

**Parliamentary control over the
Health and Social Care Information Centre**

Proposed amendment to the Care Bill

and

Briefing Note

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Care Bill [HL]

Proposed amendment

Parliamentary control over the Health and Social Care Information Centre

To insert the following Clause into the Health and Social Care Act 2012 as section 274A:

- (1) This section applies to—
 - (a) an information standard under section 250,
 - (b) guidance of the Secretary of State under section 253(1)(b),
 - (c) guidance of the Board under section 253(1)(c),
 - (d) a direction of the Secretary of State under section 254(1),
 - (e) a request of any person under section 255(1),
 - (f) a procedure of the Information Centre under section 257(1),
 - (g) exercise by the Information Centre of its power under section 259(1) and duty under section 259(8),
 - (h) exercise by the Information Centre of its duties and powers under section 260,
 - (i) exercise by the Information Centre of its powers under section 261(1), 261(4) and 261(5),
 - (j) dissemination of information by the Information Centre in reliance upon section 261(7),
 - (k) a requirement imposed on or a request made to the Information Centre to which section 262 applies,
 - (l) the code of practice on confidential information under section 263,
 - (m) the Information Register under section 264, and
 - (n) advice, guidance and requests under section 265.
- (2) The matters to which this section applies by virtue of subsection (1) shall not take effect unless an order has been made by the Secretary of State in accordance with the super-affirmative resolution procedure under section 18 of the Legislative and Regulatory Reform Act 2006; and the provisions of Part 1 of that Act shall apply to such an order as if it was to be made and was made under that Part.
- (3) Regulations under section 267, section 268, section 269, section 274 and paragraph 8A of Schedule 7 of the Care Act 2014 shall not take effect without an order as is referred to in subsection (2).
- (4) Nothing in this section shall prevent the Information Centre from performing its functions to the extent that they are functions which were previously those of the Health and Social Care Information Centre under The Health and Social Care Information Centre (Establishment and Constitution) Order 2005.

Briefing Note

1. On February 18th NHS England announced a pause in the care.data programme¹. This is the scheme under which the Health and Social Care Information Centre (HSCIC), under the direction of NHS England, can require GPs to upload patient data in an identifiable form from every GP practice throughout England in order to link them to NHS Hospital Episode Statistics (HES) and other data sets.

2. The pause was deemed necessary to allay public concern that it was not known who would have access to their NHS patient data, nor the purposes for which it would be used. The Health Select Committee expressed similar anxieties in the first session of its inquiry into care.data². These concerns have been compounded by revelations that commercial companies including insurers³ and private healthcare insurance companies such as BUPA⁴ have been purchasing NHS patient data for purposes unknown to the public. As GPs became aware of the intentions behind the care.data system, a survey of nearly 400 GPs revealed that 40% of GPs stated they intended to opt out themselves⁵ over a lack of confidence in how data will be shared, and some GPs have gone further⁶ by opting all of their patients out of the scheme in defiance of NHS England guidelines.

The HSCIC is a new arms-length body established under the Health and Social Care Act 2012 which replaces the NHS Information Centre which was responsible for the collection, processing and dissemination of patient data for many years. Recent revelations⁷ show it lacks accountability, transparency and sufficient controls over the releases and outflows of patient data.

3. The government is now trying to appease the public by bringing forward amendments in the Care Bill to amend the HSC Act 2012. However none of the tabled amendments address the fundamental concerns.

In particular, the government amendments^{8 9 10} are deficient in the following regard:

¹ <http://www.england.nhs.uk/2014/02/19/response-info-share/>

² <http://data.parliament.uk/writtenevidence/WrittenEvidence.svc/EvidenceHtml/6788>

³ <http://www.telegraph.co.uk/health/healthnews/10656893/Hospital-records-of-all-NHS-patients-sold-to-insurers.html>

⁴ <http://www.theguardian.com/technology/2013/may/17/private-firms-data-hospital-patients>

⁵ <http://www.pulsetoday.co.uk/your-practice/practice-topics/it/over-40-of-gps-intend-to-opt-themselves-out-of-caredata-scheme/20005648.article#.Uxw3doWZQT9>

⁶ <http://www.pulsetoday.co.uk/your-practice/practice-topics/it/gp-hit-with-contract-notice-over-plan-to-opt-all-patients-out-of-caredata/20005749.article#.UxxbgoWZQT8>

⁷ For example, <http://www.theguardian.com/society/2014/mar/03/nhs-england-patient-data-google-servers> and <http://www.independent.co.uk/life-style/health-and-families/health-news/hospital-records-used-to-target-ads-on-twitter-and-facebook-say-privacy-campaigners-in-latest-nhs-data-concerns-9166633.html>

⁸ Amendment NC14, pages 1772-1773, tabled by Secretary Jeremy Hunt, with further amendment by Dr Daniel Poulter: <http://www.publications.parliament.uk/pa/bills/cbill/2013-2014/0168/amend/psc1680603a.1770-1776.html>

