

Bridging the Gap

Strengthening relations
between hospices and
Muslims of Britain

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Contents

Foreword	1
Executive summary	2
Introduction	4
Research methodology	6
Why are we talking about hospice care and British Muslim communities?	7
What is important to Muslims towards the end of life?	9
Barriers to engagement between hospices and Muslims of Britain.....	11
Learning from national workshops	16
Learning from the data	19
Learning from best practice.....	24
Growth in Muslim hospice patients ...	29
Framework for good practice	31
Recommendations for hospices, policy makers and Muslim communities	34
Research limitations	36
Conclusions.....	37
References	38
Appendices	40

Foreword

It's often the case that a personal conviction drives us to prioritise an issue. A commitment to enable and empower public services in the area of diversity in end of life care is the motivation to research and write this report.

Thanks to the support and commitment from Hospice UK and Together for Short Lives, along with the Woolf Institute, this report gives us a detailed insight into end of life care in relation to one of the most talked about faiths in the world: Islam. Muslims are the second largest faith group in Britain and play a key role in British society, including public health. However, as we don't often think of Muslims as hospice users, we don't consider how both children's and adults' end of life care needs are met (or remain unmet) amongst diverse Muslim groups.

Yet hospices and Muslim communities engage with one another on an ad hoc basis in most parts of the country, whether as service users, fundraisers, volunteers in hospices or even sharing their experience of being in a hospice. Muslim communities can be key in the work of hospices located in the top five areas where Muslims reside.

This report tells the story of this engagement whilst at the same time exploring the challenges. It makes recommendations for hospices and Muslim communities to work together across the UK.

I commend it to anyone interested in end of life care

Dr Edward Kessler MBE
Founder Director
Woolf Institute

Executive summary

- Britain's hospices have steadily transformed our society's relationship with end of life care, demonstrating innovative and responsive developments to new approaches in care. This continues to be the case as hospices plan for the needs of emerging social groups that have, until now, not constituted a core segment of patients, but who represent a steadily growing sector of older people in their final years.
- Britain's Muslims, who make up the largest faith group after Christianity, have an ageing generation with specific language and cultural needs, most of who arrived as young men and women during the 1950s, 60s and 70s. In addition, there is a younger generation that requires hospice care for a range of life-limiting conditions affecting children.
- The report is interested in enhancing the impact of hospice care, in terms of reach and engagement with Muslims, and exploring gaps in communication and patient access.
- Although having a younger age profile than the national average, Britain's Muslims are getting older and family structures are beginning to thin out and spread. Greater affluence is also pointing to some young families relocating for reasons of schools and careers, which results in emergent challenges in the care of older relatives. This will have a broad impact upon hospices and broader palliative care networks, which will see a noticeable increase in Muslim patients over the coming years, particularly in local areas of significant Muslim populations.
- A Muslim patient's journey from the point when a life-limiting illness is diagnosed can travel through mosque services, palliative care services, medical experts, community links, spiritual services and burial services, many of whom engage with each other as and when called for. These working partnerships can be channelled in a more complementary manner across the care disciplines to improve understanding and services.
- There are essential omissions in primary data on Muslim deaths and hospice use, alongside a general assumption that essential primary data on the subject is clear and accessible, when it is not. Omissions in data hamper effective communication, planning and monitoring. As a result, it is difficult to quantify the extent to which Muslim homes may currently be under-utilising hospice care due to gaps in communication and understanding. Clearer hospice data on Muslim communities utilising hospice care will help an understanding of growth in the uptake of hospice care, locally and nationally.
- The general appetite and readiness to prepare for this increase and to understand its challenges is very healthy, but there are aspects that can be identified as obstacles to effective engagement between hospices and Muslims. Without effective communication, cultural and religious concerns and sensitivities will continue to act as barriers to positive engagement with hospice services.

Making progress in this subject is centred around three core areas:

Data records and essential information

- A deceased person's religion and ethnicity should be recorded (as optional fields) as primary information at the registration of death. The omission of religion at the registration of death results in a serious lack of primary data held at national and local authority levels, resulting in core omissions in the information provision necessary for effective civic planning and social monitoring.
- Hospices and service providers specialising in palliative care should also keep data on both religion and ethnicity. Where possible, the data should be included in the transfer of patients to burial services upon death. By return, Muslim burial services and mosques dealing with the final journey of deceased persons should store more detailed information regarding the deceased person's care, with a clear categorisation of where death occurred.

Communications to communities

- Hospices and service providers should utilise specialist community channels to promote hospice services, as avenues for progressing understanding and mutual cooperation. As a result of the closer cooperation between clinical and religious services providers, Muslim bodies and institutions should utilise specialist satellite television and radio channels to educate and promote end of life care services to their (Muslim) audiences.
- National conferences present platforms to discuss changing needs and explore the emergent challenges for new user groups such as Britain's ageing Muslims. Muslim bodies and hospices should also work together with mosques in the preparation of sermons (khutbas) to communicate the services provided by hospice care. Mosques should also promote how local citizens can redirect charitable services and time resources to support local hospices.

- In parallel, local hospices should actively seek to locate local women's groups and clubs where direct communication with women in the 40+ age group can be achieved and more direct connections sought.
- Local hospices should actively seek to locate opportunities where direct communication with families can be achieved, eg with local schools where there are a high number of Muslim children.
- Local palliative care services should actively seek opportunities where direct communication with pregnant women can be achieved, eg through maternity and neonatal services.
- A series of short collaborative videos explaining hospice care services and processes should be jointly developed, as a resource for families who have reached a point where hospice services should be a considered option.

Education and training

- Hospices, service providers and clinicians should seek specialist training programmes to better understand the 'last journey' protocols and services that each provides on either side of death. Good and common practices, including the systematisation of data records and the importance of legal, clinical, religious and religio-cultural practices should be explored.
- Muslim burial services should learn from the more established and more carefully monitored practice models, eg adopted by Jewish funeral services. The parallel similarities that religious protocols have surrounding death and burial arrangements means much can be learnt from a specialist religious services sector to enhance business practices.

Introduction

“Palliative and end of life care is provided by hospices for people of all ages with life-shortening illnesses, their relatives and family carers. It is delivered in partnership with others, including local communities, so as to reach out to more of those who could benefit from it, and into the many different settings where care is needed. It is a dynamic and innovative response by hospices, which are constantly adapting to meet the palliative and end of life care needs of the communities they serve. Hospice care is about dying, death and bereavement and about living with these realities.”

Commission into the Future of Hospice Care (2013)

One of the great social innovations of the twentieth century, hospice care has transformed both the way society thinks about and the way it cares for people approaching the end of their lives. Hospice care was developed in response to the recognition that, whilst our health systems have evolved to prevent, treat and cure illness, they are ill-equipped to provide people with the holistic care (psychological, spiritual and comfort care) – that people want and need at the end of life.¹ Hospices have a strong history of innovation and have been pioneers in developing new approaches to care. They continue to evolve and adapt in response to the needs of everyone in their local community who might benefit. However, the quote (above) describes a hospice service that for far too many adult and children’s hospices is an aspiration rather than a reality.

The inspiration behind the modern hospice movement was Dame Cicely Saunders (1918-2005); today we have over 200 adult and children’s hospices across the UK², many of which cater for both adults and children.

The history of ‘hospice’ is rooted in Christian traditions, and hospices have historically catered for a population that was less heterogeneous than the diversity in Britain today, but most now aspire to represent and support the community they are situated in. Hospices, particularly children’s hospices, provide services to patients and relatives both during life-limiting conditions as well as at the end of life.

Census data from 2001 and 2011 has shown the growth of minority groups, their age profile and where they reside across the country. When we explore data for faith groups we find that, after Christianity, Muslims of Britain are the second largest.³ In addition, Muslim communities, a population that migrated to Britain in significant numbers over the last sixty years, have an ageing first generation with specific language and cultural needs, and also a young generation that requires hospice care for a range of issues including life-limiting conditions affecting children amongst South Asian groups, particularly those residing in deprived areas.⁴

Adults only:	181
Children only:	25
Mixed adults and children:	13

It is for these reasons that this report asks:

- Why is there a need for hospices and Muslim communities to engage proactively?
- Are they reaching out to each other and working together?
- What are some of the challenges to this engagement?
- Can we learn from good practice whilst identifying key gaps in this relationship?

The report is especially interested in how these gaps can be filled, enhancing the impact of hospice care, both in terms of reach and outcomes⁵ and the way in which Muslim communities can access this type of palliative care support.

In order to answer these questions the report looks at three key areas:

- What do Muslim communities look like, where are they located and what is their background?
- Are hospices and Muslim communities talking to one another and what does this engagement look like where it works well?
- What are the gaps in this engagement and what can be done to bridge them in order to enhance the care hospices provide and the support Muslim communities are able to give to their local hospice?

Research methodology

Over the course of six months, a range of methodologies were used to explore the question: are hospices and Muslim communities reaching out to each other and working together?

This research builds upon earlier work undertaken by East London Mosque, Hospice UK and Together for Short Lives.

Anonymised quotes have been used throughout this report with the aim of drawing in voices of experience from both the palliative care sector and Muslim communities.

Methods

- Four structured focus groups with clinical and non-clinical hospice staff, patients and parents.
- Six semi-structured interviews with clinical and non-clinical experts.
- Two national workshops (East London and Manchester) drawing together palliative care staff, volunteers and leading members of Muslim communities. Conversations focused on some of the perceived challenges in engagement.
- Background research on existing literature and events tackling this subject.
- Direct contact with hospices, mosques and community volunteers.

Why are we talking about hospice care and British Muslim communities?

The immigration of labourers from former British colonies started as post-war Britain began to rebuild itself; the partition of the Indian Empire in 1947 soon led to a wave of migration that rose during the 1950s and continued at strength through the 1960s after a quota system was introduced following the cap placed by the Immigration Act 1962 which sought to limit numbers. Thus began a multi-layered process of new community settlements that would characterise many major cities and towns of Britain.

