

**DEVELOPMENTAL SCREENING: PREDICTORS OF FOLLOW-UP ADHERENCE  
IN PRIMARY HEALTH CARE**

by

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## **LIST OF ABBREVIATIONS**

CHW – Community Health Worker

COPC – Community Oriented Primary Care

ECCE – Early Childhood Care and Education

ECD – Early Childhood Development

EI – Early Intervention

NPO – Non-Profit Organisation

PEDS – Parents' Evaluation of Developmental Status

PEDS:DM – Parent's Evaluation of Developmental Status: Developmental  
Milestones

PHC – Primary Health Care

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## ABSTRACT

**Background:** Early identification and intervention for infants and young children with developmental delays may negate or minimise the negative effect of a disability on a child's development. Poor follow-up on early detection referrals, however, undermines the effectiveness of early intervention programmes. **Objectives:** To identify factors, including text message reminders, that influence follow-up adherence for early intervention after developmental screening in primary health care. A secondary objective surveyed reasons for follow-up default. **Methods:** The PEDS Tools was used to screen 247 high-risk children. A risk assessment questionnaire was completed with caregivers whose children were referred for speech-language and/or occupational therapy (n=106, 43%). A quasi-experimental study was employed to identify risk factors for defaulting on appointments. A thematic analysis of telephonic interviews was also employed to determine reasons for follow-up defaults. **Results:** Follow-up adherence was 17%. Participants who were divorced, widowed or never married were 2.88 times more likely to attend a follow-up appointment than those who were married or living together (95%, CI 0.97-8.63). Text message reminders did not significantly improve follow-up. More than half (58%) of participants who defaulted on appointments could be reached for telephonic interviews. During the telephonic interviews 87% of participants did not report concern about their child's development. Reasons for defaulting were employment, logistical issues, other responsibilities and forgetfulness. **Conclusions:** Detecting possible developmental delays did not lead to acceptable follow-up adherence for early intervention services at primary health care levels. Increased awareness and education regarding the importance of development for educational success is needed.

### Keywords:

Developmental screening; early intervention; follow-up adherence; follow-up default; occupational therapy; PEDS Tools; primary health care; risk factors; speech-language therapy; text message reminders

## 1. INTRODUCTION

### 1.1. Background

The importance of early identification of infants, toddlers and young children with developmental delays is well established (Elbaum, 2010; Glascoe, 2005; Meisels, 1989). Early identification can lead to timely intervention for children at risk of developmental delays (Tough et al., 2008). If support is provided early in a child's life, it may negate or minimise the negative effect of a disability on the child's development (DSD; DWCPD; UNICEF, 2012; Glascoe, 1999). A child whose developmental delay or disability has been identified early in life has a much better chance of reaching his or her full potential, because 80% of the brain's development occurs before the age of three (Ozkan, Senel, Arslan, & Karacan, 2012; UNICEF, 2013). Early Intervention (EI) has shown to positively impact on children's development, behaviour and school performance (Reynolds, Temple, Robertson, & Mann, 2001), lessening the burden on the child, family and society (Aly, Taj, & Ibrahim, 2010).

It is estimated that the prevalence of moderate to severe disability in South Africa is between 5% and 6% (Samuels, Slemming, & Balton, 2012). Children in South Africa are at an increased risk of developmental delays due to high levels of poverty and low levels of parental education (Grantham-McGregor et al., 2007; Ozkan et al., 2012). The 2011 census found that 59.2% of the population did not complete Grade 12 (Statistics South Africa, 2012) and in 2009 61.9% of children lived below the poverty line (Statistics South Africa, 2010). In addition, the high prevalence of risk factors such as low birth weight, cleft lip and palate, cerebral palsy, foetal alcohol syndrome, HIV/AIDS, multilingualism, and significant bilateral sensorineural hearing loss puts South African children at risk of communication disorders (Popich, Louw, & Eloff, 2007).

Due to the high prevalence of risk factors for developmental delays in South Africa, strategies to improve accessibility to appropriate EI services are vital (Majnemer, 1998). EI is a term used to refer to services rendered to children with developmental delays between the ages of birth to three by different therapists, ideally in a transdisciplinary team (South African Speech-Language-Hearing Association, 2011). EI services range from the early detection and identification to minimise or prevent



developmental delays, to remediation, or compensation for developmental delays (Majnemer, 1998).

In primary prevention programmes, those at high risk of developmental delays are identified before the delay manifests, thus enabling EI to inhibit or reduce the long-term effects of risk factors on development (Majnemer, 1998). Data on the age of identification of children with developmental delays in South Africa are not available, but evidence suggests that even in developed countries less than half of the children who require EI services are identified before entering school (Aly et al., 2010).

Through legislation and policies, the South African government is committed to protecting children's rights to develop their full cognitive, emotional, social and physical potential (Department of Education, 2001). Early Childhood Development (ECD) is recognised as a crucial area for development which focuses on the needs of the birth to nine years age group through education and health services (Storbeck & Moodley, 2011).

Early Childhood Care and Education (ECCE) services, an important aspect of ECD, provide developmentally appropriate educational stimulation for young children in community or home-based facilities (Biersteker et al., 2012; Biersteker, Dawes, Hendricks, & Tredoux, 2016). Approximately 35% of children in South Africa attended a formal ECCE facility in 2014 (Statistics South Africa, 2015) and the government is working to increase access to ECCE facilities (Biersteker et al., 2016). ECCE facilities have the potential to help prevent developmental delays because of the opportunity to have daily access to children (Biersteker et al., 2012).

Primary health care (PHC) clinics could also be used for primary prevention through the identification of children who are at risk of developmental delays. The reason for this is that 61.2% of the population make use of these clinics as the first line of access to health care (Jobson, 2015; Statistics South Africa, 2013).

Currently, EI is not provided on a large scale at facilities where primary prevention is possible. EI has mainly been implemented in tertiary-level public hospitals and private practices since 2000 (Samuels et al., 2012; Van der Linde & Kritzing, 2013). In tertiary-level hospitals the services are mostly on the level of secondary prevention. That is, the service is only initiated once a child has been diagnosed

with developmental delay (Majnemer, 1998). EI services in PHC are lacking because human and financial resources are limited and there is a lack of equipment, materials and effective referral frameworks (Van der Linde, Kritzinger, & Redelinghuys, 2009).

Identifying infants at risk of developmental delays is of importance in the PHC context, because the goal of EI is the prevention of delays and disorders (Van der Linde et al., 2009). More clinicians need to be employed in a permanent capacity at PHC clinics to develop and sustain EI services if developmental delays are to be prevented from occurring in the first place (South African Speech-Language-Hearing Association, 2011).

## **1.2. Rationale**

Employing screening and surveillance tools at PHC settings can facilitate early identification of children with developmental delays (Brothers, Glascoe, & Robertshaw, 2008; Claassen, Pieterse, Van der Linde, Kruger, & Vinck, 2016). This potentially enables families of all socio-economic standings to obtain EI for their developmentally delayed children (UNICEF, 2013). Various studies have, however, reported poor follow-up adherence for children who were referred for an EI evaluation (Clements, Barfield, Kotelchuck, & Wilber, 2008; De Souza, Sardesai, Joshi, Joshi, & Hughes, 2006), which results in diminished effectiveness of EI programmes (De Souza et al., 2006).

Several reasons for poor follow-up adherence to EI services have been reported (Clements et al., 2008; Litt & Perrin, 2014; Peterson et al., 2004; Wang et al., 2009). In India, a developing country like South Africa, it was found that compliance was influenced by the distance that families had to travel to the EI centre (De Souza et al., 2006). Findings in developed countries also indicate that factors such as being non-English speaking, non-White race, part of a minority group, and having fewer economic resources and young, poorly educated parents, put a family at risk of defaulting on referrals to EI (Clements et al., 2008; Jennings & Hanline, 2013; Litt & Perrin, 2014; Peterson et al., 2004).

Parents are regarded as an asset in developmental screening because they know their child best (Glascoe, 1999). However, some factors like parental experience, knowledge, education and age may influence the recognition of delays (Marshall,

Coulter, Gorski, & Ewing, 2016). Poor education has also been suggested to result in a lack of knowledge regarding the benefits of EI, negatively impacting follow-up adherence (Clements et al., 2008). A study in South Africa found that a lack of parental knowledge regarding newborn hearing screening was the most common reason for follow-up default (Scheepers, Swanepoel, & Le Roux, 2014).

A recent South African study found that one in four caregivers defaulted on a hearing rescreen because they forgot about the appointment (Scheepers et al., 2014). These authors suggested centralised data management and quality control monitoring systems that include accurate tracking of referred children through, among others, the use of text message reminders (Scheepers et al., 2014). Tracking of referred children may be critical to the efficacy and cost-effectiveness of developmental screening (Jennings & Hanline, 2013). Comprehensive tracking and follow-up systems should therefore be in place to ensure that children are not only identified through screening, but also return for the appropriate assessments and intervention (UNICEF, 2013). This entails the use of reminders, home visits and contacting people who default on appointments, to prevent them from being lost to care.

Few studies have investigated the effect of parental support and reminders on follow-up adherence; and in the studies that have been done, the results were inconclusive (De Souza et al., 2006; Friderichs, Swanepoel, & Hall, 2012; Wang et al., 2009). In India, a study investigated the effect of parental support provided by village-based government health workers on adherence to an EI programme (De Souza et al., 2006). The health workers contacted families to encourage follow-up. The results indicated that support by the government health workers did not improve adherence. A limitation of the study was, however, that a small sample of infants received support by the government health workers; therefore the power of the study to detect the effect of health workers' inputs may have been inadequate (De Souza et al., 2006).

A study in the United States of America investigated the effect of individualised and intensive parental support on whether a family would contact EI services for an assessment (Wall et al., 2005). The support included repeated telephone reminders to return for an assessment. The study found that when parents did not receive the

above-mentioned support, only 54% contacted EI services, as opposed to 94% of the families who received the support. The positive effect of telephonic reminders and home visits by community health workers (CHWs) on follow-up adherence has also been shown in South Africa (Friderichs et al., 2012). Although these results indicate that parental support and reminders may increase EI follow-up, one has to keep in mind the cost, effectiveness and sustainability of such a programme (De Souza et al., 2006).

