IGA news

Information Governance Alliance IGA

October 2015 | ISSUE 1

I'm delighted to welcome you to the first issue of IGA News.

This quarterly newsletter and will cover policy, news, views and updates across Information Governance, with regular contributions from NHS England, Information Commissioner's Office, The Centre of Excellence for Information Sharing and the Strategic Information Governance Network to name but a few.

Following a survey conducted earlier in the year, we've based our content on your feedback and we'd be happy to hear what you think about our first issue and how we can improve future issues.

Feel free to share this newsletter with others who may not have received it directly.

➡ To get in touch or subscribe please email

Peter Hall

Director of Information Governance & Standards Assurance

THE INFORMATION GOVERNANCE ALLIANCE

Since it formed in July 2014, the Information Governance Alliance has made steady progress in its aim to become a single, authoritative source of advice and guidance for the health and care sector. Over the past 18 months we have been working hard to bring together Information Governance (IG) resources and specialist knowledge from our member organisations to improve IG in health and care.

With a firm focus on not 'reinventing the wheel', we look to maximise on the excellent work and knowledge that already exists, identify gaps and then produce easy to access and easy to use guidance to bridge those gaps. This is very much a two-way conversation and we are keen to hear from anyone with an interest in IG to either flag best practice or bring any issues to our attention so we can find better ways to support organisations.

Health and care organisations looking to publish guidance that includes or references information sharing or IG are encouraged to get in touch and request IGA endorsement and quality assurance for your publications.

We are building networks of local groups for IG professionals, including Senior Information Risk Officers, Caldicott Guardians, IG specialists and records managers/data quality leads. We would like to encourage all to participate.

➡ For more information on networks of local groups for IG professionals

➡ For more information about the IGA and our work, click here

➡ If you have any comments or suggestions please get in touch

IGA NEWS ROUND-UP

- The IGA has a publication schedule with new materials being published for consultation each month. For example, we drafted and published guidance for DH to support the Health and Social Care (Safety and Quality) Act 2015 which came into force on 1 October. You can find more information about our publications and consultations on our web site.

  → Find out more here

- We are building networks of local groups for IG professionals including Senior Information Risk Officers, Caldicott Guardians, information governance specialists and records managers/ data quality leads. We are currently looking to establish whether Senior Information Risk Officers would benefit from having their own network and whether we have positioned the SIRO role at the right level across care services.

  → Find out more here

- We are offering a programme of webinars for the remainder of 2015, including a short series to support you with the new duties introduced under the Health and Social Care Act.

  → Please visit our events page to see all the webinars we are planning over the next few months

- We have been commissioned by the Health and Social Care Information Centre (HSCIC) to support the Digital Leaders Network, as part of a 6 month pilot the HSCIC has recently launched. This is an opportunity for the IGA to promote IG as a profession whilst supporting over 2,000 senior informatics staff across the care sector on IG issues.

  → Find out more here

- We are promoting a new network for Caldicott Guardians and are actively looking for local volunteers to organise and support local Caldicott Guardian Groups. We would love to hear from anyone who feels that they have the time and managerial support get involved.

  → You can request more information here

- Longer term pieces of work include the revision of the DH Records Management Code of Practice, an expansion to the existing Anonymisation for Publication standard to include the release of pseudonymised data into controlled environments and a new version of the Care Record Guarantee, which the Secretary of State asked us to develop in partnership with Dame Fiona Caldicott, the National Data Guardian. We are also working on a glossary of information governance terms to meet the recommendation in the Information Governance Review.

  → Click here to find out more about the Information Governance review

  → Click here to view the Records Management Code of Practice Consultation

WORKING TOGETHER – INTRODUCING IGA EXPERT REFERENCE GROUPS (ERGS)

One of the biggest challenges in providing IG advice and guidance for the health and care system is making sure it is useful, clear and appropriate for as broad an audience as possible.

In April 2015 we called upon local subject matter experts to offer an opportunity to feedback on early drafts of the national advice and guidance we were seeking to publish. The first group of experts that volunteered to work with us took on the challenge of providing their professional views on a suite of some 17 products designed to facilitate lawful and appropriate sharing of information within and across health and care organisations. This information sharing toolkit comprised a range of materials from multi-tier data sharing agreements through to service user awareness posters.

