent-infant touch (24–34 weeks PMA)		
	Promote social interaction and graded stimulation (32–>40 weeks PMA)		
	Facilitate participation in care and graded handling (28–>40 weeks PMA)		
	Provide guidance regarding oral stimulation and non-nutritive sucking during gavage feedings (30–34 weeks PMA)		
	Provide guidance regarding neonatal sucking of small volumes (<10 cc or <10 min) from bottle or syringe in nipple 1–2 x/day (32–37 weeks PMA)		
	Provide guidance and support to gradually increase volume and frequency of nipple feeding (35–>40 weeks PMA)		
	Provide developmental progress updates, explain need for age correction (32–>40 weeks PMA)		
	Provide guidance in movement exercises (32–>40 weeks PMA)		
	Provide guidance in active developmental activities (prone, supine, side lying, supported sit, equipment instruction e.g. supportive seats) (32–>40 weeks PMA)		
	Provide information on community resources for transition to home (35–>40 weeks PMA)		

	Provide instruction regarding a developmental home program (35–>40 weeks PMA)		
Team collaboration	* Evidence supporting all recommendations for 'Team Collaboration'	*Level V *Level V	Byrne et al. (2013b) Barbosa (2013)
	Suggest positioning aids and developmental supports (24–34 weeks PMA)		
	Progress of developmental program and update plan of care (include NIDCAP assessment results and nursing role) (28–>40 weeks PMA)		
	Progress from oral stimulation program to functional nipple feeding (24–>40 weeks PMA)		
	Collaborate with parents (ongoing) (provide anticipatory guidance) (24–>40 weeks PMA)		
	Solicit RN observations of behaviour / developmental status (24–>40 weeks PMA)		
	Assess parent needs for medical and ancillary support (e.g. lactation, social work, physician, psychiatric) (24–>40 weeks PMA)		
	Assess infant need for consultation (e.g. OT, SLP, infant development specialist, other medical professionals) (24–>40 weeks PMA)		
	Participate in d/c planning (24–>40 weeks PMA)		

* Evidence linked to the main types of recommendations, and not necessarily to a specific recommendation

Some references and levels of evidence were found in both Sweeney et al. (2010) CPG and the NICU Care Path described by Byrne et al. (2013a) and Byrne et al. (2013b). The references found in both documents are listed in Table 6.3, which makes it possible to compare the recommendations linked to the references with the levels of evidence. The researcher had to compare the references in the two documents as part of the contextualisation process.

The colours in Table 6.3 link the recommendations with references found in both documents. The corresponding recommendations found in these two documents differed in respect of phrasing, but addressed the same aspect of the management of prematurely born infants.

TABLE 6.3 REFERENCES FOUND IN BOTH THE CLINICAL PRACTICE GUIDELINE (SWEENEY ET AL. 2010) AND NICU CARE PATH (BYRNE ET AL., 2013A; BYRNE ET AL., 2013B)

Heading under which the recommendation was found in the CPG or NICU Care Path	***Recommendation***	***Level of evidence***	***Reference***
Prevention *(Sweeney et al., 2010)*	Collaborate with caregivers to reduce risk for skull deformity, torticollis and extremity malalignment through diligent positioning for symmetry and neutral alignment	Level II	van Vlimmeren et al. (2008)
		Level II	Vaivre-Douret et al. (2004)
Intervention *Positioning and Handling* (may include hydrotherapy for medically stable infants typically at least 32 weeks postmenstrual age) *(Byrne et al., 2013b)*	Address head shaping and musculoskeletal integrity (24–37 weeks PMA)	Level II	van Vlimmeren et al. (2008)
		Level II	Vaivre-Douret et al. (2004)
Intervention *(Sweeney et al., 2010)*	Support body position and extremity movement (1) sup position: semi-flexed, midline alignment using blanket swaddling containment or "nest" of positioning rolls; ar (2) prone position: vertical roll under thorax; horizontal under hips	Level II	Vaivre-Douret et al. (2004)
Intervention *Positioning and Handling* (may include hydrotherapy for medically stable infants typically at least 32 weeks postmenstrual age) *(Byrne et al., 2013b)*	Address head shaping and musculoskeletal integrity (24–37 weeks PMA)	Level II	Vaivre-Douret et al. (2004)

Intervention *(Sweeney et al., 2010)*	Support body position and extremity movement (1) supine position: semi-flexed, midline alignment using blanket for swaddling containment or "nest" of positioning rolls; and (2) prone position: vertical roll un thorax; horizontal roll under hips	Level II	Short et al. (1996)
		Level II	Ferrari et al. (2007)
Intervention *Facilitate calm state and motor organisation* *(Byrne et al., 2013b)*	Assist with non-nutritive suck (NNS), containment, skin-to-skin care, and positioning (may include hydrotherapy) (24–>40 weeks PMA)	Level II	*Positioning*: Short et al. (1996)
		Level II	Ferrari et al. (2007)
Intervention *Positioning and Handling* (may include hydrotherapy for medically stable infants typically at least 32 weeks postmenstrual age) *(Byrne et al., 2013b)*	Promote contained movement (24–34 weeks PMA)	Level II	*Nested support:* Ferrari et al. (2007)
Intervention *(Sweeney et al., 2010)*	In selected neonates with movement impairment or disorganisation, consider therapeutic handling carefully graded in intensity and paced to facilitate head and trunk control, antigravity movement, and midline orientation	Level II	Girolami et al. (1994)
Observation and assessment *Full hands-on assessment:* *(Byrne et al., 2013a)*	Standardised testing (e.g. TIMPSI, TIMP, NAPI, NANI, NBO) (32–>40 weeks PMA)	Level II	Girolami et al. (1994)

Intervention *Movement therapy* Facilitate development and strength through: *(Byrne et al., 2013b)*	Neurodevelopmental techniques (e.g. NDT) (35–>40 weeks PMA)	Level II	Girolami et al. (1994)
Intervention *(Sweeney et al., 2010)*	Provide opportunities for independent oral exploration through positioning with hands to face, and for nonnutritive sucking to improve state organisation and readiness to feed	Level I	Pinelli et al. (2005)
Intervention *Oral motor* Facilitate oral-motor organisation and functional oral feeding through: *(Byrne et al., 2013b)*	Oral stimulation and non-nutritive sucking during gavage feedings (30–34 weeks PMA)	Level I	Pinelli et al. (2005)
Intervention *(Sweeney et al., 2010)*	Determine readiness for and advancement of oral feeding trials using infant behavioral cues	Level II	Kirk et al. (2007)
Intervention *Facilitate calm state and motor organisation* *(Byrne et al., 2013b)*	Assist with non-nutritive suck (NNS), containment, skin-to-skin care, and positioning (may include hydrotherapy) (24–>40 weeks PMA)	Level II	*NNS*: Kirk et al. (2007)
Intervention *Oral motor* Facilitate oral-motor organisation and functional oral feeding through: *(Byrne et al., 2013b)*	Oral stimulation and non-nutritive sucking during gavage feedings (30–34 weeks PMA)	Level II	Kirk et al. (2007)

Intervention *Oral motor* Facilitate oral-motor organisation and functional oral feeding through: *(Byrne et al., 2013b)*	Nutritive sucking and small volume nipple feeding 1–2x/day (32–37 weeks PMA)	Level II	*Feeding readiness behaviours:* Kirk et al. (2007)
Intervention *Oral motor* Facilitate oral-motor organisation and functional oral feeding through: *(Byrne et al., 2013b)*	Progression to autonomous breast or nipple feeding (35–40 weeks PMA)	Level II	*Evidence supporting the benefits of a gradual transition from gavage to nipple feeding:* Kirk et al. (2007)
Intervention *(Sweeney et al., 2010)*	Encourage parental involvement with feeding and provide interventions for physiologic stability (pacing and slowed flow rate)	Level III	Law-Morstatt et al. (2003)
		Level II	Chang et al. (2007)
Intervention *Oral motor* Facilitate oral-motor organisation and functional oral feeding through: *(Byrne et al., 2013b)*	Gradual increase in frequency, volume and duration of nipple feedings (32–37 weeks PMA)	Level II	*Characteristics of nipples and bottles:* Chang et al. (2007)
		Level III	*Evidence supporting benefits of intervention measures to assist nipple feeding:* Law-Morstatt et al. (2003)

Intervention *Oral motor* Facilitate oral-motor organisation and functional oral feeding through: *(Byrne et al., 2013b)*	Nutritive sucking and small volume nipple feeding 1-2x/day (32–37 weeks PMA)	Level III	*Techniques for introduction of small-volume nutritive sucking:* Law-Morstatt et al. (2003)
Intervention *(Sweeney et al., 2010)*	Consider hydrotherapy before feeding for stable infants with movement impairment	Level IV	Sweeney (2003)
Intervention *Facilitate calm state and motor organisation (Byrne et al., 2013b)*	Assist with non-nutritive suck (NNS), containment, skin-to-skin care, and positioning (may include hydrotherapy) (24–>40 weeks PMA)	Level IV	*Hydrotherapy*: Sweeney (2003)

The recommendations listed by Byrne et al. (2013a) and Byrne et al. (2013b) in their NICU Care Path were similar to those listed in the CPG by Sweeney et al. (2010). In both cases the references linked to recommendations were also similar. Recommendations listed in Table 6.3 that addressed similar topics could therefore be grouped together in the questionnaire that was compiled by the researcher and used in the first round of the Delphi method in Phase 3 of this study. The researcher's comparison of the phrasing of all the recommendations listed in the CPG (Sweeney et al., 2010) and NICU Care Path (Byrne et al., 2013a; Byrne et al., 2013b) will be discussed in the following section.

6.3 COMPARISON BETWEEN THE PHRASING OF RECOMMENDATIONS MADE IN THE CLINICAL PRACTICE GUIDELINE AND THE NEONATAL INTENSIVE CARE UNIT CARE PATH

The phrasing of recommendations for physiotherapy management of the prematurely born infant in the NICU, as described in the CPG (Sweeney et al., 2010) and the NICU Care Path (Byrne et al., 2013a; Byrne et al., 2013b) had to be compared and integrated with each other as part of the contextualisation process.

This process further required the abovementioned recommendations to be integrated with patient journeys in the context of health care in SA. The researcher found that the evidenced-based recommendations specific to the physiotherapist's management of prematurely born infants, described in the CPG and the NICU Care Path, provided more details regarding the physiotherapy management of prematurely born infants than had been derived from the focus group discussions and key informant interviews (Phase 1 of the study). However, the results of the focus group discussions, key informant interviews and parent and caregiver questionnaire (Phase 1 of the current study) did enable the researcher to identify unique aspects of care that related specifically to the South African health care context, which had not been incorporated in either the CPG or NICU Care Path.

The researcher and her supervisors therefore decided to combine the CPG and NICU Care Path (Phase 2) recommendations with statements derived from the unique aspects of care in the SA health care context (results of Phase 1), and to validate the re-compiled recommendations by applying the Delphi method (Phase 3) to obtain the opinions of physiotherapists who were, at the time of the study, working in NICUs, HCUs or KMC wards in SA. The combined recommendations and statements relating to the physiotherapy management of a prematurely born infant were listed in the form of a questionnaire, which is presented in Tables 6.4, 6.5 and 6.6. The questionnaire was divided into three parts. Part I (Hospital setting) and Part II (MDT members) both included statements from the focus group discussions and key informant interviews (Phase 1 of the current study), which will be discussed in the following section.

Part III (Physiotherapy management of the infant) of the questionnaire consisted of the combined recommendations (CPG / NICU Care Path) and statements made during the focus group discussions and key informant interviews. The recommendations and statements were divided into the following sections: (i) Assessment; (ii) Prevention; (iii) Intervention; (iv) Parental / Caregiver education; (v) Holistic family care; (vi) Professional / ethical conduct of the physiotherapist; and (vii) Education and knowledge of the physiotherapist.

The references and levels of evidence linked to the recommendations were not added to the questionnaire used in the Delphi method, but were added to the recommendations included in the final product of the study, namely the CPG for physiotherapists managing prematurely born infants in NICUs, HCUs or KMC wards.

TABLE 6.4 RECOMMENDATIONS AND STATEMENTS LISTED IN PART III OF THE FIRST ROUND OF THE DELPHI QUESTIONNAIRE

Statement or recommendation	***Statement derived from focus group discussions or key informant interviews***	***Recommendations derived from CPG (Sweeney et al., 2010) and / or NICU Care Path (Byrne et al., 2013a; Byrne et al., 2013b)***
Statements or recommendations relating to assessment		
1. Screening of the infant in the NICU, HCU or KMC ward by the physiotherapist as member of the MDT could lead to early detection of impairments as well as anticipation of impairments that could arise after discharge from hospital.	✓	
2. The physiotherapist conducts a baseline observation to determine the infant's physiological and behavioural stability or readiness for evaluative handling before assessment.		✓
3. The physiotherapist does a limited hands-on assessment during the infant's diaper change or re-positioning and assesses the recoils and scarf sign.		✓
4. The physiotherapist does a limited hands-on assessment during the infant's diaper change or re-positioning and assesses the palmar and plantar grasp.		✓
5. The physiotherapist does a limited hands-on assessment during the infant's diaper change or re-positioning and assesses the non-nutritive sucking.		✓
6. The physiotherapist does a sensory assessment of the physiologically stable infant in the NICU, HCU or KMC ward to determine visual focus, tracking and auditory localisation and orientation.		✓
7. The physiotherapist makes use of the following assessment tool for infants in the NICU, HCU or KMC ward:		
- Bayley scale	✓	
- Movement ABCs	✓	
- Alberta infant scale	✓	
- Clinical observation (as the only method of assessment)	✓	
- Brazelton Neonatal Behavioural Assessment	✓	
- Prechtl's analysis	✓	
- Developmental or milestone chart	✓	
- Test of Infant Motor Performance Screening Items (TIMPSI)		✓
- Test of Infant Motor Performance (TIMP)		✓

- Neurologic Assessment of the Preterm and Full Term Newborn Infant (NANI)		✓
- Neurobehavioural Assessment of the Preterm Infant (NAPI)		✓
- Newborn Behavioural Observations (NBO)		✓
8. The physiotherapist continuously monitors the infant's physiological and behavioural status during and after assessments in order to know what adaptations are necessary during future evaluative handling with regard to the pace and sequence of handling, especially during neuro-motor assessment.		✓
Statements or recommendations relating to prevention		
1. The physiotherapist as member of the MDT monitors the respiratory function of the intubated or non-intubated infant in the NICU or HCU and will treat if indicated.	✓	
2. The physiotherapist collaborates with other MDT members to monitor the intubated or non-intubated infant in order to reduce the risk of skull deformity, torticollis and extremity malalignment through diligent symmetrical and neutral alignment and positioning to support neurodevelopment in the NICU or HCU.		✓
3. The physiotherapist as member of the MDT should monitor the effect of the environmental, social and chemical stressors on the infant in the NICU or HCU to avoid overstimulation and other complications.	✓	
4. The physiotherapist observes feeding assessments done by nursing practitioners or speech therapists in order to do respiratory care (e.g. suction of the infant) in case the infant aspirates.	✓	
5. The physiotherapist takes special care to implement sterile procedures in the NICU or HCU to prevent cross infection to the infant who has an underdeveloped immune system.	✓	
Statements or recommendations relating to intervention		
1. The physiotherapist is aware of the indications and contra-indications of physiotherapy interventions given to infants in the NICU, HCU or KMC ward.	✓	
2. The physiotherapist incorporates the view or opinion of the parents or caregivers of the infant when considering a treatment plan for the infant to empower the parents or caregivers.	✓	
3. The physiotherapist plans the timing of the intervention to accommodate the care routine and the infant's resting periods in the NICU, HCU or KMC ward.	✓	

4. The physiotherapist supports the infant's body position and extremity movement in (a) supine position through 'nesting' of the infant in a semi flexed, midline aligned position and (b) prone position with a vertical roll under the thorax and / or horizontal roll under hips.		✓
5. The physiotherapist facilitates the infant's independent oral exploration through positioning of hands to the face for non-nutritive sucking that could improve organisation and readiness for feeding.		✓
6. The physiotherapist enhances trunk mobility and diaphragmatic breathing in the physiologically stable infant in the NICU, HCU or KMC ward.		✓
7. The physiotherapist facilitates increased time in upright positions and includes guided antigravity extremity movement in the treatment of the physiologically stable infant in the NICU, HCU or KMC ward.		✓
8. The physiotherapist identifies the infants in the NICU, HCU or KMC ward with movement impairment or disorganisation s/he carefully incorporates graded intensity and paced facilitation of head and trunk control, antigravity movement and midline orientation.		✓
9. The physiotherapist performs hydrotherapy before feeding of the physiologically stable infant with movement impairment in the NICU, HCU or KMC ward if indicated.		✓
10. The physiotherapist as member of the MDT has a role in facilitating KMC (skin-to-skin contact) to improve parent or caregiver bonding with the infant in the NICU, HCU or KMC ward.	✓	
11. The physiotherapist introduces gradual exposure to multimodal stimuli for physiologically stable infants in the NICU, HCU or KMC ward approaching discharge from hospital.		✓
12. The physiotherapist anticipates potential complications that could occur and prioritises preventative management / intervention in the treatment plan of the infant in the NICU, HCU or KMC ward.	✓	
Statements or recommendations relating to parental / caregiver education		
1. Parent or caregiver education includes:		
- Benefits of KMC	✓	
- The impact of environmental stressors (e.g. noise, light and handling) in the NICU or HCU on the infant	✓	
- How to interpret the infant's physiological and behavioural cues during care and management		✓
- Information of developmental milestones (n=19)	✓	
- Meaning of terminology like corrected age		✓

- What active developmental activities to do as a home program		✓
- How to use positioning equipment e.g. supportive seats		✓
- Information on the importance of short-term follow-up assessments by the MDT up to one to two years post-corrected age to identify potential impairments / complications	✓	
2. The physiotherapist is sensitive to adapt the amount and depth of information or education to the parents or caregivers of the infant not to overwhelm the parents or caregivers.	✓	
3. The physiotherapist adapts the information or education format (e.g. verbally, physical demonstrations, pamphlets or internet-based information) to the level of the parent's or caregiver's understanding and in case of a language barrier.	✓	
Statements or recommendations relating to holistic family care		
1. As part of holistic family care the physiotherapist educates the mother of the infant who gave birth either naturally or with a caesarean on the benefits of appropriate exercises for pelvic floor muscles and abdominal exercises to promote core stability, as well as kinetic handling during the care of the infant.	✓	
2. As part of holistic family care the physiotherapist educates the mother of the infant who gave birth either naturally or with a caesarean, on the benefits of exercise for elevating serotonin levels to reduce the effect of post-partum depression that could occur.	✓	
Statements relating to the physiotherapist's professional ethical conduct		
1. A physiotherapist has to have to have postgraduate / post basic training to treat infants in NICU, HCU or KMC ward.	✓	
2. The physiotherapist should engage in professional communication with the nursing manager of the unit, or the professional nurse responsible for the infant, to discuss the status of the infant in the NICU, HCU or KMC ward, before assessment and intervention of the infant.	✓	
3. The physiotherapist should engage in professional communication with the nursing manager of the unit, or the professional nurse responsible for the infant, to discuss the parent's or caregiver's management of the infant being in the NICU, HCU or KMC ward, before interacting with the parents or caregivers with regard to providing information or education.	✓	

4. The physiotherapist should document the parent or caregiver consent, assessment and intervention according to the required professional standard.	✓	
5. The therapist's own ethical and moral values should direct the decision to treat the infant and putting the infant's needs first during the intervention.	✓	
Statements relating to the physiotherapist's education and knowledge		
1. Post-basic training in terms of knowledge and experience is needed to assess and treat infants in the NICU, HCU or KMC ward safely, effectively and efficiently.	✓	
2. Physiotherapists who are treating or educating the infants' mothers regarding muscle strengthening, posture re-education and kinetic handling during care of the infant, should be adequately trained to do so.	✓	
3. Physiotherapists in SA could benefit from a post-graduate course with both theory and supervised clinical experience in neonatal physiotherapy where the physiotherapist will gain knowledge and experience in managing the infant, as well as supporting the parents or caregivers in the NICU, HCU or KMC ward.	✓	

Part I (Hospital setting) and Part II (MDT members) of the questionnaire used in the first round of the Delphi method are discussed in the following section.

6.4 FORMULATION OF STATEMENTS FOR PARTS I AND II OF THE FIRST ROUND OF THE DELPHI METHOD QUESTIONNAIRE

The researcher included a section requiring biographic information at the beginning of the questionnaire used in the first round of the Delphi method. The information requested included information on the participants' highest qualifications, the health care sector in which they were primarily employed, their years of experience and the scope of their professional roles. This information was required to ensure that the participants actually belonged to the target population of the study (physiotherapists working in NICUs, HCUs or KMC wards in the South African health care sector). The process to obtain the statements and recommendations for the first and second round of the Delphi method is shown in Figure 6.1.

Part I (Hospital setting) and Part II (MDT members) of the questionnaire used in the first round of the Delphi method consisted only of statements derived the focus group discussions and key informant interviews. In Part I the researcher formulated the statements relating to the NICU, HCU or KMC environment as described by participants in the focus group discussions and key informant interviews who worked in the greater Tshwane Metropole (Table 6.5). These statements were included in the first round of the Delphi questionnaire to determine whether participants from across SA agreed that they truly reflected the hospital environments in which they worked.

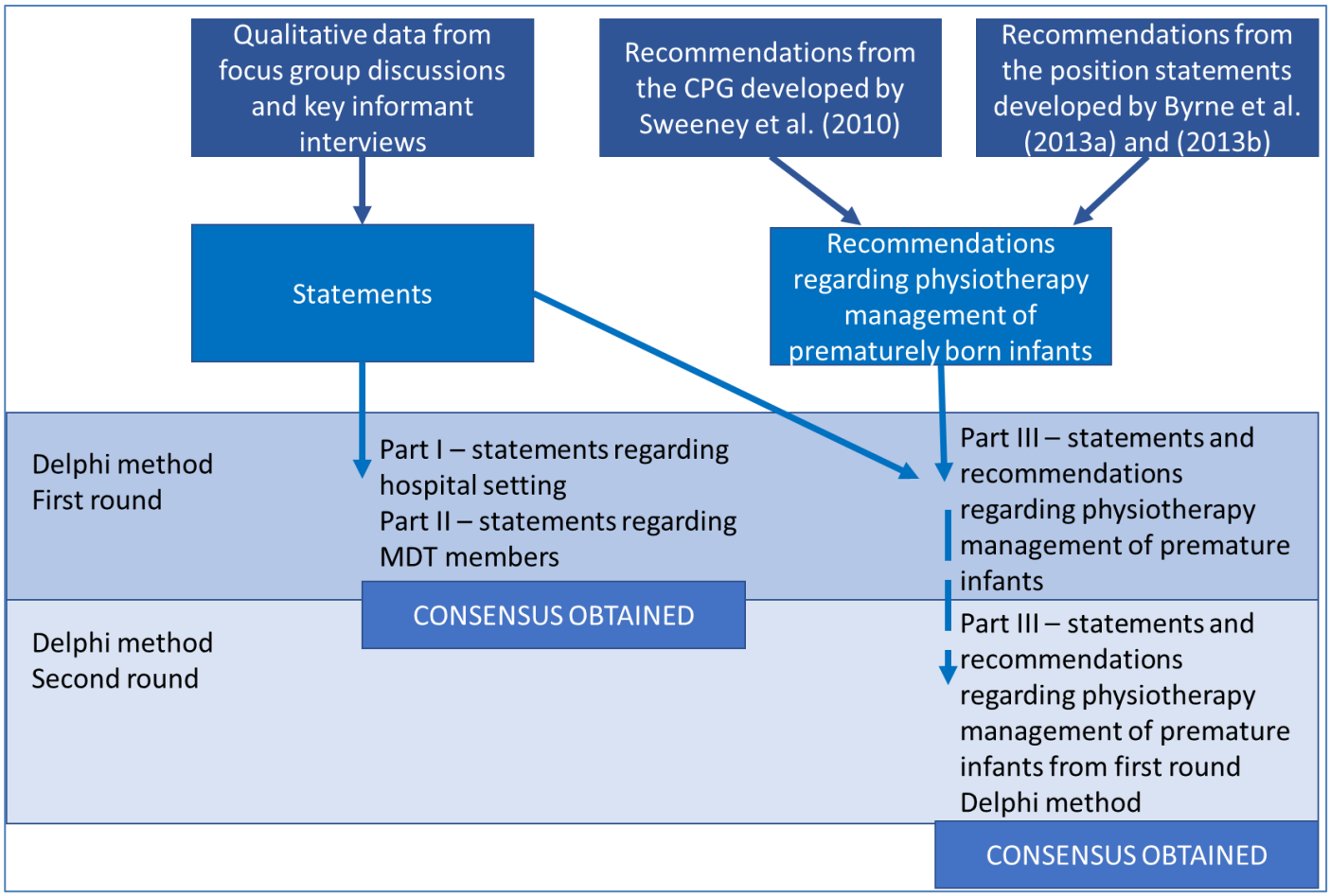


FIGURE 6.1 PROCESS OF OBTAINING STATEMENTS AND RECOMMENDATIONS FOR THE QUESTIONNAIRE IN THE FIRST AND SECOND ROUND DELPHI METHOD

TABLE 6.5 PART I (HOSPITAL SETTING) OF THE FIRST ROUND OF THE DELPHI QUESTIONNAIRE

Statements with regard to the NICU or HCU environment
1. The MDT has a standardised regime of care and management principles of the infant in the NICU or HCU.
2. The physiotherapist has a role in the care and management of the infant in the NICU or HCU.
3. The physiotherapist, and other MDT members (e.g. occupational therapist, speech therapist) are screening all infants in the NICU or HCU without a referral from the paediatrician.
4. The parents or caregivers of the infant do not have an adjustment period to manage the infant before the infant is discharge from the NICU or HCU and might lack the proper knowledge or confidence to care for the infant at home.
5. The infant will be transferred to the KMC ward before discharge home.
6. The infants who are ready to go home will be discharged from the NICU or HCU.
7. Infants are discharged from the NICU or HCU with a follow-up appointment with the MDT.
Statements relating to the KMC environment
1. Intermitted KMC is integrated as part of the routine at some NICUs or HCUs, especially if the benefits of KMC are explained to the parents or caregivers of the infant.
2. Continuous KMC is practised in the KMC ward even if the infant is on oxygen.
3. The environmental stressors like light, noise, temperature changes and handling have less of an effect on the infant in the KMC ward than in the NICU or HCU.
4. Some NICUs have a 'room-in'-facility where the parents or caregivers of the infant can stay with the infant under supervision of the nursing staff to ensure that the parents or caregivers are coping with the care and management of the infant before discharge home.
5. The infant is discharged from the KMC ward with a follow-up appointment.
6. The short-term follow-up of the infant after discharge is with the following: - Paediatrician - MDT on referral - Private / public clinic - Out-patient clinic - Cerebral palsy clinic - Developmental delay clinic - Well-baby clinic - Retinopathy of prematurity clinic - The infant does not have short-term follow-up

In Part II (MDT members) the researcher formulated the statements regarding the MDT members' involved in the management of prematurely born infants in the NICUs, HCUs or KMC wards, as well as the collaboration between MDT members as described by participants during the focus group discussions and key informant interviews (Table 6.6).

TABLE 6.6 PART II (MULTIDISCIPLINARY TEAM MEMBERS) OF THE FIRST ROUND OF THE DELPHI QUESTIONNAIRE

Statements regarding MDT members
The MDT members involved in the management of the infant in the NICU or HCU include: - Physiotherapist - Speech therapist - Audiologist - Occupational therapist - Nursing staff - Dietician - Sonographer - Ophthalmologist - Paediatrician - Counsellor - Social worker
Statements relating to collaboration between the MDT members
1. MDT members collaborate with regard to the developmental care of the infant in the NICU or HCU.
2. The MDT does regular ward rounds together in the NICU or HCU and discusses possible treatment plans.
3. Coordination of the collaboration is difficult to organise during ward rounds in the NICU or HCU because not all members are always available during the same period of time.
4. The MDT members rely on each other's written documentation in the infant's file to understand what the other members' treatment plan comprises of.
5. In settings where inter-professional collaborative practice is the management approach of the infant and his / her parents or caregivers, the roles of the MDT members overlap.
6. Inter-professional collaboration between members of the MDT is essential for promotion of growth and development of the infant without over stimulation of the infant.
7. The physiotherapist collaborates and refers to the following MDT members: - Speech therapist - Audiologist - Occupational therapist - Nursing staff - Dietician - Sonographer - Ophthalmologist - Paediatrician - Counsellor - Social worker.
Statements relating to KMC

8. MDT members, apart from the nursing staff and paediatrician, that are involved in the care of the infant in the KMC ward include: - Physiotherapist - Speech therapist - Audiologist - Occupational therapist - Dietician - Sonographer - Ophthalmologist - Counsellor - Social worker.
9. MDT members collaborate with regard to the developmental care of the infant in the KMC ward.

