

Say what you do,
do what you say
trust and transparency
around patient data

THURSDAY, 05 DECEMBER 2019

The Met Hotel, Leeds

Workshop summary

Overview and key conclusions

At **use MY data's** latest event - held at The Met Hotel in Leeds on Thursday, 05 December - delegates gathered for a workshop entitled **Say what you do, do what you say: trust and transparency around patient data.**

The programme was once again devised by **use MY data** members, who were keen to find out the progress of previous commitments given by the custodians and guardians of patient data. There were around 80 people in attendance from across the UK - comprising patient representatives, researchers, carers, clinical professionals and regulators.

Key conclusions from the workshop included:

- We must encourage further improvements in data access from the data controlling bodies, provide support and input when needed and hold them to account.
- Data access problems are largely due to the way legislation is being interpreted: the problem is not a legal one, but a policy one.
- Consistency and clarity in the terminology used when discussing and referring to patient data is key: anonymised versus anonymous, consent versus opt-out and commercial versus industry.
- We need to highlight the benefits of data being used, particularly when used by commercial partners.
- We need a 'transparency standard' that companies which use patient data must meet.
- There is scope for better coordination, or understanding, of the different patient and public involvement groups who focus on patient data.
- There is no single 'public'. We are all different and have different motivations where sharing our personal information is concerned. Individual choice must be respected.

Session 1 - Commercial access to patient data

The workshop began with a warm welcome from the Chair, **Dr Michael Chapman** - Director of Health Informatics, Health Data Research UK, Cambridge.

As is customary at **use MY data** workshops, **Michael** laid out some ground rules for the day ahead: talks should be as inclusive as possible, there should be no jargon or use of acronyms and most importantly, the day should be an **“open, honest and respectful discussion”** bringing many different views together.

The workshop was held during the pre-election period of Purdah, which meant that some speakers were restricted in what they could present and discuss.

Richard Welpton, Senior Manager at The Health Foundation, gave the opening remarks. He was described as **“one of the real thinkers in the area”** of patient data. Richard is keen to ensure the involvement of patients in data projects.

“I’m a huge fan of involving patients in our work” he told attendees. **“As a data user, most of our work relies on using data - it’s important we [Richard’s team of analysts] are transparent about how we use patient data.”**

He described some examples of the breadth of work the team undertakes, including work on understanding endometriosis and menstrual conditions, as well as projects surrounding mental health amongst teenagers and adults. None of this would be possible without the data. Richard and his team are working hard to challenge and address data access issues.

Legislation is not the problem

Stressing the importance of addressing a myriad of data issues, **Richard** focused on the fact that legislation such as the General Data Protection Regulation (GDPR) should improve the way access to data can be achieved, but that there are problems in the way legislation is being interpreted. Unless this is addressed, the ability to utilise much wider datasets, and do much more for public good, will continue to be a challenge.

“Patient records aren’t analysed just by themselves; we’re keen to understand the social determinants of health. What is it that leads people to seek help? Is it housing conditions, or, for example, the benefits system and how it’s interacting with health services?”

Richard described the huge potential for machine learning to identify new associations in data as the datasets grew, and that sometimes **“we can’t necessarily predict the outcomes of our research, and these techniques Hoover up data.”** He stressed that it is now more important than ever to iron out data access issues, and for companies to be respectful of patients’ data and be transparent about its use.

Trustworthy processes

Next was **Dr Natalie Banner**, the Lead at Understanding Patient Data (UPD) - an initiative hosted at the Wellcome Trust to support better conversations about the uses of health information. UPD champions the responsible use of data, feeds into policy development, creates accessible resources and identifies emerging issues that may affect public confidence in the use of health data.

