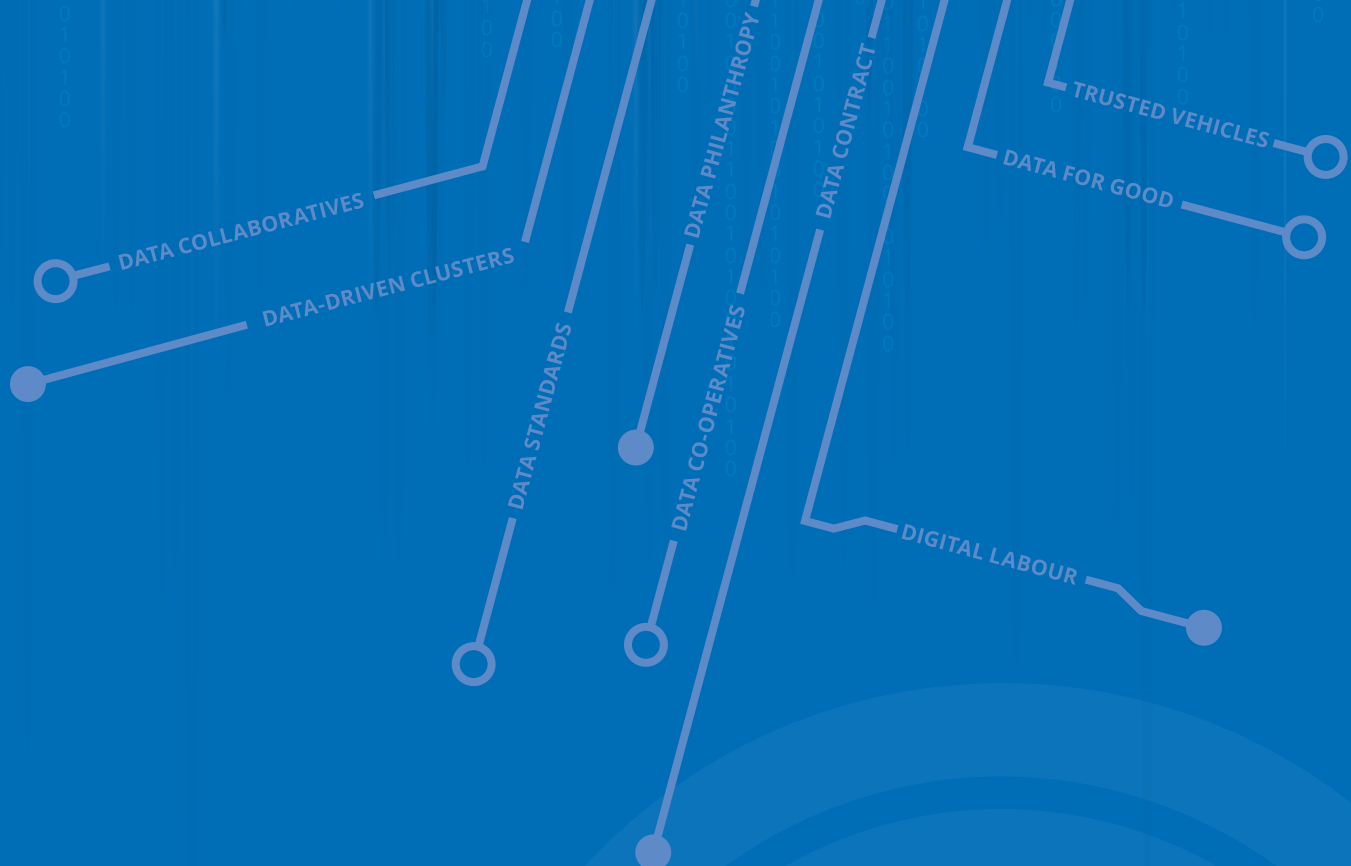


FUTURE
CARE
CAPITAL

Data
ethics



Intelligent sharing:

unleashing the potential of health and care data in the UK to transform outcomes

About us

Future Care Capital is a national charity committed to engaging, educating and involving all generations in the development and delivery of unified health and care provision. Beginning life as the National Nursery Examination Board in 1945, the charity has evolved throughout its 70-year history and we continue to have Her Majesty the Queen as our Royal Patron. We are a policy and advocacy charity that is also setting up a social impact investment fund.

Our core charitable objects focus on delivering improvements for those in receipt of care. We work to achieve better outcomes for those in receipt of care by advocating for and delivering a step-change in health and care. Our work also covers the education and training of health and care professionals, including those in allied professions. To do this, we have set out an overarching positive vision for the health and care system in 2030. We want to see a new agreement between the state and public, which sets out a commitment to support the health and care needs of everyone throughout their life. This could be achieved through a Care Covenant, which we are developing, to set out a renewed strategic ambition to deliver the best possible outcomes for the public, that are socially and organisationally borderless.

More information about us can be found via our website:

<https://futurecarecapital.org.uk/>

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Foreword

With the increasing influence of 'big data' in all areas of life, there has been a rush to consider how to best benefit from it. This has led to speculation on the value of big data, and in some fields to a kind of data arms race where firms collect large amounts of data speculatively, in hopes that it might be of great future value.

This 'big data gold rush' has led public sector entities to enter into agreements with companies to process data, without adequate long-term thinking about how to ensure that not only short term benefits to using data return to the public, but that long term governance is appropriate. Datasets often end up in proprietary format, or in repositories that are not easily accessible. This data may then be used to train Artificial Intelligence (AI) that remain the property of companies. The power and influence of digital information monopolies thus increases, and it becomes more difficult to hold these to account when public data has been shared or donated but cannot be recuperated.

It is therefore refreshing to read this report, which clearly considers the long-term social benefit of big data, but also advances concrete measures to address issues of governance and ethics. In particular, the movement to support 'data philanthropy' as a cultural movement is particularly interesting. Existing frameworks like 'gift aid' could be applied to data sharing, providing frameworks for public engagement. However, an even more significant contribution could come through the creation of collaboration tools like open APIs for data sharing, and the development of ethical and governance strategies that sustain public trust and support for the NHS, as well as allow data to generate long-term value. As international research demonstrates, trust in the institutions that steward our data is more important than technological feasibility of using data right now – and creating trustworthy ways of holding data can make them available for a variety of future uses.

Experimenting with the development of different governance forms including data cooperatives, data communities and data collaboratives will enhance the ability of data's benefits to be brought to the country as a whole while still retaining the potential for commercial re-use in particular cases.

Bringing to the public a National Health and Care Data Donor Bank and allowing Artificial Intelligence capabilities to be developed and employed for public benefit and with transparent governance would mark a significant step forward for the UK, building on the past operations of the UK Biobank. Planning carefully for the creation of data-based resources so that public trust can be maintained is of utmost importance, and this report suggests some creative and insightful ways forward.

Beyond the 'big data gold rush', health and social care data provide enormous resources that can be stewarded and managed to provide the greatest value for all.

Dr Alison Powell

Programme Director, Data & Society Programme

Department of Media and Communications

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June 28, 2017

In brief – our key recommendations

National context: enabling responsible data sharing and building public trust

- Empower the Information Commissioner's Office to tackle data-driven exploitation and discrimination to build public trust.
- Introduce new sanctions to tackle the re-identification of data subjects from anonymous data sets, where consent, legitimate interest or contract is lacking.
- Invest in technologies to positively impact social care services and task the Care Quality Commission with championing the digitisation agenda, including planning for a data-driven inspection regime to improve standards.
- Streamline information governance modelling for Integrated Digital Care Records to expedite data sharing at the local level across health and care organisations.
- Increase investment and support for data controllers to unleash health and care data in a standard and anonymised form, where there is a value in secondary analysis by third parties.
- Expand the opportunity for data subjects to contribute health and care data to integrated records and other data sharing initiatives.

Pushing the boundaries: creating a culture of data philanthropy in a digital Britain

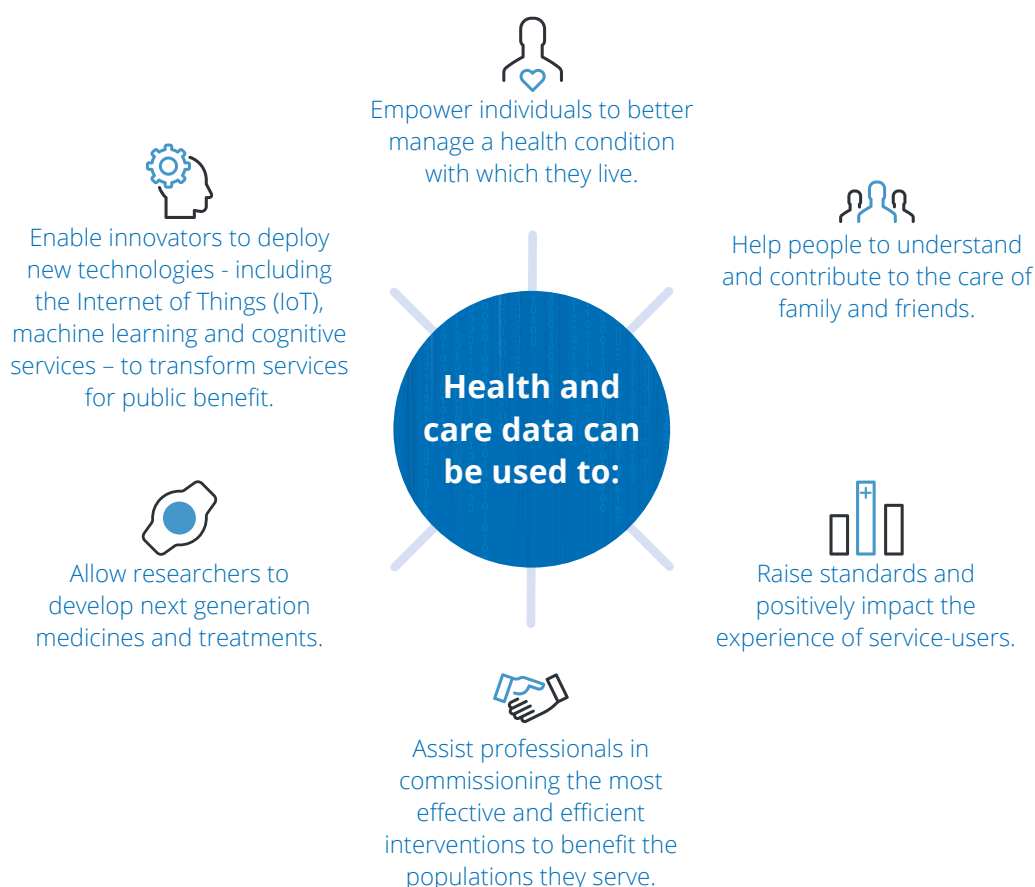
- Establish a new National Health and Care Data Donor Bank, to coordinate data from the public and help improve the alignment of research to clinical need.
- The Ministers for Digital Economy and the Third Sector, working in conjunction with the Open Data Institute and NHS Digital, business and the third sector, should develop a suite of tools to stimulate 'data philanthropy' in the UK.
- Introduce a national Government programme to pilot the development of new health and care Data Cooperatives, Data Communities and Data Collaboratives to promote a culture of data philanthropy through the demonstration of tangible health and care outcomes delivered by a range of 'trusted vehicles'.
- The Government should explore the development of a 'gift aid' style scheme for health and care data, encouraging individuals to make health and care data donations to better enable research and innovation.

Establishing a health and care data advantage: investing in skills, business and infrastructure

- Establish data-driven business clusters for new health and care enterprises backed by Government. These clusters should also offer skills training to help prepare the future workforce for the increase in demand for data-related job opportunities.
- The Government should explore the scope to introduce tax and other incentives for businesses prepared to enter into Joint Ventures with a National Health and Care Data Donor Bank to help place future services on an affordable footing.
- The new Chief Data Officer and National Data Guardian should be tasked by Government with contributing to the development of a strengthened and/or dedicated 'data privacy shield' for health and care data, applicable to any future trade negotiations outside Europe, to safeguard the public whilst improving the UK's competitiveness.
- The Government should support the establishment of 'Living Labs' to encourage innovators and entrepreneurs to develop new technologies to transform health and care outcomes. A 'Living Lab' could comprise of private dwellings, a residential care home and/or connected streets, and would involve the deployment of technologies associated with the Internet-of-Things.

Introduction

Future Care Capital seeks a step-change in health and care and believes that a concerted effort to unleash the potential of health and care data could significantly improve outcomes for everyone in our society.



This report explores how the United Kingdom (UK) might support data-driven research and innovation to transform health and care. It also makes plain that, to achieve this, the UK needs to blaze a trail in the development of 'data ethics' to proactively build trust whilst safeguarding individuals.

Context

Data is often referred to as the 'new oil' - the 21st century raw material which, when hitched to algorithmic refinement, may be mined for insight and value - and 'data flows' are said to have exerted a greater impact upon global growth than traditional goods flows in recent years (Manyika et al, 2016). Small wonder, then, that governments around the world are endeavouring to strike a balance between individual privacy rights and protections on the one hand, and organisational permissions to facilitate the creation of social, economic and environmental value from broad-ranging data on the other: 'data rights' are now of critical importance courtesy of technological advancements.

The tension between the two is particularly evident where health and care data in the UK is concerned. Individuals are broadly content with anonymised data from their medical records being used for public benefit but are, understandably, anxious about the implications of the most intimate aspects of their lives being hacked or, else, shared without their knowledge

or consent. This follows high profile data breaches and privacy incursions as per the recent case of the Royal Free NHS Foundation Trust and Google DeepMind (BBC, 2017b), but it centres upon concerns surrounding the potential for commercial exploitation or discrimination by, for example, pharmaceutical, marketing and insurance companies¹.

Meanwhile, proponents of data-driven innovation in health and care argue that health and care data harbours the potential to transform services and outcomes, and will deliver significant economic benefits for those who pursue, encourage and facilitate value creation from it over the coming decade. Hence, out of the 50 biggest UK Venture Capital investment deals in 2016, health technology start-ups formed 20%, whilst equity deal-flow to start-ups deploying machine learning to solve healthcare related challenges is projected to reach record levels by the end of 2017.

In the European Union (EU), this tension has resulted in the development of the General Data Protection Regulation (GDPR) which will come into force in 2018. The GDPR is designed to strengthen the rights of individuals to control access to and use of their personal data whilst reiterating the principle of ‘free movement of data’ in dealings between Member States, but concern surrounding data rights has already impacted the domestic health and care landscape.

Successive governments have recognised the huge potential in health and care data and have been active in promoting a range of related initiatives - ranging from the UK Biobank to Integrated Digital Care Records. Whilst good progress has been made, the Government decided to discontinue its flagship NHS data sharing programme - care.data – in 2016 (Temperton, 2016). It had, until then, aimed to create unrivalled access to pseudonymised health and care data amassed by GPs to reap associated benefits in research and innovation, but was forced to discontinue the programme faced with mounting public pressure and professional concern about ethics and security issues.

The potential for health and care data to be transformative remains, and there is growing concern that opportunities to improve the use of health and care data in peoples’ interests are being missed. It is therefore encouraging that the Government commissioned an independent report about this important issue, and has since moved to consult upon the recommendations outlined by the National Data Guardian for Health and Care in her Review of Data Security and Opt-Outs (National Data Guardian, 2016). Dame Fiona Caldicott’s Review emphasised the critically important role of public engagement and education - stressing the importance of:

- **Choice:** let me decide who has information about me
- **Care:** treat my information with care
- **Competence:** handle my information according to rules
- **Clarity:** on who uses my information and for what purpose

It also outlined new data security standards applicable to all health and care organisations.

The Government’s response to its consultation on the Review’s recommendations is eagerly anticipated, but is widely expected to reiterate that Government and its agents should function as arbiter between individuals and value creators where health and care data is concerned, in keeping with its Digital Strategy (DCMS, 2017) as well as data sharing provisions contained within the Digital Economy Act 2017. Our own research points towards there being a potentially fertile

¹ See, for example: Ipsos Mori (2016), Ipsos Mori (2014) and Given et al (2017).

‘middle ground’ – a middle ground which could be activated through education and promotion linked to new safeguards and incentives to engender a collective sense of responsibility for our well-being as a society.

It is therefore timely to consider how a new ‘digital contract’ might be forged between individuals referred to as ‘data subjects’, those stewarding or ‘controlling’ health and care data, and those who wish to use or ‘process’ it for broad-ranging reasons - the better to use health and care data for everyone.

Report structure and outline

We begin with legal definitions by way of a primer for newcomers to our subject matter. We then provide a summary of pertinent legislation, government strategies and initiatives, before presenting findings from desktop research and interviews with organisations pioneering the development of Integrated Digital Care Records. Our aim, here, is to highlight the Government’s aspirations vis-à-vis digitisation and data sharing in health and care, and to explore practical approaches to implementation in local settings. In examining the national context, we find that we are at a relatively early stage in an important journey, albeit some provisions and organisations are further ahead than others, and we make a number of recommendations to further enable responsible data sharing whilst building public trust.

Specifically, we recommend additional support for digitisation efforts in social care settings. We call upon the Government to streamline processes associated with Information Governance (IG) modelling to help data sharing initiatives that traverse organisational boundaries. We also advocate for investment and additional legal safeguards to make more anonymised data sets available for research and innovation. Crucially, we recommend expediting the scope for individuals to contribute health and care data to sharing initiatives led by the public sector through promotion, education and pilot activities – so that data is deployed to transform public health and support the ‘pivot to prevention’.

