Muslim Aged Care

Designing Aged Care for Muslims in South Australia: An Exploratory Study
Designing Aged Care for Muslims in South Australia: An Exploratory Study

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March 31, 2017

ACH Group is partnering with the Islamic Society of SA (ISSA) and the Islamic Arabic Centre to offer aged care services to Muslims. Funded by the Australian Government Department of Health.
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Acknowledgment

I express my thanks to the Commonwealth Government for the Aged Care Service Improvement Grant awarded in 2015 that has led to this research. The Grant has funded the partnership project between the Muslim community in South Australia and the ACH Group and the two-year Muslim Communities Project—A CALD Partnership Model-- was initiated in June, 2015.

I thank the two community partners, the Islamic Society of South Australia (ISSA) and the Islamic Arabic Centre, along with their volunteers, for recruiting the research participants. A few surveys were conducted in the mosque and I thank the Omar ibn al-Khattab and the Al-Khalil mosque committees.

I am thankful to Dr Giancarlo Chiro from the University of South Australia who was involved as a research consultant during the drafting of the research proposal and its submission to ACH Group’s Clinical Governance Committee.

My special thanks to Dr David Radford, also from the University of South Australia, who has been the research consultant since the study commenced. His advice and draft reviews have been very helpful in bringing greater clarity to the report.

And, finally, the research participants and their families deserve special thanks for participating in the survey, giving their time, and sharing their views.

Mahjabeen Ahmad
Project Manager
ACH Group

March 31, 2017
Executive Summary

The research project titled Designing Aged Care for Muslims in South Australia: An exploratory study was undertaken as part of the ongoing work under the government-funded aged care project titled ‘Muslim Communities Project – A CALD Partnership Model’.

No empirical research had been carried out in South Australia (SA) in regards to Muslim aged care. Therefore, there was no data available on the aged care needs or concerns of the community. Recognising the importance of research in providing evidence to drive co-design of services for the SA Muslim community, the Muslim Communities Project sought to conduct a study to find out the following:

1. What are some of the perceived aged-care needs expressed by the Muslim community?
2. What aspects of service and provider characteristics, as seen from Muslim perspectives, do providers need to consider to be able to design culturally appropriate services for Muslims?

The objective of the research was to gain a better understanding about what would make services acceptable, appropriate, and relevant for the Muslim community in terms of service, staff, and provider characteristics.

The scope of the study was limited to delivery of home care services and the participants were all drawn from the Muslim community living in Adelaide, South Australia. The major challenge of the study was the recruitment of participants while the major limitation was the small sample size. Therefore, no generalizations or any conclusive statements could be made based on the limited data that was generated.

A literature review of Muslim aged care in the Australian context shows a serious lack of culturally appropriate aged care services and a lack of understanding about the aged care system on the part of the community.

The original research plan was to use multiple methods combining both quantitative and qualitative methods; however, the research design needed to be changed due to the difficulty in getting participants. Although based on a small sample and eventually using only quantitative method, the research project has nonetheless provided some valuable insights for service providers and some useful directions for future research.
The recommendations for service providers are to:

- Understand and respect the importance of religion and cultural traditions while designing and delivering services.
- Be conscious of diversity within diversity. Stereotypes must be avoided; assumptions need to be tested.
- Build relationship with the community and not just partnership with community organisations.
- Know about the demographics and needs and preferences of the community; a needs assessment study would be very useful.
- Consider innovative ways of addressing needs that may be complex or appear to be ‘too different’ or ‘hard’.
- Forge partnership with those who your clients trust the most.
- Make communication culturally nuanced, avoiding words that have negative connotations in the community.
- Recruit people from diverse backgrounds to match, where needed, clients and staff.
- Provide cross-cultural training to your staff, especially those who are in customer-facing roles.
- Provide a culturally safe environment to minority groups to break down barriers and build trust and confidence in the aged care system.

The recommendations for future research are:

- Getting access to participants can be very challenging not only in terms of numbers but also in terms of the level of their engagement; therefore, time and patience would be critical.
- Key figures in the community are powerful influencer’s; therefore, gaining the support of, and working closely with, community leaders is essential.
- Unless the community perceives a pressing need or an immediate benefit, they may not be interested in areas that may have only research value.
- Both the research design and the researcher need to be flexible.
- Time is not a scarce commodity in the community; time is viewed as cyclic and not linear. This affects the research timeline.

This research has once again demonstrated the powerful role of key figures in the community in progressing the research. It has also shown that the community needs to drive the research agenda. Consulting with them prior to commencing a project or a service will yield dividends in both short-term as well as long-term and will have direct impact on service design and delivery.
1. Introduction

1.1 Background

In 2015, the Department of Social Services, through the Aged Care Service Improvement and Healthy Ageing Grants, funded the 'Muslim Communities Project – A CALD Partnership Model'. It is a two-year partnership project between ACH Group and two Muslim community organisations that will run until June 2017. The partners are: ACH Group, a non-religious aligned not-for-profit aged care service provider operating since 1952, the Islamic Society of South Australia (ISSA)—the oldest Muslim community organisation in the State, and the Islamic Arabic Centre that runs the largest mosque in South Australia (SA). A key outcome of the project is a partnership model that helps in co-designing aged care services to address the religious and cultural needs of the target community.

1.2 Research Problem

For practicing Muslims, their religion—Islam—is both a set of faith beliefs as well as a complete code of life that influences every aspect of their day-to-day living. Filial piety is a religious edict clearly outlined in Islamic teachings and, therefore, caring for parents is a strong tradition among families. The general uptake of aged care services has been low in the community even though some families may struggle and be stretched to their limits trying to provide the right care at home but, perhaps, without adequate external support.

Most Muslim family’s associate residential aged care with abandonment by family, and all the negativity associated with institutionalization makes residential care an option that they may not wish to consider. Even families ‘wanting’ to seek formal external support—such as home care—may be viewed as ‘outsourcing’ of one’s responsibilities or neglecting one’s duties toward one’s parents at a time when they need their children the most. Understandably, seeking external help for personal care of parents is considered as a last resort only when the situation is dire.

However, the realities of migration, changes in lifestyles and family structures, increased care needs of the elderly and other compelling factors mean that it may become increasingly challenging for families to look after their elderly members. In such situations, they may have no other alternative but to take recourse to formal aged care services. Such services need to be co-designed so that families will want to consider taking up the services as they will know that these were planned and designed, and will be delivered in a manner consistent with their faith beliefs, traditions, cultures, and values.
There may be an unsatisfied demand among Muslims in terms of a lack of greater choice in aged care services. Unsatisfied demand focuses on the extent to which consumers are not able to choose from a range of differentiated services offerings. This may arise out of service gaps when some services for which there is a need in the community may not be available under current arrangements. A small community such as the Muslim community, and the even smaller number from this community who will be accessing aged care, make it more likely that their ‘special’, ‘different’, or ‘complex’ needs would either be passed over or would seem too problematic. The consequences of culturally inappropriate care could include psychological distress for the care recipients and families as well as for carers. This may give reason to dwell upon the ‘triple jeopardy’ of being ethnic, old, and Muslim.

Among Muslims, caring for an older family member is a duty that forms part of familial obligations and, importantly, is deemed to be an act that earns God’s Pleasure. Families greatly value the opportunity to look after their parents and the community honours the role of family carers. Accessing services may enhance the family’s capacity to continue in their caring role; however, there is a significant reluctance to access services for a variety of reasons that need to be addressed. The project, therefore, seeks to understand what the community’s views and concerns are about formal aged care.

1.3 Research Question

Like many other communities, Muslims generally do not understand much about aged care, are reluctant to talk about it, or even to want to know about it. It is not just community members but also community leaders who may not often have a clear understanding of the benefits of formal services or how the aged care system works.

Muslim aged care is not a very well understood area in Australia. Till date, no empirical study has been conducted on Muslim aged care needs in South Australia. Consequently, service providers, including the ACH Group, have been offering generic services that are not grounded in evidence-based data. As such, it was important that a research be undertaken to understand the views, concerns, and preferences of older Muslims and their families around aged care which could then be used to inform service design. A major motivation for ACH Group to undertake this research project was to use the experience and findings to help them deliver a roadmap for the design and delivery of aged care services for other CALD communities in the future.

Considering the concerns raised in this study, the research questions to be addressed are:

1. What are some of the perceived aged-care needs expressed by the Muslim community?
2. What aspects of service and provider characteristics, as seen from Muslim
perspectives, do providers need to consider to be able to design culturally appropriate services for Muslims?

1.4 Research Objectives

In exploring the research question, the following objectives will be met:

1. Gain a basic understanding of how Muslims view the challenges and benefits of ageing and aged care services in Australia.
2. Gain an initial understanding of what types and aspects of actual services are important or relevant for Muslims.
3. Gain a preliminary understanding of which provider or care staff characteristics might help Muslims to have an improved care experience.

1.5 Scope

It is assumed that aged care services may become more acceptable or culturally appropriate for the Muslim community if the service, care staff, or provider aspects that participants view as important are incorporated. It is also assumed that these aspects would be similar across Australia. Residential care is not viewed as a viable option by most Muslims. The environment can be disempowering, particularly given the fact that some of the needs of a Muslim resident (e.g. personal hygiene, ablution facility, and halal diet) can differ significantly from those of other residents and may be perceived by providers as being too complex or hard to address. It is home care that is more likely to be accessed by Muslim families if it is planned, designed, and delivered, based on a proper needs assessment. Hence, this study focuses on home care. It is suggested that some of the findings of this study would find relevance in residential, respite, and other types of aged care services.

1.6 Justification for the Research

This research was conducted by taking the opportunity of a government grant under which an aged care project for SA Muslims was funded. The research would be valuable in gaining some insights into South Australian Muslim community’s aged care perspectives as no research was previously done in this area in the State. These insights could then inform culturally appropriate service design and delivery.

1.7 Limitations

There is limited literature on Muslim aged care in the Western context though a growing body of work is emerging, mostly out of the United States.

Recruiting participants and conducting the study took an unexpectedly extended period of time. The most formidable challenge was recruiting participants. Attempts to secure
participants by involving Muslim community leaders and organisations did not yield the expected result. The research design needed to be revised during the project because there were not enough participants. The sample size had to be reduced twice, resulting in a much smaller sample. One linguistic group and one country of origin was over-represented. There was a very low representation of younger family members, such as adult children.

Due to the exploratory nature of the research and the small sample size, the study does not attempt to generalize the findings across the Muslim community. Rather, the tentative nature of the results provides indications and insights that, while helpful, may require further research.

1.8 Research Design

The research design is exploratory in nature. An exploratory study utilizes a small sample size as indicated above and, therefore, the findings of the study cannot be generalised. The research process was flexible, contributing to the tentative nature of results and conclusions.

Muslim aged care is a relatively new service concept in Australia and, as alluded to earlier, the Western model of aged care is also largely unfamiliar to the Muslim community. There is not much research of any kind available in this area in the Australian context and very little empirical research done at all.

