

HDR UK Better Care Insights Sharing Day

24 February 2022

Introduction

The latest quarterly Better Care Insights Sharing Day heard about the progress made by teams working across the UK. Attendees were informed about and discussed issues of far-reaching significance from public and patient engagement and involvement (PPIE) to the challenges of using health data in biomedical research.

Key insights

- Learning health systems can help bring continuous improvement but a strong narrative explaining their benefits is needed in order to win more resources and support.
- High-quality, timely data is essential to the Better Care approach. The Alleviate Pain Data Hub is making significant progress in this area by making UK pain datasets findable, accessible, interoperable, and reusable.
- The DataMind Hub is pressing forward with initiatives to build mental health data research capacity and to ensure that mental health issues have greater prominence in multi-morbidity research – again, assuring high-quality and timely.
- The ability of health data research to advance knowledge and improve care is fraught with challenges and potential pitfalls. To provide meaningful insights we must question whether we are using the right real-world data, develop and adopt best-practice in research and find ways to examine the potential weaknesses in our data and research methods.
- The bottom up approach taken in the development of CogStack is successfully providing a new, fast and effective way for clinicians, researchers and others to make use of unstructured healthcare data to drive forward healthcare.

Measuring our impacts

HDR UK has developed a detailed Progress and Impact Framework (PIF) to understand how its programmes are delivering impacts and to enable continuous improvement. The PIF shows that in the last two quarters the Better Care programme has made progress, for example in engaging with patients and the public.

[Victoria Platt](#), Executive Director of Business Operations HDR UK and [Kate Sanders Wilde](#), Continuous Improvement and Business Systems Manager led a session outlining how the PIF works and invited attendees to help consider how it can be used to provide wider benefits in the future. Attendees said they felt it important to strike a balance between the reporting burden and useful insights, but acknowledged the importance of demonstrating an impact from our work. Victoria and Kate emphasised that the aim is to ensure that PIF metrics are refined to provide the greatest insight and help drive continuous improvement.

Advancing Learning Health Systems

The Better Care approach, which assures ready access to timely and accurate data, is essential for effective Learning Health Systems (LHSs). [Tim Horton](#), [Tom Hardie](#), [Nell Thornton-Lee](#) and [Ellen Coughlan from the Health Foundation](#) gave an update on the [Better Care Policy and Insight Catalyst workstream](#) which is identifying the actions needed to enable implementation of LHSs across the UK. The team say LHSs represent a set of activities and assets that use data to enable continuous learning and improvement. They can enhance many aspects of health and care from clinical effectiveness and safety to the better use of technology and patient centred care.

A recent survey by the team, in which they spoke to 126 senior stakeholders across the NHS and academia as well as public representatives, highlighted a series of priority policy actions. These included more funding and support to:

- improve digital maturity and help create infrastructure
- build capability to implement improvements to care
- develop a clear narrative about why they are important
- build specialist analytical and data science capability
- help providers meet interoperability standards.

The survey also emphasised the need for a strategic commitment from organisations to support LHS development and scaling. Key actions required from NHS and research organisations to implement LHSs include ensuring protected staff time for LHS work, senior leadership oversight and an active LHS strategy.

Attendees spoke about the importance of developing a clear narrative to describe the advantages LHSs bring. This was seen as fundamental to securing greater resources, organisational support and the buy-in of the public and patients to implement LHSs.

Hub update 1: Alleviate

Updates on the Alleviate Pain Data Hub and the DataMind Mental Health Hub highlighted the progress that each is making towards ensuring that researchers have ready access to timely and accurate data.

[Emily Jefferson](#), Director and [Jenni Harrison](#), Deputy Director, outlined the latest developments in Alleviate, which was established to make UK pain datasets findable, accessible, interoperable, and reusable (FAIR). This will help enable new and improved approaches to the treatment of a wide range of chronic and debilitating conditions. One of the major issues to date has been that pain data is not routinely collected by the NHS but Alleviate is working to address this challenge.

