Health Literacy Driving Health Engagement in the Pluralist Context of Migrant Health in Australia

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Dedication

In loving memory of Mandy Parish.

For Ilyas, Koshan, Mileka, Suraya and Aisha.
**Glossary of Terms**

**Acculturation** is “the process of cultural change and adaptation that occurs when individuals from different cultures come into contact” (Gibson, 2001, p. 19).

**Body mass index** (BMI) is body weight in kilograms, divided by the square of height in meters (AIHW, 2016).

**Culturally and linguistically diverse (CaLD)** is a broad and inclusive descriptor for communities with diverse language, ethnic background, nationality, dress, traditions, food, societal structures, art and religion characteristics (ECCV, 2012).

**Health literacy (HL)** is “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health” (Nutbeam, 1999, p. 357).

**Migrant** is any person who is moving or has moved across an international border or within a state away from his/her habitual place of residence, regardless of (1) the person's legal status; (2) whether the movement is voluntary or involuntary; (3) what the causes for the movement are; or (4) what the length of the stay is (IOM, 2011).

**Migration health** addresses the state of physical, mental and social well-being of migrants and mobile populations (IOM, 2015).

**Migration** is the movement of a person or a group of persons, either across an international border or within a state, and is conceptualised as not a single act but rather a lifelong process that can have a corrosive effect on cultural boundaries and may be marked by inequalities and serious human rights abuses (UNESCO, 2015).

**Receiving country** is a country of destination or a third country. In the case of return or repatriation, also the country of origin. A country that has accepted to receive a certain number of refugees and migrants on a yearly basis by presidential, ministerial or parliamentary decision (IOM, 2011).

**Refugee** is a person who, owing to a well-founded fear of persecution for reasons of race, religion, nationality, political opinions or membership of a particular social group, is outside the country of their nationality and is unable or, owing to such fear, is unwilling to avail themselves of the protection of that country (IOM, 2011).
Social determinants of health are factors in the social environment that impact health. Structural determinants and conditions of daily life constitute the social determinants of health and cause much of the health inequity between and within countries (Marmot et al., 2008).
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**Thesis Abstract**

**Background**
Overall, migrants have equal or better health than non-migrants largely due to pre-migration factors such as rigorous selection processes. Some migrant groups continue to maintain good health in developed countries, such as Asians who show a 36% lower mortality rate compared to non-migrants. However, other migrant groups experience a health decline as early as two years’ post-migration. Health literacy (HL) is a determinant of health and may contribute to the observed migrant health decline.

Initially HL was a narrowly conceived literacy related theory but has been recently reconsidered as a complex, multidimensional concept. There is a paucity of data on migrant HL, warranting research that may identify mechanisms that cause and potentially mitigate the migrant health decline. In addition, commonly used HL measures, based on narrow concepts such as health-related literacy and numeracy ability, i.e. functional HL, developed for clinical and/or general populations may not be effective in capturing the HL needs of migrants.

**Aim**
This thesis uses a broad measure of HL to explore HL in three groups of migrants to determine if HL can provide insight into their health beliefs and practices and into enablers that might strengthen health system engagement and, ultimately, improve their health.

**Methods**
A mixed method study was conducted with Somali, Chinese and Indian migrants. Data were collected using: a) the nine-dimension Health Literacy Questionnaire (HLQ, 80 from each group); b) cognitive interviews (n=18), which provided insights into respondents’ interpretations of the HLQ; and c) in-depth interviews (n=45) exploring health beliefs, practices, barriers and enablers to accessing health care. Data from the three migrant groups were compared to an Australian group to identify HL strengths and limitations.

**Results**
The three migrant groups, Somali, Chinese and Indian, have marked heterogeneity in HL strengths and limitations and in health conceptualisations. Each of the three groups exhibited a range of common and unique functional and interactive/communicative HL competencies that were highly influenced by culturally-bound explanatory models of health. The HLQ data
suggests that Somali migrants had the highest HL. The Australian biomedical health care system is generally non-responsive to the needs of migrant groups largely due to the lack of accommodation or acknowledgement of health approaches outside of a biomedical paradigm. Migrant groups were observed to develop compensatory mechanisms to engage with the health care system, however, structural and contextual barriers excluded their full participation. The low levels of participation observed in prevention, screening, mental health and self-management may contribute to the migrant health decline.

Dimensions of HL such as agency, decision making, navigation, information finding, help-seeking, practitioner interaction, health engagement and communication were expressed using culturally normative mechanisms. Health literacy was viewed as a collective skill by participants who leveraged competencies distributed within their cultural network to augment individual abilities. Also, this study provides evidence that migrants have embedded health beliefs and practices that are inter-exchanged and negotiated within a contemporary biomedical context. The migrants who participated in the study appear to have a pluralist approach to health that is situated within a transnational frame of reference and which strongly determines their HL and health system engagement.

**Discussion**

HL practices in the three migrant groups were divergent from normative practices as defined by common HL measures. This observation challenges previous findings of low functional HL in migrant groups. In addition, HL in the three migrant groups was operationalised as a collective skill to augment individual level HL, a finding that has important implications for health system responses and intervention development. Further, current approaches to migrant health do not accommodate a pluralist paradigm and do not explain the partial health system engagement patterns observed in this study.

**Conclusion**

Migrants have a range of unrecognised HL skills that are not adequately understood or addressed within the health sector. This study demonstrates the urgency for a renewed focus on HL and the need for tailored HL interventions among migrant populations. Despite the lack of accommodation of pluralist approaches to health by the biomedical health system, migrants have developed effective compensatory mechanisms that, if supported, may optimise HL and engagement by this population.
I have proposed a new ‘health engagement convergence model’, that recognises the pluralist paradigm in which migrant’s function. This model has the potential to reduce the avoidable morbidity and mortality in migrant groups. Importantly this model uses a strengths based approach to leverage the skills and social assets within migrant groups to augment HL and engagement.

The findings of this study have policy, public health and practice level implications that, if adopted, may increase the HL and health engagement of migrant groups and minimise their subsequent health decline.
**Prologue**

**Mariam’s story**

Mariam, a young Somali woman, lies on a bed in an Australian hospital listening to the slowing of her heart beat and feeling the strength ebb from her body. She knows her health is deteriorating but for the first time in her twenty-four years of life is at a loss to know how to help herself. Looking around her uniform green room she has the disturbing sensation of floating away from her life and all she has understood up to this point.

The nurse comes in and while closing the blinds explains that she has told Mariam’s visitors to go away so that she and her yet-to-be-born baby can rest. Mariam wants to tell her that all this rest and being alone is killing her but she doesn’t have the words and does not want to offend the nurse. Obediently, she lies perfectly still in the overheated room, pining for her community, reciting *a du'as* (prayer to restore health) and trying to avoid the eye of death.

She closes her eyes and remembers the last time she was sick back in Mogadishu in Somalia as a young girl. The doctors had told her parents she was going to die from malaria and to take her home. She remembers being carried out on a stretcher into the courtyard of her home and seeing the whole community gather to be with her. One by one they hugged her, told her that Allah was with her and encouraged her to be strong.

In her feverish, semi-conscious state she heard the women singing and the comforting humming prayers of the Sheik and she recognised the sharp smell of goat’s blood that was being slaughtered nearby. The hot night air swirled and vibrated with the stucco rhythms of drums, joyous ululation and the uplifting smell of herbs being thrown by the handful into the vats of caramelising onions. Hunger stirred within her and she sat up for the first time asking for food. The crowd clapped and cheered as she sipped warm, fresh cow’s milk. Her fever broke at dawn and she drifted off to sleep to the thrilling sound of the *fajr* call to prayer knowing that Allah was not ready for her yet.

Back in her hospital room she watches the poisonous intravenous fluid invade her body and feels her nerves flinch at the beep of the heart monitor. Her stomach howls with hunger but she cannot eat the hospital food laden with chemicals that sit like cow pads on her table. She wonders how she, who has escaped a civil war, picked her way through dead bodies while running from aerial bombing, who survived the omnipresent dangers of a refugee camp, is to die alone in a hospital room in a country that was not her home. She decides to save herself.
She calls her husband to come and ignoring the pleas of the nurse she discharges herself. As they drive down the street where they live she can see that the community are there. The women are cooking in large cauldrons while the men pray and she sits in her garden and feels her strength return. For three days, they come to be with her, to cook and make her laugh. They soothe her with stories and poems of home and in that moment, she feels as though she is home.

A month later she gives birth to a healthy daughter and twenty years later she sits in her beautiful garden and recounts this story to me. She tells me that if she had stayed in the hospital that day, she and her baby would not have survived.

“Look what we have survived … the Somali people … we are very strong … but we are not single individual peoples, we are all one together and our spirit gets sick when we are not with our stories. Our community are first with us before the ambulance [laughs] when we are sick … that is our way. First, we pray and then we ask for health advice from our communities and then, finally, we go to the doctor.”

**About this study**

I have had a long-held interest in exploring the nexus between health and culture, largely as a result of my experiences over a thirty-year period of working in the health sector. When working as a nurse it became apparent to me that individuals born overseas held very different understandings of health. Over the years I observed illness expressed as loud lamenting and sobbing, humble petitioning prayers, hypnotic singing or stoic withdrawal. Some patients called for religious leaders, astrologers or healers to their bedside while others would sit quietly in the arms of their community, waiting for their time to end.

In truth, the diverse expressions of illness often had the disquieting effect of challenging the authority of we health professionals. We would try to take control and make the patients conform to our idea of normal by limiting the number of visitors or asking them to quieten down on the pretext that they were scaring other patients. I observed how migrants were marginalised with their behaviour explained as aberrant or inferior. How the system provided a one-size-fits-all service that showed preference to the needs of the Australian-born population and intolerance of the ‘other’. In hindsight, we could have done better to understand their need to behave in ways that were familiar and comforting to them. It is my hope that this study may help health professionals today to do better in accommodating the needs of migrants.
Dissertation introduction

This thesis presents the findings of a series of studies which applied a novel approach to identify factors that have the potential to strengthen the HL and health system engagement of three Australian migrant groups (Somali, Chinese and Indian). The thesis is divided into three parts: Part I (Chapters 1 to 3) provide a literature review of current approaches to migrant health, HL including an examination of HL measures and engagement patterns of migrants within the Australian health context. Part II (Chapter 4) provides an overview of the mixed methods approach used in the study that included a multidimensional HL measure. Part III (Chapters 5 to 9) presents findings from each of the three migrant groups culminating in a synthesis of these findings in the final chapter. Also, engagement strategies, policy considerations and suggestions for further research on migrant HL are included. This study will be of interest to policy makers and health-sector actors who seek to engage with migrant populations.
Chapter 1: The Rise and Rise of Health Literacy

Introduction

In this chapter, I provide an overview of the evolution of HL research from its inception as a literacy related term through to the current framing as a multi-dimensional concept. The conceptual evolution of HL is explored through definitional iterations and the development of increasingly complex HL conceptual models. In addition, I examine the utility of commonly used measures of HL and discuss the development of more recent multidimensional measures based on broader conceptualisation of the concept. The chapter concludes with a summation of the current gaps in HL research with a particular focus on the needs of migrant groups.

What is health literacy?

There are many definitions of HL but one of the most commonly referenced definitions published is by the World Health Organisation in 1998:

> HL is the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health. (Nutbeam, 1999, p. 357)

Although this definition is commonly used it is no longer considered definitive or inclusive of the full range of HL concepts. This point is discussed in more detail later in the chapter.

Why does health literacy matter?

Although the evidence is not strong, HL is often referred to in the literature as a determinant of health outcomes, with low HL linked to poorer health outcomes and higher mortality. Low functional HL (i.e., health-related reading and numeracy ability) has also been associated with variance in uptake of health care services, such as lower use of primary care and public health services and interventions (Keleher & Hagger, 2007), less participation in screening and immunisation (Berkman et al., 2011b), lower levels of self-care (Riegel et al., 2009), increased hospitalisations (Baker et al., 2002) and emergency care, and poorer overall health status and higher mortality (Berkman et al., 2011b; McNaughton et al., 2015). Low functional HL is also thought to contribute to racial disparities in health outcomes (Berkman et al., 2011b).

In addition, low HL is considered to be a factor associated with increased health care utilisation and costs (Mantwill & Schulz, 2015). Whilst there have been few robust studies on the health care costs associated with low HL only one study proposed a cost saving estimation with increased HL of up to 8% in some high risk population groups (Haun et al., 2015). However, the
validity of this estimation is in doubt as the supporting data were drawn from correlational data from which causal claims should be drawn cautiously. As will become apparent later in this chapter there remains a need for further research linking HL and health outcomes.

Prevalence

The prevalence of low health-related literacy is common across populations in developed countries. Three large scale studies conducted in North America (Kutner et al., 2006), Canada (Canadian Council on Learning, 2007) and Australia (ABS, 2008) found that on average half of the population had low or inadequate levels of health-related literacy (North America 47%, Canada 53%, Australia 59%). Findings from the above studies showed that native-born, white, adult, educated women had the highest level of health-related literacy (Kutner et al., 2006). Low HL correlated with low education attainment (Rockwell & Riegel, 2001; Yamashita & Kunkel, 2015), immigrant status, low levels of English proficiency (Beauchamp et al., 2015; Sentell & Braun, 2012) and low socioeconomic status (Newman et al., 2015). However, the results of these studies have been challenged by proponents of broader definitions/conceptualisations of HL. Critics of these studies suggest proxy measures of HL were used (Jordan et al., 2011) based on a narrow definition of HL such as the following:

Using printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential. (Kutner et al., 2006, p. 2)

The weaknesses of these and any other studies purporting to measure HL are examined in more detail below in this chapter in the section titles: HL measurement.

An evolution of health literacy

HL was initially conceived as a unidimensional literacy related concept in the 1970s when an education academic, Scott Simonds, argued for a broadening of the school curriculum to include HL (Simonds, 1974). Low HL was associated with individual knowledge and literacy related deficits such as poor reading and writing abilities with interventions to improve HL focused on health education (Nutbeam, 2000). Population risk at this time was conceived as the sum of individual risk, therefore, improving individual HL capacity was understood to have broader population health outcomes (Krieger, 1994).

Over the past forty years the concept of HL has evolved beyond the field of literacy with the emergence of more comprehensive definitions and broader conceptualisations of the term (Sørensen et al., 2012) that were informed by a range of health-related fields such as:
psychology, sociology, health promotion (Nutbeam, 2000), environmental science (Nutbeam & Harris, 1995) and literacy (Nutbeam, 2000). In 1998 Nutbeam defined HL as:

The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health. (Nutbeam, 1999, p. 357)

Nutbeam argued, is more than reading pamphlets and making appointments; it is also the ability to use health information in ways that improve patient empowerment (Nutbeam, 2008). The literacy-based conceptualisation of HL also had implications for the development of HL measures. The ‘first generation’ (de Leeuw, 2012) of measures were developed (Baker et al., 1999; Davis et al., 1993; Parker et al., 1995) that placed skills in reading, writing and numeracy as the core set of skills required for HL (Parker et al., 1995). Subsequently, Ratzan and Parker’s (2000) definition went beyond information seeking and added service access:

The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. (Ratzan & Parker, 2000, p. 4)

However, whilst these and other definitions (Sørensen et al., 2012) conceptualised HL more broadly they continued to place the focus on the individual. In Nutbeam’s definition, individual cognitive and social skills are the primary determinants of HL abilities with the onus on the individual’s ability to interact and communicate with health professionals. Also, according to Nutbeam, education and health promotion interventions aimed at the individual would lead to population-level HL improvements, however, there is little evidence to support the effectiveness of this approach. A key limitation of Nutbeam’s approach is the lack of recognition of the influence of wider cultural, social, political and structural barriers (Buchbinder et al., 2011) impacting HL. A second important limitation was the theoretically driven development of the concept with limited input from end users such as practitioners and consumers.

Nutbeam (2000) went on to develop a model of HL (Nutbeam, 2000) that has been highly influential in subsequent conceptualisations and clinical applications of the concept (Sørensen et al., 2012). His theoretically-based model that was developed from an existing literacy model (Nutbeam, 2000) distinguishes between three different levels of HL and it is one of the most widely used classification systems. The three HL levels in the model are:
1. **Functional HL**, which involves having the reading, writing and information processing abilities to effectively participate in one’s own care, and it relates strongly to one’s personal use of health information.

2. **Interactive HL** relates to how a person obtains and applies health information through interaction with others, including health professionals, and it is a major factor that determines how effectively people access and use health services.

3. **Critical HL** is the skill that supports critical reflection about information or advice received, including recognition of the influence of wider social determinants of health. These include the ability to obtain, understand and critically appraise different sources of information, and the ability to engage in shared decision-making. Critical HL is strongly related to people’s ability to participate in debates and advocacy about issues that affect the health (Nutbeam, 2000, p. 263).

The model assisted in evolving HL into a more complex multi-level concept and marked an important milestone in the field. The model not only outlined a broad range of skills required to manage health but also provided a progressive HL pathway from basic (functional level) to more complex HL skills (interactive and critical levels). The model successfully integrated the previously disparate clinical and public health components of HL into a unified concept (Pleasant & Kuruvilla, 2008; Sørensen et al., 2012) through the use of medical terminology (level 1) and by identifying individual and community level outcomes (Sørensen et al., 2012). In addition, the model introduced the concept of critical HL aimed at enhancing capacity to act politically to address social and economic determinants of health. Whilst Nutbeam’s model progressed the concept of HL it has several limitations.

Critics argued that the constructs outlined in Nutbeam’s model already existed in the health promotion field (Wills, 2009) and therefore did not bring anything new to the field. They also claim that the connections between the three levels in the model were unclear (Tones, 2002; Wills, 2009) with the association between an individual’s level of competency and health outcomes and behaviours untested. One critic of Nutbeam’s comprehensive model wrote that “the new omnibus edition of HL incorporates all of the major psychological, social and environmental constructs that influence health choices” (Tones, 2002, p. 289). Further, Nutbeam’s model (2000) is focused on the individual with a lack of recognition of the influence of the social, cultural and structures surrounding the individual. However, despite its weaknesses the model has been highly influential in progressing HL from a simple concept based on the field of literacy into a more complex and multi-layered model.
The limitations of Nutbeam’s model (2000) were in part addressed by a subsequent expanded model of HL developed by Zarcadoolas et al., (Zarcadoolas et al., 2005) that characterised four domains of HL: fundamental literacy (reading, writing, speaking and numeracy), science literacy, civic literacy and cultural literacy. This model broadened the concept of critical HL by identifying underlying constructs such as science, media and communication, and the influence of culture on an individual’s understanding of health concepts. The authors defined HL as,

…a wide range of skills and competencies that people develop to seek out, comprehend and evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life. (Zarcadoolas et al., 2006, p. 196)

A point of difference with this definition was that it articulated the process of becoming health literate as dynamic and ongoing. The multi-dimensional model conceptualised the four domains as the foundations to improve HL and they are intrinsically linked. The four domains were defined as:

- Fundamental literacy: the skills and strategies involved in reading, speaking, writing and interpreting numbers (numeracy)
- Science literacy: levels of competence with science and technology, including some awareness of the process of science
- Civic literacy: abilities that enable citizens to become aware of public issues and become involved in decision making processes
- Cultural literacy: ability to recognise and use collective beliefs, customs, world-view and social identity in order to interpret and act on health information

This model incorporated key elements of Nutbeam’s model through the inclusion of functional literacy (fundamental literacy) and interactive and critical literacy (civic literacy) but expanded the concept to include an understanding of science and technology and the critical influence of culture in shaping health understandings and health behaviours. These two elements of science and culture may be more important mediating factors than English language proficiency in the HL capabilities of migrant populations. This expanded model broadened the concept of HL into new and important dimensions of HL. However, it continued to focus on the individual and omitted areas such as engaging with professionals or services.

Up to 2004 HL research had been largely conceptually and theoretically based with little evidence of an association with health outcomes. This began to change in 2004 with the first of many reviews that made the link between HL and health outcomes.
An influential systematic review (DeWalt et al., 2004) found that people with low HL were 1.5 to 3 times more likely to experience a poor health outcome. This comprehensive review of forty-four HL related studies found that patients with low literacy had poorer health outcomes, including knowledge, intermediate disease markers, and measures of morbidity, general health status, and use of health resources. The authors found the studies to be of fair to good quality, with most studies failing to adequately address both confounding and the use of multiple comparisons. A key weakness of the studies included in the review was the HL measures used. These studies used the Rapid Estimate of Adult Literacy in Medicine (REALM), the Test of Functional HL in Adults (TOFHLA), the short TOFHLA (S-TOFHLA), the Schwartz–Woloshin Numeracy Test and the Wide Range Achievement Test (WRAT) math subtest. Each have several limitations that are examined in more detail in the later section ‘HL measurement’.

A subsequent review update (Berkman et al., 2011a) conducted seven years later that examined ninety-nine HL related studies found both similar and new results. This update showed that low HL was also associated with differential use of certain health care services, including increased hospitalisations and emergency care and decreased mammography screening and influenza immunisations. Differences in health-related outcomes included a poorer ability to demonstrate taking medications properly and interpret medication labels and health messages and, among elderly persons, poorer overall health status and higher mortality. This evidence also indicated a link between lower HL and racial disparities in health outcomes. However, once again, the findings of the review were influenced by the quality of the studies, which the authors rated as from fair to good. Additionally, it is important to note the authors found no studies that examined health outcomes by oral (verbal) component of HL, which has important implications for migrant populations (Harrington & Valerio, 2014).

Other studies found an association between functional HL and self-management skills (Mancuso & Rincon, 2006; Paasche-Orlow et al., 2005; Rockwell & Riegel, 2001), higher levels of education (Rockwell & Riegel, 2001), being symptomatic (Rockwell & Riegel, 2001) and empowerment (Eyuboğlu & Schulz, 2016; Gwynn et al., 2016b). These findings gave rise to a new area of research linking higher risk of low HL and poorer health outcomes to particular population groups (low socioeconomic, low English proficiency and indigenous groups) that positioned HL as a mechanism to influence health equity. However, whilst an association between HL and health outcomes had been established, the causal pathways were yet to be explored through longitudinal and interventional studies.
A second influential model of HL was developed by Paasche-Orlow and Wolfe (Paasche-Orlow & Wolf, 2007) who published a conceptual, causal model linking HL with health outcomes. The significance of the model was the conceptualisation of HL as both a patient and a health system phenomenon. It was one of the first models to link patient abilities with health system factors such as complexity, tiered delivery systems and health practitioners’ abilities as equally important in shaping HL. Importantly, the model links a wide range of factors such as cognitive ability, socioeconomic status, ethnicity, environment, culture and social support as influencing HL. But the most significant heuristic contribution of this model was in showing how health outcomes were impacted by the interplay of disparate elements (patient, health practitioner, health system and extrinsic factors) within the system. The model describes multiple points of intervention that could be strengthened to improve HL abilities and, more distally, health outcomes. The model also had a number of limitations such as not being empirically validated (Sørensen et al., 2012) and presenting a simplistic, linear representation of a causal pathway which is not reflective of the often dynamic and complex nature of the relationships. However, despite these limitations this causal model, like Nutbeam’s (2000), has been influential in the evolution of HL.

In the past decade, there has been an exponential increase in the number of HL papers published (Sørensen et al., 2012; Weiss, 2015). However, much of this research has focused on assessing individual HL with little focus on the social or cultural context (Guzys et al., 2015). The interest in HL has been driven by a number of factors such as the emergence of prevalence data showing the scale of low functional HL in developed countries, evidence of the association between low HL and poor health outcomes (Easton et al., 2010), lower service use (Berkman et al., 2011b; DeWalt et al., 2004), recognition of the increased HL demands from a more complex health system (Kickbusch, 2008) and the global epidemic of chronic disease with its disproportionate burden on low socioeconomic communities (FitzGerald & Poureslami, 2014). Pressure to develop the concept of HL even further came from the WHO Commission on Social Determinants of Health, Health Equity Report (Sheiham, 2009) that called for the expansion in the scope of HL to include the ability to understand and communicate information related to the social determinants of health.

Subsequently, Sorenson et al. (Sørensen et al., 2012) made a significant contribution to expanding the concept of HL with the development of a new comprehensive model. The model was derived from the integration of key elements of previous definitions and models and combined them into an expansive, comprehensive model of HL. The conceptual model encompassed the main dimensions of HL and its determinants as well as pathways to health.
outcomes. It moves from the individual level towards a population HL level that, like Nutbeam’s model, brought together both the clinical and public health domains. The model identifies twelve dimensions of HL and competencies related to accessing, understanding, appraising and applying health information to the domains of health care, disease prevention and health promotion. Importantly for migrant groups, Sorenson et al. includes culture as a distal factor with other environmental and societal determinants and they position social support, and family and peer influences as situational determinants. Whilst this model significantly expands the concept of HL, an important limitation of the model is the lack of empirical testing of the domains with health outcomes. This model led to the development of the European HL Survey Questionnaire (HLS-EU-Q) (Sørensen et al., 2013) which is being used in Europe.

In recent years, conceptual development has been influenced by a greater understanding of HL as dependant on the relative demands on an individual and the social context in which they live. This recognition has informed the development of empirically based research approaches. More recent empirically based research derived from qualitative studies with patients and health care professionals identified a range of abilities considered important for accessing, understanding and using health information (Buchbinder et al., 2011; Jordan et al., 2010). The work of Jordan, Osborne and Buchbinder that encompassed the perspectives of HL stakeholders beyond the research world has had a significant impact on the conceptualisation of HL. This work was instrumental in the development of new measures of HL. However, before moving on to new measures, it is important to understand the limitations of some of the more commonly used measures of HL.

**HL measurement tools and their limitations**

HL measurement has proven to be a highly contested area, with the authors of existing tools implying that they measure HL but they are based on differing conceptualisations of HL and with differences in purpose, approach and design (Sørensen et al., 2013). Some authors have suggested that to be effective, the tools should be comprehensive and multi-dimensional measures of HL that are based on broad conceptual HL frameworks that are sensitive to contextual comparisons including culture, life course, population group and research setting, and encompass both public health applications and clinical screening (Pleasant et al., 2011). This section examines the limitations of commonly used instruments.

Two commonly cited Australian HL prevalence studies (ABS, 2008; Barber et al., 2009) revealed limited HL levels in the general population ranging from between 26% (Barber et al., 2009) and 57% (ABS, 2008). The wide variation in findings of the two studies may be explained
by the differences in measures of HL used and serve to illustrate the complexities and challenges in HL assessment.

The HL prevalence study most commonly referred to in the Australian context is the Adult Literacy and Life Skills Survey (ALLS) (ABS, 2008). This study was conducted in Australia in 2006 as part of an international literacy study coordinated by Statistics Canada and the OECD (Organisation for Economic Cooperation and Development). The study measured knowledge and skills across four areas: prose literacy, document literacy, numeracy and problem solving. HL in this study was defined as the knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies and staying healthy. One hundred and ninety-one health-related items across the four domains of prose and document literacy, numeracy and problem-solving, and relating to one of five health-related activities (health promotion, health protection, disease prevention, health care maintenance and systems navigation) were included. Outcome scores ranged from levels 1 (low) to 5 (high) with level 3 “…the minimum required for individuals to meet the complex demands of everyday life and work in the emerging knowledge-based economy” (ABS, 2008). The 15,105 participants who completed the survey were male and female aged between 15 to 74 years.

Results showed 59% of the Australian general population with low or inadequate levels of HL (level 2 or below). This figure was higher for people born overseas (67%), and higher again (73%) for those who arrived in Australia during the past five years and for people whose first language was not English (74%) (ABS, 2008). People whose first language was not English were more likely to be assessed at lower skill levels. Among this population, 25% were assessed at level 1 or below, compared to 12% of people whose first language was English.

The study had a number of weaknesses including the use of a narrow conceptual framework of HL, measurement of narrow literacy and numeracy content domain categories that were poorly discriminated and with the study scoring not made publicly available. In addition, the survey aggregated results into a single summative score that provided little insight into the HL strengths and weakness of the Australian population (Jordan et al., 2011).

A second smaller prevalence study (Barber et al., 2009) provided very different results with only up to 26% of the general population found to have limited HL. The study measured HL in a representative sample of the Australian general population using three commonly used health-related and numeracy measures of HL: The Rapid Estimate of Adult Literacy in Medicine (REALM), the Test of Functional HL in Adults (TOFHLA) and the Newest Vital Sign (NVS).
The study found that the proportion of participants with less than adequate HL levels varied across instruments with 26.0% for the NVS, 10.6% for the REALM and 6.8% for the TOFHLA. Importantly the study showed that there was a marked variation in the results between the three HL measures which indicated that there was uncertainty about the accuracy of data being produced in relation to HL levels at an individual and population level.

These commonly used measures of HL which, like the instrument used in the ALLS discussed previously, are based on a narrow conceptual framework of HL and have a number of weaknesses including poor validity, reliability and feasibility (Jordan et al., 2011). Whilst there are a number of HL measures, the most commonly used are the Rapid Estimate of Adult Literacy in Medicine-Short Form (REALM-SF) (Baker et al., 1999), which tests reading ability through word recognition and pronunciation; The Test of Functional HL in Adults (TOFHLA), which requires people to read and complete missing sections of selected passages of information to measure reading comprehension, as well as to read and understand the information on medication labels and appointment slips to assess numeracy (Baker et al., 1999); and the Newest Vital Sign (NVS), an assessment of reading comprehension and numeracy that requires respondents to read a nutritional label then answer six problem-solving questions (Weiss et al., 2005). All three tools are focused on individual functional HL assessment within a clinical setting.

All three of the above measures have a number of measurement limitations due to variations in definitions of HL, use of narrow conceptual frameworks of HL and lack of adequate psychometric development and testing procedures (Jordan et al., 2011). The tools measure narrow content such as reading, comprehension and numeracy skills, providing data on a limited range of skill sets. In addition, scoring categories are poorly defined and may not be mutually exclusive, and few indices had been assessed for reliability (Jordan et al., 2011). The feasibility limitations include the increased time needed to administer in research and clinical settings (particularly evident in the longer version of the REALM), the need for interviewer training (REALM, TOFHLA) and a lack of integration with patient record systems means that manual scoring is required (Jordan et al., 2011).

A review of nineteen HL instruments by Jordan, Osborne and Buchbinder (Jordan et al., 2011) found that the composition of underlying constructs and content varied widely across instruments with none appearing to fully measure the HL domains of the ability to seek, to understand and to use health information. The authors concluded that HL was not consistently measured, making it difficult to interpret and compare HL at individual and population levels.
They identified the need for more comprehensive HL instruments to be developed using empirical methods to demonstrate validity and reliability.

Further criticisms of the HL measurement tools include the fact that they focus on the individual’s ability and do not assess the HL responsiveness of the health system or health organisations (Baker, 2006) or of persons or populations outside of the health system (Peerson & Saunders, 2009). Also, they were developed using patients drawn from single racial, ethnic, age or socioeconomic groups often excluding non-English-speaking people and they have not been validated across different population groups (Ownby et al., 2014). Further, they do not measure related health engagement skills such as oral communication skills (Harrington & Valerio, 2014), listening or writing skills or visual literacy (Entwistle & Williams, 2008), and they do not consider age, gender, language, culture and other contextual and setting factors (Baker, 2006; Rootman & Ronson, 2005; Scudder, 2006).

In addition, differential item functioning (DIF) occurs when individuals from different groups, such as men or women or persons from racial groups, have the same level of ability but have different probabilities of answering an item correctly (Ownby et al., 2014). DIF is a type of bias where other factors are influencing a person’s responses such as cultural background, lack of familiarity with the content or socio-demographic factors. A further criticism of the measures of HL is that they were developed using a top-down development approach limited to the perspectives of researchers, health professionals and literacy experts, with minimal consultation with health consumers (Jordan et al., 2011).

Limitations of the HL measures for non-English speakers include limited number of language translations and lack of psychometric procedures to ensure equivalence across the languages. Also, the measures may be biased toward those with recent experience of the health care system and content areas, they may lack cultural sensitivity and they may show bias towards certain populations (Pleasant et al., 2011) and those with low English proficiency (Elder et al., 2012).

There is a growing understanding that HL is multi-dimensional (Jordan et al., 2011) and encompasses a wide range of abilities other than literacy such as decoding (Elder et al., 2012), interpreting and assimilating health messages. It is therefore important that HL measures should be sensitive to or capture broader determinants of HL such as cultural and social contexts and diverse conceptualisations of health (Andrulis & Brach, 2007). In addition, areas of health-related decision making and oral (verbal) components of HL (Hewitt & Institute of, 2013) have been neglected to date and they need to be considered to reflect the diverse HL capabilities in particular population groups.
Finally, there is also a body of evidence showing the interconnectedness of HL, health disparities and health inequity (Beauchamp et al., 2015; Gwynn et al.; Hasnain-Wynia & Wolf, 2010; Lee et al., 2015a); (Mantwill & Schulz, 2015). Building the HL capacity of individuals, communities and systems has the potential to improve health equity, however, measures which purport to measure HL but are proxy measures of literacy have the potential to increase health inequities.

New approaches to health literacy measurement

As a consequence of the identified limitations of existing HL measures a number of empirically based studies have conceptualised HL from the perspective of the lived experience of service users and health professionals. One study (Jordan et al., 2010) that aimed to conceptualise HL from the patient perspective, developed a conceptual framework of HL derived from interviews and concept mapping. Items were generated using statements from participants in a chronic disease self-management program and from emergency department attendees.

Consultations generated eight scales each with four or five items such as: understanding health information, accessing GP health care services, communication with health professionals, being proactive and using health information, patient attitudes towards their health, social support and socioeconomic considerations. The eight scales formed the basis of a new measure of HL known as the HL Management Scale (HeLMS) and represented a new approach to the development of measures of HL. The tool was found to have acceptable psychometric properties when assessing a range of HL constructs important to patients seeking, understanding and using health information within the health care system.

However, with further testing the HeLMS was found to have substantial weaknesses such as low sensitivity to less severe HL limitations, and one item scale within the HeLMS, which related to the economic barriers to care, was found to have wide variance. To address these limitations, the authors conducted further consultations and reanalysed the original consultation data used in the development of the HeLMS which led to the development of a new, strengthened HL measure known as the HL Questionnaire (HLQ) (Osborne et al., 2013).

The HLQ (Osborne et al., 2013) was developed using systematic grounded methods, a validity-driven approach, and has nine independent indicators of HL that reflect important elements from the perspective of the general population, practitioners and policymakers. The authors stated that the HLQ detects and describes the HL needs of people at community and population levels and measures outcomes of public health and clinical interventions designed to improve HL (Batterham et al., 2016; Osborne et al., 2013). It was designed to be sensitive to the full range of
HL abilities from mild to severe limitations (Osborne et al., 2013). In addition, the scales within the HLQ are linked to Nutbeam’s model (2000) (Nutbeam & Harris, 1995) including Basic, Communicative and Critical Health Literacies (Osborne et al., 2013) with items graded to capture increasingly complex HL capabilities. In addition, the nine scales capture a wide range of the lived experiences of people attempting to engage in understanding, accessing and using health information and health services. Importantly, the scales provide a reflection of the quality of health and social service provision (Osborne et al., 2013).

The HLQ addresses the limitations of the commonly used measures of HL in a number of significant ways including its method of development (grounded approach capturing the lived experience of end-users) and that it is based on a broad definition of HL, tested in end-user groups and encompasses the concept of health system responsiveness to the needs of the populations they serve. The nine distinct constructs within the HLQ are conceptually robust with representative items found to have good to excellent psychometric properties. In addition, the HLQ is translated into a number of languages with extensive psychometric testing undertaken to achieve linguistic and cultural equivalence. As a consequence, interventions developed from HLQ data are focused on building the capacity of both individuals and systems to affect HL. The HLQ also has the potential to generate more equitable health outcomes through the reorientation of health systems to meet the needs of health consumers. In addition, whilst the HLQ was only released in 2013 it has undergone substantial additional psychometric testing in Australia (Elsworth et al., 2016), Germany (Nolte et al., 2017), Denmark (Maindal et al., 2016) and Slovakia (Kolarcik et al., 2017).

However, the HLQ also has a number of limitations such as the need to conduct complex analysis of the data to derive targeted interventions, the lack of published studies in different ethnic groups and the feasibility of administering the lengthy (forty-four-question) survey. Finally, as with all other HL questionnaires, showing an association between the nine domains of the tool and health outcomes is in its infancy although early data has shown some HL optimisation. Further work is required in these areas.

The other significant development in HL measurement has been the previously mentioned European HL Survey Questionnaire (HLS-EU-Q) (Sørensen et al., 2012; Sørensen et al., 2013) (See the later section, ‘An evolution of HL’). This multi-dimensional tool is also based on a broad conceptualisation of HL:

HL is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments
and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course. (Sørensen et al., 2012, p. 13)

The broad conceptual framework is comprised of a twelve-cell matrix positing the key processes of accessing, understanding, appraising and applying health-related information within three domains:

1. The domain of *health care*, where HL refers to the ability to access information on medical or clinical issues, to understand medical information, to interpret and evaluate medical information, and to make informed decisions on medical issues and comply with medical advice.

2. The domain of *disease prevention*, where HL involves the ability to access information on risk factors for health, to understand information on risk factors and to derive meaning, to interpret and to evaluate information about risk factors, and to make informed decisions to protecting against risk factors for health.

3. The domain of *health promotion*, where HL refers to the ability to regularly update oneself on determinants of health in the social and physical environment and derive meaning, to interpret and to evaluate information on determinants of health in the social and physical environment, and the ability to make informed decisions on health determinants in the social and physical environment and also engage in joint action.

The HLS-EU-Q also addresses many of the identified limitations of existing tools by the multi-dimensional content that distinguishes HL from communication. It also treats HL as a ‘latent construct’ and follows a principle of compatibility, permitting comparisons in different populations and encompassing both public health and clinical use. The tool has a four-point Likert scale differentiated response with an “I don’t know” category option. Feasibility of the tool has been enhanced by a relatively short administration time (average of twenty to thirty minutes).

**Generating health literacies**

The field of HL is now entering the ‘second wave’ and ‘third generation’ in its evolution. The ‘first generation’ defined HL as a set of ‘risks’ and patients as passive recipients of expert interventions (Chinn, 2011) with tools and mechanisms to educate and train patients to acquire health knowledge to return to health (de Leeuw, 2012). The ‘second wave’ of HL research was influenced by multiple literacies (reading and writing, speaking, e-literacy, political literacy)
with links to individual autonomy, choice and empowerment (Chinn, 2011). The ‘third generation’ of HL (de Leeuw, 2012) challenges researchers to bring together pedagogical theories and multiple literacies with empowerment and broader determinants of health (Sørensen et al., 2012). This paradigm shift is aligned with the democratisation of the health framework which encompasses the values of universalism, equity and solidarity (Spiers, 2012) and that centralises a literate health system which generates equitable health solutions (de Leeuw, 2012) that are responsive to the HL needs of consumer (Beauchamp et al., 2015).

**Conclusion**

Finally, despite the significant advances in the field of HL, an area that remains under-developed is in understanding the HL needs of migrant groups. The vast body of health literature research to date has been conducted in developed countries and has focused on the needs of mainstream populations. This omission has resulted in a research gap in understanding of migrants’ HL strengths and limitations which is therefore the focus of the following study.
Chapter 2: Migrant Health

Introduction

Despite over a half of the Australian population being either a first or second-generation migrant there has been little research focus on the health, HL or health system engagement patterns of this group. This chapter provides an overview of migration trends in Australia, Australian migration policy and migrant health policy. Also, the political environment and public discourse on migration is examined to provide an understanding of the context and settings which migrants are required to negotiate upon entry to Australia. In addition, the evidence on pre- and post-migration health and the robustness of research into the health of Australian migrants is closely examined.

Who is a migrant?

There is no universally accepted definition of the term migrant (IOM, 2015). The term is usually understood to refer to individuals who move from one country to another country or region to better their material or social conditions and to improve the economic prospects for themselves or their families (IOM, 2011). However, migration has become increasingly complex and the term has broadened to involve subgroups of migrants which do not fit the definition of ‘economic migrants’. The term ‘migrant’ is used to describe persons who live outside of their country of birth or are internally displaced and may be: permanent or temporary, in regular or irregular situations, asylum seekers, victims of trafficking, refugees, displaced persons, returnees or skilled migrants (IOM, 2015). For ease of reference, the term ‘migrant’ in this thesis will be used as a proxy for all persons living in a country in which they were not born.

Migration trends in Australia

There are more migrants, refugees and displaced persons in the world now than at any time in human history with an estimated one billion international and internal migrants (IOM, 2015). In 2015: the number of international migrants worldwide reached 244 million, an increase of 71 million, or 41 per cent, compared to the year 2000. The countries hosting the largest numbers of international migrants are; Northern America, followed by Germany, Russia and Saudi Arabia (Hewitt et al., 2016). Australia’s migrant population of 6.6 million is (ABS, 2015b) relatively small compared to other receiving countries, however, Australia has one of the highest proportions of migrants relative to its overall population size, making up almost one third of the total population (UNHCR, 2015). In 2014: 28% (ABS, 2015b) of the Australian population was
born overseas with this figure projected to rise to 32% in 2050 (Cully, 2012). In Australia, migration trends over the past two decades have seen a reduction in persons born in the United Kingdom while those born in New Zealand, China and India have increased substantially (Hugo, 2004; Migration Australia, 2013-14, 2015).

**Australian migration policy and discourse**

The following section examines the historical context and political environment into which migrants enter Australia that has been marked by policies of exclusion and a public discourse ranging from benign acceptance to the ascribing of negative stereotyping of particular migration groups.

Australia is and has been a land of migrants since the arrival of European settlers in 1788 (Henrich, 2013) making cultural diversity a defining characteristic of the Australian population (Megalogenis, 2015). Australian migration policy has changed dramatically in the past 150 years from its inception that was based on theories of racial superiority and aimed at the exclusion of non-whites and non-engagement with regional countries (Jupp, 1995). Australia insulated itself from its geographical region by adopting ‘The Restrictive Immigration policy’, under the Commonwealth Immigration Restriction Act of 1901 (Jupp, 1995), commonly referred to as the ‘White Australia Policy’. Although the exclusion of non-whites was never explicitly written into law, the Act permitted absolute discretion to prohibit undesirable immigrants without specifying the basis of such undesirability. The Act used a dictation test as a mechanism to enforce the exclusion of non-whites (Jupp, 1995). Prime Minister John Howard introduced a similar concept known as the ‘Citizenship Test’ in 2007 which was found to exclude particular groups such as humanitarian visa holders (Ryan, 2015).

In response to the post-Second World War refugee crisis and to address labour shortages in Australia, large scale migration was introduced under the White Australia Policy which privileged entry of European migrants. The scale of this migration was unprecedented in Australian history and the thousands of migrants entering Australia from Europe were generally viewed with fear and suspicion (Damousi, 2013). Migrants were officially and commonly referred to as ‘new Australians’ (Garrett et al., 2010), a term that implied a denial of their past (Damousi, 2013) or that they were a *tabula rasa*—a blank slate—or someone without culture. The policy carried expectations of assimilation through which migrants would seamlessly merge into Australian life (Damousi, 2013). Assimilation, which is conceptualised as the adoption of the cultural practices of the host country (Berry, 2003), required the suppression of cultural and political practices and identities (Henrich, 2013). Although cultural expressions were celebrated.
at cultural events, they were generally viewed as nostalgic and of little relevance to Australia (Henrich, 2013).

In 1951 the United Nations Convention Relating to the Status of Refugees (UN) was created largely in response to the mass migration of Jewish refugees during and after World War II. Australia became a signatory and ratified the convention in 1954 and amended the subsequent 1967 protocol in 1973.

A growing concern that the White Australia Policy was restricting economic prosperity led to its dismantling in the mid-1970s, paving the way for non-European migration, especially from Asia (Jupp, 1995; Rao et al., 2006). In the 1970s, a policy of multiculturalism was introduced which involved a set of programs and services designed to improve the social and economic welfare of Australians (Henrich, 2013). ‘Australian multiculturalism’ refers to policies that are responsive to the rights, obligations and needs of a culturally diverse population and which promote social harmony among the different cultural groups (DIMA, 2002).

A succession of different terms were introduced such as ‘ethnic’ or ‘new migrant’ to NESB (non-English-speaking background) people (Garrett et al., 2010) and finally to the current term of CaLD (culturally and linguistically diverse). These terms are reflective of the way in which migrants were perceived and often served to separate migrant population from the Australian general population. Underpinning migrant policy were expectations of acculturation.

Acculturation is a multi-dimensional “…process of cultural change and adaptation that occurs when individuals from different cultures come into contact” (Gibson 200, p.19). Acculturation is often portrayed as a unidirectional process from migrant to non-migrant, which denies the heterogeneous nature of any adaptive process (Berry, 2003). One explanatory model of acculturation (Berry, 2003) conveys the complexity of this process by outlining four acculturation strategies employed by migrants. The first is assimilation, which is the complete acquisition of the dominant culture and lack of interest in maintaining the immigrant’s own culture. The second is integration, which refers to embracing, valuing and integrating both the dominant and the ethnic culture. The third is separation, which refers to the maintenance of the immigrant’s ethnic culture and rejecting or avoiding contact with the dominant culture. The fourth strategy is marginalisation, which refers to the disconnection or exclusion of immigrants, whether voluntary or not, from their ethnic culture as well as the dominant culture. Patterns of acculturation influence immigrants’ health and health practices (Jadalla et al., 2015) and may explain differences in health outcomes between migrants and migrant groups. The health impacts
of acculturation will be examined in more detail in the following section, ‘The migrant health decline’.

In the late 1990s, the concept of multiculturalism began to be challenged in the political arena (Koleth, 2010). The then Prime Minister, John Howard, and another politician, Pauline Hanson, called for the abolition of multiculturalism and for a radical review of immigration policy (Hamish, 2012; Hawthorne; Szego, 2005). The political discourse during this time challenged notions of multiculturalism and immigration levels, and fuelled contestation over what it meant to be Australian (Garrett et al., 2010; Koleth, 2010). This discourse continues in current migration policy which defines non-immigrants as legitimate and immigrants as different, and therefore marginal and potentially less legitimate (Garrett et al., 2010).

The current discourse on asylum seekers is an example of the use of terminology to marginalise migrant populations. ‘Asylum seekers’, which is a term that is not recognised under the Refugee Convention (1951), are referred to by the Federal Government as ‘queue jumpers’ who support a dangerous trade in people smuggling and threaten Australian national security (Clyne, 2005). This discourse has served to support a policy of exclusion which employs methods such as offshore processing which have been found to contravene the 1948 United Nations Convention on Human Rights (Kim et al., 2013). Australia’s policy of offshore detention has been criticised by many commentators including the UN Human Rights Committee (OHCHR) for violating the prohibition on arbitrary detention under Article 9 of the International Covenant on Civil and Political Rights (ICCPR) (1966) and has called on Australia to abide by international law (Millar, 2015).

The changing discourse on migrants has served to define this population as distinct and different to non-migrants. This difference has been ascribed characteristics such as having ‘culture’. Migrant groups are often viewed as having ‘culture’ with non-migrant groups as being culturally neutral (Boutin-Foster et al., 2008). The concept of culture is complex, multifaceted and difficult to define. One definition of culture describes it as “…the dynamic system of beliefs, values, that are passed from one generation to the next of particular population groups” (Kagawa-Singer, 2000, p. 894). The ‘culture’ ascribed to migrant groups is often viewed as problematic and as a barrier to assimilation (Kumas-Tan et al., 2007).

Whilst there is strong evidence of the benefits of migration to the Australian economic, social and civil sectors (Cully, 2012; Hugo, 2004), migration continues to be contested in the political and social spheres. Australians are generally tolerant of migration (Barber et al., 2009) however, research shows that 10% of the population believe that some races are naturally inferior or
superior, and that persons from different cultural backgrounds should live separately (Kevin Dunn)

**Migrant health policy**

With over half of the Australian population either first or second generation migrants (ABS, 2015a) the health of this population group has important economic (Cully, 2012; De Freitas et al., 2014; Productivity Commission, 2010), political (IOM, 2015; Rechel et al., 2013), sociocultural and health security implications (Faustine Kyungu Nkulu et al., 2016) for the entire population. Australia is a member state of the World Health Organisation and therefore obliged to follow the directive of the 61st World Health Assembly (WHA) Resolution 61.17 on the Health of Migrants (WHO, 2008) and the action framework developed at the subsequent global consultation (WHO, 2010).

To meet this obligation, Australia, like other developed countries, has focused on improving the quality of, and access to, health care provisions for their multicultural populations. However, whilst population diversity is a feature of the health policies of developed countries (DoH, 2014) the systematic translation and implementation of policy statements is slow, often inadequately resourced and lacking effective planning and evaluation (Gil-González et al., 2015; Minas et al., 2013; Vázquez et al., 2013; Ziguras, 1997). Empirical data indicates that migrants are healthier than native populations on arrival (Biddle et al., 2007; Kennedy et al., 2006) but structural barriers within the receiving countries may increase their risk of adverse health outcomes (Agudelo-Suárez et al., 2012; Gil-González et al., 2015; Irving & Mosca, 2010; Larson, 2003). Across developed countries, migrants are systematically discriminated against, ignored or the data from distinct groups are collapsed into a single typology in homogenous national health policies (Irving & Mosca, 2010; McDonald & Kennedy, 2004; Powell, 2008). They are also a missing population in national health data collection and research (De Freitas et al., 2014; Garrett et al., 2010; Minas et al., 2013), making evidence-informed policy difficult (Garrett et al., 2010). Lack of inclusive and effective policy frameworks for migrant populations may lead to inequities, which are commonly experienced by migrant groups around the world (Gil-González et al., 2015; Irving & Mosca, 2010; Lorant & Bhopal, 2010). Countries like Australia, with a taxation funded, universal health care system, are better equipped to incorporate migrant health policies (Mladovsky et al., 2012); however, a universal health policy only represents an entitlement to services (Baum et al., 2009) and is not a guarantee of universal access (Gil-González et al., 2015). A secondary level of policies is also needed to operationalise entitlement and ensure sensitivity of the health-services needs of migrant groups (Mladovsky et al., 2012).
Inability to access services in a timely and effective manner can lead to increased disadvantage and disengagement for migrants and has flow-on costs to the health system, public housing, criminal justice system and other government services (Victorian Auditor-General’s Report, 2014). There is limited evidence that this policy has been effectively enacted by the Australian health system to ensure access for migrant populations and some evidence (2009; Victorian Auditor-General’s Report, 2014) that it has failed at this point of implementation.

A recent report (Victorian Auditor-General’s Report, 2014) within the state of Victoria by the Victorian Auditor-General on the effectiveness of Victorian Government departments to deliver multicultural services found systemic gaps between policy and implementation. The Victorian Government has a whole-of-government policy approach to delivering multicultural services (VMC, 2008) however, the audit found that whilst all service delivery departments could demonstrate an understanding of multicultural principles, only one (Department of Health) could demonstrate, at a strategic level, that it understands the complex and multiple needs of migrants, refugees and asylum seekers.

Furthermore, the report found substantial weaknesses across departments in the areas of understanding effective access, implementing strategies and programs, monitoring and reporting services and coordination of service delivery. The report stated that there are limited mechanisms to more broadly assure the Federal Government that the departments’ efforts to provide appropriate services to the people who most need them are effective. The report identified a lack of cultural competency that may lead to the omission, intentional or unconscious, of migrants in service delivery, resulting in discrimination in practice, and thus disadvantaging individuals or groups based on particular characteristics (Sundararajan et al., 2007).

In summary, whilst Australian health policy is often inclusive of the needs of migrant groups, policy implementation commonly omits migrant groups, thus creating structural barriers that result in discrimination in practice.

**Migrant health research**

Migrant health and multicultural research are important and underdeveloped areas of research. Critics assert that migrant health and cross-cultural research in Australia is neglected (Garrett et al., 2010), limited (FECCA, 2015; Garrett et al., 2010; Rao et al., 2006), fragmented (Minas et al., 2013), small scale (Minas et al., 2013) and uneven (Garrett et al., 2010). Validity problems such as the following have been identified by a number of authors: narrow methodological approaches (Worthington et al., 2007), over-reliance on non-representative convenience
sampling (Worthington et al., 2007), focus on particular immigrant groups whilst omitting new and emerging migrant communities (FECCA, 2015; Garrett et al., 2010), inadequate focus on the compounding disadvantage or intersectionality (FECCA, 2015), and epidemiological errors (Bhopal, 1997). As well, many studies are of poor quality (Gil-González et al., 2015).

Sundararajan et al. (Sundararajan et al., 2007) asserts that the importance of ethnicity in population based research is minimised and often treated as “…an extraneous variable to be statistically controlled at the time of analysis” (Sundararajan et al. 2007 p. 22). Kuma-Tan, Z., et al. (Kumas-Tan et al., 2007) expresses the view that culture is seen as peripheral to health research with ethnicity and race conceptualised as attributes possessed by the ‘ethnic’ or ‘other’ (Kuma-Tan, Z., et al. 2007 p. 551).

An important barrier to robust research into migrant health is the lack of ethnicity-specific health data. Health policy does not require Australian health organisations to collect data on specific country of origin. The Australian Institute for Health and Welfare has adopted the approach of reporting immigrant health in four broad geographical categories that include: (1) UK and Ireland, (2) Europe, (3) Asia, and (4) an ‘other’ category which includes Africa, the Americas, the Middle East, New Zealand and the Pacific Islands (AIHW, 2014b). Use of these broad categories results in significant gaps in epidemiological data and creates a barrier to “…meaningful, theoretical, cultural or ethnic discussions” (Sundararajan et al., 2007, p. 23).

Two of the largest data sets encompassing health indicators relating to migrant health in Australia, the Longitudinal Survey of Immigrants to Australia (LSIA) (Cobb-Clark, 2001) and the Household, Income and the Labour Dynamics in Australia (HILDA) survey (Jatrana et al., 2014), use self-rated measures of well-being which may be subject to reporter bias. Policy and processes related to data collection, analysis and reporting in the area of migrant health reduce the quality of available evidence (Minas et al., 2013).

