

HDR UK Better Care Insights Sharing Day
14 January 2021

Meeting summary

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Key messages

- The COVID-19 pandemic has galvanised the health and care data community and shown the value of working together across disciplines, integral to the Better Care approach. How can we maintain this collaboration into recovery and beyond?
- By harnessing new technologies, we can empower patients to take ownership of and engage with their data so that they can better manage their health and make informed decisions about their care.
- Understanding clinical timescales and making data easy for clinicians to collect and use helps to embed large-scale data and advanced analytics in routine care.
- Digital maturity helps but it is not enough: we need to set standards, develop a shared language and common approaches to achieve interoperability and scale better care.
- There are still challenges to overcome and balances to strike: how do we embrace technology while recognising that it is people who have to use it? How do we work collaboratively with industry partners and regulators? How do we moderate between building minimally viable products and improving through learning, and waiting for “perfect”?

Introduction

In the third of our Better Care Insights Sharing meetings, more than 80 participants gathered to discuss how the Better Care approach is being delivered in practice to embed the use of large-scale data and advanced analytics in routine care. The Better Care approach aims to improve people’s lives by equipping clinicians and patients in the UK with the best possible data-based information to make decisions about their care.

*“Having everyone
focused on one
problem helps”*

Elizabeth Sapey

Alastair Denniston, meeting chair and Better Care Research Co-Director, Director of INSIGHT and consultant ophthalmologist at the University of Birmingham, emphasised as he welcomed attendees, “It’s not all about COVID: **there’s an awful lot of fantastic work going on across the whole [health and care data] landscape.**” But, of course, the pandemic has continued to be a major and urgent focus for health and care data and analysis and been a rapid accelerator for progress.

Better Care in a critical time

In the meeting's first session, we heard how Better Care approaches have been used in COVID response and recovery. Participants reflected on the ways in which **the pandemic has galvanised the health and care data community** and encouraged the collaboration that's so essential to embedding a data-driven and learning approach. Elizabeth Sapey, Director of PIONEER, the Health Data Research Hub for Acute Care, explained that "having everyone focused on one problem helps," and has been a key factor to enable a data-driven response to manage the virus and its impact on acute care in their hospital network across the West Midlands. PIONEER is also part of a much bigger picture, contributing to national datasets and sharing information with 167 researchers across England.

As Sukhmeet Panesar, Deputy Director, Strategy and Development, Data, Analysis and Intelligence Service, NHS England and NHS Improvement (NHSE&I), explained, "**The world is a 'team of teams'**". He told meeting participants about the incredible growth of the FutureNHS Collaboration Platform, a workspace that was launched in March 2020 to connect and empower the whole data community to share COVID-19 data, analytics and learning. Through the platform – which now has 14,000 members – analysts can share their analyses and tools, discuss with one another and access regular talks. It has rapidly accelerated sharing and learning across the country and has shown what can be done as a community.

Sukhmeet Panesar also noted that he was "pleasantly surprised" at the type of involvement the platform had seen from industry partners, with engagement centred on sharing rather than selling. And necessity has also driven closer collaboration in the innovation space, as Daniel Bamford (Deputy Director AI Award, Accelerated Access Collaborative, NHSE&I) explained.

Throughout the day, we heard about **the value of multidisciplinary collaborations that brought together clinicians, analysts and informatics**. In developing and populating data models to inform its COVID-19 response and recovery, NHS Bristol, North Somerset and South Gloucestershire CCG (HDR South-West) brought together academics, local authority representatives and healthcare managers. This enabled them to simulate the surge capacity of their intensive care units to limit capacity-dependent deaths, estimate bed demand and anticipate the knock-on effect of pandemic on patient waiting times as non-urgent care was pushed back.

"Patients and citizens don't care about our tribe – nor will the pandemic"

Sukhmeet Panesar,
Deputy Director, Strategy and Development, Data,
Analysis and Intelligence Service, NHSE&I

A close working relationship with Mersey Care was a key highlight from the Strategy Unit's work on the impact of COVID on mental health care – though they reflected that as their emphasis shifted towards the model's technical production, they perhaps didn't manage to maintain engagement with some of the

research community. This last example is a reminder that **collaboration relies on ongoing and trusted relationships – whether these are with analysts or industry, clinicians or patients.**

There’s much more that we can do to strengthen researcher–health community collaboration. We need to encourage collaboration without creating a time burden – particularly for health and care workers at the “coal face” whose participation is essential to translating knowledge into practice to make concrete improvements. One participant suggested covering clinicians’ time so that they feel more able to attend – “otherwise you get a meeting of the interested and early adopters and not the wider clinician group who are more resistant and sceptical about change”.

