BCS ASSIST consultation response to

Liberating the NHS: An Information Revolution

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BCS
The Chartered Institute for IT
First Floor, Block D
North Star House
North Star Avenue
Swindon SN2 1FA
1. Foreword

*Liberating the NHS: An Information Revolution* sets out a vision of a future health care system in which the provision of information is a crucial part in enabling the flow and delivery of care services. We welcome the opportunity to respond and reiterate our commitment to working in partnership with the Department of Health, suppliers, UKCHIP and others to help deliver the informatics agenda, which will be crucial to the successful implementation of *Liberating the NHS* and in achieving the desired outcomes for the population of England.

While the notion of a revolution is attractive way of signalling a step change, for many working in the field of health informatics, the vision set out in *An Information Revolution* feels more like a further step in the process of continual evolution of policy. This should not be seen negatively; evolution is generally better and more affordable than revolution, a lesson learnt from the previous strategy with its emphasis on ‘ruthless standardisation’ of systems.

There are new and welcome changes – previous strategies have always emphasised the importance of patient centred information, but the emphasis in *An Information Revolution* of seeing the patient in control of their own records is a significant shift, although not one without many cultural and behavioural challenges.

The proposals for the publication of raw and unpolished data are new and again provide both opportunities and risks. The absence of any statements about ruthless standardisation of systems is a positive indication of learning from recent history, although we still need to adopt a strong stance on the implementation of appropriate and ‘fit for purpose’ standards.

Some of the key principles that run through the strategy remain sound from previous iterations of NHS IM&T strategies, stretching right back over 30 years to Dame Edith Körner’s principle that information should be a by-product of operational systems and the emphasis on patient rather than organisational centred information systems. This shows that there are elements from the previous regimes that stand the test of time, and the selective and judicious protection of those elements will be key, especially in a climate where we do not have the funds to re-implement systems which are actually ‘fit for purpose’.

Our members are concerned that at the same time that information is finally being recognised as central to facilitating the policy changes set out by the coalition government, the health informatics profession is under increasing pressure. Many highly skilled staff with transferable skills are now looking to move outside of the NHS and the public services more widely. While we recognise that there is a huge and challenging agenda, we believe that the health informatics community that BCS ASSIST represents is a key and valuable asset and one that needs to be supported through the transition. Given our members’ direct engagement with the delivery of current and future information strategies, we would welcome the opportunity to further engage with the Department of Health on this matter and provide advice on the operational aspects of delivery of *An Information Revolution* as policy moves into practice.

Adam Drury, Chair – BCS ASSIST National Council
2. Introduction

2.1. About BCS ASSIST

BCS ASSIST is a professional association for those working in and for informatics in health care and social care and is a member group of BCS. Its objective is to develop professionalism and professional standards, and to work with other bodies including government to provide a voice for informatics professionals.

BCS ASSIST provides a vehicle for quickly and effectively engaging frontline health informatics professionals at all levels, operating through its membership and branch networks. It currently has approximately 1300 members and works closely with other organisations such as the UK Council for Health Informatics Professions (UKCHIP) to support the professional development of health and social care informatics staff.

2.2. What is health informatics?

Over the past few years, the term ‘health informatics’ has been accepted increasingly as: ‘the knowledge, skills and tools which enable information to be collected, managed, used and shared safely to support the delivery of health care and promote health’.

This concept is illustrated in the diagram below, which shows how the generic sciences of health care, information and computer technology interact to create the domain of health informatics.

2.3. Our consultation process

The consultation took place over the period 1 December – 23 December 2010.

The consultation involved four workshops in Liverpool, London, Birmingham and Leeds to which all members of BCS ASSIST were invited. The invitation was extended to others working in the social
care field, although as a result of the short timescales the response from this group was limited. In total over 50 BCS ASSIST members participated in the workshop events.

BCS ASSIST members were invited to contribute by phone and email to the consultation facilitator.

The results of all the feedback has been assimilated and forms the basis of this consultation response. The draft response was then reviewed by members of the BCS ASSIST National Council on behalf of the wider membership before final submission.

This response represents the views of BCS ASSIST members as health informatics professionals. It does not attempt to represent the views of their employers, whether as public or private organisations.

2.4. Structure of this response

Following this introduction, the response introduces an assimilated summary of the views expressed by BCS ASSIST members based around the six themes of the consultation. It does not seek to respond to every question; many of the consultation questions are targeted at particular stakeholder groups, and thus the BCS ASSIST members have only an indirect interest.
3. Our response

3.1. An Information Revolution – the challenge and opportunity

The first section of *An Information Revolution* consultation paper describes the challenge which faces the provision of health and care services in the future, as well as the opportunities that are presented through the use of information both in terms of helping individuals take informed decisions about their health and related services, as well as the way that information can support the direct delivery of care.

One key comment to make about the overall context of the whole document, and this chapter in particular, is the continual reference to health and social care. This is strongly welcomed by BCS ASSIST, recognising the reality of a world where individuals receive a package of health and social care services and where there are certainly opportunities for the provision of better, more integrated services through new ways of working, supported by the use of information and information technologies.

Q1: What currently works well and what needs to change?

The first question of the consultation asks for views on what works well now and what needs to change.

BCS ASSIST members are clear that those elements that are already in place and that are delivering value should be retained. Not only would it be a retrograde step to dismantle and replace such elements of the national infrastructure, but in a time of tight financial constraints there are other uses for such funds as are available.

