Insight Report: Digital health online public involvement session on using artificial intelligence to improve health and care in North West London

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Background

The National Institute for Health Research (NIHR) currently funds 20 Biomedical Research Centres (BRCs) across England. These are collaborations between world-leading universities and NHS organisations that bring together academics and clinicians to translate lab-based scientific breakthroughs into potential new treatments, diagnostics, and medical technologies. The Imperial BRC is a collaboration between Imperial College, London and Imperial College Healthcare NHS Trust and is currently funded until 2022. It has 12 research Themes, 4 of which are cross cutting.

As part of the reapplication for the BRC competition run by the NIHR, a new Digital Health Theme has been proposed for the next Imperial BRC, co-led by Professor Paul Aylin and Erik Mayer.

To assist with the development of this new Theme and its programme of work, the Patient Experience Research Centre (PERC), a core facility of the current Imperial BRC facilitated three online public involvement discussion sessions on different aspects of the proposed programme of research. The first public involvement discussion was held on Wednesday 7 July 2021 and entitled "Help us build our digital healthcare programme in North West London". The second public involvement discussion was held on 21 July 2021 and entitled "How can we use digital healthcare to improve population health in NWL?"

Public Involvement is defined by the NIHR as "research being carried out '**with**' or '**by**' members of the public rather than '**to**', '**about**' or '**for**' them"[1]

Approach and purpose

Public involvement was considered a crucial component of the development of this proposed Theme's programme of research. The Digital Health Theme particularly wanted to understand:

a) the areas in which they should focus their digital health research to both improve health and care; and
b) the ways in which their proposed research priorities could address areas of health and care relevant to the North West London community served by the Imperial BRC.

Efforts were made to bring together members of the public who had not previously taken part in public involvement in research activities at Imperial College, London, or at all. The importance of capturing these views was to increase the representativeness of those individuals whose voices are not usually heard in public involvement in research which is a continuing area of focus.

Call overview and agenda

An online discussion was hosted on Wednesday 4 August 2021 (4.30pm to 6pm) via Zoom Pro and was attended by 19 members of the public from a wide range of backgrounds (see **Appendix 1** for demographics).

The aim of this particular online session was to:

- Introduce the Imperial Biomedical Research Centre and its proposed Digital Health Theme (5 mins)

[1] NIHR INVOLVE - https://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/

- Provide an overview, and an example, of Artificial Intelligence and how it's used in care and research (25 mins)
- Give attendees an opportunity to ask questions (15 mins)
- Facilitate small group discussions about the following questions (45 mins):
    a. Imagine we used AI within your electronic health record (there is a slide in the slide deck to explain what this is) to identify your risk of heart diseases or another illness. As a patient, what would you think about this?
    b. The reasons attendees gave the responses they did to the poll question "Which of the following areas do you think would benefit most from the use of Artificial Intelligence and should be prioritised by the Digital Health Theme? (Please choose your top 3)"
    c. What challenges do people experience with AI used in everyday life e.g. Siri, social media, suggested purchases online, etc?

Feedback

Following the session, attendees were sent an online feedback form to comment on ways the session could be improved and to give any additional views on the topics covered in the session. Comments received relating to the topics were integrated into the report summary. Attendees were also given the opportunity to sign up for future public involvement, engagement, and participation opportunities.

Payment

In accordance with NIHR payment guidance, participants were paid £42.50 for their time including a £5 contribution to Wi-Fi/data for accessing a virtual meeting. A PERC staff member was available to assist those who had technical difficulties during the small break out room discussions.

Attendee recruitment

Due to the rapid nature of the call and to ensure diversity, an email invite and flyer was disseminated through the following routes:

- By the North West London Clinical Commissioning Group (CCG) Engagement Manager posting it on the online "Nextdoor" platform
- By the Societal Engagement team sending it to their mailing list of White City community members
- By asking members of the Imperial BRC Public Advisory Panel to disseminate it to communities with which they have contacts

- Through the Imperial College Healthcare NHS Trust's community contacts
- To recent sign-ups to the PERC mailing list (not yet engaged in public involvement in research)
- To members of the Imperial Young Person's Advisory Network local to North West London

Key Insights Summary

Attendees of the discussion session on 4 August 2021, provided perspectives about both the benefits of using artificial intelligence within their health record to identify possible health risks as well as concerns.

Benefits

The benefits included the **ability to identify potential health risks** especially in relation to genetic conditions within families. They also considered its ability to **improve resourcing in healthcare** (i.e.. rare blood types) and to **improve healthcare more generally** e.g., for rare diseases and prevention to also be benefits.

