

# NHS in Transition: Patient Centred Digital Health and Personalised Care

Dr Timothy David Robbins  
Fellowship Report

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# Contents

Page		Contents
1	-	Title Page
2	-	Disclaimer
3	-	Contents
4	-	Abbreviations
5	-	Acknowledgements
6	-	Biography
7	-	Executive Summary
8	-	Introduction
11	-	Thematic Observations & Reflections
20	-	Summary Recommendations
21	-	References

## **Abbreviations**

BA – Bachelor of Arts

BM BCh – Bachelor of Medicine and Surgery

CCIO – Chief Clinical Information Officer

EHR – Electronic Health Record System

GMC – General Medical Council

HITECH - Health Information Technology for Economic and Clinical Health Act

ICT – Information Communication Technology

MBA – Masters in Business Administration

NAO – National Audit Office

NHS – National Health Service

NpfIT - The National Project for Information Technology

PCORI - Patient-Centered Outcomes Research Institute

RCP – Royal College of Physicians

RCT – Randomised Controlled Trail

SMS – Short Messaging Service

UK – United Kingdom

USA – United States of America

WCMT – Winston Churchill Memorial Trust

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Finally I would like to thank my family, both my parents **Peter & Eileen Robbins** and Fiancé **Rosie Tucker** for such love and support throughout this Fellowship year.



## Biography

My name is Tim Robbins, I am 29 years old, currently living in Royal Leamington Spa in the West Midlands. I work as an Academic Specialist Registrar in Diabetes and Endocrinology at University Hospitals Coventry and Warwickshire NHS Trust. I completed my pre-clinical and clinical training at the University of Oxford, graduating from Brasenose College initially in 2009 with a First Class BA in Medical Science, and then with BM BCh in 2012. I completed an Academic Foundation Programme Training and an Academic Clinical Fellowship with Warwick University Medical School, incorporating a Master's Degree in Health Sciences, from which I graduated in 2017. I am currently jointly working at a Clinical Doctor and pursuing a PhD with The Institute of Digital Healthcare, part of Warwick Manufacturing Group.

I am passionate about the successful adoption of digital technology into healthcare, particularly how to most effectively use the enormous amount of data we currently collect from our patients. I have been fortunate to publish research articles, present nationally and internationally in this area, with my current research focusing on how to most effectively utilise data to improve the discharge process for patients with diabetes.

I am engaged to Dr Rosie Tucker, who is also a practicing doctor. Together we enjoy exploring the outdoors, cookery, golf and looking after our two kittens – Luna & Fleur.

Contact: [Timothy.robbins@nhs.net](mailto:Timothy.robbins@nhs.net)

## Executive Summary

Healthcare within the United Kingdom continues to experience enormous pressure, driven from the increasing clinical demands of an ageing population. Healthcare as an industry has been slow to adopt the benefits of innovative digital technologies, often due to the complexities of existing non-digital systems and confidentiality concerns. Digital technologies however offer potentially profound benefits to healthcare systems benefitting patients, clinicians and healthcare organisations. The United States has invested significant resources into the development of digital healthcare environments and there is enormous scope for the United Kingdom to learn from what has worked and what has not worked so well.

This Fellowship incorporated visits to The American Diabetes Association, Banner Health, Cerner Corporation, Harvard Medical School, Beth Israel Deaconess Medical Centre, The Patient Centred Outcome & Research Institute, Boston Start-up Week, MassChallenge and Brigham Women's Hospital Innovation Team. Through semi-structured qualitative interviews with both the leaders and front line clinicians of these organisations six reflective themes considering the successful adoption of digital healthcare interventions were identified:

A. Patient engagement in the development of digital healthcare environments  
B. Clinician engagement in development of digital health environments  
C. Entrepreneurship & innovation  
D. Data in digital health environments  
E. Informatics training pathways for clinicians  
F. Dangers of wholesale adoption of USA practices into the UK

These themes, discussed in detail within this report supported the development of 10 key summary recommendations for dissemination and implementation within the United Kingdom, whilst offering considerable scope for further research. The key recommendations are outlined below and explained in more detail throughout the report:

1. We must engage patients meaningfully in the development and delivery of digital health innovations and environments. Once created these digital innovations have the enormous potential to engage patients directly in their care, increasing quality of care and reducing costs of care. In achieving this we must be truly diverse in our engagement activity, being particularly careful to engage hard to reach groups.

2. There is incredible opportunity to build emotional design into our digital innovations and environments, this requires considerable transparency, however the trust that is placed in UK clinicians provides an excellent foundation.

3. As the healthcare environment becomes increasingly digital there will need to be changes to how generalist and specialist clinicians are trained. Frequent rotational changes will prove a barrier to effectively and efficiently using electronic health record systems and further frustrate trainees.

