Digital health

Digital's role in health and care

A consultation in partnership with the Corsham Institute Thought Leadership Programme 2016

Report March 2016

This report was produced following a consultation at St George's House, as part of a programme of events in the Corsham Institute 2016 Thought Leadership Programme.

The report should be viewed in conjunction with reports from the series.

The consultations in the 2016 programme were:

- Digital health: Digital's role in health and care – March 2016
- Cyber and resilience: Digital's role in regaining resilience – April 2016
- Digital living: Getting the most out of digital society – May 2016
- Trust and ethics: Building a more informed digital society – June 2016

This programme hosted at St George's House was developed in partnership by Corsham Institute and RAND Europe.

St George's House is a place where people of influence and responsibility in every area of society can come together to explore and communicate their views and analysis of contemporary issues. The aim is to effect change for the better in society by nurturing wisdom through dialogue.

Corsham Institute (Ci) was formed in 2013 to explore the opportunities and benefits of the digital society, both social and economic, with particular focus on shaping a future where individuals can realise their potential in a highly connected world.

RAND Europe is a not-for-profit research institute whose mission is to help improve policy and decisionmaking through research and analysis. Lying on the spectrum between that of universities and consultancies, RAND Europe's work combines academic rigour with a professional, impact-oriented approach.

Key findings

Context

The UK's National Health Service (NHS) is reported to be at 'breaking point', with inadequate resources to manage the increasing levels of demand. Digital health and care extends the use of resources, through the use of technology, to improve the quality, affordability and accessibility of health and social care. This subject, the adoption of digital technologies in health systems, formed the basis of the discussion during the first session of the 2016 Thought Leadership programme.

Key discussion points

Is digital health going to disrupt existing health systems?

Digital health is not 're-inventing the wheel' for health systems. Many believe that digital health is a mechanism that can be integrated into current health systems, such as that of the UK, to deliver existing and new health and care services in a different, and hopefully more effective, manner.

What are the benefits associated with the adoption of digital health?

The general consensus of the group is that the current narrative focuses too heavily on the economic and cost benefits of digital health, and that more attention should be paid to the wider benefits for health services. One such benefit, which is regularly cited, is the opportunity for individuals to live more independent lives and manage their own healthcare through digital health technologies.

Is digital health the answer to problems with the NHS? What are the challenges?

Technology experts and health professionals are in agreement that digital health is not the 'silver bullet' for all the challenges facing health and care services, but it can definitely play an important role.

The group sees several challenges to the adoption and integration of digital health into health and care systems, which need to be addressed:

- The scale of the system. Scotland is cited as a good example of digital health being successfully integrated into health systems; its relatively small geographic size and population made this easier.
- The age of the system. Uptake can be slower where existing processes and systems are already in place.
- The public trust in digital technologies. There are concerns about privacy, organisations being able to access personal data and potential misuse of data.
- The attitude of healthcare professionals. Support needs to be given to healthcare professionals to adopt digital health technologies and understand their resistance to change.

Next steps

An increased take up of digital health will require the public and health and care professionals to buy into it. Further research is needed to understand the attitudes of health and care professionals towards digital health, and how policymakers, the NHS and governments can address any concerns. Clear information and a greater level of transparency need to be established on the use of personal data, so individuals feel reassured that they have control over when, how and to what level of detail it can be accessed.

At the same time, policymakers and funders need to think of innovative ways to implement digital health within national health systems, ways that do not entail a high cost or disrupt current healthcare systems. Lessons can be learned from countries such as Scotland, Denmark and Estonia, where digital health has been successfully integrated into their health systems.

Introduction

The Corsham Institute (Ci) Thought Leadership programme, which was designed and delivered in conjunction with RAND Europe, was established to explore the opportunities and challenges that digital technologies are creating within society. The programme seeks to bring together senior leaders from across academia, industry, government and non-government sectors in order to enable the emergence – through a combination of robust debate, knowledge sharing and personal reflection – of new thinking and ideas on how everyone in society can benefit from the use advantages that digital technologies can offer.

This report represents the main findings from the consultative event on digital health that was held at St George's House as part of the Ci Thought Leadership Programme 2016. Many consider digital health to be the next critical imperative in health and care if we are to meet increasing levels of demand with increasingly scarce resources and, at the same time, develop a more integrated approach to the way in which health and care services are delivered.

The primary objective set for the consultation was to consider:

'How we can support individuals to have a better quality of life by maximising the potential use of digital technologies in the delivery of health and care across society?'

Throughout our discussions, there was a real forward edge to our thinking. Drawing on a wealth of experience and evidence, participants focused on what changes might improve access to, and the quality of, health and care solutions. They also focussed on the processes needed to gain sufficient trust and acceptance from stakeholders to support the whole-system-level change which is required for digital health to play a greater role in our society.

This report is structured to reflect the focus and order of our discussions, under the following headings:

1. The background and context to digital health

2. The imperative for adopting digital health and care solutions

3. The alignment of objectives and understanding among different stakeholders, with a view to influencing adoption

4. The cultural environment and change infrastructure needed to foster the adoption of digital health and care systems

5. Conclusions and next steps[1]

From an independent standpoint, this report aims to capture the main ideas and views put forward during the consultation, with the understanding that not everybody involved in the discussions will necessarily have endorsed all of the proposals and viewpoints reported.

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[1] A précis of short- and long-term opportunities and barriers identified by participants is included as Appendix 1

As with all St George's House consultations, this report has been prepared under the 'Chatham House Rule'.[2] Any phrases that are italicised and in double quotation marks are direct, but unattributed, quotes from the discussions during the event.

Ci and RAND Europe would both like to extend their warm thanks to the participants who introduced each of our sessions and to all participants for stimulating and contributing to the high level of discussion that took place. A list of all participants is provided at the end of this report.

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[2] https://www.chathamhouse.org/about/chatham-house-rule?gclid=CKWqhM26yc8CFQ6MaQod5U0C-A

1. The background and context to digital health

Digital health and care is defined as an approach which extends the use of personal health, wellness and care resources through the use of technology to improve the quality and affordability of and access to health and social care.[3]

Throughout our discussions, we maintained a global perspective on health and care, drawing on evidence of successes and failures across the world and recognising that certain countries and communities have embraced digitally supported health and care in a much stronger way than others. For example, Denmark, Scotland, the USA, and some developing countries (where a lack of existing infrastructure has made the adoption of an integrated and digital approach more easily accepted) have already made considerable gains in terms of implementing whole-system change supported by the use of digital technologies.

Other countries, however, were highlighted as having had a more challenging set of circumstances and, as a result, have adopted digital health approaches less rapidly. Health and care services in England were regularly cited as examples of much slower adoption of digital health approaches, and it was generally recognised, that the scale and complexity of introducing wholesale change to a well-established health and care system can be particularly challenging.[4]

As contextual background, there are a number of common characteristics which participants identified as important factors to consider when introducing the level of whole-system change that digital health requires in well-established heath and care systems. These include:

- The challenge of transformational system change when an established system is in operation;
- The trend of an ageing population and the rapid increase of chronic conditions, requiring far more integration of health and care services;
- The challenges of introducing change to a stretched and, in places, failing system;
- The need to address issues of citizen trust in terms of access to, and use of, healthcare data, together with the associated issues of consent, confidentiality and privacy;
- The behavioural changes required from professionals and clinicians in adopting new ways of working, when they often feel under attack and are defensive;
- Increasing frustration among younger health and care professionals at the limited use of digital technology in terms of their working environment;

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[3] See Appendix 2: Definition and concept of digital health (reproduced from the Consultation Briefing Paper circulated in advance of the consultation).

