

Demonstrating Trustworthiness in Data Access through Patient and Public Involvement in Governance: A Shared Learning Event (1 November 2021) – Q&A session and key links to share

Questions and answers

- Are details of different patient panels available on the Gateway, so researchers can approach them for input? - Answered by Paola Quattroni, HDR UK
 - *The short answer is not yet. But HDR UK are exploring how to make various data access approaches across Alliance organisations more transparent and visible (either on the gateway or the Alliance website).*
- What do we need to embed PPIE thoroughly into practice, so it will endure even if governments decide to reduce funding for PPIE? - Answered by Alex Newberry, Welsh Government
 - *Embedding PPIE better within the whole research process is essential, as is recognising that it is a task and activity that needs resources. UK Standards for Public Involvement provide a framework for thinking about how to do it well <https://sites.google.com/nih.ac.uk/pi-standards/home>.*
- Patient and public representatives within data access committees may be seen as 'in the system' by the wider public. This may be a challenge of the model, but how can we portray to the public that they are fully independent? - Answered by HDR UK and Debbie Keatley, Public Advisory Board member
 - *This can come down in part to showing them how they could take part if they wanted to, and we should want the whole data access committee to be empowered to act independently, not just they lay members.*
- If data custodians carry out good PPIE and have robust access processes (and have dedicated resource to do so), why do we ask researchers to do further PPIE, especially when they are unlikely to have resource to do so? - Answered by Michael Chapman, NHS Digital
 - *It shouldn't be either / or on PPIE by researchers and data custodians. There is more to the PPIE in most research projects than just the data access component for example, study design, conduct and dissemination of findings, plus a depth of involvement which isn't practical for data custodians. We don't want to duplicate but we need both.*
- How does the public know to look at NHS Digital's website for the minutes, given that, generally, the public haven't heard of NHS Digital and of all the good stuff that they do? - Answered by Michael Chapman, NHS Digital
 - *I think it needs to be part of a layered process. We need to find the places where the public might engage with these issues (not sure we've cracked that yet) and signpost through for those who are interested in the detail.*

- Why was IGARD's careful process not sufficient to reassure the public when NHS Digital made its GDPR proposal? Was it due to poor communication about the safeguards? - Answered by Kirsty Irvine, IGARD
 - *IGARD is about release of data rather than collection / communication. But we should have sought input from IGARD earlier in the process. IGARD's role could have been highlighted earlier, and that may have helped assuage some fears. IGARD advise on data release and don't have a seat at the table in terms of strategic development or communications. Kirsty speaking personally, found it frustrating that many of the suggestions/challenges made in the public debate were, in fact, safeguards we already had in place. Going forward, IGARD now have a place on an oversight committee for GDPR and will see communications to the public.*

- Is IGARD accessible to applicants? - Answered by Michael Chapman, NHS Digital
 - *In general NHS Digital staff present applications to IGARD rather than the applicants as indirect communication does cause some problems in terms of understanding across all the people involved in the decisions.*

- Can NHS Digital disagree with IGARD's recommendation? Has this ever happened? - Answered by Kirsty Irvine, IGARD
 - *Yes, and yes, rarely. Any deviation from our recommendations is discussed under AOB (any other business) and noted in our minutes (and usually I have already discussed with a senior manager in advance so there are no surprises).*

- How do data access committees monitor use of data to ensure that it is used as agreed? What types of redress are applied if any misuse is identified? - answered by Kirsty Irvine, IGARD
 - *NHS Digital releases data for 1-3 years and for the data access to be renewed the applicant must be able to detail the specific benefits that have flowed from the use of the data. NHS Digital also has the right to audit data recipients - and it uses it.*

- Does Pioneer's Data Trust Committee review all data access requests? Do they read through and comment on the full request submission? - answered by Suzy Gallier, PIONEER
 - *Yes, all applications for data at PIONEER are reviewed by the Data Trust Committee. Only the public contributors on the Committee have voting rights and must approve a request with 80% agreement for it to be accepted.*

- How do data access committees resolve the dilemma of different types of data i.e., anonymised or pseudonymised? - answered by Chris Orton, SAIL Databank
 - *In working with our partners Digital Health and Care Wales (DHCW), we actually receive pseudonymised data from the NHS (just a unique ID with certain demographic information at a high enough level to not be disclosive, such as no postcodes only LSOA (Lower lay Super Output Area) of residence, week of birth not date of birth etc.). SAIL then encrypts this information before it goes to any researcher within our virtual environment, therefore the separation between pseudonymisation by DHCW and then anonymisation by SAIL, means that data provided to research teams is irreversibly anonymised - as we deliberately separate the processing. All projects also have project-specific encryption, so no one project has the same set of IDs to use on individuals in the data. We also practice data minimisation, so that only the data necessary for the project is provided, not just access everything for everything's sake. Happy to discuss further.*

Final question areas shared in chat

- General feeling is that it quite difficult to recruit to data access committees, and therefore the demand falls heavily on the patients and public members who are willing to contribute – how as an Alliance can we address this? How could we work with large companies to get their workforce more interested in taking part as Public Contributors?
- Northern Ireland was not involved in the National Data Guardian consultation – how can we work to get Northern Ireland further involved and to where it needs to be in terms of Public Involvement?
- GPs have the closer interface with patients and the public, so are they the best to talk to people about health data? How can we best work with practitioners in this area?

Key links shared

- Public Advisory Board Recommendations on Public Involvement in Data Access processes - [280621-PAB-Data-Access-procedures-paper-Building-trust-in-data-access-through-public-involvement-in-governance.pdf \(hdruk.ac.uk\)](#)
- UK Health Data Research Alliance response to Public Advisory Board Recommendations - <https://ukhealthdata.org/news/building-trust-in-data-access-through-patient-and-public-involvement-in-governance/>
- Putting good into practice - <https://www.gov.uk/government/publications/putting-good-into-practice-a-public-dialogue-on-making-public-benefit-assessments-when-using-health-and-care-data>
- Review of data release made by NHS information centre - <https://www.gov.uk/government/publications/review-of-data-releases-made-by-the-nhs-information-centre>
- NHS Digital Commercial Purpose - <https://digital.nhs.uk/services/data-access-request-service-dars/dars-guidance/commercial-purpose>
- Citizen's Summit on health data sharing - <https://www.manchester.ac.uk/discover/news/more-transparency-key-to-public-support-for-health-data-sharing-say-citizens-juries/>