Information Governance

Review of Activity

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Purpose of Paper

The purpose of this paper it to ensure that the board are sighted on the more strategically important Information Governance activities undertaken since April to support the new organisation and the new health and social care landscape and to identify the challenges that remain.

The board are asked to note progress to date and to comment on proposed future activities.

Background

Several factors have had major implications for the information governance rules that govern the health and social care system since the start of the year.

The Health and Social Care Act, which brought the new Health and Social Care Information Centre into being, also had a significant impact on the health and social care landscape.

The Health and Social Care Information Centre was established with new roles and responsibilities including the role of 'Safe Haven' for Personal Confidential Data (PCD) in support of the health and social care system and responsibility for publishing a Code of Practice for Confidential Information. The system structure which we support was changed following the decommissioning of Strategic Health Authorities and Primary Care Trusts, the introduction of NHS England (and its Clinical Support Units and Area Teams), and Clinical Commissioning Groups and the transfer of Public Health into local authorities.

Dame Fiona Caldicott's review of Information Governance, *To Share or Not to Share* brought the use and sharing of PCD into sharp focus and highlighted issues in regard to the balance between protecting confidentiality and sharing data. In particular, the report raised questions about the processing of PCD in support of commissioning and identified the need to consider implementation of Accredited Safe Havens (ASHs). The report defines ASHs as specialist, well-governed independently scrutinised and accredited environments which can undertake the linkage of personal confidential data, which requires a legal basis, or data that has been de-identified, but still carries a high risk that it could be re-identified with reasonable effort, from more than one organisation for any purpose other than direct care

The revision of the NHS Constitution restated the rights of the patient in respect of privacy and confidentiality and that the NHS will keep confidential information about them safe and secure as well as the right to be informed about how information about them is used. Of greatest significance to the HSCIC, was the identification of the right of patients to request that confidential information about them is not used beyond their care and treatment, to have their objections considered, and to be told the reasons where their wishes cannot be followed.

The NHS constitution also includes pledges to anonymise the information collected during the course of the patient's treatment and use it to support research and improve care for others, to inform the patient of research studies which they may be eligible to participate in and to provide an opportunity for the patient to object where identifiable information has to be used.

Protecting Privacy and Confidentiality

A Code of Practice for Confidential Information

Section 263 of the Health and Social Care Act requires the HSCIC to publish a code in respect of the practice to be followed in the collection, analysis, publication and other dissemination of confidential data. Significant progress has been made in developing the

Code of Practice, including widespread consultation on the scope, content and presentation of the code.

It is intended that the Code of Practice will be published in the New Year.

To meet the need for a clear and concise guide which patients, carers and health and social care staff and organisations alike can understand we have published *A Guide to Confidentiality in Health and Social Care – Treating confidential information with respect*. The guide was launched in September by the Secretary of State, Dame Fiona Caldicott and the HSCIC Chair alongside the government's response to the Caldicott information governance review.

Significant time has been taken to promote the guide through presentations at conferences and engagement with a range of stakeholders and it has been extremely well received by all.

The promotional activities will continue and will be used in future to promote the Code of Practice when published.

Privacy Impact Assessment

Board members will recall that a Privacy Impact Assessment for the HSCIC functions and activities has been approved previously. The PIA has been published on the HSCIC web site and will be updates should the need arise.

Data Sharing for Commissioning

The recommendations from the Caldicott IG Review, the Act and clarification of the availability of a legal basis for data to flow in support of purposes other than direct care has had a significant impact on data sharing to support commissioning.

The HSCIC has worked with NHS England from the start to consider how to best to support their business needs lawfully and this has required significant input from the information governance team. IG advice and guidance has been provided for the establishment of the Regional Offices for Data Services for Commissioning, support to NHS England in making their section 251 applications and the definition of the requirements and interim arrangements for Stage 1 Accredited Safe Havens (as they are referred to).

The establishment of the Data Services for Commissioning Regional Offices required iG input on a number of levels, both in terms of induction training for staff and completion of appropriate approvals but also in the assessment and audit of their infrastructure.