Patterns of community formation, needs and services would arise and develop at stages of community life, alongside a corresponding pattern of social integration that would see a gradual shift in the concept of 'home'. Britain's three million Muslim citizens today⁶ are part of this story, some three-quarters of whom have an Asian ethnic identity linked in one way or another to British India.

Whilst the 1950s was characterised by transient labourers, and the 1960s by more permanent labourers, the 1970s was characterised by wives joining their menfolk, and the emergent needs of early families, such as housing and schooling.

The 2000s onwards observed social changes that would impact community burial needs and the preceding end of life care. Muslim family homes were showing patterns of social normalisation along national socio-economic paths, as differences in wealth and economic prosperity created internal migration. This created a situation where younger families could relocate to new areas, living apart from older parents who remained in their own areas. The practice of repatriating the deceased was also falling sharply, particularly in cases where the presence of grandchildren (the third generation) meant that more immediate family were now in Britain.

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 three million at the time of writing. This makes Muslims the largest faith group after Christians, and the largest of minority faith groups.

The Muslim population is ethnically very diverse, but this diversity is not evenly spread. About 68% are ethnically Asian (there is considerable ethnic diversity within 'Asian') and 32% are non-Asian; about one in 12 of Britain's Muslims are of White ethnicity. 'White' again is a broad category and people who have changed their religion to become Muslims would be a small segment of this. Because changing faith is a personal matter, accurate numbers are not recorded although support organisations for such Muslims⁷ estimate this population count to be over 50,000. Muslims are also very diverse in their ethnic languages, socio-economic class, migrant-generational history, sectarian religious belonging (subdivisions within Islam), level of religiosity and their geography of residence. Although Muslims live in every local authority, some areas have a significant Muslim population: some 70 wards have a local Muslim population of 40% or more.

In terms of age, 33% of the Muslim population was aged 15 years or under in 2011 (the national average was 19%), whereas only 4% of the Muslim population was over 65 years (the national average was 16%). The number of older Muslims is increasing steadily and is expected to reach 250,000 before 2030.

Although there are clear overlaps with Britain's Muslim and Jewish communities when considering the impact and role of faith on end of life care issues and administration, Britain's Jews are fewer in number. They number less than 10% of Britain's Muslim population, have a much older age profile (20% are aged over 65 years), are less spread out geographically, and belong to a relatively wealthier economic class. This has yielded a more established and organised approach to end of life care for a religious group in comparison to Muslims, for whom this is an emergent and fast-growing social need.

British Muslims are the second largest faith group in the UK and it is particularly important to note that they fall into specific categories where data shows that the ethnic groups to which they belong suffer from life-limiting conditions more than other minority groups. South Asian groups, for example, have a 48% chance of having a life-limiting condition, whilst the national average is 32%.

In addition, Census data shows that Muslims reside in some of the poorest boroughs in the UK, particularly parts of East London and Greater London, where the majority of British Muslims live. Poverty and deprivation affect a range of opportunities, including health and education – both of which are key to building a stronger relationship between hospices and Muslim communities.

At the other age spectrum, there is a younger generation that requires hospice care for a range of life-limiting conditions affecting children. Children's hospices are seeing more referrals from neonatal units and there are an increasing number of specialist palliative care posts in neonatal services. A number of studies have indicated that infants who are small for their gestational age are at an increased risk of mortality.

This has been shown to be relevant to infants born to South Asian women (67.6% of Muslims are South Asian) who have below average birth-weights and present a higher group at risk.⁸ Studies have shown factors cited for lower birth weight in South Asian communities include genetic factors, sub-optimal maternal nutrition, low pre-pregnancy weight and low socio-economic status.⁹ Balchin (2007) found that South Asian women had higher rates of perinatal mortality across all perinatal mortality gestational ages compared with white and black pregnant women. The highest number of childhood deaths are from the neonatal group (aged under one year).

Finally, NICE (National Institute for Health and Care Excellence) guidelines¹⁰ place an emphasis on the importance of spirituality, religion and emotional needs to be appropriately met in clinical services:

Statement 6: "People approaching the end of life are offered spiritual and religious support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible."

This statement confirms the importance of ensuring hospices, staff and volunteers are trained and prepared to meet the holistic needs of diverse Muslim communities.

What is important to Muslims towards the end of life?

- Muslim patients look to cultural communities, religious traditions and / or scripture for guidance on how they make critical decisions about end of life care and life-limiting conditions. For Muslims the principle of preserving a life that is given by a creator and will ultimately return to its creator means that it is God who grants life and ultimately God who takes life. This leads to a deep-seated belief in prolonging life as far as is comfortable and meaningful.
- The focus of patients and relatives during the final weeks and days becomes worship and putting worldly affairs in order. This means a lot of time will be spent praying and exploring their relationship with God. It must be remembered that not all British Muslims will practice their faith, which means it's important we create the space to ask questions about how these patients would like to be cared for.
- During this time it can be challenging for those involved to consider options around pain relief and medication as this can impact the patients' ability to pray and put their affairs in order before they embark upon the next stage of their journey.
- Any physical possessions are passed on, promises are met and debts are paid to those near and far, wherever possible.
- Patients and relatives will feel comforted by being able to communicate in their primary language with staff who will understand both their clinical and non-clinical needs. During this time people can feel vulnerable which can be exacerbated by a breakdown in communication and a lack of participation in decision making. Being able to communicate fully with hospice staff will help families to make decisions that are appropriate and considered in light of their religio-cultural needs.
- Patients and their relatives should feel confident that all food and drink offered to them is appropriate and permissible according to their specific needs. For example, should a patient be observing halal dietary requirements, they ought to have confidence that staff are aware of this.
- Relatives, friends and members of communities visit a patient and their immediate family to provide support, practical help (such as bringing food and drink, looking after young children), and to offer time at the bedside and take part in any recitation of prayers. At times the number of visitors can depend on when family and friends from long distances can arrive at the hospice and therefore flexibility for visitors can be helpful.

- To be able to independently decide on whether they would like a religious leader to visit them: the offer of a chaplain or an Imam should be presented as a choice so that they have the confidence to accept or refuse, as they prefer. They may have an Imam they prefer, or may divest responsibility for matters such as a funeral to a loved one.
- Should they be able to perform prayers, any assistance in preparing and / or performing these, whether on their bed or in a prayer space, can help to give patients and their relatives spiritual strength which can affect their sense of wellbeing at the most challenging of times.
- Same gender care: for male patients to be physically moved, bathed or changed by male staff and the same for female patients. Gender etiquette can help to preserve values such as dignity at a time when a patient can feel most vulnerable. Family members are often willing to help and should be assured that the hospice will meet this need should staffing levels allow.

Care after death

In Muslim theology, death represents the parting of the soul from the body. As death approaches, it is hoped that the dying person will ‘witness’ (declare) their testimony of faith*, and families may extend the right index finger of the deceased to indicate this. When a person has died, there are the natural feelings of grief and loss, mixed with an element of hope – death is not the end but the start of a journey into an afterlife.

Although the person has just died, Muslims believe the person still senses, hears and feels. Clinical staff can continue with necessary tasks involving the body after death. Gentle handling and modesty issues are paramount, and in practical terms the body is dealt with as if still alive and able to sense pain or indignity. Limbs will most probably be kept straight before rigor mortis sets in.

Muslims are ‘hands on’ in handling death, as part of the closure process. Family are likely to want to spend time with the deceased, to pray for the soul, to comfort each other and to reflect.

Normally, the deceased will be buried within three days, or as soon as possible. The typical journey for a body is for it to be bathed, possibly taken back to the family home, then to a mosque, before going to the cemetery. The body is bathed by close relatives of the same gender with the body covered – this may happen in the hospice. It is gently prepared and perfumed by wrapping the body in a white cloth. Taking the body to the family home allows relatives to offer their ‘Farewell’. At the mosque a short special prayer is performed and members of the family and community then carry the coffin to the cemetery, where they (usually males only, although not always) will partake in the burial and join in the offering of a prayer for the deceased.

* An Arabic phrase which translate as: “I testify there is no God but God; and Muhammad is the Messenger of God.”

Barriers to engagement between hospices and Muslims of Britain

Whilst there is a focus in this report on strengthening relations between hospices and Muslim communities, some of the challenges to this engagement can be seen as universal: for example language barriers can clearly impact on communication between hospices and new communities, whilst a lack of awareness of what hospices do can impact on wider society too.

Language and translation

Language can prove to be a barrier to engaging with hospice care. At the most basic level there is no direct translation of the word 'hospice' and other complex terms such as 'palliative care', which can be problematic for professional translation services and in explaining what these terms mean.

"As one of the speakers touched upon, that is in many languages hospice probably isn't a word, I thought in Bengali, I don't think I've heard someone using it." (male)

Hospice staff discussed the difficulty in communicating with patients who don't have a fluent command of the English language, some have tackled this challenge:

"Without a doubt if you have a diverse workforce you attract people ... by the time I left we had 400 [service users] and the majority of them were South Asian because they had seen me and they thought if that organisation works with a BME person then they obviously value people like me. What I also noticed was that the biggest community we needed to reach out to was the Somali community and they had the biggest language and communication issues, languages that I don't speak. So what did I do ... just through recruitment, recruited somebody, and my god, just overnight, the number of Somali service users grew. Same with the Chinese community. So it does send out amazing messages. We are motivated, we use our free time to build links within the community ... we act as interpreters. I cannot explain how

much difference, how you can effect change overnight by employing a diverse workforce." (female)

Example of good practice

Birmingham St Mary's Hospice successfully engages black, Asian and minority ethnic (BAME) communities.

See article on ehospice:
<http://bit.ly/1l8WtOQ>



Language barriers become more crucial in palliative care settings, because there are difficult decisions to be made around treatment options and advance care planning and it is imperative that the patient is fully involved in these. In addition, the language involved can be quite technical, so translators with specific palliative care expertise are preferable.

Hospice at Home (outreach services provided by the local hospice to deliver care in the home) staff feel the pressure of poor translation most as they interact with a greater diversity of patients in the community. Language barriers can be difficult to overcome in the absence of bilingual in-house staff. Thus, the preferable option is interpreters with specific palliative care expertise who are also reflective of the cultural / ethnic diversity of patients.

