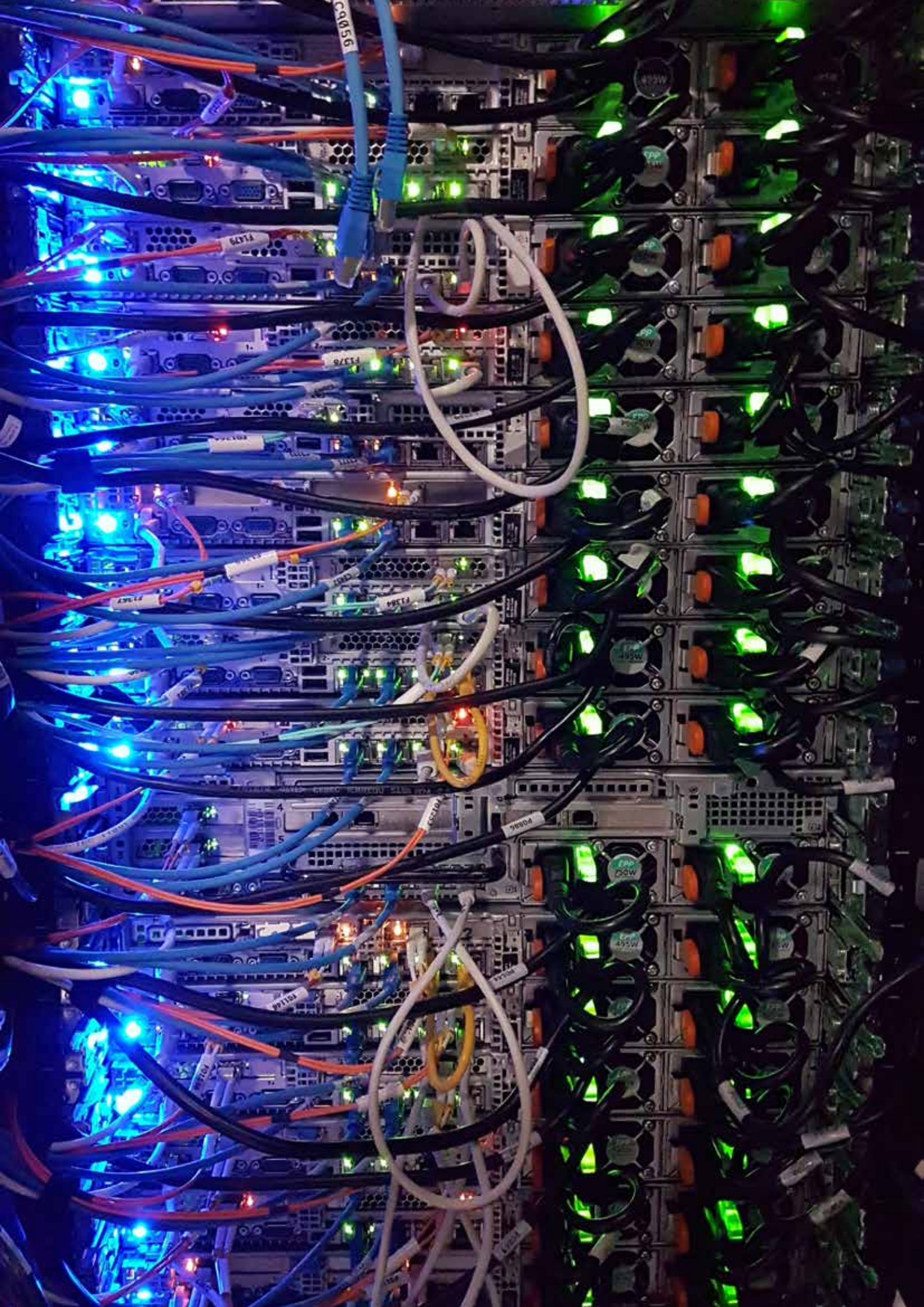
scdi Scottish Council for Development and Industry

MIND THE GAP

How data, digital and technology can help Scotland recover from Covid-19, transform health & social care and boost our economy



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SUMMARY

Closing Scotland's Data Gap

COVID-19 has tested Scotland like perhaps never before. From the NHS to care homes to community pharmacy, health & social care are on the frontline of our emergency response to the global pandemic. The sector has made important progress in harnessing data, digital and technology to tackle the virus – particularly through the Test and Protect strategy, the Protect Scotland app, the expansion of online video consultations and more timely ethical data sharing.

