

Insight Report: Online public involvement session on proposed cardiovascular research programmes

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Background

A group of researchers across Imperial College London (some of whom are also part of the Imperial Biomedical Research Centre (BRC)) are applying for £5 million funding over 5 years from the British Heart Foundation (BHF) to fund a BHF Centre for Research Excellence at Imperial to support research on various aspects of cardiovascular medicine. The purpose of the BHF funding is to help keep UK cardiovascular science at the forefront internationally, by enabling research organisations to continue to work on world-leading cardiovascular research, through:

- flexible exploration of new ideas and opportunities through discovery, translational and clinical research,
- attracting and nurturing future research leaders from the widest possible pool of people,
- bringing different areas of science together to collaborate,
- linking with other funding grants held by research organisation and with other funders.

The four research themes the funding proposal will cover are as follows:

1. Societal and Environmental Factors
2. Learning from Heart Patients
3. Vascular Ageing (Blood vessels)
4. Remote (at home) personal monitoring

To assist with the development of the BHF grant application, the Imperial Patient Experience Research Centre (PERC), a core facility of the Imperial BRC, facilitated an online discussion session to gather insights from a selection of Imperial BRC Community Partners linked with Imperial BRC research themes relevant to the proposed Centre themes.

The Imperial BRC is a collaboration between Imperial College London and Imperial College Healthcare NHS Trust, which is funded by the National Institute for Health and Care Research (NIHR) until November 2027. The Imperial BRC has 14 areas of research focus, as well as PERC which supports all the Imperial BRC themes. [Community Partners](#) are members of the public who work in partnership with each of the 14 Imperial BRC research themes and PERC, acting as a ‘critical friend’ to make sure the Imperial BRC’s work is relevant and inclusive of its North-West London population.

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

“Public” includes patients, potential patients, carers and people who use health and social care services as well as people from specific communities and from organisations that represent people

¹ <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371#definitions-of-involvement-engagement-and-participation>

who use services. Also included are people with lived experience of one or more health conditions, whether they're current patients or not.

Approach and purpose

Public involvement was considered a crucial component to the development of the BHF grant application. The Imperial researchers wanted to understand the Community Partners' views and obtain their feedback on the proposed funding application and the four proposed research themes.

The aims of this online session were to:

1. Introduce and explain the BHF funding application and the proposed research themes (15 mins)
2. Give attendees an opportunity to ask questions (15 mins)
3. Facilitate small group discussions in Zoom breakout rooms (discussion questions outlined below), with each breakout room focusing on a specific research theme (55 mins):

i. Societal and Environmental Factors

- What do you think of this theme e.g., relevance to patients, your community?
- What would you think about being asked to provide the following for this type of research:
 - provide a blood sample; and/or
 - your health data?
- What other societal factors should we consider?
- What other environmental factors should we consider?
- How should we communicate with different communities about our research?
- How best to involve patients/the public to shape our research?

ii. Learning from Heart Patients

- What do you think of this theme e.g., relevance to patients, your community?
- We need the following for our research (from people from diverse backgrounds):
 - cardiac muscle from procedure
 - diseased heart removed during transplant
 - biopsy of the heart from a medical procedure
- Would you/your community agree to donate the above samples for this research?
- Would you/your community agree to donate organs (healthy tissue) which can also be used for this research?
- How should we communicate with different communities about our research?
- How best to involve patients/communities to shape our research?

iii. Vascular Ageing (Blood vessels)

- What do you think of this theme e.g., relevance to patients, your community?

- What other periods in life (e.g. menopause) which we could look at which may speed up blood vessel aging?
- How should we communicate with different communities about our research?
- How best to involve patients/communities to shape our research?

iv. Remote (at home) personal monitoring

- What do you think of this theme e.g., relevance to patients, your community?
- Would you be happy for your doctor to use the “digital twin” model to help manage your health?
- What challenges do you see with remote personal monitoring for your community?
- How should we communicate with different communities about our research?
- How best to involve patients/communities to shape our research?

Call overview and agenda

The online discussion was hosted on Monday 7 August 2023 (5:30pm to 7pm) via Zoom and was attended by 16 Imperial BRC Community Partners from a wide range of backgrounds. In addition, two further Community Partners who were not able to attend the session subsequently provided written feedback and comments (see **Appendix 1** for Community Partner demographics).

