

Unleashing data to make a difference to people's health and care

December 2022

Introduction

The COVID-19 pandemic has accelerated the potential for global health and care systems to fully harness the power of data, including artificial intelligence (AI) and digital health technology. In Wales, there is increased priority and focus on digital health policy with the establishment of Digital Health and Care Wales (DHCW) and other supporting organisations. The Welsh health and care system has a unique opportunity to lead the way and become an exemplar in how data can be maximised by all parts of the system to deliver more prudent health and care and make a real difference to people's lives now and in the future.

To help realise this ambition, the Bevan Commission played an advisory and facilitatory role in a roundtable event, sponsored by Bristol Myers Squibb (BMS), which was attended by leaders of the Welsh health and care system. The event sought to explore potential solutions to a series of challenges around the Welsh data environment. The recommendations contained within this report are not exhaustive and whilst these solutions are multi-faceted, it is evident from the roundtable that some clear themes exist including:

- reducing fragmentation to ensure data is easily accessible and used by all parts of the system.
- having a single point of contact with responsibility for coordinating and unleashing the power of data.
- maintaining the trust of the population in NHS data systems.
- ensuring that funding from beyond the Welsh health and care system is able to match resource capacity and attract greater inward investment.

As an overarching recommendation, the roundtable attendees proposed that **a roadmap should be developed which details the key players, barriers and steps needed to overcome the challenges that exist in Wales.** This would help to clarify the challenges and the actions needed to address these. It would be led, developed and owned by a leader in the Welsh health data environment working in partnership with other key stakeholders. It would work to reduce fragmentation amongst the many stakeholders that comprise the Welsh health and care system, providing clarity and focus on the next steps. The roadmap would detail who is responsible for delivering solutions to overcome identified concerns. This report outlines a series of recommendations to meet those challenges, which we believe should form the basis of the roadmap.

It is important to note that the National Data Resource (NDR) data strategy sets out a roadmap, which may meet some of the recommendations in this report.¹ The recommendations in this report are intended to compliment and supplement the NDR roadmap. We believe that these recommendations broaden the scope of the NDR roadmap to address the key themes outlined above to enable consideration of wider areas, such as stakeholder cohesion in the health data ecosystem, public awareness and future challenges and solutions to data access in Wales.

A gap analysis needs to be undertaken between this report and the NDR data strategy to identify further actions that are needed.

The recommendations contained in this report draw on insight gathered during the Bevan Commission roundtable that was undertaken and sponsored by BMS. The roundtable, held virtually on 16th June 2022 and attended by stakeholders from across the health and care system, addressed how improved collaboration can catalyse solutions to harness the power of data.

Attendees

Baroness Finlay of Llandaff, Commissioner, Bevan Commission (meeting Chair)

Philip Bowen, Deputy Director for Digital Policy and Delivery, Technology, Digital and Transformation, Health and Social Services

Helen Howson, Director, Bevan Commission

Rachael Powell, Associate Director, Information, Intelligence & Research Digital Health and Care Wales

Scott Cooke, General Manager UK and Ireland, Bristol Myers Squibb

Martin Coombes, Director Policy Advocacy and Government Affairs, Bristol Myers Squibb

Ann Tate, Chief Executive, Cancer Research Wales

Richard Pugh, Chair, Wales Cancer Alliance and Head of Partnerships Macmillan

Dame Sue Bailey, Bevan Commissioner (facilitator)

Professor Tom Crosby, Deputy Chair, Wales Cancer Network, National Cancer Clinical Director for Wales

Prof Ronan Lyons, Co-Director, Secure Anonymised Information Linkage (SAIL) databank

Prof Dyfed Wyn Huws, Director, Welsh Cancer Intelligence and Surveillance Unit at Public Health Wales

Key Definitions

Health Data: All information that could or should be included in every patient's health record (ideally held electronically) – for example, clinical examinations, signs, symptoms and diagnostic tests including scans and laboratory tests, treatments prescribed, records of vaccination, procedures undertaken and outcome measures, as well as similar information generated during the conduct of a clinical trial.²

Digital Health Technology: Digital Health Technologies comprise a wide range of products used in the health and social care system, including apps, software and online platforms that are intended to benefit people or the wider health and social care system.³ Two key strands to digital health technology exist:

1. **Digital discovery:** comprising pharmaceutical company services, enterprise systems and support, and clinician services and support.
2. **Patient facing:** comprising digital therapies, patient diagnostics and monitoring, and patient wellness and support.

