

Insight Report: Digital health online public involvement session on building our digital healthcare programme in North West London

Maria Piggin, Halle Johnson, Dimitri Papadimitriou, Jamil Mayet, Ben Glampson, Paul Aylin, Erik Mayer. On behalf of the NIHR Imperial Biomedical Research Centre.

Correspondence: publicinvolvement@imperial.ac.uk

Date of activity: 7 July 2021

Report originally published: 20 October 2021

Updated: 01 February 2022

Contents

Background	2
Approach and purpose.....	2
Call overview and agenda	2
Feedback	3
Payment	3
Attendee recruitment	3
Key Insights Summary	4
Appendix 1: Demographic of public attendees	6
Appendix 2: Poll Results.....	7
Appendix 3: Questions asked by call participants following the presentation.....	8

SUGGESTED CITATION:

Maria Piggin, Halle Johnson, Dimitri Papadimitriou, Jamil Mayet, Ben Glampson, Paul Aylin, Erik Mayer. Insight Report: Digital health online public involvement session on building our digital healthcare programme in North West London. NIHR Imperial Biomedical Research Centre (20-10-2021), doi: [10.25561/94121](https://doi.org/10.25561/94121)



This work is licensed under a [Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License](https://creativecommons.org/licenses/by-nc-nd/4.0/)

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”.

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 7 July 2021 (5pm to 6.30pm) via Zoom Pro and was attended by 25 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)
- Provide an overview, and an example, of how digital health is used in care and research (25 mins)
- Give attendees an opportunity to ask questions (15 mins)

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

- Facilitate small group discussions about the following questions (45 mins):
 - a. How do you think we can use digital health to improve clinical care, the health of the community and research?
 - b. How can we reduce the impact of the digital divide?
 - c. How do we engage with patients about digital health?

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 7 July 2021, provided helpful insights about **how digital health could improve clinical care, the health of the community and research** especially in relation to **reducing the current fragmentation of data** across the health system. It was suggested this fragmentation could be aided by the **development of easy- to- use patient portals/apps and undertaking of remote monitoring** where patients and their families could record their own health data, access test results and scans, correct data where necessary and receive reminders to aid decision making and self- management. **Identification and understanding of community health needs** could be aided by identifying trends and local services requirements through digital health. **Addressing health inequalities** could involve digitally measuring environmental factors. Using digital tools could assist with **prevention of health conditions** as well as to **address sensitive subjects** including mental health.

However, it was noted that **a hybrid model of care** comprising face-to-face and digital health was needed to: ensure those affected by digital poverty and lack of technical knowledge were not excluded; and for situations where face-to-face assessment is more appropriate and preferable for patients. **Education** about using digital tools is necessary as is **consent**, the **ability to opt out** and provision of **assurance to the public about the security of their health data** which is a continuing concern.

Suggestions to **reduce the digital divide** focused on **ensuring underrepresented communities have access to digital health tools** including the translation of apps into different languages and utilising community leaders and groups to engage these communities appropriately. **Reducing health and social inequalities, making digital tools accessible and easy to use**, providing **education and IT support** to use digital tools and **evidencing their benefit** is also needed to reduce the digital divide.

Suggestions for **how to engage with patients about digital health** included **utilising different ways to engage both face-to-face and online**, utilising **trusted relationships** in primary and community care, **co-designing patient-centric tools and research, focusing on the benefits** of digital health and **reassuring the public about data security** were also suggested.

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 on areas on which digital health should focus

A mid-session multi-choice poll of attendees (n=24/25) revealed that “Understanding disease”, “Improving diagnosis” and “Treatment and prevention” all received equal numbers of responses (n=15) to the question: ***“On which areas do you think we should focus our digital health research to improve health and care? Please choose your top 3.”*** The next most popular response chosen was “Individualised care (personalised medicine)” (n=13). Please see **Appendix 2** for more details.

- Understanding disease (n = 15; 63%)
- Improving diagnosis (n = 15; 63%)
- Treatment and prevention (n = 15; 63%)
- Individualised care (personalised medicine) (n = 13; 54%)

