WOOLF INSTITUTE studying relations between Jews Christians & Muslims

# Advance care planning and Muslim communities

## A report commissioned by Compassion in Dying as part of the *My Life, My Decision* programme

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# About this research

***My Life, My Decision* is a two-year programme funded by the Big Lottery Silver Dreams Fund. It is a partnership between Compassion in Dying and seven local Age UKs across England. The project provides face-to-face volunteer support to people aged over 50 to plan ahead for their future treatment and care. It also raises awareness of advance care planning amongst the public, professionals and other organisations. The project worked with Black, Asian and Minority Ethnic (BAME) groups to address the challenges they face when accessing information and support to plan their care.**

Compassion in Dying commissioned the Woolf Institute to produce this short, research-based report. The report seeks to explore the context for the *My Life, My Decision* programme and its increasing importance in contemporary times for British Muslims, of whom a sizeable and growing group falls in the 50+ sector of the national population[1], and where awareness of issues and concerns around advance care planning are emerging across a wider age spectrum.

The research is conducted within a limited geographical base to assess the scope of and record experiences relevant to the aims of advance care planning charities; it explores how these aims connect with an increasingly diverse British public. Some of the questions guiding this research are:

- What do Muslims understand by advance care planning?
- What are the tensions in Islamic medical ethics?
- What are the relevant cultural factors?
- How can charities better understand 'the terrain' of citizens from one faith group?
- How do we improve advance care planning in this area?

Although initially focused on the 50+ age group, which is common for discussions on advance care planning, our early findings indicated a latent appetite from a younger generation who wanted to talk about the significance of advance care planning, which suggests that a better understanding of socio-cultural and cross-generational issues may be important factors in decision making. As a result, this research probes the scope of engagement across a wider age group, although most of the experiences cited draw out the significance of planning ahead focused on older patients, as might be expected.

Field research was piloted in two geographical areas: Lancashire and East London.

Four focus groups were conducted; two in each area with invitations sent out through social media, email and telephone to individuals and local community institutions. There were 42 (Muslim) participants (21 female, 21 male – 50:50) with ages ranging from 18 to 78. Although not a pre-requisite for the focus group, most participants had a relationship with caring (often for a parent) or handling care issues, and some worked in care professions.

In addition, three interviews were conducted with palliative care specialists in academia, hospice and hospital sectors. These in-depth interviews, explored their understanding and experiences of advance care planning and British Muslim communities.

1. Dr Philip Lodge, Consultant in Palliative Medicine, Marie Curie Hospice, London. Dr Lodge provides specialist palliative care with a joint hospital and community nurse team at the Royal Free and for in-patients at the Marie Curie Hospice.

2. Professor Aziz Sheikh, Professor of Primary Care Research and Development at the Usher Institute of Population Health Sciences and Informatics, University of Edinburgh.

3. Yunus Dudhwala, Head of Chaplaincy and Bereavement Services at Barts Health NHS Trust. He is a Muslim theologian who has served as a chaplain providing spiritual care and leads a multi-faith team of chaplains across four hospitals.

# Context: Why are we talking about advance care planning and British Muslim communities?

If attention towards advance care planning is normally felt more acutely as one is getting older, then it follows that for Britain's Muslim communities this would now be an emergent social need. A little revision of social history helps put this need into context.

With the partition of the Indian Empire in 1947 and after World War Two (WWII), labourers migrated from India as they did from the Commonwealth. The largest wave of migration from the Indian Subcontinent, including Muslim migration, had begun. It grew through the 1960s after a quota system was introduced in the Immigration Act 1962.

Whilst the 1950s was characterised by transient labourers, and the 1960s by more permanent labourers, the 1970s was characterised by wives joining their husbands (and at times, parents joining their sons). As a result, early family needs for housing and schooling emerged and community hubs that would characterise many major cities and towns of Britain formed over the coming decades.

From the 2000s a much clearer generational shift could be seen. The main language spoken in most Muslim family homes was English[2] and differences in wealth and economic prosperity emerged, leading to increased choice on where families could live, shop, work and send their children to school. In some cases younger families have, for example, relocated to different areas for aspirational reasons, living at some distance from their parents. A corresponding increase in numbers of elderly people living apart from immediate family means that issues in care choices are becoming more significant. Traditional notions of 'family looking after family' are now more challenging as Britain's Muslims are less likely to be living in the same house as their parents / grandparents, which makes 24 hour care difficult without the support of outreach clinical specialists and specialised charities. This increases the need for families to consider discussing their clinical and non-clinical needs so that the most appropriate family and non-family care – at a critical stage – can be agreed. In this way a patient's wishes on how to be cared for can be followed.