Examples of elements of the national infrastructure that are currently seen to work well include:

- the use of the NHS number;
- the national Personal Demographics Service (the Spine);
- the NHS network;
- NHS mail;
- GP to GP record transfer;
- the picture archiving and communications system (PACS);
- the Summary Care Record (SCR);
- the electronic prescription service (EPS);
- work on establishing a robust framework for information governance.

In particular there is a critical need to maintain the use of the NHS number as a unique identifier in health and social care and the use of the PDS as a means of integrating data. Maintenance of these two elements of infrastructure is essential in order to realise the vision of integrated care underpinned by integrated information.

There is general agreement that systems in primary care have great potential to work well – a situation that has been recognised internationally for decades – but they are still inconsistently implemented, used and supported, the latter issue leading to less than optimum value for money,
especially given the valuable information that could potentially be extracted from primary care data repositories.

There is a more mixed picture in hospitals and a much greater variation again in community services, although there are examples of excellent practice where integrated systems support clinical care across both primary and community settings. However there was common agreement that enhanced informatics systems have the potential to improve patient safety, clinical outcome and patient experience, particularly in the acute hospital setting through systems such as e-prescribing.

In exploring what other elements worked well, we found that there is a lack of correlation between the specific systems being implemented and their successful deployment. As an example, one application widely used in community and mental health settings was cited in examples of both good and poor information systems. The critical success factor is not the specific software itself, but rather the process and robustness surrounding the deployment, and the commitment of clinicians and managers to making the systems implementation a success.

What is absent from the consultation document are any proposals about how these key elements of the national infrastructure will continue to be managed in the future and how the continued maintenance of a national ICT infrastructure is an important element in supporting the implementation of government policy.

In terms of things that need to change, BCS ASSIST members commented on the need to:

- return ownership of information and technology related projects to a local level. A sense of local ownership, commitment and purpose is considered to be one of the most critical factors influencing successful implementations, although this does not necessarily have to be delivered solely within an NHS framework to be successful, as there are examples of successful implementations delivered by NHS organisations working with partners;

- address the exclusion of social care from the National Programme for IT; and

- reassess the applicability and ‘fitness for purpose’ of some elements of the standards framework; SNOMED CT was specifically mentioned.

**Q2 : What are the most important uses of information and who are the most important users?**

There was general consensus that particularly important elements in the area of information use and users are in:

- developing information flows in support of the care of critically ill patients;

- supporting clinicians at the point of encounter more generally with appropriate levels of detailed information about the patient, the services available and any ‘best practice’ evidence;

- capturing and integrating information about relevant social care interventions; and

- enabling patients to make informed choices about services. This is not only about choosing between different providers of similar services, but crucially in enabling patients to make informed choices about the nature of those services on offer to them; for example for patients
suffering from back pain, there will be comparative risks and benefits associated with surgical interventions as opposed to physiotherapy.

Q3: Does the description of the information revolution capture all the important elements of the information system?

Question 3 asked whether An Information Revolution captures all the important elements of an information system, by which we understand the notion of the whole system, and not any particular component.

The key area that is missing is the underpinning ‘back office’ information systems that are critical to the effective operation of health and social care services – for example the operational finance and workforce information systems. While some of these are outsourced and provided by third parties, there is still a need to ensure that financial and workforce data can be utilised alongside activity data as this is an important factor in ensuring that both commissioners and providers - certainly those in the NHS – can operate efficiently and effectively.

Another area of concern was the absence of proposals for the continued operational management of key elements of the national infrastructure.

Q4: Given the current financial climate how can the ambitions be delivered in the most effective and efficient way?

Question 4 asked for comments about how the ambitions might be used to drive better care and outcomes in the most effective and efficient way.

Affordability

There was very strong support for the message that we cannot afford not to continue to invest in modern technology. Not only has technology a key role to play in unlocking flows within the health and care system – flows of information, people and supplies - but the rapid provision of high quality information can facilitate the market dynamic that provides the opportunity for continued and innovative improvements and remove the asymmetric power balance that has strengthened those with control of information and knowledge over those without. However there was concern that such a market dynamic would also acknowledge the value of information and could result in a reluctance to share.

This latter concern was considered to be critical. Given the increasingly pluralistic nature of health and social care providers in the future and the move to Foundation Trust status for all publicly owned health care providers with the associated freedom from direct central control, there will need to be a strong regulatory function to ensure that those organisations engaged in the provision of health and social care services funded by the state recognise their responsibilities as part of a national information system, and specifically their obligations to send and receive information in a secure and controlled way and in line with national standards. We did not feel that the application of contract conditions – while powerful when applied effectively – would on their own be a sufficiently powerful lever to achieve this objective.
Patient record ownership

There were mixed views as to whether providing patients and carers with greater control over their records would be an effective means of encouraging patients to become more engaged with their own health care. While there was a view that there would be a group of patients who welcomed the opportunity, there was an equally strong view that a large majority of patients would defer to the advice of their clinical professional in such matters and would not appreciate why having control was – for them at least – beneficial.

New initiatives

It will be critical that new initiatives do not place unnecessary demands on the informatics infrastructure and that new policy initiatives have informatics assessments undertaken to ensure that the impact is clearly thought through and understood, and the associated costs are taken into account.

