THE KNOW–LEDGE CRISIS

why health services must make smarter use of our personal data

Beamtree®

Global Impact Committee

> The failure to exploit data is the biggest failure in modern healthcare.

Contents

05

Foreword

Global Impact Committee

The future of healthcare depends on how we convert information into knowledge. The early promise of data-driven improvement has been followed by stagnation in the use of quality and safety indicators despite increases in data speed, volume and integrity. We must move beyond just collecting data to focus on creating systems that allow for informed decision-making, timely interventions and patient-centred solutions. It is time to ensure data serves the patient's best interests – not just as a record, but as a tool for improving health outcomes. As a 2024 study for the Chief Medical Officer for England puts it, health data is critical national infrastructure that should underpin the health of the nation.[1]

Outcomes should be continually improving as we develop increasingly sophisticated insights into prevention, the medical and social causes of ill-health, comorbidities, long-term survival, quality, productivity, unmet need and unacceptable variations in access and service performance.

Data should bring rationality to allocating scarce resources – or at least bring transparency and evidence to debates largely controlled by vested interests, political short-termism, history and inertia. This could change the balance of resources between prevention and treatment, mental and physical health or hospital and community services. It would also inform contentious decisions such as the allocation of resources between communities.

No competently managed factory would tolerate the variations in performance and quality that are routinely tolerated in healthcare. If the pharmaceutical or microchip industries operated with the same degree of incuriosity and inaction, and accepted the same level of errors, it would be an international scandal. Yet healthcare remains largely immune to the evidence that standardised data and practice improve quality, and continues to work in ways that often border on chaotic – a series of corner shops rather than factories. Standardised data is an urgent priority.

The debate over the failure to drive care improvement through data is pressing because, in many countries and in many specialties, quality improvements have stalled. As the Beamtree Global Impact Committee demonstrated in our first report, *Quality in Retreat*, mortality rates in services such as cancer and cardiac care have plateaued or even increased, while improvements in life expectancy have faltered after a long period of improvement, and not just because of the Covid-19 pandemic.[2]

Healthcare data should be the alchemy of the 21st century, turning numbers into actionable insights which improve care and save lives. But for two decades healthcare systems in wealthy nations have known that they are awash with data which translates into pitifully little quality improvement, while many countries lack even basic infrastructure to collect and use digital data. The failure to exploit data is the biggest failure in modern healthcare. This report sets out a plan to change that. We present a Manifesto for Reform at the end of this report calling out actions for key players – governments, regulators and health service organisations. These are the minimum requirements for ensuring high quality, sustainable health and care for the long-term.

Tim Kelsey
Chair, Global Impact Committee

Prof Mark Britnell
Former Chair, Global Impact Committee

Executive Summary

Linking clinical data with information from wider public policy areas would improve patient outcomes, enable intelligent healthcare systems and support the planning of health, social care and many other public services.

Leaders of organisations and systems would see productivity and quality rise and the risks of serious harm continually reduced. Governments and payers would benefit from improvements in productivity and value for money.

Data collection is a costly, energy-intensive, time consuming, top-down managerial process. But few health economies have developed linked datasets at scale that allow health systems, researchers and policymakers to track a person's health journey from birth to death.

For two decades healthcare systems in wealthy nations have known they are awash with data which translates into little quality improvement, while many countries lack basic infrastructure to collect and use digital data. The failure to exploit data is the biggest failure in modern healthcare.

System leaders and local managers know a lot about processes but far less about quality and outcomes and how their care affects their patients' lives.

The future of healthcare depends on how we convert information into knowledge. Health data is critical national infrastructure.

Standardised data is an urgent priority. Accurate, audited data coding is key to demonstrating data integrity and ensuring the debate is about what the data tells us rather than whether it is valid.

07

Actions for governments

- Put information in the hands of consumers to help them make better decisions about their care – AI creates the potential for far richer information and choices to be put in our hands.
- Legislate for patient privacy, control and benefit – one approach would be to establish national health data agencies to act on behalf of patients. Possible applications include AI-driven real-time monitoring of care, flagging errors or missed opportunities, supporting patients in managing their care and recommending where a patient goes for treatment.
- Remove barriers to linking datasets – integrating datasets requires legal frameworks which are clear, precise and unambiguous. Data collection and coding needs to be standardised. Governments need to mandate interoperability standards across systems, services and markets.
- Integrate data across public policy – linking areas such as physical and mental health, housing, education, welfare, labour force, justice and censuses would build a longitudinal dataset so that a person's life chances, life events and health outcomes, and the factors that influence them, are understood.

Actions for regulators

- Ensure regulation is data-driven, proportionate, coherent, consistent and synchronised, with clear decision-making pathways.
- Ensure regulation supports the development and trialling of disruptive innovations.

Actions for health organisation boards

- Develop a culture of outstanding clinical governance – patient centred, clinically effective, safe and well led, supported by continuous learning, robust information management, performance monitoring and quality improvement.
- Provide effective leadership – so staff understand and embrace the vision, values and clinical governance. Roles and responsibilities are clear and consistent. Teamwork and mutual respect are natural, the culture is open, questioning and collaborative and staff feel engaged.
- Maintain public trust – explain how data is collected, stored and used. Where possible, each citizen should remain the owner and controller of their data.
- Build the goal around quality – define and measure it, publish the data and improve standards by empowering patients and professionals.

08

Chapter 1:

Introduction

The key goal of 21st century healthcare should be to record and analyse data to drive continual improvements in teams, professions, institutions, systems and countries. This needs to be based upon standardised, lifelong, real-time health records that connect treatment with cost and long-term outcomes to deliver improvements in people's health, wellbeing and life chances.

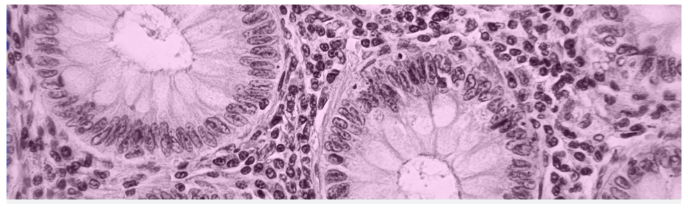
A healthcare provider needs to ensure that anybody walking through the door seeking help gets the highest quality care they can – effective, safe and decent care within the available financial envelope. When people are sick, frightened and in pain, healthcare staff have an ethical and professional obligation to describe the interventions they are going to make and define the standard to which they intend to do it. That process, and the outcomes, need to be recorded and interrogated through clinical data.

Linking clinical datasets with other information from the healthcare system and wider areas of public policy would: support the care of individual patients; enable the operation of an intelligent healthcare system, such as by managing capacity; and support the planning of health, social care and other public services.[3] The research potential of such data is unbounded.

Patients would have better outcomes through safer, more consistent and more integrated care. Clinicians would feel empowered to work to the best of their abilities and be motivated by delivering better care. Leaders of organisations and systems would see productivity and quality rise and the risks of serious harm continually reduced. Governments and payers would benefit from improvements in productivity and value for money.

Resistance is everywhere. Governments, insurance companies, private and public providers, professional bodies and individual clinicians have all played their part in keeping clinical performance data hidden, to the detriment of patients and taxpayers. This culture is partly driven by system leaders and local managers deluding themselves that they know what is going on in their organisations. In reality, they know little about how good their care is and how their services compare with others. They know a lot about processes but far less about quality and outcomes and how their care affects the lives of their patients.

While many healthcare organisations have access to terabytes of data, the challenge lies in transforming this raw information into actionable knowledge. Without the right tools, integration and analytical capacity, this data cannot be harnessed effectively to drive better patient care, personalise treatments or predict health trends. The failure to use data as an integral part of delivering and improving care in everyday practice is akin to training an athlete without a stopwatch. Without the right data you are flying blind.

