

Feedback from the Imperial BRC Public Advisory Panel on the Proposed Digestive Diseases Theme plans: 08.03.21

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Background

On 8 March 2021, Dr Nick Powell and Professor Gary Frost presented the proposed research plans for the proposed Digestive Diseases 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 precision medicine for inflammatory bowel disease (IBD), faecal transplants in gut health and IBD, liver disease and nutrition.
- Q&A (please see **Appendix 1**)
- 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 the future work areas?
 - *How can we improve our engagement given the wide diversity of projects and conditions?*
 - *How do we build strong PPI that will inform the Theme across the research journey?*
 - *How can we engage with all sections of our local community?*

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 2**.

Comments on proposed research areas

The Panel were generally supportive of the Theme's plans and expressed that **precision medicine** was a promising development, that **faecal transplants (with an alternative name)** are less invasive than some procedures, that **liver disease is a relevant issue** due to alcohol use and an aging population and that **nutrition is a crucial issue to address at as early a stage as possible**. Other areas of research were also suggested i.e. the **relationship between gut health and pre/post menopause** as well as **prevention**. **Education** was also considered to be crucial and could be **addressed through different mediums** including infographics and daily newspapers as well as and making the **language used** when discussing these conditions more acceptable i.e. using "gut" instead of "bowel". Due to the **prevalence of these conditions**, these topics are a good way to engage the wider public in research.

Suggestions on improving engagement to address research areas

Panel members suggested: **utilising hospital consultants and their clinics** to identify patients to involve (as many patients would not know they could be involved in research) however it is important to also capture those whom it may not be as easy to speak to e.g. those needing an interpreter; identifying those affected by these conditions from **existing data including primary care data; engaging children and younger people including through schools**, social media, the Imperial Young People's Network and linking with other campaigns on e.g. diet and obesity; utilising various other mediums including **social media and podcasts** and **working with GPs** to maximise pre-existing patient relationships and to share information about IBD research/opportunities; utilising **existing patient support groups, third sector organisations and communities** including engaging with community leaders. It was noted that **sensitivity** was needed when addressing socio-economic inequalities and that **building relationships between patients and researchers** was necessary to gain trust and acceptability of research.

Suggestions on building strong public involvement in the Theme

Panel members suggested: **utilising existing Imperial College resources and networks** e.g. the White City engagement team's network; **emphasising the benefits of involvement** i.e. the possible health benefit for people in the short or long term of research; **asking patients what their unmet needs** are and **undertaking research priority setting activities** e.g. jointly with charities or third sector organisations; **establishing regular open lines of communication** with public contributors to ensure a two-way dialogue; **acknowledging the value of public contributors** through building a community with the same purpose; and **ensuring the Theme resources PPIE** appropriately in order to undertake this work.

Suggestions for engaging with the wider local community

Suggestions for engaging with the wider local community included: **identifying which communities you wish to reach** and depending on their demographics, **developing an appropriate strategy** e.g. the age "spikes" in IBD between 20 and 40 years and over 60 years, **engaging with local communities in different ways** including radio stations, videos and digital engagement e.g. the VOICE platform, **create a platform where people can talk about these areas of health** and share their experiences, **involve carers especially of younger people** with these conditions and **utilise local hospitals and pharmacies** which have existing relationships with people and could support this engagement.

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: Questions asked by panel members about the presentation

- What is metabolite profiling, and does it require an invasive procedure?
- Is there a certain age group where you could expect IBD or other related diseases to affect you?
- Is IBD related to diet and does exercise help?
- Is there a commonality between Crohn's disease and ethnic minorities?
- Have you considered a holistic approach? What role does mental health and stress play in relation to gut health? What is the potential impact of COVID-19 on this?
- In relation to the relationship between ethnic minorities and IBD could the relationship be due to those communities having more natural food as opposed to Western culture where food can be more artificial?
- Have you considered what they do in holistic medicine with a gut washout with natural ingredients to get rid of the bacteria?
- Does incurable mean it is manageable?
- I had a big flare up in 2018. My [xxxxx] level was about 3000 (that's inflammation of the intestine). So, I was fine for about two years and then just suddenly at the end of last year, it just hit me. For the last three months I'm just getting over it, but it just came out of nowhere, I was perfectly fine otherwise.
- For diagnosis, are there any markers like blood tests?
- Are there many support groups, so that you could also find how you can ask for engagement and involvement?

Appendix 2: Breakout room discussions

Whilst in breakout rooms panel members were asked to respond to four questions. The details of their responses are summarised in themes below.