The study uses both primary and secondary sources. The primary source is the Muslim research participants while the secondary source is the existing literature. The primary data was generated through a questionnaire survey of Muslim older people and their family members living in Adelaide, South Australia.

1.9 Research Team

Mahjabeen Ahmad of ACH Group was the researcher. Dr Giancarlo Chiro, an adjunct faculty of the University of South Australia (UniSA), acted as a research consultant during the development of the research proposal and its submission for ethics clearance. When the actual study got underway, Dr David Radford from UniSA was engaged by ACH Group as research consultant.

1.10 Definitions

**Older, elderly, aged:** For the purpose of this Report, these terms have been used interchangeably to include people who are aged 65 years and over.
Halal: Muslims follow dietary laws based upon Islamic teachings. All food is categorised into halal and haram (Arabic terms). Halal means permitted, allowed, or lawful while Haram means forbidden.

Imam: An Imam is a Muslim prayer leader. Traditionally, an Imam has been one who led the congregational prayers and delivered sermons during Jumu’ah (weekly congregational prayer on Fridays) and the two Eids (Muslim celebrations; one marking the end of Ramadan—month of fasting, and the other marking the end of Hajj—annual pilgrimage) prayers. The role of Imams has now expanded and today, Imams may act as counsellors helping Muslims in personal and spiritual development by providing information and advice.

Culture: The word culture is used broadly to include not just ethnic culture but, importantly, religious traditions and practices.

### 1.11 Report Preview

This Report is divided into seven chapters. The Introduction chapter provides the background, purpose, and scope of the study, research questions and design, as well as the structure of the Report. Chapter 2 contains literature review covering major studies done on Muslim aged care in the West, including in Australia. An important inclusion in the literature review is issues around recruitment of research participants from CALD communities. Chapter 3 elaborates the research methodology and provides details about the research process and timeline. Some information about Muslim demographics and available aged care services for them in South Australia is provided in Chapter 4. The survey results and analyses are covered in Chapter 5 while Chapter 6 discusses the findings including the lessons learnt from this research. The report ends with Chapter 7 that includes a set of recommendations for service providers and future research, and concluding remarks. It is to be noted that Chapters 2 and 4 draw heavily on verbatim sections of the first report on Muslim aged care in SA co-authored by this researcher and Shamsul Khan\(^1\) and used with permission here.

\(^1\) Ahmad, M. & Khan, S. *Muslims in Australia and their Aged Care Needs: An Exploratory Study with Special Reference to South Australia (updated)*, Report, Islamic Information Centre of South Australia (IICSA), 2015, Adelaide
2. Literature Review

One of the pioneering research into Muslim aged care in Australia was done by Babacan who found that there was an element of fear among some Muslim communities towards residential aged care and that her respondents “did not want to see it as an option for them. There was a clear preference for wishing to remain at home and to be with families”\(^2\). While the latter part of her observation is true across cultures, the former part may be partially explained by the fact that the expression of need for aged care services and wanting to access such services are shaped by the experiences, attitudes and beliefs of older people and their families. These, in turn, can be affected by what is known to be available or by the perceived suitability or accessibility of available services\(^3\). In her study of Queensland Muslims from different ethnic backgrounds, Babacan found that halal food, appropriate prayer facilities, and respect for religion and culture were among the important things that Muslims wanted in aged care facilities\(^4\). While using interviews and surveys based on snowball sampling method, Babacan notes the challenges she encountered. Some of these were “trust issues in communities which are not easily explained”, “access to members of the community are often through key people in the community”, “a fear of government and authority generally”, and participants “did not differentiate the community nature of the study”.

Rogelia et al. (2010) identified a series of interventions that service providers could employ in relation to Muslim communities. They suggest that in order to facilitate care access there needs to be an increased quality and appropriateness of services, an enhancement of the cultural competency of staff, and strengthening and developing real collaboration and partnerships with communities and other services\(^5\). The research report mentions other studies where it was found that Australian Muslims are among the most deprived groups in the community\(^6\). The report identified a number of barriers and difficulties in accessing formal services by Muslim families including language and communication problems, distrust or negative perceptions of services, and unfamiliarity with the system. Participants believed that there was a lack of culturally and religiously appropriate aged care services to meet the needs of Muslims and mentioned that this made the services even more unacceptable. This contributed to enormous difficulty for families in deciding aged care options. Many families associate putting their older family members into formal aged care

\(^3\) Australian Institute of Health and Welfare (AIHW), Department of Health and Ageing, Older Australia at a Glance, 4th edition, Cat. No. AGE 52, AIHW, Canberra, 2007, p.102
\(^4\) Babacan, H. Care Needs of Muslim Older Adults, op. cit t. p.62
\(^6\) ibid. p.23.
with neglecting their duties toward them at a time when the elderly member is frail and vulnerable. Thus, the collectivistic values were upheld even when taking care would stretch the family finances or when there could be a shortage or lack of carer in the family.

The above report observes that even well-established Muslim families had only partial knowledge of the range of available services and identified the lack of knowledge or understanding of the system as a major barrier in seeking information about needed services and in finding how they worked.

Participants opined that there was a need to create understanding in the Muslim community about the aged care system and available support and to address cultural and other barriers of utilizing such services. The study also discovered that there was a significant reliance on religious and community leaders who are often approached by Muslim families either for direct assistance, or for linking them to the appropriate service/s or source/s of help. The study employed community consultations with leaders of Muslim community organisations followed by focus groups that included Muslim families recruited with the help of community groups and community leaders.

In 2007, the Department of Families, Community Services and Indigenous Affairs (FaCSIA) led a whole-of-government project titled Sharing Our Achievements: Symposium on Australian Muslims under its Bringing Communities Together Strategic Framework. Under this project, symposiums and expos were organised throughout Australia to highlight the positive contributions of Australian Muslims to the Australian society, as well as to provide opportunities for the wider Muslim community to identify gaps in service delivery of government and non-government agencies. One of the chief recommendations of this project was that information on community services provided by governments, community groups, and the not-for-profit sector be shared, and constructive dialogue between service providers and consumers be established.

There is an existing undercurrent of concern among Muslims about the unavailability of culturally appropriate services and a ‘pressing need’ for services such as aged care.

A study on social service providers in Canada who work with Muslim clients opine: “Service providers, educators, and social work agencies all have a role to play in ensuring that Muslims receive effective social services”.

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7 Neighbour, S. “Our High-Profile Muslim Minority”, The Australian, February 18, 2011.
An important study has been done by Zokaei and Phillips on altruism and community relations among Muslims in the UK\(^9\). Their research shows that clashes between individualistic values (regarded as western) and collectivistic values (such as encouraged in Islam) were proving to be potentially disruptive to family unity and solidarity within British Muslim families. Among the major findings of the study were the presence of strong family ties and respect for parents among Muslims. However, many respondent parents lamented the fact that their children did not share their values and adopted a lifestyle that was reflective of "too much freedom" that is enjoyed by children in a western, secular society. Parents agonised over the possibility that such an individualistic attitude could change the concept of duties and obligations toward one's family resulting in, perhaps, parents or other older family members being left to care for by outsiders. This apprehension is likely to resonate with Muslim families in other Western countries as well.

In a needs-assessment study on Muslim families in the USA, Ajrouch, citing Sengstock [1996], observes that interdependence is valued much more than individualism among Muslims, especially those from migrant backgrounds\(^10\). The study employed focus group discussions with older adults recruited through mosques, one-on-one interviews with community leaders, and a web-based survey distributed to Muslim email lists. Imams and board members of four Muslim centres along with other community leaders were interviewed. Community leaders and participants were all educated; 39 per cent of community leaders were women. The study findings show that the top need was taking care of home, followed by transportation and physical health. People were generally fearful of nursing homes mainly because these are seen to be not meeting religious or cultural needs. The idea of a Muslim aged care facility was viewed favourably as a means to mitigating care burdens of family members. Board members spoke about the need to educate and provide information to the community about aged care. Community leaders acknowledged "the challenge of community deficiencies" and spoke about their "frustration that addressing aging issues are low priority for Muslim communities"\(^11\). All participants agreed that the best way forward was for the community to care for their own. Community leaders, in particular, recognised the criticality of the community uniting and working toward making culturally appropriate services available through setting up their own facilities. The study report emphasises the importance of proactive planning and prioritizing aging in applying for grants.

In another study conducted in the US city of Detroit\(^12\), Ajrouch and Fakhoury provide a critical perspective on the needs of ageing Muslims from diverse ethnic backgrounds. Qualitative

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\(^11\) ibid. 14.

research method using focus groups was employed with participants recruited through local mosques. Quality of life and social relations, including those with inter-generational and peer groups, were the most important needs identified by participants. Both religion and culture were the major sources of strength for the groups in the way they viewed their future need and provision for aged care. Inter-generational conflicts, arising out of changes in the perceived caring roles within the family and also influenced by mainstream views about Muslims, were the key challenges for the ageing. In regards to the future course of action, there was a clear preference for aged care support to be provided from within the Muslim community to ensure cultural understanding and cultural appropriateness of care. It was also recognised that while mosques can and do play a pivotal role in building and preserving social interactions and relations, these are not sufficiently equipped to spearhead aged care services. There was a recognition that incremental steps toward Muslim aged care is the sensible approach as opposed to large-scale or drastic measures or changes. The authors recommend involving adult children’s perspectives and views on ageing in future research of this kind.

In another article on a similar matter, Abdullah elucidates the religious and moral imperatives of caring for the elderly, especially one’s parents, as emphasised in Islam. Considering this religious edict, she argues that it is critical to incorporate kinship care in any care plan for a Muslim.

It is found in a study on American Muslim families that in case of disability, 62% of participants would prefer to receive care at home for themselves and 65.7% for a family member. Should there be a Muslim aged care facility available, a significant percentage--78.3%--would consider the facility for themselves and 76% would consider it for a loved one. Citing other studies, the authors state that Muslim families are not open to the idea of using nursing homes because they are committed to the religious dictate that gives children the responsibility to look after their parents when they reach old age, and because families have serious concerns about available services not aligned to Muslim culture and traditions. The study recommends gauging Muslim attitudes toward home care so that in the US, this form of care can be made more culturally appropriate. The study employed telephone interviews with participants who were members of mosques and were recruited through Imams and mosque board members.

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In a book chapter based on an ethnographic study in a US Metropolitan area, Ross-Sheriff looks at issues facing first-generation Muslim older migrants. The study was conducted in two stages: in the first stage, key community leaders who were close to the older migrants were observed and small group discussions conducted; in the second stage, small group discussions were held with 40 first-generation older migrants. The author notes the role of grandparents who are regarded as ‘heads of households’. Feeling needed by their families was their greatest desire; becoming totally dependent on others was their greatest fear. They worried about the capacity of their families to look after them if health conditions deteriorate; they dreaded going into “old folk homes”. Citing other researchers, the author argues that awareness and information about support services to help people stay at home would greatly assuage fears and anxieties of older people and their families about the future and allow many families to continue to look after their parents at home.

