

Feedback from the Imperial BRC Public Advisory Panel on the Proposed Respiratory Theme plans: 08.04.21

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Background

On 8 April 2021, Professors Edwin Chilvers and Jane Davies presented the research plans for the proposed Respiratory 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 leads to the proposed Theme's main areas of research including:
 - to exploit the strengths in paediatric and adult immunology, allergy, infection, and data sciences to:
 - (i) understand life-course events to define susceptibility and enable earlier targeted interventions to prevent and modify respiratory disease
 - (ii) Exacerbation sciences: harness novel technologies to predict, prevent and treat respiratory 'exacerbations' and
 - (iii) focus on delivering proof-of-principle/early phase clinical trials for Advanced Therapies (e.g. genetic and cell treatments, new drugs)
- 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:
 1. *Do you have any comments on our proposed research areas?*
 2. *Do you have any suggestions on how we do further consultation with the population groups (including under-represented groups) affected by our research areas (cystic fibrosis, asthma, lung disease (COPD))?*
 3. *How do we best involve patients and the public within our research and 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**.

Comments on the Theme's proposed research areas

Panel members were **generally supportive of the Theme's proposed research areas** because these covered all age groups and addressed issues relevant to a wide section of the population, including possible environmental triggers and potential disease development, exacerbations, and those with acute needs. A suggestion was made to also look at **air quality and its effects on exacerbations**, particularly in light of Covid. The **importance of early intervention** was noted to identify risks and prevent conditions. The link to the other specialist health care providers across North West London

was considered important in working collaboratively across North West London and **addressing health inequalities**. It was noted that historical health inequalities may be reinforced by not addressing **rare or complex diseases** which attract less research and consideration needed to be given to addressing them. Other **research areas suggested** were: **acute chest syndrome in sickle cell disease**; collaborations in rarer diseases; the psychological impact of restricted breathing e.g. in asthma; respiratory health care needs of **mental health patients** (which were considered to be neglected); **prevention of respiratory diseases** including with reference to environmental factors including housing and pollution; asthma and the impact of the neurodevelopmental disorders (NDD) on the clinical relationship in **Autistic Spectrum Disorder (ASD)** patients; and research into **patient participation and what motivates people to stay on trials in different conditions**. It was recommended that the **Theme leadership included clinical staff including nurse specialists/consultants** to ensure broad perspectives. Panel members queried whether the **level of trust in AI-based prediction methodologies** had been gauged in patients and whether there may be links to, and funding available through, **the climate change agenda** e.g. through local authorities.

Suggestions on how to undertake further consultation with the relevant population groups

The Panel suggested **contacting local Breathe Easy and asthma groups and contacts** as well as **involving carers, schools** (e.g. the school nurse) and **school children**, as this is an important way to engage children from a younger age and would be important community engagement and involvement. They also suggested **consulting with underrepresented groups** in the community through GPs or patient groups and **involving allied health professionals and primary care and community healthcare contacts**. The Panel also suggested hosting **People's Research Cafes** due to the prevalence of respiratory conditions in communities and the fact that people would be interested in the research.

How to best involve patients and the public within the research and Theme

Panel members suggested: **involving patients and the public from the outset of research projects**; involving **third sector organisations and charities** e.g. Cystic Fibrosis Trust; **ensuring relationships are mutually beneficial** by providing people with information they want e.g. how to improve allergies and if they are breathing clean air; and **utilising social media and personal networks** to reach people.

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?

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

General supportive comments

- All areas are really important
- Really like the 3 areas of focus. Covers all age groups and looks at the still well the mostly well and the mostly unwell. Sounds great!
- I enjoyed it very much and it does seem very well developed already
- The three areas I think you've highlighted are really important I like all of them
- I like balance of the three areas that you identified, because you've got one, presumably a broad fairly healthy population, young population looking forward to what might be triggers in the childhood environment and development of disease later, you've got the exacerbations which presumably is costly, both to the individual in terms of time and health but also monetarily I presume to the NHS, and those with acute needs who are constantly unwell, whose quality of life is poor, looking at drugs that might deal with that. I think that you took a couple of years doing horizon scanning, looking at how you could make these things together successfully. I think you've chosen three contrasting and interesting broad three serve very wide section of the population so I would think the committee will look upon that favourably

Air quality and exacerbations

- Looking at air quality and its effects on exacerbations, particularly in the light of Covid, may also assist in preventing exacerbations.