The Census of 2011 shows the Muslim population of the UK to be 2.8 million, of which 2.7 million live in England and Wales (equivalent to 4.8% of the population in England and Wales).

Allowing for population growth since the Census, it is safe to estimate the UK Muslim population to be above 3 million at the time of writing. Muslims are the largest faith group after Christians, and the largest of all minority faith groups.

The Muslim population is ethnically very diverse, but this diversity is not evenly spread. About 68% are Asian (there is considerable diversity within 'Asian') and 32% are non-Asian; about one in twelve of Britain's Muslims are of White ethnicity. Muslims are also very diverse in their ethnic languages, socio-economic class, whether they are first, second, third or fourth generation migrants, diverse in their sectarian religious belonging and level of religiosity, as well as where in the country they reside.

Muslims have a significantly younger average age profile than the national average; this can mask an emerging ageing Muslim population, where 326,000 Muslims are aged 50+ years, representing 1.7% of the UK's population aged 50+, but also 12.1% of the British Muslim population. When we consider that 1) the younger average age will yield a faster than average rise in Muslims aged 50+, and 2) the uneven geographic spread of Muslim residency where Muslims can make up a significant proportion of the local population (see Table 1: Top 10 Muslim Population Local Authority Areas in Britain, Census 2011), a growing need for Muslims requiring and using advance care planning services can be seen. This is especially true in some Local Authority areas: about 70 local residential ward areas have a Muslim population of 40% or greater.

Britain's social history after WWII suggests an ever increasing diversity in the care of citizens will continue. By the time of the next Census, we can expect 500,000 Muslim citizens who are aged 50+. Some will be first generation migrants who will have specific language and cultural needs, but an increasing number will be competent in English, having been schooled in Britain.

# Islam and advance care planning

Not only are Britain's Muslims diverse in their ethnic and cultural identities, they are also religiously diverse, both in terms of denomination, religious interpretation and, how important religion is to the individual or to the family household. The relationship between Muslims and their faith is individual and varied.

Primary religious teachings (taken from the Quran and Hadith, reports of teachings by Prophet Muhammad) point to a pragmatic approach to advancing age or declining health. It is described as God's design – part and parcel of life's tests, which can affect any stage of life. By being a sign of God's plan, such teachings allude to ageing or illness as worthy of our observation, thought and planning, as well as being a general 'reminder' for society at large. Despite religious and spiritual guidance encouraging preparation and making decisions about one's life well before a time of ailment, many neglect this responsibility:

> **"Also looking at the way as a community we don't think about death and dying matters. The GPs and the staff put my mother on end of life care and I never knew about that, it was a shock really to digest all of this information. It had to be done very quickly because you have to make a decision very quickly. I think that as an individual, as a community, it was something very difficult to comprehend because as a family we never discuss dying or death or end of life or planning for it. There was no information and there was no support."**
> *(Male, Lancashire)*

Yunus Dudhwala shares this concern:

> **"Having had the experience of being in the hospital for nearly 20 years, having looked at this area for quite a long time, religiously you are allowed to have an advance care plan where it stipulates a limit on intervention. People can plan their care but I think that there is a lack of awareness from a religious perspective."**

The real-life manifestation of scriptural guidance can often be different when we consider how followers of a faith live their day-to-day lives. Many Muslim families will 'put off' uncomfortable conversations about planning until a time when they may become sick or suddenly unable to communicate their wishes. Some will make attempts to consider how they would wish to be cared for by providing guidance for close family.

**"I've written notes down. But nobody knows where they are. But if I go anywhere I will always update a little will that I've got. But it's not a formal legal document. It's really my last wishes."**
*(Female, Lancashire)*

**"It requires cultural changes and it requires the institutions and the community to talk about it...they don't talk about the process in the sense that when you are terminally ill. Some things are there because in Islam it is requisite to look after those who are in need and it's a hugely blessed activity but there are things where you need support and you need help. But in that sense I think that mosques are pivotal...These issues surround us. There are more cancer patients than there were before. Every other day we hear about cardio-vascular problems; and we hear about lots of people [from mosque lectures] who are ill and who we should pray for. But the guidance in a sense of how to really take it forward is lacking. I think that nobody talks about it."**
*(Male, Lancashire)*

**"I think that people do some of this stuff informally. My mother informally will occasionally talk about that her wish if she dies is to go back to Pakistan. Or, she wants a will. But sometimes what can happen, if you don't write these things down... She's had that discussion with me. When I saw this leaflet, when I saw your poster I thought 'if something happens in hospital, the children can decide what is the best route forward'. I didn't even know that you can put these things in writing. I mean, I've done a bit of training, but when you think about yourself, you don't. If some of these things were written down to clarify your parents' or your loved one's wishes about what they would really want. For example, my mother has told me that she'd want to go back to Pakistan, but if that time came and my brothers and sisters said that they wanted her to be buried here because they live here, if everybody knew her wish then their attitude might be different."**
*(Male, Lancashire)*