The level of engagement and quality of feedback from this pilot group of information governance professionals, with representation across the health and care sector, led to a recommendation to support and grow this concept. The pilot also suggested formation of such expert panels at an early stage in the IGA product development process.

We have integrated these Expert Reference Group (ERG) panels into our quality assurance process and have worked with two further groups to review the IG Glossary and the Records Management Code of Practice.

We continue to glean further valuable insight from the IGA ERGs and are refining how they operate, seeking to open up membership on a much broader scale. The next edition of IGA News will include details on how you can get involved and contribute as a member of the IGA Expert Reference Groups.

Get Involved with the IGA

→ Join the mailing list to hear more about our work here

→ Contribute to consultations on draft guidance

→ Attend webinars

→ Contribute articles for the newsletter – email here

→ Join or form a local IG group – affiliation to the national IG network

- Offer your services to the IGA as a potential member of an Expert Reference Panel – watch out for news on this.
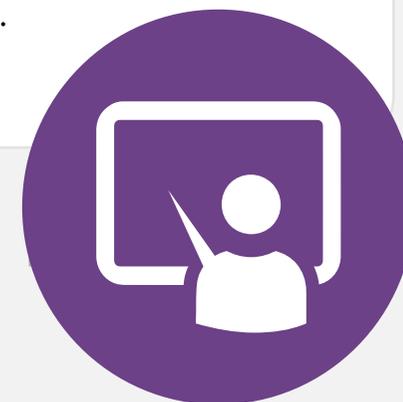
THE INFORMATION GOVERNANCE TOOLKIT

The HSCIC is committed to supporting the delivery of integrated health and social care, to building public trust in how we manage data, and to providing guidance and assurance to organisations and staff responsible for sharing patient information.

The IG Toolkit provides a roadmap for achieving excellent information governance. It is also a performance assessment, incident reporting and management tool satisfying the Cabinet Office requirement for DH to provide assurance that all parts of the NHS are meeting mandated data handling standards.

The HSCIC has released a trial version of a new module of the IG Toolkit which is specifically designed for independent contractors (general practice, dentistry, ophthalmic) and care homes.

The new module has been developed to address requests for clarity and context, enhanced functionality and streamlined requirements that were received through surveys conducted earlier in the year. Through representation on the programme board, local government has been included in the development and governance of the new assessment. In addition, Directors of Adult Social Services (ADASS), Local Chief Information Officer Council (LCIOC), and Society of IT Managers (socitm) have endorsed the new approach and will continue to input into the process in order to ensure an inclusive and integrated final product.

The trial assessment will be available until May 2016. We invite all users to explore and comment on the new format.

We are also providing a new information sharing resource hub for all users. Endorsed by the IGA, this hub brings together all the guidance and policy related to the Caldicott2 Recommendations. The hub will continue to develop as part of an IG Knowledge Base, endorsed and managed by the IGA and hosted by HSCIC.

This is a first step in updating the IG toolkit to reflect the growing and changing needs of health and social care. The next step is to develop a transparent approach towards continuous improvement, ensuring that the toolkit is efficient, effective and supports trust and sharing of information across health and care.

➡ Click here for a short video tour of the new module

➡ Click here to view the new module

➡ If you don't have a log in you may request one here

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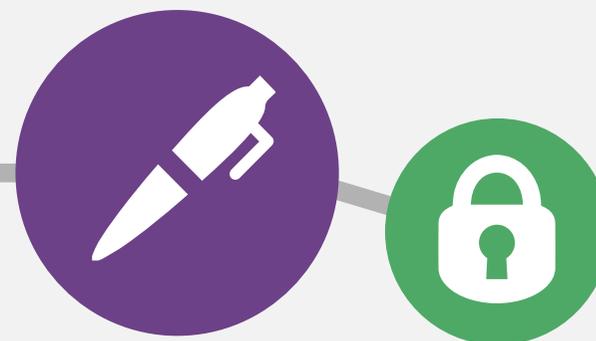
YOUR QUESTIONS

Welcome to Your Questions where, each issue, we will feature one or more hot topics from the questions sent in by our readers with answers provided by our IGA subject matter experts.