Telehealth technologies

There was a general support for the notion of telehealth and telecare technologies as a major enabler for the delivery of care into patient’s homes. This is generally recognised as an attractive option for substantial groups of patients and their carers when compared with the need for patients and/or care professionals to travel for face-to-face interactions. However, it is equally important to recognise that such technologies will, of themselves, bring little improvement without new models of care that can be delivered by local service providers and that the commissioning bodies see as meeting the needs of the populations for which they are responsible.

Q5: Where should the centre focus its resources and role to achieve greatest positive effect?

Question 5 created considerable consensus. The concept of ‘centre’ was taken to read national bodies such as the Department of Health, the NHS Commissioning Board, the NHS Information Centre, the Care Quality Commission, Monitor, Public Health England and HealthWatch England.

BCS ASSIST thinks role of the centre should be to:

• develop and set appropriate and ‘fit for purpose’ standards – e.g. data, interfaces, interoperability, supplier accreditation etc;

• police and enforce standards;

• manage delivery of key elements of infrastructure (e.g. N3, Personal Demographics Service (Spine), Interoperability ToolKit);

• enable efficient access to common ‘commodity’ products and services. The ending of the Microsoft Enterprise Wide Agreement for licensing was referred to by several members as a disappointing development given the ubiquitous use of Microsoft products and the transfer of the burden from a central function done once, to multiple local negotiations that will inevitably deliver lower value for money; and

• engage and communicate with suppliers in an honest and realistic way.

We felt that there was a role for the central organisations in changing the way they develop policy so that such policy developments include, as standard, an informatics assessment and
systematically consider what system levers they would wish to see to make their intentions effective.

Another role of the centre should be to demonstrate ‘best practice’ in action, with clear benefits. Specific examples quoted included demonstrating the value of adopting a whole systems approach that recognises that in some circumstances costs might fall to one organisation while benefits might be accrued elsewhere – for example the implementation of telehealth technologies may require investment in hospitals, but may ultimately reduce their income streams where those supporting services are delivered through primary or separate community based care organisations.

One group of members commended the approach being taken in Scotland involving the SCI Gateway\(^1\) as a tool to support integration of information from across a diverse range of systems and felt that the centre might take a leading role in supporting the development and management of similar key elements of infrastructure.

### 3.2. Information for patients, service users, carers and the public

The second chapter addresses information for patients, service users, carers and the public – the ‘consumers’.

**Q6:** As a patient or service user, would you be interested in having easy access to and control over your records?

The first question in this section asks for views about patient access to and control over records. BCS ASSIST felt that this question – like several others in the consultation – is best directly answered by patient and service user stakeholders, but that there were substantial technical and cultural issues that would need to be addressed to enable this to work.

New technologies open the boundaries of the art of the possible in terms of opening up access to information. Sophisticated mobile phones, tablet devices and the ubiquitous access to cloud computing all present options for access to information that were unthinkable only a few years ago. BCS ASSIST members are very supportive of the exploitation of new technologies as long as they are adopted in a responsible way and that users of these technologies can make well informed choices, well aware of both the benefits and the potential risks that the technology may bring. However underpinning all this is our support for the principle of putting the patient in control.

**Q7:** As a patient or service user, in what ways would it be useful for you to be able to communicate with your GP and other health and care professionals online or would you prefer face-to-face contact?

Question 7 moved the debate on to explore ways in which technology could enable choice about methods of interacting with professionals.

There was a strong recognition that the terminology used in communication would have to be carefully explored as medical terminology might sometimes prove difficult for some patients to readily understand. However it was also recognised that it is unreasonable to expect clinicians to duplicate their records, providing both a professional and a patient-accessible version. A careful balance needs to be struck between providing technical and meaningful access.

While there is undoubtedly a class of patient-professional interactions that can be delivered remotely, there will equally be an important set of interactions that could be best undertaken through face-to-face encounter. The context for what is appropriate will depend on the judgement of the clinical professional and patient together. A simple query about, for example, a request for a repeat prescription from a well known patient might be fine to be undertaken by email but a detailed exploration of a complaint of general stomach ache with an infrequent visitor to the practice would be more likely to require face-to-face contact.

There would also be differences between patient, and indeed professional groups – some would be very comfortable with the use of different technologies, while others may still be hesitant. In line with the general approach to offering choice, patients should be provided with various ways of interacting with health services. Some people may be comfortable and confident about using technology, but others may prefer to choose to have improved access to face-to-face services, supported by technology based advice.

Where new modes of interaction emerge, then there will need to be clear measures of expectations about response times. At the moment patients have an expectation about the time it will take to get a GP appointment. If their expectation is that electronic communication will result in instantaneous responses, then there is a danger that they will be disappointed and that they revert to face-to-face contact - the frequently quoted examples of patient-perceived delays in NHS Direct response times leading to patients visiting A&E ‘just in case’. Service levels for such interactions need to be carefully set, communicated and managed.

**Q8: Please indicate any particular issues, including any risks and safeguards, which may need to be taken into account in sharing records in the ways identified in this consultation document**

Provision of control – as opposed to simple access - fundamentally shifts the balance of power from the historical perspective of the providers of care services to the consumers, both directly to patients and to their carers and advocates. There are dangers associated with this shift and the management of expectations – exactly what does ‘control’ mean in these circumstances and how can patients, service users and carers be sure that they make informed decisions about how to control those records? BCS ASSIST felt that it was important to move carefully, although positively down this route, recognising that not all patients need full control over all their records immediately and that learning from working with those groups who would be keen and enthusiastic would be beneficial.

