Insight Report: Online public involvement session on the use of molecular phenomics to improve health and care

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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.

The Molecular Phenomics Theme is one of the existing 4 cross cutting Themes within the current Imperial BRC. As part of the reapplication for the BRC competition run by the NIHR, a continuation of the Molecular Phenomics Theme has been proposed for the next Imperial BRC, led by Professor Zoltan Takats.

To assist with the development of this Theme and its programme of work, the Patient Experience Research Centre (PERC), a core facility of the current Imperial BRC facilitated an online discussion session on molecular phenomics as part of the Theme's proposed programme of research. The public involvement discussion was held on Tuesday 14th September 2021 and was led by members of the Molecular Phenomics Theme, Dr Matthew Lewis, Lynn Maslen and Dr Caroline Sands.

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 Theme. As part of this online session the Theme particularly wanted to understand people's views on:

a) Molecular phenomics and the areas in which they should focus their molecular phenomics technology to improve clinical care, population health and personalised medicine
b) How molecular phenomics could address areas of health relevant to the North West London Community served by 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 Tuesday 14th September 2021 (5pm to 6.30pm) via Zoom Pro and was attended by 29 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 the Molecular Phenomics Theme (5 mins)
- Provide an overview of molecular phenomics (15 mins)

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

- Provide real life examples of how molecular phenomics can improve clinical care, population health and personalised medicine (10 mins)
- Give attendees an opportunity to ask questions (15 mins)
- Facilitate small group discussions about the following questions (45 mins):

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:

- Through clinical colleagues who work in relevant weight and fertility clinics
- Through attendee networks
- To relevant sign-ups to PERC mailing list (expressing an interest in this research area)

Key Insights Summary

Attendees of the discussion session on 14 September 2021, provided the following perspectives:

Overall attendees were supportive of the use of molecular phenomics to improve clinical care, personalised medicine, and community health with individuals noting that it is an 'interesting topic which everyone should be aware of' and the area was 'important to open a new frontier in treating disease'.

During the breakout room discussions attendees were posed three possible scenarios in which molecular phenomics could be used in the future. Their reflections are captured under the following questions:

Which scenario would you prefer, if any, and why?

A toilet in your home that can provide feedback about any aspect of your health through automated urine analysis: This scenario was considered **convenient** and was noted to save time and effort compared with having to go to the GP or walk-in clinic to undertake such a test. **Reducing burden on GPs** and the NHS was cited as a reason for this possible scenario to be preferred, as well **as being able to get results quickly** and having **greater responsibility over health** including the **ability to self-monitor and manage health**.

Concerns for this scenario were raised around **intrusiveness, accessibility** (if there was a cost implication) and most significantly the potential for having such a tool available in your own home to **cause anxiety or have a negative psychological impact**.

Providing reassurance, having the opportunity to **obtain professional interpretation of results**, and **doctors monitoring and screening feedback before it goes to the individual** were considered important**.** It was also felt that any information or feedback provided should be **accompanied with further support and advice**.

A walk-in clinic, [separate from your GP and open to all] that conducts urine tests to analyse any aspect of your health: Comments in support of the walk-in clinic scenario cited it as being **less intrusive** (compared to the first scenario) and enabling you to have **greater autonomy** over what you want to do. Being **separate from the GP** was also considered preferrable, as well as potentially being **more accessible** for people.

A urine test, conducted by your GP, which can be sent off to analyse any aspect of your health: Comments in support of having a test at the GP, noted that this was preferred as you already have an **existing relationship with your GP** and that this felt **more professiona**l. Attendees also felt that it was beneficial to be able to **follow-up or ask questions** following the test results.

Across scenarios, concerns around **accuracy** of such tests and **mistrust of results** were raised, alongside potential **issues with data sharing and security** (i.e. where the information goes and how it will be used) and **implications on insurance** if knowledge about your own health was more readily available.

What sort of information about your health would you want to know?

When asked about the type of information that they would like to find out about their health, responses were varied some attendees wished to **know everything (the good and the bad)**, which was **very detailed and comprehensive.**

Information about **early identification of disease or illness**, including information which would help **prevent and lower risk of disease** were considered important. Information on **medication responses**, **hormone imbalances**, **nutrition and diet**, and the **impact of environmental factors on health** were also highlighted. While some attendees were keen **to know their risk or genetic predisposition of having a disease,** others felt that they wo**uld not want to know while they were still young** and **if there was no cure/treatment available** for the particular disease. For attendees who did not want to know about risk of disease, it was considered acceptable for such results to be directed to a GP, or other health professional.

Further, it was considered important that any information or feedback received about health should consider the potential **psychological impact of receiving such information** and that **additional support and advice should be available** or provided. It was also suggested that **the type of tests undertaken should be the choice of the individual** and mechanisms should be in place to choose personalised options, flexibly.