Further evidence of the lack of migrant health research in Australia is provided by a systematic literature review (Garrett et al., 2010). The review examined three major Australian health care journals looking at the level, content, coverage and overall quality of research on multicultural health over a twelve-year period (1996–2008). Results of the review indicated that multicultural research represented only 2.2% of the published papers in the major health care journals. The review also found that the amount and range of multicultural health research and evidence required for equity in policy, services, interventions and implementation was limited and uneven, and mostly focused on particular immigrant groups while other communities and health issues remained unrepresented.
There is also evidence that migrants are a missing population in the field of public health research worldwide (Castañeda et al., 2013). A scoping review (Benkhalti Jandu et al., 2015) that assessed the extent to which migrants were included in health impact assessments (HIAs) and evaluations worldwide, found that of the 117 HIAs only 14% mentioned migrants, 5% analysed migrants and only 2% included them in their recommendations. It found that despite the majority of HIAs including migrants in baseline conditions and impact analysis steps, migrants were seldom included in the recommendations, frameworks or tools. The review also concluded that migrants were represented by organisations and seldom included members of the migrant community themselves. The main barriers to including migrants in the HIA impact analysis were cited as the lack of available data on migrants and the significant additional resources required to gather and analyse data.

In addition to the exclusion of migrant populations from mainstream research, much of the research including migrant populations is not conducted in a culturally competent manner (Kumas-Tan et al., 2007). A systematic review (Riggs et al., 2014) of international studies on oral health and migrant children found that of the 2059 articles analysed, all rated very poorly in terms of cultural competence when measured against the Gibbs cultural competency framework (Gibbs L, 2007). This was also identified in research undertaken by the National Health and Medical Research Council (NHMRC) which led to the development of a guide for researchers titled: Cultural Competency in Health: A guide for policy, partnerships and participation (Cultural competency in health: A guide for policy, partnerships and participation, 2005). However, despite the NHMRC’s recognition that increasing the cultural competency of the health sector and its partners was compelling and of national importance, there has been no subsequent evaluation of the implementation of the policy document. To the author’s knowledge, there is no systematic monitoring of the inclusion of overseas-born participants in NHMRC funded research or the level of cultural competence in the studies which do include overseas-born participants. This example is consistent with national public health approaches to migrant health where policy documents encompass migrant health but, at a systems level, policy intent is not operationalised.

In summary, there is evidence that migrants are a missing population in the field of public health research worldwide (Castañeda et al., 2013) with migrant health research sparse, uneven and small in scale. Representation of migrants is limited, with migrant groups often excluded from population health research. There is also evidence that research conducted with migrant groups is not always conducted in a culturally competent way. The lack of robust health research on migrant groups contributes to a limited understanding of the health needs of this cohort.
However, despite these limitations, the following two sections examine the available evidence on the pre- and post-migration health profiles of migrants.

**Healthy immigrant effect**

Many scholars have found that immigrants have better health than native-born populations, which has been termed the healthy immigrant effect (HIE). This finding has been attributed to pre-migration screening (Biddle et al., 2007; Kennedy et al., 2006; McDonald & Kennedy, 2004), self-selection, (Arenas et al., 2015; Biddle et al., 2007), salmon bias¹ (Abraído-Lanza et al., 1999; Lu & Qin, 2014) and environmental and lifestyle influences in their country of origin (Biddle et al., 2007). In some migrant groups, the continuation of the HIE related health advantage can be observed in lower mortality rates than non-migrant populations (Strong et al., 1998; Vandenheede et al., 2015b). For example, compared to Australian-born residents, mortality rates were 36% lower for Asian-born Australian residents, 15% lower for males born in northwest, southern and Eastern Europe and 24% lower for females born in these countries (AIHW, 2014b). Overseas-born Australian residents also had lower rates of potentially avoidable deaths than their Australian-born counterparts (AIHW, 2014b; Gray et al., 2007). The lower mortality rates in some migrant groups persists despite social contextual factors such as low socioeconomic status and low levels of education. The Latino community in the US serves as an example of this phenomenon (Kimbro et al., 2008). A large body of international evidence supports the finding that migrants are in good health on arrival to the host country and in some migrant groups this health advantage persists, showing lower mortality rates compared to the non-migrant population (Biddle et al., 2007; Kennedy et al., 2015; Kennedy et al., 2006).

One of the largest and most influential studies (Kennedy et al., 2006) on the health of immigrants examined data from four receiving countries (US, Canada, UK and Australia) using a set of consistently defined measures of health. The analysis found strong support for the HIE across all four destination countries. The study also measured the health of immigrants compared to the health of those from their own country who did not migrate and found that selectivity played an important role in the observed HIE. A second Australian study (Biddle et al., 2007) that compared the health of Australian immigrants to the health of the Australian-born population using self-reports of chronic diseases from three national health surveys found that the health of

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¹ ‘Salmon bias’ is the tendency of terminally ill immigrants to return to their country of origin to die thus rendering them ‘statistically immortal’ (Anikeeva et al., 2015).
Australian immigrants was better than the Australian-born population. This study also found that the health of migrants deteriorated with time spent in Australia.

Further evidence supporting the HIE is found in a number of Australian and international studies. One Australian study (Strong et al., 1998) analysed multiple data sets such as mortality and morbidity data, cause of death and hospitalisation information, and self-reported data from the Australian Bureau of Statistics (ABS) 1995 National Health Survey that included questions on risk factors such as diabetes, body weight, hypertension, high serum cholesterol, smoking and alcohol consumption, as well as health-related actions such as walking for exercise, frequency of Pap smear tests and use of sun protection measures.

Study results confirmed the presence of an HIE and found that overseas-born persons were generally healthier than their Australian-born contemporaries. Overseas-born individuals were placed into one of four groups according to place of birth: United Kingdom and Ireland, Other Europe, Asia and Other. All overseas-born population groups reported lower mortality and hospitalisation rates for all causes of disease combined compared with the Australian-born population. The Asian-born population had the lowest mortality rates with 38% less mortality for males and 30% less for females. Hospitalisation rates were also lower for the Asian-born, with males and females having 46% and 37% respectively having fewer hospitalisations compared to the Australian-born population. However, diabetes mortality was greater for males and females who were born in Other Europe, Asia and Other regions. Both males and females from the United Kingdom and Ireland showed increased mortality from lung cancer. Mortality and hospitalisation for cervical cancer was also significantly higher for Asian-born and other females. The mortality and hospitalisation data largely matched self-reported prevalence of health-related risk factors. For example, self-reported diabetes prevalence was higher for the Other Europe, Asia and Other groups. Asian and Other females reported significantly less participation in regular Pap smear tests, reflecting their increased mortality and hospitalisation for cervical cancer.

A review (Anikeeva et al., 2010) of migrant mortality and cancer mortality rates in Australia found that migrants generally have better overall mortality and cancer mortality outcomes compared to the Australian-born population, particularly for colorectal cancer and melanoma, with migrants from southern Europe, south eastern Europe, Chinese Asia and southern Asia having the greatest advantage. However, the study also found migrants were over-represented in diabetes, suicide and mental health. One of the weaknesses of this study is the use of mortality data as an outcome measure. Mortality data records the final cause of death but may obscure the
diseases or conditions leading to death. For example, chronic diseases such as diabetes are often recorded as renal or cardiovascular failure, resulting in an underestimation of the prevalence of diabetes. Also, the use of crude geographic birth origin data may obscure differences in birth groups. This study combined all age groups and both sexes in the analysis which may have skewed results as children and adults display different mortality patterns. Further limitations of this study were the lack of availability of related data such as duration of residence, age at migration and socioeconomic factors, which may have provided more information on mortality-influencing factors. Finally, the confounding effect of the ‘salmon bias’ was unable to be measured.

Therefore, whilst there is strong evidence to support the HIE the determinants remain unclear. The findings of a recent US study (Hamilton, 2015) support self-selection as a key determinant of HIE. This study which compared the health of US-born, recent migrants to the US and US-born internal migrants found the HIE was less pronounced compared to US-born migrants. These findings suggest that the health of persons who migrate is better than those who do not, and has important implications for research which uses immigrant populations as representative of the populations in their country of origin. A strength of this study was the large data set examined (30,881 US-born migrants, 1,276,682 US-born non-movers i.e., individuals who currently reside in their state of birth, and 4184 immigrants who migrated in the last year). However, an important limitation was the short migration time, which does not allow examination of health changes over time. In addition, the use of self-reported health may be subject to reporter bias. This is one of the few studies which have tested the self-selection theory when comparing foreign and native migrants. If these results were replicated in similar studies in different countries, it suggests that self-selection is an important determinant of the HIE.

In summary, there is a robust body of evidence that establishes migrant populations are healthy on arrival in the host country. Determinants include a range of pre-migration factors such as screening, self-selection, salmon bias and environmental influences in the country of origin. However, the reasons for the persistence of the migrant health advantage post-migration is the subject of considerable debate and is examined in the next section on migrant health decline (MHD).

Migrant health decline

The observation that migrant health deteriorates with additional years in the new country is known as the ‘migrant health decline’ (MHD). A large body of evidence establishes the MHD as a post-migration phenomenon rather than the result of remigration effects (Anikeeva et al., 2010;
Jatrana et al., 2014; McDonald & Kennedy, 2004). Evidence on the health of migrants indicates a trajectory of decline, from as early as two years post-migration (Kim et al., 2013) with some studies showing a convergence to the mean of the host population from ten to twenty years and other studies showing a level of deterioration to below the mean. Biologically based theoretical explanations of the migrant health decline include the health transition theory, genetic variability theory, the theory of accumulated exposures and life course perspectives (Spallek et al., 2011). Theories encompassing social determinants include acculturation theory (‘negative migration’ (Jasso et al., 2004)) socioeconomic theory, ethnic minority status, cultural enclave dwelling, HL, low utilisation of health care services, discrimination (stemming from xenophobia, racism and ‘otherness’) (Grove & Zwi, 2006; Williams, 2009), poor working conditions and sorting of immigrants into more dangerous and strenuous occupations (Orrenius & Zavodny, 2009).

Australian epidemiological statistics confirm the MHD with recent data showing a significant reduction in self-reported health ten years or more post-migration. The General Social Survey (GSS) (ABS, 2014), an Australian survey which captures self-reported measures of health, shows that recently arrived migrants report higher levels of good to very good health (95%) compared to the Australian-born population (84%), however, this trend is reversed with levels falling below the Australian-born population among migrants living in Australia after ten years (80.4%). There is a significant difference in the rate of the health decline between English-speaking migrants (82.4%) and migrants who speak another language (77.8%). In addition, there is a four-fold increase in migrant self-reports of fair/poor health from recently arrived (5.5%) migrants living in Australia longer than ten years (20%) with a 4% difference between English-speaking migrants and migrants speaking other languages. The migrant health decline does not appear to be mitigated by the accrual of increased social capital developed with increased length of residence in Australia. This data confirms the MHD is associated with length of time in Australia and is not mitigated by higher levels of social capital.

A number of studies have provided epidemiological evidence supporting the existence of the MHD (Biddle et al., 2007; Chiswick et al., 2008; Jatrana et al., 2014; Kennedy et al., 2015) with results showing poorer health outcomes when compared to their European counterparts as early as two years’ post-migration, with an uneven distribution of the decline across sub-groups. Vulnerability was impacted by gender, age, English language proficiency, education, living in an ethnic enclave and country of origin (Kim et al., 2013). The main strength of the following studies is their use of statistical analysis and large sample sizes, however, many relied on self-reported data which may be subject to reporter bias.
The first Canadian study (Kim et al., 2013) examined data derived from the Longitudinal Survey of Immigrants to Canada sampling 3309 men and 3351 women aged between 20 and 59 years. Results showed that on arrival, only 3.5% of new immigrants rated their general health as poor with steady increases in poor health during the following four years, especially among ethnic minorities such as west Asian men and among south Asian and Chinese women compared to their European counterparts. The authors concluded that immigrants are extremely healthy on arrival, but the health advantage dissipates rapidly during the initial years of settlement in Canada, and women and minority ethnic groups are more vulnerable to social changes and post-migration settlement. A limitation of this study was the use of self-rated health indicators with possible reporter bias. However, its main strength was the large sample size and use of statistical analysis providing strong evidence that a decline in self-rated health and ethnic disparities start as early as the first two years of residence in the host country.

An Australian study (Chiswick et al., 2008) that examined three waves of migration data from the Longitudinal Survey of Immigrants to Australia found a deterioration in health from three to three-and-a-half years post-migration. The study also found that higher reported health status is generally associated with a younger age, higher levels of education, being male, being proficient in English and living outside an immigrant ethnic enclave. Immigrant health was poorest for refugees and best for economically independent migrants, and declined with duration in the residence. However, the reported health of all visa groups deteriorated with duration of residence in Australia. As with the previous study, a limitation of this study was the use of self-reported data with the possibility of reporter bias. In general, the findings of this study correlate with other similar studies showing an association between health status, age, education, gender (Kim et al., 2013) and English proficiency (Beauchamp et al., 2015). However, the finding that living outside an immigrant ethnic enclave is associated with better health is not a common finding and may provide insight into the influence of social and cultural influences on health outcomes.

The authors draw on previous research to form the hypothesis that access to health care may be influenced by enclave, concentration or neighbourhood effects. They hypothesise that living in an ethnic enclave area is both beneficial to health (providing critical information on areas such as employment, health and other markets) and detrimental to migrants’ health (less access to the best available health care). The authors provide no further explanation of how immigrant enclaves reduce access to specialist care. However, a second Australian study (Weber et al., 2014) examining screening participation in migrant populations found a correlation between living in migrant enclaves and reduced participation in prevention behaviours. The study found overall lower participation rates of cancer screening in migrant groups and postulated that
immigrants in regional areas may have higher rates of participation than metropolitan based groups as they are less likely to be part of the larger, more socially contained cultural enclave. A third study (Colucci et al., 2015) found that a significant barrier for young persons from refugee backgrounds accessing mental health services was cultural perceptions that mental health problems were managed within the family and cultural group. The findings of these studies appear to position close living proximity to cultural groups as having negative impacts on health. This is contrary to previous research that asserts social capital within migrant groups has a positive effect on health (Anikeeva et al., 2010). Further empirical research is required to delineate and measure the health impacts of ethnic enclave dwelling.

Another significant Australian study (Biddle et al., 2007) confirmed the MHD through health comparisons between Australian immigrants and the Australian-born population by examining the impact of time since migration. Health was measured using self-reports of chronic diseases from three national health surveys conducted by the Australian Bureau of Statistics (ABS) in 1989/90, 1995 and 2001. The study used a sample of 66,641 persons aged 20–64 years. Of the sample, 18,328 persons were immigrants to Australia. The study found that the health of Australian immigrants was better than the Australian-born population, but the longer immigrants spent in Australia, the closer their health approximated to that of the Australian-born population. The study also demonstrated that the probability of reporting a chronic condition increased rapidly in the first 10-20 years in Australia, and then tended to plateau at a level below that of the Australian-born population.

A more recent study (Jatrana et al., 2014) of the chronic disease profiles of Australian migrants found similar results. Using data from waves 3, 7 and 9 of the Household, Income and Labour Dynamics in Australia (HILDA) survey. The study investigated differences in the reporting of any chronic condition including cancer, cardiovascular disease (CVD), arthritis, diabetes and respiratory disease, and in the total number of chronic conditions between foreign-born (FB) from English-speaking (ES) and non-English-speaking (NES) countries and native-born (NB) Australians and by duration of residence. Results showed a significant difference by birth origin in the reporting of chronic conditions, with immigrants from both ES and NES countries less likely to report a chronic condition and with fewer chronic conditions compared with the NB. Immigrants from both ES and NES countries living in Australia for less than 20 years were significantly less likely to report a chronic condition compared with the NB. However, the health of ES and NES groups converged to that of the NB population in terms of reporting a chronic condition after 20 years of stay in Australia.
The findings of the above-mentioned two studies are consistent with the findings of a study previously referred to in the HIE section (Biddle et al., 2007) which found that, whilst the HIE was supported, the longer immigrants spend in Australia, the closer their health approximated that of the Australian-born population. The authors postulated that the post-migration health deterioration indicates that the health selection and HIE effects are transitory and follow a simple health model of a reversion to the population mean. However, this explanation does not fit with the authors’ other findings of differences between migrant groups. The differences identified in health profiles between immigrants from English-speaking and non-English-speaking countries suggest environmental and cultural health effects. Also, their finding that most immigrant groups converge to levels of health below the native-born levels indicates that there are some permanent factors at work beyond those explained by the usual set of socioeconomic factors.

**Determinants of the migrant health decline**

Whilst MHD is well established in the literature, the determinants are not as well understood. One theory (Newbold & Danforth, 2003) of the MHD hypothesis is that determinants can be grouped as follows: (1) health disparities are attributable to variable genetic predispositions of members of different population groups; (2) health disparities are attributable to the socioeconomic context and culturally patterned behaviours and beliefs of the group being studied; and (3) health disparities are attributable to the behaviour of others towards the group being studied. The largest body of evidence supports the second hypothesis that health disparities are attributable to socioeconomic context and culturally patterned behaviours and beliefs (Newbold & Danforth, 2003). These studies explore the relationship between the health of migrant groups over time and acculturation factors such as the adoption of the lifestyle habits of the host country, lower levels of social capital, reduced physical activity due to an altered physical environment and acculturation stress (Biddle et al., 2007; Kim et al., 2013). Socioeconomic factors are also considered to contribute to low income and low levels of education (Braveman et al., 2010; Rechel, 2011).

A second US study (Braveman et al., 2010) examining the socioeconomic status and health of US migrants found a strong gradient pattern in a variety of health indicators suggesting a dose–response relationship for many health indicators, with factors related to social and economic advantage. The study looked at national data on five child health indicators (infant mortality, health status, activity limitation, healthy eating, sedentary adolescents) and six adult health indicators (life expectancy, health status, activity limitation, heart disease, diabetes, obesity) with income or education categories within racial/ethnic groups. The study found that health is
strongly patterned along both socioeconomic and racial/ethnic lines, suggesting links between hierarchies of social advantage and health. It must be noted that this study is observational and does not establish a causal role for income or educational attainment. However, it supports similar findings that suggest the likely causal roles in many health conditions are factors that are closely linked with income and education. Finally, although the study did find socioeconomic gradient patterns to be consistent across racial groups, one notable exception was US Hispanics for which there was less consistency.

The US Hispanic population appears to refute the growing body of evidence showing a strong relationship between health and socioeconomic status. The ‘Latino epidemiologic paradox’ is an observed phenomenon in which the North American Latino population, who are overrepresented almost every indicator of disadvantage, consistently shows a five to seven year longer life expectancy compared to non-Hispanic whites (Abraído-Lanza et al., 2005). Defying the social gradient of health (Marmot & Allen, 2015) the Latino population has reduced mortality risk compared to non-Hispanic whites for the top three causes of death: 35% lower mortality for heart disease, 43% lower for cancers and 25% lower for stroke. This phenomenon has also been observed in Asian cultures (AIHW, 2014b) and is considered to be related to protective factors unique to the Latino and Asian cultures such as dietary habits, social capital, and health beliefs and practices, however, further research in the area is needed.

The authors of another study (Newbold & Danforth, 2003) assert that barriers unique to ethnic or cultural group may account for differences in health outcomes. Newbold and Danforth suggest that diverse issues such as gender roles, trust of Western medicine, the preferential use of traditional health care providers, education and income, may also create differentials in health status and service utilisation. They conclude that poorer health in immigrant populations may be a combination of social, political, economic and cultural forces with lower socioeconomic status contributing to the decline in health.

**Explanatory theories of the migrant health decline**

One explanatory theory of the MHD relates to a shift in mortality profiles, particularly for migrants moving from less industrialised to highly industrialised countries (Razum, 2002; Spallek et al., 2011). This theory asserts that migrants pass rapidly through the ‘health transition’, which is a shift in cause-of-death from infectious to chronic diseases. The health of these migrants is impacted by improved health care and a more hygienic environment in host countries. Interaction with the health systems in receiving countries reduces the risk of infection related mortality and child mortality. A more hygienic general environment also reduces
exposure to infectious pathogens, resulting in a shift away from a profile of infectious disease mortality and towards chronic disease related mortality after a substantial lag period. However, some migrant groups may continue to perceive infectious disease as the greater mortality risk with a low level of awareness of their increased vulnerability to chronic disease mortality. This lack of awareness may decrease their sensitivity to knowledge about prevention of chronic disease, and therefore, may increase their vulnerability to chronic disease mortality.

Not all observed health differences seen in migrant populations can be explained by the health transition theory. Conditions with more rapid onset do not fit with the time lag indicated in the health transition theory. One exception is in the Southeast Asian migrant population which shows a rapid increase in risk for cardiovascular disease post-migration. A possible explanation for this is the adipose overflow hypothesis, which asserts that persons coming from an environment of caloric restriction to a setting of unrestricted caloric intake are more genetically susceptible to obesity. The physiological pathway used to explain this difference is related to the way the body deposits adipose tissue (Sniderman et al., 2007).

A second conceptualisation of migrant health takes a life course approach in the theory of accumulated exposures (Spallek et al., 2011). This theory states that migrant health is determined by additional exposures across the lifespan which may occur before, during or after migration. In assessing the level of attribution of the MHD to biological theories, the weight of evidence appears to support non-biological aetiologies such as exposure to environmental health risks and infectious diseases.

Other theories of non-biological contributors to the MHD include health knowledge deficits (Owiti et al., 2015), social isolation, low HL and low English proficiency (Sentell & Braun, 2012). A number of studies point to knowledge deficits in migrant populations as a key contributor to poorer health outcomes. These knowledge gaps have been identified in a number of areas such as disease aetiology (Owiti et al., 2015), biological processes (Greenhalgh et al., 2011; Owiti et al., 2015), risk (Ackermann Rau et al., 2014; Greenhalgh et al., 2011), disease indicators (Al-Amoudi et al., 2015), prevention of chronic diseases (Abdullahi et al., 2009; Moorley et al., 2014), medical treatment (Owiti et al., 2015) and self-management (Grotz et al., 2011; Owiti et al., 2015).

A systematic review found that low levels of health knowledge (Owiti et al., 2015) impacted migrants’ awareness and knowledge of viral hepatitis and uptake of clinical services. The study looked at fifty-one mixed method publications incorporating both small and larger studies and found migrants were more vulnerable due to low levels of awareness and knowledge,
particularly in the area of health seeking behaviours. The specific areas of knowledge deficits were disease aetiology, symptoms, transmission of risk factors, prevention strategies and treatment. The authors also attributed some of the differences in awareness and knowledge to socioeconomic and demographic factors, discrimination in countries of origin and experiences of migration.

Low English proficiency and low functional HL was found to be a contributor to poorer health outcomes in a large scale US study (Sentell & Braun, 2012). The study conducted phone interviews with 48,427 adults from the 2007 California Health Interview Survey (CHIS), including 3715 with low English proficiency (LEP), and found that those with LEP were significantly more likely to report poor health status compared to those with English proficiency: 42.9% and 14.9%, respectively (Sentell & Braun, 2012). However, it is difficult to separate the impact of LEP and low socioeconomic effects such as low levels of formal education and low income. The same study showed an association between LEP and HL. HL in the 2007 CHIS was assessed by two questions: (a) “When you get written information at a doctor’s office, would you say that it is very easy, somewhat easy, somewhat difficult, or very difficult to understand?” and (b) “When you read the instructions on a prescription bottle, would you say that it is very easy, somewhat easy, somewhat difficult, or very difficult to understand?” Results of the study showed that overall, 44.9% with limited English proficiency reported low HL, versus 13.8% of English speakers who reported low HL. The study concluded that individuals with both limited English proficiency and low HL are at higher risk for poor health. However, a central weakness of this study was the narrow conceptualisation of HL used with limited measures of functional HL skills such as accessing and understanding health information. Recent empirical studies of HL have shown HL is a multi-dimensional concept encompassing a wider range of domains outside of literacy (Buchbinder et al., 2011). In addition, persons who are unable to answer these HL questions were excluded; although the actual number excluded was low, this had the potential to skew the study sample.

Mental health in migrant groups

Migrant and refugee persons have increased risk factors for mental health disorders due to pre- and post-migration experiences (Colucci et al., 2014). However, estimations of mental health prevalence and uptake of mental health services in migrant and refugee populations are unreliable. The need for accurate mental health estimates of people of culturally diverse backgrounds is demonstrated by research that shows disparities in access to mental health services (Colucci et al., 2015; Colucci et al., 2014; Ellis et al., 2010; Minas et al., 2013), delays
in treatment seeking (Ellis et al., 2010) and involuntary admissions. Evidence on the mental health needs within migrant and refugee groups is compromised due to inadequate and problematic data collection, analyses and reporting practices (Minas et al., 2013) culturally inappropriate measures (Stolk, 2014), exclusion of migrant groups from mainstream research, poor quality of studies (Minas et al., 2013) and cultural barriers that preclude participation within some groups (Rao et al., 2006).

Available data indicate prevalence of mental health issues in migrant groups varies from lower than (Anikeeva et al., 2010), equal to (Minas et al., 2013) and higher than non-migrant groups (Comino et al., 2001) with older (FECCA, 2015; Rao et al., 2006), females (Kim et al., 2013) and humanitarian migrants showing higher levels of psychological distress (Ellis et al., 2010; Jenkinson, 2016). Uptake of mental health services by migrant groups is lower than the Australian-born population (Minas et al., 2013) however, due to the absence of epidemiological data it is not possible to measure service uptake relative to the prevalence of mental health disorders in this group (Minas et al., 2013) to determine unmet need. Also, some measures of mental health commonly used in primary care settings are not always culturally appropriate (Stolk, 2014) or consistently implemented (Comino et al., 2001) contributing to under or overestimations of the prevalence of mental health issues. Prevalence data may also be underestimated due to barriers within some cultural groups such as low levels of awareness, risk of social exclusion (Goodall et al., 2014), confidentiality (Colucci et al., 2015) and culturally influenced beliefs (Colucci et al., 2015; Ellis et al., 2010). In addition, prevalence studies are often of poor quality, highly variable (Minas et al., 2013), fragmented (Minas et al., 2013), small in scale (Minas et al., 2013), uneven in representation of migrant groups (Minas et al., 2013) and based on weaker levels of evidence. In general, research into the mental health needs in migrant groups is often unreliable due to a paucity of accurate data, culturally inappropriate measures, and poor-quality studies.

Whilst population based data are weak there are some empirical studies which provide small scale data on prevalence of mental health disorders in migrant groups. One Australian cross sectional study (Comino et al., 2001) examined the prevalence of mental health disorders (anxiety and depression) and found higher prevalence in non-Australian-born groups when compared to Australian-born groups. The study of 4753 patients attending general practices used three measures of mental health (GHQ-12, self-report and GP detection of symptoms) and four regional groupings of non-Australian-born patients; other English-speaking countries (ESB), European, Asian (predominantly South-East Asian) and other non-English-speaking (other NESB) migrants were compared with Australian born (AB) patients. The study found a higher
prevalence of anxiety and depression in three of the four groupings compared to the Australian-born population with Asian patients showing a lower mean GHQ-12 score and a lower rate of GP detection but a similar rate of self-reported symptoms. For Asian patients, 24.6% of all cases identified by self-report or by GP detection were identified by both methods, compared with 44% for Australian-born patients. Similar patterns of treatment and referral were observed for detected cases.

The study also found substantial variations in the rates of detection of anxiety and depressive symptoms in patients visiting GPs depending on the screening methods used and the use of broad ethnic background grouping of patients; this may have resulted in an underestimation in some ethnic groups. Compared with Australian-born patients, Asian and other non-English-speaking patients were more likely to desire a longer consultation with their GP to discuss their problems and receive an explanation of medications prescribed. Another significant finding was in the level of satisfaction with care across the groups. Most of the Australian-born patients were satisfied with the care provided, however, the Asian and other non-English-speaking cases were significantly less likely to agree that the advice was helpful compared with Australian-born cases. This finding has important implications for effective models of care for non-Australian-born groups.

The results of the study are strengthened by the triangulation of methods that are inclusive of subjective perspectives of patients and GPs and objective data derived from the mental health assessment measures. Another strength of the study was the large sample size of almost 5000 patients and the inclusion of a comparison Australian-born group. A key limitation of the study was the use of four broad regional groupings that does not provide accurate data on country of origin, limiting epidemiological data and the development of tailored mental health responses. In addition, the cultural appropriateness and variation in the use of screening tools may make data comparison unreliable. Despite these limitations the study results are significant and show higher prevalence of anxiety and depression in three of the four groups compared to the Australian-born population.

The results of the Comino study (Comino et al., 2001) are consistent with two systemic reviews looking at the prevalence of mental health and service usage. The first systematic review (Anikeeva et al., 2010) examined Australian studies between 1980 and 2008 (60 papers) and found that Polish, Greek and former Yugoslavian migrants had high rates of schizophrenia, and Italian and Dutch migrants had high rates of organic psychosis (Anikeeva et al., 2010). It also found lower rates of mental health disorders in Asian groups posing determinants such as
reluctance to access mental health services related to lack of knowledge about available care, communication difficulties and stigma within the Asian community. These factors may also contribute to the higher rates of involuntary admission of Asian patients to care facilities at an advanced stage of the disease when compared to English-speaking families who care for schizophrenic family members. Other Asian groups such as Vietnamese families reported higher rates of mental illness due to social isolation, language barriers, absence of extended family carers, reluctance to seek care from professional organisations and an almost complete reliance on family support. Studies that focused on the mental health status of Iranian, Sudanese, Vietnamese refugees, elderly Vietnamese and female Filipino migrants showed that migrants were generally in poorer mental health compared with their Australian counterparts. Increased psychological distress was associated with socioeconomic factors such as unemployment, low levels of social support, trauma, low English proficiency, isolation and being single. For humanitarian migrants, trauma exposure was the most important predictor of mental health status. A weakness of this study was the use of broad groupings of psychological distress or mental health status that may have masked differences in the prevalence of specific conditions between migrant groups. A further weakness was the small sample size of some migrant groups.

The finding of a second review (Minas et al., 2013) was that both prevalence data and research into the mental health of immigrants and refugees was unreliable. This review also found some evidence of underutilisation of specialist public mental health services. The study examined three data sources; literature on mental health and mental health service usage, the national data collection, and Australian research. The review found Australian research on mental health of immigrant and refugee populations and patterns of mental health service use were highly variable, fragmented, uneven and small-scale. The review found broadly consistent patterns of lower rates of utilisation of specialist public mental health services by immigrants and refugees. However, due to the absence of adequate population epidemiological data the authors were unable to determine if usage patterns were consistent with the prevalence of the mental health conditions in this population. The review also found no data on the quality of service outcomes and found multiple data gaps in national data collection, analysis and reporting. An examination of mental health studies revealed a high rate (9.1%) of exclusion from studies (usually due to low English fluency) and a much higher rate of neglect of the issue of population diversity in study design and reporting. Research into the prevalence of mental health in immigrant and refugee groups is unable to be determined due to poor data-collection practices, poor quality studies, neglect and exclusion of these groups from research with lower levels of uptake of public specialist mental health services.
An additional barrier to understanding the prevalence of mental health disorders in migrant and refugee groups is the cultural appropriateness of commonly used measures. Two screening and outcome tools used within primary care settings are the Kessler 10 (K10) and embedded Kessler 6 (K6) measures. An evidence review (Stolk, 2014) of the validity of these measures for use in CaLD populations was conducted by researchers affiliated with the Victorian Foundation for Survivors of Torture. The authors found evidence that the original K6/K10’s validity for culturally diverse groups was limited, and evidence for the cultural equivalence of translated/adapted K6/K10s in clinical settings was equivocal. In addition, responses to the K6/K10 varied considerably across cultures, as did its predictive validity in primary care, mental health and epidemiological settings, with an absence of research on the K6/K10’s sensitivity to change within culturally diverse groups. The authors concluded that there was a lack of conceptual and linguistic equivalence of translated/adapted K6/K10 arising from reports of changes in item connotation and differential item functioning. In addition, evidence for structural and criterion equivalence was inconsistent, and the majority of studies had compromised on accuracy in case prediction. The authors concluded that there was inconsistent evidence for the K6/K10’s cultural appropriateness in clinical settings and a lack of clinical norms for either majority or culturally diverse groups.

The lack of cultural appropriateness is also reflected at the service level. There is consistent evidence of underutilisation of mental health services by migrant and refugee groups (Colucci et al., 2015; Minas et al., 2013), which may be explained in part by the lack of provision of culturally appropriate services. One study, which reviewed available literature, found there was little information available on barriers and facilitators to mental service delivery for young people from refugee backgrounds. The study undertook an empirical inquiry using data from fifteen focus groups and five key informant interviews with a total of 115 service providers from twelve agencies in Melbourne, Australia, to explore barriers and facilitators to engaging young people from refugee backgrounds with mental health services. Results showed eight key themes: cultural concepts of mental health, illness and treatment; service accessibility; trust; working with interpreters; engaging family and community; the style and approach of mental health providers; advocacy; and continuity of care. Barriers and facilitators to the delivery of mental health services to refugee populations encompass a range of structural, contextual and cultural factors. There is little evidence of the cultural competency of mental health services across all access points (primary, secondary and tertiary levels).

A further evidence gap in the mental health of migrant communities relates to the conceptualisation of mental health in migrant groups. Health beliefs influence health behaviours
and factors such as lower levels of mental health awareness (Colucci et al., 2015), social stigma (Clarkson Freeman et al., 2013), low HL (Sentell & Braun, 2012), lack of trust (Colucci et al., 2015), and alternate or poorer understanding of the aetiology of mental health conditions (FECCA, 2015; Minas et al., 2013) may impact help-seeking behaviours.

Other studies have shown that older migrants have a higher risk of mental health deterioration (Chou, 2007; Rao et al., 2006). An Australian review (FECCA, 2015) into ageing and mental health issues found that older people from culturally and linguistically diverse backgrounds have a higher risk of mental health issues than other Australians. However, there is also evidence of under-use of mental health services by older people from culturally and linguistically diverse backgrounds. A second study (Chou, 2007) examined country of origin and visa types to predict psychological distress over a period of one year, monitoring variables of health, social roles, cohort effect and social support. Authors interviewed a nationwide representative sample of 431 migrants aged fifty and above in 2000–2001 with 359 re-interviewed one year after the baseline assessment using the General Health Questionnaire (GHQ-12) as a measure of psychological distress and a series of questions regarding socio-demographic characteristics. Results found deterioration over a period of one year among older migrants to Australia and country of origin and visa types were found to be significant predictors of future GHQ-12 scores. Other factors that were also significant predictors of GHQ-12 scores at one-year follow-up included; age, gender, living alone, days in Australia, poor self-rated health, the presence of heart disease, diabetes and asthma, being a student or economically inactive, widowhood or divorce and education. Refugee status was also a predictor of future psychological distress in older migrants even when other known correlates of psychological distress were controlled. Of particular interest was the finding that older Asian migrants had higher levels of psychological distress, which is contrary to the findings of previous studies showing lower prevalence of mental health disorders in Asian groups and lower mental health service usage (Anikeeva et al., 2010). The study’s weaknesses include selection bias due to the poor response rate (60%) and the possibility of higher psychological distress in non-responders. Also, the short time frame may not have been long enough for the development of mental health problems; the use of a limited range of variables may have excluded important associations to psychological distress; the lack of measures of known predictors such as acculturation, social support, functional impairment and stress or critical life events may have provided limited data on the importance of these associations; and, finally, the measure used had not been tested for cultural appropriateness.

These findings were broadly consistent with the findings of an Australian review (FECCA, 2015) into the health of older persons from culturally and linguistically diverse backgrounds.
The review, which examined available literature and consulted stakeholders across aged care, health and other relevant sectors, found that older migrants were at higher risk of mental health issues but showed lower uptake of mental health services and that people presented at later stages of illness compared to non-migrant older people. The review found a key cultural contributor to low levels of health seeking was stigma associated with disclosure of mental health problems leading to denial and later diagnosis. Other barriers included language barriers, low socioeconomic status, differing cultural practices and norms, length of time in Australia, expectations of care provision within the family, lack of service knowledge, lack of availability of culturally appropriate services, gender and country of origin. Older migrants were at higher risk for mental health disorders but showed low levels of service utilisation. As well, they face structural, contextual and cultural barriers.

In summary, ascertaining the mental health needs of migrant groups is compromised due to structural barriers relating to data collection, data analysis and reporting, lack of culturally appropriate measures and substantive weaknesses in mental health research in migrant populations. Available data indicates that the prevalence of poor mental health in some migrant groups is lower, comparable to or higher than in non-migrant groups with lower uptake of mental health services. Contextual and cultural factors in some migrant groups compromise mental health recognition, disclosure and timely help-seeking, contributing to higher levels of involuntary admission to care services at a later stage in the disease. The cultural appropriateness of mental health services is unclear, with a paucity of service level evaluation data. Structural, contextual and cultural factors contribute to a lack of understanding of the particular mental health needs of migrant groups and may contribute to over or underestimate the prevalence and poorly targeted service provision. In addition, the determinants of lower levels of mental health service usage may be multidimensional, however, there is a lack of robust data in this area. Addressing structural, contextual and cultural understanding of the mental health needs of migrant groups is likely to contribute to improved service provision.

**Gender health disparities**

Whilst population health data are sparse, available data show that migrant women have higher mortality and morbidity than non-migrant women. Also, migrant women have higher incidence of a number of conditions such as mental health disorders (Kim et al., 2013), gynaecological conditions (Collins et al., 2014), and poorer maternity and pregnancy outcomes (Gibson-Helm et al., 2014). Female migrants may face increased barriers to health-seeking which may contribute to increased mortality disparities for preventable conditions. Available evidence shows higher
rates of caesarean births, poorer pregnancy outcomes, higher prevalence of breast cancer, and higher incidence and mortality related to cervical cancer in migrant women. Particular migrant groups were more commonly found to experience health disparities as outlined below.

A systematic review (Merry et al., 2013) looked at perinatal health in migrant women by examining studies that compared caesarean rates between international migrants and non-migrants living in industrialised countries. Results showed that certain groups of international migrants consistently have different caesarean rates than women born in the receiving country. Caesarean rates between migrants and non-migrants differed in 69% of studies. Meta-analyses revealed consistently higher overall caesarean rates for Sub-Saharan African, Somali and South Asian women; higher emergency caesarean section rates for North African/West Asian and Latin American women; and lower overall rates for Eastern European and Vietnamese women.

Postulated risk factors for caesareans include the following: language and communication barriers, low socioeconomic status, poor maternal health, gestational diabetes/high body mass index (BMI), feto-pelvic disproportion and inadequate prenatal care. Suggested protective factors for a vaginal birth included the healthy immigrant effect, preference for a vaginal birth, a healthier lifestyle, younger mothers and the use of fewer interventions during childbirth. The authors did not find sufficient evidence to explain the observed differences in caesarean and non-caesarean rates and they did not cite factors such as female genital circumcision as influencing outcomes.

The results of this review were similar to an Italian study (Zanconato et al., 2011) which looked at perinatal indicators of the obstetric outcome that were monitored in all delivering women during a five-year period in a large public general hospital. The study compared rates of preterm deliveries, low birth weight, caesarean section during labour, perineal tears, and fatal acidemia in the native and immigrant participants. Results showed that immigrant women (2,768 or 29.5%) experienced very low birth weight and preterm deliveries more often than the native-born Italian women did. Among ethnic groups, data singled out Sub-Saharan African women to be at a higher risk of delivering very small premature infants and for caesarean section during labour. The study found differences in perinatal outcomes between immigrant and Italian woman with immigrant groups showing greater health disparities.

An Australian study (Gibson-Helm et al., 2014) looked at differences in maternal health and pregnancy outcomes and compared migrant women born in humanitarian (n=2,713) and non-humanitarian (n=10,606) source countries in a retrospective, observational study of singleton births, at a single maternity service in Australia in 2002–2011. Compared with women from non-
humanitarian source countries, women from humanitarian source countries were younger, had a body mass index (BMI) ≥ 25, had multiple births, anaemia, tuberculosis and syphilis. The humanitarian source country where women gave birth was independently associated with poor or no pregnancy care attendance, late first pregnancy care visits and pre-term births. Stillbirth and unplanned birth before arrival at the hospital were more common among women born in humanitarian source countries but not independently associated with women’s humanitarian source countries after adjusting for age, parity, BMI and relative socioeconomic disadvantage. A key strength of this study was the statistical power of the sample size and the use of a single site for data collection.

A US study (Gomez et al., 2010) examined the incidence of breast cancer in US Asian female migrants and found there was an increased incidence of breast cancer post-migration indicating a link to lifestyle factors in the receiving country. The study included 21,147 breast cancer cases among the six Asian ethnic groups obtained from data for 1998 through 2004 from the California Cancer Registry. The results not only refuted previous assumptions that Asian women have a very low incidence of breast cancer, but, in particular population groups the incidence was higher than non-Hispanic white US women.

The study found that US-born Asian women have an incidence rate of invasive breast cancer nearly two times higher than foreign-born Asian women in all groups examined except for Japanese women. The invasive breast cancer rates for US-born Chinese, Japanese and Filipino women approached, and for Filipino women exceeded, the rates for non-Hispanic white women. The results also showed that US-born Asian women younger than fifty-five years have higher risks of breast cancer than previously estimated and that rates among pre-and peri-menopausal US-born Chinese and Filipino women were higher than those for non-Hispanic white women. Authors postulated that the increased incidence of breast cancer in US-born Asian women is attributable to acculturation patterns with increased risks factors for non-genetic breast cancer such as diet, age at menarche, age at first birth, breastfeeding history, and other lifestyle and reproductive factors.

Whilst the evidence of differences in health outcomes between migrant women and non-migrant women is strong, the determinants of these differences has not been closely explored. There are few studies which have looked at the determinants of late stage engagement with health services or non-compliance with prevention or screening services. Therefore, to understand this area more fully, in the next section I will use cervical cancer as an exemplar to better understand the health disparities observed in migrant women.
A North American study (Seeff & McKenna, 2003) that examined cancer mortality data (1985–1996, n=4517) in the US found that deaths and death rates from cervical cancer increased for foreign-born women and decreased for US-born women. Similarly, a systematic review (Collins et al., 2014) of gynaecological cancer outcomes in North America found that while white women have a higher incidence of ovarian cancer compared to black women, the all-cause ovarian cancer mortality risk in black women was 1.3 times higher than that of white women. Further, endometrial and cervical cancer mortality in black women was twice that of white women. The literature indicates that low Pap smear completion rates (Seeff & McKenna, 2003; Sewali et al., 2015), barriers to human papilloma virus immunisation (Salad et al., 2015) and unequal care (Collins et al., 2014) are related to the higher mortality rates seen in migrant women.

Somali women migrants have one of the highest incidences of cervical cancer both in situ in Somalia and within the Somali diaspora (Morrison et al., 2013; Samuel et al., 2009). This has been attributed to HL-related factors such as low levels of knowledge about the nature of cervical cancer and the purpose of cervical screening, (Al-Amoudi et al., 2015) low risk perception (Salad et al., 2015) lack of understanding of the risk factors for cervical cancer (Sewali et al., 2015) and access related issues (Salad et al., 2015; Sewali et al., 2015). Contextual cultural factors account for some of the difference, such as the embarrassment associated with female circumcision (Sewali et al., 2015), fear (Al-Amoudi et al., 2015), low English proficiency, religious beliefs and cultural perceptions (Degni et al., 2014; Salad et al., 2015), past experiences and practical issues such as childcare (Al-Amoudi et al., 2015; Sewali et al., 2015). In addition, the concept of prevention is not easily reconciled with fatalistic beliefs that ‘God’s will’ determines health outcomes (Sewali et al., 2015).

Australia does not currently disaggregate cervical screening data to determine participation rates of different cultural groups, therefore, the scale of non-participation is unknown. The exclusion of migrant groups in data-collection practices may contribute to health disparities in this group. There is weak evidence that the lack of cultural relevance in health promotion initiatives to migrant groups may exacerbate low levels of participation in prevention activities. One qualitative study (Salad et al., 2015) of Somali girls living in Holland found a number of barriers to participation in the cervical cancer vaccination program. Barriers included the following: a lack of information and knowledge; inaccessible modes of delivery of information; lack of participation in development of information; distrust towards the Dutch health care system and government; the young age that young girls are vaccinated; language barriers; FGM (female
2 Female genital mutilation (FGM) involves partial or total removal of the external female genitalia, or other injury to the female genital organs for non-medical reasons (WHO, 2017).
Conclusion

Policies of migration and multiculturalism continue to be influenced by differing political agendas that are fuelled by a political and public discourse of exclusion. Australian health policies are inclusive of migrant groups, however, policy implementation has often failed to meet the health needs of this cohort. Research into migrant health is sparse, uneven and often of poor quality, and migrants are a ‘missing population’ in population research.

There is strong evidence to support the ‘healthy immigrant effect’ in which migrants arrive in the host country as healthy with this health advantage persisting in some migrant groups. However, evidence also supports the view that there is a decline in health post-migration observed in some migrant groups. Whilst acculturation and social determinants account for some of the differences in health outcomes they do not fully explain the uneven distribution of the health decline across migrant groups.
Introduction

Health inequities are the result of a complex web of social and economic processes (Sheiham, 2009) that may be reinforced within systems (Gideon & Thomas, 2013). Health inequities give rise to health disparities that are disproportionately observed in disadvantaged groups such as racial and ethnic minorities who experience greater barriers to accessing health care than non-migrant populations (Cooper et al., 2015). This chapter examines the literature on structural barriers within health systems that may limit engagement of migrant populations within health systems (Sundararajan et al., 2007) and contribute to health disparities. The chapter focuses on the following structural barriers: the marginalisation of culture, inaccessible models of care, limited cultural competence, barriers to access and discrimination. There is also an examination of contextual barriers for migrants to health system engagement including social determinants such as socioeconomic status, education and employment, language, and social networks. The recognition of increased barriers to health care access is critically important when addressing the health inequities experienced among migrant populations.

The marginalisation of culture

The literature within the disciplines of medical anthropology and sociology has demonstrated the importance of exploring cultural constructions of illness aetiology and treatment seeking, particularly when explanatory models of health and treatment differ markedly from dominant biomedical paradigms (Farmer, 1990; Kleinman et al., 1978). Culturally bound models of health and illness vary widely between cultural groups and have a pervasive influence on perception, labelling, explanation and meaning, as well as disease processes such as causality, symptomology, illness progression and treatment (Kleinman et al., 1978). Culture is defined as the shared ideas, meanings and values that are acquired by individuals as members of a society and that provide a contextual framework through which health status and health options are understood (Nielsen-Bohlman, 2004).

The inclusion of ethnicity and culture in health care is often minimised (Kumas-Tan et al., 2007), neglected (Garrett et al., 2010), perceived negatively (Anderson et al., 2003) ascribed to particular groups (Kumas-Tan et al., 2007) and marginalised within mainstream health systems (Kontunen et al., 2014). It is often perceived in health systems as either ‘present’ in particular populations such as migrants or indigenous groups or ‘absent’ among practitioners and health systems that are often depicted as culturally neutral (Boutin-Foster et al., 2008). Health
interactions are commonly presented as between the culturally neutral health practitioner and the culturally bound ethnic patient (Boutin-Foster et al., 2008). Culture is contextualised as ‘problematic’, needing to be ‘overcome’ or ‘fixed’ by specialised training (Kumas-Tan et al., 2007). The influence or recognition of the practitioner’s own cultural and demographic characteristics or of cultures within health systems such as belief systems, rituals, paradigms, customs and language, are rarely acknowledged (Boutin-Foster et al., 2008). According to Kagawa-Singer, this is a direct outcome of the representation of health systems as essentially “mono-cultural” (Kagawa-Singer, 2000, p. 93) with ethnicity represented by the outsider. This view was shared by Kumaş-Tan (Kumas-Tan et al., 2007) who stated that culture in the health context is seen as peripheral or an attribute possessed by the ethnic or ‘Other’. The process of ‘othering’ marginalises, disempowers and socially excludes those who do not fit in with the dominant group (Grove & Zwi, 2006).

In summary, culture is not viewed as omnipresent within health systems and is often contextualised as belonging to particular groups, as not belonging within practitioners’ groups, and as problematic and requiring fixing. The recognition of a practitioner’s cultural boundaries and bias within the health care system may build cultural capacity and reduce barriers between the providers and users belonging to ethnic groups (Poureslami et al., 2007).

**Inaccessible models of care**

Health care systems in developed countries are based on a model of biomedical individualism (Baum et al., 2009) that holds as a basic tenet that all persons are equally situated and motivated to access services (Gideon & Thomas, 2013) and this model may exclude migrant groups whose social systems may be based on alternate values, beliefs and practices.

Kagawa-Singer (Kagawa-Singer, 2000) asserted that Western health systems are based on a mono-cultural perspective encompassing the values of individuality, independence, agency and autonomy. This model is not always accessible to migrant groups who may operate within an alternate set of values including collectivism, dependence, consensus decision-making and community (Kagawa-Singer, 2000). Collectivism is characterised by individuals subordinating their personal needs to the needs of the social group, which is contrary to the concept of individualism, which is characterised by the prioritisation of the needs of the individual over the needs of the collective (Mojaverian et al., 2013; Triandis, 1988).

The health systems in the countries of origin of many migrant groups may reflect collectivist values and function within hierarchal structures, which place the patient as ‘dependant’ and as a
passive recipient of care. This shift in role from ‘passive recipient’ to the Western model of ‘active partner’ requires the development of a range of complex skills such as knowing when and how to seek health information, high level verbal communication skills, assertiveness, literacy, capacity to process complex information, and application of knowledge (Nielsen-Bohlman, 2004). Kagawa-Singer (Kagawa-Singer, 2000) asserts that Western systems have three main limitations that impact migrant and indigenous groups; (i) lack of recognition of and accountability to differing world views; (ii) lack of flexibility to use more appropriate and effective means to cope with sickness and life-threatening illnesses based in those differing world views; and (iii) lack of ability to hear different but equally valid ways of communicating these perspectives. These limitations constrain the cultural competency of organisations, which may further contribute to health disparities in migrant groups.

Cultural competency in health settings

The positioning of culture within a false dichotomy (present or absent) and the treatment of culture as secondary or extraneous within health systems has implications for the cultural competence of health systems. Cultural competence has been defined as “…a set of congruent behaviours, attitudes, and policies that come together in a system, agency, or among professionals and enable effective work in cross-cultural situations” (Anderson et al., 2003, p. 68). Lack of cultural competence is a major barrier for migrant groups accessing health services (Comino et al., 2001; Goodall et al., 2014; Henderson et al., 2011; Rao et al., 2006). However, evidence of the cultural competency of health organisations is difficult to ascertain due to the broad interpretation of the concept and poorly designed measures of cultural competence.

Evidence of poorly designed measures of organisational cultural competency was provided in an extensive systematic review (Kumas-Tan et al., 2007) conducted by the US Centre for Disease Control and Prevention, which examined twenty years of literature. The review found that of the fifty-four measures of cultural competency examined, the majority were based on erroneous and problematic assumptions. One common assumption is that culture with ethnicity and race are the same; a second assumption was the conceptualisation of culture as possessed by the ethnic or racialised ‘Other’. Further, cultural incompetence was presumed to arise from the deficits at the practitioner level such as a lack of exposure to and knowledge of the ‘Other’, from individual biases, prejudices and acts of discrimination rather than deficiencies within health systems. The authors found that many of the instruments assumed that practitioners are white and Western and that greater confidence and comfort among practitioners when caring for patients signified increased cultural competence. The authors concluded that existing measures embed highly
problematic assumptions about what constitutes cultural competence; these assumptions ignore the power relations of social inequality and assume that individual knowledge and self-confidence are sufficient for change. In addition, the findings reflect a worldview that culture is a confounding variable that white practitioners must contend with when they are dealing with ethnic or minority groups. The authors concluded with the finding that despite decades of research into the field of culture and cultural competency, the development of valid measures remains problematic (Kumas-Tan et al., 2007).

Cultural considerations within the migrant health context are essential and foundational to inclusive practice and to addressing health inequalities (Anderson et al., 2003; Tiilikainen, 2011). The critical problem facing Western health systems is how to meet the heterogeneous needs of migrant groups through the adoption of universal, particular or proportionate approaches (Carey et al., 2015). Central to an effective resolution of this problem is the consideration of culture as pervasive across groups within the health system including practitioners (Boutin-Foster et al., 2008), and migrant and non-migrant health consumer groups. When culture is conceptualised as present in all health interactions, then cultural considerations are more likely to become mainstreamed within health systems. Effective cultural responsiveness requires the systematic application of validated frameworks, however, evidence indicates that health services approaches are often unsystematic, not evidenced-based, and ineffectively implemented and evaluated (Henderson et al., 2011; Kumas-Tan et al., 2007).

One systematic review (Henderson et al., 2011) that examined the literature on the effectiveness of culturally appropriate interventions to manage or prevent chronic disease in culturally and linguistically diverse (CaLD) populations found few studies that met the study criteria. The review analysed randomised controlled trials and controlled studies that promoted cultural competence in health service delivery to CaLD communities looking for outcome indicators such as changes in consumer health behaviours, utilisation/satisfaction with the service and the cultural competence of health care providers. Of the 202 studies that were identified only twenty-four met the inclusion criteria. The authors could not determine the effectiveness of any of these interventions due to the poor quality of the evidence.

One intervention to increase the cultural competency of health services is the use of bi-cultural health educators. Bi-cultural health educators or health advocates are persons who have language proficiency and cultural knowledge of particular migrant groups. Greenhalgh (Greenhalgh et al., 2005) tested the effectiveness of a diabetes education intervention for culturally diverse groups led by a bilingual health advocate. The intervention found an increase in engagement by people
in the underserved cultural group and delivered subjective benefits. A number of studies (Henderson et al., 2011; Woods ER, 2016) have shown that the use of bi-cultural health workers is an effective strategy to increase service level cultural competence.

Access

Health policy and programs are intended to provide equal access to the health system for all groups in the population, however, policy implementation may vary widely (Aday & Andersen, 1974; Bellamy et al., 2015). It is well established that access to health care is associated with improved health and lower mortality, with access to primary care positively associated with lower mortality (Jerant et al., 2012; Lambrew et al., 1996). However, migrant groups experience a range of barriers to timely and appropriate care.

