

Equitable, trustworthy and safe research in healthcare technology, data and artificial intelligence

 An international dialogue



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Summary

In January and June 2024, two workshops were conducted – one in the UK and one in Uganda, to explore the public's views on improving healthcare through the use of healthcare data, technology, and artificial intelligence. These workshops aimed to help shape research priorities by identifying public's concerns and highlighting any proposed solutions from them.

Discussions during these sessions identified five key priority areas for researchers to consider during the development and design of their research as detailed in this report.



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Introduction

Healthcare is becoming increasingly digitalised, generating vast amounts of information about both populations and individual people. Some of this data is created through the delivery of clinical care, but commercial wearable devices such as smartwatches are also monitoring our health. Many researchers and clinicians believe that this information can be coupled with artificial intelligence (AI) to revolutionise healthcare technology and medicines. Advances are being made in disease identification, personalised care, and in monitoring how well treatments are working. However, many people are worried about this new approach and have concerns about the information being kept safe and confidential, about the exclusion of those who do not or cannot access technology, and about AI providing advice which might be harmful without the oversight of a human clinician. Patients, their carers, and the public need to be at the centre of this discussion, which can quickly become dominated by evolving inventions, complicated ideas, and technical language.

The way in which healthcare data is stored and transmitted is driven by the need to accommodate a wide range of sources, ensure security and privacy, and allow for efficient data processing and transfer. There are now vast amounts of data stored in the form of commercial internet-based databases, national databases or biobanks, patient-generated personal health data, and electronic health records (EHRs). However, as highlighted by the UK Goldacre Report, a clear national data strategy is required to maintain transparency, efficiency, and drive innovations which can improve patient outcomes (1).

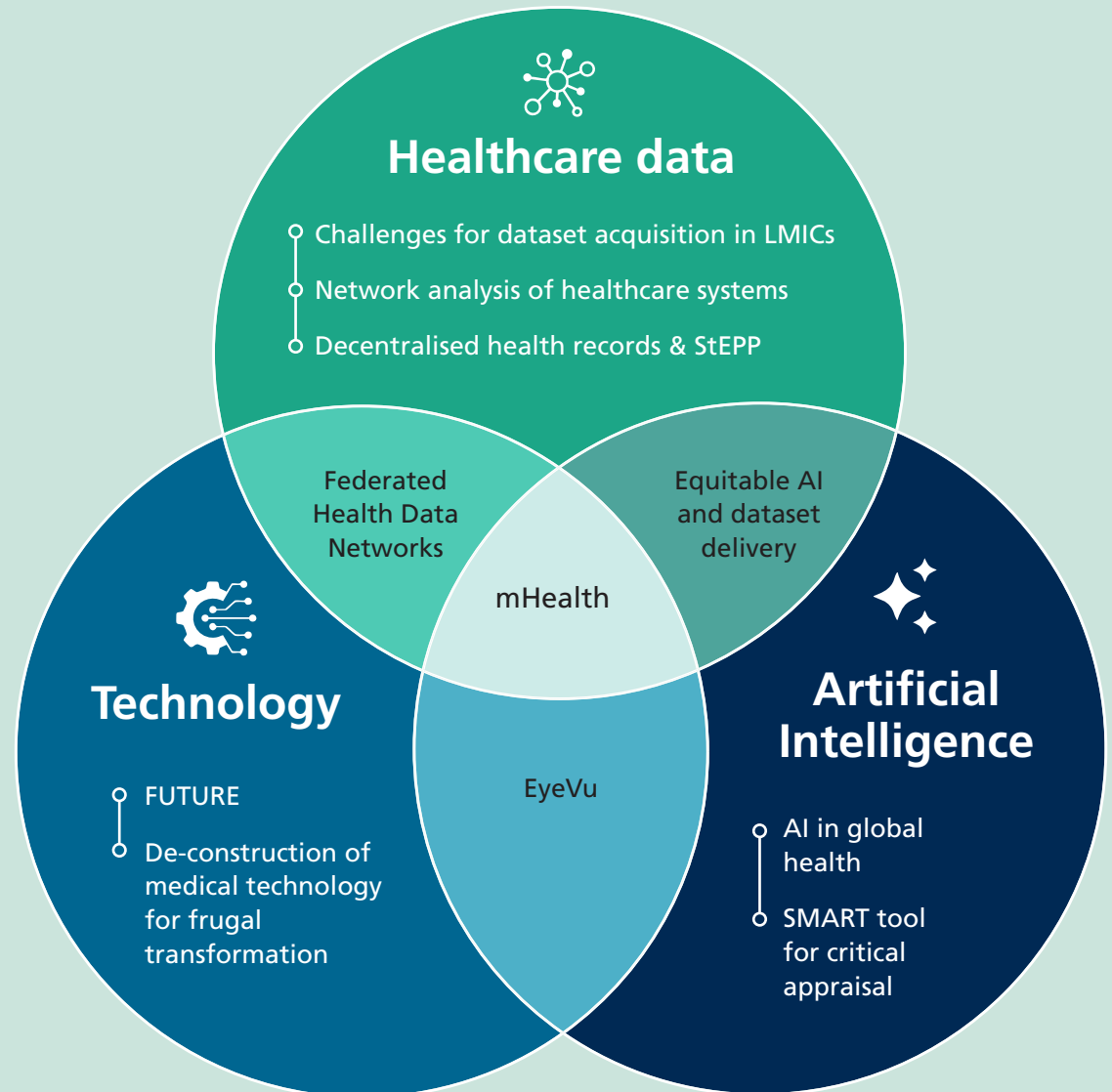
Many groups in society get worse healthcare and have worse health outcomes, often those unable to advocate for themselves such as the very young, the very old, or those with specific learning needs. Similarly, specific ethnic and socioeconomic groups have been shown to have worse health outcomes. While advances in AI and healthcare technology might help address this unfairness, the risk is that they might also

