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A mixed methods study exploring the barriers and facilitators of screening for autism spectrum disorder in Oman

By

Turkiya Saleh Al Maskari

RN, BSN, MSN

A thesis submitted to the University of Glasgow in the part fulfilment of requirements for the Degree of Doctor of Philosophy (PhD) in Nursing and Healthcare (Research)

Nursing and Health Care School

School of Medicine

College of Medical, Veterinary & Life Sciences

University of Glasgow

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Abstract

Within routine practice, specific screening for autism spectrum disorder (ASD) has been recommended, in order to facilitate early intervention and improve outcomes. Despite the substantial advantages of this process, it has also presented a variety of challenges, across clinical settings, which have not yet been explored sufficiently. There is little information available to support the introduction of ASD screening in Oman. Research is required to identify the potential facilitators of and barriers to ASD screening in Oman, prior to the implementation of a screening programme, to ensure its successful introduction.

Method

An exploratory mixed-methods design was adopted, in two sequential phases. Phase 1 involved two focus group discussions, with seven nurses and six GPs, from primary health care (PHC) settings in Oman. The participants were recruited using a purposive and snowballing technique. The discussions were audio-taped and transcribed verbatim. Framework Analysis was used to identify recurrent themes within and across groups. Data from the focus groups was then used to inform the development of a questionnaire, which was piloted on a sub-sample of volunteers from both groups. Phase two (quantitative phase) comprised of sending the final draft of the questionnaire to a random sample of primary health care providers (PHPs) (n=571) across Oman. The returned data was analysed statistically with the software program SPSS (Statistical Package for Social Sciences version 22.0). The Social Ecological Model (SEM) was then applied to interpret the final data from both phases and to draw conclusions.

Results

Qualitative data analysis revealed five themes, which voiced the major challenges facing ASD screening in Oman, as well as highlighting a few facilitators. The findings revealed that both nurses and GPs believed that introducing screening for ASD would be a positive step. However, they felt overwhelmed by their responsibilities and believed that their workplaces lacked the necessary infrastructure. Practitioners' awareness of ASD services was identified as poor, as were the essential skills required for undertaking screening. Additionally, limited public awareness of ASD and a strong interest in traditional medicine, as well as the social stigma attributed to ASD, were thought to create barriers to screening. The groups also discussed their preference for a clear, simple, paper-based questionnaire,

supported with guidance and researcher availability to reward their willingness to participate.

The findings from the focus group informed the development of a 38-item questionnaire to explore the potential barriers to and facilitators of the introduction of ASD screening in Oman. The questionnaire was short so that it could be completed within 15 minutes.

Five hundred and seventy-one questionnaires were sent to a random sample of PHP providers across Oman. Of those, five hundred and sixteen questionnaires were returned, in phase 2 (response rate 90.37%). The quantitative results of this phase were congruent with the qualitative findings, in that they suggested a deficit in the knowledge of professionals, among both older respondents and nurse respondents. In addition, a lack of resources, time constraints, workload issues and staff shortages were highlighted. The respondents also emphasised the ambiguity surrounding their role and the lack of guidance on protocols to identify or refer suspected cases. This was compounded by a lack of public awareness and knowledge of ASD identification and its potential causes, as well as the attributed social stigma.

Conclusions

The root challenges and potential facilitators for screening for ASD were examined, through the SEM. Challenges were addressed and resolved across three levels (intrapersonal, organisational, and community). At the intrapersonal level, more training and knowledge regarding ASD is required. Organisations need to implement a clear protocol, to guide the process, with greater coordination and collaboration among services. A country-wide awareness campaign, targeting social issues, may reduce the stigma and improve the uptake of screening.

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Publications arising from this thesis

Conference participations:

1. Al Maskari, T., Melville, C., & Willis, D. 2016, 'Can nurses play a role in screening for autism in non-English speaking countries?' Poster to the RCN 2016 research conference, Edinburgh, 6-8 April, viewed October 2015, <https://www.rcn.org.uk/professional-development/research-and-innovation/research-events/rcn-2016-research-conference>

2. Al Maskari, T., Melville, C., Wahid, R., A. & Willis, D. 2016, 'Nurses' and GPs' views on facilitators and barriers of screening for autism in Oman', Presentation in IIQM Qualitative Methods Conference 2016, *International Journal of Qualitative Methods*, SAGE Publications pp1-2.

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4. Al Maskari, T., Melville, C., Wahid, R., Al Farsi, Y. & Willis, D. 2016, 'Mixed methods study phase II: Exploring the facilitators and barriers of screening children for autism in Oman', Poster II to the IASSIDD 15th World Congress, Melbourne, 14-19 August, *Journal of Intellectual Disability Research*, 60**,** pp768

5. Al Maskari, T., Melville, C.& Willis, D. 2016, 'Developing a questionnaire exploring the facilitators and barriers of screening children for autism in Oman'. Abstract in the 16th European Doctoral Conference in Nursing Science, Bern University, Switzerland, 16-17 September 2016, <http://me001ned.edis.at/pflegewissenschaft/EDCNS/2016/edcns_2016_programme.html>

Author's Declaration

'I declare that this thesis is the result of my own work, except for quotations and citations which I have used and acknowledged appropriately. I also declare this thesis has not been submitted in any form for another degree or professional qualification'.

Signature:

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Tarkiya Saleh Al Maskari

Abbreviation

ARI	Acute Respiratory Infections
ASD	Autism Spectrum Disorder
BFHI	Baby Friendly Hospital Initiative
CDD	Control of Diarrhoeal Diseases Programme
CPD	Continuing Professional Development
DD	Developmental Disabilities
EM	Ecological Models
EPI	Expanded Programme on Immunisation
EVF	Ecological Validity Framework
IMCI	Integrative Management of Childhood Illness
FA	Framework Analysis
FG	Focus Group
MMR	Measles, Mumps, and Rubella
MOH	Ministry of Health
PDD	Pervasive Developmental Disorder
PHC	Primary Health Care
PHP	Primary Healthcare Provider
PPV	Positive Predictive Value
RA	Research Assistants
TD	Typical Development

Chapter 1: **Background**

1.1. **Introduction**

Autism spectrum disorders (ASD) are neurodevelopmental conditions that are characterised by an impairment in social communication and interaction as well as an increase in repetitive, restricted behaviour (American Psychiatric Association, 2013). According to the fifth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM V), children with ASD demonstrate a range of shortfalls in their social communication and behaviour across multiple contexts: 1) deficiency in their social-emotional reciprocity skills (i.e. failure to conduct a normal back-and-forth conversation or initiate a response to social interaction); 2) difficulty in understanding and using nonverbal communication (i.e. abnormal eye contact, lack of integration of facial expressions or gestures); and 3) challenges in developing and managing relationships (i.e. difficulty in adjusting behaviour to suit various social contexts, sharing imaginative play, making friends, or enjoying the presence of peers). Children with ASD also display repetitive motor movements and the use of objects, or speech, which may be associated with adherence to inflexible routines.

Despite rising prevalence rates, at present, there is no medical cure for ASD(Mohiuddin and Ghaziuddin, 2013). According to Kopetz and Endowed (2012), the estimated prevalence of ASD has increased by 2000% throughout the world, over the past decade. A global estimation, in 2010, indicated that there were 52 million cases of ASD, equating to a prevalence of one in 132 people (Baxter et al., 2015). Males are four to five times more affected than females (Vézina et al., 2013). The reason for this aetiology bias remains unclear and none of the theories presented on this subject have yet been fully confirmed (Baron-Cohen et al., 2011). However, there are conflicting views in the literature as to whether this increased prevalence of ASD is the result of more children being affected, or whether more cases are being detected due to an increased awareness of the disorder, as a consequence of improved methods of identification and diagnosis or changes in reporting practices (Hansen et al., 2015, Idring et al., 2015).

Research has consistently concluded that early detection of ASD increases opportunities for developmental and behavioural interventions, which can improve the developmental functioning of communication, social interaction and cognitive skills and reduce the core symptoms of the disorder (Brett et al., 2016, Zwaigenbaum et al., 2013, Barbaro and Halder, 2016). Despite some encouraging results from early interventions, many children and young

people with ASD do not receive intervention until late childhood or even adolescence (McPheeters et al., 2016). Disparities have been noted in the frequency and age at which ASD is diagnosed among children in terms of race/ethnicity, socioeconomic status, and language of origin. This results in the fear that certain groups of children with ASD are underdiagnosed (Siu et al., 2016, Pierce et al., 2011). A recent Centre for Disease Control (CDC) report found that the majority of children with ASD in the United States (US) are diagnosed at a median age of four years and five months, suggesting that the average age of diagnosis of ASD in the US continues to be between five and six years (Christensen, 2016) and over five years of age in the UK (Shattuck et al., 2009). Racial/ethnic differences in the identification age of ASD have also been documented in the literature. Mandell et al. (2002) examined 406 children with ASD, of which 59.6% were African American, 29.1% were white, 8.1% were Latino, and 3.2% fell into other race categories (American Indian, Asian, and "other"). The result indicated that the African American children were being diagnosed with ASD 1.6 years (i.e. at 7.9 years old) later than white children (at 6.3 years) and 2.5 years (i.e. at 8.8 years old) later for Latino children. Figures from the CDC also highlighted the fact that at eight years of age, far fewer Hispanic and African American children had been identified with ASD (Christensen et al., 2016).

1.2. **ASD screening**

One potential solution to the late diagnosis of ASD is routine screening for this disorder in primary health care (PHC) settings. Therefore, some organisations, such as the American Academy of Neurology, the American Academy of Child and Adolescent Psychiatry and the American Academy of Paediatrics (AAP), have recommended ASD screening for children under 30 months of age within routine practice (Filipek et al., 2000, Volkmar et al., 1999). In order to support and coordinate low-cost, effective routine screening services in PHC, US professional groups and affiliated organisations, such as AAP, CDC, and ASD Speaks, have developed frequently updated materials to guide clinicians on ASD care, including screening. For example, they provide information and training on available screening instruments, guidance on coding and billing, and support for practices in terms of referrals and resources (McPheeters et al., 2016)

Effective screening for ASD is viewed as essential for both short- and long-term outcomes for children affected with ASD, as it is believed to increase the opportunities for identifying children with ASD and to lead to a referral for diagnostic assessment and intervention at the

earliest possible time (Morelli et al., 2014, Pierce et al., 2011). It is also thought to reduce the stress placed on families when diagnosis is delayed (Kobak et al., 2011). Additionally, ASD screening might increase the number of intervention hours required for a diagnosed child (Stahmer and Mandell, 2007) and promote higher numbers of early intervention services than for children identified via clinical surveillance (Pierce et al., 2011).

However, other organisations do not support systematic population screening for ASD. For instance, neither the 2011 guidance from the UK National Screening Committee (NSC, 2012) nor the 2016 guidance from the Scottish Intercollegiate Guidelines Network (SIGN), recommend universal screening (SIGN, 2016). This is due to concerns over the stability of ASD diagnosis at a young age, the lack of rigorous data on screening instruments for population settings and weak evidence relating to the efficacy of treatment. The authors argue for further investigations addressing such concerns.

A recent US Preventive Services Task Force (USPSTF) also cited inadequate evidence on the benefits of and drawbacks to screening for ASD in children aged 18 to 30 months who demonstrated no previous risk. However, they did not discourage screening but rather suggested that screening decisions be based on clinical judgments for individual settings and advocated more focused and higher quality research, with a particular focus on individual populations, especially minorities, with low socioeconomic status (Siu et al., 2016).

The uptake of screening for ASD in PHC settings has been low (23%) (Dosreis et al., 2006). This may be the result of a number of challenges, such as a lack of time, resources, specific training in and knowledge of ASD, or familiarity with ASD screening instruments (Carbone et al., 2010, Gillis, 2009, Zwaigenbaum et al., 2015, Dosreis et al., 2006). Disparities were also noted in cultural backgrounds, practice approaches and in the screening instruments adopted among screened populations (Albores-Gallo et al., 2012, Matson et al., 2011, Zachor et al., 2011). The evidence indicates a variation in the cultural backgrounds, symptoms, endorsements and parental expectations of what is considered as ‘normal’ in terms of development among different cultural groups (Freeth et al., 2014, Albores-Gallo et al., 2012, Matson et al., 2011). For example, Albores-Gallo et al. (2012) highlighted that Mexican culture generally discourages direct eye contact and pointing, as a mark of respect, and therefore parents would have a lower chance of recognising and reporting such symptoms as abnormal. also pointed out that early markers of ASD (i.e. nonverbal communication/socialisation, verbal communication etc.) were viewed and reported differently among the investigated cultural groups. In addition, discrepancies in ASD

screening approaches and practice capacities were identified between countries. Matson et al. (2011) suggested that countries differed in their approaches to screening for ASD, which may affect identification processes worldwide. For example, the US recommends routinely screening children under 30 months of age for early developmental milestones and ASD during paediatric appointments, specifically at the ages of 18 months and 24 months (Matson et al., 2011, Duby and Johnson, 2009). Therefore, measures such as the Modified Checklist for Autism in Toddlers (M-CHAT; Robins *et al.*, 2001) were adopted in order to universally screen for ASD during routine paediatric appointments. In contrast, toddlers in the UK are not universally assessed for ASD, but are instead evaluated for a diagnosis of ASD after signs are identified by clinicians or family members (Tebruegge et al., 2004). With regard to variations in practice capacity, some researchers from developing countries have reported limited mental health services, especially for children (Seif Eldin et al., 2008, Al-Farsi et al., 2011a). The use of ASD screening instruments also differs among populations and cultural groups (Allison et al., 2012). The recognised challenges and variations in ASD screening across populations warrant further examination in terms of individual clinical settings and cultural groups in order to understand its effects and promote the outcome of screening and diagnosis.

1.3. **ASD screening instruments**

Since the late 1990s, global attention has been directed towards developing a screening instrument that facilitates the early identification and diagnosis of ASD in children younger than 30 months of age (Blackwell, 2002, Robins, 2008, Siu et al., 2016, Samadi and McConkey, 2015, Gillberg et al., 1996, Baron-Cohen et al., 2000). This has resulted in the production of a number of useful instruments that help professionals and caregivers to screen for ASD. These instruments were classified into two levels. Level 1 instruments were designed to screen all children, regardless of their risk level of ASD, and they were applied at the population level. Level 2 instruments were intended to be a means of differentiating between ASD and other developmental disabilities. They were aimed at those who demonstrated high-risk features, such as children who had failed an autism-specific screening instrument; younger siblings of children who had been diagnosed with ASD and those who had a congenital (preterm status) or genetic (e.g., Fragile X, Down syndrome, or Angelman syndrome) condition. Both types of instruments focused on specific questions and aided decision making within the referral and evaluation procedure. However, Level 2

instruments require a comprehensive and in-depth evaluation to be undertaken in order to arrive at a diagnosis.

Level 1 screening instruments were studied in this field in order to support the identification process during the early stages of life and to boost the outcomes of early identification (Mattila et al., 2012, Wallis and Pinto-Martin, 2008, Allison et al., 2012, Choueiri and Wagner, 2015, Ben-Sasson and Carter, 2012). This resulted in the presentation of a number of significant screening instruments that have been studied to the highest degree in this field. These include: the Checklist for Autism in Toddlers (Baron-Cohen et al., 1992); the Modified Checklist for Autism in toddlers (Robins et al., 2001); the Checklist for Autism in Toddlers-23 (Wong et al., 2004); The Early Screening of Autistic Traits Questionnaire (Dietz et al., 2006); the First Year Inventory (Reznick et al., 2007); and the Quantitative Checklist for Autism in Toddlers (Q-CHAT; Allison et al., 2008). These instruments are discussed more fully in the next section.

1.3.1 CHAT

The first known screening instrument at this level was the Checklist for Autism in Toddlers (CHAT; Baron-Cohen *et al*., 1992). Its purpose was to identify whether children at 18 months of age could initiate and respond to joint attention and pretend play, as the absence of these behaviours might indicate the presence of ASD. CHAT is a short checklist that includes two sections: an observation section, which is administered by a health care professional (5 items), and a Parent-Report section (9 items). This instrument was initially tested on a sample of 18-month-old infants (N= 41), who had a high genetic risk of being diagnosed with ASD, as they were the siblings of children who had been diagnosed with ASD (Baron-Cohen et al. 1992). The sample was then compared with a control group (N=50). In contrast to the control group, where no children were identified as having ASD, four toddlers from the sibling sample were diagnosed with ASD at 30 months of age. All of those children at 18 months of age scored above the cut-off on the CHAT (because they lacked joint attention and pretend play skills). CHAT was validated later in a large screening study in a general population of 18-month-old children (Baird *et al*. 2000). This study screened 16,235 children and followed them up at seven years of age (Baird *et al*. 2000). Eleven out of 12 children who were given a ‘high risk’ score on the CHAT at 18 months of age and again, at a repeat administration one month later, received an ASD diagnosis at seven years of age. There was a high Positive Predictive Value (PPV; 0.83) and a poor sensitivity value (0.38). This is far below the acceptable level for a screening instrument as the minimum sensitivity required is between 0.7 and 0.8 (Glascoe and Shapiro, 1996). A

recent review concluded that this instrument provided a considerably low identification rate of ASD [i.e. low sensitivity (0.21), and modest Positive Predictive Value (PPV) (0.58)] in a low-risk population (McPheeters et al., 2016).

1.3.2 M-CHAT, M-CHAT-F and M-CHAT-R/F

The second screening instrument in this area was a modified parental report version of the CHAT, known as the M-CHAT (Robins *et al*. 2001). This included 23 items and it integrated all of the key items of the original CHAT, as well as some of the items relating to sensory abnormalities and repetitive behaviours. In the M-CHAT study, 1,122 children between the ages of 18 and 24 months were screened. Participants were recruited from baby clinics and early intervention clinics (n=171) and consisted of those children who were undiagnosed with ASD but had been referred for early intervention. The initial psychometric properties of this instrument were high (a sensitivity value of 0.87, a specificity of 0.99 and a PPV of 0.8). However, this might be due to the large sample of affected children; the sensitivity of M-CHAT in the general population was unknown.

In contrast to the CHAT, the original M-CHAT relied exclusively on parental reports, with no clinical observations. Future studies on this instrument focused on addressing concerns regarding the potential risk of over-identification and recommended the requirement for a follow-up interview (Robins et al., 2014, Seif Eldin et al., 2008, Charman et al., 2016, Mohamed et al., 2016, Perera et al., 2009). Responding to these recommendations, the authors of the original instrument initiated a specific follow-up interview (M-CHAT/F) across the population, which was undertaken in person or via telephone (Robins, 2008). The result indicated a low PPV, 0.06, in an unselected sample attending well-child visits. However, following the telephone interview, the PPV increased to 0.57, with the identification of language or other global developmental delays, besides ASD (Robins, 2008).

Despite this, the M-CHAT gained wide popularity at both national and international levels. Garcia-Primo et al. (2014) reported that the M-CHAT was the most commonly used instrument in the United States (US) and Europe (Robins et al., 2001). This instrument was also recommended by the American Academy of Paediatrics (Filipek et al., 2000). According to the Official M-CHAT™ Website, this instrument was translated into more than 40 languages and examined within various populations across the world. All of the translated versions of M-CHAT, including guidelines and general recommendations for the translated versions, are freely downloadable from their link: http://mchatscreen.com/mchat-

rf/translations/. This availability may facilitate the popularity of the instrument. In addition to its other positive features, such as the short time in which it may be completed, it requires no significant training, is low cost and may be introduced within a PHC setting relatively easily.

The results of the wider application of this instrument indicated cultural variations in comprehension and in the reporting of instrument items, as well as the key identifiers (Mohamed et al., 2016, Albores-Gallo et al., 2012, Canal-Bedia et al., 2011, Nygren et al., 2012, Kara et al., 2014). Consequently, a new version of this instrument was introduced. It was known as the Modified Checklist for Autism in Toddlers, Revised with Follow-up (M-CHAT-R/F; Robins *et al*., 2014). The modifications involved: 1) deleting items that reported poor performance; 2) reordering items to guard against agreement bias in reporting; 3) simplifying items to improve comprehension; and 4) the provision of specific examples with which to anchor behavioural reporting. As a result, M-CHAT-R/F presented 20 items that were completed by parents, each of which was supported with a clarifying example. Guidelines for the follow-up interview were also provided. M-CHAT-R/F examined 16,115 toddlers between the ages of 16 and 31 months (Robins et al., 2014). This revealed more children with ASD than the MCHAT/F (67 per 10,000 vs. 45 per 10,000; p=0.003), with a lower PPV in diverse community-based PHC settings than the MCHAT/F (0.48 vs. 0.57) (McPheeters et al., 2016, Robins et al., 2014). In a similar way to the MCHAT/F, the children who were diagnosed with ASD, as a result of the screening process, differed in their conditions and were not solely diagnosed with ASD (n=123). Some also displayed global developmental delay (n=61), language delay (n=25), other unspecified diagnoses (n=1), no diagnosis (n=30), or developing in an atypical manner (n=23) (Robins et al., 2014). Although this appears to be a promising instrument, its failure to report the number of children with ASD who screened as negative on the M-CHAT-R/F at a young age or its failure to provide information on how the process operates in high-risk samples may prove problematic.

1.3.3 CHAT-23

Another measure in this area was from Hong Kong. Here, researchers introduced a combined version of CHAT and M-CHAT, as a Chinese version, known as CHAT-23 (Wong et al., 2004). This instrument included all 23 items from M-CHAT in section A, which was administered by parents, as well as the five observational CHAT items in section B, which were completed by trained assessors, in order to enhance reliability. Unlike the previous instruments, which involved a yes/no checklist, CHAT-23 involved selecting answers such as ‘never’, ‘seldom’, ‘usually’ and ‘often, using a graded scale method. This was because

many Chinese parents struggled to answer yes/no questions during the pilot study. The author examined 212 children (n=87 children with ASD and n=125 without) aging from 18 to 24 months. This instrument showed high to moderate sensitivity (0.73-0.93), specificity (0.76-0.91) and positive predictive value (PPV) (0.736-0.853). The study also identified seven discriminating questions, as opposed to the six in the M-CHAT (2, 7, 9, 13, 14 and 15), five of which were similar to the original M-CHAT (2, 7, 9, 13, and 15) and two of which were different (5 and 23). Although this instrument showed high psychometric properties in the Chinese population, it was not tested in general populations or different nations and therefore these results remain unknown. This instrument was followed up (WU et al., 2010); however, it is not reported here because it was published in Chinese.

1.3.4 14-item and 4-item version of the ESAT

The Early Screening of Autistic Traits Questionnaire (ESAT) (Swinkels et al., 2006, Dietz et al., 2006)), is another screening tool at the same level (1), which is used to screen children from the general population. The ESAT was administered by a clinician to children of 14 months of age. This instrument involved provisional 19-item dichotomous responses (yes/no) and contained three key items from CHAT. These were subsequently dropped from the final 14-item version as they proved to be less useful for children younger than 18 months of age. Preliminary data showed that the ESAT, retrospectively, could discriminate well between typically developing infants and children with ASD, with a detection rate of over 90%. However, the ESAT also detected ADHD in 19% of the children assessed. Further analyses revealed that a four-item version may be a useful pre-screening instrument because it detects around 91% of children with ASD. These four items were investigated in a population of over 30,000 aging from 14 to 15 months, and 1.2% of the population screened obtained a positive result (suspected with ASD). Of those children who were screened using the full 14-item ESAT, 39% screened positive. Of those, 18 (25%) were diagnosed with ASD, and the remaining percentage, who counted as false positives, comprised children who expressed a language delay or a developmental delay.

1.3.5 FYI

The First-Year Inventory (FYI) (Watson et al., 2007, Reznick et al., 2007) is another instrument that has been investigated in a sample of typically developing children and in a clinical sample. The FYI was a parental-report instrument that aimed to identify the risks of developing ASD at 12 months of age. It included 63 items with a variety of response patterns: 46 items with a Likert scale, 14 items with multiple-choice answers, a question asking the parent about which sounds the infant produced and two open-ended questions. The FYI was

examined and validated retrospectively by parents of children who were affected with ASD (n = 38), with Developmental Disabilities (DD) (n = 15) but not ASD, and a group of typically developing children (n = 40). The results indicated that the ASD group was rated as being at a significantly higher risk of developing ASD by their parents than the children with DD, who were rated as being at a significantly higher risk than the typically developing group in all domains. For instance, an ANOVA demonstrated a significant difference in the Social-Communication domain ($F(2, 87) = 173.5$, $p < .0001$), while the HSD post hoc analysis showed that the ASD group mean was higher (37.20, SD = 11.6, range 14.8–50) than both the DD (28.0, SD = 7.8, range 14.5–42.8), and the typical development (TD) (2.2, SD = 3.7, range 0–13.8) groups.

FYI scores at or above the 90th percentile in the normative sample gave higher psychometric properties for this instrument (i.e. sensitivity was 0.92, specificity was 0.78, positive predictive value was 0.74). Despite the promising result, Allison et al. (2008) reported two major limitations of the FYI. Firstly, it focuses on the behaviour of children of 12 months of age, and therefore there is a chance that individuals who show a pattern of typical development followed by a period of regression may be missed. Secondly, ASD screening at 12 months of age may generate a higher number of false positive cases than screening older children, where parents have a greater ability to confirm the presence or absence of key behaviours. A large-scale longitudinal research study is warranted, in order to determine whether the FYI can predict an eventual diagnosis of ASD, especially in different population groups.

1.3.6 Q-CHAT and Q-CHAT-10

The Quantitative Checklist for Autism in Toddlers (Q-CHAT; Allison et al., 2008) is a revised version of CHAT. Q-CHAT was administered by parents to children at 18 and 24 months of age. This instrument consisted of 25 items, scored on a 5-point scale (0 = never to 4 = always), which allowed respondents to report the relative frequency, typicality, or severity of the observed autistic traits, rather than their absolute presence or absence, as in the dichotomous yes/no ratings of the original CHAT. The initial study on Q-CHAT involved 754 caregivers of typically developed toddlers, aged 18 to 24 months, in the UK, 160 of which were toddlers with ASD. The total scores of this instrument were normally distributed and they indicated an internal consistency α value of 0.67, and excellent test-retest reliability after one month ($r = 0.82$). In the same study, significantly higher Q-CHAT total scores ($M = 51.8$, SD = 14.3) were identified for 41 children with established clinical diagnoses of ASD, aged 3 years and below, compared to the unselected sample ($M = 26.7$,

SD = 7.8). This provided preliminary evidence of discriminant validity. However, the psychometric properties of this instrument (sensitivity, specificity, cut-off values) were not examined.

A follow-up study used data from the same sample to identify the 10 Q-CHAT items that were able to best differentiate between toddlers with and without ASD. The Q-CHAT-10 showed high internal consistency ($\alpha = .88$) and was highly correlated with the original 25-item Q-CHAT ($r = .79$). This was followed up with a study by Auyeung et al.(2010), who used the Q-CHAT to measure autistic traits quantitatively in 141 children who were very preterm (<30 weeks of gestation) in the UK. Again, the Q-CHAT total scores were normally distributed, but significantly higher ($M = 33.7$, SD = 8.3) when compared with those of Allison et al.'s (2008) unselected sample (calculated effect size $d = .87$). This study classified the Q-CHAT items into four categories (i.e. 1. social-relatedness; 2. restricted, repetitive, stereotyped behaviours; 3. communication; and 4. sensory abnormalities). However, the calculations for the factor analysis were not reported. The authors compared the participants' mean item scores with those reported by Allison et al. (2008). The results showed that caregivers of very preterm toddlers reported significantly higher scores in 17 Q-CHAT items, with greater differences in items relating to stereotyped behaviours, communication, and sensory abnormalities. Magiati et al. (2015) highlighted the fact that none of the later studies on this instrument have examined or reported the psychometric properties of its factor structure. In conclusion, very limited information exists regarding the measuring of Q-CHAT properties. The information that is available has mainly been extracted from UK studies (Allison et al., 2012, Auyeung et al., 2010).

Obviously, most of the well-known screening instruments possess a wide range of applications for detecting ASD in children of varying ages. They also exhibit the flexibility to understand developmental milestones, specifically ASD (Schopler and Mesibov, 2013). However, these instruments are consistently criticised for their inadequacy and lack of sensitivity required for screening (specifically for ASD) at a population baseline level; hence further research is needed (Towle and Patrick, 2016). They also present cultural variations in the way they express ASD symptoms (i.e. eye contact and pointing) (Ouhtit et al., 2015), as well as discrepancies in identification markers and preference of administration (Robins et al., 2014).

1.4. **Study context**

The Sultanate of Oman is one of the Arabian Peninsula countries. It is considered the third largest state, after Saudi Arabia and the Republic of Yemen, and it covers a total land area of 309,500 square kilometres. Oman consists of diverse topography, mostly valleys, and desert, which accounts for 82% of the land mass, followed by mountains (15%) and coastal areas (3%) (World Health Organization, 2016). According to the Central Intelligence Agency (2015), Oman is classified by the World Bank as a 'middle-income economy', with a population of about 4,595,164 (National Centre for Statistics & Information, 2017)

1.4.1 Health care system in Oman

The health services in Oman are mainly managed by the Ministry of Health (MOH). The MOH funds the entire public health sector in Oman, which accounts for around 90% of the health institutions, along with a few other non-MOH and private institutions (see Figure 1-1., which illustrates the components of the health system in Oman) (Al Dhawi and West, 2006)

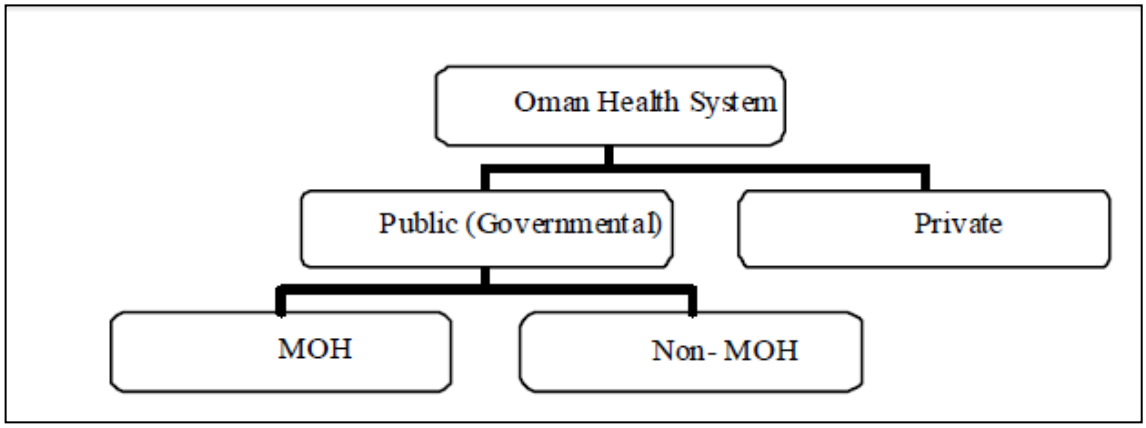


Figure 1-1 Components of the health system in Oman
This diagram is taken from (Al Dhawi and West, 2006)

The MOH provides universal health care, through well-equipped hospitals and health centres at the primary, secondary and tertiary levels. Due to the diverse geographic nature of the Sultanates (i.e. valley, desert, mountains, and costal area), the country is administratively divided into 11 governorates (muhafazah) with 61 Wilayats (provinces): Ad Dakhliyah, Ad Dhahirah, North Ash Sharqiyah, South Ash Sharqiyah, North Al Batinah, South Al Batinah, Al Wusta, Al Buraymi, Muscat, Dhofar, and Musandam. This division assists officials with the planning and distribution of health institutions across all areas, enabling access to medical services for everyone. Figure 1-2 illustrates the administrative divisions of Oman (Ministry of Health, 2013).

Figure 1-2The Administrative Divisions of the Sultanate of Oman
This diagram is taken from: http://www.moh.gov.om/en/

Primary health institutions are considered the entry point for health care services. They provide numerous activities to promote health, prevent illness and treat minor health problems. These activities are carried out at local health centres, extended health centres and local hospitals. All health institutions in Oman, whether free or private, are integrated into a well-established referral system. Patients cannot move from one level to another without a referral. The following diagram illustrates the referral system among these facilities (World Health Organisation, 2006).

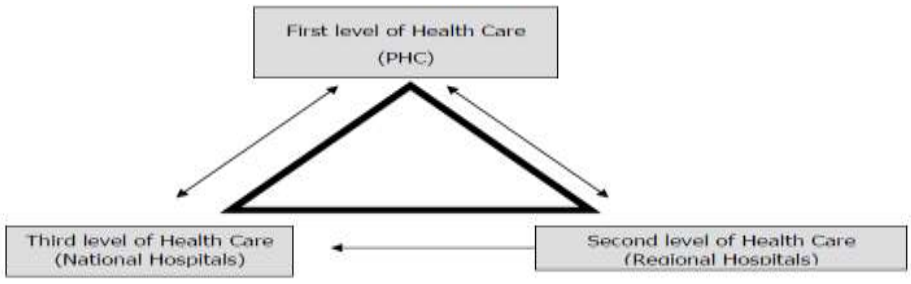


Figure 1-3 Referral chain (continuum of care)
This diagram is taken from ***(World Health Organisation, 2006).***

The rapid growth of health institutions from two hospitals and ten clinics in 1970 to 49 hospitals, 192 health centres and 24 extended health centres today, has forced the Sultanate to recruit medical personnel from all over the world, in order to manage their care services (Ministry of Health, 2012). In order to reduce dependency on overseas personnel, and develop the ability to sustain the demand for Omanis to fill the service needs, the MOH now offers national qualifications that are open to Omanis in all specialties such as general nursing, pharmacy, information management systems, allied health and health education. The General Nursing programme is the largest programme in Oman and comprises nine nursing institutions, distributed all over the country. These institutions supply the MOH hospitals and centres with about 600 diploma graduates every year. In contrast, the other allied health institutions (e.g. pharmacy, laboratory, X-ray, dentistry) are located only in the capital city, Muscat. They produce approximately 30 diploma graduates per year (Ministry of Health, 2013). Besides the MOH institutions, Sultan Qaboos University (SQU) provides another source of medical professional graduates, such as medical doctors. In 2014, around 105 medical doctors joined various health institutions across Oman.

1.4.2 Child health care in Oman

As a country with a young population, the MOH in Oman has invested in increasing its health activities and programmes. For example, investment has been made so as to increase Immunisation (EPI), the Integrative Management of Childhood Illness (IMCI), the Baby Friendly Hospital Initiative (BFHI), the Control of Diarrhoeal Diseases Programme (CDD), the Control of Acute Respiratory Infections (ARI), the Prevention and Control of Viral Hepatitis B, as well as school health programmes to improve child health within the country. As a result, a significant reduction in morbidity and mortality among children under the age of five has been recorded. For example, the mortality rate for children under five years of age decreased from 27.0 to 9.7 deaths per 1000 live births (World Health Organization, 2016).

The EPI programme was launched in 1981 and it aimed to provide free immunisation services for all children under two years of age, with consistent monitoring of their developmental milestones. In 2014, the immunisation coverage among children of one year of age was reported to have increased from 97% to 100%. The EPI programme of care was extended to monitor children's health from birth up to five years of age. Nurses and General Practitioners (GPs) play an active role in this programme, undertaking the well checks, collecting data from parents, vaccinating children and documenting this information on the

"pink card". The pink card is a universal card, issued to all children in Oman from birth until he/she reaches five years old. The card acts as a means of monitoring child development and recording health and immunisation status for parents and professionals. In addition to the EPI, there is the School Health Programme and both programmes play distinct roles in providing comprehensive and consistent health care for children. The School Health Programme continues the monitoring for ages five to 18, meaning that there is a consistent approach to promoting children's health from birth up to high school graduation.

Despite the benefits of this system for controlling childhood morbidity and mortality, it fails to address the psychosocial and developmental challenges experienced in childhood. There is a lack of services for children with special needs and mental health issues. Usually, specialist child and adolescent mental health services tend to be located in a tertiary care setting in the urban areas of Oman.

1.4.3 ASD in Oman

Little data was available on ASD in Oman until the Autism Research Group (ARG) was constituted, in September 2008. This group commenced a programme of research and, to date, has produced 16 studies that have explored various aspects of ASD in Oman: for example, the prevalence of ASD (Al-Farsi et al., 2011a); the awareness of ASD among school teachers (Al-Sharbati et al., 2015) and General Practitioners (Al-Farsi et al., 2016); the socioeconomic burden of the disorder on families (Al-Farsi et al., 2013a); malnutrition among children with ASD (Al-Farsi et al., 2011b); the association between suboptimal breastfeeding and ASD (Al-Farsi et al., 2012); and the development of a mobile application for screening for ASD (Klein et al., 2015). The ARG's efforts have contributed greatly to providing baseline data for ASD in Oman, and it may advance the ASD infrastructure, clinical management, and community services in the country. However, most of these studies are quantitative (i.e. observational studies) and either cross-sectional (Klein et al., 2015, Al-Sharbati et al., 2015, Al-Farsi et al., 2013a) or case control (Essa et al., 2012, Al-Farsi et al., 2012, Al-Farsi et al., 2013b). This method of research, in most cases, involved the use of a structured questionnaire, with closed-ended questions that reduced one's ability to fully understand the context of the phenomena (Creswell and Clark, 2007). Almost all of the above studies were undertaken in Muscat institutions (i.e. the capital city of Oman), with relatively small sample sizes ranging from 27 to 164 (Al-Farsi et al., 2016). Consequently, the results cannot always represent the actual number in reality, and the data cannot be accepted as robust enough to explain the views and perceptions of participants in this context. Future research might consider population studies using a larger sample size, with

more representative samples from different health institutions across the country. Qualitative and/or mixed-method studies might be the next step, in terms of the research required to provide detailed information explaining the status of ASD and its needs in Oman. It is especially important to ascertain the perspectives not only of professionals but also of parents, who are less recognised in Omani research.

A paper on the prevalence of ASD suggests that it is lower in Oman (0.14 in 1000 children) compared with neighbouring countries (2.9 per 1000 for PDD in UAE and 0.43 per 1000 in Bahrain) (Salhia et al., 2014) and with the rest of the world (7.6 per 1000 worldwide) (Baxter et al., 2015). However, this paper might not accurately present the actual number of ASD cases in Oman, as it used retrospective data extracted from one institution, which was believed to be the sole, formal source of records for children diagnosed with ASD in the country. To give a better estimation of the prevalence of ASD in Oman, future research might consider including all institutions, social or private, that deal with ASD services in the country. As the authors highlighted, future studies might collaborate with borderline institutions of other countries, such as the United Arab Emirates, Saudi Arabia, or Yemen, to identify further cases from Oman.

It seems obvious that the prevalence of ASD in Oman, along with other Arab countries, remains underestimated, due to ASD being undiagnosed or unrecognised in the community, especially the mild cases (Salhia et al., 2014). Al Farsi et al. (2013) suggest that this discrepancy may be largely influenced by a variety of socioeconomic factors, including differences in the cross-cultural presentation of ASD symptoms (which puts into question the reliability of the diagnostic tools), the lack of professional services and the lack of awareness and knowledge of ASD at the professional and community levels. Salhia et al. (2014) added that the lower levels of diagnosis of ASD among Arab countries might be due to a lack of screening programmes and difficulties in accessing care.

Prevalence figures in Oman are expected to increase because Oman is a country with a young population: 13.9% of its population are under five years of age and 33.7% are under 15 years of age (Ministry of Health, 2012). It has the 48th highest population growth rate in the world, with a demographic profile considered as ‘youth bulged’. Eighty-three percent of the population is under the age of 20 (Al-Sinawi et al., 2012) and as with any increase in population, the number of people affected by neurodevelopmental disorders, such as ASD, will also increase. Genetic occurrences in Oman, such as consanguinity and multiparity, are

common. This could potentially trigger developmental, social and/or intellectual conditions, leading to an increase in the prevalence of ASD (Al-Farsi et al., 2013a, Salhia et al., 2014).

Any rise in ASD will place greater demand on health and social care systems and have an impact on the economics of the country, in terms of supporting individuals with ASD. A recent study undertaken in Oman investigated the financial burden of taking care of children with ASD in 150 families from medium (n=80) and low (n=70) income groups (Al-Farsi et al., 2013a). The findings indicated that 8% of mothers had resigned from their jobs to care for their children. Of these, 5.7% of whom were from low-income families and recipients of welfare payments. It was estimated that 15% of a family's monthly income would be required to care for a child with ASD in Oman, while the income may also be reduced by 41% because of lost employment opportunities, or mothers resigning from their jobs. This financial burden might increase with a rise in the number of children affected in the family. Although few studies have examined the global burden of ASD, studies in the USA and UK have estimated higher annual costs of ASD and intellectual disabilities (ID) on the economy. These costs are in the region of several millions of dollars ($2.4 million in the US) or pounds (£1.5 million in the UK) (Buescher et al., 2014). This cost varied based on individual age. For example, during childhood the highest costs were allocated to special education services and parental productivity loss, whereas costs during adulthood fall heavily on residential care or supportive living accommodation and individual productivity. Adulthood also incurs higher costs for medical expenses. Similarly, an earlier study suggested that the cost of caring for and supporting individuals with ASD in the United Kingdom was estimated to be over £27 billion a year, of which only £2.7 billion were spent on children (Knapp et al., 2009). Therefore, early identification and intervention may reduce the estimated lifelong cost to the family and the whole society. To ensure families are supported throughout their lifespan, health care professionals and the community identified a need to improve supporting services for families affected by ASD (Al-Farsi et al., 2013a, Al-Farsi et al., 2016, Al-Farsi et al., 2011a).

Screening children for ASD within PHC practices in Oman might be an effective way to identify children at risk of ASD, whilst early intervention may reduce the potential burden on society, as well as on the families themselves. Additionally, it would help to ascertain the prevalence figures of ASD. However, a number of challenges have been recognised in the literature that might hinder the early identification and screening for ASD in Oman, such as a lack of professional and community awareness of ASD (Al-Farsi et al., 2016, Ouhtit et al., 2015, Al-Sharbati et al., 2015); a lack of required instruments and the cultural impact of

identification (Al-Farsi et al., 2011a). Practical solutions, which may overcome these barriers, include the implementation of a culturally acceptable screening process that could be used with ease. However, this would need to be explored prior to the introduction of such a screening programme.

1.5. Chapter summary

ASD is one of the fastest growing developmental disorders worldwide. Whether this increase in prevalence is due to an actual increase in the number of cases or is a result of improvements in the identification and reporting system, is an issue that needs to be addressed and managed. Discrepancies in ASD research were noted among cultural groups, in terms of prevalence rates, methods of identification and the availability of screening resources (e.g. screening instruments, expertise, early intervention services). ASD research is predominantly conducted in Western countries, which leaves a gap in our understanding of ASD across non-Western cultures. Therefore, it is important to understand the effect of culture on the expression of ASD and how it is perceived, as this will affect the outcomes of screening and diagnosis. In addition, addressing the feasibility of screening and the challenges involved in diagnosing ASD at a practical level, have the potential to improve the rate of screening, which is a necessary first step towards the goal of reducing the age of diagnosis and entry into health care services (Zwaigenbaum et al., 2015). Furthermore, an understanding of the cultural adaptations required for ASD screening and an observation of practical barriers reinforce the need for work in the area of screening for ASD in Arabic cultures, with a focus on Oman, which is the central concern of this thesis.

Chapter 2: **Systematic Review**

2.1. **Introduction**

As observed in the last chapter, over the past century, the prevalence of ASD has risen sharply worldwide by almost 2000% (Kopetz and Endowed, 2012). Alongside this, there has been an increase in support for early interventions, in order to improve outcomes (Boyd et al., 2010). Countries such as the UK and the US have examined various ASD screening measures to help healthcare professionals identify children at risk of ASD in its early stages (Baird et al., 2000, Persson et al., 2006, Robins, 2008, Carlsson et al., 2010, Windham et al., 2014, Pierce et al., 2011). Most research concerning the use of screening instruments has been conducted in Western, English-speaking industrialised countries, where there has been an increase in the recognition of the cultural impact associated with this process (Kang-Yi et al., 2013, Matson et al., 2011, Zachor et al., 2011, Wallis and Pinto-Martin, 2008). Therefore, prior to introducing screening for ASD in non-English speaking countries, it would be valuable to validate screening instruments for use within the cultural context of the individual country (Tek and Landa, 2012, Scarpa et al., 2013).

Within the literature, there have been suggestions regarding the importance of adapting valid and reliable screening tests, in order to take account of the cultural context within the country of use (Castro et al., 2010, Grinker et al., 2015, Domenech Rodríguez and Bernal, 2012). However, cultural adaptation is a complicated and challenging process that goes beyond language translation. It requires the investigator to incorporate cultural values, customs and traditions, with appropriate knowledge and skill. Castro et al. (2010) view cultural adaptation as a planned, organised, iterative and collaborative process, that often requires the involvement of a person from the targeted population for whom the adaptation is being developed. Likewise, Resnicow et al. (2000) noted the importance of the cultural competence of the investigator and of the cultural adaptation team in conducting a "deep structure analysis" of the needs and preferences of a target group. Such considerations should be taken into account when adapting and implementing screening instruments for different cultural groups.

Indeed, there is no one 'right way' to adapt cultural instruments. Within the literature, cultural adaptation is seen through a content and/or process lens (Ferrer-Wreder et al., 2012). According to Bernal and Domenech Rodríguez (2012), cultural adaptation involves changes to psychotherapy processes and/or content, with the intention of increasing the congruence

between the participants' cultural world views and the developed intervention. Beaton et al. (2007) view cultural adaptation as a process of modification, that encompasses both language 'translation' and cultural adaptation 'issues'. Process adaptation is usually considered a surface change, which might allow minor modification to interventions, such as literal language translations and ethnicity changes. However, content adaptation involves deeper structural changes that address factors such as matching the core values, competence, beliefs and normalities of the instrument developer with those of the targeted participants' culture (Bernal and Domenech Rodríguez, 2012). In other words, surface modifications involve translating the materials in order to facilitate the feasibility of the programme with minor cultural adjustment, while deep modifications require changing methods and contents to enhance the impact of the programme (Baumann et al., 2015, Resnicow et al., 2000).

With advances in the knowledge of screening for ASD, a growing body of research has attempted to adapt and develop various ASD screening instruments across cultural groups (Seif Eldin et al., 2008, Canal-Bedia et al., 2011, Ben-Sasson and Carter, 2012, Albores-Gallo et al., 2012, Beuker et al., 2014, Mohammadian et al., 2015, Mohamed et al., 2016, Wong et al., 2004, Kara et al., 2014). This has raised awareness of the importance of the quality and suitability of the adapted instrument for use in different cultural contexts. Effective cultural adaptation can aid with the maintenance of relevant screening programmes, promote instrument validity at a conceptual level across different cultures, and increase confidence in the outcome, as well as guide future work (Beaton et al., 2000, Bernal and Domenech Rodríguez, 2012, Domenech Rodríguez and Bernal, 2012). Despite the advantages of adaptation, a debate has arisen over whether it would aid the undertaking of both levels of adaptation, or achieve adequate adaptation, through the use of surface modification only (Domenech Rodríguez and Bernal, 2012, Rossello and Bernal, 1999, Bernal et al., 1995). However, the most highly recognised approach advocates the use of the level of adaptation that is deemed to be required, by matching the availability of data and resources (i.e. cost, expertise), in order to properly test the instruments adapted for supporting such decisions (Domenech Rodríguez and Bernal, 2012). Despite increasing ASD research, the information required to justify the decisions taken over the level of adaptation used, and to determine their adequacy and suitability, is limited. A recent systematic review investigated the process of adapting ASD instruments into 10 languages, in 19 countries. It concludes that there is a lack of documentation regarding the process of cultural adaptation and the adopted guidelines (Soto et al., 2015). The authors also reported that changes in the developed instruments were limited to linguistic revisions (Soto et al., 2015). Yet, this review failed to conduct a "deep structure analysis" of the adapted

instruments, as their work was guided by Guillemin et al. (1993), who provided recommendations, mainly focusing on the effective process of adaptation. Therefore, the deep cultural adaptations that go beyond translations of instrument content, to explore the modifications that involved instrument/intervention content, methods, the developer's competence, the targeted cultural preferences, and traditional involvement within the adaptation process, remain unexplored. Given these considerations, the Ecological Validity Framework (EVF) (Bernal *et al*., 1995) was adapted to guide this exploration and support a comprehensive view on the levels of cultural adaptation (i.e. content or process) employed across studies within the current review. This model has been found to be useful for elaborating the potential targets of cultural adaptation, identifying critical elements in which cultural adaptation may play a role, and addressing both surface and deep-level adaptations (Baumann et al., 2015). It also suggests the effectiveness of each study when used to adapt culturally sensitive treatments (Nicolas et al., 2009, Díaz-Santos et al., 2008, Rossello and Bernal, 1999) and when reviewing cultural adaptations or implementing evidence-based parental training programmes (Baumann et al., 2015).

As well as the importance of adaptation, knowledge of the feasibility of ASD screening, its applicability, relevance, and sustainability, in the context of diverse health care services across countries, is essential. Although ASD screening feasibility was not the main subject of the current study, the researchers believed that shedding light on this important issue was an appropriate secondary aim for the review, as it would help to build upon the sparse knowledge that exists on this topic in the literature. In addition, information on the feasibility of a newly introduced procedure was thought to be potentially relevant in improving, refining and adapting screening processes (Zenner et al., 2014). Bird et al. (2014) also indicated the importance of recognising "what is and is not feasible" within practice, in order to minimise wasted resources, inform and prioritise decisions and improve effectiveness in health care systems. With this aim in mind, the researcher adapted Bowen et al. (2009) recommendations in order to facilitate investigation and provide a comprehensive understanding of the most discussed aspects of screening feasibility within the studies reviewed.

To sum up, this review aimed to determine the extent to which cultural adaptations were considered when screening for ASD in non-English speaking countries. It also examined the literature, in order to highlight the feasibility aspects involved in screening for ASD in non-English speaking countries.

2.2. Methods

2.2.1 Study design

The literature review was undertaken in order to widen background knowledge and solidify understanding in this area of research. A literature review allows the researcher to refine the research questions, produce novel work and enrich the research field (Moule et al., 2017). There are two main types of literature review, each with distinct goals and characteristics: narrative and systematic (with or without meta-analysis). Narrative or traditional literature reviews are descriptive approaches that critically appraise published and current literature (Polit and Beck, 2004). Narrative literature review articles have an essential role to play in continuing education because they provide up-to-date knowledge regarding specific topics or themes (Polit and Beck, 2004). Nevertheless, this type of review does not describe the methodological approach that might permit reproduction of data, nor does it answer specific research questions, and it is subject to selection bias (Moule et al., 2017). On the other hand, a systemic literature review involves a comprehensive search process to addresses an explicit question and produce best evidence synthesis (Polit and Beck, 2004). As such, this type of literature review provides beneficial guidance in practice, through its specific methods, which limit bias by the identification and rejection of included studies. This improves the reliability and accuracy of the findings (Boland et al., 2013). Moreover, systematic reviews may help professionals to assimilate large amounts of information quickly. They may also help to improve the generalisation and consistency of findings, as they allow studies to be formally compared (Moule et al., 2017). Although systematic reviews are considered the stronger of the two approaches, their findings should be critically appraised using medical evidence, as they may not offer sensible or appropriate recommendations, due to limitations in the research available for review(Boland et al., 2013). Moreover, not all reviews follow universal standard guidelines (Moher et al., 2007). A recent review of 682 studies found that not all systematic reviews were equally reliable. Many were poorly conducted and poorly reported (Page et al., 2016). Page et al. (2016) suggested that using a set of universal standard guidelines for developing systematic reviews and meta-analyses, such as the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), might improve this. The authors also proposed the promotion of formal training for biomedical researchers in research design and analysis (Page et al., 2016). Savoie et al. (2003) suggested that extending searches beyond those of major databases, perhaps into the grey literature, might increase the effectiveness of reviews. Therefore, a systematic review was chosen for this study, as

the design provided a rigorous and transparent method of reviewing the literature and minimising bias (Boland et al., 2013). The review followed the guidance in the PRISMA statement for reporting on systematic reviews and meta-analyses (Moher et al., 2009), which aims to strengthen studies and improve reporting procedures.

2.2.2 Information sources

Five databases, relating to the topic, were selected: Psych INFO (EBSCOhost), MEDLINE (Ovid), CINAHL (EBSCOhost), EMBASE (Ovid) and ERIC (ProQuest); hand searches were also undertaken. ASD search terms were combined with 'screening' and 'culture' terms. In March 2016, a search was conducted. Reference lists of key studies and other reviews were scanned for potentially relevant articles. A further search was run on September 5, 2017, to update the review and this identified three more papers. Examples and results from the literature searches are provided in Appendix 1.

2.2.3 Eligibility criteria

This study examined all publications involving investigations that screened children under seven years of age for ASD, in non-English speaking countries. Only studies that used Level I screening in PHC services and described the relevant aspects of cultural adaptation processes, such as language, person, atmosphere, contents, concepts, goals, methods and context, were included. To ensure that an adequate number of studies was identified, no limitations on publication type, study design, language, or date were imposed.

2.2.4 Study selection

Searches were limited to studies that met the criteria specified in section 2.2.3 above. Search results were imported into Endnote software X7.7, which was used to remove duplicates. Initially, only the title and abstract of each study were scrutinised for relevance, by the researcher. Then, the first supervisor (CM) checked the title and abstract relevancy independently. Comparing the checks by both researchers, showed disagreement on eight papers. These disagreements were resolved through a consensus discussion. The researcher then retrieved and selected the full papers that met the inclusion criteria and compared them to CM's independent selections. There were disagreements on six studies that failed to meet the age criteria (children exceeding seven years of age). Through discussion with CM, both agreed on including a study if more than 50% of the participants were under 12 years of age.

2.2.5 Quality assessments

The quality of the quantitative study was critically appraised through the use of a validated assessment tool known as 'QUALSYST' (Kmet et al., 2004). This tool included 14 items and each study was scored in terms of the degree to which it met the criteria of the item. The results were reported as: "yes" = 2, "partial" = 1, "no" = 0. It was also possible to score a particular study design as 'not applicable' ("n/a"). This would then be excluded from the calculation of the total score. The total score obtained across the rated items was then divided by the total possible score (see Appendix 2), to produce a percentage value for each paper. The quality of any article included in the study was assessed by the researchers then compared with the second supervisor's (DW's) independent rating. Disagreements were identified on two papers and resolved, again through discussion and consensus.

2.2.6 Extracted data

Three forms were developed to extract the relevant data: 1. a study characteristic form (see Appendix 3.1), 2. a cultural adaptation form (see Appendix 3.2); and 3. a feasibility form (see Appendix 3.3). The intention of the first form was to provide general information regarding the included studies, such as author(s), country of publication, participants' age groups, assessor, and screening instrument involved.

The second form included eight questions that were developed by the researcher to examine the efforts of cultural adaptation through EVF dimensions. The EVF model has eight dimensions: language, metaphors, person, contents, concepts, methods, goals, and context. Language and metaphors are two dimensions that are required in the communication of culturally relevant ideas (in written, verbal or visual forms). 'Person' is another area, which captures the dyad dynamics of the investigators and participants, such as an ethnic match. Another aspect is the 'content', which is used to ascertain a participant's values, traditions, and interpersonal styles, at the time of screening. The concept of screening, the screening goals, and the screening methods, are other aspects that also need to be addressed (Bernal et al., 1995). These should be consistent with the cultural values and expectations of the participants. The 'context' is the final area that should be considered during the screening process.

The third form examines the feasibility of ASD screening through the lens of Bowen et al. (2009) recommendations. For that, the researcher developed eight questions intended to explore each aspect of this recommendation: accessibility, demands, implementation, practicality, adaptation, integration, expansion, and limited efficacy.

The relevant information concerning study characteristics, feasibility, and cultural adaptation was extracted by the researcher. The extracted data were reviewed by DW, who disagreed on two occasions but these disagreements were resolved through discussion. For example, DW rated the contents and practicality dimension differently to the researcher for two studies. On this occasion, both met and discussed the extracted information and finally agreed on the relevant information to include in the present study.

2.3. Results

2.3.1 Search outcomes

The database search yielded 585 papers and an additional eight papers were retrieved from the reference list search. Three hundred and forty papers were removed, as they were duplicates. Four papers were excluded because they were not presented in the English language, leaving 249 papers. Paper titles and abstracts were scrutinised for relevance and 49 papers were retained. The full texts of these 49 papers were examined and checked against the inclusion criteria by the same two reviewers; subsequently 20 papers were selected. However, there was disagreement on eight of these papers, which, again, was resolved by discussion and consensus. As a result, four papers were excluded, as they did not meet the inclusion criteria: see Appendix 4. The updated search revealed three more studies, culminating in the inclusion of 19 papers as part of this review (see the PRISMA flow chart in Appendix 5).

2.3.2 Study characteristics

This review presented 19 papers and included 20 studies, as one paper reported on two studies (see Appendix 6). These studies originated from 13 different nations, and all met the inclusion criteria for this review.

1. Arab countries (Seif Eldin et al., 2008, Mohamed et al., 2016)
2. Hong Kong (Wong et al., 2004)

3. Iran (Mohammadian et al., 2015, Samadi and McConkey, 2015)
4. Israel (Ben-Sasson and Carter, 2012)
5. Japan (Kamio et al., 2015, Kamio et al., 2014)
6. Korea (Seung et al., 2015)
7. Mexico (Fombonne et al., 2012, Albores-Gallo et al., 2012)
8. Norway (Beuker et al., 2014)
9. Sri Lanka (Perera et al., 2009, Perera et al., 2017)
10. Spain (Canal-Bedia et al., 2011)
11. Sweden (Nygren et al., 2012),
12. Turkey (Kondolot et al., 2016, Kara et al., 2014)
13. Serbia (Carakovac et al., 2016)

All of the studies used an observational design: cross sectional (n=5), case control (n=9) and cohorts (n=6). The last six years (2012-2017) have seen an increased interest in autism screening, as 16 of the studies included in this review were from that period, compared to four studies from between 2004 and 2011. The study sample size varied from 100 (Mohammadian et al., 2015) to 12,984 (Beuker et al., 2014), with a mean of 2,207. This sample included both genders, aged from 1-13 years, with a mean age of 2.6 years. The majority of studies (n=15) were conducted in clinical settings (e.g. primary care, psychiatry and hospital) (Beuker et al., 2014, Canal-Bedia et al., 2011, Kamio et al., 2015, Kamio et al., 2014, Mohammadian et al., 2015, Mohamed et al., 2016, Nygren et al., 2012, Carakovac et al., 2016, Kondolot et al., 2016, Perera et al., 2017). Two studies were undertaken in the community (e.g. day care, kindergarten, preschool centres and public primary schools) (Ben-Sasson and Carter, 2012, Samadi and McConkey, 2015), while three studies consisted of a combination of settings. Details are given of the contained process and its analysis, and these differ greatly between studies.

Almost 80% of the studies included have considered using the Modified Checklist for Autism in Toddlers (M-CHAT n=15), as well as its revised version, with the follow-up interview (M-CHAT R/F), as a screening instrument. However, other screening instruments, such as the First Year Inventory (FYI) in Israel (Ben-Sasson and Carter, 2012), the Social Responsiveness Scale-Preschool (SRS) in Mexico (Fombonne et al., 2012), the Quantitative Checklist for Autism in Toddlers (Q-CHAT) in Iran (Mohammadian et al., 2015), and the Pictorial Autism Assessment Schedule (PAAS) were also recognised in this review.

Parents were found to be the main assessors in all studies, especially mothers, although in some cases (n=6), a trained assessor, such as a medical/health science student, nurse, family physician or psychologist, was also involved. This was for validation purposes, or to meet cultural preferences (Kamio et al., 2014, Canal-Bedia et al., 2011, Nygren et al., 2012, Wong et al., 2004, Samadi et al., 2012, Seung et al., 2015, Kondolot et al., 2016, Kara et al., 2014). Training (seminars, workshops and a special study module) or aids (pamphlet slides, oral presentations, and instructional booklets) were used to promote awareness of autism among both professionals and parents. The nature of the implementation of this training, such as training programmes, assessors' roles and detailing such awareness, however, varied from author to another and was not fully documented.

2.3.3 Cultural adaptation

As explained in the extracted data section, the EVF model (Bernal et al., 1995) was used to investigate the extent of cultural adaptation within the studies. This model suggested addressing eight dimensions when culturally adapting an intervention (see Appendix 7). They are discussed as follows:

- **Language**

The first dimension within this model was that of language. It placed particular attention on presenting clear and understandable language, idioms, regionalism words and slang, in both written and verbal forms. In this review, all of the studies undertook language adaptation. Each study attempted to present a culturally appropriate language (verbal and written) as part of their adopted instrument, as well as in the follow-up interview. Despite the similarities in linguistic adaptation procedures, the studies varied in the way the findings were reported. Only two studies have detailed, in full, the steps involved in the linguistic adaptation, such as translation, back translation, the number of translators, piloting and committee review. Discussions are supported with examples (Canal-Bedia et al., 2011, Seung et al., 2015). Seventeen studies reported some of the previous steps, most commonly, the back and forth translation (Seif Eldin et al., 2008, Wong et al., 2004, Nygren et al., 2012, Ben-Sasson and Carter, 2012, Kamio et al., 2015, Fombonne et al., 2012, Mohammadian et al., 2015, Perera et al., 2009, Carakovac et al., 2016, Kondolot et al., 2016, Perera et al., 2017, Samadi and McConkey, 2015, Kamio et al., 2014, Mohamed et al., 2016, Albores-Gallo et al., 2012, Beuker et al., 2014, Kara et al., 2014). However, the translation procedure and cultural adaptation guidelines, if indeed any such guidelines were adopted, were not discernible. The exception was Nygren et al. (2012), who highlighted information regarding the use of recommended guidelines for translation. In addition to translation, the authors incorporated different dialects from nine Arabic countries. This information was

incorporated into the adapted version of M-CHAT, in order to promote parental understanding of autism in those countries. Perera et al. (2017) firstly attempted to conceptualise the screening of items in their original language and then combined each item with a photograph to facilitate parental comprehension. This stage was followed by a clarity check from a random sample of professionals and members of the public.

- **Metaphors**

This dimension addressed the incorporation of verbal (e.g. folk sayings) and visual objects, within the process. In this review, two studies expressed culturally relevant ideas in both forms, using symbols, photographs and demonstrations, which were shared with the study population. For example, Canal-Bedia et al. (2011) developed a Spanish version of the M-CHAT. In this instrument, an adaptation, using Spanish cultural idiosyncrasies, was employed, after piloting. Here, items 3, 5 and 23 were modified to include examples of Spanish toys. Perera et al. (2017) introduced photographs of local children within their screening instruments, to illustrate the text of the screening items and to promote understanding.

- **Person**

The studies present limited data relevant to the ethnical or interactional match considerations between the study participants and the investigator, or the participants' expectations of the investigator, during the screening process. 'Person dimensions' were only considered on two occasions. Firstly, studies reported a variation in the detail regarding the use of a bilanguage researcher to undertake the translation process. The second occasion was illustrated in Ben-Sasson and Carter (2012) study, where only parents who were proficient in Hebrew were involved. This enabled them to complete the adapted version of FYI on the Hebrew language and culture with more ease.

- **Contents**

Here, the culture, values, costumes and traditions of the participants were integrated within the content of the adapted instruments and/or screening process in general. Only two studies investigated the value of cultural information from the study groups and incorporated that into the contents of the screening instrument. Wong et al. (2004), for example, modified the original instrument, from a checklist format, to a graded score system. This followed the results of a pilot study, which found that many Chinese parents struggled to answer the original yes/no questions. The modified CHAT-23 involved selecting answers, such as

"never", "seldom", "usually," and "often". Another example is Perera et al. (2017), who incorporated photographs with the text content of their study, in order to improve recognition.

- **Concepts**

Ten studies described how the authors framed the adapted instruments into formats that were more understandable and consistent with the specific culture and context. This involved re-wording, describing and generalising/specifying difficult concepts or supporting them with clarifying examples, in a written or demonstrable format, or by deleting confusing, less-well-understood items. For example, in Canal-Bedia et al. (2011), three items from the screening instrument were re-worded, after piloting, to promote parental understanding (5, 8, and 17). Albores-Gallo et al. (2012) described the meaning of the '*peek-a-boo'* game as some parents, such as the Mexican parents, did not have a name for it. In Kamio et al. (2014) and Kondolot et al. (2016), the trained interviewers provided parents with specific examples for each failed item, in order to facilitate a better understanding and to enable them to judge the children's responses. Samadi and McConkey (2015) provided a general definition for some items, when translated into the Kurdish and Persian languages, to promote parental understanding. For example, item 9, regarding "finger flicking," was presented in the Kurdish instrument as "any unusual finger and hand movements." Item 10, 'fearful behaviours', was explained during the follow-up interview as reactions to social situations and new experiences. Seung et al. (2015) also re-worded three items (3, 5 and 11), and included examples for each deleted item and the three most confusing and misunderstood items (4, 8 and 22). More explicit words for a number of unspecified items were also included, to promote instrument adequacy and understanding for Korean parents, consistent with Nygren et al. (2012), who used interpreters to describe items 11, 22, and 23.

- **Goals**

From the studies reported here, it was not possible to identify whether the screening goals were constructed within the context and knowledge of values, customs and traditions, or whether there was any similarity between the assessors and participants, in terms of screening being desirable within the study context. This is with the exception of one study, in which the authors reported that both professionals and parents had expressed an interest in routine autism screening, in Spain (Canal-Bedia et al., 2011).

