The Muslim Council of Britain

ELDERLY & END OF LIFE CARE

For Muslims in the UK

HEALTH GAPS

CARE NEEDS

POPULATION FORECASTS

VALUES

A publication produced by the Muslim Council of Britain's Research & Documentation Committee in collaboration with the Centre of Islamic Studies at the University of Cambridge.

UNIVERSITY OF CAMBRIDGE

HRH Prince Alwaleed Bin Talal Centre of Islamic Studies

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FOREWORD

In 2015, the Muslim Council of Britain published *British Muslims in Numbers, A Demographic, Socio-economic and Health profile of Muslims in Britain* drawing on the 2011 Census of England and Wales. Among the issues it highlighted was the need for elderly care planning in the decades to follow. In this follow-up work, the MCB is delighted to have collaborated with the Centre of Islamic Studies at the University of Cambridge, and benefit from the expertise of Dr Mehrunisha Suleman, its research and outreach associate.

This report seeks to bring together in one document many different aspects relating to elderly and end of life care, with an emphasis on facts and evidence. It records what the elderly, carers and health professionals have to say, and also outlines the statutory responsibilities of public bodies. It seeks to convey the guiding religious values so important in the family setting. A theme in this report is the urgency of collaboration between the public bodies and faith-based organisations as the elderly population increases in the decades ahead.

The MCB is now entering its third decade since it was founded as an umbrella body representing mosques, Islamic centres and other institutions within Muslim civil society. From the outset, the purpose of its Research & Documentation Committee (ReDoc) has been to provide an informed basis for policy development. ReDoc would regard this study as a modest starting point and it welcomes feedback and comments from stakeholders committed to work together in addressing a pressing social concern.

Harun Rashid Khan
Secretary General

MESSAGE

Providing dignity and care in old age should be a fundamental right, transcending party politics and campaign slogans. This report by the Muslim Council of Britain and the University of Cambridge is timely and the first of its kind for the British Muslim community. Providing health and social care services which meet the needs of all communities in the UK should be a priority for any Government.

Social care services are in crisis with high levels of unmet need, and cuts to council budgets have a great impact on the most vulnerable in our communities. On top of this, health inequalities are widening. There have often been barriers to accessing health services for BAME communities, and this report shows there is a stark difference in health between older Muslim women and the general population.

It is therefore pertinent to see this new contribution to the evidence around health inequalities, access to services, and end of life care for Muslims in the UK. It shows the need for cultural and religious sensitivity in developing policy and is a reminder of the need to ensure our health and care services are appropriately tailored to the people they support. From ensuring end of life care is sensitive to religious beliefs, to ensuring translation services are available for those who use social care, we need to improve services to ensure they are accessible to everyone who needs them.

A Labour Government will build a National Care Service that works for all communities. We will ensure that care services provide community-based, person-centred, support which treats people needing care with dignity and respect.

Barbara Keeley MP
Shadow Minister for Mental Health and Social Care

EXECUTIVE SUMMARY

FAITH

- It is now almost two decades since the Marmot Review identified the reduction of health inequalities a matter of fairness and social justice.[1] The 2011 Census indicates that while in the younger age bands the self-declared health profile of the Muslim population was similar to the population as a whole, this is not the case for older Muslims particularly women aged 65 and above, with a much higher proportion of self-declared bad or very bad health (38% for these Muslim women, compared to 16% for all women in England). These inequalities are confirmed by the 2018 GP Patient Survey. Those at the helm of health policy-making need to take up the challenge of ensuring equity for all sections of society, including the Muslim population.

- The evidence indicates that there are issues common to the elderly in society generally – loneliness and isolation, the efforts of families for their near and dear, the impact of cuts in services; others are specific to Muslims, such as the lower priority generally within mosques and community centres to engage with the elderly and offer facilities.

- There are wide variations in the extent to which local authorities respond to faith needs of Muslim elderly – for example, the provision of halal meals in care homes; taking a carer's gender into account in the allocation of domiciliary care; provision of transport to attend Friday prayers. There is need for a more comprehensive survey and research to explain these variations where they fall within the orbit of statutory responsibilities and Public Sector Equality Duty.

HEALTH

- There are mosques and voluntary associations within Muslim civil society with a track record of collaboration with the health authorities and specialist agencies to disseminate wellbeing and care information. Policy makers need to engage with them to develop and deepen co-working and partnerships.

- Care commissioners and Care & Support planners should consider the Muslim elderly's responses to the GP Patient Survey relating to mental health: while for the elderly population as a whole in the survey sample, only 8% felt that the healthcare professional had not recognized or understood any of their mental health needs, for Muslims it was 19%. Further work is needed to address this variation, which could include involvement of mosques and community centres to raise the subject of mental health and encourage access to appropriate services.

- Local authorities can also conduct an audit to see whether the allocation of care and support plans reflect the diversity of the population.

- Evidence suggests there is a schism between the current model of end of life care and the health needs of religious and ethnic communities. Such evidence includes reports that point to an unmet need, amongst Muslims, of end of life care. This is reflected in poor uptake of advanced care planning and hospice services, including community-based services and on-site care.

CARE

- In terms of end of life care needs within the Muslim community, although hospices and palliative care services are recognising the specific needs of faith, there is scope for extending religious and cultural literacy amongst professionals. There is also potential to harness families' commitment to caring for their loved ones at home at the end of life. Muslim families' faith and cultural values mean that many may choose to care for loved ones who are terminally ill at home. Palliative and end of life care (P&EOLC) services need to better understand how these preferences can be recognised and supported. With scarce healthcare resources, ensuring that families are able to support care alongside healthcare staff may be a means of optimising available resources for patients.

- The findings also emphasise the need for a culture change, led by imams and mosque leadership, to raise issues of death and dying that can increase awareness of P&EOLC services and help counter the cultural stigma in accessing of services. There is also a need for service redesign through "community-based chaplaincy" such that Muslim patients and families can better access P&EOLC services through "trusted people and trusted spaces".

- In keeping with a trend in the wider British population, the number of elderly Muslims is set to increase in the coming decades. While in 2011, 4% of the Muslim population was aged 65 and above, by 2036 it is estimated that this will rise to 10%. In numerical terms this is an increase from around 110,000 to over 450,000. It is a step change requiring forward planning and investment now from the public services and Muslim civil society to address these demographic shifts in the UK population. **It is a 'wakeup' call for Muslim civil society – including its social entrepreneurs, charities, philanthropists – to begin preparing for these circumstances: firstly, influencing mainstream state provision so that it is appreciative of religious values in wellbeing and care, and secondly preparing for faith community specific initiatives that complement or add value to the state provisions, but require capital and infrastructure.** The case is not being made for a 'Muslim care network' to parallel that of the State. Rather, it entails developing professionalism for co-production and collaboration, though there is also a need to explore and develop a range of choices to Muslim elderly and their families. The estimates inform collective community endeavours planning for the future, for example schemes to promote employment in the domiciliary care sector, carer and care home demand, nursing care demand and cemetery demand.

- The faith traditions provide the lodestones for respect and care of the elderly. To a greater or lesser extent, attitudes and conduct are shaped by these values, and will influence interactions and expectations in dealings with care providers and health care professionals.

Endnote

1. Fair Society, Healthy Lives. 2010. *The Marmot Review.* http://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review

INTRODUCTION

BACKGROUND, APPROACH, STRUCTURE OF REPORT

The MCB report *British Muslims in Numbers* (2015) presented the demographic, socio-economic and health profile of Muslims based on the 2011 Census of England and Wales.[1] It highlighted the age distribution, with larger numbers at the base of an 'age pyramid'. Attention was also drawn to features such as poverty and deprivation, with almost half of the Muslim population of England living in the 10 most deprived local authority districts. The report also highlighted health inequalities including a much higher proportion of Muslim women aged 65 and over with self-declared poor or bad health, compared with the rest of the population.

This follow-up report draws together into one accessible document themes relating to elderly care, end of life care and after-death considerations. It seeks to present a Muslim voice in the health and social care policy discussions. It offers evidence of needs and experiences collated through interviews, focus groups and meetings, as well as offering population forecasts of Muslim elderly and their health status.

The aim of this report is to provide a framework for discussion at five levels:

- Policy makers in the health and social care services, who have a duty to implement statutory regulations and the Public Sector Equality Duty
- Elected representatives (councillors, MPs), who have to muster the political will to ensure equity at various fronts, including health and housing; representatives of faith and ethnic communities on health boards governing the provisioning and commissioning of local services
- Managers in health and social care services, who can promote programmes for increasing religious literacy
- Mosques and community centres, in their role both as influencers of attitudes and lifestyles, and partners in joint-work with health and social care services
- Networks of professionals, to be mobilised for specific follow-up work from this report: exploring sustainable care home options; examining issues of financial inclusion/exclusion and pension provisioning; population modelling; raising awareness (e.g. via information leaflets) on key terms and formal processes faced in end of life and after-death situations.

The evidence base presented in this report is drawn from several sources. Firstly, an MCB study comprising on interviews, focus groups and interactions with the elderly, carers, imams and community workers; secondly, reports of community projects and some of the published literature; thirdly, analyses from the 2011 Census and the 2018 GP Patient Survey. The inclusion of end of life and palliative care findings has been possible because of the contribution from Palliative and End of Life Care (P&EOLC) research project of the Centre of Islamic Studies, University of Cambridge. The data sets of the MCB and the Centre's have some overlaps and there are differences in analysis, but a joint presentation is warranted given the continuum in the nature of the needs and also the shared underlying statistical data. The involvement of the Centre of Islamic Studies at Cambridge is also a pilot venture for the MCB, and a welcome collaboration of a grassroots-based community organisation with a leading academic institution.

From the MCB perspective, this report is a first-step in addressing the many-layered and complex issues in the field of elderly care, end of life care and after-death considerations.

In the scope of this report, 'elderly' is considered aged 65 years and above. This can be contested, but a criterion was needed. A recent study has noted, albeit wryly:

> *"What it means to be 65 has changed utterly. In the 1950s, a 65-year-old woman in Britain could expect to live a further 14 years. Today, according to the UK's Office for National Statistics, the average 65-year-old woman can look forward a further 23.4 years. Yet 65 is now the age at which many institutions impose a concept of old age upon their citizens . . . And '65+' is often the maximum age bracket cited in questionnaires, with no other boxes to tick – as if it's the beginning of the end."*
> *– Camilla Cavendish, 10 Lessons in an Ageing World.*[2]

The forecasts of Muslim elderly and likely health categories are derived from the population projection of the Office for National Statistics (ONS). The forecasting horizon selected is just short of two decades from now. The choice of 2036 has been determined by the ONS's base point for 100-year population modelling, 2016. The seventeen years duration from now (2019) is perhaps appropriate for mobilisation of efforts and delivery of solutions in the scale required, whether in the public or private sectors.

A theme in this report is the potential of partnership work between the health and social care authorities and faith-based organisations. The MCB and many of its affiliates already have a track-record in this, but there is scope for developing this further. This is now a well-accepted view, endorsed for example, recently by the Bishop of London in her comments on the role of Church-based projects, "The NHS is under considerable pressure; increasing public expectation, increasing life expectancy, improvements in technology and limited resources. If we are able to improve our health and the health of the community, we can contribute to the better use of those limited resources".[3] The Bishop's call for a joined-up approach involving faith-based organisations is particularly important when we are faced with the cuts in public services and its impact on vulnerable groups and our ageing population. Britain has a rich tradition of faith-based community services, and the experiences of Church projects, for example, to improve the quality of life of those with dementia, or innovative Jewish elderly care residential options, offer excellent models and an opportunity for knowledge exchange and sharing of good practice.[4]

This report is in six parts:

I Findings on the health profile of the Muslim population from the decennial Census (2011) and the GP Patient Survey (2018).

II Findings on elderly care needs as collated by the MCB through interviews, focus groups and meetings; an assessment of the limitations in the delivery of services and possible responses. The role of faith-based organisations is highlighted with references to existing projects and initiatives, and supporting statements from published sources. Factors affecting Muslim elderly care are identified, such as changes to family living arrangements, pressures on the family unit as caregivers, access to services, religious literacy in primary care settings and the impact of poverty in retirement.

III Findings on palliative and end of life care needs by research at the Centre of Islamic Studies, University of Cambridge; three key themes are identified and suggestions made for improved service delivery, requiring action both within health professional circles and Muslim civil society.

IV Forecasts on the likely demand for elderly care, including nursing care, in 2036.

V Brief definitions and clarification of terminology, issues and processes e.g. LPOA, DNR, relating to end of life and after-death considerations, presented in the form of FAQs

VI Action points emerging from this study requiring the attention of various stakeholders; recommendations for further research and possible work streams facilitated by the MCB with support of its affiliate network; extracts from the sacred texts of Islam and other faith traditions, highlighting the common ground on matters relating to families, care of the vulnerable and elderly and views on ageing; to a greater or lesser extent, attitudes and conduct are shaped by these values, and will influence interactions and expectations in dealings with care providers and health care professionals.

The appendices are mainly data tables. Further detail on the approach and methodologies of the MCB and P&EOLC project is provided in Appendix A; the forecasting method is described in Appendix D.

Endnotes

1. The Muslim Council of Britain. 2015. British Muslims in Numbers - A Demographic, Socio-economic and Health profile of Muslims in Britain drawing on the 2011 Census. https://mcb.org.uk/report/british-muslims-in-numbers/

2. Cavendish, Camilla. 2019. Lessons for an Ageing World - Extra Time. London: HarperCollins. The author was formerly head of the Downing Street Policy Unit.

3. The Cinnamon Network. 2018. The Church's impact on health and care. http://www.cinnamonnetwork.co.uk/wp-content/uploads/2018/05/31513-Cinnamon-Health-Research-16pp-A5-FINAL-AW_hr.pdf

4. A church project to combat loneliness with elderly with dementia is described in the Cinnamon Network's report, ibid. The MCB is grateful to the management of Jewish Care for a site visit at the Maurice and Vivienne Wohl Campus in London, April 2017.

PART 1:
HEALTH OF THE ELDERLY

HEALTH OF THE ELDERLY

This section presents information on the health conditions of the Muslim elderly based on analyses of the decennial Census and the recent GP Patient Survey (GPPS).[1]

While the self-declared health profile was similar in the 2011 Census to the overall population in the younger age bands, the proportion with self-declared bad or very bad health is more marked in the older age bands, particularly Muslim women aged 65 and above. The GPPS data indicates that three medical conditions – diabetes, a heart condition and high blood pressure – are more prevalent among Muslims compared to the rest of the population. It is now almost two decades since the Marmot Review identified the reduction of health inequalities a matter of fairness and social justice.[2] The persistence of health gaps requires the attention of policy makers. The demands for nursing care in the elderly population in the long-term will be shaped in part by action taken now in addressing health gaps.

1.1 2011 CENSUS – SELF-DECLARED HEALTH CATEGORIES

The 2011 Census of England & Wales, and also Scotland, included a question on self-declared health categories: very good or good health; fair health; bad or very bad health. The Muslim population profile was similar to the overall population in the younger age bands, and also in the assessment of what is 'fair health' in all age bands. However, the proportion with self-declared bad or very bad health is more marked in the older age bands. The self-declared bad or very bad health is most marked among women aged 65 and above as indicated in figures 1 to 3. For example, 16% for all women in England indicate self-declared bad or very bad health; it is 38% for Muslim women. There is a similar trend in Wales and Scotland.

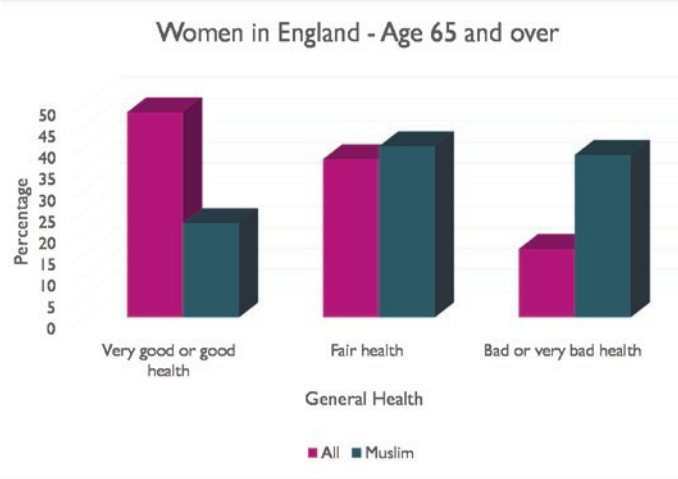


Figure 1. Women in England (Aged 65 and over).