Looking beyond technology to the people that use it

Solutions will only be fit for purpose and meet “people need” if we engage patients, practitioners and the public in developing and implementing the Better Care approach. But, as one participant noted, all too often we focus on technological solutions, rather than the people needed to make them useful. **We need to pay attention to the social and cultural factors that enable data and technology use** – especially creating the necessary learning culture. “Digital literacy is a huge challenge – particularly in communities with the highest needs” – as is digital poverty. To overcome these barriers, we need digital champions and funding to provide people with digital devices and access.

“How do we minimise the burden of data collection to ensure it is integrated into routine operation but still informs the research?”

Meeting participant

For clinicians and practitioners, providing training and support to use data and technology is essential, but we must also **embed data collection and use within day-to-day workflows – without creating an added time or resource burden.** With its COVID clerking sheet, PIONEER made it as easy as possible for clinicians to record and request structured and in-depth data (like age, weight and comorbidities) as patients came through the door. For example, clinicians can order panels of bloods for specific biomarkers associated with poor COVID outcomes with just one click, rather than having to submit separate requests.

Demonstrating the value of data collection and use is also vital, as several participants commented. This means making it easy to interpret, actionable and timely for decision-making. This last factor, timeliness, is at the heart of Informatics Consult, a platform that will allow clinicians to request and receive evidence about the efficacy and safety of a particular treatment within a matter of hours.

The Informatics Consult currently draws on anonymised linked data from 3.8 million individuals across primary and secondary care, randomised control trials, meta-analysis and trial emulation of observational data and genetic evidence through Mendelian randomisation. Initial feedback has been positive: 79% of clinicians said they found the evidence summary generated by the platform helpful to indicate risks for patients but **some stressed that it will need to be simple and easy to be accessible for all.**

In routine care, patients manage their conditions the vast majority of the time. With at-home monitoring, people with serious or chronic conditions can be empowered with data so they spend less time in hospitals and clinics (meaning more time at home, work and in education) and are more likely to stick to health guidance and treatments with direct evidence of the impact on their health. For health and care providers, patient self-management could also free up resources for other hospital users and identify and target the people who most need help.

“Patient self-management is key – particularly for Type 2 diabetes”

Tony Willis, North West London Health and Care Partnership; RADAR

In an update on the CF SmartCare app being developed by Better Care ‘Project Breathe’, we heard how **remote monitoring technology, wearables and machine learning could enable people with cystic fibrosis to spend significantly less time attending lengthy, routine in-hospital clinics while also allowing them (and their clinicians) to spot when they may need urgent care** – up to 11 days before a clinician’s decision to treat them. If the approach is found to be helpful and safe (no safety concerns have been raised by the interim assessment), it could offer wide-reaching potential for other conditions like asthma and chronic obstructive pulmonary disease.

RADAR (Risk Algorithms for Decision Support and Adverse Outcomes Reduction) is **applying and expanding predictive AI models for diabetes and developing a platform that will use this data to drive changes in clinician and patient behaviour.** For patients, this means allowing them to record health data and see in real-time how this affects their risk to encourage better self-management. This is key to improving outcomes for Type 2 diabetes. For clinicians, the platform aims to help them identify people who would benefit from more targeted and early interventions, which we know can reduce mortality, complications and hospital admissions by as much as 50%.

There is exciting potential for the dashboards being developed by Project Breathe and RADAR; **the question for evaluation will be whether patient engagement makes a difference to health outcomes.**

Technical requirements for implementation and scaling

Among the technical requirements for putting into practice and scaling the Better Care approach, **interoperability continues to be a significant challenge**. Informatics Consult is being developed so that it can draw on existing electronic health records – starting with Epic – and the team are confident that it should be transferrable to other electronic health records. This relies, in part, on a hospital’s digital maturity. The PIONEER work was successful in part due to the fact the hospitals rolling it out were digitally mature. But this is not the case across the board and participants expressed continued concern about the capacity of healthcare providers to embed data-driven care loops, with some saying that systems were not fit for purpose.

“You can’t have quality without standards”

Meeting participant

Interoperability also extends to working with industry actors and technologies. For example, Project Breathe and its CF SmartCare app took a device-agnostic approach. This means that patients could use a wearable device of their choice, whether this is Fitbit, Garmin, Apple or other, and **should help ensure the project’s transferability and sustainability**.

