* use MY data

The patient voice in the expanding data world

Thursday, 22 November 2018
10:00 to 16:00

John Charles Suite, Queens Hotel
City Square, Leeds LS1 1PJ

Summary of the day

> ***"The only source of data is the patient''***
>
> **Patient Advocate & workshop delegate**

Contents

Chair’s welcome & overview of the day

Dr Helen Bulbeck
Patient Advocate, use MY data & Director, brainstrust

The Chair, Dr Helen Bulbeck, a patient advocate, member of the use MY data Advisory Group and Director of brainstrust, opened the workshop. Helen welcomed attendees, thanking speakers and particularly patient/carer delegates for giving their time.

Helen gave an overview of the day and acknowledged the funders who had enabled today’s event to take place: the Leeds Institute for Data Analytics, NHS Digital and Health Data Research UK.

She noted that the aim of the day was to bring the patient/carer voice to a range of conversations about the use of data, together with partners including NHS England and NHS Digital. Whilst conversations about data could be complex, there is only fact around data that holds true – that the world death rate holds at 100%.

Session 1 Can Data Volunteering, Data Donation and the National Data Opt-out empower citizens to optimise data use? We have organ donation, but not data. Why?

Emma Summers
Programme Delivery Lead – NHS Digital

As one part of her work, Emma is looking at the relative merits of data donation. In putting this session together, she liaised with Mick Mullane of the National Institute for Health Research and the session included parts led by both of them.

Emma led on how we have organ donation, but not data donation. NHS Digital is now exploring options, with partner organisations, to determine whether data donation could be set up and how best to administer. Early thoughts suggest that a solution could provide a mechanism for citizens in England to supply data to the NHS, charity sector and/or researchers, to support health improvement and disease prevention for the benefit of the wider health and care sector.

Emma highlighted that the National Data Opt-Out, which was launched on 25 May 2018, gives patients in England the right to opt out of sharing data for planning and research with the default position to allow data to be used for planning and research.

Data volunteering is a related area, which was initiated by the Department of Health and Social Care (DHSC) for Lord O'Shaughnessy, with an emphasis on individuals volunteering to be part of research, trials and wider data analysis to support the Clinical Trials Gateway service.

These related concepts (opt-out, donation and volunteering) will be considered together, aligning any functionality or communications, and using some form of verification service or common solution to simplify how each is understood and used by citizens.

There was a comment that data should be donated while people are alive, so that the citizen can change their mind. There might also be a mechanism for data to be donated at death (in a similar way to organ donation).

It was noted that Wales and Scotland already have mechanisms for registering an interest in being approached about participating in research. Both countries are seeing more people registering interest to be involved in trials, though the absolute numbers are still quite small.

NHS Digital is considering a central repository and register of volunteers with an online portal which could be overseen by an independent group, such as the Independent Group Advising on the Release of Data (IGARD). This portal may in the future be able to gather new self-recoded information from patients. Options for citizens to volunteer via the NHS App were reported as being explored.

Emma accepted that this was a complex area, with similar schemes already underway or under discussion, and stressed the importance of collaboration to develop the best solution.

NHS Digital's thinking is at an early stage, and the reason for coming to the workshop was to start the engagement work as early as possible with use MY data. The audience were invited to discuss the relative benefits of data donation (including a mechanism to donate data) and data volunteering (such as being on a clinical trial consent register). They were asked what additional opportunities could be realised and what are the challenges or concerns?

Emma took questions from the audience as part of the feedback.

<u>Questions and discussion</u>

Q This is an interesting concept, but what market testing has been done with the general public? People can find data boring – Is there actually an appetite in the general public?

A Emma – Agreed this is a big challenge, but that there was certainly an appetite within health planning & research organisations. She recognised that more work needs to be done with the general public.

The audience felt that a lot of patient groups feel this already happens. It was commented that data is now becoming exciting to a wider audience. GDPR has helped raise the profile and we're all becoming aware of the trail of data that we leave.

It was noted that the team from Newcastle University had already helped lead focus groups with the public – reports online, a webinar, short videos – and these can be referenced

Members of public have called the National Data Opt-out help line to ask to opt in, although the numbers of opt outs are increasing slowly.

