HDR UK Better Care Insights Sharing Day
Thursday 21 October 2021

Meeting summary

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Key messages

This summary report from the October 2021 Better Care Insights Sharing Day is organised around the following key themes that arose from presentations and discussions on the day:

- **Data-driven predictions and modelling provide the opportunity for** improved care delivery, outcomes and experience which is better tailored to individual patients.

- To enable better care in a continual loop of learning and improvement, these **insights need to be useful and useable**. This means communicating information to users at the right time and in a way that is understandable and explainable.

- By **involving and engaging the public, patients and health and care workers in meaningful ways throughout the Better Care loop**, we can co-design solutions, draw links between projects and put research in context to improve its impact and scalability.

- **Collaborations across the health data community drive advances in care**, and this relies on making data and knowledge FAIR (findable, accessible, interoperable and reusable) through appropriate data infrastructure, architecture and governance.

- Secure, user-friendly data architecture and trusted research environments can help to **streamline research processes** and have been critical for enabling Better Care projects to advance during COVID lockdowns – providing **remote, safe and secure access** to large datasets and analytical tools.

- **Learning is central to Better Care and can be delivered through diverse routes that are tailored to the individual and the learning challenge.** Learning underpins the Better Care loop and is vital in developing a cadre of experts with the skills needed to use large-scale data and analytics to improve care.

Introduction

The latest in our series of quarterly Better Care Insights Sharing days saw a packed agenda. These events aim to bring together the Better Care community to share progress, insights and lessons learned and to identify opportunities for further collaboration to broaden the impact of our work. As well as exciting showcases from Better Care project teams across the UK (specifically HDR North and South-West), we also heard from CO-CONNECT, a platform that's making large-scale data on COVID-19 testing FAIR (Findable, Accessible, Interoperable and Reusable), updates on information architecture, public and patient involvement, the HDR UK online learning platform HDR UK Futures and Better Care training activities. We finished the day with a thought-provoking session on how games can be used to enable learning and develop skills in health data research.

Data-driven predictions for better care

Decisions about care are complex and involve lots of different, often patient-specific information. Yet many existing guidelines and decision-support tools are static and cannot respond to the individual patient circumstances – such as any other health conditions (comorbidities) or medications (polypharmacy).

The team from Bristol presented updates on their work to develop personalised National Early Warning Scores (P-NEWS). NEWS predicts an individual patient's risk of deterioration and their likelihood of needing intensive care; it is critical in allowing healthcare services to target interventions and prepare resources appropriately. The team are using machine learning techniques applied to routinely collected physiological measurements (as many as 180 different measurements for any one patient), hospital data and patient outcome data to develop a model that is personalised to individual patients. As Chris Bourdeaux (HDR UK South-West; University Hospitals Bristol NHS Foundation Trust) explained, "an elderly person with pneumonia could have the same NEWS score as a young patient with pancreatitis despite the fact that they're likely to have very different trajectories and need different levels of care." The hope is that, by developing a more personalised, predictive early warning score, clinicians can make more timely, tailored decisions, reduce unplanned admissions to intensive care and improve patient outcomes.

During the day, we heard from several projects that are using large-scale data and advanced analytics to generate dynamic insights to improve prescribing for individual patients. HDR UK North is creating a computerised index of anticholinergic drugs (ACMI), a group of commonly prescribed medications that can have harmful unintended effects on older people with frailty. Using a sample of 1.8 million linked health data records in the Connected Bradford database, the project has developed and internally validated a predictive data model for hospital admissions as a result of falls or delirium.

