

## Feedback from the Imperial BRC Public Advisory Panel on the Proposed Cardiovascular Health Theme plans: 08.03.21

### Contents

Feedback from the Imperial BRC Public Advisory Panel on the Proposed Cardiovascular Health Theme plans: 08.03.21.....	1
Background .....	2
Session Structure .....	2
Payment .....	2
Summary of Key Insights.....	2
How we used the insights .....	4
Appendix 1: Breakout room discussions.....	5
1. How can we build on our existing patient reference group? Where are the areas for improvement?.....	5
2. Do you think it is reasonable to ask patients to report symptoms on a smartphone? What issues might you foresee with this? .....	7
3. Do you think patients would be prepared to label anonymized images to help with image analysis? .....	9
4. Do you have any ideas for how we could improve PPIE within the Cardiovascular Theme? .....	10

## Background

On 8 March 2021, Dr Rasha Al-Lamee and Dr Graham Cole presented research plans for the proposed Cardiovascular Theme in the Imperial Biomedical Research Centre (BRC) (2022 to 2027) to members of the Imperial BRC Public Advisory Panel (Panel) via an online Zoom meeting.

## Session Structure

The structure of the session was as follows:

- Introduction by the Theme researchers to the proposed Theme's main areas of research including:
  - Cardiovascular Engineering
    - Electromechanical technologies
    - Tissue engineering
    - Artificial intelligence and heart imaging
    - Cardiovascular flow
    - Population data
  - Vascular Inflammation
    - Atherosclerosis and immune-mediated disease
    - Pulmonary hypertension
    - Translational vascular inflammation
    - Clinical trials
- Q&A
- Panel members were then split into two breakout rooms in order that smaller group discussions could take place facilitated by one Theme clinician/ researcher and a public involvement facilitator. During the breakout rooms, Panel members were asked to answer the following questions:
  - *How can we build on our existing patient reference group? Where are the areas for improvement e.g. diversity?*
  - *Do you think it is reasonable to ask patients to report symptoms on a smartphone? What issues might you foresee with this?*
  - *Do you think patients would be prepared to label anonymized images to help with image analysis?*
  - *Do you have any ideas for how we could improve PPIE within the Cardiovascular Theme?*

## Payment

In accordance with NIHR payment guidance, Panel members were paid for their time in accordance with NIHR payment guidelines including a £5 contribution to Wi-Fi/data for accessing a virtual meeting.

## Summary of Key Insights

The following is a summary of the themes identified in breakout room discussions, more details of which are set out below in **Appendix 1**.

### *Building on and improving the existing patient reference group*

Panel members considered that the existing ORBITA patient group could be built on and improved by **speeding up the translation of research** by involving patients and the public including in HTA

processes. **Relationships with charities** such as the British Heart Foundation (and their resources e.g. newsletters) and **GPs** could be utilised and well as the Panel's links. Due to the high prevalence of Cardiovascular disease among **ethnic minority groups**, their involvement is very important, and these groups can be reached via different mediums including community groups, public noticeboards, places of worship, religious festivals and gyms. **Groups in the population who are at risk** could also provide different insights. The Panel recommended the involvement of **carers** of patients, **young people** (through university events) and **patients treated in researchers' clinics** with known disease specific experience. Ensuring public involvement activities are **accessible to different groups** including those who work during the day and utilising interpreters and translations for those who don't speak English. Also ensuring public involvement and research participation is **more inclusive** i.e. not just involving people who already participate in research and further excluding others by moving research to an online platform. Panel members also recommended **utilising social media more** including Instagram as well as **using videos** to explain research studies and/or participation. They also recommended **emphasizing and promoting the benefits** of research including to a patient personally.

