



organ
donation



Organ Donation & The Muslim Community

May 2022

Findings Report

Background

The way we do research to inform policy isn't working. Today, most community based 'led' research is done through collaborations between large science or specialist research institutes partnering with local organisations. Whilst this is an attempt to enrich the quality of research and to bring wider social benefits, it still lacks a deeper representation of the communities they are trying to help. Where such partnerships are formed the experiences are not always productive or conducive to drawing on the knowledge and expertise of all participants, as they remain the subject, not the co-authors and co-creators of the research.

There is a need for a process to place individuals and communities as drivers of research that considers the issues they face; and lead to practical responses and recommendations from the ground up.

There is a need for a radical shift and movement in how authentic data and insights are collected from women of Black and Minority Ethnic backgrounds. In response MWC have developed an approach that focuses on the design and delivery of collaborative research to create better policy and practice, driving practical solutions that address women's health and wellbeing.

Think + Do Tank

With the support of Wellcome Trust, Smallwood Trust & Friends Provident Foundation, we hope to reverse the current trend of Muslim males and non-Muslims researching and advocating on behalf of Muslim women, especially regarding issues of health, wellbeing and bioscience.

Our approach will straddle the 'Think+Do Tank' between both policy and beneficiaries (Muslim women) and will offer authentic insight and appropriate solutions, as it will be led by the beneficiaries. We focus on the relevance, credibility, legitimacy and utility of the research we do, ensuring that we position our research for use.

MWC focuses on Muslim women from Bradford and surrounding areas. Our work aims to eradicate a climate of misogyny and patriarchy fueled by public stereotyping and male-dominated interpretations of women's roles and positions. In short, society is denying these women their ability to think and act independently or contribute to the creation of health, wellbeing and bio-science policies and practices that affect them and their community.

For example, Muslim women have not been engaged as contributors to research and policy reflective of them. It seems that most research is a male bastion, which undermines their effectiveness and puts them at a disadvantage and impacts on how they research and present the needs of women. This project will be women led and women governed, therefore putting these women at the heart of the research.



What This Study Covers

Organ donation is an intense and exhaustive process for those who donate and those awaiting their transplant. However, research completed by the NHS and the British Islamic Medical Association both show that the BAME (which is heavily populated by Muslims) community are at most risk of developing health related issues but are also the least likely to donate.

According to the British Islamic Medical Association, 'Black, Asian and Minority Ethnic (BAME) groups represent 11% of the UK population but account for 35% of people waiting for a transplant. Last year, 21% of those who died while waiting for an organ were from a BAME background.' These statistics imply that unfortunately when it comes to the BAME community there is a shortage of donors but an excess of need.

There are mixed and plentiful opinions on whether organ donation is permissible or not from an Islamic perspective. Overarching the Islamic rulings relating to organ donation is whether or not Muslims and BAME communities are equipped to understand and then decide on their own choices, perceptions and religious identity.

This study aims to explore the present understanding and various perceptions of organ donation within the broader Muslim community. British Muslims may be very aware or completely misinformed on the Islamic perspective of organ donation. This report will inform and present a clear understanding of the Islamic perspectives and viewpoints.

We will also attempt to further explore why the Muslim community specifically have particular thoughts, ideas and opinions but also the framework around the Islamic perspective. Due to the nature of this subject, there are misconceptions due to lack of knowledge and education for topics like organ donation. Using relevant information, we will provide recommendations for the future in the hope that the Muslim community can become more informed and active in their roles within society and their own homes.

There are many forms of organ donation; living donation, deceased donation, tissue donation and pediatric donation. Choosing to donate can be an especially challenging decision for Muslims, especially when considering whether this form of helping others is Islamically accepted and deemed as Halal (permissible) or not.

Key Findings

Since our research began in 2018, which involved engaging with the Muslim community and through our health influenced seminar which explored organ donation, we have found that there is a critical need for organ donors within the Muslim community. The seminar involved 200 attendees and the engagement showed that 56% of attendees would now feel comfortable being organ donors and would invest in an organ donor card as they felt informed enough on the Islamic perspective. 25% of attendees wanted more information on the Islamic perspective as they were still skeptical. However, overall all those who attended felt they were given evidence based information and insights as well as the feeling that the new knowledge provided made them more educated on the topic.

It should be highlighted that the same organ donor can in fact save up to 8 lives (through different body organs) and improve the lives of up to 50 people (by donating tissue). The issues we are having regarding organ donation are increasing the need by 5% each year, so the time to act is now.

Even with this information provided, it is unfortunate that there still is very little movement in attitudes toward organ donation from the Muslim community – this relates to both spreading awareness and proactive choices and action being taken. Therefore, this results in sustained and growing demand for donors (the need does not disappear, it is something that must be actively worked on) and health declining as people wait longer for donors. Alongside these factors these issues lead to those of BAME and Muslim backgrounds still being at risk and having higher mortality rates than those of white ethnic backgrounds.



