A REVISION OF A MATERNAL INTERVIEW QUESTIONNAIRE USED IN FETAL ALCOHOL SPECTRUM DISORDER PREVENTION PROGRAMMES IN SOUTH AFRICA

by
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DECLARATION

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ABSTRACT

This study was done in collaboration with the Foundation for Alcohol Related Research (FARR), a non-governmental organization whose primary objective is to develop and maintain Fetal Alcohol Spectrum Disorder (FASD) prevention programmes across South Africa. Research has shown the occurrence of FASD in South Africa to be much higher than in other parts of the world.

As part of their prevention programmes, FARR uses a three part diagnostic process, including a maternal interview, a dysmorphological examination, as well as a general developmental assessment. The maternal interview questionnaire that FARR currently uses takes an average of two hours per interviewee to complete. Even though a recent study indicates that FASD prevention programmes administered by FARR can potentially reduce FASD prevalence, shorter maternal interviews could improve the use of FARR resources and the ability of FASD research studies to gather meaningful information and inform future prevention efforts.

The main purpose of this study was to adjust the maternal interview questionnaire used by FARR in order to make interviews with mothers shorter while delivering the information needed for successful FASD prevention programmes.

Data related to the adequacy of the adjusted maternal interview questionnaire was collected and analysed according to an action research approach in four consecutive phases. The research procedures consisted of two separate focus group interviews with five key role players from FARR. During the first focus group interview the main problems with the questionnaire was identified as being (i) the length of the questionnaire, (ii) the unsuitability of the questionnaire to interview someone other than the biological mother, and (iii) inconsistency between interviewers when using the questionnaire. During the second phase of the study the questionnaire was adjusted and revised as part of a second focus group interview. The interviewers, data capturer and data analyst who used the adjusted questionnaire as part of a larger FASD prevention programme made several suggestions on how the questionnaire could be further adjusted to suit the needs of FARR. These suggestions were addressed during the final phase of the study, after which the adjusted questionnaire was finalized.

Findings from the study suggest that identified problems with FARR's original maternal interview questionnaire were successfully addressed by the adjusted questionnaire, while simultaneously satisfying the objectives of a maternal interview as identified by participants during the first focus group interview. Results confirmed that more maternal interviews could be conducted in the same time period using the adjusted interview questionnaire compared to when the original questionnaire was used, due to the fact that the questionnaire was shorter and took less time to administer. As part of this study an additional questionnaire was developed specifically for caregiver interviews. According to FARR role players, inconsistency between interviewers was for the most past successfully addressed by the development of this additional questionnaire and the development of an interviewer guideline. Recommendations for future research include the further development and evaluation of the caregiver questionnaire and interviewer guideline.

Key words: FASD, prevention programmes, maternal interview questionnaire, questionnaire adjustment.

OPSOMMING

Hierdie studie is uitgevoer in samewerking met die "Foundation for Alcohol Related Research" (FARR), 'n nie-regeringsorganisasie met die primêre objektief om Fetale Alkohol Spektrum Afwyking (FASA) voorkomingsprogramme in Suid-Afrika te ontwikkel en te handhaaf. Volgens navorsing is die voorkoms van FASA in Suid-Afrika beduidend hoër as in ander dele van die wêreld.

'n Drie-delige diagnostiese proses word as deel van FARR se voorkomingsprogramme gebruik, insluitend 'n onderhoud gefokus op moeders, 'n dismorfologiese ondersoek, asook 'n evaluasie van die kind se algehele ontwikkeling. Die moeder-onderhoudsvraelys wat tans deur FARR gebruik word neem gemiddeld twee ure om te voltooi. Alhoewel 'n onlangse studie aandui dat die voorkomingsprogramme deur FARR oor die potensiaal beskik om die prevalensie van FASA te verlaag, kan korter moeder-onderhoude potensieël daartoe lei dat bronne beter benut word, asook dat FASA voorkomingstudies betekenisvolle inligting versamel vir die ontwikkeling van toekomstige voorkomingsprogramme.

Die hoofdoel van die huidge studie was om die moeder-onderhoudsvraelys wat tans deur FARR gebruik word aan te pas, om sodoende die onderhoude met moeders korter te maak terwyl die nodige inligting vir suksesvolle FASA voorkomingsprogramme steeds verkry word.

Gedurende hierdie studie is data rakende die toereikendheid van die aangepaste moeder-onderhousdvraelys versamel en geanaliseer volgens 'n aksie-navorsingsbenadering in vier opeenvolgende fases. Die navorsingsprosedures het bestaan uit twee afsonderlike fokusgroeponderhoude met vyf van die sleutelrolspelers van FARR. Gedurende die eerste fokusgroeponderhoud is die hoofprobleme met die vraelys geïdentifiseer as (i) die lengte van die vraelys, (ii) die ongeskiktheid van die vraelys om 'n onderhoud met iemand anders as die biologiese moeder te voer, en (iii) die inkonsekwentheid tussen onderhoudvoerders met die gebruik van die vraelys. Gedurende die tweede fase van die studie is die vraelys aangepas en hersien as deel van 'n tweede fokusgroeponderhoud. Die onderhoudvoerders, data verwerker en data analis wat die aangepaste vraelys gebruik het as deel van 'n groter FASA voorkomingsprogram het verskeie aanbevelings gemaak rakende hoe die vraelys verder aangepas kan word om te voldoen aan FARR se behoeftes. Laasgenoemde aanbevelings is aangespreek gedurende die laaste fase van die studie, waarna die aangepaste vraelys gefinaliseer is.

Die bevindinge van die studie dui aan dat die geïdentifiseerde probleme met FARR se oorspronklike moeder-onderhoudsvraelys suksesvol deur die aangepaste vraelys aangespreek is, terwyl die objektiewe van 'n moeder-onderhoud (soos geïdentifiseer deur die deelnemers aan die eerste fokusgroeponderhoud) steeds vervul is. Resultate het bevestig dat meer moeder-onderhoude in dieselfde tydsperiode met behulp van die aangepaste vraelys gevoer kon word as met die oorspronklike vraelys, as gevolg van die feit dat dit korter was en minder tyd geneem het om te voltooi. As deel van die studie is 'n bykomstige vraelys spesifiek vir sorggewer-onderhoude ontwikkel. Volgens die FARR rolspelers is inkonsekwentheid tussen die onderhoudvoerders grootliks suksesvol aangespreek deur middel van die ontwikkeling van hierdie bykomstige vraelys asook die ontwikkeling van 'n riglyn vir onderhoudvoerders. Aanbevelings vir verdere navorsing sluit die verdere ontwikkeling en evaluasie van die sorggewer-vraelys en onderhoudvoerder riglyn in.

Sleutelwoorde: FASA, voorkomingsprogramme, moeder-onderhoudsvraelys, vraelys-aanpassing.

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1 INTRODUCTION

Fetal Alcohol Spectrum Disorder (FASD) refers to a range of disorders associated with prenatal exposure to alcohol (Viljoen et al., 2005). According to guidelines that were developed by the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect in the United States of America (USA), FASD can be defined as an umbrella term that encompasses the range of effects that can occur in an individual whose mother consumed alcohol during pregnancy (Gerberding, Cordero & Floyd, 2004). These disorders differ not only in terms of the parts of the body that are affected but also in terms of the severity of the deficits. During the nineties the continuum of effects associated with FASD was categorised and expanded into four different diagnoses including Fetal Alcohol Syndrome (FAS), Partial FAS (pFAS), alcohol-related birth defects (ARBDs) and alcohol-related neurodevelopmental disorders (ARNDs) (Stratton, Howe & Battaglia, 1996).

In cases where the child's brain development and function is affected by prenatal exposure to alcohol it is usually referred to as alcohol-related neurodevelopmental deficits (ARND). Any negative impact on the child's general physical development due to prenatal alcohol exposure is referred to as alcohol-related birth defects (ARBD). Children who are diagnosed with partial FAS (pFAS) have a confirmed history of prenatal alcohol exposure, but they may lack growth deficiency and may also present with little or none of the facial features that are characteristic of FAS. Children who are the most severely affected by maternal alcohol use during the prenatal period, and who present with a characteristic pattern of physical traits and neurodevelopmental delays, are usually diagnosed with FAS (Urban, Chersich, Fourie, Chetty, Olivier, & Viljoen, 2008). According to Warren, Hewitt and Thomas (2011) there are three primary defining features that must be present before a diagnosis of FAS can be made. These three features include the presence of characteristic facial abnormalities (e.g. a smooth philtrum), a history of prenatal and postnatal growth retardation as well as the presence of abnormalities in the central nervous system which could lead to neurological and/or behavioral problems. A child is diagnosed with FAS if deficits exist in all of the abovementioned areas and once the possibility of other genetic anomalies has been excluded (Viljoen et al., 2005).

Some of the poorest communities in South Africa are currently facing an alarming number of children born with FASD. The implication is that many families have to deal with the emotional and financial strain of having to raise a child with a disability. High rates of FASD also cause further socio-economic problems for communities that are already struggling. FASD was first identified and diagnosed among South African communities during the nineties. After the need for research in this field in South Africa became apparent, a non-governmental organisation named FARR[1] (The Foundation of Alcohol Related Research) was created in 1997 by a group of local and international health care professionals and researchers who all had a special interest in FASD. One of the overall purposes of this organisation is to create a vehicle through which the effects of alcohol abuse on South African communities, individuals as well as unborn children can be scientifically investigated. One of the first research projects by FARR was carried out in the town of Wellington in the Western Cape. The findings of this research is reported in an article in the *South African Medical Journal* (Croxford & Viljoen, 1999) and is the first paper to describe the grim reality of women abusing alcohol while pregnant in South Africa. FARR has since been responsible for some of the largest and

[1] FARR has requested the researcher to conduct the current study as part of their growing body of research on FASD in general and also more specifically on the instruments that are currently used to diagnose children with FASD. The organisation therefore asked to be named in this thesis and not remain anonymous.

most influential FASD research studies in the country, including in areas of the Western Cape, the Northern Cape and Gauteng provinces. With inception, one of FARR's goals was to provide preventative and interventional services to communities that have been severely affected by FASD, but it was only six years later that the first step towards realising this goal could be taken.

In 2003 FARR undertook the first comprehensive FASD prevention programme in South Africa in the town of De Aar in the Northern Cape. This was done after preliminary prevalence studies that were conducted between 2001 and 2003 revealed it to be the area with the highest percentage of children with FAS, not only in South Africa but in the world (Urban et al., 2008). This prevention programme has given support to many families of children with FASD in De Aar. A recent study has also shown a decrease in the number of children born with FASD in De Aar, which can for the most part be attributed to the prevention activities in this area (Chersich, Urban, Olivier, Davies, Chetty & Viljoen, 2012). Despite their success, the structure of the prevention programmes that are currently being conducted by FARR is time-consuming and costly. Prevention programmes can be viewed as an umbrella term that refers to all aspects of prevention and also intervention, including prevention research studies, early identification and diagnosis of high-risk pregnancies, early identification and diagnosis ofchildren with FASD as well as support and counselling for families who are in some way impacted by FASD. The early identification and assessment of children with a high risk for FASD form an integral part of these prevention programmes. The following processes are included as part of FARR's screening of children: (a) obtaining informed consent from a parent or caregiver for assessment of the child as well as conducting an interview where necessary (see f), (b) permission from first grade teachers, the headmasters of schools and education authorities to assess learners in their classrooms and schools, (c) screening of children for anthropometric measures below the 10th percentile[2], (d) independent clinical evaluation by two dysmorphologists, (e) neurodevelopmental assessments by a psychologist as well as (f) an interview with the mother of the child of interest, the so-called maternal interview. The purpose of the maternal interview is to obtain information on the mother's pregnancy and the birth history of the child of interest, the mother's drinking habits (current as well as during her pregnancy with the child of interest), her nutritional status as well as her smoking habits and/or use of other drugs. In the instance where the biological mother of the child of interest cannot be interviewed (e.g. when the mother is deceased or has moved out of the area for work) an interview is conducted with the primary caregiver of the child.

The maternal interview questionnaire that FARR is currently using takes an average of two hours per interviewee to complete. The fact that the questionnaire is lengthy places a strain on resources and it means that a limited number of mothers can be interviewed in any particular prevention programme. This lowers the amount of information available from a given target population for research purposes and the number of women and children who might benefit from a confirmed diagnosis of FASD through consequent access to prevention and rehabilitation services. During a two hour interview women may also not consistently provide accurate and/or thorough information, either because of the effect of fatigue or because they intentionally give short answers to complete

[2] Anthropometric measurements can be defined as a set of non-invasive, quantitative techniques for determining an individual's body fat composition by measuring, recording, and analyzing specific dimensions of the body, such as height and weight; skin-fold thickness; and bodily circumference at the waist, hip, and chest (Jonas, 2005). The height, weight and head circumference of children are normally measured as part of FASD prevention programmes (May et al., 2013). All children who have height and weight and/or head circumference measurements lower than the 10th percentile are identified as having a high risk for FASD.

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the interview. Even though the study by Chersich et al. (2012) indicate that the FASD prevention programmes that are administered by FARR have the potential to successfully reduce FASD prevalence, shorter maternal interviews as part of these prevention programmes could result in an even larger number of parents and caregivers being educated on the dangers that the consumption of alcohol holds for an unborn child, and improve the ability of FASD research studies to gather meaningful information to inform future prevention efforts.

In the field of Speech-Language Therapy (SLT) there has been a dramatic change over the last decade in terms of the profile of clients that are treated. Not only has there been an increase in the prevalence of language disorders related to intellectual disabilities among children in South Africa, but the causes of these intellectual deficits are often unknown (Adnams, 2010). Since FAS/FASD has been identified as one of the leading causes of neurodevelopmental delays in South Africa, collaboration between Speech-Language Therapists and experts on FASD has become imperative. Even though the current study does not focus on the speech and language disorders related to FASD, the Speech-Language Therapist's professional role with regards to the prevention of communication disability makes this research relevant to the field of SLT. The author is of the opinion that such research will help to bridge the gap between the fields of SLT and FASD in South Africa and possibly encourage the much needed research activity within the field of Speech-Language Therapy on FASD.

1.1 Research question and objectives

The main purpose of the study was to adjust the maternal interview questionnaire that is used by FARR in such a way that interviews with mothers are shorter yet capable of delivering all the information needed for successful FASD prevention programmes. The research question for the current study is: "Can the interview questionnaire that is currently used by FARR to conduct maternal interviews as part of their prevention programmes be adjusted in such a way that it (i) satisfies the objectives of a maternal interview and (ii) overcomes the problems that is experienced by the users of the current questionnaire?"

The study objectives are as follows:

1. To define the objectives of the maternal interview that forms part of FARR's FASD prevention programmes as perceived by the main role players in FARR's prevention programmes;

2. To identify the problems with the maternal interview questionnaire that is currently being used by FARR in FASD prevention programmes in South Africa;

3. To adjust the maternal interview questionnaire based on the problems referred to in the second objective whilst preserving the questionnaire's ability to achieve the objectives referred to under Objective 1; and

4. To evaluate the adjusted maternal interview questionnaire's ability to overcome the problems that are referred to under Objective 2, whilst achieving the objectives of a maternal interview referred to under Objective 1.

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1.2 Research design

This study followed an action research approach. Action research involves an approach to research that is directed toward studying, reframing and reconstructing social practices (Kemmis & McTaggart, 2000). According to Zuber-Skerritt (1992) an action research approach differs from traditional social research in that the research findings do not only have theoretical importance but also lead to practical changes within the field that is being studied. A study by Rajaram (2007) investigated the benefit of using an action research approach in a prevention programme, and more specifically the prevention of lead poisoning within high-risk communities. Results of this study indicated that the use of an action research approach was particularly appropriate in this case since it not only helped to create awareness of the dangers associated with lead poisoning amongst the community, but in turn also helped the researchers to become actively involved in the field of prevention. An action research approach was also deemed appropriate in terms of satisfying the main aim of the current study: to adjust the maternal interview questionnaire used to interview mothers as part of FARR's FASD prevention programmes in South Africa. The expectation was that the adjusted questionnaire would not only change the way mothers are interviewed, but would also ensure that the data that is derived from these interviews can be used effectively in future prevention, intervention and research projects. Zuber-Skerritt (1992) describes action research as a process that consists of different phases, each with its own purpose. During phase one problems are identified and analysed whereafter a strategic plan is formed to overcome these problems. Phase two of action research deals with the implementation of the strategic plan that was formed during phase one. During phase three the action that was taken is evaluated by the researcher through the use of appropriate methods. Finally, during the fourth phase, the researcher normally reflects on the research results and the process as a whole. After the researcher has taken the time to reflect on the research process and the results that were obtained, it is very likely for more phases to be included in an action research cycle, depending on whether any further problems were identified during the reflective phase. The current study used an action research approach for data collection and data analysis. This is evident from the different phases that were included in the research process as well as the nature and the sequence of these phases.

The advantage of using an action research approach in this study is that it engages individuals besides the researcher in examining the social practices that link these individuals with other people in social interaction (Kemmis & McTaggart, 2000). Action research does not only involve various individuals, but more specifically aims to support a group of people in reducing the extent to which they experience their practices of communications or social organization as unproductive or unsatisfying. The fact that the researcher collects the data in collaboration with people who directly experience the problem that is being researched, also enhances the trustworthiness and validity of the research results. A model developed by Guba in 1985 identified the following elements as being essential in determining the trustworthiness of qualitative data (Lincoln & Guba, 1985). Firstly it is important for data to have truth value, which means that the researcher must be able to establish confidence in the truth of the research results. Furthermore it is important for data to have applicability and therefore have the potential to be applied to other contexts and research subjects. Finally data can only be described as trustworthy if it is consistent and neutral. Two types of validity are defined and described by Schiavetti, Metz and Orlikoff (2011): internal validity and external validity. Internal validity of qualitative data can only be attained when the data itself and the interpretation thereof reflect the subjective realities of all of the participants that formed part of the

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research. A research study is defined as externally valid if the results that were obtained can be transferred from the specific setting in which the research was conducted to another setting with similar characteristics (Schiavetti et al., 2011).

The trustworthiness and validity of action research studies are enhanced not only by the fact that data is collected and analysed progressively and in phases, but also by the fact that the data is presented to the research participants themselves as a way of reviewing the results and subsequent findings of the study. The fact that this study was done in cooperation with several professionals who have experience in the field of FASD should assist in translating the maternal interview questionnaire into an instrument that not only improves the health of those affected by FASD, but in the long run also leads to a decrease in the prevalence and incidence of FASD across South Africa.

This study might be criticised as not fitting the traditional framework of an action research study due to the fact that the researcher was not actively involved in all of the data collection procedures. The researcher made a deliberate decision not to be present at the maternal interviews that were conducted as part of this study, to avoid compromising the anonymity of the mothers and guardians that were included in the study and possibly influencing the progression of the FASD prevention programme in the normal course of events.

The next chapter gives an overview of the current literature on FASD in South Africa and the rest of the world. This is followed by a description of the methods and instruments that were used as part of this study in Chapter 3. The final chapters present and discuss the results that were obtained throughout the study, followed by the conclusion and recommendations for future studies.

2 LITERATURE REVIEW

According to Gerberding, Cordero and Floyd (2004) it is estimated that roughly 10% of women in the USA continue to consume alcohol during their pregnancies. Furthermore, 2% of the women who continue to consume alcohol during their pregnancy tend to engage in activities of binge drinking or frequent consumption of alcohol[3] during pregnancy. Other studies estimate that roughly 0,8 to 6 children per 1000 children in the USA were born with FASD in 2005 (Carr, Agnihotri & Keightley, 2010). In 2007 O'Connor and Whaley reported that almost one out of 100 (1%) children in the USA were believed to be born with FASD. A more recent study conducted in the USA reports even higher estimates of 2 to 4% of children believed to be born with FASD symptoms (May et al., 2009). In South Africa the occurrence of FASD has been shown to be much higher than in other parts of the world, and on the increase. Urban et al. (2008) found 12% and 7.5% of children in two Northern Cape settlements in South Africa presenting with FASD symptoms in 2004. A study by May et al. (2000) examined the prevalence of FASD among Grade 1 pupils from a small rural community in the Western Cape. A significant number of children that formed part of this study were diagnosed with full-scale FAS (46 out of 988 or 4,7% of the children). In 2005 the prevalence of severe forms of FAS in the Western Cape was reported as 4.6% by May et al.

One of the biggest challenges in FASD prevention and research remains accurately identifying children who present with signs and symptoms that place them on the FASD spectrum. According to Goodlett (2010) only a small percentage of babies whose mothers consumed vast amounts of alcohol while pregnant are born with deficits that meet the diagnostic criteria for FAS or pFAS. However, this does not imply that children who were exposed to alcohol prenatally (but who do not meet the FAS or pFAS criteria) are unaffected, since there exists a great variance in the effects that prenatal alcohol exposure can have on the development of the facial features and the brain. The degree to which individual children are influenced will vary due to personal and environmental factors including the quantity of and frequency with which alcohol was consumed during the pregnancy, as well as several genetic and maternal factors. Challenges in terms of the diagnosis of FASD can be overcome by ensuring that several diagnostic components are incorporated in the process, including a detailed interview with the mother of the child.

2.1 Consequences of prenatal alcohol consumption

According to Bailey and Sokol (2011) several studies suggest that there exists a link between alcohol consumption during pregnancy and an increased risk for pre-term delivery and Sudden Infant Death Syndrome (SIDS). Beckwith (2003) defines SIDS as the "sudden death of an infant under the age of one year, which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history". More specifically a recent study by O'Leary, Nassar, Kurinczuk, & Bower (2009) found that mothers who binge drink frequently during their pregnancy are two to three times more likely to give birth prematurely. Babies who are born prematurely are at risk for health complications such as

[3] For the purpose of this study binge drinking can also be referred to as heavy episodic drinking. According to the USA Center for Disease Control and Prevention heavy episodic drinking is defined as consuming five or more drinks per epsiode for males and four or more drinks per episode for females (with the number of episodes adding up to at least 2 episodes per month). In this context an episode refers to any event where one or more alcoholic drinks are consumed. On the other hand regular drinking would be defined as heavy if it amounted to more than one drink per day on average. FARR defines one standard drink as a 330 ml bottle of beer, a 125 ml glass of wine or a tot of spirits.

respiratory problems and developmental challenges. Children who were prenatally exposed to alcohol can also present with a range of physiological and physical deficits including prenatal and post-natal growth retardation and dysmorphic facial features. A study by Fraser, Muckle, Abdous, Jacobson & Jacobson (2012) determined that babies who were frequently exposed to vast amounts of alcohol in utero presented with a reduced birth weight and head circumference at birth. In this study the babies of mothers who drank heavily during pregnancy also had poorer visual acuity at the age of 6 months, compared to babies whose mothers did not consume alcohol during pregnancy.

A recent study by Bell et al. (2010) that investigated the association between FASD and neurological problems found a significantly high prevalence of epilepsy among individuals that have been diagnosed with FASD. According to this study 11,8% of people who have been diagnosed with FASD have also been diagnosed with epilepsy before the age of five years, and a further 5,9% of individuals with FASD are diagnosed with epilepsy later on in life. This percentage is alarmingly high as epilepsy is reported to affect only 0,6% of the general population (Bell et al., 2010). According to a study by Davies et al. (2011) there exists a definite link between FASD and developmental disorders among young children. Research has shown that having FASD not only affects a child's gross and fine motor skills but it also has a negative impact on emotional development, verbal and non-verbal intelligence as well as higher cognitive functions (including planning and reasoning) (Kodituwakku et al., 2006; Hoyme et al., 2005; Viljoen et al., 2005). More specifically children who have been prenatally exposed to alcohol can present with spatial processing problems (which may cause visual and auditory processing difficulties), difficulty with acquiring mathematical skills as well as problems with executive functioning (Coles, 2011). Deficits in terms of executive functioning generally lead to problems with attention regulation, planning, organisational thinking and problem solving.

The negative impact of prenatal alcohol exposure on a child's brain development is further known to cause significant deficits in terms of social skills and emotional development. A recent study on the relationship between emotional development and prenatal exposure to alcohol found individuals who have been diagnosed with FASD to be more sensitive to stressors in the environment which could lead to an increased risk for mood and anxiety disorders later in life (Hellemans, Verma, Yoon, Yu, Young, & Weinberg, 2010). Children who have been diagnosed with FASD can also present with a range of social skill deficits including delayed social problem-solving, inappropriate social interactions, difficulty with reading social cues and communicating appropriately within social contexts (Keil, Paley, Frankel & O'Connor, 2010). These difficulties in terms of social skill development are of great concern since it might lead to or exacerbate further emotional dysfunction and behavioural disorders.

Several studies report a link between FASD and behavioural disorders like Attention Deficit and Hyperactivity Disorder (ADHD) (Burden et al., 2010; Dalen, Bruarøy, Wentzel-Larsen & Laegreid, 2009; Burd, Klug, Martsolf & Kerbeshian, 2003). A possible explanation for why children with FASD are frequently diagnosed with ADHD is explored in a recent study by Carr, Agnihotri and Keightley (2010). According to the findings from this study children who have been prenatally exposed to alcohol also have an increased risk for sensory processing difficulties. Sensory processing difficulties in itself could lead to increased distractibility, hyperactivity to surrounding stimuli and also inattention, which are some of the core symptoms associated with ADHD. According to Coles (2011) there seems to exist some differences between the hyperactivity and inattention displayed by

children with FASD versus children who have ADHD but not FASD. For instance children who have been prenatally exposed to alcohol and who also suffer from ADHD tend to have fewer behavioural problems than those children who have only ADHD. These differences can possibly be ascribed to the unique way in which alcohol impacts negatively on the development of the sensory processing neurocognitive domain, which is in part responsible for helping a child to receive, organize and understand environmental stimuli appropriately (Carr et al., 2010). According to Davies et al. (2011) a developmental disorder primarily caused by prenatal exposure to alcohol is further negatively impacted by factors associated with alcohol consumption during pregnancy, including low socio-economic status, low levels of education and maternal depression. This is believed to be due to the observation that mothers with a low socio-economic status and lower levels of education tend to put less emphasis on interaction and bonding with their children than mothers with higher levels of income and education. In the same way it is difficult to discriminate whether the cognitive deficits that are displayed by children with FASD are due to the negative effect of prenatal alcohol exposure on the one hand, environmental under stimulation on the other or a combination of both. Children who have been exposed to alcohol prenatally, and therefore present with a high risk for FASD, are in many cases further disadvantaged by negative environmental aspects including abuse, neglect and the loss of a parent (Coles, 2011).

Not many studies have specifically investigated the speech and language skills of children with FASD. A study by Kodituwakku et al. (2006) indicates that children with FASD tend to perform worse on letter and category fluency tasks than children who have not been prenatally exposed to alcohol. In the mentioned study "letter fluency" referred to the ability to generate as many words as possible starting with the same letter within a specific time period. "Category fluency" referred to the ability to name as many words as possible within a given semantic category within a specific time period. Kodituwakku et al. (2006) further indicate that children with FASD tend to present with impaired comprehension of grammar and sentence structures. It can be assumed that deficits in terms of the comprehension of language will have a negative influence on a child with FASD's ability to communicate with others as well as his/her academic development.

A recent study by Coles, Lynch, Kable, Johnson & Goldstein (2010) found the verbal memory skills of children with FASD to be significantly delayed, even more so than their non-verbal memory skills. It was further determined that children who present with dysmorphic facial features and had been diagnosed with full-scale FAS perform worse on verbal memory tasks than children who are on the FASD spectrum but do not have FAS. From these findings it can be assumed that the nature and degree of delays in a child's verbal and non-verbal memory are dependent on how severely they were affected by the alcohol in utero. Evidence from Coles et al.'s (2010) study seem to suggest that both children with full-scale FAS and broad spectrum FASD experience problems not only with the initial learning of information but also with the retrieval of information that they have learned. These results are of importance when the development of the speech and language skills of a child with FASD is taken into account. A child with a delayed verbal memory will not only find it difficult to organise and interpret what is being said, but will also find it difficult to learn and use the vocabulary, grammatical elements and sentence structures of a language. It can therefore be expected that delays in terms of receptive as well as expressive language skills will exist in children who were prenatally exposed to alcohol and as a result present with either FASD or full-scale FAS.

According to Hoyme et al. (2005) FASD can cause children to experience problems with social interaction with others. The rules that govern the use of language in social contexts are also referred to as pragmatics in the field of SLT (Bernstein & Tiegerman-Farber, 2002). Pragmatic problems that are experienced by children with FASD include talking too much, constantly interrupting others while they are talking and being unaware of the consequences of one's behaviour. This could have a further negative impact on a child with FASD's communication skills in general. The vast amount of communication related problems that a child with FASD might experience, call attention to the relevance and importance of the current study within the field of SLT. Greater awareness and knowledge of the communication problems faced by children with FASD may motivate Speech-Language Therapists to become involved in wide-ranging prevention activities. Furthermore, if the diagnostic tools (including the maternal interview questionnaire) that are used in FASD prevention programmes and research studies can be adjusted in such a way that more children are accurately diagnosed with FASD, these children will also have the opportunity to have earlier access to SLT services which will in turn decrease the negative impact that any communication problems might have on their overall development and quality of life.

2.2 History of FASD in South Africa

Although little concrete evidence exists to link FASD with the traditional "Dop" system – the partial remuneration of vineyard labourers with free wine – or the availability of free alcohol to farm workers, these factors are believed to be some of the root causes of high levels of alcohol consumption by pregnant women in the Western Cape region of South Africa. The practice of the "Dop" system was outlawed in 1960 and the ban was further enforced in 2003 when the South African parliament passed a bill that declares the payment of an employee with liquor as illegal. It has since been discontinued by most employers and wine farm owners. Viljoen et al. (2005) discuss how the current FASD prevalence is influenced by the "Dop" system, which caused a state of affairs that is now worsening as a result of a high concentration of informal bars in both the Northern Cape and the Western Cape wine regions. Since the days of the "Dop" system, excessive alcohol usage has been part of the South African vineyard labourers' culture, with alcohol being associated with recreation and relaxation. This culture is no longer limited only to farm workers in the Western Cape, but has become synonymous with many South African rural communities struggling to overcome poverty and unemployment.

2.3 Maternal factors related to FASD

A number of studies have explored the so-called maternal factors associated with FASD (May et al., 2013; May et al., 2005; Viljoen et al., 2005; May et al., 2004). The effect of prenatal alcohol exposure is different for every child and it is therefore important to have sufficient knowledge of all of the characteristics and behaviours that could determine the degree to which the child is affected (May & Gossage, 2011). By examining and understanding each of the maternal factors that might influence the effect alcohol has on an unborn child, pregnant women who are at risk of having a child with FASD can be better identified and as a result more prevention efforts can be focused on this group of women. May and Gossage (2011) suggest that maternal risk factors can be divided into three topical categories, namely the host (which refers to the pregnant woman), the agent (which refers to alcohol) and the environment (which refers to the social and natural setting of the pregnant woman's life).

The primary cause of FASD in children is the consumption of excessive amounts of alcohol by their mothers during pregnancy. Several studies have determined that it is specifically those maternal populations who have a tendency to binge drink frequently that have a higher prevalence of babies who are born with FASD (Urban et al., 2008; Viljoen et al., 2005; May et al., 2000). In communities where alcohol is excessively consumed, where the negative impact of alcohol exposure is more severe, there is a higher number of reported cases of full scale FAS. A recent study by Fraser et al. (2012) looked specifically at the negative effect of binge drinking on a fetus in a community where binge drinking among pregnant women is common but the overall alcohol consumption is low. The results from this study indicate that the babies of mothers who drank less than one standard drink per day, but who participated in binge drinking at least once during their pregnancy had a higher risk of giving birth to babies who were underweight and had a small head circumference. Not only the amount of alcohol that is consumed during pregnancy, but also the timing of the maternal drinking can determine the nature and severity of the outcome for the child. Different anatomical structures will be affected depending on the period of gestation in which alcohol was consumed, for instance the development of the facial features of the child could be affected if the mother consumed large amounts of alcohol between the 6th to 9th week of gestation (May & Gossage, 2011). In the same way cognitive or neurologically based behavioural deficits could occur if the fetus is exposed to alcohol during critical phases of brain development.

Maternal risk factors that fall under the category of “host” can be divided into three main groups namely physiological, psychological and social factors. Physiological factors that determine the degree to which the fetus is affected by alcohol, include the mother’s age and nutrition. The unborn children of women who are older, with a smaller build and a history of poor nutrition are believed to be more susceptible to the negative effects that alcohol might have on a fetus (May & Gossage, 2011; Viljoen et al., 2005). A study by May et al. (2005) found the head circumference of mothers who have children with FASD to be significantly smaller than those of mothers whose children did not have FASD. This could be an indication that some women who have children with FASD might be suffering from FAS or FASD themselves (May & Gossage, 2011; Viljoen et al., 2005). The degree to which a child is affected by prenatal alcohol exposure will also depend on the number of times that the child’s mother has been pregnant and has given birth in the past. According to May and Gossage (2011) a woman who drinks while pregnant and who has had a high number of previous pregnancies and births will have a higher risk of having a more severely affected child than a woman who is consuming the same amount of alcohol under the same circumstances but who has had fewer previous pregnancies and births. A number of studies suggest that some women might be genetically more susceptible to alcohol misuse or alcoholism and that these women are therefore at a risk of consuming alcohol during their pregnancies (Pautassi, Camarini, Quadros, Miczek & Israel, 2010; McCaul, Turkkan, Svikis & Bigelow, 1991; Wilsnack, Klassen, Schur & Wilsnack, 1991). For instance women who have close relatives who abuse alcohol are at a significantly higher risk of becoming regular binge drinkers themselves. It has also been found that children who have been prenatally exposed to alcohol are at a much higher risk of abusing alcohol later on in their own lives.

Psychological factors that might play a role in alcohol consumption during pregnancy include depression and anxiety. It is believed that women who are depressed or have a low self-esteem tend to be at a higher risk for alcohol consumption during pregnancy. According to Flynn and Chermack (2008) depression has been found to be common among mothers of children with FASD. A study by Viljoen et al. (2005) found a significant number of women who consumed alcohol excessively during

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their pregnancy to be socially isolated since they did not report having a close friend. These women stated that they were surrounded by friends and family members who also drank excessively, which could possibly intensify their feelings of social isolation. Women in this study also reported feeling extremely stressed during their pregnancies, which they reported as the main cause for consuming a large amount of alcohol during the pregnancy.

Some of the major social factors associated with excessive alcohol consumption during pregnancy include poverty, lower levels of education, having family members and/or a partner who drink heavily, as well as lower levels of religiosity (May et al., 2004). A number of research studies have indicated that disadvantaged communities that are also characterised as having the poorest living conditions tend to have a much higher prevalence of FASD. Not only do women who come from a lower socio-economic background generally have lower levels of education, but they are also more likely to be undernourished and inclined to excessive alcohol consumption, all of which are potential risk factors for having a child with FASD. A study by Mulia and Zemore (2012) investigated the relationship between socio-economic status and the rate of alcohol abuse in the USA. Results indicated that men from a lower socio-economic background have higher rates of excessive alcohol consumption and specifically binge drinking, compared to men with a higher socio-economic status. It was found that these differences in drinking patterns were mostly culturally driven and in many cases caused by higher levels of psychological distress that were experienced by the men who lived in the disadvantaged and poor neighbourhoods.

In contrast to maternal risk factors there also seems to exist key protective factors against FASD (May et al., 2005). These protective factors include adequate nutrition, a larger body size, cohabitating with a nondrinking male partner and higher levels of education and religiosity. Maternal interviewing remains one of the most reliable tools in gathering knowledge on the degree to which different maternal risk- and protective factors determine a woman's risk of having a child with FASD. It is therefore an integral part of the diagnostic process and also in the continuation of research on FASD.

2.4 Prevention of FASD/FAS

Several strategies that target different population subgroups have been developed in an effort to prevent FASD in children. According to Stratton et al. (1996) these include universal, selected and targeted strategies. Universal strategies, which are designed to include all members of a given population, have not been shown to be effective in addressing excessive alcohol consumption amongst pregnant women (Warren, Hewitt and Thomas, 2011). In contrast to this, selective prevention strategies (which are designed to target groups of women who are at a high risk for drinking during pregnancy) and targeted prevention strategies (which are even more specifically directed towards women who have been identified as drinking heavily during their pregnancies) have been shown to be more successful in decreasing the rate of alcohol abuse during pregnancy.

During the last decade a number of prevention programmes have been developed and executed in the so-called high-risk regions of South Africa such as the Northern Cape and the Western Cape, in an effort to address the high prevalence of FASD in these areas. As indicated by a recent study in the Northern Cape region of South Africa, these prevention programmes have the potential to successfully reduce the incidence of FASD. Chersich et al. (2012) found a decline in the number of children born with FASD as a result of prevention programmes in the Northern Cape towns of De Aar

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and Upington. According to Davies et al. (2011) FASD prevention programmes should promote early identification and provide counselling and additional support for pregnant women who are regularly consuming large amounts of alcohol, as this might prevent the baby from being born with FASD. This will also ensure that the mother has access to rehabilitation services and support in order to prevent alcohol consumption during future pregnancies. It is of great importance that children with FASD are identified, diagnosed and receive intervention as early as possible as this might help to lessen the secondary disabilities that these children are usually faced with (Davies et al., 2011).

2.5 The role of the maternal interview in prevention programmes

Many studies describe and report the benefits of conducting a maternal interview for the purpose of either identifying pregnant women who are consuming dangerous amounts of alcohol and are therefore at risk of having a baby with FASD, or for making a final diagnosis of FASD in children. Not only will an interview with the mother help to establish specific risk factors associated with each individual case but it will also help to make an accurate diagnosis in children who present with less severe deficits related to prenatal alcohol exposure, including pFAS.

Due to the fact that children with broad spectrum FASD or pFAS rarely present with the specific physical characteristics that are portrayed by children with full-scale FAS, a physical examination alone might not be sufficient in detecting those children that have been exposed to alcohol in utero. Even though a child might not present with any physical deficits related to FAS, early identification of children with FASD or pFAS is imperative since their cognitive development (including language) might still have been affected by their prenatal exposure to alcohol. It is only once the children who present with FASD symptoms are identified and diagnosed that they can receive the necessary therapeutic support, including Speech-Language Therapy. Early identification and diagnosis of children with FASD can also ensure that the mothers of these children receive the necessary information and support to prevent them from consuming alcohol during future pregnancies.

According to Bakhireva and Savage (2011) maternal self-report can be viewed as the most accurate way of identifying those women who present with hazardous drinking habits. Two types of maternal interviews form part of FASD prevention programmes: interviews that take place while the woman is still pregnant and interviews that are done in a retrospective manner, in other words a few years after the child in question had been born. The purpose of an antenatal interview (an interview that is conducted while the woman is pregnant) is to assess the mother’s risk of having a child with FASD and to provide the necessary intervention and support if the mother is found to be at a high risk of having a child with FASD. Retrospective interviews are used to identify those women who consumed alcohol during their past pregnancies and whose children are therefore at a high risk of having FASD. According to Hoyme et al. (2005) the use of a dysmorphological and a developmental assessment together with an interview with the mother ensures a more reliable diagnosis since a team of professionals including physicians, educational psychologists and interviewers who are specifically skilled in interviewing pregnant women regarding their past and present drinking habits are involved. The inclusion of the maternal interview as part of the diagnostic process for children with possible FASD also ensures that a differential diagnosis between FASD and other genetic disorders can be made (Hoyme et al., 2005; May et al., 2004).

Chersich et al. (2012) recently proposed that the maternal interview should form an integral part of the diagnostic process for children who possibly have FASD. In the study by Chersich et al. (2012)

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Grade 1 children were diagnosed with FASD through the use of a three part diagnostic process, including a maternal interview, a dysmorphological and neurological examination as well as a developmental assessment. During the maternal interview mothers were asked specific questions to determine the degree to which alcohol was consumed during their pregnancy and to test their knowledge regarding the dangers of alcohol consumption during pregnancy. The mothers' alcohol use during the time of the interview and also during their pregnancy with the child with possible FASD was assessed using a timeline follow-back method.

The timeline follow-back method can be briefly defined as a semi-structured interviewing technique that aids accurate self-reporting on alcohol or drug use over the previous 12 months or even prior to that (Sobell & Sobell, 2011). This method was originally developed during the 1970's and used as a self-report measure to retrospectively assess an individual's past and present drinking habits, using a calendar-based format (Robinson, Sobell, Sobell & Leo, 2012). It has been shown to be particularly useful in determining an individual's daily alcohol intake while simultaneously providing a detailed description of the individual's drinking habits, including the average number of drinks that is consumed per day and the average number of days of so-called low-risk and high-risk drinking. The fact that a timeline follow-back interview consists of questions within a timeframe of one to twelve months prior to the interview makes it a suitable tool to conduct a retrospective maternal interview as part of an FASD prevention programme. According to May et al. (2005) the sequence of questions and the interview style that is used as part of a timeline follow-back method tend to produce more accurate data than is the case with other tools that screen for alcohol use.

FARR's primary objective is to develop and maintain FASD prevention programmes across South Africa by providing clinical diagnostic services and conducting epidemiological research. They have achieved great success with their programmes designed specifically to educate mothers on the risks related to alcohol use during pregnancy. Over the last decade FARR has made use of a standardized interview questionnaire that was designed by the Institute of Alcohol Abuse and Alcoholism (IAAA) to conduct maternal interviews as part of FASD prevention programmes in the United States of America. FARR has never adjusted this questionnaire in any way, apart from translating the questionnaire into Afrikaans. The American maternal interview questionnaire that FARR's questionnaire was derived from is described by Lewis, Shipman and May (2011)[4] as a 230-item maternal questionnaire that covers basic demographic information including the general health and medical history of the mother, the amount and frequency of alcohol consumption at different times in the mother's life as well as family and close friends' drinking history. Demographic measures, such as the mother's age, education, occupation, and marital status are also included in this same questionnaire. FARR's questionnaire makes use of the timeline follow-back method and it plays an important role in identifying and diagnosing children who suffer from FASD as part of FASD prevention programmes in South Africa.

A recent study by Hannigan et al. (2010) looked at the difference between antenatal reporting of alcohol consumption on the one hand and retrospective reporting of alcohol consumption on the other. For the purpose of this study antenatal reporting was defined as a mother's recall of alcohol use while she was still pregnant, whereas retrospective reporting referred to the same mother's

[4] In the article by Lewis, Shipman and May (2011) the questionnaire that was originally designed by the IAAA is described in more detail.

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recall of alcohol use 14 years after the afore mentioned pregnancy ended. As part of this study physical and neurodevelopmental examinations were carried out on the children of the mothers who were included in the study. Hannigan et al.'s (2010) results indicated retrospective reporting to be significantly more accurate than antenatal reporting. In this study 7,2% of the women who had admitted to only light drinking during the antenatal interview, reported to have actually been drinking heavily during their pregnancy when they were interviewed again 14 years later. During the physical and neurodevelopmental assessments the children of the mothers who claimed to drink only lightly during the antenatal interview but admitted to drinking heavily during the retrospective interview, presented with several deficits related to FASD. This finding supports the argument that women might be more truthful during a retrospective interview than is the case with an antenatal interview. One of the possible explanations for retrospective reporting being more accurate could be the fact that a mother's responses might be distorted by guilt or fear of being discovered when she is asked about her drinking habits during her pregnancy. The mother might also have a fear of being judged or stigmatised by the interviewer if she admits to drinking heavily while she is pregnant (May & Gossage, 2011; Viljoen, Croxford, Gossage, Kodituwakku & May, 2002).

The current chapter explored the factors related to FASD internationally and more specifically in South Africa. Firstly the various consequences related to prenatal alcohol exposure was discussed after which a brief overview of the history of FASD in South Africa was provided. The current chapter also looked at maternal factors that not only influence a woman's decision to continue consuming alcohol during her pregnancy but also determines the degree to which the unborn child is affected by the alcohol. Finally the prevention of FASD, and more specifically the role of the maternal interview as part of FASD prevention programmes, was discussed. The following chapter provides an overview of the methods and materials that guided the procedures for data collection and data analysis for the current study. The chapter concludes with an overview of the ethical issues that were considered throughout the course of the study.

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3 METHODOLOGY

The study was done in collaboration with the non-governmental organization called the Foundation of Alcohol Related Research (FARR). Most of the people who work for FARR are paid employees of the organization. Several representatives of different professions are also employed by FARR on an ad hoc contract basis, including psychologists, medical doctors with experience in identifying and diagnosing children with FASD and also epidemiologists who are responsible for capturing data derived from FASD prevention studies. Furthermore there are a number of post-graduate students participating in projects managed by FARR as part of their research, of which the current study is an example.

The current study followed a qualitative methodological approach. The research process consisted of four consecutive phases which each made use of specific qualitative methods in order to satisfy the objectives of this study. The research procedures that formed part of each of the four phases are graphically presented in Diagram 2.1 below.

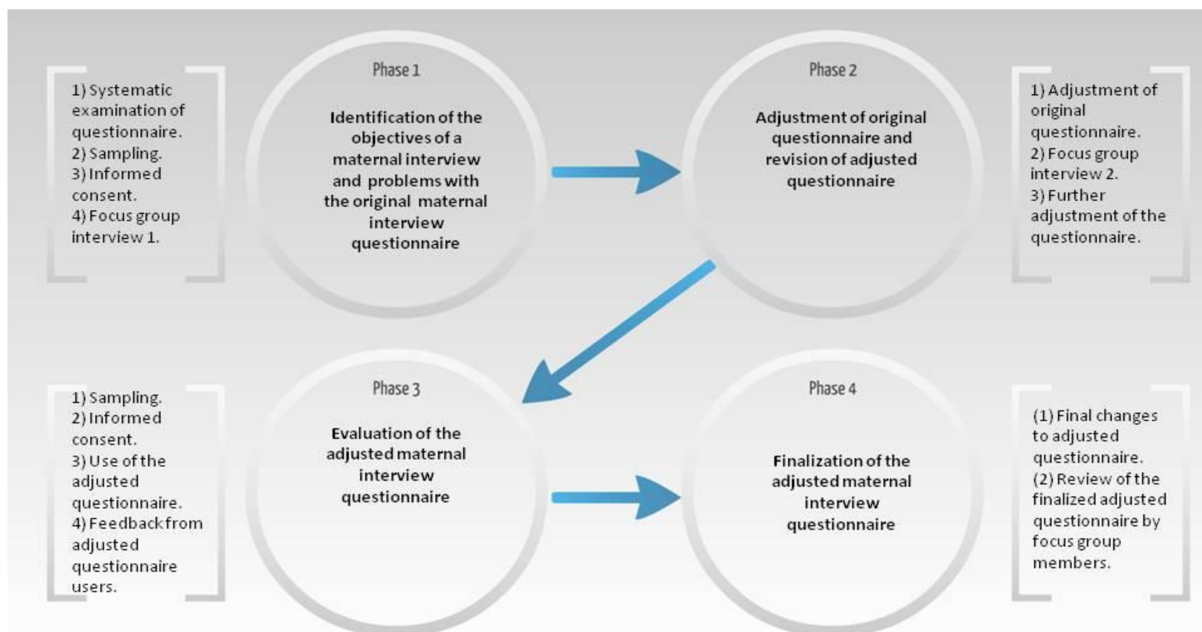

Diagram 2.1: The four phases of the research study

This chapter provides an overview of the methodology that was used to guide the processes of data collection and data analysis. Due to the fact that this study consisted of four different phases and in an effort to orientate the reader, the data collection procedures that were utilized during each of the phases are described first. This is followed by a description of the participants who took part in the study and the sampling methods that were used, as well as the materials and instruments that were used during data collection. The chapter ends off with a description of the methods that were used for data analysis as well as a brief discussion of the ethical aspects that were considered throughout the course of the study.

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3.1 Data collection procedures

Phase one

The first phase of this study commenced with a systematic examination by the researcher of the questions in the Afrikaans and English versions of the maternal interview questionnaire[5] that form part of current FASD prevention programmes driven by FARR in South Africa (for the Afrikaans and English questionnaires that were originally used by FARR, see **Appendix A**). This questionnaire currently forms an integral part of the FASD prevention programmes that are administered by FARR in South Africa, as it is used to interview mothers of school-aged children who come from so-called high-risk areas for FASD and who therefore might have been exposed to alcohol prenatally. It is designed to gather specific information regarding the mother's health as well as her eating- and drinking habits during her pregnancy with the child under investigation. The researcher grouped all the questions in the maternal interview questionnaire into categories according to their purpose. A complete list of these categories is presented in Table 1 below.