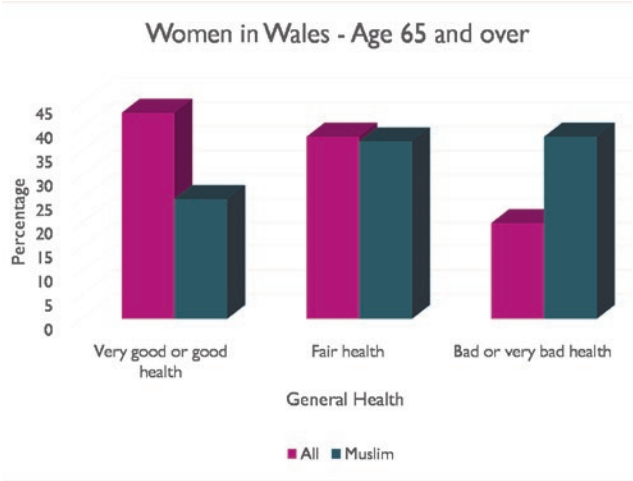


Figure 2. Women in Wales (Aged 65 and over).

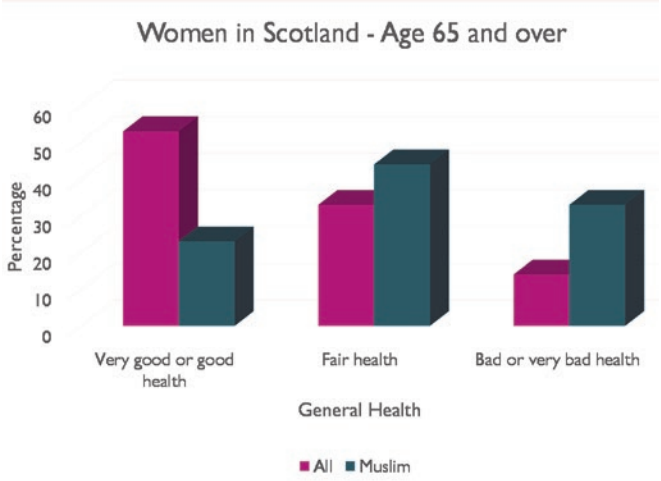


Figure 3. Women in Scotland (Aged 65 and over).

Muslim men aged 65 and above also indicate bad or very bad health to a greater extent than the general population, though less pronounced than for women, as indicated in figures 4 to 6.

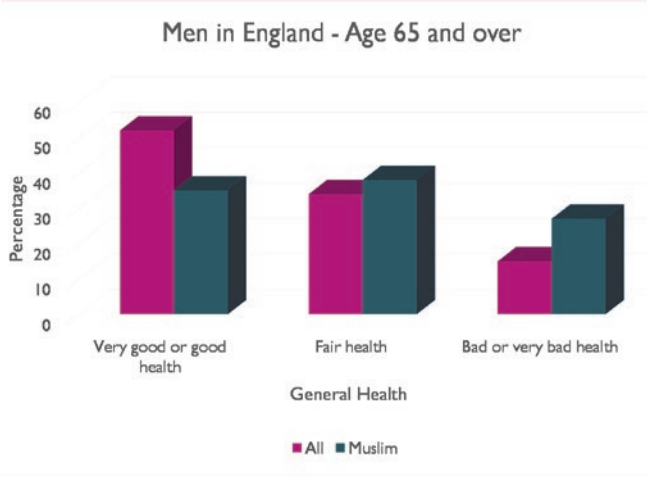


Figure 4. Men in England (Aged 65 and over).

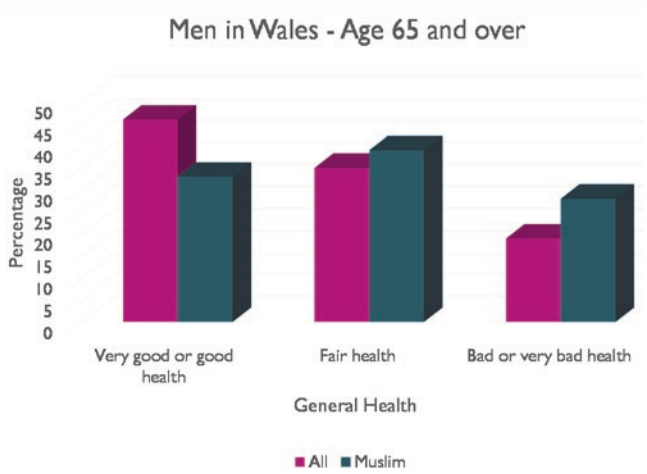


Figure 5. Men in Wales (Aged 65 and over).

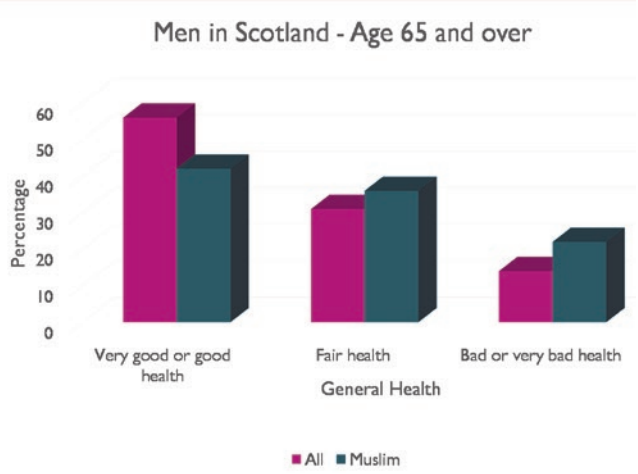


Figure 6. Men in Scotland (Aged 65 and over).

The base data for Figures 1 to 6 is provided in Appendix B.

1.2 GP PATIENT SURVEY – PREVALENT MEDICAL CONDITIONS

The GP Patient Survey (GPPS) is an independent survey run by Ipsos MORI on behalf of NHS England. The survey is sent out to over two million people across the UK.[3] The findings relating to the Muslim respondents are presented in this section. Similar to the Census results, there is evidence of poorer health of elderly Muslims in comparison with the rest of the population.

For the elderly population (aged 65 and above), three medical conditions – diabetes, a heart condition (such as angina or atrial fibrillation) and high blood pressure – are more prevalent among Muslims compared to the rest of the population, as indicated in figure 7.

Moreover, for diabetes, this is most marked among women, as also noted in figure 7.

Figure 7.

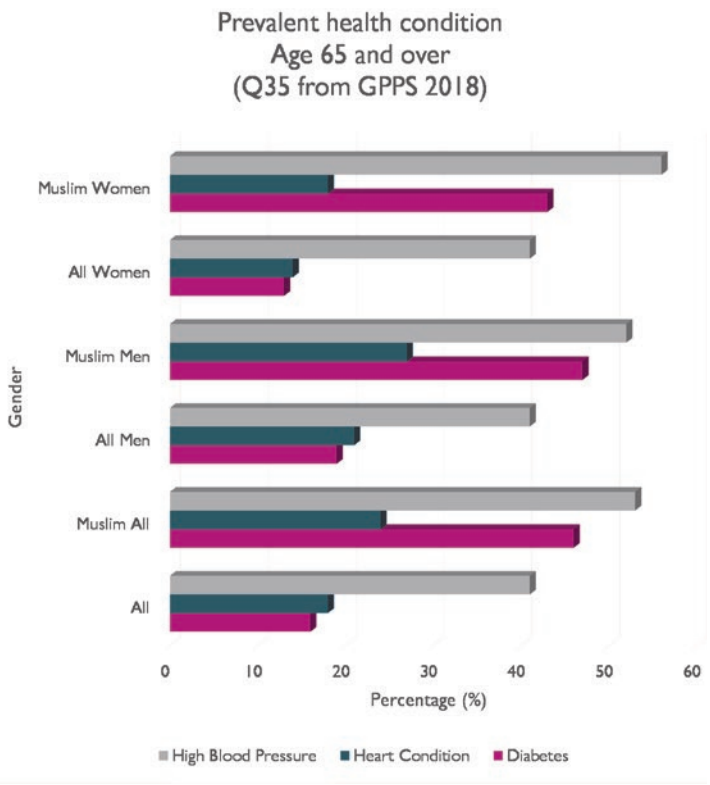
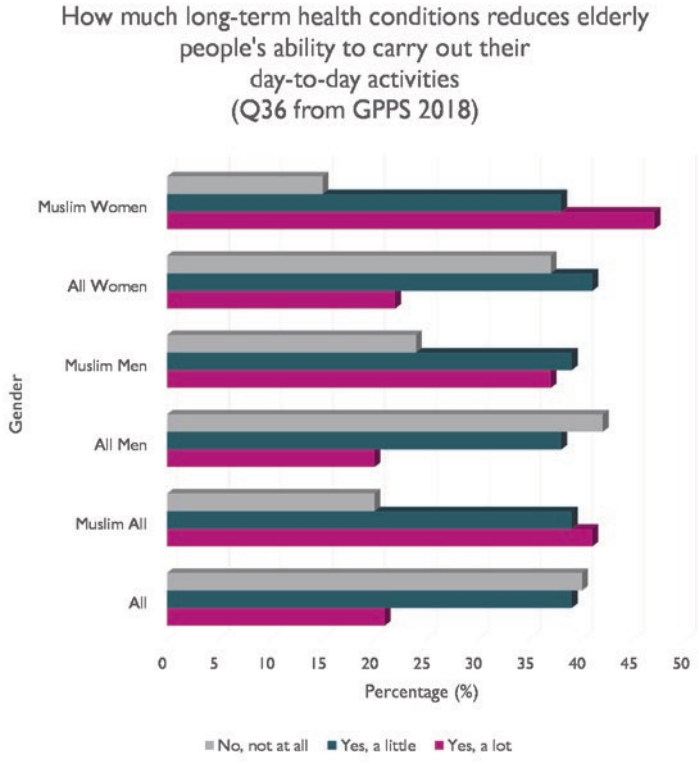


Figure 8.



The proportion of Muslims who feel their medical condition reduces their ability to carry out day-to-day duties is 20 per cent higher than for the rest of the population – figure 8.

The proportion of Muslims prescribed 5 or more medications on a regular basis is 20 per cent higher than for the rest of the population – Figure 9.

Figure 9.

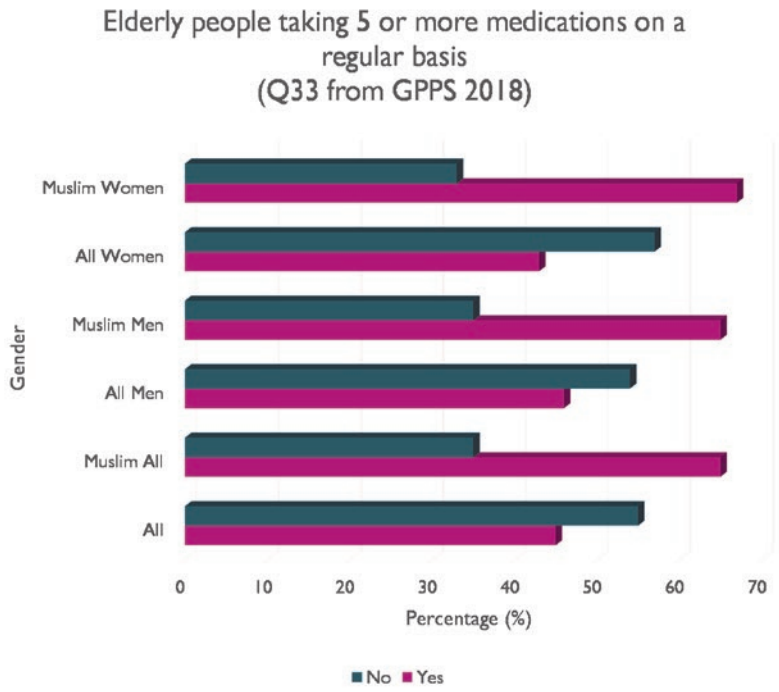
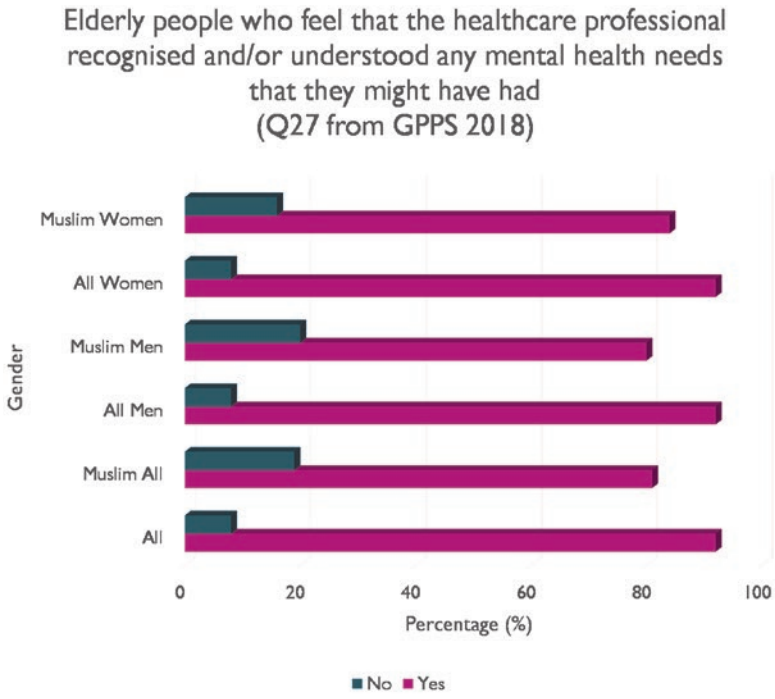


Figure 10.



The proportion of elderly Muslims feeling that the healthcare professional had not recognized or understood any of their mental health needs is higher than the rest of the population: for Muslim women, 16%, compared to 8% for all women; for Muslim men, 20%, compared to 8% for all men; overall, for elderly Muslims, 19%, compared to 8% for all elderly – figure 10.

The base data for charts above are provided in Appendix C.

Endnotes

1. Responsibility for the decennial Census is devolved - England and Wales - Office for National Statistics https://www.ons.gov.uk/census/2011census/2011censusdata. Scotland - National Records of Scotland https://www.scotlandscensus.gov.uk/census-results. Northern Ireland - Statistics and Research Agency https://www.nisra.gov.uk/statistics/census/2011-census. The GP Patient Survey is an independent survey run by Ipsos MORI on behalf of NHS https://www.gp-patient.co.uk/

2. Fair Society, Healthy Lives. 2010. The Marmot Review. http://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review

3. https://www.gp-patient.co.uk/about

PART 2:
ELDERLY CARE NEEDS

ELDERLY CARE NEEDS

2.1 FINDINGS

This section presents the health and care needs collated by the MCB in interviews, focus groups and meetings. The participants' responses are presented below verbatim, as 'community voices'.

The evidence indicates that there are issues common in the wider population – loneliness and isolation, the efforts of families for their near and dear, the impact of cuts in services; others are specific to Muslims, such as the lower priority generally within mosques and community centres to engage with the elderly and offer facilities. Ten themes emerge from the study. There is no priority implied in the order in which the views are presented.

ACCESS TO SERVICES

"The government is also making lots of restrictions. People are suffering in silence. These people who have previously received certain services are suddenly deprived of them because government's new criteria determines that they don't need these services. This doesn't make sense. They are getting older not younger and will require further service, not less." – *Care coordinator, East London*

ADVOCACY & ADVICE

"The Muslim Community has no organisation to fight for senior Muslims . . . No platform to discuss their problems with other fellow Muslims . . . There is no organisation who can help the elderly people in this area. Our people are a bit shy, cannot explain properly. This inspired us to form an association which helps the elderly people . . . [one-to-one] counselling [is provided] to the elderly- they can be selfish and expect their children to do everything without taking into account their circumstances. A taboo – some children will keep their parents at home by any means necessary but are not able to give them proper support." – *Pensioner and activist, North West London*

DIGNITY & TRUST

"They need to respect that person's age, ethnic background and the requirement they may need. For example, they do not feel dignified if they are alone in the room with a doctor, they feel more dignified if there is a chaperon, a family member. . . They should be spoken to with respect . . . and old people are not given the time they need. Old people need more time to get changed so we need to give them time to feel dignified and not being patronising when talking to them." – *Carer, East London*

COMMUNICATION

"For the Asian community, the quality of translators is very poor… some take a chaperon from own family alongside, but there are some appointments that do not allow chaperon, the elderly can't remember what the interpreter says. For example, colonoscopy or bowel cancer diagnosis, the NHS should have an interpreter and (should) allow your chaperon in there. Because the translation is poor, they may not remember." – *Informal carer in East London, MCB interview*

Additional notes by MCB researcher: Several elderly Muslims explained that they often had a relative accompany them to health checks so they could translate for them. When interviewees attended appointments on their own, they felt that they had not been able to understand everything explained to them and thus were unable to convey what had been discussed and recommended to relatives once home.