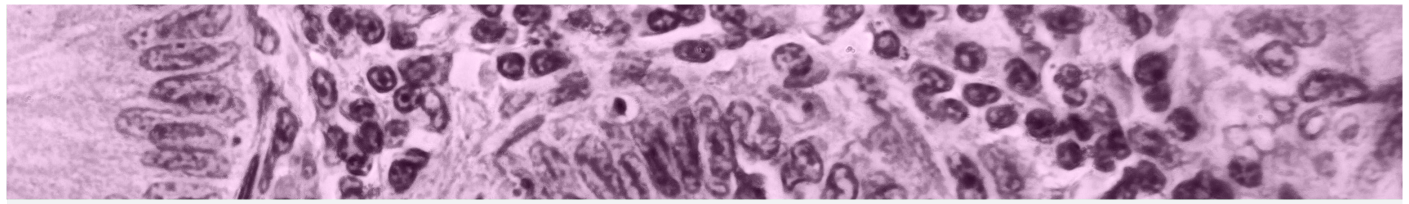


Linking cancer data across the island of Ireland

The eHealth-Hub for Cancer brings together clinical, pathological, genomic and socio-economic data from across the Republic of Ireland and Northern Ireland to inform new ways of preventing, diagnosing and treating cancer.[4,5] Established in 2024, it is led by the University of Limerick and Queen's University Belfast and has five major research areas, including blood cancer, solid tumour patient data, harmonising cancer clinical genomics data and developing cross-border cancer registries.

It uses the Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) to capture information in the same way across different institutions, simplifying data integration and analysis. The hub brings together clinicians, epidemiologists, data analysts and computer scientists and is already delivering benefits, such as showing how precision medicine targeting specific features of a tumour can deliver better care and be more cost-effective.

> This failure to publish, link and act on data allows serious patient harm to continue through unwarranted variation in surgical outcomes, medication errors, adverse events, poor productivity, inefficient resource allocation and low patient empowerment.
>
> Prof Dirk De Ridder, Professor of Urology, Katholieke Universiteit Leuven, Belgium



Using national data to drive improvement in Belgian hospitals

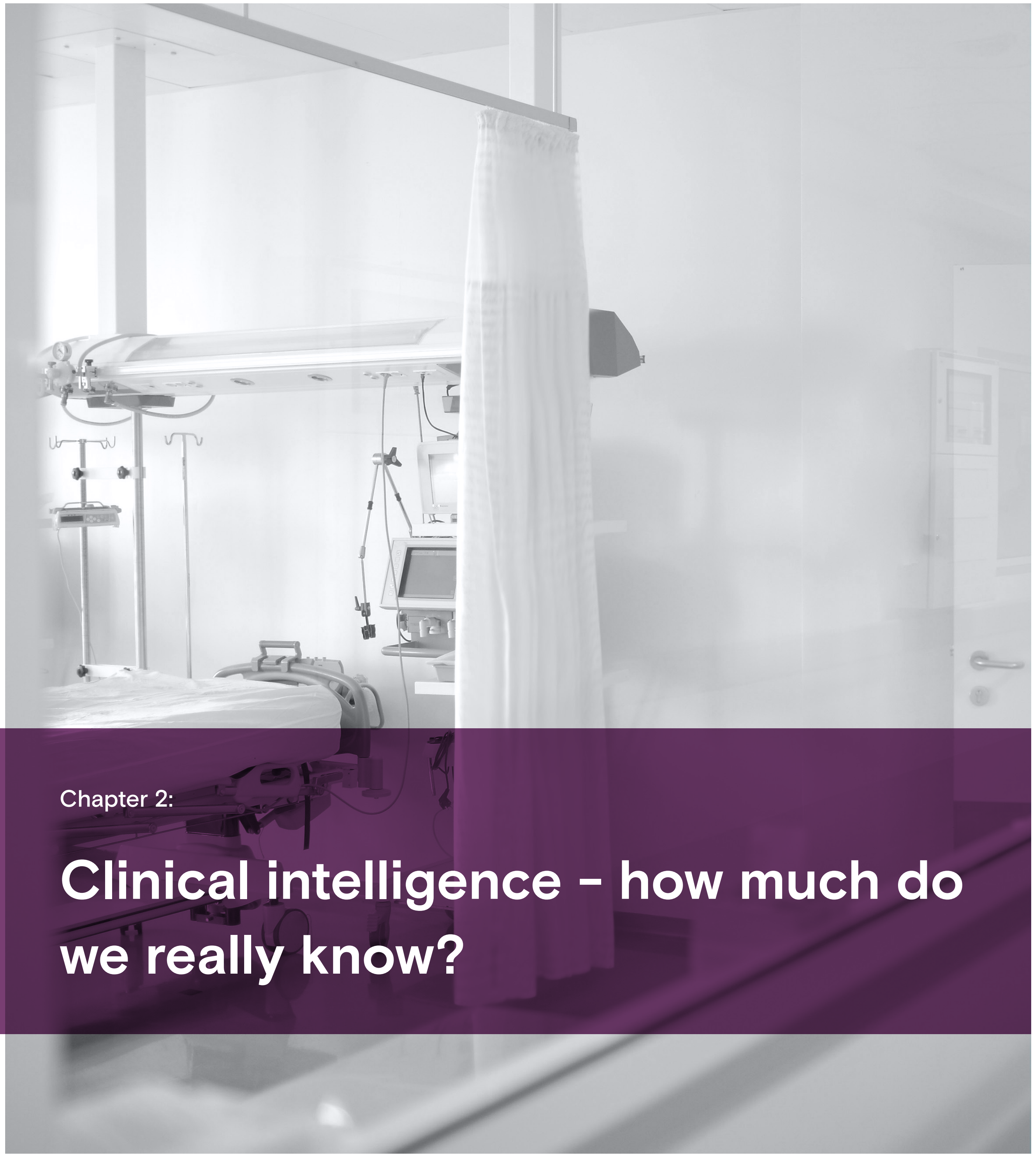
A national population analysis in Belgium identified poorly performing hospitals for mortality, readmission and prolonged length of hospital stay across multiple disease groups.[6]

Its risk-adjusted analysis of data for 4,560,993 stays between 2016 and 2018 showed that if hospitals with upper-quartile rates succeeded in improving to the median, 4076 hospital deaths, 3671 readmissions and 15,787 long patient stays could be avoided annually. It identified a group of 'high-impact-opportunity hospitals', characterised by poor performance across many major diagnostic categories (MDCs). The observed variations were not explained by region, hospital size, teaching status or admission volume.

The patient outcomes analysed included 'failure to rescue', looking at the mortality rates among patients with shock, cardiac arrest, sepsis, pneumonia, gastrointestinal bleeding, acute ulcer, deep vein thrombosis or pulmonary embolism. While the overall rate was 23% the analysis revealed wide variations between hospitals, including steep declines and increases over time alongside sustained poor performance.

Prof Dirk De Ridder, Professor of Urology, Katholieke Universiteit Leuven, Belgium, one of the leaders of the study, said, "This shows how administrative data can be turned into actionable quality indicators that improve outcomes, save lives and reduce waste. This analysis enables hospital leaders to gain a realistic understanding of their performance department by department and to develop the tools, systems and cultures to drive sustained improvement."

This failure to publish, link and act on data allows serious patient harm to continue through unwarranted variation in surgical outcomes, medication errors, adverse events, poor productivity, inefficient resource allocation and low patient empowerment. With the right data, system leaders and clinicians can identify areas for improvement, highlight good practice, optimise the allocation of resources and reduce unwarranted variation.



Chapter 2:

Clinical intelligence – how much do we really know?

> *Modern healthcare alchemy is turning data into actionable information, so the clinician can define the quality of care they aim to provide and constantly strive to do it better.*
>
> **Prof Sir Bruce Keogh (UK), Chair of Birmingham Women's and Children's NHS Foundation Trust; former National Medical Director, NHS England**

Few healthcare boards have a comprehensive overview of their institution's performance. Hospital leaders see basic data such as bed occupancy, patient flow, waiting times, elective activity, patient harm such as falls and medication errors, cancer treatment performance and readmission rates, alongside financial, compliance and operational measures. But this data overwhelmingly relates to the processes and performance of the care provider rather than its impact on patients or the community it serves.