The Stage 1 Accreditation process for the commissioning organisations has had significant implications for the work of the IG teams. The HSCIC have been tasked with the assessment of the IG Toolkit submissions and the establishment of Data Sharing Contracts and Agreements for each of the 70 organisations (compared with the expected 10 CSUs) that have applied to receive data. Recent developments in the approach to invoice validation and risk stratification may result in more Clinical Commissioning Groups seeking stage 1 ASH status.

The procedures and processes designed to meet these requirements were established at short notice and in anticipation of far fewer staff and organisations being involved. It is recognised that this has been labour intensive and are now unfit for purpose.

An aim for the coming months will be to streamline and automate the Data Sharing and Stage 1 ASH processes which are causing delays within the system. Automation of Data Sharing processes will also have benefits for a wider range of customers.

Definition of the criteria to be met by an ASH

A separate paper to the Board outlines the expectations of the HSCIC with regard to the requirements for Accredited Safe Havens as described in the Caldicott Review. The HSCIC continues to work with the IG subgroup of the Informatics Services Commissioning Group to finalise the policy with regard to Accredited Safe Havens.

Care.data

Although the IG team is responsible for providing advice and guidance to all the HSCIC programmes care.data warrants specific mention. The extract of data from GP practice systems has led to developments requiring significant IG input including advice and guidance to patients, delivery of a system to honour patient objections, and responses to Freedom of Information Act requests.

Caldicott Implementation Support Team

The Government Response to the 2012/13 Caldicott Review provided a detailed breakdown of the actions required of the Department, its Arm's Length Bodies, Local Authorities and the NHS. Oversight of the work to deliver against these assigned actions is the responsibility of the Information Governance sub-group of the Information Services Commissioning Group (ISCG IG sub-group). The HSCIC has been commissioned by the DH to create a team that is responsible for providing project and associated support, reporting to the ISCG IG sub-group and to the Independent Information Governance Oversight Panel (IIGOP), chaired by Dame Fiona Caldicott which has been formed to report to the Secretary of Health on progress in this area.

The Caldicott Review report comprised a number of specific recommendations which the government has accepted and agreed to take forward. Taken together the recommendations will contribute towards significant improvements across the health and care system.

However, an important over-arching ambition is to shape a culture change which enables a new and different approach to information sharing and management between organisation and professionals providing service to service users, the public and patients.

EU Data Privacy Regulations

The team continues to monitor the EU Data Protection Regulations which have been reported to the Board previously.

The Committee for Civil Liberties, Justice and Home Affairs (LIBE) of the European Parliament voted to approve the data protection reforms at the end of October although the implications of this remain unclear not least because the approved draft regulations include 3000 of 4000 proposed amendments from the previous draft.

The NHS European Office has contacted the team and we will continue to work with them and others to ensure we understand and plan for the implications of the new legislation.

HSCIC Assurance

IG Toolkit

The HSCIC has been established as the safe haven for PCD in the health and social care system. Vital to these credentials is our ability to demonstrate to patients, service users and the health and social care system that we are a fit and proper organisation. We continue to support the business areas through the IG working group to ensure that they continue to meet good practice standards and can demonstrate compliance with IG toolkit requirements so that we can maintain the high score from the NHS IC. PWC will provide an independent audit of the evidence we submit and we are committed to publishing our IGT score.

Freedom of Information Act and Data Protection Act Compliance

The HSCIC has become a high profile organisation which has resulted in a significant increase in both the numbers and the complexity of FOI requests. The team have supported business areas in responding to 389 FOI requests since the 1 April. For the NHS IC there were 182 for the equivalent period 12 months ago and the annual total was 367.

Subject Access Requests under the Data Protection Act have increased similarly: the team has responded to 80 SARs since the 1 April. For the NHS IC there were only 30 for the equivalent period 12 months ago and the annual total was 75.

Clearly the publicity surrounding the GP extract for care.data has impacted on the requests for information. The planned public awareness campaign with a leaflet drop to every household may further increase such requests as the public profile of the HSCIC increases.

Fair Processing

The HSCIC has been working with NHS England and liaising with the Information Commissioners Office on the public awareness campaign which includes a household leaflet drop and was prompted by the GP extract for care.data.

This campaign has presented an opportunity for the HSCIC to raise awareness of the full range of our activities, where we receive data from, how we protect it and when we share it. This has been linked with developments to the web site which will enable the public to better navigate to information they want.