Table 1: List of catergories into which questions were grouped based on the purpose of the questions

Questions with the purpose of obtaining the mother's biographical information
Questions with the purpose of acquiring information on the mother's background history
Questions with the purpose of acquiring information on the mother's history of pregnancies and births
Questions with the purpose of acquiring information on the drinking habits of individuals that form part of the mother's social network
Questions with the purpose of acquiring information on the drinking habits of the mother
Questions with the purpose of acquiring information on the history of care of the mother's children
Questions with the purpose of acquiring information on the nutritional status of the mother
Questions with the purpose of acquiring information on the smoking habits and other drug use by the mother
Questions with the purpose of assessing the validity and trustworthiness of the data that was acquired during the interview

After the questions were grouped into categories, a focus group interview was held with a group of individuals associated with FARR that use the maternal interview questionnaire on a regular basis.

[5] The maternal interview questionnaire that was originally developed by FARR was in English. They have since translated this questionnaire to Afrikaans due to the fact that a majority of the mothers and other caregivers that have been interviewed as part of FARR's FASD prevention programmes are Afrikaans speaking. The content and structure of these two questionnaires are exactly the same and they do not differ in any way besides the language of the questionnaire. Both the English and Afrikaans versions of FARR's maternal interview questionnaire were adjusted for the purpose of this study. Any reference to the original- or adjusted maternal interview questionnaire therefore includes both the English and the Afrikaans versions of the questionnaire.

According to Madriz (2002) focus group interviews can be defined as the systematic interviewing of a group of two or more people. Generally it involves five or more people that are brought together in a confidential setting in order to discuss a particular topic. Focus group interviews can either be structured, semi-structured or unstructured, depending on the nature of the study (Babbie, 2010). The focus group interview that formed part of the first phase of this study was semi-structured in nature (see **Appendix B** for the interview guide that was used for the purpose of the first focus group interview). Schwandt (2007) describes the purpose of an in-depth, semi-structured interview as forming a clear picture of the experiences of the individuals that are interviewed. This type of interview was deemed suitable for the first phase of the study since the main aim of this focus group interview was to identify the problems that clinicians and other users of the maternal interview questionnaire experience with questions in each of the aforementioned identified categories. Through focus group interaction the researcher and participants get to share information and opinions amongst each other and as a result everyone involved with the research gets to form a clearer perspective on the goal and focus of the study and its problem domain (Denzin & Lincoln, 2002). The techniques used during focus group interviews were appropriate for this study since the main aim was to improve an instrument (the maternal interview questionnaire) used by the people represented in the focus group.

To obtain the informed consent for participation in the study from the potential participants who were selected to form part of the focus group interview, the researcher first presented them with an information leaflet on the nature and purpose of the study. The information leaflet was sent to each potential participant one week before the focus group interview was scheduled to take place. After they had read through the leaflet and after they had been assured by the researcher that their identities would be treated confidentially throughout the course of the study, they were asked to provide informed consent (or refuse participation) by signing the informed consent form (see **Appendix C** for the information leaflet and informed consent form that was handed out to the potential focus group members).

The first focus group interview was conducted by the researcher at the offices of FARR in Rondebosch, Cape Town. During this focus group interview, the participants were asked to describe what they viewed as the objectives of a maternal interview within the process of diagnosing FASD. They were also asked by the researcher to identify and describe what they perceived to be problematic questions/areas in each of the categories of questions from the maternal interview questionnaire that were identified by the researcher (as described above). The interview guide for this interview as well as a copy of the original Afrikaans and English maternal interview questionnaires were sent to each focus group participant a week before the interview, so that they could start reflecting on the questions prior to the interview. During the focus group interview each of the participants were also asked to give a brief description of what their needs as particular professionals involved in the assessment of children with possible FASD were in terms of a maternal interview questionnaire.

Phase two

The second phase of the study included three procedures: (i) to adjust the original maternal interview questionnaire, based on the problems that were identified and the needs that were expressed by the focus group members during the first focus group interview, (ii) to review the adjusted maternal interview questionnaire during a second focus group interview, and (iii) to further

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adjust the maternal interview questionnaire based on the suggestions that were made by participants during the second focus group interview.

After the transcript from the first focus group interview was analysed, the original maternal interview questionnaire was firstly adjusted by changing or eliminating the problematic questions that were identified by the focus group members. More specifically questions that were viewed as redundant due to the fact that it did not satisfy any of the maternal interview objectives were eliminated, while questions that were identified as vague or unclear but still relevant in terms of meeting the objectives, were changed by simplification and/or clarification of the phrasing of the questions. During the initial focus group interview the main problem with the original maternal interview questionnaire was identified as the excessive amount of time it takes to interview one person. The adjusted questionnaire was therefore also revised by reducing the amount of open ended questions, and where possible replacing it with close-ended questions. Questions that were identified as being duplications of another question were also removed from the questionnaire. The overall structure of the questionnaire was adjusted so that questions were grouped into clearly marked sections. This was achieved by placing all questions in specific sections according to the content and the maternal interview objective that was being addressed by the question (for a list of the section headings in the adjusted maternal interview questionnaire, see Table 15 in Chapter 4 under heading 4.2.2). The names that were given to each section were derived from the section headings from the original maternal interview questionnaire. The timeline follow-back procedure was also considered during the adjustment of the questionnaire to ensure that the adjusted questionnaire could be used retrospectively.

After the questionnaire had been adjusted, a second focus group interview was held with the same participants that were selected and included in the first focus group interview in the first phase of the study. This focus group interview was again conducted at FARR's offices in Rondebosch, Cape Town. The purpose of this second focus group interview was to gain the participants' perspective on the first draft of the adjusted questionnaire as well as their recommendations regarding any additional changes to the adjusted questionnaire. The fact that the research participants were asked to review the first version of the adjusted questionnaire is an important form of data triangulation which helps to increase the trustworthiness and validity of the data (Patton, 2002). According to Janesick (2000) data triangulation can be defined as the use of multiple data sources to study a single problem. Triangulation increases the variety of the data that is collected and in turn also enhances the reliability of the conclusions that are drawn from the data.

The guide for the second focus group interview as well as a copy of the adjusted maternal interview questionnaire were sent to each participant a week before the interview (see **Appendix D** for the interview guide that was used for the purpose of the second focus group interview). The fact that the first draft of the adjusted questionnaire was sent to the focus group participants one week in advance ensured that they had enough time to reflect on the adjusted questionnaire as a whole and identify questions that they perceived to be problematic. After the second focus group interview had taken place, further changes to the adjusted maternal questionnaire were made based on the recommendations that were voiced during this interview. The second draft of the questionnaire was then sent electronically to all five focus group participants for final revision. They were asked to read through both the Afrikaans and English versions of the adjusted questionnaire and inform the researcher of any further changes they deemed necessary. Two of the participants responded with

suggestions on how a total of five questions could be changed. These changes were made and the questionnaire was again sent to all five focus group participants for review. Only after each of the participants had approved the final adjustments, the questionnaire was deemed ready for the third phase of the study.

Phase three

The purpose of the third phase of the study was to evaluate the adjusted maternal interview questionnaire's ability to overcome the problems that were identified during the first two focus group interviews, whilst achieving the objectives of a maternal interview as identified and described by the focus group members during the first focus group interview. To see the version of the adjusted questionnaire that was used to conduct maternal interviews during the third phase of the study, refer to **Appendix E**.

The adjusted maternal interview questionnaire was evaluated using real life interviews as part of a larger FASD prevention programme by FARR in the town of Kimberley in the Northern Cape province of South Africa. Two aspects influenced the researcher's decision to evaluate the adjusted questionnaire as part of this particular prevention programme. Firstly, the majority of the interviewers who conducted the maternal interviews for the purpose of the said prevention programme were experienced in using the original maternal interview questionnaire to conduct interviews. The interviewers' level of experience formed an important part of the selection criteria for the purpose of this study. Secondly, this was the first FASD prevention programme that was administered by FARR in the town of Kimberley. The researcher felt that, due to the fact that the adjusted questionnaire was the only questionnaire that was used to conduct maternal interviews as part of this newly established prevention programme, this would allow the users of the questionnaire to provide a better informed opinion on the impact that the adjusted questionnaire had on the maternal interviewing process in general.

The third phase of the study included two procedures: (i) the use of the adjusted maternal interview questionnaire (by a group of regular interviewers, a data capturer and a data analyst working for FARR). They used the adjusted questionnaire to collect, capture and analyse maternal interview data derived from interviews with a group of mothers and caregivers and (ii) to ask specific questions to the abovementioned interviewers, data capturer and data analyst in order to obtain information regarding their experience with using the adjusted maternal interview questionnaire. The mothers who formed part of this phase of the study were not merely interviewed in order to evaluate the adjusted interview questionnaire. They formed part of a larger population of mothers who were selected by FARR to take part in one of its existing FASD prevention programmes. In the same way the interviewers, data capturer and data analyst who took part in this phase of the current study were not only required to do so for the purpose of this study, but also as part of their regular FASD prevention work.

To gain the informed consent from the two interviewers for participation in phase two of the study, an information leaflet on the nature and purpose of the study was electronically sent to them one week prior to the maternal interviews were scheduled to take place. The data capturer and data analyst that formed part of this phase of the study also formed part of the focus group that was interviewed during phase one and phase two of the study and had therefore already given their informed consent for participation in the study. The two potential interviewers were assured of the

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fact that their identities would not be revealed throughout the course of the study or thereafter, for instance in potential journal articles or oral presentations. After they had read through the information leaflet and after they had telephonically indicated to the researcher that they had understood what their participation would entail, these potential participants were asked to provide (or refuse) consent for participation in the study by signing the informed consent form (see **Appendix F** for the information leaflet and informed consent form for the two interviewers).

The researcher was not present at the site where the maternal interviews were conducted, so that the interviewing process could progress in the same way as usual. This was also done as a way of ensuring the anonymity of the participants who were interviewed with the use of the adjusted questionnaire. All the maternal interviews were conducted at a primary health care facility (clinic) based in Kimberley in the Northern Cape. The maternal interviews were conducted privately and in a separate room where only the interviewer and the interviewee were present. This ensured the confidentiality of information shared during the interview. In those cases where the mother of the child of interest could not be interviewed and grandparents, fathers or other relatives of the child had to be interviewed instead (as per FARR's standard operating procedures), these caregivers were also included in the current study.

After a group of mothers and other caregivers of the child of interest had been selected[6] to take part in the larger FASD prevention programme and also the current research study, the purpose and nature of both these were verbally explained to them by the interviewers who were to conduct the maternal interviews. The potential interviewees were assured that their participation in the study was voluntary and that neither themselves, nor their children would in any way be disadvantaged if they decided to not take part in the study. The adjusted maternal interview questionnaire was the only questionnaire that was used to conduct maternal interviews as part of this particular FASD prevention programme. The mothers and other caregivers that were interviewed were therefore required to simultaneously provide or refuse consent for both the interview conducted by FARR in general as well as participation in this study. Since the maternal interviews were not audio or video recorded and the mothers were only required to provide their initials (no surname) to the interviewers, their anonymity throughout the course of the study was also guaranteed. After the potential interviewees indicated to the interviewers that they understood what participation in the study would entail, they were asked to give their informed consent (or refusal) for participation in the study by signing the informed consent form. FARR obtains informed consent from all potential interviewees who take part in their FASD prevention programmes . The standard consent form used for this purpose was therefore only slightly adjusted in order to include a request for the mother's, or any other caregiver of the child of interest who were to be interviewed, informed consent for participation in the current study (see **Appendix G** for a copy of the informed consent form for interviewees). A mother or any other caregiver of the child of interest was only included in the study once (s)he had given their informed consent to participate in the current research study.

One of the interviewers that participated in the study completed a total of 24 interviews with the adjusted questionnaire while the other interviewer-participant performed 12 interviews with the adjusted questionnaire. The maternal interviews were scheduled in advance and the number of

[6] The sampling methods that were used to select the potential participants for this study are described in detail in section 1.3 titled: "Sampling".

interviews that would be conducted by each of the interviewers was therefore pre-determined. The fact that both interviewers had the opportunity to use the adjusted maternal interview questionnaire for several interviews ensured that they would be able to make a valid comparison between the two questionnaires and provide valid comments regarding their perception of the adjusted questionnaire during their interviews with the researcher. Before the interviewing process commenced, the interviewers were asked to make notes throughout the process on their experience with the adjusted maternal interview questionnaire, especially if they found some of the questions in the adjusted questionnaire to be problematic.

After the adjusted maternal interview questionnaire had been used as part of this particular FASD prevention programme, individual semi-structured interviews were held with both of the interviewers that were included in this study. During the interviews the interviewers were asked specific questions related to the themes that were identified after the transcript from the first focus group interview had been analysed. They were also asked to make a general comparison between their experiences with using the original questionnaire versus their experiences with using the adjusted questionnaire. Finally they were asked to voice their opinion on whether they felt that the needs and the objectives of the maternal interview (as these were identified during the first focus group interview) were met by the adjusted maternal interview questionnaire. These interviews were performed telephonically due to the fact that physical distance between the interviewers and the researcher prevented the interviews from being completed in person. The telephonic interviews were scheduled a week after the last interviews with the mothers had taken place so that the interviewers had enough time to reflect upon their experiences with using the adjusted questionnaire. A copy of the interview guide was sent electronically to both interviewers one week prior to the day that the telephonic interviews were scheduled to take place in order to give them sufficient time to reflect on their experiences prior to the telephonic interviews with the researcher (see **Appendix H** for a copy of the interview guide used for the telephonic interviews with the interviewers).

As soon as the interviewing phase of the particular FASD prevention programme had finished, the adjusted interview questionnaires that were completed by the interviewer-participants during the 36 interviews with the mothers and other relatives of the child, were sent to the data capturer who is responsible for capturing all data derived from the maternal interviews conducted by FARR's interviewers. After all the data from the 36 adjusted maternal interview questionnaires had been captured, it was sent to the data analyst who had been included in the study.

The researcher wanted an opportunity to collect information about the data capturer and data analyst's perceptions of working with information collected through the adjusted questionnaire. This particular data capturer and data analyst also formed part of the focus group that was interviewed during phase one and phase two of the study. Due to the complex nature of the questions that the researcher wanted to ask these participants, a decision was made to use a questionnaire instead of an interview as a form of feedback. Babbie (2010) defines a qualitative interview as a discussion based on a set of topics to be discussed in depth rather than based on the use of standardised questions. On the other hand a questionnaire can be defined as a document containing questions and other types of items designed to solicit information appropriate for analysis (Babbie, 2010). In this questionnaire the data capturer and data analyst were asked specific questions regarding the structure and content of the adjusted questionnaire. They were also asked to reflect upon their

experience with using the original questionnaire to capture and analyse data versus their experience with using the adjusted questionnaire to capture and analyse data. The questionnaire was only sent to them after the data from all 36 interviews had been captured and after approximately 25% of the data from these interviews had been analysed (see **Appendix I** for a copy of the questionnaire that was sent to the data capturer and the data analyst). Both the data capturer and the data analyst were given a week to complete the questionnaire in writing and return it to the researcher. Following the analysis of the completed questionnaires, the researcher had individual telephonic conversations with both the data capturer and the data analyst to clear up anything in their written feedback that was ambiguous or difficult for the researcher to understand. The participants were also given the opportunity to add anything to the answers they had provided in the questionnaire during the telephonic conversation with the researcher.

Phase four

The purpose of the fourth and final phase of the study was to (i) present the maternal interview data that had been collected using the adjusted maternal interview questionnaire to the remaining focus group members (excluding the data capturer and the data analyst who had been included in the third phase of the study), (ii) and to make further changes to the adjusted questionnaire based on the recommendations of the two interviewers, the data capturer, the data analyst and the remaining focus group members.

After the data that was collected with the use of the adjusted questionnaire had been captured and analysed, it was studied and discussed by the three focus group members who did not form part of the third phase of the study. The discussion was done in the form of a case discussion meeting, something which is routinely done by FARR in order to examine the data derived from the physical examinations, maternal interviews and the neurodevelopmental assessments that form part of a particular FASD prevention programme. The researcher was not present at this meeting due to the confidential nature of the data that was discussed. During the case discussion meeting the three focus group members were asked to make specific recommendations on any further changes to be made to the adjusted maternal interview questionnaire.

After the case discussion meeting had taken place, a separate meeting was held between the researcher and one of the focus group members (Focus group member B) in order to discuss the recommendations made by the group. This particular focus group member was selected based on the fact that she had been present at all the focus group interviews as well as the case discussion meeting. The fact that she serves on the board of directors of FARR also meant that she was in a position to either approve or reject any recommendations that had been made by the participants. The suggestions that had been made by the users of the adjusted questionnaire during the third phase of the study were also discussed during this meeting between the researcher and focus group member B. This discussion was not electronically recorded. Instead, the researcher made detailed notes on all of the recommended changes presented by focus group member B. The case discussion meeting between the three focus group members as well as the meeting between the researcher and focus group member B were held at the offices of FARR in Rondebosch, Cape Town. After this meeting, the recommended changes were made to the adjusted questionnaire and a copy of the questionnaire was sent electronically to all five focus group members for review. The questionnaire was only finalised after the final changes had been approved by all the focus group members. See **Appendix J** for a copy of the final draft of the adjusted maternal interview questionnaire.

3.2 Participants

All of the participants selected for the two focus group interviews that formed part of this study were in some way involved in the process of identifying and diagnosing children whose mothers consumed alcohol during their pregnancies and were therefore at a high risk of being diagnosed with FASD. The fact that people from different professions who play different roles in the diagnosis of FASD were asked to participate in the focus group interview, ensured that standards for data triangulation were met. Specific selection criteria were used in order to identify the focus group members. The following selection criteria applied:

- Participants selected to take part in the focus group interview had to be in some way associated with FARR; they had to be involved in the process of interviewing mothers as part of FASD prevention programmes, or responsible for diagnosing children with FASD or responsible for capturing and/or analysing data related to FASD prevention projects.

- A person was only included in the study if (s)he had been involved with FARR for a period of more than two years and therefore had sufficient experience in using the maternal interview questionnaire for interviewing, diagnostic- or data analysis purposes.

Five potential subjects that met the selection criteria were approached by the researcher for participation in the study, and all of them provided informed consent to participate. The focus group participants that were included in the study after providing consent included the following: two medical doctors responsible for the physical examination of children with possible FASD, a psychologist responsible for the neurological developmental assessment of children with possible FASD, a data capturer as well as a data analyst involved with FARR's FASD prevention programmes. The psychologist included in the focus group also has several years of experience in interviewing mothers as part of FASD prevention programmes. She could therefore reflect not only on her experiences as a psychologist who uses the maternal interview data to assist in making a FASD diagnosis, but also on her experiences as an interviewer during the focus group interviews. The profession of each of the focus group participants, as well as the number of years that they have been involved with FARR, are presented in Table 2 below:

Table 2: Description of the focus group participants.

Focus group member	**Profession**	**Number of years involved with FARR**
A	Genetecist	10
B	Clinical psychologist	6
C	Genetecist	16
D	Data capturer	2
E	Epidemiologist	10

Following is a short description of each of the focus group participants in terms of their work experience in the field of FASD as well as the number of years that they have been involved with FARR:

- **Focus group member A** is a geneticist and has been working as a medical examiner of children with FASD for more than a decade. He has been involved with FARR since 2002 (that is approximately ten years before data collection for this study occurred).
- **Focus group member B** is a qualified clinical psychologist who started working in the field of FASD in 1996. She has been working as an interviewer and psychologist in the field of FASD for the last 17 years and joined FARR permanently in 2006 (that is approximately six years before data collection for this study occurred).
- **Focus group member C** is a geneticist who has been involved in research and clinical work on FAS and FASD since the mid 1980's. He has been involved in a number of FARR's FASD prevention programmes since 1996 (that is approximately 16 years before data collection for this study occurred).
- **Focus group member D** has been working as a full-time data capturer for FARR since 2010 (that is approximately two years before data collection for this study occurred).
- **Focus group member E** is an epidemiologist who has been analysing data derived from prevention programmes driven by FARR since 2002 (that is approximately ten years before data collection for this study occurred).

Of the five participants listed above, only four were able to attend the first focus group interview. Focus group member E was not present at this interview due to other work related responsibilities. Focus group member C (who was present at the initial focus group interview) was unable to take part in the second focus group interview that formed part of this study due to work related responsibilities. However, focus group member E was present for the second focus group interview.

In order to evaluate the adjusted maternal interview questionnaire's ability to overcome the shortcomings that were identified in the initial focus group interview while simultaneously satisfying the objectives of a maternal interview (as identified by the participants during the focus group interviews), the interviewers and mothers or caregivers who formed part of a particular FASD prevention programme and who had given their informed consent for participation in the current research project were considered for inclusion in the study. The following selection criteria applied to this phase of the study:

- Mothers who were selected to take part in the current research study had to form part of a specific FASD prevention programme in the town of Kimberley in the Northern Cape. In those cases where the mother of the child of interest could not be interviewed, other caregivers of the child were also included in the current study. This is in line with FARR's general selection process of participants in their prevention programmes. Each of the interviewees had to give informed consent to take part in this said prevention programme before they were considered and approached for participation in this study. FARR's general informed consent form used to gain informed consent from mothers to take part in FASD prevention programmes, was adjusted to include information on this particular study and thus obtain consent for both the FASD prevention programme and this research study at the same time.

- Interviewers who were selected to take part in phase three of the study had to be employees of FARR and with at least one year's experience in interviewing mothers or pregnant women with the original maternal interview questionnaire used by FARR in FASD prevention projects. The interviewers' level of experience served as criteria for selection in order for them to be able to make an informed and valid comparison between using the standard questionnaire to interview mothers versus using the revised questionnaire to interview mothers.

- The maternal interviews that were conducted for the purpose of this study were conducted in either Afrikaans or English in line with FARR's general process for interviewing mothers or other caregivers during prevention programmes. Interviewers employed by FARR (and therefore the interviewers who were included in this study) had to be proficient in both Afrikaans and English.

Based on the above-mentioned selection procedures and selection criteria 27 mothers and nine other caregivers of the children of interest were included in the study. Of the three interviewers who interviewed mothers as part of this particular FASD prevention programme, only two were selected to participate in this research study. The third interviewer was not included due to the fact that she did not have sufficient experience in interviewing mothers as part of FARR's FASD prevention programmes and was therefore not qualified to make an informed comparison between the original and the adjusted questionnaire. Following is a short description of the two interviewers that formed part of this study, in terms of educational level and level of experience in interviewing mothers as part of FASD prevention programmes:

- **Interviewer A** is a 59-year old female. Her first language is Afrikaans. Although English is her second language, her supervisor (for the past 5 years) confirms that her proficiency in both languages is good. She obtained a Senior Certificate in 1975. She completed a three-day training course on FASD in 2002. FARR employees attend this course as part of in service training and it is presented by members of FARR who have experience in conducting maternal interviews as part of FASD prevention programmes. During this training course, interviewers receive information on FASD and are equipped with the specific knowledge and skills to create awareness about FASD in their communities. Interviewer A was appointed as a community worker for FARR in 2003 and has been interviewing mothers as part of FASD prevention programmes since her appointment (this is approximately nine years before data collection for this study occurred).

- **Interviewer B** is a 32-year old female. Her first language is Afrikaans and her second language is English. According to her supervisor (for the past 5 years) her proficiency in both languages is good. She matriculated in 1999 and also received a further qualification in computer literacy shortly thereafter. She joined FARR as a community worker after she completed a FASD training course in 2003 and has been interviewing mothers as part of FASD prevention programmes since this time (this is approximately nine years before data collection for this study occurred).

3.3 Sampling

During the first phase of the study, judgemental sampling was used to select the participants that would form part of the two focus group interviews. According to Babbie (2010) judgemental sampling can be defined as a sampling technique in which the research subjects are purposively selected on the basis of the researcher's judgement of who will be the most useful in terms of fulfilling the objectives of the study. This sampling technique is particularly appropriate when forming focus groups for research, since the participants do not have to represent any meaningful population (Denzin & Lincoln, 2000). For the purpose of this study the researcher selected one representative from each of the professions that play a role during the FASD diagnosis process and individuals who have been involved with FARR's FASD prevention programmes over the last couple of years. This refers to the doctors and psychologists that perform the physical and developmental assessments, the individual responsible for capturing the data derived from the maternal interviews as well as the epidemiologist responsible for analysing the captured data.

The two interviewers that were included in the study were selected through judgemental sampling. This ensured that interviewers with enough experience in conducting maternal interviews were selected. An additional interviewer conducted interviews using the same questionnaires as the two experienced interviewers. The additional interviewer was less experienced than the two interviewers whose questionnaires were included in this study, and her questionnaires were therefore not included in this study. The adjusted maternal interview questionnaire was the only questionnaire used to interview mothers or other caregivers during the course of this prevention programme, regardless of whether the interviewee formed part of the current study or not.

Principles of non-probability sampling and more specifically convenience sampling were used during the selection process of the mothers and other caregivers of the child of interest that formed part of the third phase of the study. Convenience sampling is defined by Babbie (2010) as a type of non-probability sampling where the researcher relies on available subjects. According to normal procedures followed by FARR, a physical examination is performed on all the children whose parents or guardians had given permission for them to be included in the prevention programme. Maternal interviews are then conducted with the mothers or caregivers of the children who presented with physical characteristics related to FASD and were therefore placed in the high-risk category. It was determined by FARR that the two experienced interviewers that were included in the study would conduct maternal interviews over a period of two weeks, while the rest of the interviews were conducted during the same two weeks by an interviewer with less experience who was not included in the study. For this reason the maternal interview data for this study was collected over this said two-week period. All the mothers and other caregivers of the child who were scheduled to be interviewed during the course of this period were approached for participation in the study. The interviewee-participants who were not interviewed during the course of this said two-week period, were also interviewed using the adjusted maternal interview questionnaire but the data from these interviews were not included in the study.

3.4 Materials and instrumentation

The two focus group interviews were recorded using a dictaphone as well as a video camera to ensure that all verbal responses by the focus group participants were accurately captured. The functionality of the recording equipment was checked before and after each interview to ensure that there were no technical problems which could have negatively impacted on the recording

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process. The researcher also made notes on the most important aspects that were raised during the interviews to ensure that these aspects of the interaction were highlighted. According to Patton (2002) note taking by the researcher enhances recordings and transcriptions from an interview, by placing emphasis on specific verbal information and non-verbal cues. Because the presence of any recording equipment could have had an effect on the mothers' responses during their interaction with the interviewers, the maternal interviews that formed part of this study were not electronically recorded. Interviewers are required to write down interviewee's responses as part of FARR's general process of interviewing during prevention programmes. These written responses were considered to serve as sufficient record of the interview for the purpose of this research study. The telephonic interviews with the interviewers who had performed the maternal interviews, were recorded using a dictaphone.

According to Babbie (2010) one of the main problems with group interviews is that it generally gives the researcher less control than would be the case with an individual interview. For this reason the two focus group interviews were standardised yet open ended in nature. This means that the exact wording and sequence of the questions that were to be asked during the focus group interviews were determined in advance (Patton, 2002). These pre-determined questions were then used to form the interview guide for each of the two focus group interviews. Patton (2002) defines an interview guide as a list of questions or issues that are to be explored during the course of a given interview.

A total of 24 questions were included in the interview guide that was used for the first focus group interview (see **Appendix B** for a copy of the interview guide for the first focus group interview). Patton (2002) identified six kinds of questions that can be asked during the course of an interview, depending on the type of information it wishes to elicit from the respondent. Predominantly three types of these questions were asked during the first focus group interview, including questions on the participants' previous experiences, questions aimed at understanding the participants' cognitive and interpretive processes as well as knowledge questions. In order to ensure greater flexibility during the first focus group interview and due to the fact that the interview was explorative in nature, the questions that formed part of this interview guide were mostly open ended in nature. Open ended questions can be defined as questions where the respondent is asked to provide his or her own answers to the interviewers questions (Babbie, 2010). The fact that the questions were open ended allowed the participants to respond more freely during the initial focus group interview. According to Neuman (2011) open ended questions that form part of interviews during the early stages of a research study are particularly valuable since it allows the participant to answer questions in detail. Through open ended questions the researcher can also get a clear picture of the participants' frame of reference, which could lead to added insight into the research problem.

A total of 35 questions were included in the interview guide that was used for the purpose of the second focus group interview (see **Appendix D** for a copy of the interview guide that was used for the second focus group interview). Due to the fact that the main purpose of the second focus group interview was to review the first set of changes that were made to the original maternal interview questionnaire, more than 50% of the questions were closed-ended in nature. Babbie (2010) defines closed-ended questions as questions in which the respondent is asked to select an answer from a list provided by the researcher. Furthermore, questions where respondents are required to respond by simply saying "yes" or "no" can also be defined as closed-ended in nature. Closed-ended questions

were deemed fitting for the second focus group interview due to the fact that it allowed the researcher to make a more direct comparison between the answers provided by each of the focus group participants. According to Neuman (2011) closed-ended questions also create less irrelevant or confused responses by respondents, which meant that the researcher was able to form an unambiguous picture of the participants' opinions regarding the adjusted questionnaire.

The purpose of the telephonic interviews with the interviewers after they had used the adjusted maternal interview questionnaire as part of a selected FASD prevention programme was to gain the interviewers' opinion on the way that the problems with the original questionnaire, as identified during the first focus group interview, were addressed in the adjusted questionnaire. The interviewers were asked questions on each of the identified problems and specifically whether they were of the opinion that the problems were addressed appropriately during the adjustment of the questionnaire. These telephonic interviews with the interviewers were semi-structured. Even though specific questions had been formulated before the interviews were conducted, the researcher was free to deviate from the interview guide in instances where more information was required from the participants or where questions had to be formulated differently in order for the respondents to understand them. The telephonic interviews consisted of 22 questions in total of which 7 questions were closed-ended in nature. The remaining 15 questions were all open ended in nature (see **Appendix H** for the interview guide that was used for the telephonic interviews with the interviewers).

During the final phase of this study a questionnaire was used to obtain written feedback from the data capturer and data analyst on their experience with using the adjusted maternal interview questionnaire for data capturing and data analysis purposes. This questionnaire consisted of 15 questions, with a majority of the questions being open ended in nature (see **Appendix I** for a copy of the questionnaire). A questionnaire is defined by De Vos (1998) as an instrument with open- and/or closed-ended questions or statements to which a respondent must react in writing. The questions that formed part of the questionnaire were mostly knowledge questions as well as questions on the participants' previous experiences with using the original maternal interview questionnaire.

3.5 Data analysis

Qualitative data analysis can be defined as a reasoning strategy that aims to transform a complex whole into its core consistencies and meaningful parts (De Vos, 1998; Patton, 2002). More specifically inductive analysis is defined by O'Reilly (2008) as an approach to data analysis where the researcher begins with as few preconceptions as possible and allows theory to emerge from the data. Before analysis of the data from the first focus group interview commenced, the audio- and video recordings of the interview were transcribed verbatim. During this transcription process the researcher did not change any of the focus group participants' responses during the interview in any way, but rather attempted to record what had been said during the interview as truthfully and as fairly as possible. The transcription was done by the researcher herself, specifically with the objective of becoming immersed in the data. The researcher also compared the audio- and video-recordings of the interview with the written notes that had been made during the interview. Additional information from the researcher's written notes about the interaction during the focus group interview were added to the transcript, especially in those instances where the sound quality of the recording had been compromised (e.g. due to excessive background noise).

During the transcription process the interviewer identified recurring themes and patterns in the data, an important first step of data analysis (Miles & Huberman, 1994). Names were given to each of these themes (such as "inconsistency between interviewers" and "interviews with someone other than the biological mother of the child").

After the focus group interview had been transcribed, the transcription was given to a second person for review, as a way of ensuring that it was accurate and complete. The person that was selected by the researcher to review the transcription was a 60-year old female with approximately 30 years of experience in transcribing verbal interactions and audiotape recordings. The reviewer's experience with regards to transcribing and also her availability at the time of data analysis were among some of the reasons why she was approached by the researcher for the purpose of reviewing the focus group interview transcription. The identities of the participants were not revealed to this reviewer, and thus remained anonymous. Any potential errors that the reviewer identified in the interview transcript were discussed with the researcher after the reviewing process had been completed. Once these errors had been corrected, the transcript was deemed ready for analysis.

Coding was used to discover emerging categories and themes in the transcript of the first focus group interview. Coding is defined by Babbie (2010) as the process through which raw data is transformed into a standardised form suitable for analysis. Miles and Huberman (1994) emphasise the importance of creating codes before the data is analysed as this provides a conceptual framework according to which data analysis can be conducted. De Vos (1998) describes three types of coding namely open coding, axial coding and selective coding.

Open coding refers to the process where themes from the data are formed and named. The process of open coding was applied by identifying paragraphs and/or phrases in the focus group interview transcript that related to a specific theme from the list of themes that were compiled during the transcribing process. Through open coding new themes were also discovered and added to the list. All of the paragraphs or phrases that related to a specific theme were highlighted with the same colour on the interview transcript (e.g. all of the phrases that related to the theme "inconsistency between interviewers" were highlighted with yellow). After the data had been organised through open coding, the researcher applied axial coding by reading through the transcription for a second time and looking for connections between the themes that had been formed through open coding. Through the process of axial coding some of the less significant themes were combined to create general themes. Finally selective coding was applied to the focus group interview transcript by identifying the core themes and systematically relating these core themes to the other themes that had been discovered. During selective coding the researcher refines each of the themes and, where applicable, creates subthemes (De Vos, 1998). Through the process of selective coding two main themes from the interview transcript were identified, namely "purpose of the questionnaire" and "problems with the questionnaire". All the other themes were classified as subthemes of either one of these two main themes. The types of coding did not take place in sequence but was rather used simultaneously to ensure that the data analysis was done thoroughly and accurately.

The purpose of the second focus group interview was to review the changes that had been made to the original maternal interview questionnaire. For this reason the audio- and video recording of this interview was not transcribed verbatim. Instead the researcher examined and informally analysed the audio recording and written notes that were made during the interview. Although no formal

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method of analysis was used, the researcher thoroughly analysed the data by identifying, summarizing and organising the opinions and suggested changes presented by each focus group participant.

The audio recordings from the telephonic interviews with the two interviewers were transcribed verbatim. Their responses during the interviews were therefore in no way grammatically or semantically changed in the transcript. The interviews were transcribed by the researcher herself after which it was reviewed by the same person who had reviewed the transcript from the first focus group interview. The identities of the participants were again not revealed to the person who reviewed the transcripts and were thus treated confidentially. The errors in the interview transcript that were identified by the reviewer were discussed with the researcher after the reviewing process had been completed. The transcript was only analysed after the identified errors with the transcript were corrected. Once again the researcher used the written notes that were made during the interviews to supplement the transcripts and ensure data triangulation. The research questionnaires that had been completed by the data capturer and the data analyst were supplemented by any additional recommendations that were made by these two participants during the follow-up telephone conversations between them and the researcher.

Both the transcripts from the interviews with the two interviewers as well as the research questionnaires that had been completed by the data capturer and the data analyst, were coded according to the list of themes that were identified after the transcript from the first focus group interview had been analysed. Once again axial coding and selective coding was applied to formulate the three main themes of the analysis, namely (i) whether the adjusted questionnaire had the potential to overcome the identified problems with the original maternal interview questionnaire, (ii) whether the adjusted questionnaire had the ability to satisfy the objectives of a maternal interview and (iii) whether the adjusted questionnaire could replace the original version of the maternal interview questionnaire.

The discussion between the researcher and focus group member B during the fourth and final phase of the study was not recorded and therefore not transcribed and formally analysed. The researcher informally analysed the notes that she made during this meeting by identifying and summarising all the recommended changes that had been made during the case group discussion meeting as these were verbally shared with her by focus group member B. This summary of recommended changes was supplemented by the suggestions that were made by the questionnaire users during the third phase of the study. The approved changes were made to the adjusted questionnaire, after which it was electronically sent to all of the focus group participants. The final draft of the adjusted questionnaire was finalised after all of the focus group participants had approved the changes.

3.6 Ethical considerations

This study was submitted to and approved by the Health Research Ethics Committee of the Faculty of Medicine and Health Sciences of the University of Stellenbosch (reference number: **S12/06/159**. For a letter of approval from the Ethics Committee see **Appendix O**). Several ethical issues were taken into consideration during the collection and analysis of the data. Firstly, participation in the study was voluntary. When the potential research participants were given information on the study itself, they were reassured that they were under no obligation to participate in the study and that they would in no way be disadvantaged if they decided not to take part in the study. Only after the

potential participants had been given information on the purpose and nature of the study and after they had indicated that they understood what participation in the study would entail, they were asked to give their informed consent as a sign of their voluntary participation.

A second ethical aspect that was considered throughout the study was the confidentiality of the participants and the data. According to Babbie (2010) confidentiality in a research study is achieved when a researcher can identify a given participant's responses but refrains from doing so publicly. Due to the nature of this study the researcher needed to personally engage with the interviewers and focus group members that formed part of this study. Anonymity of the participants could therefore not be attained. Anonymity is only achieved in those instances where no one (including the researcher) is able to identify any of the research participants after the data had been collected (Babbie, 2010). This non-anonymity did not compromise the ethicality of the study, due to the fact that the identities of the participants were kept confidential at all times. Even though the focus group members and interviewers could not stay anonymous, the mothers and other relatives of the child who were interviewed as part of this study remained anonymous to the researcher. During the maternal interviews the interviewees were only required to give their initials (without any surname) to the interviewer, so that there would be no way of identifying them after the interview had been conducted.

Finally ethical aspects were also taken into consideration during the analysis and discussion of the research data. The researcher made a conscious effort to analyse and discuss the research results in an ethical manner. This implies that the results were, for the most part, presented in a straight-forward and honest manner with specific reference to the limitations and shortcomings that could have had a negative impact on the data that was obtained (Denzin & Lincoln, 2002).

4 RESULTS AND DISCUSSION

The previous chapter dealt with the various methods and material that were used to collect, record and analyse the data for this study. The current chapter presents and discusses the results that were obtained during each of the four phases of the study. This discussion is done on the basis of the main themes and subthemes that were identified from the first focus group interview with the FARR key role players through inductive analysis. Firstly the role that each of these identified themes played in the adjustment of the questionnaire during phase two of the study is described. Questions from the original questionnaire that were changed, eliminated or moved to another section of the questionnaire are presented under the theme it relates to. The chapter also provides an overview of the results that were obtained during the third and fourth phases of the study, while referring to how these results influenced the final adjustment of the questionnaire during the fourth phase of the study. More specifically it gives an overview of the participants' (maternal interview questionnaire users) perceptions regarding collecting, capturing and analysing data with the use of the adjusted questionnaire compared to the original questionnaire. The final adjustments that were made to the questionnaire during the fourth phase of the study are also presented.

During the analysis of the transcript from the first focus group interview, two main themes were identified: the **purpose of the questionnaire** as well as the **problems with the questionnaire**. These two themes were further divided into a number of subthemes, which will each be defined and described in the sections below. The two main themes as well as the subthemes from the first focus group interview are presented in Table 3 below.

Table 3: Main themes and subthemes identified through inductive analysis of the first focus group transcript.

PURPOSE OF THE QUESTIONNAIRE
Making a diagnosis
The need for multiple maternal interview questionnaires
- *The need for a short and a long questionnaire*
- *Interviews with someone other than the mother of the child of interest*
Intervention
Building a relationship with the mother
Research
PROBLEMS WITH THE QUESTIONNAIRE
Length of the questionnaire
Redundant questions
Repetitive questions
Open ended questions
Structure of the questionnaire
Vague/confusing questions
Inconsistency between interviewers

The first focus group interview as well as the telephonic interviews with the two interviewers that participated in the study were transcribed verbatim. This implies that the researcher did nothing to grammatically or semantically change the utterances of each respondent. The presentation and

discussion of each theme in this chapter is supplemented by extracts from the abovementioned interviews. The extracts from the first focus group interview, the telephonic interviews as well as extracts from the questionnaires that were completed by the data capturer and the data analyst are placed between quotation marks and printed in *italics* to indicate that it is the respondents' own words. Anything that has been added to the extract by the researcher is placed between brackets and is not printed in *italics*. The telephonic interviews with the two interviewers were conducted in Afrikaans due to the fact that it is their first language. For the convenience of the reader, the extracts from these interviews were translated by the researcher. These translations are placed between square brackets, printed in *italics* and is presented under each original extract.

4.1 Purpose of the questionnaire

During the initial focus group interview the participants were asked to read through the list of objectives that appear on the original maternal interview questionnaire and indicate whether they felt that any additional objectives had to be added to the list (for a list of the original objectives of the questionnaire, see **Appendix K**). Only a small number of changes were suggested by the participants to these objectives. The list of objectives as suggested by the participants is shown in Table 4 below.

Table 4: List of maternal interview questionnaire objectives as suggested by focus group participants.

1.	**To collect data on alcohol use during pregnancy to assist in diagnosing children with FASD.**
2.	**To identify women who are currently exposed to alcohol, tobacco and other drugs and offer them appropriate intervention.**
3.	**To identify factors that increase the risk of having a child with FASD.**
4.	**To describe the socio-economic circumstances of the case and control groups, in terms of income, education and employment.**
5.	**To assess the interviewee's level of knowledge of the effects of alcohol use during pregnancy.**

The list of objectives was discussed at the beginning of the focus group interview so that any changes to the questionnaire itself could be made based on and in light of the revised objectives. Two of the original objectives were omitted from the list of objectives for the adjusted questionnaire. The majority of the focus group members agreed that the information that is derived from a maternal interview does not only have an impact on the individual that is being interviewed, but also on the larger community. As can be seen in Table 3 the list of revised maternal interview objectives therefore applies to both the individual and the community that is being studied. After the specific objectives of the questionnaire had been discussed, the overall purpose of the questionnaire was further discussed. What follows is a description of the general purpose of the maternal interview questionnaire, as perceived by the focus group participants that formed part of the first two phases of this study. This description is done according to the subthemes that were identified during inductive analysis of the focus group transcript. Relevant literature that relates to each subtheme and the perceptions of the participants that used the adjusted questionnaire during phase three of the study, are also discussed.

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4.1.1 Making a diagnosis

During the initial focus group interview the order of the screening procedures that form part of FARR's prevention programmes were discussed. When a parent/caregiver has given consent for a child to be screened, the child is first examined by a medical doctor who has experience in the field of FASD to determine whether the child presents with any of the physical characteristics associated with FASD. Only the mothers of those children who are identified as having a high risk for FASD by means of the physical examination, are contacted for a maternal interview. In those instances where the biological mother of the child cannot be interviewed, a caregiver of the child is interviewed instead. The mothers of the children who do not meet the criteria for FASD as determined by the physical examination, are therefore not interviewed. After a maternal interview has been conducted with the mother/caregiver of the child, the child is seen by a psychologist with experience in the field of FASD for a neurodevelopmental examination. One of the main purposes of the maternal interview, as identified by all the focus group members, is that it has to contribute to the process of diagnosing children who are at a risk for FASD. One of the medical examiners who formed part of the focus group explained his use of the maternal interview data as follows:

Focus group member D:

"Maybe I can start and say that the only reason I would use the questionnaire in a working situation, is I want to know three questions. And I want to know is she drinking and how much and what sort of alcohol she's drinking. OK. And what are the circumstances occasionally when she drinks, you know. So, really, and I think that's it. From a diagnostic point of view, remembering I'm seeing... in a study anything between a couple of 100 to 1500 children."

One of the focus group members who has experience in interviewing mothers as part of FASD prevention programmes agreed that the medical examiners do not require a lot of information from the maternal interview before making a diagnosis. However, in order to make an accurate diagnosis, medical examiners do not only need to know whether the mother consumed alcohol during her pregnancy, but also how often she consumed alcohol, what types of alcoholic beverages she consumed and whether she currently presents with a drinking problem. Focus group member B therefore stated that it is imperative that the section of the questionnaire dealing with the mother's alcohol consumption includes enough questions to make sure that a clear picture of the mother's past and present drinking habits can be formed:

Focus group member B:

"For me I would think that a question like, uhm, a mom who says to you that she's not drinking. To ask, when did you stop drinking, you know, when did you confirm your pregnancy. Because quite often they tell you, "I stopped drinking just as soon as I heard that I'm pregnant". That would be like twelve weeks or whatever. And then just to record that, because that might also have another effect."

This same focus group member explained the process of using the data from the maternal interview to make a final diagnosis of FASD as follows:

"So, the person who... the dysmorphologist who examined the child and then the person who did the interviews and then the neurodevelopmental assessor. They sit together and then they discuss each

and every child. And then, so, for example if I did the interview I will answer the questions that he (the medical examiner) *is asking.”*

According to Hannigan et al. (2010) clinicians who are responsible for making a diagnosis have to rely on the mother’s self report of alcohol consumption during pregnancy due to the fact that a child who has FASD (especially those children who are only slightly affected) does not always present with enough physical features in order to make a positive diagnosis. Children who were prenatally exposed to alcohol but who do not meet the criteria for a diagnosis of FAS (due to the absence of specific physical traits and anomalies) might, and in most cases do, present with cognitive and or behavioural delays (Goodlett, 2010). It is therefore essential that all children with FASD are accurately diagnosed so that they can receive the necessarry intervention and support with regards to these cognitive- and behavioural delays. During the focus group interview one of the focus group members emphasised the importance of using the maternal interview data when the physical characteristics of FAS are absent or difficult to observe:

Focus group member D:

“Then we must be finding out a way of doing that (maternal interview) *first, and then the physical exams and so on. Because I think we're missing out. Our suspicions are not raised enough in the children during the physical and neurodevelopmental test, without the maternal history first.”*

Another focus group member, who is also a medical examiner and partly responsible for making the final diagnosis of FASD in patients attending FARR’s programmes, agreed that information that is shared by the mother or caregiver during the maternal interview could have an impact on the amount of children that are diagnosed with FASD. He proposed that the maternal interview could help to raise suspicion about those children that would not be otherwise identified as high risk cases, and that it should be done before the child is physically examined:

Focus group member A:

“I think the reason we do that (do the maternal interview first)*, is to describe the FASD in the whole population and they do pick up a number of kids that you would exclude if you use the screening process that we do...”* (where the physical examination on the child is performed before ((and determines whether)) the mother or caregiver is interviewed)

Focus group member D agreed that the order in which the screening procedures are currently performed could potentially lead to children being overseen when they do in fact present with FASD. He expressed his concern in the following way:

Focus group member D:

“...my own idea is that we might be missing really heavy drinking mums. Simply because, she's... you know...she's well nourished, or the child's well nourished. Or simply because it's her first child and the mom's young, you know... or you know... but down the road we've lost a major opportunity of intervention...” (due to the interview not being done prior to the physical exam).

The focus group participants thus felt that the data obtained from the maternal interviews are critically important, and in a majority of cases necessary, for making a diagnosis of FAS or FASD.

Their perceptions in this regard are well supported by the literature on FASD diagnosis (Goodlett, 2010; Hannigan et al., 2010). If all mothers were to be interviewed as part of an FASD prevention programme (and not only the mothers of the children who presented with physical characteristics of FASD) further emphasis is placed on the need for an interview questionnaire that is less time consuming and more user friendly.

According to Hannigan et al. (2010) maternal interviews are in many cases done retrospectively which means that the process of diagnosing a child with FASD becomes all the more dependent on the mother's ability to give a true account of her drinking habits during pregnancy. For the purpose of the current study retrospective interviewing refers to interviews that are conducted more than five years after the mother had been pregnant with the child of interest. Retrospective interviewing is of great value in the process of identifying and diagnosing FASD in a country like South Africa where the discrepancy between the need for and availability of health services is immense and children are often only assessed and diagnosed with FASD after the age of six. In this context the maternal interview is a valuable tool, aiding health professionals in correctly diagnosing children with FASD while they are still young. The original maternal interview questionnaire that was used by FARR, was designed using a timeline follow-back procedure, which allows for retrospective interviewing. The timeline follow-back procedure was also considered during the adjustment of the questionnaire to ensure that the adjusted questionnaire could be used retrospectively.

4.1.1.1 The need for multiple maternal interview questionnaires

The need for a short and a long questionnaire

One of the themes that was discussed during the first focus group interview, was whether a relatively long, detailed questionnaire is sufficient for all of FARR's FASD prevention programmes and whether a shorter screening questionnaire should be developed for those cases where larger prevention projects are undertaken. The reasoning behind the suggestion for a shorter form of the questionnaire by one of the focus group members was that screening procedures generally take up less time to administer, which means that a larger number of women could be interviewed in the same period of time. Several of the focus group members agreed that a very short interview questionnaire with only a few questions might be helpful when a whole population is being screened and specifically in those cases where mothers who present with a high risk for having a child with FASD have to be identified. One of the focus group members explained it in the following way:

Focus group member C:

"If you want to do a whole population study of maternal interviews, you should look at that. Before you do the physical... or the other, you may want the short version. The very short version. That you can get through in like three or four minutes. OK, then, but the longer one once you got it, you find individuals that have a few physical and developmentally signs, you know then you want to do… the longer version after that. So in other words you might need to do both in the same person occasionally, but depending on whether you do the population study, or the individual study, you might need a short and a long version."