The cost of text messages to remind people to keep appointments is negligible (Adanikin, Awoleke, & Adeyiolu, 2014), making it a viable strategy in a developing country like South Africa. The positive effect of repeated reminders to follow-up on referrals has been demonstrated (Adanikin et al., 2014; Friderichs et al., 2012; Wall et al., 2005). One study found that people who received text message reminders were 50% less likely to default on appointments than participants who did not receive text message reminders (Adanikin et al., 2014).

Using text messages to remind caregivers of appointments is time-consuming. It is therefore important to know if text message reminders are effective in improving follow-up, and if so, to identify child and family characteristics that predict poor adherence to follow-up appointments. This can allow for more efficient use of resources while decreasing the number of children with developmental delays who default on follow-up appointments (Jennings & Hanline, 2013).

Although many studies have investigated risk factors for poor follow-up adherence after a developmental screening (Clements et al., 2008; De Souza et al., 2006; Litt & Perrin, 2014; Peterson et al., 2004; Wang et al., 2009), few of these studies were done in developing countries. It may be expected that other factors could be predictive of follow-up adherence in these contexts. More information regarding risk factors in developing countries, as well as the impact of parental support (keeping in mind the cost, effectiveness and sustainability), is needed. This will enable EI programmes to focus on vulnerable populations in need of support in the follow-up process.

## **2. METHODOLOGY**

### **2.1. Aim**

The aim of this study was to determine predictive factors for follow-up adherence for EI, including the use of text message reminders, in a PHC context. The secondary aim was to survey reasons for follow-up default.

### **2.2. Research design**

The current study consisted of two phases. Phase one was a quasi-experimental study (Leedy & Ormrod, 2010) to determine the factors that influence follow-up adherence after a developmental screening in a PHC context. During phase two of the study a descriptive survey design was employed to survey reasons for follow-up default.

Data was collected from Stanza Bopape Clinic in Mamelodi, a township in the Tshwane district, Gauteng. Mamelodi is approximately 25 km<sup>2</sup> in size with an estimated population of close to a million (Darkey & Visagie, 2013). Mamelodi is characterised by diverse economic classes of people, ranging from skilled professionals to unskilled people who rely on government grants for survival (Garg & Mashilwane, 2015). Although Mamelodi is well established with large permanent residential areas, there exists substantial informal settlements comprising mostly of self-built houses (Mashigo, 2012). The people who live in Mamelodi mostly make use of PHC clinics like Stanza Bopape Clinic as their first point of access to health care.

Ethical clearance was obtained prior to data collection from the Tshwane district research committee, Department of Health as well as from the Faculties of Health Sciences and Humanities, University of Pretoria.

### **2.3. Participants**

During a developmental screening programme, 247 children at risk of developmental delays, between the ages of 6 and 36 months were screened at a PHC clinic in Mamelodi. Of these 247 children, 106 (43%) were referred for occupational and/or speech-language therapy. Data on the factors that influence follow-up adherence was obtained from the parents or caregivers of the young children who were referred. Participants were included in the study if they were proficient in English or

Afrikaans, as these are the languages in which the researcher is proficient. If the parents were unable to answer the questions as a result of a language barrier they were excluded from the study.

Stanza Bopape Clinic was the PHC clinic closest to the homes of all of the participants. The home languages of the participants were Sepedi (45.3%), isiZulu (11.3%), Setswana (9.4%), Tsonga (9.4%) and other languages (24.3%). Almost all of the participants (99.1%) were Black and the remaining 0.9% were of another race.

## **2.4. Material and apparatus**

### ***Developmental screening***

The Parents' Evaluation of Developmental Status (PEDS) Tools (Glascoe & Robertshaw, 2016; Glascoe, 2013) was used in the form of a smartphone application to screen for developmental delays. The PEDS application is programmed to automatically score the test according to the PEDS Tools scoring and interpretation algorithm (Glascoe & Robertshaw, 2016; Glascoe, 2013). A recent study confirmed the feasibility of the PEDS Tools in South Africa (Silva, 2010). Outcomes of the smartphone application has been found to correspond with the outcomes of the conventional PEDS Tools in South Africa (Maleka, Van der Linde, Glascoe, & Swanepoel, 2016).

The PEDS Tools is a combination of the PEDS and the PEDS: Developmental Milestones (PEDS:DM) with which parental concerns as well as a child's performance on domain specific developmental milestones are identified. The PEDS is a screening and surveillance tool that measures a child's development, behaviour and social-emotional or mental health status from birth to eight years of age. It consists of 10 questions that elicit parents' concerns regarding their child's language, motor milestones, self-help skills, early academic skills, behaviour and social development. It takes approximately two minutes to administer if it is conducted as an interview. The person administering the tool requires a Grade 4 to Grade 5 literacy level. The tool indicates whether a referral, second screen, patient education or monitoring of the child's development is required. The PEDS has been validated in 20 studies during 2001 to 2010 in which a total of 7213 children were assessed (Macy, 2012).

The PEDS:DM is designed for children from birth to eight years of age and takes approximately five minutes to complete (Brothers et al., 2008). It consists of six to eight items per age range, which represents the following developmental domains: fine motor, gross motor, social-emotional, self-help, expressive language, receptive language and, for older children, reading and mathematics (Brothers et al., 2008). The PEDS:DM has been standardised, has high levels of validity and reliability and excellent sensitivity and specificity (respectively 83% and 84%) (Brothers et al., 2008).

### ***Risk assessment questionnaire***

A risk assessment questionnaire (see Appendix A) was used to determine the child/familial risk factors for the children who failed the developmental screening. The risk assessment form was adapted from a participant and family information questionnaire that was used in a similar participant population. Risk factors were chosen based on factors that other studies have investigated or recommended for future studies with regards to follow-up adherence (Table 1). An additional risk factor was who the primary caregiver is. The effect of text message reminders on follow-up adherence was also investigated (Adanikin et al., 2014; Bigna, Noubiap, Kouanfack, Plottel, & Koulla-Shiro, 2014).

**Table 1: Risk factors included in the risk assessment questionnaire**

<b>Risk factors</b>	<b>Studies in which risk factors have been investigated</b>
Age of the child	Giannoni & Kass, 2010; Jennings & Hanline, 2013; Jimenez et al., 2014; Marshall, Kirby, & Gorski, 2016
Gender of the child	Barfield et al., 2008; De Souza et al., 2006; Giannoni & Kass, 2010; Jennings & Hanline, 2013; Jimenez et al., 2014; Litt & Perrin, 2014; Marshall, Kirby, et al., 2016; Olusanya & Akinyemi, 2009; Rosenberg, Zhang, & Robinson, 2008; Wang et al., 2009
Maternal and caregiver age	Chidiebere, Uchenna, & Kenechi, 2014; Clements et al., 2008; Giannoni & Kass, 2010; Jimenez et al., 2014; Litt & Perrin, 2014; Marshall, Kirby, et al., 2016; Scheepers et al., 2014; Wall et al., 2005; Wang et al., 2009
Caregiver marital status	Jimenez et al., 2014; Litt & Perrin, 2014; Marshall, Kirby, et al., 2016; Peterson et al., 2004; Wall et al., 2005
Educational qualifications	Chidiebere et al., 2014; Clements et al., 2008; De Souza et al., 2006; Giannoni & Kass, 2010; Jimenez et al., 2014; Litt & Perrin, 2014; Marshall, Kirby, et al., 2016; Olusanya & Akinyemi, 2009; Peterson et al., 2004; Wall et al., 2005; Wang et al., 2009
Employment	De Souza et al., 2006; Olusanya & Akinyemi, 2009; Peterson et al., 2004
Average household income	Chidiebere et al., 2014; Clements et al., 2008; De Souza et al., 2006; Giannoni & Kass, 2010; Jimenez et al., 2014; Litt & Perrin, 2014; Marshall, Kirby, et al., 2016; Olusanya & Akinyemi, 2009; Peterson et al., 2004; Rosenberg et al., 2008
Type of housing	De Souza et al., 2006



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Number of people living in the household	Olusanya & Akinyemi, 2009
Number of risk factors for developmental delay	De Souza et al., 2006; Jennings & Hanline, 2013

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### **Telephonic interview**

Reasons for defaulting on follow-up appointments were established by means of a telephonic interview. The interview consisted of two yes/no questions and two open-ended questions.

### **2.5. Reliability, validity and trustworthiness**

The reliability, validity and trustworthiness of the study were ensured. The PEDS Tools (Glascoe & Robertshaw, 2016; Glascoe, 2013) has been validated and is deemed reliable (Macy, 2012). The smartphone application of the PEDS Tools has been validated in South Africa (Maleka et al., 2016). The PEDS Tools was conducted and referrals were made by one of two qualified speech-language therapists who ensured that the material was administered in the same way. The data was collected at only one setting from people who came from the same area. Text message reminders were sent to participants by means of random selection. Triangulation was ensured by asking the same research questions to different study participants. The telephonic interviews also allowed participants to verify that the researcher interpreted their answers correctly.

### **2.6. Ethical considerations**

Ethical principles as described in the Declaration of Helsinki (World Health Organisation, 2013) were adhered to. The research proposal was submitted to the research ethics committees of the Department of Speech-Language Pathology and Audiology, the Faculty of Humanities, University of Pretoria, the Faculty of Health Sciences, University of Pretoria and the Tshwane Research Council for ethical clearance.

#### ***Confidentiality***

Participants' names were not included in the study. The only parties who had access to the data were the researcher and the research supervisors. Data will be securely stored at the Department of Speech-Language Pathology and Audiology at the University of Pretoria for 15 years.



### ***Informed consent***

Informed consent was obtained from the CEO of Stanza Bopape Clinic to do research at the clinic (see Appendix B). In addition, the participants gave written informed consent on the day of the developmental screening, in which they agreed to data being used for the current study and for future research (see Appendix C). Participants under 18 years of age were excluded from the study.

### ***Protection from harm***

The researcher is obligated to ensure that no risk of physical harm, physical discomfort, physiological distress, loss of privacy and loss of time or money occur (Brink, 2002). The researcher is responsible to guarantee that the risk that the participants are exposed to, does not exceed that which the participants are exposed to on a daily basis (Brink, 2002). The current study attempted to avoid all risks by keeping all procedures as close as possible to a normal clinic visit. The privacy of the participants who received text message reminders was protected by not using the contact details for any other reason than that which is specified in the research procedures. Contact information was kept strictly confidential.

### ***Honesty with professional colleagues***

The research report and article is transparent, honest and complete. The nature of the findings and procedures that were followed has not been misrepresented.