Also, and not unlike the wider population, adults may not appreciate the need or feel any urgency in making planning arrangements, even when entering long term health challenges. At times this can create challenges for loved ones who want to follow the wishes of their relative but find it difficult to identify what those wishes are and to create a consensus within families to follow these. Yunus Dudhwala explains:

> **"...When we look closely at theology it does allow us to write down whether there should be intervention at a certain stage or not. As I mentioned, the Islamic ruling is that unless there is 100% definite outcome from a certain medicine or intervention a person can say that they don't want it. So therefore a person can refuse if they feel that they don't want that intervention."** [4]

## Selected quotes from Scripture and Prophetic Teachings[3]:

*"Your Lord has commanded that... you should be kind to your parents. If either or both of them reach old age with you, say no word that shows impatience with them, and do not be harsh with them, but speak to them respectfully and lower your wing in humility towards them in kindness..."*
*– Quran 17:23*

*"It is God who creates you weak, then gives you strength, then weakness after strength, together with your grey hair."*
*– Quran 30:54*

*"It is a duty of a Muslim who has anything to bequeath not to let two nights pass without including it in his will."*
*– Prophet Muhammad*

*"Yes, you should seek medical treatment, because God, the Exalted, has let no disease exist without providing for its cure, except for one ailment, namely, old age."*
*– Prophet Muhammad*

Although there are periodic reminders from religious teachers of the imperatives within Islamic teachings for a more proactive and pragmatic approach to advance planning (particularly the writing of wills), and about the role of individual agency and responsibility for ensuring such matters have been dealt with, there is an absence of a 'planning culture'. Life insurances, wills and planning arrangements are – in practice – not given much attention. Some reasons for this overlap with the concerns of the general public for example households may not feel they have sufficient wealth to consider issues of inheritance or that private care is not appropriate for them because of a perception that care services will struggle to understand the needs of a minority religious or cultural community. Often households may not be adequately aware of support available in making advance care planning decisions and the provisions available, including support from charities that specialise in this area.

In addition, being largely from a migrant background where immediate family networks are more centralised and there is an expectation that 'the family will look after me', the need for personal ownership instinctively feels less of a priority.

Whilst this 'system of care' may offer comfort, it isn't keeping up with fast changing realities around family formation and changing family dynamics. These changes are yielding more situations where people of advanced age may be feeling more vulnerable or where their children feel insecure about meeting a parent's wish in practice, particularly when such wishes are not written down or are left to close family members to decipher and then enact. The gradual emergence of a wealthier Muslim middle class, who have smaller families and live further away from their parents, will also impact how well they understand their parents' wishes, concerns and needs.

Families living further apart can have a direct impact on increasing the need for advance care planning. An elderly parent can have greater comfort in the knowledge that their children have been part of the decision making process and know how to fulfill their stated wishes. Parents often feel ill equipped to make such decisions without family discussion for different reasons: women may wish for the advice of their husbands, parents may feel they are unable to understand language around advance care planning or the services that are available to them. As younger generations move into higher age brackets, it is likely we will see greater independence in decision making.

**"As far as treatment is concerned, or any special requests are concerned, I think that in the Muslim community that might increase in the years to come, once people have been Anglicised or whatever."**
*(Male, Lancashire)*

**"My dad had certain wishes and we fulfilled those wishes, but it's left to the people left behind in terms of what happens. His wishes were communicated to me verbally in conversations. When we couldn't fulfil all of his wishes we were saddened. We had to make decisions."**
*(Male, Lancashire)*

At the end of life stage, these factors will clearly intensify. Muslim patients and their relatives will look to religio-cultural traditions and spiritual guidance, particularly if there is a need to make critical decisions at a terminal stage or after death. Families or patients who are not normally religious may turn swiftly towards it, for guidance or answers, in the hope that they are able to fulfill last rites for their loved one.