[4] As a devolved nation, Scotland has embraced the use of digital technology as part of the greater integration of health and care services. There was a view that this integration of services has been achievable in part because of the size and discrete nature of Scotland, which has enabled the changes to be managed more effectively. This suggests there is an optimum size of population to support such a process.

- Limited and heavily scrutinized state funding; and

- Policymakers and regulators who operate in a system where the threshold for failure (of new ways of working) is very low.

Rather than taking a blank sheet as our starting point, we accepted that in many (developed) countries the adoption of digital technologies in health and care requires a complex and difficult change programme, with existing service delivery needing to continue at the same time as new approaches need to be developed. This is in sharp comparison to the experience of introducing digital health and care in developing countries, where a lack of pre-existing systems and processes has made digital health easier to implement.

Participants were also keen to highlight that digital technology should not be seen as a panacea that will address all of the challenges that are faced as we move towards a more integrated and efficient health and care system. The role of technology needs to be recognised as an essential driver for, and a component of, the transformational change that is needed, rather than the sole driver of change. Digital health is not something which can be considered as separate from health and care in general; rather, it can be a powerful agent that will help us deliver transformational change.

Summary of key points

- Implementing digital health technologies requires a whole-system change.

- Such transformational change is more difficult to implement where an established healthcare system is in place.

- There are significant challenges to be overcome in terms of behavioural change for health and care professionals.

- The adoption of digital technologies within an integrated health and care system will require the development of a new trust relationship with the citizen.

- Technology is not a panacea that will resolve all the issues involved in wholesale change, but it is a key driver and component of transformational change.

2. The imperative for adopting digital health and care solutions

As mentioned earlier, our starting assumption was that digital health and care extends the use of personal health, wellness and care resources through the use of technology to improve the quality of, affordability of and access to health and social care.

The phrase 'digital health', however, was felt by many not to be an appropriate description of what we are considering. It could be misconstrued as something 'separate' within the health and care system, while its true characteristic is in fact to be fully integrated within the health and care delivery system. It was suggested that more appropriate descriptions would be "*the delivery of health and care in a digital society*" or "*delivering health and care in modern society*".

There was also recognition that "*digital solutions are essential components for transformational integration, but until there is a shared definition of what integration means for stakeholders [in health and care] there is an unhelpful ambiguity. With the absence of the infrastructure for an integrated system, stakeholders are often distrustful*" of the application of digital solutions.

Stakeholders really need to see 'the big picture' to understand how digital technology can 'fit' within such an integrated system and how it can make change happen, before they will embrace the possibilities it can create.

Key imperatives

It was put forward that there are "*two key imperatives: economic and human*" supporting the integration of health and care services, and the adoption of digital technology.

"*Sustainability and rising financial costs are the first things to come to mind*" as an imperative to adopting digital approaches for health and care. However, while "*the growing cost of health and care, as we live longer and manage chronic disease more effectively*", was accepted by many as a key imperative for the adoption of digital technology, it was questioned whether "*concern over the continued rise in health and care costs is a 'red herring'*". It was pointed out, for instance, that food costs (as a percentage of total household income) have dropped dramatically over the past 40 years and that, while in the short term health and care costs are likely to rise steeply, they "*they could well plateau out and even fall in the future*".

It was suggested that a stronger reason for not recognising the imperative for change is the "*lack of political leadership at national and regional level*". Politicians are "*uncomfortable about taking forward the systemic change required*", not least because it is "*too long-term for them to reap the reward*" and because survival in a democratic system makes politicians inclined towards short-term success. Transformational change is bound to take longer than a five- year term, which makes politicians wary of embarking on such a journey.

This lack of political appetite to invest in "*transformative integration*" means that "*whole-system demonstrators*" are put in the category of 'too hard to tackle'. Instead, frustration grows as "*digital innovation remains nibbling around the edges*" and, more often than not, is "*neither scaled up or sustained.*" There is "*inertia in the current system, and despite the examples of systems that do work elsewhere in the world, they are not applied here*".

However, the continuing localism agenda[5] could provide a way in as, the policy is supporting Local Authorities to develop new models of local public service delivery and commissioning.

The discussion also identified the current system as one in which "*health is done to, and for people. The system encourages dependency and a lack of personal responsibility.*"[6] The current system was also described as providing "*dependent, institutionalised, episodic care, not fit for a future* in which *'commodities and interventions' are commissioned in isolation to one another*".

One question put forward was "*Who is going to bust the myth that it is too hard to change the status quo?*" It was strongly advocated that we need to "*shift the terms of debate with politicians. Language needs to be changed. It is not the cost of but investment in health, which is inextricably linked to social well-being and economic prosperity.*"

A powerful catalyst for change could be in the hands of individuals, and their self-interest in securing a better quality of life. The barrier to individuals driving forward a digitally enhanced system is lack of knowledge not only about how the health and care system operates, but also about the potential for research and new service that digital technology can support "*to create new treatments and solutions based on the integration of real-time data*". As one participant said, "*you don't know what you could have until you've got it*". The example was given of Internet supermarket shopping and home delivery. It is now commonplace, but fifteen years or so ago, little known. "*We know knowledge empowers*": the more knowledge individuals are given about health and care, and about the potential of digital health to combine data sets using real-time and real-life data to generate new ideas and medical advances, the more empowered individuals will be to demand change.

At the same time, we heard how the use of digital technology can fail to empower. A powerful example was given of a participant who was fitted with a device and told they would be monitored in real time. What they had not been told is "*who is reading the data [from the device], how often and what information is being gathered*". This approach illustrates how digital technology can continue to foster an unhealthy dependency, rather than empower individuals to feel part of the management of their own health and condition. Undoubtedly, priority needs to be given, through the use of digitally enabled research and solution design, "*to unlock individuals' knowledge so that they can make informed choices about their own health and care*".

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[5] 'For too long, central government has hoarded and concentrated power. Trying to improve people's lives by imposing decisions, setting targets and demanding inspections from Whitehall simply doesn't work. It creates bureaucracy. It leaves no room for adaptation to reflect local circumstances or innovation to deliver services more effectively and at lower cost. And it leaves people feeling 'done to' and imposed upon – the very opposite of the sense of participation and involvement on which a healthy democracy thrives.' Department for Communities and Local Government. 2011. *A Plain English Guide to the Localism Act*. London: Department for Communities and Local Government. As of 7 October 2016: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/5959/1896534.p

[6] It was reported, *"In one health authority around 70 per cent of the budget of £28m is spent on 28 families."* This was described as *"neither sustainable or, indeed, equitable".*

These discussions led us to consider that perhaps there is a greater imperative for digital health than the potential to reduce cost: "*a stronger imperative for digital health is that it can empower individuals and communities*". However, it was noted that we are still lacking a champion to support such empowerment in England. "*Without wrap-around guidance, communication and understanding of both digital information, aids and solutions and an integrated health and care system, individuals will remain in the dark*" about the possibilities.