We have already received suggestions for topics we can feature but we are always happy to receive more. We can only feature a limited amount in each issue of the newsletter but we will use all questions received to update our FAQs and to shape the future work of the IGA.

→ View FAQs page

Question: How do we identify data controllers, and their responsibilities, where records are shared between different/multiple organisations?

Some care record systems enable you to share information with partner organisations for information only while one organisation retains full control over the content. For these systems there is only one data controller. Other systems allow several organisations to contribute to the same care record and here it can be less clear.

You need to establish whether or not someone is a data controller because it is data controllers who are required to comply with the Data Act's Data Protection Principles.

→ View the Principles here

The IGA has recently published guidance about this, which sets out examples of different systems and situations and explains the data controller responsibilities for each one. You can refer to this guidance to determine whether you need to take action.

For example:

- If you have asked another organisation to hold or work with personal data – they will be your data processor and there is advice on the formal arrangements that should be in place.

- The system you use may mean that you and your partner organisations are "data controllers in common" i.e. that you both/all have responsibilities to fulfil. In this instance, it is particularly important to make sure that all data protection requirements are being effectively satisfied. The IGA guidance includes a checklist for organisations to help you to follow best practice.

→ Please click here to view the guidance

NEW DUTIES FOR HEALTH AND SOCIAL CARE BODIES

Since the introduction of The Health and Social Care (Safety & Quality) Act 2015, on 1 October, Health and Social Care bodies have two new duties: to share relevant information for the direct care of an individual and to include the NHS Number when doing so.

The 2013 Caldicott Review 'Information: to Share or not to Share' identified that a 'culture of anxiety' prevented the appropriate sharing of people's information in support of direct care. The new duty requires health and adult social care bodies to share information that is relevant to the direct provision of a person's care with other organisations directly involved in their care and treatment. The default position should be to share unless there is a reason not to.

The new duty to use the NHS number does not require those without access to the NHS Number to use it, nor for them to do so where this would require unreasonable effort, but, reflecting current best practice, where the requirement can be met is it now a legal requirement to do so.

➡ We have published guidance to explain the new duties and practical advice to support staff and organisations to implement them

➡ We are also running a series of webinars

WORKING TO SUPPORT INFORMATION SHARING AND INTEGRATED CARE

The IGA recently led a project to support Integrated Care and Support Pioneers to overcome some perceived Information Governance issues considered to be a blocker to their work. The Integrated Care and Support Pioneers Programme has been running since late 2013, with 25 localities testing new ways to join up people's care around their needs.

The Pioneers had, for some time, reported general issues with Information Governance so the IGA worked closely with four representative localities to establish the exact issues and work towards solutions. Some specific issues were identified and, as a result, new guidance documents and case studies have been produced.

Many of the templates and examples included in the blueprint are based on materials provided by other localities, with Torbay, Southend and Mersey deserving particular mention. The development process enabled the IGA to test its approach to enlisting local IG staff into Expert Reference Groups (ERGs) and we would like to give a big thanks to everyone who volunteered their time to help improve materials that will hopefully help many parts of the health and care system improve information sharing practice.

➡ Find out more about ERGs here

➡ The guidance, case studies and updates on the blueprint will be published on our web site

The IG issues identified related to:

- The proportionality of data made available and/or accessed through systems for both direct care and commissioning intelligence purposes
- The pros and cons of different configurations of data controllers for pooled data
- What constitutes adequate communications with service users about information sharing, and
- Viable models for supporting new models of care and capitated budgets.

UPDATE FROM THE CENTRE OF EXCELLENCE

The Centre of Excellence for Information Sharing

Continues its work to bring about a step-change in supporting local places to improve information sharing. The Centre aims to support the delivery of better health and social care, and to support other objectives such as improving support for those in mental health crisis, earlier intervention for children and families, and addressing help for those with multiple complex needs.

→ Click here to visit our web site

→ Make sure you don't miss out on information sharing updates from the Centre by signing up to our newsletter

Recent work with local places

- The Centre worked with Bournemouth, Poole and Dorset to think through and plan information sharing activity in support of their co-ordinated care programme, the Better Together Programme.

An information sharing charter has been designed to help partners improve their information sharing arrangements. This charter recognises that organisations involved in providing any service to the public have a legal responsibility to ensure that their use of personal information is lawful, properly controlled and that an individual's rights are respected.

