Reach Alliance

# Good Eye Health Through Responsible Data Sharing

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# The Reach Alliance

The Reach Alliance is a consortium of global universities — with partners in Ghana, South Africa, Mexico, Canada, United States, United Kingdom, Australia, and Singapore — developing the leaders we need to solve urgent local challenges of the hard to reach — those underserved for geographic, administrative, or social reasons. Working in interdisciplinary teams, Reach's globally minded students use rigorous research methods to identify innovative solutions to climate, public health, and economic challenges. The United Nations Sustainable Development Goals (SDGs) provide inspiration and a guiding framework. Research is conducted in collaboration with local communities and with guidance from university faculty members, building capacity and skills among Reach's student researchers.

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*Note:* Authors are listed alphabetically with the faculty mentor listed last.

*Cover photo:* Business leader directing group activities during a seminar (Photo by iStock)

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| Contribution | Contributor (initials) |
|---|---|
| Conception or design of the work | RCN, PR, PK |
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A slit lamp used for eye examinations

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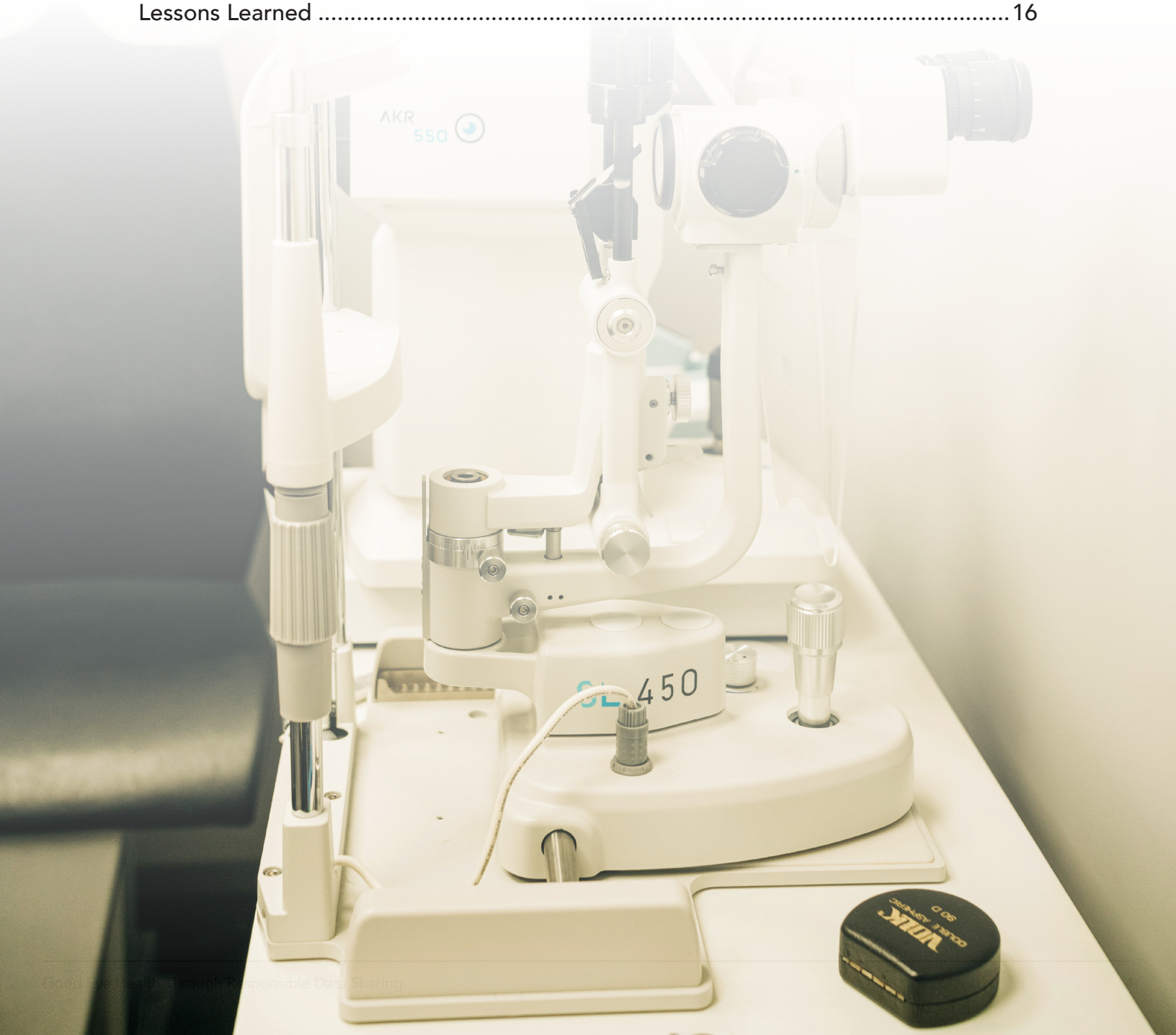

**FIGURE 1.** Two research team members conducting a focus group discussion

## Executive Summary

The UK is currently failing to meet the Sustainable Development Goals (SDGs), with only 21 per cent of domestic targets on track as of 2023. Global majority populations (GMPs) in the UK are disproportionately impacted by the failure to meet SDG 3 ("Ensure Healthy Lives and Promote Well-Being for All") and SDG 10 ("Reduce Inequality Within and Among Countries"), particularly when it comes to eye health. Current steps to improve eye healthcare increasingly rely on AI-driven innovation, but GMPs remain underrepresented in the data sets used to train these models. Since faith can shape health behaviours and most GMPs in the UK identify with a religion, we explored its influence on trust and data-sharing decisions.

Faith leaders and organizations have played important roles in delivering health education and interventions to populations who are often underserved. (Following discussions with our faith group collaborators, we have adopted the phrase "underserved" rather than "hardest to reach." Our collaborators preferred the term *underserved* because it acknowledges the barriers created by systems and services and the need for redress.) For example, during the COVID-19 pandemic, religious institutions were important sites for dispelling vaccine misinformation and delivering vaccinations. To encourage data sharing among GMPs in London, we carried out focus group discussions with members of Christian, Jewish, and Muslim communities with a view to creating a toolkit for healthcare staff to engage in a culturally competent way with GMPs when approaching data sharing and research.

Focus groups revealed that decision making was driven less by faith and more by concerns over privacy, trust in institutions, and personal or community benefits. Together, these factors led to skepticism around data sharing.

Participants in our focus groups also highlighted some key facilitators and suggested areas for improvement. This research will now inform the co-creation of a toolkit for healthcare providers, emphasizing the importance of transparent communication on how data is used, collaboration with each faith group's relevant trusted messenger, community-based education delivered in familiar sites in a culturally sensitive manner, and maintaining feedback loops to build trust by demonstrating tangible positive outcomes. Although faith plays a key role in decision making around data sharing, it is not necessarily the most important influence. GMPs often prioritize privacy, collective benefit, transparency, and trust.