Artificial Intelligence: Artificial intelligence leverages computers and machines to mimic the problem-solving and decision-making capabilities of the human mind.⁴

About the Bevan Commission and Bristol Myers Squibb

Established in 2008, the Bevan Commission is Wales's leading health and care think tank, hosted and supported by Swansea University. The mission of the Bevan Commission is to ensure that Wales can build sustainable, integrated prudent health and care services that are fit for the future. It is made up of a panel of 24 expert commissioners.⁵

BMS is a global biopharmaceutical company whose mission is to discover, develop, and deliver innovative medicines that help patients prevail over serious diseases.



Building on Wales's potential

Wales has a unique and compelling opportunity to become a data and digital health technology powerhouse.

Wales's size and proven track record of integrated health and care means measures to optimise approaches to data are more easily navigable and better shared. Building on this potential recognises the principles of Prudent Healthcare, notably around co-production, reducing inequalities, and providing transparency and systematic quality.⁶ Prudent Healthcare is at the heart of 'A Healthier Wales', the Welsh Government's long-term plan for health and care, and informs much of today's health and care policy and discussion in Wales.⁷

Wales is already a world leader in the use of data for research purposes with the creation of the Secure Anonymised Information Linkage (SAIL) system, supported by the Welsh Government.⁸ Data from SAIL played an important role in informing Welsh Government decision-making in controlling the COVID-19 pandemic.⁹ The multimillion Administrative Data Research Wales award to Welsh Government and academia by UKRI-ESRC supports data analysis to inform policy development across many non-health sectors. Integration of health and non-health data is essential to answer the many complex questions that affect population wellbeing.

There are necessary mechanisms in place which ensure the safe and appropriate use of data, particularly for patients, including meeting the Common Law Duty of Confidence and the General Data Protection Regulations (GDPR). These enablers, whilst sometimes slowing down access to data, are of fundamental importance. A more fundamental issue is that the full raft of health and social care data available in Wales is not mined for high quality analysis and subsequent appropriate intervention. This report and its recommendations seek to find solutions to more practical barriers which stand in the way of Wales becoming an exemplar data environment.

The roundtable meeting concluded that a data roadmap should be developed to help realise the potential Wales has to offer. This roadmap will outline a strategic approach to overcoming issues such as system fragmentation, sub-optimal data accessibility, a lack of accountability and limited resource provision. The roadmap is designed to complement the findings of the NDR strategy.



Overcoming Barriers to Optimise the power of Data

The data roadmap should identify the solutions needed to fully realise the power of data across health and care in Wales. In the first section of this report, we aim to clarify the key challenges and potential solutions, including ways to remove or overcome the barriers without risking patient confidence or the security of their data.

During the roundtable discussion, the following barriers were identified as essential to overcome.

Fragmentation

The health and care system comprises many different stakeholders: Health Boards and Trusts; Welsh Government; Social Care and Local Government, the patient community and the wider public; research organisations; and industry, including both larger and mid-size to smaller life sciences companies. All these stakeholders have unique perspectives and contributions to make for an exemplar data system to become a reality – it needs to be collaborative and work for everyone.

However, in Wales, despite its size, these stakeholders don't always come together with shared purpose to progress joint solutions. This means that some interested groups are overlooked and the potential will not be realised. Attendees at the roundtable pointed to examples in the past where interventions had been led and implemented by Government, without clinical engagement or ownership and without a pre-defined framework for evaluation. It was felt that without a joint approach, interventions did not meet expectations and were not as efficient or effective as they could have been.

A fragmented healthcare data system also hinders the adoption and spread of best practice and innovative approaches.

This was highlighted in the recently published 'Healthy Mum, Healthy Baby, Healthy Future' report as a key reason for causing severe detriment to individual women.¹⁰

Health Boards in Wales already provide an integrated approach to health and care as each one is a single local health organisation, responsible for delivering all health and care services within their respective geographical area.

Despite this, all too often, innovative approaches to health data occur in siloes which results in a failure to transfer important data between different providers of health and care within a particular Board. This leads to variation in care and outcomes. Such siloed working also plays out between Health Boards, leading to national variation in outcomes.

Further work and learning from the Bevan Commission's national Adopt and Spread programme is pertinent to this.¹¹ This programme allows for the spread and implementation of innovative best practice, or 'exemplars'. It is a national scheme funded by the Government. Each exemplar innovation is rolled out to multiple locations and teams, known as 'adoption sites'. Each adoption site receives support, funding, training and coaching.

Accessibility

Accessibility of data across the health and care system is a problem the world over. There are fundamental practical issues such as the steps some stakeholders, for example industry, particularly smaller companies, and research organisations, need to go through to gain permission to access data. There are also functional issues around the technology and digital infrastructure which is required to use, store, and analyse data. Cycles of innovation can prevent slow-to-adopt health systems from truly harnessing the power of data. This problem can be exacerbated by data infrastructure heterogeneity, where different stakeholders operate on different IT platforms, resulting in non-compatibility of systems to use data.