**"[A written care plan] would put my mind at ease because then I wouldn't have an organisation, doctors, the medical team, taking over what should happen to me. From what I've witnessed in hospitals they can be very rough and my daughter, I trust her a lot, but she doesn't have that knowledge."**
*(Female, London)*

Like many others, Muslims will find themselves in the difficult position of preserving life and seeking treatment and comfort for as long as possible whilst accepting the ultimate will of God who, in theological terms, determines when a soul moves on to the next phase in its linear journey, from life to afterlife. For Muslims, death is not the end but the continuation of a journey into an afterlife, and the spiritual wellbeing of the 'soul' that is moving on becomes an important consideration alongside 'doing the right thing' (in religious or cultural terms) during the last stages of life and death. Determining the particular wishes of a patient can be challenging for staff in the absence of advance care planning documentation when clear communication is no longer possible and family members liaise between the patient and staff. Whilst this type of communication can be helpful, it has been known to bring challenges in emotional family responses to 'Do Not Resuscitate' (DNR) notices for example, where family members may feel everything possible needs to be done, against the wisdom and experience of staff. For example, Yunus Dudhwala explained:

**"There is this kind of understanding within our cultures... where people think that the doctors and the nurses have to keep someone alive as much as possible and therefore if a person goes into cardiac arrest the doctors will have to resuscitate them, even though it might be harmful to the person. They think that we never ever should sign a DNR form because that's not the 'done thing'. Some people might think that it's religious but it's not. Religiously you are allowed to have a DNR form signed."**

**"Even if you try to explain to a family in intensive care, when the doctor is saying that he can't do anything more, they will argue with the doctor and tell him that he can, that he must keep the person alive."**

# Focus groups

Forty-two participants attended one of four focus groups held in Lancashire and East London. They spoke candidly on the subject of advance care planning, about their awareness, related experiences, tensions and opportunities. The outcome of these group discussions have been themed below.

## Awareness:

**"I don't know anything. I'd never heard of advance planning, never heard of wishes, never knew that this concept ever existed. I thought that sometimes someone just makes a decision for you. I didn't know that you could have actual wishes or that you could plan in advance for certain things that you'd like."**

**"I knew legally that if you own property that you would have to make a will, so I just knew that to that extent, but it has come as a surprise to me to be honest, to find out that you can actually plan your medical care and that you can say 'no' to certain things."**

**"I didn't know anything about any of these things until I started working on end of life, and I'm very conscious that my family, my friends, my circle have never talked about any of this let alone an advance care plan. I think what's really interesting coming into it from a professional perspective is that I didn't realise that it's not just the cultural stuff. There's cultural rituals, there's clinical rituals, and there's bureaucratic rituals. So there's all these three different facets which add to the whole complexity of dying and I wasn't aware."**

## Confidence in the process:

**"No, I don't think that they know the procedure. I think that they know that they have the rights. I think that there's a level of disconnect."**

**"Who's going to enforce that? If you don't have children who know you and who can argue against the system then that piece of paper is open to interpretation by whoever picks it up."**

"Sometimes it's also about challenging the doctors. I've been in a situation where I've wondered if the doctor does know best, but it's not what you say it's how you say it. So if you can ask the doctor why they are prescribing something or what the effects of it are, I think that's what we need to do ourselves."

## Appetite for engagement:

"We would never think that the Somali women[5] - because each community is so isolated - we never thought that the women would be forthcoming in discussing it [advance care planning], but they actually did it once they were told [about it.]"

"I knew it [advance care planning] because of my work, but I've never seen anybody else who's made advance care planning. For the last 16 years, I've never seen a Muslim do that."

"Advance care planning would help not only me, but the clinicians around me who are supposed to support me."

## Lack of planning: Personal experience

"She, my Mum, changed her religion and was a Muslim and she originates from a Sikh family, so after she passed away, my sister, she wasn't obviously happy with what my mother wanted, but there was nothing written down, but I knew because my mother always used to tell me, you know, do not cremate me, I want to be buried, I'm a Muslim and these are my wishes. So, when she passed away my [Sikh] sister found it really difficult... it wasn't real to her because there is nothing formal."... [Nothing was written down because] "There was no support given. There was no guidance. We didn't know."

"A friend of mine who has a family history of cancer, they have seen a number of people die and have seen the negative effects of chemotherapy on the individual. As a family, or as individuals, they don't want to have chemotherapy because they saw that it affected their quality of life. In this period of this last six months people went to perform umra [pilgrimage] or to religious activities which helped their end of life process. As a family they've made that decision and taken ownership of that situation."

"Sometimes the decision is taken out of someone's hand. If a young woman's husband dies, then people will ask the wife what their wishes are, but someone else makes the decision because everything happens so quickly and people are grieving. In these cases, the wishes of the person who died or those closest to him, often aren't being met. The decisions are made by extended family."

## Community structures:

"People don't talk about it [advance care planning] so you know that you need to approach certain organisations and get the conversations going."

"While we need to improve the way we do things, we as communities, we need to provide a voice for how we want it to be managed, but I think that you can't do that, until you've actually got a space to think about and talk about death. I don't have a space to talk about death in Islam and what it means."

"We're on new territory that's why, so there's an ambiguity at the moment, because it's not all clearly defined, because we're an emerging generation that straddles two worlds in a way and therefore, these things are only now coming up because it's new and it's unclear."