- **Methods**

This takes into consideration the incorporation of cultural knowledge into the intervention methodology. Four studies incorporated cultural knowledge and modified screening methods, to enable the screening to work well within the cultural context. For example, a study by Kara et al. (2014), found that when Turkish parents filled in the M-CHAT (Robins et al., 2001), 49% of the participants screened were found to be positive. The researchers changed the methodology in the second study and allowed trained nurses and psychologists to complete the Turkish version of the M-CHAT questionnaire. Using the answers parents provided in interviews, they were able to probe and clarify issues with parents. This method proved more effective and followed on from a recent study (Kondolot et al., 2016) where the M-CHAT (Robins et al., 2001) was completed using information gathered using face-to-face interviews. This, again, was found to be useful in the Turkish culture and presented less positive results. Another example of a methodological modification, to meet cultural preferences and improve instrument reliability, was demonstrated in a study by Wong et al. (2004), where Chinese parents did not complete the entire questionnaire checklist. An observational section, completed by a trained assessor, was found to reduce positivity. For the same purpose, other studies incorporated the screening instrument M-CHAT with different instruments, such as JA-OBS (Nygren et al., 2012) and red flag (Perera et al., 2009), or with a follow-up interview, in order to enhance reliability and meet cultural demands.

- **Context**

Context is the last dimension of the framework and takes into account the contextual issues that may affect the screening process within each culture. This review found that the authors of the described studies attempted to address issues that might have challenged autism screening and they suggested potential efforts that may be used to overcome these challenges. For example, Kara et al. (2014), identified a context issue among the Turkish population, whereby the general population was not used to completing checklists and hence preferred verbal interview formats. Low- and middle-income families in Turkey may also experience difficulties with understanding written questionnaires. The authors defend this by stating that the number of years spent in education is lower (not specified) in Turkey than in Western nations. (Seif Eldin et al., 2008) produced an Arabic version of the M-CHAT, to screen children for autism in nine Arabic countries. The participating countries were classified into four sub-groups (the Gulf area, East Mediterranean, Egypt and Tunisia) based on cultural, ethnic, political and social structure similarities, in order to reduce the impact of cultural diversity and help generate concrete conclusions; however, the authors did not report how they accounted for other cultural influences.

2.3.4 Feasibility of ASD screening

Bowen et al. (2009) recommended highlighting the feasibility aspects that have been considered in the investigated studies, when screening for autism. Only a few studies supplied information on aspects of feasibility. Some studies highlighted one or more of these aspects; however, none of the studies investigated them exclusively (see Appendix 8). The following section will detail each aspect of feasibility and how it was reflected in each study reviewed.

- **Acceptability**

With the exception of one study, perceptions of the suitability of or satisfaction with autism screening were not documented. Canal-Bedia et al. (2011), in their two-phase study, adapted and validated the M-CHAT for the Spanish population, which highlighted the *"great interest"* that parents and professionals were found to show in routine screening for communicative and social development in Spain.

- **Demand**

Only one study documented the interest in and use of autism screening within current practice. Nygren et al. (2012) trained doctors and nurses in child health care settings to screen children for autism, within the two and a half years of the age check-up window. The study highlighted that the trained assessors continued to use their newly acquired skills to refer suspected cases of autism (in children both younger and older than two and a half years) for evaluation, even after the completion of the study.

- **Implementation**

Although the studies varied in their design, purpose and results, screening for autism seemed to be implemented, as planned, for the intended participants successfully. However, the studies investigated here varied in the details provided of the implementation process. Five studies provided full details of the planning and implementation process associated with screening (Canal-Bedia et al., 2011, Ben-Sasson and Carter, 2012, Seung et al., 2015, Wong et al., 2004, Beuker et al., 2014). The remaining studies briefly explained what they had undertaken (Mohammadian et al., 2015, Fombonne et al., 2012, Kamio et al., 2015, Perera et al., 2009, Albores-Gallo et al., 2012, Seif Eldin et al., 2008, Mohamed et al., 2016, Kondolot et al., 2016, Perera et al., 2017, Samadi and McConkey, 2015, Kara et al., 2014). The shortened explanations might be the result of journals' restrictions on word limits.

- **Practicality**

Aspects of practicality, such as the adequacy of instruments, the time required, cost and training, which involved incorporating the existing resources in order to facilitate autism screening, were addressed in most studies. Some reported the acceptable properties of the seven included screening instruments (M-CHAT, M-CHAT R/F, CHAT 23, Q-CHAT, SRS, FYI and PAAS) to identify autism. The M-CHAT instruments and their revised versions, including follow-up interviews, were adopted by almost 80% (n=16) of the studies reviewed. They were implemented either separately or with another instrument (CHAT, ESAT, CBCL/15.5-5 Hiva and follow-up interviews) for cultural preferences or for validation purposes. Despite the disparity in implementation, analysis and adaptation methods, targeted population similarities were noted among the M-CHAT studies. For example, studies reported that the M-CHAT can be completed either by a parent or by an assessor within 5 to 10 minutes and that the follow-up interview would need a further 10 minutes. Another similarity among studies was recognised in item 13 *"imitate you"*, as it was found to be the only discriminating item from the original M-CHAT (i.e. it can discriminate between children with or without ASD) across nations, with some variation in strength for the identification of autism cases. In contrast to the original M-CHAT discriminating items, the reviewed studies presented different discriminating items. The most common were: item 21, *"understanding"* and item 23, *"checking reaction"*. On the other hand, item 11, "*over-responsiveness to noise*" raised concerns in almost 42% (n=5) of the M-CHAT studies.

Besides M-CHAT, this review identified other instruments that showed suitability for being completed by parents, within a short time frame. For example, the FYI included 60 items, and it took about 20 minutes to rate the 60 items as: never, seldom, sometimes and often. It also included multiple-choice questions that were used to identify children at risk of autism or a related developmental disability. Similarly, SRS required 15 to 20 minutes to complete. It was a 65-item rating scale, ranging from 1 (not true) to 4 (almost always true). In contrast to the previous instruments, Q-CHAT contains 25 items, it is scored on a 5-point scale (0 - never to 4 - always) and needs 5 to 10 minutes to complete. Finally, PAAS presented 21 items with a 'yes' and 'no' scale that can be completed within 15 to 20 minutes.

Besides concerns over instrument adequacy, most of the reviewed studies highlighted the cost burden of the higher identification of instruments (Albores-Gallo et al., 2012, Beuker et al., 2014, Canal-Bedia et al., 2011, Fombonne et al., 2012, Kamio et al., 2015, Mohamed et al., 2016, Ben-Sasson and Carter, 2012) and the interventions required to redress such

limitations, like training experienced assessors and employing follow-up interviews (Albores-Gallo et al., 2012, Kondolot et al., 2016).

- **Adaptation**

Adaptations were made in all studies, with variations in accommodation for cultural values and traditions, depending on the study aims and perspective. A discussion on this was carried out at the previous section under cultural adaptation.

- **Integration**

It was clear that integrating the screening process within the existing system of the study context was recognised but not encouraged. The studies suggested the possibility of introducing autism screening at the primary level (paediatric care, surveillance programmes and routine practice) (Canal-Bedia et al., 2011, Albores-Gallo et al., 2012, Kamio et al., 2014, Ben-Sasson and Carter, 2012, Perera et al., 2009, Seif Eldin et al., 2008, Nygren et al., 2012, Wong et al., 2004, Kamio et al., 2015, Carakovac et al., 2016), the psychiatric level (Albores-Gallo et al., 2012) or within a school setting (Mohammadian et al., 2015). However, they also warned of the potential inadequacy of instruments, as well as any cultural or demographic influences on the screening context. Some studies also noted the importance of recognising individual health system's needs and capacities, prior to introducing mandatory screening programmes (Canal-Bedia et al., 2011, Wong et al., 2004, Carakovac et al., 2016, Kondolot et al., 2016, Perera et al., 2009).

- **Expansion and limited efficacy**

Most studies did not encourage autism screening beyond the study context and indicated the limited efficacy of adapting the instruments for different populations. The results of the studies varied, making it very difficult to compare them internationally and to formulate conclusions. For example, studies adapted various screening instruments for use across different psychometric levels (M-CHAT, M-CHAT R/F, Q-CHAT, CHAT-23, SRS, FYI and PAAS) (Ben-Sasson and Carter, 2012, Beuker et al., 2014, Fombonne et al., 2012, Wong et al., 2004, Nygren et al., 2012, Perera et al., 2017). They also highlighted variation in the responses to items in the M-CHAT (Albores-Gallo et al., 2012, Seif Eldin et al., 2008, Wong et al., 2004, Nygren et al., 2012, Seung et al., 2015), some cultural influences (Albores-Gallo et al., 2012), socio-demographic impacts on the adequacy of instruments (Kamio et al., 2015, Beuker et al., 2014, Albores-Gallo et al., 2012, Ben-Sasson and Carter, 2012) and variations in identifying markers.

2.4. Discussion

Nineteen papers (incorporating 20 studies), from different geographical regions, met the inclusion criteria for this review. The main aim was to determine the extent to which the content level of adaptation was considered when adapting screening instruments for autism in non-English speaking countries. In addition, it highlighted the feasibility aspects of screening for autism in the countries included, if any were reported. The identified studies varied widely in their description and documentation of cultural adaptations and feasibility aspects. However, there were some commonalities within findings that helped the reviewers to draw conclusions relevant to the adequacy of cultural adaptations and aspects of feasibility that were considered when screening for autism in non-English speaking countries.

2.4.1 Extents of Cultural Adaptations

In this review, it was clear that most of the studies used surface modifications, the main focus being translation, with only a few studies also implementing deeper level adaptations that involved concepts, methods, and contents modifications. Various steps and measures were undertaken to ensure that the verbal and written language involved in the screening process was clear, understandable, culturally appropriate and syntonic to the individual culture. However, the authors concurred with (Soto et al., 2015), in that little information was offered to enable conclusions to be drawn about how such adaptations were maintained. For example, the majority of studies mainly reported back and forth translations. Other aspects of surface modifications (e.g. metaphors) were less recognisable, and were not documented in the reviewed studies.

Translation is the first step involved in the adaptation of an instrument. It requires careful planning and equal treatment of linguistic, cultural, contextual and scientific information (Borsa et al., 2012, Tanzer, 2005). Yet, despite the significance of this step, some authors failed to report its basic details, such as how many translators were involved and what their qualifications were. Recent evidence indicated the need for a minimum of two bilingual translators, with a cultural background and proficiency in both languages, in order to minimise the risk of linguistic, psychological, cultural and understanding biases (i.e. theoretical and practical) (Borsa et al., 2012, Hambleton, 2005). Some studies also failed to include an expert review or a pilot study. Both steps are essential in synthesising the suitability of an instrument for the targeted cultural context or in approving its readiness for use(Borsa et al., 2012, Hambleton, 2005).

On the other hand, deep levels of adaption were noted in a few studies throughout the following EVF domains: concepts, contents, methods and context, in order to redress some cultural and comprehension issues. Among them, the most commonly used domain was the adaptation of concepts. In this domain, authors reported efforts to re-word some items in their instruments, using more culturally sensitive concepts for screenings, excluding confusing or difficult items, or presenting participants with clarifying examples, framed within the investigated cultural values and traditions (Albores-Gallo et al., 2012, Ben-Sasson and Carter, 2012, Beuker et al., 2014, Canal-Bedia et al., 2011, Nygren et al., 2012, Seung et al., 2015). This was followed by an adaptation in methodology that required the researcher to change the screening instrument methodology from a parental report checklist to a trained assessor observant or interview format. This type of adaptation was undertaken to improve the rigorous nature of the instrument (Wong et al., 2004, Nygren et al., 2012, Kamio et al., 2014, Perera et al., 2009, Samadi and McConkey, 2015). The least considered domains of deeper adaptation were context and contents. Very few studies have considered incorporating information on cultural values, such as the level of education, socio-economic status or the geographical and demographic characteristics of the population, within the screening process (Seif Eldin et al., 2008, Kara et al., 2014, Wong et al., 2004, Seung et al., 2015).

Reviewed studies have mainly used surface adaptations (i.e. translation with minor cultural adjustment), with limited effort devoted to deep adaptations (i.e. content adaptation). Studies lack any justification for this decision. This might be due to the absence of available information on autism screening in individual contexts. However, the body of research on autism screening is growing, both rapidly and globally. Future studies might be able to identify the required level of cultural adaptation and resources beforehand. The lack of feasibility studies in this area might be another reason why researchers were prevented from conducting deep level cultural adaptation investigations. This may be due to an inability to estimate the expected expenses and required resources for this level of adaptation. In addition to the lack of data on the practicalities of implementing autism screening and the acceptability of screening in the targeted population, cost effectiveness analysis and RCT studies, comparing the satisfaction levels of autism screening groups with that of control groups, might be valuable in advancing this area. A lack of investigator knowledge, interest, and expertise in cultural adaptations might be another reason for inadequate documentation and justification for adapting a screening instrument.

2.4.1.1. Absence of adaptation frameworks and guidelines

Additionally, studies in this review lacked comprehensive detail on the particular cultural adaptation framework that was followed, as well as the efforts taken to avoid bias. This issue was also revealed by Soto et al. (2015) and , who advocated an unambiguous description of what, why, and how it was adapted. Adequate reporting is necessary for future studies, in order to promote effective outcomes, maintain high fidelity and avoid decrements in intervention impact (Baumann et al., 2015). The literature has also advocated a number of guidelines to ensure that an adequate process is followed (Beaton et al., 2000, Hambleton, 2005, Gjersing et al., 2010, Borsa et al., 2012) and that the contents of adaptations are included (Bernal et al., 1995, Resnicow et al., 2000). Noting such guidelines and integrating them within the screening process may reduce discrepancies in results, enable researchers to replicate studies, and investigate differences between instruments within an increasingly diverse population (Hambleton, 2005).

2.4.2 Aspects of ASD screening feasibility

With advances in knowledge of autism screening, identifying the feasibility of this new programme has become essential for minimising resource waste, informing the prioritisation of decisions and improving the strength of health organisations (Bird et al., 2014). This review, therefore, intended to highlight aspects of feasibility identified in studies, in order to expand on the existing knowledge in this area. However, studies varied noticeably in the reported details for each aspect. As a result, this part of the review will focus on practicalities, as they have been greatly discussed. The remaining, less recognised aspects will then be highlighted in the next section.

2.4.2.1. Practicality of the screening instruments

The studies investigated as part of this review are generally concerned with the practicalities of screening instruments, in terms of their adequacy, time, cost and the training required to deliver effective screening. M-CHAT was highly popular as a screening instrument in non-English speaking countries (Kara et al., 2014, Mohamed et al., 2016, Beuker et al., 2014, Samadi and McConkey, 2015, Seung et al., 2015, Carakovac et al., 2016, Kondolot et al., 2016, Seif Eldin et al., 2008, Canal-Bedia et al., 2011), albeit with a number of language and cultural adaptations, as discussed earlier. Despite this, most studies have demonstrated the lower adequacy of this instrument, as it presents high rates of false cases (i.e. This limitation has encouraged authors to combine the M-CHAT with a follow-up interview, or with other instruments, which allows trained assessors to verify parents' responses and reduce the

occurrence of false identification). This method has proven effective in improving instrument properties (sensitivity, specificity, and PPV values), reducing false identification, and unnecessary burden. However, this solution has raised concerns regarding costs, in terms of training staff and allocating follow-up interviews for parents, especially in those countries with limited staff and resources.

Responding to the global evidence related to M-CHAT, a new version of this instrument, with 20 items, referred to as a Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F) (Robins et al., 2009), was released. Despite the existence of this version, all of the studies in this review, with the exception of one recent (Carakovac et al., 2016) adopted the original version of the M-CHAT, with 23 items. This might be useful when investigating differences between instruments within an increasingly diverse population and for providing comprehensive insights into the effectiveness of this instrument. Adopting the new version might reduce the challenges related to some difficult items, such as item 4, "*Play peek-aboo /hide and seek*" (Mohamed et al., 2016, Albores-Gallo et al., 2012, Canal-Bedia et al., 2011). This was excluded in the new version, which provided more general terms, with supporting examples. Item 1, "*does your child enjoy being swung, bounced on your knee?*", for example, was modified to "*does your child like movement activities (for example being swung or bounced on your knee)?*" This instrument has the ability to respond to global concerns and reduce any future misunderstanding, as well as to improve instrument properties. Carakovac et al. (2016) reported less positivity and improved results, when compared with previous M-CHAT studies. Future studies might consider using the revised version of the M-CHAT.

In congruence with previous literature, discrepancies among discriminating items were also identified in this review (Albores-Gallo et al., 2012, Kamio et al., 2014, Kamio et al., 2015). Earlier cultural impacts were mainly blamed for any inconsistencies between item responses. However, recent evidence revealed additional reasons, such as demographic characteristics. For example, the level of education (Albores-Gallo et al., 2012, Perera et al., 2009, Samadi and McConkey, 2015) might reduce a parents' ability to understand the items in the questionnaire. A lack of parental comprehension might also be the result of them sharing some autistic characteristics with the child, making it difficult for them to recognise the abnormal signs of autism (Albores-Gallo et al., 2012). This, therefore, could reduce their credibility as the sole assessors for autism screening and might explain the improved result that was achieved when a trained assessor or follow-up interview was incorporated into the parental self-report in M-CHAT studies. In order to improve the practicality of this screening

tool, such issues should be considered and investigated further in future studies, to avoid wasting time, effort and resources. Another potential reason for discrepancies was the problem of reversed coding for certain items in the M-CHAT, such as items 11, 18 and 22 (Seung et al., 2015). Seung et al. (2015) recommended adapting and using such items with caution.

Although most of the instruments in this review have demonstrated acceptable psychometric properties, attention should still be paid to their practicality. Reducing the number of items in SRS and FYI might help to speed up the screening process, facilitate its integration into a busy clinical setting, promote the cooperation of parents and make it easier for both parents and professionals, with limited experience, to comprehend the questions and complete them with ease. The majority of evidence appears to be moving towards the development of screening instruments with fewer items (e.g. 10 items). The studies have identified the greatest discriminating items for autism symptoms (Kamio et al., 2015, Samadi and McConkey, 2015, Allison et al., 2012) and proposals to increase their use in screening instruments in the future. Incorporating visual aids (i.e. photographs or pictures) and conceptualising the instrument items, using the original language, as was the case in Perera et al. (2017), may potentially facilitate a parent's comprehension and reduce cultural, as well as adaptation, barriers.

As was evident, later screening scales are moving towards quantitative measurements, with items reorganised as Likert scale types. This idea was established on the assumption that autistic traits are normally distributed in the general population, not only in parents, but also in individuals with no previous diagnosis of autism in their families (Albores-Gallo et al., 2012). Despite the advancing knowledge in this area and the promising results, these abbreviated quantified instruments warrant further validation globally with the consideration of a participant's characteristics, such as social factors, cognitive level, and medical history (Zwaigenbaum et al., 2015). This will enrich our understanding of the factors that might influence the accuracy of the instruments from a global perspective.

Due to limitations in the screening instruments, such as lack of rigour and the impact of cultural and demographic characteristics, scholars have not encouraged autism screening within routine practice or encouraged further investigation for individual cultures. For the same reasons, expanding the screening programme beyond the study context and for different populations was not favoured by most researchers, which indicated limited efficacy.

2.4.2.2. Cost effectiveness of autism screening

Cost effectiveness is an important practicality to consider when introducing a new programme (Bowen et al., 2009). However, research in the field of autism screening is limited. Assessing the costs of screening might provide a comprehensive insight into the eventual financial burden of both direct (e.g. medical expenditures) and indirect (e.g. special education/training services, lost productivity by family caregivers (Zwaigenbaum et al., 2015), parental stress and the hassle of following positively screened participants) factors. Future research in this area is recommended, in order to adequately compare various screening strategies and identify, potentially, the most cost-effective methods for each individual study context. Countries vary significantly in terms of their medical facilities and services. Regions with limited capacity for mental health assessment and services should ensure adequate resources, the sufficient coordination of services in the primary sector and early intervention prior to introducing any autism screening (Kara et al., 2014, Albores-Gallo et al., 2012, Canal-Bedia et al., 2011). Future research should investigate the required resources and cost effectiveness of introducing autism screening processes into clinical settings, as this will inform and direct future policy decisions. It is also noteworthy that coordination between healthcare and specialised services, in terms of follow-up and adequate preparation for early intervention, is crucial for enhancing the benefits of the early identification of ASD.

Despite the concerns regarding the cost, increasing professional awareness and training professionals on screening for autism were found to be useful in the studies reviewed here, in terms of facilitating the screening process and improving the rigorous nature of the instruments. Kondolot et al. (2016) also highlighted the benefits of training staff on autism screening and the fact that it might reduce the high positivity of screening instruments, compared to their use by non-experienced staff. However, studies varied in their documentation of the training received and therefore comparisons could not be made regarding the level of training required or the expenses needed to facilitate effective screening. Training professionals to recognise early signs of autism is recommended in the clinical guidelines (Crowe and Salt, 2014), as without standardised training, vital signs and differences in screening results may occur.

2.4.3 Ignored areas in cultural adaptation and feasibility models

Ultimately, there are some common areas in both models – cultural adaptation (i.e. 'person and goals') and feasibilities (i.e. 'acceptability, and demands') – that investigators failed to capture. In most studies, the participants' interests, overviews, perceptions, understandings and agreements, in relation to autism screening goals and implementations, were hardly discussed and very little was documented. These areas may increase the acceptance of the adapted programme, reduce ethnic and racial discrepancies between the investigators and the participants, promote cooperation, increase demands for autism screening, and produce a flexible screening programme, framed within the values, customs and traditions of the targeted populations (Bernal et al., 1995). Future studies may consider both domains when adapting screening programmes in order to accommodate cultural discrepancies, raise investigator credibility and improve respondent and investigator relationships, when aiming for an effective outcome.

2.4.4 Strengths and limitations

The strength of this review lies in its position as the first to consider exploring the extent of cultural adaptation and the feasibility of screening for autism in non-English-speaking countries. It may serve as a baseline for future practitioners considering adapting an ASD screening process in such regions. In terms of rigour, all stages of the process (data selection, extractions and quality validation) were cross-checked by two individuals.

Nonetheless, this review has a number of limitations. A few studies (n=4) from non-English speaking literature were excluded, due to limited resources for translation. The small number of identified studies represents only 13 cultures and thus has limited representation globally. This means that there is insufficient evidence to ensure adequate cultural adaptation and the feasibility of screening for autism in non-English-speaking countries**.** However, important themes based on the adapted frameworks, relevant across cultures and feasibility, do emerge from the reviewed studies.

2.5. Chapter summary

The results of this study indicate that ASD screening in non-English speaking countries requires the use of a rigorous process to ensure adequate adaption for a specific nation's culture. Adapting a screening instrument is a complicated process that requires knowledge, skills, and proficiency in a particular culture, which goes beyond that of language fluency.

Besides expertise, data on the instrument efficacy and the feasibility of the screening programme are essential in supporting investigators' decisions on the level of adaptation (surface or deep) required for the study context. Adopting a framework to guide the cultural adaptation process, to adequately document the adaptation and decision-making processes, is of value to the field globally, as this allows cross-cultural comparisons that could eventually improve confidence in instruments and advance their outcomes. Different cultures vary in their healthcare services, infrastructure, resources and backgrounds. Further studies are warranted to examine diverse cultural feasibility indicators, cultural adaptation methods, and screening instrument adequacy, in order to enrich the limited body of knowledge in this area. Exploring the facilitators of and barriers to screening for ASD in individual clinical settings might be an essential first step to putting in place the required resources and strategy to facilitate a smooth implementation.

Chapter 3: **Aims and Research Questions**

3.1. **Introduction**

The findings from the systematic review suggested that most of the non-English speaking countries investigated attempted to adapt screening instruments. Increasingly, the adaptation of screening instrumentation is becoming an acceptable and fast method by which to create a valid screening instrument. This is especially true for those with limited resources or expertise in this field. However, the results of the literature review (Chapter 2) revealed that the adaptation process in non-English speaking countries is not adequate, and that this requires future consideration if sufficient detail on the adaptation process is to be reported. This may involve using a framework to guide the process, acknowledging the investigator's proficiency in the adapted culture or investigating the challenges to and facilitators of introducing screening instruments in the selected setting. This was suggested as a means of evaluating the effectiveness of the adaptation process, improving the rigorous nature of the adapted instrument, or facilitating a feasible and effective screening process.

From this perspective, it is clear that Oman needs to dedicate a great deal of attention to the adaptation and validation of culturally appropriate instruments. A recent study in Oman has developed and piloted a mobile application known as *"Autism Fingerprint."* This application aims to help families screen their children for ASD, using a reliable, culturally appropriate and *"easy-to-use"* instrument (Klein et al., 2015). Autism fingerprints are based on an adapted version of the M-CHAT, and are supported with clarifying animations and comparative images, customised for the Omani culture, in order to reduce ambiguity and misunderstanding. This application demonstrated high sensitivity (0·89) and specificity (0·82), as well as strong test-retest reliability (correlation coefficient, r=0·86), suggesting that it may be a promising instrument for use in screening for ASD in the Arabic context. Another ongoing study is examining an adapted version of the M-CHAT-R/F in all Omani governorates. However, this area of research in Oman is very recent and any screening instrument will require time for validation in order to prove its rigorousness and adequacy among Omanis. In addition, the information provided by each of these studies was brief in terms of the effectiveness of the instrument. For example, the finger print publication did not detail information relating to the adaptation process, which would have enabled other researchers to examine the extent to which this instrument followed cultural adaptation strategies. The hope is that future publications consider detailing this information to enable the enrichment of knowledge in this area.

By continuing to test, develop, and adapt screening instruments, it is hoped that an adequate screening instrument will be available in the near future. However, little is known about screening settings, and whether a screening programme for ASD can be achieved across countries. The findings from Chapter 2 highlighted the fact that health care settings are distinctly varied between countries, in terms of their services, infrastructure and resources. Therefore, exploring the potential barriers to and facilitators of screening for ASD is an important first step in producing a smooth, successful, and culturally acceptable screening procedure. However, there is no survey questionnaire available in the literature to address this. Furthermore, no previous studies have been undertaken to examine the readiness or capacity for screening children for ASD within the Omani PHC setting, and the effectiveness of current surveillance and well check visits in identifying developmental abnormalities or ASD has not yet been examined. Most of the recognisable work in this area is of a quantitative nature, involving the development of structured questionnaires, generally by the researchers, and the testing of a limited number of participants from Muscat institutions. Thus, the underpinning perspectives in the area of ASD identification have yet to be explored.

This thesis therefore aims to qualitatively explore the views of Omani PHPs on potential facilitators of and barriers to screening for ASD, and to produce a questionnaire, examining this aspect from a wider perspective, in a following quantitative phase. This thesis also endeavours to propose pragmatic solutions to overcome constraints, strengthen facilitators and implement culturally acceptable screening processes. This may provide recommendations for the education and training of PHPs, in relation to assessing and screening children for ASD. In order to achieve these aims, the study has adopted an exploratory mixed-method design that includes two studies: a qualitative study and a quantitative study. Both are detailed in this thesis.

3.2. **Research questions**

1. What aspects do PHPs perceive as opportunities for facilitating screening for ASD within the PHC settings in Oman?
2. What do PHPs' perceive as the barriers to screening for ASD within the PHC settings in Oman?

3. What are the key topics and issues to be discussed when developing a survey questionnaire identifying the potential barriers to and facilitators of screening children for ASD in Oman?
4. What characteristics (age, gender, experience, position, nationality, level of education and workload) are perceived by PHPs as being barriers to and facilitators of screening for ASD in Oman?
5. Can the views of the PHPs on barriers and facilitators be generalised across Oman?

3.3. Organisation of the study

To meet the aims and answer the research questions, the researcher has organised this thesis into eight chapters. The first two chapters (i.e. 1, introduction and 2, systematic review) introduce the main ideas of the research and identify any gaps in the literature. The third chapter discusses the aims of the study and the research questions to be addressed, based on information from previous chapters. The fourth chapter describes the method underpinning the study. Chapter 5 outlines the processes undertaken, as part of the qualitative study, and the outcomes achieved. Chapter 6 discusses the development of the questionnaire. Chapter 7 analyses the quantitative study process and results, while Chapter 8 highlights the studies undertaken and provides conclusions.

3.4. Chapter summary

This chapter introduced the reader to the main aims of the project and outlined the reasons for selecting the project topic. It also highlighted the research questions to be answered as well as the studies undertaken to meet these aims. Finally, this chapter described the structure of the thesis.

Chapter 4: **Methods**

4.1. Introduction

This chapter, divided into six parts, is designed to inform the reader about the philosophical stance that underlies the methodology and the theories that underpin the thesis. The first part discusses the underlying theories of the research paradigms and the rationale for adopting the study design. The second part focuses on ethical approval and the issues which arose in this area. The third chapter details data collection tools, namely the focus group discussion, field notes and the developed questionnaire. The fourth and fifth chapters explain the process of recruiting and selecting study participants, and describe the data analysis that was undertaken, the choice of framework and the decisions made in order to reach the conclusions. The sixth part examines the rigour of the data through study phases. In all parts, the researcher presents the theory, then reflects upon and justifies the selected choice of approach or method.

4.2. Underlying theories and rationale for the study design

When conducting research, the researcher must make a number of decisions. In this section, the ontological, epistemological and methodological perspectives that guided the selection of the study paradigms are illustrated. The rationale for adopting a mixed method approach will be discussed. The design employed in this study will then be examined and a detailed justification offered for the choice of an exploratory study.

4.2.1 Overview of the research paradigm

All research enquiries are based on underlying philosophical assumptions (paradigms) that guide the choice of the appropriate method for acquiring valid knowledge in a given field. According to Kuhn (1962), cited in Antwi and Hamza (2015), a paradigm is a culture of research that constitutes a common set of beliefs, values and assumptions regarding the nature of conducting research. It provides a conceptual framework or convenient model to examine a problem and find a solution (Antwi and Hamza, 2015). Traditionally, the nature of acquiring knowledge was divided into two paradigms: positivist and interpretivist (Guba and Lincoln, 1994), and more recently, pragmatist (Johnson and Onwuegbuzie, 2004). These paradigms were underpinned by three basic philosophical concepts that directed the nature

of enquiry into the research process. These were ontology (i.e. the way the investigator defines the truth and reality), epistemology (i.e. the process by which the investigator comes to know the truth and reality) and methodology (i.e. the method used in conducting the investigation) (Antwi and Hamza, 2015, Johnson and Onwuegbuzie, 2004, Terre Blanche and Kelly, 1999).

The positivist paradigms adopt a traditional scientific approach emphasising the rationale and science involved in conducting research (Polit and Beck, 2004). At the ontological level, positivists focus on exploring social reality through observation and experimentation (Cohen et al., 2013). Positivists seek objectivity when pursuing knowledge and view it as hard, real and acquirable (Polit and Beck, 2004, Antwi and Hamza, 2015). From the epistemological view, positivists attempt to keep their personal beliefs and insights detached from the investigated phenomena to avoid bias. They prefer to combine deductive logic with precise empirical observations of individual behaviour in order to discover and confirm a set of probabilistic causal factors to predict general patterns of human activity (Antwi and Hamza, 2015). To do so, they develop objective methods to achieve the closest approximation of reality regarding how variables interact, shape events and cause outcomes (Creswell, 2014). Multivariate analyses and techniques for statistical prediction would be their major contribution in assisting the investigation of the nature of phenomena, through empirical and experimental means (Guba and Lincoln, 2005, Lincoln and Guba, 2000). The objectivist ontology and empiricist epistemology, confined in the positivist paradigm, require a quantitative research method that is objective or detached, where the emphasis is on measuring variables and testing hypotheses that are linked to general causal explanations (Antwi and Hamza, 2015). Their method relies on control and manipulation of reality. Positivists often favour experimental or quasi-experimental research designs that present quantified data (Creswell, 2014).

The interpretive paradigms, however, have rejected positivist assumptions. From the ontological perspective, this paradigm emphasises the need to place analysis in context. It accepts the fact that knowledge and meaning are acts of interpretation. Therefore, the belief of those who subscribe to this perspective is that reality consists of people's subjective experiences of the external world (Cohen et al., 2013). Epistemologically, interpretivists believe that it is impossible to fully differentiate cause and effect, or separate the insights of the researcher from the study, as they consider this to be the main source of reality (Johnson and Onwuegbuzie, 2004). They emphasise better understanding of the world through first-hand experience, truthful reporting and quotations of actual conversation from an insider's

perspective (Merriam et al., 2016). To achieve this, they employ an inductive approach to generate theory through sensitive data gathering methods within a context, such as an interview, focus group (FG) discussion, or naturalistic observation that encourages participants to speak freely and understand the investigator's quest for insight into a phenomenon that the respondent has experienced. This paradigm involves smaller sample sizes, as the focus here is not on generalisation to larger groups, which is in contrast to the positivists' quantitative design (Green et al., 2013). Interpretivist paradigms add a rich and detailed, or thick, description of the investigated phenomena (Merriam et al., 2016).

Both paradigms have their own strengths and weaknesses. In the case of the positivist (i.e. quantitative) approach, it is useful in encouraging researchers to distil topics based on observable and quantifiable metrics, and it allows for the easy integration of rigorous statistical testing. On the other hand, this distillation leads to the simplification of certain concepts and the quantitative approach may not yield the full complexity of certain experiences (Neuman and Robson, 2012). The qualitative approach's strength lies in its recognition that observation does not always lead to a single meaning, in that people will perceive certain events or phenomena in various ways. It is hampered, however, by the difficulty in analysing a wide range of interpretations in order to develop insights and answers to research questions (Punch, 2014).

The differences between the two orientations dominate the research paradigms. One research culture acknowledges the superiority of "deep, rich observational data", while the other accepts "hard, generalisable data" (Johnson and Onwuegbuzie, 2004). This had previously been presented as a persistent, irresolvable conflict between the two paradigms, which focused on their differences. More recently, a third paradigm, "pragmatism", was identified in order to bridge the gap between positivists and interpretive research (Onwuegbuzie and Leech, 2004). The goal of the pragmatism paradigm was not to replace either of these paradigms, but rather to draw from their strengths and minimise their weaknesses in single research studies and across multiple studies (Johnson and Onwuegbuzie, 2004). However, this paradigm presented a number of gaps, which may occur when integrating the two earlier approaches, requiring the researcher to address them with caution. These included the weight accorded to each paradigm within the mixed study (i.e. qualitative or quantitative, dominant or equal), and the stage at which both methods should be combined (Creswell and Plano Clark, 2007). To address such concerns, pragmatist researchers have developed a number of strategies and mixed method designs to guide novices in the successful implementation of this type of study, reducing ambiguity in the mixed method design and increasing its use

among researchers. This will strengthen both its philosophical stance and application (Johnson and Onwuegbuzie, 2004, Creswell and Clark, 2007, Tashakkori and Teddlie, 2010). Despite these efforts, the use of the mixed method approach still requires certain skills, time and resources for extensive data collection and analysis in comparison with the mono-method design (Creswell, 2014).

4.2.2 The philosophical stance of the study design

The philosophical foundation that underpins the method and design of this study is derived from the pragmatism paradigm, which combines both stances (i.e. positivist and interpretivist perspectives). Therefore, all the philosophical dimensions of this study (i.e. ontology, epistemology and methodology) combine the two broad contrasting positions of positivism (i.e. independent reality) and interpretivism (reality is the product of social processes). At the ontological level, the researcher should define the truth and reality of the investigated phenomena (Polit and Beck, 2004). The principal intention of this research was to understand the reality of participants' views and their ontological positions on ASD screening challenges/potential, and to predict a general pattern for this perspective among those who may potentially undertake screening.

Epistemology requires consideration of the process in which the researcher discovers the truth and reality surrounding the investigated problem. In this research, the literature review facilitated the exploration of the nature of knowledge, and helped to shape the design of the study. An example from the literature described studies which identified the lack of screening and underdiagnoses of ASD in Middle Eastern countries and Oman. These findings may reduce the benefits of early identification and intervention, which may place a burden on countries that are already known to have limited economic resources and mental health services. Screening for ASD may improve the outcomes for suspected children and their families, and challenge the number of low identifications and diagnoses. Nevertheless, a great deal of literature indicated inadequacy and deficiencies in rigour and cultural adaptation of most of the screening instruments for ASD. Recently, Oman decided to introduce valid, reliable and culturally acceptable instruments to aid the early identification of suspected cases, which, it was hoped, would soon be available. However, the literature suggested other challenges which might hinder screening, such as lack of knowledge and expertise among professionals and the social stigma attached to the condition. Addressing such challenges and working on them prior to initiating a screening programme may facilitate smooth, successful and culturally accepted screening programmes in the future.

Knowledge of the potential and challenges of ASD screening in Oman is limited. This fact indicated the need to explore the views and first-hand experiences of PHPs, as those practitioners would be involved in implementing the screening within their clinical settings. According to Creswell and Clark (2007), the process of the exploratory mixed design demands two sequential phases: qualitative explorations followed by a quantitative study. Therefore, this study adopted FG discussion first to capture the participants' views on the potential barriers and facilitators of ASD screening, as well as their preferences for a questionnaire, for exploring this further with other PHPs in Oman. Data from the FGs informed the development of a questionnaire, used in the following quantitative phase to examine the barriers to and facilitators of ASD screening from a wide perspective, the characteristics of respondents that might affect their views, and the possibility of generalising the findings in Oman.

Methodology is the third dimension considered in this research. It attempts to translate previous dimensions (i.e. ontological and epistemological) into guidelines, demonstrating how the research is to be conducted (Antwi and Hamza, 2015, Johnson and Onwuegbuzie, 2004), and the principles and practices that govern the research. Previous dimensions therefore guide the researcher to adopt an approach that best addresses participants' views and experiences of screening, exploring the challenges and the potential of the procedure, while, at the same time, producing measures for testing large samples, with the aim of generalising the results of the study. From the wide variety of research methods, an exploratory mixed method design was chosen, as it was considered to be the best approach in guiding this research. The exploratory design began with interpretivist principles that valued multiple perspectives and a deeper understanding of the participants' views, thoughts and experiences (Creswell, 2014). There was then a shift to positivist principles, which enabled the identification and measurement of variables and statistical trends. Justification for the use of this design and its applications is explained in the next section.

4.3. **The study design**

This present study could not be directed by a quantitative method alone, due to a deficiency in suitably validated instruments for the identification of variables relating to this phenomena, specifically for the sample pursued. It could be argued that a qualitative study would be more appropriate, allowing an individual's experiences to be explored through the interview, which would be interpreted by the researcher to provide an understanding of the individual's unique experiences. However, a qualitative study alone would not provide

robust evidence of the barriers to screening throughout Oman. Furthermore, one of the limitations of relying on a qualitative design is its dependence on small sample sizes. While it compensates for this with the richness of insight, nonetheless it is limited in terms of generalisability. Given the goal of understanding the broad context of non-English speaking and developing countries, there is a need for additional evidence that would allow for extrapolation. Another factor to consider is that certain cultural tendencies and orientations in developing countries do not directly translate to Western countries, which are primarily where the studies have been conducted. It is here that the quantitative aspect of the study becomes significant. Testing the developed questionnaire that was derived from the qualitative phase, and distributing it to a more representative group, allowed certain conclusions and inferences to be made. Creswell and Clark (2007) explained that both quantitative and qualitative data offer a unified understanding of a research problem. The analysis of this approach could also strengthen the context of research in this area and widen its implications.

To support the purpose of this study, a sequential exploratory design was chosen. This sequential nature owes to the fact that an initial qualitative phase is conducted before proceeding to the quantitative aspect of the study (Hesse-Biber and Leavy, 2010, Creswell and Clark, 2007). This was thought to be useful for this project, as insights gained from the FGs could then be reflected within the development of a new questionnaire, thereby creating a more conceptually relevant instrument. Essentially, therefore, the unknown variables are first defined through the qualitative phase (exploratory) and then tested using a hypothesis and predicted outcomes in the quantitative phase (confirmed) (Creswell et al., 2011).

Creswell and Plano-Clark (2007) argued that the strength of the sequential exploratory mixed method is that it is straightforward to design, implement and report. Hanson et al. (2005) argued that this design was ideal when the variables to be investigated are not known, and where elaboration of findings is required. In contrast, the weakness of sequential exploratory design is that it takes a considerable amount of time to implement, and analysis of the qualitative data must conclude with findings conducive to subsequent phases. To expand on this, analysis options may include using themes or subthemes for taxonomy/instrument development. One of the main weaknesses of mixed methods in general is in the way that it becomes difficult to concurrently carry out both qualitative and quantitative aspects of the research. This is addressed by the sequential approach, undertaking each one at a time. As recommended by Creswell and Clark (2007), the first step in undertaking this research was to explore qualitatively the research area with a small

representative sample of participants. The findings from this part were then used to inform the development of a culturally relevant and accepted questionnaire among the PHPs in Oman. This questionnaire was used in a second quantitative phase to identify wider perspectives (see Figure 4.1 for more details). Although the quantitative phase may be used to validate the developed measure (Creswell, 2014), this was not the intention of the current study, as the researcher was constrained by time. However, validation issues regarding this questionnaire are highlighted and discussed in Chapter 6 section 6.4.

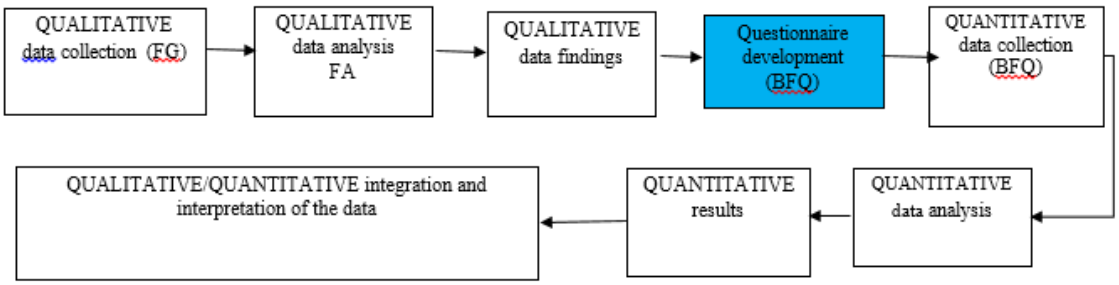


Figure 4-1: Stages of the research
Adapted from the sequential exploratory design (Creswell and Plano-Clark, 2007, p.58).
**FG: Focus Group*
**FA: Framework Analysis*
**BFQ: Barriers and Facilitators Questionnaire*

Creswell et al. (2011) suggest that there are three possible options for qualitative and quantitative strands. These can have equal priority, where both methods would have equal weighting in order to address the research problem. Where the quantitative strand has priority, more stress is placed on the quantitative source, and the qualitative part is a complementary method to help to answer the research questions. Where the qualitative strand has priority, focus is placed on the qualitative aspect, and the quantitative work is used as a complement. In this study, it made sense to use equal priority because the qualitative aspect of the study informs the quantitative heavily, while the quantitative aspect is used to confirm the findings of the qualitative part. The uppercase notation of "QUAL and QUAN" is used in Figure 4.1 to indicate this.

4.4. Ethical approval and permits

Within any study, ethical principles must be taken into consideration to ensure that the research is justified, defensible and of high quality. Ethical considerations are necessary for all research and should be included throughout the whole process of the research, from identifying the topic, to the design and data gathering, to the dissemination of the study, in order to ensure that the human rights of the participants are secured and protected (Polite and Beck, 2004). To safeguard ethical considerations, ethical principles of autonomy (governance of own actions) have been explored: beneficence (doing good), non-maleficence (doing no harm) and justice (treating cases alike) (Beauchamp and Childress, 2009).

4.5. Respect for autonomy

Autonomy is defined as the ability to make decisions on a certain topic, without interference from others or self-limitations(Beauchamp and Childress, 2009). To ensure participants' autonomy was respected, participants were informed about the proposed study in order to gain their informed consent. In the qualitative part of the study, a written consent form (Appendix 9) was obtained from all participants, to respect their autonomy. Completing and returning the questionnaire to the researcher in phase two was considered to be consent to participate. A participant's right to withdraw at any stage of the study, without negative consequences, was also explained.

4.5.1 Non-maleficence

The "non-maleficence" principle is defined as the obligation not to impose harm on others. In conducting research, it is essential to consider the potential risks and benefits of the work being undertaken (Burns and Grove, 2005), especially as it is easier to predict physical benefits, but more difficult to predict psychological, economic and social outcomes. In this study, there were no direct risks for participants, other than not being able to answer a question. However, the researcher considered the pressure participants might perceive from the recruiting process, and the time spent participating in the FG or completing the questionnaire. In both phases, the researcher was available to support participants and address their concerns, if necessary.

4.5.2 Beneficence

The principle of "beneficence" is described as an obligation to act to ensure benefit to others, and to prevent and remove any harm that might emerge from the study, including physical, psychological, social and economic aspects (Polit and Beck, 2004). Therefore, the benefits and risks should be explained to participants (Beauchamp and Childress, 2009, Polit and Beck, 2004).

In this study, the risks and benefits were made clear to all participants. Benefits were identified, such as being consulted about the possibility of introducing screening. Other tangible benefits in the qualitative phase were an attendance certificate (see Appendix 12), a flash memory stick, and a light breakfast and refreshments. Although incentives can be seen as biasing recruitment (Singer et al., 2000, Iarossi, 2006, Morgan, 1998), this is not so in the Omani culture, rather they are traditionally seen as an essential part of increasing recruitment. Furthermore, the offering of food and refreshments is considered an essential courtesy, and was seen as necessary in compensating the participants' time and contribution to the study, as well as in creating a welcoming atmosphere for participants (Winslow et al., 2002). Participants in the quantitative phase, however, did not derive any direct benefit from taking part in this study, and this fact was explained to all potential participants.

The participation of the respondents in the study should not be allowed to affect, potentially, other aspects of their lives. The opinions they provide during the present study might be negatively received in their workplace or elsewhere. Consequently, the data from participants was kept strictly confidential. An anonymous and confidential procedure satisfied this obligation. In this study, all participants were provided with a pseudonym (e.g. nurse1–nurse7 for nurses, or GP1–GP6 for general practitioners) in order to conceal their real name at the time of discussion and within the transcript. Quotations provided by the FGs, as a means of supporting the data analyses, were also anonymised, so the participants could not be identified by anyone who read the report. All collected data from both FGs and the questionnaire was held securely on a password-protected computer, in a locked cabinet in the researcher's office, at the University of Glasgow (see Chapter 5 section 5.2.9 and Chapter 7 section 7.2.5 for further details).

4.5.3 Justice

Beauchamp and Childress (2009, p. 226) define justice as "*fair, equitable, and appropriate treatment in light of what is due or owed to a person"*. In order for a research project to be

just and fair, research participants should be treated and accepted in a fair and equal manner. In both phases of this study, the recruited participants were selected not because of their availability, compromised position or manipulability, but because of their direct relationship with the study. So GPs or nurses with two years of experience working in primary health institutions in Oman were invited to participate in this study, regardless of their age, race or level of education. Participants were equally equipped with contact numbers and given access to the required information for the study, but each phase demonstrated different dimensions of equality. For example, phase 1 considered providing equal access to study venues and equal treatment for the study groups. Equality in accessibility to the study venue was also determined when the researcher allocated a place frequently used by PHPs in the centre of the capital city, for leading the FGs. Equality in treatment was viewed through the provision, for each FG, GPs and nurses, of the same venue, refreshments, studies, information and research team. Equality in access to information was ensured in phase two by the provision of a trained local assistant researcher for each governorate, to support any potential concerns or demands of the participants.

4.6. Data collection tool

Methods for data collection were proposed, based on the philosophy underpinning the inquiry (Smith, 2012). For instance, in qualitative studies, interpretive philosophy favours in-depth interviews, FGs, observation methods and document reviews, to explore a diversity of attitudes, rather than their intensity (Merriam et al., 2016). In contrast to qualitative studies, in quantitative studies positivists commonly rely on random sampling and structured data collection instruments, such as questionnaires and interviews, and attempt to fit diverse experiences into predetermined response categories (Smith, 2012). The strengths and weaknesses attributed to each method will be discussed in the following sections.

In mixed methods, data is collected using both qualitative and quantitative methods, which vary in their procedure, according to the specific mixed method design (Creswell, 2014). To illustrate, in an exploratory design the researcher first collects data qualitatively. The results are then used to inform the development of the next phase, e.g. a questionnaire that can be employed in a quantitative follow-up phase (Creswell and Clark, 2007). As this study uses an exploratory mixed method design, an FG discussion was employed at the initial qualitative phase, whilst questionnaires were developed for the quantitative phase.

4.6.1 The focus group discussion

The FGs were used to identify constructs before the deductive testing of the problem under investigation. This method reflects the epistemological commitment that emphasises the importance of understanding how individuals think and act in the world in which they live (Creswell and Clark, 2007). Unlike one-to-one interviews, FGs permit more active and dynamic social discussions, allowing a cumulative understanding of the research enquiry (Gillis and Jackson, 2002). A well-conducted FG can encourage participation by those who are reluctant to partake in a one-on-one interview, or those who feel that their views are not relevant (Stewart and Shamdasani, 2014). Moreover, FGs are deemed reasonably quick and easy to set up, and can be used to both educate the group and gather opinions on service improvement (Krueger and Casey, 2015).

Nevertheless, there are also some limitations to FGs, such as the compromising of participants' confidentiality, as all group members become aware of each other's views, once expressed, which gives participants no anonymity (Gillis and Jackson, 2002). Furthermore, a more articulate group member may perhaps silence a less confident respondent (Gillis and Jackson, 2002). Even with a skilled moderator leading the group discussion, there still might be some risk of moderator influence on the group, which perhaps may cause bias, and has been described as a "cardinal sin" in qualitative research (Fern, 2001).

The value of beginning with the qualitative phase is emphasised by the fact that incorporating key narrative data into the questionnaire from the FG discussions enhanced both validity and reliability (Creswell et al., 2011). As the study includes both nurses and GPs, more than one FG discussion was required to allow sufficient exploration of the area. In this context, issues emerging from one group can be considered in this study as triggers for the discussions in subsequent group discussions. The researcher, thereby, did not only explore the facilitators of and barriers to screening, but also created the commonality of the key points across groups.

There is no agreement with regard to the suitable number of FG discussions to be undertaken in health settings. Some authors suggest the use of the saturation method, whereby FG discussions continue until no new data emerges (Gillis and Jackson, 2002). In this study, this soft rule was not followed, because the study did not solely rely on FG discussions for drawing conclusions. The idea of conducting exhaustive sessions is to ensure that all possible insights are covered, but in this study the data was supplemented by the quantitative aspect.

Moreover, the limited timeframe for the study did not allow for several FG discussions to be conducted.

In this study, two FGs were conducted, which included six and seven participants, respectively. Polit and Beck (2004) suggest that having four to eight participants is a reasonable number, and that smaller groups allow more in-depth views to be explored. This contrasts with larger groups, which provide fewer opportunities for participants to voice their opinions (Polit and Beck, 2004). Practicalities dictated the recruitment of eight participants for each FG in the study (see Chapter 5 section 5.2.5); inclusion and exclusion criteria are described in the same section. FG topics are also addressed (Chapter 5 section 5.2.2); these were adopted in order to enhance the interaction of participants (Burns and Grove, 2005).

When adopting a qualitative approach using FGs, critical reflection should be implemented in order to provide the reader with sufficient information regarding any assumptions the researcher might have that could have affected the research process and its outcomes. This allows the transparency of the findings to be assessed (Morrow, 2005). This critical self-reflection in qualitative research is referred to as reflexivity, and is considered integral when investigating research data, as it scrutinises the researcher's understanding, as well as their choice of practice and any ethical dilemmas that may have guided the research process (McGraw et al., 2000). It also highlights the need for the researcher to become highly self-aware and conscious of their role (Merriam et al., 2016). Moreover, it helps in the understanding of cultures studied, and means that information is not only captured by the study group, on their own terms, but also through the researcher's lens (Cutcliffe, 2003).

A number of potential ways to address reflexivity are discussed in the literature. One of the most helpful and valuable approaches is to keep a self-reflective journal of the data, from inception to completion of the investigation (Morrow, 2005, Morrow et al., 2001). Within this, the researcher should maintain an ongoing record of his/her thoughts, experiences, reactions, and emerging awareness of any assumptions or biases that arise. These can then be examined and incorporated into the analysis, as required, depending on the researcher's preferred structure (Morrow, 2005). Another reflexive approach involves working with a research team or peer debriefer (Hill et al., 1997, Hill et al., 2005), who will facilitate the organisation of ideas and the responses of the researcher to the research process. They may also serve as "devil's advocates", proposing alternative views and interpretations to those offered by the researcher. Additionally, Rossman and Rallis (2012)suggested the use of a

"community of practice" approach, where a number of knowledgeable colleagues engage in "critical and sustained discussion" regarding the research process.

As part of this investigation, the concept of reflexivity was valued, and it was acknowledged that the researcher's understanding, experience and awareness of the investigated cultural setting (i.e. Oman) did have an influence in shaping the research procedure. The reflexive process was captured within the field notes (i.e. debriefing/summary notes) and discussions with peers and supervisors were undertaken. Therefore, details of the planning involved in the research process and the implementation of the FGs were discussed in an attempt to be transparent about any aspects of the research process that may have influenced the findings reported in this process. The first account can be found in the following section 4.6.1, where the researcher outlined personal thoughts and decisions for constructing FGs. The implementation process is then further reflected on in Chapter 5.

The differences in hierarchy levels among participants represented an important factor in deciding the nature of the FGs included. This is because the literature suggests that the more homogenous the group members are, the more they are encouraged to share their views (Krueger and Casey, 2015). Similarly, some participants might not feel comfortable disagreeing with their "boss" on certain issues presented, as it may be "too professionally risky to disagree" (Clark et al., 1996). GPs in Oman usually hold superior positions to nurses in PHC settings. Therefore, the professions (nurses and GPs) were separated into two different groups to alleviate this power imbalance. Additionally, at the recruitment stage, some nurses expressed low knowledge of ASD and did not feel confident to freely express their opinion regarding issues with GPs, who were seen as superior, with more knowledge and skill in this area. The difference in years of experience was not a concern within this study, as the researcher assumed that screening for ASD had not yet taken place in current practice. Therefore, there would be no difference between junior and senior practitioners in this regard.

4.6.2 The questionnaire

In order to gather suitable data to answer the research questions from a wider perspective in the second phase, a postal questionnaire was developed and distributed across the country. A questionnaire is a data collection method that is completed by targeted participants, with the intent of discovering individuals' thoughts on a specific item (Cannon, 2015). The questionnaire method has many advantages compared to the interview method. First, it generates answers from a large group of participants at low cost; secondly, questionnaires

provide respondent anonymity; and finally, there is less interviewer bias (Polit and Beck, 2004, Cannon, 2015, Burns and Grove, 2005). Questions on the barriers to and facilitators of screening for ASD questionnaire (BFSA) were crafted for this study. Note that this has not been tested for psychometric validation, and is constructed based on the insights of the qualitative aspect of the study. The questionnaire was also developed to ensure that it was a culturally and linguistically sensitive instrument. The assurance of cultural and linguistic sensitivity could be met by drawing the instrument from the actual quotes and experiences of GPs and nurses, to emphasise the fact that it is true to their context and does not impose a different world view or language.

The administration of this questionnaire provided anonymity, which enabled PHPs to express their perceptions and views honestly, without being afraid that their opinion may affect their job (Cohen et al., 2013). In contrast to the interview, using questionnaires may eliminate the potential effects of interviewer bias on participants (Parahoo, 2014). However, it must be acknowledged that questionnaires have limitations. One weakness regards the difference that may exist in question interpretation, in that the same question can be understood differently by different people. Furthermore, the questionnaire can be a problem for people with limited reading ability (Cohen et al., 2013). Questionnaires are known to attract low response rates, and provide participants with little opportunity to clarify their concerns if they do not understand an item (Parahoo, 2008). To overcome these limitations, the researcher sent an information sheet with the questionnaire, which included the research contacts (see Appendix 21) to clarify any queries the participants may have had.

There are two types of questions: closed and open. In a closed question, participants would be provided with a range of responses from which to choose. These questions could be in a dichotomous (i.e. two possible options) format, a multiple choice (i.e. several possible options) format, a constant sum (i.e. constant sum of units for few options) format, or a rating scale (i.e. set of categorical options). Questionnaires falling into the closed-ended type are often quick to complete and straightforward to code (Cohen et al., 2011). However, closed questions are limited in that they restrict participants from adding further explanations of their views. Cohen et al. (2011) argue that open-ended questions are more flexible, and provide more freedom to answer, which is useful when there is no pre-emptive potential answer to the question. This adds to the exploratory nature of the study; however, these questionnaires do tend to be less structured.

In the case of the questionnaire used in the present study, a closed-ended format was used. The decision to do this was motivated by the fact that this would be balanced with a qualitative section, which would enable participants to have the freedom to express their views on issues. Furthermore, this format was also suggested by most of the PHPs in the FGs. A Likert rating scale was employed for this questionnaire. This is essentially a graded scale that goes from one option to another in discrete intervals (Gliem and Gliem, 2003). For instance, it may go from "strongly disagree" to "strongly agree", and allows for a quick assessment of the attitude of the respondent towards a question or statement.

4.7. Sample and sample design

The sequential nature of this study allowed the researcher to explore the themes identified in phase 1 and develop a questionnaire, which was used in a larger sample in a following quantitative study. Combining both strands offered a deeper understanding of the participants' views in phase 1, and allowed wider exploration in phase 2 to provide a full picture of the situation. There are two ways in which sampling can be carried out. The first is non-probability sampling, where participants are not selected on the basis of equal chance. That is, not all members of a larger population have the same chance of being chosen to participate. The decision is primarily based on the researcher's discretion. Conversely, probability sampling utilises methods that equalise the chance for participation (Creswell and Clark, 2007).

4.7.1 Phase 1

In this study, both sampling approaches were used. For the qualitative phase, non-probability sampling, using a purposive and snowballing method, was employed. The use of non-probability sampling was chosen because of the need to acquire a range of views, in order to have strong insights from which to develop the questionnaire. Purposive sampling is the selection of participants based on the goals of the researchers. This was paired with snowballing, where participants were asked to refer other potential participants in order to create a critical mass (Creswell, 2009). Snowball sampling can be a practical "informal" method used to reach a target population where there are few participants, or where some degree of trust is required to initiate contact in vulnerable or stigmatised populations, making them reluctant to take part in more formalised studies (Baltar and Brunet, 2012). Despite the advantages of the non-probabilistic method, it has been viewed as biased, as it does not allow

researchers to make claims about generalisability within a particular sample (Baltar and Brunet, 2012). This is commonly accepted in qualitative research. In this regard, the sample design was employed, as it provided a simple approach for identifying a relevant sample for the FG discussions.

The qualitative phase focused sampling on Muscat (the capital city of Oman) health centres. The justification for this was that PHPs within Muscat health centres tend to have a more ethnically diverse background; they also have more exposure to ASD, as most of the ASD services are allocated in Muscat. Furthermore, they were thought to be more knowledgeable regarding ASD research, as they had more opportunities to participate in research due to close links with Sultan Qaboos University, the main centre for medical research in Oman. Despite the wide recruitment area for this study, only 11 PHPs from 11 health centres volunteered to participate, hence the need for snowball sampling. These participants invited their colleagues to participate, which enabled the researcher to gain five more participants for this study.

4.7.2 Phase 2

Disparities were noted among Omani governorates in terms of the size of population, geographical topography, cultural norms, beliefs, and the number of health services and health professionals available. It was therefore important to choose a representative sample from the various heterogeneous governorates. To reduce any disparities, it was useful to investigate the size of governorate populations. According to the Omani National Centre for Statistics and Information (2014), the Muscat governorate reported a population size of 740,395, while the Musandam governorate's population was 14,521. With such huge differences in populations among governorates, health services and the number of professionals would also differ; for example, PHC institutions in Muscat were run by 715 PHPs, while Musandam only had 28 PHPs. In order to select a representative sample, with sufficient participants from each governorate, proportionate stratified sampling was chosen for this phase. This type of sampling ensured the inclusion of a representative and sufficient number of individuals in the sample (GPs and nurses) from each stratum (governorate) (Polit and Beck, 2004). Proportionate stratified random sampling entails the division of the larger population into predetermined groups, and has the benefit of honing selected population characteristics, thereby creating a more representative sample, while managing overall sample size. Proportionate stratification adds another layer by ensuring that the sample randomly drawn from each selected stratum is proportional to the total population of that

particular stratum (Moule and Goodman, 2009). The use of random sampling is typical in quantitative research, as it aids in ensuring the statistical rigour of the inferences that are to be made in the study. This is especially important, as these inferences should be generalisable in nature (Moule and Goodman, 2009). However, this type of sample requires more labour and effort in order to draw the sample from multiple enumerated listings (Polit and Beck, 2004).

At the time of data collection, there had been no studies from Oman exploring this issue, and no guidance in terms of sample size. However, Sandelowski (2000) suggested that the response rate for a survey questionnaire is around 50%. Therefore, in an attempt to ensure that the sample was representative, a relatively large sample size was sought for this study. Recently, a study from Oman stated that the response rate of a survey on GP knowledge of ASD was high (96%) (Al-Farsi et al., 2016). The high response rate was explained by having trained doctors extol the importance of the study, to motivate participation.

As mentioned earlier, there are two stages in this type of sampling. The first involves the identification of a proportionate sample from each governorate, and the second involves the random selection of participants. For the first stage, the sample was divided into two groups, GPs and nurses, with 11 strata representing the number of governorates. Allowing for an error rate of 5%, with a confidence level of 95%, a sample size of 255 GPs and 317 nurses was highlighted as being required to achieve the purpose of this study, so a proportionate sample for each stratum was calculated as follows. Firstly, the average number of GPs and nurses in a given governorate was identified and then multiplied to estimate the sample size for that particular group. For example, the Al Wasta governorate had 13 GPs and the total number of GPs in Oman is 717. This presented an average of 0.081311. By multiplying this average by 255 (the required sample size for GPs), four GPs were expected to be recruited from this governorate. The proportionate sample results for all governorates are shown in Table 4-1.

Table 4-1: The procedure for selecting a stratified sample

	GPs			***Nurses***		
Governorates	*Number of GPs across Oman*	*Total (#GPs/ Total GPs)*	*Proportional Sample Size (% * Total sample size (255)) of GPs*	*Number of Nurses across Oman*	*Total (#Nurses/ Total nurses)*	*Proportional Sample Size (% * Total sample size (317)) of nurses*
Al Wasta	*13*	*0.081311*	*4*	*46*	*0.0253165*	*8*
Al Dahera	*39*	*0.051656*	*13*	*146*	*0.0803522*	*25*
North Sharqiyah	*27*	*0.035762*	*9*	*72*	*0.0396258*	*13*
South Sharqiyah	*58*	*0.076821*	*20*	*155*	*0.0853054*	*27*
South Batinah	*75*	*0.099338*	*25*	*149*	*0.0820033*	*26*
North Batinah	*124*	*0.164238*	*42*	*233*	*0.1282334*	*41*
Al Dakheliyah	*68*	*0.090066*	*23*	*171*	*0.0941112*	*30*
Al Buraimi	*7*	*0.092715*	*2*	*37*	*0.0203632*	*6*
Musandam	*7*	*0.092715*	*2*	*21*	*0.0115575*	*4*
Dophar	*78*	*0.103311*	*26*	*244*	*0.1342873*	*43*
Muscat	*221*	*0.343046*	*87*	*494*	*0.2988442*	*95*
Total	*717*		*253/sent*	*1768*		*318/sent*

GPs= General practitioners

After identifying the required sample size from each governorate, the next step was to decide how to randomly select participants from each strata. There are a number of randomisation techniques that can be adopted for this purpose, such as simple, systematic, stratified and cluster random sampling (Moule and Goodman, 2009). A systematic random sampling approach was employed during this study, as the RAs would be recruiting the participants from across the governorate. According to Moule and Goodman (2009), applying this technique required RAs to: 1) create a list of all participants in the strata at random, 2) calculate the average number of required participants for each stratum, in order to estimate the periodic interval number for each stratum, and finally, 3) choose the participants from a random starting point, then move along the list with the fixed periodic interval number identified from the second step. Further details about the application of this sample are provided in Chapter 7 (section 7.2.2).

4.8. **Data analysis**

Data analysis is referred to as the process of converting raw data into meaningful and useful information. Indeed, data analysis in quantitative and qualitative methods has similarities in that it is conducted in a set of steps:

- preparing data,
- exploring data,
- analysing data,
- representing the analysis,
- interpreting the analysis, and
- validating the data and interpretation (Creswell, 2014).

These steps are generally attempted in a linear fashion in quantitative research, while in qualitative research they are often undertaken simultaneously in an iterative process (Savenye and Robinson, 2005). In mixed method studies, data analysis involves various analytical techniques that apply to both quantitative and qualitative data, as well as to the mixing of the two forms of data concurrently and sequentially in a single or multiphase approach within the research project (Tashakkori and Teddlie, 2010). This should address the research questions or hypothesis and the mixed method question. For example, Creswell and Clark (2007) argue that in a sequential exploratory study, data should be analysed using a suitable technique for each different phase, and not merged. Consideration should be given to answering the mixed method research questions, which often investigate the extent to which quantitative results can be generalised to the qualitative findings (Creswell, 2014). Therefore, the data analysis for this study was undertaken separately and described in the subsequent section.

