Draft BCS Health Response to the Information Governance Toolkit (IGT) Consultation, November 2012

This document contains the views of BCS, The Chartered Institute for IT, and takes into account responses received in answer to our call for input from BCS members and BCS Specialist Groups. Input was provided by a number of NHS employees, including a Foundation Trust Informatics Director, several individuals supplying health informatics consultancy, systems and services to the NHS, and academics. Quotes are shown between "..", and references are shown between '..'

PAGE 2 Strategic Objectives

The IGT is currently the vehicle through which a range of strategic policy objectives are met. These include:

Satisfying the Cabinet Office requirement for DH to provide assurance that all parts of the NHS are meeting mandated data handling standards, including encryption, staff training and information risk management structures.

2.1 *The IGT only provides high level assurance for the Cabinet Office*

Providing organisations with the assessment of information quality legally required under Quality Account Regulations.

2.2 The IGT only provides a very high level assessment of information quality, which is unlikely to be enough to satisfy Quality Account Regulations in a meaningful way.

Supporting the accountability and transparency agendas by requiring organisations to assess, monitor and publish performance against a standard framework which enables comparisons and enables organisations to identify areas for improvement.

2.3 The IGT is very successful in this regard (i. e. strategic objective 3).

Providing organisations that process NHS patient data with a clearly presented and peer reviewed roadmap to effective information governance.

2.4 For those organisations who take IG seriously and have highly IG-literate staff, the IGT assessment provides a good roadmap for developing a plan for IG improvement. The guidance and real examples provided are particularly helpful. But while this is in theory a success, such roadmaps are often compiled as a one-off exercise, and not updated over the year.

Providing intelligence for the Care Quality Commission, Information Commissioner (and potentially Monitor) to support their regulatory roles.

2.5 The fact that even organisations known to be failing and to have serious IG and Records Management issues appear to have exemplary IGT scores devalues them as a stand-alone source of intelligences.

Providing a basis for establishing whether an organisation is meeting contractual obligations for effective IG.

2.6 The IGT provides a useful tick box for Commissioners.

Providing a basis for establishing whether an organisation may be 'trusted' to have access to nationally provided IT applications and services.

2.7 Too much is taken on Trust so far as IGT returns are concerned.

How well do you think IGT meets these strategic objectives?

2.8 BCS does not consider that the Information Governance Toolkit supported the strategic objectives listed on page 2 of the Questionnaire very well.

The statement in the consultation document at the top of page 2 that "The IGT is currently the vehicle through which a range of strategic policy objectives are met" is aspiration rather than fact, and not what the IGT does: rather it attempts to measure how well a range of strategic policy objectives are being met. Self-declared statements of compliance sometimes verge on the optimistic side, and many auditors are too worried about having their contracts removed to be overly candid or critical.

The principle of self-declared compliance requires completion by IG-literate staff actively supported by management at all levels and subject to effective independent audit if they are to be seen as honest and more than a product of box ticking by their readers. The IGT acts as a comprehensive framework, but relies on the staff who complete the returns being fully conversant with the relevant background (some of the IGT overlaps with the requirements of CQC, Monitor, the NHS Litigation Authority and legislation). It is apparent that all too often the staff concerned do not have this comprehensive understanding, and that as a result the IGT fails to meet its strategic objectives.

Where do you consider the IGT to be weak in meeting these strategic objectives?

2.9 The evidence available suggests that the IGT is weakest as a stimulus for improving data quality, and for providing information to support the regulatory roles of the CQC, Information Commissioner, Monitor & NHS Legal Authority. And as the respondents pointed out, organisations are rarely if ever penalised for poor performance against the IGT returns.

The IGT treatment of data quality is particularly poor. The supporting guidance doesn't provide a useable high-level definition of data, or acknowledge that data quality is more or less specific to the purpose that the would-be user has in mind. The general practice entry

doesn't have a section on data quality, despite being the only provider domain having an organisation (PRIMIS+) devoted specifically to assessing and improving the quality of GP patient records: the GP assessment is also unduly limited in most other areas.