One study (Gil-González et al., 2015) examined the evidence on barriers to migrants’ access to services by conducting an ‘umbrella review’ of primary studies and found structural and individual barriers were significant for migrants. Structural barriers included financial and legal impediments and organisational models of care that did not meet the needs of migrant groups. Individual barriers such as cultural and linguistic factors, and the lack of relevant health information provided, were characterised both as a consequence of service provision and of patient and provider beliefs. An important limitation of this study was the risk of the transmission of bias from primary studies to the reviews and then to the umbrella review. Also, the inclusion of studies with methodological deficiencies may have impacted the quality and relevance of the evidence. However, despite these limitations, this review contributes to our understanding of migrant health as impacted by structural and individual barriers.

These findings were consistent with an operational review (Victorian Auditor-General’s Report, 2014) commissioned by the Victorian Department of Health on the cultural competence of health services in Victoria, Australia. The review found a range of systemic issues that limited the ability of the health sector to meet the needs of migrants. The identified issues included the absence of or missing data, poorly designed and executed data-collection processes, lack of a quality framework, inadequate or multiple reporting processes that were poorly integrated, lack of evaluation mechanisms and inadequate reporting processes. Many of these issues are replicated at a national level in which services are not required to collect, analyse or report data on the country of origin of the users of health services. This systemic failure is a fundamental barrier to understanding and meeting the needs of migrant groups.
Health service access and HL are important determinants of health outcomes (Baum et al., 2009; Renzaho & Oldroyd, 2014) with various barriers contributing to health inequalities for migrant populations. These include the following: structural barriers (policy, organisational limitations, lack of cultural competency and inclusion practices), contextual barriers (cultural beliefs, social support, attitudes and training of health professionals and patients’ beliefs, socioeconomic status, availability of health information and acceptability of services) and individual barriers (literacy, health knowledge, help-seeking behaviours, motivation, language and education).

Disparities in use of health care services between immigrants could stem from differences in knowledge of the health care system and access rights as well as difficulty communicating with health practitioners because of linguistic and cultural barriers (Neuman, 2014). The underutilisation of health care services, that has been observed in migrant populations, such as the underuse of preventive health care, mental health services and screening (Minas et al., 2013; Weber et al., 2014) could have long term effects on immigrants’ health.

**Racial discrimination as a contributor to health inequities**

Health inequities are health differences that are socially produced and are therefore considered unfair and avoidable (Geddes & Maciocco, 2006; Whitehead, 1992). Evidence shows that racial discrimination, defined as differential treatment based on race that disadvantages a racial group, is a contributor to health inequities (Williams, 2009). Discrimination may be perpetuated through the instruments of systems such as policies, practices, structures and regulations that are collectively referred to as institutional racism (Shavers et al., 2012).

International data such as the North American National Healthcare Disparities Report (AoHRQ, 2010) indicates that discrimination is present within health systems. The report found that white patients receive better quality of care than 53% of Hispanic, 43% of African American, 38% of American Indian/Alaska Native, and 22% of Asian and Pacific Islander patients. A subsequent review (Shavers et al., 2012) found that the mechanisms by which race and ethnicity influence health in health care included the following: provider explicit and implicit biases, attitudes and beliefs that could negatively affect the health care delivered to racial/ethnic minority patients, less patient involvement in decision-making, disbelief of the existence of health care disparities, belief of a lack racial discrimination in health care disparities and implicit preferences for white race and light skin colour.
**Language and communication barriers**

Contextual factors that impact migrant health are factors that are not related to race or ethnicity. There is consistent evidence that contextual factors such as the social determinants of education and employment, language proficiency (Bellamy et al., 2015; Jaklina et al., 2013; Riggs et al., 2014), socioeconomic status (Newman et al., 2015; Sheiham, 2009) and assimilation behaviours (FECCA, 2015; Gil-González et al., 2015; Keleher & Hagger, 2007; Lorant et al., 2008) are contributors to MHD. However, evidence on the level of the contribution of these factors on MHD is less clear.

Language has also been identified as a major barrier to effective communication in health care settings (Bellamy et al., 2015; Gascón et al., 2011; Henderson et al., 2011; Riggs et al., 2014) and a contributor to health disparities (2009). Language barriers have been found to; limit patient access, undermine trust in the quality of the medical care received and the patient-health professional relationship, compromise appropriate follow-up and care, contribute to misunderstandings and inadequate comprehension of diagnoses and treatment, problems with informed consent, dissatisfaction with care, preventable morbidity and mortality, and lead to disparities in prescriptions, test ordering and diagnostic evaluations (2009). An inability to communicate with a health care provider carries potential risks such as diagnostic errors, inappropriate treatment and delayed or refused health care (Henderson et al., 2011). Also, access to interpreters and translation of health information are often poorly implemented in health care settings (Jaklina et al., 2013).

**Social capital and health effects**

The social network in which an individual exists can influence health outcomes. Social capital theory asserts that social networks are an asset for individuals and groups and influence the availability of social and economic resources which are linked to health outcomes. Bourdieu (1991) was one of the first authors to identify the value of social capital as a resource enabling access to a range of other capitals, including economic and cultural capital, through the mobilisation and leverage of social networks (*Social theory for a changing society*, 1991) and as mechanism through which advantage and disadvantage are reproduced and maintained within socioeconomic groups (Bourdieu, 1986; Putland et al., 2013). Putnam (Putnam, 2000) identified two forms of social capital: bonding and bridging. Bonding capital is characterised by dense or closed networks with limited access to resources. By contrast, bridging capital is associated with increased resources through wider and overlapping social networks.
Many migrant groups form homogenous groups (Cattell, 2001) comprised of dense networks of persons who share common characteristics such as social status, location, history, and ethnicity. Homogenous groups are characterised by high levels of bonding capital (Putnam, 2000) based on expectations of trust, ‘bounded reciprocity’ (Cattell, 2001), social exclusion and lower levels of bridging capital (Putnam, 2000). Bonding capital reinforces cultural norms and beliefs through closed information channels and limited social mobility. By contrast, heterogeneous groups are characterised by the formation of social networks outside of immediate social groups with higher levels of bridging capital that have the potential to challenge cultural norms (Cattell, 2001).

Systems of health beliefs and disease attribution vary markedly between cultures. Cultural groups which hold alternative health beliefs from Western health care models are often overrepresented in groups with health disparities. The accommodation of culturally bound health beliefs through the cultural competence of health care systems have important implications for the health of migrant groups (Kleinman et al., 1978).

**Conclusion**

In this chapter, we have seen that the MHD is well established in the literature and related to a range of structural barriers such as: the marginalisation of culture, inaccessible models of care, limited cultural competence, barriers to access and discrimination. Contextual barriers also contribute to the MHD such as socioeconomic status, education and employment, language, and social networks. The literature has shown that recognition of the increased barriers that migrants face when accessing health care is critically important when addressing the health inequities in this population. Finally, HL has also been shown to have the potential to reduce the MHD.

**Knowledge gaps identified from the literature review**

The knowledge gaps identified in the preceding literature review are extensive. Firstly, there was a paucity of knowledge in relation to the HL of migrant groups due to a range of issues such as the lack of representation of migrants within population based studies and, when included, the aggregation of data. Data aggregation in migrant groups dilutes particular and pertinent knowledge on the health needs of migrant groups. There were also knowledge gaps in relation to the barriers and enablers to health system engagement for migrant groups. Whilst it is known that health service utilisation patterns differ between migrant groups and the native-born population, there have been few studies to elucidate a rationale for these differences.
Further, knowledge gaps were also evident in understanding the HL needs of migrant groups from diverse entry pathways (skilled, humanitarian, family reunion visas). This is critical information to assist in identifying high risk groups and is hampered by the Australian Government’s policy not to collect specific country of origin data when conducting health surveys. There were also knowledge gaps in understanding the mechanisms by which cultural health beliefs and practices impact health system engagement and HL. This is potentially an important area needing further research focus to inform effective health system engagement strategies. Finally, knowledge gaps in understanding the HL strengths and needs of migrant groups were also identified, which is important to enhance migrant health system engagement and health outcomes. These identified knowledge gaps informed the development of the objectives of this study and the research undertaken.

In summary, this literature review has identified four key knowledge gaps that suggest potential determinants of migrant health and equity of access to health services. These topic areas, i.e., gaps in knowledge about specific migrant groups, mechanisms by which particular migrant groups engage or not engage with health services, and specific knowledge around the HL strengths and weaknesses of migrant groups, are needed to underpin potential initiatives to improve migrant health and thus form the rationale of this PhD. The next chapter outlines the aims of the PhD and rationale for the methods that will be used to answer these research questions.
Chapter 4: Methods

Section 1: Study overview

This study was undertaken using a grounded, mixed methods approach with the aim of advancing understanding of HL in culturally diverse groups and exploring the nexus between culturally-bound beliefs and HL practices in migrant groups. Specific tools used were a quantitative survey, cognitive interviews and semi-structured interviews with members of three Australian migrant communities (Somali, Chinese and Indian).

Study objectives

The study objectives were to;

1. assess the HL strengths and needs of three migrant groups,
2. explore a measure of HL for use with migrant groups,
3. conduct an in-depth inquiry into the health conceptualisations and health-related practices of three migrant groups, and
4. identify barriers and enablers to augment HL in three migrant groups.

A mixed methods approach was taken, as quantitative and qualitative approaches provide differing and complementary perspectives (McCusker & Gunaydin, 2015). The use of a quantitative survey, the HLQ, provided a standardised method to observe the HL strengths, needs and practices of three migrant groups and allowed comparison to a non-migrant group. The cognitive interview method provided insight into interpretations of wording, constructs and concepts within the questionnaire, allowing for an exploration of the appropriateness of this tool for use in migrant groups. Finally, the semi-structured interviews provided in-depth insight into the cultural conceptualisations of health underpinning HL practices and revealed detailed culturally bound explanatory models of health.

Rationale for use of a mixed method

Mixed methods designs can provide a number of pragmatic advantages when exploring complex research questions (McCusker & Gunaydin, 2015) and for the development, initiation and expansion of new ideas (Kaur, 2016). Both the qualitative and quantitative data generated in this study can contribute to the generation of new knowledge into HL and migrant health. However, when the two data sets are synthesised, the depth of insights generated is greater, allowing a more contextualised and nuanced analysis. The qualitative data is useful in explaining quantitative results by providing contextual information to inform targeted interventions. A
further advantage in combining quantitative and qualitative methods is the strengthening or ‘triangulation’ of the data. Triangulation is a term taken to mean a ‘broader view’ and allows for an overlaying of data to test validity (Bryman, 1984). Triangulation using different methods and contrasting analytic approaches such as deduction and induction brings “multiple observers, theories, methods, and empirical materials; … to overcome the weakness or intrinsic biases and the problems that come from single method, single observer, and single theory studies” (Kaur, 2016, p. 99). An inductive analytic process, consistent with a grounded research approach was used in this study.

**Rationale for the use of a grounded theory approach**

Grounded theory (GT) is a general methodology for developing theory that is grounded in data systematically gathered and analysed, with theory developing from the continuous interplay between data collection and analysis. The rationale underpinning the use of GT in this study was to foreground the context of the experiences of migrants and to assist in building theory relevant to their situation (Green et al., 2007). Allowing participants to articulate narratives from their constructed reality was important to generating new theory in this study. In addition, the emergent, inductive and comparative processes of GT research were effective in uncovering factors related to the diversity of experiences that influenced migrant health-related problems (Draucker et al., 2014).

Grounded theory is a qualitative research methodology commonly used in social science and health research (The Sage Handbook of Grounded Theory, 2007). Grounded Theory Method (GTM) emerged in 1967 with the publication of the text *The Discovery of Grounded Theory: Strategies for Qualitative Research* by Glaser and Strauss (Glaser & Strauss, 1967). The theory challenged conventional approaches that focused on validation and verification rather than context or theory generation (Duchscher & Morgan, 2004; Glaser, 2016). At its core, GTM is a systematic set of procedures used to develop theories of psychosocial phenomena through iterative analytic movement between empirical data and emerging theoretical constructs.

Glaser and Strauss believed that research methods should have ‘fit and relevance’ with concepts based on data in the field and must be relevant to the participants (Glaser, 2016). Glaser later wrote that their “…perspective was to start off knowing nothing, in contrast to the typical research plan of knowing the problem beforehand. GT became a no preconceptions method … participants tell us what to research with fit and relevance” (Glaser, 2016, p. 5). A core element of GTM is the constant comparative method in which data from different respondents is compared and contrasted to find interchangeable indicators that show a grounded pattern. The
authors asserted that theory emerges from the data rather than being forced to fit the data using the contrivance of what was already known.

Grounded theory has the following principles:

1. the discovery of enduring theory that is faithful to the reality of the research area
2. results make sense to the person studied
3. fits the template of the social situation, regardless of varying contexts related to the studied phenomenon
4. adequately provides for relationship amongst concepts
5. may be used to guide action or development of interventions (Duchscher & Morgan, 2004; Glaser & Strauss, 1967)

It is important to point out that whilst these principles have been upheld, the two co-creators of GTM went on to develop seemingly divergent paths in further developing and evolving GTM (Duchscher & Morgan, 2004). The two subsequent methods are; 1. Glaser’s model of theory generation, where theory rises directly and rigorously out of the data, devoid of interpretation, and 2. Strauss’s conceptually descriptive approach that encourages directive questioning and supports an interpretive stance (Duchscher & Morgan, 2004). These approaches reflect different basic philosophical paradigms and represent distinct approaches to GTM, therefore it is important for researchers to identify which philosophy and resulting analytical approach they want to use and why. In the years since the inception of GT the field has evolved beyond the Glaser and Strauss dichotomous approaches into a range of approaches and methods that remain consistent with the underlying principles of GTM.

Critics such as Charmaz (Cited in Bryant, 2007) challenged core elements of Glaser and Strauss’s GTM such as the notion of the neutrality of the researcher and the position of GTM within a positivist paradigm (Bryant, 2007). A central aim of GTM theory was to legitimise qualitative research by introducing a rigorous scientific method in line with a positivist approach. Positivist approaches assume a position of neutrality of the researcher who is considered to have a neutral point of reference. However, Charmaz challenged not only the notion of neutrality, but also the view that data emerges without influence from the researcher. Rather, Charmaz proposed that GT methodology was founded on a relativist epistemology (Higginbottom & Lauridsen, 2014) arguing that research was not separate to the researcher but influenced by the researcher’s cognitive orientation. Charmaz applied the emerging field of constructivism to GT, developing Constructivist Grounded Theory (CGT) based on the assumption that people construct the realities in which they participate (Higginbottom & Lauridsen, 2014). Charmaz’s
CGT influenced researchers to examine their own position in the research and to move beyond an objectivist perspective.

Green (Green et al., 2007) proposes that GT studies can be classified into four levels depending on the importance that racial/ethnic diversity is afforded in the research. The four levels range from having a central focus on racial/ethnic diversity (primary level), through diversity being somewhat important (complementary level), to not being central (peripheral level) and, finally, to where racial/ethnic focus is absent (absent level).

This study adopts the Green’s (Green et al., 2007) ‘primary level’ GT in which racial/ethnic diversity is central to the phenomena being explored. In this study, racial/ethnic diversity underpins all aspects including study design, aims, research questions, study participants, analysis and interpretation. This study sought to foreground the experiences and perspectives of the three groups by uncovering their ‘lived experiences’, without making direct comparisons to the perspectives of non-racial, mainstream populations.

**Rationale for the use of quantitative methods in this research**

Quantitative methods were employed in this study to gain insight into the HL strengths and needs of migrant groups. HL measurement is an emerging field of study that has seen the development of a number of tools over the past decade. The HLQ elicits information on health decisions made by and experiences of participants in relation to accessing, understanding and utilising health information and services. The central benefit of using this quantitative tool was that it offers an efficient method to standardise participant responses and facilitate a detailed analysis within and across the three migrant groups. In addition, data could be cross-analysed against results from a larger study that used the HLQ with mainly Australian-born participants (Beauchamp et al., 2015). This approach provided complex and rich data to complement the contextual data obtained through qualitative methods.

The epistemological perspective of a quantitative methodology reflects the view that “…phenomena can be reduced to their constituent parts, measured and then causal relationships deduced” (Baum, 1995, p. 462). It is derived from the positivist paradigm that is based on notions of individualism and objective truth (Baum, 1993). There are important distinctions between qualitative and quantitative research: in quantitative research all aspects of the study are carefully designed prior to commencement; the researcher knows clearly in advance what he/she is looking for and tends to remain objective; and the researcher uses tools, such as questionnaires to collect numerical data (McCusker & Gunaydin, 2015). A key benefit of quantitative data is
that it is an efficient method to test hypotheses, however, it has limited ability to capture contextual detail.

**Rationale for qualitative methods in this research**

The rationale underpinning the choice of qualitative methods in this study was to explore how migrants interpret their social world, and to provide insights into their beliefs and behaviours (Eccles et al., 2009) that are not readily accessible through other methods such as quantitative surveys. Whilst small-scale quantitative data on the HL of particular migrant groups exists (Choi et al., 2013; Gele et al., 2016; Poureslami et al., 2011), there are few studies that have inquired into the lived experiences and personal perspectives of migrants. Therefore, to gain an understanding of the perspectives of migrants, I employed qualitative methods to avoid imposing a priori categories and concepts from the literature and from my personal view. This approach has the potential to provide new insights into the hitherto little explored association between cultural beliefs, behaviours and HL practices in migrant groups. A further reason for adopting qualitative methods was to map and build a detailed understanding of the HL practices of migrant groups that often exist in parallel to or outside the health system. Without this knowledge, the health sector has limited capacity to effectively meet the needs of migrants.

Cognitive interviews were undertaken to explore the interpretation of, and responses to, the items within the HLQ by the three migrant groups. Specifically, the process involved the selection of questions from the HLQ and exploring variation in their interpretation across the three migrant groups. This phase also provided insights into levels of HL competencies using Nutbeam’s HL model (Nutbeam, 2000) as an analysis framework.

In addition, the concept of HL has been rarely explored in migrant groups. The concept of health has different meanings across cultural groups and may influence attitudes, motivation and behaviours relating to access, understanding and use of health information and services. Therefore, it was important to use qualitative methods to capture potentially unique health conceptualisations and lived experiences of the participants. This was achieved through the use of an open and exploratory process that allowed for the emergence of new information.

Qualitative data have the potential to enrich, expand and validate the study analysis by adding opinions, beliefs, perceptions, attitudes and self-reported behaviour of participants (Sniderman et al., 2007). Use of qualitative methods can provided a narrative which when expanded can enhance the generation and building of ideas, concepts and theory. To support this exchange, elements that are considered important to migrants in terms of seeking, understanding and using health information were explored, made manifest and represented. As a basis for understanding
influences on HL qualitative inquiry was undertaken to explore the ways in which health is conceptualised within Somali, Chinese and Indian migrant groups. Semi-structured, in-depth interviews were conducted with participants from these migrant groups to gain insights into their health conceptualisations, and processes such as decision making, information gathering and help-seeking.

Section 2: Study design

This is a three-phase cross-sectional study with observations made at one point in time, in several settings and contexts and using a quantitative survey, cognitive interviews and semi-structured interviews.

Phase one (See figure 4.1) commenced with the administration of the HLQ. The next phase, phase two, inquired into the interpretations of the HLQ by the three migrant groups and the meanings and understandings they ascribed to the HLQ wording and concepts. The third phase explored cultural background, knowledge and beliefs that influence HL practices. A synthesis of the three sets of data was then undertaken.
Figure 4.1: Overview of the three phases of this study

### Phase 1: Understanding the HL strengths and needs of three distinct migrant groups in Australia – Application of the HLQ
Data collection: HLQ administerd to 240 participants from three cultural groups: Somali (n=80), Chinese (n=80) and Indian (n=80).

### Phase 2: Exploration of the HLQ as a measure of HL needs of migrant groups in Australia – Cognitive interviews
Data collection: Cognitive interviews with 18 participants (drawn from Phase 1) Somali (n=6), Chinese (n=6) and Indian (n=6).

### Phase 3: Understanding the health conceptualisations of three migrant groups in Australia – Semi-structured interviews
Data collection: Semi-structured interviews with 45 participants (drawn from phase 1) from three cultural groups: Somali (n=15), Chinese (n=15) and Indian (n=15).

Alignment of study objectives with data-collection methods

The following table illustrates how the study methods align with the study objectives.

**Table 4.1: Alignment of study objectives with data-collection methods**

<table>
<thead>
<tr>
<th>Objective</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Assess the HL strengths and needs of three migrant groups</td>
<td>Phase 1: Administration of the HLQ to three migrant groups (n=80 each)</td>
</tr>
<tr>
<td>2. Explore a measure of HL for use in migrant groups</td>
<td>Phase 2: Cognitive interviews (n=18)</td>
</tr>
<tr>
<td>3. Conduct an in-depth inquiry into the health conceptualisations and health-related practices of three migrant groups</td>
<td>Phase 3: Semi-structured interviews (n=45)</td>
</tr>
<tr>
<td>4. Identify barriers and enablers to augment HL in three migrant groups</td>
<td>Phases 1, 2 and 3</td>
</tr>
</tbody>
</table>
Ethics

Ethical clearance to conduct the research was obtained from the Deakin University Human Research Ethics Committee in August 2013 (ID: 2013-188). The following procedures were employed to ensure the highest ethical standards in research practice.

Informed consent

Informed consent was obtained from all research participants. Information was provided both orally (through use of interpreters when requested) and in written form in both English and in the dominant language of the participant’s country of origin (Somali, Simplified Chinese and Hindi) to assist participants in making an informed decision to participate in the study.

The process of withdrawal from the study was explained to all participants, emphasising their right to cease participation in the interview at any time, to refrain from answering questions, to request the tape recorder to be turned off and to have the interview deleted. Participants were informed they could express concern about the study or the manner in which it was conducted at any time either to the chief investigator or to speak with a member of the Advisory.

Confidentiality and privacy

Confidentiality and privacy are issues of particular concern in migrant groups in which there is a commonly expressed fear of personal information being disclosed to other members of the community. Individual names were not used during the interviews on either the audio recording or the written documentation. Demographic questions were asked prior to the commencement of audio recording and documented separately using a unique identifier. Interviews were conducted in private meeting rooms at community centres or community gathering places, as per the request of the participants. All publications and reports produced from this study will present aggregated data only with no participant being identifiable.

Translators were not known to the participants and there were no direct familial or tribal affiliations between the translators and participants. Issues of confidentiality were discussed with translators and the bi-cultural health worker prior to collecting data. All audio and written materials are password protected as per Deakin University guidelines and kept securely and can only be accessed by myself.

Storage and management of data

Transcripts of the interviews and written materials will be kept for seven years, in line with Deakin University Human Research Ethics Committee requirements. Only the PhD researcher
and the study supervisors have access to the raw data, which is secured in a locked filing cabinet at Deakin University.

**Intellectual property**

The intellectual property generated in this study is owned by the PhD researcher. Intellectual property developed prior to this study remains the property of the original creators.

**Advisory groups**

Individuals from migrant groups may feel vulnerable due to low English proficiency and lack of familiarity with the requirements of research participation. Therefore, three separate Advisory Groups were established (one for each participating migrant group) that were made up of two to three members (see Appendix 2). Criteria for membership of the Advisory Groups included the following: persons who identified as part of one of the three migrant groups; persons who were well known and well respected within their community; ability to speak English and one or more of the languages of their community; excellent knowledge of common cultural practices within their community, and willingness to be a cultural advisor to this study. Researchers were identified through discussions with community members and then I approached the individuals to seek their interest in participating.

The role of the Advisory Groups was to provide advice and guidance on how to conduct the study in a culturally sensitive manner and provide advice on areas such as recruitment, reviewing project tools and providing support (if required) to prospective participants wishing to discuss aspects of participation in the study. Further information on the role of the Advisory Group is provided in Appendix 3: Advisory Group Terms of Reference.

Due to geographical and cultural differences, the three groups did not meet as one group but functioned independently throughout the study. The members of each group met for one initial meeting and then I contacted them individually to ask them questions on cultural appropriateness or asked them to review materials such as consent forms. It was important to work with the members one-on-one because of the difficulties of attending meetings (due to geographical or monetary limitations) and also to work within their time constraints. The advice provided by group members was vital in ensuring that the study was conducted in a culturally appropriate and competent manner. I requested and received advice on issues such as the use of correct terms when referring to community members, appropriate greetings, appropriate attire to wear when meeting with participants, appropriate times and ways to contact participants (for example, Ramadan was not considered an appropriate time for the Somali group), appropriate hierarchy in
contacting participants (for example, to contact elders first before contacting participants directly), and issues of potential concern that should be directly addressed with participants, such as the study protocol on privacy and confidentiality.

**Consideration of the needs of migrant groups**

Deliberation was given to the needs, risks and considerations of migrant groups in all phases of this study, resulting in:

1. use of best practice standards in the language translation of all materials;
2. extensive consultation with members of the advisory groups to ensure culturally competent approaches;
3. minimising inconvenience to participants by conducting the research close to areas where they lived or had connections;
4. not placing undue financial or resource burdens on participants because of participating in the research (vouchers were provided to reimburse participant costs in attending interviews);
5. providing an interpreter who was not known to the participants and not directly connected via tribal or familial ties;
6. ensuring the highest standards in confidentiality; and
7. ensuring privacy and providing the option of verbal or written consent.

**Inclusion and exclusion criteria**

Included in the study were men and women born and raised to adulthood in one of the three target countries (Somalia, China and India). The ability to speak English was not a requirement for inclusion. Excluded from this study were individuals under the age of eighteen years and those with overt cognitive impairment.

**Participants**

A sample of 240 persons (80 from each of the three migrant groups) was recruited into the study within metropolitan Melbourne and surrounding regional areas using two key strategies: 1) direct invitation to participate; and 2) snowball sampling.

The three cultural groups were chosen due to differences in their migration pathways, socio-demographic profiles and varying health outcomes. A brief overview of each group is provided below, with a more detailed profile found within the results chapters of this thesis.
The Australian Somali community has a relatively recent migration history. The majority of Somali migrants entered Australia during the 1990s under the humanitarian visa scheme (Community Information Summary Somalia-Born, 2012). In comparison to other migrant groups and the Australian-born population, Somali migrants generally have lower levels of English proficiency and formal education on arrival (Community Information Summary Somalia-Born, 2012). There is limited data on the health profiles of specific migrant groups in Australia, however small-scale studies indicate that the Somali community in Australia faces greater health challenges than the general Australian population. These challenges include; musculoskeletal problems, earlier onset of chronic diseases such as diabetes and heart disease (Komaric et al., 2012).

By contrast, the Australian Chinese community is the third largest overseas-born group in the country (Community Information Summary China-born, 2012) with a migration history stretching as far back as the early 1800s, but with numbers increasing significantly in the 1840s to fill the labour shortage that resulted from the end of convict labour (Megalogenis, 2015). Recent patterns of migration have seen the majority of Chinese migrants coming to Australia as skilled migrants (ABS, 2015b). When compared to other migrant groups, the Chinese migrants have relatively higher levels of English proficiency and formal education (Community Information Summary China-born, 2012). Asian-born migrants have up to a 28% lower mortality rate than the general Australian population (AIHW, 2014b).

The Australian Indian community, like the Australian Chinese community, is one of the fastest growing migrant groups in the country, with large numbers of Indian migrants entering Australia from the 1980s under the skilled migrant program (Community Information Summary India-born, 2011). The majority of this population, when compared to other migrant groups, has higher levels of English proficiency and formal education on arrival (Community Information Summary India-born, 2011). Health demographic data for this group is emerging, with small scale studies indicating a higher prevalence of mental health morbidity (Maheshwari & Steel, 2012) and coronary heart disease (Fernandez et al., 2015) than the Australian-born population.

**Recruitment**

An important focus of this study was the employment of culturally competent recruitment methods. The recruitment process was informed by members of the Advisory Groups. The groups provided specific advice on matters such as appropriate and effective methods of approaching the communities for recruitment, accessing influential members within the communities, understanding ethnic and tribal affiliations to assist in recruiting from diverse
groups and increasing representation, effective methods of information transfer, and typical patterns of information flow within the three groups.

In addition, a collaboration was formed with the Multicultural Centre for Women’s Health (MCWH) in Melbourne. MCWH is a national organisation that works to achieve equity and improve health and well-being for immigrant and refugee women. A key strategy of MCWH is to train accredited bilingual educators to provide culturally competent services to a range of stakeholders. The organisation has extensive links with cultural groups through its community education arm. To assist with the recruitment in this study the MCWH worked through a process of engaging external groups that are led by local group leaders who are not employed by the centre.

In the recruitment phase, the bilingual educator leveraged her extensive associations with the Chinese and Indian communities to disseminate an email invitation to participate in this study via the coordinators of community based cultural groups. As outlined in the ethics process of this study, the educator only used her networks to disseminate the email and then played no further part in the recruitment. Male and female members of each ethnic community who were interested in participating in the study were asked to email or phone myself for further information. This was an important consideration in the process to ensure that the relationship between the MCWH and the community coordinators was not compromised in any way. A key concern was that coordinators might have felt compelled to assist the recruitment process in order to maintain an effective relationship with the MCWH. The MCWH centre was not informed of who did or did not participate. This collaboration was fundamental to extending the reach of this study to a wide number of community groups both in metropolitan and regional areas.

**Recruitment and training of translators**

The language translators and the bilingual educator were utilised to support data collection. This was an important strategy to increase accessibility to the three migrant groups and to assist with the conduct of this study in a culturally appropriate manner. Translators for the Somali community were recruited through a recommendation from members of the Advisory Group. Translators for the Chinese community and Indian community were recruited through the MCWH in Melbourne, Victoria.

The translator and the bilingual educator were trained in research techniques prior to the commencement of data collection. I conducted the training that consisted of practice interviews
in which specific skills in using prompts and questions for clarification were emphasised. As the interviews aimed to record the narratives of migrants, attention was also given to allowing the participants sufficient time to tell their story and to allow this to develop over the course of the interview. The majority of Indian and Somali participants requested information and interviews in English whilst the majority of the Chinese participants requested interviews and information be provided in Chinese.

**Recruitment of Chinese and Indian participants**

The Chinese and Indian groups were recruited through an email invitation to participate, which was sent to coordinators of community-based cultural groups. A bilingual educator from the MCWH provided a connection between the organisation and the community groups. The bilingual educator had delivered health education sessions to these community groups over a number of years and had established links to the groups. The bilingual educator assisted with the recruitment of both groups through the distribution of an email invitation, including the inclusion criteria, to culturally specific community coordinators.

The community coordinators then provided information about the study to community members. The names of those wishing to participate were then forwarded to myself via the coordinators. I then contacted the people wishing to participate to arrange an interview and provided them with further information on the study’s scope, purpose, and consent and withdrawal processes, in the language of preference.

**Recruitment of Somali participants**

A snowball sampling strategy is commonly used with populations that are not readily identifiable or locatable through accessible networks or associations. The Somali community is connected with typically weaker formal connections to external agencies or communities, making access more challenging. Snowball sampling involves recruiting one or more members of a community and asking them to assist in recruiting other members of the study population (Eccles et al., 2009). The snowball sampling approach has been shown to be an effective recruitment strategy for ‘hard-to-reach’ groups as it mitigates some potential barriers such as access and trust (Sadler et al., 2010).

The Somali community is more willing to respond to channels of known associations, rather than to people they have had no prior contact with. Advisory Group members provided names and contact details of Somali leaders to contact for participation in the study. Three Somali leaders were selected from different locations and representing different Somali tribal groups (the main
tribal groups were Darod, Hawiye, Isaaq and Hararian tribal affiliations) and these leaders agreed to introduce the study to potential participants. It is important to note that whilst the Somali participants adhered to tribal affiliations in their country of origin, post-migration cross-tribal connections have developed that have led to less rigidity in social connections. Therefore, whilst the Somali leaders represented a particular tribal group, there was a mix of different tribal affiliations in each of the three groups. I was introduced to the potential participants by the three Somali leaders at which time they were provided with the selection criteria and information on the study. The leaders then spoke with community members about the study and provided my contact details to them. The members contacted me by phone or in person and made arrangements for me to meet with them.

Recruited participants then approached others within their social network who fitted the recruitment criteria (men and women born and raised to adulthood in Somalia) until the desired sample size was reached. Interviews were conducted in community centres and at social gatherings in which individuals were interviewed separately. The majority of interviews were conducted in English, however, where requested, an interpreter was provided and the interviews were conducted in the interviewee’s nominated language. I asked the questions and the translator translated these questions to the participant and the participant responded back to the researcher. The translators were not known to the participant.

Data collection

The application of a multi-dimensional health literacy questionnaire

The Health Literacy Questionnaire (HLQ) (See Appendix 4) is a multi-dimensional measure of HL competencies, based on a broad conceptualisation of healthy literacy (Osborne et al., 2013). The HLQ contains forty-four questions across nine constructs;

1. Feeling understood and supported by health care providers;
2. Having sufficient information to manage my health;
3. Actively managing my health;
4. Social support for health;
5. Appraisal of health information;
6. Ability to actively engage with health care providers;
7. Navigating the health care system;
8. Ability to find good health information; and
9. Understand health information well enough to know what to do.
See Table 4.2 for the low and high descriptors of each of the nine HLQ constructs.

**Table 4.2: The Health Literacy Questionnaire scales with low and high descriptors of each construct**

<table>
<thead>
<tr>
<th>Low level of the construct</th>
<th>High level of the construct</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling understood and supported by health care providers</td>
<td>Has an established relationship with at least one health care provider who knows them well and who they trust to provide useful advice and information and to assist them to understand information and make decisions about their health.</td>
</tr>
<tr>
<td>People who are low on this domain are unable to engage with doctors and other health care providers. They don’t have a regular health care provider and/or have difficulty trusting health care providers as a source of information and/or advice.</td>
<td></td>
</tr>
<tr>
<td>2. Having sufficient information to manage my health</td>
<td>Feels confident that they have all the information that they need to live with and manage their condition and to make decisions.</td>
</tr>
<tr>
<td>Feels that there are many gaps in their knowledge and that they don’t have the information they need to live with and manage their health concerns.</td>
<td></td>
</tr>
<tr>
<td>3. Actively managing my health</td>
<td>Recognise the importance and are able to take responsibility for their own health. They proactively engage in their own care and make their own decisions about their health. They make health a priority.</td>
</tr>
<tr>
<td>People with low levels don’t see their health as their responsibility; they are not engaged in their health care and regard health care as something that is done to them.</td>
<td></td>
</tr>
<tr>
<td>4. Social support for health</td>
<td>A person’s social system provides them with all the support they want or need for health.</td>
</tr>
<tr>
<td>Completely alone and unsupported for health.</td>
<td></td>
</tr>
<tr>
<td>5 Appraisal of health information</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------</td>
<td></td>
</tr>
<tr>
<td>No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information.</td>
<td>Able to identify good information and reliable sources of information. They can resolve conflicting information by themselves or with help from others.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. Ability to actively engage with health care providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are passive in their approach to health care, i.e., they do not proactively seek or clarify information and advice and/or service options. They accept information without question. Unable to ask questions to get information or to clarify what they do not understand. They accept what is offered without seeking to ensure that it meets their needs. Feel unable to share concerns. The do not have a sense of agency in interactions with providers.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7. Navigating the health care system</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to advocate on their own behalf and unable to find someone who can help them use the health care system to address their health needs. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8. Ability to find good health information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cannot access health information when required. Is dependent on others to offer information.</td>
</tr>
</tbody>
</table>
9. Understanding health information well enough to know what to do

| Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms. | Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required. |

Source: (Osborne et al., 2013)

The HLQ describes the HL strengths and needs of people at community and population levels, and has the potential to measure outcomes of public health and clinical interventions designed to improve HL (Batterham et al., 2016; Osborne et al., 2013). It was developed in a Western biomedical context and has not been formally tested in migrant populations (Osborne et al., 2013). The HLQ has been found to be highly reliable, even with only 4 to 6 items per scale, and provides unbiased estimates of mean group differences across key demographic indicators (Elsworth et al., 2016).

Each domain of the HLQ consists of either 4 or 5 items. Items in the first five domains are scored from 1 to 4 (strongly disagree = 1 to strongly agree = 4), while the last four domains are scored 1 to 5 (cannot do or always difficult = 1 to very easy = 5). A domain score is calculated by adding up the scores within each domain and then dividing this value by the number of items in the respective domain with higher scores indicating higher HL. Each HLQ domain has been demonstrated to be conceptually distinct and measure independent constructs using confirmatory factor analysis, consequently a total score is not generated (Osborne et al., 2013).

The HLQ was translated from English into Somali, Simplified Chinese (simplified, so it was suitable for both Cantonese and Mandarin speakers), and Hindi.

**Cognitive interviews**

In this study, cognitive interviewing was employed to gain insights into the interpretations of HLQ items across the three migrant groups. Also, these interviews sought to understand if the HLQ items were hard to understand and whether they were potentially offensive or culturally inappropriate, and how the wording could be improved. Although the HLQ has been used in other Western cultures (Kolarcik et al., 2017; Maindal et al., 2016; Nolte et al., 2017) its utility in migrant groups is largely unknown. Cognitive interviewing is a process used to see if respondents understood the intended meaning of items in the HLQ or whether they understood it in other ways that were not intended. In the current study, the use of cognitive interviews was
also used to generate nuanced information on; choice of item responses and linkages between cultural beliefs and HL practices.

In the field of survey design there is great interest in investigating and understanding the cognitive processes involved in interpreting survey questions and providing answers. Cognitive interviewing has emerged as one of the more prominent methods for investigating these processes, and has been described by Beatty and Willis (2007) this way:

Cognitive interviewing entails administering draft survey questions while collecting additional verbal information about the survey responses, which is used to explore the quality of the response or to help determine whether the question is generating the information that its author intends. (Beatty & Willis, 2007, p. 288)

According to Willis (2007) the process should include the following four core elements: (1) respondent elaborations regarding how participants constructed their answers; (2) explanations of what they interpret the questions to mean; (3) reports of any difficulties they had answering; and (4) anything else that sheds light on the broader circumstances that their answers were based upon (Beatty & Willis, 2007). Cognitive interviewing aims to reveal respondents’ thought processes and how they understand and answer the questions (Goerman & Caspar, 2010). It is a process increasingly used for pretesting translated questionnaires targeting non-English speakers (Goerman & Caspar, 2010).

**Linkage of the Nutbeam’s model of HL to the HLQ**

Following a content review, the authors of the HLQ mapped the HLQ constructs to Nutbeam’s HL model (Nutbeam, 2000) across the three levels of Basic, Communicative and Critical HL (Osborne et al., 2013). Nutbeam identified three separate but overlapping health literacies within the overarching concept of HL. Importantly, this theoretical model of HL identified the individual, community and public health levels, thus merging the previously disparate clinical and public health dimensions of HL.

The overlay of Nutbeam’s HL model (Nutbeam, 2000) in this study has the potential to generate new insights in to respondents’ HL characteristics. Previous studies have primarily focused on the basic/functional HL skills of migrants, which do not provide a comprehensive understanding of the HL skills of migrants such as in communicative or interactive levels of HL (Han et al., 2011; Rau et al., 2014; Shaw et al., 2012). This is problematic as functional HL is often assessed through literacy and numeracy tests (Jordan et al., 2011) that omit a range of HL skills that migrants may possess. This omission, known as ‘construct underrepresentation’ (Goodwin &
Leech, 2003) or ‘systemic bias’ (Downing, 2002), that occurs when a concept is measured and conclusions made that may be fallacious and potentially misleading. Categories identified in Nutbeam’s model are helpful in broadening an understanding of HL to include elements such as communication methods commonly used by migrants such as oral HL skills (Harrington & Valerio, 2014). The model also manifests strengths such as social supports within social networks (Edwards et al., 2015a; Han et al., 2011) that are also common to migrant groups.

Table 4.3: Linkages between the Nutbeam model of health literacy and the Health Literacy Questionnaire (HLQ).

<table>
<thead>
<tr>
<th>Nutbeam’s schema</th>
<th>Broad matching HLQ domains3</th>
</tr>
</thead>
<tbody>
<tr>
<td>i) Basic/functional HL: sufficient basic skills in reading and writing to be able to function effectively in everyday situations</td>
<td>9. Understanding health information well enough to know what to do</td>
</tr>
<tr>
<td></td>
<td>2. Having sufficient information to manage my health</td>
</tr>
<tr>
<td></td>
<td>8. Ability to find good quality health information</td>
</tr>
<tr>
<td>ii) Communicative/interactive HL: more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances</td>
<td>1. Feeling understood and supported by health care providers</td>
</tr>
<tr>
<td></td>
<td>3. Actively managing my health</td>
</tr>
<tr>
<td></td>
<td>4. Social support for health</td>
</tr>
<tr>
<td></td>
<td>6. Ability to actively engage with health care providers</td>
</tr>
<tr>
<td></td>
<td>7. Navigating the health system</td>
</tr>
<tr>
<td></td>
<td>8. Ability to find good quality health information</td>
</tr>
<tr>
<td>iii) Critical literacy: more advanced cognitive skills, which together with social skills, can be applied to critically analyse information, and to use this information to exert greater control over life events and situations</td>
<td>5. Appraisal of health information</td>
</tr>
<tr>
<td></td>
<td>3. Actively managing my health</td>
</tr>
<tr>
<td></td>
<td>4. Social support for health</td>
</tr>
</tbody>
</table>

Source: (Osborne et al., 2013)

3 Osborne et al. note that there is likely overlap between the three levels within the HLQ domains (Osborne et al., 2013).
Understand the health conceptualisations of three migrant groups

In-depth, semi-structured qualitative interviews were undertaken in the third phase of this study. A semi-structured life world interview “… is defined as an interview with the purpose of obtaining descriptions of the life world of the interviewee in order to interpret the meaning of the described phenomena” (Kvale & Brinkmann, 2009, p. 175). According to Kvale and Brinkmann (2009) interviewing is a craft, a knowledge producing activity and a social practice. They outline seven key stages of qualitative interviewing: (1) thematising and interview project; (2) designing; (3) interviewing; (4) transcribing; (5) analysing; (6) verifying; and (7) reporting.

Interviews offer richer and more extensive material than data from surveys alone (Eccles et al., 2009). Interviews were used in this study to gain insight into the constructed reality of the participants and to investigate the phenomenon of health in more depth (Eccles et al., 2009). The guided interviews in this study were used to validate, challenge or expand on the results from the quantitative data and the cognitive surveys. Interviews were able to reveal meaning and cultural relevance and elucidate explanatory models that increase understanding of motivation and health practices in these three groups.

Rationale for size estimation

The HLQ is a precise measure of HL where relatively small sample sizes are required to detect moderate differences. As this study was exploratory, no a priori power calculations were undertaken. However, with a sample size of 80 people in each group, and with a pooled standard deviation of 0.55 (based on data from the Ophelia study (Beauchamp et al., 2015)), power = 0.8, alpha = 0.05, the study was powered to detect a moderate difference between two groups (0.25 units, or an effect size of 0.45). For cognitive interviews, the protocol of Osborne et al., for the HLQ was followed in which at least 5 people were interviewed to explore whether the perceived item content was consistent with the intent of the items. The semi-structured in-depth interviews were conducted until data saturation was reached and when no new themes emerged.

Section 3: Three study phases

The following section provides a detailed description of each of the three study phases.

Phase 1: Understanding the health literacy strengths and needs of three distinct migrant groups in Australia – Application of the HLQ

A total of 242 participants were recruited. 240 provided complete data and were included in the study. Two individuals who had initially consented opted out because they were unable to attend
an interview (See Table 4.4 for participant demographic characteristics). Respondents were recruited from three cultural groups (Somali n=80, Chinese n=80 and Indian n=80) living in urban and regional areas of Melbourne, Australia. The mean age of participants was 39 years (ranging from 18 to 87 years), with 35% of participants aged between 27 and 35 years. Half of the sample was university educated while 41% had completed secondary school or gained a technical level certificate. Females comprised 46% of the sample with 47% speaking English at home. The Chinese (50%) and Indian (48%) groups had much higher levels of private health insurance than the Somali group (0%). Approximately 25% of the sample required assistance to complete the questionnaire by a translator or bi-cultural educator. The Ophelia study comparison group had a slightly higher number of females, with more participants who lived alone and a much higher number who spoke English at home. In addition, there were fewer university educated participants, a greater number with reported chronic conditions and a greater number of health care card holders.

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4 The ages of the Somali participants are recorded as conveyed, however, many are approximations due to the practice of not recording dates of birth in Somalia.
Table 4.4: HLQ participant demographic characteristics of Somali, Chinese and Indian participants in HL survey (n=240) with comparison group from Ophelia study (n=813)

<table>
<thead>
<tr>
<th>Descriptors</th>
<th>Somali (n=80)</th>
<th>Chinese (n=80)</th>
<th>Indian (n=80)</th>
<th>Ophelia study (n=813)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female (N, (%))*</td>
<td>40 (50)</td>
<td>30 (37.5)</td>
<td>42 (52.5)</td>
<td>505 (63%)</td>
</tr>
<tr>
<td>Age (mean, range) years</td>
<td>43 (18-70)</td>
<td>40 (23-87)</td>
<td>33 (23-74)</td>
<td>72.1 (19-99)</td>
</tr>
<tr>
<td>Lives alone</td>
<td>3 (4%)</td>
<td>15 (19%)</td>
<td>0</td>
<td>337 (44%)</td>
</tr>
<tr>
<td>English spoken at home</td>
<td>54 (68%)</td>
<td>17 (21%)</td>
<td>40 (50%)</td>
<td>723 (91%)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary education</td>
<td>1 (1%)</td>
<td>0</td>
<td>0</td>
<td>118 (15%)</td>
</tr>
<tr>
<td>Secondary (not completed)</td>
<td>15 (19%)</td>
<td>3 (4%)</td>
<td>1 (1%)</td>
<td>258 (33%)</td>
</tr>
<tr>
<td>Secondary (completed)</td>
<td>27 (34%)</td>
<td>8 (10%)</td>
<td>11 (14%)</td>
<td>160 (20%)</td>
</tr>
<tr>
<td>Technical level certificate</td>
<td>19 (24%)</td>
<td>5 (6%)</td>
<td>30 (38%)</td>
<td>138 (18%)</td>
</tr>
<tr>
<td>University</td>
<td>18 (23%)</td>
<td>64 (80%)</td>
<td>38 (48%)</td>
<td>109 (14%)</td>
</tr>
<tr>
<td><strong>Chronic health conditions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arthritis</td>
<td>1 (1%)</td>
<td>2 (3%)</td>
<td>0</td>
<td>399 (51%)</td>
</tr>
<tr>
<td>Back pain</td>
<td>7 (9%)</td>
<td>4 (5%)</td>
<td>17 (21%)</td>
<td>338 (44%)</td>
</tr>
<tr>
<td>Heart problems</td>
<td>0</td>
<td>1 (1%)</td>
<td>0</td>
<td>325 (42%)</td>
</tr>
<tr>
<td>Cancer</td>
<td>0</td>
<td>4 (5%)</td>
<td>0</td>
<td>77 (16%)</td>
</tr>
<tr>
<td>Depression / anxiety</td>
<td>0</td>
<td>5 (%)</td>
<td>1 (1%)</td>
<td>238 (32%)</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>8 (10%)</td>
<td>2 (2.5%)</td>
<td>3 (4%)</td>
<td>300 (39%)</td>
</tr>
<tr>
<td>Reports no health condition</td>
<td>64 (80%)</td>
<td>62 (78%)</td>
<td>59 (47%)</td>
<td>399 (51%)</td>
</tr>
<tr>
<td><strong>Health insurance or health care card holders</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private health insurance</td>
<td>0</td>
<td>38 (48%)</td>
<td>36 (45%)</td>
<td>298 (39%)</td>
</tr>
<tr>
<td>Health care card</td>
<td>42 (55%)</td>
<td>59 (74%)</td>
<td>14 (18%)</td>
<td>651 (82%)</td>
</tr>
<tr>
<td>Assistance to complete HLQ</td>
<td>18 (19%)</td>
<td>2 (3%)</td>
<td>8 (10%)</td>
<td>291 (38%)</td>
</tr>
</tbody>
</table>

*N (%) unless otherwise stated.

**Translation of the HLQ**

All three language translations of the HLQ (Somali, Hindi and Simplified Chinese) were subject to a rigorous translation and cultural adaptation procedure. The translation process consisted of forward translation, then blind backward translation, followed by further verification with native speakers within a consensus committee, to ensure that the intended meaning of items was consistent with the *a priori* item intent.
Consent forms were provided in English, Somali, Chinese and Hindi.

**HLQ administration procedure**

The HLQ was loaded onto secure survey software (SurveyMonkey) in English, Simplified Chinese, Hindi and Somali. The use of an iPad was tested with members of the Advisory Groups who provided feedback that the iPad was generally accessible for those with digital skills but that paper-based surveys were also preferred by some participants. Participants completed the questionnaire using an iPad or a paper survey and these results were subsequently entered into the online survey.

The consent form (See Appendix 1) was read in full to each participant who were given the option of declining to participate or providing either written or verbal consent. Participants were also asked if they would like to participate in Phases 2 and 3 of the study.

Participants were asked by the translator or myself to specify their language preference for completing the questionnaire. In addition, either the interpreter or I assisted with explaining how to complete the survey by demonstration and also offered to read the questions to the participants. On each occasion, the survey was read to the participants verbatim. It was also explained to each participant that, if for any reason they did not wish to complete the questionnaire, they were free to withdraw from the study.

**Data analysis**

The HLQ responses were entered into IBM Corp Statistical Package for the Social Sciences SPSS Version 21.0 (Armonk, Released 2012). Demographic data were initially analysed using descriptive statistics.

A comparison sample was used from the Ophelia study (Beauchamp et al., 2015). The Ophelia study was a cross-sectional using the HLQ to describe the HL profile of people (n = 813) currently using community-based health services across urban and rural Victoria (see Table 4.4). This study population was an appropriate comparison group for two reasons. Firstly, this large study was conducted within demographic sub-groups of typical adult users of services in Victoria, thus providing results that might approximate average HL range for the general Australian population. Secondly, as the study used the HLQ as a measure of HL, it permitted direct comparison with the current study. Use of this comparison group provided the opportunity to explore differences and similarities in HLQ ratings across groups.
For HLQ score comparisons across the three immigrant groups, assumptions of normal distribution were partially met. As the deviations were judged as modest, the use of 95% confidence intervals (CIs), robust analysis of variance (ANOVA) and multiple linear regression were deemed reasonable and were undertaken to compare groups.

Firstly, univariate comparisons were conducted across groups, then, for the combined sample, English spoken at home, education and gender were compared across all of the nine HLQ domains. Robust ANOVA was conducted using Welch's F test and post hoc group comparisons were conducted using the Games-Howell test. Linear regression was conducted to determine if differences existed between the three migrant groups while adjusting for potential confounders (age, education and English spoken at home).

**Phase 2: Cognitive interviews**

**Participants**

A total of eighteen participants who completed the HLQ, six from each migrant group, participated in cognitive interviews (see Appendix 5). Selection criteria included participants who were observed to hesitate or deliberate on questions whilst completing the HLQ. Participants were selected across key categories (sex, age, years since migration) to approximately achieve an even distribution across key categories. Participants who met these criteria were selected until the number of participants required was met. As shown in Table 4.5, the Somali group had the lowest levels of formal education, with four participants having no formal education, and the Indian and Somali group had higher levels of university level education.
Table 4.5: Demographic profile of participants in cognitive interviews

<table>
<thead>
<tr>
<th>Descriptors</th>
<th>Somali (n=6)</th>
<th>Chinese (n=6)</th>
<th>Indian (n=6)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-30 years</td>
<td>1</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>30-40 years</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>30-40 years</td>
<td>2</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>50 years or more</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Education levels</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal Education</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Attended religious schools</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Finished secondary school</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td><strong>Tertiary</strong></td>
<td>1</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td><strong>Years since migration</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5 years</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>5-10 years</td>
<td>2</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>10-20 years</td>
<td>4</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20 or more</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>One or more chronic diseases</strong></td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

**Procedures**

Consenting respondents were taken back through a selection of HLQ items including any they had either hesitated on, or appeared to have difficulty answering. They were asked, “What were you thinking about when you were answering that question?” This process elicited the cognitive process behind their answers. An additional prompt was also used if needed: “Why did you select that answer?” to reveal potential reasons why participants might hesitate such as: don’t understand (words, concepts), do understand but need to reflect on relevance to their life, not commonly done within their community. Data was collected using the cognitive Interview Schedule (See Appendix 5). Responses were recorded against items on the schedule.
Respondents who appeared to have some difficulty with some questions and who consented to the interview, were taken back through a selection of items including those they had hesitated on or appeared to have found difficult to answer. They were asked, “What were you thinking about when you were answering that question?” This process elicited the cognitive process behind their answers. An additional prompt was also used if needed: “Why did you select that answer?” Given previous experience, a set of codes covering potential reasons why participants might hesitate included: don’t understand (words, concepts), do understand but need to reflect on relevance to their life, not commonly done within their community. Data was collected using the cognitive Interview Schedule (See Appendix 5). Responses were recorded against items on the schedule.

Data analysis

The analysis involved a two-step process as outlined below. The first step assessed item interpretation and then matching the response to Nutbeam’s HL Mode (Nutbeam, 2000).

**Step 1 – Assessing item interpretation**

Words or terms that were identified as difficult by participants were recorded. In addition, difficulties with conceptual understanding of items were also noted. It was important to determine whether a difficulty in understanding an item was related to language issues or to the misinterpretation of item constructs. Language related issues included low English proficiency, terms that were new to the participant, and terms and concepts that were not commonly used in the individual’s community or did not resonate with the individual. Words or terms that were identified as difficult by participants were recorded. In addition, difficulties with conceptual understanding of items were also noted.

Conversely, item construct utility was analysed to determine similarities in understanding of constructs and whether one understanding parallels another, that is, a respondent may answer high or low from their own understanding of the construct, in a similar pattern to other people with their understanding. When understanding is not similar across a group and relates to different mechanisms then the utility of the item for migrant groups may need to be re-explored.

**Step 2 – Nutbeam’s HL model**

Responses from the cognitive interviews were summarised and collated under the nine HLQ domains and then matched against the criteria for Nutbeam’s three HL levels (Nutbeam, 2000). Using the HLQ domains that, according to the HLQ authors, capture elements of Nutbeam’s
model (Osborne et al., 2013), the thematic responses were grouped into the three tiers of the model to determine how well the responses matched the model criteria.

