

TUESDAY, 07 MAY 2019

Wesley Hotel, London

## Workshop summary

### Overview and key conclusions

The event held under the banner **All talk and no access?** explored the practical and regulatory obstacles to more widespread use of patient data in both academic and clinical research.

The programme was devised by **use MY data** members, keen to bring together the custodians and guardians of patient data for a collective discussion about the difficulties researchers are having accessing patient data. **use MY data** aimed for the patient voice to help find solutions to the unintended consequences of our valuable legislation, with its essential principles, restricting progress and research.

There were around one hundred people in attendance from across the UK (from patient representatives to researchers, carers, commercial organisations, clinical professionals and regulators) and there were some fantastic opportunities for attendees to dissect the arguments around this contentious issue.

Some of the key conclusions from the workshop.

- Obtaining patient data for use in meaningful clinical research is expensive, time-consuming and stymied by a conservative, risk-aware culture among the controllers/guardians of the data. But with this in mind, everyone has a part to play.
- From researchers submitting their requests in the right way and clearly communicating the aims of their studies, there are plenty of factors that can influence the speed and equity of access to this vital data.
- Meanwhile, patient groups need to push for a change in culture and understand the incentives which influence the data controllers.

## Session 1 - The challenges for data controllers

The day began with talks from a series of data gatekeepers, both on the research side and from the publicly funded arms-length bodies. But only after event Chair **Mike Birtwistle** had given his customary “no jargon or acronyms” warning - to ensure that talks were as inclusive as possible.

First up, **Richard Welpton**, Senior Data Manager at the Health Foundation, walked us through the processes involved in accessing patient data for serious, publicly beneficial research.

While the data suppliers generally aim to get an application for data access approved within 60 days, Richard said there are an array of sticking points that can make the process overly long.

Perhaps most frustratingly, although most of the organisations that Richard submits his applications to have a broad target for giving permission within a time limit, there are no such targets for other aspects, such as actually producing the data extract, and the overall time taken. This has meant that the Health Foundation typically tries to plan for a six to nine-month turn-around when trying to obtain access to hospital records from NHS Digital.

Next up was **Garry Coleman**, Service Director for Data Dissemination at NHS Digital, who explained the variety of data that his organisation holds.

**Garry** also took us through the inner workings of NHS Digital’s Data Access Request Service (DARS), emphasising the work his team does to ensure that only those with a sufficient legal basis to access such data can do so. NHS Digital currently has around 1,100 data-sharing agreements in place. He also assured attendees that his team is doing a great deal of work to make new datasets available to researchers, while solving some of the existing challenges around producing the data in a timely manner.

Finally, **Garry** outlined the processes involved in granting access permissions, especially the work of the Independent Group Advising on the Release of Data (IGARD), in evaluating new and contentious application types.

IGARD Chair **Kirsty Irvine** then explained in more detail the scope of the Group’s work. At any one time the Group’s board includes a mixture of people - patients, carers, clinicians, researchers and legal representatives. There are no NHS Digital employees sitting on the group (hence the ‘I’ in IGARD).

**Kirsty** added that the group has recommended access for potentially controversial research as a result of campaigning from patients, underlining the power of patient and public involvement in these processes.

**Tariq Malik**, Public Health England’s (PHE) Lead for the Office for Data Release (ODR), explained that the most requested data type was information held within PHE’s National Disease Registration Service. Around 85% of the data that PHE shares with researchers and other outside bodies relates to cancer registration.

While safeguards can hinder researchers quickly getting access to relevant data, PHE is reducing the time it takes from receiving research applications to approving them. The ODR’s aim is to reduce the average turnaround time down from 50 days to 45 days.

Finally, **Janet Messer**, Director of the Approvals Service at the Health Research Authority (HRA) outlined her organisation’s role. The HRA does not hold any patient data itself, but instead oversees how research using such data is conducted.

**Janet** oversees a series of research ethics committees as part of the HRA’s oversight role - and offered an open invitation to any lay people interested in taking part in these committees to apply to join them. She also revealed her team is planning to produce a leaflet to help patients understand the way in which their data is used in research.

## Session 2 - The views of patients, carers, the public

Out came the post-it notes, as attendees were split into groups to come up with questions, challenges and concerns around the barriers to constructive data-sharing. What follows is a summary of some of the main points.

