



Reach Alliance

Promoting Equitable Eye-Health Data Sharing

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The Problem

- Eye health research increasingly relies on large-scale data (e.g. imaging and screening) to drive innovation (e.g. artificial intelligence for early detection of eye disease).
- Global majority populations (GMPs) are underrepresented in these datasets, which leads to biases in research and poorer outcomes for these populations.
- Historical distrust, power imbalances, and concerns over data governance (privacy, consent, and control) limit community participation in data sharing.
- Without comprehensive and inclusive data, health inequalities risk being perpetuated, with predictive models and interventions being less accurate and less beneficial for GMPs.
- There's a need to ascertain the barriers and facilitators among GMPs in order to promote data sharing. Given that the majority of GMPs identify with a religion, focus groups were held with Christian, Jewish, and Muslim faith groups.



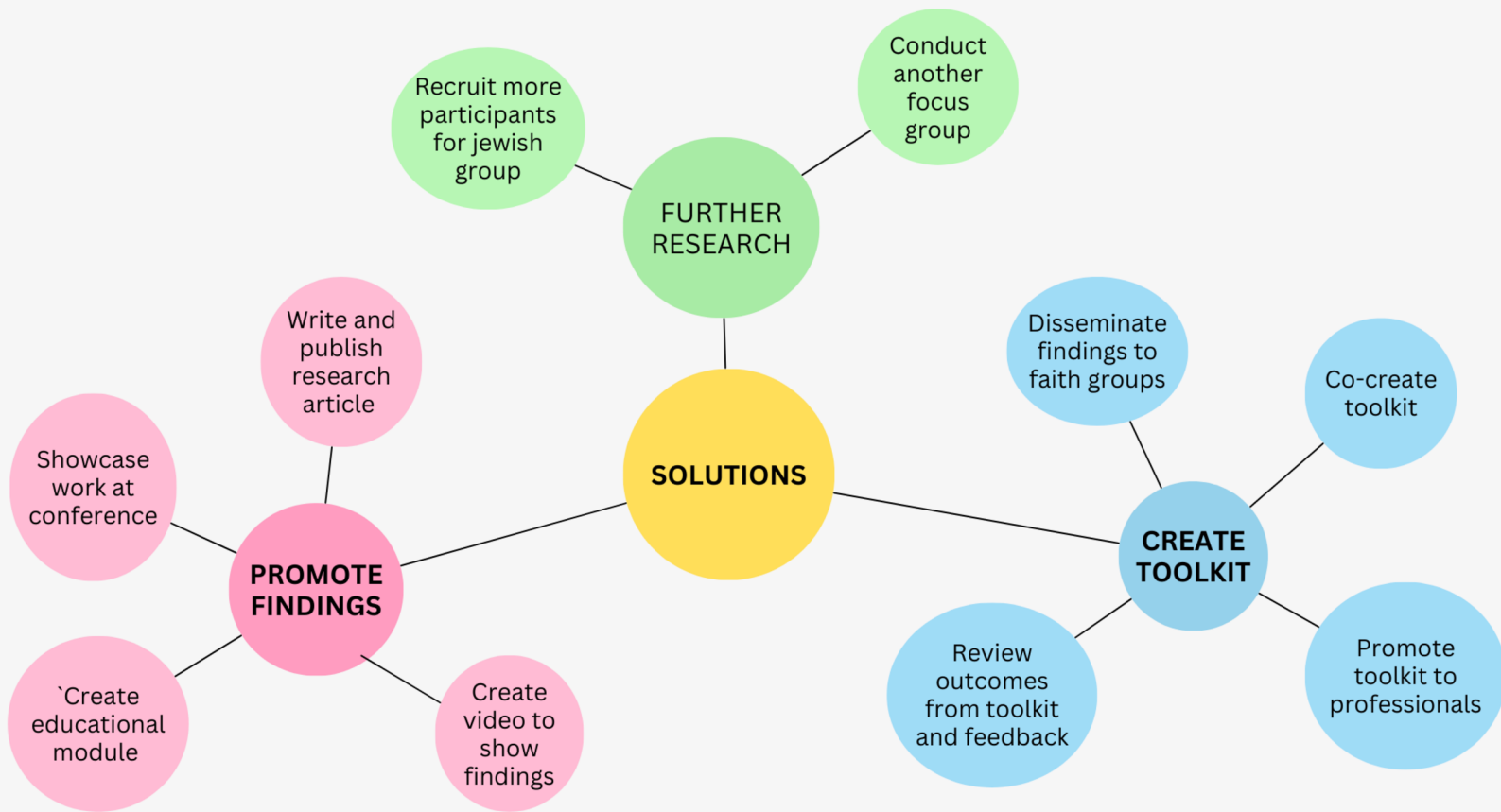
Key Insights from the Research

- Engagement with faith communities can be an effective method of understanding the barriers and facilitators of data sharing among GMPs