4. Clinical informatics training pathways and clinical informatics career models are urgently needed, potentially developing recognition as distinct speciality within the UK Healthcare Environment. The Faculty of Clinical Informatics is potentially an ideal place to lead such work with the engagement of both trainees and patients.

Page 8

5. There is a need for all clinicians to have an awareness of cyber-security measures and contingency plans. Future informatics trainees need to have a deeper understanding built into

their training curricula, who may be well placed to lead in disseminating key messages to other trainees and clinicians.

6. Clinical informatics trainees and CCIO's need to ensure that non-clinical ICT Leaders are better known to their frontline clinical staff to support engagement and communication.

7. The concept of Quality Improvement Projects, completed by each individual trainee and assessed against fixed methodological criteria needs to be re-evaluated for a digital age, with a preference for collaborative working across care environments and industrial sectors.

8. Work is needed to re-evaluate the research evidence hierarchy pyramid, increasing the value of retrospective research that can capitalise on exceedingly large diverse data sources.

9. Explorative work is needed to consider the value of meta-data contained within NHS data sources to identify opportunities for improved care processes.

10. We should capitalise on the opportunity to develop a bespoke UK digital healthcare environment that is developed from learning internationally but focused specifically on the needs of our patients and future workforce. The systems within that environment must excel at transferring data across boundaries including from non-healthcare sources.



# Introduction

## Why is it important?

The National Health Service (NHS) in the United Kingdom faces unprecedented challenges. There is an increased demand for clinical care, and yet a shortage of beds to provide that care in. It is estimated there are a third fewer beds and yet that there were 25 years ago (Imison, 2012) despite a 37% increase in emergency hospital admissions (Royal College of Physicians, 2012). It is thought that a significant driver for this increased clinical demand is that our patient populations are getting older, with increased co-morbidities, indeed 65% of people admitted to hospital are now over 65 (Cornwell, 2012). This challenge is being reflected in the workforce with 27% of Medical Registrars (the same grade as myself) reporting that their workload is unmanageable (Royal College of Physicians, 2012). The General Medical Council has since issued guidance that healthcare in the UK has reached a “Crunch Point” in the challenge of matching increased demand with the supply of services and workforce. (GMC, 2017).

Despite these challenges there are enormous opportunities within the NHS. More money is being spent on the NHS in real terms than ever in its history. We now spend an average of £2,160 per person, per year on health care. Whilst this is less than many other similar economically developed countries, it is essential to ensure this spend per capita is used in the most effective manner possible (NIESR, 2017).

A key opportunity for healthcare is looking towards the benefits of digital health. Healthcare is one of the slowest industrial sectors to have adopted digital technology. In 2015 for example 71% of all UK citizens had a smartphone and 88% of adults used the internet (Ipsos MORI, 2015), yet just 2% of the population reported any digital transaction with the NHS (Nuffield Trust, 2016). There is however significant demands among the general population for access to digital health services – with 90% stating they would use a digital service enabling them to ask a clinician a question, 80% would like to view their medical records online & 60% would monitor their disease using a mobile app were that possible (Patient.co.uk, 2012).

In addition to the general population's positive perceptions towards the adoption of digital healthcare, there are profound benefits to the healthcare system as a whole, with the potential to help mitigate increasing demand and reductions in certain areas of supply. In particular digital health interventions can improve both the efficiency and quality of clinical care. The Nuffield Trust in collaboration with KPMG have clearly delineated the potential of digital health benefit the NHS by: (Nuffield Health, 2016):

1. Enabling more systematic, high quality care
2. Delivering More proactive targeted care
3. Facilitating Better co-ordinated care
4. Encouraging Greater patient engagement
5. Improving resource management
6. Delivering system learning and improvement

If digital health interventions can support the delivery of these domains, the NHS may be able to continue to drive forward meeting the increasing demands of patient care, whilst maintaining the quality and safety of care that was envisaged back in 1948.

The adoption of digital healthcare however is profoundly complex. The National Project for Information Technology (NpfiT) was a £10billion project aimed to achieve broad spectrum digital adoption, however whilst creating benefits in some areas, ultimately it failed to digitise the hospitals and community sectors (House of Commons Committee of Public Accounts, 2013). The NpfiT was branded by some as “The biggest IT Failure Ever Seen” and for many years resulted in some reluctance at investing further in NHS ICT systems (Syal, 2013). A key challenge is that the creation of a digital healthcare system is not the simple introduction of technology and computers, but rather integrating technology with a “re-imagination of workflows.” (Nuffield Trust, 2016). Understanding how to do this effectively, and what pitfalls to avoid, will be critical to the successful adoption of digital healthcare to the United Kingdom.

