Better value digital health: the medium, the market and the role of openness

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ABSTRACT – The recent NHS 'hack days' have showcased the enthusiasm and talent of the junior doctor body as well as the potential of open source, open governance and small-medium enterprise. There still remains much scope for developing better value digital health services within the NHS. This article sets out the current state of NHS information technology (IT), how it fails to meet the needs of patients and professionals alike and suggests how better value digital health can be achieved.

KEY WORDS: Digital health services, digital health, digital strategy, open source, open governance

Introduction

The first ever NHS 'hack day' took place in London recently.[1] Supported by NHS Right Care and the NHS Information Centre, the event brought together more than 120 volunteer doctors, developers, designers and other 'geeks who love the NHS' (the NHS hack days' tagline) to work on disruptive digital health technologies that improve the NHS for patients and healthcare professionals.

The event demonstrated the relatively untapped technological understanding, skill and creativity of the junior doctor body. Prototypes made over the weekend included OpenBNF.org (a more accessible and useful version of the BNF), ChecklistHQ.com (a website for making and sharing check lists rather than relying solely on memory) and an open-source patient list app.[2]

At present there are too many unnecessary barriers in the NHS which prevent it benefiting from the willingness and ability of junior doctors and other 'geeks who love the NHS' to improve NHS information technology (IT). Doctors and patients are right to trust their sense that the digital health technology they use could be much better. In this article, I describe how IT in the NHS could be improved and set out what is needed to deliver better value digital health.

Things could be better; the NHS is missing out on the benefits of digital media

…the computer will allow immediate retrieval of all the data…multiple copies at distant terminals…and immediate correlation with large amounts of data on similar problems stored in the computer…when

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many institutions have similarly developed data banks of patients' records, they can teach and audit one another

Weed, in the *New England Journal of Medicine* (1968)[3]

With IT, information can be captured once and used many times

Downing Street briefing on a strategy for modernising NHS information systems (2002)[4]

Providers of health and care services will be able to increase their efficiency, for example from reduced duplication of work

Department of Health (2012)[5]

NHS IT systems are not as useful or usable as they should be

NHS IT systems do not support core functions such as comprehensive information retrieval, audit and research across the NHS. Because of poor interoperability and limited functionality, systems do not support the task of delivering high-quality care in an efficient manner. Due to poor design and poor usability, inefficiencies, such as the unnecessary duplication of work, are commonplace.

Clinicians and patients are frequently frustrated by systems that do not make life as easy as they should – by not being joined up and by having counterintuitive and laborious user interfaces. For hospital clinicians, simple common tasks such as referring a patient require phone calls to switchboard, fax machines and bleeps. For patients, a hospital appointment cannot be rearranged online, requiring phone calls, waiting and letters of confirmation.

Systems are frequently unreliable and full of bugs. For example, it is rare to find an electronic discharge summary system that does not lose formatting input by the user, such as space between paragraphs, on saving or printing. This significantly reduces the readability of discharge letters. A very long list could be made, but sadly, to date, little systematic effort has been made to collect, and act on, user experience feedback, as is the case with other systems – from Amazon to Sage Accounting.

Poorly designed software is wasteful and threatens patient safety

Worse than just being a nuisance, poorly designed software costs valuable clinical time, threatens patient safety and may increase mortality.[6–8] Data about safety incidents relating to computer systems in the NHS are collected through clinical incident reports submitted to the National Patient Safety Agency's

National Reporting and Learning System (NRLS). In addition, the Department of Health maintains a database of every health IT system in use in the NHS. Unfortunately, this information is not made public, and little evidence at present indicates that it is collated, analysed and used to inform local procurement or identify recurrent adverse incidents.

If we could test, learn and adapt the digital medium, we could make it more useful and usable

The big trick that the NHS seems to have missed is realising that, because we are in the information business, getting digital right matters a lot. The digital medium is pervasive and fast becoming the medium for the delivery of healthcare. Although it does not replace face-to-face contact with the patient, it is increasingly the dominant means through which healthcare professionals communicate information about their patients, request investigations and initiate treatments. The major advantages of digital as a medium are:[9]

- We can watch and learn from user behaviour, shaping the system to discover and meet user needs.
- There is immense potential for creativity, flexibility and sharing.
- We can profit from economies of scale, adding value and reducing costs.