There is almost no data reflecting the experience of an individual across multiple services, even within the same institution. A local or regional health authority has no insight into how well the interaction of inpatient, outpatient, home visit and primary care services have met an individual's needs, and how economically resources have been used.

Aggregating data to assess the value of treatments is patchy, despite its importance for optimising resource allocation. Electronic health records (EHRs), insurance records, disease registries and clinical studies provide some information, and there are recognised performance measures such as quality-adjusted life years (QALYs) and ICHOM (International Consortium for Health Outcomes Measurement) sets of patient-centred outcome measures, but the information is dispersed and disconnected.

Value-based healthcare

Value-based healthcare aims to pay providers for the outcomes they achieve for patients rather than simply the volume of services provided, to encourage an emphasis on prevention, efficiency and evidence-based practice. It asserts that the purpose of a healthcare system should be to deliver the best possible outcomes for patients for the money spent.[7] The heart of value-based healthcare is data, to personalise treatment, track performance and improve productivity. It should include a sophisticated understanding of the patient experience, so providers can see not just the outcomes, but how it feels to receive their care.

> no organisation can deliver **value-based healthcare** in isolation.

Value-based healthcare has the potential to be a powerful catalyst for innovation and improvement, changing the way healthcare providers judge their care and assess their performance, how payment models are designed, how research is directed and how clinical trials are conducted.[8]

Advocates argue that a systemwide approach is needed because no organisation can deliver value-based healthcare in isolation. Payment models, regulations, digital infrastructure, clinical training and a culture of collaboration need to be aligned.[9]

The experience of implementing value-based healthcare in Australia highlights the barriers to making it work.[10] While there have been successes, progress has been impeded by difficulties in collecting accurate and comprehensive data from multiple sources, integrating it and analysing it. There has also been a lack of consensus on which measures are most useful, and how best to use financial levers. Above all, health stakeholders are not yet united around the value-based approach.

A successful example is the Netherlands Heart Network, which brings together primary, secondary and tertiary cardiac care to maximise the outcomes which are important to patients at the lowest possible cost.[11] Physician-led teams define the care standards and guidelines for specialists and GPs, measure and analyse the outcomes and costs and implement cycles of improvement. A patients' advisory board is involved in setting strategies and prioritising improvements. Benefits include a greater focus on preventative measures such as reducing the risk of strokes.

The network has delivered better outcomes across a range of measures such as arrhythmia, blood pressure, hospitalisations and survival.

Therapeutic inertia

Outdated treatments persist through institutional and clinical inertia – sometimes called therapeutic inertia – and a lack of dedicated resource to retrain teams, replace equipment and reconfigure premises. Management of diabetes, hypertension and heart failure,[12, 13, 14] the introduction of laparoscopic and robot-assisted surgery[15, 16] and the use of genetic tests in determining cancer risk[17] are just a few examples of where patients are routinely harmed by failing to follow the data and improve care.

Clinicians often report to boards the data they want them to see. The opaque curtain around what really happens drives resistance to adopting sophisticated digital platforms because of the transparency it would bring to activity and outcomes. The frequency with which whistleblowers are instrumental in uncovering errors and malpractice demonstrates that data and governance systems are unable to identify even failures which harm scores of patients, let alone individuals.

Variations between surgeons in the time taken to perform an operation can indicate patient harm, because unnecessary deviations from standard procedures and slow operations can increase complications.[18] They can also signify that a surgical team is exhausted,[19] again jeopardising patient safety. Little of this data is acted upon.

Avoiding transparency

Reluctance to embrace transparency is exacerbated by weaponising data for 'terror and targets'. While targets can be effective in directing effort, improving performance and enhancing transparency, poorly designed or implemented targets can cause unintended consequences such as gaming of data, a poor focus on quality and safety and prioritising hitting a target over clinical need.[20] A well-designed target will focus the system on a desired outcome rather than an easy to measure input, send the right signals about how the system should respond and be supported by the management capability to make change.[21]

Clinical resistance has often been positioned as arguments around data sources and quality, the validity of outcome measures and the public's ability to interpret the results. Accurate, audited data coding is key to demonstrating its integrity, and ensuring the debate is about what it tells us rather than whether it is valid.

Hospitals spend many millions of dollars installing sophisticated EHR systems, but few invest sufficiently in training clinical and nonclinical staff to exploit the data they generate. Potential benefits include minimising medication errors, standardising protocols, improving coordination, reducing administration, monitoring quality, optimising resource allocation, predicting outcomes such as readmission risks and treatment effectiveness, real-time patient monitoring and automated alerts. But much of this capacity goes unused, resulting in harm and waste.

The consequence is that there is little **accountability for failure.**

One simple, high-impact application is using AI to assist junior doctors in the error-prone, time-consuming and tedious task of writing discharge letters. It saves time, and can improve quality and make them easier for patients to understand.[22, 23]

We don't have a rounded view of an individual's healthcare in and out of hospital, and we don't understand the connections between what happens in healthcare and what happens in people's lives. In the UK there is a growing debate about high post-pandemic worklessness among young people and its economic impact, but the ability to identify potential causes such as declining mental health and growing social isolation is impeded by the lack of joined-up data.

Among the biggest blockers of transparency are governments. If the public and the media understood the unwarranted variations in performance that transparency would expose there would be a political backlash. So it remains hidden – ministers know, clinicians know, managers know but the public is kept in the dark. It is unethical that we don't really know whether we are providing good, safe care even though we have the tools to do so. The consequence is that there is little accountability for failure.

Transparency has gone backwards in some countries. The inquiry into the failings in children's heart surgery at Bristol Royal Infirmary in England in the decade up to 1995 – which had repercussions internationally – recommended that patients should be able to access information about the performance of a hospital, specialty and consultant team.[24] In 2005 the Society for Cardiothoracic Surgery in Great Britain and Ireland published risk-adjusted mortality rates for individual cardiac surgeons.[25] This was expanded in 2013 under the Consultant Outcomes Publication, encompassing procedures such as coronary artery bypass grafting.[26] Now virtually none of that data is accessible.

Cardiac surgery, particularly in the US and UK, is an example of where transparency was driven by the profession. But the momentum behind professional bodies owning and driving transparency and improvement through data has waned, so data has become principally the preserve of managers and regulators.

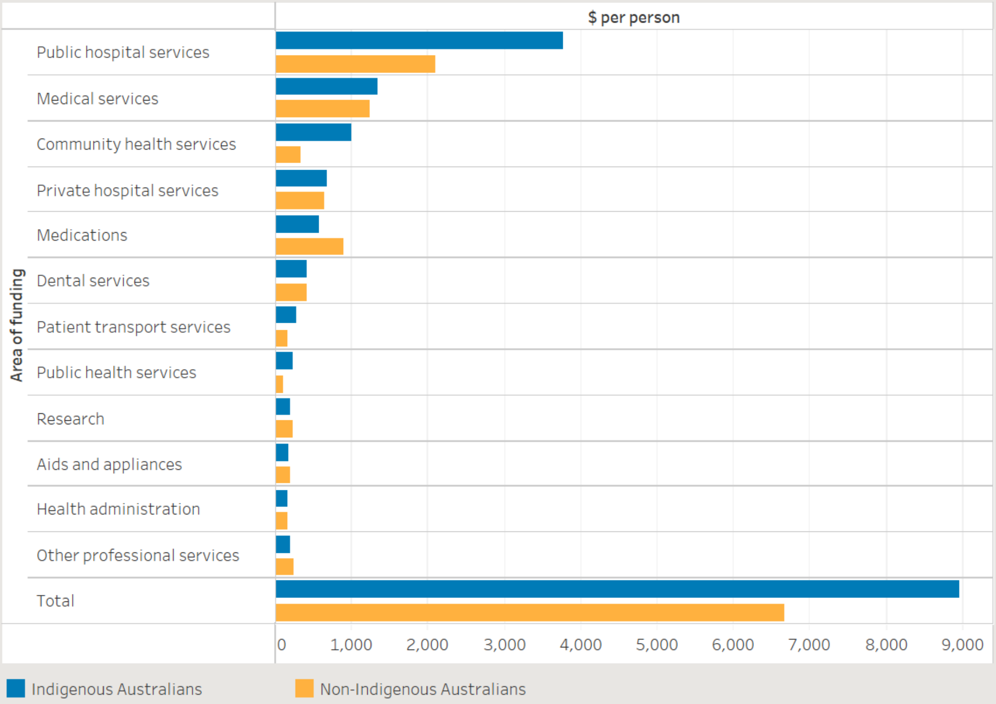
Chapter 3:

Addressing inequalities through data

While the causes of inequalities within and between communities are well understood, there are few end-to-end, linked databases which shed light on the disputed area of the relative merits of different interventions. There are numerous examples among Indigenous communities in countries such as Australia and Canada where there is a chasm between the resources invested and the improvements in people's life outcomes. In some places the mortality gap between Indigenous and Settler communities is widening. With inadequate understanding of what is failing and why, scarce resources continue to be wasted while lives continue to be blighted.