Natalie gave an overview of UPD's engagement methodologies around patient data, noting that:

- The terminology used when referring to patients' data is key: data 'sharing' means different things to different people.
- Some members of the public may wonder if they can be identified as a result of their data.
- Demographics are a consideration: very little has been done to see if there are any differences between black and minority ethnic (BAME) groups, lesbian, gay, bisexual and transgender groups, different socio-economic groups, rural/urban splits, and as a result, are we missing a trick?
- There are generic ideas of public views, yet **“there is no such thing as a public; we're all very different - and we're very much contingent on our own background and experiences.”**

Natalie then highlighted some of the interim findings in a piece of work that UPD is undertaking in conjunction with NHS England and the Office for Life Sciences. As the work is still in progress and not yet published, Natalie emphasised that her points may be subject to change or refinement.

- What constitutes a fair partnership between the NHS and researchers, charities and industry on uses of NHS patients' data and NHS operational data?
- Is the NHS set up and structured for this? (Efficiency, data quality, fragmentation, governance.)
- Is data treated as an 'asset' and could this skew the incentives of NHS managers and leaders who may see data as benefiting balance sheets rather than patients?
- What about the rest of the NHS? And what about the regions who do not have the capacity to invest in data?

A smarter NHS

Natalie concluded her talk by saying that, despite some of the above concerns and questions, there is quite a lot of optimism about the use of data, and there's an **“opportunity for the UK to be a world leader”**, create a smarter NHS and become better connected, with improved use of resources.

When it comes to the use of patient data, the motivations must primarily be about **“improving patient outcomes and NHS benefit.”** Furthermore, the public should be engaged in decision-making to ensure fairness and transparency of processes.

The use of patient data and commercial partnerships

Juliet Tizzard, Director of Policy at the Health Research Authority, spoke next. **Juliet** focused on the use of patient data in commercial partnerships between the NHS and technology companies - after all, the NHS **“can’t do it alone”**.

When it comes to sharing patient data, public acceptability depends on the ‘why’ and the ‘who’, that is, what is the purpose? And who wants to access and use it?

Juliet highlighted - **“We wanted to look at nuanced grey areas between public and private use and explore in more detail”** before providing details about a piece of research she has been working on with a focus on access to patient data for mixed public and commercial benefit.

The data is from a couple of years ago and **Juliet** acknowledged that **“attitudes might have shifted”**. The research involved 55 people across three workshops made up of South Yorkshire attendees - two of the workshops were with members of the public and the third with patients.

“We asked, is it acceptable for anonymised personal level health data to be given by the NHS to a commercial company, where there is both a commercial and a public benefit?”

Workshop participants were asked this question at the beginning of the workshop and at the end. At the beginning, 50% said it was acceptable, 44% said they did not know if it was acceptable, and 6% said it was not acceptable. The findings also indicated that some groups were less supportive, emphasising the need for conversations within the many ‘publics’.

Different viewpoints

Interestingly, **Juliet** highlighted that those supporting the use of data increased from the start of the day (50%) to the end (74%), highlighting much stronger support for the use of data when they had had a chance to hear from experts and discuss the issues. In contrast, those who viewed data sharing as not acceptable remained largely unchanged, decreasing slightly from 8% at the start of the day to 6% at the end.

Pertinent to today’s workshop, viewpoints from the South Yorkshire workshop included the acceptability of profit (via commercial companies who are using the data to develop products) if it does not undermine the public benefit.

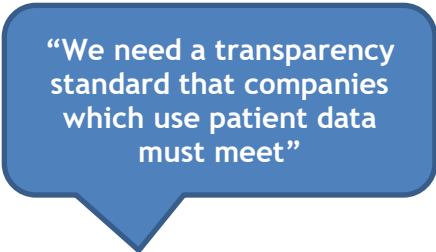
At the end of **Juliet’s** talk, a **use MY data** member, with an interest in palliative care, asked: **“How can the public identify the questions that need to be asked?”**

Juliet responded: **“There has been a development in the view that it is important to involve patients and the public in the questions that are asked - and something we are very focused on is describing what best practice is in research. Patients should be involved in influencing questions and helping design the studies.”**

Some delegates felt that the use of the word ‘commercial’ has negative connotations, and perhaps ‘industry’ would be better.

