

medConfidential and Big Brother Watch Briefing for the Public Bill Committee on the Health and Social Care (Safety and Quality) Bill

Background and Introduction

medConfidential and Big Brother Watch welcome this Bill as an important contribution to the debate around the safe delivery of high quality care; this briefing is in the spirit of preventing an unintended side-effect of a potentially positive change.

The first part of this briefing refers to the fact that an earlier draft of language from the Department for Health on this topic accidentally turned the use of NHS numbers into an ID card scheme. This Bill has avoided that problem with explicit prohibitions on uses, but leaves an unclear area which will only grow over time. This can be solved by a transparent register of uses, ensuring all uses and any investigation of the use of the NHS number outside of the NHS can be grounded in facts and firm citations.

The second part of this briefing refers to an amendment to meet the Secretary of State for Health's desire to put the National Data Guardian, Dame Fiona Caldicott, on a statutory footing "at the earliest opportunity"¹. This Bill is that opportunity.

While care.data is not directly related to this Bill, it is part of the public discourse around NHS England data programmes, so a summary of the scheme is included in an appendix to this briefing. For background, no Committee member has a constituency included in the "pathfinder" (pilot area) CCGs of the care.data scheme.

We are happy to arrange a briefing with Members prior to the Committee session on Wednesday to discuss this matter further if they so wish.

About medConfidential: medConfidential is an independent non-partisan organisation campaigning for confidentiality and consent in health and social care, which seeks to ensure that every flow of data into, across and out of the NHS and care system is an appropriate balance of *consensual, safe and transparent*. www.medConfidential.org

About Big Brother Watch: Big Brother Watch was set up to challenge policies that threaten our privacy, our freedoms and our civil liberties, and to expose the true scale of the surveillance state. Founded in 2009, we have produced unique research exposing the erosion of civil liberties in the UK, looking at the dramatic expansion of surveillance powers, the growth of the database state and the misuse of personal information. We campaign to give individuals more control over their personal data, and hold to account those who fail to respect our privacy, whether private companies, government departments or local authorities. <http://www.bigbrotherwatch.org.uk/>

¹ <https://www.gov.uk/government/news/national-data-guardian-appointed-to-safeguard-patients-healthcare-information>

Amendment 1: To prevent/monitor NHS Number proliferation

Amendment

Part 1, insert new:

(4) No public body shall request, process, or store any “consistent identifier” without a current notice of approval of the Secretary of State, to be given only for the purposes given in Regulations. All such notices shall be published, and shall expire no more than 3 years after publication.

(5) Any body, other than covered by (4), requesting, processing or storing any “consistent identifier”, other than as a “data processor” for a public body, should have a notice of approval from the Secretary of State, to be given only for purposes given in guidance published by the National Data Guardian. All such notices shall be published and shall expire no more than 3 years after publication.

a) Notices shall give the location of a record of any responsible “fully registered medical professionals” registered under section 30 (1) of the Medical Act 1983.

b) “data processor” has the same meaning as defined in the Data Protection Act 1998;

Explanation

No one knows who is using NHS numbers as there is currently no record being kept. This amendment is therefore a simple transparency amendment. The Department for Health has spoken of being able to use NHS numbers as being part of the “NHS club”. This amendment would require there to be a public membership list for that club.

The Bill currently requires some people to use NHS numbers, prohibits others from doing so, and leaves an known grey area in the middle. We propose that this grey area be covered by a register; in short, if you use the NHS number you must be registered (NHS/public bodies already do this, so it’s not a burden on them. HSCIC can consolidate various private lists into one public list, and is something easy enough to include elsewhere.) The alternative is that use of NHS numbers spread silently and we won’t know what’s happening.

This will not stop a body abusing access to NHS numbers, but will allow for an early warning process that individual organisations may be doing so, and the National Data Guardian can intervene.

Amendment 2: Place The National Data Guardian (Dame Fiona Caldicott) on a Statutory Footing

Amendment:

Insert new Part 4, and renumber:

4 The National Data Guardian

In Part 9 of the Health and Social Care Act 2012 (health and adult social care services: information), after section 251B (as inserted by section 3 of this Act) insert—

251C The National Data Guardian:

(1) There shall be a National Data Guardian, appointed by the Secretary of State, who must seek to improve the practice followed in relation to the processing of the “consistent identifier” or any relevant information, in exercising functions and when providing advice to the Secretary of State or others.

(2) The National Data Guardian shall have the power to suspend or disqualify any relevant body from processing of the “consistent identifier” or any relevant information.

(3) The National Data Guardian may request from any relevant body specified information for the purpose of enabling the Guardian to ascertain whether the relevant body has had proper regard to the processing of the “consistent identifier”; to any relevant information; or to any advice given to the relevant body by the Secretary of State.

(4) The Secretary of State may by regulation impose requirements as to the processing of the “consistent identifier”, or any relevant information, as the Secretary of State thinks fit for the purposes of clause 1, having regard to advice from the National Data Guardian.

(5) The National Data Guardian shall be a person registered under section 30 (1) of the Medical Act 1983.

Amend, National Health Service Act 2006 (1H) (3) to add:

(c) must have regard to advice from the National Data Guardian

Amend, Health and Social Care Act 2012, 253 (1) to add:

(e) the National Data Guardian

Amend, Health and Social Care Act 2012, 259 (1) (a), prepend at start:

with consent of the National Data Guardian,

Explanation:

The Secretary of State for Health, when appointing Dame Fiona Caldicott as the first National Data Guardian on 13th November, said “I intend to put the National Data Guardian on a legal footing at the earliest opportunity”². This Bill is such an opportunity, given the explicit focus on

² <https://www.gov.uk/government/news/national-data-guardian-appointed-to-safeguard-patients-healthcare-information>

the use of NHS numbers across Health and Social Care. Where the NHS number is used, or must not be used, is within the remit of the National Data Guardian.

This amendment would facilitate the display of cross-party opinion in a discussion of (and, if incorporated, deliver on) the Secretary of State for Health's commitment - given because, in his words, "we need to be as determined to guarantee personal data is protected as we are enthusiastic to reap the benefits of sharing it. Dame Fiona will oversee the safe use of people's personal health and care information and hold organisations to account if there is any cause for concern, ensuring public confidence."³

Clause 5 ensures there is General Medical Council regulation of the National Data Guardian (accountable to Parliament). The final 3 amendments add the National Data Guardian to the oversight of NHS England, HSCIC and section 259 requirements, so that the relevant bodies must consult the National Data Guardian (see care.data status addendum for details).

If this amendment is not incorporated by Jeremy Lefroy MP, any member wishing to move this as a probing amendment would be very welcome. We would be happy to discuss this possibility further.

medConfidential & Big Brother Watch
coordinator@medconfidential.org
emma.carr@bigbrotherwatch.org.uk

³ ibid