In a recent training programme delivered at Compton Hospice (Wolverhampton) the Woolf Institute explored the impact of language in providing good care for patients and their relatives. Staff noted the dramatic difference in the quality of care they were able to provide when they used in-house staff to translate to elderly patients as opposed to when they employed a professional translation service. The preference was clearly for a clinical member of staff to translate options for pain relief, although they were aware that in order to sustain this model of communication they would need to recruit diverse clinical staff in the future.

David Widdas, consultant nurse for children with complex needs at South Warwickshire Foundation Trust and Coventry and Warwickshire Partnership Trust, shares his experience of engaging with patients through professional translation services:

“I know where one parent speaks English and the other doesn’t and we had an interpreter in the meeting. The parent that didn’t speak English came and said afterwards that she felt that the interpreter wasn’t interpreting what we were saying and was sort of softening things down or changing words. So I think there are some real issues when you’re talking about sensitive palliative care and some of the decisions that need to be made in using

interpreting services that don’t have specifics or the understanding and skills and competencies around palliative care.”

“... and equally we’ve had issues around relatives interpreting because equally it’s quite difficult and sensitive you know, and obviously there can be interpretation within the interpretation as well. If you don’t understand the language you don’t know whether that’s being directly translated or not.”

In order to create an environment where communication is understood by those concerned, hospices and palliative care services would benefit from ensuring their staff profiles reflect the communities they serve. An example of good practice will include diverse in-house staff with language skills; this will go beyond departments specialising in spiritual care and diversity, and will include clinical departments also, which can help to tackle the issue of translating complex terms and procedures to patients and relatives in a language they are confident in.

Cultural norms and perceptions

Often cultural norms and values can dictate the choices people make about their lives. Muslims are no different; they consider issues such as reputation, community expectations and even what is expected of them theologically before considering hospice care. Parents and patients spoke of how they had encountered such challenges directly.

“Muslims, when we put a child in a hospital or a hospice, you know our background, families think ‘oh can’t you look after that child, why have they left her there?’ See that’s our religion and our faith and people chat a lot.” (male)

When asked whether they thought the barrier existed in the community:

“Yeah but they don’t know what a person is going through, that it can be really bad, a child can do nothing [for themselves].” (male)

“We want the facilities to come and use [hospice name] but due to my self-esteem,

and my ... you know ... proudness, I don't let her [daughter] come here. I let her come for daycare, you know, like her Mum comes with her, the siblings come with her but I wouldn't let her stay overnight." Because he had already lost a child the father wanted "to be next to my child, knowing that she's okay instead of leaving her overnight. I mean I have the facilities if I needed them, [hospice name] is a very good hospice ... I've been using them for sixteen years." (male)

Imam Yunus Dudhwala, Head of Chaplaincy and Bereavement Services, Barts Health NHS Trust, reflected on some hospices and the patients they have traditionally cared for:

"When you do offer a hospice to an Asian or Muslims they usually say no because they just don't understand what it is. That's why hospices and communities have a role in terms of education and the patients and families have a role in trying to understand what hospices really are. So I think there needs to be a lot of collaboration between different organisations to try and get this knowledge out."

In addition, research shows that when hospices and Muslim communities encounter one another, Muslim service users feel overwhelmed by the extent of support hospices provide.

Example of good practice

You are not alone: hospice support for Asian mothers – Acorns Children's Hospice

See article on ehospice:
<http://bit.ly/1OqdbWp>



Awareness of services

A focus on relevant messages can play a key role in how well Muslim communities not only access hospice care, but are aware of what a hospice can offer. Some parents spoke of how they would have used hospices much sooner had professionals provided information about support services for themselves and their children. They were unaware of what a hospice was and the services it could offer and spoke of how, once they became aware of the hospice, they had to fight for hospice care especially when social services didn't inform them of the service. Here are some quotes that clarify this further:

"I have gone through nine social workers and not even one mentioned a hospice, so I'm really disappointed because I really needed a hospice a long time ago." (female).

She ultimately came across her local hospice when she broke down in front of her doctor who then suggested she look into hospice care for her son. She went on in the focus group to say:

"I didn't have family support; I needed someone to take him for a day or two so that I get a chance to recharge my batteries, to feel fresh again so that I can look after my son. So my family wasn't really supportive and I really struggled on my own because I was actually single at the time." (female)

"Because I am educated I can do my research on the internet. But people who are uneducated, they need resources to tell them, for example, through community sources. If you have a child that is severely ill and is at the end of life you will have a community nurse and they should approach you [about hospice care]." (female)

This illustrates the idea that literate communities may be able to find information, however there is an additional challenge that goes beyond language and instead relies on the level of education an individual may have. Until recently Pakistani and Bangladeshi boys (mainly of Muslim background) were the highest

underachievers in secondary education which means it can be especially difficult for these generations to understand hospice services and what they provide.

“...when I say the hospice word, they didn’t know what it was. So I said [my son] is with nurses [when he was in hospice care]” (male)

“I didn’t know anything, I mean I have heard of hospices but I didn’t know what it was, what it catered for ... children, I had no idea.” (male)

One participant shared his story of how he came to use the hospice:

“You know at the beginning, when my daughter was about five, she was severely disabled and the way they advertised it made me a bit scared, like daunting. I thought it’s for terminally ill children so we were thinking that ... I had it in my head that they go and die there.” (male).

Some participants offered suggestions on how to tackle this:

“Acorns should be going out doing workshops at places like schools or masjids [mosques], if they [Muslim community] are not coming out then Acorns should be coming out raising awareness, going out ... and making a connection, it’s like they don’t want to be known and are hidden away.” Others spoke of their own efforts to raise awareness: “Last few years my son has worked with Acorns as a volunteer. They do some advertising and try to advertise on BBC Asian Network.” (male)

“... we need to go into the schools. Go into secondary schools to talk about what services hospices provide.” (male)

“What needs to happen are visits, particularly to community organisations in the area because I don’t think people read leaflets to be honest.” (female)

“Building up relations is really key and the way to do that is to have volunteers.” (female)

“It’s the only way you know ... if a person tells them rather than a leaflet.” (female)

Geography

Location and travel were identified as concerns for some Muslim families. When a person reaches the end of life stages, or any kind of serious illness, their families, friends and the local community visit them frequently in order to offer support. This can range from conversations to bringing food and drink, saying prayers together or even just sitting together so that the patient is not left alone. Imam Dudhwala reflected on a personal family situation where they were deciding on where an elderly person would be best cared for: in a hospital, hospice or at home. When the family decided they would keep him at home the critical reason for this was so that they

“could be next to the patient all of the time”.

Such practices are commonplace in the British Muslim community, as when patients are at home people are able to visit with complete flexibility. In a hospice this can be difficult due to a lack of appropriate space and the risk of disturbing staff and other patients for whom this practice may be new or unusual.

Hospices are often in rural locations, on the outskirts of towns, without frequent public transport links which can prevent people from visiting their loved ones – something which can act as a dissuasive factor for many.

“...we as Asians don’t want to go out; we want to stay somewhere that is local to us, where you can go by bus, by car.” (female)

“I had to stop for a while because I didn’t have transport to take my son, my son cannot do anything.” (female)

“Another barrier is the distance because hospices sometimes are not located locally like hospitals. It’s not the hospices’ fault because that’s where they are located. This can become a barrier, especially since our communities always want to be there or want to be near.” (female)

Imam Dudhwala also talked about how drawing Muslim communities into the hospice can help to raise awareness in the communities of good hospice care, despite the distance or travel:

“Once you get more and more people in the hospice they become visitors of somebody else in the family and they realise it’s very good care, then I think the barrier will come down a little bit.”

Education and confidence

Staff and volunteers in both adult and children’s hospices could benefit from a range of educational programmes that are designed to help them understand and appreciate end of life care from the perspective of Islam and Muslims. Such programmes can be designed to create cultural shifts in organisations so that hospices are increasingly seen as spaces where Muslim patients and relatives can benefit from excellent clinical care which caters for the whole person.

Training programmes, involving workshops with case studies based on real life scenarios, such as the following example, help staff to understand what is appropriate when caring for people of different faiths. The study days provide a unique opportunity for a range of staff and volunteers to consider scenarios from a range of perspectives in a safe space that enhances both understanding and service delivery in hospices.

Sample training programme: Study day – Diversity in end of life care

Faith and culture

- Sources of authority in Islam and Judaism
- Basic principles of faith and culture

Case studies workshop: exploring real life challenges

- Orthodox Jewish: Modesty
- Mixed faith: Space for prayer
- Muslim patient: Concerns over nutrition and hydration
- Orthodox Jewish: Prayer on the ward

Plenary

Open discussion with feedback and questions from the floor on above sessions

CPD accredited

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Learning from the national workshops

In order to obtain a diverse mixture of views and experiences, two workshops were held, one in East London and one in Manchester. Both workshops were oversubscribed; this recognised a national need to have open conversations about how to draw Muslim communities into hospices and how to include hospices in community and religious spaces where Muslim populations exist. Workshop programmes are included in the Appendices.

Delegates heard from hospice service users, hospice staff and experts on Islam, Muslims and public health.

'Pledge cards' were distributed in both workshops, and delegates were keen to make pledges to engage better, raise awareness and be open minded about others. Vibrant discussions took place on the following topics facilitated by a relevant case study on each of the issues:

- How to overcome barriers to mutual engagement.
- How to ensure good and effective communication between communities and local hospices.
- How to provide faith and culturally sensitive support to Muslim communities and service users.
- How to create positive relationships between Muslim communities and hospices.

Each workshop was rich in discussion about where effective collaborations and good practice was taking place and honest about where engagement could be improved. These suggestions have been grouped into sections and provide a range of views on key issues that affect both hospices and Muslim communities.