Many older Muslims tended to socialize mainly with people who share their ethnic background and have not been very active in seeking to do the same with the mainstream society, especially after 9/11. Stereotypical views and attitudes about Muslims exacerbated the challenges of migrant families to adjust and adapt to a new life in America. Community connections and, opportunities to go to the mosque or attend Muslim community events were, therefore, valued even more. A major finding of the study is the critical role that religion plays in the lives of these Muslims; the author remarks on how working towards spiritual growth and preparing for end-of-life were important to them.

Ross-Sheriff observes that Muslim community organisations had initiated some support for the elderly in the form of facilitating transportation to the mosque, enabling social connections through organising and hosting community events, and, providing emergency support during crises situations. However laudable the efforts have been to deliver these services, these programs were run by community members who may not have the skills, expertise, or experience needed for better operational efficiency and effectiveness. The author suggests collaborative partnerships with the public or social service sectors to achieve greater reach, depth, and spread of services, including carer support services.

Most of the research on recruitment of culturally diverse participants have been conducted in the US and a few in Europe. Citing multiple, predominantly European and North American sources, a study by Ejiogu et al., lists some of the barriers to recruiting research

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participants from “special populations”, such as, low socio economic or minority status and the aged. These barriers appearing a tabular representation in the article\textsuperscript{17}, as reproduced below:

<table>
<thead>
<tr>
<th>Barriers to Recruitment of Non-Traditional Research Participants</th>
</tr>
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<tbody>
<tr>
<td><strong>Individually-based barriers to participation:</strong></td>
</tr>
<tr>
<td>• Fear of being used as a “guinea pig” (Wilets et al., 2003)</td>
</tr>
<tr>
<td>• Mistrust of government entities (UyBico et al., 2007)</td>
</tr>
<tr>
<td>• Time required to participate is too much (Keyzer et al., 2005)</td>
</tr>
<tr>
<td>• Economic constraints and inability to take time off from work (G. M. Corbie-Smith, 2004)</td>
</tr>
<tr>
<td>• Transportation to and from research location (Blanton et al., 2006)</td>
</tr>
<tr>
<td><strong>Community-based barriers to participation:</strong></td>
</tr>
<tr>
<td>• No real-time benefit to participants (G. M. Corbie-Smith, 2004)</td>
</tr>
<tr>
<td>• Exploitation of a vulnerable population (LaVeist et al., 2000; Wipke-Tevis &amp; Pickett, 2008) Inadequate knowledge concerning the need for research (Wilets et al., 2003)</td>
</tr>
</tbody>
</table>

The above list shows that individual barriers to participation included mistrust of government and research institutions and personal biases. As for community-based barriers, the most significant ones are lack of research knowledge and the suspicion “that there is ongoing exploitation of community members” by research institutions. The same study by Ejiogu et al. also highlights that “.....there may be special barriers for older individuals, and it is not unreasonable to expect that minority elders may have additional issues that affect study participation\textsuperscript{18}.

Four case studies from the US, Botswana, and Malaysia discussed in an article by Merriam et al.\textsuperscript{19} challenge the simplistic assumption that researching within one’s own culture makes the researcher an ‘insider’. The authors of the study have identified three themes—positionality, power, and representation— that are particularly “relevant for

\textsuperscript{17} Ibid, p. S34
\textsuperscript{18} Ibid, p. S34
framing the insider/outsider debate”20. The study cites Villenas (1996: 722) as postulating that ‘as researchers, we can be insiders and outsiders to a particular community of research participants at many different levels and at different times’21. In regards to positionality the authors (quoting Narayan 1993: 671 –672) state: “The loci along which we are aligned with or set apart from those whom we study are multiple and in flux. Factors such as education, gender, sexual orientation, class, race, or sheer duration of contacts may at different times outweigh the cultural identity we associate with insider or outsider status”22. The resulting complexity involved in each context can be further gauged from an article by Warburton et al. referring to available literature, they emphasise the complexities and challenges of involving the community in any meaningful community-based research, without active research partnership23. It may be noted in this context that, the widely diverse backgrounds of the Muslim community put an additional layer of complexity to the insider/outsider issue along multiple ethnic and linguistic groups within the community.

Feldman et al.,24 citing other researchers (Bowes and Dar 2000; Brown and Alexander 2004; Curry and Jackson 2003; Levkoff, Levy and Weitzmann 2000; Sixsmith, Boneham and Goldring 2003; Yancey, Ortega and Kumanyika 2006), have pulled together key themes around recruitment and retention of older people from CALD communities and gaining access to the community. Not surprisingly, these include the importance of trust and established connections with CALD communities and the vital role of culturally diverse researcher or research team. The authors argue that, while there is recognition of the need to acknowledge and understand community issues using cultural lenses, crucially there is an imperative to understand that barriers to recruitment may not only be associated with research institutions alone but some of the barriers can be attributable to the communities themselves. Enumerating the key challenges in recruiting and retaining people from different cultural backgrounds, Feldman et al. stressed upon three factors: access to key local informants; paid and trained bilingual interviewers; and extending support to researchers in recruitment activities. The article also emphasises flexibility of recruitment strategy to ensure greater participation across groups.

Citing others, Feldman et al. ascribes the ‘tension’ associated with CALD participation to “lack of trust and scepticism shown by culturally diverse participants (Gallagher-Thompson et al. 2006; O’Brien et al. 2006; Moreno-John et al. 2004), the impact of a history of discrimination (Dennis and Neese 2000; Stahl and Vasquez 2004), and the

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21 Ibid, p. 411.
22 Ibid, pp. 411-12.
different values and perspectives of people from culturally diverse communities (Levkoff, Levy and Weitzmann 2000). Feldman refers to Levkoff, Levy and Weitzmann’s (2000) ‘Matching Model of Recruitment’ that stresses the criticality of matching stakeholder perspectives toward research and research participation, considered by some to be essential to recruitment success. These perspectives exist at three different levels: micro (individual participant or researcher/interviewer); mediator (gate-keeper or researcher/research team); and macro (community organisation or research body). Citing Nichols et al. (2004), Feldman et al. also posit that working with community partners and key informants (usually, well-known members of the community) could be the most successful recruitment strategy as they can provide linkages to potential participants through referrals and rapport. Feldman et al., citing Sixsmith, Boneham and Goldring (2003), also highlight the risk of using key informants to recruit—the serious potential to have only one particular ‘type’ of participant being recruited. Besides acknowledging the “local influence and the potential to add credibility and validity to a project”, a critical conclusion from Feldman et al.’s literature review was that key informants also had the power and influence to negatively affect a research project by regulating or preventing access of participants, even to “essentially shut the project down”. They go on to further argue: “Key informants, intentionally or otherwise, had a powerful role in determining who took part, why they took part, and on the dynamics of their involvement.” They also highlight findings from US studies (Brown et al. 2000; Levkoff and Sanchez 2003; Moreno-John et al. 2004) and others indicating that research participation of minority groups is more resource intensive, that ethnic matching may be important for recruitment success, and that mistrust and fear among older people from culturally diverse backgrounds is a reality that stem from their past experiences and life situations.

Briefly, the literature review from Australia and overseas have highlighted the following:

**Australia:**

- There is a paucity of empirical research on Muslim aged care in Australia.
- The Muslim community lacks information and understanding about the aged care system.
- There is a perceived lack of culturally appropriate services for Muslims.

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25 Ibid, P. 475
Overseas:

- The Muslim community and its leaders in the US are cognizant of the challenges of ageing and are proactive in determining a solution.
- A common thread across most of the findings has been the need for Muslims to have their own aged care services where religion and culture would be respected and associated needs addressed appropriately.
- Home care was regarded as the best avenue to initiate aged care and is likely to be better received than residential care.
- Studies of Muslim communities were conducted mainly with assistance from mosques and Islamic centres through which participants were most often recruited. This highlights the key role that these entities can play in facilitating an empirical study.
- The literature review brings into sharp focus the binary view of being an insider/outsider held toward a researcher even though she or he may be a member of the same community.
3. Methodology

To achieve the research outcomes, the study originally sought to use both qualitative and quantitative research and, therefore, multiple methods were planned: focus groups, semi-structured interviews, and forum discussion.

Under the partnership contract, one of the Project partner organisations—the Islamic Society of South Australia (ISSA) --- employed a Community Liaison Officer as part of the governance structure. The Muslim Communities Project funded the position. Before commencement of the research, it was agreed that the Liaison Officer would have the following tasks in regards to the research project:

- Secure research participants, contact them, and confirm their participation
- Provide researcher with a list of participant names
- Organise Focus Groups, Interviews, and Forum Discussion
- Organise and coordinate with participants the times and, where applicable, places to meet for each of the sessions
- Engage two note-takers with prior experience from the community
- Lock in the same note-taker for each day of focus group discussions and interviews
- Check and operate recording equipment
- Where applicable, book venues and manage all logistic.

Sampling Method and Recruitment of Research Participants

The method of sampling was planned to be purposive. The original target sample size was 30 as it was considered reasonable based on the size of Muslim population aged 65 and over in South Australia (443 individuals according to the last Census).

The participants were to be selected based on four major variables that, in varying degrees, have a direct bearing on participants’ aged care perspectives and implications for service design and delivery. These are:

1. Language
2. Gender
3. Age and,
4. Length of residence in Australia.
For ensuring fairness in selection criteria for participants, the following composition was decided:

- Participants from Arabic, Dari, Turkish, Urdu, and Uygur linguistic backgrounds: according to the 2011 ABS data, these were the top five languages spoken by older Muslims in South Australia;
- An equal number of males and females;
- Two age cohorts, i.e. 65-74 and 75 and above because the younger old and the older old may have different service needs and priorities;
- A mix of first-generation and second-generation older people and a mix of Australian-born and overseas-born Muslims, as migration and length of stay influence and shape attitudes and culture.

Two older Muslims from each of the top five linguistic groups were to be chosen, making a total of ten participants. Any smaller number would affect reliability and a bigger number could be unfeasible. As Muslims belong to a collectivistic culture, important decisions are usually taken in consultation with family members. Therefore, it was important that the views of older people as well as of their families, who are potential key players in the aged care decision-making process, were looked at. Therefore, two adult children of each of the participants would be asked to participate in the interviews; that meant, a total of twenty children—a mix of sons and daughters—from ten families. Ten separate interviews would be conducted for the ten families.

The participants would be divided into three groups:

1. older persons
2. Families, and
3. Combined (first and second groups together).

A brief questionnaire would be distributed to the first and second groups with the objective of gathering preliminary data that would be indicative of their level of awareness, understanding, and concerns about aged care. The questionnaire would use simple English for the benefit of participants. The survey result would help in identifying issues, topics, or themes around which to frame the semi-structured interview and focus group questions and themes.