# Background: Health Inequalities in the UK

The UK faces significant challenges in meeting its commitments to the Sustainable Development Goals (SDGs), with only 21 per cent of domestic targets on track as of 2023.[1] The SDGs, established by the United Nations, are a set of 17 global objectives designed to end poverty, improve health, and reduce inequality by 2030. Among them, SDG 3 ("Ensure Healthy Lives and Promote Well-Being for All") and SDG 10 ("Reduce Inequality Within and Among Countries") are particularly relevant to health equity. Despite these goals, disparities in healthcare outcomes among global majority populations (GMPs) in the UK remain stark and persistent. GMPs are classified as individuals who do not identify as White, and who make up the largest proportion of individuals in the world (See Figure 2). Although most UK residents are White British, the UK makes up less than 1 per cent of the world's population, and therefore if advancements in technology will contribute to global health equity, they must be programmed with the global majority in mind.

Maternal mortality rates, for example, are consistently higher among women from GMPs compared to their white British counterparts.[2] These inequities were further exposed during the COVID-19 pandemic, when GMP communities experienced disproportionately higher mortality rates.[3] Such inequalities cut across every domain of healthcare, from lower uptake of vaccines and screening programs to higher rates of morbidity and mortality in a wide range of conditions, revealing systematic barriers that continue to disadvantage GMPs. A growing area of concern is the widening inequalities in eye health.

GMPs experience disproportionately high rates of visual impairment and face elevated risks of conditions such as cardiovascular disease and diabetes, both of which are strongly associated with sight-threatening eye disorders.[4] These inequalities are further compounded by the rapid rise of digitization and artificial intelligence (AI) in eye health care. The lack of representative GMP data in the data sets driving these innovations risks reinforcing, rather than reducing, existing disparities in eye health.[5]

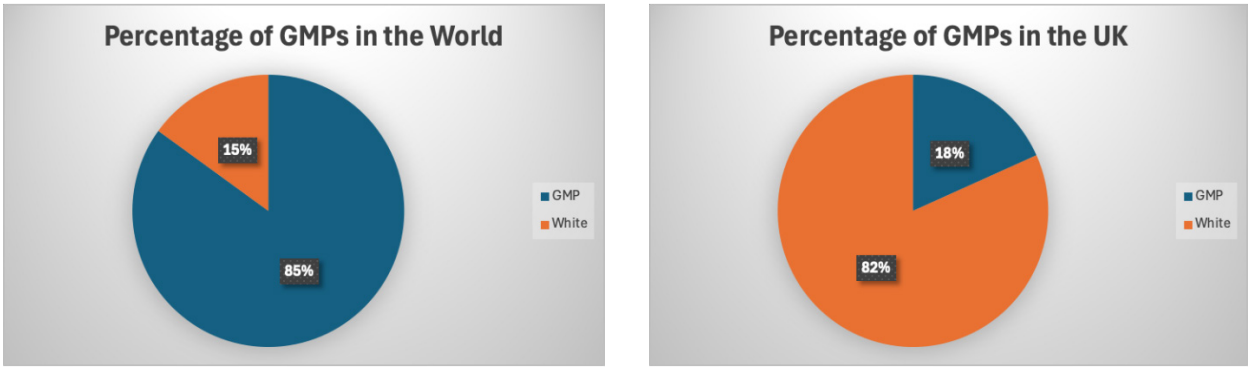


**FIGURE 2.** Global majority populations (GMPs) in the world and in the UK

1 "Halfway to 2030: How Is the UK Performing on the Sustainable Development Goals?" Global Compact, 2022.

2 "Maternal Mortality 2021–2023" Data brief, MBRRACE-UK, September 2025.

3 "Coronavirus (COVID-19) Related Deaths by Ethnic Group, England and Wales: 2 March 2020 to 15 May 2020," Office for National Statistics.

4 "Testing the Nation's Eye Q. How Smart Are We When It Comes to Looking After Our Vision and Eye Health?" Eye Health UK ; Frederick K. Ho, Stuart R. Gray, Paul Welsh, et al., "Ethnic Differences in Cardiovascular Risk: Examining Differential Exposure and Susceptibility to Risk Factors," *BMC Medicine* 20, no. 149 (2022).

5 Nikki Heinze, Lee Jones, and Bhavini Makwana, "A Rapid Review of Evidence Relating to Service Use, Experiences, and Support Needs of Adults from Minority Ethnic Communities Along the Eyecare Pathway in the United Kingdom," *Frontiers in Public Health* 11 (2023).

## UNDERREPRESENTATION OF GMPS IN EYE HEALTH DATA

Advances in digital health, especially through AI, are transforming eye care by enhancing early diagnosis and improving patient outcomes.[6] Comprehensive data sets are central to developing these technologies, however the data sets used to train these systems do not reflect the UK's ethnic diversity, and the resulting benefits of these technologies risk being unevenly distributed, further exacerbating disparities in care and outcomes for GMPs. For GMPs, this could mean delayed diagnoses, missed opportunities for early intervention, and continued disparities in care. Collecting and using GMP-specific eye health data could address these gaps by informing public health education, targeted screening, and management strategies, ensuring that AI tools and service planning reflect the needs of these communities.

However, the challenge extends beyond data availability to widespread barriers existing at the structural level through to individual communities. Within the healthcare system, these include factors such as implicit bias, lack of cultural competence, language barriers, and underrepresentation in clinical trials.[7] The 2023 Office for National Statistics report highlighted that GMPs, more than other groups, fear their information could be misused for discrimination based on their ethnicity.[8] The availability of data from GMPs is necessary to avoid treatment plans and decisions being made that are based on predominantly Caucasian populations, and that are not representative of the range of variables and risk factors that affect these groups' health. Unfortunately, marginalized groups have primarily been underrepresented in scientific engagement initiatives and studies or have been represented by unfavourable narratives, labelled as "resistant" rather than acknowledging the very real barriers to engagement.[9] Even when "inclusion agendas" are brought forward they have often not been developed with and for the needs of excluded groups.

*Unfortunately, marginalized groups have primarily been underrepresented in scientific engagement initiatives and studies or have been represented by unfavourable narratives, labelled as "resistant" rather than acknowledging the very real barriers to engagement.*

## PARTNERSHIPS BETWEEN PUBLIC HEALTH AGENCIES AND FAITH-BASED ORGANIZATIONS TO ENGAGE GMPS

An important way of alleviating healthcare inequalities is through partnerships between public health agencies and faith-based organizations. This is central to tackling ethnic health inequalities, particularly considering that the 2021 Office for National Statistics census found that 81 per cent of GMPs in the UK identified with a religion.[10] There are multiple examples that demonstrate the efficacy and success of these partnerships in the UK in promoting health care. For example, during the COVID-19 pandemic, Public Health England trained faith leaders to become vaccine

6 Jeffrey De Fauw, Joseph R. Ledsam, Bernardino Romera-Paredes, et al., "Clinically Applicable Deep Learning for Diagnosis and Referral in Retinal Disease," *Nature Medicine* 24, no. 9 (2018):1342–50.

