

Feedback from the Imperial BRC Public Advisory Panel on the Proposed Metabolic Medicine & Endocrinology Theme plans: 21.01.21

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Background

On 21 January 2021, Dr Chioma Izzi-Engbeaya and Dr Ali Abbara presented the proposed research plans for the proposed Metabolic Medicine & Endocrinology 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 diabetes (Type 1 and 2), obesity (metabolic surgery and non-alcoholic fatty liver disease) and fertility (linked to weight loss and pulsatile hormones)
- 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:
 - *Do you have any comments on our proposed research areas?*
 - *Do you have any suggestions on how we do further consultation with the population groups (including under-represented groups) affected by our research areas (diabetes, obesity, and fertility)?*
 - *What do you think of our proposed public involvement plans?*

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

Panel members were positive about the proposed three main areas of research presented i.e. diabetes (Type 1 and 2), obesity (metabolic surgery and non-alcoholic fatty liver disease) and fertility (linked to weight loss and pulsatile hormones). In relation to diabetes research, they suggested focus could be placed on the following areas: **different forms of insulin administration; diet in ethnic groups and the link to Type 2 diabetes**; and the **importance of lifestyle factors** e.g. diet, **the importance of genetic factors and Type 2 diabetes**. They also suggested research be carried out into obesity and **mental health**; obesity, diabetes, and **exercise**; and **young people**, obesity, and diabetes.

Undertaking further consultation with relevant population groups

As to suggestions on how the Theme should undertake further consultation with relevant population groups, Panel members recommended linking to **national prevention groups, utilising community champions**, emphasizing the **benefits of the research** i.e. to reduce the current burden of diabetes. They also suggested undertaking engagement in **schools and universities**, working closely with **communities and local government and public health officials** as well as **ethnically diverse third sector groups**. Providing **written information and tailored messaging** was considered to be important. For **metabolic surgery**, they suggested involving those who have and haven't had experience of metabolic surgery and **utilising fertility clinics and GPs** to undertake engagement about fertility including exploring particular **issues/challenges** these groups may have to assist with recruitment to studies.

Proposed public involvement plans

In terms of the proposed public involvement plans outlined in the presentation slides, the Panel members considered **project specific public involvement** to be integral. They considered that a **public representative should be embedded in the Theme** and that they should **attend Theme management meetings** and the Theme should have its **own PPIE strategy**.

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 summarised in themes 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 support and feedback on presentation

- Positive about research as know so many people who are obese and have diabetes
- Overall, accepting of the proposed research areas for diabetes
- Interesting and obviously following up on projects which are already underway
- Very clear presentation
- Very dynamic presentation and thorough answering of questions

Diabetes

Different forms of Insulin Administration

- Explore patient and public acceptability and views of different forms of insulin administration.
- Explore patient attitudes to changing methods of administration of insulin (some individuals may be stuck in their ways of how they are currently receiving insulin and are resistant to change)
- Type One - need to look at different options to give insulin ie very much like smoking cessation - gum, patches etc.,

Diet in Ethnic Groups and Type 2 Diabetes

- Include further exploration of diet and type 2 diabetes, particularly with exploration of diets in different ethnic groups
- How do you ask people to change their diet when it may be culturally embedded?
- Need to recognise that diabetes is disproportionately high in ethnic minority groups engage in **early** involvement/engagement with ethnic minority groups to educate them (particularly younger people) so they can make changes to their diet or engage in exercise – to really educate them on what could happen in the future.
- As the Asian community are fond of sweets which are essentially lumps of sugar could there be a warning on these like on cigarette packets?

Importance of Lifestyle Factors

- Important to explore lifestyle factors (public involvement could help ensure questionnaires/questions asked about lifestyle factors are appropriately worded/relevant to obtain better responses)
- Definitely the diet option and how to know which type of food help diabetics. It is an interesting approach.

Importance of Genetic factors and Type 2 Diabetes

- Type Two and genetics and blood glucose - stops the apportioning of blame for having diabetes

Research into Obesity and Mental health

- Will you be researching obesity and mental health as medication used in mental health can cause weight gain/obesity as it stimulates appetite - not in current portfolio but can suggest a collaboration with the mental health team
- Recommend working with counsellors and mental health before, instead of or after bariatric surgery – confirmed that this is currently done pre op e.g. CBT

Research into Obesity, Diabetes and Exercise

- Re obesity and diabetes and exercise, is there an optimum level that one should aim for to get maximum results when exercising? Researcher comment: Have research ongoing about different types of exercise but it hasn't come to a conclusion at the moment but probably the more the better in terms of weight loss. If patients have obesity, they sometimes have bad knees as well and it's not easy to exercise

Research into Young people, Obesity and Diabetes

- Obesity and diabetes is a pandemic in itself and a great threat to the future of the NHS. There is a great deal being done in NW London on diabetes with the aid of the WISIC database. The most important area must be the younger people as that's the future and would like to see proportionately larger amount of research done in relation to younger people – current work re healthy eating in
- younger age groups and diabetes is one of big risk factors for worse outcomes with COVID

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 (diabetes, obesity, and fertility)?*

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

Link to National Prevention Campaigns

- Can the research Theme utilise or link in with prevention campaigns such as the National Diabetes Prevention Programme to identify people to involve/engage new and relevant people in proposed research?