#### *Reporting symptoms on a smartphone*

Panel responses to asking patients to report symptoms on a smartphone were broadly supportive and the Zoe app was given as a good example of doing this for COVID symptoms. However, the Panel considered that **reliable smartphone and internet access** and **support and education** (to avoid excluding people) needed to be put in place to be able to do this. One Panel member was not in favour of using a different phone than their usual mobile phone to do this. **Transparency** was also considered key with people being clearly informed about the safety and purpose of the app. One Panel member said they would need to have a **relationship with the organisation** asking for this information, know how it is relevant to them and be told what it used for. The concerns identified included that **not everyone has access to a smartphone or knows how to use one**, that **seeing people face-to face is important** for fear of symptoms being missed by the patient. Other concerns were whether the **smartphone app could be translated**, whether **different smartphones' capabilities** would impact being able to do this and whether **patients would be confused** about how to report symptoms. People would also need to be **assured about the safety of their personal data** in the app.

#### *Labelling anonymized images*

Panel responses to patients' labelling anonymised images to help image analysis were **broadly supportive** and a suggestion was made to **have 'image labelling' events** which people did this in groups. However, the Panel considered the following needed to be put in place to be able to do this: their grading needed to be **anonymous**, **education** about what they were being asked to do and their **consent** provided to do this. Concerns raised included the **capability of patients to be trusted** to do such a task and the **risk of gamifying the task** which may exclude people if it is too competitive.

#### *Improving PPIE in the Cardiovascular Theme*

Panel members made the following suggestions for improvement of PPIE in the Theme: **educate younger researchers in PPIE**, provide **clear concise information** for dissemination among communities, **emphasize the benefit of involvement** and **ensure reciprocity** in the involvement relationship including **providing training** to public contributors.

### 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 Panel members 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](#).

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: Breakout room discussions

Whilst in breakout rooms panel members were asked to respond to three questions. The details of their responses are set out in themes below.

### 1. How can we build on our existing patient reference group? Where are the areas for improvement?

The following comments (which have been themed) were made in response to this question.

#### **Speed up translation of research by utilizing patients and the public**

- Need to focus on speeding up translation of research, and there may be ways to involve patients and the public to help with this process.
- One panel member highlighted that the HTA have actually had low involvement of patients and the public to date and that may be why the translation of research is so slow and often unsuccessful (see recent article they were referring to: Wale, J.L., Thomas, S., Hamerlijnck, D. *et al.* Patients and public are important stakeholders in health technology assessment, but the level of involvement is low – a call to action. *Res Involv Engagem* 7, 1 (2021). <https://doi.org/10.1186/s40900-020-00248-9>).

#### **Build on new and utilise existing relationships with charitable bodies, GPs, resources**

- Continue to build you links and relationships with charitable bodies such as British Heart Foundation
- Make use of existing facilities such as contributing to Cardiovascular charity Newsletters etc.
- You can use the BRC public advisory panel as a resource to see if they can link you up with any individuals or organisations within their networks or communities to help with recruitment.

#### **Involve ethnic minority groups through different mediums**

- Very high cardiovascular problems among ethnic minority groups so you should consider expanding to reach more ethnic minority groups.
- Don't assume that diversity correlates with demographic variables.
- The patient involvement appears very well developed already. For diversity maybe ask GPs, patient groups e.g. cardiac rehab, attend patient education groups, community groups, notices on buses asking for assistance.
- You need to reach out and proactively seek out specific groups using existing events that they will be at - Community Open Days or Community festivals (e.g. Diwali festivals),
- Family, Faith group, Gyms

#### **Involve at risk groups**

- Suggestion to reach out to specific groups within the population who are at risk of cardiovascular disease before (reaching both primary and secondary prevention groups) who might provide different insights.

#### **Involve carers and younger people**

- The carer and the family members around a cardiac problem are very important. What is the outcome that matters to the carer as well.

- Fresher's week events when they involve in different aspects of the University (to involve younger people in your research)

#### **Invite patients in clinics**

- You could begin by inviting post treatment patients to become involved to make best use of their individual unique experiences of the disease.

