

BOARD PAPER - NHS ENGLAND

Title: Publication of Directions to Health and Social Care Information Centre for the collection of primary care data

Clearance: Tim Kelsey, Director of Patients and Information

Purpose of paper:

- To present to the Board Directions to the Health and Social Care Information Centre for the collection of primary care data for approval.

Key issues and recommendations:

- NHS England has commissioned the Health and Social Care Information Centre (HSCIC) to implement a system for the extraction of primary care information and linkage to Hospital Episodes Statistics.
- This system is essential to the care.data programme.
- Before data collection may commence, NHS England must publish Directions to the HSCIC to establish a legal basis for the collection.
- The appended Directions have been developed in consultation with the HSCIC, Department of Health, Information Commissioner and BMA.
- Before publication the Directions must be approved by the Board.

Actions required by Board Members:

- To approve the publication of Directions to the Health and Social Care Information Centre for the collection of primary care data.

Publication of Directions to Health and Social Care Information Centre for the collection of primary care data

Purpose

1. The purpose of this paper is to present to the Board Directions to the Health and Social Care Information Centre for the collection of primary care data for approval.

Background

2. NHS England is committed to establishing a new, modern data system known as care.data. Its aims are to support patients' choice, advance customer services, to promote greater transparency, improve outcomes, increase accountability, and to drive economic growth.
3. In the first release of care.data, data will be extracted from GP Practice information systems and linked to data in the Hospital Episodes Statistics database held by the Health and Social Care Information Centre (HSCIC). This will for the first time facilitate analysis of information about pathways through primary and secondary care settings.
4. Under the Health and Social Care Act 2012 (the Act), the HSCIC is empowered to collect information from any health provider, but only when it has been directed or requested to do so. It can be *directed* to establish information systems by the Secretary of State for Health or by the NHS England, and can be *requested* to do so by other bodies. These Directions are legally binding and must be complied with by the recipient.
5. Although under transitional arrangements the HSCIC is empowered to continue to collect data that were collected prior to 1st April 2013, new Directions are required to specify and direct new collections. So before the HSCIC may proceed with the primary care data collection, NHS England must issue statutory Directions to establish a legal basis.
6. NHS England will need to publish revised Directions for future releases of care.data and other Directions for other purposes. The limited scope of these Directions has been helpful in providing assurance to stakeholders.

Directions to the HSCIC for the collection of primary care data

7. The Directions appended in Annex 1 have been developed in consultation with the HSCIC, as required by the Act, and also with input from the Department of Health, Information Commissioner and BMA. They have also been reviewed by NHS England's lawyers and HSCIC's lawyers
8. The Directions establish legal basis for the HSCIC to implement the GP extract as documented in the NHS England publication: Care Episode Statistics: Technical Specification of the GP Extract. This defines Release 1 of care.data. The key features of this specification that are explicitly addressed are:
 - collection of data from primary care systems and linkage to Hospital Episodes Statistics;
 - benefits for communities, patients, GPs and other clinicians;
 - data items to be collected;
 - data items to be excluded;
 - publication and dissemination; and
 - management of patient objections.
9. The Directions do not require the HSCIC to publish aggregated information as the Act already requires it to do so. However they do require that it adheres to its own guidance on anonymisation and guidance published by the Information Commissioner.
10. The HSCIC is directed to disseminate data that are appropriately pseudonymised to NHS England and commissioning organisations and other health bodies or providers where it considers the request is reasonable and a written agreement is in place. A Memorandum of Understanding (MOU) is expected to detail the criteria for reasonable.
11. In accordance with a policy statement given by the Secretary of State, individuals' objections to the disclosure of confidential information will be upheld. This is implemented using two codes in GP systems – one to indicate objection to the initial collection of GP identifiable data, and the other to indicate objection to onward disclosure following collection by the HSCIC.
12. The Directions require that where a person has objected to the initial collection, the HSCIC will respect this by only collecting identifiable data to the extent required to record the fact of the objection (non-identifiable clinical data may still be collected but will be stored separately from the identifiable information which records the objection).