7 Reema Harrison, Merrilyn Walton, Upma Chitkara, et al., "Beyond Translation: Engaging with Culturally and Linguistically Diverse Consumers," *Health Expectations* 23, no. 1 (2020): 159–68.

8 "Population Estimates for the UK, England, Wales, Scotland and Northern Ireland," Office for National Statistics, 2024.

9 Emily Dawson, "Reimagining Publics and (non) Participation: Exploring Exclusion from Science Communication Through the Experiences of Low-income, Minority Ethnic Groups," *Public Understanding of Science* 27, no. 7 (2018): 772–86.

10 "Ethnic Group by Religion: Census 2021," Office for National Statistics.

ambassadors and run vaccine-outreach programs which increased vaccine confidence among GMPs.[11] Pradeep and colleagues found that a faith-based-organization-designed education program on organ donation increased the number of South Asian registered organ donors by 37.5 per cent in two years.[12]

These examples demonstrate that partnerships between public health agencies and faith-based organizations can be an effective way of reaching GMPs through building patient education and trust in healthcare systems. However, there remains limited research on the broader potential of such collaborations in advancing equitable health data sharing, particularly in the context of eye health. We therefore aimed to explore how partnerships with faith-based organizations can support culturally competent strategies that encourage participation in data sharing, leading to more representative and comprehensive data sets that include all GMPs. Responsible data sharing informed by these approaches has the potential to reduce inequalities and improve eye health outcomes for all.

# About this Study

## DESIGN

We organized focus groups to understand the dialogue around data sharing among global majority populations (GMPs) and to co-create a practical toolkit that facilitates culturally appropriate collaboration with various faith groups, fostering long-term health partnerships to improve health outcomes. This initiative was designed to promote increased data sharing in GMPs and thereby work toward addressing disparities in the eye healthcare outcomes that they experience. We chose to engage with faith groups as a means of reaching participants, recognizing that religion often plays a central role in their lives. Focus groups were conducted with Christian participants (two groups: six women and six men), Jewish participants (one group: three participants), and Muslim participants (two groups: six women and six men). We also gave pre- and post-focus group surveys to participants to assess changes in their knowledge, perceptions, and attitudes toward data sharing.

## POSITIONALITY AND PREPARATION

Our research team represents diverse cultural and ethnic backgrounds, and shares a commitment to addressing and challenging inequalities experienced by GMPs. All team members are women and all student researchers are medical students. We recognize that our positionality might introduce potential biases, particularly in favour of both health data sharing and communication between various healthcare organizations. To combat this and ensure ethical research practices, we undertook training courses with the National Institute for Health and Care Research (good clinical practice, qualitative data collection and analysis, research inclusion) and engaged in further training on focus group discussions with our supervisors. This preparation strengthened our communication skills, ensured that our questions were open-ended rather than leading, and enabled us to create a respectful, nonbiased environment so we could accurately capture GMPs' true opinions on health data sharing.

## GOVERNANCE/DECISION MAKING/ COLLABORATING PARTNERS

To uphold respectful research methodology, we took steps to mitigate unequal power dynamics between researchers and participants. We used

11 Melodie Yunju Song, Denessia Blake-Hepburn, Anna Karbasi, et al., "Public Health Partnerships with Faith-Based Organizations to Support Vaccination Uptake Among Minoritized Communities: A Scoping Review," *PLOS Global Public Health* 4, no. 6 (2024): e0002765.

12 Agimol Pradeep, Titus Augustine, Gurch Randhawa, and Paula Ormandy, "Examining the Role of the Health Belief Model Framework in Achieving Diversity and Equity in Organ Donation Among South Asians in the United Kingdom," *Transplant International* 36 (2023).

facilitators from within the faith communities themselves to foster a more comfortable, open environment, where participants felt safe to share their perspectives. Interpreters helped to address language barriers, allowing individual participants to express themselves in the language they are most comfortable speaking.

After completion of this report, we plan to create a pilot toolkit informed by our findings. It will include the key barriers and facilitators to data sharing and the potential solutions to improve engagement with data sharing. This toolkit will then be given to faith leaders to validate the findings, enhancing their credibility by ensuring that they reflect the lived experience of the various communities involved. Feeding back to the faith leaders also works to maintain the toolkit's cultural sensitivity because they will be able to tailor guidance to reflect the unique needs and nuances of their specific communities.

### FAITH GROUP DEMOGRAPHICS

The Christian men's and women's groups were all of African ethnicity as was the Muslim men's group; the Muslim women's group was all of Bangladeshi ethnicity and participants in the Jewish faith group were ethnically Jewish.

### AGES

Participants' median ages were 45 years old for the Christian men's group, 40 for the Christian women's group, and over 65 for the Muslim men's group, Muslim women's group, and Jewish group.

### GENDER

Informed by participants' suggestions and to respect religious considerations, we separated focus groups by gender. This approach fostered psychological safety and reduced gender-related biases, creating an environment where participants felt more comfortable sharing their insights and experiences. It also ensured that diverse perspectives were heard without being overshadowed, strengthening the inclusivity and depth of the findings.

## Results: Shifting Knowledge, Perceptions, and Attitudes

### PRE- AND POST-FOCUS-GROUP SURVEYS

Pre- and post-focus-group surveys demonstrated a clear positive shift in participants' knowledge, perceptions, and attitudes toward data sharing. Among the Jewish group, understanding of the link between eye health and overall health was initially limited, but after discussion participants expressed a much stronger recognition of its importance. Muslim participants, who were the most hesitant about data sharing beforehand, showed a significant change, with all reporting greater openness and willingness to share their data following the focus group. The Christian group displayed a strong positive shift across all measures. Overall, across all groups there was a marked increase in knowledge about eye health, machine learning, and data sharing, with more participants reporting that they felt well-informed and better equipped to make decisions about data sharing. Participants were also more likely to join a health-data-sharing program and share personal data for public databases, healthcare purposes, and to train AI. These findings suggest that the focus group not only enhanced participants' knowledge but also helped foster greater trust and willingness to consider participating in health data-sharing initiatives.

### FAITH, HEALTHCARE, AND DATA SHARING

The Christian, Jewish, and Muslim groups each spoke about the pivotal roles that religious texts and faith leaders have in facilitating their engagement in healthcare and data sharing. When we asked how religious texts encourage accessing

healthcare, the Muslim group emphasized that the Qur'an encourages seeking medical treatment, noting the teaching "Allah has said go and see a doctor and get treatment." Similarly, members of the Christian group reflected on the compatibility between scripture and modern medicine, sharing the belief that "The way God heals you is through people" with medicine serving as an avenue for God's healing.

Participants also discussed how religious leaders and organizations encourage the practical application of these teachings by leading healthcare initiatives. The Christian group spoke about how their pastor regularly invites healthcare professionals to lead educational talks at the church. As a result, they feel that "this church is different. And I think it's due to exposure from the pastor to everybody," demonstrating the pivotal role that their religious leader has had in bringing healthcare to them via their faith community.