In Australia, real terms health spending by the government for Aboriginal and Torres Strait Islander people increased by 7.3% per year between 2010-11 and 2019-20, and spending tailored to meet the needs of Indigenous Australians grew in real terms over that period by 38%.[27] In 2019-20, average health expenditure per person for Indigenous Australians was 1.5 times as high as for non-Indigenous Australians, although this compares with a burden of disease that is 2.3 times higher.[28] Yet life expectancy at birth for Aboriginal and Torres Strait Islander people is 71.9 years for males, 8.8 years less than for non-Indigenous males, and 75.6 years for females, 8.1 years less than for non-Indigenous females, only a marginal improvement on recent years.[29]

While disadvantages such as low income, overcrowded and rundown housing, poor infant diet and high smoking rates all contribute to poor health outcomes,[30] healthcare data indicates that quality of life is undermined and money wasted by high spending on preventable hospitalisations for Indigenous Australians, especially for diabetes, chronic obstructive pulmonary disease (COPD), influenza and pneumonia, while poor education and literacy undermine people's capacity to use health information. This makes a strong case for further strengthening the scale of early intervention services and the cultural appropriateness of how they are delivered.



Data are presented on health funding per person, by funding source and funding category. Health funding refers to money provided by an entity for a particular area of expenditure, regardless of who provides that service.

Source: AIHW 2020. Aboriginal and Torres Strait Islander health performance framework report 2020. https://www.indigenoushpf.gov.au

Health expenditure by funding source, total funding, by area of funding, 2015–16

Chapter 4:

The data landscape

> *Healthcare is driven by the bureaucracy's and doctors' views of what patients need. There isn't much driving it towards patients' interests, such as joined-up care, because patients' influence is pitifully small.*
>
> Roger Taylor (UK), author; former chair, UK government's Centre for Data Ethics and Innovation

Data collection is a costly, energy-intensive, time consuming, top-down managerial process. But few health economies have developed linked datasets at scale that allow health systems, researchers and policymakers to track a person's health journey from birth to death. Health data is fragmented and difficult to navigate, and many records are still not digitised, even in the wealthiest countries.

Among the numerous data sources that could be brought together to form a complete picture of health, healthcare, outcomes, life chances and economic impact are: clinical data, including EHRs, hospital episode statistics, imaging, screening data, pathology results, medicines data, genomic data, disease registries and clinical research; public health surveillance data, such as immunisations, communicable diseases and environmental health factors such as air quality and temperature; social care; local and regional government; patient-generated data such as wearables, apps and patient-reported outcome measures; census data; and measures of the social determinants of health such as educational achievement, income and housing conditions.

While there is no reliable figure for the proportion of the world's data being generated by the healthcare industry, it is clear its growth is outstripping sectors such as manufacturing, financial services and media and entertainment.[31 32] One person's full genetic sequence constitutes about 30 gigabytes of data, and 10 years of Scotland's radiology imaging data amounted to around 3 petabytes, or 3000 terabytes.[33]

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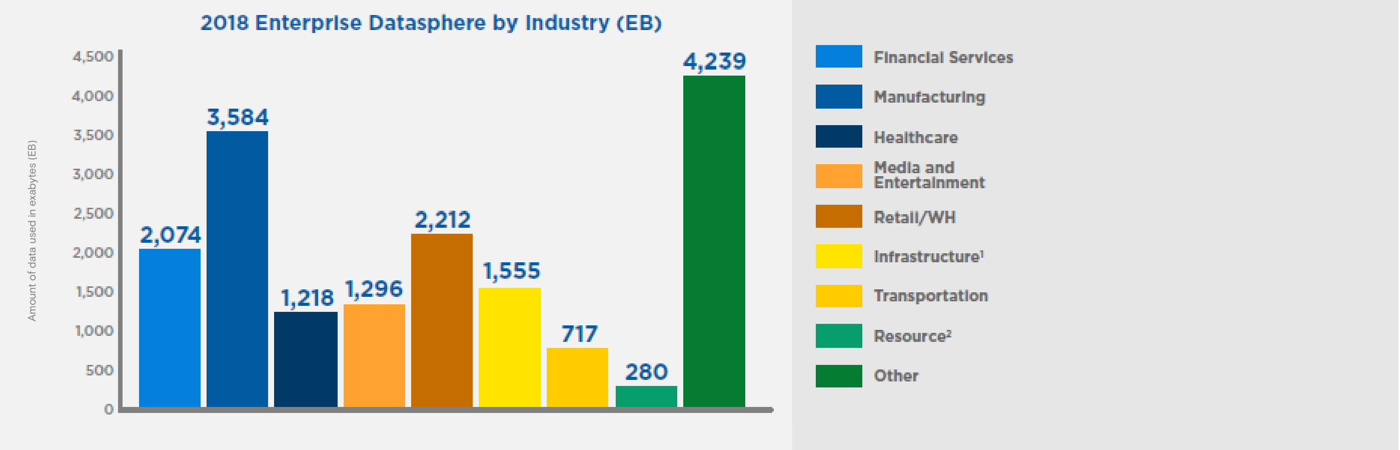

[1] Infrastructure includes Utilities, Telecommunications

[2] Resource includes Oil and Gas (Mining), Transportation of oil & gas through pipelines or shipping, Resource industries, Petroleum and coal manufacturing/refining

Source: IDC's Data Age 2025 study, sponsored by Seagate

> **The most important data is the weakest** – the experience, outcomes, long-term wellbeing and life chances of the patient.

Stakeholders in data collection, reporting and analysis include governments, statutory agencies, regulators, professional bodies, healthcare providers, insurers, pharmaceutical companies, health tech companies, charities, advocacy groups, universities, researchers, the media and of course citizens and patients.

Crudely, healthcare data falls into three types – management, improvement and consumer. Effort has overwhelmingly been skewed towards management data, but the returns on that investment have been meagre. The least effort has been put into data to support the consumer, but that is the area with the most potential.

When deciding what to measure, how to measure it and how to use the information, it is important to recognise that data is a proxy for reality. It is a way of sampling activity and outcomes, with the idea that the measures recorded get as close as possible to reflecting the outcome or activity that is of interest and generate the appropriate behaviour in response. So if you are trying to improve a process it is important to understand whether what is being measured triggers the appropriate response.

With big picture management data such as waiting times – which are a proxy for factors such as how much pain and discomfort people are experiencing and how much their disease is progressing – it undoubtedly drives a response, but too often that is an inappropriate one such as gaming the system to fix the numbers rather than, for example, driving improvements in referrals, patient flows and the use of operating theatres. This is how bureaucracies work – if you want the numbers to go down they go down, if you want them to go up they go up, but the level of human engagement is low and outcomes can be unforeseen.