Utilise community champions

- Using community diabetes champions/diabetes education champions who raise awareness of diabetes in local community, also conduct risk assessments with members of their

- community (through local authorities) to assess risk of diabetes (Denise Sime – member of BRC panel is diabetes champion in her local community)
- Suresh Akula (members of BRC panel) is linked with local Indian community groups – can reach out through this network.
 - Where to go to engage depends on the type of study you are planning. Is this to compare groups with KNOWN fertility problems, or 'public fertility'... if the latter I suggest going to public networks like 'mums net' - nearly all planning families worry about this sometime even if not in medical care!

Emphasize benefits of research

Diabetes is understood to be well managed. May be helpful to be clear on the overall burden of disease (both types) and how these new directions may help the cases less well managed now.... also the prevention vs treatment, in genetics, could go hand in hand

Undertake engagement in schools and universities

- Write to biology teachers, science teachers, head teachers (as had done in another project) in general and do a questionnaire for the kids, they would find that really interesting. You could perhaps, talk to them about your research (post lockdown). Children who are 10/12 because this is when I would have thought the hormones are changing e.g., they could keep a diary of exercise or food. This was a mixture of state schools and private schools around North West London and teachers were really keen, because that gave them a fun subject to cover and a very important one
- I also agree with a couple of other people who've spoken up on the importance of engaging with children in school. I'm a school teacher and particularly children with Type One Diabetes, it's quite stigmatising and engagement activities in school was that explain more about the differences between the two types of diabetes etc. This is really important, I read about young people who are harming health by not taking insulin because of slimming effects and because they don't want to be different to other children. So I think engagement in schools is quite key.
- I think we are missing university students, we should we start looking into how we can bring university students into research as it is a rich resource, you're not tapping into to find a way of getting them into research and getting involved, and I think if you're looking for underrepresented groups and you could also find from those university students itself

Work closely with communities

- Advocate a deep-down dive into the community. So that can include the online community because I think this generates ideas for what's current and what people are concerned with going more than half way into reaching out to people I think helps to bring some new voices into the discussion.
- Contact CCG to link researchers up with individuals in charge of health and wellbeing in the community
- Pre-covid, places of worship would have been useful to reach out to.

Work closely with local government and public health officials

- Reach out to local councils to find out prevalence of type two diabetes and engage with those that are high.
- Director of Public Health will be your contact for prevention with local community groups and educators

Work with ethnically diverse third sector groups

- South Asian communities have higher prevalence to diabetes, and definitely working together with third sectors would be great benefit. South Asian Health Foundation is a charitable organisation, and it's quite a big database of Asians who are in that organisation that you could get in touch with
- If you are really looking for particular ethnic groups, then, if you're not able to engage with them, come back to the panel members who are quite diverse in ethnicity, and we would be able to put you in touch with the local communities

Provide written information and tailored messaging

- Suggested handouts/printouts could be shared with local Indian community groups
- Standard messaging is not effective as we can see from COVID we need to think about tailoring messages in methodology technology peer educators etc.

Obesity and metabolic surgery engagement

- Engage with both people who have had metabolic surgery and those who haven't to see different views

Fertility engagement

- Reach out to fertility clinics to identify people to involve. Private Fertility clinics will accept patients that are obese when NHS would not
- Explore particular issues/challenges these groups are having, these might identify barriers which can be overcome to support recruitment to such studies.
- Reach out to GP surgeries, as patient may feel more comfortable discussing such issues with a GP, they have already built trust and a relationship with
- Overall, using GPs to share opportunities to get involved in research both as a public advisor and as a participant.

3. *What do you think of our proposed public involvement plans?*

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

Project specific public involvement

- the public involvement plans should result in a number of members of this group, getting pretty close to each research project and really working with the researchers, with more focus to help engage the right people to be publicly involved with, with this

particular research, not themselves necessarily but to aid that process. I just like to see the marriage between the researcher, and the public partner, getting as close as possible

- I think project specific public involvement is a very good way of doing it, because you're going to get somebody who might have got the condition in their family or as a carer, as they'll know more about it, as a person.
- I think they [the researchers] seem to be totally savvy about PPIE, they just need that extra help to find committed PPI advisors for each of their projects. Would ensure the people they involve are already educated on PPI.

Structure of PPIE support within the Theme

- I think the facilitator [Theme staff member] should be your project specific person [public contributor]. If you're having those three research projects, one of them could be your facilitator but that is what you get out of PERC who very often are doing that, so I am not quite sure you need that
- Rather than the proposed PPI facilitator being a member of the research team, I think there should be a public PPI lead within the Theme, and they attend the management meetings Instead of just saying "embedding PPI".
- At the time of funding there should be a specific role given to the PPI person as like the champion scheme it doesn't seem to work
- Like, in the champion scheme, there was no sanction for not involving with PPI so, we were on the side lines. There should be a very specifically set up role (as PPI person), which then you have to perform, otherwise, it won't work.

Include public involvement representation in Theme governance

- You should include the PPI person at the meetings because the whole point is that they need to see the bigger picture of how you're going to manage that. So it won't be a very specific PPI person (i.e. with lived experience), but you're going to involve them in
- During the management meeting, somebody should be able to ask these questions like what is really happening with regards to PPI? what PPI activities are taking place, and who is accountable. If PPI is not being carried out, there should be somebody from the panel
- developing the more strategic side of things
- Having PPI on the agenda sounds like a tick box
- I think it's important to routinely have PPI on the agenda, some meetings it may be longer and some it isn't, but I think it's signals the importance of PPI by making it a standard item

Need for Theme PPIE strategy

- The overall Theme needs a PPI strategy rather than just individual projects