There was considerable debate about the dangers of allowing patients to change records in circumstances where there were differences of opinions, which might occur between different professionals and also between professionals and the patients and/or their carers. The conclusion was that records should be capable of being added to but not amended so that in the event of a disagreement about a piece of information where there are legitimate opinions, both perspectives would be recorded.
There would need to be mechanisms in place that, where factual data that was clearly found to be wrong (such as a test result incorrectly entered), this data could be corrected, if not directly amended, with the agreement with the agreement of all parties.

There was also considerable concern about how to ensure that patients could make well informed decisions about how to control access to their record. While putting the patient in control is strongly supported, there will be a need for clear and accessible guidance as to the impact and consequences of sharing information, in the same way that there are clear warnings about the impact of sharing banking records with others. Is access granted on a one-off occasion, for a time period, or for life?

Members also felt that there would need to be a clear campaign promoting and explaining patients’ rights of control and access, not only to patients themselves but also to care professionals, especially where individuals are in control of information that spans health and social care services.

**Q9: What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?**

Question 9 explores the kinds of information and help that patients and service users would benefit from when stressed and anxious.

In these situations patients and carers will want to be able to rapidly access information and support services that they can rely on to offer objective and impartial advice. Continued utilisation of the NHS brand is an example of where there is a high level of patient trust and protection, and maintenance of the brand is key.

Care needs to be taken when publishing raw data. For example publication of raw mortality rates could create great anxiety in patients attending a particular hospital for surgery, but if their situation is routine while the hospital deals with a very high proportion of complex cases, then the mortality rate might naturally be expected to be higher and the individual personal risk may be significantly less.

Similarly patients looking for advice about particular treatment regimes will not always appreciate the context within which information which about specific care treatments may have been developed, potentially through sponsorship by organisations with a specific agenda, and may not realise that there may be a choice of treatments, each with its own particular benefits and risks which need to be taken into consideration.

There is also a need to ensure that material is well presented and accessible in a language appropriate for its use. There are many examples of excellent material produced by support groups and these offer valuable support to patients in times of stress.

However good the information is, there will also be a need for personal advice and guidance, and ready access to such support whether through telephone advice or appropriately secure email. This care navigation service may be provided by different organisations, although the same fundamental principles hold true – that the service must be trusted as a source of objective and impartial advice.

**Q10: as a patient or service user what types of information do you consider important to help you make informed choices. Is it easy to find where do you look?**

**Q11: what additional information would be helpful for specific groups?**
Q12: What specific information requirements do carers have?
Q13: What are the information needs of people seeking to self care or live with long term conditions?

This set of questions seeks to get more detail in terms of information for specific groups of consumers.

Question 10 elicited a substantial response. Simply knowing what questions to ask to help make an informed decision is a challenge. There was strong support for the development of simple guides to help patients know what questions they might wish to consider asking when making decisions about their health and social care and how to assess the responses to such questions.

One example quoted was the potentially different perceptions of outcome. While there may be professional expectations about the clinical outcomes from – say – a hip replacement, the outcomes as perceived by an individual patient may be more subjective and based on their personal circumstances.

There was also a view that it was not just outcomes that will be important but that there will also be process measures that patients would wish to see. Some outcomes may only be realistically measureable over a long period, and so process measures could be used as proxies; for example the regularity of contact for patients with long-term conditions as a process measure, alongside outcomes in terms of the avoidance of emergency admissions.

Q11 is primarily aimed at specific groups. There was concern expressed about the apparent exclusion of children’s services and the value of being able to share information with professionals working in children’s centres. We support the principle that there should be information provided for a broad range of groups.

Q12 is also covered by earlier comments about the importance of ensuring that when patients make decisions about who to give access to their records, they do so from a well informed position, and appreciate the consequences. Their carers today may change in the future and patients may wish to rescind control. There may also be different levels of carer - for example care homes, family members, neighbours – and the levels of access to records that patients might wish to grant. This may result in a variety of arrangements being required from the formal Power of Attorney at one extreme through close family members to informal occasional care provided by neighbours.

3.3. Information for improved outcomes

The third chapter of An Information Revolution addresses the need for information to support outcomes. This is clearly linked to the publication of the Outcomes Framework in December 2010 by the Department of Health.

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Q14: What information about outcomes from care services do you already use?
Q15: What information about outcomes would be helpful?
Q16: How can the benefits of seamless and joined up information be realised across the many organisations that a service user may encounter?
Q17: For which groups of service users or care organisations is the use of information across organisational boundaries particularly important?

There are a series of interrelated questions focused around the area of outcomes.

Once again BCS ASSIST members responded to these questions from their perspective as health informatics professionals rather than as service users.

**Information integration**

We very much welcome the shift to look at outcomes before we highlight the challenges of delivering the measures. The purpose of health care is to improve people’s health and reduce their suffering and we should measure what we set out to achieve, as well as the process of getting there. However we believe that we will need to measure process until such time as the outcome measures are well developed and understood.

In both cases – outcome or process – the key issue identified is the importance of being able to integrate information from across different care services so as to be able to successfully assess overall outcome measures and/or processes.

A specific example quoted was the need to be able to link together patient encounters for diabetic patients as those encounters may involve interaction with GP surgeries, hospitals, opticians or with podiatrists. Creating a patient’s ‘diabetic record’ in this way would make it possible to judge whether they were getting good outcomes from their package of care services.