⁹ Amendment 17, pages 1776-1777 (link above), tabled by Secretary Jeremy Hunt

- NC14 (2): the general duty to respect and promote privacy is already a duty of public authorities which are bound by Article 8 of the Human Rights Act - this would add nothing;
- NC14 (3): limiting the dissemination of information only to “the purposes of the provision of health care or adult social care” would exclude legitimate research uses, yet still permit release of data to commercial interests for example, private healthcare companies including PFI companies, health insurers, the pharmaceutical industry, management consultants and for-profit private providers such as Virgin, Group 4 and BUPA. Amendment (c) to NC14 (3) by the Under-Secretary of Health, to broaden the purposes to “the promotion of health”, would draw the purposes so widely as to permit and put on a statutory basis the very misuses that this clause purports to address.
- NC14 (4): which states that HSCIC “must have regard” to the advice of the Confidentiality Advisory Group (CAG) is inadequate. CAG is “the committee appointed by the Health Research Authority” that considers and advises on Regulation 5 / Section 251 support for releases of identifiable patient data without consent. Amendment 17¹¹ extends CAG’s remit to the release or dissemination of *some* other types of data, but without independent oversight and full transparency on every release of individual-level patient data, the public simply cannot trust what is being done with their medical information.

Other amendments to NC14¹², though clearly intended as helpful, (a) may act to narrow the purposes for which data can be disseminated but still do not rule out the commercial exploitation of patient data, and (b) simply restate what should be the duties of any competent public authority handling individual-level data.

Amendment NC25¹³ is to be welcomed in that it recognises¹³ the seriousness of the offence of misusing patient data, and in that it would provide a serious disincentive for institutional abuse but we are concerned that there is no recognition of, nor process for, misuse or breach reporting by corporate entities - the effect of which may tend to penalise public institutions more harshly than commercial companies¹⁴.

¹⁰ Amendment 18, page 1777, tabled by Secretary Jeremy Hunt:
<http://www.publications.parliament.uk/pa/bills/cbill/2013-2014/0168/amend/psc1680603a.1777-1778.html>

¹¹ Amendment 17, pages 1776-1777, tabled by Secretary Jeremy Hunt:
<http://www.publications.parliament.uk/pa/bills/cbill/2013-2014/0168/amend/psc1680603a.1770-1776.html>

¹² Laid by Dr Sarah Wollaston, Paul Burstow, Charlotte Leslie and Andrew George, page 1773:
<http://www.publications.parliament.uk/pa/bills/cbill/2013-2014/0168/amend/psc1680603a.1770-1776.html>

¹³ Amendment NC25, pages 1773-1774, tabled by Mr Jamie Reed:
<http://www.publications.parliament.uk/pa/bills/cbill/2013-2014/0168/amend/psc1680603a.1770-1776.html>

¹⁴ A failure by one team should not necessarily threaten the good work of other teams in the same large institution, if misuse or breach is reported promptly and remedial action is taken. Universities, charities and the NHS itself are often one legal entity, whereas the commercial sector can be many, legally insulated entities. So, for example, an error by a single PhD student should not necessarily suspend all of a University’s medical research using patient data, but there should have been implications for each of the 8 insurance companies working on the Staple Inn Actuarial Society paper, as recently reported in the press.

4. The classification of different types of patient data and the purposes to which they may be put are complex not least because of the difficulties in delineating between research and non-research use. The government amendments as laid fail to address these complexities. There is a need for a longer period of consultation to get the legal provisions right.

5. In the meantime, if Parliament will not reject the government's inadequate amendments, the minimum action necessary as a stopgap measure in the interests of public trust is for Parliament to retain control over the operation of the Health and Social Care Information Centre and the associated provisions of Part 9 of the 2012 Health and Social Care Act. The proposed amendment would achieve this by ensuring that the main powers and duties in that Part are all made subject to the super-affirmative resolution procedure. However, subsection (4) of the amendment would ensure that the Centre can continue to provide the important services provided by its predecessor – such as its statistics and data collections, and other services, for example publication of Hospital Episode Statistics.¹⁵ A brief explanation of the super-affirmative procedure is set out in the Box below.

Box: the super-affirmative resolution procedure explained

“The Minister has a statutory duty to consult (section 13 [of the Legislative and Regulatory Reform Act 2006]) and must lay before Parliament an explanatory memorandum for the order including, among other things, details of the consultation (section 14). The Minister cannot make the order for 60 days from the date it is laid not including periods when either House is adjourned for more than 4 days. Within the 60 days a Committee of either House charged with reporting on the draft order can recommend that no further proceedings be taken on the order, can make recommendations for amendment of the draft order or could clear it without making recommendations. The minister must have regard to any resolutions or recommendations, or any other representations made during the 60 days. After the 60 days has elapsed, the Minister can either proceed with the draft order without amendment or lay a revised draft order, and then there is a further process of non-time limited committee scrutiny and affirmative approval by both Houses. A Committee of either House can thus block an order if it believes that, even if amended, it is still unsatisfactory. Only a resolution of the relevant House can overturn the Committee's recommendation.”