The United States has been able to advance its digital health agenda more fully than the United Kingdom. 46 percent of consumers are now considered “active digital health adopters”, who remarkably have used not just one, but three or more digital health tools in categories such as telemedicine and wearables over the course of 12 months (Tecco, 2016). Furthermore, in the hospital sector, the government has vigorously promoted the adoption of digital healthcare technologies (Harrow, 2009). The most prominent US Government commitment to ICT technology in healthcare was the Health Information Technology for Economic and Clinical Health Act (HITECH), which committed \$25.9 billion to promote and expand the adoption of health information technology (Blumenthal, 2010). Understanding how this, and other digital health technology has changed the American Healthcare Environment is critical to this Fellowship – both understanding what has worked well, and not so well.

### Aims

The aim of this Fellowship was to spend time in diverse leading digital health organisations in the United States, learning about how they have successfully adopted digital health interventions, but also the challenges they faced. The Fellowship Activity targets how the understanding developed could be applied back in the United Kingdom and disseminated as widely as possible.

### Objectives

- 1) Develop a detailed, hands-on understanding of the current USA digital healthcare environment, learning from patients, corporations clinicians and policy makers.
- 2) Learn about both the opportunities and challenges encountered in developing US patient centred digital health systems. What would they do differently if they started again?
- 3) Cultivate a transnational sustainable network of individuals who share these passions. Develop this network to share ideas, perspectives and collaborations. In sharing experiences there is enormous potential to benefit patients in the UK, US and worldwide.
- 4) Widely share learning in the UK at local, regional and national levels; engaging across patient groups, healthcare providers, academic institutions and healthcare industries.
- 5) Apply this to my own innovations and career. Achieve meaningful, measurable, personalised health process changes nationally. Do this at a critical time for the NHS as it faces enormous challenges and looks towards digital health interventions.

## Approach

The approach was to try to gain a holistic viewpoint of the adoption of digital healthcare within the USA, focusing particularly on diabetes as an exemplar disease, but remaining open to learning widely from all sources. The Fellowship was designed with the express purpose to understand digital healthcare adoption from the patient perspective, clinician perspective, academic researcher's perspective, policy-makers perspective and corporate perspective. Whilst such a holistic viewpoint represents something of a challenge to achieve in the short Fellowship Period, it should be noted that there were significant areas of overlap.

The Fellowship was designed as an explorative and reflective period rather than a formal research project however utilising skills developed during my Master's Degree I aimed to take a qualitative approach through structured interviews, focus groups and reflective practice. To encompass the above perspectives, visits were arranged in advance to The American Diabetes Association, Banner Health, Cerner Corporation, Harvard Medical School, Beth Israel Deaconess Medical Centre, and The Patient Centred Outcome & Research Institute. In addition during the Fellowship, I took advantage of opportunities that arose and visits were organised to the Boston Start-up Week, MassChallenge and Brigham Women's Hospital Innovation Team.

The results of semi-structured interviews, observations and meetings from these events was recorded contemporaneously through a journal written record and then thematically appraised to create the results, recommendations and dissemination plan described below.

# Thematic Observations & Reflections

The observations and reflections gained during the Fellowship can be grouped into 6 key thematic areas which are listed below, these will be explored individually and their linkages assessed.

- 1) Patient engagement in development of digital healthcare environments
- 2) Clinician engagement in development of digital health environments
- 3) Entrepreneurship & Innovation
- 4) Data in digital health environments
- 5) Training for Clinicians in Informatics
- 6) Dangers of wholesale adoption of USA practices into the UK

## 1) Patient engagement in development of digital healthcare environments

The Fellowship demonstrated that patient engagement in the development and delivery of digital healthcare environments is critical to success. In the United Kingdom the concept of patient engagement is certainly not new, and has been championed by the National Institute for Healthcare Research (NIHR, 2017). Existing UK patient engagement has however focused primarily on engagement with research processes, rather than engagement within the provision and innovation of routine healthcare services. In the USA, it is quite different, patient involvement is not such a requisite in research however they have explored and actively exploit the benefit of patient engagement in designing and developing services – for instance one hospital had a “The 200 Patients” user group where clinical ideas and services could be suggested, explored and developed.

The PCORI centre demonstrated how patient engagement can be achieved at varying levels within the delivery of a digital healthcare environment – from engagement with an individual patient’s care, to the structure of an organisation, to healthcare policy at regional or national levels and finally engagement during healthcare research.

Digital health development benefits from patient engagement, but also can facilitate it, and there were case studies demonstrating the potential success of engagement at different levels. For example, failure to attend clinic appointments in the United States represents a major issue there, as it does in the UK, however using digital technologies to engage patients with the booking process such that they can select a preferred time and date can reduce significantly the number of patients who fail to attend.

Central to encouraging greater patient engagement is how to effectively communicate with the patients you are looking to engage. An interesting case-study was that of developing text-message adherence alerts to patients with diabetes, however pilot work demonstrated difficulty in deciding what wording to use for these alerts, successful co-production with patients enabled a tailored wording to be created that would support, without patronising patients, and producing far superior results to the initial project pilot.

