

# Welcome to the fifth edition of the information governance bulletin



Our fortnightly bulletin about information governance and the work of the task force.

Publication Gateway Reference: 503

5

Information Governance Bulletin

<p><b>Myth Busting 2</b></p> <p>This edition, we look at the data flows surrounding home oxygen services (HOS).</p>	<p><b>Updates 3</b></p> <p>Updates from each of the task force groups on progress since the last edition.</p>	<p><b>FAQs 7</b></p> <p>A new section containing a list of the most commonly asked questions. These will be made available online.</p>
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**Audience**

*This bulletin is written for:* Anyone who uses data for secondary uses: commissioners inside NHS England and within CCGs; data analytics providers; those working in clinical audit; and researchers, managers, clinicians, and patients.

## Introduction

This bulletin sets out the work that NHS England is doing on behalf of all NHS commissioners to overcome the information governance (IG) issues created by the legal and organisational changes introduced by the Health and Social Care Act 2012. In previous editions of the bulletin, we have outlined how NHS England's *information governance task force* reports to the information governance transition board, which is

chaired by the Director of Strategy and Intelligence, Christine Outram. This arrangement in turn supports a wider programme of work on information flows within the new commissioning system, a programme led by Barbara Hakin, NHS England's Chief Operating Officer.

## Myth Busters

We have received several questions this week about home oxygen services and their associated data flows. Here's a mythbuster on this topic:

### *Home Oxygen Service (HOS) and Data Flows*

**Myth:** That personal data cannot be shared between providers of home oxygen and commissioners in any circumstances

**Reality:** The provision of Home Oxygen Services is for a direct care purpose. The disclosure of patient confidential data (PCD) by providers of Home Oxygen Services is done on the basis of explicit consent and information provided to patients about the use of their information. It is lawful.

The Commissioner of Home Oxygen Services requires necessary and limited information for a particular purpose. The safety of patients is of paramount importance and the flow of information should continue where it is necessary to avoid risk of harm.

Where a patient currently receives a Home Oxygen Service, it is reasonable to support the patient's health care management and in the interests of patient safety to share necessary and limited information with commissioners. On this basis providers of Home

Oxygen Services must continue to share this information about current recipients. Patient consent needs to be renewed at the next assessment visit to ensure consent adequately covers new NHS organisations. This must be accompanied by updated information about the use of their information, who it is shared with and why.

When a patient is initially diagnosed as requiring home oxygen services, the prescribing Health Care Professional (HCP) is responsible for obtaining the patient's explicit consent to share their information with the HOS provider, the relevant Commissioning organisation and other essential services. This consent should cover all services and the sharing of information between them. With the provision of an on-going service, the Home Oxygen Service provider must ensure the patient is aware of the use of their data and understands how it is used to provide and monitor the service they receive.

Prescribing Health Care Professionals use the Home Oxygen Consent Form. These forms typically outline how the patient's information will be used and record the patient's signature. Here, informed consent provides the legal basis for information sharing. The information contained in the form needs to explain why the use of personal confidential data is necessary and how it

supports the provision of health care. Because patients may well have questions or concerns, the form should provide details of an enquiry point and where to obtain more information.

Remember, the use of a patient's data must pass the *necessity test* in that no alternative data is possible and that the data flow must support the provision of a service. The details of the consent form and the information provided to patients need to be thought through carefully: they should reflect the all parties' data requirements.

Key to getting the information governance of home oxygen service services right are:

- Designing the scope of the home oxygen service to include this requirement to share information
- Considering the data needs to support the home oxygen service (e.g., where personal confidential data are necessary and where pseudonymised or anonymised data would fulfill the function).
- Building in periodic reminders to patients about the service and the use of their information

- Capturing the patient's valid consent with a leaflet and a consent form

Further guidance will be published shortly and will cover this issue in more detail. This includes more information and links on:

- Obtaining and recording consent
- Managing issues around patient capacity
- The Consent Form

If you are aware of any apparent myths related to information governance that you would like us to consider in future editions of this bulletin, please email the details to [England.information-governance@nhs.net](mailto:England.information-governance@nhs.net)

### Update on the work programme

Since the last bulletin, two important announcements have been made affecting information governance as a whole:

#### 1. Government response to the Caldicott information governance review

The Department of Health has issued a formal response to the second Caldicott report (see link below). This response highlights the current issues with data flows. It also sets out a high-level plan of action to manage information governance policy in the future, including the

establishment of a new advisory group to be chaired by Dame Fiona Caldicott.