In Chapter Two, we explore the rationale and scope for the UK to build upon emergent practice from around the world and become a global leader in ‘data philanthropy’ - to push at the boundaries of existing plans and programmes, and support the development of and access to unrivalled health and care data sets. We look at member-controlled ‘data cooperatives’ and what we’ve termed ‘data communities’ operated by trusted intermediaries. We also explore ‘data collaboratives’ which involve the private sector engaging in data philanthropy for public benefit. Here, we make recommendations about promoting a culture of data philanthropy through the demonstration of tangible benefits to participants and the wider public, and we call upon Government to assess the appetite and feasibility of establishing the world’s first National Health and Care Data Donor Bank.

In Chapter Three, we look at how the UK can cement a ‘health and care data advantage’ to proactively stimulate innovation and support related enterprise over the coming decade. This involves building upon the Government’s Industrial and Digital strategies and ensuring its forthcoming Data Protection Bill and ‘Digital Charter’ recognise the rights and requirements of individuals and innovators but, also, identify a ‘middle ground’ in the form of collective responsibility where the two can deploy ‘data for good’ or wider public benefit. We call for investment in health and care data-driven business clusters and ‘Living Labs’ to develop the UK’s data infrastructure and harness new technologies in community settings.

We also look to the future and ask Government to explore the scope to introduce tax and other incentives for those organisations prepared to enter into Joint Ventures with a National Health and Care Data Donor Bank; we believe this could help de-risk the discovery of new treatments and technologies, better align research to need, and secure preferential terms for deployment of innovations flowing from the same. Finally, we recommend the Government develops a dedicated health and care data privacy shield applicable to future international trade discussions – this is to ensure that the UK has appropriate provisions in place and allays public concerns, but could also confer economic advantages in future.

Embracing technological change has the potential to transform health and care outcomes for the public whilst delivering significant economic benefits for the United Kingdom. To get there, we must recognise that data is perhaps more akin to ‘digital labour’ than the raw material or oil of which so many have written in recent years, and nurture a commitment to ‘intelligent data sharing’ - putting in place appropriate safeguards and incentives as we proceed - so that a new form of collective responsibility can flourish in our digital age and underpin the deployment of ‘data for good’. We must also lay the foundations for pertinent skills development, employment creation and business growth opportunities, so that the economic impact of a concerted health and care ‘data drive’ is felt throughout the country. Our vision is a society which cares for all and in which everyone benefits.

Legal definitions

This report uses a number of legal and technical terms which are defined below and included as a guide to aid newcomers to our subject matter.

Term	Description
Adequacy	Personal data shall not be transferred to a country or territory outside the European Economic Area unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data.
Anonymisation / Pseudonymisation	Anonymisation: the processing of personal data in such a manner that personal data cannot be attributed to a specific data subject. Pseudonymisation: the processing of personal data in such a manner that the personal data can no longer be attributed to a specific data subject without the use of additional information, provided that such additional information is kept separately and is subject to technical and organisational measures to ensure that the personal data are not attributed to an identified or identifiable natural person.
Data	Information which – a) Is being processed by means of equipment operating automatically in response to instructions given for that purpose; b) Is recorded with the intention that it should be processed by means of such equipment; c) Is recorded as part of a relevant filing system or with the intention that it should form part of a relevant filing system; d) Does not fall within paragraph (a), (b) or (c) but forms part of an accessible record as defined by section 68 of the Data Protection Act (1998); or e) Is recorded information held by a public authority and does not fall within any of paragraphs (a) to (d).
Data Controller	A person who (either alone or jointly or in common with other persons) determines the purposes for which and the manner in which any personal data are, or are to be, processed. Where a person is obliged by law to process personal data is the data controller.
Data Processor	In relation to personal data - any person (other than an employee of the data controller) who processes data on behalf of a data controller.
Data Subject	An individual who is the subject of personal data.
Personal Confidential Information	Personal information about identified or identifiable individuals, living or dead, which should be kept private or secret – where ‘personal’ refers to the definition in the Data Protection Act and ‘confidential’ includes ‘information given in confidence’ and ‘that which is owed a duty of confidence’.
Personal Data / Sensitive Personal Data	Personal Data: relates to a living individual who can be identified a) from those data, or b) from those data and other information which is in the possession of, or is likely to come into the possession of, the data controller. Sensitive Personal Data in the context of health data includes personal data consisting of information as to his physical or mental health or condition. See section 2 of the Data Protection Act 1998 for a full definition.
Processing	Obtaining, recording or holding the information or data or carrying out any operation or set of operations on the information or data, including a) organisation, adaptation or alteration of the information or data, b) retrieval, consultation or use of the information or data, c) disclosure of the information or data by transmission, dissemination or otherwise making available, or d) alignment, combination, blocking, erasure or destruction of the information or data.



Chapter One

National context:

enabling responsible data sharing and
building public trust

Introduction

A modern health and care service must be agile and respond to advances in digital technology to deliver better outcomes. Progress in digitising our health and care services must also be balanced with appropriate and robust safeguards to ensure health and care data is used with consideration to privacy and clear ethical parameters for sharing information. This chapter provides a summary of the legislation governing health and care data handling, together with pertinent government strategies and initiatives, before presenting findings from desktop research and interviews with organisations pioneering the development of Integrated Digital Care Records.

Our aim is to highlight the UK Government's aspirations vis-à-vis digitisation and data sharing in health and care, and to explore practical approaches to implementation in local settings. In examining the national context, we find that we are at a relatively early stage in an important journey, albeit some provisions and organisations are further ahead than others following a concerted effort on the part of policy makers and front-line professionals in recent years. Our recommendations are designed to further enable responsible data sharing whilst building public trust.

Legislative context

Legislative approaches taken to defining and handling what we have termed health and care data vary around the world, but tend to flow from a country's underlying legal system and the way in which health and care services are commissioned (funded) and provided (delivered). The United States (US), for example, has data protection provisions that are specifically concerned with 'personal healthcare information' in the form of the Health Insurance Portability and Accountability Act (HIPAAA), which was introduced to establish cross-sector standards for its electronic exchange, privacy and security. By contrast, generic data protection legislation operates alongside specific provisions concerned with publicly funded health and care service delivery as well as health and care data sharing between organisations in the UK.

What is health and care data?

In the UK, the term 'personal data' refers to any information relating to an identified or identifiable natural person ('data subject'). An identifiable person is one who can be identified, directly or indirectly, by reference to those data, or from those data and other information which is in the possession, or is likely to come into the possession, of what is termed a 'data controller'. Information held by local authorities for the purposes of delivering social care services is generally termed 'client data'. There are further legal provisions concerned with the handling or 'processing' of 'sensitive personal data' and 'personal confidential data' in the UK, as well as the forthcoming General Data Protection Regulation (GDPR) that will impact 'data concerning health', and these are taken to cover both health and care data for our purposes. We are interested in unleashing the potential of data related to the health or care of a person, including the provision of health and care services, which reveal information about his or her well-being to transform outcomes.

How is health and care data protected and when can it be shared?

The legal framework governing the use of personal confidential data is complex. It includes the NHS Act 2006, the Health and Social Care Act 2012, the Data Protection Act 1998, and the Human Rights Act 1998. Looking ahead, it will also be impacted by the Digital Economy Act 2017 and the General Data Protection Regulation (GDPR) agreed with EU Member States that is expected to underpin a new Data Protection Bill and Digital Charter announced in the Queen's Speech (Cabinet Office and Prime Minister's Office, 2017).

The law allows personal confidential data to be shared between those offering care directly to an individual, but protects their confidentiality when data about them are used for other purposes. These 'secondary uses' of data are deemed essential to providing safe, efficient and equitable health and care services and include:

- reviewing and improving the quality of care provided;
- researching what treatments work best;
- commissioning clinical services; and
- planning public health services.

In general, people using personal confidential data for secondary purposes must only use data that do not identify individuals - unless they have their explicit consent.

Under the Data Protection Act, consent is a fairly broad ground regularly relied upon by data processors. However, the General Data Protection Regulation, when in force, will significantly restrict the circumstances in which consent can be relied upon as a ground for processing personal data. The General Data Protection Regulation provides that, where personal data is being held on the basis of consent, that consent should be given by a 'clear affirmative act establishing a freely given, specific and unambiguous indication of the data subject's agreement to the processing of personal data relating to him or her' (Regulation (EU) 2016/679, Recital 32). It also provides that 'consent should not be regarded as freely given if the data subject has no genuine or free choice or is unable to refuse or withdraw consent without detriment' (Regulation (EU) 2016/679, Recital 42). Therefore, the General Data Protection Regulation substantially restricts the extent to which consent can be relied upon as a ground for processing personal data, in comparison to the rules under the Data Protection Act.

In domestic legislation, Section 251 of the NHS Act 2006 allows the Secretary of State for Health to make regulations to set aside the common law duty of confidentiality for defined medical purposes. Section 251 came about because it was recognised that there were essential activities of the NHS and medical research which required identifiable patient information – but, because patient consent had not been obtained to use people's personal and confidential information for these other purposes, there was no basis in law for them (NHS Health Research Authority, n.d.). In addition, the Health and Social Care Act 2012 created new powers to mandate the disclosure of personal confidential data from health and care professionals to support indirect care purposes, including health research, with no requirement for patient consent or opportunity for patient objection. In practice, the latter has been maintained, but this moved the UK toward a national 'opt-out' model for research using personal confidential data extracted from individual health records and processed by NHS Digital which, in turn, gave rise to the last Government's flagship health and care data sharing initiative: care.data

Key Finding: public pressure and professional concern about data ethics and security issues resulted in the Caldicott Review of Data Security and Opt-Outs (National Data Guardian, 2016) and cancellation of the Government's care.data initiative. The General Data Protection Regulation will strengthen legal provisions surrounding consent and opt-outs. Future health and care data sharing initiatives will therefore need to reflect the changes. Moreover, the use of powers regulated by the Health Service Regulations 2002 and/or provided for within the Health and Social Care Act 2012 may need to be revisited, so that Government is deemed to act in keeping with the 'spirit' of the Regulation going forward.

There is, meanwhile, continued scope to make full use of anonymised health and care data. However, where anonymised data sets are sold and/or linked, there is a growing risk of 're-identification' for individuals, and this could impact public confidence in health and care data sharing in future - particularly if it results in discernible data-driven discrimination and/or adverse press coverage. This situation is likely to be exacerbated as new technologies based upon machine learning and artificial intelligence gain further traction in our everyday lives.

Recommendation: the Government should strengthen sanctions associated with the re-identification of data subjects from anonymised data sets, where consent, Legitimate Interest or contract is lacking, and consider whether measures to tackle specific forms of data-driven exploitation and/or discrimination could further safeguard individuals and build trust were the Information Commissioner's Office (ICO) empowered to enforce them.

Policy context and government Initiatives

Many policies and government-backed initiatives have impacted health and care data handling in the UK over the course of the last twenty years, but the institutional and strategic landscape surrounding the digitisation agenda has evolved apace since 2010. Established in 2014, for example, the National Information Board's Personalised Health and Care 2020: a framework for action (National Information Board, 2014) outlines the strategic priorities for data and technology in health and care with a view to delivering the maximum benefit for everyone. The National Data Guardian has said, however, that there is growing concern that opportunities to improve the use of health and care data in peoples' interests are being missed (National Data Guardian, 2016).

Some of the concern is attributable to funding constraints upon local authorities, the NHS and provider organisations. But, it is also symptomatic of a somewhat fragmented approach to digitisation where social care is concerned, together with unease amongst members of the public, clinicians and other experts in relation to recent data sharing initiatives in health.

NHS England established its Driving Digital Maturity programme in a bid to overcome these issues, which resulted in Digital Maturity Assessments and Local Digital Roadmaps covering health and care organisations in every area of the country being published in 2016, but the extent to which they are considered fit-for-purpose and/or actionable in practice is doubted by some – and, in this regard, information governance and the interoperability of IT systems are said to remain key issues (Stevens, 2016).

Digitising health and care

The Health and Social Care Information Centre (now, NHS Digital) was formed in April 2013 as a non-departmental public body and national provider of information, data and IT systems for patients, service users, clinicians, commissioners, analysts and researchers in health and social care. Working with partners across the health and social care system, its role is to enable and support the whole health and care system to use technology, data and information to transform services.

According to the National Information Board, most social care service providers have adopted computerised record systems, but standardisation and the interoperability of systems used within local authorities and between front-line organisations remain key challenges. As those on the ground endeavour to better integrate health and care, there is, for example, little or no electronic exchange of information about the patients cared for in nursing homes and hospices. Most IT systems in care are used for administration and billing, such that they do not currently support users to take control of or manage a part of their own care, and provide little or no support for informal carers, those living with disabilities or chronic conditions. Neither are they suited to mobile working cultures in many instances. The situation is further complicated by the provider landscape – where the digital skills and maturity of public, private and third sector organisations varies enormously.

The Health and Social Care Information Centre was tasked with educating the public about the last Government's flagship data sharing initiative: care.data – a programme which aimed to create unrivalled access to pseudonymised health and care data amassed by GPs to reap associated benefits in research and innovation, and which was paused in the face of public pressure and expert concern on a number of occasions, then cancelled following publication of the Caldicott Review (National Data Guardian, 2016). Meanwhile, the NHS Five Year Forward View (NHS, 2014) set out the overarching objective of harnessing the information revolution: to make the NHS paperless by 2020 – a vision encompassed in the National Information Board's Personalised Health and Care 2020 Framework (NIB, 2014). In Information and Technology for Better Care: Health and Social Care Information Centre Strategy 2015-20, this aim was echoed and developed as follows:

"By 2020, all the citizens who want it will have access to national and local data and technology services that enable them to see and manage their own records; undertake a wide range of transactions with care providers; and increasingly manage their own health, care and well-being. By the same date, care professionals will have timely access to the information, data, analysis and decision-support systems that they need to deliver safe and effective care." (HSCIC, 2015: 9)

In late 2015, the National Advisory Group on Health Information Technology in England was formed to advise the Department of Health and NHS England on its efforts to digitise the secondary care system. Although GPs have been 99% digital since the mid-2000's, thoroughgoing integration of health and care cannot proceed until the Acute Sector makes further significant progress (Wachter, 2016). The recommendations of what is commonly referred to as the Wachter Review included adoption of a phased approach to developing 'digital maturity', extended to 2023 for those Acute Trusts in need of more time than was originally envisaged (Ibid).

Key Finding: progress in the digitisation of primary care data in the UK is acknowledged, but is slower than anticipated in acute care settings, and lags behind where social care service providers are concerned – impacting the pace and scope of service transformation as well as the potential for truly person-centred health and care.

Recommendation: we welcome the commitment from Government to invest in technologies to impact social care services. Our recommendation is that the Government supports initiatives to encourage standards and interoperability, digital record-keeping, Internet-of-Things (IoT) deployment and data-driven service development. It should also task the Care Quality Commission with championing the digitisation agenda, and with scoping the potential for a data-driven inspection regimen to help raise standards in future.

In parallel, a number of activities to begin sharing health and care data are underway at a local level. One such initiative is the Connected Health Cities programme which operates across four cities in the North of England on a pilot basis and aims to:

- develop an efficient system which will enable continuous improvement by providing health managers with key insights (a 'Learning Healthcare System');
- engage with citizens and build public trust that data is being used responsibly to deliver wider health benefits to populations; and
- encourage economic growth through digital health technology development.