- The Better Together programme is planning how best to embed a more integrated way of working, underpinned by the charter, and the Centre is supporting that process.

→ Click here to find out more

- The Centre also continues to work with Surrey, supporting key services in developing a single spine of information across mental health service providers, ensuring timely access to relevant data and enabling an appropriate response.

→ Click here to find out more

- The Centre has been providing support to the Integrated Care and Support pioneers, and other localities that are working to integrate health and social care, by capturing the learning from local places. Case studies are being developed, due for publication in the autumn, which focus on how local places have engaged and communicated with their citizens; and on how local areas are designing and implementing Integrated Digital Care Records.

KNOW YOUR PRINCIPLE 7 RESPONSIBILITIES AS A DATA CONTROLLER

Most organisations know they have obligations under the Data Protection Act and have become increasingly aware of the need to keep information secure to comply with principle 7. However, the ways in which organisations engage and work with third party suppliers (data processors) and the implications that can have for information governance is often overlooked or misunderstood.

In the data sharing environments of today there is almost always a third party data processor involved in the process. The extent to which organisations have been involved in choosing that data processor can vary, however, in order to comply with principle 7 they must:

● Choose a data processor providing sufficient guarantees in respect of the technical and organisational security measures governing the processing to be carried out

● Take reasonable steps to ensure compliance with those measures.

It is for the organisations that are data controllers to make sure that any third party they use only acts upon instruction from them and that this is made clear in a written contract between them (the data controller) and the third party (the data processor).

→ For more information about your responsibilities, please read this issue's Your Questions section

→ Visit the ICO web site for more information

Principle 7 of the Data Protection Act:

Appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data.

THE NATIONAL INFORMATION BOARD

The role of the National Information Board (NIB) is to put data and technology safely to work for patients, service users, citizens and the professionals who serve them. The NIB brings together national health and care organisations from the NHS, public health, clinical science, social care and local government and independent representatives to develop the strategic priorities for data and technology.

There are four principal reasons for using health and care data:

- To support an individual's direct care
- To run the NHS and health and care system more effectively and efficiently
- To promote research, including to develop innovative new medicines. treatments and services, and
- To protect and improve health and reduce health inequalities.

However, there are ethical, legal, professional, technical and behavioural barriers to fully utilising the UK's health and care data for these purposes. The NIB has initiated work that is directed to ensuring that public and professional confidence can be restored, sustained and strengthened in order to be able to use data safely and effectively. This trust is a prerequisite for the success of all of the NIB's work.

This work includes:

- A public dialogue using appropriate language.
- Putting the role of the National Data Guardian on a statutory footing.
- A review of the current consent and objection options in national and local systems.
- The development of a new preferences model.
- Updating the IG Toolkit.
- Actions to make sure that organisations, systems and patient data are safe and secure

from the risk of malware and other potential forms of cyber-attack.

- The IGA is working to consolidate specialist knowledge, provide a single source of authoritative and credible guidance and to establish.

→ View work stream

→ You can read more about this work and the wider work of the NIB here and get involved in local events as they are advertised

INTRODUCING THE HSCIC'S CYBER SECURITY PROGRAMME (CSP)

'Cyber security' refers to the management and application of Information Security standards. This applies to computers, computer networks, and the data stored and transmitted but it can also cover physical security.

The CSP is delivering a number of projects:

- Cyber security education and awareness through training, events and guidance material for the health and social care system.
  - Health and Care Information Security and Privacy Practitioner (HCISPP) courses for a small number of security staff across the system in the first instance, as a pilot for a wider roll-out.
  - An e-Learning platform - like the current annual IG test.

- Enhancing HSCIC's existing cyber security capabilities - as a trusted centre of cyber security expertise:
  - Enhanced HSCIC physical security throughout its estate.
  - Personal security enhancements.
  - HSCIC staff training and awareness.

  - Encouraging cultural change amongst HSCIC staff - to become more cyber security aware.
  - Open incident reporting - to learn lessons.
  - Ensuring robust HSCIC system access control management.
  - HSCIC Security Operations Centre, which will host CareCERT.