During the session, an introduction was provided to the grant and the proposed research themes and the attendees were given an opportunity to ask questions (see **Appendix 2**).

The session included four breakout rooms, with each breakout room focusing on one of the proposed research themes. Between three and five Community Partners were involved in each breakout room discussion. Within each breakout room, there was one researcher and one PERC or project team member to facilitate discussion. Discussion in the breakout rooms was guided by a series of questions specific to each research theme, which had been agreed with the researchers and project team ahead of the session. PERC staff member were available to support with the facilitation of breakout group discussions and assist with any technical difficulties that arose.

To facilitate feedback from the Community Partners, there were key questions which were similar across the breakout rooms, and between four and six theme-specific questions.

Attendee recruitment

An email invite was sent to existing Imperial BRC Community Partners linked to the following Imperial BRC research themes and also to Community Partners linked to PERC.

- Social, Genetic and Environmental Determinants of Health
- Molecular Phenotyping
- Cardiovascular
- Digital Health

Feedback

Following the session, attendees were sent an anonymous online feedback form to comment on ways in which the session could be improved and to give any additional views on the discussion questions posed in the breakout rooms (see **Appendix 3**). Comments relating to the questions discussed in the session were integrated into the Key Insights Summary below.

Payment

In accordance with NIHR payment guidance, attendees were paid £37.50 for their time as well as a £5 contribution to Wi-Fi/data expenses for accessing a virtual meeting.

Key Insights Summary

Insights raised during the discussions about the four proposed themes (and responses to the questions posed in each breakout room about the proposed theme) are summarised below.

Societal and Environmental Factors

The group were supportive of this theme, saying that this was **particularly needed in North-West London**, as the **impact of pollution, noise, and shift work felt more prevalent** in this area of London. One Community Partner working with **elderly populations** considered it to be particularly relevant to their community as the community has **multiple health conditions** including high blood pressure, diabetes and problems with their lungs or asthma. Another Community Partner noted that a **holistic view** should be considered, especially with the rise of personalised medicine.

The group shared that **diet and physical activity** were important factors. One Community Partner's community rely on his exercise classes, which are limited due to funding. In addition, the group highlighted the need to make it easier to afford **healthy food** as many who can't end up buying cheap processed foods. **Social interactions** with family, work and the wider community were also suggested to have an impact.

Shift work and sleep patterns were discussed as factors to consider, with one Community Partner noticing people within their community in their thirties and forties **developing hypertension since coming to the UK 1 to 3 years ago**. Their night shift work left them with no time to exercise and their diet is mostly protein i.e. meat. **Sleeping arrangements and adequacy of sleep** were also raised, which are also connected to an individual's housing situation and if they lived in a built-up environment.

Noise and air pollution, particularly for people who have jobs where they have no control over their workplace environment (e.g., **warehouse workers, takeaway drivers**) or **populations living near transit hubs or airports** were proposed as a factor by the group.

Tailored messaging about the theme's research for each community was proposed. There is a need for **clear messaging** about which communities were missing from the research and those communities that research is focusing on. It was suggested community groups could be approached through **community leaders and representatives to facilitate this communication**. When addressing communities, simple examples, relevant to that specific community should be used to **explain the research in language they understand**, avoiding jargon and scientific concepts.

Trust will need to be built with communities before involving them in this research – they don't want to feel like they are being used because the research needs their involvement. Communities will want to know "what is in there for me?" **Focusing on the benefits to health** was suggested as a way to attract people to be involved in this research, as well as **incentives** and **upskilling** people. In

addition, attending existing **health screening events within communities** was suggested as one way to involve people.

Learning from Heart Patients

The group were **generally supportive of this theme** in terms of advances in research especially those with medical conditions who had been helped by healthcare including someone with vasculitis and another whose mother-in-law had a triple bypass but still has ongoing issues. The question of whether **ethnicity and biology** play a role in why people are affected differently by cardiovascular disease was raised and in particular the issue of whether a **South Asian background** predisposes people to high blood pressure.