4.8.1 Phase I

In phase 1, the data was analysed by applying Framework Analysis (FA). This is a structured approach used to analyse the qualitative data. It was developed by the National Centre for Social Research, specifically for applied policy studies, and defined as a content analysis method, which involves summarising and classifying data within a thematic framework (Green et al., 2013). FA involves five key stages, undertaken in a sequential process: familiarisation, identifying a thematic framework, indexing, charting and mapping, and interpretation(Green et al., 2013). FA has many similarities with thematic analysis and immersion with the data, reducing and comparing themes. However, it is regarded as a straightforward method, with greater transparency in illustrating the process of data analysis through a series of interconnected stages (Ritchie and Lewis, 2003, Pope et al., 2000). This transparency is believed to enhance the rigour of the analytical processes and thereby improve the study's credibility (Ritchie and Lewis, 2003). FA was used as a method to

analyse the qualitative data in this study for many reasons. Firstly, it suits the analysis of descriptive data (Ritchie and Lewis, 2003). Secondly, the process of interpretation of the participants' experiences is transparent, and this guides the reader regarding how decisions were made (Ward et al., 2013, Swallow et al., 2011). Finally, this method enables flexibility and the easy retrieval of data, so that researchers can move back and forth across the data until coherence is reached (Ritchie and Lewis, 2003). FA has also been found to be useful and practical with regard to teamwork (Dixon-Woods, 2011), or in the support of novice researchers, because it provides a clear audit trail for data analysis (Ward et al., 2013).

Despite the advantages of FA, there are some drawbacks to using this method. As is the case with other qualitative data analysis methods, FA is time-consuming and requires significant effort, experience and commitment from the research team in order to allow all data to be considered, and to ensure a rigorous process is undertaken (Ward et al., 2013). FA has been criticised for lacking the theoretical context underpinning other qualitative methods, such as grounded theory and ethnography, as it is guided by existing ideas and is less focused on producing a new theory (Smith et al., 2011). However, Ezzy (2002) argues that synthesising the data at the interpretative and mapping stage can facilitate the inductive and iterative approach of this method. The application process of the FA stages is considered further in Chapter 5 section 5.2.10.

4.8.2 Phase 2

In phase 2, both descriptive and inferential statistics were used to analyse the quantitative phase of this study. Descriptive statistics were used to review and present the data collected from the respondents (Aron et al., 2005). For example, descriptive statistics were employed to describe the participants' demographic characteristics, using the mode and frequency distribution (see Chapter 7 section 7.3). In contrast, inferential statistics were utilised to draw conclusions about the barriers to and facilitators of screening for ASD, based on the collected data from the participants in phase 2 (Aron and Coups, 2005).

The returned questionnaires were first checked for missing data. Given that no questionnaires had incomplete pages, none were excluded. All data analyses were conducted using SPSS (Statistical Package for Social Sciences), software program version 22.0. In order to gain a clearer picture of the quantitative data gathered, descriptive analysis was undertaken. According to Pallant and Dawson (2010), descriptive statistics include the mean, standard deviation, range of scores, skewness and kurtosis, and provide a variety of

information regarding the study variables. In this study, the frequencies and percentages were used to describe the categorical variables, which were demographic data, such as gender, nationality and employment, whereas the mean and the standard deviation were used to describe the continuous variables, such as age, years of experience, and the number of patients seen per day.

Differentiating between the Likert items and the Likert scale assists in the understanding of the nature of the data, whether it is on an ordinal or interval scale, and ultimately which statistical method to adopt. Likert items refer to the items that were presented as separate statements and are more or less mutually exclusive: for example, “strict discipline is necessary for learning”, “team work is the culture for success” (Subedi, 2016). These items cannot be combined to form an interval scale, as they might have been designed to answer multiple questions in this research instrument. Therefore, the items should be analysed separately, and the data considered on an ordinal scale. On the other hand, items such as “head teacher demonstrates high moral standard” and “head teacher communicates high expectations”, which Subedi (2016) used in his illustration, are closely interrelated, and each of them has the capacity to measure a distinct element of the issue. The characteristics of these items may allow the researcher to combine items and construct a composite index, which measures the comprehensive stance of the participants towards the transformational leadership behaviour of a head teacher, and is referred to as an example of the Likert scale (Joshi et al., 2015).

Although the questionnaire in this study was designed in sections to measure particular constructs, such as organisational barriers or professional barriers, the items under each category were designed as individual Likert items, to describe unique aspects of the constructs and capture participants’ perceptions. For example, under the organisational barriers, the researcher measured participants’ opinions on various aspects, such as time constraints, workload, staff shortages, the referral system and the registration process. Therefore, individual Likert items in this questionnaire were assumed to represent an ordinal scale. They were reported and analysed separately, and the responses from items were not combined to form a composite scale (Boone and Boone, 2012). The descriptive statistics of the mode and median were used, as this was recommended in the presentation of ordinal data (Boone and Boone, 2012, Subedi, 2016). Therefore, two types of statistical method are commonly used to analyse Likert data: parametric and non-parametric. Parametric methods are used if the data comprises a large sample size, is normally distributed, and is continuous

in nature (Subedi, 2016), while non-parametric tests are used to measure data that is discontinuous, or not normally distributed.

Normality tests were performed using the Shapiro-Wilk test, which is highly recommended to provide accurate results, and enables the discovery of differences from normality in the data (Ghasemi and Zahediasl, 2012). The Shapiro-Wilk test showed that the data was not normally distributed ($p < 0.05$), which is common in large sample sizes (Pallant, 2016). Therefore, non-parametric tests were adopted. Both the Kruskal-Wallis test and the Mann-Whitney test were used as non-parametric tests to analyse the study data. The Kruskal-Wallis test is commonly used to analyse an independent group design, where there are three or more categories (Pallant, 2016). It was used in this study to show the statistical difference between the perceived barriers to or facilitators of screening for ASD (dependent variables) and some of the socio-demographic factors (age, gender, position, level of education, years of experience, and workload). Where significant differences ($p < 0.05$) were identified, post-hoc tests were used. Post-hoc analysis provides insight into the significant differences across pairs of variable groups.

4.9. Establishing study rigour

Validity is an integral aspect of determining the study's trustworthiness (Zimbardo and Boyd, 2015). Although this aspect can be applied to both research strands (i.e. qualitative and quantitative), the methods of comprehension and implementation attributed to each are varied (Creswell and Clark, 2007). For this reason, Creswell (2014) suggested addressing the validation of each strand separately in a mixed method design. Creswell and Clark (2007) also cautioned that emerging data in a mixed method study may compromise study validity at the stage of data collection, data analysis and/or data interpretation, and proposed a number of strategies to minimise the threat at each stage, improving study trustworthiness. For example, at the stage of data collection, Creswell and Clark (2007) encourage the drawing of a sample from the same population for both phases (i.e. quantitative and qualitative) using separate data collection methods, addressing the same question in "parallel" in both the quantitative and qualitative phases. At the analysis stage in this study, the author suggested developing a joint presentation of data, with categorical quantitative and thematic qualitative data, to facilitate later interpretation, find quotes and match statistical results. At the interpretation stage, Creswell and Clark (2007), Creswell and Plano Clark (2007) recommended addressing mixed methods questions, presenting both sets of

results in an equal way, or stating why one set was better in relation to the investigated problem, evaluating the overall research aim and ensuring the negotiation of philosophical and methodological differences.

As this study was built on a mixed design, previous strategies were employed to improve the research validity and reduce validation threats. For example, this study sample was drawn from the same population (GPs and nurses working in Omani primary health institutions). While separate data collection and methods were used for each phase, the same research questions were employed in both phases (what are the facilitators of and barriers to screening for ASD in Oman), and data at each phase was presented in a comparable manner to facilitate later interpretation. Mixed method questions were also addressed and discussed in this study, exploring whether the qualitative data could be generalised in the quantitative phase. Both sets of results were presented separately, in an equal manner, to allow the researcher to evaluate the overall project consistency. In addition, validation of each study phase was examined based on its underpinning philosophical perspective, as will be explained in the following section.

4.9.1 Phase 1

As phase 1 of this study adopts a predominantly qualitative approach, four dimensions must be considered to enhance data trustworthiness: credibility, transferability, dependability and confirmability (Lincoln and Guba, 1985). These criteria not only measure the character of the data, but also assess interpretation and conclusions (Polit and Beck, 2004).

4.9.1.1. Credibility

The first aspect in trustworthiness is credibility, which presents the extent to which the data, and its interpretation, reflect the truth (Polit and Beck, 2004). In other words, it refers to the confidence in the presented data (Ritchie et al., 2014). There are some techniques used to enhance the study's credibility. One of these is to engage with the research for an extended period of time. It is important to have sufficient time to collect data in order to gain an in-depth understanding of the study subjects (Polit and Beck, 2004). Triangulation is another technique that refers to the application of multiple sources of data, and allows a comprehensive understanding and conceptualisation of the phenomenon (Polit and Beck, 2004). More specifically, data triangulation refers to the use of several data sources, such as collecting the same data at different times, collecting data from multiple sites and collecting

data from various groups of individuals. In this study, data was collected from various practitioners and health centres. These were a representation of GPs and nurses from different health centres. Although the extent of triangulation applied is not vast, the multiple relevant perspectives covered are sufficient to provide a multifaceted investigation of the topic.

Aside from the triangulation of data sources, investigator triangulation was also used. This involves two or more investigators being employed during the data analysis stage. This was undertaken, with the research supervisor (DW) from Edinburgh Napier University and a local supervisor from Sultan Qaboos University (RAW) being involved in the research process. This enabled both researchers to monitor the process of data collection and analysis. DW also analysed the data independently and attended meetings to discuss the data presentation, this again added more rigour to the findings. Finally, methodological triangulation was used when the data was collected from multiple data sources, such as FGs and questionnaires: see examples in sections 5.2.10 and 7.3.

Peer debriefing is another technique used to enhance study credibility. This required the researcher to take part in sessions with peers regarding various aspects of the enquiry (Tashakkori and Teddlie, 2010). During peer debriefing, the researcher presents written or oral summaries regarding the emerging themes and interpretation of the data. In this study, the researcher had continuous discussions with colleagues in the department, research assistants and other PhD students, to discuss the research enquiries.

The other technique of credibility is member checking. This required participants to review and comment on the data summaries gathered, such as FG transcripts. To ensure transcript credibility in the study, the researcher used “member checking” by participants from both FGs. Member checking involved taking the findings back and ensuring their agreement. This could reach the ultimate mark of credibility, the “emic” (within) understanding, when the researcher and those who contributed to the study achieved a consensus (Green et al., 2013). Providing feedback from the findings to the participants is good practice, as it informs the research contributors about the study findings and provides an opportunity for participants to make corrections. It therefore improves the reliability checks for the quoted materials(Green et al., 2013). However, Silverman (2001) discourages this when the research goes beyond merely reporting participants’ accounts of investigated issues, voicing contradictions and conflicts within a group of participants. Therefore, the participants and the researcher may not coincide in their accounts and the validation checks may not be

necessary (Green et al., 2013). In this case, participants were asked if they wanted to volunteer as member checkers after the FGs. Two volunteers from each FG agreed to validate responses and were sent the transcript, which presented the quotes and the flow of the discussion only. This was undertaken to ensure that all quoted materials were appropriate, and gave the participants an opportunity to correct if required. At this stage, the participants gave positive feedback, confirming that all quoted materials represented their views. The final findings of this phase were not validated by participants, as this went beyond simple reporting of their views on ASD screening, highlighting all conflicts and contradictions among the participants' views (GPs and nurses).

4.9.1.2. Dependability

Dependability is the equivalent of reliability in quantitative studies. It is defined as the stability of the data over time and conditions (Polit and Beck, 2004). To assess the dependability of qualitative data, a replication of the inquiry steps and an audit trail can be used. This can be applied when two independent individuals, or a group from the same research team, deal with data and regularly compare it during the data analysis stage until an agreement is reached (Polit and Beck, 2004). Enquiry audit involves an external review of the data and relevant research documents. This approach can also be used to establish the conformability of the qualitative data.

In this study, the researcher arranged the FG discussions in Oman. Within this process a local supervisor (RAW), who had expertise in the use of FGs, was involved to monitor discussion flow and probe further, if necessary. At the end of each discussion, both conducted debriefing sessions and completed the summary forms. At the stage of data analysis, the researcher developed a coding scheme that was compared with supervisor DW's code. Meetings were then conducted until they reached an agreement and were able to produce the final theme and method of data presentation. In that way, the researcher was able to strengthen the rigour of the data analysis and the quality of data: see the example detailed in section 5.2.10.

4.9.1.3. Confirmability

Confirmability is defined as the potential compatibility of the study, wherein the collected data's accuracy, relevance or meaning can be agreed on between two or more people (Polit and Beck, 2004). In this study, the researcher documented the process of data analysis in

various documents, including the FG transcript, field notes and data analysis records, which were provided to both supervisors. Furthermore, the study methodologies, including the study design, sampling, settings, data collection methods and data analysis were described in detail. This means that there is a written record of all the data collected in the study, thereby allowing for confirmation and validation of the results of the analysis.

4.9.1.4. Transferability

Transferability is equivalent to generalisability in quantitative data, which describes the extent to which the findings can be transferred to other contexts or settings (Polit and Beck, 2004). Primarily, transferability relies on thinking through what may benefit practitioners or policy makers, in order to apply the study findings more widely (Graneheim and Lundman, 2004). For that, the researcher is required to develop a transferable strategy for shaping a health awareness message. This involves identifying misconceptions by professionals, and beliefs and cultural influences, using indigenous knowledge to provide analogies to use in health promotion (Green et al., 2013). To enhance transferability, Green et al. (2013) suggested providing a good description of the particularities of the settings, case and appropriate theoretical analysis, which allows credible general inferences to be made. In considering the transferability aspect, this study ensured detail, reflection, justification and clarification of the underpinning philosophy involved in the development of this research, at each stage. Taking the qualitative phase as an example, at the stage of data collection the researcher details how she draws the sample, the reason for selecting the FG venue, and the underlying preparation to facilitate natural and comfortable settings for the discussion. At the stage of analysis, the researcher details the framework that enabled her to present the findings. Each stage of this framework was supported with a clarifying example. At the interpretation stage, the researcher reflected on the participation rate, possible challenges, and the potential for conducting a FG in Oman among PHPs. Additionally, the researcher highlighted participants' preferences and reasons for having a homogenous discussion group on this subject (i.e. one group for nurses and another for GPs). The researcher also noted participants' views on ASD screening, misconceptions regarding procedures, cultural beliefs, and values towards screening for ASD. This in-depth explanation is thought to help build transferable strategies for future studies in similar contexts, especially those in developingMiddle eastern countries.

4.9.2 Phase 2

Validity and reliability are essential aspects of determining the study's trustworthiness from the positivist perspective (MacLean and Wilson, 2011, Zimbardo and Boyd, 2015). Validity is concerned with how easily the instrument measures what it is intended to measure, while reliability focuses on the stability or consistency of the measurement, using the test instrument (Zimbardo and Boyd, 2015).

4.9.2.1. Validity

The quantitative part of the study was based on a questionnaire that was conceptually valid, as discussed in section 6.4 below. According to Creswell et al. (2003), there are three traditional forms of validity to identify in quantitative studies. These are content validity, criterion (predictive or concurrent) validity and construct validity. In this study, validity is considered initially, regarding content (or face) validity at face value. That is, the questions appear to be measuring the content in question (Peterson, 2000). This type of validity is not sophisticated, as it involves a subjective judgement of whether the identified variables appear to theoretically measure the intended variables (MacLean and Wilson, 2011). Although this approach is recognised as being subjective, it is still considered to be a "useful first approach" in questionnaire design (Peterson, 2000, p. 79).

Two other forms of validity are recognised (construct and criterion); however, they have not been applied to this research study, given that rigorous psychometric testing was not conducted as a result of restrictions on time. Construct validity can be defined as the ability of the items to measure hypothetical constructs of concepts (Creswell, 2003). As the data will not be reduced to constructs, this form of validity was not applicable in this study. Criterion validity is assessed by considering the extent to which the questionnaire results relate to other variables or constructs which can be regarded as comparable (Peterson, 2000). The specific context of this questionnaire and the absence of other similar instruments made it unfeasible to compare it with other existing instruments.

4.9.2.2. Reliability

In terms of reliability, three measures can be considered. Namely, test retest reliability, internal reliability and inter-rater reliability. Both test retest reliability and inter-rater reliability were not demonstrated in this study. Test retest reliability is a crucial aspect in the measurement of consistency over time; for example, in the detection of a change in opinion

for the same people at two different points in time (MacLean and Wilson, 2011). The purpose of this questionnaire was not to measure participants' opinions at different time points; therefore, this type of consistency was not considered. In addition, the researcher thought it impractical to use the questionnaire consistency at different points in time, as the context of the sample to which it was administered will change over time, and therefore the responses will be expected to alter. For example, participants' awareness of or preparation of ASD may improve if they encounter a client, and therefore their responses to barriers might change. In addition, the questionnaire will not be used again in its entirety, as it will first need to be informed by a qualitative phase to ensure the elements of the specific context are permissible. It may be used as a baseline and amended to allow it to be relevant in other settings. The inter-rater reliability was also not considered, as this study did not intend to measure observations. This type of reliability is often applied when comparing the consistency rate among independent observers in certain behaviours (MacLean and Wilson, 2011).

Internal reliability was the only type of consistency measured in this study. This method referred to the assessment of data at one point in time, measuring the same variables with multiple individual measures, which eventually provided similar results to indicate the achievement of reliability (MacLean and Wilson, 2011) (see Chapter 6 section 6.7, which details the reliability process of the developed questionnaire).

4.10. Chapter summary

Research methods are crucial, since the validity of the results depends upon it. This chapter provides justifications for the research design chosen to explore barriers to and facilitators of screening for ASD. The main study design was an exploratory mixed method design within a pragmatism paradigm. The initial exploratory qualitative data collection was undertaken using FG discussions, and data was analysed using Framework Analysis. The second phase of the study involved quantitative data collection using a Likert scale questionnaire, with some open-ended questions. Data analysis was undertaken using SPSS.

Chapter 5: Phase 1, Initial Exploratory Qualitative Phase

5.1. Introduction

As explained in Chapter Three, an exploratory mixed-method design was employed to answer the research questions. The chosen design required two sequential phases. An initial qualitative phase, which explored screening for ASD with GPs and nurses, was then used to inform the development of the questionnaire. This was followed by a quantitative phase, testing the questionnaire and exploring screening for ASD from a broader perspective, using a larger sample. This chapter focuses on explaining the underpinning methods and procedures that were undertaken during Phase 1, in order to explore the barriers to and facilitators of screening for ASD within current practice in Oman, and to inform and develop a culturally acceptable questionnaire. The organising and running of the FGs, the data collection, management of data, analysis and the methods used to maintain the trustworthiness of the data will be detailed. Additionally, the five themes that emerged from this phase will also be presented.

5.2. Methods

5.2.1 The data collection tool

For the first phase of the study, two FG discussions were undertaken, one with GPs and the other with practice nurses. A topic guide was developed by the researcher from the findings of the literature review, to explore PHPs' perceptions of the potential facilitators of and barriers to screening within their current practice, and to elicit their views on developing a survey questionnaire to explore this further with other primary care practitioners in Oman. Additionally, the topic guide served as a structure for the FG discussion and as an aide-memoire for the researcher and the assistants when running the FGs (Ritchie et al., 2014). For details of the topic guide, see Appendix 10.

5.2.2 Topic questions

The questions and probes were formulated according to the laddered question technique (Price, 2002). According to this technique, the topic questions began with a non-intrusive ice-breaking question to enhance rapport. For that reason, the first question to the FG participants was ***"What's your favourite place you have visited in the last year?"*** This was

followed by broad introductory questions aimed at fostering group cohesion and beginning the discussion of the topic in question (Price, 2002). For example, ***"What do you understand about ASD?"*** This was followed by questions that explored the PHPs' experience of assessing children's development and identifying abnormalities within their current practice in greater depth. For example: ***"From your experience of completing the pink card and from interviewing parents, how effective do you think the current immunisation and surveillance programme is in identifying developmental abnormality?"*** These questions subsequently led on to the four key questions that aimed to elicit in-depth information, in order to meet the overall purpose of the study (see Table 5-1).

Table 5-1: Key questions for the FGs

1.	*What challenges would you imagine encountering when implementing a screening programme within your current practice to potentially identify children at risk of ASD?*
2.	*From your point of view, what can you do to overcome these challenges?*
3.	*What facilitators can you foresee being implemented in screening programmes within your current practice that could potentially identify children at risk of ASD?*
4.	*From your point of view, what needs to be considered when developing a survey questionnaire exploring the facilitators of and barriers to screening for ASD for PHPs in Oman?*

Two concluding questions were also formulated to see if anything had been omitted: ***"Have I missed anything?"*** and ***"Is there anything else you would like to add?"*** This helped to ensure that the researcher had covered the topic but also offered an opportunity for the FG participants to suggest questions or ideas that may not have been raised previously in the literature. Alongside the topic questions, probes were developed by the researcher to clarify and explore topics raised within the FG (see Table 5-2).

Table 5-2: Probe questions

1.	*Who do you think should convey this message to parents?*
2.	*How much time do you usually have to assess each child?*
3.	*At what age, in your mind, is it most appropriate to identify a child with ASD?*
4.	*Why do you think parents accept the first part of the pink card (vaccination) and resist the second part (developmental and surveillance assessments)?*
5.	*What areas of concern should be considered when we develop a questionnaire to identify the facilitators of and barriers to screening for ASD within primary health centres?*
6.	*What type of questionnaire do you prefer?*

Once a first draft had been developed, the topic guide was reviewed by the supervisors (DW) and (RA), who are experts in the FG method. Some revisions were made to the probing questions and a few more questions were added, to explore the participants' preferences for the questionnaire that was to be developed, such as "***What if we send the questionnaire to the PHP electronically?", "How can we stimulate your interest in completing a questionnaire?"*** and ***"How many questions would be enough?"*** Once these revisions were made, the topic guide was approved.

5.2.3 Study site

Both FGs were undertaken in Muscat, at a secondary-level polyclinic health centre, owned by the MOH, in Oman. Muscat was chosen for this phase of the study because it is the capital city and has a diverse population in terms of ethnicity and cultural backgrounds. Hence, it was thought useful to capture different perspectives for the development of the study questionnaire. Furthermore, the PHPs in Muscat are often contacted by staff from other parts of the country to help with research projects and they are therefore experienced in giving feedback on projects; furthermore, Sultan Qaboos University is located in Muscat and it is the hub of most research in Oman.

The health centre chosen to host the FGs was selected for three primary reasons. It was situated in the heart of Muscat governorate and it was convenient and readily accessible by participants from across the city. Most of the PHPs would be familiar with this clinic, as it was the main venue for training workshops and seminars. The venue was also private and comfortable and provided a neutral environment in which to conduct the FGs, as recommended by Winslow et al. (2002).

5.2.4 Ethical considerations

The study was approved by the Research and Ethical Committee of both the University of Glasgow and the Ministry of Health in Oman (see Appendix 11). There were no direct risks for the participants in this study other than being unable to answer a question. If this occurred, the researchers were on hand to support the participants. All of the participants were given a flash memory stick and an attendance certificate (see Appendix 12), as incentives for their participation. For a discussion of the ethical implications of this, see section 4.5.2. Light refreshments were available, as it was believed to be necessary to

compensate the participants for their time and contribution to the study, and to provide them with a welcoming atmosphere.

Before the FG commenced, all of the participants had the opportunity to ask questions. They were also reminded that they could withdraw at any time from the FG. They were reminded that the FG would be recorded. Reassurance was also given that no real names would be used, only pseudonyms, if the work was published, and that their views would not be shared with their managers. It was made clear that only the researcher and the supervisors would be permitted to listen to the recorded conversations. This was important for creating a non-threatening environment for discussion (Krueger and Casey, 2015). After this, the participants were given an opportunity to re-read the information sheet before giving their written consent.

The recorded discussions and the transcripts were saved in an electronic folder on the researcher's computer at the University of Glasgow, which was password protected. A code was allocated for each FG to maintain anonymity – for example, FG "A "for the GP groups and "B" for the nurses. These codes were used later during the transcription process and data analysis. All of the consent forms were stored in sealed envelopes in a secure cabinet in the researcher's office at the University of Glasgow. This also ensured confidentiality. These forms and all other relevant documents will be destroyed after ten years to comply with the University of Glasgow's policy on "Data management and support for researchers" (The University of Glasgow, 2016).

5.2.5 The sample

This study aimed to recruit 6-10 participants for each FG. According to Krueger and Casey (2015)a viable size for a FG is perceived to be 6-10 participants, sufficient to gain a variety of perspectives whilst ensuring that the number of participants is manageable. The participants for this study were drawn from a population of GPs and trained nurses who worked in the health centers in Muscat. These professionals were chosen because they were the main health care professionals responsible for child health in Oman, within the health centres. The inclusion criteria required the participants to have a minimum of two years' experience in the PHC setting. This ensured that the participants had completed their mandatory internship and orientation programme to enable them to work in the PHC setting. This criterion also ensured that they had experience in PHC activities and service requirements.

5.2.6 Recruitments procedure

Recruitment for this study involved the use of purposive and snowballed sampling. Depending on their placement, health centres in Oman have different population densities, with some being busier, supporting 35,320 people, while others are quieter, supporting roughly 527 people. To ensure that the participants were drawn from a range of health centres, the researcher classified each health centre in Muscat into two categories: 'high workload institution' (highlighted in yellow) and 'low workload institution' (highlighted in green) (see Table 5-3). For a health centre to be considered as 'high workload' it had to have a population of more than 10,000 people in the catchment area, whilst less than that meant that it would be recorded as a 'low workload' institution. It was decided to recruit six health centres from both categories. Once ethical approval had been obtained, the information regarding the study (approval letter, invitation poster, respondent information sheet and informed consent sheet) (see Appendices 13, 13.1 & 13.2) was sent to the health centres in the region.

Table 5-3: Muscat Health Centres' distribution according to the catchment region of population in 2012

Ratio of Population/ One nurse	***Nurses***	***Ratio of Population/One GP***	***GPs***	***Population***	***Health centres***
2077.7	*17*	*2522.8*	*14*	*35320*	*Ash Shaadi*
1136.4	*16*	*1298.7*	*14*	*18183*	*Al Amrat*
378.8	*11*	*1041.7*	*4*	*4167*	*Yiti*
494.4	*7*	*576.8*	*6*	*3461*	*Siya*
2037.4	*19*	*2580.7*	*15*	*38711*	*Al Kawad*
449.3	*6*	*898.7*	*3*	*2696*	*Al Mazari*
175.6	*3*	*0*	*0*	*527*	*Wadi Al Arbiyin*
308.6	*6*	*617.3*	*3*	*1852*	*Asifah*
1074.4	*19*	*1570.3*	*13*	*20415*	*Muscat*
1095.7	*17*	*1693.3*	*11*	*18627*	*Mutrah*
535.6	*6*	*803.5*	*4*	*3214*	*Bamah*
865.2	*19*	*1264.6*	*13*	*16440*	*Al Wadi Al Kabeer*
1675.4	*17*	*2034.5*	*14*	*28483*	*Al Mabeela*
961.6	*18*	*1731*	*10*	*17310*	*Ruwai*
1145.	*16*	*1526.8*	*12*	*18321*	*Al Seeb*
1460	*20*	*2085.7*	*14*	*29200*	*Al Ghubrah*
840.8	*18*	*1375.9*	*11*	*15135*	*Al Aziba*
1641.6	*16*	*1876.2*	*14*	*26267*	*Al Wattayah*
1525.7	*21*	*2136*	*15*	*32041*	*Al Khuwayr*
935.6	*19*	*1111*	*16*	*17777*	*Al Nahdah*
1002.4	*19*	*1269.7*	*15*	*19046*	*South Al Mabeela*
1278.7	*17*	*1358.7*	*16*	*21739*	*Al Mawaleh*
475	*19*	*820.5*	*11*	*9025*	*Al Ansab*
947.5	*19*	*1636.7*	*11*	*18004*	*Al Hail*
1343	*15*	*1678.8*	*12*	*20146*	*North Al Mawaleh*
567.4	*15*	*1064*	*8*	*8512*	*Al Hajer*
322.4	*18*	*829*	*7*	*5803*	*Hai Al Meena*

Green = Low working load institution, Yellow = High working load institution

After one week, the researcher made contact with the person in charge of each health centre by telephone, to confirm that they had received the information and to enquire if they needed further details or had any volunteers. During this telephone conversation, some health centres declined to participate in the study. The reason for this was unknown, but it was thought that it might be due to their remote location, which would make official communications difficult or more prolonged. In one health centre, the person in charge requested that the information be re-sent to them and volunteered to act as a gatekeeper and to inform staff about the study. As it was convenient to use the Ministry mail system for remote areas (this was estimated to take a minimum of two weeks), it would mean that by the time the gatekeeper had advertised the study within their institution, the recruitment

window would be closed. The researcher therefore decided to personally deliver the study information to the centre. Other issues encountered included concerns relating to releasing staff from duty in order to participate in the FGs, due to staff shortages. A number of participants also contacted the researcher directly to ask for clarification regarding participation. The questions asked included: whether they needed to read about the topic to ensure that they were able to answer the questions; if they needed to answer all the questions; what the protocol was surrounding an inability to respond to questions, because they knew very little about ASD; and others wondered whether the FG was being videoed. All of these questions were answered and reassurances given.

Within the recruitment window, 11 PHPs (five GPs and six nurses) had expressed their interest in taking part in the FGs. They were also asked for their demographic details such as age, gender, years of experience, workplace, contact information and nationality (see Appendix 13.3). In addition, these volunteers were approached to identify further participants from amongst their colleagues (snowball sampling). Three nurses and two GPs recruited one of their friends to participate, meaning a further five participants were identified. Once the recruitment period had closed, all those who had volunteered were sent a letter about the FG, confirming the date, time and location. Two weeks before the event, they were re-contacted to remind them of the FG and two days before the scheduled FG all of the participants received a reminder call and an SMS message.

5.2.7 Data collection process

Data were collected using two FG discussions, one with six GPs (FGA) and one with seven nurses (FGB), in January 2015. At the start of each FG, the researcher and assistant introduced themselves and asked the participants to introduce themselves. The participants were also asked to set ground rules as a group. These comprised confidentiality and respect (a copy of the ground rules can be found in Appendix 10.1), and were written on a large sheet of paper and hung up in the room to remind the participants of the rules they had identified. Following this, the FG discussion commenced, starting by asking the participants about themselves before moving on to the other questions within the topic guide, including probe questions, depending on the responses of the participants (see Table 5-2). During the FG, the facilitators listened, probed and encouraged all of the participants to explore their perceptions about the subject. The note taker took notes (using the template created by the researcher, see Appendix 10.2**)** of the interactions as they occurred within the group during

each discussion. Any variations in the discussion among the group members were recorded in the field notes and interpreted later.

Both FGs were conducted in English, except in cases where the participants found it difficult to express their thoughts in this language. Here, Arabic was used, and the researchers immediately translated what was stated and noted the translation down for later comparison. During the FG, if participants wanted further clarification this was given, for example by rephrasing a question such as: "***In your opinion… if you were"***. None of the participants requested time out or left the group during the discussion. Both FGs lasted between 50 and 75 minutes, depending on what the participants discussed. Prior to the FG, one GP and one nurse apologised beforehand, whilst one GP did not attend on the day.

After the first FG, the audio-recording was listened to carefully to ensure that no questions from the topic guide were missed during the discussion and to see if there were other questions that would be useful for the next group. Any information that was thought to be relevant was identified and put into question form ready for the next FG. For example, the GPs highlighted the fact that nurses are responsible for completing the psychological assessment of the child and that they are the ones who would interview the mother first. There was an expectation that the nurses would have received training so that they were able to identify a developmental abnormality and refer suspected cases to the doctor.

> *"…the nurse sees the kid first … fills in this psychological assessment. If she is filling it in, she should have more training to pick up any symptoms of abnormality. (GP5, P12, L272-76)*

In the second FG, two questions were added to the topic guide to explore this perception further with the nurses.

> *"From your experience within the immunisation… the surveillance programme, using the pink card and interviewing parents, how effective is this system, do you think, in assisting you to identify children with developmental abnormalities?*
>
> *"Who fills in this developmental milestone assessment checklist at each child visit?"*

5.2.8 Reflection from undertaking the FGs

The following reflection section is taken from the researcher's summary notes, which describe the researcher's experience and feelings while undertaking the FG discussion.

"I had not expected the recruitment for FGs to be so difficult, particularly as a result of shortages in staff numbers in many of the health centres, as well as issues with managers

who would not release staff to attend during work time. This was more pronounced with participants from rural areas, especially as they wanted transportation to be provided to attend the FGs. I understood why this was the case, after personally delivering information about the project to a rural health centre. The journeys to these centres are very difficult; unpaved roads, with narrow passages crossing mountains and valleys. Indeed, this type of journey would require dedicated transportation and this helped me to understand why these practitioners were reluctant to participate. I also found that many of the participants were not familiar with FGs and were uncertain about their role in the discussion. This was interesting as there were many opportunities for staff in the Muscat region to volunteer for research studies due to the University being there. I realised that many participants found ASD a new and sensitive topic, and most of the nurses felt that they did not have enough information relating to ASD to enrich a discussion as part of a FG. Interestingly, this may have been a reason why GPs were more adept at sharing their ideas in connection with the study. They readily offered information and suggested topics to be considered more fully with one another, sharing ideas and updating each other with information from their field e.g. about the electronic checklist. In contrast, the nurses demonstrated less knowledge about ASD, and their more limited dialogue often veered off topic."

5.2.9 Data management

Immediately following each FG, all audio tapes and field notes were labelled. A debriefing session took place with the moderator, co-facilitator and note taker (around 30 minutes) to identify unexpected findings, non-verbal observations, and personal impressions. A summary form was completed at this time for each FG (see Appendix 10.2.B). This form was then used to help with data analysis. The audiotapes were transferred to an electronic folder along with the field note data and stored on the researcher's computer, which was password protected in the researcher's office at the University of Glasgow.

5.2.10 Data analysis of the FGs

5.2.10.1. Transcribing

The digital audio recorded data of the FGs were transcribed verbatim by the researcher within two weeks of each FG. The first draft of the transcript was examined carefully by the supervisor DW, who suggested inserting line numbers, and increasing the line spacing and the page margins to ensure comments could be mapped back to participants and to provide room for initial ideas about the corpus. Participants' responses such as long pauses, non-

verbal communication (e.g., laughter) were also noted in the text. This was done to ensure comparable formatting for all data sets, to help to resolve any inconsistencies and to identify the context or tone of the responses. Participants were also allocated a unique number, and labelled as nurses or GPs. They were colour coded red to indicate respondents from a high workload institution and green to denote those from a lower workload institution. For example, **nurse 7** refers to a nurse from a lower working load institution who has been assigned the number 7. This process of coding and organising the transcript enabled data from each respondent to be easily reviewed while giving structure and consistency to the analysis and supporting the process of indexing. Once transcribed, the researcher checked the whole content of each transcript for errors by listening back to the audio-recording and reading the transcripts simultaneously.

5.2.10.2. Field notes

FGs can ascertain the views of the participants. However, field notes are also essential in supporting this and are recommended for use in interviews and discussions (Mulhall, 2003). Therefore, field notes were taken by the researcher in this study, to retain and record behaviours, activities, events, and other features of interest (Clifford, 1990). The field notes may commonly constitute all the data collected for a research study, as in an observational study. They also serve, as in this study, to supplement data from a conventional interview or discussion (Gerrish and Lacey, 2006). There is no one 'right way' to record field notes; however, the literature suggests including details such as the dates, the name of the interviewee and whether or not an involved individual was present. Descriptions should also include verbal portraits of the participants, a reconstruction of the dialogue, and a description of the physical setting, as well as accounts of particular descriptions of the observer's behaviour (Muswazi and Nhamo, 2013, Mulhall, 2003, Moll et al., 2006). As a result of this, the researcher in this study developed a set of formats referred to as '*FG Note Taking Forms'*. These forms encompass the dates, times and locations of the FG, the participants and their gender, as well as seating charts. They also aid with the recording of all answers, the participants' interactions and responses for each question, the views of the researchers and their thoughts on the discussions and identified themes (see Appendix 10.2.).

These notes were read by the researcher and supplied as ongoing evidence, as they formed a readily accessible record of the study data (Mulhall, 2003, Muswazi and Nhamo, 2013). An additional advantage of the field notes was their usefulness as a key for capturing data in more natural circumstances. This ultimately created meaning, as well as understanding, of

the culture, social situation, or phenomenon being studied (Mulhall, 2003, Moll et al., 2006). It also helped the researchers to make sense of their feelings and to be part of the audit trail involved in understanding the culture or developing themes (Mulhall 2003).

Despite the advantages, it is worth mentioning some drawbacks of this strategy and how the researchers solved these issues. Firstly, the field notes may be highly subjective, as they reflect the researcher's own views, interests and memories of the study and what they felt was important at the time (Silverman, 2001). Consequently, this may produce discrepancies in the data that is emphasised and the descriptions used among the research team (Muswazi and Nhamo, 2013). Most of the notes may never be incorporated into the findings, as they exhibit little coherence. They are fragments of narrative and descriptions of things that were considered important at the time (Silverman, 2001). Issues of accuracy were also recognised if there were delays in note taking, after the interview or after the discussions, as the interviewer may have forgotten important details, or remembered them differently to the interviewee's recollection (Muswazi and Nhamo, 2013). Confidentiality was also a concern if the participants requested to view the notes taken at the time of the interview or discussion (Mulhall 2003).

To negotiate these pitfalls, the researchers developed two formats in which to record field notes. The first one was carried out at the time of the discussion and was intended to capture the participants' views, thoughts and interactions on the topic discussed. A note taker was appointed in order to complete this format. She was seated at the side of the discussion table in order to promote the comfort of the participants and to allow them to share their thoughts and experiences with more ease and to reduce distractions when note taking.

The second format in which to record notes was completed at the end of each FG. This included debriefing and summary forms. The debriefing forms (see Appendix 10.2.A) were completed by the researcher after discussion with the assistants (i.e. co- facilitator and the note taker), as they met within thirty minutes of each discussion to identify the most common topics, emerging themes, any problems encountered within the discussion and suggestions for future discussion. After the debriefing, the same team summarised their thoughts and perceptions about the topics for each FG in a 'summary' from (see Appendix 10.2.B). Both forms (i.e. debriefing and summary) were intended to reduce the discrepancies and fragmentation of the reported data and to enhance the quality and consistency of the information gathered. None of the participants demonstrated an interest in viewing the field notes, raised concerns, or reported discomfort at the note taking.

During the analysis stage, two types of field notes were examined, and all were combined for the overall analysis. The first type was drawn from discussion notes, which were used to capture the participants' interactions in verbal and non-verbal forms. These were recorded during the discussions and the opinions they agreed/disagreed with the most were highlighted. For example, during the FGs, the note takers reported the participants' interactions with phrases such as '*a general agreement, nodding heads', 'loud laughter', 'noises of agreement', 'speaking authoritatively', 'opposing and disagreements'*. Those phrases were connected to the quotes at the stage of analysis and reported in bold, to represent the active engagement between the participants (see section 5.3.2). This enabled the researchers to identify those topics and quotes that the participants agreed/disagreed with most within the study. It also helped to inform the emerged themes and the questionnaire items at a later stage (see section 6.4). For example, quotes such as the following, to which most of the participants drew particular attention, were used to identify relevant themes and to help construct the questionnaire at a later stage:

> *"... We are filling in the [visit checklist] and we want to fill it in... However, we want to know what we are doing [agreement from the group, nodding heads]..... To identify any abnormality" (nurse 5 P17, L589-90)*

> *"No!! We all have it in the system... we are asked questions [on child development], and we all have to fill it in ... there is a separate checklist for each month; for example, the two months [checklist] ... Have developmental milestones [for this age group] ... we have to ask the parents and... [One GP interrupted: Does this exist...?!] [**noises of disagreement**]" (GP4 P17, L449-52)*

The second type of note taking occurred after each FG and it was used as an aide memoire for the researcher. For instance, debriefing notes from each FG were read thoroughly and compared in order to identify common issues that eventually were used to support the findings of the emerged themes from the transcript data. At the end of each theme, supporting field notes and summary notes were documented and labelled according to the relevant section (see section 5.3.2). The summary note also helped to make sense of the researchers' feelings on the discussion. Such information was used as an audit trail of the developing themes (Mulhall, 2003). In this study, for instance, the following paragraph was extracted from the summary notes of the FG and incorporated into a reflection section within the study (see section 5.2.8).

"We, therefore, conclude that knowledge is essential in conducting research studies. Participants need to understand the topic well for them to be productive during the group discussion. During the two days' FGs between GPs and nurses, it shows that GPs are more capable of sharing their ideas towards the study. They can give more information and interesting topics to be considered." (Summary-notes, Nurses Group, page 8)

5.2.10.3. Framework analysis

Framework analysis (FA) was used to analyse the transcript data; this is elaborated upon in the following sections. However, as was explained in the previous section (5.2.10.2), the data from the field notes was used to support the emerging themes from the transcripts, as well as to memorise and record information and reflect on the findings.

As explained in Chapter 3, FA involves five key stages, undertaken in a sequential process: familiarisation; identifying a thematic framework; indexing; charting and mapping; and interpretation (Ritchie et al., 1994). The application of the five steps is explained as follows:

5.2.10.3.1. Familiarisation

Both FGs were undertaken by the researcher and this helped her to immerse herself in these data. Afterwards, the researcher listened to the tapes several times, and read and checked the transcripts against the tapes. The researcher also read all the field notes from the FG discussions several times to comprehend and connect the data. This process enabled the researcher to gain an overview of the diversity and richness of the data.

5.2.10.3.2. Coding and identifying a thematic framework

After familiarisation, the researcher carefully read the transcript line by line and applied an initial 'code' for each segment of the text in the transcript. This code ranged from a few words to parts of sentences or whole paragraphs (see Figure 5.1 as an example). Codes refered to any recurrent values, beliefs, impressions or emotions that seem relevant and important to the research topic.

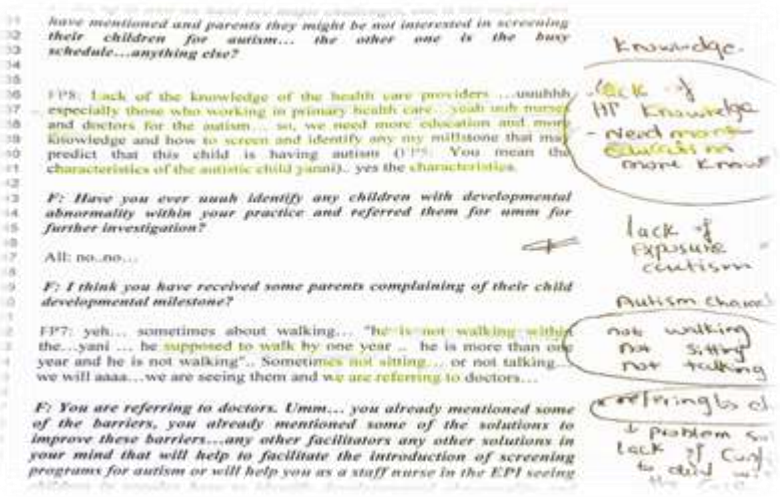


Figure 5-1: Example of initial codes taken from the researcher's notes

Independently, the supervisor (DW) put her initial code in her version of the transcribed text (see Figure 5.2 as an example).

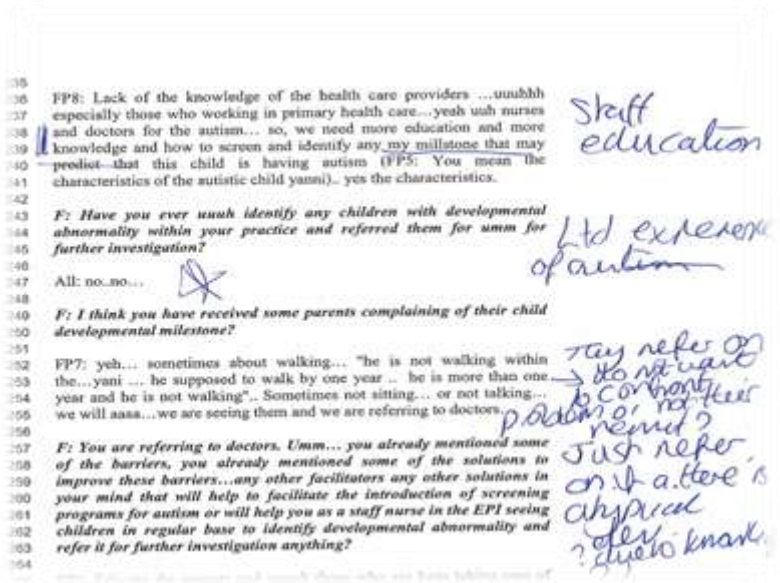


Figure 5-2 Example of initial codes taken from the supervisor's notes

Once the codes had been formed, the researcher met with DW to review the codes and to examine any similarities and differences between the initial interpretations. In some cases, the interpretations differed, for example, the supervisor labelled the phrase ***"many programmes are going on in primary health care…"*** as 'many competing priorities for parents' while the researcher viewed it as 'workload'. Through discussion, the differences were resolved by revisiting the transcript. In this case, they agreed that the term 'service structure' captured the idea and this code was applied. In some cases, the question asked informed some of the codes. For example, the answers to the question "What do PHPs

perceive as the obstacles to screening for ASD in the PHC settings in Oman?" were categorised and coded as 'organisational barriers', 'professional barriers' and 'social barriers'. By the end of this stage, 23 codes were identified (see Appendix 14)

5.2.10.3.3. **Indexing (Applying the analytical framework)**

In this stage, the researchers read the codes from the previous stage, and the transcripts, notes and field notes carefully line by line. Any thoughts, insights or experiences seen as a possible new code were also noted, detailed and referenced to the page and line number of each respondent. Once this was completed, the emergent codes were gathered together and discussed to form 'themes', which captured the broader concept of the data: see Table 5-4 below for an example of the full process. This process was undertaken to ensure that each respondent's experiences were captured. It also elaborated upon logical and intuitive thinking, as it assisted the researcher in making judgements about meaning, understanding connections between ideas, and understanding the importance of the issues (Ritchie et al., 1994, Gale et al., 2013).

Table 5-4: Example of indexing framework from GPs' FG

Question	*What do you understand about ASD?*			
Respondent	***Response***	***Initial Code***	***Notes/subtheme***	***Themes***
GP3 P4, L4	*… Difficulties… no eye contact. No special address to call someone (Mama, Dada, etc.)*	*Absence of eye contact and special address*	*Non-verbal communication difficulties*	*Signs and symptoms of ASD difficulties*
GP6 P4, L6	*…Umm… A child is living in his own world. Late communication and associated with cognitive problems*	*Alone* *Later development skills*	*Social difficulties* *Speech and language difficulties* *Cognitive problem*	
GP2 P4, L8	*Not communicating, playing alone and not talking*	*Absence of communication* *Alone*	*Speech and language difficulties* *Social difficulties*	
GP1 P4, L10	*Yes ... I think children with ASD are usually isolated and have a repetitive action*	*Alone* *Rigidity*	*Social difficulties* *Inflexibility*	

5.2.10.3.4. **Charting**

At this stage, data were lifted from their original context and placed in tables consisting of the headings and subheadings drawn up during indexing (Ritchie and Spencer, 1994). Quotes were inserted to support, explain, and justify the themes identified in the indexing stage **(see Table 5-5)**. This was done to reduce the material into understandable but brief summaries of what was discussed by the participants (Ritchie and Lewis, 2003). At this stage, six main themes were identified, incorporating 2 subthemes.

Table 5-5: Example of subject chart from the transcript of the GPs' FG

Emerged themes	*Sub-themes*
1. *Signs and symptoms of ASD difficulties*	***1.1*** *Non-verbal communication difficulties* *"No eye contact" (GP3 P4, L4)*
	1.2 *Social difficulties* *"In his own world" (GP6 P4, L6)* *"Playing alone" (GP2 P4, L8)* *"Isolated" (GP1 P4, L9)* *"Misbehaving" (GP4 P4, L11)*
	1.3 *Speech and language difficulties* *"Late communication" (GP3 P4, L6)* *"Not communicating" (GP2 P4, L8)* *"Not following parents' orders" (GP4 P4, L11)* *"Speech delay" (GP6 P4, L14)*
	1.4 *Inflexibility* *Repetitive action (GP1 P4, L10)* *Focusing on one object (GP1 P4, L13)*
	1.5 *"Cognitive problems" (GP6 P4, L6)*

5.2.10.3.5. **Mapping and interpretation**

Mapping and interpretation are the final stages of the FA. At this stage, all of the data has been sifted and charted according to the core headings and subheadings. Initially, the researcher pulled together the key characteristics of the data to interpret it as a whole (Ritchie and Spencer, 1994). This included reading and reflecting on the transcripts of the FGs, and reviewing all the research notes, comparing and contrasting the views and experiences of the PHPs in the study area, and searching for patterns and connections within the structure as a whole.

At the interpretation stage, a consensus meeting with the supervisor DW was undertaken to develop general themes that offered possible explanations for what was happening in the data. As a result, themes were generated, and some sub-themes were rearranged within the main themes to give a more structured approach. For example, the barrier sub-themes were all rearranged under three main sub-themes (organisational, professional and social barriers). Other sub-themes were amalgamated at this stage; for instance, the signs and symptoms of

ASD difficulties and the age of the child were amalgamated under one theme labelled as ASD identification (see Appendix 15).

When reading the transcript, there were some phrases that needed more understanding. One discussion was about crowdedness and what it meant. For example, a respondent in the GP group kept saying they were crowded, and that this would be a major challenge to introducing a screening programme for ASD.

> *"Sometimes with the **crowdedness** within the health centre, we do not have the time to ask and elaborate upon the history more" (GP3 P7, L130-131)*

> *"…**Overcrowding** is the most important barrier and difficulty for screening..." (GP1 P10, L224-25)*

To make 'crowded' understandable for the reader, both researchers discussed what the participants meant by that and what was concerning them. Eventually, both researchers thought that the participants were concerned about how the clinic was running, how 'busy' they were, seeing a significant number of patients with various diagnoses from different age groups on a daily basis. Therefore, all of the emerged themes concerning how the clinics were run were labelled as organisational barriers. This process was undertaken across the data. From this, five themes and related sub-themes were identified (see Figure 5.3).

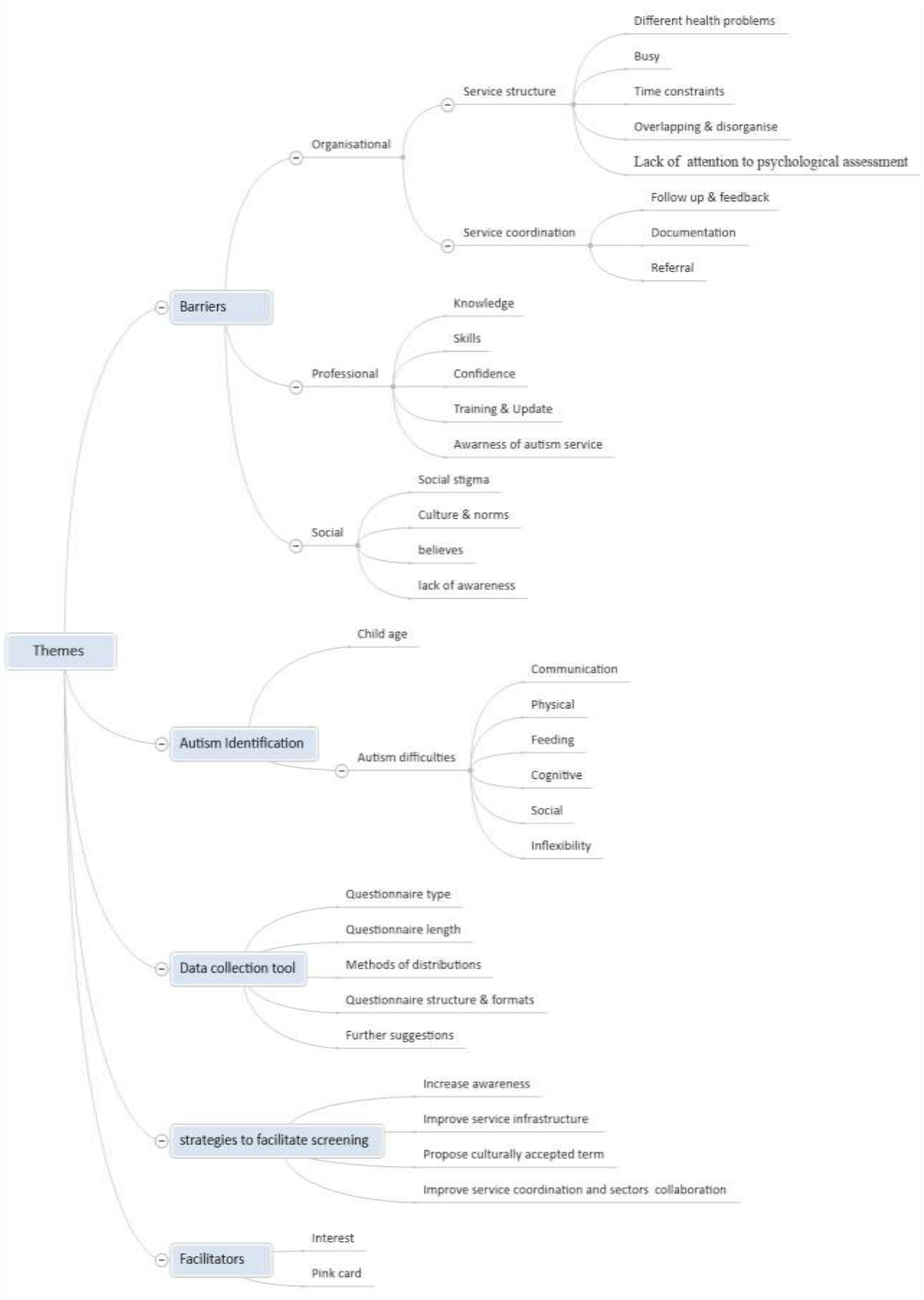


Figure 5-3: Final themes map

5.2.10.3.6. **Concept development**

In order to capture the participants' views on the emerged themes and to facilitate the understanding of the analysis and coding process, each theme was given a definition. For example, the theme *'ASD identification'* was used to describe any absence or impairment in developmental and behavioural skills in children, which enabled ASD to be identified. It also reflected the age at which professionals recognised these impairments. The second theme *'Facilitator'* denoted perceptions, feelings, experiences or thoughts that may support a potential screening programme for ASD in Oman. In contrast to '*Facilitators*', *'Barriers'* represented perceptions, feelings, experiences or thoughts that may potentially inhibit future ASD screening. Another theme recognised in this study was '*Strategies to facilitate ASD screening'*, which signified any thoughts, actions or approaches the participants believed to be necessary to resolve potential problems with introducing screening for ASD. The final theme '*Preferences for the data collection tool*' referred to the thoughts, feelings or beliefs that the participants suggested could be introduced into the questionnaire.

5.2.10.3.7. **Summary**

Two FGs were undertaken with nurses and GPs from Muscat health centres to explore the barriers and facilitators of screening for ASD. A topic guide was developed to guide the group discussion. FA was employed to analyse the data, and five themes emerged from this analysis.

5.3. **Findings**

This section discusses the findings from the analysis of the data. Five themes were identified. The first theme, *"ASD identification"* focussed on the opening questions of the discussion and was supported by data from the field notes. It explored the PHPs' knowledge about ASD. Two sub-themes emerged, '*ASD difficulties',* and *'age of identification'.* The second theme, *'facilitators'* explored participants' views on supporting the implementation of screening for ASD within the PHC settings in Oman and comprised of two sub-themes: *'interest*' and *'pink card'.* The third theme, *'barriers',* identified the potential challenges of screening for ASD, using the sub-themes '*organisational barriers,' 'professional barriers'* and *'social barriers.'* The fourth theme was '*strategies to facilitate screening'.* This explored how the

proposed challenges might be resolved. The final theme explored the suggestions about the survey tool: '*preferences for the data collection tool'*. This section is organised by describing the demographic details of the participants before leading on to discussing the five themes that emerged in this study.

5.3.1 Demographic details of the participants

Thirteen participants volunteered to participate; six were GPs (age range 27 to 42 years) with between two and nine years' clinical experience. All but one was female and Omani while the remaining respondent was an Egyptian male. The nurses' group, however, consisted of seven participants (age range 23 to 45 years) with between seven to 16 years of experience in the field of child health. All of them were female, five were Omanis and two were from India. In total, eight participants were from metropolitan areas (nurses=4, GPs=4) and five from rural (nurses=3, GP=2) areas. See Table 5-6 for further details of the respondents' characteristics.

Table 5-6: Demographic data of the FGs participants

Focus Group	***Job***	***Age range***	***Gender***	***Nationality***	***Qualification***	***Years of experience***	***Employment location***
A	***GPs***	*20-30 (n=3)* *31-40 (n=2)* *41-50 (n=1)*	*Male (n=1)* *Female (n=5)*	*Omani (n=5)* *Egyptian (n=1)*	*MBBCH (n=1)* *Diploma in child health (n=1)* *MD (n=4)*	*2-4 y (n=4)* *5-9 y (n=2)*	*Urban / high working load, HC (n=4)* *Rural / low working load, HC (n=2)*
B	***Nurses***	*20-30 (n=2)* *31-40 (n=4)* *41-50 (n=1)*	*Male (n=0)* *Female (n=7)*	*Omani (n=5)* *Indian (n=2)*	*BSN (n=1)* *Diploma in Nursing (n=6)*	*2-4 y (n=0)* *5-9 y (n=3)* *10-14 y (n=2)* *15-19 y (n=2)*	*Urban / high working load, HC (n=4)* *Rural / low working load, HC (n=3)*

MBBCH =The Bachelor of Medicine & Bachelor of Surgery, BSN= Bachelors of Science in nursing, Y= years, HC = Health Centre

5.3.2 The identified themes

5.3.2.1. ASD identification

This theme sought to ascertain the PHPs' comprehension of ASD and how they recognised children with the disorder. Their thoughts in this regard were represented by the sub-themes 'ASD difficulties', which referred to the noticeable difficulties that PHPs perceived that children with ASD may exhibit, and 'age of identification', which debated the expected age for identifying ASD. The issue most elaborated on by GPs and nurses was the social difficulties that a child may express, for example being lonely and withdrawn.

"...Playing alone [two others agreed]" (GP2 P4, L8)]
"I think children with ASD are usually…isolated"
(GP1 P4, L9)
"Social interaction may be less" (Nurse 1 P4, L63)
"…Sitting in one corner…" (Nurse 2 P6, L138-39)

Both GPs and nurses assumed that children with ASD may experience trouble in acquiring speech skills (delay, or absence of spoken language) and understanding what others say to them.

"Not communicating...Not talking "(GP2 P4, L8)
"I agree…they usually misbehave and not follow
parents' orders" (GP4 P4, L10-11)
"Not listening to us [parent]" (Nurse 5 P3, L47)

Again, both groups assumed that children with ASD display a restricted, repetitive pattern of behaviour with regard to certain interests, e.g. toys or activities.

"...I think they are focusing on one object" (GP1 P4,
L13) [nods of agreement from the group]
"They show very repetitive behaviour" (Nurse 1 P4, L55)

Along with the previous difficulties, GPs expressed the view that children with ASD might have *late development cognitively (*delayed development)

"...[ASD] associated with cognitive problems" (GP6 P4, L6).

One GP also presumed that children with ASD may experience trouble with communicating non-verbally, such as having

"no eye contact" (GP3 P4, L4).

In contrast to the GPs, nurses expressed that children with ASD might have a physical difficulty such as an absence or inadequacy in their fine and gross motor development and have trouble moving, sitting or coordinating activities.

"... Not sitting also not moving"(Nurse 7 P4 L49)
"....Some mobility like nil [absent]..." (Nurse 2, P6, L139)

Others identified feeding difficulties and noted parents complaining that children with ASD are hard to feed.

> *"Mothers also complain that they are very difficult to feed* ***[General agreement, heads nodding]"*** *(Nurse 4 P4, L61)*
> [Note: anything in terms of behaviour will be in bold]

> *"6 GPs defined ASD as a child living in his own world with different manifestations of developmental disabilities such as late cognition, difficulties in communicating (can't express his/her thoughts, no specific address to anyone), being isolated most of the time, can't play well, no eye contact, misbehaviour, inability to follow parents' orders, repetition of actions." (Debriefing-notes, GPs Group, page 3).*
>
> *"Nurses described ASD as active, always moving, lonely/isolated, hard to feed, no social interaction and with repetitive behaviours." (Debriefing-notes, nurses Group, page 2)*

Age of identification was an area where GPs and nurses had different opinions. Most GPs acknowledged that ASD could be identified before 18 months.

> *"…[ASD] can be diagnosed from one and a half years…[and] can be diagnosed even earlier…" (GP6 P11, L262-63)*

However, both groups thought that identifying ASD during the current immunisation and health-checks programme (at two to 18 months) represented a major challenge and preferred not to do this.

> *"…It is not easy to pick up ASD within the vaccination programme at the age of two-18 months"* ***[Audible agreement from all group]****." (GP6 P10, L237-39)*

> *"…Most children present with ASD after 18 months, not before that…so many patients…they told me it is like this… before 18 months, the child is fine…" (Nurse 6 P5, L111- 14)*

In summary, there were five underpinning difficulties reported by both groups in a child who may potentially have ASD. Three of these challenges were recognised by GPs and nurses: difficulties with social interaction, communication, inflexibility and rigidity of behaviour. Of the remaining difficulties, GPs reported cognitive problems, while nurses highlighted the feeding and physical difficulties that might be associated with ASD. Most of the participants were reluctant to identify children with ASD within the current immunisation and surveillance programme and considered it a challenging task.

5.3.2.2. Facilitators for screening for ASD

The second theme to emerge from this study was *'facilitators*'. Few facilitators were mentioned compared to the number of barriers. These described the PHPs' perceptions of what might support the implementation of screening for ASD within the PHC context. Two sub-themes were uncovered in this area: 'interest' and 'the pink card.'

5.3.2.2.1. Interest

Both groups seem interested in identifying ASD in children. They believed that they occupied a position that enabled them to assess children's development on a regular basis from an early age.

> *"As GPs, we are the ones who see those kids for vaccines; we can take some workshops **[interrupted by GP1: I agree with him]** or some training concentrated on ASD that can help us to identify early symptoms of ASD..."(GP6 P13, L310-15)*

> *"...We are filling in the [visit checklist] and we want to fill it in...However, we want to know what we are doing [**agreement from the group, nodding heads]**…To identify any abnormality" (Nurse 5 P17, L589-90)*

As highlighted above, if they were to do this, both groups wanted more knowledge and additional training, as without this they would not be equipped to facilitate the early identification of children with developmental delay and ASD.

> *"…We need more education and more knowledge on how to screen and identify any abnormal milestones that may predict that this child has ASD…" (Nurse 7 P8, L2287-89)*

5.3.2.2.2. Pink Card

Both groups talked about the current recording system within the health system – e.g., the pink card and electronic record systems. They currently used this card to record a child's immunisation, health, and developmental status for the first six years of life. The pink card

was seen as an effective instrument to determine any abnormalities for both parents and professionals, as they could check and compare the developmental milestones for each age group from the examples given on the pink card.

> *"The [pink card] is a very effective* ***[interrupted by two nurses: yes, very effective]****…to identify children with developmental abnormality"(Nurse 4 P5, L106-109)*

> *"I think the Immunisation and Developmental Surveillance Programme help[s] us to follow child development from the age of two weeks, with a second visit at two months and so on, to identify any milestone delays* ***[interrupted by another GP: Yeah, I totally agree] [another GP: it is]****...it also helps parents to discuss their concerns about their child's development with healthcare providers on a regular basis" (GP6, P4, L29-32)*

Some saw the utility of the card given that it was presented in different languages

> *"…This pink card is the best card in the world. So, you can see in Arabic and English what the development and motor milestones are* ***[interrupted by a few GPs: correct]*** *for child age****…"[more agreement]*** *(GP1 P6, L73-75)*

While others felt it needed modification

> *"...It is only the [vaccination] schedule that changes in the new cards, not the assessment checklist. It has been this one now for how many years, it needs to be modified" (Nurse 3 P15, L505-09)*

> *"The group stated that the pink card for immunisation is the best tool to guide child milestones. It measures growth and development. With some modification it can distinguish if the child is delayed and manifests symptoms of autism. It also guided parents' awareness." (Debriefing-notes, GPs Group, page 3).*
>
> *"The use of the Pink Card for nurses in the different health centre in Oman is very helpful and important. It serves as their comprehensive guide to diagnose a child with any manifestations of autism. They can evaluate and differentiate their observation easily towards every individual milestone." (Debriefing-notes, nurses Group, page 2)*

> *"Facilitators: Participants needed more time, awareness, connection between systems, trainings/workshops focus on (nurses GPs and parents). " (Summary-notes, GPs Group, page 5).*

Summary

Although screening for ASD within current practice was believed to be challenging, the participants expressed their interest in screening as long as they were provided with the relevant training and knowledge, and enough time to assess the children. The pink card was perceived as an effective tool to facilitate early identification of developmental abnormalities, despite some need for modifications.

5.3.2.3. Barriers to screening

The opposite of facilitators was barriers and these were divided into three different types: organisations, professional and societal barriers.

5.3.2.3.1. Organisational barriers

Organisational barriers were concerned with how the clinics were run. One issue for the clinics was their busyness, and this was one of the biggest challenges,

> *"In our health centres... 60 we reach up to 70 patients (as an average) in six hours on a daily basis. For each doctor 70 or 60 cases per day* ***[audible agreement and nodding heads]****" (GP4 P13, L330-33)*

> *"…Overcrowding is the most important barrier and difficulty for screening..." (GP1 P10, 221-222)*
> *"…We see 30, 24, 26…"(Nurse 5 P13, L426)*

Aside from the busy clinics, the vaccination programme and the pink card, both groups of practitioners also dealt with different problems; hence some believed that adding screening to these varied tasks would be very challenging:

> *"The problem is we are in the GP clinic, and we see all ages...all genders...all diagnoses...everything at the same time; so how can we keep our minds on ASD?" (GP4 P13, L315-317)*

> *"So, imagine… from the common cold to MI [myocardial infarction] or epilepsy – all these we see on the same day, and so we just cannot keep in mind ASD for each child" (GP1 P13, L324-326)*

> *"Vaccines, yellow fever vaccines…so much…"* ***[loud laughter]*** *(Nurse 5 P13, L428-29)*

Another problem that arose from being busy was the impact on time and the need to prioritise. Both groups found it very hard to concentrate on completing the psychological

assessment for children on every visit; their priority was to ensure the child was fit for the vaccine.

