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South African cultural adaptation and Northern Sotho translation of the Modified Checklist for Autism in Toddlers, Revised, with Follow-up

by

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(29026319)

A thesis submitted in fulfilment of the degree

PhD (Speech-Language Pathology)

In the Department of Speech-Language Pathology and Audiology

Faculty of Humanities

University of Pretoria

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November 2021

The language used in this thesis is English (U.K.). Stylistic and language variations required by the specific journal guidelines were implemented and specified where applicable.

Northern Sotho, also known as Sepedi or Sesotho sa Leboa, is consistently used to refer to the specific language. The correct designation for this language is an ongoing debate of which the authors are aware.

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ACKNOWLEDGEMENTS

This research project is the result of wonderful guidance and supervision; tons of love and prayers; and a fantastic support structure.

Prof K, you have been one of the most fundamental players in my academic career. I thank you for hours of dedication, guidance, wisdom, inspiration and kind words when they were needed. I hope, that when you think back on all your inspirational life achievements, you will remember the unbelievable impact you had on shaping my life and career.

Prof Jeannie, thank you for the time and knowledge you invested even when you were extremely busy. Your wisdom and guidance made a very valuable contribution to the researcher I am today. This PhD would not have been possible if you did not preplan and arrange this life-changing opportunity for me.

I could not have asked for better supervisors! I am forever grateful.

Dearest Stefan, I do not even know where to begin… Thank you for believing in my dream and being willing to bite the bullet when it was necessary. Thank you for not giving up, when all I did was work. All your efforts were noted. The Lord knew you were the perfect husband for me.

Mamma, Pappa, Ernst and Nora, you were part of the foundation of this study. When the winds of change blew, you supported me without any hesitation. Thank you that I did not even have to ask.

This PhD was made possible by the UP Postgraduate: Doctoral Research Bursary and the Organization for Autism Research. Thank you for the financial support “and a bit of pressure” when needed.

“Faith, it does not make things easy, it makes them possible” – Luke 1:37

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PUBLICATIONS AND RESEARCH OUTPUT

This thesis is based on the following original articles:

1. **Vorster, C.,** Kritzinger, A., Lekganyane, M., Taljard, E., & van der Linde, J. (2022). Cultural adaptation and Northern Sotho translation of the Modified-Checklist for Autism in Toddlers (M-CHAT-R/F™). *South African Journal of Childhood Education, 12*(1), a968
   DOI: https://doi.org/10.4102/sajce.v12i1.968
2. **Vorster, C.,** Kritzinger, A., Coetser, L., van der Linde, J. (2021). Preliminary reliability of a South African adaptation and Northern Sotho translation of the M-CHAT-R/F™. *South African Journal of Communication Disorders*, *68*(1), 1-7. https://doi.org/10.4102/sajcd.v68i1.831
3. **Vorster**, **C**., Kritzinger, A., Coetser, L., van der Linde, J. Reliability and concurrent validity of a South African cultural adaptation and a Northern Sotho translation of the M-CHAT-R/F. Submitted to *Journal of Autism and Developmental Disorders.*

Parts of this thesis have been presented at the following seminars and scientific conferences:

- **Vorster, C**., Kritzinger, A., Lekganyane, M., Taljard, E., & Van der Linde, J. (2020). Cultural adaptation and Northern Sotho translation of the M-CHAT-R/F. *Conference poster at the SASLHA/ASHA conference, Online, November 2020.*
- **Vorster, C.,** Kritzinger, A., Lekganyane, M., Taljard, E., & Van der Linde, J. (2021). Cultural adaptation and Northern Sotho translation of the M-CHAT-R/F and preliminary reliability: Access to care with autism screening. *Seminar presentation at UP Access to care webinar, Online, 18 June 2021.*
- **Vorster, C.,** Kritzinger, A., Lekganyane, M., Taljard, E., & Van der Linde, J. (2021). Cultural adaptation and Northern Sotho translation of the M-CHAT-R/F and preliminary reliability. *SA-ACAPAP Virtual Congress 2021, 29 July 2021.*

PLAGIARISM DECLARATION

UNIVERSITY OF PRETORIA

FACULTY OF HUMANITIES

DEPARTMENT OF SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY

DECLARATION

Full name: Carlien Vorster

Student Number: u29026319

Degree: PhD (Speech-Language Pathology)

Title of thesis:

South African cultural adaptation and Northern Sotho translation of the Modified Checklist for Autism, Revised, with Follow-up

I declare that this thesis is my own original work. Where secondary material is included, it has been acknowledged and referenced in accordance with university requirements.

I understand what plagiarism is and I am aware of the university policy and implications in this regard.

November 2021

Signature Date

ETHICS STATEMENT

I, Carlien Vorster, have obtained the necessary ethical clearance for the research described in this work, as well as for the use of the Modified Checklist for Autism in Toddlers, Revised with Follow-up™.

I agreed to adhere to the instruction provided by the authors of the M-CHAT:
“Please note that rights for the M-CHAT-R/F are retained by the original authors. The translation must retain the original M-CHAT-R/F copyright at the bottom of the document.”

I declare that I have observed the ethical standards required in terms of the University of Pretoria’s Code of ethics for researchers and the Policy guidelines for responsible research.

ABSTRACT

Rationale, aim and objectives

There are currently no culturally sensitive, South African autism-specific screening instruments available. The global increase in prevalence, lack of local data, limited knowledge and late identification of autism in South Africa prompted the researcher to translate a universally known autism-specific screening instrument. The aim was to culturally adapt and translate the Modified Checklist for Autism in Toddlers, Revised with Follow-up™ and to determine the reliability and concurrent validity of the newly adapted and translated checklists.

Method and results

A mixed-method research design was employed in the study. This design allowed for the qualitative analysis of expert opinions in Study 1, and feedback from caregivers in Study 2 and 3. Quantitative data were generated in Study 2 and 3 when the two checklists were compared with one another and with the results of the VABS-3.

For the three studies, experts and caregivers of children aged between 18 and 48 months were utilised as participants. In Study 1, Northern Sotho speech-language therapists identified culturally biased items in the M-CHAT-RF™ which were adapted. The adapted version of the checklist was scrutinised by an expert panel, translated into Northern Sotho and back-translated in English by professional translators. A comprehensive panel discussion and independent review of the linguistic, construct and technical equivalence of the checklists followed. The rigorous process of cultural adaption and translation resulted in an adapted English M-CHAT-R/F and a Northern Sotho translation of the source checklist.

The two versions of the M-CHAT-R/F were used in a pilot study with 21 Northern Sotho caregivers. Caregivers were selected as the M-CHAT-R/F is a caregiver checklist and the comprehensibility of the new versions had to be determined. Participants completed both M-CHAT-R/F versions in randomised order along with a socio-demographic questionnaire. The Wilcoxon Signed Ranked test showed near-perfect

agreement between the two checklists. There was no indication for any changes to the checklists.

A larger-scale study (n=158) was conducted, comparing the checklists with each other and the Vineland-3. The results showed a low Cronbach alpha value but confirmed near-perfect agreement ($p<0.001$) between the two checklists. Concurrent validity was established between the Vineland-3 sub-domains and the Northern Sotho M-CHAT-R/F with a significant association at the 5% level. A total of 33.5% developmental delay was found in the reference sample (n=158). In line with international studies, it is recommended that autism-specific screening be conducted along with developmental screening or assessment. A marginal majority of participants (55.1%) preferred the Northern Sotho M-CHAT-R/F while a smaller group (44.9%) chose the adapted English checklist. The Northern Sotho majority preference aligns well with the accuracy of the results. The adapted English version may be used more often as English is one of the prominent languages of learning and teaching in South Africa. The larger-scale study identified some checklist items that required refinement. A phrase to clarify understanding was inserted. Gender-biased terminology was changed.

Conclusion

This study adapted and translated the M-CHAT-R/F™ resulting in two new versions. With the reliability outcomes, the checklists show linguistic, technical and construct equivalence. Predictive value must still be established.

A functional framework for the cultural adaptation and translation of screening instruments is presented. Two feasible, reliable and concurrently valid autism-specific screening instruments are now available for use by caregivers, health care workers, and early childhood development practitioners in South Africa. Further investigation of developmental delay among preschool children in South Africa is required.

KEYWORDS

Autism screening

Cultural adaptation

Double translation method

Northern Sotho M-CHAT-R/F

South African adapted M-CHAT-R/F

ABBREVIATIONS

ABC-score	Adaptive Behavior Composite score
ASD	Autism Spectrum Disorder
APA	American Psychiatric Association
CAQDAS	Computer-aided qualitative data analysis software
ECD	Early Childhood Development
HICs	High Income Countries
HPCSA	Health Professions Council of South Africa
ITC	International Test Commission
JADD	Journal of Autism and Developmental Disorders
LMICs	Low- and Middle-Income Countries
M-CHAT-R/F	Modified Checklist for Autism in Toddlers, Revised with Follow-up
M-CHAT-R/F™	Modified Checklist for Autism in Toddlers, Revised with Follow-up™
NIECDP	National Integrated Early Childhood Development Policy
P1	Academic expert
P2	Academic expert
P3	Northern Sotho speech-language therapist
P4	Northern Sotho speech-language therapist
P5	Educational psychologist
P6	Second translator
PEDS	Parents Evaluation of Developmental Status
R1, R2, R3	Researcher(s)
RTHB	Road to Health Booklet
SAJCD	South African Journal of Communication Disorders
SAJCE	South African Journal of Childhood Education
SD	Standard deviation

SDGs	Sustainable Development Goals
SIAS	Screening, identification, assessment and support
SLT	Speech-language therapist
SSA	Sub-Saharan Africa
T1	Preliminary Northern Sotho M-CHAT-R/F
T2	Back translated English M-CHAT-R/F
US	United States
UNICEF	United Nations Children's Fund
VABS-3	Vineland Adaptive Behavior Scales, Third edition
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION

Chapter aim: The aim of the chapter is to provide global and local perspectives on autism screening, with a focus on evidence-based developments and research challenges in low- and middle-income countries. The lack of valid and reliable autism-specific screening tools in the different South African languages is described. A solution to improve early detection of autism with a reliable culturally adapted and translated instrument is proposed. Current guidelines to adapt, translate and validate an instrument are critically discussed. The chapter ends with the study rationale and three separate but related research questions are posed.

1.1. Advances and gaps in autism research and intervention in South Africa

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition characterised by persistent deficits in social interaction and communication. Restricted, repetitive patterns of interest, behaviour and activities form the second part of the core diagnostic criteria (American Psychiatric Association [APA], 2013). Since core behavioural symptoms are present early in life, autism can be identified and diagnosed at a young age with appropriate instruments (Hyman et al., 2020; Robins et al., 2014).

The prevalence of autism is increasing globally (Olusanya et al., 2018). One in every 59 children in the United States (US) is diagnosed with autism (Hyman et al., 2020). Prevalence statistics for low- and middle-income countries (LMICs) are scarce (Franz et al., 2017; Pillay et al., 2021). A recent study determined that 0.08% of children in the formal education system in the Western Cape province of South Africa (10% in inclusive education and 90% in specialised education) have a diagnosis of autism (Pillay et al., 2021). Similar to global trends in autism, an increase of 76.03% in the number of children attending autism-specific schools in South Africa was evident between 2016 and 2021 (Pillay et al., 2021).

Available research in the special education system in South Africa indicates that children with autism are now diagnosed at an earlier age than two to three decades ago (Erasmus et al., 2019; Pillay et al., 2021). Recent research in six autism-specific schools in South Africa showed that the mean age of learners' diagnosis is 46.6

months of age (Erasmus et al., 2019). This finding indicates a 25-month decrease in the mean age of diagnosis when compared with the mean age of diagnosis in a single autism-specific school from an earlier period, between 1990 and 2014 (Van Biljon et al., 2015). With an evident heightened awareness of autism that is reflected in the increase of autism school admissions (Pillay et at., 2021), improvements in inclusive education and a lower age of autism diagnosis (Erasmus et al., 2019), further advances in autism management and intervention in South Africa are needed.

Despite the improvements, some limitations in autism screening have been identified. High-income countries (HICs) have well-established screening and diagnostic instruments and programs, but there are limited culturally appropriate instruments in a LMIC like South Africa (Marlow et al., 2019). To improve evidence-based practice for autism in Sub-Saharan Africa (SSA), research is required to develop validated, standardised, and accessible tools for screening and diagnosis. There is a call for the development and validation of free, open access, culturally fair, and globally relevant screening and diagnostic tools for autism in South Africa (Franz et al., 2017).

1.2 Autism screening

Screening and developmental surveillance are widely used in global health care (World Health Organization [WHO], 2018). To achieve the United Nation's Sustainable Developmental Goals (SDGs) specifically relating to Good health and wellbeing, and Quality education, screening and surveillance are recommended to improve children's development, health and well-being (WHO, 2018). The Nurturing Care Framework was developed by WHO, UNICEF and the World Bank to support children to increase the human capital required to ensure that children are not left behind in attainment of their developmental potential (Black et al., 2021). Among the aims of the Nurturing Care Framework are the promotion of early childhood development and improving access to care through community-based services within the first thousand days of a child's life (Black et al., 2021).

Early childhood development may be promoted with the use of screening at regular intervals. Screening is the systematic testing of individuals to identify those at an increased risk for a specific condition and leads to diagnosis and intervention, which in turn can affect the prognosis (King et al., 2021; Robins et al., 2014). Screening for early behavioural markers is currently the most feasible approach to identify toddlers

with autism symptoms (DuBay et al., 2021). The effectiveness of a screening instrument is embedded in the accuracy of the tool, which is derived from reliability and validity data (Robins, 2020). The aim of a screening tool is to be sensitive and specific, i.e. to include as many as possible true positive cases (sensitivity) of a condition such as autism, while accurately excluding (specificity) those children without a risk for autism (DuBay et al., 2021; Lipkin & Macias, 2020).

Surveillance within the paediatric population is an active ongoing developmental monitoring process at an individual level which may also result in disorder-specific screening, referrals and intervention (King et al., 2021). The American Academy of Pediatrics recommends autism-specific screening at 18 and 24 months, supplemented by continuous developmental surveillance within primary health care settings (Hyman et al., 2020). This recommendation promotes developmental surveillance of all the children in the system with specific screening opportunities to identify children at risk. Employing surveillance can thus promote early identification of developmental delays and necessitate the screening for specific conditions like autism. In South Africa general surveillance of health and development is evident in the use of the Road to Health Booklet (RTHB), mandated by the Department of Health (Slemming & Bamford, 2018). The revised RTHB has been implemented since 2018 (Slemming & Bamford, 2018), but to date no data on its use are available.

Several studies have investigated the most effective approach for the early identification of toddlers at risk for autism. Wiggens et al. (2014) compared a broad-based screen, using the Parents Evaluation of Developmental Status (PEDS) with a disorder-specific screen, the Modified Checklist for Autism in Toddlers, Revised with Follow-up (M-CHAT-R/F™). The results of the study showed a higher agreement between autism-specific screening outcomes and diagnosis when a combination of screens is used. The authors, therefore, recommend that broad-based developmental screening be supplemented with disorder-specific screening (Wiggins et al., 2014). The combined approach also shows positive results in children from different cultural backgrounds (Barger et al., 2021). Investigating a culturally sensitive approach to autism screening in the US, a recent study found that at-risk toddlers from different cultural backgrounds are identified in greater numbers with a combination of autism-specific screening and general developmental surveillance (Barger et al., 2021).

One of the challenges in screening is the disparities evident in early identification of autism across different groups and countries (Broder-Fingert et al., 2020; Eisenhower et al., 2021; Guthrie et al., 2019; King et al., 2021). Profiles of toddlers missed in screening in the US show that they tend to be from lower socio-economic and minority groups using public insurance (Beacham et al., 2018; Guthrie et al., 2019). Different perspectives on child behaviour due to cultural differences may have an impact on the outcome of a screening instrument and should thus be carefully considered (Soto et al., 2015). The same behaviour may be viewed as typical by one group, based on their beliefs, and as at risk by another group, resulting in over- or under-identification of toddlers at risk for autism (King et al., 2021). Over- or under-identification may occur for example when a specific cultural group consider later speech development as functional whereas another group may become concerned earlier on (King et al., 2021). Because autism screening methods are currently reliant on child behaviours, different perspectives on child behaviour and development threaten the validity of screening tests.

In South Africa, disparities are multifaceted, mostly between low- and middle-income groups, with varying levels of awareness of autism across communities (Franz et al., 2018; Pillay et al., 2021). Although equity in identification of autism is a difficult goal to achieve, the research aims to contribute to earlier identification of more toddlers with autism from a certain culture and language group, in a peri-urban community, by offering two tools to Northern Sotho caregivers to use.

1.3 Local knowledge of autism and access to care

Access to care and the outcomes of the intervention may vary due to features of a child's social ecology, which includes their family and community context (Graif et al., 2021). Limited access to specialised care due to overburdened public health care systems can have a negative impact on the age of identification of toddlers at risk of autism. Another aspect, that may delay identification of toddlers at risk, is limited knowledge about child development (Erasmus et al., 2019). Research indicates that an array of factors contribute to late identification of autism (Barger et al., 2021; Erasmus et al., 2019; Guthrie et al., 2019).

Late identification of children in six government-funded autism-specific schools in South Africa has been associated with research respondents being a father, family-

caregiver or guardian, instead of a biological mother. Being a South African citizen with a lower level of education, limited access to health services and unfamiliarity with autism were also associated with later caregiver concerns that their child may be at risk for the condition. The authors of the study concluded that delayed parental concern about developmental delays and autism may also be associated with a lack of knowledge regarding typical development. (Erasmus et al., 2019).

Apart from unfamiliarity with autism, funding and access to education are more factors that pose challenges in the local context (Erasmus et al., 2019; Pillay et al., 2021). In the Western Cape, only 10% of children with autism are in inclusive education while the rest are in autism-specific schools (Pillay et al., 2021). This finding suggests that an under-representation of autism is evident in South African mainstream schools (Pillay et al., 2021). When comparing the profiles of learners in autism-specific private and public schools the researchers found that the child's age when caregivers first became concerned about possible developmental challenges was similar (Erasmus et al., 2019). The children in the private school, however, were diagnosed earlier and started school earlier (Erasmus et al., 2019). Learners typically attending private schools are white, Asian and Indian from higher-income households (Erasmus et al., 2019). The studies highlight certain modifiable factors such as improving caregiver knowledge and access to services for all which may promote earlier identification of risk for autism (Erasmus et al., 2019; Pillay et al., 2021).

Increased understanding of resource constraints, diversity of cultural beliefs, attitudes, and perspectives may promote the identification of toddlers at risk for autism (Graif et al., 2021; Grinker et al., 2012). There are currently no culturally appropriate autism screening tests available in South Africa. In a recent review of 99 screening tools for autism and developmental delay that may apply to LMICs, Marlow et al. (2019) recommended the use of the M-CHAT-R/F™. The six different autism-specific screening tools reviewed for use in LMICs by Marlow et al. (2019) were carefully considered. Based on certain superior properties of the M-CHAT-R/F like the clearly formulated checklist items, the simplified scoring procedure and the flow-chart of follow-up questions that facilitate a second-stage screening process, the screening instrument was selected for the research study.

This screening tool was selected as most appropriate for LMICs based on review criteria such as the high sensitivity and specificity of the checklist (Robins et al., 2014);

the sample size of the validation study (Marlow et al., 2019; Robins et al., 2014); the cost to use the tool (Robins et al., 2014); evidence of its use in LMICs (Marlow et al., 2019); and if the instrument can be used by community health workers (Marlow et al., 2019; Robins et al., 2014). The M-CHAT-R/F™ has high sensitivity (91%) and specificity (95%), has been standardised with a sample of more than 300 toddlers, is free, and is already being used in LMICs (Marlow et al., 2019; Wiggins et al., 2014).

Concerns relating to delayed identification of autism in LMICs highlight the need for research into culturally appropriate screening measures (De Vries, 2016; Franz et al., 2018). Important factors to consider are the effects of possible cultural differences and language barriers that may impact the successful use of screening tools (Soto et al., 2015; DuBay et al., 2021). It is necessary to consider the cultural appropriateness and the potential of introducing method bias when evaluating instruments for LMICs which were originally developed in HICs (Malcolm-Smith et al., 2013). Culturally sensitive autism screening instruments are essential for decreasing ethnic disparities in identification, diagnosis, and intervention (Rea et al., 2019). Although illness and disability are social constructs and may differ across communities (United Nations, Division for Social Policy and Development, 2017) some health constructs may be universal and can be valid after cultural adaptation and if necessary, translation (Rahman et al., 2003). Universal health constructs applying across different communities may be found in the M-CHAT-R/F which is a behavioural-based screening instrument. Typical and autistic child behaviours are described by clarifying developmental contexts and including examples, which also allow for cultural adaptations when necessary. Screening for early behavioural markers instead of biological markers is currently the most feasible approach for early identification of autism. (DuBay et al., 2021; Robins et al., 2014). Speech-language therapists (SLTs) are in a unique position to work with toddlers who present with communication and language delays from a very young age (American Speech-Language-Hearing Association, 2016). Gaining access to toddlers at risk for autism and their families, and having culturally appropriate and translated screening instruments, will address early identification concerns in a culturally sensitive manner, which may assist in earlier referrals and diagnosis of autism.

1.4 Approach to cultural adaptation and translation of screening instruments

To develop a credible body of knowledge, promote equity and increase access to autism screening in SSA, validated, standardised and accessible tools for screening are critical (Franz et al., 2017). Completing a screening tool in one's first language may promote accurate screening outcomes due to improved comprehension (DuBay et al., 2021). This finding suggests that screening tools should be available in the different local languages of a country.

A rigorous translation and adaptation process should be followed to create a tool suitable for validation and standardisation in a specific language (DuBay et al., 2021; Soto et al., 2015). Different translation approaches have been developed in the past, with the most prominent being the "forward-back" method (Soto et al., 2015). The approach involves the forward translation in the target language by one translator and the back translation by a second translator, blinded to the source translation. The two versions in the same language are then compared to determine the accuracy of the translation (DuBay et al., 2021). A single translation approach only is not sufficient as variation in psychometric properties with higher false-positive rates may be found (DuBay et al., 2021; Soto et al., 2015). Such a change in psychometric properties may be found when an instrument is linguistically translated but cultural considerations and additional levels of equivalence were not investigated (Beaton et al., 2000; Soto et al., 2015). A translation, without cultural adaptation of a tool, should therefore be avoided. The process of cultural adaptation and translation should aim to achieve equivalence of the instruments on three levels (DuBay et al., 2021; Soto et al., 2015; WHO, 2013a). The source and target translation should be equivalent on linguistic, construct and technical levels (DuBay et al., 2021; International Test Commission [ITC], 2017).

The ITC (2017) published eighteen guidelines to support cultural adaptation and translation of instruments. The guidelines are categorised into six main steps which include Pre-conditions, Test development, Confirmation, Administration, Score scales, and Interpretation and Documentation (ITC, 2017). Guidelines by the WHO for instrument translation are similar but not as detailed as those by the ITC. The WHO guidelines include forward translation, expert panel back-translation and pre-testing followed by the finalisation of the end product (WHO, 2013a). Upon critical consideration, it is evident that the WHO guidelines do not include cultural adaptation, which necessitates the use of the ITC approach in combination with the WHO

translation guidelines. Both approaches include experts reviewing the translations as well as pre-testing the instrument. More detail is included in the ITC guidelines with the psychometric property analyses and the interpretation of the instrument outcomes. To adapt and translate an instrument accurately, an integrated approach of available guidelines (ITC, 2017; WHO, 2013a) is proposed in Figure 1.1 to ensure a rigorous process and desired outcome.

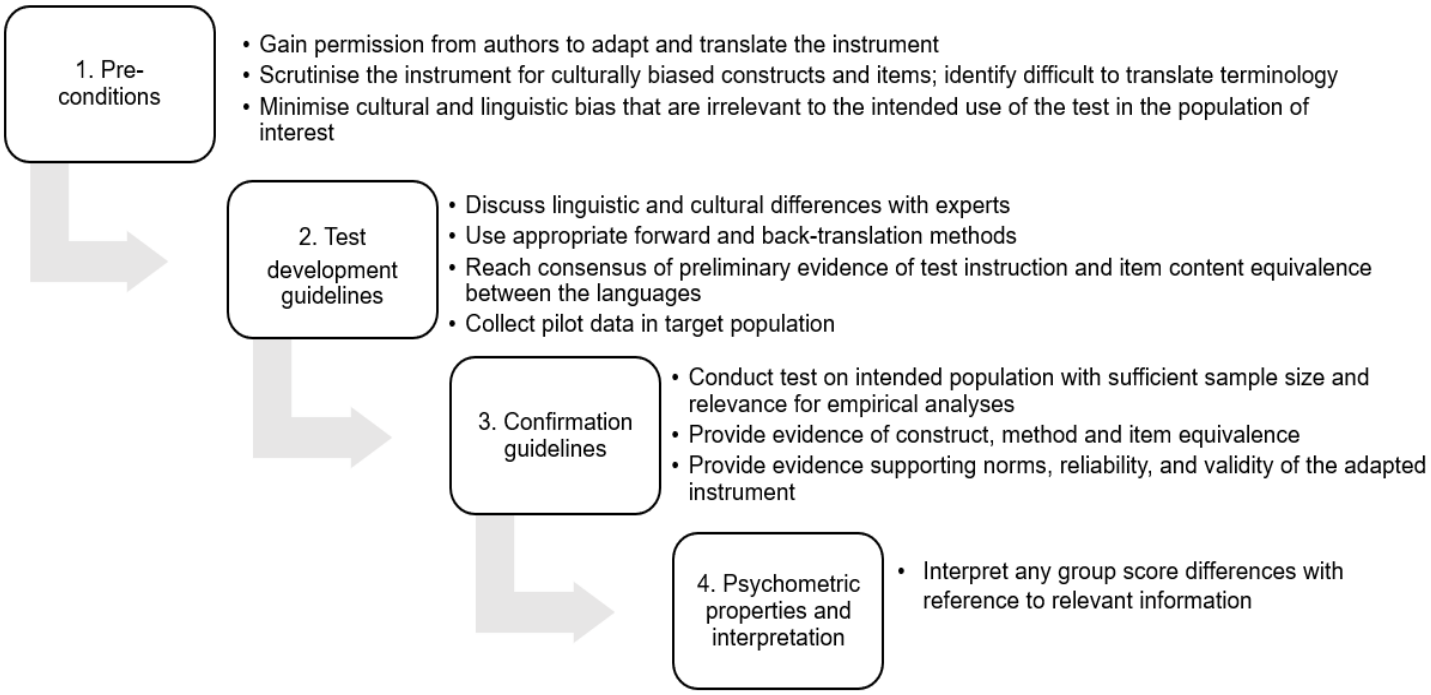

Figure 1.1**:** *Proposed integrated guidelines for the cultural adaptation and translation of a screening checklist* ***(based on ITC, 2017; WHO, 2013a)***

The need for a cultural adaption and translation of an autism-specific screening instrument for use in South Africa is clear. The South African Constitution affords equal status to the 11 official languages in an attempt to rebuild national pride and to recognise the importance of diversity through language planning (Mtsatse & Combrinck, 2018). Northern Sotho is the third most spoken African language in South Africa, with 12.4% of the total population using the language (StatsSA, 2019). Northern Sotho is also one of the most commonly spoken languages in the northern provinces of South Africa, with the highest percentage (19.4%) for a single language group in the City of Tshwane Metropolitan Municipality in Gauteng province (StatsSA, 2019). A certain peri-urban community in the municipality was thus identified as the area most densely populated by Northern Sotho speakers. Therefore, this study investigated the

cultural applicability, equivalence, reliability and concurrent validity of an adapted English version and a Northern Sotho translation of the M-CHAT-R/F™.

1.5 Research questions

The paucity of culturally and linguistically appropriate screening instruments that can promote access to care and support earlier identification of toddlers at risk for autism in South Africa led to the following research questions:

1. Which test items of the M-CHAT-R/F™ require cultural adaptation before translation, and how equivalent does the Northern Sotho translation appear in comparison to the adapted checklist?

2. How do the adapted English M-CHAT-R/F and the Northern Sotho translated checklists compare when utilised by a small group of first-language Northern Sotho caregivers?

3. How reliable and concurrently valid are the adapted English M-CHAT-R/F and the Northern Sotho M-CHAT-R/F when used by a larger-scale sample by comparing the two instruments with one another and a standardised diagnostic tool?

This is an article-based thesis, where the topic is introduced in Chapter 1 and Chapter 2 provides a description of all the methods used to conduct the three studies. Chapters 3, 4 and 5 contain the articles based on the three studies, followed by the last chapter, which provides an integrated summary, implications and conclusion to the thesis.

CHAPTER 2: METHOD

Chapter aim: The chapter provides an overview of the aim and objectives of the investigation which were subdivided in three feasible studies. Detailed description of the methods used in each study is included.

2.1 Research aim and objectives

Study aim

The aim of the study was to culturally adapt and translate the M-CHAT-R/F™, evaluate the adapted English and Northern Sotho checklists and determine the concurrent validity and reliability of each version.

Research objectives

Study 1:

To culturally adapt and translate the M-CHAT-R/F™ and its test instructions into Northern Sotho to ensure an accurate translation that reads fluently and appears authentic in the target language.

Study 2:

To collect pilot data that allow item analysis, assessment of the preliminary reliability, and confirm the degree of agreement between the two checklists.

Study 3:

To determine the reliability and the concurrent validity of both versions of the checklist in a larger-scale sample by comparing the two checklists with one another and a standardised diagnostic tool.

2.2 Research studies

The findings of the three studies have been submitted/accepted as articles in accredited peer-reviewed journals. Table 2.1 describes the titles, objectives, journals selected for publication, and publication status of the studies.

Table 2.1

Titles, objectives, journals of publication, publication status

	Study 1	**Study 2**	**Study 3**
Title	Cultural adaptation and Northern Sotho translation of the Modified Checklist for Autism in Toddlers (M-CHAT-R/F™)	Preliminary reliability of South African adaptation and Northern Sotho translation of the Modified Checklist for Autism in Toddlers, Revised with Follow-Up.	Reliability and concurrent validity of a South African cultural adaptation and a Northern Sotho translation of the M-CHAT-R/F
Objectives	To culturally adapt and translate the M-CHAT-R/F™ and its test instructions into Northern Sotho to ensure an accurate translation that reads fluently and appears authentic in the target language	To collect pilot data that allow item analysis, assessment of the preliminary reliability, and degree of agreement between the two test checklists.	To determine the reliability and the concurrent validity of both versions of the checklist in a larger-scale sample by comparing the two checklists with one another and a standardised tool.
Journal for publication	South African Journal of Childhood Education (SAJCE)	South African Journal of Communication Disorders (SAJCD)	Journal of Autism and Developmental Disorders (JADD)
Publication status	In Press	Published	Submitted
Chapter in thesis	3	4	5

2.3 Research designs

A qualitative design was employed in Study 1, focussing on perspectives, opinions and suggestions of experts. The design was supplemented with descriptive quantitative data using a self-completed questionnaire.

A comparative design was used, comparing the adapted English M-CHAT-R/F and the Northern Sotho M-CHAT-R/F, for the second study. The pilot study was conducted to enable item analysis, reliability assessment and small-scale validity data to determine if any additional revisions of the two checklists should be considered. Study 3 was a larger-scale validation study with a comparative design. The study allowed the comparison of the two M-CHAT-R/F versions for equivalence and reliability. In addition, comparison of the outcomes of the autism-specific screening checklists with the results of specific developmental domains of the Vineland Adaptive Behaviour Scales-3 (VABS-3) was conducted to investigate the concurrent validity of the instruments.

2.4 Research settings

Study 1

Experts with clinical experience, a background in test development, speech-language pathology and/or Northern Sotho were approached to participate in the instrument review process. First language Northern Sotho SLTs, proficient in English, were requested to review the original M-CHAT-R/F™ using test adaptation and translation guidelines based on two questions. The expert panel met at the research institution for a 90-minute recorded discussion.

Study 2

The pilot study included 21 participants living in a peri-urban community in Gauteng, South Africa. Two community residents known to the researcher were identified as the first point of contact for snowball sampling. They recruited Northern Sotho speaking caregivers with toddlers aged between 18 and 48 months of age. The toddlers, identified as low-risk for autism, did not attend a high-risk clinic or had any pre-existing medical diagnoses. The children of the participants in Study 2 and 3 acted as reference populations when their caregivers completed the two versions of the M-CHAT-R/F.

Study 3

Data for the larger-scale study were collected at the clinic of a local community health centre in the same peri-urban area of Tshwane in Gauteng province. Sixty-one percent of residents if the peri-urban community live in formal dwellings (StatsSA, 2022). In the current study 55.1% of the participants lived in formal dwellings. A total of 81% of

the participants received social grants to support of their children, while 29.1% of the sample were employed full time. Most caregivers (92,4%) completed matric and had English and Northern Sotho reading and writing proficiency.

The health centre was a data-rich setting for Northern Sotho speaking caregivers. Local caregivers visit the specific clinic (Family planning and Child health) for immunisations, deworming, and developmental monitoring as recommended by the RTHB. The research site was also selected as it is a primary care prevention facility with a focus on child health and general development. The toddlers attending the clinic are generally considered low risk for autism as the children with risk conditions are referred to district and tertiary hospitals with specialised clinics (Mojaki et al., 2011). Referrals to appropriate clinics are made when concerns are noted.

2.5 Research participants

Three different sample populations were utilised in the three studies, indicated by each study's objective. Studies 2 and 3 utilised similar populations, but there were variations in sampling methods, research contexts and sample sizes. Studies 1 and 3 used purposive sampling due to specific skills or traits required of the participants. Study 2 employed snowball sampling due to limited access to participant-rich settings during the South African Covid-19 lockdown period. The different sample sizes were determined based on a power analysis for Study 2 and 3. The power analysis showed the number of participants required to perform the different statistical analyses to achieve the study aims. The power analysis ran for Study 2 indicated a minimum sample size of 20 participants. As per power analysis, a total of 156 participants were required for Study 3 to achieve the aims.

Study 1

Diverse sets of participants were involved during the different stages of the overall research process. During the cultural adaptation phase of the M-CHAT-R/F™ two first-language, Northern Sotho speaking SLTs were involved. Two independent translators were included in the process to perform the forward- and back-translations. The translator responsible for the back-translation was blinded to the M-CHAT-R/F™.

To ensure a comprehensive and fair review of the adapted checklist and its equivalence with the translated checklist, a panel with expertise either in the Northern

Sotho language and culture, test development, or autism were approached to participate in the study. The multidisciplinary expert panel included four research team members and an additional four participants. Figure 2.1 shows the collaboration between different participants during the two phases of Study 1. The expert panel and their holistic review of the screening tools provided a strong foundation for the subsequent stages.

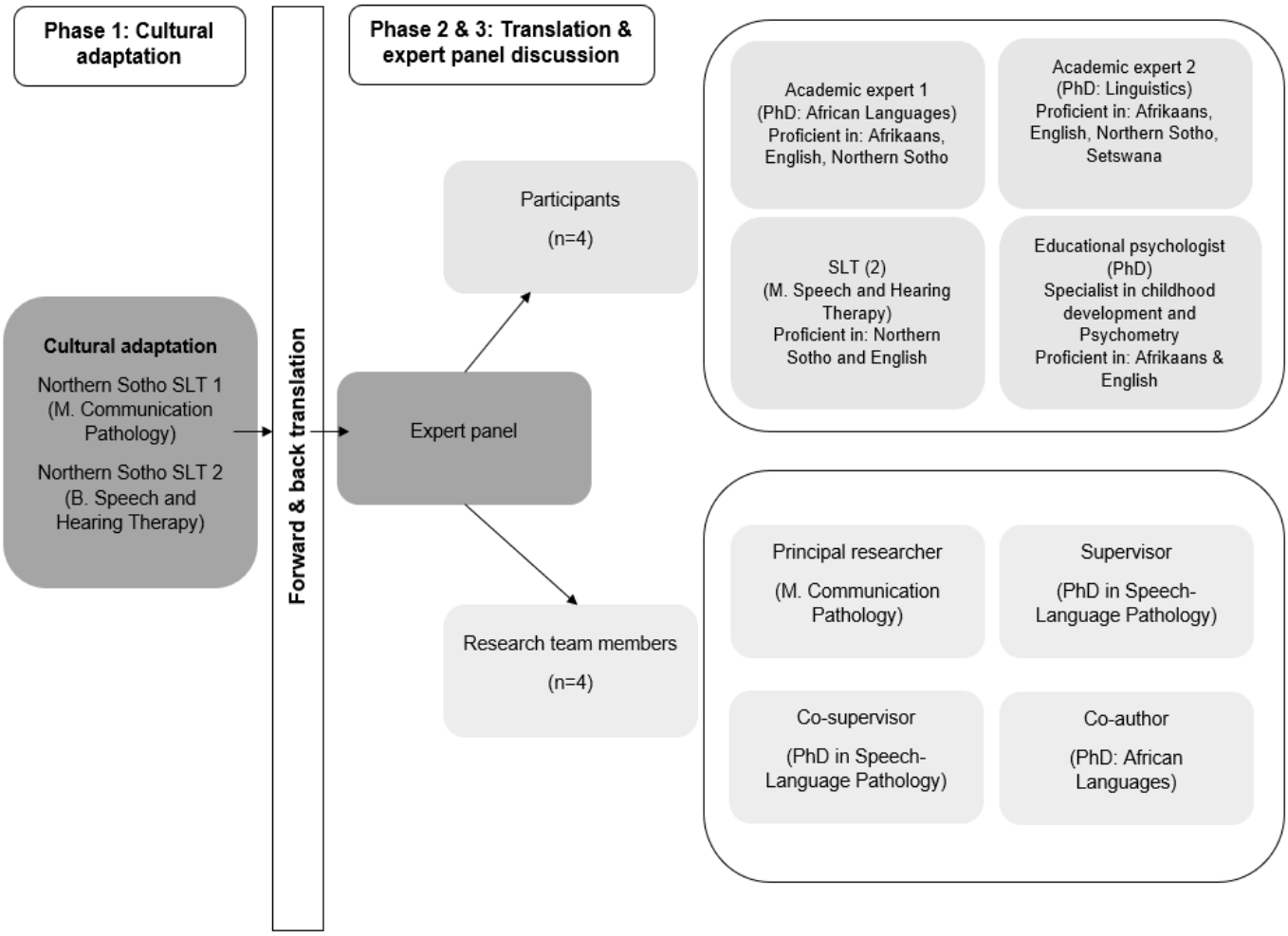

Figure 2.1: *Study 1 participants and their expertise*

Study 2

The second study included 21 Northern Sotho caregivers of toddlers aged between 18 and 48 months. Participants were selected if they were proficient in English (Grade 4 level as per M-CHAT-R/F™ guidelines) and identified Northern Sotho as their first language, as they had to read the 20 items of the M-CHAT-R/F in English and Northern Sotho. Participants' children did not have any medical condition before the screening, or a formal diagnosis such as a sensory deficit, a genetic syndrome or cerebral palsy.

The RTHB developmental screen, as well as caregiver report, were used to exclude toddlers with pre-existing developmental conditions. The reference population consisted of children with no known developmental condition and were therefore at low risk for autism.

Study 3

The larger-scale study employed a sample of 158 Northern Sotho caregivers of toddlers aged between 18 and 48 months. The mean age of the reference sample was 28.3 months. Twenty-three caregivers identified an additional home language in addition to Northern Sotho. Participants were purposively selected at a Community Health Centre's clinic when they accompanied their toddler for a visit. There were far more girls (n=101) than boys in the reference sample. The inclusion and exclusion criteria of participants and their children were similar to Study 2.

2.6 Material

Modified Checklist for Autism in Toddlers, Revised, with Follow-up [M-CHAT-R/F™] (Robins et al., 2014) Appendix A

The M-CHAT-R/F™ is an autism-specific, caregiver-reported screening checklist of child behaviour. The checklist aims to assess the risk for autism in toddlers aged between 18 and 30 months. Research showed that it may be used reliably until the age of 48 months (Yama et al., 2012). Earlier identification of toddlers at risk allows professionals to intervene at an earlier age, promoting improved developmental outcomes (Erasmus et al., 2019; Franz et al., 2018; Johnson et al., 2007).

The M-CHAT-R/F™ was the main instrument in this research project. The two-stage caregiver-completed autism screen was first published in 2014 following changes to the M-CHAT. The revised version (Robins et al., 2018) includes 20 simplified Yes/No items and a newly added Follow-up section with structured questions to gather additional information on possible at-risk behaviours when a child scores medium risk for autism. The most recent revision (2018) which includes minor revisions was used in the study (Appendix A). The language use, as well as the examples of behaviour associated with autism, were simplified in the 2014 and 2018 revisions of the checklist. An English reading proficiency equivalent to Grade 4 is recommended for users.

The first ten items of the checklist are the Best 7-score in the revision (Robins et al., 2014). The Best 7-score includes the most prominent items which support the high sensitivity and specificity of the checklist (Robins et al., 2018). Items 2, 5, and 12 require “No” to screen negative for autism and for the remaining 17 items “Yes” is also indicative of a negative screen. Items relating to motor development were included to act as foils. A score of one is allocated for each item with a positive screen answer. With completion of the initial 20 items, the toddler is categorised into three possible risk groups, Low-risk (0 to 2), Medium-risk (3 to 7) and High-risk for autism (≥8).

In case of medium-risk for autism, the Follow-up items (Stage 2) should be completed to provide the caregivers with an opportunity for clarification to promote understanding while more comprehensive behaviour descriptions are given. As per instructions the Follow-up items are selected by a test administrator based on the items failed in Stage 1. Only failed items need to be followed up. The Follow-up questions are presented in a flowchart format, with questions to be answered by the caregiver until a “Pass” or “Fail” result is achieved. Guiding questions, as well as new examples of child behaviour, not included in Stage 1, are used to gather more information on the toddler’s behaviour. A high-risk category is indicative of an immediate referral to a specialist for a comprehensive autism-specific assessment.

The M-CHAT-R/F™ is a caregiver-reported screening tool, which can be used by caregivers and various professionals and health care workers as it requires little or no training (Robins et al., 2014). caregivers, allied health care professionals, medical doctors, community health care workers and possibly teachers can use the checklist. The checklist is free of charge for clinical use and is available on the M-CHAT™ website (https://mchatscreen.com/). The electronic version can be completed and scored online while a hard copy may be used in contexts with limited internet access. The checklist already shows many advantages as advocated by Franz et al. (2017) and Marlow et al. (2019).

Adapted English Modified Checklist for Autism in Toddlers, Revised, with Follow-up (Appendix B)

The English adaptation was generated during Study 1 when culturally biased items and technical items which were difficult to translate, were identified and changed by the two Northern Sotho speaking SLTs and the expert panel. Four changes were made

to the original M-CHAT-R/F™. The adapted checklist was used during Studies 2 and 3 so that its equivalence could be tested against the Northern Sotho translation of the M-CHAT-R/F. The four changes to the original checklist are typed in bold in Table 2.2. Linguistic gaps were addressed using different terminology formation strategies, such as direct borrowing, transliteration or loan translation, paraphrasing, semantic specialisation and compounding (Gauton et al., 2008). The scoring procedures of the adapted English M-CHAT-R/F are the same as the M-CHAT-R/F™

Table 2.2

Cultural adaptations made to the M-CHAT-R/F™ (Study 1)

Item	**Original language in the M-CHAT-R/F™**	**Adaptation in English**
3.	*Does your child play pretend or make-believe? (For example, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)*	*Does your child **act**? (For example, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or a **toy**?)*
4.	*Does your child like climbing on things? (For example, furniture, playground, equipment, or stairs)*	*Does your child like climbing on things? (For example, furniture, **trees**, or stairs)*
14.	*Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?*	*Does your child look in **your direction** or in the eye when you are talking to them?*

Northern Sotho Modified Checklist for Autism in Toddlers, Revised, with Follow-up (Appendix C)

The Northern Sotho M-CHAT-R/F is the translation of the adapted English version. The translation was conducted following the guidelines of the ITC (2017) and the WHO (2013a) and is shown in Figure 1.1. The process is comprehensively described in Chapter 1 and as an article in Chapter 3 of the thesis.

Item Translation and Adaptation Review Questionnaire (Hambleton & Zenisky, 2011)

The questionnaire was used in Study 1 during the reconciliation phase as it provided a comprehensive review of the content, the culturally biased aspects in the checklist as well as an evaluation of the physical layout of the instrument. The review

questionnaire included five categories, *General, Item format, Culture, Grammar and phrasing, and Passage translation.* The categories are judged according to a 4-point Likert scale (Yes, No, Unsure, and Not Relevant). Panellists were asked to complete specific sections of the questionnaire according to their field of expertise. The templates of the *Item Translation and Adaptation Review Questionnaire* for the different panellists are included as Appendix D.

Vineland Adaptive Behaviour Scale-Third edition (Sparrow et al., 2016)

The Vineland Adaptive Behaviour Scales, Third Edition (VABS-3) is the latest edition of a comprehensive measure of adaptive behaviour functioning for individuals aged zero to 90. The VABS-3 is mainly used to assess the development of functional skills typically affected by intellectual disability, developmental delays and possible autism. It is recommended that the VABS-3 is used as part of a comprehensive test battery for the assessment of autism as it provides information on adaptive behaviour skills which are typically affected by autism (Sparrow et al., 2016). The VABS-3 was used as part of the inclusion criteria of the reference population in Study 3 to exclude possible intellectual disability in referent participants, but those with developmental delay or typical development were selected for the study. The aim was to determine the possible presence of conditions in the child such as developmental delays and intellectual disability. The use of the VABS-3 also allowed the researcher to determine the concurrent validity of the M-CHAT-R/F versions by comparing the screening outcome with the communication and socialisation levels of functioning. A third reason for the selection of the VABS-3 was to use an autism-specific screen in combination with a broad developmental instrument as recommended by Barger et al. (2021) and Wiggins et al. (2014).

The specific form used in the current research is known as the Comprehensive Parent/Caregiver Form. The form is typically completed by caregivers to obtain a comprehensive description of a child's functioning, without a structured interview. Three core domains in this form include Socialisation, Communication and Daily Living Skills. The Motor development domain was not included in the study as the results from the three core domains only are used to determine the overall Adaptive Behavior Composite score (ABC-score).

The VABS-3 questions were read to the participants (caregiver of child) whereafter the principal researcher scored the answers according to a 3-point Likert scale. Possible scores are 0 (never), 1 (sometimes), and 2 (often or usually), all relating to the developmental functioning of the child. The ABC-score was used to determine the child's current level of functioning, which could be Low, Moderately low, Adequate, Moderately high and High according to the norms. Adequate and above indicate typical development while Moderately low and Low signal developmental delay. The VABS-3 has not been standardised for South Africa, but has been used with success in various research studies and is recommended for local use (Allen et al., 2014; Du Toit et al., 2021; Watermeyer et al., 2006).

Socio-demographic questionnaire (Appendix E)

The questionnaire, based on the risk assessment by Kritzinger (2018) was used in a structured caregiver interview. The data from the questionnaire were analysed in combination with the VABS-3 and the RTHB which guided participant and child inclusion or exclusion from the study. Data also ensured a comprehensive participant description. The questionnaire included questions about the mother and child's general background information, pre- and perinatal history, possible established risk conditions and the child's developmental history.

2.7 Data collection procedures

Figure 2.2 provides an overview of the phases of the data collection process across the three studies.

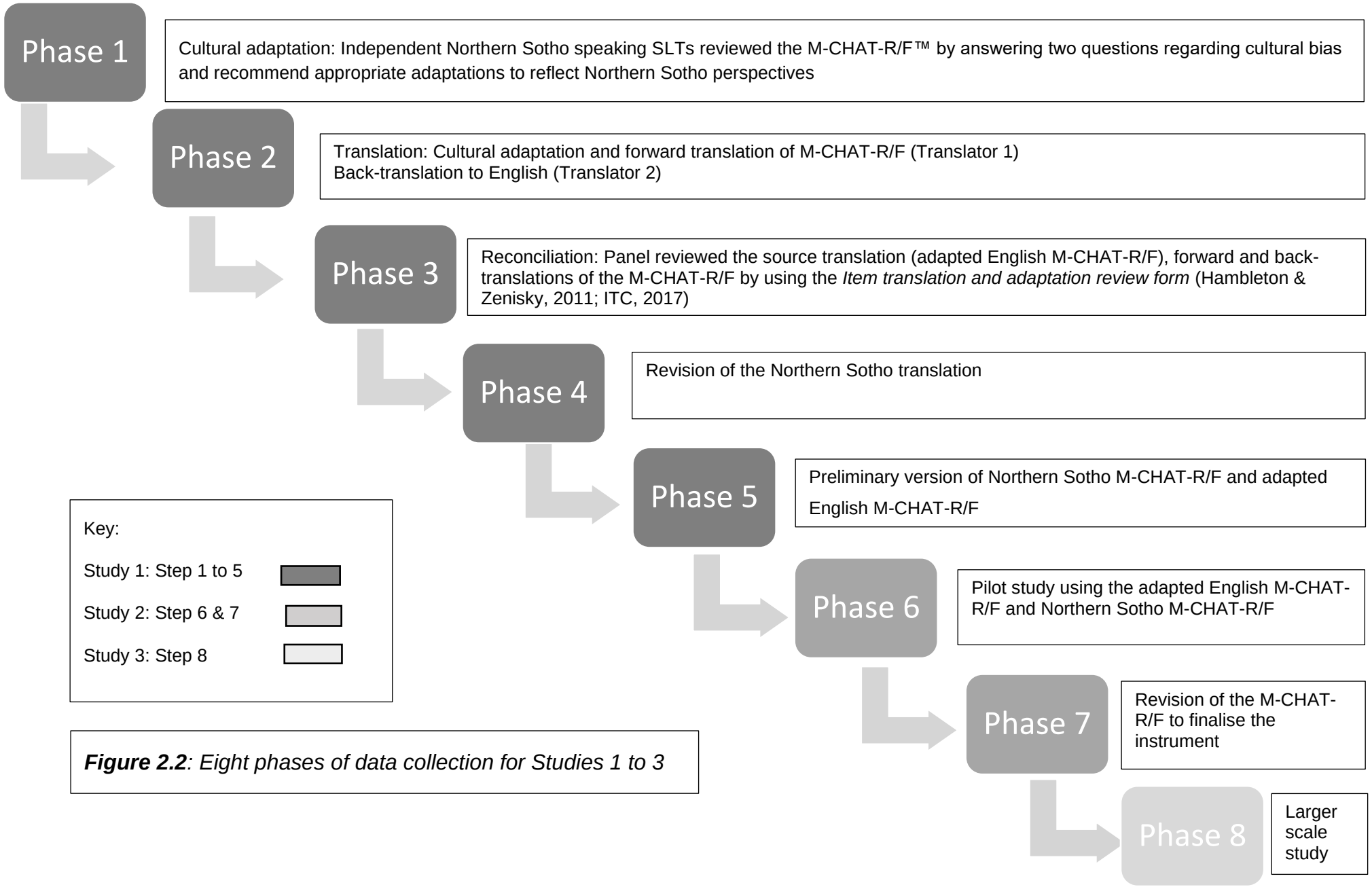

***Figure 2.2**: Eight phases of data collection for Studies 1 to 3*

Study 1

Data collection for Study 1 is represented by Phases 1 to 5 in Figure 2.2. Two Northern Sotho speaking SLT's identified linguistic and cultural incompatibilities of the M-CHAT-R/F™ by answering two questions, *Which test items and instructions in the English version are culturally specific and may not be applicable to Northern Sotho?;* and *Which concepts or words will be difficult to translate to Northern Sotho*?. The remarks and recommendations were discussed with the first translator and members of the research team to reach a consensus. The accepted changes were applied, which resulted in the preliminary South African adapted English M-CHAT-R/F, the source translation.

The source translation was translated into Northern Sotho by a registered English – Northern Sotho translator. Following the forward translation, a second registered translator, blinded to the original M-CHAT-R/F™ and the adapted English checklist, conducted the back-translation. At the end of Phase 2, I had the original M-CHAT-R/F™, preliminary adapted English M-CHAT-R/F (source translation), preliminary Northern Sotho M-CHAT-R/F (T1) and the back-translated English M-CHAT-R/F (T2) available for review.

Phase 3, the reconciliation phase, was a 90-minute recorded expert panel discussion. The participants reviewed the checklists according to the *Item Translation and Adaptation Review Questionnaire* (Hambleton & Zenisky, 2011). Participants not proficient in Northern Sotho were required to use the original M-CHAT-R/F™ to review the source translation and back-translation (T2). Participants critically evaluated whether there was cultural and linguistic equivalence between the source translation and the preliminary Northern Sotho M-CHAT-R/F. The panel identified translation challenges and offered possible solutions to consider. The best recommendations were accepted. The recording was transcribed and analysed using ATLAS.ti 8.

ATLAS.ti 8 is a software programme that enables a researcher to use computer-aided qualitative data analysis software [CAQDAS] (Saldana, 2016). ATLAS.ti 8 assisted with the management and organisation of the verbatim transcripts. The program also provided a summary of the themes and a content analysis according to the labels identified by the primary researcher.

Study 2

Data for Study 2 were collected using snowball sampling (Phase 6, Figure 2.2). Participants who were all caregivers completed the preliminary adapted English M-CHAT-R/F and the preliminary Northern Sotho M-CHAT-R/F in a randomised order, and the socio-demographic questionnaire. Participants also answered three questions relating to the M-CHAT-R/F, 1. *Do you prefer to answer the test in English or Northern Sotho/Sepedi?;* 2. *Were there any words that you did not know? If yes, please list the words.* 3. *Were there any items in the M-CHAT-R/F that you did not really understand? If yes, please mark the items.* Data were analysed using descriptive and non-parametric statistics due to the small sample size.

Study 3

Data collected during Phase 8 were used to determine the reliability and concurrent validity of both the adapted English M-CHAT-R/F and the Northern Sotho M-CHAT-R/F. The developmental screen in the child's RTHB was used to exclude pre-existing conditions or diagnoses. Participants completed the adapted English and Northern Sotho checklists in a predetermined randomised order. If the same version of the checklist is completed first every time, biased answers can be expected. The principal researcher asked the VABS-3 questions, starting at a level corresponding with the child's chronological age in a face-to-face interview with participants. The sequence of data collection instruments minimised fatigue and counteracted a learning effect when completing the second checklist. The VABS-3 results were used to determine the current level of functioning of the participants. Referent participants were included if they presented with typical development as well as with a developmental delay. Exclusion would have been considered for children with intellectual disability. Data were collected over four months.

2.8 Data processing and analysis

The different data preparation, entry, processing and analysis for each study are discussed according to the three studies.

Study 1

As Study 1 generated both qualitative and quantitative data, different data preparation procedures were used for verification, editing and coding (Fouché & Bartley, 2015). Qualitative data from the two Northern Sotho SLTs were divided into two categories,

Culturally specific items not applicable to Northern Sotho and Concepts difficult to translate. Overlapping concerns were identified and discussed so that adaptations could be made. Data from the recorded panel discussion were transcribed verbatim, classified, coded, tabulated and summarised according to specific constructs identified by the principal researcher, using ATLAS.ti 8 (Schurink et al., 2015; Sutton & Austin, 2015).

A three-cycle approach involving both manual and electronic coding was used. The first cycle involved clustering data into the five main categories of the *Item Translation and Adaptation Review Questionnaire* (Hambleton & Zenisky, 2011). The second cycle employed *splittering* when more detailed codes were assigned to describe specific errors and incompatibilities identified during the panel discussion. In the final cycle, the splittered codes were lumpered (grouped) according to the five main themes which allowed me to determine which theme emerged most prominently (Saldana, 2016). Quantitative data from the questionnaire were analysed using descriptive statistics.

Study 2

In Studies 2 and 3 similar data checking and processing were used as all data from the adapted English M-CHAT-R/F, Northern Sotho M-CHAT-R/F, and the socio-demographic questionnaire were populated in Excel documents. Specific codes were assigned to data from the socio-demographic questionnaire to simplify data analysis. The VABS-3 data were also populated in an Excel spreadsheet according to the specific sub-domains, v-values and standard scores. Where possible, means, standard deviations (SDs) and modes were determined for Studies 2 and 3.

Due to the small sample size (n=21) non-parametric statistics were used in Study 2. The Wilcoxon Signed Ranked Test, the equivalent to the related t-test, was used to determine similarities or differences between the two checklists (Field, 2009). The Wilcoxon Signed Ranked test was used to determine the item correlation at the 5% level.

Study 3

As the aim of this study was to determine the concurrent validity and reliability of the adapted M-CHAT-R/F and the Northern Sotho M-CHAT-R/F using various statistical tests to determine the association between the two checklists and to compare the

outcomes of each M-CHAT-R/F version and the VABS-3. Descriptive statistics were used to describe the findings and conduct an item analysis of the answers from both checklists. Cronbach's alpha was calculated to determine the internal consistency of the adapted English and Northern Sotho checklists. Pearson's Chi-square test was used to determine the degree of association between the two checklists. Inter-rater (participants were regarded as raters) reliability was calculated determining Cohen's Kappa. (Field, 2009). The VABS-3 results and the M-CHAT-R/F outcomes were analysed using biserial correlations to determine the concurrent validity of the instruments.

2.9 Ethical considerations

Social research requires the researcher to apply strict ethical choices and careful decision making (Bless & Higson-Smith, 2013). Careful consideration of procedures and the potential risks are of the utmost importance when investigating human development and behaviour.

Permission to use the M-CHAT-R/F™ was requested from and provided by the authors (Appendix F). Ethical clearance from the Research and Ethics committee of the Faculty of Humanities and the Faculty of Health Sciences, University of Pretoria, was obtained (HUM041/0919). Following Institutional Research Board clearance, permission from the Tshwane Department of Health Research Committee was obtained. The ethical considerations and principles applied during the research process are included in Table 2.3.

Table 2.3

Ethical principles and considerations applied during the research process

Ethical Principle	**Application to Study**
Ethical clearance The research proposal should be submitted for consideration, guidance, comment, and approval to a research ethical committee	The study only commenced once ethical approval and clearance was obtained from: 1. Department of Speech-Language Pathology and Audiology RESCOM 2. Faculty of Humanities Research Ethics Committee of the University of Pretoria (Appendix G) 3. Faculty of Health Sciences Research Ethics Committee of the University of Pretoria (Appendix H)

	4. Tshwane Research Committee (Appendix I) 5. Stanza Bopape Community Health Centre permission (Appendix J)
Actions and competence of the researcher	The researcher is registered as an independent SLT (ST 0009237) at the Health Professions Council of South Africa (HPCSA), and has nine years of clinical experience with parents/caregivers, assessing, and treating young children with autism.
Confidentiality implies that the researcher and possibly members of the research team should protect the participant information (Leedy & Ormrod, 2015)	The participants (parents or legal guardians) were informed that identifying information and other personal information obtained during the interaction will be kept strictly confidential, in line with the Protection of Personal Information Act (PoPIA). All the coded data will be stored electronically on the University of Pretoria's repository as per institutional guidelines. Restricted access to the data is ensured allowing only the owners of the data to have access to, use and destroy the data. Anonymous participation was not possible, due to interaction with the parent/caregiver. An arrangement was made with the clinics to provide a private area where the instructions could be provided and where participants could complete the questionnaires. Questions and feedback were addressed in the area.
Voluntary and informed participation	Participation in the study was strictly voluntary and all participants provided written informed consent for participation (Appendices K, L, M, N, O) All participants were caregivers older than 18 years, therefore they could give informed consent without their caregivers' consent.
Beneficence	Children identified with a risk of autism or developmental delay were referred to specialists for the necessary management of the case (Appendix P)

2.10 Reliability and validity of methods

The methods employed in this study are evidence-based. Evidence-based practice is designed to endorse the reliable use of scientifically validated interventions and information. Utilising evidence-based practice results in contributions to theoretical research development. (Delport & De Vos, 2015). The use of the ITC (2017) and WHO (2013a) translation guidelines provided an evidence-based foundation for the cultural adaptation and translation of an already valid and reliable instrument, the M-CHAT-R/F™. The combination of qualitative and quantitative data allowed for the analysis of equivalence, reliability and concurrent validity. The VABS-3 is a standardised instrument and was used for comparison with the adapted and translated checklists.

CHAPTER 3: CULTURAL ADAPTATION AND NORTHERN SOTHO[1] TRANSLATION OF THE MODIFIED-CHECKLIST FOR AUTISM IN TODDLERS (M-CHAT-R/F™)

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Journal: South African Journal of Childhood Education (SAJCE)

Stylistic and language variations required by the specific journal guidelines were implemented and specified where applicable.

Impact factor: 0.3

Date submitted: 18/12/2020

Date accepted: 14/10/2021 (Appendix Q)

3.1 Abstract

Background: In recent reviews of Autism Spectrum Disorder screening tools, the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F^{TM}) has been recommended for use in lower-middle-income countries to promote earlier identification.

Aim: The study aim was to culturally adapt and translate the M-CHAT-R/F^{TM} into Northern Sotho, a South African language.

Setting: An expert panel were purposively selected for the review and focus group discussion which was conducted within an academic context.

Method: The source translation (English) was reviewed by bilingual Northern Sotho-English speech-language therapists who made recommendations for cultural adaptation. A double translation method was used, followed by a multidisciplinary expert panel discussion and a self-completed questionnaire.

Results: Holistic review of test, Additional remarks, and Grammar and phrasing were identified as the most prominent themes of the panel discussion, emphasising the equivalence of the target translation.

Conclusion: A South African culturally adapted English version of the M-CHAT-R/F^{TM} is now available along with the preliminary Northern Sotho version

[1] Northern Sotho is also referred to as Sepedi or Sesotho sa Leboa. The correct designation for this language is an ongoing debate of which the authors are aware.

of the M-CHAT-R/F^{TM}. The two versions can now be confirmed by gathering empirical evidence of reliability and validity.

Keywords: autism screening test, cultural adaptation; test translation; Northern Sotho M-CHAT-R/F^{TM}; South Africa; double translation method; test equivalence.

3.2 Introduction

Autism Spectrum Disorder (ASD) is universally recognised as a rising public health concern (World Health Organisation 2013: 6), yet almost all knowledge gained about the condition stems from high-income countries (HICs). In a scoping review of ASD research in Sub-Saharan Africa (SSA) it was found that studies published prior to October 2015 mainly targeted communicable diseases, with a limited focus on neurodevelopmental disorders like ASD (Franz et al. 2017: 723). The latest report of ASD diagnosis in the US indicates a rising trend, from 1 in 69 children in 2012 to 1 in 54 in 2020 (Centers for Disease Control and Prevention 2012; Hyman et al 2020:2). Since the extent of ASD in SSA is not well known the need for early identification programmes is amplified.

The World Health Organization (2013) considers early identification as a high priority, as detection at a young age may decrease the impact of impairments. Awareness and early identification of ASD in infancy are vital to improve long-term outcomes and optimise opportunities for children with ASD to benefit from early intensive intervention (Hyman et al. 2020: 1; Zwaigenbaum et al. 2015: s10). Despite international efforts to increase awareness of ASD using screening, large scale studies conducted in the US still indicate that the mean age of diagnosis remains at four to five years of age and even later in lower socio-economic communities because of the heterogeneity of symptoms (Centers for Disease Control and Prevention 2014:1; Hyman et al. 2020: 2; Robins et al. 2014: s11). Early identification and intervention for young children with ASD, therefore, remain a challenge that requires a global effort, with lower-middle-income countries (LMICs) actively contributing.

While screening tools are well established in HICs (Marlow, Servili & Tomlinson 2019: 177), research from LMICs highlights the need for culturally appropriate ASD screening and diagnostic tools. Standardised screening tools from HICs have been validated for their particular settings, but the use of these tools in other cultures or LMICs are often associated

with significant limitations in score interpretation and feasibility (Abubakar et al. 2008:217; Fischer et al. 2014:314; Hyman et al. 2020:12). The interpretation of screening tools is complicated when used in different contexts since the content, reliability and validity have been developed for a specific population and language (Rahman et al. 2003:1). The feasibility of the tool in another setting is influenced by aspects such as lack of clinician and parental knowledge, limited time for orientation, different cultural perceptions, and restricted human resources and finance (Kautzky & Tollman 2008: 24; Morelli et al. 2014:9; Soto et al. 2015; Stewart & Lee 2017: 528; Van der Merwe et al. 2017:1). A possible solution for barriers posed is the development of a contextually relevant caregiver-administered screening test, by means of adaptation and translation, to identify ASD across different socio-economic backgrounds and cultures without requiring extensive resources (Fyvie et al. 2016: 417; Rahman et al. 2003: 1)

The Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F^{TM}) is deemed an appropriate caregiver-administered screening test for the LMIC context and is already translated into 56 languages (Marlow et al. 2019:189; M-CHAT^{TM} website, accessed 13 March 2020). The recommendation for use is based on reviewing criteria such as the sensitivity and specificity of data; the sample size of the validation study; the cost to conduct the tool; the use in LMICs; and if the instrument can be used by Community Health Workers. The M-CHAT-R/F^{TM} showed high sensitivity [91%] and specificity [95%] (Robins et al. 2014, 41). In addition, the tool was standardised with a sample of more than 300 toddlers, is free of charge, and adapted versions are already used in countries classified as LMICs (Marlow et al. 2019: 188). With the revision of the M-CHAT-R/F^{TM} in 2014 meaningful reduction in the screen-positive rate (an increased risk of having ASD) and an increase in the detection of ASD in the US was observed (Robins et al. 2014: 37).

Recent research showed that children with ASD are still being overlooked with the use of the English version of the instrument (Beacham et al. 2018: 687; Guthrie et al. 2019: 8). It appears that children from lower-income households, who receive public health care and have been exposed to a language other than English, are being overlooked or incorrectly identified as at risk when the English version of the M-CHAT-R/F^{TM} is used (Guthrie et al. 2019). This oversight may result in lower sensitivity and specificity. Lower specificity may be attributed to unfamiliarity with the cultural and linguistic concepts used in the M-CHAT-R/F^{TM} providing a rationale for the adaptation and translation of this test. To limit the variance in early diagnosis

due to cultural differences, adaptation and validation measures are necessary (Hyman et al. 2020: 8).

While the development of new instruments is expensive and time-consuming, most health constructs are universal thus allowing application in various populations after cultural adaptation and if necessary, translation (Rahman et al. 2003: 1). The M-CHAT-R/F™ is already available in many official translations of the English version, but none of the translations includes any of the indigenous languages of South Africa (M-CHAT™ website, accessed 13 March 2020). Northern Sotho is the third most spoken indigenous language in South Africa, with 12% of the population communicating in the language (StatsSA 2019). The language is most commonly spoken in the northern provinces of South Africa, with 42% of the residents of Mamelodi, a township within the City of Tshwane Metropolitan Municipality, using Northern Sotho. The aim of the study was thus to culturally adapt and translate the M-CHAT-R/F™ and its test instructions into Northern Sotho. This adaptation and translation aimed to ensure an accurate version that reads fluently and appears authentic in the target language.

3.3 Method

Research design and ethical considerations

A qualitative design was used so that perspectives, opinions, and suggestions of experts could be reflected. Data were derived from self-completed questionnaires which included rating scales and structured review questions adapted from the International Test Commission (ITC) were used (ITC 2017). Following the ITC and World Health Organization (2013) guidelines, a test adaptation and double translation method were adopted. This method aimed to avoid a literal translation by rather ensuring the similar meaning of constructs (equivalence) across the two languages (ITC 2017). The source translation was adapted to remove cultural biases and improve relevance before translating the test into the target language followed by a back-translation. A comparative approach where the source, target, and back translations were compared for functional, conceptual, and linguistic equivalence, was followed (ITC 2017). This implied that the study was conducted in three consecutive phases, the Adaptation, Translation, and Reconciliation phases. Permission to use and translate the tool was given by the official M-CHAT™ team on behalf of Diana Robins.

Participants

Panel members involved in the different phases of the study were specialists from diverse multidisciplinary fields as required by the task they had to perform (See Table 3.1). The purpose was to draw on diverse specialist opinions, thereby following a comprehensive approach to test adaptation and translation. Two professional translators ensured the linguistic and conceptual equivalence of the target and back translations to prevent literal and direct translation. An educational psychologist, Northern Sotho linguists, speech-language therapist (SLT) practitioners with clinical experience working with parents and children with ASD, as well as researchers with expertise in instrument development and translation were included. Four of the nine panel members had in-depth knowledge of Northern Sotho culture in order to identify references that will be misunderstood in Northern Sotho.

Table 3.1: Participants' expertise and role

Participant code	Participant description	Highest qualification	Field of expertise	Role
P1	Academic expert	PhD	Multilingual speaker proficient in Afrikaans, English, and Northern Sotho. Northern Sotho linguist	Member of the expert panel: Review of *Grammar and phrasing, and Passage translation*
P2	Academic expert	PhD	Multilingual speaker proficient in Afrikaans, English, and Northern Sotho. Northern Sotho linguist.	Member of the expert panel: Review of *Grammar and phrasing, and Passage translation*
P3	SLT	M. Communication Pathology: Speech-	Bilingual Northern Sotho-English SLT.	Cultural adaptation

		Language Pathology		
P4	SLT	B. Speech and Hearing Therapy	Bilingual Northern Sotho-English SLT.	Cultural adaptation Member of the expert panel: Review of *General, Item format, Culture*
P5	Educational psychologist	PhD	Specialist in childhood development and psychometry. Bilingual Afrikaans-English speaker.	Member of the expert panel: Review of *General, Item format, Culture*
P6	Second translator	Language Practitioner	Professional translator. Bilingual Northern Sotho-English speaker.	Back translation
R1	Researcher	PhD	SLT and ASD specialist. M-CHAT-R/F user. Bilingual Afrikaans-English speaker.	Member of the expert panel: Review of *Grammar and phrasing, and Passage translation*
R2	Researcher	PhD	SLT, specialist in tool development and translation. Bilingual Afrikaans-English speaker.	Member of the expert panel

R3	Researcher	PhD	Professional translator. Multilingual speaker proficient in Northern Sotho, Setswana, English, and Afrikaans.	Translation of source text into Northern Sotho Member of the expert panel

Material

The English M-CHAT-R/F™ (Robins, Fein & Barton 2018) was the source translation used in the study. The electronic or hard copy administered screening test consists of two sections (20 yes/no questions with related child behavioural examples, and Follow-Up questions), completed by caregivers with a minimum Grade 4 level education. The test was developed to screen for risk of ASD-specific traits in children aged 16- to 30-months. For all 20 questions except items 2, 5, and 12, 'No' indicates a risk for ASD. A child's total score is categorised according to low-risk (zero to two), medium-risk (three to seven), and high-risk (eight to 20) categories for ASD. Medium-risk classification requires monitoring the child and completing the Follow-Up section. The section is presented in a user-friendly flowchart format with questions and different behavioural examples from the first section, indicating PASS/FAIL. When a toddler fails two or more of these questions a referral for a diagnostic evaluation is recommended. High-risk requires immediate referral to a specialist doctor. The design of the Follow-Up section allows the parent to answer the same questions as the initial 20 questions, but with different child behaviour examples. By offering different examples in the two sections more opportunities for clarification of behaviour are provided, preventing risk identification based on one example only. This feature contributes positively to the validity of the test, resulting in less false positive cases. If the toddler is still identified as being at risk after completion of the Follow-Up questions, a referral to a professional is required.