"Current prescribing practices mean that a 22-year-old with no medical history is as likely to be given antibiotics for an upper respiratory infection as an older patient with other health conditions"

Tjeerd van Staa, HDR UK North; University of Manchester

Antimicrobial resistance is one of the greatest challenges facing the world today, causing 700,000 deaths each year. Viruses, bacteria and other microbes are becoming more and more resistant to antibiotics, making infections harder to treat and more likely to cause severe illness and death. Prescribing antibiotics also poses other clinical risks, increasing the chances of adverse drug reactions and interactions, and complications such as clostridium difficile infection (CDI), which is highly contagious and potential fatal. But efforts to improve prescribing practices in the past have had limited impact. Moreover, with the emergence of COVID-19, rates of CDI have increased among older men – suggesting that antibiotic prescribing may also have risen. Better Care projects led by HDR UK South-West and HDR UK North are analysing linked data to optimise antibiotic choices for patients based on individual history and clinical characteristics, the risk of adverse drug reactions (or interactions), and the risk of resistance. The HDR UK South-West Partnership is using linked primary and secondary care data and laboratory records from the Bristol, North Somerset and South Gloucestershire (BNSSG)

Systemwide dataset to improve antibiotic prescribing "in the age of antimicrobial resistance and COVID-19". For example, as part of this work, the team are using time series data to optimise the use of antibiotics to treat sepsis and are investigating the possible links between COVID-19, antibiotic prescribing and rates of CDI. Better Rx, an HDR UK North project, is using integrated care record data from Graphnet to improve antibiotic prescribing in primary care by developing data-driven insights and feeding these back to prescribers and their patients.

Ensuring Better Care research is more than just numbers

Making insights useful and useable

How we deliver data-driven insights is as important as the insights themselves; large-scale data and analysis cannot contribute to continual learning and improvement in care if they are not useful or usable. Both Better Rx and the ACMI project are building their algorithms into electronic health systems (e.g. SystmOne and EMIS) so that relevant information is available at the point of care. They are also involving patients and clinicians to make sure it tells them what they need to know in a way that's understandable and explainable (that is, "more than just numbers"). This is vital for decision-making: clinicians are sceptical when asked simply to trust information and patients need to understand *why* a change is being suggested and how it will affect them.

It's also important that information is specific and relevant. During workshops for the Better Rx project, clinical leaders explained that red flags are unhelpful because they don't provide detail on the likelihood or severity of a particular risk for a particular patient, which enables the clinician to make an informed decision. Generalised feedback on prescribing practices was also said to be unhelpful because it didn't allow clinicians to identify critical change. In response, the project is developing dashboards that benchmark primary care providers against comparable peers in terms of, for example, their location and the types of patients and conditions they see, for example.

> *"If you want to see a good example of something important that's not communicated well, take a look at the current guidance on drug interactions: it's a 200-page document of dense information"*
>
> **Tjeerd van Staa**, HDR UK North; University of Manchester

Involving and engaging patients and public throughout the Better Care loop

In his update on the ACMI project that's using data and analytics to improve anticholinergic prescribing in older people (see previous), Andy Clegg (HDR UK North; University of Leeds) reflected that the project's co-design process has been especially valuable in beginning to develop the data model into a tool to support decision-making. The ACMI team has prioritised collaboration with patient representatives and clinical leaders, engaging the two groups regularly throughout the design process and shape how the algorithm supports decision-making. The Better Care North Patient and Public Involvement and

Engagement (PPIE) team, academic co-lead [Bridget Young](#) (Liverpool University) said that the project provided a really good example of how to make PPIE work: "Within the anticholinergic project, PPIE is well supported – there's a philosophy of making it [PPIE] everyone's business, so it's not just falling to a relatively small number of leads."

The PPIE workstream that is run through the HDR UK North partnership is also developing a strategy to guide and enhance PPIE through all projects led by HDR UK North. The strategy focuses on improving the diversity of representatives, facilitating greater collaboration and human connections, developing case studies to show the benefits and opportunities generated by effective PPIE, and training and supporting both researchers and patients and members of the public to develop confidence, understanding and skills to participate.

HDR North Patient and Public Advisory Group Chair Joyce Fox explained that it's important for researchers to see public contributors as critical friends: "We ask awkward questions, but we want it to be productive. We want to work with you to make the research better by putting it in the context of real-world experiences." Good PPIE can also add value by linking across different Better Care projects, spotting synergies and making connections to advance efforts and make them more than the sum of their parts. Bridget Young noted that the benefits of having a public lead as Chair of the Patient and Public Advisory Group and for the group to meet regularly with academic leads.