6.5 SUMMARY OF THIS CHAPTER

In this chapter the process followed to allocate and compare the levels of evidence and phrasing of recommendations in the CPG (Sweeney et al., 2010) and the NICU Care Path (Byrne et al., 2013a; Byrne et al., 2013b) was explained. The combination of statements or recommendations that was used in the questionnaire for the first round of the Delphi method concluded this chapter.

In the next chapter the researcher will discuss the results from the first and second rounds of the Delphi method (Phase 3 of the current study), as well as the changes that were made to the phrasing, categorisation and inclusion of the statements, and recommendations for the final round of the Delphi method.

CHAPTER 7

DELPHI METHOD TO OBTAIN CONSENSUS ON THE EVIDENCE-BASED STATEMENTS AND RECOMMENDATIONS

7.1 INTRODUCTION TO THE CHAPTER

In this chapter the list of statements that were based on the information gathered during Phase 1 (focus group discussions, key informant interviews and parental or caregiver questionnaire) and the recommendations identified in Phase 2 (from current CPG or position statements used by physiotherapists in high-income countries) was validated by physiotherapists in SA with a special interest in paediatrics and neonatology. The statements and evidence-based recommendations were validated by consensus during two rounds of the Delphi method.

In this chapter, the researcher provides the results obtained during the two rounds of the Delphi method and explains how the questionnaire used in the first round was adapted for use in the second round. Obtaining the opinions of experts in the field is an essential step in the contextualisation process (Gonzalez-Suarez et al., 2012). The Delphi method made it possible to gain the opinion of physiotherapists working in NICUs, HCUs or KMC wards and at academic institutions across SA. The results of the second round of the Delphi method were used to formulate the contextualised CPG, which was the purpose and end product of the study.

7.2 RESULTS OF THE FIRST ROUND OF THE DELPHI METHOD

The research process, including the recruitment of the participants, was described in Chapter 3, section 3.5.1.

In the first round of the Delphi method, 43 participants (n=43) agreed, by way of informed consent, to participate.

The *biographic information* requested from the participants included:

(i) **Age**

Only 34 participants (n=34) provided their dates of birth. Of these, four (n=4) provided the date on which they completed the survey; therefore only 30 participants' birth dates were available to the researcher. Their age group distribution is shown in Table 7.1.

TABLE 7.1 AGE GROUPS OF PARTICIPANTS (N=30)

Age group in years	***Number of participants***
50–59	7
40–49	8
30–39	13
20–29	2

(ii) **Gender**

Only 36 participants (n=36) provided an answer, of which 34 were female (n=34) and two were male (n=2).

(iii) **Level of qualification**

Thirty-seven (37) participants answered the question relating to their levels of qualification as physiotherapists.

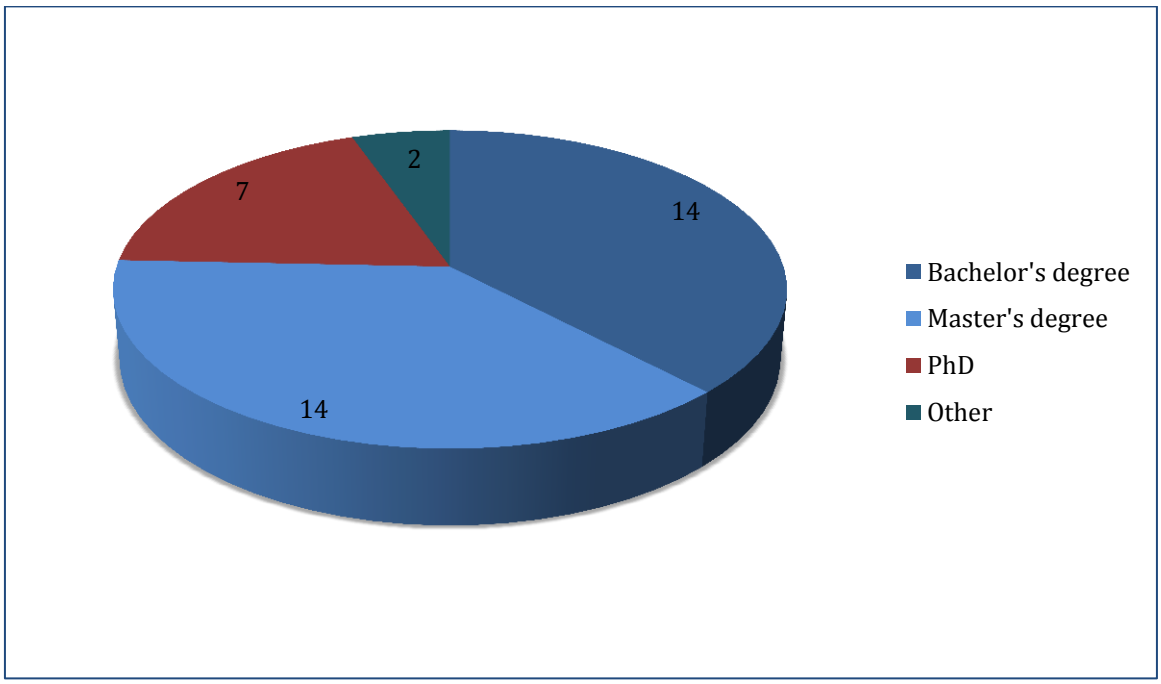


FIGURE 7.1 PARTICIPANTS' LEVELS OF QUALIFICATION (N=37)

Equal numbers of physiotherapists (participants) had master's and bachelor's degrees. No information was requested on the fields in which postgraduate qualifications had been obtained.

The two participants who indicated 'Other' had completed a National Diploma in Physiotherapy and a Postgraduate Diploma in Management respectively.

(iv) **Primary employment**

The participants were asked in which health care sector they were primarily treating prematurely born infants. Participants' (n=39) answers are presented in Figure 7.2.

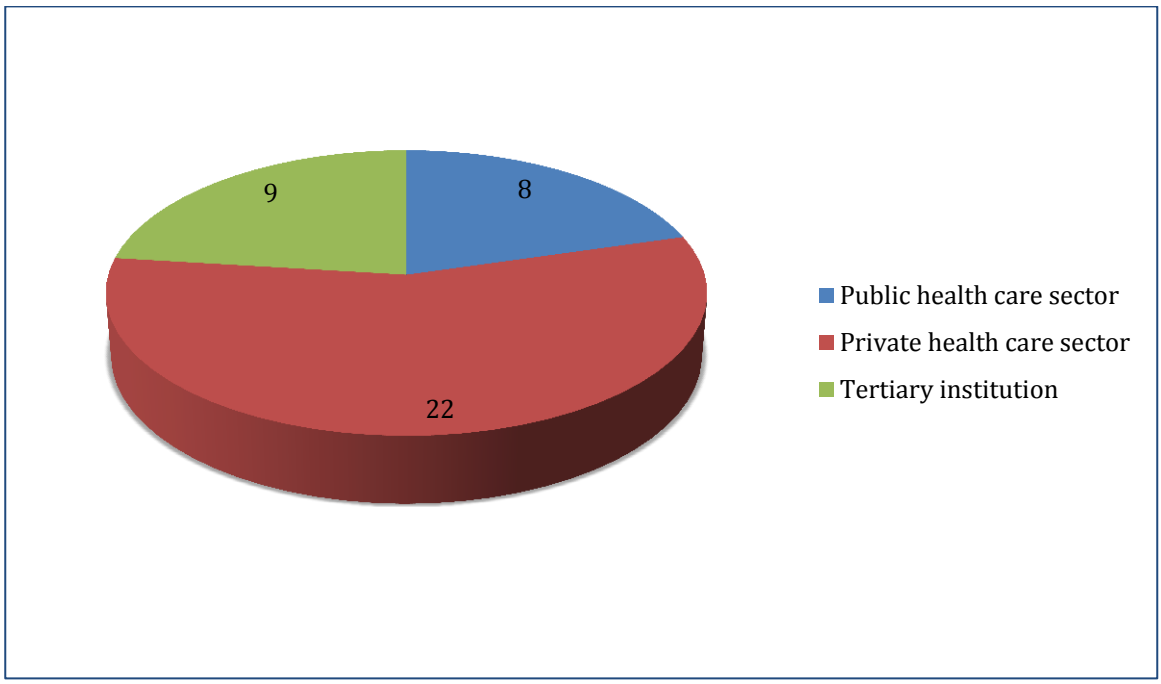


FIGURE 7.2 HEALTH CARE SECTOR IN WHICH PARTICIPANTS (N=39) WERE PRIMARILY EMPLOYED

Tertiary institutions are usually also part of the public health domain, but have an additional assignment, namely the clinical training of undergraduate / postgraduate students. Physiotherapists working in the private health care sector were clearly in the majority in this phase of the study.

(v) **Years of experience in treating prematurely born infants**

The participants were asked to indicate their number of years of experience in treating or working with prematurely born infants. Thirty-six (n=36) participants answered the question (Figure 7.3).

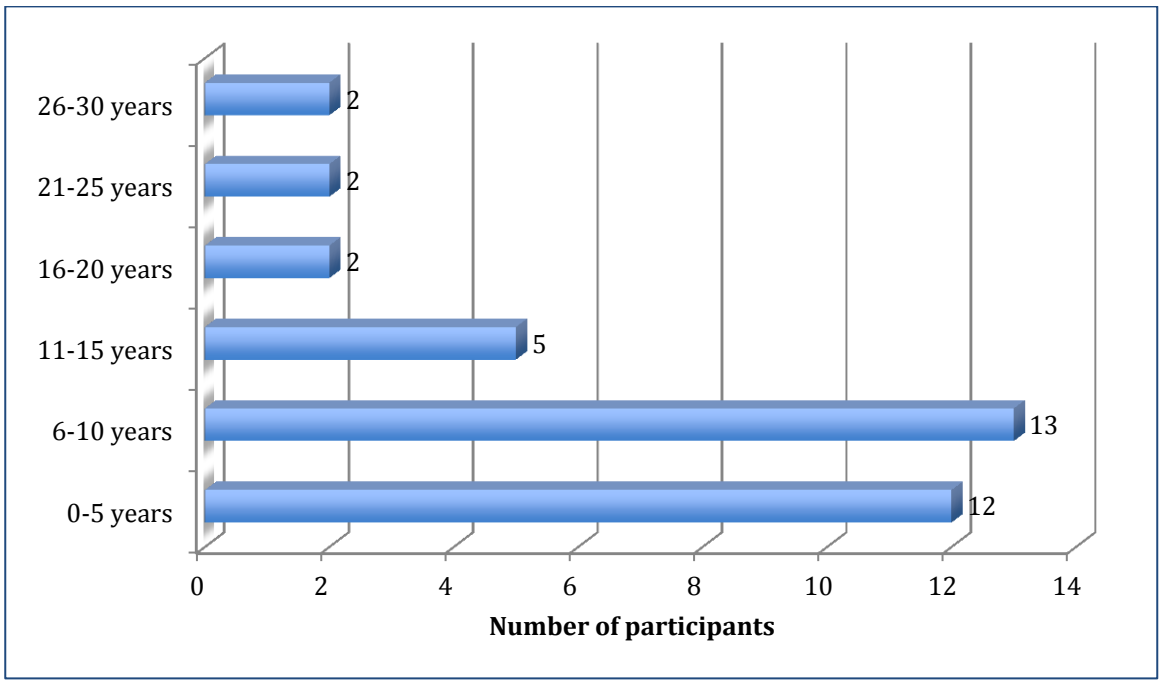


FIGURE 7.3 PARTICIPANT'S NUMBER OF YEARS OF EXPERIENCE IN TREATING PREMATURELY BORN INFANTS (N=36)

(vi) **Participants' professional roles**

The participants were asked to specify what their professional roles in the NICU, HCU or KMC ward entailed. They were allowed to give more than one answer (Table 7.2).

TABLE 7.2 PROFESSIONAL ROLE OF PARTICIPANTS IN THE NEONATAL INTENSIVE CARE UNIT, HIGH CARE UNIT OR KANGAROO MOTHER CARE WARD

The professional roles in the NICU, HCU or KMC ward included:	***Number of participants***
Clinical management of infants	29
Clinical teaching	12
Academic – teaching students at a tertiary institution	10
Researcher	5
Other	4
Policymaker (developing or monitoring policies)	2

Under the heading 'Other', the participants mentioned (i) working at a school for special-needs children; (ii) educating parents; (iii) currently not working in the areas mentioned; and (iv) postgraduate teaching.

As discussed in Chapter 6, section 6.3, the statements and recommendations tested in the first round of the Delphi method were divided into three parts: Part I – Hospital setting; Part II – MDT members; and Part III – Physiotherapy management of the premature infant.

The participants were asked to respond to each statement / recommendation: First, they had to indicate whether the statement or recommendation was relevant or was in fact being implemented in their current practice; and second, they were asked to indicate whether the same statement or recommendation should be part of the standard physiotherapy practice.

The content of the questionnaire is presented with the addition of two columns indicating the percentage of participants who thought the statement was applicable to their current practice and the percentage who felt that the statement / recommendation should be part of physiotherapy practice (Table 7.4).

The colours and percentages in Tables 7.4, 7.5 and 7.6 are explained in Table 7.3.

TABLE 7.3 INTERPRETATION OF THE COLOURS AND PERCENTAGES USED IN TABLES 7.4, 7.5 AND 7.6

Colours included:	***Meaning of the colour included:***	
	Statements derived from coded transcripts of focus group discussions and key informant interviews (Phase 1)	
	Recommendations derived from the CPG (Sweeney et al., 2010) and the NICU Care Path (Byrne et al., 2013a; Byrne et al., 2013b) (Phase 2)	
	80%–100% of the participants agreed with a statement or recommendation	Strong recommendation for inclusion in the next round of the Delphi method
	60%–79% of the participants agreed with a statement or recommendation	Moderate recommendation for inclusion in the next round of the Delphi method
	59% or fewer of the participants agreed with a statement or recommendation	Weak recommendation, therefore excluded in the next round of the Delphi method

As mentioned in Chapter 3, section 3.5.3, the statements or recommendations that obtained a consensus of 80% or higher in the first round of the Delphi method were included in the questionnaire for the second round.

Statements or recommendations that obtained a consensus of between 60% and 79% were included in the next round once they had been edited in accordance with the participants' opinions / comments. Statements or recommendations that scored below 60% were removed from the questionnaire for the second round of the Delphi method.

In Tables 7.4, 7.5 and 7.6, the researcher also added the participants' opinions, or comments made during the first round, in a column below the relevant statement / recommendation.

TABLE 7.4 PART I OF THE DELPHI QUESTIONNAIRE - STATEMENTS REGARDING THE HOSPITAL SETTING

Statements included in the first round of the Delphi method	***Current practice***	***What practice should be***
Statements referring to the NICU or HCU		
1. The MDT has a standardised regime of care and management principles for the infant in the NICU or HCU. * n=26	54% disagree 38% agree 8% don't know	77% agree 12% disagree 12% don't know
1. Participants' opinions: - *"... evidence-based guidelines need to be in place to guide service, but care needs to be individualised based on the child and family needs."* - *"Doctors are not clear on our role so don't refer regularly enough."* - *"MDT do not exist everywhere. Therapists are not familiar with others' roles." "...infants are in NICU for survival primarily"*		
2. The physiotherapist has a role in the care and management of the infant in the NICU or HCU. *n=26	69% agree 31% disagree	96% agree 4% disagree
2. Participant's opinion: - *"Physiotherapists need proper training or knowledge of neuro-behaviour in terms of state regulation and organisation and effect on brain development. Preservation of brain function and promoting neural growth and integrity is paramount."*		
3. The physiotherapist and other MDT members (e.g. occupational therapist, speech therapist) are screening all infants in the NICU or HCU without a referral from the paediatrician. *n=26	62% disagree 27% agree 12% don't know	73% agree 23% disagree 4% don't know
3. Participants' opinion: *The overall opinion was that physiotherapists are not allowed to screen infants in the NICU or HCU without a referral, but that infants should be risk-stratified and then screened based on their risk of developmental complications. Screening should be done with parental consent. Participants also felt that parents or caregivers should be informed / educated and should have the opportunity to request screening if they consider it to be necessary.*		
4. The parents or caregivers of the infant do not have an adjustment period to manage the infant before the infant is discharge from the NICU or HCU, and might lack the proper knowledge or confidence to care for the infant at home. *n=25	52% disagree 48% agree	60% disagree 36% agree 4% don't know

4. Participants' opinion: *The overall opinion was that this differs from one hospital to the next, but generally parents or caregivers do not have an adjustment period before discharge, especially in the private health care sector, due to the cost of care in the NICU or HCU. Participants did feel that this is very important and that the MDT should attach high priority to supporting and educating the parents or caregivers as much as possible during the hospital stay, so that when the infant is discharged the parents or caregivers will feel empowered. A 48-hour follow-up after discharge, as is common practice at some hospitals, was also suggested.*		
5. The infant will be transferred to the KMC ward before discharge home. *n=25	52% disagree 36% agree 12% don't know	80% agree 16% disagree 4% don't know
5. Participants' opinion: *The overall opinion of physiotherapists employed in the private health care sector was that there were no KMC wards and that KMC could only be encouraged in the NICU or HCU if the nursing practitioners were willing to allow this.*		
6. The infant will be discharged home from the NICU or HCU. *n=25	80% agree 20% disagree	64% disagree 36% agree
6. Participants' opinion: *The overall opinion was that this statement is correct, but participants felt that parents or caregivers should receive more support and time to adjust to the situation before their infants are discharged from the NICU or HCU. A 'room-in' facility was suggested where parents or caregivers can adjust to caring for the infant for a day or two under the supervision of the MDT. One participant said: "I was a parent of a preemie and I would have appreciated having even two days, like the moms with full-term babies in the maternity ward have."*		
7. Infants are discharged from the NICU or HCU with a follow-up appointment with the MDT. *n=25	68% agree 28% disagree 4% don't know	100% agree
7. Participants' opinions: *All the participants agreed that infants should have a follow-up appointment with the MDT, but stated that this is not currently the case. Participants highlighted some problems:* - *"due to the referral basis many infants in the NICU do not get seen by therapists and therefore do not receive follow-up. Only infants that are treated during their admission receive follow-up* [appointments] *with the therapist."* - *"lack of MDT approach and knowledge of different roles"*		
Statements with regard to KMC		
1. Intermittent KMC is integrated as part of the routine at some NICUs or HCUs, especially if the benefits of KMC are explained to the parents or caregivers of the infant. *n=25	76% agree 20% disagree 4% don't know	92% agree 4% disagree 4% don't know
1. Participants' opinion: *The overall opinion was that KMC is not currently practised in all NICUs, but the participants felt that is should be an important part of routine care.*		

2. Continuous KMC is practised in the KMC ward even if the infant is on oxygen. *n=25	64% agree 20% disagree 16% don't know	92% agree 8% don't know
2. Participants' opinion: *The overall opinion was that continuous KMC is not currently practiced in all NICUs, but the participants felt that is should be an important part of routine care.*		
3. The environmental stressors like light, noise, temperature changes and handling have less of an effect on the infant in the KMC ward than in the NICU or HCU. *n=25	40% agree 36% disagree 24% don't know	56% agree 24% disagree 20% don't know
3. Participant's opinion: *"The infant is still immature and environmental modulation remains important."*		
4. Some NICUs have a 'room-in' facility where the parents or caregivers of the infant can stay with the infant under supervision of the nursing staff to ensure that the parents or caregivers are coping with the care and management of the infant before discharge home. *n=25	60% disagree 36% agree 4% don't know	96% agree 4% disagree
4. Participants' opinion: *The overall opinion was that although this should preferably be made available to parents or caregivers, it is not currently provided for at many hospitals. The participants agreed that there was a need in this regard and that it was important to ensure that when infants are discharged, their parents or caregivers feel empowered and able to cope with them at home.*		
5. The infant is discharged from the KMC ward with a follow-up appointment. *n=25	64% agree 16% disagree 20% don't know	84% agree 16% don't know
5. Participants' opinion: *The overall opinion was that infants should be discharged with a follow-up appointment with the MDT.* - *"due to the referral basis many infants in the NICU do not get seen by therapists and therefore do not receive follow-up* [appointment]. *Only infants that are treated during their admission receive follow-up* [appointment] *with the therapist"*		
6. The short-term follow-up of the infant after discharge is with the following:		
- Paediatrician	Twenty-three participants (n=23) agreed	
- MDT on referral (n=21)	Twenty-one participants (n=21) agreed	
- Private / public clinic	Seven participants (n=7) agreed	
- Out-patient clinic	Four participants (n=4) agreed	
- Cerebral palsy clinic	Three participants (n=3) agreed	
- Developmental delay clinic	Five participants (n=5) agreed	
- Well-baby clinic	Five participants (n=5) agreed	
- Retinopathy of prematurity clinic	Four participants (n=4) agreed	

- The infant does not have short-term follow-up	One participant (n=1) agreed
- Other follow-up options included: • Neonatal follow-up with whole team (doctor, dietician, physiotherapist, occupational therapist and speech therapist) • Depends on each infant • Early childhood intervention clinic for high-risk infants • MDT team from NICU • High-risk clinic in the public health care sector • High-risk clinic or management by MDT (should not need a referral)	Six participants (n=6) provided an additional answer under the heading 'other'

* Number of participants who answered the question

TABLE 7.5 PART II OF THE DELPHI QUESTIONNAIRE - STATEMENTS CONCERNING THE MULTIDISCIPLINARY TEAM MEMBERS

Statements included in the first round of the Delphi method	***Current practice***	***What practice should be***
The MDT members involved in the management of the infant in the NICU or HCU include:		
- Physiotherapist	Twenty-four participants (n=24) agreed	
- Speech therapist	Nineteen participants (n=19) agreed	
- Audiologist	Seventeen participants (n=17) agreed	
- Occupational therapist	Ten participants (n=10) agreed	
- Nursing staff	Twenty-three participants (n=23) agreed	
- Dietician	Twenty participants (n=20) agreed	
- Sonographer	Twelve participants (n=12) agreed	
- Ophthalmologist	Fifteen participants (n=15) agreed	
- Paediatrician	Twenty-three participants (n=23) agreed	
- Counsellor	Eleven participants (n=11) agreed	
- Social worker	Fourteen participants (n=14) agreed	
- Other MDT members involved in the management of the infant included: • Neonatologist • The team depends on the needs of the infant. It is not routine for all members to be involved with all infants.	Two participants (n=2) provided an additional answer under the heading 'Other'	
Statements with regard to collaboration between MDT members		
1. MDT members collaborate with regard to the developmental care of the infant in the NICU or HCU. *n=24	54% agree 46% disagree	100% agree
1. Participants did not give an opinion		
2. The MDT does regular ward rounds together in the NICU or HCU and discusses possible treatment plans. *n=24	50% disagree 42% agree 8% don't know	100% agree

2. Participants' opinion: *The overall opinion was that ward rounds involving all the MDT members occur at only a few hospitals, but that it would be beneficial. With regard to current practice, one participant stated: "No formal ward rounds as a MDT occurs. Ward rounds are only done with the doctor. Each profession tries to give feedback with regard to progress of treatment to the doctor whenever possible."*		
3. Coordination of the collaboration is difficult to organise during ward rounds in the NICU or HCU because not all members are always available during the same period of time. *n=24	63% agree 33% disagree 4% don't know	46% agree 46% disagree 8% don't know
3. Participants' opinion: *The overall opinion was that it is difficult to organise MDT ward rounds, but that the MDT should be available for clinical discussions and that ward rounds as a team could be very beneficial.*		
4. The MDT members rely on each other's notes in the infant's file to understand what the other members' treatment plan comprises of. *n=24	83% agree 13% disagree 4% don't know	63% agree 37% disagree
4. Participants' opinions: - *"Team members should discuss the patient in order to establish common goals and discipline-specific goals and plan of treatment."* - *"Notes are not sufficient."*		
5. In settings where interprofessional collaborative practice is the management approach of the infant and his / her parents or caregivers, the roles of the MDT members overlap. *n=24	83% agree 13% disagree 4% don't know	79% agree 17% disagree 4% don't know
5. Participants' opinion: *The overall opinion was that the different MDT team members' approaches are complementary, but not the same, and that an interprofessional collaborative approach could be more cost effective for parents or caregivers.*		
6. Interprofessional collaboration between members of the MDT is essential for promotion of growth and development of the infant without over-stimulation of the infant. *n=24	88% agree 8% disagree 4% don't know	96% agree 4% disagree
6. Participants' opinion: *Participants were of the opinion that excessive early intervention by members from all the disciplines in the NICU is not beneficial to the infant and might not promote growth and development. An interprofessional collaborative approach might limit interventions.*		
7. The physiotherapist collaborates with, and refers to the following MDT members:		

- Speech therapist	Twenty-one participants (n=21) agreed, and their reasons for collaborating included: - Feeding, sucking or swallowing difficulties - Possible aspiration when drinking - Cerebral palsy - Speech problems - Cleft palate - Infant not gaining weight
- Audiologist	Fifteen participants (n=15) agreed and their reasons for collaboration included: - Auditory screening - Hearing loss - Cerebral palsy - Infants on ototoxic medicines - Infants who had jaundice
- Occupational therapist	Seventeen participants (n=17) agreed, and their reasons for collaboration included: - Developmental support - Sensory integration problems - Visual and neurodevelopmental delays - Cognitive assessment - Splinting
- Nursing staff	Sixteen participants (n=16) agreed, and their reasons for collaboration included: - Developmental supportive care - Education during follow-up appointments - Support for breast-feeding - If parent or caregiver has questions regarding nursing care

- Dietician	Ten participants (n=10) agreed, and their reasons for collaboration included: - Optimal nutrition - Feeding difficulties and failure to thrive - Infants with malnutrition - Infants not gaining weight
- Sonographer	Three participants (n=3) agreed, and their reasons for collaboration included: - Brain scans - GIT problems
- Ophthalmologist	Six participants (n=6) agreed, and their reason for collaboration was: - Visual acuity concerns
- Paediatrician	Fifteen participants (n=15) agreed, and their reasons for collaboration included: - Any medical conditions - Monitoring of growth - Requesting special tests - Orthopaedic, respiratory or neurological conditions
- Counsellor	Seven participants (n=7) agreed, and their reasons for collaboration included: - Parental support - Social issues - Mother with postnatal depression - Support in dealing with grief - Parents of infants with complications with lifelong impact

- Social worker	Fourteen participants (n=14) agreed, and their reasons for collaboration included: - Social assistance - Grant applications - Counselling parents or caregivers - Parents or caregivers with socio-economic problems - Parents or caregivers of infants with poor prognosis - Abandonment of infant
- Other MDT members with whom the physiotherapist collaborates included: • Psychologist	One participant (n=1) provided an additional answer under the heading 'Other'. Reasons for collaboration included: - Support for grieving parents or caregivers - Mothers with postnatal depression or problems bonding with infant
Statements with regard to KMC	
8. MDT members, other than the nursing staff and paediatrician, who are involved in the care of the infant in the KMC ward:	
- Physiotherapist	Twenty participants (n=20) agreed
- Speech therapist (n=16)	Sixteen participants (n=16) agreed
- Audiologist (n=12)	Twelve participants (n=12) agreed
- Occupational therapist	Thirteen participants (n=13) agreed
- Dietician	Sixteen participants (n=16) agreed
- Sonographer	Six participants (n=6) agreed
- Ophthalmologist	Ten participants (n=10) agreed
- Counsellor	Seven participants (n=7) agreed
- Social worker	Eleven participants (n=11) agreed

- Other options included: • Participants indicating that the question is not applicable to them as there is no KMC ward at the hospital where they are employed	Four participants (n=4) provided an additional answer under the heading 'other'.	
9. MDT members collaborate with regard to the developmental care of the infant in the KMC ward. *n=24	50% agree 25% disagree 25% don't know	83% agree 17% don't know
9. Participants' opinion: - *"Insufficient knowledge of different systems"*		

* Number of participants who answered the question

TABLE 7.6 PART III OF THE DELPHI QUESTIONNAIRE - STATEMENTS OR RECOMMENDATIONS REGARDING THE PHYSIOTHERAPY MANAGEMENT OF INFANTS