The second tool, the *Item Translation and Adaptation Review Questionnaire* (Hambleton & Zenisky 2011:71) was used in the Reconciliation phase of the study. The in-depth review questionnaire includes five categories, *General, Item format, Culture, Grammar and phrasing, and Passage translation,* judged according to a four-point Likert scale (Yes, No, Unsure, and

Not Relevant). Specialists were requested to complete the questionnaire based on the different translations, prior to the panel discussion. Selected panel members (P.1, P2, P4, P5, R2) were requested to complete the questionnaire a second time, following additional changes during the Reconciliation phase.

Procedures and data collection

According to the Pre-condition Guidelines (ITC 2017) of the Adaptation phase, permission to use the M-CHAT-R/F^{TM} was obtained, where after the Northern Sotho-English SLTs identified the possible linguistic and cultural incompatibilities of the test. After careful consideration of the source translation, P3 and P4 answered two questions: 'Which test items and instructions in the English version are culturally specific, and may not be applicable to Northern Sotho?' and 'Which concepts or words will be difficult to translate to Northern Sotho?' P3 and P4 were also requested to propose culturally appropriate solutions or adaptations which were discussed with R3.

The next phase entailed the translation of the adapted test aiming for conceptual equivalence between the two translations. P6, blind to the original English version of the M-CHAT-R/F^{TM}, conducted the back translation into English. The aim of the back translation was to allow the expert panel to double-check the target version and to reconcile the two translations while maintaining content and construct equivalence (ITC 2017: 13). The back translation thus served as a measure to evaluate the accuracy of the target translation for panel members who were not Northern Sotho speakers and was discarded afterwards.

During the Reconciliation phase the expert panel met for a 90-minute recorded discussion of the translations, facilitated by the principal researcher. The panel members studied the translations and completed the *Item Translation and Adaptation Review Questionnaire* prior to the discussion. As all participants were not Northern Sotho speakers, only three members (P1, P2, P4) of the panel compared the source translation as well as target translation and back translation. the other panel members reviewed the target translation and back translation or the source translation and back translation. This allowed the panel to critically evaluate the linguistic and cultural equivalence between the Northern Sotho and source translation. Recommendations were considered and the best solutions were identified during a critical

discussion. The linguists (P1 & P2) identified linguistically correct options and first language Northern Sotho speakers (P4 & R3) confirmed the local use of the vocabulary. A verbatim transcription of the voice recording of the panel discussion was analysed.

Data analysis

Qualitative data of the cultural adaptation were analysed according to the contribution of each participant. Data were classified, coded, tabulated, and summarised according to specific constructs (Sutton & Austin 2015: 227; Schurink, Fouché & De Vos 2015:402).

The panel discussion data were analysed in three cycles, including both manual and electronic coding, thereby providing a more trustworthy account (Saldaña 2016: 27). During the preliminary analysis, cycle data were clustered into the five main categories of the *Item Translation and Adaptation Review Questionnaire* (Hambleton & Zelenski 2011: 71). The second cycle involved 'splittering' separating content into smaller codes. 'Splittering' implied that more detailed descriptive codes were assigned to the content of the five categories to identify specific errors and incompatibilities indicated during the panel discussion. The CAQDAS software (ATLAS.ti Version 8) was used for 'splittering'. The third cycle involved the reconfiguration of codes into themes. Detailed codes were 'lumpered' (grouped together) according to five main themes, in order to determine which theme emerged as most prominent during the panel discussion (Saldaña 2016).

3.4 Results

Adaptation phase

Table 3.2 depicts the results of the questions posed to the two Northern Sotho SLTs and the adaptations made to the source translation based on the proposed suggestions.

Table 3.2: Cultural adaptations to the M-CHAT-R/F™

Question	P3 (SLT)	P4 (SLT)	Adaptations	Justification
'Which test items and instructions in	'Does your child look	'Eye contact'	'Does your child look in your direction or in the	In Northern Sotho culture, it is culturally inappropriate for children to make eye contact

the English version are culturally specific, and may not be applicable to Northern Sotho?'	you in the eye'		eye when you are talking to them?'	with older or superior people when talking to them.
		'Make-believe'	'Make-believe' was adapted to 'acting'.	Both 'Make-believe' and 'pretend play' are words not familiar to Northern Sotho culture, with no conceptual equivalent in Northern Sotho. Make-believe may be interpreted as an attempt to deceive someone in Northern Sotho culture.
'Which concepts or words will be difficult to translate into Northern Sotho?'	'Pretend play'	'Soft toy'	'Pretend play' was regarded as synonymous to 'Make-believe' and was adapted to 'acting'.	
	'Equipment'	'Playground equipment'	'Soft toy' was simplified to 'toy', 'Playground equipment' was changed to 'tree'.	Both 'soft toys' and 'playground equipment' are culturally different and limited access may affect comprehension as children from disadvantaged communities may not have access to outdoor Jungle Gym equipment.

There was agreement between the two SLTs (P3 and 4) that a child making eye contact when communicating with an elder is culturally specific and not typically observed in Northern Sotho culture. This non-verbal communication custom is also evident in other Southern African cultures, as it is considered a sign of respect when a minor refrains from making eye contact with a superior (Mncwango 2009: 51). The construct of 'make-believe' or 'pretend play' was also identified by both SLTs as not applicable in Northern Sotho culture and a concept that will be difficult to translate. It appears that the concept of 'pretend play' does not feature within Northern Sotho culture. 'Playground equipment' was identified as an unfamiliar concept in disadvantaged communities in South Africa. Since the aim of a test translation is to achieve maximum comprehension by its users while still maintaining conceptual equivalence, it was

important to find acceptable solutions.

Translation phase

The adapted English version of the test was used as source translation. The forward translation to Northern Sotho was completed within 14 days. P6 performed the back translation while blinded to the source translation. The translation phase, therefore, produced the target translation and back translation.

Reconciliation phase

Figure 3.1 depicts the broad outline of the three cycles and corresponding codes and themes that were identified during analysis of the 90-minute-long panel discussion recording.

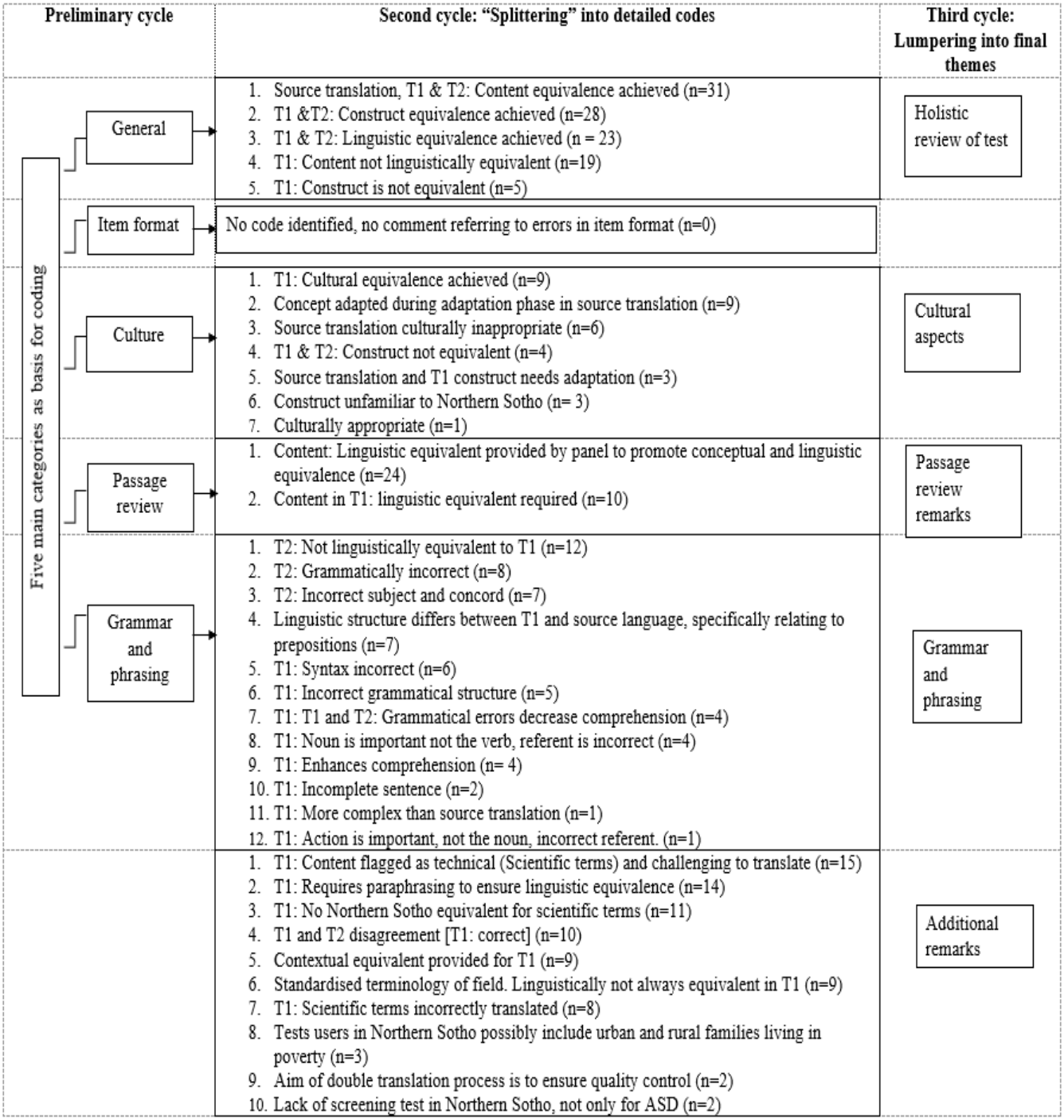

Figure 3.1: Cycles analysis and identification of codes and themes.

*T1: Target translation, T2: Back translation

The category *Item format* initially included in the preliminary cycle was omitted. The original user-friendly organization and item format of the M-CHAT-R/F^{TM} were retained. Four of the initial five categories were identified as themes with *Additional remarks* replacing *Item*

format as the fifth theme. The identification of an additional nine detailed codes, not relating to the other categories, is evidence of the scope and comprehensiveness of the panel discussion.

Detailed codes discussed most often where those under the theme *Holistic review of test.* Five detailed codes (discussed 106 times) were 'splittered' under the theme. The detailed code occurring most frequently was the confirmation that content equivalence was achieved between the different test items in the source translation, target translation and back translation.

Facilitator: *The example said 'pointing to a snack or a toy' which was back-translated to 'point to a light food'?*

P2: *It is a snack in Northern Sotho.*

The following example indicates that construct and linguistic equivalence between the source translation, target translation and back translation were achieved, even though the vocabulary differs.

Facilitator: *Does your child try to copy you? The back translation says 'Does your child imitate or copy what you are doing…'*

The panel agreed that the linguistic meaning was preserved between the three different translations.

Twelve of the twenty test items of the source M-CHAT-R/F™ version were accurately translated in the target translation. An example of the equivalence of the double translation:

Source translation item-nr 2: *Have you ever wondered if your child might be deaf?*

Target translation: *Naa o ile wa nagana gore ngwana wa gago e ka ba e le sefoa?*

Back translation: *Have you ever wondered/think if your child is deaf?*

Recommendations were made when there was a lack of linguistic (n=19) and construct (n=5) equivalence between the target translation and the source translation. With the combined knowledge of the expert panel, most of the translation problems were therefore solved during the discussion.

The second most discussed theme was 10 detailed codes under *Additional remarks* (Theme 5). These codes related to and clarified instances where linguistic equivalence was not achieved in Theme 1. The most prominent code referred to the content that was flagged as technical and scientific terms that were challenging to translate (n=15).

P2: *I think this is a difficult thing to translate because of the technical nature.*

R2*: If I can just say that the technical stuff is something that we have to make sure that we find solutions for because those…*

P2: *I think it is a very technical one and if you don't have a little bit of knowledge of the subject field it may obviously make it difficult to translate.*

P1: *No, and it is very technical.*

The technical nature of the scientific terms used in the test instructions, such as 'false positive rate and screen positive', was emphasised during the panel discussion. The technical nature of the test led to the detailed code regarding the need for paraphrasing (n=14). Another code that featured was that there is no Northern Sotho equivalent for some of the scientific terms (n=11). The technical nature of the content sometimes resulted in a lack of linguistic and content equivalence as there was no Northern Sotho word for the term, resulting in incorrect translation from the source translation to target translation. The solution posed during the panel discussion was to paraphrase the technical term to convey an accurate idea of the concept in target translation.

An example of paraphrasing was - *Source translation (English): The primary goal of the M-CHAT-R*^{TM} *is to maximize sensitivity, to detect as many cases of ASD as possible.* The sentence was changed to:

The main goal/objective of the M-CHAT-R™ is to detect/find as many cases of Autism as possible.

Grammar and phrasing, produced 12 codes that were referred to a total of 54 times. The most noticeable codes related to the back translation not being linguistically equivalent to the target translation; back translation being grammatically incorrect (n=8) and back translation showing incorrect subject and concord (n=7). The combined themes *Holistic review of test, Additional remarks*, and *Grammar and Phrasing* not only showed the high level of linguistic, construct, and content equivalence that were achieved between the different translations, but also indicated the effect of technical or scientific terminology problems on the translation process. Differences in language structures between English and Northern Sotho also contributed to challenges with the back translation. The panel identified those instances where the target translation was accurately translated (n= 10) and indicated where differences between the target translation and back translation resulted in inaccuracies when compared with the source translation. The results and recommendations derived from the panel discussion were used in the reconciliatory test translation.

Item Translation and Adaptation Review Questionnaire

The questionnaire was completed before and after the panel discussion. Panel members answered questions according to their field of specialization.

There was full agreement between the panel members in the written answers of the *Item Translation and Adaptation Review Questionnaire* regarding the *Passage* translation including the test introduction as well as the instructions. All the panel members agreed that the language used in the target translation does not depict individuals (e.g., toddlers at risk of ASD) in a stereotypical fashion or involve controversial topics relating to ASD. All agreed that the *Item format* of the test remained the same, confirming the results of the panel discussion (See Figure 1).

Minor differences in the answers of the panel members involved their views on the modification made to item structure on a grammatical level, and that the different versions convey similar content and ideas. It was indicated that some specific words may result in

confusion due to multiple meanings in the target translation and that some of the content may be unfamiliar to the reader due to the technical nature.

Evidence of the value different fields of expertise represented in the panel members became apparent in the following two questions, where zero agreement was observed: 'Are there any grammatical structures in the source language version of the item that do not have parallels in the target language?' and 'Are there any gender or other references that might make this item be cued in the target language version?' The Northern Sotho linguist (P1) was able to identify that all the grammatical structures have parallels in the target language and that gender will not have an effect in the target language. The other participants were either unsure or identified changes in structure that were evident in the back translation as they were only able to review the source translation and back translation.

One of the first language Northern Sotho SLTs (P3) and a SLT specialising in ASD (R1) reviewed the questions on *General, Culture,* and *Item format.* The one question leading to a difference in opinion, related to Culture, was: "Are there cultural differences that would have an effect on the likelihood of a response being chosen when the item is presented in the source and target language?". The differences were identified during the panel discussion where three concepts were identified as still requiring adaptation to improve the relevance of the concepts. The additional variances included uncertainty regarding the commonality of some of the technical terms and the effect that these terms might have on the difficulty of the content. The Northern Sotho SLT (P3) was able to identify more of the cultural aspects and the increase in complexity of the content due to her background and understanding of Northern Sotho. The SLT specialising in ASD (R2) was again able to identify when the constructs were still equivalent even if technical language was employed.

The data obtained from the *Item Translation and Adaptation Review Questionnaire* confirmed the findings from the panel discussion. The convergence in the findings obtained from the expert panel discussion and the questionnaire are indicative of successful triangulation to confirm the validity of the results (Leedy & Ormrod 2015: 104). The review questionnaire allowed the participants to systematically consider the various translations. Each panel

member's unique skill set influenced the rating of the translations and ensured for a comprehensive panel discussion.

Discussion

Since most ASD screening tests are developed in HICs and therefore culturally specific (Marlow et al. 2019: 177) a double translation method was employed to adapt the M-CHAT-R/F^{TM} and translate the tool into Northern Sotho. By following a comprehensive three-phase process of cultural adaptation and translation it was possible to create a culturally appropriate English version of the M-CHAT-R/F^{TM}, as well as a Northern Sotho version of the M-CHAT-R/F^{TM} that is linguistically and conceptually equivalent. By creating a culturally sensitive screening test the research may contribute to valuable data on at-risk rates within LMIC contexts and also result in early identification of toddlers at risk for ASD (Marlow et al. 2019: 186).

Based on the answers from panel members with lived experience of the target culture, it was necessary to make four adaptations to the source translation during the Adaptation phase. A common cultural phenomenon in South Africa, including Northern Sotho culture, is the notion that it is culturally inappropriate for children to make eye contact with older people when talking to them. Children should refrain from making eye contact as a sign of respect for elders or higher status (Mncwango 2009: 51). Test Item 14 was adapted to 'Does your child look in your direction or in the eye when you are talking to them?'. While the cultural reference of eye contact had to be adapted, it is a valid test item to include in a screen for ASD as atypical reaction to direct eye contact by an individual with ASD is one of the most characteristic hallmarks of the condition (Madipakkam et al. 2017:1). Both SLTs identified 'make-believe' and 'pretend play' (test Item 3) as words not familiar to the culture when referring to child play behaviour, with no conceptual equivalent in Northern Sotho. Since make-believe is interpreted as an attempt to deceive someone in Northern Sotho culture the construct was adapted to 'acting'. The lack of shared symbolic play is a valid behavioural marker for ASD. The trait is included as part of the latest diagnostic criteria for ASD (American Psychiatric Association 2013) emphasising that children with ASD do not typically partake in make-believe or pretend play.

The concepts 'Toy' and 'Equipment' were identified as 'difficult to translate'. Both toys and play equipment are cultural references and limited exposure by children from

disadvantaged communities may lead to poor comprehension of the word by parents. 'Playground equipment' in test Item 4 was adapted to a more contextually and culturally relevant concept, a tree, as children within resource-limited LMIC contexts may not be familiar with commercial playground equipment. Children from LMICs are often adversely affected by poverty, inadequate learning opportunities, and lack access to equipment (Samuels et al. 2012: 334).

A contextually and culturally adapted English version of the M-CHAT-R/F™ may be useful in South Africa as a preference for English was observed in a recent study conducted (Van der Merwe et al. 2017: 5). A translation study conducted in South Africa found that younger isiZulu speaking parents preferred to answer the Parents' Evaluation of Developmental Status (PEDS) tool (Glascoe, 2013) in English rather than their first language, whereas the older parents preferred the isiZulu translation (Van der Merwe et al. 2017: 5). By adapting the source translation to Northern Sotho cultural references, the comprehensibility of the English version of the test was therefore enhanced for South African communities. If adaptations were not included before translation, the translation would have contained less common vocabulary which could have had a negative impact on the comprehension of specific items. Cultural adaptations to the source translation have enhanced the comprehensibility of the English version of the test not only for Northern Sotho speakers but also for other groups in Southern Africa.

The detailed codes reflected both positive and negative aspects with the review of the adaptations made in the target and back translation during the panel discussion. The review highlighted that after the initial cultural adaptation, only three constructs still required adaptation. Ortiz-Gutiérrez and Cruz-Avelar (2018: 204) found that performing adaptations prior to the translation of the test enforces cultural nuance before the actual translation, this is evident as limited cultural adaptations had to be made post-translation.

Following on the discussion of the adaptation the most prominent positive code was that content equivalence was achieved between the target translation, back translation, and the source translation. This is an indication that all the translations were indeed scrutinized to determine whether the content of the source language and the reconciliatory Northern Sotho

translation were linguistically and conceptually equivalent. The high score for linguistic and concept equivalence thus implies that the target translation was a successful translation. In comparison, fewer comments were made regarding poor linguistic equivalence between the source and target translations. The most important reason for non-equivalence was related to technical language used in the source translation.

Technical terminology used in the source translation resulted in the identification of a significant number of detailed codes addressed during the discussion under the theme *Additional remarks*. This theme provides evidence that additional aspects emerged that were unrelated to the initial four themes. These detailed codes highlighted the difficulty of translating technical or scientific terms into another language that does not have a single synonymous word in the target language. According to Gouws and Prinsloo (2005: 158) linguistic gaps (or, in this particular translation process, a terminological gap) occur when the speakers of both the source and target languages are familiar with a particular concept, but the target language lacks a term to designate the concept. In the current study linguistic gaps were filled by using different term formation strategies, e.g., direct borrowing, transliteration or loan translation, paraphrasing, semantic specialisation and compounding (Gauton et al. 2008: 163). These strategies did not change the construct equivalence but affected the length of the test items and instructions as more words were required to paraphrase the sentence. Paraphrasing was the strategy used most often during the current translation.

According to Gauton et al. (2008) a translator is almost invariably confronted with cases of zero-equivalence in any translation. Challenges related to zero-equivalence are particularly prevalent when (a) the target language is an African language (Gauton et al. 2008: 148), and (b) the source language veers towards the technical side, as is the case with the M-CHAT-R/F text. Translation of technical texts requires the availability of term equivalents in the target language for terms used in the source text. Apart from the fact that terminological equivalents are not always readily available to African language translators, an additional challenge is the non-standardized nature of African language terminology (Taljard, 2008). Due to a lack of coordinated terminological planning evident in African languages, the translator is often confronted with multiple terms for a single concept, with no recourse to any authoritative

source providing a standardized term to be used in a translation for a specific concept (Taljard 2008).

Detailed codes relating to the theme *Grammar and phrasing*, more specifically to the back translation, occurred frequently during the panel discussion. The purpose of the back translation was to determine the accuracy of the target translation but lead to a comprehensive discussion due to questions regarding the linguistic equivalence between the target and back translation. Grammatical errors were identified in the back translation. The differences observed in back translation typically demonstrates language interference. Language interference occurs when the surface structure of a speaker's first language is embedded in the second language (Aixela 2009: 75). The absence of the definite and indefinite articles 'a', 'an' and 'the' in Northern Sotho further complicated the back translation from Northern Sotho to English. A second instance of language interference was the non-distinction between masculine and feminine pronouns – in Northern Sotho no formal (morphological) distinction exists between 'he / him' and 'she / her', thus leading to grammatical errors in the back translation. This explains the inconsistency between the target translation and back translation, indicating that the construct was still the same but the literal linguistic equivalence varied. Another aspect that had to be considered was the lack of prepositions, e.g., 'to', 'from', 'at' in Northern Sotho. The notion of prepositionality is mostly embedded in the verb stem itself or derived by means of pre-or suffixes. This complicated the back translation to English, where prepositions and referents were required as separate words. The lack of linguistic equivalence between the target translation and back translation can thus be explained by differences in surface structure and use of paraphrasing to avoid a literal translation from the source translation to target translation. When moving past the linguistic incompatibilities, construct equivalence was still evident between the target and back translation and aligned with the aim of the double translation process of the study.

It is recommended that the current Northern Sotho version of the M-CHAT-R/F^{TM} should be evaluated to determine the feasibility, as well as the reliability and validity of the instrument. Investigating the language preference of South African M-CHAT-R/F^{TM} users may also indicate whether adaptation and translation of this instrument into other African languages should be considered as it may promote knowledge of ASD in SSA.

Limitations of the study:

A possible limitation of the study was not including a community member as a stakeholder in the panel discussion, as the panel only included specialists and relied on the Northern Sotho specialists' cultural knowledge for the adaptation, as the Northern Sotho specialists are also considered community members.

3.6 Conclusion

The Northern Sotho translation of the M-CHAT-R/F^{TM} is not a literal translation but a carefully constructed and culturally relevant translation of the source language which included the paraphrasing of technical terms to promote linguistic equivalence. While the double translation process highlighted some instances of differences between the target translation and back translation, it also contributed to an adapted and translated test that is equivalent and not only a literal translation of the source text. Including various specialists from different fields in the panel discussion and self-completed questionnaire allowed for a multidimensional, transdisciplinary review and interpretation of the target translation. The holistic review resulted in triangulated results supporting the translation of a culturally relevant screening test. The preliminary English adaptation, as well as the Northern Sotho translation of the M-CHAT-R/F^{TM}, can now be confirmed by gathering empirical evidence of reliability and validity.

3.7 References

Abubakar, A., Holding, P., Van Baar, A., Newtown, C. R. J. C., & Van de Vijver., F. J. R. 2008, "Monitoring Psychomotor Development in a Resource-Limited Setting: An evaluation of the Kilifi Developmental Inventory." *An of Trop Paediatric* 28:217-226.

Aixela, F. J. 2009, 'An Overview of Interference in Scientific and Technical Translation.' *The Journal of Specialised Translation*, 11, .75-87. ISBN 978-84- 249-3626-6

American Psychiatric Association. 2013. *Diagnostic and Statistical Manual of Mental Disorders (DSM-5*), American Psychological Publishing, Arlington, TX.

Beacham, C., Reid, M., Bradshaw, J., Lambha, M., Evans, L., Gillespie, S., Klaiman, C., & Richardson, S., 2018, 'Screening for Autism Spectrum Disorder: Profiles of Children Who are Missed.', *Journal of Developmental and Behavioral Pediatrics* 39 (9),673-82. https://doi 10.1097/DBP.0000000000000607.

Centers for Disease Control and Prevention, 2012, 'Prevalence of Autism Spectrum Disorder – Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008.', *Morbidity and Mortality Weekly Report* 61 (3), 1-19. https://doi.org/ss6103a1 [pii].

Centers for Disease Control and Prevention, 2014, 'Prevalence of Autism Spectrum Disorder among Children Aged 8 Years.', *Morbidity and Mortality Weekly Report Surveillance Summaries (Washington, D. C.:2002)* 63 (2), 1-21. http://www.ncbi.nlm.nih.gov/pubmed/24670961.

Fisher, V. J., Morris, J., & Martines, J., 2014, 'Developmental Screening Tools: Feasibility of Use at Primary Healthcare Level in Low- and Middle-Income Settings', *Journal of Health Population Nutrition* 32(2), 314-326. ISSN 1606-0997.

Franz, L., Chambers, N., Von Isenburg, M., & De Vries, P. J., 2017, 'Autism Spectrum Disorder in Sub-Saharan Africa: A Comprehensive Scoping Review.', *Autism Research* 10 (5),723-749 . https://doi.org/10.1002/aur.1766.

Fyvie, L., Anderson, J., Kruger, C. J., Le Roux, M., & Van der Linde, J., 2016, 'The Outcome of a Developmental Screening Tool (PEDS) in English and Northern Sotho: A Comparative Study.', *Language Matters* 47 (3),415-26. https://doi.org/10.1080/10228195.2016.1196718.

Gauton, R., Taljard, E., Mabasa, T., & Netshitomboni, L., 2008, 'Translating Technical (LSP) Texts into the Official South African Languages: A Corpus-based Investigation of Translators' strategies.', *Language Matters* 39(2), 148-180.

Gouws, R. H., & Prinsloo, D. J., 2005, *Principles and Practice of South African Lexicography*. Stellenbosch: African Sun Media.

Guthrie, W., Wallis, K., Bennett, A., Brooks, E., Dudley, J., Gerdes, M., Pandey, J., Levy, S., Schultz, R.T., & Miller, J. S., 2019, 'Accuracy of Autism Screening in a Large Pediatric Network.', *Pediatrics* 44(4), e20183963. https://doi.org/10.1542/peds.2018-3963.

Hambleton, R. K. & Zenisky, A. L., 2011, 'Translating and Adapting Tests for Cross-Cultural Assessment.' In *Cross-Cultural Research Methods in Psychology* edited by Mutsamoto, D., & Van de Vijver, F. J. R. (ed.), 46-74. New York, United States of America: Cambridge University Press.

Hyman, S. L, Levy, S. E., Myers, S. M., & AAP Council on Children with Disabilities, Section on Developmental, and Behavioural Pediatrics, 2020, 'Identification, Evaluation, and Management of Children with Autism Spectrum Disorder.', *Pediatrics* 124(1),e20193447. https://doi.org/10.1542/peds.2019-3447.

International Test Commission, 2017, *ITC Guidelines for Translation and Adapting Tests: Second Edition*. Accessed October 12, 2019. https://www.intestcom.org/files/guideline_test_adaptation_2ed.pdf

Kautzky, K., & Tollman, S. M., 2008, 'A Perspective on Primary Health Care in South Africa.', *South African Health Review* 17-30.

Leedy, P. D., & Ormrod, J. E., 2015, *Practical Research: Planning and Design*. England: Pearson.

Madipakkam, A. P., Rothkirch, M., Dziobek, I., & Sterzer, P., 2017, 'Unconscious Avoidance of Eye Contact in Autism Spectrum Disorder.', *Scientific Reports* 7 (13378), 1-6. https://doi.org/10.1038/s41598-017-13945-5.

Marlow, M., Servili, C., & Tomlinson, M., 2019, 'A Review of Screening Tools for the Identification of Autism Spectrum Disorder and Developmental Delay in Infants and Young Children: Recommendations for Use in Low- and Middle-Income Countries.', *Autism Research* 12, 176-199. https://doi.org/10.1002/aur.2033.

Morelli, D. L., Pati, S., Butler, A., Blum, N. J., Gerdes, M., Pinto-Martin, J., &. Guevara, J.

P, 2014, ‘Challenges to Implementation of Developmental Screening in Urban Primary Care: A Mixed Methods Study.’, *Pediatrics* 14(16), 1-11.http:/www.biomedcentral.com/1471-2431/14/16.

Mncwango, E. M., 2009, ‘Language and the Current Challenges in the South African Schools System.’, *Inkanyiso: Journal of Humanities and Social Sciences* 1(1), 51- 54. https://journals.co.za/docserver/fulltext/uz_inka/1/1/uz_inka_v1_n1_a9.pdf.

Ortiz-Gutiérrez, S., & Cruz-Avelar, A., 2018, ‘Translation and Cross-Cultural Adaptation of Health Assessment Tools.’, *Actas Dermosifiliograficas* 109(3), 202-206. https://doi: 10.1016/j.ad.2017.09.012.

Rahman, A. Z., Waheed, I. W., & Hussain, N., 2003, ‘Translation and Cultural Adaptation of Health Questionnaires.’, *The Journal of the Pakistan Medical Association* 53(4), 1-8.

Robins, D. L. ‘M-CHAT™ Autism Screening.’ Accessed March 13, 2020. https://mchatscreen.com/

Robins, D. L., Casagrande, K., Barton, M, Chen, C. A., Mumont-Mathieu, T., & Fein D., 2014, ‘Validation of the Modified Checklist for Autism in Toddlers, Revised with Follow-Up.’, *Pediatrics* 133(1), 37-45.

Robins, D. L., Fein, D., & Barton, M., 2018, ‘Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F).’ Self-published.

Saldaña, J., 2016, *The Coding Manual for Qualitative Researchers*. 3rd edn. Sage Publishing. ISBN 978-1-4739-0248-0.

Samuels, A., Slemming, W., & Balton, S., 2012, ‘Early Childhood Intervention in South Africa in Relation to the Developmental Systems Model.’, *Infants and Young Children* 25 (4), 334-345. https://doi: 10.1097/IYC.0b013e3182673e12.

Schurink, W., Fouché, C. B., & De Vos, A. S., 2015, ‘Qualitative data analysis and interpretation.’ *In Research at Grass Roots* edited by A. S. De Vos, H. Strydom, C. B. Fouché, and C. S. L. Delport (ed.), 397-423. Cape Town, South Africa: Van Schaik Publishers.

Soto, S., Jacobstein, K. L. D., Biel, M., Migdal, T., & Anthony, B. J., 2015, ‘A Review of Cultural Adaptations of Screening Tools for Autism Spectrum Disorders.’, *Autism* 19 (6), 646-61. https://doi.org/10.1177/1362361314541012.

StatsSA, 2019, *City of Tshwane: People*. Retrieved July 11, 2019, from http://www.statssa.gov.za/?page_id=993&id=city-of-tshwane-municipality

Stewart, L. A., & Lee, C. I., 2017, 'Screening for Autism Spectrum Disorder in Low- and Middle-Income Countries: A Systematic Review.', *Autism* 21 (5), 572-39. https://doi.org/10.1177/1362361316677025.

Sutton, J., & Austin, Z., 2015, 'Qualitative Research: Data Collection, Analysis, and Management.', *Canadian Journal of Hospital Pharmacy* 68 (3), 226 - 231.https://doi.org/10.4212/cjhp.v68i3.1456.

Taljard, E., 2008, 'Terminology Practice in a Non-standardised Environment: A Case Study.' Paper presented at EURALEX International Congress, Barcelona, Spain, July 15-19.

Van der Merwe, M., Cilliers, M., Maré, C., Van der Linde, J., & Le Roux, M., 2017, 'Evaluation of a Zulu Translation of the Parents' Evaluation of Developmental Status.', *African Journal of Primary Health Care and Family Medicine* 9 (1), 1-6. https://doi.org/10.4102/phcfm.v9i1.1365

World Health Organization, 2005, 'Disability, Including Prevention, Management and Rehabilitation. Agenda Item 13.13. In: Fifty-eight World Health Assembly.', Geneva: World Health Organization, 97-100

World Health Organization, 2013a, 'Process of Translation and Adaptation of Instruments.', Accessed June 15, 2019. https://www.who.int/substance_abuse/research_tools/translation/en/

World Health Organization, 2013b, 'Autism Spectrum Disorders & Other Developmental Disorders. From Raising Awareness to Building Capacity.' Geneva. Retrieved 15 August 2019 from http://apps.who.int/iris/bitstream/10665/103312/1/9789241506618_eng.pdf

Zwaigenbaum, L., Bauman, M. L., Stone, W. L., Yirmiya, N., Estes, A., Hansen, R. L., McPartland, J. C., et al., 2015, 'Early Identification of Autism Spectrum Disorder: Recommendations for Practice and Research.', *Pediatrics* 136, S-S40. https://doi:10.1542/peds.2014-3667

CHAPTER 4: PRELIMINARY RELIABILITY OF SOUTH AFRICAN ADAPTATION AND NORTHERN SOTHO TRANSLATION OF THE MODIFIED CHECKLIST FOR AUTISM IN TODDLERS, REVISED WITH FOLLOW-UP

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Journal: South African Journal of Communication Disorders (SAJCD)

Stylistic and language variations required by the specific journal guidelines were implemented and specified where applicable.

Cite score, based on SCOPUS, Elsevier: 1.2

Date accepted: 02 June 2021

Proof of publication: Appendix R

Published: 22 July 2021

DOI: https://doi.org/10.4102/ sajcd.v68i1.831

Note: This article was written according to the specific journal's author guidelines and specifications. The style may differ from the rest of the thesis.

4.1 Abstract

Background: There is a shortage of validated autism screening tests in the 11 official languages of South Africa. The Modified Checklist for Autism in Toddlers, Revised with Follow-up (M-CHAT-R/FTM), a validated and well-known screening test, had already been adapted (in English) and translated into Northern Sotho for use in South Africa.

Objectives: The aim was to collect pilot data to determine the preliminary reliability and feasibility of the two tests to confirm the equivalence of the adaptation and translation.

Method: The study was conducted in a peri-urban community in South Africa. Twenty-one first-language Northern Sotho caregivers of children aged between 18 and 48 months were recruited by employing snowball sampling. The participants were asked to complete the Northern Sotho and the culturally adapted English M-CHAT-R/F, which were presented in random order.

Results: The preliminary content validity and equivalence were evident, with no difference at the 5% interval of the Wilcoxon signed rank test. All 21 toddlers screened presented with a low risk for autism following the recommended execution of the Follow-up section for the toddlers in the medium risk category. All participants completed the two screening tests, with none indicating unfamiliar words or constructs. A higher preference for the English adapted version was found but a need for the Northern Sotho screening test was also evident

Conclusion: The Northern Sotho translation of the M-CHAT-R/F, as well as the adapted English version, appears feasible and is ready for comprehensive validation.

Keywords: autism screening; M-CHAT-R/F-Northern Sotho translation; preliminary reliability; low and middle-income country; South African adapted English M-CHAT-R/F.

4.2 Introduction

The lack of culturally appropriate screening instruments for autism has become a universal concern (Hyman et al., 2020; Malcolm-Smith et al., 2013). Most autism screening tools are available in English only, as they derive from English-speaking countries (Soto et al., 2015). Cultural and linguistic differences in the understanding of test items and concepts are some of the factors that may lead to disparities in screening outcome (Barton et al., 2012; Soto et al., 2015). In an attempt to address the shortage of validated cultural and linguistic appropriate screening tools, and amidst a worldwide steady increase in the prevalence of autism (Maenner et al., 2020), the authors had previously adapted and translated one of the most commonly used autism screening tests for use in South Africa (Vorster et al., In Press).

Limited research has been performed to develop and validate screening instruments on the African continent (De Vries, 2016; Franz et al., 2017). In a multi-cultural and multilingual country such as South Africa, local translation and validation of autism screening tools are important (Franz et al., 2018). Early detection of developmental conditions is a high priority and advocated by the World Health Organisation (WHO), as identification at a young age may decrease the impact of impairments as it promotes early management (WHO, 2013b).

The original English Modified Checklist for Autism in Toddlers, Revised with Follow-up [M-CHAT/RF^{TM}] (Robins et al., 2014) was adapted and translated into Northern Sotho. The International Test Commission (International Test Commission [ITC], 2017) and (WHO, 2013a) guidelines were used. A rigorous translation and adaptation methodology, which involves cultural adaptation, forward and back translation, has become well established in recent years (ITC, 2017). A multidisciplinary specialist panel reviewed the test after a double translation procedure. The comprehensive process resulted in two versions of the original test, a South African culturally adapted English version as well as a culturally appropriate Northern Sotho translation of the M-CHAT-R/F (Vorster et al., In Press). Test translation without cultural adaptation may ignore item bias and may therefore contribute to invalid screening outcomes (ITC, 2017).

The value of a screening test in an indigenous African language and an adapted English version was shown by Van der Merwe et al. (2017). The study investigated the language preference of isiZulu-speaking parents of two versions of a developmental screening tool, the Parents' Evaluation of Developmental Status [PEDS] (Glascoe, 2013) in a peri-urban community. The results showed that 54% of the isiZulu speaking participants preferred the English version of the PEDS, whereas 46% preferred the isiZulu translation. This finding demonstrates that both the English as well as the indigenous language versions are accepted and desired in South Africa, as English is considered an urban language (Posel & Zeller, 2016).

Apart from variation in the language preference of caregivers who complete a screen, it is also important to consider cultural variability in the perception of child behaviour. Differences in the perception of behaviour may influence screening outcomes (Barton et al., 2012; Soto et al., 2015). Since most parent-completed questionnaires are based on observed child behaviour, a

clear rationale is evident for the cultural adaptation of instruments. To promote fairness in testing, screening tools need to be developed for populations who are not first-language English speakers (Hyman et al., 2020). The M-CHAT™ has already gone through a rigorous revision process to simplify the language for greater comprehensibility, making it an ideal screening test to translate (Robins et al., 2014).

Numerous translations and/ or adaptations of the M-CHAT™ and M-CHAT-R/F™ resulted in 67 different versions of the instrument (Robins et al., 2018a). An example of such an adaptation and translation was carried out by Brennan et al. (2016). The authors developed an Albanian version of the M-CHAT-R/F (M-CHAT-R-A) by translating the instrument and removing three test items. The omission of items improved the positive predictive value, supporting the need for test adaptation for a specific setting. A systematic review of cultural adaptation and translation of autism-specific screening instruments found that rigorous adaptation and translation often result in more modifications such as adding cultural appropriate information and/or behavioural examples, employing alternative words and constructs (Soto et al., 2015).

With the current adaptation of the screen for South African users, unfamiliar cultural constructs were identified in word use, interpretation, and descriptions of child behaviour. Four changes were made to the M-CHAT-R/F™. The first involved a child's eye contact when communicating with a caregiver. Making direct eye contact with superiors is inappropriate in various Southern African cultures (Mncwango, 2009). The item was thus adapted to "Does your child look in *your direction* or in the eye when you are talking to them?". "Make-believe", "soft toys", and "playground equipment" were also identified as unfamiliar constructs in Northern Sotho culture and were adapted to "acting", "toys", and "trees" respectively. These items respectively read: "If you point at something across the room, does your child look at it? (For example, if you point at a *toy* or an animal, does your child look at *the toy* or animal?)"; "Does your child *act*?" and "Does your child like climbing on things? (For example, furniture, *trees*, or stairs)". The greatest challenge with the translation of the M-CHAT-R/F™ was ensuring accurate and equivalent translation of the technical content of the test administration instructions.

The two versions of the M-CHAT-R/F were available to be tested by the intended users, i.e. Northern Sotho speaking caregivers in South Africa. The study aim was to collect pilot data that allowed item analysis, assessment of the preliminary reliability, and degree of agreement between the two test versions. A second aim was to describe the referral rate of the adapted and translated versions. Lastly, caregivers' preference of the two versions of the test was investigated. If any discrepancies between the tests or difficulties were shown by the results, adjustments could have been made before further validation with a large sample. A descriptive comparative design was employed to achieve the study aims.

4.3 Method

Participants

A total of 21 participants, living in a peri-urban community in Gauteng, South Africa, were selected with snowball recruiting. The first point of contact was two active community

residents known to the researcher. These residents identified families with toddlers aged between 18- and 48-months, with no diagnosed conditions, at a community church and a day care centre. Participants were first-language Northern Sotho speaking mothers and grandmothers of 18- to 48-month old toddlers. The M-CHAT-R/F was initially developed for toddlers between the ages of 18-30 months. Yama et al (2012) however, found that the M-CHAT-R/F™ is relevant for children up until 48 months of age. Similar to the requirements to complete the original M-CHAT-R/F™ participants had to have passed Grade 4, and being able to read Northern Sotho or Sepedi[2] and English. Participants were excluded from the study if their toddler had been diagnosed with conditions such as a sensory deficit such as hearing loss, a genetic syndrome or cerebral palsy. Using the Road to Health Booklet developmental screen and parental report, the aim was to exclude toddlers with developmental conditions while including typically developing children in the reference population.

Table 4.1: Participant characteristics (n=21)

Participant characteristics		**n (%);**	**Mean (SD)**	**Mode**
Additional language	English Xitsonga Setswana isiZulu	n=21 (100.00%) n=4 (19.05%) n=2 (9.52%), n=1 (4.76%)		English (n=21), 100%
Gender of child	Female Male	n=18 (85,7); n=3 (14,29)		Female (n=18); 58,7%
Age of child	18 – 23 months 24 – 35 months 36 – 48 months	n=5 (23,80%) n=8 (28,10%) n=8 (38.10%)	29 months; (9 months)	18-months (n=4); 19.05% 24-months (n=4); 19.05% 36-months (n=4); 19.05%
Age of participants	18 years 19 – 22 years 23 – 26 years 27 - 30 years 31 – 34 years 35 – 40 years 46 – 50 years	n=2 (9.52%) n=0 (0.00%) n=3 (14.29%) n=4 (19.05%) n=7 (33.33%) n=4 (19.05%) n=1 (4.76%)	30 years and 8 months	Age category 31 ≤ 34 (n=7); 33.33%
Participant education	Grade 9 Grade 12 Degree Not specified	n=4 (19,05%) n=14 (66.67%); n=2 (9.52%) n=1 (4.76%)	Grade 12 (National Senior Certificate)	Grade 12 (National Senior Certificate) (n=14); 66.67%
Social support grant for child	Yes No	n=16 (76,19%) n=5 (23.81%)		Yes, receives a grant (n=16); 76.19%

[2] Northern Sotho is also referred to as Sepedi or Sesotho sa Leboa. The correct designation for this language is an ongoing debate of which the authors are aware.

The culturally adapted English M-CHAT-R/F, as well as the Northern Sotho, translated M-CHAT-R/F were used as screening instruments. A socio-demographic questionnaire was included to allow for comprehensive sample description. Following the completion of the 20 questions of each version of the M-CHAT-R/F participants were requested to complete the caregiver feedback form which included three questions about the test: 1) "Do you prefer to answer the test in English or Northern Sotho/Sepedi?"; 2) "Were there any words that you do not know? If yes, please list the words"; 3) "Were there any items in the M-CHAT-R/F that you did not really understand?" "If yes, please mark the items".

Following institutional ethical clearance, participants were required to provide written informed consent. The two versions of the M-CHAT-R/F were presented in a random order to participants. Eleven participants completed the Northern Sotho translation first and the remaining 10 completed the English adaptation first. The random presentation controlled for a learning effect to ensure reliability of data. When a toddler was identified as being at medium-risk for autism, the Follow-up section of the instrument was conducted telephonically afterwards as per M-CHAT-R/F™ instructions. No high-risk cases were identified.

Data analysis

Both screening instruments were scored according to the existing test instructions, to determine the child's risk for autism. Questions 2, 5 and 12 requires "No" or "Aowa" as the negative screen. For the remaining items "Yes" or "Ee" was deemed an accurate answer for a negative screen. For each answer deviating from the prescribed norm, a score count of one was allocated. Following the allocation of zero or one, the sum of the score was determined, whereafter the risk category was identified. Three risk categories for autism are indicated in the test. Low-risk occurs when a score between zero and two is obtained, medium-risk is a score between three and seven and a high-risk score is more than eight. If a toddler obtains a medium-risk score the Follow-up section of the M-CHAT-R/F should be completed following the initial completion of the screen. If a high-risk score is identified a child should be referred to a medical professional immediately.

The two sets of completed test items were compared to determine inconsistencies in the participants' answers. Descriptive statistics were used to describe the population and the percentage agreement between the two versions. The non-parametric test was employed to determine if there were any significant differences between the two caregiver-completed test versions. Non-parametric statistical analysis was used due to the small sample size employed in the pilot study. Wilcoxon Signed Ranked Test was used to determine agreement between test items of the two versions, supporting the preliminary reliability. The risk profiles were analysed to describe the referral rate of the two versions. Data were further interpreted to determine which items were not completed, not understood, or required clarification.

4.4 Results

The 21 data sets represented 420 pairs of completed test items. Two participants showed a single response difference, answering "Yes" to a specific question in the one screening test and "No" in the other. A third participant had two items with a difference in answers. This

difference resulted in 416 pairs (99%) yielding an equivalent answer and four pairs (1%) presenting differing answers. The differences are evident in Table 4.2 and Figure 4.1. In Figure 4.2 this difference is evident with 18 data sets having no difference and three data sets presenting with "a negative difference".

Table 4.2: Response frequency for Northern Sotho and adapted English M-CHAT-R/F

Question	Yes (Northern Sotho)	Yes (Adapted English)	No (Northern Sotho)	No (Adapted English)	% Agreement
1	21	21	0	0	100
2	0	0	21	21	100
3	**20**	**21**	**1**	**0**	**95**
4	19	19	2	2	100
5	7	7	14	14	100
6	20	20	1	1	100
7	20	20	1	1	100
8	21	21	0	0	100
9	21	21	0	0	100
10	21	21	0	0	100
11	**19**	**21**	**2**	**0**	**90**
12	1	1	20	20	100
13	**18**	**19**	**3**	**2**	**95**
14	21	21	0	0	100
15	21	21	0	0	100
16	21	21	0	0	100
17	20	20	1	1	100
18	20	20	1	1	100
19	20	20	1	1	100
20	21	21	0	0	100

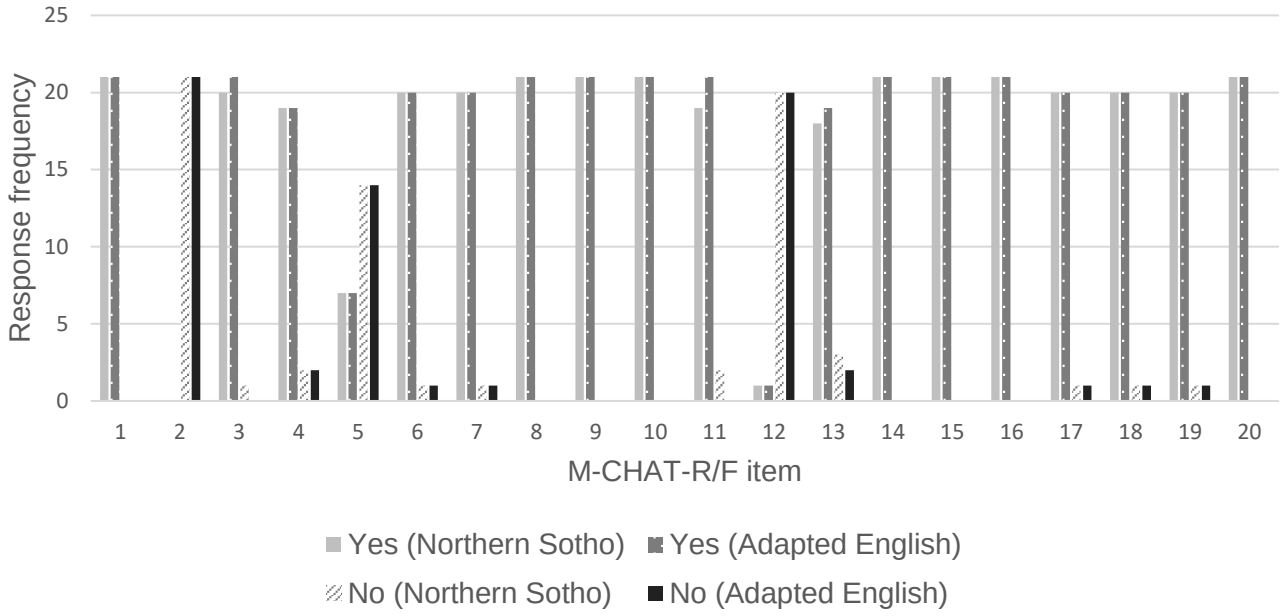

Figure 4.1: Comparison between Northern Sotho versus adapted English M-CHAT-R/F

*The single differences identified are evident at items 3, 11, and 13.

The Wilcoxon Signed Rank Test was used to determine item correlation between the two versions. Despite only three item differences in participant answers between the English and Northern Sotho versions, the Wilcoxon Signed Rank Test identified no

difference between the two versions of the M-CHAT-R/F scores at a 5% level, with a score of 0,102. This provides preliminary evidence of near-perfect agreement and reliability of the two versions. Figure 2 indicates the agreement between the two versions and depicts three differences between the English/Northern Sotho versions.

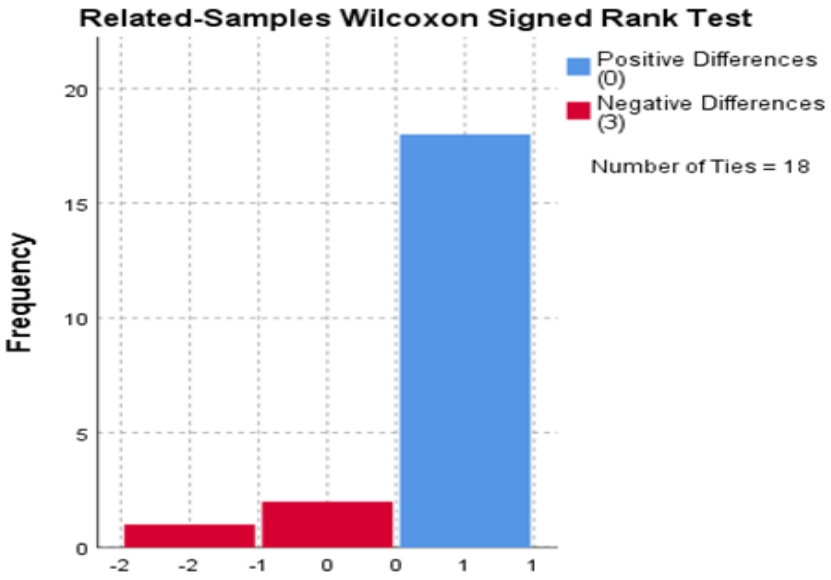

Figure 4.2: Wilcoxon Signed Rank Test results with item correlation between adapted English version and Northern Sotho version of the M-CHAT-R/F

* Note: Positive difference = No difference between the languages

Negative difference = Difference between Northern Sotho and English response

The two items showing a once-off difference in two different data sets were Items 3 and 13. Two of the three identified participants additionally presented with a difference when answering Item 11. In all instances, participants gave a "Yes" answer in English and a "No" answer in Northern Sotho. In two of the three cases, the English version was completed first. For instance, a participant indicated "Yes" that the toddler smiles back when the caregiver smiles at her, but in the Northern Sotho version she stated "No" it does not happen. Another example shows "Yes", the child can walk and in the Northern Sotho version "No" the child does not walk. In the case history completed by the participants, no delayed milestones were identified. None of the participants indicated that they had any difficulty understanding words or concepts with no underlying pattern in the errors evident.

Similar risk profiles of the toddlers were found in the two versions of the test. The mean risk-score of the adapted version was 0.810, (σ=0,814) [total raw score of 0-2 indicates low-risk for autism]. No Follow-up questions were therefore necessary. The mean risk-score for the Northern Sotho version, before completing the Follow-up questions, was 1.0 (σ=1), also low-risk. As evident in Figure 2, the Northern Sotho Follow-up questions were required for two participants whose children scored in the medium-risk category (total raw score between 3 and 7), while no participants required Follow-up from the adapted version. The Follow-up questions were Items 5, 11 and 13 in both sets respectively. After completion of the Follow-up questions the two toddlers showed low-risk profiles.

Although no risk for autism, the children showed some developmental risks such as pre-term birth with a gestational age lower than 36 weeks, low birth weight, and APGAR scores below five.

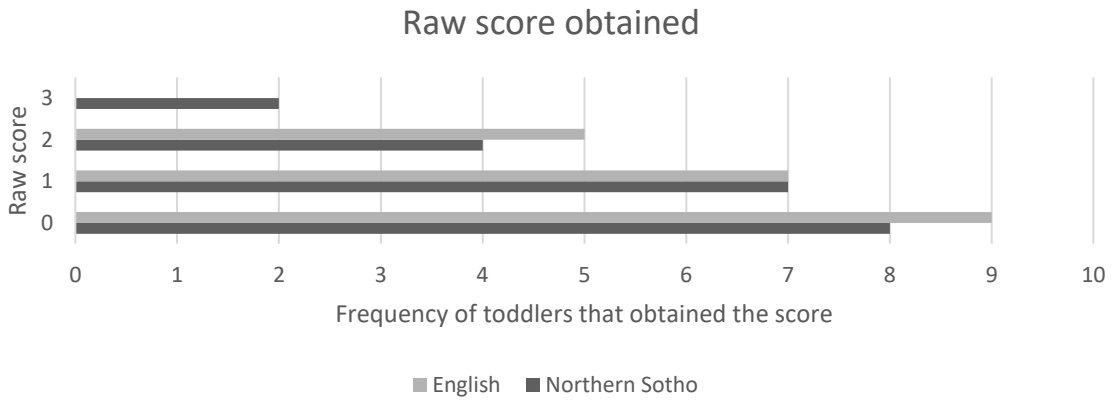

Figure 4.3: Risk profile according to the raw score for each version of the M-CHAT-R/F

Of the 21 participants, only eight (38%) of the participants indicated that they prefer the Northern Sotho version and 13 (62%) participants stated that they would rather complete the English adapted version of the screening test. The small sample size did not allow for statistical analysis to determine if a correlation exists between the participants' language preference, age, and level of education

4.5 Discussion

Key findings

The two South African versions of the M-CHAT-R/F were previously developed by our team (Vorster et al., In Press) and were now piloted with a small sample of Northern Sotho speaking caregivers. The study aimed to determine the agreement, equivalence, and preliminary reliability of the two South African versions of the screening test. Additionally, participants' understanding of the language and constructs used in the tests, and their test version preference were investigated.

Equivalence between the two test versions, with no difference at the 5% level regarding item correlation, is evident. Linguistic, construct and technical equivalence were shown by comparing the answers to both versions as recommended by DuBay et al. (2021). The absence of variation between the response to the two versions is an indication that the versions yielded the same answers, confirming the preliminary test re-test reliability of the tests. Both the initial 20 questions, as well as specific Follow-up questions were used in this study. This resulted in comprehensive use of the two test versions. No additional changes are necessary before a large-scale validation study can commence.

The referral rate of the Northern Sotho version, with two children initially showing a medium risk for autism, but low risk after the Follow-up questions was similar to that of the initial validation study of the M-CHAT-R/F™ conducted by Robins et al. (2014). Despite a smaller sample size (n=21) the construct validity of the translated Northern Sotho version appears to be similar to the M-CHAT-R/F™ when comparing the Follow-up rate. In the current study a total of 90,4% of the screenings indicated that the toddlers were low risk for autism (screening negative) and (n=2) 9,6% of the toddlers identified required the Follow-up questions. The two toddlers were respectively 25- and 36-months of age. The large validation study (n=16 071) identified 92,5% toddlers as screening negative (low-risk) for autism and 7,5% screening positive for a Follow-up session (Robins et al., 2014). The function of the Follow-up questions is to provide caregivers with an opportunity for clarification since different examples of behaviour are included to prevent false-positive results. With the completion of the Follow-up questions, none of the pilot study participants' toddlers was found to be at risk for autism showing that an additional opportunity to clarify their answers was necessary.

The high number of low-risk cases found in the pilot study is to be expected with a sample size of only 21 despite the global increase in the prevalence of autism. Consistent with the use of snowball sampling there may have been selection bias, thereby including more toddlers who were typically developing than could be expected from a random population sample. As the aim of the study was to test the preliminary reliability of the two versions of the screen based on parental understanding of the test items, sample bias may not have affected the results. According to Hyman et al. (2020), an increased rate of one in every 59 children is currently diagnosed with autism in the United States. No prevalence data is available for South Africa due to a lack of resources for epidemiological studies (De Vries, 2016).

Like the study conducted by Van der Merwe et al. (2017) the test language preference of the participants was leaning towards English. In a multicultural, multilingual country such as South Africa, language proficiency and preference are commonly investigated topics. Posel and Zeller (2016) investigated the change in language use in South Africa from 1996 until 2011 by using the national census results. The study found that English is considered a dominant language in the public office, business and education spheres, including literacy. The Language-in-Education Policy 3(4)(m), National Education Policy, 1996, encourages first language instruction for learners and recommends the acquisition of English as a second language. The research was conducted in a peri-urban area which is part of a large city where English is commonly used (Posel et al., 2020). The preference for English by participants supports the development of the culturally adapted English version of the M-CHAT-R/F.

The Northern Sotho version of the M-CHAT-R/F was accepted by all participants, even though it was preferred by the minority. Greater support for the use of the Northern Sotho M-CHAT-R/F may be expected in rural areas of South Africa where less prominent use of English is evident (Posel and Zeller, 2016). According to the census 61% of citizens that identified Northern Sotho as their home language did not have a second language in 2011, with only 19,8% of individuals identifying English as their second language (StatsSA, 2011). Most indigenous African language speakers still prefer to use their home language as it has a 'symbolic significance as a marker of their identity' (Posel and Zeller, 2016; Posel et al., 2020). The need for a Northern Sotho translation was confirmed as 38% of participants indicated that they would rather complete the screening test in Northern Sotho.

Strengths and limitations

The study results agree with the initial validation study of the M-CHAT-R/F™ (Robins et al., 2014). The sample size, in line with a pilot study, limited the statistical analyses but fulfilled the purpose of determining feasibility of the two versions of the screening test in the current study. Participants indicated a desire for both versions of the South African M-CHAT-R/F.

Implications or recommendations

The two South African versions of the M-CHAT-R/F are ready for validation which will support early identification of toddlers at-risk for autism in the multicultural and multilingual LMIC context. Early identification may contribute to earlier diagnosis and intervention. A large-scale validation study is thus recommended before the publication of the instruments.

4.6 Conclusion

The adapted English and Northern Sotho M-CHAT-R/F were shown to be equivalent versions of the M-CHAT-R/F™ in a small-scale pilot study. Preliminary reliability was established. A need for the validation of the Northern Sotho version as well as the adapted English version was identified.

**Please contact the first author for access to the two preliminary versions of the M-CHAT-R/F. We would gladly make the two preliminary versions of the M-CHAT-R/F available to readers, but the tests are undergoing further validation and changes may be indicated. As soon as the final versions of the tests become available, the link will be made available to the editor

of the SAJCD. It is anticipated that the two versions will eventually be available on the official M-CHAT website.

4.7 References

Barton, M. L., Dumont-Mathieu, T., & Fein, D. (2012). Screening young children for autism spectrum disorders in primary practice. *Journal of Autism and Developmental Disorders, 42*(6), 1165–1174. https://doi.org/10.1007/s10803-011-1343-5

Brennan, L., Fein, D., Como, A., Rathwell, I. C., & Chen, C. M. (2016). Use of the Modified Checklist for Autism, Revised with Follow Up-Albanian to screen for ASD in Albania. *Journal of Autism and Developmental Disorders*, *46*(11), 3392–3407. https://doi.org/10.1007/s10803-016-2875-5

Cnattingius, S., Norman, M., Granath, F., Petersson, G., Stepahnsson, O., & Frisell, T. (2017). APGAR score components at 5 minutes: Risks and prediction of neonatal mortality. *Paediatric and Perinatal Epidemiology*, *31*(4), 328-337. https://doi.org/10.1111/ppe.12360

De Vries, P. J. (2016). Thinking globally to meet local needs: Autism spectrum disorders in Africa and other low-resource environments. *Current Opinion in Neurology*, *29*(2), 130–136. https://doi.org/10.1097/WCO.0000000000000297

DuBay, M. (2020). *Translation and cultural adaptation of autism screening tools.* [University of North Carolina]. https://doi.org/10.17615/fcwc-c425

Franz, L., Adewumi, K., Chambers, N., Viljoen, M., Baumgartner, J. N., & De Vries, P. J. (2018). Providing early detection and early intervention for autism spectrum disorder in South Africa: Stakeholder perspectives from the Western Cape province. *Journal of Child and Adolescent Mental Health*, *30*(3), 149–165. https://doi.org/10.2989/17280583.2018.1525386

Franz, L., Chambers, N., Von Isenburg, M., & De Vries, P. J. (2017). Autism spectrum disorder in Sub-Saharan Africa: A comprehensive scoping review. *Autism Research*, *10*(5), 723–749. https://doi.org/10.1002/aur.1766

Glascoe, F. P. (2013). *Collaborating with parents: Using Parents' Evaluation of Developmental Status to detect and address developmental and behavioural problems.* (Second edn.). Nashville, TN. Retrieved from PEDStest.com

Hyman, S. L., Levy, S. E., Myers, S. M., & AAP Council on Children with Disability.

(2020). Identification, evaluation, and management of children with Autism Spectrum Disorder. *Pediatrics*, *145*(1), e201934447. https://doi.org/10.1542/peds.2019-3447

International Test Commission. (2017). *The ITC guidelines for translating and adapting tests (Second edn.)*. Retrieved from www.InTestCom.org

Maenner, M. J., Shaw, K. A., Baio, J., Washingtong, A., Patrick, M., DiRienzo, M., … Dietz, P. M. (2020). Erratum: Prevalence of autism spectrum disorder among children aged 8 years - Autism and developmental disabilities monitoring network, 11 Sites, United States, 2016. *Morbidity and Mortality Weekly Report*, *69*(16), 503-511. https://doi.org/10.15585/MMWR.MM6916A4

Malcolm-Smith, S., Hoogenhout, M., Ing, N., Thomas, K. G. F., & De Vries, P. (2013). Autism spectrum disorders - Global challenges and local opportunities. *Journal of Child and Adolescent Mental Health*, *25*(1), 1–5. https://doi.org/10.2989/17280583.2013.767804

Mncwango, E. M. (2009). Language and the current challenges in the South African school system. *Inkanyiso: Journal of Humanities and Social Sciences*, *1*(1), 51–54.

Posel, D., Hunter, M., & Rudwick, S. (2020). Revisiting the prevalence of English: language use outside the home in South Africa. *Journal of Multilingual and Multicultural Development*, 1–13. https://doi.org/10.1080/01434632.2020.1778707

Posel, D., & Zeller, J. (2016). Language shift or increased bilingualism in South Africa: evidence from census data. *Journal of Multilingual and Multicultural Development*, *37*(4), 357–370. https://doi.org/10.1080/01434632.2015.1072206

Robins, D. L., Casagrande, K., Barton, M., Chen, C.-M. A., Dumont-Mathieu, T., & Fein, D. (2014). Validation of the Modified Checklist for Autism in Toddlers, Revised With Follow-up (M-CHAT-R/F). *Pediatrics*, *133*(1), 37–45. https://doi.org:10.1542/peds.2013-1813

Robins, D. L., Fein, D., & Barton, M. (2018). Modified Checklist for Autism in Toddlers, Revised with Follow-Up. Retrieved January 12, 2019, from https://mchatscreen.com/

Soto, S., Linas, K., Jacobstein, D., Biel, M., Migdal, T., & Anthony, B. J. (2015). A review of cultural adaptations of screening tools for autism spectrum disorders. *Autism*, *19*(6), 646–661. https://doi.org/10.1177/1362361314541012

StatsSA. (2011). *Statistical Release: Census 2011*. *Statistics South Africa*.

https://doi.org/10.1016/s0022-5223(11)01322-5

Van der Merwe, M., Cilliers, M., Maré, C., Van der Linde, J., & Le Roux, M. (2017). Evaluation of a Zulu translation of the Parents' Evaluation of Developmental Status. *African Journal of Primary Health Care and Family Medicine*, *9*(1), 1–6. https://doi.org/10.4102/phcfm.v9i1.1365

Vorster, C., Kritzinger, A., Lekganyane, M., Taljard, E., & Van der Linde, J. (2021). Cultural adaptation and Northern Sotho translation of the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F). *In Press*.

World Health Organization. (2013a). Process of translation and adaptation of instruments. *Who*, 10–12. https://doi.org//entity/substance_abuse/research_tools/translation/en/index.html

World Health Organization. (2013b). *Autism spectrum disorders & other developmental disorders. From raising awareness to building capacity*. Geneva. Retrieved from https://www.who.int/mental_health/maternal-child/autism_report/en/

CHAPTER 5: RELIABILITY AND CONCURRENT VALIDITY OF A SOUTH AFRICAN CULTURAL ADAPTATION AND A NOTHERN SOTHO TRANSLATION OF THE M-CHAT-R/F

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Journal: Journal of Autism and Developmental Disorders (JADD)

Stylistic and language variations required by the specific journal guidelines were implemented and specified where applicable.

Impact factor: 4.291

Date submitted: 08/10/2021

Proof of submission: Appendix S

5.1 Abstract

Currently no culturally and linguistically adapted autism screening tools are available in South Africa.

The aim was to determine the reliability and concurrent validity of the adapted English and Northern Sotho translated M-CHAT-R/F by comparing the two checklists with one another and a standardized diagnostic tool.

Reliability was confirmed with near-perfect agreement ($p<0.001$) between the two checklists in a sample of 158 Northern Sotho/English bilingual mothers of children with a low-risk for autism. Concurrent validity between the Northern Sotho M-CHAT-R/F and the communication and socialization sub-domains of the Vineland-3 was established with the significant association at the 5% level. A third (33.5%) of the children showed a developmental delay.

The checklists are valid and reliable and may improve early identification and diagnosis which will render better long-term outcomes for children with autism in South Africa. Autism screening should be combined with developmental assessment.

Keywords

Autism screening, Northern Sotho M-CHAT-R/F translation; Culturally adapted English M-CHAT-R/F; South Africa; Concurrent Validity; Reliability

Acknowledgements

This project was funded by the Organization for Autism Research (G011/2021)

5.2 Introduction

Autism screening is limited in South Africa, resulting in delayed identification, diagnosis and intervention. Limited screening and therefore late identification of autism are caused by several constraints such as a paucity of resources, limited community awareness and knowledge of autism, a lack of culturally and linguistically appropriate instruments, and service delivery, as well as an overburdened health system (Amaral et al., 2019; Franz et al., 2017, 2018; Malcolm-Smith et al., 2013). The global increase in autism prevalence (Olusanya et al., 2018) emphasizes the need for screening with reliable culturally appropriate instruments. In a review of the past 30 years, Amaral et al. (2019) reported that Sub-Saharan Africa and South East-Asia have shown the largest increase in developmental disabilities, including autism. A factor contributing to the increase in autism across regions include heightened awareness among health professionals resulting in improved diagnosis of the condition (Amaral et al., 2019; Erasmus et al., 2019). While there is no formal autism screening and surveillance program in South Africa, it is clear that investment is required as detection opens the pathway to diagnosis and intervention (Choueiri et al., 2021).