### ***Non-discrimination***

No discriminatory practices were applied during the course of the research. All participants and their families were treated equally and with respect.

### ***Competence and practices of the researcher***

The researcher is registered as an independent practitioner in Speech-Language and Hearing Therapy at the Health Professions Council of South Africa.

## **2.7. Procedures**

The key outcome measure was follow-up on early identification referral within three months of failing the PEDS developmental screening test. The current study follows on a protocol, which is being implemented in the Stanza Bopape district. Families attend clinics in the area on a regular basis for check-ups and immunizations. These clinics are ideal for early identification of developmental delays because families visit

the clinics periodically and development can therefore be monitored regularly.

***Phase one – Risk factors for follow-up default and the effect of text message reminders on follow-up adherence***

Written parental or caregiver informed consent was obtained before collecting the data. The PEDS Tools was conducted by one of two qualified speech-language therapists on each participant in the form of a smartphone application. The PEDS and PEDS:DM questions were asked as an interview to parents or caregivers. If the children failed the developmental screening, a risk assessment form was completed in the form of an interview with the parents or caregivers to collect data on child and familial risk factors. Either a qualified speech-language therapist or a CHW, who was trained to conduct the interview, completed the risk assessment form. Thereafter they were given a referral letter with an appointment date for a follow-up visit, so that they could receive a second screen, further referral or patient education (see Appendix D). The reason for a follow-up appointment was explained to all participants.

Through random assignment, 51% of the referred participants received a text message to remind them of their appointment five days before the scheduled appointment and again one day before the scheduled appointment. The remaining 49% of participants did not receive a reminder. The text messages read: "Good day. This is to remind you to take <name> to therapy (speech and/or occupational) on <date> at <time>." It was one-way messages that were sent during the day.

Through collaboration with the clinic it was established whether the participants adhered to the follow-up appointments. The impact of the following variables on follow-up adherence was investigated: number of risk factors for developmental delay, age and gender of the child, maternal and caregiver age, who the primary caregiver is, marital status of caregivers, educational qualifications, employment, average household income, type of housing, number of people living in the household and whether text message reminders were received.

If the participants defaulted on the follow-up appointments and did not make a new appointment within three months, it was assumed that they were not going to follow up on the referral. A time frame of three months was selected to give participants enough time to reschedule appointments.

### ***Phase two – Qualitative reasons for follow-up default***

Reasons for defaulting on the follow-up appointments were established by means of telephonic interviews with participants. The telephonic interviews were conducted at least three months after the appointment to allow sufficient time for follow-up. Telephone calls were made between eight and five o'clock during the week. The researcher attempted to contact each participant three times on three different days. Participants who were unavailable during those times, were excluded from phase two of the study. Answers were recorded on a spreadsheet for later analysis.

### **2.8. Data analysis**

Microsoft Excel 2010 was used to capture the data in table format. Data was entered into a Microsoft Excel 2010 spreadsheet. The variables (number of risk factors for developmental delay, child's age, child's gender, maternal age, caregiver age, who the primary caregiver is, marital status of the caregiver, educational qualifications, employment, average household income, type of housing, number of people living in the household and whether text message reminders were received) were entered into the spreadsheet for each participant. The data from phase one of the study was analysed by using descriptive statistics, Chi-squared tests, Wilcoxon rank tests, Spearman's rank correlations and logistic regression. Statistical significance was set at 5% and confidence intervals at 95% for all tests.

For phase two of the study, descriptive statistics were used to analyse the yes/no questions and thematic analysis was used to analyse the open-ended questions. Thematic analysis allowed for common trends or central themes to be identified among the participants.

### 3. ARTICLE

**TITLE:** *DEVELOPMENTAL SCREENING: PREDICTORS OF FOLLOW-UP ADHERENCE IN PRIMARY HEALTH CARE*

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#### 3.1. Abstract

**Background:** The importance of early identification of infants and young children with developmental delays is well established. Poor follow-up on referrals, however, undermines the effectiveness of early intervention programmes. **Objectives:** To identify factors, including text message reminders, that influence follow-up adherence for early intervention after developmental screening in primary health care. A secondary objective surveyed reasons for follow-up default. **Methods:** The PEDS Tools was used to screen 247 high-risk children. A risk assessment questionnaire was completed with caregivers whose children were referred for speech-language and/or occupational therapy (n=106, 43%). A quasi-experimental study was employed to identify risk factors for defaulting on appointments. A thematic analysis of telephonic interviews was also employed to determine reasons for follow-up defaults. **Results:** Follow-up adherence was 17%. Participants who were divorced, widowed or never married were 2.88 times more likely to attend a follow-up appointment than those who were married or living together (95%, CI 0.97-8.63). Text message reminders did not improve follow-up. More than half (58%) of participants who defaulted on appointments could be reached for telephonic interviews. Interviews showed that 87% of participants were unconcerned about their child's development. Other reasons for defaulting were employment, logistical issues, other responsibilities and forgetfulness. **Conclusions:** Follow-up adherence for early intervention services following a positive primary health care screen was

poor. Increased awareness and education regarding the importance of development for educational success is needed.

**Keywords:**

Developmental screening; follow-up adherence; occupational therapy; PEDS Tools; primary health care; speech-language therapy; text message reminders

**3.2. Introduction**

The importance of early identification of infants, toddlers and young children with developmental delays is well established (Elbaum, 2010; Glascoe, 2005; Meisels, 1989). Early identification can lead to timely intervention for children at risk of developmental delays (Tough et al., 2008). If support is provided early in a child's life, it may negate or minimise the negative effect of a disability on the child's development (Glascoe, 1999; Scherzer, Chhagan, Kauchali, & Susser, 2012; Tough et al., 2008). EI positively impacts children's development, behaviour and school performance (Reynolds et al., 2001), lessening the burden on the child, family and society (Aly et al., 2010).

It is estimated that the national prevalence of moderate to severe disability in South Africa is between 5% and 6% (Samuels et al., 2012). Although the average age of identification of children with developmental delays in South Africa is not available, evidence suggests that even in developed countries, less than half of the eligible children are identified before entering school (Aly et al., 2010).

In addition to late identification in South Africa, few clinicians are employed in a permanent capacity in rural communities to develop and sustain EI services (South African Speech-Language-Hearing Association, 2011). EI has been implemented in South Africa since 2000, but only in tertiary-level public hospitals and private practices (Samuels et al., 2012; Van der Linde & Kritzing, 2013). EI services would be more accessible if it were provided at PHC settings because the majority of the population (61%) makes use of public sector clinics as a first point of access to medical services (Statistics South Africa, 2013).

Employing screening and surveillance tools at PHC settings can facilitate early identification of children with developmental delays (Brothers et al., 2008). This potentially enables families of all socio-economic standings to obtain EI for their

children (UNICEF, 2013). Comprehensive tracking and follow-up systems are however required to ensure that children are not only identified through screening, but also return for the appropriate assessments and intervention (UNICEF, 2013). Various studies have, however, reported poor follow-up adherence for children who were referred for an EI evaluation (Clements et al., 2008; De Souza et al., 2006; Giannoni & Kass, 2010; Wang et al., 2009). Low participation rates lead to diminished effectiveness of EI programmes (De Souza et al., 2006).

Various reasons for poor follow-up adherence to EI services have been reported (Clements et al., 2008; Litt & Perrin, 2014; Peterson et al., 2004; Wang et al., 2009). In developed countries findings indicate that factors such as being non-English speaking, non-White race, part of a minority group, and having fewer economic resources and young, poorly educated parents, put a family at risk of defaulting on referrals for EI (Clements et al., 2008; Litt & Perrin, 2014; Peterson et al., 2004). In developing countries studies have found that adherence was also influenced by the distance that families had to travel to the EI centre (De Souza et al., 2006) and the fact that people forgot about appointments (Adanikin et al., 2014; De Souza et al., 2006; Scheepers et al., 2014).

Centralised data management and quality control monitoring systems that include accurate tracking of referred children through, among others, the use of text message reminders, have been suggested to improve follow-up (Scheepers et al., 2014). The positive effect of repeated reminders to follow up on referrals has been demonstrated (Adanikin et al., 2014; Friderichs et al., 2012; Wall et al., 2005). One study found that people who received text message reminders were 50% less likely to default on appointments (Adanikin et al., 2014). The cost of text messages to remind people to keep appointments is negligible (Adanikin et al., 2014), making it a viable strategy in a developing country like South Africa.

The aim of this study was to determine predictive factors for follow-up adherence for EI, including the use of text message reminders, in a PHC context.

### **3.3. Methods**

The current study consisted of two phases. Phase one was a quasi-experimental study to determine the factors that influence follow-up adherence after a developmental screening in a PHC context. During phase two participants who did

not return for a follow-up visit were contacted telephonically to survey reasons for follow-up default.

Data was collected from Stanza Bopape Clinic in Mamelodi, a township in the Tshwane district, Gauteng. Mamelodi is approximately 25 km<sup>2</sup> in size with an estimated population of close to a million (Darkey & Visagie, 2013). Mamelodi is characterised by diverse economic classes of people, ranging from skilled professionals to unskilled people who rely on government grants for survival (Garg & Mashilwane, 2015). Although Mamelodi is well established with large permanent residential areas, there exists substantial informal settlements comprising mostly of self-built houses (Mashigo, 2012). The people who live in Mamelodi mostly use PHC clinics like Stanza Bopape Clinic as their first point of access to health care.

Ethical clearance was obtained prior to data collection from the Tshwane district research committee, Department of Health as well as from the Faculties of Health Sciences and Humanities, University of Pretoria.

### **3.4. Participants**

During a developmental screening programme, 247 children at risk of developmental delays, between the ages of 6 and 36 months were screened at a PHC clinic in Mamelodi. Of these 247 children, 106 (43%) were referred for occupational and/or speech-language therapy. Data on the factors that influence follow-up adherence was obtained from the parents or caregivers of the young children who were referred. Participants were included in the study if they were proficient in English or Afrikaans, as these are the languages in which the researcher is proficient. If the parents were unable to answer the questions as a result of a language barrier they were excluded from the study.

Stanza Bopape Clinic was the PHC clinic closest to the homes of all of the participants. Home language distribution was Sepedi (45.3%), isiZulu (11.3%), Setswana (9.4%), Tsonga (9.4%) and other languages (24.3%). Almost all of the participants (99.1%) were Black and the remaining 0.9% were of another race.