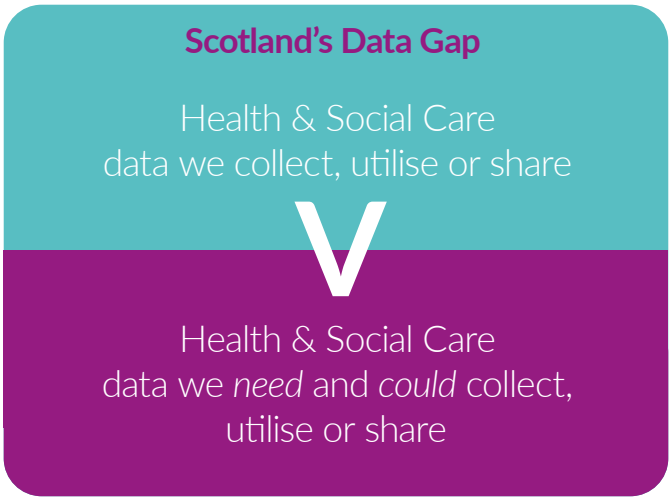
But there is much more still to do. Even before the pandemic, Scotland faced a series of major and escalating public health challenges and crises which will continue to damage our society and the economy if they are not tackled, preventing our nation and its people from achieving our potential.

We need to learn the lessons of COVID-19. A healthy society is essential for a healthy economy. Access to real-world health & social care data has informed and enhanced decision-making and policymaking throughout the crisis, helping to identify and control outbreaks, develop appropriate restrictions and roll out vaccines.

Long-term, strategic investment in health & social care innovation is critical. New and emerging technologies – enabled and underpinned by ethical, robust and secure data – can and should play a vital role in transforming health & social care.

Nations which recognised these priorities long before the pandemic – albeit with different political and health systems, such as Singapore, South Korea and Taiwan – have better utilised data, digital and technology to respond more swiftly and more successfully to the virus. Their action and investment has saved lives, protected livelihoods and minimised disruption to daily life.

If we act now to close Scotland's Data Gap between the health & social care data we have and the health & social care data we need, there will be big social and economic gains for everyone. As we look to recover and build resilience from the COVID-19 crisis, it has never been more important.



Our Vision for 2024

Our vision is of a health & social care sector transformed by the Fourth Industrial Revolution, harnessing data, digital and technology to close Scotland's Data Gap, deliver big social and economic gains and improve public health to among the best in Western Europe by 2040.

We believe Scotland can become a world leader in data, digital and technology in public health, attracting health & social care professionals and researchers, entrepreneurs and innovators, investors and industry, from around the world.

We believe Scotland can build on our strengths across the public, private and third sectors to close the Data Gap. Our nationally integrated, publicly owned NHS is globally unique. Our data, life sciences and tech sectors are diverse, growing and supported by a renowned ecosystem of world-class academics, research universities and new centres of expertise and innovation.

However, in the global recovery from COVID-19, Scotland has a narrow window of opportunity to establish itself as a world leader and to win the global race for investment, jobs and inclusive growth to boost our economy.

Researchers and industry are primarily interested in insights from aggregated, anonymised data at a regional and national level, rather than identifiable health & social care data at an individual level, which could potentially breach personal privacy if not used in the right way. Personal health & social care data must be ethical, secure and anonymised as far as possible with robust and transparent governance arrangements. Data must be trustworthy

Social and Economic Gains

Data saves lives, time and money. Harnessing and sharing data, digital and technology in health & social care can deliver big gains for patients and service users, staff, communities and taxpayers through improved care, better outcomes, higher productivity, lower costs and new jobs.

Scotland's health & social care data could be worth an estimated £800 million every year for our society and our economy. Big Data Analytics could also deliver an estimated £5.4 billion in savings for NHS Scotland, 38% of its current budget and three times its predicted budget shortfall by 2025, which could be reinvested in health & social care. The health tech sector could be Scotland's next key growth sector to rival FinTech.

Overview of Social and Economic Gains

Social

- **Saving lives and delivering better outcomes for patients and service users**
- **Improving physical and mental health, wellbeing and quality of life**
- **Reducing health inequalities**

Economic

- **Attracting investment and creating jobs**
- **Reducing economic inactivity and sickness absence**
- **Increasing productivity and inclusive growth**
- **Easing demand pressures on health & social care staff and services**
- **Delivering value and protecting the long-term future of the NHS**

Four Pillars of a New Data Strategy for Health & Social Care

We welcome the Scottish Government's commitment in the Programme for Government 2020/21 to 'create a dedicated data strategy for health & social care for the first time'. We believe that this new national Data Strategy – due to be published later in 2021 – should be backed by a Health & Social Care Transformation Fund which invests in strengthening four key pillars to close Scotland's Data Gap:

STRATEGY

Developing an ambitious, collaborative and innovative national approach to harnessing data to transform health & social care which maximises social and economic gains.

CULTURE & LEADERSHIP

Empowering leaders to drive change by building an ambitious and collaborative national culture of innovation in data, digital and technology.

SKILLS

Investing in reskilling, upskilling and lifelong learning to develop a health & social care workforce better equipped to harness data, digital and technology.

INFRASTRUCTURE

Modernising and upgrading health & social care infrastructure to build a single national data architecture which integrates systems, enables ethical data sharing and creates secure digital health records.

The Scottish Government is leading the development of the new Data Strategy. However, the new Data Strategy and the Transformation Fund should also be designed and delivered in partnership with the diversity of partners and stakeholders across the sector – especially citizens, patients and service users, and including the voice of staff and industry – to build understanding, trust, support and agency across our society and our economy as the foundation for the future of health & social care.