Studies show a reduction in the average age of autism diagnosis in the six government-funded autism-specific schools in South Africa in recent years (Erasmus et al., 2019; Van Biljon et al., 2015). In a retrospective case study of an autism-specific school, the mean age of autism diagnosis of learners (n=141) was 71.6 months from 1990-2014 (Van Biljon et al., 2015). Yet,

in a prospective follow-up study, the mean age of diagnosis in the six autism-specific schools was much lower (46.6 months) (Erasmus et al., 2019). The positive decline of 25 months in the age of autism diagnosis for school-going children in South Africa is encouraging, but identification and assessment efforts need to increase further to reap the benefits of early intervention, as an accurate diagnosis of autism can already be made as early as 14 months of age (Pierce et al., 2019). Benefits of early identification and intervention include reduced severity of core symptoms of autism, improved long-term language development, and enhanced child and family outcomes (Franz et al., 2018; French & Kennedy, 2018; Fuller & Kaiser, 2020).

Research has consistently shown that autism screening is feasible and necessary to lower the age of diagnosis (Camarata, 2014; Hyman et al., 2020; Marlow et al., 2019; Robins et al., 2014; Zwaigenbaum & Penner, 2018). There are, however, differences in accuracy of screening methods and procedures implemented (Wallis, 2021). When broad-based developmental screening and disorder-specific screening are compared, autism-specific screens show significantly higher agreement with diagnosis of the condition (Wiggins et al., 2014). Universal autism-specific screening in combination with developmental screening is recommended to prioritize referrals to autism specialists and improve reliability (Wiggins et al., 2014). Similarly, a combined approach of developmental monitoring and screening was the best solution for early identification across different ethnic communities (Barger et al., 2021). Universal autism screening in low- and middle-income countries (LMICs) has been recommended but is a challenge as reliable and culturally appropriate resources, tools, and supporting policy guiding referrals are limited (Franz et al., 2018; Lee & Meadan, 2021; Marlow et al., 2019).

The Modified Checklist for Autism in Toddlers, Revised with Follow-up [M-CHAT-R/F™] (Robins et al., 2014) is globally the most used and translated autism-specific screening

instrument (Lord et al., 2018; Robins et al., 2018). The Cronbach alpha (internal consistency) of the updated version of the M-CHAT with the Follow-up section is 0.8, adequate to support reliability (Robins et al., 2014). The M-CHAT-R/F™ was identified as an applicable instrument to use in LMICs as it does not require extensive training, is free of charge, and can be used by all health care professionals, caregivers and community health workers (Marlow et al., 2019). The screen can be completed electronically on the M-CHAT™ website or in hard copy format. The electronic format provides the child's risk score immediately after completion (Robins et al., 2018). For settings where access to the internet and technology is limited the hard copy is available, making it easily accessible allowing increased coverage of screening.

To reliably identify children at risk for autism, culturally sensitive instruments should be used as accurate identification is affected by the child's age, culture, socio-economic circumstances and gender (Guthrie et al., 2019; Wallis, 2021). Children from lower socio-economic circumstances and minority groups are generally identified later (Guthrie et al., 2019; Zeleke et al., 2019). The use of instruments that lack cultural adaptation may result in unreliable outcomes, varying prevalence estimates, with unintended over- or under-identification of children at risk (DuBay et al., 2021; Rea et al., 2019; Soto et al., 2015). This poses a great challenge, as there is currently no culturally adapted, autism-specific screening instruments available in South Africa (Franz et al., 2017). Given the late identification of autism and the shortage of culturally appropriate and validated screening tests in South African languages, the M-CHAT-R/F™ was adapted, translated into Northern Sotho and piloted (Vorster et al., 2021b; Vorster et al., in Press). Northern Sotho, one of the 11 official South African languages, is widely used in the greater Tshwane region, a densely populated urban and peri-urban area of South Africa, where the study was conducted. The most recent census by Statistics South Africa (2011) showed that 19.4% of the households in the region identified Northern Sotho (also known as Sepedi) as their dominant language.

A culturally adapted English version and a Northern Sotho translation of the M-CHAT-R/F were developed by two professional translators and an expert panel of eight members including linguists, speech-language therapists and researchers, of which three were first-language Northern Sotho speakers (Vorster et al., In Press). The comprehensive process involved checklist-item scrutiny, forward and back translation, two panel discussions and written feedback based on the *Item translation and adaptation review form* (Hambleton & Zenisky, 2011). A total of four items were culturally adapted (Items 3, 4, 9, and 14) with linguistic gaps posing the greatest challenge with the translation of technical terms. The adapted English M-CHAT-R/F and Northern Sotho M-CHAT-R/F were shown to be equivalent versions of the M-CHAT-R/F™ in the small-scale pilot study (Vorster et al., 2021b). Preliminary reliability of the two checklists was therefore established with no difference evident at the 5% interval of the Wilcoxon signed ranked test (Vorster et al., 2021b). A need for investigation of the validity of both the Northern Sotho M-CHAT-R/F as well as the adapted English M-CHAT-R/F was identified, as the pilot sample was too small to determine psychometric properties of the checklists. Preferably, the concurrent validity of the screening checklists should be as high as possible, while acknowledging the limitations of the caregiver-report format of the M-CHAT (DuBay et al., 2021). The current study aimed to determine the reliability and the concurrent validity of both versions of the checklist in a larger-scale sample by comparing the two checklists with one another and with a standardised diagnostic tool.

5.3 Method

Ethical clearance

Permission to adapt and translate the M-CHAT-R/F™ was obtained from the original authors. The study was approved by the institutional research board (HUM041/0919), the provincial health ethics board and the local clinic where data collection was conducted. All participants (aged ≥18-years) gave written informed consent after reading the study information brochure.

Research design

A comparative within-subject design that involved correlational research with inferential statistics was used to assess the reliability and concurrent validity of the adapted English M-CHAT-R/F and the Northern Sotho M-CHAT-R/F. An item-level analysis was performed, allowing comparison between the adapted English checklist and Northern Sotho M-CHAT-R/F. The overall pass/fail rate of the two M-CHAT-R/F versions were compared by investigating the level of agreement among participants' responses using the two checklists, utilizing their own child as reference with each application. The internal consistency of the two M-CHAT-R/F versions was calculated and compared to determine the reliability and equivalence of the two M-CHAT-R/F versions. Concurrent validity was investigated by comparing the outcome of the M-CHAT-R/F versions with the results of the communication and socialization sub-domains of the Vineland-3 Comprehensive Parent/Caregiver Form (Sparrow et al., 2016).

Participants

The study participants comprised of 158 mothers of children aged between 18- and 48-months (mean age: 28.3-months, standard deviation [SD]: 9.6), identified with purposive sampling at a local government clinic in a peri-urban area of a large city in South Africa. Typical reasons for child clinic attendance are immunizations, deworming, growth monitoring and surveillance according to the Road to Health Booklet (RTHB) developmental screen. The RTHB, mandated by the National Department of Health, is a record of a child's immunizations, health interventions and growth, and includes developmental information for caregivers (Slemming & Bamford, 2018). The reference population was typically low-risk for autism as they were not assigned to high-risk clinics due to established risk and diagnosis. The inclusion of a low-risk population allowed us to truly assess the understanding of the constructs by participants

without interference of additional developmental factors in the children, similar to the validation study of the M-CHAT-R/F™ (Robins et al., 2014). Participants had to identify Northern Sotho or Sepedi as the dominant language spoken in the household. They also had to be proficient in English, with Grade 4 reading ability as per M-CHAT-R/F™ guidelines for caregivers who complete the checklist. In South Africa, English is identified as dominant language in education, public office and business (Posel & Zeller, 2016). The child's RTHB was perused to exclude a previously diagnosed health condition or developmental disability, but children with low birth weight and preterm birth were included. Additional descriptive information regarding the caregivers and the reference child population is included in Table 5.1.

Table 5.1

Caregiver sample characteristics (n=158)

Caregiver characteristic	Frequency (%)
Additional home language (n=23)	
IsiNdebele	2 (8.7%)
IsiXhosa	1 (4.3%)
IsiZulu	1 (4.3%)
Sesotho	2 (8.7%)
Setswana	4 (17.4%)
Siswati	1 (4.3%)
Xitsonga	8 (34.9%)
Other	4 (17.4%)
Maternal education	
Primary school only (4 – 7 years)	4 (2.5%)
Grade 9	38 (24.1%)
Grade 12	104 (65.8%)
Bachelor's degree	12 (7.6%)

Age	
≤ 37 years	151 (95.6%)
≥ 38 years	7 (4.4%)

Reference population characteristics (n=158)	
Age (child)	
18 – 23 months	53 (33.5%)
24 – 35 months	53 (33.5%)
36 – 48 months	52 (33.0%)
Mean: 28.3 months	
Median: 24.0 months	
Standard deviation (SD): 9.6 months	
Gender	
Male	57 (36.1%)
Female	101 (63.9%)
Pregnancy duration	
≤ 36 weeks	13 (8.2%)
≥ 37 weeks	145 (91.8%)
Birth weight	
≤2499g	27 (17.1%)
≥2500g	131 (82.9%)
APGAR score (10-minutes)	
0 – 6	15 (9.5%)
7 – 10	143 (90.5%)
Attending daycare or crèche	
Yes	57 (36.1%)
No	101(63.9%)

The participant mothers all identified Northern Sotho as their home language, with 14% (n=23) speaking an additional language at home. The home language diversity reflects the multilingual nature of South Africans. The use of purposive sampling may have contributed to a skewed

gender sample, with more girls than boys in the reference population. A large number of participants (n=101; 63.9%) did not attend a crèche/daycare at the time with COVID-19 national restrictions being a prominent explanation. Based on the mothers' responses it appears that more children would have attended crèche/day care if it was not for the Covid-19 pandemic and subsequent lockdown of childcare facilities. Preterm birth in the reference sample (8.2%) is lower than the national preterm birth rate, but low birthweight (17.1%) is higher than the latest available statistic of 14.6% for Gauteng, the province where the study was conducted (National Perinatal Morbidity and Mortality Committee, 2016).

Materials

Four instruments were used in the research study. A socio-demographic questionnaire with questions relating to the child's developmental and medical history, developmental risk factors and current living conditions were used for comprehensive participant description. Both the adapted English M-CHAT-R/F and the Northern Sotho M-CHAT-R/F were used. The Vineland-3 Comprehensive Parent/Caregiver Form (Sparrow et al., 2016) was used to obtain information relating to the child's current level of functioning based on caregiver report and to further exclude children with diagnosed genetic and neurological conditions or sensory disorders. The Vineland-3 communication and socialization sub-domains were used to investigate the concurrent validity of the M-CHAT-R/F versions.

The adapted English M-CHAT-R/F has four adaptations to checklist items based on the expert panel's recommendations (Vorster et al., in Press). Changes were made to items 3, 4, 9 and 14. Items 3, 4, and 9 were adapted due to unfamiliar constructs in the Northern Sotho culture which appear in the original checklist. "Soft toys", "playground equipment" and "make-believe" were replaced with more familiar, yet similar concepts, "toys", "trees", and "act". Item 14, relating

to the child's eye contact was adapted from "Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?" to "look in *your direction* or in the eye" to compensate for the local customary avoidance of eye contact with an elder. In some Southern African cultures, direct eye contact with a superior is perceived as disrespectful behavior (Mncwango, 2009). No changes were made to the format of the initial 20 items nor the Follow-up section. The Northern Sotho M-CHAT-R/F was created by translating the adapted English version to Northern Sotho. The scoring of both checklists remained as described in the M-CHAT-R/F™ (Robins et al., 2018).

The Vineland-3 Comprehensive Parent/Caregiver Form (Sparrow et al., 2016) is a reliable instrument to formally assess a child's level of functioning and adaptive behavior based on caregiver report. The form was found to be reliable for use in South Africa in a recent study by Du Toit et al. (2021). The standardization of the third revision of the Vineland utilized a large sample of 2,560 individuals from different contexts and different diagnoses. The test-retest reliability showed an *r*-value ranging from .64 to .94. Corrected correlations were used to measure the reliability (.61 to .87) representing strong correlations (Pepperdine & McCrimmon, 2018). The parent/caregiver form includes four subdomains, Communication, Daily Living Skills, Socialization, and Motor Skills. For this study, the Motor skills subdomain was omitted as it does not contribute to the Adaptive Behavior Composite score (ABC-score). The ABC-score is determined by calculating the sum of the three subdomain standard scores (Communication, Daily Living Skills and Socialization) and allows for the description of the current level of functioning of an individual. The descriptors of child functioning are categorized into five groups: High (ABC score: 130-140), Moderately high (ABC-score: 115-129), Adequate (ABC-Score: 86-114), Moderately low (ABC-score: 71-85), and Low (ABC-score: 20-70). A score below 86, at the 90% confidence interval, is indicative of a

developmental delay. Adaptive behavior scores are fundamental to the diagnosis of intellectual disability and developmental delay. The scores may not be definite of autism, but there are noticeable patterns of results, especially in Communication and Socialization. When combining the Vineland-3 with other diagnostic measures, the Vineland-3 is a valuable component of an autism evaluation, as children with autism demonstrate lower levels of adaptive functioning. (Peters & Matson, 2019; Sparrow et al., 2016). The study thus employed a combined screening method using both an autism-specific screen and a developmental screening instrument, as recommended by researchers (Barger et al., 2021; Wiggins et al., 2014).

Procedures

The two versions of the M-CHAT-R/F were prepared and numbered to ensure random variation in the presentation of the two checklists to participants. Both versions of the M-CHAT-R/F were self-completed by participants in the predetermined randomized order to prevent a learning effect between the two checklists and fatigue influencing the accuracy of a specific checklist's responses. Once both versions of the M-CHAT-R/F were completed the first author asked the Vineland-3 questions to participants in an area separate from the mothers waiting in line at the clinic. The structured questions were asked in a short interview to ensure accurate understanding, limit fatigue in participants and shorten the time of the data collection session. The socio-demographic questionnaire was completed last, as the questions were the least complex. Refreshments were offered to participants following the completion of the set of instruments. After completion by the mothers, the screening checklists were scored immediately so that the Follow-up questions could be asked to the mother in case of a medium risk score, and referrals can be made in case of a high-risk for autism score. Caregivers of the children identified with developmental delay received a referral letter and contact details of the relevant specialists in both public and private health sectors.

Data processing and analysis

The raw data from the instruments were scored according to the guidelines described in the test manuals. The M-CHAT-R/F scores were categorized as low-risk (0 to 2) [Pass], medium-risk (3 to 7) [Refer], and high-risk for autism (≥8) [Refer]. If a child scored in the medium-risk category the mandatory follow-up questions were posed to participants. A high-risk score required direct referral to a specialist. The Vineland-3 data were processed by determining the *v-scale* score, the age equivalent, and the growth scale value. The sum of the *v-scale* score was used to determine the standard score of each subdomain. The sum of the standard scores was used to determine the ABC-score identifying the presence or absence of a developmental delay, with an ABC-score below 86 indicating a delay. Concurrent validity was investigated by determining the biserial correlations using the M-CHAT-R/F outcome in both English and Northern Sotho as well as the Communication and Socialization sub-domains of the Vineland-3. The Communication and Socialization domains were investigated in particular as core symptoms of autism are typically evident in these domains.

The data were populated in a Microsoft Excel spreadsheet to be analyzed using descriptive statistical analyses and SPSS. Cronbach's alpha (internal consistency, 0.7 – 0.9), Cohen's Kappa, Initial frequencies, Pearson Chi-square, item level analysis and Cross-tabulation were used to investigate the reliability and validity of the two checklists. An item analysis was conducted to calculate the percentage of children that failed each item.

5.4 Results

Preferred language options

After completion of the two checklists participants were requested to choose their preferred language option. A marginal majority (n=87; 55.1%) chose Northern Sotho as the preferred

language in which they wanted to complete the M-CHAT-R/F, while the remaining (n=71; 44.9%) chose English.

Referral rate

Despite a few differences, the comparison of the adapted English and the Northern Sotho M-CHAT-R/F showed near-perfect agreement with a significant association ($p<0.001$) between the two versions. Figure 5.1 illustrates the risk categories of the two checklists, before and after the Follow-up questions were posed to the participants.

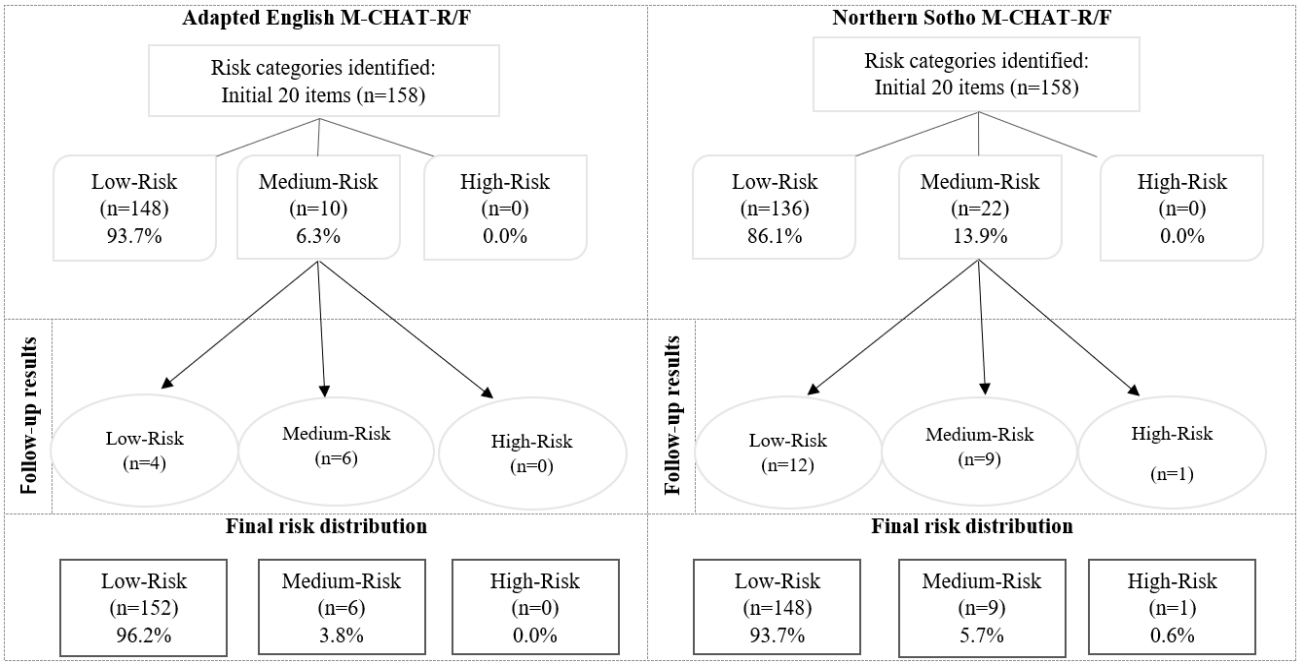

Figure 5.1: *Comparison of risk categories of the two checklists before and after the Follow-up questions*

Following the M-CHAT step-wise screening procedure, and as expected from a low-risk sample, no child was identified as high-risk for autism with the 20 item-screen. The Follow-up questions were asked to mothers whose children obtained a medium-risk for autism score, 10 (6.3%) children with the English screen, and 22 (13.9%) children with the Northern Sotho screen. The final risk distribution showed that more children moved to the low-risk category, with only six (3.8%) on the English screen and nine (5.9%) children on the Northern Sotho

screen in the medium-risk category after the prescribed Follow-up questions were asked. The Northern Sotho M-CHAT-R/F had a slightly higher referral rate (n=10; 6.3%) than the adapted English screen (n=6; 3.7%). With the English screen no high-risk cases were identified, while a single high-risk toddler was identified with the Northern Sotho checklist. The child was referred to the high-risk clinic of the local tertiary hospital to be assessed by a pediatric neurologist; the outcome was still unknown at the time of submission of the article.

Item analysis

Item-level analysis was conducted to gain insight into the reliability and concurrent validity of both M-CHAT-R/F versions. All 158 data sets were used for the item-level analysis (Table 5.2). Seven items from the total of 20 showed perfect agreement between the adapted English checklist and the Northern Sotho M-CHAT-R/F. Thirteen items showed response differences between the two tests. Ten of the 13 items showed near-perfect agreement with ≥95% agreement between the two checklists. The items with the greatest number of differences were Item 11 with a 6.3% difference in answer distribution and items 12 and 5 which showed a 12.5% and 13.3% variation respectively.

Table 5.2

Comparison of item responses and percentage of disagreement between adapted English M-CHAT-R/F and Northern Sotho M-CHAT-R/F

	Adapted English		Northern Sotho		% Disagreement
Item	Yes	No	Yes	No	
1	157	1	157	1	**0.0**
2	4	154	9	149	3.7
3	154	4	151	7	1.9
4	149	9	144	14	3.7
5	34	124	55	103	13.3*
6	156	2	153	5	1.9
7	158	0	156	2	1.3

8	153	5	153	5	**0.0**
9	153	5	152	6	0.6
10	155	3	156	2	0.6
11	158	0	148	10	6.3*
12	34	124	54	104	12.7*
13	158	0	158	0	**0.0**
14	157	1	157	1	**0.0**
15	157	1	157	1	**0.0**
16	155	3	155	3	**0.0**
17	153	5	153	5	**0.0**
18	154	4	155	3	0.6
19	156	2	152	6	2.5
20	154	4	148	10	3.8

*Three items with the greatest disagreement

The item response comparison was further analyzed to show within-group results to determine the equivalence and inter-rater reliability between the adapted English and the Northern Sotho M-CHAT-R/F for each age group. The analysis was also conducted to verify if specific items were less reliable for certain age groups, as the child's age and therefore the developmental level could influence how mothers answered the questions. The oldest group, the 36- to 48-month-old sample presented with greater disagreement between the two language versions of the checklist, with more than two data sets presenting with a difference in seven items compared to the six items for the other two age groups. The two younger groups presented with a higher level of agreement.

Items 5 and 12 were the two items showing the most salient disagreement in responses between the two checklists and across the three child age categories. Item 5 "Does your child make unusual finger movements near his or her eyes? (*For example,* does your child wiggle his or her fingers close to his or her eyes?" showed the highest disagreement (13.3%). Participants

frequently mentioned that the child rubs their eyes, possibly indicating an irritation in the eyes or drowsiness, and responded “Yes” to the question in the Northern Sotho version. It appears that the typical autistic behavior of unusual finger movements close to the eyes (finger flicking), was confused with eye rubbing. Item 12 “Does your child get upset by everyday noises? (*For example,* does your child scream or cry to noise such as a vacuum cleaner or loud music?)” resulted in 12.7% disagreement. With both items, more participants indicated “Yes” in Northern Sotho and “No” in the adapted English checklist version. Interestingly, 24.1% of the data sets that showed variation of Item 5 were first time caregivers. Despite the few instances of disagreement, the majority of items with more agreement supports the preliminary reliability and equivalence between the two versions, indicating the internal consistency of the adapted English checklist and the Northern Sotho M-CHAT-R/F.

Internal consistency

Similar to the item-level analysis the internal consistency of the total sample, a measure of reliability, was determined for both checklists. The internal consistency for the total sample (n=158) of the adapted English screen was Cronbach alpha 0.251 which was lower than the 0.543 of the Northern Sotho checklist, and the expected 0.7 to 0.9. With further investigation of the different age groups, internal consistency improved for some groups compared to the overall value. The adapted English checklist showed a stronger value for the 24- to 35-month-old sample, with a Cronbach alpha of 0.446. The internal consistency for the 18- to 23-month-old sample of the English adaptation was low, with 0.101 and 0.008 for the oldest group. The Northern Sotho version showed stronger internal consistency for the 18- to 23-month (0.655≈0.7), 24- to 35-month (0.359) and 36- to 48-month (0.526) groups. The greater internal consistency observed with the Northern Sotho checklist aligns with the participants’ preference for the Northern Sotho version (55.1%).

Concurrent validity

The Vineland-3 results were not only used to identify developmental delays and risk for autism in the reference population, but also to investigate the concurrent validity of the two M-CHAT-R/F versions. A significant association between the Northern Sotho M-CHAT-R/F and the Vineland-3 sub domains of communication and socialization was evident at the 5% level, thereby supporting concurrent validity. The adapted English M-CHAT-R/F did not present with any significant association as shown in Table 5.3. No association was found between the overall Vineland-3 outcome (ABC-score) and preterm birth and low birth weight respectively.

Table 5.3

Concurrent validity of M-CHAT-R/F versions and the Vineland-3

	Sub-domain	Biserial correlation	p-value
Northern Sotho M-CHAT-R/F	Communication	0.276	0.0278*
	Socialization	0.2572	0.0436*
Adapted English M-CHAT-R/F	Communication	0.2414	0.1211
	Socialization	0.2827	0.07

*Significant association at 5% level

Age effect

Using the Pearson Chi-square, a significant age effect (p-value <0.001) was evident with the Vineland-3 overall outcome. The youngest age group showed five (9.4%) children with developmental delay followed by 23 (43.4%) children in the 24- to 35-month group. The oldest group showed the greatest number of children with developmental delay (n=25; 48.1%). Overall, 53 (33.5%) of children showed developmental delay. No age effect was evident with the two M-CHAT-R/F versions.

5.5 Discussion

A marginal majority of participants preferred the Northern Sotho checklist over the adapted English version. The Northern Sotho language preference may be linked to better comprehension as it was the self-identified home language of the participants (Mophosho et al., 2019). A total of 44,9% of participants indicated a preference for the adapted English checklist, showing that both versions of the South African M-CHAT-R/F will be used, with the possibility of greater use of the adapted English checklist by other language groups as English is often the language of learning and teaching in South Africa (Posel et al., 2020).

The referral rates of the adapted English checklist and Northern Sotho M-CHAT-R/F showed near-perfect agreement ($p<0.001$). The two versions also displayed similarities with the M-CHAT-R/F^{TM} validation study. With the larger-scale validation study of 16, 115 participants, 92.6% of children had a negative screening outcome after completion of the initial 20 items (Robins et al., 2014). The results of the current study align well with the initial M-CHAT-R/F^{TM} validation study where 93.7% (n=10) of children passed the adapted English version prior to Follow-up while 86.2% (n=22) of children passed the Northern Sotho M-CHAT-R/F (Robins et al., 2014). However, the distribution of the Northern Sotho child risk categories post-Follow-up were more similar to the initial validation study with 93.7% negative screen outcome than the adapted English version (96.2%).

The item-level analysis showed perfect agreement and near-perfect agreement between 17 items of the two M-CHAT-R/F versions. The equivalence between the two versions is similar to the pilot study results (Vorster et al., 2021b). Only three of the 20 items (Items 5, 11, and 12) showed slight variations between the Northern Sotho and the adapted English versions with Item 11 displaying 90% agreement in the pilot study and 93.7% agreement in the current study (Vorster et al., 2021b). The variations in Items 5 and 12 became apparent in the larger-scale study. Consistent with Northern Sotho being the preferred language in which participants

wanted to complete the screen (55.1%), the Northern Sotho M-CHAT-R/F also showed higher internal consistency (Cronbach alpha 0.543) than the adapted English checklist. A recent study reported that participants showed improved comprehension in their home language when answering questions that require in-depth knowledge of their child's behavior (DuBay, 2020). Therefore, better understanding of questions could have played a role in the higher internal consistency that was observed in the Northern Sotho version when compared to the English adaptation.

The confirmed equivalence in the current study between the adapted English M-CHAT-R/F and the Northern Sotho M-CHAT-R/F permitted further investigation by considering internal consistency as a measure of reliability (Field, 2009). The internal consistency for each checklist was lower than the expected 0.7 to 0.9. A lower Cronbach alpha value could be anticipated as the 20 M-CHAT-R/F items are not closely related as a group. The checklist does not investigate a unitary dimension, as three items indicate a risk for autism if the answer is "Yes" while the remaining 17 items indicate a risk score when the answer is "No" (Robins et al., 2014). The higher internal consistency of the Northern Sotho M-CHAT-R/F (0.543) may be ascribed to the stronger preference for Northern Sotho. The internal consistency values of the Northern Sotho M-CHAT-R/F results for the 18- to 23-months (0.66) and 36- to 48-months (0.53) age groups were more similar to the initial validation study of the M-CHAT-R/F™ (0.63) (Robins et al., 2014). The reverse coding of the responses for Items 2, 5, and 12 may have resulted in higher Cronbach alpha values for the adapted English checklist (0.45). A possible explanation for the low Cronbach alpha (less than the ideal 0.7 to 0.9) may thus be the specific binary dimension inherent in the M-CHAT-R/F.

Further evidence of the performance of the Northern Sotho checklist was found in the significant association between the Northern Sotho M-CHAT-R/F and the Vindeland-3

subdomains. This is indicative of the concurrent validity of the Northern Sotho M-CHAT-R/F with the Vineland-3 Communication and Socialization subdomains, which are typically affected in children with autism. The adapted English M-CHAT-R/F was not significantly associated with the outcome of two subdomains. It can be concluded that the Northern Sotho M-CHAT-R/F presented with higher validity even though both instruments were shown to be reliable.

Based on the reliability and validity results of the study, final changes were made to both checklists. Clarification was included for Item 5, adding the phrase "not rubbing the eyes" to the explanation in both checklists. Participants appeared to confuse unusual finger movements near their eyes with eye rubbing, possibly being unaware of the association between autism and stimming using one's fingers and/or hands (Lilley, 2017). The pronouns used in the adapted English version were changed from "his/her" to "they" to include gender-neutral terminology. This change was not included in the Northern Sotho M-CHAT-R/F as pronouns are gender-inclusive in Northern Sotho (Aixela, 2009).

The current study also indicated the feasibility of combining autism-specific screening with developmental assessment, using the Vineland-3 to support identification of autism, intellectual and developmental disabilities, and developmental delay. The results of the caregiver reported Vineland-3 assessment showed that a high number (33.5%) of participants' children, particularly the older age group, had developmental delay. A recent study in the same peri-urban area in South Africa also found a high prevalence of developmental delay among children, with more delays in an older age group. In this study the mHealth Parents' Evaluation of Developmental Status (PEDS) tools and the Vineland-3 were used to assess three- to seven-

year-old children (du Toit et al., 2020). Based on the results of the current study and international trends, the use of an autism-specific screening instrument in combination with developmental assessment or screening is recommended (Barger et al., 2021; Wiggins et al., 2014). The combined approach may promote early identification of autism and developmental delay at the same time. Further research is required.

5.6 Limitations

The sample size of the study was smaller than expected due to limited access to the data collection site during the different lockdown levels. Due to an overburdened health system diagnostic confirmation of the referred case was not possible, limiting the investigation of sensitivity and specificity of the two checklists.

5.7 Recommendations for future research

A larger-scale study with confirmation of an autism diagnosis in participants is required to determine the sensitivity and specificity of the adapted English and Northern Sotho M-CHAT-R/F versions. A comparison with the original M-CHAT-R/F™ is recommended for further confirmation of the sensitivity and specificity of the two new checklists.

5.6 Conclusion

The study showed the reliability and concurrent validity of the adapted English M-CHAT-R/F as well as the Northern Sotho M-CHAT-R/F. The Northern Sotho M-CHAT-R/F showed slightly more significant psychometric properties. The South African culturally adapted and translated checklists for autism are now available for use. A combined approach of autism screening and developmental assessment is strongly recommended. It is anticipated that the new screening tools may contribute to improved access to care for more children. The checklists may contribute to decrease the average age of autism identification, opening the

pathway to diagnosis and improved long-term outcome for children with autism in South Africa.

5.7 References

Amaral, D. G., Anderson, G. M., Bailey, A., Bernier, R., Bishop, S., Blatt, G., Canal-Bedia, R., Charman, T., Dawson, G., de Vries, P. J., Dicicco-Bloom, E., Dissanayake, C., Kamio, Y., Kana, R., Khan, N. Z., Knoll, A., Kooy, F., Lainhart, J., Levitt, P., … Whitehouse, A. (2019). Gaps in current autism research: The thoughts of the autism research editorial board and associate editors. *Autism Research, 12*(5), 700–714. https://doi.org/10.1002/aur.2101

Barger, B., Rice, C., Benevides, T., Salmon, A., Sanchez-Alvarez, S. & Crimmins, D. (2021). Are developmental monitoring and screening better together for early autism identification across race and ethnic groups? *Journal of Autism and Developmental Disorders, Online,* 1-22.. https://doi.org/10.1007/s10803-021-04943-8

Camarata, S. (2014). Early identification and early intervention in autism spectrum disorders: Accurate and effective? *International Journal of Speech-Language Pathology, 16*(1), 1–10. https://doi.org/10.3109/17549507.2013.858773

Choueiri, R., Lindenbaum, A., Ravi, M., Robsky, W., Flahive, J. & Garrison, W. (2021). Improving early identification and access to diagnosis of autism spectrum disorder in toddlers in a culturally diverse community with the rapid interactive screening test for autism in toddlers. *Journal of Autism and Developmental Disorders, Online,* 1-16. https://doi.org/10.1007/s10803-020-04851-3

Du Toit, M., Van der Linde, J. & Swanepoel, D. W. (2021). Early childhood development risks and protective factors in vulnerable preschool children from low-income communities in South Africa. *Journal of Community Health, 46,* 304–312. https://doi-

org.uplib.idm.oclc.org/10.1007/s10900-020-00883-z

DuBay, M. (2020). *Translation and cultural adaptation of autism screening tools.* [University of North Carolina]. https://doi.org/10.17615/fcwc-c425

DuBay, M., Watson, L. R., Baranek, G. T., Lee, H., Rojevic, C., Brinson, W., Smith, D. & Sideris, J. (2021). Rigorous translation and cultural adaptation of an autism screening tool: First years inventory as a case study. *Journal of Autism and Developmental Disorders, Online*, 1-13. https://doi.org/10.1007/s10803-020-04837-1

Erasmus, S., Kritzinger, A. & Van der Linde, J. (2019). Onset of intervention for learners in autism-specific government-funded schools in South Africa. *International Journal of Disability, Development and Education, 68*(1), 46–61. https://doi.org/10.1080/1034912X.2019.1653449

Field, A. (2009). *Discovering statistics using SPSS* (Third edn.). SAGE Publications.

Franko Aixela, J. (2009). An overview of interference in scientific and technical translation. *The Journal of Specialised Translation*, *11*, 75–87.

Franz, L., Adewumi, K., Chambers, N., Viljoen, M., Baumgartner, J. N. & de Vries, P. J. (2018). Providing early detection and early intervention for autism spectrum disorder in South Africa: Stakeholder perspectives from the Western Cape province. *Journal of Child and Adolescent Mental Health*, *30*(3), 149–165. https://doi.org/10.2989/17280583.2018.1525386

Franz, L., Chambers, N., Von Isenburg, M. & de Vries, P. J. (2017). Autism spectrum disorder in Sub-Saharan Africa: A comprehensive scoping review. *Autism Research*, *10*(5), 723–749. https://doi.org/10.1002/aur.1766

French, L. & Kennedy, E. M. M. (2018). Annual research review: Early intervention for

infants and young children with, or at-risk of, autism spectrum disorder: A systematic review. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *59*(4), 444–456. https://doi.org/10.1111/jcpp.12828

Fuller, E. A. & Kaiser, A. P. (2020). The effects of early intervention on social communication outcomes for children with autism spectrum disorder: A meta-analysis. *Journal of Autism and Developmental Disorders*, *50*(5), 1683–1700. https://doi.org/10.1007/s10803-019-03927-z.

Guthrie, W., Wallis, K., Bennett, A., Brooks, E., Dudley, J., Gerdes, M., Pandey, J., Levy, S. E., Schultz, R. T. & Miller, J. S. (2019). Accuracy of autism screening in a large pediatric network. *Pediatrics*, *144*(4). https://doi.org/10.1542/peds.2018-3963

Hambleton, R. K. & Zenisky, A. L. (2011). Translating and adapting tests for cross-cultural assessment. In D. Mutsamoto & F. J. R. Van de Vijver (Eds.), *Cross-cultural research methods in Psychology* (pp. 46–74). Cambridge University Press.

Hyman, S. L., Levy, S. E., Myers, S. M. & AAP Council on Children with Disability. (2020). Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics*, *145*(1), e201934447. https://doi.org/10.1542/peds.2019-3447

Lee, J. D. & Meadan, H. (2021). Children with autism spectrum disorders in low-resource settings: Reported experiences and needs of parents in Mongolia. *Journal of Autism and Developmental Disorders*, *Online*, 1-10. https://doi.org/10.1007/s10803-020-04818-4

Lilley, R. (2017). What's in a flap? The curious history of autism and hand stereotypies. *Neurosocieties Symposium: Explorations of the Brain, Culture, and Ethics*, 25 *August*, 1–21.

Lord, C., Elsabbagh, M., Baird, G. & Veenstra-Vanderweele, J. (2018). Autism spectrum disorder. *The Lancet*, *392*(10146), 508–520. https://doi.org/10.1016/S0140-

6736(18)31129-2

Malcolm-Smith, S., Hoogenhout, M., Ing, N., Thomas, K. G. F. & De Vries, P. (2013). Autism spectrum disorders - Global challenges and local opportunities. *Journal of Child and Adolescent Mental Health*, *25*(1), 1–5. https://doi.org/10.2989/17280583.2013.767804

Marlow, M., Servili, C. & Tomlinson, M. (2019). A review of screening tools for the identification of autism spectrum disorders and developmental delay in infants and young children: Recommendations for use in low- and middle-income countries. *Autism Research*, *12*(2), 176–199. https://doi.org/10.1002/aur.2033

Mncwango, E. M. (2009). Language and the current challenges in the South African school system. *Inkanyiso: Journal of Humanities and Social Sciences*, *1*(1), 51–54.

Mophosho, M., Khoza-Shangase, K. & Sebole, L. L. (2019). The reading comprehension of Grade 5 Setswana-speaking learners in rural schools in South Africa: Does home language matter? *Per Linguam*, *35*(3), 59–73. https://doi.org/10.5785/35-3-844

National Perinatal Morbidity and Mortality Committee. (2016). Napemmco Triennial report 2014-2016 Saving Babies report. In *Department of Health* (1,1). https://www.westerncape.gov.za/assets/departments/health/napemmco_triennial_report_2014-2016_saving_babies.pdf

Olusanya, B. O., Davis, A. C., Wertlieb, D., Boo, N. Y., Nair, M. K. C., Halpern, R., Kuper, H., Breinbauer, C., de Vries, P. J., Gladstone, M., Halfon, N., Kancherla, V., Mulaudzi, M. C., Kakooza-Mwesige, A., Ogbo, F. A., Olusanya, J. O., Williams, A. N., Wright, S. M., Manguerra, H., … Kassebaum, N. J. (2018). Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: A systematic analysis for the global burden of disease study 2016. *The Lancet Global Health*, *6*(10),

e1100–e1121. https://doi.org/10.1016/S2214-109X(18)30309-7

Pepperdine, C. R. & McCrimmon, A. W. (2018). Test review: Vineland Adaptive Behavior Scales, third edition (Vineland-3) by Sparrow, S. S., Cicchetti, D. V., & Saulnier, C. A. *Canadian Journal of School Psychology*, *33*(2), 157–163. https://doi.org/10.1177/0829573517733845

Peters, W. J. & Matson, J. L. (2019). The relationship between developmental functioning and screening outcome for autism spectrum disorder. *Journal of Developmental and Physical Disabilities, Online*,1-14. https://doi.org/10.1007/s10882-019-09689-x

Pierce, K., Gazestani, V. H., Bacon, E., Barnes, C. C., Cha, D., Nalabolu, S., Lopez, L., Moore, A., Pence-Stophaeros, S. & Courchesne, E. (2019). Evaluation of the diagnostic stability of the early autism spectrum disorder phenotype in the general population dtarting at 12 months. *JAMA Pediatrics*, *173*(6), 578–587. https://doi.org/10.1001/jamapediatrics.2019.0624

Posel, D., Hunter, M. & Rudwick, S. (2020). Revisiting the prevalence of English: language use outside the home in South Africa. *Journal of Multilingual and Multicultural Development,* 1–13. https://doi.org/10.1080/01434632.2020.1778707

Posel, D. & Zeller, J. (2016). Language shift or increased bilingualism in South Africa: Evidence from census data. *Journal of Multilingual and Multicultural Development*, *37*(4), 357–370. https://doi.org/10.1080/01434632.2015.1072206

Rea, K. E., Armstrong-Brine, M., Ramirez, L. & Stancin, T. (2019). Ethnic disparities in autism spectrum disorder screening and referral: Implications for pediatric practice. *Journal of Developmental and Behavioral Pediatrics*, *40*(7), 493–500. https://doi.org/10.1097/DBP.0000000000000691

Robins, D. L., Casagrande, K., Barton, M., Chen, C.-M. A., Dumont-Mathieu, T. & Fein, D.

(2014). Validation of the Modified Checklist for Autism in Toddlers, Revised With Follow-up (M-CHAT-R/F). *Pediatrics*, *133*(1), 37–45. https://doi.org:10.1542/peds.2013-1813

Robins, D. L., Fein, D. & Barton, M. (2018). *Modified Checklist for Autism in Toddlers, Revised with Follow-Up*. Self Published. https://mchatscreen.com/

Slemming, W. & Bamford, L. (2018). The new Road to Health Booklet demands a paradigm shift. *South African Journal of Child Health*, *12*(3), 86–87. https://doi.org/10.7196/SAJCH.2018.v12i3.1595

Soto, S., Linas, K., Jacobstein, D., Biel, M., Migdal, T. & Anthony, B. J. (2015). A review of cultural adaptations of screening tools for autism spectrum disorders. *Autism*, *19*(6), 646–661. https://doi.org/10.1177/1362361314541012

Sparrow, S., Cicchetti, D. V. & Saulnier, C. A. (2016). *Vineland Adaptive Behaviour Scales - Third Edition*. Pearson.

Van Biljon, S., Kritzinger, A. & Geertsema, S. (2015). A retrospective case report on demographic changes of learners at a school for children with Autism Spectrum Disorder in the Gauteng Province. *South African Journal of Childhood Education*, *5*(1), 20. https://doi.org/10.4102/sajce.v5i1.349

Wallis, K. E. (2021). The roadmap to early and equitable autism ddentification. *Pediatrics*, *148*(July), e2021050693E. https://doi.org/10.1542/peds.2021-050693E

Wiggins, L. D., Piazza, V. & Robins, D. L. (2014). Comparison of a broad-based screen versus disorder-specific screen in detecting young children with an autism spectrum disorder. *Autism*, *18*(2), 76–84. https://doi.org/10.1177/1362361312466962

Zeleke, W. A., Hughes, T. L. & Drozda, N. (2019). Disparities in diagnosis and service

access for minority children with ASD in the United States. *Journal of Autism and Developmental Disorders*, *49*(10), 4320–4331. https://doi.org/10.1007/s10803-019-04131-9

Zwaigenbaum, L. & Penner, M. (2018). Autism spectrum disorder: Advances in diagnosis and evaluation. *BMJ (Online)*, *361*, 1–16. https://doi.org/10.1136/bmj.k1674

CHAPTER 6: INTEGRATED SUMMARY, IMPLICATIONS AND CONCLUSION

The chapter provides an integrated summary of the research findings. A functional framework for the adaptation and translation of screening instruments is presented. The implications, strengths and limitations of the study are discussed along with the recommendations for future research priorities.

Early detection of children at risk for autism is of the utmost importance as the brain is primed to develop language and social skills from birth to six years of age (Lewis et al., 2014). When children at risk are identified at the earliest possible time, early intervention can improve the long-term prognosis and empower caregivers to support their children (Franz et al., 2018). International researchers advocating for early identification of autism support the notion of universal screening for the condition as it promotes earlier identification of children at risk, especially children affected by health disparities (Franz et al., 2018; Hyman et al., 2020). Disparities in autism are clear in South Africa. For example, most children diagnosed with autism who are currently in the Western Cape formal education system are English speaking, and from white households (Pillay et al., 2021). Developing a culturally appropriate autism screening checklist which is also available in a local language, can contribute to alleviating the lack of valid and reliable autism screening instruments in South Africa. Using valid and reliable screening instruments may promote early identification and access to support services and education for more children with autism. Appropriate screening checklists may be the first step in the right direction but an early detection policy guideline for autism and strategies to use the tools in existing health and education frameworks still need to be developed.

6.1 Summary of main research findings, theoretical and clinical implications

The research project followed a systematic process that resulted in three separate studies. An integrated summary of the three studies follows.

One of the main findings during the cultural adaptation and translation phase of the research project was the value of a labour-intensive rigorous scientific translation and adaptation process. The outcome was two screening instruments that proved to be

equivalent to each other, with reliability and concurrent validity established in the subsequent studies.

An integrated guide was developed and used to steer the scientific processes of cultural adaptation, translation and determining the feasibility of the screening instruments in Chapters 1 and 2 (Figure 1.1 and Figure 2.2). Upon reflection after the research a functional framework is now presented in Figure 6.1 which explains the chronological steps of cultural adaptation, translation and testing of a screening instrument in more detail. The ITC (2017) and the five WHO (2013a) guidelines were expanded upon on the figure.

The framework is also characterised by the involvement of different stakeholders. As the study was led by a researcher without a Northern Sotho background, greater effort was invested to insure linguistic, content and technical equivalence of the adapted and translated instruments. The process thus required the researcher to carefully guide the adaptation and translation, with the active engagement of all experts on a continuous basis. Engaging in informal and formal discussions with experts led to data rich explanations and valuable solutions to address the linguistic and terminology gaps, initially missed in the forward and back-translation process. The importance of an interactive process lead to the recommendation that a smaller panel discussion early on in the adaptation process is most valuable. A comprehensive expert panel discussion was followed by the independent analysis of the instruments. The panel was requested to complete a formal review form prior to the discussion, thereby assisting them to prepare for the discussion. The panel discussion was led by the researcher based on the quantitative feedback received from each panel members' review form. The discussion added depth to the qualitative research and allowed for clarification and identification of the best possible solutions, not only from a linguistic perspective but also from a cultural point of view.

As further indicated in Figure 6.1 another important stakeholder perspective on the instruments was the involvement of the participants of Study 2 and 3. The caregivers contributed to the dynamic process by providing feedback based on questions after the completion of the checklists. Participants could identify items that they did not understand or constructs that were unfamiliar to them. No changes were recommended by the participants of the pilot study or the larger-scale study. Involving parents of typically developing children in Study 2 and 3 showed the need to include

parents of children with autism as stakeholders as they will be more familiar with the behavioural aspect of the condition. The functional framework therefore reflects a dynamic and interactive process between researcher and different stakeholders, and as not merely an assignment to review a screening instrument. In-depth knowledge of the culture, the condition, in this case autism, and the Northern Sotho language was used to adapt, translate and test the M-CHAT-R/F.

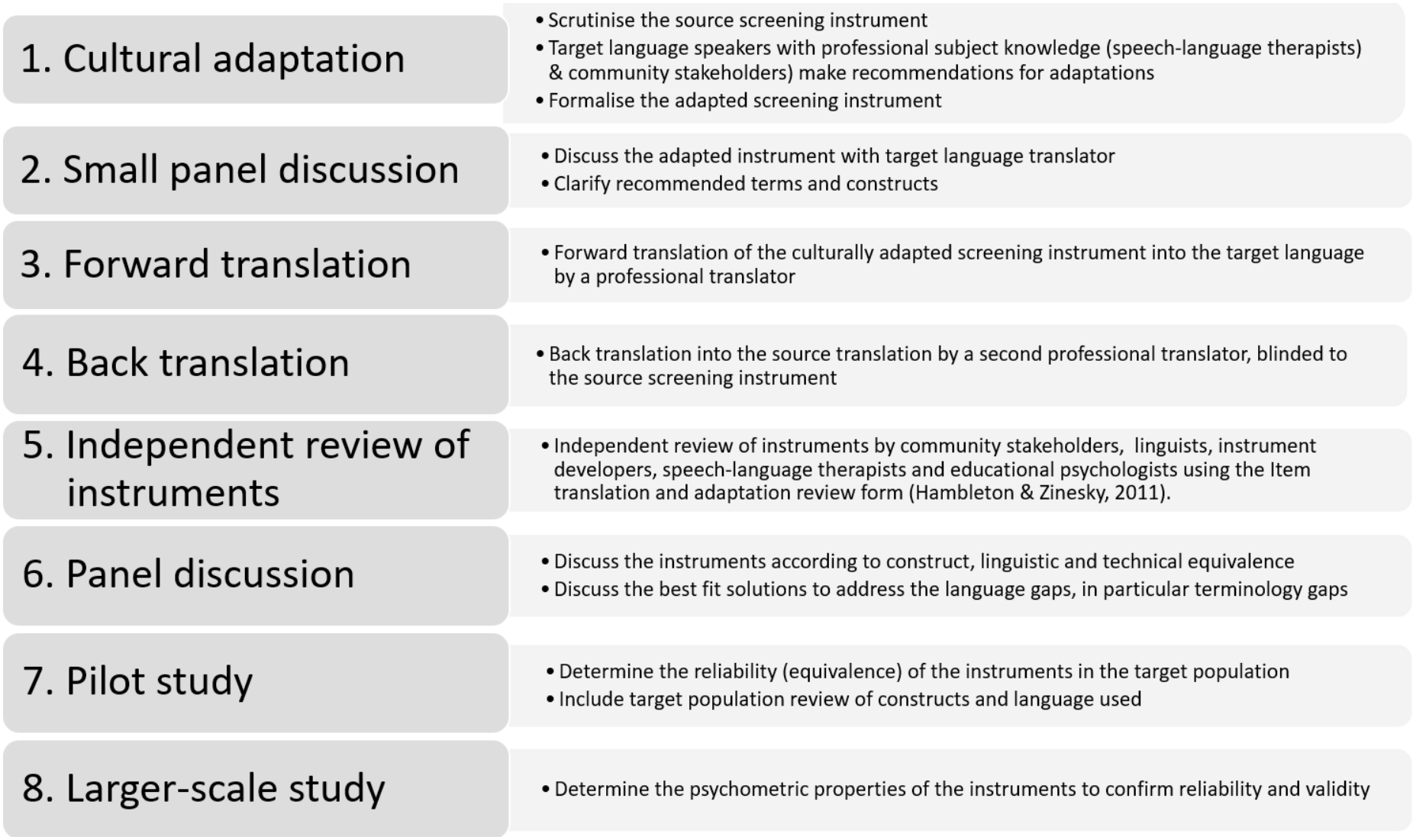

Figure 6.1: *Functional framework for the cultural adaptation and translation of screening instruments* (ITC, 2017; WHO, 2013a)

The utilisation of first-language speakers of the target language and carefully selected experts allowed for scrutiny of the adapted and translated checklists. The four cultural adaptations in the instrument were the result of constructs not familiar to the Northern Sotho culture and culturally inappropriate aspects, such as the descriptions of behaviour, in particular the cultural avoidance of eye contact with an elder. The language gaps discovered during the translation process were resolved by the expert panel using different terminology formation strategies like direct borrowing, transliteration or loan translation, paraphrasing, semantic specialisation and compounding (Gauton et al., 2008).

The initial aim of Study 1 was to adapt and translate the source screening instrument, resulting in a Northern Sotho version of the M-CHAT-R/F. The rigorous process, however, resulted in an additional instrument, the culturally adapted English M-CHAT-R/F. The need for such a rigorous process partly became necessary because the principal researcher is a bilingual Afrikaans/English speaker, with limited Northern Sotho linguistic knowledge. Recruiting first-language Northern Sotho SLTs as participants allowed the researcher to tap into their combined knowledge of autism and Northern Sotho culture. The linguists specialising in Northern Sotho were able to analyse the different versions of the checklists for technical aspects such as construct equivalence and grammar of Northern Sotho. The SLTs specialising in autism and test development, along with the educational psychologist ensured the accuracy of the clinical and behavioural representation of autism. The rigorous process resulted in linguistically accurate, culturally sensitive and clinically reliable versions of the source screening instrument, the M-CHAT-R/F^{TM}. The formalised process also resulted in the development of the functional framework for cultural adaptation and translation that may be used in future screening test translation projects (Figure 6.1).

The second study provided pilot data to support the reliability of the adapted English and Northern Sotho versions of the M-CHAT-R/F. The preliminary content validity and equivalence of the two checklists were evident after 21 data sets were completed by a small sample of the target population. Bilingual Northern Sotho/English caregivers of children 18 to 48-months, with a low risk for autism, were selected as participants. No difference between the two checklists was evident at the 5% interval of the Wilcoxon signed rank test. None of the participants identified constructs or terms that they were unfamiliar with, suggesting the checklists were ready for a larger-scale

study. The outcome of the pilot study provided additional quantitative data to support the accuracy and thus the equivalence of the M-CHAT-R/F versions. The use of the functional framework (Figure 6.1) in combination with a high-quality source screening instrument, the M-CHAT-R/F^{TM}, resulted in two M-CHAT-R/F versions that did not require additional changes following the pilot study.

The 158 participants included in Study 3 were selected with exactly the same characteristics as the pilot study caregivers and reference child population. Utilising a low-risk target population, allowed the participants to focus on the content of the instruments rather than on their child's difficulties. The participants were requested to identify words or constructs that they do not know or find difficult to understand. Focussing on the content and language use enabled the participants to critically consider the two translations of the items and their understanding thereof.

The participants completed both versions of the M-CHAT-R/F and the Vineland-3 Comprehensive Parent/Caregiver Form (Sparrow et al., 2016) was used as a formal assessment of the reference population's development in an interview. The combination of all three instruments allowed the analysis of reliability and concurrent validity. The reliability of the adapted English and Northern Sotho M-CHAT-R/F versions were established with near-perfect agreement with a significant association ($p<0.001$). The concurrent validity was confirmed when the M-CHAT-R/F outcomes were compared with the communication and socialisation subdomains of the Vineland-3. The Northern Sotho M-CHAT-R/F and Vineland-3 were significantly associated at the 5% level. This finding aligned well with the majority preference for the Northern Sotho translation as the dominant language of the participants. A substantial number of participants (44.9%) preferred the adapted English M-CHAT-R/F, supporting the need for the culturally adapted checklist.

A few final revisions were made to both checklists following the comprehensive process to ensure user-friendly checklists. To ensure bias-free language use, pronouns were changed to the inclusive form in the adapted English M-CHAT-R/F. Further clarification was added to Item 5 in both the adapted English M-CHAT-R/F and Northern Sotho M-CHAT-R/F versions to avoid misunderstanding of typical autistic behaviour.

An unexpected finding of the third study was the number of children identified with developmental delay. The rationale for the use of the Vineland-3 was to determine the concurrent validity of the M-CHAT-R/F, expecting that a risk on the autism checklists will also indicate a delay on the Vineland-3. Very few children were identified with risks on the autism checklists, but a third (33.5%) of the reference sample was identified with developmental delay. The underlying causes cannot be described at this stage. The number of children with delays increased the older the children were, similar to other recent studies in South Africa (Du Toit et al., 2021; Van der Linde et al., 2015; Van der Merwe et al., 2019). This finding led to the recommendation that autism-specific screening should not be conducted in isolation, but rather in combination with developmental screening or even a developmental assessment. The recommendation is in agreement with international trends in autism screening procedures (Barger et al., 2021; Wiggins et al., 2014). The combination of developmental and autism-specific screening is already enforced in the US at child-well visits (Barger et al., 2021; Wiggins et al., 2014). The combined approach may be conducted using the model proposed by Du Toit (2021) following a multidisciplinary approach to service delivery. The suggested team may include community health workers, school health nurses, early childhood development (ECD) practitioners, health care professionals i.e., SLTs and caregivers.

6.2 Screening for autism: Implications for policy, service provision and families

The National Integrated Early Childhood Developmental Policy [NIECDP] (South African Government, 2015) was developed by the Department of Social Development to transform early childhood development services. The NIECDP aims to address gaps and enhance service provision making it more comprehensive, promoting equity and access to care for all children from birth until the year in which they turn seven. The purpose of the policy is to provide an overarching multi-sectorial framework and to define a comprehensive program for early childhood development services that align with the Good Health and Well-being, and Quality education SDGs (Slemming & Bamford, 2018; South African Government, 2015). Although the NIECDP aims to address gaps and service provision, there is no formal autism identification and screening program currently in South Africa. Some groundwork addressing this gap

has been conducted by the Centre for Autism Research in Africa (Franz et al., 2018; Pillay et al., 2021) but no evidence of policy changes could be found.

A study investigating the perspectives of stakeholders regarding early detection and intervention of autism in the Western Cape province identified the NIECDP as the most applicable document regarding services for families of children with autism (Franz et al., 2018). The policy, however, lacks specificity where autism is not distinguished from other developmental disabilities. Based on the recommendation emanating from the results of Study 3, it appears that the aim of developmental screening and assessment programs could indeed be non-specific, but that autism-specific screening should always be included.

Franz et al. (2018) found that the goals of the Departments of Health and Social Development do not align to support autism-specific early detection as the focus is on developmental disabilities in general. The Department of Health focuses on early identification and intervention of all developmental conditions while the Department of Social Development is responsible for the management and education of children with autism under five years (Franz et al., 2018). A disconnect is evident as the departments appear to operate in silos, not collaborating on an interdepartmental level to ensure optimal management of children with autism (Franz et al., 2018). Autism-specific early detection and intervention are, however, included in the goals of the Department of Education as part of the Policy on Screening, Identification, Assessment and Support (SIAS) of 2014. The SAIS policy provides a framework for service provision for learners who require additional support, including autism (Department of Basic Education, 2014). Improved collaboration between the various departments is required to ensure that no child with autism and their family remain undetected due to a lack of collaboration between different departments and sectors.

Universal screening for autism in South Africa may not be a viable option as the health care system and health care workers are overworked and understaffed (Fusheini & Eyles, 2016). Using the internationally recommended approach where developmental monitoring is supplemented with autism-specific screening (Barger et al., 2021; Wiggins et al., 2014), may prove to be a viable option in South Africa. This approach may use caregiver-completed checklists, mHealth applications and input from caregivers, teachers and primary care clinic staff. The use may potentially decrease the burden on the health system by providing a more holistic view of the child's

functioning before referral to specialised services is recommended (Van der Merwe et al., 2017; Du Toit el al., 2021).

6.3 Study strength and limitations

Study strengths

The most prominent strength of the study is the rigour of the comprehensive cultural adaptation and translation process of the two screening checklists. Expertise from multiple participants with in-depth insight into Northern Sotho culture and language structure allowed me to develop, fine-tune and revise the checklists to ensure reliability and concurrent validity. The expressed need by a significant number of participants for the culturally adapted English checklist may also be considered a strength of the study as the need for both versions was evident.

According to the M-CHAT™ website (accessed on 24 October 2021), the cultural adaptation and translation of the M-CHAT-R/F is the first official adaptation and translation of the screening instrument for the South African context. The South African adapted English version may promote access to an autism-specific screening instrument for a wider range of caregivers than the Northern Sotho translation. English is the most prominent language of learning and teaching in the formal school system (Posel et al., 2020) and is widely used as a common language in multilingual settings in South Africa. The M-CHAT-R/F requires only a Grade 4-level English proficiency. Both checklists will be made available on the official M-CHAT™ website following the completion of this research project. Once available on the website, the checklists can be accessed and completed by anyone including caregivers, ECD practitioners, health care workers, health professionals and allied health care professionals. The checklists are free, available through open-access and culturally fair as recommended by Franz et al. (2017).

Limitations

A limitation of the first study may be that specific community stakeholders, such as caregivers and ECD practitioners were not included as participants in the panel discussion of Study 1. Expert panel members allowed for high-quality scrutiny of the checklists, but the early involvement of the community members may have avoided

challenges, such as the confusion between finger flicking and eye rubbing, which were only identified at a later stage.

Study 2 included a small yet sufficient sample size for a pilot study (n=21) which limited the statistical analysis of the preliminary reliability of the adapted English M-CHAT-R/F and the Northern Sotho M-CHAT-R/F. A sample greater than 50 participants would have allowed for a more comprehensive statistical analysis.

The larger-scale study had a smaller sample size than intended due to limited access to participants at the data collection site during the various Covid-19 lockdown levels. An additional limitation of the final study was the lack of diagnostic confirmation of the referred case, caused by an overburdened health system.

6.4 Recommendations for future research

It is recommended that a larger-scale study with confirmatory diagnostic information is conducted to determine the sensitivity, specificity and positive predictive value of both versions of the M-CHAT-R/F. A comparison of outcome between the M-CHAT-R/F™, the adapted English M-CHAT-R/F and the Northern Sotho M-CHAT-R/F is also recommended. Translation into other official South African languages should also be considered along with the use of mHealth strategies. Further efforts should be invested to determine an effective model for the early identification of autism and developmental delays, using an autism-specific screening checklist in combination with formal developmental assessment or screening, as recommended by Barger et al. (2021).

6.5 Conclusion

A functional framework for the cultural adaptation and translation of screening instruments was developed which may be used in future cultural adaption and translation protocols of tools. The process resulted in two South African versions of the M-CHAT-R/F^{TM} with strong reliability, content and concurrent validity data. The availability of the adapted English M-CHAT-R/F and the Northern Sotho M-CHAT-R/F may enable caregivers to better understand and identify their children's behaviour while using the caregiver-completed checklists. It is anticipated that with open access to the online versions of the instruments or the use of low-tech paper copies, more children at risk of autism will be identified earlier. Earlier identification may result in

earlier intervention which can have a positive effect on the long-term prognosis of both the child with autism and their family.

REFERENCES

Abubakar, A., Holding, P., Van Baar, A., Newtown, C. R. J. C. & Van de Vijver, F. J. R. (2008). Monitoring psychomotor development in a resource-limited setting: An evaluation of the Kilifi Development Inventory. *An of Trop Paediatric*, *28*, 217–226.(Doi not available)

Aixela, J. F. (2009). An overview of interference in scientific and technical translation. *The Journal of Specialised Translation*, *11*, 75–87.(Doi not available)

Allen, A. B., Finestone, M. & Eloff, I. (2014). The role of parenting in affecting the behavior and adaptive functioning of young children of HIV-infected mothers in South Africa. *AIDS and Behaviour*, *18*(3), 605–616.(Doi not available)

Amaral, D. G., Anderson, G. M., Bailey, A., Bernier, R., Bishop, S., Blatt, G., Canal-Bedia, R., Charman, T., Dawson, G., De Vries, P. J., Dicicco-Bloom, E., Dissanayake, C., Kamio, Y., Kana, R., Khan, N. Z., Knoll, A., Kooy, F., Lainhart, J., Levitt, P., … Whitehouse, A. (2019). Gaps in current autism research: The thoughts of the autism research editorial board and associate editors. *Autism Research*, *12*(5), 700–714. https://doi.org/10.1002/aur.2101

American Psychiatric Association [APA]. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (Fifth edn.). APA.

American Speech-Language-Hearing Association. (2016). *Scope of Practice in Speech-Language Pathology [Scope of Practice].* www.asha.org/policy.

Barger, B., Rice, C., Benevides, T., Salmon, A., Sanchez-Alvarez, S. & Crimmins, D. (2021). Are developmental monitoring and screening better together for early autism identification across race and ethnic groups? *Journal of Autism and Developmental Disorders*, *Online*, 1–22. https://doi.org/10.1007/s10803-021-04943-8

Barton, M. L., Dumont-Mathieu, T. & Fein, D. (2012). Screening young children for autism spectrum disorders in primary practice. *Journal of Autism and*

Developmental Disorders, *42*(6), 1165–1174. https://doi.org/10.1007/s10803-011-1343-5

Beacham, C., Reid, M., Bradshaw, J., Lambha, M., Evans, L., Gillespie, S., Klaiman, C. & Richardson, S. S. (2018). Screening for autism spectrum disorder: Profiles of children who are missed. *Journal of Developmental and Behavioral Pediatrics*, *39*(9), 673–682. https://doi.org/10.1097/DBP.0000000000000607

Beaton, D. E., Bombardier, C., Guillemin, F. & Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*, *25*(24), 3186–3191. (Doi not available)

Black, M. M., Behrman, J. R., Daelmans, B., Prado, E. L., Richter, L., Tomlinson, M., Trude, A. C. B., Wertlieb, D., Wuermli, A. J. & Yoshikawa, H. (2021). The principles of Nurturing Care promote human capital and mitigate adversities from preconception through adolescence. *British Medical Journal Global Health*, *6*(4), 1–9. https://doi.org/10.1136/bmjgh-2020-004436

Bless, C. & Higson-Smith, C. (2013). *Fundamentals of social reseach methods* (Fifth edn.). Juta & Company Ltd.

Brennan, L., Fein, D., Como, A., Rathwell, I. C. & Chen, C. M. (2016). Use of the Modified Checklist for Autism, Revised with Follow Up-Albanian to screen for ASD in Albania. *Journal of Autism and Developmental Disorders*, *46*(11), 3392–3407. https://doi.org/10.1007/s10803-016-2875-5

Broder-Fingert, S., Mateo, C. M. & Zuckerman, K. E. (2020). Structural racism and autism. *Pediatrics*, *146*(3), 2019–2022. https://doi.org/10.1542/PEDS.2020-015420

Camarata, S. (2014). Early identification and early intervention in autism spectrum disorders: Accurate and effective? *International Journal of Speech-Language Pathology*, *16*(1), 1–10. https://doi.org/10.3109/17549507.2013.858773

Centers for Disease Control and Prevention. (2012). Prevalence of autism spectrum disorders — Autism and developmental disabilities Monitoring Network, 14 Sites, United States, 2008. *Morbidity and Mortality Weekly Report*, *61*(3), 1–19. https://doi.org/ss6103a1 [pii].

Centers for Disease Control and Prevention. (2014). Prevalence of autism spectrum disorder among children aged 8 years. *Morbidity and Mortality Weekly Report. Surveillance Summaries (Washington, D.C.: 2002)*, *63*(2), 1–21. http://www.ncbi.nlm.nih.gov/pubmed/24670961

Choueiri, R., Lindenbaum, A., Ravi, M., Robsky, W., Flahive, J. & Garrison, W. (2021). Improving early identification and access to diagnosis of autism spectrum disorder in toddlers in a culturally diverse community with the rapid interactive screening test for autism in toddlers. *Journal of Autism and Developmental Disorders*, *Online*, 1–16. https://doi.org/10.1007/s10803-020-04851-3

Cnattingius, S., Norman, M., Granath, F., Petersson, G., Stepahnsson, O., & Frisell, T. (2017). APGAR score components at 5 minutes: Risks and prediction of neonatal mortality. *Paediatric and Perinatal Epidemiology*, *31*(4), 328-337. https://doi. org/10.1111/ppe.12360

De Vries, P. J. (2016). Thinking globally to meet local needs: Autism spectrum disorders in Africa and other low-resource environments. *Current Opinion in Neurology*, *29*(2), 130–136. https://doi.org/10.1097/WCO.0000000000000297

Delport, C. S. L. & De Vos, A. S. (2015). Professional research and professional practice. In A. S. De Vos, H. Strydom, C. B. Fouché & C. S. L. Delport (Eds.), *Research at grass roots* (Fourth edn., 45–60). Van Schaik Publishers.

Du Toit, M., Van der Linde, J. & Swanepoel, D. W. (2021). Early childhood development risks and protective factors in vulnerable preschool children from low-income communities in South Africa. *Journal of Community Health*, *46*, 304–312. https://doi.org/10.1007/s10900-020-00883-z

DuBay, M. (2020). *Translation and cultural adaptation of autism screening tools.* [University of North Carolina]. https://doi.org/10.17615/fcwc-c425

DuBay, M., Watson, L. R., Baranek, G. T., Lee, H., Rojevic, C., Brinson, W., Smith, D. & Sideris, J. (2021). Rigorous translation and cultural adaptation of an autism screening tool: First years inventory as a case study. *Journal of Autism and Developmental Disorders*, Online, 1-13. https://doi.org/10.1007/s10803-020-04837-1

Eisenhower, A., Martinez Pedraza, F., Sheldrick, R. C., Frenette, E., Hoch, N., Brunt, S. & Carter, A. S. (2021). Multi-stage screening in early intervention: A critical strategy for improving ASD identification and addressing disparities. *Journal of Autism and Developmental Disorders*, *51*(3), 868–883. https://doi.org/10.1007/s10803-020-04429-z

Erasmus, S., Kritzinger, A. & Van der Linde, J. (2019). Onset of intervention for learners in autism-specific government-funded schools in South Africa. *International Journal of Disability, Development and Education*, *68*(1), 46–61. https://doi.org/10.1080/1034912X.2019.1653449

Erasmus, S., Kritzinger, A. & Van Der Linde, J. (2019). Profiles of public and private autism-specific schools in Gauteng. *South African Journal of Childhood Education*, *9*(1), 1–10. https://doi.org/10.4102/sajce.v9i1.691

Field, A. (2009). *Discovering statistics using SPSS* (Third edn.). SAGE Publications.

Fischer, V. J., Morris, J. & Martines, J. (2014). Developmental screening tools: Feasibility of use at primary healthcare level in low- and middle-income settings. *Journal of Health Population and Nutrition*, *32*(2), 314–326. (Doi not available)

Fouche, C. B. & Bartley, A. (2015). Quantitave data analysis and interpretation. In A. De Vos, H. Strydom, C.B. Fouché & C. S. Delport (Eds.), *Research at grass roots* (Fourth edn.), 248–294. Van Schaik Publishers.

Franz, L., Adewumi, K., Chambers, N., Viljoen, M., Baumgartner, J. N. & De Vries, P. J. (2018). Providing early detection and early intervention for autism spectrum disorder in South Africa: Stakeholder perspectives from the Western Cape province. *Journal of Child and Adolescent Mental Health*, *30*(3), 149–165. https://doi.org/10.2989/17280583.2018.1525386

Franz, L., Chambers, N., Von Isenburg, M. & De Vries, P. J. (2017). Autism spectrum disorder in Sub-Saharan Africa: A comprehensive scoping review.

Autism Research, *10*(5), 723–749. https://doi.org/10.1002/aur.1766

French, L. & Kennedy, E. M. M. (2018). Annual research review: Early intervention for infants and young children with, or at-risk of, autism spectrum disorder: A systematic review. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *59*(4), 444–456. https://doi.org/10.1111/jcpp.12828

Fuller, E. A. & Kaiser, A. P. (2020). The effects of early intervention on social communication outcomes for children with autism spectrum disorder: A meta-analysis. *Journal of Autism and Developmental Disorders*, *50*(5), 1683–1700. https://doi.org/10.1007/s10803-019-03927-z.

