Intelligent sharing: unveiling the potential of health and care data in the UK to transform outcomes
**Introduction**

The power of data to deliver improved health and care outcomes for everyone in our society is potentially very significant – whether it:

- empowers individuals to better manage a health condition with which they live;
- helps people to understand and contribute to the care of family and friends;
- raises standards and positively impact the experience of service-users;
- assists professionals in commissioning the most effective interventions to benefit the populations they serve;
- allows researchers to develop next generation medicines and treatments; or
- enables innovators to deploy leading-edge machine learning techniques and cognitive service developers to revolutionise well-being.

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. Our 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.

In pursuit of this ambition, it provides a summary of pertinent strategies and initiatives, presenting findings from desktop research and interviews with organisations pioneering the development of Integrated Digital Care Records, highlighting the Government’s aims and practical approaches to implementation in local settings – their strengths and their weaknesses. It explores the rationale and scope for the UK to build upon emergent practice from around the world and become a global leader in data philanthropy and, thereby, push at the boundaries of existing plans and programmes to amass unrivalled health and care data sets. It also outlines how the UK can establish what we’ve termed a health and care data advantage to proactively stimulate innovation and support enterprise as the country becomes more global in its outlook.

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 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 felt throughout the country. Our vision is a society which cares for all and in which everyone benefits.
Context

Data is often referred to as the ‘new oil’ - with ‘data flows’ said to be exerting a greater impact upon global growth than traditional goods flows in recent years. Small wonder, then, that governments right 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 of critical importance, courtesy of technological advancements over the course of the past twenty-five years, and particularly where peoples’ health and care data 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. 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. This has resulted in the development of the General Data Protection Regulations by EU member states, which will strengthen the rights of individuals to control access to and use of their personal data, at the same time as it further enshrines the principle of ‘free movement of data’ in dealings between them. It has also impacted the health and care landscape in the United Kingdom in recent years.

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 progress has been made, the last Government took the decision to discontinue its flagship NHS data sharing programme - care.data – in 2016¹, which had until then aimed to create unrivalled access to pseudonymised health and care data amassed by the NHS to reap associated benefits in research and innovation. It took the decision because it faced mounting public pressure and professional concern about ethics and security issues, which exposed the need for improved engagement and education, but 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 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) in the interim. 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.

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The Government’s response to its consultation on the Review’s findings is eagerly anticipated, but is widely expected to reiterate that government and its agents should function as arbiter between individual privacy rights and value creation for wider benefit where health and care data is concerned. Our own research points towards there being 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 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.

Preparation of our report involved research in keeping with the following methodology:

- broad-ranging literature review;
- soliciting legal input to review applicable UK, EU and international legislation and practices vis-à-vis data protection;
- detailed case study development following review of Integrated Digital Care Record pioneers and structured interviews with local stakeholders;
- 1-2-1 discussions and correspondence with experts in statistics, data, technology investment and technology development; and
- generation of recommendations oriented towards commissioners and providers, third and private sector agents as well as government.

A detailed summary of our recommendations is provided below and includes:

**Investment in skills and data-driven business clusters across the country** – we urge the Government to establish data-driven business clusters for new health and care enterprises. It is important to encourage and support early stage health and care start-ups and SMEs to succeed. The clusters would provide skills training to help prepare the future workforce for the increase in demand for data-related job opportunities.

**A National Health and Care Data Donor Bank** – we believe a trusted intermediary for individuals consenting to donate their health and care data for the purposes of research and innovation would positively impact health and care outcomes and support professionals to transform important services. We envisage that the Data Bank would be a national asset held up as an international exemplar in what we term data philanthropy.

**A health and care data privacy shield for the UK** – the UK will adopt the General Data Protection Regulation it has developed with other EU member states in 2018, and negotiate independent data sharing arrangements with countries outside the European Economic Area following our exit negotiations with the EU. We recommend the government develops a dedicated health and care data privacy shield applicable to future international trade discussions to ensure that the UK has appropriate provisions in place.
Summary findings and recommendations

National Context: enabling responsible data sharing and building public trust

Health and care organisations 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.

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. There is 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.

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.

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.
Key Findings: 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.

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 – 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.
Pushing the Boundaries: creating a culture of data philanthropy in a Digital Britain

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. 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.

Key Finding: a growing body of evidence 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.
**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.
Establishing a Health and Care Data Advantage: investing in skills, business and infrastructure

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 cornerstones 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 (IoT). Ultimately, we believe an 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.

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.

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.
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.

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

Our 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 – “intelligent data 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.
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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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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