SCOTLAND'S DATA STRATEGY FOR HEALTH & SOCIAL CARE

Strategy | **Culture & Leadership** | **Skills** | **Infrastructure**

Trust & Transparency

Strategy

Successful small nations are more agile and can unite behind a national mission. Scotland is small enough to link and manage health & social care data together nationwide, while also big enough to provide a demographic critical mass for research and insights by global academia, industry and others.

But Scotland's historic approach to health & social care data innovation has often been incremental. There has been a failure to scale-up nationally. Despite the extraordinary spirit of partnership and collaboration during the pandemic, the health & social care landscapes remain complex, fragmented and siloed. The lack of a common commitment or approach to issues such as data standards or governance is a barrier to collecting, sharing and harnessing ethical and secure data.

The new Scottish approach should be focused on driving forward innovation at pace and at scale for the benefit of all. The new Data Strategy for Health & Social Care in Scotland will be an essential part of our recovery from COVID-19 and must be aligned – in its design and in its delivery – with Scotland's many other relevant strategies for the sector.

Culture & Leadership

Change should be people-led to overcome cultural barriers. NHS Scotland, service providers and health & social care professionals should be risk-aware rather than risk-averse, flexible to new ways of working and open to collaboration for the common good with public, private and third sector partners. There should be strong, joined-up leadership at a political level and across government and the public sector to drive change and build a national culture of innovation.

Health & social care needs to attract, retain and nurture data champions at all levels and in all areas, as well as act to increase workforce diversity. Senior leaders and decision-makers need to have the personal and professional experience and expertise which the sector needs to understand, support and implement cultural and technological change.

There needs to be more action to invest in data research and innovation, identify and spread best practice and accelerate national scale-up. Public Health Scotland's Data Driven Innovation directorate could act as such a hub for Scotland's national culture of health & social care data innovation.

Skills

Health & social care's workforce has proven extraordinarily flexible and resilient in its emergency response to COVID-19. But they will need support to adapt to the disruption of the Fourth Industrial Revolution, working alongside technology to harness data. Existing roles will change, new ones will be created, some may be displaced. The health & social care workforce of the future will need to be data and digital ready. 90% of all NHS jobs will require digital skills by 2040.

Everyone will need to be data and digital literate, as well as understand data privacy and security. Many will need to interpret data to gain insights and deliver applied intelligence. Some will need practical skills to service, maintain and protect tech infrastructure. The sector's informatics workforce of data scientists and analysts will require investment to expand Big Data Analytics capacity.

Reskilling, upskilling and lifelong learning for all health & social care workers, at all stages and in all careers will be essential. Developing knowledge and skills in data, digital and technology, and exploring related ethical and safety issues, should be a core part of all health & social care learning, from undergraduate and postgraduate degrees to work-based learning and CPD. Employers and educators will have to keep pace with change and refresh curricula more frequently.

Infrastructure

Health & social care needs the right physical and digital infrastructure to close the Data Gap and achieve our vision. The sector lags others in the use of technology. Much of the sector is burdened with archaic, inadequate or obsolete technology and equipment. Many facilities and workers struggle without basic software and hardware or with poor connectivity. The NHS estate and Scotland's wider health & social care infrastructure urgently requires significant investment to get the basics right, while also unlocking opportunities to prepare for an accelerated transition to a high-tech future.

The sector's myriad systems do not link to or communicate with each other, preventing access to or ethical and secure sharing of data. The openness, integration and interoperability of data sets and systems to create a single national data architecture – underpinned by common data standards – would facilitate ethical and secure data sharing at a national level and the creation of a single, comprehensive digital health record for everyone in Scotland across primary, secondary, tertiary and social care. The ongoing project by NHS Education for Scotland to build a National Digital Platform for health & social care is an important first step.

Fully integrated personal data giving a holistic picture of patients' and service users' experiences and outcomes could then be ethically and securely accessed by health & social care professionals to enhance patient care and better inform clinical decision-making for the short-term benefit of individuals. Consistent, high quality aggregated, anonymised Big Data at a national or regional level could be accessed by researchers and innovators for the long-term benefit of all.

Our Key Recommendation

The Scottish Government's new Data Strategy for Health & Social Care should be backed by a Health & Social Care Transformation Fund which invests in Strategy, Culture & Leadership, Skills and Infrastructure to close Scotland's Data Gap.

INTRODUCTION

Recovering from COVID-19: Innovation, Resilience & Transformation in Health & Social Care

COVID-19 has tested Scotland like perhaps never before. We have all made difficult sacrifices to protect and help each other. From the NHS to care homes to community pharmacy, health & social care are on the frontline of our emergency response to the pandemic.

Our doctors, nurses, social care professionals, pharmacists and other key workers across the health & social care sector have given so much in the fight against the virus, demonstrating extraordinary courage, commitment and skill. The sector has responded to the immediate challenges and imperatives of the crisis by making important progress in harnessing data, digital and technology to tackle COVID-19 and protect public health.[1]

Test and Protect – Scotland's system for implementing its 'test, trace, isolate, support' strategy – has gathered and utilised large quantities of data to monitor, suppress and prevent the transmission of the COVID-19 across the country, as well as informing decision-making about restrictions and support for workers, businesses and communities.[2] The rollout of the Protect Scotland app has enlisted over 1 million citizens to help track and control the virus.[3] Access to NearMe online video consultations has expanded massively to enable patients and service users to consult GPs remotely and safely.[4]

But there is much more still to do.