> *"So many children will be waiting for immunisation, so we do not go through the [developmental checklist] one by one" (Nurse 6 P7, L214-15)*

> *"If we are busy, we are not concentrating, and sometimes we forget about...psychological problems...you will just possibly see if he is fit to take his vaccine or not this is what we are concerned about* ***[everybody agreed: yaah]****" (GP6 P16, L420-422)*

The GPs expressed more views on the organisational barriers than the nurses, believing that the current system was not able to adequately evaluate and detect any delayed development in children. The main issue again related to a lack of time for undertaking the basic investigations and tests for child development.

> *"…We [assess children] for a few minutes; there is not much time" (GP3 P5, L43-44)*

> *"…yes we do not have the time or staff to ask about and elaborate more upon a [child's] history…" (GP2 P7, L131-32)*

This was echoed by the nurses, who acknowledged that the psychosocial assessment had a reduced priority and that they left it for the doctors to complete.

> *"Usually, we do not pay much attention to the normal developmental stages…because of the lack of time available to us…so we will leave it to the doctor sometimes…" (Nurse 2 P17, L584-86)*

Additionally, GPs believed that they might fail to detect children within their practice for several reasons, such as not following protocol,

> *"that is because some doctors do not follow the protocol" (GP4 P18, L480-81)*

or errors in picking up symptoms:

> *"Maybe we miss these [ASD] cases in our evaluations" (GP5 P5, L43-44)*

Overall both groups believed that if screening were to come in they would have to follow protocol and psychological assessments would have to be prioritised:

> *"Maybe because of we…we are not concentrating on that area [psychological assessment]...Not following protocol – which could relate to the time factor" (GP2 P16, L413-414)*

> *"… Sometimes we need to focus more on the assessment and …tackle the specific problem that the child is having or may have…so, in this, we can follow more…and…give a period to monitor the child, and consult the doctor of course…" (Nurse 2 P6, L157-60)*

Service structure

Likewise, the GPs criticised the service structure of immunising and assessing child development. They felt the current system was disorganised, repetitive and time consuming for parents.

> *"…Parents first [go to] the vaccination room... for the measurements (e.g. Weigh the child)…then go to the doctors and they queue again* ***[interrupted by one GP: really!] [other GPs confirmed it: yes, yes****]…you and then again quiet for the EPI [vaccination]…so that is why parents are angry and they…wait for…more than three or four hours..." (GP1 P9, L201-05)*

The GPs believed that parents viewed the immunisation and surveillance programme as a service to ensure that their children received the recommended vaccines at certain ages. Yet parents were thought to resent having to stand in long queues for a GP consultation, especially if the nurse could undertake the vaccination and complete the developmental check. Hence the GPs empathised the parents' frustration at the current service structure.

> *"…Sometimes I notice that the parents are refusing or are complaining about why they have to see a doctor to vaccinate their child. It is all about the injection, and that is it, so they are thinking they are wasting their time by seeing a doctor. So why, why are they not going directly to an EPI room and just vaccinating the child?" (GP1 P9, L183-88)*

> *"And they will wait twice: once to see the doctor and again for the EPI* ***[another GP: Are they waiting in the same place?]****... No, no, different...****[So different rooms?]...****different rooms... and they have to go to the doctor first and then for the vaccine" (GP4 P9, L199-202)*

Another issue raised by the GP group was the lack of service coordination between PHC settings and other assessments, and diagnostic and therapeutic facilities.

> *"Suppose in one area you have ten children with ASD... already picked up and diagnosed...what is the follow-up process? What do you do for them? What secondary care service do you arrange for them?...Is there any change before and after? These are critical questions to consider before you start…[implementing screening program]. It's not clear at the moment "(GP5 P24, L695-700)*

The GPs also noted the slow progress in improving the co-ordination of the current system, despite frequent requests.

> *"…They promised us two or three years back that they would connect the health centre primary and secondary levels. Now, after three years…in 2015 there is no connection or even some feedback when a child is found to be autistic" (GP4 P28, L834-36)*

The GPs were critical of the current system and were resistant to any potential screening programme for ASD, as there were no clear referral routes or feedback policies in place. Furthermore, the current system was seen to rely on the individual and it was open to variation.

> *"After [referral]…I do not know what happens to them. I missed them."* ***[general laughter]*** *(GP2 P7, L110-11)*

> *"…Usually, I ask the referred patient…I ask parents to bring in their report if diagnosed, to see...to know about child's condition, and we will write it in the system "(GP3 P27, L789-90)*

Controversially, one GP said that they did not receive feedback about the child's condition because not all doctors followed the protocol and sent a comment about the referred condition.

> *"There is a feedback mechanism on the system…however,... most doctors do not send feedback. Some cases we see with feedback, but not all cases that we refer" (GP3 P29, L838-41)*

Within the current system, there was also no process for documenting any cases referred or suspected cases for further investigation within the health centres. Furthermore, there was no reporting or recording of the number of children who were ultimately diagnosed with ASD.

> *"…If we refer five children per month for a secondary health care evaluation for ASD or any other psychiatric disease…Moreover, we do not receive feedback as to whether they are autistic....We do not know exactly in one year how many ASD cases have been diagnosed…the number of cases that [we refer] and are already diagnosed…"* ***[general agreement]*** *(GP4 P28, L808-816)*

> *"If you ask me how many cases of ASD are in your area… I will not be able to reply..."* ***[loud laughter]*** *(GP6 P28, L822-823)*

> *"Even me – how many of them? I do not know because I send ten cases and maybe some of them are ASD. How can I tell you when I have no feedback? I have no information…I have no data" (GP1 P28, L824-26).*

5.3.2.3.2. **Professional barriers**

The second constraining factor that emerged from this study was professional barriers, which explored the staff's knowledge, experience, and confidence in identifying ASD.

Knowledge of ASD

The GPs believed that their comprehension of ASD needed to be updated as they had not been exposed to the topic since they were students at medical college.

> *"We need to be updated on ASD because our knowledge since we were students…**[every body agree heads]**" (GP6 P16, L428-429)*

Similarly, the nurses felt that they lacked the knowledge to recognise children with ASD or other developmental abnormalities:

> *"…Lack of knowledge of healthcare providers…you, especially those who are working in primary health care… …" (Nurse P8, L236-38)*

Many reasons were given for their lack of knowledge, such as not being able to recognise signs and symptoms of ASD.

> *"…Because most of them [nurses]…do not know the signs, symptoms… "(Nurse 4 P12, 394-96)*
> *"…The milestones of autistic children will be normal… during childhood…from that, we cannot identify."(Nurse 1 P5, 133-36)*
> *"We cannot Yanni in my opinion; I cannot know if this is ASD or if this is a normal child…"(Nurse 5 P6, 142-43)*

Others acknowledged that the nursing curriculum or staff development programme did not cover developmental and behavioural abnormalities or ASD.

> *"...We lack knowledge of developmental and behavioural problems in the nursing curriculum and lack a continued educational training programme" **[audible agreement]** (Nurse 2 P4, L69-71)*

Interestingly, all of the nurses stated that they had never detected or referred a suspected child with ASD because they did not have the appropriate training:

> *"…There is no training…self-training only" (Nurse 7 P14, L535)*

Confidence in identifying ASD

The lack of training seemed to impact on PHPs' confidence in identifying ASD. Both groups expressed limited experience and confidence in identifying children with ASD. They may

be able to suggest signs and symptoms, but the application of this and giving a child a label posed challenges.

> *"…Not a clear picture of the staff because we have not had to face this…we have not seen a child with ASD…" (Nurse 4 P7, L195-197)*
> *"I feel I cannot pick up ASD in a child..." (GP6 P11, L265-66)*
> *"…However, when it comes to practice…we never can do...I mean cannot practice or apply what we have learned [about ASD] in our work..." (GP1 P10, L227-28)*
> *"I do not know what ASD is because I have not faced a child with ASD…" (Nurse 5 P7, L206-207)*

Confidence and lack of knowledge were also compounded by lack of familiarity with the health care system. Some practices were paper based, others computerised. During the discussion, most of the GPs were not aware of the electronic version of the psychological assessment and were only completing the paper-based checklist attached to the pink card. Furthermore, some GPs from rural institutions were under the impression that the electronic version was available to urban health centres only, whilst others were completely unaware of it.

> *"…Normally...We have…[A psychosocial assessment checklist] in the pink card…[one GP interrupted: Not on the computer…You may have it in Muscat?... (GP5 P16, L443-45)*

Only one GP from an urban health centre confirmed the presence of the electronic version across the Omani health centres and explained how it could be accessed.

> *"No!! We all have it in the system...we are asked questions [on child development], and we all have to fill it in...there is a separate checklist for each month; for example, the two months [checklist] …Have developmental milestones [for this age group]...we have to ask the parents and...[One GP interrupted: Does this exist...?!] [**noises of disagreement**]" (GP4 P17, L449-52)*

This GP acknowledged that even in her health centres, few GPs were using it. Even the Information Technology department informed her that she was the first person who sought further clarification on how to complete it.

> *"When I asked [about the computerized system of psychological assessments] they said you are the first doctor who asks this question **[loud laughter].**.." (GP4 P18, L479-80).*

Awareness of ASD services in Oman

Both groups lacked awareness of the availability of services for children with ASD in Oman and gave varying responses.

> *"From my information, there is no specific governmental centre..." (GP4 P27, L801)*

> *"Usually, I think they are referred to tertiary care…to Sultan Qaboos University (SQU) or uuuh...to I do not know?...or to Royal Hospital as well...?" (GP1 P28, L805-07)*

> *"I think there is a school only for autistic kids. They do training like behavioural therapy and intervention yaani (i.e. meaning) to improve their behaviour" (GP6 P31, L910-11)*

> *" ...I think in Athaiba there is one place...(There is one place...is it governmental or private?) No idea…I think governmental" (Nurse 3 P18, L606-07)*

> *"...Maybe a normal psychiatric clinic" (Nurse 3 P18, L615)*

Interestingly, nurses thought doctors would be more knowledgeable about the availability of health services for ASD in the country, as they are the ones who referred and dealt with such cases.

> *"...Doctors must know [ASD health services in Oman]" (Nurse 5 P18, L611)*

Yet, there was variation in the responses and uncertainty over when to refer a suspected case of ASD for further investigation from both groups. Some felt unsure and questioned if they had to refer the child as soon as they identified the abnormality, or just wait and monitor the child for the first two years within the PHC setting.

> *"If you picked out a case, when would you refer it to a paediatrician? If you notice, for example, any abnormality like not smiling... would you refer directly or wait for two to three years to follow up at a PHC visit? " (GP5 P25, L712-15)*

> *"If you notice the motor developmental delay, and you feel that you want to give the child a greater chance to develop…, you give him two more months to improve you will give…However, if you feel the child is already one-year-old, and he is not crawling, and he is not sitting, that is too much...you will refer [**nodding heads**]" (GP3 P25, L728-732)*

> *"He is not walking within the…When he supposed to walk by one year...he is more than one year, and he is not walking...Sometimes not sitting…or not talking…we will refer them to doctors…" (Nurse 6 P8, L301-05).*

Others believed it was better to send the child with the suspected disorder for further investigation.

> *"…Sometimes we have to send the child for a second opinion." (GP1 P25, L723-724)*

Nurses, however, preferred to rely on the GPs for psychological assessment, believing them to be more skilled and knowledgeable in this regard.

> *"…We leave it [psychological assessment] to the doctor sometimes..."(Nurse 3 P17,L592-93)*

The GPs voiced concerns over early ASD screening and felt there would be no benefit to it without a well-developed system or intervention being introduced to change or improve children's behaviours.

> *"…So, what is the value of early diagnosis? Yaani (i.e. meaning) what is the value or benefit of diagnosing a child at one year?...okay, you will not embark upon any secondary intervention for the child. You will not change his behaviour… you will not change his case like that...so, what is the benefit to you discovering this big thing at such an early stage?!!" (GP5 P26, L752-58).*

5.3.2.3.3. **Social barriers**

The third type of barrier identified comprised social barriers, which included social stigma along with other social issues that might interfere with the endorsement of a screening program in Oman. A major problem that participants identified as a social barrier to the effective screening and identification of children with ASD in Oman was social stigma.

> *"[Barrier]…To me?...Social stigma…**[Audible agreement from the everybody else: yeah]**" (GP1 P7, L129)*

> *"They [parents] focus a lot on social stigma" (GP2 P5, L50-51)*

> *"Maybe…they [parents] socially…they do not want it to be known" (Nurse 1 P7, L235)*

> *"Maybe they think…people will think badly about them" (Nurse 2 P7, L242)*

Another issue raised by GPs was the title of the screening process. This was seen to be a significant factor in either promoting or de-motivating the screening process. They believed some illness/diseases/conditions had been culturally stigmatised. For example, in relation to

asthma, a father preferred to state that his child was suffering from a chest allergy rather than admit that it was asthma.

> *"…it is also about the name [of the disorder] when we translate ASD from English to Arabic. When a child came to me, I asked the father…of his seven years son having asthma, in Arabic "rabow"; he said no rabow my child ma eendahrabow. He has no asthma; he has hasasiatsaderie – a "chest allergy* ***[loud laughter, followed by audible agreement].*** *They accepted hasassader 'chest allergy' …but not rabow 'asthma' no…" (GP4 P14, 372-74)*

Other participants gave examples of a screening camp for AIDS that nobody attended; but when they revised the title to "screening for immunity deficiency", the screening process became more accepted, and its promotion was more successful.

> *"…even in our health centre, we had a programme for HIV …screening any patient; who wants to do it just comes and does it... When we first just said AIDS, nobody came at all ... we changed it to "naqesalmanah" (i.e., "immunity deficiency") and they, at least, accepted it, but not AIDS" (GP5 P15, L392-94)*

> *"…and even in the premarital clinic for blood investigation, I asked them if they wanted an AIDS test...they said no doctor Bismillah la!! (i.e. in the name of God!! No)* ***[general laughter and a node of agreement].*** *Okay, what about naqeselamanah (i.e., immunity deficiency)? An immunity deficiency test was okay" (GP1 P15, L395-98)*

Therefore, the GPs suggested generalising the screening process and using a more general term than ASD"Al twahed"in Arabic to reduce cultural sensitivity to the disorder. Yet, both participant groups felt that parents would still deny their children's abnormalities

> *"…They say their child is okay, and they have noticed no abnormality" (GP3P5, L65-66)*

> *"…Even the parents, if they notice some abnormalities in the child and especially if the child is the youngest one and there are like other siblings in the family...uh, they all try to deny…that this behaviour is not normal...they say that no, he is like his sister and brothers" (GP1 P5, L50-54)*

> *"…Like a denial, they do not want…they do not want to believe that their child has ASD…(it is very difficult also)… very difficult" (Nurse 4 P16, L593-94)*

In Oman, denial was seen to be used to avoid any diagnosis and/or any follow-up in the psychiatric clinic.

> *"…When I even said psychiatry [clinic] they were angry with me" (GP5 P7, L104))*

They believed that parents avoided labelling their children with ASD because this might cause them embarrassment in the community. This might make it hard for doctors to identify or refer children suspected of having ASD.

> *"…I think still…some people feel shy about saying their child has ASD (because of the stigma)…" (Nurse 6 P9, L340-41)*

> *"….Parents were very sad...don't want to have this diagnosis" (Nurse 3 P6, L207)*

Both the GPs and nurses believed that the parents did not seek health care services, except for genuine reasons, such as childhood illnesses or mandatory vaccinations. They also believed that the parents place less value on extra health care services such as screening.

> *"Immunisation – okay, this is a must for them and is important so they will come... If you tell parents to come so that you can examine their child for ASD, they might not come" (GP5 P14, L356-58)*

Reasons for not engaging with screening were seen by the nurses to be due to the large number of children they were caring for.

> *"…In one house, there were so many children….So many children – 10, 12 or 13 or something like that...they might not get proper care ...just basic" (Nurse 1 P9, L335-37)*

Awareness and misconceptions

Both groups noted a lack of parental awareness of normal child developmental milestones. They felt that parental knowledge was essential for accurate reporting to healthcare professionals to occur.

> *"…I ask some parents if their child is smiling at two months of age and is the child smiling to their face… they look at me strangely wondering why I am asking these questions* ***[general laughter]****" (GP3 P5, L63-65)*

> *"..Some parents also wonder why we ask them about the behaviour of the child...they are not saying that...for example: is he playing? She says okay...he is somewhat ...like that... they do not reveal the exact uh behaviour of the child – maybe they think he is okay" (GP5 P5, L33-38)*

It was noted that parents had many misconceptions, for example about the measles, mumps, and rubella (MMR) vaccine being the main cause of ASD.

> *"...one parent told me…her child, even before 18 months started talking…he was fine…uhh after 18 months,…he came for vaccination [and] he started this behaviour, so maybe it caused that alteration" (Nurse 6 P5, L172-75)*

Practitioners thought parents placed a low value on the importance of reporting their child's progress at each immunisation and health check visit, as often rather than attending in person, they sent other family members or housemaids. Very often, these people lacked knowledge about the child's history.

> *"More than 70% of children who come in for a vaccination do so without their mothers **[general agreement, nodding heads]**" (GP4P8, L 171-172)*

> *"...they send their child with an aunt or with an uncle… yeah or with the grandmother…who lack knowledge on the child's history" (GP1 P8, L161-162)*

Housemaids often brought children to the immunisation program and tended not to speak either Arabic or English. This made it difficult for GPs to take a full history, and often the housemaids preferred not to divulge information about a child's history, fearing their sponsor's anger or blame.

> *"…Housemaids bring the child [for immunisation]… but they are not Arabic, and so we cannot take the history" (GP4 P8, L148-149)*

> *"…Housemaids are…dishonest about child behaviour for fear of sponsor's anger and blame" (GP5 P8, L58-59)*

In contrast, it was noted that the housemaid spent more time with the children and therefore potentially knew more about the child's condition.

> *"…Housemaids spend more, or, at least, a long, time with the child ...more than the mother" (GP5 P8, L155-56)*

> *"When we ask the mother something she will first look to the housemaid and ask her...Has he passed a stool or not passed a stool? (GP4 P8, L151-52)*

The GPs were of the opinion that the system lacks a mechanism to increase public awareness in this regard and therefore, further work was imperative in this area.

> *"…We do not have programmes that enhance the awareness of parents...in this regard" (GP6 P6, L92-93)*

Additionally, GPs elaborated upon the fact that most of the emotional, cognitive impairments and psychosocial disorders in Oman were often perceived as manifestations controlled by spiritual or supernatural forces, such as hassad (contemptuous envy), sihr (sorcery) or the 'evil eye.'

> *"We know our culture yaani (supernatural power] and again... i.e., black [evil] eye" (GP4 P7, L110-11)*

Healing was thus sought by way of traditional medicines and Quran therapy.

"...They go for the traditional and Quran that...we know our culture" (GP5 P7, L107-08).

"Here are a lot of barriers in implementing screening programs. One of this is a social stigma that parents deny if child diagnosed to have autism. Most of the parents nowadays are sending their children to consult a doctor for immunisation with their relative or housemaids which are not helpful as they don't have enough knowledge/information about child history. Crowdedness and timing is not helpful for the providers as they don't have enough time to elaborate more about patient's condition. They are rushing to see patients due to high demand (max. of 60-70 patients each day). System can also challenge as it measures the effectiveness of the treatment. Waiting time can be triggering the parents to ignore treatments and leave the clinic. Patients' assessments need time for thorough examination. Parents' awareness is major barrier as they are the one to educate in asking care of their children." (Debriefing-notes, GPs group, page 3).

"Social Stigma and Parents Denial are the biggest challenges that the nurses are facing in their area. They cannot do a tough examination of those children who diagnosed to have Autism. Parents keep avoiding medical treatment as they don't believe about their child's condition. Parents' awareness can challenge them as it is important to educate people explaining the importance of vaccination, when they need to go back for follow up, what they are going to do if they manifest any signs and symptoms that are triggeed during the immunisation. Busy Schedule can also challenge them as they don't have enough time to examine patients completely." (Debriefing-notes, Nurses group, page 2).

> *"The main themes that emerged from this groups were time constraints, social stigma, system structure, lack of awareness, and resources." (Summary-notes, GPs group, page 5).*
>
> *"Lack of knowledge about the topic, lack of time, busyness and social stigma seem to be the main themes for this group" (Summary-notes, nurses group, page 4)*

In summary, various barriers at an organisational, professional and social level have been explored within this theme. Practitioners felt overloaded in their role with different tasks and responsibilities to undertake within the short time frame of the consultation. Most felt they had limited experience and confidence to identify developmental abnormalities. The absence of clear protocols to guide current practice, referral procedures and coordinated services, documentation as well as administration, all added to the burden of the PHPs in Oman. Above all, cultural and personal values regarding the perception of health and identifying developmental abnormalities were seen to present a significant challenge to introducing a screening process for ASD in Oman.

5.3.2.4. Preference for data collection tool

This theme "data collection tool" explored what the practitioners believed were the best means to ascertain views about screening for ASD from other nurses and GPs across Oman. It tracks the process of developing the questionnaire.

5.3.2.4.1. Give us a choice but make it short....

When asked about their preference for the type of question format in the questionnaire, both groups expressed a preference for short, closed questions with multiple-choice answers, perceiving this to be quick and easy to complete.

> *"It makes it [the survey] easy when the questions come with choices…like multiple choice…It is easy to fill in and very fast" (GP4 P18, L506-08)*
> *"The hardest questionnaires I ever have to fill in and that I hate to do are those where you just write the answer" (GP3P19, L509-11)*
> *"…So maybe yes or no questions or something too… (Choices)...yeah multiple choice questions, maybe (okay) are easier to fill in. (Nurse 3 P11, L388-90)*

There was some resistance to open-ended questions but preference for ten to 20 questions not exceeding two pages.

> *"Sometimes we feel bored when there are many questions..." (GP2 P19, L535)*

> *"…Maybe not more than two pages (okay), Yanni let's say… ten questions…(ten to 15)" (Nurse 5P11, L355-56)*

They also noted that the answers should be short, not exceeding three lines.

> *"The answer is not supposed to be very long...[no] more than two or three lines each. .." (GP4 P18, L506-08)*

When asked about the content and structure of the questionnaire, the GPs emphasised the importance of ensuring that each subject was kept together in a natural flow. Most of the GPs recommended beginning with an introduction that equipped the participants with the required knowledge prior to completing the questionnaire.

> *"Provide a definition of ASD. Tell them why we are doing this...what the purpose of our survey is" (GP1 P20, L553-56)*

Obtaining some demographic details from the participants to help describe the sample was also seen as important:

> *"at the beginning ask personal questions about the individual completing the questionnaire, like his experience.... how long he has been working as a GP or nurse...the average number of children below five…years he sees on average per day or month?" (GP6 P20, L561-67)*

> *There were suggestions about the content, for example, listing both barriers (GP6 P24, L686)and facilitators (GP3 P24, L689)*

The nurses suggested exploring knowledge of the milestones:

> *"...you can add the abnormal milestones that … expected to be present with ASD ….I think* [they] should be included…" (*Nurse* 2 P13, P458-62)

Both groups thought it is necessary to look at the myths about vaccines causing ASD.

> *"...Alternatively, if there is any relationship between ASD and the vaccination… parents believe that it is related as one of them said maybe it is related to MMR," (Nurse 7 P14, L474)*

Emphasis was also put on the clarity of the questionnaire. They requested a questionnaire with straightforward and clear terms because like them, many other practitioners may be unfamiliar with what ASD is.

> *"…the problem is not about the questionnaire, but how to ask the [participants]…your way of asking the question… [one nurse interrupted: You mean, to clarify the questions?]…Yes in simple words…" (Nurse 5P11, L357-62)*

> *“And define any difficult concepts or signs… so we can know what they are exactly…" (Nurse 1 P11, L383-84)*

Both GPs and nurses felt that the PHPs would need some time to complete the questionnaire. There was a debate about where the participants should fill out the questionnaire, whether at home or in the clinic, to avoid lost and missing questionnaires.

> *"Give enough time to fill in the questionnaire" (Nurse 2 P17, L573)*

> *"distribute it in the clinic from early morning…at the end of the day I will come back to return it...so I feel this is better and when I get the time I will fill it in...but if I take it home I will not bring it back" (GP3 P22, L618-20)*

There was a preference for a paper-based questionnaire rather than an on-line version. This was mainly due to a lack of internet services and inconsistency in checking emails.

> *"...prefer a paper-based questionnaire **[general agreement]**" (Multiple Nurse 1,3,5 P13, L452)*

> *“No, if someone is checking their email every day this is okay...but other people check once a month and so it will be very difficult to do this electronically” (GP1 P22, L615-17)*
> *"...Because the internet is not available at all health centres" (Nurse 6 P13, L453)*

Others felt more comfortable with using a paper questionnaire, as it is easier to access, read and answer compared to the electronic version.

> *“easy to read and answer and...no need to open device or anything” (GP3 P23, L664)*

Using incentives were seen as a way to enhance co-operation for completing the questionnaire:

> *“If we are given a pen or something with the questionnaire …it will motivate them…"(Nurse 1 P12, L424-26)*
> *"If you bring lunch all of them will attend [to fill in the questionnaire]" (GP2 P23, L666)*

This was tempered by ensuring participants are willing to complete the questionnaire and not forced to take part.

> *“Before you give the survey paper to GPs or other health care providers…ask them if they are willing to fill it in or not **[few GPs nods of agreement]**" (GP4 P21, L585-87)*

GPs believed that completing the questionnaire had nothing to do with interest, but was part of their job description and therefore it should be completed.

> *"…During my work, within my job description, I should not consider whether it is a matter of interest or consider it to be optional" (GP5 P28, L647-49)*

Participants suggested putting a value on the questionnaire by introducing potential participants to the topic and explaining to them the importance of their opinion.

> *"Maybe you can meet the people whom you want...you just ask for a ten-minute meeting…just to introduce the themes of your work that...and they can get an idea so that it is not just a paper to fill in..." (GP6 P22, L638-40)*

In acknowledging the difficulty of introducing the questionnaire to each health institution in the country, appointing a focal point of contact in each health centre was proposed:

> *"I think this is difficult…you cannot visit all the health centres...all institutions in Oman; you need more staff, more people working; this is very difficult..." (GP5 P23, L643-46)*

> *"Maybe you could get from each health centre a focal point for you…and you would contact them personally" (GP3 P23, L672-73)*

In contrast, the nurses voiced a preference for the questionnaire to be formulated in such a way as to not make participants feel that they were being tested. They also suggested equipping participants with the required information prior to asking them to complete the survey.

> *"…maybe they first need, before completing the questionnaire, to give…brief…information about ASD, signs, symptoms or…tell them to refer or to read about it…then they will have an overview of it…" (Nurse 5 P12, L400-04)*

At the end of each FG, all of the participants were asked if they had any further suggestions. All of the participants agreed that it would be useful to survey outside of primary care.

> *"…Can you make any survey for the secondary hospital for ASD…particularly from a paediatric clinic in the secondary care level" (GP5 P30, L882-84)*

The GPs wanted questions to be included that enabled the researcher to gain an insight into each clinician's awareness of the registry and referral processes for suspected ASD cases.

> *"…How many cases diagnosed with ASD or ASD are picked up by primary care health centres?" (GP4 P30, L893-95)*

In contrast, the nurses suggested asking questions about the preferred amount of time needed to screen children for ASD at the time of their consultation, and revising the age of the well visit check for the psychological assessment.

> *"…[ASD screening] may be done routinely when the child… comes to seek…any health consultation…I think we also…*

need to increase [psychological assessment] maybe for children up to 12 years…" (Nurse 3 P7, L227-30.

"GPs suggested that the questionnaire must be simple and short by using multiple choices. It should be well designed, categorised and organised. Maximum of 10 to 15 questions. Willingness to respond must be considered. Must have introduction stating the subject and purpose. Should include personal details in the beginning (participants' experiences, position, etc..), time consideration to finish answering the questionnaire." (Debriefing-notes, GPs group, page 4).

"For nurses, they preferred questionnaire to be paper based. It should be short format and language simple, no scientific words, answerable by true or false, more comfortable to answer multiple choice with easy options, not exceed 2 pages with 10-15 questions only." (Debriefing-notes, Nurses group, page 3).

In summary, the participants preferred to have a clear, simple, short, paper-based questionnaire with closed-ended questions. They also wanted the time that the participants spent filling in the questionnaire to be appreciated and for them not to be forced to complete it. The introduction of focal contact points to distribute the questionnaire and answer participants' concerns was found to be a useful point to consider, as was surveying secondary level and triage settings.

5.3.2.5. Strategies to facilitate the screening

This theme sought to explore the suggested strategies to overcome past challenges and facilitate the implementation of ASD screening, such as increasing awareness, and making improvements to organisational structure and service coordination.

5.3.2.5.1. Increasing awareness

To overcome the challenges of introducing a screening programme, the majority of participants suggested enhancing public and professional awareness.

"We need to increase more and more what is called (awareness...) of parents about the disorder" (GP5 P5, L41-42)

"Educate the parents and those who are…taking care of the child of the signs and symptoms that...tell them to bring the child or the child has something wrong" (Nurse 3 P8, L316

317)

> *"Increase awareness by way of healthcare providers (Nurses, doctors, health educators, medical orderlies) and others (teachers, the media)" (GP6 P6, L84-86)*

They believed that such a step might help to reduce the cultural stigma and sensitivity towards ASD screening in the community. It would also help to facilitate parental co-operation in identifying developmental abnormalities earlier.

> *"…maybe awareness regarding ASD would reduce stigma, it is very important…" (GP2P14, L366-67)*

> *"Parents should be made aware of the symptoms of delay, delayed development during the... this period of two months to 18 months (GP3 P5, L66-69)*

In addition, the nurses suggested other ways to improve parental awareness, such as preparing a pamphlet about the signs and symptoms of ASD:

> *"…it would be good to create a pamphlet about the signs… symptoms…this will help staff and mothers to know if the… the child has ASD or not.…Like the Glucose-6-phosphate dehydrogenase (G6PD)…leaflet about the signs and symptoms and its preventive measures…" (Nurse 5 P9, L321-26)*

> *"There is…a TV channel called Al-Hayat…It is showing a series of episodes about ASD…This will be helpful…" (Nurse 6 P9, L346-50)*

GPs also highlighted that TV, radio, social media and educational institutions such as schools, if equipped with the correct information, could play a significant role in advancing community awareness of ASD.

> *"Not just important in the health sector, but even in the education sector or anything we can get in the media [one GP interrupted: such as school]…we can transfer the message (to the community)". (GP4 P6, L87-89)*

Both groups believed that in terms of enhancing outcomes and acceptability, reducing the effects of stigma in the community was important.

> *"…We have to remove this stigma…mothers cannot be shy… about ASD" (Nurse 5 P16, L581-82)*

It was felt that this might encourage parents, especially mothers, to report any concerns regarding their child's development at the well check visit,

> *"Also, we need a reminder [from mothers]... we need a reminder (reporting abnormal signs...)" (GP8 P16, L427-428)*

5.3.2.5.2. **Improve the current organisational structure**

With regard to accommodating ASD screening, GPs were more vocal in proposing improvements to the current PHC setting structure. A major change proposed was to allocate an specific timeframe on a specific day or afternoon in which to screen the children:

> *" we should have a specific day and specific hours just to see children, even those with just a common cold, but we need more time for each child – at least half an hour – just to take the history, and if he is fine that is it…" (GP4 P13, L322-324)*
>
> *"More time is needed by us to examine and by the nurse, the mother, the parents, or the caregivers to report us the symptoms [behavioural abnormality] that the child exhibited …" (GP6 P12, L285-89)*

Conversely, others believed allocating a place and time just for screening ASD would stigmatise the clinic and discourage parents from attending.

> *"Considering the social stigma you mentioned earlier, no one will come" (GP5 P14, L350)*

The preference was to integrate the screening programme within the current system, using protocols for children under two years such as a modified version of the current 'well check visit checklist' to include specific questions on ASD in a paper and/or electronic form.

> *"Some questions like that for assessment for ASD…for screening, psychological assessment…included in the computer…the doctor…should see this check and determine whether the child is normal or abnormal" (GP5P16, L443-47)*

One GP shared their experience.

> *"In Muscat but not Sur, they have separate rooms for vaccinations…this room has a staff nurse plus a doctor...the child will come with an appointment…be weighed and measured and, at the same time, the doctor will see...and examine the child and give the vaccination in the same room, the same place..." (GP6 P10, L212-19).*

Within this, the issue of a longer time frame in which to assess children was again raised. Similarly, coordination of the primary level and diagnostic services alongside a clear protocol were also seen to be needed. If this was in place, participants believed that it could enhance diagnostic skills.

> *"…If there is a connection between the systems; we know that out of each five suspected cases one will be diagnosed with ASD…we are aware exactly of the red flag signs that show ASD" (GP4 P28, L819-21)*

They also recommended providing specific training on ASD for both GPs and nurses. Both groups felt that with adequate training and knowledge, staff would be equipped to facilitate the early identification of children with developmental delay and ASD.

> *"…We need more education and more knowledge on how to screen and identify any abnormal milestones that may predict that this child has ASD…" (Nurse 7 P8, L238-40)*

> *"Nurses should undergo additional training to enable them to pick up any symptoms that are abnormal symptoms..." (GP5 P12, L272-74)*

GPs also suggested a red flag system where reaching a certain criteria of symptoms would trigger a referral process for further investigation and support the diagnosis procedure.

> *"For some surgical cases, like an umbilical hernia, for example, we do not refer directly. We [wait] until the age of one year. If there is no resolution, you have to refer directly…In this case, we have to follow up at each vaccination visit....So like in this surgical case, you have to follow up, so it is dependent on the situation. …"(GP1 P25, L733-740).*

"To overcome the challenges, GPs suggested attending different workshops, training, seminars and any other topics related to identifying cases with autism. Immunisation strictly recognised and implemented (use of pink card). Giving enough time to each patient for precise and specific treatments. GPs to use acceptable words in dealing with parents' use of checklist and assessments questions for milestone monitoring, improvement of protocols, provide more resources and facilities, and educate parents for appropriate intervention." (Debriefing-notes, GPs group, page 3).

> *"To overcome the challenges, nurses suggested educating and instructing parents, relatives and caregivers in observing any signs and symptoms of their child's condition. To distribute leaflets and strictly follow the pink card. To seek follow-up treatment from time to time. To confront parents for those children who diagnosed as having autism. Also, they suggested using TV channels to give family members more information about autism or any related issues. Giving health education about autism similar to the current running education programme such as G6PD screening and the importance of breastfeeding." (Debriefing-notes, Nurses group, page 2).*
>
> *"Nurses also suggested attending training, seminars and workshops to gain more knowledge about several topics of autism." (Debriefing-notes, Nurses group, page 3).*

Summary

Various approaches were suggested to facilitate the implementation of a smooth and culturally acceptable screening programme for ASD in Oman. Much of this focused on increasing public and professional awareness, improving organisational structure and service coordination.

5.4. Chapter summary

The views of PHPs on the facilitators of and barriers to screening for ASD within PHC settings in Oman were sought using a FG approach. The perceptions of PHPs in connection to developing a questionnaire, identifying the potential barriers and facilitators of screening for ASD within current practice, as well as possible problem-solving strategies, were uncovered.

Both groups were positive about introducing screening but felt they lacked the knowledge and skills necessary to undertake this. They were also concerned about the current organisational structure, and the lack of infrastructure and service co-ordination to support those identified with problems. The responses gathered also indicated varying degrees of awareness of the referral system and availability of ASD services in Oman. Stigma and other cultural factors were seen as the main barriers to the successful introduction of ASD

screening. Certainly, any such introduction would necessitate adequate training and knowledge about ASD for practitioners, alongside public awareness campaigns to reduce stigma and encourage greater up-take from parents.

Of the five themes that emerged from this study, four were instrumental in formulating the survey content, whilst the final one has informed the structure of the study. The findings of this chapter provided valuable information to enable the construction of a questionnaire aimed at exploring the facilitators of and barriers to screening for ASD within the PHC setting in Oman.

Chapter 6: Constructing and Testing the Questionnaire

6.1. Introduction

As explained in Chapter 4, the FG discussion alluded to five dominant themes: ASD identification, barriers, facilitators, strategies to facilitate screening and preferences for developing the questionnaire instrument. These themes enabled the researcher to build a questionnaire to explore the facilitators of and barriers to screening for ASD, within the PHC setting in Oman. It also informed decisions about the distribution of the questionnaire. This chapter describes the process of questionnaire construction and pre-testing, as well as the quality of the questionnaire; it identifies the instruments used in its development and explains the methods of distribution of the questionnaire.

6.2. Questionnaire development procedure

The primary goal of the study was to identify any barriers to screening that might be faced by health centres across Oman and the recognition of potential facilitators. Hence, a questionnaire was developed to capture this information. Developing a rigorous questionnaire is a challenging task that requires time, expertise, and guiding frameworks throughout (Slavec and Drnovsek, 2012). Therefore, the process of questionnaire development and the decisions made are detailed in the following sections.

The framework guiding the development of the study questionnaire was adapted from a recent review by Slavec and Drnovsek (2012). This review investigated the eight most common recommendations for creating a new measure, and proposed a model with ten steps in three phases, see Figure 6.1.

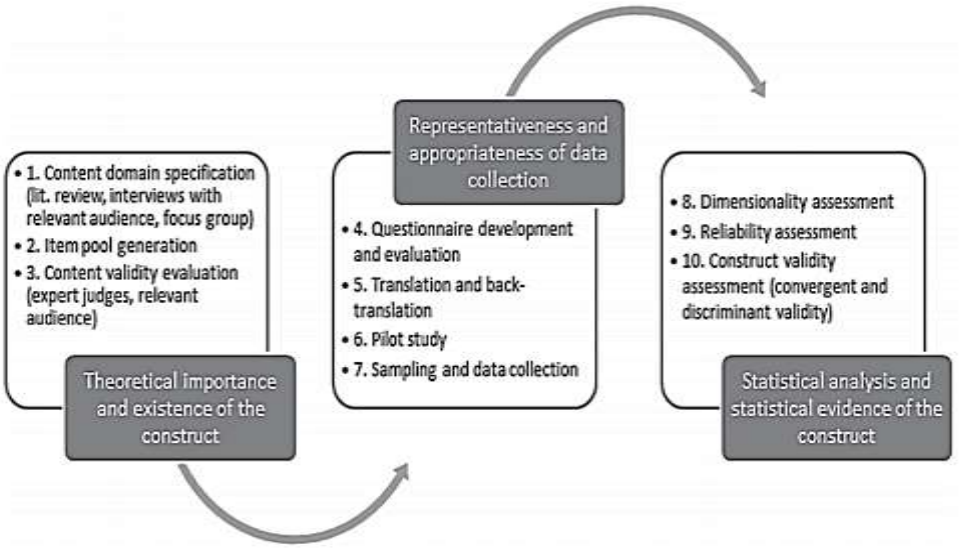


Figure 6-1 Slavec and Drnovsek (2012) proposed steps and phases for developing new measures.*This figure is adopted from (Slavec and Drnovsek, 2012)*

The present study considered using most of the steps allocated in the three phases, except step 6, because translation was not required for this research. As shown in the above diagram, phase one concentrates on the theoretical importance and existence of the construct, if it is available. The second phase focuses on the representativeness and appropriateness of data collection. Phase three includes statistical analysis and the statistical evidence of the construct. The following section will elaborate on how each of these phases was implemented in the process of developing the questionnaire.

6.3. Theoretical importance and construct development

According to Slavec and Drnovsek (2012), this phase concentrates on theoretical explanations for the developed contents (i.e. constructs, dimensions and scale), the developed items and the degree to which the elements of a measurement instrument (i.e. items, response formats and instructions) are relevant to and representative to what the researcher intends to measure. All of these steps are detailed in the following sections.

6.3.1 Content domain specification

Identifying what the researcher intends to measure is considered the first integral step in developing a new measure. Slavec and Drnovsek, (2012) suggest this involves exploring the theoretical construct of the new measure and its dimensions, through a detailed and thorough literature review, and interviewing relevant individuals or conducting focus groups. Additionally, researchers should provide an explanation of how the developed construct is

different from other existing or related constructs and define the developed constructs that were modified during the scale development process (Slavec and Drnovsek, 2012).

As explained in previous chapters, reviewing the literature identified a few barriers to screening for ASD and very few had been sufficiently examined or presented for the study context (i.e Oman). Due to the absence of a valid questionnaire examining the barriers to and facilitators of screening for ASD, and the limited information on this area, the researcher decided to conduct focus groups (FGs). One of the aims of the FGs was to explore the participants' preferences for a survey questionnaire and to explore relevant constructs related to barriers/facilitators of screening for ASD in Oman. Data from the FG discussions as well as the literature review on ASD screening barriers/facilitators were used to create the theoretical basis for developing the constructs and dimensions, before proceeding with the questionnaire (Slavec and Drnovsek, 2012, Netemeyer et al., 2003, DeVellis, 2003). For example, as documented in Chapter 5, the FG analysis identified five themes that were conceptually divided into two categories: 1. those that underpinned the questionnaire contents and 2. those that informed the methods of the developed questionnaire (i.e. formats, question type, method of distribution, length) (see Figure 6-2).

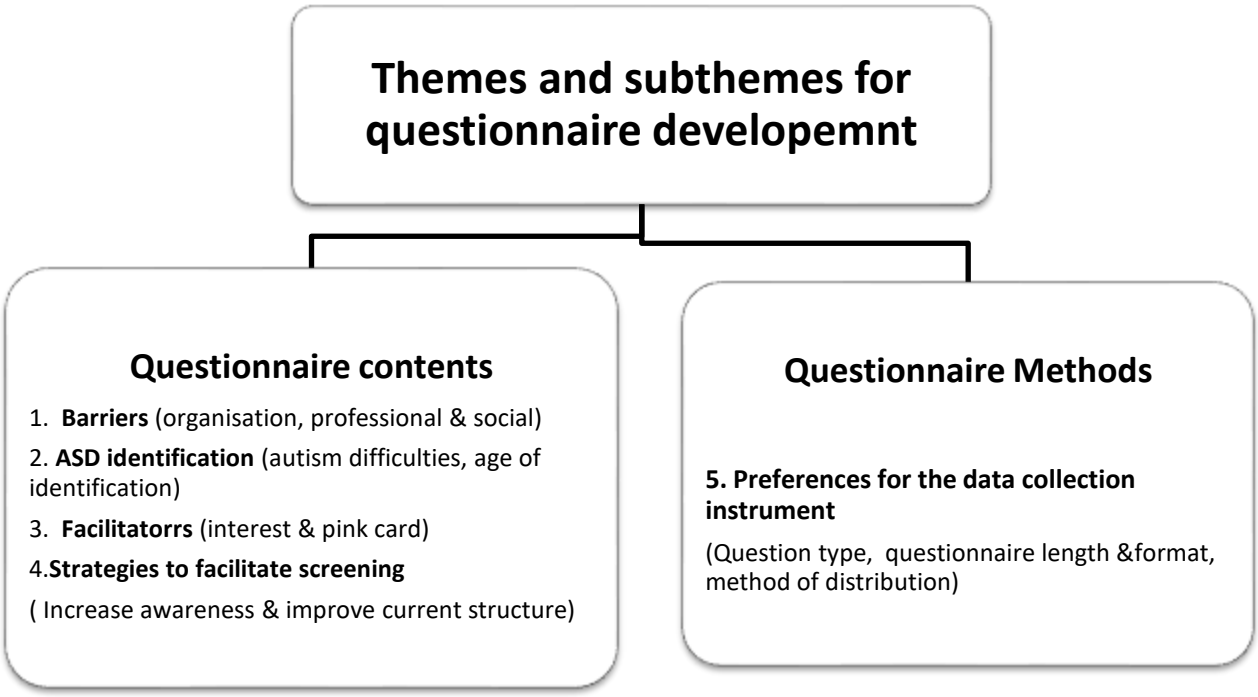


Figure 6-2: Classification of the dominant themes from the focus groups

From the content, two constructs (barriers and facilitators) that met the study's aim were selected to inform the questionnaire scales. The barrier scale was intended to measure the

challenges and obstacles that PHPs perceive when screening for ASD, within their current practice. However, the facilitators measured the participants' opinions on what they viewed as enablers for screening for ASD. The dimensions used to measure each scale were derived from the qualitative data set. For example, the barrier scale was measured through three dimensions (i.e. organisational, professional and social). These dimensions represent the sub-themes of the barrier construct (see Chapter 5, section 5.3.2.3). In addition, other difficulties and obstacles that emerged from other themes, such as ASD identification (theme 3), were incorporated within this scale. For further details, see Appendix 16. Similarly, the facilitators' scale presented two dimensions: interest and pink card, in addition to the data that emerged from the strategies put forward to facilitate screening (theme 4). As a result, the two scales presented in the questionnaire highlighted the barriers and facilitators. The former included three-dimensional organisational, professional, and social questions, intended to measure the potential challenges to screening, while the latter involved both two dimensional facilitators and changes to facilitate screening (see Appendix 16).

6.3.2 Items generation

After specifying the scale domain and defining the purpose of the construct, it became essential to generate a large pool of items for potential inclusion in the scale. To achieve this, phrases from verbatim quotes from the transcript for each theme were read thoroughly and noted, to capture the new construct domain. Then, question statements relevant to each theme and associated quotation were developed. This process was undertaken to ensure appropriate wording and to preserve the sense of the original statement that expressed the ideas of the PHPs on the topic. For example, from the quotation below, the researcher took the phrases and developed the rating question ***'I think parents would visit the health agencies to treat their child's sickness rather than to screen for behavioural abnormalities.'***

> *"I think parents do not like to come to the hospital unless… their children…are sick, they will not bring them for screening or anything extracurricular..." (GP6, L283-85)*

Only quotations that had frequent occurrences were selected. Although this meant that some contents did not form part of the questionnaire items, this decision was made to ensure that the questionnaire items would answer the research questions (barriers and facilitators for screening) in the qualitative data sets. This also meant that the questionnaire remained as short as possible and measured only the most salient constructs from the qualitative data sets. The remaining, less numerous quotes, were also addressed by combining them with the major constructs or presenting them within the demographic data sections. A table describing

how the qualitative findings corresponded with each questionnaire statement can be found in Appendix 18.

Once the stage discussed above was completed, each statement was revisited, to ensure that the developed items reflected the aims and were simple, clear and specific (Oppenheim, 2001). Care was also given to avoid unnecessary duplication of questions, to limit the length of the questionnaire and make it easier to administer. Brevity was in keeping with the FG theme instrument preference, in that it was seen to encourage participation and enhance completion of the questionnaire. The researcher acknowledges that a larger questionnaire might have provided more information, leading to a better understanding of the phenomenon and a better instrument quality for some sensitive topics (Boynton and Greenhalgh, 2004). Despite this, the researcher wanted to stay true to the advice given in the FG, especially as the participants, while enthusiastic about the study, emphasised that they had larger roles to play and may not have been able to allocate much time to answering the questionnaire. A shorter questionnaire also helped to reduce questionnaire fatigue; long questionnaires become labour intensive and can encourage participants to answer haphazardly in order to end the process (Maloney, Grawitch, & Barber, 2011). A mixture of both positive and negative items was included in the questionnaire to minimise the danger of bias and of participants responding in the same way to different items (Williams, 2003).

6.3.3 Questionnaire responses and layout

It was also important to consider the layout of the questionnaire and the relevance of the participants' responses. This fell under the third step of content validity and evaluation; the responses, formats and instructions for the measurements proposed needed to be clear, relevant and representative (Slavec and Drnovsek, 2012). Consulting the preferences for the data collection instrument category (see Chapter 5, section 5.3.2.4) and the literature regarding questionnaire development (Rattray and Jones, 2007, Boynton and Greenhalgh, 2004), a closed-question approach was adopted in this questionnaire. This was because closed questions were quicker to complete, and therefore help to accommodate busy PHC professionals (Williams et al., 2013). Often, responses for closed-ended questions can be presented as simple yes/no choices or ticking multiple boxes; alternatively, subjects may be requested to rank choices in order of preference or to complete a scale (Fowler Jr, 2013, Williams, 2003).

Despite their popularity, closed questions are criticised for restricting the depth of a respondent's response, and thus the quality of the data collected, may be seen to be diminished or incomplete (Rattray and Jones, 2007). However, in the present study, this was not a concern, as the barriers to and facilitators of ASD screening were qualitatively explored in phase 1. In addition, a free text response was provided at the end of each section in the questionnaire, allow participants to expand upon their answers in more depth.

Besides considering the type of question to ask, it is also important to be clear on the type of scale and response that should be used, prior to developing the questionnaire. This is because there are a range of scales and response styles available, and each one results in different types or levels of data, which in turn influence the analysis options (Rattray and Jones, 2007). The most common type of scale is the summated rating scale, which is also known as the Likert scale. There is also the equal interval scale, referred to as the Thurstone scale, and the cumulative scale, referred to as the Guttman scale (Streiner et al., 2015).

According to Rattray and Jones (2007), summated scales are considered when establishing how often a target behaviour or event has occurred, while Thurstone scales use empirical data derived from judges, to ensure that measured attitudes or behaviours are spaced along a continuum, with equal weighting/spacing. However, the Guttman scale is a hierarchical cumulative scaling technique that shows a one-dimensional continuum for the measured concept. Agreement in one item on this scale implies agreement in items of a lower rank.

In this study, a Likert scale was chosen for its straightforwardness, speed of construction and administration, as well as its ease in coding, its extensive use in gauging attitudes or opinion and its high reliability when using fewer items (Streiner et al., 2015). This ordinal scale makes the assumption that attitudes/opinions can be measured through a fixed choice response, ranging from four to ten (Chang, 1994), with the neutral point being 'neither agreeing nor disagreeing' (Dawes, 2008). However, the use of this scale is controversial with regard to the response range, the inclusion of neutral points and the analysis; these points need to be addressed with caution when developing the questionnaire. Researchers have explored adapting the response range and have suggested that providing a greater number or variety of responses/options would be useful for participants and would, in turn, increase the probability of meeting the objectives (Joshi et al., 2015, Chang, 1994). Others advocate more format options (e.g. a 7-point scale) to improve the reliability of the instrument and to increase validity and the response rate (Ogbonna and Harris, 2000, Churchill Jr and Peter, 1984). However, other researchers argue for having fewer response options (e.g. a 5-point

scale), assuming that this would be less confusing and increase response rates (Bouranta et al., 2009). It would also be simpler for the interviewer to read out the complete list of scale descriptors (‘1 equals strongly disagree, two equals disagree …’) (Dawes, 2008). Based on the latter recommendation, a 5-point scale was adopted for the present study questionnaire.

The inclusion of the neutral point was debated and the researcher eventually decided to omit this option, considering that a neutral point category could result in participants being non-committal, which may be perceived as having no value to the research (Losby and Wetmore, 2012, Tsang, 2012). However, some scholars have indicated that removing this option might force respondents to choose a response, thus leading to irritation and thereby increasing the non-response bias (Losby and Wetmore, 2012, Rattray and Jones, 2007). Nevertheless, the researcher decided that the removal of a neutral response would benefit the analysis, as it would provide a more definitive gauge of the barriers assessed in the study. The researcher also assumed that even with the absence of neutral points, participants could leave the question unanswered if they did not feel able to commit to an answer. This resulted in a 4-point scale for the present questionnaire: Strongly Disagree, Disagree, Agree and Strongly Agree.

Analysing the Likert scale highlighted another controversial point, namely whether the Likert scale data would result in the production of an ordinal or interval scale. Some scholars assume that Likert items cannot produce interval scales, and should therefore be considered as ordinal scales and analysed accordingly (Subedi, 2016). Others argue that Likert items can produce interval scales and therefore suggest that parametric tests are conducted (Carifio and Perla, 2007). The data from this questionnaire were treated on an ordinal scale and analysed using non-parametric tests. This was undertaken on the assumption that the researcher’s primary interest was to capture the feelings and pragmatic opinions of the PHPs regarding mutually exclusive challenges and the potential for ASD screening. In this case the scale used was referred to as a Likert type and individual items were analysed to ascertain the participants’ collective level of agreement on this issue (Joshi et al., 2015). Further details addressing this controversial view are discussed later in Chapter 7, section 7.3.

In addition to the Likert scale, a ranking order question was introduced in section five to capture the participants' opinions of the most necessary changes required to facilitate screening, as this could not be assumed using the Likert scale. According to Polit and Beck (2004), this type of question is useful for providing a clearer insight into what is important to the participants, and therefore what is required in order to help make improvements, based

on their preferences. As this is an ordinal scale, ranking each question does not provide the distance between each level of importance. However, this is not a concern in the present study, as the data were analysed for each individual item using percentage and frequency. Polit and Beck (2004) also cautioned against ranking more than ten alternatives, to avoid misunderstandings and fatigue. Therefore, eight alternatives were proposed for this question.

The layout and formatting of the questionnaire was another area that Slavec and Drnovsek (2012) suggested the researcher should consider carefully with regard to clarity and appropriateness. The questionnaire used in the present study was reviewed for its appropriateness and clarified with the supervisor (CM) in order to facilitate data coding and analysis at a later stage. For example, the questionnaire was divided into various sections and each question was numbered, e.g. A1–7; B1–8, etc. Each question was separated from the next with a black line, to help to make the questionnaire clear to read and to denote the end of that question. Clear and specific instructions were provided on a sheet at the top of the questionnaire, so that the subjects could navigate their way through the questions. A bold script was also used to highlight each section and response range on each page. The questionnaire was printed in colour on good-quality paper. This was to ensure that answers were not influenced by reading questions through the paper (Williams, 2003). Furthermore, the quality of paper has been shown to give the impression of a significant and well-funded study, further aiding participation (Williams, 2003).

6.4. Representativeness and appropriateness of the questionnaire

Developing a questionnaire involves testing the level at which the elements of a measurement instrument (e.g. items, response formats and instructions) are relevant to and representative of the targeted constructs for a particular assessment aim (Slavec and Drnovsek, 2012, Haynes et al., 1995). It also requires the researcher to keep in mind whether the instrument accurately measures what it is supposed to measure (validity) and exhibits consistency and stability in its responses (reliability) (Frazer and Lawley, 2000).

Two steps were undertaken to validate this questionnaire – expert examination and piloting. The first step involved three supervisors, two from the Edinburgh Napier University(DW), University of Glasgow (CM) and form Sultan Qaboos University (YAF). All were expert on ASD and questionnaire development. Thus, all of the questionnaire items, responses and

instruction formats were reviewed by them, to check for the face and content validity for the end user (DeVellis, 2003).

Initially, the questionnaire was reviewed by the supervisors DW and CM independently. The researcher met with the supervisors on several occasions, individually and together, to discuss the questions and make changes regarding the wording, ordering, structure, response alternatives to questions and navigational rules of the questionnaire. Their suggestions aimed to improve the content, and the cognitive and usability standards of the questionnaire. For example, neutral points ***'Neither agree nor disagree"*** were omitted, more negative items were added, duplicated items were removed, and a few words were changed, for a clearer question. For example, the statement ***"Our institution is too crowded with the number of patients and provided programmes"*** was changed to ***"our institution is seeing the maximum number of patients each day."***

Once the final changes from these discussions had been made, it was useful for a local supervisor and researcher from Oman (YAF), with a medical background and experience in ASD, to see the questionnaire. Moreover, the questionnaire was sent to RAW, an experienced qualitative researcher, with a background in nursing, working in Oman. After reviewing the questionnaire, they provided feedback on what they believed the proposed questionnaire appropriately measured, what it was intended for and whether it was clear and culturally sensitive.

Once the ethical approval for the study had been gained (see Chapter 4, section 4.4), the questionnaire was piloted on a volunteer sub-sample from both FGs (4 GPs and 3 Nurses). They were asked to give feedback on the content and clarity of the questionnaire, the time needed to complete it, and its logical flow. Participants reported that the questionnaire reflected their view of the FGs, was easy to read and could be completed within 5 to 10 minutes. There was one exception: one GP thought that the questionnaire was long and might need more than 17 minutes to complete, especially for those who were reading it for the first time.

Feedback from the pilot work resulted in minor amendments, mainly rewording a few items. For example, "***I had not encountered a child with ASD within my practice before",*** was modified to ***"I have identified a child with ASD previously."*** Another item was not fully understood by the participants: ***"Propose culturally accepted term for ASD would encourage the acceptance of ASD screening".*** The question was reworded to

"At the time of screening, using a more general term instead of "Al-Tawhid" might increase the uptake of screening for ASD." The piloting of the questionnaire and the consideration of the corrections from the pilot work also fulfilled the third step of developing this questionnaire.

6.5. Statistical analysis and statistical evidence of the construct

As discussed in Chapter 4 section 4.9.2.2, internal reliability was measured in this study. This was done by using Cronbach's alpha, which is considered to be one of the most widely recognised methods for determining the internal reliability measure. It examines the average correlation between each item in the measure and every other item (Krabbe, 2017).

In this study, Cronbach's alpha was calculated for each dimension in the questionnaire (see Table 6-1).

Table 6-1 Cronbach Alpha for the questionnaire dimensions

Questionnaire's Dimensions	***Cronbach's alpha***
Organisational Barriers	*0.371*
Professional Barriers	*0.697*
Social Barriers	*0.658*
Facilitators	***0.859*
Total	**0.780*
****Acceptable Cronbach alpha***	*0.70*
*****Good Cronbach alpha***	*0.8*

According to Nunnally and Bernstein (1994, cited by Krabbe (2017), a reliability coefficient of 0.80 is considered sufficient in the initial stages of developing a measure. However, some researchers have stressed the need to set higher standards for reliability. Others have said that in the case of Cronbach's α, coefficients between 0.7 and 0.9 are usually acceptable, as >0.9 implies some possible redundancy of values. The scope of this questionnaire has demonstrated acceptable internal consistencies, which were estimated by Cronbach's alpha to be 0.780 (i.e. barriers, 0.692 and facilitators, 0.859). In the questionnaire, the internal consistency estimates ranged from -0.181 to 0.745, with a mean of 0.115. Some of the reliability estimates were lower than 0.70, which the developers attributed to the heterogeneous nature of the items in the barrier subscales, such as time constraints, staff shortages, deficits in resources, and lack of protocols.

6.6. The developed questionnaire

Eventually, a 38-item questionnaire comprising of six sections was developed. The first part of the questionnaire included nine items concerning the participants' demographics such as age, qualification and years of experience. The second, third and fourth sections included six to ten items exploring the barriers to screening for ASD under three areas (organisational, professional and social). Sections 4 and 5 investigated the facilitators for screening for ASD. See Appendix 19 for the completed questionnaire.

6.7. Assistant researchers' recruitment and preparation

As discussed in Chapter 5 section 5.3.2.4.1, participants perceived initial in-person invitations (i.e. via phone calls or meetings) to take part in the research project is better than sending a postal questionnaire as it gives value to the study project and allows immediate clarifications. Recognising the difficulties in terms of the time and resources needed for in-person invitations across a large country like Oman, participants from the FGs suggested appointing a "focal contact point" or a research assistant (RA) from each governorate. Their main role would be to invite respondents randomly from their areas by phone, and then to send the study questionnaire with the instruction sheet through the MoH post to the invited health centres. After that they would collect the returned questionnaires(usually posted on) and then send them to the researcher.

Having RAs facilitated valuable invitations and potentially enabled faster data collection procedure across the country, which ultimately may encourage participation. For that reason, the researcher made initial contact with the authorities of the Expanded Program on Immunisation (EPI), seeking advice on recruiting RAs to advertise, distribute, and collect the questionnaire. The authorities suggested 11 nurses, each one representing one governorate. All 11 nurses worked as focal points for the EPI program and liaised between the MoH and the EPI staff in the health centres to keep both parties updated and to maintain reports. The researcher contacted each one by telephone, seeking their assistance for inviting, distributing and collecting the research questionnaire from their regions. Of the 11 approached, four declined due to other obligations, but recommended some of their colleagues who might be interested and all eventually accepted.

During recruitment, the nurses raised concerns about their lack of knowledge about ASD and the sensitivity of the topic and they requested some training to equip them with

information. They believed this would prepare them to answer the queries of the potential participants and enhance their role as research assistants; hence the researcher organised an orientation day.

A five-hour orientation programme was developed to equip the RAs with the information needed to fulfil their duties for this study (see Appendix 20). The programme for the day was discussed with DW, who made suggestions such as developing a list to summarise the RAs' role. The programme was designed to give an overview of ASD, identify literature and, as requested by the nurses, two parents who had children with ASD came to speak. It also familiarised the RAs with the study and survey questionnaire, and gave them training in terms of distributing and collecting the questionnaire. At the end of the programme, the RAs were able to raise any concerns related to the role, and to discuss solutions to overcome these. Afterwards, each RA received a package containing the research questionnaire and an information sheet, with a list that elaborated their role as an RA and provided the researcher's contact information. It is worth noting that the RAs were very keen to continue the discussion with the parents at the end, raising questions related to their experience with the diagnostic and therapeutic services that provided care for their children. Hence, the programme was extended for one and a half hours for this purpose. Both parents and RAs found the programme useful and informative and the RAs were especially appreciative of the parents' efforts and involvement within the programme. This step was useful as the RAs were then able to explain the topic of the questionnaire to potential participants in person, adding value to the questionnaire and increasing participation.

6.8. Chapter summary

The five themes that emerged from the FG discussions were used to inform the development of the questionnaire regarding its content and structure. The final questionnaire was developed and comprised 38 items, which explored the potential barriers to and facilitators of screening for ASD. The questionnaire was piloted on a sub-sample from both FGs and some amendments were then made. To facilitate the distribution of the questionnaires, RAs were recruited from 11 governorates. They were also given an orientation programme to equip them with the required knowledge and skills to distribute and collect the questionnaires.

Chapter 7: **Phase 2, the Quantitative Phase**

7.1. **Introduction**

A questionnaire is a powerful tool that may be employed to answer many questions. The developed questionnaire from Chapter 5 was used to answer the research questions in phase 2 of this study. This chapter, therefore, will focus on describing the procedure that was undertaken in order to collect, manage, analyse, and report the questionnaire.

7.2. **Methods: materials and process**

7.2.1 **The data collection tool**

As explained in Chapter 6, a structured questionnaire was developed for use in the present study. The questionnaire included 23 questions and covered the demographic details of the respondents (for example gender, age and nationality); it also included questions that represented workload, such as the approximate numbers of patients seen per day, the number of staff per shift and the numbers of programmes that are run by each institution. The remaining sections concentrated on the barriers to screening, (organisational, professional and social barriers). The questionnaire attempted to measure the type of barriers that might constrain ASD screening within the PHC settings in Oman.

To enhance the questionnaire, a further two sections were developed. The section on facilitators consisted of eight questions using a four-point Likert-type scale on the potential for screening for ASD in Oman. The final section was a 'prioritising' question that included eight items and the respondents had to rate the three most necessary changes that might facilitate screening within their current practise. At the end of each section, a free text response was provided to capture the respondents' opinions and give them the opportunity to expand their opinions about that section.

7.2.2 **The sample and the study site**

As mentioned in section 4.7.2 earlier, this study aimed to recruit a potential of 572 respondents randomly selected from GPs and registered nurses who worked in the Ministry of Health PHC centres across Oman. To be included in the study, the respondents were required to have a minimum of two years' experience in PHC. This criterion ensured that

the respondents had completed their internship programmes and had experience in PHC activities and service requirements.

7.2.3 Ethical considerations

As explained in Chapter 6 section 6.9, all of the respondents were invited to participate in the study by a trained RA. Consent to participate was assumed when the respondent completed and returned the questionnaire. There were no direct risks to the respondents, other than an inability to answer the questionnaire, and if this happened the respondents could skip the question or contact the RA. Confidentiality and the anonymity of the respondents were maintained as there was no information that could identify the participants; furthermore, the returned questionnaire was given a unique identification code. This also facilitated the data analysis. The returned questionnaires were stored in sealed envelopes in a secure cabinet in the researcher's office at the University of Glasgow for security and after 10 years all forms and all other relevant documents will be destroyed in order to comply with the University of Glasgow's policy on "data management and support for researchers" (The University of Glasgow, 2016).

7.2.4 Recruitment and data collection process

Recruitment for this study involved the use of a systematic random sampling technique, as explained in the method chapter, section 4.7.2. Research assistants randomly selected the required number of respondents from their individual governorate. Then, each RA invited him/her by phone to participate in this study. If the respondents showed an interest in being involved, the RA would send the questionnaire package to their health centre. The package included the study questionnaire and the questionnaire's instruction sheet, which clearly explained what was required of them and what the study was about, as well as who to contact for further clarification (Appendix 21). It also informed respondents that the questionnaire would take approximately 10-15 minutes to complete and that there was no consent form, as the return of the questionnaire was considered to constitute consent for the respondents in the study. Those respondents who were interested in the study could complete the form and send it back to the RA through the MOH postal service, preferably within two weeks. If the respondents declined or did not send the questionnaire back within a month, then the RA would randomly select and invite another respondent for the study, in order to maintain the required number of respondents for each governorate.

