

Digital maturity of local health and social care systems

Summary report of a meeting held on 21 July 2017
by the Academy of Medical Sciences and Oxford
Academic Health Science Network.

Oxford Academic Health Science Network

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Opinions expressed in this report do not necessarily represent the views of all participants at the event, Oxford Academic Health Science Network, the Academy of Medical Sciences, or its Fellows.

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Executive summary

On 21 July 2017, the Academy, in partnership with Oxford Academic Health Science Network, held a FORUM roundtable to explore an assessment model for the digital maturity of local health and social care systems. The meeting convened representatives from across different sectors to explore the industry perspective on 'what good looks like' and the industry needs from digital infrastructure across health and social care. The following areas were identified as key to building a digitally mature system:

- Robust data management structures that facilitate data access and support collection of real-time, real world data, which is increasingly valuable to industry for both research and commercial activities.
- Coherence and interoperability of digital infrastructure across regions and for different stakeholders, with the ability to carry out data linkage and feed into higher level national databases where beneficial.
- Functionality to allow continued incorporation of a wide range of datasets, even beyond primary/secondary/tertiary and social care. This should recognise the growing role of data for services, research and product evaluation and the utility of a broader dataset beyond that on direct health outcomes.
- Establishing mechanisms for feedback into, and iteration of, the digital system to drive improvements in digital capabilities.
- Ensuring that the fundamental capacity and capability – including resource and skills required – is in place and available so that healthcare organisations are able to engage with industry for research. This was termed as 'readiness' for digital activities.
- Driving a culture change in healthcare organisations to recognise and promote the benefits of digital maturity. This can be facilitated, in part, by incentivising uptake and demonstrating the value of digital maturity for health and social care systems (whether for improving health, system efficiencies or cost savings). In addition, it was noted that some stakeholders may be less willing than others to share data for purposes other than direct care, such as social care, and so the value of doing so needs to be appropriately communicated.

Background

Advances in the development and use of digital technologies have the potential to transform research and development through to patient care and service delivery, ultimately translating into health improvements and system efficiencies. There is an increasing opportunity to maximise collection and use of real-time, 'real world' data to better inform processes across the entirety of the bench to bedside pathway, as recognised in the Accelerated Access Review.¹ However, the extent to which digital capabilities and technologies are currently utilised across the UK health and social care system is highly variable.

Therefore NHS England has commissioned the development of a model to assess place-based digital maturity of health and social care systems, looking to identify where digital technologies are used effectively to improve outcomes and experiences. The model is being developed by Oxford Academic Health Science Network (Oxford AHSN) in partnership with Greater Manchester AHSN and Arden and Greater East Midlands Commissioning Support Unit, and in discussion with key stakeholders.

'Place-based digital maturity' reflects the extent to which digital technologies are used across local health and care systems to improve outcomes including effectiveness, efficiency, safety and experience. An effective digital framework will support the service redesign goals in Sustainability and Transformation Plans, and help healthcare providers to identify, prioritise and address key gaps in their digital capabilities. Mike Denis, Director of Information Strategy, Oxford AHSN, described a need to move away from the current model designed around perceived capabilities in digital maturity to one designed around real world experience and outcomes, founded on three core components: experience of citizens and patients as they move through the system; experience of frontline clinicians; and the industry perspective and 'needs'.

Therefore the Academy, in partnership with the Oxford AHSN, held a FORUM roundtable to explore the industry perspective on the development of an assessment model, or 'toolkit', for digital maturity of local health and social care systems. This roundtable convened senior representatives from across multiple sectors including large pharma and biotech, financial and insurance services, data solutions companies and healthcare service providers, amongst others. For industry, it is important to understand how the proposed toolkit can help the delivery of the Life Sciences Industrial Strategy to advance the research agenda and enable more effective partnership working across different regions.² Participants discussed 'what good looks like' for digital maturity from the industry perspective, and the proposed toolkit for assessment.

¹ Accelerated Access Review (2016). www.gov.uk/government/uploads/system/uploads/attachment_data/file/565072/AAR_final.pdf

² Life Sciences Industrial Strategy: A report to Government from the life sciences sector. (2017).

www.gov.uk/government/uploads/system/uploads/attachment_data/file/640696/life-sciences-industrial-strategy.pdf

Discussion: Building a model to assess digital maturity

What does good look like?