Learning the Lessons of COVID-19

COVID-19 has underlined the benefits of long-term, strategic investment in the innovation, resilience and transformation of health & social care and the importance of access to real-world health & social care data. We need to learn the lessons of the pandemic and from the success of other nations – including those in different contexts and with different political and health systems, which Scotland would not and should not replicate.

Singapore, Taiwan and South Korea, for example, recognised this as a national priority long before COVID-19 after the SARS outbreak in East Asia in 2002. They have had much greater success in suppressing or even eliminating the virus, as well as in minimising disruption and negative impacts of the pandemic on their public health, societies and economies.[5] They have harnessed data, digital and

1 www.digihealthcare.scot/wp-content/uploads/2020/07/Scotlands-digital-health-and-care-response-to-Covid19_JUNE-2020.pdf
2 www.nhsinform.scot/campaigns/test-and-protect
3 www.protect.scot
4 www.nearme.scot
5 www.thelancet.com/journals/lanwpc/article/PIIS2666-6065(20)30044-4/fulltext

technology to ensure less transmission and fewer deaths per capita; minimise or prevent restrictions on business activity and community life; and better protect livelihoods, employment and prosperity.[6]

By investing in data, digital and technology in health & social care to harness its full potential we can ensure we are better prepared for the public health challenges, crises and disruptions of the future. COVID-19 and our response to it will have a lasting impact, with lag effects and unintended consequences which we need to prepare for too.

If we act now to close Scotland's Data Gap between the health & social care data we have and the health & social care data we need, there will be big social and economic gains for everyone. If we fail to, the price will be high for us and for future generations.

The pandemic has been a social, economic and health crisis which has underlined that a healthy society is essential for a healthy economy. Our physical and mental health impacts on our wellbeing and quality of life as individuals, our income and productivity as workers and the public services we access as citizens.[7]

However, even before the pandemic Scotland faced a series of major and escalating public health challenges and crises which will continue to damage our society and the economy if they are not tackled, preventing our nation and its people from achieving our potential.[8] [9]

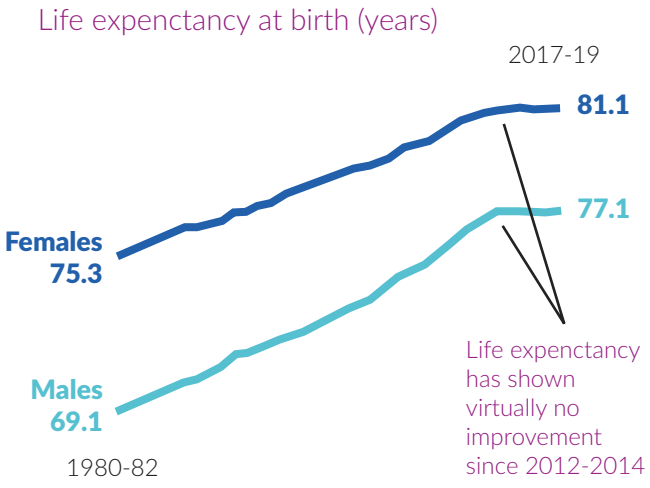
Severe inequalities in outcomes are entrenched across Scotland, with life expectancy dramatically lower in deprived communities. Mental health issues from anxiety to stress to depression are affecting increasing numbers of people, especially young people. The costs to families, communities and taxpayers of long-term ill-health are high, as are levels of obesity, alcohol misuse and substance abuse.[10]

Scotland's public health challenges

Lowest life expectancy in Western Europe [11]

Scotland	79 years old
Belgium	81 years old
Germany	81 years old
Denmark	81 years old
Netherlands	82 years old
Wales	82 years old
Northern Ireland	82 years old
Norway	82 years old
Spain	82 years old
England	83 years old
France	83 years old
Portugal	83 years old
Italy	83 years old
Sweden	83 years old

Life expectancy increases have stalled in recent years



Source: www.nrscotland.gov.uk

6 https://knowledge.wharton.upenn.edu/article/singapore-south_korea-taiwan-used-technology-combat-covid-19
7 www.who.int/choice/publications/d_economic_impact_guide.pdf?ua=1
8 www.gov.scot/collections/scottish-health-survey
9 www.gov.scot/binaries/content/documents/govscot/publications/corporate-report/2018/06/scotlands-public-health-priorities/documents/00536757-pdf/00536757-pdf/govscot%3Adocument/00536757.pdf
10 www.gov.scot/collections/long-term-monitoring-of-health-inequalities
11 www.scotpho.org.uk/population-dynamics/healthy-life-expectancy/data/international-comparisons

High levels of drug and alcohol abuse

1 in 4 people in Scotland consume alcohol at hazardous levels [12]

Alcohol harm costs Scotland £3.6bn every year in health & social care, crime, lost productivity and wider impacts [13]