How would you like to receive information about your health?

Views on the frequency and mode of delivery of information about health were varied, some individuals wanted **information as soon as possible**, while others felt that **being able to delay when information was received** may be beneficial. Many preferred to **receive information face-to-face** or **in person (via phone or video call)** and wanted **information to be delivered by a professional** (e.g. GP), so they could **follow up and ask any further question**s. Others felt that **sharing information via the NHS app or other smart app** would be preferred.

Overall, the preferred mode of delivery was largely dependent on the seriousness of information with individuals wanting the **information to be delivered in person by a health professional if more serious** while **minor information could be received via text, email, app or phone call**.

A **personalised approach** was again cited as important, with **individuals giving the choice and flexibility to decide how and when they receive information**.

Are there any other ways that you think we can use molecular phenotyping to improve clinical care and the health of our local community?

Early identification of disease and illness such as **diabetes, heart problems, cancer a**nd **lung disease** were considered a priority, as was **identifying other ailments such as intolerances and allergies, pain** and **depression,** if technology permitted**.** Exploring response to treatment was also considered important, particularly in regard to **new medications**, and **identifying any adverse reactions** following treatment. **Personalised health** was also raised as an important area with individuals wanting to know **what medications suit them best**, **what lifestyle changes they should be undertaking to prevent disease**, and to **support nutrition**, **inform pregnancy** and **weight loss**. Using molecular phenomics to; e**xtend research into the areas which 'most people are suffering'**, increase **accessibility to healthcare** and **help manage long-term conditions** were also raised as a priority.

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.

Appendix 1: Demographic of public attendees

Table 1: Demographic characteristics provided during event registration for discussion group (N=28)

Characteristics	**n (%)**
Age (in years)	
Mean (range)	37 (17-75)
Age groups (in years)	
Under 18	1 (3.6%)
18-24	10 (35.7%)
25-34	4 (14.2%)
35-44	1 (3.6%)
45-54	2 (7.1%)
55-64	3 (10.7%)
65-74	3 (10.7%)
75+	1 (3.6%)
Prefer not to say	3 (10.7%)
Gender	
Female	19 (67.9%)
Male	8 (28.6%)
Prefer not to say	1 (3.6%)
Ethnic group	
White	
English/Welsh/Scottish/Northern Irish/British	0 (0.0%)
Irish	1 (3.6%)
Gypsy or Irish Traveller	0 (0.0%)
Other White background	2 (7.1%)
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	1 (3.6%)
Asian/Asian British	
Indian	6 (21.4%)
Pakistani	0 (0.0%)
Bangladeshi	4 (14.2%)
Chinese	0 (0.0%)
Other Asian background	5 (17.9%)
Black/African/Caribbean/Black British	
African	0 (0.0%)
Caribbean	1 (3.6%)
Other Black/African/Caribbean background	1 (3.6%)
Other	

Arab	3 (10.7%)
Any other ethnic group	1 (3.6%)
Prefer not to say	3 (10.7%)

^Note demographics for one individual who did not register are not available

Appendix 2: Questions asked by call participants following the presentation

Questions answered during call:

- Can you do always this for either blood or urine? Or does one work better according to what you're looking for? If so which one, would you rather use and why?
- Would this do away with MRI scans?
- Do you have to compare people within their own race and even possibly more specifically country of living for example or male against female...etc?
- Could you also possibly see differences in my pain levels? Perhaps by an increase of certain hormones?
    - Would you be able to know with the toilet, when my pain increases?
    - sometimes pain is hard to describe
    - If we knew what pain was going to be like in the next 6 to 12 hours then we would be able to manage and plan a bit better, and potentially not make it worse by pushing to hard.
    - Pain is difficult, because it is a such a subjective area, that's why it's difficult to gauge..
- How would this be possible on a large scale? Would this only be used for people with specific diagnoses such as diabetes or general health?
- How can we measure and market this on a large public scale? Wouldn't this be deemed quite intrusive to begin with as well as time consuming?
- Could metabolic cause diabetes?
- You're talking about what this will or might be able to do? What might it not be able to do? What diseases will this process not work for ?

Comments:

- The mention of 23&me is very interesting as I've had mine analyzed and eg I've various variants particularly macular degeneration variants
- Ethics might be a barrier for some of this even if feasible in practice
- Depressing and being suicidal, all of those things would be fantastic if you could quantify them
- This is a interesting new field. I wish to see its success
- It's an interesting topic which I believe everyone should be aware about. As in everyday life all are busy with their stuff, sessions like this are truly informative to others.
- Very interesting topic.
- Waiting to see will this open a new frontier in treating the diseases