It was also felt that leadership is not forthcoming from many professionals and clinicians in the health and care system because the risk of change is often seen as too great. Such health and care professional work in a system that has "*a very low threshold of tolerance for error. Potentially they have too much to lose. The transparency that digital health could provide could be uncomfortable for those working in a culture of blame and mistrust.*"

Moreover, it could be argued that given the age profile of those in authority in health and care, they are less likely to commission significant change using digital technologies because they are less familiar with its use and potential, compared with younger generations. Among some, there is a real concern about the "*shockwave that digitalisation has created in other sectors, such as retail and finance*" and a fear that introducing digital technologies could create enormous upheaval and risk to the health and care system, "*compromising or losing what it's got at the moment*" with respect to quality and range of service delivery.

Despite digital health having a clear and strong benefits case, the imperative for using digital technology to support integration of the health and care system is floundering because of a very conservative stance taken by those who have the power to authorise change. Digital has the potential to "*democratise the system*", but inertia, lack of vision and a low risk threshold are significant barriers in preventing this from happening.

Digital: A transforming agent

The Venn diagram below, drawn during the event, illustrates how digital technology could transform and support the development of a more integrated health and care system.
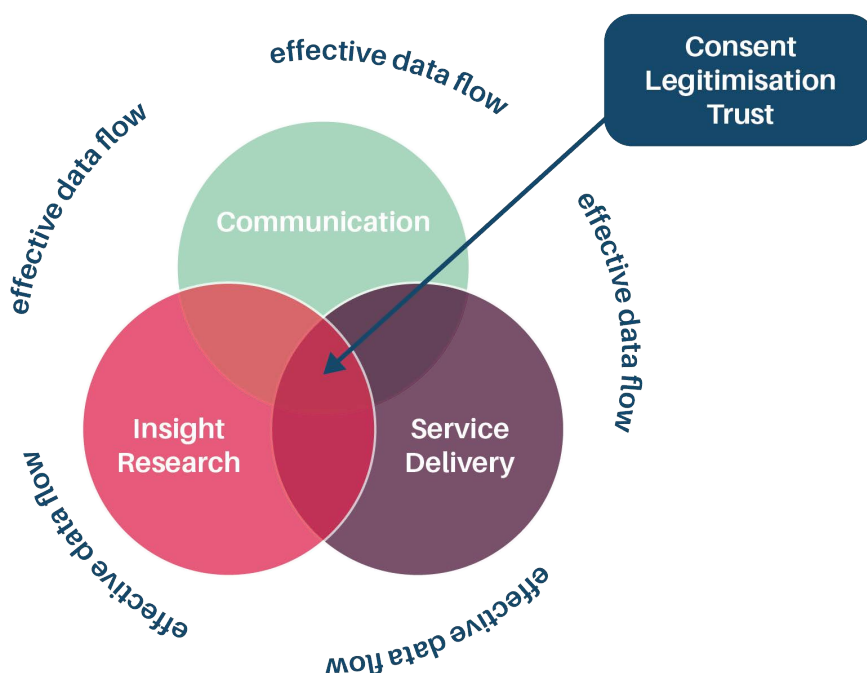
Communication, insight and research (through combining data sets) and service delivery are all interconnected and wrapped around by "*effective data flow*". At the core of and underpinning such a digitally enabled system is a framework of "*consent, legitimisation and trust*".

At the same time, it was recognised that digital technology has the capacity to ensure a more consistent process and workflow, increasing process governance, quality and safety through creating clearer gateways and greater reliability. This is not necessarily in terms of diagnosis, but by ensuring that once a diagnosis has been made there is a consistent approach and workflow, with stronger oversight of the different gateways in that process. While digital offers many process and governance advantages, it should also be recognised that there are risks associated with systematising a suboptimal process, and that the design of pathways needs to careful to ensure the latter does not occur.

Ownership of data

One of the greatest barriers to integration, and the 'smart' use of technology, was considered to be the 'ownership' of data. Institutions and regulators protect individuals' data so it cannot be shared. Yet it was convincingly argued that individuals "*want their data shared when it is in their own and community interests to do so*." What they need is to be able to trust that their data won't be used unscrupulously.

There was a view that institutions may want to limit access to data because it is in their interests both politically and professionally to do so. As one participant commented, "*blockers know what they're doing by withholding access to data*". It was agreed that transparency can be uncomfortable for some.

Individuals' presumed consent to share their data (subject to certain assurances) could redefine the relationship between themselves and the health and care professionals they interact with. It is an opportunity to empower individuals and enable greater personal involvement in the individual's own health and care. One participant advocated that individuals should be encouraged to view themselves as "*custodians of data*", rather than owners, and that it is in their own and the wider community interest to share it.

Keeping data in silos and individuals' not knowing what is kept, its accuracy, or the purpose for which it is used does not provide any sort of foundation for integration of health and care. Nor does this approach provide a platform for digital technology to "*transform the delivery of new medical advances through evidence-based research drawing on data at an individual level*".

With the availability of individual data, together with iterative processes for updating and validating it, the scope is immense. Inter-connectivity of such data flows would support a preventative agenda, as well as providing a sound evidence base for insights, research, communications and innovation in service delivery.

Summary of key points

- The title of this consultation ('Digital health: The way forward for heath and care?') is unhelpful in terms of describing the aspiration that is needed. Digital technologies have the capacity to support transformative change in health and care systems and to encourage greater integration; however, the introduction of digital technologies should not be the primary focus. A more appropriate title would have been 'The delivery of health and care in a digital or modern society'.

- The key imperatives for much greater adoption of digital technology were clearly identified as being economic; more robust and quicker research; better, more consistent health outcomes; systematic workflow; and process efficiencies.

- The current imperative is too focused on cost savings and does not provide sufficient focus on the wider research and health benefit outcomes of adopting digital technology.

- Digital technology offers process reliability and governance benefits which can support a more efficient and robust workflow, but this requires strong initial design.

- Wholesale change is uncomfortable for politicians, resulting in a lack of leadership in moving forward. The UK government's localism agenda may provide an opportunity for political leadership in developing a digitalised health and care approach at a significant scale.

- Health and care professionals and clinicians are often averse to leading change. They perceive the risk to be too great in a system that has a low tolerance of error. Younger health and care professionals, however, are frustrated by the slow rate of adoption of digital technologies to support the health and care system.

- There is a need to educate and empower individuals to demand and drive change. Society needs to have a greater understanding of the potential of digital technology in creating an integrated health and care system that will meet their needs.

- Digitalisation has the potential to be a transforming agent within a framework of consent, legitimisation and trust.

- Opening up access to personal data, with individuals' consent, is a priority in realising the potential of digitalisation and in empowering individuals.

3. The alignment of objectives and understanding among different stakeholders, with a view to influencing adoption

On the 'demand' side,[7] we identified three key stakeholder groups:

- Individuals/citizens
- Legislators, regulators and funders of health and care
- Professionals and clinicians working within the health and care sectors

In relation to change, these stakeholder groups were described as *"conservative"* (in reference to citizens), *"very conservative"* (in reference to legislators, regulators and funders) and *"ultra-conservative"* (in reference to professionals and clinicians working within the health and care sectors). Participants also felt that there is a lack of recognition among these stakeholders that "*a lot of technology is already with us".* What is missing is a 'joined up' approach in the application of technology as a way of driving forward and supporting an integrated system of health and care.