Participants agreed that a lack of standardisation was a major and neglected area and a significant barrier to interoperability. This lack of standardisation extends across technology, terminology and data modelling, coding and alignment. It is not only a problem for data quality but also for data use and embedding the Better Care approach.

The Better Care Policy & Insight team will be investigating data-related challenges and opportunities further, to support Better Care implementation and inform changes to policy and practice beyond the project. Participants suggested that **we need to know more about what the common data alignment and modelling issues are**, the factors and incentive structures that drive data quality, and what data is useful to inform decision-making. **We need to develop common standards and approaches, which some participants suggested could come from regulation**. For example, we lack uniform coding for patient-entered or reported data, and for fitness-tracking data such as step count or active minutes.

Throughout the day, meeting attendees discussed how to **transfer and scale Better Care to different systems and geographies**. This was one an area that several people felt most needed attention from the Policy & Insight workstream. Project Breathe has already scaled up from 100 to 200 patients, with plans to expand into other areas of the UK and Canada’s largest cystic fibrosis facility. RADAR is looking to extend its work to look at per patient cost of different patient-appropriate intervention intensities. For this project, a key challenge will be scaling the flow of data, which currently comes from GP systems.

For NHS Bristol, North Somerset and South Gloucestershire CCG (HDR South-West), the challenge in distributing their models for assessing intensive care capacity, bed demand and the impact of COVID-19 on

patient waiting times was **the complexity of the models themselves**. Both BNSSG and the Strategy Unit also spoke about the challenges in modelling the impact of COVID on mental health care in particular. This is due to the complexity of referrals, different entry points and divergent approaches across trusts and providers. The Strategy Unit imposed a generic service structure to make its model relevant national but cautioned that this could limit its validity.

Embracing diverse data sources and new technologies

The models developed by NHS BNSSG and the Strategy Unit drew on diverse data sources. Richard Wood, Head of Modelling and Analytics and NHS BNSSG, explained that their ICU simulations used demand projections from Imperial College London and length-of-stay and patient outcomes data from Italy and Wuhan, where COVID had struck sooner, while their bed demand analysis trawled the latest data and briefings to calibrate model parameters on a weekly basis. The Strategy Unit's modelling used judgements on possible rates of people entering the mental health care system based on evidence where possible (such as numbers of people newly unemployed and the rates of depression among unemployed people), and guidance from Mersey Care experts on how these people might present and what services they may be referred to.

Health monitoring technologies and platforms, such as those being developed by Project Breathe and RADAR, were an exciting area for discussion throughout the day. COVID-19 has shown the importance of developing remote health monitoring tools and approaches, with people – particularly those with chronic health conditions – worried about going to routine in-hospital clinics. Wearables and new remote monitoring technologies are opening up more potential.

“Patients are delighted to be able to take back control of their disease”

Charles Haworth, Royal Papworth Hospital; Project Breathe

But participants agreed that **harnessing wearable technology is not without challenges**. For example, how we can work with wearable providers who do not open up their infrastructure? How do we know if Fitbit change their algorithm for how a resting heart rate is calculated? How can we harness data collected through consumer tech like wearables when it may not be to clinical standard and quality and accuracy may vary? Can we develop common coding for such data and agree this with providers? These were avenues that participants identified for further analysis by the Better Care Policy & Impact team.

Funding is a key factor in harnessing technology and innovation to enable better care. As part of its bold ambition to make the UK a global centre of excellence for AI in health and social care innovation, the UK government has created the AI Award, worth £140 million, which is administered and delivered by the Accelerated Access Collaborative within NHS England & Improvement. But, as the Award's Deputy Director Daniel Bamford, explained, securing funding and meeting evidential thresholds is not a guarantee of reaching patients. **The pathway to adoption extends beyond demonstrating an innovation's safety and**

efficacy and navigating sometimes tricky regulatory frameworks, to futureproofing and more a holistic appreciation of to embed innovation into a complex NHS system. Award applicants need to show awareness of this journey. And, if they are successful in securing support, the ACC can help them to map out and navigate this.

A valuable space to connect and learn

The day provided an important opportunity to share, reflect and learn. Participants found it hugely value, and throughout drew connections to the work they are doing and identified opportunities for future collaboration. As we develop these links, we expand the reach of the Better Care approach and its potential to transform lives.