Keeping in mind the cultural sensitivities around gender segregation, separate hour-long focus groups were planned for the ten older Muslim male and female participants. Ten separate 30-minute semi-structured interviews would be conducted with two family members of each of the 10 participants (10X2= 20) who were in the first group. A third group comprising of the ten older Muslims and their 20 family members (10+20=30 in total) would be invited for a forum discussion.
With prior written consent of the participants, the focus group discussions were to be recorded through video recordings and the interviews were to be audio-taped. As a back-up measure to counter any technical malfunction of recording equipment, two note-takers with prior experience in focus groups would be recruited from the community to work in pairs during the focus group sessions and later, during debriefing. There were to be note-takers, too, for the interviews and the forum discussion. The researcher would work directly from the audio and video tapes to analyse results and prepare the research report. The forum, however, was not to be recorded for logistical reasons.

Recruitment of participants by the Islamic Society of South Australia (ISSA) ---one of the Project partner organizations--- was chosen because ISSA had access to, and established relationships with, the SA Muslim community. The researcher met with ISSA several times to explain the research problem and objectives, the methodology and the process, the timeline, and the participant selection criteria and sought cooperation in getting the target number of participants. She planned with ISSA the dates, venues, and other logistic.

In accordance with the ethics approval, the researcher needed to give each participant a copy of the Plain Language Statement that outlined the research objectives, methodology, participant role, how the data will be collected and used, the process of feedback to the participants, and other relevant details. Further, the participants were required to sign a Consent Form prior to participating. In addition, a Withdrawal Form that stated the right of participants to withdraw at any point should they wish, with no obligations and consequences for them, was to be handed out in case any participant decided to withdraw. The researcher gave ISSA copies of the participant invitation letter (see Appendix 1), Plain Language Statement (see Appendix 2), Consent Form (see Appendix 3), and Withdrawal Form (see Appendix 4) to be given to prospective participants days before the survey was to begin so that participants would have the time to discuss with family members or have the information translated, if needed, for informed consent. ISSA would return the signed Consent Forms to the researcher. The researcher would also carry copies of the forms when she met the participants to ensure that if anyone who had not received them before, could get one.

**Research Process**

Unavailability of target sample hampered the research process. When the situation did not improve despite repeated attempts, the original research design was scaled back and, in the end, only a questionnaire survey (see Appendix 5) with 17 participants could be conducted.

At the outset of the research study, the Project Manager had met with the Community Liaison Officer several times to explain his tasks, discuss the best ways to achieve the research milestones, and set up a timeline to mark the milestones and track progress.
It soon became clear that the designated tasks were not able to be accomplished. The Project Manager kept ACH Group informed and met with ISSA several times to voice concerns about it.

After a long delay, when ISSA finally contacted the participants, the researcher met with the participants on three different occasions--twice in the mosques and once in a different venue. Each time, the participant turnout was much lower than expected. The researcher spoke about the research project and addressed queries from the participants. Refreshments were provided and the participants were informed that they would get a $50 gift card from ACH Group at the end of their participation when the forum discussion was complete. It was also the times when the first questionnaires were administered.

Although some participants filled out the questionnaire properly, some did not complete it while some filled it out for others. It is relevant to restate here that this questionnaire was to inform themes and questions for the focus groups and interviews. Ultimately, the focus groups could not be held due to the lack of adequate number of older Muslims willing to participate; for the same reason, interviews with adult children could not commence.

Given that the research needed to be completed and the report written within a given time frame, it was decided to change the research design to deal with the problems of securing participants; however, the target sample size was kept at 30. The requirement in regards to family composition was relaxed to include any adult extended family member who was, or is likely to be, involved in care giving or care decision-making. The criterion of getting people from the top five linguistic and ethnic backgrounds had to be abandoned for lack of representation; instead, it was decided to include anyone irrespective of specific linguistic and ethnic backgrounds. Conducting the survey online was suggested by partner organisation should the number not increase in the next two months. Because of the high probability that adult children or other family members would most likely fill up the questionnaires and the actual views and aged care needs and concerns of older Muslims may not be known, the researcher decided not to pursue the online survey suggestion.

Even with the flexible research design, it was difficult to meet the recruitment target. Recruitment was slow, and the study ran behind schedule. When it became clear that participant recruitment was becoming an insurmountable problem, upon the advice of ISSA it was decided that only a quantitative method of data collection using questionnaire survey would be employed. The final sample design included a non-probability and convenience sampling strategy.

Since the focus groups and the forum could not be held, the original questionnaire needed to be revised. A few additional multiple-choice and three open-ended questions were included in the new questionnaire.
It was agreed with ISSA that they would again make contacts and help set up appointments with older Muslims and their family members and the researcher would meet with them either in their homes or in the mosques, whichever they preferred. She would use the questionnaire to talk to the participants and, in their presence, fill out the responses based on the conversation. This would ensure fair representation of participants' responses and provide opportunities to the older participants to express their opinions themselves and not be represented by a family member. This would also ensure that every questionnaire was read, understood, and then responded to.

The researcher met with individual participants, and their families where applicable, and began by explaining the Plain Language Statement and getting the Consent Form signed. The researcher read out and explained each question and, in the presence of the participants, filled out the responses based on the conversation and took notes regarding responses to the open-ended questions. All communication was conducted in English as, except two, all participants possessed, at least, functional-level English. For the two participants who did not speak English, their family members translated for them.

By the time that the survey was underway, Ramadan—the Muslim month of day-long fasting—had arrived. This is a special time of the year for Muslims who try to spend as much time as possible to devote to various acts of worship. To avoid any further delay in the research and to continue with the questionnaire survey, the researcher decided that after breaking her fast and performing the special night congregational prayers in the mosque, she would meet with one family per evening wherever they preferred to meet --at the mosque or in their homes. Participants could not be expected to be flexible with their availability, and so, the researcher, to the extent possible, met with them whenever and wherever they agreed to meet.

Eventually, only 17 questionnaires could be administered. As is evident, the number was short of the projected 30 due to extreme difficulties in recruiting participants as mentioned earlier. Each of these 17 participants received a thank-you card and a $50 gift card on behalf of ACH Group.
4. Muslim Community and Aged Care in South Australia

This chapter provides an overview of the Muslim community in South Australia and a brief description of the limited aged care services available to them.

Muslim Demographics of South Australia

The following tabular displays provide demographic data on South Australian Muslims. As details from the latest Census data of 2016 is yet to be published, the last available data from the 2011 Census has been used to develop the tables.

South Australia has 4.1 percent of the total Muslim population of Australia and comes fifth after New South Wales, Victoria, Western Australia, and Queensland. The 2011 Census reports a total of 19,511 Muslims in South Australia; among them 10,589 are males and 8,922 females. At 11 per cent, the Adelaide suburb of Gilles Plains is home to more Muslims than any other place in the State27

The top ten countries of origin and the top ten languages spoken by Muslims in SA are:

<table>
<thead>
<tr>
<th>Top Ten Countries of Origin of Muslims in SA</th>
<th>Top Ten Languages Spoken by Muslims in SA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>Arabic</td>
</tr>
<tr>
<td>Afghanistan</td>
<td>Dari</td>
</tr>
<tr>
<td>Pakistan</td>
<td>English</td>
</tr>
<tr>
<td>Iran</td>
<td>Urdu</td>
</tr>
<tr>
<td>Bangladesh</td>
<td>Persian (excluding Dari)</td>
</tr>
<tr>
<td>Iraq</td>
<td>Hazaraghi</td>
</tr>
<tr>
<td>Indonesia</td>
<td>Bengali</td>
</tr>
<tr>
<td>Malaysia</td>
<td>Bosnian</td>
</tr>
<tr>
<td>Saudi Arabia</td>
<td>Malay</td>
</tr>
<tr>
<td>Bosnia and Herzegovina</td>
<td>Indonesian</td>
</tr>
</tbody>
</table>

Source: ABS 2011 Census

The top ten Local Government Areas (LGAs) in Adelaide with the highest concentration of Muslims are:

<table>
<thead>
<tr>
<th>Top ten Adelaide LGAs with highest concentration of Muslims</th>
<th>Number of Muslims</th>
</tr>
</thead>
<tbody>
<tr>
<td>Port Adelaide Enfield (C)</td>
<td>3846</td>
</tr>
<tr>
<td>Salisbury (C)</td>
<td>3088</td>
</tr>
<tr>
<td>Charles Sturt (C)</td>
<td>2034</td>
</tr>
<tr>
<td>West Torrens (C)</td>
<td>1415</td>
</tr>
<tr>
<td>Marion (C)</td>
<td>1324</td>
</tr>
<tr>
<td>Tea Tree Gully (C)</td>
<td>1004</td>
</tr>
<tr>
<td>Playford (C)</td>
<td>925</td>
</tr>
<tr>
<td>Mitcham (C)</td>
<td>803</td>
</tr>
<tr>
<td>Onkaparinga (C)</td>
<td>655</td>
</tr>
<tr>
<td>Adelaide (C)</td>
<td>628</td>
</tr>
</tbody>
</table>

Source: ABS 2011 Census

The table below displays the number of Muslims living in regional local government areas (LGAs) of South Australia. No data is available on the number of older Muslims living in these places. Owing to their small number in regional areas, some Muslims may have been reluctant to state their religious affiliation on the Census form. This means that some regional LGAs have not been able to record any Muslims under ‘Islam’ in their population breakdown by religions.

<table>
<thead>
<tr>
<th>Regional LGAs</th>
<th>Number of Muslims</th>
<th>Regional LGAs</th>
<th>Number of Muslims</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alexandrina</td>
<td>25</td>
<td>Naracoorte and Lucindale</td>
<td>155</td>
</tr>
<tr>
<td>Barossa</td>
<td>16</td>
<td>Northern Areas</td>
<td>12</td>
</tr>
<tr>
<td>Berri and Barmera</td>
<td>19</td>
<td>Port Augusta</td>
<td>37</td>
</tr>
<tr>
<td>Coober Pedy</td>
<td>21</td>
<td>Port Lincoln</td>
<td>18</td>
</tr>
<tr>
<td>Copper Coast</td>
<td>14</td>
<td>Port Pirie City and</td>
<td>40</td>
</tr>
<tr>
<td>Light</td>
<td>20</td>
<td>Districts</td>
<td>215</td>
</tr>
<tr>
<td>Loxton Waikerie</td>
<td>27</td>
<td>Renmark Paringa</td>
<td>18</td>
</tr>
<tr>
<td>Mallala</td>
<td>12</td>
<td>Roxby Downs</td>
<td>36</td>
</tr>
<tr>
<td>Mid Murray</td>
<td>13</td>
<td>Tatiara</td>
<td>11</td>
</tr>
<tr>
<td>Mount Barker</td>
<td>49</td>
<td>Victor Harbor</td>
<td>38</td>
</tr>
<tr>
<td>Mount Gambier</td>
<td>45</td>
<td>Wattle Range</td>
<td></td>
</tr>
<tr>
<td>Murray Bridge</td>
<td>220</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The breakdown of Muslim population in South Australia by gender and three age cohorts is shown next:

<table>
<thead>
<tr>
<th>Gender</th>
<th>65-74 years</th>
<th>75-84 years</th>
<th>85+ years</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>177</td>
<td>57</td>
<td>18</td>
<td>252</td>
</tr>
<tr>
<td>Total</td>
<td>309</td>
<td>108</td>
<td>26</td>
<td>443</td>
</tr>
</tbody>
</table>

Source: ABS 2011 Census

The data in the above table is particularly relevant for both aged care providers and the Muslim community. In this context, it is important to note that the under 65’s have moved into the ‘older’ category [aged 65 and over] since 2011 just as people in other age cohorts have moved to higher age brackets.