Summary of discussion following this question: There is an appetite within the health sector for this. But as yet, it is unknown if there is a public appetite. Many people think this type of data sharing is already taking place. The news stories about GDPR have raised the profile of 'data' so the concept of data donation may well be timely.

It was noted that the original name/concept of use MY data was 'donate MY data'. After a short time, members asked for this to be changed, as their data had already been donated, and they wanted the focus to be on usage (hence use MY data). Perhaps the discussion has come full circle?
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Q What kind of data are we talking about (for inclusion in the donation) and is it any different to the existing NHS Digital datasets?

A Emma – discussions are about connecting things together, rather than inventing new datasets.

Q An audience member said that he has spoken to 100 people in the public about sharing and using patient data and had only had one negative response. His view was – if data is safe and anonymised then everyone will want to give it.

A Emma noted that she had heard that viewpoint and noted that anonymous record level data is already available for research and planning purposes. The concept of allowing citizens to donate identifiable data about themselves was discussed as an option for consideration e.g. where citizens are participating in trials.

Q Would this extend beyond healthcare data?

A Summary of discussion following this question: The option to donate non-healthcare data was briefly debated. Data from life style apps was suggested as suitable for donation by citizens.

Other comments (**C**) and questions (**Q**) were raised:

Q How many people have the time/interest in data donation?

Q Would the data donation mechanism give people the option to see what they are giving?

Q How would this relate to social care?

Q How do you make sure you collect the correct data?

C Some patients are scared of sharing data. Some patients do not have a clue if they opted in or out. Patients not particularly interested until they are quite ill and need to do a trial.

Q A lot of patients don't actually know what data is held about them. Uptake of on-line access to GP clinical records is relatively low. For the data donation, can you actually see what you're giving?

Q Could this have a big impact in terms of data quality – with data from life style apps for instance?

Q What does it mean for Section 251?

C People want to know where the data is going and what it is going to be used for. It is the dissemination – "how helpful can I be to the next generation, to people coming forward with a condition like mine"? People need to know where it is going and that it's anonymised.

Q All the conversations have been about sharing – but with technology shouldn't it be accessing, rather than sharing?

Due to time constraints, Emma noted all these questions and comments and promised to feed these inputs into the discovery project.

Following on from Emma, Mick Mullane talked about the potential for having a meaningful conversation about your data through your mobile and for recording views on consent for the uses of your data. He explained that the National Institute for Health Research (NIHR) built a demonstration app approximately three to four years ago, to look at a potential 'consent' process using a smartphone.

Mick commented that consent is no longer just about 'taking' things from you, but is about giving things back too. A cycle could perhaps be: collect data – donate data – receive some benefit back.

Mick highlighted that there is great interest in lifestyle data, which could be recorded and provided by patients and the public themselves through an app. Potentially, and if the donor agreed, that data could then be connected back to the person's healthcare record.

Mick outlined how an ethical approval button could allow citizens to withdraw from a clinical trial and to withdraw data submitted through that app.

Mick showed a brief presentation on the National Institute for Health Research's '10,000 footsteps' app. This was created as a proof of concept and demonstrated that lifestyle data can be gathered for research.

Q What is the due diligence around using apps based on Android technology (in terms of its security)?

A Global Data Standards are being established that are supported by leading technology companies in mobile, fitness, lifestyle and health.

Where data is linked it is good practice to show where it is travelling to.

Also, if we know where data has been used in a study, when we find out the results of the study, we can let the individual know, so that they can see the benefits of the study to others**.**

Q Regarding engagement with GPs – following the high number of Care.data opt outs, how well are you engaging GPs to ensure equity?

A Mick responded that they were engaging with GPs but were also looking at how not to engage GPs at all, by providing a patient-held solution that could circumvent the health professional and give the patient the ability to opt in to research directly.

A delegate, who is an RCGP data champion, commented that this highlighted a really important point about the role of the GP and the role of the individual.

Session 2

Session 2
The Local Health and Care Record Exemplars (LHCRE) programme – the Joined up Yorkshire and Humber engagement

Rebecca Nichells
Communications Lead, Yorkshire & Humber Local Health and Care Record

Rebecca Nichells, Communications Lead for Yorkshire & Humber Local Health and Care Record, introduced the session, saying that she wished to present a whistle-stop tour of a Local Health and Care Record Exemplar (LHCRE).