Digital maturity within health systems can deliver a range of benefits – whether it is for the purpose of initiating and driving research or for better patient care, with application across both research and commercial aspects such as product and patient pathway evaluation. Such data can be used for a variety of research including monitoring the safety, efficacy and effectiveness of health interventions, epidemiological studies to investigate causes of disease and aspects of public health including disease surveillance, evaluation and/or audit of care quality and health services such as screening programmes, and identification of potential study participants.³ It was agreed that this should include an NHS ‘pull’ for industry engagement through a compelling research/data offering and so the model should reflect the **ability to conduct small test studies at pace and scale**, and must consider study delivery timelines. In addition, maturity should not only reflect quantity of data but also that such data is returning value.

Participants separated out two key considerations for digital maturity: what good looks like for NHS data collection and digital capabilities; and how this might look for datasets that the NHS does not own such as social care data. It was highlighted that ‘what good looks like’ across different stakeholders should be sufficiently detailed rather than becoming too generic, so that regions are adequately supported to deliver true value through digital infrastructure. For example, the ‘I statements’ being developed as part of the toolkit addressed high-level statements such as ‘I am able to access and assess real-world information on the use of innovations and associated outcomes’. However, further information is needed to support delivery of this including aspects such as types of data, data quality and standardisation, and the different outcomes that this might involve.

Data management

The retail and transport sectors were upheld as exemplars of digital maturity and it was agreed that in comparison, data management in healthcare is significantly lacking in ability to derive insight from data. Therefore data management should be considered a key part of a digitally mature system. **Real world data is increasingly important** with industry wanting to track uptake of interventions through the system including use, adherence and outcomes as part of the product evaluation process. Whereas this data is usually collected by industry for ongoing Phase IV evaluation of products, it was observed that NHS systems will be able to provide this data package themselves and so will require the associated skills for handling this type of data. In addition, it was noted that where healthcare professionals currently contribute significantly towards data collection, this could be made more efficient by patients collecting these data themselves. In particular, the value of patient reported outcomes for research was highlighted.

Coherence and shared infrastructure

Participants were in agreement on the importance of **digital coherence across regions**, particularly for industry engagement, and so debated the utility of a ‘place-based’ model. However, it was emphasised that ‘place-based’ is actually intended to reflect a positive shift away from individual, siloed systems to linked, multi-organisation environments integrating digital capabilities from across different stakeholders. A stepwise approach to achieving a

³ Academy of Medical Sciences (2011). *A new pathway for the regulation and governance of health research*. <https://acmedsci.ac.uk/file-download/35208-newpathw.pdf>

shared vision of national digitalisation of services was outlined, first moving away from organisational silos and then progressing to focus on integration across the entirety of the patient journey. It was agreed that the aim must be to ensure that this is viewed as one system by the patient whether across primary and secondary or social care. Genomics England was referenced as an exemplar for collating and linking data across regions with integration across multiple Genomic Medicine Centres.⁴

Therefore it was recognised that digital infrastructure needs to be shared, not only between organisations but also with key stakeholders such as patients themselves. The infrastructure must be meaningful to patients so that they are not just able to see their data but also able to interpret it themselves. Industry emphasised the value of **interoperability of platforms** between health and social care with potential for linking data across different systems; Estonia and Sweden were flagged as two illustrations of such data linkage. It was noted that for rare diseases with smaller patient populations, digital maturity would need to reflect the **ability to escalate local data upwards** into a larger national database to ensure value for industry through sufficiently robust data repositories which cover appropriately large populations with large enough 'signals'. In ensuring interoperability so that data can be merged and linked, it is essential to address the need for standardisation and consistency in data collection which is currently highly variable across the healthcare system.

Data flows and system feedback

One participant proposed that the model should also integrate data from employers, who have a significant impact on citizen health. This would move beyond focusing on direct health outcomes to **consider a broader definition of value** in relation to health, including social aspects such as employment and days off work. It was noted that this mirrors the shift in health technology assessment which is increasingly looking for demonstration of broader utility of interventions beyond efficacy. Recognising that this may not be practicable initially, participants proposed that first, the basic digital architecture is built across healthcare systems, **with functionality to then incorporate these wider datasets** that will be valuable for industry and others.⁵ Looking to other sectors for examples of integrating different datasets was again suggested, such as in retail.

Data access is essential for industry to initiate and support research, as well as to enable the other activities outlined above. AHSNs can play a central role in providing further clarity around data processes and access. In addition, it was agreed that **feedback on, and iteration of, systems** is an important component of digital maturity, enabling system improvements and demonstrating the tangible benefits of advances in digital maturity – termed as the '*tech UK*' approach – which will generate further buy-in for establishing digital capabilities. Participants discussed where accountability for this feedback lies and the need to establish skilled persons with responsibility for ensuring such iteration and budget flexibility to enact change.

