Introduction

In July 2016 (ISC)², the largest nonprofit membership body of certified cyber, information, software, privacy and infrastructure security professionals worldwide, wanted to bring together perspectives from many areas of the healthcare industry and give them the opportunity to talk freely and anonymously about their thoughts and experiences as the sector undergoes digital transformation. The move to a paperless system in an effort to improve patient care is an ambition central to the Government’s Personalised Health and Care 2020 framework. Our aim was to explore a range of issues, including the reasons why patients were showing a reluctance to trust the sector’s efforts to go through this change, and barriers that should be addressed in the effort to create a culture of trust.

This subject is important to (ISC)² for several reasons. We have members working within the healthcare sector around the world, 50 of whom are subject matter experts within the NHS. We understand that they are seeking to better understand current trends, such as the rising value patient data and the threat of online theft, as well as the growing frustration with the effort to progress the sector digitally. This was an opportunity to create a resource for them and other stakeholders, providing a snapshot of the front-line experiences and current insights of these trends within the sector. Among those around the table were representatives from the Cabinet Office and Department of Health, academia, a patient advocacy group, an IT company that specialises in health records, a business consultancy focussed on healthcare services, a well-known international management consultancy, as well as current and past clinicians. It was clear that everyone in the room believed that the move to a paperless environment was both inevitable and desirable. They were united in their belief that the sector was collapsing under the weight of outdated processes, and at risk of missing significant opportunities for improvement in both management and clinical outcomes.

Initially they came to learn how to foster a culture of public trust in the management of healthcare data, but we soon discovered that this wasn’t the sole focus. Trust is a symptom of circumstance, and the discussion revealed many influences that could undermine the move to a paperless environment: from a lack of clarity around goals, to the skills required to make the transition. Our discussion illuminated some of these wider issues, highlighting the differences and common ground, and helping all to develop an understanding of how we can move forward.

Here we present their input in the form of questions that have yet to be fully answered, but highlight concepts that will be relevant to all interested in assuring a culture of trust as the healthcare sector undergoes its digital transformation.
The group admitted that moving from a paper-based system to an electronic system adds complexity, with different systems serving different needs. In addition, the ability to parse existing data in many ways emphasises a need to examine the current definitions and assess whether they can be universally understood and agreed upon.

What are patients concerned about?
During the session we asked about the group’s understanding of current patients’ perspectives and concerns on the transition to paperless records. It was clear that there was a poor appreciation and patience for the measures that are being taken to ensure confidential patient information is protected, and/or only be accessed by the correct people. Patients question the motivation and methods around how information contained in records could feasibly and safely be shared for reasons beyond direct patient care. They expect, but question how records can be managed to allow different clinicians to view the data they need, while keeping other sensitive data confidential.

The discussion led to debate about whether records pertaining to certain conditions, such as HIV, should be treated with a different level of confidentiality should it be requested by the patient, and how such a scenario would be managed in an electronic record system. The obvious reason given was the level of distress caused in the event of a data breach where patient confidentiality was compromised, such as in 2015 when the 56 Dean Street Clinic accidentally revealed details of more than 700 users of an HIV service.

What is a patient record, exactly?
Part of the discussion in the move to digital healthcare agreeing a common understanding of various concepts. One of the central considerations during the July roundtable session was the definition of a ‘healthcare record’. Some of the key questions the group sought to understand included: What do we mean when we talk about a patient ‘record’? Will the move to a paperless sector impact the confidentiality of records? Will the move to a paperless sector impact the doctor/patient relationship?

What do we mean when we talk about a ‘patient record’?
The lack of a common understanding for what constitutes a patient record became evident early in the discussion, as everyone was referring to ‘the record’ as they raised points and scenarios. One participant paused to check if everyone had the same understanding when they were referring to ‘a record’ and it became clear that they perhaps didn’t.

This brought to light a fundamental requirement, the need to clearly define what constitutes a record in a paperless healthcare sector. The options offered were varied. Some suggested the foundation was based on the General Practitioner (GP) notes, while others understand it to mean a collection of notes from the GP and clinicians at a hospital. A third viewpoint referred to the patient’s Summary Care Record (SCR). The discussion explored whether a record should mean a file which outlines all of the patient’s past medical history, from any GP’s surgery where they’ve been registered in their lifetime and any hospital visit they’ve ever had. The group pointed out that people are often surprised to learn that there isn’t a consolidated system where patients can access a centralised ‘record’ that is readily accessible to clinicians.