### **3.5. Material**

***Developmental screening:*** The Parents' Evaluation of Developmental Status (PEDS) Tools (Glascoe & Robertshaw, 2016; Glascoe, 2013) was used in the form



of a smartphone application to screen for developmental delays. The PEDS application is programmed to automatically score the test according to the PEDS Tools scoring and interpretation algorithm (Glascoe & Robertshaw, 2016; Glascoe, 2013). Outcomes of the smartphone application has been found to correspond with the outcomes of the conventional PEDS Tools in South Africa (Maleka et al., 2016).

The PEDS Tools is a combination of the PEDS and the PEDS: Developmental Milestones (PEDS:DM) with which parental concerns as well as a child's performance on domain specific developmental milestones are identified. The PEDS Tools are screening and surveillance tools that measure a child's development, behaviour and social-emotional or mental health status from birth to eight years of age. It takes less than 10 minutes to administer and score the test. The PEDS has been validated in 20 studies during 2001 to 2010 in which a total of 7213 children were assessed (Macy, 2012). The PEDS:DM has been standardised, has high levels of validity and reliability and excellent sensitivity and specificity (respectively 83% and 84%) (Brothers et al., 2008). Furthermore a recent study confirmed that use of the PEDS Tools is feasible in South Africa (Silva, 2010).

***Risk assessment questionnaire:*** A risk assessment questionnaire was used to determine the risk factors for defaulting on follow-up appointments. The risk factors were chosen based on factors that other studies have investigated or recommended for future studies with regards to follow-up adherence. The risk factors were the age (Giannoni & Kass, 2010) and gender (Barfield et al., 2008; De Souza et al., 2006; Giannoni & Kass, 2010; Litt & Perrin, 2014; Olusanya & Akinyemi, 2009; Rosenberg, Zhang, & Robinson, 2008; Wang et al., 2009) of the child, maternal and caregiver age (Chidiebere, Uchenna, & Kenechi, 2014; Clements et al., 2008; Giannoni & Kass, 2010; Litt & Perrin, 2014; Olusanya & Akinyemi, 2009; Scheepers et al., 2014; Wall et al., 2005; Wang et al., 2009), who the primary caregiver is, marital status of caregivers (Litt & Perrin, 2014; Peterson et al., 2004; Wall et al., 2005), educational qualifications (Chidiebere et al., 2014; Clements et al., 2008; De Souza et al., 2006; Giannoni & Kass, 2010; Litt & Perrin, 2014; Olusanya & Akinyemi, 2009; Peterson et al., 2004; Wall et al., 2005; Wang et al., 2009), employment (De Souza et al., 2006; Olusanya & Akinyemi, 2009; Peterson et al., 2004), average household income (Chidiebere et al., 2014; Clements et al., 2008; De Souza et al., 2006; Giannoni & Kass, 2010; Litt & Perrin, 2014; Olusanya & Akinyemi, 2009; Peterson et al., 2004;



Rosenberg et al., 2008), type of housing (De Souza et al., 2006), number of people living in the household (Olusanya & Akinyemi, 2009) and the number of risk factors for developmental delay (De Souza et al., 2006; Jennings & Hanline, 2013). In addition the effect of text message reminders on follow-up adherence was investigated (Adanikin et al., 2014; Bigna et al., 2014).

**Telephonic interview:** Reasons for follow-up default were established by means of a telephonic interview consisting of two yes/no questions and two open-ended questions.

### 3.6. Procedures

**Phase one:** Written parental or caregiver informed consent was obtained before collecting the data. The PEDS Tools was conducted by two qualified speech-language therapists on each participant in the form of a smartphone application. The PEDS and PEDS:DM questions were asked as an interview to parents or caregivers. If the children failed the developmental screening a risk assessment form was completed in the form of an interview with the parents or caregivers to collect data on child and familial risk factors. Either a qualified speech-language therapist or a CHW, who was trained to conduct the interview, completed the risk assessment form. Thereafter they were given an appointment for a follow-up visit so that they could receive a second screen, further referral or patient education. The reason for a follow-up appointment was explained to all participants.

Through random assignment, 54 (51%) of the referred participants received a text message to remind them of their appointment five days before the scheduled appointment and again one day before the scheduled appointment. The remaining 52 (49%) participants did not receive reminders. The text messages read: "Good day. This is to remind you to take <name> to therapy (speech and/or occupational) on <date> at <time>." It was one-way messages that were sent during the day.

If the participants defaulted on the follow-up appointments or did not make a new appointment within three months, it was assumed that they were not going to follow up on the referral. A time frame of three months was selected to give participants enough time to reschedule appointments.

**Phase two:** Reasons for defaulting on follow-up appointments were established by

means of telephonic interviews with participants. The telephonic interviews were conducted at least three months after the appointment to allow sufficient time for follow-up. Telephone calls were made between eight and five o'clock during the week, unless the participant specifically asked to be phoned at a different time. The researcher attempted to contact each participant three times on three different days. Participants who were unavailable during those times, were excluded from phase two of the study. Answers were recorded on a spreadsheet for later analysis.

### **3.7. Data analysis**

Descriptive statistics were used to determine the referral rate and the adherence rate. During phase one Chi-squared tests were used to identify significant associations between categorical variables. Similarly, significant differences between respondents attending a follow-up visit and those who did not, were evaluated with Wilcoxon rank tests. Spearman's rank correlation coefficients, with a Bonferroni adjustment for multiple correlations, were used to determine the significance of correlations between variables. Logistic regression was carried out on the data, with adherence to a follow-up visit being the dependent variable. Statistical significance was set at 5% and confidence intervals at 95% for all tests.

For phase two of the study, descriptive statistics were used to analyse the yes/no questions and thematic analysis was used to analyse the open-ended questions. Thematic analysis allowed for common trends or central themes to be identified among the participants.

### **3.8. Results**

#### ***Phase one***

A total of 106 (43%) of the 247 at-risk children screened for developmental delays were referred for speech-language therapy and/or occupational therapy. The majority of referred children (n=78, 74%) had one to three risk factors for developmental delay and 26% (n=28) of referred children had four or more risk factors for developmental delay. Text messages to remind participants of the follow-up appointment were sent to 51% (n=54) of participants. Only 17% (18/106) of participants returned for the follow-up appointment, of which 56% (10/18) received text message reminders (Table 2).

**Table 2: Participant characteristics according to adherence to follow-up appointment (OR = Odds Ratio; CI = Confidence interval)**

Participant Characteristics	Attended Follow-up N=18 (%)**	Did not Attend Follow-up N=88 (%)**	Total N=106 (%)**	Odds Ratios (OR), (95% CI)	P values
Child Age					
6 – 18 months	8 (44.4)	51 (58.0)	59 (55.7)	1.72 (0.61-4.83)	0.293
19 – 36 months	10 (55.6)	37 (42.0)	47 (44.3)		
Maternal Age***					
18 – 30 years	10 (58.8)	62 (70.5)	72 (68.6)	1.67 (0.57-4.91)	0.344
31 years and older	7 (41.2)	26 (29.6)	33 (31.4)		
Caregiver Age***					
18 – 30 years	9 (50.0)	52 (61.9)	61 (59.8)	1.63 (0.58-4.57)	0.350
31 years and older	9 (50.0)	32 (38.1)	41 (40.2)		
Monthly Income****					
0 – R2000	9 (50.0)	46 (52.9)	55 (52.4)	1.12 (0.40-3.11)	0.824
More than R2000	9 (50.0)	41 (47.1)	50 (47.6)		
Child Gender					
Male	12 (66.7)	51 (58.0)	63 (59.4)	0.69 (0.24-2.02)	0.493
Female	6 (33.3)	37 (42.0)	43 (40.6)		
Primary Caregiver					
Mother, father or both parents	13 (72.2)	70 (79.6)	83 (78.3)	1.50 (0.47-4.78)	0.492
Grandparents, extended family, foster parents	5 (27.8)	18 (20.5)	23 (21.7)		
Caregiver Education					
Gr 10 or less	5 (27.8)	25 (28.4)	30 (28.3)	1.03 (0.33-3.21)	0.957
Gr 11 -12, Tertiary	13 (72.2)	63 (71.6)	76 (71.7)		
Caregiver Marital Status					
Living Together / Married	6 (33.3)	52 (59.1)	58 (54.7)	2.88 (0.97-8.63)	<b>0.045*</b>
Never Married, Widowed or Divorced	12 (66.7)	36 (40.9)	48 (45.3)		
Text Message Reminder					
Yes	10 (55.6)	44 (50.0)	54 (50.9)	1.25 (0.45-3.48)	0.667
No	8 (44.4)	44 (50.0)	52 (49.1)		
Housing					
Own house, Staying with others	12 (66.7)	49 (55.7)	61 (57.6)	0.63 (0.21-1.84)	0.390
Own/renting informal housing	6 (33.3)	39 (44.3)	45 (42.4)		
Number of residents per house					
2 – 4	6 (33.3)	46 (52.3)	52 (49.1)	2.19 (0.74-6.46)	0.143
5 or more	12 (66.7)	42 (47.8)	54 (50.9)		
Employed Primary Caregiver					
Yes	2 (11.1)	18 (20.5)	20 (18.9)	0.49 (0.10-2.34)	0.515
No	16 (88.9)	70 (79.5)	86 (81.1)		
Number of risk factors for developmental delay					
1-3	13 (72.2)	65 (73.9)	78 (73.6)	1.09 (0.42-2.73)	0.886
4+	5 (27.8)	23 (26.1)	28 (26.4)		

\*Significant association (p<0.05); \*\* Column %; \*\*\*Maternal and caregiver age do not add to 106 because some participants were either the mother or the caregiver, not both; \*\*\*\*Monthly income adds to 105 because one participant could not provide information on income

Spearman's rank correlation coefficients, with Bonferroni adjustment, were used to identify significant correlations between categories. The number of residents in a house was significantly correlated to caregiver marital status ( $r=0.324$ ,  $p=0.046$ ), indicating that caregivers who were never married or were widowed or divorced lived in households with more than five residents. The number of residents in a house also significantly correlated with the type of housing ( $r=0.455$ ,  $p<0.001$ ). If a household consisted of more than five residents they were more likely to stay in informal housing than owning their own house or staying with others in a house.

Chi-squared tests and Wilcoxon rank tests indicated that the only significant association between the categorical variables and follow-up adherence was for caregiver marital status ( $p=0.045$ ).