We considered the main insights for each stakeholder group separately.

Individuals

Some individuals are engaging in and using digital health and care solutions. But they are often not what might be considered 'engaged' users. They have "*limited or no understanding of what data is collected, what it is being used for and what might happen as a result of sharing it*". This was described as "*the black hole syndrome*", which can be acutely disempowering. Individuals could understandably be of the view that they are "*simply a cog in the system with no power or rights, and understandably question whether the data they are providing will really help them, or whether they are just a component.*"

The challenge for encouraging individuals to buy in to sharing their data and adopting the use of new, technology-driven ways of delivering health and care is to ensure that digital solutions are widely recognised by this group as empowering. This means finding ways of *"assuring individuals that they will retain their identity as an individual, and will not be seen simply as a node in the system".* This will require a new relationship and the building of trust between individuals and the providers of digital technology looking to innovate and offer technology solutions in the health and care system. Naturally, health and care professionals, regulators and legislators will also be of critical importance in affirming the new relationship and encouraging trust.

Legislators, regulators and funders of health and care

It was felt that legislators, regulators and funders of healthcare tend to be risk averse and are driven in great part by professional bodies and associations who set the standards. There is a *"regulatory desire for certainty, with the continuous concern about unintended consequences of change".* A fear that the downside of a change could be catastrophic, resulting in death, together with the resultant press coverage, only helps to reinforce a preference for the status quo. It was, however, recognised that attitudes towards risk will

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[7] We view the 'supply' side as being digital industry companies looking to innovate and apply technology solutions in the health and care system.

vary according to different cultures and the level of rigidity in the system. Countries with well-established healthcare systems have stronger resistance to change compared with those in the developing world, where there is less structure already in place.

Some pointed out that austerity can also drive innovation and new ways of doing things. *"The closer the NHS is to financial meltdown, the more likely there is to be support for the wholesale transformation of the delivery model."* Others felt that because of the risk aversion endemic among legislators, regulators and funders, there is bound to be *"a huge variation in the pace of adoption, and the trick will be to focus on areas that can act as vanguards to systemic change".*

Health and care clinicians and professionals

Unsurprisingly, given that they work in an environment where change is constantly introduced, it was felt that professionals and clinicians in health and care generally have the least appetite for change and innovation. Change is often viewed by these groups as a threat to or erosion of their roles and responsibilities, resulting in a potential loss of status. In addition, a common attitude among this group is that they *"lack the time to manage change on top of their workload and are sceptical of the value and benefits of change for either themselves or in providing a better service. They are quick to squash innovation because there is no evidence of its success."*

It was asserted that health professionals and clinicians often *"respond to incentives and need to understand what the benefits are for them"*. An illustration was given within the current system. Change is being driven in primary care with a range of incentives. This is not the case in secondary care, where there is *"no push happening because of a lack of incentives".* It was proposed that a way of influencing professionals to adopt digital solutions to health and care requirements could be through showing *"how it could really help them to work at the top of their licence, not the bottom"*. Others were not convinced. They pointed out that *"digitalisation will give much more transparency about how well you're performing your job"*. This type of transparency may not be universally welcome within the professions and may have unintended consequences in terms of reinforcing a risk-averse culture. Throughout this discussion it was noted, however, that professionals and clinicians display a discrepancy both by age and between their professional and personals lives. Many utilise digital technology and the benefits it offers in their personal lives, and yet resist its use in a more professional setting. These attitudes and drivers of resistance need to be explored in more detail.

Some felt that there hasn't been enough research to pinpoint the type of incentives that would encourage professionals and clinicians to be more receptive to adopting digital information and solutions. Looking at this stakeholder group as a whole, one participant observed, *"the incentives don't line up",* and asked, *"is there an approach that would help line them up?"* This question brought to the fore the wide breadth of individuals who are contained within this group, and the need to consider the barriers to and incentives for change at a more granular level.

To do this, we chose to explore the motivations and barriers within four subgroups among the many that are included within the category:

- GPs
- Hospital consultants
- Nurses
- Social workers

What was immediately striking was that the incentives to adopt digital technology are very different for different parts of the clinicians and professionals group. Common to all was the need to feel that "*they were master not slave*" to digitally enabled ways of working, and that "*those who are going to work with any type of digitalised approach need to be involved in its design. Every system you build incorporates values. What you record shouldn't be decided by default or assumption but by those who will depend on its efficacy.*"

Avoiding the pitfall of 'assumption' was illustrated when we considered nursing. Some felt that human comfort was always an essential part of effective nursing. Others disagreed. One person cited an example where anonymity is favoured in preference to a personal approach: in the USA, veterans often prefer to use telecommunication rather than personal interviews to disclose personal issues. This difference in the preferred and effective relationship between individuals and nurses highlights the care that needs to be exercised in not making 'blanket' assumptions. The guiding principle that should govern all new advances in working is that "*human and technological resources need to be used in the most appropriate way.*"

There needs to be "*continued dialogue between representatives of stakeholders about the deciding factors of what should and shouldn't be digitalised".* This dialogue can only begin when there is an acceptance by all stakeholders that "*there is learning to be done about what is needed to advance integrated health and care services and potential technological solutions*". The distrust between industry and healthcare professionals can be dispelled by a willingness to learn on both sides. As long as the belief held by both remains that the other doesn't understand, there is limited scope for progress.

Many felt that there was a major disconnect between healthcare and industry: "*healthcare professionals feel that they have to do everything*". Something is needed to shift this perception. It was suggested that a major step forward could be to "*commercialise the data held [by the NHS] and bring money back into the system".* This idea was predicated by an understanding that individuals would have the right to say how, and with whom, they were prepared to share their data. The big win could be that by "*democratising data, the health and care services would be able to begin to break down working in silos and stop doing things that don't work".*

A nuanced strategy

We recognised that we are "*not looking at an all or nothing strategy for integrating health and care using digital technology; much is already happening*". The key questions we wanted to tackle were "*how do we grow, how can it be done, and why is it not happening here in England compared with the other countries?*"

Looking internationally, successful adoption of digital solutions tends to utilise *"a push and pull strategy"* to move forward. In essence, this involves *"individuals seeing the benefits that digitalisation can bring [the pull], and clinicians and regulators willing to push forward changes in response to public demand."* In all cases this has involved raising public awareness and incentivising individuals to create 'the pull'. *"Citizens have a role in forcing change."* The challenge is, how do we empower the citizen so that they are aware of how health and services could change and to that they demand those changes of the system? What are the behavioural change levers that can be deployed?

The NHS was described as the third-largest employer in the world. High profile government digital projects have been *"consistently over budget, late and [have] failed to deliver"*. Consequently, confidence in digital solutions is low, and there is a lack of political or professional leadership in both adopting large-scale digital solutions or integrating health and care. In all, on an individual level, citizens often regard the scale and complexity of the barriers to change as insurmountable. However, collectively, if citizens are empowered with knowledge, their demands could create the pull required.