Phase 3: Semi-structured interviews

Participants

Forty-five participants were involved in this phase of the study (See Table 4.6), fifteen from each of the three migrant groups (Somali, Chinese and Indian). Participants who completed the HLQ were asked to participate in this phase of the study. Of those who consented, purposive sampling was conducted to select for sex, age and length of time in Australia, where possible. A total of forty-five participants were chosen to provide adequate data to achieve a point of saturation. Saturation is a concept originating in Grounded Theory in which variability in responses is reduced, allowing for the relationships between data categories to be tested and validated, thus allowing new theories to emerge (O’Reilly & Parker, 2013).

There were more female participants than male (29 and 17 respectively), with the Somali and Indian groups slightly younger than the Chinese group. Participants from the three groups were generally healthy with between two and four participants per group reporting a chronic disease. The Indian participants had the highest number of recently arrived participants (between one and five years since arrival) and the Chinese group had the most participants with tertiary level education.

Table 4.6: Demographic profile of participants in semi-structured interviews

<table>
<thead>
<tr>
<th>Descriptors</th>
<th>Somali (n=15)</th>
<th>Chinese (n=15)</th>
<th>Indian (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>5</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Female</td>
<td>10</td>
<td>11</td>
<td>8</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-30 years</td>
<td>3</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>30-40 years</td>
<td>6</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>40-50 years</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>50-80 years</td>
<td>2</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Years since migration</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5 years</td>
<td>3</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>5-10 years</td>
<td>4</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>10-20 years</td>
<td>4</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>
### Procedures

An interview schedule (See Appendix 9) was derived and tested with members of each of the three Advisory Groups to ensure it was culturally appropriate. A small number of changes were made to simplify the wording following testing. The interviews were recorded and they took between 30 and 60 minutes.

The process commenced by establishing rapport and building a level of trust with the interviewee/s and, when asking questions, assuming a position of neutrality (Kvale & Brinkmann, 2009) The interview questions were asked by myself in English and when required a translator or the bi-lingual educator assisted. The translator or bilingual educator, who was not known to the participants prior to the interviews, then translated the question to the interviewee. The interviewee’s response was then translated into English. The semi-structured interviews commenced with the seeding question:

> Thinking about the experiences of (Chinese/Indian/Somalian) people in Australia, in trying to look after their health (or the health of their family), what do they need to assist them to get and use the information and health care they need?

During the interviews, an approach of active listening and sensitivity to the participant responses was employed. Participants were encouraged to tell their own story about their health and their health beliefs in as much detail as they wished, with prompt questions used to expand on points or to clarify a response.

### Data analysis

Data were subjected to a six phase thematic analysis process (Braun & Clarke, 2006) using Vivo qualitative data analysis Software (QSR, 2012);

1. Data were transcribed and interviews checked for accuracy by a second researcher and then read and re-read, noting down initial ideas.

<table>
<thead>
<tr>
<th>Educational level</th>
<th>20 years or more</th>
<th>4</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>No formal education</td>
<td>5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Attended religious schools</td>
<td>15</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Finished secondary</td>
<td>7</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Tertiary</td>
<td>3</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td><strong>One or more chronic diseases</strong></td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
2. Initial codes were generated using a systematic process across the entire data set and data relevant to each code were collated.

3. The codes were collated into potential themes, gathering all data relevant to each potential theme.

4. The themes were checked by a second researcher to see if they worked in relation to the coded extracts and the entire data set to generate a thematic ‘map’ of the analysis.

5. Finally, themes were defined and named, and then analysed to refine the specifics of each theme and the overall story the analysis told, generating clear definitions and names for each theme.

6. The final selected extracts were checked against the research question.

Summary

In summary, this study employed a range of innovative, robust methods to generate data that will advance the understanding of HL in migrant groups. Through the triangulation of qualitative and quantitate methods this study will provide greater contextual and explanatory data than previous studies.

In the following chapters I present the results for each migrant group separately across the three phases of the study, followed by a synthesis of the three groups.
Chapter 5: Somali Participant Health Literacy

Section 1: Somali-Australian migrants

Introduction
This chapter begins with a description of the socio-demographic and cultural profile of the Somali-Australian population, including an overview of their traditional health practices and health outcomes of the Somali diaspora. This is followed by an analysis of data collected on the Somali group obtained through the application of a range of methods including the administration of the HL questionnaire (HLQ) and cognitive and semi-structured interviews. This chapter concludes with a discussion of the findings that compares and contrasts the current literature with the findings to reveal new contributions to the field and the potential of these findings to influence systemic HL approaches and practices.

Somalia’s descent into conflict
The first known occurrence of the ethnic name 'Somali' was in the fifteenth century in an Ethiopian hymn celebrating the victories of the Abyssinian king, Negus Yeşhaq, at the time of the holy wars against surrounding Islamic principalities (Lewis, 2004). Somalia is located on the east coast of Africa and has a long history of colonisation by various foreign powers such as Italy, Ethiopia, Britain and France (The World Fact Book: Somalia, 2016). Foreign interests and clan-based conflict have destabilised Somalia since 1978 (The World Fact Book: Somalia, 2016) producing one the largest refugee populations in the world with the Somali diaspora now extending into Europe, United States, Asia and Australia (UNHCR, 2015). The Somali-Australian population has a recent migration history to Australia under the humanitarian refugee and family reunification programs (Community Information Summary Somalia-Born, 2012). Small numbers of Somalis began to arrive in Australia in the 1980s, with a much larger migration in the early 1990s following the toppling of the Somalian President Siad Bar and the ensuing collapse of the Somali state (Gascoigne, 2001).

5 The term “diaspora” is used to signify transnational movement as well as a shared historical context of displacement but does not imply homogeneity within migrant groups (Clifford, 1994).
**Somali-Australian population**

According to the 2011 census (Community Information Summary Somalia-Born, 2012) there were over 5,000 Somali-born persons living in Australia, however, this number may underestimate the actual number of Somalis in Australia. Due to external and internal disruption many thousands of ethnic Somalis reside in countries surrounding Somalia such as Ethiopia, Kenya and Djibouti (Nations). These individuals may be categorised as belonging to the nationality of the most recent country of residence and may not identify as Somali.

The majority of the Somali population in Australia lives in Victoria, with a comparatively young median age of 30 years (Community Information Summary Somalia-Born, 2012) which is lower than the median age of overseas-born populations (45 years) and lower than the median age of the Australian-born population (33 years) (Migration Australia 2014–15). Most of the Australian Somali-born population speak a language other than English in the home and observe the Islamic faith (Community Information Summary Somalia-Born, 2012). Somali is the official language of Somalia, but Arabic, English and Italian are commonly spoken (Scuglik et al., 2007). Somalis’0 may also speak other dialects or languages related to clan affiliations and/or the geographical regions they are from (The World Fact Book: Somalia, 2016)

**Oral traditions of Somalia**

Somali’s emanate from an oral tradition, with the written form of the language not recorded until 1973 (Scuglik et al., 2007). This and a range of other disruptive factors has limited the education of Somalis and contributed to the low levels of literacy of Somali-Australians in their own language.

Oral tradition has an essential role in the life of the Somali people who have a long history of memorising long poems and practising the art of speech (Abokor, 1987). According to the renowned Somali scholar Axmed Cali Abokar, Somalis have valued oratory for centuries and built vast repertoires of stories and poems (Abokor, 1987). In Somali culture, orality and literacy are synonymous with oral prowess integral to survival (Cassanelli, 2006). For example, in the justice system it is the better orator who will sway the judge to his cause and great poets hold great power to influence public opinion (Abokor, 1987). The role of poetry is broader than entertainment; it is used as both a method of instruction and an effective mechanism to transfer information quickly across the country (Abokor, 1987). It is said that Somalis venerate both their camels and their poets, with their bodies nourished by camel’s milk and their hearts nourished by the poet’s oratory (Abokor, 1987; Carruth, 2014).
Family structure in Australia

In Somali culture, the family is a source of identity and security as reflected in the common greeting “Whom are you from?” rather than “Where are you from?” (Scuglik et al., 2007) or “Who are you?” A Somali person is required to reveal his or her identity through clan relations, and Somali children are taught from a very young age to memorise their lineage (Ali, 2006). Somalis do not use racial identity but their kinship system, which provides protection from enemies and is used to regulate the sharing of scarce resources (Bokore, 2013). This becomes their identity and security when moving from place to place within Somalia (Ali, 2006) and within the wider Somali diaspora.

The Somali culture is based on a patriarchal family structure and a clan system (Lewis, 2004) with Somalis first affiliation to their family then the extended family followed by the sub-clan and clan (Luling, 2006). Genealogical descent refers to the system by which kinship is traced over generations and constitutes the heart of the Somali social system. The two main branches of the nation emanated from the brothers Samaale and Sab and their father Hiil, the supposed ancestor of all the Somali nation. These were followed by the Sheikhs Daarood and Isaaq, who came from Arabia to preach the Islamic faith and through them descent can be traced to the Prophet’s lineage of Quraysh (Luling, 2006). The genealogical tree has been extended and now consists of six clan families—Isaaq, Daarood, Awiye, Dir, Digil and Rahawayn (Lewis, 2004). Family history is traced through the male genealogical line, with a person’s full name composed of his or her given name followed by the father, grandfather and back up to six generations (Lewis, 2004).

Religion

Whilst Somalis largely follow the Sunni teachings of Islam, their pre-Islamic Cushitic religious beliefs have been fused with mystical Sufism and the traditional spirits or Jinns widely Islamised (Tiilikainen, 2003). Sufism was the original form of Islamisation in many Somali areas before the ‘re-Islamisation’ process that has been carried out in the last two decades by the neighbouring Arab countries (Declich, 2000). Islam is critically important to both Somali personal and national identity (Ali, 2006). It provides both spiritual and physical guidance and influences all aspects of Somali life (Clarkson Freeman et al., 2013). Somali migrants are generally homogeneous in adherence to Islamic practice (Clarkson Freeman et al., 2013) and this has acted to unify Somalis during clan destabilisation (Spitzer, 2006).
The Somali-Australian population

Almost half of the Somali-Australian community resides in the lowest socioeconomic group within Australian society with a median income below the poverty line, at $295 per week per person compared to the incomes of both overseas-born ($538), and the Australian-born population ($597) (Community Information Summary Somalia-Born, 2012). The low income levels seen in the Somali community are related to employment barriers such as language, skill limitations and discrimination (Community Information Summary Somalia-Born, 2012), as the majority of Somalis arrived in Australia with low levels of formal education (Community Information Summary Somalia-Born, 2012). Somalis are generally educated in Islamic madrasas and schooled in formal Arabic as expressed in the religious text, the Quran (Hoben, 1988). In 2011, the labour force participation rate among Somali-born people aged 15 years and over was 51.8% (compared to 65% in the Australian population) and the unemployment rate was 22.1% (compared to 5.6% in the Australian population). Somalis demonstrate entrepreneurial skills with many being self-employed, predominantly in the transport and childcare sectors. In addition, the majority of Somalis live in the lowest ranked socioeconomic areas of disadvantage (See Table 5.1).

Table 5.1: Socioeconomic indexes for areas ranking for place of residence of Somali group in Australia

<table>
<thead>
<tr>
<th>Socioeconomic Index for Areas (SEIFA) ranking (ABS, 2013)</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (highest socioeconomic disadvantage)</td>
<td>45</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>10 (lowest socioeconomic disadvantage)</td>
<td>2</td>
</tr>
</tbody>
</table>
Health risk profile

Studies on the health of Somali migrant populations are scarce, therefore the following section may not reflect the full range of relevant health issues. Somali women have increased risk factors for chronic disease such as obesity, hypercholesterolemia and hypertension (Kumar & Einstein, 2012) and Somalis are more likely to report having preventable diseases (Al-Amoudi et al., 2015). Population based Australian data show that compared to the Australian-born population, Sub-Saharan (SS) Africans have higher rates of risk indicators for smoking, obesity and high blood pressure and are less likely to participant in regular exercise (ABS, 2014).

Studies show that Somalis’ have low rates of screening participation (breast, cervical and colorectal) (Abdullahi et al., 2009; Al-Amoudi et al., 2015; Morrison et al., 2013; Morrison et al., 2012; Raymond et al., 2014; Samuel et al., 2009; Sewali et al., 2015; Weber et al., 2014). International studies indicate that East African women have one of the highest cervical cancer incidence rates. The incidence of cervical cancer among Somali women is up to seven times higher than Australian women (Bruni et al., 2016), with a mortality rate that is up to eighteen times higher than Australian women, which is one of the highest in the country (Bruni et al., 2016; Sewali et al., 2015). In addition, African-American women have one of the highest percentages of late stage presentation for breast cancer (Ndukwe et al., 2013). Somalis also have a low uptake of the Human Papilloma Virus (HPV) vaccine (Bruni et al., 2016; Dailey, 2013; Farnsworth, 2016) prompting trials of HPV self-sampling in underscreened groups such as Somali women (Farnsworth, 2016; Sewali et al., 2015). A US study found that low risk perception, fatalism, stigma and privacy are among the major factors that affect female African immigrants’ decision not to seek preventative screening measures for breast and cervical cancer (Ndukwe et al., 2013).

Health literacy

A number of studies found that Somalis’ have low levels of HL (Gele et al., 2016; Geltman et al., 2014; Gerritsen et al., 2006b; Odunukan et al., 2015; Wångdahl et al., 2014b). A recent study (Gele et al., 2016) conducted in Norway with 302 Somali women, using the short version of the European HL Questionnaire found that 71% of Somali women had inadequate HL. The study found that employment, used as a proxy indicator for acculturation, and social integration were associated with higher levels of HL. This study used a HL measure validated in the general population only and was not situated within a cultural framework in the study design, analysis or reporting.
Divinity, camel’s milk and dawo: Traditional and biomedical approaches among Somali migrants

Somalia’s traditional medicine or dawo dhaqmeed is a composite of religious, spiritual and herbal approaches influenced by Islamic medicine and Sufi healing practices (Carruth, 2014). “Somalis’ notions of health and wellbeing are largely dependent upon two forces: balance between bodily fluids or humors, and ultimate divine causality” (Carruth, 2014, p. 407).

Somalis view health through a religious and spiritual lens and believe that ill health is caused by external factors that can be controlled through prayer or observance of cultural customs. Individuals do not have agency to prevent illness, which may be caused by a communicable disease, by God, by spirit possession or by the ‘evil eye’. Mental illness is believed to be caused by spirit possession or as a punishment from God (Waldron & Gayle, 2002). Religious leaders or ‘Sheikhs’ are considered powerful individuals who can restore the relationship between the individual and Allah thus restoring health (Declich, 2000).

Within the Somali culture, rituals are continually observed to limit the power of external forces. For example, when a compliment is bestowed on an individual this must be followed by the term Masha Allah which protects the individual against ‘sexir’, the evil eye that can be cast by a person who is jealous or envious (Johnsdotter et al., 2011). Traditional spiritual healers use religious rituals for healing and individuals often wear amulets to keep away evil spirits. Traditional treatments include religious remedies such as prayers, reciting the Quran, and the use of ingredients advised by the Prophet such as honey, garlic, and habbat al-saudi (black seeds) (Tiilikainen, 2011) with herbal remedies including teas, mixtures and herbal lotions. Ensuring humoral balance is achieved by reducing excessive digestive bile (dacar) and resuming humoral flows by triggering diarrhoea or vomiting, inducing bleeding, fasting or feasting, consuming camel milk or chewing khat leaves (a mild narcotic, very popular among Somali men) (Carruth, 2014).

However, a number of studies show that Somalis incorporate biomedical approaches within their traditional health approaches when available to them (Carruth, 2014; Mölsä et al., 2010). One small study conducted among Somali immigrants in Finland reported a high level of satisfaction with biomedical care. However, in the same study, half of the participants indicated that they perceived that doctors did not value Somali health care beliefs and practices (Tiilikainen, 2011). Tiilikainen, who has been exploring Somali culture for many years proposes that a pluralist
approach or 'transnational medical care', in which traditional health approaches are incorporated within the biomedical model, has not been given adequate focus in medical research and practice. Further, she asserts that the development of transnational health care approaches would increase resilience in the Somali migrant population by reducing alienation during health encounters that emphasise biomedical methods and marginalise indigenous health care approaches. Also, according to Tiilikainen, the development of transborder health promotion options that recognise communally based conceptions of health also builds resiliency in the Somali diaspora (Tiilikainen, 2011).

**Mental health**

There is limited data on the mental health of Somalis living in Australia due to; low levels of mental health service utilisation (Ellis et al., 2010; Ziguras, 1997), a lack of country-of-origin health service information (AIHW, 2014a) and exclusion of migrant groups from population based studies (Garrett et al., 2010) Internationally, mental health studies on Somali migrant populations show mixed results. For example, a Finnish study (Rask et al., 2016) that looked at the mental health of three migrant populations, including Somali migrants, found their levels of depression and anxiety were lower than other migrant groups and similar to the Finnish population. These findings were similar to those found in a study (Gerritsen et al., 2006a) conducted in the Netherlands where Somalis had better rates of mental health compared to other migrant groups; however, as noted by the study authors, these studies may have been affected by reporting bias related to mental health stigma within the Somali community.

Conversely, a third study (Bhui et al., 2006) that used culturally competent methods such as bi-cultural research assistants, found that over a third of Somalis had a common mental health disorder. Importantly, two other Finnish studies (Mölsä et al., 2010; Talle, 2008) found differences in the conceptualisation of mental health within the Somali group. For example, mental disorders were seen by Somalis’ as spiritual and/or social problems rather than a medical problem. Different understandings of health and illness, as with mental illness, impacted low service utilisation and low self-rated prevalence rates. Somalis have a range of terms for mental health such as; ‘dhimir’, a formal term that designates mental ill health in general; ‘murug’ is a

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6 The term ‘transnational medical care’ is related to the concept of transnationalism that is a process by which migrants create social fields that cross national boundaries (Schiller et al., 1992). In a health context, this is a similar concept to medical pluralism (Lambert, 2012).
mildly depressive state and a state of worry, with ‘buufi’ the term for the more severe condition characterised by being tense and even paranoid (Johnsdotter et al., 2011). Any form of mental illness is associated with significant social stigma within the Somali community and that may promote help-seeking outside of the health system (Johnsdotter et al., 2011). Other studies have found that African persons are more likely to present for treatment of physical symptoms related to a mental illness rather than acknowledge mental illness and to seek care for that condition (Norredam et al., 2010; Scuglik et al., 2007; Tiilikainen, 2011).

Tiilikainen’s empirical research (Tiilikainen, 2011) reported that Somali migrants repeatedly emphasised that Western doctors do not understand or deal with the realm of spirits, evil eye and witchcraft. For these problems, they were forced to seek out Islamic or other specialist healers either in the receiving country or in Somalia. Tiilikainen (Tiilikainen, 2003, 2011). Waldron (Waldron, 2010; Waldron & Gayle, 2002) argues that a primary barrier to accessing mental health services for African and Somali migrants is the poor fit of Western psychological approaches with cultural conceptions of mental illness and the failure of medical systems to accommodate pluralist approaches. Waldron calls for the integration into practice healing and treatment approaches that combine both biomedical and indigenous approaches to mental health that will augment greater engagement with this group (Waldron, 2010).

The following section presents the results from the three study phases for the Somali group.

**Section 2: Results**

The results from the Somali participants are presented in the following sequence:

1. Health Literacy Questionnaire results are presented as mean scores across the nine domains showing HL strengths and limitations.
2. Results from cognitive interviews exploring Somali participants’ understandings and interpretations of the HLQ item content are presented across the nine HL domains.
3. Semi-structured interviews exploring cultural dimensions of HL are presented, providing insights into conceptualisations of health, health beliefs, cultural health practices, and barriers and enablers to accessing health services and information.

**Somali Health Literacy Questionnaire responses**

The HLQ was administered to 80 Somali participants. The mean age of the group was 42 years (range of 19–70 years), 16% had not completed secondary education, 68% spoke English at home, 55% had a health care card, 19% needed assistance to complete the questionnaire, 20% reported at least one existing health condition and the group was evenly divided between men
and women (See Table 5.2). In addition, almost half of the Somali sample (45%) resided in areas of greatest socioeconomic disadvantage (See Table 5.1).

By comparison the Ophelia group was older than the Somali group with the mean age of 72 years (range 19 to 99), with 34% having at least four chronic conditions. Females comprised 63% of the sample, 67% were born in Australia and 90% spoke English as their main language at home. Approximately 37% of the sample required assistance to complete the questionnaire.

Table 5.2: Demographic description of Somali and Ophelia comparison group

<table>
<thead>
<tr>
<th>Descriptors</th>
<th>Somali group (n=80)</th>
<th>Ophelia group (n=813)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>40 (50%)</td>
<td>505 (63%)</td>
</tr>
<tr>
<td>Male</td>
<td>40 (50%)</td>
<td>298 (37%)</td>
</tr>
<tr>
<td>Age (mean, range) years</td>
<td>43 (18-70)</td>
<td>72 (19–99)</td>
</tr>
<tr>
<td>Lives alone</td>
<td>3 (4%)</td>
<td>337 (44%)</td>
</tr>
<tr>
<td>English spoken at home</td>
<td>54 (68%)</td>
<td>723 (91%)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary education only or less</td>
<td>1 (1%)</td>
<td>118 (15%)</td>
</tr>
<tr>
<td>Secondary (not completed)</td>
<td>15 (19%)</td>
<td>258 (33%)</td>
</tr>
<tr>
<td>Secondary (completed)</td>
<td>27 (34%)</td>
<td>160 (20%)</td>
</tr>
<tr>
<td>Technical level certificate</td>
<td>19 (24%)</td>
<td>138 (18%)</td>
</tr>
<tr>
<td>University</td>
<td>18 (22%)</td>
<td>109 (14%)</td>
</tr>
<tr>
<td><strong>Self-reported health conditions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arthritis</td>
<td>1 (1%)</td>
<td>399 (51%)</td>
</tr>
<tr>
<td>Back Pain</td>
<td>7 (9%)</td>
<td>338 (44%)</td>
</tr>
<tr>
<td>Heart problems</td>
<td>0</td>
<td>325 (42%)</td>
</tr>
<tr>
<td>Cancer</td>
<td>0</td>
<td>77 (16%)</td>
</tr>
<tr>
<td>Depression/Anxiety</td>
<td>0</td>
<td>238 (32%)</td>
</tr>
<tr>
<td>Diabetes Mellitus</td>
<td>8 (10%)</td>
<td>300 (39%)</td>
</tr>
<tr>
<td>Reports no health condition</td>
<td>64 (80%)</td>
<td>35 (4%)</td>
</tr>
<tr>
<td><strong>Health insurance and health care card</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private Health Insurance</td>
<td>0</td>
<td>298 (39%)</td>
</tr>
<tr>
<td>Health care card holders</td>
<td>42 (55%)</td>
<td>651 (82%)</td>
</tr>
<tr>
<td><strong>Assistance to complete HLQ</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assistance</td>
<td>18 (19%)</td>
<td>8%</td>
</tr>
</tbody>
</table>

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Mean scores for the HLQ scales are shown in Table 5.3. For the first five scales (range 1 to 4), the highest overall score was seen for scale 4, ‘Social support for health’ with a mean score of 3.6 (SD 0.46). The lowest score was for scale ‘5, Appraisal of health information’ with a mean score of 3.29 (SD 0.65). For the last four scales (range 1 to 5), highest and lowest scores were for scale ‘3, Ability to actively engage with health care professionals’ with a mean score of 4.34 (SD 0.66) and scale ‘9, Understanding health information enough to know what to do’ with a mean score of 4.14 (SD 0.71).

A comparison of means across the nine HLQ scales showed the Somali cohort reported higher mean scores across all domains relative to the comparison Ophelia group (see Table 5.3). Overall, women had higher scores compared with men, as did those who spoke English at home compared with those who spoke another language at home and health care card holders compared to non-health care card holders.

When the Somali cohort was compared with the Ophelia cohort, large differences in scoring patterns were observed. The Somali cohort scored higher in every domain, with the largest differences in domains 4, Social support for health (Somali 3.60: Ophelia 3.03); 5, Appraisal of health information (Somali 3.28: Ophelia 2.78); 3, Ability to actively engage with health care professionals (Somali 4.21: Ophelia 3.97); 7, Navigating the health care system (Somali 4.30: Ophelia 3.82); 8, Ability to find good health information (Somali 4.21: Ophelia 3.65); and 9, Understand health information enough to know what to do (Somali 4.41: Ophelia 3.85).

**Table 5.3: Health Literacy Questionnaire scores for Somali and Ophelia groups**

<table>
<thead>
<tr>
<th>HLQ Domains</th>
<th>Somali</th>
<th>Ophelia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>1. Feeling understood and supported by health care professionals</td>
<td>3.44 (0.58)</td>
<td>[3.31, 3.57]</td>
</tr>
<tr>
<td>2. Having sufficient information to manage my health</td>
<td>3.40 (0.59)</td>
<td>[3.26, 3.53]</td>
</tr>
<tr>
<td>3. Actively managing my health</td>
<td>3.34 (0.59)</td>
<td>[3.21, 3.47]</td>
</tr>
<tr>
<td>4. Social support for health</td>
<td>3.60 (0.46)</td>
<td>[3.49, 3.7]</td>
</tr>
<tr>
<td>5. Appraisal of health information</td>
<td>3.29 (0.65)</td>
<td>[3.14, 3.43]</td>
</tr>
<tr>
<td>6. Ability to actively engage with health care professionals</td>
<td>4.34 (0.66)</td>
<td>[4.19, 4.48]</td>
</tr>
<tr>
<td>7. Navigating the health care system</td>
<td>4.30 (0.65)</td>
<td>[4.16, 4.44]</td>
</tr>
<tr>
<td>8. Ability to find good health information</td>
<td>4.21 (0.71)</td>
<td>[4.06, 4.37]</td>
</tr>
<tr>
<td>9. Understand health information enough to know what to do</td>
<td>4.14 (0.71)</td>
<td>[3.98, 4.3]</td>
</tr>
</tbody>
</table>
Abbreviations = SD Standard deviation, CI confidence interval

Somali understandings and interpretations of the Health Literacy Questionnaire

Six Somali participants (4 men, 2 women) who completed the HLQ also participated in individual cognitive interviews. The main purpose of these interviews was to gain insight into Somali participants’ understandings and interpretation of the wording, questions and constructs within the HLQ to gauge whether these were understood as intended and to seek explanations for respondents’ interpretations and how they operationalised concepts with the HLQ. Questions were asked across the nine domains but not against every item within the domains.

HLQ item interpretation

The cognitive interviews with the Somali-Australian group show (See Appendix 6) that the content of items, when referenced against the a priori item intents, were understood as intended. Some items contained wording or concepts that were difficult to understand however, responses indicated that their overall understanding of the construct remained consistent with the original meaning. Importantly, there were no items or domains that proved to be offensive or culturally inappropriate in this group. In addition, all nine domains were understood from a cultural perspective.

Examples of difficulties that the Somali participants had with particular wording included the term ‘health practitioner’, a term not commonly used by Somalis, who expressed a preference for the term ‘doctor’. This preference may reflect Somali migrants’ experiences with health systems in their country of origin and with the concept conveyed by participants that the doctor was a person of higher status and should be addressed in their formal role. However, this did not prove to be a barrier to answering the questions, as respondents were orientated to the HLQ instructions in which they were invited to consider health practitioners to be doctors, nurses or traditional healers, as was relevant to them. The HLQ was provided in the Somali language with attention paid during the translation process to the use of the most appropriate term for doctor in this language.

Other items that were challenging for the Somalis was items 3.8 ‘I spend quite a lot of time actively managing my health’ and 5.2 ‘I compare health information from different sources’. Participants stated that the term ‘actively managing’ was new to them however, they understood this term to be looking after themselves which is consistent with the intent of the question. For the domain 5, ‘Appraisal of health information’ with questions such as 5.2 ‘I compare health information from different sources’ the Somalis used multiple trusted sources to compare and
appraise information that were often outside of the health system such as family, community or religious leaders. Information appraisal or comparisons were based on the cultural and religious appropriateness of health information rather than verification within a health context or between health information sources. Information seeking and having sufficient information were operationalised within this group as, seeking oral or verbal information from known sources such as from Somali community members, which is consistent with the intent of the items. Somalis did not interpret these questions as seeking written or digitally based formats.

Also, item 9.51 ‘Read and understand all of the information on medication labels’ was operationalised as asking the pharmacist to read and show them what is on the label. The Somalis outsourced these tasks to professionals that could give them the visual and oral information they needed to comply with medical treatments. While many did not engage in the reading aspect of the ‘read and understand’ element of the item, they clearly felt they could accurately respond to the intent of the question.

For scale 4: ‘Social support for health’, the concepts were interpreted broadly as social, emotional and religious support within the Somali community, as well as practical support during periods of ill health. The domain 7, ‘Navigating the care health system’ appeared to be interpreted narrowly as access to GPs and emergency rooms. Other elements of the health care system that might require navigation, such as allied health, prevention, screening or specialist care were not generally referred to by the Somali participants. Also, the domains relating to information finding and understanding health information were operationalised as harnessing the HL capabilities of the wider community. Somali’s indicated that, in answering many of the questions, their point of reference was the health system in their country of origin. The health system in Somalia is relatively harder to access, offers a limited range of services and patients play a passive role in the health interaction. Their country of origin as their reference point appeared to be reflected by responses that indicated they found it easy to access and engage in health services in Australia as it has a universal health care system that is considerably more accessible than what was available in their homeland.

In summary, the data from the cognitive interviews confirmed that Somali participants interpreted and responded to the HLQ constructs as intended. Difficulties with some concepts were overcome by referring to the HLQ instructions which provided a broad interpretation of terms such as ‘health practitioner’. The HLQ instructions included this specific definition because there is no universal Australian term to describe health providers. Also, none of the respondents indicated that any items or wording were offensive or culturally inappropriate.
Wording changes are not recommended as the items were interpreted as consistent with the construct intent. Importantly, critical information surfaced that elicited cultural perspectives on areas such as help and information seeking and information appraisal that were operationalised as social activities reflecting cultural practices.

**Somali health conceptualisations, beliefs and practices**

Thematic analysis of data derived from the semi-structured interviews with 15 Somali participants resulted in 10 dominant themes that are outlined below. Rich data were obtained from 15 participants until data saturation was reached and no new themes emerged (Marshall, 2010).

The Somali participant group comprised of 4 men and 11 women aged 22 to 86 years (See Table 4.6). All participants arrived in Australia under a Humanitarian Visa Program and had lived in Australia between 8 and 30 years; they were all followers of the Sunni version of the Islamic faith. The Somali participants were diverse in terms of languages spoken (Somali, Arabic, Amharic, Harian and Oromo), region of origin within the Horn of Africa (Ogaden region of Ethiopia, Somaliland, Djibouti and Somalia), length of stay in Australia and tribal affiliations. The majority of participants spoke one or more languages, were self-employed and were educated in Islamic schools prior to migration. Three participants had completed a university qualification and six had completed Technical and Further Education (TAFE) qualifications in Australia post-migration.

Ten themes emerged from the semi-structured interviews: intersection of religion and health, health is a gift from God, intuitive approach to health, distrust of health care, there is no mental health, just sadness or madness, hierarchy of help and information seeking, fear of environmental poisons, community is healing; isolation is sickness, an aversion to receiving a diagnosis, individual agency versus collective responsibility. These themes are outlined below.

1) **Intersection of religion and health**

The Somali participants expressed a belief in a strong intersection between religion and health. Spiritual observance was viewed as a primary health prevention strategy, whilst living outside of the daily edicts of the Quran was associated with ill health. Lifestyle habits such as eating non-
halal or haram (non-allowed) foods, and not observing salat (prayer) were strongly associated with increased risk of ill health. Participants also expressed concern about damage to their spiritual health because of practices within the health system, such as the use of pig-based medicines, women’s bodies being viewed by male health professionals, and not being able to fast.
during Ramadan due to medical treatments. In addition, religious observance was viewed as being strongly associated with the restoration of health and health maintenance. Participants indicated that addressing ill health required the assistance of health practitioners and religious leaders to attend to both physical and spiritual health.

Somalis’ belief in the intersection between religion and health is illustrated in the following statements:

Somali participant 5: “We believe this is our closeness to Allah, if we forget him then we get sick then we must pray together.”

Somali participant 9: “If I go to the man’s doctor I can’t do anything. I can’t say no I want a woman’s doctor and so I am going against Allah, this is bad things.”

2) Health is a gift from God

Participants commonly used the term ‘Insh Allah’ (God’s will) and stated that life, health and death were all predetermined in the Lawh Mahfuz (a divine or life script written for every individual). Whilst lifestyle habits were perceived as being either ‘health enhancing’ or ‘health diminishing’, the Somalis believed that the influence of lifestyle was relatively inconsequential in comparison to Allah’s power to bestow good or ill health. Participants generally perceived health and illness as part of their larger, spiritually contextualised life experiences, rather than something that they could influence. This view contributed to a perception of a lack of agency in influencing their health and also reduced motivation to participate in prevention and screening. The Somali participants commonly expressed scepticism at the ability of doctors or science to detect or cure ill health without reference to a higher religious power. Suffering such as ill health was seen as a form of testing and part of Allah’s plan.

This belief in determinism over science is illustrated in the following participants’ statements:

Somali participant 7: “You know we have the Insh Allah saying that whatever God wills it will happen, so I do not even have to go there.”

Somali participant 14: “Nothing to do to change, your future is in Lawh Mahfuz, it is written.”

3) Intuitive approach to health

Many participants spoke of trusting an intuitive approach to health over a biomedical approach. An intuitive approach was articulated as listening to one’s body and being aware of one’s own health. Using an intuitive approach to health was valued more highly than ‘excessive medical interference’, particularly in relation to pregnancy. Some Somali participants expressed the view
that Australian’s had lost touch with their bodies whilst Somali’s were more in tune with theirs. Some participants provided a non-science based conceptualisation of bodily function such as; a belief that cholesterol can be dissolved by drinking lemon juice and/or that high blood pressure was a consequence of too much physical exercise.

A belief in an intuitive based approach to health is illustrated in the following statements:

Somali participant 1: “I came when I was pregnant so that I had to straight away go to the doctors for checking ... that was my first point of confusion, because we did not so much necessarily do the monthly regular visits to the doctors so that to me was a bit too hard … to go the doctors all the time … I have been a mother four times before my fifth one, so I feel like I know when something is wrong and I think we also use very much our intuitive abilities and feel like if there is something wrong then we feel it within ourselves.”

Somali participant 10: “So for us I think you listen to the body and I think there is that depth of listening … wisdom comes through.”

4) Distrust of health care

Some participants expressed distrust and fear of medical interventions and of the Australian health system in general. Some participants expressed very clear expectations of being given medicine by health professionals that would cure their illness. When these expectations were not met participants were dissatisfied and distrusted the doctor’s ability to cure their illness. Lifestyle modification and self-management expectations of health professionals were perceived as confusing and ‘hard’ for many Somalis who felt that their lifestyles conformed to the needs of the family, community and religious obligations, not to the needs of the individual. Some participants indicated that medications were often not completed due to a fear that it was making them sicker. Some expressed the view that medications had a different effect on Africans than it did on Australians.

One specific concern for participants was their perception that the high rate of autism in the Somali community was linked to vaccinations (International evidence reports rates of Autism Spectrum Disorder (ASD) in second generation Somalis to be equal to or up to five times higher compared to non-Somalis with significantly higher rates of intellectual delay with ASD) (Barnevik-Olsson et al., 2010; Donald G. McNEIL, 2009; Hewitt et al., 2016; Miller-Gairy & Mofya, 2015). Some also expressed a belief that screening programs cause ill health, such as that breast screening causes cancer and that early detection and intervention do not improve outcomes. There was also a strong fear of damage to spiritual health as a result of medical
interventions, such as being injected with pork products or women’s bodies being seen by male doctors.

Examples of distrust in the health system are illustrated in the following participants’ statements:

Somali participant 11: “Sometimes there are rumours … ‘Oh, this has happened to me and it was because of what the doctors gave me.’”

Somali participant 14: “At home we are strong and we live to 100 or over. Here we are sick, they give our children injections and make them sick. We never know this thing autism in Somalia.”

Somali participant 2: “If I take these vaccines full of haram things, I will suffer in the next life. This is a hard thing for us. Why do they lie to us? There are bad things happen from medicines and they don’t tell us. We are afraid of the medicines.”

Somali participant 6: “Why should I have x-ray to see if I have cancer. I still die. Better not to know and maybe the x-ray put the cancer in me.”

5) **There is no mental health, just sadness or madness**

The majority of Somali participants did not recognise the existence of ‘mental health’. Participants stated that they did not see a distinction between mental health and health generally and indicated that they were confused when people talked about the ‘mind’ as separate from the whole person. Some participants acknowledged ‘sadness’ or ‘worries’, but these were considered reasonable responses to difficult life situations and not contextualised as ‘mental health issues’.

All participants considered that mental health services were irrelevant to Somalis as mental health was considered to be the result of external, malevolent forces such as a ‘madness’ induced by the ‘evil eye’ or from ‘Jinn’s’. Jinn’s are devil-like or supernatural creatures in Islamic mythology that may enter and inhabit a person and alter their behaviour (Clarkson Freeman et al., 2013). Persons who are not protected by prayer were seen as being more vulnerable and are more likely to be inhabited by a Jinn. Jinn’s can only be removed by a religious practitioner such as a Sheik as is the case with the evil eye that can be bestowed on an individual by a jealous person. Participants stated that they used the term ‘Masha Allah’ (Praise to God) frequently to protect themselves from Jinn’s or the evil eye. Participants considered that ‘talking’ about their mental health problems would not be effective, as their mental health issues required the help of a religious specialist.

Rejection of mental health and related treatments are illustrated in the following participants’ statements:
Somali participant 9: “What good is talking about your problems with a stranger … this is absolutely not the right thing. The Sheik is good for this.”

Somali participant 1: “We do not believe in talking about our problems in this way. Somalis have a lot of sadness but talking is not the solution, but prayer and community is. We believe these things will help us.”

6) **Hierarchy of help and information seeking**

Somali participants indicated that they used a distinct hierarchical pattern of help-seeking preferences. Somali social networks were highly trusted and a ‘first-line’ option for information either in Australia or internationally and GPs were their second option. Participants described help-seeking as an informal process in which Somalis openly discussed their health conditions with the wider community. Other members of the community will come forward and share either their personal experiences or the experiences of persons known to them. Providing health advice is the role of all Somalis, with a high degree of credence given to persons who have direct experience of the condition. Those giving health advice will commonly provide detailed information about their symptoms, experiences and solutions that worked for them. Other community members may corroborate this information with their own experiences. Somalis indicated that they may share medications or healing remedies, or provide the name of Sheiks or healers to consult with about their health problems. Another trusted source was a United Kingdom produced television program delivered by Somali doctors on a variety of health issues (accessed via satellite television). Print or internet sources of information were not commonly used.

Somalis expressed an aversion to negative health promotion messaging (e.g. ‘One in eight women will develop breast cancer’), which they found fear inducing and demotivating. They expressed a preference for positive or gain-framed health messaging (e.g. ‘physical exercise will reduce your chances of developing diabetes’). Participants indicated that health promotion materials that were text-based and embedded in biomedical concepts were accessed less often, instead they favoured culturally congruent, oral, narrative based and visual materials.

Examples of help-seeking are illustrated in the following participants’ statements:

7 Breast Cancer Network Australia; Understanding breast cancer.
https://www.bcna.org.au/understanding-breast-cancer/
Somali participant 7: “They [Somali people] don’t watch Australia television or read … these things. No, they are watching Somali TV … they are not hearing the Australia informations [sic] on their health, no, this is not the way it goes.”

Somali participant 5: “We don’t like to read; we love to talk! That is why we always have to be together to get informations [sic]. We love stories and this is our way of getting to know about everything.”

7) Fear of environmental poisons

Somali participants commonly referred to perceived threats to their health from the environment. Of chief concern to them was the level of chemicals in the food in Australia. There was a strong belief that chemicals were pervasive, toxic and were slowly contributing to a deterioration in their health. Somali participants were very interested in seeking out fresh, organic sources of food which they believed promoted and restored good health. However, many were unable to buy organic food due to the high cost of these food items. Other environmental threats included germs in the air that can be inhaled causing Somali women to exercise extreme diligence in house cleaning and in ridding the environment of all forms of germs or pests. Extreme cold was also perceived as highly threatening to their health. The fear of ill health from cold temperatures was illustrated by one Somali participant who said; “Heat hurts but cold kills”, an adage that was recorded in Richard Burton’s exploration of Somalia in 1856 (Burton, 2015). This saying also reflects a humoral conception of health.

Fear of illness emanating from the environment is illustrated in the following participants’ statements:

Somali participant 7: “The food in Australia is full of chemicals and slowly is killing us. In Africa everything was fresh, organic and pure. No chemicals. We are all being poisoned from the chemicals. What can we do?”

Somali participant 2: “Here the weather is very cold, this is hard for us. Our children are sick with the cold. We are always fighting the cold.”

8) Community is healing; isolation is sickness

Most participants expressed the view that being connected to the wider Somali community was important for health, particularly heart health. Participants indicated that social connectedness was associated with lower risk of ill health. Many women expressed the view that Somali celebrations were important for health because they provided an avenue for social support and a
safe environment to express concerns or problems. Conversely, isolation from the community was associated with illness and sadness.

Examples of Somalis’ belief in the connection between community and health are illustrated in the following participant’s statement:

Somali participant 1: “Because we were very far from each other and they [Somalis] did not know how to take the bus or the transport was bad so I mostly spent the time on my own and I think that contributed a little bit to my health issues. I developed a heart problem, so I think, yes, it is an isolation … and especially when you know that when you have family around you the circumstances are so much more better.”

9) **Aversion to the concept of a ‘diagnosis’**

Somali participants indicated that they often delayed help-seeking for fear of a diagnosis which they viewed negatively. Some participants expressed a preference not to receive a formal diagnosis, particularly in relation to a chronic health issue, due to concerns that it would induce anxiety or depression-like symptoms. Somali participants associated a diagnosis with imminent death, they considered that being given a diagnosis work hasten their death by inducing depression-like symptoms.

Examples of aversion to the concept of a diagnosis are illustrated in the following participant’s statement:

Somali participant 10: “Back home they just look at you and give you medicine, they never say you have this things like diabetes, cancer … if you know things you get sicker very quick … better not to know and just die.”

10) **Individual agency versus collectivist responsibility**

Many participants spoke of the need for their health decisions to be in synchronised with the needs of the community and their particular social and religious obligations. Lifestyle changes in particular were very difficult to accommodate at an individual level due to family and community responsibilities. Women in particular talked about the difficulties in making changes to diet and physical activity levels due to; financial, religious and practical barriers such as the need to cook for the family as a whole. The Somali participants indicated that making changes as an individual was extremely difficult due to the need to conform to the community norms.

Some participants spoke of their doctor’s inability to understand the constraints they faced in making changes to their lifestyle habits such as eating communally, following a Somalian diet, observing religious obligations, such as fasting, and the lack of social support for women to
exercise. The Somali diet generally consists of rice or spaghetti with various meat sauces and low levels of vegetables. Food is often eaten by the family and community members from a central dispensing dish. It is the responsibility of Somali women in particular to ensure meals are cooked in the traditional manner and deviation from this pattern is not generally accepted. Also, the needs of family and community are considered to be more important than the need for the individual to undertake physical activity. In addition, practices such as Ramadan, which often leads to weight gain and inactivity related to the requirement to fast from sunup to sundown, do not allow for individual flexibility as the family break their fast (iftar) together with traditional meals. Also, the need to attend to communal social responsibilities has an impact on Somalis’ ability to make individual level changes. For example, when a Somali person passes away, the community gathers for three days and is required to pray and prepare food for the whole community. Finally, financial limitations also reduce Somalis’ ability to enact lifestyle changes.

Examples of the tension between the individual needs and the needs of the community are illustrated in the following participants’ statements:

Somali participant 5: “Firstly it is the community, this is very important. Without community, we have nothing. Then it is our own health. First Allah, then community, then us. This is the way.”

Somali participant 1: “I try and do the right things but it is hard. Especially with children and the community you know? We have hard work here, we don’t have our family, we are alone. I must cook for the whole family and at the end [of the day] I am finished. I can’t go to walking or gyms because I have nothing left in me.”

Section 3: Discussion

To my knowledge this is the first study to explore the health beliefs and HL capabilities of a predominately well Somali migrant population. In this study, a systematic process has been applied to understand micro-elements of the relatively new field of HL, in a new context. Additionally, this study has tested the application of a HL tool which has been found to be robust in other settings and populations, in an under-researched, ‘hard to reach’ population. Qualitative inquiry was undertaken to understand the sociocultural context of Somali participants and explore the HL conceptualisations in this group.

This study provides insights into a novel approach to understand the determinants of HL and makes a contribution to an understanding of the unique HL practices within the Somali migrant group in Australia. Finally, it also provides robust evidence to drive the development of effective HL approaches for Somali migrants.
The health literacy competencies including strengths and needs of the Somali group

The unexpectedly higher HLQ scores for the Somali group when compared to the mainstream Ophelia group may be explained, in part, by contextual factors. The common frame of reference of the Somali participants was the health system of Somalia and countries of transition, which, by comparison, are less accessible than the Australian health care system and may explain the relatively higher scores relating to accessibly. Further, expectations of the level of engagement of Somalis with health practitioners was also tempered by previous experiences of a health system in which the patient plays a passive, recipient role. In addition, access to a universal health care system with no or low-cost entry was viewed as a significant enabling factor for this group.

Scoring also reflected the distributed nature of HL (Edwards et al., 2015b) through family and social networks that was enhanced by the very high levels of social support. Finally, the point must be made that the vulnerability of a migrant Muslim population within the current political context may also have influenced higher scoring patterns in the Somali group. Therefore, the higher HLQ scores can be in part attributed to contextual factors such as previous experiences of health systems and socio-economic and socio-political factors.

It is useful to compare the Somali HLQ results to a commonly referenced HL model (Renkert & Nutbeam, 2001) to gain further insights into the HL strengths and needs of this group.

Nutbeam’s model articulates three HL levels: functional, interactive and critical. Somali results indicated that they are competent in functional HL as defined in the model (Renkert & Nutbeam, 2001). Scale 9, ‘Understanding health information well enough to know what to do’, which is a strong indicator of functional HL was the highest score for this group. This appears to be related to strong social support that augmented individual level HL. Also, diverse and culturally unique approaches to understanding and using health information appear to be an effective mechanism, however there were limits to how effective this approach was in accessing evidence-based information. The results of this study are contrary to other studies which have found Somalis to have low levels of functional HL (Geltman et al., 2014; Wångdahl et al., 2014a) and studies showing low functional HL in migrant groups more generally (Sentell & Halpin, 2006).

However, as indicated in Chapter 3, many of these studies used narrow measures of HL and commonly defined functional HL in relation to literacy-based skills.

Somalis also have a high level of competency in the second level of Nutbeam’s model, communication/interactive HL. This was observed in the HLQ data and then supported by the interviews. The Somalis utilised their high levels of social capital to find, use and understand health information and to seek referrals to practitioners such as GPs, healers and Sheiks.
Somali participants indicated that highly developed communication strategies were used to obviate low English proficiency, such as use of family and community persons with higher levels of English proficiency to assist with communication. In addition, strong verbal communication skills were used in which Somali participants often asked health professionals to ‘show them’ what they were required to do (relating to correct use of medication etc.). Participants also used narrative based examples provided by community members to gain a greater understanding of health issues. The verbal strengths of the Somali group may reflect the strong oral tradition embedded in Somali culture and written forms of communication are a relatively new form of knowledge transfer among this population.

Results for Somalis show they perform well against the third level of the Nutbeam model. However, whilst the HLQ domains capture control of health they may not be broad enough to determine ‘more advanced cognitive skills’ and ‘greater exertion of life events and situations’. Individual agency is reduced for members of a collectivist culture, such as the Somalis’, however the responses indicated that they perform well in this HL level this conclusion needs to be regarded with caution.

**The HLQ as a measure of HL in Somali**

The HLQ has been validated in a predominantly Australian-born population (Beauchamp et al., 2015; Osborne et al., 2013) and this is the first study to test the tool in Australian migrant populations. Results indicated that the HLQ constructs were largely understood as intended and that the tool was appropriate for use in this migrant population. The key contribution of using a multi-dimensional measure of HL (HLQ) in this study was revealing important HL elements for migrant populations, such as social capital and help and information seeking. These findings also confirm the importance of the contextual dimensions of HL (Batterham et al., 2017) such as a cultural perspective in the analysis and the further verification of the HLQ findings within a cultural framework.

In summary, the HL capabilities of Somalis was assessed using cognitive interviews against each HLQ item (n=44), which stem from nine separate conceptual elements of HL derived from the Australian community. The data generated by the HLQ was consistent with the rich, culturally specific data that emerged from the cognitive interviews. These results suggest two potential approaches for the assessment of HL in cultural groups. The first is the employment of a complementary approach using both the HLQ and supportive qualitative data, and the second is the suggestion that the HLQ’s conceptual elements be broadened to include culturally relevant metadata. In addition, it is also possible that the Somali population has distinct characteristics.
from other migrant populations and therefore the HLQ may be more appropriate in particular migrant groups. To test this theory, further research is needed.

**The health conceptualisations and health-related practices of the Somali group**

The Somali participants were homogenous both in their view of health as situated within an Islamic framework, and in their cultural practices. Participants articulated culturally shaped health perceptions, such as a holistic view of health that encompassed both spiritual and physical dimensions. Culturally bound beliefs were reflected in practices such as help-seeking, information gathering and a hierarchy of help-seeking. In addition, observance of spiritual health was considered a primary health prevention strategy.

A hierarchical pattern of information and help-seeking followed patterns of cultural communication. Somali community members were the most trusted and first-line source of health information such as referral to practitioners such as healers, Sheiks or medical professionals. Culturally congruent sources of health information that were provided using oral, visual or narrative formats, were most commonly used by Somalis while text-based health information sources were the least used sources of health information. Results also showed that Somalis have adopted a hybridised approach to health through the convergence of a biomedical model within their health belief system where there are points of compatibility. This concept is further explored in the Chapter 9 in the section titled Health Engagement Convergence Model.

**Barriers and enablers**

The study showed that current approaches to knowledge transfer in the Australian health system was a significant barrier for the Somali group. Participants indicated that mechanisms of information transfer such as text-based information embedded in biomedical concepts were accessed less often, in favour of culturally congruent, oral, narrative based and visual materials. In addition, negative health promotion message framing was also a barrier. Equally, expectations of patient/health practitioner engagement are a challenge for Somalis who are more familiar with a didactic interaction led by the ‘doctor’ with the patient playing a passive role.

Social capital within the Somali group acted as both an enabler and a barrier to health system engagement. The high levels of social support within the community provided social, emotional and physical support during ill health and assisting in navigation of the health system and in communicating with health practitioners. Social support was of great importance in augmenting individual levels HL abilities particularly in functional HL. However, results also showed that social support contributed to Somalis’ low levels of engagement in areas of the health system
such as prevention, screening and mental health, as health knowledge limitations of the benefits of early engagement and the low levels of trust in the health system permeated through the community. Health interventions such as bi-cultural health educators and cultural health champions would be effective to enhance distributed HL and potentially augment HL.

**Strengths and limitations**

The limitations of the study include its cross-sectional design and causal conclusions could not be made. Another limitation is the self-reported survey, which is prone to a number of biases such as recall bias and response bias. Also, the use of a snowballing recruitment method may result in a narrow representation of participants, however, in order to limit this weakness, recruitment was conducted through three index cases resulting in greater diversity in tribal and social affiliations that minimised sampling bias.

One of the important findings of this study is the presentation of the HL strengths and limitations of the Somalis, who are among the most vulnerable groups in Australia. Commonly, studies aggregate data on migrants, which may mask the health disparities that exist in each subgroup, whereas the findings from this study enabled a specific focus on each group and in particular on a vulnerable group. Another strength was the use of a mixed methods approach based on a broad conceptualisation of HL and situated within a cultural framework.

**New approaches to migrant groups from oral based cultures**

A unique contribution of this study is the revelation of the HL strengths of the Somali group, which have not been revealed in previous studies. The results also showed that migrant groups from oral cultures such as the Somalis may be disadvantaged within societies and cultures that predominantly use text-based information transfer methods. These findings suggest that health promotion practice needs to be orientated towards a compendium of modalities of health information provision such as oral, visual and narrative based formats that utilise positive health messaging (Carroll et al., 2007). These findings challenge the view that functional HL abilities are foundational to the development of higher levels of HL abilities, and they may inform a public health perspective that HL dimensions can differ between populations. Lastly, the study revealed that the high levels of social support within the Somali group had both positive and negative impacts on health system engagement.

Evidence shows that the migrant health decline is unevenly distributed across migrant groups with the mechanisms of distribution poorly understood. This study provides evidence that differences in cultural health beliefs and practices and the subsequent limitations of the health
system in meeting the needs of groups such as Somali’s may account for the migrant health decline.

**Conclusion**

In conclusion, the results from the analysis of three sets of data derived from Somali participants provide evidence that culturally influenced health beliefs and practices impact health system engagement and may explain observed patterns of health behaviours in some migrant groups such as delayed help-seeking and lack of participation in prevention activities.

The higher mean scores in the Somali group were influenced by contextual factors such as past experiences that strongly influenced their common frame of reference, and socioeconomic and political factors. The HL strengths of the Somali group are in interactive/communication HL competencies in which innovative and creative approaches were evident. Somali participants utilise unique and effective practices for information gathering, decision making and help-seeking that are not well understood or accommodated within the Australian health system.

Further, persons from oral cultures may be at a greater disadvantage in countries with dominant text-based information provision practices. Functional HL competencies may be enhanced by information provision practices that meet the needs of persons from oral cultures such as use of visual, oral, narrative based approaches. High levels of social capital in the Somali group acted as both a barrier and enabler to health system engagement. Finally, HL in collectivist migrant groups such that of the Somalis is a communal rather than an individual asset. This study provides robust evidence to drive intervention development such as the provision of bi-cultural health educators and health information transfer mechanisms utilising oral, visual and narrative based approaches.
Chapter 6: Chinese Participant Health Literacy

Section 1: Chinese-Australian migrants

Introduction

In the first section of this chapter I provide a socio-demographic and cultural profile of the Chinese-Australian population, including an overview of traditional Chinese health practices and international data on health outcomes within the Chinese diaspora. The results of this chapter draw on the same methods used during data collection with the three groups, including the administration of the HLQ and cognitive and semi-structured interviews, are they will be analysed and presented in the second section. This chapter concludes with section three where the study findings are compared and contrasted with the current literature to reveal new contributions to the field and a discussion on the potential of these findings to influence systemic HL approaches and practices.