Two of the focus group members highlighted the benefits of having a long questionnaire where several aspects besides the mother's drinking habits are covered, such as the history of previous pregnancies and births as well as the mother's nutritional status. One focus group member

emphasised the importance of being able to use the maternal interview data for future research studies, and therefore the importance of ensuring that all the related risk factors (and not only the mother's drinking habits) are addressed in the interview questionnaire:

Focus group member C:

"And you need to be able to have that information. And then that adds a whole weighting to the situation, already. And, what's more, is that it allows us to know … you see a change happening in the population."

"I'm worried, because, I'm really worried that there's a changing situation here, that … nutrition might be changing...you know... all sorts of things might be changing in the background. And we're missing, you know, I'm worried especially with the kid involved..."

The group came to the conclusion that the specific objectives for each prevention programme (whether it is for pure diagnostic benefits or research purposes) would determine whether a long, more detailed questionnaire or a shorter, more focused questionnaire is used. They collectively felt that a long questionnaire should be used in those instances where the data from the interviews are to be used for research purposes whereas a short questionnaire might be more beneficial when a large population of mother/caregivers are interviewed with the sole purpose of diagnosing children with FASD.

During the third phase of this study the data capturer and data analyst who had used the adjusted questionnaire to capture and analyse data from maternal interviews, were asked whether they felt that the adjusted questionnaire was sufficient for use in all situations or whether there still existed a need for a screening questionnaire. As can be seen from the following extract, the data capturer felt that the adjusted questionnaire could be used in all situations due to the fact that it was shorter than the original questionnaire.

Data capturer:

"Talking from my point of view as a capturer I strongly believe that the adjusted questionnaire will most definitely work perfectly (as the only interview questionnaire) *because it's short and straight forward questions."*

The data analyst felt that there might still be a need for a shorter questionnaire, especially in those situations where resources are limited. He agreed that two different questionnaires (one for screening and one for diagnostic purposes) should not be used to interview women as part of the same prevention programme, due to the discrepancy it might create in the results obtained for research purposes:

Data analyst:

"A shorter questionnaire is needed for proxy interviews, and maybe for control women (referring to control groups used in research studies). *It would be hard to justify having a short and long interview in one site as then some data would be missing from some women. If resources were particularly constrained a short interview for women could be done, just to capture info on their drinking during the pregnancy, and no other variables."*

A study by Russell (1994) examined the different screening questionnaires that are generally used to assess a woman's consumption of alcohol during pregnancy. According to Russell (1994) screening questionnaires can only be used successfully in FASD prevention programmes if they are high in both sensitivity and specificity[7]. Russell goes on to say that the problem with most screening procedures is the fact that they are very rarely highly sensitive and highly specific at the same time. Screening questionnaires tend to give priority to sensitivity with less emphasis on specificity. Lower specificity creates a problem in a country like South Africa with limited resources for the delivery of health care. Health care professionals are currently using several screening questionnaires to identify pregnant women with dangerous drinking habits which could possibly place them at risk of having a baby with FASD. The problem with these questionnaires is the fact that they have not been designed to use specifically with pregnant women. Most of these questionnaires have also not been designed to use in a retrospective manner, apart from the AUDIT screening questionnaire which asks questions about the person's drinking habits during the past 12 months (Russell, 1994). To overcome all of the abovementioned problems a new screening questionnaire would have to be designed that (i) is specific to the population of pregnant women, (ii) has a high level of both specificity and sensitivity, and (iii) can be used retrospectively.

For the purpose of this study the focus was on the adjustment of the original maternal interview questionnaire. However, there seems to exist a realistic need for an even shorter questionnaire designed specifically to screen large populations of pregnant women and/or mothers and identify those women who present with risky drinking behaviour, either during a past pregnancy or during their current pregnancy. It is recommended that further research be done on what the specific needs are related to a FASD screening questionnaire that could be used specifically to interview pregnant women or mothers in South Africa, and that such a questionnaire ultimately be developed and evaluated.

Interviews with someone other than the mother of the child of interest

During the focus group interview one of the participants touched on the fact that there are many instances during FASD prevention programmes where the biological mother of the child of interest cannot be interviewed. The mother is in many cases not the primary caregiver of the child possibly due to the fact that she is deceased, works far away from home or is financially unable to care for the child. In those cases other relatives of the mother or the child of interest have to be interviewed (for instance the father or the grandparents of the child). He expressed his frustration with the fact that the same questionnaire that was used to interview mothers was also used to interview these relatives, as can be seen in the following extract from the interview:

Focus group member D:

"Is there a way where maybe you can come up with questions that are not based on the mother? Because in some cases we get grandmothers who live with the children. So what happens now is the grandmother skips about 85% of the questions... So is there a way that you can find the questions also relating to the person who lives with the child?"

7 Sensitivity can be defined as the extent to which a screening measure is successful in identifying all the women who are risk drinkers in a given population. Specificity is the accuracy with which a screening procedure identify those women who are not risk drinkers within a given population (Russell, 1994).

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According to this focus group member many of the questions in the maternal interview questionnaire are not applicable to or may be difficult to answer accurately by someone other than the mother of the child of interest. This is problematic since it may cause inconsistent behaviour between interviewers. Individual interviewers might for instance spontaneously omit certain questions in an effort to accommodate the person that is being interviewed. Another focus group member agreed that interviews with someone other than the biological mother of the child of interest was problematic when using the existing maternal interview questionnaire. He suggested that a different questionnaire be developed to help resolve this problem:

Focus group member C:

"So for instance the guardian or the foster mother or the what have you is going to have a totally different set-up. She's not likely to know what's going on, necessarily with the biological mother or the biological parents. So, you probably have another questionnaire for the foster parents... or the whatever... The non-biological mother, put it that way."

In an effort to resolve this problem a second questionnaire for interviews with someone other than the mother of the child of interest was developed during the second phase of this study. This questionnaire is shorter and more focused and designed to use specifically in those instances where someone other than the mother of the child of interest is being interviewed (for the first draft of the Afrikaans and English version of the questionnaire ((Questionnaire B)), see **Appendix L**). During the third phase of this study the two interviewers were asked whether they felt that this second questionnaire was successful in getting all of the needed information from someone other than the mother. The interviewers indicated that they had both used this second questionnaire to interview other guardians of the child on five separate occasions each. They both agreed that there existed a need for a separate questionnaire that could be used on those occasions when the interviewee is someone other than the mother of the child, as can be seen in the following extract from the interview with Interviewer A.

Interviewer A:

"Ja, is so. Dis 'n goeie ding dat ons nou twee vraelyste het. Ja, dis heelwat dat mens dit kry (onderhoude met iemand anders as die biologies ma van die kind). *Of die ouma maak die kind groot, die ma het gaan werk. Of die ma is oorlede en die pa kyk nou na die kind."*

[Yes, that is true. It is a good thing that we have two questionnaires now. Yes, you get that a lot (where someone other than the mother of the child is interviewed)*. Or the grandmother is raising the child, or the mother is working. Or the mother has passed away and the father is looking after the child.]*

Even though both interviewers approved of the use of a second questionnaire, they also felt strongly that this questionnaire could be developed even further. According to the interviewers the questionnaire can be expanded by including more questions about the development of the child of interest. According to Interviewer A an interviewer can also get some of the basic information on the child that the caregiver might be unfamliar with (e.g. the birth weight) by consulting the child's clinic card, which is usually brought to the interview by the caregiver:

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Interviewer A:

"Byvoorbeeld die oumas weet as hulle die kind kliniek toe bring, dan bring hulle die kliniekkaart saam. So jy kan voorsiening maak nogsteeds vir die kind se geboortegewig. Ja, die geboortegewig nogsteeds van die kind…en dan…wat was daar dan nou nog? Ek dink die kind se geboortegewig en die ma se geboortedatum was mos nou daar op. En die ma se naam en die kind se naam."

[For instance the grandmothers know that when they bring the child to the clinic, they must also bring the child's clinic card with. So you can include a question about the birth weight. Yes, the birth weight still of the child…and what else was there? I think the child's birth weight and the mother's date of birth was on there. And the mother's name and the child's name.]

According to the interviewers the caregiver of the child are in some cases more equipped than the mother to answer questions regarding the child because they have been looking after the child for an extended period of time. Interviewer B mentioned that there are instances where the grandmother becomes the primary caregiver immediately after the child's birth, as can be seen in the following extract:

Interviewer B:

"Kyk die vyf (versorgers van die kinders onder bespreking) *waarmee ek onderhoude gevoer het, is van geboorte af met die kinders besig. Die ma's het net gaan kraam en toe is dit ouma se kind."*

[Look, the five (caregivers of the children of interest) *that I interviewed, has been involved with the child since birth. The mothers just gave birth and after that it was the grandmother's child.]*

According to the interviewers the current caregiver of the child might not be able to answer all the questions regarding the mother's background or even her past and current drinking habits, but they are usually able to provide more information on the child than is currently catered for in Questionnaire B. This questionnaire can therefore be further developed by including more questions on the child of interest, as suggested by the interviewers in the following extracts:

Interviewer B:

"Want die oumas praat baie oor die kleinkinders van hulle. So ek sal weer 'n gedeelte van die vrae wat vir die ma ook gevra word, moet hier ook vir die ouma gevra word. Kyk, dis nie eintlik veel werd om so by Vraelys B te vra oor die ma nie. Die oumas praat sommer en sê kyk die ma het so gedrink en so gedrink en so gedrink. So ek sal graag wil die vrae wat ons vra rondom die kind in Vraelys A, ook vra in Vraelys B. Wanneer het hy skool toe gegaan en so en so…"

[Because the grandmothers talk a lot about their grandchildren. So a portion of the questions that the mothers are asked, I will also ask the grandmothers. Look, it is not really worth much to ask about the mother in Questionnaire B. The grandmothers just talk and say look, the mother drank like this and this and this. So I will ask the same questions that we ask about the child in Questionnaire A, in Questionnaire B as well. When did he go to school etc…]

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Interviewer A:

"Ek het gedink ons moet miskien byvoeg, want van die vrae…die inligting was eintlik te min. Want as jy die vrae vra vir sê nou maar die ouma, dan kan jy sien jy die ouma wil eintlik nog meer gesels."

[I thought we should maybe add, because some of the questions…the information was actually too little. Because when you ask the grandmother the questions, then you can see that the grandmother wants to talk some more.]

From the feedback that was received from the data capturer and the data analyst, it seems as though frustration stemming from having the same questionnaire to interview the mothers as well as other caregivers of the child was experienced by the interviewers and the data capturer, but less so by the person responsible for analysing the data. According to the data capturer the development of a second questionnaire had a positive impact on the capturing of the data derived from the interviews:

Data capturer:

"The original copy did not have the second copy for the foster parent, the interviewer had to indicate on the copy that the mother passed away/mother is in prison etc., whereas the adjusted copy has two questionnaires A + B. Whereby if anything happened to the parent questionnaire B is then used, so as for me when capturing the data I automatically know questionnaire B is strictly for foster parents, it's much more easier for me to capture now and the questions are much more shorter."

Even though the data analyst did not express a specific need for the development of a second questionnaire for caregiver interviews, he agreed that a questionnaire that had been designed specifically for these type of interviews was useful, and creates a meaningful division in the population group between children with FASD who are cared for by their biological mothers and children with FASD who are cared for by a foster parent.

Questionnaire B was further developed and adjusted after the researcher discussed the interviewers' suggestions as well as recommendations from the other focus group members with focus group member B during phase four of the study. After these final adjustments had been made the adjusted Questionnaire B was sent via e-mail to and subsequently approved by all the focus group members (see **Appendix M** for the final draft of the Afrikaans and English Questionnaire B). The additional questions that were included and approved for inclusion in Questionnaire B during the final phase of the study are presented in Table 5 below. The question is shown in the right column, while the number of the question as it exists in the questionnaire is shown in the left column.

Table 5: Questions that were included in the final draft of the caregiver questionnaire according to suggestions made by the focus group members and users of the questionnaire.

BACKGROUND INFORMATION	
15.	If the mother is deceased, how did she pass away?
16.	To which ethnic/ racial group does or did the mother belong?
17.	For how many years did the mother go to school?
18.	What was the highest grade that the mother of the child of interest completed?
19.	How important is/was religion to the mother?
20.	What type of work does the mother usually do? (do not ask if the mother is deceased)
21.	What is the mother's current work status? (do not ask if the mother is deceased)
INFORMATION REGARDING THE PREGNANCY AND BIRTH OF THE CHILD OF INTEREST	
25.	Were there any complications during the birth of the child of interest?
26.	If yes, explain these complications.
27.	Was the child of interest prematurely born?
28.	What was the birth weight of the child of interest?
INTERNAL AUDIT QUESTIONS	
29.	Do you think that you possibly received incorrect information from the caregiver?[8]

The two questions shown in Table 6 below was eliminated from Questionnaire B during the final phase of the study since it was perceived by the focus group members and users of the questionnaire to be redundant and difficult for the interviewers to complete.

Table 6: Questions that were eliminated from the first draft of the caregiver questionnaire according to suggestions made by the focus group members and users of the questionnaire.

INTERNAL AUDIT QUESTIONS	
19.	In which risk category do you feel this mother falls to give birth to a baby in future that is affected by alcohol?
20.	Which research group applies to the mother?
21.	Referrals/Plan of Action:

4.1.2 Intervention

The second subtheme under the main theme "Purpose of the questionnaire" was identified as "Intervention". In this context intervention refers to any support, counseling and information that the mother receives to prevent her from consuming alcohol during a current or future pregnancy. Intervention as part of an FASD prevention programme can also refer to the therapeutic services that are offered to a child who has been diagnosed with FASD (e.g. speech-language therapy, occupational therapy and learning support). Two recent South African studies by Chersich et al. (2012) and Davies et al. (2011) examined the role that intervention plays in lowering maternal drinking rates and ultimately also reducing the number of children that are born with FAS/FASD. The study by Chersich et al. (2012) found intervention efforts that were focused on communities that presented with a high risk for FASD to be successful. More specifically, there was a definite decrease

[8] In the section titled "Intenal Audit Questions", of which question number29 forms part,the interviewer is asked specific questions about the interview itself, in order to verify the reliability of the information that was provided by the person who was interviewed. In this particular question the interviewer is therefore asked whether they felt as though they had received the correct information from the caregiver that was interviewed.

in the number of children that were born with FAS/FASD within a specific community as a direct result of the FASD intervention programmes within that community. According to a study by Davies et al. (2011) the early diagnosis of FASD in an individual as well as early intervention directed at the individual's developmental difficulties are essential for preventing further secondary disabilities related to FASD. Not only does the maternal interview play an important role in identifying those children who are at risk of having FASD, but the final diagnosis of FASD is in a lot of cases dependent on the information that was shared by the mother during the interview. During the focus group interview it became clear that the questions asked during a maternal interview is not only important when making a diagnosis but also for intervention purposes directed at the child of interest as well as the interviewee. One of the focus group members explained it in the following way:

Focus group member C:

"...if you want to have an intervention for that particular person. And I think some of these questions...in the questionnaire, do kind of lend themselves to identifying people where you can make specific interventions. So you know, that's another kind of role for the questionnaire. The person has got a drug problem as well where you think you need to look at social issues or whatever..."

Another focus group member felt that the original questionnaire was not appropriate to serve as an intervention tool since it was too long and took up too much time to complete. She added that a shorter, more focused questionnaire might help to generate more opportunities for intervention during or directly after the interview.

Focus group member B:

"Because for intervention you might still be saying we ask one question of each of those things that we think we could intervene on. Whether it be contraception or knowledge or whatever. Without exploring it in detail...With a questionnaire like that (referring to an adjusted questionnaire), *we will surely use it for intervention."*

It is important to note that the function of the maternal interview extends beyond the diagnosis of FASD and may also serve as an opportunity for intervention. Due to the sensitive nature of the information that is shared during the interview it is also a very important vehicle for counselling the mother. The mother might feel ashamed or guilty about the fact that she consumed alcohol during her pregnancy and possibly harmed her child. The mother's emotional state influences the way in which she interacts with her child. Findings from a recent South African study suggests that mothers who report feeling depressed tend to be less involved, less sensitive and more negative when they interact with their infants than those women who do not feel depressed (Davies et al., 2011). This does not only affect the bond that is formed between the mother and child but also the development of the child's cognitive, social and communication skills. The interview should therefore create an opportunity for the interviewer to find out how the mother feels after sharing certain information and then also provide the support and guidance that the mother might need.

A study by O'Connor and Whaley (2007) examined the effectiveness of so-called brief intervention[9] efforts in helping women to abstain from consuming alcohol during pregnancy. O'Connor and Whaley (2007) found pregnant women to be receptive to brief intervention efforts. Furthermore the women who participated in the study tended to consume less alcohol during their pregnancies, which resulted in their newborn babies presenting with more positive outcomes than was the case with a control group of pregnant women. Even though the maternal interviews that form part of FARR's FASD prevention programmes are conducted retrospectively it can still present as an opportunity where principles of brief intervention can be effectively applied. Interviewers should utilise this opportunity by not only helping the mother to overcome her possible feelings of guilt and shame (brought on by her revelations of alcohol consumption during past pregnancies) but also to provide enough information that would prevent her from consuming alcohol during any future pregnancies. In several cases the maternal interview might be the only contact session that an organisation such as FARR has with the mother of a child with FASD which puts further emphasis on the need for using the interview as an opportunity and a tool for intervention.

4.1.3 Building a relationship with the mother

During the first focus group interview one of the purposes of the maternal interview was identified as it being a tool for building a relationship with the mother or the person being interviewed. According to one of the focus group members this relationship is key if the mother is expected to be truthful in sharing information as personal as her alcohol use. He explained it in the following way:

Focus group member C:

"... you need to actually induce the mother to actually reveal this stuff to you as well. You know what I mean? I don't say a long questionnaire, but you need one or two or three steps...Now I don't have a cooking clue as to whether that is what those steps are. I think you need to approach the person … you know…sort of slowly … not just `whack`: `Are you drinking?` And if the answer is `no` then you must have the woman's true history."

Another focus group member (who also has experience in interviewing mothers as part of FASD prevention programmes) added that some interviewees might need a little more time before they start warming to the interviewer and as a result respond truthfully to questions. This had to be taken into account in the adjustment of the questionnaire.

Focus group member B:

"It depends on the client. How open she is. Because sometimes you need to prompt a little bit."

The focus group participants felt that the relationship between the interviewer and the interviewee does not only have an impact on how comfortable the mother might feel about sharing certain information during the interview but it may also determine the success of any future intervention efforts attempted by the interviewer. If the mother felt that she had formed a bond with the interviewer, she might be more willing to accept the support offered to her through intervention.

[9] In the study by O'Connor and Whaley (2007) **brief intervention** is described as an approach that uses 10-15 minute sessions of counseling. Its focus is on the reduction of alcohol use in nondependent individuals (individuals who have not been diagnosed as being dependant on or addicted to alcohol) by using time-limited, self-help strategies instead of a more comprehensive intervention plan.

During telephonic interviews with the interviewers that had used the questionnaire, both interviewers agreed that the maternal interview was an important relationship building tool. In the following extract Interviewer A explains the way she uses the interview to form a relationship with the mother:

Interviewer A:

"Want wat ek maar doen…jy stel jouself voor aan die ma en dan gesels jy maar so 'n bietjie. Sommer oor enigiets waaroor sy wil gesels,net om bietjie die ma se vertroue te wen. So mens gesels maar oor elke vraag en dan maak jy so 'n grappie tussen-in en dan vra jy maar vir die ma: "Is jy nog oraait, kan ons maar aangaan na die volgende vraag toe?" En sommige van die goed kom dan sommer so self uit terwyl jy met die ma gesels daai tyd."

[Because what I do…you introduce yourself to the mother and then you talk to her a little bit. About anything that she wants to talk about, just to get the mother to trust you. So you talk about each question and then you make a little joke in between and then you ask the mother: "Are you still o.k., can we move on to the next question?" And some of the things just come out by while you and the mother are talking like this.]

One of the concerns that was raised during the initial focus group interview was that a shorter questionnaire could have a negative impact on the relationship building aspect of the interview, since less time would be spent with each of the interviewees. Hoewever, both the interviewers felt that the adjusted maternal interview questionnaire allowed them to build a relationship with the mother, while also gaining the necessary information regarding the mother's pregnancy and her child's birth history as well as her drinking habits. In the following extract Interviewer B explains why she feels that the adjusted questionnaire enhances the relationship that is formed with each interviewee, specifically due to the fact that it allows for the interview to be shorter than before:

Interviewer B:

"Ja, die vraelys is 'n bietjie korter en as gevolg van die dat jy nou met hulle praat…noudat die vraelys so kort is. Byvoorbeeld as jy nou klaar is met die vraelys, veral by daai Vraelys B…as jy nou klaar is met hom, dan het jy seker so 15 of 20 minute gebruik dan is jy klaar met hom. Dan is jy mos nou klaar met hom, dan sê jy "Baie dankie dat jy gekom het." Nou daarna dan maak die ma sommer nou oop, dan praat hy sommer nou alles. Want sy het nou gehoor die ding waaroor dit gaan alles, dan praat sy sommer nou die hele saak."

[Yes, the questionnaire is a little bit shorter and because of that you now talk with them…now that the questionnaire is that short. For instance when you have completed the questionnaire, especially with that Questionnaire B…when you have completed it, then you've probably used about 15 or 20 minutes before you have finished it. Then you are finished with it, then you say: "Thank you very much for coming." Well, after that the mother opens up, then she tells you everything. Because she has heard what it is all about, and then she tells you everything.]

From the above extracts it seems that the relationship with the person that is being interviewed is not always formed during the interview itself, but rather during the spontaneous conversations that take place before, during and/or after the interview. This creates a strong case for a shorter questionnaire that would allow for a shorter interview. This would allow more time for the

interviewee to talk spontaneously about his/her feelings and concerns, which would in turn create more counseling/intervention opportunities for the interviewer.

4.1.4 Research

All the participants that formed part of the initial focus group interview were in agreement that one of the main aims of the maternal interview questionnaire ought to be the collection of data that may be used in potential research studies. One of the medical examiners, who has done extensive research in the field of FASD, expressed the need for this use of the questionnaire in the following way:

Focus group member C:

"You see, down the road what we might be able to do is other things like, how these kids are doing at ten, how are they doing at twelve, how are they doing at fifteen, and so on, etc, etc. You know. And they were exposed heavily, you know what I mean. And they didn't seem to be affected initially but suddenly there's a change in their academic set up..."

Despite all of the focus group members agreeing on research being one of the main purposes of the questionnaire, one of the focus group members (who interviews mothers on a regular basis) admitted that the questionnaire hasn't been used effectively for research purposes in the past:

Focus group member B:

"We've never, since I arrived at FARR, gone back to questionnaires and looked at questionnaires and said: 'let's analyse the questionnaires and see if there are trends'."

During the focus group interview it came to light that the data that has been collected through the original maternal interview questionnaire in FARR's prevention programmes has not been used for research, due to specific problems with the questionnaire and the manner in which it was administered. Due to the fact that the maternal interview was time consuming only a small number of women could be interviewed as part of FASD prevention programmes, which made it impossible to generalize results obtained in this manner to the larger population of women. One of the focus group members felt that some of the questions in the questionnaire were not answered appropriately by the interviewees, either due to the mothers being unable to answer the question or the interviewers not completing the question comprehensively.

Another focus group member felt that the time that was spent on the interviewing process did not allow for control interviews to be done, which compromised the chances for the collected data to be used for research[10]. These two focus group members' concerns are shown in the following extracts from the focus group interview:

[10] As part of FARR's FASD prevention programmes, control groups are randomly selected from the community that the participants in the programme come from. These control groups represent women that either consumed alcohol during their pregnancies or not and whose children might therefore potentially have FASD. The mothers who form part of the control group are not included in the FASD prevention programme and are therefore not interviewed. The inclusion of control groups in prevention programmes is necessary for research aimed at evaluating the prevention programmes.

Focus group member C:

"Because it is not just is the question useful but is the information from it reliable, is it...do people answer it in good numbers so that you can get something that you can actually analyse."

Focus group member A:

"...there are issues, definitely. Partly in terms of what information you want to know when you come to actually putting an article together. And sometimes … it's not just related to the questionnaire but also who was interviewed as part of the questionnaire, because you should be doing controls and so that's an aspect from where we are deficient from a research point of view..."

The first South African research studies on FASD were conducted during the nineties. The main focus of these studies was to determine the prevalence of FASD amongst children entering primary school in certain parts of the Western Cape, one of the areas with the highest risk for FAS in South Africa and the world. The earliest research was done in collaboration with a number of universities from the United States of America, who provided the expertise and resources needed to ensure reliable research results. The first research paper on FASD in South Africa was published in 1999 in the *South African Medical Journal* (see Croxford & Viljoen, 1999). This paper was the first of many to describe and highlight the gravity of women consuming alcohol during their pregnancies and the consequent harm it was causing to their unborn children in South Africa. Over the last decade research has also been conducted in areas of South Africa other than the Western Cape, including Gauteng and the Northern Cape. Despite the progress that has been made in terms of the availability of knowledge about FAS in South Africa, more research needs to be done to determine whether FASD prevention programmes are effective in terms of correctly identifying and diagnosing children who present with FASD. Further research may also enable FASD intervention efforts that are suitable for addressing the growing need for such services in South Africa.

In the questionnaires that were completed by the data capturer and the data analyst during the third phase of this study, they both felt positive that the adjusted maternal interview questionnaire provided data that was analysable and that the adjusted questionnaire could be used in future research studies. The adjusted maternal interview questionnaire thus has the potential to contribute meaningfully to FASD research data in South Africa.

4.2 Problems with the questionnaire

During the first phase of the study, which included a focus group interview with all the FARR key role players, several problems with the maternal interview questionnaire were identified and discussed. What follows is a brief description of each problem as it was identified during the initial focus group interview as well as each of the following phases of the study. Where applicable a list of questions that were changed or eliminated from the original questionnaire during each phase will also be provided.

4.2.1 Length of the questionnaire

During the initial focus group interview the questionnaire was described as being very long, which caused the maternal interviews to take up approximately two hours per interview. According to one of the focus group members (who also has a great amount of experience in interviewing mothers as part of FASD prevention programmes) the extensive length of the interview caused mothers to become tired:

Focus group member B:

"I am sure you experience that sometimes you know, these questions are just scary. Because it's like you get to this part here, and if you go to take the woman through this, forget it, you're going to lose her. She's not going to be able to... she's not going to be awake to answer this."

Another focus group member blamed the time consuming interviewing process for the fact that not enough control interviews (the interviews that are conducted with mothers that form part of the control group) are being done as part of FASD research programmes:

Focus group member A:

"We are not doing enough control interviews and that again comes back to the length of the interview."

"You might even say, ok we'll do the control interviews, we'll just sort of do the alcohol questions or maybe...I don't know...But we definitely need to be doing...I would say...more interviews, but on less people for the school survey kind of scenario."

When asked about the length of the original maternal interview questionnaire, both interviewers agreed that it took up a significant amount of time to complete a single interview with this instrument. Interviewer A felt that the extensive number of questions in the original questionnaire caused mothers to become uncomfortable and unresponsive during an interview, mainly due to the fact that they found it challenging to remember the details of their past pregnancies:

Interviewer A:

"En dit was lank en as gevolg van, dit is nou 'n kind wat nou miskien al 6 jaar oud is en die ma kan miskien nou nie onthou nie. So sommige van die vrae was dan nou net dat hulle nie kan onthou wat het in die vorige tyd gebeur nie, van in die swangerskap nie. Want sommige van die ma's het mos nou al weer kinders gekry na daai kind. So dis maar net die rede hoekom ons gevoel het dat die vraelys is te lank vir hulle en so."

[It was long and because of this, this is now a child who is 6 years old already and the mother possibly cannot remember anymore. So some of the questions was just that they could not remember what had happened in the past pregnancy. Because some of the mothers had had more children after that child. So that is the reason why we felt that the questionnaire is too long for them.]

Interviewer B felt that the extensive length of the original questionnaire had a negative impact on the trustworthiness of the information obtained from the mothers during the maternal interview. In the following extract she explains that some mothers might have provided unreliable responses to questions in an effort to complete the interview within a shorter time period:

Interviewer B:

"Die rede is want daar was tye gewees…want die vraelys is lank. En dan kan jy optel daar is moeders, daar is vroue wat net wil antwoord om klaar te maak."

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[The reason is because there were times…because the questionnaire is too long. And then you can tell that there are mothers, there are women who just want to answer to get it over with.]

Before conducting the interviews with the mothers using the adjusted interview questionnaire, the researcher requested the interviewers to record the time that it took them to complete each of the interviews. Both interviewers reported that it took them between 30-45 minutes to interview one mother using the adjusted questionnaire. This is significantly shorter than the estimated two hours that interviewers required to complete one interview using the original maternal interview questionnaire. Interviewer B felt that the shorter, adjusted questionnaire helped mothers to feel comfortable and relaxed during an interview:

Interviewer B:

"Dit is baie positief om 'n kort onderhoud te hê…want ek het gesien dit laat nie die vrou onder druk nie, sy's nie vol spanning nie. Sy is vry, as jy begin met haar. Hulle is gemaklik met die vrae wat jy vir hulle vra. Want die vrae is nie te lank nie."

[It is very positive to have a short interview…because I saw that it didn't put the woman under pressure, she is not full of stress. She is free, when you start with her. They are comfortable with the questions you ask them. Because the questions aren't too long.]

According to Interviewer A the shorter adjusted questionnaire caused the interviewer and the mother to feel less rushed than before and it allowed for more time to talk freely about each question during the interview.

Interviewer A:

"…die vrae was van so 'n aard, hulle het dit geniet. Want mens kon tussenin gesels, byvoorbeeld. oor "Hoekom sê jy jy het minder gedrink…?" Verstaan jy? So mens kan lekker gesels rondom een vraag."

[…the questions were of such a nature, they enjoyed it. Because one could chat in between e.g. about "Why do you say you drank less?" Do you understand? So you can have a nice chat about each question.]

Both the data capturer and the data analyst agreed that the maternal interview was too long when the original questionnaire was used and that this had a negative impact on the process of capturing and analysing the data. As can be seen in the following extract, the data analyst felt that shorter maternal interviews could have a positive impact on both the quantity and the quality of the data:

Data analyst:

"No, I think the current length is optimum, previous ones were too long. The time saved by having fewer interviews can be used for having more interviews, as positive consequences overall. Also data will be more valid as with a shorter interview the woman and interviewer will be able to focus throughout."

A major problem that the focus group members and the interviewers reported with regards to the original maternal interview questionnaire was thus its extensive length and the great amount of time it took to complete one interview. The focus group members and the interviewers felt that this had serious negative influences on the interviews with mothers for instance that the mothers became

tired and unresponsive during the interview. The focus group members and the interviewers also deemed the quality of the information that was collected from mothers using this lengthy questionnaire to be sub standard. More specifically the focus group members felt that the length of the questionnaire caused interviewers to be inconsistent by leaving out questions at random (inconsistency between interviewers is discussed in more detail under section 4.2.4). The data that was derived from these long questionnaires was also difficult to capture. During the initial focus group interview in phase one of the study, the extensive length of the questionnaire was mainly ascribed to three factors: the high number of open ended questions, the repetition of questions as well as the inclusion of unnecessary or redundant questions. The questionnaire was therefore adjusted by eliminating or changing these questions with the specific purpose of shortening the questionnaire. During the third phase of the study the interviewers, data capturer and data analyst expressed their satisfaction with the adjusted questionnaire being much shorter than the original questionnaire and therefore allowing for maternal interviews that are shorter and more focused. Presented below is an overview of the questions that were eliminated or changed based on the fact that they were deemed to be redundant, a repetition of a previous question, or open ended in nature.

4.2.1.1 Redundant questions

During the first focus group interview, a decision was made to eliminate 51 questions from the original questionnaire because they were found to be redundant and unnecessary in terms of fulfilling the objectives of the maternal interview questionnaire (as described earlier in this chapter). Questions that were identified as redundant and have therefore been eliminated from the original questionnaire are presented in Table 7 below (to see these questions as they appear in the original questionnaire as well as their accompanying answer choices, see the original maternal interview questionnaire in **Appendix A**). The questions are presented in table 6 in the same manner (grouped in sections) as they appeared in the original questionnaire. The following questions are all closed-ended in nature. This implies that the mother had to answer the question by simply saying “yes” or “no” or by choosing between a number of given options. The numbers in the left column correlate with the question numbers in the original questionnaire.

Table 7: Questions that were eliminated from the original maternal interview questionnaire because of being perceived as redundant by the participants from focus group one.

BACKGROUND HISTORY	
7.	**This interview pertains to: (options given)**
8.	**Where were you born?**
12.	**Who are the adults that you live with? (husband, partner etc.)**
14.	**Who are the children or adolescents that you live with?**
15.	**Total number of individuals living with the mother (including herself)?**
16.	**How stressful is your life generally?**
25.	**Would you be interested in receiving adult education?**
27.	**If yes, to which religious group do you belong?**
28.	**Does your religion require attendance at religious gatherings, how often do you attend?**
29.	**Do you pray, and how often do you pray?**
33.	**Tick the occupation group which is most similar to the work the mother described: (options given)**
35.	**If the mother is a seasonal worker, what is the approximate number of weeks worked**

	each year?
36.	How much money do you receive per week when you work?
39.	What is the total weekly income of all working members of your immediate family?
42.	Have you been legally married, if more than once, how many times?
47.	If you are using contraception, what method of contraception are you currently using?
48.	With how many different partners have you had children?
49.	How long are you/were you with the father of the child of interest?
56.	How many times during your pregnancy with the child of interest did you receive prenatal care?
57.	How many times did a doctor or a sister/nurse examine you?
60.	Were you involved in any accident or did you sustain injuries while you were pregnant with the child of interest?
DRINKING HABITS OF INDIVIDUALS IN THE MOTHER'S SOCIAL NETWORK	
61.	Is your father still alive?
62.	If deceased, what was the cause of his death?
63.	If deceased, was his death alcohol related?
64.	Is your mother still alive?
65.	If deceased, what was the cause of her death?
66.	If deceased, was her death alcohol related?
67.	How would you describe your father's drinking habits while you were growing up?
72.	Is your best friend a man or a woman?
73.	How many of your co-workers drink alcohol?
74-79	Table indicating drinking habits of the mother's family members while growing up (see p. 11 of the original questionnaire in Appendix A).
NUTRITION	
121.	What do you usually eat for breakfast?
122.	What do you usually eat for lunch?
123.	What do you usually eat in the evening (dinner)?
128.	How often during your pregnancy were you hungry due to lack of food?
129.	If yes, what time of the week or month did this usually happen?
132.	Do you currently take multi-vitamins?
133.	Do you currently take any prescribed medication?
134.	Did you take prenatal vitamins during your pregnancy with the child of interest?
137.	In general, how stressful was your life while you were pregnant with the child of interest?
SMOKING HABITS	
165.	Did your smoking habits change during the first trimester of your pregnancy with the child of interest?
166.	If your smoking habits changed during the first trimester, what do you think was the reason for this and how did it change?
167.	Did your smoking habits change during the second trimester of your pregnancy with the child of interest?
168.	If your smoking habits changed during the second trimester, what do you think was the reason for this and how did it change?
169.	Did your smoking habits change during the third trimester of your pregnancy with the child of interest?
170.	If your smoking habits changed during the third trimester, what do you think was the reason for this and how did it change?

The questions that are presented in Table 8 below were at first included in the adjusted questionnaire. However after a short discussion about each question in the first draft of the adjusted questionnaire during the second focus group interview (in phase two of this study), the participants

identified these questions as redundant considering the agreed-upon objectives of the maternal interview. They therefore requested the researcher to eliminate the eight questions presented in Table 8 from the questionnaire.

Table 8: Questions that were eliminated from the first draft of the adjusted maternal interview questionnaire because of being perceived as redundant by participants during the second focus group interview.

BACKGROUND HISTORY	
53.	**How old were you when you were pregnant with the child of interest?**
DRINKING HABITS OF THE MOTHER	
82.	**Have you consumed alcohol in the last 30 days?**
85.	**Are you still drinking?**
114.	**How many times have you tried to stop drinking?**
ALTERNATIVE CARE OF CHILDREN	
118.	**Why and how many times were any of your children taken from you by a social worker and placed in foster care?**
120.	**Why and how many times have any of your relatives taken care of your children for long periods of time?**
NUTRITION	
130.	**Why (if ever) was there not enough food in the house?**
206.	**What was the primary source of "risk" in the mother's life at the time of this pregnancy?**

During the first focus group interview a significant amount of time was spent discussing the section titled "Drinking habits of the mother" in the original maternal interview questionnaire. All the focus group participants agreed that this section contained the most critical questions of the maternal interview but it was also the most problematic section of the questionnaire due to the fact that it took longer than any of the other sections to complete. Following this discussion the focus group participants decided that this particular section had to be adjusted by replacing a group of questions from this section with a table that was more focused in terms of getting the necessary information from the mother in an efficient manner. These changes are presented below. The questions that are presented in Table 9 (question 94-96 and question 98-101) are from the original maternal interview questionnaire and were designed to get information on how often the mother consumed alcohol during her pregnancy with the child of interest, how often she participated in binge drinking activities and also what types of alcohol she consumed.

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Table 9: Questions from the "Drinking habits of the mother" section from the original maternal interview questionnaire that were replaced because of being perceived as redundant by the participants from focus group one.

DRINKING HABITS OF THE MOTHER	
94.	**When do you usually drink during the week – meaning Monday through to Thursday?**
95.	**If you drink during the weekend, do you usually drink on Friday evening, Saturday, Sunday, or on all three days?**
96.	**If you drink during the weekend, on which day and at what time do you drink?**
98.	**How much alcohol do you usually drink during the week? (total number of drinks and describe)**
99.	**How much alcohol do you usually drink on a Friday? (total number of drinks and describe)**
100.	**How much alcohol do you usually drink on a Saturday? (total number of drinks and describe)**
101.	**How much alcohol do you usually drink on a Sunday? (total number of drinks and describe)**

The questions in Table 9 were replaced by the following table in the adjusted questionnaire:

Table 10: Table that replaced questions 94-96 and 98-101 in the section titled "Drinking Habits of the Mother" of the original maternal interview questionnaire.

57. Indicate the **number and type of drinks** (eg. write 2 to indicate 2 drinks) consumed per day of the week.

1 Drink = 1 can or bottle of beer (350 ml.), 1 glass of wine (129 - 200 ml.), 1 mixed drink (coctail) or 1 shot of **strong** liquor.

Type of alcohol	**Monday**	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
Traditional beer							
Beer							
Wine							
Fortified wine							
Spirits							
DOP							
Mixed (frizzers,coolers ,ciders)							
Other							
Total							

In the original questionnaire, the two sections that contained questions regarding the mother's smoking habits and her use of other drugs were found to be lengthy and too detailed for the purpose of the maternal interview. In the adjusted questionnaire these two sections were combined into one section with only a limited number of questions. To view the two separate sections and also the adjusted combined section, see p 23-26 in the original maternal interview questionnaire in **Appendix A** and p 11-13 in the final version of the adjusted questionnaire in **Appendix F**.

During the third phase of the study both interviewers expressed their satisfaction with the number of questions that were eliminated from the original maternal interview questionnaire. They were for the most part satisfied with the questions that were included in the adjusted questionnaire. When asked whether they felt that there were questions that could still be added to the adjusted

questionnaire, Interviewer B responded by saying that she felt that the most important questions had been included and that it was sufficient in terms of gathering the necessary information from the mother:

Interviewer B:

"Nee, ek het nogal nie gevoel daar is inligting wat ek gekort het nie. Want dit is net 'n verkorte weergawe van die ou ene. Dis net bietjie korter gemaak en daarom het ek nie 'n probleem daarmee gehad nie."

[No, I didn't feel as though there was information that I still needed. Because it is just a shortened version of the old one. It has just been shortened a little and that's why I didn't have a problem with it.]

Both the data capturer and the data analyst agreed that most of the redundant questions had been successfully eliminated from the adjusted questionnaire. When asked whether there were any sections or questions of the adjusted questionnaire that had to be further revised the data analyst responded with a list of questions that he felt were still redundant and could possibly be eliminated or changed. He based his suggestions on the way in which these questions were answered by the majority of mothers who formed part of this study. For instance during the analysis of the data it was observed that all the mothers responded "no" to certain questions, which could indicate that these particular questions are not applicable to this population of mothers. The suggestions made by the data analyst as well as recommended changes that were made during a case discussion meeting between three of the focus group members were discussed with focus group member B during phase four of the study. During this discussion a decision was made to eliminate four more questions from the second draft of the adjusted questionnaire (that was used to interview mothers as part of this study) based on the fact that it was viewed as redundant by the majority of the focus group as well as the data analyst who had analysed the data from the adjusted questionnaire. These eliminated questions are all closed-ended in nature and is presented in Table 11 below. The question numbers in the left column correlate with the actual question numbers in the second draft of the adjusted maternal interview questionnaire.

Table 11: Questions that were eliminated from the second draft of the adjusted maternal interview questionnaire because of being perceived as redundant by the focus group members and users of the adjusted questionnaire.

DRINKING HABITS OF INDIVIDUALS THAT FORM PART OF THE MOTHER'S SOCIAL NETWORK	
44.	**How would you describe your *mother's drinking habits while you were growing up?** *** Please note: This question refers to the maternal grandmother of the child of interest**
NUTRITION	
84.	**How much weight did you gain while pregnant with the child of interest?**
SMOKING HABITS AND OTHER DRUG USE	
89.	**If you stopped during your pregnancy, did you start smoking or chewing tobacco again after the child of interest was born?**
90.	**If yes, how soon after the child of interest was born did you start smoking or chewing tobacco again?**

During the discussion between the researcher and focus group member B in the final phase of the study, the relevance of asking for the mother's full name and surname as well as that of the child of interest was discussed. More specifically focus group member B expressed her concern about the fact that the ethics of FASD prevention programmes might be compromised if the identity of the interviewees were known. In the end it was determined that only the initials of both the mother and the child would be sufficient for the purpose of the interview and prevention programme. A question that asks about the mother's home address was kept in the final draft of the adjusted questionnaire to ensure that FARR would have a way of contacting the mother in future, if necessary. After the final recommendations regarding redundant questions were discussed with focus group member B, the changes were electronically presented to and approved by all the focus group members.

4.2.1.2 Repetitive questions

Several of the participants that formed part of the first focus group interview identified the number of repetitive questions in the original questionnaire as another factor that contributed to the length of the maternal interviews. One of the focus group members, who also interviews mothers on a regular basis, expressed her frustration in the following way:

Focus group member B:

"But then there are questions like, if I just can refer to specific questions here like question 31. What type of work do you do? And then compare that with 32 and 33. And then 34. And then 35. So, those questions are like repeating, repeating, repeating."

A total of four closed-ended questions were eliminated from the original questionnaire due to the fact that they were viewed by the initial focus group participants as a repetition of or too similar to a previously asked question. The numbers in the left column of Table 12 correlate with the question numbers in the original questionnaire.

Table 12: Questions that were eliminated from the original maternal interview questionnaire because of being perceived as a repetition of another question in the questionnaire by participants from focus group one.

BACKGROUND HISTORY	
20.	**How old are you today?**
30.	**Are you currently working?**
51.	**Were you practising some sort of birth control before becoming pregnant with the child of interest?**
52.	**What type/method of birth control did you use?**

During the telephonic interviews in phase three of the study both interviewers agreed that the repetition of questions in the original maternal interview questionnaire was a source of frustration for them. In the first extract below, Interviewer A expresses her satisfaction with the way in which the repetitive questions were minimized during the adjustment of the questionnaire. However she feels that the section on the mother's smoking habits and use of other drugs still contained an

element of repetition and that it could be further adjusted. She identifies the problematic questions in the second extract below and also suggests how these questions could be changed:

Interviewer A:

Extract 1:

"Maar by hierdie ene (verwys na die aangepaste vraelys)*… is alle vrae wat gevra word vrae wat moet gevra word. En ek dink vrae wat eintlik vir ons inligting kan gee van het die ma gedrink of het sy nie gedrink nie"*

[But with this one (referring to the adjusted questionnaire)*…all questions that are asked, are questions that must be asked. And I think questions that can actually give us information about whether the mother drank or whether she did not drink.]*

Extract 2:

"Dit was bereik…maar daar was een vragie…ek dink dit was: "Het jy al dwelms gebruik?" Dan staan daar mos "Nee". En as jy sê nee, dan gaan jy mos na die volgende vraag toe, van: "Het jou dwelmgebruik verander?" En van die ma's wat nogal bietjie slim was het dan gesê, nee maar ek het dan nou net vir jou gesê ek het nog nooit dwelms gebruik nie. So wat ek nou gedink het: in daai kolomme, daar is nie voorsiening gemaak vir "nooit gebruik nie". So mens kan dit weer vra, want dan maak mens mos nou maar dubbel seker. So dit hoef nie uitgehaal te word nie. Maar wat mens kan bysit daar by, waar jy nou moet kies vir antwoordjies, kan mens mos nou byskrywe: "nooit gebruik nie.""

[It was achieved…but there was one question…I think it was: "Have you ever used drugs?" Then it says: "No". And if you say no, then you move on to the next question, of: "Has your drug use changed?" And some of the mothers who were a bit clever then said, no but I have just told you that I have never used drugs. So what I thought: in those columns, provision isn't made for "never used." So you can ask it again, because then you make sure. So it doesn't have to be taken out. But what you can add to it, where you have to choose answers, you can also write: "never used".]

When asked about the occurrence of repetitive questions in the adjusted questionnaire, both the data capturer and the data analyst indicated that they did not observe any repetition while capturing and analysing the data obtained through the adjusted maternal interview questionnaire. During the final phase of the study the questions that were perceived to be repetitive by the interviewers were presented to and discussed with focus group member B. During this discussion it was decided not to eliminate any of the suggested questions, since it was not truly repetitive but rather a way of confirming some of the information that had been provided by the interviewee earlier in the interview. After the recommendations regarding repetitive questions were discussed with focus group member B during phase four of the study, the final changes were electronically presented to and approved by all the focus group members.

4.2.1.3 Open ended questions

For the purpose of this research study open ended questions can be defined as those questions in the interview where the mother is not given a list of answers to choose from but where she is required to verbalise her experiences or "tell her own story". During the first focus group it became

apparent that the inclusion of several open ended questions is viewed as one of the main problems with the original maternal interview questionnaire. Not only do these questions take a lot of time to complete during the interview, but they also create difficulties for the people who are responsible for capturing and analysing the data from each interview. One of the focus group members (responsible for capturing the data from the questionnaires) identified open ended questions as his main problem with the original questionnaire:

Focus group interviewer (that is the researcher):

"What I think too, and we're actually moving on to the second question already, to what your needs are in terms of the questionnaire as well, in terms of data capturing, do you have any specific needs, any frustrations that you currently have …?"

Focus group member D:

"Just the open ended questions."

The difficulties with data analysis that was experienced with the original questionnaire in the past were also addressed on several occasions during the interview:

Focus group member A:

"Realistically the open ended questions are not analysable...unless you have someone that has a huge amount of time that can classify those open ended answers into sort of...groups and you know... that actually is functionally very difficult."

"It's just open ended, you know (referring to one specific question in the questionnaire). *So to analyse it is actually very hard."*

"And then you...but you know, those things that are focused on intervention could be fairly open ended... But where you want to have it quantitatively analysable it's easier to have it closed ended."

Several discussions during the initial focus group interview revolved around how certain open ended questions could be changed to closed ended questions, in an effort to minimize the problems relating to capturing and analyzing the maternal interview data. One such discussion (about a specific open ended question) is shown below:

Focus group member C:

"But if you ask and they say "two drinks"...that's something you calculate. You don't ask them. So you ask: "How much do you drink?" and they'll say: "A bottle of wine." And then you ask "What size bottle?" and then you've got your different size bottles there and then you pull those out and then they say which one. You know? So you actually work out how many drinks there are. Then you write in two drinks, or four drinks or six drinks. And maybe one of the questions can be two times and you just tick it. Or four drinks and you just tick it...and until I'm drunk could be one of those. You know what I mean?"