Attendees of the roundtable discussed that, in Wales, despite an integrated approach to health and care, data ownership operates in siloes. While improvements are being made in some areas such as the 'single patient record', data exchange within and between different parts of the health and care system remains limited. This can lead to less effective and streamlined patient journeys through the system, with data on health and care outcomes not being available to all those who might develop and deliver patient care services, including patients themselves. Further research ought to be completed to audit and quantify these limitations so those responsible for implementing solutions are able to do so effectively.

A whole system approach

In harnessing the power that data can have for the health and care system, co-production is paramount. All partners can benefit from greater data accessibility. Industry is better able to deliver successful product launches if it knows where within patient pathways, and with which patient cohorts, health technologies have the greatest impact. Examples of this include the use of genomic and demographic data to identify populations that are at a high risk of certain conditions and in turn, target screening and treatment. This reduces inappropriate treatment. Real-world evidence is an effective way to do this, but it relies on efficient data interoperability and not overly bureaucratic means to access data.

Even before a product reaches the market, a rich data environment can assist research organisations and industry to further research and development (R&D) capabilities. This is true for medicines, medical technology, diagnostics and digital health technologies. The SAIL system does this to a certain extent.

However, as previously mentioned, SAIL does not yet have all the data available which would be beneficial. A data environment that better enhances R&D capabilities in Wales will result in greater investment from industry. Similarly, as companies look to develop products for patients in the NHS, they need to understand where the greatest unmet need is. Data is key to identifying that unmet need, which is fundamental to ensure that the life sciences industry works for the benefit of future populations.

Data can also be used by actors within the health and care system to improve existing services. Data driven service redesign not only recognises opportunities for service improvement, but also allows users to measure the success of changes which have been implemented.

Rich data is available for all of this to happen. However, some bureaucratic processes with a lack of clarity around who the ultimate decision maker is, act as a barrier to the life sciences industry making truly informed, real-world data driven decisions. This topic is being addressed by the NDR data strategy.

Industry can act as an important enabler for this to happen. Whilst it cannot unlock data access alone, it is well placed to bring stakeholders, including Government, clinicians and patient organisations, together around well specified issues. Ultimately, health and care innovation, driven by identified needs from those working directly with clinical services, will be better able to deliver on the benefits afforded by increased, appropriate data accessibility.

All companies should abide by the Association of the British Pharmaceutical Industry's (ABPI), Governance Principles of the Use of Health Data.¹²

It is essential that industry continues to work with the health and social care system, as well as patients directly, to build trust and maintain confidence.

The infrastructure used to manage and house data also endures perpetual teething problems. Whether this be the applications used to store data or the IT platforms embedded within NHS computer systems, data is an intrinsically evolving resource. As data and digital health technologies rapidly evolve, so does the need for digital infrastructure to keep pace with innovation. If different hospitals, GP surgeries, and all other users of health data operate on different systems without common data standards, then poor data interoperability slows down progress. Yet importantly, as patient access to data increases, the robustness of firewalls must be strengthened to prevent illicit use of data and hacking.

Empowering patients to access their own data

Patient and public access to their own data is an important issue and can empower patients to take an active role in the management of their own health and care. The conversation around access to personal data has developed through COVID-19, when a move to digital appointments and a greater requirement for digital literacy was needed by NHS users. Many of today's population are familiar with digital health technology and are adaptable to such change. However, if these changes continue, the system must be cognisant of any health disparities which may be exacerbated, particularly amongst the elderly and people with limited English literary skills – the language of most data platforms. For Wales, it is important to recognise that patients often move across the border to England and that a single language (UK English) should be used to record information. This does not impede one to one communication with patients and families being in the language of their choice, whether Welsh or another language, but safety in data collection and use requires a stipulated single language format, with clearly recognised terminology to avoid errors in translation or interpretation.

The roundtable also highlighted that conversations around data use should be transparent, to ensure buy-in from the public around the use of their health data for purposes other than for direct care. In particular, these must fully align with the Caldicott Principles.¹³ Attendees of the roundtable caveated that a transition to digitally enabled care, had an impact on patient centred care, reinforcing the need to ensure patient centred digitisation of services. Without open conversations about how data is used, trust will be eroded.

Accountability

Users of health and care must know who is accountable for their data, which is an issue often compounded by fragmentation. In Wales, the NHS Caldicott Guardians (CGs) are the individuals responsible for the data held by their organisations. Health Boards have named CGs, as does DHCW. However, beyond those working within the NHS, other health system stakeholders need to have clear communication routes into those accountable.