Chinese history of migration to Australia

The Chinese have been making the journey to Australia for over 170 years arriving as early as the mid-nineteenth century. The culmination of internal conflict and natural disasters in China led many Chinese migrants to Australia from the 1850s onwards to take advantage of the gold rushes in Victoria and New South Wales (Cronin, 1982). Under the Mafeking Treaty the Chinese were allowed entry into British colonies such as Australia, however, many Australians were openly hostile to their arrival (Megalogenis, 2015). Chinese migrants were subjected to a campaign of discrimination such as the introduction by the Victorian Government of a ten-pound tax specifically on Chinese migrants in an effort to reduce their numbers (Megalogenis, 2015). Migration numbers declined after 1901 as a result of the passing of the Immigration Restriction Act which discriminated against Asian migration to Australia (Ang, 2014). However, after a series of policy changes commencing with the Menzies government signing the South-East Asia Collective Defence Treaty (SEATO, 1954) migration increased (Henrich, 2013). Currently, Chinese-Australian migrants are the third largest group of overseas-born residents (2% of the Australian population) (Migration Australia, 2013-14, 2015).

The Chinese-Australian population

The main languages spoken at home by China-born people in Australia according to the 2011 census were Mandarin and Cantonese with the main religious affiliations of Buddhist and Catholic and 63% stating no religion (Community Information Summary China-born, 2012).
Also, despite the Chinese-Australian community having slightly higher levels of formal education compared to the Australian-born community (58% compared to 55% respectively) their median income in 2011 was substantially lower than other migrant groups and the Australian population ($328 per week compared to $538 for all overseas-born and $597 for all Australia-born). The employment participation rates for the Chinese-Australian population in 2011 was 57% with the majority in the skilled managerial, professional or trade occupations. Approximately 20% lived in regions classified as being in the second lowest category of disadvantage with 63% living in the areas of least disadvantage (See Table 6.2).

Table 6.1: SEIFA ranking for place of residence of Chinese participants

<table>
<thead>
<tr>
<th>Socioeconomic Index for Areas (SEIFA) ranking (ABS, 2013)</th>
<th>N %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (highest socioeconomic disadvantage)</td>
<td>0%</td>
</tr>
<tr>
<td>2</td>
<td>22%</td>
</tr>
<tr>
<td>3</td>
<td>8%</td>
</tr>
<tr>
<td>4</td>
<td>3%</td>
</tr>
<tr>
<td>5</td>
<td>2%</td>
</tr>
<tr>
<td>6</td>
<td>16%</td>
</tr>
<tr>
<td>7</td>
<td>6%</td>
</tr>
<tr>
<td>8</td>
<td>19%</td>
</tr>
<tr>
<td>9</td>
<td>5%</td>
</tr>
<tr>
<td>10 (lowest socioeconomic disadvantage)</td>
<td>11%</td>
</tr>
<tr>
<td>Incomplete data</td>
<td>4%</td>
</tr>
</tbody>
</table>

Health risk profile

There is a paucity of data on the health of the Chinese-Australian population in part because data is aggregated into the broad category of ‘Asian’. Asian-born Australians are generally healthier than non-Asian migrants with a mortality rate of 36% (RR = 0.64) lower than Australian-born residents (AIHW, 2014b; Anikeeva et al., 2012b). In addition, Asian-born residents have lower rates for all ten leading causes of death. For example, disaggregated epidemiological data show that Chinese Asian migrants have lower overall cancer mortality compared to non-migrants (Anikeeva et al., 2012a). However, exceptions to this trend are a higher rate of breast, cervical
and lifestyle related cancers in combination with lower screening rates and late presentation with advanced tumours.

Asian-Australian immigrants have a higher incidence of cancers that are strongly dependent on dietary factors or have a viral or bacterial aetiology, such as nasopharyngeal, stomach and liver cancers compared to the Australian-born population and other migrant populations (Anikeeva et al., 2012b). This finding is supported by evidence from the US where there is a higher rate of cancers of the oral cavity and pharynx, stomach and liver, and higher rates of tuberculosis and hepatitis B virus (HBV) in Asian-American migrants when compared to other US immigrant groups (Chen et al., 2010b).

Breast cancer is the leading cause of death in Asian-American women (Gomez et al., 2013; Tanjasiri et al., 2007) coupled with a disproportionately high mortality rate due to late presentation with advanced tumours (Wu, 2005). Australian and US studies show that Asian women have one of the lowest breast and cervical screening rates when compared to the native-born population (Gomez et al., 2013; O'Byrne et al., 2000; Wu, 2005) with a number of studies noting the lack of culturally sensitive information which contributes to the low screening rates (Tanjasiri et al., 2007; Wu, 2005). Other studies have found that factors such as low risk perception and fear of a cancer diagnosis (Tsu-Yin et al., 2008) also impacted low screening rates.

**From tiger’s penis to tetracycline**

Traditional Chinese medicine (TCM) is called ‘the harmony of nature’, a set of intricate and harmonious links between the ‘three forces’ (sancai) of heaven (tian), earth (di), and man (ren) (Piron et al., 2000). TCM has been used for thousands of years and holds as a central tenet that health is an outcome of forces such as the five xing's (wuxing): water, fire, wood, metal and earth and the opposing forces of yin (earth, moon, night, cold, female) and yang (heaven, sun, day, and heat, male) (Green et al., 2006). Health and well-being are aligned with the flow of energy, called qi (or chi), circulating in meridians or channels throughout the body (Green et al., 2006; Kwan & Holmes, 1999).

It is important to understand some of the essential differences between traditional Chinese and Western philosophical discourses to more fully comprehend the Chinese approach to health. The philosophies of Confucianism, Taoism and Buddhism remain highly influential in Chinese conceptions of health with all three promoting a holistic approach to health and happiness (Kwok
Two essential philosophical differences are the ‘principle of immanence’ and the concept of ‘binary relations’ (Rosker, 2012).

The principle of immanence reflects a worldview of the universe as interrelated and holistic. To illustrate this concept, the exhalation of breath is always spoken of as following inhalation, however, Chinese philosophers point out the inhalation was preceded by an exhalation with this cycle extending ad infinitum (Rosker, 2012). This principle of immanence is based on the idea that there is no defined beginning or end, just a continuous interplay of a life-force (chi) that shifts between binary forces (e.g. yin and yang). This concept is in contrast with the Western Cartesian notion of transcendental metaphysics that is based on the concept of separate spaces such the divine and mortal, cognitive and non-cognitive representations, and, the mind–body dichotomy (Slingerland, 2013). The second important feature of traditional Chinese philosophy is the concept of binary relations. Binary forces (such the Taoist, yin and yang) represent a duality or polarity that seeks, through relativity, to identify the ‘real state’ expressed as the tension between two oppositional concepts (Rosker, 2012). A binary model of the universe assists in the identification of imbalance and provides a framework for intervention design that aims to restore humoral balance. These binary forces are complementary and interdependent, which is fundamentally different from the Western philosophy of contradiction and refutation that forms the basis of the scientific hypotheses and of biomedical theory. These philosophical underpinnings of the principle of immanence and binary relations promote an explanatory model of health that is based on a holistic view of health.

Specifically, the Confucian and Taoist philosophies emphasise the importance of maintaining physical, emotional, social and environmental harmony to protect health (Kwok & Sullivan, 2007). The Confucian doctrine of the ‘golden mean’ or chung-yung is concerned with reaching harmony or attaining equilibrium by encouraging people to maintain a ‘middle’ or neutral position when examining or responding to all phenomena (Allinson, 1989). Similarly, a central teaching of Taoism is to ‘let it be’, which encourages people to perceive events in an open and optimistic manner while exercising mercy, thriftiness and humility (the three tenets of Buddhism). Chinese traditional culture has a strong emphasis on health promotion through the uptake of a plethora of tonics, exercises, eating regimes, massage and types of meditation (Kwok & Sullivan, 2007) aimed to maintain good health. The Chinese approach to health is also underpinned by a pervasive belief in fatalism, positivism and the concept of living harmoniously (Kwok & Sullivan, 2007). This approach can impact health prevention messaging that may be construed as negatively focused on disease. Focusing on negative realities can, it is believed, be illness inducing (Kwok & Sullivan, 2007). In addition, a prevention approach is premised on a
belief in a physical causation of disease which ignores spiritual, cultural and emotional influences. Other fundamental differences between TCM and Western medicine include “…theories of pathology, physiology, aetiology of disease, diagnosis, diagnostic tools used and therapeutic modalities” (Zhu et al., 2009, p. 286).

Demand for TCM is on the rise in Australia (Moore et al., 2016; Zhu et al., 2009) with Chinese migrants commonly using a combination of TCM and Western medicine (Green et al., 2006). Many Chinese view TCM and Western medicine on a continuum of treatment options with Western medicine used for severe and acute illness while TCM is used for constitutional problems such as to restore energy and mental health, and to prevent disease and chronic health problems (Green et al., 2006; Kleinman, 1975). There is a growing body of evidence that points to a range of problems with the use of TCM within a biomedical context. Identified risks and challenges include the quality and safety of imported traditional Chinese medicines (Genuis et al., 2012) reduced efficacy of Western medicines when used in combination with TCM and patient non-engagement in areas of Western medicine such as prevention. In summary, despite the long migration history of the Chinese to Australia and the growing consumer demand for TCM, recognition of TCM and its integration into the Australian health system has not been fully realised (Xiaoshu et al., 2009; Zhu et al., 2009).

**Mental health**

Evidence on the prevalence of mental health disorders among Asian immigrants is mixed. A large number of American epidemiological studies showed that, overall, immigrants from European backgrounds had higher rates of mood and anxiety disorders compared to immigrants from Asian and African backgrounds and that immigrants from non-Caucasian backgrounds showed reduced risk for mood and anxiety disorders amongst first and second generation cohorts (Salas-Wright et al.). Conversely, other research indicates that Chinese migrants have a low utilisation of mental health services but a high proportion of involuntary admissions to mental health services in Australia (Chen et al., 2010a) with patterns of delayed help-seeking of up to eight years (Ka Po et al., 2008). An Australian study (Hu & Wang, 2016) of 414 Chinese-Australian migrants found almost one in five had moderate to high levels of risk for mental health disorders with a correlation between migrants’ negative experiences and perceptions of GP services and elevated levels of psychological distress. A second study (Sharma, 2012) found similar rates of psychological distress in Chinese-Australian migrants from an analysis of data from the National Survey of Health and Wellbeing (2007). The authors of that study found that overseas-born persons from non-English-speaking countries had higher levels of psychological
distress than migrants from English-speaking countries and that they were at higher risk of non-intervention by health professionals for mental health issues.

Except for psychiatric visits for serious disorders, recent Chinese immigrants diagnosed with severe and persistent mental illness used fewer mental health services and are less likely to use other types of mental health services (Chen et al., 2010a). A study of Chinese immigrants in British Columbia found that Chinese migrants’ lower utilisation of mental health services other than psychiatric visits may be linked to the social stigma about mental health issues within the community. Another study (Blignault et al., 2008) of nine in-depth interviews with Chinese-Australians found a range of barriers to uptake of mental health services such as limited access to mental health care, perceived poor quality of care received, mental HL, cross-cultural communication difficulties, stigma, confidentiality concerns, service constraints and discrimination. Results showed that knowledge of the Australian health system among the China-born community members, including those who had been living in Australia a long time, was very poor. There was also a strong preference for seeking health care from a practitioner within the Chinese community rather than from a Western doctor or health professional.

The following section presents the results from the three study phases for the Chinese group.

Section 2: Results

The results from the Chinese participants are presented in the following sequence:

1. HL Questionnaire results are presented as mean scores across the nine domains showing HL strengths and limitations.
2. Results from cognitive interviews exploring Chinese participants’ understandings and interpretations of the HLQ item content are presented across the nine HL domains.
3. Semi-structured interviews exploring cultural dimensions of HL are presented, providing insights into conceptualisations of health, health beliefs, cultural health practices, and barriers and enablers to accessing health services and information.

Chinese health literacy questionnaire responses

The mean age of the Chinese respondents was 42 years (range 19–87 years), with a higher number of males (62%) than females (37%) (see Table 6.1). Around one in five respondents spoke English at home, 80% were university educated and almost half having private health insurance and 22% reported at least one existing health condition.
By comparison, the Ophelia comparison group was older than the Chinese group with a mean age of 72 years and overall less healthy with 34% of participants reporting at least 4 chronic conditions. The Ophelia group had a higher number of female participants (63%) compared to the Chinese (37%). In addition, the Ophelia group predominantly spoke English as their main language at home (90%) compared to the Chinese (21%). Conversely, a much higher number of participants (44%) lived alone compared to the Chinese group (19%) with a significant difference in the number of university educated participants (Ophelia 14% compared to the Chinese 80%). Lastly, a higher number of Ophelia participants (38%) required assistance to complete the questionnaire compared to the Chinese participants (4%).

Table 6.2: Demographic description of Chinese and the Ophelia comparison group

<table>
<thead>
<tr>
<th>Descriptors</th>
<th>Chinese (n=80)</th>
<th>Ophelia group (n=813)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>30 (37%)</td>
<td>505 (63%)</td>
</tr>
<tr>
<td>Male</td>
<td>50 (62%)</td>
<td>298 (37%)</td>
</tr>
<tr>
<td>Mean age (range)</td>
<td>40 (23–87)</td>
<td>72 (19–99)</td>
</tr>
<tr>
<td>Lives alone</td>
<td>15 (19%)</td>
<td>337 (44%)</td>
</tr>
<tr>
<td>English spoken at home</td>
<td>17 (21%)</td>
<td>723 (91%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary education level</td>
<td>0</td>
<td>118 (15%)</td>
</tr>
<tr>
<td>Secondary (not completed)</td>
<td>3 (4%)</td>
<td>258 (33%)</td>
</tr>
<tr>
<td>Secondary (completed)</td>
<td>8 (10%)</td>
<td>160 (20%)</td>
</tr>
<tr>
<td>Technical level certificate</td>
<td>5 (6%)</td>
<td>138 (18%)</td>
</tr>
<tr>
<td>University</td>
<td>64 (80%)</td>
<td>109 (14%)</td>
</tr>
<tr>
<td>Reported health conditions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arthritis</td>
<td>2 (3%)</td>
<td>399 (51%)</td>
</tr>
<tr>
<td>Back pain</td>
<td>4 (5%)</td>
<td>338 (44%)</td>
</tr>
<tr>
<td>Heart problems</td>
<td>1 (1%)</td>
<td>325 (42%)</td>
</tr>
<tr>
<td>Cancer</td>
<td>4 (5%)</td>
<td>77 (16%)</td>
</tr>
<tr>
<td>Depression/anxiety</td>
<td>5 (6%)</td>
<td>238 (32%)</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>2 (2.5%)</td>
<td>300 (39%)</td>
</tr>
<tr>
<td>Reports no health condition</td>
<td>62 (78%)</td>
<td>35 (4%)</td>
</tr>
<tr>
<td>Health insurance and health care card</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private health insurance</td>
<td>38 (48%)</td>
<td>298 (39%)</td>
</tr>
<tr>
<td>Health care card</td>
<td>59 (74%)</td>
<td>651 (82%)</td>
</tr>
<tr>
<td>Assistance to complete the HLQ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assistance</td>
<td>2 (3%)</td>
<td>291 (38%)</td>
</tr>
</tbody>
</table>
Table 6.3: Health Literacy Questionnaire scores for Chinese and Ophelia groups

<table>
<thead>
<tr>
<th>HLQ Domains</th>
<th>Chinese</th>
<th>Ophelia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Feeling understood and supported by health care professionals</td>
<td>2.58 (0.60)</td>
<td>[2.45, 2.72]</td>
</tr>
<tr>
<td>Having sufficient information to manage my health</td>
<td>2.78 (0.44)</td>
<td>[2.68, 2.88]</td>
</tr>
<tr>
<td>Actively managing my health</td>
<td>2.61 (0.58)</td>
<td>[2.48, 2.74]</td>
</tr>
<tr>
<td>Social support for health</td>
<td>2.94 (0.41)</td>
<td>[2.85, 3.03]</td>
</tr>
<tr>
<td>Appraisal of health information</td>
<td>2.77 (0.44)</td>
<td>[2.67, 2.87]</td>
</tr>
<tr>
<td>Ability to actively engage with health care professionals</td>
<td>3.50 (0.66)</td>
<td>[3.36, 3.65]</td>
</tr>
<tr>
<td>Navigating the health care system</td>
<td>3.45 (0.68)</td>
<td>[3.31, 3.61]</td>
</tr>
<tr>
<td>Ability to find good health information</td>
<td>3.66 (0.56)</td>
<td>[3.54, 3.79]</td>
</tr>
<tr>
<td>Understand health information enough to know what to do</td>
<td>3.71 (0.58)</td>
<td>[3.58, 3.84]</td>
</tr>
</tbody>
</table>

Abbreviations = SD Standard deviation, CI confidence interval

Mean scores for the HLQ scales are shown in Table 6.3. For the first 5 scales (range 1 to 4), the highest overall score was observed for scale ‘4, Social support for health’ with a mean score of 2.94 (SD 0.41). The lowest score was for scale 1, ‘Feeling understood and supported by health care professionals’ with a mean score of 2.58 (SD 0.60). For the last 4 scales (range 1 to 5) the highest and lowest scores were for scales 9, ‘Understand health information enough to know what to do’ with a mean score of 3.71 (SD 0.58) and scale 6, ‘Ability to actively engage with health care professionals’ with a mean score of 3.5 (SD 0.66).

When the Chinese group was compared with the Ophelia group many of the scales showed similar scores such as; scale 2, ‘Having sufficient information to manage my health’ with a mean score of 2.78 (0.44) compared to 2.98 (0.54); 4, scale 4, ‘Social support for health’ with a mean score of 2.94 (0.41) compared to 3.03 (0.55); scale 5, ‘Appraisal of health information’ with a mean score of 2.77 (0.44) compared to 2.78 (0.54); scale 8, ‘Ability to find good health information’ with a mean score of 3.56 (0.56) compared to 3.65 (0.75) and scale 9, ‘Understand health information enough to know what to do’ with a mean score of 3.71 (0.58) compared to 3.85 (0.74).
The biggest differences were in the following four scales in which the Chinese group had lower mean scores than the Ophelia group; scale 1, ‘Feeling understood and supported by health care professionals’ with a mean score of 2.58 (0.60) compared to 3.21 (0.54); scale 3, ‘Actively managing my health’ with a mean score of 2.61 (0.58) compared to 3.02 (0.50); scale 6, ‘Ability to actively engage with health care professionals’ with a mean score of 3.5 (0.66) compared to 3.97 (0.69) and scale 7, ‘Navigating the health care system’ with a mean score of 3.45 (0.68) compared to 3.82 (0.67).

Chinese respondents’ understandings and interpretations of the health literacy questionnaire

Six Chinese participants (2 men, 4 women) completed individual cognitive interviews which lasted between 20 and 30 minutes. Participants had lived in Australia from 2 to more than 20 years, were aged between 30 and 50 years and the majority were tertiary educated and one person had a disability.

HLQ item interpretation

Similarly, to the Somali-Australian group the cognitive interviews with the Chinese-Australian group show (See Appendix 7) that the content of items, when referenced against the a priori item intents, were understood as intended. Some items contained wording or concepts that were difficult to understand however, responses indicated that their overall understanding of the construct remained consistent with the original meaning. Importantly, there were no items or domains that proved to be offensive or culturally inappropriate in this group. In addition, all nine domains were understood from a cultural perspective.

Examples of difficulties the Chinese participants had with wording in the HLQ included the term ‘health practitioner’, a term not commonly used by Chinese, who like the Somali expressed a preference for the term ‘doctor’. This did not prove to be a barrier to answering the questions, as respondents were orientated to the HLQ instructions in which they were invited to consider ‘health practitioners’ to include doctors, nurses or traditional healers, as was relevant to them. The HLQ was provided in Simplified Chinese with attention paid during the translation process to the use of the most appropriate term to capture the concept of ‘healthcare practitioners’ in this language.

Also, items with concepts underpinned by an assumption of equal status between the health practitioner and patient such as item 6.41 ‘Have good discussions about your health with doctors’, lacked cultural congruence for the Chinese group. Participants expressed their
relationship with health professionals as formal and they recognise the higher social status of the doctor. This formal relationship precluded any discussion of an informal nature. The participants expressed concern that the term ‘discuss’ may serve to challenge the formal power dynamics between doctor and patient causing the doctor to ‘lose face’. However, responses showed that whilst participants felt uncomfortable in asserting all of their needs they were able to provide information about their health condition and symptoms which is consistent with the intent of the construct. Aspects they particularly felt uncomfortable discussing were the use of traditional medicines which they felt the doctor would not be receptive to and requesting medication when they were told they did not require this medicine (such as with they had a virus).

The cognitive interviews also revealed how HL practices were operationalised. Similar, to the Somali information seeking behaviour Chinese participants’ sought information from known sources within the Chinese community and from the internet (in their first language) which is consistent with the intent of the items. For the domains related to appraisal of health information such as item 5.2, ‘I compare health information from different sources’ the Chinese used multiple trusted sources to compare and appraise information, which were often outside of the health system such as family, community (in Australia and in China) and the Internet. Information appraisal or comparisons were often biased toward cultural appropriateness of health information rather than verification within a biomedical health context or between health information sources.

For the scale 4 ‘Social support for health’, the concepts were interpreted broadly as spiritual, social and emotional support within the Chinese community, as well as practical support during periods of ill health. The scale 7, ‘Navigating the health care system’ appeared to be interpreted narrowly as access to GPs and emergency rooms. Other elements of the health care system that might require navigation, for example, allied health, prevention, screening or specialist care were not generally referred to. Also, the term ‘understanding health information’ was operationalised as harnessing the HL capabilities of the wider community. Chinese participants primary point of reference was the health system in their country of origin. The health system in China is centred around hospitals and rural clinics and does not have a focus on primary care. Many participants were very happy with aspects of the Australian health care system such as the emphasis on confidentiality and the fact that it is a universal health care system. In China, basic health care is free however patients are generally required to pay a fee to the health practitioners to receive a higher level of care.
In summary, the data from the cognitive interviews confirmed that Chinese participants interpreted and responded to the HLQ constructs as intended. Also, none of the respondents indicated that any items or wording were offensive or culturally inappropriate. Wording changes were not recommended as the items were interpreted as consistent with the construct intent. Importantly, critical information surfaced that elicited cultural perspectives on areas such as help and information seeking and information appraisal that were operationalised as social activities reflecting cultural practices.

**Chinese health conceptualisations, beliefs and practices**

Thematic analysis of data derived from the semi-structured interviews with participants resulted in nine themes outlined below. Rich data were obtained from fifteen participants until data saturation was reached and no new themes emerged (Marshall, 2010).

The Chinese group was comprised of seven men and eight women and their age ranged from 27 to 80 years, who had resided in Australia for between 10 and 28 years. Eleven participants had immigrated under the skilled migrant program, and four under the family reunion program.

Nine themes emerged from the semi-structured interviews: the mental health taboo, the inheritance of health, ‘Saving face’ in a health context, food is medicine, an uncaring system, unrealised expectations, low level of belief in prevention/screening and health information transfer through cultural health networks. These themes are outlined below.

1) **The mental health taboo**

Many participants indicated that mental health problems were very rare in the Chinese community. Whilst many acknowledged ‘sadness’ or a ‘lack of happiness’ these were contextualised as a reasonable reaction to life circumstances. All participants indicated that mental health issues were not openly discussed in the community and that negative social stigma was associated with mental health conditions. Many participants said they knew of persons with mental health issues but that this was usually discussed in terms of physical health problems such as low energy, exhaustion, family issues etc. Many participants expressed doubt about the existence of mental health issues and/or the effectiveness of Western medical approaches to mental health treatment. All participants acknowledged that openly discussing mental health concerns was considered taboo in the community although some younger participants believed there was an increasing level of acceptance nowadays. Many participants attributed poor mental health to physical ill health or negative experiences, such as displacement or loss, and was commonly expressed as somatic symptoms (tiredness, lack of appetite or insomnia). Participants
believed that ‘being busy’ and TCM were effective approaches to alleviate mental health issues; they also believed in the importance of ‘striving to be happy’ which required self-discipline.

Mental health is a taboo topic within the Chinese community as illustrated in the participants’ statements below:

Chinese participant 3: “If the community knows you have a weakness, especially a mental health weakness then they may push you away. You might have trouble getting a job or getting married and you know they are talking about you. This is a big, big shame.”

Chinese participant 14: “My father has been depressed for many years but we do not say this. Instead, as a family we keep seeking out traditional healers to balance his system. We will never say as a family that he has a mental health problem; we don’t want to hurt him and bring shame on us.”

2) The inheritance of health

Participants spoke of being the beneficiaries of a cultural inheritance that was health focused. A number of participants indicated they did not see themselves as health orientated but believed that the Chinese lifestyle was very healthy and that they were fortunate to inherit these practices. Two participants indicated that the Chinese lifestyle was the result of the ancient teachings of Confucius to ‘try for harmony and balance in all things’. This is also related to humoral balance and the need to keep calm and emotionally even, otherwise the humours (yin and yang) will tip and an imbalance of the humours will cause ‘sickness’. Emotional and spiritual balance was also important with the need to have certain lifestyle practices to maintain humoral balance and prevent illness. Many cited the healthy diet of fresh food that was cooked daily, as central to their good health. Most participants indicated they did not exercise regularly as this was not ‘their way’ but that they kept active. The majority of participants strongly believed that family and community support was central to health and happiness. They believed that the community had an ethos of ‘striving’ in all things including health, and taking responsibility for one’s own health was highly valued.

The transfer of cultural health practices is illustrated in the participants’ statements below.

Participant 12: “I don’t think that I am very focused on my health but when I look at people from other communities I realise that we are healthy without really thinking about it.”

Participant 6: “We are lucky to be Chinese because we have healthy ways of doing things.”
3) ‘Saving face’ in a health context

Participants spoke of the need within the Chinese community to maintain a good reputation. Being both physically and mentally healthy contributed to having a good reputation. Many participants spoke of confidentiality concerns particularly when accessing Chinese doctors and interpreters and their fears of personal information leaking into the community. Community awareness that an individual had health issues, particularly mental health issues, was a major contributor to loss of reputation. Loss of reputation had social, financial and mental health consequences for the individual and the wider family. Many indicated that they choose to go to non-Chinese doctors to ensure confidentiality. Participants feared that if information about their health, including relatively minor conditions such as arthritis were known to the community this could be negatively interpreted and result in a loss of their reputation.

The importance of taking measures to maintain their reputation is illustrated in the following participants’ statements:

Chinese participant 8: “Even little things can cause problems with people saying things like; ‘Oh she has arthritis so she is getting old now and cracking up.’ This is not good and so we don’t want people to know anything about our health.”

Chinese participant 2: “When I was in hospital I said no to the Chinese interpreter because I was scared they would tell the community. I said, please give me the written information in Chinese and they did. This was better so I didn’t have to worry. Some of the information didn’t make sense but I understood what I had to do.”

4) Food is medicine

All participants spoke of the relationship between food and health with many indicating that food plays an important role in preventing, improving and curing disease. Many spoke of the need to balance foods between ‘hot’ and ‘cold’ and of paying attention to eating freshly prepared food every day that was purchased from local markets. Many participants indicated that they do not have time for exercise because food preparation was a large component of their day. Food was viewed as the first option for restoration of health and rebalancing humoral health.

The importance of food in health is illustrated in the following participant statements:

Chinese participant 9: “I try Australian food you know, pizza and pies but I come back to Chinese food … it is the best food, fresh and you feel better.”

Chinese participant 5: “Good health begins and ends with good food. It is the most important thing to do every day.”
5) The health care continuum

Many participants viewed the Australian health care system and TCM within a pluralist framework and on a continuum. For example, they accessed the Australian health care system for health concerns such as severe colds or diabetes while traditional healers were consulted for conditions underpinning general health such as a weak immune system or a chronic condition such as eczema or stomach complaints. Although participants were comfortable moving within this pluralist framework they indicated that both systems had limitations. A key barrier to accessing TCM was cost, and participants expressed the view that the universal health care system should include both traditional and Western systems of care. Almost all participants said that they did not discuss their traditional therapies and treatments with their GP as they did not believe the GP would understand they were concerned that consulting traditional healers may be perceived as challenging the efficacy of the prescribed treatments. However, many participants consulted Chinese-speaking GPs whom they believed understood the widespread use and efficacy of traditional medicines. None of the participants believed that there was a problem in using medicines from both the Australian health care system and traditional medicines simultaneously and expressed the belief that Chinese medicines were benign with low risk of side-effects.

The pluralist perspective was illustrated in the following participants’ statements:

Chinese participant 4: “I prefer Chinese doctor; he gives me acupuncture and herbs which are good for me … but very expensive … I can’t pay for this.”

Chinese participant 7: “Sometimes the medical doctors can’t help so we go to traditional healers you know. Like if we have skins problems or we are very tired. You know they can help us with these things.”

6) An uncaring system

All participants expressed positive views of the Australian health care system except for access to specialist care and many participants expressed concern about the time delay seeing a practitioner and the high cost of health care. Their common point of reference was the Chinese medical system in which medical care (traditional and allopathic care) was provided in the hospital setting where patients would remain until the health problem was resolved. Some participants indicated they had known Chinese people who had to return home to China to have their health issue addressed rather than wait to see a specialist in Australia. Their specific
concern was for the exacerbation of the health issue before they could access specialist care in Australia and the perceived lack of concern for their health by the health care system.

The dissatisfaction with the delay in accessing specialist care was illustrated in the following participants’ statements:

Chinese participant 10: “Why do they say I am sick and then leave me for six weeks. In this time, I can be better or dead.”

Chinese participant 5: “In China when we are sick the doctors look after us until we are well. We are not told to go here for an x-ray and then back to the doctor and then wait for a very long time for a specialist. Do they care about me if I wait for so long?”

7) Unrealised expectations

Many participants spoke of the frustration and dissatisfaction when visiting a GP particularly when they were told they did not need medication or a health intervention, such as the provision of a script for medication or referral to hospital. Many participants said they were used to the Chinese hospital system of care that promptly provided a range of treatments such as intravenous antibiotics, or surgery for more serious conditions. Many participants felt they were uncared for when GPs told them they had a virus and did not need any medication. This left many participants fearing for their health and with low levels of trust in the medical practitioners. Many preferred traditional approaches by TCM practitioners who provided a range of interventions such as acupuncture, cupping or herbal medicine.

The level of dissatisfaction by participants with GPs was evidenced in the following statements:

Chinese participant 10: “Why am I wasting my time if the doctor tells me I don’t need any medication? If I am sick, then he should give me something. I feel like he doesn’t care for me and I can die because he did not give me medicine.”

Chinese participant 2: “In China we always got treatment. If you have a cold they will give you intravenous antibiotics. That is the way we like this. We expect to be treated if we are sick and not told to go away with nothing. This is a bad system that tells you to go home alone when you are sick.”

8) Low level of belief in prevention/screening

Participants indicated a low level of belief in prevention interventions such as screening. Women, in particular, had concerns about the efficacy and safety of breast screening which they stated may cause cancer. They felt that breast and pap screening were highly embarrassing and
sometimes painful (mammograms in particular) interventions and for this reason many women avoided the procedures, if possible. Participants spoke of understanding prevention as underpinning all of their lifestyle habits such as eating well and living in balance and not as related to a procedure such as screening. Also, participants indicated that they feared receiving a diagnosis which they viewed as meaning they were close to death. This view was held despite having friends and family with a diagnosis such as diabetes who had lived a long period of time with effective treatment. Finally, participants said that if their GP directed them to screening and prevention activities they were more likely to participate because an authoritative figure referred then, rather than a belief in the screening activity itself.

Participants’ view of prevention and screening activities by participants was evidenced in the following statements:

Chinese participant 7: “If my GP says that I must have a test then I must do this, otherwise she may not see me next time.”

Chinese participant 14: “I am scared for them to say I have cancer or something bad. I don’t know how I would cope with this. Sometimes we say it is better to live and not know this.”

9) **Health information transfer through cultural health networks**

The primary source of health information for the Chinese community were Chinese family and friends, followed by cultural networks. Cultural networks are geographically located networks that act as a social and cultural centre of the Chinese community. The networks invite experts to speak at cultural gatherings on many topics including prevention, screening, and signs and symptoms of common conditions such as diabetes, as well as navigation of the health system. Health professionals such as doctors or bi-cultural health educators provide information in English or Cantonese or Mandarin (depending on the language expertise of the speaker) which is translated into the languages spoken by members of the group. This process allows for language and cultural adaptation of the health information and provides an opportunity for members to ask questions related to their specific context. The role of bi-cultural health educators was viewed particularly favourably by participants and played a unique and critical role in bridging the divide between Chinese and Australian conceptions of health and by explaining the importance of engagement in all areas of the Australian health system.

The transfer of health information within cultural health networks is illustrated in the following participants’ statements:
Chinese participant 7: “The doctor talks first and then we talk with each other and the information goes into the community. This is very important and we are confident in this way.”

Chinese participant 15: “We can ask questions of the doctors like; how much rice can I eat for my blood sugar? For some of us our English is not good and we need to ask questions to know what we can do for ourselves.”

**Section 3: Discussion**

The key findings for the Chinese participants were that Western medicine was viewed as a component of an overall health system in which TCM was a major component. Disengagement with sections of the Australian health care system occurred because participants view TCM as more effective in areas such as prevention and treatment of chronic conditions. Areas of difficulty in health system engagement such as communicating with health practitioners and concepts of self-management were highly influenced by cultural norms and practices.

**The health literacy competencies including strengths and needs of the Chinese group**

The HLQ scores for the Chinese group were relatively lower than the comparison Ophelia group. The lower scores reflected areas of HL weakness in health practitioner engagement and perceived support, in ‘actively managing’ health and in health system navigation. Qualitative data indicates that expectations of the level of engagement with health practitioners was tempered by previous experiences of the Chinese health system in which the patient plays a passive, recipient role. Participants stated that having discussions with health practitioners was considered disrespectful and could be perceived as challenging the authority of the doctor. Participants indicated that they accepted the advice of the health practitioner and asked questions to fully understand instructions that ensured compliance with health treatments. This behaviour is consistent with the qualitative data in which Chinese participants said they did not disclose their use of traditional medicines as this may convey a perception of a lack of belief in the efficacy of mainstream/biomedical advice and treatments that were being prescribed.

The low score in health care navigation may reflect strong dissatisfaction with referral processes to specialist care. Participants were very concerned with the lack of system coordination in which they were forced, in their view, to wait long periods of time to see a specialist. This was perceived as a lack of concern for the welfare of patients by the Australian health system and participants reported that some members of the community had returned to China for treatment rather than wait to see a specialist.
Areas of HL strengths included the high levels of social support that contributed to the distributed nature of HL through family and social networks (Edwards et al., 2015b). The Chinese group demonstrated a high level of trust in information sources from within the community. Chinese community organisations invited bi-cultural health educators or health practitioners into their cultural networks which was perceived as a highly successful strategy to augment the HL of the community.

It is useful to compare the Chinese HLQ results to a commonly referenced HL model (Nutbeam, 2001) to gain further insights into the HL strengths and needs of this group. Nutbeam’s HL model articulates three HL levels: functional, interactive and critical.

These findings indicate that this group is competent in functional HL as defined in the model (Nutbeam, 2001). The highest score for the Chinese group was in the HLQ scale nine, which is a strong indicator of functional HL, suggesting that the Chinese group’s diverse approaches to understanding and using health information are effective. These results are confirmed in the cognitive and the qualitative interviews and are contrary to other studies which have found Chinese immigrants have low levels of functional HL and also to studies showing low functional HL in migrant groups more generally (Sentell & Halpin, 2006). However, as indicated in Chapter 3, many of these studies used narrow measures of HL and commonly defined functional HL in relation to literacy based skills. The Chinese respondents may have difficulty with health-related literacy tests such as the TOFHLA (Parker et al., 1995) but are able to participate in the HLQ conceptualisation of functional HL that requires responses such as ‘agree’ or ‘strongly agree’ statements about being able to understand things well enough to know what to do.

The Chinese group also had a high level of competency in the second level of Nutbeam’s model, communication/interactive HL. This was observed in the HLQ data and then supported by the interviews. The cognitive and qualitative interviews provided strong evidence that people in the Chinese group utilised their high levels of social capital to find, use and understand health information. In addition, the Chinese participants indicated that highly developed communication strategies were used to obviate low English proficiency, such as using family and community persons with higher levels of English proficiency to assist with communication.

Results for Chinese in the third level of Nutbeam’s model, critical HL, are represented across the related HLQ domains. However, whilst the HLQ domains capture indicators of specific skills and control over health issues and services they may not be broad enough to capture ‘more advanced cognitive skills’ and ‘greater exertion over life events and situations’. Individual
agency is reduced for members of a collectivist culture such as the Chinese, so, although the responses indicated they perform well in this HL level, this conclusion needs to be regarded with caution.

The value of using two different HL models in the collection and analysis phases of this study strengthened the study findings. The HLQ, which was developed using grounded empirical methods, contrasts with the theoretically derived HL model developed by Nutbeam. The HLQ model provides ‘bottom up’ data that reflects the ‘real world’ or ‘lived experiences’ of participants which is critical to the development of meaningful new theory. Conversely, Nutbeam’s theoretical HL model uses a ‘top down’ approach that provides a framework from which data may be compared and contrasted. This analysis is important in revealing the HL strengths and limitations of each of the three migrant groups.

The HLQ as a measure of HL for the Chinese group

In a similar way to the findings from Somali participants, the HL capabilities of the Chinese participants were assessed using cognitive interviews against each of the 44 HLQ items, which stem from nine separate conceptual elements of HL derived from the Australian community. The HLQ provided wide-ranging data on HL strengths and limitations which complemented the rich culturally specific data that emerged from the cognitive interviews. These HLQ results are more closely aligned to the largely Australian-born comparison group (Ophelia group) and suggest that the tool was an appropriate measure of the HL strengths and limitations of Chinese migrants. However, these findings confirm the importance of considering the contextual dimensions of HL (Batterham et al., 2017), such as a cultural perspective in the analysis and provide further verification of the HLQ findings within a cultural framework.

The health conceptualisations and health-related practices of the Chinese group

The Chinese participants were homogenous in their holistic view of health that was bookended by the binary of TCM and the contemporary biomedical system. Participants articulated culturally shaped health perceptions, such as restoration of their humoral balance and of moderation in all aspects of life. Lack of participation by Chinese migrants in prevention and screening appears to be related to the belief that wellness creation is attributed to a positive attitude and living in spiritual, emotion and physical harmony rather than attributed to physical causation. This belief undermines motivation to access prevention services. Also, a strong belief in fatalism may contribute to non-engagement in services in the health system, such as prevention and screening that were perceived as futile in the face of an individual’s fate that is
predetermined. Culturally bound beliefs were reflected in practices such as information gathering and a hierarchy of help-seeking.

Chinese community members were the most trusted and first-line source of health information. Culturally congruent verbal sources of health information were the most commonly used by Chinese participants and text based health information sources were the least used sources. Results also showed that the Chinese participants have adopted a fusion approach to health through the convergence of a biomedical model within their health belief system where there are points of compatibility. This concept is further explained in the final chapter in the section ‘Health engagement convergence model’.

**Barriers and enablers**

The study revealed a number of barriers to improving HL levels for the Chinese group, such as the use of text-based health information, negative health messaging, expectations of patient/health practitioner engagement and individual agency. Contemporary approaches to knowledge transfer in the Australian health system were a significant barrier for the Chinese group in accessing health information in a culturally congruent way. Participants indicated that mechanisms of transfer such as text based information embedded in biomedical concepts were less accessible due to language barriers and the lack of cultural tailoring of the health information. However, participants’ HL levels were positively impacted by culturally congruent methods such as information sharing through social and community groups.

In addition, negative health promotion messaging was also a barrier. Participants were reluctant to seek medical advice for fear of receiving a diagnosis that participants viewed as indicating they were close to dying. Expectations of patient/health practitioner engagement were a challenge for Chinese participants who are more familiar with a didactic interaction led by the doctor with the patient playing a passive role. Finally, individual agency in decision making and lifestyle changes for Chinese participants was difficult due to the expectations of conformity from membership of a collectivist group in which the needs of the group may take precedence over the needs of the individual.

The high level of social capital within the Chinese group acted as both an enabler and a barrier to health system engagement. Social support enhanced social, emotional and physical support during ill health and the participants’ navigation of the health system and communication with health practitioners. However, results also showed that the knowledge limitations and low levels of trust contributed to low levels of engagement in areas of the health system such as prevention,
screening and mental health. Health interventions such as bi-cultural health educators were effective in impacting distributed HL and augmenting HL.

Finally, an important enabler to health system engagement was the role of the GP in recommending screening activities. Participants were more likely to participate in screening activities if their GP made a strong recommendation for them to do so. This compliance was related to the role of the GP as a person of authority rather than an intrinsic belief in the health benefits of prevention and screening activities, however, this appeared to be a potential strategy to increase participation.

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**Strengths and limitations**

The study strengths and limitations for the Chinese group are similar to the Somali group and include its cross-sectional design, which limits the ability to draw causal conclusions. Another limitation is the self-reported survey, which is prone to a number of biases, however, the qualitative interviews served to clarify the quantitative self-report (questionnaire) data and helped to explain why respondents gave the scores they did. In addition, study participation was by invitation, therefore it is likely that persons with higher levels of HL may have self-selected resulting in under representation of Chinese persons with lower HL levels.

One of the strengths of this study is the focus on a specific migrant group with sufficient sample size to uncover trends or patterns in the data that identify HL strengths and limitations. Commonly, studies aggregate data on migrants, which may mask the health disparities that each subgroup faces, whereas findings from this study enabled a specific focus on the needs of a migrant sub-group. Another strength was the use of a mixed methods approach based on a broad conceptualisation of HL and situated within a cultural framework. Lastly, an important element of this study was the development of a democratic partnership between the researcher and the Chinese community with stakeholders involved in the design and implementation of the study, and the exploratory nature of the grounded approach increased engagement with participants.
New approaches to migrant groups

Results indicate that potential health interventions aimed at increasing engagement of Chinese immigrants are likely to be ineffective if delivered in a socio-cultural vacuum. These findings provide guidance for health practitioners to integrate cultural conceptions of health into primary practice. Asking Chinese patients about their perspectives on health prevention and screening would be an appropriate starting point to augment engagement in these areas. In addition, the non-judgemental GP inquiry into the use of TCM may also build trust and help to develop a health plan that is meaningful to the Chinese patient. Practitioners also need to understand that Chinese migrants use the biomedical health system as complementary to TCM for particular health conditions. Chinese participants have low expectations of health practitioner engagement and concepts such as self-management which may result in limited engagement by Chinese patients. Also, GPs should understand that Chinese patients are more likely to participate in screening activities if the GP makes a strong recommendation for them to do so.

These findings suggest that health promotion practice needs to be orientated towards a compendium of modalities of health information provision, such as oral formats, particularly delivered within a cultural context. These findings challenge the view that functional HL abilities are foundational to the development of higher levels of HL abilities, and may inform a public health perspective that HL dimensions can differ between populations. Lastly, the study revealed that the high levels of social support within the Chinese group had both positive and negative impacts on health system engagement. Providing a bi-cultural health educator program with the Chinese community is likely to be an effective intervention to augment HL in this group.

Conclusion

In conclusion, the results from the Chinese group provides evidence that culturally influenced health beliefs and practices impact health system engagement and may explain observed patterns of health behaviours in some migrant groups such as delayed help-seeking and lack of participation in prevention. This in turn impacts the MHD through higher rates of avoidable morbidity and mortality due to late presentation with advanced, preventable disease.

The lower mean scores in the Chinese group were influenced by cultural health beliefs and contextual factors such as past experiences with the health system in their country of origin. Chinese participants utilise unique and effective practices for information gathering, decision making and help-seeking that are not well understood or accommodated within the Australian health system. Functional HL levels for Chinese migrants may be enhanced through the
resourcing of an effective information transfer mechanism of bi-cultural outreach health educators. In addition, the integration of TCM in the bio-medical model may increase engagement in areas such as prevention and screening. Finally, results showed that HL in collectivist migrant groups such as the Chinese migrants is a communal rather than an individual asset, that may be harnessed to increase HL abilities.

Finally, this study provides robust evidence that health system engagement by Chinese migrants could be improved if the focus is shifted to strengthening the communal approach to health through; the strategic use of bi-cultural workers, incorporation of a pluralist approach within the biomedical system and inclusive and tailored health promotion strategies. These interventions will increase health system responsiveness to the needs of this migrant group.
Chapter 7: Indian Participant Health Literacy

Section 1: Indian-Australian migrants

In the first section of this chapter a socio-demographic and cultural profile of the Indian-Australian population is provided, including an overview of traditional Indian health practices and international data on health outcomes within the Indian diaspora. The data-collection methods employed in this chapter are the same as used with Somali and Chinese migrants, that is, the administration of the HLQ followed by cognitive and semi-structured interviews. This chapter concludes with a comparison of findings with the literature, a discussion on the new contributions to the HL field and the potential of these findings to influence HL approaches and practices.

Indian migration to Australia

South-East Indians have a long history of migration to Australia, arriving in four waves beginning from the 1800s (Megalogenis, 2015). In the first wave of migration, small numbers were brought to Australia as ‘Indian coolies’ (Megalogenis, 2015) or slave labour between 1800 and 1860 to work as labourers and domestic servants, with many opting to work in the goldfields. The second wave (Naujoks, 2009) took place from 1860 to 1901 where mainly Sikhs and Muslims from Punjab took up rural or agricultural jobs. However, migration from India was curtailed around the turn of the 20th Century as the Australian Government implemented the Commonwealth Immigration Restriction Act of 1901 known as the ‘White Australia Policy’ (Jupp, 1995) that discriminated against Asian migrants (Megalogenis, 2015). The third wave of migration occurred after Prime Minister Menzies signed the South-East Asia Collective Defence Treaty (SETO) in 1953 (Uhlmann, 2010).

Following India’s independence from Britain (1947) the number of Anglo-Indians and India-born British citizens immigrating to Australia increased (Jupp, 1995; Naujoks, 2009). The fourth and current wave of immigrants has seen India emerge as the dominant source country of immigrants in recent years (ABS, 2015b). In 2015 India was the fourth largest migrant community and make up 2% of the Australian population (ABS, 2015b). It is anticipated that Indians will be the largest immigrant group in Australia by the end of the 2030 (Megalogenis, 2015).
The Indian-Australian population

In the 2011 census, Indian-Australians reported around 300 different ancestries including Indian (236,343), English (23,043) and Punjabi (8246). The main languages spoken at home by Indian-Australians were English (62,862), Hindi (59,055) and Punjabi (57,144). Of the 232,502 India-born who spoke a language other than English at home, 93.3% spoke English very well or well, and 53% spoke English not well or not at all. Major religious affiliations among Indian migrants were Hinduism, Sikhism and Catholicism.

In 2011 the Indian-Australians had a labour force participation rate was higher (77%) than the Australian-born population (65%), with an unemployment rate also slightly higher (6.3% compared to 5.6%). The employment rate of Indian migrants (48%) was the same as the Australian-born population (48%). The Indian-Australian median individual weekly income was $663 compared with $538 for all overseas-born and $597 for all Australia-born, with the majority working in management, a profession or a trade. Additionally, more Indian-Australians have completed a form of higher education (80%) than the Australian-born population (55%). Lastly, approximately 80% of participants in this study lived in the five lowest areas of socio-economic disadvantage (see Table 7.1).

A study (Voigt-Graf, 2005) of the migration patterns of Indian-Australians exposes the role of kinship as a critical factor in the operation of transnational networks and economic links back to India. The study draws attention to the importance of transnational kinship networks in the process of migration and settlement in Australia that ensures the continuation of cultural support and influences on Indian-Australian migrants. These ‘transnational spaces’ (Voigt-Graf, 2005) may be influential in the preservation of traditional health approaches within the Indian-Australian community.
Table 7.1: SEIFA ranking for place of residence of Indian participants

<table>
<thead>
<tr>
<th>Socioeconomic Indexes for Areas (SEIFA) ranking (ABS, 2013)</th>
<th>N %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (highest socioeconomic disadvantage)</td>
<td>53%</td>
</tr>
<tr>
<td>2</td>
<td>5%</td>
</tr>
<tr>
<td>3</td>
<td>4%</td>
</tr>
<tr>
<td>4</td>
<td>15%</td>
</tr>
<tr>
<td>5</td>
<td>2%</td>
</tr>
<tr>
<td>6</td>
<td>5%</td>
</tr>
<tr>
<td>7</td>
<td>4%</td>
</tr>
<tr>
<td>9</td>
<td>6%</td>
</tr>
<tr>
<td>10 (lowest socioeconomic disadvantage)</td>
<td>1%</td>
</tr>
</tbody>
</table>

Health risk profile

Asian-born Australians are generally healthier than non-Asian migrants with a mortality rate 36% (RR 0.64) lower than the rate for Australian-born residents (AIHW, 2014b; Anikeeva et al., 2012b). However, this aggregated data obscures health outcomes for migrants from particular Asian countries. There is a paucity of data on the health of the Indian-Australian population.

A large international body of evidence shows that the South-East Indian-born population has a high prevalence rate of, and significant mortality and morbidity from, coronary heart disease (Farooqi et al., 2000; Fernandez et al., 2015; Khanna et al., 2012). Results from the well-known Framingham Heart Study\(^8\) (Khanna et al., 2012) in the US found that Indian migrants were at higher risk of heart disease at an earlier age compared to the general US population. Metabolic syndrome, which is strongly associated with heart disease, was commonly observed in Indian people. Up to 70% of Indian people with metabolic syndrome had a 10-year cardiovascular risk of greater than 10%. In addition, Indian people with metabolic syndrome had higher incidences of double or triple vessel disease and much lower incidence of having normal coronary arteries.

\(^8\) For further information on the Framingham Heart Study see www.framinghamheartstudy.org/about-fhs/.
as compared to those without metabolic syndrome. These findings were supported by a systematic review (Chen et al., 2013) of cohort studies looking at the metabolic syndrome in east and South-East Asian populations and the associated risk of coronary heart disease mortality. South-East Asians had an increased risk of death for coronary heart disease in individuals with a body mass index greater than 35 compared to the East-Asians.

In addition, studies confirm an increased risk of coronary heart disease in Asian Indians who have immigrated to other countries (Fernandez et al., 2015; Khanna et al., 2012). A comparison study (Patel et al., 2006) of coronary heart disease risk factors amongst South Asian migrants living in Britain with non-migrating Indians living in India found that exposure to increased fat intake and obesity related to migration explained the disproportionate combination of established and emerging coronary heart disease risk factors prevalent in South Asian migrants. Whilst the causes of the excess coronary heart disease risk in South Asian migrants remains unclear, an Australian study (Mohan et al., 2006) found that diet (high in oil), lack of physical exercise, access to food abundance in Australia, disappointment with Australian health services and a culture of self-reliance were contributing factors to high prevalence rates of coronary heart disease in Asian-Australians.

Health literacy

A qualitative study of South-East Asian migrant women in Taiwan (Tsai & Lee, 2016) found that the majority of immigrant women had inadequate HL to manage health information and navigate the Taiwan health care system. Four major themes were identified as key areas of difficulty: 1) gaining access to health information, 2) navigating in the health care delivery system, 3) interactions during health care encounters, and 4) capability of using health information and services. A key finding of this study was the lack of recognition by the health system of the personal limitations of the women (education, social and language) and how these impacted their HL abilities. No other HL studies were identified.

From Ayurveda to amoxicillin

The Indian Government has had a policy of supporting a pluralistic model of public health care since 2005 (Lambert, 2012). India’s health care system is medically diverse, offering a biomedical model in tandem with an eclectic range of health systems, such as ayurveda, siddha and unani. A key strategy supporting this policy is a shift away from the employment of only fully qualified biomedical practitioners towards the use of trained health providers from a variety of medical traditions (Lambert, 2012).
Mahatma Gandhi, a highly influential political and spiritual leader of India (1869–1948), supported a pluralist health system, however, he viewed the role of Western medicine as limited, with traditional spiritual practices having a greater relevance to the Indian people (Khan, 2006). He believed that traditional health approaches promoted self-discipline and holistic health practices particularly in relation to prevention whilst Western medicine promoted a lack of discipline and unhealthy practices such as overeating. Gandhi believed that the overemphasis on cure and lack of focus on spirituality by Western medicine meant that it would only ever have a small role to play within India’s health system (Khan, 2006).

The literal meaning of *Ayurveda* is ‘science of life’, however, it has evolved to become a generic term for traditional Indian medicine. It is a health system based on the combination of organoleptic (sense-based) empirical medicine with religious ritual perspectives encompassing physical, mental, spiritual and environmental dimensions (Niemi & Ståhle, 2016; Pole, 2013). *Ayurveda* is considered to have developed around 2500–500 BC (Pandey et al., 2013) with its roots in the Vedic religion, however, due to globalisation, the term has been modernised to include a range of self-care related activities such as massage, diet and yoga (Niemi & Ståhle, 2016; Pandey et al., 2013). It is known that Indian immigrants commonly use *Ayurveda* medicines with a number of recorded cases of toxic poisoning from lead and other toxic metals (Datta-Mitra & Ahmed, 2015; Mathee et al., 2015; Orchard et al., 2015).

A Swedish qualitative study (Niemi & Ståhle, 2016) showed that *Ayurveda* was being used in combination with other methods, including various diets, other alternative medicine methods and conventional medicine, with participants using *Ayurveda* as a complement to conventional medicine, or in cases when conventional medicine had been experienced as insufficient in terms of diagnosis or treatment. Many participants reported positive experiences of pulse diagnostics, which was the main diagnostic method used in an *ayurvedic* consultation.