1. Do you have any comments on the future work areas?

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

Generally supportive

- Is important area of research as unless you have IBD (or other relevant diseases) or know someone who has it you don't really understand the impact of these diseases on people's lives.
- All interesting relevant areas to focus on
- I found the presentation totally fascinating; they seem to have a lot of ideas but recognise they need more PPI.

Precision medicine

- Precision medicine looks promising for the future and PPI could help guide that in a suitable direction.

Faecal transplants

- Faecal transplants, with an off-putting sounding name, could be altered! Seem very suitable, more accessible, and less invasive than some procedures.

Liver disease

- Liver disease is always an issue with folk drinking more and living longer.

Nutrition

- Nutrition is crucial but needs to be addressed at an early stage.

Other potential areas of research suggested

- Would you consider looking at the relationship between gut health and pre/post menopause?

Need to include prevention

- When I was growing up, every six months we were forced to take castor oil. How can we prevent this if it's preventable? When I looked at your main areas of studies, there wasn't much on prevention. It was more on the actual disease itself, but I think there should be something about prevention.
- We're talking about an incurable disease, and therefore my mind immediately turns to prevention. I would like a great deal of publicity and research and engagement with the public who may not understand this. I know how difficult, education on nutrition is, but I really do believe that is a really important element of this
- I just agree with everything that's been said, particularly the prevention, and the education aspect. I think that's crucial

Need for education through different mediums and change in language

- Education is so important. So instead of starting off with the word “bowel” start off with “gut health”, “how to improve your gut health” because gut health would lead to everything else. Use the words “gut health” in big letters and the word “bowel” somewhere small.
- In terms of getting “bowels” and “faeces” more publicised, maybe some articles in magazines that people might read or in the Metro
- I just agree with everything that's been said, particularly the prevention, and the education aspect. I think that's crucial.
- With regards to education and also drawing the right people to the studies or to get involved is being very innovative e.g. using infographics, cartoons, make it light hearted, catch their eye because it is something funny.

Engage wider public in research due to prevalence of these conditions

- I imagine that due to the prevalence of conditions and link with everyday life, nutrition/Gut health would be a good way to engage wider public into research.
- Not many people are aware of the events that you get from ulcerative colitis and you lose an enormous amount of vitamin D and you can start to get osteoporosis.

2. [How can we improve our engagement given the wide diversity of projects and conditions?](#)

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

Utilise hospital consultants/clinics to identify patients to involve

- I am a patient and would definitely be interested in contributing to this research and finding out more about it, but I haven't been aware of it or these particular areas of research. We're always seeing consultants so I wonder if the consultant can just hand the patient something or just tell the patient to look at something (even just on a broadsheet or website) to let them know that this research exists. If I had known the areas that you've been focusing on, I'd definitely be interested in participating. So I do wonder if the consultant can direct the patient when they're talking to them, because that happens quite regularly.
- Putting up posters isn't a great way to engage people especially because this is not an area that is publicly known, or people are really engaging with unless you're a carer for someone or you're actually going through that. So, maybe the consultants, who are seeing them, make sure you have the leaflet next to you that's already been designed inviting people to subscribe to your website, or to get involved so when they come, you can easily give them the leaflet and they can take it away with them.
- One panel member highlighted that if you are just using your clinics to identify people to involve and having conversations with people at that moment you may miss the opportunity to speak with those who you may not easily have conversations with i.e., those who have an interpreter, carer, and other levels of support.

Identify those affected from existing data

- Suggestion to look at the data on IBD and other related conditions and see who it affects most, in which groups is prevalence rising and target those specific groups for involvement.

- Access local GP records?

Engage children and younger people including through schools

- What about the use of social media? Would the platforms that you are using reach out to the younger demographic who use Snapchat, Instagram, Tik tok? As a university student there is a lot information we see all the time which is actually from sponsored adverts from Facebook. I know Tik tok has been given a bad name with all the dances but there is a lot of information like random cooking tutorials. For example, today is International Women's Day, and I wouldn't have really known that unless it was publicised all over Instagram and everyone was posting about it. What about hiring someone who uses those platforms to help?
- What better place than schools?
- One panel member noted that they were diagnosed quite young in life and that it ended up changing the way they lived their life. They suggested the Theme involve children and young people with IBD and related diseases who will also gain the benefit of being educated about the disease and help them through potential complications they might face as life changes.
- Panel members suggested reaching out to school groups
- Could you integrate with other campaigns with young people looking at diet and obesity due to the link between your areas?
- Reach out to the [Imperial Young Persons' Advisory Network](#) facilitated by PERC

Utilise social media/podcasts

- One panel member also suggested Instagram (and social media) has lots of links and adverts to podcasts and a podcast would be a good idea to reach people more generally.