Statements or recommendations included in the first round of the Delphi method	***Current practice***	***What practice should be***
Statements or recommendations with regard to assessment		
1. Screening of the infant in the NICU, HCU or KMC ward by the physiotherapist as member of the MDT could lead to early detection of impairments as well as anticipation of impairments that could arise after discharge from hospital. *n=21	76% agree 19% disagree 5% don't know	100% agree
1. Participants did not give an opinion		
2. The physiotherapist conducts a baseline observation to determine the infant's physiological and behavioural stability or readiness for evaluative handling before assessment. *n=20	75% agree 20% disagree 5% don't know	100% agree
2. Participants did not give an opinion		
3. The physiotherapist does a limited hands-on assessment during the infant's diaper change or re-positioning and assesses the recoils and scarf sign. *n=20	60% agree 30% disagree 10% don't know	80% agree 15% disagree 5% don't know
3. Participants' opinions: - *"Physiotherapists have very limited hands-on assessment during diaper change if anything, not involved at all due to the clinical set-up of the NICU and increased workload, not dedicated physio to NICU, so miss out on this aspect"* - *"I don't think this should be a routine assessment in the NICU – I believe hands-off approach with educating staff and parents is more beneficial and using Prechtl, a non-invasive assessment approach is more beneficial for the infant."*		
4. The physiotherapist does a limited hands-on assessment during the infant's diaper change or re-positioning and assesses the palmar and plantar grasp. *n=20	60% agree 30% disagree 10% don't know	80% agree 15% disagree 5% don't know
4. Participants did not give an opinion		
5. The physiotherapist does a limited hands-on assessment during the infant's diaper change or re-positioning and assesses the non-nutritive sucking. *n=20	55% agree 40% disagree 5% don't know	80% agree 15% disagree 5% don't know
5. Participant's opinion: - *"I think you need to only handle these infants from a certain gestational age. Not all 'prems' should get this assessment."*		

6. The physiotherapist does a sensory assessment of the physiologically stable infant in the NICU, HCU or KMC ward to determine visual focus, tracking and auditory localisation and orientation. *n=21	76% agree 19% disagree 5% don't know	90% agree 10% disagree
6. Participant's opinion: - *"Only from a certain gestational age"*		
7. The physiotherapist makes use of the following assessment tool(s) for infants in the NICU, HCU or KMC ward:		
- Bayley scale	Five participants (n=5) agreed	
- Movement ABCs (n=3)	Three participants (n=3) agreed	
- Alberta infant scale (n=4)	Four participants (n=4) agreed	
- Clinical observation (as the only method of assessment)	Ten participants (n=10) agreed	
- Brazelton Neonatal Behavioural Assessment	Six participants (n=6) agreed	
- Prechtl's analysis	Fourteen participants (n=14) agreed	
- Developmental or milestone chart	Thirteen participants (n=13) agreed	
- Test of Infant Motor Performance Screening Items (TIMPSI)	Three participants (n=3) agreed	
- Test of Infant Motor Performance (TIMP)	Two participants (n=2) agreed	
- Neurologic Assessment of the Preterm and Full Term Newborn Infant (NANI)	None of the participants (n=0) agreed	
- Neurobehavioural Assessment of the Preterm Infant (NAPI)	Two participants (n=2) agreed	
- Newborn Behavioural Observations (NBO)	Four participants (n=4) agreed	
- Other assessment tools included: • Hammersmith Infant Neurological Examination (HINE)	Three participants (n=3) provided an additional answer under the heading 'Other'.	
8. The physiotherapist continuously monitors the infant's physiological and behavioural status during and after assessments in order to know what adaptations are necessary during future evaluative handling with regard to the pace and sequence of handling, especially during neuro-motor assessment. *n=20	80% agree 15% disagree 5% don't know	95% agree 5% disagree
8. Participants did not give an opinion		
Statements or recommendations with regard to prevention		
1. The physiotherapist as member of the MDT monitors the respiratory function of the intubated or non-intubated infant in the NICU or HCU and will treat if indicated. *n=20	60% agree 40% disagree	85% agree 5% disagree 10% don't know

1. Participant's opinion: - *"There is another physiotherapist who deals with the respiratory problems."*		
2. The physiotherapist collaborates with other MDT members to monitor the intubated or non-intubated infant in order to reduce the risk of skull deformity, torticollis and extremity malalignment through diligent symmetrical and neutral alignment and positioning to support neurodevelopment in the NICU or HCU. *n=20	75% agree 20% disagree 5% don't know	100% agree
2. Participant's opinion: - *"I spend limited time in NICU – only see those specifically referred to me."*		
3. The physiotherapist as member of the MDT should monitor the effect of the environmental, social and chemical stressors on the infant in the NICU or HCU to avoid overstimulation and other complications. *n=20	70% agree 25% disagree 5% don't know	100% agree
3. Participant's opinion: - *"I spend limited time in NICU – only see those specifically referred to me."*		
4. The physiotherapist observes feeding assessments done by nursing practitioners or speech therapists in order to do respiratory care (e.g. suction of the infant) in case the infant aspirates. *n=20	50% disagree 40% agree 10% don't know	55% agree 30% disagree 15% don't know
4. Participants' opinions: - *"Speech therapist does this with nurses"* - *"The nursing personnel are trained to do the suctioning. Physiotherapists not that often in the ward."*		
5. The physiotherapist takes special care to implement sterile procedures in the NICU or HCU to prevent cross infection to the infant who has an underdeveloped immune system. *n=20	90% agree 5% disagree 5% don't know	100% agree
5. Participants did not give an opinion		
Statements or recommendations with regard to intervention		
1. The physiotherapist is aware of the indications and contra-indications of physiotherapy interventions in the NICU, HCU or KMC ward. *n=20	90% agree 5% disagree 5% don't know	100% agree
Participant's opinion: - *"Since this is a highly specialised care, few physiotherapists are trained to observe these."*		
2. The physiotherapist incorporates the view or opinion of the parents or caregivers of the infant when considering a treatment plan for the infant to empower the parents or caregivers. *n=20	85% agree 10% disagree 5% don't know	95% agree 5% disagree
2. Participants did not give an opinion		

3. The physiotherapist plans the timing of the intervention to accommodate the care routine and the infant's resting periods in the NICU, HCU or KMC ward. *n=20	85% agree 10% disagree 5% don't know	100% agree
3. Participants did not give an opinion		
4. The physiotherapist supports the infant's body position and extremity movement in (a) supine position through 'nesting' of the infant in a semi flexed, midline aligned position and (b) prone position with a vertical roll under the thorax and / or horizontal roll under hips. *n=20	85% agree 10% disagree 5% don't know	95% agree 5% disagree
4. Participant's opinion: - *"All babies need variety. If you are familiar with the current research regarding general movements and neuronal group selection theory, all babies need variety but within a contained environment. Two positions is not going to cut it! The brain needs a variety of positions. There are 360 degrees from being supine, turning and back to supine. Use all degrees, plus variety of arm position, leg position, pelvic position. As long as their saturation are maintained, use your imagination and give them as much variety as possible in a resting position."*		
5. The physiotherapist facilitates the infant's independent oral exploration through positioning of hands to the face for non-nutritive sucking that could improve organisation and readiness for feeding. *n=20	85% agree 10% disagree 5% don't know	95% agree 5% disagree
5. Participants did not give an opinion		
6. The physiotherapist enhances trunk mobility and diaphragmatic breathing in the physiologically stable infant in the NICU, HCU or KMC ward. *n=20	75% agree 20% disagree 5% don't know	90% agree 10% disagree
6. Participants did not give an opinion		
7. The physiotherapist facilitates increased time in upright positions and includes guided antigravity extremity movement in the treatment of the physiologically stable infant in the NICU, HCU or KMC ward. *n=20	80% agree 15% disagree 5% don't know	90% agree 10% disagree
7. Participant's opinion: - *"Need to clarify upright positions. Don't see the need of antigravity extremity movements in preterm infants. Guessing that's passive movements – then no, we don't do that at all, not relevant in preterm infants."*		
8. The physiotherapist identifies the infants in the NICU, HCU or KMC ward with movement impairment or disorganisation s/he carefully incorporates graded intensity and paced facilitation of head and trunk control, antigravity movement and midline orientation. *n=20	80% agree 15% disagree 5% don't know	100% agree
8. Participants did not give an opinion		

9. The physiotherapist performs hydrotherapy before feeding of the physiologically stable infant with movement impairment in the NICU, HCU or KMC ward if indicated. *n=20	75% disagree 0% agree 25% don't know	30% disagree 20% agree 50% don't know
9. Participants' opinion: *The overall opinion was that hydrotherapy is not being practised at all in the NICU or HCU by physiotherapists and that they have no experience in practising hydrotherapy with prematurely born infants.*		
10. The physiotherapist as member of the MDT has a role in facilitating KMC (skin-to-skin contact) to improve parent or caregiver bonding with the infant in the NICU, HCU or KMC ward. *n=20	75% agree 20% disagree 5% don't know	90% agree 5% disagree 5% don't know
10. Participants' opinions: - *"Nurses can do that with caregivers. We encourage it but not our role with parents."* - *"… nurses territory still"*		
11. The physiotherapist introduces gradual exposure to multimodal stimuli for physiologically stable infants in the NICU, HCU or KMC ward approaching discharge from hospital. *n=20	70% agree 25% disagree 5% don't know	90% agree 5% disagree 5% don't know
11. Participants did not give an opinion		
12. The physiotherapist anticipates potential complications that could occur and prioritises preventative management / intervention in the treatment plan of the infant in the NICU, HCU or KMC ward. *n=20	75% agree 20% disagree 5% don't know	95% agree 5% don't know
12. Participants did not give an opinion		
Statements or recommendations with regard to parental / caregiver education		
1. Parent or caregiver education includes:		
- Benefits of KMC	Nineteen participants (n=19) agreed	
- The impact of environmental stressors (e.g. noise, light and handling) in the NICU or HCU on the infant	Eighteen participants (n=18) agreed	
- How to interpret the infant's physiological and behavioural cues during care and management	Nineteen participants (n=19) agreed	
- Information of developmental milestones	Nineteen participants (n=19) agreed	
- Meaning of terminology like corrected age	Twenty participants (n=20) agreed	
- What active developmental activities to do as a home program	Twenty participants (n=20) agreed	

- How to use positioning equipment e.g. supportive seats	Seventeen participants (n=17) agreed	
- Information on the importance of short-term follow-up assessments by the MDT up to one to two years post-corrected age	Twenty participants (n=20) agreed	
- Other types of education included: • Benefits of breast-feeding and tips to build up a supply of breastmilk while your baby cannot yet be breastfed • Unsure of what is currently being taught at our hospital	Two participants (n=2) provided an additional answer under the heading 'Other'.	
2. The physiotherapist is sensitive to adapt the amount and depth of information or education to the parents or caregivers of the infant not to overwhelm the parents or caregivers. *n=19	90% agree 5% disagree 5% don't know	100% agree
2. Participants did not give an opinion		
3. The physiotherapist adapts the information or education format (e.g. verbally, physical demonstrations, pamphlets or internet-based information) to the level of the parent's or caregiver's understanding and in case of a language barrier. *n=19	90% agree 5% disagree 5% don't know	100% agree
3. Participants did not give an opinion		
Statements or recommendations with regard to holistic family care		
1. As part of holistic family care the physiotherapist educates the mother of the infant who gave birth either naturally or with a caesarean on the benefits of appropriate exercises for pelvic floor muscles and abdominal exercises to promote core stability, as well as kinetic handling during the care of the infant. *n=19	69% disagree 26% agree 5% don't know	84% agree 11% disagree 5% don't know
1. Participants did not give an opinion		
2. As part of holistic family care the physiotherapist educates the mother of the infant who gave birth either naturally or with a caesarean, on the benefits of exercise for elevating serotonin levels to reduce the effect of post partum depression that could occur. *n=19	53% disagree 42% agree 5% don't know	95% agree 5% don't know
2. Participants did not give an opinion		
Statements with regard to the physiotherapist's professional ethical conduct		
1. A physiotherapist has to have to have postgraduate / post basic training to treat infants in NICU, HCU or KMC ward. *n=19	79% agree 21% disagree	79% agree 16% disagree 5% don't know

1. Participants did not give an opinion		
2. The physiotherapist should engage in professional communication with the nursing manager of the unit, or the professional nurse responsible for the infant, to discuss the status of the infant in the NICU, HCU or KMC ward, before assessment and intervention of the infant. *n=19	95% agree 5% don't know	100% agree
2. Participants did not give an opinion		
3. The physiotherapist should engage in professional communication with the nursing manager of the unit, or the professional nurse responsible for the infant, to discuss the parent's or caregiver's management of the infant being in the NICU, HCU or KMC ward, before interacting with the parents or caregivers with regard to providing information or education. *n=19	69% agree 26% disagree 5% don't know	95% agree 5% disagree
3. Participants did not give an opinion		
4. The physiotherapist should document the parent or caregiver consent, assessment and intervention according to the required professional standard. *n=19	79% agree 16% disagree 5% don't know	100% agree
4. Participants did not give an opinion		
5. The therapist's own ethical and moral values should direct the decision to treat the infant and putting the infant's needs first during the intervention. *n=19	100% agree	100% agree
5. Participants did not give an opinion		
Statements with regard to education and knowledge of the physiotherapist		
1. Post-basic training in terms of knowledge and experience is needed to assess and treat infants in the NICU, HCU or KMC ward safely, effectively and efficiently. *n=19	68% agree 32% disagree	90% agree 5% disagree 5% don't know
1. Participants did not give an opinion		
2. Physiotherapists who are treating or educating the infants' mothers regarding muscle strengthening, posture re-education and kinetic handling during care of the infant, should be adequately trained to do so. *n=19	79% agree 16% disagree 5% don't know	95% agree 5% disagree
2. Participants did not give an opinion		

3. Physiotherapists in SA could benefit from a post-graduate course with both theory and supervised clinical experience in neonatal physiotherapy where the physiotherapist will gain knowledge and experience in managing the infant, as well as supporting the parents or caregivers in the NICU, HCU or KMC ward. *n=19	63% agree 32% disagree 5% don't know	95% agree 5% disagree
3. Participants did not give an opinion		

* Number of participants who answered the question

7.3 DISCUSSION OF RESULTS OF THE FIRST ROUND OF THE DELPHI METHOD

Biographic information

The participants in the first round of the Delphi method were generally highly qualified and had adequate experience in the management of prematurely born infants, which made their opinions very valuable. Twenty-three participants (n=23) had postgraduate degrees or diplomas, and 24 (n=24) had more than five years' experience in the field. The majority (n=29) had experience in the clinical management of infants and 22 (n=22) were involved in the clinical or academic teaching of students / postgraduate students at tertiary institutions. Five participants (n=5) indicated that they were researchers, which implies that they were familiar with the principles of research (evidence-based practice). The fact that 22 participants were employed primarily in the private health care sector was important to the researcher, since this group had the lowest representation in the focus group discussions and key informant interviews in Phase 1 of the study. The opinions of the physiotherapists who were employed in the private health care sector during the application of the Delphi method brought balance to the overall comments of physiotherapists in the public and private health care sectors.

The role of the physiotherapist in the South African health care context

Table 7.4 contains statements with regard to physiotherapists employed in the health care sectors in South Africa. Areas of concern that were highlighted during the coding of the transcripts in Phase 1 of the study were confirmed by the participants in the first round of the Delphi method.

These areas of concern included:

- The lack of a standardised regime of care and management principles to be followed by the MDT, including the physiotherapist, during the care of prematurely born infants in NICUs, HCUs or KMC wards. Only 69% of the participants felt that physiotherapists have a role in the care and management of prematurely born infants during the hospitalisation phase. The contextualised CPG, which is the envisaged end product of the current study, may therefore make a contribution towards clarifying the role of physiotherapists and setting standards for the treatment of infants in NICUs, HCUs or KMC wards. The CPG contextualised through the research process in the current study may also contribute to clarifying the role of physiotherapists as members of MDTs working in NICUs, HCUs and KMC wards, and could contribute towards improving the MDT's awareness of what physiotherapy could contribute to the management of prematurely born infants in the South African health care system.

  The results of the questionnaire confirmed that there is currently no standardised screening of infants by the MDT, including the physiotherapist, as there is no memorandum of understanding or a specific standardised referral from the medical doctor / paediatrician that recommends the routine screening of infants by physiotherapists. This highlights the fact that the MDT / physiotherapist is unfortunately not consulted regarding the management of many infants who, during an initial screening in the NICU, HCU or KMC ward, might have been identified as having possible impairments or being at risk for developmental delays. It also highlights the fact that only the few infants whose parents or caregivers are referred to the MDT (excluding the nursing staff or paediatrician) / physiotherapist have an initial meeting with the team members / physiotherapist during which they might be made aware of the benefits of short- and long-term follow-up sessions after discharge.

- Intermittent or continuous KMC has positive physiological effects on prematurely born infants and could potentially strengthen the parent-infant bonding process that may be compromised in the NICU or HCU (Zeiner et al., 2016).

Participants expressed the opinion that physiotherapists do not currently support or educate parents or caregivers on the benefits of KMC, which would be an aspect that they should improve on / incorporate in the management of parent / caregiver education.

- Only a few parents or caregivers of prematurely born infants in NICUs or HCUs have an adjustment period before their infants are discharged. These parents or caregivers were better equipped and had more confidence in the care of the infant during the transition to their home environment.

  Participants in the focus group discussions and key informant interviews (Phase 1 of the study) suggested that before discharge, parents or caregivers who had access to KMC wards in the public health care sector could adjust to being the main carers of the infants under the close supervision of the MDT.

  There are no KMC wards in the private health care sector, but the participants felt that a facility or service similar to a KMC ward, for example a "room-in" facility, could be very beneficial to assist parents or caregivers in making the transition to their home environments easier.

- Not all infants are discharged with a follow-up appointment having been made with a member of the MDT. Participants were of the opinion that routine follow-up appointments were essential, especially in the case of infants identified as high-risk infants in the NICU, HCU or KMC ward. It was found that most infants had a follow-up appointment with a paediatrician after discharge, but that a referral from the paediatrician was needed for a follow-up appointment with any other member of the MDT, including the physiotherapist.

Collaboration between the MDT members

With regard to the statements in Table 7.5, which relate to the collaboration between MDT members in the South African health care sectors, the participants responded as follows:

- Approximately half of participants felt that the MDT members collaborate with regard to the developmental care of infants in the NICU, HCU or KMC ward.

However, all the participants were of the opinion that collaboration between MDT members should be improved in order to establish common, discipline-specific goals and a collaborative treatment plan for each infant. Only 50% of the participants had MDT ward rounds at their places of work, during which specific as well as common goals could be established and discussed. All the participants agreed that although MDT ward rounds are difficult to arrange due to the members' individual work schedules, such rounds are beneficial to the team and their approach to the care of the infants.

- The participants agreed that where an interprofessional collaborative approach is followed, the roles of different disciplines overlap. They further expressed the opinion that although the roles of the various disciplines are complementary, they are not the same. The benefits mentioned by the participants included that such an approach could be more cost effective for the parents or caregivers and potentially less invasive / overstimulating for the infant.

Physiotherapy management of the infant

The participants identified areas in which current practice does not fully align with the statements or recommendations. In response to these questions, they indicated that they found the statements or recommendations relevant to future practice. However, they did highlight a few areas of concern with regard to assessment, intervention and parental or caregiver education (Table 7.6). These concerns included:

- Although the assessment of non-nutritive sucking was not performed in their practice, the participants agreed that it should be done. However, they pointed out that physiotherapists do not observe feeding assessments done by speech therapists or nursing practitioners to intervene with respiratory care (by performing chest physiotherapy or suctioning) in the event that an infant aspirates, but that the nursing practitioners do the suctioning if indicated as the physiotherapist is not always present in the NICU / HCU or KMC ward. They also indicated that they find it unnecessary to observe the speech therapy assessment.

- Another form of intervention with which the participants strongly disagreed was hydrotherapy in the NICU, HCU or KMC ward.

They stated that this is not an intervention used at all in the health care system in the South African context and that they were not trained to use hydrotherapy in the local patient population.

- The participants agreed that they do not, as part of holistic family care, educate mothers who have given birth to prematurely born infants, either naturally or by caesarean, on the benefits of exercise to elevate serotonin levels to reduce the effects of possible postpartum depression. They were, however, of the opinion that education on the benefits of exercise could be beneficial to the mothers and recommended it for future practice.

7.4 CHANGES MADE TO RECOMMENDATIONS AND STATEMENTS IN PREPARATION FOR THE SECOND ROUND OF THE DELPHI METHOD

In the second round of the Delphi method, the researcher included the questions regarding the participants' biographic information and the statements and recommendations from Part III of the first-round Delphi questionnaire. The statements from Parts I and II of the questionnaire used in the first round of the Delphi method were excluded. The reason for the exclusion was that the participants in the first round of the Delphi method had confirmed that the statements regarding the hospital setting (NICUs, HCUs or KMC wards) and MDT members' roles and collaboration accurately described what the participants had found in their places of work. A summary of the hospital setting and MDT roles / collaboration will be included in the final version of the contextualised CPG (which is the end product of the current study).

Part III of the questionnaire that was used in the first round of the Delphi method contained the statements and recommendations concerning the physiotherapy management of infants in NICUs, HCUs and KMC wards. The statements and recommendations were rephrased based on comments made by the participants in the first round. The statements and recommendations were reorganised under the headings:

(i) *Clinical reasoning, clinician attitude or environmental factors*

(ii) *Prevention*

(iii) *Assessment*

(iv) *Intervention*

(v) *Family support and education*

(vi) *Holistic family care*

The statements relating to the physiotherapist's professional ethical conduct, education and knowledge, which formed part of the questionnaire used in the first round of the Delphi method, was also excluded from the questionnaire used in the second round. The reason for the exclusion of those statements was that the participants in the first round of the Delphi method had confirmed that the statements were relevant and that all but one of the statements received a consensus score of 90% and above. The one statement regarding the necessity of a postgraduate / post basic training for physiotherapists who treat prematurely born infants obtained a consensus score of 79%.

The results of the answers provided to the questions included in the questionnaire used in the second round of the Delphi method will be presented in the following section.

7.5 RESULTS OF THE SECOND ROUND OF THE DELPHI METHOD

The same procedure was used to provide the link to the questionnaire (second round of the Delphi method) to physiotherapists working in NICUs, HCUs or KMC wards or academic institutions across SA (see Chapter 3, section 3.5.1). In the second round of the Delphi method, 24 participants (n=24) gave their informed consent to participate. The identities of the participants were not divulged to the researcher (by the program used – LimeSurvey) and it was therefore not possible to determine whether they were the same participants who has participated in the first round of the Delphi method.

The *biographic information* of the participants included:

(i) **Age**

Only 21 participants (n=21) provided their date of birth. Table 7.6 shows the detailed distribution of participants according to age.

TABLE 7.7 AGE GROUPS OF PARTICIPANTS (N=21)

Age group in years:	*Number of participants*
60–70	2
49–59	5
39–48	4
29–38	9
28 or younger	1

(ii) **Gender**

Of the 21 participants (n=21) who answered this question, 20 were female (n=20) and 1 male (n=1).

(iii) **Level of qualification**

Figure 7.4 illustrates the level of qualification for the 23 participants (n=23) who answered this question. The two participants (n=2) who answered 'Other' had qualified with a National Diploma in Physiotherapy and a Postgraduate Diploma in Management.

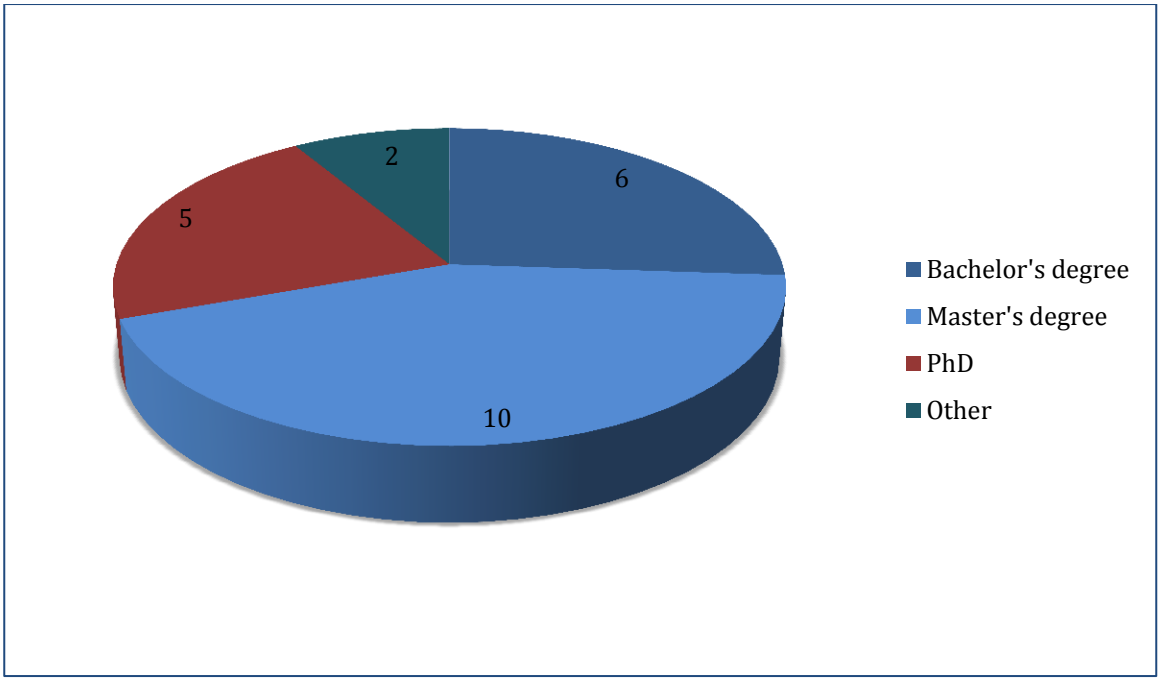


FIGURE 7.4 PARTICIPANT'S LEVEL OF QUALIFICATION (N=23)

(iv) **Primary employment**

The participants were asked in which health care sector they primarily treated prematurely born infants. They could give more than one answer (Figure 7.5).

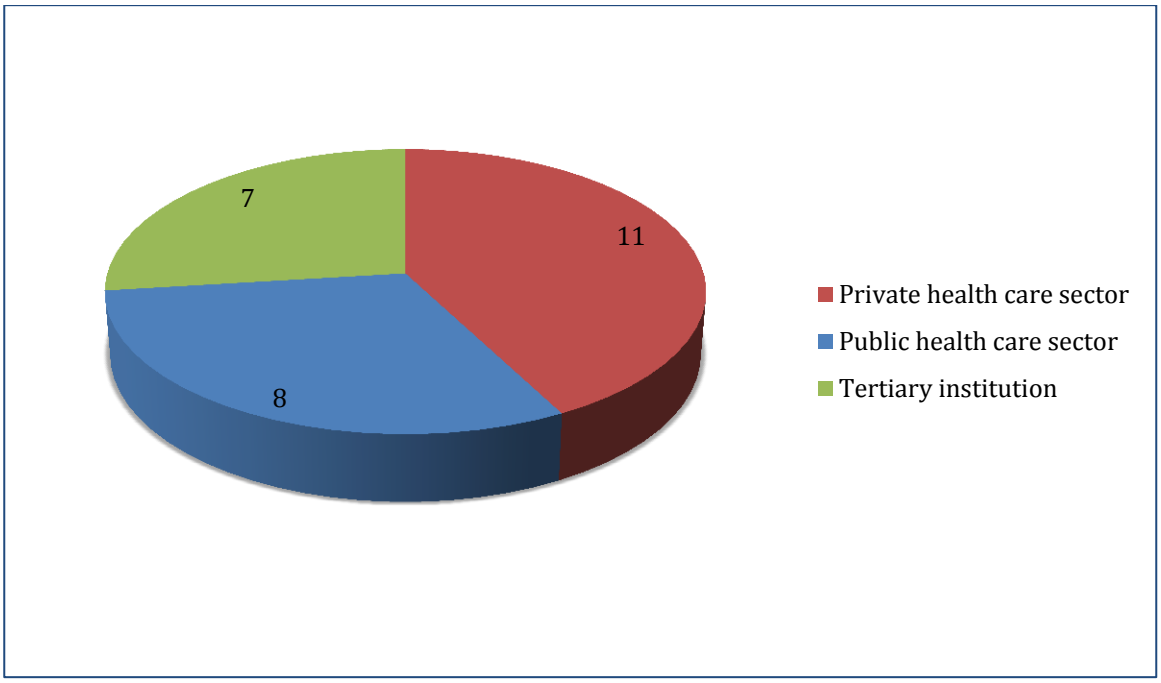


FIGURE 7.5 HEALTH CARE SECTOR IN WHICH PARTICIPANTS WERE PRIMARILY EMPLOYED (N=23)

(v) **Years' experience treating prematurely born infants**

The participants were asked to indicate the number of years of experience they had had in treating or working with prematurely born infants. Twenty-one (21) participants answered the question (Figure 7.6).