A logistic regression model was fitted to the data to identify predictive factors contributing to follow-up adherence by participants. The only significant contributor to the odds of attending follow-up remained caregiver marital status, with respondents divorced, widowed or never married 2.88 times more likely to attend than those who were living together or married.

### ***Phase two***

Of the 88 participants who defaulted on the follow-up appointments, 51 (58%) could be reached telephonically. Informed consent was obtained for 92% ( $n=47$ ) of these participants; the remaining 8% ( $n=4$ ) did not consent to an interview and were therefore excluded from phase two of the study.

The 37 (42%) participants who could not be reached, had telephone numbers that repeatedly went directly to voicemail ( $n=18$ ; 49%), did not exist ( $n=8$ ; 22%), were not answered ( $n=7$ ; 19%) or were incorrect ( $n=4$ ; 11%).

Of the participants who received text message reminders, 43% ( $n=23$ ) could not be reached telephonically. The reasons for this were that 43% ( $n=10$ ) of the numbers went directly to voicemail, 26% ( $n=6$ ) of the numbers had no answer, 22% ( $n=5$ ) of the numbers did not exist and 9% ( $n=2$ ) of the numbers were incorrect.

Participants who could be reached telephonically were asked whether they were concerned about their child's development. Forty-one participants (87%) indicated 'no' and six (13%) indicated 'yes'. They were also asked whether they understood

why their child was referred for speech and/or occupational therapy. Twenty six (55%) of the participants indicated ‘yes’, 20 (43%) of the participants indicated ‘no’ and one (2%) was unable to answer because she was not the person who received the referral at the clinic.

Participants were then asked two open-ended questions, namely the reasons for being concerned or unconcerned about their child’s development; and reasons for not adhering to the follow-up appointment. Central themes, together with illustrative quotes from participants who were concerned and participants who were not concerned about their child’s development, are presented in Table 3 and Table 4 respectively.

**Table 3: Participants who were concerned about their child’s development (n=6): Themes and illustrative quotes from telephonic interviews**

Themes	Quotes
<b><i>Reasons for being concerned about child’s development</i></b>	
Delayed development	She is not doing what other children of her age are doing. He is not walking.
Behavioural problems	He is learning bad things.
<b><i>Reasons for not attending the appointment</i></b>	
Employment	I could not get off at work. I had a job interview.
Awareness	I was not aware of the appointment. I do not remember why I did not go, but I wanted to go.
Logistical issues	We were in Limpopo (visiting family).

**Table 4: Participants who were not concerned about their child’s development (n=40): Themes and illustrative quotes from telephonic interviews**

Themes	Quotes
<b><i>Reasons for not being concerned about child’s development</i></b>	
Development	She can do everything and talks fluently.
Health	My child is healthy and is eating well. He is not sick.
Unable to provide reason	I do not know. I can’t explain.
<b><i>Reasons for not attending the appointment</i></b>	
Employment	I was at work. I went for a job interview.
Development	I did not think it was necessary because she had started talking. I didn’t think it was necessary because the child is fine.
Other responsibilities	My other child was not feeling well. I was at a funeral. I was busy.
Awareness	I do not remember why I did not go. I forgot about the appointment.
Logistical issues	I was two hours early and then the therapists were not there to

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help me, so I went home.  
I went to the clinic but I could not find the therapists.  
I was in Limpopo.  
By the time of the appointment my child was not living in Mamelodi anymore.  
The taxis and buses were striking on that day.

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### 3.9. Discussion

Poverty, parental education less than the 9<sup>th</sup> grade, unemployment, single parenthood and lack of a stable residence put a child at risk of developmental delays (Hillemeier, Morgan, Farkas, & Maczuga, 2011; Ozkan et al., 2012; Rossetti, 2001). Every referred child in the current study had at least one risk factor for developmental delay (Hillemeier et al., 2011; Ozkan et al., 2012; Rossetti, 2001), resulting in a high referral rate of 43%, similar to that of a recent study at a PHC clinic in the Tshwane district (Van Der Linde, Swanepoel, Glascoe, Louw, & Vinck, 2015). Although many children in this population may be in need of EI, 83% of children who were screened for developmental delays did not follow up on the referrals.

Text message reminders showed very little effect compared to previous studies performed in developing countries (Adanikin et al., 2014; Bigna et al., 2014; Lester et al., 2010; Lund et al., 2014), with no significant increase in follow-up adherence. The lack of an observed effect may be explained in part by the prevalence of cellular phone turnover. Cellular phone turnover has been reported to be common in a semi-urban area in South Africa due to theft or loss (39%) and/or damage (28%) (Crankshaw et al., 2010). Of the participants who received text message reminders, 43% (n=23) could not be reached telephonically and 9.3% (n=5) of the numbers no longer existed. It is unclear whether these numbers also did not exist or were not in use at the time that the text message reminders were sent. In future, multiple contact numbers could be obtained from caregivers so that text messages could be sent to more than one recipient. Contact numbers should be verified to ensure that they are functional and owned by the client and it should be confirmed that text message reminders were received. If resources permit, a phone call plus text message reminder could be used, as this has been successful in a previous study (Bigna et al., 2014).

The only predictor for poor follow-up that could be identified from the risk assessment form was marital status. Contrary to what other studies (Litt & Perrin, 2014; Peterson et al., 2004) have found, there was a significant association between caregiver marital status and follow-up adherence, with respondents divorced, widowed or never married being more likely ( $p=0.045$ ; CI 0.97-8.63) to attend than caregivers who were married or living together. Single caregivers also tended to live in informal housing with five or more residents. It may be that single caregivers feel a stronger need for support from experts as they are the sole provider and caregiver of their child. This association needs to be explored further, however.

A recurring theme in the telephonic interviews was that persons who were employed did not attend the appointment because they were unable to get leave from work. This was applicable to participants who were concerned about their child's development as well as those who were unconcerned. Poor adherence has been reported amongst employed people in other studies too (Adeponle, Obembe, Suleiman, & Adeyemi, 2007; Olusanya & Akinyemi, 2009). Participants also defaulted on the follow-up appointment due to job interviews. High rates of unemployment exist in this research setting (Statistics South Africa, 2012), providing a possible explanation for the prioritisation of work over follow-up adherence for EI.

Some participants defaulted on follow-up appointments due to unforeseeable responsibilities like caring for an ill child or attending a funeral. Other participants defaulted due to difficulties with transport or because they were out of town. These reasons have also been reported in a previous study (Saba, Warren, Weber-Gasparoni, & Dawson, 2014). Some participants forgot about the follow-up appointment, as has also been reported in other studies (Jamil, Ismail, Zulkifli, Majid, & Van Rostenberghe, 2011; Scheepers et al., 2014). More should be done to encourage parents to reschedule appointments if they were unable to attend. Initiatives such as community oriented primary health care may be utilised to follow up on infants and young children and to create awareness on developmental delays and the importance of EI by means of home visits by CHWs (Bam, Marcus, Hugo, & Kinkel, 2013). Telephone call reminders and home visits by CHWs to reschedule missed appointments have been found to be successful in a hearing screening programme in South Africa (Friderichs et al., 2012).



Participants may not have rescheduled because motivation to attend the follow-up appointments were low. Most participants (87%) were not concerned about their child's development and more than half (55%) of these participants indicated that they understood why their child was referred for occupational and/or speech-language therapy. Thus, most participants remained unconcerned about their child's development despite understanding the reasons for referral. Some parents therefore believed that if their child is healthy there is nothing to be concerned about. Mothers who do not suspect that their child may have developmental problems are less likely to adhere to programmes that provide health services (Ballantyne, Stevens, Guttman, Willan, & Rosenbaum, 2013). Caregivers need to be educated on the importance of timely intervention for developmental delays.

Parent and caregiver education can perhaps be better achieved by including a parent education feature on the PEDS application. The application could provide a short explanation for the reason for referral in understandable language at the end of the screening. Written information on the importance of EI could be provided to parents so that they can remember the importance of and reasons for the referral.

The current study provides a unique perspective on factors influencing follow-up adherence after developmental screening in South Africa. It has advanced our understanding of exploring more effective ways to improve follow-up of developmentally delayed children for EI in urban communities. There were, however, some limitations to the study.

Limitations of the current study included a potential language barrier between the researcher and participants. Even though English is generally the accepted language for communication between people with different home languages (Van der Merwe, 2014), neither English nor Afrikaans was the home language of participants, with the exception of one participant who spoke Afrikaans. This may have resulted in difficulty understanding the importance and reason for referrals. The use of CHWs to administer the PEDS Tools has been found to be successful (Maleka et al., 2016) and future research could evaluate the effect thereof on follow-up adherence, as the CHWs speak the caregivers' language and understand the culture (Friderichs et al., 2012).



A replication of the study with a larger sample size is also recommended. This will improve the chances of finding significant contributors to follow-up. Parental knowledge and beliefs on early childhood development may have had an effect on follow-up adherence. This should also be explored further in future research.

### **3.10. Conclusion**

In this study early identification of possible developmental delays in most cases (83%) did not translate to acceptable follow-up adherence for EI services. Participants who were divorced, widowed or never married were more likely to attend a follow-up appointment than those who were married or living together. The use of text message reminders did not improve follow-up adherence significantly. Most participants (87%) had poor motivation for follow-up because they reported not being concerned about their child's development. Participants also did not follow up on referrals because of employment, logistical issues, other responsibilities and forgetfulness. Improving follow-up adherence for EI after a developmental screening is complex and requires further consideration. Parents, caregivers and communities should be educated regarding the importance and benefits of EI to ensure that children with developmental delays are not only identified through developmental screening but also receive timely EI services.

## 4. DISCUSSION AND CONCLUSION

### 4.1. Discussion of results

Poverty, parental education less than the 9<sup>th</sup> grade, unemployment, single parenthood and lack of a stable residence have been described as risk factors for developmental delays (Hillemeier et al., 2011; Ozkan et al., 2012; Rossetti, 2001). In South Africa, 45.5% of the population live in poverty (Statistics South Africa, 2014), 36.7% only have some secondary education (Statistics South Africa, 2015), 40% are unemployed based on the expanded definition of unemployment (Statistics South Africa, 2012), 41.8% live with only one parent (Statistics South Africa, 2010) and 12.9% of South Africans live in informal housing (Statistics South Africa, 2015). South Africa therefore has a large number of children at risk of developmental delays.