increase the bias against certain groups in the population. In response to this, in the UK, an independent review was initiated by the Secretary of State for Health and Social Care to ensure that 'equity elements' are built into medical devices used within the NHS, especially in those that are particularly prone to bias: 'optical' devices like pulse oximeters which measure blood oxygen but are affected by skin tone, those assisted by AI, and genetics-based risk scores (2).

In 2022, Data and Analytics Research Environments (DARE) UK launched a public consultation on 'Building a trustworthy national data research infrastructure' to improve trustworthiness in the handling and use of sensitive data, leading to their publication of a comprehensive set of recommendations (3). Central to these is the need to ensure that public involvement and engagement with research using sensitive data should be 'inclusive, from its design through to its recruitment and reporting'.

The International Health Systems Group (IHSG) at the University of Cambridge works with partners in both the UK and Uganda, and with the National Institute of Health Research (NIHR) Global Health Research Group on Acquired Brain and Spine Injury, to explore ways of improving health systems through technology, data analysis, and artificial intelligence. In light of the recommendations by DARE UK, in 2024, we convened a series of community engagement events using financial support from the Cambridge NIHR Biomedical Research Centre and the Cambridge Academy of Therapeutic Sciences to explore these issues across both settings. This report outlines the delivery and findings of these workshops, seeking to provide others working in this area with insights to shape future research (Figure 1).

Figure 1: Key research areas and projects undertaken by IHSG researchers

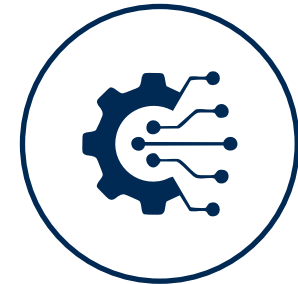
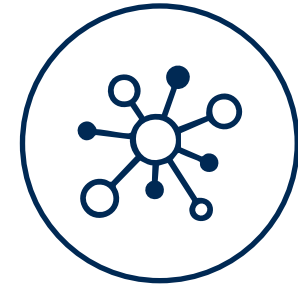


Aim and objectives

We conducted two workshops, one in Uganda and one in the UK. The aim was to develop an in-depth understanding of attitudes to research involving the use of healthcare data, technology, and artificial intelligence.

