

<b>Institution:</b> University of Cambridge		
<b>Unit of Assessment:</b> UoA 25		
<b>Title of case study:</b> Islam, bioethics, and end of life care: Values, challenges and opportunities		
<b>Period when the underpinning research was undertaken:</b> 2016-2020		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Dr Mehrunisha Suleman	Research Associate	October 2016-July 2020
<b>Period when the claimed impact occurred:</b> 2016-2020		
<b>Is this case study continued from a case study submitted in 2014?</b> No		
<p><b>1. Summary of the impact</b> (indicative maximum 100 words)</p> <p>Dr Suleman's research on Islam and Bioethics at the University of Cambridge has demonstrated the need for healthcare professionals and policy makers to better understand and address the needs of the Muslim community as they interface with healthcare and science, particularly pertaining to ethical decision-making at end of life. It has had three principal impacts:</p> <p>(1) influencing national medical (NHS), political and religious organisations (Muslim Council of Britain) on the needs, barriers and inequalities faced by Muslims when accessing End of Life Care (ELC) Services;</p> <p>(2) improving the training of around 350 healthcare professionals, faith leaders and community representatives through collaborative partnerships with primary care trusts and community organisations; and</p> <p>(3) her appointment to strategic bodies such as the Nuffield Council of Bioethics. She has collaborated on numerous international projects and publications, offering expertise and helping shape a nascent field of research.</p>		
<p><b>2. Underpinning research</b> (indicative maximum 500 words)</p> <p>As a post-doctoral researcher, junior doctor and Islamic scholar, Suleman has undertaken a sustained programme of research on challenges and opportunities pertaining to Islam and bioethics, focussing on the moral challenges encountered by professionals, patients and families who are deliberating ethical questions at the interface of religion and biomedical science.</p> <p>1) Between 2016 and 2020, Suleman was appointed as a post-doctoral researcher at the Centre of Islamic Studies, University of Cambridge, to undertake primary research to examine the values and experiences of patients, families and professionals deliberating ELC decisions. The findings have shown that there is a growing need amongst healthcare professionals to understand and respond to the religious and cultural sensitivities of minority faith and ethnic groups, in negotiating end of life decisions [R1, R2]. In particular, healthcare professionals have expressed a need for greater support to understand and negotiate values, such as hope and acceptance, which carry theological significance for patients and families. The study shows that the lack of such resources leads to moral anxiety and frustration amongst healthcare professionals [R3].</p> <p>Patients, families and community stakeholders have also expressed that the current provision of palliative and ELC services does not meet their needs, and more effort needs to be made to incorporate their views and experiences within existing and emerging models of care, to address the current barriers to them accessing appropriate services [R4, R3].</p> <p>Suleman's work also highlights that little research or engagement has been done to understand and meet the needs of minority religious and cultural groups. The research findings suggest ways in which this could be improved including the role of 'trusted people in trusted places', such as community faith leaders and mosques, that can help start and sustain discussions, so the needs of these populations can be better understood and met. Suleman was also co-author of a collaborative report for local and national policy makers examining the impact of an ageing Muslim population and how policy makers, practitioners and community organizations can better</p>		

understand and meet their needs. The report is the first of its kind in the UK and represents a successful academic-community organization partnership led by Suleman [R3].

From 2017 to 2019, Suleman collaborated on numerous programmes examining the impact of emerging biomedical technologies on minority faith and ethnic groups, and, in particular, Muslims. She analysed religious texts, edicts and associated literature as part of the Nuffield Council on Bioethics' programme to examine the potential impact of the statutory limit for maintaining human embryos in culture. She found that theological and moral understandings of the beginning of life would impact on Muslim perspectives and, in particular, acceptance of changes to the statutory limit, and uptake of associated technologies. In addition, given the plurality of perspectives, within the Islamic tradition and amongst Muslims, policy makers ought to engage with a diverse cohort of the Muslim community to ensure adequate understanding of policy changes amongst these groups.