Failing to exploit the advantages of digital as a medium is an opportunity cost for the NHS. If we tested NHS digital systems by collecting data on how people use them, we could learn, adapt and improve services to better meet user needs. Beyond improving services to offer a more usable and useful user experience for clinicians and patients alike, the opportunity to use routinely collected data to improve healthcare is also being missed.

Economies of scale come from adopting or building on widely used, more general purpose, open technologies. These technologies evolve rapidly because of the large collective investment of time and money they receive and because large communities of software developers also form around them. The net effect is the possibility to deliver greater value at lower cost.

If we could use the digital medium to test, learn and adapt healthcare delivery, we could improve healthcare quality and efficiency

Imagine a future where user-friendly digital health systems help clinicians to do their jobs, have sensible evidence-based defaults and are themselves both subject to and used to support pragmatic randomised controlled trials.[3,10,11] The recent Cabinet Office paper *Test, learn, adapt: developing public policy with randomised controlled trials* sets out how randomised controlled trials need not be expensive or complicated to carry out, can support public service efficiencies and can improve the performance of digital services.[12] At a time when the NHS is under pressure to improve the quality of care delivered while making £20 billion of efficiency savings, the need for rigorous analytics and scientific method to ensure the best use of resource is made has never been greater.

Understanding digital, disintermediation and buying smarter

It is hard to get a good deal when you do not understand what you are buying. *Can you recognize the million pound chair?* is the title of a blog post by Tom Steinberg, founder and director of mySociety. He points out that, although we all possess the skill to buy an office chair, can be reasonably confident about what sort of chair will meet our needs and can recognise an unreasonably priced chair, technology procurement is different and requires a specialist skillset.[13] Unfortunately, it is not at all clear that the NHS and Department of Health possess such skills and, because the business of healthcare is increasingly carried out through and using digital technologies, this is costly.

Too often in the NHS there is information asymmetry between sellers and buyers of software systems comparable to that of vendors and purchasers of used cars, which is a so-called lemon market.[14] The typical buyer of a used car is in a weak position, because he or she lacks knowledge about the technical fitness of the product, is blind to everything but price and has no way of identifying poor-quality used cars – the lemons.

Continuing the analogy, rather than putting second-hand car-buying requirements out for tender and inviting bids, a smart second-hand car buyer will actively seek out a good deal and may enlist a mechanic friend to check the car over before buying. A smart second-hand car buyer would also take into account maintenance costs, as a car with non-generic specialist parts will require a more expensive specialist garage, and it would probably be best to avoid a car that required payment of a release fee when you wished to change it. The NHS must redress the deficiency of mechanics by identifying people with a deep understanding of technology and recruiting them to positions of procurement influence.

Employing technology talent

Typically, NHS IT users are compelled to use particular systems that they have little or no ability to influence or improve. Suppliers sell to middle men who implement systems for users in a coercive fashion.

The personal computing revolution could soon catch on in the NHS, with patients and employees alike being free to choose their preferred technology from a competitive market of fungible digital goods. For this to happen, NHS trusts would need to open up their data and allow different users to use different products (endpoint variation); most trusts already do this with their websites, which are made available in standards-compliant hypertext mark-up language (HTML) and accessed via the end-users' preferred browser and device.

Where users are able to exercise choice, as they are over which browser or device they use, for example, the market tends to be more efficient and responsive to user needs. Conversely, where a person using a digital product has no ability to choose otherwise or to improve or influence what they use, the market does not function well and their needs tend to be unmet.

Employing technology talent – for example, software developers and designers in the fashion of the Cabinet Office's Government Digital Service[15] – cuts out the middle man, brings technology

expertise in house to support informed procurement decisions and promotes the growth of a digital ecosystem that more efficiently meets user needs. By developing digital services in house and sharing the technology throughout the NHS, users benefit in three ways:

- The NHS builds a source of in-house technology expertise in order to inform smarter procurement of technology.
- Existing vendors have to raise their game and offer the NHS a better deal for competing technologies, because the NHS will develop and use technologies developed in house if they do not (technologies developed outside the NHS that are not interoperable and substitutable with technologies developed in house would not be permitted in order to prevent lock in).
- Development of 'core-platform' services by an in-house software development team would permit and facilitate growth of a market for higher level applications that build on the existing platform in order to deliver more value to users.

These measures would promote variation and innovation in health IT and support the growth of non-government provision by small and medium enterprises.

