

Introduction to Digital Health For patients, the public and professionals

Adapted for the participants of the Oxford Patient and Public Involvement Training. Published 11.03.2020

This resource pack provides an overview of key concepts and links to informational sources about digital health. As part of an evolving training programme, the informational material is subject to refinement. Please let us know if you feel that this overview fact sheet could be improved or you would like to discuss digital health training. Please email Associate Professor Andy Gibson - andv.gibson@uwe.ac.uk; or John Kellas - john@thisequals.net.

What do people mean by 'Digital Health' and 'data'?

'Digital health' refers to the use of digital technologies for health and healthcare. Digital Health involves the use of information and communication technologies to help address the health problems and challenges faced by people. These technologies include both hardware and software solutions and services, including telemedicine, web-based analysis, email, mobile phones and applications, text messages, wearable devices, and clinic or remote monitoring sensors.

Digital health is a multi-disciplinary domain involving many stakeholders, including clinicians, researchers and scientists with a wide range of expertise in healthcare, engineering, social sciences, public health, health economics and data management

Generally, digital health is concerned with the development of interconnected health systems to improve the use of computational technologies, smart devices, computational analysis techniques, and communication media to promote health and wellbeing, and prevent, diagnose and treat illness. Digital Health is associated with **promises** of efficiency, effectiveness, joined-up services, modernisation (...disruption), overcoming barriers to access (social, geographical), autonomy (self-care, self-management), transparency.

The **challenges** of digital health include unintended consequences of how patients and staff see themselves, how staff and patients interact with each other, how staffs' work is organised as well as how patients' health is managed. Also, implementation of robust digital health solutions is hard, especially when there are multiple sources of complexity to navigate.

<u>Data</u> is recorded information. Information about patients is strictly regulated. 'Primary use' of patient data refers to the use of data for direct care; 'secondary uses' of data include health service improvement and health research. The UK currently has an opt out policy for storage and reuse of patient data.

Key national organisations / networks

- NHS X: 'a new unit driving forward the digital transformation of health and social care'
 link
- NHS Digital: 'national information and technology partner to the health and social care system using digital technology to transform the NHS and social care'- link
- Understanding patient data: focused on supporting conversations with the public, patients and healthcare professionals about the uses of health information for care link
- **Health Research Authority (HRA):** protecting and promoting the interests of patients and the public in health and social care research. <u>link</u>
- Information commissioner's office (ICO): The UK's independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals. link
- Academic Health science Network(s) (AHSNs): the only bodies that connect NHS and academic organisations, local authorities, the third sector and industry link

Active in Oxford

- The Hill (Academic Health Science Centre): Oxfordshire's digital health innovation catalyst
 bringing together patients, carers, nurses, doctors, healthcare professionals, designers,
 developers, researchers, business leaders and investors. link
- Digital Health Meetup group link (connected to 'Digital Health Oxford link)
- Oxford Academic Health Science Network link
- Oxford and Thames Valley ARC (Applied Research Collaborative) link
- Oxford BRC (Biomedical Research Centre) link
- Oxford Health BRC link
- Oxfordshire Care Summary Record link
- Thames Valley and Surrey LHCRE (Local Health and Care Record Exemplar): regional connected care initiative - <u>link</u>

Introductory videos

- **NHS X Apps and tools.** New digital apps and tools are empowering people to take control of their health and improving patient care.- <u>link</u>
- GP Connect a service that will allow GP practices and authorised clinical staff to share and view GP practice clinical information and data between IT systems, quickly and efficiently.- link
- Health and Social Care Network Health and Social Care Network (HSCN) provides a reliable, efficient and flexible way for health and care organisations to access and exchange electronic information. - Link
- World Health Organization <u>link</u>
- Emerging technologies at CES technology fair (Feb 2020) link
- Health Data Research UK Youtube channel <u>link</u>