Fusheini, A. & Eyles, J. (2016). Achieving universal health coverage in South Africa through a district health system approach: Conflicting ideologies of health care provision. *BMC Health Services Research*, *16*(1), 1–11. https://doi.org/10.1186/s12913-016-1797-4

Fyvie, L., Anderson, J., Kruger, C. J., Roux, M. Le & Van der Linde, J. (2016). The outcome of a developmental screening tool (PEDS) in English and Northern Sotho: A comparative study. *Language Matters*, *47*(3), 415–426. https://doi.org/10.1080/10228195.2016.1196718

Gauton, R., Taljard, E., Mabasa, T. & Netshitomboni, L. (2008). Translating technical texts into the official South African languages: A corpus-based investigation of translators' strategies. *Language Matters*, *39*(2), 415–426. https://doi.org/10.1080/10228195.2016.1196718.

Glascoe, F. P. (2013). *Collaborating with parents: Using Parents' Evaluation of Developmental Status to detect and address developmental and behavioural problems.* (Second edn.). www.PEDStest.com

Gouws, R. H. & Prinsloo, D. J. (2005). *Principles and practices of South African lexicography*. African Sun Media.

Graif, C., Meurer, J. & Fontana, M. (2021). An ecological model to frame the delivery of pediatric rreventive care. *Pediatrics*, *148*(July), e202105693D. https://doi.org/10.1542/peds.2021-050693D

Grinker, R. R., Chambers, N., Njongwe, N., Lagman, A. E., Guthrie, W., Stronach, S., Richard, B. O., Kauchali, S., Killian, B., Chhagan, M., Yucel, F., Kudumu, M.,

Barker-Cummings, C., Grether, J. & Wetherby, A. M. (2012). “Communities” in community engagement: Lessons learned from autism research in South Korea and South Africa. In *Autism Research*,*5*(3), 201–210. https://doi.org/10.1002/aur.1229

Guthrie, W., Wallis, K., Bennett, A., Brooks, E., Dudley, J., Gerdes, M., Pandey, J., Levy, S. E., Schultz, R. T. & Miller, J. S. (2019). Accuracy of autism screening in a large pediatric network. *Pediatrics*, *144*(4), e20183936. https://doi.org/10.1542/peds.2018-3963

Hambleton, R. K. & Zenisky, A. L. (2011). Translating and adapting tests for cross-cultural assessment. In D. Mutsamoto & F. J. R. Van de Vijver (Eds.), *Cross-cultural research methods in Psychology* (pp. 46–74). Cambridge University Press.

Hyman, S. L., Levy, S. E., Myers, S. M. & AAP Council on Children with Disability. (2020). Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics*, *145*(1), e201934447. https://doi.org/10.1542/peds.2019-3447

International Test Commission. (2017). *The ITC guidelines for translating and adapting tests (Second edn.)*. www.InTestCom.org

Johnson, C. P., Myers, S. M., Lipkin, P. H., Cartwright, J. D., Desch, L. W., Duby, J. C., Elias, E. R., Levey, E. B., Liptak, G. S., Murphy, N. A., Tilton, A. H., Lollar, D., Macias, M., McPherson, M., Olson, D. G., Strickland, B., Skipper, S. M., Ackermann, J., Del Monte, M., … Yeargin-Allsopp, M. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, *120*(5), 1183–1215. https://doi.org/10.1542/peds.2007-2361

Kautzky, K. & Tollman, S. M. (2008). A Perspective on Primary Health Care in South Africa. *South African Health Review 2008*, 17–30.

King, R. B., Neilson, E. & King, T. M. (2021). Challenges and opportunities to bolster the effectiveness of childhood screening. *Pediatrics*, *148*(July), e2021050693K. https://doi.org/10.1542/peds.2021-050693K

Lee, J. D. & Meadan, H. (2021). Children with autism spectrum disorders in low-resource settings: Reported experiences and needs of parents in Mongolia.

Journal of Autism and Developmental Disorders, *Online*, 1–10. https://doi.org/10.1007/s10803-020-04818-4

Leedy, P. D. & Ormrod, J. E. (2015). *Practical Research: Planning and Design* (Eleventh edn.). Pearson.

Lewis, J. D., Evans, A. C., Pruett, J. R., Botteron, K., Zwaigenbaum, L., Estes, A., Gerig, G., Collins, L., Kostopoulos, P., McKinstry, R., Dager, S., Paterson, S., Schultz, R. T., Styner, M., Hazlett, H. & Piven, J. (2014). Network inefficiencies in autism spectrum disorder at 24 months. *Translational Psychiatry*, *4*, e388. https://doi.org/10.1038/tp.2014.24

Lilley, R. (2017). What's in a flap? The curious history of autism and hand stereotypies. *Neurosocieties Symposium Proceedings : Explorations of the Brain, Culture, and Ethics*, 25 *August*, 1–21.

Lipkin, P. H. & Macias, M. M. (2020). Promoting optimal development: Identifying infants and young children with developmental disorders through developmental surveillance and screening. *Pediatrics*, *145*(1), e20193449. https://doi.org/10.1542/peds.2019-3449

Lord, C., Elsabbagh, M., Baird, G. & Veenstra-Vanderweele, J. (2018). Autism spectrum disorder. *The Lancet*, *392*(10146), 508–520. https://doi.org/10.1016/S0140-6736(18)31129-2

Madipakkam, A. P., Rothkirch, M., Dziobek, I. & Sterzer, P. (2017). Unconscious avoidance of eye contact in autism spectrum disorder. *Scientific Reports*, *7*(13378), 1–6. https://doi.org/10.1038/s41598-017-13945-5

Maenner, M. J., Shaw, K. A., Baio, J., Washington, A., Patrick, M., DiRienzo, M., Christensen, D. L., Wiggens, L. D., Pettygrove, S., Andrews, J. G., Lopez, M., Hudson, A., Baroud, T., Schwenk, Y., White, T., Hall-Lande, J., Poynter, J. N., Hallas-Muchow, L., Constantino, J. N., … Dietz, P. M. (2020). Erratum: Prevalence of autism spectrum disorder among children aged 8 years - Autism and developmental disabilities monitoring network, 11 Sites, United States, 2016. *Morbidity and Mortality Weekly Report*, *69*(16), 503–511. https://doi.org/10.15585/MMWR.MM6916A4

Malcolm-Smith, S., Hoogenhout, M., Ing, N., Thomas, K. G. F. & De Vries, P. (2013).

Autism spectrum disorders - Global challenges and local opportunities. *Journal of Child and Adolescent Mental Health*, *25*(1), 1–5. https://doi.org/10.2989/17280583.2013.767804

Marlow, M., Servili, C. & Tomlinson, M. (2019). A review of screening tools for the identification of autism spectrum disorders and developmental delay in infants and young children: Recommendations for use in low- and middle-income countries. *Autism Research*, *12*(2), 176–199. https://doi.org/10.1002/aur.2033

Mncwango, E. M. (2009). Language and the current challenges in the South African school system. *Inkanyiso: Journal of Humanities and Social Sciences*, *1*(1), 51–54. (Doi not available)

Mojaki, M. E., Basu, D., Letskokgohka, M. E. & Govender, M. (2011). Referral steps in district health system are side-stepped. *South African Medical Journal*, *101*(2), 109. https://doi.org/10.7196/samj.4385

Mophosho, M., Khoza-Shangase, K. & Sebole, L. L. (2019). The reading comprehension of Grade 5 Setswana-speaking learners in rural schools in South Africa: Does home language matter? *Per Linguam*, *35*(3), 59–73. https://doi.org/10.5785/35-3-844

Morelli, D. L., Pati, S., Butler, A., Blum, N. ., Gerdes, M., Pinto-Martin, J. & Guevara, J. . (2014). Challenges to implementation of developmental screening in urban primary care: A mixed methods study. *Pediatrics*, *14*(16), 1–11. https://doi.org/http:/www.biomedcentral.com/1471-2431/14/16

Mtsatse, N. & Combrinck, C. (2018). Dialects matter: The influence of dialects and code-switching on the literacy and numeracy achievements of isiXhosa Grade 1 learners in the Western Cape. *Journal of Education*, *1776*(72), 19–36. https://doi.org/10.17159/2520-9868/i72a02

National Perinatal Morbidity and Mortality Committee. (2016). Napemmco Triennial report 2014-2016 Saving Babies report. In *Department of Health*, *1*(1), 1-92. https://www.westerncape.gov.za/assets/departments/health/napemmco_triennial_report_2014-2016_saving_babies.pdf

Olusanya, B. O., Davis, A. C., Wertlieb, D., Boo, N. Y., Nair, M. K. C., Halpern, R., Kuper, H., Breinbauer, C., De Vries, P. J., Gladstone, M., Halfon, N., Kancherla,

V., Mulaudzi, M. C., Kakooza-Mwesige, A., Ogbo, F. A., Olusanya, J. O., Williams, A. N., Wright, S. M., Manguerra, H., … Kassebaum, N. J. (2018). Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: A systematic analysis for the global burden of disease study 2016. *The Lancet Global Health*, *6*(10), e1100–e1121. https://doi.org/10.1016/S2214-109X(18)30309-7

Ortiz-Gutiérrez, S. & Cruz-Avelar, A. (2018). Translation and Cross-Cultural Adaptation of Health Assessment Tools. *Actas Dermo-Sifiliográficas (English edn.)*, *109*(3), 202–206. https://doi.org/10.1016/j.adengl.2018.02.003

Pepperdine, C. R. & McCrimmon, A. W. (2018). Test review: Vineland Adaptive Behavior Scales, Third Edition (Vineland-3) by Sparrow, S. S., Cicchetti, D. V., & Saulnier, C. A. *Canadian Journal of School Psychology*, *33*(2), 157–163. https://doi.org/10.1177/0829573517733845

Peters, W. J. & Matson, J. L. (2019). The relationship between developmental functioning and screening outcome for autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, *Online*, 1–14. https://doi.org/10.1007/s10882-019-09689-x

Pierce, K., Gazestani, V. H., Bacon, E., Barnes, C. C., Cha, D., Nalabolu, S., Lopez, L., Moore, A., Pence-Stophaeros, S. & Courchesne, E. (2019). Evaluation of the diagnostic stability of the early autism spectrum disorder phenotype in the general population dtarting at 12 months. *JAMA Pediatrics*, *173*(6), 578–587. https://doi.org/10.1001/jamapediatrics.2019.0624

Pillay, S., Duncan, M. & De Vries, P. J. (2021). Autism in the Western Cape province of South Africa: Rates, socio-demographics, disability and educational characteristics in one million school children. *Autism*, *25*(4), 1076–1089. https://doi.org/10.1177/1362361320978042

Posel, D., Hunter, M. & Rudwick, S. (2020). Revisiting the prevalence of English: language use outside the home in South Africa. *Journal of Multilingual and Multicultural Development*, 1–13. https://doi.org/10.1080/01434632.2020.1778707

Posel, D. & Zeller, J. (2016). Language shift or increased bilingualism in South

Africa: Evidence from census data. *Journal of Multilingual and Multicultural Development*, *37*(4), 357–370. https://doi.org/10.1080/01434632.2015.1072206

Rahman, A., Iqbal, Z., Waheed, W. & Hussain, N. (2003). Translation and cultural adaptation of health questionnaires*. The Journal of the Pakistan Medical Association 53*(4), 1-7. (Doi not available)

Rea, K. E., Armstrong-Brine, M., Ramirez, L. & Stancin, T. (2019). Ethnic disparities in autism spectrum disorder screening and referral: Implications for pediatric practice. *Journal of Developmental and Behavioral Pediatrics*, *40*(7), 493–500. https://doi.org/10.1097/DBP.0000000000000691

Robins, D. L. (2020). How do we determine the utility of screening tools? *Autism*, *24*(2), 271–273. https://doi.org/10.1177/1362361319894170

Robins, D. L., Casagrande, K., Barton, M., Chen, C.-M. A., Dumont-Mathieu, T. & Fein, D. (2014). Validation of the Modified Checklist for Autism in Toddlers, Revised With Follow-up (M-CHAT-R/F). *Pediatrics*, *133*(1), 37–45. https://doi.org/10.1542/peds.2013-1813

Robins, D. L., Fein, D. & Barton, M. (2018). *Modified Checklist for Autism in Toddlers, Revised with Follow-up*. Self Published. https://mchatscreen.com/

Saldana, J. (2016). *The coding manual for qualitative researchers* (Third edn.). SAGE Publications.

Samuels, A., Slemming, W. & Balton, S. (2012). Early childhood intervention in south africa in relation to the developmental systems model. *Infants and Young Children*, *25*(4), 334–345. https://doi.org/10.1097/IYC.0b013e3182673e12

Schurink, W., Fouche, C. B. & De Vos, A. S. (2015). Qualitative data analysis and interpretation. In A. S. De Vos, C. B. Fouche, H. Strydom & C. S. L. Delport (Eds.), *Research at grass roots* (Fourth edn.), 397–423. Van Schaik Publishers.

Slemming, W. & Bamford, L. (2018). The new Road to Health Booklet demands a paradigm shift. *South African Journal of Child Health*, *12*(3), 86–87. https://doi.org/10.7196/SAJCH.2018.v12i3.1595

Soto, S., Linas, K., Jacobstein, D., Biel, M., Migdal, T. & Anthony, B. J. (2015). A review of cultural adaptations of screening tools for autism spectrum disorders. *Autism*, *19*(6), 646–661. https://doi.org/10.1177/1362361314541012

South African Government. (2015). National Integrated Early Childhood Development Policy 2015. *Government Printers*, 140. https://www.gov.za/documents/national-integrated-early-childhood-development-policy-2015-2-aug-2016-0000

Sparrow, S.S., Cicchetti, D. V. & Saulnier, C. A. (2016). *Vineland Adaptive Behaviour Scales - Third Edition*. Pearson.

StatsSA. (2011). Statistical Release: Census 2011. In *Statistics South Africa*. https://doi.org/10.1016/s0022-5223(11)01322-5

StatsSA. (2019). *City of Tshwane: People*. http://www.statssa.gov.za/?page_id=993&id=city-of-tshwane-municipality

Stewart, L. A. & Lee, L. C. (2017). Screening for autism spectrum disorder in low- and middle-income countries: A systematic review. *Autism*, *21*(5), 527–539. https://doi.org/10.1177/1362361316677025

Sutton, J. & Austin, Z. (2015). Qualitative research: Data collection, analysis, and management. *Canadian Journal of Hospital Pharmacy*, *68*(3), 226–231. https://doi.org/10.4212/cjhp.v68i3.1456

Taljard, E. (2008). Terminology practices in a non-standardised environment: A case study. *EURALEX International Congress*.

United Nations: Division for social policy and development (DSPD). (2017). Culture, beliefs, and disability. In *Toolkit On Disability For Africa*.

Van Biljon, S., Kritzinger, A. & Geertsema, S. (2015). A retrospective case report on demographic changes of learners at a school for children with Autism Spectrum Disorder in the Gauteng Province. *South African Journal of Childhood Education*, *5*(1), 42–61. https://doi.org/10.4102/sajce.v5i1.349

Van der Linde, J., Swanepoel, D. W., Glascoe, F. P., Louw, E. M. & Vinck, B. (2015). Developmental screening in South Africa: Comparing the national developmental checklist to standerdized tool. *African Health Sciences*, *15*(1), 188–196. http://dx.doi.org/10.4314/ahs.v15i1.25

Van der Merwe, M., Cilliers, M., Maré, C., Van der Linde, J. & Le Roux, M. (2017). Evaluation of a Zulu translation of the Parents' Evaluation of Developmental Status. *African Journal of Primary Health Care and Family Medicine*, *9*(1), 1–6.

https://doi.org/10.4102/phcfm.v9i1.1365

Van der Merwe, M. N., Mosca, R., Swanepoel, D., Glascoe, F. P. & Van der Linde, J. (2019). Early detection of developmental delays in vulnerable children by community care workers using an mHealth tool. *Early Child Development and Care*, *189*(5), 855–866. https://doi.org/10.1080/03004430.2018.1480481

Vorster, C., Kritzinger, A., Coetser, L. & Van der Linde, J. (2021). Preliminary reliability of South African adaptation and Northern Sotho translation of the Modified Checklist for Autsim in Toddlers, Revised with Follow-Up. *South African Journal of Communication Disorders*, *68*(1), 1–7. https://doi.org/10.4102/sajcd.v68i1.831

Vorster, C., Kritzinger, A., Lekganyane, M., Taljard, E. & Van der Linde, J. (2021). Cultural adaptation and Northern Sotho translation of the Modified Checklist for Autism in Toddlers, Revised with Follow-up (M-CHAT-R/F). *South African Journal of Childhood Education*, *(In Press)*.

Wallis, K. E. (2021). The roadmap to early and equitable autism ddentification. *Pediatrics*, *148*(July), e2021050693E. https://doi.org/10.1542/peds.2021-050693E

Watermeyer, B., Swarz, L., Lorenzo, T., Schneider, M. & Priestley, M. (2006). *Disability and social change: A South African agenda*. HSRC Press.

Wiggins, L. D., Piazza, V. & Robins, D. L. (2014). Comparison of a broad-based screen versus disorder-specific screen in detecting young children with an autism spectrum disorder. *Autism*, *18*(2), 76–84. https://doi.org/10.1177/1362361312466962

World Health Organization. (2005). *Disability, Including Prevention, Management and Rehabilitation*. Agenda Item 13.13. In: Fifty-eight World Health Assembly., Geneva: World Health Organization, 97-100

World Health Organisation. (2013a). *Process of translation and adaptation of instruments*. https://doi.org//entity/substance_abuse/research_tools/translation/en/index.html

World Health Organization. (2013b). *Autism spectrum disorders & other developmental disorders. From raising awareness to building capacity*.

https://www.who.int/mental_health/maternal-child/autism_report/en/

World Health Organization. (2018). *Primary health care: Closing the gap between public health and primary care through integration*. 20. https://www.who.int/health-topics/primary-health-care#tab=tab_1

Yama, B., Freeman, T., Graves, E., Yuan, S. & Karen Campbell, M. (2012). Examination of the properties of the Modified Checklist for Autism in Toddlers (M-CHAT) in a population sample. *Journal of Autism and Developmental Disorders*, *42*(1), 23–34. https://doi.org/10.1007/s10803-011-1211-3

Zeleke, W. A., Hughes, T. L. & Drozda, N. (2019). Disparities in diagnosis and service access for minority children with ASD in the United States. *Journal of Autism and Developmental Disorders*, *49*(10), 4320–4331. https://doi.org/10.1007/s10803-019-04131-9

Zwaigenbaum, L. & Penner, M. (2018). Autism spectrum disorder: Advances in diagnosis and evaluation. *British Medical Journal (Online)*, *361*, 1–16. https://doi.org/10.1136/bmj.k1674

APPENDICES

Appendix A: Modified Checklist for Autism in Toddlers, Revised with Follow-Up™

Modified Checklist for Autism in Toddlers, Revised, with Follow-Up

(M-CHAT-R/F)™

Diana L. Robins, Ph.D.
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Acknowledgement: We thank the M-CHAT Study Group in Spain for developing the flow chart format used in this document.

For more information, please see www.mchatscreen.com
or contact Diana Robins at mchatscreen2009@gmail.com

Note. This version contains minor corrections. August 10, 2018.

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Permissions for Use of the M-CHAT-R/F™

The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is a 2-stage parent-report screening tool to assess risk for Autism Spectrum Disorder (ASD). The M-CHAT-R/F is available for free download for clinical, research, and educational purposes. Download of the M-CHAT-R/F and related material is authorized from www.mchatscreen.com.

The M-CHAT-R/F is a copyrighted instrument, and use of the M-CHAT-R/F must follow these guidelines:

(1) Reprints/reproductions of the M-CHAT-R must include the copyright at the bottom (© 2009 Robins, Fein, & Barton). No modifications can be made to items, instructions, or item order without permission from the authors.

(2) The M-CHAT-R must be used in its entirety. Evidence indicates that any subsets of items do not demonstrate adequate psychometric properties.

(3) Parties interested in reproducing the M-CHAT-R/F in print (e.g., a book or journal article) or electronically for use by others (e.g., as part of digital medical record or other software packages) must contact Diana Robins to request permission (mchatscreen2009@gmail.com).

(4) If you are part of a medical practice, and you want to incorporate the first stage M-CHAT-R questions into your own practice's electronic medical record (EMR), you are welcome to do so. However, if you ever want to distribute your EMR page outside of your practice, please contact Diana Robins to request a licensing agreement.

Instructions for Use

The M-CHAT-R can be administered and scored as part of a well-child care visit, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT-R is to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk will be diagnosed with ASD. To address this, we have developed the Follow-Up questions (M-CHAT-R/F). Users should be aware that even with the Follow-Up, a significant number of the children who screen positive on the M-CHAT-R will not be diagnosed with ASD; however, these children are at high risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive. The M-CHAT-R can be scored in less than two minutes. Scoring instructions can be downloaded from http://www.mchatscreen.com. Associated documents will be available for download as well.

Scoring Algorithm

For all items except 2, 5, and 12, the response "NO" indicates ASD risk; for items 2, 5, and 12, "YES" indicates ASD risk. The following algorithm maximizes psychometric properties of the M-CHAT-R:

LOW-RISK: **Total Score is 0-2**; if child is younger than 24 months, screen again after second birthday. No further action required unless surveillance indicates risk for ASD.

MEDIUM-RISK: **Total Score is 3-7**; Administer the Follow-Up (second stage of M-CHAT-R/F) to get additional information about at-risk responses. If M-CHAT-R/F score remains at 2 or higher, the child has screened positive. Action required: refer child for diagnostic evaluation and eligibility evaluation for early intervention. If score on Follow-Up is 0-1, child has screened negative. No further action required unless surveillance indicates risk for ASD. Child should be rescreened at future well-child visits.

HIGH-RISK: **Total Score is 8-20**; It is acceptable to bypass the Follow-Up and refer immediately for diagnostic evaluation and eligibility evaluation for early intervention.

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M-CHAT-R™

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer no. Please circle yes or no for every question. Thank you very much.

1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)	Yes	No
2. Have you ever wondered if your child might be deaf?	Yes	No
3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)	Yes	No
4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs)	Yes	No
5. Does your child make unusual finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)	Yes	No
6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach)	Yes	No
7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)	Yes	No
8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)	Yes	No
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)	Yes	No
10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Yes	No
11. When you smile at your child, does he or she smile back at you?	Yes	No
12. Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?)	Yes	No
13. Does your child walk?	Yes	No
14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Yes	No
15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)	Yes	No
16. If you turn your head to look at something, does your child look around to see what you are looking at?	Yes	No
17. Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me"?)	Yes	No
18. Does your child understand when you tell him or her to do something? (FOR EXAMPLE, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket"?)	Yes	No
19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Yes	No
20. Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee)	Yes	No

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M-CHAT-R Follow-Up (M-CHAT-R/F)™

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The Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is designed to accompany the M-CHAT-R. The M-CHAT-R/F may be downloaded from www.mchatscreen.com.

The M-CHAT-R/F is a copyrighted instrument, and use of this instrument is limited by the authors and copyright holders. The M-CHAT-R and M-CHAT-R/F may be used for clinical, research, and educational purposes. Although we are making the tool available free of charge for these uses, this is copyrighted material and it is not open source. Anyone interested in using the M-CHAT-R/F in any commercial or electronic products must contact Diana L. Robins at mchatscreen2009@gmail.com to request permission.

Instructions for Use

The M-CHAT-R/F is designed to be used with the M-CHAT-R; the M-CHAT-R is valid for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorder (ASD). Users should be aware that even with the Follow-Up, a significant number of the children who fail the M-CHAT-R will not be diagnosed with ASD; however, these children are at risk for other developmental disorders or delays, and therefore, follow-up is warranted for any child who screens positive.

Once a parent has completed the M-CHAT-R, score the instrument according to the instructions. If the child screens positive, select the Follow-Up items based on which items the child failed on the M-CHAT-R; only those items that were originally failed need to be administered for a complete interview.

Each page of the interview corresponds to one item from the M-CHAT-R. Follow the flowchart format, asking questions until a PASS or FAIL is scored. Please note that parents may report "maybe" in response to questions during the interview. When a parent reports "maybe," ask whether most often the answer is "yes" or "no" and continue the interview according to that response. In places where there is room to report an "other" response, the interviewer must use his/her judgment to determine whether it is a passing response or not.

Score the responses to each item on the M-CHAT-R/F Scoring Sheet (which contains the same items as the M-CHAT-R, but Yes/No has been replaced by Pass/Fail). The interview is considered to be a screen positive if the child fails any two items on the Follow-Up. If a child screens positive on the M-CHAT-R/F, it is strongly recommended that the child is referred for early intervention and diagnostic testing as soon as possible. Please note that if the healthcare provider or parent has concerns about ASDs, children should be referred for evaluation regardless of the score on the M-CHAT-R or M-CHAT-R/F.

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M-CHAT-R Follow-Up™ Scoring Sheet

Please note: Yes/No has been replaced with Pass/Fail

1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)	Pass	Fail
2. Have you ever wondered if your child might be deaf?	Pass	Fail
3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal)	Pass	Fail
4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs)	Pass	Fail
5. Does your child make unusual finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)	Pass	Fail
6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach)	Pass	Fail
7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)	Pass	Fail
8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)	Pass	Fail
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)	Pass	Fail
10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Pass	Fail
11. When you smile at your child, does he or she smile back at you?	Pass	Fail
12. Does your child get upset by everyday noises? (FOR EXAMPLE, a vacuum cleaner or loud music)	Pass	Fail
13. Does your child walk?	Pass	Fail
14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Pass	Fail
15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)	Pass	Fail
16. If you turn your head to look at something, does your child look around to see what you are looking at?	Pass	Fail
17. Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me")	Pass	Fail
18. Does your child understand when you tell him or her to do something? (FOR EXAMPLE, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket")	Pass	Fail
19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Pass	Fail
20. Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee)	Pass	Fail

Total Score: _____

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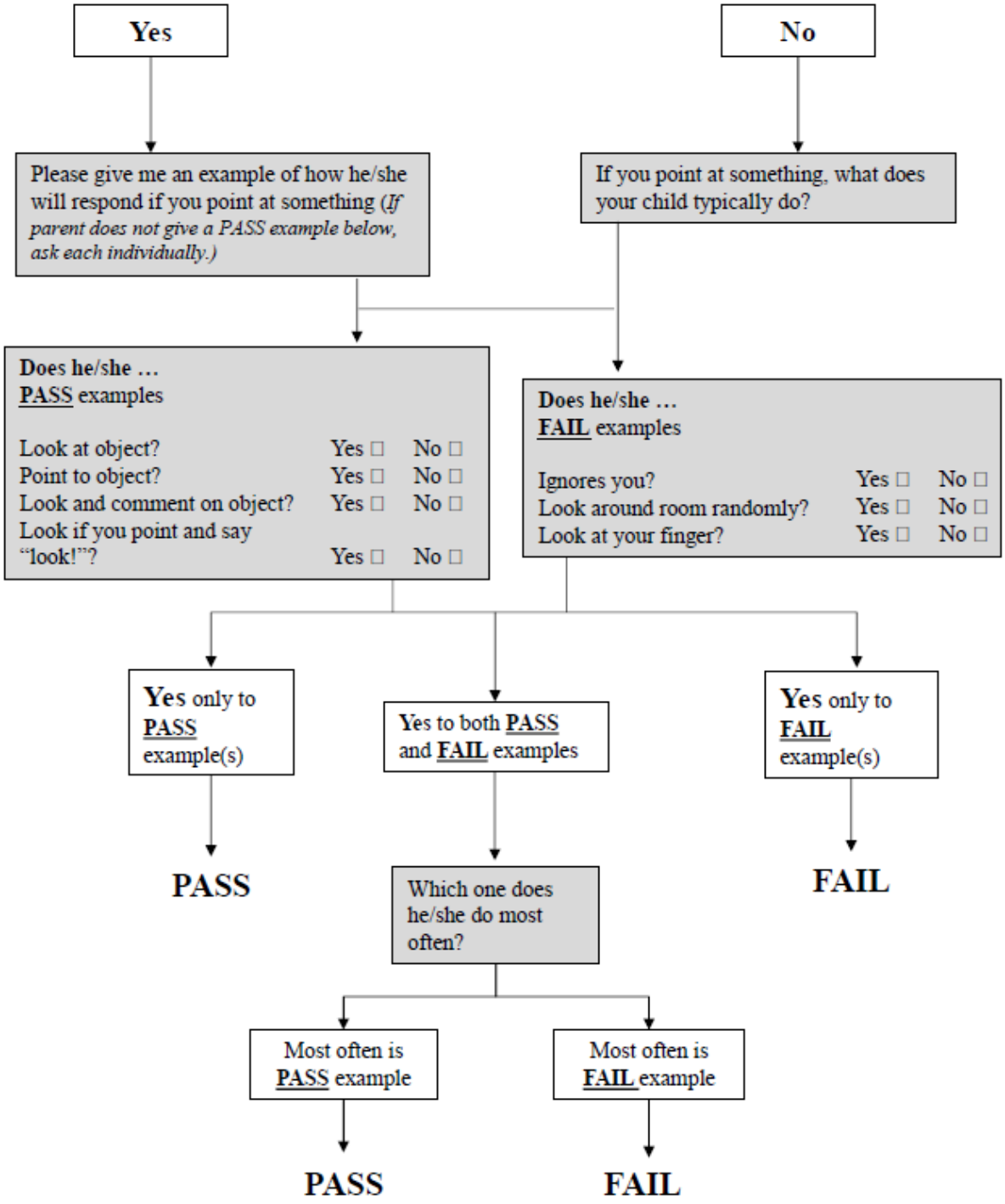
1. If you point at something across the room, does _____ look at it?



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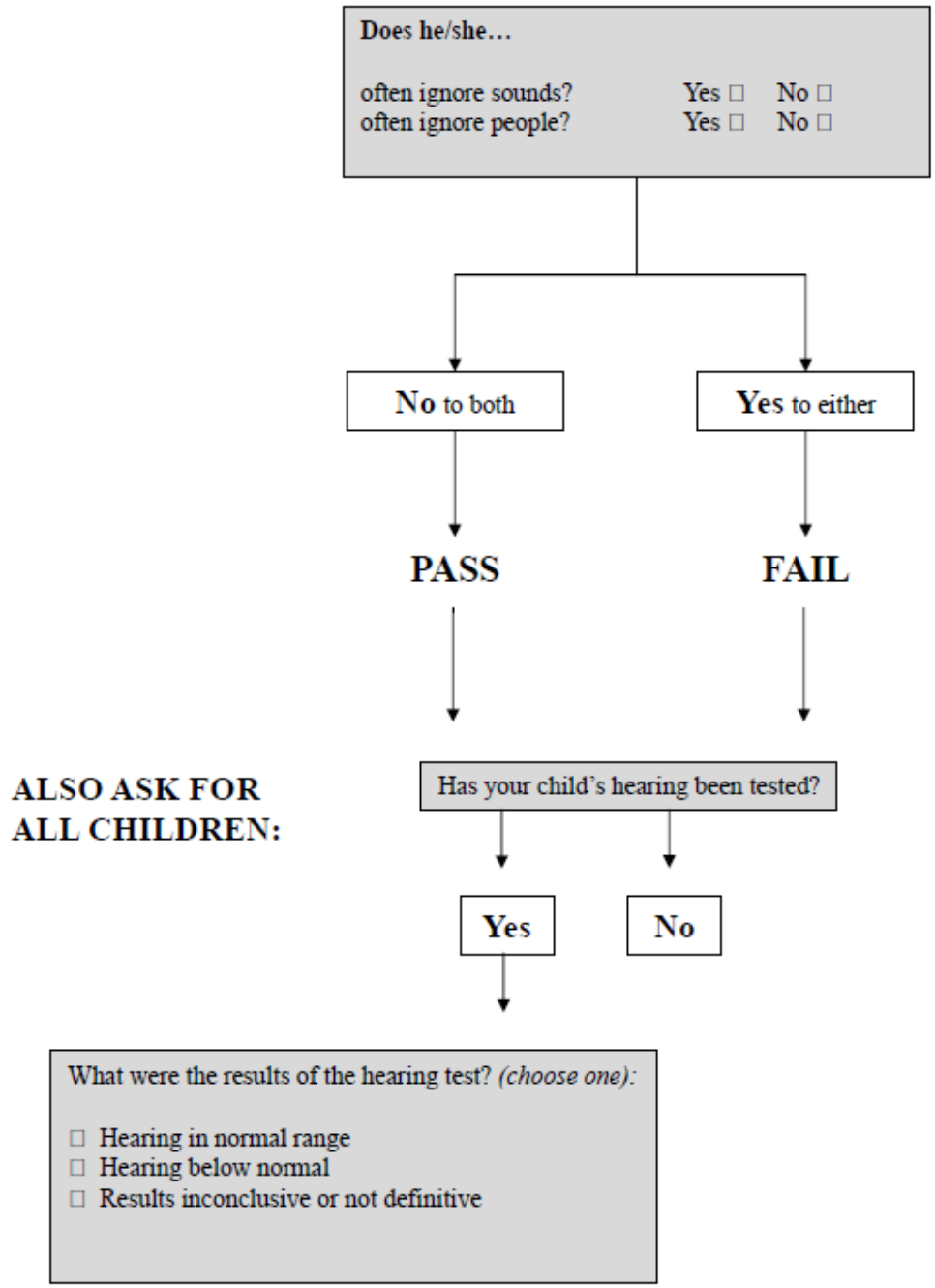
2. You reported that you have wondered if you child is deaf. What led you to wonder that?



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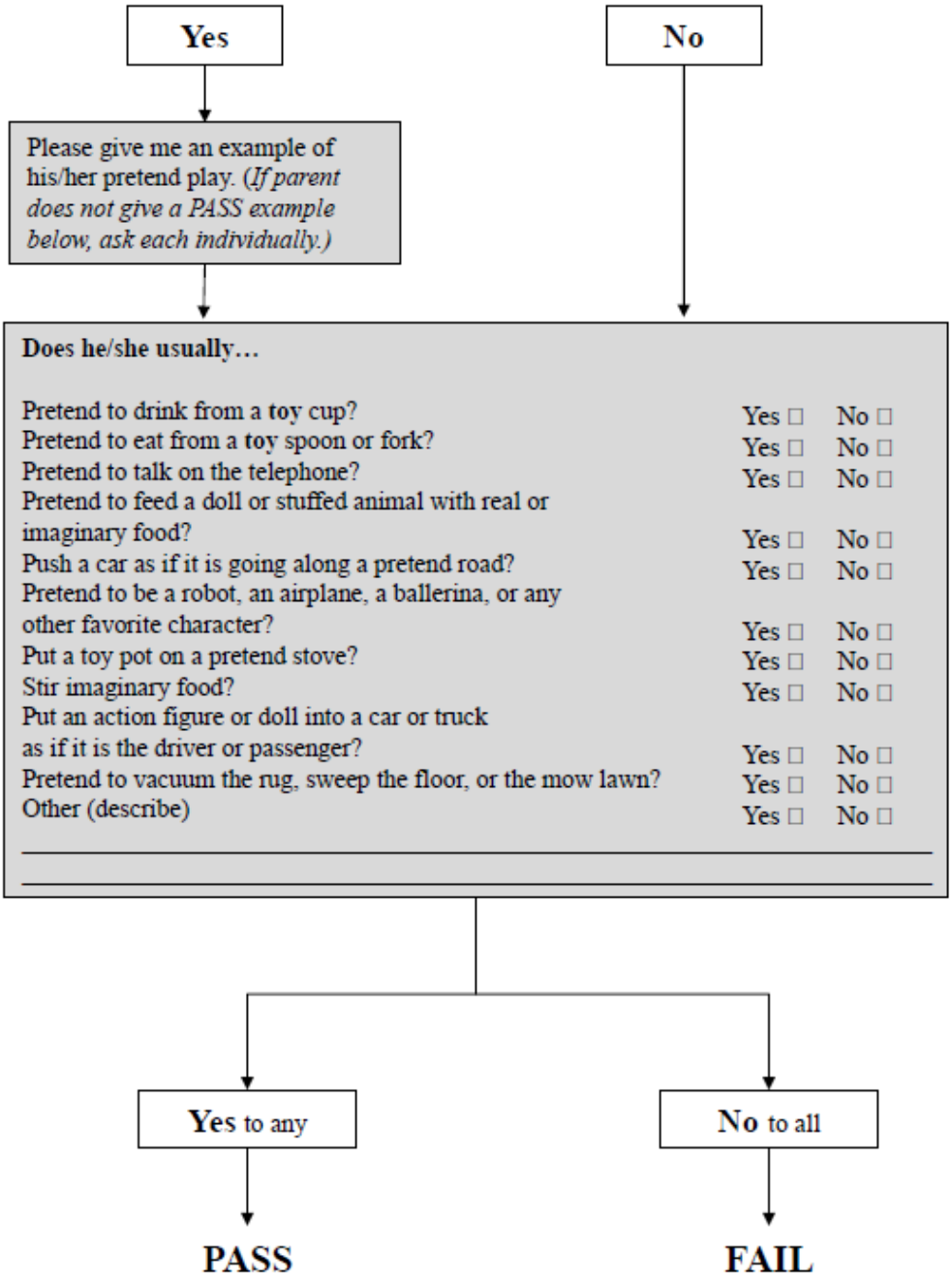
3. Does _____ play pretend or make-believe?



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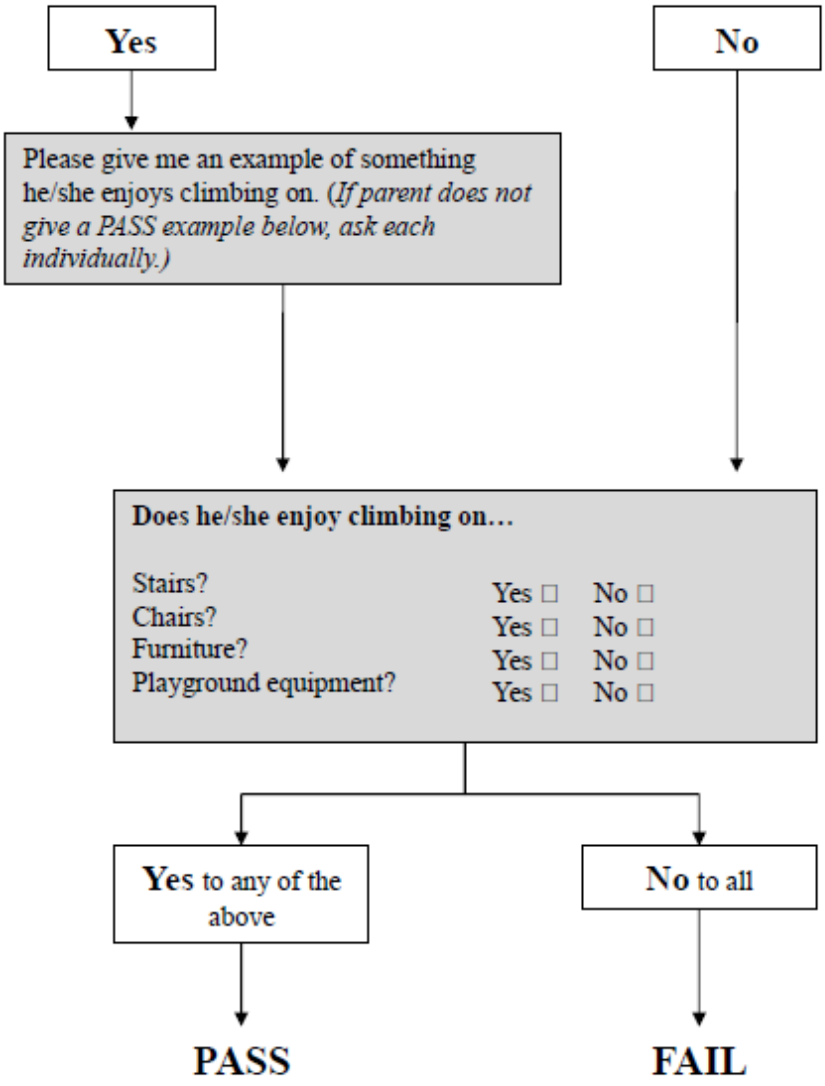
4. Does _____ like climbing on things?



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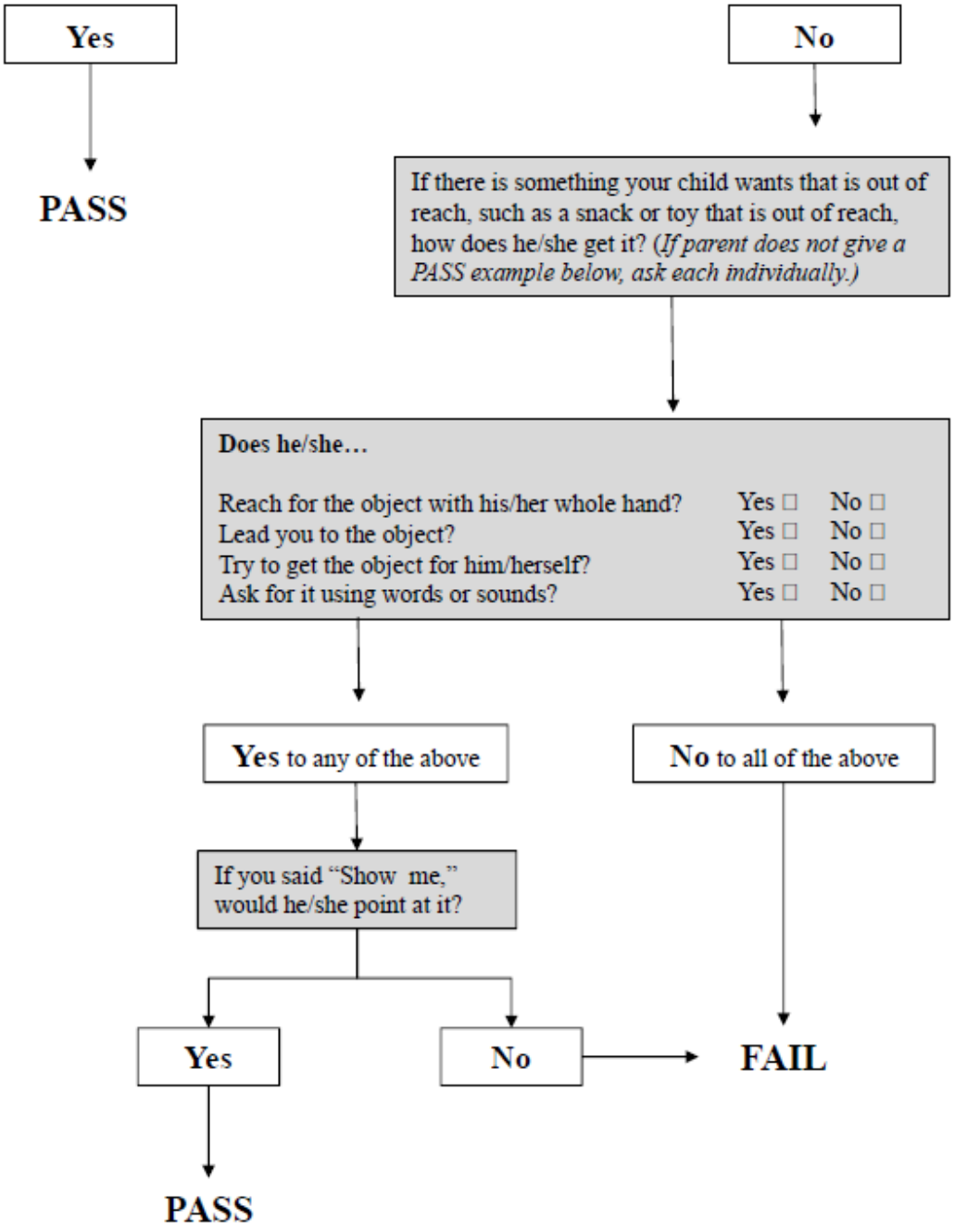
6. Does _____ point with one finger to ask for something or to get help?



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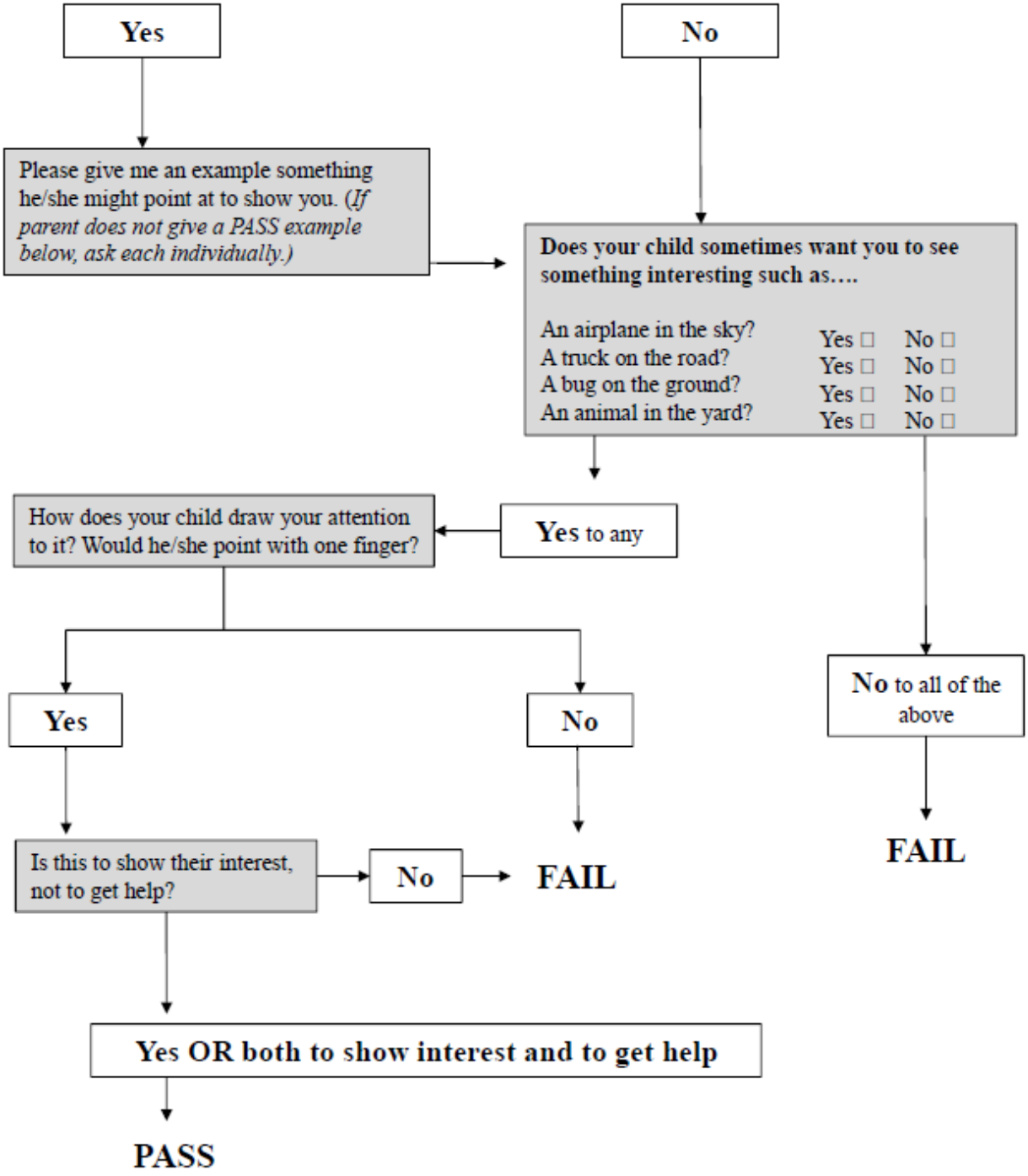
7. * **If the interviewer just asked #6, begin here: We just talked about pointing to *ask* for something, ASK ALL → Does _____ point with one finger just to show you something interesting?**



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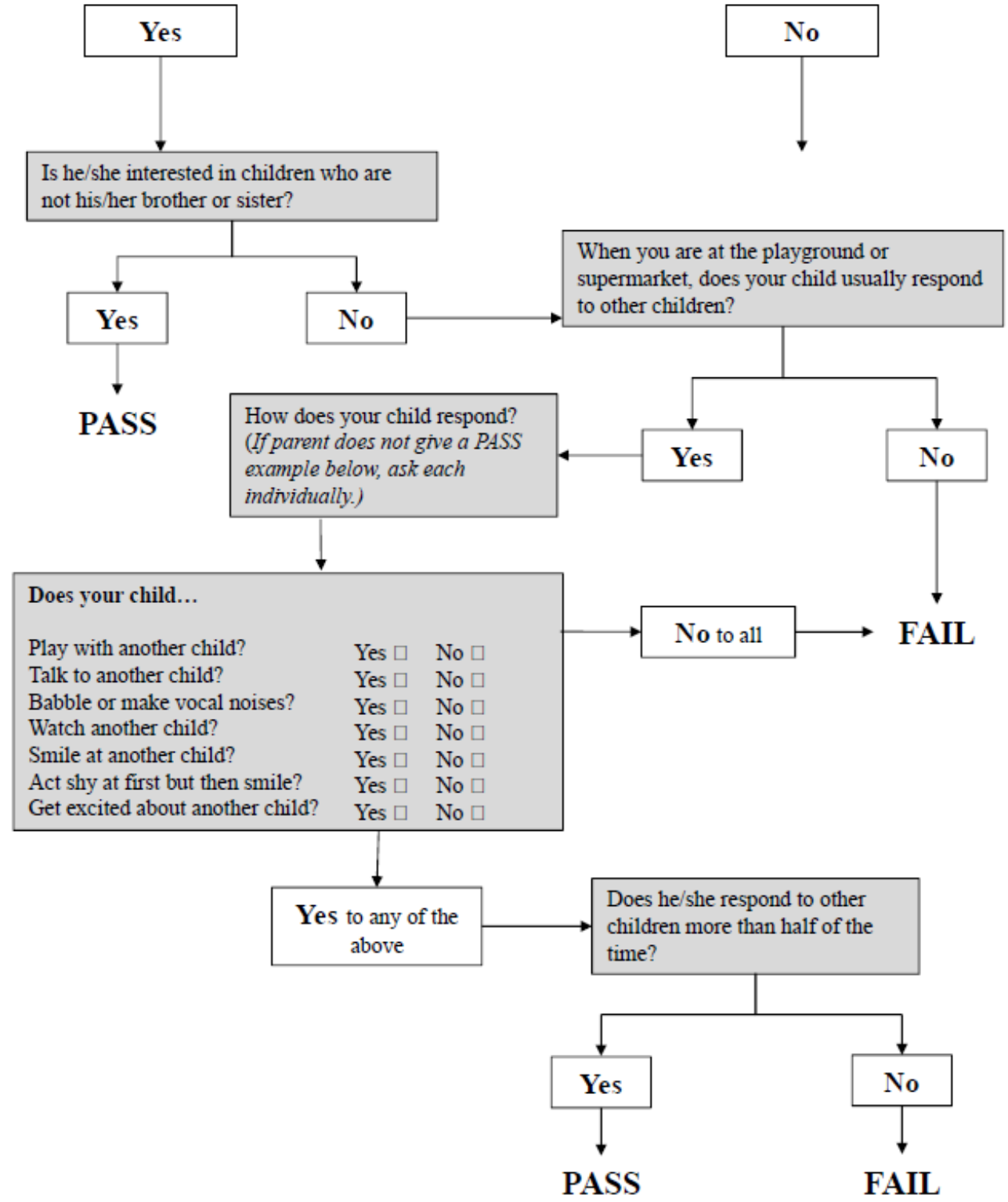
8. Is _____ interested in other children?



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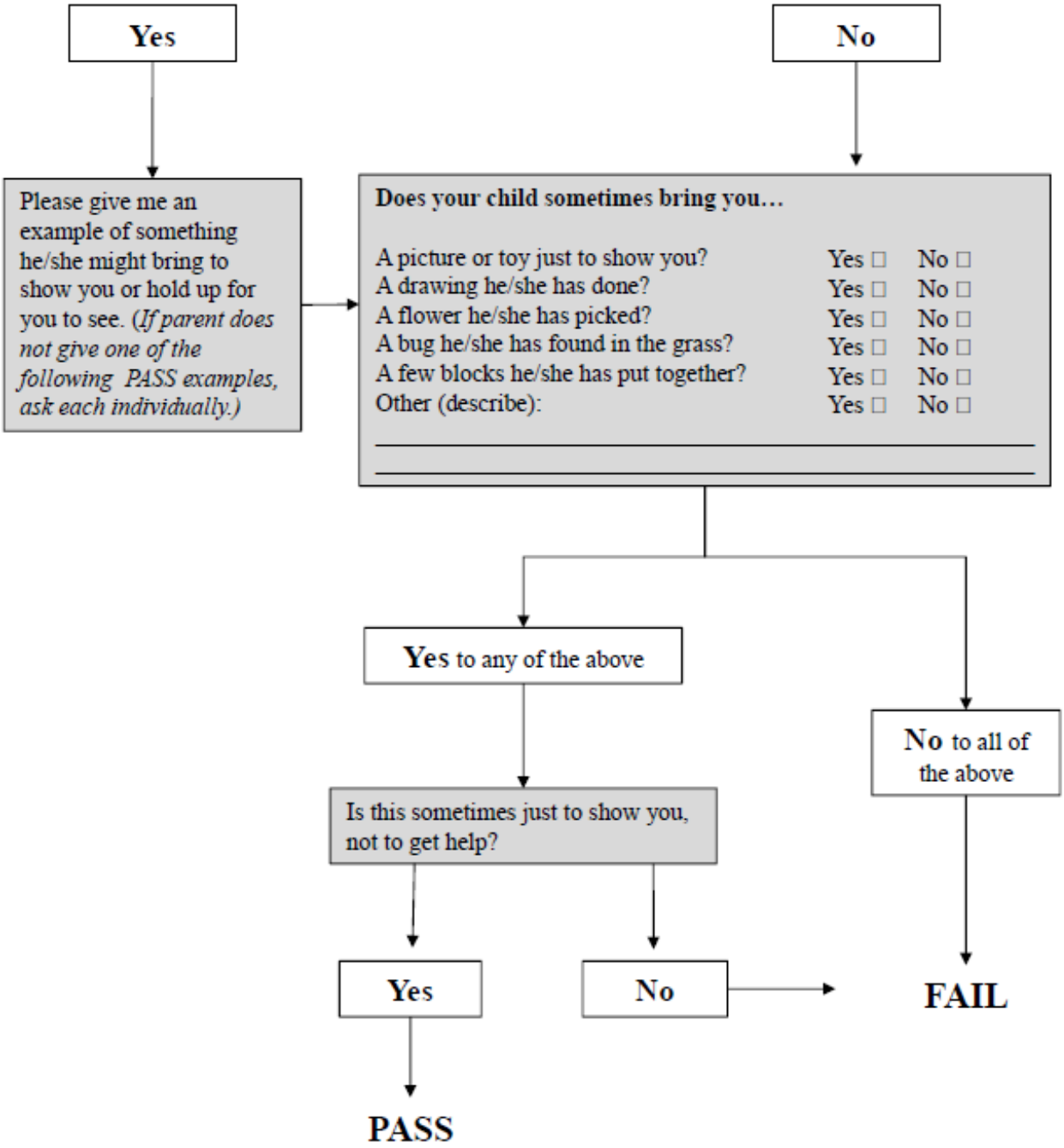
9. Does _____ show you things by bringing them to you or holding them up for you to see? Not just to get help, but to share?



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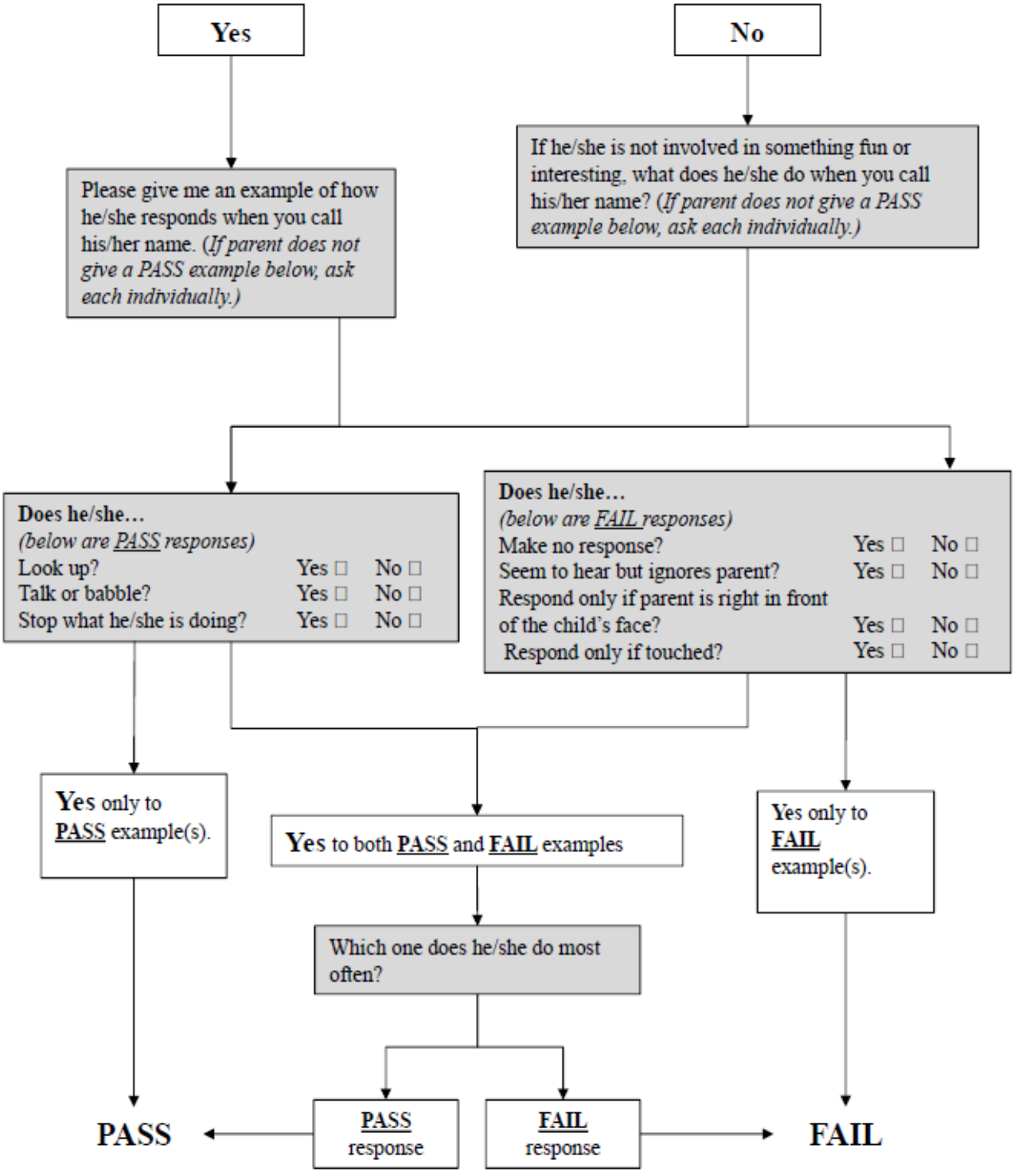
10. Does _____ respond when you call his/her name?



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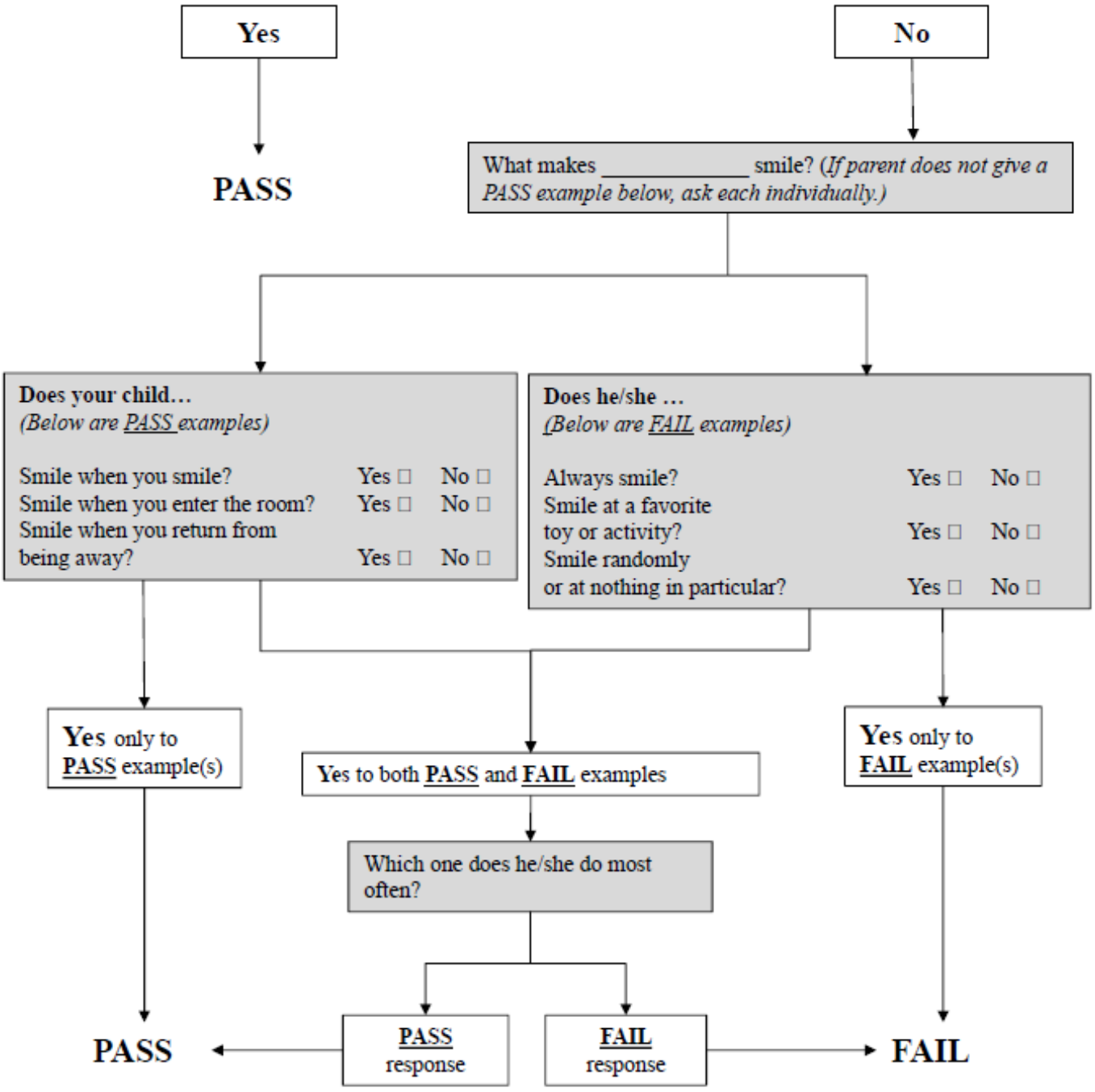
11. When you smile at _____, does he/she smile back at you?



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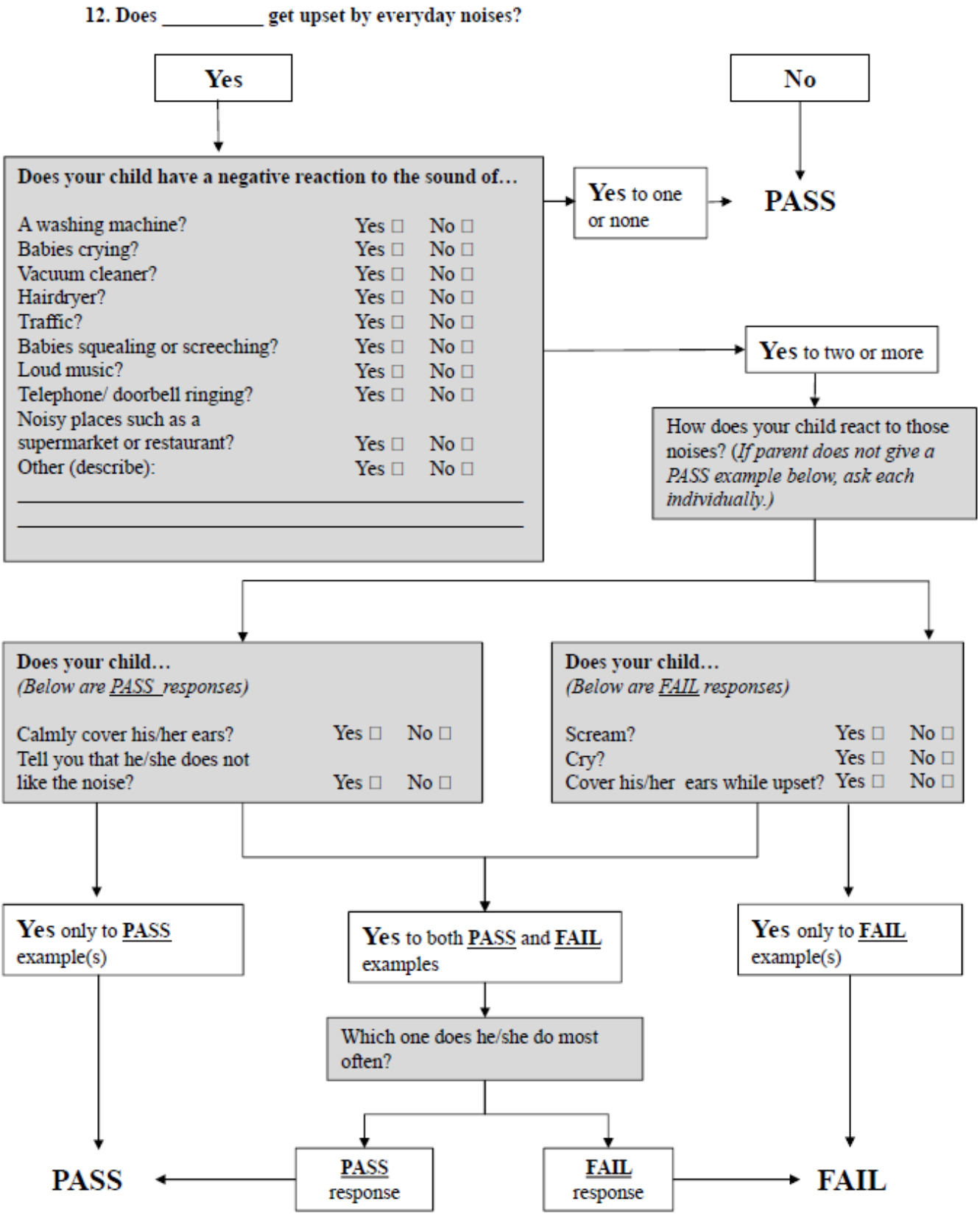

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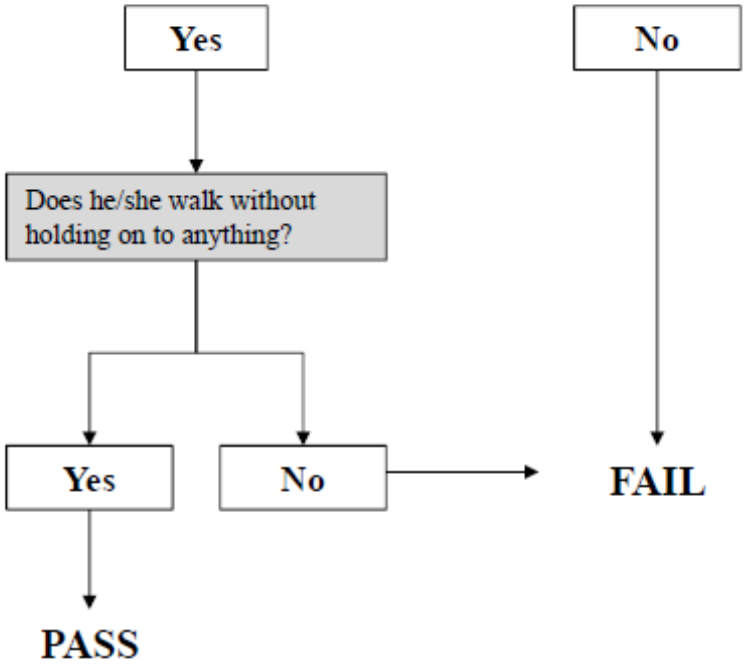
13. Does _____ walk?