Some of the beliefs and attitudes that Muslims hold about organ donation

﴿Whosoever helps another will be granted help from Allah.﴾

(Prophet Muhammad (pbuh) – Regardless of sect division and personal beliefs, most Muslims believe that the role of a Muslim is to help others and in so please Allah to reap the benefits from Allah.

‘It is a complicated issue with a diversity of beliefs and apparently the Hanafi madhab (school of thought) hold the strictest of views on organ donation.’ There are many schools of thought, sects and sub sects some of which are more conservative, traditional or ‘strict’ than others. However, due to the diversity within Islam because of the segregation of schools of thought it therefore diversifies the beliefs, life choices and opinions made by Muslims.

There are three opinions:

- 1) Majority opinion based on fatwas from many individuals and institutions is that organ donation is allowed both from a living person and a dead person.
- 2) Donations are only allowed from a living person and not a dead person.
- 3) A minority opinions that organ donation is not permitted either from a living or dead person.' – Through speaking to Muslims around the subject of organ donation, these are the three opinions that are prevalent, as well as not having an opinion at all (due to lack of knowledge/education).

👉 If we hold a belief that we are not permitted to donate organs then we should hold onto that belief firmly when we or our loved ones need an organ to be donated as well. 📌

– Some Muslims use the Islamic knowledge they have but also take a morally motivated route when considering the opposing opinions. The point shared here is interesting and also valid as people's opinions tend to change when their families are affected.

'Whosoever saves a life, it would be as if he saved the life of all mankind.' (Holy Qur'an, chapter 5, vs. 32) – A common way of thinking for Muslims is to refer back to the Quran and Hadith as these sources were created for guidance and answers therefore instilling faith and trust into any decision made by a Muslim. Therefore, it can be stated that Muslims tend to make decisions based on their understanding and practice of Islam.

'The sanctity of life and preserving life is paramount in Islam and it trumps everything else.' – This can be further interpreted and understood as the principle within Islam that in severe circumstances the prohibited is permitted, therefore, some Muslims believe that organ donation may be extreme but can be done in the right situation.

'...those [of] an Asian background are more likely to need an organ transplant than the rest of the population as they are more susceptible to illnesses such as diabetes and hypertension, which may result in organ failure and the need for a transplant.' – Statistics show that individuals from a BAME background are more likely to need organ transplants and due to this are less likely to be donors. This takes away from lack of education and morals but to a health-based decision showing that BAME communities physically cannot be donors.

'It is permitted but it is in fact a commendable thing to do.' – This view helps us to promote that organ donation is not only Islamically correct but is valued and commended and as Muslims we are rewarded generously.

'The conclusions from the Doctors, one of whom was a religious scholar, were that it is permissible as he was quoting from Hadith & Quran. Most Middle Eastern countries have had ijtemah (scholarly discussion) on this subject and ruled that it is permissible.

However, South Asia is a bit of a sticking point as usual getting religion and culture mixed up.’ – This point is interesting and understandable as culture is easy to rely on and conflate with religion and some cultures are more rooted and stuck in their traditions than others, but there are things we can do to change this. Such as:

- Becoming informed through appropriate sources of education. This does not mean just reading the Quran and figure out the correct answers: the Quran is often difficult to interpret – so what we can do is speak to our community and religious leaders to learn the tools to further understand.
- Being open and honest with our extended family, parents and grandparents, is something that may not seem normal or comfortable to do. However, this may be a steppingstone in relation to this topic, and beginning at home is important.

From the discussion and feedback points, we are aware that many Muslims have a clear and well thought through understanding and perception on organ donation. The aim for us is to push for more communities and cultures to come together and view organ donation as a positive step.



The question is, how do we do that?

Clinicians and health care professionals from various backgrounds who work within the NHS and the private health care sector, should and can be providing patients and service users with information that is culturally and religiously appropriate surrounding organ donation. Often, the concept of organ donation to Muslims of particular backgrounds has never been thought about or understood. However, if they are provided with information that they can not only understand (through the use of home languages being used) but feel is applicable to them on a religious level (the use of Hadith and Qur'anic verses) they are more likely to either donate or just be aware that organ donation is Halal.

The lack of adequate health literature and cultural and religious competence within health care practice can often result in a further lack of education and understanding from the Muslim community when considering organ donation. However, many Muslims have a clear and knowledge based opinion and understanding around this topic so this can help to educate and spread correct and up to date information.

As discussed above, Muslims tend to make decisions according to the religion of Islam, therefore, some Muslims feel very strongly that it is not only important but a form of worship and a fardh (obligation) on Muslims to help one another. This is both a morally motivated response and opinion from Muslims but also an opportunity to please Allah (God) and to live a life defined by good and virtuous deeds.