A starting point could be to *"put quality assurance more into the citizen's 'space'. Don't wait for the system"*. The idea would be to use digital technology *"to assure the agility of feedback from citizens"* using health and care services. This could help to *"pinpoint areas where change most needs to happen and inform and challenge the safety of the regulatory system"*.

Industry, too, has a role in creating 'pull'. In the USA, one of the most effective levers in getting professionals and clinicians to adopt digital technologies is 'fear of missing out' (FOMO). Companies promote their digital solutions to health and care providers on the basis that it will give them a competitive edge in both cost and/or quality. Providers that are not approached to adopt digital technology experience FOMO and are therefore more receptive to exploring new ways of working.

We heard that, in Denmark, administrators have worked with individuals to create the 'pull'. The use of digital technology to create integrated health and care has been taken forward incrementally over 20 years, with an active resistance to political influence and interference. Likewise, in Scotland, there is has been a political will to democratise health and care. Citizens are expected to share their personal data as foundation blocks on which to build a new, integrated health and care system.

Of course, there is a familiar response to change that has happened elsewhere: it's different there! They have a different population scale and/or demographic, health and care infrastructure, regulatory control, funding regime. These differences are all given as reasons for why approaches developed elsewhere can't happen here. In response to these 'reasons', we identified that utilisation of FOMO could yield dividends.

There are also 'push' levers within the system to consider. For example, *"by focusing on clinicians' imperatives that are non-negotiable for them, and looking at how digitalisation can help them meet these imperatives."* The strength of this lever for change is the *"outrage factor if these imperatives are not met"*.

Summary of key points

- We identified three key groups of stakeholders on the 'demand' side. All are conservative in their appetite for the adoption of digital technology for different reasons.

- Creating 'demand' for use of digital technologies in health and care services will require a differentiated approach for each stakeholder group.

- Individuals require greater knowledge about the potential of digital technology in an integrated health and care system, and they need to feel empowered by and able to trust such digital processes. Once individuals have a sense of empowerment, they will be well positioned to provide the 'pull' in terms of the demand for change.

- Legislators, funders and regulators of health and care need to be convinced that digital adoption can be achieved without major disruption to current delivery of health and care services and that it can be managed in a way that minimises risk of unintended outcomes.

- Health and care professionals should not be viewed as a single group of stakeholders, because incentives to adopt new technology and different ways of working appear to differ greatly by age and specialism within health and care. There is also a discrepancy between the use of digital technology in a 'personal' capacity compared with a more professional setting. The attitudes and potential incentives for professionals and clinicians need to be understood, mapped and aligned with each other to create greater coherence and maximum impact.

- A 'push and pull' strategy for adopting digitalisation is required. Both individuals and health and care professionals can create 'pull' in demand, while industry has a key role in providing the 'push'. 'Fear of missing out' (FOMO) has been used with significant success in other settings.

4. The cultural environment and change infrastructure needed to foster the adoption of digital health and care systems

Trust and ethics

Two issues that dominated our discussions throughout were those of trust and ethics. There was wide affirmation to the statement "*technology has disrupted our confidence in who we can and can't trust*." That is, until we considered who we were referring to when talking about 'our' confidence. It was pointed out that the majority of citizens under 40 years "*have chosen to share everything*" in the emerging digital world. Although the participants of the meeting were conscious of the dangers of sharing personal information, we accepted that this is now "*the reality we live in*."

It was argued that established ways of protecting data through legislation are obsolete. "*Data protection is shaped by institutions rather than citizens. We need to ask citizens to explain the parameters of what they wish to be recorded and shared. The worst of all worlds is for institutions to guard our privacy and create barriers that individuals would not put in place themselves.*"

There are also international anomalies in terms of the collection of data. In the UK, unlike in Germany, "*legislation is interpreted as requiring descriptors of how the data will be interrogated before consent is given for its collection*". This requirement "*blocks using the data for anything other than the originally stated intent: this prevents evidence-based organic growth*".

It was accepted that sharing personal information is part of everyday life. Citizens happily use loyalty cards in return for incentives, and so "*why should health data be treated differently?*" One participant also pointed out that "*our view of privacy is a Western view. Research is a global experience, so there needs to be a global regime that supersedes national and cultural attitudes to data sharing and privacy.*"

There was strong support that "*there should be an obligation on citizens to share some data about themselves, for their own benefit and that of communities*". Some went further and advocated that sanctions should be invoked on those who refuse to share their data. They argued that with empowerment also comes responsibility.

However, we recognised that, in order for citizens to feel confident about sharing their data, new types of protection need to be put into place. The policy of 'No Decision About Me Without Me'[8] should be adapted to include "*brought into the field, enhanced and used appropriately*".

In addition, the concept of 'dynamic consent'[9] was raised as one way in which maximum scope could be created in terms of data interrogation with the consent of individuals.

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[8] Department of Health. 2012. 'Liberating the NHS: No Decision about Me, without Me.' [UK Government consultation response]. London: Department of Health. As of 7 October 2016: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf

[9] Williams. H., K. Spencer, C. Sanders, D. Lund, E.A. Whitley, J. Kaye & W.G. Dixon. 2015. 'Dynamic Consent: A Possible Solution to Improve Patient Confidence and Trust in How Electronic Patient

Data use is controlled through the consent of the individual, who, at any point, can stop their data being used for a particular piece of research. Others pointed out that while it is intuitively appealing, 'dynamic consent' poses fundamental challenges to the research process and to researchers' ability to use evidence cumulatively and efficiently.

There was a consensus that "*consent, transparency of process and security are they key building blocks of trust*". However, at the heart of creating stronger trust is the need to change attitudes and to generate a shared commitment that data will be collected, stored and shared in a responsible manner.

Some felt we should go further in ensuring greater access to personal data: they advocated "*consent for sharing health and care data should be presumed*". In Scotland, public engagement has demonstrated that people assume this is already happening. A process of public dialogue held in Scotland suggested that people already assume their notes will be passed from, say, their GP to those responsible for specific areas of their treatment and care, and they were surprised when this did not happen automatically.

At the same time, we noted that, if it is the citizen's responsibility to provide raw data, digital health and care systems must demonstrate "*response ability in helping professionals to access the data they need amongst the 'noise' [which is also present]*". There is real risk of clinicians being swamped by the amount of data being collected and available, and not therefore being able to spot important information among the large volumes – with potentially catastrophic results. This risk will need to be removed if clinicians are to feel confident about using digitally collected data to inform their professional practice.

Linked to this is the issue of creating a central data repository to share existing data for the purposes of research and service development, and the potential issue or health warning: "*When you try and integrate data sets for health and care, there is often a misalignment of terminology and data fields. There is a need for a common lexicon and data set structures*", together with a system of verification by individuals on the accuracy of their personal data.

Trust covenant

Trust is therefore seen as crucial to the future adoption of digitally enabled health and care solutions. However, we concluded that a new, more robust framework is needed if such trust is to generated among the different stakeholders operating within the health and care landscape. As outlined in the previous section of this report, stakeholders all have different and in some cases competing requirements in terms of offering, storing and accessing personal data. The benefits of the sharing of personal health and care data have been clearly identified as:

- The ability to combine data sets and undertake better medical research using real-life data
- The opportunity to enhance knowledge sharing and medical understanding
- The ability to deliver more effective and efficient treatments
- The ability to deliver better medical outcomes

Records Are Used in Medical Research.' JMIR Medical Informatics. Published online 13 January. doi: 10.2196/medinform.3525

However, there remains a need to address the concerns of individuals and health and care professionals in terms of how data is collected, stored, shared and accessed.