In the current study the population is characterised by diverse economic classes of people, ranging from skilled professionals to people who rely on government grants for survival (Garg & Mashilwane, 2015). More than 70% of people living in Mamelodi did not complete secondary schooling (Statistics South Africa, 2012). A substantial number of informal settlements, comprising mostly of self-built houses, exist in the area (Mashigo, 2012). The children of Mamelodi can therefore be described as a population with a high risk for developmental delays.

Each referred child in the current study had at least one risk factor for developmental delays, as has also been found at another PHC clinic in the Tshwane district (Claassen et al., 2016). A high referral rate was therefore expected in the current study. A referral rate of 43% was found, which is similar to that of a recent study at a PHC clinic in the Tshwane district (Van Der Linde et al., 2015). Although many children in this population may be in need of EI, 83% of children who were screened for developmental delays did not follow up on the referrals.

WHO encourages the use of cellular phones to assist in health care delivery in resource-limited settings (World Health Organisation, 2011). The increase of cellular phone use in Africa (Lester, Gelmon, & Plummer, 2006) has led to various medical programmes successfully using text message reminders to improve adherence to intervention programmes. Non-attendance at postnatal clinics in Nigeria was

reduced by 21.5% by text message reminders (Adanikin et al., 2014) and in Kenya, text message reminders significantly improved antiretroviral treatment adherence (Lester et al., 2010).

In the current study, text message reminders showed very little effect compared to previous studies performed in developing countries (Adanikin et al., 2014; Bigna et al., 2014; Lester et al., 2010; Lund et al., 2014). There was not a significant increase in follow-up adherence. The lack of an observed effect may be explained in part by the prevalence of cellular phone turnover. Cellular phone turnover has been reported to be common in a semi-urban area in South Africa due to theft or loss (39%) and/or damage (28%) (Crankshaw et al., 2010). Of the participants who received text message reminders, 43% (n=23) could not be reached telephonically and 9.3% (n=5) of the numbers no longer existed. It is unclear whether these numbers also did not exist or were not in use at the time that the text message reminders were sent.

The only predictor for poor follow-up that could be identified from the risk assessment form was marital status. Contrary to what other studies (Litt & Perrin, 2014; Peterson et al., 2004) have found, there was a significant correlation between caregiver marital status and follow-up adherence, with respondents divorced, widowed or never married being more likely ( $p=0.045$ ; 95%, CI 0.97-8.63) to attend follow-up appointments than parents who were married or living together. Single caregivers also tended to live in informal housing with five or more residents. It may be that single caregivers feel a stronger need for support from experts as they are the sole provider and caregiver of their child. This association needs to be explored further, however.

With the exception of caregiver marital status, all other odds ratios were not significant. Although the odds were not significant, for several of the categories the odds of adhering to follow-up appointments correlate with the findings of other studies. Older children are more likely to be brought for a follow-up appointment than younger children (Jennings & Hanline, 2013), older mothers and caregivers are more likely to attend follow-up appointments than younger mothers (Clements et al., 2008), caregivers with a higher household income are more likely to attend follow-up appointments than caregivers with a lower household income (Marshall, Kirby, &

Gorski, 2016), parents or caregivers with male children are more likely to attend follow-up appointments than parents with female children (Jimenez et al., 2014; Litt & Perrin, 2014) and text message reminders improve follow-up adherence (Adanikin et al., 2014; Bigna et al., 2014; Lester et al., 2010; Lund et al., 2014). With a larger sample size these odds ratios could perhaps be significant.

A recurring theme in the telephonic interviews was that persons who were employed did not attend the appointment because they were unable to get leave from work. This was applicable to participants who were concerned about their child's development as well as participants who reported no concern about their child's development. Poor adherence has been reported amongst employed people in other studies too (Adeponle et al., 2007; Olusanya & Akinyemi, 2009). Participants also defaulted on the follow-up appointment due to job interviews. High rates of unemployment exist in this research setting (Statistics South Africa, 2012), providing a possible explanation for the prioritisation of work over follow-up adherence for EI.

Some participants defaulted on the follow-up appointments due to unforeseeable responsibilities like caring for an ill child or attending a funeral. Other participants defaulted due to difficulties with transport or because they were out of town, visiting family. These reasons have also been reported in a previous study (Saba et al., 2014). Some participants forgot about the follow-up appointment, as has been found in other studies (Jamil et al., 2011; Scheepers et al., 2014). None of the participants rescheduled appointments if they were unable to attend.

Participants may not have rescheduled because motivation to attend the follow-up appointments were low. Most participants (87%) did not report any concern about their child's development and more than half (55%) of these participants indicated that they understood why their child was referred for occupational and/or speech-language therapy. Thus, most participants reported no concern about their child's development despite understanding the reasons for referral. Some parents therefore believed that if their child is healthy there is nothing to be concerned about. Mothers who do not suspect that their child may have developmental problems are less likely to attend programmes that provide health services (Ballantyne et al., 2013), therefore caregivers need to be educated on the importance of timely intervention for developmental delays.

Another possible explanation for low motivation is that caregivers may be less concerned about their child's development because of the young age of the child (Marshall, Kirby, et al., 2016). If this is the case, caregivers and clinicians could discuss the referral and if the referral is declined, a plan for developmental monitoring with clear guidelines for future referral may be established, as suggested by another study (Jennings & Hanline, 2013). CHW are in a position to help caregivers monitor development and should be utilised for this goal.

#### **4.2. Clinical implications**

Developmental screening at PHC clinics has the potential to timeously identify children who may require EI because children are seen at regular intervals (Aly et al., 2010) and it is the first point of access to medical care for 61.2% of South Africans (Statistics South Africa, 2013). However, the current study shows that achieving a successful EI programme in PHC is not as simple as mere developmental screening and referral to the appropriate health care professionals.

One of the factors that participants cited as reasons for not adhering to the appointment was forgetfulness. It is clear from the study that appointment reminders in the form of text messages are not sufficient in this format alone. Almost half (43%) of the caregivers could not be reached for a telephonic interview because they no longer had the same cellular phone number. This has implications for the use of text message reminders. In future, multiple contact numbers could be obtained from caregivers so that text messages could be sent to more than one recipient. Contact numbers should be verified to ensure that they are functional and owned by the client, and it should be confirmed that text message reminders were received. Contact details would also have to be updated regularly because the caregiver's cellular phone number may change (Crankshaw et al., 2010). If resources permit, a phone call reminder plus text message reminder could be used, as this has been successful in a previous study (Bigna et al., 2014)

Another factor is parental motivation. Few parents reported a concern about their child's development, possibly due to a lack of knowledge and incorrect beliefs regarding early childhood development. Education should be provided to parents, caregivers, teachers and the broader community regarding early childhood development and the importance of EI.

Parent and caregiver education should be part of developmental screening initiatives. In this particular instance a parent education feature on the PEDS application could have provided a short explanation for the reason for referral in understandable language at the end of the screening. Findings from a study in South Africa indicate that caregivers who receive written information about screenings have a more accurate understanding of, and positive association with, the services (Scheepers et al., 2014). Written information explaining the developmental screening and providing information on the importance of EI could therefore be provided to caregivers. This may help them understand the reason for the referral and why follow-up is important.

More should be done to encourage caregivers to reschedule appointments if they were unable to attend. Initiatives such as community oriented primary care (COPC) may be utilised to follow up on infants and young children to create awareness on developmental delays and the importance of EI by means of home visits by CHWs (Bam et al., 2013). Telephone call reminders and home visits by CHWs to reschedule missed appointments have been found to be successful in a hearing screening programme in South Africa (Friderichs et al., 2012).

Teacher education at ECCE facilities should also be provided. Teachers should be trained to provide age-appropriate stimulation to prevent developmental delays from occurring in the first place (Farah et al., 2008). They should also be trained to detect developmental delays early on and have referral protocols in place so that children can be referred to the appropriate service providers.

Broader awareness of the importance of EI should be created by means of community education. This should be done in collaboration with COPC. COPC aims to advance health literacy and social capabilities in the Tshwane district (Geiger, 2002). These services are mostly provided together with community-based non-profit organisations (NPOs) that are already involved in the community (Bam et al., 2013). NPOs could potentially contribute significantly to the planning and implementation of education programmes because they are familiar with the specific needs of the community (Bam et al., 2013).

If parents, caregivers, teachers and the broader community are educated about early childhood development and the importance of EI, factors such as employment,

logistics and other responsibilities may have a smaller impact on follow-up adherence. This may result in improved effectiveness of EI programmes.

### **4.3. Critical evaluation**

The current study was a mixed method design. Quantitative data collection in phase one provided objective results regarding the factors that influence follow-up adherence. Qualitative data collection in phase two allowed for a more comprehensive understanding of subjective reasons for defaulting on appointments. This has advanced our understanding of the challenges that we face in developmental screening and follow-up. It has also assisted in guiding future exploration of more effective ways to improve follow-up of developmentally delayed children for EI in urban communities. There were, however, some limitations to the study.

The current study had a high referral rate (43%). The study population was an at-risk population in which there are high rates of poverty, poor education, unemployment, single parenthood and lack of a stable residence. Every referred child in the study had at least one risk factor for developmental delays, making the high referral rate plausible. In addition, the referral rate correlates with a previous study conducted with a similar population in Tshwane (Van Der Linde et al., 2015). Less stringent interpretations should, however, be considered that are in line with service delivery capacity.

The number of participants (108) were initially thought to be adequate to identify various risk factors with a positive predictive value for follow-up adherence. The poor follow-up adherence (17%) resulted in a small sample size that was to be compared to the participants who defaulted on the appointment. A follow-up study, using the same methodological approach but with a larger initial population, is recommended. Ideally the sample population would be no smaller than 200 participants for the best statistical strength. The small sample size was, however, unavoidable for this study and as such should be kept in consideration when discussing or applying the findings of the study.

A potential language barrier existed between the researcher and participants. Even though, in South Africa, English is generally the accepted language for



communication between people with different home languages (Van der Merwe, 2014), neither English nor Afrikaans was the home language of participants, with the exception of one participant who spoke Afrikaans. This may have resulted in difficulty understanding the importance of and reason for referrals.

The procedures that were followed were designed to work in a normal clinic visit so that the same protocol can be used in practice. The study succeeded in administering developmental screenings without disrupting the clinic staff or patients. It has therefore shown that routine developmental screenings at PHC clinics are feasible, and should be used for the early identification of children with developmental delays.

