

Feedback from the Imperial BRC Public Advisory Panel on the Proposed Paediatrics & Child Health Theme plans: 08.04.21

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Background

On 8 April 2021, Dr Aubrey Cunnington and Professor Sudhin Thayyil presented the proposed research plans for the proposed Paediatrics and Child Health 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:
 - Infections
 - Lung disease
 - Allergy
 - Genetic contribution to disease
 - Injury to the developing brain
 - Predicting and improving future health
- 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:
 - *Enabling all children to be involved or participate in research?*
 - *Routine electronic health record data*
 - *How important is personalised medicine for children?*
 - *Focus on "common diseases"?*

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**.

Enabling all children to be involved/participate in research

Panel members recommended that **schools and young childhood education facilities** were integral with which to engage, raise awareness of research and utilise their resources e.g. wifi and existing relationships with children and parents to access participants and conduct research. **Utilising electronic health record (EHR) data** was supported but the **need for consent** was emphasized. **Parents, families, and siblings as well as young children** should be engaged and involved and **engagement with children should be age appropriate**. Links should be made with **maternity and health visiting teams as well as**

the third sector. Children should be **given access to their data** to improve its quality and **health inequalities should also be considered and addressed** in relation to child health.

Importance of personalised medicine for children

With regard to the importance of personalised medicine for children, panel members were generally supportive with one being surprised that it was not already taking place for young children. Suggestions were made for future research areas including research into **treatment for new-borns** and a **predictive tool to help identify those at risk**. The **importance of long-term outcomes** for children were emphasized. **Relieving the burden on the NHS and families** both in cost and other ways e.g. psychological impact was considered important as was **personalising care to a child's unmet needs** as well as **taking an integrated care approach** to personalised medicine.

Focus on "common diseases"

Panel members considered that **obesity** was common and should be addressed. The **importance of prevention** was discussed and the **need to recognise that there are a variety of causes for disease** including environmental, social, genetic, and also potentially human error. **Rare and more common diseases were considered to need equal focus** and **collaboration with other stakeholders** e.g. GOSH should be undertaken to improve data.

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. How do we enable all children to be involved and/or participate in research?

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

Build relationships with schools, nurseries

- Building relationships with local schools could be an important way to raise awareness about health in children and young people and start to get them engaged and involved in research
- Go to where the children are, ie school, nurseries, playgroups.

Utilise schools to facilitate research

- Has the last year where presumably you have had more interaction online with patients been a positive thing, going forward? Because for children to be taking time out of school, for appointments but in particular for research appointments could be problematical, but that could easily be offset by online interaction I would think people would love it to be quite honest, I mean I'm a school teacher, so I see this aspect from an educational point of view
- Potentially schools could facilitate clinical appointments and research appointments
- You have a parent or carer who comes to the school, you have the effective internet that the school provides and there is enough rooms/offices/the school nurse and the privacy needed to leave the child and the parent to talk to the researcher or the clinician. Now that people are used to having a certain number of appointments online this might be acceptable, and we've all gotten used to trying to avoid having time wasted by travelling backwards and forwards to different places and people have got used to the idea that there could be another model.
- This may facilitate the future of research, especially in paediatrics where it conflicts with education which is always a tricky one.
- Education is crucial, particularly for a child who may have problems and is contributing to research
- I think schools would be a good environment for even focus groups
- In my experience, schools are often keen to be part of research as long as the children get something back. This I found was the scientist/researcher being involved in one of their projects or even coming to present their research to the children. Basically, you will need to invest your time for the 'reward' part.

Utilise electronic health record (EHR) data with consent

- The use of EHRs and children's data to widen participation in research is important and could be very valuable, however you will need to consider consent (parental consent) and how that would be obtained. This might require further consultation with parents/young people to understand their feelings and attitudes towards this
- Parents will need to consent using routinely collected data.
- The routine electronic health record is essential to do the bigger picture data research – is the participation of older children through for example schools the most essential think would be to get their opinion on the electronic health record because as parents we are really inclined to be

extremely cautious about our kid's data as it feels very risky to the parents, but they don't mind their own data being used/included. It doesn't seem that this has been done so wouldn't it be a good way to focus that research to open up that opportunity more because the data is there, and presumably it's coming in spades now?

- The prevention prediction part relies on the maternal population where I would say generally the buy in would be quite good. So, you've got two completely different sets of data and one requires the buy in of the children, whereas the other is more access to data generally so do you find there is a big difference in terms of the access you get to the data you need to do this research between the prediction/prevention where you need maternal data and the paediatric data?

Involve young children

- Members of the panel agreed that even children from quite a young age (5 – 6) can have strong opinions about their health, and felt that there were ways of engaging and involving children at this age by use of flexible methods (e.g., drawing on their experiences rather than talking about them)
- You shouldn't set a specific age of who you will be involving, it will likely depend on the project/research you are doing and if you carefully consider the way/method you are involving individuals any age group should be possible.
- You want to involve and engage people as young as possible so they continue to be involved as they get older, and this could benefit them throughout their lifespan
- I agree that getting children engaged with their health at a very early age is crucial for the future of NHS, prevention again
- Getting children engaged with their health at a very early age is crucial for the future of NHS and prevention. Care Information Exchange is a bonus in the work, and older children can add extra information to it. I also like the personalisation aspect that you mentioned. That's appealing as a distinguishing feature.