Workshop suggestions

Education

- "We need to go into the schools to talk about what services hospices provide."
- "Quite often people are amazing scholars in Islam but they don't understand the legislative or practical context in the UK. So when you're having people come to you and talk to you and give you information, it would be really good if you could give them information as well so that they can be empowered enough to realise, ah, this is how it works. So a two-way is just so important."
- "How do we ensure training and equality within the workforce? How does our workforce represent the local community, how do our policies and procedures influence the way we work?"
- "As a professional we all need to know what our patients care needs are and I don't think we are providing good service to patients if we don't know about my patient's culture, how I can provide them with the little things is important."

Communication

- "Unless they see an image in the publicity materials of a BME person they subconsciously assume this is not for me."

- “BME communities use different media and methods of communication. So to put an advert on a Muslim channel would get a lot more publicity.”
- “Sometimes the words that we are using, the way we say things, people do not really understand even if English is their first language.”

Awareness

- “It would be good to have more liaison between a hospice and the different faiths’ burial services. I had to Google it and I was lucky that I Googled it two weeks prior to her death.”
- “I come from an advertising background. Like any other product, if you look at the genius behind advertising this is no different because you know that in the entire country people are getting into these situations. If you are subtly made aware of it [hospice services] in the background when you go and see your GP, a poster there ... So when you do come across a tragedy you know, oh I remember something about ... and you tell someone else. So there needs to be better advertising among this whole hospice community. ... But because it is put in a little corner, tucked away, that is why people have a negative view of hospices. Because I have to say I thought the same thing, that you go there to die, I didn’t realise ... and we should be aware of it before [we need it].”
- “I don’t know if you watch these programmes, 24 hours in A&E, what if there was a series like that one based in a hospice?”

Understanding and taboos

- “You know we are raised to believe that we will take care of our parents, it is our duty and we are happy to do that. But not all are able to do that. So make people aware that you can still have loved ones in a hospice and it’s okay. And this is one of the biggest challenges that people like you [hospice staff] have in getting over the taboo that Muslims have ... about not caring for you parent. You know I quit my job to care for my mum I was lucky to be able to do that, I realise not all people can afford that. And then you feel guilty that you can’t.”

- “Should we almost have a question at the beginning to say to people ‘is there anything I need to know about you, and your faith, and your culture that is going to make it ok for us to work together and almost have that as an addition, have that as an initial care plan when we meet people.”

Resources

- “I would suggest a database of all your staff, no matter what job they do, for the languages they speak.”
- “If you can recruit people from the Muslim community you can use this as a selling point.”
- “I think hospices tend to be very white and middle class and that’s the reality ... lots of senior members of staff are white and middle class and that can be difficult if you are trying to provide a service to a community on a grassroots level. Certain things are not talked about, like publicity and leaflets, how certain communities are portrayed [on the leaflets].”

Workshop delegates felt it was important to make a pledge of action during the national meetings. In order to facilitate this, postcards were circulated so that respondents could choose an action and explain why it was important for them to do this.

Workshop pledges

Education

- Write an article on this workshop for our mosque newsletter.
- Educate myself and visit [the local] hospice.
- Increase knowledge of traditions and culture around bereavement.
- Gain further understanding of the Muslim community to enhance our impact as a hospice (children).
- Learn more about how different faiths see death and dying.
- Visit Bolton Hospice with a group of older people from my Asian community.
- Take the palliative care specialist nurses to visit the local mosque.

- Bridge knowledge sharing across communities and institutions.
- Show the DVD about palliative care to a girls group at our mosque.

Communication

- Talk about today's event to a group of GPs later today.
- Ask our mosque to have a community talk about death and dying / hospice care.
- Speak to care co-ordination team about interpreters when meeting new families.
- Provide information to my community and encourage to use the service.
- Make contact with as many diverse groups within the borough our service is provided.
- Proactively engage with Muslims in our [hospice] area.
- Support my local hospice and raise awareness within the Muslim community and vice versa.

Awareness

- Increase awareness that the BME population is under-represented in patients, staff and volunteers within our hospice.
- Find out where our local Imam is based.
- Visit as many hospices as possible.
- Increase awareness at my local hospital of end of life care needs specific to Muslim communities.
- Better understand the services provided by hospices by visiting a hospice.
- Do what I can to move the situation on from recognising and repeating that there are inequalities, to action addressing them.
- Promote hospice services to our local community.
- Disseminate information and contacts gathered at this event to my work colleagues and be more generous with my time.

- Arrange for one of the mosques who fundraises for the hospice to visit.

Resources

- Look at our workforce and develop more roles to help reflect diversity.
- Create a faith pack at the children's hospice I work for.
- Give more time to patients when approaching difficult situations.
- Run a session around peer support or set this [workshop] up.

When hospices and Muslim communities are in touch, they often work together to fundraise and volunteer; however workshop delegates clearly felt that there is a lot more that can be done beyond raising funds and volunteering. Opportunities range from understanding religious and cultural traditions of Muslim communities to reflecting diversity within staff, from understanding what a hospice can do to support patients and their relatives to dealing with cultural taboos from within Muslim communities.

Learning from the data

What can we learn from data records to help shed light on Muslims and hospice care? Do Muslim deaths occur in hospices in proportion with national patterns and what can primary data from areas of significant Muslim populations tell us about current and future user patterns?

Exploring primary data

In 2013, 5.3% (27,102) of all deaths recorded in England and Wales occurred in a hospice building.¹¹ (Numbers of deaths supported by hospice care in the home are not available.) The question of how many of those deaths recorded were Muslim deaths is, however, less easy to verify. This research explored preliminary information to verify data held on Muslim patients through an exploration of primary data and corresponding service data.

In order to build a picture of Muslim engagement and how it can be improved, the following data research was examined:

- where Muslims reside and where they die;
- the top five local authorities where there is a significant Muslim population;
- how death is recorded by private and public health services in these areas;
- data on how faith communities record deaths and consider examples of good practice.

Death certification and place of birth (as a proxy for ethnicity and religion)

At the outset, we were confronted by a clear lack of primary data to be able to substantiate patterns of death and preceding care. Crucially, the process of death registration, which is concerned with the causation and legal process, excludes both the religion and ethnicity of the deceased, both of which are self-classifications and therefore highly

subjective fields of identity. The omissions of both religion and ethnicity give rise to real challenges in the exploration of social patterns in deaths and, accordingly, in patterns of end of life care.

The place of birth can give some guide to ethnicity. However, the Office for National Statistics (ONS) data output for 'Deaths by Country of Birth of Deceased' discontinued the release of this data table from 2005 due to quality issues with its essential data. This largely stems from the large degree of discrepancy in the information provided. Normally, 'country of birth' data is provided by an informant, often the relative of the deceased and it is a very unreliable method. This is reflected in a large number of discrepancies and gaps, which has eventually led to the discontinuation of this dataset.

The problem of birthplace is compounded by the nature of major geopolitical change in the Indian Subcontinent affecting India, Pakistan and Bangladesh. A very high level of inconsistency can be expected when relatives act as official informants for the purpose of death registration. It is quite conceivable that within their lifetime, the deceased held three specific national identities. By way of an example, a person born in British India may have migrated to Britain as an East Pakistani and would later identify their background as Bangladeshi. Moreover the place of birth may be stated as India on early documentation.

Data on deaths measured by place of birth is wholly unreliable in respect of Muslims.

Census and population data

An individual's religion is a most personal matter and, in due consideration of this, its eventual inclusion in the Census from 2001 was made an optional entry. The broader goals and aims of planning services and understanding social change was deemed important enough to justify its inclusion, not dissimilar to the inclusion of ethnicity within the Census a decade earlier, from 1991.

A correlation between the ethnic group and social disadvantage of citizens and comparatively poorer health, both in the short or longer term, has long been measurable by quantitative health data. Black and Asian Minority Ethnic (BAME) groups evidently continue to have poorer health than the overall population, although patterns vary across different groups and for different health conditions.¹² However, the absence of primary data means that local data at a civic or institutional level becomes significant in locating social patterns.

Table 1: Top 10 Muslim population Local Authority areas in Britain, Census 2011

Measured by population	Measured as percentage of Local Authority Area
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

CCGs and NHS hospital data

The top five NHS CCGs (Clinical Commissioning Groups), measured by Muslim population, (from Table 1) were contacted to explore hospital data in respect of deaths measured by religion or ethnicity.

The enquiries made show that hospitals are not recording religious or ethnicity data on death certification records. Standard information data recorded by hospitals such as patient admissions data, service performance data and user response data (patient experience feedback) did often gather data on ethnicity but this could not be cross-referenced against death and end of life care data.

The NHS has largely stopped using hospital deaths as a measure and has started using 'deaths in preferred place of death / preferred place of care'.¹³ However, measuring hospital deaths by religion would provide a clearer means to assess whether choices in palliative care were measurably different for Muslim (or other) patients and possibly why such gaps or discrepancies existed. Choices about where patients spend their last days, the impact that the medical conditions affecting patients has on those choices, and the communication or awareness of choices can be analysed with greater clarity. In practice, no systematic recording is taking place and, consequently, measuring discrepancy is more challenging than it could be.

Although some academic research has been done that demonstrates the underrepresentation and access of British Muslims: "Place of death varies significantly by ethnic minority – a strong indicator of disparities in quality and access; one study finds that 76% of Pakistanis and 78% of Bangladeshis aged over 65 die in hospital, compared with 62% of White British people."¹⁴

Hospice data

Twenty-eight hospices, serving both adults and children, located within the five top areas were contacted (see Appendix 2). No adult hospice was able to identify users based on religion as this data was not recorded. Children's hospices, however, were often able to differentiate user numbers based on ethnicity and religion – this was the case at least with Acorns Children's Hospice, which records and shares information on patient diversity measured by ethnicity or religion.¹⁵

Acorns Children's Hospice has three 10-bedded hospices across the West Midlands, with variances in demographics and user religions. Nearly half the children admitted to the Birmingham hospice are Muslim (48%), in the Black Country Hospice in Walsall, one in five were Muslim (20%) whereas in Worcester 6.5% were Muslim.¹⁶

The children's hospice Richard House, serving the areas of Newham and Tower Hamlets, also records the religion of children they care for. Forty-two per cent of child patients were from Muslim families, the highest segment when identified in this way¹⁷ (followed by 38% of children from Christian homes). However, the clarity and ease of availability of statistics on service user background and religious affiliation appears to be a case of exception not extending to adult hospice care.