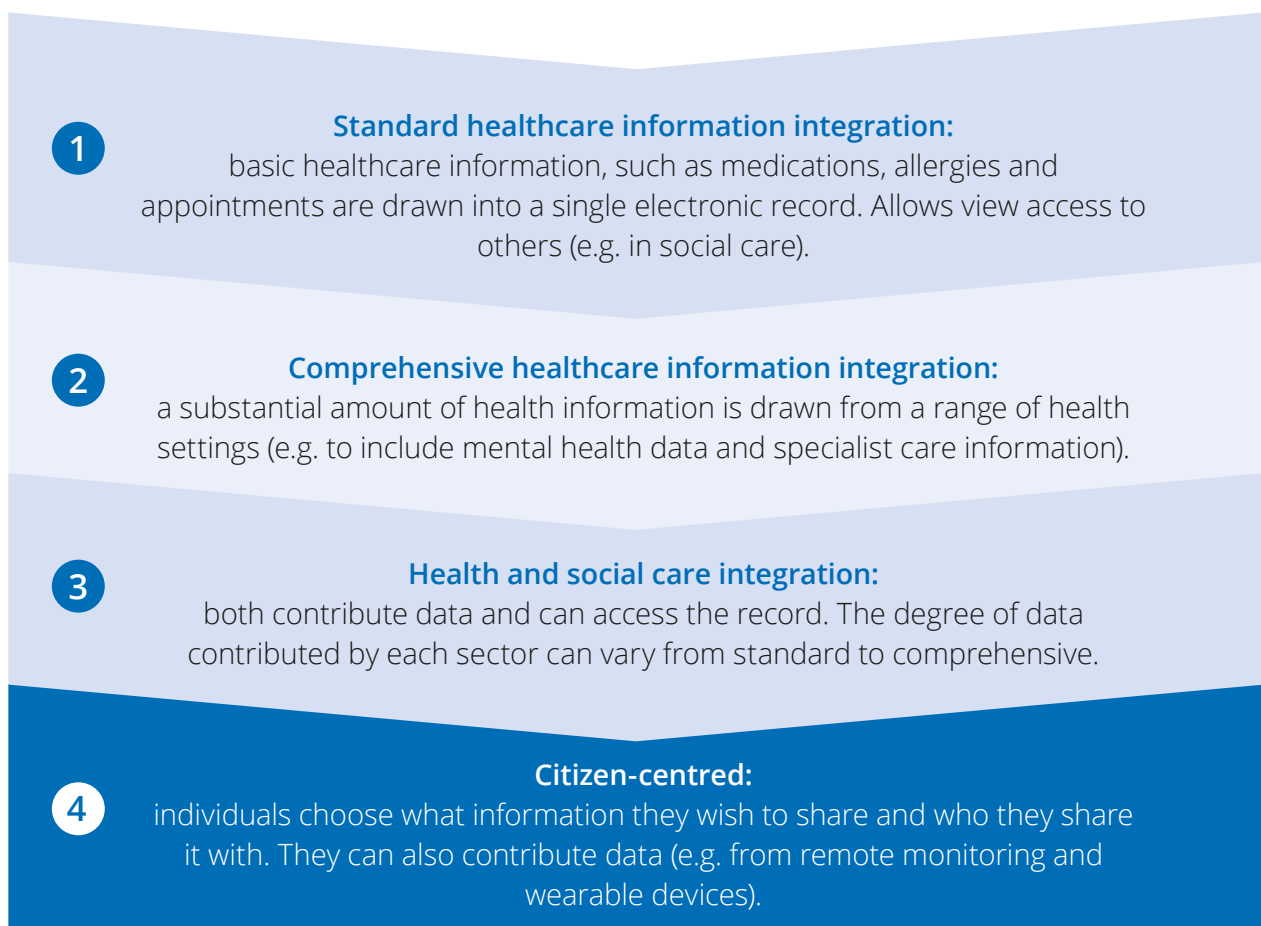
A case study provided at Appendix I provides further information about the Connected Health Cities programme's design and looks in-depth at Connected Yorkshire.

Spotlight: Integrated Digital Care Records – data sharing at the local level

The Health and Social Care Act 2012 placed a duty upon local health and care organisations to share information about individuals to improve direct care. Both the National Information Board's Personalised Health and Care 2020: a framework for action (NIB, 2014) and NHS Digital's strategy commit commissioners and providers to building upon the same to help deliver health and care integration (HSCIC, 2015). Health and care data is also being shared at the local level through the development of Integrated Digital Care Records.

What is an integrated digital care record?

Integrated Digital Care Records draw data from any number of organisations involved in the provision of health and care co-located in a geographical area, and function to provide a range of professionals with a more comprehensive understanding of an individual's needs. Their development in one form or another is referenced in most Sustainability and Transformation Plans (STPs), and whilst the aims and aspirations of stakeholders differ to reflect local challenges and opportunities, can broadly be categorised as follows:



The different categories flow from the degree of data sharing and the locus of control. The first three represent a medical model and focus upon providing access to professionals, whereas the fourth represents a citizen-centred model to information creation and sharing. In practice, Integrated Digital Care Records will rarely fit one of these ideal types and vary along a range of other lines – including, whether they ask individuals to consent to data sharing and whether the data is used for secondary purposes other than direct care provision. Such nuances are explored in more detail in our case studies.

Case studies

To explore the development and scope of Integrated Digital Care Records, we produced five case studies to highlight different approaches to record development. These case studies based in Dorset, Leeds, Cheshire, Hampshire and North West London are summarised overleaf and provided in full at Appendix II, and they illustrate the journey that those areas have undertaken. The case studies of the Dorset Care Record (DCR), Leeds Care Record (LCR) and Hampshire Health Record (HHR) were supplemented by interviews with a key stakeholder to understand the journey of Integrated Digital Care Record development in greater depth, and we are grateful to the organisations who contributed for their time and insight.

Local context and record development

- LCR** Maximising benefits from efficient IT use is one of the Leeds Health and Wellbeing Strategy's priorities, the LCR is one of the routes being considered to help improve patient access to records.
- HHR** The HHR is one of the earliest IDCs in England, set up in 2005. The original focus of the HHR was to produce a data repository for research and analysis - more recently the primary purpose has shifted to supporting the direct provision of care.
- DCR** The development of the DCR began in 2014 and rollout is expected in Autumn 2017. This is considered critical in working towards becoming a "digitally-enabled Dorset", outlined in the Dorset STP.
- CCR** Launched in early 2016, the CCR, together with the nearby Wirral Care Record, is regarded as a key enabler in meeting the ambitions of the Cheshire and Wirral STP.
- CIE** Delivered through the technology partner Patients Know Best, the CIE, which aims to put patients in control of information sharing, began in 2014. The CIE features significantly in the Local Digital Roadmap for North-West London and the North-West London STP, where it is seen to contribute to key delivery areas.

How health and care data is being used in Integrated Digital Care Records to deliver better outcomes

Data sharing

- LCR** **Standard health information**¹ is drawn into the LCR, alongside **limited social care information** including care team details and open referrals.
- HHR** **Standard health information** is drawn into the HHR, alongside **limited social care information** including care team details, needs assessment and care package receipt.
- DCR** **Standard health information** is drawn into the DCR.
- CCR** **Comprehensive health information** is drawn into the CCR including observations (e.g. blood pressure and smoking levels), oncology data and chronic disease monitoring. **Social care information** includes needs assessment and case details.
- CIE** **Standard health information** can be included by professionals, with additional options for them to share advice materials with the patient. **Patient contributed data** can include appointments, journal entries and remote monitoring input, e.g. from blood pressure, glucose monitors and activity trackers.

Organisations that can access the record

- LCR** **CCGs, GP surgeries, hospitals, NHS community and mental health trusts, and the Local Authority.** **Hospices** and an **ambulance service** can also access the record but do not contribute data. Safeguarding access has been requested but not granted as the focus of the record is only on direct care provision.
- HHR** **CCGs, GP surgeries, hospitals, and the Local Authority.** Out of hours GP services and a local ambulance service have access but do not contribute data.
- DCR** **CCGs, GP surgeries, hospitals, an NHS community and mental health trust, and local authorities.**
- CCR** **CCGs, GP surgeries, hospitals, NHS community and mental health services, specialist care** (including cancer services), **hospices, out of hours provision and local authorities.**
- CIE** As a patient-focused system, individuals are invited to participate by care professionals. Participating organisations using the CIE include: **CCGs, acute community and mental health provision, ambulance service, urgent care centres and local authorities.**

Public involvement

- LCR** **Consent** is on an opt-out basis. **Access** is not currently provided to the public. **Engagement** meetings were held and produced key insights (there was lesser public concern over the inclusion of social care data than expected). A public facing website and explanatory material have been produced too.
- HHR** **Consent** for the creation of a HHR is provided on an opt-out basis, however in order for information to be accessed individuals must opt-in with multiple sharing options. Consent for secondary data processing, through a separate database, is on an opt-out basis. **Access** is not currently provided to the public. **Engagement** has been conducted – explanatory material was produced in partnership with a local carers charity, complimented by a public facing website.
- DCR** Every individual will automatically have a record however **consent** for data sharing is on an opt-in basis, with multiple sharing options. **Access** is not currently provided to the public. **Engagement** has been key – thousands of patients' views from a clinical services review fed into its development, and the record utilises social media and a public facing website.
- CCR** Consent for the creation of a CCR is provided on an opt-out basis, however the first time an individual's CCR is accessed, active consent i.e. 'opting in' is required before proceeding. Access is not currently provided to the public. The record has a public facing website and social media presence.
- CIE** There is a **high degree of citizen control** over the sharing of their information via the patient portal. In addition to **accessing** their own records, individuals can **choose to share their record** with various care providers, relatives and friends, choosing the information they would like each party to access.

Future plans

- LCR** **Extending functionality** to provide alerts and notifications, which could assist clinicians and benefit patient safety, e.g. alerting to the prescription of certain drugs.
- LCR** **Adding social care data** which could support hospital discharges, e.g. care team contact details.
- LCR** **Extending access to the public** and **developing a more user-friendly experience**.
- LCR** **Addressing organisational inconsistencies** in information upload and record access.
- LCR** **Extending functionality** to provide alerts, e.g. flagging hospital attendants to a GP.
- HHR** **Combining HHR with other analytical tools**
- HHR** **Extending access to the public**.
- DCR** **Adding additional information** including social care data, additional health information including from other nearby NHS facilities, and remote monitoring/patient contributed data, e.g. connecting remote cardiac monitors for people at high risk of stroke.
- DCR** **Extending access** to the public and all organisations that contribute data.

Which records we looked at

- LCR** Leeds Care Record – www.leedscarerecord.org
- HHR** Hampshire Health Record – www.hantshealthrecords.nhs.uk
- DCR** Dorset Care Record – www.news.dorsetforyou.gov.uk/dorset-care-record
- CCR** Cheshire Care Record* – www.cheshirecarerecord.co.uk
- CIE** Care Information Exchange* – www.careinformationexchange-nwl.nhs.uk

Acronyms:

- Care Information Exchange (CIE)
- Cheshire Care Record (CCR)
- Clinical Commissioning Group (CCG)
- Dorset Care Record (DCR)
- Integrated Digital Care Record (IDCR)
- Leeds Care Record (LCR)
- Sustainability and Transformation Plan (STP)

¹We categorised standard health information as that which is largely covered within all IDCRs and distinguish this from comprehensive coverage which includes additional details such as specialist care data and disease monitoring. For the full breakdown of data included in each record, please see Appendix 2.

Integrated Digital Care Records: the story – so far

Our case studies are illustrative of local efforts to pioneer the use of technology and share health and care data across organisational boundaries. Some are already delivering tangible benefits to professionals and individual service users, whilst others are at an earlier stage in their development.

The Integrated Digital Care Records we examined are designed to draw data from a range of systems that, until recently, could not be linked – demonstrating considerable technical progress to overcome complex interoperability challenges, as well as a substantial time investment in information governance modelling. Their shape and scope is also underpinned by professional buy-in to the benefits of health and care service integration, insofar as they acknowledge data sharing can support direct care and a transition to the more person-centred approach sought in those national policies and strategies outlined above.

At the same time, the national picture is one of significant variation, to the extent that consent models, contents, controls and technologies differ substantially from one area to the next – and this could result in future challenges impacting:

- national policy initiatives reliant upon Integrated Digital Care Records;
- public understanding of and confidence in Integrated Digital Care Records;
- the portability of data about an individual and their records between areas;
- user experience and take-up/usage of different Integrated Digital Care Records related to their design; and
- flexibility in commissioning maintenance/development work (where open standards are not writ large in technical specifications for Integrated Digital Care Records).

Our research and interviews with local stakeholders also underline that most remain focused upon improvements to the provision of direct care by professionals at present. This flows, in part, from the complexities surrounding Information Governance (IG) modelling, which proved time-consuming in every instance and in spite of NHS Digital's IG Toolkit, but it also reflects professional concerns about public confidence in health and care data sharing for secondary uses of personal confidential data.

Key Findings: a growing number of organisations are making progress in integrating health and care record data at the local level, but the complexities surrounding Information Governance (IG) modelling are impacting associated timescales as well as the potential for such data to be put to beneficial secondary uses. The process took those we interviewed up to twelve months to finalise, and none plans to integrate substantial information from social care home providers at present, which would almost certainly take more time. Only one of our interviewees used the data collected for purposes other than direct care, and provided third party access for research based upon informed consent.

Recommendation: we recommend streamlining the Information Governance modelling process for stakeholders developing Integrated Digital Care Records to compress associated timescales and, with that, pave the way for them to draw upon information from all prospective constituents of Accountable Care Systems in future. We also recommend investment and support for joint data controllers to unleash the potential of the data underpinning such records in a standard and anonymised form, where there is a perceived value in secondary analysis by third parties.

The stakeholders involved in our case studies are eager to explore the potential for citizens to access and, in future, contribute data to Integrated Digital Care Records and other health and care data sharing initiatives – where that is not already the case – albeit they are mindful of the potential for the latter to impact workloads. For example, a number of them talked to us about the potential to link remote monitoring and wearable devices. In four of the five cases we examined, Integrated Digital Care Records are currently focused on providing access to professionals - representing a medically centred approach pursued for the purpose of improving direct care provision.

The Care Information Exchange (CIE) is different insofar as it places the individual at the centre of their own health and care data, enabling them to control access to and co-create their own records. Research summarised by 2020 Health suggests that public access to records can lead to a range of benefits, including increased levels of patient self-management, knowledge about their condition and improved satisfaction (Cruickshank et al, 2012), while the active involvement of patients in monitoring their condition has also been found to improve outcomes in some cases (Basch et al, 2017). It is therefore encouraging that all of the stakeholders we spoke to are eager to further improve direct care and empower individuals and their carers to take a more active role in their health and care in future.

Key Finding: the emphasis of those currently pioneering Integrated Digital Care Records and other health and care data sharing initiatives is upon the provision of 'read-access' for a range of professionals and, in time, data subjects themselves – reflecting concerns articulated in the National Information Board's Personalised Health and Care 2020: a framework for action (NIB, 2014) that valuable information remains 'locked' in GP records and is largely inaccessible to patients – with 'write-access' or the facility for individuals to contribute additional data from e.g. wearable devices, 'smart home' gadgets / sensors a longer-term aspiration.

Recommendation: we recommend expediting the scope for data subjects to contribute data to Integrated Digital Care Records and other data sharing initiatives to transform public health through personalisation, to help bring about the 'pivot to prevention' that is outlined in the NHS Five Year Forward View (NHS, 2014), and to effect rapid growth of the health and care data made available in anonymised form for research and innovation. Specifically, we recommend this be undertaken through pertinent promotion, education and pilot activities (which could, for example, trial automated 'nudge notices' tailored to individual data contributions to explore the scope to impact prevention efforts).

Conclusion

Organisations responsible for health and care at a local and national level are at a relatively early stage in an important journey to transform their approach through the use of health and care data. There are exceptions and some provisions and organisations are further ahead than others following a concerted effort by policy-makers and professionals in recent years. We have made recommendations to further enable responsible data sharing whilst building public trust. We have also recommended measures to streamline and speed up the process of digitisation so that health and care systems are better able to exchange and make use of valuable information. It is important that momentum is not lost and investment in this area continues because the status quo will not be fit for purpose in future years where health and care data governance and usage is concerned. It also seems entirely logical that interoperability between systems handling data, whether in health or care, should adhere to a set of common standards and use open APIs to facilitate the straightforward electronic exchange of data. Conceptually, this is akin to electrification and, from our perspective, paramount when conjoining health and care data.



Chapter Two

Pushing the boundaries:

creating a culture of data philanthropy
in a digital Britain

Introduction

In examining the national context, we looked at what work is already underway to both generate and share health and care data in the UK. In this chapter, we assess the potential for a new 'digital contract' to nurture collective responsibility and underpin the deployment of health and care 'data for good'.

We explore the rationale and scope for the UK to build upon emergent practice from around the world and become a global leader in 'data philanthropy' - to push at the boundaries of existing plans and programmes, and support the development of and access to unrivalled health and care data sets. We look at member-controlled 'data cooperatives' and what we've termed 'data communities' operated by trusted intermediaries. We also explore 'data collaboratives' which involve the private sector engaging in corporate data philanthropy for public benefit. We go on to make recommendations about promoting a culture of data philanthropy through the demonstration of tangible benefits to participants and the wider public, and we call upon Government to assess the appetite and feasibility of establishing the world's first National Health and Care Data Donor Bank.

A new digital contract and data for good

The UK Government is preparing to introduce a new Digital Charter which aims "... to make Britain the best place to start and run a digital business and the safest place in the world to be online" (Conservative and Unionist Party, 2017: 77). It has also talked of plans to institute an expert Data Use and Ethics Commission to advise regulators and parliament on the nature of data use and how best to prevent its abuse" (Ibid), which would reflect recommendations from the British Academy and Royal Society in their recent report Data management and use: Governance in the 21st Century (2017). The Government will bring forward a new Data Protection Bill to reflect adoption of the General Data Protection Regulations, and put the National Data Guardian for Health and Social Care on a statutory footing to ensure data security standards are properly enforced over the course of the next parliament (Conservative and Unionist Party, 2017).

The Digital Charter provides a welcome opportunity for industry but, also, civil society to contribute to the development of a new digital contract between data subjects, controllers and processors, and could usefully seek to embed a contemporary form of collective responsibility in our digital age. Specifically, it could underpin the deployment of data for good, and put in place forward-thinking safeguards and incentives to enable the same. This would build upon the Digital Economy Act 2017, which affords the UK Government new powers to share anonymised data for research purposes for the public good, and the UK Digital Strategy which commits Government to 'encourage innovative uses of data by making it easier where possible to access and use data held by both government and businesses' (DCMS, 2017).

According to the UK Digital Strategy, the Government will create legal frameworks that keep pace with new data technologies, support the innovative use of data by business, and provide robust protection for people's privacy rights. Any Data Use and Ethics Commission it moves to establish would help it develop the principles and rules to give people confidence that their data is being handled properly in future.

Taken together, development of the Digital Charter and the prospect of such a Commission represent an unprecedented opportunity to unleash the potential of health and care data for good in the UK. The prevailing view is that Government and its agents should function as arbiter between individuals and value creators where health and care data is concerned. There is, however, a potentially fertile 'middle ground' – a middle ground which could be activated through education and promotion, linked to new safeguards and incentives, to engender a collective sense of responsibility geared to improving our overall well-being as a society.