Qualifications

The benefits of using artificial intelligence within their health record to identify possible health risks were considered to be subject to certain things being put in place or existing including their **consent** to use artificial intelligence within their health record in this way, the need for the **results to be accurate**, the need for transparency about **artificial intelligence** being used in this way, **medical professionals having the confidence and skill of to use** artificial intelligence and the need for artificial intelligence **to be used as a tool rather than to make a final decision.**

Concerns

Attendees expressed the following concerns about using artificial intelligence within their health record to identify possible health risks: **lack of trust and understanding** of artificial intelligence, the **limitations in communicating about** artificial intelligence to diverse communities**,** the **negative reputation of** artificial intelligence from other contexts e.g. school exam results and the **quality/quantity of the data** used in the artificial intelligence e.g. the fact that medical records are not always correct. Other concerns were the **relationship between healthcare professionals and** artificial intelligence not being clear i.e. does it benefit both doctor and patient?, **data security and confidentiality** e.g. what if the data is used against you or is released through error, the need to **retain a relationship with the healthcare professional** especially to discuss results identified by artificial intelligence**.** The **consequential burden on the NHS** from what is identified by artificial intelligence and **too much reliance by doctors** on artificial intelligence was also seen as a concern e.g., will the doctors default to just using artificial intelligence.

Explanations for poll responses

Attendees provided more details about the reasons for their responses to the poll question: “Which of the following areas do you think would benefit most from the use of Artificial Intelligence and should be prioritised by the Digital Health Theme? (Please choose your top 3).”

Monitoring responses to treatments: to stop treatments that are causing more problems or harm, this presents is a lot of benefit and potential and the fact this is a logical/measurable task which can be delegated to a non- sentient function.

Identifying at risk patients: the doctor would need to confirm the patient was at risk after identification by artificial intelligence. This would assist with prevention and encourage a healthier

lifestyle. It is a logical/measurable task which can be delegated to a non- sentient function and digital tech is less likely to mess up and exacerbate an illness.

Improving patient experience: making artificial intelligence accessible to all especially by using simple language, rectifying a bad experience through use of artificial intelligence, using artificial intelligence to learn patient availability for appointments and improving the patient experience would mean patients are more inclined to seek help early on (and improve outcomes) and digital tech is less likely to mess up and exacerbate an illness.

Assisting with clinical decision making: to be used as a support tool only by healthcare professionals and used properly and responsibly. The large amount of data available means it can be used extensively and it may encourage the doctor to explore certain diagnostics or treatment pathways which may not have been done otherwise and help reduce human error. However, it was noted there is a risk of depersonalising medicine or diminishing the patient/doctor relationship. It was also seen as a logical/measurable task which can be delegated to a non- sentient function.

Monitoring responses to treatments: to be used as a support tool only by healthcare professionals.

Artificial intelligence was seen as good for yes or no answers but that it depended very much on the algorithm to get reasoned answers.

Challenges with artificial intelligence in everyday use

Attendees identified the following challenges with artificial intelligence in everyday use: **lack of accessibility to digital devices and wifi to access** artificial intelligence**,** the fact that **voice recognition does not always pick up accents** and the **risk of racial profiling.** Another challenge was that artificial intelligence **has been incorrect** as it doesn't always understand what is meant, suggest things accurately and changes choices.

Other comments made to this question were **the lack of understanding of artificial intelligence** in the population including underrepresented communities, the need to **engage the older population** about artificial intelligence and the risk of **hacking and ransom attacks** being a concern in light of recent examples e.g. the Irish HSE.

How we used the insights

This insight report summarising key points from the session was made available to Theme leads and the BRC Executive in order to shape the BRC application. The report was also provided to the members of the public who took part in the involvement activity. A full report on all public involvement activities undertaken in preparation for the BRC application can be found here.

Through the process of conducting this and other public involvement activities, we have established a wider and more diverse network of contacts for ongoing involvement.

We would like to thank all those members of the public who gave their time and thoughtful insights through these activities, and the researchers who engaged enthusiastically in the process.

Poll

A mid-session multi-choice poll of attendees (n=17/19) asked the following multi-choice question:

Which of the following areas do you think would benefit most from the use of Artificial Intelligence and should be prioritised by the Digital Health Theme? (Please choose your top 3)

- Identifying at risk patients
- To diagnose new conditions
- Assisting with clinical decision making
- Helping with providing the best care pathways
- Monitoring responses to treatments
- Improving patient experience
- Other (Please share in chat)

The poll responses were as follows:

Monitoring responses to treatments	76% (13/17
Identifying at risk patients	59% (10/17)
Improving patient experience	53% (9/17)
To diagnose new conditions	35% (6/17)
Assisting with clinical decision making	35% (6/17)
Helping with providing the best care pathways	35% (6/17)
Other	6% (1/17)

No comments were recorded in the call chat function by those who chose “Other”. Please see **Appendix 2** for more details.