'Readiness' of the system

Participants emphasised the importance of assessing the base 'readiness' of a system, as part of the AHSN's proposed 'readiness framework'. The Glasgow region and Wirral University Teaching Hospital NHS Foundation Trust were cited as two examples where investment in the base capacity and systems has been prioritised to enable development and use of digital technologies. It is essential that the **systems have the fundamental capacity to engage with industry**, and participants agreed several important aspects to consider based on past engagement:

- Ensuring basic IT capabilities to deliver digital services. An example was given where a hospital had built a valuable IT Staff Administration System, but had not trained staff to use it.

⁴ www.genomicsengland.co.uk/about-genomics-england/

⁵ These wider datasets could extend beyond social care such as education data pooled from schools.

- Availability of resource in IT departments. Concern was expressed that there is often limited capacity for innovative research as even with the necessary skills and financial support, IT departments may be too overwhelmed with 'business as usual' and addressing day-to-day issues that arise.
- Addressing the full costs of data projects within a proposal. It was agreed that sometimes a certain level of IT provision and capabilities may be assumed, but that this should be fully accounted for in a proposal and costing. Some participants proposed that only research programmes outlining full IT costs should be taken on.

These aspects fall within the need for a **wider culture change that addresses capacity, skills and resource issues**, including empowerment of clinicians working with data and fostering leadership so that digital capabilities are no longer viewed as an additional 'checkbox' exercise. To drive this, it is essential that there is a widespread understanding of the importance and role of research, and the value of partnership with industry to capitalise on such rich datasets. Finally, delegates cautioned against parachuting systems into areas, referencing the Cambridge University Hospitals NHS Trust Epic electronic patient record system which initially encountered difficulties in implementation as the Trust was not adequately prepared for the system.

Next steps for digital maturity

Driving improvements and culture change around digital maturity

Participants noted that a key challenge to promoting digital maturity is inertia of health and social care systems. Disruptive innovation often requires reorganisation of services, and this level of system change is particularly challenging in healthcare. Therefore it was suggested that change could be driven by asking the NHS to identify its key challenges, and **demonstrating the value of digital innovations** in addressing these challenges and reducing costs. A compelling case for the benefits and outcomes delivered by digital maturity is needed to demonstrate value across different stakeholders, and case studies such as those collected by Understanding Patient Data will be valuable in building this argument and incentivising implementation.⁶ It was observed that the Life Sciences Industrial Strategy proposes that capacity is only built into areas where it can drive the highest value for the NHS. To enable this, it was suggested that a higher proportion of the NHS budget may need to be initially focused in some Trusts to produce exemplars in data and research, with diffusion of the benefits more widely across the UK as well as stimulating other regions to put these capabilities in place. In addition, these case studies demonstrating the benefits and uses of health and social care data will help to address some of the wider concerns around data sharing including supporting patients and the public to make informed decisions around health data sharing through a better understanding of why, and how, their data might be used.

Finally, participants suggested that there is resistance in social care to contributing data for secondary uses such as research, whereas healthcare organisations are often more accepting of this. Therefore delegates supported that contribution of social care data should be mandated at a higher, national level. This might require a dialogue with all stakeholders to ensure that they understand where and how this data might be used and the value it delivers, such as use in epidemiological research or enhancing drug development processes. The need for more national directive compared with supporting regional autonomy in implementation were discussed, and it was agreed that this would somewhat depend on the incentives in the system for providing and sharing data. In addition, data from outside the NHS might require further legislation or a separate consent system to integrate, as well as extensive public engagement.

Implementation of the toolkit

⁶ <https://understandingpatientdata.org.uk/case-studies>

Overall, it was suggested that rather than a rigid, defined scoring system, a framework could be created to link certain delivery targets to the toolkit and allow a more tailored assessment for an individual organisation. The utility of a scoring mechanism for the digital maturity toolkit was debated. On the one hand, it was felt that scoring has negative connotations and could be used to penalise those at the lower end, as well as potentially creating the wrong incentives in the system to simply meet targets or acquire funding rather than a fostering a self-motivated drive and buy-in to improve capabilities. However, other participants argued that a score enables assessment of progress and provides useful targets for guiding organisations if it manages not to impart bias or unwanted competition (such as for funding). External partners could also use such scores to quickly assess if organisations are capable of meeting their needs. The HIMSS Electronic Medical Record (EMR) Adoption Model was upheld as a valuable measure of EMR maturity in healthcare organisations that has avoided driving the negative behaviours described, rather being used to generate understanding of how to reach the next 'level'.⁷

It is important to ensure that there is communication and feedback from the NHS on the toolkit, to ensure improvements and dissemination of where digital maturity strategies have not worked. In addition, when considering information governance, it was suggested that this should not only consider legislation but also the ethical aspect of data use. Participants agreed that Information governance and cyber security should be seen to facilitate access rather than unnecessarily restricting it.