In addition, specific objectives were explored in each context:

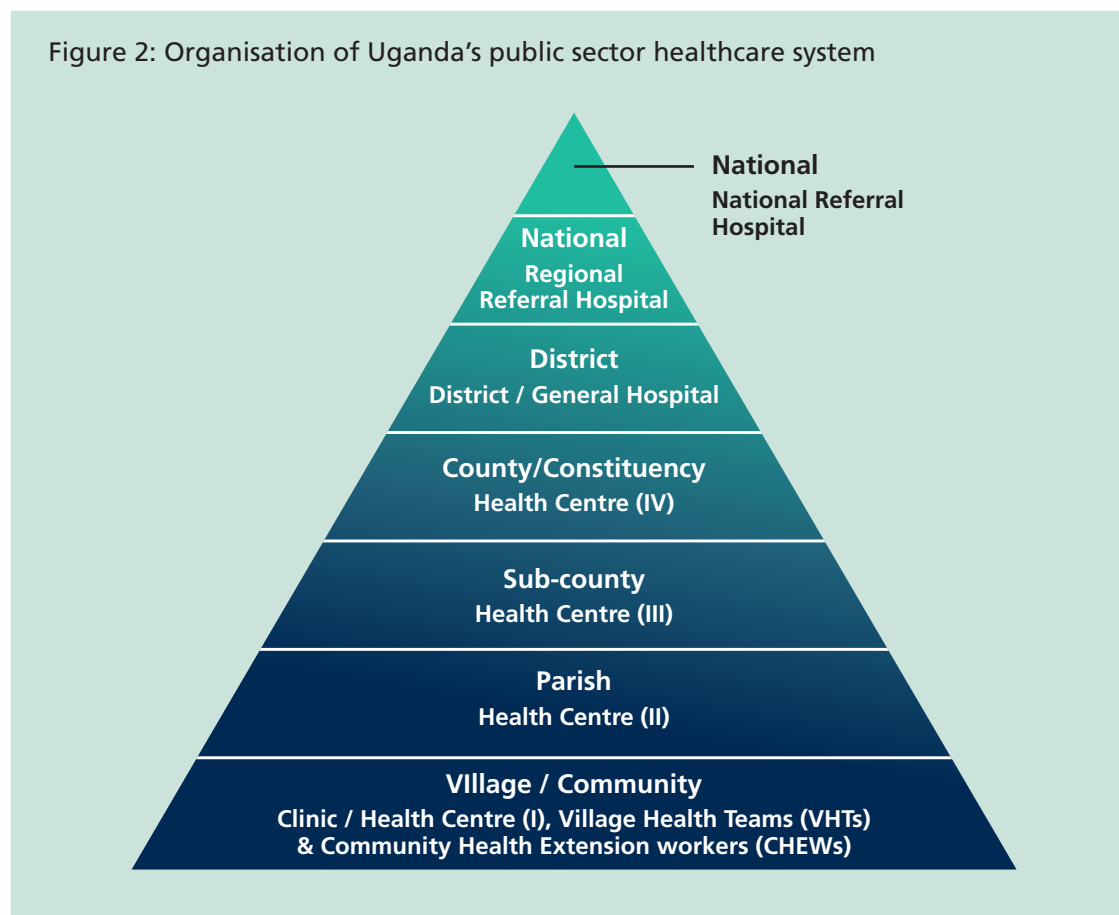
- To explore community perceptions of healthcare data and the use of mobile devices for healthcare in a low-resource setting.
- To identify key research priorities and barriers to the translation of research within a high-income context.
- To identify common priority areas for research within healthcare data, technology, and artificial intelligence from the UK and Uganda.



Workshop 1: Kampala, Uganda

The Future of Health Data workshop took place on 9th January 2024 at Mulago National Referral Hospital (MNRH) in Kampala, Uganda. Uganda was selected to represent a single low-resource setting owing to an existing research collaboration through the Uganda-UK Health Alliance (UUKHA), the International Health Systems Group (IHSG) at the University of Cambridge and InciSion Uganda. The activity was jointly funded by the Wellcome Trust through the Cambridge Academy of Therapeutic Sciences Future of Therapeutics awards, and by the NIHR Global Health Research Group on Acquired Brain and Spine Injury (ABSI).

The health system in Uganda comprises both public (Figure 2) and private sector facilities, with the public sector facilities organised by administrative divisions.



Five researchers from the IHSG facilitated the workshop (Figure 3), working in pairs, with one lead facilitator and one scribe per table. Participants were a combination of medical students from Uganda, students in allied health disciplines, and specialty doctors from MNRH. The total number of attendees was 16. Recruitment was driven through the member base of InciSion Uganda.

