Reflections on Information Governance in May 2012

1. Introduction

Information governance (IG) in the NHS has become a ‘hot topic’ for 2012. The latest NHS reorganisation involves significant changes in the organisations and legal entities that generate, utilise and share person level data, which in turn requires the alignment of suitable data protection mechanisms in new and existing organisations. The reorganisation also led to grumbling about the operation of, and restrictions caused by, IG in the NHS. The murmuring was sufficiently voluble that the Secretary of State for Health instigated a review of data sharing in NHS England entitled ‘to share or not to share’\(^1\), which is due to produce a draft report in late 2012.

Presciently in December 2011, BCS ASSIST commissioned a set of workshops entitled ‘NHS IG – Vision and Practice’. The aim of the workshops was to enable BCS ASSIST members working in IG to reflect on the current state of IG in the context of the imminent ‘Information Revolution’, and to discuss the gap between current practice and future vision for IG. This in turn would be expected to identify major issues and problems, some of which may be solved within the workshops. However, the state of play in IG and the more knotty matters raised would help form the basis of a BCS ASSIST ‘thought piece’ on the state of IG as perceived by some practitioners.

Three workshops were held for BCS ASSIST members in the North West, Yorkshire & Northern and London & South East Branches in April and May 2012. Approximately 120 people attended the three sessions representing some 80 NHS organisations that utilise patient data in their operations. The delegates were a mix of IG practitioners, senior IG managers, some Trust directors, senior managers from other allied disciplines as well as users of data and external consultants working in IG.

The workshops were run on behalf of BCS ASSIST by two experienced and expert practitioner members, David Stone and Wally Gowing, supported by their host organisations Apira and Capita Health respectively. The workshops were sponsored by MetaCompliance and FairWarning.

The format of the workshops was a presentation about the purpose of IG and aspects of the implementation and operation within the NHS in England. This was followed for the larger part of each workshop with facilitated discussion of points raised by attendees, with ‘Chatham House’ rules being applied.

The timing coincided with the announcement of the IG Review being led by Dame Fiona Caldicott, giving an added impetus to the workshops for potentially developing a BCS ASSIST submission to the Review.

This report sets out a set of findings from the main issues arising in the lively workshops. The findings are based on the themes that emerged in the discussions, which identified problems and sought to suggest possible solutions. The latter have been supplemented to a limited extent by discussions subsequent to the workshops. The findings are followed by a set of conclusions.

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1 See [http://caldicott2.dh.gov.uk/](http://caldicott2.dh.gov.uk/)
2. The Findings

The findings have been developed from common themes emerging across the workshops. Within the sessions, delegates were requested to raise issues during and at the end of the presentation section. These issues were then grouped by common strands (on flip charts) to enable a more structured discussion to be undertaken with notes being taken. Such discussions enabled more points to be raised and the gaining of more evidence, as well as potential solutions to be discussed.

The flip charts and notes were brought together in a set of reflections on each workshop and these have been used to develop the themes set out below to form the basis of the findings.

The main themes can be summarised as:

A. Putting IG on a sound cultural footing
B. Dealing with organisational change
C. Developing IG expertise and staff
D. Major specific issues.

A. Putting IG on a sound cultural footing

Evidence of poor IG culture and operation

- Widespread lack of senior management engagement (except in a limited number of organisations, mainly where breaches have occurred, fines been imposed or have been narrowly averted)
- Lack of leadership from the top of the NHS, evidenced by the expected annual ‘threatening’ letters from NHS CEO
- In some organisations, IG is marginalised as a silo activity within the organisation with Senior Information Risk Owners (Siro) and Caldicott Guardians (CGs) who have more pressing core job roles
- IG is stereotyped in parts of the NHS as ‘IG says NO’ and is considered in terms of ‘absolutely no risks’ instead of risk management to be assessed on a ‘case by case’ basis
- Abuse of identifiable data, with lip service paid to IG rules and with ‘arm twisting’ of IG staff to enable inappropriate access to identifiable data
- Technical jargon preventing intelligent discussion within organisations
- The IG Toolkit (IGT) for assessing the state of implementation of IG within an organisation has become a ‘tick-box’ exercise – and is often not completed honestly within the spirit of the intent
- Lack of clarity in understanding, implementing and operating IG – it is not always clear to IG practitioners on the ground which is the most important legislation or policy to apply; clinical staff have guidance produced by Royal Colleges that may be at odds with NHS policy guidance; different ‘rules’ on a specific subject may be operated in neighbouring organisations. There was also citing of some variation in the knowledge and skills of practitioners
- Lack of authoritative guidance – when seeking to resolve unfamiliar issues, the lack of clarity above leads to confusion as there is a Department of Health Informatics Directorate (DHID) policy body, the IGT, National Information Governance Board (NIGB), Ethics and Confidentiality Committee (ECC) and Information Commissioner’s Office (ICO) for seeking guidance related to approving developments (such as research applications within an organisation), but there is not a single body that NHS staff can turn to for authoritative guidance
- Inconsistent implementation across the NHS – as evidenced by the range of IGT scores and anecdotes concerning the variation in how issues have been resolved in different organisations.