"My wife and I care for my elderly mother who had to be routinely taken to various appointments at her GP as well as the local hospital. When she was admitted to hospital due to her deteriorating health situation, she found herself being looked after by a male nurse. He clothed her, brought her the food, her medication. The mother spoke no English and no efforts were made in order to provide such a service [from a female] either. I was only made aware of this when mother mentioned it. Upon discovering this, I consulted the doctors and others at the hospital and met with unsatisfactory responses. My mother felt humiliated and unable to challenge this due to her language barrier but I felt unable to anything about it." – *Family informal carers, East London*

FAMILY RESPONSIBILITY

"As Muslims, we believe that we should look after our elderly. It is in the Qur'an and hadith. It is a religious duty - but what is happening in this country? Families are not living in the traditional way where they are close to one another and providing support to the elderly. Siblings are living miles away from each other so looking after their parents is becoming difficult. Also, a lot of Muslims live in overcrowded houses, so it becomes difficult for them." – *Community worker, East London*

Islam teaches us to look after our elders. Therefore, we will need to look after them. But many [elderly people] are living alone. It is the duty of children to look after their parents. This, however, is easier said than done . . . You can't even say 'uff'. . . We need to do a lot of work with youngsters."
Community worker, East London

"There is a story of an elderly father who would break all of his plates, so his son makes him a wooden plate and the grandson sees his father making a plate for his father and he imitates his father. I could give anything to be with my late parents." – *Chairman of a mosque and community centre, North East London*

"Our lifestyles are changing where (the children) both husband and wife are working . . . We need to come up with a solution that is culturally and religiously acceptable . . . Maybe a family rota system and perhaps also respite care. The family is responsible, but support should be available – from a religious perspective, families are responsible . . . the Muslim community currently has no other infrastructure to fill this need . . . There is a stigma, where the primary responsibility lies with the family, so the family feels guilty about putting their elderly loved ones in care . . ." – *Director of a mosque and community centre, East London*

Additional notes by MCB researcher: Informal carers explained that they felt obliged to take time off work in order to attend doctors' appointments with their relative, thus putting a strain on working arrangements. 'British Muslims in Numbers', drawing on 2011 Census data, reported that of Muslim women in the 16-74 age band, 18% were 'looking after home and family' compared to 6% in the general population; moreover, there were increased numbers of Muslim women in full-time education.[1] Many Muslim women thus face challenges when seeking to live up to their educational attainments and career aspirations, and balancing carer responsibilities.

LONELINESS & SOCIAL ISOLATION

"We want to bring people out of their homes to reduce loneliness. [There is] no platform [for them] to discuss their problems with other fellow Muslims." – *Community Worker, North London*

"A lot of people are suffering from loneliness and depression and they have strangers looking after them . . . People are really suffering. The Muslim community is slowly going in that direction and we need to do something about it."
– *Community worker, East London*

Additional notes by MCB researcher: As part of our research, we visited a care home in Tower Hamlets where we met with three elderly Muslims. They were religious and had the Qur'an and prayer mats in their rooms, visible even as you walk past. The importance of faith is crucial in their lives and this is a need that should be recognised for by the authority. The elderly Muslims may feel they are not allowed to make such requests due to perceptions of becoming a burden or that they do not have such rights. They all prayed separately – a communal prayer space could help with tackling loneliness. All three of these patients suffer from dementia yet faith is still very important to them.

MOSQUES' ROLE

"We have daily tajweed classes for the elderly, but we are not doing enough. Our focus is on the youth, but we must start something for the elderly – coffee mornings . . . this is a hidden problem, our elderly are invisible."
– *Mosque Imam, South England*

"Our mosque is sometimes almost like a day centre. Older people tend to become religious when older. Elderly people spend a lot of time in the mosque conversing with each other. There is a social environment here in different languages. Many come in the morning and leave in the evening."
– *Mosque director, East London*

HOUSING

"On a practical level, housing is one of the main issues. For instance, if bedroom is upstairs and if the elderly person needs to come down, this could be an issue. But these are universal issues."
– *Muslim GP & community organiser , North West London*

"Physical constraints - overcrowding".
– *Director of a mosque and community centre, East London*

MISTREATMENT IN THE FAMILY SETTING

"I was in a meeting with [name withheld] and they pointed out instances of abuse of the elderly within the Asian community. I am not necessarily flagging this up as a major issue, but it does exist . . . When people grow old their value and importance seem to reduce. . . I know of a case where an elderly man cannot access the phone without his children permitting him to have access".
– *Pensioner and activist, London*

"Elder abuse, sons would harass parents. Came across a case where a lady would wear all of her jewellery when she went out. Upon knowing her properly, I learnt that she fears her son might steal them as he is involved in drugs. She is very afraid of son."
– *Manager of a Muslim women's centre*

Picture: Khidmat Centre outing.

MUSLIM CARE HOMES, WIDER COMMUNITY RESPONSIBILITIES

"Talk of Muslim care homes indicates traditional family values are eroding. Traditional family units are breaking down and people are also living longer. The Muslim community are becoming more aware and conscious of health. Local authorities and other sectors need to invest more . . . more resources should be invested in social programmes which address loneliness and spiritual care."
– Mosque imam, East London

"Our business community should look at things like housing and care homes. Mosques should be investing in such projects. They should be offering day care, counselling, psychological support and recreation. Why can't we turn mosques into support provisions which provide advice and activities? Mosques have the resources and they have a primary role. Money can be better spent on these issues. This will be good for us, it will improve our image. Mosques should do practical things."
– Muslim GP & community organiser, North West London

"I ran a care home - it closed down two years ago. There were lots of statutory and other costs. There had to be a ratio like so many patients per nurse; has to be supported by care assistance. Somebody had to be in charge at night time. There had to be entertainment and recreation due to local guidelines. Huge competition to get qualified staff. You had to pay to register every qualified staff. It is your duty to check staff. We should perhaps have care homes that are primarily but not strictly for Muslims. Or we should have schemes to work with existing institutions and systems to cater for the Muslim elderly - or both."
– Pensioner and activist, East London

"Community should not depend entirely on local authorities. Maybe service users and families can partially pay for services. Muslim community are starting to raise awareness over these issues, however they spend a lot of time spending for causes overseas but not domestic causes in the Muslim community, such as elderly care."
– Care coordinator, East London

"Community needs to think about developing services for those terminally ill. People think illnesses mean either the GP or burial – (there is) no emphasis on end of life services, no emphasis on bereavement. Services available for bereavement are simplistic, not holistic . . . There is a rise in costs in burial and will continue to rise. It has risen from around £1500 to £4000 and is likely to rise to around £6000-£7000. Cremation [in society as a whole] is around 78%. Will Muslims go the same way?"
– Care coordinator, East London

2.2 SUGGESTIONS FOR IMPROVED SERVICE

An increasing older-age population across Britain is leading to rising need for social care services, in the context of reduced funding … Parliamentary inquiries have concluded that many councils in England have reduced the care available to the minimum required and so are potentially unable to comply with their duties to promote wellbeing and provide care in accordance with need (Health Committee, 2016; Communities and Local Government Committee, 2017). – Equality & Human Rights Commission, *Is Britain Fairer? The state of equality and human rights,* 2018[2]

Respondents [directors of Adult Social Services in England] were asked about levels of confidence in being able to meet specific statutory duties over the next four years. These duties are: Information and advice; Prevention and wellbeing; Assessment (carers and people using services); Personal budgets/services sufficient to meet eligible need; Safeguarding; Market Sustainability (including National Living Wage).

150 directors answered this question. In 2019/20 35% are fully confident that budgets will be sufficient to meet all of these statutory duties in the year, with 59% being partially confident. For later years very few directors (under 5%) are fully confident of their ability to meet all statutory duties. – Association of Directors of Adult Social Services, *Budget Survey,* 2019[3]

The services provided by the health and social care authorities are assessed in this section by comparing their statutory obligations with findings on elderly care needs. The perceived limitations or gaps in service delivery are identified, with suggestions on possible responses and solutions. The role of faith-based organisations is highlighted. References are made to existing projects and initiatives, with supporting statements from published sources.

Various types of support are suggested here as essential for the health and well-being of an elderly person: Medical and Social Services; Shelter; Financial & Legal; Travel & Subsistence; Education; Political Engagement; Employment (where appropriate). Further some are broken down to a further level of detail, as indicated in Table 1. This also notes whether a service can be considered a statutory responsibility, and where there is a perceived shortfall or gap, the potential contribution from faith-based organisations.

STATUTORY RESPONSIBILITIES& GUIDELINES

The Care Act 2014

The Care Act 2014 introduced a general duty on local authorities to promote an individual's 'wellbeing' – this should be in mind when making decisions about them or planning services. Wellbeing can relate to physical and mental health and emotional wellbeing, suitability of living accommodation, personal dignity and participation in work, education or recreation, amongst other considerations.

In addition, the Public Sector Equality Duty (PSED) explains that having due regard for advancing equality involves:

- Removing or minimising disadvantages suffered by people due to their protected characteristics.
- Taking steps to meet the needs of people from protected groups where these are different from the needs of other people.
- Encouraging people from protected groups to participate in public life or in other activities where their participation is disproportionately low.

The 'protected' groups include sections of British society such as the ethnic populations and faith groups.

(From www.carersuk.org and for the public sector equality duty, www.citizensadvice.org.uk)

Table 1: Assessment of service delivery

Theme	Detail	Statutory Provision?	Gaps in Statutory Provision	Role for mosques, faith-based organisations
Medical & Social Services	'Person-centred' care as policy	✔	Persistent health gaps, particularly women aged 65 and above	✔
	Personal hygiene, personal care	✔	Service delivery varies across local authorities; need for religious & cultural awareness by care providers	–
	Care & Support plan (adult social care)	✔	Access to mental health services; possible gaps if 'hard to reach' smaller populations unaware of service; cuts in translation services	✔
	Physical Activity - exercise	–		✔
	Social/community connectivity	✔	Facilities vary across local authorities	✔
Shelter	Home adaptation	✔		–
	Care home services and facilities	✔	Media reports point to unsatisfactory care homes; demand is exceeding supply	✔
	Home over-crowding	✔	New builds not matching demands in terms of accommodating extended families	✔
Financial & Legal	Financial services: bank, cash points	✔	Closure of bank branches & reliance on internet banking presents difficulties for elderly & leading to financial exclusion	✔
	Financial Planning: pension provisioning, retire-ment planning, care funding	✔	Access to financial advice is not within the scope of statutory provision	✔
	Will-writing, Lasting Power of Attorney &'Do Not Resuscitate' formalities, organ donation issues	–		✔
	Burial concerns	✔	Public health funerals are the responsibility of local authorities; for the rest local authorities' charges subject to residence	✔
Travel & Subsistence	Halal diet	✔	Service delivery varies across local authorities	✔
	Transport	✔	Service delivery varies across local authorities	✔
	Food preparation	–	Service delivery varies across local authorities	✔
	Shopping	–		✔
Education	Library facilities, adult education, TV licence	✔	Library facilities affected by cuts in local authority funding; no financial support to pensioners for adult education	✔
Political engagement	Participation in national, local elections	✔	Transportation on polling day	✔
Employment	Age discrimination	✔	Lax monitoring of age discrimination e.g. in recruitment	✔

STATUTORY RESPONSIBILITIES & GUIDELINES

The NHS's pledge

In terms of the values set out in the NHS Constitution for England, NHS England recognises that equality, diversity and reducing health inequalities are central to meeting pledges made to patients and the public and achieving the values enshrined in the NHS Constitution: i) working together for patients; ii) respect and dignity; iii) commitment to quality of care; iv) compassion; v) improving lives; iv) everyone counts. *(from the NHS constitutional values hub)*

Human care and human rights

Extracts from guidance published by the Equality & Human Rights Commission:
". . . Everyone using home care is entitled to get good quality services . . . The Human Rights Act helps to protect everyone from poor treatment by public services . . .
Dignity - This includes: Am I being treated with respect? Am I being listened to and not ignored? Is there respect for my cultural heritage or religion? Am I being provided with adequate care as stated in my care plan?
Privacy - This includes: Do I have privacy and respect for my modesty when I am getting dressed and bathing . . .
Safety and security - This includes: Am I being physically well-treated? Do my care workers have enough skill and experience? . . .
Social contact - This includes: Am I able to maintain relationships with family and friends? Am I able to participate in my community? Can I vote in elections if I want to?"
(From www.equalityhumanrights.com)

Medical & Social Services

• The health and care authorities – commissioners, policy makers – are committed to a vision that is "person-centred: personalised, coordinated, and empowering; [in which] services are created in partnership with citizens and communities; [in which] focus is on equality and narrowing inequalities; carers are identified, supported and involved; [in which] voluntary, community and social enterprise and housing sectors are involved as key partners and enablers; volunteering and social action are recognised as key enablers." [4] Those at the helm of health policy-making need to take up the challenge of ensuring equity for all sections of society, including the Muslim population. Why have past policies devised to address health inequalities not delivered?

• An important first step in an institutional recognition that faith matters in the provision of health care and wellbeing was the Department of Health's initiative to establish the 'Muslim spiritual care provision in the NHS', launched in 2007. This has been followed up with the involvement of mosques and community centres in information dissemination e.g. promoting self-care and improved life styles, medication and diet compliance for diabetic patients and regular exercise for men and women. There are several examples in the MCB network: Penny Appeal's Team Orange volunteers offer company and a listening ear for older people by hosting tea parties with trained entertainers at care homes across the country; the British Islamic Medical Association (BIMA), in collaboration with Cancer Research UK, has conducted seminars in mosques to raise awareness of the importance of timely cancer screening;[5] the Finsbury Park Mosque, in conjunction with the National Autistic Society, has organised an event to spread awareness about autism.[6] There are thus precedents, and further opportunities, for developing co-working and partnership.

• Personal hygiene, personal care: there are variations in the extent to which local authorities and their care providers respond to faith needs in care provision – e.g. carer gender being taken into account for help in washing and dressing.[7]

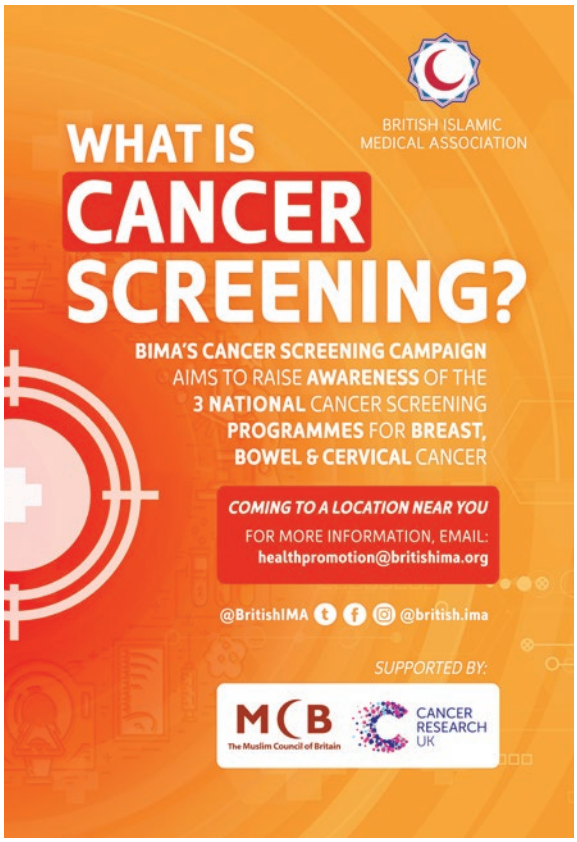
• Care & Support Planning – Care commissioners and Care & Support planners should consider the Muslim elderly's responses to the GP Patient Survey relating to mental health: while for the elderly population as a whole in the survey sample, only 8% felt that the healthcare professional had not recognized or understood any of their mental health needs, for Muslims it was 19%. Further work is needed to address this variation, which could include involvement of mosques and community centres to raise the subject of mental health and encourage access to appropriate services.

Picture: Penny Appeal's Team Orange in action.

STATUTORY RESPONSIBILITIES & GUIDELINES

Care & Support Plan responsibility

Councils vary widely in the approaches they have adopted for delivering care and support planning for both adults with care and support needs and carers, and in their readiness for implementation of the Care Act . . . Care and support plan [is] a document prepared by a local authority which specifies the needs of an individual, which needs meet the eligibility criteria, what needs the local authority will meet and how, the personal budget, and advice and information about reducing and preventing needs."
(From www.thinklocalactpersonal.org.uk)



• There is scope for local authorities to increase awareness of Care & Support Plan processes particularly within 'harder to reach' communities that may not be within the Census count. Access to services can be hindered by lack of English language proficiency particularly amongst elderly women; faith-based organisations can consider offering voluntary support.