*‘Love failure’ and other exogenous explanatory models of mental health*

The prevalence of mental health issues in the Indian migrant population is equal to or higher than the general Australian population (Maheshwari & Steel, 2012) with a lower uptake of mental health services compared to the non-migrant populations (Abe-Kim et al., 2007; Maheshwari & Steel, 2012; Tiwari & Wang, 2008). An Australian study (Maheshwari & Steel, 2012) which randomly sampled 71 Indian-Australian family groups living in Sydney measured levels of psychological distress, functional disability, service use and social capital and found similar levels of psychological morbidity to the general Australian population. Amongst participants, 15% reported high to very high levels of psychological distress with significantly lower level of
help-seeking (91% of participants with identifiable mental health needs did not seek any mental health advice which is much lower than the general Australian population with identifiable mental health needs 35%).

Some studies reported that South-East Asian women have high rates of depression, suicidal ideation (Chew-Graham et al., 2002) psychological disorders, schizophrenia (Asian women over the age of 30 years) and self-harm (in younger women). Many of these studies attribute this increased risk to social, political and economic factors, such as domestic violence (Chew-Graham et al., 2002), language barriers (Chew-Graham et al., 2002), social isolation (Dutt & Webber, 2010), discrimination (Chew-Graham et al., 2002), financial difficulties (Anand & Cochrane, 2005; Chew-Graham et al., 2002), distrust of services (Chew-Graham et al., 2002) and pressure to ‘do well’ in the migration country (Chew-Graham et al., 2002; Sharma, 2012).

One study focusing on ‘depression literacy’ or the ability to articulate words or concepts related to depression in urban and rural Indians living in Malaysia (314 participants), found that urban dwelling Indians had higher levels of depression literacy. A key finding of the study was the contribution of culturally shaped beliefs about depression in influencing depression literacy. Depression was generally attributed to external sociological forces, such as ‘love failure’ (unrealised romantic aspirations), financial difficulties and/or familial obligations. The study found that mental health interventions needed to accommodate a pluralist approach to address knowledge and beliefs about depression among urban and rural Indian Malaysians.

The following section presents the results from the three study phases for the Indian group.

**Section 2: Results**

The results from the Indian participants are presented in the following sequence:

1. Health Literacy Questionnaire results are presented as mean scores across the nine domains showing HL strengths and limitations.
2. Results from cognitive interviews exploring Indian participants’ understandings and interpretations of the HLQ item content are presented across the nine HL domains.
3. Semi-structured interviews exploring cultural dimensions of HL are presented, providing insights into conceptualisations of health, health beliefs, cultural health practices, and barriers and enablers to accessing health services and information.
Indian Health Literacy Questionnaire responses

The HLQ was administered to 80 Indian participants (See Table 7.2) with a mean age of 34 years (range 19–74 years), with a slightly higher number of females (52%) than males (47%). None of the participants lived alone and half spoke English at home. Almost 40% had a technical qualification and almost half were university educated. Back pain was the most reported health condition (21%) and 45% had private health insurance and 10% needed assistance to complete the HLQ.

By comparison, the Ophelia group was considerably older with the mean age of 72 years and overall less healthy than the Indian group, and 34% of participants reported at least four chronic conditions. The Ophelia comparison group had a higher number of female participants (63%) compared to the Indian group (52%) and more Ophelia participants spoke English as their main language at home (90% compared to the Indian group of 50%). Participants from the Ophelia were much more likely to live alone (44%) and to have not achieved university level education compared to the Indian group (14% compared to Indian group’s 80%). Lastly, a higher number of Ophelia participants (38%) required assistance to complete the questionnaire compared to the Indian group (10%).

Table 7.2: Demographic description of Indian and the Ophelia comparison group

<table>
<thead>
<tr>
<th>Descriptors</th>
<th>Indian (n=80)</th>
<th>Ophelia group (n=813)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>42 (52%)</td>
<td>505 (63%)</td>
</tr>
<tr>
<td>Male</td>
<td>38 (47%)</td>
<td>298 (37%)</td>
</tr>
<tr>
<td>Age (mean, range) years</td>
<td>33 years (23-74)</td>
<td>72 years (19–99)</td>
</tr>
<tr>
<td>Lives alone</td>
<td>0</td>
<td>337 (44%)</td>
</tr>
<tr>
<td>English spoken at home</td>
<td>40 (50%)</td>
<td>723 (91%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary education</td>
<td>0</td>
<td>118 (15%)</td>
</tr>
<tr>
<td>Secondary (not completed)</td>
<td>1 (0%)</td>
<td>258 (33%)</td>
</tr>
<tr>
<td>Secondary (completed)</td>
<td>11 (14%)</td>
<td>160 (20%)</td>
</tr>
<tr>
<td>Technical level certificate</td>
<td>30 (38%)</td>
<td>138 (18%)</td>
</tr>
<tr>
<td>University</td>
<td>38 (48%)</td>
<td>109 (14%)</td>
</tr>
<tr>
<td>Reported health conditions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arthritis</td>
<td>0</td>
<td>399 (51%)</td>
</tr>
<tr>
<td>Back pain</td>
<td>17 (21%)</td>
<td>338 (44%)</td>
</tr>
</tbody>
</table>
Heart problems 0 325 (42%)
Cancer 0 77 (16%)
Depression/anxiety 1 (1%) 238 (32%)
Diabetes mellitus 3 (4%) 300 (39%)
Reports no health condition 59 (47%) 35 (4%)

**Health insurance and health care card**
Private health insurance 36 (45%) 298 (39%)
Health care card 14 (18%) 651 (82%)

**Assistance to complete the HLQ**
Assistance 8 (10%) 291 (38%)

Mean scores for the HLQ scales are shown in Table 7.3. For the first 5 scales (scale ranging from 1 to 5), the highest overall score was observed for scale 4, ‘Social support for health’ with a mean score of 3.12 (SD 0.53). The lowest score was for scale 5, ‘Appraisal of health information’ with a mean score of 2.68 (SD 0.58). For the last 4 scales (scale ranging from 6 to 9), the highest and lowest scores were for scales, 9 ‘Understand health information enough to know what to do’ with a mean score of 4.13 (SD 0.62) and scale 6, ‘Ability to find good health information’ with a mean score of 3.56 (SD 0.78).

**Table 7.3: Health Literacy Questionnaire scores for Indian and Ophelia groups**

<table>
<thead>
<tr>
<th>HLQ Domains</th>
<th>Indian</th>
<th>Ophelia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>1. Feeling understood and supported by health care professionals</td>
<td>3.02 (0.51) [2.91, 3.14]</td>
<td>3.21 (0.54) [3.17, 3.25]</td>
</tr>
<tr>
<td>2. Having sufficient information to manage my health</td>
<td>2.80 (0.58) [2.67, 2.93]</td>
<td>2.98 (0.54) [2.94, 3.01]</td>
</tr>
<tr>
<td>3. Actively managing my health</td>
<td>3.01 (0.53) [2.89, 3.13]</td>
<td>3.02 (0.50) [2.99, 3.06]</td>
</tr>
<tr>
<td>4. Social support for health</td>
<td>3.12 (0.53) [3.00, 3.24]</td>
<td>3.03 (0.55) [2.99, 3.07]</td>
</tr>
<tr>
<td>5. Appraisal of health information</td>
<td>2.68 (0.58) [2.55, 2.81]</td>
<td>2.78 (0.54) [2.75, 2.82]</td>
</tr>
<tr>
<td>6. Ability to actively engage with health care professionals</td>
<td>3.85 (0.62) [3.71, 3.99]</td>
<td>3.97 (0.69) [3.92, 4.02]</td>
</tr>
<tr>
<td>7. Navigating the health care system</td>
<td>3.60 (0.73) [3.44, 3.76]</td>
<td>3.82 (0.67) [3.78, 3.87]</td>
</tr>
<tr>
<td></td>
<td>Ability to find good health information</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>----------------------------------------</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>Ability to find good health information</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3.56 (0.78) [3.39, 3.73]</td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>3.65 (0.75) [3.60, 3.71]</td>
<td>9.</td>
</tr>
</tbody>
</table>

Abbreviations = SD Standard deviation, CI confidence interval

The HLQ scores for the Indian and Ophelia group were closely aligned. The main differences were in the following three scales in which the Indian group had lower scores than the Ophelia group: scale 1, ‘Feeling understood and supported by health care professionals’ with a mean score of 3.02 (0.51) compared to 3.21 (0.54); scale 2, ‘Having sufficient information to manage my health’ with a mean score of 2.80 (0.58) compared to 2.98 (0.54); and scale 7, ‘Navigating the health care system’ with a mean score of 3.60 (0.73) compared to 3.82 (0.67). Only in scale 9, ‘Understand health information enough to know what to do’ with a mean score of 4.13 (0.62) did the Indian group score higher than the Ophelia group: 3.85 (0.74).

**Indian understandings and interpretations of the HLQ**

Six Indian participants (2 men, 4 women) completed individual cognitive interviews (See Table 4.5), which lasted between 20 and 30 minutes. Participants had lived in Australia from 2 to more than 20 years, were aged between 30 and 50 years with the majority tertiary educated and one person had a disability.

**HLQ item interpretation**

Consistent with the Somali and Chinese groups the cognitive interviews with the Indian-Australian group show (See Appendix 8) that the content of items, when referenced against the a priori item intents, were understood as intended. Some items contained wording or concepts that were difficult to understand however, responses indicated that their overall understanding of the construct remained consistent with the original meaning. Importantly, there were no items or domains that proved to be offensive or culturally inappropriate in this group. In addition, all nine domains were understood from a cultural perspective.

Similarly, with the other two migrant groups the Indian participants had difficulty with particular wording in the HLQ such as the term ‘health practitioner’, a term not commonly used by Indian participants, who expressed a preference for the term ‘doctor’. This preference may reflect Indian migrants’ experiences with health systems in their country of origin and with the concept conveyed by participants that the doctor was a person of higher status and should be addressed in
their formal role and their lack of familiarity a primary care health system or allied health professionals. However, this did not prove to be a barrier to answering the questions, as respondents were orientated to the HLQ instructions in which they were invited to consider health practitioners to be doctors, nurses or traditional healers, as was relevant to them. The HLQ was provided in Hindi with attention paid during the translation process to the use of the most appropriate term for health care professional in this language.

Also, similarly to the Chinese group the Indian group had some difficulty with the domains 1. ‘Feeling understood and supported by healthcare providers’ and 6. ‘Ability to actively engage with healthcare providers’. Responders identified the same issue as the Chinese group where there was an unequal power relationship between the doctor and patient. The doctor/patient relationship in India as in China is a formal one and premised on the higher status of the doctor. They did not wish to appear rude or offend the doctor by challenging their authority through excessive questioning or asking for different treatments or approaches. They indicated that they were able to provide information about their health issue and accepted the information provided to them without further discussion. This was the case even if they did not always agree with the treatment. However, as with the Chinese participants, the Indian participants were able to convey their health issue and ask for sufficient information to understand the instructions provided by the doctor. This approach was consistent with the intent of the item construct.

Another item that participants appeared to have difficulty with initially (similar to the Somali group) was item 3.8 ‘I spend quite a lot of time actively managing my health’. The difficulty appeared to relate to the term ‘actively’ which may be more linguistically related than conceptual and on further elaboration respondents indicated that this concept did fit with a holistic view of health and was culturally congruent. Indian participants viewed caring for health as integrated with all aspects of their lives therefore, they did spend a lot of time managing their health. This interpretation was consistent with the item intent.

The cognitive interviews also revealed how HL practices were operationalised. For example, information seeking from known sources such as from Indian community members and from the internet, which is consistent with the intent of the items. For the scale 5, ‘Appraisal of health information’, Indian participants used multiple trusted sources to compare and appraise information that were often outside of the health system such as family, community and the internet. Information appraisal or comparisons (similarly to the other two groups) were based on the cultural appropriateness of health information rather than verification within a biomedical health context or between health information sources.
For scale 4, ‘Social support for health’, the concepts were interpreted broadly as spiritual, social and emotional support within the Indian community, as well as practical support during periods of ill health. The scale 7, ‘Navigating the health system’ appeared, as with the other two groups, to be interpreted narrowly as access to GPs and emergency rooms. Other elements of the health care system that might require navigation, such as allied health, prevention, screening or specialist care, were not generally referred to.

Functional HL as indicated by scale 9, ‘Understanding health information well enough to know what to do’ was understood to encompass the practical supports provided by the community than increased individual abilities. Indian participants indicated that in answering many of the questions their point of reference was the health system in their country of origin. The health system in India is a pluralist system in which people have direct access to specialist care (for those persons with means to pay for this care) and to the hospital setting that employs both biomedical and traditional practitioners. Many participants were very satisfied with aspects of the Australian health care system such as Medicare (taxpayer funded health care).

In summary, the data from the cognitive interviews confirmed that Indian participants interpreted and responded to the HLQ constructs as intended. Difficulties with some concepts were overcome by referring to the HLQ instructions which provided a broad interpretation of terms such as ‘health practitioner’. The HLQ instructions included this specific definition because there is no universal Australian term to describe this group. Also, none of the respondents indicated that any items or wording were offensive or culturally inappropriate. Wording changes are not recommended as the items were interpreted as consistent with the construct intent. Importantly, critical information surfaced that elicited cultural perspectives on areas such as help and information seeking and information appraisal that were operationalised as social activities reflecting cultural practices.

**Indian health conceptualisations, beliefs and practices**

Thematic analysis of data resulted in the emergence of five dominant themes that are outlined below. Rich data were obtained from fifteen participants until data saturation was reached and no new themes emerged (Marshall, 2010).

The Indian group was comprised of seven men and eight women with an age range of between 27 to 74 years old, who had resided in Australia for between 5 and 20 years. Ten participants had immigrated under the skilled migrant program, and five under the family reunion program. The majority were university educated with the main languages spoken of Hindi and English.
Five themes emerged from the semi-structured interviews: toleration of power; migration related stressors, satisfaction and dissatisfaction with health professionals and the health system, use of traditional health care approaches, mental health and aversion to the concept of diagnosis. These themes are outlined below.

1) **Toleration of power; migration related stressors**

Many participants spoke of the increased levels of ill health in the Indian-Australian migrant community and of the high levels of migrant related stressors that were responsible for this ill health. These stressors were identified as family tensions, adapting to the fast pace of Western life, loss of culture and religion, the lack of family and social support, discrimination, fear of losing good health due to the changed environment, work tensions, expectations from family of financial success, and providing material support to family.

In the Indian group, a number of male participants spoke of the particular stress they felt in meeting the cultural expectations for them to care for their parents and extended family. It is very common for Indian parents to live with the first son’s family (sometimes referred to as a ‘joint’ family in which two or more families are living together), which at times caused a great deal of tension. The participants spoke of the expectations put on them to provide for all of their parent’s needs, such as money and physical support in attending medical appointments and for the whole family to meet social obligations to the Indian-Australian community. These men spoke of feeling exhausted from working long hours for low pay and sometimes dangerous conditions (three of the men were taxi drivers). They stated that they often felt mentally ‘low’ as a consequence of these combined stressors and felt trapped between the cultures of India and the expectations of being an Indian-Australian migrant.

Conversely, many of the women spoke of the stressors of entering the family of their husband upon marriage and of their role in meeting the needs of their parents-in-law. They stated that many parents visited Australia for long periods which meant they were obliged to hold down their job whilst meeting all of the needs of their parents-in-law as well as running the home and raising the children. Many stated that they had large mortgages and had put their children into private schools so money was always an issue. They often experienced a range of symptoms such as headaches, fatigue and feeling ‘down’. Participants indicated that to remain healthy they tried both traditional and Western medicines. Some had tried practices and treatments related to traditional systems of belief such as Ayurveda (oils and creams), herbs, tablets, yoga, meditation and also some homeopathy. In addition, some asked for medication from the doctor to help with
sleep and problems such as indigestion and headaches. Many of the participants spoke of the stress of living within a communal culture in a Western context and the many problems this created.

Migration related stressors were evidenced in the following statements:

Indian participant 14: “People who live in joint family … have to have the toleration power and if someone is angry or something there is a need for some toleration. We are very good at this practice of the toleration of power or we will not be a family but many families are forgetting this in Australia.”

Indian participant 2: “I am the first son so it is on my shoulders to take care of my parents and make sure they have a good life. They cared for us and now it is our time to return this but in Australia this is harder because I work many long hours for little money and I have to pay the mortgage and everything … Sometimes I feel very low with this problem.”

Indian participant 12: “It is not always easy to live in joint family and I feel my own life is gone in together and all of my emotion and I can’t tolerate these people and I bicker and bicker and I have stress in my brain and I have allopathic medicine and a side effect and another two problems came and somebody told me about homeopathy. I have that and slowly, slowly my situation is getting better and that headache is gone and I go back to my family where I can adjust and financially I have independence and now I am very happy.”

2) Satisfaction and dissatisfaction with health professionals and the health system

Many participants expressed varying levels of satisfaction with health professionals and in the health system in Australia. All participants were very satisfied with the universal Medicare system and the high level of professionalism of doctors, which also ensured professional confidentiality. Participants relayed experiences of the Indian health system in which the level of care was not always of the highest standard with stories of individuals falling ill or dying as a consequence. Many also had a number of concerns about the Australian health system. The specific concerns were the following: discrimination by medical staff, short consultation time, delays in accessing specialist care, over-medicalisation of care in pregnancy and costs of care, including of dentists and allied health professionals. Some participants talked about being made to wait longer for care than Australians, of receiving a lower standard of care and also of their resentment at having to pay so much money for care (the requirements of work or study visas are that individuals need to pay for all medical care). They believed that this was a practice of discrimination against Indian migrants. They also expressed confusion at not being able to access
specialist care directly which was the system they were used to in India. Both men and women discussed their concerns about the over-medicalisation of pregnancy care and their fears that their babies may suffer from the effects of ultrasounds and other interventions such as blood tests. In India, there was a practice of minimal intervention during pregnancy, which is why some women chose to return to India for the birth of their babies.

Satisfaction and dissatisfaction with the Australian health care system is evident in the following statements:

Indian participant 5: “We are extremely pleased with the Australian health system because it is a very safe system and very professional. In India, it can be very corrupt and you cannot be overconfident you will get good care, particularly if you are poor.”

Indian participant 9: “I went to emergency because I burnt my hand at work and they made me wait. They took the others before me who were in less need and they made me wait because I am not Australian. And then they rushed my through with my treatment like they hated me being there.”

3) **Use of traditional health care approaches**

All participants indicated that they had used a pluralist approach to health by combining traditional health approaches with Western biomedical health care. Most had a very high level of confidence in traditional methods of healing but indicated they would also use Western medicine when they were very ill. The traditional methods ranged from herbs, pills, yoga, breathing methods, *Ayurveda* and meditation. Participants generally spoke of combining a spiritual approach to health with various treatments. They did not believe that just taking treatments alone, without consideration of their spiritual health, would work. Older women expressed a high level of satisfaction with traditional methods, with some women assuming the role of health healer or health broker within their families and in their communities. There was a great deal of respect paid to the health brokers in the community who took responsibility for the health of the whole family. This role included recognition of illness among family members and providing remedies directly or brokering access to appropriate healers either in Australia or in India. Many spoke of the church community as a good source of spiritual and health information. It was also common for participants to combine health care with a return visit to India, particularly in relation to dental health which was regarded as too expensive in Australia. One person relayed her experience of infertility that was cured on return to India and seeing a traditional healer. Also, if a diagnosis was given participants indicated that they were very likely to try both traditional and Western medicines to cure the condition.
Use of a pluralist approach to health is evident in the following statements:

Indian participant 6: “If I am sick I will go to hospital but I believe that health is also about prevention and paying respect to God. I have used traditional medicines with success and I believe they can be of benefit.”

Indian participant 2: “I am the person they come to if they are sick. I learnt from my father who was a well-respected healer and now I do these things. I watch my family and I know what is best for them and I get remedies sent to me from my home. They are the best quality that you can’t get here.”

4) Mental health

Participants indicated that mental health was not usually discussed in the community and they were not aware of any persons who had a mental illness. The only exception to this view was expressed by a young woman who had been put on antidepressants for low mood, however she felt that the medication did not help her and she tried herbal medicine instead. Participants also indicated that if they were experiencing sadness they would seek advice from someone within their community such as religious leaders or a trusted family member. Participants’ spoke of many cases where participants returned home to India to cure their mental health problems.

Examples of participants’ perceptions of mental health are seen in the following statements:

Indian participant 14: “If you were feeling unhappy or sad you generally do not mention this but you might say you are having family troubles or not feeling right. We do not talk about mental health.”

Indian participant 15: “Mental health is about looking after your spiritual and emotional health. It is bigger than just your mind; it is also the body and the spirit. If we don’t pay attention to all these things something will go wrong.

5) Aversion to the concept of a ‘diagnosis’

Health and illness prevention was conceptualised as a holistic approach to health that sat within the traditional Indian healing approach with few participants stating that prevention and screening were necessary. Participants indicated they would participate in screening, such as blood tests for diabetes, if the GP strongly insisted. Many participants knew of family members or friends who had diabetes and therefore they were aware they were at high risk of acquiring
this condition. However, there was a strong resistance to getting a diagnosis, which was considered to be related to a terminal illness. Western medicine was not curative in their view, rather, they considered that traditional medicine was very likely to restore health.

These views were evidenced in the following statements:

Indian participant 5: “We Indians don’t like to get a label you know, like diabetes. So many people have diabetes and it is like the end. We want hope so we go back to traditional practices and pretend we do not have this disease, like we can cure ourselves.”

Indian participant 3: “It is very depressing to get a diagnosis and some people take this very badly. This can have the bad effect of people just giving up. We want to believe that if we follow the right way, the spiritual way, then we can get back to health.”

Section 3: Discussion

The results of this study show that the Indian-Australian population have a pluralist approach to health and use Western medicine as a component of a larger system of health care. Similar to the Somali and Chinese groups, interaction with the Australian health system involved higher levels of engagement with the primary and acute sectors, and less with prevention, screening, mental health services and some treatments. This selective pattern of health system engagement was related to participants viewing traditional health approaches as more effective in some areas particularly in prevention and chronic disease. The higher level of English proficiency in this group appeared to reduce access barriers, however, it did not increase health system engagement compared to the Chinese and Somali groups who had lower levels of English proficiency. This is an important finding and suggests that cultural influences may be equally or more important as English language proficiency, to health system engagement.

The health literacy competencies including strengths and needs of the Indian group

The HLQ scores for the Indian group were relatively lower than the Australian Ophelia comparison group. This finding is difficult to explain given that the Indian group had the highest levels of English proficiency of the three migrant groups and therefore likely to experience fewer barriers to accessing health information and services. English proficiency did not appear to increase HL skills in the areas of health engagement, self-management, information finding and appraisal and health system navigation. It would appear other factors were at play such as cultural barriers. Of interest is the highest score for this group in scale 9, ‘Understand health information enough to know what to do’, which is a good indicator of functional HL. It is unclear if the Indian participants were considering health information from the Australian health
system or from culturally congruent sources in their response to this scale. Cognitive interviews suggest the high level of interest in tradition therapies may account for the higher score in this scale.

Areas of HL strengths included the high levels of social support that contributed to a pattern of distributed HL (Edwards et al., 2015b) through family and social networks. The Indian group demonstrated a high level of trust in information sources from within the community. Also, the higher level of English proficiency and tertiary education levels in this group are likely to have strengthened HL abilities.

When these findings are referenced against the Nutbeam model, relative strengths can be seen in the functional and interactive HL levels. Domain nine of the HLQ, which is a strong indicator of functional HL was the highest score for the Indian group, suggesting that Indian’s diverse approaches to understanding and using health information are effective. The much higher level of English proficiency in this group most likely contributed to higher levels of functional HL. Half of the Indian participants were university educated and spoke English at home (See Table 5.2). The results of this study are contrary to the findings in other studies which found that Indians to have low levels of functional HL (Nesoff et al., 2017; Tsai & Lee, 2016) and other studies showing low functional HL in migrant groups more generally (Poureslami et al., 2007; Sentell & Halpin, 2006; Todd & Hoffman-Goetz, 2011). However, as indicated in Chapter 1, many of these studies used narrow measures of HL and commonly defined functional HL in relation to literacy-based skills.

The Indian group also had a high level of competency in the second level of Nutbeam’s model, communication/interactive HL. This was observed in the HLQ data, and then supported by the interviews. Indians utilised their high levels of social capital to find, use and understand health information. In addition, the Indian participants indicated that highly developed communication strategies such as use of family and community persons with higher levels of English proficiency to assist with communication.

Results for Indians in the third level of Nutbeam’s model appear to show they perform less well in the critical level of HL. Whilst the HLQ domains capture control of health they may not be broad enough to determine ‘more advanced cognitive skills’ and ‘greater exertion of life events and situations’. Individual agency is reduced for members of a collectivist culture such as the Indian culture, so although the responses indicated they perform well in this HL level, this conclusion needs to be regarded with caution. Further research is required to explore the role of ‘collectivist agency’ for groups such as Indian migrants.
The HLQ as a measure of health literacy among Indian participants

The HLQ has been validated in a predominantly Australian-born population (Beauchamp et al., 2015) and this is the first study to test the tool in Australian migrant populations. Results report that the HLQ constructs were largely understood as intended and that the tool was appropriate for use in the Indian migrant population. The key contribution of this multi-dimensional measure of HL (HLQ) in this study was in revealing important HL elements, such as social capital and expectations of health practitioner engagement.

In summary, the cognitive interviews assessed cognitive understanding of each HLQ item (n=44), which stem from nine separate conceptual elements of HL derived from the Australian community. The data generated by the HLQ was broad when compared with the rich culturally specific data that emerged from the cognitive interviews. These results closely approximate to the comparison, largely Australian-born group (Ophelia group) and suggest that the tool was an appropriate measure of the HL strengths and limitations of the group. These findings confirm the importance of considering the contextual dimensions of HL (Batterham et al., 2017) such as a cultural perspective in the analysis and the further verification of the HLQ findings within a cultural framework.

The health conceptualisations and health-related practices of the Indian group

The Indian participants were homogenous in their holistic view of health and their view of health within a pluralist activity. Participants articulated culturally shaped health perceptions, such as restoration of humoral systemic balance. Lack of participation by Indian migrants in prevention and screening may be explained by a perception that traditional approaches are more effective in aspects of care such as prevention and chronic disease management. Further, a reluctance to engage in screening may be impacted by the strong aversion to being given a ‘diagnosis’. Participants indicated that they associate a diagnosis with the permanent loss of health that was not reversible. Culturally bound beliefs were reflected in practices such as help-seeking, information gathering and a hierarchy of help-seeking. Of particular concern among this group was the high level of reported ‘migration related stress’ that may be under-recognised by health professionals.

Indian community members were the most trusted and first-line source of health information. Culturally congruent sources of health information that were verbal were most commonly used by Indians with text-based health information sources being the least used. Results also showed that the Indian group had adopted a combined approach to health through the convergence of a
biomedical model within their health belief system where there are points of compatibility. This concept is further explored in the final chapter in the section titled ‘Health engagement convergence model’

**Barriers and enablers to health literacy in the Indian group**

The study showed that current approaches to knowledge transfer in the Australian health system was a significant barrier for the Indian group. Participants indicated that mechanisms of transfer, such as text based information embedded in biomedical concepts, were accessed less often, with culturally congruent methods, such as social and community groups, used more often.

The high level of social capital within the Indian group, as evidenced in both the higher scoring in scale 4, of the HLQ and the semi-structured interviews, acted as both an enabler and a barrier to health system engagement. Interviews showed that social support was operationalised in a health context and evidenced in enhanced areas such as; social, emotional and physical support and navigation of the health system, and in communication with health practitioners. However, results showed that the knowledge limitations and low levels of trust contributed to low levels of engagement in areas of the health system such as prevention, screening and mental health.

**Strengths and limitations**

In a similar way to the studies of Somali and Chinese immigrants discussed in the previous sections, the study of Indian immigrants has limitations including its cross-sectional design, which limits drawing causal conclusions. Another limitation is the self-reported survey, which may be prone to a number of biases such as recall bias. In addition, entry into the study by participants was by direct invitation therefore it is possible that persons with higher levels of HL may have self-selected, resulting in a potentially lower representation of Indian-Australian persons with lower HL levels. Another strength was the use of a mixed methods approach based on a broad conceptualisation of HL and situated within a cultural framework. Lastly, an important element of this study was the development of a democratic partnership between the researcher and the Indian community with stakeholders involved in the design and implementation of the study and the exploratory nature of the grounded approach increased engagement with participants.

**New approaches to migrant groups**

Results indicate that interventions aimed at increasing engagement of Indian immigrants are likely to be ineffective if developed and applied without careful attention to culture and context.
These findings provide the impetus for health practitioners to integrate cultural conceptions of health into primary practice. Practitioners need to appreciate that Indian migrants use the biomedical health system as complementary to traditional approaches and also that they may have low expectations of the health practitioner and may struggle with concepts such as self-management. Asking Indian patients about their perspectives on health prevention and screening would be an appropriate intervention to potentially augment engagement in these areas. In addition, the non-judgmental inquiry into the use of complementary medicines may also build trust and help to develop a health plan that is meaningful to the Indian patient.

Of concern in this group was the high level of ‘migration related stress’ reported by participants, which impacted on their mental well-being. However, participants also articulated an aversion to the concept of ‘mental health’ and Western treatments in this area. Therefore, it is important for health practitioners to adopt a new approach to inquiring about the mental health and stress indicators of Indian-Australian patients that may be framed as overall health rather than within a mental health framework.

These findings challenge the view that functional HL abilities are foundational to the development of higher levels of HL abilities, and may inform a public health perspective that HL dimensions can differ between populations. Lastly, the study revealed that the high levels of social support within the Indian group had both positive and negative impacts on health system engagement.

**Conclusion**

In conclusion, the Indian-Australian community is the fastest growing migration group with numbers expected to increase considerably over the next decade. Therefore, it is important to increase levels of engagement of this group with the Australian health system. The results from the Indian group provide evidence that culturally influenced health beliefs and practices, such as delayed help-seeking and lack of participation in prevention, impact health system engagement and may explain observed patterns of health behaviours in some migrant groups.

This study provides evidence that the Indian-Australian population works within a pluralist model of health that is not recognised or accommodated within the Australian health care system. Low levels of engagement with aspects of the health care system are related to use of traditional health care methods that are viewed by Indians as more effective in relation to prevention and restoration of overall health. An important theme that emerged among the Indian group was the high level of migration related stress that may be under recognised by health
professionals. Indian-Australians are reluctant to seek help for mental health issues and therefore it is important for health professionals to use the terminology of overall well-being as opposed to Western terms for mental health.

Finally, results showed that HL in collectivist migrant groups such as the Indian-Australian community is a communal rather than an individual asset which may be leveraged to increase HL abilities. The Nutbeam model supports the use of interventions that utilise a strengths based approach to improve HL focusing on functional and interactive HL skills, whilst the HLQ results indicate there is no need to invest in functional HL. In conclusion, this study provides robust evidence that health system engagement by the Indian-Australian community may be augmented through the delivery of culturally relevant interventions at the individual/family, practitioner and systemic levels.
Chapter 8: Health Literacy of Three Migrant Groups

In this chapter, I present a synthesis of the results across the three migrant groups and compare these results with the Australian Ophelia group.

The findings of this thesis provide evidence that the three migrant groups (Somali, Chinese and Indian) showed marked heterogeneity in their HL strengths and limitations (See Table 8.1 and Figure 8.1) and health conceptualisations. The Somali group had higher mean scores across eight of the nine HLQ scales when compared to the other two migrant groups with scale 9, ‘Understand health information well enough to know what to do’ being similar between the groups. After adjusting for potential confounders, such as age, education, language spoken at home, between group differences remain (See Table 8.3). Cognitive interviews show that the HLQ constructs were understood as intended, indicating the HLQ is potentially an appropriate measure of HL in these migrant groups. Finally, semi-structured interviews, like the HLQ results, also showed marked heterogeneity across the groups.

HLQ results

The HL strengths of the Chinese and Indian groups were similar to the mean scores of the comparison Australian Ophelia group (See Table 8.1 and Figure 8.1). For these three groups, mean scores were similar on three scales: 2, ‘Having sufficient information to manage my health’; 4, ‘Social support for health’; and 8, ‘Ability to find good health information’.

Conversely, there were larger differences in two scales, with the Ophelia group showing higher scores than the Chinese and Indian participants: 1, ‘Feeling understood and supported by health care providers’ and, 7, ‘Navigating the health care system’. Lastly, the Ophelia group showed higher scores for the scales 3, ‘Actively managing my health’, and 9, ‘Understand health information well enough to know what to do’, than the Chinese group.
Table 8.1: Comparison of health literacy of Somali, Chinese, Indian and Ophelia participants using the nine scale Health Literacy Questionnaire

<table>
<thead>
<tr>
<th>Scale</th>
<th>Group</th>
<th>Mean [95% CI] *</th>
<th>SD**</th>
<th>ANOVA***</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling understood and supported by health care providers</td>
<td>Somali</td>
<td>3.44 [3.31, 3.57]</td>
<td>0.58</td>
<td>f=34.56 (p=0.001)</td>
</tr>
<tr>
<td></td>
<td>Indian</td>
<td>3.02 [2.91, 3.14]</td>
<td>0.51</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chinese</td>
<td>2.58 [2.45, 2.72]</td>
<td>0.60</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ophelia</td>
<td>3.21 [3.18, 3.25]</td>
<td>0.54</td>
<td></td>
</tr>
<tr>
<td>2. Having sufficient information to manage my health</td>
<td>Somali</td>
<td>3.40 [3.26, 3.53]</td>
<td>0.59</td>
<td>f=20.87 (p=0.001)</td>
</tr>
<tr>
<td></td>
<td>Indian</td>
<td>2.80 [2.67, 2.93]</td>
<td>0.58</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chinese</td>
<td>2.78 [2.68, 2.88]</td>
<td>0.44</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ophelia</td>
<td>2.98 [2.94, 3.01]</td>
<td>0.54</td>
<td></td>
</tr>
<tr>
<td>3. Actively managing my health</td>
<td>Somali</td>
<td>3.34 [3.21, 3.47]</td>
<td>0.59</td>
<td>f= 20.95 (p=0.001)</td>
</tr>
<tr>
<td></td>
<td>Indian</td>
<td>3.01 [2.89, 3.13]</td>
<td>0.53</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chinese</td>
<td>2.61 [2.48, 2.74]</td>
<td>0.58</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ophelia</td>
<td>3.02 [2.98, 3.06]</td>
<td>0.50</td>
<td></td>
</tr>
<tr>
<td>4. Social support for health</td>
<td>Somali</td>
<td>3.60 [3.49, 3.70]</td>
<td>0.46</td>
<td>f= 37.89 (p=0.001)</td>
</tr>
<tr>
<td></td>
<td>Indian</td>
<td>3.12 [3.00, 3.24]</td>
<td>0.53</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chinese</td>
<td>2.94 [2.85, 3.03]</td>
<td>0.41</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ophelia</td>
<td>3.03 [2.99, 3.07]</td>
<td>0.47</td>
<td></td>
</tr>
<tr>
<td>5. Appraisal of health information</td>
<td>Somali</td>
<td>3.29 [3.14, 3.43]</td>
<td>0.65</td>
<td>f= 16.58 (p=0.001)</td>
</tr>
<tr>
<td></td>
<td>Indian</td>
<td>2.68 [2.55, 2.81]</td>
<td>0.58</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chinese</td>
<td>2.77 [2.67, 2.87]</td>
<td>0.66</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ophelia</td>
<td>2.78 [2.70, 2.82]</td>
<td>0.54</td>
<td></td>
</tr>
<tr>
<td>6. Ability to actively engage with health care providers</td>
<td>Somali</td>
<td>4.34</td>
<td>[4.19, 4.48]</td>
<td>0.66</td>
</tr>
<tr>
<td>---</td>
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<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Indian</td>
<td>3.85</td>
<td>[3.71, 3.99]</td>
<td>0.62</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>3.50</td>
<td>[3.36, 3.65]</td>
<td>0.68</td>
<td></td>
</tr>
<tr>
<td>Ophelia</td>
<td>3.97</td>
<td>[3.92, 4.01]</td>
<td>0.69</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7. Navigating the health care system</th>
<th>Somali</th>
<th>4.30</th>
<th>[4.16, 4.44]</th>
<th>0.65</th>
<th>f= 24.39 (p=0.001)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indian</td>
<td>3.63</td>
<td>[3.44, 3.76]</td>
<td>0.73</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>3.46</td>
<td>[3.31, 3.61]</td>
<td>0.69</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ophelia</td>
<td>3.81</td>
<td>[3.76, 3.85]</td>
<td>0.67</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8. Ability to find good health information</th>
<th>Somali</th>
<th>4.21</th>
<th>[4.06, 4.37]</th>
<th>0.71</th>
<th>f= 15.57 (p=0.001)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indian</td>
<td>3.56</td>
<td>[3.39, 3.73]</td>
<td>0.78</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>3.66</td>
<td>[3.54, 3.79]</td>
<td>0.56</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ophelia</td>
<td>3.66</td>
<td>[3.61, 3.71]</td>
<td>0.74</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>9. Understanding health information well enough to know what to do</th>
<th>Somali</th>
<th>4.14</th>
<th>[3.98, 4.30]</th>
<th>0.71</th>
<th>f= 10.68 (p=0.001)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indian</td>
<td>4.13</td>
<td>[4.00, 4.27]</td>
<td>0.62</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>3.71</td>
<td>[3.58, 3.84]</td>
<td>0.58</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ophelia</td>
<td>3.85</td>
<td>[3.80, 3.91]</td>
<td>0.74</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*CI= Confidence interval

**SD = Standard deviation

***ANOVA = Analysis of Variance
Figure 8.1: Boxplot comparisons of the health literacy of Somali, Chinese, Indian and Ophelia participants using the Health Literacy Questionnaire

For full scale names refer Table 8.1.

Figure 8.1 presents a box plot of the distribution of health literacy of the three migrant groups and the comparison Australian Ophelia group. The vertical lines extending form the boxes (whiskers) indicates variability outside the upper and lower quartiles. The maximum range of score for scales 1–5 is 4, and for 6–9 is 5. The dots above and below the whiskers represent the outliers or scores that fell more than 1.5 times the interquartile range above the third quartile or below the first quartile.

An additional finding across all three migrant groups was the HL of females (See Table 8.2 and Figure 8.2). When compared to males, females had slightly higher mean scores across the following three domains: 4, ‘Social support for health’ (male - 3.16, female - 3.29); 5, ‘Appraisal of health information’ (male - 2.84, female - 2.99); 8. ‘Ability to find good health information’ (male - 3.78, female - 3.86).
Table 8.2: Comparisons of the health literacy scores of males and females and language spoken at home in Somali, Chinese and Indian participants using the nine-scale Health Literacy Questionnaire

<table>
<thead>
<tr>
<th>Scale*</th>
<th>Sex</th>
<th>Language spoken at home</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Men (n=128)</td>
<td>Women (n=112)</td>
</tr>
<tr>
<td></td>
<td>Mean (SD) 95% CI</td>
<td>Mean (SD) 95% CI</td>
</tr>
<tr>
<td>HPS</td>
<td>2.97 (0.65) [2.86 - 3.09]</td>
<td>3.07 (0.67) [2.94 - 3.19]</td>
</tr>
<tr>
<td>HSI</td>
<td>2.93 (0.64) [2.81 - 3.04]</td>
<td>3.07 (0.57) [2.96 - 3.18]</td>
</tr>
<tr>
<td>AMH</td>
<td>2.93 (0.64) [2.82 - 3.05]</td>
<td>3.04 (0.63) [2.93 - 3.16]</td>
</tr>
<tr>
<td>SS</td>
<td>3.16 (0.54) [3.07 - 3.25]</td>
<td>3.29 (0.54) [3.19 - 3.39]</td>
</tr>
<tr>
<td>CA</td>
<td>2.84 (0.63) [2.73 - 2.95]</td>
<td>2.99 (0.60) [2.88 - 3.10]</td>
</tr>
<tr>
<td>AE</td>
<td>3.83 (0.71) [3.70 - 3.95]</td>
<td>3.98 (0.75) [3.84 - 4.12]</td>
</tr>
<tr>
<td>NHS</td>
<td>3.73 (0.79) [3.59 - 3.87]</td>
<td>3.85 (0.77) [3.71 - 3.99]</td>
</tr>
<tr>
<td>FHI</td>
<td>3.78 (0.77) [3.64 - 3.91]</td>
<td>3.86 (0.73) [3.72 - 3.99]</td>
</tr>
<tr>
<td>UHI</td>
<td>3.99 (0.64) [3.88 - 4.10]</td>
<td>4.00 (0.70) [3.87 - 4.13]</td>
</tr>
</tbody>
</table>

* For full scale names refer to Table 8.1.
Figure 8.2: Boxplot comparisons of the health literacy of males and females in Somali, Chinese and Indian groups using the nine-scale Health Literacy Questionnaire

For full scale names refer Table 8.1.

Figure 8.2 presents a box plot of the distribution of health literacy of males and females in the migrant groups. The vertical lines extending from the boxes (whiskers) indicates variability outside the upper and lower quartiles. The maximum range of score for scales 1–5 is 4, and for 6–9 is 5. The dots above and below the whiskers represent the outliers or scores that fell more than 1.5 times the interquartile range above the third quartile or below the first quartile.

English spoken at home (See Table 8.3 and Figure 8.3) was strongly associated with higher HL scores. This finding is consistent with studies (Beauchamp et al., 2015; Rau et al., 2014) that showed that English language proficiency is associated with higher levels of HL. Between groups, differences in HL scores for health care card holders and those without health care cards were small. Finally, there were few differences between persons living alone and those not living alone. Relatively few participants who reported living alone in the three migrant groups (Somali 2%, Chinese group 12%, Indian 0%) compared to the Ophelia group (43%).
Figure 8.3: Boxplot comparisons of health literacy for those who spoke English at home and those who spoke a language other than English at home in the Somali, Chinese and Indian groups using the nine-scale Health Literacy Questionnaire

For full scale names refer to Table 8.1.

Figure 8.3 presents a box plot of the distribution of health literacy for those who spoke English at home and those who spoke a language other than English at home within the three migrant groups. The vertical lines extending from the boxes (whiskers) indicates variability outside the upper and lower quartiles. The maximum range of score for scales 1–5 is 4, and for 6–9 is 5. The dots above and below the whiskers represent the outliers or scores that fell more than 1.5 times the interquartile range above the third quartile or below the first quartile.
Table 8.3: Association between health literacy and group membership adjusting for age, language spoken at home and education (multiple linear regression)

<table>
<thead>
<tr>
<th>HLQ scale*</th>
<th>Chinese</th>
<th>Indian**</th>
<th>Somali</th>
<th>Chinese</th>
<th>Indian**</th>
<th>Somali</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Coefficient (95% CI)</td>
<td>Coefficient (95% CI)</td>
<td>Reference</td>
<td>Coefficient (95% CI)</td>
<td>Coefficient (95% CI)</td>
<td>Reference</td>
</tr>
<tr>
<td>HPS</td>
<td>-0.86 (-1.03, -0.68)</td>
<td>-0.42 (-0.59, -0.24)</td>
<td>0.00</td>
<td>-0.69 (-0.90, -0.48)</td>
<td>-0.33 (-0.51, -0.14)</td>
<td>0.00</td>
</tr>
<tr>
<td>HSI</td>
<td>-0.62 (-0.79, -0.45)</td>
<td>-0.59 (-0.76, -0.42)</td>
<td>0.00</td>
<td>-0.59 (-0.79, -0.39)</td>
<td>-0.58 (-0.76, -0.40)</td>
<td>0.00</td>
</tr>
<tr>
<td>AMH</td>
<td>-0.73 (-0.91, -0.55)</td>
<td>-0.33 (-0.50, -0.15)</td>
<td>0.00</td>
<td>-0.65 (-0.87, -0.44)</td>
<td>-0.29 (-0.48, -0.10)</td>
<td>0.00</td>
</tr>
<tr>
<td>SS</td>
<td>-0.66 (-0.80, -0.51)</td>
<td>-0.47 (-0.62, -0.33)</td>
<td>0.00</td>
<td>-0.62 (-0.80, -0.44)</td>
<td>-0.45 (-0.61, -0.30)</td>
<td>0.00</td>
</tr>
<tr>
<td>CA</td>
<td>-0.52 (-0.69, -0.34)</td>
<td>-0.61 (-0.78, -0.43)</td>
<td>0.00</td>
<td>-0.58 (-0.79, -0.37)</td>
<td>-0.63 (-0.81, -0.44)</td>
<td>0.00</td>
</tr>
<tr>
<td>AE</td>
<td>-0.84 (-1.04, -0.63)</td>
<td>-0.49 (-0.69, -0.28)</td>
<td>0.00</td>
<td>-0.79 (-1.04, -0.55)</td>
<td>-0.48 (-0.69, -0.26)</td>
<td>0.00</td>
</tr>
<tr>
<td>NHS</td>
<td>-0.84 (-1.06, -0.63)</td>
<td>-0.70 (-0.91, -0.49)</td>
<td>0.00</td>
<td>-0.77 (-1.03, -0.51)</td>
<td>-0.69 (-0.92, -0.46)</td>
<td>0.00</td>
</tr>
<tr>
<td>FHI</td>
<td>-0.55 (-0.77, -0.33)</td>
<td>-0.66 (-0.87, -0.44)</td>
<td>0.00</td>
<td>-0.69 (-0.95, -0.43)</td>
<td>-0.72 (-0.95, -0.49)</td>
<td>0.00</td>
</tr>
<tr>
<td>UHI</td>
<td>-0.43 (-0.63, -0.23)</td>
<td>-0.01 (-0.21, -0.19)</td>
<td>0.00</td>
<td>-0.47 (-0.71, -0.23)</td>
<td>-0.07 (-0.28, 0.15)</td>
<td>0.00</td>
</tr>
</tbody>
</table>

*For full scale names refer Table 8.1.

** Sample size as 80 from all analysis except from one respondent in the Indian group was missing a value for ‘English spoken at home’, so for these analysis the sample size was 79.

Given that there were potential confounders that may explain the observed differences between the groups, multiple regression was undertaken to determine whether differences between the groups remained after adjusting for age, education and language spoken at home (See Table 8.3). The Chinese and Indian participants had lower mean scores across all HLQ scales compared to the Somali group, with the exception of scale 9, ‘Understanding health information well enough to know what to do’, in which no differences were seen between Indian and Somali participants.
Cognitive interviews

Results showed that whilst some items in the HLQ had concepts or wording that were culturally incongruent with the three migrant groups such as item 3.8, ‘I spend quite a lot of time actively managing my health’, and 5.2, ‘I compare health information from different sources’, however, overall the HLQ constructs were largely understood as intended. The HLQ items were broadly understood as intended given the construct definitions and did not contain culturally inappropriate or stigmatising wording or concepts. The cognitive interviews provided evidence that the items are acceptable to respondents and potentially appropriate in migrant groups.

Semi-structured interviews

The themes that emerged from semi-structured interviews, like the HLQ results, showed marked heterogeneity between the three migrant groups (See Table 8.4). Common themes that were expressed in culturally diverse ways were: mental health, distrust of health care and an aversion to receiving a diagnosis. The Somali group had the largest range of additional themes, ranging from; health is a gift from God, intersection of religion and health, hierarchy of help and information seeking, fear of environmental poisons, community is healing, isolation is sickness, intuitive approach to health, individual agency versus collective responsibility. The Chinese group’s additional themes were: food is medicine, the inheritance of health, unrealised expectations, low level of belief in prevention/screening, health information transfer through cultural health networks, and ‘saving face’ in a health context. Lastly, the Indian group’s additional themes were: toleration of power, migration related stressors and use of traditional health care approaches.
Table 8.4: Comparison of themes that emerged from interviews about health beliefs and practices in people from three migrant groups.

<table>
<thead>
<tr>
<th>Somali</th>
<th>Chinese</th>
<th>Indian</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Broadly common themes across three groups</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is no mental health, just sadness and madness</td>
<td>The mental health taboo</td>
<td>Mental health</td>
</tr>
<tr>
<td>Distrust of health care</td>
<td>An uncaring system</td>
<td>Satisfaction and dissatisfaction with health professionals and the health system</td>
</tr>
<tr>
<td>Aversion to the concept of a ‘diagnosis’</td>
<td></td>
<td>Aversion to the concept of a ‘diagnosis’</td>
</tr>
<tr>
<td><strong>Unique themes across the three groups</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health is a gift from God</td>
<td>Food is medicine</td>
<td>Toleration of power; migration related stressors</td>
</tr>
<tr>
<td>Intersection of religion and health</td>
<td>The inheritance of health</td>
<td>Use of traditional health care approaches</td>
</tr>
<tr>
<td>Hierarchy of help and information seeking</td>
<td>Unrealised expectations</td>
<td></td>
</tr>
<tr>
<td>Fear of environmental poisons</td>
<td>Low level of belief in prevention/screening</td>
<td></td>
</tr>
<tr>
<td>Community is healing; isolation is sickness</td>
<td>Health information transfer through cultural health networks</td>
<td></td>
</tr>
<tr>
<td>Intuitive approach to health</td>
<td>‘Saving face’ in a health context</td>
<td></td>
</tr>
<tr>
<td>Individual agency versus collective responsibility</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Chapter 9: Discussion

Overview

Health is an outcome of a constellation of factors such as genetic inheritance, socioeconomic context, and environmental and cultural influences on an individual’s life (Marmot & Allen, 2015). Whilst most of these health determinants are fixed, HL can play a mediating role in how an individual can achieve, restore or maintain good health (Lytton, 2013). Research on HL is rapidly increasing with significant advances in the conceptualisation and measurement of the concept (Jordan et al., 2013; Jordan et al., 2011; Paasche-Orlow & Wolf, 2007; Sørensen et al., 2012). HL has evolved from humble beginnings as a literacy related concept focused on individual skills into a multi-dimensional concept with increasing recognition of social, cultural, structural and individual components (Batterham et al., 2017; Sørensen et al., 2013). A critical addition to the modern approaches to HL is a greater emphasis on health system responsiveness (Batterham et al., 2016).

However, advances in migrant HL have been minimal despite strong evidence of higher rates of avoidable mortality and morbidity in this population group (Anikeeva et al., 2015; Stirbu et al., 2006). Until recently, HL measures focused on a limited range of HL skills that may misrepresent the HL strengths and limitations of migrants. Through the application of a cultural lens this study advances our knowledge of the HL of migrant groups.

In the following sections, I present an analysis of the findings as they relate to the following study objectives: understanding the HL strengths and limitations of three migrant groups, testing the HLQ as a measure of HL in migrant groups, exploring health conceptualisations and health-related practices of three migrant groups, and identifying the barriers and enablers to augmenting HL in three migrant groups. In addition, I compare and contrast the findings of my study with the literature to determine how this new knowledge advances our understanding of the migrant-health field. Finally, I present a model that, if adopted, may increase health-system engagement by migrants. The chapter concludes with recommendations for further research, and policy and practice implications.

Health literacy strengths and limitations of three migrant groups

The findings show that the three migrant groups, Somali, Chinese and Indian, have marked heterogeneity in HL strengths and limitations and in health conceptualisations (See Table 8.1 and Figure 8.1). The Somali group had higher HL across almost all the domains of HL as expressed by the HLQ.
The overall higher scores in the Ophelia group compared to the Chinese and Indian groups, in scales 1 and 7 may be due to the increased exposure of this group to the Australian health system due to the higher prevalence of chronic disease (the Ophelia group was recruited from a health care setting where they were receiving services for chronic conditions and disability) compared to the three migrant groups. The similarities in HL scoring between the Chinese, Indian and Ophelia group may reflect factors such as the relatively long migration history of both the Chinese and Indian groups (when compared to the more recently arrived Somali group) in Australia, resulting in greater familiarity with the Australian health care system.

The higher HL in the Somali group relative to the other three groups (Chinese, Indian and Ophelia) was unexpected as previous research has found low levels of HL in Somali (Geltman et al., 2014; Morrison et al., 2013; Wångdahl et al., 2014b) and similarly in disadvantaged migrant populations (Shaw et al., 2012).

This result may be due to several factors such as individuals generating their responses in reference to previous experiences of health systems in Somalia and transition countries and against normative cultural practices within the Somali community. Among the Somali group there was a low expectation of practitioner engagement, which was based on their experiences of traditional health systems in their home country and, importantly, the socio-political positioning of a refugee Muslim group in a Western country.

Cognitive testing and interview data revealed that Somali participants viewed the Australian health system in very positive terms and as highly accessible, due to factors such as no-cost or low-cost medications and the close location of GP services. The common point of reference for this group was the health system in their country of origin and/or health systems in transition countries that were less accessible due to a relatively high cost of services, long waiting time and the location of services. Also, expectations of health practitioner engagement among the Somalis were influenced by experiences in their country of origin where the traditional and hospital-based systems operated in an environment in which patient and doctor/healer have minimal interaction. Therefore, the willingness of health practitioners in Australia to interact with patients was viewed favourably by Somalis as reflected in the score for scales 1. ‘Feeling understood and supported by health care providers’ and 6. ‘Ability to actively engage with health care providers’. However, cognitive interview data provided more nuanced insights into how the Somalis viewed the concept of interaction. Whilst they understood the construct as intended the Somalis spoke of the doctor/patient interaction as an opportunity to explain their health issue and for the doctor to respond by providing information and/or treatment. These data showed that the
expectation of interaction by the Somali was to engage in a brief didactic encounter and not as a more robust exchange between patient and doctor.

In addition, the Somali group showed that the two HL scales 2. ‘Having sufficient information to manage my health’ and 8. ‘Ability to find good health information’ were specifically interpreted to include information gained from local sources within the Somali community such as self-appointed community health advisors or from hadiths in the Quran, and for some participants it was the UK-based television programme (delivered by Western-trained Somali doctors and accessed by satellite TV). Somali participants used multiple sources of information to make health decisions and they had a very clear hierarchy of which sources were most trustworthy. Known sources within the local or international Somali community (including religious leaders) were the most trusted sources of health information followed by GPs. Verbal, visual and narrative information sources were the most accessible for this group.