Within three months of being launched Alleviate had made metadata about all the pain datasets, to which it can enable access, available on the [HDR UK Innovation Gateway](#). Many more datasets will be added in future. By using the Cohort discovery tool the Gateway allows researchers to dynamically query this metadata and identify datasets to which it would be valuable to seek further access.

Alleviate draws on the trusted research environment (TRE) at Dundee University (where the hub is based) to make this pain data available to accredited researchers in a safe, secure environment.

The architecture being built by Alleviate adopts a hybrid model for data discovery, management and provision. Partners have the option of providing a complete copy of their dataset to be managed and curated by Alleviate, or there is a separated spoke for those preferring to manage data in their own environment. The hub has wide-ranging plans for the future, it is already committed to onboarding six large genomic and imaging datasets and 16 small, deep phenotyped datasets and hopes this number will increase greatly.

“We are doing research at pace and scale, meaning hopefully it reaches patients faster.”

Emily Jefferson, Director of Alleviate; University of Dundee

Hub update 2: DataMind

The [Ann John](#), Principal Investigator and Co-Director and [Rob Stewart](#), Co-Director, provided an update on the aims and progress of the DataMind Mental Health Hub. They reported that the hub faces distinctive challenges because mental health data is often regarded as more personal and sensitive than physical health data. Ann said the hub has taken a federated approach and has worked towards making data sets available to researchers through a number of TRES, including its own which is hosted by the SAIL Databank at the University of Swansea. From the outset they are prioritising a four nations approach, ensuring the leadership team comes from all parts of the UK.

DataMind is supporting capacity building, to ensure that there are sufficient people with data and computer science expertise available to work in mental health research. It is also puts a focus on multi-morbidity research, as research in this area often fails to consider the unique impacts on mental health.

Rob added that the hub is undertaking a series of short sprint projects to make rapid progress in developing mental health data science including one that is focusing on excluded and underserved populations and another on natural language processing.

DataMind objectives

- To embed patient, personal experience and public participation to ensure that the hub is driven by the needs of the population and considers key ethical issues pertinent to MH data
- To curate and enhance the interoperability of data for research, development and innovation
- Be guided by and responsive to the needs of users (academia, the NHS, third sector, policy makers and industry) in the data gathered and resources provided
- To develop global standards to meet industrial research and development needs
- To make datasets visible, accessible and available securely for research, development and innovation

Patient and public involvement and engagement

The drive to embed PPIE into all Better Care activity has been a consistent theme throughout this and previous Insight Sharing Days. Both hub updates emphasised the efforts being taken to ensure the public and patients understood, and were able to trust, that their health care data was being collected and used responsibly for valid purposes.

Better Care PPIE representatives Rosanna Fennessy and Michaela Regan led a session in which they introduced themselves, discussed public and patient perspectives on data use and explored what attendees saw as the value and significance of PPIE.