Yorkshire and Humber is one of five ‘exemplars’ across parts pf England. The Yorkshire and Humber LHCRE covers a population of just over 5 million and intends to use new technologies to build on existing local shared records in the Yorkshire and Humber area. The LHCRE programme will only deliver if it has good leadership – from health and care professionals and from citizens. It is local health and care, designed locally and delivered locally.

The LHCRE concept is about making sure that local health and care services (not just the NHS) are involved. Yorkshire and Humber are trying to get a single electronic patient record, and this involves 74 organisations and 725 GP practices. In the initial stages this would concentrate on cancer pathways and emergency care pathways, as these were seen to be amongst the most developed and best understood clinical pathways. Citizen involvement will be crucial to the success of the LHCRE.

Rebecca introduced Fiona Fylan from Brainbox Research, who in turn introduced the Joined up Yorkshire and Humber research project.

Fiona is a health psychologist, interested in why people make the choices they do about their health. Her role is to engage with individuals who are not informed/interested in health and wellbeing data, aiming to initiate thinking about data and could it/should it be shared?

Fiona described the many people that are taking point in the work in Yorkshire and Humber. Their focus is on ’people’ and they have worked with various focus groups, speaking in public places and seeking feedback on what people see as good/bad for them.

Joined Up Yorkshire and Humber is a deliberative research project, using case studies to generate interest and enthusiasm. Fiona then challenged delegates with a series of case studies on potential data sharing. The case studies were designed to stimulate thinking about what should happen to health and care data, and why. The audience was asked to consider the challenges and the dangers.

First case study

This was about Sheila, 83 years of age and living alone. She was in good health, but she was unsteady and at risk of falling. Sheila was visited by a charity worker, who then arranged to have grab-rails fitted. Delegates were asked to record their thoughts on this scenario and the benefits and the dangers of sharing patient data, including any rules which they would like to be applied to this situation,

Points from the delegate feedback were:

“Concerned about the approach – there needed to be an introduction via text/letter to the person, from

somebody she knows/trusts. Not cold calling."

"Concerned that Sheila was surprised by this approach – where was the informed consent process? Loss of agency."

Overall the audience felt that the end result was positive, though friends/family network could have been consulted.

Second case study
This featured Mohammed, 42 years of age and with a recent diabetes diagnosis. A local support group for patients with diabetes had been set up, as many people were being diagnosed locally. This followed the NHS using information from the healthcare records of everyone in a particular region, to find out where new healthcare services were needed. What are the dangers, benefits, rules of using patient data in this way?

Points from the delegate feedback were:

"How has the data been arrived at in the first instance?"

"I couldn't see the LHCRE connection – can't you use the aggregate data?"

"Who contacted Mohammed to tell him about the service in the first place? Is it via a nurse, or Capita? The devil is in the detail."

"There could be people in the area who may not access the service – some may win, others lose."

Third case study
This featured a patient called Saffi. NHS researchers looked at everyone's medical records to find out what makes it more likely that someone will have cancer. They searched the records to find people who are more at risk and shared this with local health clinics. Saffi's records showed she is at higher risk and she was contacted. She was surprised to get a letter from the clinic. At the appointment they explained why she's more likely to get cancer, gave lifestyle advice and offered a screening test.

Points from the delegate feedback were:

"How does the original information get there?"

"How did the predictive data algorithms get developed, and who tested them?"

"What's the difference between the NHS screening programme and the study cohort group?"

"Where is the communication about how the original data was acquired?"

"Some things are implied but not clear."

"What is the cancer that we're screening for? What is the false positive rate, and are you actually increasing anxiety, rather than helping?"

The Chair then brought the session to a close, thanking all speakers. Helen thanked NHS Digital for sharing early thoughts and bringing them to delegates for review and feedback

Session 3 **Auditing your own health record – how, what, why?**
What is proposed, what are the plans, and how do you get involved?

Dr Will Turner
User Researcher, Experience Design, Digital Delivery Centre, NHS Digital

Helen introduced the session chair, Will Turner, a user researcher in NHS Digital's Digital Delivery Centre.

Will gave a practical illustration of his programme of work, all of the work has arisen from the recommendations in the National Data Guardian's report of 2016, and the subsequent Government response.