Data as digital labour

Data is often referred to as the 'new oil' - the 21st century raw material which, when hitched to algorithmic refinement, may be mined for insight and value - and 'data flows' are said to have exerted a greater impact upon global growth than traditional goods flows in recent years (Manyika et al, 2016). Accordingly, there is considerable interest in unleashing data to address a range of challenges related to health and care. And, yet, international studies indicate that most existing datasets are nowhere near fully exploited, with companies surveyed estimating that they are analysing just 12% of their data (Gualtieri and Yuhanna, 2014).

There is, also, growing concern that so-called data monopolies are too powerful and stand in the way of progress, insofar as they hoard or charge significant fees for access to the data they hold. From the point of view of the private sector, this manifests itself in ever louder calls for modern anti-trust laws (The Economist, 2017) and legal action against corporate data sharing that is fuelled by a fast-paced mergers and acquisition culture (Griffin, 2016). Meanwhile, a growing number of initiatives are geared towards encouraging the release of more open data from state actors.

This is, in many respects, to approach data as an asset – something to be owned, valued and traded in markets as per other commodities. It underpins the fixation on data flows that is enshrined in emergent legal provisions and international trade talks, as well as moves to erect digital borders (BBC, 2017a) and to pursue what has been termed 'data nationalism' as a digital strategy elsewhere (Weber, 2017). And, yet, most data are not treated as assets in strict legal terms – i.e. as property of one form or another. Moreover, if we are to nurture collective responsibility and a cross-sector commitment to intelligent data sharing in any new digital contract, it would perhaps make more sense to approach data as 'digital labour' – as Glen Weyl has helpfully suggested (The Economist, 2017) – the better to value its contribution as well as safeguard against its exploitation and the potential for it to result in discrimination.

This could involve a system to measure the value of individual data contributions to create a basis for a fairer exchange, which Weyl is said to be working towards. It could, also, potentially, give rise to some form of digital labour movement - rather than future debates about data centring upon the pendulum that currently swings between proponents of privacy and value creation. Here, however, we are more interested in the potential of digital labour to give rise to a culture of 'data philanthropy' and a range of what we've termed 'trusted vehicles' to reflect the spectrum of views held by the public about contributing health and care data for good.

Activating digital labour through data philanthropy

The collection of data from individuals in accordance with largely impenetrable terms and conditions by dominant web platform operators has, to some extent, resulted in our 'learned helplessness' over the past decade – where it has not deterred data subjects from agreeing to share information altogether. To consider how best to activate what we have termed digital labour, and thereby stimulate the proactive creation of new health and care data sets and set free broad-ranging data already being collected by organisations to transform health and care outcomes, we explored broad-ranging data for good initiatives from around the world. We have since concluded that it might be achieved through education and promotion of data philanthropy.

Data philanthropy is taken, here, to mean:

- an informed contribution of data to a trusted vehicle by a data subject for mutual benefit OR
- an informed contribution of data to a trusted vehicle by a data subject for public benefit OR
- data philanthropy on the part of a corporate entity - allowing it to “give back in a way that produces meaningful impact, and reflecting the businesses’ core competencies while preserving or expanding value for shareholders” (Stempeck, 2014).

As such, it does not cover the publication of open data by state actors but, instead, reads across to distinct forms of trust vehicle which we examine in more depth below: namely, Data Cooperatives, Data Communities and Data Collaboratives.

Attitudes toward data philanthropy in the UK

Research into public attitudes towards data sharing illustrates the willingness of individuals living in the UK to engage in data philanthropy for public good - subject to certain conditions. The success of existing donor initiatives in the UK also points toward the scope for further action designed to deliver health and care benefits through data philanthropy, including the potential to establish a new National Health and Care Data Donor Bank.

- 1 Attitudes to data sharing indicate **support for doing so in the interests of public good**, with **trusted organisations**, and with certain **safeguards** and provisions in place.

- a There is **broad public support for data sharing** that contributes to **research in the public interest**.

Reviews of research literature by Ford et al (2017) and Aitken et al (2016) found that people were generally willing to share information in their health records to enable research for *'the greater good'*.

- b **Levels of trust** in data usage **vary by organisation**

In the UK, the highest levels of trust in organisations using data appropriately is found among the NHS, with trust in a range of private companies being among the lowest – lower than, but roughly following general trends in organisational trust reported (Ipsos Mori, 2014).

Statistics taken from Ipsos Mori (2014) In response to the question 'Please tell me on a scale of 0-10 how much you personally trust each of the institutions below to use your data appropriately. High trust is regarded as scores between 8 and 10. Other research has reported differing and higher findings. (see Given et al, 2017)

- c **Measures can improve public trust**

Key areas to be addressed in order to build public trust include issues of **education**, **confidentiality**, **privacy** and **data security**.

While health data is considered particularly sensitive, awareness of its current usage is low. On behalf of the British Medical Association, research into the secondary uses of data found similarly low levels of knowledge. The research also found that individuals were more likely to consent to data usage when they have a clear understanding of why and how their data is used (BritainThinks, 2015).

Ipsos Mori (2016) research into public attitudes on the sharing of health data with commercial organisations, found that when safeguards were mentioned, acceptability of information sharing rose.

There is the potential to harness strong levels of public support for data sharing in certain circumstances and promote a culture of data philanthropy

- 2 Levels of public support for donorship activities indicate a **fertile ground for better enabling the pro-social or selfless motivations of individuals** to be recognised.

- a People are **willing to contribute their time and data to help lead new health advances**.

Numbers of participants who have signed up to longitudinal research studies and projects such as the UK Biobank indicate willingness to contribute data to produce health benefits. This is the case, even when this costs them time, and does not result in direct benefits to the individual.

- b **Opt-in models can work, where the public feel strongly as to the cause**.

Over 1/3rd of the UK population - over 23 million people - have opted in to the Organ Donor Register - in England this is over 19 million (NHS Blood and Transplant, 2017a, 2017b).

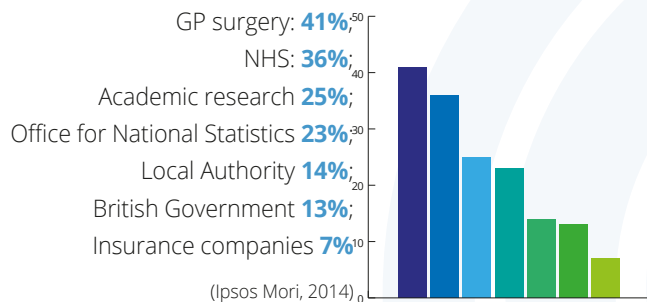
- c **Data donorship is a growing trend**.

Initiatives such as Data Does Good, which enables individuals to donate internet browsing data to a selected non-profit organisation, offer increasingly convenient opportunities for people to donate data, at no cost to themselves.

a **77%** 

Almost **four in five** people surveyed would be willing share their anonymous medical records for research purposes.
(Wellcome Trust, 2016)

b **Levels of trust in data usage**



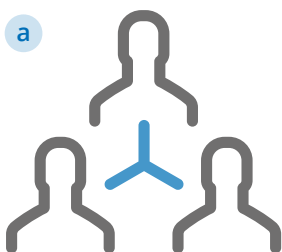
The addition of **safeguards** improved levels of public support for data sharing from **49% to 60%** on average.

(Ipsos Mori, 2016)

c 
Research found that only **1/3rd of participants**

had heard a great deal or a fair amount about how the NHS is using health data, falling to **18% for academic research** and **16% for commercial organisations**.

(Ipsos Mori, 2016)



With **500,000** participants contributing time, health records and medical samples to the **UK Biobank**.

b over **23 million** people have opted in



Yes I donate
ORGAN DONATION

Key Finding: a growing body of evidence from research and practical initiatives in the UK points towards there being a genuine willingness amongst individuals to engage in data philanthropy to transform health and care outcomes. The UK is already leading the way internationally insofar as Government is supporting a number of related initiatives, but we believe it could go further and consider embedding a culture of data philanthropy in a new digital contract.

Recommendation: we recommend the Government explores the appetite for and scope to establish a new National Health and Care Data Donor Bank, which might also involve an Artificial Intelligence/Machine Learning/Deep Learning capability to improve the alignment of research with clinical need.

A Donor Bank would need to reflect the recommendations of the Caldicott Review and provisions in the forthcoming General Data Protection Regulations – prioritising informed consent and contract with individual donors as well as cyber security – and could draw upon, for example, the expertise of the Secondary Uses Service and proven design and operation of the NHS Organ Donor Register and/or UK BioBank and 100,000 Genomes initiative. It would also need to add up from the point of view of cost-benefits, which might involve exploration of the scope to design such a bank along decentralised lines using the blockchain, given the potential otherwise for very substantial data storage costs.

Establishing trusted vehicles for data philanthropy

The ability and willingness of individuals and organisations to engage in data philanthropy will differ according to circumstance, sector and market. Government support to establish a variety of trusted vehicles is therefore considered prudent. We have already recommended a National Health and Care Data Donor Bank be explored, to build upon the leading-edge work being progressed by, for example, the UK BioBank.

UK Biobank

Overview: The UK Biobank is a charity which aims to improve the prevention, diagnosis and treatment of a range of serious illnesses (for example, cancer, diabetes and dementia). Beginning with the recruitment of participants in 2006, the Biobank was established by a range of stakeholders: the Wellcome Trust, Medical Research Council, Department of Health, Scottish Government and the Northwest Regional Development Agency. It is also supported by the NHS. Initial funding of £62 million was granted and has since been supplemented by funding attached to the development of specific additional functions.

What data donors contribute: to date, 500,000 individuals have volunteered to participate in the work of the UK Biobank. Participants aged between 40-69 at the time of recruitment consent to the Biobank accessing their health records, provide blood, urine and saliva samples. They also provide detailed information about their health and agree to make an ongoing contribution upon request. One fifth of participants have worn a 24hour activity monitor for a week and, recently, a major study has begun to scan a range of organs working with 100,000 participants.

Access: any health scientist - whether within or outside the UK and from academia or industry - can apply to request access to the anonymised data held by the UK Biobank to conduct health research 'for the public good'.

Outputs: upon completion, researchers must submit their findings to the Biobank so that others can benefit. Publication outputs are presented on the UK Biobank's website and, so far, include:

- the largest study ever to examine individuals' genetic make-up and, related to that, their risk of developing lung disease – illustrating the risk of developing a deadly lung disease amongst certain groups.
- a study exploring the identification of risk genes for insomnia; and
- the largest study of its kind which found cycling to work halves the risk of cancer and heart disease.

For further information about the UK Biobank: <http://www.ukbiobank.ac.uk/>

However, our research identified three types of trust vehicle which Government might also consider supporting – whether to stimulate the generation of new health and care data, or to provide access to existing data to underpin related research and innovation. These are examined in greater depth below.

Spotlight: data cooperatives

Broad-ranging initiatives are adopting innovative approaches to Information Governance that are explicitly designed to empower individuals or data subjects. These are sometimes referred to as 'platform cooperatives', where they are principally concerned with democratising the ownership of data-driven organisations, and have tended to arise as ethical alternatives to sharing or gig economy platforms fashioned in Silicon Valley like Uber, AirBnB and Task Rabbit (Platform Cooperativism, n.d.). Here, we are interested in 'data cooperatives' – a subset of the platform cooperative movement - where user-members are empowered to contribute and control access to/use of the personal data that underpins them for mutual benefit.

A data cooperative leverages mutual benefit from the personal data contributions of its user-members. Examples of generic data cooperatives include The Good Data and Our Data Mutual – both of which are designed to function as data brokers to generate a financial return for re-investment in good causes or distribution amongst members.

The potential benefits of data cooperatives outlined by Tait include:

- they are owned by their membership and therefore should be more accountable;
- they have the potential to put a halt to the over-collection of personal data through representing data subjects and advocating on their behalf;
- they have data policies that reflect the wishes of their membership;
- they can form around single issues or scale with many data subjects; and
- they can help their membership understand how their data is used – i.e. improve data literacy (Tait, 2015).

From the point of view of health and care, the best-known data cooperative is the MiData Coop initiative established in Switzerland, which will formally launch in Autumn 2017.

MiData Coop

MiData is a health data cooperative. Once it is launched in earnest, it will offer a platform to which user-members can upload copies of their medical data, as well as real-time information from a range of mobile and wearable devices. MiData hopes to become a gatekeeper for this data, attracting researchers, while permitting users a high degree of control over who can access and make use of their personal data in the service of specific aims. Companies will pay a fee to use the data for research purposes, and any surplus revenue generated will be re-invested by the cooperative's General Assembly – which is comprised of MiData's user-members – in pertinent research projects with a public benefit mission.

Midata has already succeeded in funding much of its development via paid research trials to explore post-operative well-being after bariatric surgery and test the effectiveness of a new treatment for patients with chronic multiple sclerosis – attracting early users to the platform and demonstrating proof of concept to researchers. Looking ahead, although MiData will be a cooperative for Swiss citizens, the software it has produced will be freely licensed to other data cooperatives that meet its community guidelines, and talks are underway to establish a German health data cooperative in the first instance. It will also seek to establish a global federation of data cooperatives and is developing software to facilitate data sharing between them (Platform Cooperativism, 2017).

For further information about MiData Coop, see: <http://www.midata.coop>

Despite considerable international interest in data cooperatives in recent years, relatively few have been developed in practice or, else, remain under development at present. There are, nonetheless, related initiatives in train – including the Decode Project – which are piloting the development of tools to put individuals in control of their personal data. When considered alongside interest in new blockchain-based technologies, these point toward the potential of data cooperatives to function as user-led trusted vehicles to facilitate health and care data philanthropy in future.

Spotlight: data communities

Most trusted vehicles that currently benefit from health and care data philanthropy are managed by an intermediary operating in the space between individual data donors and researchers, and they are what we have termed 'data communities', to the extent that they tend to be oriented towards solving specific challenges and read-across to a natural community of interest.

Examples include the 100 for Parkinson's initiative - which aims to become a global movement for people to learn more about their own health, support people living with Parkinson's and help change healthcare through data contributed around the world via a dedicated smart phone app - and the US-based Genetic Alliance - which was founded to support people with rare genetic disorders, but engages individuals and families in a range of opportunities to be active participants in health service development and research.

100,000 Genomes Project

Overview: the 100,000 Genomes Project is run by Genomics England, a private company owned by the Department of Health. Launched by the then Prime Minister, David Cameron, in 2012 to “see the UK lead the world in genetic research within years” (Gallagher, 2014), the aim of the project is to “produce new capability and capacity for genomic medicine that will transform the NHS” (Genomics England, 2017:6), to be achieved through sequencing 100,000 human genomes (from approximately 75,000 individuals), and link this data to a standardised account of diagnosis, treatment and outcomes.

To meet these ambitious aims, a range of stakeholders are involved, including: NHS England, Public Health England, Health Education England, NHS Trusts, the Northern Ireland Department of health and several Health and Social Care Services in Northern Ireland organisations.

What volunteers contribute: participants consent to Genomics England accessing their health records, providing samples of blood and biopsies (where applicable). They also agree to future contact. Often, two close relatives are invited to also take part. Whilst the principal beneficiaries are expected to be future patients, participants receive information about their condition, which can otherwise take many months to obtain.

Access: any individual affiliated with a UK academic research institution (or a non-UK academic research institution that carries out significant research activity), NHS trust or authority, charity directly related to the focus of the project, national and international government departments that carry out significant research activity, or foreign healthcare organisations that undertake significant research activity can apply for access. UK-based private healthcare institutions or commercial companies are not eligible to apply.

Outputs: much of the research is ongoing but key developments, to date, include using whole genome sequencing to identify different strains of TB.

For further information about the 100,000 Genomes Project:

<http://www.genomicsengland.co.uk>

Data Communities have the potential to stimulate data philanthropy in support of particular health and care goals, although we note that most are currently concerned with making use of health data, rather than functioning to enrich social care service transformation efforts. Data Communities are also the most closely aligned to more traditional forms of volunteering and charitable endeavour. As such, we recommend Government supports expanding the range of challenges that are addressed by this form of trust vehicle in future.

Data collaboratives

The term ‘data philanthropy’ is most commonly used to refer to corporate entities sharing data to support timely and targeted policy action. It has been the subject of considerable interest since 2009, when the Global Pulse initiative was set up by the UN Secretary-General as an R&D lab to explore the potential for big data to contribute to the same. Its importance is also alluded to in the UK Digital Strategy.

Global Pulse usefully identified four strategies that corporate entities tend to pursue when engaging in data philanthropy:

- 1 share aggregated and derived data sets for analysis under non-disclosure agreements (NDAs);
- 2 allow researchers to analyse data within the private company's own network, under NDA;
- 3 pool and aggregate data in real-time data commons between multiple companies of the same industry to protect competitiveness; or
- 4 mine data behind their own firewalls and share indicators (Pawelke and Tatevossian, 2013).

Where corporate entities pursue data philanthropy to deliver public benefits working with others, we have termed trusted vehicles that are underpinned by corporate data philanthropy 'Data Collaboratives'.