In looking to engage patients, for instance in booking their desired clinic times through and on-line portal, or co-producing SMS based reminders there was something of a tendency to

look towards treating patients as consumers, rather than 'unwell patients' seeking healthcare. The increasing drive for "mobile first" solutions to patient engagement was a good example. To some extent this supports engagement as creating a consumer like environment, such as might be found when internet shopping, enables patients to feel more comfortable. A number of electronic health record providers had historically pushed towards this "normal consumer experience" citing it as an aid to engagement. My time at Cerner however was eye-opening in that it illustrated that the assumed benefits of a normal consumer environment may not actually be so readily apparent. Typically when designing a digital service for consumers (e.g. an online shopping platform, or video on demand service) there is a desire from the designer to encourage consumers to both visit initially and subsequently frequently return to the digital service. Similarly when consumers visit these environments they want to be there often as part of their leisure time. In contrast healthcare is quite significantly different, patients would much rather not be ill, nor having to seek the advice of a healthcare profession, and the healthcare industry aims to reduce re-admissions and re-visits as much as possible. In engaging patients therefore there needs to be quite distinct process and culture compared to the 'normal consumer experience' approach.

The approach being developed by Cerner was therefore really quite refreshing and it focused around two key concepts. The first was designing digital environments to effectively engage patients through breaking healthcare down into "Condition, Venue & Experience" where the aim is to focus on the final patient experience, matched to what meet the patient's needs through their condition and their location of care. Overlaying this was the concept of emotional design, moving beyond simply digital solutions for clinical care but building emotion and empathy into healthcare processes. Successful emotional design they felt often relied on mere moments of care, however too successfully deliver those moments requires intensive pattern recognition based around patients individual conditions, venues and previous experiences.

The delivery of emotional design within a digital healthcare environment engages patients strongly in their care, however requires interaction beyond simply collection of clinical facts such as biochemistry or radiology results. It requires patients and clinicians to engage with emotionally and transparently. To achieve this requires trust. The corporate environment of healthcare within the USA has eroded trust in healthcare professionals and therefore it is interesting to reflect that in the UK, where doctors represent one of the most trusted professions (IPSOS, 2017) it may be easier to capitalise on the profound benefits of emotional digital design.

Whilst patient engagement and emotional design are truly exciting concepts, they are not without challenges. Patients are truly diverse, and successfully engaging with those patients requires engaging with diverse groups. The PCORI Centre highlighted that to date much of the patient engagement around developing digital software has been with white middle class Americans, rather than harder to reach populations. The American Diabetes Association have strong links to these harder to reach populations, who are often most in need of healthcare support. Some are unable to afford Insulin for themselves or their children, unable to afford testing strips to monitor their disease or unable to afford the healthy foods that would support their diabetes care. Similarly a particularly hard to reach population were the prison population who frequently come to The American Diabetes Association for support. These population groups often need written material from the American Diabetes Association and struggle to access digital support interventions, similarly they may struggle to have sufficient time to engage in the development of new digital environments, given much more pressing needs on their time. Time itself can be a challenge to patient engagement in the delivery of digital healthcare interventions. Digital technology is fast moving and the time for development (for

instance of a new app) can be very short before it is out-dated. The organisations I met therefore were trying to see how to engage patients most efficiently in development activities – something that still remains a major challenge.

Whilst undoubtedly there are challenges to patient engagement, successfully achieving it should not be ignored – it concisely summarised to me “that the most effective way to reduce care costs is to recruit patients as part of the care team.” Co-producing digital healthcare environments in the UK to achieve this is an opportunity that must not be missed!

## 2) Clinician engagement in development of digital health environments

The introduction to this report highlighted the challenges faced by healthcare professionals working in the UK, with staff shortages and burnout being key risks. In the United States the retention and engagement of physicians was seen as a major priority and many were surprised by working practices in the United Kingdom. Just as using the development of digital healthcare environments to engage patients, the development of such systems to engage physicians can bring significant benefits.

Electronic health record systems (EHR), which represents the digital interface clinicians use on a daily basis are becoming increasingly complex. There is enormous opportunity to use these systems to support and engage physicians. Many EHR's enable personalisation of their interfaces to enable clinicians to choose how information is presented to them as they log-in, and these interfaces can vary depending on the venue where the clinician is logging in from (e.g. on a ward, in a clinic or at home). Clinicians can personalise the system much more deeply including bespoke short-cuts and auto-filled forms, all designed to support the efficiency of their clinical work and the quality of care they provide. Such personalisation of digital systems was enormously popular with clinicians in the United States, however underpins a significant complexity of the clinical systems they are using. These systems take significant amounts of time to learn to use, both through initial training and ‘on-the-job-learning.’ High retention rates of physicians in US Hospitals gives the time necessary to develop an understanding of these systems. In the UK however junior clinicians for the first 9 years or more of their medical career rotate up to every 4 months, it would be impossible in this context for individual hospitals to engage such physicians fully in their electronic health records if they are moving on so frequently – this represent a major barrier to the introduction of diverse yet complex EHR's to the UK and should be treated with caution.