Scotland has more drug deaths per capita than any other European country [14]

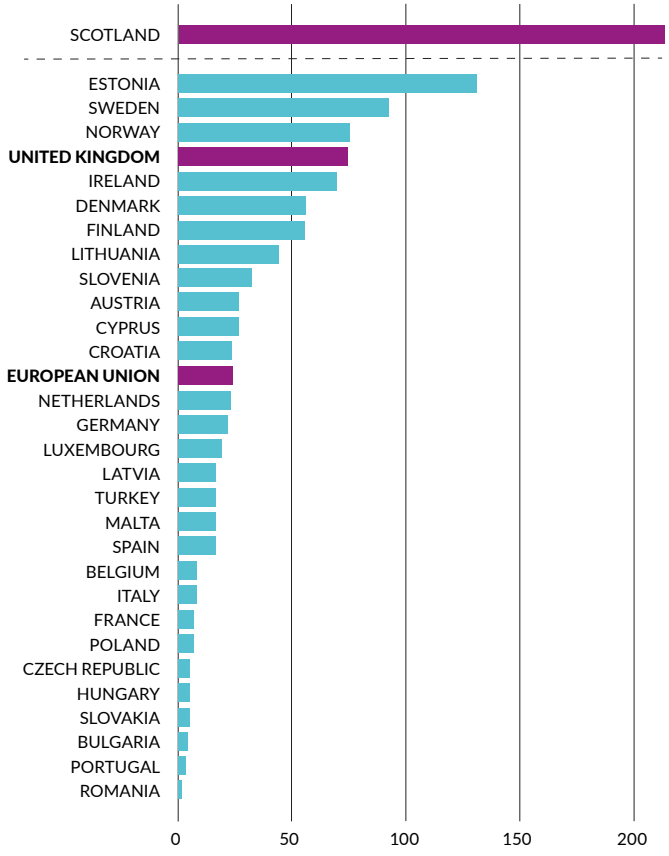
Entrenched health inequalities

LGBT people are more than twice as likely to attempt suicide [15]

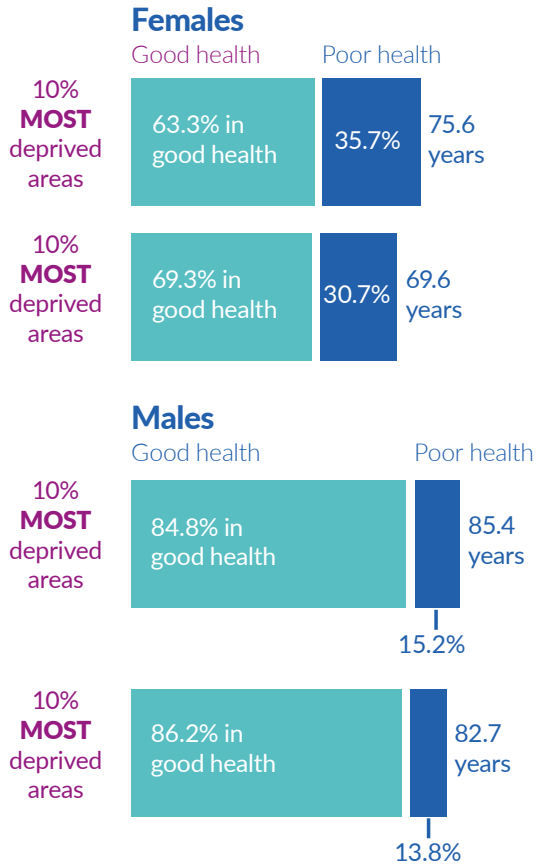
Gypsy/Travellers are twice as likely to suffer from health problems and disabilities [16]

Scotland has more drug deaths per capita than any European country

Number of deaths per million people, latest available data



Source: National Records of Scotland. Note: No data available for Greece



The unparalleled scale and intensity of the COVID-19 crisis has exacerbated the underlying challenges of demand and capacity faced across the health & social care sector. Our NHS is facing unprecedented pressures on its finite resources, mature infrastructure and stretched staff. The expanding role of community pharmacy is creating new challenges for the sector after under-investment in its workforce and infrastructure. Social care has been struggling to deal with the intensifying pressures of meeting demand from a rapidly ageing population.

12 www.alcohol-focus-scotland.org.uk/alcohol-information/alcohol-facts-and-figures
13 www.alcohol-focus-scotland.org.uk/alcohol-information/alcohol-facts-and-figures
14 www.nrscotland.gov.uk/files//statistics/drug-related-deaths/2019/drug-related-deaths-19-pub.pdf
15 www.stonewallscotland.org.uk/our-work/stonewall-research/lgbt-scotland-%E2%80%93-health-report
16 www.gov.scot/publications/ethnic-groups-poorest-health

Our Report

This independent report was commissioned by Janssen UK and authored by SCDI with input from a Steering Group composed of representatives from Janssen UK, The Data Lab, ABPI Scotland, the University of Strathclyde and the Scottish Government.