Mapping and predicting flu outbreaks using Google and Twitter

Internet search engine Google and social media site Twitter have both enabled research in the United States leading to models which track and predict flu epidemics in real-time. The Centers for Disease Control and Prevention (CDC) collaborated with Google and launched Google Flu Trends in 2008, a website that tracks flu-related searches and user location to track the spread of the flu. Meanwhile, researchers cross-referenced Twitter status messages with CDC's influenza-like activity data to predict the spread of seasonal flu in real time (Achrekar et al, 2011).

Pooling corporate data for analysis: data for climate action

UN Global Pulse hosts an annual competition or challenge where private sector data is pooled, and made available to expert research teams to "discover new frontiers in the use of their data for public good" (UN Global Pulse, n.d.). The 2017 challenge – Data for Climate Action – is underpinned by commercial data from a range of sources, including: data analytics, telecommunications, a traffic and navigation app and a weather and lighting sensor network operator. The aim of the challenge is to harness big data to provide innovative approaches to climate change mitigation, and influence decision-making at the global level.

Pooling corporate data to fight disease: Worldwide Antimalarial Resistance Network

The Worldwide Antimalarial Resistance Network represents an unprecedented data collaborative that brings together global data from a range of sources - including clinical, molecular, pharmacological and medicine quality data from over 20 data contributors and collaborators - to track drug-resistant malaria. Key insights include analysis by the network which indicated that a certain drug was less effective among young children – suggesting that they seemed to be receiving a lower intake and might need higher doses. Building on this, a clinical trial focused on this area to determine if higher doses would be safe/effective, and the World Health Organisation then changed its recommendations for children taking the drug (Piansi and Botchway, 2016).

Strava Metro data-driven bicycle and pedestrian planning

The Strava app, using GPS facilities, allows individuals to record physical activities – mapping their route and providing them with detailed performance data. In 2016, Strava established the data service Strava Metro which makes anonymised, aggregated data available to government departments and city planning groups and has, to date, worked with over 70 organisations. Using this data enables organisations to understand the flows of people within a locality. In Glasgow the GoBike campaign, which aims to promote cycling by campaigning, analysed data which illustrated the need for new infrastructure on a street that was thought to have no bike usage. Additionally, The Oregon Department of Transportation used Strava Metro data to inform their decision of where to place bike counters to capture more details about cycling behaviour (Strava Metro, n.d.).

The UK Government plans to support industry to further unlock value from data and, in particular, has said it will work with organisations such as the Open Data Institute to create an environment to open up customers' data across more sectors through the use of Open Application Programming Interfaces (APIs).

Whilst Data Collaboratives underpinned by corporate data philanthropy have already delivered health and care benefits, our research indicates that they have tended to either make use of big data to track the spread of disease in real-time – performing a form of crisis function to support policy makers - or have only indirectly contributed to the day-to-day health and care challenges that most people deem important in a UK context. More could and should be done to unleash the potential of data held by corporate entities to tackle pressing health and care issues in future.

Key Finding: the number of trusted vehicles designed to facilitate data philanthropy remains relatively limited in the UK and, with it, the number of people actively engaged in the same. We believe that this flows, in part, from the relative absence of institutional support to promote data philanthropy along ethical, legal and technical lines.

Recommendation: we recommend the Ministers for Digital Economy and the Third Sector, working in conjunction with the Open Data Institute and NHS Digital, business and the third sector, develop a suite of tools to stimulate data philanthropy in the UK. This could include establishing an appropriate ethical framework in discussion with relevant experts, publishing national technical standards and open APIs to guide developers and encourage interoperability, as well as guidance in respect of organisational and information governance to support founders and members.

Finding: a range of stakeholders in the UK benefit from direct experience of leading-edge programmes underpinned by data philanthropy. Working together, there is the potential for them to further promote its benefits in health and care on a cross-sector basis.

Recommendation: Government should invite those with pertinent knowledge and expertise to help it design a national programme to pilot the development of new health and care Data Cooperatives, Data Communities and Data Collaboratives – the aim: to promote a culture of data philanthropy through the demonstration of tangible health and care outcomes delivered by a range of trusted vehicles.

Key Finding: the UK harbours the potential to become a world-leader through the introduction of forward-thinking ethical standards and policies designed to embed data philanthropy in the digital economy.

Recommendation: we recommend the Government explores the scope to develop a 'gift aid' style scheme for health and care data, and considers mandating a data philanthropy option in standard terms and conditions of service with a view to encouraging individuals to make health and care data donations for related research and innovation.

Conclusion

The UK Government should grasp the opportunity to embed a new approach to the way in which health and care data is generated and used across the country – we have called this a new ‘digital contract’. We must encourage more individuals to take an active interest in how their health and care data is used.

This means that the Government will need to create the right environment for culture change, whereby individuals take greater responsibility for recording their own health and care data as well as controlling with whom the information is shared.

It also requires a new settlement with business, and a recognition of the contribution that the data they control could make to the delivery of public benefits. A new digital contract should, in addition to safeguarding privacy and incentivising value creation from data, welcome and recognise efforts to proactively contribute ‘data for good’. The Government should champion a middle ground, founded upon a culture of ‘data philanthropy’, to push at the boundaries of existing policies and provisions – putting in place the ethical, legal and technical frameworks needed to stimulate the creation of appropriate ‘trusted vehicles’.



Chapter Three

Establishing a health and care data advantage:

investing in skills, business and infrastructure

Introduction

A race is on around the world to unleash the potential of health and care data – with governments and corporates committing substantial funds to establish vast data repositories and develop related technologies. To build a global health and care data advantage, the UK must invest in pertinent skills development, create the space for data-driven health and care enterprises and commit to appropriate infrastructure. It must also sponsor the emergence of a ‘high trust’ data sharing environment underpinned by world-class data ethics.

This chapter looks at how the UK can cement a health and care data advantage to proactively stimulate innovation and support related enterprise over the coming decade. Specifically, we call for investment in health and care data skills, data-driven business clusters and ‘Living Labs’ to harness new technologies in community settings. We also ask Government to explore the scope to introduce tax and other incentives for organisations prepared to Joint Venture with any National Health and Care Data Donor Bank. Finally, we recommend the Government develops a dedicated health and care data privacy shield applicable to future international trade discussions – this is to ensure the UK has appropriate provisions in place and allays public concerns, but could also confer economic benefits, following exit negotiations with the European Union.

Skills development, business support and innovation: policy context

The Industrial Strategy Green Paper (BEIS, 2017a) and UK Digital Strategy (DCMS, 2017) set out the ambitions of the Government and detail investment in 21st century skills development, business support and innovation. A synopsis to contextualise our analysis of the implications for health and care data handling and usage follows.

The Industrial Strategy Green Paper is regarded by Government as an important roadmap for establishing a competitive advantage for the UK in future. Ministers want to develop a plan that offers greater economic opportunities not just for London and the South East, but the whole country. There is also a commitment to put in place measures to enhance growth and productivity. The Government believes that one of Britain’s advantages lies in its expertise in research and development and the creation of new technologies. This strategy also emphasises the importance of skills and providing the right environment to attract global business to the UK.

This is complemented by the direction of travel set out in the UK Digital Strategy. The strategy majors on building world-class digital infrastructure. The strategy commits to helping digital business grow, and to exploring how best to deliver digital government by embracing new technology. There is also an emphasis on skills: a Digital Skills Partnership is tasked with tackling the skills gap to create a pipeline of people with specialist skills in coding and cyber in the future.

Industrial strategy green paper

From the point of view of health and care outcomes, the most relevant parts of the strategy focus upon improving procurement in health and, with that, measures to improve the uptake of digital and technological advances published integral to the Accelerate Access Review (AAR, 2016).

Specifically, the Review recommended:

- The creation by NHS England of a unit that works with industry to look at future innovations, negotiate early access to them and procure new technology that will benefit the health system and achieve value for money.
- More capacity for Academic Health Science Networks (AHSN) and research-led tertiary trusts to support local health economies and adopt new technologies.
- Development of a new supply chain so that the NHS is more aware of the market and has improved horizon-scanning for innovative products that it should adopt.

In April 2017, the Business Secretary also announced an Industrial Strategy Challenge Fund which committed £1 billion over the next four years to six key areas – including: healthcare, medicine, robotics and artificial intelligence. The purpose of the fund is to stimulate innovation and create new opportunities for businesses and sectors across the country; for example, investment in new technologies for the manufacturing of drugs and treatments (BEIS, 2017b).

UK digital strategy

The UK Digital Strategy focuses on several initiatives and areas of investment pertinent to health and care data handling and usage, including:

- A focus on digital health and care, bioscience and biotechnology working through the Digital Catapult Centre.
- Investment in research and innovation using the Internet-of-Things through the IoT UK programme - including test-beds to support people living with diabetes and dementia, and an IoT Research Hub focusing on privacy, ethics, trust, reliability, acceptability and security.
- Support for personalised service development in health, including digital tools and technologies for the elderly at home.
- New health apps to help patients manage long-term conditions.
- Implementation of the recommendations of the National Data Guardian's Review of Data Security and Consent.
- Investment in better real-time digital information – for example, digitising health and care records by 2020.
- The introduction of the MyNHS website to improve the quality of data about NHS performance for patients and professionals.

The Government has also looked at how to improve the handling of data by the public sector in the round through its Transformation Strategy (Cabinet Office and Government Digital Service, 2017):

- data should be an enabler for improvements in public services;
- barriers should be lifted so that Government can make effective use of data;
- expand the use of data science and analytical capability across Government;
- ensure public sector workers understand the ethics of data sharing;
- open access to Government data where appropriate; and
- change to way The Government stores and manages data.

Our review of the policy context surrounding skills development, business support and innovation in the UK highlights several initiatives that are expected to involve or impact health and care data handling and usage over the coming years. It is beyond the scope of our work here to comment upon the extent to which the investment outlined in key strategies is sufficient. Neither is our intention to recommend what more could be done in the round to embrace new technologies to transform health and care outcomes – save where activities read-across to unleashing the potential of health and care data, and might also contribute to establishing a global health and care data advantage for the UK.

We are, nonetheless, concerned to note the relative lack of investment and activities to harness new technologies and transform the adult social care landscape given the growing number of people affected. We are mindful of the National Information Board and NHS Digital's important work in this regard. There does, however, seem to be something of a 'digital black hole' when it comes to significant measures designed to positively impact those living with disabilities, learning disabilities and/or in receipt of care in later life, at least, when compared with explicitly health-related initiatives.

Skills development, business support and innovation: data-driven health and care

Looking ahead, we believe it may be worthwhile Government examining the scope to incentivise the establishment of health and care data-driven business clusters in vanguard locations. This reflects the emergence of area-wide Accountable Care Systems but also the potential harboured by those innovative data sharing initiatives outlined in earlier chapters. The realisation of these elements could help position the UK as a world leader in the delivery of data-driven insights in health and care and generate commensurate economic benefits.

The move towards Accountable Care Systems and a focus on population health, together with an Industrial Strategy for the UK which aims to benefit people in every region of the country, lends itself to the creation of health and care data-driven business clusters. Clusters would involve new and existing businesses, universities and pertinent academic networks, and would provide 21st century skills and employment opportunities enabled by appropriate investment and incentives. They would be geared towards next generation product and service development, and fuelled by health and care data generated at the local level.

Their success would, in part, reflect the ability and willingness of people in health and care organisations to push at the boundaries of existing arrangements. As such, the Government should consider how best to bolster the knowledge, skills and capacity of health and care organisations to engage with data-driven developments; this could, for example, involve the introduction of pertinent training and qualifications for health and care professionals.

Key Finding: the UK is well-placed to build upon the ambitious initiatives it has pioneered in recent years and lead in data-driven health and care research, products and services. The move towards Accountable Care Systems and a focus on population health, together with an Industrial Strategy for the UK which aims to benefit people in every region of the country, lends itself to the creation of health and care data-driven business clusters.

Recommendation: Ministers should invest in pertinent skills development, business support and clusters. Health and care data-driven business clusters across the country could help stimulate job creation and prepare the workforce of tomorrow so that they benefit from the right skills in our digital economy for decades to come. We also recommend attention is paid to bolstering the knowledge, skills and capacity of health and care organisations to engage with data-driven developments.

Living Labs: data-driven care in the community

The use of technology, at home and in the community, can help break down important barriers to independence faced by disabled people and the elderly. Moreover, as the potential of new technologies is fully realised, health and care services will be more and more delivered at home and in community settings. One way in which the Government could support innovators and entrepreneurs to pioneer the introduction of new technologies to transform health and care outcomes is by sponsoring the establishment of 'Living Labs'.

A 'Living Lab' could comprise of private dwellings, a residential care home and/or connected streets, and would involve the deployment of technologies associated with the Internet-of-Things (IoT). The IoT connects sensors and devices across the internet and enables them to talk to us, to applications as well as to one other. It is most commonly talked about in terms of 'smart appliances', 'smart homes' and 'smart cities' – the remote control of devices and urban flows of people and transport – but we believe it has the potential to add significant value to health and care outcomes by better enabling data-driven care in the community.

We outline two examples of IoT-enabled geographies below to illustrate how they are currently benefiting residents.

Bukchon Living Lab, Seoul

In South Korea, the Seoul Metropolitan Government is investing substantially in Internet-of-Things (IoT) technologies and hopes to become the world leading digital city by 2020.

The village of Bukchon, termed a 'living lab' (Korea Joonang Daily, 2017), has been a particular hot-bed for recent IoT pilots through a public private partnership - whereby The Government allows technology companies to test IoT devices such as cameras and wireless sensors within the locality to deliver improved services to residents. Initiatives include one focused on fire prevention and response, where a number of buildings were fitted with wireless sensor devices capable of detecting temperature, humidity, oxygen, carbon dioxide and dust levels – together detecting indications of a fire in real-time; this system provides an automatic alert to Korea's emergency response service when conditions signifying a fire are reported (Seoul Metropolitan Government, 2016).

Building on the success of these projects, The Government plans to roll-out IoT infrastructure to a further 99 locations across the city by 2020. Discussing the Digital 2020 plan, Seoul mayor Park Won-soon recently said that citizens, through better use of digital technologies would establish most policies related to IoT deployment. "Plus, through a new digital industry, our city will create jobs, which will stimulate the economy, and solve various urban problems," he said (Moore, 2016).

CityVerve, Manchester

The UK's first smart city demonstrator is being set up after being selected as the winner of a £10m Government-led funding competition in 2015. The project will demonstrate IoT applications across the four areas of health, energy and environment, transport, culture and community.

Health initiatives connected to the CityVerve project include plans to set up:

- a 'biometric sensor network' to better enable the management of chronic respiratory conditions; and
- air quality monitoring through infrastructure such as lamp posts - an aspiration, here, is that data produced can be provided to those with health conditions as well as to help guide healthier walking routes.

In order to deliver these aspirations, the project seeks to tackle potential barriers to the deployment of IoT in cities - including the development of user trust, ensuring data security and allowing for scalability of initiatives (DCMS, 2015).

For further information about CityVerve: <http://www.cityverve.org.uk>

IoT technology can be used to automate certain household tasks and help more people stay at home for longer – thereby reducing pressures on traditional health and care services. Deployed in ‘smart homes’, for example, it can be used to detect changes in activity levels, hydration and other vital signs from a distance, as well as regulating temperature, lighting and, even, the re-ordering of contents for a person’s fridge. Deployed in sheltered and residential care homes, it can help improve the quality of care delivered and, in future, could provide real-time information to the Care Quality Commission with a view to raising standards through the digitisation of some inspection activities. Applied to streetscapes in our communities, the IoT points toward wider applications, which might include:

- improved guidance for the visually impaired;
- the provision of real-time information about access-friendly areas for those with mobility impairments; and/or
- location tracking and monitoring for vulnerable adults linked to appropriate responder services.

We therefore welcome forward-thinking NHS test-beds exploring the potential for the IoT to transform outcomes for people living with diabetes and dementia in Manchester and Surrey respectively, but encourage Government to do more to encourage IoT deployment in future by establishing new Living Labs to transform health and care outcomes.

Notably, our discussions with service innovators have highlighted a number of challenges associated with existing ethics frameworks and traditional approaches to research, research cycles and new technologies – in particular, where they involve machine learning and Artificial Intelligence. These would need to be resolved to properly transition from ‘smart cities’ comprised of connected objects, toward connected citizens empowered by smart technologies, but it is clear to us that the IoT could better enable data-driven care in the community and support related innovation and enterprise than is the case at present.

Key Finding: health and care services will be delivered increasingly at home and in community settings as the potential of emergent technologies are fully realised. Key stakeholders could do more to develop the infrastructure needed to stimulate innovation in respect of data-driven care in the community.

Recommendation: we recommend that the Government, working with Local Economic Partnerships and constituents of Accountable Care Systems, sponsor Living Labs to stimulate innovation in respect of data-driven care in communities. This would involve moving beyond deployment of the Internet of Things (IoT) for ‘smart cities’ - toward IoT infrastructure investment to improve care in communities, residential homes and/or smart homes. It would also involve key stakeholders addressing challenges associated with existing ethics frameworks and programmed approaches to research, research cycles and new technologies.

Learning from experience: feedback loops and quid pro quo arrangements

Trust in the institutions that steward our data is more important than the technological feasibility of using it at present. The New Zealand authors of the Data Commons Blueprint also suggest that there is more value to be gained from what they term a 'high-trust' model for data sharing than a low-trust one (Aotearoa New Zealand Data Commons Project, 2017). We agree – but existing legal provisions surrounding data protection are under considerable strain insofar as they pitch data subjects against value creators in many respects. They could, more usefully, flow from collective rights and responsibilities applicable to all digital economy stakeholders to help deploy data for mutual benefit in future (British Academy and Royal Society, 2017).