Suleman has also carried out research focusing on the scientific and theological impact of emerging genetic technologies and explored their global impact on religious scholarly and public engagement. The findings show that narratives rooted in the Islamic tradition provide novel perspectives to the understanding of the human person and ethical considerations surrounding genomics [R5].

Building on the research and analyses she has been conducting on these ethical issues, Suleman has also contributed to the Scottish Council on Bioethics' programme on the 'Ethics of Generating Posthuman Persons'. This work has raised important theological and ethical questions around who the creators are, how they interact with one another and the relationship they ought to have with these new kinds of persons. The study also provides novel insights on whether and how these new creatures may view their existence, and how Islamic perspectives on whether there is an ethical manner to bringing these creatures into existence [R6].

### 3. References to the research (indicative maximum of six references)

- [R1] Mohiuddin, A., Suleman, M., Rasheed, S., & Padela, A. I. (2020). When can Muslims withdraw or withhold life support? A narrative review of Islamic juridical rulings. *Global Bioethics*, 31(1), 29-46. [\[DOI\]](#).
- [R2] Parker, M., Suleman, M., Hope, T. (2020). Medical ethics. In J. Firth, C. Conlon, T. Cox (Eds.), *Oxford Textbook of Medicine* (6<sup>th</sup> ed., Section 1.5). Oxford University Press. ISBN: 9780198746690. [\[DOI\]](#).
- [R3] Suleman, M. (2019). Islam, ethics and care. In A. Gallagher, C. Herbert (Eds.), *Faith and ethics in health and social care: Improving practice through understanding diverse perspectives* (pp. 121-134). Jessica Kingsley Publications. ISBN: 9781785925894.
- [R4] Suleman, M. et al. (2019). *Elderly and end of life care for Muslims in the UK*. Centre of Islamic Studies (University of Cambridge) and the Muslim Council of Britain. ISBN: 9781905461066. [\[Link\]](#).
- [R5] Ahmed, A., Suleman, M. (2018). On the human person and the genome question: Why the soul matters. In M. Ghaly (Ed.), *Islamic ethics and the genome question* (pp. 139-168). Brill. ISBN: 9789004392137. [\[DOI\]](#).
- [R6] Suleman, M. (2020). *Islam and biomedical research ethics*. Routledge. ISBN 9780367191474. [\[DOI\]](#).

[R1, R3, R4 R5, R6] are all peer reviewed and published in international presses. [R2] distills the research for a policy and health professional readership.

#### 4. Details of the impact (indicative maximum 750 words)

Suleman's research in the field of 'Islam and Bioethics' has been impactful in terms of capacity building, shaping practice and influencing policy in relation to the training needs of professionals, and in improving the healthcare access needs of minority faith and cultural groups.

##### 1) Muslim Perspectives on ELC – capacity building, shaping practice and influencing policy

*Capacity building:* Suleman's research on stakeholder experiences and perspectives on ELC has revealed a knowledge and training gap amongst healthcare professionals about the experiences and needs of minority faith groups. In response, she has worked closely with beneficiaries to design and deliver relevant training and education resources. Through knowledge exchange workshops, a validated casebook and national, regional and local training days, her research has been disseminated widely to hundreds of UK healthcare and religious professionals and academics. The co-production of these resources has allowed both stakeholders and beneficiaries to be involved, and has been central in ensuring their relevance and impact. Stakeholders, such as NHS Blood and Transplant, the Royal Free Hospital, London, and hospices across the UK, have regularly approached Suleman with requests for training and resources. Participants of the training noted that: *'Work with Dr Suleman is influential in our understanding of how we can meet the needs of families from a Muslim background, not only to support best end of life care for their loved ones, but to understand how we can support more organ donation decisions ... needed for the wider community.'* **[E1]** Testimonial from NHS Blood and Transplant training lead). *'As a hospital chaplain it is crucial to have as wide as possible an understanding of people from different background ... I now have more confidence to support our Muslim patients and will be looking to further resources to grow in my understanding'* (Hospital Chaplain) **[E2]**. *'After attending the conference on Palliative and ELC for Muslim patients, it gave me new food for thought. With an innocent ignorance and limited knowledge of the Muslim faith, it encouraged me to consider if some of the barriers that are faced when trying to provide end of life care are often unintentionally based on White British beliefs and values, and not always understanding that what could be considered as a barrier to accepting is rather more of a cultural/religious belief'* (Palliative Care Nurse). **[E3]**.