*Participants also discussed how religious leaders and organizations encourage the practical application of these teachings by leading healthcare initiatives.*

Regarding faith's influence on data sharing, a member of the Jewish group pointed out that "data sharing is not a new concept as Moses conducted a number of censuses." This group also noted that because the most important tenet in Judaism is to "do everything you can to save a life," it is their religious duty to share healthcare data if it helps others. Some members of the Christian group echoed this and mentioned that they share their data with health research for altruistic purposes. This group noted that their pastor encourages them to share their health data as part of research projects and stresses the importance of ensuring that their religious and ethnic group are not underrepresented in research.

The Jewish group also spoke about how the cultural aspect of their Jewish identity has facilitated their engagement in healthcare and data sharing. Several members mentioned that there is a strong feeling of gratitude in the Jewish community toward British society for welcoming them in as refugees in the wake of the Holocaust. This gratitude motivates them to share their healthcare data to give back to society.

**Conflict between faith, healthcare, and data sharing.** We heard some concerns that scriptural teaching on data sharing was less established. The Muslim group made the point that "There's not really many scholars talking about this topic," highlighting the need for further discussions on how to relate historical faith teachings to the advancements in present-day life. This lack of religious guidance made members of the Muslim group feel more uncertain about engaging with data sharing — it was unclear to them whether data sharing is religiously condoned.

While many members in each group spoke about the compatibility between religion and healthcare, some of the Christian group preferred using their prayer and faith to heal themselves rather than accessing healthcare. This was largely because they lacked trust in the healthcare system and believed that God's healing powers are stronger than those of the healthcare system. For example, one focus group participant said, "I probably will never trust GPs [general practitioners] … but I know because of God my family don't need GPs." This contrasts with other Christian group members mentioning God working through medical professionals. One member mentioned that rather than believing that the healthcare system is an intermediary for God's healing, he believes that he is directly led by God and therefore "none of the professors of medicine know my body half the way I know it." Many members of the Christian groups also agreed with this idea that medical professionals are highly prone to error and implied that they preferred to put their trust in their infallible God.

Members of the Christian groups also spoke about how their faith and culture intertwine and how both come into conflict with the modern healthcare system. The majority of the Christian group were of African descent and several members spoke about their belief in self-medicating with herbal medicine, which they see as more natural, trustworthy (i.e., with generations of usage and evidence of treatment), and powerful than Western medicine.

The Jewish group also highlighted circumstances in which their religious law has conflicted with healthcare, such as the debate over whether organ donation is kosher (which has recently been resolved by Jewish scholars). However, overall, the Jewish group felt that healthcare and religion were very separate, suggesting a more compartmentalized approach. As a result, they interpreted making decisions about their healthcare data as a personal issue rather than a religious one. The group clarified that within Judaism, "everyone has their own red lines."

For example, some ultra-Orthodox Jews may find healthcare much less accessible and be less open to sharing health data as a result of their strict observance of religious law. Jewish participants also mentioned the ultra-Orthodox overarching religious body, Skyver Hasidic, which "recently released an edict banning the use of artificial intelligence."[13] This ultimately impacts general views on AI and may limit data sharing, but participants noted that Jewish people "are not a homogeneous grouping," so "some will not have computers or TVs in their houses and some embrace IT to its fullest development ... and would be content to share data for the universal health and well-being benefit it produces" if they trust it will.

**The importance of healthcare professionals with a similar faith background.** Considering how religion's influence on healthcare and data sharing is so complex and varied, members of all the groups stated that they would prefer to receive information about health data from people who are of the same religious and cultural background. This was exemplified by the Christian group's willingness to trust and engage with healthcare and data-sharing initiatives recommended by their pastor, even though several of these members typically do not otherwise trust the healthcare system. However, because of the heterogeneity in each religious group, this is not as simple as assigning a Jewish doctor to a Jewish patient. For example, ultra-Orthodox Jews and modern Orthodox Jews can have very different beliefs and so it is vital to find healthcare professionals who have the same religious perspectives as the target population. The female Muslim group also highlighted the importance of considering intersectionality when identifying healthcare professionals of similar backgrounds for religious groups. They felt that ideally, they would be able to speak to a female Muslim doctor, especially for certain healthcare issues that are stigmatized and therefore uncomfortable to discuss with a male doctor, even if he was Muslim.

However, this does not mean that people of faith backgrounds would necessarily be unhappy about speaking to healthcare professionals who have a different religious perspective. Some members of the Muslim groups noted that the Qur'an encourages Muslims not to discriminate against those of different religious beliefs. As a result, these members would still engage and share data with healthcare professionals who are not Muslim though they would be more comfortable with Muslim healthcare professionals. The Jewish group also mentioned a previous effective healthcare initiative where Jewish healthcare professionals introduced their non-Jewish colleagues to Jewish patients at immunization clinics. This recommendation created an "open door" for non-Jewish healthcare professionals and built a rapport between them and the Jewish community.

13 The group approves regulations for the community.

## UNDERSTANDING DATA SHARING

When it came to the issue of data sharing in healthcare, there was a range of responses from limited understanding and mistrust to optimism and interest in greater education on the topic. Most participants in the Muslim group highlighted a widespread lack of knowledge on health data: "We're not sure if [we] completely do understand what information is kept in health data." When we asked the Muslim women's group if they knew how health data is shared among healthcare providers or other organizations, they responded with: "We don't know how it's spread." Participants of both Muslim focus groups expressed interest in education on three main elements: what information would be shared, where it would be stored, and to what level it would be shared.

*When the purpose of data in research is not communicated explicitly, it creates friction and othering, with participants believing they are not the target beneficiaries of data sharing.*

These practical benefits of health data sharing were discussed more widely among the Christian group. However, regarding research, participants described two main apprehensions. When the purpose of data in research is not communicated explicitly, it creates friction and othering, with participants believing they are not the target beneficiaries of data sharing. One told us, "They need the data anyway to advance their own cause, rather than it being helpful to people like us [Christian man]." The Christian women also highlighted how historical trauma of being exploited by the West has increased fear of data sharing and has led to increased reliance on traditional medicine as self-preservation:

> A lot of things that have been passed down from the old generation to say — okay — when you're dealing with this Western world, be careful what you put out there because they're just going to use you. And then everyone is trying to protect their space to say, okay, no, I don't need you. I can always go back to our concoction if anything is happening. We can use our own medication to heal ourselves.

This view culminates in an unwillingness to engage. However, participants described how, when they are given the opportunity to actively engage in data sharing for healthcare research, unease begins to fade and trust starts to be rebuilt, with a Christian man stating, "I would love to see [how data is stored, collected, and used] even if it's just a page," highlighting how increased transparency, however minimal, would work to tackle some of the uncertainty around data sharing. Participants described both the issue and the potential resolution stemming from a lack of effective communication.