Its conclusions have been informed and shaped by months of engagement with key stakeholders, leaders, experts and workers from across the health & social care, data and technology sectors. We have also listened to the insights and priorities of SCDI members from all sectors and all geographies of the Scottish economy.

In Numbers: Our Evidence-Build

It builds on SCDI's other recent work in this space – including our Automatic... For the People? (2018)[17], Building a World-Leading AI and Data Strategy for an Inclusive Scotland (2019)[18] and Upskilling Scotland (2020)[19] reports – which identified the major challenges and opportunities for Scotland in the Fourth Industrial Revolution and presented a roadmap towards an AI Strategy for Scotland, which is now being developed.

In this report we propose an ambitious new vision for data, digital and technology in health & social care in Scotland. We identify the major priorities and urgent actions which must be taken together by the Scottish Government, NHS Scotland, industry and the other service providers and stakeholders across the sector as part of the new national Data Strategy due to be published later in 2021.

Our Vision

Data will fuel the global economy of the future. Large, complex data sets are being generated, digitised and analysed by automation and AI to develop rich new evidence, information and insights, opening a whole new plane of knowledge about our people, our society and our economy, as well as enabling new and emerging technologies. Over 90% of the world's data has been generated in the past two years alone as the Fourth Industrial Revolution gathers pace.[20]

Fourth Industrial Revolution technologies

Automation = Automatic working of a machine, process or system by mechanical or electronic devices without human intervention

Artificial/Assistive/Augmented Intelligence = Set of techniques used to allow computers to perform tasks normally requiring human intelligence (e.g. visual perception, speech recognition, translation, decision-making)

Big Data Analytics = Collection, organisation and analysis of high volume, velocity and variety of data sets to systematically extract information or insights to inform decision-making

Connected and Autonomous Vehicles = Vehicles which utilise advanced AI and sensors to undertake all aspects of dynamic driving tasks in all conditions without input from a driver

cont/-

Data-driven insights can inform and shape policymaking and decision-making by governments,

17 www.scdi.org.uk/policy/automatic-for-the-people
18 www.scdi.org.uk/policy/ai-and-data
19 www.scdi.org.uk/policy/skillsleadershipgroup
20 http://download.microsoft.com/documents/en-us/sam/bsadatastudy_en.pdf

Digitisation = Restructuring and transformation of processes or operations with digital technologies (e.g. computers, software, internet- and cloud-based services)

Internet of Things = Networked devices or sensors connected via the internet to collect, send and receive citizen-generated data (e.g. via wearables) or clinician-generated data (e.g. hospital equipment)

Nanotechnology = Design, manufacture and application of materials on a very small scale, including in the discovery and development of new medicines

Precision Medicine = Medicine personalised to the individual characteristics, especially genetic profile, of each patient to deliver 'the right drug, for the right patient, at the right time'

Smart Hospitals = Facilities which embed new data, digital and automated technologies into their design, operations and delivery of care

businesses, scientists, workers, consumers and citizens alike. In every sector – not least health & social care – ethical and secure data-driven insights can be harnessed to develop new innovations, design new products and services and improve outcomes.

Big Data can be utilised to monitor the effectiveness of all interventions along the care pathway. Big Data can be utilised to develop new medicines and technologies, as well as design new forms of care, such as personalised and precision medicine. Whether generated by health & social care professionals and service providers or by citizens, patients and service users themselves, Big Data provides real-world evidence which can complement evidence from randomised controlled trials and give us richer knowledge about outcomes. We can ethically and securely harness data-driven insights and innovations to create jobs, support cutting-edge research and attract inward investment, delivering big social and economic gains for everyone in Scotland.

But health & social care in Scotland today faces a Data Gap between the health & social care data we collect, utilise or share and the health & social care data we need and could collect, utilise or share.

We believe Scotland can build on its strengths to close the Data Gap and become a world leader in the fifth wave of public health. Our vision is of a health & social care sector transformed by harnessing the technologies of the Fourth Industrial Revolution, utilising data, digital and technology to deliver big social and economic gains so that Scotland's public health is among the best in Western Europe by 2040.

A Fifth Wave of Public Health? [21]

1. Structural – e.g. public works like clean water, sewers, drainage
2. Biomedical – e.g. early scientific progress in vaccines, antibiotics
3. Clinical – e.g. tackling lifestyle-related diseases
4. Social – e.g. tackling inequalities, social determinants of health
5. **Technological – e.g. Big Data & Digital Health**

Scotland's world-class academics, researchers and entrepreneurs, together with our universal, publicly owned NHS, provides a globally unrivalled platform for innovation and competitiveness. Our NHS is at the heart of Scottish life with strong support across society, politics and the economy, with a shared commitment to make sure it is fit for the future. Scotland has a renowned life sciences sector, a burgeoning tech sector and a pharmaceutical industry contributing £2.5bn to the Scottish

21 Adapted from https://pubmed.ncbi.nlm.nih.gov/21256366

economy, 5,600 direct jobs and £575m in exports.[22] Scotland attracts a third more UK public research funds than our population share would suggest.[23]

However, the pace of progress elsewhere, from the Baltics and Scandinavia to East Asia, means that Scotland must strive to keep up by raising the level of our ambition, the scale of our investment and the pace of our action. Other countries' faster and more effective responses to COVID-19 have reflected their more advanced and more mature data, digital and technology capacities in health & social care.[24]

In the global recovery from the pandemic, Scotland has a narrow window of opportunity to establish itself as a world leader and to win the global race for investment, jobs and inclusive growth to boost our economy.