- NHS Digital is mandated to create a digital system by December 2018, for individuals to check who has accessed their Summary Care Record (SCR).

- There is a requirement by March 2020, to create an online service for individuals to see how their personal confidential data has been used beyond direct care. This has to comply with the Digital Service Standard.

Will explained that the methodology towards developing a service included several steps to look at user needs: discovery – alpha – beta – live. Will is conducting user-needs work very widely.

There is the opportunity to participate in the very first trial of the SCR audit service and Will asked delegates to contact him, if they would like to part of this early stage work.

Dr Joel Minion, Policy, Ethics and Life Sciences (PEALS), at Newcastle University, then took over the session. The main interest of Joel's team is the secondary use of healthcare data as studied by their research team called D2K – Data to Knowledge. The team began by focussing on health data, biobanks and longitudinal studies across Europe. All of these areas now have an expanded remit, covering public and patient engagement. The team has been increasingly working on the co-development of studies, with the public. Joel was taking part in the workshop under the auspices of Connected Health Cities (CHC) and the Great North Care Record. He pointed out that findings of this work should be able to extend from regional to national.

Joel explained that he had established a link with Will's team quite recently and the work nicely fits with the workshop agenda. Over the last five years Joel's team has been developing a tool called ECOUTER (French for 'to listen'). The tool aims to overcome geographical barriers, to bring people together around a central question and construct a mind map that draws on a wide range of sources. Joel has been granted research ethics approval to do this work from Newcastle University. In 2014, the team did a similar ECOUTER on Care.data.

Delegates were invited to participate in Joel's research and to answer questions. Joel's research team will collate responses into a conceptual framework and will then check back with use MY data to gauge how the developed framework captures their views. Afterwards, the results can form the basis of recommendations for research, governance, practice and/or policy.

Delegates gave some feedback during the research work:

- Collecting data and making this process transparent is essential. Collection also implies the data will all be in one place and, if this is the case, this should also be made clear. It would be easier to give patients a 'complete view' of their data, if it was in one place. It is the accessibility of the data that is important, as giving access in this way will also make sure the data collection and usage are both as transparent as possible.

- Several members felt that it was important to focus on improving access to data, which is still seen by many as an issue. It should also be possible for patients to see where their data has been used.

Will pointed out that we need to take care with any wording (collect, usage, access, sharing). This is just the first step and the discovery part of their work.

- One delegate felt that basic data will need to stay with the GP and local hospital. To protect the data, it all needs to go, suitably anonymised, to a central location. He felt that this needs one solid control – not six places around the country. He noted that the central cancer registry has his details and have done so without hacking or security problems. But he also pointed out that we need to analyse everything, to create cures and stop people getting diseases. This requires all data to be in the same place, not just his cancer data.

- Another delegate felt that we need to educate professionals who are actually holding and creating these databases. Giving patients access and transparency is vital, but there is a huge job to be done around educating the workforce too.

- We need to look at a number of different dimensions, including security, access, single version of the truth. Some of these are considerations which are the domain of an IT data architect.

- A delegate asked why is it still not possible to use the same system in the whole country? Though on the positive side, she had learned that in her local area in London, hospitals are no longer taking fax/letter referrals and have moved to a shared referral system.

Bringing the session to a close Will thanked delegates for their work during the session and noted his intention to feed delegate responses into his work.

Session 4 **General Data Protection Regulation, Common Law, Consent – where are researchers struggling and how could the patient voice help?**

Professor Adam Glaser
Leeds Institute of Cancer & Pathology
Research Lead, Leeds Children's Hospital

Adam is a clinician, a researcher and a carer. He explained that he wanted the audience's help.

His clinical background is as a paediatrician and paediatric oncologist. He has also worked with national cancer policy teams on defining and developing national policy on adults living with and beyond cancer. When working on developing national policy, Adam found that there was no robust evidence base. He subsequently bid for money to set up a patient reported outcome programme and was working as part of a £2m grant from the Department of Health. This work was lost as a result of the 2012 health service reforms. Thankfully, some of the work had been reclaimed via other routes, principally academic research.

As members of the public we want our data to be used and we believe our data is being used. However, there are some blocks to this. Cancer data is being collected and used selectively, but not as well as it could be. It is an amazing resource, but tweaks are needed if we are to make better progress.

