

medConfidential briefing on [Health and Care Bill](#) 2nd reading ([PDF](#))

In the midst of a pandemic, and with a Government that has a... unique approach to detail, we first pick up on some of what is missing from the Bill, and then what it intends to do.

We are happy to go into more detail on any point as useful as the Bill progresses. Please contact: coordinator@medConfidential.org

What's missing:

Unexpectedly – No clauses for shared care records and interoperability

DHSC's proposal for "Shared Care Records"¹ should have at least a 'hook' in primary legislation, if it wishes to avoid an implementation shambles.

We would expect the Government to amend the Bill at some point to add a clause or clauses to this effect. Such amendments should be required to include *explicit* clarity on a single dissent by patients who do not wish to have a shared care record, versus the current 'postcode lottery' of opt in and opt out processes.

Unsurprisingly – Nothing to put the National Data Opt-out onto a statutory footing

Given the language in Clause 81(2)(b) and (c), the competitive tension *must* be addressed with a statutory National Data Opt-out, otherwise the "balance" would be entirely in favour of NHS England – especially given the lack of protection from the "statutory" safe haven powers being reassigned to someone else via Clause 88(3). The Bill as drafted would in effect hand NHS England full powers to determine what data it takes, who that data can be sold to and what rules apply, without any external oversight.

Another power grab – no statutory basis for what replaces Public Health England

Does the Government intend to restructure Public Health provision in England by executive powers, or will a large amendment be laid? While it is, of course, the role of Secretaries of State to apportion powers within their Department and associated bodies, it is notable that this Bill makes no mention of the new bodies established in and around Public Health over the past year.

Powers relating to GP data

Can the Government confirm that there are no powers in this Bill to compel GPs or their IT suppliers to provide patients' personal data to any DHSC or NHS body for secondary uses, and that the Government is not going to amend this Bill at a late stage to add any such powers?

¹ <https://medconfidential.org/2021/shared-care-records/>

Bill Priority – Clause 1

Given the many serious and significant issues confronting health and care right now, the chosen focus of Clause 1 perfectly demonstrates the navel-gazing approach of DHSC to the challenges it faces.

It is however notable that nowhere in the Bill is provision made for the Health and Social Care Information Centre (HSCIC) to be formally renamed NHS Digital in statute. Perhaps it is not intended for NHS Digital to exist for much longer? See, for example, Clauses 86-88...

Powers to *require* information – Clause 19

Given issues caused by such powers to **require** information in HSCA 2012, awarding NHS England a general power to require information from integrated care boards [14Z58 *Power of NHS England to obtain information*, page 25] for the breadth of purposes defined in 14Z61(1)(e) on page 27 seems injudicious:

(e) the disclosure is made to any person in circumstances where it is necessary or expedient for the person to have the information for the purpose of exercising functions of that person under any enactment,

It is understood that NHS England will need “information” (e.g. statistics, aggregate counts) in order to fulfill its statutory obligations, but – given the intention to implement patient-level ‘shared care records’² within and across integrated care systems, and NHS England’s repeated attempts to take copies of patients’ data for purposes beyond their own care – **it should be explicit that this does not (or does) allow personal data to be required.**

Data – Clauses 79-85

Clause 79 – Why does NHS England receive a carve-out?

Clause 79(2)(c) appears to remove the explicit obligation that previously existed under Section 250(6)(b) of HSCA 2012 that NHS England “must have regard to an information standard published under this section”, replacing it with a power for such obligations to be waived by Regulation.

Question for Committee, with a leave-out amendment: “Can the Minister confirm that this clause grants no powers to NHS England that it does not already have, and what powers it would be denied if this clause was left out?”

“Can the Minister confirm that these powers will not relate to personal data?”

We note that sub-clauses 79(2)(c) (6B) and 79(3)(3) may interact badly, and that Clause 79(2)(b) removing the requirement for guidance about implementation is a retrograde step.

² <https://medconfidential.org/2021/shared-care-records/>

Clause 80 – “Anonymised” or “anonymous”?