A couple of people were **supportive of donating tissue** to be used for research in this theme however there was a general assumption that biopsies to obtain heart tissue are **invasive, painful and leave scars**. The words **“collecting samples”** was considered to be linked to being invasive. The concept of a biopsy was also connected with **breast or other cancers** and for the many people in the population who have had these kind of biopsies, it was suggested they would need an explanation of how this biopsy differs (i.e. the biopsy is taken when a patient is already having a clinical procedure or surgery). **Obtaining consent** to obtain tissue samples from people who are **very unwell** and not in the frame of mind to properly consider this request was considered a **possible barrier**. It was suggested that having a **doctor who was treating a patient** ask the patient for consent to take samples by explaining there was a lot that was not known and that research may make a real difference. Having **clear written requests** for consent which are made **whilst the patient is in hospital and before treatment** was also suggested. It was acknowledged that obtaining consent from **younger patients was challenging** and perhaps there should be an **opt out system for organ donation** or that donation should be linked to riding a **motorbike or an electric scooter**. The **media** was suggested as a way to raise awareness about the importance of organ donation e.g., through a TV programme, Tik Tok.

Communication about this theme to **different communities** was suggested by raising awareness through community groups via **community leaders** or through community leaders introducing researchers to their communities so people can ask questions and exchange information. **Lack of understanding** was considered to be a reason why people, especially ethnic minority communities, were not consenting for their tissue or organs to be used for this type of research. One Community Partner stated that as her **knowledge has increased** through her Community Partner role, she is now more open to consenting to provide tissue or organs than she was one year ago. Conversely her mother-in-law who had a heart bypass would not be aware of any of this information and it would be too difficult to explain this to her without more expertise. The **misunderstandings** which exist were exemplified by the group’s understanding of what was meant by a “sample”. It was noted that people need to be **motivated** to donate tissue by helping scientific knowledge improve through a positive act and to be able to **understand it in a concise way**. “You’ve got to make people feel special and that it’s not hurting them”, “It is about leaving people feeling that they’re doing something good.” One attendee gave the example of his participation in a tissue bank as being motivated by **hearing about how some of the samples** from the tissue bank had been used and the positive results that they had found from those samples. **Presenting results from previous research** and what more could be done if the research carried on would be useful to motivate people. “People relate better to the ones that look similar to them - maybe **have representatives in their team from**

various ethnic backgrounds.” Engagement skills were noted as necessary to be able to communicate effectively about this theme.

One suggestion to **involve patients and communities** in this theme was to present the results of the research to more people **in language that is easy to understand**.

Vascular Ageing (Blood vessels)

The group were **generally supportive of this theme** and considered that it especially relevant for **ethnic minorities** and that their involvement was particularly relevant to ensure the research is representative of the population. This is especially relevant for the **South Asian community** where cardiovascular disease, diabetes and obesity is prevalent with the **South Asian Biobank** suggested as an additional resource for this theme. Black and minority ethnic communities and long-term conditions were also considered relevant. There is a need to **raise their awareness about preventative measures** they could be taken to address and improve vascular ageing including **lifestyle advice** including stopping smoking, the use of drugs, more exercise and addressing the issue of obesity.

Periods in life which were suggested which may speed up vascular ageing which could be explored in this theme included moving into adulthood, **stress and stressful events** such as moving house, working with the public (especially in a mental health setting), post-traumatic stress disorder, bereavement, changing work environment and changing family dynamics. **Comorbidities** were also suggested as relevant factors including auto –immune diseases, cancer and other major illnesses and major surgery. A **sedentary lifestyle** or jobs where sitting down is common were noted to increase weight gain including transitioning from student life which is fairly active to office working where physical activity decreases. **Weight gain** was also be attributed to taking medications e.g., for depression. The impact of **COVID** was also highlighted as a relevant factor with research showing the damage this causes to the vasculature. The prevalence of **Long COVID** was also relevant together with the ongoing and long term impact of this on people's lives, the workforce, the health service and the economy. **Menopause** and **pregnancy** were also confirmed as relevant period of life to explore.

Communication about this theme to different communities was proposed through **schools and youth groups** due to vascular ageing affecting young people too. **NHS channels** could be used including information/leaflets provided during hospital and GP appointments and through London Ambulance. Meaningful communications could be shared via TV and radio ads. **Community groups** could be addressed in their own spaces and could be connected to researchers by Community Partners who could also share information with their communities. Those with **lived experience** of cardiovascular conditions could be addressed to ensure preventative measures are taken especially if the condition is genetic. **Charities** like British Heart Foundation and their magazine “Heart Matters” could share information. **Other research projects** like the South Asian Biobank might also share their database information.