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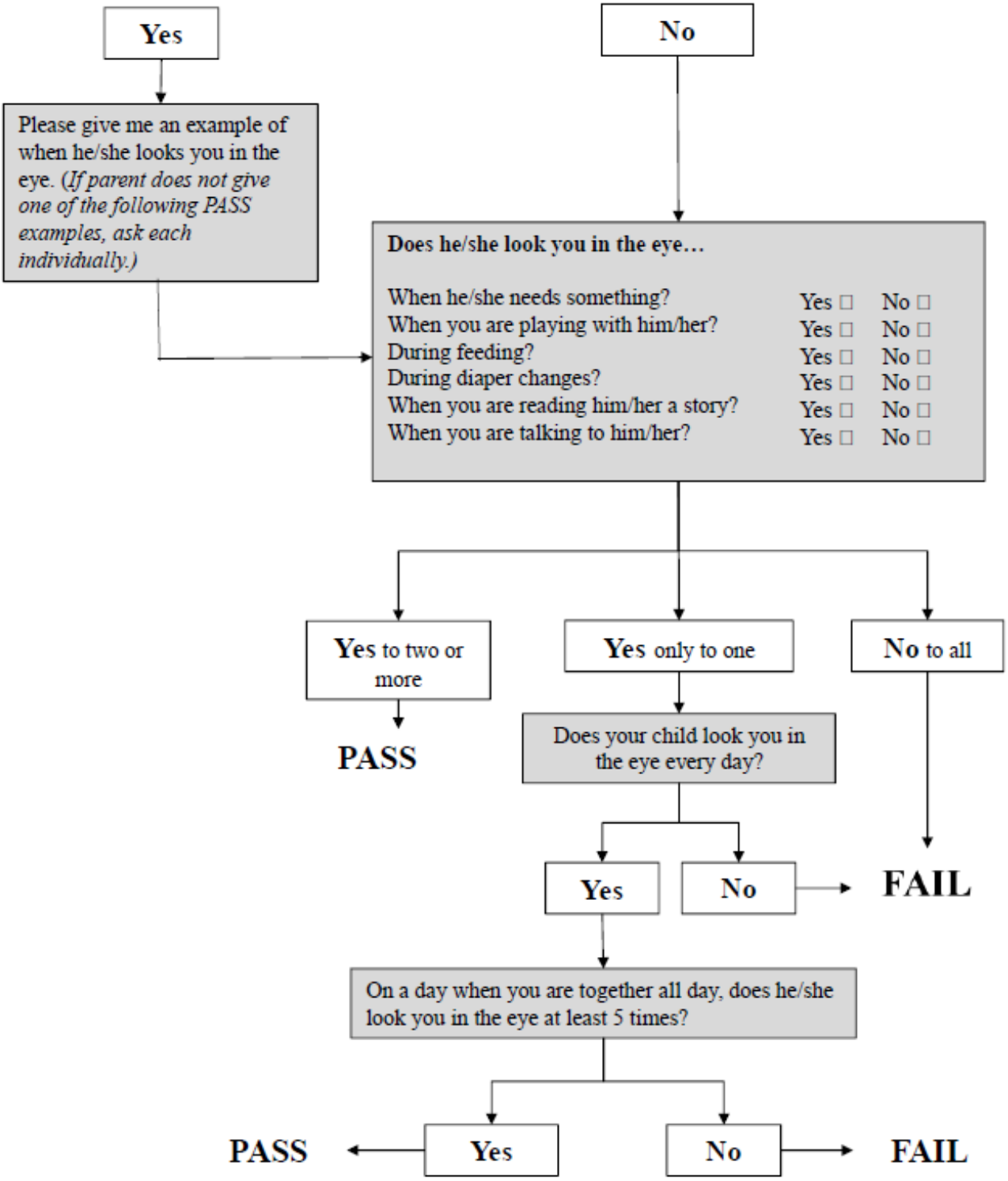
14. Does _____ look you in the eye when you are talking to him/her, playing with him/her, or changing him/her?



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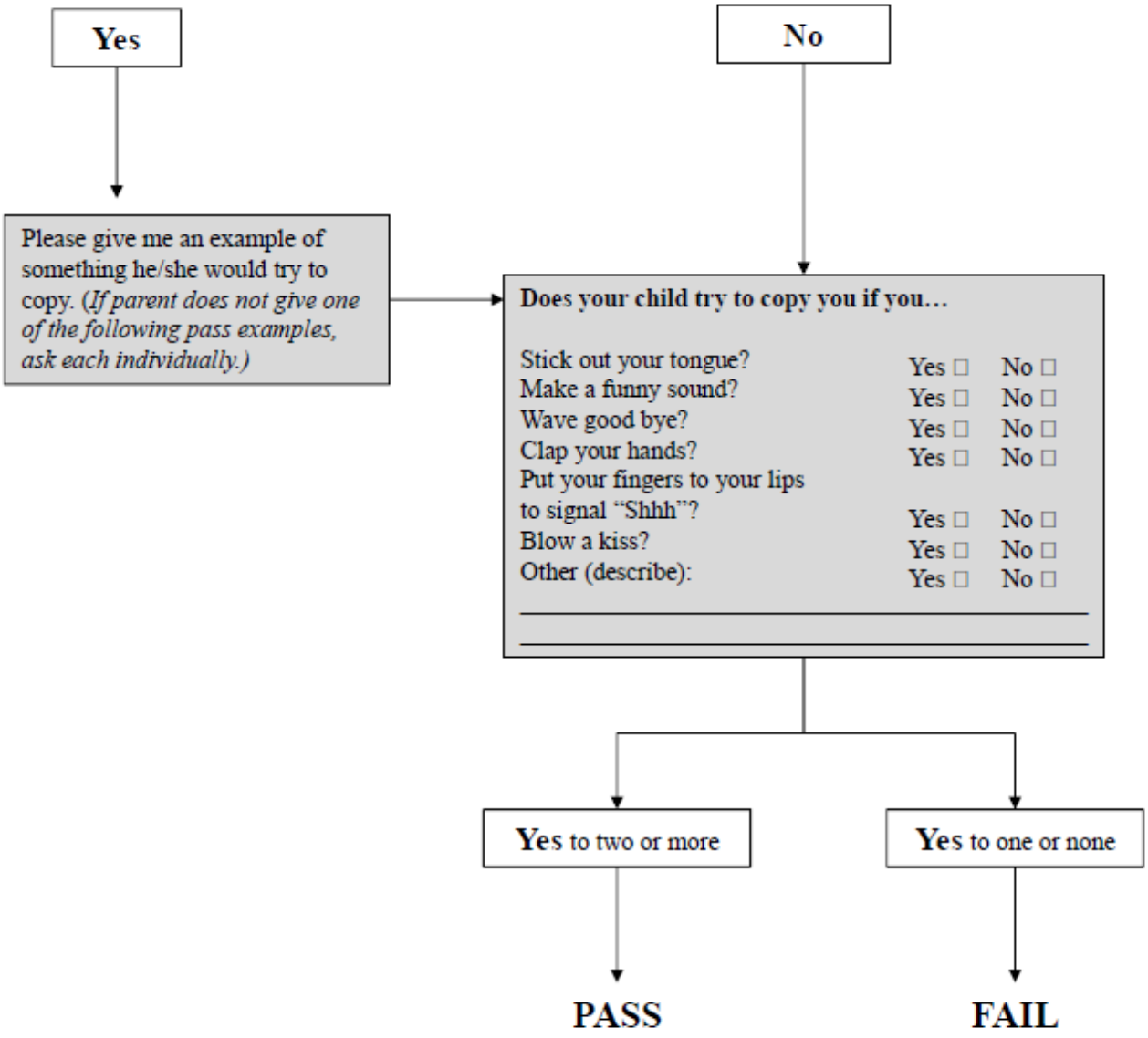
15. Does _____ try to copy what you do?



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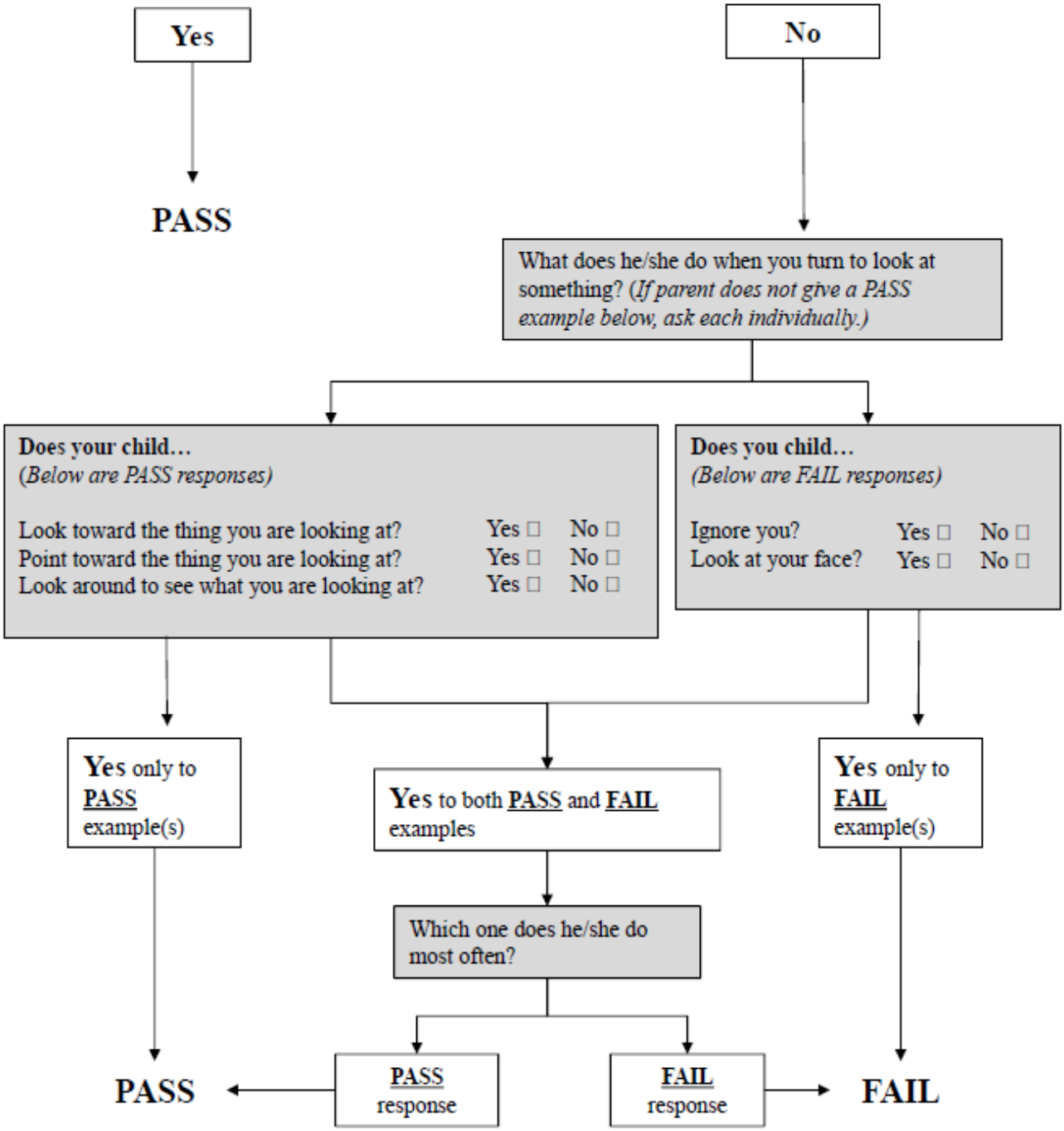
16. If you turn your head to look at something, does _____ look around to see what you are looking at?



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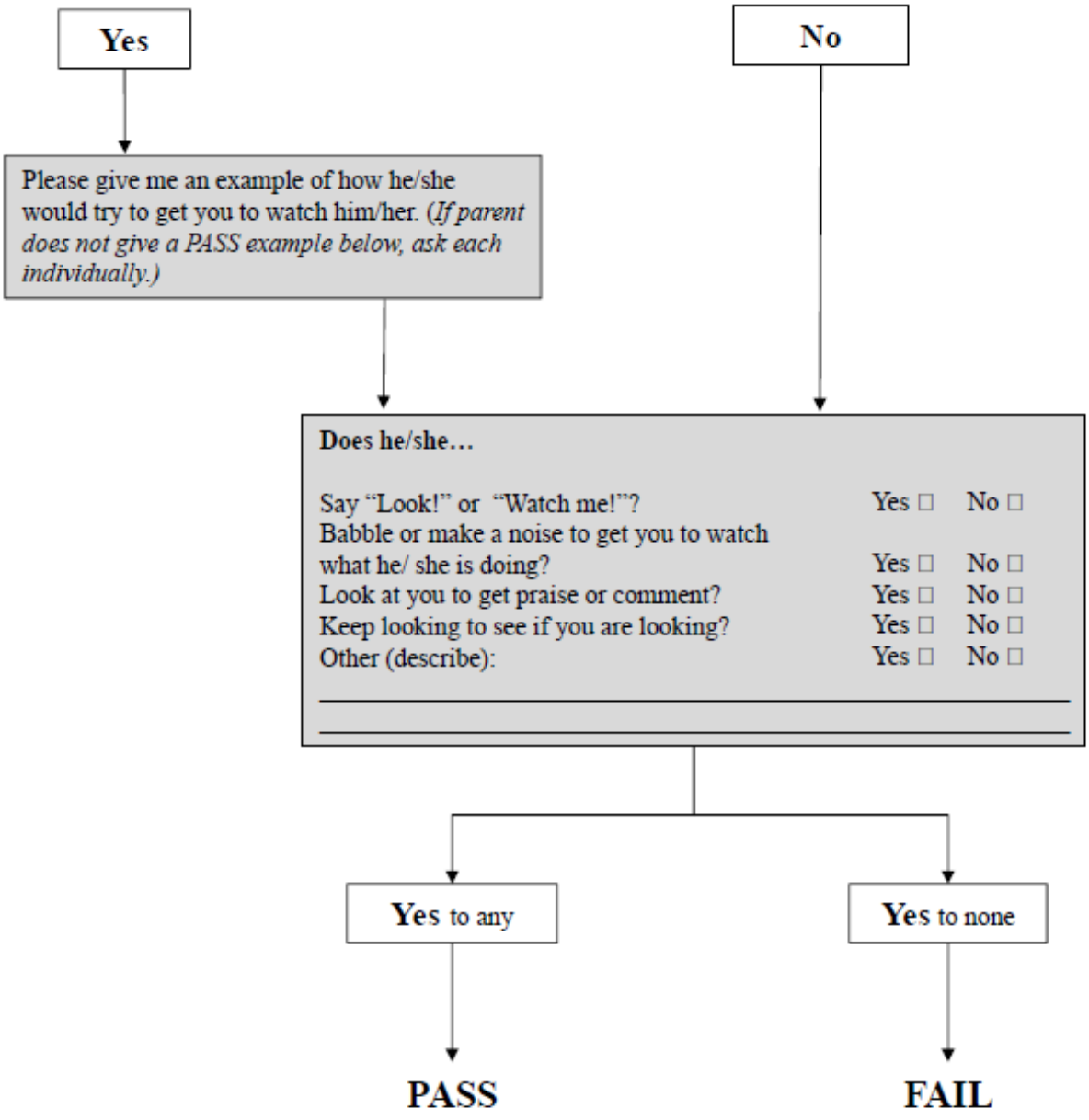
17. Does _____ try to get you to watch him/her?



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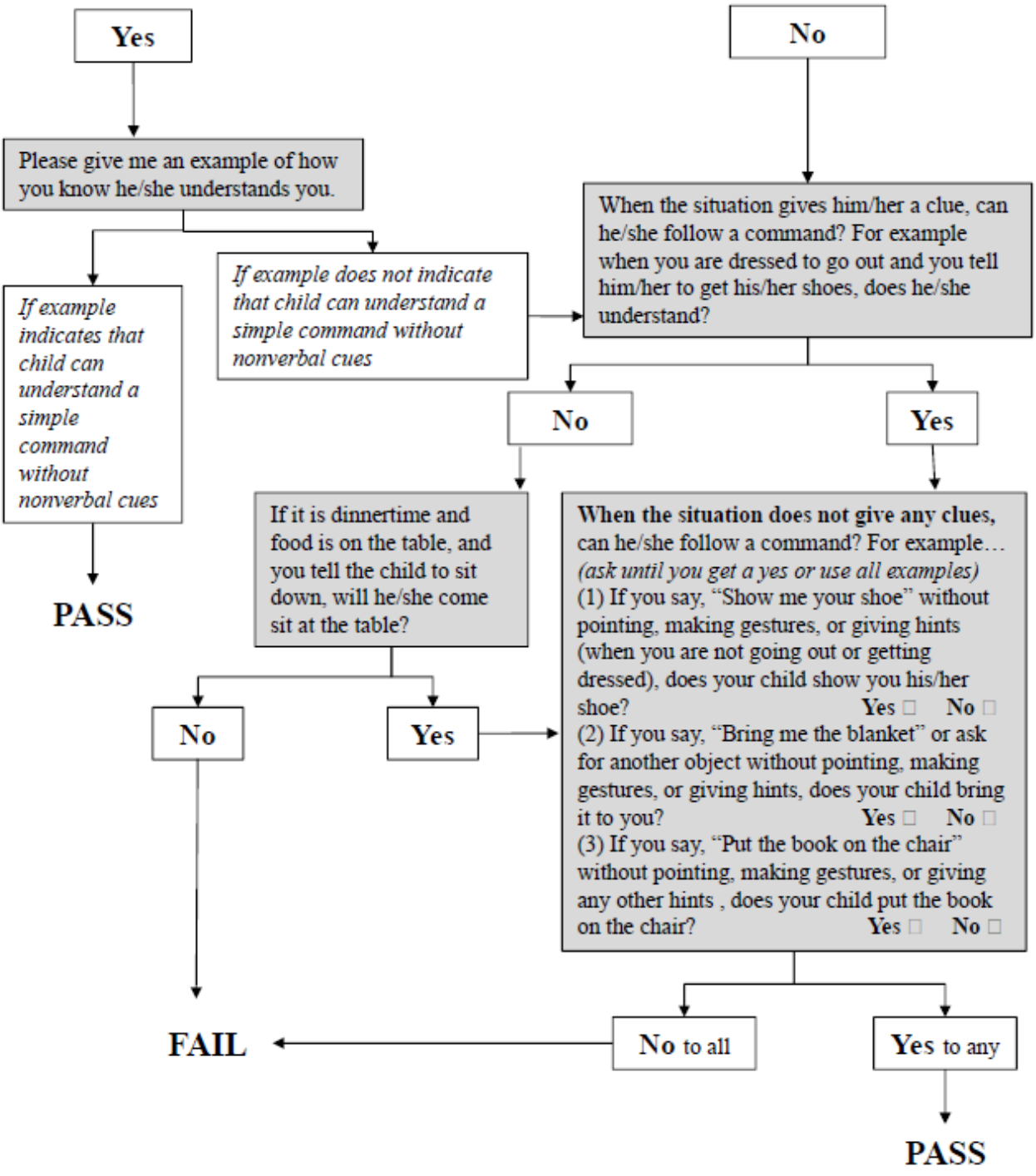
18. Does _____ understand when you tell him/her to do something?



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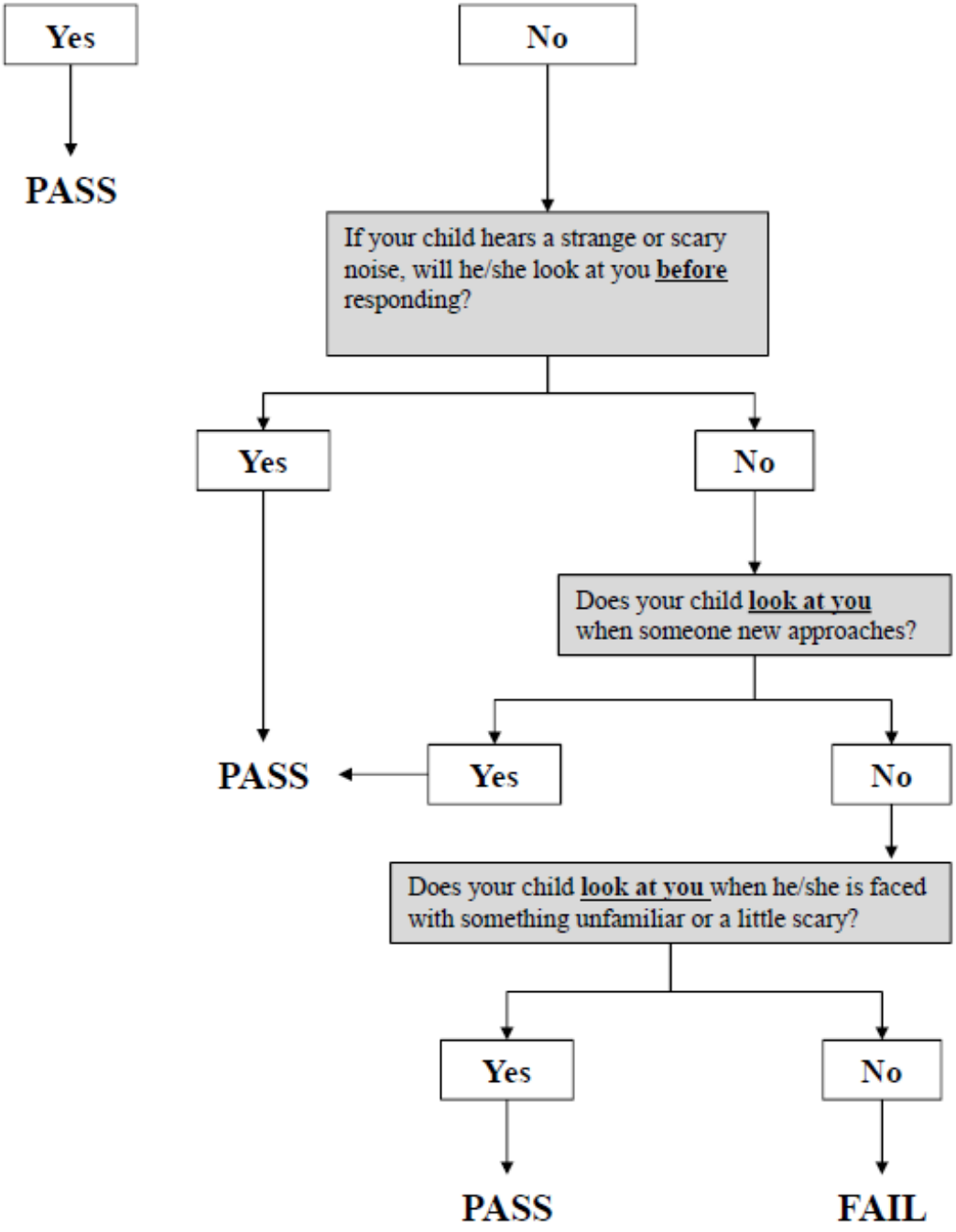
19. If something new happens, does _____ look at your face to see how you feel about it?



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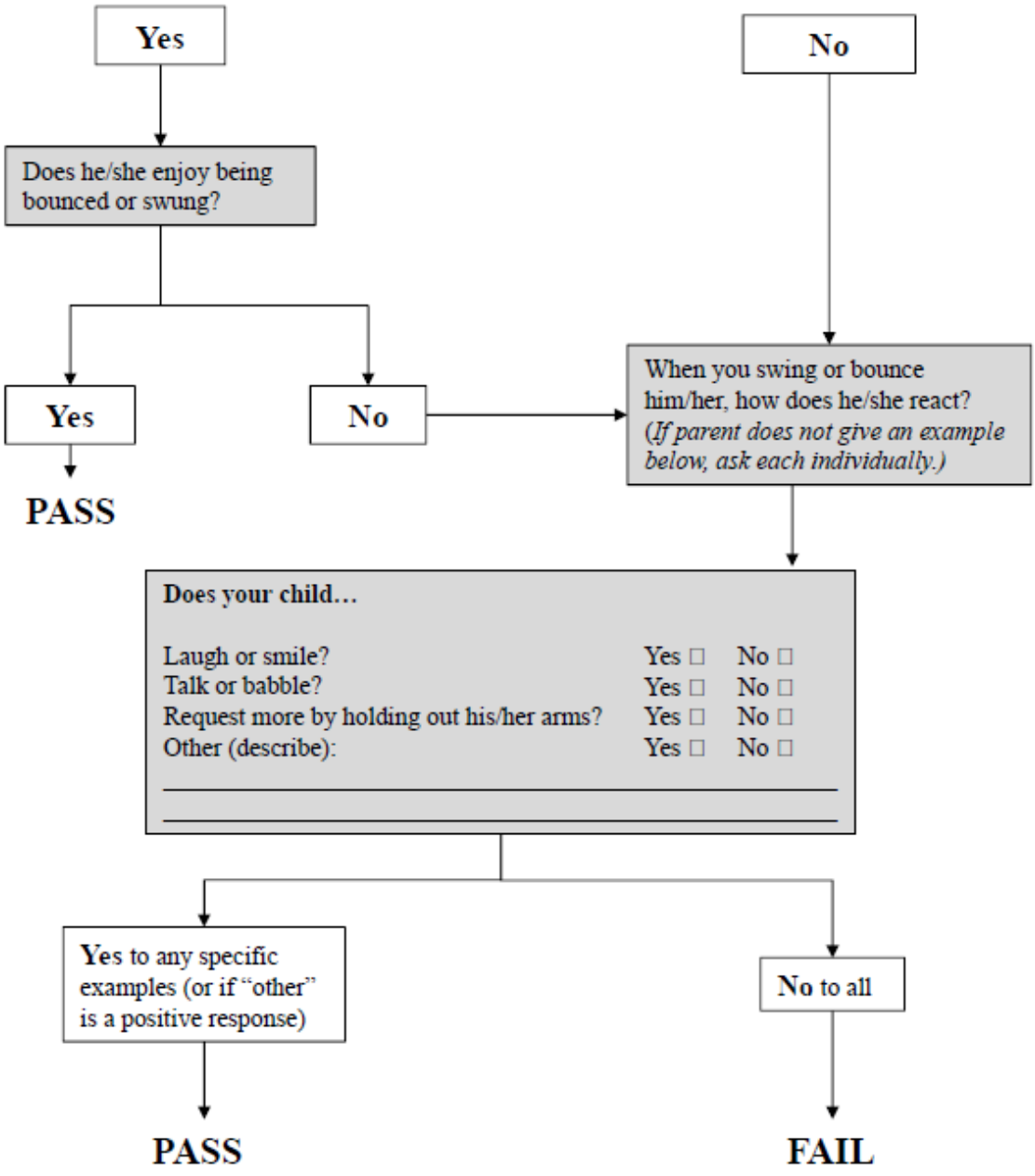
20. Does _____ like movement activities?



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Appendix B: Adapted English M-CHAT-R/F

Modified Checklist for Autism in Toddlers, Revised, with Follow-Up

(M-CHAT-R/F)™

Diana L. Robins, Ph.D.
Deborah Fein, Ph.D.
Marianne Barton, Ph.D.

Acknowledgement: We thank the M-CHAT Study Group in Spain for developing the flow chart format used in this document,

For more information, please see www.mchatscreen.com
or contact Diana Robins at mchatscreen2009@gmail.com

Note. This version contains minor corrections, August 10, 2018

© 2009 Diana Robins, Deborah Fein, & Marianne Barton
Adapted by: Vorster, C., Kritzinger, A., Lekganyane, M., Taljard, E., & Van der Linde, J. (2020)

Permissions for Use of the M-CHAT-R/F*TM*

The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is a 2-stage parent-report screening tool to assess risk for Autism Spectrum Disorder (ASD). The M-CHAT-R/F is available for free download for clinical, research, and educational purposes. Download of the M-CHAT-R/F and related material is authorized from www.mchatscreen.com.

The M-CHAT-R/F is a copyrighted instrument, and use of the M-CHAT-R/F must follow these guidelines:

(1) Reprints/reproductions of the M-CHAT-R must include the copyright at the bottom (© 2009 Robins, Fein, & Barton). No modifications can be made to items, instructions, or item order without permission from the authors.

(2) The M-CHAT-R must be used in its entirety. Evidence indicates that any subsets of items do not demonstrate adequate psychometric properties.

(3) Parties interested in reproducing the M-CHAT-R/F in print (e.g., a book or journal article) or electronically for use by others (e.g., as part of digital medical record or other software packages) must contact Diana Robins to request permission (mchatscreen2009@gmail.com).

(4) If you are part of a medical practice, and you want to incorporate the first stage M-CHAT-R questions into your own practice's electronic medical record (EMR), you are welcome to do so. However, if you ever want to distribute your EMR page outside of your practice, please contact, Diana Robins to request a licensing agreement.

Instructions for Use

The M-CHAT-R can be administered and scored as part of a well-child care visit, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT-R is to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk will be diagnosed with ASD. To address this, we have developed the Follow-Up questions (M-CHAT-R/F). Users should be aware that even with the Follow-Up, a significant number of the children who screen positive on the M-CHAT-R will not be diagnosed with ASD; however, these children are at high risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive. The M-CHAT-R can be scored in less than two minutes. Scoring instructions can be downloaded from http://www.mchatscreen.com. Associated documents will be available for download as well.

Scoring Algorithm

For all items except 2, 5, and 12, the response "NO" indicates ASD risk; for items 2, 5, and 12, "YES" indicates ASD risk. The following algorithm maximizes psychometric properties of the M-CHAT-R:

LOW-RISK: **Total Score is 0-2**; if child is younger than 24 months, screen again after second birthday. No further action required unless surveillance indicates risk for ASD.

MEDIUM-RISK: **Total Score is 3-7**; Administer the Follow-Up (second stage of M-CHAT-R/F) to get additional information about at-risk responses. If M-CHAT-R/F score remains at 2 or higher, the child has screened positive. Action required: refer child for diagnostic evaluation and eligibility evaluation for early intervention. If score on Follow-Up is 0-1, child has screened negative. No further action required unless surveillance indicates risk for ASD. Child should be rescreened at future well-child visits.

HIGH-RISK: **Total Score is 8-20**; It is acceptable to bypass the Follow-Up and refer immediately for diagnostic evaluation and eligibility evaluation for early intervention.

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M-CHAT-R/F™

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behaviour a few times, but they do not usually do it, then please answer no. Please circle yes or no for every question. Thank you very much.

1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)	Yes	No
2. Have you ever wondered if your child might be deaf?	Yes	No
3. Does your child act? (FOR EXAMPLE, act as if they drink from an empty cup, act like they talk on a phone, or pretend to feed a doll?)	Yes	No
4. Does your child like climbing on things? (FOR EXAMPLE, furniture, trees, or stairs)	Yes	No
5. Does your child make unusual finger movements near their eyes? (FOR EXAMPLE, does your child wiggle their fingers close to their eyes? Not rubbing the eyes)	Yes	No
6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach)	Yes	No
7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)	Yes	No
8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)	Yes	No
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, an animal, or a toy truck)	Yes	No
10. Does your child respond when you call their name? (FOR EXAMPLE, do they look up, talk or babble, or stop what they are doing when you call their name?)	Yes	No
11. When you smile at your child, do they smile back at you?	Yes	No
12. Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?)	Yes	No
13. Does your child walk?	Yes	No
14. Does your child look in your direction or in your eyes when you are talking to them, playing with them, or dressing them?	Yes	No
15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)	Yes	No
16. If you turn your head to look at something, does your child look around to see what you are looking at?	Yes	No
17. Does your child try to get you to watch them? (FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me"?)	Yes	No
18. Does your child understand when you tell them to do something? (FOR EXAMPLE, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket"?)	Yes	No
19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if they hear a strange or funny noise, or sees a new toy, will they look at your face?)	Yes	No
20. Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee)	Yes	No

M-CHAT-R Follow-Up (M-CHAT-R/F)TM

Permissions for Use

The Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is designed to accompany the M-CHAT-R. The M-CHAT-R/F may be downloaded from www.mchatscreen.com.

The M-CHAT-R/F is a copyrighted instrument, and use of this instrument is limited by the authors and copyright holders. The M-CHAT-R and M-CHAT-R/F may be used for clinical, research, and educational purposes. Although we are making the tool available free of charge for these uses, this is copyrighted material and it is not open source. Anyone interested in using the M-CHAT-R/F in any commercial or electronic products must contact Diana L. Robins at mchatscreen2009@gmail.com to request permission.

Instructions for Use

The M-CHAT-R/F is designed to be used with the M-CHAT-R; the M-CHAT-R is valid for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorder (ASD). Users should be aware that even with the Follow-Up, a significant number of the children who fail the M-CHATR will not be diagnosed with ASD; however, these children are at risk for other developmental disorders or delays, and therefore, follow-up is warranted for any child who screens positive.

Once a parent has completed the M-CHAT-R, score the instrument according to the instructions. If the child screens positive, select the Follow-Up items based on which items the child failed on the M-CHATR; only those items that were originally failed need to be administered for a complete interview.

Each page of the interview corresponds to one item from the M-CHAT-R. Follow the flowchart format, asking questions until a PASS or FAIL is scored. Please note that parents may report "maybe" in response to questions during the interview. When a parent reports "maybe," ask whether most often the answer is "yes" or "no" and continue the interview according to that response. In places where there is room to report an "other" response, the interviewer must use his/her judgment to determine whether it is a passing response or not.

Score the responses to each item on the M-CHAT-R/F Scoring Sheet (which contains the same items as the M-CHAT-R, but Yes/No has been replaced by Pass/Fail). The interview is considered to be a screen positive if the child fails any two items on the Follow-Up. If a child screens positive on the M-CHAT-R/F, it is strongly recommended that the child is referred for early intervention and diagnostic testing as soon as possible. Please note that if the healthcare provider or parent has concerns about ASDs, children should be referred for evaluation regardless of the score on the M-CHAT-R or M-CHAT-R/F.

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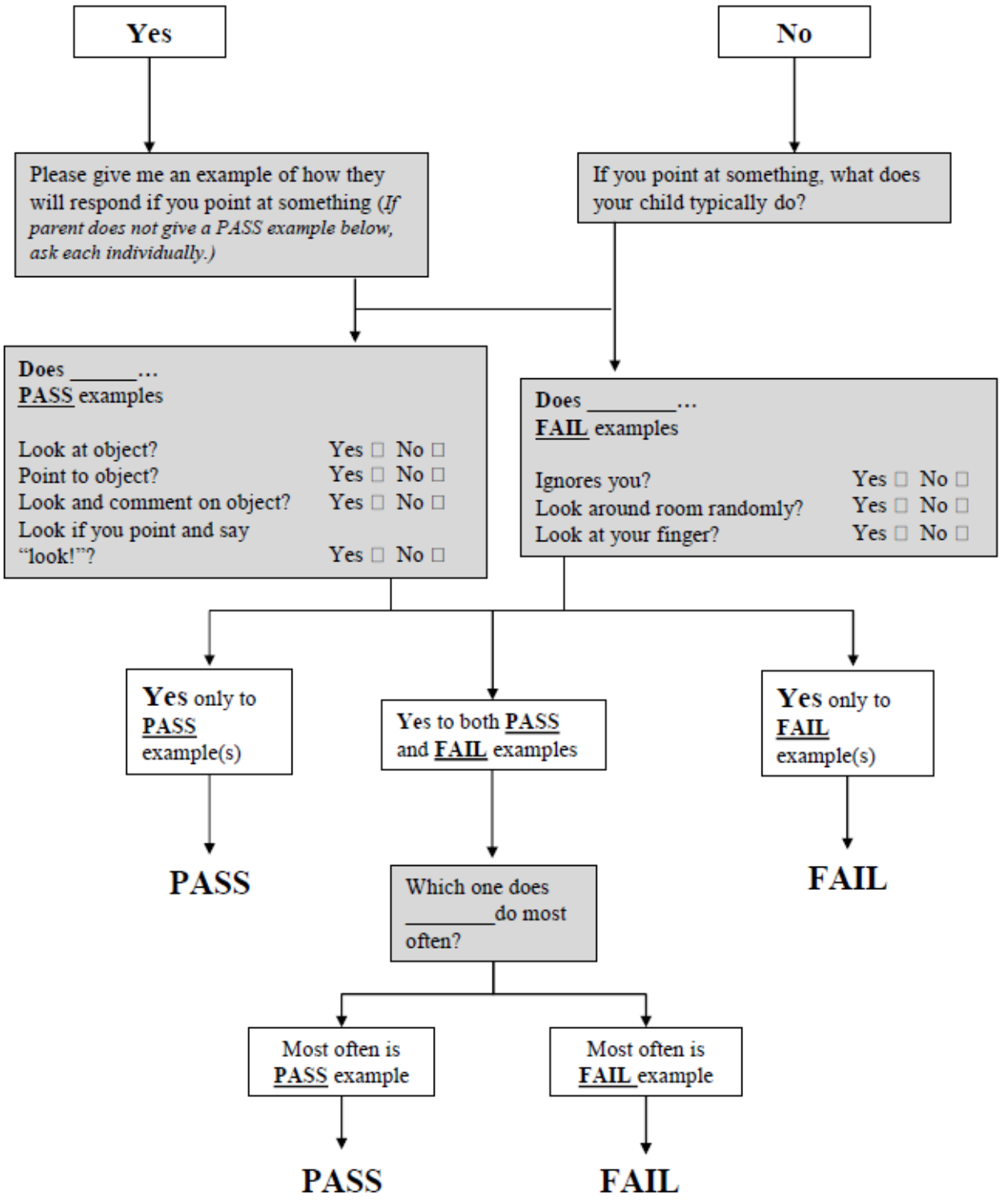
M-CHAT-R Follow-Up™ Scoring Sheet

Please note: Yes/No has been replaced with Pass/Fail

1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)	Pass	Fail
2. Have you ever wondered if your child might be deaf?	Pass	Fail
3. Does your child act? (FOR EXAMPLE, act as if to drink from an empty cup, act like they talk on a phone, or pretend to feed a doll?)	Pass	Fail
4. Does your child like climbing on things? (FOR EXAMPLE, furniture, trees, or stairs)	Pass	Fail
5. Does your child make unusual finger movements near their eyes? (FOR EXAMPLE, does your child wiggle their fingers close to their eyes? Not rubbing the eyes)	Pass	Fail
6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach)	Pass	Fail
7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)	Pass	Fail
8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)	Pass	Fail
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a toy, or a toy truck)	Pass	Fail
10. Does your child respond when you call their name? (FOR EXAMPLE, do they look up, talk or babble, or stop what they are doing when you call their name?)	Pass	Fail
11. When you smile at your child, do they smile back at you?	Pass	Fail
12. Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?)	Pass	Fail
13. Does your child walk?	Pass	Fail
14. Does your child look in your direction or in your eyes when you are talking to them, playing with them, or dressing them?	Pass	Fail
15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)	Pass	Fail
16. If you turn your head to look at something, does your child look around to see what you are looking at?	Pass	Fail
17. Does your child try to get you to watch them? (FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me"?)	Pass	Fail
18. Does your child understand when you tell them to do something? (FOR EXAMPLE, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket"?)	Pass	Fail
19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if they hear a strange or funny noise, or sees a new toy, will they look at your face?)	Pass	Fail
20. Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee)	Pass	Fail

1. If you point at something across the room, does _____ look at it?



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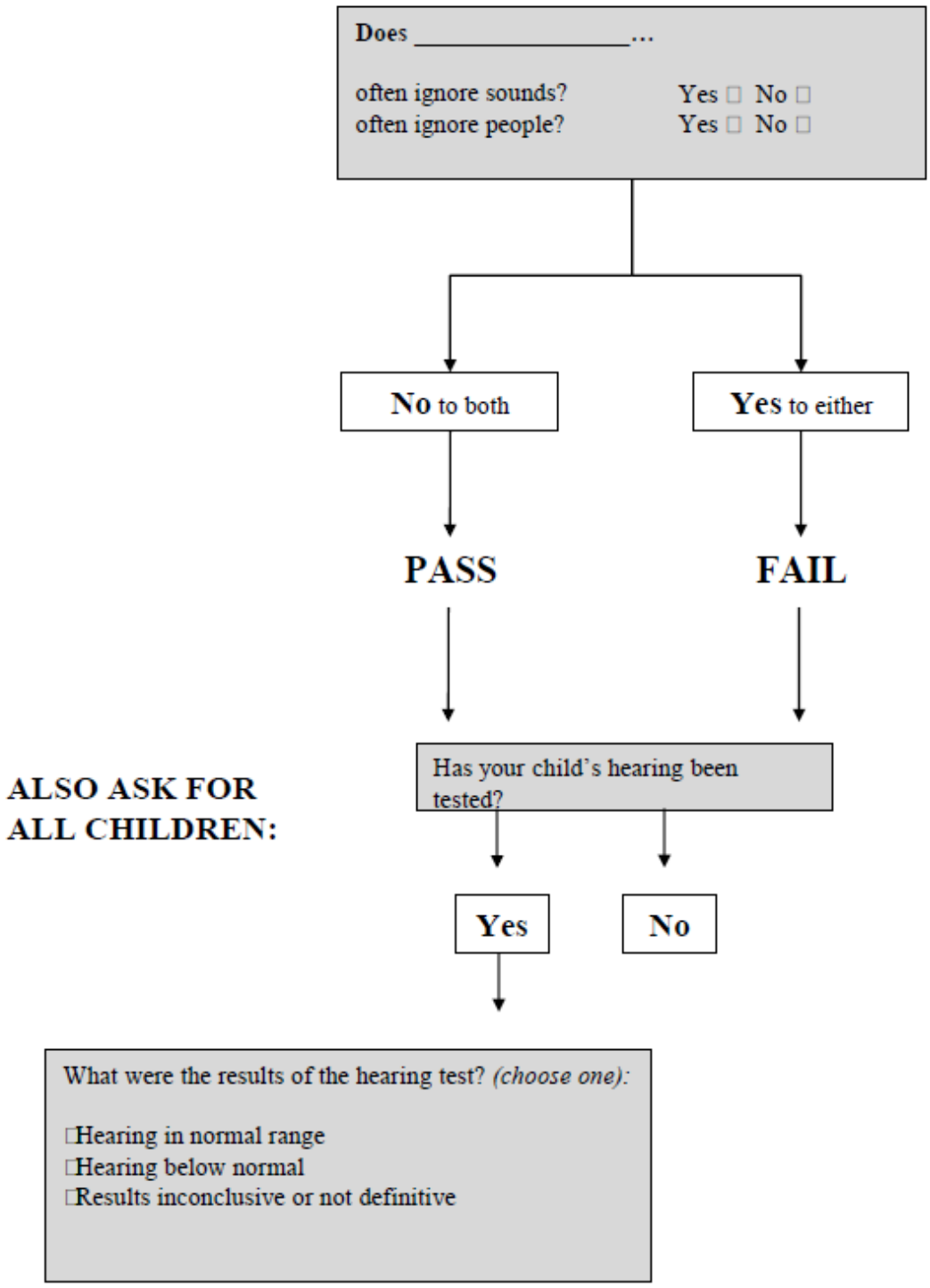
2. You reported that you have wondered if you child is deaf. What led you to wonder that?



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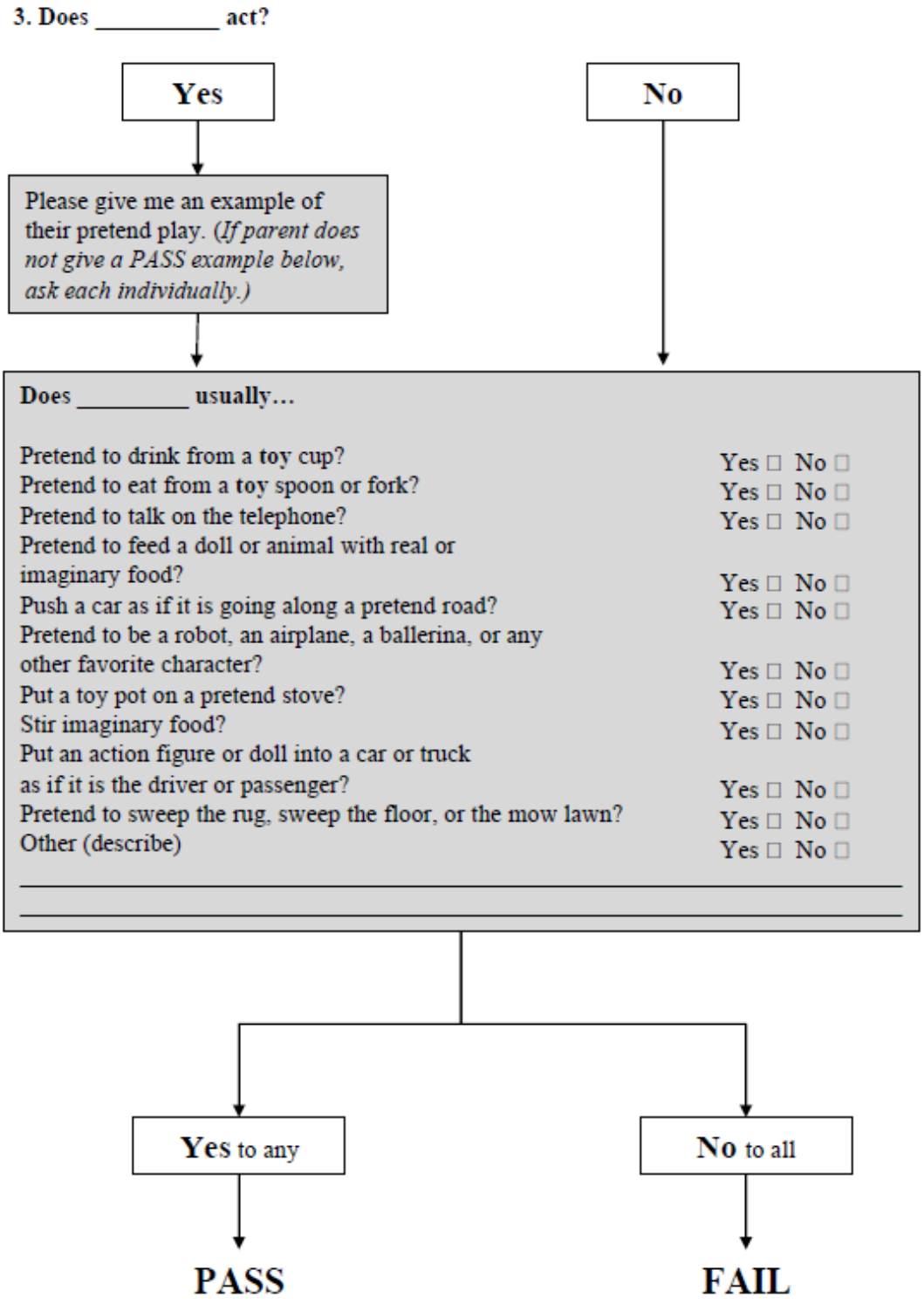

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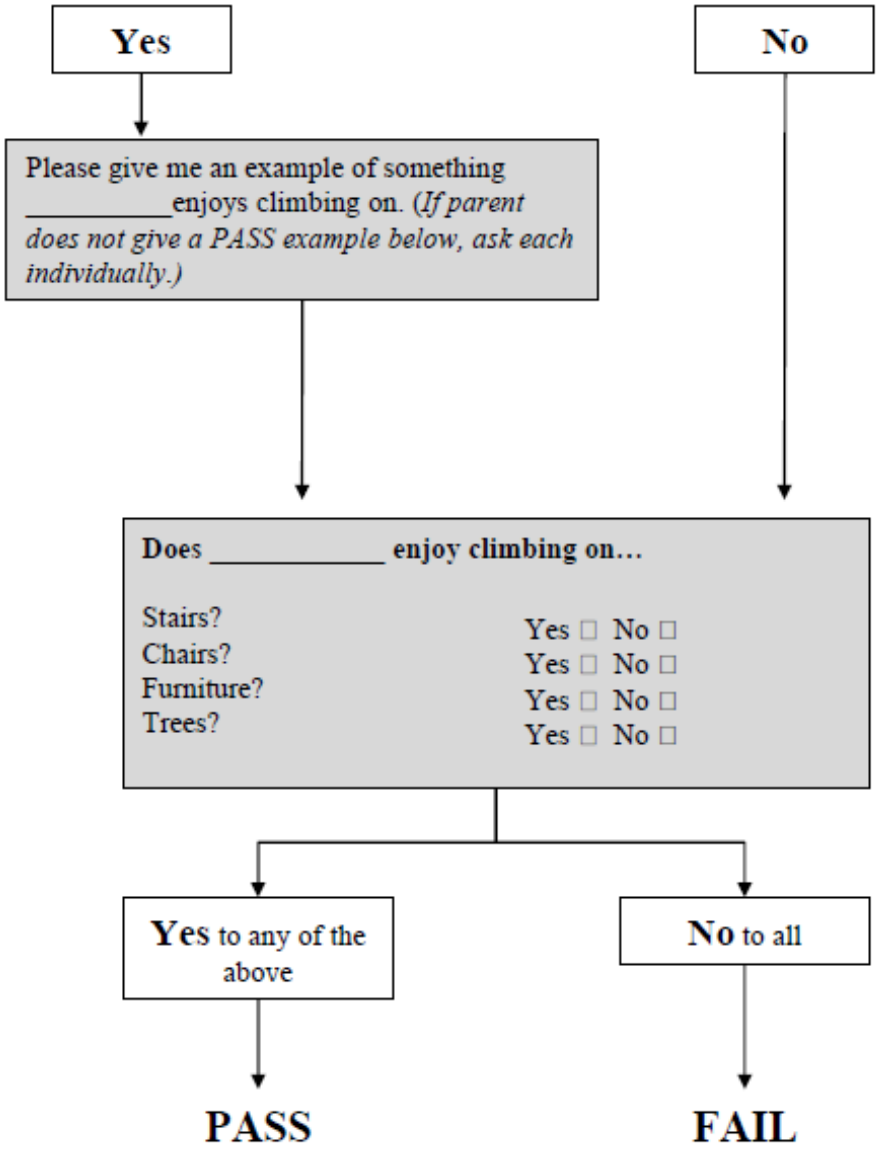
4. Does _____ like climbing on things?



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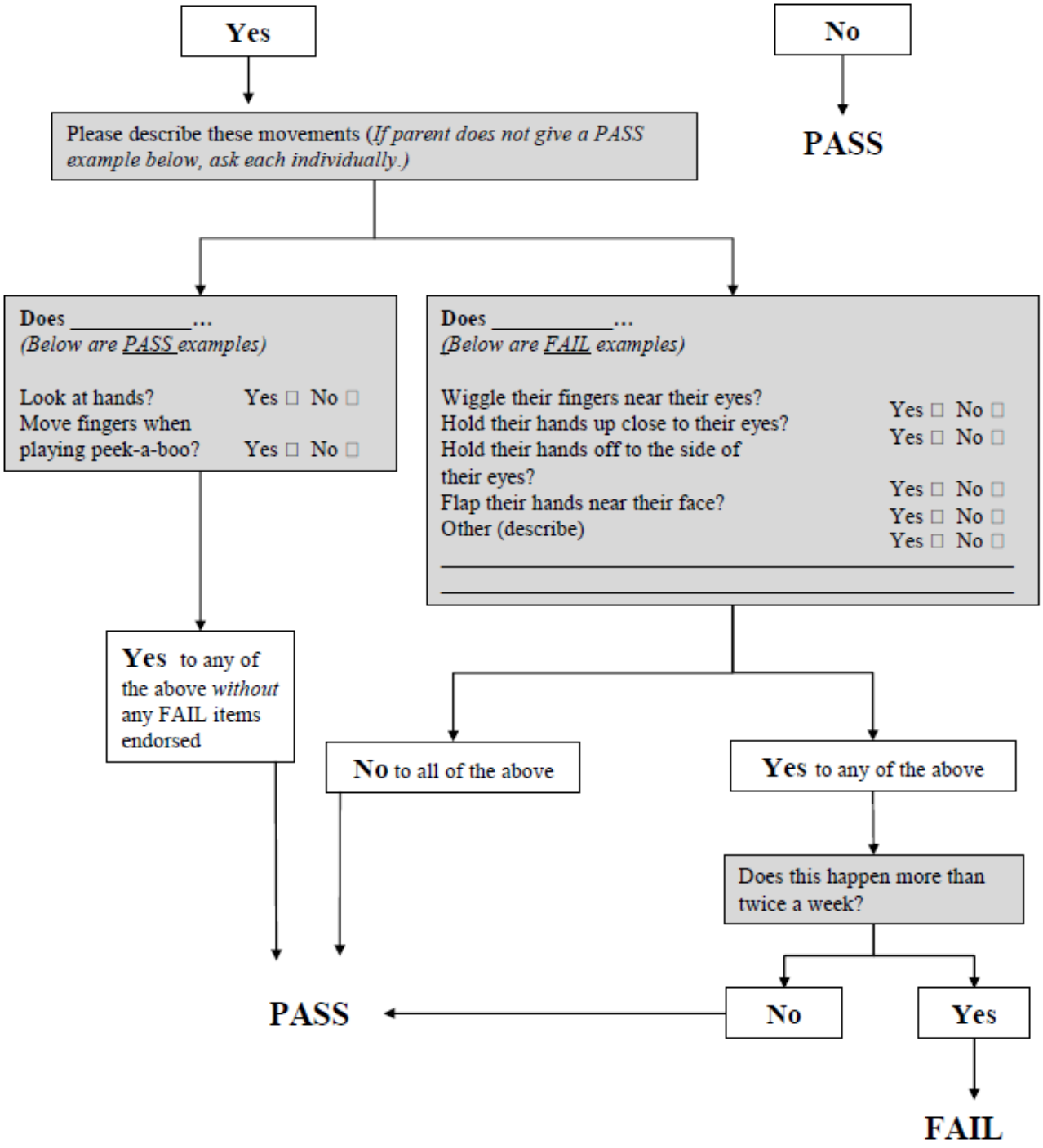
5. Does _____ make unusual finger movements near their eyes? (Not rubbing their eyes)



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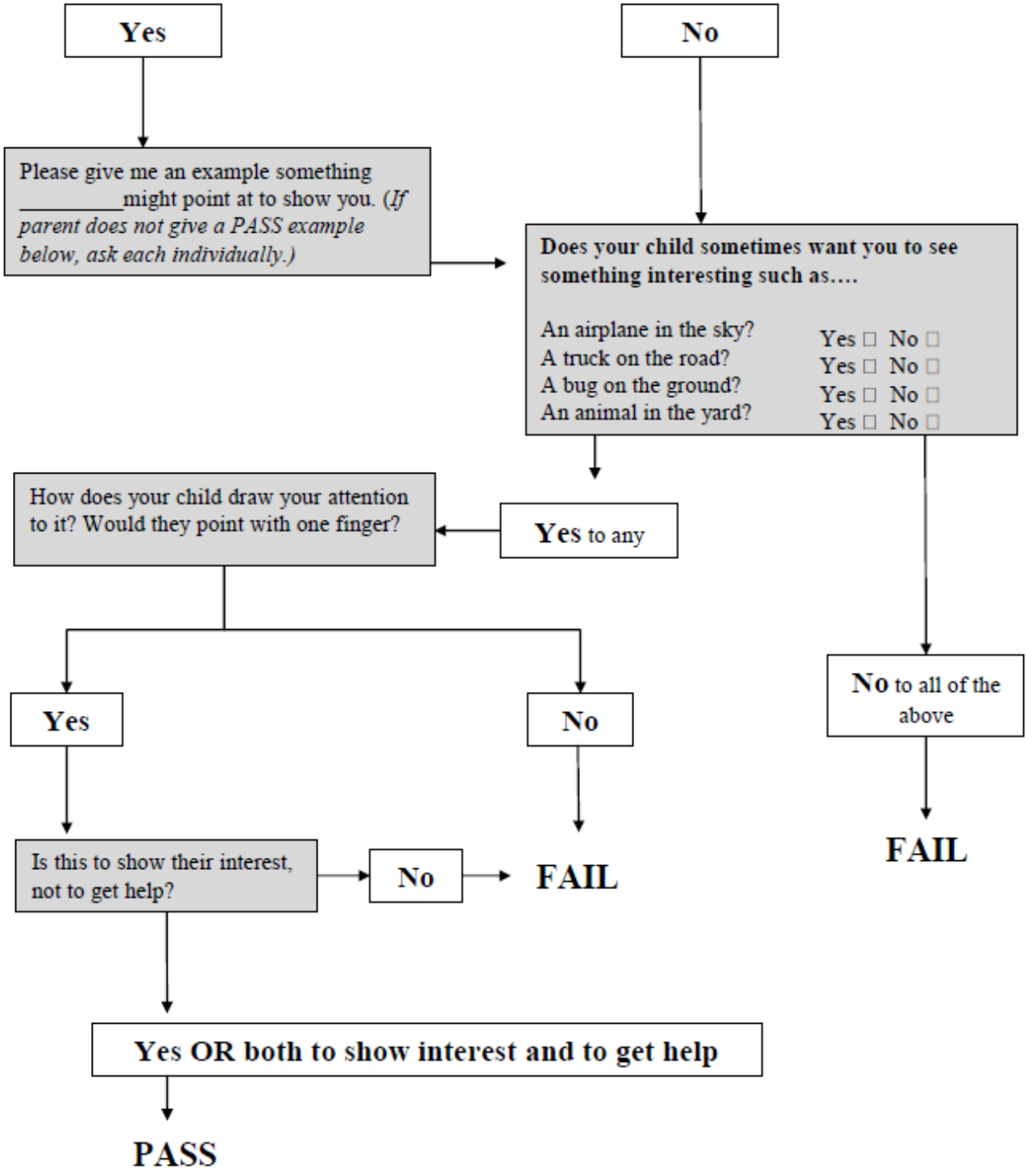
7. * **If the interviewer just asked #6, begin here: We just talked about pointing to *ask* for something, ASK ALL □ Does _____ point with one finger just to show you something interesting?**



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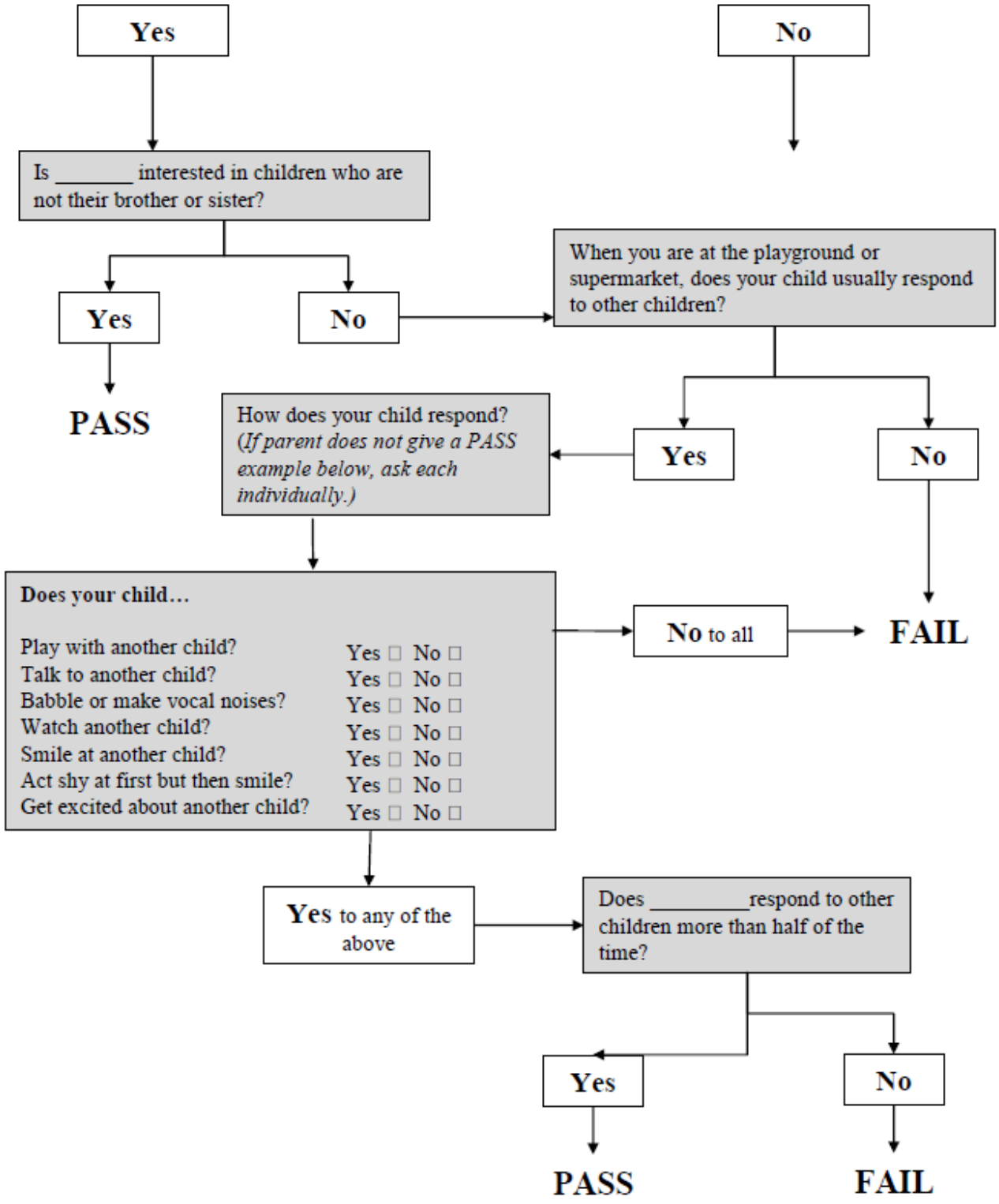
8. Is _____ interested in other children?



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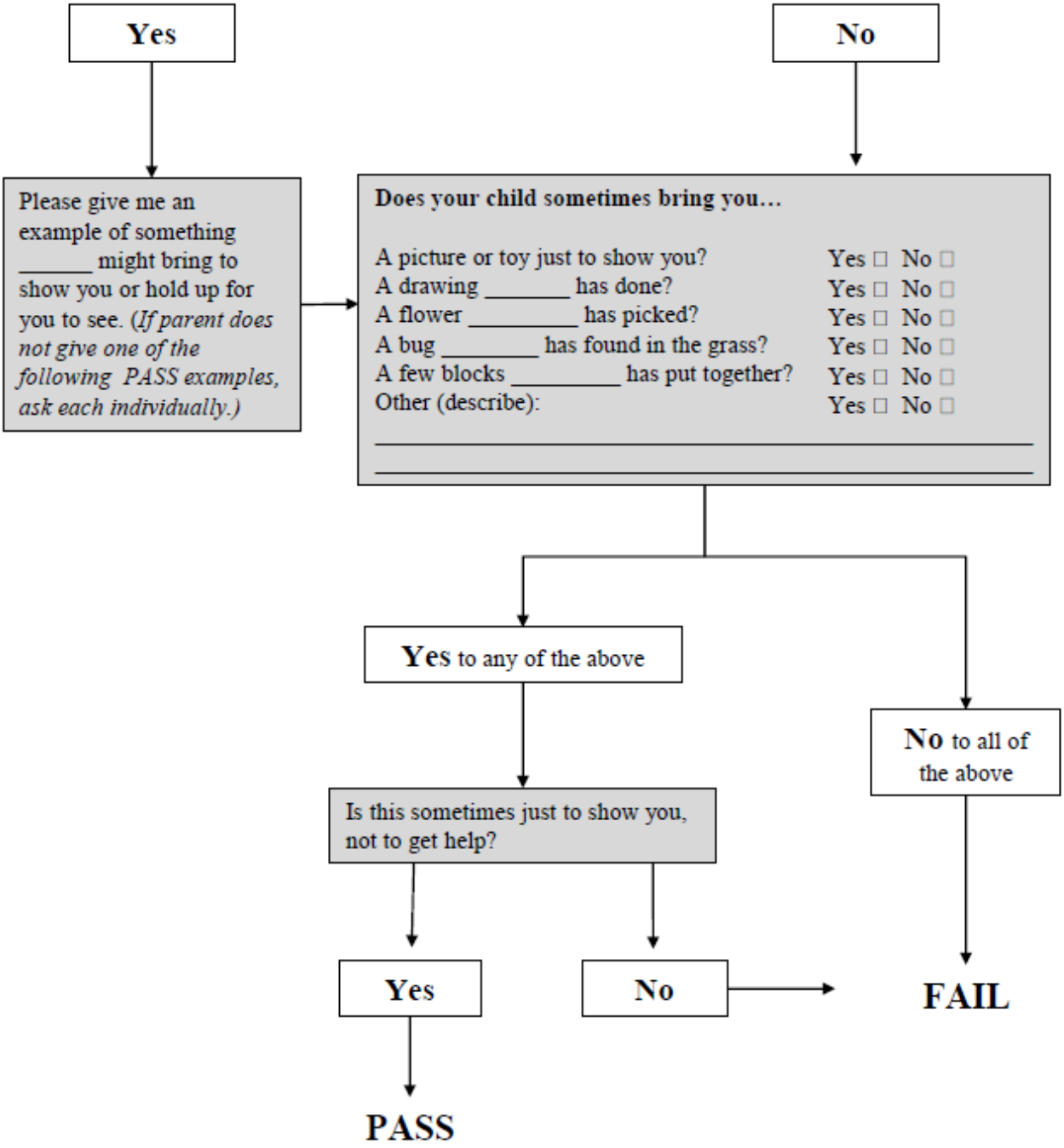
9. Does _____ show you things by bringing them to you or holding them up for you to see? Not just to get help, but to share?



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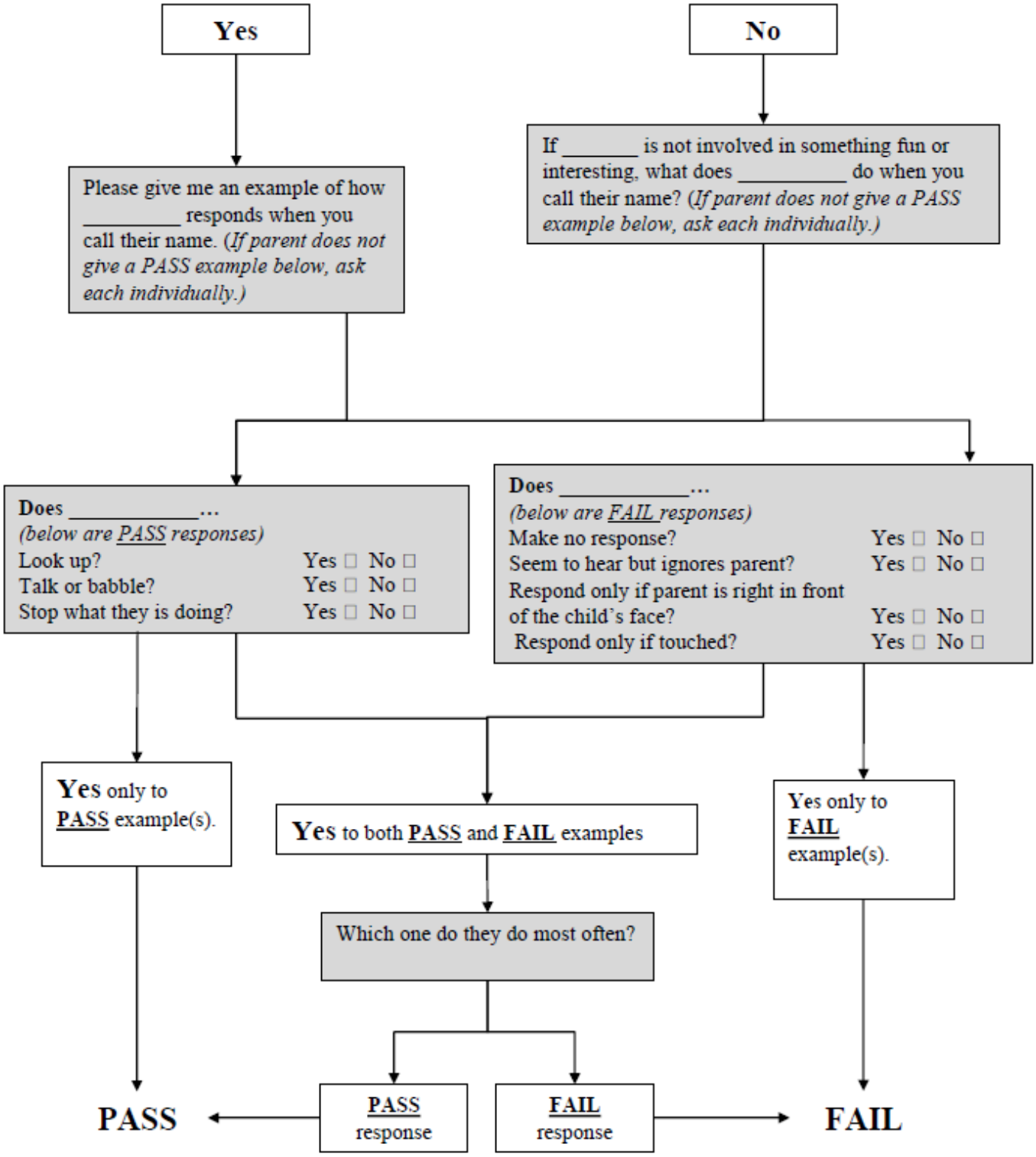
10. Does _____ respond when you call their name?



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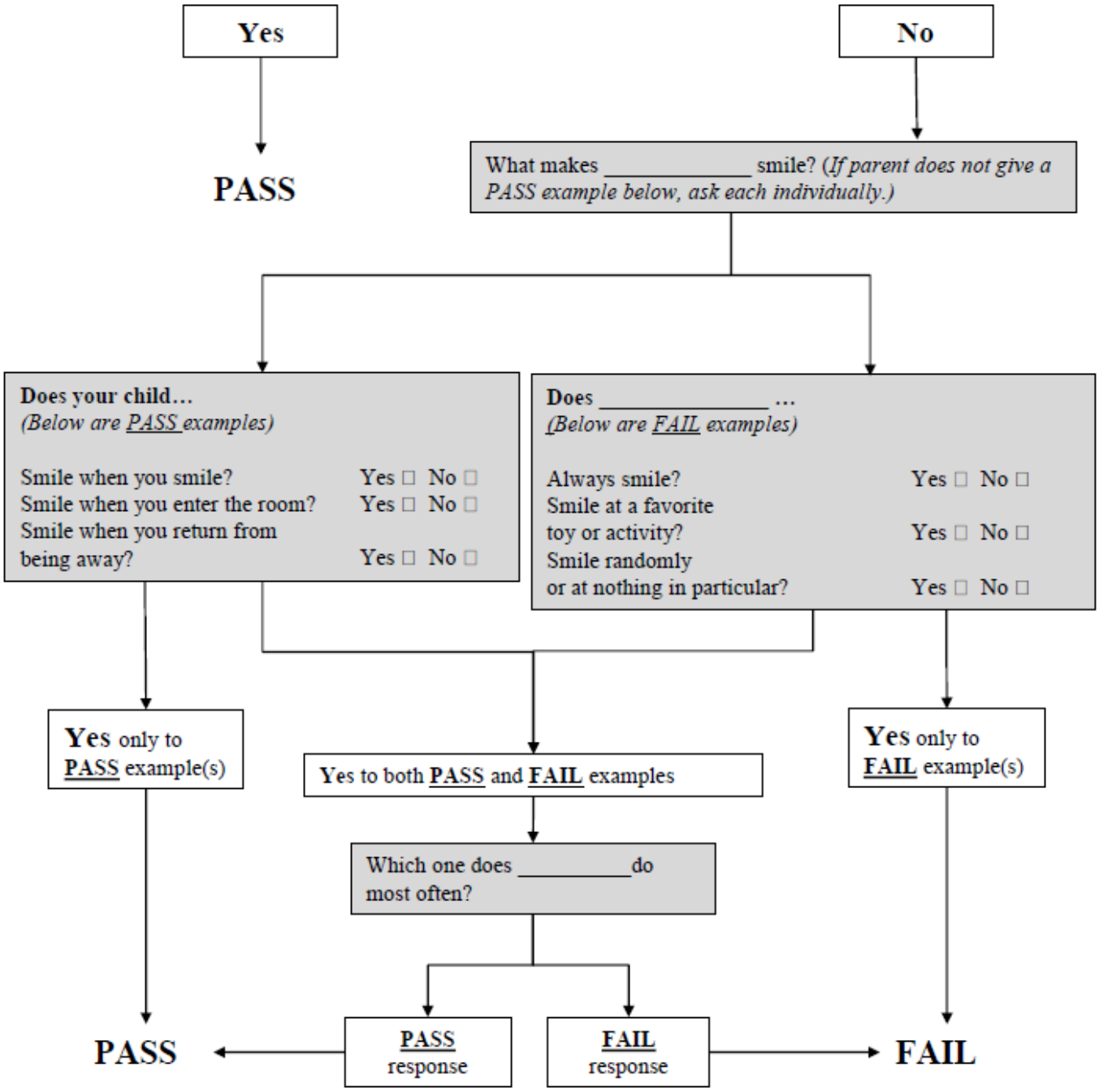
11. When you smile at _____, does your child smile back at you?



