

Feedback from the Imperial BRC Public Advisory Panel on the Proposed Brain Sciences Theme plans: 21.01.21

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Background

On 21 January 2021, Professor Paul Matthews and Dr David Owen presented the research plans for the proposed Brain Sciences 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 Theme researchers to the proposed Theme's main areas of research including (*see slides presented to the meeting*):
 - New approaches to cognitive impairment and dementia therapeutics and care
 - Real-world patient monitoring and remote enabling of treatment in the home
 - Promoting lifelong mental health
 - Clinical data science for discovery and care pathways in neuroscience and mental health
- 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:
 1. *Do you have any comments on our proposed research areas?*
 2. *Are there specific areas you think the application should focus on?*
 3. *Do you have any suggestions on how we do further consultation with people with lived experience relevant to the proposed sub themes?*

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

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

Comments on proposed research areas and on what the application should focus

Panel members were **broadly positive** about the proposed research areas and noted that as **childhood mental health and dementia/Alzheimer's** are much more prevalent (particularly with Covid) and were underserved and underfunded that these should perhaps take priority. **Mental health, and in particular children and young people's mental health**, was considered to be a very important area including the impact on children's education attainment and learning capability and the need to explore their family history. There was support for **the use of technology in young people's mental health research**, however it should be **co-developed with young people** from the outset and **schools** should be directly involved. **Queries** were raised about whether moods could be monitored using technology and that young people may not always be aware of their changing mood and **parents, GPs and carers needed to be involved too**. Other suggested areas of research

included: understanding whether **psychiatric disorders** are a result of nature or external factors e.g., social pressures; **early detection and the role of genetics in schizophrenia**; and **stroke research** due to the link to the Parkinson's Brain Bank.

Suggestions on how to undertake further consultation with those with lived experience

The Panel suggested that **communication and coordination** was needed between each research project and in order to integrate public contributors into research teams including keeping them regularly updated. It was recommended that the Theme needs to have **a culture of researchers genuinely wanting to involve the public** including **building capacity** in public involvement. A **PPIE strategy** should be created using an iterative process which needs to be appropriate to how the Theme works. It was also recommended that **public involvement be included in Theme governance** and someone in the **Theme be accountable for PPIE**. Other suggestions were to: **involve the public early and meaningfully through the research cycle; undertake public involvement appropriate to each research area;** and to focus on **co-development and co-production** with shared power and influence. The Panel also suggested involving **carers and family members** specifically when patients lack capacity as well as **social services for both adults and children**. It was considered that further consultations could be undertaken **with population groups by involving people with lived experience** in each of the research areas including by linking with contacts' networks, NHS specialist services and their patient clinical reference groups and online patient groups. It was also suggested that **partnering** with dementia charities and third sector organisations for the reapplication would be beneficial for all parties.

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 themed below.

1. Do you have any comments on our proposed research areas? Are there specific areas you think the application should focus on?

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

Positive support for proposed research areas

- Overall enthusiasm about the research areas proposed.
- The themes you have identified also look very good.
- I feel all their themes are relevant, but childhood mental health and Alzheimer's are much more prevalent, particularly with Covid and should perhaps take priority.
- The areas that have been identified in particular children/mental health and dementia are generally underserved and underfunded areas.
- Looks like an area where a lot needs to be explored. Difficult to know what the priorities are.

Importance of mental health research especially children's mental health research

- Panel agreed this was a particularly pertinent issue.
- Exploration of child development relating to mental health issues. View that children fall behind (in terms of education) and have difficulties with learning capabilities.
- Include exploration of family history/clinical history when exploring child/young people mental health

Use of technology in young people's mental health research supported

- Supportive of using technology to improve health outcomes.
- A company who developed an app for children with cancer was co-developed with a panel of children affected, siblings, and children who were not affected at all. It is a great way to get feedback to actually form a children panel (<https://xploro.health/>)
- Any sort of technology for young people should be co-developed with them from the **start** to ensure that it is acceptable and usable.
- Meaningful opportunity to work directly with schools through school projects. Suggestion that schools would be particularly interested to be involved in such a relevant real-world project.
- Can you use technology to monitor the moods of young people at an early stage? How do you engage young people to be aware and act on their mood, be aware that their mood is changing? They might not be able to act on their mood changes as already depressed. Need to also engage parents, GPs, carers to support the young person. How do you overcome the issue that individuals aren't always aware of their own symptoms?

Other suggested research areas

- Understanding of psychiatric disorders - is it nature due to genetics or otherwise i.e. social environmental pressures?
- Would like to see research into early detection of schizophrenia and the role of genetics in schizophrenia.

- I think that Imperial hosts the Parkinson's brain bank, and GripAble has been a success for stroke and Imperial has a big stroke unit. Will there be no activity in this area?

2. Do you have any suggestions on how we do further consultation with people with lived experience relevant to the proposed sub themes?

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

Communication and coordination needed

- Need for communication and coordination between each research project – sharing of information and ideas will be important.
- Focus on communication to integrate public involvement members into the rest of the team and keep them regularly updated – need frequent communication and a point of contact within the team

Theme needs genuine culture of involvement

- There needs to be a culture within Themes with researcher genuinely wanting to involve public members.

Ensure PPIE capacity building

- Need to upskill researchers so they have a good understanding of how public involvement works, how they can engage with public members and how they capture and report the impact of involvement.

Creation of a Theme PPIE Strategy

- Don't rush into strategies, really explore what you need and work with people with lived experience to get it right. It also needs to fit with how you work.
- A strategy will likely be an iterative process.
- Need a strategy which incorporates how you are going to make researchers engaged and interested in carrying out public involvement.

PPIE leadership at Theme level needed

- Need someone accountable for public involvement – to ensure it takes place, and can support researchers
- PPI leadership is necessary at Theme level, and visited on management meeting agenda, but also at project level with people with lived experience of the condition plus carers.
- You should have a central public involvement representative who can attend management meetings and represents public involvement activities.

Involve the public early and meaningfully through the research cycle

- Involve the public early in developing these plans.
- It's not just about having public members review plain English summaries, it's about how you are engaging members of the public throughout the whole research cycle.

Undertake public involvement appropriate to each research area

- Recognition that there are differences between research areas, and agreement that public involvement would need to be specific for each group.
- PPI should be integrated, but I think it also should be separate. I think it should be separate for each individual study that you're doing, because the topics are completely different

Focus on co-development and co-production

- A focus on co-development and co-production with shared power and influence

Involve carers and family members

- Very important to involve carers/families (particularly informal carers e.g. family and friends) in this research, specifically when some patients lack capacity. Often these groups can offer more insight on day- to- day observances, changes, behaviour etc.
- They seem to be surprised on the number of ideas coming their way. That is what PPI brings and I would encourage them to let go more of their ownership of the subject and let families and carers guide them more

Involve social services

- I think it would be good to engage with social services in relation to both adults and children

Consult further with population groups

- Encouraged to consult further with people with lived experience within each of the research areas.
- Linking with NHS specialist services and their patient clinical reference groups to involve people with relevant lived experience.
- Individuals with lived experience also have their own networks which you can tap into – worth asking them what other groups, organisation, charities they work with.
- BRC panel members will also have links and networks that they can link researchers with if needed
- Get the PPI members to check what are hot topics in online patient groups too, and go deep into the community to engage with people for focus groups etc

Partner with charities and third sector organisations

- Linking with the Dementia Action Alliances/partnership in the Bid would be positive alliance for both parties in the application.