In contrast, the Chinese and Indian groups had lower scores for scales 2. ‘Having sufficient information to manage my health’, and 8. ‘Ability to find good health information’. These two groups broadly interpreted the two scales as; written forms of information, internet-based information (in the Chinese language), information from within the community and/or verbal information from GPs. Responses from these two groups indicated that language and conceptual barriers limited their capacity to access health information.

To further explain the higher scores in the Somali group, consideration must be given to the socio-political context of this group. The Somali group were distinct from the other two migrant groups because they have a refugee background and belong to the Muslim faith. These differences have the potential to influence responses through social desirability bias (Leite & Beretvas, 2005). Social desirability bias is the tendency of responders to provide socially acceptable responses even if they are not true (Crowne & Marlowe, 1960; Leite & Beretvas, 2005). Crowne and Marlowe (1964) proposed that socially desirable responses are motivated by the need of subjects to respond in culturally sanctioned ways in order to obtain social approval (Leite & Beretvas, 2005). This consideration underscores the need for researchers to understand the broader socio-political positioning of migrants, particularly when comparing migrant groups.

Whilst results show that the strengths and limitations of the three migrant groups are diverse there are some similarities across the three groups in the three following domains: 6. ‘Ability to actively engage with health care providers’, 8. ‘Ability to find good health information’, 7. ‘Understanding health information well enough to know what to do’. These results show strengths in finding and understanding health information and engagement with health care
provides, which are contrary to several other studies that showed low skill levels in migrant
groups in information finding (Geltman et al., 2014; Shaw et al., 2012; Wångdahl et al., 2014a),
understanding (Cooper et al., 2012; Geltman et al., 2014; Shaw et al., 2012; Wångdahl et al.,
2014a) and engaging with health practitioners (Jatrana et al., 2014). This contrast in findings
serves to demonstrate how studies using limited or unidimensional HL measures have the
potential to misrepresent the HL abilities of migrant groups. The three migrant groups self-rated
their abilities in these scales as equal to or higher than the Australian Ophelia comparison group
and qualitative data provided rich illustrative examples of the unique practices (examples are
provided in the following sections) used by the three groups. Therefore, the findings of this study
demonstrate the value of utilising a range of methods when researching migrant groups to
provide a comprehensive picture of the HL strengths of the migrant groups.

Areas of relative HL limitations for the Indian and Chinese groups were: 1. ‘Feeling understood
and supported by health care providers’, 2. ‘Having sufficient information to manage my
health’, and, for the Chinese group, 3. ‘Actively managing my health’. Of particular interest is
the score in the Chinese group for 1. ‘Feeling understood and supported by health care
providers’, which was the lowest in this study and somewhat lower than previous HLQ studies
(Beauchamp et al., 2015; Jessup et al., 2017). As consistent with the literature (Kleinman et al.,
1978) HL practices in all three migrant groups were influenced by cultural beliefs and practices,
social norms and with pre-migration factors such as English proficiency and experiences with
health systems in the country of origin. Common across the three groups was a pluralist
approach to health, utilising traditional practices alongside the Australian biomedical system and
resulting in blended HL practices. All three groups demonstrated partial health engagement
patterns with the Australian health system, commonly entering the system during an illness
phase and presenting to acute services and low utilisation of prevention/screening services,
mental health services. In addition, they demonstrated a low level of compliance with some
treatments that did not fit with explanatory models of health. Partial or differential health system
engagement is consistent with findings of other studies in groups with low HL (Berkman et al.,
2011b; Durà-Vilà & Hodes, 2012; Henderson & Kendall, 2011; Wimmer-Puchinger et al., 2006).

The finding that females in the three migrant groups had higher HL than males is consistent with
other studies (Cotton et al., 2006; Kolarcik et al., 2017; Lee et al., 2015b; Wong et al., 2012).
Women’s higher HL scores may reflect the gendered burden placed on women to take primary
responsibility for the health of family and community members. However, what is unexpected in
this study is the finding that migrant women have higher HL than their male counterparts. This
finding is inconsistent with an emerging area of research on intersectionality and health showing
that migrant women face additional barriers to finding, understanding and using health information (may have less opportunities to learn English, or gain digital literacy skills), relative to migrant men, and increased barriers to achieving optimal health (Hankivsky, 2012). Exploring how migrant women may have overcome marginalisation to show relatively higher HL ability in this study warrants further inquiry.

The strong association with low HL scales and speaking a language other than English at home was consistent with similar studies (Beauchamp et al., 2015; Jessup et al., 2017). However, these studies do not explore in detail how language and HL interact. Whilst low English language proficiency may act as a barrier to effectively engaging with health professionals and with health information access, this study suggests other factors are at play. Findings from the three migrant groups showed that low English language proficiency was effectively compensated by the collective HL of the cultural group. In addition, the Indian group, which has the highest level of English proficiency, indicated that they had difficulties accessing health information. Conversely, the Somali group with low English proficiency had the highest scale score for interaction with health professionals. These findings suggest that information provision and health-professional interaction are a complex interexchange between language, health beliefs, health practices and culture. These points are further explored later in this chapter.

Also, the nuanced findings of this study such as the diverse approaches each of the three groups showed in areas such as information finding, help-seeking and harnessing social support to augment HL, highlight the importance of analysing the results from each of the three groups separately. Each of the three groups had different HL strengths and limitations and perspectives on health derived from localised determinants such as country-specific experiences and cultural influences which cast doubt on the value of comparisons between sub-groups. The aggregation of the results of the three groups, without verification by the qualitative data, would obscure the HL variances between the three groups and would not provide the robust information required to generate effective health system responses.

Finally, the observed HL heterogeneity in the results of this study may also be attributed to the diverse entry pathways of the three migrant groups such as; skilled migrant, humanitarian and family reunion. When people come enter Australia under different schemes, they are likely to have a different set of encumbrances/assets, and these will influence their ongoing success/failure to engage with the Australian health care system. In addition, as outlined previously, refugee groups such as the Somali have been found to have increased barriers to participation in the health system and worse longer-term health outcomes. The similarities in
HLQ scoring in the Chinese and Indian group may reflect the skill migrant entry pathways of these two groups.

The HLQ as a measure of HL for migrant groups

HL skills and abilities are not evenly spread across the population, with a number of studies showing that migrant groups have lower HL levels than non-migrant groups (Poureslami, Rootman, Doyle-Waters, Nimmon, & Fitzgerald, 2011; Sentell & Braun, 2012; Shaw et al., 2012; Smith, Brice, & Lee, 2012; Todd & Hoffman-Goetz, 2011). However, many of these studies were based on a narrow conceptualisation of HL that used health-related literacy and numeracy as their measure of HL (Jordan et al., 2011) which does not fully represent the construct of HL abilities of the general population nor for migrant groups. In addition, studies of migrant HL are often inadequately powered to ensure the reliability of the estimates of differences and similarities across subgroups (i.e., race, age, ethnicity and gender) (Haun et al., 2014) and show sampling bias towards those with higher English language proficiency (Elder et al., 2012). Therefore, there is a need for a comprehensive, validated measure of HL that is psychometrically robust, based on a broad, valid conceptual framework of HL and suitable for administration across diverse populations (Haun et al., 2014). Jordan et al. (2010) developed a broad model of HL that included health care system factors, socioeconomic factors, patient attitudes and experiences, social support, and education and cultural influences. This model informed the development of the HLQ, which has proved to be a robust measure of HL in Australian (R. W. Batterham et al., 2014), Danish (Maindal et al., 2016), German (Nolte S, 2017) and Slovakian populations (Kolarcik et al., 2017). This is the first study in which the HLQ has been used with non-European migrant groups thus enabling the testing of the relevance of the constructs in a new setting.

Analyses of data derived from the HLQ has identified the specific relative HL strengths of each of the three migrant groups and areas of HL need. This provides evidence of the issues that need to be addressed to improve health outcomes in these groups. Importantly, the HLQ has been found to provide largely unbiased estimates of mean differences in composite scores between groups in Victoria (Ophelia study) (Elsworth, Beauchamp, & Osborne, 2016) however, this has not been tested in migrant groups. This is particularly important, because individuals from different migrant groups may interpret the meaning and content of questionnaire items differently, thus introducing bias in estimates of group differences that relate to cultural or linguistic factors and not the actual HL of the respondent groups. The HLQ scales have been found to provide equivalent measurement across several socio-demographic groups, with only
minor bias in scales 7 to 9. In practice, this means that small overestimates of HL may occur in people with lower levels of education from non-English backgrounds. While these findings are promising, whether measurement bias exists between migrant groups has yet to be explored, either quantitatively or qualitatively.

Results of this study indicate that whilst some items in the HLQ had concepts that were not culturally congruent with the three migrant groups such as item 3.8, ‘I spend quite a lot of time actively managing my health’, and 5.2, ‘I compare health information from different sources’, the HLQ constructs were largely understood as intended and the tool was appropriate for use in these three migrant groups. However, further work is needed to confirm the utility of these dimensions in large-scale studies of these three migrant groups and in other migrant groups from non-European countries. Importantly, no respondents stated that the wording in any of the item/s was offensive or culturally inappropriate. Other elements of the HLQ that were relevant for these three migrant groups and perhaps for marginalised groups more generally were the inclusion of structural, community and individual level aspects such as health care access, patient experiences, health-needs assessment, and community-related assets such as social support.

Whilst the HLQ provided insights into the HL strengths and limitations in the three migrant groups, the findings also confirm the importance of the careful consideration of the contextual dimensions of HL (Batterham et al., 2017). Contextual factors such as cultural perspectives gained through the verification of the HLQ findings with qualitative data. Whilst the HLQ was useful in revealing the microelements of HL it did not capture the diverse methods of operationalising HL practices observed in migrant groups. Therefore, the cognitive and semi-structured interviews were important in revealing that the relationship between item content and the lived experience/behaviour of participants was broadly congruent. Participants responded congruently to the construct by drawing on ‘different’ elements of their lives to attend to the questions, showing different mechanisms to fill the needs as implied in the HLQ items. The data generated from respondent answers to the HLQ items provided insights into the overall HL abilities of the three groups. However, culturally relevant metadata captured from the cognitive and semi-structured interviews were crucial in interpreting and contextualising HLQ results. This context was important in interpreting HLQ scores and when seeking to make decisions about how the data should be used. Robust data, that uncovers the diversity of HL strengths and limitations in a population or group, will support the design of targeted interventions that are responsive to diverse needs.
The validity of the HLQ for migrant groups

The appropriateness of the HLQ in fully representing the HL of migrants has been challenged in this study. Responses from both the cognitive and semi-structured interviews, and the wide variation in HLQ scores, suggest a level of complexity in the HL of the three migrant groups that has not been fully captured by the nine HLQ scales.

Whilst construct validity was observed in the data from the three migrant groups, some items within the instrument were found to be culturally incongruent. Validity is dependent on respondents’ (with similar characteristics) collective understanding of items, eliciting similar responses. This may explain why there were differences in how items were understood across groups, with greater consistently shown within groups. Response variation at the individual level may be due to different reference points, and the way they attend (understand) particular items. The study participants appear to have drawn on different elements of the item intent, and quite strongly at times.

These results suggest that within group comparisons (e.g., between Somali men and women, old/young, or time since arrival) would be a more reliable than between group comparisons (e.g. migrant group differences, or between women in the three groups). Further empirical testing through psychometric procedures should be used to verify this speculation. It is also important that the validity of between group comparisons is verified by further psychometric testing before the HLQ is used for making conclusions between migrant groups.

A further key issue in relation to the appropriateness of the HLQ in representing the HL of migrants relates to construct representation. The qualitative data indicates there are is an underrepresentation of issues contributing to migrant HL in the HLQ. This seems reasonable given that the HLQ was developed within a native-born Australian population. The findings from the Somali group, in particular, suggest that the HLQ may not be a complete measure of health literacy in this group.

Whilst, item intents within the HLQ are broad to allow respondents to draw on a wide range of understandings and experiences that are relevant to each person, they appear to not fully encompass all the issues relevant to migrants. It appears that each of the three groups were drawing on diverse frames of reference which influenced the heterogeneity of the results. The issues captured in the qualitative data that are underrepresented in the HLQ were: information seeking/finding, hierarchy of help seeking, influence of cultural beliefs on disease causation and wellness attribution, agency, alternate/pluralist health practices, distributed
decision making, risk perception and most importantly, communal HL enablers. A broadening of the domains within the HLQ may address the underrepresentation.

It is important to state that before conclusions can be made about whether the three groups are different according to the HLQ, invariance testing needs to be undertaken to establish whether unbiased estimates of differences between the groups can be generated. The three groups have profoundly different backgrounds and experiences so it is likely that the mechanisms leading to migrant health decline are likely to be different. Differences in areas such as; pre-migration influences, migration pathways, levels of education, English language proficiency, health systems in the country of origin, cultural health beliefs and practices, social support and access to economic resources, are all factors that influence health literacy and health outcomes.

These are important findings that will inform future research. Finally, the identified limitations warrant a degree of caution in drawing assumptions from the observed variation in outcomes with these specific populations.

In addition, the use of two different HL models, the HLQ (Osborne et al., 2013) and the Nutbeam HL model (Nutbeam, 2000), in the analysis of data from this study was useful in providing a higher order structural understanding of the HL strengths and limitations of the three migrant groups. The nine HLQ scales are a grounded person-level model, whilst Nutbeam’s model poses a higher order model that the nine HLQ scales can be organised into, to undertake higher level analysis of the data.

**Health conceptualisations and health-related practices of three migrant groups**

One of the important contributions of this study was to identify the adaptive HL practices of the three migrant groups to the Australian health system. The following section describes the previously unrecognised adaptive and innovative HL practices observed in the three migrant groups and discusses the potential of these data to inform the development of interventions to augment HL in underserved migrant groups.

**Migrant health literacy practice**

Migrant HL is commonly reported as deficient within models using English language proficiency and reading as proxies for literacy (Gele et al., 2016; Schonlau et al., 2011; Sentell & Braun, 2012; Wangdahl et al., 2014) and literacy as a proxy for HL (Nutbeam, 2000). Literacy based HL models are problematic as they infer that people with low literacy or who have low English proficiency have ‘inadequate’ HL despite evidence that some groups demonstrate alternate methods of accessing and using health information and services (Batterham et al.,
Few studies have moved beyond the narrow conceptual confines of deficit models to measure HL of migrants, despite calls to expand HL indicators to include areas such as science literacy, oral (speaking) literacy and aural (listening, comprehension) literacy (Nielsen-Bohlman, 2004; Paasche-Orlow & Wolf, 2007). The findings of this study are heuristic in documenting adaptive skills in migrant groups used to effectively find, understand and use health information and services. This study has provided empirical evidence that migrants leverage particular strengths such as oral HL skills and extensively use social resources to create effective HL approaches. This study suggests that the use of limited measures of HL in migrant groups are likely to misrepresent migrant’s HL and are unlikely to uncover the elements of HL needed to guide effective intervention development or fully uncover the limitations of the health system in meeting their needs.

**Cultural help-seeking and information-gathering practices**

Jordan et al., (Jordan et al., 2010) found that knowledge related to help-seeking was perceived as a key component of successfully dealing with health problems. Nutbeam’s model (Nutbeam, 2008) situated help-seeking knowledge as a component of functional HL. Previous studies, unsurprisingly, have shown that migrant groups have lower levels of functional HL compared to non-migrant groups (Shaw et al., 2012; Smith et al., 2012; Stewart et al., 2014). However, the results of this study challenge the findings of the above studies and suggest that a broader conceptualisation of help-seeking and information gathering by migrants reveals that they have a high level of competency in these skill areas.

The three groups in this study used culturally congruent practices for help-seeking and information gathering that was often transnational in nature, which is similar to an observation previously made by Tiilikainen (Tiilikainen, 2011). A cultural practice can be defined as the selection of the behaviours of an individual which are replicated by other individuals in a cultural context (Andery, 2015). A central characteristic of cultural practices is that they make sense within a given cultural context and may be incomprehensible outside of that context (Leite & de Souza, 2012). Cultural values and attitudes influence help-seeking and information gathering propensity in two ways. The first is enculturation, or the process of being socialised into and retaining cultural norms of a person’s own heritage and culture, and another is acculturation (Berry, 2003), or the process of adaptation to the norms of the majority culture while downplaying the process of retention of a person’s own heritage and cultural norms. In this study, migrants demonstrated that they retained cultural norms in health conceptualisations and
of conforming to normative cultural practices in help-seeking and information gathering with some level of adaption to local contexts.

All three groups demonstrated a hierarchy of help-seeking in which culturally congruent resources such as traditional healers and practices, health brokers and community members were used as a first preference, with the Western health system often used as a last option. Cultural practices were used when engaging with health practitioners to compensate for skills such as English proficiency and literacy skills. Compensatory practices included the presence of distributed HL within the community to assist in health system navigation, language interpretation, communication with health practitioners, and orientating consultations towards their skills in auditory and visual learning such as asking practitioners to demonstrate health instructions/treatments, for example, pouring doses of medication or drawing pictorials explanations of treatments. Many participants indicated that the use of translated health information often had limited use if they had low levels of literacy in their own language and limited conceptual understanding of Western medical practices.

The three migrant groups used culturally congruent information gathering and help-seeking channels that were generally disconnected from population-based health promotion, thus reducing their access to evidence-based health information (Green et al., 2006; Ka Po et al., 2008; Weber et al., 2014) and contributing to low HL. This finding suggests that current approaches to knowledge transfer in the Australian health system acts as a barrier for the three migrant groups. This finding is consistent with an international report showing that health resources only partially reach immigrants, often because of economic, cultural and social barriers (WHO, 2013). Participants indicated that mechanisms of information transfer such as text-based information with complex biomedical concepts were accessed less often, in favour of culturally congruent, oral, narrative and visual materials. In addition, negative health promotion message-framing was also a barrier (Rothman & Salovey, 1997) to the uptake of information and materials by three groups.

Members of the three groups reported that their most trusted sources of health information were from friends, family and community members, and from contacts outside Australia. Many regarded health advice from these sources to be more than, or as reliable as, that provided by doctors in the Australian health system. This practice is recognised in Putnam’s social theory (Putnam, 2000) which claims that higher levels of social bonding, as seen in many migrant communities, can contribute to the following: reduced health information seeking intention (Henderson & Kendall, 2011; Kim et al., 2015), active avoidance of surveillance services such as
screening (*BreastScreen Australia monitoring report 2011-2012*, 2014; Moorley et al., 2014; Weber et al., 2014), delay in health care seeking (Stewart et al., 2004), and non-participation in self-management activities (Cooper et al., 2012). These observations concur with the findings in this study, that is, low social contact outside of the cultural group results in low levels of health system engagement.

**Health system engagement**

Mainstream expectations relating to participation in health services are often at odds with cultural norms, approaches and beliefs. Many migrants do not agree with mainstream views about the nature of illness and appropriate approaches to treatment, and many study participants provided examples of their experiences in the health system whereby they had to accept or decline treatments or approaches that violated their deeply held cultural beliefs. Examples include women being examined/screened by a male clinician (forbidden under Islamic law), and having a child vaccinated, which is thought to cause autism. Also, treatments such as antibiotics did not fit with their cultural explanatory models of disease that does not encompass the germ theory. Some participants were strongly averse to receiving a diagnosis which was viewed as catastrophic and had a demotivating effect rather than driving engagement with the health system.

In addition, an important distinction exists between low HL and an informed decision not to participate in a treatment or program. For example, some participants expressed a desire not to participate in health engagement activities such as health screening that were based on cultural health beliefs about disease causation. These actions may be erroneously interpreted as an outcome of low HL abilities. Much work still needs to be done to bridge the communication gap so that clinicians, organisations and policy makers understand which factors are at play when participation is declined. Equally, expectations of patient/health practitioner engagement presented a challenge for all three groups who are more familiar with a didactic interaction led by the ‘doctor’ with the patient playing a passive role. The power differential between the patient and practitioner was most evident in the Somali group but was apparent in the Indian and Chinese groups.

The Indian and Somali groups in particular relied heavily on non-health-provider supports such as family, religious leaders and community, and had limited capacity to effectively engage with the mainstream health system. By contrast, the Chinese group reported an effective strategy to bridge the gap between community and mainstream health providers. Many Chinese participants spoke about a method of information seeking in which they invited health providers to attend
their community forums. This process facilitated the integration of mainstream health information into cultural networks. This finding suggests there is a role for cultural translators within the group to transfer this information to the wider cultural group. This process also occurs informally in the Somali and Indian communities but within the Chinese community this was a highly organised activity that is replicated in many Chinese cultural networks in Australia. Evidence of the effectiveness of a bicultural model is strong (Greenhalgh et al., 2015; Henderson & Kendall, 2011; Henderson et al., 2011) and therefore this approach has the potential to be replicated in other migrant communities to test its effectiveness in increasing HL.

This study, confirms findings of other studies reporting the common use of traditional medicines among Indian and Chinese migrants (Genuis et al., 2012; Jiang & Quave, 2013). However, few participants reported disclosing the use of traditional medicines to their doctors, indicating migrants do not feel they are able to share their cultural views about health and their health practices with mainstream health providers. Many participants felt that Western practitioners would not understand or approve of their use of traditional medicines. This concern contributes to non-disclosure, which increases risks such as side-effects and adverse interactions between traditional and conventional therapies (Genuis et al., 2012), and limits open dialogue that might enhance knowledge and understanding. This finding highlights the importance of practitioners routinely making non-judgemental and curious inquiries into the use of traditional medicines by immigrants and engaging openly in discussions about opportunities to safely integrate traditional and mainstream treatments.

In addition, given the key issues around trust in mainstream health services that were identified in this study, the health sector may need to invest further in the development of timely, and culturally and linguistically appropriate messaging to inform migrant communities of basic details relating to the safety and effectiveness of mainstream medical interventions. Australian-born residents begin their engagement with the Western health system in childhood, therefore, by adulthood they have developed and acquired much knowledge and experience of the health system. This process is reversed for migrants who are immersed in an unfamiliar health system. People migrating to Australia however, may have been exposed to very different health systems and messages, and this same level of trust in mainstream health services may not exist. Building trust takes time, requires patient explanation and open discussion, and relies upon accumulated

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9 A cultural translator is someone who understands and can articulate the dominant idioms of wellness and distress of their cultural group (Arnault, 2009).
positive experiences with the health system. Each interaction a new migrant has with mainstream health services provides an opportunity to build trust. Unfortunately, these opportunities are not always seized and, instead, migrants’ experiences of the health system can be disempowering and culturally incongruent and may deter further attempts to engage.

The Edwards et al. (2012) distributed model of HL provides an explanatory model of adaptive HL that may apply to migrant groups. The model conceptualises HL as a dynamic process that is impacted by contextual factors and is distributed through social interactions. The model asserts that when the HL demands on the individual are greater than their abilities then other skills can compensate. For example, in this study when the demands for literacy and/or English proficiency skills were greater than the individual’s ability to respond they drew on their social skills and assets. Family or community members provided support to understand health information, navigate the health system and to make decisions, showing that a large range of HL compensations are at play. This model illustrates that there are many paths an individual can take to get the health information and care they need and that migrant groups have different pathways compared to the local English-speaking population in some HL areas. This finding is consistent with previous findings that cultural models differ in that they emphasise the importance of the group over the individual and that the availability of social networks can greatly expand access to resources (Arnault, 2009). These findings suggest that strengthening the HL abilities of the broader community has direct impacts on individual’s level of HL function. It also highlights the challenge to the health system in developing interventions at the individual, family and community levels that provide equitable outcomes for the whole community.

These compensatory or adapted skills are examined in detail in the following sections under the two main domains of adapted help-seeking practices and health-system engagement.

To summarise, I observed that, in order to overcome access barriers to the Australian health system, migrants leverage the social resources that are available to them, such as language, discordant cultural health conceptions, inaccessible information and the lack of accommodation of traditional health practices. This gives rise to the development of adaptive health practices that are consistent with a pluralist health paradigm. The three migrant groups in this study showed adaptive HL in the areas of help and information-seeking and in utilising distributed HL to maximise individual level HL. Migrants’ HL strengths are in oral communication and interaction, and in blending traditional beliefs and practices with a Western model of health that aggregate into higher levels of HL abilities than previously recognised. Therefore, accommodation of pluralist health approaches within the Western health system is critical to
increasing HL, health system responsiveness and, in turn, engagement. I will return to the topic of distributed HL in more detail in subsequent sections of this chapter.

**The limits and possibilities of social support in a health literacy context**

The high levels of social support, defined as resources provided by a network of individuals and social groups (Lepore et al., 1991), within the three migrant groups were observed to have both positive and negative impacts on HL. Social support greatly increased access to a range of community level health assets such as distributed HL (Arnault, 2009; Edwards et al., 2015a) that augmented individual HL knowledge and skills, the provision of practical support in help and information-seeking, assistance in navigation of the health system, language and cultural translation during health consultations, provision of culturally congruent mental help-seeking support, and financial, social, spiritual and practical support during illness. Conversely, social support also limited the availability of health assets, a finding observed in previous studies (Chiswick et al., 2008; Weber et al., 2014). Social support perpetuated barriers to health information and services by; promoting the use of cultural health practices at the exclusion of biomedical services, limiting exposure to new information (Eriksson, 2011), perpetuating distrust of health services (Eriksson, 2011) particularly in health promotion, disease prevention, screening (Weber et al., 2014) and mental health services (Minas et al., 2013), thus contributing to delayed help-seeking (Southam et al., 2011). This finding recognises the social influences on health beliefs and decision making that have been identified by authors such as Rapley and Edwards (2008) and it will be expanded on in the following section.

Rapley coined the term ‘distributed decision making’ (Rapley, 2008) to describe common patterns of health decision making. According to Rapley health decision are often not made by an individual at one point in time but as collective decisions made over a number of encounters. Edwards et al. (Edwards et al., 2015a) expanded this concept to encompass ‘distributed HL’ in which community based HL mediators support the individual to draw on the collective HL skills of the wider social group. However, neither of these authors discussed in detail the limits of a collective approach to HL as observed in this study. Distributed decision making and HL are highly contingent on the knowledge and normative patterns within the social network (Eriksson, 2011). Therefore, by logical extension, migrant groups who are ‘closed groups’ (Putnam, 2000), who have less interaction with the groups outside of their networks are at increased risk of low HL as they have fewer health and information resources to draw upon.

The limits of a collective HL were observed in this study as individuals were directed towards traditional health and social behaviour from within their cultural group that may delay or exclude
uptake of health information or services from the Australian health system. This was most apparent for mental health services, which were almost universally considered irrelevant by all three of the groups. Screening was also considered unnecessary, potentially harmful and contributing to poorer health outcomes. This may explain the findings observed in some studies of an association between cultural enclave living and lower health service utilisation (Anikeeva et al., 2012a; Weber et al., 2014).

Another important area to address in relation to social support is the promulgation of misinformation and distrust of health services within migrant communities. This study revealed a range of misinformed beliefs that may have deleterious impacts on migrant health such as the belief that vaccination causes autism and/or that breast screening may cause cancer. These beliefs are supported and perpetuated within cultural enclaves driving health system disengagement and potentially exacerbating health disparities in migrant groups. Further, non-compliance with public health policy such as whole-of-population vaccination programs has the potential to harm the wider community. It is critical to recognise that closed communities such as the Somali community have profound challenges in help and information finding when compared to other migrant groups and the general population. The failure of the health system to understand the role of social structures in disseminating and perpetuating misinformation is a lost opportunity to influence these harmful emic or endemic beliefs and practices.

In this study, only the Chinese group were observed to have a successful mechanism to overcome the limits of community level HL. As previously noted, this group had a highly organised process of inviting health experts inside of their cultural networks to act as health mediators. This process enabled the cultural and language translation of the information provided by the experts, thus augmenting the collective HL knowledge and skills of the group. It is important to point out that this mechanism to increase the collective HL of the Chinese groups requires a high level of social organisation and an openness of the community to building bridging capital (Putnam, 2000). This mechanism may be transferable to ‘open’ migrant groups and may not be applicable to ‘closed’ migrant groups.

Current mainstream HL interventions are generally focused on building individual skills and focus on the needs of the mainstream population and are therefore unlikely to be effective within collective groups. It is imperative that further work is conducted into how to leverage social action within migrant groups to positively impact HL. The work of Eriksson (Eriksson, 2011) has shown how social capital can build or weaken the health of communities. Her work has revealed the potential value of mapping the social networks within a community using Putnam’s
framework of bonding, bridging and linking social capital (Putnam, 2000) to provide guidance on the development of interventions that promote community action processes. The development of interventions to address this area needs to find the appropriate balance between cultural autonomy and diversity, and the safety of both the individual and the wider-community. Further, in this chapter I will propose a new model that has the potential to increase engagement of migrant groups and which may disrupt mechanisms within cultural groups that support the dissemination of misinformation.

**Building health-system responsiveness and engagement for migrant groups**

The findings of this study show that migrants do not arrive as ‘tabula rasa’ but bring embedded cultural health perspectives that are inter-exchanged and negotiated within a contemporary biomedical context, thus creating pluralist HL approaches that are situated within a transnational frame of reference. Pluralism evolves as a consequence of the tension that arises when migrants attempt to transpose their experiences, skills, culture and ways of dealing with health onto a Western medical context. The resultant push-back from the Western system gives rise to the development of adapted ways of engaging in the host country health system. Migrants relinquish aspects of past health approaches and develop new methods in an attempt to get the best from both the traditional and Western systems, while attempting to fulfil obligations to their community, religion, family and culture. However, whilst methods of working within the Western system evolve, traditional conceptualisations of health may remain fully or partially intact.

**Pluralism in health practice**

The three migrant groups worked within a pluralist medical paradigm framed by traditional conceptions of health. Medical pluralism can be defined as the employment of more than one medical system or, specifically, the use of both Western and traditional medicine for health and illness (Wade et al., 2008). Participants moved between traditional and Western approaches viewing components of each system as more or less effective for particular areas of health. In addition, information gathering and help-seeking practices used pluralist approaches, often referencing cultural knowledge and resources as a first line option and utilising Western medicine as a second or last resort option. The lack of recognition within the health system of medical pluralism may lead to the misrepresentation of migrant HL strengths and limitations and serve to drive disengagement in migrant groups. The literature supports the proposition that changes to the system that better accommodate pluralism are likely to have the effect of
reengaging these groups (Carruth, 2014; Green et al., 2006; Jatrana et al., 2014; Komaric et al., 2012). To address the issue of medical pluralism, in the following section I explore an existing model to position and help understand the findings of this study.

**Modifying Nutbeam’s health literacy model**

Nutbeam’s HL model was one of the first to provide a classification of HL levels and continues to be frequently referenced in HL research and practice. The model, derived from an existing literacy model (Nutbeam, 2000), was conceptualised for mainstream populations without particular consideration of the needs of migrant groups. Due to the continuing influence of this model on health promotion practice and health system engagement approaches it is important to ensure the model reflects migrant HL strengths and practices.

This study shows that migrant HL strengths include the development of compensatory HL practices that obviate the need for skills such as literacy or English proficiency that Nutbeam considered fundamental (Nutbeam, 2000). In addition, Nutbeam’s model was conceived as a linear progression from level 1 (Functional HL) through to levels 2 (Interactive HL) and 3 (Critical HL) and suggests that persons with low literacy or low English proficiency have low or zero HL. However, adaption of the model from a linear, unidirectional concept to a dynamic model with multiple entry points would more accurately represent the HL of migrants. This modified model reflects migrant HL which begins simultaneously at both the interactive and functional levels that is enabled by the social support provided through the distributed HL of the community and also shows the process of acquiring HL skills.

Also, there is a need to extend the definition of the communication/interactive level of HL (level 2) to accommodate a broader range of communication skills that were observed in the three migrant groups. The definition is modified below, making it more inclusive and reflecting the experiences of migrant groups (additions in italics):

More advanced *range of communication skills that enable individuals to extract information and derive meaning from different forms of communication (oral/verbal, auditory, visual, social); to apply new information to changing circumstances; and to interact with greater confidence with information providers such as health care professionals.*

The inclusion of information gathering skills, i.e., from ‘literacy’ to oral/verbal, auditory, visual and social skills, encompasses the range of communication methods used by persons with low
English proficiency. In conclusion, these proposed additions to Nutbeam’s HL model would better reflect the HL practices of the three migrant groups in this study.

**Building an HL model for migrants**

Whilst we have observed migrant adaption to Western medical systems the reverse has not occurred. In this study, I have found little evidence of the Australian health system effectively adapting to the pluralist needs of migrants. This study provided evidence of a range of deficits within the Western model of health in meeting the needs of migrants. The deficits include the negation of culture, the lack of recognition and accommodation of pluralist approaches to health, and the implicit assumption of acculturation of migrants to a Western health perspective. Also, there is a lack of recognition of the HL characteristics of migrants such as verbal/oral skills, interactive skills, communal decision making, innovative communication strategies and the distributed nature of HL in collectivist groups. These data provide evidence of the need for health care providers to become negotiators of the different realities of migrants to increase their engagement to health services.

In addition, the current practice of the orientation of health information systems to the strengths of a Western population such as the use of text-based health information transfer, that underpins the Western conception of health and drives disengagement for migrant groups. These identified systemic level gaps make a compelling case for the development of new models that are more responsive to the needs of migrant groups. Additionally, there is a need to address community HL and to develop tools for assessing HL at the group or community level, as well as strategies to engage in the community conversations and relational dynamics that shape health beliefs (Batterham et al., 2017).

One model that may address many of these deficits is contained within the *Information and Support for Health Action Questionnaire* (ISHA-Q) (Dodson S, 2015). The ISHA-Q was developed to measure HL in low- and middle-income settings, and cultures where decision making about health often occurs as a collective activity of family or peer groups. It was developed by the Thailand Health Systems Research Institute in collaboration with Mahidol University under the guidance of Deakin University. It was developed using advanced methods similar to the HLQ. In a similar way to the HLQ, it is a multi-dimensional tool that helps identify and understand the HL strengths and limitations of individuals and populations and informs the development and selection of responses to improve equity in health outcomes and access. However, whilst this tool appears promising, it has not been published in the peer reviewed literature and it has been applied in limited settings in Thailand.
In the following section, a new theoretical model is proposed to increase health system responsiveness to the needs of migrant groups.

**Migrant health engagement model of convergence**

Migrants arrive in a new country with established approaches to health derived from a process of enculturation\(^{10}\) and shaped by exposure to health systems in their country of origin or countries of transition. However, within Western health systems there is an expectation of medical acculturation that is manifest and operationalised in a ‘one-system-fits-all’ biomedical health model. Despite policy approaches that attempt to address the health needs of migrant groups, Australia provides a universal health care system (AIHW, 2016) in which culturally tailored health services do not form part of standard care, resulting in uneven care across the population (Henderson et al., 2011).

Migrants enter a mono-cultural biomedical system based on an implicit assumption that the process of repeated exposure will result in the relinquishing of traditional health conceptualisations in exchange for the adoption of Western medical approaches (Kagawa-Singer, 2000). It is my contention that assumptions of medical acculturation in first generation migrants are not supported by the findings in this study or by the literature (Afable-Munsuz et al., 2009; Rodriguez, 2013; Sayegh & Knight, 2013). Rather, migrants remain bound to cultural or traditional explanatory health models (Kleinman et al., 1978) that have a significant influence on the way they engage with health systems leading to partial or selective health system engagement patterns (Cheng et al., 2015; Faustine Kyungu Nkulu et al., 2016; McDonald & Kennedy, 2004; Norredam et al., 2010; Rau, 2014; Shaw et al., 2009; Weber et al., 2014) and the consequent negative health impacts (Gray et al., 2007). In light of these engagement patterns it is crucial that the health transition of migrants is understood through the lived experiences of migrants as dynamic and bidirectional and not through notions of unidirectional acculturation.

**Medical acculturation**

Medical acculturation is defined as an adaptation to a biomedical approach of health and the relinquishing of traditional approaches and behaviours. Extant assumptions of medical acculturation are conceptualised within a linear model of acculturation (Landrine & Klonoff, 2004) with bidirectional movement from a traditional health model to a biomedical model (See Figure 7.8 further in this chapter). The limitations of this model include it’s failures to recognise

\(^{10}\)Enculturation is the process of being socialised into and retaining cultural norms of one’s heritage culture (Mojaverian et al., 2013).
the diversity within traditional health models or to explain or address the partial and selective nature of health system engagement observed in migrants and does not accommodate pluralist (Carruth, 2014) or bicultural (Landrine & Klonoff, 2004) approaches adopted by migrants. As observed in this study, migrants’ partial engagement exposes them to higher risk of chronic and preventable diseases and has been attributed to low levels of functional HL (Gazmararian et al., 1999; Rau et al., 2014; Shaw et al., 2012; Smith et al., 2012). Failure to address their partial engagement in the health system results in the continuation of gaps in services and products received that perpetuate further disengagement of migrants. Figure 9.6 provides a pictorial representation of the selective engagement patterns of migrants with the Australian health care system.

Medical acculturation model

A medical acculturation model (See Figure 9.8) is a unidirectional one (Titzmann & Fuligni, 2015) in which migrants relinquish the traditional belief model and adopt a biomedical model. A biomedical model sits within a business paradigm in which the health practitioner is in the role of service provider and the patient in the role of the health consumer. Within this paradigm the consumer forms a partnership with the health practitioner from which an implicit agreement is formed known as a health or care plan. Within this agreement there is a reciprocal obligation on the part of both the service provider and the health consumer to contribute towards positive health outcomes. This agreement is reviewed by both parties at each health visit with inputs modified to maximise the benefit to the health consumer. There is an expectation that the practitioner works within a science-based knowledge framework and that the health consumer has sufficient HL to carry out their role in the health partnership (Kickbusch, 2008).

Within the biomedical model the (passive) intervention for migrant transition is repeated exposure and is embedded in a belief that exposure increases familiarisation and understanding and hence transition of migrants towards the adoption of the biomedical model. However, an increasing body of evidence drawn from both theoretical and empirical research has shown that simple models of cultural adaptation may fail to describe the complex reality of migrants (Titzmann & Fuligni, 2015). The limitations of this model for health service improvement are that it does not reflect the lived experiences of migrants, is unlikely to accommodate or augment HL, does not explain partial health engagement patterns among migrants and cannot predict which health conditions or which migrant/s groups will engage and which groups will not.
Traditional health model

Conversely, a traditional model is situated with a cultural context underpinned by spiritual (Tiilikainen, 2011), religious, cultural and philosophical systems of belief (Kleinman, 1975). Within a traditional model the healer represents the omnipotent and interacts only briefly with the patient. In many cultures, the healer communicates with external forces such as gods, spirits and signs within the natural environment or relies on practical knowledge of healing remedies or of balancing forces within the body. The healer–patient interaction is often framed as an act of beneficence or cultural obligation in which the healer is the main actor who bestows healing on the passive beneficiary. This interaction is premised on the recognition of the authority of the healer by the patient.
Acculturation

Evidence on the health effects of acculturation shows contrasting impacts on ethnic minorities (Landrine & Klonoff, 2004). For example, length of stay in the host country is positively associated with increased prevalence of chronic disease in migrant groups (Jatrana et al., 2014; McDonald & Kennedy, 2004; Sharma, 2012; Vandenheede et al., 2015a). Conversely, other data shows there are health improvements after entry into the host country (AIHW, 2014b; Anikeeva et al., 2010; Gray et al., 2007; McDonald & Kennedy, 2004) with a poor understanding of which
groups of migrants will experience better or worse health outcomes. This variation in health outcomes between migrant groups is poorly understood (Landrine & Klonoff, 2004) and has been largely attributed to factors such as lifestyle changes (Gray et al., 2007; Jadalla et al., 2015; Mohan et al., 2006; Razum, 2002). However, selective health engagement patterns may also account for observed health disparities in some migrant groups. I propose that partial health engagement patterns are a consequence of strongly held traditional beliefs rather than a failure to understand a biomedical health model. For example, some traditional beliefs such as the causation of infection have a different explanatory model to that offered by Western medicine, that is, the germ theory.

In this study examples of how traditional health conceptualisations impacted health system engagement were observed in all three groups. All three groups viewed the Australian health system as a component of a wider traditional health framework. Both the Indian and Chinese groups viewed the key strengths of the Western system to be in the provision of acute services, however, they viewed the system’s limitations as being in prevention and cure of chronic diseases. Therefore, these participants were more likely to consult traditional practitioners for preventive services and for chronic conditions.

In summation, it is important to recognise the determinants of partial health engagement patterns among migrant groups to inform effective interventions that augment health system engagement. The failure to fully understand the lived experiences of migrants will result in the continuance of segment engagement with the consequent health impacts. The evidence is clear that reduced engagement, particularly in prevention, can contribute to the development and exacerbation of chronic disease and migrants’ presentation to acute services with preventable conditions at an advanced stage in the disease process.

**Acculturation theory**

A dominant theory of acculturation, the bi-dimensional model (Lefringhausen & Marshall, 2016) asserts that acculturation entails two opposing behavioural changes: 1) losing behaviours, beliefs, practices and values specific to the minority culture, and simultaneously, 2) gaining behaviours, beliefs, practices and values of the host culture. Landrine and Klonoff (Landrine & Klonoff, 2004) noted that the bi-dimensional model is limited in explaining health behaviours of migrants i.e. which migrant groups will maintain or lose the migrant health advantage. They provide an operant acculturation theory (Landrine & Klonoff, 2004) that combines bi-dimensional acculturation model with behaviour theory and conclude that cultural behaviours are reinforced and maintained by cultural meta-contingencies (Krispin, 2016).
Meta-contingencies, or cultural supports, function at a group level to reinforce and maintain cultural normative behaviours in an indigenous cultural context. This theory may explain the lower levels of health engagement seen in enclave-living migrant groups (Chiswick et al., 2008; Weber et al., 2014) and partial health engagement patterns. Therefore, given the extensive insights derived from this study, I propose that the development of meta-contingencies (which will be explained in more detail in the next section) within the biomedical model could better support the transition of migrants to health system engagement across the spectrum of services.

The empirical findings of this study, and reinforced by the literature (Gibson, 2001; Henderson et al., 2011; Kleinman, 1987; Owiti et al., 2015), show that first generation migrants’ health behaviours are inextricably linked to culturally bound health beliefs and practices and the transition from a traditional system of belief to a biomedical system is one of convergence rather than acculturation. The higher levels of engagement in components of the health system such as emergency care, general practitioners and hospital care but lower levels of engagement in prevention, screening and mental health care is manifested and well supported by the literature (Colucci et al., 2015; Colucci et al., 2014; Henderson & Kendall, 2011; Minas et al., 2013; Weber et al., 2014). This study’s results have shown that the three groups had consistent explanatory health models for selective engagement that were coherent with broader culturally informed health beliefs and maintained by cultural meta-contingencies.

Convergence is defined as; “The act of converging and especially moving toward union or uniformity” (Merriam-Webster, 2017), however, I propose defining convergence in the context of migrant health as ‘a process in which beliefs and practices are selectively merged according to points of compatibility, available resources and need’. This process results in the development of pluralist practices in which aspects of the new systems are selectively adopted and merged with traditional systems. In this model, a key difference between medical acculturation and convergence is that health practices in migrants continue to be informed by prior health beliefs and cultural health norms with points of convergence selected for compatibility, convenience, affordability and availability. This study has shown that components of the biomedical system that are not compatible and may not be adopted (prevention, screening, selective treatments such as those embedded in germ theory, mental health services). According to the literature, this engagement has selective health implications and may account for variations in health outcomes observed in migrant groups (Colucci et al., 2014; Cooper et al., 2012). To address this, the addition of meta-contingencies or cultural supports within the biomedical system could reduce selective engagement and promote full engagement.
Meta-contingencies

The term meta-contingency (Leite & de Souza, 2012) stems from behaviourist theory and asserts how cultural norms are maintained in population-level behaviour (Landrine & Klonoff, 2004). Meta-contingencies are positive and negative reinforcers and discriminative stimuli that are delivered to and experienced by an entire population. In the context of health, meta-contingencies are cultural health beliefs and health norms that are practised within a cultural group. I claim that whilst meta-contingencies may exist informally within some health systems, the formal and structured inclusion of meta-contingencies in the health setting will augment health engagement and extend the boundaries between traditional beliefs and a biomedical health model (See Figure 7). Examples of meta-contingencies in health practice include the articulation of cultural beliefs and traditions, verbal behaviour that reinforces cultural practices, contextualising treatments within the health belief system of migrants (Greenhalgh et al., 2015; Tiilikainen, 2011), bicultural workers (Greenhalgh et al., 2005; Henderson et al., 2011), accommodation of distributed HL practices (Edwards et al., 2015a; Lee et al., 2015a), recognition of cultural health norms such as collective agency (Greenhalgh et al., 2015) and extension of health promotion practice to include culturally relevant content.

Figure 9.7: Meta-contingencies positively influencing health engagement patterns of migrants

- The systemic recognition of culture as a HL determinant
- Pluralist approaches
- Community level HL strategies
- Cultural translators
- Recognition of culturally influenced normative HL practices
- Extension of health promotion practice

Migrant’s partial engagement patterns

Maximised engagement patterns of migrant’s

Improved health outcomes and greater health equality

(This figure is a modification of Figure 6 showing how meta-contingencies may increase health system engagement of migrants.)
Migrant Health Engagement Convergence Model

The health engagement convergence model derived from the data presented in this thesis (See Figure 8) is bidirectional and dynamic where individuals move between the traditional health care engagement approaches and the biomedical care system, which is described as a pluralist or bicultural model of health engagement. In consideration of these pluralist behaviours, interventions are proposed that if adopted may influence the speed and breadth of engagement of migrants with Western health systems.

The important elements of this model include the recognition of pluralist practices and a cogent explanatory framework of the partial health engagement patterns observed in the three migrant groups, as well as a framework for guiding the development of interventions to augment both health engagement and HL. It is imperative that health professionals understand the process of health convergence to orient practice towards increasing empowerment and resilience in migrant groups (Tiilikainen, 2011).

In addition, it follows that the inclusion of meta-contingencies that can influence the speed of transition to optimal health system engagement may decrease the health disparities observed in migrant groups. It is well established that chronic disease development in migrant groups begins as early as two years’ post-migration (Kim et al., 2013) therefore the need to influence the transition time of health convergence is important to influence health outcomes. In addition, whilst associations between HL and medical acculturation (Geltman et al., 2014; Todd & Hoffman-Goetz, 2011) have been observed, the mechanisms of impact have not been clearly identified and there are many barriers to engagement with the wider community, particularly for closed groups such as Somalis. Therefore, an understanding of the lived experiences and context of a migrant group is pivotal to HL augmentation.

An example of how the application of this model may increase the health engagement within the Somali group is provided here;

Actors within the health systems would recognise particular access and engagement barriers such as fear of spiritually harmful practices, modesty violations and concerns about the presence of pork in medicines. The system would provide alternatives, such as the option of booking consultations by women with female practitioners. In addition, the system would increase the HL of cultural leaders to dispel health misconceptions within the community, such as that vaccination causes autism, and explain the non-causal, temporal relationship between the appearance of autistic symptoms and the administration of the measles, mumps and rubella (MMR) vaccination. It would also be explained that
breast screening reduces the risk of death from breast cancer and is not causal, and that breast screening services are staffed by female radiographers. Screening services could facilitate group bookings of women who often function as a collective. Health practitioners would avoid using detailed biomedical explanations of disease, rather they would plain-language approach, providing visual explanations of health concepts such as drawings and using teach-back\textsuperscript{11} techniques to check patients’ understanding. In addition, effective health promotion materials would be developed using video technology available on smart phones in which Somali speakers provide explanations of many issues including which medicines contain pork products and what the alternatives are. Also, health messaging would use a gain-framed (e.g. “You will live longer if you give up smoking”) approach (Rothman & Salovey, 1997) and not negative messaging or ‘inevitability messaging’ (e.g. “Africans have a much higher risk of developing many chronic diseases”). Further, the health practitioner would contextualise treatments within a traditional model through explaining that treatments assist the body to restore usual health and are not harmful or long lasting within the body. In addition, recommendations of lifestyle changes could acknowledge the lack of agency of the individual and changes would be able to be implemented by the whole community. Such recommendations could relate to reversion to traditional diets and culturally appropriate ways of exercising such as screened swimming sessions for Muslim women and walking groups for Somali men. Finally, health practitioners would allow decision making to be distributed over a number of visits within which various community members could also attend and enquiries should be made as to what, if any, traditional remedies are being used in conjunction with biomedical medicines.

**Recommendations**

It is recommended that health systems begin to dispense with ineffective models of migrant health acculturation and adopt a model that reflects the pluralist reality in which migrant groups operate. Failure to change current ineffective approaches will perpetuate health disparities in migrant groups. Health care adaption must be a reciprocal process between the Western health system and migrants. This Health Engagement Convergence Model (See Figure 9.8) provides

\textsuperscript{11} Teach-back is a communication technique that assists health professionals to test the understanding of end users of health information provided. For further information, go to: http://www.teachbacktraining.org/
clear guidance on how the Western health system could adapt to the needs of migrants. This model could be used to guide policy and program development, training and support for a broad range of practitioners across the health and social care systems. Intervention development teams should conduct cultural mapping to detect the appropriate range of meta-contingencies for each cultural group. In tandem, pertinent acculturation activities could be identified and implemented that preserve the essential or foundational cultural norms but maximise prevention and treatment engagements that reduce the health inequalities.

Health practitioners need to obtain cultural competency in the accommodation of meta-contingencies into practice and develop effective communication competencies and skills that will more effectively engage migrant groups. For example, practitioners need to influence beliefs on the value of exchanging some traditional practices for evidence based Western practices and also to actively dispel misinformation about perceived harms of some Western treatments. Practitioners must orientate their practice towards the lived reality of migrants and ask probing questions about health conceptualisations and traditional medicine use and approaches that accommodate migrant perspectives. Importantly, practitioners must understand migrant health as a communal asset and harness collective approaches to health education and information transfer.

Figure 9.8: Schema of ‘Medical acculturation model’ and ‘Health engagement convergence model’

**Medical acculturation model**

<table>
<thead>
<tr>
<th>Traditional health model</th>
<th>Biomedical health model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Migrants on arrival</td>
<td>Post arrival</td>
</tr>
<tr>
<td>-Collective agency</td>
<td>-Individual agency</td>
</tr>
<tr>
<td>-Holistic</td>
<td>-Science based</td>
</tr>
<tr>
<td>-Non-partnership based – practitioner has higher status than consumer</td>
<td>-Health partnership – equal status between practitioner and consumer</td>
</tr>
</tbody>
</table>
Finally, recognition must be made that this proposed model does represent a change to the current health care model, and therefore, has resourcing implications. This model would require resources such as; additional health professional cultural competency training, additional time in interacting with consumers with migrant backgrounds and potentially, increased costs of health assessment and treatment. There would also be additional costs in the development and dissemination of effective and targeted health promotion resource, education, information and communication strategies.
However, these additional costs need to be weighed up against the costs of excess morbidity and mortality observed in some migrant groups. Health care initiatives, such as the model proposed, that increase awareness, early intervention and contribute to a delay or mitigate the onset of chronic disease, have the potential to reduce costs in the health system. Therefore, a health economic analyses, that accounts for health service utilisation, health-related quality of life, disability-adjusted life year (DALY), as well as length of life, may find that the application of this model is cost neutral or, cost saving, over the longer-term.

**Study strengths**

This study has used a range approaches to ensure the cultural safety of the three migrant groups. These approaches include recruitment strategies that harnessed cultural networks of known associations, consultations with cultural advisors, the option of an oral consent process and use of bilingual health translators. Another strength was the development of democratic partnerships between the researcher and the three migrant communities with stakeholders involved in the design and conduct of the study. Also, the exploratory nature of the grounded method was pivotal to increasing engagement with participants.

A further strength was the use of a mixed methods study design that was based on a broad conceptualisation of HL and situated within a cultural framework. Importantly, this study was conducted within local contexts, employing culturally appropriate methods, which are likely to resonate in similar migrant populations, using different health care systems, in other countries. A further strength was the use of data from three disparate migrant groups providing evidence of marked heterogeneity between the groups, countering ‘one-size-fits-all’ approaches to migrant health.

In addition, through using a local comparison sample of non-migrants (Ophelia group), I was able to provide context to the data. Further, the inclusion of the Somali community, a cultural group that is rarely systematically studied, provides rich insights into the health beliefs and practices of a cultural group that is increasing in Australia. The current study is the first to explore the nexus of health literacy and health engagement and the findings may well be relevant too other African and migrant groups.

**Study limitations**

A limitation of the study is the cross-sectional design which limits causal inferences. Therefore, whilst these results demonstrate that HL scores differ between the three groups, it is important to
acknowledge that we do not yet know what has caused these differences. While differences have been identified, and some groups have higher or lower HL scores, the thresholds for high or low HL have not been established. Consequently, even when HLQ scale scores were found to be low for a particular group we cannot assume that this represents a need. This is because some individuals may adequately compensate for a limitation in one HL domain through other strengths, including in other HL domains. The differences may also be explained by an unmeasured confounder. While several covariates were included in the multivariate analyses to adjust for potential confounders, other group differences are likely to be present and explain part of the differences. While the data were broadly normally distributed, future work should include larger samples, the use of more sophisticated statistical models (including non-parametric approaches), and population-based sampling to rule out, as much as possible, potential confounding of the results. Nonetheless, the differences observed and, importantly, the patterns were very clear and certainly advances the understanding of the HL of these groups. While other confounders might be at play, the triangulation through the qualitative analyses provides evidence that supports the quantitative results.

Also, whilst this study advances the field of migrant HL, it is not fully representative of the views of all Somali, Chinese and Indian groups from these vast countries. However, it does provide insights into the HL strengths and difficulties of migrant groups which have had little research focus to date.

For the Somali group, snowball recruitment was used, which potentially introduced a bias (Rog & Bickman, 2009) favouring the particular social networks of the index cases. To minimise this risk, three influential index cases were engaged from three separate groups within the Somali community. Also, the sampling from within these groups may have been influenced by self-selection bias that may have excluded people with low English proficiency, low literacy and low HL. However, to reduce this risk, referral was assisted by community leaders who verbally conveyed the study details to potential participants minimising the need for high-level English proficiency or English reading skills.