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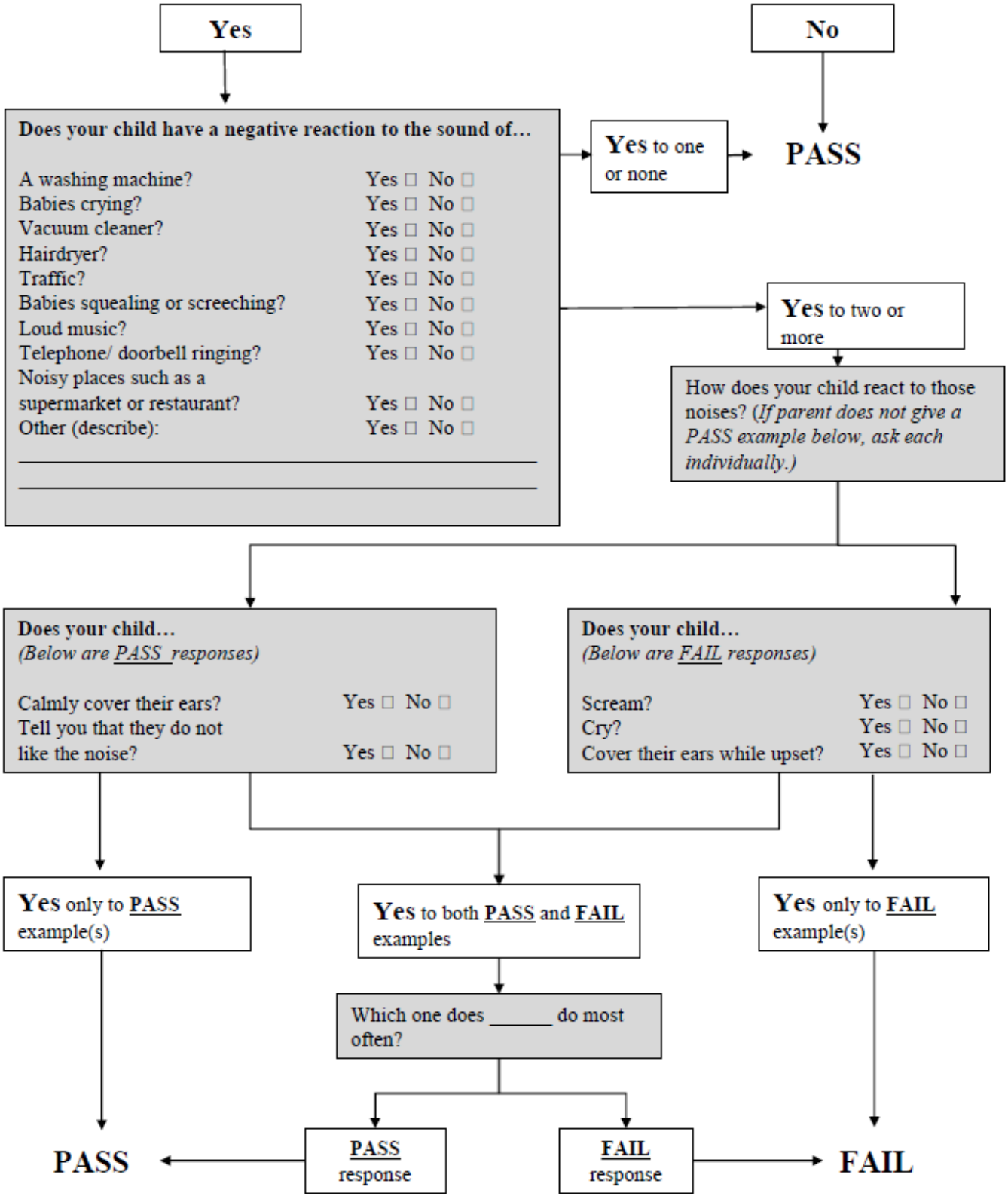
12. Does _____ get upset by everyday noises?



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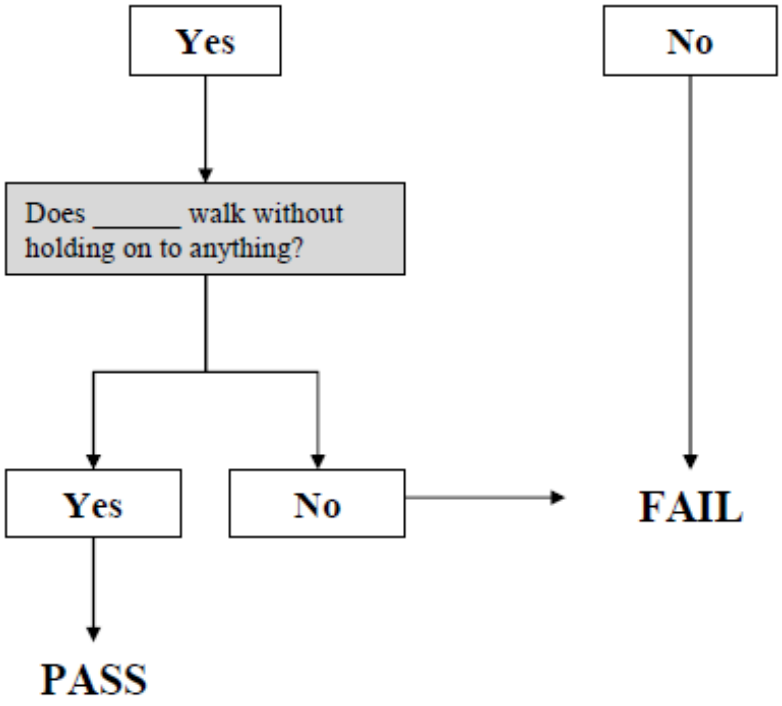
13. Does _____ walk?



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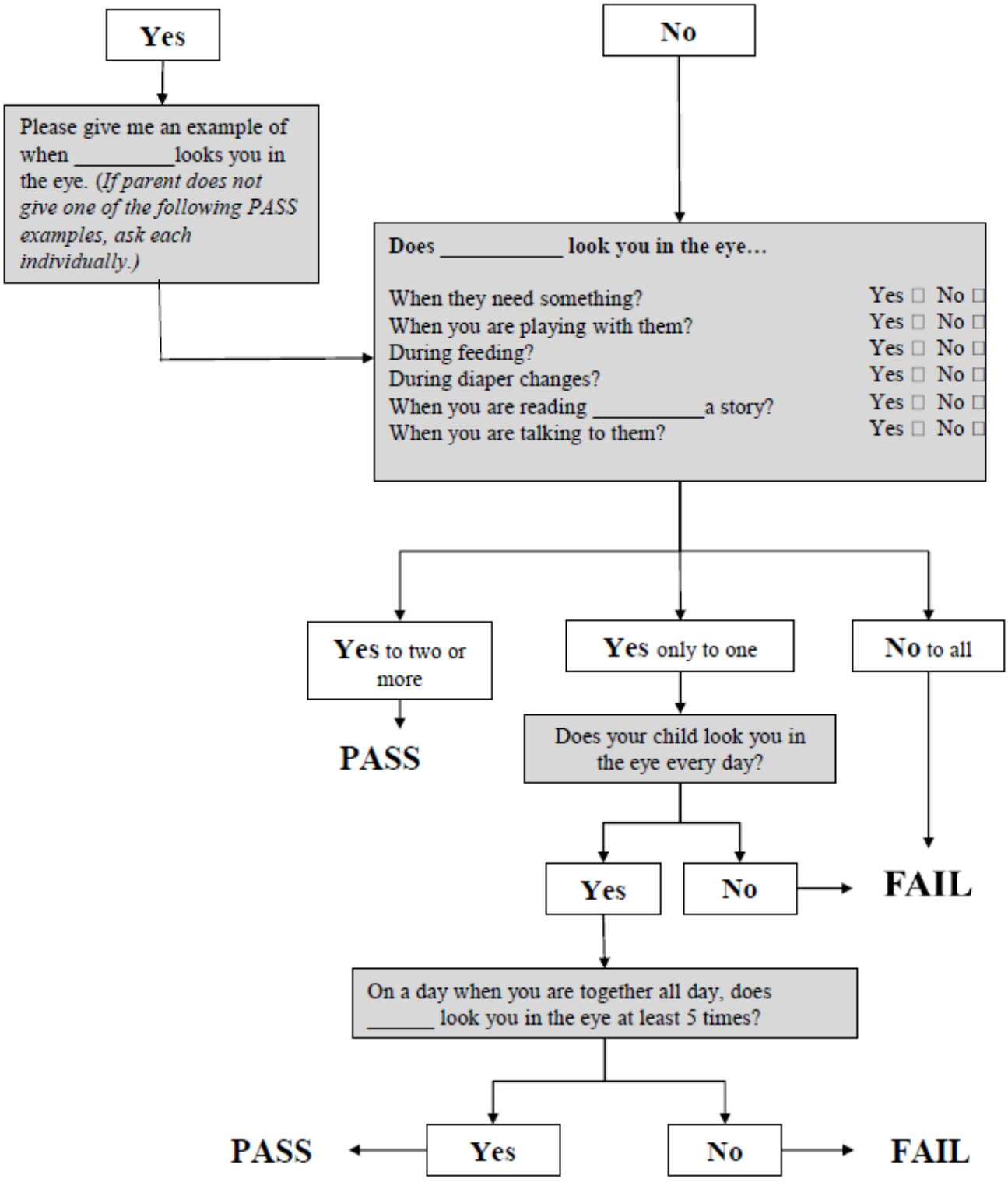
14. Does _____ look in your direction or in your eyes when you are talking to them, playing with them, or changing them?



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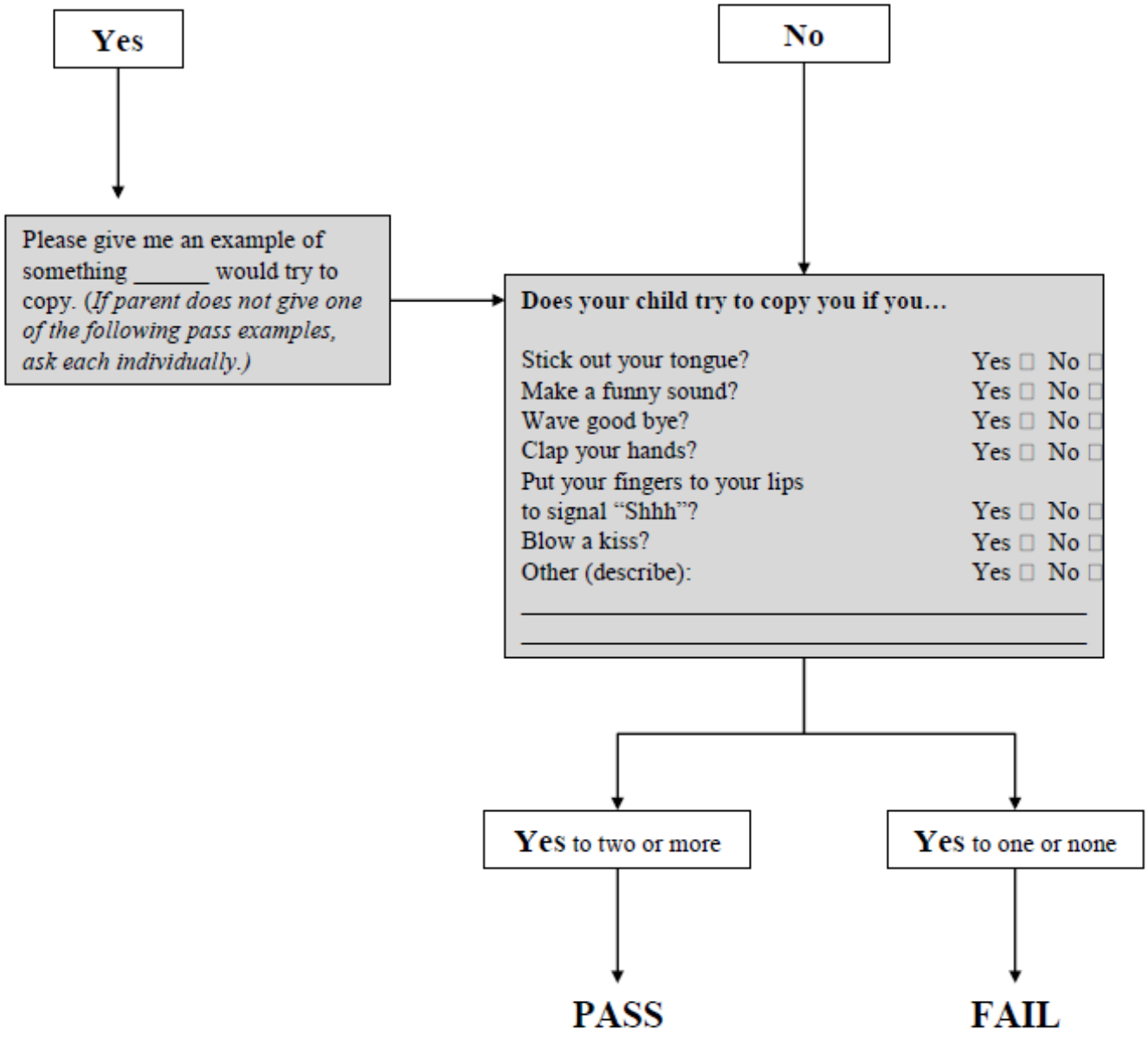
15. Does _____ try to copy what you do?



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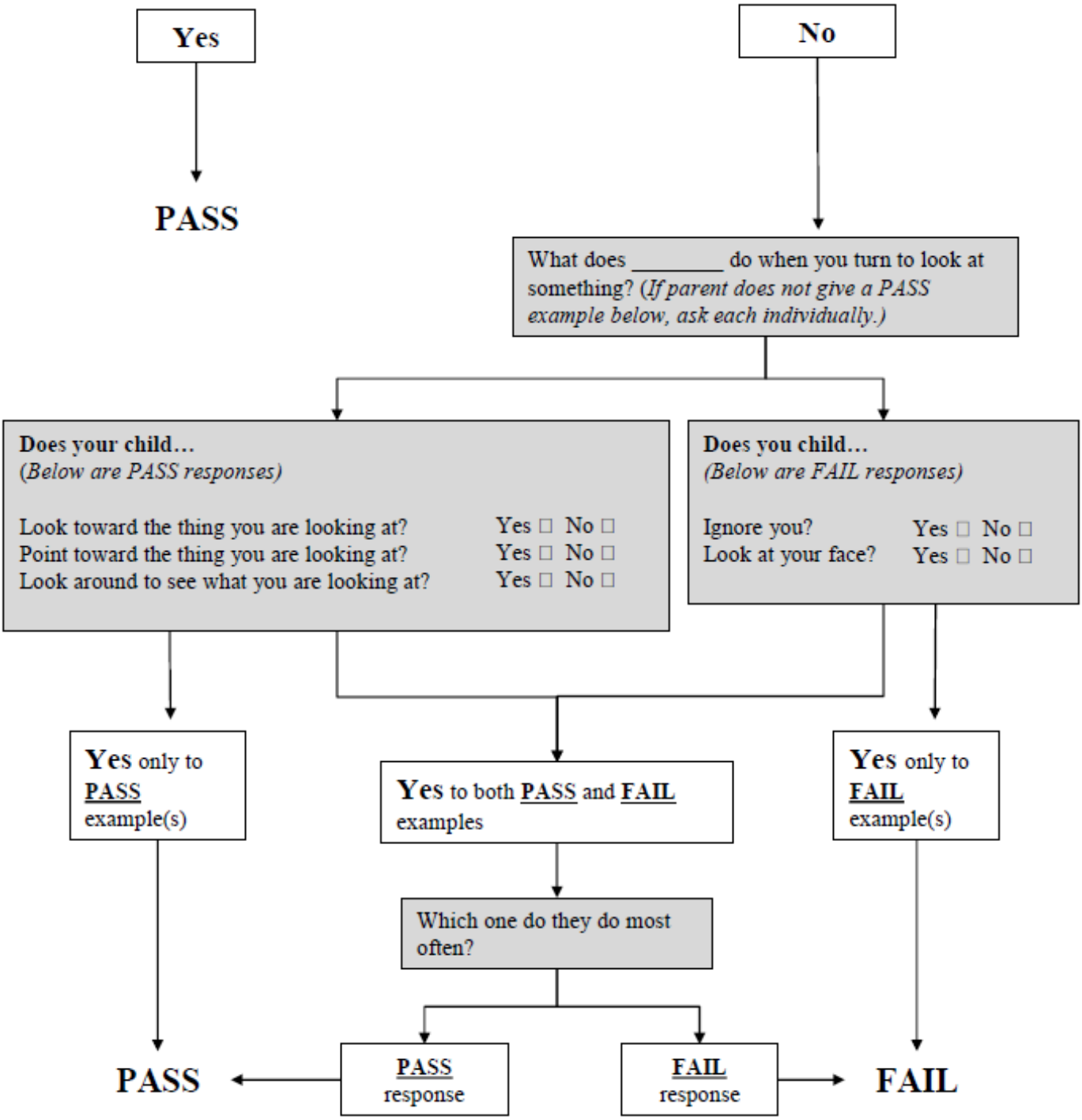
16. If you turn your head to look at something, does _____ look around to see what you are looking at?



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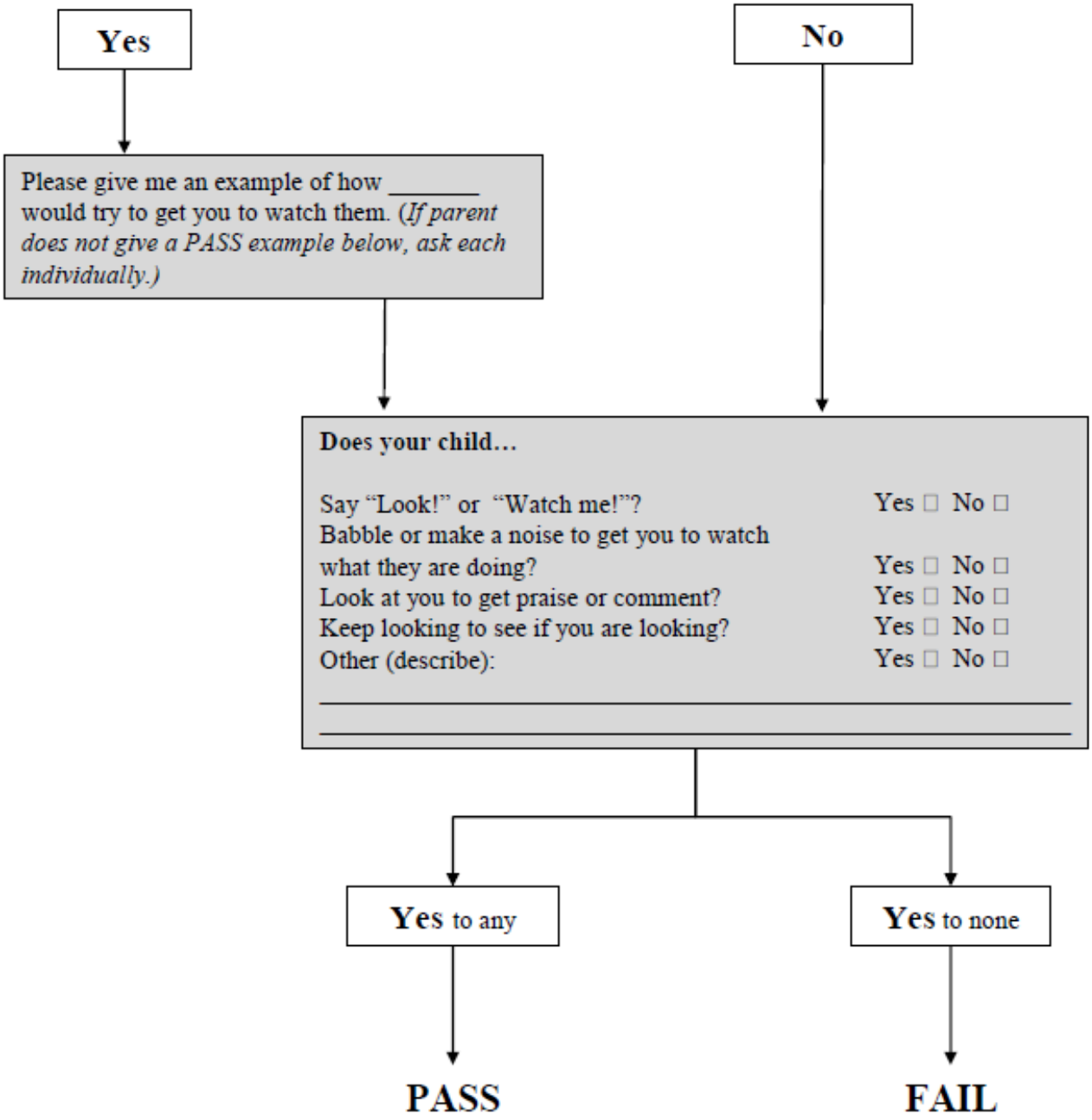
17. Does _____ try to get you to watch them?



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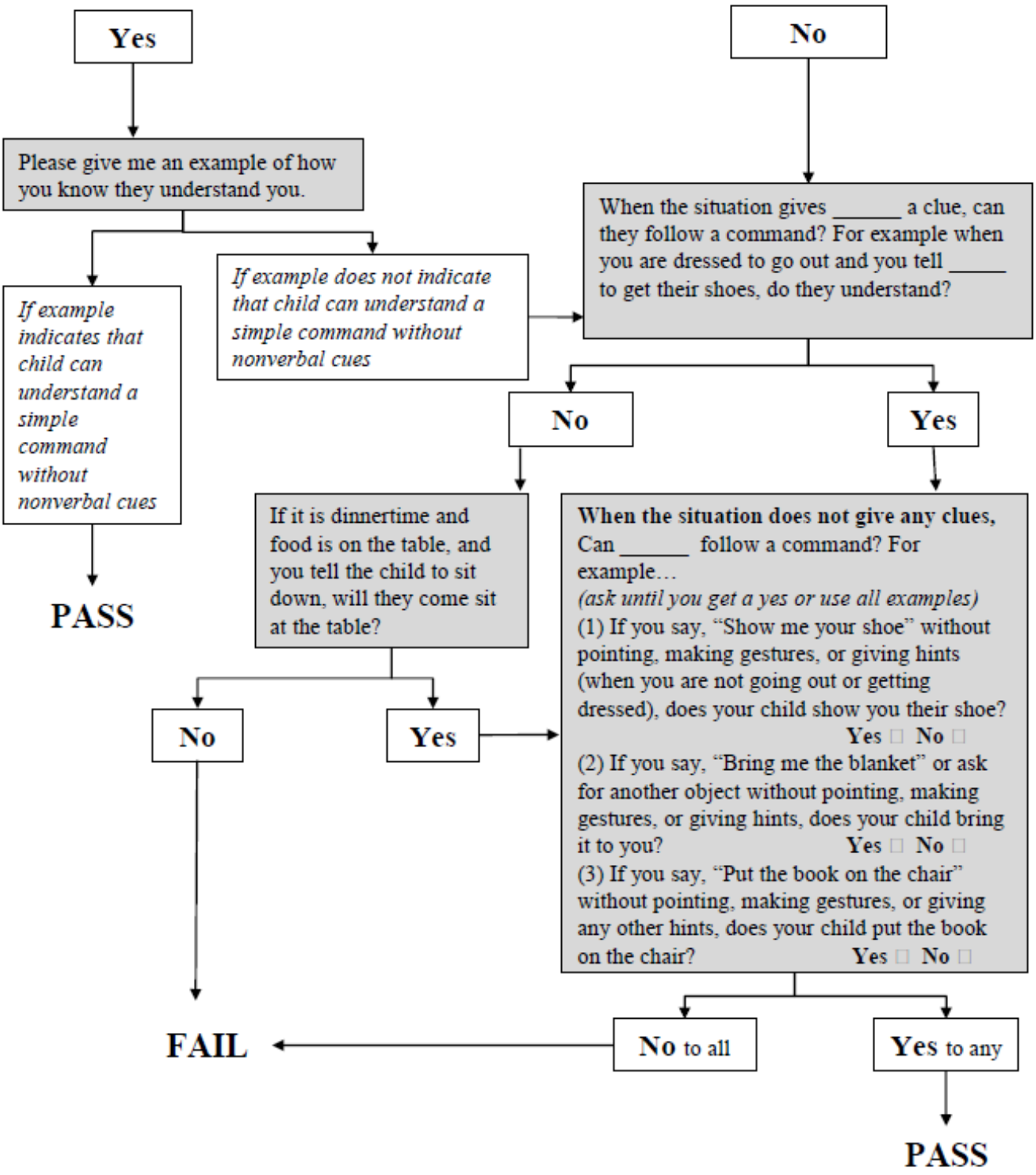
18. Does _____ understand when you tell them to do something?



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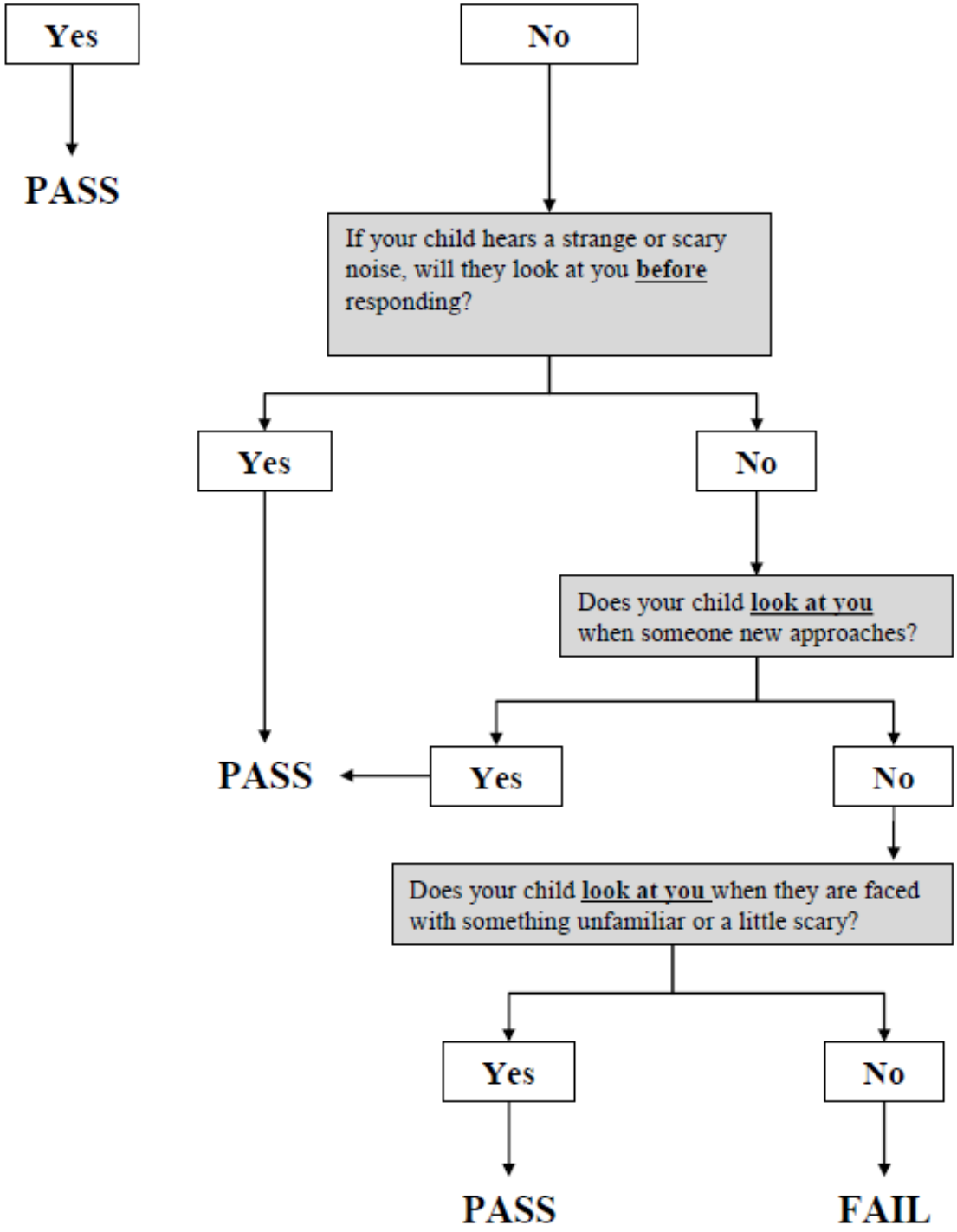
19. If something new happens, does _____ look at your face to see how you feel about it?



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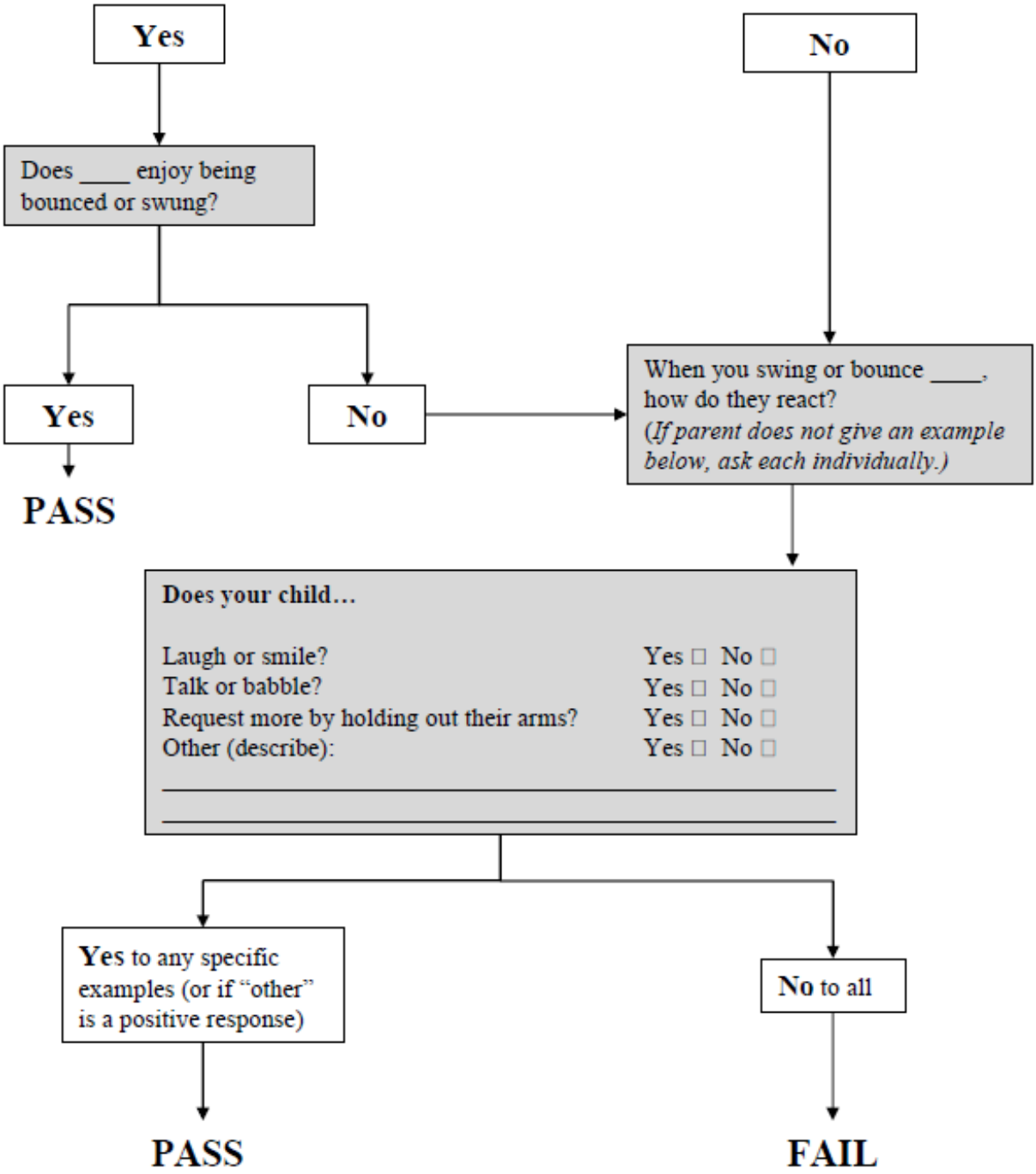
20. Does _____ like movement activities?



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Appendix C: Northern Sotho M-CHAT-R/F

Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHART-R/F) ™

Diana L. Robins, Ph.D.
Deborah Fein, Ph.D.
Marianne Barton, Ph.D.

Kamogelo: Re leboga sehlopha sa Dinyakišišo tša M-CHAT ka lefaseng la Spain ka go dira mokgwa wa tšhate ya peakanyo wo o šomišitšwego ka tokumenteng ye,

Go hwetša tshedimošo ka botlalo, o kgopelwa go lebelela www.mchatscreen.com goba go kgokagana le Diana Robins go mchatscreen2009@gmail.com

Ela hloko. Kgatišo ye e na le diphošollo tše dinnyane, Phato, 10, 2018

Northern Sotho: Vorster, C., Kritzinger, A., Lekganyane, M., Taljard, E., & Van der Linde, J. (2020)

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Ditumelelo tša Go šomiša M-CHAT-R/F™

Lenaneo la tekolo leo le mpshafaditšwego la Othisimo mo go Bana ba go Abula, le βoeleditšwe ka Ditatišišo (M-CHAT-R/F; Robins, Fein, & Barton, 2009) ke teko ya tekolo ya pego ya motswadi. E na le dikarolo tše pedi le diteko tša kgonagalo (kotsi) ya Othisimo. O ka taonelouta M-CHAT-R/F ntle le tefo gomme wa e šomišetša dinyakišišo, go ruta le mabaka a kalafo. Go taonelouta M-CHAT-R/F go dumeletšwe go tšwa go www.mchatscreen.com

M-CHAT- R/F ke sedirišwa seo se nago le tokelo ya ngwalollo, gomme tšhomišo ya M-CHAT- R/F e swanetše go latela ditlhahli:

(1) Dikgatišogape/dipušološo tša M-CHAT-R di swanetše go akaretša tokelo ya ngwalollo ka fase (© 2009 Robins, Fein, & Barton). Ga go na dimpshafatšo tšeo di ka dirwago go dintlha, ditaelo, goba tatelano ya dintlha go se a hwetšwa tumelelo go mongwadi.

(2) M-CHAT-R/F ka moka e swanetšwe go šomišwa. Dinyakišišo di bontšha gore ge o šomiša fela dintlha tše dingwe teko ga se tša maleba.

(3) Dihlopha tšeo di nago le kgahlego tša go tšweletša M-CHAT-R/F ka go gatiša (mohlala, puku goba athekele ya jenale) goba ka elektroniki gore di šomišwe ke ba bangwe (mohlala, bjalo ka karolo ya rekoto ya kalafo ya titšitale goba kgobokanyo ya softwere) ba swanetšwe ke go kgokagana le Diana Robins go kgopela tumelelo (mchatscreen2009@gmail.com).

(4) O dumeletšwe go šomiša M-CHAT-R bjalo ka sehlopha sa kalafo. Ge o šomiša dipotšišo tša karolo/lagato ya mathomo bjalo ka karolo ya rekoto ya kalafo ya elektroniki (EMR), o swanetše go botšiša Diana Robins ge e le gore o ka abelana ka rekoto ya gago.

Ditaelo tša Go šomiša

M-CHAT-R e ka dirwa le go skorwa bjalo ka karolo ya ketelo ya tlhokomelo ya ngwana. E ka šomišwa ke dingaka le ditsebo tše dingwe go dirat diteko tša kotsi/kgonagalo ya Othisimo.

Nepo ye kgolo ya M-CHAT-R ke go utolla ditiragalo tše dintši ka moo go gonegago tša Othisimo.

Ga se ka moka bana bao go nago le kgonagalo ya go ba le Othisimo ba ka bago le yona.

Modiriši o swanetše go lemoga gore le ka Tatišišo, bana ba bantši bao go nago le kgonagalo (kotsi) ya Othisimo go ya ka teko, ba ka se phekolwe ka Othisimo. Bana bao go nago le kgonagalo (kotsi) ya godimo go ya ka teko go na le kgonagalo (kotsi) ya diemo tše dingwe tšeo di fetogago go dititelego. Ge kgonagalo (kotsi) ya godimo yaOthisimo e skorilwe, go swanetšwe go dirwa tekolo.

Alkorithime ya Go skora

Go dilo ka moka ntle le 2,5, le 12, karabo ya "AOWA" e ra kotsi ya ASD; go dilo tša 2,5, le 12, "EE" e ra kotsi ya ASD. Alkorithime ye e latelago e godiša kgobokanyo ya saekometriki tša M-CHAT-R:

KOTSI YA FASE: Palomoka ya Dintlha ke 0-2; ge ngwana a le ka fase ga dikgwedi tše 24, lekola gape ka morago ga letšatši la matswalo la bobedi. Ga go na magato a mangwe ao a nyakegago ntle le ge ditlhahlobo di bontšha kotsi ya ASD.

KOTSI YA MAGARENG: Palomoka ya Dintlha ke 3-7; Laola Tatišišo (legato la bobedi la M-CHAT-R/F) go hwetša tshedimošo ya tlaleletšo ka ga dikarabo tša kotsi. Ge dintlha tša M-CHAT-RF di dula di le go 2 goba go feta, seo se ra gore ngwana o na le bolwetši. Magato ao a nyakega: romela ngwana go tekolo ya phekolo le tekolo ya maswanedi ya tsenogare ya ka pela. Ge skoro sa Tatišišo e le 0-1, ngwana ga a na bolwetši. Ga go na magato a mangwe ao a nyakegago ntle le ge ditlhahlobo di bontšha kotsi ya ASD. Ngwana o swanetše go lekolwa gape diketelong tša ka moso go netefatša ge ngwana a phetše gabotse.

KOTSI YA GODIMO: Palomoka ya Skoro ke 8-20; Go a dumelelega go hlokomologa Tatišišo gomme ngwana a romele ka bjako go tekolo ya phekolo le tekolo ya maswanedi ya tsenogare ya ka pela.

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Northern Sotho: Vorster, C., Kritzinger, A., Lekganyane, M., Taljard, E., & Van der Linde, J. (2020)

M-CHAT-R/F™

O kgopelwa go araba dipotšišo ka ga ngwana ka ga ngwana wa gago. Gopodišiša ka moo ngwana wa gago a itshwarago ka gona ka mehla. Ge o bone ngwana wa gago a dira maitshwaro, eupša e se ao a tlwaetšego go a dira, araba ka **aowa**.

1.	Ge o šupa se sengwe seo se lego ka phapošing, naa ngwana wa gago o a se lebelela? (Mohlala, ge o šupa sebapadišwa goba tafola, naa ngwana wa gago o lebelela sebapadišwa goba tafola?)	Ee	Aowa
2.	Naa o ile wa nagana gore ngwana wa gago e ka ba e le sefoa?	Ee	Aowa
3.	Naa ngwana wa gago o bapala papadi ya go ekiša (**MOHLALA,** go ekiša o ka re o nwa go tšwa komiking yeo e se nago selo, go ekiša o ka re o bolela mogaleng, goba go ekiša o ka re o leša mpop?)	Ee	Aowa
4.	Naa ngwana wa gago o rata go namela dilo? (**MOHLALA,** fenišara, mehlare, ditepisi)	Ee	Aowa
5.	Naa ngwana wa gago o šikinya menwana moo go se a tlwaelegago kgauswi le mahlo a gagwe? (**MOHLALA,** naa ngwana wa gago o sepediša menwana ya gagwe kgauswi le mahlo a gagwe? E sego go fogohletša mahlo)	Ee	Aowa
6.	Naa ngwana wa gago o šupa ka monwana o tee go kgopela se sengwe goba go hwetša thušo? (**MOHLALA,** go šupa sesolana goba sebapadišwa seo se sa fihlelegego)	Ee	Aowa
7.	Naa ngwana wa gago o šupa ka monwana o tee go go bontšha se sengwe sa go kgahliša? (**MOHLALA,** go šupa sefofane lefaufaung goba lori ye kgolo tseleng)	Ee	Aowa
8.	Naa ngwana wa gago o na le kgahlego go bana ba bangwe? (**MOHLALA**, naa ngwana wa gago o lebelela bana ba bangwe, o a ba myemyediša, goba go ya go bona?	Ee	Aowa
9.	Naa ngwana wa gago o go bontšha dilo ka go di tliša go wena goba go di swara gore o di bone – e sego go hwetša thušo eupša go abelana fela? (**MOHLALA,** go go bontšha letšoba, phoofolo ya go phela goba sebapadišwa sa lori)	Ee	Aowa
10.	Naa ngwana wa gago o a arabela ge o bitša leina la gagwe? (**MOHLALA**, naa o lebelela godimo, go bolela goba go go ngunanguna, goba o emiša seo a se dirago ge o bitša leina la gagwe?)	Ee	Aowa
11.	Ge o myemyediša ngwana wa gago, naa le yena o a buša a go myemyediša?	Ee	Aowa
12.	Naa ngwana wa gago o tshwenywa ke lešata la letšatši le lengwe le lengwe? (**MOHLALA,** naa ngwana wa gago o a goelela goba go lla ge go na le lešata la modumo wa tladi goba mmino wa godimo?)	Ee	Aowa
13.	Naa ngwana wa gago o a sepela?	Ee	Aowa
14.	Naa ngwana wa gago o a go lebelela ge o bolela le yena, ge o bapala le yena, goba ge o mo apeša	Ee	Aowa
15.	Naa ngwana wa gago o leka go ekiša seo o se dirago (**MOHLALA,** go šadiša gabotse ka letsogo, go phaphatha, goba go dira lešata la go segiša ge o le dira)	Ee	Aowa
16.	Ge o retolla hlogo ya gago go lebelela se sengwe, naa ngwana wa gago o a lebelela go bona gore o lebeletše eng?	Ee	Aowa
17.	Naa ngwana wa gago o leka go dira gore o mmogele? (**MOHLALA**, naa ngwana wa gago o a go lebelela gore o mo rete, goba o re "bona" goba "ntebelele"	Ee	Aowa
18.	Naa ngwana wa gago o a kwešiša ge o mmotša gore a dire se sengwe? (**MOHLALA**, ge o sa šupe, naa ngwana wa gago a ka kwešiša ge o mmotša go "bea puku setulong" goba "mphe lepai"?)	Ee	Aowa
19.	Ge se sengwe se seswa se ka direga, naa ngwana wa gago o go lebelela ka mahlong? (**MOHLALA**, ge a ekwa lešata la go makatša goba la go segiša, goba a bona sebapadišwa se sefsa, naa o go lebelela sefahlegong?)	Ee	Aowa
20.	Naa ngwana wa gago o rata mešongwana ya mosepelo? (**MOHLALA**, go dikologa ka ngwana a le khurung ya gago)	Ee	Aowa

Tatišišo ya M-CHAT-R (M-CHAT-R/F) TM

Ditumelelo tša go šomiša

Lenaneo la tekolo leo le mpshafaditšwego la Othisimo mo go Bana ba go Abula, le Boeleditšwe ka Ditatišišo (M-CHAT-R/F; Robins, Fein, & Barton, 2009) ke teko ya tekolo ya pego ya motswadi. E na le dikarolo tše pedi le diteko tša kgonagalo (kotsi) ya Othisimo. O ka taonelouta M-CHAT-R/F ntle le tefo gomme wa e šomišetša dinyakišišo, go ruta le mabaka a kalafo. Go taonelouta M-CHAT-R/F go dumeletšwe go tšwa go www.mchatscreen.com.

M-CHAT- R/F ke sedirišwa seo se nago le tokelo ya ngwalollo, gomme tšhomišo ya sedirišwa e beetšwe magomo ke mongwadi le beng ba tokelo ya ngwallolo. M-CHAT-R le M-CHAT- R/F di ka šomišetšwa mabaka a kalafo, dinyakišišo le thuto. Le ge re sa lefiše sedirišwa mo ditšhomišong tše, materiale wo o na le tokelo ya ngwalolla gobo ga se mothopo wo o ka dirišwago ke mang le mang.Yo mongwe le yo mongwe yoo a nago le kgahlego ya go šomiša M-CHAT-R/F go ditšweletšwa tše dingwe le tše dingwe tša kgwebo goba tša elektroniki o swanetše go kgokagana le Diana L. Robins at mchatscreen2009@gmail.com go kgopela tumelelo.

Ditaelo tša Go šomiša

M-CHAT-R/T e akanyeditšwe go šomišwa le M-CHAT-R; M-CHAT-R e loketšwe go lekola bana ba go abula ba gare ga dikgwedi tše 16 le 30, go ela kotsi ya bolwetši bja spektramo sa othisimo (ASD). Bašomiši ba swanetše go lemoga gore le ka Tatišišo, palo ye ntši ya bana bao ba palelwago ke M-CHARTR ba ka se phekolwe ka ASD; le ge go le bjalo, bana ba kotsing ya malwetši a mangwe a go gola goba **titelego**, ka gona , tatišo e a hlokega go ngwana yo mongwe le yo mongwe yo tekolo e bontšhago gore o na le bolwetši.

Ge motswadi a tladitše M-CHAT-R, skora sedirišwa go ya ka ditaelo. Ge ngwana a lekolwa go ba le bolwetši, kgetha dilo tša Tatišišo go lebeletšwe gore ke go selo sefe moo ngwana a palelwago go M-CHATR; dilo fela tšeo peleng di paletšwego di swanetšwe go laolelwa poledišano ye e feletšego.

Letlakala le lengwe le lengwe le sepelelana le selo se tee go tšwa go M-CHAT-R. Latela mokgwa wa tšhate ya peakanyo, o botšiša dipotšišo go fihla go skorwa TŠWELELA goba PALELWA. O kgopelwa go lemoga gore batswadi ba ka bega "mohlomongwe" go araba dipotšišo nakong ya dipoledišano. Ge motswadi a bega "mohlomongwe, botšiša gore gantši karabo ke "ee" goba "aowa" gomme o tšwele pele go ya ka karabo yeo. Moo go nago le sebaka sa go bega karabo ya "tše dingwe", mmolediši o swanetše go šomiša kahlolo ya gagwe go bona ge e le gore ke pego ya go tšwelela goba aowa.

Skora dikarabo go selo se sengwe le se sengwe go Letlakala la Sekoro la M-CHAT-R/F (leo le nago le dilo tša go swana bjalo ka M-CHAT-R, eupša Ee/Aowa di emetšwe legato ke Tšwelela/Palelwa). Poledišano e tšewa go ba e lekotše go ba le bolwetši ge ngwana a ka palelwa ke dilo tše dingwe le tše dingwe tše pedi mo Tatišišong. Ge ngwana a ka lekolwa go ba le bolwetši mo go M-CHAT-RF, go digelwa kudu gore ngwana a romelwe go tsenogare ya ka pela le diteko tša phekolo ka pela ka moo go kgonegago. O kgopelwa go lemoga gore moabi wa tlhokomelo ya maphelo goba motswadi o dumeletše diASD, bana ba swanetšwe go romelwa go lekolwa go sa lebelelwe skoro mo go M-CHAT-R goba M-CHAT-RF.

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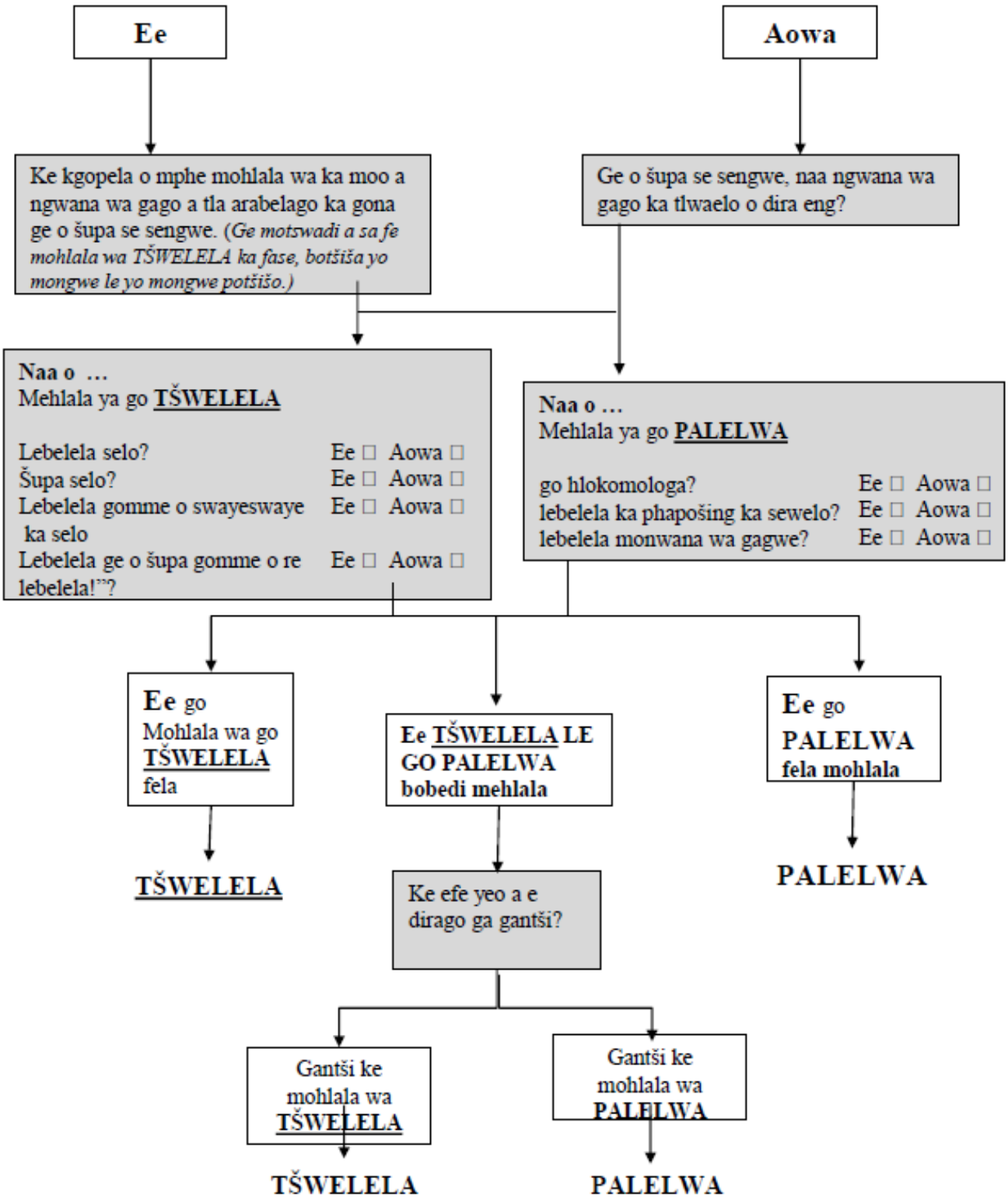
Northern Sotho: Vorster, C., Kritzinger, A., Lekganyane, M., Taljard, E., & Van der Linde, J. (2020)

Letlakala la go Skora la Tatišišo ya M-CHAT-R ™

1.	Ge o šupa se sengwe seo se lego ka phapošing, naa ngwana wa gago o a se lebelela? (Mohlala, ge o šupa sebapadišwa goba tafola, naa ngwana wa gago o lebelela sebapadišwa goba tafola?)	Tšwelela	Palelwa
2.	Naa o ile wa nagana gore ngwana wa gago e ka ba e le sefoa?	Tšwelela	Palelwa
3.	Naa ngwana wa gago o bapala papadi ya go ekiša (**MOHLALA,** go ekiša o ka re o nwa go tšwa komiking yeo e se nago selo, go ekiša o ka re o bolela mogaleng, goba go ekiša o ka re o leša mpop?)	Tšwelela	Palelwa
4.	Naa ngwana wa gago o rata go namela dilo? (**MOHLALA,** fenišara, mehlare, ditepisi)	Tšwelela	Palelwa
5.	Naa ngwana wa gago o šikinya menwana moo go se a tlwaelegago kgauswi le mahlo a gagwe? (**MOHLALA,** naa ngwana wa gago o sepediša menwana ya gagwe kgauswi le mahlo a gagwe? E sego go fogohletša mahlo)	Tšwelela	Palelwa
6.	Naa ngwana wa gago o šupa ka monwana o tee go kgopela se sengwe goba go hwetša thušo? (**MOHLALA,** go šupa sesolana goba sebapadišwa seo se sa fihlelegego)	Tšwelela	Palelwa
7.	Naa ngwana wa gago o šupa ka monwana o tee go go bontšha se sengwe sa go kgahliša? (**MOHLALA,** go šupa sefofane lefaufaung goba lori ye kgolo tseleng)	Tšwelela	Palelwa
8.	Naa ngwana wa gago o na le kgahlego go bana ba bangwe? (**MOHLALA**, naa ngwana wa gago o lebelela bana ba bangwe, o a ba myemyediša, goba go ya go bona?	Tšwelela	Palelwa
9.	Naa ngwana wa gago o go bontšha dilo ka go di tliša go wena goba go di swara gore o di bone – e sego go hwetša thušo eupša go abelana fela? (**MOHLALA,** go go bontšha letšoba, phoofolo ya go phela goba sebapadišwa sa lori)	Tšwelela	Palelwa
10.	Naa ngwana wa gago o a arabela ge o bitša leina la gagwe? (**MOHLALA**, naa o lebelela godimo, go bolela **goba** go go ngunanguna, goba o emiša seo a se dirago ge o bitša leina la gagwe?)	Tšwelela	Palelwa
11.	e o myemyediša ngwana wa gago, naa le yena o a buša a go myemyediša?	Tšwelela	Palelwa
12.	Naa ngwana wa gago o tshwenywa ke lešata la letšatši le lengwe le lengwe? (**MOHLALA,** naa ngwana wa gago o a goelela goba go lla ge go na le lešata la modumo wa tladi goba mmino wa godimo?)	Tšwelela	Palelwa
13.	Naa ngwana wa gago o a sepela?	Tšwelela	Palelwa
14.	Naa ngwana wa gago o a go lebelela ge o bolela le yena, ge o bapala le yena, goba ge o mo apeša	Tšwelela	Palelwa
15.	Naa ngwana wa gago o leka go ekiša seo o se dirago (**MOHLALA,** go šadiša gabotse ka letsogo, go phaphatha, goba go dira lešata la go segiša ge o le dira)	Tšwelela	Palelwa
16.	Ge o retolla hlogo ya gago go lebelela se sengwe, naa ngwana wa gago o a lebelela go bona gore o lebeletše eng?	Tšwelela	Palelwa
17.	Naa ngwana wa gago o leka go dira gore o mmogele? (**MOHLALA**, naa ngwana wa gago o a go lebelela gore o mo rete, goba o re "bona" goba "ntebelele"	Tšwelela	Palelwa
18.	Naa ngwana wa gago o a kwešiša ge o mmotša gore a dire se sengwe? (**MOHLALA**, ge o sa šupe, naa ngwana wa gago a ka kwešiša ge o mmotša go "bea puku setulong" goba "mphe lepai"?)	Tšwelela	Palelwa
19.	Ge se sengwe se seswa se ka direga, naa ngwana wa gago o go lebelela ka mahlong? (**MOHLALA**, ge a ekwa lešata la go makatša goba la go segiša, goba a bona sebapadišwa se sefsa, naa o go lebelela sefahlegong?)	Tšwelela	Palelwa
20.	Naa ngwana wa gago o rata mešongwana ya mosepelo? (**MOHLALA**, go dikologa ka ngwana a le khurung ya gago)	Tšwelela	Palelwa

1. Ge o šupa se sengwe seo se lego ka phapošing, naa ngwana wa gago o a se lebelela?



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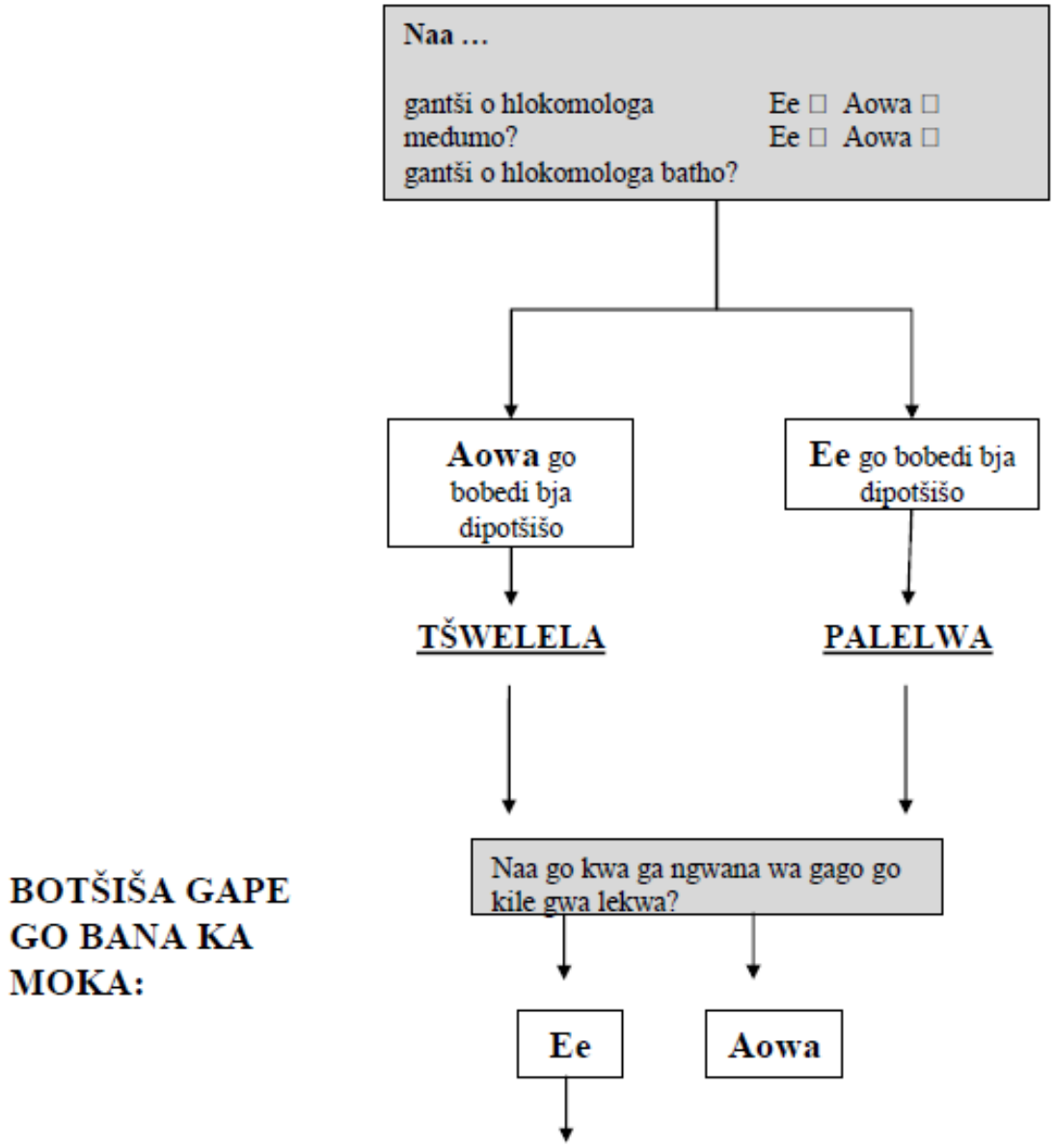
2. O begile gore o kile wa ipotšiša ge e le gore ngwana wa gago ke sefoa. Ke eng ye e go dirilego gore o ipotšiše?



BOTŠIŠA GAPE GO BANA KA MOKA:

Naa dipoelo tša teko ya go kwa e bile dife? *(kgetha ye tee):*

□O kwa ka mokgwa wa tlwaelo
□O kwa ka fase ga tlwaelo
□Dipoelo ga di kgodiše goba ga se tša felela

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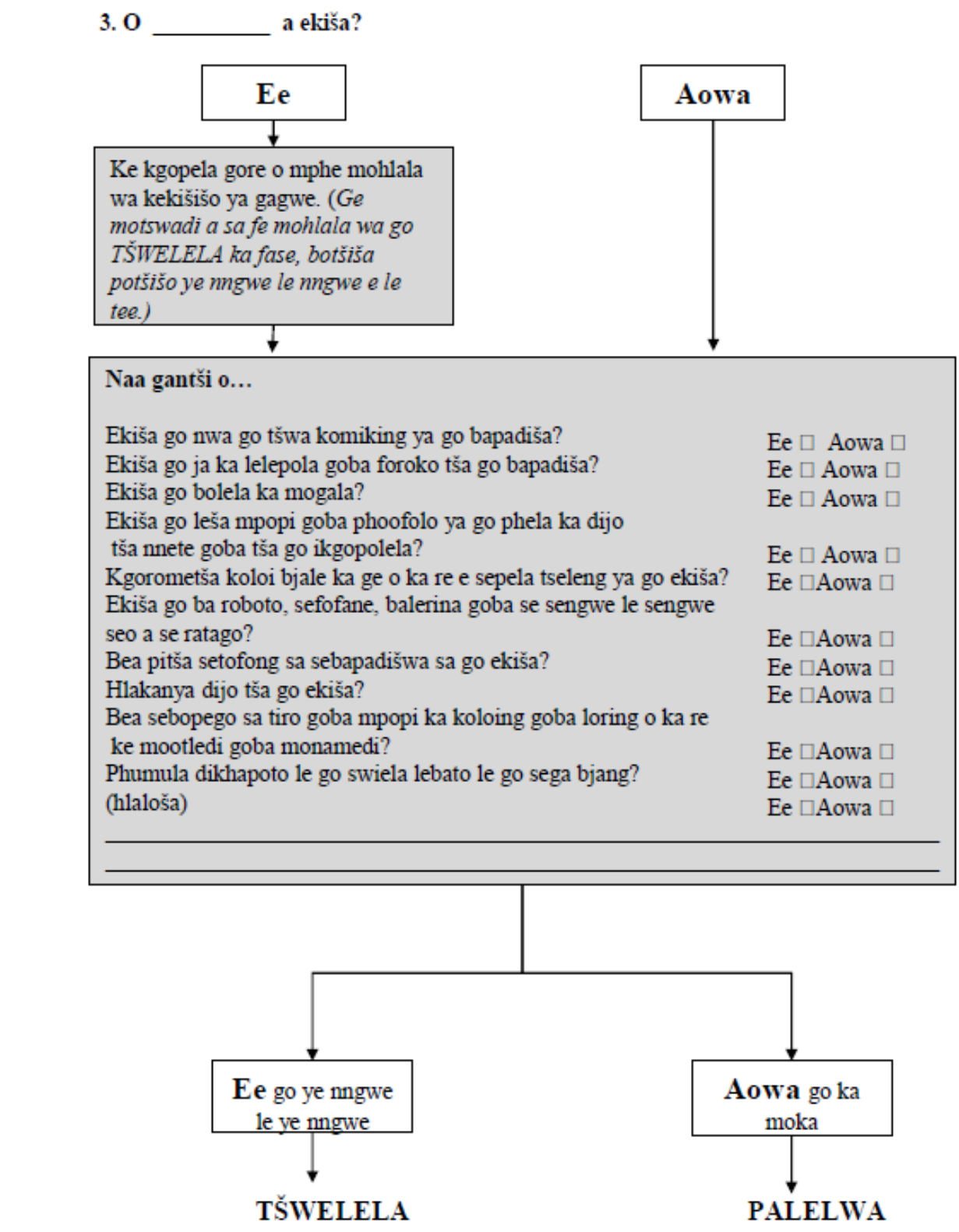

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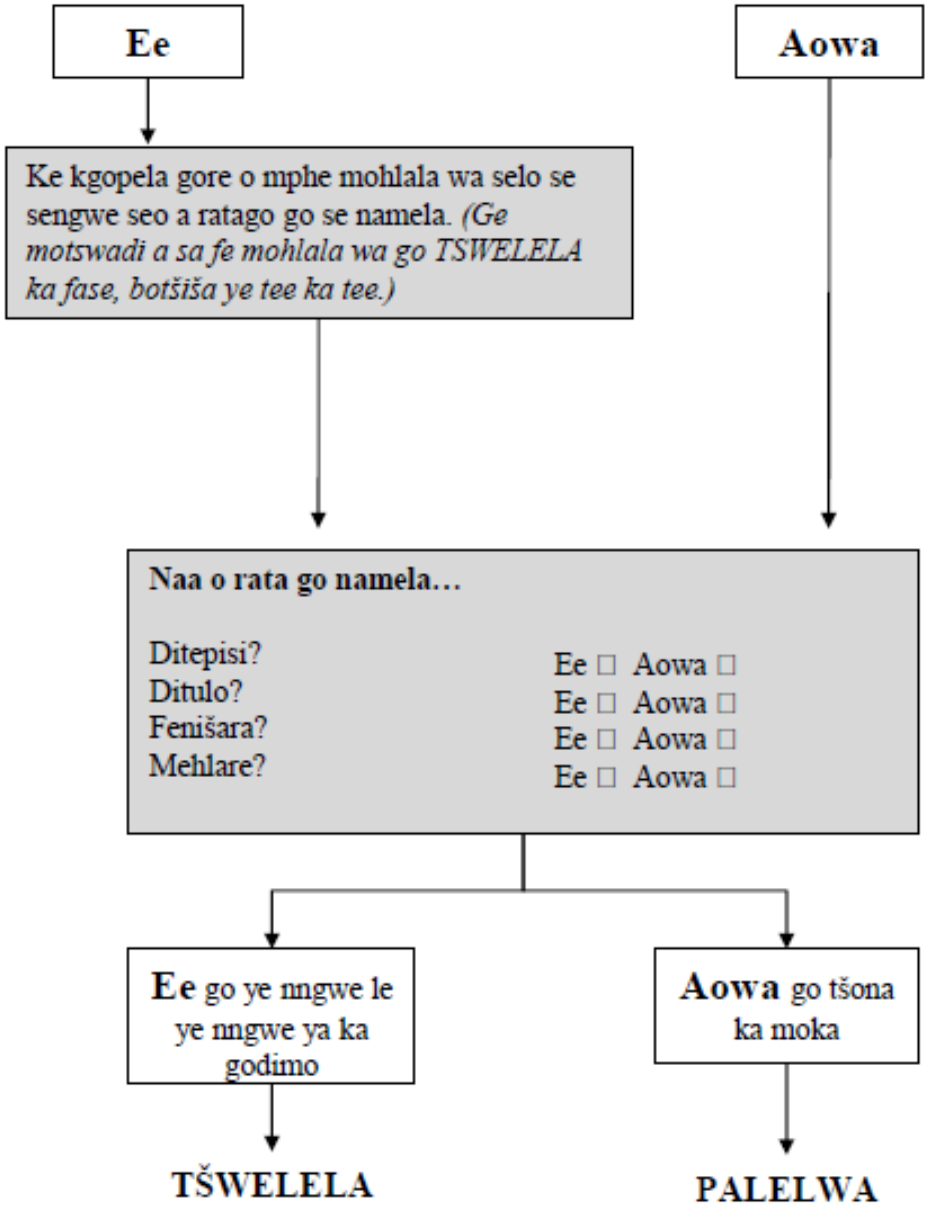
4. Naa ngwana wa gago o rata go namela dilo?