Digital Health and Data slide deck presentations

- Digital health and uses of data workshop slides link
- Empowering people through digital health and care services (Indra Joshi NHS England) link
- The Human Challenges of Digital (James Freed, CIO, Health Education England, Programme Director, Building a Digital Ready Workforce) - link
- Empowering people through digital technology for health and care (Leanne Summers |
 Digital Strategy Delivery Lead | NHS England) link
- The possibilities and dangers of using patient data (Dr Natalie Banner, Understanding Patient Data Lead, Wellcome) - link
- How PHE Social Marketing is using digital innovation to change behaviour at scale (Alexia Clifford Deputy Director, Marketing Activation. Public Health England) - link

Additional national/international resources (key websites and policy docs)

- NHS X Artificial Intelligence: How to get it right (2019) link
- Code of Conduct for Data Driven Health and Care link
- Evidence standards framework for digital health (NICE) link
- NHS Digital Guideline Information Asset Management Policy link
- Local Authority Reuse of Public Sector information link
- Local Authority Transparency Code link
- Royal Academy of Engineering: Data sharing guidance and case studies link
- Exploring the unexpected effects of digital health tools link
- NHS Long term plan <u>link</u>
- Topol Review Digital Ready Workforce link
- The NHS constitution <u>link</u>
- NHS Transforming Digital Health site link
- 20 Pilot programme for Digital Inclusion link
- NHS Open Source <u>link</u>
- NHS Open Data <u>link</u>
- Watcheter review (2016): Making IT Work (in health and care): link
- EU General Data Protection Regulation <u>link</u>
- Tech UK link
- Nesta Digital Health ongoing project work <u>link</u>
- Digital Health publication <u>link</u>
- Open data lexicon link



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GLOSSARY	
Analytics	Discovery, interpretation, and communication of meaningful patterns in data.
Anonymised data	This is information from many people combined together, so that it would not be possible to identify an individual from the data. It may be presented as general trends or statistics.
Artificial Intelligence	An area of computer science which involves the creation of machines that work and react like humans.
Business Intelligence	A set of strategies, processes, applications, data, technologies and technical architectures which are used by organisations to support the collection, <u>analysis</u> , presentation and dissemination of information.
Caldicott Principles	General rules that health and social care organisations should use when reviewing their use of patient information.
Chief Clinical Information Officer	Responsible for developing clinical strategy in overseeing the digital technology being implemented in the Trust.
Chief Information Officer	Job title commonly given to the most senior executive in an organisation responsible for the information technology and computer systems that support organisational goals.
Connecting Care	Local electronic patient record that allows health and social care professionals directly involved in a patient's care, to share a summary of their medical record.
Data Dictionary	A set of information describing the contents, format, and structure of a database and the relationship between its elements, used to control access to and manipulation of the database.
Definition of data	Facts and statistics collected together for reference or analysis.
De-personalised data	Information that does not identify an individual, because identifiers have been removed or encrypted. However, the information is still about an individual person and so needs to be handled with care. It might, in theory, be possible to re-identify the individual if the data was not adequately protected, for example if it was combined with different sources of information.
Hacking	Can mean unauthorized intrusion into a computer or a network or altering something to accomplish a goal that differs from the original purpose.



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Health informatics	The capture, communication and use of data to support health professionals.
Health Research Authority	An organisation established to promote and protect the interests of patients, streamline regulation and promote transparency in health and social care research.
Information Asset Register	A way to help organisations understand and manage the information they hold.
Information Commissioners Office	The UK's independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals.
Linked data	An approach to publishing and sharing information that gives a unique reference to each item in the data in a way that means it can be connected with other information.
Local Digital Roadmap	Regional plans for how health and social care organisations will achieve the ambition of operating Paper-free at the Point of Care by 2020.
Malware	Software which is specifically designed to disrupt, damage, or gain authorized access to a computer system.
Open data	Data that can be freely used, re-used and redistributed by anyone - subject only, at most, to the requirement to attribute and share alike.
Open Source Software	A system, programme or other product that people can modify and share because its design is publicly accessible.
Primary use of data	Using data for individual care.
Secondary use of data	Using data for Improving health, care and services through research and planning.
Senior Information Risk Owner	Owns an organisation's overall information risk policy and risk assessment process ensuring we have a robust incident reporting process for information risks.
Understanding Patient Data	A Wellcome Trust led initiative which aims to support discussions with the public, patients and healthcare professionals about uses of health and care data.