

# Care Bill Amendments

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## Background

The data collected across health and care in England is the envy of the world. The care.data programme which is being commissioned by NHS England on behalf of the National Information Board (NIB), intends to offer the ability to link existing data securely and safely to produce information that can save lives, quickly find new treatments and cures, and support research to benefit all of us.

In February 2014, NHS England announced that it would be extending the public awareness campaign for care.data by six months in order to ensure that there is a better appreciation of the purpose of the programme. NHS England will be leading that work and the Department of Health and the Health and Social Care Information Centre (HSCIC) fully support NHS England's decision to extend the public awareness campaign.

In the meantime, the Secretary of State announced a package of measures to help rebuild confidence and support for the care.data programme. Having listened to key stakeholders and also to discussions in Parliament, this package of measures – including amendments now made to the current Care Bill – are designed to respond to those concerns to address the approaches Ministers have heard will help give the public confidence that their data is safe. The measures relate to the statutory role and functions of the HSCIC and are set out below, along with an assessment of their implications for the HSCIC.

## Details of the package of measures

Measures announced by the Secretary of State include<sup>1</sup>:

1. Confirming - **on a legal basis** - that **a patient's right to object to their information being used for purposes other than direct care will be respected** - if they object, identifiable data will not flow to the HSCIC for purposes other than direct care. This will be addressed through Directions to the HSCIC.
2. New legislation to **expressly prevent HSCIC from disseminating information** where there is **not a clear health care or adult social care purpose** i.e. **not** for purposes that would undermine people's privacy such as to inform the calculation of insurance premium or for direct marketing, or where it is solely for commercial purposes. This legislative change will not affect the publication of anonymous data and will be addressed through an amendment to the Care Bill.
3. New power in the Care Bill to **create strict new criteria in statute to govern the advice of the expert advisory group (i.e. the Confidentiality Advisory Group or CAG) on releasing identifiable or potentially identifiable patient data** – for example, the release is for the good of health and care, that patient privacy will be respected and that the applicant has not breached these rules in the past. Proposed amendments would ensure that organisations which misuse data provided under licence would not be able to receive such data in the future.

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<sup>1</sup> Please note these are not the amendments to the Bill itself but a description of the intention.

4. New legislation creating external scrutiny by that **expert advisory committee (i.e. the Confidentiality Advisory Group)** for HSCIC's decisions to release data (for purposes other than direct care) which could potentially be used to identify individuals. This legislative change will not affect the publication of anonymous data and will be addressed through an amendment to the Care Bill.
5. New addition to the HSCIC statutory code of practice to be clear that **an independent assessment of the ethical basis for the request must be provided** before any application can be considered.
6. New legislation to expressly bind **the Health and Social Care Information Centre to protect individuals' confidentiality when anonymised data is released** – in line with the Information Commissioner's Office's strict code of practice on using anonymous data. This will be addressed through secondary legislation.

This intention is, subject to the will of Parliament, for amendments to the Care Bill and the other Directions, Regulations etc. to come into force as soon as is practical, and certainly before the end of the current calendar year.

## Implications for the HSCIC

Set out below is the initial assessment of the implications of this package of measures for the HSCIC:

1. **Patient Objections:** The HSCIC was already working on the basis that patient objections will be respected across all collections of primary care data by the HSCIC and all data dissemination. Work is already underway to put in place robust policies and processes to achieve this, including clear communications to data recipients. This will require a significant amount of work, particularly in relation to the implementation of patient objections to their identifiable data leaving the HSCIC (often referred to as a type 2 objection). It is unclear how other organisations in the health and care system who receive identifiable data from GP systems will uphold an objection. Clarification will be sought from departmental colleagues that CAG will ensure objections are respected where approval to collect personal confidential data from GP systems is given to other organisations under s251 Regulation 5 approvals.
2. **Purpose:** The amendment to the Care Bill to prevent HSCIC from disseminating information where there is not a clear health care or adult social care purpose will assist the HSCIC in ensuring there is absolute transparency in relation to the purposes under which data may be released. However, further clarity is required in relation to: any restrictions which may be placed on the geographical scope of data release; why the purpose is for adult social care and not social care per se and what the implications of this may be; and, to confirm what types of information this will relate to. Work is already underway, following the Health Select Committee hearing on 25<sup>th</sup> February 2014, to review and strengthen controls around the release of data for purposes other than direct care as part of the 'Transparency and Information Assurance Programme' and clarification will be sought through this route.

3. **Confidentiality Advisory Group (CAG):** CAG already considers requests for data made to the HSCIC and the inclusion of criteria in statute to govern the advice of CAG is essential in that it will serve to assure the public that there is absolute transparency in relation to the purposes under which data may be released by the HSCIC. The Board may wish to offer support in the development of the criteria given their expertise.
4. **External scrutiny of HSCIC's decisions to release data which could potentially be used to identify individuals:** Clarification is required from departmental colleagues that the proposed scrutiny will extend to other bodies including Public Health England.
5. **HSCIC code of practice:** The HSCIC will work with departmental colleagues to clarify the intent in relation to this proposal during the development of the code of practice. In particular to confirm whether the independent assessment of the ethical basis for a data request should apply to requests to the HSCIC for data collections, data processing by the HSCIC and data release. This will then be formalised in the code of practice. The Transparency and Information Assurance Programme will oversee the implementation of any consequent changes to scrutiny.
6. **Compliance with the Information Commissioner's Anonymisation Code of Practice:** The HSCIC has already adopted the Information Commissioner's Code of Practice. We are aware, from our discussions with the Information Commissioner's Office (ICO), that they did not develop this Code of Practice with the intention of it being adopted in legislation. The decision to adopt it in legislation may have implications which require wider consideration.

The HSCIC welcomes the speed with which the legislative changes are being addressed, as set out in these measures. The HSCIC has a critical role to play in the design and delivery of care.data. Our infrastructure and data services will be the means by which the programme is implemented, and we have a package of work in progress aimed at ensuring that our delivery platform is ready to support the care.data programme. The programme will address technology, information governance and security requirements.

## Actions Required of the Board

*This paper is provided for information and for comment.*