Work with GPs

- Suggestion to work with GPs and GP clinics to get them sharing information about IBD research/opportunities to get involved with potential patients. Patients have a better relationship (pre-existing relationship) with their GP and therefore may be more likely to listen and act on what they say compared to a researcher they don't know (could relate to both recruiting to be involved and to participate in research)

Utilise existing patient support groups, third sector and communities

- One panel member highlighted that there are a lot of patient support groups for different conditions, where patients exist in their own right and talk to each other for support. They suggested whether researchers could gain access or build relationships with these groups or communities to even just listen to what patients talk about with each other in an informal setting to see what might be important to them at the time (could also potentially do the same with online support groups/forums – one panel member highlighted <https://www.healthtalk.org/>).
- Join patient support groups?
- Develop relationships with support groups
- Reach out to existing charity and voluntary sector organisations in regard to gut health.
- Via condition specific charities
- Perhaps go out to areas where the targeted folk live.
- Engage with various community group leaders

Ensure sensitivity

- Need to consider sensitivity if you are needing to ask direct questions in relation to environmental setting e.g. deprivation/affluence – this could be a barrier.

Build relationships between patients and researchers

- The patient should be followed between relapse to build trust and a strong relationship between research and patient. The patient should agree, for example, to change something in his or her diet and will be informed by the researcher if that change will affect their health or not.
- Research won't work if patients don't find it acceptable in the long-term.

3. [How do we build strong PPI that will inform the Theme across the research journey?](#)

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

Utilise existing Imperial College resources and networks

- Consult with the Imperial CRUK Science PPI Group, and with the BRC PERC Public Advisory Panel at the onset of research ideas and projects. The Imperial White City Community could also be very useful, the White City Community Engagement Manager is Priya Pallan. She is extremely helpful.

Emphasize benefits of involvement

- Patients are willing to help if they understand there is health benefit for them in the short or long term.

Ask patients what their unmet needs are/undertake research priority setting activities

- One panel member suggested asking patients what their unmet needs are and what are the most important outcomes that matter to them.
- One panel member highlighted the importance of building a relationship with a patient and taking time to listen to what needs they have that are currently unmet.
- One panel member suggested holding joint webinars with existing charities and voluntary sector organisation to undertake priority setting discussions similar to James Lind Alliance do.

Establish regular open lines of communication

- Panel suggested frequent communication and an opportunity for two-way dialogue.

Acknowledge value of public contributors

- Panel member suggested that there is an important role of feeling like you are part of a group, and you are part of a community of people with commonality, similar values, and purpose (e.g. patient advocacy). In these sort of groups people can also feedback off each other.

Ensure Theme PPIE resource

- One panel member noted that it needs to be manageable, for instance there will need to be someone to be on top of the administrative duties of having a patient group as well as keeping up communication and being a point of contact for the group.

- In relation to the above one panel noted that you can try and get funding to take on someone who could lead your PPI group

4. How can we engage with all sections of our local community?

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

Identify which communities, you wish to reach

- If you're going to go about recruiting people from a diverse community you need to identify which community you are looking for, because sometimes we have researchers come up with a blanket statement saying they are looking for people from 'hard to reach' communities so you need to identify which 'hard to reach' communities you're actually targeting, and then we (Panel members) could actually help you to reach out to those communities.
- It really depends on what particular demographics and feedback you're after, and then that will determine your strategy, whether you use Tik tok or social media or videos. Do you have particular demographics and communities that you want to engage with? It was confirmed that the Theme wishes to have involvement from all sectors of the population where the disease is prevalent. There are two big spikes between 20 and 40 which can be targeted and then the spike in the over 60's.

Engage local communities in different ways

- Engage with the local communities and local radio stations.
- Use video which can be uploaded onto various platforms and have this video in different languages.
- Use the [VOICE platform](#).

Create a platform where people can talk about these areas of health

- If it is important for people to talk about it, then create a platform where we can invite many people to share their experiences and talk about it.

Involve carers

- When you're recruiting people to get involved, ensure you include carers as well because you mentioned patients could be young.

Utilise pharmacies and local hospitals

- Patients collect medication from pharmacies so you can speak to specific pharmacists to help you involve people e.g. in Harrow where I live, is one of the largest Asian communities. So how do you use the community to recruit the participants or find people to get involved? The hospitals located in that community can do quite a lot to support as well.