In relation to a comment from a delegate, **Natalie** highlighted that the assumption that ‘old people’ do not use technology needs to be challenged.

One patient delegate, a **use MY data** member, was keen to emphasise that he has previously given data for research - **“It doesn’t worry me at all - I was told it would be perfectly safe and it would help in patient research.”**



“We need a transparency standard that companies which use patient data must meet”

Demonstrating how data is used

A delegate, from a large national data organisation, offered her view regarding the way companies communicate how they use the public's data - “[When we talk about companies who use our data] what we don't do is do case studies and demonstrate how data is being used. I'd be curious to find out what information people want to see from these studies...wouldn't it be good to bring these studies to life so people can see [the benefits that have come from] them?”

Another delegate, from a different data organisation said the results of research should be better communicated - “Why keep it a secret?”

Juliet referenced [information for patients](#) produced by the Health Research Authority to explain how their data is used in research studies. At the moment this is largely used by researchers to explain this to their participants but could be used more widely.

Following the presentations, the key points from the round-table work across the room included:

- There is a general confusion about the difference between consent versus the ability to opt-out of data being used.
- There is a confusion about the definition of ‘anonymous’ versus ‘anonymised’.
- There should be a standard transparency process, which all companies have a duty to meet.
- What are the qualifying criteria for an organisation to access NHS data - who decides who is allowed access to it?
- Is it wrong to pay for NHS data, which may then benefit the NHS?
- Are we lacking a ‘celebrity champion’ to help people connect/engage with data sharing/use?
- Data should not necessarily be given to commercial companies. If they do receive NHS data, they should be required to share some of the financial benefits with the NHS.
- Could these companies pass the data on?
- In terms of data sharing versus demographics, are there advocates for people who might be underrepresented?
- How do attitudes to data sharing change over time - and what aspects might lead to changing attitudes?
- Can we learn from others in the UK - or the world - to find a way of smoothing out access to data?
- Can we have a continued focus on the availability of data and the struggles to access it?
- Are we looking at the quality and accuracy of data?

In general, delegates were in favour of commercial access to patient data. However, transparency regarding how their data is used has a big part to play in their willingness to share data.

Session 2 - An update on data access developments

Richard Welpton, Senior Data Manager at the Health Foundation, facilitated Session 2, dividing it into two parts.

The first part focussed on data access developments with updates and insight from NHS Digital, Public Health England and the Health Research Authority.

Richard began the session by detailing the commitments the organisations gave at the previous [use MY data](#) workshop [Patient data - balancing access and protection - All talk and no access?](#) held in May 2019. These were:

- NHS Digital
 - Would review what they are doing and what they can do better.
- Public Health England
 - The Office for Data Release at Public Health England is reducing the time it takes from receiving research applications to approving them. The Office for Data Release aimed to reduce the average turnaround time from 50 days to 45 days.
 - Would produce communications, to show what the Office for Data Release is doing to improve data access.
- Health Research Authority
 - Would accelerate the process of making more information available about how data is used for research, so that people can understand it better and trust it more.

Garry Coleman, Associate Director, Data Access, NHS Digital, gave the first update. **Garry** attended the previous workshop and recapped that attendees had said:

- Data should be used for research.
- Data must be used safely, securely and legally.
- The overall process was too complicated and it felt very disjointed.

Since May, NHS Digital has:

- Published standards to help researchers understand what is needed for each part of an application.
- Shared these standards with other data controllers.
- Published precedents to enable faster data access (78% of applications to NHS Digital now use these).
- Established a secure location for researchers to access data, so less data needs to be moved outside of NHS Digital.
- Published details on how data has been used: [Clinical review: The impact of data released through the Data Access Request Service](#).

NHS Digital is also:

- Working in partnership with funders to deliver new services.
- Working with researchers to make survey data more available and enable data to be shared by researchers.
- Delivering a major change programme through the first six months of 2020 to make more data available, faster.
- Working transparently, with appropriate controls and governance.

What else is happening?