Comments about **how best to involve patients and communities** in this theme were based around two main themes: **patient centred research** where the patient voice is at the centre of any research to make sure it's representative of the affected communities with the need to have patients involved all the way through the project, including in the management of the study. This includes recognising that the public bring their **professional skills** to a project rather than “just being patients”. Public involvement in the **writing of the funding application was encouraged**. The other theme was to make **research more accessible** by breaking down barriers with the public, patients and community partners.

Remote (at home) personal monitoring

The group were supportive of this theme, mentioning its relevance to family members with experience of cardiovascular disease and linked conditions, such as diabetes. They considered the theme would be of great benefit as it would take into account **underrepresented communities and their patient experience** to help assist patients with similar illnesses.

The group highlighted benefits the theme could bring to patients to enable them to be monitored at home, which would **reduce the need to travel to their GP or hospital to be monitored** and which **promote patients' involvement in their own care**. They questioned if there was potential to **expand this monitoring** to rare conditions and if dental care should be included, given the **correlation between gum disease and heart disease**. The group identified that **intergenerational differences** should be considered; typically younger people may be more digital literate, however, older family members are likely to have more knowledge of the family history of health conditions.

The group were enthusiastic about the possibility of doctors using a **digital twin model** to help manage their health, noting that “**too much in medicine is predominantly one size fits all**” and that this would offer the potential for **personalised care** and enable patients to play a part in **better managing their own health**. The group were supportive of seeing their data in a **patient-facing dashboard** with the option to choose how much data is shown for those less comfortable or not interested in viewing all their data. Suggestions for an **interactive dashboard** were proposed, which included a **colour-coded dashboard** (e.g., traffic light system) and the ability to **input different scenarios to forecast the potential outcomes on their health**.

Compatibility with existing wearable devices was raised as a potential challenge, not just in terms of ease of use, but it could be a particular concern for some autistic people who for example, don't like the tension of straps (e.g., a watch) and would instead prefer to use their own familiar devices. This also highlighted the need for **alternative forms of devices that were not intrusive to the user**. Others were concerned that **some users may not be as consistent in using their device or app**, and efforts to **raise digital literacy** would be needed. The group were **largely comfortable with sharing their data** for the purposes of remote personal monitoring as they saw that the **data would directly benefit them**; however, they emphasised that **communication will be key to address stigma towards data collection and privacy concerns**.

Communication about this theme was proposed through a framework of "**Cardiology Champions**", alike the existing Imperial BRC Community Partners or Community Champions in councils. These Cardiology Champions would **help spread key messages to their communities**. Communities could also be reached through community centres and community leaders. Reaching out to people in different ways was highlighted. **NHS channels** could also be used including information provided during hospital and GP appointments, and the use of hospital radio. **Charities** like Action On Disability, Age UK as well as lottery funded projects, and food banks could also share information. Other suggestions for communicating about this theme included via religious groups, social media, carers networks, assisted technology hubs, gyms and sport clubs.

Involving patients and communities in this theme was based around the content of the apps and what the monitoring devices look like. For example, the materials used and what they might feel like, which would be particularly important to OCD patients and autistic people, and involving the public in testing the devices.

Appendix 1: Demographics of attendees

Table 1: Demographic characteristics provided during Community Partner expression of interest (N=18)

Characteristics	n (%)
Age groups (in years)	
17-25	1 (5.6)
26-35	0 (0.0)
36-45	4 (22.2)
46-56	4 (22.2)
56-65	5 (27.8)
66 – 75	4 (22.2)
76+	0 (0.0)
Prefer not to say	
Gender	
Female	11 (61.1)
Male	7 (38.9)
Prefer not to say	0 (0.0)
Ethnic group	
White	
English/Welsh/Scottish/Northern Irish/British	5 (27.8)
Irish	0 (0.0)
Gypsy or Irish Traveller	0 (0.0)
Other White background	3 (16.7)
Mixed/Multiple Ethnicity	0 (0.0)
White and Black African	2 (11.1)
White and Black Caribbean	1 (5.6)
White and Asian	0 (0.0)

Other Mixed/Multiple background	0 (0.0)
Asian/Asian British	
Indian	2 (11.1)
Pakistani	0 (0.0)
Bangladeshi	1 (5.6)
Chinese	0 (0.0)
Other Asian background	3 (16.7)
Black/African/Caribbean/Black British	0 (0.0)
African	0 (0.0)
Caribbean	1 (5.6)
Other Black/African/Caribbean background	0 (0.0)
Other	
Arab	0 (0.0)
Any other ethnic group	0 (0.0)
Prefer not to say	0 (0.0)