Self-declared statements of compliance tend to err on the optimistic side and encourage a 'tick box' mentality, which is fostered amongst other things by an inadequate understanding of information governance by a number of those using the IGT ,and the IGT content itself. For more on our view of the content of the IGT, see above and answer 7.1.

PAGE 3 Additional Objectives

The two IGT workshops identified a number of alterations to and additional strategic objectives. These are listed below. For each statement answer the following question.

Do you agree that the IGT is an effective vehicle for addressing the additional strategic objectives identified by the workshops?

Alteration to the first objective to embrace those in the independent sector

3.1 ***Yes.*** *BCS believe this should be done without delay now that the Health and Social care Act 2012 is coming into force with the explicit intention of encouraging any qualified care provider to provide NHS-funded care. The IGT elements applying tor independent & commercial organisations should correspond to those that apply to any equivalent type(s) of NHS organisation.*

To support the sharing of information along the care pathway securely and safely to achieve safe care;

3.2 ***Yes,*** *we assume that the term 'care pathway' as used here corresponds to the journey the patient takes through the NHS during an episode of care.*

Certainly IGT element 10-203 is unduly negative about sharing patient information: it is in the patient's interests that ***relevant*** *information about him or her is shared with other professional staff providing his or her care. Not doing so may disadvantage the patient, and occasionally result in serious avoidable harm. The objective above should be reworded to include "relevant information" rather than "information" to be in line with principle three of the Data Protection Act 1998.*

At the same time, care professionals should where possible inform the patient/his proxy of their intention to share, and take into account any objection(s) to it raised by the patient/proxy (q.v. IGT 10-202 & 203)

To achieve cultural change and embed IG within organisations and within business processes to support patient care related objectives;

3.3 ***Yes,*** *however the IGT in its current form is ill-equipped to achieve this. It focuses on defining policies and processes rather than their outcomes, and does not seek to assess whether the policies and processes (which may be very good) are implemented effectively. It is also written at too high a level while at the same time contains some unnecessary detail. The range of knowledge sources referred to is overly limited, consisting in the main of DH publications.*

There should be a single assurance mechanism that serves all assurance purposes without duplications and overlaps;

3.4 ***BCS agrees in principle****: however, it is not possible to answer this question without having a clear definition of what is meant by "all assurance purposes" and the IGT team need to provide this. As a principle, any extension of the scope of the IGT should not impact adversely on the organisation and content of the material on IG.*

To provide assurance to public/customer base and to inform the public of the organisational performance linked to IG

3.5 ***BCS agrees in principle*** *but in its present form the IGT is unlikely to provide the necessary assurance.*

Interoperability standards are essential and should be incorporated within IG

3.6 ***BCS does not support this statement.***
This is two questions. The answer to the first would always be ***yes: our*** *answer to the second is n****o****. Interoperability standards are essentially technical specifications of mechanisms for sharing data, and may include facilities for requesting, transferring and implementing the authority to do so.*

IG deals amongst other things with the rules governing how data may be shared, with whom and for what, irrespective of the mechanism actually used to do the sharing. IG and interoperability are therefore orthogonal to each other. Including interoperability standards in the IGT could further muddy waters that are already unduly opaque. While it is opportune to encourage the rapid extension of digital interoperability, any national assessment of capability/practice in this area should be the subject of a separate survey.

If you would like to explain your answer or if you disagree with any of the additional objectives please comment here.

3.7 What follows are general observations about the suitability of the IGT process to meet the additional objectives. Observations specific to a particular objective have already been given under the objective concerned.

The NHS Commissioning Board should IG enforce professionalism and training standards with recognised qualifications across the healthcare ecosystem. These collectively need to be

oriented to IG and the relevant statutes and regulations, so that there is a core of competent staff within each organisation. There should also be an independent mechanism that verifies their continued competence in matters concerning IG.

Are there any additional strategic objectives that you feel are, or should be, satisfied by an IG performance assessment and support mechanism? List up to 3 below.

3.8 Encourage the appropriate and legal sharing of patient data for secondary uses, taking into account any explicit personal dissent.

Would the IGT be an effective vehicle for addressing the additional strategic objectives identified by you?