#### **Be more inclusive and accessible**

- Enable greater involvement of women, and people who work during the day by having meetings in the evening or on weekends. Ask people what is stopping them from being involved and try and work around it.
- Having an interpreter may help involve people who don't speak English as a first language and might not feel confident to be involved.
- language (translation in their mother tongue)
- When patients come into the clinic, they'll be given the iPad or want to go through the questions and they find it interesting, but this would not be a level playing field, and you're only taking the opinion of those who attend the clinic.
- Making sure there is inclusion of everyone. The whole thing about using a digital platform to report on outcomes and also read x rays and read scans may mean that some people who don't have access to telephones or don't have enough mobile, internet, or capacity on their phones because they have pay as you go or use burner phones might be excluded from this fantastic experience. So it's just thinking about what more the hospital can do to ensure it's not just involving the people who may participate in research anyway, and then are further excluding others by the fact that this research is moving on to an online platform. How will you capture their views as well?

#### **Utilise social media and videos**

- I'd like to see the use of social media platforms taken advantage of and utilised when I use Instagram, I get so many pop ups from different company advertisements. Some are a bit annoying, and others really useful. But I think it's a good way to engage.
- I do the idea of having the explanatory video [about studies you are doing or requesting participation in studies] as well.

#### **Emphasize benefits of research**

- Would current patients be more likely to join and be involved if they were aware of the potential benefits for them, including learning more about their disease?
- The benefits of being involved need to be clear and promoted and also maintained otherwise it will be demotivating for patients/public.

## 2. Do you think it is reasonable to ask patients to report symptoms on a smartphone? What issues might you foresee with this?

The following comments (which have been themed) were made in response to this question.

### Positive responses

- If they use a smartphone then I very much doubt it would be seen by them as an unreasonable mode of reporting.
- I'm really in favour of the use of the smartphone and smartphones apps. I think they've worked so well which we've seen in recent times as well with COVID. It does work and I use pretty much everything. I don't have real big issues with worry about security or data sharing. I think a lot of people would have confidence in the NHS systems that are being rolled out for all those apps. I think it's a positive thing. And also, it's just so quick, when you're using that kind of device. I wasn't so keen on the suggestion of having given people a separate phone to use unless they just don't have access to a phone at all. I just think for people to have their phone and then another phone it's not convenient.
- I think that the COVID app (the Zoe app) has about 4.6 million people registered on this. What I find the most gratifying about this (and I'm not somebody who gives her data easily and I have finally joined Patient Knows Best etc.) but COVID has changed a huge amount for me in the sharing of data. And I think this is a fantastic opportunity to take advantage of it. We're always looking at the negative side. But let's look at the positive side. People have been quite happy and felt that they should share (re the Zoe app). What Tim Spector does is, that he gives back (to me, anyway). Every week, we get some charts, we get some information, we get some new information, we get some updates on the data. And every week, he says, "Because of you, we are getting some results". But then he says, you may be interested in this webinar. Now, I've been on these webinars on YouTube. It's absolutely fantastic. You know, this is simple. These are things which of course, take your time. But think of the amount of data you could collect, by doing these things. I really like the personalization of your own area on the Zoe app. For example, I don't know how you would do this, but this could be a focus group topic to see what areas people would like to have.

However, it was noted by attendees that the following things needed to be addressed to be able to report symptoms on a smartphone.

### Reliable smartphone and internet access

- Yes, provided they have a reliable smartphone and internet access

### Support and education

- Yes, some will require assistance and education. There does need to be an alternative method though for those who have no wish to use an app. It could be seen as a bit excluding?

### Transparency

- They need to be clearly informed about the safety and purpose of this reporting and they need to know if they could get any gain regarding own health

- And this is AI which could add to your enrichment of AI. So, to me, the Zoe app is a very, very good example of incredibly good engagement and involvement

#### **Need for established relationship and be made aware of outcomes**

- In terms of things like the Care Information Exchange I am a big fan of that, in terms of monitoring, tests and things, it's fantastic. When it comes to doing surveys and things, I have to say I'm not particularly engaged because I don't have any particular relationship with the survey makers. So when it comes to things like getting patients to report symptoms on the smartphone, I imagine there needs to be some sort of relationship with those patients. They should be getting something back from that, so that they can see the use of it, and they can get feedback on what they're providing. They should get something out of it so they can see how useful they're being. And that's one of the main barriers I find when I'm being asked to engage with things that I have no idea about and not really understanding why or what the outcome is for, how it can potentially benefit me or other people. I think for me some way to show how my contribution is helping, possibly not exactly like you said, but just to know that my contribution is helping or has specifically helped in this area would be useful for me personally. And what sort of learnings have come out of, my contribution, this is how you've affected people, and this is the impact you've had.

