

## The new goal for the Centre for Expertise in and Improving Data Collaboration

DHSC's creation of the 'Centre for Expertise in Data' – now called the 'Centre for Improving Data Collaboration' – was partially in response to data missteps across the NHS. It has so far not been seen as effective, but that is largely due to a lack of a strategic shared vision for what good really looks like.<sup>1</sup>

Meanwhile, Shared Care Record providers – or, more specifically, the ICBs that run them – have told patients they can only opt out of sharing for their direct care by talking to care providers from whom they have never received care.<sup>2</sup>

In addition, the complete absence of published IG “journeys” for planning or research<sup>3</sup> means areas are ‘doing their own thing’ with regard to secondary uses – something NHS England will be unable to walk back when it predictably turns into a postcode lottery. (It also means that millions of patients are currently being misinformed that ShCRs will be *for their direct care only*, when the clear intention is for planning and research uses as well.)

How exactly does this meet Dame Fiona's exhortation of “No Surprises”?

Having “expertise” without an actual vision to implement does not encourage change; **the Centre's key objective should therefore be to monitor and encourage implementation of open ways of working, applied to all data projects, to support replication of findings, and to minimise the cost to the NHS overall.**

For a centre of expertise to operate effectively, it needs not just fine words but an overarching model from which to work. The Goldacre recommendation to move to **open ways of working** is such a model; it should be resourced and enforced, with data published regularly about how implementation is going across both DHSC and the NHS.

With this shared goal, it will be more straightforward to ask questions and ensure meaningful, measurable answers are given of data projects, like:

- How will all of the NHS benefit?
- How can new projects benefit from other (recent) ones?
- Will the data outputs all be published, and reproducible?

Thereby offering two major improvements; the shutting down of secrecy and profiteering models.

Part of enforcement should also be to amend NHS procurement, so that if you are *buying* a data driven/based tool, or a model/service derived from data, you are told upon which data it was trained.

It should also be the job of the centre to check that those who say they've used data are actually those who did – promoting those who follow good practice and restricting those who take shortcuts, to deliver the recommendations of the Goldacre Review. Action in this regard will be an early sign of whether (and how) the Review will be implemented, or whether it just sits on the shelf.

---

<sup>1</sup> 'Frameworks' couched in management-speak are neither strategic, nor visionary.

<sup>2</sup> Correspondence with NHSx in early 2021 confirms this is a deliberate decision. By making the opt-out work only at individual organisation level, the ICS puts undue burden on those who want a 'blanket' opt-out, which – as with Summary Care Records – could (still) be offered as an option.

<sup>3</sup> Journeys 3 & 4 appear in IG Framework drafts as far back as 2019, but are *not mentioned at all* in this: <https://www.nhs.uk/information-governance/guidance/summary-of-information-governance-framework-shared-care-records/information-governance-framework-for-integrated-health-and-care-shared-care-records/>