Appendix 2: Questions asked/comments made by Community Partners during the introduction session

Questions asked or comments made during the introduction to the proposal for an Imperial BHF Centre for Research Excellence, and its associated four research themes, are set out below:

- Are we assuming that the quality of medical care at the various hospitals in Northwest London is consistent?
- You mentioned when people move out to the outskirts of London that you see a drop in life expectancy. Is that because in London you have better public transport and people are more likely to be out and about, whereas when you move out towards the outskirts, people starting using cars more because of lack of public transport. Could this be one of the reasons for drop in life expectancy?
- Regarding health sensors, some people may have access to smart devices but those devices might not be as smart, so how do you envisage doing that? For example, will you provide them with smart devices?
- How much does overlap with, or how much are you going to take into account current research and previous research on COVID-19 and Long COVID? Because we know that endothelial damage causes vascular ageing and increased risk of cardiovascular events, including stroke and with the remote monitoring side there has a lot of that going on with COVID and Long COVID research, so will you be learning anything from that or thinking of creating something yourself from scratch? It is a shame to redo work when there is potentially already something suitable out there. For, example I have been using the Visible app to track Long COVID – I can put my finger on the back of the camera to track my heart rate variability, so there's obviously quite a lot of technology out there that may be of use.
- Are we controlling for ethnicity and wealth?
- Will you be investigating super particulates? By super particulates, I am referring to the specific impact of pollens, air pollution (London Heathrow Airport) and vehicles (the M3 M4 M40 M25 junctions) – these impact asthma.
- I understand that the quality of "after-care" in Harrow is not as good as the other seven boroughs in Northwest London – does that get reflected in the quality of medical health provided at hospitals in Harrow (e.g., Northwick Park)?
- In terms of wearables – are you considering data from people's personal wearables e.g., Fitbit?
- Do you know if similar research has been done in the UK?
- During the pandemic, it seemed that the Black and Ethnic Minority groups were more effected by Covid-19 virus than other people (e.g., Europeans). Did anyone publish any research results related to that?
- Of course, there is the question of data security and privacy. Increasingly people are aware of how easily they can be identified and will reject anything that captures personal data. Also, what happens to life insurance when risk factors can be identified at such a low level.
- In the field of Type 2 Diabetes, they have invented Continuous Glucose Monitors (CGM) devices, which can display graphically the results of eating a meal on sugar spikes. Is there anyway of monitoring the effect of life-style changes on the individual heart muscle cells?
- In central London there is less residential population than in outer boroughs. They have the privilege of most facilities being in higher concentration, including main hospital care and

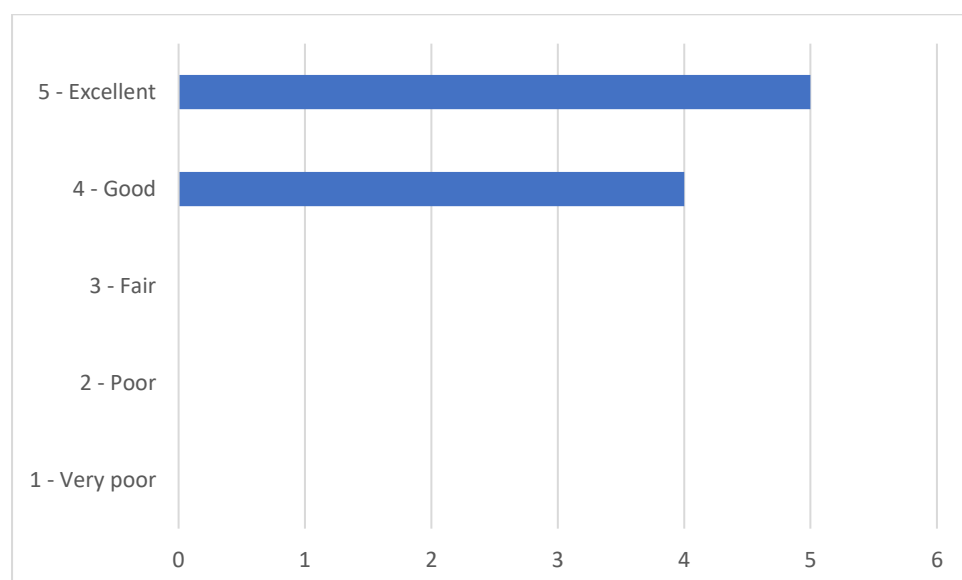
elite specialist clinics. If data is from everyone like a census, then the minute you hit high density regeneration areas of London where transport links are in disrepair or too expensive than you will see obvious evidence of lower life expectancy. I live in one of these areas with high levels of asthma, diabetes and probably these heart conditions.