"We used to look after our parents in big cities, but now some elderly people have started to go into old people's homes. The care that we used to provide is dying out unfortunately; slowly but surely."

## Personal conflict with faith:

"There are people who would say that making a plan is like making yourself God and deciding that 'I'm going to die'. But it should only be God who decides. So if someone says that you should do advance care planning because the doctor says that you are going to die within six weeks then she will say, but the doctor, he is not God, and you will have to say well anyway, let's make a plan, even if you don't agree with that. She'd say, if I do that, it means I'm cheating God."

"When the doctor says that [terminal illness], it means that you accepting your doctor to be God and deciding for you that you are going to die. Therefore, to stop that yourself, you can say, God, I've got faith in you, I'm begging you to give me a long life and I'm not going to think about advance care planning, I'm not going to think about it. And if I put any doubt in myself by making advance care planning, I'm saying that you might not give me a long life."

"I think that as a Muslim, when we talk about topics like this I realise that I lack knowledge because there are certain rights and rituals that we've got to adhere to and perform and we don't know about them so how can we inform other people? We need to start with us, to find out what our duties and responsibilities are."

## Importance of awareness across a greater age range:

"To me it's not positive. I think the lifestyle and the culture here is different. For example if a younger person has elderly parents with a huge mortgage, who is going to pay that? There are other problems which young people face, sometimes they can end up in very difficult situations and they want to look after their parents but they can't."

"My parents don't know what they're doing and my children aren't going to know what they're doing. So there is a complete disconnect but that knowledge in between hasn't been filtered and we don't know what we're doing."

"It needs to be an open process where younger people in the family engage. It's not only for the elderly people."

"There is a question that we need to think about regarding who should make the decision. For example, my mum and in most Asian families, the decision is not made by the person but by the family."

"Being dependent on your children and your GP is not okay; it's not getting easier on the children. It's wrong for their happiness and is selfish on our part."

"I've spoken to my family about this but they're not bothered about it. They don't want to think about it. Whatever happens your children will look after you, they will make decisions, it's very rare for people to think about these things, only people who are very sensitive."

## Outreach by charities:

"I think that they've [Compassion in Dying] got a big task because we don't know what we want. As a community we can't decide whether donating organs is acceptable or not."

"We don't necessarily need to establish a separate Muslim charity to deal with this, but if an organisation already addresses this then we need to engage with them, and bring the different groups together to engage."

"I think that it's about informed choice. Healthcare professionals should be able to tell their patients what the choices are in a clear and accessible way."

"I think that's [committing to writing a care plan] a very good idea, but not everybody's able to do that. If you're unable to do it, I think that it's unfair that it's not offered to them."

"I think that there is a lack of knowledge about these issues. We become very trusting in the health professionals so in some ways whatever pathways they put us on, we tend to just accept that not knowing that there are other alternatives."

# Specialist interviews

## Imam Yunus Dudhwala: A Muslim Theologian / Chaplain's perspective

The researchers interviewed Yunus Dudhwala, Head of Chaplaincy and Bereavement Services at Barts Health NHS Trust.

### Community reluctance is tied to a lack of familiarity:

"I don't think that there's been much awareness or engagement with advance care planning within the Muslim community... on the whole I think that it's something which the majority, if not nearly all Muslims, are not aware of."

"Initially, if you tried to put an advance care plan in front of the Muslim community, I think that they might be a bit reluctant because they're not aware that it's allowed theologically... In reality I think that once it's clarified that it's good, that it will be helpful to them and their family, and that it's encouraged by our religion, then I think that you would get a good response."

### Theology encourages taking ownership in planning:

"A will is very much encouraged according to one saying of the Prophet Muhammad. Also, anything that needs to be taken care of, in terms of your family, in terms of your children, you should be thinking about that. Therefore, an extension of that would be to ask what would happen if you became ill, and couldn't communicate or became incapacitated, have you taken care of that?... I definitely encourage settling one's affairs; writing things down. From an Islamic perspective you have to."

"...When we look closely at theology it does allow us to write down whether there should be intervention at a certain stage or not. As I mentioned, the Islamic ruling is that unless there is 100% definite outcome from a certain medicine or intervention a person can say that they don't want it. So therefore a person can refuse if they feel that they don't want that intervention."

### Institutional engagement can be productive, if its strategy is appropriately directed:

"You've got to involve people that know their theology because without that I don't think that you're going to get success. Then you've got to look at your engagement strategy within that institution... If there is a Muslim community then how do we engage with that community? It's trying to think of an engagement strategy first to link in with the communities."

"For me, it's about going into the heart of communities. From a higher level, it's not going to get through, so if you're going to try to get a message out from organisations that are not embedded within the communities then I think it's not going to work."

