

**Update to the GPES IAG on the care.data programme
February 2015**

Background

On 11 September 2014, the GPES IAG considered an updated addendum that proposed that the linked general practice and HES data that will be held by the HSCIC should be able to be released by the HSCIC not just for commissioning purposes, but also for two additional classes of purposes: research, and health intelligence (including public health and healthcare regulatory purposes).

The GPES IAG made the recommendation by majority vote that this requirement should proceed subject to changes and/or further approvals. This document provides an update to the GPES IAG on progress.

Progress in meeting GPES IAG recommendations

<p>1. The current lack of clarity about the data disclosure controls that will be in place following the care.data pathfinder stage was a significant cause of concern, and more information would be welcomed about commitments beyond the pathfinder stage.</p> <p>Only data from the pathfinder practices should be made available for the additional two purposes set out in the updated addendum. Expansion to purposes beyond commissioning should receive further consideration at the end of the pathfinder stage.</p>	<ul style="list-style-type: none"> • The patient/public and NHS facing materials provide information about data disclosure controls during the pathfinder stage and post pathfinder stage. (See Annex A). • HSCIC webpages have been developed with programme stakeholders and wider partners and have now been published on the HSCIC website. These include details of what data are to be extracted, how they will be processed and who will have access. • The webpages are referenced in the pathfinder materials so patients can keep themselves updated with any changes. • During the pathfinder stage access to data is limited to analysts from the HSCIC, NHS England, the Care Quality Commission and Public Health England and CCGs accessing their own data • There will be a full evaluation of the pathfinder stage before further roll out and extension of access beyond the Secure Data Facility is given.
<p>2. As part of their advice on whether data extraction from pathfinder practices is ready to commence, the Independent Information Governance Oversight Panel should be asked to consider whether they are satisfied that the pathfinder communications and fair processing activities have resulted in satisfactory understanding within the</p>	<ul style="list-style-type: none"> • The Independent Information Governance Oversight Panel (IIGOP) has agreed to advise the care.data Programme Board and Senior Responsible Owner on the first phase of the implementation of the programme in its role advising, challenging and reporting on the state of information governance across the health and care system in England. • The Programme Board received the IIGOP Report on the Pathfinder Stage of the care.data Programme on 17 December. • No data will be extracted from GP practices until

<p>pathfinder practice populations.</p>	<p>Dame Fiona Caldicott advises the Secretary of State that she is satisfied with the proposals and safeguards. It should be noted that the report received in December is not that advice.</p> <ul style="list-style-type: none"> • An initial response to the report was provided in December 2014 and fuller formal response was sent at the end of January 2014. • The programme has considered the questions and tests articulated in the report and has discussed these with colleagues within the four participating pathfinder areas. • The programme and pathfinders believe they are well placed to answer the questions raised, and to provide the evidence required to meet the tests/conditions set. Feedback from CCGs will form part of the evidence provided to Dame Fiona Caldicott.
<p>3. The HSCIC and NHS England should ensure that all the IAG's recommendations for the previous care.data addendum made on 12 September 2013 are met in full. These are as follows:</p> <p>(i) Applications to the HSCIC for disclosure of data from the Care Episode Service should be subject to appropriate governance controls, including independent external scrutiny that would consider whether data disclosure would be in the public interest</p> <p>(ii) Details should be published about those governance controls and about the data disclosure decisions made</p>	<ul style="list-style-type: none"> • Progress in meeting the September 2013 recommendations is as follows: <p>(i) Section 122 (4) of the Care Act 2014 amends the Health and Social Care Act 2012 to provide that when publishing or otherwise disseminating information, the HSCIC must have regard to any advice given to it by the Confidentiality Advisory Group (CAG); the independent expert advisory group appointed by the Health Research Authority.</p> <p>In addition access to the data via the Secure Data Facility will be controlled through the HSCIC Data Access Request Service (DARS) (www.hscic.gov.uk/dars) process in the same way as requests are managed for other types of data access and release. The Data Access Advisory Group (DAAG) is an independent group, which will consider applications for sensitive data made to the HSCIC's Data Access Request Service.</p> <p>(ii) See FAQ at Annex A, which will provide information to the public about the controls in place. Information is also included in the care.data Privacy Impact Assessment, which will be published in February 2015.</p>