Doctors have their own construct of quality and success, which will be closer to the realities of being a patient than the management data but still removed from the experience of what matters to the individual, and will to some extent be distorted by self-interest such as managing workload. The debilitating side-effects of a cancer treatment mean that a clinical success can feel strikingly different to the patient. This disconnect can cause the doctor to underestimate the importance of finding better treatments which do less harm to the patient's quality of life. The most important data is the weakest – the experience, outcomes, long-term wellbeing and life chances of the patient.

The differences in the perspectives of managers, clinicians and patients cause friction in the system. Management may be pressing for waiting times to be reduced, but clinicians may argue that it is causing harm by forcing them to treat the wrong patients at the wrong time. Patients have pitifully little data to work with so their influence over what happens to them is negligible. Being a patient is astonishingly disempowering. But giving them a window into their treatment options, and in particular how different parts of the system work together for their overall care, could be transformative. The object must be to shift the power balance to give patients more agency.

19

Poor understanding of aged care

Aged care is particularly poorly served, with a lack of community services data, lack of social care data and often no linkage of death certificates to other records. Death certificates should be integrated with health records so inferences can be drawn from when and how someone died and the healthcare they received. With long-term care spending outpacing GDP growth and overall healthcare spending[34] there are serious economic consequences for the lack of understanding of the quality and value of aged care services.

Spending the last days and weeks of life in hospital is often wasteful of healthcare resources and adds to the distress of the dying patient and their family, demonstrating how joining up data such as patient and family experiences with use of resources could drive better coordination between hospital, community and social care services.

Measuring what did not happen

With many obstacles to recording and understanding what did happen, it is no surprise that there is little opportunity to record and understand what did not. Often the only occasions when inaction is examined are during an investigation into a never event or an inquiry into a medical scandal.

A rounded view of care which maximises opportunities for learning would include data on opportunities missed, such as chances for prevention, earlier intervention or lower cost treatments.

Health Roundtable in Australia and New Zealand

The Health Roundtable is a membership organisation founded in 1995 which brings together more than 200 hospitals across Australia and New Zealand. Supported by Beamtree, it publishes a wide range of deep, validated data, dashboards and reports, while communities of practice share innovations and support each other in improving care, outcomes and hospital performance.

In March 2025 Health Roundtable unveiled a forecasting tool to enhance the management of safety and quality. It helps hospitals pinpoint potential safety and quality concerns before they escalate, enables teams to set data-driven improvement goals and enables organisations to test strategies before implementation. The NHS Confederation, which represents healthcare providers, is collaborating with Beamtree to bring the Roundtable concept to the UK in a project called The Evolve Collaborative.

Chapter 5:

Barriers to data-driven improvement

In the executive suite you cannot know exactly what's going on. The trick is to identify the signals that tell you when a service might be going off the rails.

Prof Keith McNeil (Australia), Commissioner, Commission for Excellence and Innovation in Health, South Australia

Lack of public trust

The ability of healthcare stakeholders such as researchers, hospitals and private companies to share and integrate data is constrained by what the public will tolerate.

Attitudes shift around sharply. In 2020-21, during the Covid-19 pandemic, 905,790 people in England participated in studies related to the outbreak, including 35,488 recruited to commercial studies.[35] But around that time a class-action lawsuit was launched on behalf of more than a million people whose confidential medical records were shared with Google by the Royal Free London NHS Foundation Trust during the development of an app to identify patients at risk of developing acute kidney injury.[36] Even teenagers are losing trust in big tech companies.[37]

Concerns include: fear of privacy breaches and misuse caused by unauthorised access; exploitation of data for profit; fear of data being used to exclude access to essential services such as insurance and mortgages; the risk of legitimate data-holders falling prey to cyber-attacks; worries about data spreading on criminal networks such as the dark web; lack of informed consent from citizens and patients about how data is used; confusion over who owns data; and errors in medical records causing harm.

The willingness of people to participate in Covid-19 research gives clues to how public trust can be secured. The purpose of the research was clear. The public benefit was obvious. Participation encouraged feelings of altruism and contributing towards a great endeavour.

OpenSAFELY, led by the University of Oxford, is an imaginative solution to supporting both privacy and research. It is a highly secure, transparent, publicly auditable, open-source software platform which provides research access to the GP records of the entire 58 million population of England, alongside hospital records, death records and numerous research datasets.[38] All the intellectual property behind the project is shared openly, and the data controller is the NHS nationally.

Privacy risks are managed by researchers been given dummy data to develop their analysis, which they then submit for automated remote execution against real patient records, without ever directly interacting with them. Patient data never leaves the secure environments where it is already kept.

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Poor data and coding quality

Clinical coding translates medical terminology from patient records into standardised codes, such as the International Classification of Diseases (ICD) maintained by the World Health Organization (WHO). It is on version 11, although ICD-10 is commonly used.[39]

The accuracy of clinical data and its coding has a direct impact on care quality, funding, performance benchmarking, clinical decision-making, population health management and service planning. Standardised, accurate coding is the cornerstone of activities such as billing and reimbursement, costing studies, risk stratification, patient segmentation, equitable resource allocation, quality improvement, data analysis, research and clinical decision support tools. It is essential for everyday care, such as ensuring the accurate sharing of information between clinicians and flagging risks. Accurate coding is supported by activities such as auditing, coding quality performance indicators and, increasingly, exploiting the EHR to automate coding.

On the financial side, systems cannot have clear sight of the distribution of costs and revenues or make informed decisions about allocating funds without an assurance on data quality. When it comes to clinical quality, accurately coded data supports clinical engagement with improvement by providing comparative performance insights.

Coding accuracy varies wildly. In one study in a London hospital, 68 of 123 cases examined needed coding corrections, with an average increase in payment due to the hospital per patient of £318.[40] A study at Guy's Hospital in London of coding associated with sickle cell patients resulted in additional payments to the haematology department of £58,813 over 16 weeks after student doctors checked if codes had been missed or incorrectly entered.[41] Other studies have assessed coding accuracy at anywhere between 52% and 98%.[42]

Among the causes of poor coding accuracy are incomplete or inaccurate clinical records, illegible writing on paper records, insufficient training and experience among coders, excessive workload of coding teams and poor communication between coders and clinicians.

Currently, clinical coding is a labour-intensive business, with posts including coders, auditors, documentation improvement specialists, health information managers, information technicians and medical transcriptionists. Skilled and experienced coders and trainers are in short supply and coding teams are often under-resourced. The critical importance of the work and the lack of people to do it is driving an increasing focus on automation. Advantages include greater speed and accuracy, a reduced risk of bias and greater consistency in interpreting standards.

Low clinical confidence in performance data

Inaccurately coded data undermines physicians' confidence in its messages. More broadly, the willingness of clinicians to be open to improving their practice will depend on factors such as leadership culture, whether they feel empowered and supported in making changes rather than undermined and controlled and whether they feel that the activity being measured is a valid proxy for quality.

Impenetrable data presentation

Data is of limited use if it is not presented in a coordinated and accessible form. Australia has the National Hospitals Data Collection (NHDC) and the MyHospitals platform, administered by the Australian Institute of Health and Welfare, but it lacks an intuitive interface for patients to find information and some data is buried in spreadsheets.[43][44] England publishes general practice data dashboards, national general practice profiles and GP patient survey results in different places, none of which enables patients to make an informed view about care quality.[45][46][47]

In the US there is lots of data on Medicare and Medicaid services, but its presentation is so impenetrable that it is almost impossible for a member of the public to understand.

Disconnected systems

Fractures between data sources are everywhere. Reimbursement systems use different infrastructure to the EHR. Primary community, social care and mental health services are marginalised or absent. Problems with incompatible systems persist.

Chapter 6:

Information apartheid

> *In many countries in Africa the public sector does not collect, analyse and use enough data, while the private sector collects and analyses it but doesn't make it public. Both need to change.*
>
> Dr Anuschka Coovadia (South Africa),
> Executive Director, Usizo Advisory Solutions

Many countries lack the infrastructure and skilled staff to build accurate, comprehensive, coded data, and lack the regulators to oversee the governance of privacy, consent and data sharing.