The Jewish group felt very well informed on what health data is, emphasizing that they do not feel any different from the general population with the same level of understanding and relevant concerns. However, they did express a sense of not being able to keep up with newer developments such as not "knowing how [data] is stored anymore or what it's used for." This was particularly true when considering AI. The group recounted that they had several discussions among themselves and with friends about their uncertainties over its "phenomenal … pace of change" and the ability of "bad actors" to infiltrate and misuse it.

**Uncertainty over data sharing.** Among the Christian, Jewish, and Muslim groups there were varying levels of trust in data governance by large organizations. Exploring feelings of mistrust, the groups shared a common concern of not knowing what their data was being used for. The Muslim group expressed worries, with one member stating, "what damages are going to happen to

the community or me if I pass the information to them? And what's in it for me?" This feeling of uncertainty seemed to stem from past negative experiences with data sharing, as echoed in discussions where Christian participants described having their data shared to other organizations which they did not consent to. They shared how this lack of data protection affected "future engagement" with organizations because their trust in them had been broken: "And then randomly, I got, you know, a letter saying you gave consent about your eye. But this data is now being used for your lung health. I will not trust you anymore. And this may affect future, you know, engagement." These worries highlight the lack of transparency and necessary safeguards on data use by organizations, which makes individuals less likely to trust them with their personal data.

*Overall, the groups were more likely to trust in data governance if they knew that their data was being used for a good purpose.*

Another barrier that came up among the Muslim women was a reluctance to share health data, particularly if they were not certain it would remain with healthcare professionals. As they said, "it is my body … why would someone else get it?" The sensitive nature of their information affects their decision to not share their data due to the risk that other companies may be able to access it.

In discussions the Jewish group brought up a sense of fear due to political and historical racial attitudes toward the Jewish community. For example, one participant said, "we have a history of when knowledge information has been used … to our detriment, ... and we have 6 million casualties … to evidence that." This creates a "psychological resistance" against sharing personal information. For example, some community members have refrained from listing their dietary requirements when admitted to hospital in the fears of "putting a label" on themselves.

**Positive impact of data sharing.** Overall, the groups were more likely to trust in data governance if they knew that their data was being used for a good purpose. The Muslim group shared that if the data is being used to "benefit" their health and "treat other people" then they would be willing to share it. This sentiment was also apparent in the Christian groups who wanted to know that the data is for the "purpose of improvement" and to "facilitate health treatment." Underlying these reasons is the need for transparency from the organizations to ensure patients are informed on how exactly their data is being used. They also said that showing how it is helping to "make a change" would increase their trust in it.

**Organizations' credibility.** Another factor that influenced people's likelihood to share data was the reputation of the organization. Regarding the National Health Service (NHS), the Christian group mentioned that they are more likely to trust them with their data as they are "credible" and "recognized." Because of this, they believe the NHS "should have measures in place to protect [their] data," including having necessary training on safety around data sharing. Among the Jewish group, there was a sense of trust in the NHS that their data would not be used for "nefarious purposes … in the context of health research," and that they felt "excited" that their data could contribute toward healthcare. The Christian group highlighted that seeing "names and emails" of researchers helped enforce the credibility of organizations and thus made them more open to engage when they knew who they could contact if needed regarding their data.

**Faith leaders' role in building trust.** When discussing methods to build trust in data sharing, members of the Christian and Muslim groups mentioned the role of faith leaders. The Christian group described their pastor as a trustworthy

figure — they know he is "more exposed, more informed than I am." Because of this they said that members of their church are more "receptive" to data sharing and more likely to consent if he encourages it. By contrast, the Muslim group pointed out that their religious scholars may not agree with the use of data, especially for computer learning, due to it being "hidden." However, they identified that there is a lack of understanding and experience with AI and data sharing among their religious community which affects this opinion. The Jewish group highlighted the greater role of the community as a trusted means of sharing information because the "mainstream Jewish community is very organized," with "recognized channels" from regulatory organizations such as the board of deputies that influence the individual synagogues. This has created "social cohesion" which has enhanced effective promotion of health information.

**Safeguards for data sharing.** In discussions we heard how participants want more transparency about how their data is being used, by whom, and what the "end result" is. Measures to enforce the credibility of organizations would also reassure individuals that there is a high standard of data protection, so they can be more trusting that their data is used only for what they consented to. Together these could greatly affect the perspective of these faith communities on data sharing because they would feel more assured that organizations are handling their data securely and for a good purpose that can benefit others.

They also discussed a requirement regarding AI-guided decisions that if a computer came to a diagnosis based on their data, they would still want a doctor to "call to receive the results or discuss in person" because they do not fully believe that a computer can make decisions about their health. They have greater trust in doctors who have a better contextual understanding of their condition.

## CULTURAL AND COMMUNITY CONSIDERATIONS

When considering cultural and community factors that influence data sharing, religion and ethnicity shape some differences, but the most consistent factors across all faiths were trusted leaders, respect for religious observance, recognition of historical trauma, and the need for transparency. In other words, although faith plays a central role in the lives of GMPs in London, it is not the only factor when people are making decisions about data sharing in healthcare.

**Community impression of health data sharing.** Participants across all faiths were supportive of health data sharing and would advise members of their community to do the same. The Christian men's group responded with a resounding "absolutely, yes" when asked whether they would encourage data sharing and Jewish participants said that they "don't understand why anyone … certainly any of the Jewish people [they] know, would refuse" to share data. Across all faith groups, participants supported such statements by linking them to improving healthcare practices. For example, the Christian men said "sharing of data is highly encouraged for continuous improvement … till the Messiah returns there will be room for improvement" and the Muslim women's group said that it would be "good for [their] health." Jewish participants, in particular, emphasized their positive experiences with data sharing,

*When considering cultural and community factors that influence data sharing, religion and ethnicity shape some differences, but the most consistent factors across all faiths were trusted leaders, respect for religious observance, recognition of historical trauma, and the need for transparency.*

referencing the importance of being included in health data given the prevalence of certain conditions in the Ashkenazi community: "Jewish people know that they need to be in the system. They need to be registered. They need to understand how their personal genes are going to work for or against them."

The main exception, however, was the Muslim men's group, where a majority of participants were reluctant to share their health data and "[couldn't] give nobody any advice," citing the lack of transparency in how their data is used and shared. Across all groups the main deciding factor in whether their community would share data tended to centre conversations about community benefit, transparency, and privacy rather than religion, with the Muslim men's group explicitly mentioning there is "no connection at all" between faith and data sharing. The Muslim women's group was able to provide more context to this, highlighting that there were "not many hadiths" around this subject, so they did not have a concrete religious basis to make such decisions.

All groups recognized that they could not speak for their entire community. Christian women, for example, highlighted that views on data sharing differ within their community. They emphasized that "the age first" is often more influential than "ethnic community … and the religion." In other words, generational differences, such as levels of understanding and knowledge about data sharing, play a greater role in shaping attitudes. Equally, the Jewish group mentioned that faith-based regulations may be more relevant for the "ultra-Orthodox"— that they themselves felt "not distinct from the rest of the community," explaining that their views around data sharing are influenced by the same factors that shape the general population's views. Even within the Muslim men's group, opinions differed: where many expressed reluctance, one participant was "happy to share" his health data as "other people can benefit … from [his] information."