Juliet Tizzard, Director of Policy, Health Research Authority, provided the update, reporting that [information for patients](#) has now been published online about how data is used in research studies.

It was not possible for the Office for Data Release to send a representative. However, **Tariq Malik**, Lead for Office for Data Release, Public Health England, supplied a report for the workshop. The report highlighted:

- Public Health England, in partnership with the National Cancer Research Institute (NCRI), has appointed a Data Access Manager to improve the speed of data access. This has led to an improvement in the efficiency and speed of data access.
- The Office for Data Release now runs regular training webinars to help applicants navigate the data access process.
- The Public Health England Data Release Register was updated and published in September 2019 to include releases made from 1 April 2019 - 31 July 2019. For this period all published releases were accompanied by a lay summary. Work will commence in 2020 to further develop the release register into a more user-friendly and accessible tool for the public.
- During the last six-month period, the average elapsed time from the Office for Data Release receiving a complete application to data being sent to the applicant, was 48 working days. This is an improvement to the previous year and the Office for Data Release is committed to reducing this further.

The second part of the session featured **Caroline Cake**, Chief Operating Officer & Deputy Director, Health Data Research UK (HDR-UK). **Caroline** introduced HDR UK and their mission to unite the UK's health data to enable discoveries that improve people's lives - **"We're a national institute for health data science and we work in partnership with patients, NHS, universities and charities to create a world-leading and robust health data infrastructure."**

While the UK has good health data resources, these can be difficult to identify and access. Currently, data research and innovation take place outside of the UK because of the difficulty in working with UK data.

Members of the public support research using health data, where this is transparent and leads to benefits to the NHS.

"We need to be clear and concise on the benefits, risks and how these will be managed, creating a clear strategy for engaging patients and the public."

HDR-UK aims to bring benefits to all - researchers, patients, corporations and businesses - in a bid to allow drugs, devices and procedures to be tested faster.

In support of this, dedicated Health Data Research Hubs have been created to focus on specific areas, including disease-focused hubs, hubs focusing on clinical trials and others on real-world data.

The Hubs will provide a common access point to UK health research data for accredited researchers and innovators, making the data discoverable via a data gateway (a library which describes where different datasets reside, who controls the dataset, and what it contains) before the end of 2020.

The Hubs will involve patients and the public in shaping the research activities and will improve secure and responsible access to data.

Transparency (specifically in relation to data access processes and ongoing developments) was, again, the buzzword of the session.

Session 3 - What about the patient groups?

This session focussed on the views of lay members of patient data groups, who brought their individual perspectives and experience to a panel discussion. The panel comprised:

- **Chris Carrigan**, Patient Involvement Lead, DATA-CAN - The Health Data Research Hub for Cancer & Expert Data Adviser, [use MY data](#)
- **Paul Charlton**, Advisory Group Member, [use MY data](#)
- **Maria Clark**, Lay Member, Independent Group Advising on the Release of Data, NHS Digital
- **John Marsh**, Deputy Chair, Independent Advisory Panel for Data Release, Public Health England & Advisory Group Member, [use MY data](#)

Paul asked: **What has your organisation done to inform the public/improve their understanding on how their data is used?** It should be an obligation as part of the data sharing agreement to inform the public on how their data is used. He also asked about adults with learning disabilities - what happens to their data?

“...we should explain the benefits [of using patient data] in ways people can understand”

John has a background in consumer data and, in his own words - **“I had no interest in health data, until I became health data.”** After becoming ill, **John** became involved in several patient initiatives, including Cancer Research UK and the Bowel Cancer Intelligence UK. He has found the delays in access to patient data frustrating.

Widening inclusivity

Following a question from a delegate, the panel discussed widening inclusivity and ensuring those who are not easily represented, for example the homeless, can become involved with data sharing initiatives.

Chris agreed that it is not about one group, but many - **“Let’s say there are 80 people in here, each of you will know people. If each of us have access to four other groups, it’s our responsibility to communicate with them. It’s about individual responsibilities, social media and using lots of different means to get the message across.”**

“How can we ensure that selected patients are representative of the general population?”