The big idea emerging from these discussions was the concept of a new trust covenant, a vehicle which is capable of setting out the roles and responsibilities of all stakeholders involved in the offer, handling and management of personal health and care data. Such a covenant would need to be capable of "*embedding the values that drive the technology*" and providing everyone with a basis upon which higher levels of trust could be created.

The trust covenant would need to articulate the obligations on all parties, including industry, professionals and clinicians, as well as individuals, and would embody the reciprocity that is expected from different stakeholders, as well as the new relationship between them: "*individuals need to be willing to offer up personal information truthfully and openly and industry/clinicians need to be clear about who will use the data, what it will be used for, and what will result.*"

The purpose of a covenant would be to provide a clear explanation of what an individual can expect in terms of security and behaviour regarding access to, and use of, their personal data. This includes *"transparency of process"* and incorporating ideas such as those used in Denmark, where all citizens can see who is looking at and accessing their personal health and care data. It was stressed that the process of developing a new trust covenant would be as important to its success and to its content, and will require all stakeholder groups to be engaged in the process.

In terms of creating a new trust covenant, the following was strongly recommended by participants:

- **Learn from other sectors and global brands:** We need to *"understand what other industry sectors do, such as car manufacture and aeronautics, where the public's trust is critical to their success".* Companies such as Unilever, which have reputations as *"ethical and trustworthy",* may also provide useful insight.
- **Involve stakeholders in the design process:** The example given was of the process adopted by the Alaska Health Care Commission,[10] which highlights the benefits of involving citizens in the transformation of health and care services. Others felt that *"co-design with stakeholders is essential"* for this process. In Scotland, *"strong levels of trust have been achieved through low-key, local dialogues with citizens, to create the framework for an integrated health and care system and gain consent to access personal data".*
- **Review other covenants to identify best practice:** Draw on the experience of other covenants that have proved successful in the UK, such as the Armed Forces Covenant.[11]

It was agreed that a working group should be established to take this concept forward, and to explore how a trust covenant might be created with the buy-in of different stakeholder groups, including individual citizens.

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[10] Alaska Health Care Commission. 2012. *Transforming Health Care in Alaska.* As of 7 October 2016: dhss.alaska.gov/ahcc/Documens/2012Report1-15-13FINAL.pdf

[11] Veterans UK & Ministry of Defence. 2016. 'Armed Forces Covenant.' As of 7 October 2016: www.gov.uk/government/policies/armed-forces-covenant

Change Infrastructure

A number of countries and regions, including, Scotland, Denmark, Catalonia and the USA (particularly with the Veterans Association), were cited as exemplars of how an integrated health and care system can be created through the use of digital technology. We heard of the need to consider the development of a health and care infrastructure as a series of inter-related and hierarchical layers, in the form of 'rainbow diagram', as shown below.

regulators

complex service integration

new organisational arrangement teams

professional integration

core processes

enhanced social care drawing on technology mechanisms

Within each layer of the rainbow there are important issues to consider, including "*commissioning and contracting: who should do what*", how overlaps and gaps can be avoided in terms of service offering, and how integrated packages of health and care services can be organised around the individuals. Critical to success throughout is the flow of shared data that is meaningful to all actors in the system.

Where approaches differ is in terms of the business models that are used. There are two fundamentally different models: a federated alliance structure and a centralist approach.

The federated model brings together existing health and care services "*co-producing something that they're not sure what it will look like*" to meet a shared objective: integrated services that can be tailored to meet the needs of individuals. During the period of development, regulation remains vertical, with each service meeting its specific regulatory requirements. *"Only at the end game can clear, integrated regulation be put in place.*"

The centralist model requires a review of regulation which will govern each element of service delivery from the outset. On a national or regional level, health and care services are aligned to improve delivery and bring together management, funding and regulation. While this approach entails greater upheaval in the early stages in rewriting regulations to support the quality and delivery of an integrated service, it was argued that, once established, the model is "*easier to control and regulate*".

Summary of key points

- Current legislation to protect personal health and care data is considered obsolete and needs to be revised.
- Control over the use of data currently lies in the hands of institutions rather than with the individuals who have provided the data; this is both disempowering and out-dated practice.
- In other sectors, citizens are sharing data as part of their everyday living; this is particularly evident among the younger age segments of the population.

- Citizens should have a responsibility to share their data for both personal and societal gain; however, alongside such personal responsibility, the health and care sector needs to demonstrate 'response ability' for the data that is made available – meaning that any data given is accessed and analysed correctly to ensure clarity and accuracy of conclusions.

- While there should be an obligation on citizens to share data, there is also a need for greater trust to provide reassurance in terms of how data will be collected, stored, shared and accessed, and to create greater transparency in terms of the obligations and protections which are available to citizens.

- The concept of a new trust covenant was identified as a new vehicle that could be used to set out the roles and responsibilities of all stakeholders (including citizens) within the health and care landscape, and to enable greater levels of trust to evolve through a clear articulation of the obligations and ethical requirements for anyone either providing, storing or accessing personal health and care data.

- There are two models for digitally supported integration health and care: a federated alliance structure, which involves incremental alignment of services, and a centralist system, which brings together (and changes from the outset) funding, management and regulation to support the delivery of integrated services.

5. Conclusions and next steps

This consultation has identified that there is an economic as well as human imperative for the adoption of digital technology in the delivery of health and care and that, at the same time, there are clear societal benefits from the implementation of new, and potentially more integrated, approaches to health and care services.

It was concluded, however, that the economic benefits alone are not sufficiently strong to drive the levels of change needed, and that the human benefits need to be considered alongside the pure economics of implementing digital health and care solutions. These human benefits of digitally enabled health and care include:

- The ability to empower citizens to take greater control of their healthcare
- The opportunity to undertake more effective research and develop more effective treatments
- The design and implementation of more robust and efficient delivery processes
- Overall stronger health outcomes are in fact human outcomes should be considered

At the same time, two further challenges were identified as part of our discussions. First, how can the degree of whole-system change that is needed for digital technology to be brought in to the centre of health and care service delivery be brought about? Second, to what extent can digital technology be a catalyst for creating a more integrated approach to the delivery of health and care services? We concluded that these two challenges, while interrelated, should, in fact, be considered separately, because the second will hopefully evolve from the successful implementation of the first.

Three essential ingredients were identified to achieve the degree of whole-system change that will be needed to make digital technology a more central feature in health and care service delivery:

- *"Strong leadership,*
- *Clear policy direction, and*
- *A stubbornness to keep trying*!"

Given that the third ingredient is the one we recognised as being within our grasp, we considered levers that could help influence and strengthen the leadership available and clarify the policy direction. The following levers were identified as possible ways of influencing the future direction:

- Utilise the concept of FOMO (fear of missing out) to create stronger interest in trying new approaches.
- Create more 'safe harbours'.[12]
- Consider using direct citizen incentives. For example, in Belgium, citizens who agree to share their data are offered a rebate on their health contributions. Similarly, a broader example, outside digital health, is where mothers who agree to breastfeed their babies are also offered an additional two-week period of maternity leave.