• Physical activity; Social & community connectivity – services to be provided in a community setting e.g. the Khidmat Centre's long-standing work and also the innovative social-cum-sport activity pioneered by The Abbeyfield Society serve as good models for wider implementation. There is an increasing awareness that mosques need to offer facilities for persons with disabilities e.g. wheelchair access or sign language facilities for those with hearing impairments. Several mosques now provide live BSL during the Friday sermons and Ramadan *taraweeh* prayers.

The 2011 Census indicates that the London Borough of Tower Hamlet's population aged 65 and over was 15,570 , with a Bangladeshi population in this age band of 3,318 (20%). According to data provided by the Borough, in 2017-2018 there were 1, 509 'care and support' plans for clients aged 65 and over, of which 365 (24%) applied to clients of Bangladeshi ethnicity. Census data provides a means for checking whether the take-up of such plans reflects local diversity.[8]

Khidmat Centres, Bradford

In recognition and anticipation of the emerging needs of Muslim elders, the Council for Mosques (CfM, Bradford) established two social, health and wellbeing centres as far back as the mid 1980s in two separate neighbourhoods of the City with sizable Muslim populations. Very quickly both centres developed into much sought after safe social places for Muslim men and women elders catering for their social and health needs. Over the years, the physical and mental health of our Muslim elders has emerged as a major area of need compounded by age and changing family circumstances. Isolation and loneliness appeared to be common concerns along with medical conditions such as diabetes, dementia, cardiac, blood pressure and obesity.

Our ethos is about elderly people feeling welcomed into safe and culturally appropriate social spaces and being in a position to exercise control over their lifestyles and choices.

We also offer a range of activities reflective of the needs, interests and choices of our elderly service users e.g.

- Weekly swimming sessions reflective of religious and cultural arrangements.
- Group walking.
- Healthier cook & eat sessions.
- Trips and outings.
- Light exercise.
- Allotments.

Source: Ishtiaq Ahmed, Policy and Strategic Support, Khidmat Centres

The Abbeyfield Society: Launch of Clock Cricket

Abdul A. Ravat, Head of Development & Relationships at The Abbeyfield Society, a national older people's charity providing housing and residential care is keen to promote an innovative social and sporting activity – Clock Cricket, which has been designed to be played indoors whilst sitting down and tailored to enhance the physical and mental wellbeing of older people and those with limited mobility. It is played with a foam bat and a sponge ball that has a metal rattle in so it can be tracked by those hard of hearing. The rules permit the ball to be bowled underarm, one-bounce, from a seated position to a batsman opposite who faces eight balls and scores runs, including if it hits a wall (four runs) or the ceiling (a 6!). He notes, "What we're trying to do is tackle inactivity and social isolation and Clock Cricket enables interaction, movement and encourages residents, staff and volunteers to come together in a fun way."

Source: Abbeyfield sees the potential of Clock Cricket.[17]

Shelter

• Home adaptation – Local councils fund home adaptations through the Disabilities Facilities Grant.[10]

• Care home services and facilities - the Care Quality Commission (CQC) sets the mandatory standards and is responsible for monitoring compliance.[11] In practice it is easier to 'tick box' the provision of nursing and medical care e.g. timely medication. What can slip through the inspectors' attention are the less tangible aspects, such as efforts made for social interaction and addressing loneliness. Faith-based organisations will have the 'soft skills' to meet such needs.[12]
In addition to quality of care, there is a crisis because demand is exceeding supply.

The strategy of 'opting out', of establishing care provisions separately, is neither sustainable nor desirable. The case is not being made here for Muslim faith-based organisations to consider a care network parallel that of the State. A public health and social care policy needs to meet the needs of all sections of society. Rather, it entails developing professionalism for co-production and collaboration, though there is also a need to explore and develop alternative offerings that the elderly might find preferable.

• Home overcrowding and non-decent housing is associated with low-income and poverty. Local councils have considerable lee-way in the allocation of housing stock and the social housing element in 'new builds'. The emphasis on 1 and 2-bedroom apartments does not cater for extended families. Those in charge of housing policy need to hear these voices. There may also be scope for innovative thinking in modular building design e.g. the ability to split a larger apartment into smaller units, depending on need.[16]

The UK is running out of care home places and soon there will not be enough to look after the growing number of vulnerable older people needing specialist care, the president of the British Geriatrics Society has warned. Prof Tahir Masud, fears that because so many care homes have collapsed in the past few years that the quality of those left will also decline as a result . . . Then where are all these vulnerable, older people going to go? At the moment, [the system is] just about hanging in and it'll probably be OK for a year or two, but after that, the wheels could come off completely. Slowly, things are going to wind down. Quality will go down." – *Report by Amelia Hill in The Guardian, 6 June 2019*[13]

Cohousing is a form of group living which clusters individual homes around a 'common house' - or shared space and amenities. Run and controlled entirely by members of the group working together, it is based on mutual support, self-governance and active participation. Physically, it is designed to promote easy social interaction among its members and generally has a 'common house' or equivalent for shared meals and events. Two cohousing models exist – the intergenerational or family-based model and senior cohousing, for age-peer groups over the age of fifty or so . . . Key facilitators to senior cohousing's progress [include] . . . Support and understanding by local authority departments such as planning, housing and adult social care is central to getting projects off the ground. *Maria Brenton. Senior cohousing communities – an alternative approach for the UK? , 2013*[14]

The scheme has a mixture of 28 flats and cottages designed around three sides of a quadrangle with a central Meeting Hall (which was rebuilt in 1931) and a beautiful central garden to which residents add many pots of flowers outside their homes. It is close to local transport links and the bustling Kingsland High Street. Extensive work has been done to fit new kitchens and begin the process of bringing the delightful flats up to modern day standards. A full social programme takes place at this scheme with trips and outings regularly taking place.
Retirement housing managed by the Metropolitan Benefit Societies' Almshouses[15]

Financial & Legal

• Pension provisioning and care funding – there are provisions at the statutory level such as the basic state pension and income-related benefits e.g. pension credit. However, there is a need to promote awareness of savings for old age.

A critical analysis of the different tiers of pension schemes provided through the UK pension system indicate that many BMEs are unable to access occupational and private pension schemes due to the structural arrangements and eligibility criteria that are in place. These contribute to the disadvantage faced by the BME group in making provisions for retirement and indicate a heavy reliance on the Basic State Pension (BSP) in retirement. – *Beverley Preddie, Retirement Provision among the Black and Minority Ethnic Group in the UK, 2014.*[18]

• Access to financial services is not within the scope of statutory provision, though there has been a call for Government action.

The ongoing closures of bank branches, and an increasing reliance on digital services, pose a number of challenges for customers. The Post Office provides a wide range of banking and financial services through an extensive branch network. The majority of customers, however, are simply unaware that these services exist. The current waste of this untapped potential is not acceptable, and needs to be addressed through a concerted joint effort from Government, the banks and the Post Office. Vulnerable groups including the elderly, those suffering from mental health problems and people living with disabilities are particularly ill-served by the growing number of bank closures, and we make specific recommendations to support these groups . . .
Just 53% of single pensioners had internet access in 2016 and 93% of those aged 80 and over do not use internet banking." – *House of Lords Select Committee on Financial Exclusion, 2017* [19]

• Will-writing, Lasting Power of Attorney & 'Do Not Resuscitate' formalities, organ donation issues – services to be provided in a community setting. The East London Mosque Trust for example offers a will-writing service and organises sessions with lawyers for pro-bono legal advice.[20]

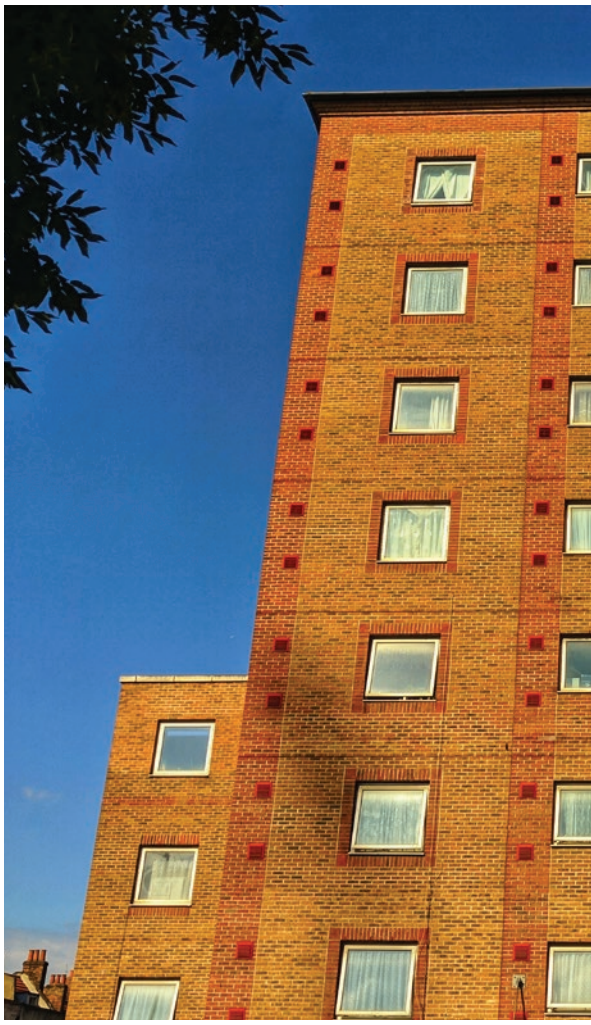
• Burial concerns – burial costs vary considerably across local authorities; several community bodies offer financial support to needy families.[21]

Travel & Subsistence

• Halal diet - there are variations in the extent to which local authorities and their care providers respond to dietary requirements.

• Transport – catered for by local authority facilities such as the freedom pass, dial-a-ride service and the taxi card scheme. There are variations in the extent to which local authorities and their care providers offer transport to attend Friday prayers, which can be catered for by community initiatives.

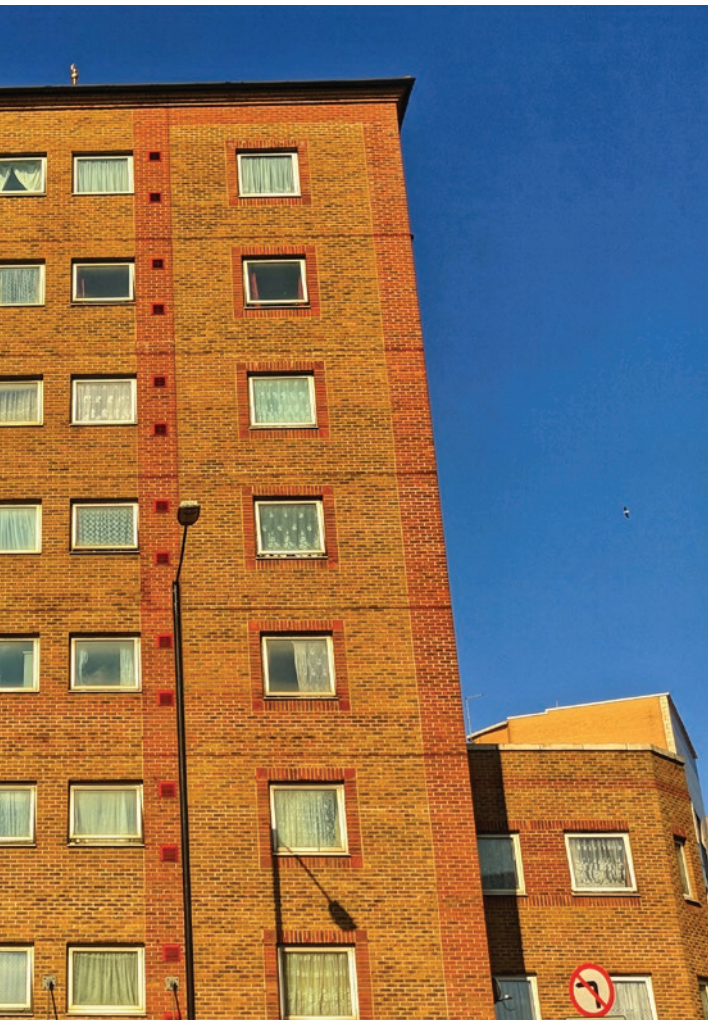
A far-sighted move



Flats for the elderly adjacent to the East London Mosque, established 2001.

One sad experience

"I have seen both the positive and negative approaches to supporting someone who is living with dementia within the context of their religious beliefs . . . Sadly, a Muslim lady had a far more negative experience when she moved into the home. Despite requiring a strict Halal diet, some carers were caught feeding this lady non-Halal meat. When these carers were questioned about the food, they said that this lady's dementia was so severe she wouldn't know what she was being given and had been willing to eat it so it made no difference."
Source: "Keep the faith", d4dementia.blogspot.com, 2013.[22]



• Food preparation, shopping – social care services provide home meals for the elderly who face difficulty in cooking. There are variations in the extent to which local authorities help to prepare meals, order food online or help in eating or drinking. These are needs that can be met through community initiatives.

Education

• Library facilities, adult education - TV licence free for over the over 75. Some mosques organise *tajweed* (Qur'an recitation) classes but adult education at mosques is currently of limited scope; mobile libraries are now rare, and reading rooms and libraries in community centres are uncommon – both services that can be provided by community initiatives.

Political Engagement

• Postal voting is available on request for all elections in England, Scotland and Wales. Muslim organisations, including the MCB, promote voter registration campaigns; some community organisations organise transport on polling day.

Employment

• Age discrimination in employment is against the law, though there is likely age bias in practice in recruitment, and women face particular difficulties in accessing work in later life.[23] There is an opportunity within the Muslim voluntary sector to evaluate its 'age-friendly' employment procedures and draw on the skills and experience of older people keen to remain in the workforce.

Endnotes

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7. Personal care e.g. the carer giving the elderly client a shower; for those with special needs – use of specially designed toilets; changing nappies - incontinence pads; many require help in the toilets.
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11. Care Quality Commission. The Fundamental Standards. https://www.cqc.org.uk/what-we-do/how-we-do-our-job/fundamental-standards. The website https://ukcareguide.co.uk/ provides information and guidance on residential care, home care and related topics.
12. An example is the Cinnamon Network's 'Care Home Friends' project for befriending older people in care homes. https://www.cinnamonnetwork.co.uk/care-home-friends/. While this report was under preparation, a carer provided the MCB with a poignant example of an elderly Muslim woman receiving domiciliary care – she would request her Muslim carer to recite to her from the Qur'an during visits. Unfortunately this stopped when the carer was transferred to other assignments and the replacement was not able to provide the same solace.
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16. About half of the Muslim population in England live in the 10% most deprived local authority districts in England – see The Muslim Council of Britain. 2015. British Muslims in Numbers - A Demographic, Socio-economic and Health profile of Muslims in Britain drawing on the 2011 Census. p. 46. https://mcb.org.uk/report/british-muslims-in-numbers/ A Joseph Rowntree Foundation study associated low-income households with non-decent and over-crowded housing – see https://www.jrf.org.uk/data/non-decent-housing-and-overcrowding
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21. An example is Eden Care's Muslim Burial Fund https://www.edencareuk.com/campaigns/muslim-burial-fund/. See also Abu Mumin et al. "Simple acts of kindness: respectful burials for needy Muslims within a holistic end of life service." BMJ Supportive and Palliative Care Volume 6, Issue Suppl 1 (2016). https://spcare.bmj.com/content/6/Suppl_1/A18.1
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MCB

The Muslim Council of Britain

UNIVERSITY OF CAMBRIDGE

HRH Prince Alwaleed Bin Talal Centre of Islamic Studies

HEALTH INEQUALITIES

There are persisting health gaps amongst elderly Muslims – especially women. 38% of Muslim women aged 65 and above self-declared having bad or very bad health.

BIG THREE

Diabetes, heart condition and high blood pressure are three most prevalent medical conditions among Muslims aged 65 and over.

ACCESS

Demand for increased access to care by the elderly is not being met in a timely way. Elderly Muslims may not ask for services due to perceptions of being a burden, lack of awareness of due rights, lack of information.

OUR VISION

Empower communities in the UK achieve a state of readiness with respect to elderly care.

MISSION

Work towards establishing a faith-based organisations' (FBOs) network that can add value to State care provisions.

ELDERLY & END OF LIFE CARE

For Muslims in the UK

MUSLIM ELDERLY

The number of Muslims aged 65 and over is estimated to increase from 110,000 to 450,000 by 2036.

WAKE UP CALL

The elderly population is increasing in challenging times for adult social care, care home provision and recruitment of care workers. FBOs should plan, build capacity, and collaborate.

AWARENESS

Many health care professionals and care agencies need additional education regarding the needs of faith groups and appreciation of religious values.

MOSQUES & IMAMS

Mosques serve as both places of worship and community hubs, so imams are essential partners to be engaged in promotion of improved life styles, health living, and other wellbeing information.