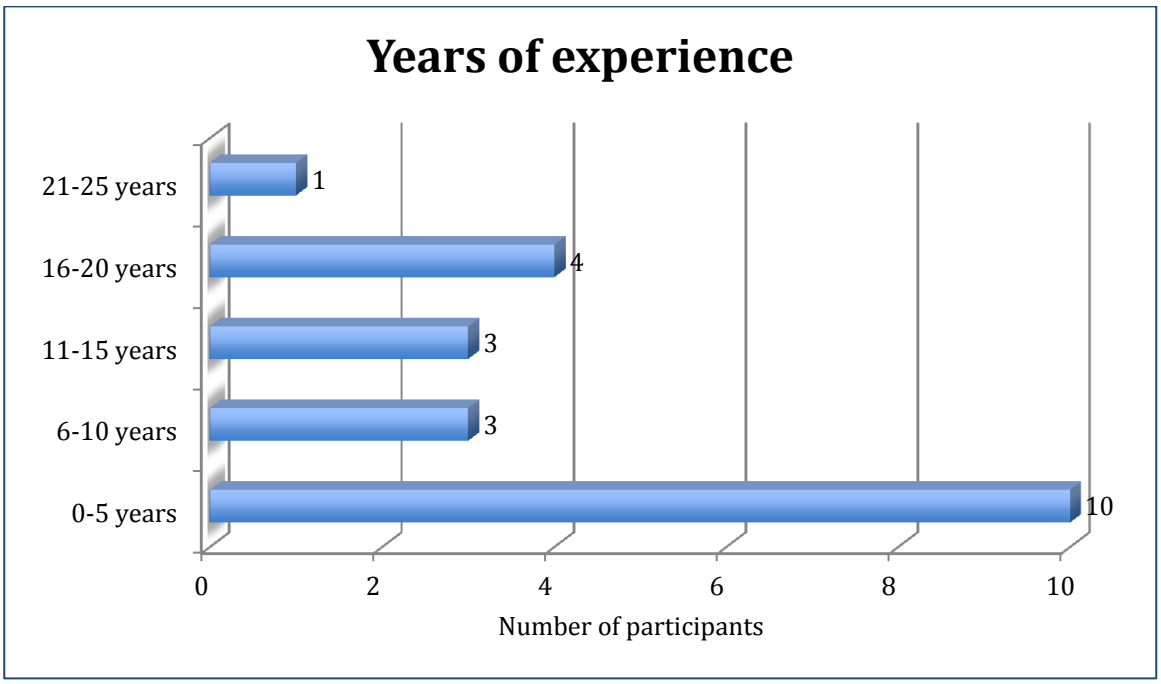


FIGURE 7.6 PARTICIPANTS' NUMBER OF YEARS OF EXPERIENCE IN TREATING PREMATURELY BORN INFANTS (N=21)

(vi)**Professional role**

Table 7.8 contains a summary of the participants' professional roles in the NICU, HCU or KMC ward. They were allowed to give more than one answer.

TABLE 7.8 PROFESSIONAL ROLE OF PARTICIPANTS IN THE NEONATAL INTENSIVE CARE UNIT, HIGH CARE UNIT OR KANGAROO MOTHER CARE WARD

The professional role in the NICU, HCU or KMC ward included:	***Number of participants***
Clinical management of infants	17
Policymaker (developing or monitoring policies)	3
Clinical teaching	9
Academic teaching of students at a tertiary institution	5
Researcher	7

Table 7.10 presents the participants' opinions regarding the statements and recommendations in the questionnaire for the second round of the Delphi method. Table 7.9 provides the interpretation of the colours used in Table 7.10. The changes made to the phrasing of statements or recommendations from the questionnaire used in the first round of the Delphi method are also indicated in Table 7.10.

Statements or recommendations used in the questionnaire for the first round of the Delphi method are printed in black text, and the rephrased versions used in the second round of the Delphi method are printed in blue text.

TABLE 7.9 INTERPRETATION OF THE COLOURS AND PERCENTAGES USED IN TABLE 7.10

Colours included:	***Meanings of the different colours:***	
	Statements derived from coded transcripts of focus group discussions and key informant interviews (Phase 1)	
	Recommendations derived from the CPG (Sweeney et al., 2010) and the NICU Care Path (Byrne et al., 2013a; Byrne et al., 2013b) (Phase 2)	
	80%–100% of the participants in agreement with a statement or recommendation	Strong recommendation for inclusion in contextualised CPG
	60%–79% of the participants in agreement with a statement or recommendation	Moderate recommendation for inclusion in contextualised CPG
	59% and less of the participants in agreement with a statement or recommendation	Weak recommendation, therefore excluded from contextualised CPG
Statements or recommendations in black text represent the phrasing used in the first round of the Delphi method.		
Statements or recommendations in blue text represent the rephrasing used in the second round of the Delphi method.		

TABLE 7.10 RESULTS BASED ON THE RESPONSES TO THE QUESTIONNAIRE USED IN THE SECOND ROUND OF THE DELPHI METHOD

Statements or recommendations included in the second round of the Delphi method	***Current practice***	***What practice should be***
Physiotherapy management of the infant		
Statements relating to clinical reasoning, clinician attitude or environmental factors		
1. The physiotherapist as member of the MDT monitors the respiratory function of the intubated or non-intubated infant in the NICU or HCU and will treat if indicated. 1. As member of the MDT, the physiotherapist monitors the respiratory function of the intubated or non-intubated infant and will treat if indicated. *n=18	61% agree 28% disagree 11% don't know	83% agree 6% disagree 11% don't know
1. Participants' opinions: *The overall opinion was that physiotherapists could only monitor the respiratory function of infants referred to them, and that if respiratory intervention was required, some physiotherapists would refer to a physiotherapist with special interest in respiratory care.* - *"don't think there is place in NICU for chest physiotherapy"* - *"the doctors don't want me involved with the management of the very small and sick kids."* - *"currently the nursing staff monitor the respiratory function and the neonatologist requires me to do the neurodevelopmental work and positioning."* - *"physiotherapy treatment (respiratory or neurological) depends on referral from the doctor."* - *"… I actively monitor the respiratory function but will refer to another physiotherapist if treatment is required."* - *"another physiotherapist available for respiratory physiotherapy… could do it more effectively."* - *"physiotherapy treatment (respiratory or neurological) depends on referral from the doctor."*		
2. The physiotherapist takes special care to implement sterile procedures in the NICU or HCU to prevent cross infection to the infant who has an underdeveloped immune system. 2. Takes special care to implement sterile procedures to prevent cross infection to the infant who has an underdeveloped immune system. *n=18	83% agree 17% don't know	89% agree 11% don't know

<table>
<tr><td colspan="3">2. Participants' opinions:
- "sterility is important for these patients as they are still developing immune system."
- "... most procedures done by physiotherapists in the NICU or HCU are clean and not sterile. You only wash and disinfect your hands with alcohol and they are not sterile? Even endotracheal or nasopharyngeal suctioning is considered a clean and not a sterile procedure?"
- "the unit is very strict on hand-washing techniques and sterile procedures, so [I] would assume so but not involved in the respiratory care."
- "infection control procedures are well established in our unit."</td></tr>
<tr><td>3. Screening of the infant in the NICU, HCU or KMC ward by the physiotherapist as member of the MDT could lead to early detection of impairments as well as anticipation of impairments that could arise after discharge from hospital.

3. Screening of the infant could lead to early detection of impairments as well as anticipation of impairments that could arise after discharge from hospital.
*n=18</td><td>78% agree
11% disagree
11% don't know</td><td>94% agree
6% don't know</td></tr>
<tr><td colspan="3">3. Participants' opinions:
The overall opinion was that the General Movement Assessment is very useful for screening infants, but this should be done with parental or caregiver consent. In the private health care sector, physiotherapists are only allowed to screen infants in the NICU or HCU on referral.
- "when asking parents if I can do developmental and general movement assessments the reaction has been mixed. Some are happy for me to go ahead. Others are not keen. Sometimes it is an added cost thing and sometimes they just want the baby to feed and get out of NICU and aren't interested in developmental stuff."
- "doctors at clinical hospital do not agree with routine screening of all NICU babies, so we only work on a referral system."</td></tr>
<tr><td>4. The physiotherapist is aware of the indications and contra-indications of physiotherapy interventions in the NICU, HCU or KMC ward.

4. Is aware of the indications and contra-indications of interventions given to prematurely born infants.
*n=18</td><td>94% agree
6% disagree</td><td>94% agree
6% disagree</td></tr>
<tr><td colspan="3">4. Participants' opinions:
- "... because some interventions could be dangerous, e.g. too much handling results in de-saturation."
- "... there are general indications and contra-indications, but the doctor and / or nursing staff are consulted before a treatment as well."
- "I am unsure of current practice at our institution."</td></tr>
</table>

5. The physiotherapist incorporates the view or opinion of the parents or caregivers of the infant when considering a treatment plan for the infant to empower the parents or caregivers. 5. Incorporates the view or opinion of the parents or caregivers of the infant when considering a treatment plan for the infant to empower the parents or caregivers. *n=18	83% agree 11% disagree 6% don't know	94% agree 6% disagree
5. Participants' opinions: - *"This needs a lot of time to educate mothers to participate. I would rather support education to re-enforce parent's understanding."* - *"Therapy is only once or twice a week, so parent involvement is crucial."* - "[There are] *Staffing and time constraints."*		
6. The physiotherapist plans the timing of the intervention to accommodate the care routine and the infant's resting periods in the NICU, HCU or KMC ward. 6. Plans the timing of the intervention to accommodate the care routine and the infant's resting periods. *n=18	72% agree 22% disagree 6% don't know	100% agree
6. Participants' opinion: *The overall opinion was that this is very important and that treatment should be strictly before a feed and not during a resting period. Participants found it difficult to time interventions in order to accommodate the care routine of the infant. One factor was time constraint, i.e. that the therapist has only specific times available to treat infants in the NICU, HCU or KMC ward. Therapists also have to take into account the unit's routine, and not only that of each individual infant. Timing of each infant's individual treatment by the therapist is therefore not always practical for the therapists, but they agreed that it is something to strive for.*		
7. The physiotherapist anticipates potential complications that could occur and prioritises preventative management / intervention in the treatment plan of the infant in the NICU, HCU or KMC ward. 7. Anticipates potential complications that could occur and prioritises preventative management / intervention in the treatment plan of the infant. *n=17	88% agree 12% don't know	94% agree 6% don't know
7. Participants did not give an opinion		
Recommendations with regard to prevention		

1. The physiotherapist collaborates with other MDT members to monitor the intubated or non-intubated infant in order to reduce the risk of skull deformity, torticollis and extremity malalignment through diligent symmetrical and neutral alignment and positioning to support neurodevelopment in the NICU or HCU. 1. Collaborate with caregivers to reduce risk for skull deformity, torticollis, and extremity malalignment through diligent positioning for symmetry and neutral alignment. *n=17	76% agree 12% disagree 12% don't know	100% agree
1. Participants' opinion: *The overall opinion was that this recommendation would require parental or caregiver education, i.e. teaching parents or caregivers how to handle the infant and emphasising the importance of varying the infant's positions during the day.* - *"Agree, but educating the parents should be enough, it is not necessary to place a baby in a good position and walk out and charge medical aid rates for therapy. Unless it is a baby with severe complications that requires physio intervention."* - *"… again due to resource limitations, this is not always easy as treatment is most often offered to children in need before prevention is taken on board, but should be done routinely."* - *"… there are risks related to handling, it is important to educate caregivers on correct handling skills especially first-time mothers."* - *"Regular position changing rotating through various positions is the key here, not just positioning."* - *"Caregivers limited by nurses taking over and not implementing positioning guidelines as the physio prescribes."*		
Recommendations with regard to assessment		
1. The physiotherapist conducts a baseline observation to determine the infant's physiological and behavioural stability or readiness for evaluative handling before assessment. 1. Conduct baseline observation to determine physiologic and behavioural stability (readiness) for evaluative handling. *n=17	88% agree 6% disagree 6% don't know	100% agree
1. Participant's opinion: - *"Physiological stability is always assessed prior to any handling. Behavioural stability observations need time, which we don't always have, and nurses do not have time to observe thoroughly to give information. We don't have full-time therapists in the neonatal wards."*		
2. Observation of the following:		

2.1 Behaviour (e.g. state transition, tolerance to routine care). *n=17	88% agree 6% disagree 6% don't know	100% agree
2.1 Participants' opinion: - *"Physiological stability is always assessed prior to any handling. Behavioural stability observations need time, which we don't always have, and nurses do not have time to observe thoroughly to give information. We don't have full-time therapists in the neonatal wards."* - *"Treatments are often multidisciplinary with the occupational therapist."*		
2.2 Vital signs (e.g. heart rate, temperature, saturation, pain with the Behavioural Indicators of Infant Pain (BIIP) or the Premature Infant Pain Profile (PIPP)). *n=17	82% agree 12% disagree 6% don't know	100% agree
2.2 Participants' opinion: *The overall opinion was that vital signs are observed, but that the participants do not use the BIIP or PIPP scales in practice.* - *"Vital signs* [are] *monitored. Observing pain but not using pain indicators as mentioned above. Doctors have started doing this."*		
2.3 Screen the musculoskeletal system (observe spontaneous movements) for infants 24–31 weeks gestational age. *n=17	82% agree 12% disagree 6% don't know	100% agree
2.3 Participants' opinion: *Participants mentioned that they make use of the General Movement Assessment to screen infants up to 20 weeks corrected age.*		
2.4 General movement (GM) assessment for infants >30 weeks gestational age. *n=17	88% agree 6% disagree 6% don't know	100% agree
2.4. Participants did not give an opinion		
3. Limited hands-on assessment:		
3.1 Diaper change (24-31 weeks gestational age). *n=17	59% agree 18% disagree 23% don't know	76% agree 6% disagree 18% don't know
3.1 Participants' opinions: - *"Depend on child's clinical situation and need for care."* - *"The doctors limit my involvement. I am not involved in all babies … they refer when they think a child needs help. I'd like to work preventative and consult with all pre-terms and parents, but unfortunately this doesn't happen."* - *"…. the nursing staff do this …"* - *"… the physio observes if changing is happening when we are present"* - *"Not always possible to be there when the diaper is changed, but try to assess with limited hands-on."*		

3.2 Re-positioning (24–31 weeks gestational age). *n=17	70% agree 18% disagree 12% don't know	88% agree 6% disagree 6% don't know
3.2 Participants' opinions: - *"In our unit the OT generally treats from a sensory perspective and includes re-positioning in her treatment."* - *"Depend on child's clinical situation and need for care"* - *".... nursing staff, with my guidance and explanation, do this where I worked."*		
3.3 Gentle facilitated movement (30–34 weeks gestational age). *n=17	65% agree 23% disagree 12% don't know	82% agree 12% disagree 6% don't know
3.3 Participants' opinions: - *"Only if it is clearly necessary. It should not be used routinely. These babies should be handled by mom unless abnormalities can already be seen."* - *"This was so dependent in their overall status, but I did not consider this an essential intervention at this time unless there were clear signs of pathology."*		
3.4 The physiotherapist does a limited hands-on assessment during the infant's diaper change or re-positioning and assesses the recoils and scarf sign. 3.4 Recoils and scarf sign (30–40 weeks gestational age). *n=17	59% agree 23% disagree 18% don't know	76% agree 12% disagree 12% don't know
3.4 Participants' opinions: - *"I believe General Movement assessments are more valuable."* - *"Other things more commonly observed. I should include this more often."* - *"Not currently used routinely."*		
3.5 The physiotherapist does a limited hands-on assessment during the infant's diaper change or re-positioning and assesses the palmar and plantar grasp. 3.5 Palmar and plantar grasp (28–40 weeks gestational age). *n=17	82% agree 12% disagree 6% don't know	94% agree 6% disagree
3.5 Participants' opinions: - *"I believe General Movement assessments are more valuable."* - *"Other things more commonly observed. I should include this more often."*		
3.6. The physiotherapist does a limited hands-on assessment during the infant's diaper change or re-positioning and assesses the non-nutritive sucking. 3.6 Non-nutritive sucking (30–34 weeks gestational age). *n=17	65% agree 23% disagree 12% don't know	88% agree 12% disagree

3.6 Participants' opinions: - *"Normally done by the speech therapist and not physio as we practise within an MDT."* - *"… can be observed by the physiotherapist as part of her assessment, but also forms part of the feeding assessment done by the speech therapist."* - *"This tires the baby. I do it last to be able to complete my assessment. If the baby is ok I will do that, or will consult with the speech therapist."*	
4. Full hands-on assessment (>32 weeks gestational age): 4.1 Standardised testing using the:	***Participants' opinion:***
• Prechtl's analysis	Eleven participants (n=11) / 65% agreed, stating: - *"Only by those who are trained. Training is expensive and requires leave to be taken."* - *"It is not hands-on, it is not invasive."*
• Developmental or milestone chart	Eleven participants (n=11) / 65% agreed, stating: - *"At the neonatal follow-up clinic and hypoxic-ischemic encephalopathy (HIE) clinic, i.e. as outpatients, usually a month post discharge*
• Clinical observation (as the only method of assessment)	Six participants (n=6) / 35% agreed, stating: - *"Feasible in SA NICU context"*
• Brazelton Neonatal Behavioural Assessment	Five participants (n=5) / 29% agreed, stating: - *"Feasible in SA NICU context"* - *"only after 35 weeks"*
• Bayley scale	Four participants (n=4) / 23% agreed, stating: - *"after 40 weeks"*
• Alberta infant scale	Four participants (n=4) / 23% agreed, stating: - *"only when older"* - *"post-discharge"*
• Newborn Behavioural Observations (NBO)	Four participants (n=4) / 23% agreed

• Movement ABCs	Seven participants (n=7) / 41% agreed, stating: - *"when older"* - *"at age 4 (I find 3 years old to be unreliable)"*	
• Test of Infant Motor Performance Screening Items (TIMPSI)	Three participants (n=3) / 18% agreed, stating: - *"when older"*	
• Test of Infant Motor Performance (TIMP)	Two participants (n=2) / 12% agreed, stating: - *"when older"*	
• Neurobehavioral Assessment of the Preterm Infant (NAPI)	Four participants (n=4) / 23% agreed	
• Hammersmith Infant Neurological Examination (HINE)	Four participants (n=4) / 23% agreed, stating: - *"after 40 weeks"*	
• Neurologic Assessment of the Preterm and Full Term Newborn Infant (NANI)	Four participants (n=4) / 23% agreed	
• Other standardised testing included: - Clinical observation included with more objective measures - Infant Neuromotor Assessment (INA)	Two participants (n=2) / 12% gave an additional answer under the heading 'Other', stating: - *"INA at 16-20 weeks corrected age, at neonatal follow-up clinic and HIE clinic"*	
4.2 Oral-motor control and feeding assessment using the:		
4.2.1 Neonatal Oral-Motor Assessment Scale (NOMAS) *n=17	41% disagree 24% agree 35% don't know	41% agree 35% disagree 24% don't know
4.2.2 Preterm Infant Breastfeeding Behaviour Scale (PIBBS) *n=17	47% disagree 18% agree 35% don't know	42% agree 29% disagree 29% don't know
4.2.3 Nursing Child Assessment Feeding Scale (NCAFS) *n=17	35% disagree 18% agree 47% don't know	35% agree 24% disagree 41% don't know
Participants' opinion: (4.2.1 – 4.2.3) *The overall opinion with regard to oral-motor control and feeding assessment was that it does not fall within the physiotherapist's scope of practice and should be done by the speech therapist. The participants did not feel qualified to do these assessments, which are not included in their undergraduate training. They agreed that it could be beneficial if these assessments were done as an MDT activity, since physiotherapists should be aware of what the infant's ability is as it impacts their assessment and treatment.*		

5. Sensory assessment: Vision / Hearing (>32 weeks gestational age):		
5. The physiotherapist does a sensory assessment of the physiologically stable infant in the NICU, HCU or KMC ward to determine visual focus, tracking and auditory localisation and orientation. 5.1 Visual focus *n=17	76% agree 12% disagree 12% don't know	94% agree 6% don't know
5.1 Participants' opinions: - *"in conjunction with OT if available."* - *"Physiotherapist is not consulted in this regard. Instead optometrist and speech therapist would be consulted. It is important for physiotherapists to be involved as these impairments adversely limit the infant's level of participation and interaction with the environment during play."* - *"I will check the vision – if a baby is able to make eye contact from 40 weeks gestational age."*		
5.2 Visual tracking *n=17	76% agree 12% disagree 12% don't know	94% agree 6% don't know
5.2 Participants' opinions: - *"Mostly done by speech therapist unfortunately"* - *"Crude vision (visual) screening is done as part of physiotherapy evaluation, but may be insufficient. A formal evaluation of vision by an ophthalmologist may be required based on the risk profile and clinical findings, e.g. ROP."* - *"I will check vision – if a baby is able to track from 40 weeks gestational age."*		
5.3 Auditory localisation and orientation *n=17	59% agree 12% disagree 29% don't know	76% agree 24% don't know
5.3 Participants' opinions: - *"This practice not done by physiotherapists in clinical practice."* - *"Crude hearing screening is done by physiotherapists during evaluation, but may be insufficient. A formal hearing screening by an audiologist may be required based on the risk profile (severe jaundice, meningitis etc.) and clinical findings."*		

6. The physiotherapist continuously monitors the infant's physiological and behavioural status during and after assessments in order to know what adaptations are necessary during future evaluative handling with regard to the pace and sequence of handling, especially during neuro-motor assessment. 6. Provide continuous physiologic and behavioural monitoring during and after evaluative handling to determine adaptation to evaluative handling and so signal the need for modification of pace and sequence, given expected physiologic changes, particularly during neuromotor test procedures. *n=17	82% agree 12% disagree 6% don't know	100% agree
6. Participants' opinions: - *"Mostly done by occupational therapist and not physio"* - *"... intervention is often multidisciplinary with an occupational therapist"*		
Recommendations with regard to intervention		
○ ***Facilitate calm state and motor organisation***		
1. The physiotherapist as member of the MDT should monitor the effect of the environmental, social and chemical stressors on the infant in the NICU or HCU to avoid overstimulation and other complications. 1. Collaborate with caregivers to create a developmentally supportive environment with modulated stimulation from light, noise and handling. *n=17	88% agree 6% disagree 6% don't know	100% agree
1. Participants' opinions: - *"Within constraints of the environment, yes"* - *"We educate mothers, but nurses not always on board and the environment is not conducive to being quiet and dark. Some nurses are actually obstructive in providing quiet environments."* - *"I am not in the ward on a daily basis. I try to implement this, but it is difficult when not officially part of the team."*		
2. The physiotherapist facilitates the infant's independent oral exploration through positioning of hands to the face for non-nutritive sucking that could improve organisation and readiness for feeding. 2. Assist with non-nutritive suck, containment, skin-to-skin care (KMC) and positioning. *n=17	82% agree 6% disagree 12% don't know	94% agree 6% don't know

2. Participant's opinion: - *"Sucking often done by speech therapist"*		
○ ***Positioning and handling***		
3. Address head shaping and musculoskeletal integrity (24–37 weeks gestational age). *n=17	82% agree 6% disagree 12% don't know	94% agree 6% don't know
3. Participant's opinion: - *"Normally nurses would implement this on children not seen by physio."*		
4. The physiotherapist enhances trunk mobility and diaphragmatic breathing in the physiologically stable infant in the NICU, HCU or KMC ward. 4. Promote comfort and respiratory function, including skin-to-skin care (KMC) (24–34 weeks gestational age). *n=17	88% agree 6% disagree 6% don't know	100% agree
4. Participant's opinion: - *"Nurses have the biggest role in guiding mothers on KMC."*		
5. Promote skin integrity (assist with scar management) (24–37 weeks gestational age). *n=17	47% agree 18% disagree 35% don't know	65% agree 6% disagree 29% don't know
5. Participants' opinion: *The overall opinion was that this is not part of current physiotherapy management of the infant.* - *"I am not sure what is meant by scar management."* - *"I do not feel qualified to do this."*		
6. Promote contained movement (24–34 weeks gestational age). *n=17	82% agree 6% disagree 12% don't know	94% agree 6% don't know
6. Participants did not give an opinion		
7. Promote gentle range of motion as indicated (>32 weeks gestational age). *n=17	59% agree 12% disagree 29% don't know	76% agree 6% disagree 18% don't know
7. Participants' opinions: - *"Only if evidence-based … not sure if passive movements plays a role in functional outcome during this time period."* - *"Depends on the case"* - *"I disagree with giving routine passive movements, as preterm infants are usually hypotonic and have a greater than normal (term) range of motion … may damage joint integrity and may not have developmental advantages."*		
8. Splinting as needed (>32 weeks gestational age). *n=17	35% agree 30% disagree 35% don't know	47% agree 24% disagree 29% don't know

8. Participants' opinion: *The overall opinion was that splinting falls within the occupational therapist's scope of practice and is not done by physiotherapists in the NICU or HCU.* - *"... depends on the case. Splinting is not always appropriate as the baby [is] pushed into the splint, which gives resistance. They are just building muscles and reinforcing neural pathways in the direction you don't want them to go!"*		
9. Facilitate periods of exploratory movement (>35 weeks gestational age). *n=17	70% agree 6% disagree 24% don't know	82% agree 18% don't know
9. Participants did not provide an opinion		
10. The physiotherapist supports the infant's body position and extremity movement in (a) supine position through 'nesting' of the infant in a semi flexed, midline aligned position and (b) prone position with a vertical roll under the thorax and / or horizontal roll under hips. 10. Support body positioning and extremity movement (1) supine position: semiflexed, midline alignment using blanket for swaddling containment or 'nest' of positioning rolls; and (2) prone position: vertical roll under thorax; horizontal roll under hips. *n=17	76% agree 12% disagree 12% don't know	94% agree 6% don't know
10. Participants' opinions: - *"Have not heard about this prone positioning."* - *"We don't use prone as much since caregivers are not always present and nurses are very short-staffed to supervise adequately."* - *"Prone if infant permits, taking ventilation and CPAP into account"*		
11. Promote alerting and interaction (e.g. auditory, tactile, visual and vestibular program (ATVV) (>35 weeks gestational age). *n=17	59% agree 18% disagree 23% don't know	88% agree 12% don't know
11. Participants' opinions: - *"This also falls within the domain of the OT in the SA context. General principles of sensory stimulation are addressed by physiotherapists, but more complex sensory difficulties often referred to sensory integrated trained therapists (OT)."* - *"As appropriate, sometimes even at this stage containment is more appropriate."* - *"Done more as outpatients, not while in hospital still. OT does more of this in a structured way."* - *"I don't know the programme, but interaction and stimulation are always important depending on the physical status of the neonate. The neonate must first survive."*		
○ ***Movement therapy***		
12. Guided extremity movements (allow infant to push against you) (>32 weeks gestational age). *n=17	53% agree 12% disagree 35% don't know	70% agree 6% disagree 24% don't know

12. Participants' opinion: - *"… evidence-based for this age population?"* *Participants were therefore not sure if guided extremity movements are evidence-based for prematurely born infants.*		
13. Increased time in upright position (>35 weeks gestational age). *n=17	65% agree 6% disagree 29% don't know	76% agree 24% don't know
13. Participants' opinion: *The overall opinion was that this should be achieved with KMC and that it depends on each individual infant. Participants also mentioned that the areas in the NICU or HCU are not always suitable for doing KMC comfortably due to insufficient seating for mothers.*		
14. Varied developmental positions (>32 weeks gestational age). *n=17	82% agree 6% disagree 12% don't know	100% agree
14. Participant's opinion: - *"Educating the staff and parents should be sufficient."*		
15. The physiotherapist enhances trunk mobility and diaphragmatic breathing in the physiologically stable infant in the NICU, HCU or KMC ward. 15. Enhancement of trunk mobility and diaphragmatic breathing (>35 weeks gestational age). *n=17	53% agree 12% disagree 35% don't know	76% agree 24% don't know
15. Participants' opinion: *The overall opinion was that this is not currently done in practice. However, the participants felt that this could be beneficial if incorporated with the management of the infant.*		
16. Promotion of antigravity movements (>35 weeks gestational age). *n=17	64% agree 18% disagree 18% don't know	76% agree 12% disagree 12% don't know
16. Participants' opinion: - *"My intuitive sense is that they should still be in utero so not impacted by gravity to any extent, so wait until at least 40 weeks gestation."* - *"Would rather promote brain coordination in general than anti-gravity movements"*		
17. Neurodevelopmental techniques (e.g. NDT) (>35 weeks gestational age). *n=17	65% agree 12% disagree 23% don't know	82% agree 18% don't know