The NHS should use modern design principles

Modern 'lean' digital design principles are user-focused. The following principles are adapted from the Cabinet Office's Government Digital Service:[9]

- start with needs (real user needs)
- understand context (design for people; consider how they will use the system in their environment)
- do less (if someone else can do it, encourage this; concentrate on the irreducible core)
- build digital services not websites (service does not begin or end at the website)
- iterate, then iterate again (iteration reduces risk; it makes big failures unlikely and turns small failures into lessons)
- design with data (learn from real-world behaviour)
- do the hard work to make it simple (if users are compelled to use our service, we have a duty not to waste their time)
- make things open, as it makes things better (the more eyes on a service, the better it gets).

The merit of these principles is sufficiently strong, and widely accepted outside of the NHS, that their adoption in the NHS is to be strongly recommended.

The NHS should embrace openness

Openness refers to the use of open governance and open-source software.[16] Openness matters because it allows social collaboration (peer production), which brings more minds to bear on problems and more efficiently matches available talent to problems. Put another way, because no single organisation can own all of the talent, it makes sense to allow people from outside of the organisation to work with you. The competitive advantage of openness results in higher quality code, more innovation and

lower costs. For this reason, openness is now standard to the technology industry and many parts of government (eg the UK's Cabinet Office). The model also fits well with the openness found in medical and academic culture, in which enlightenment principles leave no room for the use of black boxes or components that are not fully explained, proven and subject to peer review.

Open governance

Open goverance in software projects is key to realising the potential benefits of open source software, such as investment in improving the software from those outside of the organisation. Open goverance in software projects has four main characteristics:

- access: availability of the latest source code, developer support mechanisms, public roadmap and transparency of decision making
- development: the ability of developers to influence the content and direction of the project
- derivatives: the ability for developers to create and distribute derivatives of the source code in the form of spin-off projects
- community: a community structure that does not discriminate between developers.

Open source

'Open source' refers to software that comes with rights that proprietary software does not, such as the right to study, change, improve and distribute the software. This has particular advantages in healthcare digital services, because it lowers costs, promotes interoperability and makes open standards possible.

Interoperability is easier with open-source software, because how the software functions is not hidden and you have control of the code. This makes it much harder for a supplier to follow a business strategy that involves making software that deliberately does not interoperate with other software.

Why not just have standards instead?

Standard setting is complex and highly political because of the strategic importance it holds for industry. Businesses are keenly interested in establishing dominant standards, where possible, to keep out their competitors; if this is not possible, ensuring their products interoperate with the dominant standard is a priority. This is why compatibility issues are frequently encountered when one tries, for example, to open a Microsoft Word 2007 document on a computer that is not using a Microsoft operating system – or even a computer not using the same version of Microsoft Word.[14]

Reasons to have standards are:

- They encourage interoperability and avoid fragmentation; sadly this is not guaranteed, as it is possible for different implementations of a standard not to interoperate.
- They reduce costs by producing a healthier market, more choice, preventing lock-in, providing greater flexibility and increasing the number of players because of lower barrier to entry, including smaller vendors.
- Innovation is diffused.

Reasons not to have standards are:

- they can be subverted by large corporations to create fragmentation and higher costs
- they can be resource intensive (to establish and maintain)
- poorly described standards inhibit the ability of talented software developers to contribute to projects.

What is needed to have a successful standard? A successful standard:

- balances not allowing extension, which may prevent evolution of the standard and stifle innovation, with allowing proprietary extensions, which can lead to the subversion of a standard
- achieves and maintains the aim of having competing implementations of the same standard, making the substitution of alternative components possible in reality not just in theory.

In practice, successful standards are much more likely where open-source implementation exists, because open-source implementation acts as a reference implementation, revealing standard specifications that are unnecessarily hard to implement or that contain specification flaws. Open-source software tends to enjoy wide diffusion and dissemination, facilitating adoption of the standard.

Making it happen

Clinical leadership

How can we build an environment in which world-class NHS digital services flourish? Through leadership that understands technology and is bold enough to modernise digital services delivery by embracing openness (open governance and open source). There is a real need for clinical leadership and advocacy to ensure that usable and useful digital health systems are put in place as promptly as possible.

Roadmap for better-value digital health

Better-value digital health is desperately needed in the modern NHS in order to meet the expectations and needs of clinicians and patients, to improve quality and to contain costs. A roadmap for better-value digital health would include:

- developing procurement ability by investing in digital talent
- employing software developers directly
- adopting openness (open governance and open source)
- using modern software design principles
- testing, learning and adopting the medium and the service.

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