**Muslim Aged Care in South Australia**

Muslims in South Australia have very limited access to culturally appropriate care. Bene, the renamed aged care services of the Italian Benevolent Foundation SA Inc. (IBF), partnered with the Tatar Bashkurt Community of SA to provide culturally and linguistically appropriate home care such as domestic assistance, social support, and home maintenance to the elderly Tatar Bashkurts residing in the Northern-Eastern Metropolitan Region of Adelaide; most Tatar Bashkurts are Muslims. The Muslim Women’s Association of South Australia (MWASA) received government funding to assist older Muslims who are cared for at home; this assistance is in the form of activities aimed at reducing feelings of isolation among consumers and engaging them with the rest of the community.

A few Muslims have chosen church-based providers, such as Anglicare and Uniting Care. These faith-based organizations, or what are sometimes described as religious organizations (such as in the Aged Care Service List of the Department of Health), and charitable organizations are believed to have significant competence and knowledge to contribute, born of a tradition of providing services and support. Their experience and support could be valuable for planning aged care services for Muslims. In this context, it may be pertinent to mention the coverage in The New York Times28 of Muslim students enrolling in American Catholic colleges and universities in greater numbers than in the past. These students, in particular the Muslim women students who wear head coverings, chose Catholic institutions over secular ones as they felt welcomed, accepted, and comfortable in such places. These institutions, they felt, respected their faith, and shared many similar values which greatly aided them in continuing with their lifestyle. An example closer to home is Our

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Lady of the Sacred Heart, a Catholic girls’ school in South Australia, with a significant enrolment of Muslim students. At Tenison Woods College, a regional Catholic school in Mt. Gambier, South Australia, Muslim students and their families have been offered the use of a room in the Church Hall for their prayers. Anecdotal evidence suggest that church-based providers offer some degree of culturally appropriate care to their Muslim residents, and their families are comfortable with the care arrangement.

29 Independent Education Union (South Australia), Public Submission to Review of School Funding, March 31, 2011, p. 88
30 ibid. p. 15.
5. Survey Results and Analysis

A two-part 20-item questionnaire was administered (see Appendix 1); the first section asked for demographic information and the second contained questions that would be indicative of the level of participants’ awareness, understanding, preference, concerns, and views about aged care. Section A had six questions while section B had 14. In section B, questions 1-11 were mainly multiple choices with a few having spaces to explain or elaborate on an answer; Questions 12-14 were open-ended. The multiple-choice questions were designed to make it easier for participants to answer while the open-ended questions were broad and were included to understand participant views or experiences of ageing in their adopted country.

Following the sequence in the questionnaire, the following tables show the responses to each question in both actual numbers and percentages. It starts with documenting responses to Section A of the questionnaire that pertained to demographic information about participants and then tabulates responses to Section B that contained questions relating to aged care.

There were nine males and eight females in the group of 17 participants. The researcher met with three participants in the mosque and the rest in their own homes.

The first question about postcode was aimed at identifying the suburbs that the participants lived in to better understand the geographical concentration or dispersion of older Muslims.

<table>
<thead>
<tr>
<th>Postcode</th>
<th>Number N=17</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>5006</td>
<td>1</td>
<td>5.88</td>
</tr>
<tr>
<td>5038</td>
<td>4</td>
<td>23.52</td>
</tr>
<tr>
<td>5043</td>
<td>5</td>
<td>29.41</td>
</tr>
<tr>
<td>5076</td>
<td>2</td>
<td>11.76</td>
</tr>
<tr>
<td>5113</td>
<td>1</td>
<td>5.88</td>
</tr>
<tr>
<td>5162</td>
<td>2</td>
<td>11.76</td>
</tr>
<tr>
<td>5441</td>
<td>2</td>
<td>11.76</td>
</tr>
</tbody>
</table>

Table 1: Residence Postcodes
Table 2 captures the linguistic background as well as the main language(s) participants spoke at home:

<table>
<thead>
<tr>
<th>Language</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arabic</td>
<td>15</td>
<td>88.20</td>
</tr>
<tr>
<td>Urdu</td>
<td>1</td>
<td>5.88</td>
</tr>
<tr>
<td>Turkish</td>
<td>1</td>
<td>5.88</td>
</tr>
<tr>
<td>Speaks both English and first language</td>
<td>5</td>
<td>29.40</td>
</tr>
</tbody>
</table>

Table 2: Language(s) spoken at home

The high percentage of Arabic-speaking participants reflects the 2011 Census data result that reports Arabic to be the top language spoken in South Australia across all age groups in the Muslim community, as well as the top language spoken by SA Muslims who are 60 and above.

According to the 2011 Census, Australia and Iraq were among the top countries of origin of SA Muslims. Although Pakistan, and not India was among the top ten, however, Indian Muslims generally speak Urdu which is the state language of Pakistan.

Table 3: Country of origin

<table>
<thead>
<tr>
<th>Country of birth</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lebanon</td>
<td>11</td>
<td>64.68</td>
</tr>
<tr>
<td>Iraq</td>
<td>3</td>
<td>17.64</td>
</tr>
<tr>
<td>Turkey</td>
<td>1</td>
<td>5.88</td>
</tr>
<tr>
<td>India</td>
<td>1</td>
<td>5.88</td>
</tr>
<tr>
<td>Australia</td>
<td>1</td>
<td>5.88</td>
</tr>
</tbody>
</table>

As for length of stay in Australia, only one participant was born in this country. The following table shows that 11 participants (64.68 per cent) migrated to Australia when they were young and have been living here since then, working, raising families, and now contemplating ageing in their adopted country. Among the six participants (35.28%) who came in the 70s,
five (29.40%) were from Lebanon; this was a time when a fierce civil war was raging in that country.

<table>
<thead>
<tr>
<th>Year of arrival</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1950s</td>
<td>2</td>
<td>11.76</td>
</tr>
<tr>
<td>1960s</td>
<td>3</td>
<td>17.64</td>
</tr>
<tr>
<td>1970s</td>
<td>6</td>
<td>35.28</td>
</tr>
<tr>
<td>1980s-2010</td>
<td>5</td>
<td>29.40</td>
</tr>
<tr>
<td>Born in Australia</td>
<td>1</td>
<td>5.88</td>
</tr>
</tbody>
</table>

Table 4: Arrival in Australia

As for who they live with, the following table shows that, an overwhelming majority of participants live with only their spouses, not with other family or extended family members. This challenges the oft-made assumption about people from diverse cultures that they have their children or other extended family members living under the same roof and, therefore, will have family carers on hand. Although based on a small sample, the data from Table 4 indicates that there could be a change happening in the Muslim community around household composition. This probable change needs to be studied in future research because it has implications for care design and delivery and carer fatigue as the spouse may need greater carer support.

<table>
<thead>
<tr>
<th>Living with family</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>With spouse</td>
<td>12</td>
<td>70.56</td>
</tr>
<tr>
<td>With unmarried children</td>
<td>2</td>
<td>11.76</td>
</tr>
<tr>
<td>With married children</td>
<td>2</td>
<td>11.76</td>
</tr>
<tr>
<td>With in-laws</td>
<td>1</td>
<td>5.88</td>
</tr>
</tbody>
</table>

Table 5: Household Composition

The Australian Institute of Health and Welfare (AIHW), an independent national statutory agency, refers to those who are aged 65 and over as ‘older’. However, there is no agreed definition of ‘older people’ and Australia’s Aged Care Act does not specify any particular age.
Following the AIHW definition, there were 12 (70.56%) older participants and five (29.40%) younger family members.

<table>
<thead>
<tr>
<th>Age</th>
<th>Number N=17</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>65 and over</td>
<td>12</td>
<td>70.56</td>
</tr>
<tr>
<td>50 - 64</td>
<td>4</td>
<td>23.52</td>
</tr>
<tr>
<td>Under 50</td>
<td>1</td>
<td>5.88</td>
</tr>
</tbody>
</table>

Table 6: Age Cohorts

The following tables capture responses to questions about aged care.

**Q1. How would you feel about wanting to access formal aged care services and why?**

The reasons provided for feeling positively toward formal aged care services (N=10; 58.80%) included their trust in the health care system (see table 7) which they believe does its best to provide good care; they hoped that the aged care system would not be any different. The participants also expressed their confidence that, being a “fair-dinkum country” Australia will have necessary safeguards in place to protect the vulnerable aged. Some accepted the reality of ageing and of care needs becoming greater, together with the inability of a nuclear family to look after them at home. Therefore, they tried to focus on the benefits of formal services.

The negative feelings about aged care stem from unfamiliarity with the system and the belief that paid staff can never replace the loving care that only a family can give. There is a clear expectation of family members to carry out their obligations toward one another. There is also a resigned acceptance of the possible reality of having to accept formal services in the future.

<table>
<thead>
<tr>
<th>Type of Feeling</th>
<th>Number N=17</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear/anxiety</td>
<td>1</td>
<td>5.88</td>
</tr>
<tr>
<td>Uncomfortable</td>
<td>2</td>
<td>11.76</td>
</tr>
<tr>
<td>Not sure</td>
<td>1</td>
<td>5.88</td>
</tr>
<tr>
<td>Okay</td>
<td>3</td>
<td>17.64</td>
</tr>
<tr>
<td>Positive</td>
<td>10</td>
<td>58.80</td>
</tr>
</tbody>
</table>

Table 7: Responses to Q1
Q2. Who would be involved in the decision to access or not to access formal aged care services?

In regards to decision-making, table 8 demonstrates the reliance on one’s spouse. There was option to choose from more than one category and all except one participant wanted to be involved in their own care decisions; this one participant did not want to experience the stress of decision-making. Among the 13 (76.44%) who wanted their spouses to be involved, only three (17.64%) would also like their children to participate in the decision-making but only in case of inability of their spouses. Only one participant, who was in the youngest age cohort wanted to decide for herself and not have anyone else to be involved. It would be useful for researchers to study the extent of prevalence of what is displayed in the data above---that the tradition of joint decision-making among Muslim families may be undergoing a change for those who live in the West and, increasingly joint decision-making is narrowing down to the spouse’s involvement only. It may be important, therefore, for service providers to engage on a continual basis with spouses.