<https://www.gov.uk/government/publications/caldicott-information-governance-review-department-of-health-response>

#### 2. New Confidentiality Guide launched

On 12 September, the Health and Social Care Information Centre (HSCIC) published an important new *Guide to Confidentiality in Health and Social Care*. The guide sets out expectations around the use of patient information. It adopts the seven *Caldicott Principles*, and it sets out five rules of confidentiality, namely:

- Confidential Information about service users or patients should be treated confidentially and respectfully
- Members of a care team should share confidential information when needed for the safe and effective care of an individual
- Information that is shared for the benefit of the community should be anonymised
- An individual's right to object to the sharing of their confidential information should be

respected

- Organisations should put policies, procedures and systems in place to ensure that confidentiality rules are followed

These rules are elaborated in a series of examples and are supported by a reference document that adds details about the obligations and laws outlined in the guide. Also included are helpful examples of best practice.

The HSCIC published the guide under section 263 of the Health and Social Care Act 2012, which gives the guide statutory authority. All health and social care providers are therefore required to pay due regard to the guide. The HSCIC will review and update the guide where necessary (for example when new laws are introduced).

The guide can be found at:

<http://www.hscic.gov.uk/media/12822/Guide-to-confidentiality-in-health-and-social-care/pdf/HSCIC-guide-to-confidentiality.pdf>

#### Update on the five work streams of the information governance task force programme

The IG task force is overseen by the Chief Data Officer, Dr. Geraint Lewis. The task force has five work streams, and here we report on their work over the past couple of weeks.

## 1. Data system design work stream

The *system design* work stream team are working through the business requirements of the various commissioning areas within CCGs and within NHS England. They are working with business analysts from the HSCIC and with an IG expert group to examine each requirement and to determine what, if any, are the IG legal constraints to data flowing. They will then agree what the short, medium and long term solutions are to each data requirement.

We will shortly be sending invitations to a wide range of relevant organisations, in the hope that they will help check our working assumptions and review our existing list of data requirements.

Through a series of workshops and other consultation events, we hope to identify a comprehensive list of problems and solutions. If you would like your organisation to be included in this programme of workshops, please contact Jeanette Hall via [jeanettehall@nhs.net](mailto:jeanettehall@nhs.net).

At the moment, our priority areas are:

- Invoice validation
- Integrated care
- risk stratification
- Direct commissioning by NHS England (i.e., specialised services, offender health etc.)

Workshops on the data flows for armed forces health care are being held in York on 7 October and in Chippenham on 8 October. At these workshops, we will be reviewing the barriers and solutions to the necessary data flows. The key people within NHS England, plus CSU staff, who carry out who armed forces commissioning will be attending. We are planning similar workshops for offender health and public health.

### Coming up:

We have recently submitted an application to the Confidentiality Advisory Group (CAG) for a 12-month extension to our current

Section 251 support for commissioning data sets. This request is intended, to support the establishment of *commissioning accredited safe havens*, as well as the transition of local data flows to *Data Service for Commissioners Regional Offices* (DSCROs).

We will provide a more detailed update on this application in the next IG bulletin.

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We will provide a more detailed update on this application in the

next IG bulletin.

## 2. Care.data

The Health and Social Care Act 2012 provides a legal basis for the HSCIC to collect confidential data from providers when directed by the Secretary of State for Health or by NHS England. Before the HSCIC may proceed with such data collections, NHS England must issue statutory Directions. Directions for the collection of primary care data have now been approved by the Board of NHS England, and we are now in the process of formally issuing these Directions to the HSCIC.

Whilst the Health and Social Care Act 2012 establishes the legal basis for the collection of these data, the principles of the Data Protection Act 1998 continue to apply. Particularly relevant is the principle that data must be processed fairly. In practical terms, this means that data controllers must ensure that patients are made aware of how their confidential data will be processed, used and shared. GPs as data controllers are therefore responsible for ensuring that their patients are aware of the extraction of GP data as well as their right to object to this extraction.

NHS England and the HSCIC have been working closely with the BMA and the RCGP to develop materials to support

GPs with these obligations.

These materials have now been sent to every GP practice in England, including patient leaflets, a poster, and a GP practice how-to guide. GPs should work proactively to raise awareness with their patients – for example, by

- informing patients at reception when they visit the practice;
- including information on practice websites and in regular mailings, such as those for screening programmes;
- using other routine practice communications to patients; and
- through practice patient groups (PPGs)

NHS England will be supporting local communications through regional and national awareness-raising activities and we will be publicising our detailed plans shortly. GP practices should be reassured that 8 weeks is the minimum period of raising awareness rather than a maximum time.