Big Data can be harnessed to…

- Save lives and deliver better outcomes for patients and service users
- Improve public health, wellbeing and productivity
- Deliver value and protect the long-term future of the NHS
- Build an infrastructure which attracts inward investment
- Create high quality, high skill jobs in health & social care, data science, technology and innovation

Our Values

The trust and support of citizens, patients and service users is essential to achieve our vision. Public awareness of and sensitivity to data privacy and security issues has grown in recent years after high-profile controversies about the misuse of personal data. Personal health & social care data must be ethical, secure and anonymised as far as possible with robust and transparent governance arrangements.

Researchers and industry are primarily interested in insights from aggregated, anonymised data at a regional and national level, rather than identifiable health & social care data at an individual level which could breach personal privacy. The NHS Charter of Patient Rights and Responsibilities must be respected, including the 'right to privacy and for my personal health information to be protected when using NHS services'.[25]

Personal health and social care data – whether generated by health & social care professionals and services providers or citizens, patients and service users themselves – should only be used by the NHS, direct providers, service users or those seeking to develop innovations for patient benefit. Appropriate governance arrangements need to be in place to ensure privacy, security and custodianship by the NHS, patients and service users to build understanding, trust, support and agency. Data must be trustworthy and trusted.

Our Pillars

This report is structured around four pillars, which we have identified as supporting our vision, and which must rest together upon a strong foundation of trust and transparency:

Strategy
Scotland's national strategy needs to deliver an ambitious, collaborative and innovative national approach to harnessing data to transform health & social care which maximises social and economic gains.

Culture & Leadership
Scotland's political and health & social care leadership need to drive change by building an ambitious and collaborative national culture of innovation in data, digital and technology.

22 www.abpi.org.uk/publications/the-economic-contribution-of-the-pharmaceuticals-sector-in-scotland
23 www.gov.scot/binaries/content/documents/govscot/publications/research-and-analysis/2015/10/delivering-innovation-through-research-scottish-government-health-social-care-research/documents/00488082-pdf/00488082-pdf/govscot%3Adocument/00488082.pdf
24 https://knowledge.wharton.upenn.edu/article/singapore-south_korea-taiwan-used-technology-combat-covid-19
25 www.nhsinform.scot/care-support-and-rights/health-rights/patient-charter/the-charter-of-patient-rights-and-responsibilities

Skills
Scotland needs to invest in reskilling, upskilling and lifelong learning to develop a health & social care workforce better equipped to harness data, digital and technology.

Infrastructure
Scotland needs to modernise and upgrade health & social care infrastructure to build a single national data architecture which integrates systems, enables ethical data sharing and creates secure digital health records.

Chapter 1 asks: What and Why? What is the Data Gap? Why should closing it be a national priority? What would be the social and economic gains for everyone in Scotland?

Chapters 2, 3, 4 and 5 ask: How? How can we close the Data Gap? What do we need to do to maximise the social and economic gains for a healthy society and a healthy economy? What should be the priorities of the new Data Strategy for Health & Social Care?

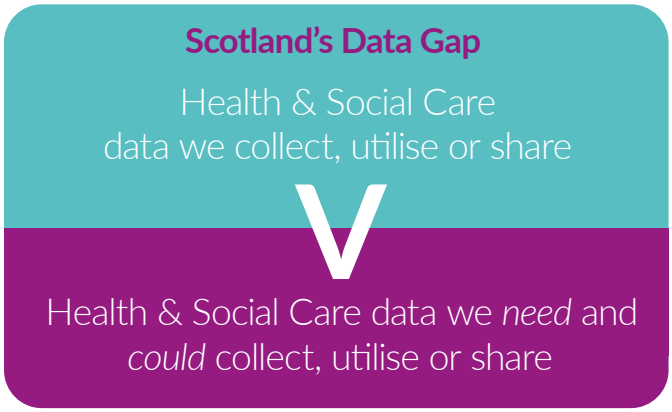
CHAPTER 1
Data Saves Lives, Time & Money: Social & Economic Gains of Closing the Data Gap

Mind the Gap

Scotland's Data Gap is about the health & social care data the sector collects, utilises or shares today, and the health & social care which it needs to collect, utilise or share to improve public health and to enable new and emerging technologies to be harnessed.