<table>
<thead>
<tr>
<th>Decision maker</th>
<th>Number N=17</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yourself</td>
<td>16</td>
<td>94.08</td>
</tr>
<tr>
<td>Spouse</td>
<td>13</td>
<td>76.44</td>
</tr>
<tr>
<td>Children</td>
<td>3</td>
<td>17.64</td>
</tr>
</tbody>
</table>

Table 8: Responses to Q2.

Q3. How confident are you that accessing formal services would lead to the right level and regularity of care?

The levels of confidence that participants have in regards to formal services are depicted in table 9. It is interesting to compare Tables 7 and 9. A majority of participants were open to accessing formal services as depicted in Table 7 whereas less than half of the participants feels very confident about getting the right level and regularity of care from accessing services, as seen above. Some participants spoke about their fear and anxiety about not being able to afford aged care to the extent that may be needed and, therefore, perhaps having to end up with less.

<table>
<thead>
<tr>
<th>Confidence Level</th>
<th>Number N=17</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>1</td>
<td>5.88</td>
</tr>
<tr>
<td>Not sure</td>
<td>5</td>
<td>29.40</td>
</tr>
<tr>
<td>Somewhat</td>
<td>4</td>
<td>23.52</td>
</tr>
<tr>
<td>Very</td>
<td>7</td>
<td>41.16</td>
</tr>
</tbody>
</table>

Table 9: Responses to Q3
Q4. How important are/could the following services be if receiving home care?

Table 10 demonstrates which services are viewed as important to the participants and which are deemed not so important. They put 1 in the box next to a service to indicate not so important and 10 indicating important. They could use the same number as many times as needed.

Meal preparation, nursing, and house cleaning are the top three priorities. Transport, respite services, garden and home maintenance, podiatry and physiotherapy, shopping, showering and dressing, and social support are services that are not considered very important.

<table>
<thead>
<tr>
<th>Services</th>
<th>Important</th>
<th></th>
<th>Number</th>
<th>Percentage</th>
<th>Not so important</th>
<th></th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=17</td>
<td>Percentage</td>
<td>Number</td>
<td>%</td>
<td>N=17</td>
<td>Percentage</td>
<td></td>
</tr>
<tr>
<td>Meal preparation</td>
<td>15</td>
<td>88.20</td>
<td>2</td>
<td>11.76</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>House cleaning</td>
<td>12</td>
<td>70.56</td>
<td>5</td>
<td>29.40</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shopping</td>
<td>11</td>
<td>64.68</td>
<td>6</td>
<td>35.28</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transport</td>
<td>9</td>
<td>52.92</td>
<td>8</td>
<td>47.04</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Garden &amp; Home maintenance</td>
<td>10</td>
<td>58.80</td>
<td>7</td>
<td>41.16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Showering and dressing</td>
<td>11</td>
<td>64.68</td>
<td>6</td>
<td>35.28</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing</td>
<td>13</td>
<td>76.44</td>
<td>4</td>
<td>23.52</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Podiatry and Physiotherapy</td>
<td>10</td>
<td>58.80</td>
<td>7</td>
<td>41.16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td>11</td>
<td>64.68</td>
<td>6</td>
<td>35.28</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respite services</td>
<td>9</td>
<td>52.92</td>
<td>8</td>
<td>47.04</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 10: Responses to Q4

Q5. If you or your family are unable to cook your meals in the future for an indefinite period of time, what other arrangement would you prefer?

Regarding the supply of meals during times when cooking at home is interrupted for an extended or indefinite period, all except two (11.76%) participants wanted a halal Meals-on-Wheels type service. As this service is currently not available in South Australia, the
participants stressed the importance of someone in the community taking the lead to make it happen. There seems to be a huge reluctance to burden others in their network, such as family, friends, or neighbours as shown in the table below.

<table>
<thead>
<tr>
<th></th>
<th>Number (N=17)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expect others to help</td>
<td>2</td>
<td>11.76</td>
</tr>
<tr>
<td>Halal Meals-on-Wheels-type service (if made available)</td>
<td>15</td>
<td>88.20</td>
</tr>
</tbody>
</table>

Table 11: Responses to Q5

Q6. Given that currently there are no Muslim aged care provider in SA, which provider are you most likely to go to?

Table 12 shows that a clear majority (N=10; 58.80%) prefers to take services from an aged care provider who has a Muslim manager or coordinator to look after and advocate for the interests of Muslims. A high proportion (N=7; 41.16%) is likely to go to a provider that partnered with a Muslim community organisation. These two responses are significant in that they reflect the confidence and trust that comes with having someone from their own religious background in an otherwise alien or unfamiliar space. It also brings to the fore the underlying concerns and stress of having to deal with a system without this vital internal support.

<table>
<thead>
<tr>
<th>Type of provider</th>
<th>Number (N=17)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any provider</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Any provider providing services to Muslims</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>A provider partnering with Muslim organisations</td>
<td>7</td>
<td>41.16</td>
</tr>
<tr>
<td>A provider employing a dedicated Muslim coordinator or manager</td>
<td>10</td>
<td>58.80</td>
</tr>
</tbody>
</table>

Table 12: Responses to Q6

Q7. Preferred Provider Affiliation

As seen in table 13, the number of participants who preferred ethno-specific (N=2; 11.76%) and church affiliated (N=2; 11.76%) providers was equal; so was the number of those for whom provider affiliation did not matter as long proper care was provided. Those who wanted ethno-specific providers cited language barriers as the main reason for their preference. For those who preferred church affiliations, the reason cited was that church affiliated providers would better understand the importance of faith beliefs and practices and would
accommodate those needs. Those who had no problems in using services provided by mainstream/secular organisations were confident that in a secular country, such as Australia, service providers would treat people equally without any discrimination and since freedom to practice one’s own religion is granted to citizens, there should not be any problem. Interestingly, all five participants (29.40%) said in one form or another that when one has chosen to live in a secular country, choosing a secular/mainstream provider should not be an issue at all. One participant opined that a secular provider is preferable to an ethno-specific or church-affiliated provider because there is a risk that the latter two could be prejudiced or biased against a group or community, whereas a secular provider is more likely to be fair to everyone. About 35 per cent (N=6), however, were not sure about what they would prefer. There seems to be a general openness and a positive attitude toward non-Muslim care staff that is reflected again in Table 15.

<table>
<thead>
<tr>
<th>Provider affiliation</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secular/mainstream</td>
<td>5</td>
<td>29.40</td>
</tr>
<tr>
<td>Ethno-specific</td>
<td>2</td>
<td>11.76</td>
</tr>
<tr>
<td>Religious (Christian church-based)</td>
<td>2</td>
<td>11.76</td>
</tr>
<tr>
<td>It does not matter</td>
<td>2</td>
<td>11.76</td>
</tr>
<tr>
<td>Not sure</td>
<td>6</td>
<td>35.28</td>
</tr>
</tbody>
</table>

Table 13: Responses to Q7

**Q8. Importance of having Muslim Care Staff**

Table 14 paints a clear picture of the importance of having Muslim care staff with about 70 per cent (N=12) participants saying it is important to them to be cared for by a fellow Muslim. Although nearly 30 per cent (N=5) said the religious background of care staff did not matter to them, no one checked off the “Not very important” box; this indicates that participants are clear in their views.

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Important</td>
<td>12</td>
<td>70.56</td>
</tr>
<tr>
<td>Not very important</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Does not matter</td>
<td>5</td>
<td>29.40</td>
</tr>
</tbody>
</table>

Table 14: Responses to Q8
Q9. Responses to having non-Muslim care staff

Table 15 provides data on whether it would matter if the care staff was a non-Muslim. The numbers were equally split between those who said that having non-Muslim staff is okay (N=6; 35.28%) and those for whom the non-Muslim background of care staff did not matter (N=6; 35.28%). Those who said that they would prefer not to have non-Muslim care staff were in the minority (N=5; 29.40%). They explained that cultural differences may prevent non-Muslims from “understanding and respecting” the faith beliefs and practices of Muslims, which in turn, may lead to culturally inappropriate service delivery. Those who said it was okay to have non-Muslim care staff were confident that provider organisations would have proper staff training program and that should dispel any worries in this regard. More than one-third of participants said that religious backgrounds of staff should not matter if they knew how to do their job well and received cultural sensitivity training to better equip them to show respect to other cultures and traditions. Some also remarked that staff must be judged on the quality of their work and not on their religious backgrounds. Service providers would do well to reciprocate this goodwill and confirm and reinforce these positive assumptions and attitudes. Through encouraging and facilitating cross-cultural experiences among staff, providers can help make the actual care experiences of Muslim families positive.

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Okay</td>
<td>6</td>
<td>35.28%</td>
</tr>
<tr>
<td>Not okay</td>
<td>5</td>
<td>29.40%</td>
</tr>
<tr>
<td>Would not matter</td>
<td>6</td>
<td>35.28%</td>
</tr>
</tbody>
</table>

Table 15: Responses to Q9

Q10. Services that providers need to offer to Muslims

In response to the question as to what are the three most important things that service providers should consider for Muslims, the responses included the usual menu of services, such as cleaning and personal care. However, the responses also included Muslim-specific service needs such as, halal food. This was mentioned ten times—the highest number of times any service has been listed. The need for Muslim chaplaincy services was mentioned twice and residential care (either a separate wing or a Muslim-friendly environment) was mentioned five times.

Tables 16 and 17 depict the most and the least preferred sources of information (Table 16) and advice (Table 17) about aged care. On the questionnaire, 1 indicated the least likely and 5 indicated the most likely source to go to. Participants could choose any number from 1 to 5 on the rating scale more than once. Both tables show a clear preference for trusting family
members for reliable information and advice. In a collectivistic culture that most Muslims belong to, this is a natural tendency. The Internet fared the least well.

Q11a. Preferred source of information about aged care

It is important to note that although no one gave the Muslim community organisations the lowest rating of 1 on the scale as seen in table 16, these organisations received a low of 2 given by 76.44 per cent of participants and a 4 by 11.76 per cent. Imams received a 4 given by 17.64 per cent of participants. Friends, relatives, and neighbours were given a 4 by 52.92 per cent of participants and although GPs were given that rating by less than 30 per cent, the results signify that after family, it is GPs and friends, relatives, and neighbours that people trust the most for information. The implication for provider organisations is that these groups of trusted individuals need to be engaged with.