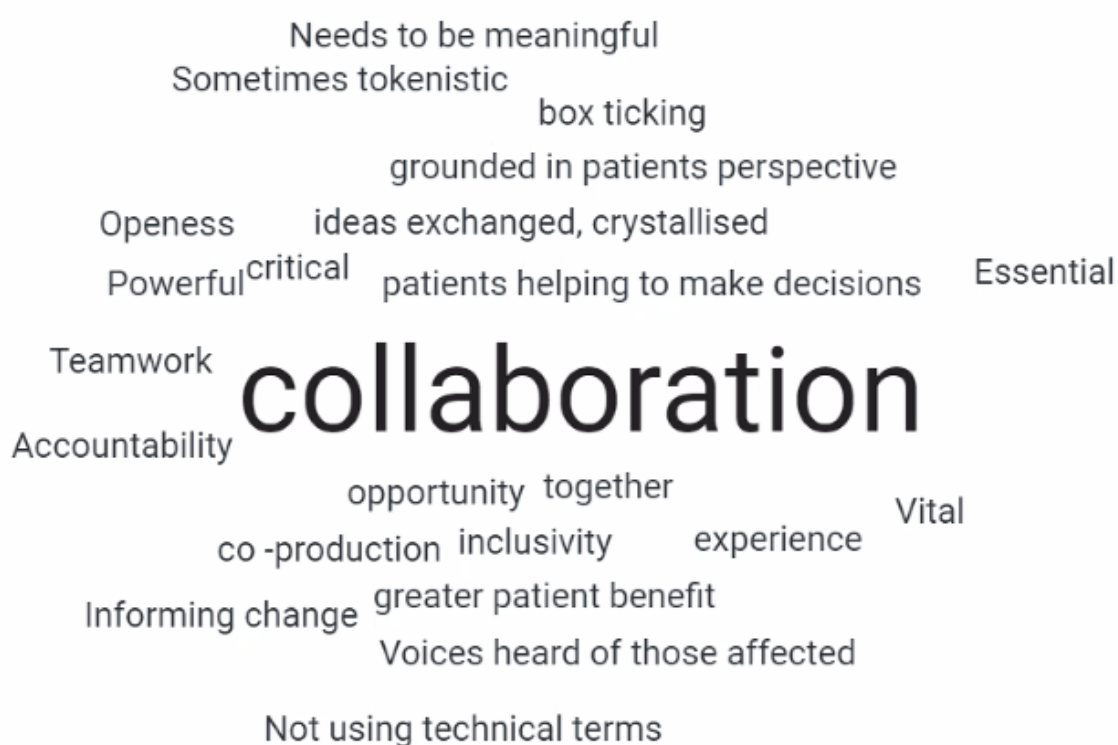
Rosanna addressed the issue of potentially differing perceptions of the meaning of Better Care. She said: "I'm a patient with a long term health condition. I'm sure we produce mountains of data every time we visit hospitals and doctors. And it's really great to see that data being used. But for me and lots of other patients, it's very much about data being used for better care. But I'm really interested in what Better Care (as a national research priority) means. It might mean different things to different people and to patients in particular."

Michaela added that her involvement with HDR UK had been very positive. She said: "It's been really helpful to see how important it is to have proper clear data on the impact of treatments." At a time when so many people are facing long waits for treatment and when there is so much potential for errors in treatment or patient record keeping, she sees health data research as having a great deal to offer.

Rosanna and Michaela said there is a need for patients and the public to have a greater role in driving research agendas and that people coming in from the outside need time, information, support and opportunity to learn about the fields they are getting involved with – making them feel part of the team.

A poll of attendees showed that half felt PPIE was fully embedded in their work. Attendees also contributed to a word cloud describing what PPIE meant to them – the result highlighted collaboration.

What do you think of when you hear patient and public involvement and engagement?



Reflections on using health data for biomedical research

Health data research can only achieve step-changes in knowledge and care if we have the right data and it is properly understood – this is often far from being the case. Chairing the session [Anthony Brookes](#), University of Leicester, said the field is “plagued” with problems such as data that is incomplete, inaccurate, inconsistent, biased, misleading or poorly contextualised. As such, there is a real danger of drawing false conclusions. A series of speakers from HDR UK Midlands explored these issues and identified potential solutions.

[Keith Abrams](#), University of Warwick, says that a critical consideration in any health data research, must be why the data is there in the first place. He raised the issue of how well data from specialist registries represents the whole population of people with a particular disease. He cited the example of trying to estimate life expectancy of patients with the rare condition Duchenne muscular dystrophy. Evidence from studies using specialist registry data suggested significant improvements, but was it representative? The answer may lie in also using population-based data sources, such as [CPRD](#), to provide evidence from a broader patient population.