17. Participants' opinion: *The overall opinion was that it could be beneficial for infants where it is indicated, and especially after discharge at follow-up appointments.* - *"… also MAES therapy"* - *"Basic NDT principles are applied. Neurodevelopmental therapy usually only initiated post-discharge at follow-up where neurodevelopmental deficits are identified to improve developmental outcomes."*		
18. The physiotherapist identifies the infants in the NICU, HCU or KMC ward with movement impairment or disorganisation s/he carefully incorporates graded intensity and paced facilitation of head and trunk control, antigravity movement and midline orientation. 18. In selected neonates with movement impairment or disorganisation, consider therapeutic handling carefully graded in intensity and paced to facilitate head and trunk control, antigravity movement and midline orientation. *n=17	82% agree 6% disagree 12% don't know	94% agree 6% don't know
18. Participants' opinions: - *"Head and trunk nuanced coordination rather than control. Promote variety rather than just midline and antigravity."* - *"Using a NDT (neurodevelopmental technique) approach"*		
19. The physiotherapist introduces gradual exposure to multimodal stimuli for physiologically stable infants in the NICU, HCU or KMC ward approaching discharge from hospital. 19. Consider gradual exposure to multimodal stimuli for stable neonates approaching hospital discharge. *n=17	76% agree 6% disagree 18% don't know	100% agree
19. Participants' opinions: - *"If the doctor refers"* - *"In particular in conjunction with the occupational therapist."* - *"Important not to expose to too much stimuli. The neonate already had too much exposure to stimuli especially in the NICU."*		
○ ***Oral motor***		
20. The physiotherapist facilitates the infant's independent oral exploration through positioning of hands to the face for non-nutritive sucking that could improve organisation and readiness for feeding. 20. Providing opportunities for independent oral exploration through positioning with hands to face, and for non-nutritive sucking to improve state organisation and readiness to feed. *n-17	70% agree 24% disagree 6% don't know	94% agree 6% disagree

20. Participants' opinion: *The overall opinion was that this is included in the speech therapist's role.*		
21. Determine readiness for and advancement of oral feeding trials using infant behavioural cues. *n=17	35% disagree 30% agree 35% don't know	64% agree 18% disagree 18% don't know
22. Encourage parental involvement with feeding and provide interventions for physiologic stability (pacing and slowed flow rate). *n=17	65% agree 23% disagree 12% don't know	76% agree 18% disagree 6% don't know
23. Initiate nutritive sucking with small amounts of breastmilk or formula (30–34 weeks gestational age). *n=17	35% disagree 30% agree 35% don't know	54% agree 23% disagree 23% don't know
24. Nutritive sucking and small volume nipple feeding 1–2x / day (32–37 weeks gestational age). *n=17	35% disagree 24% agree 41% don't know	52% agree 24% disagree 24% don't know
25. Gradual increase in frequency, volume and duration of nipple feedings (32–37 weeks gestational age). *n=17	35% disagree 24% agree 41% don't know	52% agree 24% disagree 24% don't know
26. Progression to autonomous breast or nipple feeding (35–40 weeks gestational age). *n=17	35% disagree 30% agree 35% don't know	52% agree 24% disagree 24% don't know
Participants' opinion: (21 – 26) *The overall opinion was that in the South African context this does not fall within the scope of practice of physiotherapists, but should rather be managed by the speech therapist, nursing practitioners and lactation specialists.*		
Recommendations and statements with regard to family support and education		
1. How to interpret the infant's physiological and behavioural cues during care and management. 1. Educate parents on infant behaviour, cues and developmental status (parent facilitates transition between states and recognises infant's readiness for feeding and play) to mitigate parental stress and to improve parental mental health outcomes. *n=17	76% agree 18% disagree 6% don't know	100% agree
1. Participant's opinion: - *"it just needs to be done correctly without causing more stress for the parents"*		

2. Benefits of KMC 2. Promote skin-to-skin (KMC) holding and parent-infant touch (24–34 weeks gestational age). *n=17	88% agree 6% disagree 6% don't know	100% agree
2. Participant's opinion: - *"Beyond 34 weeks gestational age as well"*		
3. The impact of environmental stressors (e.g. noise, light and handling) in the NICU or HCU on the infant 3. Provide information on the impact of environmental stressors (e.g. noise, light and handling) on the infant. *n=17	88% agree 6% disagree 6% don't know	100% agree
3. Participant's opinion: - *"Together with occupational therapist"*		
4. Promote social interaction and graded stimulation (>32 weeks gestational age). *n=17	82% agree 6% disagree 12% don't know	100% agree
4. Participant's opinion: - *"In conjunction with occupational therapist"*		
5. Facilitate participation in care and graded handling (>28 weeks gestational age). *n=17	76% agree 12% disagree 12% don't know	94% agree 6% don't know
5. Participant's opinion: - *"Done more by the occupational therapist in our unit"*		
6. Provide guidance regarding oral stimulation and non-nutritive sucking during gavage feedings (30–34 weeks gestational age). *n=17	35% disagree 35% agree 30% don't know	59% agree 29% disagree 12% don't know
6. Participants' opinion: *The overall opinion was that the speech therapist educates parents or caregivers of prematurely born infants regarding oral stimulation and non-nutritive sucking during gavage feedings. Participants felt that this is not within the scope and practice of the physiotherapist.*		
7. Provide guidance regarding neonatal sucking of small volumes (<10cc or <10 min) from bottle or syringe in nipple 1–2x / day (32–37 weeks gestational age). *n=17	35% disagree 30% agree 35% don't know	52% agree 30% disagree 18% don't know
8. Provide guidance and support to gradually increase volume and frequency of nipple feeding (>35 weeks gestational age). *n=17	35% disagree 24% agree 41% don't know	47% agree 29% disagree 24% don't know

Participants' opinion: (7–8) *The overall opinion was that in the SA context this does not fall within the scope of practice of physiotherapists, but should rather be managed by the speech therapist, nursing practitioners and lactation specialists.*		
9. Meaning of terminology like corrected age. 9. Provide developmental progress updates, explain need for age correction (>32 weeks gestational age). *n=17	82% agree 6% disagree 12% don't know	100% agree
9. Participant's opinion: - *"Very few babies are referred for neurodevelopmental screening or get placed on a developmental monitoring programme"*		
10. What active developmental activities to do as a home program. 10. Provide guidance in movement exercises (>32 weeks gestational age). *n=17	64% agree 6% disagree 30% don't know	82% agree 18% don't know
10. Participants' opinions: - *"Once discharged yes, but whilst still in NICU I would be careful."* - *"I consider this only needed if there are clear indications that there is a concern about their movement patterns."*		
11. How to use positioning equipment e.g. supportive seats. 11. Provide guidance in active developmental activities – prone, supine, side lying, supported sit, equipment instruction (e.g. supportive seats) (>32 weeks gestational age). *n=17	82% agree 12% disagree 6% don't know	100% agree
11. Participants' opinions: - *"I would suggest only when they are ready for discharge. The NICU environment in itself is stressful and overstimulated, so I would be careful to give too much stimulation."* - *"Only if there are clear indications"* - *"Only gets done for the few babies that get referred to physio"*		
12. Provide information on community resources for transition to home (>35 weeks gestational age). *n=17	64% agree 12% disagree 24% don't know	88% agree 12% don't know
12. Participants' opinions: - *"Doctors don't refer all* [infants] *discharged or let me know when patients are being discharged."* - *"Not aware of these for communities using public health facilities."* - *"Not being done"*		

13. Information on the importance of short-term follow-up assessments by the MDT up to one to two years post-corrected age to identify potential impairments / complications. 13. Provide information on the importance of short-term follow-up assessment by the MDT up to one to two years post-corrected age to identify potential impairments / complications. *n=17	76% agree 12% disagree 12% don't know	94% agree 6% don't know
13. Participants' opinions: - *"If doing general movement assessments you need to follow up at 12–19 weeks corrected age. And for early intervention you should be following up at least by 12 months, 24 months is too late for early intervention."* - *"… I disagree that it should be limited to two years corrected age. High-risk children should also be assessed during the preschool years and at school entry to identify problems that may not be apparent by the age of two years, e.g. ADHD, autism, learning disabilities."* - *"Most doctors do not believe in the importance of a developmental monitoring programme for all high-risk infants."*		
14. Provide instruction regarding a developmental home program (>35 weeks gestational age). *n=17	70% agree 18% disagree 12% don't know	88% agree 6% disagree 6% don't know
14. Participants' opinion: *The overall opinion was that this is only possible for the few infants referred for physiotherapy by the doctors and is not available to all infants in the NICU or HCU.*		
15. The physiotherapist is sensitive to adapt the amount and depth of information or education to the parents or caregivers of the infant not to overwhelm the parents or caregivers. 15. Is sensitive to adapt the amount and depth of information or education to the parents or caregivers of the infant not to overwhelm them. *n=17	82% agree 12% disagree 6% don't know	100% agree
15. Participants' opinions: - *"Very, very important"* - *"We prefer 2–3 sessions with the parents before discharge."*		

16. The physiotherapist adapts the information or education format (e.g. verbally, physical demonstrations, pamphlets or internet-based information) to the level of the parent's or caregiver's understanding and in case of a language barrier. 16. Implement multiple methods of instruction for parents and caregivers (demonstrations, discussion, video and written materials). *n=17	70% agree 24% disagree 6% don't know	100% agree
16. Participants' opinions: - *"I should include more written material."* - *"*[I should] *most especially* [include] *demonstrations and then* [also, as a] *therapist, observe* [the] *parent."*		
Statements with regard to holistic family care		
1. As part of holistic family care the physiotherapist educates the mother of the infant who gave birth either naturally or with a caesarean on the benefits of appropriate exercises for pelvic floor muscles and abdominal exercises to promote core stability, as well as kinetic handling during the care of the infant. 1. Educate the mother of the infant who gave birth either naturally or with a caesarean on the benefits of appropriate exercises for pelvic floor muscles and abdominal exercises to promote core stability, as well as kinetic handling during the care of the infant. *n=17	53% disagree 29% agree 18% don't know	94% agree 6% don't know
1. Participants' opinions: - *"In the government sector NICUs and maternity wards are not always in the same hospital, making treating of the mother more difficult."* - *"Medical aids do not pay … which make providing this service difficult, as parents can't afford all the sessions required."* - *"…. I am not sure this falls within the scope of neurodevelopmental programme. Though I do feel addressing the needs of the mother is important considering the mother child dyad. This falls outside of the expertise of a neurodevelopmental physiotherapist, and perhaps better addressed by a woman's health physiotherapist. However the neonatal physiotherapist can reinforce the information."* - *"I discuss handling of the infant, not pelvic floor exercises."* - *"Not done routinely, limited time. Screen for mothers who need to be referred for women's health services."*		

2. As part of holistic family care the physiotherapist educates the mother of the infant who gave birth either naturally or with a caesarean, on the benefits of exercise for elevating serotonin levels to reduce the effect of post-partum depression that could occur. 2. Educate the mother of the infant who gave birth either naturally or with a caesarean on the benefits of exercises for elevating serotonin levels to reduce the effect of post-partum depression that could occur. *n=17	54% disagree 23% agree 23% don't know	82% agree 6% disagree 12% don't know
2. Participants' opinions: - *"I agree that general physical activity requirements for health should be reinforced. However I am of the opinion that mothers of high-risk infants should be formally screened for psychosocial risk to identify those mothers who will likely benefit from psychological and educational interventions to mediate PTSD, stress, anxiety and depression associated with having a child in the NICU."* - *"I don't usually do this."* - *"Not done routinely. Have to be able to recommend cost-effective and safe ways to exercise in township areas. If moms didn't do exercise prenatally, they may need a lot of guidance and support in the community."*		

* Number of participants who answered the question

7.6 SUMMARY OF RESULTS OF THE SECOND ROUND OF THE DELPHI METHOD

Biographic information

The participants in the second round of the Delphi method were highly qualified as no less than 70% had postgraduate degrees or diplomas. Their input was of great value to the study as they were familiar with the principles of both research and evidence-based practice. This group of participants were well balanced with regard to experience in the management of prematurely born infants in their places of work. Ten participants (n=10) had five years' or less experience in the field and 11 (n=11) had worked in the field for at least six years. Their places of work were also equally distributed between the public and private health care sectors. The majority of the participants in the first round of the Delphi method were employed in the private health care sector.

A high percentage (71%) of participants in the second round of the Delphi method were involved in the clinical management of prematurely born infants, or were involved in the clinical or academic teaching of students at tertiary institutions (58%).

Seven (n=7) participants indicated that they were researchers and it was therefore expected that they would have a sound knowledge of the principles of research and evidence-based practice.

Physiotherapy management of the infant

The opinions of the participants on the relevance of the statements or recommendations that were included in the questionnaire for the second round of the Delphi method are discussed under the headings under which they were listed in the questionnaire (Table 7.10). The researcher focused on the statements or recommendations that achieved a consensus score below 60% in the column under the heading 'What practice should be'. Statements or recommendations that scored below 60% will not be included in the contextualised CPG (the end product of this study).

(i) *Assessment:*

The participants were adamant that the oral-motor control and feeding assessments (recommendation numbers 4.2.1–4.2.3) did not fall within the scope of practice of physiotherapists in SA. In their opinion, the speech therapist, lactation specialist or nursing practitioners should do those assessments. Participants also mentioned that physiotherapists do not receive training in oral or feeding assessments in their undergraduate training course, and that those who would like to be able to assess oral-motor control or feeding would have to complete a postgraduate course. Further training is therefore recommended before this can be added as a recommendation for future physiotherapy practice in SA.

(ii) *Intervention:*

The following was part of the physiotherapy interventions recommended for assisting in the *positioning and handling* of the infant:

The majority of the participants were of the opinion that splinting did not form part of the physiotherapist's scope of practice for the management of prematurely born infants.

They pointed out that splinting was mostly done by occupational therapists in the NICU, HCU or KMC ward and should not form part of physiotherapy management in future practice.

The following was part of the physiotherapy interventions recommended for assisting the prematurely born infant's *oral-motor* function:

Participants were of the opinion that physiotherapists could determine readiness for and advancement of oral feeding trials by following infant behavioural cues (64%), and could also encourage parental involvement in feeding by including interventions for physiological stability (76%) in future practice. However, the participants agreed that nutritive feeding interventions do not fall within the physiotherapist's scope of practice in SA and should be managed by the nursing practitioner, speech therapist or lactation specialist (Recommendations 23–26).

(iii) *Family support and education*

As noted during the discussion on oral feeding assessments and interventions, the participants were also adamant that it does not fall within the physiotherapist's scope of practice to provide education or information on the feeding of the infant to parents or caregivers (Recommendations 6–8). Parental or caregiver education regarding oral stimulation or feeding is therefore not recommended for inclusion in the future practice of physiotherapists treating prematurely born infants in NICUs, HCUs or KMC wards.

Having identified the statements or recommendations that were excluded from the contextualised CPG developed in the current study, the researcher will now describe the formulation of the end product, namely the contextualised CPG for physiotherapists treating hospitalised prematurely born infants.

7.7 CONTEXTUALISED CPG FOR THIS STUDY

The SASP's Professional Development Portfolio Committee provided guidelines regarding the format and content of a CPG developed for implementation by SASP members (e.g. background information, document structure, explanation of the context, statements and recommendations, numbering of statements and recommendations, colours to use in the layout of the document, font type, other potential criteria, etc.). The researcher will collaborate with the SASP in the final drafting of the document as the CPG document should be distributed among SASP members for implementation.

The consensus scores of 80% and above achieved by the statements and recommendations in the 'What practice should be' section (the green section in Table 7.11) in the second round of the Delphi method are an indication to potential users that those statements and recommendations are of high relevance, and can therefore be strongly recommended for application in clinical practice. The statements and recommendations in the 'What practice should be' section that were allocated scores of between 60% and 79% in the second round of the Delphi method are listed in the orange section in Table 7.11. Those statements and recommendations are indicated as being of moderate relevance to clinical practice.

The researcher also indicated the levels of evidence of each statement and recommendation, contextualised from the CPG by Sweeney et al. (2010), the NICU Care Path by Byrne et al. (2013a) and Byrne et al. (2013b), as well as those that were generated by this study (Van der Walt et al., 2019). The statements (derived from Phase 1 of the study and found to be relevant by participants in the second round of the Delphi method) received a level V rating, which indicates that they were based on expert opinion (according to the hierarchy of evidence described by Sweeney et al. (2010)). Table 7.11 contains the final list of statements and recommendations generated by the current study, which will be included in the contextualised CPG.

TABLE 7.11 STATEMENTS AND RECOMMENDATIONS INCLUDED IN THE CONTEXTUALISED CLINICAL PRACTICE GUIDELINE

Recommendations of high relevance		
Statements or Recommendations	***Level of evidence***	***References***
Clinical reasoning, clinician attitude or environmental factors		
As member of the MDT, the physiotherapist monitors the respiratory function of the intubated or non-intubated infant and will treat if indicated.	Level V	Van der Walt et al., (2019) (this thesis)
The physiotherapist takes special care to implement sterile procedures to prevent cross-infection to the infant who has an underdeveloped immune system.	Level V	Van der Walt et al., (2019) (this thesis)
Screening of the infant could lead to early detection of impairments as well as anticipation of impairments that could arise after discharge from hospital.	Level V	Van der Walt et al., (2019) (this thesis)
The physiotherapist is aware of the indications and contra-indications of interventions given to prematurely born infants.	Level V	Van der Walt et al., (2019) (this thesis)
The physiotherapist incorporates the view or opinion of the parents or caregivers of the infant when considering a treatment plan for the infant to empower the parents or caregivers.	Level V	Van der Walt et al., (2019) (this thesis)
The physiotherapist plans the timing of the intervention to accommodate the care routine and the infant's resting periods.	Level V	Van der Walt et al., (2019) (this thesis)
The physiotherapist anticipates potential complications that could occur and prioritises preventative management / intervention in the treatment plan of the infant	Level V	Van der Walt et al., (2019) (this thesis)
Prevention		
Collaborate with caregivers to reduce risk for skull deformity, torticollis and extremity malalignment through diligent positioning for symmetry and neutral alignment.	Level II	van Vlimmeren et al. (2008)
	Level II	Vaivre-Douret et al. (2004)
	Level II	Monterosso et al. (2003)
Assessment		
Conduct baseline observation to determine physiologic and behavioural stability (readiness) for evaluative handling.	Level II	Sweeney (1987)
Observation of the following:		
• Behaviour (e.g. state transition, tolerance to routine care).	Level V	Campbell (1999)
• Vital signs (e.g. heart rate, temperature, saturation, pain with the Behavioural Indicators of Infant Pain	Level V	Duhn et al. (2004)
	Pain:	

(BIIP) or the Premature Infant Pain Profile (PIPP).	Level I	Holsti et al. (2005)
	Level V	Holsti et al. (2011)
	Level IV	Grunau et al. (2006)
	Level II	Holsti et al. (2007)
	Level IV	Ahn et al. (2007)
	Level IV	Morison et al. (2003)
	Pain & KMC:	
	Level II	Johnston et al. (2003)
• Screen the musculoskeletal system (observe spontaneous movements) for infants 24–31 weeks gestational age.	Level V	Byrne et al. (2013a)
	Level V	Sweeney et al. (2002)
• General movement (GM) assessment for infants >30 weeks gestational age.	Level V	Einspieler et al. (2004)
	Level II	Snider et al. (2008)
	Level V	Noble et al. (2012)
	Level IV	Prechtl et al. (1997)
	Level IV	Ferrari et al. (2007)
	Level V	Cioni et al. (2007)
Limited hands-on assessment:		
• Re-positioning (24–31 weeks gestational age)	Level IV	Heimler et al. (1992)
	Level IV	Levy et al. (2006)
	Level V	Sweeney et al. (2002)
	Level IV	Grenier et al. (2003)
	Level V	Najarian (1999)
	Level V	Neufeld et al. (2000)
• Gentle facilitated movement (30–34 weeks gestational age).	Level V	Byrne et al. (2013a)

• Palmar and plantar grasp (28–40 weeks gestational age).	Level IV	Futagi et al. (1999)
	Level IV	Zafeiriou (2000)
	Level V	Schott et al. (2003)
• Non-nutritive sucking (30–34 weeks gestational age).	Level II	Neiva et al. (2008)
	Level I	Elserafy et al. (2009)
	Level V	Garber (2013)
Full hands-on assessment (>32 weeks gestational age):		
Sensory assessment: Vision / Hearing (>32 weeks gestational age):		
• Visual focus	Level II	White-Traut et al. (2002)
	Level V	Graven (2004)
• Visual tracking	Level V	Avery et al. (2005)
Provide continuous physiologic and behavioural monitoring during and after evaluative handling to determine adaptation to evaluative handling and so signal the need for modification of pace and sequence, given expected physiologic changes, particularly during neuromotor test procedures.	Level II	Sweeney (1987)
Intervention		
Facilitate calm state and motor organisation:		
Collaborate with caregivers to create a developmentally supportive environment with modulated stimulation from light, noise and handling.	Level I	Symington et al. (2006)
	Level II	Westrup et al. (2004)
	Level I	Peters et al. (2009)
Assist with non-nutritive suck, containment, skin-to-skin care (KMC) and positioning.	*Physiological stability*:	
	Level II	Buehler et al. (1995)
	Organised state:	
	Level I	Als (1994)
	Non-nutritive sucking:	
	Level II	Kirk et al. (2007)
	Level II	Boiron et al. (2007)
	Positioning:	
	Level I	Axelin et al. (2009)
	Level IV	Neu et al. (1997)

	Level II	Short et al. (1996)
	Level IV	Heimler et al. (1992)
	Level IV	Corvaglia et al. (2007)
	Level IV	Grenier et al. (2003)
	Level II	Ferrari et al. (2007)
	Skin-to-skin:	
	Level IV	Föhe et al. (2000)
	Level II	Bier et al. (1996)
	Level II	Wahlberg et al. (1992)
	Level II	Feldman et al. (2002)
Positioning and handling		
Address head shaping and musculoskeletal integrity (24–37 weeks gestational age).	Level V	Sweeney et al. (2002)
	Level II	Vaivre-Douret et al. (2004)
	Level V	Najarian (1999)
	Level V	Neufeld et al. (2000)
	Level II	van Vlimmeren et al. (2008)
	Level V	McManus et al. (2008)
Promote comfort and respiratory function, including skin-to-skin care (KMC) (24–34 weeks gestational age).	*Skin-to-skin benefits respiratory function:*	
	Level V	Cleary et al. (1997)
	Respiratory function:	
	Level IV	Heimler et al. (1992)
	Level IV	Levy et al. (2006)
	Level I	Axelin et al. (2009)
Promote contained movement (24–34 weeks gestational age).	*Contained movement*:	
	Level IV	de Vries et al. (2010)

	Level V	Prechtl (1990)
	Nested support:	
	Level II	Ferrari et al. (2007)
Facilitate periods of exploratory movement (>35 weeks gestational age).	Level V	Byrne et al. (2013b)
	Benefits:	
	Level IV	van Wijk et al. (2007)
	Level IV	Bhat et al. (2003)
Support body positioning and extremity movement (1) supine position: semiflexed, midline alignment using blanket for swaddling containment or 'nest' of positioning rolls; and (2) prone position: vertical roll under thorax; horizontal roll under hips.	Level II	Vaivre-Douret et al. (2004)
	Level II	Monterosso et al. (2002)
	Level II	Short et al. (1996)
	Level II	Ferrari et al. (2007)
Promote alerting and interaction (e.g. auditory, tactile, visual and vestibular program (ATVV) (>35 weeks gestational age).	*Calm alert state:*	
	Level V	Brazelton et al. (1995)
	ATVV program:	
	Level IV	White-Traut et al. (1997)
	Level II	White-Traut et al. (1993)
	Level II	White-Traut et al. (2002)
Movement therapy		
Varied developmental positions (>32 weeks gestational age).	*Varied holding positions:*	
	Level V	Hummel et al. (2005)
	Level V	Byrne et al. (2013b)
	Varied play positions:	
	Level IV	Majnemer et al. (2005b)
	Level IV	Dudek-Shriber et al. (2007)
	Level IV	Fetters et al. (2007)
	Infrequent prone position:	
	Level IV	Murney et al. (1998)

	Level IV	Kennedy et al. (2009)
Neurodevelopmental techniques (e.g. NDT) (>35 weeks gestational age).	Level II	Girolami et al. (1994)
	Level V	Sweeney et al. (2010)
In selected neonates with movement impairment or disorganisation, consider therapeutic handling carefully graded in intensity and paced to facilitate head and trunk control, antigravity movement and midline orientation.	Level II	Girolami et al. (1994)
Consider gradual exposure to multimodal stimuli for stable neonates approaching hospital discharge.	Level I	Symington et al. (2006)
Oral motor		
Providing opportunities for independent oral exploration through positioning with hands to face, and for non-nutritive sucking to improve state organisation and readiness to feed.	Level I	Pinelli et al. (2005)
Family support and education		
Educate parents on infant behaviour, cues and developmental status (parent facilitates transition between states and recognises infant's readiness for feeding and play) to mitigate parental stress and to improve parental mental health outcomes.	Level II	Kaaresen et al. (2006)
	Level I	Melnyk et al. (2006)
	Level V	(Byrne et al., 2013b)
	Level V	Blauw-Hospers et al. (2007)
	Level I	Heathcock et al. (2009)
	Level I	Heathcock et al. (2008)
Promote skin-to-skin (KMC) holding and parent-infant touch (24–34 weeks gestational age).	Level V	(Byrne et al., 2013b)
	Level V	Blauw-Hospers et al. (2007)
	Level I	Heathcock et al. (2009)
	Level I	Heathcock et al. (2008)
Provide information on the impact of environmental stressors (e.g. noise, light and handling) on the infant.	Level V	Van der Walt et al., (2019) (this thesis)
Promote social interaction and graded stimulation (>32 weeks gestational age).	Level V	Byrne et al. (2013b)
	Level V	Blauw-Hospers et al. (2007)

	Level I	Heathcock et al. (2009)
	Level I	Heathcock et al. (2008)
Facilitate participation in care and graded handling (>28 weeks gestational age).	Level V	Byrne et al. (2013b)
	Level V	Blauw-Hospers et al. (2007)
	Level I	Heathcock et al. (2009)
	Level I	Heathcock et al. (2008)
Provide developmental progress updates, explain need for age correction (>32 weeks gestational age).	Level V	Byrne et al. (2013b)
	Level V	Blauw-Hospers et al. (2007)
	Level I	Heathcock et al. (2009)
	Level I	Heathcock et al. (2008)
Provide guidance in movement exercises (>32 weeks gestational age).	Level V	Byrne et al. (2013b)
	Level V	Blauw-Hospers et al. (2007)
	Level I	Heathcock et al. (2009)
	Level I	Heathcock et al. (2008)
Provide guidance in active developmental activities – prone, supine, side lying, supported sit, equipment instruction (e.g. supportive seats) (>32 weeks gestational age).	Level V	Byrne et al. (2013b)
	Level V	Blauw-Hospers et al. (2007)
	Level I	Heathcock et al. (2009)
	Level I	Heathcock et al. (2008)
Provide information on community resources for transition to home (>35 weeks gestational age).	Level V	Byrne et al. (2013b)
	Level V	Blauw-Hospers et al. (2007)
	Level I	Heathcock et al. (2009)
	Level I	Heathcock et al. (2008)