In low- and middle-income countries, progress towards establishing and using robust data is slow. Across Africa there has been strong resistance to adopting digital platforms for recording activity, payments and outcomes because clinicians fear greater scrutiny and loss of income. There are major challenges in data quality, integrating data across different care providers and connecting data between the public and private sectors.

Data disparities in countries such as South Africa mirror the inequalities in the healthcare system, amounting to an information apartheid. About 16% of South Africans receive healthcare from the private sector through insurance, while most of the population depend on the public sector.[48] Around 72% of the White population benefits from private health, compared with 10% of the Black population.[49]

Powerful, well-resourced companies such as financial services groups have extensive, high quality datasets driven by the need to bill, while little data is collected in the public sector. This means there is far more data about White people than Black people, and data is overwhelmingly used for building market share and driving profit rather than clinical improvement or patient empowerment.

Data disparities in countries such as South Africa mirror the inequalities in the healthcare system, amounting to an information apartheid. About 16% of South Africans receive healthcare from the private sector through insurance, while most of the population depend on the public sector.

Around

72% **of the White population benefits from private health**

compared with

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The South African government has not set up the regulations or infrastructure to manage data standards, so the private sector uses its data largely in a regulatory vacuum. This creates a lack of transparency among the oligopoly of large hospital groups and insurers. There is also resistance among doctors because rigorous data would force them to declare all their earnings and they are wary of having their practice questioned by clinical or forensic audits.

In poorer towns and villages patient records are overwhelmingly still sheets of paper in filing cabinets. Basic infrastructure such as clinical coding, Wi-Fi connections and cloud computing are scarce. The problem is most stark in rural areas.

Regulatory overreach

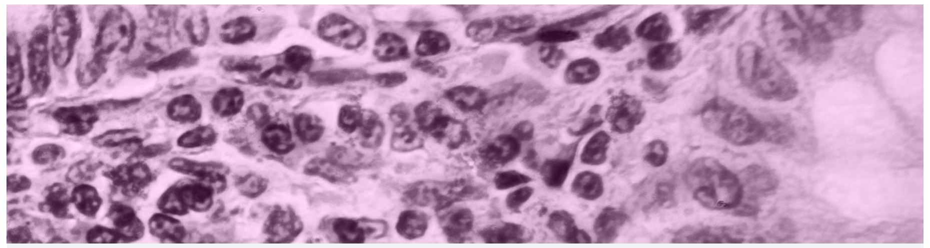
While regulation is essential in building and maintaining public trust in storing and using data, excessive and poorly structured regulation impedes the use of data to benefit of patients and populations.

Complicated and overlapping responsibilities for data custodians and controllers, and the rules and legislation around them, can make it hard to link datasets or access them for research. Access can be delayed for months or even years.[50]

Imprecise rules such as the European Union's General Data Protection Regulation (GDPR) create misconceptions among data owners and users and lead to erroneous or excessively cautious interpretations.[51]

Dispersed ownership and location of data, such as among individual GP surgeries, make it difficult to access complete datasets and allow different interpretations of the rules to impede data sharing.

A contentious area is the risk of deliberate re-identification of de-identified data. The NHS believes the risk of this happening is extremely small.[52] However, with health databases being a target for cyber criminals and the potential for AI tools to re-identify data, this risk needs to be constantly reassessed and mitigated.



Making the most of national data assets in England

The fragmentation of data systems and datasets across the NHS is an illustration of poor data interoperability experienced by many countries.

Darryn Hale, partner with law business DAC Beachcroft, says, "Fragmentation is a longstanding problem driven by four main factors: the lack of interoperability between IT systems; weak incentives for system providers to make them interoperable; an overly conservative approach to data privacy; and a distributed approach to procuring technology."

One solution being developed in England is the NHS Federated Data Platform (FDP) which securely connects and integrates data across NHS and social care systems. Its goal is to overcome long-standing data silos to enable better care coordination and drive improvements in care quality.

It ensures interoperability by using common information standards and can provide real-time insights on priorities such as bed availability, staffing and medical supplies, helping to drive improvements such as improved theatre productivity or tracking the workflows around the care of cancer patients. It also allows local areas to retain control over their data.

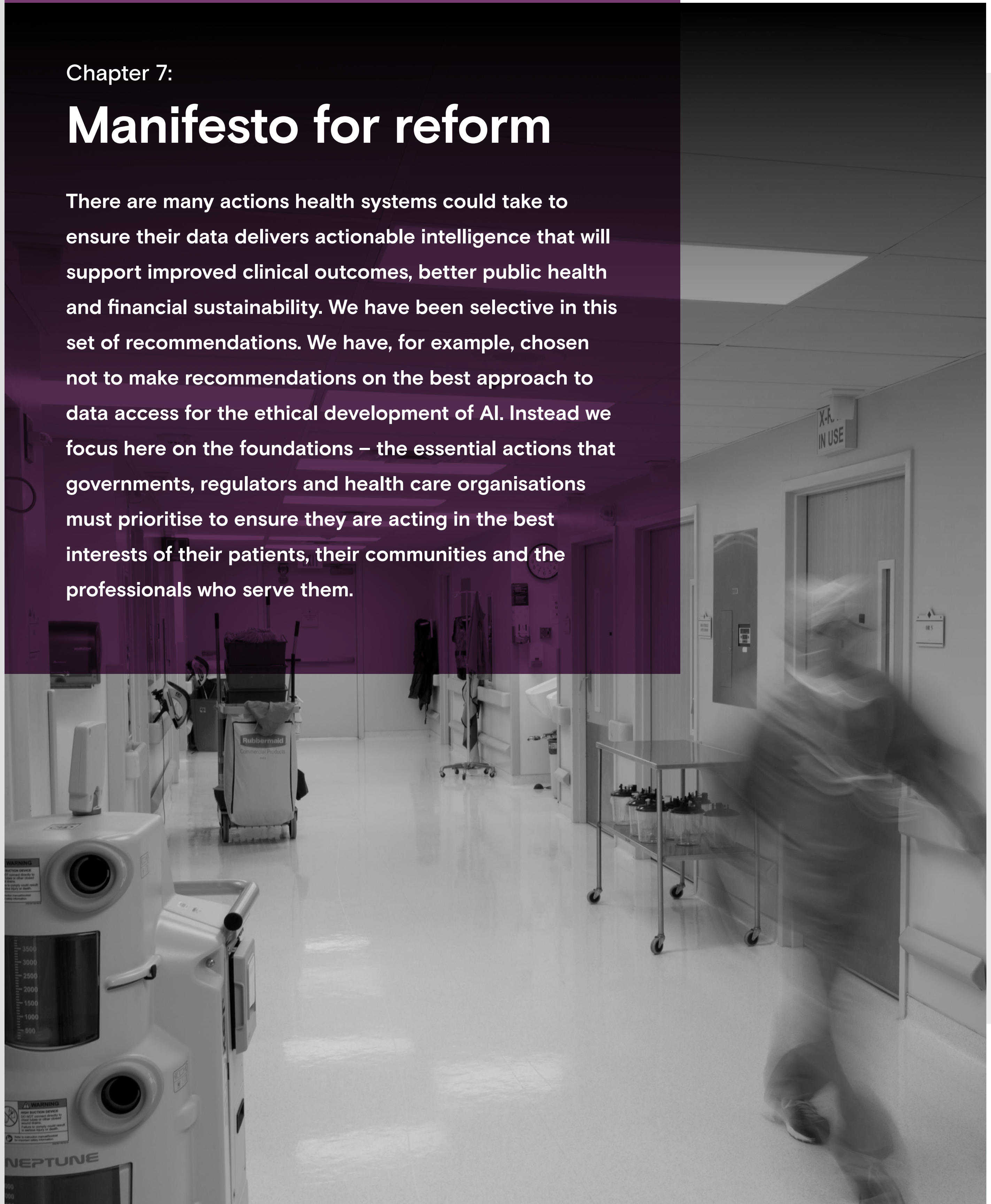
It will support greater innovation in AI by enabling AI models to be trained on datasets from multiple NHS organisations with a more diverse population, while protecting privacy by ensuring sensitive data never leaves its origin.