13. The Directions do not specifically cover objection to onward disclosure, as in any event the Directions require any onward dissemination to be limited to fully-pseudonymised data, so there is no need to make provision to take account of individual objections. However the legislation also gives HSCIC direct powers to disclose identifiable information in certain circumstances and NHS England does not have the power to direct HSCIC on the exercise of these powers. The MOU will identify the way in which this power may be used and how both organisations can manage the public's expectations from the Secretary of State's assurance that objections to disclosure will only be overridden in exceptional circumstances within the framework of the requirements of the primary legislation – the Health and Social Care Act 2012.
14. The Information Commissioners Office and the two organisations are still considering whether the HSCIC is the sole Data Controller or whether NHS England and the HSCIC should be joint Data Controllers. The relationship between the two organisations, in the context of data protection, will be detailed further in the MOU.
15. The Directions will be reviewed at least annually, and when new collections are agreed.

Recommendation

16. The Board is asked to approve the publication of Directions to the Health and Social Care Information Centre for the collection of primary care data.

Tim Kelsey
National Director for Patients and Information
September 2013

DIRECTIONS

NATIONAL HEALTH SERVICE, ENGLAND

**The Health and Social Care Information Centre
(Establishment of Information Systems for NHS Services:
Collection and Analysis of Primary Care Data) Directions
2013**

The National Health Service Commissioning Board hereby gives the following Directions to the Health and Social Care Information Centre in exercise of the powers conferred by sections 254(1), (3) and (6), 260 (4)(a), 262(1), (3)(a), (5),(7)and 304(9), (10) and (13) of the Health and Social Care Act 2012.

In accordance with section 254(5) of the Health and Social Care Act 2012, the National Health Service Commissioning Board has consulted the Health and Social Care Information Centre before giving these Directions.

Citation and commencement

1. (1) These Directions may be cited as The Health and Social Care Information Centre (Establishment of Information Systems for NHS Services: Collection and Analysis of Primary Care Data) Directions 2013 and shall come into force on [insert date].

(2) These Directions are given to the Health and Social Care Information Centre by the National Health Service Commissioning Board.

Interpretation

2. In these Directions:-
“the Act” means the Health and Social Care Act 2012;
“the Board” means the National Health Service Commissioning Board established by section 1H(1) of the National Health Service Act 2006;
“the Health and Social Care Information Centre” means the body corporate established by section 252 of the Act;
“the HSCIC” means the Health and Social Care Information Centre;

“HES” means the Hospital Episodes Statistics database held by the HSCIC;
"identifiable data" means information which is in a form which identifies any individual to whom the information relates or enables the identity of such an individual to be ascertained;
“primary care data” means data collected or generated by systems operated in support of general medical services, personal medical services or alternative provider medical services;
“pseudonymised” has the meaning given in Appendix C of Care Episode Statistics: Technical Specification of the GP Extract published by the Board on 29th May 2013 and attached at Annex 1 of these Directions; and
"re-identification" has the meaning given in Appendix C of Care Episode Statistics: Technical Specification of the GP Extract published by the Board on 29th May 2013 and attached at Annex 1 of these Directions and "re-identify" shall be interpreted accordingly.

Establishment of Information Systems: primary care data

3. (1) In exercise of its powers in section 254 (1) and Section 254(6)) of the Act the Board hereby directs the HSCIC to establish and operate systems for the collection and analysis of information as further described and specified in sub-paragraph 3(2) and paragraph 4.

(2) The HSCIC is directed to establish and operate systems pursuant to sub-paragraph 3(1) to collect primary care data and to analyse that data, including analysis through linking that data to HES data held by the HSCIC, to enable the activities described in paragraph 3(4). The detailed description of the primary care data to be collected and of the actions to be taken by HSCIC to analyse the data is further specified in paragraph 4.

(3) In accordance with section 254(3) of the Act, the Board confirms that it is necessary and expedient for it to have the information which will be obtained through the HSCIC complying with these Directions in relation to the exercise of functions in connection with the provision of NHS services, and in particular to enable the effective and appropriate commissioning of NHS services by the Board and other NHS commissioners as further described in sub-paragraph 3(4).