Adam outlined the different legal and policy frameworks within which academic research now operates.

The General Data Protection Regulation (GDPR) sets the minimum standards for data processing in the EU. It gives rights and controls back to individuals. Adam has spent some time searching for a clear interpretation of GDPR, it is difficult to understand and, perhaps, more tailored to interactions with commercial companies.

The benefits of GDPR are focused around the protection of personal data. It is important to take confidentiality seriously, despite frustrations around blocks to using data.

GDPR has to go hand in hand with the new Data Protection Act (DPA) 2018. This is meant to bring GDPR into law and to make our data protection laws fit for purpose in the digital age. It will also support us post-Brexit.

The Common Law Duty of Confidentiality makes it clear that we owe a duty of confidence to our patients in the way that data is used. There is a strong focus on what the "reasonable expectations" around data usage are, and in particular what information has been made available (in a fair and transparent way) on which patients can actually make an informed choice.

However, all this continues to cause problems for researchers.

Notably, researchers must deal with multiple statutory bodies – numerous groups who may all interpret the law in different ways. There is a tendency to be risk adverse and not to give the data to researchers.

As a researcher (and also reflecting the views of colleagues in other areas too), Adam receives very varying, inconsistent interpretations of GDPR and the Common Law.

In terms of bodies and groups involved in adjudicating or advising about data access, there are:

- Health Research Authority (HRA) and its Confidential Advisory Group (CAG)

- NHS Digital (accepted as a safe haven) and its Independent Group Advising on the Release of Data (IGARD)

- Public Health England and its Office for Data Release (ODR).

Adam gave the example of a single research project he was involved with, which led to dealing with a Research Ethics Committee, the Confidentiality Advisory Group at the Health Research Authority, the Independent Group Advising on the Release of Data at NHS Digital and the Office for Data Release at Public Health England. The impact of Care.data has instilled caution about sharing data.

In practice the system makes it very difficult for researchers to access data. There seems to be significant duplication of checks to ensure researchers comply with registration. This often results in extremely complicated consent forms. Researchers are increasingly forced to include prescriptive statements which result in complex, lengthy patient information sheets; these are not always in the best interests of the patient. For young people there are simplified patient information sheets – these are, in practice, frequently the best way to find out what a study is about in an easily 'accessible' format.

In making sure we are protected in the way we use and share data, we have created a problem for ourselves. The pendulum has swung so far across, so that common sense has been lost and we need to find a way to change this.

Our valuable legislation, with its essential principles, is actually having unintended, unwanted consequences, restricting progress and valuable research that the public are keen happens. There is a waste of the public purse with public bodies policing the same thing. This is really about current policy, not the law. It increases costs and delays/hinders research.

What can the patient voice do to help? Adam asked the audience for their thoughts and feedback:

- "Absolutely right about the privacy notices, which I feel are not GDPR compliant. They are not concise, transparent, intelligible, and do not use plain language. We need to go on the offensive about this."
- "I have experienced many of the frustrations – I am now employed by a research organisation to manage these things on behalf of analysts and did the same at my previous role. Is now so complicated that data managers are employed to navigate analysts through these processes. Within GDPR there are a lot of clauses that enable access to data."
- "I was involved in an application which was challenged about its PPI involvement. There had actually been significant involvement but then afterwards a data and ethics team added text which skewed the application."
- "As an involved patient I review a lot of patient information sheets and I am sick of redoing them. I have not yet seen a seminal piece of work that explains what GPDR is. It's the modern culture of being too risk averse. This can also be seen in academic writing too. We are looking for remedies to a problem that shouldn't exist. "
- "GDPR requires concision, clarity and transparency so it should be on the researcher's side."
- "Involving patients and the public in these processes makes a big difference. For example, involving them in writing privacy notices."
- "Because of the time-consuming processes, a PhD student could spend most of their study time awaiting data."
- "Obtaining access to data is a multi-disciplinary team effort."
- "There are clearly several bodies involved in the sign-off for a research application. Could we ask them all to come to a workshop, at the same time, to explain their positions collectively?"

- “Could some of this be the fear about patients suing the NHS. Our health research system could be top of the world if people worked together.”