SERVICE DELIVERY

There are wide variations in the extent to which authorities respond to cultural and religious needs e.g. carer gender, dietary needs. This may be because of lack of advocacy or Adult Social Services priorities, but inconsistencies in service delivery should be addressed.

FBO VALUE-ADDED

FBOs can bring both 'soft' and 'hard skills' to the table in co-production with the care agencies e.g. addressing social isolation, but also running health screening programmes.

HOSPITAL CHAPLAINCY

NHS initiatives in 'spiritual care provision' to be commended but continuing effort needed support the work of lead hospital chaplains to meet needs of all faith groups.

LANGUAGE

Lack of English language proficiency is a barrier specifically for elderly female Muslims in their communication with health and care professionals.

MENTAL HEALTH

Mental health issues in elderly have traditionally received less importance. A greater proportion of Muslim women aged 65 and over perceive the healthcare professional had not recognized or understood their mental health needs.

ISLAMIC VALUES

Muslims attitudes and conduct in dealings with health care professionals are predominantly shaped by Islamic values and influence their interactions and expectations.

FAMILY-BASED CARE

Women are traditionally carers but support is needed to balance educational ambitions, career aspirations with elderly care responsibilities for family members.

PALLIATIVE & END OF LIFE CARE (P&EOLC)

Muslims approach to P & EOLC services is dominated by their deep religious values than the scientific data and biomedical trends offering information about prognosis.

EDUCATION

Lack of education and understanding of the P&EOLC services on offer by Muslim patients and families results in poor confidence in services and having less access.

DEATH AND DYING

Care providers, commissioners and policy makers need to increase their effort to understand and recognise the deeper values and underlying commitments that govern Muslim patients' and families' deliberations around death and dying.

ADEQUACY

Services are not adequately equipped to provide care for religious-ethnic minorities, reflected in poor uptake of advanced care planning and hospice services, including community-based services and on-site care.

INCLUSIVITY

Hospice teams and GPs in the community often find it challenging to produce advanced care planning and evidenced based practice which is inclusive of patients' and families' values and beliefs

PART 3:
END OF LIFE CARE NEEDS

END OF LIFE CARE NEEDS

3.1 FINDINGS

Drawing on work of the Centre of Islamic Studies, University of Cambridge, this section presents perspectives on palliative and end of life care from the analysis of 75 interviews, with patients, families, healthcare professionals, imams and other relevant stakeholders.

The evidence points to an unmet need amongst Muslims of end of life care. It notes some of the positive responses in hospitals and hospices but calls for greater religious literacy amongst service providers. The findings also emphasise the need for a culture change, led by Imams, to raise issues of death and dying that can increase awareness of Palliative and End of Life Care (P&EOLC) services and help counter the cultural stigma in the accessing of services.

Evidence suggests there is a schism between the current model of end of life care and the health needs of religious and ethnic communities. Such evidence includes reports that point to an unmet need amongst Muslims of end of life care. This is reflected in poor uptake of advanced care planning and hospice services, including community-based services and on-site care. Reports also suggest that services are not adequately equipped to provide care for religious-ethnic minorities, whose spiritual needs are central to their end of life care.[1] There is a growing concern that a lack of understanding in relation to what course of management is considered appropriate for minority populations, in the UK, may lead to confusion, misunderstanding, unnecessary conflict, or even unseemly clinical events.

Three key themes emerge from the study: lack of awareness & inability to access services; lack of awareness and training amongst staff regarding faith values and their impact on P&EOLC; challenges in initiating advanced care plans; trust in P&EOLC services and the role of chaplaincy services.

Lack of awareness & inability to access services

One of the key themes identified in the research and through the expert meetings, when considering barriers faced by Muslim patients and families accessing P&EOLC, was a lack of education and understanding of the services on offer. Family members explained that they were unaware of being able to access services, particularly for terminal conditions that were not related to cancer.

"The perception of palliative care for some Muslim patients I think is very difficult. From a social perspective I think they feel they need to be seen doing everything possible for their relative and it's a sign of love and it's what's expected of them by their wider family. It's hard for them to say do the Western thing and that it's all going to end now." – *Hospice Nurse in Birmingham*

Participants also explained that there are perceptions within the Muslim community that may act as barriers to patients and families accessing P&EOLC. Some of these include a cultural stigma to 'handing over' the care of elderly or infirm relatives. This is due to religious and cultural beliefs in caring for the sick and elderly. Others also explained that often there is a lack of awareness of hospices and P&EOLC staff being able to provide care that would be respectful of their religious and/or cultural needs.

One of the family members interviewed explained that after her mother had opted not to have palliative surgery, healthcare teams assumed that she and her family would not want any further P&EOLC support. This left her daughter caring for her mother in isolation, unsure of how to access hospice and/or respite care:

"The hospital . . . when my mum made that decision she wasn't going to have the treatment, I was told by the nurse that the hospital were going to, if that's the decision my mother made and she doesn't want any medical intervention, then that was it. They weren't going to continue any further. They wouldn't offer her any additional appointments or anything else. And that she would need to go to her GP if she needed anything. And that was it . . . And we're getting nowhere. But she's very slowly, incrementally she is having more symptoms . . . She's been deprived of some quality within her condition. And I think that's sad, because that's sad for her – And it just seems very sad and tragic. It's very difficult because I'm living it with her in a way . . . The thing is though, the stumbling part to hear is that the patient is the one that has to come and ask for the support. And at this particular moment in time, we cannot convince her to seek and ask that part . . . And then when I tried to go and find assistance, I mean I called cancer research and I've spoken to the nurse. And I've explained the kind of situation and scenario. And again, she said, "I'm really sorry, but I think you need to speak to your GP about yourself. I think your GP needs to know the kind of pressures that you're under, because you need care. You need support."

. . . That nurse at Cancer Research actually said, "I'm sorry to say this, but I think your situation means that you're just going to have to wait till something quite dramatic and drastic happens, like she has a fall. And then you're going to have to call the ambulance. And then it's out of your hands. It's out of her hands. And it goes into the medical profession's hands as to what they choose to do." – *Family Member, Birmingham*

She explained the struggles she is facing as a sole carer, unable to access support on behalf of her mother. She described how her mother's decision to opt out of palliative surgery was rooted in her religious beliefs of relying on God and that the clinical team assumed she would not want any further medical, including palliative, assistance for her care.

Challenges in initiating advanced care plans

When staff and experts were asked about what they consider to be the factors that lead to unequal access to hospice and palliative care they discussed in detail the challenges of initiating end of life care conversations, with Muslim patients and families, as being key. Advanced care planning, that is carried out by hospice teams and GPs in the community rely on co-operation from patients and families. GPs and hospice nurses described how it was challenging to ensure that such conversations were open to patients' and families' values and beliefs, whilst aligning with end of life care evidence-based practice guidance. When patients and families were unwilling to accept such planning, healthcare professionals in the community and hospice setting often described such conversations as a 'tick-box' or 'detached' exercise, one where clinical and patient/family goals were unaligned.

"I think there's many drivers for advanced care planning. I'd say advanced care planning is a good thing . . . some people may never be at that . . . Some people might not want that conversation with you . . . I do slightly worry about it as being held up as, the must do. There's much more sensitivities to it, I think than that." – *Hospice Nurse in Birmingham*

Lack of awareness and training amongst staff regarding faith values and their impact on P&EOLC

Efforts have been made to ensuring that cultural, linguistic and ritual requirements of Muslim patients and families are met, as a means of addressing barriers to P&EOLC services. However, a persisting challenge faced by care providers, commissioners and policy makers is the ability to understand and recognise the deeper values and underlying commitments that govern Muslim patients' and families' deliberations around death and dying. For example, the study shows that for some Muslims, beliefs about 'what is a good death' and 'what is suffering' is pivotal in determining their choices around sedation and pain relief and perceptions about P&EOLC services.

One of the findings emerging from the data is the importance that Muslim patients and families place on ensuring that decision-making within the healthcare context is not incongruous with their faith. Many explained their theological commitments to beliefs in an afterlife and how illness and disease within their Islamic worldview are manifestations of suffering which offer a means of spiritual cleansing or of elevating the devotee and that death is considered a transition into the afterlife. Several participants also explained that for Muslim patients and families a 'good death' is centred on being able to complete rituals of dying including the remembrance of God and invocations of testimonies of faith. Opiates such as morphine are offered as part of the end of life care treatment plan to address pain and reduce anxiety, such interventions, however, can also induce altered consciousness. The latter causes anxiety for Muslim patients and families as they worry that the patient will be unable to recite prayers necessary for their harmonious transition. Such anxieties are shared by the community and may act as barriers to them accessing P&EOLC services.

"We get that with Muslim patients (and families) . . . They are worried that you are going to give a lot of morphine to their loved one. You are going to render them unconscious. You are going to sedate them. And again, sometimes they worry that you might be sedating them excessively or that if you want start morphine that (it) is inevitably going to hasten their death, or towards the end when they become unconscious, (from) the progression of the illness, they will blame it on the morphine that they're getting for pain relief . . . It's uncomfortable. And again, you see, it's not just uncomfortable for me, it would also be uncomfortable for the other medical staff, for the nurses who are looking after the patient." – *Palliative Care Doctor in London*

Trust in P&EOLC services & the role of chaplaincy services

A persisting issue around ensuring access to P&EOLC services, amongst Muslim patients and families, is trust. One of the key findings from the research is that although individuals and families may be aware of the care provision available to them, they may not access services as they are not adequately familiar with the relevant institutions and individuals and therefore are unwilling to place their trust in them. Familiarity can be overcome through engagement of hospice and palliative care teams with the community. However, the study shows that there are deeper and persisting issues to do with the values, beliefs and practices of Muslims that the participants of this study highlight that need further consideration. Such considerations relate to the types of relationships that are encountered and the type of trust that is built by/around the patient. Participants and experts emphasized that understanding trust and relationships is key when we are thinking about the barriers and facilitators to ensuring access to P&EOLC services.

For example, participants' views highlighted that patients and families are experts of their history, languages, values, beliefs and contexts. They make decisions about end of life in light of their particular understanding of death and dying. These understandings they share with other stakeholders, such as their family, Imams and chaplains, and confer on them trust as the latter offer patients and families guidance and support through religious knowledge, language and authority.

"I think they're more together as families … often living locally, which is really supportive. They've got strong bonds, and… they respect. It's just expected that they will care for them, you know, whatever. You'll have sons who work all day and then will look after their dad all night. Because that is just what they will do and they just don't want any support, they just want advice when they need it. They will do all the personal care, thank you very much. It's very important for them to do that at that time… We might think we are very important, that we are very clever, but they might be getting advice from other areas as well, there is that going on…I feel, that I don't know what my patients want because the family are in charge. If they aren't speaking English and they won't let me bring an interpreter, then I have a slight concern sometimes… Just that I might be missing something from the patient's perspective and it's what they want. If I'm really nervous I will get an interpreter in. They may be too weak or too poorly to actually talk about [other] points as well…" – *Hospice Nurse*

"I also feel there's that clash still where some of the Muslim community still don't have that trust for the medical system… 'cause I already feel where sometimes you do get a family where there is that split with the medics, they don't have that trust. It's always like they don't have that trust." – *Hospital Chaplain*

The data show that as patients and families rely on religious values, beliefs and rituals to construct meaning, they depend on those conversant in such tenets, such as chaplains and Imams, to assist in their deliberations. Decision making for them is not simply negotiations around scientific data and biomedical trends offering information about prognosis, rather they require a deep consideration of their theological values to ensure their evaluation is cognisant with their faith. Chaplaincy services are, therefore, incredibly important for families who are interacting with P&EOLC services for whom their faith is an integral component to establish meaning around end of life.

3.2 SUGGESTIONS FOR IMPROVED SERVICE DELIVERY

The section calls for service redesign through community-based chaplaincy such that Muslim patients and families can better access P&EOLC services through "trusted people and trusted spaces". There is also a need for a culture change, led by Imams, to raise issues of death and dying, in order to increase their congregations' awareness of P&EOLC services and help counter the cultural stigma in accessing of services.

Recognising needs

Hospices and palliative care services are recognising the specific needs of faith and are making a concerted effort to ensuring their services are adequately designed to improve access for such groups. For example, during the research it has been observed that many hospices are ensuring the following cultural, linguistic and ritualistic requirements for Muslim patients and families are met:

- Diverse workforce to enhance engagement and communication
- Translator services
- Allocated prayers spaces
- Provision of halal food
- Access to Muslim chaplains/ Imams,
- Ability to face a patient's bed towards Makkah
- Enabling family to offer prayers and read Qur'an in the patient's room
- Ability to accommodate large numbers of visitors (this is so that the family can recreate a home environment in the hospice)
- Provision of washing facilities

for the deceased (*ghusl*) and funeral shroud (*kafan*)
- Ability to offer timely death certification to enable burial
- Support development of infrastructure and policy to allow the deceased to be kept at the mosque prior to burial, rather than at a mortuary
- Contact with the local mosque for funeral arrangements

Religious literacy, training & outreach

There is scope for improving religious literacy among professionals, for example through:

- Including education and training about minority ethnic/faith groups in all national P&EOLC training schemes for doctors, nurses, other allied healthcare professionals and volunteers. E.g. Training Day on Muslim perspectives on End of Life Care that was run by the Centre of Islamic Studies, University of Cambridge, on 27 March 2018.
- Ensuring an appreciation of the diversity in beliefs and practices amongst Muslims, through access to the necessary education and training to prevent assumptions and stereotyping. Adapting 'diversity and equality' and 'unconscious bias' training such that these can offer specific guidance on religious-ethnic populations, may be a step towards equipping staff with the necessary awareness and skills to address such challenges.
- Recognising faith as an asset for delivering effective and efficient P&EOLC services. As Muslim families may be committed to caring for patients at home, palliative care and hospice teams need to understand better how this can be best supported. With scarce healthcare resources, ensuring that families are able

STATUTORY RESPONSIBILITIES& GUIDELINES

NHS England

Death and dying are inevitable. The quality and accessibility of this care will affect all of us. The needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities, must be addressed, taking into account their priorities, preferences and wishes.[2]

NICE Guidelines on care of dying adults in the last days of life

Extracts from guidelines published by the National Institute for Health Care and Excellence (NICE):

". . . If it is thought that a person may be entering the last days of life, gather and document information on:

- the person's physiological, psychological, social and spiritual needs
- current clinical signs and symptoms
- medical history and the clinical context, including underlying diagnoses
- the person's goals and wishes
- the views of those important to the person about future care." [3]

Commission into the Future of Hospice Care

Extract from 'Future needs and preferences for hospice care', section on *Engaging more with the community*:

- Hospices have to re-engage with the concept of death as a social process, of which clinical is a part, rather than a clinical process of which social is a part.
- Making the hospice building more community focused to enable more listening and engagement in communities. Increase in self help groups and volunteer led activities, including bereavement support.
- Using expensive facilities in innovative ways to engage community support and break down barriers.
- Supporting existing informal networks in communities and working out where the hospice fits in, not disempowering people and communities. Community hubs - bringing the community into the hospice to demystify what hospices can provide to the local population. [4]

to support care alongside healthcare staff may be a means of maximising available resources for patients. Offering basic manual handling training for family members/carers as well as education and training of how and when to call for extra support may empower families to better care for patients and palliative and hospice teams to manage scarce resources. Such interventions may also help to reduce unexpected and unnecessary ambulance call outs and emergency admissions.

- Hospices and palliative care services can form partnerships with national and local faith-based organisations. Such partnerships can be a means of disseminating education programmes about P&EOLC services, enable staff to gain a familiarity with religious/cultural commitments and needs, and foster trust between P&EOLC services, faith leaders and the Muslim community.
- Utilise local and national media platforms (TV, radio, websites, social media) that are popular with minority ethnic/faith groups to disseminate information about P&EOLC services.
- More investment in research on the views and values of minority ethnic/faith groups on P&EOLC services.

Culture change, Muslim chaplaincy & Imams

As is prevalent in the population nationally, there is also reluctance amongst the Muslim population to discuss death and dying. Additionally, the research findings show that the healthcare setting, including primary care, may not be an ideal place for initial conversations about death and dying to take place. Social change is necessary to enable families and community-based organizations such as mosques to initiate, support and develop such conversations. An initiative within Muslim civil society may provide an ideal means of starting a national conversation about death and dying in the Muslim community. Such an enterprise may also include focus on Friday sermons as a unique and effective way to engage congregations in the spiritual and practical considerations around death and dying. These sermons and engagements may also be means of educating the community about P&EOLC services and to help counter the cultural stigma in the accessing of services. Such an initiative would emphasise the need for family-based discussions on death and dying and would help to reinvigorate such conversations back into the community.

