Health

Enabling the information society

Patient engagement in the Information Revolution

Notes from BCS Health hosted open debate
London
13 December 2010

1. Introduction

BCS Health hosted this open debate as its first event for one its key strategy and policy themes this year - 'Patient engagement and self-service'.

The timing of this event will also enable the output to feed into the NHS Information Revolution consultation on proposals for which BCS are submitting a response.

The open debate was hosted by BCS and involved patient/citizen groups (Mind, Mencap, National Union of Students, Macmillan, Terrence Higgins Trust, and Thalidomide Trust), National Voices, and BCS health informaticians. The event was also attended by a Department of Health representative working on the NHS Information Revolution consultation and the Department of Health's National Director for Patient and External Affairs.

The event offered an opportunity to discuss the NHS proposals for an information revolution amongst patient groups in the context of informatics consequences and requirements. Three short presentations were given to set context and raise challenges prior to a round table facilitated debate:

Introduction to the vision of the information revolution
Marlene Winfield
Director for Patients and Public, Department of Health, Informatics Directorate

Informatics considerations for patient engagement
Dr Justin Whatling
Vice Chair, Strategy and Policy, BCS Health

Introducing the patient perspective
Adrian Sieff
National Voices

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.

With thanks to our BCS 'patient engagement and self-service theme' leads Marlene Winfield and Chris Exeter.

Dr Justin Whatling
Vice Chair, Strategy and Policy
BCS Health

2. Information, health literacy and activation

- **Information does not equal power**
- **Information does not equal knowledge**
- Information requires context and support for it to become knowledge
- **Information and knowledge alone do not create behaviour change** but clinicians continue to believe it does despite evidence to the contrary. The use of terms such as “Information Prescription” only enforces the wrong model.
- What improves outcomes is **health literacy and patient activation based on a belief that they can influence their outcomes**
- Information needs to be delivered and supported in ways that increase health literacy and improve outcomes – ‘I want someone to walk behind me on my journey’
- **Information, education and support must be delivered together** to enable participation in decisions and care planning
- As we shift from crisis management to health management, **people will need a health management adviser through life**. Is this a role for the GP? But they are more used to very discrete transactions.
- Will the Information Revolution **fix problems in the system rather than activating patients?** Using information on quality of providers and their services as a mechanism to drive choice and marketplace when people expect a minimum standard of care in the NHS is fundamentally a way of trying to fix an imperfect system. This is a very different purpose to sharing information to enable activation of people in their health and wellbeing. We need to be clear on the purpose(s) of the information revolution and that they are individually approached in the right way to achieve the desired outcomes. The purposes and being muddled.
- When a service moves to more patient activation (ie asking the patient to do more for themselves) there might be an initial reaction against it but this will dissipate if people understand why it is better for them and feel supported. It is **important to deal with reactions when services change**, including explaining the rationale (examples are physiotherapy and dental services).

3. Co-creating and sharing power

- Informatics, choice of provider, and datasets are second order issues for patients. **Shared decision making is the first order issue**
- ‘Are patients willing to revolt?’ Where’s the evidence? There is nothing wrong in **some people wanting to hang on to the old relationship**. We must accommodate a range of care decision models to support patient preferences. This means that care professionals will need to accommodate different degrees of shared decision making from patient to patient.
- Some people are ‘activated’ from the beginning but **others tend to become activated when a wrong decision is made**. They go along with the first treatment option, not seeking choice. If that doesn’t work or something goes wrong, then they will want to make choices.
- **Changing relationships are key**; **relationships determine what people do and how they use information**. Without relationships, information’s ability to achieve activation and behaviour change is diminished.
- Co-creating health is about a **partnership of trust**, letting go of power in favour of supporting independence
- Ironically, people will become more independent if their GP tells them to do it. There is no silver bullet but the **messenger and the prevailing norms are key**.
- Are we moving in the wrong direction with initiatives like QoF and Payment by Results? Do they mitigate against a partnership of trust?

