Feedback from the Imperial BRC Public Advisory Panel on the Proposed Multiple Long-Term Conditions Theme plans: 08.09.21

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Background

On 8 September 2021, Professor Ioanna Tzoulaki and Laura Downey presented the research plans for the proposed Multiple Long-Term Conditions 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 to multiple long-term conditions (also known as multimorbidity) and the proposed Theme's research aims:
    - To identify clusters of diseases responsible for the greatest burden of premature death and disability
    - To explain the mechanisms (possible causes) responsible for the clustering of these diseases
    - To determine optimal and patient-centred treatment and management strategies for people with multiple conditions
- Panel members were given the opportunity to ask questions and asked to answer the following questions:
    - *What is North West London's highest priority disease clusters?*
    - *What are the top patient experience priorities?*
    - *How can we best involve the NWL community throughout our research process?*

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 from responses to each of the three questions, more details of which are set out below in **Appendix 1**.

What are North West London's highest priority disease clusters?

Panel members were very supportive of research into **clusters of disease linked to mental health** as well as finding **biomarkers for mental health**. Other clusters identified as priorities were **diabetes and cardiovascular diseases, allergies, immunology, and the mechanisms of autoimmune diseases**. **Frailty** as well as **inflammation** were identified as priority areas. There was wide support for **addressing the treatment of one condition or its side effects then causing another condition** e.g. medication for heart disease leading to kidney failure. The need to look at **intersectionality** around sexuality, religion, socioeconomic status etc was considered a priority and not just looking at people in different silos e.g. men or women. **Health inequalities and inequity** was also considered a priority to include the specific protected characteristics covered by The Equality Act 2010. **Lifestyle factors**

were considered relevant including those which did not necessarily link to socio-economic status. Links between **obesity and deprivation**, and **obesity and high BMI generally underlying many conditions. Environmental aspects** which for example, cause allergy symptoms were also considered to be very relevant especially in London. It was also **recommended that a wider priority setting exercise be undertaken across North West London** e.g. a James Lind Alliance priority setting exercise to find out from a larger number of people within the community what their research priorities are.

What are the top patient experience priorities?

The Panel agreed that **communication between healthcare professionals was paramount** and that improved sharing of information and communication between healthcare professionals and between different departments **would improve patient experience.** This was also reflected in a recent James Lind Alliance Priority Setting Partnership on multimorbidity. **Linking up patients with the same conditions was seen as beneficial to patients** so they could meet others like them**.** The use of "**multimorbidity or co-morbidity" was not considered to be easily understood** by lay people and that using "more than one long term condition" was preferable and easier to understand. Plain language more generally was considered essential e.g. the meaning of primary and secondary care are not easily understood. **Quality of life** and **quality of death** (especially for family members) were also considered to be priorities for those with multimorbidities. **Timing of appointments** was also relevant for patient experience e.g. elderly people can't use their travel cards early in the morning and no one with a condition would want to travel to an appointment during rush hour on public transport.

How can we best involve the NWL community throughout our research process?

Panel members suggested **utilising existing connections with the White City community** through Priya Pallan in the Societal Engagement Team to involve different groups of the community.

Other comments

Panel members were **enthusiastic about, and supportive of, the Theme's research plans** and made some further recommendations to the Theme including **utilising both qualitative and quantitative research to** add strength to the discussion; **utilising GPs to undertake surveys** about those with co-morbidities if possible, **utilising research from countries which may also be relevant for the North West London population** including India, China as well as Eastern Europe. It was also recommended that the Theme **collaborate with other research** groups undertaking research on multimorbidity to ensure there is no duplication, including with the Applied Research Collaborative (ARC) North West London which also has a mental health theme.

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

Panel members were asked to respond to three questions. The details of their responses are themed below.

1.What are the North West London's highest priority disease clusters?