So even within communities, opinions can diverge based on generation, level of religious observance, and personal judgment calls.

**How should healthcare workers engage with the community to build trust around data sharing?** When asked how they would like to be approached in the future for health data collection, sharing, and research, it became evident that tailored strategies would be needed for each faith group, who all highlighted different avenues for building trust and engagement. However, a few common themes emerged, namely recognition of historical trauma and subsequent distrust of institutions; employing faith leaders or professionals as gateways to the community; and transparency.

*Acknowledge historical and current trauma.* Both Christian and Jewish groups highlighted specific concerns concerning data sharing, with one participant in the Christian women's group fearing that "for ethnic community … when they get your data, they just use you as a guinea pig."

Jewish groups, despite expressing comparatively increased trust in British institutions, drew on collective memory and recent events. They referred to the Holocaust as a reminder of the potential weaponization of data sharing. More recent concerns around anti-Semitism were also raised, where one participant recounted an anecdote about family members who avoided requesting kosher meals out of fear that being recognized as Jewish could risk prejudicial treatment from healthcare staff. Both groups valued acknowledgement of these injustices and assurance that steps are being taken to avoid it, with the Jewish group highlighting that they would need to be sure that their data would never be used for "fascist" or "totalitarian" purposes.

*Using trusted messengers.* All groups highlighted the importance of tailored channels when delivering information. Christian women highlighted successful health and well-being programs delivered through the pastor. The

Christian men further added that we should continue to "go through faith leaders … [as] you get a better result than when you go through individuals," explaining that members of the community may not trust researchers and healthcare staff, so reaching them requires a trusted liaison such as a pastor. The women further highlighted that this route would be particularly helpful in building trust with the older members of the community, who are best reached within the church.

The Jewish group also directed campaigns to enhance data sharing toward "recognized channels" such as working with the British Board of Deputies, community leadership council, the Chief Rabbi's office of the synagogues, and individual synagogues. Using these verified routes is more likely to yield positive results. As a Jewish participant succinctly put it, "if you've got someone you trust that looks like you and sounds like you, whatever faith you are, it works. And there's a trust there." They also emphasized the importance of practical consideration regarding faith, such as avoiding the Sabbath when organizing certain events and ensuring all religious dietary requirements are appropriately fulfilled. The Muslim men also supported information and outreach being delivered through imams.

The Muslim women, however, slightly differed in their chosen approach. They preferred to hear information from "the doctors or people who made the computers, because they're the ones who know about it." Muslim women made a clear distinction between what they believed to be within the imam's remit (religious queries) and the healthcare professionals (health-data-sharing queries). They further added that they believed that religious scholars may oppose data sharing, particularly with regard to AI, due to the lack of transparency and mixing of "gender," concluding overall that they would like to receive information from whoever is most knowledgeable about the subject. This group of Muslim women also preferred that future contact be directed back to them, instead of through a faith leader. If a faith leader was to be involved, they said they would prefer a woman.

All groups expressed interest in more community-based sessions, with people coming to them, and regular contact, ensuring that we close feedback loops and maintain visibility within the community. As one Christian woman put it, "if you can do more, not just one off … maybe in another six months?" The Christian group also explained that community sessions "in my church" can start conversations, where people present for the discussion "might tell their family as well" and then through peer-to-peer conversation word "will spread."

*Transparency and openness.* Finally, all faith groups highlighted the importance of transparency within data sharing. One Muslim man was concerned that he "doesn't know what level of information" is being shared and the Christian group emphasized that "you have to be transparent. You have to be truthful [about] what you do with the data."

The Jewish focus group also agreed with this sentiment but to a slightly lesser extent, especially if the outcome was beneficial to the health of the wider community. Instead, they highlighted the importance of treating them as knowledgeable partners, referencing their thorough experience in using data. Others highlighted that the Jewish community is "very organized" and "aware that there are certain diseases … specific to us."

## BALANCING PRIVACY WITH COLLECTIVE BENEFIT

All groups felt tension when it came to reconciling the desire to maintain personal data privacy with the wish to behave altruistically. On one hand, several Muslim participants had personal concerns about their private health information being shared with strangers. One participant emphasized that his health data is "private to [him]" and that he "[doesn't] like people sharing [his] information with anybody at all" regardless of

anyone's faith. However, another emphasized their willingness as "other people may benefit from [his] information." This indicates some debate over whether personal privacy is more important than sharing data to benefit others.

The Christian group echoed the importance of having adequate safeguards in place to protect individual privacy and maintain trust. One member noted that without these safeguards, "It will be hard to start sharing." However, collectively, these participants agreed that the benefit to the community that could be achieved through data sharing supersedes the concerns to individual privacy. Several Christian women made the point that "the populations over individual privacy" must be considered. Here, faith intersected to shape this belief through the concept of responsible stewardship of resources and opportunities. One woman referred to the development of large language models like ChatGPT by tying its creation into faith because "God gave them the wisdom to innovate."

For participants, the consensus was that the duty to support their community through innovation predominated, with participants willing to share "as long as it's helping somebody" [Christian woman]. Another participant noted, "I don't mind sharing my data for improvements of the service — if it's to improve the service" [Christian woman]. Participants described how data sharing could relate to altruism and how they may have benefitted from this: "if someone has gone ahead of me to share their data and then now I am coming, I get that opportunity of this medication — whatever — that's on a platter of gold — you know — I'll be happy. I'll be the happiest person on earth."

Participants in the Jewish group also acknowledged that there were inherent risks, for instance, challenges in storing data securely, that could lead to the compromise of personal information: "breaches happen, you know — mistakes happen." They were also concerned about data being "sold on" to an insurance company which could hinder them in the long run if the company used the data to "make some sort of a decision that they're not going to give you a ... car insurance policy (et cetera)." However, overall, the scale and volume of data was believed to reduce the risk to any individual: "I don't believe I'm important enough to worry too much. If someone can identify who I am who cares? ... And the information is more important than the individual." Participants emphasized what can be achieved with leveraging health data, particularly citing eye health and AI as an example, owing to "the sheer complexity of it and the number of computations that need to be done and that it's able to do." They acknowledged the validity of people's fears surrounding data sharing but ultimately saw it as necessary for "the greater good." When questioned on the reasoning behind this response, the collective response was "[Because] saving a life is saving the universe." For the participants, this desire to support and look after extended beyond their immediate Jewish community, with one participant stating, "[for] greater community … because, thank God, the community's been very good to us." The Jewish group seemed to prioritize collective benefit over privacy.

## MACHINE LEARNING AND HEALTHCARE

**Benefits and efficacy of AI in healthcare.** Interviewees from all faith groups demonstrated an understanding for the potential benefit of AI in healthcare.