- Ratings are a worry – we rate ease of access, functions, rudeness of service etc – whereas healthcare is actually **'generating an experience' and this is what is important to people**. Compare this to 5 star hotel ratings.
- What would help is **personal health budgets** with health brokers to advise people how to spend them and get the best deals.People need to be able to make what clinicians perceive as wrong or suboptimal choices. 'Ill people make lousy shoppers'
- When people are ill, they are vulnerable, and seek assurance. We fall naturally into the role of passive recipients of care. **We have to believe we can take control** and those providing care have to believe it too and let go.
- Those who have power will retain power without some disruptive intervention. Need to **look for ways to diffuse innovation and models quickly** across the system.
- **A change of mindset is needed**: 'I am that person's clinician', not 'that person is my patient'
- **Co-creation offers the potential for increasing efficiency** in the NHS: re-defining the role of consumer/patient/person and provider
- People will change as you **journey with them**, they will want to do more for themselves as they gain confidence. We can't just apply a 'patient focus' as people are on different journeys. People need choice and journeying – there could be a role for "navigators", to help people find their way around the system
- Clinicians have to go on a journey too if the health model is going to change. They will need to **train for change, and quickest way is on a whole team basis**. They need to believe that supporting people works. Whereas the health service currently errs on the side of being judgemental.
- The new health model should be embodied in **a contract between the patient and clinician or clinical team** and not a 'prescription'.

4. Providing information

- Information is not standalone: **Information needs to be integrated with decision-making** and cover a range of topics beyond the immediate health issue. It needs to **support the person pathway, not the care pathway**. It needs to support care across boundaries.
- Healthcare should **give people choices and then go on the journey with them**. They may not make good decisions at the outset but as they go on their journey they will start to make good decisions.
- The health system errs on the side of non-holistic support because of the costs.
- People currently seek support depending on what they think is wrong with them. There is **nowhere to go for holistic assessment and advice**. Even the third sector's funding is usually for condition-specific work.
- People should be able to **seek information depending on their own priorities**.
- People will want **information in different ways, at different times** in their journey. Systems, both IT and people systems, need to be flexible enough to provide it. One size does not fit all. We need to be aware that **people receive and perceive information differently**.
- The **first point of contact for a health problem is not usually a health professional**. It is often a relative, friend or the Internet. If you were to design a computer today, you wouldn't incorporate an outmoded keyboard based on the typewriter. How would you design a health model if you were starting with a clean slate? **Most people will go to a source they trust**, they have to trust the source.

5. IT in health and illness

- **Students may prefer an IT-delivered service**, not having to speak to anyone.
- IT has the power to move the population into a much more constructive relationship with their health. **IT needs to support people to have a healthy lifestyle** rather than just being there when people are ill.
- Experience and evidence can help change culture, for example the telephone consultation was at first resisted for the same reasons online communications are being resisted but it proved its worth and more and more clinicians and patients adopted it. We need to **put in services and see how they fare rather than waiting for the culture to change**. Incentives and suitable tariffs are needed.
- We **need pragmatism**. We must shy away from holy grails. We need to look around the world for good ideas.
- Will just giving patients more tools change things? Give patients more tools to change things – get them out there.

6. Third sector as information intermediaries

- People want **holistic information and support but third sector organisations are often funded for their condition-specific work**. There are no universal intermediaries – this is not provided by the third sector.
- The third sector is particularly good at being intermediaries for people who have difficulty accessing services. **How will third sector organisations meet increasing expectation and need with its current resources?**
- The **third sector could be commissioned** by the NHS to be information intermediaries. The third sector is starting to place values on their transactions in order to be commissionable.
- Intermediaries must be trusted. Trust is key – by professionals as well as patients. To be trusted intermediaries, **third sector organisations need resources and skilling**.
- **Liability issues are huge**, especially when using data in ways it was not specifically collected for and dealing with data from different sources. It is a huge ask of the third sector to take this on. 'What if we get it wrong?'
- The expectation that they will provide information in a **timely manner will put considerable pressure on third sector** organisations
- For accountability perhaps it is better to have a **single provider of information** like NHS Choices that third sector organisations would contribute to so that the information has a trusted brand and is dated. However, we need to acknowledge there is increasing disintermediation with how the public accesses information – and this is likely to continue.
- There is a risk of 10 different providers concluding and telling patients 10 different things from the same data.
- **Face to face contact is a key element** for third sector information intermediaries, and more time is required if for example people have a learning disability. Third sector organisations don't want to lose the face to face element but would be **difficult to scale up without resources**.
- The NHS is sometimes guarded about allowing third sector intermediaries to be based in their facilities
- The **Information Standard needs more publicity**.