Health

Enabling the information society

Liberating the NHS – An Information Revolution

Notes from BCS Health hosted open debate
London
3 December 2010

Sponsored and facilitated by:

KPMG

Introduction

BCS has organised a number of strategy and policy activities to engage the informatics community in debating and responding to the NHS Information Revolution consultation.

This document contains the write up from the event that was held in London on 3 December 2010. The debate was opened with a set of presentations from senior figures in the Department of Health's Informatics Directorate, followed by breakout discussion sessions and open debate on four key themes:

- Setting the direction for information strategy;
- Informatics professionalism;
- Privacy, security and risk management;
- Informatics standards, interoperability.

The day offered an opportunity to raise issues and feedback directly to those managing the consultation process for the DH. The output has been captured and written up here to be shared amongst the attendees for use in any response they wish to make to the Information Revolution consultation, and will contribute as input for consideration in BCS's own independent response to this consultation.

Despite extreme weather conditions, there were over 60 participants and a good mixture of informaticians, managers, clinicians, academics, industry, policy and think tank organisations. The event was open to both BCS and non-BCS members.

The content of this document is the collective views shared by the audience on the day and as such does not necessarily represent the views, positions or opinions of BCS.

We would like to recognise and thank KPMG for sponsoring the event and facilitating the breakout and open debate sessions.

Dr Justin Whatling
Vice Chair, Strategy and Policy
BCS Health

1. Liberating the NHS – an information revolution *(Paul Jones, NHS CIS, DH, Information Directorate/ Kathy Mason, Director, Strategy & Planning, DH, Informatics Directorate)*

Paul Jones gave a brief overview of the purpose and scope of the NHS Information Revolution consultation, stressing that people's input is needed in order to find out what points are critical for the subsequent development of the NHS information strategy and what direction it should take.

One of the fundamental aspects of the consultation paper is to put the patient at the heart of what the NHS is doing. The information revolution is part of the patient revolution ('no decision about me without me'), and the paper has been launched alongside the paper entitled: A revolution for patients – Consultations on an information revolution and greater choice and control. There are three main policy aspects to the patient revolution: choice, information revolution, and patient enablement.

The main objectives are:

• for information to support and improve patient care by
- capturing information at the time of care and thereby reducing errors;
- gathering information in a sensible way that can be passed on to researchers who can work on treatments and solutions;

• for information systems to help drive improvements in efficiency.

Paul emphasised that, in the context of the consultation, it is important to differentiate between different 'types' of information, for example:

- patient care information (supports the individual patient/ carer);
- data in health service (aggregated data that can be used to produce (performance) reports);
- information for clinicians/ patients that helps to understand what the condition is and what treatment is available.

Some key points:

1. Patient control – this doesn't just mean giving patient access, but it means encouraging a relationship between clinicians and patients, making standard reports available electronically, so patients can share reports with communities/ for research/ advise on best treatment.
2. Transparency – 'publish, not polish'. With caveats, if the NHS has data, it will be put in the public domain.
3. Structure & coding of data – how do we go about extracting meaningful data? What role can technology play in this?
4. Primary purpose of data collection should be improving patient care.
5. Engage the public – provide new channels of patient engagement and self-monitoring.

Some challenges:
- Market: Healthcare is not a global market, and SMEs are the largest suppliers. What do we need to do to stimulate the market?
- Capacity/ capability: IT at the moment is set up as an operational part, focusing on keeping things running. We need to look at how IT can drive business benefits and IT needs to engage with the CEO.
- NHS leadership: Many have a poor view of IT and don't know what it can deliver.

Kathy Mason then briefly outlined the scope and processes of the consultation process, stressing that the policy framework that has been set up needs to be fleshed out and that they are seeking dialogue with all stakeholders. She pointed out that in the current situation, they faced the additional challenge of developing an information strategy in a system that is itself changing. She stressed that in all this, it is important to ensure that what is being set out is implementable and realistic.

1.1 Q&A

Q: What activities do you have for NHS leads and leadership in terms of input into the consultation?

- Consultation process with NHS management and leadership.
- Consultation and connecting with stakeholders through the Strategic Health Authorities (SHAs).
- Some work with key providers, and we're talking across the DH to people who are leading.

Q: Is this also going to an audience that is not usually involved in the agenda and that is on the fringes? How do you reach them?
Consultation process is fairly comprehensive.