[Alastair Denniston](#), Director of INSIGHT, is leading a project on AI bias, in particular data collection and whether we are “building models that reflect only some parts of the population”. A review of all publicly available ophthalmic imaging datasets found that only 20% carried demographic information allowing you to see whether the cohorts were representative. And the evidence suggested that many studies only covered small parts of the world. Research on skin datasets has raised concerns that apps are being developed, and healthcare professionals trained, on the basis of narrow and incomplete data. The group is looking at best-practice models to ensure the quality of algorithms.

[Olalekan Lee Aiyegbusi](#), University of Birmingham, looked at the safeguards needed to ensure the trustworthiness of information gathered in patient reported outcome measures (PROMs) questionnaires. PROs (patient reported outcomes) provide valuable insights in many contexts from clinical trials to shared decision-making as they provide the patient’s unmediated view of their health condition. But care must be taken in questionnaire design. This includes testing to ensure that patients understand the questions in the way the researcher intends. Equally, incomplete forms can produce distortion so paper forms should be ideally checked before submission and electronic ones prompt the patient to answer every question.

[Paul Lambert](#), University of Leicester, discussed the need for researchers to understand and address the imperfections in their work and, if necessary, make changes. One example of the problems that can occur is in comparisons of cancer survival rates between countries. Comparisons are common but not always fair as there can be major differences in national registration practices, the completeness and quality of data. One way to try to compensate is simulation. This involves simulating a perfect category history and estimation process, then simulating cohorts of patients with cancer. Researchers can then introduce known errors to see the difference they make.

[Theo Arvanitis](#), University of Warwick, presented the idea of using synthetic datasets as a potential solution to concerns about privacy, data misuse and other issues in the development of intelligent healthcare applications. Work conducted by Theo and his colleagues has shown that it is possible to manufacture synthetic data sets that are statistically equivalent to ones created using actual patient or personal data. This has clear advantages both in terms of public trust, and in the ability of researchers to compensate for the bias or incompleteness of real-world datasets.

CogStack – unlocking the potential of electronic health records

The [CogStack](#) information extraction and retrieval platform is a prime example of how HDR UK is using technology to enable better care. Some 80% of the rich data in electronic health records (EHRs), including clinical and discharge notes is unstructured, making it difficult to access and analyse. [Tom Searle’s](#) introduction to CogStack described it as “**an ecosystem of loosely coupled technologies that tries to surface the data that's hidden within the record, making it available for researchers.**”

Already used at eight English NHS trusts, and at UMC Utrecht, the CogStack team is looking towards a national rollout – saying the technology helps address a variety of needs for clinicians, academics and population health analysts. Major benefits include being fast and simple to use. Clinicians can get answers to questions by using a single query box, and researchers can swiftly gather data that would previously have taken months to collect. CogStack can also enable rapid clinical audits and faster identification of potential cohorts for clinical trials.

“Our approach has been bottom up - going to each individual trust and saying, ‘what kind of questions do you want to answer with your data and how can we make that happen’.”

Tim Searle, CogStack developer, King’s College London

Recurring themes

There have now been seven Better Care Insight Sharing Days and as we look back over the meeting series we see several common themes which reflects their importance for enabling the Better Care approach. A few of the key themes which were again raised in this meeting are summarised below together with opportunities to ensure that we continue to drive progress and shared learning in these areas:

- **How technology is/should be used by Better Care:** Future sessions should continue to highlight the impact of technology by presenting examples where it has made a difference, or instances where technology may not have worked as anticipated.
- **Engagement:** How is the Better Care community enabling participation and ensuring inclusivity by using different engagement routes? Future sessions should continue to explicitly demonstrate the effects of positive engagement.
- **Collaboration:** Linked to engagement, future sessions should continue to detail ways of collaborating effectively.
- **Data and data integration:** Data availability to support both clinical practice and research is key to successfully delivering the Better Care approach. Future sessions should continue to provide updates on available data, identify future priorities and highlight routes for data linkage and integration.