Focus group member B:

"I like that. Because then you need to have something like "Beer, wine, spirits", something like that and then some kind of a graph with one drink, two drinks, three drinks or whatever...and then you can even say 300 ml is whatever. Then you can just tick that off...and then "I don't know"/ "Until I'm drunk.""

A total of seven open ended questions were eliminated from the original maternal interview questionnaire, based on the perception that they created problems with the completion of the questionnaire and also complicated the capturing and analysis of the maternal interview data. The open ended questions that were eliminated from the original questionnaire are shown in Table 13 below. The majority of the participants from the first focus group interview felt that these open ended questions could be eliminated from the questionnaire since it yielded information that was not necessary to fulfil the objectives of the maternal interview. Once again the questions in Table 13 are presented as it appears in the original questionnaire, under each corresponding section. The numbers in the left column correlate with the question numbers from the original maternal interview questionnaire.

Table 13: Open ended questions that were eliminated from the original maternal interview questionnaire because of being perceived as redundant by participants from focus group one.

BACKGROUND HISTORY	
10.	**What is the name of the place where you currently live (if in an informal settlement, describe how to reach your house)?**
11.	**Please describe your current home circumstances.**
17.	**What is/are the sources of stress in your life?**
32.	**Describe exactly the type of work that you do?**
DRINKING HABITS OF THE MOTHER	
93.	**Does your consumption of alcohol ever change? How does it change? Why does it change?**
138.	**Why was your life stressful during your pregnancy with the child of interest?**
GENERAL QUESTIONS	
198.	**Tell me what you think: how can one convince a mother that uses alcohol or other drugs, or smokes while she is pregnant, to stop doing so for the sake of the health of her baby?**

Both the interviewers that formed part of the third phase were for the most part satisfied with the way in which the various open ended questions from the original maternal interview questionnaire were either transformed, retained or excluded in the adjusted questionnaire. They indicated that the closed-ended questions took up less time to complete during an interview, which means that they could spend more time talking to the interviewee and less time completing the questionnaire. The data capturer also responded positively to the fact that most of the open ended questions had been eliminated from the original questionnaire. In the following extract he explains how the data capturing process is less time consuming as a direct result of the adjusted questionnaire containing a smaller amount of open ended questions:

Data capturer:

"It works for me as a capturer perfectly because now I don't spend that much time on typing everything, so the transformation of the open ended questions is working out just fine for me."

Despite the fact that closed ended questions ensure that the maternal interviews are shorter and the data capturing process less time consuming, it seems as though these types of questions were not always easy for the mothers to understand and respond to. In the following extract Interviewer A mentions that some of the mothers were unsure about how to respond to closed ended questions:

Interviewer A:

"Ja, dit is makliker dat hulle van die vrae kies, né? Waar hulle kies is hulle nog bietjie baie onseker oor…"nooit gedrink", "het gedrink" ens. Hulle verstaan dit. Maar mens kan sien daar is nog bietjie onsekerheid in hulle."

[Yes, it easier when they can choose with some of the questions. Where they choose they are still a little unsure about "never drank", "drank" etc. They understand it. But you can see that there is still a little bit of uncertainty in them.]

From the above extract it seems as though some mothers felt inhibited in answering at least some of the closed ended questions. A possible explanation for the mothers' hesitance in answering closed-ended questions is that they had difficulty in understanding the questions and/or the answer options, especially in those instances where they were required to choose between closely related words such as "sometimes", "never" or "usually". Mothers with little formal education might not be familiar with this type of closed ended question format and would probably have found it easier to respond to open ended questions (where she was allowed to formulate her own answer). The fact that the mothers were given options to choose from (as is the case with many of the closed ended questions that forms part of this questionnaire) could also have led them to think that there is a "wrong" and a "right" answer to each question. This possibly increased their feelings of uncertainty and hesitancy about how to respond to each question. According to Neuman (2011), closed-ended questions can create confusion for respondents, especially if many answer choices are offered. Misinterpretation of this type of question by a respondent might also go unnoticed by the interviewer, which could have a negative impact on the accuracy with which these questions are completed.

The data analyst agreed that most of the open ended questions were eliminated from the original maternal interview questionnaire. In the following extract he points out that the inclusion of a few open ended questions in the questionnaire should still be considered:

Data analyst:

"One or two carefully selected open ended questions makes good sense, agree not more than that, even just one question, something like what do you think could be done in this community to help women not to drink during pregnancy? Or why did you drink during pregnancy? It would be nice to make 1 or 2 more open ended questions about the woman or the child."

Interviewer B was also in favour of open ended questions still being incorporated into the adjusted maternal interview questionnaire. In the following extract from the telephonic interview she reveals how open ended questions can lead the mother to "tell her story" and that they are therefore important in gathering all the necessary information during an interview:

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Interviewer B:

"Ek dink, ja wat oop is. Dat hulle jou kan vertel. Maar ek dink nie daai vrae moet verwyder word nie. Ek dink die vrae moet daar bly."

[I think, yes that are open. So that they can tell you. But I don't think that those questions should be removed. I think those questions should stay there.]

During the final phase of the study the data analyst's and interviewers' suggestions to include more open ended questions in the adjusted interview questionnaire, was discussed between the researcher and focus group member B. A decision was made to include one additional open ended question in the final draft of the adjusted questionnaire. The final draft of the adjusted questionnaire contains a total number of six open ended questions. Despite the fact that open ended questions might be easier for some of the mothers to respond to, the majority of the focus group members felt that the data capturing complications that these types of questions currently create outweighs the advantages of including more open ended questions in the questionnaire.

Table 14: Open ended question that was included in the final draft of the adjusted maternal interview questionnaire based on recommendations by focus group members and interviewers using the adjusted questionnaire.

HISTORY OF PREGNANCIES AND BIRTHS	
39.	**If there were any complications during the birth of the child of interest, explain these complications.**

4.2.2 Structure of the questionnaire

During the initial focus group interview the structure of the original maternal interview questionnaire was described as problematic due to two reasons. Firstly the participants complained that there were no clear headings for the different sections of the questionnaire and secondly they perceived the questions to be poorly or incorrectly grouped into sections or categories. One of the focus group members described it as follows:

Focus group member B:

"... and also the questions are so spread out. So you get to questions that's pertaining to the social economic status of the family and then later in the questionnaire you get to that as well. It is not in sections. For example if you want to know about the nutritional status it would be nice if you can look at page 2 or 3. There you will get the information. But it's like spread out."

Two of the focus group members criticised the way in which questions were organised in the section dealing with the mother of the child of interest's drinking habits. Collectively they felt that if the questions in this section were arranged differently, it would not only ensure that the questionnaire stays true to the timeline follow-back procedure (on which it was originally based) but might possibly also cause the mother to be more truthful when answering these sensitive questions:

Focus group member C:

"I'm just worried about guys...you know...denying the alcohol. By them sort of saying...by giving them this sort of blanket to duck. You know what I mean? Like almost: "Do you drink daily?" No? "How many time a week do you drink?" You know what I mean? So if you can step it up like this...so if you hit the higher numbers first...because the lower numbers are thought to be more appropriate answers by the individual."

Focus group member A:

"Yes. I definitely think the questions should be reworked a bit so that you're getting a nice timeline."

During the revision process these factors were taken into consideration and in the end two changes were made with regards to the structure of the questionnaire. Firstly the different sections of the original questionnaire were clearly divided and given appropriate headings. In Table 15 below the names of the section headings and also the order in which it appears in the second draft of the adjusted questionnaire, are presented.

Table 15: The names of the section headings and the order in which it appears in the second draft of the adjusted maternal interview questionnaire.

1.	**Biographical and client information**
2.	**Background history**
3.	**History of pregnancies and births**
4.	**Drinking habits of individuals that form part of the mother's social network**
5.	**Drinking habits of the mother**
6.	**Alternative care of children**
7.	**Nutrition**
8.	**Smoking habits and other drug use**
9.	**Internal audit questions**

The order of the questions in the original maternal interview questionnaire was also adjusted by grouping all the questions that related to a specific topic within the same section (see a copy of the second draft of the adjusted questionnaire in **Appendix C** to view these changes).

During the third phase of the study both the interviewers expressed their satisfaction with the way in which the structure of the questionnaire was adjusted. They felt that the headings for each section were clear and appropriate and that the questions were better organised than in the original version of the questionnaire. The data capturer and the data analyst also agreed with the way in which the structure of the questionnaire was revised and they felt that it was an improvement on the structure of the original questionnaire. As can be seen in the extract below, the data analyst felt

that the structure of the adjusted questionnaire could be improved even further. More specifically he felt that questions within each section could be placed in a particular order, where general questions are asked before the mother is expected to answer more personal questions. This would ensure that a relationship can be formed between the interviewer and the mother before the mother is required to reveal personal information that might cause her to feel uncomfortable or embarrassed. If the mother feels as though she had built up some rapport with the interviewer, she might be inclined to be more truthful and feel less pressured to provide socially desirable answers about her personal circumstances and habits.

Data Analyst:

"It is much improved, the order of questions needs only minor tinkering. For the order of questions generally we ask bland, non-emotional stuff as much as possible, before asking private or potentially embarrassing things since the women will say socially desirable things if they haven't built up rapport with the interviewer yet. Things like do you have a best friend is an example. Religion is generally more private than work, so comes after work... the questionnaire is fine, but you could move some more private stuff to lower down, once the interviewer has built rapport with the women through asking the bland questions. The order is good otherwise, makes sense."

During the final phase of the study the recommendation made by the data analyst with regards to the structure of the adjusted questionnaire was discussed between the researcher and focus group member B. A decision was made to rearrange the order of the different sections that form part of the questionnaire. More specifically it was decided that the section titled "Drinking habits of the mother" ought to be moved towards the end of the questionnaire. This would not only ensure that the interviewer is able to gain the trust of the mother before she is required to answer any questions related to her past and present drinking habits, but the mother might also be more inclined to answer these questions truthfully if she feels as though she has formed a bond with the interviewer. Table 16 below presents the names of the sections and also the order in which it now appears in the final draft of the adjusted maternal interview questionnaire.

Table 16: The names of the section headings and the order in which it appears in the final draft of the adjusted maternal interview questionnaire.

1.	**Biographical- and client information**
2.	**Background history**
3.	**History of pregnancies and births**
4.	**Alternative care of children**
5.	**Nutrition**
6.	**Drinking habits of individuals that form part of the mother's social network**
7.	**Drinking habits of the mother**
8.	**Smoking habits and other drug use**
9.	**Internal audit questions**

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The data analyst's recommendation regarding the order of the questions in some of the sections was also discussed with focus group member B. During this discussion a decision was made to rearrange the questions that form part of the section titled: "Background history" so that more personal questions (e.g. "How important is religion to you?" and "Do you have a best friend") are asked after more general questions (e.g. "What type of work do you do?"). This would ensure that the mother was more comfortable with the interviewer before she was required to answer questions of a more personal or sensitive nature. After the recommendations regarding the structure of the questionnaire had been discussed with focus group member B, the final changes were electronically presented to and approved by all the focus group members.

4.2.3 Vague/confusing questions

Confusing questions that were difficult to answer were identified by members of the initial focus group interview as another problem with the original maternal interview questionnaire. These questions were described as confusing due to the fact that the meaning of the questions was ambiguous and as a result could be misinterpreted by either the interviewer or the interviewee. Consequently these questions also created problems with the capturing and analysis of the data derived from the maternal interviews. A decision was made to eliminate some of these questions because they were perceived to be redundant in nature. However, a number of the questions that were perceived to be confusing were not eliminated but rather adjusted based on the focus group members' opinion that these questions contributed positively to the fulfilment of the objectives of the maternal interview questionnaire. The questions that were perceived to be vague yet valuable by the focus group members were addressed by changing the way in which these questions were phrased. A total number of 14 questions were identified by the focus group members to be vague and redundant in nature and were therefore eliminated from the questionnaire. These questions are presented in Table 17 below.

Table 17: Questions that were eliminated from the maternal interview questionnaire because of being perceived as confusing or vague by participants from focus group one.

BACKGROUND HISTORY	
37.	**If you are a seasonal worker, explain if different amounts are received?**
38.	**How much money do you receive from other sources (child care etc.)?**
DRINKING HABITS OF THE MOTHER	
86.	**If you have stopped drinking alcohol, when did you stop?**
90.	**Does your consumption of alcohol change by season?**
91.	**Does your consumption of alcohol change because of the weather?**
92.	**Does your consumption of alcohol change for some other reason?**
107.	**In general, how much of the alcohol you drink, is from DOP?**
108.	**How much of the alcohol you drink, is purchased or otherwise obtained by you or your husband/partner?**
112.	**Why do you think that you have a drinking problem?**
149 (b)	**Table on p 22 to calculate the number of alcoholic drinks consumed per week by the mother**
NUTRITION	
124 (a)	**Table describing the quantity of all food and beverages that have been consumed by the mother during the last 24 hours (see p 18 of the original questionnaire in Appendix A).**
124 (b)	**Calculate the number of calories according to the food and beverages indicated in the table.**
125.	**How similar were your eating habits while you were pregnant with the child of interest compared to what you ate and drank during the past 24 hours?**
126.	**In general, how was your appetite during the time that you were pregnant with the child of interest?**

The two questions that are presented in Table 18 below were included in the first draft of the adjusted questionnaire but were eliminated after the second focus group interview, based on the fact that they were regarded as ambiguous and therefore difficult to answer:

Table 18: Questions that were eliminated from the first draft of the adjusted maternal interview questionnaire because of being perceived as confusing by participants from focus group two.

HISTORY OF BIRTHS AND PREGNANCIES	
58.	**At what month of the pregnancy was the child of interest born (gestational age)?**
QUESTIONS ASKED DURING INTERVIEW WITH SOMEONE OTHER THAN THE MOTHER	
210.	**On a scale from 1 to 5, with 1 meaning minimal closeness and 5 being close, how close do/did you feel to the mother of the child of interest?**

During the first focus group interview a number of the questions in the original questionnaire were identified as confusing yet valuable since it contributed positively to the fulfilment of the objectives of the maternal interview questionnaire. These questions were therefore rephrased and retained in the adjusted questionnaire. In question 18 of the original questionnaire the mother is asked through an open ended question about the length of time that she has been living at her current home address. In the adjusted maternal interview questionnaire answer options are provided so that the mother can choose among possible answers rather than expecting of her to state the exact number of years. Other questions that were changed based on the fact that they were vague or unclear in the original questionnaire are shown in Table 19 below. In the left-hand column of the table the question appears as it exists in the original questionnaire (with the corresponding number), while the question as it was changed in the adjusted questionnaire is shown in the right-hand column (with the corresponding number). The majority of these questions were closed ended in nature (to view the answer options for each question, see **Appendix A** for the original questionnaire and **Appendix J** for the adjusted questionnaire that was used to conduct maternal interviews during phase three of the study). These changes were presented to and approved by the focus group participants during the second focus group interview.

Table 19: Questions from the original maternal interview questionnaire that were rephrased and included in the adjusted questionnaire because of being perceived as confusing or vague by participants from focus group one.

ORIGINAL QUESTIONNAIRE		ADJUSTED QUESTIONNAIRE	
23.	**For how long did you go to school?**	**24.**	**For how many years did you go to school?**
24.	**What standard (grade) did you complete?**	**25.**	**What was the highest standard (grade) that you completed?**
127.	**Were you often hungry while pregnant with the COI because there was not enough food in the house for you to eat?**	**91.**	**Did you ever skip meals while you were pregnant with the COI because there was not enough food in the house?**
131.	**Thinking about your eating and drinking habits, do you eat when you are drinking?**	**83.**	**When you were pregnant with the child of interest, did you eat while you were drinking?**
135.	**Did you take any prescribed medication during your pregnancy with the COI?**	**40.**	**Did you take any prescribed medication or "nonprescribed" medication (medication you bought yourself or received at the clinic or from someone else) during your pregnancy with the COI?**
164.	**Did you smoke cigarettes or use smokeless tobacco during your pregnancy with the COI?**	**85.**	**Did you smoke or chew tobacco during your pregnancy with the COI?**
204.	***Confidence rating: is the above information significantly distorted by the mother's misinterpretation?** *(this question as well as the following two questions are answered by the interviewer)	**98.**	***Confidence rating: do you feel that you have received the incorrect information because the mother answered the questions incorrectly?** *(this question as well as the following two questions are answered by the interviewer)
205.	**Confidence rating: is the above information significantly distorted by the mother's inability to understand?**	**99.**	**Confidence rating: do you feel that you have received the incorrect information because the mother did not understand the questions?**
207.	**Risk category of the mother today for producing a future affected child?**	**99.**	**In which risk category do you feel this mother falls to give birth to a baby in future that is affected by alcohol?**

During the telephonic interviews that were conducted as part of the third phase of this study, both Interviewer A and Interviewer B agreed that the original questionnaire contained numerous vague questions that the mothers had difficulty responding to. In the first extract below, Interviewer A states that the content of the questions in the adjusted questionnaire were for the most part clear and easily grasped by the persons who were interviewed. She points out that the majority of the interviewees seemed to understand what was meant by most of the questions in the adjusted questionnaire. It therefore seems that, even though the structure of some of the questions in the adjusted questionnaire (specifically the closed ended questions) created confusion for some of the interviewees, the content/wording of most of the questions in the adjusted questionnaire was easily understood by the majority of the people that were interviewed. In the second extract Interviewer B

also refers to the discomfort that the mothers normally display in response to questions that are confusing. She points out that the mothers she interviewed seemed more relaxed during the interviews where the adjusted questionnaire was used and she attributes this to the fact that the questions were clear and easily understandable.

Interviewer A:

"Ek dink die positiewe gevolge is dat die, soos wat ek met die ma's praat…dit is baie duidelik verstaanbaar, in die eerste plek. So dis nie vrae wat mense laat ongemaklik voel het nie. So dis een positiewe kant, dat die mense was baie gemaklik met die vrae en die vrae was nie baie diep dat hulle nou moet…dat jy kan sien die ma is nou ongemaklik om die vraag te antwoord nie. So dit was vir my positief, so die mense was meer oop…met die vraelys (die aangepaste vraelys)*."*

[I think the positive consequences are that, as I am talking to the mothers…it is very clearly understandable, in the first place. So it's not questions that made people feel uncomfortable. So that's one positive side, that the people were very comfortable with the questions and the questions were not very deep so that they had to… so that you can see the mother is uncomfortable to answer the question. So that was positive to me, so the people were more open…with the questionnaire (the adjusted questionnaire).*]*

Interviewer B:

"Ja. Vir my maak dit sin. In die verlede sal ek sê was dit amper vir my soort van 'n swarigheid, so platweg sal ek dit nou maar net so sê. Dit het eintlik die vroue bietjie gestrem. Hulle het toegeklap met die vrae wat so…Maar ek dink met die nuwe vrae wat ons nou gekry het rondom die vroue…dit was baie oop en die vrou kan vir jou baie mooi antwoord."

[Yes. To me it makes sense. In the past I would say it was almost a type of difficulty for me, I will put it that plainly. It actually hampered the women a little bit. They shut off with the questions that were so…But I think with the new questions that we now received about the women…it was very open and the woman can answer you very well.]

In the following extract, Interviewer A reveals that she was more inclined to establish whether the mother had understood the questions when she used the adjusted questionnaire compared to when she was using the original questionnaire. This could be due to the fact that the adjusted questionnaire allows for a shorter interview, which creates more time for the interviewer to verify the mother's understanding of the questions.

Interviewer A:

"Dit was duidelik en verstaanbaar. Want wat ons nou maar doen is, ons vra dit twee keer en dan vra ons: "Het jy dit verstaan?" voordat ons aangaan. So ek dink dit was maklik bekombaar vir die ma's."

[It was clear and understandable. Because what we do now is, we ask it twice and then we ask: "Did you understand?" before we continue. So I think it was easier for the mothers to get.]

Both the data capturer and the data analyst felt that the elimination and transformation of confusing questions from the original questionnaire were successful. The data analyst recommended that the wording of the answer choices to the close ended questions nine, 30, 31 in the adjusted

questionnaire be changed in an effort to make them less ambiguous. This suggestion, as well as recommendations by the focus group members that formed part of the case discussion during phase three of the study, were discussed between the researcher and focus group member B during the final phase of the study. During this discussion it was decided that question 23 in the second draft of the adjusted questionnaire ought to be changed to include more answer options. Several of the focus group members felt that the question "What was the highest grade that you completed?" has been difficult to interpret by mothers in the past. They felt that this specific question (question 23) might be less confusing if the mothers were given more definite answer options to choose from. Other questions that were adjusted during the final phase of the study based on the fact that they were vague or unclear are shown in Table 20 below. All the questions in Table 20 is closed ended in nature and the majority of the questions (with the exeption of question nine) provides answer options that the interviewee has to choose from (to view the answer option for each of the questions see **Appendix A** for the original questionnaire and **Appendix J** for the final draft of the adjusted questionnaire). In the left-hand column of the table the question appears as it exists in the second draft of the adjusted questionnaire (with the corresponding number), while the question as it was changed for the final draft of the adjusted questionnaire is shown in the right-hand column (with the corresponding number).

Table 20: Questions from the second draft of the adjusted maternal interview questionnaire that were rephrased and retained in the final draft of the adjusted questionnaire because of being perceived as confusing by the focus group members and users of the adjusted questionnaire.

SECOND DRAFT OF ADJUSTED QUESTIONNAIRE		FINAL DRAFT OF ADJUSTED QUESTIONNAIRE	
9.	**What month and year did the child enter Grade 1 for the first time?**	**9.**	**What year did the child enter Grade 1 for the first time (e.g. 2012)?**
24.	**Do you currently belong to a religious group?**	**30.**	**How important is religion to you?**
55.	**Do you usually drink until you are drunk?**	**61.**	**Do you often drink until you are drunk?**
56.	**Do you usually drink until you pass out?**	**62.**	**Do you often drink until you pass out?**
68.	**Is there a difference between your drinking habits now and what it was in the months before you fell pregnant with the child of interest?**	**74.**	**Did you drink any alcohol in the months before you fell pregnant with the child of interest and if yes, how often?**

4.2.4 Inconsistency between interviewers

Several participants in the initial focus group interview mentioned their frustration with the inconsistencies between interviewers in completing the original maternal interview questionnaire. According to one of the members (who has experience as an interviewer and has therefore also worked closely with other interviewers) the biggest problem was the fact that interviewers often omitted questions when completing the questionnaire. This can once again be ascribed to the extensive length of the questionnaire:

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Focus group member B:

"Some people will complete it and some not but it's because the questionnaire is so long. I think if it's shorter it will work."

Inconsistencies between interviewers was identified as one of the reasons why it was difficult to obtain valuable population data from the completed maternal interview questionnaires that could be used in future research studies. Another focus group member expressed the urgency for consistency between interviewers as follows:

Focus group member A:

"But then I think we must focus on...once we've got what we want, it múst be filled in. It just gotta have integrity, you know?"

Inconsistency amongst the interviewers in terms of the completion of the questionnaire was not the only problem mentioned by the participants in relation to the interviewers. During the focus group interview it came to light that there are usually differences between the interviewers in terms of their educational level as well as their level of experience in using the questionnaire to interview mothers as part of FASD prevention programmes. These differences also had to be taken into consideration during the revision of the questionnaire so that valid and reliable information can be obtained through the maternal interviews. One of the focus group members expressed the need for certain terms that were used in the questionnaire to be clarified in order to assist those interviewers with a lower educational level:

Focus group member B:

"...with pre-term, can we just have a cut off? What is pre-term? 'Cause just remember it's not always professional nurses who's doing this so people can become a little confused."

During the first focus group interview several terms were identified that could potentially be interpreted incorrectly by interviewers with less experience in the field of FASD. In an effort to overcome this problem the identified terms were discussed and defined by the focus group members during the initial focus group interview. The definitions were presented to the focus group members as part of the first draft of the adjusted questionnaire during the second focus group interview. All the participants agreed with the definitions for the identified terms. Table 21 presents a list of these terms in the left column and the definition for each term as it appears in the final draft of the adjusted questionnaire in the right column.

Table 21: List of terms and corresponding definitions in the final draft of the adjusted maternal interview questionnaire.

TERM	DEFINITION
Adult	Someone who is eighteen years or older.
Child / teenager	Someone who is younger than eighteen years.
Full term pregnancy	After week 37 of pregnancy.
Born prematurely / too early	Before week 37 of pregnancy.
Miscarriage	Fetus was not born alive between week 4 and week 20 of pregnancy.
Stillbirth	Baby was not born alive between week 20 and week 40 of pregnancy.
Neonatal death	Baby died less than 7 days after he/she was born.
High fever	Body temperature of more than 38 °C.

The abbreviation "COI" is used throughout the original maternal interview questionnaire to refer to the child of interest. A decision was made during the second focus group interview to rather use the complete term (e.g. "child of interest") to avoid confusing the interviewer or the interviewee.

During the telephonic interviews that formed part of the third phase of this study, both interviewers agreed that there was inconsistency between interviewers when using the original questionnaire to conduct interviews. In the following extract Interviewer A admits that she excluded certain questions when she used the original questionnaire. She points out that she mostly omitted questions that were long and took up too much time to complete and also left out questions if she felt that it was a repetition of one of the previous questions.

Interviewer A:

"Ja, daar was van die mense wat dit so gedoen het. En jy kan sê miskien ook een of twee van die vrae het ek ook uitgelaat. Van die vrae wat te lank was…Of veral as dit nie regtig van toepassing was op hierdie ma nie. Byvoorbeeld as jy nie vanoggend gehoor het die ma het nie gedrink nie, dan is daar van die vrae wat jy weer moet vra. En as jy die ma ken en jy weet die ma het nooit gedrink nie, dan skip jy maar van die vrae. Veral in tye of so wat jy die ma ken en jy voel nou maar van hierdie vrae word dubbel gevra. So ek skip *nou maar die vrae."*

[Yes, there were some of the people (onderhoudvoerders) *who did it like that. And you can say perhaps that I also omitted one or two questions. Some of the questions that were too long…Or especially if it didn't really apply to this specific mother. For instance if you haven't heard that morning the mother did not drink, then there are some of the questions that you must ask again. And if you know the mother and you know that she never drank then you skip some of the questions. Specifically in those cases where you know the mother, then you feel as though some of these questions are being asked twice. So then I skip some of the questions.]*

In the above extract, the interviewer admits to excluding certain questions when the interviewee was someone she knew. This is concerning since she seems to assume how the interviewee would respond to certain questions without having the person answer the questions herself. It is also possible that the interviewer felt embarrassed about having to ask questions of a sensitive nature to the person she was familiar with. The fact that interviewers might feel tempted to leave out

questions based on their own assumptions or feelings places emphasis on the need for specific guidelines that interviewers must adhere to when using the questionnaire to interview mothers. When asked about the consistency with which the interviewers had used the adjusted questionnaire, both the data capturer and data analyst agreed that the interview questionnaires that were developed during this study had been completed with a high level of consistency. The data capturer added that it was important that interviewers understand the overall purpose of the maternal interview as well as the specific aim behind each question. As can be seen in the extract below, he felt that the interviewers would be less inclined to omit questions if they understood the reasoning behind each question.

Data capturer:

"You know in my own opinion I strongly believe that the most important role in these interviews is for the interviewers to fully understand the whole package of the questionnaire. I believe in most cases it's the lack of understanding the context of the questions being asked therefore they (the interviewers) *tend to ignore some questions."*

As part of this research study a short guideline for interviewers was developed in order to enhance the consistency with which the adjusted questionnaire is completed during an interview (for a copy of this guideline, see **Appendix N**). This guideline was given to the interviewers before they conducted maternal interviews as part of this study. Both interviewers felt that it was a good idea to equip interviewers with specific guidelines on how to use the questionnaire. Even though they are both experienced interviewers, they felt that the guideline had helped them to be more consistent when using the adjusted maternal interview questionnaire. It is recommended that this guideline be developed even further by the FARR team to ensure greater consistency between the interviewers.

During the final phase of the study the feedback from the data capturer and the interviewers with regards to interviewer consistency was discussed between the researcher and focus group member B. Focus group member B expressed that inconsistency seemed to be a problem, even in those cases where interviewers had had a lot of experience in conducting maternal interviews. In an effort to improve the inter and intra-interviewer consistency during maternal interviews, a decision was made to train interviewers more specifically on how to use the adjusted maternal interview questionnaire to conduct an interview[11]. It was decided that this training should not only include information on why specific questions are asked but it should also create an opportunity for interviewers to take part in simulated interviews before they are required to conduct a "real-life" interview.

The guideline that was developed as part of this study was electronically presented to and approved by all of the focus group members.

[11] All interviewers are required to complete a three-day FASD training course before they start conducting maternal interviews. Until this research study was completed, this training course had not involved any specific training on using the maternal interview questionnaire to conduct an interview.

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5 CONCLUSION AND RECOMMENDATIONS

The previous chapter presented and discussed the results that were obtained in this research study. More specifically the main themes and subthemes that were identified from the initial focus group interview with FARR's key role players were presented, while simultaneously discussing the impact each of these themes had on the adjustment of the maternal interview questionnaire. The previous chapter also referred to the feedback that was received from the two interviewers, the data capturer and the data analyst who used the adjusted questionnaire during the third phase of the study and provided an overview of how the adjusted questionnaire was finalised during the fourth and final phase of this study. The current chapter presents a summary of the data that was presented in the previous chapter and also interprets the main findings from this study. This is followed by a brief discussion on the larger significance of these findings and also a description of the limitations of the study. The chapter concludes with recommendations for future research studies in the field of FASD in South Africa.

Table 22 below provides a summary of the results of the study. The two rows that are shaded and where the content appears in capital letters refer to the two main themes that were identified after the transcript from the initial focus group interview was analysed. The other shaded rows with text that does not appear in capital letters refer to the subthemes that were identified after the two main themes were further analysed. In the column titled "Action", a description is provided of actions that were taken by the researcher in response to each of the identified themes. In the column titled "Feedback" the perceptions and experiences of the participants who had used the adjusted maternal interview questionnaire to conduct interviews, as well as to capture and analyse data, are described. The number of the study objective that relates to each of the themes is presented in the column titled "Objective". The objectives at the onset of the study were as follows:

1. To define the objectives of the maternal interview that forms part of FARR's FASD prevention programmes, as perceived by the main role players in FARR's prevention programmes;
2. To identify the problems with the maternal interview questionnaire used by FARR in FASD prevention programmes in South Africa;
3. To adjust the maternal interview questionnaire based on the problems referred to in the second objective whilst preserving the questionnaire's ability to achieve the objectives referred to under Objective 1; and
4. To evaluate the adjusted maternal interview questionnaire's ability to overcome the problems that are referred to under Objective 2, whilst achieving the objectives of a maternal interview referred to under Objective 1.

Table 22: A summary of the results of the study.

ACTION	FEEDBACK	OBJECTIVE
PURPOSE OF THE QUESTIONNAIRE		
5.1.1 Making a diagnosis.		
-	According to the participants of this study, the adjusted maternal interview questionnaire aids the process of making a diagnosis of FAS/FASD.	• Objective 1
The need for a short and long questionnaire.		
-	According to the data capturer, the original maternal interview questionnaire had been sufficiently shortened to be used as a screening tool. The data analyst felt that further research could focus on the development of a more concise screening tool that can be used in circumstances where resources are particularly limited.	• Objective 1
Interviews with someone other than the mother of the child of interest.		
A second questionnaire was developed to be used specifically when someone other than the mother of the child of interest is being interviewed.	All the users felt that the development of a questionnaire that could be used to interview a caregiver of the child of interest was for the most part successful. Suggestions were made by both interviewers on how this questionnaire could be further improved. These suggestions were discussed with focus group member B during the final phase of the study, after which it was approved and added to the final draft of questionnaire B.	• Objective 1

ACTION	FEEDBACK	OBJECTIVE
5.1.2 Intervention.		
-	According to the participants of this study, the adjusted maternal interview questionnaire is capable of providing an opportunity for brief intervention (e.g. counselling the mother).	• Objective 1
5.1.3 Building a relationship with the mother.		
-	Both interviewers that formed part of the study felt that the adjusted maternal interview questionnaire allows them to form a relationship with the mother.	• Objective 1
5.1.4 Research.		
-	Both the data capturer and the data analyst felt that the adjusted maternal interview questionnaire provides data that is analysable and can be used in future research studies.	• Objective 1
PROBLEMS WITH QUESTIONNAIRE		
5.2.1 Length of the questionnaire.		
In order to address the problem of the maternal interview being too time consuming, several questions were adjusted or eliminated from the original questionnaire.	Both interviewers reported that the maternal interview took up significantly less time when they used the adjusted questionnaire compared to when they used the original questionnaire. The data capturer reported that the process of capturing the data that was collected through the shorter adjusted questionnaire was easier and faster than when the original questionnaire was used. The data analyst felt that the shorter questionnaire has a positive impact on the reliability of the data in general.	• Objective 2 • Objective 3 • Objective 4

ACTION	FEEDBACK	OBJECTIVE
5.2.1.1 Redundant questions.		
During the adjustment phase of the study the identified redundant questions in the original questionnaire were either adjusted or eliminated from the questionnaire.	Most of the study participants felt that redundant questions had been successfully eliminated from the original maternal interview questionnaire. After analysing the data collected through the adjusted questionnaire, the data analyst suggested that a number of questions in the adjusted questionnaire be revised and possibly eliminated based on the fact that they were redundant. These suggestions, together with other recommendations from the remaining focus group members, were discussed with focus group member B during the final phase of the study. Two more questions were perceived to be redundant and were eliminated from the final draft of the adjusted questionnaire.	• Objective 2 • Objective 3 • Objective 4
5.2.1.2 Repetitive questions.		
The questions that were identified as being repetitive were eliminated from the questionnaire during the adjustment phase.	All the participants who had used the adjusted maternal interview questionnaire felt that the repetitive questions were successfully eliminated from the original questionnaire.	• Objective 2 • Objective3 • Objective 4

ACTION	FEEDBACK	OBJECTIVE
5.2.1.3 Open ended questions.		
During the adjustment phase, some of the identified problematic open ended questions were either changed to closed ended questions or eliminated from the questionnaire.	The interviewers, data capturer and data analyst were all satisfied with the fact that several of the open ended questions in the original questionnaire were eliminated or changed to closed-ended questions. Both interviewers and the data analyst felt that some open ended questions during the maternal interview might be valuable, albeit time consuming, since it allowed the mother to talk more freely and spontaneously. This suggestion was discussed with focus group member B during the final phase of the study. One additional open ended question was included in the final draft of the adjusted questionnaire.	• Objective 2 • Objective 3 • Objective 4
5.2.2 Structure of the questionnaire.		
During the adjustment of the questionnaire, the problems with the strucuture of the original maternal interview questionnaire were addressed by creating clearer divisions between the different sections and providing each section with an appropriate heading. Questions that did not seem to belong within a specific section were moved to a more appropriate section.	Most of the participants that had used the adjusted questionnaire, felt that the structure of the adjusted questionnaire was an improvement on the structure of the original questionnaire. The data analyst felt that the structure of the adjusted questionnaire could be further revised. He felt that it was important to limit personal questions at the beginning of each section and to include questions that are personal in nature towards the end of a section. This would allow the interviewer to build a relationship with the mother before she is asked to reveal personal information about herself or her child. These recommended changes were discussed and approved during the final phase of the study. In the final draft of the adjusted questionnaire the sections are ordered in such a way that questions of a sensitive nature are asked later in the interview.	• Objective 2 • Objective 3 • Objective 4

ACTION	FEEDBACK	OBJECTIVE
5.2.3 Vague/confusing questions.		
During the adjustment of the questionnaire, the questions in the original maternal interview questionnaire that were identified as being vague were either rephrased or eliminated from the questionnaire. After the questionnaire had been adjusted for the first time, a second focus group interview was held with the same participants. During this interview several more questions that could create confusion during an interview were identified and these were subsequently changed.	During the telephonic interviews with the interviewers who hadused the adjusted questionnaire, both reported that the elimination of vague questions from the original questionnaire had been meaningful. One of the interviewers mentioned that, when previously using the original questionnaire, mothers had seemed uncomfortable when they found a question to be confusing and did not know how to respond to the question. She reported that the mothers seemed to understand the content of most of the questions in the adjusted questionnaire. Even though the data analyst felt that the elimination of vague questions from the questionnaire was for the most part successful, he made a suggestion on how one of the questions from the adjusted questionnaire could be further changed. This recommendation, as well as suggestions by the focus group members that formed part of the case discussion meeting, were discussed with focus group member B during the final phase of the study. A total of five questions from the second draft of the adjusted questionnaire were perceived to be vague and were therefore changed before being included in the final draft of the adjusted questionnaire.	• Objective 2 • Objective 3 • Objective 4

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ACTION	FEEDBACK	OBJECTIVE
5.2.4 Inconsistency between interviewers.		
The problem of inconsistency between interviewers was addressed during the adjustment of the questionnaire by developing a guideline that could be used by the interviewers when using the adjusted questionnaire to interview someone. Terms that could be difficult to interpret by interviewers (e.g. "premature") were also defined in the adjusted questionnaire to clear up any possible misunderstanding.	Even though the interviewers who had used the adjusted questionnaire for the purpose of this study were both experienced interviewers, they reported that the guideline helped them to be more consistent when interviewing the mothers. The data capturer and data analyst reported that the adjusted questionnaires which had been completed by the interviewers for the purpose of this study had been completed with a high level of consistency.	• Objective 2 • Objective 3 • Objective 4

5.1 Interpretation of the results

This study produced several significant findings that influenced the way in which the FASD maternal interview questionnaire has been adjusted. The results of the study also form a base for future research studies in the field of FASD in South Africa, particularly on the topic of the maternal interview questionnaire and its use as part of FASD prevention programmes and research studies. FARR is one of only a few organisations in South Africa that have focused specifically on the prevention of FASD in communities with a suspected high prevalence of the disorder over the last two decades. Research has shown their prevention efforts to be largely successful, with recent statistics indicating a decline in the number of babies born with FASD in De Aar - a town that has been described as the FAS capital of the world (Chersich et al., 2012).

During the first focus group interview that was conducted with the key role players from FARR, the following were identified as the key objectives of a maternal interview:

1. To collect data on alcohol consumption during pregnancy to assist in diagnosing children with FASD.
2. To identify women who are currently exposed to alcohol, tobacco and other drugs and offer them appropriate intervention.
3. To identify factors that increase the risk of having a child with FASD.
4. To describe the socio-economic circumstances of the case and control groups, in terms of income, education and employment.
5. To assess the interviewee's level of knowledge of the effects of alcohol use during pregnancy.

One of the main findings of the current study is that, even though the adjusted maternal interview questionnaire is much shorter than the original questionnaire, it is still able to capture the essence of the information needed to assist in making a diagnosis of FASD. Even though the participants in the

initial focus group interview were concerned that a shorter interview might bear negative consequences for the rapport that is built between the interviewer and the mother, the data from this study has shown the contrary. Both interviewers who had used the adjusted maternal interview questionnaire as part of this study reported that they felt better enabled to form a relationship with the mother when this shorter questionnaire was used, specifically due to the fact that the shorter questionnaire allowed for more time to have spontaneous conversations with the mother. Not only will this relationship influence the mother's honesty during the interview but it will also influence the success of any future intervention efforts in which the interviewer is involved. The results of this study further indicate that the elimination of redundant, vague and repetitive questions from the questionnaire allow less complications in terms of capturing the data, which in turn may result in data that is easier to analyse and can be used in future research studies. The adjusted questionnaire therefore has the potential to satisfy the majority of the identified objectives of a maternal interview, including diagnosing high-risk cases of FASD, providing an opportunity for intervention as well as contributing to potential research studies.

Data that was obtained throughout the course of the study suggested that interviewers acted inconsistently when using the original maternal interview questionnaire to interview mothers. This complicated the process of data capturing which meant that the data collected through the maternal interviews could not always be used for research purposes. As a result valuable research opportunities were lost. An estimated one in four males and one in ten females in South Africa present with symptoms related to alcohol addiction (Parry, 2005). Risky drinking behaviours among South African adults have led to a significant number of children being born with FAS/FASD. South Africa's high FASD burden places the emphasis on the need for further research studies in this field, particularly related to the prevention of FASD. Despite the research studies that have been undertaken in many parts of South Africa, there are still large parts of the country with no known FASD prevalence and incidence rates. The identification of geographical areas with a high risk for FASD is essential for prevention programmes to become more targeted[12].

Even though limited research has been done on the success of targeted prevention programmes in the field of FASD, a small number of studies have shown that these methods are able to produce a change in the drinking habits of pregnant women and as a result lower the number of children born with FASD in high-risk areas (Warren et al., 2011). Section 2.4 of this thesis provided an overview of the recent success of targeted FASD prevention programmes in identified high-risk areas in South Africa (Chersich et al., 2012). It is also only once the FASD incidence and prevalence rates for a specific area are known that the success of prevention programmes in this area can be measured more accurately. It is therefore imperative that the maternal interviews that form part of FASD prevention programmes provide data that is both easy to capture and easy to analyse in order for this data to be used in potential research studies.

The interviewer guideline that was developed as part of this study seemed to create a higher level of consistency between the interviewers. Results from the study suggested that greater consistency between the interviewers will not only simplify the data capturing process but is also likely to allow

[12] Targeted prevention programmes are prevention programmes that are specifically directed at women who are either known to drink frequently and in a high-risk manner, women who have been diagnosed as being dependent on alcohol use or women who have previously given birth to a baby with FASD (Warren et al., 2011).

for data that can effectively be used in future research studies. Such research will not only help to determine the incidence and prevalence of FASD in various parts of South Africa, but it will also help to develop prevention programmes that are targeted and capable of fulfilling the unique prevention needs of each community.

During the initial focus group interview with the key role players from FARR the extensive use of open ended questions was identified as an aspect that impacted negatively on the amount of data from the maternal interviews that could be used effectively in research studies. The original questionnaire contained a number of open ended questions that contributed to the extensive time spent on a maternal interview and created complications with the capturing and analysis of the data. A main focus during the adjustment phase of the questionnaire was to either change these open ended questions to closed ended questions or to eliminate them from the questionnaire. An interesting finding that was obtained after the questionnaire had been adjusted and used to conduct maternal interviews was that, even though open ended questions take a lot of time to complete during an interview, all the participants indicated that some open ended questions are valuable and that a few questions of this nature should be included in a maternal interview. Open ended questions were thought to be particularly valuable when the mother was asked to describe her drinking habits throughout her pregnancy, as this would give the interviewer a better overall picture of how much and how often the mother consumed alcohol while she was pregnant with the child of interest.

All of the participants that formed part of the first focus group interview agreed that the maternal interview is an important tool for building a relationship with the mother. Perhaps the most significant finding of this study was that open ended questions seem to enhance the relationship that is formed between the interviewer and the interviewee, as it provides an opportunity for the interviewee to talk freely and spontaneously about her situation. The majority of the participants felt that a relationship between an interviewer and a mother is formed through the mother being able to “tell her story” in response to open ended questions, rather than merely responding to what is being asked during the interview. It was the perception of the focus group members and the participants who had used the adjusted maternal interview as part of this study that, if the mother is given enough time and opportunity to “tell her story”, she will not only be more open about her drinking habits, but she will also be more likely to respond honestly to closed ended questions. Maternal interview questionnaires that are completed honestly and therefore accurately will not only deliver data that can be used in future research studies, but it will also ensure that FASD intervention efforts are more focused in nature.

The argument for including some open ended questions in the maternal interview questionnaire is reinforced by the suggestion from this study that some interviewees might find it easier to answer questions that are open ended, compared to questions that are closed ended. One of the interviewers reported that some of the mothers seemed unsure of how to respond to closed ended questions in the adjusted interview questionnaire. One explanation for this could be that, because a number of possible answers were provided for most of the closed ended questions, the mothers might have felt that there was a “right” and a “wrong” answer and that one of the options were more socially desirable than the others. It is also possible that some of the mothers were less familiar with the format of a closed ended question due to their lower level of education and therefore less experience in answering these types of questions.

A total of six open ended questions were included in the final draft of the adjusted maternal interview questionnaire. The majority of these open ended questions appear in the section titled "Drinking habits of the mother", so that the interviewer can get as much information as possible on how much and how often alcohol was consumed during the pregnancy with the child of interest. Because the questions in this section is of a sensitive nature and might create feelings of guilt and shame for the mother, she might also feel more at ease if she was given the opportunity to "tell her story" in response to open ended questions. During the final phase of the study this section (the section titled "Drinking habits of the mother") was moved to the end of the questionnaire so that the mother would only be asked about her drinking habits later on in the interview. All the study participants agreed with the fact that a mother might be more inclined to respond truthfully to questions regarding her drinking habits if she felt as though she had been able to form a bond with the interviewer.

Section 2.3 of this thesis presents a detailed description of the different maternal factors that are associated with FASD. These factors include the physical characteristics of the mother (including nutrition), psychological factors as well as social influences on the mother (including religiosity) (Viljoen et al., 2005). During the initial focus group interview with FARR's key role players the majority of the participants agreed that it was imperative that the maternal interview questionnaire contained questions related to each one of the known maternal risk factors. This would not only help to measure the individual risk for having a child with FASD of each mother, but it would also ensure that valuable data on maternal risk factors in general is collected. All the focus group members agreed that the purpose of the maternal interview is not to explore each maternal risk factor in detail, but rather to provide an overview of the mother's overall risk for having a child with FASD. The participants felt that, since alcohol consumption by a pregnant woman is the primary risk factor for a child to be born with FASD, questions on the mother's consumption of alcohol during pregnancy and also at the time of the interview should be detailed enough to provide an accurate description of her drinking habits.

Through out the course of the study and specifically during the focus group interviews with the key members of FARR, the important role that the maternal interview plays in the FASD diagnostic process was stressed. A detailed portrayal of the role that the maternal interview currently plays in FASD prevention programmes can be found in section 2.5 of this thesis. According to Chersich et al. (2012) FARR makes use of a three part diagnostic process to diagnose children with FASD. Firstly, all the Grade 1 children from a specific school whose parents have given consent are physically examined by a medical doctor with experience in the field of FASD. Only the mothers or caregivers of the children who present with physical characteristics of FASD are then interviewed. Lastly a developmental assessment is performed on the children who were identified as high risk cases after the physical examination and the interview with the mother or caregiver had been completed.

During the initial focus group interview several of the participants questioned the order in which the physical examination, interview and developmental assessment were performed. Since many children who have FASD do not present with the physical traits related to FAS (Hoyme et al., 2005), one of the focus group members raised the concern that such children could possibly be overlooked during the physical examination and as a result be identified as low risk cases (and their mothers might therefore not be invited to an interview), when they in fact do possibly have FASD. He proposed for the maternal interviews to be completed prior to the physical and developmental

assessments. This would ensure that those mothers with a high risk profile, and particularly the mothers who consumed alcohol during their pregnancy, can be identified before the child is physically and developmentally assessed.This might lead to more accurate identification of children with FASD.

Data from this study indicates that it is far less time consuming to interview mothers and capture the interview data using the adjusted maternal interview questionnaire compared to when the original questionnaire was used. This finding has significance in that a larger number of women can now be interviewed in a shorter time span, which implies that it would be possible to interview all the mothers of the children who have been selected for screening within a given population. This might lead to more children being correctly identified as having FASD and to more mothers and children at risk of or affected by FASD receiving appropriate intervention services.

5.2 Relevance of the study

The main objective of the current study was to revise and adjust the maternal interview questionnaire that is currently used by FARR as part of their FASD prevention programmes. This was achieved by conducting two separate focus group interviews with the key role players from FARR to identify the purpose of the maternal interview questionnaire (as perceived by the participants), as well as identifying the main problems with the original questionnaire.

During the initial focus group interview (that formed part of the first phase of the study) several problems were identified and discussed with the two main problems being the extensive length of the questionnaire as well as the inconsistency with which the interviewers used the questionnaire. Not only did these two problems cause the maternal interviews to be time consuming, but it also prevented the interview data from being used in research. During the second phase of the study the questionnaire was shortened by eliminating questions that were redundant, repetitive or vague. Open ended questions were also minimised in an effort to limit the amount of time it took to complete one interview. The problem with inconsistency between the interviewers was addressed by developing a guideline for the interviewers to use in an effort to lead to more uniform interviewing practices among interviewers.