**use MY data** called on four experts to navigate and discuss the concerns and questions raised:

- **Professor Adam Glaser** - Professor of paediatric oncology and late effects, University of Leeds & Consultant paediatric oncologist, Leeds Teaching Hospitals NHS Trust
- **Phil Booth** - Co-ordinator, MedConfidential
- **Dr Natalie Banner** - Lead, Understanding Patient Data
- **Richard Stephens** - Patient Advocate, **use MY data**

A key question raised was one of process - Why are there multiple systems to do essentially the same thing i.e. vet and approve requests for data access?

**Adam Glaser** said he was asked similar questions by different 'gatekeeper' organisations based on the same set of laws. To him, this essentially amounts to a waste of public money.

To **Phil Booth** the duplication of these relatively opaque processes can feel like the experience that many patients go through when navigating the health system's bureaucracies. **"It sounds like we're patients turning up to different parts of the NHS, having to explain our stories again and again."**

**"Sunlight is a great disinfectant"** he added. Making the process as transparent as possible would give those trying to access the data much more clarity about why data requests are processed in the way they are, and why they take the time they do.

**Natalie Banner** suggested that while these processes are meant to exist to protect patient interests, the system has evolved in such a complex way that it has created a big web that undermines its original purpose.

On top of which, there is a default 'no' culture, where the public bodies vetting the data access requests are very risk averse. This was a theme that other speakers returned to throughout the afternoon.

For **Richard Stephens**, the system built to process and police data access has made things **"slowly and inexorably"** worse. While he appreciated that, within the system, there are competent people simply doing their jobs, none of this was reducing the time taken to conduct research.

**"All these bodies put individual freedom above public benefit and we need a change of culture. We as patient groups have a job to change the culture."**

Next came a discussion on how preference is sought from patients for the ways in which their data can be used. The issues surrounding patients who choose to 'opt out' of their data being shared for anything other than direct care purposes also played a part in the exchanges.

One attendee floated the idea that permission should not need to be sought from patients at all, suggesting that patients have an obligation to allow their information to be shared for research. This was pushed back by several others in the room, including **Phil**, who argued that individual privacy would always need to be provided.

**Adam** pointed to an example of the avoidable harms that can go undetected if data sharing is not properly administered. He suspected that one of the consequences of the failure of Care.data was that deaths relating to patients' use COX-2 inhibitors (a non-steroidal anti-inflammatory drug) were not picked up sooner by clinicians.

## Session 3 - Exploring available options

So where does this leave us today? A trio of speakers shared news of the work currently underway to both strengthen researchers' ability to access data more efficiently and, crucially, amplify the public voice in decision-making around the data sharing agenda.

First to speak was **Dr Alex Bailey**, Programme Manager from the Medical Research Council's (MRC) Regulatory Support Centre.

**Alex** gave an incredibly helpful primer on the contrasting state of research data access in each part of the UK and the role that the MRC, as a major funder of research, plays within this landscape.

**"In short, if you think it's bad in England, it doesn't get much better if you want to do UK-wide research,"** was **Alex's** first observation. What followed was a whistle-stop tour through the national and devolved bodies that researchers need to reach out to, in order to obtain various permissions for data usage.

Interestingly, while Northern Ireland has legislation around the way in which confidential patient data can be accessed, the fact that Northern Ireland hasn't had a functioning devolved government for two years, has meant that data access permissions have been governed using common law.

**Alex's** team has previously worked with NHS Digital to map out the process of applying for and obtaining data and **Alex** showed the room a complex web of processes that need to happen. Crucially, thanks to the work of the MRC and Garry Coleman's team at NHS Digital, the process has now been simplified compared to the work required two years ago. Work continues between the MRC and NHS Digital to streamline the approvals process.

**Alex** acknowledged that challenges remain. Legal constraints can tie the hands of research approvers even when applications are deemed reasonable and sufficiently beneficial to the public at large.

**Alex** also pointed to the fact that there simply are not enough staff within organisations like NHS Digital and Public Health England to walk every researcher through the particular application requirements of their projects.

However, work is being done to pull down some of these structural barriers. One such initiative is the Research Advisory Group (RAG). RAG is hosted by NHS Digital and includes representatives from a range of government bodies, research groups and the private sector to determine how NHS Digital can best provide its services.

A key part of this work is around identifying a common language to ensure that all stakeholders have exactly the same technical and legal understanding of terms such as 'identifiable data' and 'consent' in the context of data usage.