Furthermore, GP practices will be notified in advance of the first data extraction. NHS England and the Health and Social Care Information Centre are liaising closely with the Information Commissioners Office about all of these arrangements.

A privacy impact assessment for

care.data has been drafted and will be published in the coming weeks. This document will support patients in understanding the care.data programme, together with the privacy implications and the information governance controls that have been put in place to protect their confidentiality.

A series of communication events for care.data have been held across England over the past few weeks, with the last scheduled event due to be held in London on 2 October.

Further information about the care.data programme is available at: <http://www.england.nhs.uk/ourwork/tsd/care-data/>

### 3. System Change

We are continuing the process of recruiting staff to this work stream in order to provide additional capacity.

A plan is being formulated to implement the *20 Year Rule* of the Public Records Act within the NHS. As part of Trusts' obligations under this Act, the NHS will have to consider how best to manage this rule in practice. In future editions of this bulletin, we will publish more details about what this rule means for the NHS, why it needs to be followed, and how the NHS is going to comply with it.

Colleagues will be aware of the current need to report *Serious*

*Incidents Requiring Investigation* (SIRIs) that relate to information in both *Strategic Executive Information System* (STEIS) and the IG Toolkit (IGT) incident reporting tool. It is important to remember that Incidents reported via the IG Toolkit will be published on a quarterly basis. The content and tone of the submissions need appropriate consideration and it is important to be clear and accurate about what is reported, especially if cutting-and-pasting between systems. More information on SIRIs will follow as we develop our guidance and communications.

Changes to version 11 of the IGT are due in October and we are currently in discussion with colleagues in a range of partner organisations. Discussions about version 12 are also due to begin shortly.

### 4. Communications

We are recruiting a full time communications lead to widen the degree of communication about the programme. As the range of new information, FAQs and new guidance is developed, we will expand the distribution of the bulletin and other communications.

### 5. Programme Management

#### ***Directions for the Health and Social Care Information Centre Approved***

As noted above, the NHS England Board has recently

approved Directions to the HSCIC, for the collection and analysis of primary care data. Once issued, these Directions will establish a legal basis for the HSCIC to implement the GP data extract for the care.data programme. The key features of these Directions are:

- direction to collect data from primary care systems and to link these data to the Hospital Episodes Statistics (HES) database;
- benefits for communities, patients, GPs and other clinicians;
- details of the data items to be collected and the data items to be excluded;
- requirements for publication and dissemination; and
- requirements for the management of patient objections to disclosure.

The care.data programme's aims are sixfold: to support patients' choice, to advance customer services, to promote greater transparency, to improve outcomes, to increase accountability, and finally to drive economic growth. These Directions will give the programme a legal mandate to proceed.

### **Additional capacity:**

We have added new staff members to the task force team, who are adding to our capacity to develop materials and to answer queries.



Welcome to Mark Douglas who has recently joined the programme as a business analyst for a six-month period. Mark has previous experience of data analysis, service level agreements, and performance management within the Department of Health. He has also worked in business improvement and process redesign within the criminal justice department of West Yorkshire Police. Mark will be providing specialist support for the data system design work-stream.

Welcome also to **Hayden Thomas** who joins us on a permanent basis as an IG subject matter specialist. He was previously with the South London Commissioning Support Unit.

**Enquiries** – We continue to receive a large number of enquiries, many of which are complex and. In order to answer these queries, we often need to clarify our policy or guidance, which may require co-ordination and agreement with other organisations such as the Department of Health and the HSCIC. We aim to turn all queries that have general applicability into FAQs so that the advice can be shared by as many interested parties as possible.

### **Frequently Asked Questions**

This is our first selection of NHS England's 'frequently asked questions' relating to the work of the IG task force. We will use this bulletin to provide you with updates and answers to the questions we receive.

We'll be adding all of these FAQs to our website each week at:

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

Our colleagues in the HSCIC will be publishing the same FAQs as well, on their website.

We've included a question reference number and a version number, as we will be updating and adding details to our FAQs.

**Our enquiry email address is:**  
[England.information-governance@nhs.net](mailto:England.information-governance@nhs.net)