Secular funeral information

An alternative avenue for trying to measure where deaths occur measured by religion would be to explore data collated from Notice of Burial forms, which are used by funeral directors when corresponding with a local authority for burial plots. These forms contain more detail than Certificates of Death. There is no specific field for stating the religion of the deceased. However, greater detail would make it possible to glean information on religion, based on factors such as grave plot details, the funeral director used and the address for collection of the body. In practice local authorities design and use their own Notice of Burial forms, and no systematic set of data is released by the ONS. Should datasets in

the future allow an understanding of where Muslims are dying, a cross-sectional analysis would enable us to compare this with various age groups in the Muslim community.

Muslim burial services data

Muslim burial services are an emergent community service sector. Localised funeral director services have existed since the 1980s at least, but act more as individuals who liaise with council departments on behalf of mosques and local citizens. Contact was made with the two largest of such services, Gardens of Peace and Eternal Gardens, both serving the London area. Neither organisation stores data on the place of death and is unable to determine from its records the number of people dying in hospices. Eternal Gardens has been in some dialogue with local hospices in an effort to understand what hospices specialise in and the services they can provide for Muslim patients and their relatives.

The East London Mosque (one of the largest in the UK) has long outsourced burial services to an established specialist independent provider, who have been providing repatriation and burial services since the 1960s, and currently undertakes around 700 UK Muslim burials per annum. This funeral service does not store data on the place of death and cannot determine the proportion of deaths in hospices.

Birmingham Central Mosque on the other hand does record deaths by place of occurrence. The recording of such data does allow for instant comparisons to be made with ONS primary data. The differences in where deaths occur based on data held by the mosque compared to deaths recorded by Birmingham's Primary Care Trusts points to a much higher proportion of Muslim deaths occurring in hospitals, far fewer occurring at home and a visible difference in deaths occurring in hospices (see Table 2 on the next page).

Table 2: Comparison of data held about place of death in Birmingham

	Home	Nursing Home	Hospice	Hospital	Other
Birmingham Central Mosque	12.9%	0.5%	0.5%	78.6%	7.6%
Birmingham PCTs	21.7%	9.8%	5.8%	60.7%	2.0%
Percentage difference	-8.8%	-9.3%	-5.3%	17.9%	5.6%

Because of the limited supply of data held by Muslim funeral specialists within the five areas, enquiries were extended to the city of Leicester, which has the seventh largest Muslim population; the Muslim Burial Council of Leicestershire (MBCOL) does record where deaths occur, making it more of an exceptional case amongst Muslim funeral companies.

Table 3 shows the places of death occurrence for burials undertaken by MBCOL during the year April 2014 to March 2015, compared to that of Leicester City Primary Care Trust for 2012.¹⁸

Table 3: Where deaths occurred in Leicester

	MBCOL (2014)		Leicester City PCT (2012)	
Hospital	129	63.5%	1,185	50.7%
Home	61	30%	540	23.1%
Hospice	8	3.9%	107	4.6%
Nursing home	5	2.5%	445	19%
Other	0	0%	59	2.52%
Total	203		2,336	

Sources: (1) ONS Deaths by Primary Care Trust 2012;
(2) mbcol.org.uk

NB. This data is for different years. The Leicester PCT count would include Muslims who make up 18.6% of the city population but who have a younger age profile.

The case for recording such data was explained by Suleman Nagdi, Chair, Muslim Burial Council of Leicestershire:

“We record these numbers separated out like this because they are a helpful resource allowing us to address any gaps in the kinds of services available as people are approaching death and need a more delicate and sensitive type of care. Data like this also helps policy makers with the future planning of service provision.”

The data is useful in an early analysis and seems to point to differences in where death occurs. There is a significant gap in the proportion who die in hospital, with 12.8% (or one in eight) more Muslim deaths occurring in hospital. More Muslims are also dying at home (6.9% more) which, although it is widely held as the most preferable place to die, may mask the broader burden and impact of caring for long term health problems by family members as well as access and awareness issues regarding care choices available in nursing homes and hospices. Only eight deaths are shown as having occurred in a hospice for a population demographic that is much larger.

Learning from best practice

Spiritual support

In times of illness and stress spiritual care can help to restore a sense of balance and peace that enables patients and their relatives to feel a sense of control over their situation.

Hospices and communities can work better together in order to ensure physical, cultural and spiritual dimensions are cared for in a sensitive and appropriate way. This can be useful when patients and relatives are not especially observant of their faith but in an end of life context this can change for a lot of people.

Imam Dudhwala has encountered such experiences:

“Especially at the end of life faith usually comes back. I had a case recently in London where somebody was in a hospice and the chaplain there called me to ask ‘how do I deal with the case?’ The patient had never been to a mosque in twenty years but the faith came back in the end. So my point is that it doesn’t matter where you are in life, faith usually returns. So, we need to cater for every community, for Muslims halal food, prayer space, 24 hour access, large family, all these will impact on their decision on whether to use hospices or not.”

In a hospice context it is comforting for Muslim patients and their relatives when staff and facilities are inclusive of these priorities. When spiritual needs are met it can help patients and relatives to focus on their priorities, for example by being able to pray together they can draw strength to deal with their circumstances better.

Understanding the role of the hospice

Hospices are becoming more aware of the need to draw Muslim (as well as other) communities who require hospice care into the hospice space in either day care or inpatient care.

But what do we mean when we speak of hospice care?

The Commission into the Future of Hospice Care (2013) explains a hospice fit for the future:

“Hospice care helps and supports people who are living with life-shortening conditions or who face the processes of dying, death and bereavement. It is focused on helping individuals, families and communities through these most difficult challenges...”¹⁹

Other hospice websites explain day care as a service that:

“enhances quality of life for patients by maintaining their independence and providing personalised care in a homely and relaxing environment,”

whilst inpatient care specialises in:

“providing access to a full range of clinical services, we help many patients to regain their independence and return home... If appropriate, support may continue to be provided by the community care team.”²⁰

Engagement

Mosques are not known to speak publicly about hospices. In the experience of patients and parents who took part in this research there was a real absence of public conversations about the hospice movement and what local hospices had to offer. This was especially significant as some service users recalled that an Imam would visit the local hospice to talk about Muslim funerals, however the conversation both in the hospice and communities needs to be broader.

“The Imam I know now, he’s an Imam from the Central Mosque, he’s been coming here and I know him as a family friend as well. He’s

come here [hospice] to explain about Muslim funerals.” (female)

“I believe there should be some sort of a meeting at Masjid, like an advert that says come to the workshops and we will talk about it [hospice care].” (female)

Engagement needs to include conversations about palliative care and issues around managing pain relief, what is important to Muslim families in the context of hospice care and why Muslim communities should consider engaging in the hospice movement before they require care.

“In Muslim communities, verbal communication is how it goes, that is how you can get into BME communities.” (female)

This can help to build relations between the two groups so that when they need support from each other there is an existing working relationship to lean on.

Example of good practice

Dying Matters film highlights end of life needs of the Muslim community

See article on ehospice:
<http://bit.ly/1KZtbH4>



Fundraising and volunteering for a hospice and relying on religious leadership to support Muslim patients are important but these relationships can lack depth and sustainability and should not depend simply on a few individuals but instead should be targeted to specific needs both in hospices and communities:

“I thought you made a really good point about the differences ... quite often people are amazing scholars in Islam but they don't understand the legislative or practical context in the UK. So when you are having people [Imams] come and talk to you and give you information, it would be really good if you could give them information as well so that they can be empowered enough to realise, ah, this is how it works. So two-way [learning] is just so important.” (female)

“Not everyone should be assumed to be knowledgeable.” (female)

Other avenues of long term engagement should include:

- training for both hospices and Muslim communities on understanding one another;
- entering each other's spaces (especially community spaces);
- building direct connections by employing diverse staff;
- inviting diverse members of communities onto Boards;
- looking beyond the religious institutions and labels for support from Muslim communities.

Children's hospices such as Acorns in Birmingham and Richard House in East London are forging working relationships with local Imams and funeral directors, incorporating Muslim chaplains onto boards and committees. The Imam and Khateeb (Imam who delivers the Friday sermon) at East London Mosque, for example, has been a patron of Richard House since 2010 and has forged a relationship with St Joseph's Hospice too, one of the largest adult hospices in London with an employed Muslim Chaplain. This appointment is stated on the mosque's official website²¹, on accepting the position Imam Abdul Qayum explained:

“A hospice is about delivering care and support to the people and the families that really need it. Both hospices are happy environments that offer so much to all members of the diverse community we live in. And that's one of the many reasons why I am delighted to become a patron of Richard House and to work with St

Joseph's. I will be taking that message back to the East London Mosque and will be delivering a 'khutbah' (Islamic sermon) about making people more aware about palliative care and the wonderful services both Richard House and St Joseph's offer."

Other local mosques have sought to raise awareness of hospice services through weekly sermons and official noticeboards.

Prayer space

In addition to raising awareness of clinical services, hospices can also provide other types of support for patients and relatives. For Muslim communities this includes the use of an appropriate space for reflection and prayer, prayer mats and key texts that can help with spiritual support and strength. A hospice that does this well is making an invaluable contribution to the wellbeing of patients and their families:

"You get brilliant care, 24-hour access, prayer room, they understand your needs. So they provide care properly according to the needs of a particular community, then I think word spreads very quickly." (male)

"We have in recent years had a multi-faith prayer and reflection room for patients, visitors, family and staff and in our recent building work we have developed this even further by creating a purpose built multi-faith room with ... ablution rooms."²² (female)

Parents using Acorns Children's Hospice (Birmingham) have appreciated the emphasis that was given to spirituality in the hospice:

"... I'll be honest with you; they went the extra mile ... they had the Quran ... and that is what you want at that time, that is what gives me peace and has pulled me through." (female).