#### *Concerns identified about reporting symptoms on a smartphone*

##### **Digital exclusion**

- One panel member noted that not everyone has access to a smart phone or knows how to use them, particularly the older generation.

##### **Face-to face important**

- You potentially miss things if you don't see people face to face – sometimes carers or people close to the patient can spot new symptoms that a patient themselves wouldn't see

##### **Accessibility issues**

- Would there be options for translation on the smartphone app?
- With people having different smartphones and different capabilities, do you have that as an option? Would it be too confusing to have many different ways that patients can report? What's your main kind of strategy? Would you not really use smartphones?

##### **Data security**

- The big worry is the safety of personal data. Everybody does not know how safe it is, who is listening to conversations on the smartphone. So that has to be initially established to convince the participants to use the app.

### 3. Do you think patients would be prepared to label anonymized images to help with image analysis?

The following comments (which have been themed) were made in response to this question. A question posed about this is set out in Appendix 1.

#### **Positive response**

- Again, if they know the purpose of this image and how it will change their own diagnosis later on, they will be more likely to do it
- I recently came across a case study on liver diseases and the conclusion was diagnosis by AI was far more accurate than the individual consultant's opinions which vary a lot so maybe you know when AI comes here, there'll be a lot of positivity from that
- Use the Invention Rooms in White City and call it a 'labelling party' or 'image labelling party' or something. Make it a fun event, make it an around group of people you get together, you have a chat, you have a drink at the end of it etc.

However, it was noted by attendees that the following things needed to be addressed for patients to be prepared to label anonymised images.

#### **Grading anonymity required**

- Yes, so long as their label grading was also anonymised.

#### **Education required**

- Yes, I think this is an excellent way to get patients involved, will require some education.

#### **Consent required**

- As long as people know they are getting involved in research and there are consent processes and people are able to withdraw then yes.

#### *Concerns identified about labelling images*

#### **Capability of patients**

- The data is so important and as coders are absolutely vital in the hospital, I am amazed that you want to ask patients to label imaging. Would you have to check it? How would you trust it? At the end of the day, in the hospital, if your coding is wrong, your whole thing is wrong?

#### **Limitations to gamifying the task**

- Be careful with competitions that could put people down. I appreciate the gaming aspect can be quite fun, but I think you need to be careful. The fact that maybe people just feel that they want to get together to do something useful towards AI and the NHS.

#### **Question posed re Breakout Room Question 3**

- Would the labelling be to train AI or a neural network or would that be something you'd be looking to people do all the time because I think others may be asking a similar thing

#### 4. Do you have any ideas for how we could improve PPIE within the Cardiovascular Theme?

The following comments (which have been themed) were made in response to this question.

##### **Positive responses**

- PPI seems highly developed, enthusiastic, and ongoing. Very encouraging.

##### **Educate younger researchers**

- Upskilling PhD students and supporting them to understand the importance of PPIE and how to do it meaningfully (including how to respond to critical feedback)– important to start ensuring people are doing PPIE early on in their career.

##### **Provide clear, concise information**

- Clear and short information passed from the patient to friends and family.

##### **Emphasize benefit**

- There was a lot of information and the approach around the patient is amazing and should be developed further by showing a clear result/benefit from their cooperation

##### **Ensure reciprocity including training**

- What does the patient get back from being involved in your research?
- Do you have any training particularly for those who are particularly interested? Because CLAHRC Northwest London, did lots of lots of work at one stage in developing representatives to understand more about research and be more engaged in research, even gain academic qualifications to pick up a high level of education