- Decision-making about being involved in data sharing was driven less by faith and more by concerns over privacy, trust in institutions, and personal or community benefits
- Building trust is not just technical (e.g. security and anonymisation), but also relational, GMPs value who leads the research, who else is involved, and how decisions are made
- Community engagement needs to be long term to sustain trust, feedback loops, and legitimacy
- Key barriers: Lack of transparency in the usage of data; lack of understanding in the newer developments in AI in healthcare; historical trauma; lack of religious guidance; language barriers
- Key facilitators: Faith promoting ideas of altruistic data sharing; leveraging trusted messengers including faith leaders and doctors with similar cultural and religious background to build trust; willingness to share if data was helpful for general population; transparency; engagement with the community in providing education and building trust



The Solutions

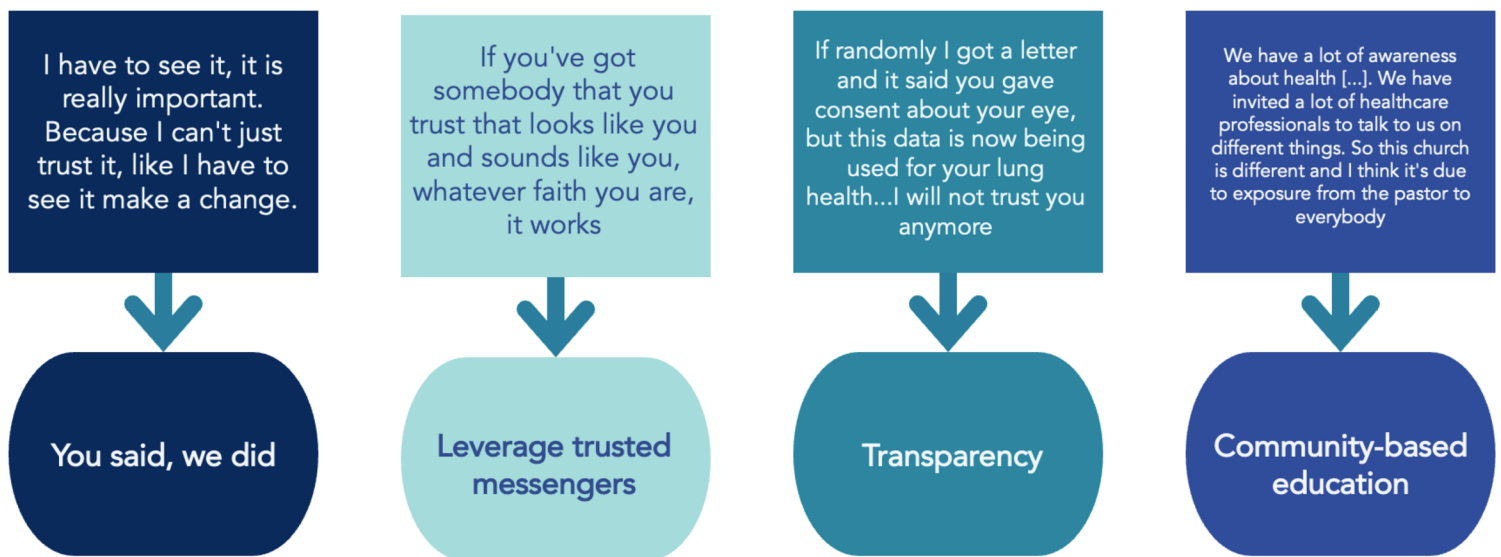
Proposed suggestions (see below) following our research include the co-creation of a toolkit, further research, and promotion of findings to broad audiences.