Next, **Amanda White**, Director of Communications and Engagement at Health Data Research UK (HDR UK) introduced her organisation, which was established in April 2018.

The Chair, **Mike Birtwistle**, suggested the body **"does what it says on the tin"**, and Amanda outlined the various strands of important work underway.

She explained the four pillars of the organisation's strategy. Firstly, a process of building public trust in the way that data is used for research is underway, with the creation of a Public Advisory Board.

The next pillar is around scaling the science and research that comes from the use of patient data. **"We want to be able to use the largest health research and patient data that's available at a national scale, not just within regions. We also want to be able to give researchers access to data about millions of people."**

Thirdly, empowering health data scientists. **Amanda** pointed out that HDR UK aims to create 10,000 health data scientists, spanning all career stages. She noted that HDR UK has seen people from a lot of different backgrounds coming into the profession.

Finally, there's infrastructure. Last year, HDR UK was commissioned by the UK government to develop a Digital Innovation Hub programme, designed to address the fragmented structure and inconsistent approach to data research across the UK.

As part of this work, HDR UK has been in dialogue with around 3,000 people across different sectors, including patients and the public, to find out what scientists, innovators and researchers need from health data to do their work.

From this, the plan over the four years of the programme is to design a system and a model that will work in the UK.

Finally, **Richard Stephens**, one of **use MY data's** very own avuncular patient advocates took to the stage once more, to set out the role that advocates can play in driving the data access agenda forward.

**Richard** has had many contacts with healthcare professionals over the years. He highlighted: "One of the problems I have as a patient is that when anything happens to me - I don't think of it as data. Most of us don't. But when things do happen to us, we have some pretty common questions. What's going to happen to me? If I take this medication what will happen to me? We know about drug symptoms, for instance, because of data from patients."

He suggested an interesting solution to getting more patients involved in pushing for more safe data usage by the research community: "My suggested solutions to some of these problems is actually to get patients involved in data. But just don't tell them it's data. Get them to sit on a committee or a group where they have a specific function."

This way, **Richard** explained, patients can drive momentum for getting their data used in research, because they want it to help people - possibly their family members.

He cited the example of Genomics England's Participant Panel as a prime example of the kind of patient action he advocates. "Some of those people have been trained up and they sit on the Data Access Review Committee. But nobody thinks of it as data access review. It's actually the committee that looks at every single application from those who want to go and look at genomes."

**Richard** ended by suggesting a relatively easy and practical step any patient who wants to better identify how their data is being used can take:

"We're all entitled to go to our NHS Trust's Annual General Meeting. We can ask questions:

- Who are the patients you have sitting on whatever committee it is that decides which data you're going to release?
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- How much are you going to charge for it?

We're entitled to ask these questions. Particularly, how do you report to patients what you have released and what benefit it has had?"

## Session 4 - How can we ensure this workshop makes a difference?

The day ended with a concluding discussion from attendees, with both speakers and audience examining the ways in which the day's conversations could be translated into practical action.

For NHS Digital's **Garry Coleman** it was an ambition to do more to engage his NHS Digital colleagues about the issues raised. He added that he would be interested to see this workshop re-run in order to see how bodies like NHS Digital are responding to the challenges raised - specifically **"to review what we are doing at NHS Digital and what can NHS Digital do better?"**

Public Health England's **Tariq Malik** said that his team was looking at producing communications to show the work that they are currently doing on this agenda. **"We need to show the research community and the public how data can be better - and more quickly - accessed"** he added. Furthermore, he offered an invitation to researchers in the audience to contact him to discuss some of the practical issues they identified throughout the day.

