

medConfidential's Initial Questions on a Central Care Record [October 2024]

Secretary of State has [announced](#) and then re-announced the Central Care Record.

The record will be available wherever the NHS logo is shown – pharmacy, GP, hospital, physio, dentist, ambulance, etc. While not all the record will necessarily be available in all places (one presumes - but there are details to work through), there are enough edge cases where sensitive data would always be available (e.g. medications) that role/purpose based access control is necessary but not sufficient.

Whatever technical design chosen for that record, we here look at trustworthiness. Whoever is thinking of how Ministerial oversight for how this project will work should [read Lord Freud's book](#). We'd like additional clarity given the [breaking](#) of pandemic-only use GDPR promises and the inaccuracy of Ministerial statements about the Data Uses and Abuses Bill.

It is utterly perverse that DHSC will classify their memo/chats about this note at a higher level than the consolidated medical history and medical notes of every citizen in the country. The entire database should be treated as if it was a bulk personal dataset and then be Classified accordingly ([item 5](#)).

The first necessary topics needing clarity from DHSC:

- 1. Will accesses be hidden away from patients, or will the NHS App show people where/when their central care record has been accessed?** (by default, almost immediately, for everyone who can see prospective access to GP documents)

If patient access information is hidden, if there's secrecy, or if NHS England covers up access, then the entire system will be untrustworthy by design. It doesn't have to be this way, but it's a choice for DHSC/E. Choose better.

If the answer to that question is yes – everyone with prospective access to documents can see when/where their central care record has been accessed – then Ministers can (and must) clearly and repeatedly say that one of the principles underpinning the project will be *no secrecy from patients* about where their record has been accessed. People may have concerns about their record, but they will have evidence in the app to support or assuage those concerns. Secrecy and obfuscation by the Department of Health in England is the main reason none of this happened already - care.data could have worked in 2014 with minor tweaks to be consensual, safe, and transparent; patient interests were refused and the programme collapsed.

To genuinely demonstrate their commitment, Ministers should focus on tangible outcomes that showcase progress from past failures. A quick win would be to make available in the App existing audit trails for Summary Care Records (held by E) and then GP Connect (held either by E or TPP/EMIS). This would not only provide an immediate benefit but also serve as a catalyst for future improvements.

- 2. The promised “cast iron guarantees” in primary legislation. [Right intent](#), timing... tbc?**

Questions where we need more clarity on DH thinking:

3. What will happen to those people who have S-flags today? How will the evolution of them be managed? (ie what protection will be put on Wes Streeting's Central Care Record? Or Mrs Whitty's? Can a domestic violence victim whose abuser works in A&E get the same protections? What do they have to do to get that? What happens about individual sensitive records – can a new MP hide their depressive episodes as a teenager? What does that do for clinical care? - lots of questions, need answers)
4. This is a new system with new policy, so should have a more robust and transparent implementation of the National Data Opt Out – and the opt out should mean opt out; if you have an NDOO, then no data leaves the central care record for any secondary uses (including by the Department).
 - a. For those who wish their data used for research, there will need to be proper minimisation processes, selecting only the variables needed etc (the model for openSAFELY works here, but we've also [previously mocked something up](#) for DARS). The notion of “take all of HES” will degrade in the longer term as HES degrades as a cohesive entity.
5. **Mandation:** Does DHSC want having a central care record to be a direct consequence of having an NHS number – ie will a central care record be mandatory? We have assumed that it will be, but that is not necessarily certain? If it isn't mandatory, how will people make informed choices about it? If it is mandatory, that places a very high bar on protecting the data within it, and will require very careful drafting of primary legislation to get there from here. If everyone must have a central care record, and GPs must check it before prescribing as it is the system of record for the patient, in the medium term what is the need for TPP/EMIS and, more critically, what are all the consequences for GP?

Big proviso:

medConfidential will assess what information is (or should be) available at each stage of the project, and reassess the viability and trustworthiness of changes and the programme as a whole. That we have not asked about something in week one does not mean we will not become newly aware of it in year five...

Currently everyone is putting their own goals and objectives onto the plans, which will need stable leadership (hence: [read Lord Freud's book](#)) and a stable vision that everyone understands.¹ Most of the emails medConfidential have received since coverage of the announcement have been saying something like “I don't see why you're so critical as *it could be good if they just also did ...*”, and often those suggestions were sensible improvements. But we have to point out that, based on public information, the system will not be what they think sensible, and then they are much less welcoming of what Ministers are talking about...

¹ The themes in this document were written on our website in 2016 when we were asked the question “what should we do after care.data?” <https://medconfidential.org/information/towards-every-flow/>