In addition, whilst participants’ length of stay in Australia varied across the three groups, the experiences of newly arrived migrants (within five years of arrival) may have been underrepresented (with higher representation in the Indian group) and it may be that more recent arrivals experience greater difficulty than those who have lived in Australia for some time. Also, the demographic characteristics within the groups may have introduced some bias. For example, it is not known if the higher education levels in the Chinese group are representative of this
population group in Australia and if this produced less or more emphasis on certain findings. However, there are no population-based reference data on each of the three groups to determine whether the demographic distribution is skewed. Nonetheless, this study provides the first in-depth analysis of the HL among these groups.

Finally, whilst the quantitative study had a small sample size, the HLQ is a precise measure of HL where relatively small samples are required to detect moderate differences. Large differences were observed and these remained following multivariate analyses. In addition, whilst rich qualitative data were obtained from participants until data saturation was reached, it is possible that further themes could have emerged with a larger more representative sample.

Despite these limitations, this study makes an important contribution to the migrant health literature, particularly given the limited research into HL in migrant groups and between migrants and non-migrants.

**Future research**

Future research could extend the findings of this study in many ways. Firstly, research could include a larger sample inclusive of a range of migrant groups that could seek to replicate the findings and determine the presence of HL strengths and limitations and thus confirm or refute the findings of this study. These studies could also confirm the utility of HLQ constructs for use in diverse migrant groups. Also, focusing on the HL of newly arrived migrants is needed, to better understand their needs compared to migrants residing in Australia for longer periods.

Of importance is research into predictors of migrant health outcomes and whether HL mediates these. To achieve this, HL researchers may need to utilise a broad definition of HL to include the culturally variable explanatory models of disease that inform patients health-related abilities. In addition, future inquiry is needed into the HL strengths and limitations between men and women to better understand the finding of this study that migrant women had relatively greater HL strengths than males.

In addition, further research could map how distributed HL acts to augment and compensate HL skills at the individual level. The Edwards model of distributed HL (Edwards et al., 2015b) and the role of HL mediators in guiding HL intervention development could be further explored. Also, there is a need to better understand how the exchange of social resources can predict culturally related help-seeking strategies, and once this is understood it may help service providers identify risk groups and develop culturally relevant services. Lastly, understanding HL as a communal asset raises the challenge for the health system in the development of
interventions at the individual, family and community levels to bring health benefits to the whole community and reduce health inequality.

Of importance also, was the finding of the dual effects of social support in influencing health system engagement. Social support both enhanced and limited health system engagement and warrants further investigation. Research focussing on migrants from ‘closed’ and ‘open’ groups (Eriksson et al., 2009) is needed to better understand the diverse needs of these groups. Such research could focus on how individual level pre-migration factors such as literacy, education, HL and first-language proficiency may impact the ability to benefit from community level HL support in the new country.

Another important finding was the limitations in reach and impact of mainstream health promotion strategies and health information transfer to migrant groups. Overall, the three migrant groups were unable to find, understand or use the health information they required in a way that was accessible to them. The resultant information vacuum compels migrants to rely on the information transfer practices within their cultural groups that may not be of the highest standard. This study showed that migrants’ health information needs, particularly those from oral traditions, are addressed by mechanisms that often lie outside of the Australian health system and that may not be evidence based or accurate. Therefore, research into the health information needs, effective modalities and dissemination strategies that will optimise HL in migrants is required.

At a policy level, the underrepresentation of migrants in research should be addressed. Current data-collection practices that collapse country of origin data into the four large geographical regions of United Kingdom & Ireland, Other Europe (Western and Eastern Europe, the former USSR and the Baltic States), Asia (Northeast, Southeast and Southern Asia, the Middle East and Northern Africa) and Other (Southern Africa, the Americas, New Zealand and the Pacific region) (AIHW, 2014a) mask particular health outcomes for specific migrant groups and contribute to knowledge gaps. These knowledge gaps contribute to the current ‘one-size-fits-all’ HL policy and intervention approaches that, given the diverse HL strengths and needs observed between the three migrant groups, are unlikely to be effective. It is therefore imperative that national health policy recognises the need for disaggregated data collection and reporting methods that are sensitive to the needs of migrant populations that make up over one quarter (28%) of the Australian population.

More broadly, HL research has focused largely on reading and numeracy skills, with far less attention given to other literacies such as science literacy, oral literacy and cultural literacy. The
importance of science literacy in migrant groups has been under-recognised and may be highly relevant for migrant groups. Although science literacy was not examined in this study, many of the participants indicated that understanding a science based conception of health was at times challenging. Many participants had not been exposed to a science based understanding of health in their countries of origin, thus creating a barrier to engaging with health services and information (Kelaher et al., 1999). Science literacy was described by Zarcadoolas, Pleasant and Greer (2005) as inclusive of “…knowledge of fundamental scientific concepts, ability to comprehend technical complexity, an understanding of technology and an understanding of scientific uncertainty and that rapid change in the accepted science is possible” (Zarcadoolas et al., 2005, p. 197). Further research is needed to examine the contribution of science literacy to health participation by migrant groups and effective methods of augmenting science literacy in this group.

Cultural competence is also an important consideration for health systems in order to increase the level of responsiveness to the needs of migrant populations. The concept of ‘culture’ was not well considered in HL research until the development of models during the mid-2000s (Paasche-Orlow & Wolf, 2007; Sørensen et al., 2012). At this time, models began to recognise the role of collective beliefs, customs, worldview and social identity in HL. There are gaps in the literature regarding how to improve the cultural responsiveness of health systems.

In addition, as previously stated, some migrant groups show equal to, or better, longer-term health outcomes than the Australian born population. Therefore, it must be acknowledged that this health advantage may relate to both pre-migration factors and to the current health care system in meeting the health care needs of some migrant groups. As evidenced in the qualitative data of this study, accessibility factors such as; a universal (no-cost) health care system, access to a telephone interpreter service during consultations and the existence of a primary care sector, all acted as enablers to health care engagement. However, understanding which migrant groups optimise their health within the current health care system and which groups are less able to do so should be a focus for future research.

Finally, further research could be conducted into the utility of the Migrant Engagement Convergence Model as an approach to service redesign. The model could be implemented across primary health services and evaluated to explore improvements in migrant health and equity of service provision.
Contribution to new knowledge

In summary, this thesis provides new insights into the health gap between non-migrant and migrant populations. It has, for the first time, uncovered HL strengths and limitations of three migrant groups and, to the knowledge of the author, is the first study to explore first-generation migrant HL in Australia.

Through the use of a mixed methods study design, and the use of a broad conceptualisation of health literacy situated within a cultural framework, robust data were generated. This thesis is the first to use the HLQ in the migrant setting and study some elements of its validity to provide not only new knowledge on migrants, but also new knowledge about the veracity of the findings of the HL strengths and limitations of migrant groups. In addition, this study was conducted within local contexts, employing culturally competent research methods, which are likely to resonate in similar migrant populations using different health care systems in other countries.

This study provides new evidence relating to the dimensions of HL. For example, factors such as agency, decision making, navigation, information finding, help-seeking, practitioner interaction, health engagement and communication were expressed using culturally normative mechanisms that were divergent from practices as defined in common HL measures. The findings indicate that culture is a system-level phenomenon enacted at group and individual levels which must become a core consideration for health systems in the context of HL. Importantly, these findings serve to challenge previous studies that report low levels of HL in migrant groups. In addition, the heterogeneity of the HL strengths and limitations within the three migrant groups provides evidence that the commonly employed ‘one-size-fits-all’ approaches to migrant health care are unlikely to be effective.

Further, this study has provided evidence of HL, as conceptualised within this thesis, as a causal link between health information/services and health, which provides stimulus for the development of more effective information transfer mechanisms. This study has expanded our understanding of the exchange and distribution of HL resources within cultural groups that will assist in understanding and predicting culturally-related help-seeking strategies. This detailed knowledge will help service providers identify groups at greatest risk of the MHD, develop culturally relevant services and provides direction to health systems to better harness distributed HL to increase health system engagement. In addition, the culmination of the extensive quantitative and qualitative work, and the synthesis of these data alongside a review of the international literature, enabled the development of a new model. The Migrant Health Engagement Model of Convergence. If this model were implemented, it may generate earlier...
engagement of migrants in the health system and expand upstream engagement inclusive of prevention and early intervention.

The contribution of this research comes at a seminal time given the unprecedented increase of immigration all over the globe. It improves our understanding the HL related mechanisms through which migrants gradually lose their health advantage and will help prevent or delay a health decline, thus enabling greater health system responsiveness to the needs of migrant groups. Finally, this study provides robust evidence of the need to improve HL in migrants to deliver equitable health outcomes for this population group.

**Conclusion**

The key contributions of this study, which include an understanding of the HL strengths and limitations of three migrant groups, recognition of the intersection between pluralist approaches and partial engagement patterns in migrant groups, could, if extended, make substantial improvements to health policy and practice and increase migrants’ engagement in the health system.

Despite efforts to improve engagement with health care systems, many migrant Australians continue to experience health inequalities, avoidable morbidity and excess mortality. The lack of progress in systematically reducing health inequalities in migrant populations may be a consequence of the lack of understanding of the diverse HL needs and contexts of marginalised migrant groups. Therefore, this study provides new evidence to advance the field of migrant HL.

In this thesis, I have proposed a new health engagement model that recognises the pluralist paradigm in which migrant’s function. I propose that this model be adopted to reduce selective engagement, commonly observed in migrant groups, to increase engagement across the full spectrum of services including prevention and screening. This model has the potential to reduce avoidable morbidity and mortality observed in migrants by reducing the time in which migrants become fully engaged with the health system following migration. Importantly this model uses a strengths based approach to leverage the skills and social assets within migrant groups to augment HL and engagement.

Finally, this study provides evidence of the need to develop structural, community and individual-level HL responses, which promote equitable health outcomes across migrant communities. The findings have implications at the policy level and at the public health and practice level, which, if adopted, would increase the HL and health engagement of migrant groups and minimise their subsequent health decline.
Appendix 1: Participant Consent Form

Participant consent form

Full Project Title: Enhancing HL to optimise health equity across Victorian CaLD communities.

I have read and understood the attached Participant Information and freely agree to participate in this project according to the conditions outlined in the Participant Information.

I have the Participant Information Form to keep.

The researchers have agreed not to reveal my identity in any report, publication, or presentation.

I understand that my decision to participate or not to participate or to withdraw WILL NOT affect my relationship with the Multicultural Women’s Health Service or Deakin University in any way.

I consent to being interviewed by a researcher about my HLQ answers. Yes No

Withdrawal of Consent Form

Date:

Full Project Title: Enhancing HL to optimise health equity across Victorian CaLD communities.

I hereby wish to WITHDRAW my consent to participate in the interview phase of the above research project. I understand that such withdrawal WILL NOT affect my relationship with the Multicultural Centre for Women’s Health or Deakin University in any way.

Participant’s Name (printed) … … … … … … … … … … … … … … … … … … … … … … … 

Signature … … … … … … … … … … … … … … … … … … … … … … … … … … … … … 

Date … … … … … … … … … … … … … … … … … … … … … … … … … … … … … 

Please post this form to:

Rhonda Garad
Deakin Population Health Strategic Research Centre
Deakin University
221 Burwood Highway
Burwood VIC 312
## Appendix 2: Member Profiles of the Three Study Advisory Groups

<table>
<thead>
<tr>
<th>Groups</th>
<th>Somali</th>
<th>Chinese</th>
<th>Indian</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. in each group</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Gender</td>
<td>M 1 F 2</td>
<td>M 1 F 2</td>
<td>M 1 F 2</td>
</tr>
<tr>
<td>Country of origin</td>
<td>Somalia</td>
<td>China</td>
<td>India</td>
</tr>
<tr>
<td>Advisory Group member profiles</td>
<td>Somali woman (bilingual educator) who works extensively with the Somali community and leads an African Women’s Advocacy Group.</td>
<td>Chinese woman (bilingual educator) who was a doctor before migrating and is very active in the Chinese community in Australia.</td>
<td>Indian male (machinist) is a highly respected leader in the Indian migrant community in the South-East of Melbourne.</td>
</tr>
<tr>
<td></td>
<td>Somali women (bilingual educator) has extensive experience in research recruitment and is an accredited translator. She has strong connections with the Somali Hararian community.</td>
<td>Chinese female elder who is a highly respected member of the Chinese community and who has extensive connections to the older members of the Chinese community.</td>
<td>Indian woman who works in administration and is has extensive connections to the younger Chinese migrant’s groups in the Box Hill and surrounding areas.</td>
</tr>
<tr>
<td></td>
<td>Somali male (owner/driver) works extensively with the community as an advisor and leader.</td>
<td>Chinese male (engineer) very committed to community work within the Chinese community.</td>
<td>Indian women with extensive connections to the older members of the Indian community and who has a strong interest in traditional Indian health remedies.</td>
</tr>
</tbody>
</table>
Appendix 3: Advisory Group Terms of Reference

Project: Enhancing HL to optimise health equity across Victorian migrant communities

Terms of reference for the Advisory Group

An Advisory Group will be established with members drawn from the three culturally and linguistically diverse (Migrant) groups targeted in the research project (Chinese, Indian and Somali).

Roles and functions

- To provide cultural advice and guidance to all aspects of the research project;
- To answer questions participants may have relating to their involvement in the project;
- To review project materials and processes to ensure they are culturally appropriate.

Membership

Members are from each of the three cultural groups, making a total of nine members of the Advisory Groups. The individuals are well respected within the cultural groups. Potential members of the group will be approached by the PhD researcher and provided with an overview of the project and the role of the Advisory Group. Employees or volunteers of the Multicultural Centre for Women’s Health will not be asked to participate in the advisory committee. Members of the committee will not act as participants in the project.

Meetings and activities

The Advisory Group will meet on a quarterly basis or as required by the project researchers and will be consulted on the cultural appropriateness of project materials and processes. Changes to materials suggested by the Advisory Group, which have been approved the Deakin University Human Ethics Committee (DUHREC), will be submitted via a request for a modification process before being sent out. Members will be asked to participate in the Advisory Group for the duration of the three-year project.

Accountability

The role and functions of the Advisory Group are advisory in nature. In the event that members of the advisory committee are contacted by participant(s) with concerns, the members will be advised to contact the principle researcher; Professor Richard Osborne. It is not the role of the Advisory Group to resolve complaints but to refer onto Professor Osborne. The advisory members also have the option of contacting the Manager of the Office of Research Integrity. Professor Osborne will report back to Deakin any complaints received and information on how the complaint will be managed and resolved.
### Appendix 4: HLQ Psychometric properties of items * and scales

<table>
<thead>
<tr>
<th>Difficulty (95% CI)</th>
<th>Ordered</th>
<th>Factor Loading (95% CI)</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling understood and supported by healthcare providers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>I have at least one healthcare provider who…</td>
<td>0.19 (0.15-0.24)</td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td>I have at least one healthcare provider I can…</td>
<td>0.10 (0.07-0.13)</td>
<td>Yes</td>
</tr>
<tr>
<td>3</td>
<td>I have the healthcare providers I need…</td>
<td>0.18 (0.15-0.22)</td>
<td>Yes</td>
</tr>
<tr>
<td>4</td>
<td>I can rely on at least one…</td>
<td>0.10 (0.08-0.13)</td>
<td>Yes</td>
</tr>
<tr>
<td>Model Fit – $\chi^2_{\text{WLSMV}}(2) = 10.15$, p= 0.0063, CFI = 0.998, TLI = 0.995, RMSEA = 0.100, and WRMR = 0.367.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Composite reliability = 0.88 (0.86-0.90)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Difficulty (95% CI)</th>
<th>Ordered</th>
<th>Factor Loading (95% CI)</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Having sufficient information to manage my health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>I feel I have good information about health…</td>
<td>0.11 (0.08-0.14)</td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td>I have enough information to help me deal…</td>
<td>0.21 (0.18-0.26)</td>
<td>Yes</td>
</tr>
<tr>
<td>3</td>
<td>I am sure I have all the information I…</td>
<td>0.27 (0.22-0.31)</td>
<td>Yes</td>
</tr>
<tr>
<td>4</td>
<td>I have all the information I need to</td>
<td>0.25 (0.21-0.30)</td>
<td>Yes</td>
</tr>
<tr>
<td>Model Fit – $\chi^2_{\text{WLSMV}}(2) = 5.24$, p= 0.0730, CFI = 1.000, TLI = 0.999, RMSEA = 0.063, and WRMR = 0.337.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Composite reliability = 0.88 (0.87-0.90)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Difficulty (95% CI)</th>
<th>Ordered</th>
<th>Factor Loading (95% CI)</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Actively managing my health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>I spend quite a lot of time actively managing…</td>
<td>0.30 (0.25-0.34)</td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td>I make plans for what I need to do to be…</td>
<td>0.15 (0.12-0.18)</td>
<td>Yes</td>
</tr>
<tr>
<td>3</td>
<td>Despite other things in my life, I make time…</td>
<td>0.21 (0.17-0.25)</td>
<td>Yes</td>
</tr>
<tr>
<td>4</td>
<td>I set my own goals about health and fitness</td>
<td>0.13 (0.10-0.17)</td>
<td>Yes</td>
</tr>
<tr>
<td>5</td>
<td>There are things that I do regularly…</td>
<td>0.20 (0.16-0.24)</td>
<td>Yes</td>
</tr>
<tr>
<td>Difficulty</td>
<td>Ordered</td>
<td>Factor Loading</td>
<td>R²</td>
</tr>
<tr>
<td>------------</td>
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</tr>
<tr>
<td>(95% CI)</td>
<td></td>
<td>(95% CI)</td>
<td></td>
</tr>
</tbody>
</table>

Model Fit – $\chi^2_{WLSMV}(5) = 31.96$, p<0.0001, CFI = 0.992, TLI = 0.983, RMSEA = 0.115, and WRMR = 0.775.

Composite reliability = 0.86 (0.84-0.88)

4. Social Support for health

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I can get access to several people who…</td>
<td>0.16 (0.13-0.20)</td>
</tr>
<tr>
<td>2</td>
<td>When I feel ill, the people around me really…</td>
<td>0.30 (0.26-0.35)</td>
</tr>
<tr>
<td>3</td>
<td>If I need help, I have plenty of people I…</td>
<td>0.18 (0.14-0.22)</td>
</tr>
<tr>
<td>4</td>
<td>I have at least one person…</td>
<td>0.19 (0.15-0.23)</td>
</tr>
<tr>
<td>5</td>
<td>I have strong support from…</td>
<td>0.10 (0.08-0.14)</td>
</tr>
</tbody>
</table>

Model Fit – $\chi^2_{WLSMV}(5) = 37.36$, p<0.0001, CFI = 0.987, TLI = 0.975, RMSEA = 0.126, and WRMR = 0.925.

Composite reliability = 0.84 (0.81-0.86)

5. Appraisal of health information

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I compare health information from different</td>
<td>0.18 (0.15-0.22)</td>
</tr>
<tr>
<td>2</td>
<td>When I see new information about health, I…</td>
<td>0.38 (0.34-0.43)</td>
</tr>
<tr>
<td>3</td>
<td>I always compare health information from…</td>
<td>0.34 (0.30-0.39)</td>
</tr>
<tr>
<td>4</td>
<td>I know how to find out if the health…</td>
<td>0.30 (0.25-0.34)</td>
</tr>
<tr>
<td>5</td>
<td>I ask healthcare providers about the quality…</td>
<td>0.38 (0.33-0.43)</td>
</tr>
</tbody>
</table>

Model Fit – $\chi^2_{WLSMV}(5) = 18.05$, p= 0.0029, CFI = 0.990, TLI = 0.980, RMSEA = 0.080, and WRMR = 0.610

Composite reliability = 0.77 (0.74-0.81)

6. Ability to actively engage with healthcare providers

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Make sure that healthcare providers understand…</td>
<td>0.23 (0.19-0.27)</td>
</tr>
<tr>
<td>2</td>
<td>Feel able to discuss your health concerns with a…</td>
<td>0.15 (0.11-0.18)</td>
</tr>
</tbody>
</table>
### Difficulty

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Factor Loading</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Have good discussions about your health…</td>
<td>0.18 (0.14-0.22)</td>
<td>0.72</td>
</tr>
<tr>
<td>4</td>
<td>Discuss things with healthcare providers…</td>
<td>0.23 (0.19-0.28)</td>
<td>0.76</td>
</tr>
<tr>
<td>5</td>
<td>Ask healthcare providers questions to get…</td>
<td>0.24 (0.20-0.28)</td>
<td>0.77</td>
</tr>
</tbody>
</table>

Model Fit – $\chi^2_{WLSMV}(5) = 74.91$, p<0.0001, CFI = 0.986, TLI = 0.973, RMSEA = 0.185, and WRMR = 0.944.

Composite reliability = 0.90 (0.88-0.92)

### Navigating the healthcare system

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Factor Loading</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Find the right healthcare</td>
<td>0.19 (0.16-0.23)</td>
<td>0.57</td>
</tr>
<tr>
<td>2</td>
<td>Get to see the healthcare providers I need to</td>
<td>0.07 (0.05-0.10)</td>
<td>0.37</td>
</tr>
<tr>
<td>3</td>
<td>Decide which healthcare provider you need…</td>
<td>0.20 (0.17-0.24)</td>
<td>0.84</td>
</tr>
<tr>
<td>4</td>
<td>Make sure you find the right place to get…</td>
<td>0.19 (0.16-0.23)</td>
<td>0.88</td>
</tr>
<tr>
<td>5</td>
<td>Find out what healthcare services you are…</td>
<td>0.42 (0.37-0.47)</td>
<td>0.60</td>
</tr>
<tr>
<td>6</td>
<td>Work out what is the best care for you</td>
<td>0.28 (0.24-0.33)</td>
<td>0.63</td>
</tr>
</tbody>
</table>

Model Fit – $\chi^2_{WLSMV}(9) = 21.74$, p= 0.0097, CFI = 0.998, TLI = 0.996, RMSEA = 0.058, and WRMR = 0.451.

Composite reliability = 0.88 (0.87-0.90)

### Ability to find good health information

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Factor Loading</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Find information about health problems</td>
<td>0.21 (0.17-0.25)</td>
<td>0.72</td>
</tr>
<tr>
<td>2</td>
<td>Find health information from several…</td>
<td>0.27 (0.23-0.32)</td>
<td>0.74</td>
</tr>
<tr>
<td>3</td>
<td>Get information about health so you are…</td>
<td>0.23 (0.19-0.27)</td>
<td>0.75</td>
</tr>
<tr>
<td>4</td>
<td>Get health information in words you…</td>
<td>0.20 (0.17-0.24)</td>
<td>0.66</td>
</tr>
<tr>
<td>5</td>
<td>Get health information by yourself</td>
<td>0.26 (0.22-0.30)</td>
<td>0.70</td>
</tr>
</tbody>
</table>

Model Fit – $\chi^2_{WLSMV}(5) = 57.06$, p<0.0001, CFI = 0.989, TLI = 0.977, RMSEA = 0.160, and WRMR = 0.820.
<table>
<thead>
<tr>
<th></th>
<th>Difficulty (95% CI)</th>
<th>Ordered</th>
<th>Factor Loading (95% CI)</th>
<th>$R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Composite reliability</strong></td>
<td>0.89 (0.87-0.91)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>9. Understanding health information well enough to know what to do</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Confidently fill medical forms in the correct…</td>
<td>0.13 (0.10-0.17)</td>
<td>No</td>
<td>0.80 (0.75-0.84)</td>
</tr>
<tr>
<td>2</td>
<td>Accurately follow the instructions from…</td>
<td>0.08 (0.06-0.21)</td>
<td>No</td>
<td>0.82 (0.77-0.87)</td>
</tr>
<tr>
<td>3</td>
<td>Read and understand written health…</td>
<td>0.15 (0.12-0.19)</td>
<td>Yes</td>
<td>0.84 (0.81-0.88)</td>
</tr>
<tr>
<td>4</td>
<td>Read and understand all the information on…</td>
<td>0.16 (0.13-0.20)</td>
<td>Yes</td>
<td>0.83 (0.79-0.87)</td>
</tr>
<tr>
<td>5</td>
<td>Understand what healthcare providers are…</td>
<td>0.14 (0.11-0.17)</td>
<td>Yes</td>
<td>0.88 (0.85-0.92)</td>
</tr>
<tr>
<td><strong>Model Fit</strong></td>
<td>$\chi^2_{WLSMV}(5) = 35.70, \ p&lt;0.0001$, CFI = 0.992, TLI = 0.983, RMSEA = 0.123, and WRMR = 0.671</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Composite reliability</strong></td>
<td>0.88 (0.86-0.90)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Appendix 5: Cognitive Interview Schedule**

**HLQ interview schedule template**

**Purpose of the project**

The purpose of this project is to gain an understanding of how you understand the question in this questionnaire.

**Procedure**

- Participants will have provided consent to be interviewed.
- Participants will have completed the HLQ.
- Interviews to be recorded with the permission of the participant.

Interviewer has prepared the interview document prior to the interview

Allocate constructs (five per respondent—three from Part 1 and two from Part 2)

Item randomisation: 1-x or x-1 (match these with clinician interview schedule)

Insert participant’s HLQ answers to the items

Read each item, as well as the participant’s HLQ answer to that item, to the participant.

Ask how they came to that answer. Use the prompt questions if needed

**Example Introduction**

Thank you for taking the time to talk with me today. I’m going to ask you about the answers you gave on the questionnaire you recently completed.

The information you provide will help the researchers improve the usefulness of this questionnaire for people born overseas. There are no right or wrong answers, so please answer every question based on your own experience. If you need to stop the conversation at any time, just let me know.

Now I’m going to read out some questions from the questionnaire and the answers you gave, and then I’ll ask you about why you selected those answers.
### PART 1

<table>
<thead>
<tr>
<th>Item no.</th>
<th>HLQ items Read each item to participant with their answer</th>
<th>Strongly Disagree (SD), Disagree (D), Agree (A), Strongly Agree (SA) Participant’s answer</th>
<th>Can you tell me why you answered in that way? [Prompt] Why did you select that answer?</th>
</tr>
</thead>
</table>

### Scale #:

For the following questions, you were asked to indicate how strongly you disagreed or agreed with the statements by crossing the response that best described you at the time you completed the questionnaire. Response scale = Strongly Disagree, Disagree, Agree, Strongly Agree.

<table>
<thead>
<tr>
<th>Item no.</th>
<th>HLQ items Read each item to participant with their answer</th>
<th>Strongly Disagree (SD), Disagree (D), Agree (A), Strongly Agree (SA) Participant’s answer</th>
<th>Can you tell me why you answered in that way? [Prompt] Why did you select that answer?</th>
</tr>
</thead>
</table>

### Scale #:

Keeping mind that you were asked to indicate how strongly you disagreed or agreed with the statements by crossing the response that best described you at the time you completed the questionnaire, let’s talk about the following questions and the answers you gave.

[Remind them of the response scale] Response scale = Strongly Disagree (SD), Disagree (D), Agree (A), Strongly Agree (SA)

<table>
<thead>
<tr>
<th>Item no.</th>
<th>HLQ items Read each item to participant with their answer</th>
<th>Strongly Disagree (SD), Disagree (D), Agree (A), Strongly Agree (SA) Participant’s answer</th>
<th>Can you tell me why you answered in that way? [Prompt] Why did you select that answer?</th>
</tr>
</thead>
</table>
### Change of response options for Qs 7, 8, 9, 10: now Cannot Do–Very Easy

**PART 2**

| Scale #:
<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>For the following questions, you were asked to indicate how easy or difficult the following tasks were for you to do at the time you completed the questionnaire.</td>
</tr>
<tr>
<td>[Remind them of the response scale] Response scale 1. Cannot do or always difficult 2. Usually difficulty, 3/4/5 were the same] Very Difficult (VD), Quite Difficult (QD), Quite Easy (QE), Very Easy (VE)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item no. (HLQ no. in bold)</th>
<th>HLQ items</th>
<th>Cannot Do (CD), Very Difficult (VD), Quite Difficult (QD), Quite Easy (QE), Very Easy (VE)</th>
<th>Can you tell me why you answered in that way? [Prompt] Why did you select that answer?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Read each item to participant with their answer</td>
<td>Participant’s answer</td>
<td></td>
</tr>
</tbody>
</table>
Scale #.

Keeping in mind that you were asked to indicate how easy or difficult the following tasks were for you to do at the time you completed the questionnaire, let’s talk about the following questions and the answers you gave.

[Remind them of the response scale] Response scale = Cannot Do (CD), Very Difficult (VD), Quite Difficult (QD), Quite Easy (QE), Very Easy (VE)

<table>
<thead>
<tr>
<th>Item no.</th>
<th>HLQ items</th>
<th>Participant’s answer</th>
<th>Cannot Do (CD), Very Difficult (VD), Quite Difficult (QD), Quite Easy (QE), Very Easy (VE)</th>
<th>Can you tell me why you answered in that way? [Prompt] Why did you select that answer?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Read each item to participant with their answer</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Close the interview

Check that the respondent has said all they need to say. Thank them for their time and the information they have provided to the project.
### Appendix 6: Cognitive Testing Responses to Individual HLQ Questions by Domain (Somali Group)

<table>
<thead>
<tr>
<th>Domain no.</th>
<th>Item no.</th>
<th>HLQ items</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>I have at least one health care provider that knows me well</td>
<td>Strongly agree</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>I go to GP from [sic]10 years and she knows me very well. I am a very long time with her. She is with me and my children’s. She is with all every time. If I don’t know I ask her anything. I say please tell me what to do, or I say please show me …</td>
</tr>
<tr>
<td>1</td>
<td>22</td>
<td>I can rely on at least one health care provider</td>
<td>Agree</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>I go to my local doctor and sometimes I see a different doctor but they know me. I am happy with them. One of them speaks Arabic and so we talk in this language and I am happy with that.</td>
</tr>
<tr>
<td>1</td>
<td>8</td>
<td>I have at least one health care provider I can discuss my health problems with</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>There is Somali doctor and she is very good for me. She tells me everything and I like her very much. She looks after my children’s and she looks after me and anyting [sic] I can ask. If my children’s are sick and I don’t read the medicine I say please show me. And she gives the medication to my childrens.</td>
</tr>
<tr>
<td>1</td>
<td>8</td>
<td>Get to see the health care providers I need to</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes we can see a GP no problems. This is a very good system in Australia. If we need a specialist this is not ok because it takes so long, so long that maybe the problem is gone. This is also very expensive. So this is Ok except for the specialist.</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>Make sure that health care providers understand your problems properly</td>
<td>Very easy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes they understand me always. I say please, I have this problem and they listen to me and give me tablets and they understand me. This is easy. It is OK. I ask them anythink [sic], in Australia it is ok to talk about anythink [sic]. I like this way, it is better. In Somalia you do not ask questions you just say – I have a pain here and they give you medicine. Also if I say no I can’t do that because you know the Quran … they say ok let’s do this another one.</td>
</tr>
<tr>
<td>1</td>
<td>17</td>
<td>Read and understand all of the information on</td>
<td>Very easy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>This is very easy because my GP tells me and I also ask the chemist what to do. I say ‘show me’ and they put the medicine into the thing and I can see. They give me picture of the sun and the moon and I know what times I take the tablets. This is very, very good for me.</td>
</tr>
<tr>
<td>Question</td>
<td>Rating</td>
<td>Comment</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>--------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>I have all the information I need to look after my health</td>
<td>2</td>
<td>Strongly Agree</td>
<td>Yes I think so. We have this because in Australia it is very good. The doctors are very, very good to us and it is free and we have everything we need. I can ask people and someone will know about all health things. Someone will have this thing in my community you know. Also, on the computer we can find Somali doctors talking or someone is talking about this problem. We can find this things.</td>
</tr>
<tr>
<td>I have enough information to help me deal with my health problems</td>
<td>2</td>
<td>Strongly agree</td>
<td>Yes, I have, I have. I have information - from my community. I ask people and I say ‘I have this problem’ and they say oh ‘I had that thing and you need to do these things’. Also, I have Somali TV and I listen to the doctors and they tell us everything. I can get enough informations. If I am very sick I go to the GP. Also, first thing is the Quran for us.</td>
</tr>
<tr>
<td>Get information about health so you are up to date with the best information</td>
<td>2</td>
<td>Very easy</td>
<td>Yes I can do this. I can talk to my GP and people in the community, they know. For example we know what diseases we have and we talk about this and someone says that they did this or this, then we know. Also we watch the Somali doctors from UK on the TV.</td>
</tr>
<tr>
<td>Find the right health care</td>
<td>2</td>
<td>Very easy</td>
<td>Yes this is easy because I ask my doctor where should I go and she will say oh you go here. And I go there, this is easy for me. Also in the community we talk. We say oh you have this thing then you go here and do this. This is our way.</td>
</tr>
<tr>
<td>Despite other things in my life I make time to be healthy</td>
<td>3</td>
<td>Strongly Agree</td>
<td>We must do this because we have gone through a lot in our lives and we must try to keep well for our children. It is not easy when you have financial worries and have worries about our childrens but we must make ourselves healthy. This is what the Quran tells us to do and we must do this. But it is not easy.</td>
</tr>
<tr>
<td>Understand what health care providers are asking you to do</td>
<td>3</td>
<td>Strongly Agree</td>
<td>Yes they tell us and we do this. Take the tablets or go for walk. We understand this and sometimes we can do this and sometimes we cannot. But yes, we understand this. Also if they say read this and I say ‘oh we don’t like to read’ then they will tell us. This is what we do.</td>
</tr>
<tr>
<td>ID</td>
<td>Score</td>
<td>Question</td>
<td>Response</td>
</tr>
<tr>
<td>----</td>
<td>-------</td>
<td>--------------------------------------------------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>3</td>
<td>13</td>
<td>Despite other things in my life, I make time to be healthy</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>I spend quite a lot of time actively managing my health</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>3</td>
<td>18</td>
<td>Get health information by yourself</td>
<td>Very easy</td>
</tr>
<tr>
<td>3</td>
<td>9</td>
<td>Accurately follow the instructions from health care providers</td>
<td>Quite easy</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>I spend quite a lot of time actively managing my health</td>
<td>Active</td>
</tr>
<tr>
<td>4</td>
<td>15</td>
<td>I have at least one person who can come to medical appointments with me</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>4</td>
<td>15</td>
<td>Discuss things with health care providers until you understand all you need to</td>
<td>Very easy</td>
</tr>
<tr>
<td>Score</td>
<td>ID</td>
<td>Statement</td>
<td>Answer</td>
</tr>
<tr>
<td>-------</td>
<td>----</td>
<td>---------------------------------------------------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>4</td>
<td>19</td>
<td>Work out what is best for you</td>
<td>Very easy</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>I can get access to several people who support me</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>4</td>
<td>11</td>
<td>If I need help, I have plenty of people to rely on</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>5</td>
<td>7</td>
<td>When I see new information about health, I check up on whether it is true or not</td>
<td>Agree</td>
</tr>
<tr>
<td>5</td>
<td>12</td>
<td>Read and understand written health information</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>5</td>
<td>4</td>
<td>I compare health information from different sources</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>5</td>
<td>12</td>
<td>Read and understand written</td>
<td>Quite difficult</td>
</tr>
<tr>
<td>Score</td>
<td>Description</td>
<td>Agree</td>
<td>Disagree</td>
</tr>
<tr>
<td>-------</td>
<td>-------------</td>
<td>-------</td>
<td>----------</td>
</tr>
<tr>
<td>5</td>
<td>I always compare health information from different sources and decide what is best for me</td>
<td>Agree</td>
<td>Disagree</td>
</tr>
<tr>
<td>5</td>
<td>I ask health care providers about the quality of the health information I find</td>
<td>Disagree</td>
<td>No, if the doctor gives me some information’s I am going to take that. They are trained and I respect their knowledge. I am not going to say is this right? No, I am not going to do this. In our culture we respect the people who is helping us and no, I am not shaming the doctor by asking this thing.</td>
</tr>
<tr>
<td>5</td>
<td>I compare health information from different sources</td>
<td>Strongly agree</td>
<td>No, we are not readers. We do not like to read we like to talk. So, this ones is hard. Sometimes I can read but I prefer to talk and ask for the information.</td>
</tr>
<tr>
<td>5</td>
<td>Read and understand written health information</td>
<td>Quite difficult</td>
<td>No, we are not readers. We do not like to read we like to talk. So, this ones is hard. Sometimes I can read but I prefer to talk and ask for the information.</td>
</tr>
<tr>
<td>6</td>
<td>Have good discussions about your health with your doctors</td>
<td>Easy</td>
<td>I talk with my GP. I say this is happening and we talk about this. We also talk about my family and what is happening. She is like my friend now. I am very happy with her.</td>
</tr>
<tr>
<td>6</td>
<td>Discuss things with health care providers until you understand</td>
<td>Easy</td>
<td>This is very possible. We talk and I say what do I need to do and they say maybe – take this tablet or drink this and that is ok. I understand what this is. English is sometimes hard for our community so then we need to take someone who has been here a long time. This is very possible because we help each other. No one goes to the doctor alone. Not many.</td>
</tr>
<tr>
<td>Score</td>
<td>Font Size</td>
<td>Task Description</td>
<td>Rating</td>
</tr>
<tr>
<td>-------</td>
<td>-----------</td>
<td>-----------------------------------------------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>7</td>
<td>8 pt 2</td>
<td>Get to see the health care providers you need to see</td>
<td>Very easy</td>
</tr>
<tr>
<td>7</td>
<td>11 pt 2</td>
<td>Decide which health care provider you need to see</td>
<td>Agree</td>
</tr>
<tr>
<td>7</td>
<td>16 pt 2</td>
<td>Find out which health care services you are entitled to</td>
<td>Easy</td>
</tr>
</tbody>
</table>
### Appendix 7: Cognitive Testing Responses to Individual HLQ Questions by Domain (Chinese Group)

<table>
<thead>
<tr>
<th>Domain no.</th>
<th>Item no.</th>
<th>HLQ items</th>
<th>Response</th>
<th>Response details</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Q2.</td>
<td>I have at least one healthcare provider who knows me well</td>
<td>Strongly agree</td>
<td>I have a local GP who I have been seeing since I came to this country. She speaks my language and she understands me. I don’t live near her anymore but I will travel back to see her.</td>
</tr>
<tr>
<td>1</td>
<td>Q2.</td>
<td>I have at least one healthcare provider who knows me well</td>
<td>Strongly agree</td>
<td>I have a local GP who I have been seeing since I came to this country. She speaks my language and she understands me. I don’t live near her anymore but I will travel back to see her.</td>
</tr>
<tr>
<td>1</td>
<td>Q. 8</td>
<td>Get to see the healthcare providers I need to</td>
<td>Agree</td>
<td>Everything is easy for me because my daughter does this for me. If I did not have her I would not be able to see the doctors that I see.</td>
</tr>
<tr>
<td>1</td>
<td>Q17.</td>
<td>I have at least one healthcare provider I can discuss my health problems with</td>
<td>Agree</td>
<td>I have my GP which I can discuss all of my health problems with in my language. He tells me what I am to do and I am very obedient!</td>
</tr>
<tr>
<td>1</td>
<td>Q22.</td>
<td>I can rely on at least one healthcare provider</td>
<td>Agree</td>
<td>I have a doctor I see mostly and I see my healer also.</td>
</tr>
<tr>
<td>1</td>
<td>Q22.</td>
<td>I can rely on at least one healthcare provider</td>
<td>Disagree</td>
<td>Actually I see many different doctors at our local super clinic.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Question</td>
<td>Response</td>
<td>Reason</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>----------------------------</td>
<td>----------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>2</td>
<td>Q1</td>
<td>I feel I have good information about health</td>
<td>Disagree</td>
<td>I am sometimes very confused, they say eat this one day and the next day the say something else. I am not sure.</td>
</tr>
<tr>
<td>2</td>
<td>Q10</td>
<td>I have enough information to help me deal with my health problems</td>
<td>Agree</td>
<td>I think I can ask my family or my doctor about what to do for my health. My daughter looks after my heart… I am old now and she cooks for me and talks to the doctor. I am lucky to have her.</td>
</tr>
<tr>
<td>2</td>
<td>Q14</td>
<td>I am sure I have all the information I need to manage my health effectively</td>
<td>Disagree</td>
<td>I am not sure because it is hard. I read information in Chinese on the web that is helpful but it about China and not here.</td>
</tr>
<tr>
<td>2</td>
<td>Q23</td>
<td>I have all the information I need to look after my health</td>
<td>Agree</td>
<td>I can ask for information from my doctor, my family, my community group. Yes, I am fine for this one.</td>
</tr>
<tr>
<td>3</td>
<td>Q6</td>
<td>I spend quite a lot of time actively managing my health</td>
<td>Disagree</td>
<td>I try to be healthy but I work hard and it is hard to find the time for exercise but my wife is a good cook.</td>
</tr>
<tr>
<td>3</td>
<td>Q9</td>
<td>I make plans for what I need to do to be healthy</td>
<td>Disagree</td>
<td>I am not sure of this. I want to be healthy but it is very hard and I think I could be better.</td>
</tr>
<tr>
<td>3</td>
<td>Q13</td>
<td>Despite other things in my life, I make time to be healthy</td>
<td>Agree</td>
<td>I like to walk and keep healthy. I have grandchildren and I want to be with them.</td>
</tr>
<tr>
<td>3</td>
<td>Q18</td>
<td>I set my own goals about health and fitness</td>
<td>Disagree</td>
<td>No, I just do what I can but I don’t have goals like …pumping iron! …</td>
</tr>
<tr>
<td>Q21</td>
<td>Q21. There are things that I do regularly to make myself more healthy</td>
<td>Agree</td>
<td>Every day I cook and go to the market for fresh food.</td>
<td></td>
</tr>
<tr>
<td>Q3</td>
<td>Q3. I can get access to several people who understand and support me</td>
<td>Strongly agree</td>
<td>I have my daughter who looks after me and my family. Also, I go to the Chinese Association and I have many friends.</td>
<td></td>
</tr>
<tr>
<td>Q5</td>
<td>Q5. When I feel ill, the people around me really understand what I am going through</td>
<td>Agree</td>
<td>Yes, this is how it is. I do not get sick often but my husband cares for me and my friends.</td>
<td></td>
</tr>
<tr>
<td>Q11</td>
<td>Q11. If I need help, I have plenty of people I can rely on</td>
<td>Strongly agree</td>
<td>I also have people to look after me. I look after them and they look out for me. In our community it is important to care for everyone.</td>
<td></td>
</tr>
<tr>
<td>Q15</td>
<td>Q15. I have at least one person who can come to medical appointments with me</td>
<td>Strongly agree</td>
<td>Yes, my wife always comes with me. We always go together.</td>
<td></td>
</tr>
<tr>
<td>Q19</td>
<td>Q19. I have strong support from family or friends</td>
<td>Strongly agree</td>
<td>I have many family and friends. The Chinese community is very together most of the time.</td>
<td></td>
</tr>
<tr>
<td>Q4</td>
<td>Q4. I compare health information from different sources</td>
<td>Disagree</td>
<td>My doctor tells me what to do and I do this. I don’t compare his information. It would not be right for me to question my doctor. His is an expert and I am not.</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Q7</td>
<td>When I see new information about health, I check up on whether it is true or not</td>
<td>Disagree</td>
<td>No, I do not do this. I talk to my family and my doctor and this is all.</td>
</tr>
<tr>
<td>----</td>
<td>-----</td>
<td>--------------------------------------------------------------------------------</td>
<td>----------</td>
<td>-----------------------------------------------------------------------</td>
</tr>
<tr>
<td>5</td>
<td>Q12</td>
<td>I always compare health information from different sources and decide what is best for me</td>
<td>Agree</td>
<td>I talk to my family, my community and my doctor and my traditional healer and I decide what is best for me.</td>
</tr>
<tr>
<td>5</td>
<td>Q16</td>
<td>I know how to find out if the health information I receive is right or not</td>
<td>Disagree</td>
<td>No, I am not sure of this.</td>
</tr>
<tr>
<td>5</td>
<td>Q20</td>
<td>I ask healthcare providers about the quality of the health information I find</td>
<td>Disagree</td>
<td>No, I would not ask my doctor, this is showing respect.</td>
</tr>
<tr>
<td>6</td>
<td>2pt2</td>
<td>Make sure that healthcare providers understand your problems properly</td>
<td>Usually easy</td>
<td>Yes, my doctor understands me. My English it not bad now. When I came first it was 3 years before I have the courage call the doctor. I was ashamed for my English.</td>
</tr>
<tr>
<td>6</td>
<td>4pt2</td>
<td>Feel able to discuss your health concerns with a healthcare provider</td>
<td>Usually easy</td>
<td>This is easy for me. He speaks and I listen. I tell him what I am worried about and he gives me medicine.</td>
</tr>
<tr>
<td>6</td>
<td>7pt2</td>
<td>Have good discussions about your health with doctors</td>
<td>Sometimes difficult</td>
<td>It is not good to have discussions but to listen. It is better to listen and follow my doctor’s words.</td>
</tr>
<tr>
<td>6</td>
<td>15pt2</td>
<td>Discuss things with healthcare providers</td>
<td>Sometimes difficult</td>
<td>I ask what I need to know but I do not discuss these things.</td>
</tr>
<tr>
<td>#</td>
<td>Text</td>
<td>Difficulty</td>
<td>Reason</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Ask healthcare providers questions to get the health information you need</td>
<td>Usually easy</td>
<td>I ask the questions to know what to do with the medicine but not to many questions.</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Find the right health care</td>
<td>Sometimes difficult</td>
<td>I would like to see a traditional healer. I use acupuncture for my back but I have to pay a lot of money. I wish it was free like the GP.</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Get to see the healthcare providers you need to</td>
<td>Sometimes difficult</td>
<td>I would like to see a specialist and I have to wait. This is very bad. I need a doctor and I have to wait. In china, you see a doctor until the end.</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Decide which healthcare provider you need to see</td>
<td>Usually easy</td>
<td>I can see my doctor when I need her.</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Find information about health problems</td>
<td>Usually difficult</td>
<td>I read the internet but the information in Chinese but it is sometimes old. I don’t understand the English ones.</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Get information about health so you are up to date with the best information</td>
<td>Usually easy</td>
<td>I listen to the doctor who comes to my community group. He is very good and I know this is the best information.</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Get health information by yourself</td>
<td>Always difficult</td>
<td>I talk to my family and community for information but sometimes this information is</td>
<td></td>
</tr>
</tbody>
</table>
from China and not the best information.

<table>
<thead>
<tr>
<th>9</th>
<th>5pt2</th>
<th>Confidently fill medical forms in the correct way</th>
<th>Always difficult</th>
<th>My daughter fills in the forms for me. I cannot do this by myself, I am lucky I have family.</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>9pt2</td>
<td>Accurately follow the instructions from healthcare providers</td>
<td>Usually easy</td>
<td>I listen to my doctor and follow what she tells me, very much.</td>
</tr>
<tr>
<td>9</td>
<td>12pt2</td>
<td>Read and understand written health information</td>
<td>Usually difficult</td>
<td>No, I read English but reading about my health is very hard. I don’t understand.</td>
</tr>
<tr>
<td>9</td>
<td>17pt2</td>
<td>Read and understand all the information on medication labels</td>
<td>Usually difficult</td>
<td>This is hard for Chinese people. We do not know how to understand information because this is not our way of health.</td>
</tr>
<tr>
<td>9</td>
<td>21pt2</td>
<td>Understand what healthcare providers are asking you to do</td>
<td>Usually easy</td>
<td>I try to do what I am told to do.</td>
</tr>
</tbody>
</table>
**Appendix 8: Cognitive Testing Responses to Individual HLQ Questions by Domain (Indian Group)**

<table>
<thead>
<tr>
<th>Domain no.</th>
<th>Item no.</th>
<th>HLQ items</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>I have at least one health care provider who knows me well</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>I have at least one health care provider who knows me well</td>
<td>Disagree agree</td>
</tr>
<tr>
<td>1</td>
<td>8</td>
<td>Get to see the health care providers I need to</td>
<td>Agree</td>
</tr>
<tr>
<td>1</td>
<td>17</td>
<td>I have at least one health care provider I can discuss my health problems with</td>
<td>Agree</td>
</tr>
<tr>
<td>1</td>
<td>22</td>
<td>I can rely on at least one health care provider</td>
<td>Disagree</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
<td>I feel I have good information about health</td>
<td>Disagree</td>
</tr>
<tr>
<td>2</td>
<td>10</td>
<td>I have enough information to help me deal with my health problems</td>
<td>Disagree agree</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----</td>
<td>----</td>
<td>-------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>2</td>
<td>14</td>
<td>I am sure I have all the information I need to manage my health effectively</td>
<td>Disagree</td>
</tr>
<tr>
<td>2</td>
<td>23</td>
<td>I have all the information I need to look after my health</td>
<td>Disagree</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>I spend quite a lot of time actively managing my health</td>
<td>Disagree</td>
</tr>
<tr>
<td>3</td>
<td>9</td>
<td>I make plans for what I need to do to be healthy</td>
<td>Disagree</td>
</tr>
<tr>
<td>3</td>
<td>13</td>
<td>Despite other things in my life, I make time to be healthy</td>
<td>Agree</td>
</tr>
<tr>
<td>3</td>
<td>18</td>
<td>I set my own goals about health and fitness</td>
<td>Agree</td>
</tr>
<tr>
<td>3</td>
<td>21</td>
<td>There are things that I do regularly to make myself healthier</td>
<td>Agree</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>I can get access to several people who understand and support me</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>When I feel ill, the people around me really understand what I am going through</td>
<td>Agree</td>
</tr>
<tr>
<td>4</td>
<td>11</td>
<td>If I need help, I have plenty of people I can rely on</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>4</td>
<td>15</td>
<td>I have at least one person who can come to</td>
<td>Strongly agree</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>We always go together.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>-------------------------</td>
</tr>
<tr>
<td>4</td>
<td>19</td>
<td>I have strong support from family or friends</td>
<td>Strongly agree</td>
</tr>
<tr>
<td>5</td>
<td>4</td>
<td>I compare health information from different sources</td>
<td>Easy</td>
</tr>
<tr>
<td>5</td>
<td>7</td>
<td>When I see new information about health, I check up on whether it is true or not</td>
<td>Disagree</td>
</tr>
<tr>
<td>5</td>
<td>12</td>
<td>I always compare health information from different sources and decide what is best for me</td>
<td>Agree</td>
</tr>
<tr>
<td>5</td>
<td>16</td>
<td>I know how to find out if the health information I receive is right or not</td>
<td>Disagree</td>
</tr>
<tr>
<td>5</td>
<td>20</td>
<td>I ask health care providers about the quality of the health information I find</td>
<td>Disagree</td>
</tr>
<tr>
<td>6</td>
<td>2 pt 2</td>
<td>Make sure that health care providers understand your problems properly</td>
<td>Usually easy</td>
</tr>
<tr>
<td>6</td>
<td>4 pt 2</td>
<td>Feel able to discuss your health concerns with a health care provider</td>
<td>Usually easy</td>
</tr>
<tr>
<td>6</td>
<td>7 pt 2</td>
<td>Have good discussions about your health with doctors</td>
<td>Sometimes difficult</td>
</tr>
<tr>
<td>6</td>
<td>15 pt 2</td>
<td>Discuss things with health care providers</td>
<td>Easy</td>
</tr>
<tr>
<td>Level</td>
<td>Points</td>
<td>Task Description</td>
<td>Difficulty</td>
</tr>
<tr>
<td>-------</td>
<td>--------</td>
<td>------------------</td>
<td>------------</td>
</tr>
<tr>
<td>6</td>
<td>20 pt 2</td>
<td>Ask health care providers questions to get the health information you need</td>
<td>Difficult</td>
</tr>
<tr>
<td>7</td>
<td>1 pt 2</td>
<td>Find the right health care</td>
<td>Easy</td>
</tr>
<tr>
<td>7</td>
<td>8 pt 2</td>
<td>Get to see the health care providers you need to</td>
<td>Sometimes difficult</td>
</tr>
<tr>
<td>7</td>
<td>11 pt</td>
<td>Decide which health care provider you need to see</td>
<td>Usually easy</td>
</tr>
<tr>
<td>8</td>
<td>3 pt 2</td>
<td>Find information about health problems</td>
<td>Usually difficult</td>
</tr>
<tr>
<td>Level</td>
<td>Font Size</td>
<td>Task Description</td>
<td>Difficulty</td>
</tr>
<tr>
<td>-------</td>
<td>------------</td>
<td>------------------</td>
<td>------------</td>
</tr>
<tr>
<td>8</td>
<td>10 pt 2</td>
<td>Get information about health so you are up to date with the best information</td>
<td>Easy</td>
</tr>
<tr>
<td>8</td>
<td>18 pt 2</td>
<td>Get health information by yourself</td>
<td>Always difficult</td>
</tr>
<tr>
<td>9</td>
<td>5 pt 2</td>
<td>Confidently fill medical forms in the correct way</td>
<td>Always easy</td>
</tr>
<tr>
<td>9</td>
<td>9 pt 2</td>
<td>Accurately follow the instructions from health care providers</td>
<td>Usually easy</td>
</tr>
<tr>
<td>9</td>
<td>12 pt 2</td>
<td>Read and understand written health information</td>
<td>Usually easy</td>
</tr>
<tr>
<td>9</td>
<td>17 pt 2</td>
<td>Read and understand all the information on medication labels</td>
<td>Usually difficult</td>
</tr>
<tr>
<td>9</td>
<td>21 pt 2</td>
<td>Understand what health care providers are asking you to do</td>
<td>Usually difficult</td>
</tr>
</tbody>
</table>
Appendix 9: Schedule of Interview Questions

Seeding question

“Thinking about the experiences of (Chinese/Indian/Somali) people in Australia in trying to look after their health (or the health of their family), what do they need to assist them to get and use the information and health care they need?”

Guiding interview questions

If you or your family are sick where or to whom do you go to seek help?

What are some of the difficulties in getting help when you or your family need it?

Where do you get information about health?

What have your experiences of health care been like in Australia?

Do you understand what the doctor or nurse is telling you?

If you did not understand what the doctor or nurse said would you ask questions?

Do you follow the doctor’s instructions?

Who do you trust to provide you with health advice?

In your home country, if you or your family were sick, where and to whom did you go to for help?

What does health or wellbeing mean to you?

What do you believe makes you healthy?

What do you believe makes you sick?

What does health prevention mean to you?
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