Given the key role chaplains play in offering faith groups pastoral and spiritual support as well as a means of understanding the clinical context, there may be value in establishing a Muslim community chaplaincy. Such a service would strengthen Advanced Care Planning in primary care enabling patients and families to learn about the services from someone they recognise and trust and to enable decision to occur earlier, rather than at a time of crisis.

Additionally, trust building with religious-ethnic groups may require experts, such as chaplains in the hospital and community, who are able to sensitively convey clinical decisions, dispel misunderstandings and rumours and offer the trust they have built as a bridge for patients, families and healthcare professionals.

STATUTORY RESPONSIBILITIES& GUIDELINES

'PRISMA' Programme Extracts from journal article by Natalie Evans et al, BMC Health Services Research Journal, 2011

Recommendations for service improvement from the End-of-Life Care Strategy

- Commitment to equal access to services
- Recognition of distinct preferences regarding: the chaplaincy service; support needs of carers and families; organ donation; care and disposal of the corpse; and, bereavement care
- The holistic assessment of needs, includes spiritual and cultural needs
- Awareness raising about death and dying in 'religious organisations such as churches, mosques, synagogues'
- The need for interpretation services
- The need for the ethnicity and religion monitoring
- The need for 'spiritual, religious and cultural care competences' to be 'adopted within all core training' [5]

Community Imams may benefit from basic training and education about P&EOLC services so they can better inform their congregation and gain a familiarity with the healthcare context. Understanding P&EOLC services may mean they are able to develop the necessary trust and rapport with the services thereby making them more likely to recommend the services to their congregation and provide advice regarding preparation of wills and advanced directives.

Although Muslim female chaplains were interviewed as part of the research, recruitment into the CIS EOLC research revealed a scarcity of this category of professionals within P&EOLC. It would be important for future research to engage with the question of the impact of this on P&EOLC needs of Muslims and in particular Muslim women.

STATUTORY RESPONSIBILITIES& GUIDELINES

Public Health England & Partners report
Extracts from report by Natalia Calanzani et al, Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK, Demographic profile and the current state of palliative and end of life care provision, 2013

Where do we go from here?:
We feel that a nationwide initiative to promote and disseminate best practices is needed. Without this initiative, there is the risk that those from BAME groups/ belonging to a particular religion who live in less ethnic diverse areas (for example the North East) might not benefit from them . . .[6]

Endnotes

1. Calanzani, Natalia et al. Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK – Demographic profile and the current state of palliative and end of life care provision. 2013. Public Health England, King's College London, Marie Curie Cancer Care. https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/diversity-and-inclusion-research/palliative-care-bame_full-report.pdf

2. NHS England. End of Life Care. https://www.england.nhs.uk/eolc/

3. National Institute for Health Care and Excellence (NICE). Care of Dying Adults in the last days of life. 2015. https://www.nice.org.uk/guidance/ng31

4 Commission into the Future of Hospice Care. Future needs and preferences for hospice care: challenges and opportunities for hospices. 2013. https://www.hospiceuk.org/docs/default-source/default-document-library/future-needs-and-preferences-for-hospice-care-challenges-and-opportunities-for-hospices.pdf

5. PRISMA project ('Reflecting the Positive diveRsities of European prIorities for reSearch and Measurement in end of life cAre') reported by Evans et al vans et al. "Appraisal of literature reviews on end-of-life care for minority ethnic groups in the UK and a critical comparison with policy recommendations from the UK end-of-life care strategy." BMC Health Serv Res. 2011; 11: 141 (2011). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3146404/

6. Calanzani op.cit. p.50.

PART 4:
FORECASTS:
CARE NEEDS IN 2036

ELDERLY CARE NEEDS

4.1 ELDERLY POPULATION

The 2011 Census data indicates that the total population of Britain was 61,371,315, with 10,113,407 aged 65 and over (16.5%). The Muslim population count was 2,782,803, with 109,353 aged 65 and over (4%). The starting point for population forecasts is the 100-years 2016-based principle national population projection prepared for Britain by the Office for National Statistics (ONS).[1] This indicates that in 2036 the total population of Britain will be 69,827,506, with 16,605,338 aged 65 (23.8%). Based on the 100-year ONS projection and a comparison of the Muslim population provided by the census in 2001 and 2011, the MCB estimates that the Muslim population in all age bands in 2036 will be about 4.5 million, i.e. 6% of the population of Britain. The Muslim population aged 65 and over will be approximately 450,000 i.e. 1 in 10 – see Table 2. For Britain as a whole in this age band, about 3% will be Muslim. The MCB's estimating method is described in Appendix D.

Table 2
ONS Population Estimates for 2036 - Age 65 and over - England, Wales & Scotland

ONS Projection	Aged 65-69	Aged 70-74	Aged 75-79	Aged 80-84	Aged 85+	Total 65+
All Men – England	1,750,094	1,634,456	1,293,088	936,817	1,060,475	6,674,930
All Women – England	1,862,676	1,781,823	1,448,762	1,112,725	1,456,457	7,662,443
All Men – Wales	100,693	97,289	78,043	57,298	64,439	397,762
All Women – Wales	108,922	106,014	87,726	68,167	87,059	457,888
All Men – Scotland	171,439	164,849	132,120	91,701	89,480	649,589
All Women – Scotland	189,968	184,810	152,151	111,178	124,619	762,726
						16,605,338

MCB Population Estimates for 2036 - Age 65 and over - England, Wales & Scotland

MCB Estimation	Aged 65-69	Aged 70-74	Aged 75-79	Aged 80-84	Aged 85+	Total 65+
Muslim Men – England	86,680	54,279	39,596	24,643	14,950	220,148
Muslim Women – England	76,909	49,391	37,687	25,611	21,910	211,507
Muslim Men – Wales	1,577	1,004	770	408	204	3,963
Muslim Women – Wales	1,199	744	597	353	269	3,162
Muslim Men – Scotland	2,807	1,706	1,273	690	338	6,814
Muslim Women – Scotland	2,294	1,402	1,108	600	440	5,844
						451,438

The Muslim population aged 65 and over will increase from 109,353 in 2011 to an estimated 451,438 in 2036 i.e. 300% increase.

The trend in the proportion of increasing elderly is shared with other faiths, for example, 189% and 195% for Hindus and Sikhs respectively – these comparative faith estimates are provided in Appendix E. It is most marked with Muslims because the population in 2011 was skewed towards age bands below 45, a proportion of whom will have reached 65 in 2036; the base number was smaller with only 4% of the Muslim population aged 65 and over in 2011.

In decades to come, the cohorts in the younger age bands will gradually become older, a proportion of whom will require some form of specialist care: domiciliary care with or without a nursing component; independent living facilities or sheltered housing with or without a nursing component; nursing home care. This is a 'wakeup' call for Muslim civil society – social entrepreneurs, charities, philanthropists - to begin preparing for changes to the demographic profile and future needs of a growing proportion of elderly Muslims

within the British Muslim population: firstly, influencing mainstream state provision so that it is appreciative of religious values in wellbeing and care, and secondly preparing for faith community specific initiatives that complement or add value to the state provisions, but require capital and infrastructure.

The estimates inform collective community endeavours planning for the future, for example schemes to promote employment in the domiciliary care sector, carer and care home demand, nursing care demand and cemetery demand.

4.2 HEALTH CATEGORIES

The previously cited evidence from the Census and the GPPS indicates that the Muslim population reports ill heath to a greater and different extent compared to the general population. There is further supporting evidence that Muslims are the most disadvantaged faith group, and as health inequality is greater in older age, elderly Muslims are likely to be particularly affected by this. This has implications for elderly care planning, both in terms on the type and level of nursing care that might be needed in a home or sheltered housing context, or in nursing home provision. Assuming the proportion of Muslims in each of the Census's health categories remains unchanged from year to year, the MCB estimates that by 2036 there are likely to be over 145,000 Muslim senior citizens in the 'bad or very bad health category' either in a domiciliary, sheltered housing or nursing home care setting – a further 'wakeup' call! These numbers are also relevant in forecasting the need for men and women carers – details in Appendix F.

There are a range of options to be considered in this planning process: for example care can be at home, at a day centre, at sheltered housing, at a nursing home, at a hospice, independent living schemes with support at hand if needed.

Endnotes

1. Office for National Statistics (ONS). Population Projections. National Population projections by single year of age (2016). Analysis: output data for a single date or range of dates. The Nomis website allows selections based on geography, age (band), projected year and sex. E.g. to obtain the population in England in the age band 65-69 of males (result is 1,750,094) https://www.nomisweb.co.uk/query/construct/submit.asp?forward=yes&menuopt=201&subcomp=

2. ONS. How would you support our ageing population? 2019. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/howwouldyousupportourageingpopulation/2019-06-24

3. ONS. Living Longer: caring in later working life. 2019.https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2019-03-15

FROM THE OFFICE FOR NATIONAL STATISTICS (ONS)

. . . With improvements in life expectancy having outpaced improvements in healthy life expectancy in recent years, people are living an increasing number of their later years in poor health. *How would you support our ageing population? 2019*[2]

. . . An ageing population means that more older workers may need to take on caring responsibilities, particularly for a parent, in the future. Informal care providers are hugely important to the economy and society. Yet being a carer can come at great personal cost. Most carers are women, who are likely to be working part-time. These part-time jobs will be lower paid than full-time equivalents, leading to lower future pension security. *Living longer: caring in later working life. 2019*[3]

PART 5:

TERMINOLOGY, ISSUES AND PROCESSES RELATING TO END OF LIFE AND AFTER-DEATH PROCESSES – FAQS

TERMINOLOGY, ISSUES AND PROCESSES RELATING TO END OF LIFE AND AFTER-DEATH PROCESSES – FAQS

WHAT IS AN LPA?

"If you become unable to make decisions for yourself in the future, someone will need to make decisions for you. Who does this will depend on the situation. Generally, professionals will make decisions about your health and social care, and your family or carers will decide on day-to-day matters. If you wish, you can officially appoint someone you trust to make decisions for you. This is called making a lasting power of attorney (LPA), and enables you to give another person the right to make decisions about your care and welfare. You can also appoint an attorney to decide on financial and property matters. There are special rules about appointing an LPA."[1]

WHAT IS DNACPR AND WHAT ARE MUSLIMS' VIEWS ON IT?

Do No Attempt Cardiopulmonary Resuscitation or DNACPR (often abbreviated as DNR) is "a decision made in advance that attempted CPR would not be likely to be appropriate for a person in the event of a cardiac arrest (when the heart stops pumping)."[2] A DNACPR decision may be made and recorded by the healthcare team, because "CPR should not be offered to a person who is dying from an advanced and irreversible condition and therefore CPR will not prevent their death".

Although Muslims may be keen to avail themselves of all possible treatments during illness, once at the end of life there is a commitment to ensuring dignity and preventing harm to the dying person. As CPR is a vigorous physical intervention with a minimal chance of success, once the heart stops in someone with advanced and irreversible disease, it is acceptable to forgo such an intervention.[3]

WHAT ARE MUSLIM VIEWS ON ORGAN DONATION?

The majority of Muslim scholars appeal to the principle of prioritising the saving of human life and support organ donation. There are, however, differing opinions on living and deceased donation. Many scholars permit live transplants as long as the donor is not going to suffer poor health as a result. Although many support living donation there is disagreement about deceased donation and in particular 'brain death' donation.[4]

EXTRACTS FROM MUFTI MOHAMMED ZUBAIR BUTT'S 'ORGAN DONATION AND TRANSPLANTATION IN ISLAM – AN OPINION', 2019

Organ Donation After Circulatory Determination of Death (DCDD)

This refers to the situation in which organs are removed after a patient is observed to have both stopped breathing and been without a pulse for a minimum of five minutes (in the UK). These are typically patients who are ventilator dependent due to disease, spinal cord injury or neurological trauma that does not meet brain-death criteria, etc. After the specified period without evidence of the return of circulatory or respiratory function, the patient is declared dead on the premise that irreversibility has been achieved, and the organs are expeditiously removed .Whilst 2 minutes (in fact 65 seconds) are sufficient to discount autoresuscitation, no one has ever maintained that it is impossible to successfully resuscitate patients after they have been pulseless for 5 minutes or more, since many such successful resuscitations have been documented both within hospitals and by paramedics in the field . . . Whilst contemporary Muslim scholars have recognised cardio respiratory arrest as a reliable sign of departure of the soul, they have also required it to be irreversible. This stipulation of "irreversibility" is to ensure that the soul has indeed departed and, whilst this stipulation is a recent introduction to the definition of death, it is arguable that it was always implied but had to be expressly stated only because we decided we would interfere with the body of the dying/deceased. Thus, DDCD is not permissible until the point of elective irreversibility has lapsed.

[p. 99, 101]

Organ Donation After Neurological Determination of Death (DDBD)
In the UK, this refers to the situation in which organs are removed after brain injury is suspected to have caused irreversible loss of the capacity for consciousness and irreversible loss of the capacity for respiration before terminal apnoea has resulted in hypoxic cardiac arrest and circulatory standstill. This is also known as heart beating donation (HBD) …I too am of the opinion that brainstem death or even whole brain death alone are not sufficient to indicate departure of the soul and that cardio respiratory function supported by mechanical ventilation cannot be discounted when determining death. Thus, DDBD following irreversible loss of the capacity for consciousness combined with the irreversible loss of the capacity for respiration is not permitted before terminal apnoea has resulted in irreversible hypoxic cardiac arrest and circulatory standstill. This position is contrary to the view expressed in 1995 by the Muslim Law (Shariah) Council, which endorsed brainstem death criteria.
[p. 101, 103]

Deceased Organ Donation and Transplantation
In the event that all requirements have been satisfied to indicate the departure of the soul from the body, and in the absence of any clear evidence to prohibit the transplantation of human organs and in the pursuit of public interest, it would appear that Deceased organ donation and transplantation of all organs/tissues besides the gonads is permissible provided:
1. The situation is one of medical necessity.
2. There is a reasonable chance of success.
3. The organ or tissue is donated with the willing consent, whether express or implied, of the deceased.
4. The procedure is conducted with the same dignity as any other surgery.
[p.103] [5]

WHAT ARE MUSLIM PREFERENCES RELATED TO RITES AND RITUALS AT THE END OF LIFE?

When a Muslim person is at the end of life, both the individual and family will be keen to offer prayers, ensure reading of the Qur'an and encourage recitation of the testimony of faith by the dying person. Muslim patients, if able, may continue to offer the five daily prayers, and may need support for performing ablution and have their bed arranged so that it is facing Makkah. Family members will want to support and comfort their loved one and healthcare teams may find that they need to accommodate larger groups of visitors.

WHAT ARE MUSLIM VIEWS ON PAIN RELIEF?

Although Muslims are allowed to avail themselves of pain relief, there may be concerns about the sedative effects of medication on a patient's ability to perform prayers and recite the testimony of faith, at the end of life. Patients may find it helpful to discuss pain relief and sedation options with the healthcare team as well as a Muslim chaplain. On the issue of pain killers impairing cognitive ability, the last recitation by the patient before losing any faculties will be regarded as their last recitation/reading since they are no longer able to recite/read.

WHAT ARE MUSLIM PREFERENCES RELATED TO RITES AND RITUALS AFTER DEATH?

Once a Muslim has died the eyes and mouth is closed, the deceased is turned to face Makkah, and the body is washed and shrouded.

Once the body is washed and shrouded, prayers are commonly offered at the community mosque followed by burial at a local cemetery.

Muslims are obligated to bury their dead and there are growing concerns around the affordability and availability of burial spaces. Local Councils and national bodies will be required to work closely with the Muslim community to ensure that such a religious commitment is supported in an equitable and sustainable way.

WHAT ARE MUSLIM VIEWS ON DEATH CERTIFICATION AND POST-MORTEMS?

As Muslims consider it a religious requirement to bury their dead as soon as possible, and ideally within 24 hours, Muslim families commonly require assistance in ensuring no delays with death certification. Families may thus be distressed if there are delays to them being able to fulfil the rites and rituals owed to the deceased.

Concurrent with a commitment to ensuring a speedy burial are beliefs about bodily resurrection and prohibitions on mutilating the body. Many Muslim

families would therefore express distress if there were a requirement for an invasive post-mortem. Given such religious commitments, there is an increasing demand amongst Muslim communities in the UK for the provision for scanning services or non-invasive post-mortems. Coroners that have a sizable Muslim demographic may need to consider the commissioning of scanning services for their population.[6]

WHAT ARE MUSLIM VIEWS ON BEREAVEMENT AND COPING WITH LOSS?

