

Event Summary

Demonstrating Trustworthiness in Data Access through Patient and Public Involvement in Governance: A Shared Learning Event (1 November 2021)

Background to the event

While people may be content to share their de-identified data for planning and research if they are sure their privacy will be protected and it will not be used for marketing or insurance purposes, they want reassurance about users' motivations for requesting access to the data and their competence to protect it. This requires an approach to data access requests that is fully transparent, open to public scrutiny, and regularly reviewed. Patient and public involvement in the committees tasked with making these decisions should be standard practice and information on assessment procedures and approved uses of the data should be publicly available and accessible.

Building and maintaining public trust through transparent data access procedures is a key priority for HDR UK and for the UK Health Data Research Alliance. A [report](#) from the National Data Guardian underlined the crucial importance of transparency throughout the data life cycle (collection, storage, assessment, and use) and of engaging a wide range of people in all aspects of governance, including reviewing data access requests. Other recent studies ([Foundations of fairness: views on uses of NHS patients' data and NHS operational data](#), [Addressing trust in public sector data use](#)) have reinforced this, highlighting five governance principles (transparent, mutually beneficial, sustainable, responsive, legally compliant) that the public expects to see underpinning data governance. The importance of transparency, accountability, and public involvement to demonstrate trustworthiness has recently been reiterated in [debates](#) about plans for replacing the [General Practice Extraction Service \(GPES\) with an upgraded system](#). The negative headlines this has generated underscore the urgent need to ensure that all data controllers tackle this issue now. [HDR UK Public Advisory Board \(PAB\) members](#) who highlighted this as a priority area and have participated in a number of workshops and meetings on data access over the last year, noted a lack of consistency in relation to public and patient involvement in procedures for governing access to data. At the [December 2020 Public Advisory Board meeting](#) the Board agreed to survey Alliance members about their current and future plans for involving lay people in data access approval procedures. [The survey achieved 22 responses from 20 of the 45 Alliance member organisations.](#)

Following on from the results of the survey, PAB made a number of recommendations on how public and patient understanding of, and involvement in, data governance procedures should be improved in order to demonstrate trustworthiness. The Board also recommended that the Alliance establish a forum to encourage shared learning across organisations, drawing on the views and experiences of patient/public members involved in existing approval processes, with a view to securing meaningful public involvement in all stages of the data lifecycle.

To find out more about the recommendations and the experience of the Public Advisory Board in putting them together, you can read their full recommendations paper [here](#), and a case study about their experiences [here](#).

The first shared learning event took place on Monday 1st November 2021.

Overview of the session

We kicked off this event with PAB member Debbie Keatley, discussing the PAB's experience in developing their recommendations. She explained that the reason public involvement in data access committees across the Alliance came up as a priority for the PAB is that there were a lot of gaps across different data custodians in terms of public involvement, and it became apparent that organisations were not sure what they should be doing and what others were currently doing. Given that it is early days for many data custodians in setting up their data access committees, the PAB feel we have a good opportunity to share good practice and understand the barriers to involving patients and the public in data access processes, so that we can develop and maintain public trust.

Following this, Vicky Chico (Senior Privacy Specialist at the National Data Guardian) gave a thought-provoking talk on *'Putting good into practice – developing guidance based on public dialogue'*. This focused on how the National Data Guardian (NDG) carried out public dialogues to understand what the public consider to be beneficial about the use of health and adult social care data for purposes beyond direct care and explore how people weigh up the risks and benefits of its use. They held several workshops across the country which revealed three top priorities for patients and the public. The public want to ensure that there is proportionality in the approach to access to health and adult social care data, so that governance is not overly restrictive to prevent research, but ensures that access to data is in line with public benefit. It was also key that data access requests communicated the value of the data use to society, and that the access to health data for research carefully balanced the risks and benefits associated.

Experiences of involving patients and the public in data access processes

For this event we're thankful to the representatives from three different organisations who were open and honest when sharing their experiences of involving patients and the public in data access processes. Each provided a different perspective on the achievements and challenges involved in this, with reflections from public contributors in two of the three presentations.

NHS Digital and IGARD – involving patients and the public in data access

Michael Chapman – Director, Research and Clinical Trials

Kirsty Irvine – Chair, IGARD

Michael and Kirsty talked us through the NHS Digital data access process and the role of the [Independent Group Advising on Release of Data](#) (IGARD). Senior staff within NHS Digital approve data sharing agreements, with IGARD, made up of a mix of specialists and lay members, providing recommendations to NHS Digital on the release of the data. IGARD prides itself on being open and transparent with all recommendations and minutes from meetings available in the public domain, and they are well-resourced and supported to manage the high volume of complex applications coming in. They recognise the challenges that IGARD do come to at the end of the data access process, and that public contributors may become experts due to the number of requests they review and therefore may not be able to represent the public viewpoint. Finally, Kirsty reflected on



her experiences of involvement, and that being remunerated for her role has been vital to allow her to be involved. Being on IGARD is incredibly challenging but also incredibly rewarding, and she has been impressed on the care that NHS Digital takes with health data following the Partridge Review. By going through this difficult time, NHS Digital has developed a deep understanding of digital ethics and the importance of maintaining public trust and confidence.