## Dr Philip Lodge: A Palliative Care Consultant's perspective

The researchers interviewed Dr Philip Lodge, Consultant in Palliative Medicine.

### The right emphasis is constructive:

"Even though we clearly are talking with an emphasis on Muslim communities, there are so many similarities between all communities. In my line of work, actually every community finds the idea of advance care planning a challenge. People are not, I feel, widely prepared for their final illness, they do not think about things very much in advance."

"The emphasis is very much on prolonging life and people do not, I feel, consider what happens when that is no longer the emphasis... When we embark on a treatment with chemotherapy or dialysis, what we don't do well as medics at the moment is say that this will have to stop at some stage because either the disease won't respond, or you will become more unwell and can't tolerate it anymore, or the treatment itself will make you too unwell, or you may say to us 'I've had enough, thank you, I don't want anymore'."

### Pragmatism and strong belief can be harmonised, but this is not always easy:

"I think that religious Muslim people and Orthodox Jewish people are extremely similar in their approach to seeking medical care in what they will and won't contemplate in terms of decision making. I think the strongly held belief that you must do absolutely everything you possibly can to prolong life no matter what is a real barrier to some conversations and some decisions. But even when I am looking after someone from a religious Muslim or Jewish background, they don't always, by any means, hold to that absolute ideal."

"Some of the most difficult conversations with religious patients' families have been around DNR. No matter how we phrase the conversation, there are some people who will insist that it [resuscitation] must be done because of religious reasons, or they say to us 'so you're just going to let them die', or 'you're murdering my relative through inactivity'. These are really difficult conversations and there sometimes is no resolution."

"When the person themselves cannot tell us how they feel because they've lost capacity, then it's really tricky because then we're faced with the dilemma that our code of practice brings, which is not to do things to people when it's futile or harmful. Yet the family is actually, literally on occasion, begging us to do things..."

### Advance care planning can be at the heart of patient-family experience:

"We would have much greater confidence and indeed have a very powerful reason for putting the [advance care] plan in place. So the patient's voice is definitely the most powerful."

"We all see that there is a need to be more open, honest and to have these discussions sooner than we're doing currently. I think that challenges are on both sides in terms of how we get better at this."

## Professor Aziz Sheikh: An Academic's perspective

The researchers interviewed Professor Aziz Sheikh, Professor of Primary Care Research and Development and the Head of Medical Informatics based at the University of Edinburgh on the research subject. The interview explored a positive approach to advance care planning dealing with sensitive issues:

"I think that overall, having the starting position of advance care planning is in general a very good move, because what it involves is trying to facilitate open discussion about making provisions about end of life. I think that anything that facilitates communication and promotes patient and family-centered care in that context is very welcome because what we are all trying to do, I think, policy-wise or clinician-wise is trying to make that care experience as appropriate and as sensitive and as nuanced as possible."

### The importance of conveying the breadth of scope under advance care planning provisions is a challenge that needs to be tackled:

"I think that where the issue sometimes arises is that traditionally it has been spoken about in a very narrow sense with decisions concerning only end of life care provision. People have concerns that sometimes there are decisions being made without appropriate discussion, understanding and consent. I know that's not in the spirit of advance care planning but I think that sometimes it is misinterpreted or misconstrued and it's not only by Muslims or minority ethnic or faith groups but there are wider concerns as well and I think that's where the challenge lies."

### A lack of understanding of different needs can lead to negative experiences that are often avoidable:

"I think that it [advance care planning] can be interpreted differently by different stakeholders. I think that if there is confusion around 'Do Not Resuscitate' orders, for example then that is potentially problematic…There have been some instances where professionals have acted inappropriately…I think that some of the ways that this has been played out in the media hasn't been particularly helpful either. I think that there are all sorts of parties that are potentially at fault here and that can be problematic…the challenge comes when there are concerns, and I heard these raised by some Muslims, where they feel decisions have been taken around resuscitation without their consent, or that's the way they perceive it. That then becomes potentially very, very problematic."

### Examples of instances where treatment objectives result in conflicting expectations due to a lack of adequate planning and/or foresight:

"For example, a couple of the areas where I have got involved has been around kids who are in vegetative states and there have been decisions where the professionals have assessed that there is no chance of any meaningful recovery and the carers will have a different perspective on that."

"There are instances where there are elderly relatives that have been admitted and there have been decisions taken around 'Do Not Resuscitate' and this has been done without the appropriate discussion with individuals and family members. [It] is a very difficult area because it involves prognostication [forecasting the inevitable future] and that's really something for people to get their heads around. I've seen this with Muslims, but I've seen it with other communities as well. So is it specific to Muslims? No, absolutely not. Are these issues extenuated in the case of Muslims? Some of the time, possibly."

