

## EVENT REPORT

# Health and Care Data: Improving Lives Through Research December 2018

## Introduction

On 3 December 2018, over 150 colleagues from the NHS and academia came together with patients to attend a partnership event organised by Health Data Research UK, NHS Digital and the NIHR at the Queen's Hotel in Leeds. The aim was to celebrate how health and care data has been used for research that has changed lives and to create connections between colleagues.

Attendees included researchers, trainees, clinicians and other professionals with an interest in/or a role in health data and research. We were also joined by patients who contributed to the discussions and panel sessions.

Hosted by Louise Wood, the meeting was a mix of talks, expert panels, workshops and a fun balloon debate. The slides presented at the event can be downloaded from our [Dropbox](#) folder.

One of our patient panel members, Derek Stewart, has also provided a blog about the event here: <http://derek-online.blogspot.com/>

## Speaker highlights

### **Patient panel: Health Data Research Changes Lives**

The event started with a panel chaired by Simon Denegri and included Molly Watt, Derek Stewart and Richard Stephens as guest speakers. The panel discussed what was most important to them regarding health data research. Much of the discussion centred around the idea of remembering that there are people at the end of the data and that some of those feel a desire to be actively involved with the use of their data.

Molly Watt mentioned that initial awareness is important and reminded us not to wait until someone's diagnosis has reached critical point before engaging in a discussion about their data and what it can do. Richard Stephens told us that we need to be more specific when we describe things such as 'most people with your condition' or 'many people who have gone through what you have gone through.'. Richard then went on to suggest the possibility of patients instructing doctors what to do with their data rather than simply giving consent.

Simon Denegri posed the question of how we create the right environment for data. The consensus was around making the use of data completely transparent. Derek Stewart encourages those in the audience to

continue to publish journals and articles about the constructive use of data and spread the word. Similarly, Richard asks hospitals to publish and celebrate the people who do choose to share their data and the good it is doing. He then goes on to mention that there is not enough input on panels from the patients whose data we are using and not enough talk of what we are doing to protect that data.

Molly also highlighted the need to be clear with communications with the public and patients and make information about how data is used accessible. There are many different tools that can be used, including online information and videos that we should make better use of.

## **Health Data Research UK – Options and Opportunities**

Andrew Morris set out global trends and the opportunities for successful health data research at scale across the UK. He highlighted the triple aim for Health Data Research UK – science, training and data infrastructure – with co-production with patients and the public and a culture of team science at the heart of our vision.

## **Innovation for the Future**

NHS England's Sam Roberts talked about the evidence that research active organisations deliver better health outcomes and outlined the themes of research in NHS England's Long-Term Plan. She also explained how it takes a whole ecosystem, and effective partnership working across organisations, to make data-driven research effective.

## **Panel: Working Together to Deliver Impact Highlights**

A second panel, chaired by Vivienne Parry, saw Chris Holmes, Andrew Morris, Jonathan Sheffield, Sam Roberts, Tom Denwood and Simon Denegri discuss working together to deliver impact.

Vivienne began by asking what is being done to remove barriers to collaboration. The key thoughts that came out of the discussion were around engaging with the right people across our organisations, not having a top down approach and being humble – recognising that taking charge is not always the best approach.

When asked what they are doing to help the public understand industry involvement, Simon Denegri answered that we must use the increasingly open doors from industry as well as engaging in a broader debate about expectations. Andrew Morris mentioned that true meaningful dialogue will require a sharing of benefits. He also mentioned that we need to be cautious of exclusivity.

Vivienne then drew the panel to the question of what funding mechanisms we can use to tweak the system to encourage no hoarding of data. Jonathan Sheffield stated that if people have donated their data for research, we have a duty to make sure it is published to them and ask if they want it to be publicly available. In return, Vivienne argued that sometimes it is difficult for patients to argue with clinicians about what happens to their data.

## **Research cohorts into action**

Cathie Sudlow presented examples of research cohorts that provide rich data for improving care. In particular, Cathie highlighted the work of UK Biobank, a great example of an open access resource for public health research.

## **Clinical Trials into Action**

Martin Landray discussed the current challenges in clinical trials and shared some important lessons for the future. He highlighted how in order to tell the difference between moderately effective treatments and treatments which have no effect, scale and randomisation are crucial. 80% of trials fail to recruit adequate participants and explained that we are seeing new opportunities which can drive efficient recruitment and engagement with patients.

## **Health Data Research Changes Lives – A Healthcare Professional’s Perspective**

Charles Gutteridge gave an insightful talk on how clinicians and healthcare professionals can be involved in health data research and built on his experience in east London. He gave the example of East London Genes and Health to show how citizens can lead research. He explained how our learning and use of language to describe and classify conditions has evolved and described how linear classifications don’t work. Instead we should use structured language and ontology to describe the things we see and do. Charles also shared his excitement of using both clinical and computational studies to improve health and outcomes for patients.

## **Workshops**

In the afternoon, attendees had the opportunity to attend workshops to generate discussion and debate on topics that are fundamental for successful health data research in the UK:

- Analytical approaches to distributed data – led by Simon Ball and Jackie Pallas
- Advanced analytics – led by Declan O’Regan
- Privacy regulation and governance – led by Kerina Jones
- Linking emerging data types – led by Daniel Ray and Kambiz Boomla
- Patient and public engagement – led by Simon Denegri and Natalie Banner

## The Great Balloon Debate

The event ended with a fun and high energy debate designed to showcase some of the fundamental issues required for successful health data research in the UK. Our guest speakers were invited to present their opinion on the single most important issue in our quest to harness health data for research and public benefits is:

- Artificial intelligence and new technology - Chris Holmes
- Maintaining public trust - Natalie Banner
- Genomics and new data types - Joanne Hackett
- Addressing digital maturity in the NHS - Tom Denwood
- Training current and future generations – Jonathan Sheffield
- Politics – Alex Markham

After two rounds of debates and votes from the audience, and expert chairing from Andrew Morris, the winner was Natalie Banner who articulately presented that maintaining public trust is the single most important factor in our work. Congratulations to Natalie!