Q: [Re information as an overloaded term]. Information about service, performance and quality is absolutely critical. Only by exposing data can it improve, but we need to distinguish between patient identifiable data and general data.

- Identifiable patient data will not be published.
- Transparency and availability of data will drive quality.
- There are concerns that healthcare providers will have to employ staff to deal with local press.

Q: A group of researchers has been looking at the architecture that would be needed and looked at developing a prototype. Who would they need to talk to to put ideas forward?

- Talk to the DH.
- Would have to be a prototype that would help to take things forward as NHS can already track data, collate data etc.

Q: [Re putting the patient at the centre]: Problem is that care is fragmented and we need to look at organisations rather than individual clinicians and ask whether they focus on patients. Organisations are highly fragmented and not patient-centred. They need to stop thinking that they own the data.

- We don't make it easy for clinicians to record data in a shareable way.
- One practice captures data for financial reasons, but this is no use for patients as it covers too high a level.
- Providers need to come together.

Q: [Re publish not polish] Do we need accreditation of information/ systems and how do you ensure that people comply with standards?

- No need to accredit information at the centre.
- NHS Information Centre has statutory obligation to make data available.
- If data is published, it will be taken up by someone and used – do they need to be accredited then?

Q: [Re publish not polish] How do you publish data quickly and correctly and make sure that the information going in is the same that is going out?

- If this is not already the case, we need to make it so. Data will be published generically, so others can analyse it.
- You can't pretend that, once it's published, the data and information is still under your control.

Q: How do you encourage suppliers around Europe to provide services for the health service? The problem is that there's no money in the system and it works on very tight margins, so it's difficult to make a business case for investing in the health sector.

- One of the challenges – ideas and suggestions welcome.

Q: [Re publish not polish] What about social care – are they included?

- A few social care elements included, but there is a separate white paper on social care. Government stance: ALL information that is held will be published.

Q: Lack of trust in the government with regards to data – how do people know what is happening with their data and where do you think the DH is in terms of this trust relationship?

- NHS needs to make sure that people are informed.
- Everything will be done under the Data Protection Act.

2. The future in five slides *(Dr Simon Eccles, Medical Director, Clinical Division, DH, Informatics Directorate)*

Simon Eccles looked at data collection and use in the NHS and outlined what needed to change to ensure effective data use and information sharing. He explained that, often, data that could help clinicians and staff make decisions had been captured electronically, but not collated and presented in a form that supports evidence-based medicine.

He said that the information revolution needs to come out of four different concepts:

- Patient access and control
- Interoperability and shared clinical records
- Data analysis for research and care improvement
- Public wellbeing

When all these play together, this should lead to

- availability of full patient record (which doesn't need to be presented in a beautiful database)
- excellent data flow
- better public health
- personalised prevention (people do not like to be preached at, but like to have the necessary information to make a decision)

Simon then described the new health system, where

- policy is the responsibility of the government;
- standards falls under the auspices of national and GP commissioning;
- delivery lies with the providers; and
- enforcement is part of quality and financial regulations.

He stressed that there needed to be a mix between centralisation and a move towards localisation in the NHS, from DH policy drive to market-driven changes. In general, market forces, local and regional commissioning should play a stronger role.

He said that, while it should be vital for feedback data to clinicians to demonstrate data quality and use, this was not happening as much as it should be at the moment. He explained that part of the problem was the fact that many clinicians were not interested in IT. Therefore it is necessary to make IT matter routinely to clinicians and show that it can make their lives easier.

The NHS has so far not managed to bring all systems together, so even though it is a world leader in coding in primary care, it still has a long way to go in secondary care.

2.1 Q&A

Q: You cannot phone a secondary care consultant – is this because we don't have the technology to record and then charge? Isn't it about time we were able to do this?

- Other industries are miles ahead of NHS (for example, car insurance, they check the recording of the original phone call when you have a query).
- Many would prefer phone or email.

Q: Neuron-response pilot for MS patients: offered multi-channel support via email, video phone and conference. It was really well received, GPs and patients loved it. At the end of the pilot the Trust was told that it was unaffordable as no there was no reimbursement mechanism. Now we're looking to charities to fund the project.

- Agreement that tariffs are obstructing the ability to provide care and innovate services.