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

a) Clusters including mental health

i. are there biomarkers for mental as well as physical health - can we look at both in the research? We're not just looking at physical health, but mental health as well. I think if we could find biomarkers around mental health as well, that would be really useful
ii. And they are, as already mentioned almost all combined with mental health issues
iii. definitely mental health that leads to other conditions and causing mental health condition

b) Diabetes and cardiovascular

i. things like diabetes and cardiovascular being common ones that I've come across
ii. The clusters that I can see are really priorities in NWL and elsewhere are Type Two Diabetes, which is being very effectively tackled in NWL, I'd have to say that I'm sure the scope for more research, cardiovascular, and particular to catch those with atrial fibrillation, so they do not develop more serious cardiovascular diseases. And work is now going on with COPD. Which again, I think this is another very important project.

c) Immunology

i. I like the idea of research clusters, because always seeing disease as something that is unbalanced in the body. And everything that goes in the direction of linking the body as a whole is for me something so, so I'm happy to see that they will be looking at different diseases and trying to link them together. So, I think the priorities for me, I have a daughter with lupus but my impression, is that everything that is linked to allergy immunology is something that can lead to comorbidity in the long term. And I think it will be a priority because it affects anyone, nowadays in northwest London, is either asthmatic or has a pollen allergy and would be linked to co-morbidities
ii. Are, you said looking at all of the mechanisms of autoimmune diseases which might possibly cluster different things together.

d) Treatment for one condition causing another condition

i. One of my concerns is like how one treatment has created another morbidity. So where you're providing a care for one treatment, I'll give my own personal example, I've been treating with receiving care for my mental health and the medication that I have taken has caused other physical illnesses. So now I have got multi-morbidities. So is there an avenue for you to take into account, a multi morbidity which has been caused by another treatment that you have provided, which is very common
ii. I agree with xxx that collecting multiple medications, either for disease or to treat side effects, affects people's health

iii. And the point that she raised around how one condition can lead to another my father had heart disease, took medication for heart disease, which led to him having kidney failure. So the whole thing about the links for medication for one disease can lead to something else might be something worth looking at

e) Intersectionality

i. the whole intersectionality now is coming more functional to talk about when we're not looking at people in silos anymore, we need to look where the overlap is. So I think we need to consider those groups in our planning and what we're looking at going forward, not just looking at men or women or whatever, we have to look at the intersectionality around sexuality, religion, status, all those things. I think those things are important and people drop through the gaps if we're looking at one group in different silos. Because if we look at women, usually black women are involved in that. A big one is menopause you look for information around menopause, of course, all you see is white women, you don't see black women in menopause. So I'm thinking about those particular issues, but anything, we're talking about we need to look at intersectionality, around those discussions and issues

f) Frailty

i. Are you bringing frailty into the mix?

g) Health inequalities and inequity

ii. one of my questions was to do with the health inequalities, and inequity. And also, to me, the lifestyle is also very important. Of course, like I mentioned earlier, the deprivation, area, poverty and all these things plays a significant part. We know from the COVID outcome, the areas that are deprived indeed certain ethnic minority, that is the difference in the number of COVID.

iii. There are many communities in North London, many of them and again, I'm involved, suffering from inequalities of access. And I'm sure that will be an aspect that you will definitely want to be looking at. And I have a lot of connections with those work in those communities

iv. specific protected characteristics covered by The Equality Act 2010

h) Lifestyle factors

i. lifestyle factors. I would suspect plays some part. And anecdotally. Quite an odd anecdote is Australians that move to London seem to end up with more allergies, and they've had before just when I first moved here, I was warned about that. And I've noticed that I've had more allergies.

i) Lifestyle factors and health inequalities

i. it's quite difficult when you're looking at sort of lifestyle issues and health inequalities, because that there can be sort of a link there with lifestyle factors, but it doesn't always just link into poverty, there can be bad lifestyle choices that aren’t always linked to poverty. The obesity issue, even though I agree, poverty is a link and there's health inequalities definitely there, but I think there's other lifestyles which used to be taken into consideration as well.

j) Obesity and high BMI

i. obesity is always considered as one of the causes for any disease. If you look at anything. I have got diabetes, you are overweight, heart condition, you are overweight, your cholesterol, you're overweight. The first thing that they talk about is your weight and your BMI. Is there something that we really need to look at seriously.

ii. So you say you're looking to see what links potential cluster so presumably, something that triggers something else, which is the potential cascade to the link. So, you've mentioned obesity rates. I'm assuming that automatically comes with that would be deprivation.

k) Environment

i. And of course with London and I'm involved in these Planet studies talking about the environment that causes these other allergy symptoms and you know, insects and things that are just beginning to come up. So that is another area that we might not have looked at that before

l) Undertake a wider priority setting exercise within the population

i. because I think you would already know [the priorities] based on the care that is being sought after in, in Northwest London, you could do the research and you know, what, what are the clusters at the moment, but if you ask me personally what would be my priority, it would have to go through something like the James Lind Alliance priority setting, find out from quite a number of people within the community, what areas would be a priority to look at.