The aim is that this can be used to meet the fair processing responsibilities for other users of PCD for purposes other than direct care such as researchers and audits. The HSCIC web site will become a hub for links to their patient information.

Directions and Data Controllership

The Health and Social Care Act sets out the need for the Secretary of State or NHS England to direct the HSCIC to establish data collections systems. While the HSCIC was established to continue collecting data that it used to as the NHS Information centre any new collections require directions.

The shaping and completions of these directions by NHS England has been undertaken in consultation with ourselves and has required significant IG input as well as advice from the HSCIC lawyers to ensure that the directions are lawful and deliverable.

A key issue for the HSCIC board has been concern about Data Controllership of the data that is collected under a Direction. Following discussion with the Information Commissioners office they have provided the advice attached as Appendix 1

Data Sharing Contracts and Agreements

The IG team has developed a template for a Data Sharing Contract and Agreement to meet the requirements of the s251 support for commissioning. The Confidentiality Advisory Group also required approval from the Information Commissioner's Office which has been obtained.

The aim will be to roll the same template out across all HSCIC business areas where data is shared with customers.

System-wide Controls and Assurance

Information Governance Toolkit

The team are responsible for the maintenance and development of the IG Toolkit. The have developed the system to reflect the new Health and Social Care landscape e.g. assessment sets for NHS England, the HSCIC, Public Health England.

The latest release also included the new reporting tool for serious IG incidents such as data losses or data breaches which is required by the DH and recommended by the ICO and provides escalation and reporting to both. We are currently developing an MOU with the Information Commissioners Office with regard to this tool.

We are also involved in a project led by Leeds city council to explore the development of a Local Authority version of the IGT, a product that will be developed in partnership with Leeds City Council and the Local Authority CIO Council (HSCIC lead with DH support).

Finally the team has worked with the DH Economic Regulation team to map several of the NHS Constitution Rights and Pledges against the IG toolkit requirements

Information Governance Training

Provision of a national IG Training tool has been extended for a further 12 months but the IG subgroup of the ISCG are likely to commission the HSCIC to collaborate with other to deliver a strategic review of IG training needs and the role of e-learning products in meeting those needs.

Aggregator Assurance Framework

The Operational Security Team is finalising the implementation of a new Aggregator Assurance Framework which builds upon the success of the Pharmacy Aggregator model and opens up the market for leading suppliers to provide connectivity to the N3 network using assured infrastructure and processes which reduces the burden on smaller organisations delivering services into Health and Social Care. Final agreements relating to commercials and contracts are being worked upon and it is hoped that the first 3 assured aggregators will be online and offering services in Q1 2014.

IG Advice and Guidance to health and social care system

Not surprisingly, given the significant changes in the system the IG teams continue to be asked questions in relation to IG matters and are providing advice through a number of different channels: where appropriate we work closely with NHS England e.g. to ensure that we cross reference our Frequently Asked Questions

Second Annual Data Quality Report

The HSCIC has published the second annual Data Quality report which aims to re-emphasise the importance of good quality data to the health and social care sectors, especially in light of the findings and recommendations of the Francis report and the Caldicott IG review. The report explains how and why the HSCIC assesses and reports on the quality of the data it receives and processes. It looks at some of the key data quality issues and what is being done to resolve them. It also presents examples of what the HSCIC perceives as good and poor data quality practice

Information Security

Cyber Security Initiative

The Board is aware and have accepted the findings of the Interim Cyber Security Review. The board has endorsed the initiation of a programme to implement the recommendations, including the establishment of an Information Assurance Executive Committee with non-executive input and advice.   The Programme Initiation has begun.

Supporting mobile data collection

The team has worked very closely with teams across the organisation to develop a tactical solution with Virgin Care Limited which has supported the implementation of an iPad based solution which will allow nurses to spend a greater amount of time with patients rather than being required to input data at a PC. This work has resulted in an innovative approach to the use of smart cards and opens up the possibility to develop this into a strategic solution for use across the system. The team is working with Communications and Media to develop a use case which is hoped to be delivered as part of the Busting Bureaucracy programme update by the Secretary of State in January.

Data Controllership – ICO advice

Data Controllership letter191113.pdf