Q: [Re Patient access/ control] Patients can create their own data, for example on HealthSpace. Patients, especially those with chronic conditions, could input a lot.

- HealthSpace is too limited at the moment.
- Need to get the right disruptive technology in health, and the rest will follow (example of cash machines: the public decried as end to traditional banking, resulting in chaos. But hole in the wall led to internet banking, putting the customers in control).

3. Feedback and recommendations

3.1 Information standards and interoperability – key points

Idea/ issue/ challenges	Recommendation
Standards are either too complex to be useful or too constraining. Need to be usable.	Research feedback and experiences in the use of standards.
	Focus on the really important ones.
	Include international standards in the review
	Review current standards from a clinician and patient perspective, removing those that are not working.
	Consider the continuum of mandated to open standards.
	Balance of national and local standards to keep flexibility for innovation.
Decentralisation will only work with shared standards, but decentralisation makes evolution of shared standards difficult	Strong central drive for standards.
What will the GP consortia use as currency for buying care?	Work closely with GPs and GP consortia, to define new / rationalise existing standards.
Get patient- or clinician-driven standards instead of cost- or efficiency-driven ones.	Stimulate patient demand.
	Offer and support multiple channels for patient engagement; communicate benefits of new channels.
Introduce and use novel technology.	Enable quick take-up of novel technology solutions from outside healthcare (e.g. SMS, Facebook, phone apps etc.) by identifying and decreasing barriers to entry.
	Involve clinicians and staff in design of novel exploratory interfaces to assist in coding (beyond the drop-down menu).
	Piloting is essential.
	Learn from other fields in informatics (the 'Google' for health informatics/ semantic analysis technologies).
Include suppliers	Encourage dialogue with suppliers to incentivise them to drive standard market.
	Use of international standards to drive scale
	Embrace innovative, supplier-led platforms (e.g. Microsoft and Google electronic personal health records)

	Enable niche players to drive new standards and innovation.

Other points

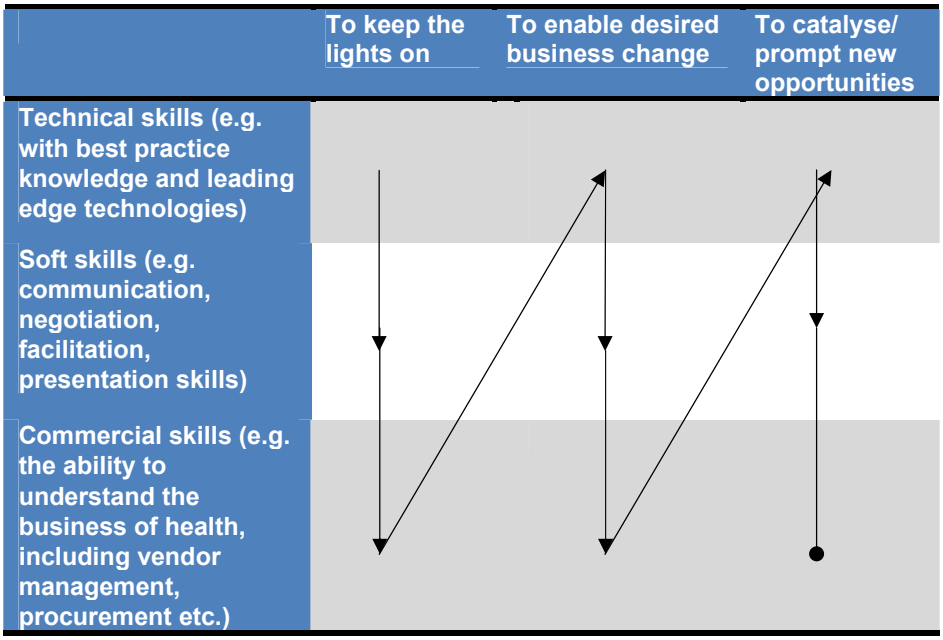
One of the main problems with standards is that they are at various levels. Have to be careful not to become perfectionist. A minimal set of standards for common transactions will probably deliver about 60 per cent of the value. The long-term planning needs to be done, but we might be missing the low-hanging fruit by going for overkill through standards. It is possible to yield real benefits without perfected standardisation.

