

Public Advisory Board meeting – March 2022 – Discussion Summary

For background information and context, please refer to pre-reads. All key actions are in the Action Log.

Updates on key activities

1. Data Access Committee Working Group

- Edited the survey that was completed last year by data custodians to understand their data access processes.
 - Will focus on the extent to which the recommendations made last year have been implemented across the Alliance.
- Working group will continue to work on current draft over the next week or so before sending it across to the wider Public Advisory Board for sign off.
- The survey and surrounding work will be highlighted to the Alliance Board at their next meeting on 12 April 2022.
 - When sending out the survey, vital to have names of key people amongst Alliance members that the survey needs to be sent to so as to avoid multiple people completing the survey for the same organisation.
- Group are considering following up with a small number of Alliance members for in-depth interviews post-survey results – this needs to be considered further before defining plans.
- To enable transparency around data access processes that are in place, propose developing a template that could sit as part of the Alliance website so that there is some consistency and all in one place.

2. Follow up from Consultation Response – Science and Technology Committee

Andrew Morris presented to the Science and Technology Committee in the House of Commons to give evidence following HDR UK's response to an open consultation in which the Public Advisory Board helped shape. A fantastic opportunity for us to share with Government our views on what needs to be done across the UK ecosystem to ensure that data research is trustworthy and ethical.

QQR – Quinquennium Review

Amanda White presented an overview of the background to QQR (more details in the slide deck) and our proposed plans for the future. The proposal for Patient and Public Involvement and Engagement for the next five years was shared as a pre-read (but remains confidential at this time).

The remainder of the session was a Q&A to gain a better understanding of the QQR proposal – a brief summary:

Why is there not a driver programme on mental health given its importance?

Whilst there is not a dedicated programme on mental health, it will likely be included in some of the proposed research driver programmes. For example, the research driver programme titled ‘Big Data for Complex Disease’ is primarily looking at cancer and cardiovascular disease, but mental health might come into that as well. Another example is the ‘Medicines in Acute and Chronic Care’ research driver programme.

Found the overview quite confusing, could it be simplified? Currently also missing the ‘real-life relevance’ for patients and the public Agreement that there is still work to do to make it clearer. The document has been created based on the criteria and structure provided by the funders. It was also an extremely collaborative document which was fantastic to see but hard to streamline. Would like to work with PAB and other public contributors on developing accessible communication (around Feb-March 2023) once funding and proposals have been agreed.

Have the impression there has been a lot of patient and public involvement in developing the proposal but doesn’t jump out as a strength. How much patient involvement was there in deciding and running the research driver programmes?

Team are keen to explore further as to how to highlight more of the patient and public involvement and identify it as a strength in a variety of areas including around changing research culture – the team will follow up with individuals to discuss further.

In terms of influencing which research driver programmes would go forward, HDR UK went out to the health data community and asked them to submit ‘Blue Sky’ proposals which outlined their ideas on how to make a transformative difference to public health and people's health through data research. The Public Advisory Board reviewed these proposals in detail (alongside additional public contributors) and shared their views. Andrew Morris, as Director, made the final decision on which programmes would be most impactful where we knew there was expertise in the UK, partnerships we could build, as well as great leadership. These decisions were made using the input from the Public Advisory Board, additional public contributors and other key stakeholders.

All of the research driver programmes have a requirement to embed meaningful patient and public involvement and engagement and using different approaches, have worked with patients and the public to shape their proposals with some programmes having named

individuals who will be in the programme's leadership team as a patient/public partner. The team also had discussions with each of the research driver programmes to ensure the patient and public involvement and engagement plans are aligned.

Additionally, as part of the Milestones in the next five years of funding, will need to report on our patient and public involvement and engagement activities. Over the next year, will need to explore how the Public Advisory Board are involved in the milestones – not just in reviewing but also advising to help programmes progress.

Unclear on the role of the regional centres

Having physical regions will be important for coverage and connections into health systems locally to enable us to have clear impact for patients. Also want to have the network of the Substantive Sites (which already exist) and plan to provide a small amount of funding for them whilst creating opportunities to branch out in terms of academic and research opportunities as well as connecting into NHS integrated care systems. Important that the research driver programmes and the infrastructure services are involving and utilising expertise across the UK.