Closing the Better Care loop: evidence for learning and improvement

For large-scale data, advanced analytics and meaningful PPIE to improve care and deliver better outcomes, they need to be part of a learning process. Through the Better Care loop, projects are piloting the systems and approaches they're developing and will then evaluate the extent to which they contribute to better outcomes in health and care. This data is fed back into the Better Care loop to enable ongoing improvement. Outside the Better Care programme, this isn't always the case; Director of HDR UK North [Munir Pirmohamed](#) noted that technology-enabled 'solutions' are often rolled out without any evidence to demonstrate that they contribute to better care or do not cause harm.

The [Learning Care Homes project](#) is part-way through its evaluation of HealthCall, an app that aims to support care home and community staff in deciding the most appropriate course of action when a resident becomes unwell. Using the app, staff can make a structured referral and provide real-time observations to the relevant community NHS team. This team then reviews the resident's GP record and make an informed action plan. The Learning Care Homes team are evaluating this new process quantitatively and qualitatively. The findings will be used to refine the app as part of a continuous Better Care 'learning loop', with the aim of rolling it out on a larger, national scale.

The team is analysing linked data from routine care (from the County Durham & Darlington NHS Foundation Trust Hospitals, community matrons, care home readings, COVID-19 testing and the Trust's summary information) to quantify changes in service use, clinical patient outcomes and costs to the NHS since the introduction of the app. Initial findings from this analysis suggest that the app may have contributed to a 50% reduction in hospital admissions and generated an £8 million saving in the system. Interviews with residents, their families, care home staff and the community NHS team aim to better

understand people's experiences of using the app and how they feel about it. So far, responses suggest that the tool is useful and easy to use overall, but the skills needed to use the technology and the cultural or behavioural changes required remain challenging.

This underlines the importance of looking beyond data-driven solutions to the people who use them which it isn't just a question of technological knowledge and capability. Graham King explained that, in the case of HealthCall, care home staff are reluctant to use the app for many reasons – some are fearful because it threatens their existing ways of working or requires them to learn new skills; others simply like making referrals by telephone so have little desire to adopt a new approach.

The HDR South-West project, Improving Patient Flow between Acute, Community and Social Care project (IPACS) is helping to build the evidence base for anticipating and allocating resource needs once a patient is discharged from hospital into downstream social care. Current approaches – which rely largely on average calculations in spreadsheets – can't reliably predict needs, leading to a loss of 500,000 bed days at a cost of £1 billion every year and a poor patient experience. The project is currently developing a stochastic model to inform the business case to renew discharge-to-access services in Bristol, North Somerset and South Gloucestershire for the next 18 months. It is the first time that stochastic modelling has been used in a business case of this type and, similar to the experience in the HealthCall app roll-out, they have had to build familiarity among users (in this case, clinicians and healthcare managers).

COVID-19 has significantly increased pressure on health system resources. But even before the pandemic, hospitals have struggled to manage capacity for elective procedures (like hip and knee replacements) amid increasing emergency admissions – particularly during winter flu season. One HDR UK South-West project is combining, analysing and modelling operational data from Bristol NHS Trust and BNSSG Systemwide data to develop a forecasting system that enables hospitals to better plan elective orthopaedic surgery in real time.

The initial phase of the project's Better Care loop has been to look at what lessons can be learned from the 2017/18 experience of cancelling and restarting hip and knee surgeries due to capacity limitations. The team are analysing trends in patient characteristic (e.g. age or comorbidity) and day/date of consult. The next step is to use machine learning, time series analysis and other methods to forecast non-elective emergency admissions and bed capacity. This forecasting and predictive analysis will feed into a series of "What-if" scenarios to help answer questions about how changes to current services (e.g. more operations in summer) could increase hospital capacity and throughput.