3.2 Informatics professionalism – key points

Idea/ issue/ challenge	Recommendation
IT professionals need to be advocates of how IT can enable the business.	IT professionals need a mix of technical and soft skills; an understanding of business needs. Avoid 'ghettoisation'.
	IT professionals need to be involved at board level. Empower best informaticians to be part of solution Trusts are working for.
	Remove siloed thinking in training and education – many training programmes are too technically focused.
	IT profession needs to demonstrate it understands business change and drives. If it adds enough value, the board will to them.
	Need to understand information technology *and* information management.
Senior level staff don't necessarily understand the benefits and opportunities provided by IT/ information.	Executives need to communicate the needs and priorities of the business better.
	IT professionals need to help leaders understand the implications of intelligence and information.
	Learn from private sector.

Other points

- Informatics professionals need to develop their technical, commercial and soft skills through a phased maturity model as demonstrated below:



- Informatics professionals need to remember information management is everyone's responsibility (everyone who uses a system to input data of any sort). This fact places a burden upon quality IT training, hence, there is a shift needed from seeing IT training as a burden to IT training as relating to NHS goals around patient care and health pathway quality.
- Clarification needed as to the role of CIO: someone who understands information or information technology?
- Business management and IT need to work hand-in-hand – two-way street. Success of IT should be measured by its effect on the business.

3.3 Privacy, security and risk management – key points

Idea/ issue/ challenge	Recommendation
Definition of the word 'control'.	Needs very clear definition as control means something different to different people (e.g. politician/ informatician).
	Use 'access' rather than control. Also, ownership not helpful. Better: rights and responsibilities.
	Data Protection Act
Clinicians tend to act as individuals, which makes collaboration across systems difficult.	Implement training and education around the importance of data sharing and control mechanism that enable it to occur safely.
Data controls inhibit potential secondary uses of data.	Patients should be encouraged to 'donate' their data.
Patients need to be able to trust that their identifiable data is kept secure.	Identify clinical services that can be provided electronically and securely.
	Any policy has to be modular and flexible to accommodate different attitudes to privacy (e.g. younger/ older patients).
	NHS Constitution (when patient accepts care, they also accept that clinicians will keep record of care and share data as appropriate).
	Patients have right to say that a piece of information can only be shared with their consent.

Other points

- What does control look like when you take a record out of the NHS and pass it on to third parties?
- Mental health: how far does a mental health patient have control? Clinicians should provide patients with the right amount of intelligence and information needs to be easily understandable.

3.4 Setting the direction – key points

Idea/ issue/ challenge	Recommendation
Revolution	Understand all patient interactions and processes to base information strategy on.
	Transformation must include innovation/creativity.
	Enable culture and behavioural change through IT/ information.
	Use term 'transformation' rather than revolution (revolution might imply chaos).
	Look at process change.
	Create a strategy based on clear vision and with a timescale. Introduce the right incentives.
Sharing of data	Requires a federated network of information.
	Don't publish information blindly. Identify and classify information to determine what should be published.
	Centralisation of information is not necessary.
	Ensure that information is captured in such a way that best practice information can be determined and shared amongst organisations to express the requirements for IT products. Means best IT systems will be used in the right areas.
	Provide quality mark for information.
	Federated network of information – shouldn't mean that information needs to be brought together in one place for people to have access to it. It can be decentralised and browsed securely.
	Patients to carry around their record (as with mothers to be).
Leadership	Need to consider framework over time as priorities will change. Identify steps in the journey.
	Learn from the best of previous information strategies.
Localisation/ centralisation?	Local clinical ownership in context of local issues.
	Focus on solving local issues to get buy-in. Engage informal care networks in this.
	Local areas to define their own success factors within a framework of clinical ownership. Recognise that everyone is different. Keywords: REUSE and INCENTIVES.
	Wiki for professional/ informal care.
	Local clinical ownership.

	'Good enough' system should be the accepted standard, doesn't need to be perfect.
Data / information	Ensure quality at capture source.

Other points

Data/ information

- There needs to be an appreciation that when you're dealing with complicated datasets, you need good interface design. Drop down menus don't work c.f. Apple iPhone interfaces.
- We think of information as something passive, but when information changes, some action is generated. There will be actions from shared records; it is not a passive business.
- People who find it suitable could provide information about themselves before going to an appointment

Vision

- Do something a little more mundane, do something you do today better rather than going for something big, exotic.
- We want to see effective analysis of how we can assist patients in this strategy.