Draft Communications Data Bill Joint Committee, First Report,
Appendix 7: Procedure for super-affirmative resolution, 28th November 2012.
<http://www.publications.parliament.uk/pa/jt201213/jtselect/jtdraftcomuni/79/7918.htm>

¹⁵ <http://webarchive.nationalarchives.gov.uk/20120802111034/http://www.ic.nhs.uk/statistics-and-data-collections>

6. A brief explanation of the provisions affected by the proposed amendment – all in Part 9 of the 2012 Act, save one which would appear in the Care Act – is set out in the Appendix on pages 7 - 9.

7. We respectfully urge MPs and members of the House of Lords to propose and support the proposed amendment set out above.

Appendix

Provisions affected by the proposed amendment

A. *Provisions of the Health and Social Care Act 2012 referred to in subsection (1) of the proposed amendment*

Section 250 enables the Secretary of State and the NHS Commissioning Board (the Board) to set standards for health services or adult social care in England about the processing of information, such as technical standards (e.g., systems' specification and interoperability), data standards (e.g., structure and type of information to be recorded such as date of birth and clinical condition) and information governance standards.

Section 253(1)(b) and (c), respectively, gives the Secretary of State and the Board power "as [they] may require" to issue guidance that the Information Centre [IC] must have regard to in exercising its functions.

Section 254(1) gives the Secretary of State and the Board power Powers to direct the IC "to establish and operate a system for the collection or analysis of information" specified in the direction.

Section 255(1) gives the power to any person (not being the Secretary of State or the Board) to request the IC "to establish and operate a system for the collection or analysis of information" specified in the request.

Section 257(1) imposes a duty on the IC to publish procedures for making, considering, and reconsidering requests.

Section 259(1) gives the IC power to require provision of information from health and social care bodies and from persons providing services under arrangements with a public body; and to request information from others. Section 259(8) requires the Centre to publish a procedure for notifying persons of requirements imposed and requests made.

Section 260 imposes a duty on the IC to publish – with four exceptions - all information it obtains as a result of complying with a direction from the Secretary of State or the Board under section 254, or with a request under section 255. Those exceptions are: (a) information in a form which identifies a corporate or individual care provider or which enables their identity to be ascertained, provided that the IC considers that it is not appropriate to publish it after taking into account the public interest and the interests of the provider, and unless a direction overrides the exception; (b) the information is in a form which identifies an individual who is not a provider or enables their identity to be ascertained; (c) the IC considers that the section 250 information standards are not met and publication would not be in the public interest; and (d) the information is of a description specified in a direction from

the Secretary of State or the Board.

***Section 261(1)** gives the IC power to disseminate (other than by way of publication) any information it obtains as a result of complying with a section 254 direction or a section 255 request in five instances. The three main ones are if the information (a) is required to be published under section 260; (b) it identifies or enables the identity to be ascertained of a corporate or individual care provider and they have consented or the IC considers there to be a public interest override; or (c) it identifies or enables the identity to be ascertained of an individual and they have consented. **Section 261(4)** gives the IC the further power to disseminate the information so obtained (whether falling within one of the five instances or not) if the information could have been lawfully disclosed by the person from whom the IC collected it. **Section 261(5)** gives the IC further disclosure powers, such as if there has been previous lawful disclosure, if it is necessary or expedient for the exercise of any statutory function or if in connection with a criminal investigation. **Section 261(7)** allows the IC to disseminate information under any other (unspecified) statutory provision.*

***Section 262** imposes a duty and confers a power on the IC to disseminate information obtained pursuant to a section 254 direction or to a section 255 request, respectively, generally in accordance with the direction or request.*

***Section 263** requires the IC to prepare and publish a code of practice on the collection, analysis, publication and other dissemination of information which identifies an individual or enables their identity to be ascertained and of other information subject to an obligation of confidence.*

***Section 264** requires the IC to maintain and publish an information register with descriptions of information obtained by virtue of Chapter 2 of Part 9.*

***Section 265** imposes a duty and confers a power on the IC to give advice or guidance to certain bodies.*

B. Provisions referred to in subsection (3) of the proposed amendment

These five provisions relate to powers conferred on the Secretary of State to make regulations, relating to:

- *establishing and operating the accreditation scheme for information service providers, under either the IC or under “such other person as the Secretary of State may specify in the regulations” (**Section 267**).*
- *conferring functions on the IC about establishing, maintaining and publishing database quality indicators (**Section 268**).*
- *conferring on the IC functions about verifying the identity of GPs (**Section 269**).*

- *conferring powers on the Secretary of State to give additional directions (Section 274).*
- *factors or matters that an advisory committee which the Health Research Authority (which would be established under clause 108 of the Care Bill) must appoint under Schedule 7 of the Bill must have regard in giving advice (Schedule 7, paragraph 8A) (See Amendment 18, page 1777 of 'NOTICES OF AMENDMENTS given up to and including Thursday 6 March 2014'.)*

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