Although Muslims accept death as a transition into an eternal life, loss of a loved one is recognised as being difficult. Relatives and the community may offer much needed comfort and support. Families may also find invaluable religious and culturally sensitive resources and guidance from specialist bereavement services on coping with loss and understanding grief through an Islamic perspective.[7]

CORONER GUIDANCE

Extracts from the Chief Coroner's Guidance – the use of post-mortem imaging (adults), 2013 & updated 2018:

"The use of images from CT scanning is one possible way of reducing the number of autopsies. Certain faith groups are particularly keen to avoid an autopsy, and many others would be pleased to avoid one . . . But this is a developing field, so care should be taken that the results from CT scan images are used cautiously and effectively. At the same time it must be recognised that there are limitations on the scope of imaging for ascertaining reliably the cause of death and that there are some differing views about the efficacy of cross-sectional imaging of this type both as an adjunct to invasive post-mortems and as an alternative . . . The Department of Health is currently considering recommendations for an integrated national cross-sectional autopsy imaging service, based on a regionalised service provided by mortuary-based imaging centres . . .

Where a non-invasive autopsy is requested and a CT scan may be considered potentially useful in all the circumstances, the pathologist must first conduct a thorough external examination of the body. If the pathologist then considers that a CT scan would be inappropriate he should report to the coroner who will decide what type of examination should take place.

If the coroner considers that a CT scan is appropriate, a radiographer or trained mortician carries out the scan. A specially trained radiologist (or pathologist specially trained in interpreting post-mortem imaging) analyses the results of the scan."[8]

Extract from the Chief Coroner's report, 2018:

"The Chief Coroner is of the view that the investigation of deaths in England and Wales will be greatly enhanced by the proper implementation of the medical examiner (ME) system as set out in the 2009 Act. The ME scheme should supplement and complement the work of the coroner service. Working alongside coroners MEs should provide a more comprehensive independent system of death investigation in England and Wales. It should mean more accurate medical certificates of the cause of death and ensure more appropriate referrals of deaths to coroners. It should also produce more accurate data about the causes of death, particularly in hospitals."[9]

Endnotes

1. NHS. Lasting Power of Attorney. End of Life care. https://www.nhs.uk/conditions/end-of-life-care/lasting-power-of-attorney/

2. Resuscitation Council. Do Not Attempt CPR (DNACPR). CPR involves "rapid, repeated compression of a person's chest, blowing air or oxygen into their lungs, if necessary by inserting a tube into their windpipe, delivery of high-voltage electric shocks through their chest and injection of drugs." The subsequent quotation is also from the document. https://www.resus.org.uk/faqs/faqs-dnacpr/

3. Permanent Committee for Scholarly Research and Ifta. 1989. Ruling on Resuscitating the Patient if he is dead, his health condition is not fit for resuscitation or his disease is incurable. Fatwa Number 12086.

4. For further information see http://nhsbtmediaservices.blob.core.windows.net/organ-donation-assets/pdfs/islam_and_organ_donation.pdf

It should be noted that a growing numbers of scholars are now permitting the donation of organs upon death – note the opinion of Mufti Mohammad Zubair Butt, Organ Donation and Transplantation in Islam, An Opinion. Institute of Islamic Jurisprudence, Bradford. 2019. https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/16300/organ-donation-fatwa.pdf

5. ibid

6. For further information see https://www.lancashire.gov.uk/births-marriages-and-deaths/deaths/coroners/non-invasive-post-mortem-examination/ and the Chief Coroner 's Guidance https://www.judiciary.uk/wp-content/uploads/2013/09/guidance-no-1-use-of-port-mortem-imaging.pdf

7. For further information see the website of the Muslim Burial Support Service http://mbss.org.uk

8. https://www.judiciary.uk/wp-content/uploads/2013/09/guidance-no-1-use-of-port-mortem-imaging.pdf

9. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/764720/report-of-the-chief-coroner-lord-chancellor-2017-18.pdf

PART 6:
CONCLUSIONS

CONCLUSIONS

6.1 ACTIONS ARISING

FOR HEALTH AND SOCIAL CARE AUTHORITIES

1. Health policy makers – Clinical Commissioning Groups of the Boards of NHS Trusts, appropriate local authority officers and councillors – to investigate the impact of past policies devised to address health inequalities and involve stakeholders in improving their effectiveness.
2. There are variations in the extent to which local authorities respond to faith needs of Muslim elderly; there is need for a more comprehensive survey and research to be funded to explain these variations where they fall within the orbit of statutory responsibilities and Public Sector Equality Duty.
3. Policy makers need to engage with mosques and voluntary associations to develop and deepen co-working and partnerships. This can start by identifying the respective 'assets' each can bring to the table e.g. the 'soft skills' from the voluntary sector like addressing social isolation, and the need for capacity building for service delivery.
4. Evidence suggests an unmet need amongst Muslims for end of life care. This is reflected in poor uptake of advanced care planning and hospice services, including community-based services and on-site care. Palliative and end of life care services need to better understand how faith and culturally based preferences of individuals and their families can be recognised and supported.
5. Improved end of life care requires "community-based chaplaincy" such that Muslim patients and families can better access P&EOLC services through "trusted people and trusted spaces". This can build on the experience of the NHS and MCB in promoting the 'Muslim spiritual care provision in the NHS' project that was launched in 2007.

FOR MUSLIM CIVIL SOCIETY

6. The MCB will issue a call to its affiliates to collect evidence of projects and facilities that cater for, and engage, the elderly. Good practice examples can be brought to wider attention and adopted or adapted as appropriate. A pilot programme led by MCB and delegated to its affiliate the British Islamic Medical Association (BIMA) should be funded to undertake this, and analyse local arrangements in major conurbations with high Muslim population densities. BIMA can begin conversations with NHS Trust management, Clinical Commissioning Groups (CCGs), local authorities, mosques and charities to establish a plan of action.
7. The MCB will issue a call through its networks to initiate discussions involving social entrepreneurs, the charity sector, entrepreneurs and the public services for planning and investment to address future needs of a growing population of elderly Muslims within the British Muslim population:
   - The role here for the Muslim charitable sector e.g. in funding small scale projects in mosques to address the leisure, educational, physical health needs.
   - The role of Muslim philanthropy to commission work to help plan for these emerging trends and needs in UK Muslim population.
   - Resources needed from within the community to supplement the demands made on the statutory sector to improve equality in outcomes.
   - The role of Muslim investors when it comes to the provision of services for Muslim elderly? both commercial and impact investing models - how can they be used to meet future challenges in this sector.
8. There is need for a culture change, led by imams and mosque leadership, to raise issues of death and dying that can increase awareness of palliative and end of life services and help counter the cultural stigma in accessing of services.
9. Similarly, the topic of mental health needs to be raised by imams and mosque leadership with their congregations to dispel it from being a taboo subject.
10. Given the step change in the Muslim elderly population by 2036 and the number that may be in poor health, there is urgency for planning to begin now to forestall a future crisis. Networks of professionals need to be mobilised for specific follow-up work, ranging from developing professionalism for co-production and collaboration with health and social care authorities, to exploring care home options. There is scope for benefiting from past experiences in this sector and 'leap frogging' to sustainable and humane solutions.

6.2 AREAS FOR FURTHER RESEARCH

The MCB's Research & Documentation network plans to initiate a number of work streams as a follow-up to this report and the feedback received. These include

- exploring sustainable care home options
- examining issues of financial inclusion/exclusion, pension provisioning and future care home planning
- population modelling
- preparing information resources on key terms and formal processes faced in end of life and after-death situations.

Interested parties can email redocoffice@mcb.org.uk to register their interest.

COMMENDATION

"The publishing of this very useful document is the step in the right direction at a time when NHS is developing and promoting its 'Integrated Care Programme' for taking care of patients, particularly elderly and those at the End of their life journey, out of the hospitals and in the community. This report will prompt other faith communities to develop their own." – *Manhar Mehta, Chairman, Vanik Council UK & Coordinator, Jain Spiritual Healthcare*

6.3 LAST WORD, SHARED WORDS

Family ties, respect and care of the elderly, burial of our near and dear – these are part of life's journey. The faith traditions provide the lodestones for conduct, with much common ground. Some of these teachings and precepts are presented below, because to a greater or lesser extent, attitudes and conduct are shaped by these values, and will influence interactions and expectations in dealings with care providers and health care professionals.

DUTIES TO PARENTS

Your Lord has decreed that you worship none but Him, and that you be kind to parents. Whether one or both of them attain old age in your life, say not to them (even) uff, nor repel them, but address them in terms of honour. – *The Qur'an 17:23*

Children, obey your parents in the Lord. This is right and proper. 'Honour your father and your mother' – this is the first commandment that comes with a promise attached! – 'so that things may go well with you and that you may live a long life on earth.' – *New Testament, Ephesians 6*

"Do you have a mother?" He said: "Yes." He said: "Then stay with her, for Paradise is beneath her feet."
– *Sunan An Nasai Book 25 Hadith 20*

Honour your father and your mother, so that you may live long in the land the Lord your God is giving you.
– *Old Testament, Exodus 20:12*

If you honour your parents, your children will honour you. – *Guru Granth Sahib*

FACING OLD AGE

It is Allah who creates you and takes your souls at death; and of you there are some who are sent back to a feeble age, so that they know nothing after having known (much): for Allah is All-Knowing, All-Powerful.
– *The Qur'an 16:70*

It is He Who has created you from dust then from a sperm-drop, then from a leech-like clot; then does he get you out (into the light) as a child: then lets you (grow and) reach your age of full strength; then lets you become old - though of you there are some who die before - and lets you reach a Term appointed; in order that you may learn wisdom. – *The Qur'an 40:67*

Old age in the Torah is associated with wisdom and knowledge - indeed the term 'elders' is used as a synonym for judges, leaders and sages - and is connected to the exhortation to fear, honour and obey one's parents. Indeed, it is a biblical obligation for children to look after their parents' - the fifth commandment is to honour them - and the courts in Talmudic times could compel people to do so. – *Religion, Culture and Institutional Care,* extract from an article by Oliver Valins.

Do not express your wish to die, and do not pray for death before it comes on you, because death will terminate your good deeds, while prolonged living will further increase the good deeds of the faithful.
– *Sahih Muslim Book 48 Hadith 15*

END OF LIFE

Every soul shall taste death, and you will only be given your [full] compensation on the Day of Resurrection. So he who is drawn away from the Fire and admitted to Paradise has attained the object (of Life): For the life of this world is but goods and chattels of deception.
– *The Qur'an Chapter 3 Verse 185*

It is He who created death and life to test you [as to] which of you is best in deed – and He is the Exalted in Might, the Forgiving. – *The Qur'an Chapter 67 Verse 2*

REFLECTIONS ON FAMILY TIES

Archbishop of Canterbury Justin Welby

"Our Christian Tradition reinforces the family as a place of selfless giving and of love sown as grace (gratuity), not for hope of reward … Households come in all forms, from single people to large and numerous groups. All need to be valued and esteemed. Love, hospitality and compassion, as well as the biblical emphasis on respect for the elderly, should lead to a much stronger emphasis on extended families liturgically and socially within the Church as an example to society. The celebration of the extended family reflects the grace that it brings."

From Reimaging Britain, Foundations for Hope, Bloomsbury, 2018

A REFLECTION ON AGEING

Dr. Muhammad Abdul Bari

"Old age is a feared reality of life. Imam Abu Hanifa, an intellectual giant in early Islam, was once heard to make a thoughtful remark on this – 'when you first see grey hairs on the head, welcome the new phase of your life'. After a life of strength, it is painful to be dependent on others, even if it is on the children who were once reared with immense love and pain. But old age is by no means meaningless. It is the phase of wisdom in one's life and as such can be of enormous help in the extended family."

From Building Muslim Families, Ta Ha Publishers, 2002

APPENDICES

APPENDIX A: APPROACH AND METHODOLOGY

MCB STUDY

The MCB's Research & Documentation Committee (ReDoc) launched its elderly care planning project in 2015. A part-time policy analyst intern was assigned the task of conducting interviews with the elderly, carers and community activists. Preliminary findings were presented at a community event in Ilford in January 2017. A project steering group, which included representation from the elderly, carers and community activists met regularly under the chairmanship of Dr. Shuja Shafi to review findings and obtain expert briefings on topics such as the statutory regulations. ReDoc members working on the project in a voluntary capacity also held fact-finding meetings with AgeUK and visited the facilities provided by JewishCare. Two policy analysts were assigned short-term contracts in 2018 to conduct further interviews and focus groups. Approximately seventeen semi-structured interviews were conducted, three of which were group interviews. Three focus groups were also conducted. The interviews and focus groups were held in Essex, East and West London and Birmingham, with conversations with imams in various locations. The MCB appreciates that it has drawn on a limited sample size (about 15 men and 25 women), but through its broad range of affiliate organisations across the UK, the findings and observations presented here can be considered representative, though not comprehensive or exhaustive.

CENTRE OF ISLAMIC STUDIES, UNIVERSITY OF CAMBRIDGE - END OF LIFE CARE (EOLC) RESEARCH

The aim of the CIS EOLC research was to collate evidence that can better inform practitioners and policy makers about the values, beliefs, processes and practices that Muslim patients and families rely on when making end of life decisions and to what extent these are informed by their faith commitments. The study also aimed to highlight examples of good practice as well as challenges and gaps underlined by care providers when meeting the needs of Muslim patients and families.

Given the aim of the study, the following types of key stakeholders were identified as important and included in recruitment:

- Muslim patients and family members
- Healthcare professionals (doctors, nurses, physiotherapists, psychologists etc) - Muslim and non-Muslim
- Bereavement staff, funeral service staff, mortuary staff and coroners - Muslim and non-Muslim
- Chaplains (multi-faith and/or Muslim)
- Imams and/or Islamic Scholars involved in End of Life Care decision making

The rationale for sampling these five types of interviewees was because (a) they constitute the five groups most likely to be able to provide insight into the role of Islam and the beliefs, values and practices of Muslims as pertaining to decision-making within EOLC and (b) have insights on how EOLC is provided and (c) have experienced the particular challenges of dealing with members of faith communities. The reason for interviewing diverse actors, at multiple levels and throughout the pathway of patient and family care, was to allow for an assessment of the multiple relevant perspectives within end of life care in the different contexts. A purposive sampling method was employed to capture a range of experiences. 75 interviews have been conducted in total. This number was based on my being able to interview a sufficient number of suitable individuals within each of the participant categories such that data saturation was reached i.e. until a point was reached beyond which it was judged the addition of new themes was unlikely.

For in-depth interviews with participants, an open-ended thematic topic guide was developed to ensure that the same themes were covered in each of the five interview tiers.

The CIS EOLC research is led by Dr. Mehrunisha Suleman – https://www.phpc.cam.ac.uk/people/pcu-group/pcu-visiting-staff/mehrunisha-suleman/

APPENDIX B: 2011 CENSUS DATA, SELF-DECLARED HEALTH CATEGORIES

		Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
England	All women	4,815,690	2,290,175	48%	1,761,133	37%	764,382	16%
	Muslim women	51,720	11,515	22%	20,443	40%	19,762	38%
	All men	3,844,839	1,988,119	52%	1,295,930	34%	560,790	15%
	Muslim men	53,505	18,699	35%	20,542	38%	14,264	27%
Wales	All women	311,222	132,711	43%	117,417	38%	61,094	20%
	Muslim women	710	177	25%	262	37%	271	38%
	All men	251,322	116,605	46%	87,319	35%	47,398	19%
	Muslim men	891	294	33%	347	39%	250	28%
Scotland	All women	506,595	269,943	53%	166,672	33%	69,980	14%
	Muslim women	1,110	258	23%	485	44%	367	33%
	All men	383,739	213,980	56%	117,782	31%	51,977	14%
	Muslim men	1,417	596	42%	513	36%	308	22%

APPENDIX C: GP PATIENT SURVEY 2018, SELECT QUESTIONS & RESPONSES

Q35. Which, if any, of the following long-term conditions do you have?

Weighted Base: England All Elderly (150,999), England Muslim Elderly (1,919), England All Elderly Men (72,179). England Muslim Elderly Men (1,189), England All Elderly Women (78,192), England Muslim Elderly Women (716)

	All Elderly Person	Muslim Elderly Person	All Elderly Men	Muslim Elderly Men	All Elderly Women	Muslim Elderly Women
	National (%)	National (%)	National (%)	National (%)	National (%)	National (%)
Diabetes	16	46	19	47	13	43
A heart condition, such as angina or atrial fibrillation	18	24	21	27	14	18
High blood pressure	41	53	41	52	41	56

Q36. Do any of these conditions reduce your ability to carry out your day-to-day activities?

Weighted Base: England All Elderly (127,830), England Muslim Elderly (1,670), England All Elderly Men (61,796). England Muslim Elderly Men (1,015), England All Elderly Women (65,513), England Muslim Elderly Women (643)

	All Elderly Person	Muslim Elderly Person	All Elderly Men	Muslim Elderly Men	All Elderly Women	Muslim Elderly Women
	National (%)	National (%)	National (%)	National (%)	National (%)	National (%)
Yes, a lot	21	41	20	37	22	47
Yes, a little	39	39	38	39	41	38
No, not at all	40	20	42	24	37	15

Q33. Do you take 5 or more medications on a regular basis?