At the beginning of the session, a 15-minute presentation was delivered about the two discussion topics and wider research context. The first topic explored mobile phone usage and cellular network accessibility across Uganda. A case prompt of SMS for follow-up of patients post-discharge was used to stimulate discussion (Figure 4). The second session explored Federated Health Data Networks (FHDNs), a concept outlined in the summary of session two.

Figure 3: International Health Systems Group at the Future of Health Data Workshop



Session 1: Mobile phone usage in Uganda

In Uganda, phone ownership is widespread, but it is influenced by several factors, including geography, sociodemographic status, religion, and age. Participants reported that device ownership fell into 5 distinct tiers. Participants perceived that a significant portion of the population (estimated at around 90%) falls within Tiers 0 and 1.5 in terms of phone accessibility and usage.

KEY ISSUES

- Device ownership is low outside of urban centres and the middle classes.
- Shared mobile devices and rapidly circulating SIMs raise issues of data security.
- SMS-driven communication is expensive and lacks a human component. Individuals are unlikely to respond due to cost, literacy, and data security.
- Telephone calls have been used in some health contexts with success but do not bridge the gap between healthcare providers and all populations.
- Mistrust is prevalent in the security of technologies to communicate personal data.
- Gaps in health service delivery may be further exacerbated rather than bridged if mobile device accessibility is not understood.

Phone Ownership and Demographics

Geographical Influence: Participants noted that urban areas tend to have higher rates of phone ownership compared to rural areas. They felt this disparity was largely due to better infrastructure and economic conditions in cities. According to the participants, remote and rural regions also face challenges such as lack of electricity and poor road networks, which they believe limit phone usage despite reportedly good 2G coverage.

Sociodemographic Factors: Income levels were suggested to play a significant role in phone ownership. They observed that, in their communities, higher-income individuals seemed more likely to own mobile phones. The participants also felt that education level affects phone usage, noting that in their experience, more educated individuals appeared to have higher phone ownership rates and better digital literacy skills.

Religion and Age: There were shared observations that certain religious groups appeared to have cultural norms that either encouraged or discouraged phone use, though they emphasised that this varied widely. Regarding age, many participants felt that younger members of their communities tended to have higher phone ownership and usage rates. They attributed this trend to what they perceived as younger people's greater adaptability to technology and more frequent engagement with social media platforms.

Infrastructure and Accessibility

Mobile Network Coverage: Uganda has relatively good 2G coverage across the country. They felt this facilitated basic mobile communication services such as calls and SMS in their communities. Regarding more advanced networks, some participants, particularly those from urban areas, mentioned ongoing rollouts of 3G and 4G networks. These participants believed that these newer networks were enhancing data services and internet access in their localities, though they noted that experiences varied depending on location.

Electricity and Charging Issues: Participants with knowledge of remote regions highlighted the lack of electricity as a significant challenge in the communities. They reported that even those who owned phones often struggled to keep them charged due to unreliable power sources. Some participants mentioned the existence of community charging stations in certain areas, but they felt these were often limited and insufficient to meet local demand. Several participants shared personal experiences of having to travel considerable distances or rely on inconsistent power sources to charge their devices, which they believed impacted their ability to use phones regularly.

SIM Card Regulation and Use

National ID Requirements: The requirement to link SIM cards with national IDs in Uganda was discussed, with participants reporting that each ID holder is allowed to register up to 10 SIM cards. While some felt this regulation was intended to improve security and reduce fraud, others expressed that it complicated the process for users needing multiple numbers for different purposes. Several participants shared personal experiences or anecdotes about the challenges they or their community members faced when trying to obtain or register SIM cards, particularly for those without national IDs or those requiring more than the allowed number of SIM cards.

Frequent SIM Swapping: There is a common practice of changing or swapping SIM cards on a single device in Uganda. They reported various reasons for this behaviour, including taking advantage of different network promotions, managing costs, and addressing connectivity issues.

Some participants expressed concern that this practice leads to rapid circulation of phone numbers, which they believed contributed to a high quantity of spam messages and calls they experienced. Participants generally reported that text messaging (SMS) was infrequently used in their communities, citing cost and literacy as potential barriers. They observed that phone calls and mobile money services seemed to be preferred. Many participants noted that mobile devices weren't commonly used to communicate about health needs in their experience.

