

**HDR UK Better Care Insights Sharing Day**  
**22 April 2021**

**Meeting summary**

# HDR UK Better Care Insights Sharing Day

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## Introduction

In the next of our series of quarterly Better Care Insights Sharing days, attendees heard the latest from a range of exciting Better Care projects working across the UK's four nations. Attendees also had a key opportunity to discuss and help shape the Better Care programme's national patient, public and practitioner involvement and engagement strategy as an integral aspect of all programme work.

## Key insights

- Structured, computer-readable knowledge is a key route to transferring and scaling Better Care. By developing interoperable computable clinical guidelines and integrating them within routine care through digital health systems, we can support clinician and patient decision-making and enable better, safer, more personalised care – particularly in areas such as acute medicine, paediatrics and managing comorbidities.
- People matter. Even as we look to digital technologies to solve challenges and continually improve care, AI and computable knowledge, large-scale data, analytics and innovation will only be successful and truly scalable if it meets people's needs and aligns with their behaviour. We need to not only engage practitioners, patients and public to communicate and share our outputs but also involve them in co-designing solutions.
- Collaboration is key. Better Care is dependent on a broad spectrum of people with different skills, disciplines and perspectives working together. There are enthusiastic communities innovating diverse and exciting approaches to improve care; we need to bring these communities together, valuing variety but also sharing ideas and aligning efforts to make them greater than the sum of their parts. The Better Care community – and events like the Insights Sharing Days – offer a valuable opportunity to foster and enable this collaboration.

## Using digital tools to transform how we apply knowledge for Better Care

One of the fundamental ways that evidence from trials and research influences routine health and care is through clinical guidelines – written documents, like those published by NICE, that are developed by experts to inform clinicians of best practice in a specialist area. But these guidelines aren't in a format that computers can interpret. Instead, using this knowledge at the point of care means digging through piles of paperwork or PDFs and manually making sense of different, sometimes conflicting recommendations.

By making guidelines computable and linking them into digital health systems, Krish Nirantharakumar (University Hospital Birmingham and HDR Midlands) explained, we can automatically **provide clinicians with the right guidance at the right time**. He described how his team at University Hospital Birmingham have translated best-practice guidelines into a programmable data model for COVID-19 care and have built this into a clinical decision support system that interprets patient data to provide personalised care advice.

In this way, **computable guidelines can also ‘close the Better Care loop’**: as data from practice is captured in electronic health records, new knowledge is generated through automated and advanced analytics to inform future clinical practice. The project’s ambition is to develop a computable approach for managing the care of patients with very specific conditions or needs that may not be covered by standard guidelines, generating recommendations based on other, similar patients across the UK.

*“Computer interpretable guidelines could allow a profound transformation of the care we can offer for patients with comorbidities”*

**Theodoros N. Arvanitis**, HDR Midlands; University of Warwick

Computable models for care are **invaluable when multiple factors and activities (and therefore guidelines) need to be considered in parallel** – which can be a particularly complex task for patients with many different conditions. Theodoros Arvanitis (HDR Midlands) and a team at Warwick University are creating and validating computable guidelines for managing the care of patients with multiple conditions – specifically diabetes, cardiovascular disease, renal failure and depression.

The project team created their own category-based approach, developing an unambiguous, programmable model that could reconcile any overlaps, interdependencies or contradictions – like different treatment times or drug interactions. By rapidly and reliably making sense of lots of different information and translating this into clear recommendations based on the latest evidence and individual patient data, computer interpretable guidelines could allow a profound transformation of the care we can offer for patients with comorbidities.

## Looking beyond technology to the people that use it

As digital health expert Jeremy Wyatt (University of Southampton) explained, **it’s often psychological and behavioural factors that limit the use of knowledge** – computable or not – and things like simply making language more accessible and actionable can significantly improve uptake and impact of digital tools. In an update from RADAR project lead Tony Willis, we heard about some of the **small but important changes being made to wording** in the MyWay Diabetes app in response to patient and public user feedback. These changes, which included clarifying descriptions, providing more positive messaging and ensuring consistent use of pronouns (‘My test results’, ‘Reducing my risks’ etc.), were highlighted by the pilot users as key factors helping to ensure the app is actually used by patients and clinicians to manage their risk of diabetes complications.

**We also need to make data and analytics relevant to the people using it.** The BetterRx project aims to help doctors decide when to prescribe antibiotics to older patients with frailty. The project team have shown that giving GPs tailored data and insights telling them how their prescribing behaviours compare to other practices *locally* is a fairer and more effective way to encourage a change in approach than using national, practice-level comparisons. As Tjeerd van Staa (project lead; HDR North) commented, “It’s no good comparing apples and oranges.”

Based on data from 70 general practices and 6,000 GPs, the BetterRx team found clear regional variations at the practice level and variations at individual GP level – in part because of the different types of patients and cases they might tend to see. During a workshop, GPs all stressed that they needed feedback that was relevant to them and their specific practice. In response, the project team has developed a personalised feedback report that shows individual GPs how they compare to their peers across six prescribing measures. The next stage will be to evaluate the effectiveness of this personalised feedback in changing antibiotic prescribing and ultimately improving patient outcomes and care delivery.

Another example of how **harnessing data and analytics to meet user needs** was shown by the Better Care team development and evaluation of the HealthCall Digital Care Homes app. The app enables care home staff to rapidly access clinical advice or referrals when a resident is showing signs of illness. Care home staff can record information in the app which is then assessed by a community clinician with the appropriate skills and expertise to make an evidence-led assessment of whether the resident needs secondary care referral. The project has reinforced the importance of equipping people to use digital tools; **sharing information and building confidence is key**, as one specialist clinical trainer noted: “Some [staff] are very, very afraid of digital technology.” The BetterRx study highlighted a similar trend, with GPs saying that they needed to be supported to use the prescribing data and analysis, and that feedback needed to shift from “telling off” to “empowering and educational”.