Their son had been on life support in the local hospital where a nurse drew their attention to the local hospice service, which they hadn't heard of:

"I did not know, being born and bred in England, I didn't know what a hospice was. So we decided yes, because the hospital was not going to do anything ... [we] came here and it felt like home." (female)

When they came to the hospice they were encouraged to consider funeral arrangements for their son. Now, five years on, their son uses the hospice for daycare support. Clearly they have experienced an exceptional journey with their son, the key difference being that they were made aware of the services offered by the local hospice which led to an improvement in the management of their son's condition.

Fundraising

Mosques across the country raise funds for their local hospice.

A group of Imams representing 14 mosques in East London came together in 2014 to pool their resources and raise £17,000 for their local children's hospice, Richard House. This support came through the ongoing work of Imam Dudhwala, who spends a few hours each month working to support Richard House.

In addition family members of a deceased will volunteer in shops or in spiritual care teams, as in the case of Pendleside Hospice where the daughter of a former patient volunteered to support the Spiritual Care Coordinator. Others from Muslim communities have set up small charities and projects that support the work of hospices; this community volunteering includes the Myriad Foundation, Children of Jannah (Heaven) and Eden Care.

These partnerships are in their infancy, often cited by hospices and religious institutions alike as new developments that are viewed as positive indications of mutual collaboration. The organic nature of these liaisons means that they are reliant on personal experiences. This means that the reach of communication remains very limited, and that the general awareness of the range of services hospices provide will remain unchanged in the broader perception. However, an appetite for change, and a willingness to reach out, to help to fundraise and volunteer, is evident, providing a promising outlook for long term mutual engagement.

"As a mosque we feel it is essential that we support and engage with our local communities.

Over the past few years we have supported Pendleside Hospice by raising over £3,000.” (Imam Sajid ul Qadri, Jamia Masjid Ghausia, Burnley)

“It’s vital that we raise awareness of the work of our Hospice, particularly amongst Muslim communities so if at any point anybody needs support, they know how and where to get it. Our relationship with Pendleside also allows us to educate staff on sensitive issues, raise awareness about the beliefs and barriers to accessing palliative care, end of life decisions and religious obligations for Muslims.” (Afrasiab Anwar, volunteer at Pendleside Hospice and Trustee, Jamia Masjid Ghausia, Burnley)

Members of the Watford mosque committee visited Peace Hospice to make a financial donation, the money for which was raised through local fundraising, particularly donations at Friday prayers, at the Watford Central Mosque.

“We are here to support the local hospice. We try to make a regular donation. . . . We believe they provide a vital service and we want to be a partner in that to make sure the service is alive and the good service is kept as it is. Services in Watford are going to reach us as much as everybody else. We’re very lucky to have this type of service.” (Imam Saleem, Watford Central Mosque)²³

Non-financial support

“Give A Gift is focused on bringing smiles to people’s faces – whether that smile is achieved by donating cash, baking cakes, or sitting by the side of a child in a hospice. It is about doing good, reaching out, giving of your time and yourself and helping others. The Prophet Muhammad (peace be upon him) has taught, ‘Even a smile is charity [sadaqa]’”²⁴ (Qari Muhammad Asim, Leeds Makkah Mosque, Imams Online)

The concept of giving in charity holds a strong place in Islamic traditions. Muslims are encouraged to give to others over and above an obligatory amount that is given as alms to the poor each year. Sadaqa encourages Muslims to give financial donations as well as non-monetary value resources such as time,

energy, good manners and of course, as the quote above says, a smile. With this in mind workshop participants mentioned the importance of reminding Muslims that they can support local hospices by volunteering, supporting and raising awareness of their activities.

Example of good practice

Landmark event hails new era of collaboration between Muslim and hospice communities

See article on ehospice:
<http://bit.ly/1PcXrpR>



“If I could just add . . . doing a similar thing at third sector events fairs, for BME communities and if you put a stand it really sends a massive message to people. It is like the lady said people genuinely do think this service is not from me so doing things like being present at fairs sends a message ‘we are here for you’.” (female)

“Also images are really important. Unless they see in the publicity materials an image of a BME person they subconsciously assume this is not for them. Another thing that they talked about was that BME communities use different media. So to put an advert on a satellite channel would get a lot more publicity. One of the things we’re noticing is that there is the community over here, hospice is here and the communication is missing, everyone is missing each other. Written information in different languages is completely unhelpful, because BME communities are quite often, looking at migration patterns, they

may not speak the language that we assume they do. So they like videos 'cause you can put different voices on there in different languages, community members would be happy to do that on a voluntary basis." (female)

Social media

The use of social media to raise awareness of the work of hospices, especially public events and fundraising opportunities, is becoming increasingly common. In addition social media, Facebook particularly, is used to share stories of hospice care for relatives. The Mayor of Brierfield chose to share his story of how the local hospice cared for his mum; interestingly he mentioned his mum benefitted from hospice care despite having a large family. The power of anecdote in getting messages across is especially relevant here. Stories are particularly powerful in dispelling myths and stereotypes about the other. Here he tackles the common misconception that families ought to look after their loved ones without availing of hospice care.

A son's tribute

"I would like to tell you about my Mum who sadly passed away last year. My Mum was a wonderful individual, she was very strong, confident, caring, kind and so polite. I think I get some of my strength from her and I just hope I have made her proud of me. I considered my Mum to be young, she should have had lots of years ahead of her but unfortunately with cancer it doesn't always work out that way. My Mum's cancer was treated with chemotherapy but sadly the cancer spread to her bones so she had further chemotherapy and radiotherapy.

Mum used to come to the hospice for complementary therapy. She really enjoyed coming and my sister was able to go along with her. The minibus would pick them up and take them back home again.

I have visited the hospice on a couple of occasions in my capacity as Mayor. I have seen the therapy room Mum had treatment in; you can't really take it in until you have seen it for yourself. Even though we are a big family we also had Hospice at Home to provide that extra help. They always came with a smile and the respect they showed Mum was outstanding. For us it was just a wonderful experience.

I really want to raise awareness of hospice services in the Asian community. I want to share the message that you and your family don't have to struggle and suffer by yourself; there is help just around the corner. It's a choice people have to make but people don't always know the wonderful things on offer at the hospice."²⁵

Rizwan Asghar, Mayor of Brierfield, Lancashire (2014-2015)

Growth in Muslim hospice patients

Demographic data tells us that the number of people from minority ethnic groups, which includes Muslims, will increase, and a substantial number of them will be older people who might need care.²⁶ All demographic indications point to Britain's older Muslim citizens becoming in need of hospice and broader end of life care services, in increasing numbers over the coming years, especially in the top five areas this report has explored.

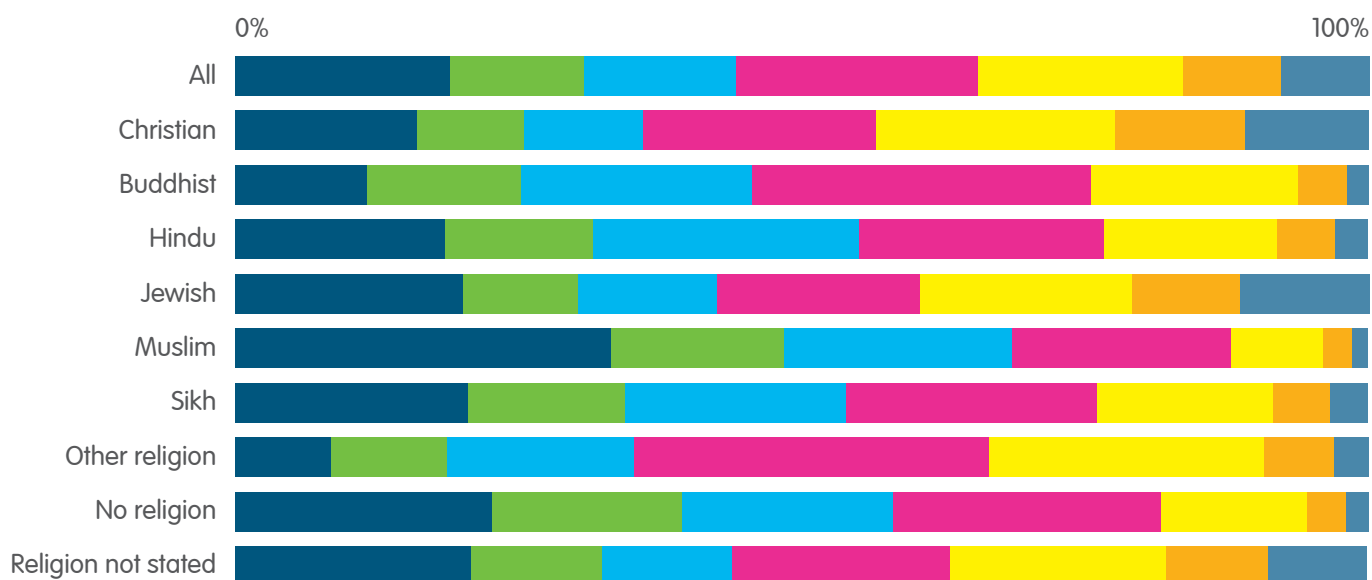
The practice of repatriating the deceased (eg transporting bodies to Pakistan) has also fallen sharply over the last two decades. This will impact Britain's hospices who must consider how well prepared they are to meet a growing social need.

Table 4 on the next page shows that 33.1% of Muslim were under the age of 16 and 54.4% of Muslims were below 25 in 2011, thereby having the youngest age profile of all groups. A high proportion of children indicate the growing family stages typical of communities with a migratory element over the last fifteen to twenty years. Although the number of Muslims aged 50 is still small, it has grown by 46.4% since the 2001 Census. This points to a shift towards a more settled community pattern where the migratory make up is diminishing and an elderly segment is occurring.

This increase of elderly people coupled with a gradual shift towards more nuclear and smaller family groups will mean that the number of users requiring palliative care services will increase significantly over the period of a generation. A safe assumption is that Muslim patients are under-represented users but the degree to which this is true cannot be determined due to a lack of accurate and consistent data from palliative care bodies.