## Further research into this area of advance care planning is needed:

"I think that some more research on this area would be welcome. I think that there's been very little historically that involved Muslims. We've done longitudinal, qualitative, in-depth work with Triad[6]. So if that kind of work was focused on this issue [advance care planning and Muslim communities], that would potentially be very valuable."

# Recommendations

There is a healthy, yet latent, appetite to explore and increase awareness of advance care planning amongst British Muslim communities. This applies not only across the typical age of 50+ but moves across three generations. Not unlike the wider population however, we can also expect a greater urgency for taking positive action at a later stage in life, where we see a steady growth in numbers. British Muslims aged 50+ years of age represent 1 in 8 of all British Muslims, numbering 326,000 in the 2011 Census and projected to exceed 500,000 by 2021.

**Recommendations based on this research:**

- The pattern of social migration for most Muslims means that both understanding and decision making are shared across generations. Information sharing and awareness initiatives therefore need to reach out to, and be shared across, a wide age range and also connect to grassroots communities.
- Muslim communities have a responsibility to stimulate discussions around advance care planning, including the adaptability and facilitation (or lack of) within their own faith teachings and/or cultural traditions. There is hesitancy amongst Muslims around the extent to which they can or should engage in an advance care plan, a hesitancy that is rooted in notions of Divine Will or God's purpose that yields a 'what is to happen, will happen' philosophy. This philosophy finds itself in tension with other instructions found in faith teachings that endorse planning ahead, and in fact, strongly encourage committing such plans to record. Communities are realising that stimulating these discussions through a range of initiatives that encourage conversation brings real benefit both to them and to their loved ones.
- Charities (such as Compassion in Dying) have an opportunity to stimulate discussions and raise awareness amongst Muslims (and by extension, other minority faith groups) to further interest in this area. A series of short collaborative videos, explaining advance care planning provisions and processes should be developed, as a resource for families, aiming at a wide age range. Face to face initiatives that bring in younger ages to consider advance care planning, both for themselves and for older family members, would advance these aims. Engagement with younger age groups (i.e. younger than 50 years) would also stimulate theological debate as most of the drive for contextualising faith traditions comes from younger generations who are born and raised in a local British context.

- In theological terms there is considerable support for the notion of advance care planning but little is known about this amongst healthcare services specialising in this area. This is likely to lead to areas of confusion for both the families and support or advice services: families may not appreciate the level of personal discretion given to, for example, an elderly patient as an independent person in their own right. On the other hand, services may encounter cultural and sub-denominational factors that would mean there is no 'one size fits all' model of religious practice for Muslim individuals across Britain's diverse Muslim communities.

- Direct engagement between charities and Muslim institutions can help bring about clarity on the rights, provisions and benefits of advance care planning, alongside the theological considerations that support it. Access to specialist media and national events can bring these conversations straight into living rooms so that groups across age, gender and ethnic spectrums, which may not be reached through more traditional places of worship, can be accessed. Multi-lateral engagement is essential.

- There can be additional concerns that (Muslim) women may have regarding personal aspects of care. Community discussions around a woman's intimate care being handled by female nursing staff as a strong preference (when one's capacity to communicate is diminished) can incentivise the need to plan ahead. This could be approached at a time of better health or capacity and can be a useful avenue for public awareness. Additional outreach options can include women's faith groups and specialist media channels which provide dedicated spaces for such issues to be explored from a female perspective, often during daytime hours.

- Charities, care providers and other stakeholders should seek specialist training programmes to better understand topics such as: Muslim diversity (religious and cultural diversities), theological perspectives on advance care planning and related matters, contemporary issues and generational differences, religious rites of passage and community / family dynamics – all of which will improve understanding of issues related to advance care planning.

- Further research into advance care planning and British Muslim communities across a national spectrum and to explore theological and community issues at a deeper level would greatly enhance the reach and aims of charities such as Compassion in Dying and its broader social and personal impact on communities across the country, particularly in towns and cities where sizeable Muslim communities reside.