## Addressing the needs that matter most

The HealthCall evaluation showed that **successful approaches to improving care are those that address a clear need** and offer real value to patients, practitioners or the public. Deciding when to refer a care home resident to hospital when they become unwell is difficult for care home staff. When they do make a referral, this often involves significant time on the phone: as one user explained, “We were really excited just for the simplicity of [the app and the process] and I think just the reduction in our time.”

Some health and care challenges – and their potential solutions – often “go under the radar” but can have a significant impact on patients. Andy Clegg (HDR North) shared updates from a Better Care project that is developing an index of anticholinergic drugs, commonly prescribed for many different reasons but whose side effects can **have serious consequences for older people with frailty** like falls or delirium. There are hundreds of these drugs and it’s difficult for clinicians to remember which have anticholinergic effects. By linking three large datasets, this project is creating an index to help clinicians make better-informed decisions when prescribing anticholinergic drugs to older people with frailty in order to prevent poor outcomes and a loss of independence.

It is also important to recognise when a promising solution might **not be addressing a need, having an impact or improving outcomes**. Take, for example, automated reminders delivered by digital clinical decision-making support tools. Reminders will only improve care if clinicians are forgetting to take an action – like ordering tests – that are likely to improve patient outcomes. There may be many other reasons for failing to act and the evidence shows us that automated reminders are only effective in a limited number of scenarios.

In some cases, interventions may even have a negative effect on outcomes. For example, while we know we need to reduce antibiotic prescribing to guard against growing drug resistance, high antibiotic prescribing can lead to better clinical outcomes, as Tjeerd van Staa noted. This is where the data-driven evaluation seen in all Better Care projects is critical, identifying the most appropriate strategy to balance these two risks at the individual patient level.

## Involving and engaging patients, practitioner and the public

Importantly, addressing needs and improving outcomes means **involving and engaging patients, public and practitioners as partners in a process of co-design and continual learning** – validating theories of change *before* we develop solutions as well as providing feedback on the products of research and innovation. During the Insights Sharing day, attendees discussed the Better Care Patient, Practitioner and Public Involvement and Engagement strategy, considering **where and how these groups can have the greatest impact on research within the Better Care loop**. Participants agreed that it was vital that patient, practitioners and the public are included in all stages of a research project – though recognised that involvement at some points of the Better Care loop can be easier than at others.

There was some discussion about the fact that **patients or service users might not feel equipped to engage in Better Care research**. They may not have the confidence to say what they need or may not have enough knowledge to suggest what better-quality care might look like. Attendees suggested that providing patients and the public with mentors, buddies or advocates who have greater familiarity with health and care systems could help overcome this.

### 5 GUIDING PRINCIPLES FOR INVOLVING AND ENGAGING PATIENTS, PRACTITIONERS AND THE PUBLIC IN BETTER CARE

1. Focus on impact for patients, practitioners, carers and the public.
2. Respond to our audience needs to enable inclusive, impactful and implementable Better Care research.
3. Learn and share experience and insights to maximise patient, practitioner, carer and public engagement and involvement in Better Care research.
4. Prioritise patient, practitioner, carer and public views to enable research which considers real world implementation.
5. Draw on patient, practitioner, carer and public insights to identify how Better Care research can be transferred and scaled.

Attendees also noted that involving particular groups may be easier than others. This may be for a range of reasons. For example, social media, online forums and other digital platforms offer the potential to engage some people, but **we need different approaches to reach those who don't have access to or are unable to use digital tools**; in obstetrics and mental health, service users may be more familiar with being asked about their health and care goals and so may feel more comfortable or better equipped to engage in feedback loops.

## Deepening collaboration and aligning efforts

Co-designing and collaboration are key features in all Better Care projects and were discussed throughout the Insights Sharing Day. In the case of computable guidelines, there's an enthusiastic community of data scientists, practitioners and guideline creators working on various projects but to make real progress we need to work together. For example, Andrew Mitchell from NICE explained that, although it would make sense for guideline creators to make this knowledge computable at source, they simply aren't set up to do it; they are faced with "a sea of guidelines" and internal structures, skills and staff that are oriented towards more traditional publication of human-readable content.

Philip Scott (University of Portsmouth) discussed his efforts to improve collaboration on computable guidelines through the [HDR UK Better Care collaborathon](#) and the creation of the [UK Mobilising Computable Biomedical Knowledge \(MCBK\) working group](#), which includes BCS – the Chartered Institute for IT, the Faculty of Clinical Informatics, NICE and Health Education England. One challenge he noted was that human nature would rather create from scratch than use something someone else had created, which leads to a proliferation of different approaches and tools. Participants agreed that this variety and reproducibility is valuable for validation but expressed real **interest in developing a shared vision and roadmap** for developing and implementing computable guidelines that could help make these efforts more than the sum of their parts.

In moving towards more coordinated collaboration, open science will be critical. For example, many coding languages – like PROforma – are open source, but other platforms are not. Sharing and collaboration is a fundamental part of the Better Care programme and Monica Jones (HDR North) described how she has been working to create a knowledge hub for resources and insights from across the three Better Care projects on frailty and older patient care. In this respect, the Better Care programme plays an important role, with events like the Insights Sharing Days offering valuable spaces for different people (from data scientists to patients) to share ideas and spot opportunities to align. As Better Care Research Director and meeting chair Simon Ball underlined, "**Without an open science approach, things will go nowhere.**"