This reiterates the critical importance of the use of a unique identifier, such as the NHS number. For too long the clear national policy associated with the use of the NHS number has not been matched in practice.

With the introduction of multiple care providers from the public, private and voluntary sector, and the increasing need to be able to make judgments on outcomes based on the combination of care services provided to individuals, we believe that the use of the NHS number will become even more critical and in particular it will need to be made more accessible and usable by non-NHS organisations including social care providers.

Given the shift away from central Department of Health management and direction of the NHS, we believe that there is value in considering the degree to which the NHS number is accurately and effectively used being part of the assurance processes undertaken by the regulatory bodies such as the CQC. We believe that the use of the NHS number should be a critical element of the regulatory review processes, not just for the purposes associated with the integration of information to monitor outcomes, but as part of a wider picture that seeks to ensure patient safety and other uses such as child protection.

Furthermore we believe that there should be a responsibility placed on all accredited providers of care to ensure that the NHS number is used appropriately and accurately within their organisation.
In terms of Q17 we believe that the issue of protection of children and vulnerable adults is particularly important and should be treated as a priority. Merely using a common identifier will not in itself be a guarantee of increased safety, though it is certainly a key enabler in supporting the appropriate processes.

Q18: What are your views on the approach being taken and the criteria being used to review central data collections?

Q19: How could feedback from you be used to improve services?

Q20: What would be the best ways to encourage more widespread feedback from patients, service users, their families and carers?

We support the criteria that are being proposed and believe that it is essential that every data collection has clarity over its purpose and a simple, clear and demonstrable business case to show that the costs of collection are outweighed by the benefits. Furthermore we believe that to move towards a greater integration of health and social care data, reviews of all ‘central returns’ in both health and social care should adopt similar review processes.

In terms of Q19, BCS ASSIST feels that the best way to encourage feedback was to ensure that such feedback was collected in a simple way, through a variety of communication channels, and published in a fair and transparent way. Patients should be encouraged to submit details of their positive experiences as well as less good experiences, and organisations should be held to account to demonstrate to the public that they had listened to feedback and had taken action as a result. This might be achieved through the Quality Accounts.

We noted the comment that Quality Accounts are reports from providers of NHS health care. To encourage choice we believe that this should be extended to cover providers of all NHS-funded health care, requiring private and voluntary sector care providers to publish forms of Quality Accounts that can be comparable with those of NHS providers.

It is also important that feedback mechanisms are sensitive to the relevant priorities of different population groups parts of the community and do not assume that ‘one size fits all’ in respect of the standards and norms that different groups expect in terms of their health care experiences.

Finally consideration should be given to the opportunity for patient (carer, family, public) reporting of potentially adverse incidents, e.g. drug reactions, device malfunction. This would mean that patients are contributing to the overall knowledgebase and their views can be combined with the experience of clinical professionals and others.

Q21: What are the key changes in behaviour, systems and incentives required to make the NHS and adult social care services genuinely responsive to feedback and how can these be achieved?

Q22: Which questions, if asked consistently, would provide useful information to help you compare and choose services?

Q23: What will help ensure that information systems - and the data they collect - are appropriate to support good commissioning at different levels, including decisions by individual patients, GP practices, GP consortia, service providers, local authorities and the NHS Commissioning Board?
Publication of data in a clear and transparent way will help, but organisation performance improvement should be judged against starting points and credit given to the most improved organisations as well as those that are best in class.

Publication of this data should be accompanied by contract levers which encourage and reward continuously improving performance.

BCS ASSIST strongly supports the proposition that central data collection and feedback systems need to be aligned to the desired outcome measures – for example a national policy based around a shift to a focus on outcomes should result in the development of feedback systems that align patient feedback with those outcome objectives and are not in conflict with them.

To ensure appropriateness we would encourage all organisations – whether individually or in collaboration – to adopt sound proven and fit for purpose tools to define requirements clearly with input from end users, identify and appraise options in a robust, transparent and open manner, and implement systems and associated processes within the clear context of the benefits that they seek to deliver.

Where implementation and deployment of systems does not deliver the desired benefits, then there should be objective appraisal of the reasons and action taken to address that, even to the extent of halting implementation or use if that is most appropriate course of action. Often we see organisations struggling to make systems work but which were perhaps acquired inappropriately or which have not been implemented properly in a heroic attempt to retrospectively justify what was fundamentally a bad decision.

In terms of information systems that specifically support commissioning, then we believe that as with all uses of information, the sources and provenance of the underlying data should be clear, that the presentation of the information is done in a contextually appropriate way and that the underlying data should be widely available for legitimate use. The information that is used should be derived from operational data where appropriate and subject to ensuring the confidentiality of patient data in line with the principle of the patient as the owner of the records of those encounters.

### 3.4. Information for professionals

Section 4 of *An Information Revolution* looks at the use of information by professionals.

**Q24: How can health and care organisations develop an information culture and capabilities so that staff at all levels and of all disciplines recognise their personal responsibility for data?**

**Changing the culture**

The challenge posed in Q24 is a long-standing one which impacts on staff at all levels and of all disciplines and their need to recognise their personal responsibility for data.