<table>
<thead>
<tr>
<th>Source</th>
<th>Number N=17</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Most likely</td>
<td>Least likely</td>
</tr>
<tr>
<td>Family</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>GP</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Friends, relatives, or neighbours</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Imam</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Muslim community organisations</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Internet</td>
<td>2</td>
<td>13</td>
</tr>
</tbody>
</table>

Table 16: Responses to Q11a

Q11b. Preferred source of advice about aged care

Interestingly, a higher proportion—4 out of 17 (23.52%)-- gave a rating of 5 to Imams as opposed to only 2 out of 17 (11.76%)—half that of Imams’—giving it to GPs (see table 17). GPs were rated 4 by five (29.40%) whereas three (17.64%) felt the same about Imams. Seven (41.16%) participants gave GPs a low rating of 2 as opposed to only one (5.88%) who gave the same rating to the Imam. Five participants (29.40%) gave a low rating of 2 to Muslim community organisations. In contrast seven (41.16%) rated these organisations 4. This

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31 In this table, only figures for the highest and the lowest rating (Most likely=5; Least likely=1) are given. Figures for ratings 2—4 are used in the text but not in the table.
32 In this table, only figures for the highest and the lowest rating (Most likely=5; Least likely=1) are given. Figures for ratings 2—4 are used in the text but not in the table.
contrasts with the 2 (11.76%) who rated Muslim community organisations the same in regards to preferred source of information as seen in table 16.

The combined result tables 16 and 17 show that Imams and community organisations are respected and trusted sources when it comes to advice on aged care services but less so when seeking information. The implication for service providers is to involve Imams and community organisations in co-designing services and during key stages of partnerships.

Questions 12 – 14 were open-ended questions

Q12. Challenges of ageing in Australia today

The key themes emerging from the responses in regards to the challenges of ageing in Australia today were:

- Concerns about lack of understanding and respect for the community, and the culture and needs of Muslims
- Concerns about providers not understanding the critical importance of faith in daily routines of Muslims
- Absence of Muslim aged care providers
- Lack of culturally appropriate day care centres
- Individual-specific challenges such as limited social network, language barrier
- Likelihood of family becoming unable to be, or continue as, carers
- Complexity of the Australian aged care system and challenges of navigation
- Affordability issues

Consideration of access and equity issues would require service providers to address as many of the above concerns as possible. This would go a long way toward improving uptake of services by the Muslim community and providing them with a culturally safe environment.

Q13. Comparison of the benefits of ageing in Australia

Responses to question 13 paint a comparative picture of the benefits of ageing in Australia as viewed by the participants when compared to ageing in their countries of origin. The key themes to emerge were:

- Safety, security, freedom, and dignity of individuals are protected in Australia.
- Australia is safe, peaceful, and fair.
- In Australia, systems are in place to look after the vulnerable, including the aged; this brings peace and comfort to the twilight years of one’s life.
- Services to cater to people’s various healthcare needs are available in Australia; availability of disability services is a lifeline.
- Services are reliable in Australia.
Australia encourages and provides everyone, including older people, with needed support to live an active life.

Overall, there was a deep sense of gratitude and appreciation among the participants for the support and services Australia makes available to its citizens which stands out in stark contrast to the total absence or poor quality of available services in their home countries. There was, however, one participant who mentioned that his home country offers free health and aged care to pensioners that is not available in Australia.

Q14. How personal views and ideas about aged care have changed over the years

The final question, question 14 sought to look at, why, and how personal views and ideas about aged care have changed over the years. The two main themes that emerged were:

1. Reduced negative feelings overtime toward aged care due to access and exposure and,
2. The persistent fear and anxiety about life in residential facilities.

The more familiar participants became with the aged care system, the more comfortable they have felt. Nonetheless, there was a strong desire and hope to be looked after at home by family, yet tempered by the harsh reality that in the fast-paced society with young people juggling careers and families, children may not always be available in carer roles. There was acknowledgment of the responsibility of the community to understand the system, engage with key agents of service design and delivery, and advocate for Muslim aged care needs.
6. Discussion

It has been deemed worthwhile to include in this report a discussion of the experiences and challenges that the researcher faced in undertaking this research with the Muslim community in South Australia.

Muslim communities have, by and large, been seen to be inward-looking, and the Muslim community in South Australia seems to be no exception. This further exacerbates engagement with external agencies. Depending on exposure, integration and acculturation levels, the Muslim community are at different points on the research engagement and participation continuum. Compared to most other states in Australia, the South Australian Muslim community is relatively smaller. It is also young and has more recent migrants than established families; most of the established families are Arabic-speaking. An overwhelming number of people leading most community organisations are from an Arab background. All these have been influential factors affecting the survey sample size and composition.

Initially, there were suspicions about the research project because of some the community members’ past experiences with government authorities/agencies in their adopted and/or home countries, experiences of war and conflict back home, migration experiences, and concerns with government-funded support being affected through information that is given by them for the research. A small number of participants were anxious about signing the Consent Forms. Many were of the view that the research would have added value if it were conducted for setting up aged care services that would be owned and operated by the community. Participants were curious to know how the research findings would influence non-Muslim providers to modify or expand their service repertoire to include Muslim-specific services and deliver them in a culturally appropriate manner. Some participants felt that if this did not happen then this research would be of little consequence.

Any research or its findings would be of less or no relevance for the community when community priorities do not determine research agenda. For the same reason, the research experience will be less highly valued by the community or not valued at all. If community research is done and there is no subsequent service differentiation, then establishing credibility in the community would become difficult.

The challenge of this research project has been the apathy and disinterest of the Muslim community—the participants as well as key people. Some of the barriers to participant recruitment were anticipated, other barriers were not. Appreciating the value of social research and understanding the connection between research and actual aged care services seemed to be missing among most participants and key community figures. It was inordinately difficult to get participants to commit for a serious session of questionnaire survey. Some participants did not appear very eager to participate. They could not be motivated enough even with immediate tangible benefits of participation, such as
refreshments, gift vouchers, and the enormous flexibility provided in terms of meeting time and place. While the researcher was unable to explore it further, anecdotal evidence suggests that possible reasons could be the inexperience of the community with social research, the generally inward-looking attitude of the community, not seeing a direct or immediate benefit of the research for the community, seeing no relevance for this research as the Muslim aged care project (under which this research was being conducted) had already started, or no urgent need for the participants to receive aged care.

The insider/outsider debate referred to in Chapter 2 has relevance for this research. In her interactions with participants, the researcher mostly felt like an insider. However, despite sharing the same religious identity as the key figures in the community, most of the times the researcher (a female) was more of an outsider in terms of influencing the key figures to acknowledge the research priorities. This was unanticipated and occurred in subtle ways. This ‘positionality’ issue was perhaps because the researcher was neither from the main ethnic or linguistic group nor was she directly associated with any Muslim community organisations. The proximity or distance from community power base as measured by how closely one is, or is perceived to be, associated with community organisations or leaders may have had substantial impact upon the research process resulting in a high degree of dependence on community organisations and leaders for creating the right narrative for participants to be motivated to participate.

There is a noticeable apathy by key figures to seriously address ageing issues or aged care options as aged care is still seen as a family responsibility, not a community responsibility. At this stage, it appears that the aged care needs of the Muslim community are not the top priority for most of the Muslim community organisations.
The study demonstrated that family members are the most reliable and preferred source of information and advice. Spouses are regarded as a constant and trusted support in old age. The general anxiety around aged care seems to lessen with awareness and access to information; however, concerns about the unavailability of culturally appropriate aged care services persist. Culturally competent aged care staff is regarded as essential to providing culturally appropriate services.

The Muslim community is very diverse and ethnic and linguistic backgrounds may become powerful identifiers that may determine or, at least, influence the insider/outsider status of the researcher.

Support and cooperation of key people in the community is critical. Their active participation or lack of it in recruitment of participants either aids or hinders the process of getting the right number and mix of participants. The key people must be able to understand the value of aged care research.

If community needs and preferences drive the research agenda, it is likely to be supported by those who may be affected by the results; the community would also like to see benefits flowing from research.

The results of this research study suggest that both aged care providers and Muslim community organisations should develop meaningful community engagement to better understand community needs, concerns, and aspirations in regards to care needs of Muslim families and to involve them in planning and designing services. The study also suggests that, to improve outcomes for the community it is important for the provider organisation to analyse the demographics of the target community and conduct a needs assessment prior to embarking on any project. A needs assessment is a sine qua non for strategic decisions around setting up services.

Even though a small step, the involvement of Muslim older persons and their families in this research would hopefully encourage more such participation of the community in the future.

It has been acknowledged earlier in the report that owing to the small sample size, no definite conclusions can be drawn or generalizations made. However, the research outcome and data analyses have provided tentative insights that may give helpful suggestions for service providers. Some key lessons learnt from this study may also benefit future researchers.
The recommendations for service providers are:

- Understand and respect the importance of religion and cultural traditions while designing and delivering services.
- Be conscious of diversity within diversity. Stereotypes must be avoided; assumptions need to be tested.
- Build relationship with the community and not just partnership with community organisations.
- Know about the demographics and needs and preferences of the community; a needs assessment study would be very useful before planning services.
- Consider innovative ways of addressing needs that may be complex or appear to be ‘too different’ or ‘hard’.
- Ensure availability of halal food.
- Forge partnership with those who your clients trust the most.
- Recruit people from diverse backgrounds to match, where needed, clients and staff.
- Provide cross-cultural training to your staff, especially those who are in customer-facing roles.
- Provide a culturally safe environment to minority groups to break down barriers and build trust and confidence in the aged care system.

The recommendations for future research are:

- Getting access to participants can be very challenging not only in terms of numbers but also in terms of the level of their engagement; therefore, time and patience would be critical.
- Key figures in the community are powerful influencers; therefore, gaining the support of, and working closely with, community leaders is essential.
- Unless the community perceives a pressing need or an immediate benefit, they may not be interested in topics or activities that may have only research value.
- Both the research design and the researcher need to be flexible.
- Time is not a scarce commodity in the community; time is viewed as cyclic and not linear. This affects the research timeline.
Appendices
Appendix I: Letter of Invitation

Date:

Dear Brother/Sister in Islam,

Assalaamu alaykum.

On behalf of the Muslim Communities Project, I would like to invite you to take part in a research on Muslim aged care, the first of its kind in South Australia.

The Muslim Communities Project is a partnership between ACH Group—an aged care service provider, and two Muslim community organisations: the Islamic Society of South Australia and the Islamic Arabic Centre. Alhamdulillah, under this Project we have already started to provide support to our elderly.

We invite you to participate in the questionnaire survey because we believe that your views and preferences in regards to the care that you would want for yourselves or a family member (elderly parents or other relatives) would add immense value to the way we design and deliver services to achieve the best outcomes for our community.

Jazak Allah Khair! May Allah Azzawajaal reward you and your family. Ameen!

Mahjabeen Ahmad
Project Manager, Muslim Communities Project
22 Henley Beach Road Mile End SA 5031
PO Box 646 Torrensville Plaza, Torrensville SA 5031
T 08 8159 3600
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DESIGNING AGED CARE FOR MUSLIMS IN SOUTH AUSTRALIA: AN EXPLORATORY STUDY

RESEARCH STUDY--PLAIN LANGUAGE STATEMENT
Research Study – Plain Language Statement

**Research Project Title:** Designing Aged Care for Muslims in South Australia: An Exploratory Study  
**Researcher:** Mahjabeen Ahmad, ACH Group; Email: mahmad@ach.org.au  
**Consultant:** Dr David Radford, University of South Australia; Email: david.radford@unisa.edu.au

1. Your Consent

You are invited to take part in this research project. This Plain Language Statement contains detailed information about the research project. Its purpose is to explain to you as openly and as clearly as possible your role in this project before you decide whether to take part in it. You do not have to take part and there will be no consequences if you choose not to. Please read this Plain Language Statement carefully.