In addition, the government's Data (Use and Access) Bill introduces powers for the health and social care secretary to issue information standards to be met by those providing IT systems to the care system. "Those standards could mandate interoperability between providers, similar in purpose to US legislation in the 21st Century Sickness Cures Act designed to accelerate innovation in medical technologies," says Hale.

Chapter 7:

Manifesto for reform

There are many actions health systems could take to ensure their data delivers actionable intelligence that will support improved clinical outcomes, better public health and financial sustainability. We have been selective in this set of recommendations. We have, for example, chosen not to make recommendations on the best approach to data access for the ethical development of AI. Instead we focus here on the foundations – the essential actions that governments, regulators and health care organisations must prioritise to ensure they are acting in the best interests of their patients, their communities and the professionals who serve them.



Actions for Governments

- Put information in the hands of consumers
- Legislate for patient privacy, control & benefit
- Remove barriers to linking datasets
- Integrate data from across public policy

Actions for Regulators

- Ensure regulation is data-driven and proportionate

Actions for Health Organisation Boards

- Develop a culture of outstanding clinical governance
- Provide effective leadership
- Maintain public trust
- Build the goal around quality

Manifesto for reform:

Actions for governments

> AI creates the potential for far richer information and choices to be put in the hands of consumers.

Put information in the hands of consumers

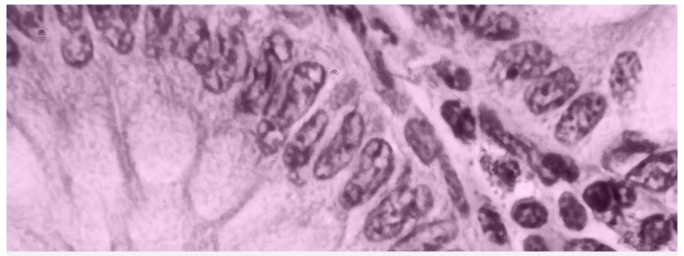
Governments need to ensure that information is put in the hands of consumers to help them make better decisions about their care. In the US, an example of what can be achieved was provided by the Dartmouth Atlas of Health Care from 1996 to 2023.[53] It highlighted wide disparities in healthcare provision across the country, advocated for shared decision-making, helped patients decide between treatment options depending on their preferences and identified unwarranted variation in care quality.

In Germany, the Weisse Liste (White List) provides consumers with information on hospitals and physicians, including treatment quality and patient satisfaction,[54] while in Canada, Your Health System provides data on hospital performance, patient safety and readmission rates.[55] Australians can access MyHospitals to get information such as waiting times for elective surgery and emergency department care.[56]

AI creates the potential for far richer information and choices to be put in the hands of consumers. It could compare available treatment choices with an individual's medical history and preferences, such as how a treatment and its recovery will affect their lifestyle, estimate the type and likelihood of complications based on their health status and predict the likelihood of a good outcome.

Over time this highly personalised approach could improve outcomes for both individuals and healthcare providers, by providing a better match between patients and services. It could also improve patient safety, such as by helping a pregnant woman expecting a high risk birth ensure she is being cared for in the most appropriate place.

Connecting health wearables such as smart watches to personal health records would encourage preventative lifestyle changes such as taking more exercise to reduce the risk of cardiovascular disease.



GenesisCare cardiology quality programme in Australia

Healthcare provider GenesisCare has implemented a quality programme in cardiology, focusing on enhancing the standards of cardiovascular imaging, particularly echocardiography. This led to the development of the GenesisCare Cardiovascular Outcomes Echo Registry (GCOR-Echo), a national clinical quality registry aimed at improving data acquisition, completeness and reproducibility in echocardiographic studies.[57] The components of the quality programme are:

- Data standardisation and structured reporting – this ensures consistency and accuracy in echocardiographic assessments
- Real-time data collection – this facilitates dynamic auditing and benchmarking of key performance indicators
- Independent auditing – to maintain data quality, 5% of studies are independently audited.

The combination of data standardisation, real-time collection and independent auditing delivered an improvement in data completeness of 72% to 87% and secured improved compliance with quality guidelines.

Legislate for patient privacy, control & benefit

Data protection laws need to ensure patient consent before their health record is shared. The purposes for which health data can be used need to be clearly defined and there must be strict limits to secondary uses.

Encryption and other security measures such as access controls need to be mandatory, and security audits need to keep pace with evolving threats.

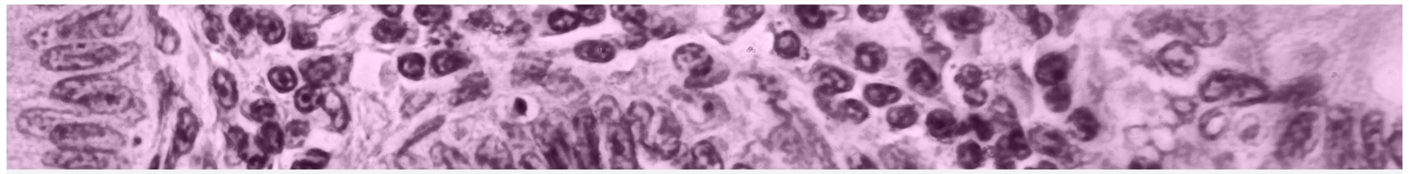
Patients must have a right to access their own records and correct inaccuracies, and have the right to opt out of data sharing for non-essential purposes, including research.

Independent regulators need to be created to oversee compliance with health data laws. Transparency around data breaches needs to be strictly enforced.

One approach would be to establish a national health data agency to act on behalf of patients. It would ensure data is available to each person and set rules for who can access and share it. Possible applications include providing AI-driven real-time monitoring of care and flagging errors or missed opportunities, and supporting patients in managing their own care. It could also recommend where a patient goes for treatment, taking account of factors such as waiting times and quality.

Manifesto for reform:

Actions for governments



Finland's integration of health and social care data

Finland has digitised all its patient, social care and prescription records, accessible to citizens and health professionals through the Kanta system.[58] In 2017 it launched the FinnGen Project, which has collected biological samples from almost 500,000 people – around a tenth of the population – to advance genetic research.[59]

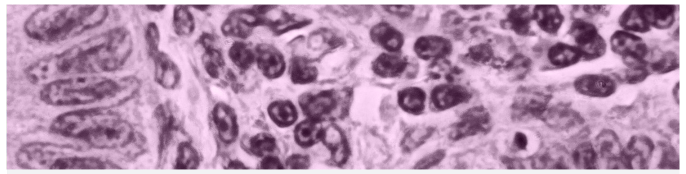
The country prioritises building trust in the way patient data is stored and used. A single authority, Findata, brings together citizens' health and social care data, streamlining access for research while ensuring privacy.[60]

That would provide patient choice, transparency, accountability, competition and incentives to improve. It would also help identify patterns of poor care, such as avoidable neonatal deaths, botched surgery or poor cancer survival rates, early.

This represents disintermediation on an industrial scale to maximise patient control over their own care and lives, and could reach the point where someone who is not caring directly for the patient could make an equally valid judgement about their care needs. The more comprehensive the record, the greater the ability of AI or another doctor to assess the accuracy of a diagnosis or the appropriateness of treatment.

Building on existing technology such as the NHS app in England or My Health Record in Australia, this approach will amount to having an AI-powered doctor in your pocket, revolutionising access, diagnosis, patient power and clinical quality.

A technical aid to extracting and transferring large volumes of patient data, enabling the retrieval of data across the whole population with a single request, is Bulk FHIR (Fast Healthcare Interoperability Resources).[61] Bulk FHIR is valuable for applications such as population health management, quality management, research studies and training AI algorithms with large datasets.[62]



Estonia's 1.3 million inhabitants benefit from some of the most joined up healthcare data in the world. Since 2008 the Estonian National Health Information System (HIS) has consolidated data from healthcare providers into a unified record accessible online by patients. Virtually every piece of health data is digitised. It includes summaries of visits, treatments, discharges, referrals, diagnostic reports and medical procedures, providing a compressive resource for health professionals and patients alike, all presented in a standard format.[63] Healthcare providers must participate. Citizens use the system to manage appointments and prescriptions and communicate with healthcare staff.