Wales needs an authoritative single point of contact, answerable to the Welsh Government. This will allow for coordination and consistency in how decisions are made, which will provide transparency for patients, the third sector, industry, researchers, and the Welsh Government.

This accountability goes beyond the day-to-day operational responsibilities that CGs have and encompasses wider policy and strategic challenges to ensure that Wales becomes a leading health data system. Attendees of the roundtable discussed how different parts of the system will often rely on others to provide solutions. Most typically, this accountability falls between the remit of Health Boards, DHCW, Welsh Government and other data and technology related organisations. Without clear accountability, implementing solutions to challenges are confusing, often delayed and progress limited.

In addition, much of the guidance around data approaches in Wales are not mandatory. Attendees of the roundtable recognised the need to have mandated guidance to encourage and support local innovation and collaboration. If this does not happen, the impetus and incentive to develop such approaches is absent and opportunities are missed. This can lead to inappropriately risk-averse decisions being taken, which decrease the analysis of currently held data for the benefit of Wales's population.

Resource and Capability

To date, financing the data revolution in Wales has been funded by the health budget. This budget has already been thinly stretched due to the COVID-19 pandemic and years of increased demand. This has meant that despite world-leading capabilities in Wales, the capacity and resource to deliver on the data ambition has not been met.

It can be challenging to upskill the health and care workforce to keep pace with the speed of data and digital innovation. If those already over-stretched health and care workers are not supported to adopt new technology rapidly, the true potential to harness the power of data will not be realised.



Realising The Welsh Data Potential

Overcoming these challenges represents a unique opportunity for the Welsh health and care system to lead the way to **become ‘a world-leading health and care system which utilises the power of data in the most efficient, optimal and equitable manner, to improve the health outcomes of its entire population’.**

To achieve this vision the following fundamental elements will need to be put in place and addressed to form the basis of the approach:

1. A truly integrated Welsh health and care system where information moves beyond the confines of one stakeholder group and clear mechanisms of communication exist between all those with a vested interest in the Welsh health data environment. Integration and inclusion results in shared outcomes that meet the priorities of the whole system.
2. Data and the safe and effective use of it is made readily available to all actors within the system. The clinical community, industry and the third sector are able to identify where to place interventions into the pathway to have maximum impact and best outcomes for people. Applying the principles of prudent healthcare, prudent practice is adopted and spread systematically across the country to reduce variations in care and health inequalities and ensure best use of all skills and resources. All those coming into contact with health and care services should be empowered and upskilled to access their own data to drive more patient owned responsibility for their care.
3. When challenges do arise, or when improvements need to be made, there is widespread responsibility on those with accountability to implement change. The owner of this responsibility becomes the centre for guiding and disseminating gold standard practice around approaches to data, and should have powers to mandate guidance in a manner which incentivises local adoption and cross-system collaboration.
4. A long-term, cross-departmental budget package needs to be available at national, regional and local levels so the Welsh health and care system can fully realise its potential to become and sustain its position as a world-leading health data-rich environment. This will lead to greater life sciences and digital investment in Wales, benefiting both the health and care system and the wider economy.



Solutions and delivering change

The roadmap set out in the NDR data strategy may go some way towards achieving the fundamental elements set out above, but we await to see evidence of this working in practice. We would further recommend:

1. Confirmation of who the dedicated and accountable body is for all future health data policies and guidance.
2. An audit of all the data challenges in the Welsh health and care system with an assessment of the opportunity cost for meeting each challenge.
3. The establishment of a task and finish forum for representatives of all areas of the health and care system to continue to collaborate and develop joint solutions to realising Wales's data potential.
4. The legislative framework underpinning the "data promise" set out in the NDR roadmap needs to ensure that data access and interoperability can safely exist between different health and care systems and its actors.
5. Guidelines from the Welsh Government for the Welsh health and care system to support access to anonymised data under appropriate governance (consistent with Caldicott) to enable appropriate collaboration with external partners, including industry and the third sector.
6. A public awareness and targeted education programme to ensure all members of society can have access and the capability to utilise and own their personal health and care data. This could be led by the newly implemented Citizen Voice Body who would be responsible for taking these recommendations, along with the NDR roadmap, to members of the public.
7. A commitment from the Welsh Government for a long-term, cross-departmental budget package that can be accessed by national, regional and local system stakeholders to improve approaches to health data, driving inward investment.

If you would like to discuss the contents of this report in further detail, please contact Bevan Commission [here](#) or BMS at jagtar.dhanda@bms.com.

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