Climate change agenda funding opportunities

- We are aware of the climate change agenda and I was wondering whether through the work that you're doing, whether you're able to tap into any of the funding that's available, and certainly available to local authorities but I don't know if it's also available to yourselves, to tap into through that agenda?
- As part of your leadership group, are you doing any sort of joined up thinking with local authorities in the area, because I know that they have their own strategies? Many have declared climate change emergencies and a lot of it ties into the links between pollution, and then the health issues that result from those.

Importance of early intervention

- Early intervention is really important to identify risks and prevent the respiratory condition.

Supportive of links across NWL

- I like the link with Harefield as geography is across the breadth of NW London

Address health inequalities

- I'll just pick up on Patrick's point because I think it's quite an important one in relation to the whole health inequalities argument, we know where money goes, we know who's generally affected, but some of the rare diseases or some of the complex diseases and some of the diseases where we still haven't got there yet, it might be because of that historical health inequalities that we're just reinforcing. So I think if there's an opportunity as Patrick says to put ourselves forward and make that leap, make that link even though it's not there already, then I think we're forced to do that because COVID has shown us that, the reasons why we have these health inequalities is no one's brave enough to challenge those barriers. So I think, you know, why not, you know we can't lose. They could just say no, or it doesn't fit, but I think we need to widen and broaden the argument.
- I'm very pleased you included Harefield just because of the population there. So, again, that whole inequalities, you know the difference that you might find in the population.

Other suggested research areas for Theme

- Would like to see further research into **sickle cell disease** as one of the major problems with this disease is acute chest syndrome- they are one of the disease groups which have been left behind from research. Would be happy to link the team with relevant charities and support groups for this condition. As the chair of London Specialised Commissioning, I really had to fight very hard for the funding for that department to be started on first of January [1930], simply because regardless what specialised disease you are, you know, you are struggling, and everyone needs to help each other when you have got the opportunity to do so. So therefore, regardless of my interest because my son has sickle cell and I was involved with this, there's always a priority, and you always got to look at that and help when you can to improve things, so hopefully sometimes you'll get your turn. What I'm saying is that, generally speaking, unfortunately, sickle cell it's always been lagging behind everything else, and in some cases, I mean like, I think acute chest syndrome, which is what could be quite a part of your study quite easily.
- Would be great to see collaborations with **rarer disease**
- One panel member noted that they had asthma as a child, and noted they seldom came across the mental impact that this difficulty to breathe had – this sort of **mental side** of things might also need to be considered in your research as well as thinking about how this might impact individual's motivations to participate/be involved in research
- Yes, it is my concern that the respiratory health care needs of **mental health patients** are neglected given the high incidence of smoking etc., In people with SMI.
- I myself suffer from asthma and have been using all sorts of different kinds of inhalers in the hospital so I really welcome this study. I want to know more about it. Because I'm also involved in another study, I'm not sure whether you have heard about it or not, it's called "Planet". It's about the environment and asthma. You mentioned earlier about developed clinical applications to scientific breakthroughs, translate discoveries into new treatments for patients, I'm just looking to, to even talking about translating whatever findings into new treatments. What about **prevention** because we know a lot of asthma or lung disease, due to conditions that we could it could be prevented so it's an area that we already know, but not much have been done. For me, I can't stand a damp room, we know a lot of housing problems, we have the old buildings full of damp, and nothing can be done about it. I can't walk on the street where it's really heavy traffic, so I have to find a different path when I'm We already know some of the issues so where is the prevention in your application?