Proposals for addressing the evidence

- Undertake investigation of ‘return on investment’ to make the ‘business case’ for operating IG appropriately in order that senior management can understand the need for investment in staff and processes to protect and utilise data. This has been brought sharply into focus with the ICO now being able to levy financial penalties
• Ensure that Data and Information Management is a mandatory part of risk reporting at Boards of all NHS organisations (including the NHS Board) and supplier organisations (via commissioning contract if necessary)
• Ensure that a board director that has direct responsibility for risk management (SIRO) has sufficient training and access to expert resource to undertake the role in a credible manner
• Decisions in IG on the use of identifiable data become context dependent in relation to what data is requested, for what purpose and for use by whom. Many such situations (possibly following the 80:20 rule) can probably be dealt within a straightforward framework. However, the remainder need to be seen in the perspective of the risks posed to the data subjects and the organisation and judgements undertaken by trained staff, the equivalent of the SIRO, CG and senior IG staff member
• IG definition – develop a simpler and smarter all encompassing definition of IG to enable better understanding of purpose and to aid senior management and wider cultural engagement, in effect seek to simplify the language of IG
• Shift the emphasis of IG to being about enabling use of sensitive personal data whilst properly respecting the privacy of the individual
• Modify the IGT to become a benchmark of model ‘organisational IG maturity’ with independent auditing over a number of years
• NHS Commissioning Board to emphasise need for IG and to mount a suitable proactive publicity campaign within the NHS including some ‘myth busters’
• A ‘common version of the truth’ is required to avoid reinvention of the wheel and to ensure clarity across and between organisations (NB: this may already be being addressed by the NHS IG Code of Practice being developed by the Health and Social Care Information Centre (HSCIC) under section 263 of the Health and Social Care Act 2012)
• In addition to the Code of Practice, there is a need for a respected authoritative source of guidance. Whilst it is recognised that there may be legal implications associated with the provision of such guidance, ultimately provision of guidance on decision-making must be feasible ahead of an inappropriate decision that subsequently involves the ICO in punitive action. This may be the role of the NIGC (formerly NIGB) under CQC from April 2013
• A formal professional standard of practice possibly based on existing ISEB qualifications structured specifically to meet health and social care needs.

B. Dealing with Organisational Change and its consequences

Evidence of shortfall

• Awareness of organisational changes taking place is high, but only superficially of the resulting impact on IG. Previous experience of organisational change indicates that major changes to NHS organisations or operating practices affect the sharing of data and related IG without the ramifications being thought through. These changes need clarity and leadership with authoritative good practice guidance to enable accurate and smooth transition
• The policy of Any Qualified Provider (AQP) is expected to cause further problems with contracting and having appropriate IG expertise in the commissioning function (i.e. Clinical Commissioning Groups (CCG)) and data processing organisation s (i.e. Commissioning Support Services (CSS)) going forward to make sure that the various legislation and good practice is adhered to
• Major changes to NHS organisations and operating practices where effective guidance and support is required include
  o Health & Social Care integration
  o Multi-agency working
  o AQPs
  o The transition process from PCTs to sub-clusters to NHS Commissioning Board (NHS CB) Clusters with CCGs and CSSs
• Information lifecycle – previously has not been a significant issue, but situations are arising for which guidance and experience are lacking, such as
  o Ending of contracts through exit or bankruptcy
Organisations ceasing to exist, e.g. PCTs commissioning arms, providers and SHAs.

- Legal issues abound, such as
  - Data Controller and Data Processors – impact on CCGs, e.g. not legal entities yet
  - Information sharing and contracts
  - Identifiable data requested for commissioning purposes by CCGs.

**Proposals for addressing**

- Transition guidance is needed with ongoing support as indicated in A above
- Clarity and leadership is needed from the ‘top’
- Involvement of operational IG staff in resolving issues
- Workshops and updating relevant websites to disseminate good practice as developments occur.

**C. Developing IG expertise and staff**

**Evidence of shortfall**

- As raised under Theme A, the use of jargon by IG staff, i.e. technical terms that may not be clear to other health service staff
- Attitude of other staff to data subject privacy, e.g. response of ‘IG says NO’, ‘arm twisting’ of IG staff to enable inappropriate access to identifiable data
- Difficulty in knowing where to turn to gain advice which indicates lack of expertise locally, lack of recognisable source of expertise and lack of effective communications and networks in IG across the NHS
- Observed reduction in staff numbers in IG during the Reorganisation, especially in commissioning organisations.