- Are you looking at blood type too?
- A project called WellHome run by Imperial College London can feed data into this project about indoor as well as outdoor pollution. Some plastics emit pollutants throughout their life span, flooring, furniture and even clothing.

Appendix 3: Post-session feedback from attendees (n=9/16)

A post-session anonymous feedback form was emailed to attendees who were asked practical questions about the session including how they rated it, their motivations for joining and which parts they liked the most. Respondents were also asked if they had any further responses to the questions posed in their particular breakout rooms and these responses have been consolidated with those provided in the breakout rooms above in the Key Insight Summary. As the discussion questions differed between the breakout rooms, the attendees were sent a specific feedback form related to their assigned breakout room, however their responses have been grouped below.

Question 1.1: On a scale of 1-5, how would you rate the session?

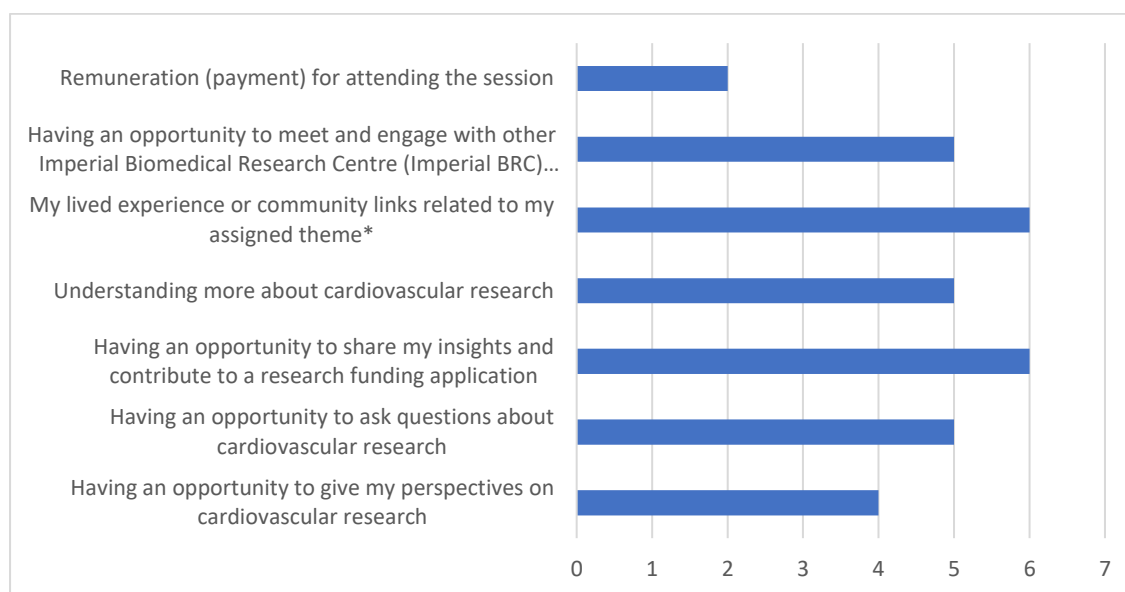


Answer	Count	%
5 - Excellent	5	55.6
4 - Good	4	44.4
3 - Fair	0	0
2 - Poor	0	0
1 - Very poor	0	0

Question 1.2: Please tell us why you chose the above rating:

Very lively and informative interaction with diverse community partners
Very Interactive and plenty of time and opportunities to discuss the topic.
Very clear and informative.
The session was well organised, the information was well presented and the researchers has clear answers for us
Well organised with seamless transitions to break out rooms.
Very well organised, good structure, relevant information, good break-out room discussions.
The information was well presented and there was a good level of interactive exchange.
The session would have been excellent if a little bit more time had been allowed for the discussion part.
The researchers ensured their explanations were, as far as possible, in layman's terms, thus enabling them to be understood. They were happy to answer questions in detail and to take on board comments/suggestions. I was actually interested in more than one of the themes, so it was a shame not to be able to take part in more than one workshop.