During the recruitment process, potential respondents in some health centres did not receive the questionnaire or they missed it. Therefore, RAs sent them another package. Two rural

governorate health centres asked why they were excluded from the study and insisted on participation. Despite explanations from the RAs that respondents were selected randomly and not based on their centre's location, personnel from these health centres called the researcher and requested to share their views on this study. For example, calculations undertaken for Musandam governorate sampling (see section 4.7.2) suggested that eight nurses and four GPs were required to participate. However, based on a number of requests, nine nurses and six GPs for this governorate were included in the study. In contrast, RAs from urban areas such as Muscat reported many who declined to participate (n=44) and failed to recruit the required number of respondents. Furthermore, some of the returned questionnaires were found to have been completed by practitioners other than GPs and nurses, such as lab and X-ray technicians (n=26), who were not targeted in this study. To address this, two further weeks were allocated to recruit more respondents and maintain the required number for this governorate. Eventually, 516 questionnaires were received from all governorates, with relatively few questionnaires going missing (n= 55).

7.2.5 Data management

Completed questionnaires were sent to the researcher through the MOH post, which was considered the most trustworthy method; however, copies were kept by the RA just in case they went missing. As soon as the researcher received the questionnaires, she contacted the RA and instructed them to destroy the backup copy according to the MOH rules on destroying official documents. Once the questionnaires were received, each questionnaire was given a code for their governorate and a unique number, and then stored in a locked cabinet in the researcher's office at the University of Glasgow.

7.3. Data analysis

7.3.1 Questionnaire statistical analysis

The returned questionnaires were first checked for missing data. Given that there were a few questions that were left unanswered but no incomplete pages on any questionnaire, none were excluded. All data analyses were conducted using SPSS (Statistical Package for Social Sciences) software programme version 22.0. In order to gain a clearer picture of the quantitative data gathered, descriptive statistics were calculated. Descriptive statistics are often used to describe the basic features of the data collected and allow the presentation of a simple summary of the statistics, employing measurements such as mean, median and standard deviation (Pallant and Dawson, 2010). Analysis of the inferential statistics was

undertaken to draw conclusions regarding the barriers to and facilitators of screening for ASD, based on the data collected from the respondents (Pallant and Dawson, 2010).

As discussed previously, there are debates about whether Likert scale data produce ordinal or interval scale data (Subedi, 2016). For a fuller discussion, see section 4.8.2. Non-parametric methods were used to analyse the data. Mann-Whitney U tests were adopted to compare differences in perceived barriers to or facilitators of screening for ASD (dependent variables) between two independent groups (Pallant, 2016), such as gender, position or nationality. The Kruskal-Wallis test was used when three or more categories were being analysed: for example, the identification of any statistical difference between the dependent variables and the level of education of the respondents (Diploma, Bachelor of Science, or specialty). In addition, the Spearman's rho test was applied to examine the association between the barriers to and facilitators of screening for ASD, and some of the continuous socio-demographic characteristics, such as age, years of experience, number of patients seen per day, number of staff and number of programmes that ran at each institution.

As this questionnaire combined both positively and negatively worded items, attention was given to reverse negative items in order to prevent response bias (Pallant, 2016). The highest score, '4', was given to the high barriers to/facilitators of screening for ASD in Oman. For example, item 2 ***"Our institution is seeing the maximum number of patients each day"*** was worded in a positive way, so a high score of '4', strongly agree, indicated high barriers. In contrast, item 3 ***"We have enough staff to carry out the daily clinic activities"*** was negatively worded in terms of barriers, so a high score on this item of '4' indicated low barriers and '1', strongly disagree, represented high barriers. To report consistent results and avoid response bias, the median and mode of negatively worded items were reversed from '1' strongly disagree to '4' strongly agree or from '2' disagree to '3' agree. Further explanation is provided in the results section.

7.3.2 Free text response analysis

The process for analysing the data provided in the free text questions was demonstrated in the qualitative data (see section 5.2.10.3).

After analysing the quantitative data, all of the free text responses for each question were transcribed and coded separately for all the questionnaire sets. Then, FA was used to analyse the free text responses. As explained in Chapters 3 and 4, this method involved five

sequential steps: familiarisation; identifying a thematic framework; indexing; charting and mapping; and interpretation (Ritchie et al., 1994). In order to complete step one (familiarisation), the researcher read the respondents' responses several times for accurate comprehension, connecting the data and gaining an insight into the diversity of the data. After familiarisation, step two was applied (identifying a thematic framework). In this step, both the supervisor (DW) and the researcher carefully read the transcript line by line and applied an initial 'code' for each response in the transcript, independently. Once the codes had been created, the researchers met to review the codes and to examine similarities and differences between their initial interpretations. Differences were resolved by revisiting the transcript and discussing any issues that arose. By the end of this stage, 26 codes were identified. Subsequently, an indexing stage was employed. Here the researchers read the quotes and the codes from the previous stage, line by line, to identify any new experiences and insights. Once this was completed, the emergent codes were gathered together and discussed to form 'themes' that captured the broader concept of the data. The next step was charting, where data was lifted from its original context and placed into tables consisting of themes and sub-themes, which were drawn up during indexing (Ritchie et al., 1994). Quotes were inserted to support, explain and justify the themes identified in the indexing stage. This was undertaken in order to break up the material into understandable but brief summaries of what was discussed by the respondents (Ritchie and Lewis, 2003). Finally, data was sifted and charted according to the core themes and subthemes. At the final stage of the FA, the researcher pulled together the key characteristics of the data in order to interpret it as a whole (Ritchie and Spencer, 1994). This involved reading and reflecting on the transcripts of the respondents' responses, comparing and contrasting the views and experiences of the PHPs in the study area and searching for patterns and connections within the structure as a whole. It also required a consensus meeting with the supervisor, DW, to develop general themes, which offered plausible explanations for what was happening in the data. As a result, themes were generated, and some sub-themes were rearranged within the main theme to produce a more structured approach. This resulted in three themes being identified: constraints, family, and professional education.

7.4. Results

7.4.1 Response rate and included questionnaires

Five hundred and seventy-one questionnaires were sent to a proportionate sample of PHPs across Oman. The total number of returned questionnaires was 516, resulting in a response rate of 90.37% (see Table 7-1). However, only 490 questionnaires were included in the

analyses. Twenty-six (5.2%) questionnaires were excluded because they were completed by practitioners other than GPs or nurses, such as pharmacists, X-ray and lab technicians, who were not targeted by this study. This left 490 questionnaires which were included in this study.

Table 7-1: Response rate and the included questionnaire

Region	***Respondents***		****Number of questionnaires returned***		***Included questionnaires Frequency (Percent %)***
	Nurse	*GP*	*Nurse*	*GP*	
Al Wasta	*8*	*4*	*9*	*6*	*14(2.9)*
Al Dahera	*25*	*13*	*25*	*13*	*37(7.6)*
North Sharqiyah	*13*	*9*	*14*	*9*	*23(4.7)*
South Sharqiyah	*27*	*20*	*22*	*16*	*36(7.3)*
South Batinah	*26*	*25*	*25*	*25*	*46(9.4)*
North Batinah	*41*	*42*	*41*	*42*	*77(15.7)*
Al Dakheliyah	*30*	*23*	*30*	*23*	*50(10.2)*
Al Buraimii	*6*	*2*	*6*	*2*	*8(1.6)*
Musandam	*4*	*2*	*4*	*3*	*6(1.2)*
Dophar	*43*	*26*	*43*	*20*	*58(11.8)*
Muscat	*95*	*87*	*80*	*58*	*135(27.6)*
Total	*318*	*253*	*299*	*217*	*490(100)*
Grand Total	*571*		*516*		*490*

GP= General Practitioners
**Total number of returned questionnaires, whether or not complete*

7.4.2 Demographic characteristics:

The study sample included 490 PHPs from various health centres across Omani governorates (see Table 7-1). These institutions were mostly run by Omani practitioners (65.7%), although there was a wide range of non-Omani respondents, e.g., Indian (7.9%), Sudanese (7.1%), Egyptian (6.9%), Filipino (5.1%), Pakistani (3%), Bangladeshi (2.6%), Tunisian (1.1%), Iraqi (0.4%) and Iranian (0.2%). As expected, some institutions in rural governorates in Oman were mostly run by non-Omani people. For example, all the respondents from Al Wasta Governorate were non-Omani (n=14), followed by 63.8% of respondents from Dhofar (n=37). The smallest number of non-Omani respondents were from Muscat governorate, the capital city in Oman, where they comprised 13.5% (n=18) (see Figure 7-1).

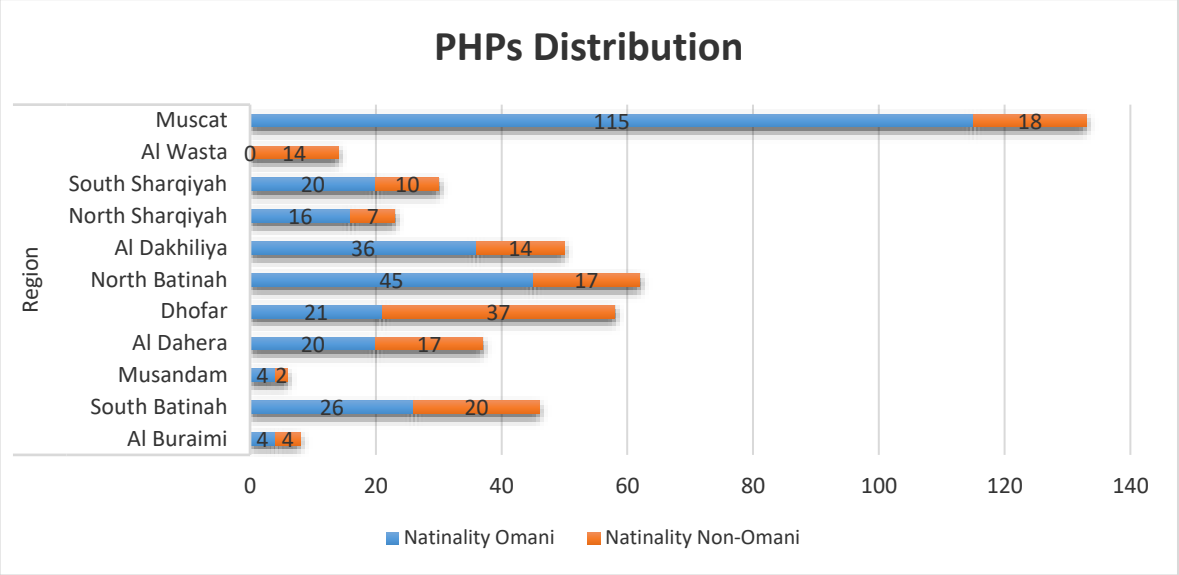


Figure 7-1: Distribution of PHPs' nationality

Females dominated the profession in PHC settings. Most of the respondents were young female nurses (94.9 %), in their twenties (41.8%), with low-level qualifications, holding a diploma certificate in nursing (77.5%), or a baccalaureate (12.4%). Few nurses possessed higher qualifications, such as a speciality qualification (10.2%). In contrast, almost half of the GPs were male (45.7%), non-Omani (59.6%) and aged 36 or over (42.9%). The GPs' lowest qualification was the baccalaureate degree, which accounted for the majority of the respondents (86.8%), and 13.2% possessed a speciality qualification. Fifty percent of the GPs reported seven years of experience or less, while nurses ranged from less than seven years' experience to over 13 years (see Table 7-2).

The respondents believed that they saw a large number of patients on a daily basis, especially nurses. The majority of GPs (53.4%) reported that they saw almost 40 patients per day, while most nurses (45%) cared for double that number (81 patients per day). The majority of both groups also reported three or fewer staff working per shift. Besides patient care, respondents also ran other PHC programmes, such as an expanded programme of immunisation, birth spacing, prevention and management of diabetes mellitus and control of diarrhoeal disease. The majority of both groups carried out a minimum of eight programmes per institution (see Table 7-2).

Table 7-2: Demographic characteristics

Characteristics (n=490)		***Position***	
		GPs *Frequency (Percent %)*	***Nurses*** *Frequency (Percent %)*
Gender	*Male*	*79(45.7)*	*15(5.1)*
	Female	*94(54.3)*	*278(94.9)*
	Total	*173(100)*	*293(100)*
Age	*<= 30.00*	*42(28.2)*	*104(41.8)*
	31.00 - 35.00	*43(28.9)*	*92(36.9)*
	36.00+	*64(42.9)*	*53(21.3)*
Nationality	*Total*	*149(100)*	*249(100)*
	Omani	*67(40.4)*	*234(79.6)*
	Non-Omani	*99(59.6)*	*60(20.4)*
	Total	*166(100)*	*294(100)*
Qualification	*Diploma*	*0(0.0)*	*213(77.5)*
	BSc	*145(86.8)*	*34(12.4)*
	Specialty	*22(13.2)*	*28(10.2)*
	Total	*167*	*275(100)*
Experience	*<= 7.00*	*83(50.3)*	*95(33.6)*
	8.00 - 12.00	*46(27.9)*	*96(33.9)*
	13.00+	*36(21.8)*	*92(32.5)*
	Total	*165(100)*	*283(100)*
No. of patients seen (per day)	*<= 40.00*	*79(53.4)*	*69(34.2)*
	41.00 - 80.00	*51(34.5)*	*42(20.8)*
	81.00+	*18(12.2)*	*91(45)*
	Total	*148(100)*	*202(100)*
No. of staff (per shift)	*<= 3.00*	*44(35.8)*	*92(42)*
	4.00 - 6.00	*38(30.9)*	*74(33.8)*
	7.00+	*41(33.3)*	*53(24.2)*
	Total	*123(100)*	*219(100)*
No. of programmes carried by each institution	*<= 8.00*	*61(48.4)*	*75(38))*
	9.00 - 11.00	*35(27.8)*	*55(27.9)*
	12.00+	*30(23.8)*	*67(34)*
	Total	*126(100)*	*197(100)*

GPs= General Practitioners, No= Number

7.4.3 Organisational barriers

For the purpose of this study, the respondents were asked to evaluate seven barriers related to their organisation: time constraints, workload, staff shortage, limited resources, referral protocols, on-the-job training on ASD and documentation. In general, the majority of respondents reported a high percentage of agreement (agreed and strongly agreed) with these barriers. The highest agreement score for a barrier was given to ‘resource availability’: see

Table 7-3. Eighty-two percent of respondents were in significant agreement (i.e. ‘4’ median and mode) and thought that the current setting was lacking the necessary resources (i.e. expertise, infrastructure and screening tools) to initiate screening for ASD. The lack of on-the-job training on ASD was also identified as a significant barrier (‘3’ median and ‘4’ mode) to future screening by 80% of the respondents. Although 76% of the respondents indicated a lack of documentation for identified and referred suspected cases within their current practice and viewed this as a substantial barrier to screening, (‘4’ median and mode), this item is a negatively worded item. When both the mode and median were reversed from “1” strongly disagree to “4” strongly agree, 73% of the respondents (3 median and 4 mode) reported a lack of protocol to clearly guide their referrals to the diagnostic services for suspected cases of ASD. This perhaps presents a major challenge to screening for ASD within current settings. Workload was another challenge, which was proposed by 71% of the respondents. The respondents emphasised that adding a screening programme, within current practice, may heighten the workload that respondents experience on a daily basis. Time constraints were also introduced by 69% (‘3’ median and mode) of the respondents as a major barrier to screening for ASD within the current practice. The lowest agreement score for a barrier at this level was given to item ‘3’, as almost half of the respondents (55%) emphasised the challenge that staff shortages may pose to potential screening for ASD in Oman.

Table 7-3: Number, percentage, median and mode of response to organisational barriers

Sr.	*Items*		*Disagreement (1&2)*	*Agreement (3&4)*	*Total*	*Median*	*Mode*
1.	*We don't have enough time to screen children for ASD in our current practice.*	*Freq.*	*154*	*334*	*488*	*3*	*3*
		%	*32%*	*69%*	*100%*		
2.	*Our institution is seeing the maximum number of patients each day.*	*Freq.*	*138*	*341*	*479*	*3*	*4*
		%	*29%*	*71%*	*100%*		
3.	**We have enough staff to carry out the daily clinic activities.*	*Freq.*	*269*	*217*	*486*	*2 (3)*	*3(2)*
		%	*55%*	*45%*	*100%*		
4.	*We don't have the required resources (such as screening tools, space, expertise…etc.) to screen for ASD in our institutions.*	*Freq.*	*154*	*334*	*486*	*4*	*4*
		%	*18%*	*82%*	*100%*		
5.	*We are lacking clear mechanisms for referring/following up the suspected cases of ASD to the diagnostic services.*	*Freq.*	*130*	*351*	*481*	*3*	*4*
		%	*27%*	*73%*	*100%*		
6.	*Despite the various educational programmes offered in our institution, ASD is not included as a subject.*	*Freq.*	*96*	*384*	*480*	*3*	*4*
		%	*20%*	*80%*	*100%*		
7.	**In this institution, we keep a register of all the suspected cases of ASD that were referred to diagnostic services.*	*Freq.*	*353*	*123*	*476*	*1(4)*	*1(4)*
		%	*74%*	*26%*	*100%*		

*******indicated reversed negative items , Freq.=Frequency, %=Percent, 1=Strongly Disagree, 2=Disagree, 3=Agree, 4=Strongly Agree*

7.4.3.1. Organisational barriers by gender

Table 7-4 presents the relationships between organisational barriers and respondents' gender. The only significant difference between males and females was in their response to barriers related to the documentation of suspected and referred cases of ASD (Z=-2.43, Sig=0.015). Males (mean=258.0) rated this item as a barrier to a greater extent than females (mean=224.6).

Table 7-4: Relationship between organisational barrier items and respondents' gender

Sr.	*Barriers*	*Mean Rank*		*Z*	*Sig*
		Male	*Female*		
1	*We don't have enough time to screen children for ASD in our current practice.*	*226.0*	*239.8*	*-0.922*	*0.356*
2	*Our institution is seeing the maximum number of patients each day.*	*245.4*	*229.9*	*-1.055*	*0.291*
3	*We have enough staff to carry out the daily clinic activities.*	*224.9*	*238.9*	*-0.931*	*0.352*
4	*We don't have the required resources (such as screening tools, space, expertise…etc.) to screen for ASD in our institutions.*	*249.5*	*232.6*	*-1.245*	*0.213*
5	*We are lacking clear mechanisms for referring the suspected cases of ASD to the diagnostic services.*	*221.1*	*236.8*	*-1.077*	*0.282*
6	*Despite the various educational programmes offered in our institution, ASD is not included as a subject.*	*229.0*	*234.7*	*-0.397*	*0.692*
7	*In this institution, we keep a register of all the suspected cases of ASD that were referred to diagnostic services.*	*258.0*	*224.6*	*-2.433*	*0.015*

7.4.3.2. Organisational barriers by position

Interestingly, Table 7-5 shows that there was no significant difference in the evaluation of organisational barriers between GPs and nurses.

Table 7-5: Relationship between organisational barrier items and respondents' position

Sr.	*Barriers*	*Mean Rank*		*Z*	*Sig*
		GP	*Nurse*		
1	*We don't have enough time to screen children for ASD in our current practice.*	*232.6*	*235.7*	*-0.250*	*0.802*
2	*Our institution is seeing the maximum number of patients each day.*	*235.7*	*227.4*	*-0.683*	*0.494*
3	*We have enough staff to carry out the daily clinic activities.*	*226.2*	*237.8*	*-0.935*	*0.350*
4	*We don't have the required resources (such as screening tools, space, expertise…etc.) to screen for ASD in our institutions.*	*243.9*	*227.4*	*-1.458*	*0.145*
5	*We are lacking clear mechanisms for referring the suspected cases of ASD to the diagnostic services.*	*233.8*	*229.3*	*-0.373*	*0.709*
6	*Despite the various educational programmes offered in our institution, ASD is not included as a subject.*	*236.4*	*227.8*	*-0.730*	*0.466*
7	*In this institution, we keep a register of all the suspected cases of ASD that were referred to diagnostic services.*	*230.0*	*228.4*	*-0.143*	*0.887*

7.4.3.3. Organisational barriers by nationality

Table 7-6 presents the relationship between organisational barriers and respondents' nationality. Among the seven organisational barrier items, there was a significant difference between Omani and non-Omani people, in terms of three items: time constraints, limited resources for screening and lack of on-the-job training on ASD. Omani respondents reported higher agreement with time constraints being a barrier (mean rank=245.2) compared to non-Omani people (mean rank=209.06, Z= -2.845, Sig=0.004). On the other hand, non-Omani people reported higher agreement with resource constraints as a barrier (Z=-3.406, Sig=0.001) and the lack of on-the-job education on ASD (Z=-2.549, Sig=0.009).

Table 7-6: Relationship between organisational barrier items and respondents' nationality

Sr.	*Barriers*	*Mean Rank*		*Z*	*Sig*
		Omani	*Non-Omani*		
1	*We don't have enough time to screen children for ASD in our current practice.*	*245.2*	*209.06*	*-2.845*	*0.004*
2	*Our institution is seeing the maximum number of patients each day.*	*229.8*	*227.5*	*-0.186*	*0.852*
3	*We have enough staff to carry out the daily clinic activities.*	*225.7*	*244.1*	*-1.455*	*0.146*
4	*We don't have the required resources (such as screening tools, space, expertise…etc.) to screen for ASD in our institutions.*	*218.6*	*257.5*	*-3.406*	*0.001*
5	*We are lacking clear mechanisms for referring the suspected cases of ASD to the diagnostic services.*	*228.2*	*231.9*	*-0.306*	*0.760*
6	*Despite the various educational programmes offered in our institution, ASD is not included as a subject.*	*218.8*	*249.8*	*-2.594*	*0.009*
7	*In this institution, we keep a register of all the suspected cases of ASD that were referred to diagnostic services.*	*234.3*	*215.6*	*-1.611*	*0.107*

7.4.3.4. Organisational barriers by qualification

Table 7-7 presents the relationships between organisational barriers and respondents' qualifications (diploma, BSc and specialty). There was a significant relationship between qualifications and three organisational barriers: limited resources, lack of on-the-job education on ASD and a lack of documentation for identified and referred cases of ASD. The mean rank increased with the participants' qualifications for limited resources and lack of on-the-job education on ASD in Oman. Therefore, respondents with specialised qualifications found these factors a greater challenge to screening than the respondents with a diploma. In contrast, the lack of registration of suspected cases decreased as a potential barrier with increasing qualifications. Respondents with a diploma highlighted this issue as a barrier to the greatest extent.

Table 7-7: Relationship between organisational barriers' items and respondents' qualification

Sr.	*Barriers*	*Mean Rank*			*Chi-Square*	*Sig*
		Diploma	*BSc*	*Specialty*		
1	*We don't have enough time to screen children for ASD in our current practice.*	*225.95*	*221.57*	*202.66*	*1.51*	*0.47*
2	*Our institution is seeing the maximum number of patients each day.*	*221.74*	*218.73*	*203.77*	*0.90*	*0.64*
3	*We have enough staff to carry out the daily clinic activities.*	*228.14*	*218.42*	*204.7*	*1.69*	*0.43*
4	*We don't have the required resources (such as screening tools, space, expertise…etc.) to screen for ASD in our institutions.*	*200.9*	*235.44*	*252.14*	*13.67*	*0.00*
5	*We are lacking clear mechanisms for referring the suspected cases of ASD to the diagnostic services.*	*214.98*	*222.65*	*218.25*	*0.40*	*0.82*
6	*Despite the various educational programmes offered in our institution, ASD is not included as a subject.*	*204.63*	*223.09*	*256.33*	*8.68*	*0.01*
7	*In this institution, we keep a register of all the suspected cases of ASD that were referred to diagnostic services.*	*223.42*	*218.23*	*175.5*	*7.36*	*0.03*

7.4.3.5. Organisational barriers by respondents' characteristics

Age correlated significantly (rho=0.126, $p<0.05$) with the lack of on-the-job education on ASD presented in item #6; older respondents were more likely to consider this item as a barrier. However, the most experienced respondents showed a significant difference to younger respondents for item #5, which highlighted the lack of referral protocols for guiding their practice (rho=0.095, $p<0.05$).

As the number of patients observed by each institution increased, the respondents gave higher scores to barriers relating to patient load (rho=0.111, $p<0.05$). Lower scores were found for documenting issues (rho= - 0.158, $p<0.01$) and staff availability (rho=-0.234, $p<0.01$)

Increases in the number of staff per shift were also found to increase scores relating to barriers regarding time constraints (rho=0.128, $p<0.05$), patient load (rho=0.110, $p<0.05$) and lack of documentation (rho=0.181, $p<0.01$).

As the number of programmes run by the institutions increased, the respondents gave higher scores to barriers relating to the lack of on-the-job education on ASD (rho=0.147, p<0.01), and screening resources (rho=0.126, p<0.05), See Table 7-8 below.

Table 7-8: Spearman correlations between organisational barriers and respondents' age, experience, patient numbers, staff numbers and programme numbers

		Age (yrs.)	*Work Experience (yrs.)*	*No. of patients (per day)*	*No. of staff (per shift)*	*No. of programmes*
1	*We don't have enough time to screen children for ASD in our current practice.*	*0.083*	*0.079*	*0.033*	*.128**	*-0.106*
2	*Our institution is seeing the maximum number of patients each day.*	*0.036*	*0.076*	*.111**	*.110**	*-0.093*
3	*We have enough staff to carry out the daily clinic activities.*	*0.056*	*0.035*	*-.234***	*0.067*	*0.059*
4	*We don't have the required resources (such as screening tools, space, expertise…etc.) to screen for ASD in our institutions.*	*0.03*	*0.037*	*0.018*	*-0.049*	*.126**
5	*We are lacking clear mechanisms for referring the suspected cases of ASD to the diagnostic services..*	*0.072*	*.095**	*0.037*	*0.001*	*0.094*
6	*Despite the various educational programmes offered in our institution, ASD is not included as a subject.*	*.126**	*0.057*	*-0.003*	*-0.077*	*.147***
7	*In this institution, we keep a register of all the suspected cases of ASD that were referred to diagnostic services.*	*-0.011*	*-0.018*	*-.158***	*.181***	*0.036*

***. Correlation is significant at the 0.01 level,*. Correlation is significant at the 0.05 level*

7.4.4 Professional barriers

Secondly, the respondents were asked to evaluate barriers relating to their professional knowledge, confidence and skills in identifying and referring children suspected to have ASD. Table 7-9 presents the descriptive statistics (frequency, percentage, median and mode) for each professional barrier. Similarly to the results for organisational barriers, most respondents chose the "agree" and "strongly agree" options for the presented barriers.

In this phase, the respondents' knowledge of ASD was varied in its dimensions and sources. For example, 67% of the respondents thought that they were more educated on the signs and symptoms of ASD than they were on other aspects of care and management for this disorder.

Knowledge of ASD was gained through one or more of the following approaches: self-updates (75.2%), professional training (71.4 %,) and/or talking to parents of children with ASD (62.2%). However, 65.4% of them did not feel confident in demonstrating this knowledge and would rather use the pink card for scheduling the child's immunisations than for monitoring and identifying developmental abnormalities. ASD identification was also limited; few respondents stated that they had identified a child with ASD earlier (41.30 %), with high agreement (median '3' and mode '4') to this item as a barrier.

Referring a child suspected of having ASD for further investigation and assessment was identified as a major barrier ('3' and '4') to potentially screening for ASD. Just over three quarters of respondents (75.7%) favoured referring the identified child to diagnostic services. However, a few respondents (35.30%) suggested monitoring the suspected child for a few weeks before referral, while others (24.50%) were in favour of monitoring such children for longer periods of up to two years before referral. The discrepancy among professionals suggests a lack of consensus on when to refer a child suspected of having ASD. Another related challenge identified was where to refer suspected cases. Most of the respondents (61.5%) were in favour of referring children to secondary level institutions, which contradicts the current protocol of referring children within the primary level. Over half (58.80%) seemed to follow the current protocol and refer children suspected of having ASD within the primary level. This discrepancy in opinion might relate to a lack of knowledge of protocol and/or ASD services, as 76% of the respondents felt unfamiliar with the services provided for children with ASD in Oman. This was identified as a major barrier to screening for ASD, with '3' median and '4' mode.

Table 7-9: Number, percentage, median and mode of response to the professional barriers

Sr.	*Items*		*Disagreement (1&2)*	*Agreement (3&4)*	*Total*	*Median*	*Mode*
1.	**My Knowledge of ASD is based on the information I studied during my professional training.*	*Freq.*	*135*	*338*	*473*	*3(2)*	*4(1)*
		%	*28.50%*	*71.40%*	*100%*		
2.	**I learned about ASD from the parents of children with ASD.*	*Freq.*	*176*	*290*	*466*	*3(2)*	*3(2)*
		%	*37.70%*	*62.20%*	*100%*		
3.	**I learned about ASD through self-updates and training.*	*Freq.*	*116*	*352*	*468*	*3(2)*	*3(2)*
		%	*24.80%*	*75.20%*	*100%*		
4.	**I think I have more knowledge on the signs and symptoms of ASD, such as speech delay, lack of eye contact…etc. than the ongoing care and management of ASD.*	*Freq.*	*160*	*324*	*484*	*3(2)*	*3(2)*
		%	*33.10%*	*67.00%*	*100%*		
5.	*I feel most educated in the use of the pink card to immunise children, rather than the use of it to identify developmental and behavioural abnormalities.*	*Freq.*	*168*	*317*	*485*	*3*	*4*
		%	*34.60%*	*65.40%*	*100%*		
6.	**I have identified a child with ASD previously.*	*Freq.*	*276*	*194*	*470*	*2(3)*	*1(4)*
		%	*58.70%*	*41.30%*	*100%*		
7.	*When I suspect ASD I follow the case within the clinic for a few weeks before I refer.*	*Freq.*	*280*	*153*	*433*	*3*	*4*
		%	*74.70%*	*35.30%*	*100%*		
8.	**I prefer to monitor the suspected cases of ASD until they have completed two years and then refer.*	*Freq.*	*320*	*104*	*424*	*4*	*4*
		%	*75.50%*	*24.50%*	*100%*		
9.	*I refer the suspected cases within the primary level (psychiatric clinic or paediatric clinic) if I suspect ASD.*	*Freq.*	*183*	*262*	*445*	*3(2)*	*4(1)*
		%	*41.10%*	*58.80%*	*100%*		
10.	*I refer the case to the secondary level when I suspect ASD.*	*Freq.*	*163*	*260*	*423*	*3*	*4*
		%	*38.50%*	*61.50%*	*100%*		
11.	**I think I am familiar with most of the ASD services in Oman.*	*Freq.*	*355*	*102*	*476*	*2(3)*	*1(4)*
		%	*76.00%*	*24.00%*	*100%*		

***** *indicates reversed negative items*

Freq. = Frequency, %= Percent, 1=Strongly Disagree, 2=Disagree, 3=Agree, 4= Strongly Agree

7.4.4.1. Professional barriers by gender

Females stated that their knowledge of ASD was based on information provided by the parents of children with ASD (Z=-2.514, Sig=0.012), while males stated that their

knowledge of ASD was based on information acquired through self-updates and training (Z=-2.210, Sig=0.027) (see Table 7-10).

When a case of ASD was suspected, males were more likely than females to refer the case within the primary level, psychiatric clinic or paediatric clinic (Z=-4.134, Sig=0.001), and then to the secondary level (Z=-3.026, Sig=0.002). Males displayed more familiarity than females with most of the ASD services in Oman (Z=-2.188, Sig=0.029).

Table 7-10: Relationship between organisational barriers' items and respondents' gender

Sr.	*Item*	*Mean Rank*		*Z*	*Sig.*
		Male	*Female*		
1.	*My knowledge of ASD is based on the information I studied during my professional training.*	*228.47*	*229.77*	*-0.090*	*0.928*
2.	*I learned about ASD from the parents of children with ASD.*	*197.08*	*233.41*	*-2.514*	*0.012*
3.	**I learned about ASD through self-updates and training.*	*252.52*	*221.05*	*-2.210*	*0.027*
4.	*I think I have more knowledge on the signs and symptoms of ASD, such as speech delay, lack of eye contact…etc. than the ongoing care and management of ASD.*	*228.27*	*236.71*	*-0.574*	*0.566*
5.	*I feel most educated in the use of the pink card to immunise children, rather than the use of it to identify developmental and behavioural abnormalities.*	*224.91*	*238.18*	*-0.887*	*0.375*
6.	*I have identified a child with ASD previously.*	*234.84*	*226.29*	*-0.581*	*0.561*
7.	*When I suspect a child with ASD I follow the case within the clinic for a few weeks before I refer.*	*217.95*	*208.58*	*-0.672*	*0.502*
8.	*I prefer to monitor the suspected cases of ASD until they have completed two years and then refer.*	*205.95*	*206.01*	*-0.005*	*0.996*
9.	*I refer the suspected cases within the primary level (psychiatric clinic or paediatric clinic) if I suspect ASD.*	*261.65*	*203.61*	*-4.134*	*0.001*
10.	*I refer the case to the secondary level), when I suspect ASD.*	*238.28*	*196.8*	*-3.026*	*0.002*
11.	*I think I am familiar with most of the ASD services in Oman.*	*251.38*	*220.62*	*-2.188*	*0.029*

7.4.4.2. Professional barriers by position

Table 7-11 shows the relationship between professional barrier items and respondents' position. GPs stated that their knowledge of ASD was based on the information studied during their professional training (Z=-3.634, Sig=0.000), and information gained through self-updates and training (Z=-2.838, Sig=0.005). Nurses on the other hand stated that their

knowledge of ASD was based on the information acquired from the parents of children with ASD (Z=-2.259, Sig=0.024).

When a case of ASD was suspected, GPs were more likely than nurses to refer the case within the primary level, psychiatric clinic or paediatric clinic (Z=-4.387, Sig=0.000), and then to the secondary level (Z=-4.061, Sig=0.000).

Table 7-11: Relationship between professional barrier items and respondents' position

Sr.	*Items*	*Mean Rank*		*Z*	*Sig.*
		GP	*Nurse*		
1.	*My knowledge of ASD is based on the information I studied during my professional training.*	*254.28*	*210.61*	*-3.634*	*0.000*
2.	*I learned about ASD from the parents of children with ASD.*	*206.37*	*233.46*	*-2.259*	*0.024*
3.	*I learned about ASD through self-updates and training.*	*245.98*	*212.46*	*-2.838*	*0.005*
4.	*I think I have more knowledge of the signs and symptoms of ASD, such as speech delay, lack of eye contact…etc. than the ongoing care and management of ASD.*	*238.34*	*229.06*	*-0.762*	*0.446*
5.	*I feel most educated in the use of the pink card to immunise children rather than the use of it to identify developmental and behavioural abnormalities.*	*226.54*	*236.79*	*-0.828*	*0.408*
6.	*I have identified a child with ASD previously.*	*237.59*	*218.43*	*-1.583*	*0.114*
7.	*When I suspect a child with ASD I follow the case within the clinic for a few weeks before I refer.*	*211.58*	*206.71*	*-0.420*	*0.674*
8.	*I prefer to monitor the suspected cases of ASD until they have completed two years and then refer.*	*196.84*	*207.49*	*-0.987*	*0.324*
9.	*I refer the suspected cases within the primary level (psychiatric clinic or paediatric clinic) if I suspect ASD.*	*245.54*	*193.84*	*-4.387*	*0.000*
10.	*I refer the case to the secondary level when I suspect ASD.*	*231.43*	*185.19*	*-4.061*	*0.000*
11.	*I think I am familiar with most of the ASD services in Oman.*	*227.92*	*222.43*	*-0.469*	*0.639*

7.4.4.3. Professional barriers by nationality

Table 7-12 presents the relationships between professional barriers and respondents by nationality. Omani and non-Omani people differed significantly in five professional barriers. Non-Omani people provided a higher response to the item regarding their knowledge of ASD being based on the information studied during their professional training (Z=-6.011, Sig=0.000), and information learnt through self-updates and training (Z=-2.964, Sig=0.003).

Non-Omani people were also in agreement, to a greater extent, with referring children for further investigation to the primary level when they were suspected of having ASD (Z=-

2.138, Sig=0.033) and to the secondary level (Z=-3.774, Sig=0.000). On the other hand, Omani people showed more agreement with following the child within their own clinic for two years before referring him/her for further investigation (Z=-2.806, Sig=0.005).

Table 7-12: Relationship between professional barrier items and respondents' nationality.

Sr.	*Items*	*Mean Rank*		*Z*	*Sig.*
		Omani	*Non-Omani*		
1.	*My knowledge of ASD is based on the information I studied during my professional training.*	*200.24*	*273.57*	*-6.011*	*0.000*
	I learned about ASD from the parents of children with ASD.	*222.56*	*220.87*	*-0.138*	*0.891*
2.	*I learned about ASD through self-updates and training.*	*211.36*	*246.98*	*-2.964*	*0.003*
3.	*I think I have more knowledge of the signs and symptoms of ASD, such as speech delay, lack of eye contact…etc. than the ongoing care and management of ASD.*	*223.65*	*246.6*	*-1.854*	*0.064*
4.	*I feel most educated in the use of the pink card to immunise children rather than the use of it to identify developmental and behavioural abnormalities.*	*232.76*	*229.05*	*-0.296*	*0.768*
5.	*I have identified a child with ASD previously.*	*223.17*	*228.54*	*-0.437*	*0.662*
6.	*When I suspect a child with ASD I follow the case within the clinic for a few weeks before I refer.*	*208.96*	*202.83*	*-0.513*	*0.608*
7.	*I prefer to monitor the suspected cases of ASD until they have completed two years and then refer.*	*212.1*	*181.02*	*-2.806*	*0.005*
8.	*I refer the suspected cases within the primary level (psychiatric clinic or paediatric clinic) if I suspect ASD.*	*203.29*	*229.05*	*-2.138*	*0.033*
9.	*I refer the case to the secondary level when I suspect ASD.*	*186.66*	*230.84*	*-3.774*	*0.000*
10.	*I think I'm familiar with most of the ASD services in Oman.*	*225.24*	*218.59*	*-0.558*	*0.577*

7.4.4.4. Professional barriers by qualification

Table 7-13 presents the relationship between professional barriers and respondents' qualifications. There were significant differences in two professional barriers by qualification: *"My knowledge about ASD is based on the information I studied during my professional training"* and *"When I suspect a child with ASD I follow the case until he/she has completed two years and then refer."* In both items, the responses varied significantly among the three groups. An inspection of the mean rank suggests that the BSc group has the highest professional knowledge. However, the diploma group was found to be the highest group in terms of preference for postponing the referral process for children suspected of having ASD.

Table 7-13: Relationship between professional barrier items and respondents' qualifications

Sr.	*Items*	*Mean Rank*			*Chi-Square*	*Sig.*
		Diploma	*BSc*	*Specialty*		
1.	*My knowledge of ASD is based on the information I studied during my professional training.*	*189.57*	*246.51*	*203.09*	*22.819*	*0.000*
2.	*I learned about ASD from the parents of children with ASD.*	*205*	*166*	*49*	*5.105*	*0.078*
3.	*I learned about ASD through self-updates and training.*	*204*	*170*	*50*	*3.098*	*0.212*
4.	*I think I have more knowledge of the signs and symptoms of ASD, such as speech delay, lack of eye contact…etc. than the ongoing care and management of ASD.*	*212*	*178*	*49*	*0.853*	*0.653*
5.	*I feel most educated in the use of the pink card to immunise children rather than the use of it to identify developmental and behavioural abnormalities.*	*213*	*177*	*50*	*0.718*	*0.698*
6.	*I have identified a child with ASD previously.*	*206*	*171*	*49*	*2.611*	*0.271*
7.	*When I suspect a child with ASD I follow the case within the clinic for a few weeks before I refer.*	*194*	*158*	*45*	*3.415*	*0.181*
8.	*I prefer to monitor the suspected cases of ASD until they have completed two years and then refer.*	*209.52*	*185.82*	*185.82*	*11.788*	*0.003*
9.	*I refer the suspected cases within the primary level (psychiatric clinic or paediatric clinic) if I suspect ASD.*	*193*	*165*	*47*	*5.363*	*0.068*
10.	*I refer the case to the secondary level when I suspect ASD.*	*180*	*159*	*47*	*3.921*	*0.141*
11.	*I think I'm familiar with most of the ASD services in Oman.*	*205*	*174*	*48*	*1.017*	*0.601*

7.4.4.5. Professional barriers by respondents' characteristics

Age (rho=-0.104, p<0.05), experience (rho=-0.198, p<0.01) and patients load(rho=-0.146, p<0.01), were negatively correlated with the item *"My knowledge of ASD is based on the information I studied during my professional training",* which indicated that the older and more experienced respondents those who works in busy institutions possessed less professional training on ASD. Older respondents acquired information on ASD through *"self-updates"* (rho= 0.207, p<0.01) and preferred to refer a suspected case of ASD to the secondary level (rho=0.164, p<0.01).

An increasing number of patients seen per day was seen to decrease the score given to the items on *"professional training"* (rho=-0.146, p<0.01), *"self-updates"* (rho=-0.107, p<0.05) and *"referral to the secondary level"* (rho= -0.154, p<0.01).

Similarly, the increasing number of staff per shift lowered the *"professional training"* score (rho=-0.153, p<0.01). However, when respondents worked in institutions that had a large number of programmes and activities, they were generally less familiar with ASD services (rho=-0.144, p<0.05) and would discourage following up suspected cases of ASD until the child was two years of age (rho=-0.119, p<0.05).

Table 7-14: Relationship between professional barrier items and respondents' characteristics

Sr.	*Items*	*Age (yrs.)*	*Work Experience (yrs.)*	*No. of patients (per day)*	*No. of staff (per shift)*	*No. of programmes*
1	*My knowledge of ASD is based on the information I studied during my professional training.*	*-.104**	*-.198***	*-.146***	*-.153***	*-0.056*
2	*I learned about ASD from the parents of children with ASD*	*0.012*	*0.088*	*0.1*	*0.002*	*0.048*
3	**I learned about ASD through self-updates and training.*	*.207***	*0.074*	*-.107**	*-0.018*	*-0.068*
4	*I think I have more knowledge of the signs and symptoms of ASD such as speech delay, lack of eye contact…etc. than the ongoing care and management of ASD.*	*0.001*	*-0.024*	*0.039*	*0.01*	*-0.067*
5	*I feel most educated in the use of the pink card to immunise children rather than the use of it to identify developmental and behavioural abnormalities.*	*-0.036*	*0.003*	*0.024*	*0.015*	*0.069*
6	*I have identified a child with ASD previously.*	*0.059*	*0.038*	*-0.055*	*0.037*	*-0.094*
7	*When I suspect a child with ASD I follow the case within the clinic for a few weeks before I refer.*	*-0.057*	*0.008*	*-0.064*	*0.005*	*-0.08*
8	*I prefer to monitor the suspected cases of ASD until they have completed two years and then refer.*	*-0.062*	*-0.038*	*0.059*	*0.065*	*-.119**
9	*I refer the suspected cases within the primary level (psychiatric clinic or paediatric clinic) if I suspect ASD.*	*0.07*	*-0.039*	*0.002*	*-0.057*	*-0.086*
1	*I refer the case to the secondary level when I suspect ASD.*	*.164***	*0.029*	*-.154***	*-0.043*	*0.037*
1	*I think I'm familiar with most of the ASD services in Oman.*	*-0.052*	*-0.076*	*-0.06*	*0.088*	*-.144**

***. Correlation is significant at the 0.01 level, *. Correlation is significant at the 0.05 level*

7.4.5 Social barriers

The respondents were asked to evaluate five items relating to social barriers. These included barriers relating to a lack of parental awareness, devaluing screening, a decline in parental concern over developmental abnormalities, a belief in traditional medicine and Quran therapy, as well as social stigma. Table 7-15 presents the descriptive statistics (frequency, percentage, median and mode) relating to each social barrier. Out of the five social barrier items, the highest agreement score, 84.9%, was given to 'deficiency in parental awareness of ASD'. Both the median and mode for this item were highly significant, '4', indicating a strong barrier to screening for ASD in Oman. Social stigma was recognised by 78% of the respondents as another barrier to screening for ASD, which had high agreement ('3' median and mode). Similarly, devaluing screening had high agreement ('3' median and '4' mode) and 76.7% of the respondents believed that parents may undervalue screening activities and prefer to seek health care services for sickness and mandatory programmes, such as immunisation, rather than screening. The majority of the respondents, 73.3%, also reported a decline in parental concern regarding developmental abnormalities. Parents preferred to give their children time to develop normally before seeking consultation. This item gained high agreement as a barrier, with a median and mode of '3'. Item 4 displayed the lowest agreement score, 71.3%, which highlighted the preference of parents to try Quran and traditional medicines first, when dealing with developmental abnormalities. The median and mode indicated an agreement with this item as a barrier, with median 3 (agree) and mode 4 (strongly agree).

Table 7-15: Number, percentage, median and mode of response to the social barriers

Sr.	Items		Disagreements 1&2	Agreements 3&4	Total	Median	Mode
1.	I think the lack of parental awareness of ASD may challenge potential screening for ASD.	Freq.	73	410	483	4	4
		%	15.1%	84.90%	100%		
2.	I think parents would visit health agencies to treat their children for sickness rather than to screen for behavioural abnormalities.	Freq.	112	369	481	3	4
		%	23.2%	76.70%	100%		
3.	Parents would rather give their children more time to develop normally before seeking medical consultation.	Freq.	128	353	481	3	3
		%	26.6%	73.30%	100%		
4.	Parents might try traditional medicine and Quran therapy when dealing with developmental and behavioural abnormalities, at first.	Freq.	137	340	477	3	4
		%	28.7%	71.30%	100%		
5.	Parents might avoid social embarrassments of early ASD diagnosis.	Freq.	104	368	472	3	3
		%	22.0%	78.00%	100%		

Freq. = Frequency, %= Percent, 1=Strongly Disagree, 2=Disagree, 3=Agree, 4= Strongly Agree

7.4.5.1. Social barriers by gender

Table 7-16 presents the relationships between social barriers and respondents' gender. Among the five social barrier items, there were no significant differences between males and females.

Table 7-16: Relationship between social barrier items and respondents' gender

Sr.	Items	Mean Rank		Z	Sig.
		Male	Female		
1	I think the lack of parental awareness of ASD may negatively influence potential screening for ASD.	247.6	231.7	-1.145	0.252
2	I think parents would visit health agencies to treat their children for sickness rather than to screen for behavioural abnormalities.	221.0	238.0	-1.187	0.235
3	Parents would rather give their children more time to develop normally before seeking medical consultation.	223.7	236.7	-0.884	0.377
4	Parents might try traditional medicine and Quran therapy when dealing with developmental and behavioural abnormalities, at first.	210.3	237.5	-1.849	0.064
5	Parents might avoid social embarrassments of early ASD diagnosis.	210.1	235.1	-1.751	0.080

7.4.5.2. Social barriers by position

Table 7-17 presents the relationship between social barriers and respondents' position. GPs reported higher responses to the social barrier item "*I think the lack of parental awareness of ASD may negatively influence potential screening for ASD"*, compared with nurses (Z= -3.010, Sig=0.003). Nurses, however, reported higher responses to the social barrier item *"Parents might try traditional medicine and Quran therapy when dealing with developmental and behavioural abnormalities, at first"* (Z=-2.697, Sig=0.007).

Table 7-17: Relationship between social barrier items and respondents' position

Sr.	*Items*	*Mean Rank*		*Z*	*Sig.*
		GP	*Nurse*		
1	*I think the lack of parental awareness of ASD may negatively influence potential screening for ASD.*	*254.2*	*219.4*	*-3.010*	*0.003*
2	*I think parents would visit health agencies to treat their children for sickness rather than to screen for behavioural abnormalities.*	*237.3*	*228.8*	*-0.708*	*0.479*
3	*Parents would rather give their children more time to develop normally before seeking medical consultation.*	*228.2*	*233.5*	*-0.434*	*0.664*
4	*Parents might try traditional medicine and Quran therapy when dealing with developmental and behavioural abnormalities, at first.*	*209.5*	*242.3*	*-2.697*	*0.007*
5	*Parents might avoid social embarrassments of early ASD diagnosis.*	*226.4*	*228.2*	*-0.149*	*0.881*

7.4.5.3. Social barriers by nationality

Table 7-18 shows the relationship between social barriers and respondents' nationality. Omani and non-Omani people differed significantly in terms of two social barriers. Omani respondents were found to have a higher mean rank on parental awareness of ASD and the effect of screening, as well as the use of traditional medicine, when compared with non-Omani people.

Table 7-18: Relationship between social barrier items and respondents' nationality

Sr.	*Items*	*Mean Rank*		*Z*	*Sig.*
		Omani	*Non-Omani*		
1	*I think the lack of parental awareness of ASD may negatively influence potential screening for ASD.*	*301*	*160*	*-4.065*	*0.000*
2	*I think parents would visit health agencies to treat their children for sickness rather than to screen for behavioural abnormalities.*	*301*	*159*	*-0.998*	*0.318*
3	*Parents would rather give their children more time to develop normally before seeking medical consultation.*	*300*	*159*	*-0.990*	*0.322*
4	*Parents might try traditional medicine and Quran therapy when dealing with developmental and behavioural abnormalities, at first.*	*299*	*158*	*-5.852*	*0.000*
5	*Parents might avoid social embarrassments of early ASD diagnosis.*	*298*	*153*	*-0.475*	*0.634*

7.4.5.4. Social barriers by qualification

Table 7-19 presents the relationship between social barriers and respondents' qualifications. There were significant differences in two social barriers by qualification. Inspecting the mean rank showed that concern over the lack of parental awareness of ASD and its influence on screening, as well as the role of traditional medicine, decreased with an increasing level of qualification.

Table 7-19: Relationship between social barrier items and respondents' qualification

Sr.	*Items*	*Mean Rank*			*Chi-Square*	*Sig.*
		Diploma	*BSc*	*Specialty*		
1	*I think the lack of parental awareness of ASD may negatively influence potential screening for ASD.*	*211*	*178*	*49*	*6.758*	*0.034*
2	*I think parents would visit health agencies to treat their children for sickness rather than to screen for behavioural abnormalities.*	*210*	*178*	*50*	*1.524*	*0.467*
3	*Parents would rather give their children more time to develop normally before seeking medical consultation.*	*210*	*177*	*50*	*3.332*	*0.189*
4	*Parents might try traditional medicine and Quran therapy when dealing developmental and behavioural abnormalities, at first.*	*210*	*175*	*50*	*11.034*	*0.004*
5	*Parents might avoid social embarrassments of early ASD diagnosis.*	*207*	*175*	*49*	*1.302*	*0.522*

7.4.5.5. Social barriers by respondents' characteristics

Older respondents assumed that parental awareness of ASD would influence the success of screening processes in Oman (rho=0.102, p<0.05). However, they gave a lower rank to the idea that "*traditional medicine and Quran therapy"* would be the first approach that parents might try when they suspected a developmental abnormality in their children (rho=-0.105, p<0.01), see Table 7-20.

As the number of patients seen per day increased, the respondents gave higher scores to the barrier *"Parents would rather give their children more time to develop normally before seeking medical consultation"* (rho= 0.165, p<0.01) and the barrier *"Parents might try traditional medicine and Quran therapy when dealing with developmental and behavioural abnormalities, at first"* (rho=0.138, p<0.05). There were no significant correlations between social barriers and work experience, the number of staff per shift or the number of programmes run in the institution.

Table 7-20: Spearman correlations between social barriers and respondents' age, experience (yrs), patient numbers, staff numbers and programme numbers.

Sr	*Items*	*Age (yrs.)*	*Work Experience (yrs.)*	*No. of patients (per day)*	*No. of staff (per shift)*	*No. of programmes*
1	*I think the lack of parental awareness of ASD may negatively influence potential screening for ASD.*	*.102**	*0.028*	*-0.007*	*0.038*	*0.018*
2	*I think parents would visit health agencies to treat their children for sickness rather than to screen for behavioural abnormalities.*	*-0.002*	*0.04*	*0.062*	*0.058*	*-0.106*
3	*Parents would rather give their children more time to develop normally before seeking medical consultation.*	*0.007*	*0.016*	*.165***	*0.057*	*-0.063*
4	*Parents might try traditional medicine and Quran therapy when dealing with developmental and behavioural abnormalities, at first.*	*-.105**	*-0.012*	*.138**	*0.057*	*0.001*
5	*Parents might avoid social embarrassments of early ASD diagnosis.*	*-0.016*	*-0.03*	*-0.005*	*0.061*	*-0.046*

***. Correlation is significant at the 0.01 level,*. Correlation is significant at the 0.05 level*

7.4.6 Facilitators

The respondents were asked to evaluate items relating to the facilitators. Table 7-21 presents the descriptive statistics (frequency, percent, median, and mode) of each facilitator. Again,

the dominant trend was that most of the results tended towards the "agreed" continuum. Out of the facilitator items, the highest agreement score (94.7%, median and mode 4=strongly agree) was given to the "*increasing awareness"* and "*improving health and education sectors' collaboration"* items. Most of the respondents (93.7%) indicated significant agreement ('4' for both median and mode) with the importance of coordination between assessment/diagnostic and intervention services to facilitate future screening. Slight differences were noted among the respondents with regard to where to introduce an ASD screening programme, with 90.8% preferring to design specific screening programmes for ASD within the primary settings. However, 90.4% favoured integrating ASD characteristics within the pink card and ASD screening within the current well check visit. Again, significant agreements, '4', were given to this item as a possible facilitator of screening. In this phase, the importance of choosing a general term for the screening process, rather than "ASD" screening, was also highlighted by 89.5% of the respondents who were in strong agreement – '4'. In contrast to the findings from phase 1, the respondents seemed interested in screening for ASD if their institutions were well equipped for screening. This item achieved the lowest agreement score (76.3%, median 3=agree and mode 4=strongly agree) in this phase and was indicated by the item: *"I think I would be in a unique position to screen for ASD, if I received the appropriate training and education"*.

Table 7-21: Number, percentage, median and mode of response to the facilitators

Sr.	*Items*		*Disagreements (1&2)*	*Agreements (3&4)*	*Total*	*Median*	*Mode*
1.	*I think I would be in a unique position to screen for ASD, if I received the appropriate training and education.*	*Freq.*	*112*	*361*	*473*	*3*	*4*
		%	*23.70%*	*76.30%*	*100%*		
2.	*In order to facilitate ASD screening, our service would need to integrate ASD characteristics into the pink card's child health check part.*	*Freq.*	*44*	*416*	*460*	*4*	*4*
		%	*9.60%*	*90.40%*	*100%*		
3.	*In order to facilitate ASD screening, our service would need to design a specific screening programme for ASD within PHC settings.*	*Freq.*	*43*	*423*	*466*	*4*	*4*
		%	*9.20%*	*90.80%*	*100%*		
4.	*I believe improving coordination between the assessment/diagnostic and intervention services in Oman would advance the advantages of early ASD screening.*	*Freq.*	*30*	*443*	*473*	*4*	*4*
		%	*6.30%*	*93.70%*	*100%*		
5.	*Increasing public and professional awareness of ASD would reduce the social embarrassments of the disorder.*	*Freq.*	*25*	*447*	*472*	*4*	*4*
		%	*5.30%*	*94.70%*	*100%*		
6.	*Collaboration between health and educational services is needed to facilitate the early identification of ASD.*	*Freq.*	*25*	*447*	*472*	*4*	*4*
		%	*5.30%*	*94.71%*	*100%*		
7.	*At the time of screening, using a more general term instead of "Al Twahed" might increase the uptake for screening for ASD.*	*Freq.*	*48*	*412*	*460*	*3*	*4*
		%	*10.40%*	*89.50%*	*100%*		

Freq. = Frequency, %= Percent, 1=Strongly Disagree, 2=Disagree, 3=Agree, 4= Strongly Agree

7.4.6.1. Facilitators by gender of participants

Table 7-22 presents the relationship between social barriers and the respondents' gender. Among the eight facilitator items, there were no significant differences between males and females.

Table 7-22: Relationship between facilitator items and respondents' gender

Sr	*Items*	*Mean Rank*		*Z*	*Sig.*
		Male	*Female*		
1.	*I think I would be in a unique position to screen for ASD, if I received the appropriate training and education.*	*242.6*	*226.9*	*-1.076*	*0.282*
2.	*In order to facilitate ASD screening, our service would need to integrate ASD characteristics into the pink card's child health check part.*	*225.7*	*223.6*	*-0.164*	*0.870*
3.	*In order to facilitate ASD screening, our service would need to use a specific tool to screen for ASD within the current immunisation and surveillance programme.*	*228.9*	*223.3*	*-0.438*	*0.662*
4.	*In order to facilitate ASD screening, our service would need to design a specific screening programme for ASD within PHC settings.*	*228.5*	*226.0*	*-0.197*	*0.844*
5.	*I believe improving coordination between the diagnostic and intervention services in Oman would advance the advantages of early ASD screening.*	*246.2*	*225.7*	*-1.616*	*0.106*
6.	*Increasing public and professional awareness of ASD would reduce the social embarrassments of the disorder.*	*242.2*	*226.1*	*-1.371*	*0.170*
7.	*Collaboration between health and educational services is needed to facilitate the early identification of ASD.*	*238.2*	*227.2*	*-0.984*	*0.325*
8.	*At the time of screening, using a more general term instead of "Al Twahed" might increase the uptake for screening for ASD.*	*210.3*	*226.9*	*-1.220*	*0.222*

7.4.6.2. Facilitator by position

Table 7-23 presents the relationship between facilitators and the respondents' position. GPs reported a significantly higher agreement than nurses to three facilitators: *"Improving coordination between the diagnostic and intervention services"* (Z=-2.410, Sig=0.016), *"Increasing public and professional awareness"*, (Z=-2.110, Sig=0.035), and improving "*health and educational service collaboration",* (Z=-2.517, Sig=0.012).

Table 7-23: Relationship between facilitator items and respondents' position

Sr	*Items*	*Mean Rank*		*Z*	*Sig.*
		GP	*Nurse*		
1.	*I think I would be in a unique position to screen for ASD, if I received the appropriate training and education.*	*241.8*	*219.0*	*-1.913*	*0.056*
2.	*In order to facilitate ASD screening, our service would need to integrate ASD characteristics into the pink card's child health check part.*	*227.8*	*217.7*	*-0.937*	*0.349*
3.	*In order to facilitate ASD screening, our service would need to usea specific tool to screen for ASD within the current immunisation and surveillance programme.*	*225.6*	*219.8*	*-0.540*	*0.589*
4.	*In order to facilitate ASD screening, our service would need to design a specific screening programme for ASD within PHC settings.*	*241.9*	*213.0*	*-2.727*	*0.006*
5.	*I believe improving coordination between the diagnostic and intervention services in Oman would advance the advantages of early ASD screening.*	*243.3*	*217.8*	*-2.410*	*0.016*
6.	*Increasing public and professional awareness of ASD would reduce the social embarrassments of the disorder.*	*239.6*	*219.2*	*-2.110*	*0.035*
7.	*The collaboration between health and educational services is needed to facilitate the early identification of ASD.*	*241.5*	*218.2*	*-2.517*	*0.012*
8.	*At the time of screening, using a more general term instead of "Al Twahed" might increase the uptake for screening for ASD.*	*232.8*	*214.0*	*-1.665*	*0.096*

7.4.6.3. Facilitators by nationality

Table 7-24 shows the relationship between facilitators and respondents' nationality. Omani and non-Omani people differed significantly in the first seven facilitators. Omani people were in stronger agreement with all of the facilitators compared to non-Omani people.

Table 7-24: Relationship between facilitator items and respondents' nationality

Sr.	*Items*	*Mean Rank*		*Z*	*Sig.*
		Omani	*Non-Omani*		
1.	*I think I would be in a unique position to screen for ASD, if I received the appropriate training and education.*	*297*	*154*	*-5.184*	*0.000*
2.	*In order to facilitate ASD screening, our service would need to integrate ASD characteristics into the pink card's child health check part.*	*287*	*152*	*-2.104*	*0.035*
3.	*In order to facilitate ASD screening, our service would need to use a specific tool to screen for ASD within the current immunisation and surveillance programme.*	*290*	*150*	*-3.050*	*0.002*
4.	*In order to facilitate ASD screening, our service would need to design a specific screening programme for ASD within PHC settings.*	*289*	*155*	*-3.679*	*0.000*
5.	*I believe improving coordination between the diagnostic and intervention services in Oman would advance the advantages of early ASD screening.*	*293*	*158*	*-3.204*	*0.001*
6.	*Increasing public and professional awareness of ASD would reduce the social embarrassments of the disorder.*	*292*	*158*	*-2.141*	*0.032*
7.	*Collaboration between health and educational service is needed to facilitate early identification of ASD.*	*295*	*155*	*-3.964*	*0.000*
8.	*At the time of screening, using a more general term instead of "Al Twahed" might increase the uptake for screening for ASD.*	*292*	*146*	*-0.110*	*0.912*

7.4.6.4. Facilitators by qualifications

Table 7-25 presents the relationship between facilitators and respondents' qualifications. There were significant differences in four facilitators by qualification: the need for screening instruments, incorporating the screening programmes within the PHC settings, improving service coordination, and increasing public/professional awareness. In all items, those respondents with a diploma level education awarded a higher score, while those possessing a speciality qualification reported the lowest score.

Table 7-25: Relationship between facilitator items and respondents' qualification

Sr.	*Items*	*Mean Rank*			*Chi-Square*	*Sig.*
		Diploma	*BSc*	*Specialty*		
1.	*I think I would be in a unique position to screen for ASD, if I received the appropriate training and education.*	*201*	*169*	*49*	*1.614*	*0.446*
2.	*In order to facilitate ASD screening, our service would need to integrate ASD characteristics into the pink card's child health check part.*	*202*	*172*	*47*	*1.366*	*0.505*
3.	*In order to facilitate ASD screening, our service would need to use a specific tool to screen for ASD within the current immunisation and surveillance programme.*	*201*	*174*	*49*	*15.513*	*0.000*
4.	*In order to facilitate ASD screening, our service would need to design a specific screening programme for ASD within PHC settings.*	*204*	*177*	*50*	*7.554*	*0.023*
5.	*I believe improving coordination between the diagnostic and intervention services in Oman would advance the advantages of early ASD screening.*	*204*	*177*	*50*	*7.917*	*0.019*
6.	*Increasing public and professional awareness of ASD would reduce the social embarrassments of the disorder.*	*207*	*174*	*50*	*9.300*	*0.010*
7.	*Collaboration between health and educational services is needed to facilitate early identification of ASD.*	*204*	*169*	*47*	*1.010*	*0.604*

7.4.6.5. Facilitators by respondents' characteristics

Age was positively correlated with facilitators, with older practitioners being more in favour of "*Improving coordination*" (rho=0.119, $p<0.05$), and "*Increasing awareness*" (rho=0.120, $p<0.05$) than their younger colleagues. However, the most experienced respondents assigned higher scores to the facilitator: "*specific tool to screen for ASD within the current immunisation and surveillance programme",* (rho=0.098, $p<0.05$). On the other hand, when there was an increase in the number of staff on a shift, they assigned higher scores to the facilitator that encouraged using a general term for the screening programme, other than "ASD", to increase the uptake (rho=0.129, $p<0.05$). There were no significant correlations between the facilitators and the number of patients seen per day or the number of programmes run by the institution (see Table 7-26).

Table 7-26: Spearman correlations between social barriers and respondents' age, experience (yrs), patients, staff, and programmes.

Sr.	*Items*	*Age (yrs.)*	*Work Experience (yrs.)*	*No. of patients (per day)*	*No. of staff (per shift)*	*No. of programmes*
1.	*I think I would be in a unique position to screen for ASD, if I received the appropriate training and education.*	*0.08*	*0.014*	*0.026*	*-0.058*	*0.045*
2.	*In order to facilitate ASD screening, our service would need to integrate ASD characteristics into the pink card's child health check part.*	*0.062*	*0.091*	*0.024*	*0.014*	*0.046*
3.	*In order to facilitate ASD screening, our service would need to use a specific tool to screen for ASD within the current immunisation and surveillance programme.*	*0.083*	*.098**	*0.032*	*-0.063*	*0.046*
4.	*In order to facilitate ASD screening, our service would need to design a specific screening programme for ASD within PHC settings.*	*0.045*	*0.008*	*0.013*	*-0.01*	*-0.006*
5.	*I believe improving coordination between the diagnostic and intervention services in Oman would advance the advantages of early ASD screening*	*.119**	*0.023*	*0.069*	*-0.055*	*0.023*
6.	*Increasing public and professional awareness of ASD would reduce the social embarrassments of the disorder.*	*.120**	*0.051*	*-0.014*	*-0.029*	*-0.044*
7.	*Collaboration between health and educational services is needed to facilitate the early identification of ASD.*	*0.069*	*0.036*	*-0.004*	*-0.024*	*-0.005*
8.	*At the time of screening, using a more general term instead of "Al Twahed" might increase the uptake for screening for ASD.*	*0.001*	*0.02*	*0.025*	*.129**	*-0.082*

***. Correlation is significant at the 0.01 level, *. Correlation is significant at the 0.05 level*

7.4.7 The most important changes to facilitate ASD screening in Oman

The respondents were asked to rank eight different changes that would facilitate screening for ASD in the PHC system in Oman (Table 7-27). The item regarding increasing awareness was ranked as the greatest facilitator by 52.7% of respondents. This item was selected as the

number one facilitator. The second greatest facilitator, selected by 52.0% of respondents, involved providing resources (i.e. screening tools, expertise, and training). The third greatest facilitator, selected by 35.5%, looked at encouraging both health and education collaboration.