What should be noted is that not every Muslim will have the same opinion on health care, medicine and the human body, all of which directly link to organ donation as they all play a role in our views on life and our sense of being, especially as Muslims.

Many Muslims believe that there are treatments that do not require the assistance or knowledge from doctors, nurses and the public health sector generally. Honey and black seed oil, for example, are known to hold healing and positive health benefits, and also feature as part of the sunnah (practice) of the prophet Muhammad (PBUH). But also, cultures have their own forms of medicine and cures. Alongside this, for Muslims, everything is dependent on the Will of Allah. Similarly, when it comes to health, for many, believe praying and asking God for guidance and better health is an important element of belief and practice.

On the flip side, some Muslims are more open to the possibilities of science and medicine and tend to have more faith and trust in the health care system than their older generations. However, this can sometimes make little change as beliefs can be intergenerational and simply be diluted into the newest generation.

Due to the diverse make up of beliefs and preconceptions around organ donation it can become difficult to form a well-rounded agreement from Muslims from different ethnic and cultural backgrounds.

But this is also due to health adversities that are faced by those of different ethnic backgrounds, so not all of the decision made is a result of just religious beliefs, but in fact health inequality making those of the BAME community or the elderly population more vulnerable to be donors and in some cases not even have the choice.



Key Recommendations

Based on the above findings, we suggest the following recommendations that would provide meaningful and effective changes that would improve the knowledge and understanding of organ donation within the Muslim community.

- Health promotion campaigns that are education and evidence based are needed to improve health as well as our understanding of organ donation within our local communities. This can involve the role of community leaders and community based approaches which will promote cultural competence and coherence, as well as trust and confidence in our services.
- A bigger focus on health literacy such as language and culturally specific information on risks, symptoms, prevention and treatment. This will allow for a better understanding from our communities and a reason to understand as they are more likely to want to read and further their knowledge when they are able to do so independently.
- An effort should be made to promote and create a larger knowledge base on organ donation. This can involve the ways to minimise susceptibility and to manage lifestyle habits and further the ways we can make informed decisions. Within the Muslim community there is a lack of initiatives with adequate information allowing people to understand organ donation from an Islamic perspective and a medical perspective. This means knowing our rights and duties as Muslims but also the significance of transplants and medicine.
- Medical examinations and service received in GP practices and hospitals should be meeting a standard of care that is tailored to different cultures and religions. Any care or information provided must be delivered with a full understanding of the service user or patient who is present in order to provide substantial and appropriate delivery of care. This will help with trust and education between service providers and service users.
- Forms of screening and MRI's should be made mandatory (whether this is annually) for those who are predisposed to health issues and forms of organ failure and disease. This form of prevention will act as a deterrent from more communities being vulnerable. As well as this, screening can show us whether people are healthy enough to become organ donors which promotes an uptake of those who are able to be organ donors.
- Due to the mix of opinions between different cultures and different schools of thought within Muslims, there should be a middle ground established which allows Muslims to be open about their views through the use of public services such as Mosques and community centres.



Case Study

Shagufta* had suffered chronic kidney disease for many years, which affected her growth and day to day activities. Her kidneys could no longer filter waste properly, and she was undergoing regular treatments of dialysis, where a machine removes waste from the bloodstream.

Shagufta's sister Neelam* was a year younger than her and had a deep bond with her sister. She was very upset to see her elder sister in pain, and started looking into kidney donation as a living donor. Neelam spoke to the doctors at the hospital, and underwent tests to see if her kidney would be a match for Shagufta. Initially, their parents were hesitant for Neelam to look into the procedure, as they were worried about any potential long-term implications for Neelam's health. The family spoke to the consultant who reassured them about the careful screening process and explained everything in detail, especially about the ability to live well with one healthy kidney.

Neelam's screening tests resulted in her being a good match for Shagufta, and she decided to go ahead with the transplant operation.

The kidney transplant surgery took approximately three hours to complete, and both Neelam and Shagufta spent a few days in hospital to recover and for doctors to check the transplanted kidney was working. Once successfully attached, Shagufta's new kidney started working efficiently to replace one of her failed kidneys.

Over time, Shagufta no longer needed dialysis, so she had more freedom to enjoy her life, experiencing increased strength, stamina and energy. Shagufta was on a special diet and medication to help with the transplant, ensuring her body did not reject the new organ.

Neelam was very emotional to see her sister healthy and enjoying better quality of life. She was very happy that she decided to become a living donor, and shares her story with her friends and networks, hoping to encourage more people to become donors.

***Names & identifying details have been changed to protect the privacy of individuals.**

References

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**Report created by the Think + Do Tank
participants supported by the MWC team.**