(4) The collection and analysis of primary care data by the HSCIC pursuant to these Directions, including the linking of primary care data to the HES, will enable the Board and other NHS commissioning organisations or others acting on their behalf to identify and evaluate the overall NHS care pathway, across primary and secondary care, in relation to particular categories of patient or condition, resulting in the following benefits in relation to the exercise of commissioning and other health service functions:

For communities

- (a) enabling the design of health services according to comprehensive needs assessment;
- (b) enabling communities to become more active in the planning, redesign and prioritisation of local care services through the provision of information that reflects the end-to-end process of care;
- (c) enabling the provision of integrated care through the use of linked data;

For patients

- (d) accommodating patients' right to know that unexplained variations in how care is provided will be identified and addressed swiftly;
- (e) providing confidence that services are planned in a coordinated way, and that planning is centred on patient pathways;
- (f) ensuring that clinical outcomes are measured in transparent ways, based on an appropriate set of data;

For GPs and other primary care clinicians

- (g) improved monitoring of outcomes through linkage between primary and secondary care;
- (h) improved monitoring of performance through linkage between primary and secondary care;
- (i) earlier diagnosis of illness;
- (j) improving the contribution of primary care to wider Clinical Commissioning Group outcomes;
- (k) improved data quality;
- (l) monitoring and understanding trends;
- (m) predictive modelling;
- (n) evaluation of preventive services and interventions;
- (o) exploring patient pathways;
- (p) detecting unwarranted variation.

Data to be collected and analysed

4. (1) The HSCIC is directed by the Board pursuant to paragraph 3 of these Directions to collect from General Practitioner practices the data items listed in Appendix A of Care Episode Statistics: Technical Specification of the GP Extract published by the Board on 29th May 2013 attached at Annex 1 of these Directions.

(2) However the HSCIC is directed to de-select at the point of collection, those clinical data entries that contain any of the "sensitive" codes listed in Appendix B of Care Episode Statistics: Technical Specification of the GP Extract published by the Board on 29th May 2013 attached at Annex 1 of these Directions.

(3) The HSCIC is further directed by the Board pursuant to paragraph 3 of these Directions to analyse the primary care data collected in accordance with subparagraphs 4(1) and 4(2) through:

- (a) linking it to data held in HES in accordance with Care Episode Statistics: Technical Specification of the GP Extract published by the Board on 29th May 2013 attached at Annex 1 of these Directions; and
- (b) carrying out such other forms of data analysis in relation to the data, including data manipulation and report-generation, as the HSCIC determines to be reasonable or as are reasonably requested by the Board or other NHS commissioning organisations.

Publication and dissemination

- 5. In exercise of its powers under section 260(4)(a) the Board hereby directs the HSCIC that publication of any information which was obtained by complying with these Directions shall only be made in a form which complies with:
 - (1) the guidance published by the Information Commissioner's Office: Anonymisation: managing data protection risk code of practice attached at Annex 2 of these Directions (or as the same may be updated from time to time) ; and
 - (2) the Anonymisation Standard for Publishing Health and Social Care Data Specification published by the Information Standards Board dated 21 February 2013 attached at Annex 3 of these Directions (or as the same may be updated from time to time),including the approach to small number suppression set out in those documents.
- 6. In exercise of its powers under section 262(1) and 262(3)(a) and 262(7) of the Act, the Board makes the following directions to the HSCIC:
 - (1) The Board directs the HSCIC to disseminate information obtained by complying with these Directions (including the primary care data, any information obtained through analysis of that data as required by these Directions and any sub-set of that data or information) pursuant to section 262(1) of the Act and by exercising its power under sections 261 (4) of the Act to the NHS Commissioning Board, other NHS commissioning organisations and other bodies to the extent that the HSCIC considers such a request to be reasonable, where the conditions set out in sub-paragraph (2) are met;
 - (2) The HSCIC may only disseminate the data under paragraph 6(1) if:
 - a. The recipient is a health service body, a provider of NHS-funded services or a local authority engaged in joint commissioning with an NHS organisation, or a person acting on behalf of any such body, and the information is to be used by that person or body for purposes relating to the exercise of public functions;
 - b. The data are pseudonymised and the HSCIC is appropriately assured that the recipient would not be able to re-identify individuals from the information to

be provided when linked to other information held by or likely to come into the possession of the recipient; and

- c. The recipient has signed a written agreement with the HSCIC which specifies the data to be made available, the purpose for which the recipient will use the data and the terms on which that data may be shared and re-used.
7. In exercise of its powers under section 262(5) of the Act the Board hereby directs the HSCIC not to exercise its power under section 261(1) or (4) in relation to information that it obtains by complying with these Directions to disseminate:
- a. identifiable data; or
 - b. pseudonymised data to the extent that the HSCIC reasonably considers that the proposed recipient of the data would be able to re-identify individuals from the information to be provided when linked to other information held by or likely to come into the possession of the recipient.