They felt there was limited interaction with healthcare professionals using phones, and instead perceived a reliance on friends or family with connections in the medical field when seeking medical knowledge.

When discussing the potential use of SMS for communication with healthcare professionals, particularly for injury surveillance, many participants expressed reluctance. They cited concerns about cost and security. Some participants also mentioned worries about data security on devices due to frequent SIM switching and the risk of theft, which they felt contributed to a hesitation to input personal data into electronic devices.

Several participants from rural regions shared experiences of telephone use for communicating about outpatient clinics. They noted ongoing expansion of telecommunication services to support this in their areas. According to these participants, patients might receive calls a day before their appointment to confirm attendance, but they emphasised that appointments themselves were not conducted over the phone. Many participants highlighted their perception that patients often prefer the personal touch of voice calls over text-messaging or other communication strategies.

A concept frequently mentioned was 'mobile money,' which they described as being built upon a technology known as Unstructured Supplementary Service Data (USSD) or quickcodes. Participants explained that USSD allows real-time, interactive communication between mobile phones of all types without requiring internet connectivity. They reported current uses for it in finance and hospitality, with some noting its recent application in health contexts. Many participants felt that USSD was surpassing SMS in its use in their communities.



Figure 4: Research student Orla Mantle facilitating discussion on SMS for follow-up of patients post-discharge

Session 2: Understanding Federated Health Data Networks

KEY ISSUES

- There is currently little infrastructure to record healthcare data. Electronic Health Record (EHR) systems are fragmented, and there are lots of unapproved and duplicate systems between specialties in the same hospital, and between government and private hospitals.
- Patients have ownership of paper medical records, and this is the key way of transmitting health data.
- There is some mistrust in the use of technology to reliably record personal data, and a risk of widening inequalities with data ownership.

Session 2 was designed and developed to explore health data, using Federated Health Data Networks (FHDNs) as a concept for discussion. Federated health data networks are collaborative systems that allow multiple healthcare organisations to share and analyse patient data with other trusted organisations while maintaining control over their own information. Instead of centrally pooling the data, each participating organisation agrees to make it accessible for approved

research or analysis purposes. This approach enables healthcare providers and other partners, such as researchers, to tap into a much larger and more diverse dataset than they would have access to individually, without compromising patient privacy or data security. FHDNs are an advanced concept and rely on robust and existing technological systems. As a result, the focus of this session more broadly explored how data is created, transformed, and analysed.

This session emphasised the lack of building blocks to unify electronic health data in a local and national capacity. Participants highlighted a need for state buy-in and improved policies for governance, including funding for research and infrastructure. There are current efforts to implement EHR through the Uganda District Health Information Software 2 (DHIS2), an open-source, web-based platform used by the Ugandan government to manage health information and facilitate the monitoring and evaluation of health programs across the country. The platform can be customised and is scalable, making it suitable for use at local, national, and international levels. It aims to be functional in facilities with no or limited access to the internet.

Workshop 2: Cambridge, UK

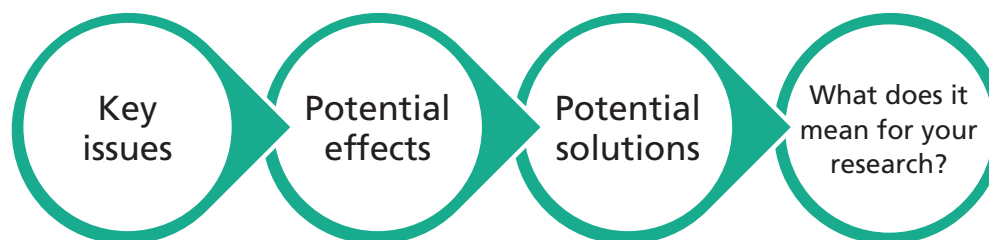
The workshop on the 6th of June 2024 in the UK was conducted to inform the directions of a variety of ongoing and future research projects in the fields of healthcare data, technology, and artificial intelligence (Figure 5). The workshop included 18 self-selected diverse groups of participants from the local community. Recruitment was supported by the NIHR BRC Patient and Public Engagement (PPIE) team through mailing lists, social media, support groups, and electronic screens within Cambridge University Hospitals. Three discussion sessions were professionally facilitated, using a round-robin style, on the topics of technology, data, and AI in healthcare.