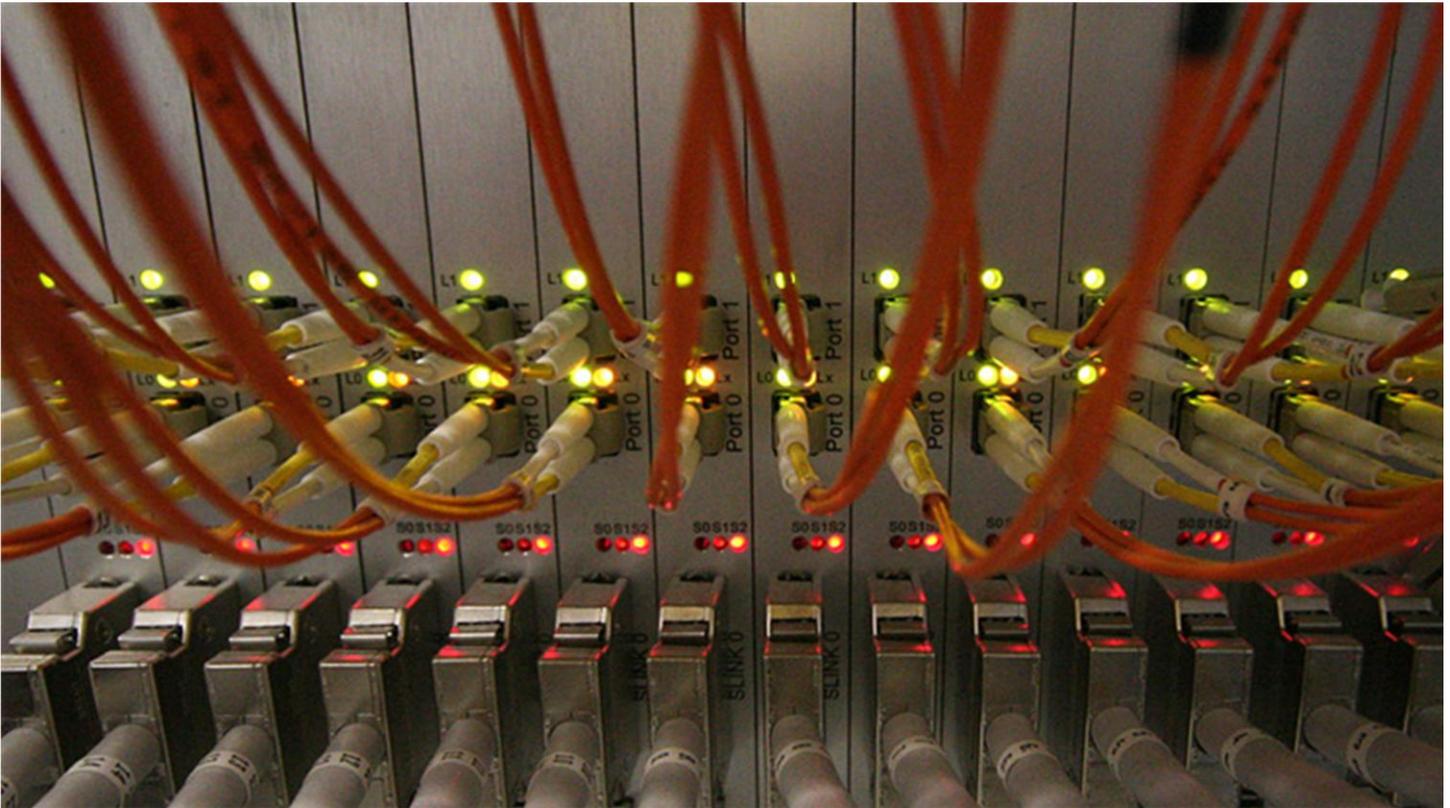
Reference	Issue	Version	Theme	Response
0001	What will happen when the section 251 exemption ends in October?	v1.0.0	General	We are currently discussing the current s.251 exemptions with the Confidentiality Advisory Group (which advises the Secretary of State) and further information will be available shortly.
0002	Will NHS England review our data sharing agreement or framework?	v1.0.0	General	NHS England would not generally comment on individual data sharing agreements or frameworks. We would instead expect organisations to consult with their own information governance resource.
0003	What advice would you give to help my organisation get Information Governance right?	v1.0.0	General	<p>Both the Department of Health and the Information Commissioner's Office agree that asking the right questions at the start of any change process is the key to successful information governance.</p> <p>The starting point is therefore to understand your organisation's needs and the legal framework in which it operates. To help with this process, you should contact your local information governance resource early in the planning stage. This IGT can be found at: <a href="https://www.igt.hscic.gov.uk/">https://www.igt.hscic.gov.uk/</a></p>
0004	I haven't had a response to my enquiry yet	v1.0.0	Enquiries	<p>Please accept our apologies for the delay, and bear with us as we draft a response to your question and/or establish a link to the relevant FAQ.</p> <p>NHS England has received a very large number of enquiries as a result of the significant legal and organisational changes introduced by the Health and Social Care Act 2012. We have established an IG task force to help manage the scale of the challenge and to answer the queries received. The task force is currently prioritising communications, recruitment of staff to the task force, and proactive solutions to the IG challenges faced by the NHS.</p>