They all acknowledged that AI can be used to increase the efficacy of the healthcare system, being able to "get through lots of data," for example. Members of the Muslim and Jewish communities also spoke of the beneficial use of AI in radiology. The specific benefits of AI to eye care were also mentioned, with one interviewee explicitly sharing their view of AI being "enormously helpful in ophthalmology."

All groups were able to share simultaneously their understanding for how AI might be used in the

future with current concerns about how their data would be obtained and stored.

**Data privacy, security, and transparency in AI systems.** Transparency about the use of data was a significant theme in the Christian and Muslim groups. They shared a particular concern about data being used beyond their initial healthcare purposes. It was important that the data shared was kept secure so as not to "fall into the wrong hands."

**Trust in AI for healthcare decisions.** Feelings were varied regarding how best AI might be implemented in the healthcare system. People thought AI would not be appropriate for emotionally sensitive or complex issues. One Christian interviewee stated that "a machine cannot understand how I feel."

Some were clearly against receiving a diagnosis from AI, while others mentioned factors that would contribute to their trust, such as knowing who programmed the AI.

The diagnostic capabilities of AI were less of a concern for the Jewish group, however novel terms, such as the "black box" of AI, raised concern and a request for more education on the subject.

## IMPACT OF EYE CONDITIONS

Several participants across all the faith groups have been greatly affected by eye conditions, whether personally or through a close relative. Many expressed "difficulties … in life" and "discomfort," and one individual's mother had to "give up reading" because of her eye condition. All groups mentioned negative experiences specifically following operations. In the Muslim group, someone was "refusing another operation" after feeling "uncomfortable" following the first one. In the Christian group one participant knew of a family friend who had an operation and suddenly went blind. A member of the Jewish group shared how his father had operations for cataracts and retinal detachment, but "he never got the vision back properly." Since many people had personally experienced eye problems, or had a close family member who did, it sparked discussions around the importance of eye health.

**Importance of eye health.** The importance of eye health differed between individuals across all groups. The Christian men held it in high regard because their "eyes are so precious," and they related its value to their faith: "after becoming Christian, I know it is the light of my entire body." The Christian women linked the importance of eye health to their work, saying "it is one of the tools that bring me money" and good eye health means employers can "get the best of you as well." This view was also expressed in the Jewish group who felt worried because their eyesight is necessary for their job and they "just want to be able to see." However, some others in this group ignored their visual health only until "things started to change."

Frequency of eye tests were irregular across all groups. Those who were affected by eye conditions go regularly, whereas most would go every one to two years or whenever they started to struggle with daily activities such as reading or using their phone.

**Eye-care-specific data sharing.** General opinions toward eye-care-specific data sharing were positive. One individual in the Muslim group said that data sharing in eye care has been "helpful to [him] personally" because he was treated for uveitis with a medication that was used for "virtually everyone" due to research based on the data shared by others. This supports what was said by the Christian group, who felt encouraged toward eye-care-specific data sharing for "continuous improvement" and "good practice."

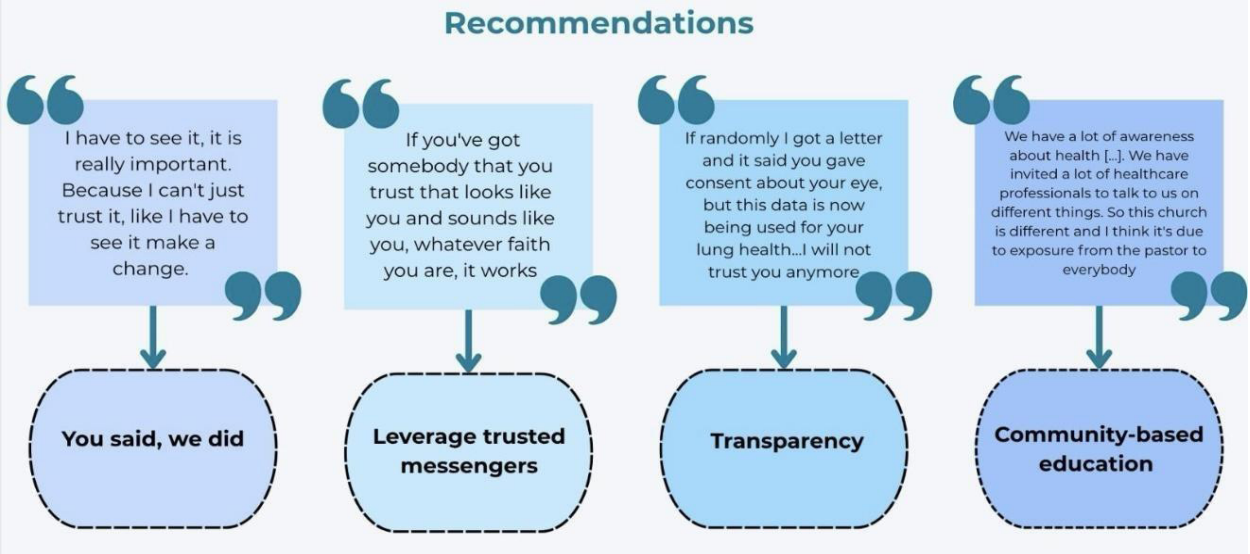


**FIGURE 3.** Proposed toolkit informed by participant priorities

## Our Proposed Toolkit

Speaking with these groups allowed us to identify barriers and facilitators to health data sharing. These were distilled from the different groups and represent shared priorities. Each recommendation maps back to the key themes raised, showing how our research responds directly to participants' voices (see Figure 3).

Our recommendations include developing a toolkit following the "You said, we did" format that was originally used by university representatives to rebuild trust with students. Similarly, where trust is highlighted as an issue within our focus groups, this format can help highlight that their input leads and suggestions have led to tangible change. Throughout our discussions with all the groups it became clear that they were highly outcomes focused, so by emphasizing direct benefits, we can begin to build and maintain trust.

Participants across all focus groups also raised concerns over the lack of transparency in how their data is being used. As part of our toolkit we will recommend that researchers and clinicians are clear and upfront about what their data is used for and who it is to be shared with. We will mirror this commitment within our toolkit itself by explaining how we used participant data to design these interventions.

Educational sessions within familiar community settings, such as places of worship, can help foster early engagement, stronger channels of communication, and greater transparency. Not only will such sessions build trust, but they will also position participants as active, informed partners in data sharing rather than passive recipients of information. However, such sessions must be handled sensitively. Discussions should be structured as a two-way dialogue, considering the existing understandings and concerns related to data sharing and AI, to maintain a partnership with participants. Sessions must also strike an appropriate balance by being transparent about pros and cons but ensuring not to alarm participants.

Engaging individuals who understand the participants' cultural beliefs and values is essential for building trust and delivering information effectively. This can be done by employing the relevant religious leader, a trusted community

member, or a well-informed healthcare professional when having discussions/education sessions about AI and data sharing. The toolkit that is being developed will also be piloted with clinicians to ensure that they are able to have culturally relevant discussions when broaching requests for data sharing. We will then collect feedback from these clinicians on its utility. Results from this will then be looped back to participants, ensuring a complete feedback loop, reinforcing trust and collaboration.