Undertake age- appropriate engagement

- It is important to approach different age groups in a different way, and knowing their background is important as well. Ages 7 to 13 will want to be involved in something fun and attractive for their age and if they are past puberty then they would want to feel like it's something social.

Parent/family/sibling engagement

- Where engagement/involvement of children was not possible either due to age or disability engagement with parents and the family would be necessary.
- Involving siblings might also be important – each child has its own strengths and characteristics which might not necessarily be determined by age or childhood.
- Common diseases are often not 'attractive' to research but often are so important to parents. It might help to get a range of children, siblings, parents/carers together to see which common disease is the most interesting for them

- A lot of parents of children who have these brain injuries will already be involved in charities, and will have given a lot from their own experience to others so it would be easy to address them if the parents understand that they are helping

Link with maternity and health visiting teams and third sector

- link with maternity and health visiting teams, SEND Co-ordinators and school nurses also question to be asked around the antenatal checks and test the mother had (or did not have) prior to having her baby and specialist organisations i.e., MENCAP etc., Autism Society etc.,

Give children access to their data to improve its quality

- Incompleteness of data sets in different settings for adults so this may be similar for children - completeness of data can take place if the children are able to have access to the systems
- One panel member agreed that EHRs were an important way to raise children's interest in their own health at a young age (to see their own records and engage with them). They noted that in NWL there is the care information exchange and would advocate that this included children's records as well.

Address health inequalities

- "all children" is an issue as we are aware of health inequalities
- Individuals on the panel agreed that it was really important to look at the role of socioeconomic class and ethnicity in this research as it still so much unknown about these variables' relationship to health.

2. How important is personalised medicine for children?

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

General feedback

- Panel members were impressed by the Theme's proposal and ambition to take this concept forward
- Felt that this was a crucial area of research and Imperial has adequate expertise to take this forward – one panel member noted the potential impact both locally and internationally.
- the BRC Panel initially started with the 100,000 Genome project which was focused on personalised medicine, so it is definitely a theme which is important to the BRC more widely.
- One panel member was surprised that precision medicine had not be done in young children before.
- Feedback from people with lived experience should guide the work that you do
- Personalised medicine is important for all, particularly in the growing skeleton where all features are developing at an uneven pace.
- Extremely important
- Personalised medicine equals individual goal setting
- As important as for adults

- Such an important area of research as childhood is the basis of a healthy life

Potential for future research areas

- There are still a lot of unknowns around treatment for new born babies, for instance dosage of medication given to this group is usually done as a trial-and-error basis and it is only through follow up overtime that the effects of the medication could be established and understood by researchers to help inform future care for other babies.
- End/output of this kind of research would be to develop a predictive tool to help identify those at risk

Importance of long- term outcomes

- While short term outcomes remain important for this group, the long- term outcomes may be even more important – for instance to prevent things when they are 50 – 60 years old
- The panel felt this concept was really important
- Investing in a child’s long-term health is just as important as a “moment of science”

Relieving burden on NHS and families

- The cost on a health care system and on the family of a child who is unwell and continues to be unwell is catastrophic – as well as the impact of the parents and family mentally.
- We always start with the older generation because of all the comorbidities, we start from there because the numbers are bigger, so I think it's important when you look at child health that you're not just taking care of the children but you're also relieving the parents and the carers from potential burden.

Personalise care to child’s unmet needs

- As children are extremely aware about what they live through, they are incredibly clever, basically, and we don't realise how much they seem to assimilate especially when one is transparent, would it not be quite useful if you want to go into personalised medicines to actually personalise it to the extent of trying to work for outcomes that matter to those children, and how they want their life to change rather than just bringing in data which is anonymous? Would that be a real outcome to actually manage to work on their unmet needs, and work all the way to the outcome that matters to them, and to be able to measure it and to see how that would develop

Integrated care approach to personalised medicine

- When it comes to your personalised medicine, and considering that the child may go through different departments, and from what we've been learning about the NHS, different departments operate in different ways, how would you bring that together with the research that you're doing, how would you maintain the personalised medicine being integrated between the departments as the child grows e.g. how would the department know, say, a child presents

itself with a fever, how would a department or the treating person know what to do with that (the bigger picture) so they can apply the appropriate treatment/

3. Focus on “common diseases”?

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

Obesity

- One of the most common childhood diseases that children take through into adulthood is obesity, and it’s probably the nations worst health problem in terms of the potential impacts (diabetes etc). Is this something you will be looking at? Or can you link with other BRC Themes exploring this issue to ensure the child health perspective?

Other factors which influence health

- Important to recognise that there are a variety of causes for disease: environmental, social, genetic, and also potentially human error.

All diseases equally important

- Both rare and common disease are equally important – will be important for the Theme to look at the evidence out there, and establish what gaps there are in research landscape for both common and rare diseases
- There is still so much to be done with almost every specialised or rare disease, and they need a programme of data collection and monitoring to improve and advance research in this area.

Collaboration with other stakeholders to improve data

- Need to get good data from the initial stages, and I would welcome collaboration between GOSH and other childhood research centres to make this happen.

Importance of prevention

- I feel attempting to prevent is crucial and could solve a lot of problems.