In addition, the Estonian Genome Center has collected genomic data for over 200,000 people. Combining genomic data with the national health records is increasingly enabling clinicians to tailor diagnoses and treatments to individual genetic profiles. This is beginning to turn precision medicine into everyday healthcare.

There are strong privacy controls. Only licensed clinicians can access the system, patients have the option to restrict access to their data and they can monitor who has viewed their information. The use of blockchain technology ensures data integrity and helps protect against cyber threats.

Remove barriers to linking datasets

Integrating datasets requires legal frameworks for collecting, sharing and integrating data which are clear, precise and unambiguous. The EU's GDPR tries to be adaptable by using language such as "legitimate interest" and "proportionality", but it has led to confusion, uncertainty and inconsistency in the way it is applied. While big companies have the resources to navigate its complexities, GDPR is a significant hurdle to tech start-ups.

Data collection and coding needs to be standardised. It is hopeless to try to integrate datasets if personal or institutional identifiers are inconsistent. Governments need to mandate interoperability standards across systems, services and markets.

Data ownership needs to be rational and manageable. In England, GP practices are the data controllers for the patient data they hold. This means that over 6000 bodies need to cooperate with initiatives such as the NHS app. A few are refusing to allow their patients to access their data through the app, undermining their right to see it and impeding access to services.

Integrate data from across public policy

Governments need to provide the legislation and the infrastructure to bring together datasets from across policy and service areas such as physical and mental health, housing, education, welfare, labour force, justice and censuses. The aim is to build a longitudinal dataset so that a person's life chances, life events and health outcomes, and the factors that influence them, can be understood.

Manifesto for reform:

Actions for regulators

> The inherent risk with healthcare regulation is that it gets increasingly restrictive in response to each high-profile patient safety breach.

Ensure regulation is data-driven and proportionate

The inherent risk with healthcare regulation is that it gets increasingly restrictive in response to each high-profile patient safety breach. Institutional regulators, professional regulators, regulators of drugs and devices and federal and regional governments mean that healthcare providers are routinely dealing with multiple regulators, often with indistinct boundaries, conflicting rules and excessive and overlapping demands for data.

The problem of proportionate regulation is becoming more acute as the speed of technological innovation in digital devices, AI, drugs and therapies accelerates and developments such as hybrid closed-loop systems for type I diabetes blur the boundaries between technologies.[64]

In Europe, an implantable device using AI to control a drug dose is likely to be governed by general pharmaceutical rules, the medical devices regulation, the in vitro diagnostics regulation, the AI Act and the European health data space regulation, among others.[65]

Governments and regulators need to ensure that healthcare regulation:

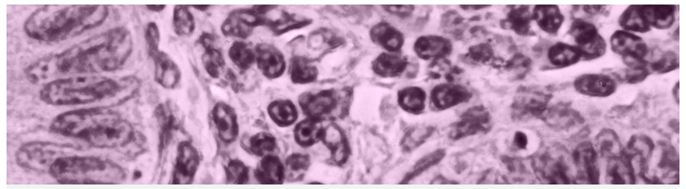
- Is proportionate, coherent, consistent and synchronised, with clearly defined decision-making pathways.[66] This includes collaborating internationally to try to ensure consistency between countries and between international organisations and standards.
- Supports the development and trialling of disruptive innovations, by using techniques such as regulatory sandboxes, an approach that originated in the financial technology sector to test ideas in a safe environment.[67]

As coding becomes more accurate and automated and real-time data and analysis becomes increasingly routine, regulatory regimes will need to be reinvented. Retrospective examination of results and somewhat performative activities such as inspection teams descending on an institution will become obsolete, while time consuming and burdensome activities such as professional revalidation could be rethought.

Ideas can be transferred from other industries. In Italy, projects in construction, occupational health and safety and food safety use machine learning to predict non-compliance.[68] In the construction sector, for example, it is enabling scarce resources to be targeted at the building sites where there is most likely to be an accident, while taking a proportionate approach to operators with a good safety record.

Data is brought together from a multitude of agencies, which helps reduce overlap between regulators. Using machine learning encourages the development of clear definitions for risk factors and increases understanding of what contributes to risk.

Analysis of the Italian projects shows that a machine learning approach can produce significantly better results than traditional regulatory regimes based on inspectors and outside experts.[69]



Regulatory overreach – the CQC in England

In the UK, poor care at Mid Staffordshire NHS Foundation Trust between 2005 and 2009 led to the creation of the Care Quality Commission. A recent inquiry into a crisis at the organisation – its second[70] – identified a loss of credibility which undermined the ability of care providers to deliver improvements.[71] Its assessment framework is complicated, difficult to understand and fails to explain what represents good performance.[72]

Hospital leaders complain that CQC inspections are time-consuming, encourage a focus on compliance rather than meeting the needs of patients and promote a risk-averse culture over the pursuit of better ways of working.

Manifesto for reform:

Actions for health organisation boards

Staff in a well led organisation understand and embrace its vision, values and clinical governance.

Develop a culture of outstanding clinical governance

Clinical governance is about understanding and learning. It provides a framework in which organisations are accountable for prioritising patient safety and care quality through a culture of continuous improvement. Questioning and learning without allocating blame are encouraged, staff feel valued and supported and patients are treated as partners in their care.[73] The seven pillars of clinical governance are:[74]

- Patient centred – patients are involved in decision-making and their preferences are respected
- Clinically effective – care is evidence-based, treatments and outcomes are tracked, clinical processes are continuously evaluated and medical advances are incorporated
- Safe – with robust and transparent reporting systems for adverse events, regular risk assessments and adherence to safety protocols
- Well led – with clear lines of responsibility, good leadership development and an organisational structure that supports the delivery of high quality care
- Robust information management – systems are in place to collect, analyse and disseminate accurate and timely data to track performance, inform decisions and identify areas for improvement
- Training and development – continuous learning is essential to delivering up-to-date care
- Performance monitoring and quality improvement – with regular audits, reviews and evaluations.

Provide effective leadership

Staff in a well led organisation understand and embrace its vision, values and clinical governance. The role and responsibilities of individuals and teams are clear and consistent. Teamwork and mutual respect are natural and the culture is open, questioning and collaborative. Staff feel engaged.

Maintain public trust

Like all parts of the system, providers need to explain how data is collected, stored and used. Where possible, each citizen should remain the owner and controller of their data, be able to see what is being shared with whom, how and why, and to modify those permissions. Any breaches must be reported publicly and addressed openly.

Build the goal around quality

The NHS Outcomes Framework provides a clear and simple structure for tracking healthcare performance across five domains:

- Preventing premature deaths
- Enhancing quality of life for long-term conditions
- Supporting recovery from illness or injury
- Ensuring safe care
- Providing a positive patient experience.

Different health systems will of course have different priorities, such as a greater emphasis on reducing communicable diseases, but the five domains of this outcomes framework are intuitive and equally valid for a clinical team, healthcare provider, local or national system or government.

Building on the work of Prof Sheila Leatherman, the NHS has identified seven steps – all dependent on data – to achieving high quality care:[75]

- Define quality – be clear about what high quality care looks like in all specialties and reflect this in setting standards
- Measure quality – to improve, activity and outcomes need to be measured, which requires a robust measurement framework
- Publish quality performance – make data on how well the service is doing easily available to staff, patients and the public. Publication is essential in understanding variation and good practice and focusing on improvement
- Recognise and reward quality – ensure the right measures and incentives are in place to support quality improvement for organisations and individual staff
- Raise standards – improve quality by empowering patients and professionals
- Safeguard quality – protect the gains made by regulation and oversight
- Stay ahead – constantly redefine high quality care by supporting innovation and following the evidence.

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Acknowledgements

We are grateful to colleagues who shared their expertise and time for this report:

Richard Vize (UK) who authored the report

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