The Data Protection Act 1998 currently defines a health record as: “Any electronic or paper information recorded about a person for the purpose of managing their healthcare”. However, the conversation illustrated that those who have extensive experience of working in or with the sector, have different interpretations. It is arguably unlikely, therefore, that the public will have a clear understanding of what constitutes a healthcare record.

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It also became clear that patients want assurances that are difficult to communicate. They want to know that their records are in order and kept safe as the system for keeping and managing them is changed. At present, however, if you ask a patient or a healthcare professional exactly where a record is kept, or where their information is held, they may not be able to answer.

**What about doctor/patient confidentiality?**

The move to a paperless sector is inevitably leading to a culture shift as digital records create new far-reaching opportunities to access the information. The group highlighted that there was a time when a GP might be offended if another healthcare professional asked to view the records they keep. The move to a paperless sector and the ability for patient information to be entered into systems that would be accessed by teams of professionals are leading to a culture of shared ownership that doesn’t always sit comfortably with the professionals involved. There is, for example, a strong ethos within the sector driven by the belief that much of what is discussed between the GP and their patient should be kept between them. It was also suggested, however, that such an evolution could lead to a stronger culture of accountability and better record keeping which could outweigh the traditional stance.

What was clear was the need for much more conversation with those on the front-lines of practice who are working with this information around the types of information at play, levels of confidentiality needed, and how all of this should be managed in practice.

**Can healthcare keep up with changing expectations?**

As the healthcare sector evolves during the transition to a paperless system, consumer trends will play a role in what it will need to deliver, and how it is delivered. These trends are already shaping expectations that patients have of the sector. Consumers are used to, and want, more control of their data and this increased level of control is leading to a culture of ‘Bring Your Own Healthcare Data’ (BYOHC). The group around the table evaluated how consumer trends are shaping expectations around how much control patients currently have over their healthcare information, and how much they actually want.

**Will we see the blending of healthcare delivery and personal devices – ‘BYOHC’?**

Deloitte’s 2016 Global Healthcare Outlook report stated that there were five areas in digital and connected health that are growing rapidly, which include wearables. These highlight a desire among consumers to understand their own personal health data, such as what they can collect and manage themselves. The rise in popularity of activity trackers like Fitbit, and Apple’s acquisition of Glimpse - which enables users to pull their own medical data into a virtual space and create a shareable healthcare ‘profile’ - point to a future of patients having more involvement in, and control of, their own data.

News of the proliferation of such consumer-driven data sits in sharp contrast to reports from the NHS which in October 2016 admitted that 61.7 million records belonging to patients who have opted out of sharing their data have been removed by NHS Digital. It would be interesting to understand the reasons why patients decided to opt-out, and if the number would be less if patients had more knowledge about how their data is managed, or if they had more control over their data.

While so many choose to ‘opt-out’ of NHS Digital sharing their data, it is interesting to note that so many people are willing to hand over their data to Fitbit or Apple, potentially without the same level of concern. It was suggested that people aren’t driven by concerns when making these
decisions to share their data, but rather convenience and a clear understanding of a service that these applications afford them. In the case of Fitbit, consumers are driven by the desire for easy access to new information about themselves.

A comparison was also made with how patients view or manage their finances online. People readily use banking applications without asking many questions about who within the bank will be able to view their personal financial information, or how their data is managed. People seem to be driven by benefits that outweigh concerns they may have, and perhaps have fewer concerns around the data risk, even if it is their money. A bank can ‘fix’ the problem of a data breach so to speak, by replacing stolen funds, and providing a new bank card, whereas when patient data is compromised, the impact can’t be reversed.

It is also possible that there is a higher level of trust in the financial sector’s ability to secure and manage data compared to that of the healthcare industry. The lesson for the healthcare as it undergoes digital transformation lies in the need to communicate benefits and understand incentives that will drive individuals to share data.

Where will consumer-driven information end up in the future?

The wearables trend brings to light a whole host of questions about who will have access to the data, as the potential develops for it to be integrated into ‘official’ healthcare records. There will be a need to consider how integrity across such records can be both achieved and communicated. It’s interesting to note that Glimpse aimed to put data back in the hands of the patient, bypassing the process burden the healthcare sector has in terms of holding records.

How much control do NHS patients currently have?