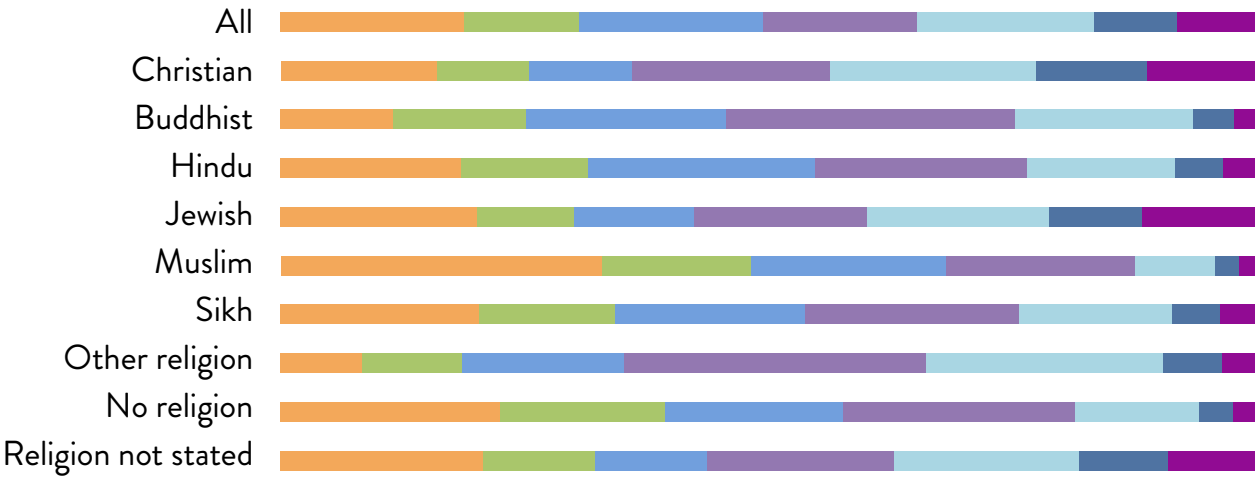
# Appendix: Demographic data

## Table 1:
## The Muslim population in Britain, Census 2011

| Ranked by population in Local Authority areas | Ranked by percentage of population in Local Authority areas |
|---|---|
| 1. Birmingham | 1. London Tower Hamlets |
| 2. Bradford | 2. London Newham |
| 3. London Newham | 3. Blackburn |
| 4. London Tower Hamlets | 4. Bradford |
| 5. Manchester | 5. Luton |
| 6. London Redbridge | 6. London Redbridge |
| 7. Leicester | 7. Slough |
| 8. Kirklees | 8. London Waltham Forest |
| 9. London Brent | 9. Birmingham |
| 10. London Waltham Forest | 10. London Brent |

## Table 2:
## Religion by age in England & Wales, Census 2011

| Age | Religion not stated | No religion | Other religion | Sikh | Muslim | Jewish | Hindu | Bud-dhist | Chris-tian | All |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 to 15 | 20.8% | 22.6% | 8.4% | 20.5% | 33.1% | 20.1% | 18.5% | 11.6% | 16.0% | 18.9% |
| 16 to 24 | 11.5% | 16.8% | 10.3% | 13.9% | 15.3% | 10.1% | 13.0% | 13.6% | 9.5% | 11.9% |
| 25 to 34 | 11.5% | 18.6% | 16.5% | 19.5% | 20.1% | 12.3% | 23.5% | 20.4% | 10.5% | 13.4% |
| 35 to 49 | 19.3% | 23.7% | 31.3% | 22.1% | 19.4% | 17.9% | 21.7% | 29.9% | 20.5% | 21.3% |
| 50 to 64 | 19.0% | 12.8% | 24.3% | 15.6% | 8.1% | 18.7% | 15.2% | 18.3% | 21.1% | 18.1% |
| 65 to 74 | 9.0% | 3.5% | 6.1% | 5.0% | 2.5% | 9.6% | 5.1% | 4.3% | 11.5% | 8.7% |
| 75 + | 8.8% | 2.0% | 3.1% | 3.3% | 1.5% | 11.4% | 3.0% | 1.9% | 10.9% | 7.8% |



# References


1 326,000 Muslims are aged 50+ years representing 1.7% of the national 50+ population (Source: Census 2011, ONS)

2 52.4% of Muslims stated English as their main language and a further 35.3% spoke it very well or well – Census 2011 (Source: ONS Table CT0557)

3 Prophetic teachings are taken from reference books of 'Hadith' which contain eyewitness reports or statements about what Muhammad said or did.

4 A lack of a "100% definite outcome" allows scope for an individual to make a personal choice, or leave an instruction, that they choose not to receive a treatment or medication if it may not save them in any case. However if the treatment or medication is clinically proven to work, then Islamic teachings prescribe it should be taken. There is therefore, scope for personal choice in end of life treatment that should be based upon medical facts.

5 As part of *My Life, My Decision* Compassion in Dying partnered with Women's Health and Family Services in East London to explore advance care planning with a group of older Somali women. Over the course of eight workshops the women shared their preferences for the end of life and experiences of end of life care in the UK.

6 TRIAD I-The Realistic Interpretation of Advanced Directives, Ferdinando L Mirarchi Journal of Patient Safety 4(4):235-240 · December 2008

WOOLF INSTITUTE studying relations between Jews Christians & Muslims

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