- “With the testing of the National data Opt-out (NDOO) we engaged 2,500 people over eighteen months to ask one question, with a yes or no answer. It takes time and resources to simplify things.”

- “I do not like the words ‘review’ and ‘feedback’. We should be talking about co-production.”

- “If you can point us in the right direction, we (patients) can bombard the powers that be to overhaul the system, so you (researchers) can get on and do the work that matters. To get bogged down in the paper jungle that benefits nobody, is actually crazy.”

- “If organisations are responsible for collecting and holding large sets of data they are in a very difficult position. For instance, NHS Digital does not have direct contact with patients, so will inevitably feel they are in a risky and exposed position. They need the support of groups like use MY data to work on co-production. We need to help those organisations who are in the difficult position of ‘damned if you do, damned if you don’t’. And then we need to be ready to back them.”

Emma Summer from NHS Digital highlighted that they were working on piece of work to join data access between NHS Digital and Public Health England and was happy to take views back.

Tariq Malik from the Office for Data Release (ODR), Public Health England, said that he would be happy to come to a future meeting and be part of a collective conversation and discussion. The ODR is working with the Medical Research Council, Clinical Practice Research Datalink, NHS Digital and other colleagues to try and get more transparency around this agenda.

Adam emphasised that he is suggesting we do not target individuals but instead we need to support the organisations holding and releasing data to work together and trust each other’s judgement and interpretations of the legislation. They are all doing a good job and they all know each other, so we need to support them and empower the infrastructure to work together.

In thanking the audience for their thoughts, Adam summarised by saying there were two parts of the solution:

1. Stop duplication of activities by public organisations (Health Research Authority, NHS Digital, Public Health England) in providing approvals for data sharing

2. Have clear guidance to support consistent and reproducible recommendations.

Helen brought the session to a close, nothing that she reviews many patient information sheets and so much of the information is the same. Perhaps there is a need to have a generic element, so that people can sign once, and the clinical trial information can be in a special section.

Session 5 **Take-aways and next steps – how do we use what we've learned today to make a difference?**

Dr Helen Bulbeck
Patient Advocate, use MY data
Director, brainstrust

Helen started the final session by stating that we need to stop the silo of 'them and us' with regard to patients and professionals. As patients/care givers and professionals we are all both, or we will be both at some point.

Helen posed the following questions:

1. For health professionals: do you feel differently thinking about this as a professional, compared to when you are a patient or carer? If so, why is it different? How do you see the benefits, dangers and rules?

2. For the public: why might you be keener than others to share your data? What has made this difference? And how do you see the benefits, dangers and rules?

Everyone was given two tasks to complete:

1. What is your take-out for today – what are you going to communicate to others?

2. What is your 'data pledge' – what do you intend to go away and do?

Helen also asked delegates to take away some of the data citation cards and stickers, to encourage others and particularly researchers, to use the citation.

Helen posed a final question to the audience**: What should the focus for use MY data be – where should we be going, what should use MY data do next?**

After a short discussion period member of the audience fed back some thoughts:

- Establishing a patient data charter – unless one exists already – following along the lines of the work Understanding Patient Data has done. Whom would we invite?

- Continue to highlight examples of how our data today, helps future generations, not the present one.

- James Lind Alliance and research priorities – use MY data could help prioritise what needs to be researched from a patient perspective. Could we do something around data?

- There are lots of groups similar to use My data, all discussing/wanting the same thing. There needs to be a central group of groups, so that we improve communication and avoid duplication.

- Education is key for the public to make sure their health is good, and that data is used – this needs to be done at a school level

- People need to take responsibility for their health and sharing their data can be part of that.

- Many people don't want to know if they are fit/well. We need to be better, look after ourselves – be co-pilots with the NHS.

Helen thanked all the delegates for being so engaged and responsive. She reminded everyone that "the only source of data is the patient".

Closing remarks

Chris Carrigan
Expert Data Adviser, use MY data

Chris Carrigan, Expert Data Adviser to use MY data, concluded the day.

He reflected that communication is key and that failures of past data initiatives relate largely to poor communication. We can all have a role in improving communications, collectively and individually - all voices are important. The use of plain language and clarity is essential if we are to engage a wider patient and public audience in an accessible way.