Table 5 on the next page shows that within the five areas identified, there has been a significant increase in the size of local Muslim populations (largely due to the younger age profile and larger than average family sizes). Within these areas, Muslims also make up a significant proportion of the total population. The local hospices within these areas will inevitably see a steady increase in the number of adult users, as indicated in Calanzani et al.²⁶ It is also conceivable that privately run Muslim hospices will emerge to meet a growing demand for adults for those in a position to afford them.

**Table 4: Religion by age in England and Wales
– Census 2011**



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

Table 5: Increase in Muslim population in top five areas

	Muslims 2001	Muslims 2011	Increase	Increase %	Muslim % of All People (in 2011)
Birmingham	140,033	234,411	94,378	67.4%	21.8%
Bradford	75,188	129,041	53,853	71.6%	24.7%
Newham	59,293	98,456	39,163	66%	32%
Tower Hamlets	71,389	87,696	16,307	22.8%	34.5%
Manchester	35,806	79,496	43,690	122%	15.8%

Framework for good practice

The hospice sector has long been engaged in a struggle to demonstrate its purpose that palliative care is not just about end of life, but encompasses a wide range of help and support. Understanding of this is poor across the general public particularly amongst minority groups, including British Muslims. Addressing this will naturally have a positive impact on engagement with Muslims, as it will with everyone else. But as part of this broader stream of public awareness work, the hospice sector needs to think about how to engage specifically with Muslims,

especially in tackling ideas around the religious identity of hospices and removing obstacles such as language and cultural barriers. British Muslims will be receptive to messages that promote hospice support and services that can demonstrate that hospices understand Muslim communities in light of their religious and cultural traditions.

The checklist on the next two pages provides a useful framework to support hospices with this work.

Checklist for staff and volunteers on a 2-year learning curve

Key Players	Key Outputs
	6 months
Hospice Trustee Boards	Identify Muslim organisations and individuals you would benefit from engaging with Invite 'guest' Muslims to Board meetings as listeners and / or to share insights into Muslim communities and end of life care
Hospice Chief Executives	Allocate resources for all Trustees, staff and volunteers to undertake Muslims in end of life care training Identify and build partnerships with local and national Muslim individuals and organisations
Managers and Communications Staff	Meet with local Muslim communities (institutions and others) and engage in direct conversations
Clinical Staff	All staff to attend training programme on Islam and Muslims in end of life care
Non-Clinical Staff	All staff to attend training programme on Islam and Muslims in end of life care
Volunteers	All volunteers to attend training programme on Islam and Muslims in end of life care

Key Outputs	
12 months	24 months
All Trustees to attend training programme on Islam and Muslims in end of life care	Identify and invite key Muslims to become Trustees on Boards Ensure hospice communication is proactively targeted to British Muslim groups in an appropriate fashion
Prioritise creating video resources that will explain hospice services to minority groups in different languages To understand local demographics and periodically assess your progress in reaching all local communities	All Chief Executives to attend training programme on Islam and Muslims in end of life care Take regular input and advice from independent individuals who can help to reflect on impact of existing engagement and new ways of connecting with British Muslims
All Managers to attend training programme on Islam and Muslims in end of life care To understand local demographics and periodically assess your progress in reaching all local communities Understand local Muslim communication, TV and social media channels	Employ bilingual Muslim staff across both clinical and non-clinical departments Use all available communication channels to promote and explain hospice services to Muslim communities Conduct regular evaluations measuring level and impact of engagement
Arrange for staff to visit local Muslim community groups and for the communities to visit a hospice coffee morning that includes direct communication with clinical staff	Recruit more diverse clinical staff by targeted advertising Engage with antenatal and women's groups
Identify and employ a Muslim Chaplain with good English language skills	Regular engagement with schools and after school clubs, further education colleges, community groups and places of worship, to promote understanding at all generation levels
Share voluntary experience of working in a hospice in spaces where Muslim communities are engaged	Regular engagement with schools and after school clubs, further education colleges, community groups and places of worship, to promote volunteering

Recommendations for hospices, policy makers and Muslim communities

Data records and essential information

- Inclusion of religion and ethnicity field at registration of death and by local authorities (as optional fields). The omission of a person's religion at the registration of death results in a loophole in basic population analysis. Other primary data sources held by the ONS, such as the place of occurrence of death, also cannot easily be cross-referenced with religion, the result of which is core omissions in information provision necessary for effective civic planning and social monitoring.
- Hospices and service providers specialising in palliative care should keep data on both religion and ethnicity. In order to build a fuller picture of how and where Muslims are accessing hospice care, data capture methods must be reviewed so that we know, for example, the correct ethnicity and religion of a person. Where possible, the data should be included in the transfer of patients to burial services upon death. Providers must ensure that they measure outcomes such as reach into British Muslim communities.
- Muslim burial services and mosques dealing with the final journey of deceased persons should store more detailed information regarding the deceased person's end of life care, with a clear categorisation of where death occurred. Good practice models regarding data collection across this growing sector is encouraged, as well as records regarding the time between death and burial and any movement of bodies from one local authority area to another.

Communications to communities

- Hospices and service providers should utilise specialist community television and radio channels to promote hospice services. By following this recommendation hospices are accessing the same 'spaces' as many members of Muslim communities, and can reach women, working professionals and community sections often not accessed through community mosques. Satellite television channels such as British Muslim TV, as well as community radio stations such as Unity FM (Birmingham) and regional 'Ramadan' radio stations such as Radio Ramadan Glasgow (set up during the Islamic month of fasting) provide platforms for discussing services and evolving change within and around end of life care. Large-scale national events such as the Living Islam Festival and other regional platforms are built around discussion forums and avenues for progressive understanding and mutual cooperation.
- National hospice conferences by bodies such as Hospice UK and Together for Short Lives present opportunities to discuss changing needs and explore the emergent challenges for new user groups such as Britain's ageing Muslims. This can explore presentations and workshops on population change, findings of research and surveys and developments in community engagement.
- Muslims representative bodies and major burial service providers should have a presence and hold stalls at these national conferences held by Hospice UK and Together for Short Lives in order to raise awareness of British Muslim communities and engage in discussions with hospices from across the UK.

- Muslim bodies and hospices should work together with mosques in the preparation of sermons (khutbas) to communicate the services provided by hospice care and the religious encouragement to approach end of life care as an opportunity for spiritual fulfillment, which in many cases may be best achieved in the caring and understanding environment of a hospice.
- Mosques should promote how citizens can redirect charitable services and time resources to support local hospices as part of the religious duty to give in 'sadaqa' back to their local community.
- Local hospices can call upon local mosques to meet their senior staff to explain the processes of hospice referral, the range of services offered and the space for spiritual care. Posters and other material should be provided for mosque noticeboards.
- Local hospices should actively seek to locate local women's groups and clubs where direct communication with women in the 40+ age group can be achieved. Information specifically for maternity and neo-natal services could be vital for women, where it is known that a baby is born with a serious illness or disability.
- Development of a series of short collaborative videos explaining hospice care services and processes. This can include voices from hospice bodies, hospices, Imams, care staff, patients or patients' families and / or major burial service providers. Such information tools can prove invaluable as a resource for families who have reached a point where hospice care services should be a considered option. These videos could be appropriate for schools to demystify hospice care for teachers, children and parents and also for specific health settings where hospice care needs explaining, eg oncology, renal and diabetic clinics. Such a project would see other forms of communication spring from the videos, including jointly approved handbooks and dedicated online resources. Translations of videos could be an advantageous and a relatively inexpensive addition.

Education and training

- Hospices, service providers and clinicians should seek specialist training programmes to better understand the 'last journey' protocols and services that each provides on either side of death. Good and common practices, including the systematisation of data records and the importance of legal, clinical, religious and religio-cultural practices should be explored.
- Muslim burial services and mosques should arrange training programmes in conjunction with hospices and palliative care to understand the processes, services and opportunities that exist in this service sector. Joint training has the benefit of exploring common issues, generating synergy, building liaisons and developing operational processes or strategies.
- Such working relationships between palliative care services and Muslim burial services will serve to help bridge gaps in data collection and create an unbroken chain of events from when a patient approaches death to burial and the completion of burial rites of passage. Muslim burial service providers which have direct and thoughtful engagement with families and work closely with mosques regarding prayer and washing facilities, are in an advantageous position to relay the work and services of hospices to enhance the shared understanding of what hospices do. Greater working alliances and communication with care providers can also help families choosing the family home or a hospice as the place where a loved one dies, rather than a hospital ward.
- Muslim burial services should learn from the more established and more carefully monitored practice models, eg those adopted by Jewish funeral services. The parallel similarities that religious protocols have surrounding death and burial arrangements means that much can be learnt from a specialist religious services sector to enhance business practices.

Research limitations

Restricted data collection from death certificates, burial services and service providers clearly can limit the kind of information that is available for a study such as this. This report would benefit from further analysis in other locations in the UK, for example is there a difference in community and hospice engagement in places like Cardiff and Glasgow? We know that there are clear distinctions in how Muslim communities in England see themselves compared with Muslim communities in Wales and Scotland – there are differentiators in how they perceive their own identity as reports have clearly indicated.²⁷ However, it would be useful to explore whether identity – or indeed other markers such as affluence, heritage and geography – impact on the way in which hospices and Muslim communities engage with each other and the impact of the generational shift in these communities.

Further investment in this research would look to build on this report by exploring these issues as well as providing a similar insight into other faith and cultural groups, especially newly migrating communities.

The limited scope of this research has focused on the current picture of engagement between hospices and Muslim communities; it has done this by utilising existing data (where possible) and engaging with new audiences through workshops, focus groups and interviews. However it does not claim to provide a detailed national picture of engagement and the gaps that lie therein. Instead the report provides a snapshot into the hospice movement and Muslim communities that clearly need to engage with each other in order to provide meaningful support for both local services and communities.

Conclusions

Britain's Muslims are getting older and family structures are beginning to thin out and spread. Greater affluence is also pointing to some young families relocating for reasons of schools and careers, which results in emergent challenges in the care of older relatives, yielding a larger Muslim patient base. This will have an impact upon hospices and broader palliative care networks.