Provide information on the importance of short-term follow-up assessment by the MDT up to one to two years post-corrected age to identify potential impairments / complications.	Level V	Van der Walt et al., (2019) (this thesis)
Provide instruction regarding a developmental home program (>35 weeks gestational age).	Level V	Byrne et al. (2013b)
	Level V	Blauw-Hospers et al. (2007)
	Level I	Heathcock et al. (2009)
	Level I	Heathcock et al. (2008)
The physiotherapist is sensitive to adapt the amount and depth of information or education to the parents or caregivers of the infant not to overwhelm them.	Level V	Van der Walt et al., (2019) (this thesis)
Implement multiple methods of instruction for parents and caregivers (demonstrations, discussion, video and written materials).	Level V	Dusing et al. (2008)
Holistic family care		
Educate the mother of the infant who gave birth either naturally or with a caesarean on the benefits of appropriate exercises for pelvic floor muscles and abdominal exercises to promote core stability, as well as kinetic handling during the care of the infant.	Level V	Van der Walt et al., (2019) (this thesis)
Educate the mother of the infant who gave birth either naturally or with a caesarean on the benefits of exercises for elevating serotonin levels to reduce the effect of postpartum depression that could occur.	Level V	Van der Walt et al., (2019) (this thesis)
Recommendations of moderate relevance		
Statements or recommendations	***Level of evidence***	***References***
Assessment		
Limited hands-on assessment:		
• Diaper change (24–31 weeks gestational age) **This depends on the clinical presentation of the infant. The physiotherapist is not always present during diaper changes, but should attempt to assess the infant by uisng limited hands-on techniques.*	Level V	Byrne et al. (2013a)
• Recoils and scarf sign (30–40 weeks gestational age). ** The General Movement Assessment might be more valuable as an assessment and physiotherapists do not routinely assess the recoils and scarf sign.*	Level IV	Dubowitz et al. (1970)
	Level V	Dubowitz et al. (1999)
	Level IV	Allen et al. (1990)

	Level V	Amiel-Tison (1968)
	Level IV	Lekskulchai et al. (2000)
Full hands-on assessment (>32 weeks gestational age):		
Standardised testing using one or more of the following tools:		
• Prechtl's analysis ** This is a non-invasive form of assessment, but physiotherapists need to receive appropriate training before this type of assessment can be included in their daily practice.*	Level V	Van der Walt et al., (2019) (this thesis)
• Developmental or milestone chart ** This assessment can be used for infants admitted to the hospital for long periods, or after discharge at short-term follow-up clinics.*	Level V	Van der Walt et al., (2019) (this thesis)
Assessment tools with weak recommendations that might be useful, depending on the individual infant:		
• Clinical observation (as the only method of assessment) • Brazelton Neonatal Behavioural Assessment • Bayley scale • Alberta infant scale • Newborn Behavioural Observations (NBO) • Movevement ABCs • Test of Infant Motor Performance Screening Items (TIMPSI) • Test of Infant Motor Performance (TIMP) • Neurobehavioural Assessment of the Preterm Infant (NAPI) • Hammersmith Infant Neurological Examination (HINE) • Neurologic Assessment of the Preterm and Full term Newborn Infant (NANI) • Infant Neuromotor Assessment (INA)		
Sensory assessment: Vision / Hearing (>32 weeks gestational age):		
• Auditory localisation and orientation ** A formal hearing assessment / screening by an audiologist may be required based on the risk profile of the infant (e.g. severe jaundice, meningitis, etc.) and clinical findings.*	Level V	Hall (2000)
	Level V	Avery et al. (2005)
	Level V	Graven (2000)
	Level II	Caskey et al. (2011)
Intervention		
Positioning and handling		
Promote skin integrity (assist with scar management) (24–37 weeks gestational age). ** Recommended only for physiotherapists who have received adequate training in this area.*	*Skin integrity:*	
	Level IV	Marcellus (2004)
	Scar management:	
	Level I	O'Brien et al. (2006)

	Level IV	Karagoz et al. (2009)
	Level IV	Sakuraba et al. (2011)
	Level IV	Wigger-Albert et al. (2009)
	Level IV	Engrav et al. (2010)
	Level I	Li-Tsang et al. (2010)
Promote gentle range of motion as indicated (>32 weeks gestational age). **This will depend on each individual infant's risk profile and clinical findings, therefore to be used only when indicated.*	*Contra-indications*:	
	Level IV	Dabezies et al. (1997)
	Level V	Weinstein (1994)
Movement therapy		
Guided extremity movements (allow infant to push against you) (>32 weeks gestational age) **This will depend on each individual infant's risk profile and clinical findings, therefore to be used only when indicated.*	*Joint molding (as normally occurs in utero):*	
	Level V	Sweeney et al. (2002)
	Decrease bone demineralisation:	
	Level I	Litmanovitz et al. (2003)
	Level I	(Moyer-Mileur et al., 2000)
Increased time in upright position (>35 weeks gestational age). **Increased time in the upright position could be incorporated with KMC, during which the physiotherapist then also assists with parent-infant bonding.*	*Supported sitting:*	
	Level V	Tecklin (1994)
	Level V	Byrne et al. (2013b)
	Positions after discharge:	
	Level IV	Bartlett et al. (2003)
Enhancement of trunk mobility and diaphragmatic breathing (>35 weeks gestational age). **Enhancement of trunk mobility and diaphragmatic breathing does not currently form part of physiotherapy management of the infant, but might be beneficial if incorporated.*	*Support lung function*:	
	Level II	Friedrich et al. (2006)
	Level II	Hutten et al. (2010)
	Level V	(Byrne et al., 2013b)
	Level IV	Dimitriou et al. (2002)
	Positioning effect on gastric emptying and reflux:	

	Level IV	van Wijk et al. (2007)
Promotion of antigravity movements (>35 weeks gestational age). **This will depend on each individual infant's risk profile and clinical findings, and should therefore be used only when indicated.*	*Antigravity movements:*	
	Level II	Green et al. (1995)
	Level II	Fallang et al. (2003b)
	Level II	Heathcock et al. (2004)
	Level IV	Heathcock et al. (2005)
	Level II	Dusing et al. (2005)
	Level I	Fallang et al. (2003a)
	Level II	Heathcock et al. (2009)
	Level II	Heathcock et al. (2008)
	Level II	Jeng et al. (2004)
	Level IV	Luo et al. (2009)
	Supine, prone and supported sitting antigravity movement:	
	Level I	Heathcock et al. (2009)
	Level V	Bly (1999)
	Level V	Boehme et al. (1990)
Oral motor		
Determine readiness for and advancement of oral feeding trials using infant behavioural cues. ** Recommended only for physiotherapists who have received adequate training in this area.*	Level II	Kirk et al. (2007)
	Level II	McGrath et al. (2002)
Encourage parental involvement with feeding and provide interventions for physiologic stability (pacing and slowed flow rate). ** Recommended only for physiotherapists who have received adequate training in this area.*	Level III	Law-Morstatt et al. (2003)
	Level II	Chang et al. (2007)

*Reason for categorising the statement or recommendation in the moderately relevant section

7.8 CONCLUSION OF PHASE 3

In this chapter, the researcher demonstrated how two rounds of the Delphi method were used to validate the statements and recommendations to be included in the CPG for the physiotherapy management of prematurely born infants in NICUs, HCUs or KMC wards in SA. The information included in the contextualised CPG should accurately describe the patient journeys of prematurely born infants in SA as established in this study by gathering information from MDT members involved in the care and management of prematurely born infants, from physiotherapists who were working in this field across the whole of SA during the time of the research, and from parents or caregivers who had prematurely born infants in NICUs, HCUs or KMC wards. This information was then compared to the appraised CPG and NICU Care Path identified in the literature, which are currently being used by physiotherapists in high-income countries. The results of each round of the applied Delphi method were provided and the implications of those results for the next step in the contextualisation process were discussed. A contextualised list of statements and recommendations generated with a view to compiling a CPG for physiotherapists working with prematurely born infants NICUs, HCUs and KMC wards in SA, which was the main aim of the current study, was completed as the end product of the study in Phase 3.

In the next and final chapter, the researcher will summarise the findings of the study.

CHAPTER 8

CONCLUSION OF THE STUDY

8.1 INTRODUCTION

In this final chapter, the researcher discusses the answer derived at in response to the research question posed at the beginning of the study. The discussion is therefore structured based on how the aims and objectives of the study were systematically achieved in order to contextualise a CPG for physiotherapists treating prematurely born infants in NICUs, HCUs or KMC wards in the South African public and private health care sectors. The methodology that was followed during the contextualisation process is reviewed to describe the procedural limitations of the study. Opportunities for the implementation of a CPG, and challenges that may be faced are also discussed, and recommendations for future research are made.

8.2 REVISITING THE AIMS AND OBJECTIVES OF THE STUDY

The primary aim of the study was to contextualise a CPG for physiotherapists treating prematurely born infants in NICUs, HCUs or KMC wards in the South African public and private health care sectors. In order to achieve the primary aim, the researcher had to address three secondary aims, which was done in three phases.

The first secondary aim (Phase 1 of the current study) was to *identify and describe the care pathways (patient journeys) of prematurely born infants and their parents or caregivers in NICUs, HCUs or KMC wards.* Since the initial literature search strategy on the care path of prematurely born infants during their hospital phase did not identify any relevant literature, a qualitative research approach was subsequently followed. The researcher aimed to achieve triangulation of data by gathering data from three different sources. The first source was focus group discussions and key informant interviews with MDT members who, at the time of the study, were treating prematurely born infants in both the private and public health care sectors. The second was structured interviews conducted with, and an online survey completed by parents or caregivers of prematurely born infants.

Based on the data obtained from the MDT and parents or caregivers of prematurely born infants, four patient journeys were constructed to indicate the health care context in which prematurely born infants are managed in the South African health care system. The third source was an integrative literature review**.** The literature review identified the CPG developed by Sweeney et al. (2010) and the NICU Care Path by Byrne et al. (2013a) and Byrne et al. (2013b), which describe the current practice of physiotherapists in NICUs or HCUs in high-income countries. The information on the current practice of physiotherapists in NICUs / HCUs provided the researcher with information on the role of the physiotherapist in the patient journey of prematurely born infants. The research methodology for Phase 1 was described in Chapter 3, section 3.3.

The second secondary aim (Phase 2 of the current study) was the *formulation of evidence-based statements and recommendations.* During this phase of the study, the patient journeys that represented the South African health care context were compared and integrated with the evidence-based recommendations included in the CPG (Sweeney et al., 2010) and NICU Care Path (Byrne et al., 2013a; Byrne et al., 2013b) identified during the integrative literature search. This enabled the researcher to compile the first list of evidence-based statements and recommendations that would be relevant to the South African health care context.

The third secondary aim (Phase 3 of the current study) was to *validate the evidence-based statements and recommendations based on the South African health care context*. The validation process involved the implementation of two rounds of the Delphi method. In the first round, the participating physiotherapists who were working in NICUs, HCUs or KMC wards or at academic institutions across SA awarded a score to each statement or recommendation. A combined consensus score was subsequently determined for each statement or recommendation. Statements or recommendations that obtained a consensus score of 60% or above were included, with or without the modifications suggested by the participants in the second round of the Delphi method. After the second round of the Delphi method, the consensus scores were again determined. Statements or recommendations that obtained a consensus score of 80% or above were included in the contextualised CPG as recommendations of high relevance. Statements or recommendations that obtained a consensus score of between 60% and 79% were included in the contextualised CPG as recommendations with moderate relevance.

Phase 3 of the study was therefore completed with the presentation of the list of evidence-based statements and recommendations which forms the basis of the contextualised CPG for physiotherapists treating prematurely born infants in NICUs, HCUs and KMC wards in SA.

The compilation of this list of validated evidence-based statements and recommendations completed the research process undertaken to achieve the primary aim of this study. This list will be used to write the final CPG document which will be presented to the Professional Development Portfolio Committee of the SASP for distribution to its members.

8.2.1 Interpretation of the current clinical practice guideline in terms of the eco-systemic model of influences on the development of prematurely born infants in neonatal intensive care units, high care units or kangaroo mother care wards

The researcher adapted the eco-systemic theory described by Bronfenbrenner (1979) to explain how the inherent qualities of children and their environments interact to influence their growth and development in order to establish and describe how the hospital environments influence the growth and development of prematurely born infants being treated in NICUs, HCUs and/or KMC wards (Chapter 1, Section 1.2), and how the treatment received may influence their future developmental potential.

Figure 1.3 (Chapter 1, Section 1.2) illustrates how the different levels of the Bronfenbrenner theory / model (1979) influence the infant during the hospitalisation phase on the *micro level* (infant's anatomical and physiological development in the NICU / HCU / KMC ward), the *meso level* (the influence of the hospital environment on the infant), the *exo level* (MDT policies and practices in the NICU, HCU or KMC ward) and the *macro level* (cultural influences and expectations of the parents or caregivers and the MDT with regard to the infant's development while being hospitalised).

Figure 8.1 is a duplication of Figure 2.9 (Chapter 2, section 2.2.2.3), which indicates how Bronfenbrenner's (1979) eco-systemic theory integrates with the dynamic systems and ICF models used by Sweeney et al. (2010).

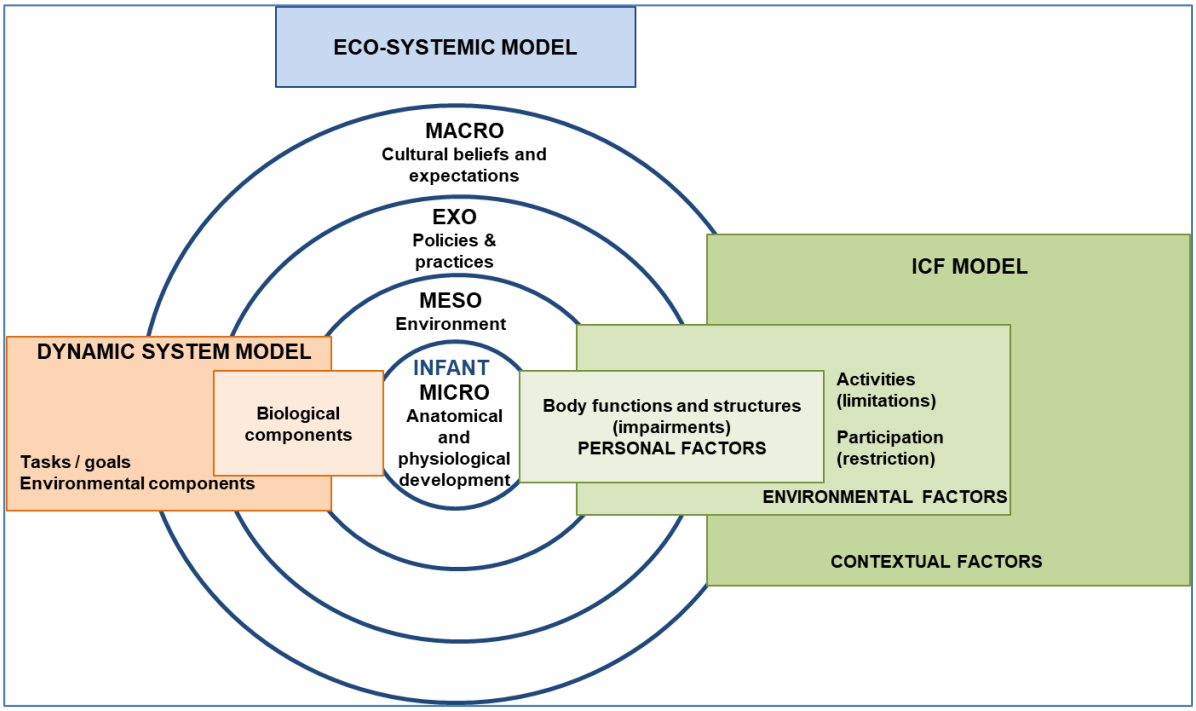


FIGURE 8.1 INTEGRATION OF THE DYNAMIC SYSTEMS MODEL, ECO-SYSTEMIC MODEL AND ICF MODEL

The contextualised statements and recommendations are categorised according to the various aspects of the three models (Table 8.1). The statements or recommendations in the green blocks are considered to be of high relevance, while those in the orange blocks are considered to be of moderate relevance to physiotherapy practice in SA.

TABLE 8.1 CATEGORISED STATEMENTS AND RECOMMENDATIONS

Bronfenbrenner theory / model	***Dynamic systems theory***	***International Classification of Functioning and Disability (ICF)***	***Statements / Recommendations***
Micro level	Biological components	Personal factors: body functions, structures, impairments	***Clinical reasoning, clinician attitude or environmental factors:***
			"… monitors the respiratory function … and will treat if indicated"
			"screening of the infant could lead to early detection of impairments …"
			"… plans the timing of the intervention to accommodate … the infant's resting periods"
			"… anticipates potential complications … prioritises preventative management / intervention …"
			Prevention:
			"… reduce risk for skull deformity, torticollis and extremity malalignment …"
			Assessment:
			"… determine physiologic and behavioural stability …"
			Observation of the following: • Behaviour • Vital signs • Screening of the musculoskeletal system • General movement assessment

			Limited hands-on assessment: • Re-positioning • Gentle facilitated movement • Palmar and plantar grasp • Non-nutritive sucking
			• Diaper change • Recoils and scarf sign
			Full hands-on assessment:
			Sensory assessment: • Visual focus • Visual tracking
			• Auditory localisation and orientation
			"… continuous physiologic and behavioural monitoring during and after evaluative handling …"
			Standardised testing using one or more of the following tools: • Prechtl's analysis • Developmental or milestone chart, etc.
			Intervention:
			Positioning and handling:
			"Address head shaping and musculoskeletal integrity …"
			"Promote comfort and respiratory function, including skin-to-skin care …"
			"Promote skin integrity …"

			"Promote gentle range of motion as indicated …"
			Movement therapy:
			"… facilitate head and trunk control, antigravity movement and midline orientation"
			"Guided extremity movements …"
			"Increased time in upright position …"
			"Enhancement of trunk mobility and diaphragmatic breathing …"
			"Promotion of antigravity movements …"
			Oral motor:
			"Determine readiness for and advancement of oral feeding trials using infant behavioural cues …"
Meso level	Tasks / goals and environmental components	Environmental factors: activity limitations and participation restrictions	***Clinical reasoning, clinician attitude or environmental factors:***
			"… implement sterile procedures …"
			Intervention:
			Facilitate calm state and motor organisation:
			"… supportive environment with modulated stimulation from light, noise and handling"
			"Assist with non-nutritive suck, containment, skin-to-skin care (KMC) and positioning"
			Positioning and handling:

			"Promote contained movement …"
			"Facilitate periods of exploratory movement …"
			"Support body positioning and extremity movement (1) supine … (2) prone …"
			"Promote alerting and interaction …"
			Movement therapy:
			"Varied developmental positions …"
			"Neurodevelopmental techniques …"
			"… exposure to multimodal stimuli …"
			Oral motor:
			"… independent oral exploration … improve state orgainisation …"
			"Encourage parental involvement with feeding and provide interventions for physiologic stability …"
			Family support and education:
			"Promote social interaction in care and graded stimulation …"
			"Facilitate participation in care and graded handling …"
			"Provide guidance in active developmental activities … equipment instruction, e.g. supportive seats …"
			"Provide instruction regarding a developmental home program…"

Exo level	-	-	***Clinical reasoning, clinician attitude or environmental factors:***
			"… aware of the indications and contra-indications of interventions …"
			Family support and education:
			"Educate parents on infant behaviour, cues and developmental status …"
			"Promote skin-to-skin (KMC) holding and parent-infant touch …"
			"Provide information on the impact of environmental stressors …"
			"Provide developmental progress updates, explain need for age correction …"
			"Provide guidance on movement exercises …"
			"Provide information on the importance of short-term follow-up assessment by the MDT …"
			"Implement multiple methods of instruction for parents and caregivers …"
			Holistic family care:
			"Educate the mother … [on the] benefits of appropriate exercises …, as well as kinetic handling …"

			"Educate the mother…[on the] benefits of exercise … [to] reduce the effect of postpartum depression …"
Macro level	-	Contextual factors	***Clinical reasoning, clinician attitude or environmental factors:***
			"… incorporates the view or opinion of the parents or caregivers … when considering a treatment plan … empower the parents or caregivers"
			Family support and education:
			"Educate parents … to mitigate parental stress and to improve parental mental health outcomes"
			"Provide information on community resources for transition to home …"
			"The physiotherapist is sensitive to adapt the amount and depth of information or education to the parents or caregivers of the infant not to overwhelm them."

As can be seen in Table 8.1, the statements and recommendations formulated in the current study are aimed firstly at the physiotherapy management of the prematurely born infant on the *micro* and *meso levels* of the eco-systemic model. The physiotherapist aims to decrease the potential negative impact of the NICU, HCU and KMC ward environments (*meso level*) on the infant's anatomical and physiological development (*micro level*). The statements or recommendations relating to physiotherapy management also impact the biological and environmental components of the dynamic system model, and the personal and environmental aspects of the ICF model.

The second aim was to guide the physiotherapists' practice (*exo level*), as well as the family (parent / caregiver) support, education and holistic family care provided by them.

On the third (*macro)* level of the eco-systemic model, the statements and recommendations included in the contextualised CPG might impact the cultural beliefs and expectations of the infants' parents or caregivers, as well as those of the MDT. The potential impact of the cultural beliefs and expectations of the parents or caregivers could be achieved if the physiotherapist incorporated the views or opinions of the parents or caregivers in the plan for the management of their infant and tried to reduce the impact of stress on the parents or caregivers. The statements and recommendations that address the *macro level* of the eco-systemic model also address the contextual factors in the ICF model.

The categories of Bronfenbrenner (1979) model / theory address more aspects of the holistic management of prematurely born infants and their parents or caregivers, and therefore provide not only a more holistic, but also a more detailed model for the care of prematurely born infants in NICUs / HCUs and KMC wards.

Table 8.1 contains the list of statements and recommendations which forms the basis of the contextualised CPG. The final CPG document will be written in the format of the SAGE guide.

The challenges and opportunities identified during the course of this research study are discussed in the following section.

8.2.2 Challenges and opportunities identified

Participants in the focus group discussions and key informant interviews expressed the opinion that not enough physiotherapists are currently involved in the care and management of prematurely born infants during their hospitalisation and the short-term follow-up visits after discharge from the hospital. Reasons for the lack of physiotherapists treating prematurely born infants in NICUs, HCUs or KMC wards and at the follow-up clinics included a shortage of physiotherapists specialising in this field, as a result of which physiotherapists had to prioritise the clinical areas in which their time would be best spent, e.g. treating infants in the NICU, HCU or KMC ward versus treating them at the short-term follow-up clinics.

Another reason for the lack of involvement of physiotherapists in the care of these infants could be attributed to MDT's uncertainty regarding the exact role physiotherapists should fulfil in the treatment of prematurely born infants. Especially in the private sector, where prematurely born infants are not routinely assessed and treated by physiotherapists, they are not referred for physiotherapy since MDT members are not sure of the extent to which physiotherapists could contribute to the well-being and development of infants in the NICU, HCU or KMC ward. One reason for not referring prematurely born infants for physiotherapy that was mentioned by the MDT members was that they were not sure that physiotherapists had the knowledge or experience needed for the treatment of this vulnerable group of patients due to a the lack of CPD / postgraduate training subsequent to their undergraduate qualification. Prematurely born infants in NICUs, HCUs or KMC wards who are denied treatment by physiotherapists, or referral to a physiotherapist at a follow-up clinic, are deprived of the unique contribution of physiotherapy to their well-being and optimal development.

Unfortunately physiotherapists in SA currently do not have access to postgraduate training (holistic continuing professional development) that can improve their knowledge of the management of prematurely born infants, or to practical experience under the supervision of experienced / specialist therapists.

Interprofessional collaborative practice could be an opportunity to address the basic need for various forms of intervention in the case of infants in NICUs, HCUs and KMC wards in order to minimise the possibility of overstimulation. According to the findings of this study, interprofessional collaboration is not the current practice in NICUs, HCUs or KMC wards in SA. Rose (2011) mentions that MDTs working in ICUs have to cope with complex, highly stressful and dynamic environments, and the researcher found this to also be true for those working in NICUs. Rose (2011) and Dunn, Cragg, Graham, Medves and Gaboury (2013) further suggest that effective interprofessional collaboration could potentially result in improved outcomes for critically ill patients (for example prematurely born infants) and explains this type of collaboration as the process of promoting and optimising the active participation of all health care professions (MDT members) in the clinical decision-making with the focus on patient needs whilst ensuring respect for each team member's contribution.

Aspects of effective interprofessional collaboration listed by Rose (2011) include: (i) shared goals and partnerships including explicit, complementary and interdependent roles; (ii) mutual respect; and (iii) power sharing. The researcher agrees with this author, but feels that the MDT should be educated in the application of this collaborative approach to patient care if it is to be effectively applied in the South African health care context. The MDT will also need education on the role and scope of practice of each individual discipline before interprofessional collaboration can be possible.

In this study the researcher also identified an opportunity for the physiotherapist to provide better support to the parents or caregivers of prematurely born infants. The parents or caregivers who had completed the questionnaire on the patient journey, especially those in the private health care sector where there is no standardised follow-up care for infants as is available in the public health care sector, expressed a need for support and education after the infant's discharge. Physiotherapists should emphasise the importance of short-term follow-up and should educate parents or caregivers on the possible benefits of follow-up visits for both them and the infant. During follow-up visits, parents or caregivers will be able to consult with appropriate health care professionals and would not have to wait for a paediatrician to refer the infant to the MDT.

Based on the list of contextualised statements and recommendations, the contextualised CPG developed in this study could standardise evidence-based clinical care, which is an important aspect in the management of prematurely born infants (Bhutta et al., 2013). The contextualised CPG could also assist in creating awareness and improved knowledge with regard to the role of the physiotherapist in the management of prematurely born infants, not only for fellow physiotherapists but also other MDT members which might improve collaboration – another important aspect in the management of prematurely born infants (Bahtsevani Rn et al., 2010). The contextualised CPG could further improve the patient outcome of these infants through a reduction in the variation of practice / treatment, the length of hospitalisation which could lead to a reduction in cost (Almazrou Mazrou, 2013).

8.3 LIMITATIONS OF THE STUDY

Limitations experienced during the different phases should be taken into account when considering the findings of the study.

The limitations identified during Phase 1 were:

- The information used for the formulation of the patient journey was gathered only at hospitals or practices in the greater Tshwane Metropole (Gauteng Province).

  The researcher acknowledges that the journey for prematurely born infants may be different in provinces with fewer tertiary / academic hospitals or private hospitals with NICUs. However, any prematurely born infant being treated in a NICU and / or HCU requires specialised health care, which should be the same throughout SA. Treatment of a prematurely born infant in a KMC ward, where the mother or caregiver is the main provider of care under the supervision of, and with specialised guidance from a nursing sister and the medical doctor / paediatrician, should also be standardised throughout the nine provinces. Potential differences in the standard of care may occur as a result of differences in the expertise of health care personnel and the availability of health care professionals who are qualified to render a specialised service.

  During the two rounds of the Delphi method, the researcher aimed to limit the effect of the potential difference in the standard of physiotherapy management of prematurely born infants by incorporating the contributions made by as many physiotherapists as possible from all nine provinces in order to validate the evidence-based statements and recommendations.

- The participants in both the focus group discussions / key informant interviews with MDT members and the structured interviews / online survey conducted with parents or caregivers were mainly female, therefore very little male input was obtained. Input from the fathers of the infants on how they experienced their infants' patient journeys would have enriched the data and it is recommended for inclusion in future studies in order to find a way to more effectively address the needs of this group.

- The MDT members who participated in the focus group discussions and key informant interviews were typical / representative of teams working in NICUs, HCUs or KMC wards. The fact that the interviewer (researcher) is a physiotherapist might have influenced the responses of the participants. However, since both positive and negative aspects of the role of physiotherapy were freely discussed during discussions and interviews, the researcher is of the opinion that researcher bias could have had only a minimal effect on the results.

- An interpreter was available during the structured interviews with parents or caregivers who were not English or Afrikaans speaking, but none of the participants opted to make use of this service. The parents or caregivers might have felt intimidated by the fact that the interview was being conducted by a health professional (researcher), but it was made clear that the interviewer was not involved in the treatment of their infants. However, the respondents who agreed to participate in the interviews could still have felt too intimidated to give their honest opinions despite having been reassured that their opinions would not influence their infants' health care.

- The researcher used the same questionnaire that was used during the structured interviews in a secured online survey for parents or caregivers. The online survey was sent to appropriate support groups for parents or caregivers and they were asked to voluntarily log into the questionnaire. Although these respondents were not exposed to the researcher and potential intimidation by her presence when they posted their answers, only a limited number of potential respondents had access to the internet, and therefore to the online survey, and were consequently not representative of parents or caregivers from all the different socio-economic backgrounds. The online survey was, however, complementary to the face-to-face interviews conducted to recruit participants from all walks of life.

- The researcher included the perspectives of parents or caregivers from only one province, and concedes that parents or caregivers from other provinces of SA might have experienced the patient journey differently.

The limitations identified for Phase 2 were:

- The aim of the search strategy was to identify CPGs, competency frameworks or position statements that are currently being used by physiotherapists in practice and are focused on the physiotherapy management principles applied when treating prematurely born infants during the hospitalisation phase. The researcher acknowledges that guidelines may exist that have not been published, or may not be in English, and would therefore not have been identified during the literature search. The search strategies were conducted by the researcher as well as a librarian who is familiar with the field of physiotherapy.