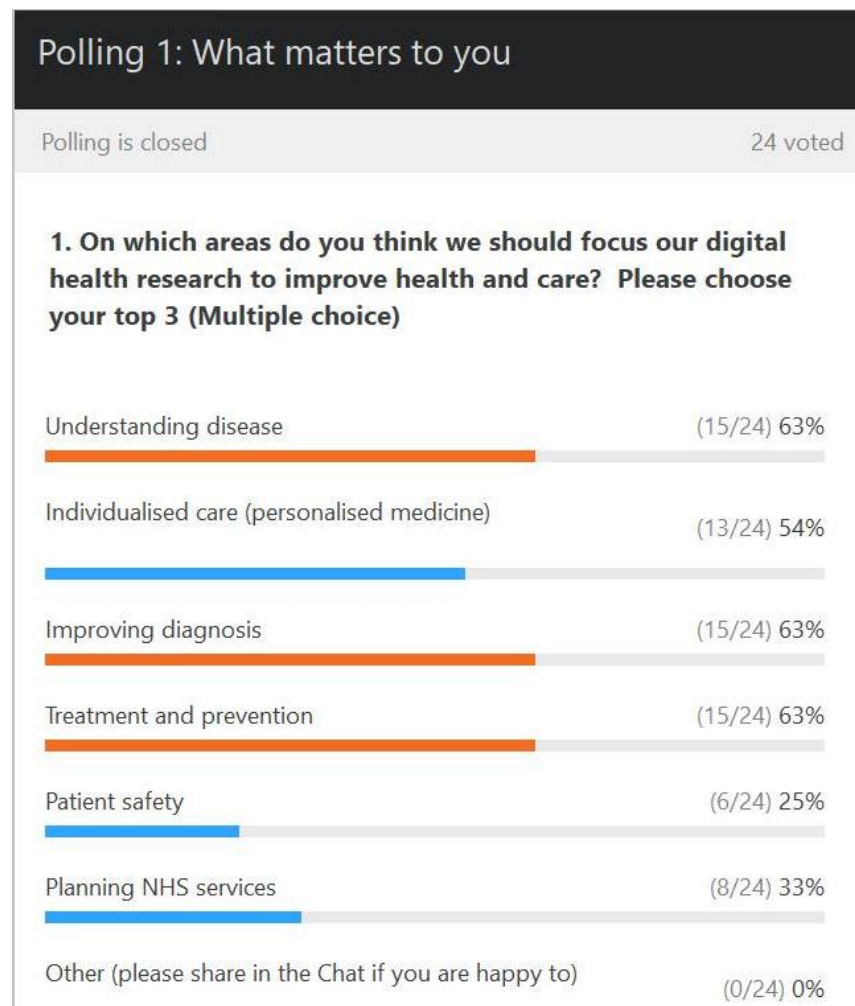
Appendix 1: Demographic of public attendees

Table 1: Demographic characteristics provided during event registration for discussion group (N=25)

Characteristics	n (%)
Age (in years)	
Mean (range)	43 (17-77)
Age groups (in years)	
18-24	5 (0.2)
25-34	5 (0.2)
35-44	2 (0.08)
45-54	2 (0.08)
55-64	4 (0.16)
65+	4 (0.16)
Prefer not to say	3 (0.12)
Not provided	0 (0.00)
Gender	
Female	15 (0.6)
Male	10 (0.4)
Prefer not to say	0 (0.00)
Ethnic group	
White	
English/Welsh/Scottish/Northern Irish/British	7 (0.28)
Irish	0 (0.00)
Gypsy or Irish Traveller	0 (0.00)
Other White background	0 (0.00)
Mixed/Multiple Ethnicity	
White and Black African	0 (0.00)
White and Black Caribbean	0 (0.00)
White and Asian	0 (0.00)
Other Mixed/Multiple background	0 (0.00)
Asian/Asian British	
Indian	5 (0.2)
Pakistani	2 (0.08)
Bangladeshi	2 (0.08)
Chinese	0 (0.00)
Other Asian background	1 (0.04)
Black/African/Caribbean/Black British	
African	4 (0.16)
Caribbean	1 (0.04)
Other Black/African/Caribbean background	1 (0.04)
Other	
Any other ethnic group	2 (0.08)
Prefer not to say	0 (0.00)

Appendix 2: Poll Results

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



Other (collected in chat).

Although this did not show up in the poll as a response under “Other”, one attendee commented: “I am most interested in joined up data. As a patient I have found there is “Communication without Trace” I have submitted evidence to the Commons committee investigating Digital Transformation in the NHS.”

Appendix 3: Questions asked by call participants following the presentation

Answered during call/group sessions

- Is there any way that the system can know the severity of the condition of the caller who rings 999 or 111?
- Can 999 or 111 look you up using DOB or postcode so can see medical history?
- How are we addressing the sale of patients' data that has been raised?

Comments

- Called 111 and was on the phone for over an hour as had to ring back and second call couldn't find content of first call as it is contracted out to different contractors so had to repeat all of symptoms.
- I have no problem sharing my data with NHS and public funded research in line with NHS values. What I am very concerned about is the recent revelation of what has been referred to as a Data Grab where our data can be sold to private corporations.
<https://lowdownnhs.info/privatisation/a-rash-dash-for-your-patient-data/>
- I also object to data being sold & grabbed by corporations. I am all for the public benefit of data sharing for the good of the community at large
- Patient data and disease surveillance has existed and progressed over the period of our life time. It's something which brings enormous benefit to prevention, case management and resource allocation
- Patients should have a drop down menu where they can consider if they want to allow their data to be used in various ways.