We sought views from patients and the public on several key topics including the centralisation of healthcare data sharing, ownership of health data, data governance, and the security risks of federated platforms. In terms of technology, we explored views on using smartphones and wearables for self-managing healthcare, the impact of technology on healthcare models, and the role of multinational corporations in health technology. Discussions about AI focused on the public's current understanding of its everyday and healthcare applications, perceived benefits and concerns, algorithmic biases, and factors that could enhance the trustworthiness of AI models used for risk prediction.

Over the course of the discussion, three key themes emerged. These were the need for:

- 1. Improved infrastructure for data sharing, transparency, and ownership.**
- 2. Safer, personalised, and more accessible technology.**
- 3. Safer medical AI with trust, governance, and accountability.**

We report the key issues, potential effects, and potential solutions identified by the public, with recommendations on what it could mean for your research.



1. A call for improved infrastructure for data sharing, transparency, and ownership

KEY ISSUES

A fragmented healthcare data ecosystem:

- People expressed some concerns about how having 'multiple fragmented systems' to store health data affected communication between primary and secondary care, leading to repetitive data entry and inaccuracies.
- Additionally, the lack of linked systems within the healthcare systems meant the responsibility for reporting data fell onto patients.

Ownership of data

- The majority felt that despite the lack of coordination of healthcare data, they did not want all providers to have access to all information, with permissions ideally resting with the patient.
- Many also recognised that self-management of data can be challenging and may widen health inequities due to varying levels of executive function among people, language barriers, visible and invisible disabilities.

Data sharing

- It was felt that consent around data sharing, particularly anonymised data, for research purposes was not clear. It was also felt that clearer consent processes were essential and should be adaptable, allowing individuals to provide or withdraw consent.
- People also recognised that data sharing practices might be influenced by personal, generational, cultural, or political factors, and agreed that addressing these issues is important.
- There was a concern that data sharing platforms had 'indistinct boundaries', with many expressing a lack of awareness about where their healthcare data is stored, to whom it is shared, and how it is used.
- For research purposes, the workshop participants felt they were more willing to share their data if it is anonymised, proper consent is obtained, and there is complete transparency regarding its use.

Lacking human interface

- The lack of a clearly designated contact person for addressing amendments to healthcare data and for providing information on how their health data is stored and used decreased a sense of ownership.

Who is responsible for governance?

How do we have control over what companies have access to?

Do we need to educate people about data?

Potential effects

There was a sense of mistrust from the public in sharing healthcare data for research purposes. This mistrust was a result of uncertainties about how data would be shared and used. However, the lack of interlinked healthcare data networks and concerns about clinicians acting based on inaccurate or outdated information could potentially cause patient harm and increase health anxiety of individuals.



Figure 5: Community Engagement Workshop, West Hub, Cambridge, UK

Potential solutions proposed by participants

- A traffic light system for data sharing: Implement a traffic light system to categorise data sharing based on usage restrictions with clear guidelines for consent, access, storage, and sharing.
- Data champions: Appoint dedicated data champions to advocate to promote best practices in data sharing.
- Strengthen local governance frameworks: Improve governance, consent processes, and transparency of data handling practices to build trust between patients, public, and researchers.
- Centralisation of data for holistic diagnosis or care: Integrate data between primary and secondary infrastructures, and private and public healthcare infrastructures, to provide clinicians with sufficient up-to-date information for clinical decision-making and coordinated care.
- Opt-in or opt-out systems for personal data sharing: Transition to opt-in or opt-out system for healthcare data sharing based on research purpose, increasing sense of ownership amongst individuals.
- Data amendment and arbitration service: Establish a mechanism for easy amendment of data on medical records with an arbitration service to address any conflict between patients and healthcare providers regarding data accuracy, with accompanying notes to log any disagreements.

2. A call for safer, personalised, and more accessible technology

KEY ISSUES

Lack of standardised methods for usability testing:

- Some felt that technologies were poorly developed as they were “project-based” with short-term aims and that it was “all very reactive not proactive”.
- Participants also felt that this limited sustainability of these interventions and lacked resilience to change.