Maria agreed, suggesting people should use their networks to their advantage - and putting their trust in grassroots organisations - **“...have faith in smaller organisations. It might not have the funding, but it doesn’t mean it isn’t doing fantastic work. I work with a few organisations; it’s not in my nature to sit back. The really positive engagement is when the organisation is really involved and will listen to the people. The committee which has the most impact is led by a lay person. In those committees, we have a slot for a lay person. It’s a really good example of how lay people are involved.”**

Delegates commented on the positivity of seeing a panel comprising patient representatives.

“We have to remember that the NHS is free [only] at the point of service.” said **Maria**, **“Sometimes, people don’t understand what patient data is used for. There needs to be more awareness of what it’s used for. It’s a personal decision. As much as I’d like people to say: ‘yes use my data’, it’s up to them.”**

“As much as I’d like people to say: ‘yes use my data’, it’s up to them”

A ladder of participation

John commented: “In most of the patient groups I’ve been involved with, there has been an induction process. Some people don’t feel confident talking in meetings. Maybe we need to find ways, when people get vaguely interested, that we can take them up a ladder of more participation. I don’t want to be too brainwashed that I begin to start behaving like the organisation I’m involved with; I want to think differently. It’s a fine balance. We’ve talked about trying to widen the group. We need to find ways of helping people participate if they want to participate.”

Juliet Tizzard added: “We had a conversation about how, as a researcher, seeking research and data approvals can feel like a bureaucratic process. It got on to a discussion about...how can we get the people applying for approval and those making the decisions, to understand one another better - so we have a process that is as streamlined as it needs to be, but as protective as it needs to be. And what can the public and lay voice do to help us?”

Some of the questions and points raised throughout were:

- Why isn’t Public Health England talking to NHS Digital and improving data access together? There are too many people involved in national data holding - perhaps there should be an element of consolidation.
- There needs to be elected representatives leading this conversation, and a government body. It’s sorely lacking accountability.
- How can we encourage more diverse representation on patient groups?

Paul noted: “Conversations are going on all over the place. What annoys me is when organisations ask their staff to respond to performance indicators. I think it’s nonsense. Be far more outward looking in the way you approach the task.”

“If we are all individuals, then we should be allowed our own individual control of the data”

Inclusivity is key

Chris commented that we should explain the benefits of using patient data in ways people can understand. The best way to do that is to get people to write these explanations or stories for you, in a way they can explain to their friends and family, instead of writing it in a way ‘professionals’ think others can understand it.

Maria felt that people need to be involved on a deeper level - and to be able to better interpret what’s important to them, rather than what an academic might think.

“What does good patient and public participation look like (not just lip service)? And how do you get that?”

Paul’s thoughts reflected this. He said we should “bring equality to the table - through patient experience or applied intelligence and acknowledge the co-production of ideas.”

Chris made the point that the public is much more interested in how data is used when they become, say, a bowel cancer patient themselves.

The general feeling during the session was that underrepresented sectors of the population could benefit from stronger engagement where data sharing and/or awareness is concerned.

Session 4 - Ensuring this workshop makes a difference

So, how do we ensure this **use MY data** workshop makes a difference?

Reviewing the day, the workshop began with a rundown of different attitudes towards the commercial uses of patient data, before moving on to updates from key national bodies. We then opened the floor for discussions about the role of the public/patient representatives and how that is actually working.

The workshop covered a wealth of information and raised a significant number of suggestions, questions and actions from the delegates during the day.

Going forwards, it is key we share what is working, as well as simplifying and consolidating processes and highlighting how organisations are working together to make a positive change in the way patients' data is accessed and used.

In general, delegates were in favour of commercial access to patient data - but the transparency regarding how their data is used had a big part to play in their willingness to share data. There was a strong feeling that patient choice, including opt-outs, must be communicated and respected.

