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Exploring patient and public participation in the STANDING Together initiative for healthcare artificial intelligence (AI) in healthcare

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Public members of STANDING Together reflect on their experience in developing standards to tackle bias in artificial intelligence health technologies.

It wouldn't be acceptable to train a doctor who could only diagnose pneumonia for patients of a certain gender, sex, race, ethnicity, social or economic class. Similarly, it shouldn't be acceptable to build artificial intelligence (AI) health technologies that only work in one group of people, to the exclusion or harm of others. We write as public members of the STANDING Together initiative, part of an international team creating recommendations for data diversity and inclusivity to underpin the building of AI health technologies that can be more inclusive and reliable for a diverse population.

The STANDING Together recommendations represent the culmination of two years of research and consensus building across the globe, reaching 58 countries. The recommendations highlight the need for teams curating and using datasets, including AI developers, to be: thoughtful and self-questioning in the curation and usage of datasets, from design and collection through to dataset choice and reporting; and to be fully transparent about who is, and who is not, represented in these datasets, how they have been represented and how key decisions were made along the way.

The STANDING Together recommendations are described in full elsewhere,[1,2] but here the authors reflect on the role of public members in this project, and the collective learning about the benefits, and practicalities, of empowering the public to participate in AI research.

Experts in our own right

"We are experts of our own, and of our family and of community lived and living experience", says Jude Beng, equity, diversity, and inclusion (EDI)and Inclusive Health Research PPIE Advocate and Champion, School of Medicine and Population Health, University of Sheffield.

The STANDING Together programme is about equity, equality, diversity, fairness and inclusion. As public members of the project, we want everybody to benefit from the advances in healthcare that AI technologies may bring. There is a risk that when only AI experts and clinicians are brought together, they can lose themselves in technical brilliance, personal beliefs or detail, and lose sight of the ultimate objective of patient and societal benefit.

Public participation, also referred to as public and patient involvement and engagement (PPIE), is the act by which members of the public are actively involved in the design, delivery and dissemination of the research process. Throughout the process we public contributors brought our own expertise and perspectives as those who will be impacted by these technologies. We are the people who stand to benefit the most, but who also will live the consequences if AI does not work as intended.

Public contributors helped the STANDING Together initiative keep sight of this purpose, and to ensure that the 'north star' throughout the process was to benefit patients and avoid harm and inequity. A key contribution was the design of the consensus process, which was at the core of the STANDING Together program, but public contributors also provided impact in less visible roles as members of the steering group, helping to design the study protocols, co-authoring the publications, contributing to dissemination and helping plan future work. As one of the public members noted, *'we weren't here just for decoration!'*

Many voices

"The demonstrable diversity (in almost all aspects) was visible, audible, as well as palpable, and that definitely enriched our discussions, and debates, and made them more inclusive," says Jude Beng, EDI and Inclusive Health Research PPIE Advocate and Champion, School of Medicine and Population Health, University of Sheffield.

There is not a single 'patient voice'. The public members of the STANDING Together team brought a diversity of perspective. Diversity within the group was recognised in multiple contexts, including age, gender, sex, ethnicity, disability, geographical location, country of origin, culture, occupation, expertise, and previous public participation experience. Each member brought lived experience and knowledge of health inequalities in these contexts and were able to connect the STANDING Together team to the wider community. The backgrounds of members ranged from having had no previous public engagement experience to being a co-author of the UK Standards for Public Involvement.[3] One particular challenge, therefore, was creating a space where less experienced members felt comfortable voicing their opinions, especially if they were raising concerns.

Diversity of representation should be encouraged in all research, but it was particularly important in this project due to its focus on diversity and inclusion. With that in mind, researchers should be reflective about who may not have been represented during the process; there is an ethical and moral imperative to ensure that people not represented are more effectively engaged with and represented in future work.

Providing different platforms for participation

"Most of our patient and public participation meetings were held online, with the opportunity for some of us to meet with the wider working group and project members in-person, during the project consensus meeting," says Cassandra Leung, a first-time PPIE sub-committee member with continuous experiences with healthcare systems in the UK and Germany.