Magnitude of information

- Many felt that continuous monitoring can cause anxiety as it constantly exposes individuals to both positive and negative data, which may sometimes feel overwhelming and can be “anxiety-inducing”.
- Some suggested that there should be a system that filters out and prioritises relevant data to ensure that end-users are not overloaded with information.

Internet connectivity

- Participants also felt very concerned about cybersecurity risks when there was poor network connectivity or a blackout, which may sometimes be influenced by the government actions.
- Inadequate internet infrastructure can lead to limited access in various regions or countries that are not equipped to support certain technologies.

What's in it for me?

Who are you comparing my results with?

When technology works so seamlessly and you don't feel like you're using it, it's brilliant

Potential effects

Many felt that healthcare technology can be useful, but expressed concerns about reliability or safety, especially if there were any network connectivity issues. They also felt that continuous monitoring with healthcare technologies such as wearables can result in increased health anxieties due to the ‘overwhelming’ amounts of information that gets generated with different levels of complexity and baseline level of knowledge among end-users. Additionally, there was a fear of widening inequalities between those with different levels of executive function and ability to use these technologies effectively.

Potential solutions proposed by participants

- Creation of national innovation and improvement hubs: To support dedicated funding streams and provide resources or expertise to drive forward and test healthcare innovations on a national scale.
- Build stronger academia-public/private partnerships: These partnerships can help align priorities of different stakeholders and strategies. They felt that 'If we don't have these partnerships, it's very difficult to scale'. Implementing large-scale challenges require effective collaborations between these different groups with potentially different agendas.
- Designing resilient and adaptable technology: To cope with the aging population, new diseases, and complexity of healthcare, it would be essential to develop technology that is simple, configurable, and resilient to change. Flexibility for repurposing this technology in various settings by having a 'think tank' and drawing from other industries outside of healthcare could prove to be valuable.
- Prioritise user-centric technology: Engaging with different users of healthcare technology – patients, clinicians, and administrators – during the design process can ensure that the solutions meet their needs.
- Strengthen network connectivity infrastructure: Ensuring consistent broadband and internet connectivity especially in underserved areas for equitable access to healthcare technology.

Figure 6: Community Engagement Workshop, West Hub, Cambridge, UK



3. A call for safer medical AI with trust, governance, and accountability

KEY ISSUES

Misinformation and mistrust:

- There was a widespread mistrust of AI in healthcare due to the complexity of the data that is trained on, the limited public understanding of how algorithms work, and the 'black box' nature of some AI models.
- Many were also sceptical of receiving information from sources like ChatGPT, as it is trained on internet-based data which was viewed as unreliable for making health-related decisions.

Bias

- Many raised concerns about how biases in the training of AI algorithm in healthcare could result in healthcare decisions being driven by biased information, posing a risk to patient safety. There were also worries that some algorithmic bias was driven by commercial or financial interests of healthcare industry.
- Participants also expressed a certain level of hesitancy in trusting AI models for diagnostic purposes as they don't consider potential 'confounding variables' such as lifestyle and social choices, and human prejudice can be carried forward into AI.

- They also acknowledged that cultural differences between countries can affect how output from models are interpreted or used. Particularly in large language models, they felt that the cultural differences may also lead to different suggestions being considered by end-users.

Lack of governance and accountability

- Some felt that they 'did not know what (they) did not know'. Lack of accountability with the outcomes that AI presents was a concern to many in those models that utilised healthcare data as the regulatory standards for AI medical device development and governance of any error management is not apparent to the public. .

Cost of AI

- There was also some consideration about the significant environmental and economical burden to develop and sustain the maintenance of AI systems. Some expressed worry over the lack of a solid foundation to address these challenges.

We don't tend to mind biases until it affects us

We need to decide what we want AI to do

AI is more of "augmented intelligence" not just artificial intelligence

Potential effects

Concerns from the patient and public on reliability of AI and potential accumulation of bias in AI systems can result in reluctance to engage with AI-driven healthcare technologies, pose risk to patient safety, and cause harm. Over-reliance on AI in healthcare may also lead de-skilling of some specialists and decrease in human interactions which patients and public felt would affect the quality of their healthcare experience.