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[12] A 'safe harbour' is a provision of a statute or a regulation that specifies that certain conduct will be deemed not to violate a given rule. It is usually found in connection with a vaguer, overall standard.

- Explore whether a "*way in could be as part of the localism agenda*" and focus on piloting digitally enabled health and care services in a discrete but sufficiently large region, such as one of the new devolved conurbations (e.g. the Greater Manchester Combined Authority).

- Provide information and assurance to health and care professionals that introducing digital technology is "*about providing a transformative capability, something which will augment and improve the current system, rather than create a separate vision of what is to be achieved through digital technology*".

- "*Get the language right. The same terms in health and care can mean different things.*" Using language that may be 'alien' to the speaker but known professionally by those whom the speaker is addressing is a powerful way of demonstrating empathy and of convincing the listeners that their concerns and viewpoints are understood.

- Continue and enhance communication with thought leaders across the health and care sectors. For example, at the next World Health Organization (WHO) meeting, there will be a discussion on integrated health and care endorsements.

At the end of the consultation, participants were invited to put forward specific ideas that they felt will address the issues identified and help to influence stakeholders in the adoption of digital technology in the delivery of health and care services. In outline, these included:

- Conduct additional work to explore what a trust covenant would include, and to design the process needed for its development.

- Look outside of the health and care sector for digital solutions and approaches. For example, NIKE have been researching the use of power tools to explore if there are lessons to be learned from power tool technology that could be adapted for use in their shoes to help reduce physiological impact.

- Find a safe way of reporting 'near misses' and 'mistakes'. The current system does not encourage such reporting, and therefore we are not able to learn as rapidly.

- Develop a more positive and forward-looking narrative for digital health, and create a counter-narrative which explores what is likely to happen if nothing changes.

- Introduce a 'failed well' prize to commend those who may have failed in achieving their objective but have learnt much in the process.

- Explore in-depth the concept of 'response ability' and what this will require in terms of data analytics, with a view to improving research-building capacities and responsibilities.

- Assess how well digital pilots and service models might be scaled up and replicated across the private and public sectors. It is important to ensure that solutions which might be effective on a small scale can cope with a larger-scale implementation associated with whole-system change.

- Discover more about the incentives which might encourage clinicians to change their attitudes and approaches to digital technology, through further research to understand "*what would make their lives easier, involving them in design, and producing 'mouth-watering' end user benefits*".

- Undertake research specifically among younger professionals and clinicians, to discover what their attitudes are and what might encourage them to adopt digital technology at a faster pace, including why "*younger clinicians are pushing smarter ways of learning using technology not tagged as digital health*".

- Explore further collaborative ways of working. For example, the WHO has established a research observatory, and there could be scope to add a digital technology element to that observatory.

- Identify and map thought leaders across the health and care sector/industry and consider who among them are most likely to influence future change. The WHO has already has established networks of leaders in health and care which could be utilised. Communities of interest could be grown from these networks and provide a platform for thought leadership conversations on specific aspects of digital technology with the health and care sector.

Recommendations

This consultation has generated considerable insight into the opportunities and challenges which are faced in terms of transforming the delivery of health and care services, and it has helped to identify a number of big ideas that can be taken forward as next steps from this discussion. These are briefly outlined below:

(i) **A trust covenant.** There is a clear need to redefine trust to meet the growing complexities of a digitally enabled world, and citizens need to feel confident in terms of how their personal health data will be collected, stored and accessed if digital technology is to feature more prominently in health and care. Many of the benefits which digital technology can deliver within health and care are only achievable if personal health and care data is accessible to different stakeholders. However, this requires a clear set of principles and standards if citizens are to feel confident that their data is protected and used appropriately. A new framework for data assurance is required, and the idea of a new trust covenant needs to be further explored and considered with stakeholders so that a new, robust framework can be created and adopted.

(ii) **Further research with health and care professionals.** Health and care professionals are clearly central to the successful implementation of new ways of working and the use of digital technology. To date there has been no programme of research to consider how this community views digital technology and its use in the delivery of health and care services. This lack of insight makes it difficult to understand what barriers exist, and it hinders the development of new communications strategies to raise awareness of the use and benefits of digital technologies in the delivery of health and care services among professionals and clinicians.

(iii) **A new knowledge-sharing platform.** Considerable knowledge and insight already exists around the successful introduction of digital technology in health and care services around the world. However, to date this knowledge has not been collected in one place, nor has a mechanism been created to enable the sharing of such knowledge among stakeholders. There is a need to consider the creation of a central (digital) repository where such knowledge and insight could sit and be available for anyone considering the introduction of digital technology into the health and care sector.

Insight should include evaluation data on what has worked, as well as strategic information about how challenges have been overcome and how the case for change has been made. Further work is needed on how and where such a repository should be created, as well the resources required and likely funding models; however, as a resource, this was considered important for driving forward the sharing of knowledge and insight.

Next steps

This consultation was one of four topics covered in the Corsham Institute 2016 Thought Leadership Programme investigating the opportunities and challenges created by digital technologies in society.

The other topics were:

- Cyber and resilience: Digital's role in regaining resilience
- Digital living: Getting the most out of digital society
- Trust and ethics: Building a more informed digital society

A key findings report[13] highlighting the overarching themes to emerge from across this year's programme, as well as the key findings from each of the four consultative events, is now available for download on the Corsham Institute website.

Ci and RAND Europe look forward to building on the findings from the 2016 Thought Leadership programme with a series of further Thought Leadership consultative events to be held during 2017 that will focus on:

- Education
- Open science
- Currency
- Civic engagement

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[13] Corsham Institute and RAND Europe. 2016. Thought Leadership 2016 Programme: Key Findings. RR-1771-CI Santa Monica, Calif.: RAND Corporation.

Participants

First Name	Surname	Position and organisation
Virginia	Ache	Executive Director, Research, Medical and Innovation, The Association of the British Pharmaceutical Industry
Claire	Alexander	Chief Operating Officer, Corsham Institute
Samuel	Beatson	Chairman, Smart Societies Institute
Joanna	Chataway	Director, Innovation, Health and Science, RAND Europe
George	Crooks	Medical Director, NHS 24 Scotland
Philip	Dawson	Chief Executive Officer, Assured Digital Group
Kevin	Dean	Managing Director, Smart Health Science Limited
Joan	Dzanowegis	Senior Scientist, eHealth, World Health Organization
Bruce	Finnamore	Chairman, My Life Digital Ltd
Nicholas	Goodwin	Chief Executive Officer, International Foundation for Integrated Care
Joanne	Harding	Director of Transformation, Shropshire Doctors Co-operative Ltd
Krysia	Hudek	Rapporteur
Alistair	Kent	Director, Genetic Alliance UK
Jake	Lebiecki	Director, Global Policy and International Public Affairs, Pfizer
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Hans	Pung	President, RAND Europe
Lester	Russell	Senior Director, Health & Life Sciences EMEA, Intel Corporation
Jeremy	Sanders	Director, Corsham Institute
Daniel	Sprague	Technical Director, Smart Societies Institute
Bayju	Thacker	Founder and Director, Doctor Care Anywhere
Jeffrey	Thomas	Director, Corsham Institute
Justin	Whatling	Vice President, Population Health Europe, Cerner Corporation
Petra	Wilson	Board Member, Digital Health & Care Institute, Scotland
Terry	Young	Professor of Health Care Systems, Brunel University London