3.9 Additional Strategic Objective 1 ***Yes**, given that our other comments and observations about the IGT and its users in this questionnaire are addressed.*

PAGE 4 Assurance of IG

Does the IGT provide you with adequate assurance regarding the different aspects of YOUR OWN organisation's IG?

4.1 ***No***

If you would like to explain your answer, please comment here

4.2 The IGT only provides minimal data quality information, and IGT users have to perform separate and largely different processes to satisfy Trust Boards, Monitor and their Commissioner. This leads to a massive replication of effort.

The IGT often only reports whether policies and processes are in place, rather than testing whether they are being put into regular practice.

Does the IGT provide you with adequate assurance regarding the different aspects of OTHER organisations' IG?

4.3 ***No***

If you would like to explain your answer, please comment here

4.4 There is strong anecdotal evidence that IGT standards are being interpreted differently by different organisations.

NHS organisations have been known to have very low IG scores (e.g. c 40%) for much of the year but to then announce an unexpected improvement, despite a lack of any evidence as to why this should be.

PAGE 5 Development of IGT

How could the IGT be improved or supported to provide a more robust assessment of performance?

5.1 For our views on the IGT content see the other answers in our response.

For our views on how the IGT results can be made more trustworthy and consistent, see answers 2.8 and 3.7.

Do you know of any other practicable ways and/or alternative mechanisms that are equal or superior to the IGT and that may meet the strategic objectives identified in the previous sections?

5.2 ***Yes***

If you have answered YES could you please list your suggestions, and tell us their pros and cons

5.3 BCS believes that the DoH / NHS-CB needs to set up a working party comprised of representatives from the NHS, the CQC, NHS LA, Monitor and those responsible for the IGT at the DoH. Their objective should be to develop a standard 'assessment' language that is understood in the same way by all who complete, and/or use the output from, the IGT.

By recognising where the same assessment (in terms of language and requirement) occurs in different types of return (e.g. the CQC, Monitor and NHS Litigation Authority Assessments for Records Management and the IGT Requirement for Records Management), and requesting the same information from the completing organisation, a great deal of duplicated (or worse) effort will be saved by all the organisations concerned

Do you think central support for IG is helpful?

5.4 ***Yes.***

5.5 If YES please complete the matrix below

Guidance	Not Helpful ☐	Slightly Unhelpful ☐	Neither Helpful nor Unhelpful ☐	Slightly Helpful ☐	Very Helpful ◉
Conferences	Not Helpful ☐	Slightly Unhelpful ☐	Neither Helpful nor Unhelpful ☐	Slightly Helpful ◉	Very Helpful ☐
Policy	Not Helpful	Slightly	Neither Helpful nor	Slightly	Very

documents	☐	Unhelpful ☐	Unhelpful ☐	Helpful ☑	Helpful ☐
Workshops	Not Helpful ☐	Slightly Unhelpful ☐	Neither Helpful nor Unhelpful ☐	Slightly Helpful ☐	Very Helpful ☑
Practical tools	Not Helpful ☐	Slightly Unhelpful ☐	Neither Helpful nor Unhelpful ☐	Slightly Helpful ☐	Very Helpful ☑
Exemplar materials	Not Helpful ☐	Slightly Unhelpful ☐	Neither Helpful nor Unhelpful ☐	Slightly Helpful ☐	Very Helpful ☑
Master classes	Not Helpful ☐	Slightly Unhelpful ☐	Neither Helpful nor Unhelpful ☐	Slightly Helpful ☑	Very Helpful ☐
Online networks	Not Helpful ☐	Slightly Unhelpful ☐	Neither Helpful nor Unhelpful ☑	Slightly Helpful ☐	Very Helpful ☐
Helpdesk	Not Helpful ☑	Slightly Unhelpful ☐	Neither Helpful nor Unhelpful ☐	Slightly Helpful ☐	Very Helpful ☐
E-learning packages	Not Helpful ☐	Slightly Unhelpful ☐	Neither Helpful nor Unhelpful ☐	Slightly Helpful ☐	Very Helpful ☑
Newsletters	Not Helpful ☐	Slightly Unhelpful ☐	Neither Helpful nor Unhelpful ☑	Slightly Helpful ☐	Very Helpful ☐
Any other support	Not Helpful ☐	Slightly Unhelpful ☐	Neither Helpful nor Unhelpful ☐	Slightly Helpful ☐	Very Helpful ☑