**Proposals for addressing**

- As indicated in Theme A, there is a need to simplify the language of IG in terms of definitions and couch in simpler terms concerning privacy
- Develop clear short statements of policy concerning access to identifiable data for use in all NHS organisations and those commissioned by the NHS to provide services
- Train IG staff to use ‘business language’ and deal with real world issues
- Train IG staff to be proactive about management of data and associated risks, that with engagement by senior management enables proactive dialogue with staff
- Improve the training facilities available for IG experts
- Improve access to pooled expertise and IG networks, such as enabling the continuation of the existing SHA IG Groups and encourage wider membership
- Develop professional leadership and professional development of IG specialists (possibly a task in which BCS ASSIST could support)
- Employment of IG staff will obviously be the subject of the same financial regime as other staff, however there needs to be sufficient expertise available to the organisation to enable its legal obligations to be met. Guidance should be provided by the DH in the form of a minimum level of skills and knowledge required by organisations, whether employed directly or not.

**D. Specific Issues**

**Evidence of issues**

There are a number of major issues arising from policy and legal changes, which will affect IG and its operation in all NHS related organisations. Currently IG staff are aware of the issues, but wish to be involved in understanding how the policy will be implemented or issues will be resolved, as well as gaining understanding in time to implement effectively. The issues include:

- Major development with drive for patients access –
  - How to give patients access to their data
  - Better understanding the risks and issues
• Dissent and consent
  o In short –term managing dissent and in future consent
  o Impact of Draft EU Regulation with its emphasis on explicit consent
• Cultural change in society regarding use of data and privacy rights.

In addition there are specific subject matters where help/guidance was sought. These include:

• Privacy audits
• De-identification.

These issues are stated with the expectation that taking these issues forward will be in the context of the improvements suggested in the proposals in themes A to C.

3. Conclusions

The IG practitioner and IG manager delegates at the workshops were open about the issues and the difficulties that they face in their work. The overall picture is that there is a large gap between the ‘Practice of IG in the NHS’ compared with the ‘Vision for IG’, reflected in the sections below.

**Current ‘state of play’ of IG** - In the course of the workshops, it was evident from delegates, as set out above, that all is not well in the practice and operation of IG across the NHS and within NHS organisations. Given that patient information can be seen as the ‘lifeblood’ of the effective operation of the NHS, there is clear evidence that the place of IG in the culture of NHS is not what it should and needs to be. Examples are that patient privacy is not comprehensively well respected and IG is often treated as a side issue by management except where penalties may be incurred. Unfortunately, barriers have been created around IG seemingly because it has been treated as a niche specialist subject, often dealt with as a subset of Information and IT departments, coupled with the jargon and complex language used in IG policy documents and by IG practitioners.

These elements are then compounded by the lack of clarity and leadership within the IG world, where authoritative and clear guidance is often lacking, leading to inconsistencies in implementation and further weakening the effective operation of well-intentioned IG policies. Further, IG needs to be seen as an integral component of the risks that organisations manage and be treated as such by senior management, instead of it being kept in a silo with the expectation of simple ‘black and white’ answers.

In addition to the context above, major organisational change is being undertaken and requires aspects of IG implementation and operation to be accurate (e.g. which organisations are Data Controllers) and effective (e.g. who has the right to see identifiable data in new organisations). The changes also bring with them the movement and, seemingly, a loss of IG staff at a time when there is more IG work to be undertaken than ever before. Fortunately, this reorganisation is being accompanied by a greater realisation of the importance of IG and of ‘getting the IG right’ when making changes – although there is a long way to go yet to get things right. This may have been aided by the recent announcements by the ICO of significant financial penalties in respect of other organisational change where IG developments have fallen short of basic standards.

**IG Toolkit** - The IG Toolkit appears to be a good thing in providing a list of the things that need doing in IG and providing a means of tracking an organisation’s progress in implementing and operating IG. On the other hand, it appears to have become a tick-box exercise that is ‘gamed’ to provide a suitable status for the organisation through its use as a self-assessment mechanism. Whilst the IGT provides a knowledge base, it does not provide a framework to support and enable and assist organisations with their IG implementation and operations. It is suggested that such a framework be developed and that independent audit of IG progress is undertaken at a sufficient scale to be effective (e.g. enough organisations each year over a three or five year cycle to ensure that all organisations are paying enough attention to IG).

**IG Staff** - The implementation and operation of effective IG depends on access to expertise and knowledge by NHS organisations and commissioned external health care service suppliers. The
expertise is delivered through SIROs, Caldicott Guardians and IG staff. In some organisations, these arrangements do not appear to be wholly effective. This situation can be aggravated by the position of the IG staff within an organisation and their need to have sufficient expertise, knowledge and experience to handle and manage the wide range of issues thrown up within IG. Appropriate development opportunities and professional standards are needed to prepare IG staff to enable them to function effectively to ensure that their organisations operate legally and effectively whilst protecting patients’ rights.

**In conclusion** - This exercise by BCS ASSIST has identified a set of issues and barriers to effective practice and working of IG in NHS England and ways are proposed for attempting to tackle the resultant problems. It is proposed that a suitable submission is made by BCS ASSIST to the Caldicott IG Review based on the outcomes of these workshops to raise the main issues and potential remedial actions.