Weighted Base: England All Elderly (167,733), England Muslim Elderly (2,170), England All Elderly Men (79,066). England Muslim Elderly Men (1,352), England All Elderly Women (87,895), England Muslim Elderly Women (799)

	All Elderly Person	Muslim Elderly Person	All Elderly Men	Muslim Elderly Men	All Elderly Women	Muslim Elderly Women
	National (%)	National (%)	National (%)	National (%)	National (%)	National (%)
Yes	45	65	46	65	43	67
No	55	35	54	35	57	33

Q27. During your last general practice appointment, did you feel that the healthcare professional recognised and/or understood any mental health needs that you might have had?

Weighted Base: England All Elderly (51,281), England Muslim Elderly (1,062), England All Elderly Men (25,088). England Muslim Elderly Men (660), England All Elderly Women (25,904), England Muslim Elderly Women (396)

	All Elderly Person	Muslim Elderly Person	All Elderly Men	Muslim Elderly Men	All Elderly Women	Muslim Elderly Women
	National (%)	National (%)	National (%)	National (%)	National (%)	National (%)
Yes	92	81	92	80	92	84
No	8	19	8	20	8	16

APPENDIX D: POPULATION FORECASTS – METHOD & BASE DATA

The starting point is the 2011 Census and the ONS's population projections, starting with the 2016 population estimate available by gender. The following steps have then been followed:

- In 2011, the population of all men and women in England in the age band 60-64 was 1,557,140 and 1,615,137 respectively.
- In 2011, the population of Muslim men and women in England in the same age band was 21,952 and 24,297 respectively (i.e. 1.41% and 1.50% of the population of all men and women in England in the band 60-64 respectively).
- In 2016, the ONS's population estimate of all men and women in England in the age band 65-69 (i.e. 5 years later) is 1,470,578 and 1,561,477 respectively.
- It has been assumed that the proportion of Muslim men and women in 2016 in England in the age band 65-69 will be in the same proportion as in 2011 in the age band 60-64 i.e. 1.41% and 1.50% respectively.
- This assumption can be justified by comparing the 2001 and 2011 Census outputs that provide actual population data: the cohort of men in the age band 60-64 in 2001 in England comprised 1,174, 457, with 20, 746 Muslims i.e. a factor of 1.77%. In 2011, this cohort would be in the 70-74 age band. The 2011 Census indicates that the total male population in the 70-74 age band was 967,953. If the Muslim male population had not been available from the 2011 Census, the estimate would be 1.77% of 967,953 i.e. 17,133. However, the actual population is available from the 2011 Census, which is 17,542. The difference is small.
- The factor-based approach has been adopted in estimating Muslim population increases at 5-yearly intervals. The proportion of Muslims say in the 65-69 age cohort will be the same as it was 5 years previously i.e. in the cohort 60-64. This principle has been applied for subsequent intervals to 2036, as shown in Tables 1-6 and accompanying histograms.
- The same factor-based approach as above has been used to project the Muslim population in the age band 85 and over. A weighted average method, which would have been more accurate, has not been because of lack of data. This means that in 2036 all Muslim aged 85 and over are assumed to be in the age band 85-89. The resulting error is not materially significant as the numbers involved are very small and the life expectance of Muslim at aged 85 and over is low.
- To get the total projected Muslim population in years after 2011, it has been assumed that the proportion of Muslims in the age band 0-4 stays the same as that in year 2011. The results are indicated in Tables 7-8.

Base data – Population forecasts by gender and country

Table 1
England – Muslim Men

Year	Aged 60-64	Aged 65-69	Aged 70-74	Aged 75-79	Aged 80-84	Aged 85+	Total 65+
Total 2011	1,557,140	1,217,965	967,953	755,703	519,650	383,568	3,844,839
Muslim 2011	21,952	15,911	17,542	11,738	5,733	2,581	53,505
Muslim as a % of total 2011	1.41	1.31	1.81	1.55	1.10	0.67	1.39
2016	37,790	20,732	14,859	15,003	9,074	5,201	64,868
2021	49,547	35,975	19,090	12,967	11,783	8,629	88,445
2026	60,528	47,298	33,372	16,822	10,429	11,945	119,866
2031	90,238	57,961	44,091	29,736	13,708	10,876	156,373
2036	113,598	86,680	54,279	39,596	24,643	14,950	220,148

Table 2
England – Muslim Women

Year	Aged 60-64	Aged 65-69	Aged 70-74	Aged 75-79	Aged 80-84	Aged 85+	Total 65+
Total 2011	1,615,137	1,290,189	1,076,176	913,642	739,123	796,560	4,815,690
Muslim 2011	24,297	17,036	15,655	10,706	5,486	2,837	51,720
Muslim as a % of total 2011	1.50	1.32	1.45	1.17	0.74	0.36	1.07
2016	34,395	23,490	16,424	14,084	8,919	6,359	69,276
2021	43,693	33,462	22,280	14,977	11,849	10,550	93,118
2026	52,918	42,524	31,877	20,415	12,781	14,385	121,983
2031	78,769	51,570	40,620	29,426	17,555	15,566	154,738
2036	100,440	76,909	49,391	37,687	25,611	21,910	211,507

Table 3
Wales – Muslim Men

Year	Aged 60-64	Aged 65-69	Aged 70-74	Aged 75-79	Aged 80-84	Aged 85+	Total 65+
Total 2011	100,867	81,116	64,504	48,994	32,888	23,820	251,322
Muslim 2011	320	261	329	173	72	56	891
Muslim as a % of total 2011	0.32	0.32	0.51	0.35	0.22	0.24	0.35
2016	641	306	241	275	131	62	1,015
2021	963	619	282	206	211	118	1,436
2026	1,103	933	573	244	162	204	2,116
2031	1,616	1,072	869	503	195	163	2,801
2036	2,178	1,577	1,004	770	408	204	3,963

Table 4
Wales – Muslim Women

Year	Aged 60-64	Aged 65-69	Aged 70-74	Aged 75-79	Aged 80-84	Aged 85+	Total 65+
Total 2011	104,018	84,891	70,039	59,208	46,344	50,740	311,222
Muslim 2011	321	249	216	141	65	39	710
Muslim as a % of total 2011	0.31	0.29	0.31	0.24	0.14	0.08	0.23
2016	492	311	236	192	115	73	927
2021	703	480	293	212	158	129	1,273
2026	796	687	455	265	177	184	1,768
2031	1,220	781	653	413	224	207	2,278
2036	1,588	1,199	744	597	353	269	3,162

Table 5
Scotland – Muslim Men

Year	Aged 60-64	Aged 65-69	Aged 70-74	Aged 75-79	Aged 80-84	Aged 85+	Total 65+
Total 2011	164,725	124,671	100,691	76,818	48,592	32,967	383,739
Muslim 2011	622	441	548	270	108	52	1,419
Muslim as a % of total 2011	0.38	0.35	0.54	0.35	0.22	0.16	0.37
2016	1,176	579	396	449	198	90	1,711
2021	1,684	1,107	519	331	335	169	2,462
2026	1,947	1,594	1,004	441	253	309	3,602
2031	2,938	1,853	1,458	867	343	244	4,765
2036	3,665	2,807	1,706	1,273	690	338	6,814

Table 6
Scotland – Muslim Women

Year	Aged 60-64	Aged 65-69	Aged 70-74	Aged 75-79	Aged 80-84	Aged 85+	Total 65+
Total 2011	171,797	136,527	119,903	101,296	75,933	72,936	506,595
Muslim 2011	607	390	340	222	118	40	1,110
Muslim as a % of total 2011	0.35	0.29	0.28	0.22	0.16	0.05	0.22
2016	891	580	363	296	176	122	1,537
2021	1,355	856	538	320	237	185	2,136
2026	1,540	1,305	799	478	261	259	3,102
2031	2,369	1,488	1,225	717	393	293	4,116
2036	2,833	2,294	1,402	1,108	600	440	5,844

Table 7

		MUSLIM POPULATION AS A PERCENTAGE (%) OF TOTAL POPULATION					
		2011			2036		
		ALL	MUSLIM	MUSLIM %	ALL	MUSLIM	MUSLIM %
England	Men	26,069,148	1,383,834	5.3%	30,269,509	2,203,325	7.3%
	Women	26,943,308	1,276,282	4.7%	30,635,970	2,089,527	6.8%
Wales	Men	1,504,228	25,456	1.7%	1,612,515	38,652	2.4%
	Women	1,559,228	20,494	1.3%	1,638,617	32,806	2.0%
Scotland	Men	2,567,444	41,241	1.6%	2,774,300	61,013	2.2%
	Women	2,727,959	35,496	1.3%	2,896,595	56,987	2.0%
Total	Men	30,140,820	1,450,531	4.8%	34,656,324	2,302,990	6.6%
	Women	31,230,495	1,332,272	4.3%	35,171,182	2,179,320	6.2%
	Grand Total	61,371,315	2,782,803	4.5%	69,827,506	4,482,310	6.4%

Table 8

		MUSLIM POPULATION AGED 65+ AS A PERCENTAGE (%) OF TOTAL POPULATION AGED 65+					
		2011			2036		
		ALL	MUSLIM	MUSLIM %	ALL	MUSLIM	MUSLIM %
England	Men	3,844,839	53,505	1.4%	6,674,930	220,148	3.3%
	Women	4,815,690	51,720	1.1%	7,662,443	211,507	2.8%
Wales	Men	251,322	891	0.4%	97,762	3,963	1.0%
	Women	311,222	710	0.2%	457,888	3,162	0.7%
Scotland	Men	383,739	1,417	0.4%	649,589	6,814	1.0%
	Women	506,595	1,110	0.2%	762,726	5,844	0.8%
Total	Men	4,479,900	55,813	1.2%	7,722,281	230,925	3.0%
	Women	5,633,507	53,540	1.0%	8,883,057	220,513	2.5%
	Grand Total	10,113,407	109,353	1.1%	16,605,338	451,438	2.7%

APPENDIX E: POPULATION FORECASTS AND FAITH COMPARISONS

Table 1
England – Men

	Age 65 and over			
Year	ALL	HINDU	MUSLIM	SIKH
2011	3,844,839	31,491	53,505	16,169
2016	4,491,470	41,140	64,868	20,781
2021	4,920,106	53,701	88,445	28,158
2026	5,464,004	65,855	119,866	34,645
2031	6,120,580	75,846	156,373	40,309
2036	6,674,930	88,990	220,148	48,532

Table 2
England – Women

	Age 65 and over			
Year	ALL	HINDU	MUSLIM	SIKH
2011	4,815,690	33,738	51,720	18,967
2016	5,391,371	45,374	69,276	24,883
2021	5,784,012	59,057	93,118	32,286
2026	6,333,604	73,672	121,983	39,490
2031	7,046,287	85,918	154,738	46,023
2036	7,662,443	99,305	211,507	54,372

Table 3
Wales – Men

	Age 65 and over			
Year	ALL	HINDU	MUSLIM	SIKH
2011	251,322	378	891	80
2016	290,788	519	1,015	113
2021	314,627	626	1,436	155
2026	342,498	743	2,116	204
2031	374,594	832	2,801	251
2036	397,762	1,045	3,963	316

Table 4
Women – Women

	Age 65 and over			
Year	ALL	HINDU	MUSLIM	SIKH
2011	311,222	261	710	73
2016	343,849	384	927	104
2021	365,414	554	1,273	145
2026	394,323	691	1,768	204
2031	430,043	836	2,278	254
2036	457,888	1,002	3,162	332

Table 5
Scotland – Men

	Age 65 and over			
Year	ALL	HINDU	MUSLIM	SIKH
2011	383,739	388	1,417	226
2016	444,356	471	1,710	331
2021	488,080	539	2,461	459
2026	544,126	597	3,601	614
2031	605,567	721	4,765	771
2036	649,589	1,018	6,814	946

Table 6
Scotland – Women

	Age 65 and over			
Year	ALL	HINDU	MUSLIM	SIKH
2011	506,595	242	1,110	281
2016	554,496	355	1,537	351
2021	591,019	468	2,136	478
2026	645,282	588	3,102	625
2031	711,036	707	4,116	775
2036	762,726	914	5,844	937

APPENDIX F: POPULATION FORECASTS AND SELF-DECLARED HEALTH CATEGORIES

Base data from the 2011 Census and forecasts

Table 1
England - All Men

Year	Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
2011	3,844,839	1,988,119	52%	1,295,930	34%	560,790	15%
2016	4,491,470	2,322,484		1,513,882		655,105	
2021	4,920,106	2,544,126		1,658,356		717,623	
2026	5,464,004	2,825,369		1,841,681		796,954	
2031	6,120,580	3,164,877		2,062,984		892,719	
2036	6,674,930	3,451,524		2,249,832		973,574	

Table 2
England - Muslim Men

Year	Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
2011	53,505	18,699	35%	20,542	38%	14,264	27%
2016	64,868	22,670		24,905		17,293	
2021	88,445	30,910		33,956		23,579	
2026	119,866	41,891		46,020		31,955	
2031	156,373	54,649		60,036		41,688	
2036	220,148	76,938		84,521		58,690	

Table 3
England - All Women

Year	Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
2011	4,815,690	2,290,175	48%	1,761,133	37%	764,382	16%
2016	5,391,371	2,563,949		1,971,664		855,758	
2021	5,784,012	2,750,675		2,115,255		918,081	
2026	6,333,604	3,012,042		2,316,245		1,005,317	
2031	7,046,287	3,350,970		2,576,879		1,118,439	
2036	7,662,443	3,643,992		2,802,211		1,216,240	

Table 4
England - Muslim Women

Year	Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
2011	51,720	11,515	22%	20,443	40%	19,762	38%
2016	69,276	15,424		27,382		26,470	
2021	93,118	20,732		36,806		35,580	
2026	121,983	27,158		48,215		46,609	
2031	154,738	34,451		61,162		59,125	
2036	211,507	47,090		83,601		80,816	

Table 5
Wales - All Men

Year	Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
2011	251,322	116,605	46%	87,319	35%	47,398	19%
2016	290,788	134,916		101,031		54,841	
2021	314,627	145,976		109,314		59,337	
2026	342,498	158,908		118,997		64,593	
2031	374,594	173,799		130,148		70,646	
2036	397,762	184,548		138,198		75,016	

Table 6
Wales - Muslim Men

Year	Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
2011	891	294	33%	347	39%	250	28%
2016	1,015	335		395		285	
2021	1,436	474		559		403	
2026	2,116	698		824		594	
2031	2,801	924		1,091		786	
2036	3,963	1,308		1,543		1,112	

Table 7
Wales - All Women

Year	Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
2011	311,222	132,711	43%	117,417	38%	61,094	20%
2016	343,849	146,624		129,726		67,499	
2021	365,414	155,820		137,862		71,732	
2026	394,323	168,147		148,769		77,407	
2031	430,043	183,379		162,245		84,419	
2036	457,888	195,252		172,751		89,885	

Table 8
Wales - Muslim Women

Year	Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
2011	710	177	25%	262	37%	271	38%
2016	927	231		342		354	
2021	1,273	317		470		486	
2026	1,768	441		652		675	
2031	2,278	568		841		869	
2036	3,162	788		1,167		1,207	

Table 9
Scotland - All Men

Year	Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
2011	383,739	213,980	56%	117,782	31%	51,977	14%
2016	444,356	247,781		136,387		60,188	
2021	488,080	272,162		149,808		66,110	
2026	544,126	303,415		167,010		73,701	
2031	605,567	337,675		185,868		82,023	
2036	649,589	362,223		199,380		87,986	

Table 10
Scotland - Muslim Men

Year	Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
2011	1,417	596	42%	513	36%	308	22%
2016	1,711	719		619		371	
2021	2,462	1,034		890		534	
2026	3,602	1,513		1,302		782	
2031	4,765	2,001		1,723		1,034	
2036	6,814	2,862		2,463		1,479	

Table 11
Scotland - All Women

Year	Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
2011	506,595	269,943	53%	166,672	33%	69,980	14%
2016	554,496	295,467		182,432		76,597	
2021	591,019	314,929		194,448		81,642	
2026	645,282	343,843		212,301		89,138	
2031	711,036	378,881		233,934		98,221	
2036	762,726	406,424		250,940		105,361	

Table 12
Scotland - Muslim Women

Year	Age 65 and over	Very good or good health - Number	Very good or good health - %	Fair health - Number	Fair health - %	Bad or very bad health - Number	Bad or very bad health - %
2011	1,110	258	23%	485	44%	367	33%
2016	1,537	357		672		508	
2021	2,136	496		933		706	
2026	3,102	721		1,355		1,026	
2031	4,116	957		1,798		1,361	
2036	5,844	1,358		2,554		1,932	

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