The group pointed out that the UK government is working to encourage people to be actively involved in the management of their own healthcare. NHS Choices states that GP surgeries must offer patients the opportunity to input into their Summary Care Record (SCR) to provide more information that could help with their care. However there appear to be barriers to readily accessing personal medical records. For example, there are cases where individuals may need to pay a fee if you wish to see original records or get physical copies of them. It was also suggested that many patients aren’t aware of their opportunities and/or aren’t offered enough information about access to their records. That being said, there were over one billion recorded visits to the NHS Choices website in 2014 — which could arguably be an indication that there is an appetite for information. Our roundtable participants agreed that more information, more actively communicated to NHS patients is needed to ensure a better understanding about how records are managed and the choices available.

How much control do patients actually want?

The discussion naturally raised the question of how much control people may want over their healthcare data, and whether they were really interested in understanding how it is managed. In practice, the majority may not actually be too concerned about how the NHS is managing their data, or take advantage of the opportunity to access it. This was a conclusion made in a series of Citizen Juries exploring patient attitudes toward their healthcare data. There was little interest in becoming actively involved in accessing or managing their data, but rather a demand for assurance that the storage system works and is trustworthy. A comparison was made with how people tend to skip read Terms & Conditions for many services, particularly when it comes to software updates on devices and their phone. They’ll simply accept, fuelled by a trust that they’ll be on the receiving end of a better service.

The Citizens’ Jury also illustrated that attitudes can be influenced by the interest of public good. When patients were provided with more information about both the risks and opportunities that emerge for the wellbeing of all patients from sharing their data, they were more likely to be willing for their information to be shared.

The discussion prompted consideration over whether consumer trends could or should shape the sector as it
evolves digitally. Could, for example, the way healthcare data is managed within the NHS ever be like the financial sector and how it approaches online banking? Ultimately, observing the digital transformation trends that are shaping society could pave the way to understanding how patients assess benefits of participating in the transformation of their healthcare too.

**Why is trust so elusive?**

It became evident during the session that a key barrier to progressing digital healthcare lay in a persistent lack of trust in the Government’s (and by association the NHS) potential use of the volumes of data collected, as well as the ability to secure and manage it. This is manifested in both a lack of trust from the public, and from those working within the sector. The concern persists despite evidence of measures taken to mitigate cybersecurity risks, and the Government effort to outline its intent within the Personalised Health and Care 2020 plan, its Care.data database project before it was cancelled due to lack of patient support.

The group explored this concern by discussing how well patients understand the benefits of digital health and whether enough was being done to communicate them.

**How far do patients trust?**

When it came to patient trust in the sector’s digital initiatives, questions were raised as to how well the public understood the benefits that could come as part of the aim to undergo digital transformation.

The Government’s Personalised Health and Care 2020 plan aims to increase data sharing to give care professionals access to all the information they need to improve patient outcomes, make the quality of care transparent, and help to advance research efforts to help cure diseases. But whether the public understands what this would mean to them remains a key question.

The benefits of Care.data were rooted in the use of the information collected to better inform where resources were needed in the sector, and thereby improve services for the public. Despite this, one million people reportedly opted out of Care.data, and it was understood that many of these people were discouraged by the prospect of their information being shared for purposes beyond their direct care. Discussions since around why Care.data didn’t succeed, often cite the failure to explain the benefits of the database simply enough to engage patients.

Further, the public has seen many news stories about data breaches and the related fines that have been imposed on several NHS Trusts, as this is a public service and therefore required to report them to the Information Commissioner’s Office (ICO). However, they are not exposed to the many positive stories regarding the digitalisation of patient records and its benefits, leaving an imbalance of influence over public perception.

Some participants believed that transparency could counter the trend. For example, patients who are discouraged by the prospect of third party researchers having access to their data for reasons beyond their direct care might feel differently if they were told that it could result in public good that could affect the lives of thousands of people for the better.

Without effective communication of public or personal benefits, individuals will not be motivated to engage and trust will be difficult to build. One suggestion in the room advocated that patients should be invited to be more actively involved in the giving of their consent at various
Further, IT and information security skill levels vary, leaving incompatibility and fragmentation to develop and cause confusion and frustration for those who work within the sector.

Lost in this development is any understanding or confidence in the integrity of what is being done with information as it travels across different parts of the NHS. It was suggested that more transparency is needed between trusts and institutions to increase the understanding and confidence of the controls that are in place across the organisation.

So, can we move forward?