After the questionnaire had been adjusted, it was used by two interviewers, a data capturer and a data analyst who participated in a larger FASD prevention programme. When questioned on their experience with using the adjusted questionnaire and/or the data it provided, all the so-called interview users agreed that most of the identified problems with the original maternal interview questionnaire were successfully addressed in the adjusted version of the questionnaire. More specifically the results of this research study suggest that more maternal interviews can be conducted in the same time period using the adjusted interview questionnaire compared to when the original questionnaire was used, due to the fact that it is shorter and thus takes less time to complete. Both interviewers also made mention of the fact that the adjusted questionnaire allowed more time for having spontaneous conversations during the interview, which assisted in building a relationship between the mother and the interviewer.

The users of the adjusted maternal interview questionnaire made several suggestions on how the adjusted maternal interview questionnaire could be further adjusted to suit the needs of FARR. These suggestions were addressed during the final phase of the research process, after which the

adjusted questionnaire was finalised. Some of the users' suggestions during the final phase of the study are related to recommendations for future research studies, which are discussed in more detail in the last section of the current chapter. The maternal interview questionnaire that was adjusted as part of this study, has since replaced the maternal interview questionnaire that was originally used by FARR. It is currently the only instrument that is used by FARR to conduct maternal interviews as part of their FASD prevention programmes.

This study followed an action research approach. Greenwood and Levin (2007) defines action research as a form of social research that is carried out by a team (which includes the researcher and the members of an organisation) with the sole purpose of improving the participants' situation and ultimately creating social change. This type of research is usually carried out in stages during which (i) the problems that are to be examined are identified, (ii) actions are taken to overcome these problems and (iii) the results of the actions are interpreted based on what has been learnt during the course of the research. In this study an instrument (the maternal interview questionnaire) that aims to improve the process through which children with FASD are identified and diagnosed, was adjusted by a team comprising of the researcher and a group of key role players from FARR as well as the users of the instrument. The fact that the key role players of FARR were included in all four phases of this study did not only have a positive impact on the validity and trustworthiness of the data that was obtained, but it also ensured that a product (the adjusted maternal interview questionnaire) was developed that is unique in terms of satisfying the needs and objectives of a maternal interview as expressed by FARR's key role players during the first focus group interview.

Findings from this study have indicated that more mothers and caregivers could be interviewed within a given time period using the adjusted maternal interview questionnaire compared to when the original questionnaire was used, due to the fact that the adjusted questionnaire was shorter and took less time to administer. If maternal interviews can be conducted with all of the mothers and caregivers whose children have been included in a particular FASD prevention programme, it could lead to fewer children being overseen based on the fact that they do not present with any physical characteristics related to FASD. The adjusted questionnaire can therefore play an integral role in the early diagnosis of those children who, based on the physical examination, have not been categorised in the high-risk group but who might still have been prenatally exposed to alcohol. For FASD prevention programmes to be influential, the resources used to diagnose children who present with a high risk for the disorder need to be as effective and efficient as possible.

A Speech-Language Therapist can be defined as someone who assists in the promotion of normal communication, as well as the identification, prevention, treatment and management of a variety of developmental or acquired speech, language and oral disorders (DOH, 2012). According to this definition, SLTs have an active role to play, not only in the treatment of communication disorders, but also the prevention of disorders that can lead to communication disorders. The fact that the results of this study will ultimately influence the nature of the FASD prevention programmes that are administered by FARR and the diagnostic processes through which a child is diagnosed with FASD, makes the study relevant to the field of SLT. Research shows that children who have been diagnosed with FASD present with a variety of deficits linked to speech and language including an impaired comprehension of grammar and sentence strucutures, delayed verbal memory as well as problems with the use of language (also known as pragmatic skills) (Coles et al., 2010; Kodituwakku et al., 2006 and Hoyme et al., 2005). As a result of the variety of communication problems that children with

FASD can experience, early identification and diagnosis of these children will ensure that they are referred to an SLT that can provide them with the necessary therapeutic and academic support. If children with FASD are diagnosed at an early age this will not only provide the child and his/her caregivers with the necessary intervention and support but it will also help to prevent secondary Speech-Language disorders.

5.3 Limitations of the study

The main findings from this study were obtained by interviewing some of the key role players from FARR as well as the interviewers, a data capturer and a data analyst who had used the adjusted maternal interview questionnaire as part of an FASD prevention programmes administered by FARR in the town of Kimberley in the Northern Cape. A possible limitation of the study is that these findings were therefore based on the participants' personal experiences and perceptions, which could have impacted negatively on the reliability and validity of the results. The quality of this study's findings could have been enhanced if a more objective method of data collection had also been used. The researcher could for instance have examined completed questionnaires from previous prevention programmes where the original maternal interview questionnaire was used, in order to identify and describe the problems with the data collected through this questionnaire from an outsider's perspective. Such observations and interpretations could then have been discussed with the FARR members that formed part of the research team to ensure that ownership of the research remains with the people who initiated the research and who will implement the instruments and processes suggested by the findings of the research study.

One of the main findings of the study was that the maternal interviews were significantly shorter when the adjusted interview questionnaire was used, compared to when the original interview questionnaire was used. More mothers can thus be interviewed in the same amount of time when the adjusted questionnaire is used. Despite this, the interviewing process that forms part of an FASD prevention programme continues to take up a lot of time. Maternal interviews can only be scheduled once a parent or caregiver of the child has given their consent and this process can be time consuming. Due to time constraints related to this research study only a relatively small sample of mothers and other caregivers of identified children were included in the current study and interviewed using the adjusted maternal interview questionnaire. This highlights another limitation of the study, since the two interviewers, the data capturer and the data analyst could possibly have made a better informed comparison between the adjusted questionnaire and the original questionnaire if they had more experience with using the adjusted questionnaire.

In the current study only the adjusted maternal interview questionnaire was used to interview mothers as part of an FASD prevention programme. This might have negatively influenced the quality of the data that was collected, since the participants had to draw on their past experiences with using the original questionnaire when asked to make a comparison between the two questionnaires. If they had used both the adjusted questionnaire and the original questionnaire as part of the current study, it might have allowed them to make a more direct comparison between the two questionnaires.

Another limitation of this study is the fact that the two interviewers that formed part of this study did not form part of the focus group interviews that were conducted during the first and second phases of the study. They were therefore not explicitly informed regarding the changes that were

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made to the maternal interview questionnaire prior to using the adjusted questionnaire to interview mothers. Due to their absence from the focus group discussions their perceptions could also not be considered in the initial phases of adjusting the questionnaire. Upon selection of the participants that would partake in the focus group interviews, the researcher felt that it was sufficient to select one person who has had experience in interviewing mothers as part of FASD prevention programmes. However, with the benefit of hindsight it is clear that it would have been benefitial to have had input from the two interviewers that formed part of the study, specifically regarding the problems they might have experienced in using the original maternal interview questionnaire. Furthermore, the interviewers were also not given any indication as to which aspects of the questionnaire they would be questioned on during the telephonic interviews. Even though this ensured that the interviewers were not influenced in any way when they conducted the maternal interviews using the adjusted questionnaire, it also meant that they were less conscientious of the aspects that they were going to be questioned on during the telephonic interviews. The interviewers that formed part of the study were able to answer all of the questions during the telephonic interviews between them and the researcher. They were also able to convey to the researcher how they experienced interviewing mothers with the adjusted questionnaire and, more specifically, how this experience compared to using the original questionnaire to conduct maternal interviews. However, it might have been beneficial to have had an informal discussion with the interviewers before they had used the adjusted questionnaire to conduct the maternal interviews so as to orientate them with regards to the general themes that would be addressed in the telephonic interviews afterwards. This might have improved their ability to provide feedback on their perceptions of and experiences with using the adjusted questionnaire during the telephonic interviews, since they would have been more conscious about these aspects while using the adjusted questionnaire to conduct the maternal interviews.

The discussion between the researcher and focus group member B was not electronically recorded or transcribed. During the discussion the researcher made detailed notes and all final adjustments to the questionnaire were made according to these written notes. The fact that the discussion was not recorded could have had a negative influence on the reliability of the results and therefore serves as a limitation of the study. The reliability of the coding decisions that were made regarding the transcripts of the focus group interviews and the telephonic interviews could have been advanced if these were reviewed by a second analyst with experience in terms of qualitative data analysis.

5.4 Recommendations for future research

As part of this study a second questionnaire (questionnaire B) was developed to be used when someone other than the biological mother of the child of interest is being interviewed. Even though the interviewers, data capturer and the data analyst were positive about the development of a second questionnaire for this purpose, both interviewers felt that it could be revised even further. According to one of the interviewers the majority of the caregivers who are interviewed have been caring for the child of interest since the birth of the child. Caregivers are thus likely to be capable of providing more information on the child than is currently catered for in questionnaire B. During the telephonic interviews with the interviewers they indicated that they had used questionnaire B to interview a caregiver of a child on a number of occasions. Talking about their experience with maternal interviews from previous FASD prevention programmes, they reported that it was not unusual for the caregiver of a child to be interviewed, due to the fact that a number of the biological

mothers were deceased or uninvolved in the child's life. The interviewers' suggestions with regards to questionnaire B were discussed with focus group member B during the final phase of the study. Several changes were made to the final draft of this questionnaire, mainly by including more questions on the child of interest. However it is recommended that further studies (that are similar to the current study) be conducted with the purpose of further developing and evaluating this questionnaire B to ensure that it is capable of fulfilling its purpose.

The original English maternal interview questionnaire that was adapted by FARR, was originally only translated into Afrikaans. The focus of the current study was therefore only on the adjustment of these two versions of the questionnaire. It is recommended that future research studies examine the need that FARR might have for the adjusted maternal interview questionnaire to be translated into some of the other official South African languages.

During the initial focus group interview several of the focus group members commented on the inconsistency with which interviewers used the maternal interview questionnaire. Not only did this impact negatively on the data capturing process, but it also created limitations in terms of the suitability of the data for research purposes. In an effort to overcome inconsistency between interviewers, a guideline was developed to instruct interviewers on how to conduct the interviews. Both interviewers that formed part of this study admitted that they had been inconsistent in using the original maternal interview questionnaire in the past. They felt positive about the interviewer guideline that was developed as a part of the current study. Even though they are both experienced interviewers, they indicated that the guideline had helped them to be more consistent when using the adjusted maternal interview questionnaire. It therefore seems as though this interviewer guideline has the potential to increase the consistency with which interviewers use the adjusted questionnaire. Improved consistency in how the adjusted questionnaire is used to conduct maternal interviews will not only have a positive impact on the data capturing process, but it will also ensure that the data from the interviews can be used in future research studies. During the final phase of the study a decision was made that FARR will offer interviewers more focused training on the use of the adjusted maternal interview questionnaire. It is recommended that research be conducted to evaluate whether the interviewer guideline and the accompanied training increase interviewer consistency. FARR can then further revise the interviewer guideline and the proposed training programme in order to ensure a greater level of consistency between interviewers when using the adjusted questionnaire.

During the initial focus group interview, one of the focus group members expressed the need for not only the adjustment and shortening of the original interview questionnaire, but also for the development of a screening questionnaire that could be used to identify mothers with a high risk of having a child or future children with FASD. After the original interview questionnaire had been adjusted, the majority of the focus group members felt that the adjusted questionnaire was short enough to fulfil the role of a screening tool. During the third phase of the study the data analyst indicated that there might still exist a need for a very short screening questionnaire that can be used specifically in those instances where there are constraints with regards to time, finances and personnel. It is recommended that future research focus on (i) determining what the needs and objectives are for a maternal screening questionnaire and (ii) identifying the questions that should be included in such a screening questionnaire. After a screening questionnaire had been developed

it is recommended that it be evaluated as part of a larger FASD prevention programme in an effort to determine its usefulness in identifying cases with a high-risk for FASD.

The quality of the data for this study was possibly negatively influenced by the fact that only the adjusted questionnaire was used to interview mothers. This meant that the participants who used the adjusted questionnaire had to refer back to their past experiences with using the original interview questionnaire when they were asked to make a comparison between the two questionnaires. The fact that they were not able to report on how using the adjusted questionnaire compared to using the original questionnaire within the same population of mothers, might have had a negative impact on the feedback that they were able to give. The quality of the results might also have been negatively influenced by the relatively small number of mothers and caregivers that was interviewed with the adjusted maternal questionnaire. It is recommended that further research on the suitability of the adjusted maternal interview questionnaire is conducted wherein both the original- and adjusted maternal interview questionnaire are used to interview mothers within the same study population. This might enable the interviewers to better compare the two questionnaires. Future studies should also focus on testing the adjusted questionnaire on a larger sample of mothers in order to strengthen the validity of the research results. For the purpose of this study only the so-called users of the maternal interview questionnaire (including the interviewers, the data capturer and the data analyst) were questioned on their experiences with using the adjusted maternal interview questionnaire. It is recommended that future research studies also investigate the perspective of the mothers who are interviewed using the adjusted questionnaire, as this might help to eliminate problems with the questionnaire that the mothers themselves might experience.

According to the focus group members and interviewers that formed part of this study the adjusted maternal interview questionnaire has the ability to overcome most of the problems that were experienced with the original maternal interview questionnaire. The adjusted questionnaire is shorter and takes less time to administer, which means that more mothers and caregivers can be interviewed as part of FARR's FASD prevention programmes. The adjusted questionnaire has since replaced the original questionnaire and is currently the only instrument that is used by FARR to conduct maternal interviews as part of their FASD prevention programmes. Despite the fact that the adjusted questionnaire takes less time to administer, capturing of the maternal interview data continues to be a time-consuming process. Further research on the capturing and analysis aspects of FARR's maternal interview data is recommended to ensure that the interview data can be effectively used in future studies.

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APPENDICES

Appendix A

- Original maternal interview questionnaire (English)

- Original maternal interview questionnaire (Afrikaans)

Appendix B

- Interview guide for the first focus group interview

Appendix C

- Information leaflet and informed consent form for focus group members

Appendix D

- Interview guide for the second focus group interview

Appendix E

- Adjusted maternal interview questionnaire used to conduct interviews as part of prevention programme (English)

- Adjusted maternal interview questionnaire used to conduct interviews as part of prevention programme (Afrikaans)

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- Information leaflet and informed consent form for interviewers (Afrikaans)

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- Informed consent form for mothers and other caregivers who were interviewed (English)

- Informed consent form for mothers and other caregivers who were interviewed (Afrikaans)

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- Interview guide for the telephonic interviews with the interviewers (Afrikaans)

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- Questionnaire for the data capturer and the data analyst

Appendix J

- Final draft of the adjusted maternal interview questionnaire (English)

- Final draft of the adjusted maternal interview questionnaire (Afrikaans)

Appendix K

- List of the original objectives of the maternal interview questionnaire

Appendix L

- First draft of the Questionnaire B (English)

- First draft of the Questionnaire B (Afrikaans)

Appendix M

- Final draft of the Questionnaire B (English)

- Final draft of the Questionnaire B (Afrikaans)

Appendix N

- Guideline for interviewers (English)

- Guideline for interviewers (Afrikaans)

Appendix O

- Letter of approval from the Health Research Ethics Committee of the Faculty of Medicine and Health Sciences of the University of Stellenbosch

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APPENDIX A

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Child of Interest (COI): Maternal Risk Interview (Witzenberg Project)

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Questions regarding background history

1. Name of Interviewer ....

2. Date of interview .... / .... / ....

3. Mother's initials

4. Child's Subject Number [ ] Mother's Subject Number [ ]

5. Child's name ....

6. Child's date of birth ....

7. This interview pertains to:

   (1) FAS child [ ] (2) Deferred child [ ] (3) Control child [ ]

8. Where were you born? (city / name of farm)

   (1) Name of city / village ....

   (2) Name of farm ....

   (3) Unknown [ ] Do not know [ ]

9. Where do you live now?

   (1) On a farm [ ] (2) Informal settlement [ ]

   (3) In a city / village [ ] (4) Other (specify) [ ] ....

10. (1) What is the name of the place where you currently live (if in an informal settlement, describe how to reach your house)

....

....

....

   (2) Please describe your current home circumstances (motivate mother to discuss family situation in order to get a sense of her background, e.g. housing, who does she share the house with, how many individuals in the house, stability in house and family, as well as the risks she faces everyday in the day-to-day living).

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....

....

....

....

11. How many adults do you live with?

12. Who are those adults? (husband, partner, mother, sister, brother, aunt, etc)

....

....

13. How many children do you live with?

14. Who are those children or adolescents? (son(s), daughter(s), niece(s), nephew(s), children of partner, etc)

....

15. Total number of individuals living with mother (INCLUDING herself)?

16. How stressful is your life generally?

(1) Not at all stressful
(2) Somewhat stressful
(3) Medium stressful
(4) Very stressful
(5) Extremely stressful

17. What is / are the sources of stress in your life?

....

....

....

18. How long have you living at your current address? ☐ years ☐ months

19. Where did you live during your pregnancy with the COI?

(1) Same place as in question 7?

Yes	No

(2) Other place

20. How old are you **TODAY**?

[ ] years [ ] months [999] Unknown / do not know

21. What is your date of birth?

day [ ] month [ ] year [ ]

22. To which ethnic or racial group do you belong?

(1) Black [ ] (2) White [ ]
(3) Mixed [ ] (4) Other (specify) [ ]

____

23. For how long did you go to school? [ ]

24. What standard (grade) did you complete? [ ]

25. Would you be interested in receiving adult education?

(1) Yes (2) No (3) Unknown / do not know

26. Do you belong to a religious group?

(1) Yes (2) No (3) Unknown / do not know

27. If yes, to which group do you belong to?

....

28. Does your religion require attendance at religious gatherings, how often do you attend?

(1) Never [ ] (2) Not very often (once per month) [ ]
(3) Often (twice per month) [ ] (4) Very often (weekly) [ ]
(9) Unknown / do not know [ ]

29. Do you pray, and how often do you pray?

(1) Never [ ] (2) Not very often [ ]
(3) Often [ ] (4) Very often [ ]
(9) Unknown / do not know [ ]

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30. Are you currently working?

(1) Yes ☐ (2) No ☐ (3) Unknown / do not know ☐

31. What type of work do you do?

(1) Factory work ☐
(2) Farm work ☐
(3) Office work ☐
(4) Other (specify) ☐ ....
(9) Unknown / do not know ☐

32. Describe exactly the type of work that you do

....

....

33. Tick the occupation group which is most similar to the work that the mother described

(1) Higher executives, major professionals, owners of large businesses ☐
(2) Business managers, medium businesses, lesser professionals, school teachers ☐
(3) Administrative personnel, small businesses, minor professionals ☐
(4) Clerical and Sales, technician, small businesses ☐
(5) Skilled manual (craft workers, artists) ☐
(6) Semi-skilled (factory worker, farm worker who operates machinery) ☐
(7) Unskilled (farm worker, tender of vines, unspecified and unemployed) ☐
(8) Homemaker ☐
(9) Student, person with disability, or no occupation ☐

34. What is your employment status?

(1) Fulltime ☐
(2) Part time (less than 20 h.p.w.) ☐
(3) Seasonal ☐
(4) Unemployed ☐
(5) Not employed because of disability ☐
(6) Not employed and not looking for work ☐
(9) Unknown / do not know ☐

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35. If a seasonal worker, what is the approximate number of weeks worked each year?

[ ] weeks per year

36. How much money do you receive per week when you do work? R

37. If you are a seasonal worker, explain if different amounts are received?

38. How much money per month do you receive from other sources? (pension, child care grant, maintenance, etc)

R

R

39. What is the total weekly income of ALL working members of your immediate family? R

40. Calculate the TOTAL MONTHLY INCOME of all working people in the house R

41. What do you read, listen to, or watch to stay ahead of current events (books, newspapers, radio, television)

(1) None [ ] (2) Newspaper [ ]

(3) Radio [ ] (4) Television [ ]

(5) Hear news from family or friends [ ] (6) Other [ ]

(9) Unknown / do not know [ ]

42. Have you been legally married, if more than once, how many times?

(1) Legally married [ ] (99) Unknown / do not know [ ]

43. History of pregnancy (pregnancies)

(1) How many times have you been pregnant? [ ]

(2) How many children were born at term (term of 9 months)? [ ]

(3) How many children were born too early (pre-term)? [ ]

(4) Have you had any miscarriages? [ ]

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(5) How many of your children are still living?

44. How many of your children are currently staying with you?

45. Do you think that you pregnant now?

(1) Yes (2) No (3) Unsure / maybe

46. If no, are you currently using contraception (family planning)?

(1) Yes (2) No (3) Not currently in a relationship

47. If yes, what method are you currently using?

48. With how many different partners have you had children?

49. How long are you / were you with the father of the COI?

years months

50. Did you plan to have this COI?

(1) Yes (2) No (3) Unsure / maybe

51. Were you practising some sort of birth control before becoming pregnant with the COI?

(1) Yes (2) No (3) Unsure / maybe

52. What type / method of birth control did you use?

53. How old were you when you were pregnant with COI? years

54. What was your marital status while you were pregnant with COI?

(1) Married (2) Widowed

(3) Divorced (4) Separated from husband / partner

(5) Single (6) Unmarried, living with partner

55. During what month of your pregnancy with COI did you first receive prenatal care? month

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56. How many times during your pregnancy with COI did you receive prenatal care? ☐ times

57. How many times did a doctor or a sister / nurse examine you? ☐ times

58. What was the gestational age of COI? (at what month was COI born)

(1) Full term ☐ ? months (2) Pre-term ☐ ? months

59. What problems, if any, did you experience during your pregnancy with COI?

(1) High blood pressure ☐

(2) Diabetes ☐ During what month of your pregnancy? ☐ ? month

(3) Excessive vomiting ☐

(4) Vaginal bleeding ☐

(5) Viruses, for example chicken pox ☐

(6) High fever (over 38^{0}) ☐

(7) Other illness / infection

____

____

(8) Pre-term labour ☐

(9) Some other health problem(s)

____

____

No problems ☐

60. Were you involved in any accident or did you sustain any injuries while you were pregnant with COI?

(1) Yes, specify ....

(2) no

Background history: Now I would like to ask you some questions about your parents, your brothers and sisters. (Try and get as much information as possible regarding the mother's parents, siblings and their children. Are there signs of psychiatric problems in the family? Ask about the cause of death of deceased relatives.)

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61. Is your father still alive?

(1) Yes	(2) No	(3) unknown

62. If deceased, what was the cause of his death?

63. If deceased, was his death alcohol related?

(1) Yes	(2) No	(3) Unknown

64. Is your mother still alive?

(1) Yes	(2) No	(3) Unknown

65. If deceased, what was the cause of her death?

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66. If deceased, was her death alcohol related?

(1)	Yes	(2)	No	(3)	Unknown

67. How would you describe your father's drinking habits while you were growing up?

(1)	Do not know		(2)	Did not drink/light drinking	
(3)	Drank on occasion / mild drinking		(4)	Drank frequently / heavy drinking	
(5)	Had a drinking problem		(6)	Stopped drinking	

68. How would you describe your mother's drinking habits while you were growing up?

(1)	Do not know		(2)	Did not drink/light drinking	
(3)	Drank on occasion / mild drinking		(4)	Drank frequently / heavy drinking	
(5)	Had a drinking problem		(6)	Stopped drinking	

69. How would you describe the drinking habits of your child's father while you were pregnant?

(1)	Do not know		(2)	Did not drink/light drinking	
(3)	Drank on occasion / mild drinking		(4)	Drank frequently / heavy drinking	
(5)	Had a drinking problem		(6)	Stopped drinking	

70. How many of your friends drink alcohol?

(1)	None		(2)	Some	
(3)	Half of my friends		(4)	Most of my friends	
(5)	All		(6)	Does not have friends	

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71. Do you have someone whom you consider to be your best friend?

(1) Yes (2) No (3) Does not have any friends

72. If yes, is your best friend a man or a woman?

Man	Woman

73. How many of your co-workers drink alcohol?

(1)	None		(2)	Some	
(3)	Half of my friends		(4)	Most of my friends	
(5)	All		(6)	Does not have co-workers	

Questions 74 to 79 relate to the DRINKING HABITS of individuals in the mother's social network.

Complete in respect of ALL PERSONS mentioned in the table on page 11.

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Drinking habits of the mother's parents while growing up, all brothers, sisters, current friends and the father of her child while she was pregnant – Table I

	Relative	Usual beverage of choice?	Usual quantity consumed during single drinking session?	Frequency of drinking sessions?	Ever had a drinking problem(s)?	Had a drinking problem in the past?	If not currently a drinker, in recovery?
		1	2	3	4	5	6
74.	Mother's father						
75.	Mother's mother						
76.1	Brother no 1						
76.2	Brother no 2						
76.3	Brother no 3						
76.4	Brother no 4						
76.5	Brother no 5						
76.6	Brother no 6						
76.7	Brother no 7						
76.8	Brother no 8						
76.9	Brother no 9						
76.10	Brother no 10						
77.1	Sister nr 1						
77.2	Sister nr 2						
77.3	Sister nr 3						
77.4	Sister nr 4						
77.5	Sister nr 5						
77.6	Sister nr 6						
77.7	Sister nr 7						

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77.8	Sister nr 8						
77.9	Sister nr 9						
77.10	Sister nr 10						

78.	Child's father while pregnant						
79.	Best friend						

80. Have you consumed alcohol at any time in your life?

(1) Yes (2) No **If NO, go directly to Question 117.**

81. Have you consumed alcohol in the last 12 months?

(1) Yes (2) No

82. Have you consumed alcohol in the last 30 days?

(1) Yes (2) No

83. How old were you when you **first** drank alcohol?

[ ] year Cannot remember 333

84. How old were you when you started drinking alcohol **regularly**?

[ ] year Cannot remember 333

85. Are you still drinking?

(1) Yes (2) No **If NO, go directly to Questions 86 and 97 and then directly to Question 104.**

86. If you have stopped drinking alcohol, when did you stop?

87. If you are still drinking, with whom do you usually drink?

(1) Do you usually drink when you are alone?

(2) Do you usually drink with family members?

(3) Do you usually drink with your friends?

(4) Do you usually drink with your husband / partner?

88. If you are still drinking, what alcoholic beverages do you usually drink?

(1) Beer

(2) Fortified wine (sweet wine, sherry, etc)

(3) Spirits, mixed drinks (brandy, vodka, whiskey, gin, cocktails)

(4) Wine

(5) Combination (specify)

(6) Other (specify)

89. If you are still drinking, where do you usually drink?

(1) At home

(2) At family member's home

(3) At a friend's home

(4) At a shebeen

(5) Outdoors somewhere

(6) On street in town

(7) Some other place (specify)

90. Does your consumption of alcohol change by season?

(1) Yes (2) No

91. Does your consumption of alcohol change because of the weather?

(1) Yes (2) No

92. Does your consumption of alcohol change for some other reason?

(1) Yes (2) No

93. How does it change? Why does it change?

94. When do you usually drink during the week – meaning Monday through to Thursday? (keeping in

mind DOP)?

(1) Does not drink during week
(2) Morning before 12 o'clock
(3) Afternoon from 12 to 6 pm
(4) Evenings from 6 pm until bedtime
(5) Morning and afternoon
(6) Afternoon and evening
(7) Right through the day

95. If you drink during the weekend, do you usually drink on Friday evening, Saturday, Sunday, or on all three days?

(1) Does not drink during weekends
(2) Usually only on Friday evening
(3) Usually on Saturday only
(4) Usually on Sunday only
(5) Usually on Friday and Saturday
(6) Usually on Saturday and Sunday
(7) Usually on all three days (right through the weekend)

96. If you drink during the weekend, on which day and at what time do you drink?

	(1) Friday	(2) Saturday	(3) Sunday
(1) Does not drink during weekends			
(2) Drinks morning before 12 o'clock			
(3) Drinks afternoon from 12 to 6 pm			
(4) Drinks evening from 6 pm until bedtime			
(5) Drinks right through the day			

97. Why do you drink, or why did you drink in the past?

(1) For special occasions
(2) To be social
(3) To be polite
(4) To help me relax
(5) To overcome boredom
(6) To overcome shyness

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(7) Because the people that I know, drink

(8) To feel less anxious or depressed

(9) To feel less tense or nervous

(10) To help me forget my worries

(11) To be part of a group

(12) To help me cope with grief

(13) To help me cope with poverty

(14) Other (specify)

98. How much alcohol do you usually drink during the week?

Total number of drinks

Describe

99. How much alcohol do you usually drink on a Friday?

Total number of drinks

Describe

100. How much alcohol do you usually drink on a Saturday?

Total number of drinks

Describe

101. How much alcohol do you usually drink on a Sunday?

Total number of drinks

Describe

102. Calculate the total number of standard drinks per week

103. Calculate the total number of days per week that alcohol is used

104. Have you every received DOP at anytime in your life?

(1) Yes (2) No **If NO, go directly to Question 109.**

105. Did you get DOP while you were pregnant with the COI?

(1) Yes (2) No

106. Do you currently get DOP?

(1) Yes (2) No

107. In general, how much of the alcohol you drink, is from DOP?

(1) Some : 1 – 2.5%

(2) A lot, but not half: 26 – 50%

(3) More than half, but not all: 51 – 75%

(4) Allmost all: 76 – 100%

108. How much of the alcohol you drink, is purchased or otherwise obtained by you or your husband / partner?

(1) Some : 1 – 2.5%

(2) A lot, but not half: 26 – 50%

(3) More than half, but not all: 51 – 75%

(4) Allmost all: 76 – 100%

109. How many times during the past 12 months have you gotten "high" or drunk on alcohol? times

110. Do you think that you now have a drinking problem?

(1) Yes (2) No (3) Unknown

111. Do you think that you ever had a drinking problem?

(1) Yes (2) No (3) Unknown

112. Why do you think that you have a drinking problem?

....

113. Have you ever tried to stop drinking?

(1) Yes (2) No

114. If yes, how many times have you tried to stop drinking?

times Cannot remember 333

115. Have you ever received treatment for your drinking problem?

(1) Yes (2) No

116. Would you like some help for your drinking problem?

(1) Yes (2) No

Alternative care of children

117. Have any of your children ever been taken from you by a social worker and placed in foster care?

(1) Yes (2) No

118. Why and how many times did it happen?

....

....

119. Have any of your relatives ever had to take care of any of your children for long periods of time?

(1) Yes (2) No

120. Why and how many times did it happen?

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Questions 121 to 123 relate to the mother's DIET.

Complete the table on page 18 indicating everything that the mother had been eating and drinking during the past 24 hours (INCLUDING ALCOHOL).

121. What do you usually eat for breakfast?

122. What do you usually eat for lunch?

123. What do you usually eat in the evening (dinner)?

NUTRITION CHART

Describe the quantity of all food and beverages that you have consumed during the last 24 hours, as well as the time of the day that you had it – Table II

	Time	Type of food	Brand Name	Amount	Preparation
Breakfast					
Beverage					
Morning snack					
Beverage					
Lunch					
Beverage					
Morning snack					
Beverage					
Supper (dinner)					
Beverage					
Morning snack					
Beverage					

124. Calculate the number of calories according to the food and beverages indicated in the table on page 18.

125. How similar were your eating habits while you pregnant with the COI compared to what you ate and drank during the past 24 hours?

(1) About the same ☐ (2) Ate less ☐

(3) Ate more ☐

126. In general, how was your appetite during the time that you were pregnant with COI?

127. Were you often hungry while pregnant with COI because there was not enough food in the house for you to eat?

(1) Yes ☐ (2) No ☐

128. If yes, how often did this happen? (prompt: daily / once a week / once a month, etc)?

129. If yes, what time of the week of month did this usually happen?

130. Why was there not enough food in the house?

(1) Not enough money to buy food ☐ (2) No transport to the shops ☐

(3) Other ☐ Specify

131. Thinking about your eating and drinking habits, do you eat when you are drinking?

(1) Yes ☐ (2) No ☐

(3) Stopped drinking ☐ (4) Not applicable ☐

Describe

132. Do you currently take multi-vitamins?

(1) Yes ☐ (2) No ☐

133. Do you currently take any prescribed medication?

(1) Yes ☐ (2) No ☐

134. Did you take pre-natal vitamins during your pregnancy with the COI?

(1) Yes ☐ (2) No ☐

135. Did you take any prescribed medication during your pregnancy with the COI?

(1) Yes ☐ (2) No ☐

136. If yes, what did you take?

....

137. In general, how stressful was your life while you were pregnant with COI?

(1) Not at all stressful ☐ (2) Somewhat stressful ☐

(3) Quite stressful (medium) ☐ (4) Very stressful ☐

(5) Extremely stressful ☐

138. Why was your life stressful during your pregnancy with COI?

....

139. How much weight did you gain while pregnant with the COI?

(1) Almost nothing ☐ (2) Little ☐

(3) A lot ☐

140. Exactly how much weight did you gain while pregnant with COI?

☐ kg Cannot remember 333

141. Is COI your first, second third child, etc?

....

142. Try to remember: is there a difference between your drinking habits now and what it was in the months before you became pregnant with the COI?

(1) Drank about the same ☐ (2) Drank less ☐

(3) Drank more ☐ (4) Not applicable, did not drink immediately before pregnancy ☐

143. Did you drink alcohol during your pregnancy with the COI?

(1) Yes ☐ (2) No ☐

144. Did your drinking habits change during the *first trimester* of your pregnancy with COI?

(1) Drank about the same ☐ (2) Drank less ☐

(3) Drank more ☐

145. If drinking habits changed during the *first trimester*, why and how did it change?

....

146. Did your drinking habits change during the *second trimester* of your pregnancy with COI?

(1) Drank about the same ☐ (2) Drank less ☐

(3) Drank more ☐

147. If drinking habits changed during the *second trimester*, why and how did it change?

....

148. Did your drinking habits change during the *third trimester* of your pregnancy with COI?

(1) Drank about the same ☐ (2) Drank less ☐

(3) Drank more ☐

149. If drinking habits changed during the *third trimester*, why and how did it change?

....

....

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Use of alcohol during pregnancy with COI

Number of alcoholic drinks usually consumed per week and number of drinking days per week

A standard drink is 350 ml, i.e. 1 can or bottle of beer, 1 glass of wine (129 – 200 ml equals 4 – 7 ounces), 1 mixed drink (cocktail) or 1 shot of liquor.

Type of alcohol	**Monday**	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
Beer							
Wine							
Fortified wine							
Spirits (brandy, mixed drinks, etc)							
DOP							
Other							
Total							

150. Calculate the total number of standard drinks per week

151 Calculate the number of drinking days per week

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Smoking habits

152. Have you smoked or used tobacco at anytime in your life?

(1) Yes (2) No **If NO, go directly to Question 171.**

153. Have you smoked or used tobacco in the last 12 months?

(1) Yes (2) No

154. Have you smoked or used tobacco in the past 30 days?

(1) Yes (2) No

155. How old were you when you **first** smoked or used tobacco?

[ ] years unknown 333

156. How old were you when you started smoking or using tobacco **regularly**?

[ ] years

157. Do you still smoke?

(1) Yes (2) No

158. If you stopped smoking, when did you stop?

....

159. If you smoke cigarettes, how many cigarettes do you smoke per day?

....

160. If you smoke tobacco, what size packet?

(1) Small 12 g [ ] (2) Medium 25 g [ ]

(3) Large 50 g [ ]

161. If you smoke tobacco, how many packets per day? [ ] packets

162. Calculate the total gram tobacco or number of cigarettes smoked during the week

....

163. Try and remember: is there a difference between your drinking habits now and what it was in the months before you became pregnant with COI?

(1) Smoked about the same ☐ (2) Smoked less ☐
(3) Smoked more ☐

164. Did you smoke cigarettes or use smokeless tobacco during your pregnancy with COI?

(1) Yes (2) No

165. Did your smoking habits change during the *first trimester* of your pregnancy with COI?

(1) Smoked about the same ☐ (2) Smoked less ☐
(3) Smoked more ☐

166. If your smoking habits changed during the *first trimester*, what do you think was the reason for this and how did it change?

....

167. Did your smoking habits change during the *second trimester* of your pregnancy with COI?

(1) Smoked about the same ☐ (2) Smoked less ☐
(3) Smoked more ☐

168. If your smoking habits changed during the *second trimester*, what do you think was the reason for this and how did it change?

....

....

169. Did your smoking habits change during the *third trimester* of your pregnancy with COI?

(1) Smoked about the same ☐ (2) Smoked less ☐
(3) Smoked more ☐

170. If your smoking habits changed during the *third trimester*, what do you think was the reason for this and how did it change?

....

....

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Other types of drugs

171. Have you ever used other drugs such as marijuana, cocaine, heroin at any time in your life?

(1) Yes (2) No **If NO, go directly to Question 192.**

172. What other drugs have you used?

---

173. Have you used other drugs in the last 12 months?

(1) Yes (2) No

174. Have you used other drugs in the last 30 days?

(1) Yes (2) No

175. How old were you when you **first** used drugs?

[ ] year unknown 333

176. How old were you when you started using other drugs **regularly**?

[ ] year unknown 333

177. Are you still using other drugs?

(1) Yes (2) No

178. If you have stopped using other drugs, when did you stop?

---

179. How often do you use other drugs?

(1) Once p.m. (2) Two to four times p.m.

(3) Two to three times p.w. (4) More than four times p.w.

180. How much of these other drugs do you normally use?

---

181. Try and remember: is there a difference between your habits to use other drugs now and what it was in the months before you became pregnant with COI?

(1) Used about the same (2) Used less

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(3) Used more ☐

182. Did you use drugs other than tobacco or alcohol during your pregnancy with COI?

(1) Yes ☐ (2) No ☐ **If NO, go directly to Question 192.**

183. What other drugs did you use during the *first trimester* of your pregnancy with COI?

184. Did your habits to use other drugs change during the *first trimester* of your pregnancy with COI?

(1) Used about the same ☐ (2) Used less ☐

(3) Used more ☐

185. If your drug using habits changed during the *first trimester*, what do you think was the reason for the change and how did it change?

....

186. What other drugs did you use during the *second trimester* of your pregnancy with COI?

....

187. Did your habits to use other drugs change during the *second trimester* of your pregnancy with COI?

(1) Used about the same ☐ (2) Used less ☐

(3) Used more ☐

188. If your drug using habits changed during the *second trimester*, what do you think was the reason for the change and how did it change?

....

189. What other drugs did you use during the *third trimester* of your pregnancy with COI?

190. Did your habits to use other drugs change during the *third trimester* of your pregnancy with COI?

(1) Used about the same ☐ (2) Used less ☐

(3) Used more ☐

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191. If your drug using habits changed during the *third trimester,* what do you think was the reason for the change and how did it change?

....

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General Questions

192. Did you breastfeed COI after birth? (1) Yes (2) No

193. If you did, for how long did you breastfeed COI? ____ months

194. Was your drinking habit different during the first two years of COI's life compared to what you have discussed now?

(1) Drank about the same		(2) Drank less	
(3) Drank more		(4) Not applicable	

195. Was your smoking habit different during the first two years of COI's life compared to what you have discussed now?

(1) Smoked about the same		(2) Smoked less	
(3) Smoked more		(4) Not applicable	

196. Was your drug using habit different during the first two years of COI's life compared to what you have discussed now?

(1) Used about the same		(2) Used less	
(3) Used more		(4) Not applicable	

197. Think back to the first two years of COI's life: if you could have those two years back, and make or do things differently, what would you do differently, how would you now bring up COI, what exactly would you do or change? (*The reason for this question is to give some support and nurturance to the mother for the good that she did manage to do and give to her child.*)

....

....

198. Tell me what you think: how can one convince a mother that uses alcohol or other drugs, or smokes while she is pregnant, to stop doing so for the sake of the health of her baby?

....

....

199. What are you hopes and wishes for COI?

....

200. What is the mother's height?

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201.	What is the mother's weight?	
202.	What is the mother's head circumference?	
203.	Calculate the body mass index for the mother.	

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Internal Audit Questions

Confidence rating: is the above information significantly distorted by:

204. The mother's misrepresentation? (1) Yes (2) No

205. The mother's inability to understand? (1) Yes (2) No

206. What was the primary source of "risk" in the mother's life at the time of this pregnancy? Tick all answers that apply to her situation.

(1) Excessive family involvement in alcohol

(2) Significant other uses alcohol

(3) Mother uses other drugs

(4) Mother uses alcohol

(5) Other psychiatric diagnosis (es)

(6) Other (specify) ....

(7) Friends use alcohol

207. Risk category of the mother TODAY for producing future affected child?

(1) High risk

(2) Medium risk

(3) Low risk

(4) Lowest risk

208. Which research group applies to this mother?

(1) Drank during pregnancy: gave birth to FAS child

(2) Drank during pregnancy: gave birth to a deferred child

(3) Drank during pregnancy: gave birth to a child with one or more key features <u>but not FAS OR deferred</u>

(4) Drank during pregnancy: no apparent damage to child

(5) Did not drink during pregnancy: no damage to child

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If data collected is from a source other than the mother, the following two questions must be completed

209. What is / was your relationship with the mother of COI?

(1) Mother
(2) Father
(3) Former husband or life partner
(4) Sister
(5) Brother
(6) Friend
(7) Aunt
(8) Uncle
(9) Grandmother
(10) Grandfather
(11) Specify ....

....

210. On a scale from 1 to 5, with 1 meaning minimal closeness, and 5 being close, how close do / did you feel to ……………………………………………….?

Not at all close		**Medium**		**Extremely close**
1	**2**	**3**	**4**	**5**

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Factors to be considered in response to above questions

1. (a) Contradictory information in child's chart (documentation of intoxication at birth)

   (b) Contradictory information from reliable source

   (c) Contradictory response to questions within the interview

   (d) Subjective assessment / evaluation of the interviewer based on interaction with and observation of the mother or other source of data during the interview e.g. body language, etc.

2. (a) Language

   (b) Intellectual ability

   (c) Psychiatric disorders

   (d) Contradictory responses to questions during the interview

3. (a) **High risk**

   (1) The mother is currently drinking and pregnant
   (2) The mother is currently drinking and is not using any form of birth control
   (3) The mother is currently using other drugs

   (b) Medium risk
   (1) The mother has been abstinent<ly, but is not using any form of birth control
   (2) The mother has been abstinent<ly, however, her husband / partner is still drinking and/or the mother has not made any positive changes to her social situation
   (3) The mother drank only before her pregnancy was diagnosed; she was abstinent for the remainder of the pregnancy
   (4) The mother has been abstinent<ly, and her husband / partner has had a vasectomy

   (c) **Low risk**

   (1) The mother has been abstinent>ly, currently she does not have a husband or partner who is drinking or she does not have a husband / partner
   (2) The mother has been abstinent>yr, and she has made positive changes to her social situation
   (3) The mother is using a semi-permanent method of birth control (depo-provera, norplant)
   (4) The mother has been abstinent>ly and her husband / partner has had a vasectomy
   (5) The mother is currently pregnant and there is no information to suggest any use so far in her pregnancy

   (d) **Lowest risk**

   (1) The mother has had surgical sterilization, tubal legation or a hysterectomy

Guidelyne to questions

1. **Beverage of choice**

    (1) Beer

    (2) Fortified wine

    (3) Spirits (liquor / mixed drinks)

    (4) Wine

    (5) Combination (specify) ……………………………………………………………

    (6) Other (specify) ……………………………………………………………...

    (88) Does not know for sure

    (99) Not applicable; never drank

2. **Usual quantity of alcohol consumed**

    (1) ……………………………………. drinks (prompt: 1 drink, 2, etc)

    (88) Does not know for sure

    (99) Not applicable; never drank

3. **Frequency of drinking**

    (1) At most, once a year

    (2) Several times a year

    (3) One to two times in 3 months

    (4) Once a month

    (5) One to two times a week

    (6) Two to three times a week

    (7) Three to four times a week

    (8) Almost every day

    (9) Every day

    (88) Does not know for sure

    (99) Not applicable; never drank

4. **Has individual ever had a drinking problem which has resulted in loss of a job, trouble**

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with the law, health problems, etc?

(1) Yes

(2) No

(88) Does not know for sure

(99) Not applicable; never drank

5. **Has individual had a drinking problem in the past?**

(1) Yes

(2) No

(88) Does not know for sure

(99) Not applicable; never drank

6. **In recovery?**

(1) Yes

(2) No

(88) Does not know for sure

(99) Not applicable; never drank

COI Maternal Risk Interview

(Witzenberg Project)

Compiled by staff of the Foundation for Alcohol Related Research (FARR):

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Kind onder Bespreking (KoB):

Onderhoud om Risikos vir Moeder te bepaal

(Witzenberg Projek)

INHOUD

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Vraelys om agtergrondsgeskiedenis in te samel

1. Naam van persoon wat onderhoud voer ....

2. Datum van onderhoud .... / .... / ....

3. Moeder se voorletters ....

4. Onderwerp nommer van kind [ ] Onderwerp nommer van moeder [ ]

5. Naam van kind ....

6. Kind se geboortedatum ....

7. Hierdie onderhoud is in verband met 'n kind wat

   (1) [FAS het] (2) [Volle diagnose benodig] (3) [In kontrole groep is]

8. Waar is jy gebore? (stad, dorp, plaas)

   (1) Naam van stad/dorp ....

   (2) Naam van plaas ....

   (3) Onbekend [ ] Weet nie [ ]

9. Waar woon jy nou?

   (1) Op 'n plaas [ ] (2) Informele gemeenskap [ ]

   (3) In 'n stad / dorp [ ] (4) Ander (spesifiseer) [ ] ....

10. (1) Wat is jou adres? (indien informeel, beskryf hoe om jou huis te bereik)

....

....

....

   (2) Vertel asseblief vir my meer oor jou huislike omstandighede (moedig persoon aan om oor algemene situasie te praat om 'n beeld van haar agtergrond te kry, bv. behuising, saam met wie woon sy, hoeveel individue in die huis, stabiliteit binne familie/gesin, asook die tipes risikos waarmee sy daagliks te doene het).

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11. Hoeveel volwasse persone woon saam met jou? [ ]

12. Wie is hulle (man, lewensmaat, familielid – ouers, susters, broers, ens)

....

....

13. Hoeveel kinders en/of adolesente woon in jou huis? [ ]

14. Wie se kinders en/of adolesente is hierdie? (eie kinders – gee geslag, neefs, niggies, kinders van lewensmaat)

....

15. Gee totaal van mense in die huis (moeder ingesluit) [ ]

16. Hoeveel spanning ervaar jy daagliks in jou lewe?

(1) Ervaar nie spanning nie [ ] (2) 'n Bietjie spanning [ ]

(3) Middelmatige spanning [ ] (4) Baie spanning [ ]

(5) Spanning is te veel vir my (spanningsvlak is baie hoog) [ ]

17. Wat is die oorsaak/oorsake vir jou spanning?

....

....

....

18. Hoe lank woon jy al hier? [ ] jare [ ] maande

19. Waar het jy gewoon terwyl jy KoB verwag het?

(1) By dieselfde plek as in vraag 7 hierbo?

Ja	Nee

(2) Ander plek (spesifiseer) ....

20. Hoe oud is jy **VANDAG**?

[ ] jare [ ] maande [999] Onbekend / weet nie

21. Wanneer is jy gebore (datum van geboorte)

dag [ ] maand [ ] jaar [ ]

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22. Aan watter etniese of rassegroep behoort jy?

(1) Swart ☐ (2) Wit ☐

(3) Gemeng ☐ (4) Ander (spesifiseer) ☐

____

23. Hoeveel jaar was jy op skool? ☐

24. Watter standerd het jy klaargemaak? ☐

25. Sal jy daarvan hou om deel te wees van opleiding vir volwasse persone?

(1) Ja (2) Nee (3) Onbekend / weet nie

26. Behoort jy aan 'n kerk of godsdienstige groep?

(1) Ja (2) Nee (3) Onbekend / weet nie

27. Indien wel, wat is die naam van die kerk of godsdienstige groep waaraan jy behoort?

....

28. Verwag die kerk of godsdienstige groep dat jy dienste bywoon, en hoe dikwels woon jy dit by?

(1) Nooit ☐ (2) Nie dikwels (een maal p.m.) ☐

(3) Dikwels (tweekeer p.m.) ☐ (4) Baie dikwels (elke week) ☐

(9) Onbekend / weet nie ☐

29. Indien jy bid, hoe dikwels bid jy?

(1) Nooit ☐ (2) Nie dikwels nie ☐

(3) Dikwels ☐ (4) Baie dikwels ☐

(9) Onbekend / weet nie ☐

30. Werk jy op die oomblik?

(1) Ja (2) Nee (3) Onbekend / weet nie

31. Watter tipe werk doen jy gewoonlik?

(1) Fabriekswerk ☐ (2) Plaaswerk ☐

(3) Kantoorwerk ☐ (4) Ander (beskryf) ☐

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(9) Onbekend / weet nie ☐ ....

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32. Beskryf vir my presies wat jy doen by jou werk.

....

....