The key to aligning stakeholder interests lies, to some extent, in reconceiving of the relationship between digital labour undertaken by individual data subjects and value creation activities on the part of data processors, such that a virtuous feedback loop between the two is established:

“The more you enable value and inclusion, the greater risks people are likely to take to do more data sharing, because they themselves get that value from it. By the same token, the more you improve control and trust, the more people will be willing to try sharing to realise some potential value, because they are still in control and can reverse their decision if trust is eroded.

But this feedback loop can also spiral downwards. If you erode trust, people will cease sharing, meaning loss of value, making people more sceptical and so feeding back into increased mistrust – because the perceived risk outweighs value...The important point to grasp here is that it is not a dilemma, it's a feedback loop. You have to consider both sides of this equation together to build a thriving data sharing ecosystem. If you just think of value without trust, this will unravel. If you just focus on risk, you end up unable to realise value and so remain sceptical.” (Aotearoa New Zealand Data Commons Project, 2017: 29-30)

Indeed, feedback loops are already emerging in the form of community rules and incentives to participate, where some forward-thinking health and care data sharing initiatives are concerned. Data contributors involved in the Midata Coop project, for example, will be afforded nuanced data sharing controls, and can expect to benefit from research findings of direct relevance to their health and care needs where researchers have made use of their personal data. Meanwhile, participants in Project Baseline can expect to receive:

- certain health data and test results to share with their doctor;
- compensation for their time and perks for their involvement;
- regular updates on the project's progress and early insights into discoveries; and
- exclusive access to the Baseline community and events.

These are clearly welcome developments. However, the UK benefits from a unique asset which could be used to underpin a more robust feedback loop and, with that, contribute to a global health and care data advantage.

The NHS is amongst the most trusted and supported of UK institutions, so measures explicitly designed to benefit 'our NHS' in and of themselves might leverage widespread commitment to data philanthropy on the part of UK citizens. A forward-thinking feedback proposition to impact public health might involve a high profile promotional campaign offering personalised feedback about an individual's health and care status in exchange for data contributions in future. But, it could go further and indicate: by contributing data to a National Health and Care Data Bank, individuals will directly benefit the transformation and sustainability of health and care services in the UK into the future.

In keeping with the spirit of our proposal to enshrine collective rights and responsibilities for all digital economy stakeholders in a new digital contract, this proposition could be cemented by invitations to data-driven enterprises to Joint Venture with any National Health and Care Data Bank – whether such arrangements were premised upon the UK Government taking some kind of stake in new drugs and technologies later rolled out around the world, or involved long-term deals to secure low-cost access to the same, having made use of the Bank's data for R&D purposes. Joint Ventures could then underpin the communication of perceptible benefits accruing to the NHS and Adult Social Care services in the medium to long-term direct to data donors.

Key Finding: learning from efforts to design a 'data commons' for New Zealand underlines that trust is paramount in data sharing initiatives. It also highlights the importance of providing data contributors with feedback about the use of their data and associated outcomes to encourage long-term participation. The Midata Coop and Project Baseline initiatives recognise the importance of providing individual participants with feedback pertinent to their own health and care, but the UK might also want to consider leveraging popular support for the NHS, and explicitly promoting a culture of data philanthropy to support health and care services in future.

Recommendation: the Department of Health, Department for Business, Energy and Industrial Strategy (BEIS) and HMT should explore the scope to introduce incentives for businesses prepared to enter into Joint Ventures with a National Health and Care Data Donor Bank – the aim: to help de-risk the discovery of new treatments and technologies using its health and care data, better align research to need, and secure preferential terms for the deployment of innovations flowing from the same.

A global outlook on data ethics: towards a health and care data privacy shield

The world today is comprised of numerous trading blocs and agreements which regulate international data flows between signatories and, with them, the scope to conduct digital business with one another. Such agreements are essential if we are to nurture innovation and enterprise and develop the health and care interventions of the future. They also function to safeguard individual data subjects from unwanted exploitation and data-driven discrimination.

At present, the UK belongs to the EU, and it will adopt its General Data Protection Regulation (GDPR) from May 2018 so that business within the European Economic Area (EEA) can continue thereafter, and new rights are introduced to better protect the public. The GDPR permits ‘free movement of data’ between Member States, members of the EEA, and a relatively short list of countries which are deemed to offer an ‘adequate’ level of protection for data subjects in relation to the processing of personal data. It also facilitates the transfer of data between the EU and United States of America (US) via a separate ‘Data Privacy Shield’ agreement.

The EU:US Data Privacy Shield agreement should automatically continue to apply to the UK if, as and when it leaves the EU; this is on the basis that the aim of the Great Repeal Bill is to ensure that all EU law continues in force from Brexit. There is, however, ambiguity surrounding the form that Brexit will take following negotiations, and the Great Repeal Bill has still to make its way through parliament. Moreover, Matt Hancock MP, Minister of State for Digital and Culture, stated in February 2017 that the UK intends to enter a similar agreement to the EU:US Data Privacy Shield directly with the US (Thomson Reuters, 2017) - i.e. a UK:US Data Privacy Shield – which could well reflect a desire from Government in the UK to conduct its own negotiations about data handling and usage with countries outside the EEA in future.

The UK might, then, proceed to develop its own Data Privacy Shield applicable to future international trade discussions. It is beyond the scope of our work here to specify in detail what form a new Data Privacy Shield should assume and to which countries/technologies it should apply. Nonetheless, we believe it must serve to allay public concerns in respect of health and care data sharing, whilst functioning to benefit related research, innovation and enterprise in the UK. We recommend Government develops a dedicated health and care Data Privacy Shield with a view to establishing a ‘high trust’ data sharing environment underpinned by the collective rights and responsibilities of all digital economy stakeholders to transform health and care outcomes in the UK.

Key Finding: following the UK's exit negotiations with the EU, it will need to ensure adequate protections applicable to health and care data are in place to safeguard the public whilst stimulating related innovation and enterprise activities.

Recommendation: Government should task the new Chief Data Officer and National Data Guardian with developing a dedicated health and care data privacy shield applicable to future international trade discussions – this would allay public concerns, but could also confer economic benefits upon the UK and contribute to a health and care data advantage.

Conclusion

A big data race is on around the world and harbours enormous potential to transform health and care outcomes as well as to benefit the global economy when coupled with the emergence of leading-edge technologies. We believe the UK can and should take steps to establish what we have termed a health and care data advantage in this important regard.

We have suggested it might do that by further investing in pertinent skills, business support and infrastructure – the corner-stones of its digital economy – building upon the solid foundations of its world-class research and science base. We have also highlighted the scope for data-driven care in the community to contribute to a digital revolution in the delivery of adult social care through deployment of the Internet of Things to orient the UK beyond 'smart cities' comprised of connected objects, toward 'connected citizens' empowered by smart technologies over the years ahead.

Any advantage will flow from enabling a 'high trust' data sharing environment in future – one that seeks to align stakeholder interests and encourage the use of data for mutual benefit – and we have called for active pursuit of Joint Ventures and the development of a dedicated health and care Data Privacy Shield to help bring it to life. Looking ahead, the UK will need to consider carefully how it enables such an environment in respect of health and care data, but we believe it has the potential to attract and retain innovators and leading-edge enterprise to function in this space if it moves to develop provisions on the basis of a forward-thinking ethical framework.

Conclusion

This report sets out a clear path for the UK to unleash the potential of health and care data on the basis of a new digital contract underpinned by collective rights and responsibilities – and characterised by ‘intelligent sharing’. Future Care Capital believes there is a real opportunity for the UK to become a global leader in harnessing ‘data for good’ - making the most of new and emergent technologies to transform treatments and services.

We call upon the Government to blaze a trail in the development of data ethics and rights that are fit for the 21st century to build trust and safeguard everyone’s privacy, whilst encouraging data-driven innovation and enterprise to flourish.

We have outlined a number of ambitious measures to achieve this, as well as presenting practical recommendations as to what more could be done in the short and medium-term. None of this can be achieved without the support and involvement of the public.

Future Care Capital is a charity committed to engaging everyone in the design of health and care provision. It is by being strategic and planning for the future together that we can deploy data to deliver better health and care outcomes for everyone in our society.

References

- 100 for Parkinson's (n.d.) *100 for Parkinson's: a global study for everyone*, [online]. Available from: <https://www.100forparkinsons.com/the-project>
- Achrekar, H., Gandhe, A., Lazarus, R., Yu, S.-H. and Liu, B. (2011) 'Predicting flu trends using Twitter data', *Computer Communications Workshops 2011 IEEE Conference* pp. 702-707, 2011, [online]. Available from: <http://ieeexplore.ieee.org/abstract/document/5928903/?reload=true>
- Aitken, M., de St. Jorre, J., Pagliari, C., Jepson, R. and Cunningham-Burley, S. (2016) 'Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies', *BMC Medical Ethics*, 17 (1), [online], doi: 10.1186/s12910-016-0153-x
- Aotearoa New Zealand Data Commons Project (2017) *Data Commons Blueprint: a high-trust, lower-cost alternative to enabling data integration and reuse*, v1.3, [online]. Available from: <https://static1.squarespace.com/static/57ad3087579fb3721152748f/t/58aea6b217bffc1271903b2e/1487840951842/Data+Commons+Blueprint+V1.3.pdf>
- Basch, E. Deal, A., Dueck, A., Scher, H., Kris, M., Hudis, C. and Schrag, D. (2017) 'Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment'. *JAMA*, [online], doi:10.1001/jama.2017.7156.
- BBC (2017a) China data protection tightened in new laws. *BBC News*, 31 May 2017, [online]. Available from: <http://www.bbc.co.uk/news/technology-40106826>
- BBC (2017b) Google DeepMind NHS medical trial broke UK privacy law, *BBC News*, 3 July 2017, [online]. Available from: <http://www.bbc.co.uk/news/technology-40483202>
- BritainThinks (2015) *Secondary uses of healthcare data public workshop debrief*, [online]. Available from: https://www.bma.org.uk/-/media/files/powerpoint/working%20for%20change/bma_data%20public%20workshop_debrief%20final.pptx?la=en
- British Academy and the Royal Society (2017) *Data management and use: Governance in the 21st century*, [online]. Available from: <https://royalsociety.org/~media/policy/projects/data-governance/data-management-governance.pdf>
- Cabinet Office and Government Digital Service (2017) *Government Transformation Strategy: better use of data*, [online]. Available from: <https://www.gov.uk/government/publications/government-transformation-strategy-2017-to-2020/government-transformation-strategy-better-use-of-data>
- Cabinet Office and Prime Minister's Office (2017), Queen's Speech 2017, delivered 21 June 2017, [online]. Available from: <https://www.gov.uk/government/speeches/queens-speech-2017>
- CityVerve (n.d.) *What is CityVerve? Introducing Manchester's smart city demonstrator*. Available from: <http://www.cityverve.org.uk/what-is-cityverve/>
- Cruickshank, J., Packman, C. and Paxman, J. (2012) *Personal Health Records: Putting patients in control?* 2020 Health, [online]. Available from: <http://www.2020health.org/2020health/Publications/publications-2012/Public-Health-Records.html>
- Decode (n.d.) *What is Decode?* [online]. Available from <https://decodeproject.eu/what-decode>
- Department for Business, Energy and Industrial Strategy (2017a) *Building our Industrial Strategy*, [online]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/611705/building-our-industrial-strategy-green-paper.pdf
-

Department for Business, Energy and Industrial Strategy (2017b) *Business secretary announces Industrial Strategy Challenge Fund investments*, [press release], [online]. Available from: <https://www.gov.uk/government/news/business-secretary-announces-industrial-strategy-challenge-fund-investments>

Department for Digital, Media, Culture and Sport (DCMS) (2017) *UK Digital Strategy 2017*, [online]. Available from: <https://www.gov.uk/government/publications/uk-digital-strategy/uk-digital-strategy>

Department for Digital, Media, Culture and Sport (DCMS) (2015) *Manchester wins £10m prize to become world leader in 'smart city' technology*, [Press release], [online]. Available from: <https://www.gov.uk/government/news/manchester-wins-10m-prize-to-become-world-leader-in-smart-city-technology>

Digital Economy Act 2017, (c30), [online]. Available from: <http://www.legislation.gov.uk/ukpga/2017/30/contents/enacted>

Ford, E., Stockdale, J., Jackson, R. and Cassell, J. (2017) 'For the greater good? Patient and public attitudes to use of medical free text data in research', *International Journal of Population Data Science*, 229 (1), [online] Available from: <https://ijpds.org/article/view/249/231>

Gallagher, J. (2014) DNA project 'to make UK world genetic research leader', *BBC News*, 1 August 2014, [online]. Available from: <http://www.bbc.co.uk/news/health-28488313>

Given, J., Dolk, H. and Robinson, G. (2017) 'Public attitudes to linkage and sharing of health data', *Informatics for Health*, 24-26 April, Manchester Central, [online]. Available from: <http://uir.ulster.ac.uk/37036/>

Genetic Alliance (n.d.). *Programs*, [online]. Available from: <http://www.geneticalliance.org/programs>

Genomics England (2017) *The 100,000 Genomes Project Protocol v3*, [online]. Available from: <https://www.genomicsengland.co.uk/100000-genomes-project-protocol/>

Griffin, A. (2016) Whatsapp threatened with legal action over Facebook sharing deal, *The Independent*, 20 September 2016 [online]. Available from: <https://www.independent.co.uk/life-style/gadgets-and-tech/news/whatsapp-threatened-with-legal-action-over-facebook-data-sharing-deal-a7318981.html>

Gualtieri, M. and Yuhanna, N. (2014) *The Forrester Wave: Big Data Hadoop Solutions*, Q1 2014. Forrester Research, [online]. Available from: http://resources.idgenterprise.com/original/AST-0127029_The_Forrester_Wave_Big_Data_Hadoop_Solutions_Q12014.pdf

Health and Social Care Information Centre (2015) *Information and technology for better care: Health and Social Care Information Centre Strategy 2015-2020*, [online]. Available from: http://content.digital.nhs.uk/media/16232/HSCIC-Draft-Strategy-2015-2020-Information-and-technology-for-better-care/pdf/80435_HSCIC_Strategy_2015-2020-v1f.pdf

Ipsos Mori (2016) *The one-way mirror: public attitudes to commercial access to health data*. Ipsos Mori and the Wellcome Trust, [online]. Available from: <https://wellcome.ac.uk/sites/default/files/public-attitudes-to-commercial-access-to-health-data-wellcome-mar16.pdf>

Ipsos Mori (2014) *Public attitudes to the use and sharing of their data*. Ipsos Mori and The Royal Statistical Society, [online]. Available from: <https://www.slideshare.net/IpsosMORI/public-attitudes-to-the-use-and-sharing-of-their-data>

Korea Joongang Daily (2017) '[Korea and the fourth industrial revolution] Sleek technologies for the city slicker', Korea Joongang Daily, [online]. Available from: <http://mengnews.joins.com/view.aspx?ald=3034351>

Manyika, J., Lund, S., Bughin, J., Woetzel, J., Stamenov, K. and Dhingra, D. (2016) *Digital globalization: the new era of global flows*. McKinsey Global Institute, [online]. Available from: <http://www.mckinsey.com/~/media/McKinsey/Business%20Functions/McKinsey%20Digital/Our%20Insights/Digital%20globalization%20The%20new%20era%20of%20global%20flows/MGI-Digital-globalization-Full-report.ashx>

Moore, S. (2016) Lessons from Seoul: How eGovernment can drive citizen engagement, *Public Technology*, [online]. Available from: <https://www.publictechnology.net/articles/features/lessons-seoul-how-egovernment-can-drive-citizen-engagement>

NatCen (2015) *British Social Attitudes 32*, [online]. Available from: http://www.bsa.natcen.ac.uk/media/38972/bsa32_fullreport.pdf

National Data Guardian (2016) *National Data Guardian for Health and Care Review of Data Security, Consent and Opt-outs*, [online]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/535024/data-security-review.PDF

National Information Board (2014) *Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens: A Framework for Action*. HM Government, NHS and National Information Board, [online]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/384650/NIB_Report.pdf

NHS Blood and Transplant (2017a) Organ Donation and Transplantation Activity Data: England, [online]. Available from: <https://nhsbtdbe.blob.core.windows.net/umbraco-assets/1070/england.pdf>

NHS Blood and Transplant (2017b) Organ Donation and Transplantation activity Data: United Kingdom, [online]. Available from: <https://nhsbtdbe.blob.core.windows.net/umbraco-assets/1616/united-kingdom.pdf>

NHS (2014) *Five Year Forward View*. NHS England, [online]. Available from: <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

NHS Health Research Authority (n.d) *What is Section 251?*, [online]. Available from: <http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/what-is-section-251/>

Our Data Mutual (n.d) *Our Data Mutual: our data for our benefit*, [online]. Available from <http://www.ourdatamutual.org/#manifesto>

Pawelke, A. and Tatevossian, A R. (2013) Data philanthropy: where are we now?, *United Nations Global Pulse*, 8 May 2013, [online]. Available from: <http://www.unglobalpulse.org/data-philanthropy-where-are-we-now>

Piansi, E. and Botchway, S. (2016) *Learning from the pioneers: lessons about data platforms drawn from the WWARN experience*. The Wellcome Trust, [online] Available from: <https://dx.doi.org/10.6084/m9.figshare.4476308.v1>