### STUDY LIMITATIONS

Recruiting Jewish participants for the focus groups proved challenging, particularly when engaging the ultra-Orthodox community. As a result, the Jewish group was very small, consisting of only three individuals, including just one woman. This prevented gender-based analysis and limited our ability to generalize findings. There was also a language barrier in the Muslim group. In the men's session, this challenge was compounded by the reliance on a facilitator for translation, making it difficult at times to distinguish the facilitator's viewpoints from those of the participants.

## Lessons Learned

Our research consisted of a literature review on the prevalence of visual impairment in global majority populations (GMPs), the potential for AI in preventing these visual impairments, and factors that have contributed to GMPs becoming underserved by such scientific advancements and in healthcare generally. We then conducted focus groups with members of the Christian, Jewish, and Muslim faith groups to gain further insight into these issues. We sought to understand the degree to which faith formed the lens through which issues of health, data sharing, and use of AI were perceived. We also sought to understand the current level of understanding on these issues.

We found that the literature aligned with the responses from interviewees regarding issues of trust in how data is managed and whether it will be used for more than the advertised purposes. Interviewees vocalized their internal conflict between a desire for privacy and their ability to contribute to a common good. This emphasis on contributing to the common good appeared a more significant theme in focus groups than literature reviews. The focus groups also provided insight on generational and gender divides on this topic. Overall, groups were open to data being used if it was to benefit their health, with the caveat that data safeguards should be in place and that people prefer human interaction to AI for emotionally sensitive cases.

The literature also demonstrated a need for cultural sensitivity in healthcare. This may align with the interviewees' preference to receive guidance on data sharing from those who can understand their religious and cultural context. This could take the form of informed religious leaders, however awareness of these topics among religious leaders varied in the groups we met with. These findings have contributed to the suggestions we have made regarding the best ways this research could be implemented.

Members of all groups had been significantly impacted by eye diseases as the literature predicted. Overall, people shared a positive outlook on data being used to improve health, and although some would engage with eye healthcare services only when they noticed a decline in their vision, others highlighted that good vision was a significant contributor to their ability to engage fully in their physical and spiritual lives. The aim of this research is to inform culturally competent approaches that encourage participation and support the development of comprehensive data sets inclusive of all GMPs. Responsible data sharing from these efforts will ultimately contribute to improving eye health for everyone.

# Research Team

**Marie Cilliers** is a fourth-year medical student at University College London, with a first class honours iBSc degree in clinical sciences. Throughout her studies, she has developed a strong interest in medtech, artificial intelligence, and improving equitable access to healthcare. Her dissertation focused on using photoacoustic imaging to enhance the visualization of hernia mesh, a project that combined cutting-edge imaging technology with practical surgical applications. This research was recognized nationally, winning Best Poster at the Royal Society of Medicine's Innovation Conference. Marie continues to explore the intersection of medicine and technology, with a particular interest in how AI can be leveraged to improve patient outcomes.

**Anna Hoang** is a fifth-year medical student at University College London with an intercalated bachelor's degree in pediatrics and child health. She has a strong interest in the relationship between health and faith, inspired by her work volunteering with a charity supporting young women of Jewish heritage in learning breast cancer self-examination. Keen to build a more inclusive healthcare system, Anna helped create and lead a teaching program for prospective medical students from global majority backgrounds in her role as a medical student ambassador at Great Ormond Street Hospital. She was also awarded the UCL F. Stoney Reflective Writing Prize for her essay exploring the importance of addressing personal biases within healthcare.

**Sancia Lam** is a fifth-year medical student at University College London, with a first class honours iBSc degree in surgical sciences. She has a strong interest in ophthalmology, having conducted research projects on vitreoretinal surgery and genetic retinopathies at Great Ormond Street Hospital and Moorfields respectively. She is also keen on spreading awareness about health education as project lead for Eyeducate, a UCL volunteering organization of medical students who hold teaching sessions at primary schools to educate students on the importance of looking after their eye health.

**Abigail Omotosho** is a fifth-year medical student studying at University College London. She has an interest in preventable blindness which she investigated during her anatomy BSc, completing a dissertation on the genetic basis for congenital eye diseases. Abigail is passionate about health equity, in particular, achieving this through more equal access to health education.

**Hiranmayee Sudarsan** is a fifth-year medical student studying at University College London, where she also graduated with a first-class honours in global health. She has a keen passion for inclusion health, having completed her dissertation project on factors impacting mental health care access for adolescent refugees. Committed to reducing health inequity within the community, she has contributed to an audit at UCLH aimed at improving

inclusion health-training programs for healthcare staff. Alongside academic projects, she currently serves as project lead for UCL's Save a Baby's Life initiative, where she teaches infant CPR to new mothers in the neighbouring community centres.

**Roxanne Crosby-Nwaobi** is a clinical academic ophthalmic nurse, professor of ophthalmic health and care at UCL Institute of Ophthalmology, and the program director for the NIHR Senior Research Leader program. She has a particular interest in population health for underserved communities. She received the *Nursing Times* award for Clinical Research Nursing in 2021 for the Research Opportunities at Moorfields (ROAM) online platform which increases patient/public access to research conducted at Moorfields. She is the recipient of numerous national and international awards including the RCN Researcher of the year 2023, ARVO Advocacy in Eyes and Vision research, and Fellow of the RCN.

**Pearse Keane** is professor of artificial medical intelligence at UCL Institute of Ophthalmology, and a consultant ophthalmologist at Moorfields Eye Hospital NHS Foundation Trust. He is also director of the INSIGHT health data research hub program based at Moorfields Eye Hospital. Since 2020, Pearse has been funded by UK Research and Innovation (UKRI) as a Future Leaders Fellow, and in 2023 he became a National Institute for Health Research (NIHR) senior investigator. Pearse leads a multidisciplinary research group of clinician scientists at UCL and Moorfields, focused on developing and implementing AI systems in healthcare.

**Poppy Pierce** is a medical doctor and researcher with an interest in health equity and inclusion health. She graduated with first-class honours in women's health from University College London, where she also completed her MBBS. Her research experience spans women's health, digital health, and homeless and refugee health. Poppy has carried out national research on the COVID-19 response for homeless populations, as well as projects on childhood adversity, such as homelessness and neglect. She recently won the UCL Shaper Prize for leading a project that directly informed a successful funding bid to improve cervical screening uptake for women with learning disabilities across Kent, UK.

**Polly Rawlinson** is the research program manager at the Institute of Ophthalmology, University College London, where she works with Pearse Keane to support the delivery of cutting-edge research in AI and ophthalmology. She has previously worked in research management in a range of disciplines, including preventive neurology, cancer prevention and screening, and epidemiology, holding positions at Imperial College London, Queen Mary University of London, and King's College London. Before moving to academia, she worked in the creative industries, specializing in music supervision and script development.

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