<p>(iii) Additional information should be provided about which types of organisations would be eligible to receive data.</p> <p>(iv) The information materials produced should sufficiently describe the intended wider audience for Care Episode Service data. They should be updated to make patients and the public aware that data could be shared with other organisations outside the NHS</p> <p>(v) The two Privacy Impact Assessments referred to in the Information Governance Assessment should be completed and published, as should the updated template data sharing agreement for use between the HSCIC and data recipients.</p>	<p>(iii) During the pathfinder stage access will be limited to a small number of organisations (see recommendation 1 above). Access will be dependent on purpose for which the data will be used rather than type of organisation. This will be explained to patients (see FAQ at Annex A)</p> <p>Section 122 (3) of the Care Act 2014 expressly prevents the HSCIC from generally disseminating information where there is not a clear health care or adult social care purpose or purpose for the promotion of health.</p> <p>Each quarter the HSCIC now publish a Register of all data access agreements identifying what data has been released, to what organisation and the legal basis for that release. The register information is available at: www.hscic.gov.uk/dataregister.</p> <p>(iv) Co-production of draft core GP and patient-facing materials is well underway and a second review cycle is in progress with CCGs and stakeholders. The materials make clear that data could be shared with organisations outside of the NHS.</p> <p>(v) The HSCIC PIA is available at: http://www.hscic.gov.uk/media/12931/Privacy-Impact-Assessment/pdf/privacy_impact_assessment_2013.pdf.</p> <p>NHS England published a Privacy Impact Assessment for the care.data programme in January 2014. (http://www.england.nhs.uk/wp-content/uploads/2014/01/pia-care-data.pdf). An updated version was approved by the care.data Programme Board and will be published in February 2015.</p>
<p>4. Clearer definitions of 'research' and 'health intelligence' should be proposed by the care.data programme.</p>	<ul style="list-style-type: none"> • There will be external oversight and scrutiny for the purposes for which information will be put. • The Care Act 2014 restricts access to health care or adult social care purpose or purpose for the promotion of health. • The factors and matters that CAG are required to have regard to will be set out in regulations to be tabled in February 2015. Extracts of data from GP

	<p>practices will not begin until the regulations have been tabled in parliament.</p> <ul style="list-style-type: none"> • Patients and the public will be able to see who has accessed the data via the HSCIC's data release register (www.hscic.gov.uk/dataregister) • A benefits booklet, which includes examples of data being used for research, will form part of the suite of patient materials. • Access to the data in the pathfinder stage will be restricted to a limited number of organisations as set out above so the purposes the data are used for will be limited. .
<p>5. The IAG also suggested independent evaluation of how far the data collected has met the examples given of benefits envisaged.</p>	<ul style="list-style-type: none"> • An Expert Reference Group (ERG) has been established to guide the approach to analysis during the Pathfinder stage of the care.data programme. The group includes research, clinicians and commissioners and will make recommendations to the care.data programme board and consult with the care.data Advisory Group on any related matters. • Membership of the ERG is attached at Annex B.

Who will my information be shared with after it has been collected as part of the care.data programme?

Decisions about whether to share patient information are based on what it will be used for and not based on the type of organisation requesting the information. Information can only be shared if it will benefit health and care. Information will never be shared with organisations that wish to use it for solely commercial purposes, such as insurance or direct marketing. A private healthcare provider may therefore receive information for health research purposes but it would not be allowed to use it for insurance purposes.

During the pathfinder stage, there will be an initial restricted period where only a very limited number of approved analysts will be able to access the connected information from hospitals and GP practices in a Secure Data Facility at the HSCIC. This will allow the HSCIC to assess the quality of the information and to provide guidance to organisations to aid understanding and interpretation of the information once it starts to be used more widely.

After this initial restricted period, other organisations will be able to apply to access the information in the Secure Data Facility. In time, organisations will be provided with access outside the Secure Data Facility once it is safe and secure to do so.

Where an organisation applies to the HSCIC for access to information inside or outside the Secure Data Facility it will have to go through strict approvals processes and checks and will also have to sign a data sharing contract with the HSCIC. This contract sets out terms and conditions, such as:

- how the information will be shared
- what it can and cannot be used for
- security requirements on how it is stored
- restrictions on onward sharing or publication
- when and how information must be deleted at the end of the contract.

Only then can an organisation be approved to receive the information.

After an organisation receives data, the HSCIC will audit and monitor adherence to data sharing contracts and will stop the flow of data if there are any concerns about the organisation.

You will be able to see who has accessed the information because the HSCIC publishes a register of organisations it has shared information with on its website at: www.hscic.gov.uk/dataregister. There is also independent scrutiny of who has access to the information.

Annex B - Membership of Expert Reference Group

Jon Ford, CPRD Head of Operations, MHRA (Chair)

Niccolo Stamboglis, Healthwatch

Prof John Newton, Chief Knowledge Officer, Public Health England

Martin McShane, National Medical Director, NHS England

Bethan George, Deputy Director Integrated Care WELC Integrated Care Programme,
Tower Hamlets CCG

Mike Knapton, Assoc. Medical Director, British Heart Foundation

Dr Geraint Lewis, Chief Data Officer, NHS England

Adam Steventon, Health Foundation

John Ainsworth - Senior Research Fellow, University of Manchester

& Deputy Director, HeRC, representing the Farr Institute

Prof David Ford - Professor of Health Informatics, Swansea University, representing
the ADRN and SAIL, alongside the Farr Institute

Cono Ariti – Senior Analyst, Nuffield Trust

John Varlow, Information Analysis Director, HSCIC

Jonathan Hope, Statistical Section Head, HSCIC

Richard Irvine, care.data Programme Manager, HSCIC

Kathryn Knight, Section Head - Primary Care Domain Statistics, HSCIC