For example, many nurses feel and say that it is not their job to do clerical work. As a result ward clerks are widely employed but are not present on a 24x7 basis to record patient movements in and out of wards in ‘real time’, resulting in hospital information systems holding out of date and/or inaccurate information about patients’ whereabouts. This in turn inhibits the practical use of electronic patient records.

Clerical and other non-professional staff in hospitals often have no awareness, understanding of or interest in how their work relates to what goes on elsewhere in the NHS and are not only content in
their narrow approach but are actively opposed to or at least apprehensive of change. This undermines the timely generation of high quality, accurate data, especially when the information is collected for the benefit of someone else. This is a fundamental culture problem that has not been overcome in 30 years of effort by informatics professionals.

While BCS ASSIST strongly supports the principle that information should be derived as a by-product of operational systems, the professionals involved in the direct delivery of care need to be well informed about the wider importance of the uses of information, not just for direct patient care purposes but for those of a supporting nature, whether for planning, research, public health surveillance or operational management including supporting financial flows.

This leads to a need to instil into all those involved with the capture and maintenance of data an understanding of the way in which information is used within health and social care services, and hence the responsibilities and obligations they have towards both patients and colleagues to ensure the data is of high quality.

As a means to achieving this, we believe that informatics should be a core element of all professional training at both pre- and post-graduate levels. Relevant professional codes of conduct or practice should also be amended to reflect the individual care professional’s responsibility for data quality in record keeping. Furthermore we would expect informatics to form an element of induction training for accredited care providers, and assessed as part of the regulatory regime.

Q25: As a clinician or care professional how easy is it for you to find the evidence you need?
Q26: Clinicians and others will be expected to record more data and evidence electronically. How can this be facilitated? What benefit will arise?

Questions 25 and 26 are related. In respect of Q26 this means that the process of data recording needs to be highly attuned to the environment in which staff operate.

The technologies will vary; for community-based staff the ability to access records and knowledge remotely using secure portable devices will deliver significant benefit, and those same devices need to be capable of enabling simple and quick recording of patient encounters.

For staff working in hospital environments, other technologies will be important – the use of electronic whiteboards, dictation devices and tablet devices will all have a part to play. The importance of providing an effective human computer interface is essential to achieving high quality data capture.

Q27. What are the key priorities for the development of professional information management capacity and capability to enable the information revolution?

Question 27 is a fundamental one for BCS ASSIST.

Recognition of health informatics qualifications

Many BCS ASSIST members highlighted the discrepancy between the recognition of the importance of professional qualifications for the informatics and finance functions. No Board would appoint a finance director without an appropriate financial qualification, yet Board members often have responsibility for informatics with no qualification or even experience in this area.
BCS ASSIST would strongly recommend that Board level members with responsibility for information and IT should have an appropriate recognised health informatics qualification (or equivalent experience).

**Nature of informatics services**

The way in which informatics services operate will need to change and adapt over time to reflect changing models of health and social care provision.

The range of health informatics skills applied in the planning and delivery of health and social care is a broad one, covering staff in roles such as specialist clinical coding; record management functions; information provision; creation of intelligence; business analysts, operational IT staff, project and change management, including business process redesign specialists.

It is highly unlikely that any organisation will be able to justify employing the full range of specialists and BCS ASSIST anticipates that there will be reconfiguration where certain skills can be shared across a federation of organisations; for example in providing analytical advisory services to a group of GP-led commissioning consortia. Some of these services may be hosted by one organisation and provided to a group based on a set of service levels; other services may be outsourced to other specialist providers. The exact model will depend on the needs of the local health economy and the particular nature of the services being undertaken, but it is likely to be a blend of directly employed staff and those from in-house or outsourced service providers.

The range will also be highly dependent on the nature of the services provided – a large teaching hospital will require totally different informatics capacity and capability from a small independent nursing care home provider. Nevertheless all informatics staff should have a professional duty, as recognised by an appropriate qualification, to ensure that information is managed efficiently, effectively and securely for the benefit of patients and wider stakeholders.

**Professional development**

Given the importance of informatics professionals in enabling *An Information Revolution*, BCS ASSIST strongly encourages the establishment of a professional development programme for health and social care informatics staff as well as ensuring that informatics forms part of the development programme for other staff groups. We are looking for recognition that health informatics professionals are valued, supported and developed and that the professionalism is recognised both through the accreditation of individuals and service support organisations.

Professional development applies as much to health and social care informaticians as other professional groups with a need to maintain up-to-date knowledge of their domain ensure that members strive to improve their skills and knowledge, and that they perform their work in a reliable and trusted manner appropriate to their levels of skills and competence.

We also propose that there should be encouragement given to the notion of job shadows where health informatics staff work closely with clinical and managerial colleagues to get a greater insight into the practical challenges they face, and hence be better able to provide informatics support in the most appropriate way.

**The ‘knowledge guide’**

One area that will become more prominent in the implementation of *Liberating the NHS* will be the engagement with patients, service users and carers in helping them understand and take informed decisions leading to the need for the role of ‘information and knowledge guides’. This role will need a blend of skills, not only in terms of the technical skills associated with understanding and
presenting information, but also in terms of being aware of the specific needs of different groups of
the population and interpersonal skills to work with those individuals. This role may develop as a
hybrid role involving skills of health informaticians, librarians, local government contact centres,
citizen’s advice bureaus etc.

3.5. Information for autonomy, accountability and democratic legitimacy

The fifth chapter of *An Information Revolution* is concerned with the implementation of a more open
and transparent environment for the publication of information.