33. Plaas 'n regmerk teenoor die beroepsgroep waarin die moeder val, of naaste daaraan.

(1)	Hoë bestuursvlak, hoë professionele pos, eienaar van groot besigheid	
(2)	Sakebestuurder, medium-grootte besigheid, laer vlak professionele pos, onderwyser / onderwyseres	
(3)	Administratiewe pos, klein besigheid, laagvlak professionele pos	
(4)	Klerklike en verkoopswerk, tegnies, baie klein besigheid	
(5)	Opgeleide handvaardigheid (kunsvlyt, kunstenaars)	
(6)	Semi-opgelei (fabrieks- of plaaswerker wat masjinerie bestuur / hanteer)	
(7)	Onopgelei (plaaswerk, wynlande, ongespesifiseer en werkloos)	
(8)	Huisvrou	
(9)	Student, persoon met gestremdheid, geen beroep	

34. Wat is jou werk status?

(1)	Voltyds		(2)	Deeltyds (minder as 20 ure per week)	
(3)	Seisoenwerk		(4)	Werkloos	
(5)	Werkloos as gevolg van gestremdheid		(6)	Werkloos en soek nie werk nie	
(9)	Onbekend / weet nie				

35. Indien jy seisoenwerk doen, hoeveel weke per jaar werk jy min of meer?

[ ] weke per jaar

36. Wanneer jy werk, hoeveel geld verdien jy per week? R

37. Indien jy seisoenwerk doen, word verskillende bedrae betaal?

....

38. Het jy enige ander inkomste per maand (bv pensioen, kindertoelae, onderhoud, ens.) en hoeveel is dit per maand?

.... R

....	R
39. Bereken die totale inkomste per maand van ALLE werkende familielede in die huis	R

40. Bereken die TOTALE MAANDELIKSE INKOMSTE van almal wat in die huis werk.	R

41. Wat lees jy, of waarna luister of kyk jy sodat jy kan weet wat in die land gebeur? (boeke, koerante, radio, televisie)

(1)	Niks		(2)	Koerant	
(3)	Radio		(4)	Televisie	
(5)	Hoor nuus van vriende of familie		(6)	Ander:	
(9)	Onbekend / weet nie			....	

42. Hoeveel keer was jy al wettiglik getroud?

(1)	Wettiglik getroud		(99)	Onbekend / weet nie	

43. Geskiedenis van swangerskappe

(1)	Hoeveel keer was jy al swanger?	
(2)	Hoeveel kinders is op volle termyn (9 maande swangerskap) gebore?	
(3)	Hoeveel kinders is te vroeg gebore?	
(4)	Het jy al ooit 'n miskraam gehad?	
(5)	Hoeveel kinders het jy wat tans nog lewe?	
44.	Hoeveel van jou kinders woon tans saam met jou?	

45. Dink jy dat jy op die oomblik swanger is?

(1)	Ja	(2)	Nee	(3)	Onseker / mag wees

46. Indien nie, gebruik jy voorbehoedmiddels (gesinsbeplanning)?

(1)	Ja	(2)	Nee	(3)	Nie in 'n verhouding op die oomblik nie

47. Indien ja, watter metode gebruik jy op die oomblik om NIE swanger te raak nie?

....

48. Indien jou kinders nie almal dieselfde pa het nie, met hoeveel mans het jy kinders gehad?

49. Hoe lank woon jy of het jy saam met die pa van KoB gewoon?

[ ] jaar [ ] maande

50. Toe jy swanger was met KoB, het jy die swangerskap beplan?

(1) Ja (2) Nee (3) Onseker / mag wees

51. Het jy enige tipe voorbehoedmiddel gebruik voordat jy swanger geraak het met KoB?

(1) Ja (2) Nee (3) Onseker / mag wees

52. Indien ja, watter tipe voorbehoedmiddel het jy gebruik?

53. Hoe oud was jy toe jy swanger geraak het met KoB? [ ] jaar

54. Wat was jou huwelikstatus terwyl jy KoB verwag het?

(1)	Getroud	[ ]	(2)	Weduwee	[ ]
(3)	Geskei	[ ]	(4)	Verwyderd van man	[ ]
(5)	Enkellopend	[ ]	(6)	Ongetroud, leef saam	[ ]

55. Gedurende watter maand van jou swangerskap met KoB het jy vir die eerste keer voorgeboorte-sorg ontvang? [ ] maand

56. Hoeveel keer het jy voorgeboorte-sorg ontvang terwyl jy KoB verwag het? [ ] keer

57. Hoeveel keer het 'n dokter of suster / verpleegster jou ondersoek? [ ] keer

58. Op watter stadium van jou swangerskapperiode is KoB gebore?

(1) Volle termyn [? maande] (2) Te vroeg gebore [? maande]

59. Indien jy probleme tydens jou swangerskapperiode gehad het, wat was dit?

(1) Hoë bloeddruk [ ]

(2) Diabetes [ ] Tydens watter maand van die swangerskap? [? maand]

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(3) Erge braking (opgooi)

(4) Vaginale bloeding

(5) Virusse byvoorbeeld waterpokkies

(6) Hoë koors (oor 38°C)

(7) Ander siektes of infeksies

(8) Te vroeg gebore

(9) Enige ander gesondheidsprobleme

(10) Geen probleme

60. Was jy betrokke in enige ongeluk, of het jy beserings opgedoen terwyl jy swanger was met KoB?

(1) Ja, spesifiseer

(2) Nee

Agtergrond: Nou wil ek graag 'n paar vrae oor jou familie vra. (Probeer om soveel inligting as moontlik oor die moeder se ouers, broers, susters en hul kinders te kry. Is daar enige voorkoms van psigiatriese probleme in die familie? Verkry die oorsake van familielede se dood waar moontlik.)

61. Leef jou vader nog?

(1) Ja (2) Nee (3) Onbekend / weet nie

62. Indien hy nie meer leef nie, wat was die oorsaak van sy dood?

63. Indien hy nie meer leef nie, dink jy dat hy dalk dood is as gevolg van alkoholgebruik?

(1) Ja (2) Nee (3) Onbekend / weet nie

64. Leef jou moeder nog?

(1) Ja (2) Nee (3) Onbekend / weet nie

65. Indien sy nie meer leef nie, wat was die oorsaak van haar dood?

66. Indien sy nie meer leef nie, dink jy dat sy dalk dood is as gevolg van alkoholgebruik?

(1) Ja (2) Nee (3) Onbekend / weet nie

67. Vertel vir my wat jou vader se drinkgewoontes was terwyl jy grootgeword het.

(1) Weet nie

(2) Het nie gedrink nie / het min gedrink

(3) Het nou en dan tydens gebeurtenisse gedrink

(4) Het dikwels gedrink / swaar gedrink

(5) Het 'n drankprobleem gehad

(6) Het opgehou – is nou sober

68. Vertel vir my wat jou moeder se drinkgewoontes was terwyl jy grootgeword het.

(1) Weet nie

(2) Het nie gedrink nie / het min gedrink

(3) Het nou en dan tydens gebeurtenisse gedrink ☐ (4) Het dikwels gedrink / swaar gedrink ☐

(5) Het 'n drankprobleem gehad ☐ (6) Het opgehou – is nou sober ☐

69. Vertel vir my wat jou man / lewensmaat se drinkgewoontes was terwyl jy KoB verwag het.

(1) Weet nie ☐ (2) Het nie gedrink nie / het min gedrink ☐

(3) Het nou en dan tydens gebeurtenisse gedrink ☐ (4) Het dikwels gedrink / swaar gedrink ☐

(5) Het 'n drankprobleem gehad ☐ (6) Het opgehou – is nou sober ☐

70. Hoeveel van jou vriende drink alkohol?

(1) Geeneen ☐ (2) Sommige ☐

(3) Die helfte van my vriende ☐ (4) Die meeste van my vriende ☐

(5) Almal ☐ (6) Het nie vriende nie ☐

71. Het jy 'n vriend/vriendin wat jy as jou beste maat beskou?

(1) Ja (2) Nee (3) Het geen vriende nie

72. Indien ja, is jou beste maat 'n man of 'n vrou?

Man	Vrou

73. Hoeveel van die mense saam met wie jy werk, drink alkohol?

(1) Geeneen ☐ (2) Sommige ☐

(3) Die helfte ☐ (4) Die meeste ☐

(5) Almal ☐ (6) Het nie medewerkers nie ☐

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Vrae 74 tot 79 handel oor die DRINKGEWOONTES van individue in die swanger vrou se maatskaplike / sosiale netwerke.

Voltooi ten opsigte van ALLE PERSONE wat in die tabel op bladsy 11 genoem word.

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Drinkgewoontes van die swanger vrou se ouers terwyl sy grootgeword het, alle broers, susters, huidige vriende en die kind se vader tydens swangerskap – Tabel I

	Familielid	Tipe drank gewoonlik, eie keuse?	gewoonlik gedrink per enkele drink-geleentheid?	Hoe dikwels vind drink-geleenthede plaas?	Al ooit 'n drankprobleem gehad?	Het 'n drankprobleem in die verlede gehad?	tans gedrink word, is persoon onder behandeling?
		1	2	3	4	5	6
74.	Vrou se Vader						
75.	Vrou se Moeder						
76.1	Broer nr 1						
76.2	Broer nr 2						
76.3	Broer nr 3						
76.4	Broer nr 4						
76.5	Broer nr 5						
76.6	Broer nr 6						
76.7	Broer nr 7						
76.8	Broer nr 8						
76.9	Broer nr 9						
76.10	Broer nr 10						
77.1	Suster nr 1						
77.2	Suster nr 2						
77.3	Suster nr 3						
77.4	Suster nr 4						
77.5	Suster nr 5						
77.6	Suster nr 6						
77.7	Suster nr 7						

77.8	Suster nr 8						
77.9	Suster nr 9						
77.10	Suster nr 10						

78.	Kind se vader tydens swangerskap						
79.	Beste vriend / vriendin						

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80. Het jy al ooit op enige stadium van jou lewe, alkohol gebruik?

(1) Ja (2) Nee **Indien NEE, gaan direk na Vraag 117.**

81. Het jy tydens die afgelope 12 maande alkohol gebruik?

(1) Ja (2) Nee

82. Het jy tydens die afgelope 30 dae alkohol gebruik?

(1) Ja (2) Nee

83. Hoe oud was jy toe jy alkohol vir die **eerste keer** begin gebruik het?

jaar Kan nie onthou nie 333

84. Hoe oud was jy toe jy begin het om alkohol **gereeld** te gebruik?

jaar Kan nie onthou nie 333

85. Drink jy nog?

(1) ja (2) Nee **Indien NEE, gaan na Vrae 86 en 97 en dan direk na Vraag 104.**

86. As jy nie meer alkohol gebruik nie, wanneer het jy opgehou om te drink?

---

87. Indien jy nog drink, saam met wie drink jy gewoonlik?

(1) Drink jy gewoonlik wanneer jy alleen is?

(2) Drink jy gewoonlik saam met jou familielede?

(3) Drink jy gewoonlik saam met jou vriende?

(4) Drink jy gewoonlik saam met jou man / lewensmaat?

88. Watter tipe alkohol gebruik jy gewoonlik?

(1) Bier

(2) Versterkte wyn (soetwyn, sjerrie)

(3) Sterk drank, gemende drankies (brandewyn, vodka, whiskey, gin)

(4) Wyn

(5) Kombinasie (spesifiseer)

....

(6) Ander (spesifiseer) ....

....

89. Indien jy nog alkohol gebruik, waar drink jy gewoonlik?

(1) By die huis	☐	(2) By familielede se huis	☐
(3) By 'n vriend se huis	☐	(4) By 'n sjebeen	☐
(5) Buite iewers	☐	(6) Op straat in die dorp/stad	☐
(7) Ander plekke, spesifiseer			

....

90. Drink jy meer of minder in verskillende seisoene?

(1) Ja (2) Nee

91. Drink jy meer of minder soos wat die weer verander?

(1) Ja (2) Nee

92. Drink jy meer of minder om enige ander rede?

(1) Ja (2) Nee

93. Hoe het dit verander, hoe verander dit, waarom verander dit?

....

....

94. Indien jy van Maandag tot Donderdag drink, wanneer drink jy gewoonlik? (hou in gedagte DOP)

(1) Drink nie gedurende week	☐	(2) Soggens voor 12 uur	☐
(3) Middae vanaf 12 tot 6 nm	☐	(4) Saans vanaf 6 tot slaaptyd	☐
(5) Soggens en middae	☐	(6) Middae en saans	☐
(7) Dwarsdeur die dag	☐		

95. Indien jy tydens naweke drink, drink jy gewoonlik op Vrydagaande, Saterdae, Sondae of dwarsdeur die naweek?

(1) Drink nie gedurende naweke	☐	(2) Gewoonlik net Vrydagaande	☐
(3) Gewoonlik net Saterdae	☐	(4) Gewoonlik net Sondae	☐
(5) Gewoonlik net Vrydae en	☐	(6) Gewoonlik net Saterdae en	☐

Saterdae ☐ Sondae ☐

(7) Gewoonlik op al drie dae, dwarsdeur die naweek ☐

96. Indien jy gedurende naweke drink, op watter dag en watter tyd van die dag drink jy?

	(1) Vrydag	(2) Saterdag	(3) Sondag
(1) Drink nie gedurende naweke nie			
(2) Drink soggens voor 12 uur			
(3) Drink middae van 12 tot 6 nm			
(4) Drink saans van 6 tot slaaptyd			
(5) Drink dwarsdeur die dag			

97. Waarom drink jy, of waarom het jy in die verlede gedrink?

(1) Om 'n spesiale geleentheid te vier ☐

(2) Om sosiaal te verkeer met mense ☐

(3) Om beleefd te wees ☐

(4) Om my te help ontspan ☐

(5) Om verveeldheid te oorkom ☐

(6) Om skaamheid te oorkom ☐

(7) Omdat die mense wat ek ken, drink ☐

(8) Om minder angstig of depressief te voel ☐

(9) Om minder gespanne of senuweeagtig te voel ☐

(10) Om my te help om my bekommernisse te vergeet ☐

(11) Om deel van 'n groep te wees ☐

(12) Om my te help om my hartseer te hanteer ☐

(13) Om my te help om my armoede beter te hanteer ☐

(14) Ander (spesifiseer)

....

....

98. Hoeveel alkohol gebruik jy gewoonlik gedurende die week?

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Aantal drankies ....

Beskryf ....

....

99. Hoeveel alkohol gebruik jy gewoonlik op 'n Vrydag?

Aantal drankies ....

Beskryf ....

....

100. Hoeveel alkohol gebruik jy gewoonlik op 'n Saterdag?

Aantal drankies ....

Beskryf ....

....

101. Hoeveel alkohol gebruik jy gewoonlik op 'n Sondag?

Aantal drankies ....

Beskryf ....

....

102. Bereken totale aantal standaard drankies per week [ ]

103. Bereken aantal dae per week wat alkohol gebruik word [ ]

104. Het jy ooit in jou lewe DOP ontvang?

(1) [Ja] (2) [Nee] **Indien NEE, gaan direk na Vraag 109.**

105. Het jy DOP gekry terwyl jy swanger was met KoB?

(1) [Ja] (2) [Nee]

106. Kry jy nou DOP?

(1) [Ja] (2) [Nee]

107. Hoeveel van die alkohol wat jy gewoonlik gebruik, kom van DOP?

(1) Party: 1 tot 2.5% [ ]

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(2) Baie, maar nie soveel as die helfte nie: 26 tot 50%

(3) Meer as die helfte, maar nie alles nie: 51 tot 75%

(4) Feitlik alles: 76 tot 100%

108. Hoeveel alkohol wat jy gebruik, word deur jou of jou man / lewensmaat gekoop of iewers verkry?

(1) Party: 1 tot 2.5%

(2) Baie, maar nie soveel as die helfte nie: 26 tot 50%

(3) Meer as die helfte, maar nie alles nie: 51 tot 75%

(4) Feitlik alles: 76 tot 100%

109. Hoeveel keer gedurende die afgelope 12 maande, het jy beskonke of dronk geword van alkohol? keer

110. Dink jy dat jy nou 'n drankprobleem het?

(1) Ja (2) Nee (3) onbekend

111. Dink jy dat jy ooit 'n drankprobleem gehad het?

(1) Ja (2) Nee (3) onbekend

112. Waarom dink jy dat jy 'n drankprobleem het?

....

113. Het jy al ooit in die verlede probeer om op te hou met drink?

(1) Ja (2) Nee

114. Indien ja, hoeveel keer het jy probeer om op te hou met drink?

keer Kan nie onthou nie 333

115. Het jy al ooit behandeling vir jou drankprobleem ontvang?

(1) Ja (2) Nee

116. Sou jy graag wil hê dat iemand jou moet help sodat jy kan ophou met drink?

(1) Ja (2) Nee

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Alternatiewe Sorg vir kinders

117. Is enige van jou kinders ooit deur 'n maatskaplike werker in pleegsorg geplaas?

(1) Ja (2) Nee

118. Waarom, en hoe dikwels het dit al gebeur?

....

....

119. Moes enige van jou familielede al ooit jou kinders oor 'n lang periode versorg?

(1) Ja (2) Nee

120. Waarom, en hoe dikwels het dit al gebeur?

____

Vrae 121 tot 123 handel oor die EETGEWOONTES van die swanger vrou. Voltooi ook die tabel op bladsy 18. Vul in alles wat die moeder oor die afgelope 24 uur geëet en gedrink het (ALKOHOL INGESLUIT).

121. Wat eet jy gewoonlik vir ontbyt?

....

122. Wat eet jy gewoonlik vir middagete?

....

123. Wat eet jy gewoonlik vir aandete?

____

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VOEDINGSKAART

Beskryf die hoeveelheid kos en drank wat gebruik word, asook die tyd van die dag wat dit geniet word – Tabel II

	Tyd	Tipe kos	Naam van kos	Bedrag	Voorbereiding
Ontbyt					
Drank (tee, ens)					
Happie tussen etes					
Drank (tee, ens)					
Middagete					
Drank (tee, ens)					
Happie tussen etes					
Drank (tee, ens)					
Aandete					
Drank (tee, ens)					
Happie na ete					
Drank (tee, ens)					

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124. Bereken die aantal kalorië volgens kos en drankies in tabel aangedui.

---

125. As jy dink aan wat jy gister geëet het, hoe vergelyk dit met wat jy geëet het terwyl jy met KoB swanger was?

(1) Min of meer dieselfde geëet ☐ (2) Het minder geëet ☐

(3) Het meer geëet ☐

126. Hoe was jou aptyt in die algemeen terwyl jy KoB verwag het?

---

127. Terwyl jy KoB verwag het, was jy dikwels honger omdat daar net nie genoeg kos in die huis was om te eet nie?

(1) Ja (2) Nee

128. Indien ja, hoe dikwels het dit gebeur? (probeer uitvind of dit daagliks, een keer per week of maandeliks was, ens.)

---

129. Indien ja, watter tyd van die week of maand het dit gewoonlik gebeur?

---

130. Waarom was daar nie genoeg kos in die huis nie?

(1) Nie genoeg geld om te koop nie ☐ (2) Geen vervoer na die winkels nie ☐

(3) Ander ☐ Spesifiseer

131. Dink nou goed na oor jou eet- en drinkgewoontes en vertel my of jy eet wanneer jy drink?

(1) Ja ☐ (2) Nee ☐

(3) Het opgehou met drink ☐ (4) Nie van toepassing ☐

Beskryf

---

132. Neem jy op hierdie stadium multi-vitamiene?

(1) Ja ☐ (2) Nee

133. Neem jy op hierdie stadium enige ander medisyne wat vir jou voorgeskryf is?

(1) Ja ☐ (2) Nee

134. Het jy enige vitamienes voor die geboorte van KoB geneem?

(1) Ja ☐ (2) Nee ☐

135. Het jy enige ander medisyne wat vir jou voorgeskryf was, voor die geboorte van KoB geneem?

(1) Ja ☐ (2) Nee ☐

136. Indien ja, wat was dit wat jy geneem het?

....

137. In die algemeen, hoeveel spanning het jy gehad terwyl jy swanger was met KoB?

(1) Geen spanning ☐ (2) Effens gespanne ☐

(3) Middelmatige spanning ☐ (4) Baie gespanne ☐

(5) Spanningsvlak baie hoog ☐

138. Indien jy gespanne was tydens your swangerskap, wat was die rede daarvoor?

....

139. Hoeveel gewig het jy aangesit terwyl jy swanger was met KoB?

(1) Amper niks ☐ (2) Bietjie ☐

(3) Baie ☐

140. Presies hoeveel gewig het jy aangesit terwyl jy swanger was met KoB?

☐ kg Kan nie onthou nie 333

141. Is KoB jou eerste, tweede kind, ens?

....

142. Probeer onthou: is daar 'n verskil tussen jou drinkgewoontes nou en wat dit was in die maande voordat jy met KoB swanger geraak het?

(1) Drink omtrent dieselfde ☐ (2) Drink minder ☐

(3) Drink meer ☐ (4) Nie van toepassing, het nie onmiddellik voor swangerskap gedrink nie ☐

143. Het jy alkohol gebruik terwyl jy KoB verwag het?

(1) Ja ☐ (2) Nee ☐

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144. Het jou drinkgewoontes verander tydens die *eerste drie maande* wat jy KoB verwag het?

(1) Het omtrent dieselfde gedrink ☐ (2) Het minder gedrink ☐

(3) Het meer gedrink ☐

145. Indien jou drinkgewoontes tydens die *eerste drie maande* verander het, wat dink jy was die rede daarvoor en hoe het dit verander?

....

....

146. Het jou drinkgewoontes verander tydens die *tweede drie maande* wat jy KoB verwag het?

(1) Het omtrent dieselfde gedrink ☐ (2) Het minder gedrink ☐

(3) Het meer gedrink ☐

147. Indien jou drinkgewoontes tydens die *tweede drie maande* verander het, wat dink jy was die rede daarvoor en hoe het dit verander?

....

....

148. Het jou drinkgewoontes verander tydens die *laaste drie maande* wat jy KoB verwag het?

(1) Het omtrent dieselfde gedrink ☐ (2) Het minder gedrink ☐

(3) Het meer gedrink ☐

149. Indien jou drinkgewoontes tydens die *laaste drie maande* verander het, wat dink jy was die rede daarvoor en hoe het dit verander?

....

....

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Gebruik van Alkohol tydens swangerskap met KoB

Aantal alkoholiese drankies wat gewoonlik per week gebruik was, asook die aantal dae per week wat alkohol gebruik was – Tabel III

‘n standaard drankie is 350 ml, m.a.w. 1 blikkie of ‘n bottel bier, 1 glas wyn (129 – 200 ml = 4 – 7 onse), 1 gemengde drankie (“cocktail”) of 1 ‘tot’ spiritualië (sterk drank).

Soort alkohol	Maandag	Dinsday	Woensdag	Donderdag	Vrydag	Saterdag	Sondag
Bier							
Wyn							
Versterkte wyn							
Spiritualië (brandewyn, gemengde drankies, ens)							
DOP							
Ander							
Totaal							

150. Bereken die totale aantal standaard drankies per week

151 Bereken die aantal dae per week wat die persoon gedrink het

Rookgewoontes

152. Het jy ooit op enige stadium van jou lewe gerook of tabak (twak) gebruik?

(1) Ja (2) Nee **Indien NEE, gaan direk na Vraag 171.**

153. Het jy gerook of tabak (twak) gedurende die afgelope 12 maande gebruik?

(1) Ja (2) Nee

154. Het jy gerook of tabak (twak) gedurende die afgelope 30 dae gebruik?

(1) Ja (2) Nee

155. Hou oud was jy toe jy vir die **eerste keer** gerook of tabak (twak) gebruik het?

[ ] jaar onbekend 333

156. Hou oud was jy toe jy **gereeld** begin rook of tabak (twak) gebruik het?

[ ] jaar

157. Rook jy nog?

(1) Ja (2) Nee

158. Indien jy opgehou rook het, wanneer het jy opgehou?

....

159. Indien jy sigarette rook, hoeveel sigarette rook jy per dag?

....

160. Indien jy tabak (twak) rook, watter grootte pakkie koop jy?

(1) Klein 12 g (2) Medium 25 g

(3) Groot 50 g

161. Indien jy tabak (twak) rook, hoeveel pakkies gebruik jy per dag? [ ] pakkies

162. Bereken die totale aantal sigarette of kilogram tabak (twak) gerook gedurende die afgelope week.

....

163. Probeer onthou: is daar 'n verskil tussen jou rookgewoontes nou en wat dit was in die maande voordat jy met KoB swanger geraak het?

(1) Omtrent dieselfde gerook ☐ (2) Minder gerook ☐

(3) Meer gerook ☐

164. Het jy sigarette gerook of rooklose tabak gebruik terwyl jy KoB verwag het?

(1) Ja ☐ (2) Nee ☐

165. Het jou rookgewoontes verander tydens die *eerste drie maande* wat jy KoB verwag het?

(1) Het omtrent dieselfde gerook ☐ (2) Het minder gerook ☐

(3) Het meer gerook ☐

166. Indien jou rookgewoontes tydens die *eerste drie maande* verander het, wat dink jy was die rede daarvoor en hoe het dit verander?

....

167. Het jou rookgewoontes verander tydens die *tweede drie maande* wat jy KoB verwag het?

(1) Het omtrent dieselfde gerook ☐ (2) Het minder gerook ☐

(3) Het meer gerook ☐

168. Indien jou rookgewoontes tydens die *tweede drie maande* verander het, wat dink jy was die rede daarvoor en hoe het dit verander?

....

....

169. Het jou rookgewoontes verander tydens die *laaste drie maande* wat jy KoB verwag het?

(1) Het omtrent dieselfde gedrink ☐ (2) Het minder gedrink ☐

(3) Het meer gedrink ☐

170. Indien jou rookgewoontes tydens die *laaste drie maande* verander het, wat dink jy was die rede daarvoor en hoe het dit verander?

....

....

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Ander verdowingsmiddels

171. Het jy ooit op enige stadium van jou lewe ander verdowingsmiddels soos dagga, kokaïene of heroine gebruik?

(1) Ja (2) Nee **Indien NEE, gaan direk na Vraag 192.**

172. Watter ander middels het jy gebruik?

173. Het jy enige ander middels gedurende die afgelope 12 maande gebruik?

(1) Ja (2) Nee

174. Het jy enige ander middels gedurende die afgelope 30 dae gebruik?

(1) Ja (2) Nee

175. Hou oud was jy toe jy vir die **eerste keer** ander verdowingsmiddels begin gebruik het?

jaar onbekend 333

176. Hou oud was jy toe jy ander verdowingsmiddels **gereeld** begin gebruik het?

jaar onbekend 333

177. Gebruik jy nog ander verdowingsmiddels?

(1) Ja (2) Nee

178. Indien jy opgehou het om ander verdowingsmiddels te gebruik, wanneer het jy opgehou?

179. Indien jy nog ander verdowingsmiddels gebruik, hoe gereeld gebruik jy dit?

(1) Een maal p.m. (2) Twee tot vier keer p.m.

(3) Twee tot drie keer p.w. (4) Meer as vier keer p.w.

180. Hoeveel van hierdie ander verdowingsmiddels gebruik jy gewoonlik?

181. Probeer onthou: is daar 'n verskil tussen jou gewoontes t.o.v. die gebruik van ander verdowingsmiddels nou en wat dit was in die maande voordat jy met KoB swanger geraak het?

(1) Omtrent dieselfde ☐ (2) Minder gebruik ☐

(3) Meer gebruik ☐

182. Het jy middels ander dan tabak of alkohol gebruik terwyl jy swanger was met KoB?

(1) Ja ☐ (2) Nee ☐ **Indien NEE, gaan direk na Vraag 192.**

183. Watter ander verdowingsmiddels het jy gebruik gedurende die *eerste drie maande* wat jy met KoB swanger was?

....

184. Het jou gewoontes t.o.v. die gebruik van ander verdowingsmiddels verander tydens die *eerste drie maande* wat jy KoB verwag het?

(1) Het omtrent dieselfde gebruik ☐ (2) Het minder gebruik ☐

(3) Het meer gebruik ☐

185. Indien jou gewoontes t.o.v. die gebruik van ander verdowingsmiddels tydens die *eerste drie maande* verander het, wat dink jy was die rede daarvoor en hoe het dit verander?

....

186. Watter ander verdowingsmiddels het jy tydens die *tweede drie maande* wat jy KoB verwag het, gebruik?

....

187. Het jou gewoontes t.o.v. die gebruik van ander verdowingsmiddels verander tydens die *tweede drie maande* wat jy KoB verwag het?

(1) Het omtrent dieselfde gebruik ☐ (2) Het minder gebruik ☐

(3) Het meer gebruik ☐

188. Indien jou gewoontes t.o.v. die gebruik van ander verdowingsmiddels tydens die *tweede drie maande* verander het, wat dink jy was die rede daarvoor en hoe het dit verander?

....

189. Watter ander verdowingsmiddels het jy gedurende die *derde drie maande* wat jy KoB verwag het, gebruik?

....

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190. Het jou gewoontes t.o.v. die gebruik van ander verdowingsmiddels verander tydens die *derde drie maande* wat jy KoB verwag het?

(1) Het omtrent dieselfde gebruik ☐ (2) Het minder gebruik ☐

(3) Het meer gebruik ☐

191. Indien jou gewoontes t.o.v. die gebruik van ander verdowingsmiddels tydens die *derde drie maande* verander het, wat dink jy was die rede daarvoor en hoe het dit verander?

Algemene Vrae

192. Het jy KoB geborsvoed na geboorte? (1) Ja (2) Nee

193. Indien jy wel geborsvoed het, vir hoe lank het jy dit gedoen? ☐ maande

194. Was jou drinkgewoontes anders tydens die eerste twee jaar van KoB se lewe as wat jy nou beskryf het?

(1) Het omtrent dieselfde gedrink ☐ (2) Het minder gedrink ☐

(3) Het meer gedrink ☐ (4) Nie van toepassing ☐

195. Het jou rookgewoontes verander tydens die eerste twee jaar van KoB se lewe as wat jy nou beskryf het?

(1) Het omtrent dieselfde gerook ☐ (2) Het minder gerook ☐

(3) Het meer gerook ☐ (4) Nie van toepassing ☐

196. Het jou gewoontes t.o.v. die gebruik van ander verdowingsmiddels verander tydens die eerste twee jaar van KoB se lewe as wat jy nou beskryf het?

(1) Het omtrent dieselfde gebruik ☐ (2) Het minder gebruik ☐

(3) Het meer gebruik ☐ (4) Nie van toepassing ☐

197. Dink terug na die eerste twee jaar van KoB se lewe – as jy daardie twee jaar nou kon terugkry, wat sou jy anders wou doen, sou jy jou kind anders wou grootmaak en in watter opsigte? (*Die rede vir hierdie vraag is om 'n mate van ondersteuning aan die moeder te gee vir die goeie wat sy wel ten opsigte van haar kind gedoen het.*)

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198. Wat dink jy, hoe kan 'n mens 'n vrou wat alkohol of ander verdowingsmiddels gebruik, of rook gedurende haar swangerskap, oortuig om dit terwille van die gesondheid van haar baba, nie te doen nie?

199. Wat is jou hoop en goeie wense vir die KoB?

200. Hoe lank is die swanger vrou?	
201. Hoeveel weeg sy?	
202. Wat is die omtrek van haar kop?	
203. Bereken die liggaam massa indeks vir hierdie vrou	

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Interne Oudit Vrae

Skaal van Betroubaarheid - is inligting gegee tydens onderhoud beduidend benadeel deur:

204. Die moeder het die vrae verkeerd beantwoord (1) Ja (2) Nee

205. Die moeder se onvermoë om die vrae reg te verstaan (1) Ja (2) Nee

206. Wat was die primêre bron van risiko in die moeder se lewe terwyl sy swanger was?

Merk alle antwoorde wat van toepassing is.

(1) Gesin / familie uiters betrokke by gebruik van alkohol

(2) Beduidende ander persoon se gebruik van alkohol

(3) Die moeder gebruik ander verdowingsmiddels

(4) Die moeder gebruik tans alkohol

(5) Ander psigiatriese diagnose(s)

(6) Ander (spesifiseer)

....

(7) Vriende gebruik alkohol

207. In watter risiko kategorie val hierdie moeder om in die toekoms geboorte te gee aan 'n kind wat geaffekteer kan wees?

(1) Hoë risiko

(2) Middelmatige risiko

(3) Lae risiko

(4) Laagste risiko

208. In watter navorsingsgroep sal hierdie moeder val?

(1) Het alkohol gebruik tydens swangerskap en geboorte gegee aan 'n kind met FAS

(2) Het alkohol gebruik tydens swangerskap en geboorte gegee aan 'n kind wat ten volle gediagnoseer moet word

(3) Het alkohol gebruik tydens swangerskap en geboorte gegee aan 'n kind met een of meer sleutel kenmerke (maar NIE FAS nie, en kind het nie volle diagnose

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nodig nie)

(4) Het alkohol tydens swangerskap gebruik sonder beduidende skade aan die kind

(5) Het geen alkohol tydens swangerskap gebruik nie en die kind het geen skade opgedoen nie

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Indien data van 'n ander bron verkry is, moet die volgende twee vrae gevra word

209. Wat is / was jou verhouding met die moeder van KoB?

(1) Moeder

(2) Vader

(3) Vorige man of lewensmaat

(4) Suster

(5) Broer

(6) Vriend / vriendin

(7) Tante

(8) Oom

(9) Ouma

(10) Oupa

(11) Spesifiseer

....

....

210. Op 'n skaal van 1 tot 5, met 1 as minste betrokke en 5 as baie betrokke, hoe na aan

…………………………………………………….. voel jy of het jy gevoel?

Nie regtig betrokke nie		Middelmatig betrokke		Baie na aan moeder
1	2	3	4	5

Faktore wat in aanmerking geneem moet word wanneer bogenoemde vrae beantwoord word

1. (a) Inligting op kind se geboortekaart (dokumentasie in verband met intoksikasie (onder invloed) tydens geboorte) is teenstrydig

(b) Teenstrydige inligting van betroubare bron

(c) Teenstrydige antwoorde op vrae in die onderhoud

(d) Subjektiewe assessering / evaluering van die moeder of ander bron van inligting deur die persoon wat die onderhoud voer, gebaseer op interaksie en waarneming tydens die onderhoud, bv lyftaal, ens.

2. (a) Taal

(b) Intellektuele vermoëns

(c) Psigiatriese toestande

(d) Teenstrydige reaksies op vrae in die onderhoud

3. (a) **Hoë risiko**

(4) Die vrou is swanger en gebruik tans alkohol
(5) Die vrou gebruik alkohol en geen vorm van geboortebeperking
(6) Die vrou gebruik tans ander verdowingsmiddels

(c) Middelmatige risiko

(5) Die vrou is tans sober <, maar gebruik nie enige vorm van geboortebeperking nie
(6) Die vrou is tans sober <, maar haar man / lewensmaat gebruik nog alkohol en/of die vrou het nog nie enige positiewe veranderings in haar maatskaplike omstandighede gemaak nie.
(7) Die vrou het voor haar swangerskap alkohol gebruik, maar het vir die res van haar swangerskap sober gebly.
(8) Die vrou is tans sober < en haar man / lewensmaat het 'n vasektomie gehad.

(c) **Lae ris**iko

(6) Die vrou is tans sober >, en sy het nie nou 'n man / lewensmaat nie of die man gebruik nie alkohol nie.
(7) Die vrou is tans sober >, en sy het positiewe veranderings in haar maatskaplike omstandighede gemaak.
(8) Die vrou gebruik semi-permanente vorms van geboortebeperking (depo-provera, norplant).
(9) Die vrou is tans sober > en haar man / lewensmaat het 'n vasektomie gehad.

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(10) Die vrou is nou swanger en daar is geen aanduiding dat sy tot dusver enige tipe verdowingsmiddels gebruik het nie.

(d) **Laagste risiko**

(1) Die vrou het 'n sjirurgiese sterilisasie, buis-afbinding of 'n historektomie gehad.

Riglyne vir vrae

1. **Drank van eie keuse**

    (1) Bier

    (2) Versterkte wyn

    (3) Spiritualië (sterk alkohol, gemengde drankies)

    (4) Wyn

    (5) Kombinasie (spesifiseer) …………………………………………………………

    (6) Ander (spesifiseer ……………………………………………………………..

    (88) Is nie seker nie

    (99) Nie van toepassing nie, het nooit alkohol gebruik nie

2. **Hoeveelheid alkohol wat gewoonlik gebruik word**

    (1) ……………………………………. drankies (bv 1 drankie, 2, ens)

    (88) Is nie seker nie

    (99) Nie van toepassing nie, het nooit alkohol gebruik nie

3. **Frekwensie van drinkgewoonte**

    (1) Op die meeste een keer per jaar

    (2) Verskeie kere per jaar

    (3) Een of twee keer elke 3 maande

    (4) Een keer per maand

    (5) Een of twee keer per week

    (6) Twee of drie keer per week

    (7) Drie of vier keer per week

    (8) Feitlik elke dag

    (9) Elke dag

    (88) Is nie seker nie

    (99) Nie van toepassing nie, het nooit alkohol gebruik nie

4. **Het die individu ooit 'n drankprobleem gehad wat aanleiding tot die verlies van werk, probleme met die gereg of met gesondheid gegee het?**

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(1) Ja

(2) Nee

(88) Is nie seker nie

(99) Nie van toepassing nie, het nooit alkohol gebruik nie

5. **Het die individu in die verlede 'n drankprobleem gehad?**

(1) Ja

(2) Nee

(88) Is nie seker nie

(99) Nie van toepassing nie, het nooit alkohol gebruik nie

6. **Is die individu tans aan die herstel na 'n drankprobleem?**

(1) Ja

(2) Nee

(88) Is nie seker nie

(99) Nie van toepassing nie, het nooit alkohol gebruik nie

KoB Onderhoud om Risikos vir Moeder te bepaal

(Witzenberg Projek)

Saamgestel deur personeel van die Stigting vir Alkoholverwante Navorsing (FARR):

Professor DL Viljoen

Me Leana Olivier

Vertaal deur Me Ida Wiliams

Stellenbosch University http://scholar.sun.ac.za

Geborg deur die

Departement van Maatskaplike Ontwikkeling, Wes-Kaap

in samewerking met die

Stigting vir Alkoholverwante Navorsing

met ondersteuning van die Wes-Kaapse Onderwysdepartement,

(Witzenberg Distrik)

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APPENDIX B

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INTERVIEW GUIDE FOR FOCUS GROUP ONE

1. Please reflect on and describe your experience (positive or negative) with using the original maternal interview questionnaire.
2. Please describe your needs with regards to a maternal interview questionnaire.
3. In the original maternal interview questionnaire the objectives of a maternal interview is set out as follows:

-To collect data on alcohol use during pregnancy to assist in diagnosing children with FASD

-To describe the socio-economic circumstances of the case and control groups

-To describe the reproductive health of the case and control groups

-To describe the role of alcohol, smoking and other drugs in the women's lives

-To identify factors that increase the risk of having a child with FASD

-To assess the level of knowledge of the effects of alcohol use during pregnancy

-To identify women who are currently exposed to alcohol, tobacco and other drugs, and offer them appropriate intervention

-Do you agree with these objectives?

-Would you change anything about the list of objectives (add or eliminate)?

We are now going to look at each of the sections of the original maternal interview questionnaire and I would like to ask you specific questions about each of the sections.

SECTION 1: BACKGROUND HISTORY

Take some time to read through Section 1 of the questionnaire (question 1-73)

4. Are there any questions that do not belong in this section and should be moved to another section?
5. Are there questions that do not meet the objectives of a maternal interview and should therefore be removed?
6. Please take a closer look at questions 2, 12, 14, 17, 37, 40, 47, 48, 52 and 60. Do you recommend that any of these open-ended questions be changed to close-ended questions?

SECTION 2: DRINKING HABITS

Take some time to read through Section 2 of the questionnaire (question 74-116)

7. Are there any questions that do not belong in this section and should be moved to another section?
8. Are there questions that do not meet the objectives of a maternal interview and should therefore be removed?
9. Please take a closer look at question 86. Do you recommend that this question be changed to a close-ended question?

SECTION 3: ALTERNATIVE CARE FOR CHILDREN

Take some time to read through Section 3 of the questionnaire.

10. This section is very short. Can questions in this section be included under any one of the other sections?
11. Do questions in this section meet the objectives for a maternal interview?

SECTION 4: EATING HABITS OF THE MOTHER

Take some time to read through Section 4 of the questionnaire (question 121-151)

12. Are there any questions that do not belong in this section and should be moved to another section?
13. Are there questions that do not meet the objectives of a maternal interview and should therefore be removed?
14. Please take a closer look at questions 125, 128 and 129. Do you recommend that any of these open-ended questions be changed to close-ended questions?

SECTION 5: SMOKING HABITS OF THE MOTHER

Take some time to read through Section 5 of the questionnaire

15. Are there any questions that do not belong in this section and should be moved to another section?
16. Are there questions that do not meet the objectives of a maternal interview and should therefore be removed?
17. Please take a closer look at questions 159 and 162. Do you recommend that any of these open-ended questions be changed to close-ended questions?

SECTION 6: OTHER TYPES OF DRUGS USED BY MOTHER

Take some time to read through Section 6 of the questionnaire (question 171-191)

18. Are there any questions that do not belong in this section and should be moved to another section?
19. Are there questions that do not meet the objectives of a maternal interview and should therefore be removed?
20. Please take a closer look at question 172. Do you recommend that this question be changed to a close-ended question?

SECTION 7: GENERAL QUESTIONS

Take some time to read through Section 7 of the questionnaire (question 192-203)

21. Are there any questions that do not belong in this section and should be moved to another section?
22. Are there questions that do not meet the objectives of a maternal interview and should therefore be removed?

23. Do you think the sections in the this maternal interview questionnaire are sufficient and does it satisfy all of the objectives that were set out at the beginning?

24. Would you like to add any sections to the maternal interview questionnaire?

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APPENDIX C

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PARTICIPANT INFORMATION LEAFLET

TITLE OF THE RESEARCH PROJECT:

"A revision of the maternal interview questionnaire used in Fetal Alcohol Spectrum Disorder prevention programmes in South Africa."

REFERENCE NUMBER: **(S12/06/159)**

PRINCIPAL INVESTIGATOR: Mrs. Bettie Breytenbach

ADDRESS: Division of Speech-Language Therapy

Stellenbosch University

Tygerberg Campus

CONTACT DETAILS: **083 448 8808** or **bettiestrauss@gmail.com**

Dear Colleague

My name is Bettie Breytenbach and I am currently busy with my Masters degree in Speech, Language and Hearing Therapy. I would like to invite you to participate in a research project that aims to investigate and adjust the questionnaire that is currently used to interview mothers as part of prevention projects in Fetal Alcohol Spectrum Disorders (FASD).

Please take some time to read the information presented here, which will explain the details of this project and contact me if you require further explanation or clarification of any aspect of the study. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

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This study has been approved by the Health Research Ethics Committee (HREC) at Stellenbosch University and will be conducted according to accepted and applicable National and International ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008.

As you are well aware, the maternal interview questionnaire that is currently used by FARR in FASD prevention projects presents a few challenges for all that are involved. The main concern seems to be the excessive amount of time it takes to interview a single person. The main objectives of my research study will be the following:

5. To define the objectives of the maternal interview that forms part of FARR's FASD prevention programmes as perceived by the main role players in FARR's prevention programmes;
6. To identify the problems with the maternal interview questionnaire that is currently being used by FARR in FASD prevention programmes in South Africa;
7. To adjust the maternal interview questionnaire based on the problems referred to in the second objective whilst preserving the questionnaire's ability to achieve the objectives referred to under Objective 1; and
8. To evaluate the adjusted maternal interview questionnaire's ability to overcome the problems that are referred to under Objective 2, whilst achieving the objectives of a maternal interview referred to under Objective 1.

If you agree to participate you will be invited to take part in two separate focus group interviews that will be held throughout the course of the study. The key role players that are involved in the FASD prevention programmes driven by **FARR** will be invited to take part in the focus group interviews. During the first interview you will be asked to voice your opinion on specific aspects of the current maternal questionnaire and also make suggestions on how it can be improved. After the maternal questionnaire had been adjusted, you will be invited to take part in a second focus group interview for the purpose of revising the adjusted questionnaire.

Your identity will be kept confidential through-out the course of the study and you will receive a full disclosure of the results and conclusions of the study after it had been completed.

If you are willing to participate in this study please sign the attached Declaration of Consent and hand it to the investigator.

Yours sincerely

Bettie Breytenbach

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Declaration by participant

By signing below, I …………………………………….…………. agree to take part in a research study entitled "A revision of the maternal interview questionnaire used in Fetal Alcohol Spectrum Disorder prevention programmes in South Africa."

I declare that:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ....…........……………. On (*date*) …………..………….. 2012.

...

Signature of participant

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APPENDIX D

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INTERVIEW GUIDE FOR FOCUS GROUP TWO

Please take some time to read through the objectives of the revised questionnaire.

- To collect data on alcohol use during pregnancy to assist in diagnosing children with FASD.

- To describe the socio-economic circumstances of the case and control groups
-To identify factors that increase the risk of having a child with FASD
-To assess the level of knowledge of the effects of alcohol use during pregnancy
-To identify women who are currently exposed to alcohol, tobacco and other drugs, and offer them appropriate intervention

-Do you agree with the adjusted list of objectives?

-Would you change anything about the list of objectives (add or eliminate)?

We are now going to look at each of the sections of the revised maternal interview questionnaire. I would like to ask you specific questions about each of the sections.

SECTION 1: BIOGRAPHICAL AND CASE INFORMATION
Take some time to read through Section 1 of the revised questionnaire

1. Do you agree with the way the questions had been adjusted in this section?
2. Do you feel that it is appropriate for **question 15** to be added to this section?
3. Do you agree with **question 16** being added to this section?
4. Are there any other questions that you would like to adjust, add or eliminate in this section?

SECTION 2: BACKGROUND HISTORY
Take some time to read through Section 2 of the revised questionnaire

5. Do you agree with the way the questions had been adjusted in this section?
6. Take the time to look at **question 30** specifically. Are there any other occupations that should be listed here?
7. Are there any other questions that you would like to adjust, add or eliminate in this section?

SECTION 3: HISTORY OF PREGNANCIES AND BIRTHS
Take some time to read through Section 3 of the revised questionnaire

8. Do you agree with the way the questions had been adjusted in this section?
9. Take some time to look at the table that has been added at **question 36**. Do you feel that this is sufficient?
10. Are there any other questions that you would like to adjust, add or eliminate in this section?

SECTION 4: DRINKING HABITS OF INDIVIDUALS IN MOTHER'S SOCIAL NETWORK

Take some time to read through Section 4 of the revised questionnaire

11. Do you agree with the way the questions had been adjusted in this section?
12. Are there any other questions that you would like to adjust, add or eliminate in this section?

SECTION 5: DRINKING HABITS OF THE MOTHER

Take some time to read through Section 5 of the revised questionnaire

13. Do you agree with the way the questions had been adjusted in this section?
14. Take some time to look at the table that has been added at **question 63**. Do you feel that this is sufficient?
15. Look at **questions 80, 82, and 84**. Should these open-ended questions be changed to closed-ended questions?
16. Are there any other questions that you would like to adjust, add or eliminate in this section?

SECTION 6: ALTERNATIVE CARE OF CHILDREN

Take some time to read through Section 6 of the revised questionnaire

17. Do you agree with the way the questions had been adjusted in this section?
18. Look at **questions 88 and 90**. Should these open-ended questions be changed to closed-ended questions?
19. Are there any other questions that you would like to adjust, add or eliminate in this section?

SECTION 7: NUTRITION

Take some time to read through Section 7 of the revised questionnaire

20. Do you agree with the way the questions had been adjusted in this section?
21. Are there any other questions that you would like to adjust, add or eliminate in this section?

SECTION 8: SMOKING HABITS AND OTHER DRUG USE

Take some time to read through Section 8 of the revised questionnaire

22. Do you agree with the way the questions had been adjusted in this section?
23. Are there any other questions that you would like to adjust, add or eliminate in this section?

SECTION 9: GENERAL QUESTIONS

Take some time to read through Section 9 of the revised questionnaire

24. Do you agree with the way the questions had been adjusted in this section?
25. Are there any other questions that you would like to adjust, add or eliminate in this section?

SECTION 10: INTERNAL AUDIT QUESTIONS

Take some time to read through Section 10 of the revised questionnaire

26. Do you agree with the way the questions had been adjusted in this section?
27. Are there any other questions that you would like to adjust, add or eliminate in this section?