Toolkit

- Creation of a toolkit based on the findings of the research (See Figure 2) to be employed by healthcare professionals, particularly those involved in primary data collection. To facilitate culturally sensitive practices, and to promote data sharing by encouraging a culture of transparency, regarding the uses and results obtained through data sharing.
- Findings revealed barriers and facilitators GMPs face around data sharing. This will be summarised in the toolkit in order to equip healthcare professionals with an understanding of how to adequately and sensitively address these concerns when having discussions about data sharing.

- The UK Health Research Authority and the Medicines and Healthcare Products Regulatory Agency have released guidance for researchers to increase the diversity amongst those participating in their research, this toolkit could help further facilitate that, particularly in regards to AI. ([Increasing the diversity of people taking part in research - Health Research Authority](#))
- The UK itself is working towards achieving the SDGs, particularly SDG 3, with the government health department aiming to “protect and level up the nation’s health, including reducing health disparities”. Through our literature review, it became clear that GMPs suffer worse health outcomes, including within eye health. This intervention should facilitate research, aiming to reduce these gaps in health outcomes. ([Department of Health and Social Care Outcome Delivery Plan: 2021 to 2022 - GOV.UK](#))



Further Research

- Further research is required as the small sample size of the Jewish community organisation (n=3) means that findings cannot necessarily be generalised. In addition, there was no participation from the ultra-orthodox Jewish community. This was due to difficulties in recruitment and time constraints of the research project.

Broader Promotion of Findings

- Initial news story/blog on INSIGHT website.
- Co-production of educational modules and workshops with faith group organisations.
- Preparation of an original research manuscript to be published in an academic journal.

Solution Conceptualization Plan

Toolkit

Toolkit roadmap: from conceptualisation to implementation	
1. Dissemination of findings to faith group organisations	• Distribute the case study report to faith group facilitators via email • Arrange in-person meetings with faith group organisations to share the findings and outcomes of the research, closing the feedback loop and maintaining transparency on how their information has been used for our work • Create a video/poster to succinctly summarise the findings of the research that can be easily distributed among faith group participants
2. Co-creation of the toolkit	• Present the four main recommendations from the research, and discuss preliminary toolkit ideas • Obtain feedback from faith group organisations to verify the validity of proposed solutions, document this, and implement into the toolkit. This process will be framed in a “you said” and “we did” format, demonstrating the discussion that inspired each toolkit suggestion • Review existing frameworks including the <u>Participatory Data Stewardship</u> from the Ada Lovelace Institute, as well as the <u>STANDING Together Initiative</u> (provides a tool for transparency regarding the datasets that are used for training and testing AI) when creating the toolkit. In addition, use the four pillars at the end of the brief to aid with highlighting examples of good data sharing practices

3. Practical considerations	• Anticipate challenges with toolkit implementation (e.g. hesitancy by professionals to adopt the toolkit due to workload and time constraints of consultations): Work towards ensuring the toolkit is comprehensive but also succinct and practical enough to be easily utilised • Translate toolkit into multiple languages • Obtain funding. Grant received from the UCL East Community Engagement Seed Fund to facilitate knowledge translation activities
4. Promotion of toolkit to local professionals	• Host an exhibition at HereEast to present the toolkit • Launch toolkit with press release disseminated to media, published online (INSIGHT website) with social promotion and amplification through allied organisations, and dissemination to community health centres
5. Review after toolkit implementation	• Monitor toolkit dissemination and utilisation • Feed back outcomes of its use with the faith group organisations

Further Research

- Contact Jewish faith group organisation to see if they can assist with recruitment of a large sample size of participants to be involved in the research, and if possible to include members of Ultra-orthodox Jewish groups.
- Organise another focus group with these participants, analyse findings, and incorporate into research findings and toolkit.