As NHS organisations become autonomous locally accountable bodies, the means of ensuring the
implementation of openness and transparency will need to shift from a top-down directive process
to one that is associated more with a regulatory framework where care providing organisations are
required to publish an agreed set of information according to an agreed set of standards.

We support the proposal that HealthWatch England acts as an advisory body to the NHS
Commissioning Board to enhance accountability, and we would recommend that HealthWatch
England ensures that it has sufficient professional health informatics capability and capacity to
deliver this function effectively.

Our earlier point about ensuring that Board level members of organisations have appropriate
informatics qualifications would also apply to HealthWatch England.

Q28: The presumption of openness in support of shared decision making will bring opportunities
but may also generate challenges. What are the greatest opportunities and issues for you?

Although question 28 is actually qualified by referring to care professional or service users, from the
perspective of the informatics professional there are issues to comment upon.

While the opening up of information for use is to be supported – only through use will there be an
incentive to drive up data quality – there are significant risks from exposing raw data without a clear
understanding of the provenance of that data.

Raw data may be interpreted and then presented for a variety of purposes. There are examples
where the processing of data at present is not supported by the publication of the raw data sources
and the algorithms that have been used to aggregate and analyse that data. It therefore makes it
hard for users to be in a position to understand and rely on that information to make key decisions
about their care.

We believe that the introduction of an overly restrictive regulatory regime for organisations that seek
to analyse and pre-present health and health care related data – the ‘information intermediaries’ -
would be counter-productive and could create a stifling bureaucracy. It could favour larger
organisations at the expense of smaller ones which are more focused in terms of their aims, and
wish to publish analyses around a specific condition or across a specific geographical area.

It is extremely important that users of data can trust the data that is used and the way that is
subsequently processed. We would therefore advocate a voluntary ‘code of practice’ that
information intermediaries would be invited to sign up to. Individual information intermediaries might
then wish to seek independent audit against that code of practice which would then given them the
ability to publish information to the public with a degrees of confidence, although his would not
inhibit others from processing the data.
When educating the public about the way they should be asking questions to inform their decisions (see response to question 10) this code of conduct would be one of the questions they may wish to consider when deciding how much trust to put in the information they are using.

**Q29: What benefit and issues do you think will arise as a greater range of information providers offer information?**

**Q30: Would there be benefits from central accreditation or other quality assurance systems for information providers and intermediaries? Would factors such as cost and bureaucracy outweigh any benefits?**

Question 29 follows the theme from Q28 and the response to Q28 applies here as well. The diversity of analysis is something to be welcomed, but it is important that in encouraging this diversity that individual users are able to make well informed judgements as to the provenance of that data. Quicker access may not necessarily be better and the headline grabbing data of the day may mask important long-term trends. For people with an acute condition time is likely to be more important than for those with long-term conditions.

We have covered part of our response to Q30 earlier – we believe that there should be a code of practice for information providers and intermediaries, that it should be a voluntary code, but one to which all providers and intermediaries are expected to aspire. For those organisations that wish to we believe that they should have the option of having an independent review of their implementation of the code of practice. This might result in a three tier system of information providers and intermediaries:

- basic level information intermediaries – those who do not adopt the code. These may be smaller more specialised organisations perhaps focusing on a single issue or a single area;
- mid-tier information intermediaries – those who do adopt the code but do not seek formal independent accreditation;
- top-tier information intermediaries – those who adopt the code and also achieve formal independent accreditation.

This would allow patients to take a more informed view as to the trust they choose to place in the outputs of any of these groups.

**Channel strategy**

*An Information Revolution* proposes to develop a channel strategy to provide a coherent view of the nationally managed channels. We endorse this approach but would advocate an approach that is simple and fit for purpose, acting as a gateway to other sources. Nationally managed channels - such as NHS Choices – could act as signposts to other sources of information that have been shown to meet the code of practice with specific reference to those that have undergone an independent audit.

**Q31: How can a health and social care information revolution benefit everyone including those who need care most but may not have direct access to or know how to use information technology?**
Question 31 is also a matter of great concern to BCS ASSIST. We believe that there is a risk that an information underclass develops of those people who may benefit most, yet are denied access for whatever reason.

We believe simple channels for communication of information should be made readily available, utilising a mix of media channels and technologies including, but not limited to, computers, smart phones, digital TV.

These technology channels will need to operate in conjunction with health and social care information advice and guidance centres and any ‘information guides’ as discussed earlier.

Given the high level of trust that people have in the NHS, such centres may be services that NHS bodies may choose to develop. Similarly it may be that local authority one-stop shop centres are also a suitable location for the location of such services or other local community facilities.

Regardless of where these centres develop it will be important that they can be shown to meet the code of practice to ensure that any information and advice that they provide is impartial and does not favour their host organisation at the expense of others.

We also believe that the role of families, other carers and advocates for patients and service users also offers great potential for unlocking the value of information. While we can envisage a situation where family members or carers can support an individual in accessing information, we also acknowledge that this might involve that patient proxy needing access to information about the patient’s individual circumstances. Our advice on how to ensure that individuals make informed choices about how they control access to their personal care records applies here as well.

Q32: Are there other datasets that you think could be released as an early priority without compromising an individual's confidentiality? Are there any risks associated with their release?

The final question in this section refers to additional datasets for publication. BCS ASSIST members felt that standard data collection across community settings is vital given that this is the area where the greatest volume of activity is undertaken and where there is greatest need.