Table 7-27: Ranking of changes that would facilitate screening for ASD in the PHC system in Oman

	Changes to screening	*Freq.*	*Percent (%)**
1	*Reduce time constraints*	*34*	*6.9%*
2	*Increase the number of staff in the clinic*	*130*	*26.5%*
3	*Provide required expertise, screening tools*	*255*	*52.0%*
4	*Increase professional and public awareness*	*258*	*52.7%*
5	*Activate appointment system for the immunisation and child check visit*	*68*	*13.9%*
6	*Improve service coordination between the diagnostic and intervention services*	*142*	*29.0%*
7	*Encourage educational and health collaboration to identify ASD*	*174*	*35.5%*
8	*Reduce social stigma and sensitivity to the disorder*	*89*	*18.2%*
**Percentage calculated out of the total respondents (n=490)*			

7.4.7.1. By gender and current position

As most of the male respondents were GPs, and most of the female respondents were nurses, the chosen facilitators, based on position, matched the results by gender. Both groups selected the same facilitators but their percentages differed (see Tables 7-28 and 7-29). For example, 61.9% of males and 64.0% of the GPs ranked '*the need for provision of resources'* (i.e. screening tools and expertise) as the most important facilitator. This was followed by an increase in awareness, as it was chosen by 55.7% males and 54.9% GPs.

However, 52.9% of females and 51.9% of nurses viewed *'increasing awareness'* as the number one facilitator. This was followed by '*the provision of resources',* which was highlighted by 50.3% of females and 46.8% of nurses. Encouraging collaboration between education and health was the third most highly selected facilitator, for both groups: males 32.0%, GPs 33.7%, females 36.2% and nurses 36.3%.

Table 7-28: Ranking by gender to show changes that would facilitate screening for ASD in the PHC system in Oman

Sr.	Items	MALE		FEMALE		Total
		Freq.	%*	Freq.	%*	
1	Reduce time constraints	6	6.2%	27	7.1%	33
2	Increase the number of staff in the clinic	25	25.8%	96	25.4%	121
3	Provide required expertise, screening tools	60	61.9%	190	50.3%	250
4	Increase professional and public awareness	54	55.7%	200	52.9%	254
5	Activate appointment system for the immunisation and child check visit	20	20.6%	43	11.4%	63
6	Improve service coordination between the diagnostic and intervention services	28	28.9%	112	29.6%	140
7	Encourage educational and health collaboration to identify ASD	31	32.0%	137	36.2%	168
8	Reduce social stigma and sensitivity to the disorder	25	25.8%	63	16.7%	88

***Percentage calculated out of the total males (n=97) and females (n=378)**

Table 7-29: Ranking by gender to show changes that would facilitate screening for ASD in the PHC system in Oman

Sr.	Items	GPs		Nurse		Total
		Freq.	%*	Freq.	%*	
1	Reduce time constraints	15	8.6%	19	6.4%	34
2	Increase the number of staff in the clinic	42	24.0%	80	27.1%	122
3	Provide required expertise, screening tools	112	64.0%	138	46.8%	250
4	Increase professional and public awareness	96	54.9%	153	51.9%	249
5	Activate appointment system for the immunisation and child check visit	23	13.1%	41	13.9%	64
6	Improve service coordination between the diagnostic and intervention services	50	28.6%	88	29.8%	138
7	Encourage educational and health collaboration to identify ASD	59	33.7%	107	36.3%	166
8	Reduce social stigma and sensitivity to the disorder	30	17.1%	55	18.6%	85

***Percentage calculated out of the total GP (n=175) and Nurses (n=295)**

Table 7-30: Summary of the significant results from the questionnaire analysis

Dimensions	***Results***	***Respondent characteristics associated with reported barriers /facilitators***
Barriers to screening ***1. Organisational***	*Limited resources*	• *Non-Omani* • *Higher qualifications*
	Lack of on the-job training on ASD	• *Non-Omani* • *Higher qualifications* • *Older* • *More programmes and activities run in their institutions*
	Time constraints	• *Omani*
	Lack of documentation for the identified and referred suspected cases	• *Male* • *Lower qualifications* • *More patients seen*
	Maximum number of patients seen per day	• *More programmes and activities run in their institutions*
	Lack of a guiding protocol to refer suspected cases of ASD to the diagnostic services	• *Most experienced*
	Staff shortages	• *More patients seen*
2. Professional	*Variation in professional knowledge, confidence and skills to identify ASD and developmental abnormality:* • *Knowledge of ASD was based on information provided by the parents of children with ASD*	• *Females* • *Nurses*
	• *Knowledge of ASD was based on the information studied during their professional training*	• *GPs* • *Non-Omani* • *Younger* • *Less experienced*
	• *Knowledge of ASD was based on information acquired through self-updates and training*	• *Males* • *GPs* • *Non-Omani*
	• *More educated regarding the signs and symptoms of ASD than they were in other aspects of care and management for this disorder*	*No significant differences among respondents*

	• *Less confident in monitoring and identifying developmental abnormalities and would rather use the pink card for scheduling the child's immunisations*	*No significant differences among respondents*
	• *Had identified a child with ASD earlier*	• *No significant differences among respondents*
	Discrepancy and lack of uniformity on when and where to refer a suspected case • *Refer suspected cases within the primary level, psychiatric clinic or paediatric clinic*	• *Males* • *GPs*
	• *Refer suspected cases to the secondary level*	• *Non-Omani* • *Older respondents*
	• *Prefer to refer suspected children for further investigation*	• *Non-Omani*
	• *In agreement with following the child within their own clinic for two years before referring him/her for further investigation*	• *Omani* • *Lower qualifications*
	• *Limited knowledge of the services provided for children with ASD in Oman*	• *Males* • *More programmes and activities run in their institutions*
3. Social	*Deficiency in parental awareness of ASD*	• *GPs* • *Omani* • *Lower qualifications* • *Older*
	Social stigma *Less value given to screening activities*	• *No significant differences among respondents*
	Parental denial	• *More patients seen on a daily basis*
	Trust in Quran and traditional medicine as first choice when dealing with developmental abnormalities and ASD.	• *Nurses* • *Omani* • *Lower qualifications* • *More patients seen*
Facilitators to screening	*Increase public and professional awareness of ASD*	• *GPs* • *Omani* • *Older*

	Promote coordination between assessment/diagnostic and intervention services to facilitate future screening	• *GPs* • *Omani* • *Older*
	Provision of resources	• *Omani*
	Encourage sectors' collaboration	• *GPs* • *Omani*
	Interested in screening for ASD if their institutions were well equipped for screening	*No significant differences among respondents*
	Design specific screening programmes for ASD within the primary settings	*No significant differences among respondents*
	Integrate ASD characteristics within the pink card and ASD screening within the current well check visit	• *Most experienced*
	Choose a general term for the screening process, other than "ASD" screening	*No significant differences among respondents*

7.5. Findings of the free text response

Three themes were identified from the data analysis of the free text response within the questionnaire: *'constraints', 'family', and 'professional education'*. The first theme, *"constraints"*, explored the PHPs' perceptions of potential challenges to screening for ASD. Three sub-themes emerged: *'no time', 'no structured forum',* and *'no resources'.* The second theme, *'family'*, focused on the participants' perceptions of the social and cultural aspects of screening and how to facilitate screening for ASD in Oman. This theme comprised four sub-themes: *'awareness', 'denial* and *stigma'*, *'traditional medicine'* and *'co-production'.* The final theme: "*professional education and training*", identified the PHPs' needs to facilitate an effective screening process within their current practices, under three sub-themes: '*exposure',* '*interest',* and '*education and training'*.

7.5.1.1. Constraints and potentials

This theme sought to identify the potential challenges that PHPs encounter within their current practices in screening for ASD and what steps may be undertaken to overcome these challenges. Most of the respondents elaborated that ***'Time constraints'*** were a major barrier to identifying children suspected of having ASD.

> *'there is no time to screen all the children below five years' (GP 5018/108)*

> *'We lack the time…to examine and recognise ASD' (Nurse 7019/193)*

For this reason, the participants felt that a longer time frame was important to identify children suspected of having ASD before sending them for further investigation.

> *'Mostly time constraints, proper assessments and diagnosis require time, observation and follow-up tests. At our level, we can screen if anything is suspicions and send the patient for further examination and treatment.' (GP 2030/3)*

In addition to time constraints, the participants noted that the lack of a ***'structured forum'*** might challenge the potential screening process. Participants expressed the view that the current structure of their institutions was too tight to provide a private place to assess a child suspected of having ASD or to communicate with their parents. They encouraged the allocation or construction of a place to screen.

> *'Our institution is too small/ not enough space for carrying such a programme' (Nurse 80117/147)*

> *'We need a private room to communicate with parents and assess suspected children, which is not available' (GP 5031/115)*

> *'It will be a good idea to open a clinic for this group of patients' (Nurse 7011/39)*

They also recognised that there was ***no facility*** for screening children for ASD in Oman.

> *'Still no ASD programme started in our health centre' (Nurse 1005/58)*

> *'The programme still not activated in H/C' (GP 1006/59)*

> *'We don't have a clinic for ASD' (Nurse 5030/114)*

In addition to a lack of space, the participants also considered there to be a deficit in the essential resources needed to screen for ASD. For example, they thought that they did ***not have enough staff*** to undertake the screening process and suggested increasing the number of staff.

> *'We need other buildings, staff, doctors to identify these cases' (Nurse 6060/133)*

> *'Providing extra staff is important' (GP 5010/16)*

A minor concern for participants was the ***language barriers*** when assessing and identifying children suspected of having ASD. They voiced the lack of staff diversity in some health centres.

> *'In our institution, the number of expatriate staff is more than Omani, in that it's difficult to carry out all programmes by Omani staff. Also, for ASD screening need Omani staff to communicate with the parents' (Nurse 8002/53).*

Most of the participants highlighted the ***lack of appropriate means*** or lack of screening instruments to identify children with ASD.

> *'Needs to be supplied with a screening tool for ASD' (GP 5013/17)*

> *'ASD was presented recently but did not touch upon screening tool' (GP 11136/74)*

> *'We don't have assessment tools and staff nurse not trained in this' (Nurse 9021/156)*

This led some participants to suggest the ***pink card*** as a useful tool for identifying developmental and behavioural abnormalities.

> *'The pink card is important for immunisation and to identify developmental and behavioural abnormality' (Nurse 11007/165)*

They suggested the incorporation of 'the signs and symptoms of ASD' within the pink card and the well check visit to facilitate screening.

> *'Pink card should detail the signs and symptoms and be discussed with parent' (GP 11071/170)*

> *'Integrating ASD screening in pink card check list is an important step toward early detection' (Nurse 3007/174)*

Other participants, however, disagreed with this opinion because children with ASD are commonly identified after two years of age, while the pink card should only be used for the first two years. Instead, they suggested the development of a specific screening programme to screen for ASD.

> *'I'm not with integrating ASD characteristics into the pink card because most of them we discover after 24 months of age and the pink card the parents will not bring to health institution' (GP 7026/198)*

> *'Pink card is used till year 2 of age only' (Nurse 7013/192)*

> *'Screening for ASD can be involved in vaccination card up to 2 years; between 2-5 years the most important age of separate screening programme should be documented their' (GP 5018/181)*

Specialism was viewed as an essential step to support screening and resolve constraints. Many participants called for specialisation within the field of ASD such as special screening programmes for ASD. However, this would require a specific team of ***professionals*** who were trained and who had expertise in ASD.

> *'It is better to have specialist for screening and managing autistic case if present' (Nurse 9023/57)*

In addition to staff expertise, some participants believed that such a programme would also require ***specialised settings***, which emphasised the findings regarding concerns relating to the allocation of private space for screening for ASD**.**

> *'We need special place to see ASD' (GP 4052/176)*

In addition, some participants suggested the allocation of ASD units within the PHC settings.

'All health centres must have special clinic and specialist for screening and diagnosing like this case'(Nurse 5006/12)

'Should be a clinic in PHC and trained staff to screen' (GP 11031/63)

Others felt that screening for ASD should be introduced at the secondary level because the staff at this level would be more specialised. Therefore, children suspected of having ASD at the primary level would be referred to this clinic for further investigation.

'I think paediatric staff more aware of children of ASD as they are dealing with children only but I'm in general clinic dealing with all patients of all ages' (Nurse 8013/153)

The PHPs noted the significance of having a clear ***system*** to guide the screening process within the PHC context, as there were no clear policies, referral routes or registration policies in place. They also suggested adding appointments within the developed system to provide better follow-up services for suspected cases of ASD.

'Please supply clear guidelines to identify, diagnose, and refer patients' (GP 7008/38)

'We don't have any register book or any special programme for ASD or any suspected cases' (Nurse 11007/62)

'For ASD patient must have an appointment for follow-up' (Nurse 7051/50)

7.5.1.2. Family

Family is the second theme that emerged from this study. It highlighted some of the cultural and social challenges relating to screening for ASD. It also incorporated a number of suggestions to resolve such challenges. In the first sub-theme ***'awareness'***, the participants believed that better Omani community awareness and generic knowledge of ASD were required, reflecting the views in the qualitative phase.

'There is not that much awareness in the community and not that much care in health institutions' (Nurse 7053/51)

'People need to know the signs and symptoms of ASD to detect it earlier' (GP 2020/81)

'Need to improve social awareness' (GP2020/180)

The participants also believed that a lack of awareness among the public was the main reason for under-identification of ASD, which would delay the process of diagnosis and management.

> *'Lack of awareness about ASD in our society, which means a lot of cases are suffering without detection, diagnosis and proper management' (Nurse 7011/132)*

> *'Lack of community awareness about ASD is the main reason for neglecting these children' (GP 2002/174)*

Other participants believed that a lack of awareness of the condition, social stigma, and the ***availability of health services*** for such a condition in Oman, may all lead parents to ***denial***. Others thought that the low socio-economic status of a family may restrict parental choice in seeking health care services from specialised institutions. This was because these services tended to be located in the capital city or private institutes. These challenges were also thought to encourage parents to try ***traditional medicine and Quran therapy*** first, which may delay the detection and management process and eventually lead to suffering.

> *'At first, parents are in denial with the condition of their child., maybe due to lack of knowledge about the condition, and lack of awareness about agencies that can help their child's condition improve and low socioeconomic status' (GP 10008/154)*

> *''Parent would like to treat their child with traditional medications and Quran rather than bringing them to the medical team' (Nurse 6062/125)*

Moreover, a few participants thought that the lack of social awareness, knowledge of ASD and availability of the required services were the main reasons for ***stigmatising*** the disorder. For that reason, parents may isolate their children from the wider community.

> *'...they will feel embarrassment from the community and how to deal with it[ASD child]' (Nurse 6062/125)*

> *'In most ASD cases, parents will accept the diagnosis for ADHD rather than ASD (stigma)' (GP 5018/103)*

> *'Some families feeling embarrassed to show their child who has ASD' (GP 6061/124)*

Increasing public awareness was found to be essential for reducing stress on parents, improving the process of early intervention and reducing the social stigma of the disorder.

> *'Community needs more awareness about such behavioral abnormalities (ASD) and discovering the problem early will help to treat it early' (GP 2020/180)*

> *'To raise awareness among the parents' (GP 11071/163)*

> *'Awareness about the problem to reduce social stigma' (Nurse 7022/194)*

Most participants suggested improving public awareness by organising health education and training programmes.

> *'Health education has a great role to play in society to improve public awareness about ASD signs and how to deal with patients' (GP 2037/187)*

> *'To train the parents and give them more training and knowledge' (Nurse 5030/109)*

Others suggested that the motivation of community leaders and social agencies could improve public awareness of ASD.

> *'Should start some social activities through the community leaders to educate parents for early awareness of ASD' (Nurse 7010/130)*

> *'Activate social agencies to increase awareness and decrease stigma' (GP 6008/118)*

Other ideas were also put forward, for example, the role of General Practitioners in improving community awareness.

> *'The doctors can help by providing the community with some advice, to know this disorder, causes and treatment' (GP 9031/150)*

The media was also suggested to increase parental knowledge of these disorders.

> *'Use media to educate public about ASD' (Nurse 5060/117)*

> *'Parents are educated via media/newspaper that ASD isn't something to be ashamed of but they need a lot of support from us' (Nurse 5044/113)*

Co-production was another sub-theme identified in this study, whereby all party practitioners, the public and those with ASD, could join together and use resources to facilitate early identification, early management and therefore improve children's independence.

> *'Community should cooperate with the health institution and parents of children with ASD' (GP 2004/178)*

> *'Actually, most parents are aware of the motor and social development of their children when suspect abnormality, so we should listen and support them with advice or counselling' (Nurse 5008/197)*

Although the participants encouraged involvement from both parents in noting abnormalities, they felt that mothers would be better placed to report any abnormalities to the health team.

'I think a mother can help to detect and diagnose behavioural abnormalities' (Nurse 7017/40)

'Observing hyperactive kids in the doctor's room and taking history from mother will help in detecting cases' (GP 5018/108)

'If mother complains of abnormal behaviour, so would like to refer to paediatrics' (GP 2049/87)

7.5.1.3. Professional education

The third theme to emerge from this study was 'professional education'. This theme described the PHPs' perceptions of actions that could be taken to enable them to run a successful screening programme for ASD, within the PHC context. Three sub-themes were uncovered in this area: 'exposure', 'interest' and 'education and training'.

Interestingly, some participants held contradictory views on their knowledge of ASD, as demonstrated in section 7.4.4. However, qualitative data from this questionnaire noted that some PHPs felt that they did not have the ***knowledge or the required experience*** to identify or refer a child suspected with ASD.

'Honestly, I haven't got enough knowledge about ASD. I didn't see any doctor refer any case that suspect child with ASD' (GP 2002/75)

'... most of the professionals not having more knowledge about it [ASD]' (Nurse 7046/146)

'I know nothing about ASD in Oman' (Nurse 6038/132)

'We have a lack of experienced medical officers to identify and diagnose new cases' (GP 11006/61)

The main reasons put forward were a lack of exposure to such cases and a lack of education and training.

'For ASD cases I have not observed one in institution for a follow-up, I just noted few cases outside the institutes' (GP 3002/189)

'I don't have any base on scientific data in dealing with such cases' (Nurse 5016/107)

'No training courses for health medical staff on diagnosis and dealing with autistic patients' (Nurse 5016/18)

Interestingly, the majority of the participants requested ***professional education and training*** to equip them with the required knowledge, skills and experience to screen for ASD.

> *'Arrange Continuing Medical Education (CME) regarding ASD' (GP5001/11)*

> *'Provide appropriate training and education to all staff regarding ASD' (Nurse 5060/123)*

A minority of participants noted the ***lack of access to information*** regarding ASD within the health care facilities.

> *'No hospital information management system about ASD. There is also no health publication on ASD in the hospital library' (GP7042/46)*

Despite the constraints, there was a genuine ***desire*** to screen for ASD and to have a more active programme for screening.

> *'More attention to be given to this issue' (GP 11071/68)*

> *'There is a need to add this programme to care for this group of people' (Nurse 5044/25)*

> *'Early detection of the cases will make improvement to this child and benefit them as early as possible' (Nurse 6062/186)*

PHPs reported that completing this questionnaire made them think about their lack of knowledge regarding ASD and what they can do to resolve this.

> *'Before this questionnaire, I never thought to screen the child for psychological problems or to establish special referral for behavioural problem. If mother complains of abnormal behaviour, so would like to refer to paediatrics' (GP 2049/87)*

7.6. Chapter summary

In conclusion, the opinions of PHPs on the facilitators of and barriers to screening for ASD within PHC settings in Oman were sought using a questionnaire sent to a random sample across Oman. The respondents have presented a number of constraints that might challenge the potential screening for ASD. These have been categorised into three levels: organisational, institutional and social. Despite the constraints, the respondents noted some strategies that would facilitate ASD screening if a programme were implemented. Increasing

public/professional awareness was found to be a key step in improving future screening in Oman, along with encouraging collaboration between health and education sectors.

Additionally, there are social challenges to overcome, such as facilitating parental cooperation on early identification and reducing the social and cultural stigma and sensitivities towards the disorder. Resources are required in order to build appropriate systems to guide the screening process – guidelines, policies, referrals/feedback and registration procedures. It is believed that this will increase parental trust and encourage parents to seek medical services instead of traditional medicine or healers.

Chapter 8: **Discussion**

8.1. **Introduction**

This chapter is designed to provide answers to and interpretations of the research questions, and to discuss the implications of the findings. The strengths and limitations of the study will be presented and information regarding screening for ASD in Oman will be related to the wider literature.

8.2. **Study overview**

As explained in the methods chapter (Chapter 4), a mixed-methods approach was employed to sequentially gather data from different sources, in order to strengthen the context of the research and to widen its application. Qualitative methods were adopted, initially, to explore the phenomena and to guide the development of a questionnaire. The questionnaire was used in the quantitative stage, to examine the perspectives of participants across Oman. The study sought to identify the perceived barriers to and facilitators of screening for ASD, from the perspectives of 529 PHPs (i.e. 13 participants in phase 1 and 490 in phase 2). Overwhelmingly, PHPs referred to multiple challenges in creating a screening service for ASD in Oman. Through the application of the Social Ecological Model (McLeroy et al., 1988), intrapersonal, organisational and community-level barriers were identified. Additionally, some facilitators were also revealed. Although the quantitative data strengthened the findings from the qualitative investigation, the generalisation of the results from the qualitative study provided limited information, as there was a variation in the findings across the two phases. This is elaborated on in more detail in the following sections.

8.1. **The Social Ecological Model (SEM)**

The Social Ecological Model (SEM) (McLeroy et al., 1988) is a theory-based framework, widely used in behavioural research on health, to guide prevention strategies and to promote health, as well as policy and environmental change (Kazak, 1989, Golden et al., 2015, Gruenewald et al., 2014, Swearer and Hymel, 2015). Previous studies have highlighted the use of this model in addressing numerous barriers to screening in areas of health care, such as cancer, mental health and alcohol use. Its aim is to facilitate a better understanding of these challenges, to promote screening and prevent health problems (Barry et al., 2004, Hill, 2013, Daley et al., 2011, Ghebre et al., 2015).

The SEM proposed mutual interactions between individuals and their environment, through multi and overlapping levels, at the intrapersonal, interpersonal, community, organisational and policy levels (McLeroy et al., 1988). This is represented in Figure 8-1. According to McLeroy et al., (1988), the intrapersonal level explored the influence of factors relating to an individual's physical and social environment (e.g. age, sex, economic status, religion, race, knowledge, awareness, attitudes, beliefs and perceptions) on their behaviour. The interpersonal level also considered the effect of formal and informal relationships with family, friends, peers, health care providers and co-workers, on an individual's behaviour. The community level focused on the influence of social and cultural norms, customs and traditions on an individual's behaviour. The organisational level reflected the influence of institutional rules and regulations on an individual's attitude or their approach towards the services provided. The final level is the policy level, which considered local, state, national and global laws and how resources and funds were allocated, as well as their influence on an individual's behaviour.

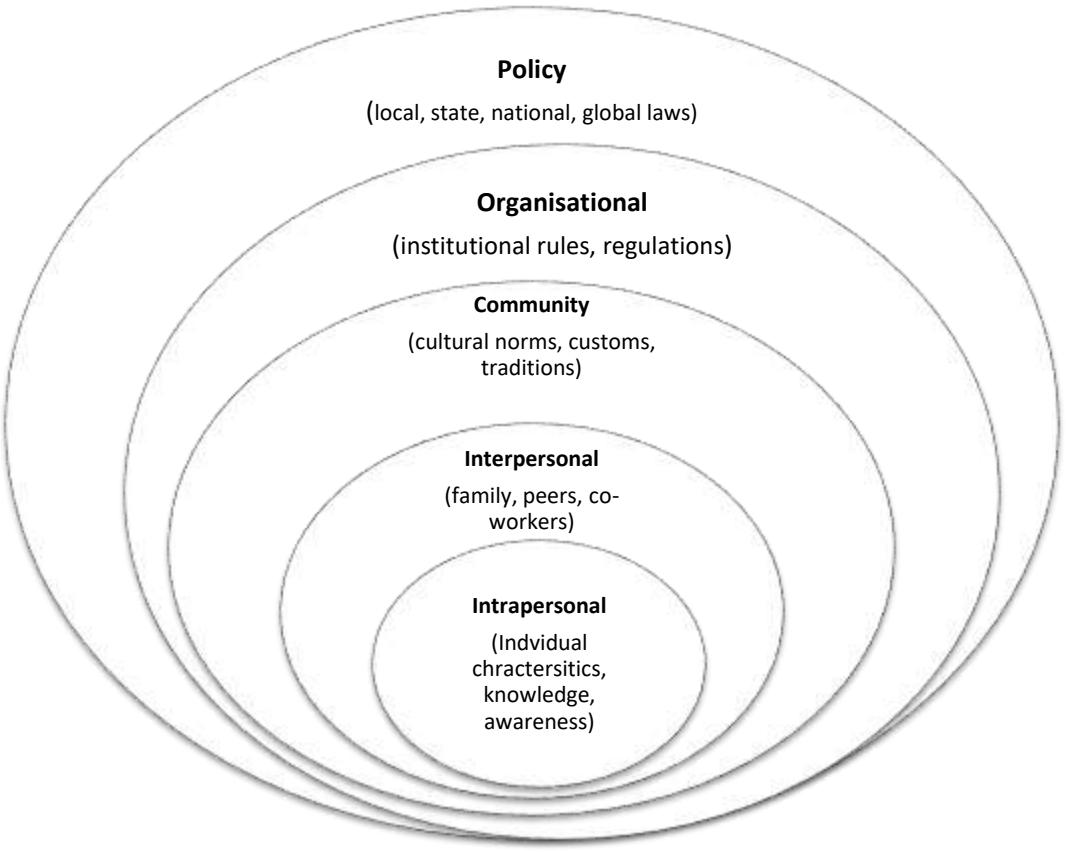


Figure 8-1 The Social Ecological Model

Source: Adapted from the Centers for Disease Control and Prevention (CDC), The Social Ecological Model: A Framework for Prevention,

http://www.cdc.gov/violenceprevention/overview/social-ecologicalmodel.html (retrieved February 1, 2018).

8.2. Applying the SEM to the barriers to screening for ASD in Oman

Examining the root challenges to screening for ASD through the social ecological lens seems appropriate. This provides a deeper understanding of the problems and guides the successful, effective and sustainable deployment of a future screening programme for ASD in Oman. As discussed earlier, the SEM model introduces five levels of influential factors. Of those, it is argued in this study that only three levels (intrapersonal, organisational and community) influence the implementation and uptake of future screening programmes for ASD in Oman (see Figure 8-2). The interconnected barriers/facilitators across and within those levels are discussed thoroughly in the following sections.

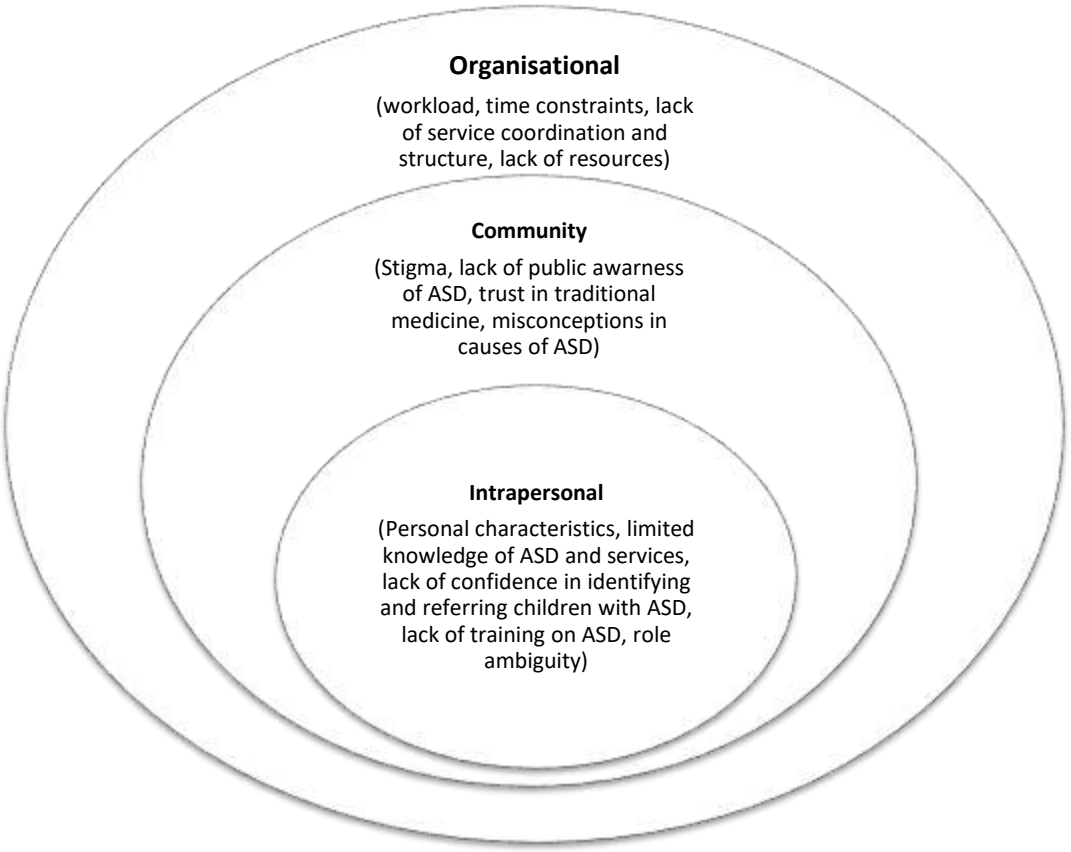


Figure 8-2 Barriers to ASD screening in Oman using the Social Ecological Model to interpret the findings

8.2.1 At the Intrapersonal level

In this study, the intrapersonal level involved PHPs highlighting characteristics, such as knowledge, awareness, attitudes, beliefs and perceptions towards barriers to screening for ASD. Congruent with previous research by Fenikile et al. (2015), Dosreis et al. (2006) and Al-Farsi et al. (2016), both nurses and GPs in the qualitative phase recognised that a lack of knowledge and skills regarding ASD may influence their ability to screen and detect children suspected of having the disorder. This was particularly true amongst nurses, who expressed their limited professional training in ASD.

In contrast, the quantitative results suggested a greater knowledge of ASD and therefore the aspect of professional knowledge was not such a barrier to future screening. An examination of the characteristics of the respondents from this study revealed that younger participants, in both groups, expressed greater knowledge of ASD, through their professional training. This might be a positive reflection on the enhancement of the current curriculum for all medical and nursing disciplines in Oman, to accommodate training in psychological and behavioural abnormalities and their care and management (Ministry of Health, 2017). Despite this knowledge, confidence remains low among participating practitioners. This was especially noted in their skills related to the reporting of children suspected of having ASD or other developmental abnormalities, which were limited in both studies. The qualitative findings revealed that none of the nurses had ever referred a child for further investigation because of developmental abnormalities or ASD. This was surprising, given the length of experience (7-16 years) of the participating nurses and their roles in the community. However, the quantitative (phase 2) results showed that only 11.9% reported having referred a child. This lack of confidence in identifying ASD and/or referring a child may be the result of a lack of specific knowledge of the symptoms, compounded by factors such as a lack of knowledge of the availability of services or a lack of guidance on when and where a child should be referred.

Besides the lack of professional preparation, the lack of on-the-job training on ASD was also mentioned as a barrier to future screening, in both phases of the work. Choi et al. (2014) found this type of training essential in improving employee productivity and job satisfaction and in keeping employees' skills current. Despite the continued efforts in Oman to develop professional capabilities and keep them up to date (Ministry of Health, 2015), there is a lack of on-the-job training in ASD, especially among non-Omani people.

The lack of clarity between the role of a nurse and the role of other providers is not a new subject in the literature (Oelke et al., 2014) and may negatively influence PHPs' behaviour

with regard to undertaking future screening. The qualitative phase revealed a misunderstanding between nurses and doctors over who should undertake the health check visits. Nurses seemed reluctant to complete the health check visit assessment, preferring the GPs to undertake this because they were seen as being more skilled and knowledgeable, as they referred the majority of those suspected of having abnormalities. The GPs, however, thought that nurses were better placed to undertake this assessment because they interviewed the parents and assessed the child initially, and at every immunisation and health check visit. Therefore, the GPs believed that nurses should be equipped with the necessary skills and knowledge to do this and to raise any concerns with the doctors. This emphasised the requirement for the participants to have a clearly defined understanding of their role and a clear mechanism for guiding the process to the next level, which is the identification and referral of a child suspected of having ASD.

8.2.2 At the Community level

This level involves community features that may influence PHPs' acceptance of ASD screening, cultural norms and attitudes towards the identification of ASD. At this level, the potential stigma presents a challenging barrier to the introduction of screening for ASD in Oman. These findings reflect previous studies, where the social stigma surrounding the diagnosis of ASD was identified as an important barrier (Kang-Yi et al., 2013, Matson et al., 2011, Zachor et al., 2011, Wallis and Pinto-Martin, 2008). ASD can be viewed negatively, stigmatising the illness and its effects on the families of affected children (Gray, 1993, Farrugia, 2009). The literature consistently highlights the shame and social exclusion that parents of children with ASD or other developmental disabilities may experience, when their child is diagnosed (Gray, 2002, Gray, 1993, Farrugia, 2009). This forces parents and individuals to avoid diagnosis or even to deny that the condition exists (MacLeod et al., 2013). The views of practitioners in this study concur with those participating in previous investigations and suggest that parents of children with ASD may deny that their child has developmental abnormalities, in order to avoid diagnosis and/or a follow-up in the psychiatric clinic, which is perceived as stigmatising (Al Ali et al., 2017). Importantly, within the Omani culture, "ASD" as a term, is culturally stigmatised, hence the participants suggested using a more general term for the screening process such as screening young children for communication and behavioural changes, in order to reduce cultural sensitivity and promote the uptake of screening.

The lack of parental awareness of normal development may prove another challenge for future screening programmes. Parents' concerns surrounding their children's development are always regarded as important in facilitating early identification (Nickel and Huang-Storms, 2017). Increasing parental awareness may have a positive influence on the screening process.

Additionally, some misconceptions regarding the cause of ASD, such as the link with the MMR vaccination, and the impact of supernatural powers (i.e. envy and the evil eye), were revealed in this study. These are believed to affect parental choice in terms of their decision over whether to seek help from health services for treating their children. This finding concurs with previous literature in that Middle Eastern cultures tend to favour the traditional healing system to a large extent when dealing with mental health problems and behavioural abnormalities (Hussein et al., 2012).

The lack of awareness of this condition, the limited guidance and support provided for parents, and the misconceptions attached to the condition could escalate the stigma and make it difficult for parents to seek identification, medical care or community support. These factors may also encourage Omani parents to seek health care from traditional medicine and Quran therapy, as opposed to health care services.

8.2.3 At the Organisational level

The primary health care institutions' rules and regulations influence the attitudes of PHPs towards screening for ASD and shape the organisational level, within the SEM. At this level and in both studies (qualitative and quantitative) the PHPs were reluctant to introduce an extra screening programme for ASD within their current practice. They quoted their high workload and staff shortages as factors that strongly challenged the introduction of an effective screening programme for ASD in Oman. These findings confirm the current statistics regarding PHPs' workload in Oman. The PHC institutions in Oman increasingly incorporate additional programmes to promote health. The growth in PHC services has escalated the utilisation of the health service from 2.97 million visits in 1990 to 9.74 million visits in 2012 (Ministry of Health, 2015). Unfortunately, this rise in use was not sufficiently supported by human resources, as current statistics indicate fewer family physicians (0.3/10,000 population), compared with the recommended policy from the Ministry of Health (2/10,000) (World Health Organization, 2016). The same report concluded that the situation for nurses was no better, with 12.21 per 10,000 population, compared with European nursing standards of 65 per 10,000 population. The findings from this study have

expressed the need to address such issues carefully and swiftly, prior to the commencement of any extra screening programmes for ASD in Oman, within the current PHC system.

Despite workload concerns, practitioners pointed to the importance of EPI and health check visits in promoting children's health and controlling childhood diseases in Oman. Indeed, the EPI programme provided free immunisation against 12 childhood diseases (e.g. tetanus, polio and diphtheria, tuberculosis, and hepatitis). This programme contributed to the eradication of some of childhood diseases (i.e. polio, tetanus and diphtheria) and the reduction in the mortality rate for children under the age of five (from 27.0 to 9.7 deaths per 1,000 live births) (World Health Organization, 2016). Despite these benefits, practitioners concluded that the current system is not robust enough to detect developmental delays in children, and/or to detect any potential cases of ASD. They were concerned about the disorganised structure of this programme as it keeps parents waiting in queues for a long time. Practitioners noted how this discouraged parental attendance, which restricted the professionals' ability to gather an accurate history of the child and to identify any problems. Therefore, it is essential to review the current service structure and address the identified constraints. This would not only help to improve the risk of mis-identification and the quality of the service provided, but it would also increase satisfaction among both professionals and parents.

Another key barrier to screening, which was highlighted at this level, was the lack of service coordination. This might be due to a lack of familiarity with the available services and guidelines, despite their availability. The World Health Organization's manual on the management and treatment of mental health disorders, which should be available in PHC clinics in Oman (World Health Organization, 2011), should be guiding practitioners. However, practitioners varied in their responses and there was uncertainty regarding when or where to refer children suspected of having ASD, especially among nurses. The nurses may be more reticent due to their perceived role in medical practice. For example, most Omani nurses with a diploma, and those who consult large numbers of patients on a daily basis, preferred not to refer a child for further investigation, unless they exhibited physical disabilities associated with other obvious symptoms. Their preference was to wait a few months, even up to two years, to see if the child developed normally, in order to avoid unnecessary stress or stigma for the parents. Additionally, the current practice in Oman officially advises the initial referral of suspected cases, within the PHC service, to the paediatric clinic. It then refers children to the psychiatric clinic and finally to the secondary/tertiary level. However, this study indicates that PHPs were not equipped with

this information, as more than half of the participants (61.5%) favoured referring suspected cases directly to secondary level institutions. Practitioners also reported receiving insufficient and fragmented feedback and documentation on referred cases. This reduced their ability to follow up cases, and to provide appropriate services, which suggested a need to furnish the institutions with properly coordinated service guidelines.

Equipping the PHPs with instruments to screen for ASD is essential for future screening for ASD and for assisting with early identification. Within the literature, there were numerous validated screening instruments (Stone and Rosenbaum, 1988, Baird et al., 2000, Robins et al., 2014) but scholars have raised concerns over the efficacy of using such instruments in different populations, as well as highlighting the effect of culture on detecting and diagnosing ASD (Kang-Yi et al., 2013, Matson et al., 2011, Zachor et al., 2011). Polarised views emerged from this study, with some practitioners suggesting integrating the screening instruments with the pink card and existing health check visits. However, the majority of the participants displayed a preference for developing a new screening tool, specifically for ASD, and suggested that it be administrated by expert practitioners, as part of the health check visit. A promising study examining an Omani version of the M-CHAT in a mobile application ("Autism Fingerprint") is being undertaken, which may soon equip parents with an easy-to-use validated screening instrument that carefully addresses the Omani culture and language (Klein et al., 2015).

As expected, the current PHP infrastructure in Oman is under pressure from many programme shortages and a lack of expertise; therefore it would be unable to accommodate an additional screening programme for ASD. The allocation of a specific clinic, or construct to screen for ASD, specific staff and screening instruments may offer an appropriate solution for effective screening. Specialisation (i.e. specific clinics, specialised staff with expertise and specialised screening instruments) could provide staff with the required skills and time to assess children in private, offering more focused attention and support for parents, and improving their awareness. However, caution should be taken when building ASD speciality, specifically when allocating specific clinics for ASD, considering the social stigma surrounding this disorder.

8.3. Applying SEM to the screening facilitators of ASD in Oman

As with the barriers, examining the facilitators of ASD screening through the social ecological lens presented three levels: interpersonal, organisational and community (see Figure 8-3). These will be discussed thoroughly in the following section.

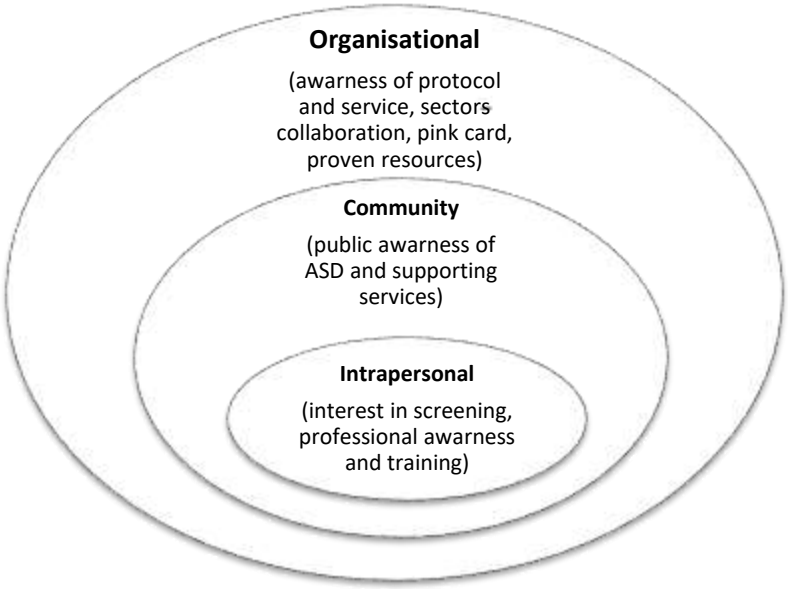


Figure 8-3 Facilitators of ASD screening in Oman, using the Social Ecological Model to interpret the findings

It is unsurprising that screening for ASD within current practice is considered difficult, and that the participants identified very few facilitators. However, those facilitators that were identified varied across both studies. For example, at the intrapersonal level, the qualitative study suggested that the participants had a genuine interest in screening for ASD, especially if they were given adequate training and knowledge, a means of assessment and the time to screen. The participants also mentioned the effective use of the pink card, with some modifications, incorporating the characteristics of ASD, in order to facilitate early detection of developmental abnormalities at an organisational level. In contrast, the respondents in the quantitative study demonstrated less interest in screening for ASD, even if they were equipped with the desired resources. They were in favour of facilitating screening through increasing awareness, increasing resources, and encouraging collaboration between sectors.

Raising public/professional awareness of ASD was considered a key aspect in overcoming each of the three types of barriers (i.e. intrapersonal, organisational and social), as well as in facilitating future screening for ASD in Oman. This concurs with global recommendations for increasing awareness and improving detection (Barbaro and Halder, 2016, Bakare et al., 2008, Igwe et al., 2011). In this study, increasing awareness of ASD was seen as an essential first step in positively influencing successful screening. Awareness was seen as a means of

reducing sensitivity towards ASD in the community and reducing the ambiguity and misconceptions related to the disorder among parents, as well as professionals. Taking this on board may increase uptake. An increase in awareness may also positively influence outcomes at both the intrapersonal and organisational levels. For example, PHPs' awareness of ASD, the availability of ASD services and the route to referral, may enable better guidance and support for parents of affected children. This may ultimately facilitate parental cooperation in the identification of ASD/developmental abnormalities, the promotion of parental trust in the health care system and the likelihood that parents will seek health care services instead of traditional medicine. The involvement of the media, local organisations and community leaders was considered an integral part of cultivating community awareness of ASD. As with all health awareness, the supply of pamphlets and brochures was also an essential component.

At the organisational level, two more aspects were identified that may potentially facilitate screening: the provision of resources and collaboration with educational and social affairs sectors. Providing an efficient screening process would require the supply of the necessary resources. These resources may be derived from a wide range of health institutions and may be considered assets, such as physical, financial or human. As with previous studies, the findings suggest a deficit in the resources available for the current provision of general practice in Oman (Al-Farsi et al., 2011a, Zwaigenbaum et al., 2015, Ws et al., 2015). This would need to be amended if a screening programme were to be implemented. According to this study, making the necessary resources available appears to be the second most important change required for screening for ASD. For that to occur, the participants suggested providing a skilled professional, who would be equipped with the necessary knowledge and skills for undertaking the screening process. They also recommended the supply of physical resources, such as buildings, intervention services, follow-up/feedback protocols and screening instruments. Although financial resources were not addressed in this study, perhaps due the availability of free public health care services in Oman, attention should be focused on this resource. ASD may impose a financial burden on public health services, either directly, through medical expenditure, or indirectly, through costs such as special education services or lost productivity by family caregivers (Zwaigenbaum et al., 2015, Kogan et al., 2008). It is also difficult to estimate the cost because there has been little research undertaken into the cost effectiveness of ASD and its treatment. This is compounded by the fact that health care facilities vary across countries (Zwaigenbaum et al., 2015). Therefore, future investigations in this area would be of value.

Collaboration between sectors (health, education, and social development) was perceived to be essential in both studies, to improve community awareness, reduce stigma, foster early identification and utilise the services provided. For example, prompt identification may encourage the enrolment rate of children diagnosed with ASD into available supportive services, across the spectrum of developmental and behavioural disabilities. In Oman, Al-Sharbati et al. (2015) reported limited enrolment at present in the special educational programmes offered by the Omani Ministry of Higher Education, but as work continues this may change.

8.4. Are the views of the PHPs, regarding the barriers to and facilitators of screening for ASD, generalisable among Omani PHPs?

Both studies enabled the researcher to gain a complete picture of the challenges/facilitators underpinning ASD screening in Oman, from both the qualitative and quantitative perspective. Although most of the views in the qualitative phase were congruent with the quantitative results, there were still some variations identified, which may hinder the generalisability of the qualitative findings, in full, to all Omani PHPs. Those areas found to exhibit variation were concerned with knowledge and interest in screening, preferences for referral times and places to refer children suspected of having ASD.

The qualitative findings suggested limited knowledge and professional training on ASD. This was seen as a major challenge to the potential for screening for ASD, especially by nurses. However, the majority of the respondents (71.4%) in the quantitative study had received professional training on ASD, especially the younger professionals. The qualitative findings also highlighted a genuine interest among participants for screening for ASD, particularly if they were equipped with the required knowledge and skills to undertake this. Participants in the quantitative phase, however, rated the item of interest as the lowest enabler of screening.

The last variation between the two studies involved the referral system. The qualitative findings supported the monitoring of children for some time before referring them for further investigation, unless the child exhibited physical disabilities associated with other obvious symptoms. This is believed to be necessary, in order to provide the child with a chance to develop normally, and to avoid unnecessary stress or stigma for the parents. Omani

respondents with a diploma, and those who see a large number of patients on a daily basis, favoured this option, as well as those questioned in the quantitative study. These particular groups of participants preferred to wait a few months, or up to two years, before referring a child suspected of having ASD for further assessment. Despite this match, the majority of respondents in the quantitative study, 75.7%, opposed waiting, displaying a preference for referring children suspected of having ASD as soon as they were identified. Although this appears promising in terms of facilitating early identification and intervention, attention should also be given to quick and unplanned referrals, as ignoring this might, ultimately, burden the secondary and tertiary health care services in Oman.

8.5. Other findings

Although the research questions in the present study were answered, and a number of barriers to and facilitators of screening for ASD were identified, this study has also highlighted some interesting findings beyond the purpose of the study. These findings were related to the preferences of participants regarding the development of a survey questionnaire, the methods of data collection.

Within this project, the researcher sought to identify relevant material to support the development of a culturally acceptable questionnaire, exploring the barriers to and facilitators of screening for ASD, with the help of PHPs in Oman. As mentioned previously, the preference was for a clear, simple, paper-based questionnaire, with closed questions. The practitioners thought that this type of questionnaire would be suitable for busy health care providers and facilitate compliance with completing the questionnaire. These findings reflected the literature, which recommended the writing of short (less than 20 words), simple and specific questions (Boynton and Greenhalgh, 2004, Iarossi, 2006, Diem, 2004). The use of closed questions also allows for quicker completion of the questionnaire and easier coding (Williams, 2003). Paper-based questionnaires were preferred, as many health care practitioners did not have access to internet services or appropriate software within their organisation, to support online surveys. They also felt more comfortable using traditional survey methods, which are easier to access, read, and answer, compared to those on electronic devices. The participants suggested that compliance could be facilitated if they were given time, e.g. one to two days, to complete the questionnaire. In other words, they should not have to do it immediately. Introducing a focal contact point for the distribution of the questionnaire was found to be of importance, adding value to the questionnaire and facilitating participation, as queries were answered quickly.

Previous studies have shown difficulties with and preferences for answering close-ended questions. For example, Chinese parents find it difficult to answer questions that have a definitive response such as 'yes' and 'no' and they prefer a rating scale that gives them a range from one to five (Wong et al., 2004). Turkish parents show a preference for a one-to-one questionnaire in an interview setting where they are able to probe and clarify questions, rather than filling in a checklist (Kara et al., 2014). The professionals in this study also revealed difficulties with completing questions that required them to report numbers and/or prioritise.

Within the questionnaire, there were a few questions that repeatedly remained unanswered. These questions asked participants to report numbers. For example, this study reported missing values for the number of programmes run by their institutions (33.2%), data on the number of staff per shifts (29.4%), the number of patients they consulted per day (28%), ages (17.8%) and the prioritising question (22%). In light of this, future studies might consider providing the participants with a range of numbers to choose from, instead of asking them to report on every one, to make it easier for the participants and to increase the response rates for such questions.

The prioritising question was intended to capture the participants' views on the three most important changes that should be made in order to facilitate screening in Oman. Although this question was answered by the majority of participants, the researcher was unable to use the data and had to code this as 'missing'. This was because the participants had rated all eight items as 1, whilst on other occasions rating all eight items as 1, 2 or 3. Where the participants had prioritised all eight items, only the first three items were included in the data. Interestingly, this issue did not present itself during the pilot work but it was believed that the question might not have been specific enough. It may also have been that the participants found it difficult to exclude any items or to prioritise one over the other, as they felt that they were all important.

It is also worth noting that recruitment for the FGs in Muscat health centres was difficult and time-consuming. Only two males expressed their interest in participating, and only one attended. This reflects the composition of the profession in Oman, as female practitioners comprise almost 82.77% of the total PHPs (Information and Statistics Department, 2015). Staff shortages in the PHC settings and the challenges of travelling from rural health centres to FG venues were identified as further reasons for the lack of participation in the study. One

point of interest highlighted the fact that FG discussions were not commonly adopted as the method of data collection among the participating groups. This may have deterred participants. Another factor, in terms of uptake, was that many participants within the study sample were not familiar with ASD, noting that they lacked knowledge and experience regarding this disorder. This meant that they would potentially have had little to add to the research.

Despite this, the participants concurred with previous studies – they found that the FGs helped them to learn many new features relating to their services, as well as updating them on these services (Krueger and Casey, 2015). They also thought that FGs could be one way of discussing future challenges and finding solutions for them. It was suggested that the use of FGs to discuss health issues and update staff was something that could be disseminated back to the Ministry of Health in Oman. This approach could foster co-productive principles and give practitioners and patients alike a feeling of empowerment in contributing towards future health care decisions.

Engagement is another aspect worth noting in this work. The researcher engaged the participants and RAs throughout the questionnaire development process in the design of the orientation programmes and in recruitment for the study (see Chapter 6). This involvement was instrumental in capturing the participants' knowledge and preferences, as well as dispelling their sensitivities regarding their lack of knowledge on ASD. It was also used to augment the appropriate recruitment strategy and enhance the quality and appropriateness of the research. The results from both phases showed a high response rate. The questionnaires themselves also created an awareness of ASD screening among the participants. The involvement and engagement of the participants might be an important aspect to examine in future research.

8.6. **Strengths and limitations**

Although the information concerning this phase of the study was valuable, there remained some key limitations within the qualitative study. Firstly, the sample comprised mainly female participants, who resided and worked in Muscat. Therefore their views might not necessarily have reflected the health and social problems observed in screening for ASD across Oman. The inclusion of FGs from outside Muscat, as well as more male participants, might have provided a more holistic view of the potential barriers to and facilitators of

screening for ASD. Moreover, this study was limited to the views of PHPs. The investigation of the views of other stakeholders, such as those of the MOH authorities and parents, may be of value in widening our understanding of screening for ASD and in strengthening the results of the study. Another methodological limitation worth mentioning is that the questionnaire used in this study was developed by the researcher and would require further validation if it were to be rolled out across the Middle East.

Despite this, each stage of the study (i.e. systematic review, qualitative and quantitative phases) demonstrated a number of strengths. For example, the systematic review provided a platform from which to understand some of the issues surrounding future cultural adaptations of ASD screening in non-English speaking countries. This was intended to facilitate the examination of the effectiveness of adaptation, the improvement of the rigour of the adapted instrument and the facilitation of a feasible and effective screening process. The qualitative study supplemented a new measure that was developed by following a step-by-step framework, including a pilot study. Similarly, the quantitative study was useful in surmounting the shortcomings of the qualitative study, and in facilitating the generality of the results, as a large sample size was taken, using respondents from across the country. In general, the findings enriched the global literature in this area and challenged the limited data presently available on screening for ASD in Middle Eastern countries. It also contributed a conceptual framework that may facilitate the future exploration of challenges and the potential introduction of a successful screening process.

8.7. **Study contribution**

This work has addressed the lack of research evidence on screening for ASD in non-western countries, through two major studies. The first study reported a systematic review that highlighted the inadequacy of previous screening research, in terms of content level. It also suggested guidelines for this level of cultural adaptation, in order to promote outcomes and to maintain high fidelity in screening instruments. Additionally, this review was the first to shed light on the feasibility of ASD screening, within practice, and to advocate the need to examine feasibility aspects further. This would reduce the wastage of resources and improve the effectiveness of screening in the health care systems of countries with limited mental health service resources and expertise.

Secondly, this study was one of the first to present a mixed-method design, to provide a deeper understanding (i.e. qualitative phase) of screening challenges, from the wider perspectives of PHPs (quantitative). This study took place prior to the commencement of the ASD screening programme, in a non-western culture, specifically Oman. It was also the first to examine the perceived challenges to and facilitators of screening for ASD through the social ecological lens, to provide theoretical evidence for guiding the sustainable deployment of a future screening programme in Oman. It also introduced a questionnaire to the literature that reflected Middle Eastern culture and examined the potential barriers to and facilitators of screening for ASD in a similar context.

8.8. Recommendations

Over the past decade, research into ASD has rapidly increased, alongside advances in identification and intervention. Many countries have experienced considerable reform within their health care systems, to accommodate problems and improve outcomes (Canal-Bedia et al., 2011, Christensen et al., 2016). There is little data available on the effectiveness of the current health care system in Oman in accommodating screening for ASD. However, this study has addressed a number of recommendations, which could facilitate the smooth and successful implementation of ASD screening.

8.8.1 Recommendations for practice

The PHC system has the ability to access a wide range of the population, encouraging the introduction of more activities and programmes and identifying risks, in order to promote health (Williams et al., 2013, Daley et al., 2011, Hill, 2013, Barry et al., 2004, Mattila et al., 2009, Barton et al., 2012). Despite the benefits, this has often been burdened with challenges (Williams et al., 2013; Daley et al., 2011; Hill, 2013), increases in health service utilisation, poorer health outcomes (Bener et al., 2012, Simon and VonKorff, 1997) and a lower quality of services provided, especially in Eastern Mediterranean regions (Saleh et al., 2015). As discussed in section 8.2.2, the PHC system in Oman has demonstrated similar workload scenarios. Therefore, there is an urgent need to address such challenges carefully and swiftly, prior to the introduction of any further screening programmes within the current PHC system.

Oman has made significant efforts, through the EPI programme and through child health visits, to promote child health, control childhood diseases and reduce the mortality rate in children under the age of five (see section 8.2.2). Despite some success, this study indicates the need for a shift in the attention given to children's practice, to that of identification and support of children with challenging developmental/behavioural disorders, such as ASD, at an early stage. This would necessitate additional examinations and a reform of the current service status (i.e. structure, coordination and collaboration) and professional education programmes in order to accommodate such conditions. This would equip the upcoming professionals with the required skills and resources for identifying risk, and provide the quality of care for a child suspected of having ASD. A by-product may be that families and practitioners may ultimately be more satisfied with the services provided.

Additionally, it is recommended that special consideration be given to the cultural characteristics of the Omani population, whilst planning for screening for ASD. For example, "ASD" as a term is culturally stigmatised. The use of a more general term for the screening process and the integration of the screening programme within the EPI and health check visits may improve the acceptance of the programme and promote higher uptake rates for screening. Integrating ASD screening within the current services may also be more convenient and acceptable to parents who might use other services (i.e. immunisation) during the same visit. This may be particularly helpful to parents who have a large number of children.

Increasing public awareness of ASD identification and its available services, through health institutions, publications (brochures, pamphlets, posters) and educational programmes, is an essential first step in attaching value to screening and in reducing cultural sensitivity towards ASD. Awareness of ASD may also encourage parental cooperation regarding concerns over abnormalities and the accurate reporting of their children's development, which is important for identification of any abnormalities (Nickel and Huang-Storms, 2017).

The establishment of a specialised institution for ASD may reduce the burden on PHC settings. This will require an appropriate infrastructure, as well as the required resources to facilitate the early identification and management of children with ASD in Oman. Such institutions might also form a centre of excellence for ASD research in Oman and contribute to the knowledge and expertise on this disorder.

Prior to initiating the screening process for ASD in Oman, it is recommended that valid and reliable screening instruments are adopted. These should address the core values, competence, beliefs and norms of the Omani culture, in order to match both the investigator and the targeted participants. Reporting the process of adaptation in sufficient detail and using a framework for guidance, ensuring adequate adaptation, are also recommended.

8.8.2 Recommendations for policy:

This study recommended revising CPD strategic planning to include ASD as a subject, in order to improve professional knowledge. Future planning might also ensure that equal opportunities are provided for all PHPs, in terms of access to CPD programmes. This is important because some rural governorates in this study were primarily managed by non-Omani people.

The present shortage in staff and the heavy workload highlight the need for proper and effective distribution of resources within PHC institutions. This study suggests dedicating clear roles and protocols to guide the screening process and ensuring a reduction in ambiguity among professionals, facilitating smooth and effective screening for ASD.

Creating a policy to regulate the documentation process for identified and referred cases of ASD, within the current system, is needed to evaluate the patterns of referral from sectors and within institutions, as well as presenting data for future research (Thomas, 2009) in order to improve the provided services.

8.8.3 Recommendations for research

The findings from this study focused primarily on the perspectives of PHPs on barriers to and facilitators of screening for ASD. Exploring the perspectives of stakeholders (i.e. authorities and parents) might be the next essential step in providing a holistic view, which would facilitate potential screening for ASD in Oman. Additionally, the investigation of all SEM levels in future research may facilitate a better understanding of these barriers and offer a rich data set with which to guide successful screening processes.

Future studies might examine the need for a standardised ‘well check’ visit in Oman and the requirement for a particular level of satisfaction amongst parents and professionals, in terms

of the services provided for children under five years of age. Further research exploring the knowledge of public support for ASD in Oman and the availability of community support is also warranted. PHPs suggested that ASD is a stigmatised disorder and viewed negatively in the community. Future research may examine the experienced of children with ASD and their parents in Oman.

Although the health care system is well developed in Oman, traditional healing is also popular, especially for those from rural areas and for those whose problems are related to mental health abnormalities (Hussein et al., 2012, Okasha, 1966). Indeed, the culture is rich, with various traditional healing modalities, which are trusted socially and work alongside the medical service. Therefore, the effectiveness of traditional healing systems and their use for children who have ASD should be explored as a means of increasing the limited knowledge in this field.

Financial resources were not addressed in this study, due the availability of free public health care services in Oman. However, attention should be paid to this resource. ASD screening may impose a financial burden on public health services, either directly, through medical expenditure, or indirectly, through costs relating to special education services or losses in productivity by family caregivers (Zwaigenbaum et al., 2015, Kogan et al., 2008). Currently, cost estimation for ASD screening is a difficult task because there has been little research conducted in this area, compounded by the fact that health care service facilities vary across countries (Zwaigenbaum et al., 2015). Therefore, future investigation in this field would be of value.

Validation of the developed questionnaire and/or examination of its use in neighbouring countries or Arab countries might be another interesting area of research and would provide the introduction of a new validated measure that reflects Middle Eastern culture in terms of the potential barriers to and facilitates of screening for ASD.

The polarised views amongst participants on where to screen for ASD deserves further exploration, in order to direct the infrastructure towards potential screening services. For instance, some practitioners would prefer to screen for ASD in a specific clinic, which ensures enough time for assessment and the facilitation of greater support and privacy to parents. Others see the integration of screening for ASD within the present service as more acceptable and convenient than allocating a specific place for screening, which could incur stigmatisation and potentially reduce uptake.

8.9. Study summary

In conclusion, despite the benefits of the immunisation and health check programme for controlling childhood morbidity and mortality in Oman, the programme is failing to address developmental and psychosocial abnormalities. This study has undertaken a systematic review and adopted an exploratory mixed-method approach, which has revealed valuable preliminary information regarding the introduction of screening for children with ASD, as part of the PHC system in Oman. The systematic review has critically evaluated the process of cultural adaptation of screening instruments and the feasibility of screening for ASD in non-English speaking countries. The results have emphasised the importance of reporting the process of adaptation in sufficient detail, using a framework for guidance, and acknowledging the proficiency of the investigator, in terms of the adapted culture and the culture and values of the participants. It is also important to investigate the challenges to and facilitators of the introduction of screening instruments in the selected setting. From these findings, the research has undertaken the first step in 'testing the water' and explored the barriers to and facilitators of screening for ASD in Oman. This was undertaken by adopting an exploratory mixed-methods design. This necessitated an initial exploratory qualitative phase, which contributed to the development of a measure that examined the perspectives of the participants in a subsequent quantitative phase.

The findings from the qualitative study noted the genuine interest of the participants in screening for ASD, if they were provided with sufficient time, knowledge and expertise to undertake this. Variations in awareness of the referral system and in the availability of ASD services in Oman were recognised among the participants. Moreover, stigma, the devaluation of the screening process, traditional medicine and the deficits in public awareness, were raised as potential social barriers. Additionally, the qualitative phase provided support for the development of a short, simple 38-item questionnaire. This could be completed within 15 minutes and was sent to 516 participants, across Oman, to identify the barriers to and facilitators of screening for ASD within the PHC system.

The results of the quantitative phase strengthened the findings above, suggesting a deficit in knowledge and training in ASD, especially among nurses. A lack of resources, time constraints, heavy workload and staff shortages were noted by the participants. Furthermore, the participants highlighted the ambiguity regarding their role, as well as a lack of guidance

from protocols on the identification or referral of children suspected of having ASD. This was compounded by a lack of public awareness and the social stigma attached to ASD.

Both phases informed decisions regarding the introduction of screening for ASD in Oman. If screening were to be advocated, then a specialised institution should be developed and the following protocol addressed: 1) the provision of comprehensive staff training to address the flagship symptoms of ASD, epidemiology and modalities of screening; 2) a review and update of current medicine and nursing curricula; 3) a review of organisational structures, to ensure that adequate time is allocated for screening and that specific staff are employed to screen and assess children for developmental abnormalities and ASD; 4) an awareness campaign to reduce the cultural sensitivity and stigmatisation of the disorder; and finally, 5) the discovery of a more socially acceptable name for the screening process, such as "screening for behavioural changes," instead of "screening for ASD." This might encourage acceptance of the screening process by parents, within residential areas.

References

Al-Farsi, Y. M., Al-Sharbati, M. M., Al-Farsi, O. A., Al-Shafaee, M. S., Brooks, D. R. & Waly, M. I. 2011a. Brief report: prevalence of autistic spectrum disorders in the sultanate of Oman. *Journal of autism and developmental disorders,* 41**,** 821-825.

Al-Farsi, Y. M., Al-Sharbati, M. M., Waly, M. I., Al-Farsi, O. A., Al-Shafaee, M. A., Al-Khaduri, M. M., Trivedi, M. S. & Deth, R. C. 2012. Effect of suboptimal breast-feeding on occurrence of autism: a case–control study. *Nutrition,* 28**,** e27-e32.

Al-Farsi, Y. M., Al-Sharbati, M. M., Waly, M. I., Al-Farsi, O. A., Al Shafaee, M. A. & Deth, R. C. 2011b. Malnutrition among preschool-aged autistic children in Oman. *Research in Autism Spectrum Disorders,* 5**,** 1549-1552.

Al-Farsi, Y. M., Al Shafaee, M. A., Al-Lawati, K. S., Al-Sharbati, M. M., Al-Tamimi, M. F., Al-Farsi, O. A., Al Hinai, J. A. & Al-Adawi, S. S. 2016. Awareness about Autism among Primary Healthcare Providers in Oman: A Cross-Sectional Study. *Global Journal of Health Science,* 9**,** 65.

Al-Farsi, Y. M., Waly, M. I., Al-Sharbati, M. M., Al-Shafaee, M., Al-Farsi, O., Al-Fahdi, S., Ouhtit, A., Al-Khaduri, M. & Al-Adawi, S. 2013a. Variation in socio-economic burden for caring of children with autism spectrum disorder in oman: caregiver perspectives. *Journal of autism and developmental disorders,* 43**,** 1214-1221.

Al-Farsi, Y. M., Waly, M. I., Al-Sharbati, M. M., Al-Shafaee, M. A., Al-Farsi, O. A., Al-Khaduri, M. M., Gupta, I., Ouhtit, A., Al-Adawi, S. & Al-Said, M. F. 2013b. Levels of heavy metals and essential minerals in hair samples of children with autism in Oman: a case–control study. *Biological trace element research,* 151**,** 181-186.

Al-Sharbati, M. M., Al-Farsi, Y. M., Ouhtit, A., Waly, M. I., Al-Shafaee, M., Al-Farsi, O., Al-Khaduri, M., Al-Said, M. F. & Al-Adawi, S. 2015. Awareness about autism among school teachers in Oman: A cross-sectional study. *Autism,* 19**,** 6-13.

Al-Sinawi, H., Al-Alawi, M., Al-Lawati, R., Al-Harrasi, A., Al-Shafaee, M. & Al-Adawi, S. 2012. Emerging Burden of Frail Young and Elderly Persons in Oman: For whom the bell tolls? *Sultan Qaboos University medical journal,* 12**,** 169.