Broader Promotion of Findings

- Initial news story/blog on INSIGHT website to announce that the report is live, summarise the faith group engagement and main findings, and mention the next steps of toolkit and UCL East event. Timeframe: 2nd week of December
- Co-produce and deliver an educational module with the Christ Apostolic Church (East District) on eye health, the importance of data sharing, and addressing concerns. Grant received from the UCL East Community Engagement Seed Fund to do this.
- Showcase our work with the INSIGHT Hub, which aims to improve healthcare for the benefit of patients by enabling safe and trust research access to anonymised data.
- Preparation of manuscript for publication: researchers have begun drafting this already. The introduction and methods have been written. The results and discussion need to be written. Once another focus group has been completed with more members of the jewish faith group organisation, these findings will be incorporated into the research paper. The first draft of the research paper will be completed by February 2026 (this deadline has been discussed among all research members).
- When identifying broader long term solutions from the research to put in the discussion and conclusion, incorporate information from the four pillars outlined below, a summary that demonstrates important considerations when promoting good data sharing practices.





Four pillars to consider when promoting good data sharing practices

Governance and Legal Infrastructure

- Policies should require governance models that include representatives from GMPs
- Ensure data is accessed through trusted, accredited environments. The UK Health Data Research Alliance already promotes accredited Secure Data Environments.
- Promote the FAIR (Findable, Accessible, Interoperable, Reusable) principles in health data sharing.
- Apply risk frameworks in data access policy e.g. Five Safes: safe people, safe projects, safe settings, safe data, safe outputs.

Community Engagement and Trust Building

- Policies should require that data-sharing initiatives demonstrate a social licence from involved communities, meaning clear ongoing engagement rather than tokenism.
- Encourage or require research funders or data institutions to support community-led design of data governance tools (e.g., consent models, data-use agreements)
- Publish criteria for data access and anonymization; maintain public registers of who is using data, for what purposes, and how consent was handled to increase legitimacy. ([The ODI](#))
- Set up formal feedback loops (forums, workshops) so communities can review how their data is used, challenge misuse, and shape future projects.

Ethics and Equity

- Benefits of research (e.g., insights, interventions) must be shared equitably with participating communities. This aligns with principles from health ethics [literature](#).
- Use funding incentives to promote data collection from groups historically under-represented in health data.
- Policy must support structural changes (capacity building, involving marginalised groups) to avoid reinforcing power imbalances.
- Build ethical reflection into every stage (design, collection, analysis, reuse). This has been effective in other settings (e.g., Big Data research with minority healthcare workers). ([BioMed Central](#))

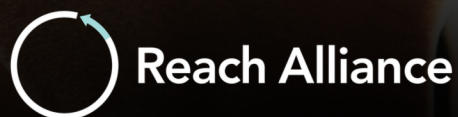
Regulatory and Institutional Support

- Support the development of national or regional health data services (e.g., through the UK Health Data Research Alliance) that institutionalize trustworthy, community-sensitive data governance. ([HDR UK](#))
- Provide funding for training both for researchers (on community engagement, ethics) and for community organizations (on data literacies, rights).
- Implement independent oversight bodies (or enhance existing ones) to monitor data access, equity, and accountability in how health data is used.

Conclusion

As eye health research becomes increasingly dependent on large-scale data to advance innovation, understanding the barriers and facilitators to data sharing among GMPs is critical. Through continued research, the development of practical tools and resources for healthcare professionals, and the widespread dissemination of findings, we can foster data-sharing practices that are transparent, culturally respectful, and designed to generate meaningful, long-term impact for communities and health systems alike.





This work builds on the 2024-25 Reach research report, "Good Eye Health Through Responsible Data Sharing," by Marie Cilliers, Anna Hoang, Sancia Lam, Abigail Omotosho, Hiranmayee Sudarsan, Poppy Pierce, Polly Rawlinson, Pearse Keane, Roxanne Crosby-Nwaobi, and all the impactful partners, community members, and mentors involved in the research.

As part of the "Pathways from Evidence to Action" series, inspired by the African Center for Equitable Development (ACED), the Reach Alliance challenged researchers to identify connections, address gaps, and develop recommendations grounded in their findings. The series comprises thirteen briefing notes developing solutions for urgent climate, public health, and economic challenges and engages practitioners and policymakers in advancing pathways to implementation.

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