The EHR's are typically thought to be the digital portal that supports the care of patients, however in the USA they are also used to care for the clinicians. A good example of this was in a primary care context, where the EHR automatically tracks physicians' actions. It can highlight to physicians themselves and their supervisors when clinicians are working unsustainably long hours or logging on frequently in their leisure time to catch up on work. This can support more effective job planning, and avoid the risks of burnout. Similarly where clinicians are not using the system effectively, for instance not using popular short-cuts or pre-formatted forms the EHR can identify this and support physicians to work more efficiently. I was naturally concerned that this might come across as an instruction or “big-brother” concern amongst physicians, but quite the opposite, those I spoke to were very supportive of the systems they were using.

Whilst the digital environment in the United States seemed generally popular, undoubtedly there remains and has previously been elements of conflict. Discussing with both the providers and users of the EHR systems is became apparent that when introducing new digital systems,

Careful communication is absolutely critical. A case study is that the new systems enable “order-sets” to be created, whereby when an initial suspected diagnosis for a patient is entered, the EHR automatically suggests which investigations should be ordered, and with as little as a single click, all suggested investigations can be ordered and scheduled automatically. To many lay readers this would seem like an ideal system, and it significantly reduces the risk of important investigations being omitted or forgotten. To clinicians however it can be considered “standardisation” whereby their professional opinion is being over-ruled and patients are not treated as individuals but rather as simply diseases. In the USA however they have overcome this by careful communication with the physicians involved. Rather than terming this approach “standardisation,” it is termed “reducing variance” and it is very clearly highlighted that the time saved through this approach enables more time to be spent with the patients identifying and supporting their emotional needs.

Engaging physicians however went beyond simply careful wording and communication, the EHR systems were designed for each healthcare organisation with panels of clinicians. For example the reduction in variation process above requires that each diagnosed condition is matched to the set of investigations that are required and the urgency of those investigations established. This was achieved at the Banner Hospital Group through “Clinical Consensus Groups” where clinicians of different grades and specialties met to agree on these groupings and review the impact of any changes made. These were again popular with clinician engaging them directly in the digital systems.

The Banner Health Group went yet further still and rather than simply having panels of clinicians inputting into the EHR design, they invested significant time and resource into ensuring they could engage in the most effective manner – for many clinicians this involved providing the time and money for them to attend mini-MBA training courses in collaboration with the local University. Leadership was seen to be essential to the successful delivery of digital interventions within this organisation, and it was noted that often ICT professionals are seen as being based in separate (often off-site) buildings and rarely seen on the clinical floor. Leadership through visibility was a major drive in the USA and it was remarkable how well the organisations non-clinical ICT leadership knew the clinicians delivering care on the frontline. This was clearly an exemplar that needs to continue to develop in the United Kingdom.

### 3) Entrepreneurship & Innovation

The presence of multiple healthcare providers within individual US cities promotes competition. This is competition for attracting patients, recruiting staff members and listing insurers. Such competition drives innovation across care and increasingly digital innovation is at the forefront of such changes. Furthermore the corporate nature of healthcare within the United States has promoted a strong entrepreneurial ethos with individual healthcare organisations small and agile enough to reach out to entrepreneurs to create digital interventions and deliver digital health based change.

There is a strong innovation ethos within healthcare in the United Kingdom, this is driven through “Quality Improvement” methodologies and is distinctly different from the innovation and entrepreneurial approaches observed in the USA. In the UK every trainee is expected annually to complete a Quality Improvement project, this is expected to follow a set Quality Improvement methodology and is assessed as part of their annual competency reviews. Digital Health Innovation in the USA takes a significantly different approach, the projects developed are in no way “individual projects” but rather cross boundaries across healthcare

providers, digital health corporations, patient groups and public sector organisations. The players within the originating healthcare organisation are diverse and work in truly collaborative relationships. Digital Health innovation necessarily requires this approach, as a diverse range of skillsets are required including clinical, managerial, information technology and data science.

The selection of which processes to innovate was also important, in the United Kingdom innovation and quality improvement is often borne out of clinicians' frustrations with existing systems, however my experiences in the USA suggested that might not be the most effective approach to achieving change. The Pulse@MassChallenge Public Private Partnership is a remarkable organisation supported by the local equivalent of a City Council to encourage innovation. Here Healthcare organisations "reverse pitch" their needs to potential innovators and entrepreneurs who suggest innovations and apply for funding from the original healthcare organisation. The Pulse@MassChallenge then provide support to the selected teams to deliver their change effectively and efficiently. This approach identifies that in the challenging healthcare environment, to be truly successful digital innovations need to do more than just save money or improve care, but simultaneously need to address strategic challenges of importance to healthcare leadership teams. It should be noted that the Academic Health Science Networks in the United Kingdom have the potential to develop similar pathways and approaches as Pulse@MassChallenge and truly make the United Kingdom a leader in Digital Health Innovation.