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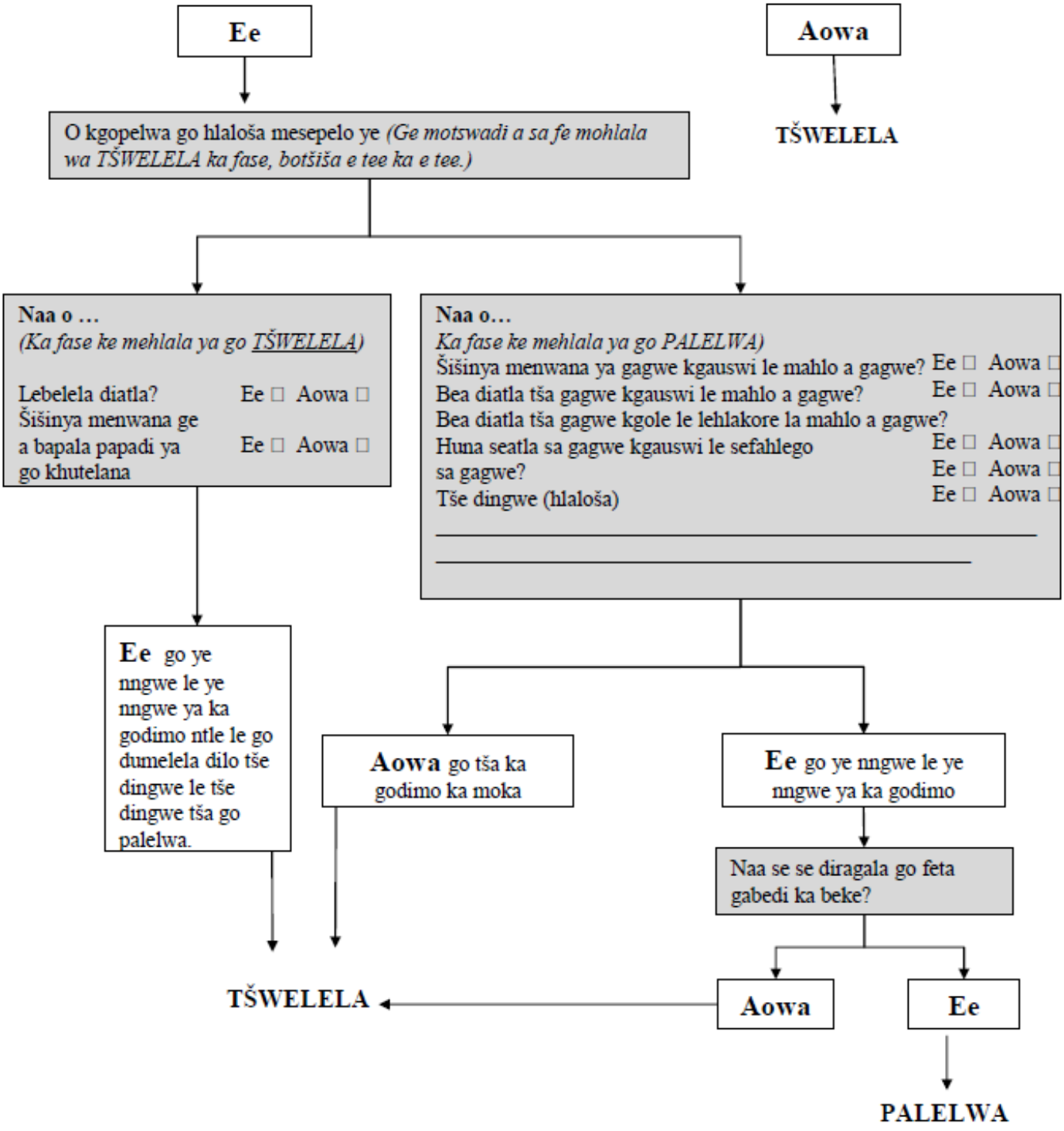
5. Naa ngwana wa gago o šikinya menwana moo go se a tlwaelegago kgauswi le mahlo a gagwe? E sego go fogohletša mahlo.



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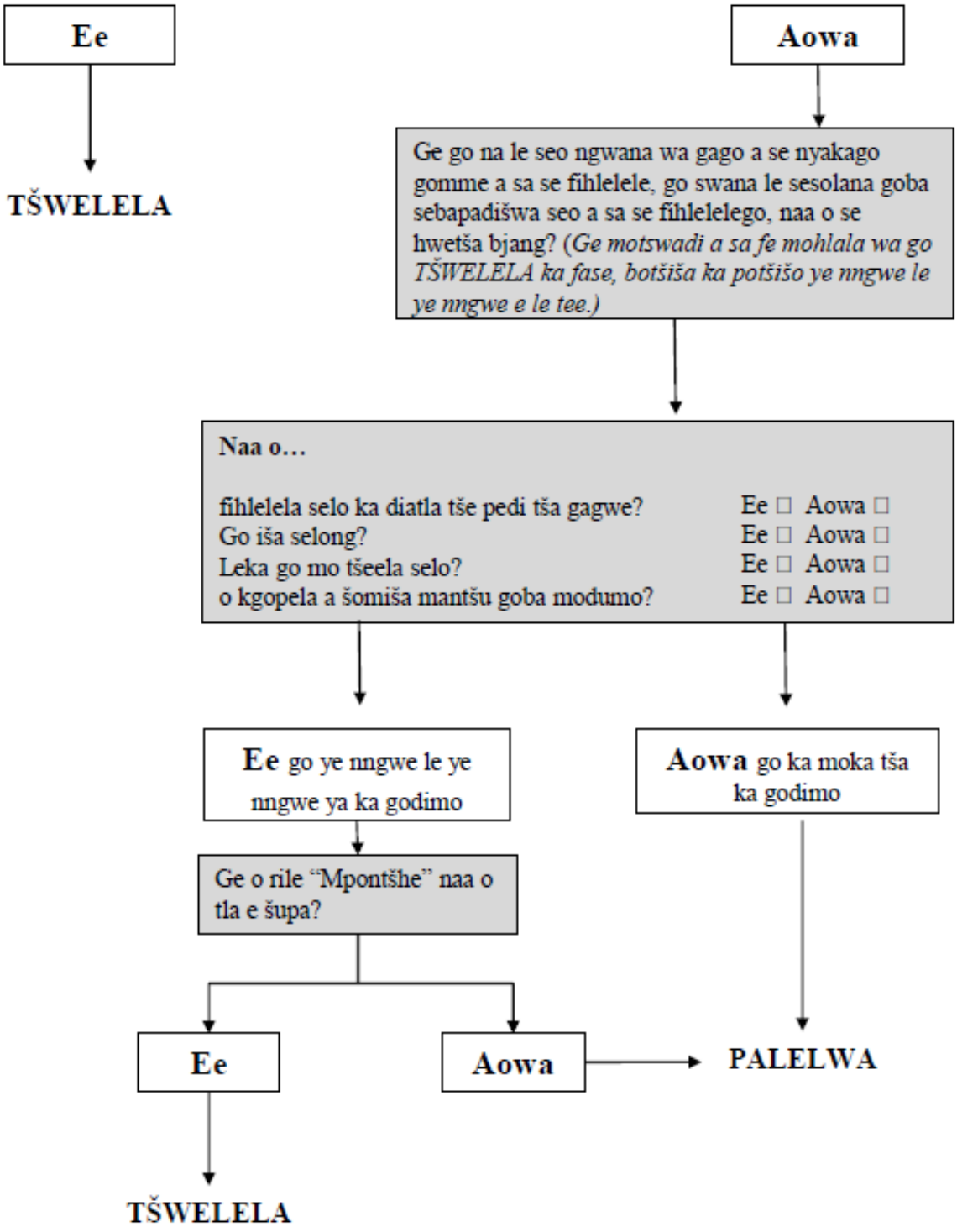
6. Naa _____ o šupa ka monwana o tee go kgopela se sengwe goba go hwetša thušo?



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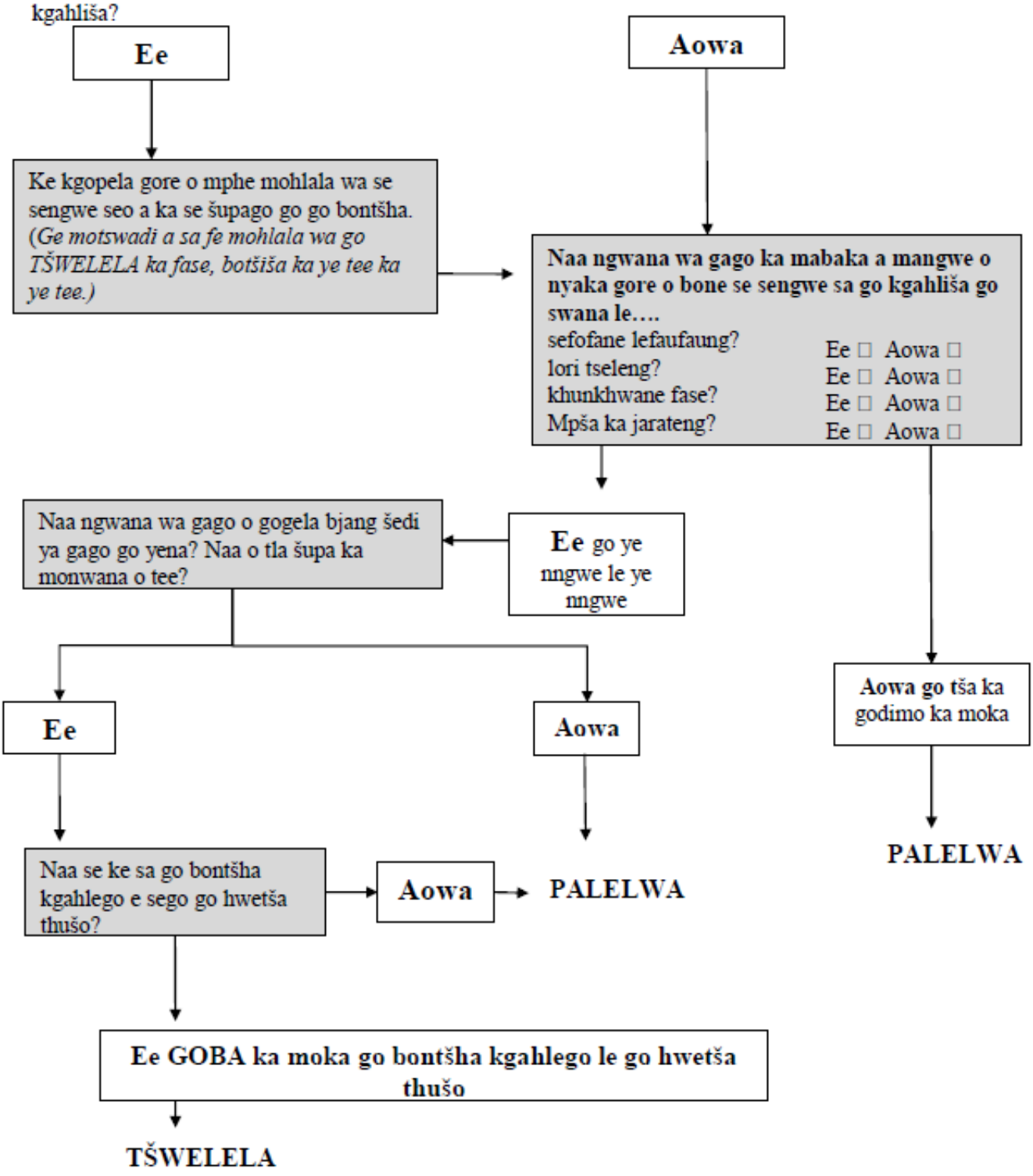
7. * **Ge mmolediši a botšiša fela #6, thoma mo: Re sa tšo bolela ka go šupa go *kgopela* se sengwe,**

BOTŠIŠA KA MOKA _ Naa_____ o šupa ka monwana o tee go no go bontšha se sengwe sa go kgahliša?



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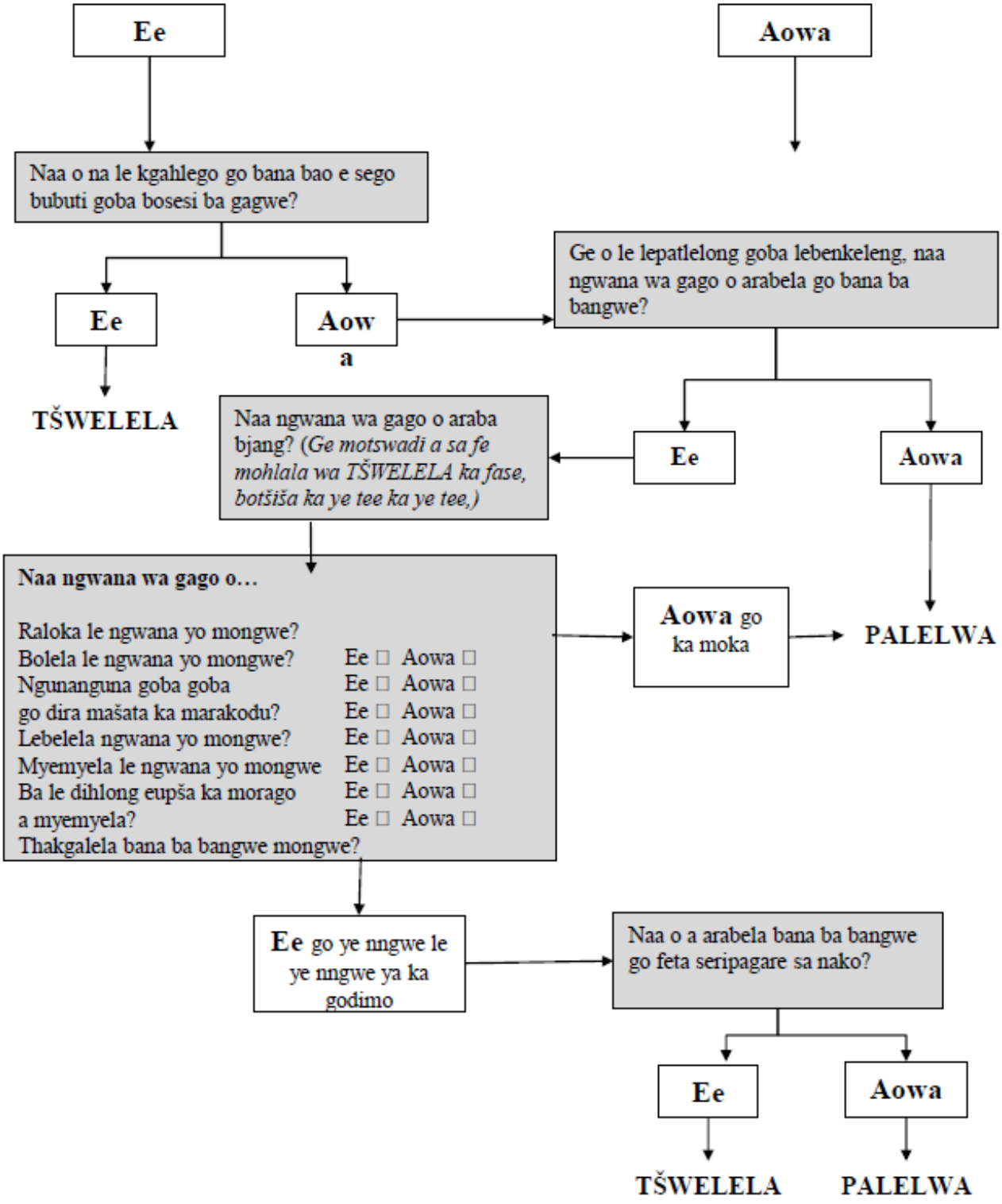
8. Naa _____ o na le kgahlego go bana ba bangwe?



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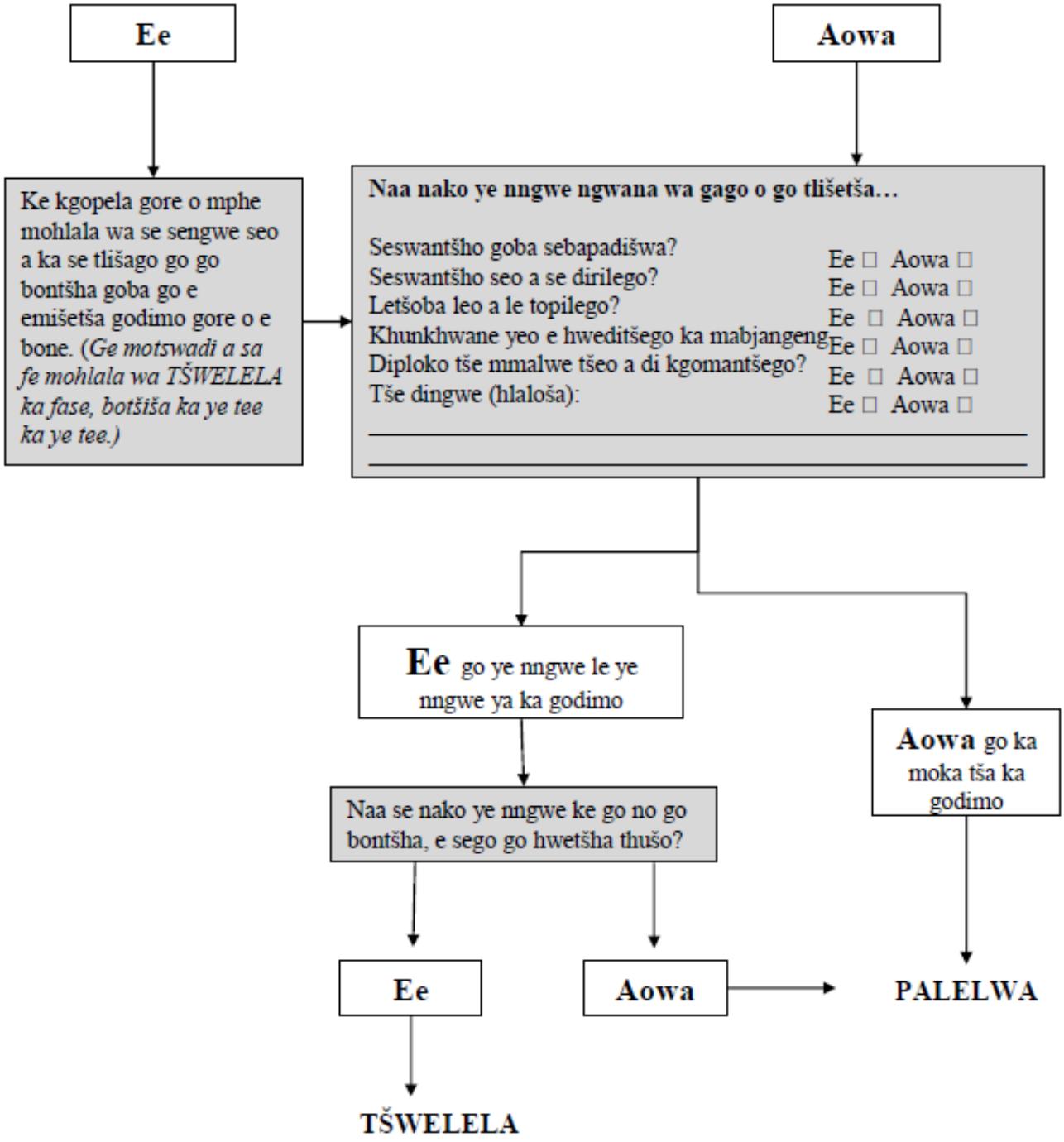
9.Naa ngwana wa gago o go bontšha dilo ka go di tliša go wena goba go di swara gore o di bone – e sego go hwetša thušo eupša go abelana fela?



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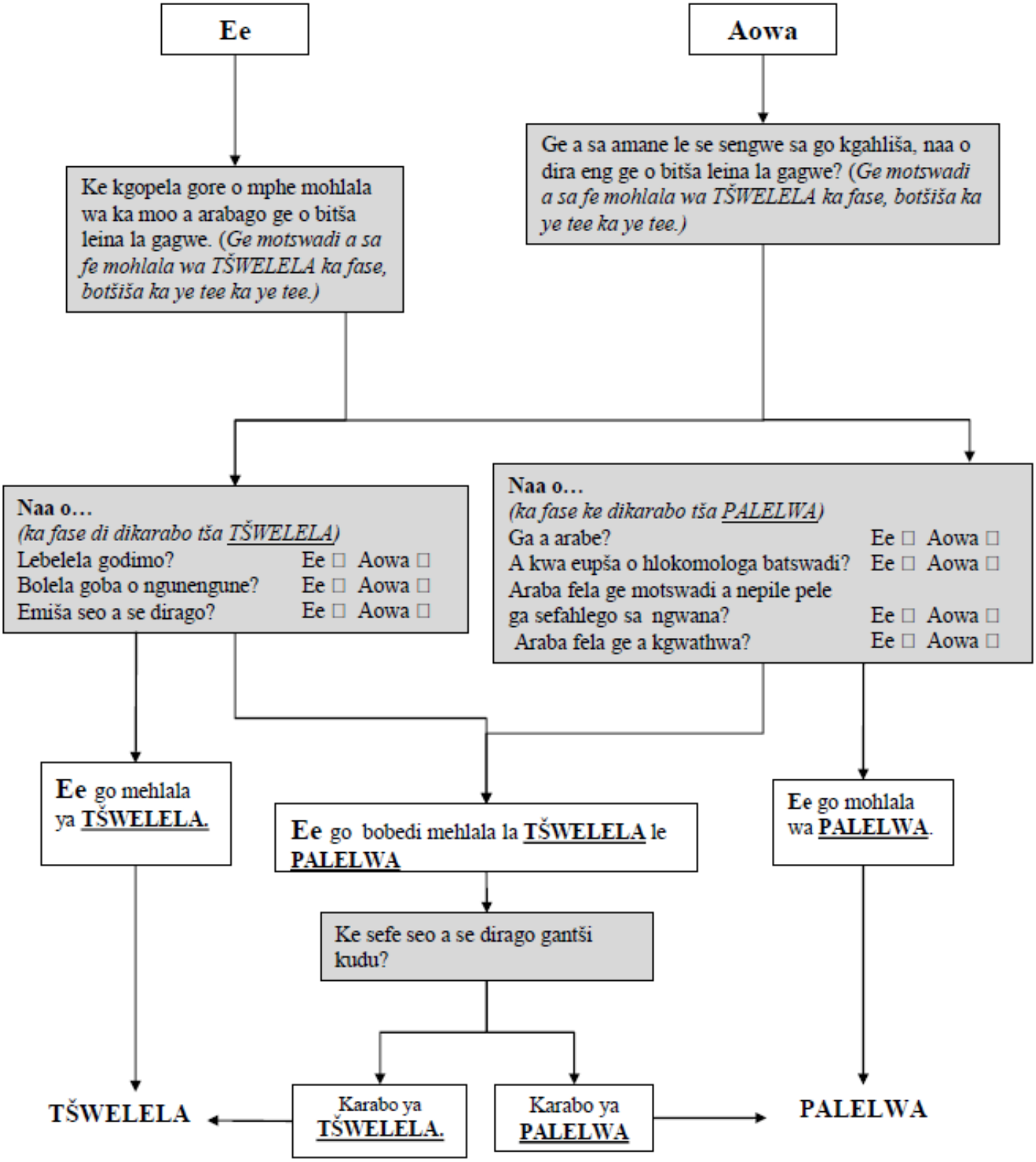
10. Naa ngwana wa gago o a arabela ge o bitša leina la gagwe?



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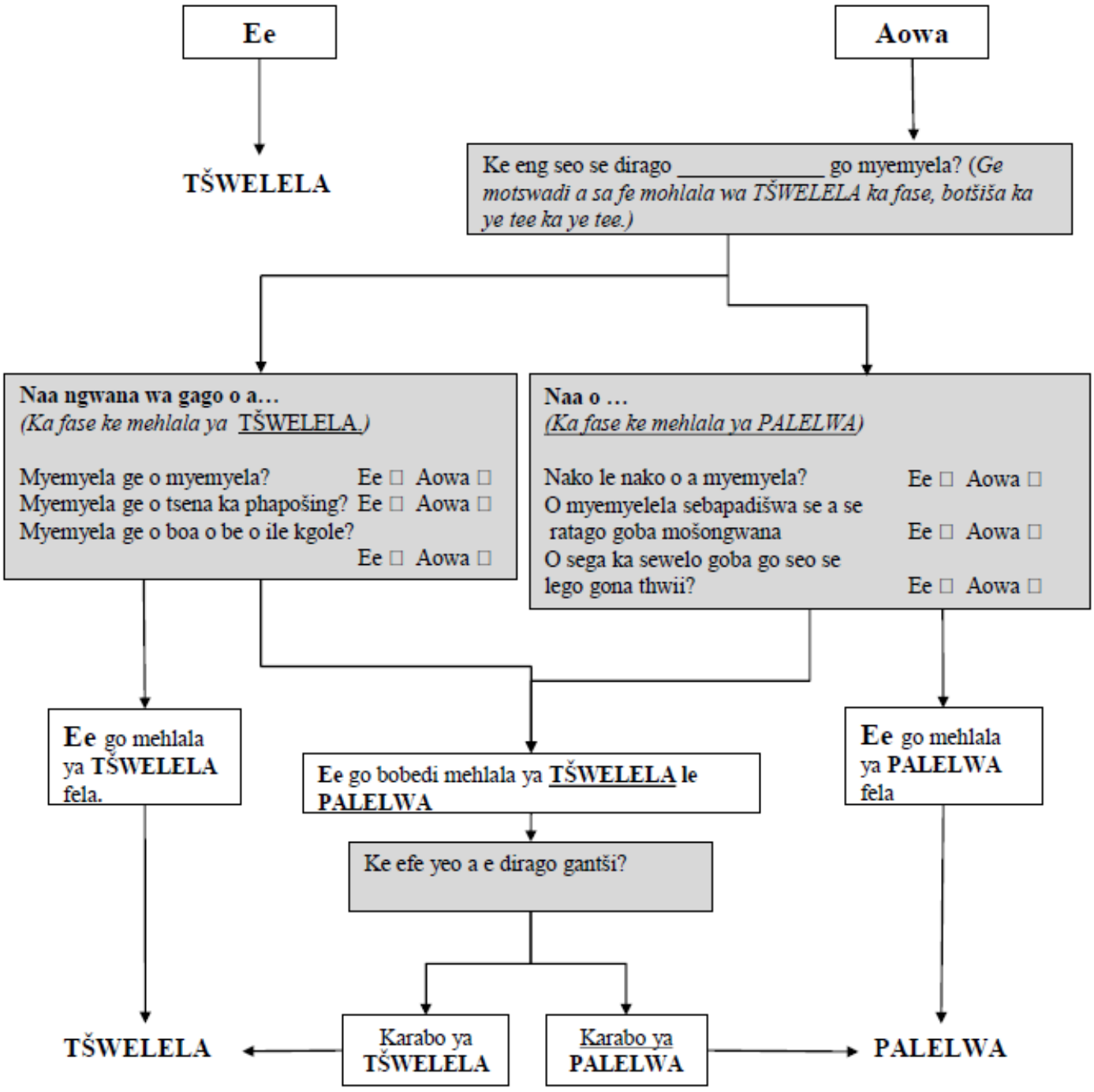
11. Ge o myemyediša ngwana wa gago, naa le yena o a buša a go myemyediša?



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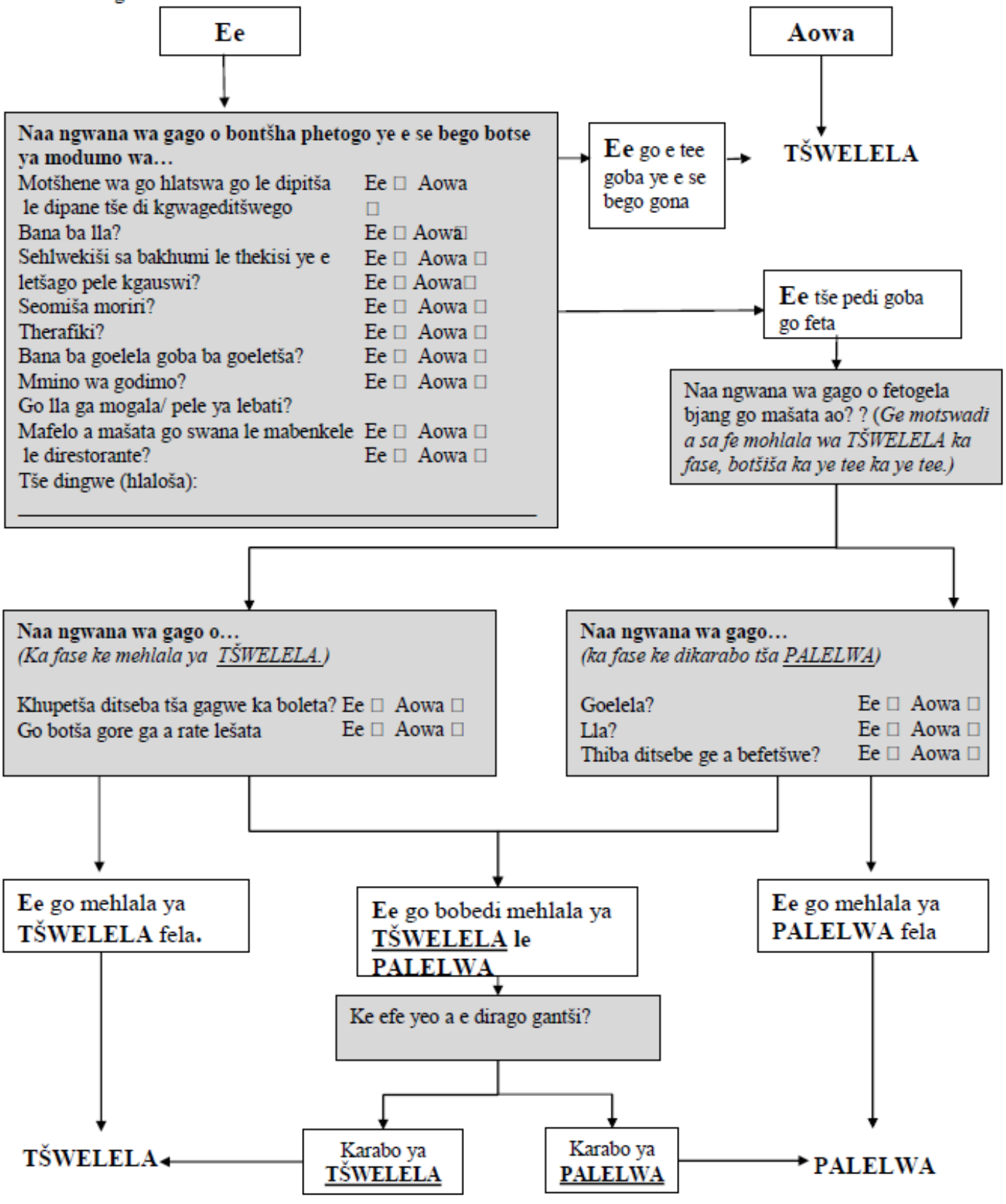
12. Naa ngwana wa gago o tshwenywa ke lešata la letšatši le lengwe le lengwe?



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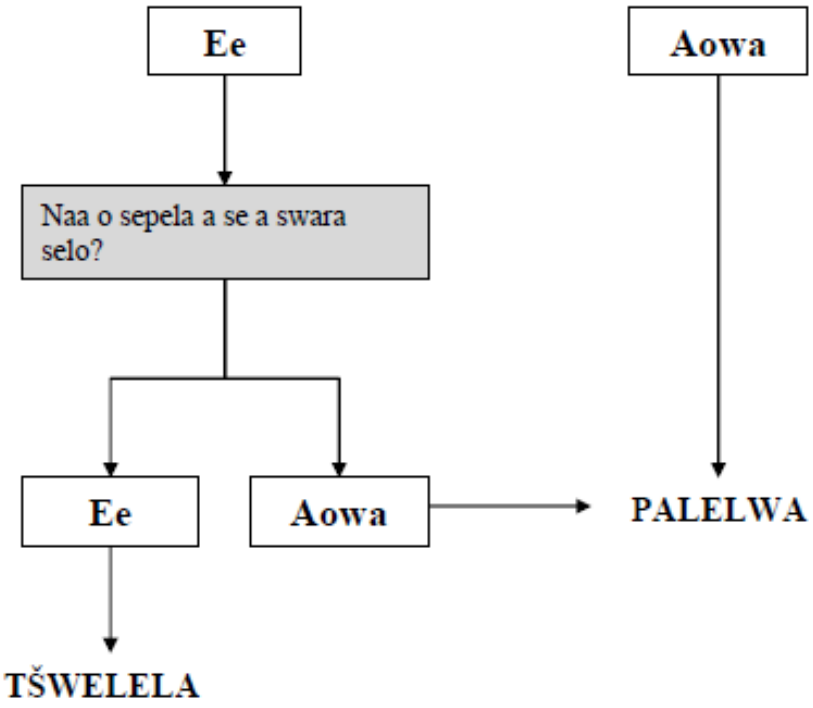
13. Naa _____ o a sepela?



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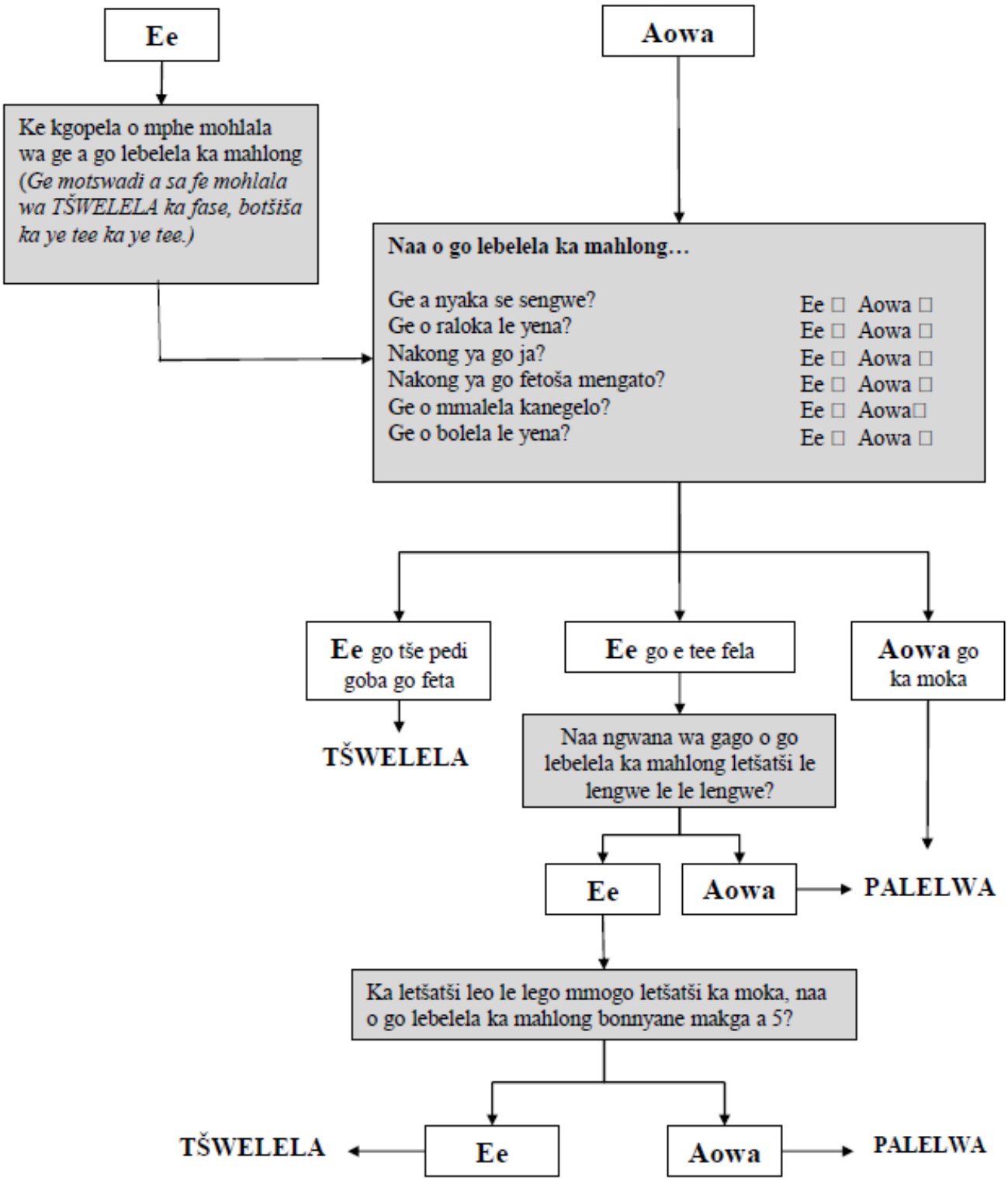
14. Naa ngwana wa gago o a go lebelela ge o bolela le yena, ge o bapala le yena, goba ge o mo apeša?



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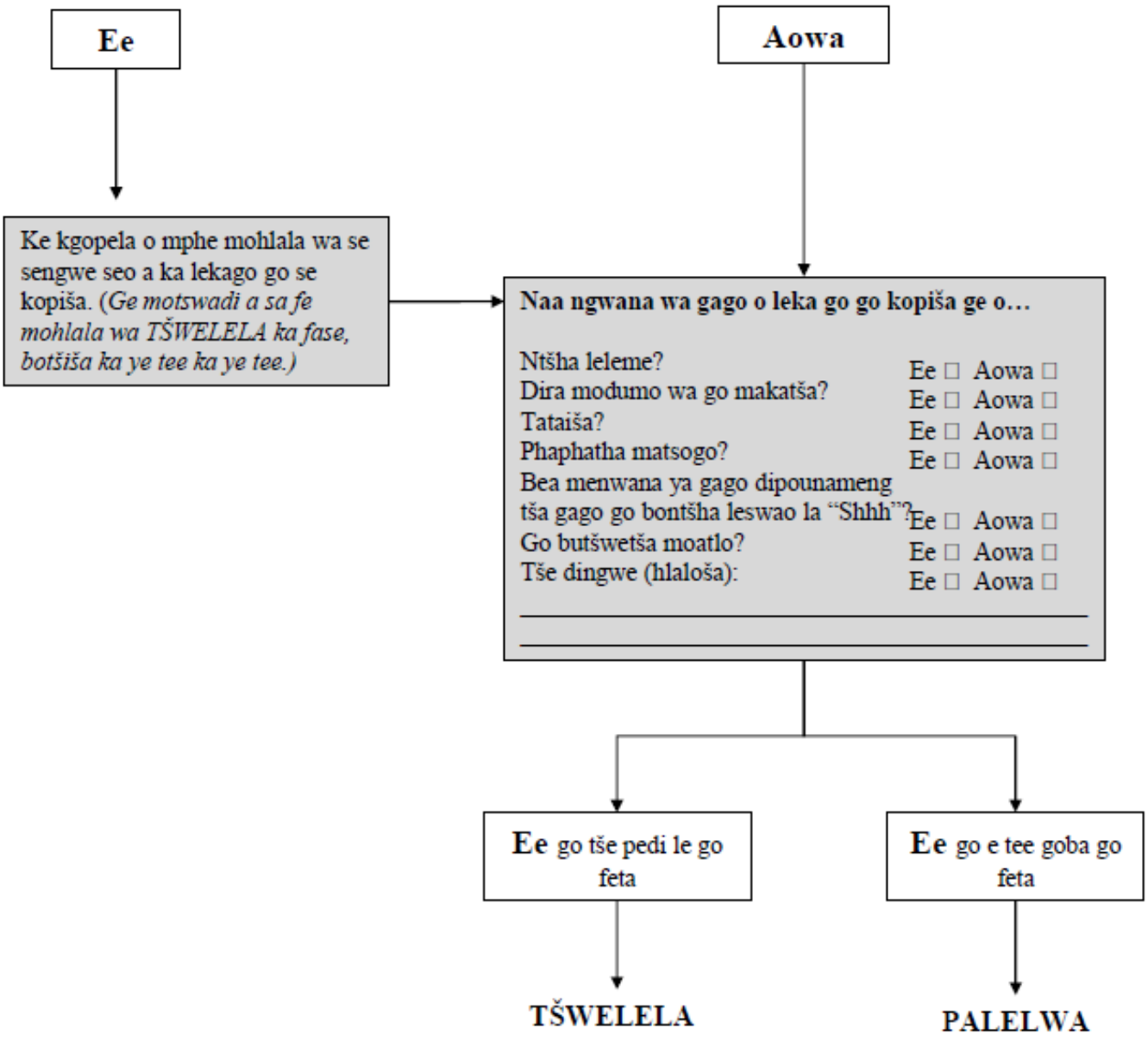
15. Naa ngwana wa gago o leka go ekiša seo o se dirago?



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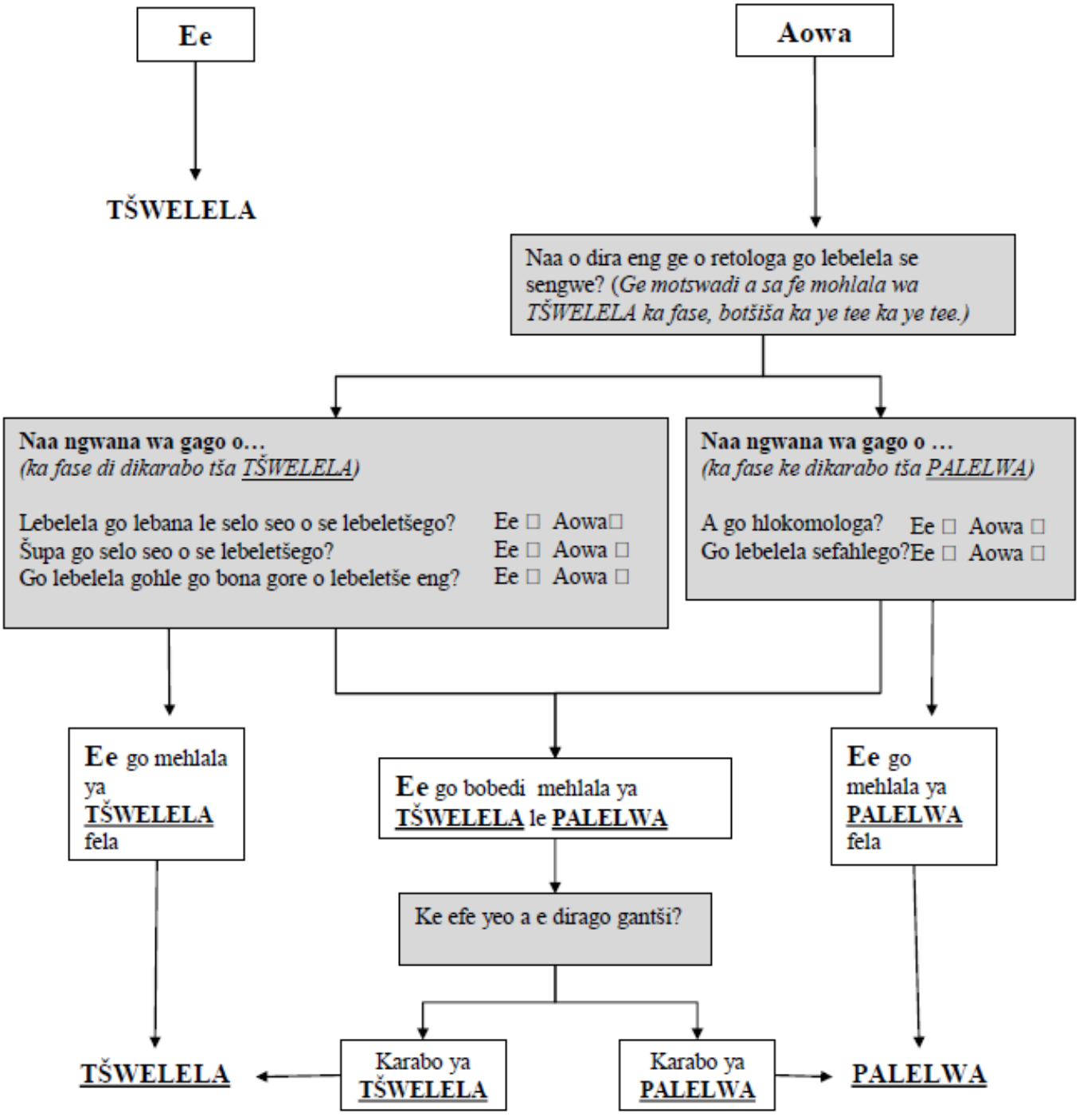
16. Ge o retolla hlogo ya gago go lebelela se sengwe, naa ngwana wa gago o a lebelela go bona gore o lebeletše eng?



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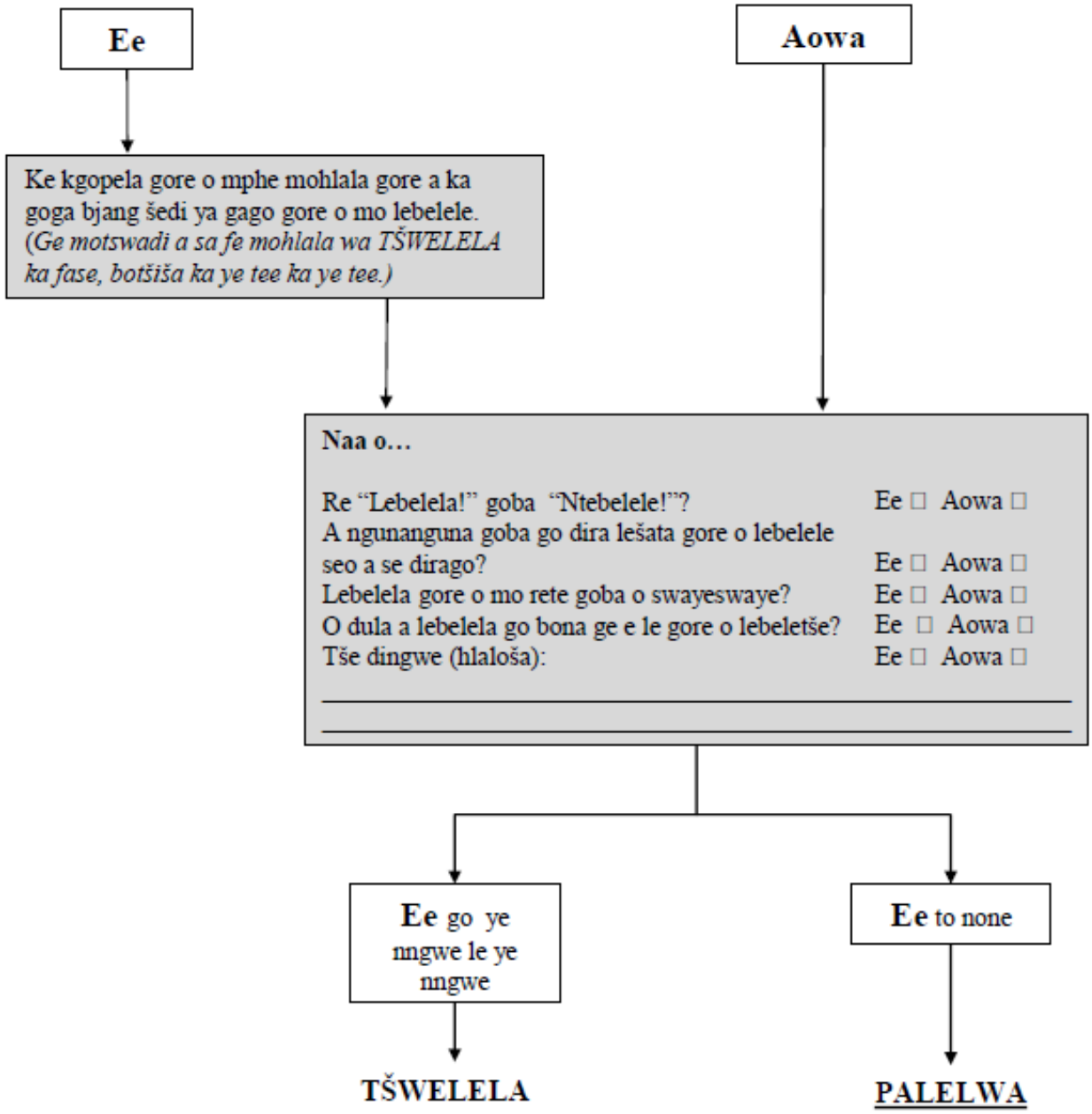
17. Naa ngwana wa gago o leka go dira gore o mmogele?



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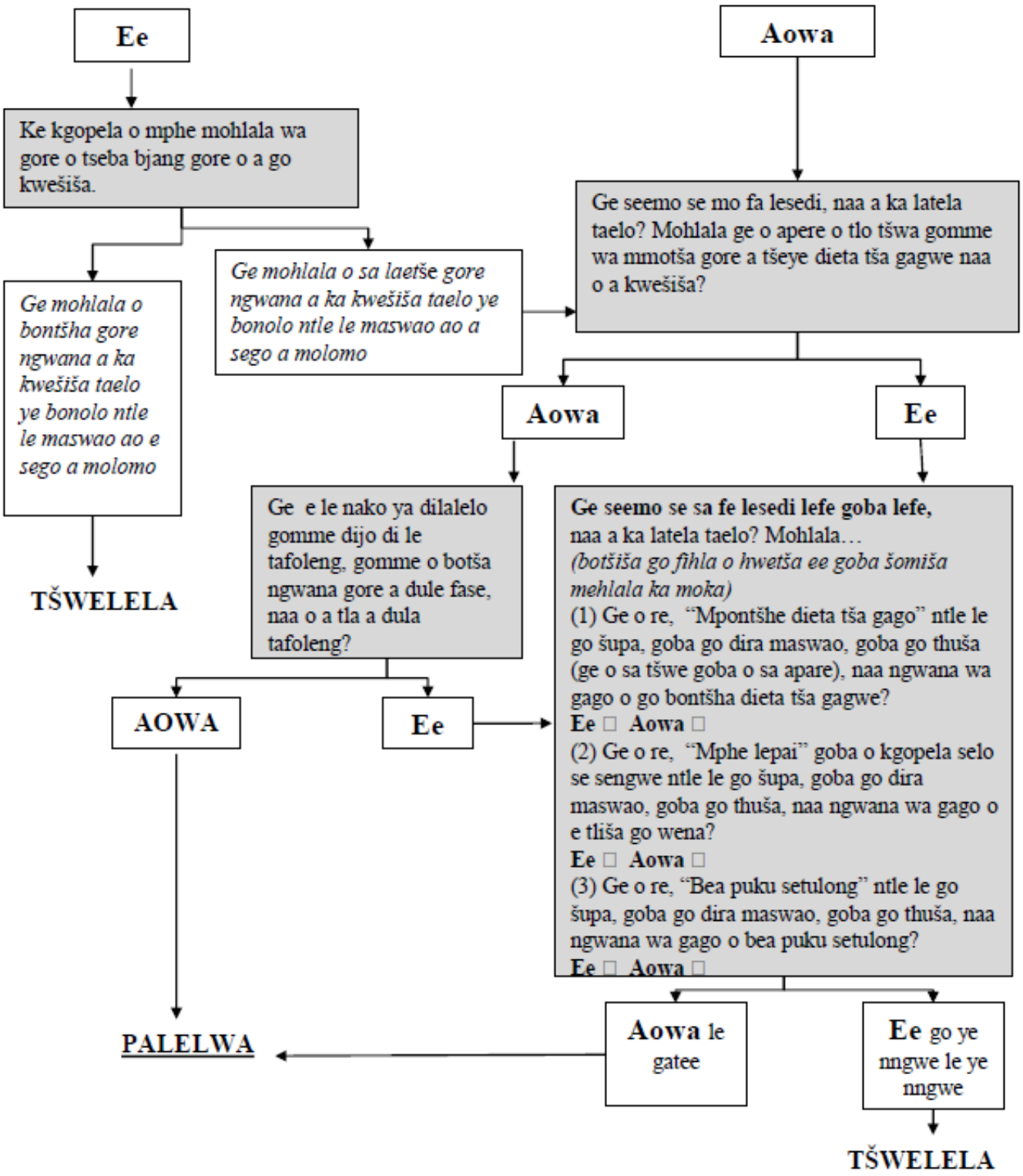
18. Naa _____ o a kwešiša ge o mmotša gore a dire se sengwe?



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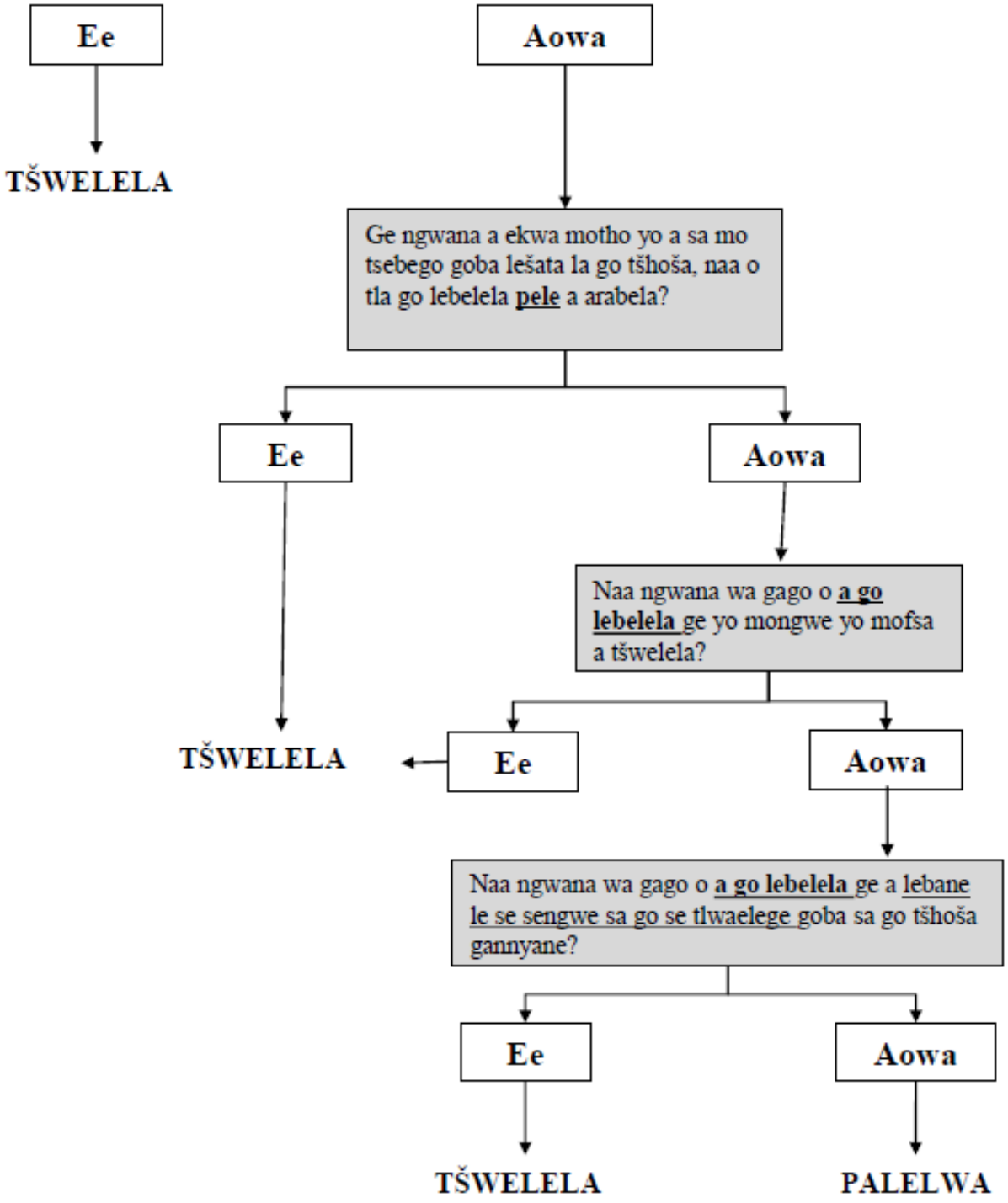
19. Ge se sengwe se seswa se ka direga, naa ngwana wa gago o go lebelela ka mahlong?



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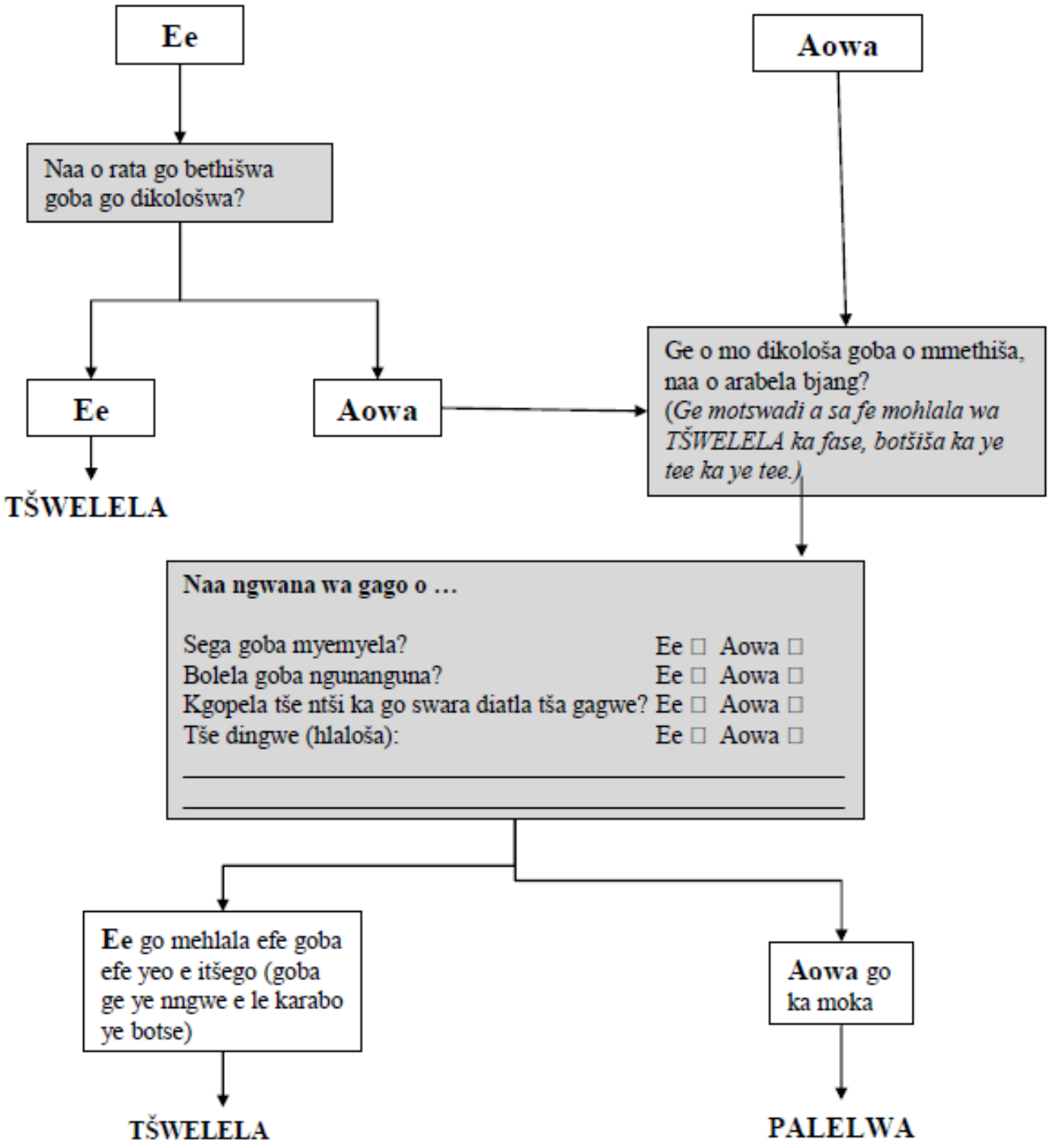
20. Naa ngwana wa gago o rata mešongwana ya mosepelo?



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Appendix D: Item translation and adaptation review forms

Item Translation and Adaptation Review Form

Independent Speech-Language Therapists

[compiled from Hambleton and Zenisky (2011) in Cross-cultural research methods in psychology: Translating and adapting tests for cross-cultural assessment]

(Hambleton & Zenisky, 2011)

Instructions: Please answer the following questions by considering the Northern Sotho M-CHAT-R/F. There are four possible answers to each question: Y = *Yes,* N = *No,* U = *Unsure,* NR = Not Relevant. Show your answer to each question by circling one of the four possible answers in the column corresponding to the test item number.

Review the M-CHAT-R/F by providing answers to all 14 questions. Please use the identified space to clarify your answer if your answer is not yes.

Thank you very much!

Question Number = X Y =Yes, N = No, U = unsure, NR = Not Relevant						
Category		**Translation and adaptation questions**	**Items**			
1. General	1.1	Does the screening instrument have the same or highly similar meaning in the two languages?	Y	N	U	NR
	1.2	Is the language of the translated item of comparable difficulty and commonality with respect to the words in the item in the source language version?	Y	N	U	NR
	1.3	Does the translation introduce changes in the text (omissions, substitutions, or additions) that might influence the difficulty of the item in the two language versions?	Y	N	U	NR
	1.4	Are there differences between the target and source language versions of the item related to the use of metaphors, idioms, or colloquialisms?	Y	N	U	NR
2. Item format	2.1	Is the item format, including physical layout, the same in the two language versions?	Y	N	U	NR

	2.2	Is the length of the item stem and, if applicable, answer choices about the same in the two language versions?	Y	N	U	NR
	2.3	Will the format of the item and task required of the examinee be equally familiar in the two language versions?	Y	N	U	NR
	2.4	If a form of a word or phrase emphasis (bold, italic, underline, etc.) was used in the source language item, was that emphasis used in the translated language item?	Y	N	U	NR
	2.5	Is there one correct answer in both the source and the target language version of the item?	Y	N	U	NR
3. Culture	3.1	Have terms in one language been suitably adapted to the cultural environment of the second language version?	Y	N	U	NR
	3.2	Are there cultural differences that would have an effect on the likelihood of a response being chosen when the item is presented in the source or target language version?	Y	N	U	NR
	3.3	Are measurement and currency units (distance, etc.) from the source language version of the item in the appropriate convention for the country using the target language version?	Y	N	U	NR
	3.4	Are the concepts covered in the item at about the same level of abstraction in the two language versions?	Y	N	U	NR
	3.5	Does the concept or construct of the item have about the same familiarity and meaning in both the source and target language versions?	Y	N	U	NR

Elaboration on answer provided:

1. General	1.1	
	1.2	
	1.3	
	1.4	
2. Item format	2.1	
	2.2	
	2.3	
	2.4	
	2.5	
3. Culture	3.1	
	3.2	
	3.3	
	3.4	
	3.5	

Item Translation and Adaptation Review Form

Expert Panel

[compiled from Hambleton and Zenisky (2011) in Cross-cultural research methods in psychology: Translating and adapting tests for cross-cultural assessment]

Instructions: Please answer the following questions by considering the Northern Sotho M-CHAT-R/F. There are four possible answers to each question: Y = *Yes,* N = *No,* U = *Unsure,* NR = Not Relevant. Show your answer to each question by circling one of the four possible answers in the column corresponding to the test item number.

Review the M-CHAT-R/F by providing answers to all 14 questions. Please use the identified space to clarify your answer if your answer is not yes.

Thank you very much!

Question Number = X Y =Yes, N = No, U = unsure, NR = Not Relevant						
Category		**Translation and adaptation questions**	**Items**			
4. Grammar and phrasing	1.1	Is there any modification of the item's structure such as the placement of clauses or other word order changes that might make this item more or less complex in the target language?	Y	N	U	NR
	1.2	Are there any grammatical clues that might make this item easier or harder in the target language version?	Y	N	U	NR
	1.3	Are there any grammatical structures in the source language version of the item that do not have parallels in the target language?	Y	N	U	NR
	1.4	Are there any gender or other references that might make this item be cued in the target language version	Y	N	U	NR
	1.5	Are there any words in the item that, when translated, change from having one meaning to having more than one common meaning?	Y	N	U	NR
	1.6	Are there any changes in punctuation between the source and target version of the item that may	Y	N	U	NR

		make the item easier or harder in the translated version?				
5. Passage	2.1	When the passage is translated from the source language to the target language, do the words and phrases of the translated version convey similar content and ideas to the source version?	Y	N	U	NR
	2.2	Does the passage depict any individual or groups in a stereotypic fashion through occupation, emotion, situation, or otherwise?	Y	N	U	NR
	2.3	Does the passage involve writing on a controversial or inflammatory topic, or might the passage be perceived as demeaning or offensive to anyone?	Y	N	U	NR
	2.4	Does the passage include content or require skills that may be unfamiliar to some students in either of the two language or cultural groups?	Y	N	U	NR
	2.5	Except for necessary translations of text or labels, are graphics, tables, and other item elements the same in the source and target language versions of the item?	Y	N	U	NR

Please turn page over

Elaboration on answer provided:

4. Grammar and phrasing	1.1	
	1.2	
	1.3	
	1.4	
	1.5	
	1.6	
5. Passage	2.1	

	2.2	
	2.3	
	2.4	
	2.5	

Appendix E: Socio-demographic questionnaire

Socio-demographic / Background history questionnaire

Socio-demographic/ Background history questionnaire							For office use only
Parent or legal guardian Name & Surname:							
Child Name & Surname:							
Date of Birth:							
Data collection site:							
Date:							
Contact details:							
Cell phone number: Email address:							
General information							
1. What is your home language?							
1. Afrikaans	2. English	3. isiNdebele	4. isiXhosa	5. isiZulu	6. Sepedi	7. Sesotho	
8. Setswana	9. Siswati	10. Tshivenda	11. Xitsonga	12. Other (Please specify)			
2. Gender:							
1. Male	2. Female						
3. Does your child have a South African birth certificate?							
1. Yes	2. No						
4. What do you do for a living?							
1. Work fulltime	2. Contract worker	3. Unemployed	4. Other				
5. Do you receive a SASSA grant							
1. Yes	2. No						
6. Is your child currently attending a daycare or crèche facility?							
1. Yes	2. No						
7. What is your child's daycare/ crèche fees per month							
1.	2.	3.	4.	5.			

R 0- 500	R 501-1000	R1001- 1500	R1501-2000	R2001-2500
6. R2501-3000	7. R3001-3500	8. R3501-4000	9. R4001-4500	10. R4501-5000

8. How do you travel mainly?

1. Public transport	2. Own transport	3. With family

9. My family lives in a:

1. Brick house	2. Informal settlement	3. Other	Please specify:

10. What is your level of education

1. Primary school	2. Grade 9	3. Matric	4. Degree	5. Masters degree	6. PhD

Prenatal information

11. How old were you during the pregnancy of this child?

1. 15≤18	2. 19 ≤22	3. 23≤26	4. 27≤30	5. 31 ≤34	6. 35 ≤40
7. 41≤45	8. 46≤50	9. Other			

12. What was the biological mother's weight during the pregnancy?

1. 45-54 kg	2. 55- 64kg	3. 65-74kg	4. 75-84kg	5. 85-94kg
6. 95-104kg	7. 105-114kg	8. >115kg	Other	

13. Was the child conceived by means of In vitro fertilization (IVF)

1. Yes	2. No	

14. Did you have any spontaneous abortions or still births

1. Yes	2. No	

15. Did the biological mother use any substances during the pregnancy

1. Yes	2. No					
16. If the answer was *Yes* at 14: Which substance was used? Please mark all applicable options						
1. Cigarette	2. Alcohol	3. Pain killer	4. Drugs	5. Other		
17. How many times have you been pregnant						
1. Once	2. More than once					
18. How many antenatal visits did you attend for this child?						
1x	2x	3x	4x	5x	6x	7x
19. Do you have a family history of any disabilities or genetic conditions						
1. Yes	2. No	If yes at 18, please provide detail?				
20. Did you have any infections while pregnant						
1. Yes	2. No					
21. If your answer at 19 was *Yes*, please specify						
1. Syphilis	2. Toxoplasmosis	3. Rubella	4. Cytomegalo -virus	5. Herpes	6. Other	
22. Have you been diagnosed with maternal diabetes						
1. Yes	2. No					
23. Do you and your child have the same blood group						
1. Yes	2. No					
24. Did you take any medication during the pregnancy						
1. Yes	2. No					
25. If your answer at 23 was *Yes*, which medication did you take						
1. Antibiotic	2.	3.	4.	5. Other		

	Chronic medication	Pain medication	Blood pressure medication		
26. Where you hospitalised during your pregnancy					
1. Yes	2. No	Reason:			
27. Were you diagnosed with any of the following					
1. Toxaemia		2. Pre-eclampsia		3. HELLP syndrome	
28. What was the duration of the pregnancy					
1. <25 week	2. 25 ≤30 weeks	3. 31 ≤36 weeks	4. 36 -40 weeks	Other:	
29. Where was the child born					
1. Private hospital	2. Government hospital	3. Clinic	4. Home	5. Other (please specify)	
Perinatal information					
30. By means of which procedure was your child born					
1. Normal vertex delivery	2. Elective Caesarean section	3. Emergency Caesarean section	4. Water birth	5. Additional measures	
6. Other (please specify):					
31. Were there complications such as Cord prolapse or Cord around the baby's neck					
1. Yes	2. No				
32. Was the baby transported after birth					
1. Yes	2. No	Reason			
33. What was your child's birth weight					
1. 1000g-1500g	2. 1501g-2000g	3. 2001g-2500g	4. 2501g – 3000g	5. 3001g -3500	
6. 3501g-4000g	7. >4001g	Actual birth weight:			

34. What was your child's APGAR score				
1. 0-3	2. 4-6	3. 7-9	4. 10	
35. Did your child need oxygen after birth?				
1. Yes	2. No			
36. Was your baby admitted to the NICU				
1. Yes	2. No			
37. If your answer at 36 is *Yes,* what was the duration				
1. 1 day	2. 2 days	3. 3 days	4. 4 days	
5. 5 days	6. 6 days	7. 1 week	8. Between 8-14 days	
9. Between 15 - 21 days	10. Between 22 – 29 days	11. More than one month	12. If more, please specify the duration	
38. For how long was your baby on oxygen				
1. Hours	2. A day	3. A week	4. More	
39. Were there any additional complications after birth, please describe				
40. Was there any medication prescribed to your baby				
1. Yes	2. No			
41. If your answer at 41 is *Yes,* please provide the name of the medication				
42. How long did it take your baby to feed well after birth?				
1. A few hours	2. A day	3. A few days	4. A week	5. Other
Established conditions				

43. Has your child been diagnosed with any of the following conditions					
1. Cleft lip/palate	2. Craniofacial anomaly	3. Epilepsy	4. Down syndrome	5. Hearing loss	6. Cerebral Palsy
7. Any Syndrome	8. Malnutrition	9. Poor vision	10. Other	Please specify	
Developmental history					
44. How old was your child when they:					
Sat:	Crawled:	Stood:	Walked:		
Said first word:	Combined words:	Other:			
45. At what age did your child go to day care or a crèche?					
1. <1 month	2. 1 month	3. 2-3 months	4. 4-5 months	5. 6-12 months	6. 1 year to 1,5 year	7. 2 years
46. Have you consulted with any other medical professionals					
1. Doctor	2. Professional Nurse	3. Occupational therapist	4. Physio-therapist	5. Speech-Language Therapist	6. Other
Please specify					
47. Are you currently concerned about any developmental area					
1. Yes	2. No				
48. Please specify if your answer at 48 was *Yes*					
1. Hearing	2. Feeding	3. Health	4. Communication	5. Social interaction	6. Other

This Case History Form was created based on the Risk Assessment (Kritzinger, 2018)

Appendix F: Permission to use the M-CHAT-R/F™

mchatscreen <mchatscreen2009@gmail.com> Thu, 31 Jan 2019, 15:28

to Carlien, diana.l.robins

Dear Carlien -

Thank you for reaching out to us. You are welcome to use the M-CHAT-R/F without charge for clinical, research, or teaching purposes. Please see www.mchatscreen.com for permissions, instructions, and downloads.

