

medConfidential note on Draft Health and Adult Social Care (Continuity of Information) Bill

Draft Bill: http://www.georgefreeman.co.uk/pdf/Health_Adult_Social_Care_Bill.pdf

No explanatory notes have been published by the Department of Health, but George Freeman MP has put a note¹ on his website. Mr Freeman's previous Private Members' Bill, the Electronic Patient Records (Continuity of Care) Bill², did not complete its passage through Parliament before the end of the last session³.

It is notable that two of the key principles of Mr Freeman's previous Bill - those of patient ownership and control of their medical records - have been dropped. His original 'maintenance' principle has been turned into measures mandating the use of the NHS number by bodies outside the NHS and a 'duty to share'.

Primary legislation seems unnecessary for the latter purpose, as shown by the equivalent mandate being implemented within the NHS. This is a rather heavy-handed way to treat health and care professionals who already have a duty of care, and seems both controversial and counter-productive.

What is significant is that use of the NHS number in information that is shared will make it much more readily available for uses *other* than patients' direct care.

That neither the NHS number itself nor secondary use of patient data is mentioned on the face of the Bill is concerning for, as Mr Freeman himself has said, wider use of the NHS number as a "default identifier" has been a "long-standing Department of Health priority". And, as the care.data and HES debacles have shown, it is secondary uses - and the conflation of them - that undermines public trust. Quite clearly, mandating the use of the NHS number is not just for patients' direct care or the purpose of maintaining a record.

The use of the NHS number as a unique identifier *outside* the NHS is deeply problematic. This would be one instance where the use of 'pseudonyms' (i.e. replacing someone's NHS number with an otherwise meaningless number that can only be re-associated with their NHS number *inside* the NHS) would be sensible, in fact necessary, if one is to avoid the misuse and undermining of a highly sensitive identifier.

The following are some concerns that medConfidential believes must be addressed:

1) In providing exceptions to when identifiers may be used or information shared, the Bill acknowledges there are serious risks in the expanded use of the NHS number, but in so doing it undermines both its own logic and the implied consent model on which direct care in the NHS fundamentally depends.

¹ <http://westminster.georgefreeman.co.uk/content/government-backs-freeman-and-patients4data-campaign-and-bill-integrated-patient-records>

² <http://www.publications.parliament.uk/pa/bills/cbill/2013-2014/0134/14134.pdf>

³ <http://services.parliament.uk/bills/2013-14/electronicpatientrecordscontinuityofcare.html>

In order for someone to object to the use of their NHS number or sharing of their information they must be properly informed of this right and how they can exercise it. Any information given in a direct care context must also address secondary uses of patients' data. If nothing else, failing to provide information about the intended uses would be unethical and a breach of fair processing.

We have seen already from care.data the devastating impact on public and professional trust when notification and consent are poorly handled.

2) Conflating implied consent for direct care with presumed consent ('opt out') for secondary uses would further erode public trust, possibly catastrophically. One cannot simply presume upon the "consent deal" between the NHS and its service users, as Dame Fiona Caldicott pointed out in the Information Governance Review⁴ with regard to commissioning.

Mandating an identifier would lead, over time, to all sorts of systems being designed to use it as their primary identifier. Economic incentives make this pretty much inevitable – it is more complex and costly to support multiple identifiers. And then there would be the systems that must 'talk to' those systems, and so on.

3) Because patient data is already linked using the NHS number and disseminated for purposes other than people's direct care, the mandated use of it as the "default identifier" for linkage across and between providers could actually threaten or undermine direct care and patient safety. It may even be people most likely to refuse consent would be amongst those who stood to benefit the most in a direct care setting.

An example might be the linking of HIV/AIDS status or prescriptions from clinics to GP records. While there may be good reasons to do this for a person's safe care, such as interactions with other prescribed medications, some still prefer not to disclose such information for other reasons, e.g. fear of discrimination or knowledge that patient-level data is routinely extracted and linked for secondary uses in other contexts.

4) Assuming companies, organisations and agencies outside the NHS were required or allowed to use the NHS number as a unique identifier, aside from 'consistency' with the Data Protection Act, the Bill is mute on what other information might be associated with or linked to a person's records on their systems.

It is difficult to see how interactions between a person's NHS number and other systems could be prevented in practice, especially if tickbox consent for the provision of care becomes the norm. And even if the Bill were amended to explicitly prohibit such associations or linkages, how would these be monitored and enforced?

Though monetary penalty notices from the Information Commissioner's Office are often quoted as a disincentive, £500,000 is hardly significant to larger companies and it is wildly optimistic to assume that the ICO would be able to identify, let alone act, in more than a fraction of cases.

5) It is relatively straightforward to discover significant amounts of personal information⁵ about

⁴ <https://www.gov.uk/government/publications/the-information-governance-review>

⁵ <http://systems.hscic.gov.uk/demographics/pds/contents>

someone from their NHS number, e.g. by looking them up on the Personal Demographics Service (PDS) to which many thousands already have access. By widening access to and use of systems like PDS - an inevitable consequence if patient details are to be checked or verified - the potential for abuse and misuse will be exacerbated.

We presume that full cost/benefit and risk analyses will be published in due course. These must factor in the administration and policing of a more general purpose system of identification. The NHS number is not 'just' a number, it is an identifier – the value of which has been protected thus far by the specificity of its use within the NHS and common understanding of that purpose.

It would be unwise to start the NHS number on its way down the slippery slope of identifiers like the SSID in the US, the problems with which are well-known. Without providing some means for people to know who is making use of their NHS number, making it more generally available on non-NHS systems undermines both the security of the identifier and the security of the people it identifies.

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