Sharing and collaboration

Sharing and collaboration is vital to advancing Better Care. All of the projects discussed are collaborative by design (involving different research institutions and clinical and patient stakeholders), but many teams are also collaborating across projects and HDR UK regions. Many also have a specific focus on open access, for example, IPACS aims to make its predictive model open source, available to health and care users. This sharing and collaboration is a fundamental HDR UK value and is crucial to scaling Better Care approaches, enabling new insights, avoiding duplication and making the best use of resources. The programme is delivering this, not only through collaborative research, but also in developing FAIR (findable, accessible, interoperable and reusable) data infrastructure and architecture.

A key part of this is good data governance. Under the cross-cutting Data Architecture and Governance theme, HDR UK North's newly established Design Authority will ensure that technical and data decisions under contribute to improving data quality, access and safety. To do this, the Design Authority have defined good data architecture and identified a number of supporting principles (Box 1). Overall, the Data Architecture and Governance theme is making significant progress, having onboarded a number of Better Care projects to the HDR UK Innovation Gateway. Through the Innovation Gateway, researchers and innovators can discover and request access to UK health datasets, and view projects, educational courses, publications and tools; it is of the ways in which HDR UK is helping to make data and knowledge FAIR.

One of the critical success factors for the Data Architecture and Governance theme is to extend the use of trusted research environments (TREs) – secure spaces for storing, connecting and analysing complex and sensitive data. A number of Better Care Principal Investigators noted that access to large-scale data can take time to secure but emphasised that it is possible. Expanded use of TREs could help streamline data access, reduce the governance burden for researchers (while keeping data secure) and improve access to advanced analytical and collaborative tools. For Better Care projects, they have proven useful – especially during COVID-19, providing remote, secure access to vast datasets when universities or other physical access points were shut down.

> *"Lots of people use data governance as an excuse to not do things. But information governance is there to help us all; it's there to enhance and accelerate data sharing for the common good."*
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> **Monica Jones**, Chief Data Officer (DATA-CAN), Associate Director (HDR UK North)

BOX 1. GOOD DATA ARCHITECTURE

Good data architecture enables collaboration; ensures high standards of data governance (including quality, relevance and stewardship); and can be adapted as technologies and data formats change.

Key principles:

- Data is a shared asset
- Users need adequate access
- Security is essential
- Common understanding requires a common language
- Data should be curated
- Data flows should be streamlined

During the day, we heard about CO-CONNECT, a project coordinated by HDR UK and led by experts from the universities of Nottingham, Dundee and Edinburgh and Public Health England, that's helping to make linked COVID-19 antibody testing data FAIR via the HDR UK Innovation Gateway. COVID-19 data, analytical approaches and knowledge are relatively new and still disparate, but need to inform public health policy at pace. CO-CONNECT aims to streamline the data discovery and access process to enable fast, high-quality research and innovation.

Building capacity for the future

Better Care is underpinned by the principle of continuous learning and relies on a wide range of experts and expertise. Alan Davies (senior lecturer in Health Data Science, Manchester University) updated Insights Sharing Day attendees on the development of the Health Information Technology curriculum under the Better Care Catalyst Workstream. The project is creating, testing and sharing a programme of online resources and simulation to help healthcare professionals and researchers develop the skills they need to implement data-driven improvement in health and care. HDR UK Director for Talent & Training Sarah Cadman shared some of the latest developments in the HDR UK training programme, including the launch of HDR UK Futures, a digital platform of learning modules for different health data research learning pathways. The platform currently has 1,400 registered users from around the world and already features modules on Better Care pathways, with opportunities for experts to develop more.

In the final session of the Insights Sharing Day, we heard from Benjamin Green, Games Lead at the Centre for Health Informatics, Manchester University about how games can play a useful role in skills development. He provided an overview of the different types of game and their features – such as how true to life they are, how flexible or practicable and what resources might be required to develop and implement it. The starting point for designing any kind of game is to ask: what's the purpose of the game, who will play it and what resources are available? Different games are more or less suitable for different uses, but they also vary significantly in cost, so thinking about the time and financial resources available (and what's justifiable in terms of returns) is important.