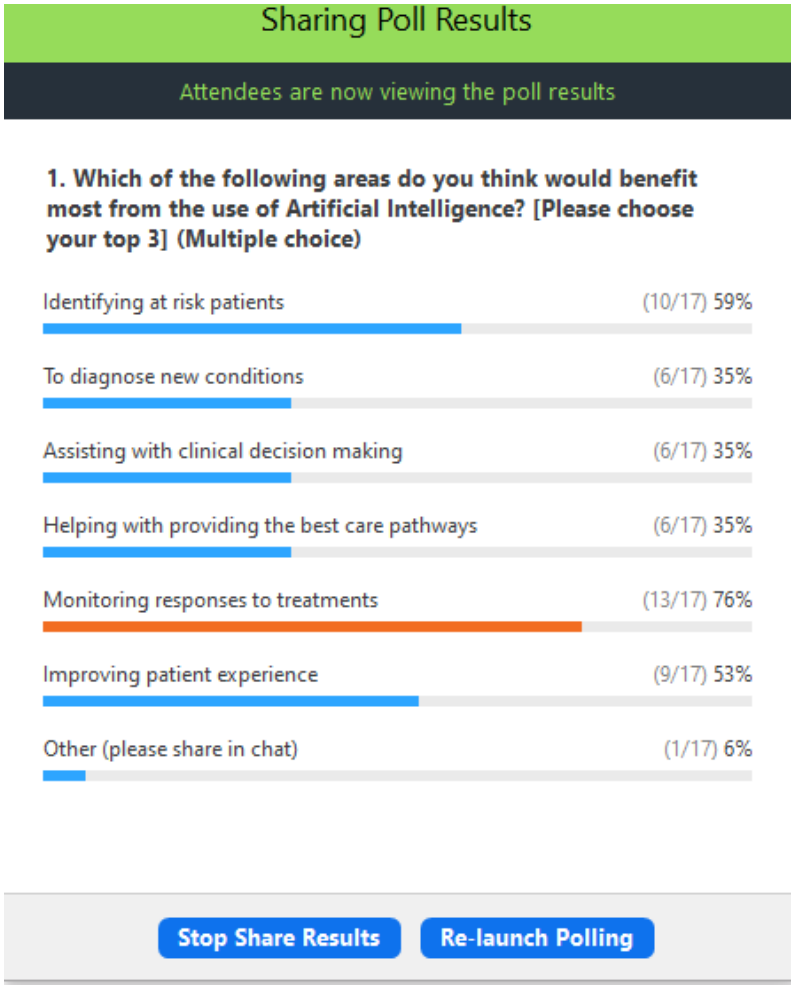
Appendix 1: Demographic of public attendees

Table 1: Demographic characteristics provided during event registration for discussion group (N=19)

Characteristics	**n (%)**
Age (in years)	
Mean (range)	43 (19-88)
Age groups (in years)	
18-24	5 (26.3)
25-34	3 (15.8)
35-44	3 (15.8)
45-54	0 (0.0)
55-64	5 (26.3)
65+	2 (10.5)
Prefer not to say	2 (10.5)
Not provided	0 (0.0)
Gender	
Female	13 (68.4)
Male	5 (26.3)
Non-binary/Gender variant	1 (5.3)
Prefer not to say	0 (0.0)
Ethnic group	
White	
English/Welsh/Scottish/Northern Irish/British	4 (21.1)
Irish	0 (0.0)
Gypsy or Irish Traveller	0 (0.0)
Other White background	1 (5.3)
Mixed/Multiple Ethnicity	
White and Black African	0 (0.0)
White and Black Caribbean	0 (0.0)
White and Asian	0 (0.0)
Other Mixed/Multiple background	0 (0.0)
Asian/Asian British	
Indian	2 (10.5)
Pakistani	1 (5.3)
Bangladeshi	2 (10.5)
Chinese	0 (0.0)
Other Asian background	1 (5.3)
Black/African/Caribbean/Black British	
African	4 (21.1)
Caribbean	1 (5.3)
Other Black/African/Caribbean background	1 (5.3)
Other	
Any other ethnic group	2 (10.5)
Prefer not to say	0 (0.0)

Appendix 2: Poll Results

This following poll (with final results) was undertaken after the introductory presentations and before attendees were moved into breakout rooms (n= 17/19).



No comments were recorded in the call chat function by those who chose “Other”.

Appendix 3: Questions asked by call participants following the presentation

Answered during call

- In terms of the patient's experience, you were saying you applied this AI tool, how do you initially, input the information that you've received?
- In my experience, there are subtleties that are missed out in all these feedback forms. And I think a whole load of stuff then gets missed out as a result, just wondering what you think about that.
- Who chooses the questions [for the patient experience surveys]?
- How widely is artificial intelligence used at Imperial trust already and what levels of increase, are you hoping for.
- My other query/concern is how the information is interpreted by the individual, and then used. So just to quickly put that in context. My GP who's relatively new GP. In terms of wealth 10 years at least but transformed the practice into a big computerised system, and basically works mainly from that system. And my experience personally as a result, is that he has either made no effort, or is so overloaded, that he no longer. We're not, I'm not a person anymore. I'm not a human being, as, as you would get in previous with previous GPS.