Question 2: What were your main motivations for attending the session? (Feel free to choose more than one)

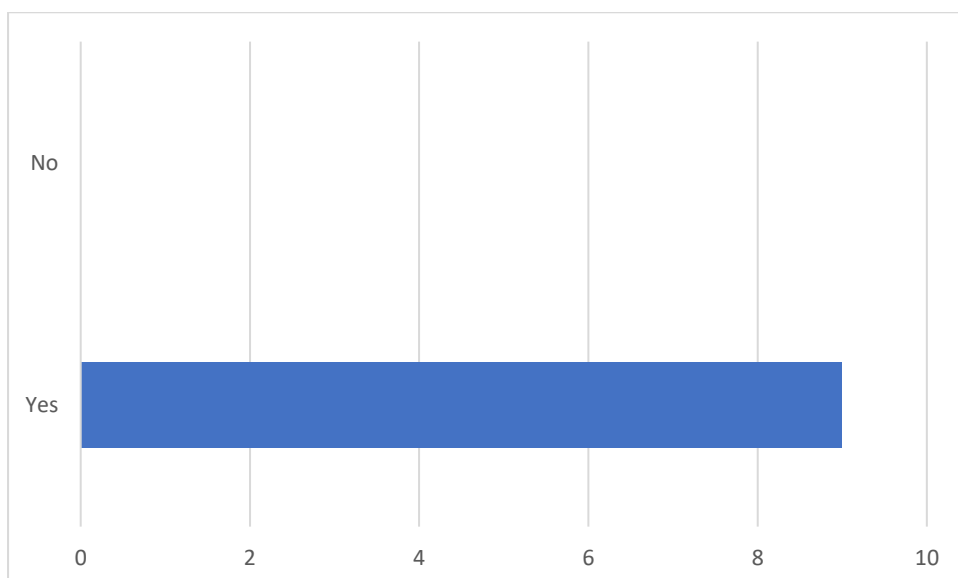


Answer	Count	%
Having an opportunity to give my perspectives on cardiovascular research	4	12.1
Having an opportunity to ask questions about cardiovascular research	5	15.2
Having an opportunity to share my insights and contribute to a research funding application	6	18.2

Understanding more about cardiovascular research	5	15.2
My lived experience or community links related to my assigned theme*	6	18.2
Having an opportunity to meet and engage with other Imperial Biomedical Research Centre (Imperial BRC) Community Partners	5	15.2
Remuneration (payment) for attending the session	2	6.1
Other - please specify		

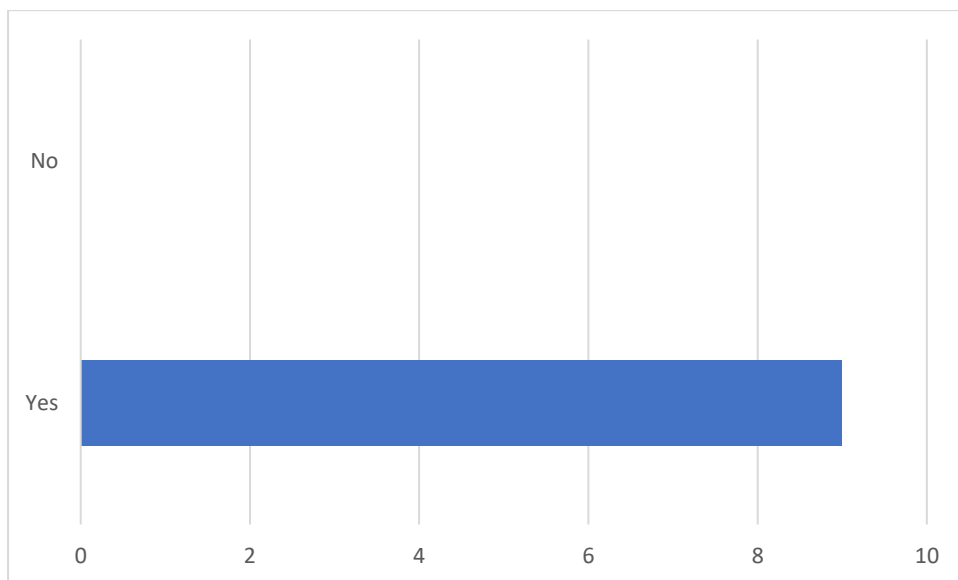
* This option was amended according to the theme discussion the attendee was assigned to

Question 3: Do you think you were provided with sufficient information about the session prior to attending?