Are these terms used to mean the same thing as within Data Protection law?

This clause would allow DHSC / NHS England to require the provision of any “anonymised” data it wants from private health care providers – mirroring 14Z58 in Clause 19 earlier in the Bill. (As an aside, if anyone thought ‘going private’ would avoid inclusion in NHS data debacles, this Clause shows that it won’t.)

As drafted, it is unclear what – if any – personal data will be excluded from this Clause, given the current practical definition of “anonymised” data used by the NHS, as debated in the Commons on 23rd June by the former Secretary of State for Health and Social Care.³

Clause 81 – Issues of public trust and confidence

Clause 81 should include a statutory obligation to uphold the National Data Opt-out where it applies, but this (sub)clause is missing.

Clause 81(2) requires NHS Digital to give regard to “the need to promote the effective and efficient planning, development and provision of health services and of adult social care in England”. While NHS England (NHSX) ‘hid behind’ research in promoting its recent GP data grab, it is notable that academic research does not appear anywhere in the definition of what NHS Digital is obliged to do.

As drafted, this Bill makes NHS England the sole authority on NHS Digital’s use of patients’ data – other than being required to implement the whims of the Secretary of State, who can change the law as he or she wishes. That is an unsustainable situation for something called a “statutory safe haven” for patient data (although we expect data scandals to emerge during passage of this Bill which will require this imbalance to be addressed).

Clause 81(2)(c), “the need to balance the needs mentioned in this subsection against one another, so far as they compete” implies a *competition* between “effective and efficient planning” and the “the need to respect and promote the privacy of recipients of health services and of adult social care in England”. This seems misconceived for services that, by their very nature, must be fundamentally grounded in public confidence.

The explanatory notes to this Clause state: “The effect of this is to place consideration of benefit to the health and care system at the centre of NHS Digital’s duties.”⁴ To benefit a system which often forgets that the data it uses is sensitive and identifiable personal data about patients, is not of necessity a public good – nor is it conducive to public trust.⁵

³ <https://hansard.parliament.uk/Commons/2021-06-24/debates/2FA13B90-5377-4E73-A941-80F6A536B560/UseOfPatientData#contribution-EDDBC93-A422-46CF-8D2E-CE967D1EE2EF>

⁴ page 114, <https://publications.parliament.uk/pa/bills/cbill/58-02/0140/en/210140en.pdf>

⁵ “Confidentiality is considered an essential element for gaining and sustaining trust. It is not absolute and other ethical considerations may supersede, but this does not mean it can be ignored or overridden wholesale by ill-defined utilitarian considerations of the ‘public good’.”- <https://www.nuffieldbioethics.org/blog/health-data-medical-confidentiality-and-the-right-to-privacy-is-gpdpr-the-new-care-data>

The only possible reason for Clause 81(3) to replace “the promotion of” health⁶ with the far broader and less specific “purposes connected with” health is to allow data uses, including use by NHS England for planning, which may undermine local health provision and/or public trust. (Undermining health clearly being one of many “purposes connected” with health.)

Closing an Accident and Emergency unit in Chorley may not promote health, but it is definitely *connected* with it – and such a change would also potentially allow a “causes of cancer” study to be run by a tobacco company (again).⁷

Clauses 86-92 – moving powers between bodies

Clauses 87 and 88 each need a subclause similar to 87(3) to protect the statutory safe haven powers of NHS Digital, i.e. to exclude any of the powers in Part 9 of HSCA 2012, and to preserve the independence of the Confidentiality Advisory Group which makes sensitive decisions about the use of personal data, including for commissioning:

Insert at end of clauses 87 and 88:

- “() Regulations under this section may not transfer:
- (a) any function described in Part 9 of the Health and Social Care Act 2012,
 - (b) responsibility for the Confidentiality Advisory Group of the Health Research Authority”.

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⁶ Noting that this amendment ‘constraining’ dissemination was added to HSCA 2012 as a direct result of the care.data and HES scandals in 2014.

⁷ <https://www.digitalhealth.net/2018/01/public-health-england-cancer-patient-data/>