#### **4.4. Recommendations for future research**

A replication of this study is recommended to see if the results remain the same in a different setting. A larger sample size is also recommended because it will improve statistical power and may allow for risk factors with a positive predictive value for defaulting on appointments to be identified.

The effect of parental support on follow-up adherence should be investigated further. Text message reminders could be expanded to include sending text message reminders to family members, to reduce the effect of cellular phone turnover. The effect of telephonic reminders and home visits by CHWs on follow-up adherence could also be investigated.

The use of CHWs to administer the PEDS Tools has been found to be successful (Maleka et al., 2016). Future research could evaluate the effect thereof on follow-up adherence, as the CHWs speak the caregiver's language and understand the culture (Friderichs et al., 2012). Furthermore, one could investigate whether home visits by CHWs encourage parents and caregivers to reschedule missed appointments.

It is also recommended that parental knowledge and perceptions on early childhood development be investigated. The effect of different strategies of parental education - for example talks, pamphlets, video material or group discussions - should also be explored. Furthermore, the effect of parental education on follow-up adherence should be investigated. This may inform on the type and intensity of parent and community education necessary to improve follow-up on referrals.



## 4.5. Conclusion

Early identification and intervention for children with developmental delays are very important, not only because the effect of the disability can be minimised or negated, but also because it lessens the burden on society in general (Aly et al., 2010). It is therefore of utmost importance that screenings and referrals result in follow-up on appointments to ensure that children are not only identified through screening, but also receive timely intervention (UNICEF, 2013).

In this study, early identification of possible developmental delays in most cases (83%) did not translate to acceptable follow-up adherence for EI services. Participants who were divorced, widowed or never married were more likely to attend a follow-up appointment than those who were married or living together. The use of text message reminders did not improve follow-up adherence significantly. Most participants (87%) had poor motivation for follow-up because they did not report concern about their child's development. Participants also did not follow up on referrals because of employment, logistical issues, other responsibilities and forgetfulness. Improving follow-up adherence for EI after a developmental screening is complex and requires further consideration. Parents, caregivers and communities should be educated regarding the importance and benefits of EI to ensure that children with developmental delays are not only identified through developmental screening but also receive timely EI services.

This study has provided interesting insights into the reasons for defaulting on appointments. Further research is required to identify successful and viable ways to improve follow-up adherence to EI services.

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## 6. APPENDICES

## 6.1. Appendix A: Risk assessment questionnaire



**QUESTIONNAIRE:**

**RISK ASSESSMENT FORM**

For Office Use

***Please answer the questions by drawing a circle around an appropriate number in a shaded box or by writing your answer in the shaded space provided***

Infant code

V1

What is the primary caregiver's **cellphone number**?

**1. What is the date of the developmental screening? (Please use dd/mm/yy)**

V2

**2. What is the date of birth of the infant? (Please use dd/mm/yy)**

V3

**3. What is the gender of the infant?**

Male	<b>1</b>
Female	<b>2</b>

V4

**4. Which ward do you live in?**

V5

**5. What is your status?**

Mother of the infant	<b>1</b>
Father of the infant	<b>2</b>
Family member of the infant	<b>3</b>
Non-family caregiver of the infant	<b>4</b>

V6

**6. What is your age as of your last birthday?**

V7

**Question 7 follows on the next page...**



**7. What is your home language? (Indicate those applicable)**

Setswana	1
Sepedi	2
IsiZulu	3
Shangaan	4
English	5
Afrikaans	6
Venda	7
Ndebele	8
Xhosa	9
Sesotho	10
SiSwati	11
Tsonga	12
Other (specify):	

V8	<input type="checkbox"/>	<input type="checkbox"/>
V9	<input type="checkbox"/>	<input type="checkbox"/>
V10	<input type="checkbox"/>	<input type="checkbox"/>
V11	<input type="checkbox"/>	<input type="checkbox"/>
V12	<input type="checkbox"/>	<input type="checkbox"/>
V13	<input type="checkbox"/>	<input type="checkbox"/>
V14	<input type="checkbox"/>	<input type="checkbox"/>
V15	<input type="checkbox"/>	<input type="checkbox"/>
V16	<input type="checkbox"/>	<input type="checkbox"/>
V17	<input type="checkbox"/>	<input type="checkbox"/>
V18	<input type="checkbox"/>	<input type="checkbox"/>
V19	<input type="checkbox"/>	<input type="checkbox"/>
V20	<input type="checkbox"/>	<input type="checkbox"/>

**8. What other languages do you speak? (Indicate those applicable)**

Setswana	1
Sepedi	2
IsiZulu	3
Shangaan	4
English	5
Afrikaans	6
Venda	7
Ndebele	8
Xhosa	9
Sesotho	10
SiSwati	11
Tsonga	12
Other (specify):	

V21	<input type="checkbox"/>	<input type="checkbox"/>
V22	<input type="checkbox"/>	<input type="checkbox"/>
V23	<input type="checkbox"/>	<input type="checkbox"/>
V24	<input type="checkbox"/>	<input type="checkbox"/>
V25	<input type="checkbox"/>	<input type="checkbox"/>
V26	<input type="checkbox"/>	<input type="checkbox"/>
V27	<input type="checkbox"/>	<input type="checkbox"/>
V28	<input type="checkbox"/>	<input type="checkbox"/>
V29	<input type="checkbox"/>	<input type="checkbox"/>
V30	<input type="checkbox"/>	<input type="checkbox"/>
V31	<input type="checkbox"/>	<input type="checkbox"/>
V32	<input type="checkbox"/>	<input type="checkbox"/>
V33	<input type="checkbox"/>	<input type="checkbox"/>

**9. In terms of the Employment Equity Act, which population group do you belong to?**

Black	1
Coloured	2
White	3
Asian	4
Other (specify):	

V34	<input type="checkbox"/>
-----	--------------------------

**Question 10 follows on the next page...**



**10. Who is the primary caregiver of the infant?**

Mother	1
Father	2
Both parents	3
Grandparents	4
Extended family members	5
Foster parents	6
Other (specify):	

V35

**11. What is the highest educational qualification of the Mother of the infant?**

I do not know	1
No formal schooling	2
Less the Grade 8	3
Grade 8 to Grade 10	4
Grade 11 to Grade 12	5
Diploma/Degree	6
Postgraduate	7

V36

**12. What is the highest educational qualification of the Father of the infant?**

I do not know	1
No formal schooling	2
Less the Grade 8	3
Grade 8 to Grade 10	4
Grade 11 to Grade 12	5
Diploma/Degree	6
Postgraduate	7

V37

**13. What is the highest educational qualification of the Caregiver of the infant?**

I do not know	1
No formal schooling	2
Less the Grade 8	3
Grade 8 to Grade 10	4
Grade 11 to Grade 12	5
Diploma/Degree	6
Postgraduate	7

V38

**14. Is the primary caregiver currently employed?**

Yes	1
No	2

V39

**Question 15 follows on the next page...**



15. What is the **average** household **income** per month?

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V40 


18. What is the **marital** status of the Mother of the infant?

I do not know	<b>1</b>
Never married	<b>2</b>
Living together	<b>3</b>
Married	<b>4</b>
Widowed	<b>5</b>
Separated	<b>6</b>
Divorced	<b>7</b>

V41 

--	--

19. What is the **marital** status of the Father of the infant?

I do not know	<b>1</b>
Never married	<b>2</b>
Living together	<b>3</b>
Married	<b>4</b>
Widowed	<b>5</b>
Separated	<b>6</b>
Divorced	<b>7</b>

V42 

--	--

20. What is the **marital** status of the caregiver of the infant?

I do not know	<b>1</b>
Never married	<b>2</b>
Living together	<b>3</b>
Married	<b>4</b>
Widowed	<b>5</b>
Separated	<b>6</b>
Divorced	<b>7</b>

V43 

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21. What is your **housing status**?

Own my house	<b>1</b>
Own my flat	<b>2</b>
Informal housing	<b>3</b>
I am renting	<b>4</b>
I stay with others	<b>5</b>

V44 

--

22. How many people are **living** in the household?

--

V45 

--	--

**Question 23 follows on the next page...**



**23. Result of Developmental Screening**

Pass	<b>1</b>
Fail	<b>0</b>

V46

***Thank you for your time and co-operation***



## 6.2. Appendix B: Letter of informed consent (Stanza Bopape Clinic)



15 April 2015

Dear Sir/Madam

**REQUEST TO CONDUCT A RESEARCH PROJECT AT STANZA BOPAPE CLINIC**

I hereby request your permission to conduct a research project titled: 'Developmental screening: Factors influencing the return rate in primary health care' at your clinic. I, Joanné Schoeman, am a Masters student at the University of Pretoria.

The aim of this research study is to determine the factors associated with follow-up return after a developmental screening in the primary health care context. The effect of text message reminders on the follow-up return rate will also be investigated. Parents or caregivers of 100 children between the ages of 6 to 36 months, who have failed a developmental screening at the clinic, will be asked to participate in the study. If the children have failed the developmental screening, the parents or caregivers will be required to return for a follow-up visit, so that a second screen can be conducted. The participants will fill in a questionnaire regarding their familial risk factors. Through random assignment 50 of the families will receive a text message reminder to follow-up on the referral and 50 will receive no reminder. If they have not returned for a follow-up within three months, it will be assumed that they are not going to follow up on the referral. For all participants, participation is voluntary and they may withdraw from the study at any time without any negative consequences. Written informed consent will be obtained.

The screening and referral of the children will be conducted by another researcher as part of a study that is already being done at Stanza Bopape Clinic. I hereby request that the Speech-Language Therapist at Stanza Bopape Clinic, Ms. Malan, keep record of which patients and their families follow up on the referrals within a three month period of the referral. The research proposal has been submitted to the Faculty of Health Sciences Research Ethics Committee as well as the Faculty of Humanities' Research Ethics Committee, University of Pretoria. Data collection will only commence when approval by these committees have been obtained. The research report will be made available to you upon request.



If you require any information or have additional queries, please do not hesitate to contact us at 012 420 2948 (Ms. van der Linde) and 082 360 3798 (Ms. Schoeman).