PIONEER - establishing a Data Trust Committee and ensuring the patient voice at the heart of our decision-making

Suzy Gallier – Deputy Director of PIONEER, HDR UK Health Data Hub for Acute Care

Following the background information on [PIONEER as a Health Data Research Hub for Acute Care](#) and their role in holding healthcare data from organisations who provide unplanned or emergency care, Suzy talked about how PIONEER has been reaching out to, talking opening with, and listening to patients and members of the public since the Hub's inception. Patients have helped to inform their guiding principles around ensuring public benefit is at the core of all decisions, seeking to understand and mitigate against public concerns around data sharing, and being transparent in all data sharing, with public/patient oversight of decisions within the Hub.

PIONEER's Data Trust Committee has been set up to ensure public and patient involvement in all data access decisions and review every data access request made to the Hub. The members of the committee have been involved right the way through in designing the decision-making process and have full voting rights to approve or reject all data access requests. PIONEER recognise that while that cannot be truly representative in their involvement activities, they strive to include a broad range of perspectives to help encourage rich and meaningful conversation with patients and the public.

SAIL Databank and SAIL Consumer Panel/Information Governance Review Panel (IGRP) – gaining and sustaining social licence

Chris Orton – Programme Manager, Population Data Science, SAIL Databank

Dot Williams – Public contributor, SAIL Consumer Panel and IGRP

Chris talked us through how SAIL Databank have worked to gain and sustain their social licence when it comes to access to linked healthcare data. He highlights that this is their number one priority and that without public trust, SAIL cannot succeed, so SAIL focus on delivering public benefit in everything they do. Rather than referring to contributors as 'patients', SAIL prefer to talk about involvement of 'people', as they find that this is more reflective of who and how they want to engage and involve others in their work. They also recognise that it may be impossible to represent the public as a whole but that we should continually try to ensure that all views are reflected.

The public are involved in two ways, through their Information Governance Review Panel (IGRP) and their SAIL Consumer Panel. The IGRP review every application to use SAIL data within their Trusted Research Environment, while the SAIL Consumer Panel helps to shape their strategies, policies, and activities around public benefit. They also ensure at least one lay reviewer on every application for data access.

Finally, Dot gave her perspectives of being involved in both the IGRP and the Consumer Panel. She shared how important she believes it is to have lay people's voices heard on research and feels that she makes a real difference to research and in ensuring that researchers understand the importance of involvement. They find that researchers now bring their applications to the panel prior to



requesting data from SAIL, as they really recognise the importance of involvement of patients and the public from the start and throughout the research cycle.

Question and answer session with the speakers

Following the presentations, attendees asked questions of Vicky, Michael, Kirsty and Suzy on some key areas. A topic of particular interest was around public attitude to access to health data for commercial organisations. On the whole, the public are generally less comfortable with this, so how do data custodians and public contributors involved in making decisions on access to data manage this?

All panellists noted that the decisions they make about access to data for any organisation, including commercial companies, are always centred around the benefit to the public and the NHS through the access to the data, and that the commercial gain by companies should be proportionally balanced against the public benefit. Public contributors involved in the decision will generally scrutinise applications by commercial organisations more closely and the benefit to the public is vital in approval. However, it is worth noting that commercial organisations can drive innovation in healthcare through access to health data, and that without providing them access we may not see as great a benefit for patients and the public.

The National Data Guardian noted that while many members of the public initially feel concerned about access to data by commercial organisations, once they were talked through the role of the organisations in bringing about public benefit, their attitudes shifted to being more positive. We also discussed how attitudes could be different depending on the way that the data is accessed. For example, if the data is being accessed within a Trusted Research Environment (TRE), people may be more comfortable with this compared to the data being distributed to the researcher.

The second question discussed by the panel was the issue around whether UK data custodians provide overseas organisations and researchers access to their data. PIONEER noted that, due to the use of their TRE, their data does not leave the UK. When NHS Digital consider access to health data for overseas organisations, they require the benefit to still be accrued to the NHS in England and Wales. The territory of use may also impact the way in which they are allowed access to the data e.g., distributed or through a TRE.

Finally, the panellists discussed the different ways in which public contributor involvement happens in data access approval as well as across the entire data access process. PIONEER note that while they have their Data Trust Committee to review all data access requests, they also look to engage patients and the public in all areas of work, and support researchers to carry out patient and public involvement, and support with communication of their work.

Kirsty feels that the public contributors and independent advisors as part of IGARD could add value at an earlier stage in the data access processes but recognises that this would take resources and time to implement. Michael explained that, with the recent issues with the GP Data for Planning and Research (GPDPR), NHS Digital has got a keener focus on how to get the public voice into their strategic workings and that while this takes a long time to get going, we are moving in the right direction.

Closing reflections

While this event may have brought up more questions than answers, it is obvious that everyone is positive about moving towards greater involvement of patients and the public. There are many different approaches across the organisations represented around involvement in data access processes, but the conversation and questions raised here are bigger than just data access committees. We must look at patient and public involvement in organisations on a larger scale, particularly how we ensure their independence, and work towards inclusion of a range of perspectives and voices, as well as what we see as public benefit, and stand strongly by it.

Next steps

As a collective, UK Health Data Research Alliance and the Public Advisory Board will shape our future activities and consider:

- How we move involvement of patients and the public in data access processes forward in terms of proportionality, transparency and the benefits/risk trade off
- How we ensure representation and reach of our involvement, and recognise that while we aren't going to be perfect, we should strive to do more
- How we reach beyond the 'digital divide' to make sure we are involving people who may not have access to technology to get involved from online means

The Q&A from the Zoom meeting chat, along with key documents shared and further discussion points are available [here](#). Speaker presentation slides are [here](#).

Infographic produced from responses to question "what do you want to get out of the session"