It was notable in the USA that healthcare organisations were not afraid to "think big" in their approach to digital health innovation. This may be something that has for some time been lost in the NHS due to budget constraints or the fallout from the National Programme for Information Technology described above. A good example of this was the Remote Operations Systems at the Banner Hospital Group where Intensive Care Units across the country are linked by in-room video-conferencing to a Remote Operations "Bunker" in Phoenix, Arizona. Here Critical Care Outreach Nurse Practitioners and Intensive Care Physicians provide remote management advice to these locations supported by staff on-site. This enables rapid deployment of highly specialist nursing and medical expertise into centres that would not otherwise be able to benefit. The real-time management of acutely unwell patients, right through to managing cardiac-arrest situations remotely was remarkable to see and a clear demonstration of what can be achieved with digital health innovation.

The creation of digital health environments within US Healthcare systems itself provided an opportunity for innovation of wider healthcare processes. The implementation of electronic healthcare records can either be modelled against existing workflows or be used to create transformation. Modelling against existing systems reduces activation energy, reduces cost, and can be standardised across healthcare organisations, however potentially loses an enormous opportunity to improve care. Conversely care needs to be taken if a "big-bang" approach to digital health systems is adopted alongside a "big-bang" approach to process change. Such approaches can represent substantially more change than an organisation can handle and have serious repercussions. An alternative approach is that as digital systems are developed, the underlying processes they are applied to are assessed and modifications occur gradually in tandem. A good example of this is in the Banner Health Group where the introduction of digital systems identified delays in getting blood test results back and X-rays performed was delaying care. As a consequence the workflow was modified so that patients' bloods are taken at 4am and X-rays performed at 6am so that all information is available for the morning ward round. The opportunity to be discharged from hospital earlier is a sufficient



driver for patients to accept being woken so early in the morning and the cost savings of early discharges readily accommodate the costs of employing staff out of hours.

Undoubtedly the organisations visited suggest digital health innovation and entrepreneurship is becoming increasingly successful in the United States. In discussions with US practitioners as to how digital innovation can be promoted in the UK, there was an interesting insight that all too frequently the risk of doing nothing is an organisational risk, and yet the risk of doing something is a personal risk. Moving away from innovation as an individual project, but rather a collaborative effort has enormous potential to overcome this seeming paradox.

#### 4) Data in Digital Health Environments

Creating successful digital health environments is dependent on handling increasingly large quantities of complex data. The United Kingdom is in a very fortunate position to be able to utilise the data we already collect on patients, based on the fact that the NHS identifies each patient with a unique identifier (the NHS Number). This is an enormous benefit to healthcare in this country and should not be overlooked – it certainly created a significant amount of envy in the United States where patients may have unlinked records with different healthcare records with different providers across the state, country or even within the same city. Whilst the UK potentially has a head start in the effective use of healthcare data, there is a significant potential to learn collaboratively from approaches trialled in the USA.

Central to the effective use of data in healthcare, is the development of effective electronic health records. Electronic health records act as both the interface to clinical data repositories but also act as the broker between different clinical processes, and business systems. The HITECH Acts described above in the USA were critical to the implementation of USA systems and the Meaningful Use Certification further drives standards. The failure of the National Programme for ICT in the UK means we have not benefited from universal high quality effective EHR's, however significant progress is being made in the procurement and development of such systems.

Within the modern healthcare environment using data effectively requires the ability to manage both transitions of care, but also transitions of data. For instance the transition of data between different clinical systems, between different hospitals, or between primary and secondary care. Increasingly the boundaries of healthcare care are becoming more blurred, with patients wishing to utilise their data on third party devices or apps, or add their own data to the healthcare record. It is important to recognise therefore that as the UK proceeds to procure new Electronic Health Records that they are able to integrate and effectively transition healthcare data. I would argue that we need to be selecting or designing EHR's based on their ability to integrate with external apps and services, rather than their usefulness as comprehensive yet closed platforms. It is quite exciting to note that healthcare data systems in the USA have historically been provided by specialist companies due to the complexities of "HIPPA" confidentiality requirements, increasingly though non specialist digital companies such as Apple or Google were reported to be actively pursuing HIPPA Compliance, potentially dramatically changing the digital healthcare landscape of the future.