Potential solutions proposed by participants

- Promote dataset diversity: Use of diverse datasets which are representative of the population that the AI model is being applied to will help build trust, improve model performance, and minimise bias. Incorporating any 'caveats' as suggested by one member of the public can ensure that considerations are made for any outliers or deviations from the norm.
- Personalise AI models: Using data that considers genetic material and accounts for potential confounding factors such as lifestyle choices can help design and develop models that are tailored to individual patients.
- Promote AI as a tool or adjunct: Using AI as an aid for clinical-decision making will ensure that it is not a replacement for human expertise, will continue to place clinicians between AI model and patient to preserve human decision making in healthcare related decisions.
- Incorporate human feedback loops: Feedback loops can improve AI systems, particularly when the feedback is from a diverse range of end-users such as patients, public, and healthcare professionals.
- Improve AI education: Improving training of researchers, clinicians, and the public about AI, its applications, limitations, and benefits to improve trust, understanding and quality of care provided with the help of AI.

Key recommendations for researchers

This programme of international community engagement highlights a range of context-specific issues relevant to the communities in Kampala and Cambridge who participated. However, several key recommendations can be made based on insights from across the different conversations.

Both optimism and mistrust existed across populations in terms of the potential roles of data, technology, and artificial intelligence in improving health. Despite varied backgrounds, participants had informed and nuanced concerns which need to be addressed at all stages of development. These centre around core issues of trust, governance, reliability, access, and equity which can be considered as two linked pairs.

1. Trust

The security of data, and assurances that it will not be sold without consent or lost, was a central concern to both populations. Researchers need to continue to focus on techniques to maintain data security while still facilitating capture, transfer, analysis, and transparency. While populations did see a trade-off between these two, they were clear that they expected data to be safely housed, and to know who was accessing it, and for what.

2. Governance

The need for governance of healthcare technology, AI, and use of healthcare data was highlighted by participants. Researching on mechanisms for public to report concerns, establishing clear principles of accountability, and having safeguards in place to keep public protected from any potential harm these technologies, including from biases that originate from the creators, would be essential to ensure sustainable governance.

3. Reliability

Both populations felt that human interaction, while fallible, was the cornerstone of healthcare and that the role of data, technology and AI was to support that interaction. All populations worried about the reliability of these emerging areas and while they noted humans to be also fallible, felt the need for reassurance that new approaches to technology or data were clinically valid.

4. Access

Participants in the UK and in Uganda both noted the existence of specific populations who are excluded by the emerging focus on healthcare technology, whether the rural poor or the elderly. As research into data, technology and AI develops, this must be directly considered at each stage in terms of exclusion by infrastructure, by ability, or by culture.

There was variation among participants in their understanding of healthcare technology and AI. Educational literacy does not always translate into technological literacy. Working with the public to ensure that AI and other technologies are both accessible and explained in a way that is understandable to non-experts can promote inclusivity and improve access.

5. Equity

Alongside access, equity was noted to be a major issue in technology and data in healthcare. Participants noted that those populations with least access were also those who already suffered the worst health and healthcare provision. Across the workshops they noted that rapid advancements created the risk of increasing this unfairness. Future efforts need to have this issue of equity rooted at all levels, from research ethics through to pragmatic delivery of emergent tools and technology.

The issue of Equity can be considered the unifying concept which has emerged from this discussion across two diverse populations. The Right to Health is a universal human right, enshrined in several international legal instruments including the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of the Child. This work suggests that this is recognised across different populations and should form a cornerstone of future research efforts. Research is explicitly required in accessible technology, equitable data collection, and unbiased artificial intelligence in healthcare.

References

1. Department of Health and Social Care (2022) Goldacre recommendations to improve care through use of data, GOV.UK. Available at: <https://www.gov.uk/government/news/goldacre-recommendations-to-improve-care-through-use-of-data>.
2. Equity in Medical Devices: Independent Review - Quick Read (no date) GOV.UK. Available at: <https://www.gov.uk/government/publications/equity-in-medical-devices-independent-review-final-report/equity-in-medical-devices-independent-review-quick-read>
3. Building a trustworthy national data research infrastructure. Available at: <https://dareuk.org.uk/involving-the-public/building-a-trustworthy-national-data-research-infrastructure/>

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