Al Ali, N. M., Alqurneh, M. K., Dalky, H. & Al-Omari, H. 2017. Factors affecting help-seeking attitudes regarding mental health services among attendance of primary health care centers in Jordan. *International Journal of Mental Health,* 46**,** 38-51.

Al Dhawi, A. A. & West, D. J., Jr. 2006 Challenging Health Care system Sustainability in Oman. *Health Sciences Management and Public Health,* 7**,** 124-135.

Albores-Gallo, L., Roldán-Ceballos, O., Villarreal-Valdes, G., Betanzos-Cruz, B. X., Santos-Sánchez, C., Martínez-Jaime, M. M., Lemus-Espinosa, I. & Hilton, C. L. 2012. M-CHAT Mexican version validity and reliability and some cultural considerations. *ISRN neurology,* 2012**,** 1-7.

Allison, C., Auyeung, B. & Baron-Cohen, S. 2012. Toward brief "Red Flags" for autism screening: The Short Autism Spectrum Quotient and the Short Quantitative Checklist for Autism in toddlers in 1,000 cases and 3,000 controls [corrected].[Erratum appears in J Am Acad Child Adolesc Psychiatry. 2012 Mar;51(3):338]. *Journal of the American Academy of Child & Adolescent Psychiatry,* 51**,** 202-212.e7.

Allison, C., Baron-Cohen, S., Wheelwright, S., Charman, T., Richler, J., Pasco, G. & Brayne, C. 2008. The Q-CHAT (Quantitative CHecklist for Autism in Toddlers): a normally distributed quantitative measure of autistic traits at 18–24 months of age: preliminary report. *Journal of autism and developmental disorders,* 38**,** 1414-1425.

American Psychiatric Association 2013. *Diagnostic and statistical manual of mental disorders (5th ed.),* Arlington, VA, American Psychiatric Publishing.

Antwi, S. K. & Hamza, K. 2015. Qualitative and quantitative research paradigms in business research: A philosophical reflection. *European Journal of Business and Management,* 7**,** 215-225.

Aron, A., Aron, E. & Coups, E. 2005. Statistical for the behavioral and social sciences. New Jersey: Pearson Education, Inc.

Auyeung, B., Taylor, K., Hackett, G. & Baron-Cohen, S. 2010. Foetal testosterone and autistic traits in 18 to 24-month-old children. *Molecular autism,* 1**,** 11.

Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J., Wheelwright, S. & Drew, A. 2000. A screening instrument for autism at 18 months of age: a 6-year follow-up study. *Journal of the American Academy of Child & Adolescent Psychiatry,* 39**,** 694-702.

Bakare, M. O., Ebigbo, P. O., Agomoh, A. O. & Menkiti, N. C. 2008. Knowledge about childhood autism among health workers (KCAHW) questionnaire: description, reliability and internal consistency. *Clinical practice and epidemiology in mental health : CP & EMH,* 4**,** 17-17.

Baltar, F. & Brunet, I. 2012. Social research 2.0: virtual snowball sampling method using Facebook. *internet Research,* 22**,** 57-74.

Barbaro, J. & Halder, S. 2016. Early identification of autism spectrum disorder: Current challenges and future global directions. *Current Developmental Disorders Reports,* 3**,** 67-74.

Baron-Cohen, S., Allen, J. & Gillberg, C. 1992. Can autism be detected at 18 months? The needle, the haystack, and the CHAT. *British Journal of Psychiatry,* 161**,** 839-43.

Baron-Cohen, S., Lombardo, M. V., Auyeung, B., Ashwin, E., Chakrabarti, B. & Knickmeyer, R. 2011. Why are autism spectrum conditions more prevalent in males? *PLoS Biol,* 9**,** e1001081.

Baron-Cohen, S., Wheelwright, S., Cox, A., Baird, G., Charman, T., Swettenham, J., Drew, A. & Doehring, P. 2000. Early identification of autism by the CHecklist for Autism in Toddlers (CHAT). *Journal of the Royal Society of Medicine,* 93**,** 521-5.

Barry, K. L., Blow, F. C., Willenbring, M., McCormick, R., Brockmann, L. M. & Visnic, S. 2004. Use of alcohol screening and brief interventions in primary care settings: implementation and barriers. *Substance Abuse,* 25**,** 27-36.

Barton, M. L., Dumont-Mathieu, T. & Fein, D. 2012. Screening young children for autism spectrum disorders in primary practice. *Journal of Autism & Developmental Disorders,* 42**,** 1165-74.

Baumann, A. A., Powell, B. J., Kohl, P. L., Tabak, R. G., Penalba, V., Proctor, E. K., Domenech-Rodriguez, M. M. & Cabassa, L. J. 2015. Cultural adaptation and implementation of evidence-based parent-training: A systematic review and critique of guiding evidence. *Children and youth services review,* 53**,** 113-120.

Baxter, A., Brugha, T., Erskine, H., Scheurer, R., Vos, T. & Scott, J. 2015. The epidemiology and global burden of autism spectrum disorders. *Psychological medicine,* 45**,** 601-613.

Beaton, D., Bombardier, C., Guillemin, F. & Ferraz, M. B. 2007. Recommendations for the cross-cultural adaptation of the DASH & QuickDASH outcome measures. *Institute for Work & Health,* 1**,** 1-45.

Beaton, D. E., Bombardier, C., Guillemin, F. & Ferraz, M. B. 2000. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine,* 25**,** 3186-3191.

Beauchamp, T. L. & Childress, J. F. 2009. *Principles of biomedical ethics,* Oxford;New York, N.Y;, Oxford University Press.

Ben-Sasson, A. & Carter, A. S. 2012. The application of the first year inventory for ASD screening in Israel. *Journal of Autism & Developmental Disorders,* 42**,** 1906-16.

Bener, A., Abdulmalik, M., Al-Kazaz, M., Sanya, R., Buhmaid, S., Al-Harthy, M. & Mohammad, A.-G. 2012. Does good clinical practice at the primary care improve the outcome care for diabetic patients? Gender differences. *Primary Care Diabetes,* 6**,** 285-292.

Bernal, G., Bonilla, J. & Bellido, C. 1995. Ecological validity and cultural sensitivity for outcome research: Issues for the cultural adaptation and development of psychosocial treatments with Hispanics. *Journal of abnormal child psychology,* 23**,** 67-82.

Bernal, G. E. & Domenech Rodríguez, M. M. 2012. *Cultural adaptations: Tools for evidence-based practice with diverse populations,* Washington, DC, US, American Psychological Association.

Beuker, K. T., Schjolberg, S., Lie, K. K., Swinkels, S., Rommelse, N. N. & Buitelaar, J. K. 2014. ESAT and M-CHAT as screening instruments for autism spectrum disorders

at 18 months in the general population: issues of overlap and association with clinical referrals. *European Child & Adolescent Psychiatry,* 23**,** 1081-91.

Bird, V. J., Le Boutillier, C., Leamy, M., Williams, J., Bradstreet, S. & Slade, M. 2014. Evaluating the feasibility of complex interventions in mental health services: standardised measure and reporting guidelines. *The British Journal of Psychiatry,* 204**,** 316-321.

Blackwell, P. B. 2002. Screening young children for autism and other social-communication disorders. *Journal of the Kentucky Medical Association,* 100**,** 390-4.

Boland, A., Cherry, M. G. & Dickson, R. 2013. *Doing a systematic review: a student's guide,* London, SAGE Publications Ltd.

Boone, H. N. & Boone, D. A. 2012. Analyzing likert data. *Journal of extension,* 50**,** 1-5.

Borsa, J. C., Damásio, B. F. & Bandeira, D. R. 2012. Cross-cultural adaptation and validation of psychological instruments: Some considerations. *Paidéia (Ribeirão Preto),* 22**,** 423-432.

Bouranta, N., Chitiris, L. & Paravantis, J. 2009. The relationship between internal and external service quality. *International Journal of Contemporary Hospitality Management,* 21**,** 275-293.

Bowen, D. J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D., Bakken, S., Kaplan, C. P., Squiers, L. & Fabrizio, C. 2009. How we design feasibility studies. *American journal of preventive medicine,* 36**,** 452-457.

Boyd, B. A., Odom, S. L., Humphreys, B. P. & Sam, A. M. 2010. Infants and toddlers with autism spectrum disorder: Early identification and early intervention. *Journal of Early Intervention,* 32**,** 75-98.

Boynton, P. M. & Greenhalgh, T. 2004. Selecting, designing, and developing your questionnaire. *Bmj,* 328**,** 1312-1315.

Brett, D., Warnell, F., McConachie, H. & Parr, J. R. 2016. Factors Affecting Age at ASD Diagnosis in UK: No Evidence that Diagnosis Age has Decreased Between 2004 and 2014. *Journal of Autism and Developmental Disorders,* 46**,** 1974-1984.

Buescher, A. V., Cidav, Z., Knapp, M. & Mandell, D. S. 2014. Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA pediatrics,* 168**,** 721-728.

Burns, N. & Grove, S. K. 2005. *The practice of nursing research : conduct, critique, and utilization,* St. Louis, Mo., Elsevier/Saunders.

Canal-Bedia, R., García-Primo, P., Martín-Cilleros, M., Santos-Borbujo, J., Guisuraga-Fernández, Z., Herráez-García, L., del Mar Herráez-García, M., Boada-Muñoz, L., Fuentes-Biggi, J. & Posada-de la Paz, M. 2011. Modified Checklist for Autism in Toddlers: Cross-Cultural Adaptation and Validation in Spain. *Journal of Autism & Developmental Disorders,* 41**,** 1342-1351 10p.

Cannon, S. 2015. *Introduction to nursing research,* Burlington, MA, Jones & Bartlett Publishers.

Carakovac, M., Jovanovic, J., Kalanj, M., Rudic, N., Aleksic–Hil, O., Aleksic, B., Villalobos, I. B., Kasuya, H., Ozaki, N. & Lecic–Tosevski, D. 2016. Serbian Language version of the Modified Checklist for Autism in Toddlers, Revised, with Follow-Up: Cross-Cultural Adaptation and Assessment of Reliability. *Scientific reports,* 6**,** 38222.

Carbone, P. S., Behl, D. D., Azor, V. & Murphy, N. A. 2010. The medical home for children with autism spectrum disorders: Parent and pediatrician perspectives. *Journal of autism and developmental disorders,* 40**,** 317-324.

Carifio, J. & Perla, R. J. 2007. Ten common misunderstandings, misconceptions, persistent myths and urban legends about Likert scales and Likert response formats and their antidotes. *Journal of Social Sciences,* 3**,** 106-116.

Carlsson, H. L., Gillberg, C., Lannero, E. & Blennow, M. 2010. Autism: Screening toddlers with CHAT in a child health care programme did not improve early identification. *Acta Paediatrica, International Journal of Paediatrics,* 99**,** 1897-1899.

Castro, F. G., Barrera Jr, M. & Holleran Steiker, L. K. 2010. Issues and challenges in the design of culturally adapted evidence-based interventions. *Annual Review of Clinical Psychology,* 6**,** 213-239.

Central Intelligence Agency 2015. *The World Factbook 2014-15*, Government Printing Office.

Chang, L. 1994. A psychometric evaluation of 4-point and 6-point Likert-type scales in relation to reliability and validity. *Applied psychological measurement,* 18**,** 205-215.

Charman, T., Baird, G., Simonoff, E., Chandler, S., Davison-Jenkins, A., Sharma, A., O'Sullivan, T. & Pickles, A. 2016. Testing two screening instruments for autism spectrum disorder in UK community child health services. *Developmental Medicine & Child Neurology,* 58**,** 369-75.

Choueiri, R. & Wagner, S. 2015. A New Interactive Screening Test for Autism Spectrum Disorders in Toddlers. *Journal of Pediatrics,* 167**,** 460-6.

Christensen, D. L., Baio, J., Van Naarden Braun, K., Bilder, D., Charles, J., Constantino, J. N., Daniels, J., Durkin, M. S., Fitzgerald, R. T., Kurzius-Spencer, M., Lee, L.-C., Pettygrove, S., Robinson, C., Schulz, E., Wells, C., Wingate, M. S., Zahorodny, W., Yeargin-Allsopp, M., Centers for Disease, C. & Prevention 2016. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years--Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *Morbidity and mortality weekly report,* 65**,** 1.

Churchill Jr, G. A. & Peter, J. P. 1984. Research design effects on the reliability of rating scales: A meta-analysis. *Journal of marketing research,* 21**,** 360-375.

Clark, J. M., Maben, J. & Jones, K. 1996. The use of focus group interviews in nursing research: issues and challenges. *NT Research,* 1**,** 143-153.

Clifford, J. 1990. *Notes on (field) notes,* Ithaca, N.Y. ; London Cornell University Press.

Cohen, L., Manion, L. & Morrison, K. 2013. *Research methods in education,* London Routledge.

Creswell, J. 2014. Research design (international student edition). Los Angeles: Sage.

Creswell, J. W. & Clark, V. L. P. 2007. Designing and conducting mixed methods research.

Creswell, J. W., Klassen, A. C., Plano Clark, V. L. & Smith, K. C. 2011. Best practices for mixed methods research in the health sciences. *Bethesda (Maryland): National Institutes of Health,* 2013**,** 541-545.

Creswell, J. W. & Plano Clark, V. L. 2007. *Designing and conducting mixed methods research,* Thousand Oaks, Calif;London, SAGE Publications.

Creswell, J. W., Plano Clark, V. L., Gutmann, M. L. & Hanson, W. E. 2003. *Advanced mixed methods research designs,* Thousand Oaks, CA, SAGE Publications.

Crowe, B. H. & Salt, A. T. 2014. Autism: the management and support of children and young people on the autism spectrum (NICE Clinical Guideline 170). *Archives of Disease in Childhood-Education and Practice***,** edpract-2013-305468.

Cutcliffe, J. R. 2003. Reconsidering reflexivity: Introducing the case for intellectual entrepreneurship. *Qualitative health research,* 13**,** 136-148.

Daley, E., Alio, A., Anstey, E. H., Chandler, R., Dyer, K. & Helmy, H. 2011. Examining barriers to cervical cancer screening and treatment in Florida through a socio-ecological lens. *Journal of Community Health,* 36**,** 121-131.

Dawes, J. 2008. Do data characteristics change according to the number of scale points used? An experiment using 5-point, 7-point and 10-point scales. *International journal of market research,* 50**,** 61-104.

DeVellis, R. F. 2003. Scale development: Theory and applications. Applied social research methods series. Bickman, L and DJ Rog. Thousand Oaks, Calif.: SAGE Publications, Inc.

Díaz-Santos, M., Cumba-Avilés, E., Bernal, G. & Rivera-Medina, C. 2008. Desarrollo y propiedades psicométricas de la escala de autoeficacia para la depresión en adolescentes (EADA). *Interamerican Journal of Psychology*, 42**,** 218-227.

Diem, K. G. 2004. A step-by-step guide to developing effective questionnaires and survey procedures for program evaluation and research. *Rutgers Cooperative Research & Extension* FS995**,** 1-6.

Dietz, C., Swinkels, S., van Daalen, E., van Engeland, H. & Buitelaar, J. K. 2006. Screening for autistic spectrum disorder in children aged 14-15 months. II: population screening with the Early Screening of Autistic Traits Questionnaire (ESAT). Design and general findings. *Journal of Autism & Developmental Disorders,* 36**,** 713-22.

Dixon-Woods, M. 2011. Using framework-based synthesis for conducting reviews of qualitative studies. *BMC medicine,* 9**,** 39.

Domenech Rodríguez, M. M. & Bernal, G. 2012. Frameworks, models, and guidelines for cultural adaptation. *In:* Bernal, G., Domenech Rodríguez, M. M., Bernal, G. & Domenech Rodríguez, M. M. (Eds.) *Cultural adaptations: Tools for evidence-based practice with diverse populations.* Washington, DC, US: American Psychological Association.

Dosreis, S., Weiner, C. L., Johnson, L. & Newschaffer, C. J. 2006. Autism spectrum disorder screening and management practices among general pediatric providers. *Journal of Developmental & Behavioral Pediatrics,* 27**,** S88-94.

Duby, J. C. & Johnson, C. P. 2009. Universal screening for autism spectrum disorders: a snapshot within the big picture. *Pediatric Annals,* 38**,** 36-41.

Essa, M. M., Guillemin, G. J., Waly, M. I., Al-Sharbati, M. M., Al-Farsi, Y. M., Hakkim, F. L., Ali, A. & Al-Shafaee, M. S. 2012. Increased markers of oxidative stress in autistic children of the Sultanate of Oman. *Biological trace element research,* 147**,** 25-27.

Ezzy, D. 2002. *Data analysis during data collection,* Victoria, Australia, Routledge.

Farrugia, D. 2009. Exploring stigma: medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness,* 31**,** 1011-1027.

Fenikile, T. S., Ellerbeck, K., Filippi, M. K. & Daley, C. M. 2015. Barriers to autism screening in family medicine practice: a qualitative study. *Primary Health Care Research & Development,* 16**,** 356-66.

Fern, E. F. 2001. *Advanced focus group research,* Thousand Oaks, Calif;London, SAGE Puplications

Ferrer-Wreder, L., Sundell, K., Mansoory, S., Stockholms, u., Samhällsvetenskapliga, f. & Psykologiska, i. 2012. Tinkering with Perfection: Theory Development in the Intervention Cultural Adaptation Field. *Child & Youth Care Forum,* 41**,** 149-171.

Filipek, P. A., Accardo, P. J., Ashwal, S., Baranek, G. T., Cook, E. H., Jr., Dawson, G., Gordon, B., Gravel, J. S., Johnson, C. P., Kallen, R. J., Levy, S. E., Minshew, N. J., Ozonoff, S., Prizant, B. M., Rapin, I., Rogers, S. J., Stone, W. L., Teplin, S. W., Tuchman, R. F. & Volkmar, F. R. 2000. Practice parameter: screening and diagnosis of autism: report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology,* 55**,** 468-79.

Fombonne, E., Marcin, C., Bruno, R., Tinoco, C. M. & Marquez, C. D. 2012. Screening for autism in Mexico. *Autism research : Official Journal of the International Society for Autism Research,* 5**,** 180-9.

Fowler Jr, F. J. 2013. *Survey research methods,* London SAGE Publications.

Frazer, L. & Lawley, M. 2000. Questionnaire administration and design: A practical guide. Brisbane, Australia: John Wiley & Sons.

Freeth, M., Milne, E., Sheppard, E. & Ramachandran, R. 2014. *Autism Across Cultures: Perspectives From Non-Western Cultures and Implications for Research,* London SAGE Publications.

Gale, N. K., Heath, G., Cameron, E., Rashid, S. & Redwood, S. 2013. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology,* 13**,** 117.

Garcia-Primo, P., Hellendoorn, A., Charman, T., Roeyers, H., Dereu, M., Roge, B., Baduel, S., Muratori, F., Narzisi, A., Van Daalen, E., Moilanen, I., de la Paz, M. P. & Canal-Bedia, R. 2014. Screening for autism spectrum disorders: state of the art in Europe. *European Child & Adolescent Psychiatry,* 23**,** 1005-21.

Gerrish, K. & Lacey, A. 2006. Communicating and disseminating research. *The Research Process in Nursing,* 5**,** 477-490.

Ghasemi, A. & Zahediasl, S. 2012. Normality tests for statistical analysis: a guide for non-statisticians. *International journal of endocrinology and metabolism,* 10**,** 486.

Ghebre, R. G., Sewali, B., Osman, S., Adawe, A., Nguyen, H. T., Okuyemi, K. S. & Joseph, A. 2015. Cervical cancer: barriers to screening in the Somali community in Minnesota. *Journal of immigrant and minority health,* 17**,** 722-728.

Gillberg, C., Nordin, V. & Ehlers, S. 1996. Early detection of autism. Diagnostic instruments for clinicians. *European Child & Adolescent Psychiatry,* 5**,** 67-74.

Gillis, A. & Jackson, W. 2002. *Research for nurses: Methods and interpretation,* Philadelphia, FA Davis Company.

Gillis, J. M. 2009. Screening practices of family physicians and pediatricians in 2 southern states. *Infants & Young Children,* 22**,** 321-331.

Gjersing, L., Caplehorn, J. R. & Clausen, T. 2010. Cross-cultural adaptation of research instruments: language, setting, time and statistical considerations. *BMC medical research methodology,* 10**,** 13.

Glascoe, F. P. & Shapiro, H. 1996. *Developmental screening,* St. Lois, MO, Mosby.

Gliem, J. A. & Gliem, R. R. Calculating, interpreting, and reporting Cronbach's alpha reliability coefficient for Likert-type scales. Midwest Research to Practice Conference in Adult, 2003 Columbus, OH. Continuing, and Community Education.

Golden, S. D., McLeroy, K. R., Green, L. W., Earp, J. A. L. & Lieberman, L. D. 2015. Upending the Social Ecological Model to Guide Health Promotion Efforts Toward Policy and Environmental Change. *Health Education & Behavior,* 42**,** 8S-14S.

Graneheim, U. H. & Lundman, B. 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today,* 24**,** 105-112.

Gray, D. E. 1993. Perceptions of stigma: The parents of autistic children. *Sociology of Health & Illness,* 15**,** 102-120.

Gray, D. E. 2002. 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness,* 24**,** 734-749.

Green, J., Thorogood, N., Askews & Holts Library, S. 2013. *Qualitative methods for health research,* London, SAGE Publications Ltd.

Grinker, R., Kang-Yi, C., Ahmann, C., Beidas, R., Lagman, A. & Mandell, D. 2015. Cultural Adaptation and Translation of Outreach Materials on Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders,* 45**,** 2329-2336 8.

Gruenewald, P. J., Remer, L. G. & LaScala, E. A. 2014. Testing a social ecological model of alcohol use: The California 50-city study. *Addiction,* 109**,** 736-745.

Guba, E. G. & Lincoln, Y. S. 1994. *Competing paradigms in qualitative research,* Thousand Oaks, CA, SAGE Publications.

Guba, E. G. & Lincoln, Y. S. 2005. *Paradigmatic Controversies,* Thousand Oaks, CA, SAGE Publications.

Guillemin, F., Bombardier, C. & Beaton, D. 1993. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *Journal of clinical epidemiology,* 46**,** 1417-1432.

Hambleton, R. K. 2005. *Issues, designs, and technical guidelines for adapting tests into multiple languages and cultures,* Mahwah, NJ, Lawrence Erlbaum.

Hansen, S. N., Schendel, D. E. & Parner, E. T. 2015. Explaining the increase in the prevalence of autism spectrum disorders: The proportion attributable to changes in reporting practices. *JAMA Pediatrics,* 169**,** 56-62.

Hanson, W. E., Creswell, J. W., Clark, V. L. P., Petska, K. S. & Creswell, J. D. 2005. Mixed methods research designs in counseling psychology. *Journal of counseling psychology,* 52**,** 224.

Havdahl, K. A., von Tetzchner, S., Huerta, M., Lord, C. & Bishop, S. L. 2016. Utility of the Child Behavior Checklist as a Screener for Autism Spectrum Disorder. *Autism*

research : Official Journal of the International Society for Autism Research, 9**,** 33-42.

Haynes, S. N., Richard, D. & Kubany, E. S. 1995. Content validity in psychological assessment: A functional approach to concepts and methods. *Psychological assessment,* 7**,** 238.

Hesse-Biber, S. N. & Leavy, P. 2010. *The practice of qualitative research,* London SAGE Publications

Hill, C. E., Knox, S., Thompson, B. J., Williams, E. N., Hess, S. A. & Ladany, N. 2005. Consensual qualitative research: An update. *Journal of counseling psychology,* 52**,** 196.

Hill, C. E., Thompson, B. J. & Williams, E. N. 1997. A guide to conducting consensual qualitative research. *The counseling psychologist,* 25**,** 517-572.

Hill, S. K. 2013. *Perceived Barriers and Facilitators to Mental and Behavioral Health Screening and Treatment in Primary Care for Women in Northeast Tennessee.* Master of Arts in Psychology Electronic Theses and Dissertations, East Tennessee State University.

Hussein, H., Shaker, N., El-Sheikh, M. & Ramy, H. A. 2012. Pathways to child mental health services among patients in an urban clinical setting in Egypt. *Psychiatric Services,* 63**,** 1225-1230.

Iarossi, G. 2006. *The power of survey design: A user's guide for managing surveys, interpreting results, and influencing respondents,* Washington, DC, World Bank Publications.

Idring, S., Lundberg, M., Sturm, H., Dalman, C., Gumpert, C., Rai, D., Lee, B. K. & Magnusson, C. 2015. Changes in prevalence of autism spectrum disorders in 2001–2011: findings from the Stockholm youth cohort. *Journal of autism and developmental disorders,* 45**,** 1766-1773.

Igwe, M. N., Ahanotu, A. C., Bakare, M. O., Achor, J. U. & Igwe, C. 2011. Assessment of knowledge about childhood autism among paediatric and psychiatric nurses in Ebonyi state, Nigeria. *Child and adolescent psychiatry and mental health,* 5**,** 1-1.

Johnson, R. B. & Onwuegbuzie, A. J. 2004. Mixed methods research: A research paradigm whose time has come. *Educational researcher,* 33**,** 14-26.

Joshi, A., Kale, S., Chandel, S. & Pal, D. 2015. Likert scale: Explored and explained. *British Journal of Applied Science & Technology,* 7**,** 396.

Kamio, Y., Haraguchi, H., Stickley, A., Ogino, K., Ishitobi, M. & Takahashi, H. 2015. Brief Report: Best Discriminators for Identifying Children with Autism Spectrum Disorder at an 18-Month Health Check-Up in Japan. *Journal of Autism & Developmental Disorders,* 45**,** 4147-53.

Kamio, Y., Inada, N., Koyama, T., Inokuchi, E., Tsuchiya, K. & Kuroda, M. 2014. Effectiveness of using the Modified Checklist for Autism in Toddlers in two-stage screening of autism spectrum disorder at the 18-month health check-up in Japan. *Journal of Autism & Developmental Disorders,* 44**,** 194-203.

Kang-Yi, C. D., Grinker, R. R. & Mandell, D. S. 2013. Korean culture and autism spectrum disorders. *Journal of autism and developmental disorders,* 43**,** 503-520.

Kara, B., Mukaddes, N. M., Altinkaya, I., Güntepe, D., Gökçay, G. & Özmen, M. 2014. Using the Modified Checklist for Autism in Toddlers in a Well-Child Clinic in Turkey: Adapting the Screening Method Based on Culture and Setting. *Autism: The International Journal of Research and Practice,* 18**,** 331-338.

Kazak, A. E. 1989. Families of Chronically Ill Children: A Systems and Social-Ecological Model of Adaptation and Challenge. *Journal of Consulting and Clinical Psychology,* 57**,** 25-30.

Klein, T. J., Al-Ghasani, T., Al-Ghasani, M., Akbar, A., Tang, E. & Al-Farsi, Y. 2015. A mobile application to screen for autism in Arabic-speaking communities in Oman. *The Lancet Global Health,* 3**,** S15.

Kmet, L. M., Lee, R. C. & Cook, L. S. 2004. *Standard quality assessment criteria for evaluating primary research papers from a variety of fields,* Alberta Heritage Foundation for Medical Research Edmonton.

Knapp, M., Romeo, R. & Beecham, J. 2009. Economic cost of autism in the UK. *Autism,* 13**,** 317-336.

Kobak, K. A., Stone, W. L., Wallace, E., Warren, Z., Swanson, A. & Robson, K. 2011. A web-based tutorial for parents of young children with autism: results from a pilot study. *TELEMEDICINE and e-HEALTH,* 17**,** 804-808.

Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M. & van Dyck, P. C. 2008. A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics,* 122**,** e1149-e1158.

Kondolot, M., Özmert, E. N., Öztop, D. B., Mazıcıoğlu, M. M., Gümüş, H. & Elmalı, F. 2016. The modified checklist for autism in Turkish toddlers: A different cultural adaptation sample. *Research in Autism Spectrum Disorders,* 21**,** 121-127.

Kopetz, P. & Endowed, E. 2012. Autism Worldwide: Prevalence, Perceptions, Acceptance, Action *Journal of Social Sciences* 8**,** 196-201.

Krabbe, P. F. M. 2017. Chapter 8 - Reliability. *The Measurement of Health and Health Status.* San Diego: Academic Press.

Krueger, R. A. & Casey, M. A. 2015. *Focus groups: a practical guide for applied research,* Thousand Oaks, California, SAGE Publications, Inc.

Lincoln, Y. S. & Guba, E. G. 2000. *The only generalization is: There is no generalization,* London, SAGE Publications

Losby, J. & Wetmore, A. 2012. CDC coffee break: Using Likert Scales in evaluation survey work. *Centers for Disease Control and Prevention,* 2**,** 14.

MacLean, R. & Wilson, S. 2011. Research methods and data analysis for psychology. United Kingdom: McGraw-Hill Education.

MacLeod, A., Lewis, A. & Robertson, C. 2013. 'Why should I be like bloody Rain Man?!'Navigating the autistic identity. *British Journal of Special Education,* 40**,** 41-49.

Magiati, I., Goh, D. A., Lim, S. J., Gan, D. Z. Q., Leong, J., Allison, C., Baron-Cohen, S., Rifkin-Graboi, A., Broekman, B. P. & Saw, S. M. 2015. The psychometric properties of the Quantitative-Checklist for Autism in Toddlers (Q-CHAT) as a measure of autistic traits in a community sample of Singaporean infants and toddlers. *Molecular autism,* 6**,** 40.

Mandell, D. S., Listerud, J., Levy, S. E. & Pinto-Martin, J. A. 2002. Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry,* 41**,** 1447-1453.

Matson, J. L., Worley, J. A., Fodstad, J. C., Chung, K.-M., Suh, D., Jhin, H. K., Ben-Itzchak, E., Zachor, D. A. & Furniss, F. 2011. A multinational study examining the cross cultural differences in reported symptoms of autism spectrum disorders: Israel, South Korea, the United Kingdom, and the United States of America. *Research in Autism Spectrum Disorders,* 5**,** 1598-1604.

Mattila, M.-L., Jussila, K., Linna, S.-L., Kielinen, M., Bloigu, R., Kuusikko-Gauffin, S., Joskitt, L., Ebeling, H., Hurtig, T. & Moilanen, I. 2012. Validation of the Finnish Autism Spectrum Screening Questionnaire (ASSQ) for Clinical Settings and Total Population Screening. *Journal of Autism and Developmental Disorders,* 42**,** 2162-2180.

Mattila, M. L., Jussila, K., Kuusikko, S., Kielinen, M., Linna, S. L., Ebeling, H., Bloigu, R., Joskitt, L., Pauls, D. & Moilanen, I. 2009. When does the Autism Spectrum Screening Questionnaire (ASSQ) predict autism spectrum disorders in primary school-aged children? *European Child & Adolescent Psychiatry,* 18**,** 499-509.

McGraw, L. A., Zvonkovic, A. M. & Walker, A. J. 2000. Studying postmodern families: A feminist analysis of ethical tensions in work and family research. *Journal of Marriage and Family,* 62**,** 68-77.

McLeroy, K. R., Bibeau, D., Steckler, A. & Glanz, K. 1988. An ecological perspective on health promotion programs. *Health education quarterly,* 15**,** 351.

McPheeters, M. L., Weitlauf, A., Vehorn, A., Taylor, C., Sathe, N. A., Krishnaswami, S., Fonnesbeck, C. & Warren, Z. E. 2016. Screening for Autism Spectrum Disorder in Young Children:A Systematic Evidence Review for the US Preventive Services Task Force:. *In:* SERVICES, U. S. D. O. H. H. (ed.) Evidence Synthesis No. 129. ed.: Rockville, MD: Agency for Healthcare Research and Quality.

Merriam, S. B., Tisdell, E. J., Askews & Holts Library, S. 2016. *Qualitative research: a guide to design and implementation,* San Francisco, CA, Jossey-Bass.

Ministry of Health 2012. Health Facts (2012). *In:* Planning, D. G. O. (Ed.). Oman: Department of Health Information & Statistics.

Ministry of Health. 2013. *Annual Health Report 2013* [Online]. Oman Depatment of Health information and Statistics Available: https://www.moh.gov.om/ar_OM/web/statistics/-/2013-chapter-5 [Accessed 11/04/2017 2017].

Ministry of Health. 2015. *Health Vision 2050* [Online]. Oman. Available: https://www.moh.gov.om/documents/16506/119833/Health+Vision+2050/7b6f40f3-8f93-4397-9fde-34e04026b829 [Accessed 11/7/2017].

Ministry of Health 2017. Course Syllabus (Theory). *In:* DEVELOPMENT, D. G. O. H. R. (ed.) *Child Health Nursing.* Oman: MoH.

Mohamed, F. E., Zaky, E. A., Youssef, A., Elhossiny, R., Zahra, S., Khalaf, R., Youssef, W., Wafiq, A., Ibrahim, R., Abd-Elhakim, R., Obada, A. & Eldin, W. S. 2016. Screening of Egyptian toddlers for autism spectrum disorder using an Arabic validated version of M-CHAT; report of a community-based study (Stage I). *European Psychiatry: the Journal of the Association of European Psychiatrists,* 34**,** 43-8.

Mohammadian, M., Zarafshan, H., Mohammadi, M. R. & Karimi, I. 2015. Evaluating Reliability and Predictive Validity of the Persian Translation of Quantitative

Checklist for Autism in Toddlers (Q-CHAT). *Iranian Journal of Psychiatry,* 10**,** 64-70.

Moher, D., Liberati, A., Tetzlaff, J. & Altman, D. G. 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of internal medicine,* 151**,** 264-269.

Moher, D., Tetzlaff, J., Tricco, A. C., Sampson, M. & Altman, D. G. 2007. Epidemiology and reporting characteristics of systematic reviews. *PLoS Med,* 4**,** e78.

Mohiuddin, S. & Ghaziuddin, M. 2013. Psychopharmacology of autism spectrum disorders: A selective review. *Autism,* 17**,** 645-654.

Moll, J., Major, M. & Hoque, Z. 2006. The qualitative research tradition. *Methodological issues in accounting research: Theories and methods.* London, : Spiramus Press Ltd.

Morelli, D. L., Pati, S., Butler, A., Blum, N. J., Gerdes, M., Pinto-Martin, J. & Guevara, J. P. 2014. Challenges to implementation of developmental screening in urban primary care: a mixed methods study. *BMC Pediatrics,* 14**,** 16.

Morgan, D. L. 1998. *The focus group guidebook,* Thousand Oaks, Calif;London;, SAGE Publications.

Morrow, S. L. 2005. Quality and trustworthiness in qualitative research in counseling psychology. *Journal of counseling psychology,* 52**,** 250.

Morrow, S. L., Rakhsha, G. & Castañeda, C. L. 2001. *Qualitative research methods for multicultural counseling,* Thousand Oaks, CA, SAGE Publications.

Moule, P., Aveyard, H. & Goodman, M. L. 2017. *Nursing research: an introduction,* London, SAGE Publications Ltd.

Mulhall, A. 2003. In the field: notes on observation in qualitative research. *Journal of advanced nursing,* 41**,** 306-313.

Muswazi, M. & Nhamo, E. 2013. Note taking: a lesson for novice qualitative researchers. *Journal of Research & Method in Education,* 2**,** 13-17.

National Centre for Statistics & Information. 2017. *Population Clock* [Online]. Oman NCSI. Available: https://www.ncsi.gov.om/Pages/NCSI.aspx [Accessed 02/04/2017].

Netemeyer, R. G., Bearden, W. O. & Sharma, S. 2003. *Scaling procedures: Issues and applications*, Thousand Oaks, CA, Sage Publications.

Neuman, W. & Robson, K. 2012. *Qualitative interviewing*, Boston, MA, Pearson Education, Inc.

Nickel, R. E. & Huang-Storms, L. 2017. Early Identification of Young Children with Autism Spectrum Disorder. *The Indian Journal of Pediatrics,* 84**,** 53-60.

Nicolas, G., Arntz, D. L., Hirsch, B. & Schmiedigen, A. 2009. Cultural adaptation of a group treatment for Haitian American adolescents. *Professional Psychology: Research and Practice,* 40**,** 378.

NSC, U. N. S. C. 2012. The UK NSC recommendation on autism screening in children. England

Nygren, G., Sandberg, E., Gillstedt, F., Ekeroth, G., Arvidsson, T. & Gillberg, C. 2012. A new screening programme for autism in a general population of Swedish toddlers. *Research in Developmental Disabilities*, 33**,** 1200-10.

Oelke, N. D., Besner, J. & Carter, R. 2014. The evolving role of nurses in primary care medical settings. *International journal of nursing practice,* 20**,** 629-635.

Ogbonna, E. & Harris, L. C. 2000. Leadership style, organizational culture and performance: empirical evidence from UK companies. *International Journal of Human Resource Management,* 11**,** 766-788.

Okasha, A. 1966. A cultural psychiatric study of El-Zar cult in UAR. *The British Journal of Psychiatry,* 112**,** 1217-1221.

Onwuegbuzie, A. J. & Leech, N. L. 2004. Enhancing the interpretation of significant findings: The role of mixed methods research. *The qualitative report,* 9**,** 770-792.

Oppenheim, A. N. 2001. *Questionnaire design, interviewing and attitude measurement,* London, Continuum.

Ouhtit, A., Al-Farsi, Y., Al-Sharbati, M., Waly, M., Gupta, I., Al-Farsi, O., Al-Khaduri, M., Al-Shafaee, M. & Al-Adawi, S. 2015. Underlying factors behind the low prevalence of autism spectrum disorders in Oman: Sociocultural perspective. *Sultan Qaboos University Medical Journal,* 15**,** e213.

Page, M. J., Shamseer, L., Altman, D. G., Tetzlaff, J., Sampson, M., Tricco, A. C., Catalá-López, F., Li, L., Reid, E. K. & Sarkis-Onofre, R. 2016. Epidemiology and reporting characteristics of systematic reviews of biomedical research: a cross-sectional study. *PLoS medicine,* 13**,** e1002028.

Pallant, J. 2016. *SPSS survival manual: a step by step guide to data analysis using IBM SPSS,* Maidenhead, Berkshire, England, McGraw-Hill Education.

Pallant, J. & Dawson, B. 2010. *SPSS survival manual: a step by step guide to data analysis using SPSS,* Maidenhead, Open University Press/McGraw Hill.

Parahoo, K. 2008. Questionnaires. *Nursing Research Designs and Methods.* Churchill Livingstone Elsevier, Edinburgh.

Parahoo, K. 2014. *Nursing research: principles, process and issues,* Basingstoke, Palgrave Macmillan.

Perera, H., Jeewandara, K. C., Seneviratne, S. & Guruge, C. 2017. Culturally adapted pictorial screening tool for autism spectrum disorder: A new approach. *World journal of clinical pediatrics,* 6**,** 45.

Perera, H., Wijewardena, K. & Aluthwelage, R. 2009. Screening of 18-24-month-old children for autism in a semi-urban community in Sri Lanka. *Journal of Tropical Pediatrics,* 55**,** 402-5.

Persson, B., Nordstrom, B., Petersson, K., Månsson, M. E. & Sivberg, B. 2006. International pediatric nursing. Screening for infants with developmental deficits and/or autism: a Swedish pilot study. *Journal of Pediatric Nursing,* 21**,** 313-324.

Peterson, R. A. 2000. *Constructing effective questionnaires,* Thousand Oaks, Calif;London;, Sage Publications.

Pierce, K., Carter, C., Weinfeld, M., Desmond, J., Hazin, R., Bjork, R. & Gallagher, N. 2011. Detecting, studying, and treating autism early: the one-year well-baby check-up approach. *The Journal of pediatrics,* 159**,** 458-465. e6.

Polit, D. F. & Beck, C. T. 2004. *Nursing research: Principles and methods,* Lippincott Williams & Wilkins.

Pope, C., Ziebland, S. & Mays, N. 2000. Qualitative research in health care: analysing qualitative data. *BMJ: British Medical Journal,* 320**,** 114.

Price, B. 2002. Laddered questions and qualitative data research interviews. *Journal of advanced nursing,* 37**,** 273-281.

Punch, K. 2014. *Introduction to social research: quantitative & qualitative approaches,* London, SAGE Publications Ltd.

Rattray, J. & Jones, M. C. 2007. Essential elements of questionnaire design and development. *Journal of clinical nursing,* 16**,** 234-243.

Resnicow, K., Soler, R., Braithwaite, R. L., Ahluwalia, J. S. & Butler, J. 2000. Cultural sensitivity in substance use prevention. *Journal of community psychology,* 28**,** 271-290.

Reznick, J. S., Baranek, G. T., Reavis, S., Watson, L. R. & Crais, E. R. 2007. A parent-report instrument for identifying one-year-olds at risk for an eventual diagnosis of autism: the first year inventory. *Journal of autism and developmental disorders,* 37**,** 1691-1710.

Ritchie, J. & Lewis, J. 2003. *Qualitative research practice: a guide for social science students and researchers,* London, SAGE.

Ritchie, J., Lewis, J., McNaughton Nicholls, C. & Ormston, R. 2014. *Qualitative research practice: a guide for social science students and researchers,* London, SAGE Publications Ltd.

Ritchie, J., Spencer, L., Bryman, A. & Burgess, R. 1994. Analysing qualitative data. *London: Routledge,* 3.

Robins, D. L. 2008. Screening for autism spectrum disorders in primary care settings. *Autism,* 12**,** 537-56.

Robins, D. L., Casagrande, K., Barton, M., Chen, C.-M. A., Dumont-Mathieu, T. & Fein, D. 2014. Validation of the modified checklist for autism in toddlers, revised with follow-up (M-CHAT-R/F). *Pediatrics,* 133**,** 37-45.

Robins, D. L., Fein, D. & Barton, M. 2009. *Modified checklist for autism in toddlers, revised, with follow-up (M-CHAT-R/F) TM* [Online]. USA: Self-published. Available: http://mchatscreen.com/wp-content/uploads/2017/07/M-CHAT-R_F_Tagalog.pdf [Accessed 2016].

Robins, D. L., Fein, D., Barton, M. L. & Green, J. A. 2001. The Modified Checklist for Autism in Toddlers: an initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of autism and developmental disorders,* 31**,** 131-144.

Rossello, J. & Bernal, G. 1999. The efficacy of cognitive-behavioral and interpersonal treatments for depression in Puerto Rican adolescents. *Journal of consulting and clinical psychology,* 67**,** 734.

Rossman, G. B. & Rallis, S. F. 2012. *Learning in the field: an introduction to qualitative research,* London;Los Angeles, Calif;, SAGE.

Saleh, S., Alameddine, M., Mourad, Y. & Natafgi, N. 2015. Quality of care in primary health care settings in the Eastern Mediterranean region: a systematic review of the literature. *International Journal for Quality in Health Care,* 27**,** 79-88.

Salhia, H. O., Al-Nasser, L. A., Taher, L. S., Al-Khathaami, A. M. & El-Metwally, A. A. 2014. Systemic review of the epidemiology of autism in Arab Gulf countries. *Neurosciences,* 19**,** 291.

Samadi, S. & McConkey, R. 2015. Screening for Autism in Iranian Preschoolers: Contrasting M-CHAT and a Scale Developed in Iran. *Journal of Autism & Developmental Disorders,* 45**,** 2908-2916 9p.

Samadi, S. A., Mahmoodizadeh, A. & McConkey, R. 2012. A national study of the prevalence of autism among five-year-old children in Iran. *Autism,* 16**,** 5-14.

Sandelowski, M. 2000. Whatever happened to qualitative description? *Research in Nursing & Health,* 23**,** 334-340.

Savenye, W. C. & Robinson, R. S. 2005. Using qualitative research methods in higher education. *Journal of computing in Higher education,* 16**,** 65-95.

Savoie, I., Helmer, D., Green, C. J. & Kazanjian, A. 2003. Beyond medline. *International journal of technology assessment in health care,* 19**,** 168-178.

Scarpa, A., Reyes, N. M., Patriquin, M. A., Lorenzi, J., Hassenfeldt, T. A., Desai, V. J. & Kerkering, K. W. 2013. The modified checklist for autism in toddlers: Reliability in a diverse rural American sample. *Journal of autism and developmental disorders,* 43**,** 2269-2279.

Schopler, E. & Mesibov, G. B. 2013. *Diagnosis and assessment in autism,* New York, Springer Science & Business Media.

Seif Eldin, A., Habib, D., Noufal, A., Farrag, S., Bazaid, K., Al-Sharbati, M., Badr, H., Moussa, S., Essali, A. & Gaddour, N. 2008. Use of M-CHAT for a multinational screening of young children with autism in the Arab countries. *International Review of Psychiatry,* 20**,** 281-9.

Seung, H., Ji, J., Kim, S. J., Sung, I., Youn, Y. A., Hong, G., Lee, H., Lee, Y. H., Lee, H. & Youm, H. K. 2015. Examination of the Korean Modified Checklist of Autism in Toddlers: Item Response Theory. *Journal of Autism & Developmental Disorders,* 45**,** 2744-57.

Shattuck, P. T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D. S., Wiggins, L., Lee, L.-C., Rice, C., Giarelli, E. & Kirby, R. 2009. Timing of identification among children with an autism spectrum disorder: findings from a population-based surveillance study. *Journal of the American Academy of Child & Adolescent Psychiatry,* 48**,** 474-483.

SIGN, S. I. G. N. 2016. Assessment, diagnosis and interventions for autism spectrum disorders A national clinical guideline. Scotland: NHS.

Silverman, D. 2001. Interpreting Qualitative Data: Methods for interpreting talk, text and interaction. London: Sage.

Simon, G. E. & VonKorff, M. 1997. Prevalence, burden, and treatment of insomnia in primary care. *American Journal of Psychiatry,* 154**,** 1417-1423.

Singer, E., Van Hoewyk, J. & Maher, M. P. 2000. Experiments with incentives in telephone surveys. *Public Opinion Quarterly,* 64**,** 171-188.

Siu, A. L., Force, U. S. P. S. T., Bibbins-Domingo, K., Grossman, D. C., Baumann, L. C., Davidson, K. W., Ebell, M., Garcia, F. A., Gillman, M., Herzstein, J., Kemper, A. R., Krist, A. H., Kurth, A. E., Owens, D. K., Phillips, W. R., Phipps, M. G. & Pignone, M. P. 2016. Screening for Autism Spectrum Disorder in Young Children: US Preventive Services Task Force Recommendation Statement.[Summary for patients in JAMA. 2016 Feb 16;315(7):718; PMID: 26881385]. *JAMA,* 315**,** 691-6.

Slavec, A. & Drnovsek, M. 2012. A perspective on scale development in entrepreneurship research. *Economic and Business Review for Central and South-Eastern Europe,* 14**,** 39.

Smith, A. M. 2012. Research Methodology: A Step-by-step Guide for Beginners. *Nurse Education in Practice,* 12**,** e25.

Smith, J., Bekker, H. & Cheater, F. 2011. Theoretical versus pragmatic design in qualitative research. *Nurse researcher,* 18**,** 39-51.

So, P., Greaves-Lord, K., van der Ende, J., Verhulst, F. C., Rescorla, L. & de Nijs, P. F. 2013. Using the Child Behavior Checklist and the Teacher's Report Form for identification of children with autism spectrum disorders. *Autism,* 17**,** 595-607.

Soto, S., Linas, K., Jacobstein, D., Biel, M., Migdal, T. & Anthony, B. J. 2015. A review of cultural adaptations of screening tools for autism spectrum disorders. *Autism,* 19**,** 646-61.

Stahmer, A. C. & Mandell, D. S. 2007. State infant/toddler program policies for eligibility and services provision for young children with autism. *Administration and Policy in Mental Health and Mental Health Services Research,* 34**,** 29-37.

Stewart, D. W. & Shamdasani, P. N. 2014. *Focus groups: Theory and practice,* London SAGE Publications.

Stone, W. L. & Rosenbaum, J. L. 1988. A comparison of teacher and parent views of autism. *Journal of Autism and Developmental disorders,* 18**,** 403-414.

Streiner, D. L., Norman, G. R. & Cairney, J. 2015. *Health measurement scales: a practical guide to their development and use,* Oxford, Oxford University Press.

Subedi, B. P. 2016. Using Likert type data in social science research: Confusion, issues and challenges. *International Journal of Conterporary Applied Sciences,* 3**,** 36-49.

Swallow, V., Lambert, H., Santacroce, S. & MacFadyen, A. 2011. Fathers and mothers developing skills in managing children's long-term medical conditions: how do their qualitative accounts compare? *Child: care, health and development,* 37**,** 512-523.

Swearer, S. M. & Hymel, S. 2015. Understanding the psychology of bullying: Moving toward a social-ecological diathesis-stress model. *The American psychologist,* 70**,** 344-353.

Swinkels, S. H., Dietz, C., van Daalen, E., Kerkhof, I. H., van Engeland, H. & Buitelaar, J. K. 2006. Screening for autistic spectrum in children aged 14 to 15 months. I: the development of the Early Screening of Autistic Traits Questionnaire (ESAT). *Journal of autism and developmental disorders,* 36**,** 723-732.

Tanzer, N. K. 2005. Developing tests for use in multiple languages and cultures: A plea for simultaneous development. *In:* HAMBLETON, R. K. & PATSULA, L. (eds.) *Adapting educational and psychological tests for cross-cultural assessment.* New Jersey: Lawrence Erlbaum Associates,.

Tashakkori, A. & Teddlie, C. 2010. *SAGE handbook of mixed methods in social & behavioral research,* Thousand Oaks, CA;London;, SAGE Publications.

Tebruegge, M., Nandini, V. & Ritchie, J. 2004. Does routine child health surveillance contribute to the early detection of children with pervasive developmental disorders?–An epidemiological study in Kent, UK. *BMC pediatrics,* 4**,** 4.

Tek, S. & Landa, R. J. 2012. Differences in autism symptoms between minority and non-minority toddlers. *Journal of autism and developmental disorders,* 42**,** 1967-1973.

Terre Blanche, M. & Kelly, K. 1999. Interpretive methods. *In:* M, T. B. & K, D. (eds.) *Research in practice: Applied methods for the social sciences.* Cape Town: University of Cape Town Press.

The University of Glasgow. 2016. *Data management support for researchers* [Online]. The University of Glasgow Available: http://www.gla.ac.uk/services/datamanagement/storageandcosts/ [Accessed 25/08/2016 2016].

Thomas, J. 2009. Medical records and issues in negligence. *Indian Journal of Urology,* 25**,** 384.

Towle, P. O. & Patrick, P. A. 2016. Autism Spectrum Disorder Screening Instruments for Very Young Children: A Systematic Review. *Autism Research and Treatment,* 2016**,** 1-29.

Tsang, K. 2012. The use of midpoint on Likert Scale: The implications for educational research. *Hong Kong Teachers' Centre Journal,* 11**,** 121-130.

Vézina, M., Sylvestre, A. & Fossard, M. 2013. Développement de la version québécoise francophone du Children's Communication Checklist–2 (CCC-2). Normalisation et équivalence métrique [Development of a Quebec French Version of the Children's Communication Checklist-2 (CCC-2). Normalisation and metric equivalence]. *Revue Canadienne d'Orthophonie et d'Audiologie,* 37**,** 156-168.

Volkmar, F., Cook, E. H., Pomeroy, J., Realmuto, G. & Tanguay, P. 1999. Practice parameters for the assessment and treatment of children, adolescents, and adults with autism and other pervasive developmental disorders. *Journal of the American Academy of Child & Adolescent Psychiatry,* 38**,** 32S-54S.

Wallis, K. E. & Pinto-Martin, J. 2008. The challenge of screening for autism spectrum disorder in a culturally diverse society. *Acta Paediatrica,* 97**,** 539-540.

Wallis, K. E. & Pinto-Martin, J. 2008. The challenge of screening for autism spectrum disorder in a culturally diverse society. *Acta Paediatrica,* 97**,** 539-540.

Ward, D. J., Furber, C., Tierney, S. & Swallow, V. 2013. Using framework analysis in nursing research: a worked example. *Journal of advanced nursing,* 69**,** 2423-2431.

Watson, L. R., Baranek, G. T., Crais, E. R., Reznick, J. S., Dykstra, J. & Perryman, T. 2007. The first year inventory: retrospective parent responses to a questionnaire designed to identify one-year-olds at risk for autism. *Journal of autism and developmental disorders,* 37**,** 49-61.

Williams, A. 2003. How to.write and analyse a questionnaire. *Journal of orthodontics,* 30**,** 245.

Williams, A., Erb-Downward, J., Bruzelius, E., O'Hara-Cicero, E., Maling, A., Machin, L., Viera-Delgado, M., Valera, P., Maysonet, N. & Weiss, E. S. 2013. Exploring cancer screening in the context of unmet mental health needs: A participatory pilot study. *Progress in community health partnerships: research, education, and action,* 7**,** 123.

Windham, G., Smith, K., Rosen, N., Anderson, M., Grether, J., Coolman, R. & Harris, S. 2014. Autism and Developmental Screening in a Public, Primary Care Setting Primarily Serving Hispanics: Challenges and Results. *Journal of Autism & Developmental Disorders,* 44**,** 1621-1632 12p.

Winslow, W. W., Honein, G. & Elzubeir, M. A. 2002. Seeking Emirati women's voices: The use of focus groups with an Arab population. *Qualitative Health Research,* 12**,** 566-575.

Wong, V., Hui, L.-H. S., Lee, W.-C., Leung, L.-S. J., Ho, P.-K. P., Lau, W.-L. C., Fung, C.-W. & Chung, B. 2004. A modified screening tool for autism (Checklist for Autism in Toddlers [CHAT-23]) for Chinese children. *Pediatrics,* 114**,** e166-e176.

World Health Organisation. 2006. *Health System Profile- Oman* [Online]. Cairo Ministry of Health. Available:

http://apps.who.int/medicinedocs/documents/s17304e/s17304e.pdf [Accessed 2016].

World Health Organization. 2016. *Health Profile 2015-Oman* [Online]. Cairo World Health Organization. Available: http://applications.emro.who.int/dsaf/EMROPUB_2016_EN_19273.pdf?ua=1&ua=1 [Accessed 2017].

Ws, A., Zwaigenbaum, L., Nicholas, D. & Sharon, R. 2015. Factors influencing autism spectrum disorder screening by community paediatricians. *Paediatrics & Child Health,* 20**,** e20-4.

WU, F.-y., XU, X., LIU, J., XIA, J.-w. & CAO, L.-j. 2010. Study on the application of Autism Screening Scale (CHAT-23)[J]. *Chinese Journal of Child Health Care,* 4**,** 015.

Zachor, D., Yang, J.-w., Itzchak, E. B., Furniss, F., Pegg, E., Matson, J. L., Horovitz, M., Sipes, M., Chung, K.-M. & Jung, W. 2011. Cross-cultural differences in comorbid symptoms of children with autism spectrum disorders: An international examination between Israel, South Korea, the United Kingdom and the United States of America. *Developmental neurorehabilitation,* 14**,** 215-220.

Zenner, C., Herrnleben-Kurz, S. & Walach, H. 2014. Mindfulness-based interventions in schools—a systematic review and meta-analysis. *Frontiers in psychology,* 5**,** 603.

Zimbardo, P. G. & Boyd, J. N. 2015. Putting time in perspective: A valid, reliable individual-differences metric. *Time perspective theory; review, research and application.* Springer.

Zwaigenbaum, L., Bauman, M. L., Fein, D., Pierce, K., Buie, T., Davis, P. A., Newschaffer, C., Robins, D. L., Wetherby, A., Choueiri, R., Kasari, C., Stone, W. L., Yirmiya, N., Estes, A., Hansen, R. L., McPartland, J. C., Natowicz, M. R., Carter, A., Granpeesheh, D., Mailloux, Z., Smith Roley, S. & Wagner, S. 2015. Early Screening of Autism Spectrum Disorder: Recommendations for Practice and Research. *Pediatrics,* 136 Suppl 1**,** S41-59.

Zwaigenbaum, L., Bryson, S. & Garon, N. 2013. Early identification of autism spectrum disorders. *Behavioural brain research,* 251**,** 133-146.

Appendices:

Appendix 1: Examples from the literature search

Psych Info (36) 22/03/2016

Search ID#	Search Terms	Results
S18	S16 AND S17	(36)
S17	nurs* or allied health or health care provider	(138,950)
S16	S14 AND S15	(886)
S15	cultur*	(295,498)
S14	S7 AND S13	(25,630)
S13	S8 OR S9 OR S10 OR S11 OR S12	(1,257,837)
S12	assess*	(628,678)
S11	detect*	(110,318)
S10	test*	(740,387)
S9	surveillance	(0)
S8	screen*	(76,978)
S7	S1 OR S2 OR S3 OR S4 OR S5 OR S6	(70,399)
S6	rett*	(1,752)
S5	kanner*	(810)
S4	pervasive*	(14,573)
S3	asperger*	(3,496)
S2	ASD spectrum disorders	(32,945)
S1	autis*	(62,874)

Appendix 2: Quality assessments of the included studies

Authors	Albores-Gallo et al., 2012	Ben-Sasson, 2012	Beuker, 2014	Canal- Bedia, 2011	Carakovac et al., 2016	Fombonne, 2012	Kamio, 2014	Kamio, 2015	Kara, 2014	Kondolot et al.,2016	Mohammed, 2012	Mohammadian, 2015	Nygren, 2012	Perera, 2009	Perera et al., 2017	Samadi, 2015	Seif Eldin, 2008	Seung, 2015	Wong, 2004
Quality Assessment Criteria **1. Question/objective sufficiently described.**	2	2	2	2	2	2	2	2	2	2	2	2	2	1	2	2	2	2	2
2. Study design evident and appropriate.	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	1	2	2	2
3. Method of subject/comparison group selection or source of information/input variables described and appropriate.	2	2	2	2	1	2	2	2	2	2	2	1	2	1	2	1	1	2	2
4. Subject (and comparison group, if applicable) characteristics sufficiently described.	2	2	2	1	1	1	1	1	1	2	2	2	2	1	2	2	1	2	2
5. If interventional and random allocation was possible, was it described?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
6. If interventional and blinding of investigators was possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

7. If interventional and blinding of subjects was possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
8. Outcome and (if applicable) exposure measure(s) well defined and robust to any measurement/misclassification bias. Means of assessment reported.	2	2	2	2	2	1	2	2	2	2	2	2	2	1	2	2	0	2	2
9. Sample size appropriate.	1	1	1	2	1	1	1	1	2	2	2	1	2	1	1	1	1	1	2
10. Analytical methods described/justified and appropriate.	2	2	2	2	2	2	2	2	1	1	1	2	2	1	1	2	2	1	2
11. Some estimate of variance is reported for the main results.	1	1	1	1	1	1	1	1	1	1	2	2	2	1	2	2	1	2	1
12. Controlled for confounding.	2	N/A	N/A	N/A	1	2	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	1	N/A	2	N/A	2
13. Results reported in sufficient detail.	2	2	2	2	1	1	2	2	2	2	2	2	2	1	2	2	2	2	2
Total sum = (number of "yes" *2) + (number of "partials" *1)	18	16	16	16	14	15	15	15	15	16	17	16	18	12	17	15	14	16	19
Total possible sum = 28 – (number of "N/A" *2)	22	20	20	20	22	22	20	20	20	20	22	20	20	20	22	20	22	20	22
Summary score: total sum/total possible sum	0.82	0.80	0.80	0.80	0.64	0.68	0.75	0.75	0.75	0.80	0.77	0.80	0.90	0.60	0.77	0.75	0.64	0.80	0.86

Yes (2), Partial (1), No (0), NA= Not applicable for this study design

Appendix 3: Extraction forms

3.1 General information

Authors	*Study Design*	*Place*	*Respondents*	*Assessor*	*Screening Tool*
1.					
2.					
3.					

3.2 Cultural adaptation dimensions

Author	*Language*	*Persons*	*Metaphors*	*Content*	*Concepts*	*Goals*	*Methods*	*Context*
1.								
2.								
3.								

3.3 Feasibility dimensions

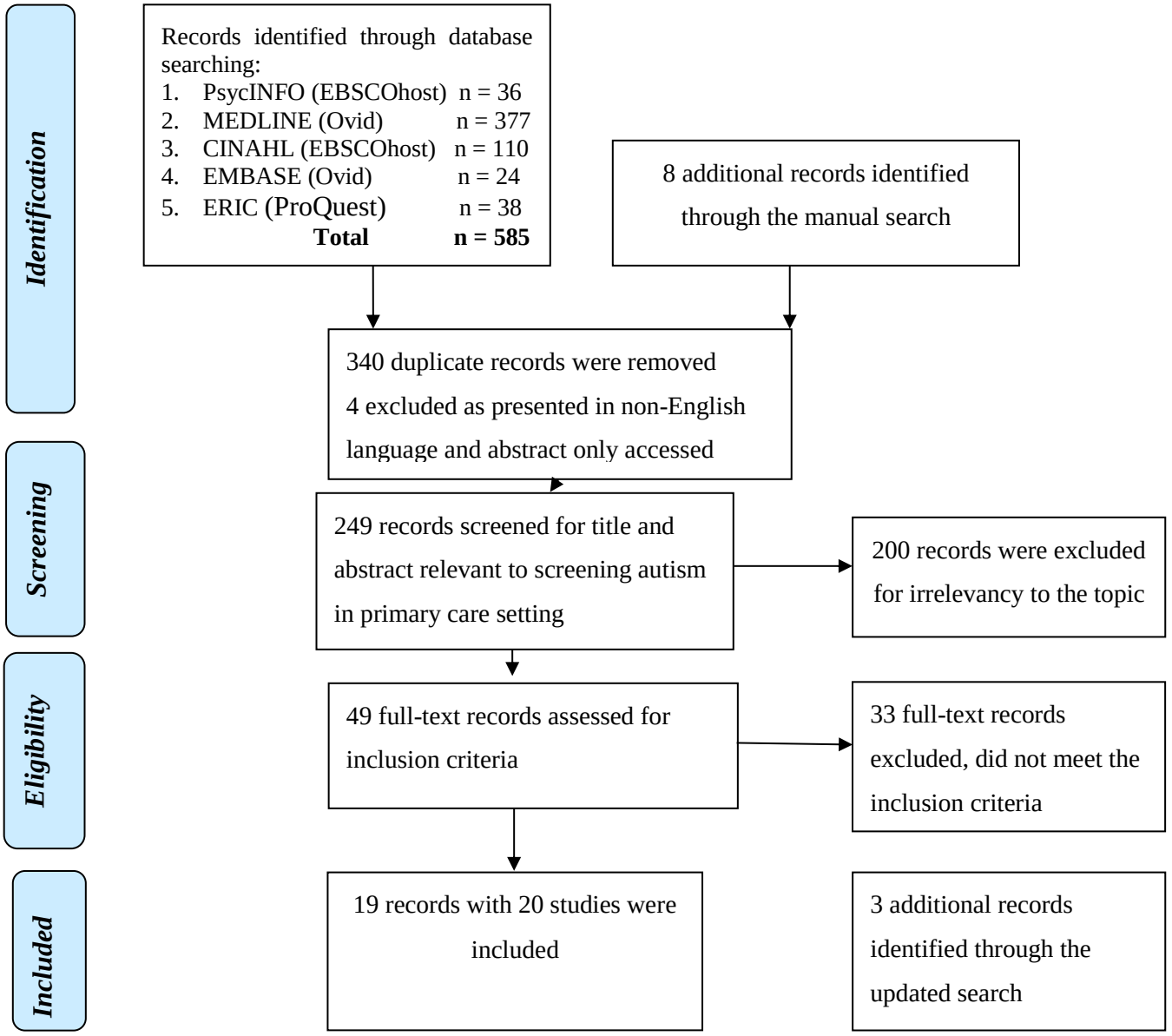
Author	*Acceptability*	*Demand*	*Implementation*	*Practicality*	*Adaptation*	*Integration*	*Expansion*	*Limited efficacy*
1.								
2.								
3.								