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28. Do you think the sections in the revised maternal interview questionnaire are sufficient and does it satisfy the list of adjusted objectives that were set out at the beginning of this interview guide?

29. Would you like to change anything else about the maternal interview questionnaire, that hasn't been mentioned during the course of this interview?

30. The revised maternal interview questionnaire will be tested as part of a FASD prevention programme shortly. Do you feel that the revised maternal interview questionnaire has the potential to meet your needs related to **interviewing a mother**, **diagnosing a child with FASD** as well as **data capturing**?

31. Would you like to make any other comments (positive or negative) about the revised maternal interview questionnaire?

32. **Discussion:** Questions or sections to be included when someone other than the mother is being interviewed.

33. **A decision was made at the previous focus group meeting that two interview questionnaires should exist i.e. a short questionnaire for screening purposes and a longer questionnaire that includes more detail for diagnostic purposes.**

Discussion:

Questions or sections to be included in the shorter, screening interview questionnaire.

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APPENDIX E

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QUESTIONNAIRE A

Biographical and client information

1 Name of interviewer ____________________

2 Mother's name and surname ____________________

3 Child's name and surname ____________________

4 Name of school ____________________

5 Child's subject number [ ]

6 Child's date of birth (dd/mm/yyyy) [/ /]

7 Mother's date of birth (dd/mm/yyyy) [/ /]

8 Date of interview (dd/mm/yyyy) [/ /]

9 What month and year did the child enter Grade 1 for the first time? (e.g. January 2012) [ ]

10 Address of mother or guardian ____________________

____

____

11 Home Language

1) English			2) Afrikaans		

		3) Xhosa	4) Zulu
		4) Other (specify)	
		5) More than one (name)	1)
			2)
			3)
12	Language of interview	1) English	2) Afrikaans
		3) Xhosa	4) Zulu
		5) Other (specify)	

13 What is the mother's height?

(e.g. 1,65 m)

m

What is the mother's weight?

(e.g. 65,4 kg)

kg

What is the mother's head circumference?

(e.g. 40,3 cm)

cm

Background history

14 Where do you live currently?

1) On a farm	2) Informal town (shack)
3) Formal town (brick house)	4) Other (specify)

15 How long have you lived there?

1) Less than 5 years			2) 5-10 years		
3) 10-20 years			4) More than 20 years		

16 How many adults do you currently live with? (older than 18 yrs)

17 How many children do you currently live with? (younger than 18 yrs)

18 What is your current marital status?

1) Married			2) Widowed		
3) Divorced/seperated			4) Single		
5) Living with partner					

19 Do you have someone whom you consider to be your best friend?

1) Yes			2) No		
3) Do not have friends					

20 Where did you live during your pregnancy with the child of interest?

1)On a farm			2) Informal town (shack)		
3) Formal town (brick house)			4) Other (specify)		

21 To which ethnic or racial group do you belong?

1) Black			2) White		
3) Mixed (Coloured)			4) Asian		
5) Indian			6) Other (specify)		

22 For how many years did you go to school? ____ yrs

23 What was the highest standard/grade that you completed? ____ standard ____ grade

24 Do you currently belong to a religious group?

1) Yes	2) No

25 What type of work do you normally do?

1) None	2) Factory work
3) Farm work	4) Office work
5) Student	6) Other (specify)

26 What is your current employment status?

1) Unemployed	2) Part time (less than 20h/w)
3) Seasonal	4) Fulltime
5)Student	

27 Do you receive any additional/further income from any of the following sources?

(make an "x" next to all the answers that apply)

1) Pension	2) Child support grant
3) Disability grant	4) Child maintenance
4) Foster care grant	5) None
6) Other (specify)	

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28 Calculate the TOTAL MONTHLY INCOME of the household (wages plus additional income)

29 Does your household own any of the following?

(make an "x" next to everything that the household owns)

1) Car		
2) Television set		
3) Fridge		

30 What do you read, listen to or watch to stay up to date with current events?

(make an "x" next to all the answers that apply)

1) None			2) Newspaper		
3) Radio			4) Television		
5) Family/friends			6) Magazines		
7) Other (specify)					

History of pregnancies and births

Please note: answers for (2 + 3 + 4 +5) must be equal to answer given at 1

31 1) How many times have you been pregnant?

2) How many children were born alive (37-40 wks)?

3) How many children were born too early (below 37 wks)?

4) How many miscarriages have you had? (between Week 4-20 of pregnancy)

5) How many stillbirths have you had? (between Week 20-40 of pregnancy)

6) How many of your children are still alive?

7) Did any children die shortly after birth (less than 7 days after birth)?

32 Was your pregnancy with the child of interest your first, second, third pregnancy etc?

33 Did you plan to have this child of interest?

1) Yes			2) No		

34 During which month of your pregnancy with the child of interest did you first receive prenatal care? [ ] mths

35 What was your marital status while you were pregnant with the child of interest?

1) Married			2) Widowed		
3) Divorced			4) Seperated		
5) Single			6) Living with partner		

36 Do you think that you are pregnant now?

1) Yes			2) No		
3) Unsure/maybe					

37 If not, are you currently using contraception (family planning)?

1) Yes			2) No		
3) Not sexually active					

38 What was child of interest's birth weight? [ ] kg

39 What problems, if any, did you experience during your pregnancy with COI?

1) None	
2) High blood pressure	
3) Diabetes	
4) Vaginal bleeding	
5) High fever (over 38 °C)	
6) Other illnesses/infections	

40 Did you take any prescribed medication (by a doctor) or "unprescribed medication" (e.g. medication you bought yourself, or received at the clinic or from someone else) during your pregnancy with the child of interest?

1) Yes			2) No		

41 If yes, what did you take?

---

42 Did you breastfeed the child of interest after birth?

1) Yes			2) No		

43 If yes, for how long? (days, weeks or months)

Drinking habits of individuals in mother's social network

44 How would you describe your ***mother's** drinking habits while you were growing up?

*** Please note: This question refers to the maternal grandmother of the child of interest**

1) Do not know			2) Did not drink		

3) Drank lightly on occasion			4) Drank heavily on occasion		
5) Had drinking problem			6) Stopped drinking		

45 How would you describe the drinking habits of your partner during your pregnancy with the child of interest?

1) Do not know			2) Did not drink		
3) Drank lightly on occasion			4) Drank heavily on occasion		
5) Had drinking problem			6) Stopped drinking		

46 How many of your friends drink alcohol?

1) None			2) Some		
3) All			4) Do not have friends		

Drinking habits of the mother

47 Have you consumed alcohol at any time in your life?

1) Yes			2) No		

If NO, go directly to Question 79

48 Have you consumed alcohol in the last 12 months?

1) Yes			2) No		

49 How old were you when you **first** drank alcohol?

		yrs
2) Cannot remember		

50 How old were you when you started drinking alcohol **regularly**? ______ yrs

2) Cannot remember		

51 How often do you drink?

1) Once a month or less			2) Most weekends		
3) Every weekend			4) Daily		

52 If you are still drinking, with whom do you usually drink?

(make an "x" next to all the anwers that apply)

1) When alone			2) With family		
3) With friends			4) With partner		

53 Where do you usually drink?

(make an "x" next to all the answers that apply)

1) At home			2) Family's house		
3) Friend's house			4) Shebeen		
5) Outdoors			6) On street in town		
7) Other (specify)			______		

54 Which alcoholic beverages do you usually drink?

(make an "x" next to all the answers that apply)

1) Beer			**2) *Fortified wine**		
3) *Spirits/mixed drinks			4) Wine		
5) Combination (specify)		______			
6) Other (specify)		______			

*** Please note:**

Fortified wine refers to sweet wine, sherry etc.

Spirits/ mixed drinks refer to brandy, vodka, whiskey, gin, cocktails etc.

55 Do you normally drink until you are drunk?

1) Always			2) Sometimes		
3) Never					

56 Do you normally drink until you pass out?

1) Always			2) Sometimes		
3) Never					

57 Indicate the **number and type of drinks** (eg. write 2 to indicate 2 drinks) consumed per day of the week.
1 Drink = 1 can or bottle of beer (350 ml.), 1 glass of wine (129 - 200 ml.), 1 mixed drink (coctail) or 1 shot of **strong** liquor.

Type of alcohol	**Monday**	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
Traditional beer							
Beer							
Wine							
Fortified wine							
Spirits							
DOP							
Mixed (frizzers,coolers ,ciders)							
Other							
Total							

58 Have you ever received DOP at anytime in your life?

(refer to the instructions for more information on DOP)

1) Yes			2) No		

If NO, go directly to Question 62

59 Did you get DOP while you were pregnant with the child of interest?

1) Yes			2) No		

60 Do you currently get DOP?

1) Yes			2) No		

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61 If yes, where do you get the DOP from?

____

62 How many times during the past 12 months have you gotten drunk on alcohol?

[ ] times

63 Do you think that you currently have a drinking problem?

1) Yes			2) No		
3) Unsure					

64 Do you think that you've ever had a drinking problem?

1) Yes			2) No		
3) Unsure					

65 Have you ever tried to stop/ cut down drinking?

1) Yes			2) No		

66 Have you ever received treatment for your drinking problem?

1) Yes			2) No		
3) Do not have drinking problem					

67 Would you like some help for your drinking problem?

1) Yes			2) No		
3) Do not have drinking problem					

68 Is there a difference between your drinking habits now and what it was in the months before you became pregnant with the child of interest?

1) Drank the same			2) Drank less		

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3) Drank more			4) Did not drink then		

69 Did you drink alcohol during your pregnancy with the child of interest?

1) Yes			2) No		

70 How far along was your pregnancy with child of interest when you first found out that you were pregnant? ______ mths

71 Did your drinking habits change during the first trimester of your pregnancy with the child of interest, compared to what they were like before you became pregnant?

1) Drank the same			2) Drank less		
3) Drank more			4) Stopped drinking		

72 If yes, why did it change?

____

____

73 Did your drinking habits change during the second trimester of your pregnancy with the child of interest, compared to what they were like before you became pregnant?

1) Drank the same			2) Drank less		
3) Drank more			4) Stopped drinking		

74 If yes, why did it change?

____

75 Did your drinking habits change during the third trimester of your pregnancy with the child of interest, compared to what they were like before you became pregnant?

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1) Drank the same			2) Drank less		
3) Drank more			4) Stopped drinking		

76 If yes, why did it change?

77 If you stopped drinking anytime during your pregnancy, did you start again after the child of interest's birth?

1) Yes			2) No		
3) Never drank					

78 If yes, how soon after the child of interest was born did you start drinking again?

	mths

Alternative care of children

79 Have any of your children ever been taken away from you by a social worker and placed in foster care?

1) Yes			2) No		

80 Have any of your relatives ever had to take care of any of your children for long periods of time?

1) Yes			2) No		

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Nutrition

81 When you were pregnant with the child of interest, did you sometimes have to skip meals because there was not enough money to buy food?

1) Always			2) Sometimes		
3) Never					

82 If yes, how often did this happen?

1) Never happened			2) Less than once a month		
3) Once a month or more			4) Once a week or more		

83 When you were pregnant with the child of interest, did you eat while you were drinking?

1) Yes			2) No		
3) Did not drink					

84 How much weight did you gain while pregnant with COI?

1) Almost nothing			2) Little (less than 5kg)		
3) Normal (10 kg)			4) A lot (more than 10 kg)		

Smoking habits and other drug use

85 Did you smoke or chew tabacco before your pregnancy with the child of interest?

1) Yes			2) No		

If NO, go to Question 91

86 If you smoked, how many cigarettes a day?

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1) Did not smoke			2) 1-5 per day		
3) 5-15 per day			4) More than 15 per day		
5) Other (specify)					

87 If you chewed tabacco, how often?

1) Did not chew tobacco			2) Once a month or less		
3) Most weekends			4) Every weekend		
5) Daily			6) Other (specify)		

88 Did your smoking- or tobacco chewing habits change during your pregnancy with the child of interest, and if yes how?

1) No change			2) Smoked/chewed less		
3) Smoked/chewed more			4) Stopped smoking/chewing		
5) Started smoking/chewing					

89 If you stopped during your pregnancy, did you start smoking or chewing tobacco again after the child of interest was born?

1) Yes			2) No		
3) Never smoked/chewed tobacco					

90 If yes, how soon after the child of interest was born did you start smoking or chewing tobacco again? ______ mths

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91 Did you use any other drugs before you became pregnant with the child of interest?

1) Yes			2) No		

If NO, go directly to Question 94

92 If yes, how often did you use drugs?

1)Once/month or less			2)Twice a month or more		
3) Weekly			4) Daily		

93 If yes, which drugs?

1) Tik/Crystal meth		
2) Dagga/Marujana		
3) Cocaine		
4) Heroin		
5) Other (specify)		

____

94 Did your drug habits change while you were pregnant with the child of interest, and if yes how?

1) No change			2) Stayed the same		
3) Used less			4) Used more		
5) Stopped using			6) Started using drugs		

95 If you stopped using drugs while pregnant, did you start again after the child of interest was born?

1) Yes			2) No		

3) Never used drugs		

96 Are you currently using any drugs?

1) Yes			2) No		

97 If yes, which drugs?

1) Tik/Crystal meth		
2) Dagga/Marujana		
3) Cocaine		
4) Heroin		
5) Other (specify)		

____

Internal audit questions

98 Confidence rating - Do you think that you have received the incorrect information because:

The mother answered the questions incorrectly

1) Yes			2) No		

The mother did not understand the questions

1) Yes			2) No		

If you feel as though the mother did not understand the questions, what do you think could be possible reasons for this?

____

____

____

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99 In which risk category do you feel this mother falls to give birth to a baby in future that is affected by alcohol?

1) High risk ☐

2) Medium risk ☐

3) Low risk ☐

4) Lowest risk ☐

The following two questions must be completed during the case discussion:

100 Which research group applies to this mother?

1) Drank during pregnancy: gave birth to FAS child ☐

2) Drank during pregnancy: gave birth to deferred child ☐

3) Drank during pregnancy: gave birth to child with one or more key features but not FAS or deferred ☐

4) Drank during pregnancy: no apparent damage to child ☐

5) Did not drink during pregnancy: no damage to child ☐

101 Referrals / Plan of Action:

___

___

___

___

___

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VRAELYS A

Biografiese- en kliëntinligting

1 Naam van onderhoudvoerder ____________________

2 Moeder se naam en van ____________________

3 Kind se naam en van ____________________

4 Naam van skool ____________________

5 Onderwerpnommer van kind [/ /]

6 Kind se geboortedatum (dd/mm/jjjj) [/ /]

7 Moeder se geboortedatum (dd/mm/jjjj) [/ /]

8 Datum van onderhoud (dd/mm/jjjj) [/ /]

9 Watter jaar en maand is die kind vir die eerste keer Graad 1 toe? [ ]

10 Woonadres van moeder of voog ____________________

11 Huistaal

1) Afrikaans			2) Engels		

		3) Xhosa	3) Zoeloe
		4) Ander (spesifiseer)	
		5) Meer as een taal (noem)	1)
			2)
			3)
12	Taal waarin onderhoud gevoer is	1) Afrikaans	2) Engels
		3) Ander (spesifiseer)	

13 Wat is die moeder se lengte?

(bv. 1,52 m)

m

Wat is die moeder se gewig?

(bv. 65,4 kg)

kg

Wat is die moeder se kop omtrek?

(bv. 40,2 cm)

cm

Agtergrondsgeskiedenis

14 Waar woon jy nou?

1) Op 'n plaas	2) Informeel dorp (plakkershut)
3) Formeel dorp (steenhuis)	4) Ander (spesifiseer)

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15 Hoe lank woon jy al daar?

1) Korter as 5 jaar			2) 5-10 jaar		
3) 10-20 jaar			4) Langer as 20 jaar		

16 Hoeveel volwasse persone woon saam met jou? (ouer as 18 jr)

17 Hoeveel kinders/ tieners woon in die huis? (jonger as 18 jr)

18 Wat is jou huidige huwelikstatus?

1) Getroud			2) Weduwee		
3) Geskei/vervreem			4) Enkellopend		
5) Ongetroud,woon saam					

19 Het jy 'n vriend/ vriendin wat jy as jou beste maat beskou?

1) Ja			2) Nee		
3) Het geen vriende					

20 Waar het jy gewoon tydens jou swangerskap met die kind onder bespreking?

1) Op 'n plaas			2) Informeel dorp (plakkershut)		
3) Formeel dorp (steenhuis)			4) Ander (spesifiseer)		

21 Aan watter etniese/ rassegroep behoort jy?

1) Swart			2)Wit		
3) Gemeng (kleurling)			4) Asiaties		
5) Indiër			6) Ander		

	(spesifiseer)

22 Hoeveel jaar was jy op skool? ____ jr

23 Wat was die hoogste standerd/ graad wat jy klaargemaak het? ____ standerd ____ graad

24 Behoort jy tans aan 'n kerk of godsdienstige groep?

1) Ja	2) Nee

25 Watter tipe werk doen jy gewoonlik?

1) Geen	2) Fabriekswerk
3) Plaaswerk	4) Kantoorwerk
5) Student	Ander (spesifiseer)

26 Wat is jou werkstatus?

1)Werkloos	2) Voltyds
3) Deeltyds (minder as 20h/wk)	4) Seisoenwerk
5) Student	

27 Ontvang jy enige verdere inkomste per maand van enige van die volgende bronne?

(maak 'n "x" by elkeen wat van toepassing is)

1) Pensioen	2) Kindertoelaag
3) Gestremdheidtoelaag	4) Onderhoud
5) Geen	6) Voog toelaag

7) Ander (spesifiseer)		

28 Bereken die TOTALE MAANDELIKSE INKOMSTE vd huishouding (salaris en ander inkomste)

29 Besit jou huishouding enige van die volgende?

(maak 'n "x" langs dit wat die huishouding besit)

1) Motor		
2) Televisie stel		
3) Yskas		

30 Wat lees jy, of waarna luister of kyk jy sodat jy kan weet wat in die land gebeur?

(maak 'n "x" langs elkeen wat van toepassing is)

1) Geen			2) Koerant		
3) Radio			4) Televisie		
5)Familie/vriende			6)Tydskrifte		
7) Ander (spesifiseer)					

Geskiedenis van swangerskappe en geboortes

Let wel: die antwoorde vir (2 + 3 + 4 + 5) moet gelyk wees aan die antwoord by 1

31 1) Hoeveel keer was jy al swanger?

2) Hoeveel kinders is lewendig gebore (meer as 37 weke)?

3) Hoeveel kinders is te vroeg gebore (minder as 37 weke)?

4) Het jy al ooit 'n miskraam gehad? (tussen Week 4-20 van swangerskap)

5) Is enige van jou babas doodgebore? (tussen Week 20-40 van swangerskap)

6) Hoeveel kinders het jy wat tans nog lewe?

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7) Is enige van jou kinders kort na geboorte dood? (minder as 7 dae oud)

32 Was jou swangerskap met die kind onder bespreking jou eerste, tweede, derde swangerskap ens?

33 Het jy die swangerskap met die kind onder bespreking beplan?

1) Ja

2) Nee

34 Gedurende watter maand van jou swangerskap met die kind onder bespreking het jy vir die eerste keer voorgeboorte sorg ontvang?

mde

35 Wat was jou huwelikstatus terwyl jy die kind onder bespreking verwag het?

1) Getroud

2) Weduwee

3) Geskei/vervreem

4) Enkellopend

5) Ongetroud, woon saam

36 Dink jy dat jy op die oomblik swanger kan wees?

1) Ja

2) Nee

3)Onseker/miskien

37 Indien nie, gebruik jy voorbehoedmiddels/ gesinsbeplanning?

1) Ja

2) Nee

3) Nie seksueel aktief

38 Wat was die kind onder bespreking se geboortegewig?

kg

39 Indien jy probleme tydens jou swangerskap met die kind onder bespreking gehad het, wat was dit?

1) Geen

2) Hoë bloeddruk

3) Diabetes

4) Vaginale bloeding

5) Hoë koors (hoër as 38 °C)

6) Ander siektes/ infeksies

40 Het jy enige voorgeskrewe medisyne (deur 'n dokter) of "onvoorgeskrewe medisyne" (bv. medisyne wat self gekoop is, by die kliniek of by iemand anders gekry is) geneem tydens jou swangerskap met die kind onder bespreking?

1) Ja			2) Nee		

41 Indien ja, wat was die naam van dit wat jy geneem het?

---

42 Het jy die kind onder bespreking geborsvoed na geboorte?

1) Ja			2) Nee		

43 Indien ja, vir hoe lank?

(dae, weke of maande)

Drinkgewoontes van individue in die moeder se sosiale netwerk

44 Vertel vir my wat jou ***moeder** se drinkgewoontes was terwyl jy grootgeword het.

*** Let wel: Hierdie vraag verwys na die ouma van die kind onder bespreking**

1) Weet nie			2) Nie gedrink nie		
3) Drink min per geleentheid			4) Drink baie per geleentheid		
5) Drankprobleem gehad			6) Het opgehou		

45 Vertel vir my wat jou man/lewensmaat se drinkgewoontes was terwyl jy die kind onder bespreking verwag het.

1) Weet nie			2) Nie gedrink nie		
3) Drink min per geleentheid			4) Drink baie per geleentheid		
5) Drankprobleem gehad			6) Het opgehou		

46 Hoeveel van jou vriende drink alkohol?

1) Geeneen			2) Sommige		
3) Almal			4) Het geen vriende		

Drinkgewoontes van die moeder

47 Het jy al ooit op enige stadium van jou lewe alkohol gebruik?

1) Ja			2) Nee		

Indien NEE, gaan direk na Vraag 79

48 Het jy gedurende die afgelope 12 maande alkohol gebruik?

1) Ja			2) Nee		

49 Hoe oud was jy toe jy vir die **eerste** keer alkohol gebruik het?

	jaar	
2) Kan nie onthou nie		

50 Hoe oud was jy toe jy begin het om **gereeld** alkohol te gebruik?

	jaar	
2) Kan nie onthou nie		

51 Hoe gereeld drink jy?

1) 1 x per maand of minder			2) Meeste naweke		

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3) Elke naweek			4) Daagliks		

52 Indien jy nog drink, saam met wie drink jy gewoonlik?

(maak 'n "x" langs elkeen wat van toepassing is)

1)Wanneer alleen			2)Saam met familie		
3)Saam met vriende			4) Saam met man/maat		

53 Waar drink jy gewoonlik?

(maak 'n "x" langs elkeen wat van toepassing is)

1) By die huis			2) Familie se huis		
3) Vriende se huis			4) By 'n sjebeen		
5) Buite iewers			6) Op straat in die dorp		
7) Ander(spesifiseer)			____________		

54 Watter tipe alkohol gebruik jy gewoonlik?

(maak 'n "x" langs elkeen wat van toepassing is)

1) Bier			2) ***Versterkte wyn**		
3) ***Sterk drank**			4) Wyn		
5)Kombinasie (spesifiseer)	____________				
6) Ander (spesifiseer)	____________				

*** Let wel:**

Versterkte wyn verwys na soetwyn, sjerrie ens.

Sterk drank verwys na brandewyn, vodka, whiskey, gemengde drankies (cocktails) ens.

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55 Drink jy gewoonlik totdat jy dronk is?

1) Altyd			2) Soms		
3) Nooit					

56 Drink jy gewoonlik totdat jy uitpaas?

1) Altyd			2) Soms		
3) Nooit					

57 Dui die aantal en tipe drankies aan (bv. skryf 2 vir 2 drankies) wat per dag van die week genuttig word.
1 Drankie = 1 blikkie of bottel bier (350 ml.), 1 glas wyn (129 - 200 ml.), 1 gemengde drankie (coctail) of 1 "tot" **sterk** drank.

Tipe alkohol	Maandag	Dinsdag	Woensdag	Donderdag	Vrydag	Saterdag	Sondag
Tradisionele bier							
Bier							
Wyn							
Versterkte wyn							
Sterk drank							
DOP							
Gemeng (“frizzers,coolers,ciders”)							
Ander							
Totaal							

58 Het jy al ooit in jou lewe DOP ontvang?

(verwys na die instruksies vir meer inligting oor DOP)

1) Ja			2) Nee		

Indien NEE, gaan direk na Vraag 62

59 Het jy DOP gekry terwyl jy wanger was met die kind onder bespreking?

1) Ja			2) Nee		

60 Kry jy nou DOP?

1) Ja			2) Nee		

61 Indien wel, waar kry jy die DOP?

____

62 Hoeveel keer gedurende die afgelope 12 mde het jy omgeval/ dronk geword van alkohol?

keer

63 Dink jy dat jy nou 'n drankprobleem het?

1) Ja
2) Nee
3) Onseker

64 Dink jy dat jy al ooit 'n drankprobleem gehad het?

1) Ja
2) Nee
3) Onseker

65 Het jy al ooit in die verlede probeer om op te hou drink of minder te drink?

1) Ja
2) Nee

66 Het jy al ooit behandeling vir jou drankprobleem ontvang?

1) Ja
2) Nee
3) Het nie drankprobleem

67 Sou jy graag wou hê dat iemand jou moet help sodat jy kan ophou om te drink?

1) Ja
2)Nee
3) Het nie drankprobleem

68 Is daar 'n verskil tussen jou drinkgewoontes nou en wat dit was in die maande voordat jy met die kind onder bespreking swanger geraak het?

1) Dieselfde gedrink
2) Minder gedrink
3) Meer gedrink
4) Nie toe gedrink nie
5) Drink nie nou nie

69 Het jy enige alkohol gedrink terwyl jy swanger was met KoB?

1) Ja			2) Nee		

70 Hoe ver was jy swanger met die kind onder bespreking voordat jy uitgevind het van die swangerskap?

	mde

71 Het jou drinkgewoontes verander tydens die eerste **drie maande** wat jy die kind onder bespreking verwag het, in vergelyking met hoe dit was voordat jy swanger geraak het?

1) Dieselfde gedrink			2) Minder gedrink		
3) Meer gedrink			4) Opgehou drink		

72 Indien ja, waarom het dit verander?

____

____

73 Het jou drinkgewoontes verander tydens die **tweede drie maande** wat jy die kind onder bespreking verwag het, in vergelyking met hoe dit was voordat jy swanger geraak het?

1) Dieselfde gedrink			2) Minder gedrink		
3) Meer gedrink			4) Opgehou drink		

74 Indien ja, waarom het dit verander?

____

____

75 Het jou drinkgewoontes verander tydens die **laaste drie maande** wat jy die kind onder bespreking verwag het, in vergelyking met hoe dit was voordat jy swanger geraak het?

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1) Dieselfde gedrink			2) Minder gedrink		
3) Meer gedrink			4) Opgehou drink		

76 Indien ja, waarom het dit verander?

____

____

77 Indien jy iewers tydens jou swangerskap opgehou het om te drink, het jy weer begin drink na die kind onder bespreking se geboorte?

1) Ja			2) Nee		
3) Nooit gedrink nie					

78 Indien ja, hoe lank na die kind onder bespreking se geboorte het jy weer begin drink?

[ ] mde

Alternatiewe sorg vir kinders

79 Is enige van jou kinders ooit deur 'n maatskaplike werker in pleegsorg geplaas?

1) Ja			2) Nee		

80 Moes enige van jou familielede al ooit jou kinders oor 'n lang periode versorg?

1) Ja			2) Nee		

Eetgewoontes van die moeder

81 Toe jy swanger was met die kind onder bespreking, moes jy ooit maaltye mis omdat daar nie genoeg geld was om kos te koop nie?

1) Altyd			2) Soms		

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3) Nooit		

82 Indien ja, hoe gereeld het dit gebeur?

1) Nooit			2) Minder as 1 x per maand		
3) 1 x per maand of meer			4) 1 x per week of meer		

83 Toe jy swanger was met die kind onder bespreking, het jy gewoonlik geëet terwyl jy gedrink het?

1) Ja			2) Nee		
3) Het nie gedrink nie					

84 Hoeveel gewig het jy opgetel tydens jou swangerskap met die kind onder bespreking?

1) Amper niks			2) Min (minder as 5kg)		
3) Normaal (10 kg)			4) Baie (meer as 10 kg)		

Rookgewoontes en ander dwemgebruik

85 Het jy gerook, gepruim (twak kou) of twak gesnuif voor jou swangerskap met die kind onder bespreking?

1) Ja			2) Nee		

Indien NEE, gaan na Vraag 91

86 Indien jy gerook het, hoeveel sigarette per dag?

1) Nie gerook nie			2) 1-5 per dag		
3) 5-15 per dag			4) Meer as 15 per dag		
5) Ander (spesifiseer)					

87 Indien jy gepruim of twak gesnuif het, hoe gereeld?

1) Nie gepruim of snuif nie		2) 1 x per maand of minder
3) Meeste naweke		4) Elke naweek
5) Daagliks		6) Ander (spesifiseer)

____

88 Het jou rook- of pruimgewoontes verander tydens jou swangerskap met die kind onder bespreking en indien ja, hoe het dit verander?

1) Geen verandering	2) Minder gerook/gepruim
3) Meer gerook/gepruim	4) Opgehou rook/pruim
5) Het begin rook/pruim	

89 Indien jy opgehou rook/pruim het tydens jou swangerskap, het jy weer begin na die kind onder bespreking se geboorte?

1) Ja	2) Nee
3) Nooit gerook/gepruim nie	

90 Indien ja, hoe lank na die kind onder bespreking se geboorte het jy weer begin rook/pruim?

______ mde

91 Het jy enige ander dwelmmiddels gebruik voor jou swangerskap met die kind onder bespreking?

1) Ja	2) Nee

Indien NEE, gaan na Vraag 94

92 Indien ja, hoe gereeld het jy dwelmmiddels gebruik?

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1) 1 x per maand of minder			2) 2 x per maand of meer		
3) Weekliks			4) Daagliks		

93 Indien ja, watter dwelmmiddels het jy gebruik?

(maak 'n "x" langs elkeen wat van toepassing is)

1) Tik		
2) Dagga		
3) Kokaïne		
4) Heroïne		
5) Ander (spesifiseer)		

94 Het jou dwelmgebruik verander tydens jou swangerskap met die kind onder bespreking en indien ja, hoe het dit verander?

1) Geen verandering			2) Minder gebruik		
3) Meer gebruik			4) Opgehou dwelms gebruik		
5) Begin dwelms gebruik					

95 Indien jy opgehou het om dwelms te gebruik tydens jou swangerskap, het jy weer begin na die kind onder bespreking se geboorte?

1) Ja			2) Nee		
3) Nooit gebruik nie					

Gebruik jy tans enige dwelmmiddels?

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96

1) Ja				2) Nee		

97 Indien ja, watter dwelmmiddels gebruik jy?

(maak 'n "x" langs elkeen wat van toepassing is)

1) Tik		
2) Dagga		
3) Kokaïne		
4) Heroïne		
5) Ander (spesifiseer)		

____

Interne oudit vrae

98 Skaal van betroubaarheid - dink jy jy het nie die korrekte inligting gekry nie omdat:

Die moeder die vrae verkeerd beantwoord het

1) Ja				2) Nee		

Die moeder die vrae nie reg verstaan het nie

1) Ja				2) Nee		

Moontlike redes vir waarom die moeder nie die vrae verstaan het nie:

____

____

99 In watter risiko kategorie voel jy val hierdie moeder om in die toekoms geboorte te gee aan n kind wat deur alkohol geaffekteer is?

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1) Hoë risiko

2) Middelmatige risiko

3) Lae risiko

4) Laagste risiko

Die volgende twee vrae moet tydens die gevalsbespreking voltooi word:

100 In watter navorsingsgroep sal hierdie moeder val?

1) Gedrink tydens swangerskap: geboorte gegee aan 'n kind met FAS

2) Gedrink tydens swangerskap: geboorte gegee aan 'n kind wat ten volle gediagnoseer moet word

3) Gedrink tydens swangerskap en geboorte gegee aan kind met een of meer sleutelkenmerke

(maar kind het nie FAS nie en het nie 'n volle diagnose nodig nie)

4) Gedrink tydens swangerskap: geen beduidende skade aan die kind

5) Gedrink tydens swangerskap: kind het geen skade opgedoen nie

101 Verwysings / Plan van aksie:

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APPENDIX F

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DEELNEMERINLIGTINGSBLAD EN - TOESTEMMINGSVORM

TITEL VAN DIE NAVORSINGSPROJEK:

"A revision of the maternal interview questionnaire used in Fetal Alcohol Spectrum Disorder prevention programmes in South Africa."

VERWYSINGSNOMMER: **(S12/06/159)**

HOOFNAVORSER: Me. Bettie Breytenbach

ADRES: Departement Spraak-Taalterapie

Universiteit van Stellenbosch

Tygerberg Kampus

KONTAKBESONDERHEDE: **083 448 8808** of **bettiestrauss@gmail.com**

U word genooi om deel te neem aan 'n navorsingstudie wat handel oor die moderonderhoudvraelys wat tans deur FARR gebruik word om onderhoude met moeders te voer as deel van hul Fetale Alkohol Spektrum Afwykings (FASA) voorkomingsprogramme . Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die detail van die navorsingstudie daarin verduidelik word. Indien daar enige deel van die studie is wat u nie verstaan nie, is u welkom om die navorser of u toesighouer daaroor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingstudie behels en hoe u daarby betrokke kan wees. U deelname is ook **volkome vrywillig** en u mag op enige stadium deelname aan die navorsing weier. U sal op geen wyse negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingstudie onttrek, selfs al het u ingestem om deel te neem.

Hierdie navorsingstudie is deur die Gesondheidsnavorsingsetiekkomitee (GNEK) van die Universiteit Stellenbosch **goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die**

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Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Die onderhoudsvraelys wat tans deur FARR gebruik word om onderhoude met moeders te voer hou verskeie uitdagings in. Dit wil voorkom asof die grootse probleem met die vraelys is dat dit uitermatig lank is en dus baie tyd neem om te voltooi. Die hoofdoel van hierdie navorsingstudie is om die huidige vraelys te ondersoek en aan te pas. Aangesien u deel vorm van die groep onderhoudvoerders wat hierdie vraelys op 'n gereelde basis gebruik om onderhoude met moeders te voer, kan u opinie en ondervinding 'n belangrike bydrae tot die navorsing lewer.

Indien u instem om deel te neem aan die studie, sal u deur die navorser gekontak word nadat u die aangepaste vraelys gebruik het om onderhoude met moeders as deel van 'n spesifieke FASA voorkomingsprogram te voer. Die navorser sal tydens 'n telefoniese onderhoud spesifieke vrae aan u vra in verband met u persepsies van die aangepaste vraelys asook hoe u dit ervaar het om die aangepaste vraelys te gebruik om onderhoude met moeders te voer.

Let wel: u identiteit sal deur die loop van die studie konfidensieel hanteer word en aan niemand buiten die navorser bekend gemaak word nie.

Indien u instem om deel te neem aan die navorsingstudie, teken asseblief die onderstaande verklaring en oorhandig dat dan weer aan u toesighouer.

Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek, ………………………………………………….., om deel te neem aan 'n navorsingstudie getiteld "A revision of the maternal interview questionnaire used in Fetal Alcohol Spectrum Disorder prevention programmes in South Africa."

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.

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- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.

Geteken te (*plek*) .... op (*datum*) .... 2005.

.... **Handtekening van deelnemer**

.... **Handtekening van getuie**

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APPENDIX G

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Jan 2013

Informed Consent

We are doing research on fetal alcohol syndrome. We are trying to learn about factors that are important in having a healthy baby. I would like to ask you some questions about your pregnancies, your family, and also about habits such as drinking and smoking. It may be difficult for you to remember or talk about some of these things. Some of this information may be sensitive, or confidential. Whatever information you provide will be kept strictly confidential and will not be shown to other persons. Your name will never be mentioned to anyone outside the study without your consent. Participation in this survey is voluntary and you can choose not to answer any individual question or all of the questions.

The interviews that we usually have with mothers is often very long. We have changed the questions so that the interviews can be shorter. We would like to test this new, shorter questionnaire to see if it gives us enough information. We would like you to help us with this. We would like to use the shorter form for your interview. The interview will happen in exactly the same way as the longer interview. Nothing bad will happen to you if you do not want us to use the shorter questionnaire.

Is there anything you want to ask me about this research before we begin?

Do you understand what I have said? ☐Yes ☐No

Do I have your permission to begin with the questionnaire? ☐Yes ☐No

Full name of client: ______________________________

Signature: ______________________________

Date: ______________________________

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Jan 2013

Onderhoud toestemming

Ons doen navorsing oor fetale alkohol sindroom. Ons probeer vasstel watter faktore belangrik is vir 'n vrou om 'n gesonde baba te hê. Ek gaan vir jou vrae vra oor jou swangerskappe, oor jou familie, en vrae omtrent jou drink-en rookgewoontes. Dit mag vir jou moeilik wees om hierdie dinge te onthou of om daaroor te praat. Die inligting is egter baie belangrik vir die navorsing en ek sal dit waardeer as jy soveel as moontlik inligting verstrek. Sommige van die inligting mag van `n sensitiewe aard wees en ook moeilik wees om oor te praat. Ek wil jou egter verseker dat alles wat jy gaan vertel baie vertroulik hanteer sal word. Jou naam sal nooit aan enige ander persoon bekend gemaak word sonder jou toestemming nie. As daar `n vraag is wat jy nie wil beantwoord nie, is dit ook jou reg om dit nie te beantwoord.

Die onderhoude wat ons gewoonlik met moeders het is baie lank. Ons het die vrae in die vraelys so verander dat die onderhoude korter kan wees. Ons wil graag hierdie nuwe, korter vraelys toets om te sien of dit vir ons genoeg inligting verskaf. Die onderhoudsproses sal presies dieselfde wees as met die langer onderhoud. Niks sleg sal met jou gebeur as jy nie wil hê dat die korter vraelys vir jou onderhoud gebruik moet word nie.

Is daar enige iets wat jy wil vra voordat ons begin?

Verstaan jy dit wat ek aan jou verduidelik het? ☐Ja ☐Nee

Het ek jou toestemming om met die vraelys te begin? ☐Ja ☐Nee

Volle naam van klient: ______________________________

Handtekening: ______________________________

Datum: ______________________________

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APPENDIX H

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ONDERHOUD MET DIE ONDERHOUDVOERDERS

Elke onderhoud sal begin met 'n kort beskrywing van die metodologie van die studie met spesifieke verwysing na die eerste en tweede fokusgroeponderhoude wat gehou is.

1. Tydens die eerste fase van hierdie studie is spesifiek gekyk na die probleme met die vraelys wat gebruik word om onderhoude met moeders te voer. Een van die probleme wat geidentifiseer is, is dat onderhoude met die moeders te lank duur as gevolg van die lengte van die vraelys. Sal u hiermee saamstem? Gee 'n rede hiervoor.

2. (a) Voordat die onderhoude met die moeders gevoer is, is u gevra om te meet hoe lank dit min of meer neem om 'n onderhoud te voer met elk van die moeders. Toe u die nuwe, aangepaste vraelys gebruik het, hoe lank het dit gemiddeld per onderhoud geneem? Sou u sê dat die onderhoude oor die algemeen korter was as toe u die oorspronklike vraelys gebruik het?

(b) Indien wel, wat voel u kan moontlik die positiewe of negatiewe gevolge wees van 'n korter onderhoud?

3. Gedurende die eerste fokusgroep vir hierdie studie het almal saamgestem dat die onderhoud met die moeders nie net 'n manier moet wees om inligting te kry nie, maar dat dit ook 'n manier moet wees waardeur die onderhoudvoerder 'n verhouding met die moeder kan bou. Voel u dat u deur middel van die nuwe aangepaste vraelys 'n verhouding kon vorm met die moeders waarmee u 'n onderhoud gevoer het? (Hoekom voel u so?)

4. (a) Gedurende die eerste fase van hierdie studie is die manier waarop die vrae in die oorspronklike vraelys saamgestel is, gekritiseer. Antwoord asb. die volgende vrae:

	ja	nee
4.1 Voel u dat die plasing van die vrae in die aangepaste vraelys sin maak (bv. is al die vrae onder die opskrif waar dit hoort)?		
4.2 'n Oop-einde vraag is daardie vrae waar die moeder kans kry om te gesels oor iets bv. "Waarom het jou drinkgewoontes tydens jou swangerskap verander?" in plaas daarvan dat sy uit 'n paar antwoorde moet kies. Een van die hoofdoelwitte van die aangepaste vraelys was om die hoeveelheid oop-einde vrae wat gevra word, te verminder		

aangesien dit baie tyd neem om dit te voltooi. Voel u asof die oop-einde vrae suksesvol verminder en verander is?		
4.3 Voel u dat die vrae in die nuwe aangepaste vraelys duidelik en verstaanbaar vir die moeder is?		
4.4 Nog 'n doelwit van die aangepaste vraelys was om vrae wat baie eenders is saam te sit sodat dieselfde vraag nie weer gevra word later in die vraelys nie. Voel u dat hierdie doelwit bereik is?		

4. (b) Indien die antwoord nee is op enige van hierdie vrae, verduidelik asb.

5. Is daar enige vrae in die oorspronklike vraelys wat weggelaat is uit die aangepaste vraelys, wat u voel waardevol is tot die onderhoud met 'n moeder? (Verduidelik asb. u antwoord)

6. (a) As deel van hierdie studie is 'n tweede vraelys ontwikkel wat spesifiek gebruik kan word wanneer die onderhoud gevoer word met iemand anders as die biologiese moeder van die kind onder bespreking. Het u by tye hierdie vraelys gebruik?

(b) Het hierdie vraelys u gehelp om die nodige inligting oor die biologiese ma en die kind onder bespreking te verkry?

7. As deel van hierdie studie is 'n stel riglyne saamgestel om onderhoudvoerders deur die onderhoudsproses te lei. Het hierdie riglyne 'n verskil gemaak aan hoe u die onderhoud met elke moeder benader het? (Verduidelik asb. u antwoord)

8. Tydens die eerste fokusgroep onderhoud van hierdie studie is bevind dat onderhoudvoerders nie almal die oorspronklike vraelys gebruik het op dieselfde manier nie, omdat die vraelys so lank was (vrae is soms uitgelaat of nie volledig voltooi nie). Sou u hiermee saamstem? Hoekom se u so?

9. Toe u die nuwe aangepaste vraelys gebruik het, sou u sê dat u dit kon regkry om met elke onderhoud deur die hele vraelys te gaan, sonder om enige vrae uit te laat? (Verduidelik asb u antwoord)

10.1 Voel u dat daar vrae of afdelings van die aangepaste vraelys is wat steeds probleme kan veroorsaak (vrae wat moontlik verder verander, weggelaat of bygevoeg moet word)?	**ja**	**nee**

10.2 Indien ja, verduidelik asb.

11.1 Dink u dat hierdie nuwe aangepaste vraelys gebruik moet word om onderhoude met moeders te voer as deel van FASD voorkomingsprogramme en dat die oorspronklike vraelys nie meer hiervoor gebruik moet word nie?	**ja**	**nee**

11.2 Indien nie, hoekom nie?

12.1 Voel u dat die aangepaste vraelys al die inligting wat nodig is van die moeder verkry?	**ja**	**nee**

12.2 Indien nie, hoekom nie?

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APPENDIX I

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QUESTIONNAIRE FOR DATA CAPTURER AND ANALYST

Please complete the following questions in writing. Where appropriate, mark with an "X".

1. During the first focus group interview the maternal interview was described as being "too long" due to the length of the questionnaire. Would you agree with that? (Please motivate your answer)

2. If you compare the adjusted questionnaire to the original questionnaire, would you say that there was a difference between the time it took to capture and or analyze the data from one interview? What do you feel are the consequences (positive or negative) of spending more/less time on capturing or analyzing the interview data?

3. During the first focus group interview, one of the participants expressed the need for both a short and long maternal interview questionnaire, depending on the purpose of the interview as well as the type of prevention project in general. In the end it was decided that the adjusted questionnaire was shortened sufficiently through the course of this study and that this would be the only questionnaire to be used in future. What are your thoughts and feelings about this decision?

4. During the first focus group interview the structure of the original maternal interview questionnaire was criticised (with specific reference to the assignment of questions to specific sections, the amount of open-ended questions and repetition of questions)

(a) What do you think about the arrangement of questions in the adjusted questionnaire?

(b) One of the main goals in adjusting the original questionnaire was to minimise the amount of open-ended questions, as open-ended questions take a lot of time to complete and capture. What do you think about the amount and the transformation of the open-ended questions that appear in the adjusted questionnaire?

(c)Another goal in the process of adjusting the original questionnaire was to combine questions that are similar in an effort to avoid the repetition of questions. What is your opinion on the repetition of questions in the adjusted questionnaire?

5. As part of this study, a second questionnaire was developed to use when someone other than the mother of the child of interest is being interviewed. What are your thoughts on this second questionnaire?

6.1. During the first focus group interview it was revealed that there has been a lot of inconsistency between interviewers when using the original questionnaire, due to the fact that it was so long (e.g. leaving out questions at random etc.). Would you agree with that statement?	**yes**	**no**

6.2. Please explain your answer in nr. 6.1.

7. In your opinion, how did the consistency with which the interviewers used the adjusted questionnaire compare to their consistency in using the original questionnaire? (Please motivate your answer)

8. During the first focus group interview, **two** of the main purposes of the maternal interview were identified as being a way of collecting data for research purposes as well as assisting the examiners in making a diagnosis of FAS/FASD. Do you feel as though the adjusted maternal interview questionnaire allows for these two purposes to be met? (Please motivate your answer)

9.1. In your opinion, are there any questions or sections of the revised maternal interview questionnaire that are still problematic (consisting of questions that need to be adjusted or eliminated)?	**yes**	**no**

9.2. If yes, please explain.

10.1. Do you recommend that this revised maternal interview questionnaire be used to interview mothers as part of FASD prevention programmes and therefore replace the original maternal interview questionnaire?	**yes**	**no**

10.2. If not, what are your objections?

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APPENDIX J

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QUESTIONNAIRE A

Biographical and client information

1 Name of interviewer ______________________

2 Mother's initials (no surname) ______________________

3 Child's initials (no surname) ______________________

4 Name of school ______________________

5 Child's subject number [ ]

6 Child's date of birth (dd/mm/yyyy) [/ /]

7 Mother's date of birth (dd/mm/yyyy) [/ /]

8 Date of interview (dd/mm/yyyy) [/ /]

9 What year did the child enter Grade 1 for the first time? (e.g. 2012) [ ]

10 Address of mother or guardian ______________________

11 Home Language

1) English		2) Afrikaans	
3) Xhosa		4) Zulu	
4) Other (specify)		______	
5) More than one (name)		1) ______ 2) ______ 3) ______	

12 Language of interview

1) English		2) Afrikaans	
3) Xhosa		4) Zulu	
5) Other (specify)		______	

13 What is the mother's height?
(e.g. 165 cm) [ ] cm

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What is the mother's weight?
(e.g. 65,4 kg)

[ ] kg

What is the mother's head circumference?
(e.g. 40,3 cm)

[ ] cm

Background history

14 Where do you live currently?

1) On a farm		2) Informal town (shack)	
3) Formal town (brick house)		4) Other (specify)	

15 How long have you lived there?

1) Less than 5 years		2) 5-9 years	
3) 10-20 years		4) More than 20 years	

16 How many adults do you currently live with? (older than 18 yrs)

17 How many children do you currently live with? (younger than 18 yrs)

18 What is your current marital status?

1) Married		2) Widowed	
3) Divorced/seperated		4) Single	
5) Living with partner			

19 Where did you live during your pregnancy with the child of interest?

1)On a farm		2) Informal town (shack)	
3) Formal town (brick house)		4) Other (specify)	

20 To which ethnic or racial group do you belong?

1) Black		2) White	
3) Mixed (Coloured)		4) Asian	
5) Indian		6) Other (specify)	

21 For how many years did you go to school? [ ] yrs

22 What is the highest grade that you completed?

Option		
1) No formal education		
2) Grade 1		
3) Grade 2		
4) Grade 3		
5) Grade 4		
6) Grade 5		
7) Grade 6		
8) Grade 7		
9) Grade 8		
10) Grade 9		
11) Grade 10		
12) Grade 11		
13) Grade 12		
14) College diploma		
15) University degree		

23 What type of work do you normally do?

Option			Option		
1) None			2) Factory work		
3) Farm work			4) Office work		
5) Student			6) Other (specify)		

24 What is your current employment status?

Option			Option		
1) Unemployed			2) Part time (less than 20h/w)		
3) Seasonal			4) Fulltime		
5)Student					

25 What is your work salary per month?

R

26 Do you receive any additional/further income from any of the following sources?
(make an "v" next to all the answers that apply)

Option			Option		
1) Pension			2) Child support grant		
3) Disability grant			4) Child maintenance		
4) Foster care grant			5) None		
6) Other (specify)					

27 Calculate the TOTAL MONTHLY INCOME of the household (salary plus additional income)

R

28 Does your household own any of the following?
(make an "√" next to everything that the household owns)

- 1) Car
- 2) Television set
- 3) Fridge

29 What do you read, listen to or watch to stay up to date with current events?
(make an "√" next to all the answers that apply)

- 1) None
- 2) Newspaper
- 3) Radio
- 4) Television
- 5) Family/friends
- 6) Magazines
- 7) Other (specify)

30 How important is religion to you?

- 1) Not important at all
- 2) Mildly important
- 3) Very important

31 Do you have someone whom you consider to be your best friend?

- 1) Yes
- 2) No
- 3) Do not have friends

History of pregnancies and births

Please note: answers for (2 + 3 + 4 +5) must be equal to answer given at 1

32 1) How many times have you been pregnant?
2) How many children were born at full term (37-40 wks)?
3) How many children were born too early (below 37 wks)?
4) How many miscarriages have you had? (between Week 4-20 of pregnancy)
5) How many stillbirths have you had? (between Week 20-40 of pregnancy)
6) How many of your children are still alive?
7) Did any children die shortly after birth (less than 7 days after birth)?