Managing patient objections

8. The HSCIC is directed by the Board pursuant to paragraph 3 of these Directions to put measures in place as part of the establishment and operation of the information systems which are the subject of these Directions to ensure that where any primary care data are coded to indicate a patient's objection to disclosure of their identifiable primary care data to the HSCIC or any third party, to the extent that the HSCIC is acting in pursuance of these Directions in relation to that patient the HSCIC will only collect non-identifiable primary care data and those data items necessary to enable the HSCIC to record the fact of the patient's objection and that the data items necessary to record the fact of the patient's objection shall be collected and stored separately from other information to be collected in order to prevent any possibility of identification or re-identification of the patient within the HSCIC.

Review of these Directions

9. These directions will be reviewed and updated as required, including where new collections are agreed, or annually if this is earlier. This review will include consultation with the HSCIC as required by section 254(5) of the Act (powers to direction Information Centre to establish information systems).

Signed by authority of the NHS Commissioning Board

**Sir Bruce Keogh
Caldicott Guardian**

[INSERT DATE]

EXPLANATORY NOTE

(This note is not part of the Directions)

These Directions are published by the NHS Commissioning Board (which operates as NHS England) in exercise of its powers under section 254 of the Health and Social Care Act 2012 to direct the Health and Social Care Information Centre (the Information Centre) to establish information systems.

The rationale behind the Directions is to facilitate the information system defined in the Care Episodes Statistics: Technical Specification of the GP Extract published in May 2013 by NHS England¹. This defines release 1 of the care.data system, which includes linkage of primary care data to data on hospital activity. Analysis of the resulting data will provide NHS Commissioners and the public with information better to understand the overall NHS care pathway, and to facilitate commissioning of services and improvement of services.

The key components of the Directions are:

- direction to the Information Centre to collect primary care data and link this to Hospital Episodes Statistics as the first stage of analysis (sub-paragraphs 3(1)-3(3) and sub-paragraph 4(3)(a));
- direction to the Information Centre to carry out further analysis including data manipulation and report generation as may be requested by commissioners (sub-paragraph 3(4) and sub-paragraph 4(3)(b));
- explanation of benefits for communities, patients, GPs and other clinicians (sub-paragraph 3(4));
- specification of the data items to be collected – with reference to the Technical Specification (sub-paragraph 4(1));
- specification of “sensitive” data items to be excluded – also with reference to the Technical Specification (sub-paragraph 4(2));
- direction to the Information Centre to comply with the guidance published by the Information Commissioner’s Office: Anonymisation: managing data protection risk

¹ <http://www.england.nhs.uk/ourwork/tsd/data-info/>

code of practice², and the Anonymisation Standard for Publishing Health and Social Care Data Specification published by the HSCIC³ (paragraph (5));

- direction to the Information Centre is to disseminate record level data to NHS Commissioners – with specified controls in place to ensure confidentiality is maintained (paragraph (6));
- direction to the Information centre not to disseminate identifiable data (paragraph (7));
- management of patient objections (paragraph (8)).

Patients are able to record an objection either to the collection of identifiable data from their GP records by the Information Centre, or to onward disclosure of *any* identifiable data held by the Information Centre, or both. They can do this by telling their GP, who will record the objection(s) in the practice information system using pre-determined codes. The Information Centre will respect a recorded objection to the collection of identifiable data from the practice system by collecting only the items necessary to record the fact of this objection, which will be held for statistical purposes. This will be held separately to non-identifiable data from the same records.

Objection to the onward disclosure of primary care data by the Information Centre is not covered, as it is directed not to disseminate identifiable data collected under these Directions anyway. Onward disclosure of data originating from other organisations is beyond the scope of these Directions.

Further Directions will be issued for further data to be collected and where the methodology is to be changed.

² http://www.ico.org.uk/for_organisations/data_protection/topic_guides/anonymisation

³ <http://www.isb.nhs.uk/library/standard/128>