2. What are the top patient experience priorities?

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

a) Lack of communication/information sharing among healthcare professionals

i. Not so long ago, James Lind Alliance Priority Setting Partnership in which I was very much involved with went into the question adult experiences of chronic conditions and the main theme that comes through is issues of communication, of lack of joining up, somebody, they're dealing with something and not knowing what's going on elsewhere. I've experienced it. And I'm sure we all have. So I think that those priorities should be should be looked at.

ii. I agree with xxx for the communication to improve the communication will improve the patient experience and any link between the different departments

iii. communication

iv. I also agree communication is paramount,

b) Linking up patients with the same conditions

i. I think everybody that has a comorbidity is always very, very, very happy to join any group and know people with the same issues. So I think anything that can be offered to the patient to know other patients will be welcome

c) Using plain language

i. I have a problem with the word comorbidity I don't know. If it's only me. I would just long-term condition more than one long term condition to address people, but I don't know maybe become common. And it's just me that has an issue with it. Yeah, that's better.

ii. I remember when we did the James Lind Alliance multimorbidity, I had a lot of difficulty trying to explain to people who were completing the survey about multi morbidity and comorbidities I had to tell them you have more than one condition. So, it's the term that laypeople understand using “more than one illness”, instead of saying comorbidity or multi morbidity.

iii. That's absolutely right and I think it's something we have to bear in mind quite widely, because there are many expressions which are commonly used to treat us and we think we're not using anything, highly technical, like, primary care, integration, and other expressions that the public at large, simply don’t understand, so it's something plain language that people can understand that is obviously most important when it comes to involving the public in the research and in the results of research

iv. that's totally true, we never receive a lecture from our GP saying this is your primary care, or from the hospital saying this is your secondary care as lay members of the public, we do not use these terms in our daily language,

d) Quality of Life

i. Re Patient Experience, I think the top of the list really is quality of life for all these comorbidities. And I think that's a very important element

e) Quality of Death

i. and for many of them, is the quality of deaths. That's an area that affects the families their carers, as well, and it's a huge issue for many people.

f) Timing of appointments

i. I think it would also be terribly helpful to not make the elderly’s appointments early in the morning as they can't use their travelcard or anything. And most of them they would be travelling on quite packed rushed hour transport, which is not the ideal situation, people with any with any morbidity

3. How can we best involve the NWL community throughout our research process?

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

a) Utilise existing networks

i. The white city centre would be a very useful thing to get people from different groups together. Priya Pallan Community Engagement Manager - Invention Rooms

Other comments

Panel members made the following additional comments to the questions including some recommendations.

a) Positive support for theme plans

i. this is a really exciting and interesting proposal and really appreciated your responses - very open and helpful
ii. Agreed, it is an exciting proposal
iii. first of all, I think your aims are absolutely absolutely the right place. What can you actually achieve is very clear.

b) Utilise mixed methods research

i. The Theme should use both qualitative and quantitative approaches - I think we need to have both, if possible. That just adds a bit of strength to the discussion and to the piece of research

c) Utilise primary care

i. Would it be worthwhile to do a survey of GPs to get an idea of the comorbidity population in that area subject to data protection?

d) Utilise research from overseas including Europe

i. Northwest London, as you know, it's very demographic. you've got very different minority groups, and my first question that I wrote down was, have you considered studies from other countries like China, Asia, definitely different ethnic population, including Europe because you just mentioned China and India, but also including Europe, because we have got big proportions of European, Eastern Europeans who are in this country and in Northwest London, so there needs to be that comparison or instead of doing a new study altogether, that it would be good to look at those figures that they have.

e) Collaborate with others undertaking multi-morbidity research

i. I'm actually on the multimorbidity theme plus mental health of the ARC NWL. Very important for your theme and the theme there to cooperate. So there's no unnecessary overlap of the two and do things that are complementary and are together more effectively. I also sit on the board as a citizen partner of Discover Now. So I know quite a lot of what is actually going on, as regards the development of the data which is available
ii. ARC has already got this multimorbidity and mental health theme, so is there any overlap? So we need to think about that as well