Increasing the storage and accessibility of data to patients and clinicians whilst transitioning this data across boundaries introduces significant cyber security concerns. My Fellowship travels coincided with the recent WannaCry Ransomware attack that compromised a number of NHS ICT systems nationally, and prompted far more to be shut down to prevent infection or attack (NAO, 2017). At Harvard Medical School, discussions on cyber security noted that

the typical refresh rate for medical computer equipment is very different to non-medical equipment and that unfortunately many ICT systems that were affected had failed to install security upgrade patches. In the USA due to the wider installation of these patches only 2 hospitals were affected. Nevertheless cyber security remains a major concern for USA healthcare networks, who were much more affected by the Petia Virus attack, not because their own systems were affected but because supplier systems often based in the Ukraine were profoundly impaired.

It was clear that US Healthcare Leadership now sees virus attacks as a part of life, and likely to increase in the future. The risk is substantial and if a ransomware attack was to encrypt patient information it would be impossible to identify if that patient information had been moved. Despite this, the suggestion was that a pervasive ransomware attack was only a matter of time and preparedness was key. Healthcare organisations need to consider not just how they would recover, but how they would recover safety critical systems quickly, and achieve speed that whilst protecting their back-up environments (which should those be compromised would prove catastrophic). The recent cyber-attacks however have increased the focus on cyber security both for healthcare leaders in the USA, but also training for clinicians on the ground and changes to working practices. It is important that the UK builds experience along with our USA counter-parts and I would argue there is significant education work to be done amongst clinicians. There was also an important concern that “Bring-your-device” to work policies, which can reduce the cost of implementing new digital environments, may add substantial cyber-security risks and whilst new EHR’s are being procured this should be taken into account.

Whilst there are substantial fears and concerns regarding the risks of increasing healthcare data availability and accessibility, the potential of such sources to benefit our understanding of health and disease is enormous. In particular risk-prediction modelling using large healthcare data sets is transforming understanding of disease and healthcare processes. Notable approaches that were being taken in the USA included automatic, continuous risk stratification to enable personalised care throughout a healthcare journey, rather than the “single point” risk stratification that is often applied in the UK. Furthermore using large data sets incorporating non-clinical data was vital, there is an underused treasure trove of so called “meta-data.” Meta-data is effectively data that sits around a data-point of initial interest; for instance a blood sugar value is a data point of interest, however meta data includes; who entered the value into the system, what time it was entered, how many times it was reviewed, who reviewed it and what actions did users take after reviewing the value. Incorporating meta-data into the ideas described above of emotional or quasi-emotional data collection has enormous research potential.

When considering the research potential of the health data that is increasing in quantity, quality and accessibility, it worth noting that our attitudes to research may need to change. Historically there has been an evidence based hierarchy of research evidence (Petrisor, 2007) with individual case studies at the bottom, followed by retrospective reviews of data a little higher, but the gold standard being randomised controlled trials (RCT’s). RCT’s are considered at the top of the pyramid for their ability to consider causality. This pyramidal structure however was conceived when there was far less data availability, where retrospective data was collected by hand from paper records, not the automated collection of enormous quantities of clinical data and meta-data across care boundaries and indeed beyond. Whilst retrospective data remains unable to identify causality such a powerful resource should not be overlooked and there is a need to reconsider the concept of a pyramid of importance, but rather the concept of different research approaches being optimised for different research questions, and true value coming when they are combined.

## 5) Training for Clinicians in Informatics

There are clear benefits to the delivery of innovative digital health environments and effective use of healthcare data. The observations discussed already however highlight that to achieve this is complex, requiring collaborations across industries, with patients, incorporating cyber security and meaningful innovation pathways. To meet these complex demands it is essential that there is a clinical workforce well versed in the language, skills and experience needed to manage such interventions and to facilitate patient co-production & engagement.

The USA have recognised clinical informatics as a dedicated healthcare speciality. Clinical informatics can be defined as the transformation of healthcare by analysing, designing, implementing and evaluating information and communication systems to improve patient care and access to care. Clinicians training in informatics in the USA spend roughly 30% of their time on clinical elements and 70% on informatics elements. At the Beth Israel Medical Centre there were 8 informatics fellows. There is an established career path with a defined syllabus, accrediting exams and then expectations that trainees will progress to Assistant Chief Medical Informatics Officers and subsequently Chief Medical Informatics Officers Roles. The Informatics training fellows are a truly valuable resource to the organisations that employ them, often acting as an in-house consulting team for digital health innovation and strategic delivery.

I was fortunate to spend time discussing Clinical Informatics Training with Professor Charles Safran, who is the Chief of Division at the Beth Israel Hospital & Harvard Medical School, as well as the immediate past president of the American Medical Informatics Association. His feeling was that establishing informatics as clinical speciality substantially changed perceptions regarding the role of informatics in healthcare both for trainees and informaticians themselves. During our discussions however it was clear that the training pathway adopted in the USA, might not be the most appropriate pathway to adopt in the UK given differences in clinical training internationally.