Beneficiaries of the research have been encouraged to hold conversations about 'ELC decision making' and to initiate difficult conversations and challenging cultural norms, to enable end of life decision-making to occur earlier, rather than at a time of crisis.

*Shaping practice:* Stakeholders attending knowledge exchange workshops and a national training day organised and delivered by Suleman, have benefited through the establishment of new collaborative partnerships leading to the design and delivery of locally adapted resources and training. Beneficiaries have described significant changes to their practices, including local policies on burial support. *'The series of meetings and training that I have been fortunate enough to attend regarding end of life care, led by Dr. Mehrunisha Suleman, have had a significant positive impact on the outcomes that we are producing. The 'burial support' document for Muslims will now have a more detailed end of life care addition, addressing wills, organ transplantation and where care can be delivered. ... Some of these discussions have historically been either treated as taboos or have been surrounded by misinformation, leading to confusion and poor decision making, both at home and in hospital settings. The document will serve to clarify issues and support informed decision making for clinicians, care providers, families and chaplains'* (Practice Manager) **[E2]**.

Furthermore, Suleman's findings documenting the anxieties faced by healthcare professionals when meeting the needs of Muslim patients and families, has resulted in the co-production of resources and training, providing beneficiaries with increased confidence in supporting Muslim patients and families. Thus, her research has underpinned significant changes in practice that have been of value to healthcare professionals, increasing cultural awareness and wellbeing in terms of providing much needed training and educational resources. A Senior Palliative Care Nurse who has attended training and casebook expert workshops notes that, *'I have learned*

*that personalised care for communities is not about a tick list but about respect and human understanding. I look forward to continued relationships.'* [E2].

Another attendee writes, '*... I have very superficial, and at times stereotypical, knowledge of Muslim beliefs and practices. The event was super informative in that respect. ... I won't feel as if there is some huge gap of perceptions and beliefs I can never cross. I also realised that I will most happily talk to an imam, and until now I've never felt I am, in fact, allowed to approach them'* [E2].

A registrar who attended a Cultural Diversity at the End of Life workshop added that Suleman's '*research gave us an excellent insight into the reasoning behind the wishes and priorities of our Muslim patients. We were also able to learn about their experiences and the importance of involving local chaplains, local religious leaders and the community in helping us bridge the gap between the secular medical world and the religious Muslim world.'* [E4].

*Influencing policy:* Recommendations made by Suleman at a policy workshop organised by the Academy of Medical Sciences (AMS) led to a dedicated section on 'Engaging communities and faith groups' in their 'End of life and palliative care: the policy landscape' report (2019). The AMS acknowledged Suleman's advice on the need for culturally competent palliative and ELC, and the requirement for more research to understand the needs of minority faith and ethnic groups in the UK. The AMS report states that:

*'Dr Suleman drew attention to the fact that when [discussions about] end of life care ... encounters minority perspectives, the result could be a mismatch in values. While there has been very little work done so far on minority perspectives, Dr Suleman suggested ways in which this could be improved. For example, the gathering of thousands of people in the Muslim community for Friday prayers can be used as a bridge between the health care infrastructure and the community. The presence of 'trusted people in trusted places' can help starting and sustaining discussions, so the needs of these populations can be understood and met.'* [E5, p.11].

In 2019, increasing recognition of Suleman's research, led to an invitation from Michelle Ballantyne (MSP Member for South Scotland) to deliver a presentation on "Muslim perspectives on end of life care" at the Scottish Parliament, as part of a cross-party group on "End of Life Choices" [E6]. Such engagement and dissemination activities have been key to increasing cultural awareness amongst policy makers, lobby groups and key stakeholders about the access challenges faced by Muslim patients and families with ELC needs.