- Whether or not the research needs of an **Autistic Spectrum Disorder (ASD) respiratory patients** are being captured and pursued i.e. asthma mainly and the impact of the Neurodevelopmental disorders (NDD) on the clinical relationship.
- Really interesting to hear about the research **looking at patient participation and what motivates them to stay on a trial. Could similar studies be done for other population groups?** Results from this may also be able to be applied to patient involvement in research (i.e., learning around how to support people to participate and be involved)
- Have you gauged the **level of trust in AI-based prediction methodologies** in this patient group? Or do you have any plans to?

Ensure leadership of Theme includes clinical staff

- My challenge really was about the leadership group. I think you could widen out to include clinical staff not just medical as it's currently all professors, which I think that's right, because your background as the experts but there are nurse consultants out there who know just as much from a different perspective than you do as a professor. You've got these nurse consultants who are leading lights in their areas so I would recommend you widen the group out to include hospital nurse consultant.

2. Do you have any suggestions on how we do further consultation with the population groups (including under-represented groups) affected by our research areas (cystic fibrosis, asthma, lung disease (COPD))?

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

Suggested contacts to involve

- Tessa Jelen was a previous BRC public advisory panel member, and she runs the Breathe Easy in Westminster – it might be worth linking up with her to see if any further networks/collaborations with patients and the public could be established.
- The PPIE seems well developed, but in order to reach more people try the local asthma group or Tess Jelen's Breathe Easy group

Involve carers

- I wondered if you had considered involving the carers and the people who live with people with COPD or other disease such as emphysema, etc, because they probably would have a huge voice on what they would like to see the loved ones, sort of not having to go through what they are going through - my mother had very advanced emphysema for years, survived amazingly a long time with it, but to watch her when she couldn't breathe and maybe by involving carers and former carers which could have some education as well from your department to learn how to cope with managing this disease that could help.
- Carers would bring a different perspective to the research which might not have been considered before
- Also involve carers

Involve schools and school children

- Involving local schools and school children seems could be an important way to engage children from a younger age and also would be important community engagement and involvement. There are so many children at school suffering with asthma and allergies at

different levels, and it could also be an opportunity to bring research more widely to children and they could play an important role in shaping your research priorities.

- Often schools have a school nurse – that could be a good contact to link with/build

Involve allied health professionals, primary care, and community healthcare contacts

- Involve physiotherapists
- Physios and community nurses.
- Local GPs may be able to assist as well as
- Link to asthma coaches in gyms
- relationships with

Consult with underrepresented groups

- To consult with underrepresented groups, perhaps by attending asthma groups etc or involving GPs who may monitor these conditions

Host People's Research Café Events

- Respiratory is such a huge subject area, and is something that is very relevant to the public, I wonder if we could do an engagement event such as a People's Research Café (which PERC have run in the past at Imperial Festival and other events), or engage people more widely using the online VOICE platform (www.voice-global.org)
- These have been very valuable in the past, not only because you can get to areas which are unheard voices and very often, You know, I'm not just talking Imperial festival here but we went to the White City for example and, and, and run some people's research Cafe there, and it brought a huge amount, not only to the researchers, but as a feedback, but the people were very enthusiastic - I just think there's so many things with respiratory that people would probably be very interested in participating, and that would be a very good way for you to gather some more research questions.

3. How do we best involve patients and the public within our research and Theme?

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

Involve patients/public from the outset of the projects

- Need to involve people right from the beginning of your research/Theme planning from setting the agenda onwards.

Involve third sector organisations and charities

- Would want to see the level of involvement from the Cystic Fibrosis Trust and patients in all population groups that you work with – building up these relationships with charities and third-party organisations can be mutually beneficial

Ensure relationships are mutually beneficial

- Panel member suggested that it will be important to ensure that relationships are mutually beneficial, ie. What are the patients/public getting out of being involved or participating in research? People want to know if they are breathing good air, if what they are eating is good for their health, how they can manage their allergies better
- Make involvement fun and social

Utilise social media and personal networks

- Get the word out on social media and via your networks