Platform Cooperativism (n.d.) *About*, [online]. Available from: <https://platform.coop/about>

Platform Cooperativism (2017). *Do you want to learn more about health-data cooperatives? Listen to this podcast about Midata.coop*, [online]. Available from: <https://platform.coop/stories/do-you-want-to-learn-more-about-health-data-cooperatives-listen-to-this-podcast-about-midata-coop>

Project Baseline (n.d.) FAQ, [online]. Available from <https://www.projectbaseline.com/faq/index.html#is-this-a-way-to-receive-free-medical-treatment-or-health-advice>

Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation), *Official Journal of the European Union* [online], Vol. L119 (4 May 2016), pp. 1-88. Available from: http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.L_.2016.119.01.0001.01.ENG

Seoul Metropolitan Government (2016) *IoT system for fire prevention and emergency services introduced in Bukchon*, [online]. Available from: <http://english.seoul.go.kr/iot-system-fire-prevention-emergency-services-introduced-bukchon/>

Stempeck, M. (2014) Sharing data is a form of corporate philanthropy. *Harvard Business Review*, 24 July 2014, [online]. Available from <https://hbr.org/2014/07/sharing-data-is-a-form-of-corporate-philanthropy>

Stevens, L. (2016) Digital roadmaps weak on “how” – review. *Digitalhealth.net*, 5 December 2016, [online]. Available from: <https://www.digitalhealth.net/2016/12/digital-roadmaps-weak-on-how-review/>

Strava Metro (n.d.) *Data-driven bicycle and pedestrian planning*, [online]. Available from: http://cdn2.hubspot.net/hubfs/1979139/Strava_Metro___Data-Driven_Planning.pdf

Tait, J. (2015) Creating a data cooperative. *LinkedIn Pulse*, 14 April 2015, [online]. Available from: <https://www.linkedin.com/pulse/creating-data-cooperative-julian-tait>

Temperton, J. (2016) NHS care.data scheme closed after years of controversy. *Wired*, 6 July 2016, [online]. Available at: <http://www.wired.co.uk/article/care-data-nhs-england-closed>

The Conservative and Unionist Party (2017) *Forward, together: Our Plan for a Stronger Britain and a Prosperous Future*. Available from: <https://www.conservatives.com/manifesto>

The Economist (2017) Data is giving rise to a new economy. *The Economist*, 6th May 2017, [online]. Available from: <https://www.economist.com/news/briefing/21721634-how-it-shaping-up-data-giving-rise-new-economy>

TheGoodData, (n.d.) *Frequently asked questions*, [online]. Available from <https://thegooddata.org/faq>

Thomson Reuters (2017) *Minister discusses EU data protection package, Brexit and EU-US data transfers*, [online]. Available from: [https://uk.practicallaw.thomsonreuters.com/w-005-7343?_lrTS=20170704114439738&transitionType=Default&contextData=\(sc.Default\)&firstPage=true&bhcp=1](https://uk.practicallaw.thomsonreuters.com/w-005-7343?_lrTS=20170704114439738&transitionType=Default&contextData=(sc.Default)&firstPage=true&bhcp=1)

UN Global Pulse (n.d.) *Challenges and hackathons*, [online]. Available from: <http://www.unglobalpulse.org/challenges-hackathons>

Wachter, R. (2016) *Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England. Report of the National Advisory Group on Health Information Technology in England*. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/550866/Wachter_Review_Accessible.pdf

Weber, S. (2017) Data, development, and growth. *Business and Politics*, 1-27. doi:10.1017/bap.2017.3

Appendix I: Connected Health Cities

Overview of the Connected Health Cities programme

The connected Health Cities (CHC) programme is a three year pilot project which began in January 2016, with the aim of better utilising data and technology to improve the health of local populations. In order to harness this potential, four Connected Health Cities have been established in the North of England - Connected Yorkshire, Greater Manchester, the North West Coast, and North East and North Cumbria, brought together through a coordinating centre in Manchester. Funded by the Department of Health and commissioned by the Northern Health Service Alliance, a non-profit membership organisation who received the funding, the programme reaches a large population across the North of England.

The three core aims of the CHCs programme are to:

- develop an efficient system which will enable continuous improvement by providing health managers with key insights (called a Learning Healthcare System);
- engage with citizens and build public trust that data is being used responsibly to deliver wider health benefits to populations; and
- encourage economic growth through digital health technology development.

Each CHC regional hub is distinct, delivering its own pathway projects to meet the needs of local populations but key principles guide the design of CHC programmes.

Data usage and sharing

Data that is used by CHC: varies according to each Connected Health City project and the care pathway focused upon. Data that is used in the programme includes data from health and social care providers as well as patient contributed data from research studies. The CHC programme uses anonymised data wherever possible - for example, in service improvement and evaluation work - although there is the potential to use personal data if individual consent is provided or an appropriate exemption is made.

Access to CHC data: is provided only to analysts and researchers working within the scope of a particular Connected Health City programme. The geographic reach of each project varies but each Connected Health City covers a broad area within the North of England and seeks to extend learning across the whole area.

How data standards are maintained: data from each Connected Health City is stored on a secure serve. In order for each Connected Health City to request access to patient data, appropriate information sharing agreements are required.

Role of citizens – consent and engagement

Role of consent: citizen consent is not required or requested for any use of data where it has been anonymised (although citizens are provided the option to 'opt-out' of sharing their anonymised data with the Connected Yorkshire database). The use of personal data requires either patient consent or a Section 251 exemption, under which patient data can be disclosed for medical purposes without an individual's consent (i.e. in cases where asking for consent is not practical and/or the use of anonymised data isn't possible).

Citizen engagement: one of the three core aims of the CHC programme is to inspire public trust in the use of data to establish a 'social contract' with citizens that provides the basis for healthcare data usage for the public good (Connected Health Cities, 2016) – as such, citizen engagement and contribution is integral to the project. Two citizens' juries were conducted in 2016 to examine public attitudes to the CHC programme, the findings of which were reported in 2017 (Connected Health Cities, 2017). Results from the citizens' juries suggested that citizens generally had a low level of knowledge about linked datasets. Citizens also reported a willingness to share data, including with commercial organisations, provided that this resulted in direct benefits to them. In addition to the juries that were held, the CHC programme has also delivered a public engagement campaign, using the hash tag #datasaveslives to highlight the potential for positive outcomes that can flow from secondary uses of medical data.

A closer look at Connected Health Cities: Connected Yorkshire

The Connected Yorkshire CHC programme covers a population of over 5 million people. One of the key aims of the project is to provide a 'population data laboratory' that links data from across Leeds, Sheffield and Bradford. This collaborative approach will involve three academic institutions; the University of Leeds, University of York, University of Sheffield and the Bradford Institute for Health Research based at Bradford Teaching Hospitals NHS Foundation Trust.

One of the care pathways being focused upon in Connected Yorkshire is 'Promoting healthier child growth'. With a focus on childhood obesity, this research project aims to develop a predictive model that uses multiple sources of data collected from a child's first year of life to determine their risk of obesity later in childhood. As a project with the focus of improving service delivery, and ultimately population health, engagement with key stakeholders is deemed a priority. Once the predictive tool has been fully developed, it will be used by health visitors across Bradford to help feed into their conversations with parents, and significant discussions with these health visitors has already taken place.

To develop the predictive tool, the project is using data from the Born in Bradford study as a sample to develop a model that will predict future risk of childhood obesity. This predictive model will then be used across the anonymised Connected Yorkshire dataset, which draws information from a number of organisations within Bradford and Airedale that have signed data sharing agreements. Organisations contributing this data include: all 88 GP practices in Bradford and Airedale, 3 NHS Trusts, 3 CCGs, the National Child Measurement Programme, Sue Ryder and Bradford Council for Adult Social Care.

Selected pseudonymised data from each of these sources will be joined together in a linked dataset, then, completely anonymised. The linked dataset will be initially hosted by Bradford Teaching Hospitals NHS Foundation Trust, before being held by the Leeds Institute for Data Analytics at the University of Leeds, which has the infrastructure required to enable secure access to the dataset by researchers.

Related Documents/References

Connected Health Cities (2016) PowerPoint presentation. Available from <https://www.connectedhealthcities.org/wp-content/uploads/2016/11/Connected-Health-Cities-Aims-and-Objectives-2.pdf> [accessed 30/05/2017]

Connected Health Cities (2017). Citizens' Juries Report. Available from: <https://www.connectedhealthcities.org/wp-content/uploads/2016/08/CHC-juries-report-Feb-2017.pdf> [accessed 30/05/2017]

Office for National Statistics (2016a) Population Estimates for UK, England and Wales, Scotland and Northern Ireland, Mid 2015. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland> [accessed 12/05/2017]

Office for National Statistics (2016b) Life expectancy at birth and at age 65 by local areas, UK. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/datasets/lifeexpectancyatbirthandatage65bylocalareasuk> [accessed 12/05/2017]

Appendix II: Integrated Digital Care Records

One way in which the power of data and technology is being harnessed at the local level is through the development of Integrated Digital Care Records (IDCRs). To explore the development and scope of IDCRs we produced five case studies to highlight different approaches to record development. These case studies, based in Dorset, Leeds, Cheshire, Hampshire and North West London, illustrate the particular journey that these areas have undertaken in their development of an IDCR. The case studies of the Dorset Care Record (DCR), Leeds Care Record (LCR) and Hampshire Health Record (HHR) were supplemented by interviews with a key stakeholder to understand the journey of IDCR development in greater depth, and we are very grateful to the organisations who contributed for their time and insight.

A summary of findings and recommendations from the case studies is presented integral to Chapter One of this report.

The Dorset Care Record

Interviews with: Director of Design and Transformation at NHS Clinical Commissioning Group and Dorset Care Record Senior Responsible Officer.

Web address: <https://news.dorsetforyou.gov.uk/dorset-care-record/>

The Dorset Sustainability and Transformation Plan identifies three key challenges to overcome in the five years to 2023: the health and well-being gap - whereby health inequalities impact upon different groups of Dorset residents; the care and quality gap - whereby some services do not meet national quality standards and result in a variation of quality; and the finance and efficiency gap in health services - projected to be £229 million per annum by 2023. The Dorset Care Record (DCR) is considered critical in overcoming these challenges and working towards achieving a 'digitally-enabled Dorset' (Dorset Sustainability and Transformation Plan, 2017).

Development of the Dorset Care Record

In 2014, clinicians in Dorset expressed a desire to share information with partners and it became clear that an integrated approach to data sharing across organisational boundaries was key to enabling new models of care. Coupled with thinking nationally around the roll-out of Summary Care Records, of which Dorset was an early adopter, and the promotion of patient access to records, the DCR was identified as the preferred solution by key stakeholders. Development of the DCR began in 2014 and partners anticipate it being rolled out to participant organisations in Autumn 2017.

Overview of the Dorset Care Record

The DCR will draw selected information from clinical record information together to provide a single electronic record which may be viewed by approved professionals working across the health and care sector. Part-funded by NHS England's Integrated Digital Care Fund, and supplemented by funding from partner organisations, the DCR has been developed with technology partner Orion Health.

Design of the Record

1. Access

- **The organisations with permission to access the DCR are:** Dorset GPs, NHS Dorset Clinical Commissioning Group, hospitals (Poole Hospital and Royal Bournemouth and Christchurch Hospitals), Dorset HealthCare University Foundation Trust (community and mental health trust) and councils (Borough of Poole Council, Bournemouth Borough Council and Dorset County Council). A longer-term aspiration is to extend the range of organisations able to access the record to include additional health and care organisations such as hospices and nearby NHS facilities - providing the record's information sharing security criteria are met.
- **Geographical reach of the DCR:** only participating organisations within Dorset will be able to access the DCR, but the project is working with Salisbury, Yeovil and Southampton hospitals to explore the scope for them to add information to the record in future, by virtue of their proximity and role within the Dorset health ecosystem.
- **Secondary data access:** there are no plans or provisions in place to share the DCR with anyone other than professionals directly involved in an individual's care.

2. Data Sharing

- **How data is shared:** selected data is drawn from an individual's records and brought together in a single electronic record - this record is then shared across a range of medical settings and the three local authorities involved in the project.
- **Data included in the record:** contact information and clinical records are shared, including:
 - patient contact details and care needs
 - diagnosed conditions
 - medications
 - allergies
 - test results
 - referrals, clinic letters and discharge information
- **Information Sharing Standards:** the Dorset Information Sharing Charter (2015) governs data sharing by professionals involved in the DCR. The DCR generates an access log recording who viewed it, when they viewed it and what information was accessed.

3. The Role of Citizens

- **Consent:** everyone registered with a participating organisation will automatically have a DCR but sharing of the record works on an opt-in consent basis (i.e. people will be asked for consent to share their record when they first visit their GP or another medical professional). Individuals will be offered multiple consent options to choose from – they can provide blanket consent enabling any professional involved in their direct care to access their record, grant consent to specific professionals, and choose to allow access either indefinitely or for a specified time period. If an individual doesn't provide consent for their information to be shared, the contents of the DCR pertaining to them will remain hidden, with the option of sharing the record in future. In keeping with the law, a patient's carer or relative can provide consent on their behalf should a patient lack the capacity to provide consent.

- **Public engagement:** as the development of the DCR was linked to Dorset's Clinical Services Review, the views of thousands of patients were heard and fed into its development. Leaflets, including an easy read version, have been produced to explain the key features of the Record. The DCR also benefits from a comprehensive public-facing website.
- **Public access to the record:** individuals will not be able to access the DCR in electronic format – although their record can be provided in hard copy format in keeping with the DPA – but the DCR has plans to launch public access to the record in 2019.

Future Plans

- **Extending the scope of information entered into the DCR:** a number of additional information sources are being considered for inclusion in the DCR which could contribute to a planned extension of the record from a patient record to one which more broadly covers the whole population.
- **Social care information:** initially social care professionals will only have read-access to the DCR - the next step is inclusion of social care information, including contact information and care plans.
- **Additional detail from healthcare organisations:** for example, looking to include access by, and data from, hospices and neighbouring hospitals.
- **Wearables/patient contributed data:** once an integrated digital care record is in place, there is the potential to incorporate information from additional data sources, including from wearable devices or remote monitoring systems. This could include connecting remote cardiac monitors, for example, to better support people with Atrial Fibrillation who are at very high risk of stroke if the condition is not well-managed - through the DCR they can be connected to a person's integrated record to provide clinician access to real-time data.
- **Extending access to the DCR:** there are plans to make information available to all partner organisations signed up to the record, including social care organisations, in future. This will enable the production of a joint care record or care plan, whereas each organisation creates its own care plan, using its own system, at the moment. Public access is expected by 2019, and is widely regarded as an opportunity which could lead to clinicians entering into digital conversations with service users – empowering individuals to become fully engaged in their own health and wellbeing.

The Leeds Care Record

Interview with: Project Manager, Leeds Care Record

Web Address: <http://www.leedscarerecord.org/>

The Leeds Health and Wellbeing Strategy (2016), which feeds into and complements the West Yorkshire and Harrogate Sustainability and Transformation Plan (2016) identifies particular challenges for the city, which include: addressing significant differences in life expectancy across areas within Leeds, shifting focus from curing illnesses to managing (often multiple) health conditions, and addressing the social, economic and lifestyle factors that contribute to poor health. The Strategy also sets out significant financial challenges, with an estimated £700m funding shortfall across health and social care organisations in Leeds by 2021, whilst the West Yorkshire and Harrogate STP, covering a broader area, also projects a significant

gap of £1.07bn. Maximising the benefits arising from information and technology forms one of the Strategy's 12 priority areas, within which the continued development of the Leeds Care Record (LCR) is highlighted, as is the aim of providing patients with access to and control over their health records (Leeds Health and Wellbeing Board, 2016).

Development of the LCR

After collaboration with key stakeholders, including senior leaders and patients, it was decided that development of the LCR would build upon existing systems within Leeds. The principal benefit of this approach is regarded as giving the team behind the LCR control over how it develops, ensuring a system that is clinically-led. With development of the LCR beginning in 2013 across four GP surgeries, the record covered all GP surgeries in Leeds by 2015, and over the last year usage of the record has grown substantially from approximately 2,000 to 4,000 active clinician users. Social care data from Leeds City Council was included in 2016-17. This seeks to make an open source platform available and promotes interoperability and flexibility in integrated digital care records.

Overview of the LCR

The LCR draws together selected data from health and social care providers into a single electronic record, which may be viewed by professionals working within an approved provider organisation. The technical solution to deliver the LCR is built upon the Leeds Teaching Hospital's trust-wide electronic patient record system developed in Leeds hospitals over 10-15 years - Patient Pathway Manager Plus (PPM+). Additional information is imported from other organisations using technical solutions that enable interoperability through open standards.

1. Access

- **Organisations that can access the LCR:** the LCR operates across all GPs in the area, 3 CGS, the Leeds and York Partnership Foundation Trust (mental health), Leeds Community Healthcare NHS Trust, Leeds Teaching Hospitals NHS Trust and Leeds City Council. Other users which can access the record but which do not contribute data are both adult hospices in Leeds, and Yorkshire Ambulance Services, which is currently in the piloting stage. A number of teams have requested access to the LCR for safeguarding purposes, but this has been rejected because the record remains focused upon direct care provision at present.
- **Geographical reach:** access is only available to participating organisations within Leeds.
- **Secondary data access:** the LCR may only be used by professionals directly involved in an individual's care and, therefore, no secondary access to LCR data is currently offered.