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				<p>Many of the queries we receive require clarification on policy or the development of new guidance, which requires co-ordination and agreement with other organisations such as the Department of Health and the HSCIC.</p> <p>The IG Bulletin will keep you updated on our current priorities and work. Please let us know if you would like to get involved with our work, for example by attending one of our workshops.</p>
0005	Could a local patient identifier be used to identify a patient for commissioners?	v1.0.0	Identifiers	<p>NHS England is currently working with partner organisations such as the Department of Health and the HSCIC to develop guidance on this issue.</p> <p>This guidance will consider the use of a local identifier (for example a patient hospital number) in a context where further identification is not possible.</p>
0006	When will issues around invoice validation been resolved?	v1.0.0	Invoice Validation	<p>Work around invoice validation is currently a key priority for NHS England. The issue is complex and is taking time to clarify then resolve.</p> <p>We hope to publish interim guidance shortly, with fuller guidance to follow a few weeks later.</p>
0007	The letter (Gateway Ref: Publications Gateway Ref No 168) dated 13 June 2013 has caused some confusion. Are CCGs allowed to handle PCD?	v1.0.0	CCGs and PCD	<p>We apologise for any confusion.</p> <p>The letter discussed powers under the Health and Social Care Act 2012 and the s. 251 applications.</p> <p>Neither the Act nor the s.251 exemptions provided a broad legal basis to CCGs, or those working on their behalf, to access to personal confidential data (PCD). Instead, the Act made it clear that the Health and Social Care Information Centre did have the power to capture and process PCD.</p> <p>Clinical Commissioning Groups (CCGs) can process PCD where they have a legal basis</p>

Reference	Issue	Version	Theme	Response
				<p>for doing so outside of the parameters of the Health and Social Care Act. For example, CCGs can process PCD where they have explicit consent for individual funding requests. This consent provides a basis for processing under Schedule 2 and Schedule 3 of the Data Protection Act. Likewise, the Civil Contingencies Act provides another statutory basis.</p> <p>Note that to process personal data fairly and lawfully, the patient must be informed about the potential uses of their information.</p>
0008	Can weakly pseudonymised data flow from GPs to ASHs?	v1.0.0	Accredited Safe Havens	<p>Currently, Accredited Safe Havens are only authorised to receive weakly pseudonymised data flows from the Health and Social Care Information Centre (via the local DSCRO).</p> <p>GP data flows would be expected to go the HSCIC.</p>

0009	Is there any guidance on chaplaincy and access to patient records?	v1.0.0	National Guidance Chaplaincy	<p>The latest chaplaincy guidance was published in 2003 and can be found through this link: <a href="http://www.nhs-chaplaincy-spiritualcare.org.uk/dh_MeetingtheReligiousNeeds2003.pdf">http://www.nhs-chaplaincy-spiritualcare.org.uk/dh_MeetingtheReligiousNeeds2003.pdf</a>. Note that the guidance is now 10 years old and requires review. There is currently no work underway to update this guidance and the information governance aspects contained in it.</p> <p>The document contains sound principles around ensuring that (a) patients are informed about the potential use or access to their information; and (b) explicit consent is sought.</p> <p>Access to health systems for chaplaincy services is a decision for each Trust. It must meet the requirements for lawful access and processing of personal confidential data. The Trust will also need to consider how it would provide access only the patient records of those who have consented (and are of the relevant faith). The Trust's information governance team (and/or a privacy impact assessment) are the first point of call.</p>
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Reference	Issue	Version	Theme	Response
0010	What is needed to apply for ASH status under the current stage 1 procedure?	V1.0	ASH	<p>In order to apply for ASH status, an organisation must have:</p> <ul style="list-style-type: none"><li>• attained level 2 on the information governance toolkit;</li><li>• signed a data sharing contract with the HSCIC (CCGs only, because NHS England has signed contract on behalf of CSUs); and</li><li>• submitted a satisfactory data sharing agreement to the HSCIC.</li></ul>



## Next issue

So as to bring the cycle of publication of this bulletin closer in line with the wider CCG bulletin, the next issue will be published on 18<sup>th</sup> October, and included in the subsequent CCG bulletin.

We are keen to draw attention to new issues and new solutions, so we will include them in the newsletter as they arise.

Please let us know about any issues you think the task force should be addressing or any information you would like us to publicise.

The next issue of this briefing will include:

- Update from each of the task force's five work streams
- New FAQs and other resources
- New issues and priorities

Edited by: Robin Burgess/Ian Townend