- Although the literature search strategies might have differed, the two sets of results were compared and complemented each other. Other CPGs for the treatment of prematurely born infants during hospitalisation may have been published since the search strategies were completed in August 2018.

The identified limitations for Phase 3 were:

- The two rounds of the Delphi method were focused mainly on validating the evidence-based statements and recommendations that had been compiled in Phase 2 through a process of consensus among physiotherapists treating prematurely born infants during their hospitalisation in NICUs, HCUs or KMC wards in the SA health care context. Participants were asked to indicate whether the statements or recommendations were relevant to their current practice, and whether they would recommend them for future practice. Participants were unfamiliar with some of the topics addressed by the recommendations, for example the use of hydrotherapy in NICUs, HCUs and / or KMC wards. Their unfamiliarity with this practice indicated that it is not used in practice by physiotherapists in SA, but if more background literature and maybe training were available, these physiotherapists might consider using hydrotherapy as part of their treatment practice. Although these topics were excluded from the contextualised CPG, the researcher will recommend that when the CPG is updated in future, the topics that were excluded be reconsidered for possible inclusion.

- The views and opinions of participants regarding the statements or recommendations in the second round of the Delphi method might not reflect the views of the entire physiotherapy community in SA and physiotherapists should therefore use the contextualised CPG based on their own knowledge, capabilities and according to its applicability in their ethical practice.

- The researcher also acknowledges that all the statements or recommendations included in the contextualised CPG might not be relevant or applicable to all NICUs, HCUs or KMC wards throughout SA. The focus of this current study was not on the implementation of the contextualised CPG; therefore the researcher cannot comment on whether will be easily applied in practice.

To implement the contextualised CPG, a different process has to be followed, which requires its adaptation to each clinical setting based on the available processes, procedures and human and other resources. However, the researcher has followed all the criteria and requirements for the contextualisation of a CPG for physiotherapy management in the SA health care context.

8.4 RECOMMENDATIONS FOR FUTURE RESEARCH AND IMPLEMENTATION

Having discussed the limitations of the study, the researcher can now make recommendations with regard to the contextualised CPG for research, clinical practice and physiotherapy education.

8.4.1 Recommendations for further research on the contextualisation of the current clinical practice guideline

The researcher will make the contextualised CPG available to the members of the SAPS's paediatric and cardio-pulmonary special interest group and will recommend that the contextualised CPG be implemented and adapted to different clinical settings throughout the nine provinces of SA. The process of adaptation will require further research. The implementation plan should address the knowledge barriers and lack of experience that might exist among physiotherapists and could be addressed by appropriate training.

Further research should also be planned and undertaken to update the statements and recommendations in the current contextualised CPG based on new research evidence that may be published on the management of prematurely born infants in NICUs, HCUs or KMC wards. Information on, or evidence of collaboration between the parents or caregivers and members of the MDT in respect of the physiotherapy management of prematurely born infants in the KMC is limited. The CPG will also have to be revised when NHI is implemented in SA. The principles and recommendations of the AGREE II instrument should be used when updating the CPG. It is also recommended that future researchers who might be involved in updating the current CPG use a transparent process and clearly communicate the development process, the level of evidence included in the formulation of the recommendations and statements of the CPG, as well as the literature search and review strategies that were used to identify relevant evidence. These processes should ensure that the updated CPG is of high quality.

The contextualised CPG developed in the current study focuses only on the physiotherapy management of prematurely born infants during the hospitalisation phase. The researcher recommends that the guidelines be extended, by way of the aforementioned contextualised processes, for the short- and long-term follow-up management of these infants after discharge. Those guidelines could include the MDT approach to the follow-up care of the infant and child.

8.4.2 Recommendations for further research in clinical practice

The researcher recommends that physiotherapists who are currently involved in the management of prematurely born infants in NICUs, HCUs or KMC wards should promote their role as MDT members to heighten awareness of the contribution they can make to the management of prematurely born infants.

Physiotherapists should also investigate the challenges of the current referral system, especially in the private health care sector, to identify the factors that prevent them from becoming fully involved in the care and support of infants and their parents or caregivers.

The researcher identified a lack of support / follow-up for infants and their parents or caregivers after discharge from hospital, especially in the private health care sector. Physiotherapists need to investigate and address this need in order to lighten the burden of possible impairments or disabilities that these infants may develop by identifying and addressing any possible problems early during the hospital phase and at short-term follow-up appointments. Early intervention could limit or prevent disability and improve the health and wellness outcomes of infants in the long term.

The researcher further recommends that research be conducted to include interprofessional collaborative practice between the key role-players in order to limit the overstimulation and exhaustion of premature infants without denying them the unique contribution that each profession can make to their health and wellness.

8.4.3 Recommendations for further research relating to under- and postgraduate physiotherapy education

The researcher recommends that research be conducted on the relevance of the undergraduate physiotherapy curriculum and the clinical training of students to equip them with the knowledge and clinical competence needed to implement the basic principles of the physiotherapy management of prematurely born infants in clinical practice.

During the application of the Delphi method, physiotherapists indicated the need for postgraduate training for physiotherapists treating prematurely born infants in NICUs, HCUs and KMC wards. Appropriate CPD courses and curricula for postgraduate degrees should be developed based on an investigation of current research practice and the development of the NHI Bill that is being considered by the SA Parliament.

8.5 SUMMARY

The final product of the current study, namely the contextualised CPG for the physiotherapy management of prematurely born infants in NICUs, HCUs and KMC wards in the SA health care system, answered the research question formulated in Chapter 1, section 1.4.

The current contextualised CPG was discussed in the context of the eco-systemic model by Bronfenbrenner (1979), which was adapted for the current study (Figure 2.9). The challenges faced and the limitations of the study were explained and the researcher also indicated how the research process had been conducted to minimise the effect of the limitations.

Recommendations were made for further research under the sub-headings: Recommendations for further research in contextualising the current CPG; Recommendations for further research in clinical practice; and Recommendations for further research relating to under- and postgraduate physiotherapy education.

The researcher concludes that although many challenges still exist for physiotherapist involved in the care and management of prematurely born infants in SA, the contextualised CPG developed in this study could be a first step in addressing these challenges.

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This reference should not be included in the reference list as it does not appear in this document's text.

ANNEXURE A WRITTEN CONSENT FROM CEO FOR FOCUS GROUP DISCUSSIONS AND KEY INFORMANT INTERVIEWS

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

KALAFONG HOSPITAL
PRIVATE BAG X396
PRETORIA
0001

ENQUIRIES : DR K.E LETEBELE-HARTELL
TEL : 012 318 6503
FAX : 012 373 6791
EMAIL : Letebele.Manei@gauteng.gov.za

TO: DR C.A EKSTEEN

RE: PERMISSION TO CONDUCT RESEARCH

TITLE: CONTEXTUALIZING PHYSIOTHERAPHY CLINICAL PRACTICE GUIDELINES FOR PREMATURELY BORN INFANTS UP TO ONE YEAR POST- CORRECTED AGE IN SOUTH AFRICA

Permission is hereby granted for the research to be conducted at **Kalafong Provincial Tertiary Hospital**. Provided that ethics clearance is first obtained from the training institution ethics committee.

Kind regards

DR K.E LETEBELE-HARTELL
SENIOR MANAGER; MEDICAL SERVICES
DATE: 03 DECEMBER 2015

GAUTENG PROVINCIAL GOVERNMENT
KALAFONG HOSPITAL / HOSPITAAL
03 DEC 2015
PRIVATE BAG / PRIVAATSAK X396 PRETORIA 0001
SUPERINTENDENT'S OFFICE

Only one letter is provided here. The other consent letters are available from the researcher on request.

ANNEXURE B INFORMED CONSENT OF PARTICIPANTS IN THE FOCUS GROUP DISCUSSIONS AND KEY INFORMANT INTERVIEWS

INFORMATION LEAFLET AND INFORMED CONSENT FOR NON-CLINICAL RESEARCH

TITLE OF STUDY:

CONTEXTUALISING PHYSIOTHERAPY CLINICAL PRACTICE GUIDELINES FOR HOSPITALISED PREMATURELY BORN INFANTS IN SOUTH AFRICA

Dear Participant

1) INTRODUCTION

I herewith invite you to participate in a research study. This information leaflet will help you to decide whether you want to participate. Before you agree to take part, you should fully understand what is involved. If you have any questions that this leaflet does not fully answer, please do not hesitate to discuss your queries with the investigator.

2) THE PURPOSE OF THIS STUDY IS TO POTENTIALLY IMPROVE THE HEALTH OUTCOME FOR PREMATURELY BORN INFANTS IN SA, AND TO POTENTIALLY BETTER EMPOWER THE PARENTS OR CAREGIVERS OF PREMATURELY BORN INFANTS IN SA.

The primary aim of this study is to **contextualise a clinical practice guideline for physiotherapists in South Africa treating prematurely born infants in Neonatal Intensive Care or High Care Units who are at risk of developing complications due to environmental, social or family, and chemical stressors in these units up to one year post-corrected age.**

The clinical practice guideline will include information on the role of each of the multidisciplinary team members working in South African Neonatal Intensive Care or High Care Units.

The sub-aim is to compile information and develop an education tool for the parents or caregivers of prematurely born infants in Neonatal Intensive Care and High Care Units to explain to them how they could best collaborate with the multidisciplinary team to optimise their prematurely born infants' care and health outcome.

As an expert physiotherapy clinician or academic **and member of the multidisciplinary team,** you are a very important source of information on what should be included in a clinical practice guideline**.**

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

This study will involve **a web-based discussion between the members of the multidisciplinary team with a view to describing the current patient journeys of prematurely born infant and their parents or caregivers up to one year post-corrected age. The patient journey (relevant to this study) for the prematurely born infant includes all the steps followed from birth up to discharge from hospital and one year post-corrected age and follow-up reports compiled by members of the multidisciplinary team.**

4) RISK AND DISCOMFORT INVOLVED:

There are no risks in participating in this study. However, participation will require some of your time and your presence at a venue determined by the researcher.

5) POSSIBLE BENEFITS OF THIS STUDY:

You will benefit directly from the study as it will culminate in the publication of a clinical practice guideline for the treatment of prematurely born infants for use in NICU or HCU environments in low- and middle-income countries such as SA.

6) WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Your participation in this study is entirely voluntary. You may refuse to participate, or may decide to end your participation at any time during the study without being expected to give a reason for your decision.

Your withdrawal will not in any way affect you or your access to the **contextualised clinical practice guidelines**.

7) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

The Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria has approved the study (Ethics Reference no. 99/2014). A copy of the approval letter will be made available on request.

8) INFORMATION AND CONTACT PERSON

The contact person for the study is **Janeske (P.J.) van der Walt.** If you have any questions about the study, please contact her at **cell (+27) 82 855 4668** or via **email** at **janeske@live.com.** Alternatively you may contact her supervisor, **Dr Carina Eksteen,** at **cell (+27) 83 235 4264.**

9) COMPENSATION

Your participation is voluntary. No compensation will be given for your participation.

10) CONFIDENTIALITY

All the information provided by you will be kept strictly confidential. Once we have analysed the information, no-one will be able to identify you. Research reports and articles published in scientific journals will not include any information that may identify you or your clinic or hospital.

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking my consent to participate in this study has informed me on the nature, process, risks, discomforts and benefits of the study. I have also received, read and understood the above written information (Information Leaflet and Informed Consent) regarding the study. I understand that the results of the study, including personal details, will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participating in the study.

I further understand that there will be no penalty should I wish to terminate my participation and that my withdrawal will not in any way affect my access to **the clinical practice guideline contextualised in the study**.

I have received a signed copy of this informed consent agreement.

Participant's name ..... (Please print)

Participant's signature: ..... Date.....

Investigator's name ..... (Please print)

Investigator's signature ..... Date.....

Name of witness ..... (Please print)

Witness' signature ..... Date.....

*The scope of the study has changed since the use of this information letter, and the sub-aim mentioned in this document is therefore not relevant to the current scope of the study.

ANNEXURE C QUESTIONNAIRE COMPLETED BY PARTICIPANTS OF THE FOCUS GROUP DISCUSSIONS AND KEY INFORMANT INTERVIEWS

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

ADDITIONAL INFORMATION SHEET

1. Date: _____

2. Name and surname: _____

3. What is your current qualification? _____

4. When did you obtain your qualification? _____

5. In which South African (SA) health sector are you currently employed?

☐ Government ☐ Private ☐ Tertiary ☐ Other

If any other, please specify _____

6. For how long have you been employed in this sector? _____

_____

_____

_____

7. Have you ever been employed in another health sector in SA?

☐ Yes ☐ No

If yes, please specify in which sector and for how long

_____

_____

_____

_____

8. Do you have a specific field of interest / specialisation? _____

_____

_____

_____

9. How did you obtain your clinical expertise?

_____

_____

_____

_____

10. In your opinion, what requirements should a clinician meet to become a clinical expert?

_____

_____

_____

_____

_____

11. Are you currently involved in the treatment of prematurely born infants?

☐ Yes ☐ No

If yes, in which phases of their care are you involved?

☐ Neonatal Intensive Care Unit (NICU)

☐ High Care Unit (HCU)

☐ Hospital nursery / Pediatric ward

☐ Follow-up care after discharge from hospital

12. Do you think that a clinical practice guideline (CPG) that delineates the role of the multidisciplinary team is necessary for physiotherapists in SA?

☐ Yes ☐ No

If yes, please provide reasons for your answer_____

_____

_____

_____

_____

_____

13. In your opinion, are the parents or caregivers of prematurely born infants equipped with the skills needed to manage the infant, and knowledge about what to expect during the first year after discharge from hospital?

☐ Yes ☐ No

Please provide reasons for your answer_____

_____

_____

_____

14. In your experience, which multidisciplinary team member(s) provide the parents or caregivers of prematurely born infants with information or education?

_____

_____

_____

_____

15. Do you think that parents or caregivers of prematurely born infants will benefit from an information or education tool that allows them to provide input on what they think should be included in it?

☐ Yes ☐ No

16. Did your graduate or postgraduate course cover the principles of evidence-based practice (EBP)?

☐ Yes ☐ No

ANNEXURE D QUESTIONNAIRE USED FOR STRUCTURED INTERVIEWS AND THE ONLINE SURVEY FOR PARENTS OR CAREGIVERS OF PREMATURELY BORN INFANTS

QUESTION GROUP	ANSWER
Biographical information:	
Date:	
Name and surname:	
Contact number or email address:	
Gender: Male / Female	
Information regarding the premature birth of infant:	
At what gestational age was your infant born? (e.g. 32 weeks) *Gestational age is the term used to measure the pregnancy in a number of weeks. A normal pregnancy can last from 38 to 42 weeks. Infants born before 37 weeks are considered to be premature.	
Was it a multiple pregnancy? *Yes / No* If yes, which of the following apply? *Twins / Triplets / Quadruplets / Other*	
Was this / Were these your first prematurely born infant(s)? Yes / No	
Do you have other children? *Yes / No* If yes, at what gestational age were they born?	
Information regarding the premature infant's hospital stay:	
Where was (were) your prematurely born infant (infants) admitted? *Neonatal Intensive Care Unit / High Care Unit / Kangaroo Mother Care ward / Maternity ward / Other*	
Which medical staff members were involved in the care of your prematurely born infant? *Paediatrician / Nursing sister / Occupational therapist / Physiotherapist / Speech therapist / Audiologist / Nutritionist*	

/ Ophthalmologist / Other	
How long was the infant's (infants') hospital stay?	
Which evaluations (tests) were done? *Chest X-ray / Blood tests / Weight measurement / Hearing test / Breathing and heart rate / Fluid input and output / Ultrasound of heart / Ultrasound of brain / Eye exam / Movements / Jaundice test*	
What were the results / outcomes of the evaluations (tests)?	
Information regarding the discharge of the infant:	
Was a follow-up appointment scheduled at the time of discharge of your infant(s)? *Yes / No*	
Which medical staff member(s) conducted the follow-up? *Paediatrician / Nursing sister / Occupational therapist / Physiotherapist / Speech therapist / Audiologist / Nutritionist / Ophthalmologist / Other*	
Approximately how long after discharge was the first follow-up appointment? *One month / Two months / Three months / Four months / Other*	
How regular were the follow-up appointments? *Monthly / Bimonthly / Every 3; 4; 6; 8; 10; 12 months / Other*	
Up to what age did the follow-up appointments continue?	
Information provided to parents or caregivers of the prematurely born infant:	
At discharge of your infant(s), did the medical staff members provide you with the information that you needed for the transition to your home? *Yes / No*	
Did they provide information on difficulties that you might encounter during the first year after discharge? *Yes / No* If yes, what type of information did you receive?	
In what format did they provide the information? *Practical demonstration / Group classes / Booklet / Link to*	

website (electronic) / Other	
Which medical staff member(s) provided you with the information? *Paediatrician / Nursing sister / Occupational therapist / Physiotherapist / Speech therapist / Audiologist / Nutritionist / Ophthalmologist / Other*	
What type of information do you recommend they provide?	
In what format would you prefer to receive the information? *Practical demonstration / Group classes / Booklet / Link to a website (electronic) / Other*	
Long-term care of the prematurely born infant:	
In your opinion, were there any long-term effects due to your infant's (infants') premature birth? *Yes / No*	
If yes, what do you think the effect was? *Respiratory problems (e.g. asthma, chronic lung disease) / Infections / Cerebral palsy / Developmental delays / Behavioural problems / Learning difficulties / Autism / Affected communication skills / Vision problems / Hearing loss / Intestinal problems / Heart problems / Feeding problems / Other*	
In your opinion, how could the care of the prematurely born infants in South Africa be improved?	
What recommendations can you make regarding the best care of the infant?	

ANNEXURE E WRITTEN CONSENT FROM CEOs FOR STRUCTURED INTERVIEWS

Permission to do conduct interviews with parents / caregivers of prematurely born infants Steve Biko Academic hospital

From: The Investigator,

Mrs. Janeske (PJ) van der Walt,

Department of Physiotherapy,

University of Pretoria

To: Chief Executive Officer /Information Officer

Steve Biko Academic Hospital

Dear Doktor

Re: Permission to do the following research at Steve Biko Academic Hospital

I am a PhD student at the University of Pretoria, Department of Physiotherapy. I am requesting permission to conduct focus group discussions (FGD) (interviews) with parents / caregivers of prematurely born infants up to the age of 1 year corrected age as well as as with staff members involved in the management of premature born infants.

The title of the study is:

Contextualizing physiotherapy clinical practice guidelines for prematurely born infants up to one year post-corrected age in south africa.

We intend to publish the findings of the study in a professional journal and/ or at professional meeting like symposia, congresses, or other meetings of such a nature. All the data with regards to the hospitals or centres and participants partaking in the focus group discussions will be kept anonymous.

We furthermore request in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000 that we be granted access to clinical records, files and databases only to identify parents / caregivers with whom the interviews can be conducted.

The questions that will be asked during the interview are listed on the following page:

We undertake not to proceed with the study until we have received approval from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

Yours sincerely

Mrs P J van der Walt (PhD Student)

Page 1 of 1

Permission to do the research study at this hospital and to access the information as requested is hereby approved.

Chief Executive Officer SBAH Hospital

Dr SS Mmamabolo

Signature of the CEO

GAUTENG PROVINSIALE REGERING
DEPT VAN GESONDHEID
STEVE BIKO AKADEMIESE HOSPITAAL
STEVE BIKO ACADEMIC HOSPITAL
2016 -03- 15
Hospital Official Stamp
PRETORIA 0001
GAUTENG PROVINCIAL GOVERNMENT
DEPT OF HEALTH

Table 4: Questions for FGD in appreciative inquiry format (refer to page 43 of the protocol)

	Main question	Elaborating questions
	Destiny (Reflexion)	
Parents and caregivers	What is the present process of care that you and your baby have undergone following his/her premature birth?	• Explain the journey that you experienced since the birht of you baby • Think about the first day you were admitted up to now.
Professionals	What is the present process of care followed for prematurely born infants?	• Think about from when the baby was born prematurely up to when they are discharged home or to a facility, up to one year corrected age.
	Discovery (Peak experiences)	
Parents and caregivers	What part of the process of care helped you the most?	• Explain the aspects that helped or supported you most during your journey until you baby was one year old. • Tell us why these aspects helped you most. • Tell us the story. • Who was involved during these

ANNEXURE F INFORMED CONSENT FORM FOR PARENTS OR CAREGIVERS WHO PARTICIPATED IN THE STRUCTURED INTERVIEWS

INFORMATION LEAFLET AND INFORMED CONSENT FOR NON-CLINICAL RESEARCH

TITLE OF STUDY:

CONTEXTUALISING PHYSIOTHERAPY CLINICAL PRACTICE GUIDELINES FOR HOSPITALISED PREMATURELY BORN INFANTS IN SOUTH AFRICA.

Dear Participant

1) INTRODUCTION

I herewith invite you to participate in a research study. This information leaflet will help you to decide whether you want to participate. Before you agree to take part you should fully understand what the study involves. If you have any questions that this leaflet does not fully answers, please do not hesitate to discuss your queries with the investigator.

2) THE PURPOSE OF THIS STUDY IS TO POTENTIALLY IMPROVE THE HEALTH OUTCOME FOR PREMATURELY BORN INFANTS IN SOUTH AFRICA, AND TO POTENTIALLY PROVIDE THE PARENTS OR CAREGIVERS OF PREMATURELY BORN INFANTS IN SA WITH MORE KNOWLEDGE ON HOW TO BEST CARE FOR THEIR INFANTS DURING THE HOSPITAL STAY AND AFTER DISCHARGE.

The primary aim of this study is **to develop a clinical practice guideline for physiotherapists in South Africa treating prematurely born infants in neonatal intensive care units (NICUs) or high care units (HCUs). The clinical practice guidelines will include information on what the treatment of each of the medical team members working with the infant within the hospital should entail.**

The sub-aim is to compile an information and education leaflet for parents or caregivers of prematurely born infants to explain how they could best work with the medical team to ensure better care of their prematurely born infants.

As a **parent or caregiver of the prematurely born infant,** you are a very important source of information on the type of information / education such a document for parents / caregivers with premature infants should include.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

Participation in this study will involve **participation in a group discussion arranged and led by the researcher.**

4) RISK AND DISCOMFORT INVOLVED:

There are no risks involved in participating in the study. Participation in the group session will require some of your time (approximately 90 minutes) and you will have to be able to attend a session at a venue chosen by the researcher. If needed, you will be compensated for transportation costs to and from the venue. The discussions will be conducted in English. The researcher will make an audio recording of the discussions so as to be able to listen to the answers again after the discussions.

5) POSSIBLE BENEFITS OF THIS STUDY:

You will benefit directly from the study as at the conclusion of the study you will receive an information and education leaflet containing information on your role, as well as the roles of the members of the medical team in potentially improving the care your infant.

6) WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Your participation in this study is entirely voluntary. You may refuse to participate, or may decide to terminate your participation at any time without being asked to give a reason for your decision. Your withdrawal will not in any way affect you or your access to **the parent or caregiver information and education leaflet**.

7) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

The researcher is applying for ethical approval from the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria and a copy of the approval letter will be made available once approval has been granted, should you wish to have one.

8) INFORMATION AND CONTACT PERSON

The contact person for the study is **Janeske (PJ) van der Walt.** If you have any questions about the study, please contact her at **cell (+27) 82 855 4668** or via **email** at **janeske@live.com.** Alternatively you may contact her supervisor at **cell (+27) 83 235 4264.**

9) COMPENSATION

Your participation is voluntary. No compensation will be given for your participation, but if needed your transport cost will be refunded.

10) CONFIDENTIALITY

All the information provided by you will be kept strictly confidential. Once we have analysed the information, no one will be able to identify you. Research reports and articles in scientific journals will also not include any information that may identify you.

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person requesting my participation in this study has informed me of the nature, process, risks, discomforts and benefits of the study. I have also received, read and understood the above information (Information Leaflet and Informed Consent) regarding the study. I also understand that the results of the study, including personal details, will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participating in the study. I understand that there is no penalty should I wish to terminate my participation at any time, and that my withdrawal will not in any way affect any access to **the parent or caregiver information and education leaflet**.

I have received a signed copy of this informed consent agreement.

Participant's name ..... (Please print)

Participant's signature: ..... Date .....

Investigator's name ..... (Please print)

Investigator's signature ..... Date.....

Name of witness ..... (Please print)

Witness' signature ..... Date.....

VERBAL INFORMED CONSENT

I, the undersigned, have fully explained the contents of the participant information leaflet, which explains the nature, process, risks, discomforts and benefits of the study, to the participant, whom I have asked to participate in the study.

The participant has indicated that s/he understands that the results of the study, including personal details provided during the interview will be anonymously processed into a research report. The participant has indicated that s/he has had time to ask questions and has no objection to participating in the interview.

S/he understands that there is no penalty should s/he wish to terminate his / her participation in the study and that his/her withdrawal will not in any way affect his / her access to **the parent or caregiver information and education leaflet that will be compiled based on the findings of this study**.

I hereby certify that the parent / caregiver has agreed to participate in this study.

Participant's name ..... (Please print)

Person seeking consent ..... (Please print)

Signature .....Date.....

Name of witness ..... (Please print)

Signature .....Date.....

ANNEXURE G QUESTIONNAIRE FOR THE FIRST ROUND DELPHI METHOD

Delphi questionnaire

Dear colleague,

I would like to invite you to participate in the final phase of the PhD study namely: *Contextualisation of physiotherapy clinical practice guideline for hospitalised prematurely born infants in South Africa.* (Ethical approval from the University of Pretoria Faculty of Health Sciences Research Ethics Committee nr. 99/2014)

The definition of the prematurely born infant is an infant born before 37 weeks gestational age and the researcher refers to this patient population as 'the infants' throughout this document.

Aim of the study:

The main aim of the study is to contextualise a clinical practice guideline (CPG) for physiotherapists working in the neonatal intensive care unit (NICU), high care unit (HCU) or kangaroo mother care (KMC) ward. A clinical practice guideline could be useful to physiotherapists in South Africa (SA), because it could standardise care of the infants in both the private and public health care sectors (HCS) and it could define the physiotherapists' role in inter-professional collaborative practice (IPCP). The CPG will exclude genetic or surgical conditions because it is not a complication due to premature birth.

Phases of the study that has been completed:

The list of clinical statements that you will be required to grade in this phase of the study had been compiled based on interviews that had been conducted with key informants and focus group discussions with the multidisciplinary team (MDT) including physiotherapists, who are involved in the care / management of the infants in the NICU, HCU or KMC wards in the Gauteng province as well as an appraisal process of the CPGs in high-income countries.

Final phase in which you will participate:

In the final phase of the study the possible users of the CPG (physiotherapists currently working with the infants in the NICU, HCU or KMC ward) are required to validate the applicability of the recommendations / statements compiled for the South African context. The validation will be done in the format of a questionnaire.

The questionnaire consists of three parts: the first part is about the *hospital setting* in which the physiotherapist currently works; part two covers the potential collaboration between the physiotherapist and other *MDT members* and the third part comprises of recommendations / statements specifically related to the *physiotherapy management* of the infant.

Potential benefits to participants:

Your opinion on what information should be included in a CPG for physiotherapists working in the NICU, HCU or KMC ward is regarded as very valuable and is expected to standardise physiotherapy practice and outcomes of the prematurely born infants.

There are 124 questions in this survey

Permission to participate

Participation in the study is completely voluntary and without compensation. All information provided by you, as the participant will be treated confidentially. If you have any questions please don't hesitate to contact the researcher at janeske@live.com or cell: +27 82 855 4668.

1 [1]Do you agree to participate in the final phase of this study? *

Please choose **only one** of the following:

- ◯ Yes
- ◯ No

2 [2]You are welcome to nominate another person that is working with prematurely born infants and that you think could provide valuable input for the study. Please provide their name and contact details if possible.

Please write your answer here:

Biographic information

Please provide the researcher with some biographic information:

3 [3]Date of birth: *

Only answer this question if the following conditions are met:
° Answer was Y'Yes' at question '1 [1]' (Do you agree to participate in the final phase of this study?)

Please enter a date:

4 [4]Gender: *

Only answer this question if the following conditions are met:
° Answer was Y'Yes' at question '1 [1]' (Do you agree to participate in the final phase of this study?)

Please choose **only one** of the following:

- ◯ Female
- ◯ Male

5 [5]What is your highest qualification? *

Only answer this question if the following conditions are met:
° Answer was Y'Yes' at question '1 [1]' (Do you agree to participate in the final phase of this study?)