Please specify Any Other Support

5.6 The most important addition to support would be genuine delivery of all of the above in a form that is very helpful -non-delivery may be due in whole or in part to the abolition of Strategic Health Authorities and PCTs. Central support went from excellent under the NHS Information Authority through mediocre at best under CfH to invisible now. Central Guidance appears to be outdated, or at least seldom updated.

In connection with this, the impending abolition of the National Information Governance Board for Health and Social Care (NIGB) seems at the very least to be counter intuitive. NIGB is the body charged with developing and providing advice on personal information IG to the NHS and Social Care domains, and its guidance is more necessary than ever at a time when NHS IG is very likely to undergo its most significant change for some years.

Do you know of any IG products developed in other organisations that would be beneficial if rolled out across all care services?

5.7 Yes

If you have answered YES please list your suggestions here

5.8 Although they are not intended to supplant the IGT, the guidance published by NIGB is comprehensive and intended for NHS IG. They, and the eight BMA General Medical Council (GMC) publications on confidentiality, are well written and deserve to be more widely publicised and used. They are rarely cited in currently as resources in the IGT: the only one noticed in a cursory examination was the Care Record Guarantee. For more detail of both, see the references in Annex A of 'Fair Shares for All'.

PAGE 6 Information Handling

As a user of care services, how important is it to you to find out whether an organisation handles your information safely and securely?

6.1 Very important.

As a user of care services, what would be a good way of letting you know how well an organisation handles your information?

6.2 Monthly reporting of IG compliance levels, incidents of data loss / abuse and complaints about IG (including data quality) would be a major step forward, as would the award of an IG charter mark from a respected independent body, such as the British Standards Institute or the Information Commissioner's Office (or best of all NIGB, were it to remain in existence).

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If you have any other comments please insert them in the box below.

7.1 Tighter wording and better and fuller definition of IGT concepts and content is needed to prevent the varying interpretations of the IGT that its users currently make. The IGT content on data quality should be completely revised. These, coupled with more focus on IG outcomes, would deal with much of the criticism made of the IGT itself in this response. Efforts should be made to ensure that the IGT also provides the evidence about information

governance required by bodies such as the Trusts themselves, their Commissioners, the CQC, Information Commissioner, NHS Litigation Authority and Monitor. More detail on the changes needed is given in the preceding answers in this response.

Although we appreciate that the IGT is intended to provide an IG comparator across organisations, its structure would benefit from more clearly recognising the basic generic IG roles that underpin the DPA 1998:

- *data controller (e.g. an Informatics Director),*
- *data processor (other staff, including IT staff, working for or on behalf of the NHS that use staff and/or patient data), and*
- *data subject (people about whom data is stored and processed: patient / staff member).*

The IGT also needs to recognise (e.g. in 10-202) that transforming personal data into pseudonymised, anonymised or aggregated data enables the increasingly desirable and much wider use of individual's data for secondary uses without the need to obtain patient consent: the IG Training Tool does cover these topics at a high level. The IGT should also cover the linkage of data from different sources using pseudonymised or anonymised data only. Awareness of these techniques is essential for data controllers who are likely to receive requests for individual data for secondary uses, and for those who make the requests, and references are required to relevant guidance and knowledge sources (see Annex A of Fair 'Shares for All').

If an improved IGT was accompanied by a corresponding improvement in its use, based on a verified and continual improvement in the IG knowledge and skills of IGT users, and independent audit of at least a sizeable sample of submitted IGT results, it would move from being viewed by many as a tick box exercise of little value to become an effective and well-regarded comparator of IG effectiveness, and a powerful stimulus for its improvement.

There is likely to be need for further and more substantial revision of the IGT soon in the light of the HaSC Act 2012, the plan to revise the NHS Constitution and the 2nd Caldicott Review, which is due out in draft form in the next month or so.