In the journey to digital health there are many considerations that have no doubt been the subject of controversial discussion. Some of these are rooted in conversations that arguably pre-date the discussions around digital health, including the arguments for and against information sharing. Others are rooted in more recent considerations, including the increasing reports of data breaches, new innovative trends creating a shift in possibility and expectation, and challenges of securing trust as outlined Dame Fiona Caldicott’s most recent report following the cancellation of Care.data.

Positive steps are already being made. The NHS is currently aiming to enhance transparency in the data it holds, and encouraging patients to be involved in their own healthcare. The NHS Choices website, for example, does outline how patients can input into their own Summary Care Records (SCR). There are also many individual initiatives such as the recent news that an NHS Trust has teamed up with Google DeepMind, in a move that could make patient access to records much easier and more convenient as it reportedly saves over half a million man hours per year.

Concerns remain, while the questions outlined in this report have yet to be widely considered. The discussion fielded many ideas for moving forward. When asked for their thoughts about what could or should be done to smooth the journey, suggestions around the room ranged from implementing a system to log and communicate all ‘access

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— Sarah Bloch-Budzier

BBC News
maintain and evolve a trusted service rather than focus on public attitude alone. This will be influenced by goals driven by three disparate perspectives that must be catered for:

a. Healthcare providers and clinicians who want to understand what needs to happen to implement digital health, be able to trust in the systems and their integrity, and participate in an open/sharing culture.

b. Patients who must be able to give informed consent, have the right to privacy, and seek confidence in the care they receive.

c. Public good (government) to support research, resource planning, and public safety.

3. Learn from other industries; be benefits driven:
Consumer trends are both revealing and influencing the way patients view the handling of their data and the convenience they require. Other sectors such as finance have arguably achieved a significant level of trust in online services, offering examples of how to communicate the benefits for the individual. It was also evident that when patients are told in a simple,
understandable format what their data can do to help others, they are more likely to allow it to be shared, while the benefits to healthcare professionals and the impact on their ability to offer care to patients could be communicated and understood clearly.

4. **Define responsibility and authority for digital patient information:** Responsibility around handling patient information needs to be clarified. The group called for more conversations with practitioners to develop a common understanding for what can and can’t be viewed, and how to manage this in practice. Expectations around what is acceptable as we move into a paperless environment is currently poorly articulated, and therefore poorly understood. It’s time to account for the experience and context that the professionals and practitioners working in the sector can provide.

5. **Invest in the skills required:** This is a requirement that will vary according to the roles and levels of responsibility, and should be driven by an understanding of the relevant balance of risks and benefits presented in a given circumstance. It must be acknowledged that digital transformation and the associated risks and rewards is a societal issue, and investment is needed to bring everyone up to speed. This includes the development of more specialist knowledge and the development of a basic understanding of concepts across the sector to help all understand how their roles and responsibilities may be changing.

6. **Acknowledge and manage the complexity:** A lot of the barriers discussed were rooted in the increasing levels of complexity developing within the sector and across its systems. This was especially evident when examining the trust that clinicians themselves have within the sector. The first step to tackling this would be a collective recognition that the complexity exists and that it is having an impact on the integrity of what can be achieved. A process-based or systems-wide approach can then be taken to develop an understanding of the systems environment and solutions required to achieve stated aims.

7. **Commit to collaboration:** The journey to paperless healthcare and digital transformation represents an evolution in the development of healthcare. It is a journey that cannot be controlled by the sector itself as trends across economies and society continue to drive change. Ultimately, more discussion needs to take place to achieve a common understanding of objectives, priorities and solutions for achieving them. In additions to the issues raised by this discussion — identifying what constitutes a record, achieving transparency, articulating benefits etc. — there are many underlying concerns that must be addressed, such as having a thorough assessment of risk, standards of practice in this new environment, ethical shifts, and the role to be played by various players, not just the NHS.

Ultimately, the aim is to have a trusted service in place that empowers citizens through knowledge, enables clinicians to feel confident in the tools they are using to provide care, and encourages clarity for everyone. It’s a given that this service must be underpinned by systems that are robust and secure, but this is an aim that is heavily reliant on clarity of its aims and direction across the sector.

**About (ISC)²**
(ISC)² is an international nonprofit membership association focused on inspiring a safe and secure cyber world. Best known for the acclaimed Certified Information Systems Security Professional (CISSP®) certification, (ISC)² offers a portfolio of credentials that are part of a holistic, programmatic approach to security. [www.isc2.org](http://www.isc2.org)