We believe that there should be a small standard dataset to start with and then a process of phased evolution, rather than a ‘big bang’ approach.

We also believe that the development of national service framework datasets and quality standards from the National Institute for Health and Clinical Excellence are valuable and would recommend a systematic process to complete the development of these.

Other examples include areas such as reports of clinical incidents (currently the responsibility of the National Patient Safety Agency), adverse drug reactions, nationally collected Secondary Uses Service data and linked data sets.

In terms of ensuring integrated services, we would also advocate early work to look at the opportunity for standard social care datasets. Given the potential benefits from integrated health and social care services, the lack of consistent and linkable data on social care activity could create a significant challenge to integrated health and social care commissioning and service delivery.
3.6. Setting the direction – the information strategy

The final element of the consultation paper sets out principles through which the Department of Health intends to develop a comprehensive information strategy.

Q33: The information revolution may deliver many improvements. What are particular challenges – including sustainability, business, rural or equality issues – that need to be considered in developing the associated impact assessment?

Q34: Are there any critical issues for the future of information in the health and adult social care sectors that this consultation has not identified?

BCS ASSIST very strongly supports the principle of establishing clear and pragmatic standards.

Adoption of a unique identifier

The use of the NHS number has been an ambition of the NHS ever since the first NHS information strategy in 1987 and has been reiterated repeatedly in subsequent revisions of the strategy.

The NHS number is clearly in widespread use within the health service, and in the absence of any viable alternative, should form the basis of a unique identification number for the future, but with a much stronger regulatory model to ensure that it is used comprehensively across all those services that are publicly funded, though not necessarily publicly delivered.

It is also important to recognise that local systems have developed their own methods of unique patient identification. Whether or not this is desirable, it is a fact and the investment in such systems cannot be abandoned. We would therefore anticipate some form of phased migration, or at least an effective mapping arrangement so that local identification systems can be clearly and unambiguously mapped onto the NHS number.

Any Willing Provider

The move towards Any Willing Provider (AWP) and a more open model of health and social care provision means that the implementation of nationally agreed standards is likely to have to become more closely associated with the regulatory process.

This will need to be managed carefully. If the standards are too high then this will act as a barrier to entry for new innovative service providers. However if they are set too low then the ability to exchange and integrate information across care providers in a safe and secure way with the consistent adoption of data exchange standards and information governance arrangements – and thus place the patient truly in control – will be put at risk.

For example, if all providers are required to interconnect their information systems to the national PDS application and there is a high cost of accreditation then this will act as a barrier to small organisations. Alternatively, if there is no requirement to interwork with the PDS then it will become much harder to assess performance based on cross organisational outcome measures.

Another potential role of the centre – whether the Department of Health or the NHS Commissioning Board – should be to consider whether there are ways to maintain the integrity of the national infrastructure while allowing suitably accredited new provider organisations – and indeed existing social care service providers – to interwork with the national infrastructure quickly, securely and at a relatively low cost.
Policy impact assessments

The experience of BCS ASSIST members suggests that the Department of Health and the NHS Commissioning Board should adopt ways of working that continually review policy and practice and assess whether any proposed change of development has specific informatics impacts, whether in terms of the need for new data collections or the adoption of new technologies.

For example if there is a shift over the coming years towards an increased use of local tariffs and potentially new, more local, currencies of care based on the delivery of outcome-based care against a service specification, then the comparability of data across the country will be affected.

This needs to be recognised and an impact assessment undertaken in advance rather than in response to such changes to ensure that investment decisions are made to reflect the progressive implementation of national policy. It would be extremely difficult to envisage a situation where new innovative forms of outcome-based commissioning arrangements are inhibited by the need to continue to operate a national tariff system. The benefits and risks associated with such a situation need to be assessed in advance.

Existing NPfIT contracts

It is clear that the financial environment will continue to be extremely tight. Investments will be prioritised towards those that show a rapid and direct return, often in association with some other aspect of service and productivity improvement. To encourage innovation informatics systems and services suppliers will need to be told honestly the degree to which funding for IM&T investments is tied up in the existing national NPfIT contracts.

BCS ASSIST believes that there are examples where some of the national contracts have led to high costs being incurred for relatively minor enhancements. Without freeing up the constraints of the national contracts there will be little incentive for smaller suppliers to offer innovative solutions.

There is a wider strategic issue at stake as well. BCS ASSIST is concerned that local service provider (LSP) contracts were tightly constrained and have not always proved entirely ‘fit for purpose’. In an environment where we anticipate more localised and integrated health and social care systems, with greater personalisation of services to fit local needs and priorities, these highly standardised solutions may be even less ‘fit for purpose’.

An early indication of the likely strategy following the end of the existing NPfIT contract lifetime would help organisations to make key strategic decisions as to whether to adopt NPfIT solutions. Without clarity over this, there is a risk that organisations may make ill informed decisions to adopt solutions that provide insufficient flexibility for the longer-term, or fail to take decisions, delaying the introduction of the very technologies that will enable An Information Revolution to take place.

Governance

BCS ASSIST welcomed the enhanced autonomy being granted to local NHS Foundation Trusts, but is concerned that there will still be a bureaucratic national business case approval process which could inhibit Trust level system change. Where there are business case approval processes in place, these need to be of an appropriate level and consistent with other approval processes for other similar levels of investments.