Appendix 4: Inclusion criteria for full text papers

Authors	***Subjects***	***Intervention***	***Setting***	***Outcome***
	Children both gender (under seven years)	*Use level 1 surveillance /screening tool*	*Non-English-speaking countries*	*Describes cultural adaptation (language, person, atmosphere, contents, concepts, goals, methods, and context)*
(Albores-Gallo et al., 2012)	✓	✓	✓	✓
(Baherzadeh et al., 2012) non-English				
(Ben-Sasson and Carter, 2012)	✓	✓	✓	✓
(Beuker et al., 2014)	✓	✓	✓	✓
(Canal-Bedia et al., 2011)	✓	✓	✓	✓
(Chiang et al., 2013)	✓	✓	✓	*X*
(Dereu et al., 2012a)	✓	✓	✓	✗
(Dereu et al., 2012b)	✓	✓	✓	✗
(Dereu et al., 2010)	✓	✓	✓	*x*
(Dietz et al., 2006)	✓	✓	✓	✗
(Duvekot et al., 2015)	✗	✓	✓	✗
(Ehlers et al., 1999)	✗	✓	✓	✗
(Ekhtiari et al., 2012)				
(Fombonne et al., 2012)	✓	✓	✓	✓
(Guo et al., 2011)	*x*	✓	✓	✓
(Havdahl et al., 2016)	*x*	*x*	✓	*x*
(Hedley et al., 2010)	✓	*x*	✓	✓
(Hoglund Carlsson et al., 2010)	✓	✓	✓	*x*
(Kakooza-Mwesige et al., 2014)	✓	✓	✓	*x*
(Kamio et al., 2015)	✓	✓	✓	✓
(Kamio et al., 2014)	✓	✓	✓	✓
(Kara et al., 2014)	✓	✓	✓	✓
(Koyama et al., 2010)	✓	✓	✓	*x*

(Kruizinga et al., 2014)	✓	✓	✓	*x*
(Lung et al., 2010)	✓	*X (broad screening, not ASD)*	✓	✓
(Magnusson et al., 1996)	✓	✗	✓	*x*
(Mattila et al., 2009)	*x*	✓	✓	✗
(Mattila et al., 2012)	✓	✓	✓	✗
(Mohamed et al., 2016)	✓	✓	✓	✓
(Mohammadian et al., 2015)	✓	✓	✓	✓
(Nygren et al., 2012)	✓	✓	✓	✓
(Ooi et al., 2011)	*x*	*x*	✓	*x*
(Oosterling et al., 2010)	✓	✓	✓	✗
(Perera et al., 2009)	✓	✓	✓	✓
(*Persson et al., 2006)*	✓	✓	✓	*x*
(Rescorla et al., 2015)non-English				
(Rudra et al., 2014))non-English				
(Samadi and McConkey, 2015)	✓	✓	✓	✓
(Samadi and McConkey, 2014)	*3-22*	✓	✓	✓
(Seif Eldin et al., 2008)	✓	✓	✓	✓
(Seung et al., 2015)	✓	✓	✓	✓
(So et al., 2013)	*x*	✓	✓	✗
(Stenberg et al., 2014)	✓	✓	✓	✗
(Sun et al., 2014)	*X (too many children over 7)*	✓	✓	✗
(Sunita and Bilszta, 2013) review	*x*	*x*	*x*	*x*
(Tsai et al., 2012)	✓	✓	✓	*X*
(Wakabayashi et al., 2007)	*x*	*x*	✓	✓
(Wong et al., 2004)	✓	✓	✓	✓

Appendix 5: Selection process using PRISMA 2009 Flow Diagram



Appendix 6: Study characteristics

Author	Study Design	Place	Participants	Assessor	Screening Tool
1. (Albores-Gallo et al., 2012)	Case control	Mexico Clinical/Psychiatric unit Community/Nurseries	N=456 18-72 months Mean age = 4.46 years	Parents	The Mexican Modified Checklist for Autism in Toddlers (MM-CHAT) Detects nonverbal children with low function autism
2. (Ben-Sasson and Carter, 2012)	Cohort	Israel Day care	N=471 Mean age = 12.7 months	Mainly mothers	The First Year Inventory (FYI)
3. (Beuker et al., 2014)	Cross-sectional	Norway Hospital	N= 12,984 18 months Mean age = 18.53 months	Mothers	The Norwegian Modified Checklist for Autism in Toddlers (M-CHAT) Norwegian Early Screening of Autistic Traits (ESAT)
4. (Canal-Bedia et al., 2011)	Stage 1: Case control	Spain Extended Health Centre & Psychiatric	N=2,480 18-36 months	Parents	The Spanish Modified Checklist for Autism in Toddlers (M-CHAT) + M-Chat Phone interview
	Stage 2: Cross-sectional		N=2,055 18-36 months		
5. (Carakovac et al., 2016)	Case control	Serbian Primary Healthcare & Psychiatric	N=148 Mean age = 22.25-23.53 months	Parents	The Serbian Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F)

6. (Fombonne et al., 2012)	Case control	Mexico Autism Developmental Disorder Clinic Public primary school	N=563 4-13 years Mean age: 8 years	Parents and teachers	Spanish version of the Social Responsiveness Scale (SRS)
7. (Kamio et al., 2015)	Cohort	Japan Routine check-up local Health Centre	N=2,516 18 months- 3 years Mean age: 18.6-19.2 months	Parents	The Japanese version of the Modified Checklist for Autism in Toddlers (M-CHAT JV)
8. (Kamio et al., 2014)	Cohort	Japan Routine check-up local Health Centre	N=1,851 18 months-3 Years Mean age: 18.7 months	Parents+ trained interviewers	The Japanese version of the Modified Checklist for Autism in Toddlers (M-CHAT JV)+ Follow up Interview (FI)
9. (Kara et al., 2014)	Cross-sectional	Turkey Well-child Paediatric	N=191 18-36 months Mean age: 27.15 months	Parents	The Turkish version of the Modified Checklist for Autism in Toddlers (M-CHAT)+FI
10. (Kara et al., 2014)	Case control	Turkey Well child Paediatric Psychiatric- autism centre	N=618 18-36 months Mean age: 27.15 months	Nurses and psychologists	The Turkish version of the Modified Checklist for Autism in Toddlers (M-CHAT)
11. (Kondolot et al.,2016)	Cross-sectional	Turkey Family Health Centres	N=4,000 18-30 months Mean age: 23-24 months	Trained interviewers	The Turkish version of the Modified Checklist for Autism in Toddlers (M-CHAT)

12. (Mohamed et al., 2016)	Cross-sectional	Egypt Primary Health Centres	N=5,546 1 to 2.9 years Mean age: 1.7years	Parents	An Arabic validated version of Modified Checklist for Autism in Toddlers (M-CHAT).
13. (Mohammadian et al., 2015)	Case control	Iran Hospital nursery Psychiatric Hospital Autism Centre	N=100 Mean age: 27.1-29.62 months	Mothers	The Iranian version of the Quantitative Checklist for or Autism in Toddlers (Q-CHAT)
14. (Nygren et al., 2012)	Cohort	Sweden Child Health Centre 2.5 year check-up	N=3,999 Mean age: 1.5 years	Mothers+ Trained nurses	The Sweden version of the Modified Checklist for Autism in Toddlers (M-CHAT) +FI+ Joint Attention Observation (JA-OBS)
15. (Perera et al., 2009)	Cross-sectional	Sri Lanka Primary Health Centre	N=374 18-24 months	Mothers	Red Flag criteria + the Modified Checklist for Autism in Toddlers (M-CHAT)
16. (Perera et al., 2017)	Case control	Sri Lanka Paediatric Hospital	N=105 18-48 months Mean age: 36-40 months	Mothers	The Pictorial Autism Assessment Schedule (PAAS)
17. (Samadi and McConkey, 2015)	Cohort	Iran Population-based Kindergarten and Pre-school Centres	N=2,941 2-5 years	Parents	Hiva + follow-up interview(FI) + the Modified Checklist for Autism in Toddlers (M-CHAT)
18. (Seif Eldin et al., 2008)	Case control	9 Arab countries not reported	N=228 18-36 months	Parents	The Modified Checklist for Autism in Toddlers(M-CHAT)

19. (Seung et al., 2015)	Cohort	Korea Day care, public HC, Hospitals, paediatric clinic	N= 2,300 16-36 months	Parents + first author for FI	The Korean Modified Checklist for Autism in Toddlers (K-M-CHAT)-2+ Phone FI
20. (Wong et al., 2004)	Case control	Hong Kong Maternal and child Health clinics Psychiatric	N=212 13-86 months	Parents + trained investigator	Checklist for Autism in Toddlers (CHAT-23)

+ = Data reported, - = Data not reported

Appendix 7: Cultural Adaptation

The Ecological Validity Framework
1. **Language:** Does the study report the use of a culturally appropriate language, idioms, regionalism words, and slang in both written and verbal forms while adopting/screening for autism?
2. **Persons:** Does the study highlight ethnic and interactional match considerations between the clients and assessors in the screening process?
3. **Metaphors:** Does the study employ any verbal (e.g., folk sayings) and/or visual forms (e.g., image, figure) of symbols that are shared with the population, while adopting instruments/screening for autism?
4. **Contents:** Does the study consider adapting the instruments' content to match the uniqueness culture of the study group?
5. **Concepts:** Does the study present any efforts to adapt clear and consistent constructs to the targeted culture?
6. **Goals:** Are the screening goals constructed within the context of cultural values, customs, and traditions?
7. **Methods:** Do the study methods facilitate smooth implementation for screening within the client's cultural context?
8. **Context:** Does the study consider the social, economic, historical, and political contexts of clients while screening?

Author	Language	Persons	Metaphors	Content	Concepts	Goals	Methods	Context
(Albores-Gallo et al., 2012)	+	-	-	-	+	-	-	-
(Ben-Sasson and Carter, 2012)	+	+	-	-	+	-	-	-
(Beuker et al., 2014)	+	-	-	-	-	-	-	-
(Canal-Bedia et al., 2011)	+	-	+		+	+	-	-
(Carakovac et al., 2016)	+	-	-	-	+	-	-	-
(Fombonne et al., 2012)	+	-	-	-	-	-	-	-
(Kamio et al., 2015)	+	-	-	-		-	-	
(Kamio et al., 2014)	+	-	-	-	+	-	-	-
(Kara et al., 2014)	+	-	-	-	-		+	+
(Kondolot et al., 2016)	+		+		+		+	+
(Mohamed et al., 2016)	+	-	-	-	-	-	-	-
(Mohammadian et al., 2015)	+	-	-	-	-	-	-	-
(Nygren et al., 2012)	+	-	-	-	+	-	+	-
(Perera et al., 2009)	+	-	-	-	-	-	+	-
(Perera et al., 2017)	+	+	+	+	+	-	-	-
(Samadi and McConkey, 2015)	+	-	-	-	+	-	-	-
(Seif Eldin et al., 2008)	+	-	+	-	-	-	-	+
(Seung et al., 2015)	+	-	-	-	+	-	-	-
(Wong et al., 2004)	+	-	-	+	-	-	+	-

Appendix 8: Feasibility

The feasibility of screening
1. Acceptability: Do the study's participants perceive an appropriateness or suitability for screening for ASD within the intended culture and context? **2. Demand:** Do the study's participants express a need and/or intention to use the screening instrument within current practice? **3. Implementation:** Was the screening process implemented as proposed? **4. Practicality:** Does the study report the cost, time and other resources required to screen for ASD? **5. Adaptation:** Does the study adapt the screening instrument for the intended population culture? **6. Integration:** Does the study highlight the possibility of integrating the screening instrument within the existing system? **7. Expansion:** Does the study perceive any opportunity to expand the use of screening within a different population in a different setting? **8. Limited Efficacy:** Does the study report limited efficacy of the screening and/or its instruments?

Author	Acceptability	Demand	Implementation	Practicality	Adaptation	Integration	Expansion	Limited Efficacy
(Albores-Gallo et al., 2012)	-	-	+	+	+	+	+	+
(Ben-Sasson and Carter, 2012)	-	-	+	-	+	+	+	+
(Beuker et al., 2014)	-	-	+	+	+	-	+	+
(Canal-Bedia et al., 2011)	+	-	+	+	+	+	-	+
(Carakovac et al., 2016)	-	-	+	+	+	+	-	-
(Fombonne et al., 2012)	-	-	+	+	+	-	+	+
(Kamio et al., 2015)	-	-	+	+	+	+	+	+
(Kamio et al., 2014)	-	-	+	+	+	+	-	-
(Kara et al., 2014)	-	-	+	+	+	-	-	+
(Kondolot et al., 2016)	-	-	+	+	+	+	-	-
(Mohamed et al., 2016)	-	-	+	+	+	-	-	-
(Mohammadian et al., 2015)	-	-	+	-	+	-	-	-
(Nygren et al., 2012)	-	+	+	+	+	+	-	+
(Perera et al., 2009)	-	-	+	-	+	+	-	-
(Perera et al., 2017)	-	-	+	+	+	+	-	-
(Samadi and McConkey, 2015)	-	-	+	+	+	+	-	+
(Seif Eldin et al., 2008)	-	-	+	+	+	+	+	-
(Seung et al., 2015)	-	-	+	+	+	-	+	+
(Wong et al., 2004)	-	-	+	+	+	+	+	+

+ = Data reported, - = Data not reported

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Appendix 9: Consent Form

University of Glasgow | College of Medical, Veterinary & Life Sciences

Ministry of Health Sultanate of Oman

Title of Project: Exploring Primary Health Professional's perceptions of facilitators and barriers of screening for autism spectrum disorders within the 'Immunization and Developmental Surveillance Program' in Oman

Name of Researcher(s): Ms. Turkiya Saleh Al Maskari

Please initial box:

- I confirm that I have read and understood the information sheet dated 23/12/2014 (version 2) for the above study and have had the opportunity to ask questions. ☐
- I understand that my participation is voluntary, that I am free to withdraw any time, without giving any reason, and without my legal rights being affected. ☐
- I agree to take part in the above study. ☐
- I agree to be contacted about the second phase to pilot the questionnaire ☐

_____	_____	_____
Name of subject	Date	Signature
_____	_____	_____
Name of person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix 10: The Topic Guide

University of Glasgow | College of Medical, Veterinary & Life Sciences

Ministry of Health Sultanate of Oman

Focus Group Study Guide

1. Focus Group facilitators:
    a. Ms. Turkiya SalehAL Maskari (Facilitator)
    b. Dr. Rasha Ahmed (Co-facilitator/observer)

2. Roles and Responsibilities of the Group Facilitators:
    - Bring all the needed materials for the focus group
    - Arrange the focus group settings and refreshments beforehand
    - Give introductions and clear guidance to the participants
    - Write up the ground rules on the flip chart with the participants' involvement
    - Try the tape recorder prior to starting
    - Tape the focus group discussion
    - Ask participants to introduce themselves briefly
    - Keep participants focused, engaged, attentive and interested
    - Monitor time and use limited time effectively
    - Use prompts and probes to stimulate discussion
        - E.g. use post-it-notes and put a blank sheet of paper on a wall so that participants can ask questions or examples without having to speak
    - Use the focus group guide effectively to ensure all topics are covered
    - Politely and diplomatically enforce ground rules:
        - Make sure everyone participates and at a level that is comfortable
        - Limit side conversations
        - Encourage one person to speak at a time
    - Be prepared to explain or restate questions
    - Diffuse and pre-empt arguments
        - E.g. If someone has a strong argument or is dominating the conversation, say 'that is really interesting – what do others think?'

- Immediately after each focus group, complete the Debrief Discussion form with the note taker. To facilitate the debriefing discussion, review the notes of the discussion, discussing areas that seemed particularly important or salient given your knowledge of the research questions. Capture these insights using the Debrief Discussion Form

3. Focus group note takers:
    a. Ms. MA. Emma.

4. Roles and Responsibilities of Note Takers:
    - Ensure that ground rules for the focus group are written clearly and neatly on a flip chart – do this beforehand
    - Assist the facilitator in arranging the room
    - Obtain consent forms and demographic data sheets from the participants
    - Record major themes, ideas, comments and observations regarding group dynamics in hand-written notes using the ***Focus Group Note Taking Form***
    - Complete the ***Debrief Discussion Form*** with the focus group facilitator immediately after each focus group
    - Do not throw away any papers with notes of the focus group discussion. These will be stored with other data collected through the needs assessment

Focus Group Checklist

Remember to bring the following:

☐ Two writing utensils (in case the lead in a pencil breaks/ a pen runs out of ink)

☐ A notepad with sufficient paper for taking notes during the entire focus group

☐ A flip chart

☐ Dry eraser and/or regular markers of different colours

☐ Name tags or badges

☐ Sticky notes

☐ Tape for affixing flip chart pages to the wall, as needed.

☐ Flat microphone

- ☐ Recording equipment:
  - a tape recorder
  - extension cord
  - extra tapes
  - extra batteries
- ☐ Consent forms (enough copies for all participants)
- ☐ Participant information sheet
- ☐ Extra pens for participants to sign consent forms
- ☐ Focus group guide
- ☐ Note taking form
- ☐ Debrief Discussion Form
- ☐ Be familiar with the primary research objectives of the study
- ☐ Be familiar with the focus group guide
- ☐ Review this checklist
- ☐ Arrive at the focus group location a few minutes before the participants to organise the room and your materials
- ☐ Welcome focus group participants, inviting them to get something to eat
- ☐ Explain, in a general and brief way, the purpose of the focus group and how information collected during focus groups will be used and towards what goal
- ☐ Introduce yourself, the note taker and the observer
- ☐ Explain participants' rights and what participating in the focus group will entail
- ☐ Remind participants of the duration of the focus group, emphasising the importance of their participation during the entire discussion
- ☐ Let people know where the closest restroom facilities are located
- ☐ Obtain written consent to participate and have the focus group recorded
- ☐ At the end of the focus group, give the participants the contact information of [whom] should they have any questions

- ☐ Complete the Debrief Discussion Form with the note taker
- ☐ Ensure that tapes are labelled appropriately
- ☐ Ensure that hand-written notes, tapes, the Debrief summary form, and consent forms are returned to the facilitator (***Turkiya AL Maskari)***
- ☐ Ask if anyone would like to have a copy of the findings when complete.

10.1 Ground Rules

Here are some of the ground rules that I thought about for this focus group – you can add your thoughts as well …

- We would like all of you to participate;
- There is no right or wrong answers:
  - Every person's experience and opinions are important.
  - Kindly speak up whether you agree or disagree
- What is discussed in the room is highly confidential:
  - It is important that members feel comfortable sharing information that might be considered sensitive in some situation. The line managers will not hear this and all data will be anonymised
- The discussion will be tape recorded
  - It is important that every piece of information you say is captured. Please note that your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your rights being affected.
  - Please be assured that every member will remain anonymous in any publications or reporting of the findings.

10.2 Focus Group Note Taking Forms

Focus Group Note Taking Form

with the field note

(To be completed by the note taker)

Location:

Date:

Focus group title:

Name of the Facilitator:

Name of the Note taker:

Start time:

End time:

Total attendance:

No of Males:

No of Females:

Seating Chart:

Make a seating chart indicating the Facilitator, Assistant Facilitator, and the participants with their identifier. Use this chart to identify speakers as you take notes.

Question No or Key word:	Responses (write down key words; use identifiers from chart to identify respondents)	Observations (e.g. expression & [dis]agreement)

10.2. A Debriefing Form

The note taker will conduct a debriefing session with the facilitator after the focus group. This will begin a maximum of 15 to 30 minutes after the discussion ends. Debriefing will help to identify any non-verbal communication, such as gestures and facial expressions. Debriefing will also help to identify any issues that came up during the discussion, and new topics that arose during the focus group.

(1) What are the main themes that emerged from this focus group?
(2) What did the participants say that was unclear or confusing to you?
(3) What did you observe that would not be evident from reading a transcript of the discussion (e.g., group dynamic, individual behaviours, etc.)
(4) What problems did you encounter? (e.g., logistical, behaviours of individuals, questions that were confusing, etc.)
(5) What questions or issues are there for follow up in the future?
(6) Does the note-taker have any suggestions for the moderator and vice versa?

10.2.B Summary Form

(After the discussion, summarise the group response/main themes for each question)

Focus Group Question #1:
Response Summary (Prevailing themes):
Focus Group Question #2:
Response Summary (Prevailing themes):
Focus Group Question #3:
Response Summary (Prevailing themes
Focus Group Question #4:
Response Summary (Prevailing themes):
Focus Group Question #5:
Response Summary (Prevailing themes):
Focus Group Question #6:
Response Summary (Prevailing themes):

10.2 C Facilitator self-assessment tool

This form will be used by the facilitators at the end of discussion to reflect on their own performance as a focus group facilitator and to identify areas of improvements as a facilitator in the future.

Indicators: A= Achieved N= Need more practice NA= Not Applicable

Check one of the most appropriate boxes for your own performance

Activities	A	N	NA	Comments
1. I was prepared for the session.				
2. I greeted and welcomed participants in an appropriate professional manner.				
3. I covered ground rules and the information/confidentiality form.				
4. Chairs were assigned in a circle to foster participation.				
5. I brought enough materials to the discussion (e.g., note taking forms, info. sheets, pencils, etc.)				
6. I sat with the group members instead of standing at the front "lecture" style.				
7. I practised active listening by showing interest.				
8. I asked a question as an icebreaker that allowed participants to share something about themselves in a non-threatening, enjoyable way.				
9. I asked open-ended questions that began with Who, What, Why, How, or Explain.				
10. I asked probing questions as needed to solicit important information from group members.				
11. I clarified/rephrased questions, as needed, throughout the discussion.				
12. I made sure all group members had an opportunity to participate.				
13. I watched for non-verbal signs that may have indicated that someone wanted to respond or ask a question.				
14. I noted non-verbal interactions/expressions between group members on the note form.				
15. I avoided allowing just a few group members to dominate the group discussion.				
16. I recognised fears or disagreements among group members and brought them out into the open as needed.				
17. I gave positive reinforcement and feedback with a nod or word of praise.				
18. I used words in questions/discussion that the participants could understand.				

19. I kept the group discussion and members on topic politely as needed.				
20. I accepted and respected feelings and ideas of group members without necessarily agreeing with their perspectives.				
21. I listened, talked with, and learned from the group members.				
22. I brought ideas together by emphasising certain points mentioned in the discussion.				
23. I resolved issues (e.g. unique personalities) in the group in a professional manner.				
24. Plans to practice and strengthen skills of facilitating group discussions:				

References:

Education Training Research (ETR) Associates. (n.d.) Conducting focus group discussions. Retrieved from http://www.etr.org/tabono/images/files/basic%20evaluation%20on%20focus%20goups.pdf

Mack, N., Woodsong, C., Macqueen, K., Guest, G., & Namey, E. (2005). Focus Group in Qualitative Research Methods: A Data Collector‟s Field Guide (Module 4). Retrieved from Family Health International: http://www.fhi.org/NR/rdonlyres/emgox4xpcoyrysqspsgy5ww6mq7v4e44etd6toiejyxalhbmk5sdnef7fqlr3q6hlwa2ttj5524xbn/datacollectorguideenrh.pdf

OMNI Institute. (n.d.) Toolkit for conducting focus groups. Retrieved from http://www.omni.org/docs/FocusGroupToolkit.pdf

Social Entrepreneurs, Inc. (2007). Needs assessment focus group toolkit. Retrieved from http://www.socialent.com/wp-content/uploads/2009/05/needs-assessment-focus-group-toolkit.pdf

Sy, A. (2011). Focus groups discussions [PowerPoint slides]. University of Hawaii at Manoa. WIC Learning Online. (n.d.). Facilitator self-assessment tool. Retrieved from http://www.nal.usda.gov/wicworks/WIC_Learning_Online/support/job_aids/assessment.pdf

Appendix 11: Ethical Approval

24 April 2015

Dr Diane Willis
Nursing & Health Care
University of Glasgow

Dear Dr Willis

MVLS College Ethics Committee

Project Title: Exploring Primary HealthCare Professional's perceptions of facilitators and barriers of screening for ASD spectrum disorders within the 'Immunization and Developmental Surveillance Program' in Oman

Project No: 200140062

The College Ethics Committee has reviewed your request for minor amendments to the above study and has agreed to them in full. Specifically, you are permitted to use the revised Questionnaire and up-dated Respondent Information Sheet. These permissions are subject to the following conditions:

- Project end date: 31 December 2015.
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)
- The research should be carried out only on the sites, and/or with the groups defined in the application. Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

Professor William Martin
College Ethics Officer
200140062Amendment.doc
Professor William Martin
Professor of Cardiovascular Pharmacology
R507B Level 5
School of Life Sciences
West Medical Building
Glasgow G12 8QQ Tel: 0141 330 4489
E-mail: William.Martin@glasgow.ac.uk

Sultanate of Oman
Ministry of Health
Directorate General of Planning and Studies

سلطنة عمان
وزارة الصحة
المديرية العامة للتخطيط والدراسات

Ref. : MH/DGP/R&S/PROPOSAL_ APPROVED/30/2014 ..... الرقم :

Date. : 04.12.2014 ..... التاريخ :

..... الموافق :

Ms. Turkiya Saleh Al Maskari
Principal Investigator

Study Title: **"Exploring Primary Health care Professional's perceptions of facilitators and barriers of screening for autism spectrum disorders within the 'Immunization and Developmental Surveillance Program' in Oman"**

After compliments

We are pleased to inform you that your research proposal **"Exploring Primary Health care Professional's perceptions of facilitators and barriers of screening for autism spectrum disorders within the 'Immunization and Developmental Surveillance Program' in Oman"** has been approved by Research and Ethical Review and Approve Committee, Ministry of Health.

Regards,

Dr. Ahmed Mohamed Al Qasmi
Director General of Planning and Studies
Chairman, Research and Ethical Review and Approve Committee
Ministry of Health, Sultanate of Oman.

Cc
Day file

P.O. Box : 393, Postal Code : 100, Muscat, Tel. : 24601161, Fax : 24696533 ص.ب : ٣٩٣ ، الرمز البريدي : ١٠٠ ، مسقط ، هاتف : ٢٤٦٠١١٦١ ، فاكس : ٢٤٦٩٦٥٣٣

Appendix 12: Attendance Certificate

University of Glasgow | College of Medical, Veterinary & Life Sciences

Ministry of Health Sultanate of Oman

Certificate of Completion

This is to certify that:

Mr/Mrs.....

Has participated in an Orientation Workshop "Exploring Primary Health Professional's perceptions of facilitators and barriers of screening for autism spectrum disorders within the 'Immunization and Developmental Surveillance Program' in Oman"

Held on 25th May 2015, at the Directorate General of Health Affairs (Conference Room), Ministry of Health, Muscat

Primary Investigator
Turkiya Saleh Al Maskari
University of Glasgow

Supervisor
Dr. Diane Willis
Edinburgh Napier University

Appendix 13: Study Information

13.1 Invitation Poster

University of Glasgow | College of Medical, Veterinary & Life Sciences

Ministry of Health Sultanate of Oman

Exploring Primary Health Professional's perceptions of facilitators and barriers of screening for autism spectrum disorders within the 'Immunisation and Developmental Surveillance Program' in Oman

We are looking for volunteers to participate in a focus group about screening children with ASD within the immunisation and developmental surveillance program in Oman. Your ideas and views will help us to develop a surveying questionnaire identifying the PHP perception of ASD screening from all over Oman.

Time	9:00 am
When	6-7/01/2015
Where	Bawshar Polyclinic conference Hall

If you want to know more about the project or want to participate please contact the Primary Investigator: **Ms. Turkiya Saleh Mohammed Al Maskari:** Acting Dean Sur Nursing Institute. Mobile: +xxxxxxxxxxx. Email: Turkiya.almaskari@gmail.com.

13.2 Participants' Information Sheet for Phase 1

University of Glasgow | College of Medical, Veterinary & Life Sciences

Exploring PHP's perceptions of facilitators and barriers of screening for autism spectrum disorders within the Immunisation and developmental surveillance program in Oman

What is in this leaflet?

You have been asked to participate in a focus group. It's your choice whether or not to participate in the focus group. Before you decide it is important to understand the purpose of the study and what it will involve. Please take time to read the following information

What is the study about?

The prevalence of autism spectrum disorder (ASD) in children is increasing worldwide. Although there is no medical cure for ASD, early intervention was found to improve outcomes. Specific ASD screening has been recommended for toddlers within routine paediatric practice, aimed at facilitating early identification, boosting the advantages of early intervention and reducing the burden on society. At present, there is no tool available to identify the barriers to and facilitators of screening children for ASD in primary healthcare settings. No study has previously been undertaken to examine the Omani primary healthcare setting's readiness and capacity to screen children for ASD. This study is aiming to develop a valid surveying questionnaire to explore the relevant facilitators and barriers of screening children for ASD in primary healthcare practice in Oman.

Why have I been invited to take part?

You have been invited to take part because you care and assess pre-schoolers for their normal growth and development on a regular basis through the immunisation and surveillance developmental program activity.

What will happen if you decide to take part?

If you decide to participate you will take part in a focus group. A focus group is where a group of people who have been brought together discuss a specific topic in depth. It is like

an interview but with 5-7 other people. Questions are asked in a group setting and participants discuss the questions with the other group members.

The focus group will take between 1-2 hours and will be held at Bawasher Poly clinic conference room in Muscat on 6/1/2015 at 9 am if you are a GP and on 7/1/2015 at 9am if you are a nurse. You will be given a break for refreshments during this time.

During the focus group we will ask you some questions. There are no right or wrong answers to the focus group discussions. We want to hear many different viewpoints and your responses, even if they may not agree with the rest of the group. If you do not want to answer a question you only have to say so. We will tape the discussion and we will also be taking notes. The discussion will be taped because we will not be able to write down everything that is said. If you feel uncomfortable being taped you may not want to participate. At the end there will be a debriefing session and you will have the opportunity to raise questions either as a group or individually with Turkiay Saleh Al Maskari.

Consent:
You will be asked to sign a 'consent form' prior to participating in the focus group to confirm that you agree to take part and understand what the research study is about. You can withdraw from the study at any time although we will not be able to erase the taped discussion because there will be other participants involved, but we can assure you that your input will not be used.

Please note that at the start of the focus group we will ask you to respect confidentiality within the group but we cannot offer you anonymity from the other group members. Anything you say within the group will not affect your rights in relation to your employment or involvement in the study. We will also ask you to complete a short questionnaire about your age, experience etc.

What are the possible benefits of taking part?
You will receive an attendance certificate as well as a small memorial gift that does not exceed 5 OR (£8) each. You will be also offered free coffee and refreshments during the focus group.

What are the possible disadvantages of taking part?
We do not foresee any disadvantages in taking part, although if any participants have difficulties there will be research assistant to offer support.

If you do not want to take part?
Participation is entirely voluntary. If you choose not to take part no one will know except you and the other researchers and it will not affect your involvement with your work.

What about the tapes and what we say?
The tapes and everything that is discussed will remain confidential. The broad content i.e. the themes of what is discussed, will be shared with the research team and we may want to publish the results to share with our peers.

The tapes have to be kept for 10 years after the research ends. The tapes will be kept in a locked office, in a locked cabinet in the PI's office. Anything you tell us may be used but no records will have your name on them. We may publish the findings in a journal but your name will not appear on anything published. Any quotes will be anonymised so that you cannot be identified.

What do you need to do?
You need to decide whether you want to take part.
Feel free to talk to friends and colleagues about this project.

If you want to know more about the project or decide to participate please contact the following:

Primary investigator: Ms. Turkiya Saleh Mohammed Al Maskari: Acting Dean Sur Nursing Institute. Mobile: +xxxxxxxxxxx. Email: Turkiya.almaskari@gmail.com

You can also contact the following supervisors for further clarification:

Dr.Diane Willis: Lecturer, Nursing & Health Care School, College of Medical, Veterinary and Life Sciences, University of Glasgow, 59 Oakfield Avenue, Glasgow G12 8LL. Tel: +44 (0)141 3305613 Email: diane.willis@glasgow.ac.uk

Dr. Craig Melville: Senior Lecturer in Learning Disabilities PsychiatryCollege of Medical Veterinary and Life Sciences, University of Glasgow Mental Health & Wellbeing**.** Tel: +44 (0)141 211 3878 Email: Craig.Melville@glasgow.ac.uk

Dr. Dr. Yahya Mohammed Al Farsi: Associate professor, Assistant Dean College of Medicine and Health Sciences, Sultan Qaboos University. Tel: +96899383220. Email:ymfarsi@gmail.com

Thank you

Respondent Demographics Data Questionnaire

Q1. Job:

- GP
- Nurse

Q2. Years of experience in current job: _____

Q3. Gender:

- Male
- Female

Q4. Age Group:

- 20-30
- 31- 40
- 41 -50
- 51- 60

Q5. Education: What is the highest degree or level of school you have completed?

_____

Q6. Employment location:

_____ Health Center

Appendix 14: The emerged codes at stage 2

1. *ASD difficulties*
2. *Age of delay recognition*
3. *Typical versus atypical development*
4. *MMR vaccination and ASD*
5. *ASD awareness of staff/parents/community*
6. *Staff knowledge/exposure/experience/confidence in understanding about ASD*
7. *Source of ASD information*
8. *Training*
9. *Social stigma*
10. *Parental denial*
11. *Service structure and coordination*
12. *Educate/raise awareness of ASD of staff/parents/community*
13. *Health values on identifying illness*
14. *Traditional therapy*
15. *Housemaid*
16. *Follow-up*
17. *Referral*
18. *Waiting time*
19. *Infrastructure*
20. *Questionnaire development*
21. *Targeted group*
22. *Focal point*
23. *Incentives*

Appendix 15: Initial Themes Chart

Themes	*Subthemes*
1. Signs and symptoms of ASD difficulties	*1.1.1 Social difficulties* *1.1.2 Speech and language difficulties* *1.1.3 Inflexibility* *1.1.4 Physical difficulties* *1.1.5 Non-verbal communication difficulties* *1.1.6 Feeding difficulties* *1.1.7 Cognitive problem*
2. Child age	*2.1.1 Age of delay recognition* *2.1.2 Age of identifying ASD*
3. Facilitators	*3.1.1 Interested and obligated staff to identify and refer child abnormalities.* *3.1.2 Availability of the:* *3.1.2.1 Pink card (developmental assessment tool)* *3.1.2.2 Surveillance programme*
4. Barriers	*4.1.1 Parental attributes* *4.1.1.1 Denial* *4.1.1.2 Sadness* *4.1.1.3 Lack of awareness* *4.1.1.4 MMR and ASD* *4.1.2 Organisational barriers* *4.1.2.1 Time constraints* *4.1.2.2 Crowdedness* *4.1.2.3 Service structure and coordination* *4.1.2.4 Social barriers* *4.1.2.4.1 Culture and norms* *4.1.2.4.2 Values* *4.1.2.4.3 Social stigma* *4.1.2.5 Professional barriers* *4.1.2.5.1 Lack of knowledge* *4.1.2.5.2 Lack of skills* *4.1.2.5.3 Lack of confidence to identify ASD* *4.1.2.6 Lack of training and updates* *4.1.2.7 Lack of awareness of ASD services*
5. Suggested strategies to overcome challenges	*5.1.1 Increase awareness (professional and public)* *5.1.1.1 Encourage collaboration between sectors and parental involvement* *5.1.1.2 Improve current system infrastructure and coordination services* *5.1.1.3 Provide training and update staff on ASD* *5.1.2 Propose a culturally acceptable term for ASD*
6. Suggestions and recommendations for developing survey questionnaire	*6.1.1 Type of questions* *6.1.2 Questionnaire length* *6.1.3 Content, structure and formatting* *6.1.4 Distribution and administration strategies* *6.1.5 Expected challenges and solutions* *6.1.6 Survey targeted group*

Final themes Chart

Themes	Sub-themes
1. Understanding about ASD	• Signs and symptoms of ASD difficulties • Child age
2. Barriers	▪ Organisational barriers ▪ Professional barriers ▪ Social barriers
3. Facilitators	• Accountability. • Utilising and improving existing resources
4. Strategies to facilitate screening	• Increase awareness (professional and public) • Encourage sector collaboration and parent's involvements • Improve current system infrastructure and coordination services • Provide training and update staff on ASD • Propose culturally accepted term for ASD
5. Preferences for the data collection tool	• Type of questions • Questionnaire length • Content, structure, and formatting • Distribution and administration strategies • Expected challenges and solutions • Survey targeted group

Appendix 16: General themes, subthemes, and quotes that serve to develop the questionnaire items

Barriers and Facilitators of Screening for ASD Questionnaire: Constructs, Items and Dimensions

The constructed items for this questionnaire were grouped under each dimension that was intended for measurement. The item's location in the questionnaire was presented to the left of each item. Negatively worded questions were highlighted.

Section B: Organisational Barriers: All items were derived from the organisational barriers data (Strongly Disagree, Disagree, Agree, Strongly Agree)

- B1 We do not have enough time to screen children for ASD in our current practice ***(negatively worded).***
- B2 Our institution is seeing the maximum number of patients each day.
- B3 We have enough staff to carry out the daily clinic activities.
- B4 We don't have the required resources (such as screening tools, space, expertise…etc.) to screen for ASD in our institutions.
- B5 We are lacking clear mechanisms for referring suspected cases of ASD for diagnostic assessment.
- B6 Despite the various educational programmes offered in our institution, ASD is not included as a subject.
- B7 In this institution, we keep a register of all the suspected cases of ASD that are referred to diagnostic services ***(negatively worded)***.

Section C: Professional Barriers: All items were derived from the professional barriers data except item C4 and C6 which incorporated understanding about ASD data (Strongly Disagree, Disagree, Agree, Strongly Agree)

My knowledge about ASD is based on the information:

- C1 I studied during my professional training ***(negatively worded)***.
- C2 I heard from the parents of children with ASD ***(negatively worded)***.
- C3 I learned through self-updates and training ***(negatively worded)***.

- C4 I think I have more knowledge about the signs and symptoms of ASD such as speech delay, lack of eye contact …etc. than the ongoing care and management of ASD ***(negatively worded)***.
- C5 I feel most educated to use the pink card to immunise children rather than using it to identify developmental and behavioural abnormalities.
- C6 I have identified a child with ASD previously ***(negatively worded)***.

When I suspect a child with ASD:

- C7 I follow the case within the clinic for a few weeks before I refer.
- C8 I follow the case until he/she completes two years and then refer.
- C9 I refer the case within the primary level (psychiatric clinic or paediatric clinic).
- C10 I refer the case to the secondary level.

- C11 I think I am familiar with most of the ASD services in Oman ***(negatively worded)***.

Section D: Social: All items were derived from the social barriers data (Strongly Disagree, Disagree, Agree, Strongly Agree)

D1 I think the deficits in parents' awareness of ASD may challenge potential screening for ASD.
D2 I think parents would visit health agencies to treat their children for sickness rather than screening for behavioural abnormalities.
D3 Parents would rather give their children more time to develop normally before seeking medical consultation.
D4 Parents might try traditional medicine and Quran therapy when dealing with developmental and behavioural abnormality, at first.
D5 Parents might avoid the social embarrassments of early ASD diagnosis.

Section E: Facilitators: All items were derived from the facilitators' data (Strongly Disagree, Disagree, Agree, Strongly Agree)

E1 I think I would be in a unique position to screen for ASD, if I received the appropriate training and education.

In order to facilitate ASD screening, our service would need to:

E2 Integrate ASD characteristics into the pink card's child health checks part.
E3 Use specific tools to screen for ASD within the current immunization and surveillance program.
E4 Design a specific screening program for ASD within PHC settings.
E5 I believe that improving coordination between the diagnostic and intervention services in Oman would advance the advantages of early ASD screening.
E6 Increasing public and professional awareness of ASD would reduce the social embarrassments of the disorder.
E7 Collaboration between health and educational services is needed to facilitate early identification of ASD.
E8 At the time of screening, using a more general term instead of "Al Twahed" might increase the uptake for screening for ASD.
E9

Section F: Changes to facilitate screening: All items were derived from the strategies to facilitate screening (rate three most important changes that would facilitate for screening for ASD in the PHC setting in Oman: 1. Greatest facilitator; 2. Second greatest facilitator; and 3. Third greatest facilitator)

F1 Reduce time constrains.
F2 Activate the appointment system for the immunization and child checks visits.
F3 Increase the number of staff in the clinic.
F4 Improve service coordination between the diagnostic and intervention services.
F5 Provide the required expertise, screening tools and space.
F6 Encourage educational and health collaboration to identify ASD.
F7 Increase professional and public awareness of ASD.
F8 Reduce social stigma and sensitivity to the disorder.

Appendix 17: Examples of the general themes and subthemes that served to developed the demographic items

Themes	*Subthemes*	*Quotes*	*Items of the questionnaire exploring the emerged themes and subthemes*
5. Preferences for the data collection instrument	***1.*** *Demographics*	*"maybe at the beginning I feel it's better to ask personal questions about the one who is filling in the questionnaire, like his experience.... how long he has been working as a GP or nurse... if the average number of children is less than 5 … years he has seen the average per day or per month .... So, we can get also an idea about his experience or his knowledge about the diseases... so this is at the beginning... and there is also a little identification – is he a GP, is he a family physician or is he a senior staff nurse? It can make a difference to his knowledge also ...so it can make a difference for you and in the questionnaire... Then, this will be the first part about the one who is filling in the questionnaire....then, we can divide [questionnaire] into barriers of getting the ASD screening and then facilitators... So, you can start with one barrier and we can make options like do you feel that crowdedness is ...one of the cause of making it difficult to identify..."(P20, L554-567)*	***Gender ?*** ***Age?*** ***Current position?*** ***Nationality?*** ***Highest qualification?*** ***Years of experience?*** ***Approximate No. of patients seen per day?***

Appendix 18: Examples of the general themes, subthemes, and quotes that serve to develop the questionnaire items

Themes	*Subthemes*	*Quotes*	*Final question statements*
1. ASD identification	ASD difficulties	*"No eye contact" (GP3 P4, L4)* *"… Playing alone " (GP2 P4, L8)]* *"Yes… I think children with ASD are usually ..isolated" (GP1 P4, L9)* *"Social interaction may be less" (Nurse 1 P4, L63)* *"… Sitting in one corner…" (Nurse 2 P6, L 138-39)*	*I think I have more knowledge about the signs and symptoms of ASD such as speech delay, lack of eye contact and social interaction… etc. than the ongoing care of ASD.*
	Understanding about ASD	*"Not communicating... Not talking "(GP2 P4, L8)* *"I agree …they usually misbehave and not follow parents' orders" (GP4 P4, L10-11)* *"Not listening to us [parent]" (Nurse 5 P3, L 47)*	
		"… It is not easy to pick up ASD within the vaccination programme at the age of two-18 months" [Audible agreement from all groups]." (GP6 P10, L237-39) *"… Most children present with ASD after 18 months, not before that… …" (Nurse 6 P5, L111- 14)*	*I have identified a child with ASD previously.*
2. Facilitators to screen ASD	Interest	*"As GPs, we are the ones who see those kids for vaccines; we can take some workshops [interrupted by GP1: I agree with him] or some training concentrated on ASD that can help us to identify early symptoms of ASD... "(GP6 P13, L310-15)* *"... We are filling in the [well visit checklist] and we want to fill it in... However, we want to know what we are doing [agreement from the group, nodding heads]….. To identify any abnormality" (nurse 5 P17, L589-90)*	*I think I would be in a unique position to screen for ASD, if I received the appropriate training and education.*

	Pink Card	*"The [pink card] is very effective [interrupted by two nurses: yes, very effective]… to identify children with developmental abnormality"(nurse 4 P5, L106-109)* *"I think the Immunisation and Developmental Surveillance Programme help[s] us to follow child development from the age of two weeks, with a second visit at two months and so on, to identify any milestone delays [interrupted by another GP: Yeah, I totally agree] [another GP: it is]... it also helps parents to discuss their concerns about their child's development with healthcare providers on a regular basis" (GP6, P4, L29-32)* *"… This pink card is the best card in the world. So, you can see in Arabic and English what the development and motor milestones are [interrupted by few GPs: correct] for child age…"[more agreement] (GP1 P6, L73-75)* *"... It is only the [vaccination] schedule that changes in the new cards, not the assessment checklist… it has been this one now for how many years [interrupted by another nurse: It's not there] it needs to be modified" (nurse 3 P15, L505-09)* *"we can do an afternoon clinic … those who are invited and to... just want to come to afternoon clinic.." (P14, L344-345)* *"we can get another protocol … for two years, for example for screening... for ASD... yaaani ...I mean as an idea "(P10. L207-209)*	*In order to facilitate ASD screening, our service would need to:* • *Integrate ASD characteristics into the pink card's child health checks part.* • *Use specific tools to screen for ASD within the current immunisation and surveillance program.* • *Design a specific screening programme for ASD within PHC settings.*

1. Barriers	*Organisational Barriers*	*Busy* *"We have a very crowded population... because it is the only health centre in the place. (GP4 P13, L336-38)* *"In our health centres... 60 we reach up to 70 patients (as an average) in six hours on a daily basis. For each doctor 70 or 60 cases per day [audible agreement and nodding heads]" (GP4 P13, L330-33)* *"... Overcrowding is the most important barrier and difficulty for screening..." (GP1 P10, L221-222)* *"... We see 30, 24, 26… "(nurse 5 P13, L426)* *"The problem is we are in the GP clinic, and we see all ages... all genders... all diagnoses... everything at the same time; so how can we keep our minds on ASD?" (GP4 P13, L315-317)*	**Approximate number of patients seen per day* *Our institution is seeing the maximum number of patients each day.* *Approximate no. of programs run by institution*

	Time constraints and prioritising psychological assessment *"... We [assess children] for a few minutes; there is not much time" (GP3 P5, L43-44)* *"... We do not have the time or staff to ask about and elaborate more upon a [child's] history..." (GP2 P7, L131-32)* *"So many children will be waiting for immunisation, so we do not go through the [developmental checklist] one by one" (nurse 6 P7, L214-15)* *"If we are busy. We are not concentrating, and sometimes we forget about it [the psychological assessment]... If you are very busy, you will not concentrate on psychological problems... you will just possibly see if he is fit to take his vaccine or not, this is what we are concerned about [everybody agreed: yaah]" (GP6 P16, L420-422)* *Service structure* *"... Parents first [go to] the vaccination room... for the measurements (e.g. Weigh the child)... then go to the doctors and they queue again [interrupted by one GP: really!] [other GPs confirmed it: yes, yes]... you and then again quiet for the EPI [vaccination]... so that is why parents are angry and they... wait for... more than three or four hours..." (GP1 P9, L201-05)* *"... Sometimes I notice that the parents are refusing or are complaining about why they have to see a doctor to vaccinate their child. It is all about the injection, and that is it, so they are thinking they are wasting their time by seeing*	*We don't have enough time to screen children for ASD in our current practice* *We have enough staff to carry out the daily clinic activities* *I feel most educated to use the pink card to immunise children rather than using it to identify developmental and behavioural abnormalities* *Activate the appointment system for the immunization and child health? check visits.*

	a doctor. So why, why are they not going directly to an EPI room and just vaccinating the child?" (GP1 P9, L183-88) *"And they will wait twice: once to see the doctor and again for the EPI [another GP: Are they waiting in the same place?]... No, no, different ... [So different rooms?]... different rooms ... and they have to go to the doctor first and then for the vaccine" (GP4 P9, L199-202)* *"I hope they will increase number of offices for doctors ... Because we don't have enough rooms for specific clinics" (P10, L223-224).* *"we can get another protocol… for two years, for example for screening... for ASD... yaaani ...I mean as an idea "(P10. L207-209).* *Service Coordination* *"Suppose in one area you have ten children with ASD... already picked up and diagnosed... what is the follow-up process? What do you do for them? What secondary care service do you arrange for them? ... Is there any change before and after? These are critical questions to consider before you start… [Implementing screening program]. It's not clear at the moment "(GP5 P24, L695-700)* *"… They promised us two or three years back that they would connect the health centre primary and secondary levels. Now, after three years… in 2015 there is no connection or even some feedback when a child is found to be autistic" (GP4 P28, L834-36)* *Referral and feedback*	*We don't have the required resources (such as screening tool, space, expertise…etc.) to screen for ASD in our institutions.*

		"After [referral]… I do not know what happens to them. I missed them." [general laughter] (GP2 P7, L110-11) *"… Usually, I ask the referred patient… I ask parents to bring in their report if diagnosed, to see... to know about child's condition, and we will write it in the system "(GP3 P27, L789-90)* *"There is a feedback mechanism on the system… however,... most doctors do not send feedback. Some cases we see with feedback, but not all cases that we refer" (GP3 P29, 838-41)* *"… If we refer five children per month for a secondary health care evaluation for ASD or any other psychiatric disease… Moreover, we do not receive feedback as to whether they are autistic.... We do not know exactly in one year how many ASD cases have been diagnosed… the number of cases that [we refer] and are already diagnosed…" [general agreement](GP4 P28, L808-816)* *"If you ask me how many cases of ASD are in your area… I will not be able to reply…" [loud laughter] (GP6 528, L822-823)* *"Even me – how many of them? I do not know because I send ten cases and maybe some of them are ASD. How can I tell you when I have no feedback? I have no information …I have no data" (GP1P28, L824-26).*	*I believe improving coordination between the diagnostic and intervention services in Oman would advance the advantages of early ASD screening.* *We are lacking clear mechanisms for referring the suspected cases of ASD to the diagnostic assessments.* *In this institution we keep a register of all the suspected cases of ASD that are referred to diagnostic services*
Professional Barriers	*Knowledge of ASD* *"We need to be updated on these things [ASD] ... because ... our understanding since we were students.. [everybody agrees, nodding heads]" (GP6 P16, L428-429)*	*My knowledge about ASD is based on the information:* • *I studied during my professional training.*	

	"... Lack of knowledge of healthcare providers…you, especially those who are working in primary health care… …" (nurse 6 P8, L236-38) *"... We lack knowledge of developmental and behavioural problems in the nursing curriculum and lack a continued educational training programme"[audible agreement] (nurse 2 P4, L69-71)* *"... There is no training… self-training only" (nurse 7 P14, L535)* *"... Giving health education in health centers and hospitals … we have health education for breast feeding…for immunisation…for uuh nutrition, we can add that points …so.. so far I didn't hear about it in the health education system…" (10, L317-320).* *Confidence in identifying ASD* *"... Not a clear picture of the staff because we have not had to face this… we have not seen a child with ASD…" (nurse 4 P7, L195-197)* *"I feel I cannot pick up ASD in a child..." (GP6 P11, L265-66)* *"... However, when it comes to practice… we never can do... I mean cannot practice or apply what we have learned [about ASD] in our work..." (GP1 P10, L227-28)* *Familiarity with the ASD services in Oman* *"From my information, there is no specific governmental centre..." (GP4 P27, L801)*	• *I heard from the parents of children with ASD.* • *I learnt through self-updates and training.* *Despite the various educational programmes offered in our institution, ASD is not included as a subject.* *I have identified a child with ASD previously.*

	"Usually, I think they are referred to tertiary care… to Sultan Qaboos University (SQU) or uuuh... to I do not know? ...or to Royal Hospital as well...?" (GP1 P28, L805-07) *"… Normally... We have… [A psychosocial assessment checklist] in the pink card… [one GP interrupted: Not on the computer]… You may have it in Muscat?... (GP5 P16, L443-45)* *"When I asked [about the computerised system of psychological assessments] they said you are the first doctor who asks this question [loud laughter]…" (GP4 P18, L479-80).* *"I think there is a school only for autistic kids. They do training like behavioural therapy and intervention yaani to improve their behaviour" (GP6 P31, L910-11)* *"He is not walking within the… When he supposed to walk by one year... he is more than one year, and he is not walking... Sometimes not sitting… or not talking… we will refer them to doctors…" (nurse 6 P8, L301-05)* *"… Sometimes we have to send the child for a second opinion. " (GP1 P25, L723-724)* *"… We leave it [psychological assessment] to the doctor sometimes…"(nurse 3 P17, L592-93)* *"… So, what is the value of early diagnosis? Yaani what is the value or benefit of diagnosing a child at one year?... okay, you will not embark upon any secondary intervention for the child. You will not change his behaviour… you will not change his case like that... so, what is the benefit to you*	*I think I am familiar with most of the ASD services in Oman.*

		of discovering this big thing at such an early stage?!!" (GP5 P26, L752-58) *When to refer a suspected child with ASD?* *"If you picked out a case, when would you refer it to a paediatrician? If you notice, for example, any abnormality like not smiling... would you refer directly or wait for two to three years to follow up at a PHC visit? " (GP5 P25, L712-15)* *"If you notice the motor developmental delay, and you feel that you want to give the child a greater chance to develop…, you give him two more months to improve… However, if you feel the child is already one-year-old, and he is not crawling, and he is not sitting, that is too much ... you will refer [nodding heads]" (GP3 P25, L728-732)* *"He is not walking within the… When he supposed to walk by one year... he is more than one year, and he is not walking... Sometimes not sitting… or not talking… we will refer them to doctors…" (nurse 6 P8, L301-05)* *"… Sometimes we have to send the child for a second opinion. " (GP1 P25, L723-724)* *"… We leave it [psychological assessment] to the doctor sometimes…"(nurse 3 P17, L592-93)*	*When I suspect a child with ASD:* *I follow the case within the clinic for a few weeks before I refer.* • *I follow the case until he/she has completed two years and then refer.* • *I refer the case within the primary level (psychiatric clinic or paediatric clinic).* • *I refer the case to the secondary level.*
	Social Barriers	*Stigma* *"[Barrier]… To me? … Social stigma … [Audible agreement from the everybody else: yeah]" (GP1 P7, L129)* *"They [parents] focus a lot on social stigma" (GP2 P5, L50-51)*	*Parents might avoid social embarrassments of early ASD diagnosis.*

	"Maybe… they [parents] socially… they do not want it to be known" (Nurse 1 P7, L235) *"… When I even said psychiatry [clinic] they were angry with me" (GP5 P7, L104))*	
	"…it is also about the name [of the disorder] when we translate ASD from English to Arabic. When a child came to me, I asked the father … of his seven years son having asthma in Arabic 'rabow'; he said no rabow my child ma eendahrabow. He has no asthma; he has hasasiatsaderie – a 'chest allergy' [loud laughter, followed by audible agreement. They accepted hasassader 'chest allergy' …but not rabow 'asthma' no…" (GP4 P14, L372-74)	*At the time of screening, using a more general term instead of "Al Twahed" might increase the uptake of screening for ASD.*
	"…even in our health centre, we had a programme for HIV …screening any patient; who wants to do it just comes and does it... When we first just said AIDS, nobody came at all ... we changed it to "naqesalmanah" (i.e., "immunity deficiency") and they, at least, accepted it, but not AIDS" (GP5 P15, L392-94)	
	Denial and health values *"… They say their child is okay, and they have noticed no abnormality" (GP3P5, L65-66)*	*Parents would rather give their children more time to develop normally before seeking medical consultation.*
	"… Even the parents, if they notice some abnormalities in the child and especially if the child is the youngest one and they are like other siblings in the family...uh, they all try to deny… that this behaviour is not normal ... they say that no, he is like his sister and brothers" (GP1 P5, L50-54)	

	"... Like a denial, they do not want… they do not want to believe that their child has ASD… (it is very difficult also)…very difficult" (nurse 4 P16, L593-94)	*I think the lack of parental awareness of ASD may challenge potential screening for ASD.*
	"... I ask some parents if their child is smiling at two months of age and is the child smiling to their face ... they look at me strangely wondering why I am asking these questions[general laughter]" (GP3 P5, L63-65) *"When we ask the mother something she will first look to the housemaid and ask her... Has he passed a stool or not passed a stool?" (GP4 P8, L151-52)*	*I think parents would visit health agencies to treat their children's sickness rather than to screen for behavioural abnormalities.*
	"Immunisation – okay, this is a must for them and is important so they will come... If you tell parents to come so that you can examine their child for ASD, they might not come" (GP5 P14, L356-58)	*Parents might try traditional medicine and Quran therapy when dealing with developmental and behavioural abnormality, at first.*
	Supernatural power and ASD *"We know our culture yaani (supernatural power and again..., i.e., black [evil] eye)" (GP4 P7, L110-11)* *"... They go for the traditional and Quran that... we know our culture" (GP5 P7, L107-08)*	

4. Strategies to facilitate screenings	*Increasing awareness* *"Awareness is the most important thing to be done" (GP2 P14, L363)* *"We need to increase more and more what is called (awareness...) of parents about the disorder" (GP5 P5,* *"Increase awareness by way of healthcare providers (nurses, doctors, health educators, medical orderlies) and others (teachers, the media)" (GP6 P6, L84-86)* *"Being aware of the vaccination... The importance of vaccination; maybe awareness regarding ASD would reduce stigma, it is very important…" (GP2P14, L366-67)* *"Not just important in the health sector, but even in the education sector or anything we can get in the media [one GP interrupted: such as school]…we can transfer the message (to the community)". (GP4 P6, L87-89)* *"…We have to remove this stigma… mothers cannot be shy … about ASD" (nurse 5 P16, L581-82)* *"Also, we need a reminder [from mothers]... we need a reminder (reporting abnormal signs...)" (GP8 P16, L427-428)* *Improve the current organisation structure* *"Give us the timeframe and also the appropriate system…" (GP5 P11, L269-70)* *"More time is needed for us to examine and for the nurse, the mother, the parents, or the caregivers to report to us the*	*Increasing public and professional awareness of ASD would reduce the social embarrassments of the disorder.* *Reduce social stigma and sensitivity to the disorder.* *Reduce time constraints*

	symptoms [behavioural abnormality] that the child exhibited ...” (GP6 P12, L285-89)	
	"... If there is a connection between the systems ... we know that out of each five suspected cases one will be diagnosed with ASD ... we are aware exactly the red flag signs that show ASD" (GP4 P28, L819-21)	*Improve service coordination between the diagnostic and intervention services.*
	".. We need more education and more knowledge on how to screen and identify any abnormal milestone that may predict that this child has ASD…” (nurse 7 P8, L238-40)	
	"Nurses should undergo additional training to enable them to pick up any symptoms that are abnormal symptoms..." (GP5 P12, L272-74)	*Increase professional and public awareness of ASD.*
	“For some surgical cases, like an umbilical hernia, for example, we do not refer directly. We [wait] until the age of one year. If there is no resolution, you have to refer directly..... In this case, we have to follow up at each vaccination visit.... So like in this surgical case, you have to follow up, so it is dependent on the situation. ...”(GP1 P25, L733-740)	*Collaboration between health and educational services is needed to facilitate early identification of ASD.*

Appendix 19: The developed questionnaire

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Barriers and Facilitators of Screening for ASD Questionnaire

Section A: Demographic Data: (Please complete the following information)

Sex: Age (yrs): Nationality:

Current Position Highest Qualification:

Work Experience (yrs):……Approximate No. of patients seen per day:

Approximate No. of staff per shift:……..

Approximate No. of programs runs by institution…… .

The Barriers (For each statement given below, please tick the category that best describes your opinion about the potential barriers for screening ASD within your current practice)

No.	***Statements***	***Strongly Disagree***	***Disagree***	***Agree***	***Strongly Agree***
Section B: Organisational Barrier					
1.	*We don't have enough time to screen children for ASD in our current practice.*				
2.	*Our institution is seeing the maximum number patients each day.*				
3.	*We have enough staff to carry out the daily clinic activities.*				
4.	*We don't have the required resources (such as screening tools, space, expertise…etc.) to screen for ASD in our institutions.*				
5.	*We are lacking clear mechanisms for referring the suspected cases of ASD for diagnostic assessment.*				
6.	*Despite the various educational programmes offered in our institution, ASD is not included as a subject.*				
7.	*In this institution, we keep a register of all the suspected cases of ASD that are referred to diagnostic services.*				

8.	*From the questions above are there any comments you would like to add?*

No.	Statements	Strongly Disagree	Mildly Disagree	Mildly Agree	Strongly Agree
Section C: Professional Barriers					
1.	My knowledge of ASD is based on the information I studied during my professional training.				
2.	I learned about ASD from the parents of children with ASD.				
3.	I learnt about ASD through self-updates and training.				
4.	I think I have more knowledge on the signs and symptoms of ASD, such as speech delay, lack of eye contact … etc. than the ongoing care and managements of ASD.				
5.	I feel most educated in the use of the pink card to immunise children, rather than the use of it to identify developmental and behavioural abnormalities.				
6.	I have identified a child with ASD previously.				
7.	When I suspect a child with ASD I follow the case within the clinic for a few weeks before I refer.				
8.	I prefer to monitor the suspected cases of ASD until they have completed two years and then refer.				
9.	I refer the suspected cases within the primary level (psychiatric clinic or paediatric clinic) if I suspect ASD.				
10.	I refer the case to the secondary level when I suspect ASD.				
11.	I think I am familiar with most of the ASD services in Oman.				
12.	From the questions above are there any comments you would like to add?				

No.	Statements	Strongly Disagree	Mildly Disagree	Mildly Agree	Strongly Agree
Section D: Social Barriers					
1.	I think the lack of parental awareness of ASD may challenge potential screening for ASD.				
2.	I think parents would visit health agencies to treat their children's sickness rather than to screen for behavioural abnormalities.				
3.	Parents would rather give their children more time to develop normally before seeking medical consultation.				
4.	Parents might try traditional medicine and Quran therapy when dealing with developmental and behavioural abnormalities, at first.				
5.	Parents might avoid the social embarrassments of early ASD diagnosis.				
6.	From the questions above are there any comments you would like to add?				

The facilitators (For each statements given below, please tick the category that best describes your opinion about the potential facilitators for screening ASD within your current practice)

No.	Statements	Strongly Disagree	Mildly Disagree	Mildly Agree	Strongly Agree
Section E. Facilitators					
1.	I think I would be in a unique position to screen for ASD, if I received the appropriate training and education.				
2.	In order to facilitate ASD screening, our service would need to integrate ASD characteristics into the pink card's child health checks part.				
1.	In order to facilitate ASD screening, our service would need to use a specific tool to screen for ASD within the current immunisation and surveillance programme.				
2.	In order to facilitate ASD screening, our service would need to design a				

	specific screening programme for ASD within PHC settings.				
3.	I believe improving coordination between the diagnostic and intervention services in Oman would advance the advantages of early ASD screening				
3.	Increasing public and professional awareness of ASD would reduce the social embarrassments of the disorder.				
4.	The collaboration between health and educational service is needed to facilitate early identification of ASD.				
5.	At the time of screening, using a more general term instead of "Al Twahed" might increase the uptake of screening for ASD.				
6.	From the questions above are there any comments you would like to add?				

Section F: From your experience rate the three (3) most important changes that would facilitate screening for ASD in the PHC setting in Oman: 1. Greatest facilitator; 2. Second greatest facilitator and 3. Third greatest facilitator.

☐ Reduce time constraints	☐ Activate the appointment system for the immunisations and child check visits
☐ Increase the number of staff in the clinic	☐ Improve service coordination between the diagnostic and intervention services
☐ Provide the required expertise, screening tools and space	☐ Encourage educational and health collaboration to identify ASD
☐ Increase professional and public awareness of ASD	☐ Reduce social stigma and sensitivity towards the disorder

Thank you for your participation.

Appendix 20: The orientation's programmes

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Exploring Primary Health Professional's perceptions of barriers to and facilitators of screening for Autism spectrum disorders within the Immunisation and Developmental Surveillance Program in Oman

Orientation's Programme

Date: 25/05/2015

Time: 9:00am – 1:00 pm

Venue: Directorate General of Health Affairs (Conference Room), Ministry of Health, Muscat

Audience: EPI Governorates' focal Points

Contact: Ms. Turkiya Saleh Al Muskari, Mobile: +xxxxxxxxxxx
Email: Turkiya.almaskari @ gmail.com

Time	***Topic***	***Speaker***
08:30-9:00am	*Registration*	*Facilitator: Ms. Zahra Al Jardani*
09:00-09:10am	*Welcome Speech*	*Mrs. Zahrah Al Jardani* *MSn, BSn, Rn* *Asistant Tutor* *ONI*
09:10-09:30am	*Briefing on ASD*	*Ms. Turkia Al-Maskari* *MSn, BSn, Rn,* *Acting Dean* *RNI-Sur*
09:30-10:00am	*ASD in Oman: Statistics and challenges*	*Mr. Muhammed Ali Al Rashidi* *Asistant Manager* *Sheikh Abu Nabhan Al Kharusi School*
10:00-10:30am	*Coffee Break*	
10:30-11:00am	*Introduction to the Research project: Barriers and Facilitators of Screening ASD within the Expanded Program of Immunization*	*Ms. Turkia Al-Maskari* *MSn, BSn, Rn,* *Acting Dean* *RNI-Sur*
11:00-11:30am	*Barriers and Facilitators of Screening ASD Questionnaire*	*Ms. Turkia Al-Maskari* *MSn, BSn, Rn,* *Acting Dean* *RNI-Sur*
11:30-12:00pm	*Roles of the EPI focal points in the research project*	*Ms. Turkia Al-Maskari* *MSn, BSn, Rn,* *Acting Dean* *RNI-Sur*
12:00-12:30pm	*Questionnaire distribution: Issues, Concerns and Prospects*	*Ms. Turkia Al-Maskari* *MSn, BSn, Rn,* *Acting Dean* *RNI-Sur*
12:30-01:00pm	*Awarding Certificates* *Closing Remarks*	*Mrs. Zahrah Al Jardani* *MSn, BSn, Rn* *Asistant Tutor-ONI*

Appendix 21: Questionnaire Instruction

University of Glasgow | College of Medical, Veterinary & Life Sciences

Ministry of Health Sultanate of Oman

Questionnaire Instruction Sheet

Exploring Primary Health Professional's perceptions of the facilitators and barriers of screening for autism spectrum disorders within the 'Immunisation and Developmental Surveillance Program' in Oman

Thank you for taking the time to fill in this questionnaire

What is the study about?

The prevalence of autism spectrum disorder (ASD) in children is increasing worldwide. This rise is expected to increase the burden on health and social care systems and impact on the economics of the country in terms of supporting individuals with ASD. In Oman, a family with an autistic child spends almost 41% of its income on that child. Screening children for ASD within the routine practice of primary healthcare settings would help to identify children at risk and interventions could be commenced at an early stage, which could improve the outcomes for the child. We are interested in identifying any barriers and facilitators from your perspective, if screening for ASD were introduced into primary healthcare settings in Oman.

Remember, we are interested in your views on this area and are not 'testing' your knowledge. Data will be used by the research team only. All data is anonymised, i.e., no one is identifiable from the responses so please feel free to answer as honestly as possible.

By completing this questionnaire, you are giving consent to participate in this study.

INSTRUCTIONS:

This questionnaire should take about … minutes to complete. There are .. questions over … pages. Please read the following instructions before answering the questionnaire:

1. Please answer all the questions. If you are unable to answer a question you can either contact the Research Assistant (**RA**) in your area –their details are below or move on

to the next question. Once you have completed it, seal the completed form in the provided envelope.

2. The sealed envelope will be collected from you by the **RA**, who will be available in your health centers from …/2014 to…. .2014. So, please feel free to hand it to him/her at your convenience within the assigned period.
3. The collected questionnaires will be sent to the researcher for further analysis.
4. For any queries please contact the **RA** in your region:……..
5. If you want to know more about the project or were not happy about the study and the way it was conducted please feel free to contact: the Primary Investigator: **Ms. Turkiya Saleh Mohammed Al Maskari:** Mobile: +xxxxxxxxxxx. Email: Turkiya.almaskari@gmail.com

I appreciate your help