Within the UK there is no distinct training programme, although the role of the Chief Clinical Informatics Officer has been developed in a number of organisations, this is supported by “on-the-job” training such as the Royal College of Physicians Chief Clinical Informatics Officer Summer School (RCP, 2017). There is clearly a need to provide those already in post with training, however I would argue a pressing need to ensure training can be delivered in a structured way throughout existing training time for trainees wishing to take up CCIO or similar posts in the future. The Faculty of Clinical Informatics is an organisation being established within the United Kingdom that looks to be a Professional Membership Body for all clinical informatics professionals across the UK. It aims to publish professional standards, support re-validation, provide accreditation and promote professional leadership. It has just appointed its Founding Fellows, first members of staff and held its first meeting. There is enormous potential of this Faculty to support the delivery of a clear training pathway for clinical informatics trainees from medical school to consultant level. Enabling sustainable, rigorous and recognised informatics training within the UK workforce will be essential to the successful delivery of digital healthcare environments for our future patients and the USA provides an excellent example in this regard to learn from.

## 6) Dangers of wholesale adoption of USA practices into the UK

Throughout this Fellowship report it is evident that there is enormous potential to learn from innovative practice that certain centres in the USA have adopted. It must be warned however that the wholesale adoption of USA practices with regard to digital health innovation should not be taken without due assessment. A good example is given above, whereby the concept of rigorous informatics training and career pathways is invaluable, differences between existing USA & UK medical training mean that in practice a successful UK pathway would look really quite different.

The importance of rigorously assessing concepts and products developed in the United States before adopting similar in the UK goes beyond simply training. The Electronic Health Records, which are at the centre of many Digital Health interventions in the United States were built as a consequence of the HITECH Act and are certified against Meaningful Use Criteria. The HITECH Act and Meaningful Use Criteria were designed with the needs of the American Health System in mind, this is profoundly different to the UK Health System. Adopting too readily American EHR's would therefore mean wrongly adopting the criteria set out by American Policy Makers. Going beyond simply policy, USA healthcare EHR's are often based around "episodes of care" where a patient is admitted, treated and discharged rather than a care journey from birth to death as would be achievable in the United Kingdom. The reasoning behind this is that in the USA healthcare providers bill insurers based around the costs of each episode of care, and therefore the digital systems is created to reflect that. We would potentially look to create something quite different in the UK.

Whilst this is something of a cautionary note, it is actually potentially one of enormous optimism, giving the opportunity to create something in the UK that is truly bespoke for our healthcare services and future patients' needs. It would be foolish not to look and capitalise on the work done in the USA and internationally, alongside many of the successful products that have been developed in the USA however engaging UK patients, UK clinicians and UK trainees to assessing and adapting those products will be essential to the future delivery of care for our country.

## Summary Recommendations

1. Clinicians & academics must **engage patients meaningfully** in the development and delivery of digital health innovations and environments. Once created these digital innovations have the enormous potential to engage patients directly in their care, increasing quality of care and reducing costs of care. In achieving this we must be truly diverse in our engagement activity, being particularly careful to engage hard to reach groups.
2. There is incredible opportunity to build **emotional design** into our digital innovations and environments, this requires considerable transparency, however the trust that is placed in UK clinicians provides an excellent foundation.
3. As the healthcare environment becomes increasingly digital there will need to be **changes to how generalist and specialist clinicians are trained**, this will need to be addressed by bodies such as Health Education England responsible for training. Frequent rotational changes will prove a barrier to effectively and efficiently using electronic health record systems and further frustrate trainees.
4. **Clinical informatics training pathways and clinical informatics career models** are urgently needed, potentially developing recognition as distinct speciality within the UK Healthcare Environment. The Faculty of Clinical Informatics is potentially an ideal place to lead such work with the engagement of both trainees and patients.
5. There is a need for all clinicians to have an awareness of **cyber-security measures and contingency plans**, this can be developed during both undergraduate and postgraduate training. Future informatics trainees need to have a deeper understanding built into their training curricula, who may be well placed to lead in disseminating key messages to other trainees and clinicians.
6. Clinical informatics trainees and CCIO's need to ensure that **non-clinical ICT Leaders are better known** to their frontline clinical staff to support engagement and communication.
7. The concept of **Quality Improvement Projects**, completed by each individual trainee and assessed against fixed methodological criteria needs to be **re-evaluated** for a digital age, with a preference for collaborative working across care environments and industrial sectors.
8. Work is needed to **re-evaluate the research evidence hierarchy pyramid**, increasing the value of retrospective research that can capitalise on exceedingly large diverse data sources.
9. Explorative work is needed to consider the **value of meta-data** contained within NHS data sources to identify opportunities for improved care processes.
10. Clinicians & Academics should capitalise on the opportunity to develop a **bespoke UK digital healthcare environment** that is developed from learning internationally but focused specifically on the needs of our patients and future workforce. The systems within that environment must **excel at transferring data across boundaries including from non-healthcare sources**.

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