Appendix 1: A précis of the short- and long-term opportunities and barriers identified by participants

SHORT TERM	
OPPORTUNITIES	**CHALLENGES**
• Alleviate clinical overload by using digital technologies to help manage the patient relationship. • Motivate professionals to change by demonstrating the benefits available from digital technologies in health and care. • Use digital marketing techniques and social media as a driver of culture change. • Communicate existing successes more effectively. • Develop open Application Programming Interface (API) standards for data integration with trusted third parties • Use NHS 'vanguard sites'[14] to test out a new trust covenant. • Build out and test the 'response ability' concept. • Study and gather evidence of what works (when and where), and share this information.	• Professional and managerial resistance • Lack of citizen (patient) incentives and buy-in • Resistance to change management among end users • Poor design of many legacy systems • Differences in education/awareness of different generations • Universal scale implementation • Cultural and political opposition • Financial environment • System inertia • Unwillingness of public sector to be associated with commercial organisations

LONG TERM	
OPPORTUNITIES	**CHALLENGES**
• Economic benefits • Leveraging of public–private partnerships • Trillion £ boost to the UK economy • Prediction of health issues and more effective development of services • Shift to a patient-centric culture and care • Personalised medicine • Greater understanding of treatment by patients due to exposure of data • Reduced travel costs for patients and staff • Whole-system care 'owned and shared' • Stronger user-led demand • Creation of evidence • Greater autonomy, responsibility and self-management • Access! Access! Access! More of it • More sustainable care systems • Greater collaboration/ • Multidisciplinarity in research • Elimination of inequity of care due to exclusion for reasons other than digital	• Making the underlying business case (Who pays?) • Clearly articulating the benefit/Return On Investment (ROI) to relevant parties • Clearly delinating the role of government vs the individual • Achieving policy coherence • Policy guidance and operational approaches • Inequality of access • Inability of civil service to assess market value of data efficiently • Change in power balance in patient–professional relationship • Transformation challenge • Vested interests • Review of national training curriculum and changes to include data sharing

[14] In January 2015, the NHS invited individual organisations and partnerships to apply to become 'vanguard sites' for the new care models programme, one of the first steps towards delivering the Five Year Forward View and supporting improvement and integration of services.

Appendix 2: A detailed description of the concept and utilisation of digital health, taken from the background paper to this consultation (pages 13–14)

Digital health and care extends the use of personal health, wellness and care resources through the use of technology to improve the quality, affordability and access to health and social care. As a concept and approach it can be characterised with the following features:

Prevention as well as treatment: digital health and care can scale knowledge sharing, advice giving, behaviour and symptom monitoring, potentially evaluation and diagnosis, as well as decision support. Digital Health could help avoid crises, and delver treatments outside traditional healthcare settings, with tighter feedback and faster escalation processes reducing harm and time to treat. It involves data collection, collaboration of systems and people, integrated communication and processes across health, social care – but also in retail, urban and home design, working environments and transport.

Information collection and sharing: digital health and care can involve information collected and shared by professionals (including clinical records, outcomes information, orders for tests and their results, prescriptions, monitoring data from medical devices, genomic data, phenotypic data etc.) and by citizens as healthy people, as carers, as patients (personal health data such as body measurements, data from home medical devices, fitness trackers, mobile phones, activity logs, diet records etc).

Offers multiple delivery channels: digital health and care can be divided into four main categories: personal health monitoring through medical devices; telemedicine (supporting a patient at a distance, usually with local clinical resource with or near the patient, via video or telephone links); telehealth (monitoring a patient's disease using remote, connected medical devices and video or telephone links); telecare & assistive living (supporting a person to be able to live safely at home through communications, devices supporting care and status monitoring technology).

The opportunity to extend knowledge and understanding: digital health and care requires information to be collected, analysed and acted upon – by the individual, their family, friends and neighbours, their supporting third-sector and statutory body/ private sector services, social care and clinical professionals - or their employer, school.

Integration with non-digital processes: digital health and care should not stand alone from traditional health & care processes, organisations and pathways, whether for prevention (of disease or crises) or treatment.

Strengthened by ubiquity: specific health monitoring devices as well as other everyday items can be connected, collecting data either directly or indirectly to reveal the status of a person's physical or mental health. Health and care processes must assume digital delivery can be available; otherwise duplicate systems of care are needed at huge cost.

Generates secondary uses based on derived information: patterns of behaviour can be used to nudge or incentivize healthy living activities and choices; consent will be key to maintaining trust from the citizen & patient.

Creates new sensing and feedback loops: the increase the number of data points, with tight feedback loops to decision-making, which can be used to create system 'awareness' – for safety, quality and process interventions.

Offers speed: real-time or near-real-time feedback of information, knowledge or advice to the individual, or to professionals, family members, local community, or commercial organisations (retailers, insurers); process interventions in real-time or near-real-time based on 'awareness' of monitoring systems with multiple complex events or metrics.

Thought Leadership 2016 programme delivered by:

Corsham Institute
http://corshaminstitute.org

Corsham Institute (Ci) is a not-for-profit organisation whose mission is to accelerate an inclusive digital society that is citizen centric and trusted. We do this by creating a physical and intellectual space to convene, connect, educate and innovate across sectors.

Ci was formed in 2013 to explore the opportunities and benefits of digital society, both social and economic, with particular focus on shaping a future where individuals can realise their potential in a highly connected world.

Our four key areas of work are promoting digital skills and education, driving research and thought leadership, powering enterprise and realising digital communities.

Our values are to work openly and collaboratively and to make a sustainable contribution to the economy for both national and commonwealth public good. We do this by imagineering, co-developing and sponsoring services for citizens and government where trust, ethics and informed consent come first.

RAND Europe
http://www.randeurope.org

RAND Europe is a not-for-profit organisation, whose mission is to help improve policy and decision-making through research and analysis.

Part of The RAND Corporation, we were founded in 1992 to provide quality impartial research and rigorous fact-based analysis, and to serve the policy needs of EU institutions, governments, charities, foundations, universities and the private sector. Our work lies between that of universities and consultancies, combining academic rigour with a professional, impact-oriented approach. In other words, we operate as a research-focused business, using a professional services model within the context of a public good mission.

We combine deep subject knowledge across many policy areas – including health, science, innovation, defence and security, transport, infrastructure, criminal justice, education, employment and social policy – with proven methodological expertise in evaluation, impact measurement and choice modelling.

St George's House
http://www.stgeorgeshouse.org

St George's House was founded in 1966 by HRH The Duke of Edinburgh and the then Dean of Windsor, Robin Woods, as a place where people of influence and responsibility can gather to grapple with significant issues facing contemporary society.

The House offers a safe physical and intellectual space, rooted in history but focused firmly on the future. The emphasis throughout our carefully-crafted consultations is on dialogue and discussion to encourage creative thinking, informed debate and sustained engagement. This is a place where participants can make a real contribution to society, where personal enrichment and social progress are mutually compatible, and where Wisdom is nurtured.