Suleman's research findings have been key in establishing a collaboration between the Cambridge Centre for Islamic Studies (CIS) and the Muslim Council of Britain (MCB), through which she authored a report on elderly and End of Life Care needs in the Muslim community in the UK [R2]. The novel community-academic partnership has underpinned the MCB's approach to the authoring and dissemination of the report. In an email, the MCB notes that Suleman '*was a pivotal member of the project team in ensuring the quality and comprehensiveness in what was the first study of its kind conducted by the Muslim community, for the Muslim community. Her End of Life Care (EOLC) research findings included in the report have been important in setting an agenda for both health professionals and the Muslim voluntary sector, with respect to training needs and chaplaincy priorities.'* [E7].

## 2) Wider expertise and engagement on Islam and Bioethics

As one of few global experts on Islam and Bioethics, in 2019, Suleman was invited to join the Nuffield Council on Bioethics as a council member, where she has made a significant contribution to Council's work on 'Research in Global Health Emergencies', the "Ageing" and "Gender Identity" working groups, as well as informing the Council's future strategy and public engagement [E8].

Suleman has also co-authored a chapter on Islamic perspectives on emerging genomic technologies, in a pioneering book on Islamic ethics and genomics. Her research on ELC has also been incorporated into publications on 'Conscientious Objection' for the *Encyclopaedia of Islamic bioethics*, as well as the Atlantic Council's report on 'Islam and human rights' (p. 3, 44, 49) [E9].

The international recognition of Suleman's work is illustrated by her having been invited to collaborate and present her work at international programmes on palliative care and ELC, including Georgetown University in Qatar and The University of Chicago. The latter led to Suleman authoring a chapter based on ELC research, which has contributed to a key book publication on 'Islam and Biomedicine'. She has also been appointed to UNESCO's Ethics Teacher Training Course (ETTC) where she has 'played a key role' towards capacity building in Malaysia, Indonesia and New Zealand [E10].

In summary, the extensive uptake of Suleman's research and expertise, by policy makers, third sector organisations, the healthcare sector, as well as academia and the wider public, highlights the relevance of understanding the relationship between Islam and Bioethics. Her commitment to this nascent field of research, sensitive collaborative working and understanding the needs of a diverse group of stakeholders is stimulating much needed capacity building, cultural awareness and implications for policy and practice.

#### 5. Sources to corroborate the impact (indicative maximum of 10 references)

[E1] Testimonial: NHS Blood and Transplant training lead.

[E2] Feedback from training days: Perspectives on End of Life Care – Caring for Muslim Patients, 18<sup>th</sup> and 27<sup>th</sup> March 2018 (Centre of Islamic Studies); Cultural Diversity at the End of Life 8<sup>th</sup> April 2019 (Royal Free Hospital);

[E3] Testimonial: Palliative Care Nurse

[E4] Testimonial: Registrar, Geriatrics and General Medicine, North Middlesex University Hospital NHS Trust.

[E5] Report: Academy of Medical Sciences (2019). *End of life and palliative care: The policy landscape. Report of a workshop held in February 2019.* [\[Link\]](#)

[E6] Scottish Parliament: Cross-Party Group on End of Life Choices. Invitation to attend; Minute of the meeting, 10<sup>th</sup> September 2019; testimonial.

[E7] Testimonial: Muslim Council of Britain.

[E8] Working group report, Nuffield Council on Bioethics. *Research in global health emergencies: ethical issues.* [\[Link\]](#) [Suleman is listed as a member of the Nuffield Council on Bioethics and her work is cited on p. 94.](#)

[E9] Encyclopaedia of Islamic Bioethics and Atlantic Council's report on "Islam and Human Rights".

[E10] UNESCO: Ethics Teachers Training Course, Jakarta: Testimonials.