Finally, participants explored how they might engage with the system, and industry emphasised the importance of clarity on the rules of engagement – that is, ensuring a consistent process of interaction and coherence across the system and also ensuring an initial willingness to engage from health and social care systems. It was felt that the AHSNs could provide a link for industry to engage with Sustainability and Transformation Plans (STPs) and an established route for feedback.

⁷ www.himss.eu/healthcare-providers/emram

Conclusion

There was general agreement on the value of establishing a more robust assessment model for digital maturity across local health and social care systems, and support for continued engagement with industry on the toolkit for assessment. It was recognised that measurement of digital maturity will be an ongoing process, and therefore the toolkit needs to be developed accordingly, with iteration and improvement of the assessment model as it becomes embedded. In addition, a forward-looking approach is key to ensure that health and social care systems are prepared for advances in digital technology and infrastructure. The industry view will be key to ensuring continued relevance of this model and so it is important to maintain ongoing engagement with the sector.

Annex I: Agenda

09.30 – 10.00	Registration, tea and coffee
10.00 – 10.05	Welcome Professor Gary Ford CBE FMedSci (chair), Chief Executive Officer, Oxford Academic Health Science Network
10.05 – 10.45	Overview of the project on digital maturity Mike Denis, Director of Information Strategy, Oxford Academic Health Science Network
10.45 – 12.30	What does a digitally mature local health and social care system look like? Mike Denis, Director of Information Strategy, Oxford Academic Health Science Network Discussion on the key aspects from each sector, and exemplars for digital maturity, followed by an overview of the proposed assessment tool: <ol style="list-style-type: none"> 1. What does good look like? Is this meaningful to industry? 2. The assessment tool: <ul style="list-style-type: none"> • I statements • Readiness Framework
12.30 – 13.00	Lunch
13.00 – 13.45	Building the model, our proposed approach Mike Denis, Director of Information Strategy, Oxford Academic Health Science Network Explanation of the options for the tools and methods, followed by discussion: <ul style="list-style-type: none"> • Our proposed approach • Should this be measured? • How should industry be involved?
13.45 – 14.00	Next steps Professor Gary Ford CBE FMedSci (chair), Chief Executive Officer, Oxford Academic Health Science Network
14.00	Close

Annex II: Participants list

Chair

Professor Gary Ford CBE FMedSci, Chief Executive Officer, Oxford Academic Health Science Network

Speakers

Mr Mike Denis, Director of Information Strategy, Oxford Academic Health Science Network

Delegates

Dr Natalie Banner, Policy Adviser, Wellcome Trust and Understanding Patient Data

Dr Angela Blake, Head of Health & Value, Pfizer

Mr Adam Collier, Director, RWES, NEMEA Region, QuintilesIMS

Professor Adrian Davis OBE, Director, AD Cave Solutions

Dr Massimo De Francesco, Senior Director, Head of Informatics, UCB

Dr Chris Exeter, Director, International Strategy Group, UnitedHealth Group

Mr Andreas Haimboeck-Tichy, Director, Healthcare and Life Sciences, IBM

Dr Shahid Hanif, Head of Health Data & Outcomes, Association of the British Pharmaceutical Industry

Mr Matthew Hodgson, Health Outcomes Consultant Manager, Sanofi

Dr Jonathan Jones, Senior Medical Director Europe North, Vertex

Professor Jonathan Knowles FMedSci, Executive Chairman, Immunocore

Mr Joseph Lu, Director - Longevity Science, Legal and General

Dr Andrew Roddam, VP & Head Real World Evidence and Epidemiology, GlaxoSmithKline

Mr Peter Taylor, NHS Outcomes Manager, Sanofi

Mr Tony Thomas, Healthcare Consultant, Janssen

Ms Doris-Ann Williams MBE, Chief Executive, British In Vitro Diagnostics Association

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