33 Was your pregnancy with the child of interest your first, second, third pregnancy etc?

34 Did you plan to have this child of interest?

- 1) Yes
- 2) No

35 What was your marital status while you were pregnant with the child of interest?

1) Married	2) Widowed
3) Divorced	4) Seperated
5) Single	6) Living with partner

36 During which month of your pregnancy with the child of interest did you first receive prenatal care? ______ mth

37 What problems, if any, did you experience during your pregnancy with COI?

1) None
2) High blood pressure
3) Diabetes
4) Vaginal bleeding
5) High fever (over 38 °C)
6) Other illnesses/infections

38 Were there any complications during the birth of the child of interest?

1) Yes	2) No

39 If yes, explain these complications.

____

____

40 Was the child of interest born prematurely?

1) Yes	2) No

41 What was child of interest's birth weight? ______ kg

42 Did you breastfeed the child of interest after birth?

1) Yes	2) No

43 If yes, for how long? (days, weeks or months)

44 Do you think that you are pregnant now?

1) Yes	2) No
3) Unsure/maybe	

45 If not, are you currently using contraception (family planning)?

1) Yes	2) No
3) Not sexually active	

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Alternative care of children

46 Have any of your children ever been taken away from you by a social worker and placed in foster care?

1) Yes			2) No		

47 Have any of your relatives ever had to take care of any of your children for long periods of time?

1) Yes			2) No		

Nutrition

48 When you were pregnant with the child of interest, did you sometimes have to skip meals because there was not enough money to buy food?

1) Always			2) Sometimes		
3) Never					

49 If yes, how often did this happen?

1) Never happened			2) Less than once a month		
3) Once a month or more			4) Once a week or more		

Drinking habits of individuals in mother's social network

50 How would you describe the drinking habits of your partner during your pregnancy with the child of interest?

1) Do not know			2) Did not drink		
3) Drank lightly on occasion			4) Drank heavily on occasion		
5) Had drinking problem			6) Stopped drinking		

51 How many of your friends drink alcohol?

1) None			2) Some		
3) All			4) Do not have friends		

Drinking habits of the mother

52 Have you consumed alcohol at any time in your life?

1) Yes			2) No		

53 Have you consumed alcohol in the last 12 months?

1) Yes | 2) No

54 How old were you when you **first** drank alcohol? ____ yrs | 2) Cannot remember

55 How old were you when you started drinking alcohol **regularly**? ____ yrs | 2) Cannot remember

56 How often do you drink?
1) Once a month or less | 2) Most weekends
3) Every weekend | 4) Daily
5) Never drink

57 If you are still drinking, with whom do you usually drink?
(make an "√" next to all the answers that apply)
1) When alone | 2) With family
3) With friends | 4) With partner

58 Where do you usually drink?
(make an "√" next to all the answers that apply)
1) At home | 2) Family's house
3) Friend's house | 4) Shebeen
5) Outdoors | 6) On street in town
7) Other (specify) ____

59 Which alcoholic beverages do you usually drink?
(make an "√" next to all the answers that apply)
1) Beer | **2) *Fortified wine**
3) *Spirits/mixed drinks | 4) Wine
5) Coolers | **6) Home brew**
7) Combination (specify) ____
8) Other (specify) ____

*** Please note:**
Fortified wine refers to sweet wine, sherry etc.
Spirits/ mixed drinks refer to brandy, vodka, whiskey, gin, cocktails etc.
"Home brew" refers to beer that is brewed at home.

60 How often do you drink until you are drunk?
1) Always | 2) Sometimes
3) Never

61 How often do you drink until you pass out?
1) Always | 2) Sometimes

3) Never		

62 Indicate the number and type of drinks (eg. write 2 to indicate 2 drinks) consumed per day of the week.

1 Drink is:

1 can or bottle of beer (300ml)

1 glass of wine (150ml)

1 mixed drink (cocktail)

1 "tot" of strong liquor (25 ml)

Type of alcohol	Monday (Mo)	Tuesday (Tu)	Wednesday (We)	Thursday (Th)	Friday (Fr)	Saturday (Sa)	Sunday (So)
(a)Home brew							
(b)Beer							
(c)Wine							
(d)Fortified wine							
(e)Spirits/mixed drinks							
(f)DOP							
(g)Mixed (frizzers, coolers, ciders)							
(h)Other							
TOTAL							

63 Have you ever received DOP at anytime in your life?

1) Yes 2) No

64 Did you get DOP while you were pregnant with the child of interest?

1) Yes 2) No

65 Do you currently get DOP? 1) Yes 2) No

66 If yes, where do you get the DOP from?

____

67 How many times during the past 12 months have you gotten drunk on alcohol?

______ time

68 Do you think that you currently have a drinking problem?

1) Yes 2) No

3) Unsure

69 Do you think that you've ever had a drinking problem?

1) Yes 2) No

3) Unsure

70 Have you ever tried to stop/ cut down drinking?

1) Yes 2) No

71 Have you ever received treatment for your drinking problem?

1) Yes
2) No
3) Do not have drinking problem

72 Would you like some help for your drinking problem?

1) Yes
2) No
3) Do not have drinking problem

73 Did you drink any alcohol in the months before you became pregnant with the child of interest and if yes, how often?

1)Once a month or less
2) Most weekends
3) Every weekend
4) Daily
5) Did not drink

74 Did you drink alcohol during your pregnancy with the child of interest?

1) Yes
2) No

75 When you were pregnant with the child of interest, did you eat while you were drinking?

1) Yes
2) No
3) Did not drink

76 How far along was your pregnancy with child of interest when you first found out that you were pregnant?

_____ mth

77 Did your drinking habits change during the first trimester of your pregnancy with the child of interest, compared to what they were like before you became pregnant?

1) Drank the same
2) Drank less
3) Drank more
4) Stopped drinking
5) Have never drank
6) Started drinking

78 If yes, why did it change?

____

____

79 Did your drinking habits change during the second trimester of your pregnancy with the child of interest, compared to what they were like before you became pregnant?

1) Drank the same
2) Drank less
3) Drank more
4) Stopped drinking
5) Have never drank
6) Started drinking

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80 If yes, why did it change?

____

81 Did your drinking habits change during the third trimester of your pregnancy with the child of interest, compared to what they were like before you became pregnant?

1) Drank the same	2) Drank less
3) Drank more	4) Stopped drinking
5) Have never drank	6) Started drinking

82 If yes, why did it change?

____

83 If you stopped drinking anytime during your pregnancy, did you start again after the child of interest's birth?

1) Yes	2) No
3) Never drank	4) Never stopped drinking

84 If yes, how soon after the child of interest was born did you start drinking again?

[ ] mth

Smoking habits and other drug use

85 Did you smoke or chew tobacco before you became pregnant with the child of interest?

1) Yes	2) No

86 If you smoked, how many cigarettes a day?

1) Did not smoke	2) 1-5 per day
3) 5-15 per day	4) More than 15 per day
5) Other (specify)	______

87 If you chewed tobacco, how often?

1) Did not chew tobacco	2) Once a month or less
3) Most weekends	4) Every weekend
5) Daily	6) Other (specify)

____

88 Did your smoking- or tobacco chewing habits change during your pregnancy with the child of interest, and if yes how?

1) No change	2) Smoked/chewed less
3) Smoked/chewed more	4) Stopped smoking/chewing
5) Started smoking/chewing	6) Never smoked/chewed

89 Did you take any prescribed medication (by a doctor) or "unprescribed medication" (e.g. medication you bought yourself, or received at the clinic or from someone else) during your pregnancy with the child of interest (e.g. Grandpa or coughing mixture)?

1) Yes			2) No		

90 If yes, what did you take?

___

91 Did you use any other drugs before you became pregnant with the child of interest?

1) Yes			2) No		

92 If yes, which drugs?
(make a "√" next to each one that applies)

1) Have never used		
2) Tik/Crystal meth		
3) Dagga/Marujana		
4) Cocaine		
5) Heroin		
6) Other (specify)		

___

93 If yes, how often did you use drugs?

1)Once/month or less			2)Twice a month or more		
3) Weekly			4) Daily		
5) Have never used					

94 Did your drug habits change while you were pregnant with the child of interest, and if yes how?

1) Stayed the same			2) Used less		
3) Used more			4) Stopped using		
5) Started using drugs			6) Have never used		

95 If you stopped using drugs while pregnant, did you start again after the child of interest was born?

1) Yes			2) No		
3) Never used drugs					

96 Are you currently using any drugs?

1) Yes			2) No		

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97 If yes, which drugs?

(make a "√" next to each one that applies)

1) Do not use drugs		
2) Tik/Crystal meth		
3) Dagga/Marujana		
4) Cocaine		
5) Heroin		
6) Other (specify)		

Internal audit questions

98 Do you think it is possible that you were given the incorrect information by the mother?

1) Yes			2) No		

99 If yes, what do you feel was the reason for this?

The mother answered the questions incorrectly

The mother did not understand the questions

100 **If you feel as though the mother did not understand the questions, what do you think could be possible reasons for this?**

101 In which risk category do you feel this mother falls to give birth to a baby in future that is affected by alcohol?

1) High risk

2) Medium risk

3) Low risk

4) Lowest risk

102 Any additional comments:

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VRAELYS A

Biografiese- en kliëntinligting

1	Naam van onderhoudvoerder	______
2	Moeder se voorletters (geen van)	______
3	Kind se voorletters (geen van)	______
4	Naam van skool	______
5	Onderwerpnommer van kind	
6	Kind se geboortedatum (dd/mm/jjjj)	/ /
7	Moeder se geboortedatum (dd/mm/jjjj)	/ /
8	Datum van onderhoud (dd/mm/jjjj)	/ /
9	Watter jaar is die kind vir die eerste keer Graad 1 toe (bv. 2012)?	
10	Woonadres van moeder of voog	______
11	Huistaal	1) Afrikaans; 2) Engels; 3) Xhosa; 3) Zoeloe; 4) Ander (spesifiseer) ______; 5) Meer as een taal (noem) 1) ______ 2) ______ 3) ______
12	Taal waarin onderhoud gevoer is	1) Afrikaans; 2) Engels; 3) Ander (spesifiseer) ______
13	Wat is die moeder se lengte? **(bv. 152 cm)**	cm

Wat is die moeder se gewig? [ ] kg
(bv. 65,4 kg)

Wat is die moeder se kop omtrek? [ ] cm
(bv. 40,2 cm)

Agtergrondsgeskiedenis

14 Waar woon jy nou?

- 1) Op 'n plaas
- 2) Informeel dorp (plakkershut)
- 3) Formeel dorp (steenhuis)
- 4) Ander (spesifiseer)

15 Hoe lank woon jy al daar?

- 1) Korter as 5 jaar
- 2) 5-9 jaar
- 3) 10-20 jaar
- 4) Langer as 20 jaar

16 Hoeveel volwasse persone woon saam met jou? (ouer as 18 jr)

17 Hoeveel kinders/ tieners woon in die huis? (jonger as 18 jr)

18 Wat is jou huidige huwelikstatus?

- 1) Getroud
- 2) Weduwee
- 3) Geskei/vervreem
- 4) Enkellopend
- 5) Ongetroud,woon saam

19 Waar het jy gewoon tydens jou swangerskap met die kind onder bespreking?

- 1) Op 'n plaas
- 2) Informeel dorp (plakkershut)
- 3) Formeel dorp (steenhuis)
- 4) Ander (spesifiseer)

20 Aan watter etniese/ rassegroep behoort jy?

- 1) Swart
- 2)Wit
- 3) Gemeng (kleurling)
- 4) Asiaties
- 5) Indiër
- 6) Ander (spesifiseer)

21 Hoeveel jaar was jy op skool? [ ] jr

22 Wat was die hoogste graad wat jy klaargemaak het?

- 1) Geen formele onderrig
- 2) Graad 1
- 3) Graad 2
- 4) Graad 3
- 5) Graad 4
- 6) Graad 5
- 7) Graad 6
- 8) Graad 7
- 9) Graad 8
- 10) Grrad 9
- 11) Graad 10
- 12) Graad 11
- 13) Graad 12
- 14) Kollege diploma
- 15) Universiteitsgraad

23 Watter tipe werk doen jy gewoonlik?

1) Geen	2) Fabriekswerk
3) Plaaswerk	4) Kantoorwerk
5) Student	6) Ander (spesifiseer)

24 Wat is jou werkstatus?

1)Werkloos	2) Voltyds
3) Deeltyds (minder as 20h/wk)	4) Seisoenwerk
5) Student	

25 Wat is jou werksalaris per maand? R

26 Ontvang jy enige verdere inkomste per maand van enige van die volgende bronne?
(maak 'n "v" by elkeen wat van toepassing is)

1) Pensioen	2) Kindertoelaag
3) Gestremdheidtoelaag	4) Onderhoud
5) Geen	6) Voog toelaag
7) Ander (spesifiseer)	

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27 Bereken die TOTALE MAANDELIKSE INKOMSTE vd huishouding (salaris en ander inkomste)

R

28 Besit jou huishouding enige van die volgende?
(maak 'n "v" langs dit wat die huishouding besit)

1) Motor
2) Televisie stel
3) Yskas

29 Wat lees jy, of waarna luister of kyk jy sodat jy kan weet wat in die land gebeur?
(maak 'n "x" langs elkeen wat van toepassing is)

1) Geen
2) Koerant
3) Radio
4) Televisie
5)Familie/vriende
6)Tydskrifte
7) Ander (spesifiseer)

30 Hoe belangrik is godsdiens vir jou?

1) Glad nie belangrik
2) Matig belangrik
3) Baie belangrik

31 Het jy 'n vriend/ vriendin wat jy as jou beste maat beskou?

1) Ja
2) Nee
3) Het geen vriende

Geskiedenis van swangerskappe en geboortes

Let wel: die antwoorde vir (2 + 3 + 4 + 5) moet gelyk wees aan die antwoord by 1

32 1) Hoeveel keer was jy al swanger?
2) Hoeveel kinders is voltermyn gebore (meer as 37 weke)?
3) Hoeveel kinders is te vroeg gebore (minder as 37 weke)?
4) Het jy al ooit 'n miskraam gehad? (tussen Week 4-20 van swangerskap)
5) Is enige van jou babas doodgebore? (tussen Week 20-40 van swangerskap)
6) Hoeveel kinders het jy wat tans nog lewe?
7) Is enige van jou kinders kort na geboorte dood? (minder as 7 dae oud)

33 Was jou swangerskap met die kind onder bespreking jou eerste, tweede, derde swangerskap ens?

34 Het jy die swangerskap met die kind onder bespreking beplan?

1) Ja
2) Nee

35 Wat was jou huwelikstatus terwyl jy die kind onder bespreking verwag het?

1) Getroud			2) Weduwee		
3) Geskei/vervreem			4) Enkellopend		
5) Ongetroud, woon saam					

36 Gedurende watter maand van jou swangerskap met die kind onder bespreking het jy vir die eerste keer voorgeboorte sorg ontvang?

	md

37 Indien jy probleme tydens jou swangerskap met die kind onder bespreking gehad het, wat was dit?

1) Geen	
2) Hoë bloeddruk	
3) Diabetes	
4) Vaginale bloeding	
5) Hoë koors (hoër as 38 °C)	
6) Ander siektes/ infeksies	

38 Was daar enige komplikasies tydens die geboorte van die kind onder bespreking?

1) Ja			2) Nee		

39 Indien ja, verduidelik hierdie komplikasies.

____

____

40 Was die kind onder bespreking prematuur gebore?

1) Ja			2) Nee		

41 Wat was die kind onder bespreking se geboortegewig?

	kg

42 Het jy die kind onder bespreking geborsvoed na geboorte?

1) Ja			2) Nee		

43 Indien ja, vir hoe lank?
(dae, weke of maande)

44 Dink jy dat jy op die oomblik swanger kan wees?

1) Ja			2) Nee		
3)Onseker/miskien					

45 Indien nie, gebruik jy voorbehoedmiddels/ gesinsbeplanning?

1) Ja			2) Nee		

3) Nie seksueel aktief

Alternatiewe sorg vir kinders

46 Is enige van jou kinders ooit deur 'n maatskaplike werker in pleegsorg geplaas?

1) Ja | 2) Nee

47 Moes enige van jou familielede al ooit jou kinders oor 'n lang periode versorg?

1) Ja | 2) Nee

Eetgewoontes van die moeder

48 Toe jy swanger was met die kind onder bespreking, moes jy ooit maaltye mis omdat daar nie genoeg geld was om kos te koop nie?

1) Altyd | 2) Soms
3) Nooit

49 Indien ja, hoe gereeld het dit gebeur?

1) Nooit | 2) Minder as 1 x per maand
3) 1 x per maand of meer | 4) 1 x per week of meer

Drinkgewoontes van individue in die moeder se sosiale netwerk

50 Vertel vir my wat jou man/lewensmaat se drinkgewoontes was terwyl jy die kind onder bespreking verwag het.

1) Weet nie | 2) Nie gedrink nie
3)Drink min per geleentheid | 4) Drink baie per geleentheid
5) Drankprobleem gehad | 6) Het opgehou

51 Hoeveel van jou vriende drink alkohol?

1) Geeneen | 2)Sommige
3) Almal | 4) Het geen vriende

Drinkgewoontes van die moeder

52 Het jy al ooit op enige stadium van jou lewe alkohol gebruik?

1) Ja | 2) Nee

53 Het jy gedurende die afgelope 12 maande alkohol gebruik?

1) Ja | 2) Nee

54 Hoe oud was jy toe jy vir die **eerste** keer alkohol gebruik het?

	jaa
2) Kan nie onthou nie	
3) Nooit gedrink nie	

55 Hoe oud was jy toe jy begin het om **gereeld** alkohol te gebruik?

	jaa
2) Kan nie onthou nie	
3) Nooit gedrink nie	

56 Hoe gereeld drink jy?

1) 1 x per maand of minder		2) Meeste naweke	
3) Elke naweek		4) Daagliks	
5) Drink nooit nie			

57 Indien jy nog drink, saam met wie drink jy gewoonlik?
(maak 'n "V" langs elkeen wat van toepassing is)

1)Wanneer alleen		2)Saam met familie	
3)Saam met vriende		4) Saam met man/maat	
5) Drink nooit nie			

58 Waar drink jy gewoonlik?
(maak 'n "V" langs elkeen wat van toepassing is)

1) By die huis		2) Familie se huis	
3) Vriende se huis		4) By 'n sjebeen	
5) Buite iewers		6) Op straat in die dorp	
7) Drink nooit nie			
8) Ander(spesifiseer)		____________	

59 Watter tipe alkohol gebruik jy gewoonlik?
(maak 'n "V" langs elkeen wat van toepassing is)

1) Bier		2) ***Versterkte wyn**	
3) ***Sterk drank**		4) Wyn	
5) "Coolers"		6) ***"Home brew"**	
7)Kombinasie (spesifiseer)	____________		
8) Ander (spesifiseer)	____________		

*** Let wel:**
Versterkte wyn verwys na soetwyn, sjerrie ens.
Sterk drank verwys na brandewyn, vodka, whiskey, gemengde drankies (cocktails) ens.
"Home brew" verwys na bier wat tuis gemaak is.

60 Drink jy gereeld totdat jy dronk is?

1) Altyd			2) Soms		
3) Nooit					

61 Drink jy gereeld totdat jy uitpaas?

1) Altyd			2) Soms		
3) Nooit					

62 Dui die aantal en tipe drankies aan (bv. skryf 2 vir 2 drankies) wat per dag van die week genuttig word.

1 Drankie is:

1 blikkie of bottel bier (300ml)

1 Glas wyn (150 ml)

1 Gemengde drankie (cocktail)

1 "tot" sterk drank (25 ml)

Tipe alkohol	Maandag (Ma)	Dinsdag (Di)	Woensdag (Wo)	Donderdag (Do)	Vrydag (Vr)	Saterdag (Sa)	Sondag (So)
(a)"Home brew"							
(b)Bier							
(c)Wyn							
(d)Versterkte wyn							
(e)Sterk drank							
(f)DOP							
(g)Gemeng (frizzers, coolers, ciders)							
(h)Ander							
TOTAAL							

63 Het jy al ooit in jou lewe DOP ontvang?

1) Ja			2) Nee		

64 Het jy DOP gekry terwyl jy wanger was met die kind onder bespreking?

1) Ja			2) Nee		

65 Kry jy nou DOP?

1) Ja			2) Nee		

66 Indien wel, waar kry jy die DOP? ______________________

67 Hoeveel keer gedurende die afgelope 12 mde het jy omgeval/ dronk geword van alkohol?

[ ] kee

68 Dink jy dat jy nou 'n drankprobleem het?

1) Ja			2) Nee		
3) Onseker					

69 Dink jy dat jy al ooit 'n drankprobleem gehad het?

1) Ja			2) Nee		
3) Onseker					

70 Het jy al ooit in die verlede probeer om op te hou drink of minder te drink?

1) Ja			2) Nee		
3) Nooit gedrink nie					

71 Het jy al ooit behandeling vir jou drankprobleem ontvang?

1) Ja			2) Nee		
3) Het nie drankprobleem					

72 Sou jy graag wou hê dat iemand jou moet help sodat jy kan ophou om te drink?

1) Ja			2)Nee		
3) Het nie drankprobleem					

73 Het jy enige alkohol gedrink in die maande voordat jy swanger geraak het met die kind onder bespreking en indien ja, hoe gereeld?

1) 1 x per maand of minder			2) Meeste naweke		
3) Elke naweek			4) Daagliks		
5) Nooit gedrink nie					

74 Het jy enige alkohol gedrink terwyl jy swanger was met KoB?

1) Ja			2) Nee		

75 Toe jy swanger was met die kind onder bespreking, het jy gewoonlik geëet terwyl jy gedrink het?

1) Ja			2) Nee		
3) Het nie gedrink nie					

76 Hoe ver was jy swanger met die kind onder bespreking voordat jy uitgevind het van die swangerskap?

	md

77 Het jou drinkgewoontes verander tydens die eerste **drie maande** wat jy die kind onder bespreking verwag het, in vergelyking met hoe dit was voordat jy swanger geraak het?

1) Dieselfde gedrink		2) Minder gedrink	
3) Meer gedrink		4) Opgehou drink	
5) Nog nooit gedrink		6) Het begin drink	

78 Indien ja, waarom het dit verander?

____

____

79 Het jou drinkgewoontes verander tydens die **tweede drie maande** wat jy die kind onder bespreking verwag het, in vergelyking met hoe dit was voordat jy swanger geraak het?

1) Dieselfde gedrink		2) Minder gedrink	
3) Meer gedrink		4) Opgehou drink	
5) Nog nooit gedrink		6) Het begin drink	

80 Indien ja, waarom het dit verander?

____

____

81 Het jou drinkgewoontes verander tydens die **laaste drie maande** wat jy die kind onder bespreking verwag het, in vergelyking met hoe dit was voordat jy swanger geraak het?

1) Dieselfde gedrink		2) Minder gedrink	
3) Meer gedrink		4) Opgehou drink	
4) Nog nooit gedrink		6) Het begin drink	

82 Indien ja, waarom het dit verander?

____

____

83 Indien jy iewers tydens jou swangerskap opgehou het om te drink, het jy weer begin drink na die kind onder bespreking se geboorte?

1) Ja		2) Nee	
3) Nooit gedrink nie		4) Nooit opgehou drink nie	

84 Indien ja, hoe lank na die kind onder bespreking se geboorte het jy weer begin drink?

__________ md

Rookgewoontes en ander dwelmgebruik

85 Het jy gerook, gepruim (twak kou) of twak gesnuif voor jou swangerskap met die kind onder bespreking?

1) Ja			2) Nee		

86 Indien jy gerook het, hoeveel sigarette per dag?

1) Nie gerook nie			2) 1-5 per dag		
3) 5-15 per dag			4) Meer as 15 per dag		
5) Ander (spesifiseer)					

87 Indien jy gepruim of twak gesnuif het, hoe gereeld?

1) Nie gepruim of snuif nie			2) 1 x per maand of minder		
3) Meeste naweke			4) Elke naweek		
5) Daagliks			6) Ander (spesifiseer)		

88 Het jou rook- of pruimgewoontes verander tydens jou swangerskap met die kind onder bespreking en indien ja, hoe het dit verander?

1) Geen verandering			2) Minder gerook/gepruim		
3) Meer gerook/gepruim			4) Opgehou rook/pruim		
5) Het begin rook/pruim			6)Nooit gerook/pruim		

89 Het jy enige voorgeskrewe medisyne (deur 'n dokter) of "onvoorgeskrewe medisyne" (bv. medisyne wat self gekoop is, by die kliniek of by iemand anders gekry is) geneem tydens jou swangerskap met die kind onder bespreking (bv. Grandpa of hoesmedisyne)?

1) Ja			2) Nee		

90 Indien ja, wat was die naam van dit wat jy geneem het?

91 Het jy enige ander dwelmmiddels gebruik voor jou swangerskap met die kind onder bespreking?

1) Ja			2) Nee		

92 Indien ja, watter dwelmmiddels het jy gebruik?

(maak 'n "√" langs elkeen wat van toepassing is)

1) Nooit gebruik nie		
2) Tik		
3) Dagga		
4) Kokaïne		

5) Heroïne		
6) Ander (spesifiseer)		

93 Indien ja, hoe gereeld het jy dwelmmiddels gebruik?

1) 1 x per maand of minder			2) 2 x per maand of meer		
3) Weekliks			4) Daagliks		
5) Nooit gebruik nie					

94 Het jou dwelmgebruik verander tydens jou swangerskap met die kind onder bespreking en indien ja, hoe het dit verander?

1) Geen verandering			2) Minder gebruik		
3) Meer gebruik			4) Opgehou dwelms gebruik		
5) Begin dwelms gebruik			6) Nooit gebruik nie		

95 Indien jy opgehou het om dwelms te gebruik tydens jou swangerskap, het jy weer begin na die kind onder bespreking se geboorte?

1) Ja			2) Nee		
3) Nooit gebruik nie					

96 Gebruik jy tans enige dwelmmiddels?

1) Ja			2) Nee		

97 Indien ja, watter dwelmmiddels gebruik jy?
(maak 'n "v" langs elkeen wat van toepassing is)

1) Gebruik nie		
2) Tik		
3) Dagga		
4) Kokaïne		
5) Heroïne		
6) Ander (spesifiseer)		

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Interne oudit vrae

98 Dink jy jy het moontlik die verkeerde inligting van die moeder gekry?

1) Ja 2) Nee

99 Indien ja, wat was volgens jou die rede hiervoor?

1) Die moeder het nie die vrae korrek beantwoord nie

2) Die moeder het nie die vrae reg verstaan nie

100 **Indien jy voel asof die moeder nie die vrae reg verstaan het nie, wat dink jy kan moontlike redes hiervoor wees?**

101 In watter risiko kategorie voel jy val hierdie moeder om in die toekoms geboorte te gee aan n kind wat deur alkohol geaffekteer is?

1) Hoë risiko

2) Middelmatige risiko

3) Lae risiko

4) Laagste risiko

102 Enige verdere opmerkings:

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APPENDIX K

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List of the original objectives of the maternal interview questionnaire

Nr.	Objective
1.	To collect data on alcohol use during pregnancy to assist in diagnosing children with FASD.
2.	To describe the socio-economic circumstances of the case and control groups.
3.	To describe the reproductive health of the case and control groups.
4.	To describe the role of alcohol, smoking and other drugs in the women's lives.
5.	To identify factors that increase the risk of having a child with FASD.
6.	To assess the level of knowledge of the effects of alcohol use during pregnancy.
7.	To identify women who are currently exposed to alcohol, tobacco and other drugs, and offer them appropriate intervention.

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APPENDIX L

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QUESTIONNAIRE B

Biographical and client information

1 Name of interviewer ____________________

2 Mother's name and surname ____________________

3 Child's name and surname ____________________

4 Name of school ____________________

5 Child's subject number [ ]

6 Child's date of birth (dd/mm/yyyy) [/ /]

7 Mother's date of birth (dd/mm/yyyy) [/ /]

8 Date of interview (dd/mm/yyyy) [/ /]

9 What month and year did the child enter Grade 1 for the first time? (e.g. January 2012) [ ]

10 Address of mother or guardian ____________________

____

____

11 Home Language

1) English			2) Afrikaans		

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	3) Xhosa	4) Zulu
	4) Other (specify)	
	5) More than one (name)	1)
		2)
		3)
12 Language of interview	1) English	2) Afrikaans
	3) Xhosa	4) Zulu
	5) Other (specify)	

Background history

13 What was your relationship with the mother of the child of interest?

1) Mother
2) Father
3) (Former) husband or partner
4) Sister
5) Brother
6) Friend
7) Aunt
8) Uncle
9) Grandmother
10) Grandfather
11) Other (specify)

14 Why does the child of interest not live with his/her mother at present?

1) Mother has passed away.

2) Child was taken away from mother due to social welfare problems or problems at home.

3) Mother is unable to care for child due to financial reasons.

4) Mother is currently working somewhere far away from home.

5) Mother does not want to care for child.

6) Other (specify).

---

15 According to your knowledge, do you think that the mother used alcohol during her pregnancy with the child of interest?

1) Yes			2) No		

16 Were there any problems during the pregnancy or birth of the childof interest?

1) Yes			2) No		

17 If yes, specify:

Internal audit questions

18 Confidence rating - Do you think that you have received the incorrect information because:

The person answered the questions incorrectly

1) Yes			2) No		

The person did not understand the questions

1) Yes			2) No		

If you feel as though the person did not understand the questions, what do you think could be possible reasons for this?

____

____

____

19 In which risk category do you feel this mother falls to give birth to a baby in future that is affected by alcohol?

1) High risk ☐

2) Medium risk ☐

3) Low risk ☐

4) Lowest risk ☐

____

The following two questions must be completed during the case discussion:

20 Which research group applies to this mother?

1) Drank during pregnancy: gave birth to FAS child ☐

2) Drank during pregnancy: gave birth to deferred child ☐

3) Drank during pregnancy: gave birth to child with one or more key features but not FAS or deferred ☐

4) Drank during pregnancy: no apparent damage to child ☐

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5) Did not drink during pregnancy: no damage to child ☐

21 Referrals / Plan of Action:

Stellenbosch University http://scholar.sun.ac.za

VRAELYS B

Biografiese- en kliëntinligting

1 Naam van onderhoudvoerder ______________________

2 Moeder se naam en van ______________________

3 Kind se naam en van ______________________

4 Naam van skool ______________________

5 Onderwerpnommer van kind [/ /]

6 Kind se geboortedatum (dd/mm/jjjj) [/ /]

7 Moeder se geboortedatum (dd/mm/jjjj) [/ /]

8 Datum van onderhoud (dd/mm/jjjj) [/ /]

9 Watter jaar en maand is die kind vir die eerste keer Graad 1 toe? [ ]

10 Woonadres van moeder of voog ______________________

____

11 Huistaal

1) Afrikaans			2) Engels		
3) Xhosa			3) Zoeloe		

4) Ander (spesifiseer)	
5) Meer as een taal (noem)	1) 2) 3)

12 Taal waarin onderhoud gevoer is

1) Afrikaans	2) Engels
3) Ander (spesifiseer)	

Agtergrondsgeskiedenis

13 Wat is/ was jou verhouding met die moeder van die kind onder bespreking?

1) Moeder
2) Vader
3) (Vorige) man of lewensmaat
4) Suster
5) Broer
6) Vriend/vriendin
7) Tante
8) Oom
9) Ouma
10) Oupa
11) Ander (spesifiseer)

14 Waarom woon die kind onder bespreking nie tans by sy/ haar moeder nie?

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1) Moeder is oorlede.

2) Kind is weggevat by moeder weens maatskaplike (huislike) probleme.

3) Moeder kan nie vir die kind sorg nie as gevolg van finansiële redes.

4) Moeder werk iewers ver weg van die huis af.

5) Moeder wil nie vir die kind sorg nie.

6) Ander (spesifiseer).

15 Met die kennis wat tot jou beskikking is, dink jy die moeder het alkohol gebruik tydens haar swangerskap met die kind onder bespreking?

1) Ja 2) Nee

16 Was daar enige probleme tydens die swangerskap of geboorte van die kind onder bespreking?

1) Ja 2) Nee

17 Indien ja,spesifiseer:

Interne oudit vrae

18 Skaal van betroubaarheid - dink jy jy het nie die korrekte inligting gekry nie omdat:

Die persoon die vrae verkeerd beantwoord het

1) Ja 2) Nee

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Die persoon die vrae nie reg verstaan het nie

1) Ja			2) Nee		

Moontlike redes vir waarom die persoon nie die vrae verstaan het nie:

---

19 In watter risiko kategorie voel jy val hierdie moeder om in die toekoms geboorte te gee aan n kind wat deur alkohol geaffekteer is?

1) Hoë risiko ☐

2) Middelmatige risiko ☐

3) Lae risiko ☐

4) Laagste risiko ☐

Die volgende twee vrae moet tydens die gevalsbespreking voltooi word:

20 In watter navorsingsgroep sal hierdie moeder val?

1) Gedrink tydens swangerskap: geboorte gegee aan 'n kind met FAS ☐

2) Gedrink tydens swangerskap: geboorte gegee aan 'n kind wat ten volle gediagnoseer moet word ☐

3) Gedrink tydens swangerskap en geboorte gegee aan kind met een of meer sleutelkenmerke (maar kind het nie FAS nie en het nie 'n volle diagnose nodig nie) ☐

4) Gedrink tydens swangerskap: geen beduidende skade aan die kind ☐

5) Gedrink tydens swangerskap: kind het geen skade opgedoen nie ☐

21 Verwysings / Plan van aksie:

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Stellenbosch University http://scholar.sun.ac.za

APPENDIX M

QUESTIONNAIRE B

Biographical and client information

1 Name of interviewer ______________________

2 Mother's initials (no surname) ______________________

3 Child's initials (no surname) ______________________

4 Name of school ______________________

5 Child's subject number [ ]

6 Child's date of birth (dd/mm/yyyy) [/ /]

7 Mother's date of birth (dd/mm/yyyy) [/ /]

8 Date of interview (dd/mm/yyyy) [/ /]

9 What year did the child enter Grade 1 for the first time? (e.g. 2012) [ ]

10 Address of mother or guardian ______________________

____

____

11 Home language of guardian

1) English			2) Afrikaans		
3) Xhosa			4) Zulu		
4) Other (specify)			______		
5) More than one (name)			1) ______ 2) ______ 3) ______		

12 Language of interview

1) English			2) Afrikaans		
3) Xhosa			4) Zulu		
5) Other (specify)			______		

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Background history

1
3 What was your relationship with the mother of the child of interest?

1) Mother ☐
2) Father ☐
3) (Former) husband or partner ☐
4) Sister ☐
5) Brother ☐
6) Friend ☐
7) Aunt ☐
8) Uncle ☐
9) Grandmother ☐
10) Grandfather ☐
11) Other (specify) ____________________
12) None (explain) ____________________

1
4 Why does the child of interest not live with his/her mother at present?

1) Mother has passed away. ☐
2) Child was taken away from mother due to social welfare problems or problems at home. ☐
3) Mother is unable to care for child due to financial reasons. ☐
4) Mother is currently working somewhere far away from home. ☐
5) Mother does not want to care for child. ☐
6) Other (specify). ☐

1
5 If the mother is deceased, how did she pass away?

1 To which ethnic or racial group did/does the mother of the child of interest belong?

6

1) Black			2) White		
3) Mixed (Coloured)			4) Asian		
5) Indian			6) Other (specify)		

17 For how many years did the mother go to school? [ ] yrs

18 What is the highest grade that the mother of the child of interest completed?

1) No formal education		
2) Grade 1		
3) Grade 2		
4) Grade 3		
5) Grade 4		
6) Grade 5		
7) Grade 6		
8) Grade 7		
9) Grade 8		
10) Grade 9		
11) Grade 10		
12) Grade 11		
13) Grade 12		
14) College diploma		
15) University degree		

19 How important is/was religion to the mother?

1) Not important at all		
2) Mildly important		
3) Very important		

20 What type of work does the mother of the child of interest normally do?
(do not ask this question if the mother is deceased)

1) None			2) Factory work		
3) Farm work			4) Office work		

5) Student			6) Other (specify)		
7) Mother deceased					

21 What is the mother's current employment status?
(do not ask this question if the mother is deceased)

1) Unemployed			2) Part time (less than 20h/w)		
3) Seasonal			4) Fulltime		
5)Student			6) Mother deceased		

Information on the pregnancy and birth of child of interest

22 Were there any problems during the pregnancy with the child of interest?

1) Yes			2) No		
3) Unknown					

23 If yes, specify:

____

____

____

24 According to your knowledge, do you think that the mother used alcohol during her pregnancy with the child of interest?

1) Yes			2) No		
3) Unknown					

25 Were there any complications during the birth of the child of interest?

1) Yes			2) No		
3) Unknown					

26 If yes, explain these complications.

____

____

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27 Was the child of interest born prematurely?

1) Yes			2) No		
3) Unknown					

28 What was the child of interest's birth weight?

	kg
2) Unknown	

Internal audit questions

29 Do you think it is possible that you were given the incorrect information by the person that was interviewed?

1) Yes			2) No		

30 If yes, what do you think was the reason for this?

The person answered the questions incorrectly	
The person did not understand the questions	
The person did not know the mother of the child of interest well enough	

31 **If you feel as though the person did not understand the questions, what do you think could be possible reasons for this?**

____

____

____

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VRAELYS B

Biografiese- en kliëntinligting

1 Naam van onderhoudvoerder ______________________

2 Moeder se voorletters (geen van) ______________________

3 Kind se voorletters (geen van) ______________________

4 Naam van skool ______________________

5 Onderwerpnommer van kind [ ]

6 Kind se geboortedatum (dd/mm/jjjj) [/ /]

7 Moeder se geboortedatum (dd/mm/jjjj) [/ /]

8 Datum van onderhoud (dd/mm/jjjj) [/ /]

9 Watter jaar is die kind vir die eerste keer Graad 1 toe (bv. 2012)? [ ]

10 Woonadres van moeder of voog ______________________

____

11 Huistaal van die voog

1) Afrikaans	2) Engels
3) Xhosa	3) Zoeloe
4) Ander (spesifiseer)	
5) Meer as een taal (noem)	1) 2) 3)

12 Taal waarin onderhoud gevoer is

1) Afrikaans	2) Engels
3) Ander (spesifiseer)	

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Agtergrondsgeskiedenis

13 Wat is/ was jou verhouding met die moeder van die kind onder bespreking?

1) Moeder
2) Vader
3) (Vorige) man of lewensmaat
4) Suster
5) Broer
6) Vriend/vriendin
7) Tante
8) Oom
9) Ouma
10) Oupa
11) Ander (spesifiseer) ______
12) Geen (verduidelik) ______

14 Waarom woon die kind onder bespreking nie tans by sy/ haar moeder nie?

1) Moeder is oorlede.
2) Kind is weggevat by moeder weens maatskaplike (huislike) probleme.
3) Moeder kan nie vir die kind sorg nie as gevolg van finansiële redes.
4) Moeder werk iewers ver weg van die huis af.
5) Moeder wil nie vir die kind sorg nie.
6) Ander (spesifiseer).

15 Indien die moeder oorlede is, hoe is sy oorlede?

16 Aan watter etniese/rassegroep behoort of het die moeder van die kind onder bespreking behoort?

1) Swart	2)Wit
3) Gemeng (kleurling)	4) Asiaties
5) Indiër	6) Ander (spesifiseer)

17 Hoeveel jaar was die moeder op skool? ______ jr

18 Wat was die hoogste graad wat die moeder van die kind onder bespreking klaargemaak het?

1) Geen formele onderrig
2) Graad 1
3) Graad 2
4) Graad 3
5) Graad 4
6) Graad 5
7) Graad 6
8) Graad 7
9) Graad 8
10) Grrad 9
11) Graad 10
12) Graad 11
13) Graad 12
14) Kollege diploma
15) Universiteitsgraad

19 Hoe belangrik is/was godsdiens vir die moeder?

1) Glad nie belangrik
2) Matig belangrik
3) Baie belangrik

20 Watter tipe werk doen die moeder van die kind onder bespreking gewoonlik?
(moenie hierdie vraag vra indien die moeder oorlede is nie)

1) Geen	2) Fabriekswerk
3) Plaaswerk	4) Kantoorwerk
5) Student	6)Ander (spesifiseer)
7) Moeder oorlede	

21 Wat is die moeder se werkstatus?
(moenie hierdie vraag vra indien die moeder oorlede is nie)

1)Werkloos	2) Voltyds
3) Deeltyds (minder as 20h/wk)	4) Seisoenwerk
5) Student	6) Moeder oorlede

Inligting aangaande die swangerskap en geboorte van die kind onder bespreking

22 Was daar enige probleme tydens die swangerskap van die kind onder bespreking?

1) Ja	2) Nee
3) Onbekend	

23 Indien ja,spesifiseer:

___

___

___

24 Met die kennis wat tot jou beskikking is, dink jy die moeder het alkohol gebruik tydens haar swangerskap met die kind onder bespreking?

1) Ja 2) Nee

3) Onbekend

25 Was daar enige komplikasies tydens die geboorte van die kind onder bespreking?

1) Ja 2) Nee

3) Onbekend

26 Indien ja, verduidelik hierdie komplikasies.

___

___

27 Was die kind onder bespreking prematuur gebore?

1) Ja 2) Nee

3) Onbekend

28 Wat was die kind onder bespreking se geboortegewig? kg

2) Onbekend

Interne oudit vrae

29 Dink jy jy het moontlik die verkeerde inligting van die voog gekry?

1) Ja 2) Nee

30 Indien ja, wat was volgens jou die rede hiervoor?

Die persoon het die vrae verkeerd beantwoord

Die persoon het nie die vrae reg verstaan nie

Die persoon het nie die moeder van die kind onder bespreking goed geken nie

31 **Moontlike redes vir waarom die persoon nie die vrae verstaan het nie:**

___

___

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APPENDIX N

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INSTRUCTIONS FOR INTERVIEWERS

1. When the mother of the child of interest is being interviewed, use **Questionnaire A.** When someone other than the mother of the child of interest is being interviewed, use **Questionnaire B.**

2. Before the interview begins, introduce yourself to the client (e.g. "Good morning, my name is Leana"). Tell the client that they are more than welcome to use your name when addressing you. Ask the client how he/she would like to be addressed. Explain to the client that the child of interest has already been examined and that you are now going to specific questions in order to get some more information. Reassure the client by reminding him/her that the examination as well as the interview is in the child's best interest. Thank the client for giving permission for the child to be examined.

3. Ask for the child of interest's clinic card.

4. If possible, the client should only be addressed in his/her home language during the interview.

5. All the questions that have been included in the questionnaire, must be asked as part of the interview. No questions should be left out.

6. Mark all relevant answers with a "√". If an answer was marked incorrectly, make a "x" next to the incorrect answer before marking the correct answer with a "√". If the person is unable to answer a question, write a question mark next to the question number. The question should under no circumstances be left out.

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INSTRUKSIES VIR ONDERHOUDVOERDERS

1 Wanneer die onderhoud met die moeder van die kind onder bespreking self gevoer word, gebruik **Vraelys A.** Wanneer die onderhoud met iemand anders as die moeder van die kind onder bespreking gevoer word, gebruik **Vraelys B.**

2 Voordat die onderhoud begin, stel jouself voor aan die kliënt (bv. "Goeiemôre, my naam is Leana"). Noem aan die kliënt dat hulle die vrymoedigheid kan hê om jou op jou naam te noem. Vra vir die kliënt hoe hy/sy verkies word om aangespreek te word. Verduidelik aan die kliënt dat die kind onder bespreking reeds ondersoek is en dat jy nou spesifieke vrae gaan vra om verdere inligting te verkry. Stel die kliënt gerus deur hom /haar te herinner dat die ondersoek en die onderhoud in die kind se beste belang is. Bedank die kliënt dat hy/sy toestemming gegee het dat die kind ondersoek kan word.

3 Vra vir die kind onder bespreking se kliniekkaart.

4 Die kliënt moet tydens die onderhoud (indien moontlik) slegs in sy/haar huistaal aangespreek te word.

5 Al die vrae wat by die vraelys ingesluit is, moet as deel van die onderhoud gevra word. Geen vraag behoort uitgelaat te word nie.

6 Merk alle toepaslike antwoorde met 'n "√". Indien 'n antwoord verkeerdelik gemerk is, maak 'n kruisie in die ooreenstemmende blokkie voordat die regte antwoord met 'n "√" gemerk word. Indien die persoon nie die vraag kan beantwoord nie, maak 'n vraagteken langs die vraagnommer. Moet onder geen omstandighede die vraag net uitlos nie.

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APPENDIX O

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Approval Notice
New Application

20-Jul-2012
Breytenbach, Elizabeth E
Stellenbosch, WC

Ethics Reference #: S12/06/159

Title: **A REVISION OF THE METERNAL INTERVIEW QUESTIONNAIRE USED IN FETAL ALCOHOL SPECTRUM DISORDER PREVENTION PROGRAMMES IN SOUTH AFRICA**

Dear Mrs Elizabeth Breytenbach,

The **New Application** received on **19-Jun-2012**, was reviewed by members of **Health Research Ethics Committee 1** via Expedited review procedures on **20-Jul-2012** and was approved.
Please note the following information about your approved research protocol:

Protocol Approval Period: **20-Jul-2012** -**20-Jul-2013**

Please remember to use your **protocol number** (**S12/06/159**) on any documents or correspondence with the REC concerning your research protocol.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:
Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired.
The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number projects may be selected randomly for an external audit.
Translation of the consent document in the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.
For standard REC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further help, please contact the REC office at 0219389657.

Included Documents:
Protocol
Information leaflet
Application Form
Investigators declaration
Checklist
Consent Forms
Synopsis

Sincerely,

Stellenbosch University http://scholar.sun.ac.za

Franklin Weber
REC Coordinator
Health Research Ethics Committee 1

Stellenbosch University http://scholar.sun.ac.za

Investigator Responsibilities

Protection of Human Research Participants

Some of the responsibilities investigators have when conducting research involving human participants are listed below:

1.Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research.

2.Participant Enrollment. You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use. If you need to recruit more participants than was noted in yourREC approval letter, you must submit an amendment requesting an increase in the number of participants.

3.Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (15) years.

4.Continuing Review. The REC must review and approve all REC-approved research protocols at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period.** Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in REC approval does not occur.** If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.

5.Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate**any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

6.Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to the REC within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch Universtiy Health Ethics Committee Standard Operating Procedures www.sun025.sun.ac.za/portal/page/portal/Health_Sciences/English/Centres%20and%20Institutions/Research_Development_Support/Ethics/Application_package All reportable events should be submitted to the REC using the SAE Report Form.

7.Research Record Keeping. You must keep the following research related records, at a minimum, in a secure location for a minimum of fifteen years: the REC approved research protocol and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC

8.Reports to MCC and Sponsor. When you submit the required annual report to the MCC or you submit required reports to your sponsor, you **must** provide a copy of that report to the REC. You may submit the report at the time of continuing REC review.

9.Provision of Emergency Medical Care. When a physician provides emergency medical care to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognized as research nor the data used in support of research.

10.Final reports. When you have completed (no further participant enrollment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the REC.

11.On-Site Evaluations, MCC Inspections, or Audits. If you are notified that your research will be reviewed or audited by the MCC, the sponsor, any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.