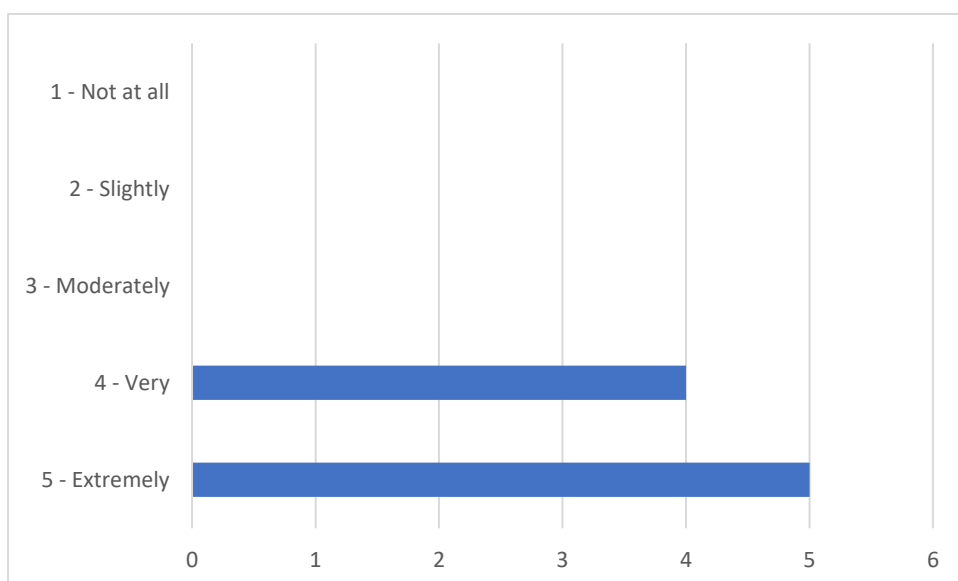
Answer	Count	%
Yes	9	100
No	0	0

Question 4: Did you find the presentations easy to understand?



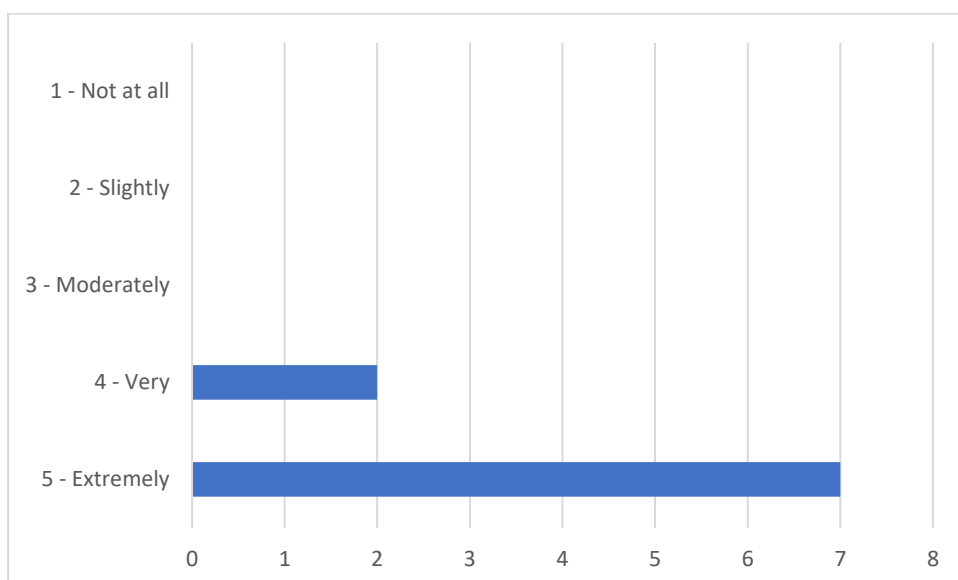
Answer	Count	%
Yes	9	100
No	0	0

Question 5: How informative did you find this session?



Answer	Count	%
5 - Extremely	5	55.6
4 - Very	4	44.4
3 - Moderately	0	0
2 - Slightly	0	0
1 - Not at all	0	0

Question 6: How likely are you to attend a session like this again?



Answer	Count	%
5 - Extremely	7	77.8
4 - Very	2	22.2
3 - Moderately	0	0
2 - Slightly	0	0
1 - Not at all	0	0