Worth noting, funding through the QQR process will only form a percentage of the overall funding that we will need to deliver work across HDR UK; the rest will be through leveraging funds from other programmes, e.g., BHF for the BHF Data Science Centre.

What will be the role of the Public Advisory Board in the next five years of funding?

For the Patient and Public Involvement and Engagement section of the QQR proposal, the Chair and Deputy Chair of the Public Advisory Board have been put forward to be part of the Leadership team and be part of strategic decision-making. The Board will continue to provide strategic advice to the organisation and guiding the delivery of the involvement and engagement programme.

Members also highlighted how the work the Public Advisory Board already links in well with the proposed four work packages put forward in the Patient and Public Involvement and Engagement section of the proposal.

Requested clarity on one of the proposed outcomes – ‘the technology service ecosystem will be built on the foundation of deserved public trust and confidence that UK Data custodians and TREs will want a need to participate in’

It's important to demonstrate to all stakeholders that we have been working with the public to develop the technology to ensure it will be developed and run in a trustworthy manner. This could be very impactful and make these products and services more attractive for data custodians and researchers.

Is there scope for market research to prioritise groups and populations we engage with, e.g., in public awareness campaigns? What about work with healthcare professionals?

Will be exploring some work to understand sentiments and opinions amongst the public around access and use of data for research. The Office for National Statistics have great expertise in this and will take learnings from their approaches.

Some Alliance members are already involving and engaging healthcare professionals – want to build on existing work and learnings. As part of the engagement work with the GP community that NHS England are leading as part of the GP Data for Planning and Research programme, they will need to work through issues with the community. We will want to consider our role in moving the conversations forward.

Need to raise awareness but also work through the knotty issues that are of concern to the public. How do we ensure we talk to, learn from and understand the wider public viewpoints (particularly given the future of Understanding Patient Data)?

Agreement to explore methods such as Citizen Juries and deliberative engagement. Would like to do a sector-wide priority setting exercise to identify what the range of challenging and complex issues are to enable us to then determine which ones to focus on.

Exploring how to ensure resources by UPD continue to be used, including hosting them on our website / partner website. Another related programme of work is the Public Engagement in Data Research Initiative – a partnership with organisations across the sector including Office for National Statistics, ADR UK, NHS, Ada Lovelace Institute, Cancer Research UK and many more. Aim is to pool resources, build on expertise and knowledge, ensure best practice in involvement across the sector and run a joint UK-wide public campaign. Whilst it would not cover the policy work by UPD, it would somewhat cover the public awareness and understanding of public attitudes work.

Some proposed HDR UK programmes involve different actors other than healthcare providers. Is it a strategic decision that the involvement and engagement section has a focus on healthcare providers?

Healthcare practitioners, particularly GPs, are a trusted voice for the public but also have their own views on the access and use of data for research. They have great influence so is important to actively involve and engage this group. All other research driver programmes and infrastructure services have a requirement to embed patient and public involvement and engagement. Through this, we will work with them to ensure alignment and collaboration as appropriate to enable us to work with a broader range of groups and populations.

Ways of Working to Deliver on Activities:

- Support for continuing to run meetings in 1.5 hours and having the working groups format
- Need to ensure enough time for discussions – instead of presentations, send this information as pre-reads
- PAB would benefit from further clarity on how PAB align and work towards the overall HDR UK strategy
- Question around internal resourcing raised
 - Project team members will be taking on a leading role in moving work forward with PAB (with PPIE team to advise and support)
 - Recruiting for a public engagement officer and a public involvement officer whose focus will be the Public Advisory Board
 - Also exploring how we draw on the involvement and engagement expertise across the Institute and joining up more
- Recognise there is a lot of work across HDR UK and will be difficult to be involved in everything – need to prioritise
- Focus for next six months will be Trusted Research Environments, data access processes/governance, shaping patient and public involvement and engagement plans as part of QQR and building relationships with the research driver programmes and infrastructure services.