One challenge was how public contributors can interact with each other and with the rest of the study team, ranging from in-person meetings, on-line video-conferencing, email, or to other online tools. Most interactions took place via video-conferencing, with some email and with some of the public members contributing to an in-person meeting held at the end of the STANDING Together consensus process.

The wider research team worked with public members individually to overcome accessibility barriers so everyone could participate comfortably; this included supplying documents in accessible formats and offering 1:1 check-ins. Whilst this worked, there is a danger that dependence on electronic platforms will inadvertently exclude vital voices. Conversely, 'in person' meetings may narrow the geographic range of people that can contribute, increase travel costs, and exclude people who cannot leave the house, travel long distances or who could not risk exposure during the COVID-19 pandemic. There is no perfect solution to this, but research teams should have diverse ways that people can get involved, including those who do not have technical skills. When a hybrid meeting is taking place, it requires extra effort to ensure that those not physically present are actively included in the conversation.

In all cases it was important that time and the financial cost is recognised. As one of our members noted: "The best public participation is very well organised, as was the case here. The public participation team has been well looked after in terms of questions, remuneration, in fact - in every way."

Ensuring meaningful participation through training

"In addition to any background training required, a learner focussed approach to training is essential," says Adewale Adebajo, EDI Co-Lead and Patient and Public Involvement Executive Member, NIHR Sheffield Biomedical Research Centre (BRC).

Within the public contributor group there was a wide range of expertise in the field of AI research, ranging from no background knowledge to experienced professionals working in digital fields. Prior knowledge should not a barrier to involvement, and so as the project progressed, the STANDING Together team provided a range of explainers via a range of mediums to help understand relevant issues such as: how AI health technologies are trained and tested; the impact of non-diverse datasets; and how bias in an AI system can cause harm. One public member described that: *"whilst refining and improving the data recommendations - with the aims of reducing bias and mitigating health inequities at all levels, I am certain we all learned from each other, consciously and unconsciously - and that has enhanced our health data literacy and some emerging AI technologies in the delivery of health care."*

The technical nature of this study put higher demands on some public members. In addition to the general 'explainers', additional support with a named contact from the research team was available for when public members identified knowledge gaps. Although this was generally popular, one member did note that there was a risk that *"the burden of identifying and addressing knowledge gaps would be on the public members, rather than the researchers."* There is a balance which needs to be struck between: enabling anybody to be included regardless of pre-existing technical knowledge; equipping them with enough domain knowledge to be able to optimally contribute; and not overwhelming them. This should be considered at the outset of a project, so that any training material or time requirements are appropriately budgeted in funding applications.

Part of the research team

"We need to be included everywhere and right from the start of the project," says Jacqui Gath, an experienced PPIE contributor with an IT background.

Contributions made by public members have been integral to the development of the STANDING Together initiative. The research team recognised that these contributions improved the quality and trustworthiness of the recommendations. Public members within the group have had different roles and different levels of engagement reflecting their personal circumstances, and capacity, but all have been recognised as valued members of the research team. Public contributors have been involved from the start, including as co-applicants and in designing the study protocols. As one public member said, "PPIE [patient and public involvement and engagement] has a role in everything to do with a study". Another noted, "Knowing the background and environment in which we work is very important, which is why we need to be included everywhere and right from the start of the project. Public participation helps researchers to work out solutions to ethical dilemmas, so that they are resolved before funding application is made, or a study goes to ethics proper. Being prescriptive and limiting our input to a limited set of activities doesn't work.*"*

Committed to making a difference

Feeling valued as part of the team also means that public contributors are committed for the long term. The STANDING Together initiative doesn't end with a set of recommendations, but with an impact in practice. AI research needs public participation that improves democratic accountability, encouraging research to be conducted in the public interest. If empowered to do so, participants can offer insights and viewpoints that researchers might overlook, thereby reducing the likelihood of echo chambers and groupthink.

The experiences from STANDING Together have highlighted that there is no single correct way to work with patients and the public. An effective strategy needs to consider both the needs of the project and the needs of the participants themselves. It must also recognise the challenge of digital literacy; AI is a new technology with which many members of the public will not be familiar. It is important that researchers offer some training or venue by which technical questions can be safely asked.

The establishment of an active network of public members who are empowered to meaningfully contribute to research is a key outcome of the STANDING Together project, which should provide valuable support to future research initiatives.

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