We would be interested in hearing about the findings from your study. We also are happy to post the reference for any publications involving the M-CHAT-R/F, when available.

Thank you,

Terri

Sent on behalf of Diana L. Robins, Ph.D.

www.mchatscreen.com

Appendix G: Ethical clearance: Faculty of Humanities

11 November 2019

Dear Mrs C Vorster

Project Title:	A cultural adaptation, Northern Sotho translation, and evaluation of the M-CHAT-R/F
Researcher:	Mrs C Vorster
Supervisor:	Prof AM Kritzinger
Department:	Speech Language Path and Aud
Reference number:	29026319 (HUM041/0919)
Degree:	Doctoral

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 11 November 2019. 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 the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely

Prof Maxi Schoeman
Deputy Dean: Postgraduate and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: PGHumanities@up.ac.za

Research Ethics Committee Members: **Prof MME Schoeman (Deputy Dean);** Prof KL Harris; Mr A Bizos; Dr L Blokland; Dr K Booysens; Dr A-M de Beer; Ms A dos Santos; Dr R Fasselt; Ms KT Govinder Andrew; Dr E Johnson; Dr W Kelleher; Mr A Mohamed; Dr C Puttergill; Dr D Reyburn; Dr M Soer; Prof E Taliard; Prof V Thebe; Ms B Tsebe; Ms D Mokalapa

Appendix H: Ethical clearance: Health Sciences

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020.

30 January 2020

Approval Certificate
New Application

Ethics Reference No.: HUM041/0919
Title: A cultural adaptation, Northern Sotho translation, and evaluation of the M-CHAT-R/F

Dear Mrs C Vorster

The **New Application** as supported by documents received between 2019-11-11 and 2020-01-29 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 2020-01-29.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year and needs to be renewed annually by 2021-01-30.
- Please remember to use your protocol number (HUM041/0919) 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, monitor the conduct of your research, or suspend or withdraw ethics approval.

Ethics approval is subject to the following:

- 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) MPharmMed PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health)

Appendix I: Ethical clearance: Tshwane Research Committee

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: Dr. Mpho Moshime-Shabagu
Tel: +27 12 451 9036
E-mail: Mpho.Moshime@gauteng.gov.za

TSHWANE RESEARCH COMMITTEE: CLEARANCE CERTIFICATE

DATE ISSUED: 06/02/2020
PROJECT NUMBER: 11/2020
NHRD REFERENCE NUMBER: GP_202001_052

TOPIC: A cultural adaptation, Northern Sotho translation, and evaluation of the Modified Checklist for Autism in Toddlers, Revised with Follow-up

Name of the Researcher:	Mrs Carlien Vorster
Name of the Supervisor:	Prof. A.M. Kritzinger Prof. J. van der Linde
Facilities:	Stanza Bopape CHC
Name of the Department:	University of Pretoria

NB: THIS OFFICE REQUEST A FULL REPORT ON THE OUTCOME OF THE RESEARCH DONE AND

NOTE THAT RESUBMISSION OF THE PROTOCOL BY RESEARCHER(S) IS REQUIRED IF THERE IS DEPARTURE FROM THE PROTOCOL PROCEDURES AS APPROVED BY THE COMMITTEE.

DECISION OF THE COMMITTEE: APPROVED

.....
Dr. Mpho Moshime-Shabangu **Date.** 10/02/2020
Acting Chairperson: Tshwane Research Committee

.....
Mr. Mothomone Pitsi **Date:** 2020.02.10
Chief Director: Tshwane District Health

Appendix J: Permission letter: Stanza Bopape Community Health Centre

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Annexure 1

Declaration of intent from the clinic manager or hospital CEO

I give preliminary permission CARLIEN VORSTER (name of researcher) to do ~~his or her~~

research on A CULTURAL ADAPTATION, NORTHERN SOTHO TRANSLATION, AND
(research topic) in EVALUATION OF THE M-CHAT-R/F

_____ (name of clinic) or

Stanza Bopape CHC (name of CHC) or

_____ (name of hospital).

I know that the final approval will be from the Tshwane/Metsweding Regional Research Ethics Committee and that this is only to indicate that the clinic/hospital is willing to assist.

Other comments or conditions prescribed by the clinic or CHC manager or hospital CEO:

Signature
~~Clinic Manager~~/CHC Manager/CEO

08/10/2019
Date

Appendix K: Study 1 Information brochure and informed consent form (Northern Sotho/English Speech-language therapists)

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100. 1919 - 2019

Cultural adaptation and translation of the Modified Checklist for Autism in Toddlers in Northern Sotho

Principal Investigator: Mrs C Vorster

Supervisors: Prof. A M Kritzinger & Prof. J van der Linde

Institution: University of Pretoria

DAYTIME TELEPHONE NUMBER(S):

Daytime number/s: (012) 420 2355

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

			:	
date	**month**	**year**	**Time**	

Dear Prospective Participant/ Colleague

1) INTRODUCTION

You are invited to volunteer for a research study. I am conducting research for Doctoral degree purposes at the University of Pretoria. The information in this document is presented to help you to decide if you would like to participate in this study. Before you agree to take part in this study you should fully understand what it entails. If you have any questions, which are not fully explained in this document, do not hesitate to ask the researcher. You should not agree to take part unless you are completely clear about all the procedures involved.

2) THE NATURE AND PURPOSE OF THIS STUDY

Currently there are limited or no Autism Spectrum Disorder (ASD) screening instruments that are culturally adapted and translated in different indigenous home languages in South Africa. In a 2019 review of screening instruments for the identification of ASD, the Modified Checklist for Autism in Toddlers, Revised with Follow-up (M-CHAT-R/F) was found to be the most appropriate tool for Lower- to Middle-Income Countries (Marlow,

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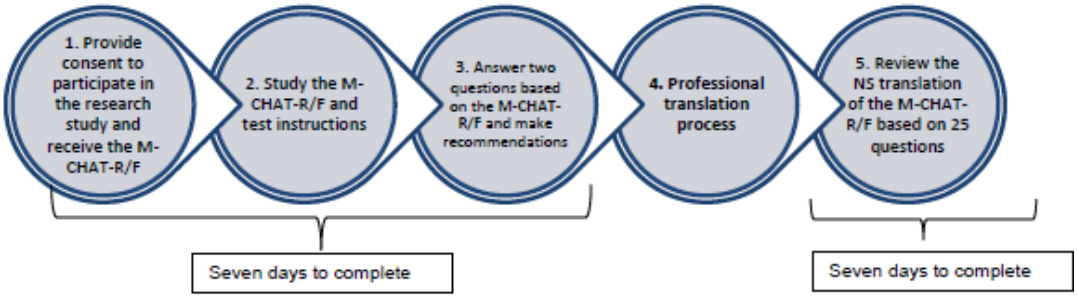
www.up.ac.za

Servili, & Tomlinson, 2019). The M-CHAT-R/F is an ASD specific screening instrument that includes twenty questions with *yes/no* answers and is only available in one of our official languages, English. The test is self-completed by parents or caregivers of children who may show symptoms of autism. The aim of the study is to utilize first language Northern Sotho Speech-Language Therapists to assist with the cultural adaptation of the English version of the M-CHAT-R/F, translate the instrument in Northern Sotho by means of a professional translator, and evaluate the Northern Sotho translation afterwards. In order to conduct the study, I require qualified Speech-Language Therapists who are first language Northern Sotho speakers and has knowledge about the culture to participate before and after the translation. You do not need any prior knowledge of the M-CHAT-R/F to participate in the study.

3) EXPLANATION OF PROCEDURES AND WHAT WILL BE EXPEXTED FROM PARTICIPANTS

Once you have provided informed consent the M-CHAT-R/F screening test will be provided. You will be required to read through the English version of the M-CHAT-R/F and its test instructions, and answer two questions. The aim is to identify words, concepts and expressions in the test and instructions that may not be used or understood by Northern Sotho parents, or may be difficult to translate. The test was developed in the US.

Please send me your answers recorded on the two tables provided, within seven days. Based on your recommendations, a professional translator will translate the M-CHAT-R/F in Northern Sotho and include the proposed cultural adaptations. After the translation, you will be required to answer 25 questions with *Yes/No/Unsure/Not relevant* answers regarding the Northern Sotho translation, which will be included in a panel discussion. I would welcome additional clarifying remarks in writing. I would appreciate it if you could return your answers to me within seven days. If you prefer a hard copy of the M-CHAT-R/F, it can be delivered and collected. You are also welcome to email your recommendations to carlien.vorster@up.ac.za. With your permission, you will be included in steps 1,2,3, and 5.



4) POSSIBLE RISKS AND DISCOMFORTS INVOLVED

There are no medical or other risks associated with the study. You will not be disadvantaged if you are unfamiliar with the M-CHAT-R/F or have not used it. Your contribution will be to share your insider perspective of the Northern Sotho language and culture. The only possible discomfort involved is the time it will take to complete the questionnaire and make the recommendations. The revision of the M-CHAT-R/F, Step 2, may take an hour to complete, while the review of the translated version may take 30 minutes.

5) POSSIBLE BENEFITS OF THIS STUDY

Although you may not benefit immediately, the study results may provide a screening instrument for ASD in Northern Sotho that can be validated in further research studies. Once the Northern Sotho M-CHATR/F is fully developed and validated, you will receive a copy. You will then be able to use it in your clinical practice as a parent completed instrument. It is anticipated that the Northern Sotho M-CHAT-R/F will contribute to public and private healthcare.

6) COMPENSATION

You will not be paid to take part in the study. There are no costs involved for you to be part of the study.

7) YOUR RIGHTS AS A RESEARCH PARTICIPANT

Your participation in this study is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. Your withdrawal will not affect your access to and use of the validated Northern Sotho M-CHAT-R/F at a later stage.

8) ETHICS APPROVAL

This Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria, telephone numbers 012 356 3084 / 012 356 3085 and written approval has been granted by that committee. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2013). A copy of the Declaration may be obtained from the investigator should you wish to review it.

9) INFORMATION

The contact person is Carlien Vorster. If you have any questions about the study please contact me at the following telephone numbers (012) 420-2355. Alternatively, you may contact her supervisors at (012) 420 2815/2357. If you want to send an email, you may send it to carlien.vorster@up.ac.za; alta.kritzinger@up.ac.za or jeannie.vanderlinde@up.ac.za .

10) CONFIDENTIALITY

All information obtained during the duration of this study will be regarded as confidential. Each participant that is taking part will be provided with an alphanumeric coded number e.g. A001. This will ensure confidentiality of information collected. Only the researcher will be able to identify you as participant. Results will be published or presented in such a fashion that participants remain unidentifiable. The hard copies of all your records will be kept in a locked facility at the Department of Speech-Language Pathology and Audiology, The University of Pretoria for 15 years.

Thank you very much for your time and consideration.

Yours sincerely

C Vorster
Researcher
carlien.vorster@up.ac.za

Prof. AM Kritzinger
Supervisor
alta.kritzinger@up.ac.za

Prof. J van der Linde
Co-Supervisor
Head of Department
Speech-Language Pathology & Audiology
jeannie.vanderlinde@up.ac.za

11) CONSENT TO PARTICIPATE IN THIS STUDY

- I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.
- I have also received, read and understood the above written information about the study.
- I have had adequate time to ask questions and I have no objections to participate in this study.
- I am aware that the information obtained in the study, including personal details, will be anonymously processed and presented in the reporting of results.
- I understand that I will not be penalised in any way should I wish to discontinue with the study and that withdrawal will not affect me.
- I am participating willingly.
- I have received a signed copy of this informed consent agreement.
- I give permission to use the data in future research.

_____
Participant's name (Please print)

_____ _____
Participant's signature Date

Researcher's name: C Vorster

_____ _____
Researcher's signature Date

Appendix L: Study 1 Information brochure and informed consent form (Professional translator)

Cultural adaptation and translation of the Modified Checklist for Autism in Toddlers in Northern Sotho

Principal Investigator: Mrs C Vorster

Supervisors: Prof. AM Kritzinger & Prof. J van der Linde

Institution: University of Pretoria

DAYTIME TELEPHONE NUMBER(S):

Daytime number/s: (012) 420 2355

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

			:	
date	**month**	**year**	**Time**	

Dear Professional Translator

1) INTRODUCTION

You are approached as one of two professional translators to participate in the development of the Northern Sotho Modified Checklist for Autism in Toddlers (M-CHAT-R/F) translation. I am conducting research for Doctoral degree purposes at the University of Pretoria. The information in this document is presented to help you to decide if you would like to participate in this study. Before you agree to take part in this study you should fully understand what it entails. If you have any questions, which are not fully explained in this document, do not hesitate to ask the researcher.

2) THE NATURE AND PURPOSE OF THIS STUDY

Currently there are limited or no Autism Spectrum Disorder (ASD) screening instruments that are culturally adapted and translated in different local languages in South Africa. In a 2019 review of screening instruments for the identification of ASD, the M-CHAT-R/F was found to be the most appropriate tool for Lower- to Middle-Income Countries (Marlow, Servili, & Tomlinson, 2019). The M-CHAT-R/F is an ASD specific screening

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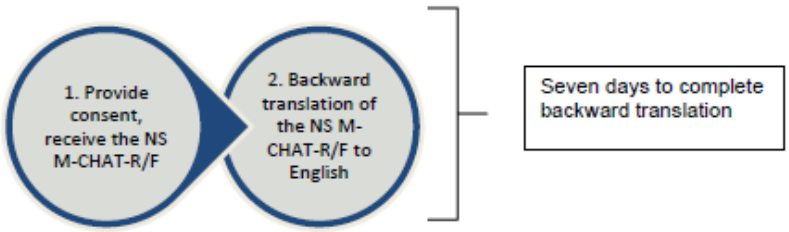
www.up.ac.za

instrument that includes twenty questions with *yes/no* answers and is completed by parents. The M-CHAT-R/F is currently only available in one of our official languages, English. The aim of the study is to utilize first language Northern Sotho speech-language therapists to assist with the cultural adaptation of the English version of the M-CHAT-R/F, translate the instrument in Northern Sotho by means of professional translators, and review the translation afterwards.

We aim to include you in the study, as a professional translator doing the back-translation into English.

3) EXPLANATION OF PROCEDURES AND WHAT WILL BE EXPECTED FROM PARTICIPANTS

This study includes multiple steps. The first step includes first language Northern Sotho speech-language therapists, working in clinical settings. They will make recommendations regarding cultural adaptations and content that might cause difficulty with the forward translation. During step two, a professional translator will translate the M-CHAT-R/F to Northern Sotho. *After the initial translation, you will be requested to translate it back to English* without viewing the source instrument. The necessary adaptations will then be made to the NS M-CHAT-R/F. The next step of the study will include an expert panel discussion, of six experts, to review the Northern Sotho M-CHAT-R/F translation and answer 11 questions regarding the grammar, phrasing and the translation of passages. There are four possible answers to each question *yes/no/unsure/not relevant.* If your answer is *no/unsure/not relevant* clarification will be required. At the same time the two Northern Sotho speech-language therapists will also review the translated M-CHAT-R/F, commenting on the item format and cultural equivalence. The sequence of the steps is thus to review the M-CHAT-R/F by speech-language therapists, to make adaptations, conduct the forward and back-translation, and review the Northern Sotho M-CHAT-R/F translation. The procedures relating to your participation are provided in the figure below.



4) POSSIBLE RISKS AND DISCOMFORTS INVOLVED

There are no medical or other risks associated with the study. You are not required to have prior knowledge of the M-CHAT-R/F in order to participate in the study. You will be required to complete the back-translation in seven days.

5) POSSIBLE BENEFITS OF THIS STUDY

Although you may not benefit directly, the study results may provide a much-needed screening instrument for ASD in Northern Sotho that can be validated in further research studies. You will be making a valuable contribution to the area of early identification of children with ASD in the South African context.

6) COMPENSATION

You will not be paid to take part in the study. There are no costs involved for you to be part of the study.

7) YOUR RIGHTS AS A RESEARCH PARTICIPANT

Your participation in this study is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. Your withdrawal will not affect your access to the validated Northern Sotho M-CHAT-R/F.

8) ETHICS APPROVAL

This Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria, telephone numbers 012 356 3084 / 012 356 3085 and written approval has been granted by that committee. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2013). A copy of the Declaration may be obtained from the investigator should you wish to review it.

9) INFORMATION

The contact person is Carlien Vorster. If you have any questions about the study please contact me at the following telephone numbers (012) 420-2355. Alternatively, you may contact her supervisors at (012) 420 2815/2357. If you want to send an email, you may send it to carlien.vorster@up.ac.za; alta.kritzinger@up.ac.za or jeannie.vanderlinde@up.ac.za .

10) CONFIDENTIALITY

All information obtained during the duration of this study will be regarded as confidential. Each participant that is taking part will be provided with an alphanumeric coded number e.g. A001. This will ensure confidentiality of information collected. Only the researcher will be able to identify you as participant. Results will be published

or presented in such a fashion that participants remain unidentifiable. The hard copies of all your records will be kept in a locked facility at the Department of Speech-Language Pathology and Audiology, The University of Pretoria.

Thank you very much for your time and consideration.

Yours sincerely

C Vorster
Researcher
carlien.vorster@up.ac.za

Prof. AM Kritzinger
Supervisor
alta.kritzinger@up.ac.za

Prof. J van der Linde
Co-Supervisor
Head of Department
Speech-Language Pathology &
Audiology
jeannie.vanderlinde@up.ac.za

11) CONSENT TO PARTICIPATE IN THIS STUDY

- I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.
- I have also received, read and understood the above written information about the study.
- I have had adequate time to ask questions and I have no objections to participate in this study.
- I am aware that the information obtained in the study, including personal details, will be anonymously processed and presented in the reporting of results.
- I understand that I will not be penalised in any way should I wish to discontinue with the study and that withdrawal will not affect me.
- I am participating willingly.
- I have received a signed copy of this informed consent agreement.
- I give permission to use the data in future research.

_____
Participant's name (Please print)

_____ _____
Participant's signature Date

Researcher's name: C Vorster

_____ _____
Researcher's signature Date

Appendix M: Study 1 Information brochure and informed consent form (Expert panel members)

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100. 1919 - 2019

Cultural adaptation and translation of the Modified Checklist for Autism in Toddlers in Northern Sotho

Principal Investigator: Mrs C Vorster

Supervisors: Prof. AM Kritzinger & Prof. J van der Linde

Institution: University of Pretoria

DAYTIME TELEPHONE NUMBER(S):

Daytime number/s: (012) 420 2355

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

				:
date	**month**	**year**		**Time**

Dear Experts

1) INTRODUCTION

You are approached as one of two linguistic experts, specialising in Northern Sotho, to participate in the development of the Northern Sotho Modified Checklist for Autism in Toddlers (M-CHAT-R/F) translation. I am conducting research for Doctoral degree purposes at the University of Pretoria. The information in this document is presented to help you to decide if you would like to participate in this study. Before you agree to take part in this study you should fully understand what it entails. If you have any questions, which are not fully explained in this document, do not hesitate to ask the researcher.

2) THE NATURE AND PURPOSE OF THIS STUDY

Currently there are limited or no Autism Spectrum Disorder (ASD) screening instruments that are culturally adapted and translated in different local languages in South Africa. In a 2019 review of screening instruments for the identification of ASD, the M-CHAT-R/F was found to be the most appropriate tool for Lower- to Middle-Income Countries (Marlow, Servili, & Tomlinson, 2019). The M-CHAT-R/F is an ASD specific screening

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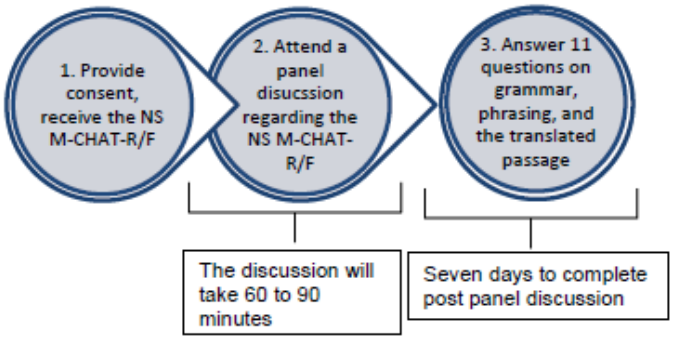
Email carlien.vorster@up.ac.za
www.up.ac.za

instrument that includes twenty questions with *yes/no* answers and is completed by parents. The M-CHAT-R/F is currently only available in one of our official languages, English. The aim of the study is to utilize first language Northern Sotho speech-language therapists to assist with the cultural adaptation of the English version of the M-CHAT-R/F, translate the instrument in Northern Sotho by means of professional translators, and review the translation afterwards.

We aim to include you in the study, as part of the expert panel. The expert panel will be required to review the Northern Sotho translation of the M-CHAT-R/F.

3) EXPLANATION OF PROCEDURES AND WHAT WILL BE EXPECTED FROM PARTICIPANTS

This study includes multiple steps and you will only be part of the final step for this study. The first step includes two first-language Northern Sotho speech-language therapists, working in clinical settings. They will make recommendations regarding cultural adaptations and content that might cause difficulty with the forward translation. During step two, a professional translator will translate the M-CHAT-R/F to Northern Sotho. After the initial translation, a second professional translator will translate it back to English. The necessary adaptations will then be made to the NS M-CHAT-R/F. In the final stage of the study you will be required to attend a panel discussion, consisting of six to eight experts, to review the Northern Sotho M-CHAT-R/F translation. As part of the discussion, you will be requested to answer 11 questions regarding the grammar, phrasing and the translation of passages. There are four possible answers to each question *yes/no/unsure/not relevant*. If your answer is *no/unsure/not relevant* clarification will be required. At the same time the Northern Sotho speech-language therapists will also review the translated M-CHAT-R/F, commenting on the item format and cultural equivalence. The sequence of the steps is thus to review the M-CHAT-R/F by speech-language therapists, to make adaptations, conduct the forward and back-translation, and review the Northern Sotho M-CHAT-R/F translation. The procedures relating to your participation are provided in the figure below.



4) POSSIBLE RISKS AND DISCOMFORTS INVOLVED

There are no medical or other risks associated with the study. You are not required to have prior knowledge of the M-CHAT-R/F in order to participate in the study. The date and time of the panel discussion will be arranged at your convenience. The only possible discomfort involved is the time it will take to complete the questionnaire and make the recommendations, if there are any. The discussion will be approximately 60 to 90 minutes in duration.

5) POSSIBLE BENEFITS OF THIS STUDY

Although you may not benefit directly, the study results may provide a much-needed screening instrument for ASD in Northern Sotho that can be validated in further research studies. You will be making a valuable contribution to the area of early identification of children with ASD in the South African context.

6) COMPENSATION

You will not be paid to take part in the study. There are no costs involved for you to be part of the study.

7) YOUR RIGHTS AS A RESEARCH PARTICIPANT

Your participation in this study is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. Your withdrawal will not affect your access to the validated Northern Sotho M-CHAT-R/F.

8) ETHICS APPROVAL

This Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria, telephone numbers 012 356 3084 / 012 356 3085 and written approval has been granted by that committee. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2013). A copy of the Declaration may be obtained from the investigator should you wish to review it.

9) INFORMATION

The contact person is Carlien Vorster. If you have any questions about the study please contact me at the following telephone numbers (012) 420-2355. Alternatively, you may contact her supervisors at (012) 420 2815/2357. If you want to send an email, you may send it to carlien.vorster@up.ac.za; alta.kritzinger@up.ac.za or jeannie.vanderlinde@up.ac.za.

10) CONFIDENTIALITY

All information obtained during the duration of this study will be regarded as confidential. Each participant that is taking part will be provided with an alphanumeric coded number e.g. A001. This will ensure confidentiality of information collected. Only the researcher will be able to identify you as participant. Results will be published or presented in such a fashion that participants remain unidentifiable. The hard copies of all your records will be kept in a locked facility at the Department of Speech-Language Pathology and Audiology, The University of Pretoria.

Thank you very much for your time and consideration.

Yours sincerely

C Vorster
Researcher
carlien.vorster@up.ac.za

Prof. AM Kritzinger
Supervisor
alta.kritzinger@up.ac.za

Prof. J van der Linde
Co-Supervisor
Head of Department
Speech-Language Pathology & Audiology
jeannie.vanderlinde@up.ac.za

11) CONSENT TO PARTICIPATE IN THIS STUDY

- I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.
- I have also received, read and understood the above written information about the study.
- I have had adequate time to ask questions and I have no objections to participate in this study.
- I am aware that the information obtained in the study, including personal details, will be anonymously processed and presented in the reporting of results.
- I understand that I will not be penalised in any way should I wish to discontinue with the study and that withdrawal will not affect me.
- I am participating willingly.
- I have received a signed copy of this informed consent agreement.
- I give permission to use the data in future research.

_____
Participant's name (Please print)

_____ _____
Participant's signature Date

Researcher's name: C Vorster

_____ _____
Researcher's signature Date

Appendix N: Study 2 Information brochure and informed consent form in English and Northern Sotho (Pilot study)

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019

The Northern Sotho M-CHAT-R/F translation: A pilot study

Principal Investigators: Mrs C Vorster

Supervisors: Prof. A M Kritzinger & Prof. J van der Linde

Institution: University of Pretoria

DAYTIME TELEPHONE NUMBER(S):

Daytime number/s: (012) 420 2355

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

			:
date	month	year	Time

Dear Prospective Participant

1) INTRODUCTION

You are invited to volunteer for a research study. I am conducting research for Doctoral degree purposes at the University of Pretoria. The information in this document is presented to help you to decide if you would like to participate in this study. Before you agree to take part in this study you should fully understand what it entails. If you have any questions, which are not fully explained in this document, do not hesitate to ask the researcher. You should not agree to take part unless you are completely clear about all the procedures involved.

2) THE NATURE AND PURPOSE OF THIS STUDY

I have already adapted and translated a screening test into Northern Sotho. The test is to identify children who may be at risk for autism. I now want to test how good the adaptation and translation is. I would like you to complete the test in Northern Sotho and in English, and give feedback on how you find the translations. *In order to study the risk for Autism, I need to include children who are at risk of autism and children without any*

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Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

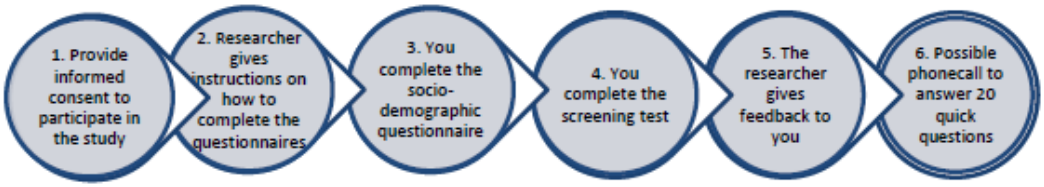
signs of autism. If you agree to participate in the study, it does not mean that your child has a problem such as autism.

> Autism is a term used for a group of complex disorders of brain development. Autism is a developmental condition. Children with Autism may communicate, interact, behave, and learn in ways that are different from most other children. The learning, thinking, and problem-solving abilities of children with Autism can range from gifted to severely impaired. Some children with Autism need high support (a lot of help and intensive intervention) while others need low support (less help and less intensive intervention). -AutismSA.

3) EXPLANATION OF PROCEDURES AND WHAT WILL BE EXPECTED FROM PARTICIPANTS.

This screening test involves answering questions about to your toddler's behaviour and development. You, the parent or caregiver of the toddler, will be included as the participant in the study.

You will be required to complete the Demographic questionnaire, the English M-CHAT-R/F, and the Northern Sotho M-CHAT-R/F translation. You will also be asked which words were difficult for you to understand and which questions were difficult to answer. If you need help, the researcher can read the questions, without providing additional information to you.



4) POSSIBLE RISKS AND DISCOMFORTS INVOLVED

There are no medical risks associated with the study. The only possible discomfort involved is the time it might take to complete the questionnaires. The researcher will be present while you complete the questionnaires. The demographic questionnaire is the only questionnaire that would require more effort than answering *yes/no*. With the support of the research, the demographic questionnaire should not take longer than 15 minutes to complete. The screening test includes 20 yes/no questions which will take 10 minutes to complete.

Answering all the questions will thus take a maximum of 30 minutes of your time. If a follow-up phone call is necessary, you will only be asked a maximum of seven questions, which will take five minutes.

5) POSSIBLE BENEFITS OF THIS STUDY

Although you may not benefit directly, the study results will help to develop a screening instrument in Northern Sotho. The results of the screening test will be discussed with you on the day that you complete it. If the screening test shows more than three specific traits or delays in your child's case, your child may need extra help. I will give you a referral letter that you can give to the paediatrician that treats your child at the clinic. If you do not attend a clinic, we will give you names of clinics that you can go to. Some of the clinics are private practices and will charge you a consultation fee. Please ask if you are uncertain about the private practice sites.

6) COMPENSATION

You will not be paid to take part in the study. There are no costs involved for you to be part of the study.

7) YOUR RIGHTS AS A RESEARCH PARTICIPANT

Your participation in this study is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. Your withdrawal will not affect your access to other medical care.

8) ETHICS APPROVAL

This Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria, telephone numbers 012 356 3084 / 012 356 3085 and written approval has been granted by that committee. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2013). A copy of the Declaration may be obtained from the investigator should you wish to review it.

9) INFORMATION

The contact person is Carlien Vorster. If you have any questions about the study please contact her at the following telephone numbers (012) 420-2355. Alternatively, you may contact her supervisors at (012) 420 2815/2357. If you want to send an email, you may send it to carlien.vorster@up.ac.za; alta.kritzinger@up.ac.za or jeannie.vanderlinde@up.ac.za .

10) CONFIDENTIALITY

All information obtained during the duration of this study will be regarded as confidential. Each participant that is taking part will be provided with an alphanumeric coded number e.g. A001. This will ensure confidentiality of information collected. Only the researcher will be able to identify you as participant. Results will be published

or presented in such a fashion that participants remain unidentifiable. The hard copies of all your records will be kept in a locked facility at the Department of Speech-Language Pathology and Audiology, The University of Pretoria.

Thank you very much for your time and consideration.

Yours sincerely

C Vorster
Researcher
carlien.vorster@up.ac.za

Prof. AM Kritzinger
Supervisor
alta.kritzinger@up.ac.za

Prof. J van der Linde
Co-Supervisor
Head of Department
Speech-Language Pathology & Audiology
jeannie.vanderlinde@up.ac.za

11) CONSENT TO PARTICIPATE IN THIS STUDY

- I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.
- I have also received, read and understood the above written information about the study.
- I have had adequate time to ask questions and I have no objections to participate in this study.
- I am aware that the information obtained in the study, including personal details, will be anonymously processed and presented in the reporting of results.
- I understand that I will not be penalised in any way should I wish to discontinue with the study and that withdrawal will not affect me.
- I am participating willingly.
- I have received a signed copy of this informed consent agreement.
- I give permission to use the data in future research.

_____
Participant's name (Please print)

_____ _____
Participant's signature Date

Researcher's name: C Vorster

_____ _____
Researcher's signature Date

Phetolelo ya Sesotho sa Leboa (Sepedi) ya M-CHAT-R/F: Dinyakišišo tša teko

Monyakišišimogolo: Mdi C Vorster

Balekodi: Prof. A M Kritzinger le Prof. J van der Linde

Institušene: Yunibesithi ya Pretoria

DINOMORO TŠA MOGALA TŠA MOŠOMONG:

Dinomoro tša mogala tša mošomong: (012) 420 2355

TŠATŠIKGWEDI LA POLEDIŠANO YA MATHOMO YA TUMELELO YA TSEBO:

			:
tšatšikgwedi	kgwedi	ngwaga	Nako

Mokgathatema yo a Letetšwego yo a rategago

1) MATSENO

O laletšwa go ithaopa go kgatha tema go thuto ya dinyakišišo. Ke dira dinyakišišo tša tikrii ya Bongaka Yunibesithing ya Pretoria. O fiwa tshedimošo ye e lego ka tokumenteng go go thuša go tšea sephetho sa ge e le gore o nyaka go kgatha tema ka dinyakišišong tše. Pele o dumela go kgatha tema o swanetše go kwešiša ka botlalo gore e akaretša eng. Ge o na le dipotšišo dife goba dife, tšeo di se a hlalošwago ka botlalo ka tokumenteng ye, o se ke wa dikadika go botšiša monyakišiši. O se ke wa dumela go kgatha tema ntle le ge o kwešiša gabotse ka ga ditshepedišo ka moka tšeo di akareditšwego.

2) MOHUTA LE NEPO YA DINYAKIŠIŠO TŠE

Ke šetše ke kaonafaditše le go fetolela teko ya tekolo go Sesotho sa Leboa (Sepedi). Teko ke ya go utolla bana bao ba ka bago kotsing ya go swara ke othosimo. Bjale ke nyaka go leka gore kaonafatšo le phetolelo di gabotse. Ke rata gore o tlatše tekolo ka Sesotho sa Leboa (Sepedi) le Seisemane, gomme o fe karabo ya gago gore phetolelo e bjang. *Gore ke ithute ka kotsi ya Othosimo, ke hloka go akaretša bana bao ba lego kotsing ya go swarwa ke othosimo le bana bao ba se nago maswao afe goba afe a othosimo. Ge o dumela go kgatha tema mo dinyakišišong tše, ga se gore ngwana wa gago o na le bothata bja go swana le othosimo.*

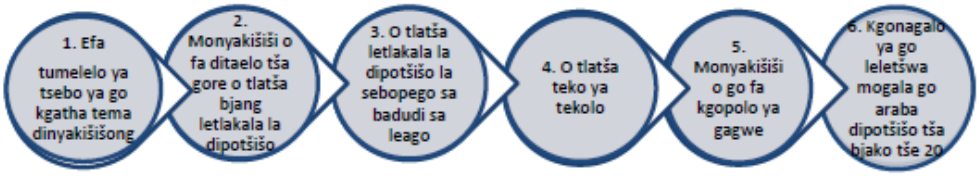
Othosimi ke lereo leo le šomišetšwago malwetši a go raragana a kgolo ya bjoko. Bana bao ba phelago ka bolwetši bja Othosimo ba ka kgokagana, ba šomišana, le go ithuta ka mekgwa ya go fapana le bana ba bangwe ba bantši. Go ithuta, go nagana, le mabokgoni a go rarolla mathata a bana bao ba phelago ka

Othisimo di ka tloga go bana ba go kgona go ya go ba go se kgone kudu. Bana ba bangwe bao ba phelago ka othisimo ba nyaka thekgo ye kgolo (thušo ye ntši le tsenogare ya go tsenelela) mola ba bangwe ba nyaka thekgo ye nnyane (thušo ye nnyane le tsenogare ya go tsenelela ye nnyane). AutismSA.

3) TLHALOŠO LE DITSHEPEDIŠO LE GORE GO KA LETELWA ENG GO BAKGATHATEMA.

Teko ye ya tekolo e akaretša go araba dipotšišo ka ga ngwana wa gago wa go abula le go gola ga gagwe. Wena, motswadi goba mohlokomedi, le tla akaretšwa bjalo ka bakgathatema ka dinyakišišong .

Go tla nyakega gore o tlatše letlakala la dipotšišo ka ga Sebopego sa Badudi, le phetolelo ya M-CHAT-R/F ya Seisemana, le M-CHAT-R/F ya Sesotho sa Leboa (Sepedi). O tla kgopelwa gape go bolela gore ke mantšu afe ao a bego a le bothata go ka a kwešiša le gore ke dipotšišo dife tšeo go bego go le bothata go di araba. Ge o nyaka thušo, monyakišiši a ka bala dipotšišo, ntle le go go fa tshedimošo ya tlaleletšo.



4) DIKOTSI LE GO SE IKETLE TŠEO DI KA BAGO GONA

Ga go na dikotsi tša maphelo tšeo di amanywago le thuto ye. Kgonagalo fela yeo e amanywago ke nako yeo e ka tšewago go tlatša letlakala la dipotšišo. Monyakišiši o tla ba gona ge o tlatša letlakala la dipotšišo. Letlakala la dipotšišo la sebopego sa badudi ke letlakala la dipotšišo le le tee leo le tla nyakago maatla a mantši go na le go araba ka ee/aowa. Ka thekgo ya monyakišiši, go ka se tšeye metsotso ye 15 go tlatša dipotšišo tša maemo a badudi. Teko ya tekolo e akaretša dipotšišo tše 20 tša ee/aowa tšeo di tla tšeago metsotso ye 10 go di tlatša. Go araba dipotšišo ka moka e tla ba magomo a metsotso ye 30 ya nako ya gago. Ge mogala wa go latišiša o hlokega, o tla kgopelwa go tlatša fela magomo a dipotšišo tše šupa, tšeo di tla tšeago metsotso ye mehlano.

5) DIKHOLEGO TŠA DINYAKIŠIŠO TŠEO DI KA BAGO GONA

Le ge o ka se holege thwii, dipoelo tša dinyakišišo di tla thuša go dira sedirišwa sa tekolo ka Sesotho sa Leboa (Sepedi). Go tla boledišanwa le wena ka dipoelo tša teko ya tekolo ka letšatši leo o tlatšago letlakala la dipotšišo ka lona. Ge go hlokega, monyakišiši o tla go fa lengwalo la phetišetšo leo o ka le fago ngaka

ya bana yeo e alafago ngwana wa gago kliniking. Ge o sa ye kliniking, re tla go fa maina a dikliniki tšeo o ka yago go tšona.

Ge diteko tša tekolo di bontšha mekgwa ye e itšego goba dititelego mo bothateng bja ngwana wa gago, ngwana wa gago a ka hloka thušo ye nngwe. Ke tla go fa lengwalo la taelelo leo o ka le fago ngaka ya bana yeo e alafago ngwana wa gago kliniking. Ge o sa ye kliniking, re tla go fa maina a dikliniki tšeo o ka yago go tšona. Tše dingwe tša dikliniki ke tša praebete gomme di tla go lefiša tefo ya kopano. O kgopelwa go botšiša ge o se na nnete ka mafelo a ditshepedišo tša praebete

6) TEFO

O ka se lefelwe go kgatha tema mo dinyakišišong. Ga go na ditshenyagelo tšeo di akaretšwago gore o be karolo ya dinyakišišo.

7) DITOKELO TŠA GAGO BJALO KA MOKGATHATEMA DINYAKIŠIŠONG

Go kgatha tema ga gago mo dinyakišišo ke ga go ithaopa gomme o ka gana go kgatha tema goba wa emiša nako ye nngwe le ye nngwe ntle le go fa mabaka. Go ikgogela morago ga gago go ka se ame tlhokomelo ye nngwe ya maphelo.

8) TUMELELO YA MAITSHWARO

Prothokholo ye e išitšwe go Komiti ya Maitshwaro a Dinyakišišo ya Lefapha la Maphelo, Yunibesithing ya Pretoria, dinomoro tša mogala 012 356 3084 / 012 356 3085 gomme tumelelo ya go ngwalwa e filwe ke komiti yeo. Dinyakišišo di beakantšwe go ya ka Pego ya Helsinki (e mpshafaditšwe la mafelelo: Diphalane 2013). Kopi ya Pego e ka hwetšwa go monyakišiši ge o ka nyaka go e sekaseka.

9) TSHEDIMOŠO

Motho yo o ka ikgokaganyago le yena ke Carlien Vorster. Ge o na le dipotšišo dife goba dife ka ga dinyakišišo o kgopelwa go ikgokaganya le yena mo dinomorong tše tša mogala (012) 420 -2355. Goba, o ka ikgokaganya le balekodi ba ka go (012) 420 2815/2357. Ge o nyaka go romela emeile, o ka e romela go carlien.vorster@up.ac.za; alta.kritzinger@up.ac.za goba jeannie.vanderlinde@up.ac.za.

10) SEPHIRI

Tshedimošo ka moka yeo e hweditšwego nakong ya dinyakišišo e tla tšewa go ba ya sephiri. Mokgathatema yo mongwe le yo mongwe yoo a kgathago tema o tla fiwa khouto ya ditlhaka le dinomoro mohlala A001. Se se tla kgonthiša sephiri sa tshedimošo yeo e kgobokeditšwego. Ke fela monyakišiši yoo

a tla kgonago go go utolla bjalo ka mokgathatema. Dipoelo di tla phatlalatšwa goba tša fiwa ka tsela yeo e lego gore mokgathatema o tla dula a sa tsebje. Dikopi tšeo di gatišitšwego tša direkoto tša gago ka moka di tla bolokwa ka senolofatšing seo se notletšwego ka Kgorong ya Phatholotši le Odiolotši tša Polelo-Leleme, Yunibesithing ya Pretoria.

Re leboga kudu nako le dikakanyo tša gago.

Ka boikokobetšo

C Vorster
Researcher
carlien.vorster@up.ac.za

Prof. AM Kritzinger
Supervisor
alta.kritzinger@up.ac.za

Prof. J van der Linde
Co-Supervisor
Head of Department
Speech-Language Pathology & Audiology
jeannie.vanderlinde@up.ac.za

11) TUMELELO YA GO KGATHA TEMA DINYAKIŠIŠONG

- Ke kgonthiša gore motho yo a kgopelago tumelelo ya ka ya go kgatha tema dinyakišišong o mpoditše ka mohuta le tshepetšo, dikotsi dife goba dife goba go se iketle, le dikholego tša dinyakišišo.
- Gape ke amogetše, go bala le go kwešiša tshedimošo ye e ngwetšwego ya ka godimo ka ga dinyakišišo.
- Ke bile le nako yeo e lekanego go botšiša dipotšišo gomme ga ke ganane le go kgatha tema mo dinyakišišong.
- Ke a lemoga gore go tla šoganwa le tshedimošo yeo e hweditšwego, go akaretšwa tshedimošo ya motho le go fiwa ge go begwa dipoelo go sa tsebege gore ke ya mang.
- Ke a kwešiša gore nka se otlwe ka mokgwa ofe goba ofe ge nka nyaka go se sa tšwela pele ka dinyakišišo gape go ikgogela morago go ka se nkame.
- Ke kgatha tema ka go rata ga ka.
- Ke amogetše kopi ye e saenwego ya tumelelano ya tumelelo ya tsebo.
- Ke fa tumelelo ya go šomiša data go dinyakišišo tša ka moso.

_____

Leina la mokgathatema (O kgopelwa go gatiša)

_____	_____
Tshaeno ya mokgathatema	Tšatšikgwedi

Leina la monyakišiši: C Vorster

_____	_____
Tshaeno ya monyakišiši	Tšatšikgwedi

Appendix O: Study 3 Information brochure and informed consent form in English and Northern Sotho

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019

Validity and test-retest reliability of the Northern Sotho M-CHAT-R/F translation

Principal Investigators: Mrs C Vorster

Supervisors: Prof. AM Kritzinger & Prof. J van der Linde

Institution: University of Pretoria

DAYTIME TELEPHONE NUMBER(S):

Daytime number/s: (012) 420 2355

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

			:
date	**month**	**year**	**Time**

Dear Prospective Participant

1) INTRODUCTION

You are invited to volunteer for a research study. I am conducting research for Doctoral degree purposes at the University of Pretoria. The information in this document is presented to help you to decide if you would like to participate in this study. Before you agree to take part in this study you should fully understand what it entails. If you have any questions, which are not fully explained in this document, do not hesitate to ask the researcher. You should not agree to take part unless you are completely clear about all the procedures involved.

2) THE NATURE AND PURPOSE OF THIS STUDY

I have already adapted and translated a screening tool in Northern Sotho. The aim of the tool is to identify children who may be at risk for autism. I now want to test how good the adaptation and translation is. *In order to study the risk for autism, I need to include children who are at risk of autism and children without any signs*

Room 3-18, Communication Pathology Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2491
Email carilen.vorster@up.ac.za
www.up.ac.za

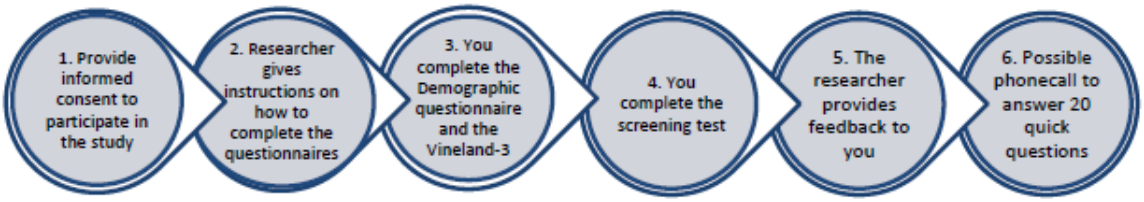
of autism. If you agree to participate in the study, it does not mean that your child has a problem such as autism.

> Autism is a term used for a group of complex disorders of brain development. Autism is a developmental condition. Children with Autism may communicate, interact, behave, and learn in ways that are different from most other children. The learning, thinking, and problem-solving abilities of children with Autism can range from gifted to severely impaired. Some children with Autism need high support (a lot of help and intensive intervention) while others need low support (less help and less intensive intervention). -AutismSA.

3) EXPLANATION OF PROCEDURES AND WHAT WILL BE EXPECTED FROM PARTICIPANTS

You will be requested to sign the informed consent form, once the researcher explained the study to you. This study involves answering questions about your toddler's behaviour and development. You as parent or caregiver of the toddler will be included as the participant in the study.

You will be required to complete the M-CHAT-R/F, and Northern Sotho M-CHAT-R/F. If you need help, the researcher can read the questions, without providing additional information to you. You will also be requested to participate in a 30-minute interview. During this interview the researcher will ask you questions in order to complete the demographic questionnaire and the Vineland-3. After all the forms have been completed, the researcher will give you feedback on the screening instrument. You might receive a phone call about three weeks after completing the forms at the clinic. During this phone call we will ask you 20 quick *yes/no* questions in Northern Sotho.



4) POSSIBLE RISKS AND DISCOMFORTS INVOLVED

There are no medical risks associated with the study. The only possible discomfort involved is the time it might take to complete the questionnaires and the interview. The researcher will be present while you complete the questionnaires. The demographic questionnaire and the Vineland-3 are the only questionnaire that would

require more effort than answering *yes/no* or circling *0/1/2,* but these instruments will be completed during the *interview*, which should not take longer than 30 minutes.

5) POSSIBLE BENEFITS OF THIS STUDY

Although you may not benefit directly, the study results will help the researcher to develop a much-needed screening instrument in Northern Sotho. It is anticipated that the translation will greatly benefit Northern Sotho parents in future. The results of the screening test will be discussed with you on the day that you complete it. If the screening test shows more than three specific traits or delays in your child's case, your child may need extra help. I will give you a referral letter that you can give to the paediatrician that treats your child at the clinic. If you do not attend a clinic, we will give you names of clinics that you can go to. Some of the clinics are private practices and will charge you a consultation fee. Please ask if you are uncertain about the private practice sites.

6) COMPENSATION

You will not be paid to take part in the study. There are no costs involved for you to be part of the study.

7) YOUR RIGHTS AS A RESEARCH PARTICIPANT

Your participation in this study is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. Your withdrawal will not affect your access to other medical care.

8) ETHICS APPROVAL

This Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria, telephone numbers 012 356 3084 / 012 356 3085 and written approval has been granted by that committee. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2013). A copy of the Declaration may be obtained from the investigator should you wish to review it.

9) INFORMATION

The contact person is Carlien Vorster. If you have any questions about the study please contact me at the following telephone numbers (012) 420-2355. Alternatively, you may contact her supervisors at (012) 420 2815/2357. If you want to send an email, you may send it to carlien.vorster@up.ac.za; alta.kritzinger@up.ac.za or jeannie.vanderlinde@up.ac.za .

10) CONFIDENTIALITY

All information obtained during the duration of this study will be regarded as confidential. Each participant that is taking part will be provided with an alphanumeric coded number e.g. A001. This will ensure confidentiality

C Vorster
Researcher
carlien.vorster@up.ac.za

Prof. AM Kritzinger
Supervisor
alta.kritzinger@up.ac.za

Prof. J van der Linde
Co-Supervisor
Head of Department
Speech-Language Pathology &
Audiology
jeannie.vanderlinde@up.ac.za

11) CONSENT TO PARTICIPATE IN THIS STUDY

- I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.
- I have also received, read and understood the above written information about the study.
- I have had adequate time to ask questions and I have no objections to participate in this study.
- I am aware that the information obtained in the study, including personal details, will be anonymously processed and presented in the reporting of results.
- I understand that I will not be penalised in any way should I wish to discontinue with the study and that withdrawal will not affect me.
- I am participating willingly.
- I have received a signed copy of this informed consent agreement.
- I give permission to use the data in future research.

_____
Participant's name (Please print)

_____ _____
Participant's signature Date

Researcher's name: C Vorster

_____ _____
Researcher's signature Date

Go tshepagala ga teko le teko gape le go ba molao ga mokgwa (wa go sepela gotee) ga phetolelo ya Sesotho sa Leboa (Sepedi) ya CHAT-R/F

Monyakišišomogolo: Mdi C Vorster

Balekodi: Prof. A M Kritzinger le Prof. J van der Linde

Institušene: Yunibesithi ya Pretoria

DINOMORO TŠA MOGALA TŠA MOŠOMONG:

Dinomoro tša mogala tša mošomong: (012) 420 2355

TŠATŠIKGWEDI LA POLEDIŠANO YA MATHOMO YA TUMELELANO YA TSEBO:

			:
tšatšikgwedi	kgwedi	ngwaga	Nako

Mokgathatema yo a Letetšwego yo a rategago

1) MATSENO

O laletšwa go ithaopa go kgatha tema go thuto ya dinyakišišo. Ke dira dinyakišišo tša tikrii ya Bongaka Yunibesithing ya Pretoria. O fiwa tshedimošo ye e lego ka tokumenteng go go thuša go tšea sephetho sa ge e le gore o nyaka go kgatha tema ka dinyakišišong tše. Pele o dumela go kgatha tema o swanetše go kwešiša ka botlalo gore e akaretša eng. Ge o na le dipotšišo dife goba dife, tšeo di se a hlalošwago ka botlalo ka tokumenteng ye, o se ke wa dikadika go botšiša monyakišiši. O se ke wa dumela go kgatha tema ntle le ge o kwešiša gabotse ka ga ditshepedišo ka moka tšeo di akareditšwego.

2) MOHUTA LE NEPO YA DINYAKIŠIŠO TŠE

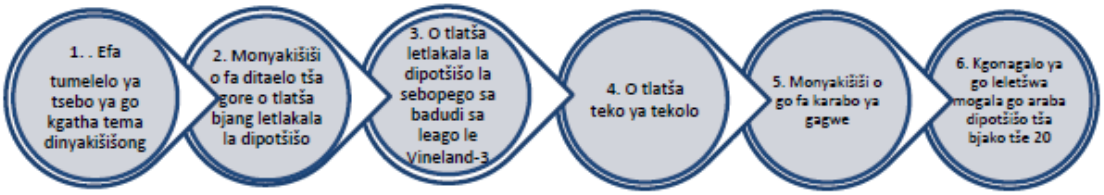
Ke šetše ke kaonafaditše le go fetolela teko ya tekolo go Sesotho sa Leboa (Sepedi). Maikemišetšo a teko ke go utolla bana bao ba ka bago kotsing ya go swara ke othosimo. Bjale ke nyaka go dira teko go bona ge kaonafatšo le phetolelo di le gabotse. *Gore ke ithute ka kotsi ya Othosimo, ke hloka go akaretša bana bao ba lego kotsing ya go swarwa ke othosimo le bana bao ba se nago maswao afe goba afe a othosimo. Ge o dumela go kgatha tema mo dinyakišišong tše, ga se gore ngwana wa gago o na le bothata bja go swana le othosimo.*

Othosimi ke lereo leo le šomišetšwago malwetši a go raragana a kgolo ya bjoko. Bana bao ba phelago ka bolwetši bja Othosimo ba ka kgokagana, ba šomišana, le go ithuta ka mekgwa ya go fapana le ya bana ba bangwe ba bantši. Go ithuta, go nagana, le mabokgoni a go rarolla mathata a bana bao ba phelago ka

Othisimo di ka tloga go bana ba go kgona go ya go ba go se kgone kudu. Bana ba bangwe bao ba phelago ka othisimo ba nyaka thekgo ye kgolo (thušo ye ntši le tsenogare ya go tsenelela) mola ba bangwe ba nyaka thekgo ye nnyane (thušo ye nnyane le tsenogare ya go tsenelela ye nnyane). AutismSA.

3) TLHALOŠO LE DITSHEPEDIŠO LE GORE GO KA LETELWA ENG GO BAKGATHATEMA.

O tla kgopelwa go saena fomo ya tumelelo ya tsebo, ge monyakišiši a go hlalošeditše dinyakišišo. Dinyakišišo tše di akaretša go araba dipotšišo ka ga ngwana wa gago wa go abula le go gola ga gagwe. Wena bjalo ka motswadi goba mohlokomedi, o tla akaretšwa bjalo ka mokgathatema ka dinyakišišong.
Go tla nyakega gore o tlatše letlakala la dipotšišo ka ga Sebopego sa Badudi, Vineland-3, le M-CHAT-R/F ya Sesotho sa Leboa (Sepedi). O tla kgopelwa gape go kgatha tema mo poledišanong ya metsotso ye 30. Nakong ya poledišano monyakišiši o tla go botšiša dipotšišo gore o tlatše sebopego sa badudi le Vineland Ge o nyaka thušo, monyakišiši a ka bala dipotšišo, ntle le go go fa tshedimošo ya tlaleletšo. Ka morago ga ge difomo ka moka di tladitšwe, monyakišiši o tla go fa karabo ka ga sedirišwa sa tekolo. O ka amogela mogala mo dikgweding tše tharo ka morago ga go amogela difomo kliniking. Nakong ye ya mogala re tla go botšiša dipotšišo tša bjako tša *ee/aowa* ka Sesotho sa Leboa (Sepedi).



4) KGONAGALO YA DIKOTSI LE GO SE IKETLE

Ga go na dikotsi tša maphelo tšeo di amanywago le thuto ye. Kgonagalo fela yeo e amanywago ke nako yeo e ka tšewago go tlatša letlakala la dipotšišo le poledišano. Monyakišiši o tla ba gona ge o tlatša letlakala la dipotšišo. Letlakala la dipotšišo la sebopego sa badudi le Vineland-3 ke matlakala a dipotšišo a le tee ao a tla nyakago maatla a mantši go na le go araba ka ee/aowa goba go dira sediko go *0/1/2*, eupša didirišwa tše di tla tlatšwa nakong ya dipoledišano.

5) KGONAGALO YA DIKHOLEGO TŠA DINYAKIŠIŠO

Le ge o ka se holege thwii, dipoelo tša dinyakišišo di tla thuša go dira sedirišwa sa tekolo ka Sesotho sa Leboa (Sepedi). Go letetšwe gore phetolelo e tla thuša kudu batswadi bao ba bolelago Sesotho sa Leboa

(Sepedi) ka moso. Go tla boledišanwa le wena ka dipoelo tša teko ya tekolo ka letšatši leo o tlatšago letlakala la dipotšišo ka lona. Ge go hlokega, monyakišiši o tla go fa lengwalo la phetišetšo leo o ka le fago ngaka ya bana yeo e alafago ngwana wa gago kliniking. Ge o sa ye kliniking, re tla go fa maina a dikliniki tšeo o ka yago go tšona.

Ge diteko tša tekolo di bontšha mekgwa ye e itšego goba dititelego mo bothateng bja ngwana wa gago, ngwana wa gago a ka hloka thušo ye nngwe. Ke tla go fa lengwalo la taelelo leo o ka le fago ngaka ya bana yeo e alafago ngwana wa gago kliniking. Ge o sa ye kliniking, re tla go fa maina a dikliniki tšeo o ka yago go tšona. Tše dingwe tša dikliniki ke tša praebete gomme di tla go lefiša tefo ya kopano. O kgopela go botšiša ge o se na nnete ka mafelo a ditshepedišo tša praebete

6) TEFO

O ka se lefelwe go kgatha tema mo dinyakišišong. Ga go na ditshenyagelo tšeo di akaretšwago gore o be karolo ya dinyakišišo.

7) DITOKELO TŠA GAGO BJALO KA MOKGATHATEMA DINYAKIŠIŠONG

Go kgatha tema ga gago mo dinyakišišong ke ga go ithaopa gomme o ka gana go kgatha tema goba wa emiša nako ye nngwe le ye nngwe ntle le go fa mabaka. Go ikgogela morago ga gago go ka se ame tlhokomelo ye nngwe ya maphelo.

8) TUMELELO YA MAITSHWARO

Prothokholo ye e išitšwe go Komiti ya Maitshwaro a Dinyakišišo ya Lefapha la Maphelo, Yunibesithing ya Pretoria, dinomoro tša mogala 012 356 3084 / 012 356 3085 gomme tumelelo ya go ngwalwa e filwe ke komiti yeo. Dinyakišišo di beakantšwe go ya ka Pego ya Helsinki (e mpshafaditšwe la mafelelo: Diphalane 2013). Kopi ya Pego e ka hwetšwa go monyakišiši ge o ka nyaka go e sekaseka.

9) TSHEDIMOŠO

Motho yo o ka ikgokaganyago le yena ke Carlien Vorster. Ge o na le dipotšišo dife goba dife ka ga dinyakišišo o kgopelwa go ikgokaganya le nna mo dinomorong tše tša mogala (012) 420 -2355. Goba, o ka ikgokaganya le balekodi ba ka go (012) 420 2815/2357. Ge o nyaka go romela emeile, o ka e romela go carlien.vorster@up.ac.za; alta.kritzinger@up.ac.za goba jeannie.vanderlinde@up.ac.za.

10) SEPHIRI

Tshedimošo ka moka yeo e hweditšwego nakong ya dinyakišišo e tla tšewa go ba ya sephiri. Mokgathatema yo mongwe le yo mongwe yoo a kgathago tema o tla fiwa khouto ya ditlhaka le dinomoro,

mohlala A001. Se se tla kgonthiša sephiri sa tshedimošo yeo e kgobokeditšwego . Ke fela monyakišiši yoo a tla kgonago go go utolla bjalo ka mokgathatema. Dipoelo di tla phatlalatšwa goba tša fiwa ka tsela yeo e lego gore mokgathatema o tla dula a sa tsebje. Dikopi tšeo di gatišitšwego tša direkoto ka moka tša gago di tla bolokwa ka senolofatšing seo se notletšwego ka Kgorong ya Phatholotši le Odiolotši tša Polelo-Leleme, Yunibesithing ya Pretoria.

Re leboga kudu nako le dikakanyo tša gago.

Ka boikokobetšo

C Vorster
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Supervisor
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Prof. J van der Linde
Co-Supervisor
Head of Department
Speech-Language Pathology &
Audiology
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11) TUMELELO YA GO KGATHA TEMA DINYAKIŠIŠONG

- Ke kgonthiša gore motho yo a kgopelago tumelelo ya ka ya go kgatha tema dinyakišišong o mpoditše ka mohuta le tshepetšo, dikotsi dife goba dife le go se iketle, le dikholego tša dinyakišišo.
- Gape ke amogetše, go bala le go kwešiša tshedimošo ye e ngwetšwego ya ka godimo ka ga dinyakišišo.
- Ke bile le nako yeo e lekanego go botšiša dipotšišo gomme ga ke ganane le go kgatha tema mo dinyakišišong.
- Ke a lemoga gore go tla šoganwa le tshedimošo yeo e hweditšwego, go akaretšwa tshedimošo ya motho le go fiwa ge go begwa dipoelo go sa tsebege gore ke ya mang.
- Ke a kwešiša gore nka se otlwe ka mokgwa ofe goba ofe ge nka nyaka go se sa tšwela pele ka dinyakišišo gape go ikgogela morago go ka se nkame.
- Ke kgatha tema ka go rata ga ka.
- Ke amogetše kopi ye e saenwego ya tumelelano ya tumelelo ya tsebo.
- Ke fa tumelelo ya go šomiša data go dinyakišišo tša ka moso.

_____

Leina la mokgathatema (O kgopelwa go gatiša)

_____	_____
Tshaeno ya mokgathatema	Tšatšikgwedi

Leina la monyakišiši: C Vorster

_____	_____
Tshaeno ya monyakišiši	Tšatšikgwedi

Appendix P: Referral letter

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Humanities 100.
1919 - 2019

Dear Parent/ Caregiver

Thank you very much for the opportunity to include you in the research study.

During the parent interview and completion of the instruments, the following was noted:

_____

For this reason I would like to refer you to:

Medical Professiona/ Allied Healthcare Profession		Reason, as dicussed in the feedback session	
	Audiologist		Comprehensive hearing assessment
	Occupational Therapist		Motor/ Sensory/ Perceptual deficits
	Pediatrician		
	Speech-Language Therapist		Language/ Communication Deficit

Please refer to the attached lists of professionals as possible service providers. You may however visit any professional of your choice, this list is provided as a possible guideline.

Kind regards

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Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

List of possible medical professionals and allied healthcare professionals:

Audiologist	
Department of Speech-Language Pathology and Audiology, University of Pretoria	Hatfield Campus Lynnwood Road 012 420 2816
Rialette Gous & Marike Venter Inc	Mediclinic Muelmed Pretorius Street (012) 341 4450
Earinstitute	Ear Institute, Queenswood 1240 Webb Street Queenswood (012) 333 3130 Ear Institute, Lynnwood 76 Alcade Road (C/o Lynnwood Rd and Glenwood Rd), Lynnwood (012) 471 4800
Steve Biko Academic Hospital: Audiology Department	The Steve Biko Academic Hospital c/o Steve Biko and Malan Street, Capital Park, Pretoria (012) 354 4293
Ear-Nose- and Throat Specialist	
Dr. Jannie Enslin	Denneboom Road Wilgers 012 807 0774
Dr Johan Kluge	Groenkloof Hospital 50 George Storrar Drive (012) 346 0879
Steve Biko Academic Hospital: ENT Department	The Steve Biko Academic Hospital c/o Steve Biko and Malan Street, Capital Park, Pretoria (012) 354 2724
Occupational Therapist	
Melanie Campbell	1263 Walter Avenue, Waverley, 0186 +27 83 329 3557
Big Tree Therapy: Vina Leas	Lombardy Office Park, Block 6, unit number 98 Cnr of Graham and Cole Roads, Shere AH, Pretoria East 082 455 8383
Steve Biko Academic Hospital: Occupational Therapy	The Steve Biko Academic Hospital c/o Steve Biko and Malan Street, Capital Park, Pretoria 012 354 1665
Pediatrician	
Dr J. A. Erasmus	Moot Algemene Hospital, 572 18th Avenue, 012 330 2084

Steve Biko Academic Hospital: Pediatrics Department	The Steve Biko Academic Hospital c/o Steve Biko and Malan Street, Capital Park, Pretoria 012 354 1622
Steve Biko Academic Hospital: Pediatric Neurology Department	The Steve Biko Academic Hospital c/o Steve Biko and Malan Street, Capital Park, Pretoria 012 354 5105/5579
Dr F. French	Room 104 Mediclinic Kloof 511 Jochemus Street, Erasmus Kloof (012) 347 3953
Speech-Language Therapist	
Department of Speech-Language Pathology and Audiology, University of Pretoria	Hatfield Campus Lynnwood Road 012 420 2816
Steve Biko Academic Hospital: Speech Therapy	The Steve Biko Academic Hospital c/o Steve Biko and Malan Street, Capital Park, Pretoria (012) 354 4293
Coralie Vermaak Spraakterapie	8th Street Menlopark 0824410166

Appendix Q: Proof of acceptance (Article 1)

SAJCE 968: Manuscript Accepted for Publication, Sent to Editing

aosis@sajce.co.za
to me, alta.kritzinger, matemane.lekganyane, elsabe.taljard, jeannie.vanderlinde

****

Ref. No.: 968
Manuscript title: Cultural Adaptation and Northern Sotho Translation of the Modified-Checklist for Autism in Toddlers (M-CHAT-R/F™)
Journal: South African Journal of Childhood Education

****

Dear Carlien Vorster, Alta Kritzinger, Matemane Lekganyane, Elsabe Taljard, Jeannie van der Linde

We are pleased to confirm your manuscript's acceptance for publication on 14-Oct-21.

We can also confirm that the Submission and Review Department released your manuscript to our Finalisation Department to commence the various editing processes to secure online publication within the next 90 days (if not sooner).

Kindly note:
1. If you need to make contact with AOSIS Publishing during the finalisation stage of your manuscript, kindly contact us per email or phone.
2. The finalisation procedure works as follows: (a) The first stage is the language editing that is returned to the corresponding Author for review. This will be the final opportunity for the corresponding Author to make text changes to the manuscript. (b) At a later stage, the editorial staff will send the corresponding author one set of galley proofs, at which time the Author will have two working days to mark any typographical errors.
3. Manuscript tracking is available on the submitting authors' journal profile. The submitting Author could visit their home page frequently to assess the stage of the manuscript.

Thank you for your continued patience and support, and we hope you have

Appendix R: Proof of publication (Article 2)

South African Journal of Communication Disorders
ISSN: (Online) 2225-4765, (Print) 0379-8046

Preliminary reliability of South African adaptation and Northern Sotho translation of the Modified Checklist for Autism in Toddlers, Revised with Follow-Up

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Dates:
Received: 14 Mar. 2021
Accepted: 02 June 2021
Published: 22 July 2021

How to cite this article:
Vorster, C., Kritzinger, A., Coetser, L.E., & Van der Linde, J. (2021). Preliminary reliability of South African adaptation and Northern Sotho translation of the Modified Checklist for Autism in Toddlers, Revised with Follow-Up. *South African Journal of Communication Disorders*, *68*(1), a831. https://doi.org/10.4102/sajcd.v68i1.831

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Background: There is a shortage of validated autism screening tests in the 11 official languages of South Africa. The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F™), a validated and well-known screening test, had already been adapted (in English) and translated into Northern Sotho for use in South Africa.

Objectives: The aim was to collect pilot data to determine the preliminary reliability and feasibility of the two tests to confirm the equivalence of the adaptation and translation.

Method: The study was conducted in a peri-urban community in South Africa. Twenty-one first-language Northern Sotho caregivers of children aged between 18 and 48 months were recruited by employing snowball sampling. The participants were asked to complete the Northern Sotho and the culturally adapted English M-CHAT-R/F, which were presented in random order.

Results: The preliminary content validity and equivalence were evident, with no difference at the 5% interval of the Wilcoxon signed rank test. All 21 toddlers screened presented with a low risk for autism following the recommended execution of the Follow-Up section for the toddlers in the medium risk category. All participants completed the two screening tests, with none indicating unfamiliar words or constructs. A higher preference for the English adapted version was found but a need for the Northern Sotho screening test was also evident

Conclusion: The Northern Sotho translation of the M-CHAT-R/F, as well as the adapted English version, appears feasible and is ready for comprehensive validation.

Keywords: autism screening; M-CHAT-R/F-Northern Sotho translation; preliminary reliability; low and middle-income country; South African adapted English M-CHAT-R/F.

Introduction

The lack of culturally appropriate screening instruments for autism has become a universal concern (Hyman, Levy, Myers, & AAP Council on Children with Disability, 2020; Malcolm-Smith et al., 2013). Most autism screening tools are available in English only, as they derive from English-speaking countries (Soto et al., 2015). Cultural and linguistic differences in the understanding of test items and concepts are some of the factors that may lead to disparities in screening outcome (Barton, Dumont-Mathieu, & Fein, 2012; Soto et al., 2015). In an attempt to address the shortage of validated, cultural and linguistic appropriate screening tools, and amidst a worldwide steady increase in the prevalence of autism (Maenner et al., 2020), the authors had previously adapted and translated one of the most commonly used autism screening tests for use in South Africa (Vorster et al., 2021).

Limited research has been performed to develop and validate screening instruments on the African continent (De Vries, 2016; Franz, Chambers, von Isenburg, & de Vries 2017). In a multicultural and multilingual country such as South Africa, local translation and validation of autism screening tools are important (Franz et al., 2018). Early detection of developmental conditions is a high priority and advocated by the World Health Organisation (WHO), because identification at a young age may decrease the impact of impairments as it promotes early management (WHO, 2013a).

The original English Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F™) (Robins et al., 2014) was adapted and translated into Northern Sotho. The

JADD-D-21-01115 - Submission Confirmation

Inbox x

Journal of Autism and Developmental Disorders (JADD) <em@editorialmanager.com> Fri, Oct 8, 1:46 PM (13 days ago)

to me

The submission id is: JADD-D-21-01115

Please refer to this number in any future correspondence.

Dear Mrs Vorster,

Thank you for submitting your manuscript,

"Reliability and concurrent validity of a South African cultural adaptation and a Northern Sotho translation of the M-CHAT-R/F", to Journal of Autism and Developmental Disorders

During the review process, you can keep track of the status of your manuscript by accessing the Journal's website.

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With kind regards,
Lori Klein
Managing Editor
Journal of Autism and Developmental Disorders