- CareCERT, which stands for Care Computer Emergency Response Team, which will deliver:
  - A central service, and will provide coordination in dealing with the cyber threat, and in dealing with incidents.
  - Cyber security coordination across health and social care.
  - A national cyber security incident management function.
  - A means of issuing national level threat advisories, for immediate broadcast to organisations across the health and social care sector. This will encompass all N3 network endpoints including all connected computers and other devices throughout the health and social care system.
  - Publishing good practice guidance on cyber security for the health and social care system.
  - Information regarding CareCERT is available at:
    → www.hscic.gov.uk/carecert

IGARD CONSULTATION RESPONSES CREATE OPPORTUNITY AND CHALLENGE

A consultation on the draft terms of reference for the proposed new Independent Group Advising on the Release of Data (IGARD) ran from 16 June to 31st August 2015. Of the 43 respondents, many were broadly supportive of the proposals, but most felt that they could go further in terms of facilitating access to data, wider stakeholder membership, transparency and clarity of purpose.

In general terms, responding organisations were principally concerned about getting access to data, while individual responses were mostly concerned with privacy issues. Overall, the responses represent both a significant opportunity and challenge to HSCIC.

Many respondents reiterated concerns about difficulties getting access to data and felt that HSCIC took a 'risk averse' approach to data disseminations. Some respondents were unclear about the DAAG/ IGARD role as an advisory group to HSCIC rather than a decision-making body.

There was strong support for an open process of appointment for members and the chair and a clear consensus amongst respondents that the IGARD membership should better reflect the user community interests.

There was also strong support for lay representation that could be through membership of IGARD.

Nearly all respondents called for increased transparency of IGARD's processes, in terms of its ways of working and decision-making, indicating this would be essential in creating public trust and confidence in the system. Several respondents highlighted the need for HSCIC to establish to what degree IGARD can be independent of HSCIC and where and how it should be accountable.

Concerns were raised that the process for data applications was not well understood, transparent or joined-up. Respondents called for a clear and agreed description of the roles and relationships between the various organisations that have responsibilities to release data.

Dr Alan Hassey, Clinical IG lead and Deputy Caldicott Guardian for the Health and Social Care Information Centre says: "It will be a challenge to develop these ideas further in an updated IGARD Terms of Reference to specifically address the themes identified and present a coherent and accountable process that is fit for purpose and has the confidence of the public and stakeholders."

Formal feedback on the consultation will be ready for publication in October.
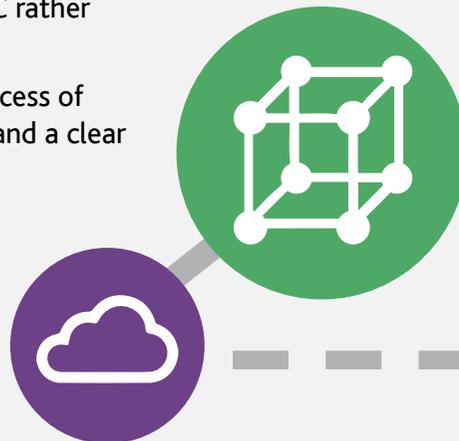
INDEPENDENT REVIEW

As the use of technology increases, so does the need to reassure the public that their personal medical data is being held and used securely.

The health and care system has not yet earned the public's trust in this area and must be able to assure the security of confidential data. This includes being clear with citizens and professionals how personal health and care data needs to be used, and the benefits of doing so, how privacy is protected and the choices available to people to object to data about them being used.

To address these concerns, the Secretary of State has commissioned an independent review to be led by the Care Quality Commission (CQC) and the National Data Guardian, Dame Fiona Caldicott. CQC have been asked to review the effectiveness of current approaches to data security in NHS organisations in relation to their handling of patient confidential data. The National Data Guardian has been asked to develop new data security standards that can be applied to all health and care organisations, and with CQC, develop a method of testing compliance with the new standards. The National Data Guardian has also been asked to propose a new consent/opt-outs model for data sharing.

Role of the National Data Guardian

The National Data Guardian role was established by the Secretary of State in November 2014, with a remit to speak without fear or favour about the safe use of personal health and care information. Dame Fiona Caldicott was appointed the first National Data Guardian (NDG).

A public consultation is underway to seek views on the roles and functions of the National Data Guardian for health and social care and closes on 17 December.

→ Click here to view the consultation

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