Once you understand what the research project is about and if you agree to take part in it, you will be asked to sign the Consent Form. You will be given a copy of both the Consent Form and this Plain Language Statement for your records.

By signing the Consent Form, you are acknowledging that you understand the information outlined in this Plain Language Statement, that you give your consent to participate in this research project, and that you agree to the information/data collected to be used for purposes of the research as described in section 3 below.

You will receive a thank-you card and an ACH Group gift voucher as tokens of appreciation for your participation.

2. Background

The ACH Group (Aged Care and Housing Group) is a not-for-profit organisation that has been providing aged care services to people in South Australia and Victoria since 1952.

The ACH Group has partnered with the Islamic Society of South Australia (this Society runs the Marion Mosque and the Wandana Mosque) and the Islamic Arabic Centre (this Centre runs the Al-Khalil Mosque) to provide aged care services to Muslims in South Australia. The Muslim Communities Project was launched in June 2015 under Federal Government funding.

3. Research Purpose

The research will be the first of its kind in South Australia with the potential of informing policy makers, decision-makers, service providers, the community, and other stakeholders in the design and delivery of appropriate services. The objective of this research project is to gain an understanding of the aged care needs and concerns of Muslim communities in South Australia to better design and deliver services based on what is important to them. It will also help ACH Group to apply the results of the present study in the design and delivery of appropriate services for other CALD communities.
The research team will explore opportunities to expand and develop this study for a future university-led research project and subsequent possible publication of the research in an academic peer-reviewed journal.

Your views and suggestions are valuable; we hope that your active participation in the research will result in better, safer, and more appropriate aged care services for the Muslim community.

4. Research Method
You will be asked to fill out a set of simple questions that will help the researcher understand your views and concerns about aged care services. It will include some general questions as well, such as your gender, the country of your birth, the language that you speak at home, and so on. The questionnaire will be anonymous - it will not ask for your name.

5. Confidentiality and Disclosure of Information
All the information gathered by the researcher during this research will be treated as strictly confidential. The information will only be used for the purposes for which the research is being undertaken as stated in Section 3 above. Your responses will remain anonymous as no names will be mentioned in the research report. No identifying data or information will be released to anyone except if required by law.

There are no right or wrong answers to the questionnaire. We want to hear many different viewpoints and would like to hear from everyone. We hope you will freely express your views.

6. Participation is Voluntary
Your participation in the research is voluntary. If you do not wish to take part, you are not obliged to do so. If you decide to take part and later change your mind, you are free to withdraw at any stage. You will not be penalised in any way if you decide to withdraw from the research; you will only be asked to fill out the Withdrawal Form.

Before you make your decision to participate or withdraw, you can ask the researcher any related question you may have about the research project. You can also ask for any related information. Only sign the Consent Form once you have had a chance to ask your questions and have received satisfactory answers.

7. Cost for participation
There is no cost for you what so ever for being part of this research. You are also not liable for any cost associated with this project.

8. Results of Research Project
All the participants will be informed in writing about the results of the research after the research project is complete.
9. Further Information or Any Problems
If you require further information or have any problems concerning this research project, you can contact the principal researcher. The researcher primarily responsible for this project is:

Name: Mahjabeen Ahmad, Project Manager, ACH Group
Phone Number: 08 81593600
E-mail: mahmad@ach.org.au

10. Ethical guidelines
This research will be conducted following the National Statement on Ethical Conduct in Human Research (updated May 2015) guidelines.

11. Other Issues
Should you have any concern about the conduct of this research project, please contact:
Chair, Clinical Governance Committee, ACH Group
22 Henley Beach Rd, Mile End, SA 5031
PO Box 646 Torrensville Plaza, Torrensville SA 5031
Tel 8159 3600
DESIGNING AGED CARE FOR MUSLIMS IN SOUTH AUSTRALIA: AN EXPLORATORY STUDY

RESEARCH STUDY—CONSENT FORM
Research Study – Consent Form

**Research Project Title:** Designing Aged Care for Muslims in South Australia: An Exploratory Study  
**Researcher:** Mahjabeen Ahmad, ACH Group; Email: mahmad@ach.org.au  
**Consultant:** Dr David Radford, University of South Australia; Email: david.radford@unisa.edu.au

- I ……………………….  
  - (Full name)
- Being over 18 years of age hereby consent to participate in the questionnaire survey/ group discussion/ interview/ forum discussion as part of the research conducted by ACH Group under its Muslim Communities Project.
- I have read and understood the attached Plain Language Statement outlining the nature and purpose of the research study.
- I have discussed my participation in this study with the researcher named below. I have had the opportunity to ask questions and I am satisfied with the answers I have received.
- I have been informed about possible risks, if any, of taking part in this study.
- I have understood that all the information gathered by the researcher in conducting this research will be treated as confidential.
- I acknowledge that the research data gathered for the study and my quotes may be published provided identifying information is not disclosed.
- I freely consent to participating in the research project as described in the Plain Language Statement.
- I understand that my participation is voluntary and that I am free to withdraw at any time during the study.

__________________________________________________________________________________________  
Name of Participant  
Signature of Participant  
Date

__________________________________________________________________________________________  
Name of Researcher  
Signature of Researcher  
Date
If the participants have any complaint regarding the way the research project is conducted, it should be directed to:

Chair, Clinical Governance Committee

ACH Group

22 Henley Beach Rd

Mile End, SA 5031

PO Box 646 Torrensville Plaza, Torrensville SA 5031.

Tel 8159 3600

(Note: All parties signing the consent section must date their own signature.)
Appendix IV: Withdrawal Form

DESIGNING AGED CARE FOR MUSLIMS IN SOUTH AUSTRALIA: AN EXPLORATORY STUDY

RESEARCH STUDY—WITHDRAWAL FORM
Research Study – Consent Form

**Research Project Title:** Designing Aged Care for Muslims in South Australia: An Exploratory Study

**Researcher:** Mahjabeen Ahmad, ACH Group; Email: mahmad@ach.org.au

**Consultant:** Dr David Radford, University of South Australia; Email: david.radford@unisa.edu.au

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**Declaration by Participant**

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my current or future aged care services or my relationships with the researcher or the organisation.

__________________________  ___________________________  ________________
Name of Participant    Signature of Participant    Date

__________________________  ___________________________  ________________
Name of Researcher    Signature of Researcher    Date

In the event that the participant’s decision to withdraw is communicated verbally, the researcher must provide a description of the circumstances below.

..............................................................................................................................
..............................................................................................................................
..............................................................................................................................
..............................................................................................................................
..............................................................................................................................

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**Declaration by Researcher**

I have given a verbal explanation of any implications of withdrawal from the research project and I believe that the participant has understood that explanation.

__________________________  ___________________________  ________________
Name of Researcher    Signature of Researcher    Date
Appendix V: Questionnaire

QUESTIONNAIRE

SUPPORT FOR OLDER MUSLIMS

Location: Mosque ☐ Home ☐

Who participated? Relationship legend:

- Father F ☐ Mother M ☐ Father-in-law FIL ☐ Mother-in-law MIL ☐
- Son S ☐ Daughter D ☐ Son-in-law SIL ☐ Daughter-in-law DIL ☐
- Sister SiS ☐ Brother B ☐ Grandson GS ☐ Granddaughter GD ☐
- Husband H ☐ Wife W ☐ Others O ☐

SECTION A

1. Your postcode: ☐

2. Major language(s) you speak at home:

3. Your country of birth:

4. Year of your arrival in Australia:

5. You: live alone ☐ with family ☐

6. Your age: 65 and over ☐

   50---64 ☐

   Under 50 ☐
SECTION B

1. How would you feel about wanting to access formal aged care services and why?
   - Fear/anxiety
   - Uncomfortable
   - Not sure
   - Okay
   - Positive

2. Who would be involved in the decision to access or not to access formal aged care services? You may check more than one box if applicable.
   - Yourself
   - Your family member (s) (please specify)
   - Others (please specify)

3. How confident are you that accessing formal services would lead to the right level and regularity of care? Please indicate the level of your confidence on a scale of 0 to 4 by circling the applicable number below with 0 signifying no confidence at all and 4 indicating very high level of confidence.
   - 0 Not at all
   - 1 A little
   - 2 Not sure
   - 3 Somewhat
   - 4 Very

4. Please consider the current and the foreseeable future and rank the following services according to how important these are/would be for you or a family member if receiving care at home from a service provider. Please use numbers 10 to indicate ‘important’ and 1 to indicate ‘not so important’.

<table>
<thead>
<tr>
<th>Meal preparation</th>
<th>Showering and dressing</th>
</tr>
</thead>
<tbody>
<tr>
<td>House cleaning</td>
<td>Nursing</td>
</tr>
<tr>
<td>Shopping</td>
<td>Podiatry and Physiotherapy</td>
</tr>
<tr>
<td>Transport</td>
<td>Social support</td>
</tr>
<tr>
<td>Garden and Home maintenance</td>
<td>Respite services</td>
</tr>
</tbody>
</table>
5. If you or your family are unable to cook your meals in the future for an indefinite period of time, you would:

- Expect your relatives, friends, and neighbours to supply you with meals
- Prefer to buy from halal Meals on Wheels-type service, if available

Any other option please explain:

6. Given that currently there are no Muslim aged care provider in SA, which provider are you most likely to go to?

- Any provider who can provide you with services you need
- Any provider who are providing services to other Muslims in SA
- A provider partnering with a Muslim organisation (a mosque, a community organisation)
- A provider that has a Muslim coordinator or manager who looks after the interests of Muslim customers

7. Which type of provider would you prefer the most?

- Secular/mainstream
- Ethno-specific
- Religious (non-Muslim)
- It does not matter
- Not sure

Can you please explain your answer?

8. How important is it for you/your family member to have a Muslim care worker?
Important □
Not very important □
does not matter □

9. How would you feel if the care worker is a non-Muslim?

Okay □
Not okay □
Would not matter □

Can you please explain why?

10. Please list three things in order of importance that you think service providers need to offer older Muslims:

1.
2.
3.

11. Where or who are you likely to go to for information and advice on aged care services? With 1 indicating least likely and 5 indicating most likely, please rank the following. You may use the same number more than once, if applicable.

a. For information:

   Family □
   You're GP □
   Friends, relatives, or neighbours □
   Imam □
   A Muslim community organisation □
   Internet □
b. For advice:

- Family
- Your GP
- Friends, relatives, or neighbours
- Imam
- A Muslim community organisation
- Internet

12. What are the challenges of ageing in Australia for a Muslim?

13. What are the benefits of ageing here compared to your country of origin?

14. Have your ideas about aged care changed over the years? If so, how and why?

THANK YOU!