Chris encouraged all of the audience to use the data citation cards and stickers – to put them on posters where you do not see an acknowledgement of the use of patient data, or to spread the use of the citation amongst the different communities represented at the workshop.

He felt there is a growing view that there may be a need for a shift in the societal balance for privacy and usage. While privacy and usage need not be mutually exclusive, and we should work to that point, Chris felt that that there was perhaps too much emphasis on privacy. The work to highlight and articulate the benefits of data usage is important, as is the need to understand the potential harm of *not* using data.

use MY data is a movement of people. It is important to think about what we can do collectively, and about what we need to do individually too. Chris prompted all audience members to complete and return their ‘data pledge’ cards, which would be publicised on the use MY data website.

Chris thanked the venue staff and the AV team. He thanked the speakers for their openness and honesty. He also thanked Claire and Emily for their help during the day, the use MY data Advisory Group members for their advice on the agenda content, Helen for chairing and Alison for organising the day. Finally, Chris again thanked all the delegates for their time and efforts.

Acknowledgements and thank yous

For their contributions to the workshop, use MY data gratefully acknowledges and thanks:

- Our workshop chair and speakers, for so generously giving their time
- Our delegates for their participation and time
- Paul Affleck, Emily Boldison and Claire Eckert for their assistance on the day
- The funders who enabled the workshop to take place:
  - Health Data Research UK
  - Leeds Institute for Data Analytics
  - NHS Digital

Appendix 1 Organisations to whom delegates will feed back

brainstrust

Connected Health Cities North East and North Cumbria

Greater Manchester Cancer

INVOLVE

Leeds Academic Health Partnership

Local health clinic parish nurse project

NHS 24 Public Partnership Forum

NHS Digital

North Lanarkshire Disability Forum Carers Together

Open Health

PPG

PPI groups especially those at the Department of Public Health – Primary Care

Research projects I am involved with

Speak Easy Public Partnership Forum (PPF)

The Brain Tumour Charity

Understanding Patient Data

West Yorkshire Cancer Patients Forum & Cancer Patients Alliance

Appendix 2 Data Pledges made by attendees

Recognising that we all have a part to play, delegates were asked to write a data pledge and all of the pledges are listed here.

My data pledge is……

- to feed back the information I have learnt today to my team so that we can make better the way we interact with patients and how we explain our usage of their data to them.
- to spread the word. SHARE – with people and groups I have contact with.
- to talk with [name] and [name of researcher] about improving their patient information sheet to make it more understandable.
- to talk to my grandchildren about the importance of sharing data for health.
- to keep learning more about data and sharing with friends and other groups.
- to share information from today with my focus and support groups.
- to, as always, promote the use of data whenever and wherever, using the information learned from use MY data sessions – all excellent.
- to carry on promoting patient and carer influence on good healthcare and involvement.
- to retain focus on clearly and simply communicating what happens to patient data in an ever-moving landscape.
- to use data responsibly and support safe but rational policing of the legislation.
- to write to my MP about these issues!
- to involve patients in how we acquire their data for research.
- to make contact with several participants after today, to expand the focus of my research.
- to improve access to data for research and planning purposes where patient/citizen consent is given.
- to do more to unblock the blockages!
- to work towards a national sign-up for sharing (my) data for research.
- to keep learning and to promote the use of data where and when I can. I am working on a project at work which will enable the use of health data for research.
- to raise data issues wherever possible. Continue to insist on plain English, brevity and providing useful info.
- to use data in the best interests of patients.
- to tell everyone who is prepared to listen all the benefits in data sharing, because I believe in it.

- to encourage other people not to opt-out of sharing their NHS data.
- to keep talking and listening to others with similar goals. AND keep publicising our past and ongoing public engagement work!
- to work to help connect researchers (SMEs) with the right datasets to enable their research through the appropriate data controllers.
- to make online health websites about data easy to use, so the public comprehend and make informed choices.
- to keep the information I present robust, yet simple and easy to understand.
- to continue to stay involved in data being used in the right place, by the right people, for the right purpose.
- to shout out about equal use of data rather than only making it (data) work for a select group of people.
- to request my Summary Care Record.
- to discuss with friends and colleagues the importance of understanding ‘their’ data and why sharing is important.

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