Please choose **all** that apply:

- ☐ Bachelors degree
- ☐ Masters degree
- ☐ PhD
- ☐ Other:

6 [6]In which healthcare sector do you primarily work, or treat prematurely born infants? Please specify *

Only answer this question if the following conditions are met:
° Answer was Y'Yes' at question '1 [1]' (Do you agree to participate in the final phase of this study?)

Please choose all that apply and provide a comment:

- ☐ Private healthcare sector
- ☐ Public healthcare sector
- ☐ Academic institution
- Other:

7 [7]How many years experience do you have working with prematurely born infants? *

Only answer this question if the following conditions are met:
° Answer was Y'Yes' at question '1 [1]' (Do you agree to participate in the final phase of this study?)

Please write your answer here:

8 [8]Does your professional role in the NICU, HCU or KMC ward include: Please specify *

Only answer this question if the following conditions are met:
° Answer was Y'Yes' at question '1 [1]' (Do you agree to participate in the final phase of this study?)

Please choose all that apply and provide a comment:

- ☐ Clinical management of infants
- ☐ Policy maker (developing or monitoring policies)
- ☐ Clinical teaching
- ☐ Academic teaching students at a tertiary institution
- ☐ Researcher
- Other:

Part I (Hospital setting)

Please indicate how relevant you find the following statements with regard to the *hospital setting* that you work in. If you strongly disagree with a statement please indicate your reason for this in the comment box provided.

Definitions:

In this questionnaire the term 'infants' refer to prematurely born infants, born before 37 weeks gestational age.

The term 'caregiver' refers to the person that is mainly and/or legally responsible for the care of the infant after discharge from hospital and might not be the biological parents.

9 [16]

Neonatal Intensive Care Unit and High Care Unit

1. The MDT has a standardised regime of care and management principles of the infant in the NICU or HCU. *

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

10 [16a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

11 [17]

2. The physiotherapist has a role in the care and management of the infant in the NICU or HCU.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

12 [17a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

13 [20]

3. The physiotherapist, and other MDT members (e.g. occupational therapist, speech therapist) are screening all infants in the NICU or HCU without a referral from the paediatrician.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

14 [20a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

15 [21]

4. The parents or caregivers of the infant do not have an adjustment period to manage the infant before the infant is discharged from the NICU or HCU, and might lack the proper knowledge or confidence to care for the infant at home.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

16 [21a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

17 [23]

5. The infant will be transferred to the Kangaroo Mother Care (KMC) ward / care before discharged home.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

18 [23a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

19 [24]

6. The infant will be discharged home from the NICU or HCU.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

20 [24a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

21 [27]

7. Infants are discharged from the NICU or HCU with a follow-up appointment with the MDT.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
What practice should be	○	○	○	○	○	○	○

22 [27a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

23 [28]

Kangaroo Mother Care

1. Intermitted KMC is integrated as part of the routine at some NICUs or HCUs, especially if the benefits of KMC are explained to the parents or caregivers of the infant. *

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

24 [28a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

25 [34]

2. Continuous KMC is practised in the KMC ward even if the infant is on oxygen.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

26 [34a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

27 [29]

3. The environmental stressors like light, noise, temperature changes and handling have less of an effect on the infant in the KMC ward than in the NICU or HCU.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

28 [29a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

29 [50]

4. Some NICUs have a 'room-in'-facility where the parents or caregivers of the infant can stay with the infant under supervision of the nursing staff to ensure that the parents or caregivers are coping with the care and management of the infant before discharge home.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

30 [50a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

31 [53a]

5. The infant is discharged from the KMC ward with a follow-up appointment.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

32 [53aa]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

33 [53b]6. The short-term follow-up of the infant after discharge is with the following: *

Please choose **all** that apply:

- ☐ Paediatrician
- ☐ MDT on referral
- ☐ Private / Public clinic
- ☐ Out-patient clinic
- ☐ Cerebral palsy clinic
- ☐ Developmental delay clinic
- ☐ Well-baby clinic
- ☐ Retinopathy of prematurity clinic
- ☐ The infant does not have short-term follow-up
- ☐ Other:

Part II (MDT members)

Please indicate how relevant you find the following statements with regard to the collaboration of the MDT members in the NICU, HCU or KMC ward. If you strongly disagree with a statement please indicate your reason for this in the comment box provided.

34 [54]The MDT members involved in the management of the infant in the NICU or HCU include: *

Please choose **all** that apply:

- ☐ Physiotherapist
- ☐ Speech therapist
- ☐ Audiologist
- ☐ Occupational therapist
- ☐ Nursing staff
- ☐ Dietician
- ☐ Sonographer
- ☐ Ophthalmologist
- ☐ Paediatrician
- ☐ Counsellor
- ☐ Social worker
- ☐ Other:

35 [119]

Collaboration between the MDT members

1. MDT members collaborate with regard to the developmental care of the infant in the NICU or HCU.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

36 [119a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

37 [120]2. The MDT does regular ward rounds together in the NICU or HCU and discusses possible treatment plans.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

38 [120a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

39 [122]3. Coordination of the collaboration is difficult to organise during ward rounds in the NICU or HCU because not all members are always available during the same period of time.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

40 [122a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

41 [121]4. The MDT members rely on each other's notes in the infant's file to understand what the other members' treatment plan comprises of.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

42 [121a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

43 [123]5. In settings where inter-professional collaborative practice is the manegement approach of the infant and his / her parents or caregivers, the roles of the MDT members overlap.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

44 [123a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

45 [124]6. Inter-professional collaboration between members of the MDT is essential for promotion of growth and development of the infant without over stimulation of the infant.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

46 [124a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

47 [138]

7. The physiotherapist collaborates and refers to the following MDT members:

(Please state the reason / what conditions you typically refer to these members)

Please choose all that apply and provide a comment:

- ☐ Speech therapist
- ☐ Audiologist
- ☐ Occupational therapist
- ☐ Nursing staff
- ☐ Dietician
- ☐ Sonographer
- ☐ Ophthalmologist
- ☐ Paediatrician
- ☐ Counsellor
- ☐ Social worker
- Other:

48 [126]8. Which members of the MDT, apart from the nursing staff and paediatrician, are involved in the care of the infant in the KMC ward?

Please choose all that apply and provide a comment:

- ☐ Physiotherapist
- ☐ Speech therapist
- ☐ Audiologist
- ☐ Occupational therapist
- ☐ Dietician
- ☐ Sonographer
- ☐ Ophthalmologist
- ☐ Counsellor
- ☐ Social worker
- Other:

49 [125]9. MDT members collaborate with regard to the developmental care of the infant in the KMC ward.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

50 [125a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

Part III (Physiotherapy management of the infant)

Please indicate how relevant you find the following statements with regard to the role and scope of practice of the physiotherapist working in the NICU, HCU or KMC ward. If you strongly disagree with a statement please indicate your reason for this in the comment box provided.

51 [137]

Assessment

1. Screening of the infant in the NICU, HCU or KMC ward by the physiotherapist as member of the MDT could lead to early detection of impairments as well as anticipation of impairments that could arise after discharge from hospital.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice shoud be	○	○	○	○	○	○	○

52 [137a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

53 [132]

2. The physiotherapist conducts a baseline observation to determine the infant's physiological and behavioural stability or readiness for evaluative handling before assessment.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

54 [132a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

55 [133]3. The physiotherapist does a limited hands-on assessment during the infant's diaper change or re-positioning and assesses the recoils and scarf sign.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

56 [133a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

57 [134]4. The physiotherapist does a limited hands-on assessment during the infant's diaper change or re-positioning and assesses the palmar and plantar grasp.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

58 [134a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

59 [135]5. The physiotherapist does a limited hands-on assessment during the infant's diaper change or re-positioning and assesses the non-nutritive sucking.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

60 [135a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

61 [139]6. The physiotherapist does a sensory assessment of the physiologically stable infant in the NICU, HCU or KMC ward to determine visual focus, tracking and auditory localisation and orientation.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

62 [139a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

63 [140]7. The physiotherapist makes use of the following assessment tool for infants in the NICU, HCU or KMC ward:

Please choose all that apply and provide a comment:

- ☐ Bayley scale
- ☐ Movement ABCs
- ☐ Alberta infant scale
- ☐ Clinical observation (as the only method of assessment)
- ☐ Brazelton Neonatal Behavioural Assessment
- ☐ Prechtl's analysis
- ☐ Developmental or milestone chart
- ☐ Test of Infant Motor Performance Screening Items (TIMPSI)

- ☐ Test of Infant Motor Performance (TIMP)
- ☐ Neurologic Assessment of the Preterm and Full Term Newborn Infant (NANI)
- ☐ Neurobehavioural Assessment of the Preterm Infant (NAPI)
- ☐ Newborn Behavioural Observations (NBO)
- Other:

64 [141]8. The physiotherapist continuously monitors the infant's physiological and behavioural status during and after assessments in order to know what adaptations are necessary during future evaluative handling with regard to the pace and sequence of handling, especially during neuro-motor assessment.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

65 [141a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

66 [127]

Prevention

1. The physiotherapist as member of the MDT monitors the respiratory function of the intubated or non-intubated infant in the NICU or HCU and will treat if indicated.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

67 [127a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

68 [128]2. The physiotherapist collaborates with other MDT members to monitor the intubated or non-intubated infant in order to reduce the risk of skull deformity, torticollis and extremity malalignment through diligent symmetrical and neutral alignment and positioning to support neurodevelopment in the NICU or HCU.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

69 [128a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

70 [129]3. The physiotherapist as member of the MDT should monitor the effect of the environmental, social and chemical stressors on the infant in the NICU or HCU to avoid overstimulation and other complications.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

71 [129a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

72 [130]4. The physiotherapist observes feeding assessments done by nursing practitioners or speech therapists in order to do respiratory care (e.g. suction of the infant) in case the infant aspirates.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	◯	◯	◯	◯	◯	◯	◯
What practice should be	◯	◯	◯	◯	◯	◯	◯

73 [130a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

74 [131]5. The physiotherapist takes special care to implement sterile procedures in the NICU or HCU to prevent cross infection to the infant who has an underdeveloped immune system.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	◯	◯	◯	◯	◯	◯	◯
What practice should be	◯	◯	◯	◯	◯	◯	◯

75 [131a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

76 [142]

Intervention

1. The physiotherapist is aware of the indications and contra-indications of physiotherapy interventions given to infants in the NICU, HCU or KMC ward.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	◯	◯	◯	◯	◯	◯	◯

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
What practice should be	○	○	○	○	○	○	○

77 [142a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

78 [144]2. The physiotherapist incorporates the view or opinion of the parents or caregivers of the infant when considering a treatment plan for the infant to empower the parents or caregivers.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

79 [144a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

80 [143]3. The physiotherapist plans the timing of the intervention to accommodate the care routine and the infant's resting periods in the NICU, HCU or KMC ward.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

81 [143a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

82 [145]4. The physiotherapist supports the infant's body position and extremity movement in (a) supine position through 'nesting' of the infant in a semi flexed, midline aligned position and (b) prone position with a vertical roll under the thorax and / or horizontal roll under hips.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

83 [145a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

84 [146]5. The physiotherapist facilitates the infant's independent oral exploration through positioning of hands to the face for non-nutritive sucking that could improve organisation and readiness for feeding.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

85 [146a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

86 [148]6. The physiotherapist enhances trunk mobility and diaphragmatic breathing in the physiologically stable infant in the NICU, HCU or KMC ward.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

87 [148a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

88 [147]7. The physiotherapist facilitates increased time in upright positions and includes guided antigravity extremity movement in the treatment of the physiologically stable infant in the NICU, HCU or KMC ward.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

89 [147a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

90 [149]8. The physiotherapist identifies the infants in the NICU, HCU or KMC ward with movement impairment or disorganisation s/he carefully incorporates graded intensity and paced facilitation of head and trunk control, antigravity movement and midline orientation. *

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

91 [149a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

92 [150]9. The physiotherapist performs hydrotherapy before feeding of the physiologically stable infant with movement impairment in the NICU, HCU or KMC ward if indicated.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

93 [150a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

94 [153]10. The physiotherapist as member of the MDT has a role in facilitating KMC (skin-to-skin contact) to improve parent or caregiver bonding with the infant in the NICU, HCU or KMC ward. *

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

95 [153a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

96 [154]11. The physiotherapist introduces gradual exposure to multimodal stimuli for physiologically stable infants in the NICU, HCU or KMC ward approaching discharge from hospital.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

97 [154a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

98 [152]12. The physiotherapist anticipates potential complications that could occur and prioritises preventative management / intervention in the treatment plan of the infant in the NICU, HCU or KMC ward.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

99 [152a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

100 [161]

Parental / caregiver education

1. Parent or caregiver education includes:

Please choose all that apply and provide a comment:

- ☐ Benefits of KMC
- ☐ The impact of environmental stressors (e.g. noise, light and handling) in the NICU or HCU on the infant
- ☐ How to interpret the infant's physiological and behavioural cues during care and management

- ☐ Information of developmental milestones
- ☐ Meaning of terminology like corrected age
- ☐ What active developmental activities to do as a home program
- ☐ How to use positioning equipment e.g. supportive seats
- ☐ Information on the importance of short-term follow-up assessments by the MDT up to one to two years post-corrected age to identify potential impairments / complications
- Other:

101 [158]2. The physiotherapist is sensitive to adapt the amount and depth of information or education to the parents or caregivers of the infant not to overwhelm the parents or caregivers.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

102 [158a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

103 [159]3. The physiotherapist adapts the information or education format (e.g. verbally, physical demonstrations, pamphlets or internet based information) to the level of the parents' or caregivers' understanding and in case of a language barrier.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

104 [159a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

105 [163]

Holistic family care

1. As part of holistic family care the physiotherapist educates the mother of the infant who gave birth either naturally or with a caesarean on the benefits of appropriate exercises for pelvic floor muscles and abdominal exercises to promote core stability, as well as kinetic handling during the care of the infant.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

106 [163a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

107 [164]2. As part of holistic family care the physiotherapist educates the mother of the infant who gave birth either naturally or with a caesarean, on the benefits of exercise for elevating serotonin levels to reduce the effect of post partum depression that could occur.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

108 [164a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

109 [167]

Professional ethical conduct of the physiotherapist

1. A physiotherapist has to have postgraduate / post basic training to treat infants in NICU, HCU or KMC ward.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

110 [167a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

111 [168]

2. The physiotherapist should engage in professional communication with the nursing manager of the unit, or the professional nurse responsible for the infant, to discuss the status of the infant in the NICU, HCU or KMC ward, before assessment and intervention of the infant.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

112 [168a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

113 [165]3. The physiotherapist should engage in professional communication with the nursing manager of the unit, or the professional nurse responsible for the infant, to discuss the parents' or caregivers' management of the infant being in the NICU, HCU or KMC ward, before interacting with the parents or caregivers with regard to providing information or education.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

114 [165a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

115 [166]4. The physiotherapist should document the parent or caregiver consent, assessment and intervention according to the required professional standard.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

116 [166a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

117 [170]5. The therapist’s own ethical and moral values should direct the decision to treat the infant and putting the infant’s needs first during the intervention.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

118 [170a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

119 [171]

Education and knowledge of the physiotherapist

1. Post-basic training in terms of knowledge and experience is needed to assess and treat infants in the NICU, HCU or KMC ward safely, effectively and efficiently.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

120 [171a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

121 [173]2. Physiotherapists who are treating or educating the infants' mothers regarding muscle strengthening, posture re-education and kinetic handling during care of the infant, should be adequately trained to do so.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

122 [173a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

123 [175]3. Physiotherapists in SA could benefit from a post-graduate course with both theory and supervised clinical experience in neonatal physiotherapy where the physiotherapist will gain knowledge and experience in managing the infant, as well as supporting the parents or caregivers in the NICU, HCU or KMC ward.

Please choose the appropriate response for each item:

	1 (strongly disagree)	2	3	4	5	6 (strongly agree)	7 (don't know)
Current practice	○	○	○	○	○	○	○
What practice should be	○	○	○	○	○	○	○

124 [175a]If you strongly disagree or would like to comment on the statement, please use the comment box below.

Please write your answer here:

Thank you for participating in the research study, your opinion is valued and appreciated.

"The common facts of today are the products of yesterday's research" (Duncan MacDonald)

01.01.1970 – 00:00

Submit your survey.
Thank you for completing this survey.

ANNEXURE H E-MAIL CONSENT FROM AUTHORS OF THE CPG AND POSITION PAPERS INCLUDED IN THIS STUDY

Hello Petronella

Thank you for reaching out to me. I would be happy for you to site my work. Thank you for thinking of it.

I have included my papers in attachments in this email.

Good luck!! And, please share your work with me in the future.

Thanks so much.

Eilish Byrne, PT, DSc, PCS
Supervisor, Physical Therapy
Center for Rehabilitation Services
Stanford Children's Health | Lucile Packard Children's Hospital Stanford
*LOCATIONS IN: PALO ALTO * EMERYVILLE * LOS GATOS * SAN FRANCISCO * WALNUT CREEK*
725 Welch Road, Suite 350
Mail Code: 5533
Palo Alto, CA 94304
Dept: 650-497-8218
Fax: 650.497.8491
Discover Stanford Children's on Facebook, Twitter, LinkedIn, and YouTube

From: Janeske van der Walt [mailto:Janeske@live.com]
Sent: Monday, February 20, 2017 4:16 AM
To: Byrne, Eilish M. <EByrne@stanfordchildrens.org>
Cc: Carina Eksteen <Carina.Eksteen@up.ac.za>; Carin Maree <cmaree.research@gmail.com>
Subject: Clinical practice guideline for physiotherapist in NICU

Dear mrs Byrne,

I am a PhD (Physiotherapy) student from the University of Pretoria, South Africa. My study is contextualization physiotherapy clinical practice guidelines for prematurely born infants up to one year post-corrected age in South Africa. I have received ethical approval (99/2014) from the Faculty of Health Sciences Research Ethics Committee to conduct the study.

In the current phase I need to identify current clinical practice guidelines or competency frameworks used by physiotherapists in the NICU. I have identified two of your documents

nl. *Physical Therapy Observation and Assessment in the Neonatal Intensive Care Unit*, and *Physical Therapy Intervention in the Neonatal Intensive Care Unit*.

I would like to obtain your permission to include the two papers in my study. Can you please advise me on the nature of the articles, for instance is it a position paper, or competency framework or as what will you classify it?

Kind regards,
Petronella van der Walt

Janeske,
I am copying Dr Sweeney to this email. Published CPGs are available for use by everyone. I am not sure how you intend to use them in your research but if you respect the copyright and acknowledge authorship, i see no issues with using them.
Do you also have part 1 published in 2009?
The articles available on Medline contain the full information available.
I am on vacation without my laptop and am not able to send you the PDF versions of the articles. I could send them to you next week if you still need them.
Good luck with your research.
Yvette

Sent from my iPhone

On Aug 14, 2017, at 4:57 AM, Janeske van der Walt <Janeske@live.com> wrote:

Dear Dr Blanchard,

I am a PhD student from the University of Pretoria in South Africa. My research study is about contextualization of current CPGs for premature infants in the NICU in South Africa.

I would like to ask permission to include the CPG: Neonatal Physical Therapy. Part II: Practice Frameworks and Evidence-Based Practice Guidelines into my study.

I have tried to contact Dr Sweeney, the corresponding author, but unfortunately my e-mails has not reached her successfully.

I would also like to find out if a full version of the CPG is available or was it just published in article format?

Your assistance in the matter is much appreciated.

Kind regards,

Janeske van der Walt

Dear Janeske,
Thank you for your interest in our NICU practice guidelines. How are you planning to use them in your research? Are you in a graduate studies program, teaching, or working clinically in a NICU?

I have had difficulty with accessing email through my Rocky Mountain University of Health Professions email address and finally had a software update applied 3 days ago. I am pleased you contacted Dr. Blanchard to get an alternate email connection and her help in solving the email problem.

The guidelines are a three article series including a third article addendum on a restricted neonatal physical therapy role and activities for the physical therapist student. I have included this article for you and assume you have access to the two part NICU practice guidelines published in 2009 and 2010. An erratum statement was published in 2010 to indicate wording errors in Part II on the table indicating neuronal mapping description from the Neuronal Group Selection Theory.

The full version was published. A separate document is not available.

Best regards,
Jane K. Sweeney PT, PhD, PCS
Catherine Worthingham Fellow, APTA
Professor and Program Director
Pediatric Science Doctoral Programs
Rocky Mountain University of Health Professions
Provo, UT

ANNEXURE I ETHICS APPROVAL TO CONDUCT THE STUDY

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.
- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020.

30/08/2018

Approval Certificate
Amendment
(to be read in conjunction with the main approval certificate)

Ethics Reference No: 99/2014

Title: Contextualisation of physiotherapy clinical practice guidelines for hospitalised prematurely born infants in South Africa

Dear Mrs Petronella van der Walt

The **Amendment** as described in your documents specified in your cover letter dated 31/07/2018 received on 3/08/2018 was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 29/08/2018.

Please note the following about your ethics approval:
- Please remember to use your protocol number (**99/2014**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:
- The ethics approval is conditional on the receipt of **6 monthly written Progress Reports**, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

*** Kindly collect your original signed approval certificate from our offices, Faculty of Health Sciences, Research Ethics Committee, Tswelopele Building, Room 4.59 / 4.60.*

Dr R Sommers; MBChB; MMed (Int); MPharMed,PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health).

Research Ethics Committee
Room 4-60, Level 4, Tswelopele Building
University of Pretoria, Private Bag X323
Arcadia 0007, South Africa
Tel +27 (0)12 356 3084
Email deepeka.behari@up.ac.za
www.up.ac.za

Fakulteit Gesondheidswetenskappe
Lefapha la Disaense tša Maphelo

ANNEXURE J COMPLETE LIST OF THEMES AND CATEGORIES LINKED TO THE IDENTIFIED CODES OF THE HOSPITALISATION PHASE

Themes	Categories	Concepts
Admission to or transfers within the hospital	Admission or transfers to NICU / HCU / KMC/ Baby room public HCS	14
(19 concepts)	Admission or transfers to NICU / HCU / Baby room private HCS	5
Prematurely born infants not entering the HCS in hospitalisation phase	Prematurely born infants not entering HCS	2
(2 concepts)		
Hospitalisation of prematurely born infant	Hospitalisation Tertiary / Academic hospital public HCS	4
(43 concepts)	Hospitalisation Secondary / District hospital public HCS	6
	Hospitalisation Public HCS	7
	Hospitalisation Private HCS	26
NICU environment	Professionalism	1
(19 concepts)	Sterile environment	2
	NICU environmental stressors	12
	NICU environment private HCS	3
	Maintenance of equipment public HCS	1
Ethical conduct of MDT in NICU	Ethical conduct	2
(7 concepts)	Knowledge and training of MDT in NICU	3
	Unnecessary treatment of prematurely born infant	2
Parent or caregiver bonding with prematurely born infant (hospitalisation phase)	Infant / parent or caregiver bonding	6
(17 concepts)	Infant / parent or caregiver bonding public HCS	4
	Infant / parent or caregiver bonding private HCS	7
KMC of prematurely born infants in hospital	KMC public HCS	17
(23 concepts)	KMC private HCS	5
	KMC	1
KMC environment	KMC environment public HCS	8
(8 concepts)		
Parent / caregiver adjustment before discharge from hospital	Parent / caregiver adjustment private HCS	1
(3 concepts)	Parent / caregiver adjustment public HCS	2
Referral in hospital	Referral for admission to NICU / HCU / KMC	4
(5 concepts)	Referral between public and private HCS	1
MDT referral in hospital	Referral to physiotherapist	5
(34 concepts)	Referral to dieticians	5
	Referral to occupational therapist	4
	Referral to speech therapist	3
	Referral to social worker	1
	Referral to ophthalmologist	1
	Referral to MDT	11
	Referral between MDT	4
Problems with referral during hospitalisation phase	NICU / HCU access	4
(18 concepts)	Admission policy	3
	Transport between rural hospital and NICU at district / secondary or tertiary	1

	/ academic hospitals	
	Late referral to MDT	4
	Use of false address	1
	Referral between MDT members	3
	Staff shortage	2
Multidisciplinary management of prematurely born infants in hospital	Physiotherapy management public HCS	3
(59 concepts)	Physiotherapy management private HCS	7
	Physiotherapy management	9
	Physiotherapy, Occupational therapy and Speech therapy management private HCS	2
	Speech therapy management public HCS	2
	Speech therapy management private HCS	4
	Speech therapy management	3
	Occupational therapy management public HCS	1
	Occupational therapy management private HCS	2
	Occupational therapy management	1
	Nursing management public HCS	1
	Nursing management private HCS	5
	Nursing management	2
	Dietician management public HCS	2
	Dietician management private HCS	3
	Paediatrician management public HCS	1
	Paediatrician management private HCS	2
	Paediatrician management	2
	MDT collaboration public HCS	2
	MDT collaboration private HCS	1
	MDT collaboration	3
	NGO outreach public HCS	1
MDT involved in care and management of prematurely born infants in public HCS (hospitalisation phase)	MDT public HCS	11
(46 concepts)	Physiotherapy public HCS	14
	Nursing staff public HCS	3
	Paediatrician public HCS	5
	Speech therapy public HCS	4
	Occupational therapy public HCS	3
	Audiology public HCS	1
	Dietician public HCS	3
	Counsellor public HCS	1
	Social worker public HCS	1
MDT involved in care and management of prematurely born infants in private HCS (hospitalisation phase)	MDT private HCS	15
(35 concepts)	Physiotherapy private HCS	7
	Nursing staff private HCS	1
	Paediatrician private HCS	2
	Speech therapy private HCS	3
	Occupational therapy private HCS	2
	Ophthalmology private HCS	2
	Dietician private HCS	2
	Sonographer private HCS	1
MDT involved in care and management of prematurely born infants in both public & private HCS (hospitalisation phase)	MDT public & private HCS	18
(35 concepts)	Physiotherapy public & private HCS	6

	Nursing staff public & private HCS	5
	Speech therapy public & private HCS	2
	Occupational therapy public & private HCS	3
	Dietician public & private HCS	1
Physiotherapy involvement in hospital	Limited physiotherapy involvement	7
(7 concepts)		
Clinical practice guideline for physiotherapists in NICU in SA	CPG in first world countries	1
(8 concepts)	CPG for physiotherapist in SA	4
	Process of developing CPG	2
	CPG for MDT in SA	1
Nursing staff knowledge (hospitalisation phase)	Lack / differences of knowledge nursing staff	6
(6 concepts)		
MDT collaboration (hospitalisation phase)	Limited MDT collaboration	10
(10 concepts)		
Knowledge on MDT role (hospitalisation phase)	Limited knowledge on role of MDT	10
(10 concepts		
Education of the MDT in hospitalisation phase	Paediatrician	2
(52 concepts)	Gynaecologist	1
	Nursing staff	10
	Physiotherapy	10
	Occupational therapy	2
	Speech therapy	3
	MDT	24
MDT relationship with parents or caregivers of prematurely born infants in hospital	MDT relationship with parents or caregivers in hospital	16
(21 concepts)	Paediatrician relationship with parents or caregivers in hospital	2
	Nursing staff relationship with parents or caregivers in hospital	3
Screening of the prematurely born infant in hospital	Screening public HCS	17
(38 concepts)	Screening private HCS	16
	Screening	5
Education of parents or caregivers of prematurely born infants (hospitalisation phase)	Parents / Caregivers of prematurely born infants	6
(6 concepts)		
Parent / Caregiver information and education in hospitalisation phase	Information and education by MDT in hospital	21
(52 concepts)	Information and education by physiotherapist in hospital	6
	Information and education by nursing staff in hospital	16
	Information and education by dietician in hospital	1
	Information and education by occupational therapist in hospital	4
	Information and education by speech therapist in hospital	1
	Transition period for parents or caregivers in hospital	3
Parent / Caregiver education hospitalisation phase	Parent / Caregiver education in private HCS	4
(6 concepts)	Parent / Caregiver education in public and private HCS	2
Financial Implications private HCS (hospitalisation phase)	MDT remuneration private HCS	8
(11 concepts)	Medical aid private HCS	2
	Parent / Caregiver and infant bonding	1

	private HCS	
Financial Implications both private HCS and public HCS (hospitalisation phase)	NGO funding	1
(2 concepts)	NIDCAP program	1
Legal issues in NICU	Legal issues due to incompetence	1
(2 concepts)	Protection against legal issues	1
Patient journey of prematurely born infant (hospitalisation phase)	Patient journey in public HCS	3
(13 concepts)	Patient journey in public and private HCS	10
NGO	NGO finances	1
(1 concept)		

*HCS – health care sector