2. Data Sharing

- **How data is shared:** selected data from several health and social care systems is drawn into the LCR. As a 'view only' portal, information cannot be added to the LCR, but changes made by professionals to the systems from which LCR data is drawn are reflected in the record. The data that is shared varies across provider organisations:

Information from health providers can include:

- patient contact details
- contact details of professionals involved in a patient's care
- diagnosed conditions

- medications
- allergies
- test results
- referrals, clinic letters and discharge information
- healthcare plans

Information from social care providers can include:

- contact details of care professionals
 - indicators to active or open referrals
- **Information Sharing Standards:** the LCR produces an access log, recording details whenever it is accessed, including details of who viewed it, when they viewed it, and which information was accessed.

3. Role of Citizens

- **Consent:** individuals registered with a participating organisation in Leeds will automatically have a LCR. Consent is provided through an 'opt-out' model, whereby an individual can contact the LCR to have their information removed from the record. This consent can be given or revoked at a later date should an individual change their mind.
- **Public engagement:** engagement meetings were conducted to understand citizen's views and inform them about the LCR. These produced key insights - for example, prior to engagement, it was thought that the public might oppose inclusion of social care data in the LCR, but the feedback from them was that concern was not widespread. A public-facing website and a range of leaflets and posters have also been developed to inform individuals about the record.
- **Public access to the record:** individuals cannot access their LCR at present - although demand for access to a patient portal has been identified within the future scope for development of the record, stakeholders have yet to decide whether the LCR represents the best technical solution to enable patient access to information. Access is nonetheless provided in accordance with the DPA which allows individuals to make a 'subject access request' to the organisation that holds the records upon which the LCR is based.

Future Plans

- **Extending the functionality of the LCR:** to provide alerts and notifications - this could have benefits to patient safety (for example, in the case of prescription of certain categories of drugs) as well clinical safety (for example, alerts about potentially violent behaviour).
- **Extending the geographical reach of the LCR**
- **Ongoing review of technical solutions:** developing the user experience - data is currently presented in an organisation-specific manner through different tabs. Once access to structured data across all settings is obtained, the LCR hopes to provide a patient summary which will combine all views.

- **Extending access to citizens:** stakeholders are considering how best to provide citizens with access to their information and some initial citizen engagement has already taken place.
 - **Extending the scope of data within the LCR:** to include more information from social care providers, which could support hospital discharge processes – for example, the contact details of social workers and free text annotation of the last contact that a social worker had with an individual.
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The Cheshire Care Record

Highlighting issues in health and social care that affect the broader area of Cheshire and Merseyside, the Cheshire and Merseyside Sustainability Transformation Plan (2016) points to challenges that include: high rates of hospital admissions relating to alcohol, poor mental health and wellbeing, and increasing prevalence of diseases related to older age. The Cheshire Care Record (CCR), together with the Wirral Care Record, is regarded as a key enabler in meeting the ambitions of the Cheshire and Merseyside Sustainability Transformation Plan (2016).

Overview of The Cheshire Care Record

The CCR draws selected information from across health and social care services into a separate electronic record which may be viewed by professionals working within a participating health or care organisation. Launched in early 2016, the records of 739,000 citizens are now shared through the CCR. The project has benefited from funding from the Department of Health's Integrated Digital Care Fund and has been developed with the technology partner Graphnet.

1. Access

- **Organisations that can access the CCR:** GPs across four Clinical Commissioning Groups, hospitals, mental health services, community care, specialist care (including cancer services and hospices), out-of-hours services and councils (Cheshire West and Chester and East Cheshire Councils).
- **Geographical reach:** the CCR can only be viewed by participating organisations within the Cheshire area.
- **Secondary data access:** the CCR can only be viewed by professionals directly involved in an individual's care - no secondary access to data is offered.

2. Data Sharing

- **How data is shared:** selected information is drawn from multiple health and social care providers and combined in a view-only, digital record. This record can be viewed by professionals within participating organisations (once consent requirements are met). As a 'view only' record, information cannot be added to the CCR, but changes made by professionals to the underlying systems from which the CCR record is drawn are reflected in the CCR.
- **Data included in the record:** the CCR makes comprehensive data available to professionals with view permissions.

Information from health providers includes:

- patient contact details, including carer if applicable
 - contact details of care professionals
-

- medications
- allergies
- test results
- referrals, clinic letters and discharge information
- observations and lifestyle indicators (e.g. blood pressure, weight and smoking levels)
- vaccinations and immunisations
- GP family history
- child health
- chronic disease monitoring
- pregnancy, birth and post-natal
- end of life care plan
- GP and hospital appointments
- oncology data (including tumour details and radiotherapy/chemotherapy appointments)
- community data (including referrals, events and observations)
- mental health data (including referrals, events and appointments)

Information from social care providers includes:

- disabilities
 - risks
 - summary case details
 - assessment summary
- **Data Sharing Standards:** the CCR is hosted as a secure database, maintained by the Countess of Chester Hospital. An Information Governance Group oversees the security of the CCR, with membership comprising of the Caldicott Guardians responsible within each participating organisation, as well as patient representatives. Each participating organisation must also sign a Data Sharing Agreement, which sets out standards to which they must conform. The CCR also produces an access log of who has accessed a record which participating organisations can review.

3. Consent and Public Engagement

- **Consent:** individuals registered to a participating organisation within Cheshire are automatically provided with a CCR - consent for data linkage is provided on an 'opt-out' basis, such that an individual must inform their GP surgery if they do not want an integrated record. Explicit consent is then requested so that the record can be shared – i.e. data sharing is provided on an 'opt-in' basis. This consent provides access to all health and care professionals in participating organisations (in line with access requirements), but if an individual wishes to only give consent to a professional on a certain day, they can consent to access for a 24 hour period only. For those who choose to 'opt-out' of the CCR, they can change their mind and 'opt-in' again through their GP surgery.

- **Public access to the record:** individuals do not currently have from access to their own records through the CCR, although access to a patient portal has been identified within the scope of future plans. Individual access is therefore limited to a right to request a copy of a record, which the CCR notes is provided through the Freedom of Information Act 2000; to request a copy of a CCR, individuals must contact their GP. Individuals are also able to request an audit report listing professionals who have accessed their record, including details of when it was accessed and where.
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The Hampshire Health Record

Interview with: Chief Clinical Information Officer, Hampshire Health Record

Web Address: <http://www.hantshealthrecord.nhs.uk/>

Hampshire faces a number of key challenges including, but not limited to: delayed discharges from hospitals, the management of long-term chronic conditions and mental health service provision. Its Sustainability and Transformation Plan sets out how these challenges will be met by stakeholders deploying a range of mechanisms – one of which is patients taking more control of their health. A patient portal, where patients can view their records online, is regarded as an enabler in this regard. Development of the HHR began in 2005, making it one of the earliest integrated digital record systems in England. Although the original focus of the record was to produce a repository of data for research and analysis, the primary purpose of the record has more recently shifted towards one of supporting the provision of care, and is now regarded as a ‘mission critical’ system. Within this shift, use of the record has undergone substantial growth, and applied to some 1.9 million individuals by January 2016 – a reach which extends beyond the Hampshire population.

Overview of the HHR

The HHR draws clinical information from health and social care services, bringing it together in one single electronic record. This electronic record can be viewed by professionals directly involved in an individual’s care across participating health and care organisations. The HHR is funded by the seven Hampshire CCGs, with a contribution from the University of Southampton. It is managed by the South, Central and West Commissioning Support Unit and delivered by technology partner Graphnet.

1. Access

- **Organisations that can access the HHR:** CCGs, GP surgeries, hospitals, and Hampshire County Council contribute information to the HHR as well as being able to view the record. Others can view the HHR but do not contribute data, and include out-of-hours GP services and the South Central Ambulance Service.
 - **Geographical reach:** the HHR can be viewed by participating organisations within Hampshire. A key development has been the addition of discharge and clinic letters from Royal Bournemouth and Christchurch Hospitals NHS Trust. Due to the proximity of these services, such information is now routinely added to the records of patients who are otherwise registered to a GP in West Hampshire.
 - **Secondary data access:** the HHR shares some information with other organisations, including CCGs and university research partners. Data for research comes from the HHR
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Analytics (HHRA) database, which is hosted separate from the HHR. Before being sent to the HHRA, data is 'pseudonymised', with patient identifiers removed from the data. Patient data is automatically sent to the HHRA, however individuals can choose to opt-out of this secondary processing activity. Research access to HHRA data is decided by a digital panel comprised of clinical staff and non-clinicians. Research conducted using the HHRA includes research into pneumonia risk among those with lung conditions, which was based upon a HHR cohort of over 6,700 patients. Data in the HHR/HHRA is never shared with commercial organisations.

2. Data Sharing

- **How data is shared:** the HHR draws selected information from health and social care services, and links it together in the form of a single electronic record. This electronic record can then be viewed by professionals in participating organisations across health and care services (providing access requirements are met). There is a small amount of 'write' access whereby clinicians can fill in certain forms, such as end of life preferences, but this isn't actively used and has been superseded by other ways of inputting this data.

- **Data included in the record:**

Information from health providers includes:

- allergies
- medication
- diagnosis
- test results
- treatments
- clinical correspondence from hospitals
- discharge summaries and outpatient appointments

The record has also announced a new option to include preferences for end of life care.

Information from social care providers includes:

- social care team/s involved in the person's care
 - the person's assessment of need
 - type and frequency of care being received by social services
- **Data Sharing Standards:** the HHR record is hosted as a secure database, maintained by the NHS in Hampshire. A full audit trail of access to the record is kept, including who accessed the record and what information is viewed. Caldicott Guardians for the HHR maintain overall responsibility for the security of the record. Furthermore, a Security and Consent Framework sets out data security arrangements and guidelines for the protection of data held within the HHR.

3. Consent and Public engagement

- **Consent:** people are automatically provided with a HHR – consent as to whether data is linked is provided on an 'opt-out' basis. However, for information to be shared, individuals must 'opt-in' by providing active consent for their record to be shared in each case. This can be amended at a later time, should the individual change their mind.

- **Public engagement:** working in partnership with Carers Together, a local charity representing individuals and their carers, a set of posters were developed to promote understanding of the HHR and made available across participating organisations.
- **Public access to the record:** citizens do not currently have access to the HHR – although they can request access in accordance with the Data Protection Act together with a copy of the audit trail for their record. Exploration of a patient portal is underway – this could be within the HHR or through other mechanisms designed to make access as straightforward as possible for users.

Future Plans

Looking ahead, stakeholders have ambitious plans for the HHR - some of which may take up to ten years to be realised – but building on the current infrastructure and abilities of Hampshire and the HHR is regarded as key:

- **Identifying and addressing gaps in the coverage of the HHR:** including gaps in the data being recorded, organisations failing to upload information and organisations not accessing the HHR.
- **Ongoing review of technical solutions:** future plans will revisit the data sharing model that underpins the HHR and consider how much data is collected and pooled. Combining analytical tools used in healthcare systems (for example, risk stratification or financial performance tools) will also be explored - bringing these together in one intelligence hub could improve intelligence systems and better identify populations at risk / help manage them.
- **Extending the functionality of the HHR:** for example, providing alerts (for example, flagging hospital attendance information to a GP).
- **Extending access to patients:** a patient portal is being actively worked on, with the present focus on defining priorities. A nationally recognised patient held record is currently being developed by a hospital in Southampton, delivered through Microsoft HealthVault. Options being explored include the possibility that a participating individual's HealthVault record could be linked to the HHR containing their data.

Care Information Exchange

Encompassing the eight boroughs of Hounslow, Hillingdon, Harrow, Ealing, Brent, Westminster, Kensington and Chelsea, and Hammersmith and Fulham, North West London broadly covers a population of over 2 million people. Technological development and digital advances are identified as a key means through which the challenges facing the area can be met, and the Care Information Exchange (CIE), a patient-centred integrated digital record, is regarded as critically important. In the North-West London Sustainability and Transformation Plan, the CIE is said to contribute towards three of the five main delivery areas, including: upgrading prevention and wellbeing, achieving better care for older people and ensuring high quality, sustainable acute services.

Care Information Exchange Overview

The CIE is a web-based application that pools selected information from health providers with data contributed by individuals themselves. The CIE can be accessed by citizens and shared with a range of health and care providers as well as other parties with whom an individual wishes to share (for example, relatives and friends). As a citizen-centred application, one of the key aims of the CIE is to enable individuals (both service-users and carers) to work with professionals - moving towards a model of joint decision making. It is also designed to support them to build the confidence to manage their own health and wellbeing, and to support them to find the care that they need.

The CIE is delivered through Patients Know Best – a patient portal which is currently used in over thirty healthcare settings in the UK - and puts patients in control of information sharing. Funded by the Imperial College Healthcare Charity, the CIE programme began in 2014. Initial pilots of the CIE have focused on patients who have the greatest need for health and care services, including the over 65s and those with chronic conditions, although the ultimate goal is that all citizens in North West London will have access to the CIE. Looking ahead, the CIE will also feature in the work of the Chelsea and Westminster Hospital NHS Foundation Trust and Imperial College Healthcare Trust as a Global Digital Exemplar to highlight world-class use of digital technology and data.

1. Access

- **Access to the CIE:** selected groups of patients are using the CIE at present, when invited to participate by the care professionals working with their pathway. The range of organisations working with the CIE overall include NHS Trusts and Foundation Trusts across acute, community and mental health services, 8 CCGs, the NHS 111 service, ambulance service, urgent care centres and a range of local authorities.
- **Geographical reach:** the CIE is being used in specified pathways within North West London, however the overarching goal of the project is to ensure that the CIE is available to all individuals in North-West London.
- **Secondary data access:** CIE data is a patient-focused data sharing portal and does not use the data for any other purpose.

2. Data sharing

- How data is shared: selected data from healthcare providers, as well as patient contributed data, is drawn into the patient portal, provided through a web-based platform and accessed through a password-protected user account.
- Data included in the record: the type of data included in the CIE varies according to the project or patient pathway and can be entered only where a hospital or GP system is connected to the CIE.

When this is the case, data from healthcare providers can include:

- care plan, providing a record of treatment, including medications
- past and future appointments
- test results
- links and advice materials (including leaflets, audio files and videos)

Patient contributed data can include:

- appointments (manually entered, if the organisation they attend isn't connected to the CIE)
- journal entries recording thoughts and observations on their own health

Patient contributed data from healthcare devices:

- blood pressure monitors
- glucose monitors
- activity trackers (e.g. Fitbit)

Additional operating features include:

- communication options of messaging and video conferencing
- How data standards are maintained: participating organisations must sign and abide by an Information Sharing Agreement and the CIE is held on a secure NHS server.

3. Consent and public engagement:

- As the CIE does not currently provide universal coverage, individuals may be invited to join the CIE by a professional involved in their care. For CIE participants, citizen control is high, with individuals exercising control over who can access their information via the patient portal. Beyond the scope offered by most integrated digital care records, the CIE allows citizens to choose to share their record with various care providers, relatives, friends and carers. Individuals can choose the information they would like each party to be able to access. In emergency situations, however, health and care professionals can access an individual's CIE record without obtaining prior consent – in these cases, an audit trail is kept detailing the person who accessed the record and the reason for this.

Related Documents/References

Cheshire and Merseyside Sustainability Transformation Plan (2016). Cheshire & Merseyside Sustainability and Transformation Plan, v 4, [online]. Available from: <http://www.westlancashireccg.nhs.uk/wp-content/uploads/Cheshire-Merseyside-STP.pdf>

Dorset Information Sharing Charter (2015) DiSC Dorset Information Sharing Charter: by sharing information we work better together, [online]. Available from: https://www.dorsetforyou.gov.uk/media/211142/DISC-final-version/pdf/DISC_Final_version.pdf

Dorset Sustainability and Transformation Plan (2017) Our Dorset: Sustainability and Transformation Plan for local health and care, [online]. Available from: <http://www.dorsetccg.nhs.uk/Downloads/aboutus/Our%20Dorset%20STP/Our%20Dorset%20Sustainability%20and%20Transformation%20Plan%202004%2017.pdf>

Hampshire and Isle of Wight Sustainability Transformation Plan (2016) Hampshire and Isle of Wight Sustainability and Transformation Plan Summary, Draft November 2016, [online]. Available from: <http://www.uhs.nhs.uk/Media/SUHTInternet/News/HIOW-STP-summary-Nov-2016.pdf>

Leeds Health and Wellbeing Board (2016) Leads Health and Wellbeing Strategy, [online]. Available from: <http://inspiringchangeleeds.org/wp-content/uploads/2016/05/Leeds-Health-and-Wellbeing-Strategy-2016-2021.pdf>

North West London Sustainability and Transformation Plan (2016) Our plan for North West Londoners to be well and live well, [online]. Available from: https://www.healthiernorthwestlondon.nhs.uk/sites/nhsnwlondon/files/documents/nwl_stp_october_submission_v01pub.pdf

West Yorkshire and Harrogate Sustainability and Transformation Plan (STP) (2016). Draft Proposals October 2016, [online]. Available from: <http://www.southwestyorkshire.nhs.uk/wp-content/uploads/2016/10/Final-draft-submission-plan.pdf>



Further Information

For further details about us, our Mission and Values, the Board of Trustees and the Executive Team please visit our website or follow us on twitter.

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