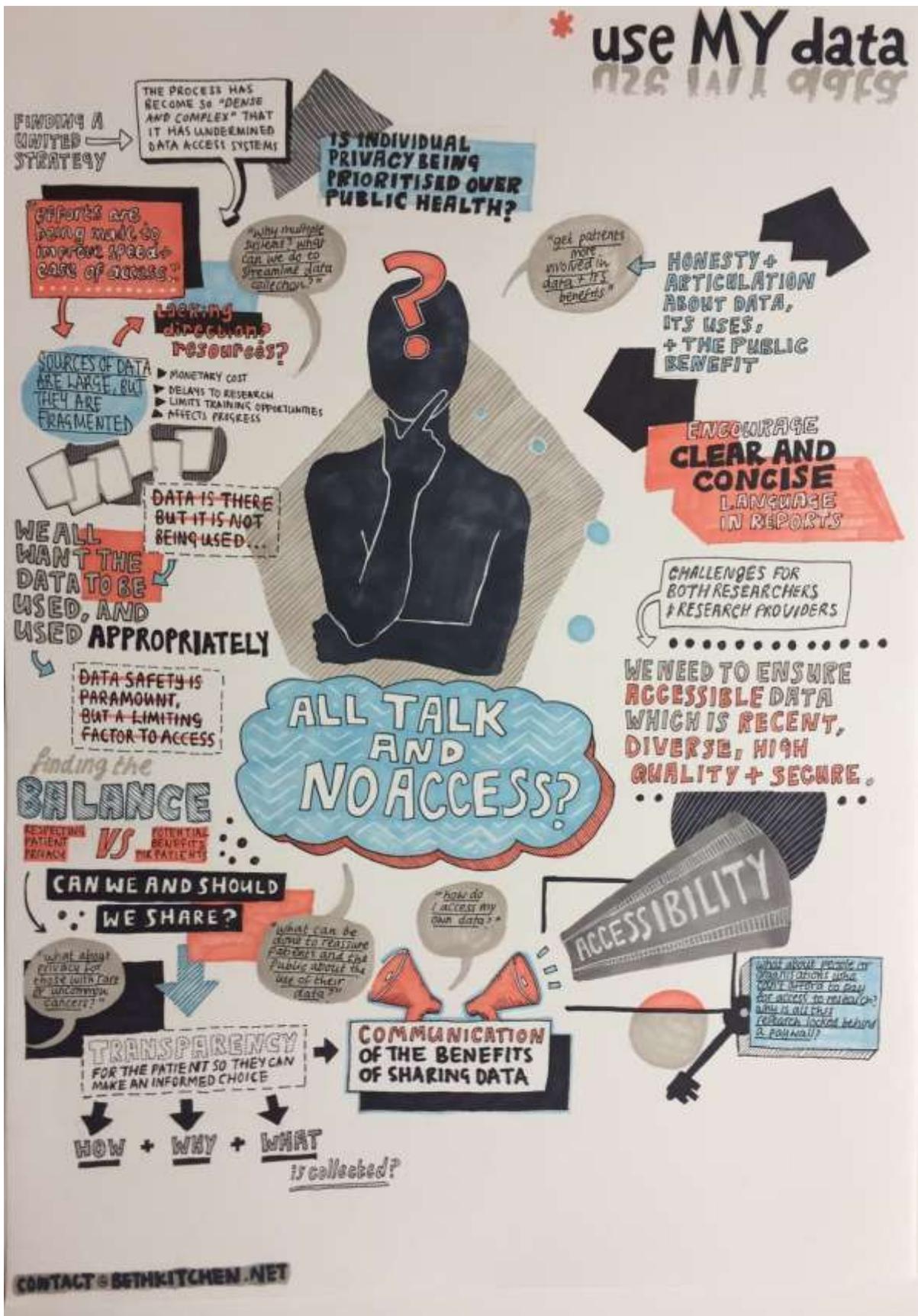
**Janet Messer** said that the Health Research Authority was in the process of making more information available about how data is used for research **"so people can understand it better and trust it more"** and would like to accelerate that, as a result of the workshop. Janet called for more funding for her team.

Wrapping up the day's proceedings, Chair **Mike Birtwistle** reminded attendees that previous **use MY data** workshops had resulted in practical, tangible changes. He gave the example of a campaign that is now getting underway, around the under-use of tissue samples in tissue banks. This has come about due to the issue being raised and examined at a previous **use MY data** workshop. **use MY data** has now been granted some funding to assist the campaign, which will work to ensure that tissue samples given to tissue banks are used.

With thanks given to funders, speakers and delegates the workshop came to a close.

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## About use MY data

use MY data is a movement of patients, carers and relatives

use MY data supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

use MY data endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.

use MY data aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

## Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

## What we do

- ❖ We promote the benefits of sharing and using data to improve patient outcomes with sensible safeguards against misuse.
- ❖ We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.
- ❖ We provide learning resources for patient advocates on patient data issues, including:
  - hosting workshops for patients and the public, focussing on topics related to patient data
  - a library of resources of data security, consent
  - narratives from individuals about how collecting, storing and using data can help patients.
- ❖ We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.

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