More work is needed to define the 'fair value' between the NHS and commercial partners. One way to move this forward and include the patient voice, could be to design a future workshop at which commercial organisations would be asked to describe how they operate, what they do and open up their views of 'fair value' for discussion. Having some direct examples such as this was seen as a practical, positive way to approach the topic, and would be in line with the positive engagement philosophy of **use MY data**.

Acknowledging the need to further reduce barriers to data access, and to ensure awareness of this, **Garry Coleman** offered to report back on practical action that NHS Digital and Public Health England are jointly taking, to align their approaches.

Wrapping up the day's proceedings, the Chair **Michael** reminded attendees that all **use MY data** workshops are designed by the members, and that feedback from the day would be used to inform future workshops.

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

With grateful thanks to the writer of our summary

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With grateful thanks to **Understanding Patient Data**
who provided the funding for the summary

Visual minutes



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With grateful thanks to the creator of our visual minutes

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With grateful thanks to **Understanding Patient Data**
who provided the funding for the visual minutes

Appendix - Comments, questions, suggestions and notes from delegates

The following is a record of points raised by delegates during the workshop. These are grouped into themed areas for clarity.

There was strength of feeling that we should work actively with commercial companies

- Why are there no commercial companies on the panel today?
- Why no industry representatives here? How are we going to involve them?
- Have commercial entities fund the next meeting/workshop.
- Trust varies depending on the company. Work with companies to improve or simply avoid worst.
- Have a standard that companies need to meet transparency (define boundaries, give guidance, monitor compliance).

Do we need clearer understanding of involvement activities, including representation?

- Do we have too many [PPIE] panels?
- Publish sampling/recruitment process for these groups.
- How do patients get involved in the DATA-CAN hub?
- Each HDR-UK Hub should explain to use MY data how patient/public can get involved in each of the Hubs.
- Do we differentiate adequately between public involvement and patient involvement (what do we expect from each category?)
- To what extent do patients/public get involved in the design of the process?
- Fine to involve patients in consultation but how do you keep individuals involved in how their data is accessed?
- How can we ensure that selected patients are representative of the general population?
- What does good patient and public participation look like (not just lip service) and how do you get that?
- How can you approach and work with organisations to ensure we are engaging with more groups so that research is more representative?
- Get seldom heard groups involved.
- How do you select your public advisory members and how often do they rotate?
- There's lots of PPIE going on but do we need a more joined up approach and better dissemination of findings?

The continuing need for clear communications, wording and transparency

- Anonymised data - is it really anonymous?
- What is pseudonymised - what does this mean?
- Are we always using completely anonymised data or pseudonymised?
- Consent, choice, opt-out. What's the difference?
- Can we please use simple, plain, understandable English?
- Clear wording - "life sciences", "citizens juries", "university spin-out"
- Why are we talking about consent? HRA guidance says research shouldn't rely on consent.
- How can patient data access be promoted for public benefit?
- What information do people want to see from commercial studies (case studies)? We need to share this.
- Publicity about data use could be in a pictorial form as well as text (reading age in UK about 9 years).
- Better information on how commercial companies use data for the benefit of patients.
- Do we celebrate enough?
- How do you get the public to engage with health data?
- Better education on data use.
- Patients think their data is shared across the NHS.
- Is it really so difficult to let people access their own data?
- Why no thought in providing patient portals in process of using my data leading to commercial data? e.g. patients may be happy for research but not for commercial use.
- Concerns from patients - will data be compromised?

Some points around commercial access to patient data

- What is the qualifying criteria for accessing NHS patient data? Who sets this?
- For the Office for Data Release: why can't they take responsibility for all data and 'trade' it? Why can't they control it, and make money from the data?
- There are too many [data controller] groups trying to "muddy the water".
- Concerns about how the patient data will be used especially insurance companies.
- Why can't there be a requirement for all commercial research involving public (university) research?
- Commercial companies must be subject to a contract if they fail to meet purpose.
- Fear that commercial companies will pass data on further without consent.
- Is the problem trust? Is the solution Data Trusts?

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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