Kind regards

Joanné Christine Schoeman  
Student

Jeannie van der Linde  
Supervisor

Prof D. W. Swanepoel  
Supervisor

Prof B. Vinck  
HEAD: Dept. of Speech-Language Pathology and  
Audiology

**PERMISSION TO CONDUCT A RESEARCH PROJECT AT STANZA BOPAPE CLINIC**

I, Sr. Da Gama, hereby grant permission for the research project titled: 'Developmental screening: Factors influencing the return rate in primary health care' to be conducted at Stanza Bopape I. The researcher, Joanné Schoeman, may fill in questionnaires with parents and caregivers whose children have failed a developmental screening. Ms. Roxanne Malan, the Speech-Language Therapist at Stanza Bopape Clinic, may keep record of which patients and their families follow up on the referrals within a three month period of referral.

Signature

06 July 2015

Date

### **6.3. Appendix C: Letter of informed consent (participants)**



## **PARENT/CAREGIVER INFORMATION LEAFLET & INFORMED CONSENT FORM**

**Title of the research study: Developmental screening: Factors influencing the return rate in primary health care.**

### **INTRODUCTION**

As a parent/caregiver you are invited to volunteer to participate in a research study. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved.

### **WHAT IS THE PURPOSE OF THIS TRIAL?**

It is important to know what factors put a child at risk for not following up on the referrals that are made in the clinic. By gathering information on children and families, we hope to establish these risk factors. All parents/caregivers whose children (aged 6-36 months) are referred after a developmental screening at Stanza Bopape Clinic will be asked to participate in the research study.

### **WHAT IS THE DURATION OF THIS TRIAL?**

If you decide to participate in the study, you will be one of 100 parents/caregivers. The study will be conducted during 2015. The testing time will not take more than 15 minutes of your time.

### **EXPLANATION OF PROCEDURES TO BE FOLLOWED**

This study involves answering some questions from a questionnaire with regard to your demographical information. You will also be asked to provide your cell phone number.

### **HAS THE STUDY RECEIVED ETHICAL APPROVAL?**

This research study Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee as well as the Faculty of Humanities' Research Ethics Committee, University of Pretoria and written approval has been granted by these committees. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2008), which deals with the recommendations guiding doctors and allied health care professionals in biomedical research involving human/subjects. A copy of the Declaration may be obtained from the investigator should you wish to review it.

### **WHAT ARE YOUR RIGHTS AS A PARTICIPANT IN THIS RESEARCH STUDY?**

Your participation in this trial is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. Your withdrawal will not affect you or your child's access to other medical care. If it is detected that you did not give an accurate history and or did not follow the guidelines of the trial and the regulations of the trial, you may be withdrawn from the trial at any time.

**MAY ANY OF THESE PROCEDURES RESULT IN DISCOMFORT OR INCONVENIENCE?**

Since the PEDS tools and questionnaire are conducted in an interview form, no discomfort or inconvenience will be caused by the research study.

**WHAT ARE THE RISKS INVOLVED IN THIS RESEARCH STUDY?**

No risks are involved when participating in the research study.

**CONFIDENTIALITY**

All information obtained during the course of this trial is strictly confidential. Data that may be reported in scientific journals will not include any information which identifies you or your child in this research study. You and your baby's name will not be used and the results will be kept confidential. Data will be securely stored, electronically and on hardcopy, for a minimum of 15 years at the University of Pretoria.

Please indicate whether you give permission that the data may be used for future research. Herewith I give consent that the data obtained in the current study may be used for future research as well:

Yes  No

(Please tick the relevant block)

**INFORMED CONSENT FOR PARENTS / GUARDIANS**

I, hereby confirm that I have been informed by the investigator, Ms Joanné Christine Schoeman about the nature, conduct, benefits and risks of the research study titled: "Developmental screening: Factors influencing the return rate in primary health care". I have also received, read and understood the above written information (Patient Information Leaflet and Informed Consent) regarding the research study.

I am aware that the results of the study, including my and my child's personal details regarding date of birth, initials and diagnosis will be anonymously processed into a research report.

I may, at any stage, without prejudice, withdraw my consent for my participation in the trial. I have had sufficient opportunity to ask questions and (of my own free will) declare that I am prepared to participate in the trial.

Parent/Guardian(s) Name \_\_\_\_\_  
(Please print)

Parent/Guardian(s) Signature \_\_\_\_\_ Date \_\_\_\_\_

Child's Name \_\_\_\_\_  
(Please print)

Investigator's Name \_\_\_\_\_  
(Please print)

Investigator's Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness's Name \_\_\_\_\_ Witness's Signature \_\_\_\_\_ Date \_\_\_\_\_  
(Please print)

### VERBAL PATIENT INFORMED CONSENT

I, the undersigned, Joanné Christine Schoeman, have read and have explained fully to the parent/caregiver, named ..... and/or his/her relative, the patient information leaflet, which has indicated the nature and purpose of the research in which I have asked the parent or caregiver to participate. The explanation I have given has mentioned both the possible risks and benefits of the trial and the alternative treatments available for his/her child's illness. The parent/caregiver indicated that he/she understands he/she will be free to withdraw from the research at any time for any reason.

I hereby certify that the parent/caregiver has agreed to participate in this trial.

Parent/Caregiver Name \_\_\_\_\_  
(Please print)

Investigator's Name \_\_\_\_\_  
(Please print)

Investigator's Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness's Name \_\_\_\_\_ Witness's Signature \_\_\_\_\_ Date \_\_\_\_\_  
(Please print)

## 6.4. Appendix D: Referral to early intervention





Infant code: \_\_\_\_\_

Date: \_\_\_\_\_

**Dear parent/ guardian**

Thank you for your participation. During the evaluation it was noted that your child may need intervention.

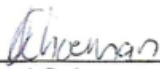
We would like to refer your child to:


	Professional person:	Reason:
	<i>Audiologist</i>	<i>Complete hearing evaluation</i>
	<i>Occupational therapist</i>	<i>Gross and fine motor evaluation</i>
	<i>Speech-language therapist</i>	<i>Communication assessment and follow-up</i>
	<i>Eye specialist</i>	<i>Eye test</i>
	<i>Medical doctor</i>	<i>Medical evaluation</i>
	Other:	

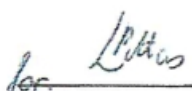
We urge you to attend to this problem as soon as possible at \_\_\_\_\_

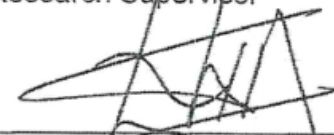
If you would like more information please contact me at (012) 420 2948.

Kind regards

  
\_\_\_\_\_  
Mrs J Schoeman  
Researcher

  
\_\_\_\_\_  
Mrs. J Van der Linde  
Research Supervisor

  
\_\_\_\_\_  
Prof D Swanepoel  
Research Supervisor

  
\_\_\_\_\_  
Prof B Wrick  
**HEAD: Department of Speech-Language  
Pathology and Audiology**

## 6.5. Appendix E: Ethical clearance (Faculty of Humanities)



28 October 2015

Dear Prof Vinck

**Project:** Developmental screening: Factors influencing the return rate in primary health care  
**Researcher:** J Schoeman  
**Supervisor:** Prof DCD Swaepoel  
**Department:** Speech-Language Pathology and Audiology  
**Reference number:** 29029814 (GW20150518HS)

Thank you for the your response to the Committee's correspondence 11 June 2015.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 27 October 2015. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

**Prof. Karen Harris**  
**Acting Chair: Research Ethics Committee**  
**Faculty of Humanities**  
**UNIVERSITY OF PRETORIA**  
**e-mail: karen.harris@up.ac.za**

Kindly note that your original signed approval certificate will be sent to your supervisor via the Head of Department. Please liaise with your supervisor.

## 6.6. Appendix F: Ethical clearance (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 20 Oct 2016.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 22/04/2017.



30/04/2015

**Approval Certificate  
Amendment**

**(to be read in conjunction with the main approval certificate)**

**Ethics Reference No.: 102/2011**

**Title:** Researching the Development, Application and Implementation of Community Oriented Primary Care (COPC) a study in Gauteng (Tshwane) and Mpumalanga Province.

Dear Prof Johannes Hugo

The **Amendment** as described in your documents specified in your cover letter dated 11/03/2015 received on 17/03/2015 was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 29/04/2015.

Please note the following about your ethics amendment:

- Please remember to use your protocol number (102/2011) 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 amendment 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

**Dr R Sommers; MBChB; MMed (Int); MPharMed.**

**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 2004 (Department of Health).*

♦ Tel: 012-3541330      ♦ Fax: 012-3541367      Fax2Email: 0866515924      ♦ E-Mail: [fhsethics@up.ac.za](mailto:fhsethics@up.ac.za)  
♦ Web: [//www.healthethics-up.co.za](http://www.healthethics-up.co.za)      ♦ H W Snyman Bld (South) Level 2-34      ♦ Private Bag x 323, Arcadia, Pta, S.A., 0007

## **6.7. Appendix G: Ethical clearance (Tshwane Research Committee)**





*Kuyasheshwa! Gauteng Working Better*

**GAUTENG PROVINCE**  
HEALTH  
REPUBLIC OF SOUTH AFRICA

427 Hilda Street, 4<sup>th</sup> floor, The Fields Building, Hatfield Pretoria 0001 South Africa. Tel: +27 12 451 9036  
Enquiries: Dr. Molapane Chueu-Shabangu  
e-mail: [Molapane.Shabangu@gauteng.gov.za](mailto:Molapane.Shabangu@gauteng.gov.za)

**TSHWANE RESEARCH COMMITTEE**

**CLEARANCE CERTIFICATE**

**Meeting: N/A**

**PROJECT NUMBER: 42/2015**

**Title: Developmental screening: Factors influencing the return rate in primary health care.**

**Researcher: Joanné C. Schoeman**  
**Supervisor: Professor D. W. Swanepoel**  
**Co-Supervisor: Me. J. van der Linde**

**Department: University of Pretoria**

**DECISION OF THE COMMITTEE**

**Approved**

**NB: THIS OFFICE REQUESTED A FULL REPORT ON THE OUTCOME OF THE RESEARCH DONE**

**Date: 13/10/2015**

.....  
**Dr. Molapane Chueu-Shabangu**  
**Chairperson Tshwane Research Committee**  
**Tshwane Health District**

.....  
**Mr. Pitsi Mothomone**  
**Chief Director: Tshwane District Health**  
**Tshwane District**

**NOTE:** Resubmission of the protocol by researcher(s) is required if there is departure from the protocol procedures as approved by the committee.