The general appetite and readiness to understand the challenges and discuss the future is good, but there are some challenges that are clearly acting as obstacles to serious engagement. These include a heavy assumption that essential primary data on the subject is clear and accessible, when it is not. Omissions in data and shortfalls in user access both necessitate targeted communication and outreach methods, along with the revision of internal processes and data monitoring, by both care and religious providers. Despite the readiness to engage, fuller interaction, as explored in this report and its recommendations, is yet to be realised, even where significant Muslim populations reside.

A patient's journey from the point when a life-limiting illness is diagnosed can travel through mosque services, palliative care services, community links and burial services, all of whom engage with each other in practical terms as and when called for. These working partnerships become separate clusters of communication rather than becoming collective strategies, programmes or synergy. Such ad hoc clusters of working relationships can be channelled to better care practices in a more complementary manner across the care disciplines.

What remains difficult to quantify is the extent to which Muslim homes may currently be under-utilising hospice care because of gaps in

communication and understanding. However, better planning, education and communication can help to reduce any shortfall and prepare both hospices and families to plan for the delivery of hospice care. Clearer hospice data on Muslim communities utilising hospice care will help to understand any growth in the uptake of hospices, locally and nationally.

The readiness to reach out and understand the realities, either the social realities of Muslim communities by hospices, or the operational realities of palliative care by communities, echoes across the report and could be heard in all discussions. It is an invaluable ingredient and the extent of such goodwill is the glue for exploring and binding together the many communication opportunities in a helpful and constructive way.

The older generation of British Muslims who will be users of hospice care, and the more able adults making crucial care decisions in the family home, are thinking and feeling in culturally domestic terms. The language of discussion is in English and the approach will be increasingly about what is realistic and pragmatic. But cultural and religious concerns and sensitivities will still act as barriers to a positive engagement with hospice services, in the absence of positive, clearer understanding.

This understanding is also relevant to the increasing number of younger Muslim parents caring for children living with life-limiting conditions. These families could achieve huge benefit from the holistic family care that children's hospices offer, once the stigma and cultural taboos are overcome. Many of the communication challenges are similar to those faced in reaching older patients – the solutions are similar: better data, a will to embrace and understand, and shared stories by those who have seen the difference that hospice care can make.

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Appendices

1. Fieldwork: interviews and focus groups with palliative care staff and service users including

- **David Widdas**, Consultant Nurse for children with complex needs; South Warwickshire Foundation Trust and Coventry and Warwickshire Partnership Trust.
- **Professor Bee Wee**, Associate Professor, Head of Research, Group Head, Consultant Physician, Fellow and Unit Director; Nuffield Department of Medicine, University of Oxford and National Director for End of Life Care NHS England.
- **Emma Aspinall**, Director of Care and designated lead for Safeguarding; Acorns Children's Hospice.
- **Mohammed Al-Rahim**, Founder, President, CEO; Freshwinds.
- **Professor Aziz Sheikh**, Chair of Primary Care Research and Development; University of Edinburgh.
- **Imam Yunus Dudhwala**, Head of Chaplaincy and Bereavement Services; Barts Health NHS Trust.

Focus groups with:

- Acorns Children's Hospice (service users)
- Richard House Hospice (staff)
- St Joseph's Hospice (staff)
- Mixed group of palliative care professionals

2. Service providers contacted in top areas

Area	Service Provider	Type of Service	
West Midlands	St Mary's Hospice	Adult Hospice	
	Bradbury Day Hospice	Adult Hospice	
	John Taylor Hospice	Adult Hospice	
	Marie Curie	Adult Hospice	
	Acorns Children's Hospice	Children's Hospice	
	Islamic Funeral Services	Islamic Burial Service	
	Birmingham Central Mosque Funeral Services	Islamic Burial Service	
West Yorkshire	Marie Curie	Adult Hospice	
	Overgate Hospice	Adult Hospice	
	Sue Ryder Manorlands	Adult Hospice	
	Sue Ryder Wheatfields	Adult Hospice	
	Forget Me Not	Children's Hospice	
	Muslim Funeral Service	Islamic Burial Service	
London	Greenwich and Bexley Hospice	Adult Hospice	
	Marie Curie	Adult Hospice	
	Demelza	Children's Hospice	
	Haven House	Children's Hospice	
	Richard House	Children's Hospice	
	North London Hospice	Adult Hospice	
	St Christopher's Hospice	Adult Hospice	
	St John's Hospice	Adult Hospice	
	St Joseph's Hospice	Adult Hospice	
	Trinity Hospice	Adult Hospice	
	Pembridge Palliative Care	Adult Service	
	Margaret Centre	Adult Service	
	Haji Taslim Funerals	Islamic Burial Service	
	Moulana Essad Funerals	Islamic Burial Service	
	Ali Funerals	Islamic Burial Service	
	The Islamic Centre	Islamic Burial Service	
	Greater Manchester	Bury Hospice	Adult Hospice
		Dr Kershaw's Hospice	Adult Hospice
		Springhill Hospice	Adult Hospice
St Ann's Hospice		Adult Hospice	
Willow Wood Hospice		Adult Hospice	
Francis House		Children's Hospice	
Manchester Mosque Funeral Service		Islamic Burial Service	

3. Workshop programmes

Bridging the Gap (Manchester) Strengthening relations between faith and hospice	
Morning	<p>Keynotes</p> <p>Imam Yunus Dudhwala, Chaplain, Newham University Hospital</p> <p>Dr Leigh Vallance, Chief Executive, Bolton Hospice and Ibrahim Kala, CEO, Bolton Council of Mosques</p> <p>Community support for hospice care: case study</p> <p>Hafizah Ismail, Chief Executive Officer & Founder, Children of Jannah</p> <p>Short film: 'I didn't know that'</p> <p>Facing challenges in mutual engagement (Workshops I)</p> <p>Facilitators: Imam Yunus Dudhwala, Richard House Children's Hospice; Imtiaz Hussain, Jinnah Day Care Centre; Liz Lyles, Nurse Consultant; Ally Paget, Demos</p>
Afternoon	<p>Community support for hospice care: case study</p> <p>Rupina Begum, Programme Manager, Eden Care</p> <p>Facing challenges in mutual engagement (Workshops II)</p> <p>Facilitators as above</p> <p>Reflections from workshops</p> <p>Personal reflection: Ghzala Ahmad, Acorns Children's Hospice service user</p> <p>Q&A with panel, speakers from throughout the day</p> <p>Closing remarks and feedback forms</p>

Bridging the Gap (East London) Strengthening relations between faith and hospice	
Morning	<p>Peter Ellis, CEO, Richard House Children’s Hospice</p> <p>Short film: ‘I didn’t know that’</p> <p>Louise Palmer, Community Involvement Manager, NCPC</p> <p>Facing challenges in mutual engagement (Workshops I)</p> <p>Facilitators: Dr Kumail Versi, SICM (Mahfil Ali); Peter Ellis, Richard House; Ally Paget, Demos; Naved Siddiqi, Woolf Institute</p>
Afternoon	<p>How Muslim Groups Support Hospice Care:</p> <p>Rasheedah Agbalaya, Children of Jannah</p> <p>Facing challenges in mutual engagement (Workshops II)</p> <p>Facilitators as above</p> <p>Reflections from workshops</p> <p>Sheikh Abdul Qayum, Imam, East London Mosque</p> <p>Panel discussion with experts</p> <p>Closing remarks and feedback forms</p>

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About the Woolf Institute

The purpose of the Woolf Institute is to serve the public good. The Institute studies how relations between faith communities can enhance our understanding of key concepts of public life: community and identity, mutual respect, personal responsibility, and social solidarity. Combining theology with the social sciences and the humanities, the Woolf Institute seeks to strengthen the ethical framework that is needed for our political, economic and social life.

Our teaching and research examines common purpose and points of difference between communities of faith from a multidisciplinary perspective. In addition to the pursuit of knowledge, the Woolf Institute designs public education programmes aimed at improving public and voluntary sector services and linking difference with the broader sustainability of communities. Our training and consultancy in diversity and end of life care has been especially successful over the last six years.

In our training we aim to situate knowledge of religion and belief within a specific professional context.

Sughra Ahmed is Programmes Manager at the Woolf Institute in the Centre for Policy and Public Education, where she has responsibility for the design and delivery of research and training on issues such as faith, belief, communities and integration. Previously, she worked as Research Fellow in the Policy Research Centre where she explored the migratory and settlement experiences of first generation Muslim women and men in the UK (www.generation1.org.uk), and worked with a number of organisations to consider the issues young people face whilst growing up in the UK and the impact of this on wider British communities. She has published a number of papers and key reports: *Seen and Not Heard: Voices of Young British Muslims*

(2009) and *British by Dissent* (2014). She is active in interfaith and intercultural work to help build stronger and more effective relationships across communities of faith and belief.

Sughra is Chair of the Islamic Society of Britain and a Trustee of the Inter Faith Network UK. Sughra has a BA (Hons) English Language and Literature and an MA Islamic Studies; she is a qualified Chaplain and holds a Diploma in Islamic Jurisprudence. She regularly contributes to debates in the media and is a contributor to Radio 4's *Thought for the Day*. In 2014 she was awarded the Noor Inayat Khan Memorial Award for Muslim Woman of the Year at the British Muslim Awards.

Naved Siddiqi is a social scientist and Consultant Researcher at the Woolf Institute. Prior to his appointment he was a Research Fellow of the Policy Research Centre, which specialises in policy concerns and training on civil issues and faith communities. Naved led the Centre's training and has delivered training to over 1,000 participants across the public and third sector. He has over 10 years of experience in field research and statistical analysis, and he has contributed to several important research publications with key research institutions including the Open Society Institute and the Institute for Public Policy Research.

With his formative years as a legal adviser, Naved has a law degree and is a reader in anthropology and comparative law, including the contextualisation of Sharia. He was tutored in theology and in Islamic social and political history by the late Professor Zaki Badawi, and possesses over 20 years of community-based experience on Muslim engagement and issues. Naved is a trustee of New Horizons in British Islam.



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