Some areas of health & social care in Scotland are acknowledged to be relatively data rich. Primary care has high-quality data on millions of patients. The project to build a National Digital Platform for health & social care aims, in time, to connect all of Scotland's health and care data for all patients and service users.[1]

However, across the sector data collection needs to be improved and expanded, and data needs to be better utilised in a consistent way with common data standards to enhance health & social care and scale-up innovation nationally. Scotland needs to better utilise existing health & social care data and to close the Data Gap across large parts of the system. Real-world and citizen-generated data, together with randomised controlled trials evidence, in relation to the effectiveness of medicines and other interventions along the care pathway can deliver truly holistic health & social care insights.[2]



The rollout of the Test and Protect strategy and the Protect Scotland app during the pandemic has demonstrated the power of data to save lives, time and money. Data has been vital in efforts to monitor, suppress and prevent the transmission of COVID-19 – including identifying outbreaks, tracing contacts, managing resources, increasing digital service accessibility and rolling out vaccines to priority groups.[3]

Consistent, high quality aggregated and anonymised data can be analysed and interpreted to review effectiveness to better inform clinical decisions

1 https://nds.nhs.scot
2 Scottish Government's Data Scoping Taskforce (2018) Medicines Use and Digital Capabilities – Building capability to assess real-world benefits, risks and value of medicines: Towards a Scottish Medicines Intelligence Unit
3 www.protect.scot

about care, prevention, prescriptions, value of interventions and reimbursement, as well as innovation to improve drug discovery, design and manufacture. It is also a critical enabler for technologies like AI and automation. Health & social care professionals could then utilise all available data to gain new insights to help them provide better care for patients and service users.

> Randomised controlled trials evidence & Real-world data => Holistic health & social care insights

Primary, secondary, tertiary and social care data is not yet linked to enable a fully holistic view of patient experiences, journeys and intervention outcomes and to provide informed and truly integrated health & social care. Currently, many GP surgeries, care homes and hospitals lack the fundamental infrastructure required to record, track and analyse basic patient data or to support rollout of digital services like NearMe.

Data needs to be consistent in quality, as well as securely connected and ethically shared across systems throughout health & social care without geographical, sectoral or organisational silos. A single, comprehensive digital health record for everyone in Scotland would be transformational.

Citizen-generated data, commercial data and the Internet of Things (IoT) could be rich sources of valuable qualitative and quantitative data for health & social care. For example, smart sensors utilised to predict and prevent falls or heart attacks in at-risk or elderly people living independently or in care homes. Data already collected by the private and third sectors, such as by wearables or service providers, could be better utilised to inform clinical decision-making, service design and the allocation or targeting of resources at communities or groups most in need.

Last year's inquiry into the supply and demand of medicines by the Scottish Parliament's Health and Sport Committee argued that an 'almost complete absence of useable data' was holding back the system and harming public health. It found that there was a 'lack of data collection and analysis on outcomes achieved via the prescriptions of medicines' with the 'impact on individual patients' neither being sought nor examined by GPs, pharmacists or others across primary care.[4] This lack of qualitative and citizen-generated data, and the failure to utilise commercial data which already exists to benefit public health, is a major part of Scotland's Data Gap.

The result of the Data Gap is a major knowledge deficit in public health in Scotland, which is bad for patients and service users, health & social care professionals and our economy and society. Poor quality data means that we understand less about the people we need to help, the problems they face and the effectiveness of treatments and interventions along the care pathway at improving their health, wellbeing and quality of life. Closing the gap would deliver big social and economic gains for patients, service users, health & social care professionals, NHS, government and industry.

> *"Accurate data is the lifeblood of good policy and decision-making."*
> **Antonio Guterres**
> Secretary-General, United Nations

It is estimated by EY that the data held across the NHS across the UK could be worth £9.6 billion every year in social and economic gains, including saving lives, improving patient outcomes and creating new jobs. For Scotland, this could represent a health & social care data dividend of up to £800 million every year for our society and our economy.[5]

Social Gains

The social costs of the status quo are clear and

4 www.parliament.scot/parliamentarybusiness/CurrentCommittees/113038.aspx
5 www.ey.com/en_uk/life-sciences/how-we-can-place-a-value-on-health-care-data

significant. Many patients and service users receive sub-optimal health & social care due to poor quality, inconsistent, or unshared data, leading to:

- Lower levels of happiness and wellbeing and poorer quality of life.
- Higher levels of health inequalities.
- Lower levels of household income and wealth due to economic inactivity from long-term and chronic ill-health.

Data saves lives. Quantitative data about patient health and qualitative data about patient lived experience and quality of life enriches and expands the information which doctors, nurses, pharmacists, carers and other health & social care professionals can draw on to deliver better care. Data enhances prevention, prescribing and treatments to be more effective. Currently, many patients and service users have poorer outcomes or will even die because their data is not collected or shared. The use of data globally in the fight against COVID-19 has demonstrated the power of data to save lives, from identifying and suppressing outbreaks to supporting rollout of vaccines to at-risk priority groups.[6]

Data empowers the health & social care workforce to design and deliver precision medicine or care personalised to patient or service user needs. A single, comprehensive digital health record for everyone in Scotland could deliver a truly integrated, informed care and a seamless, holistic patient experience by storing all lifetime patient data in one place. The creation of digital health records requires complex integration of data sets, systems and architecture across health & social care, as well as greater investment in other Fourth Industrial Revolution technologies to maximise gains for patients or service users. Data can enable service change, accelerate technological transformation and underpin a truly seamless patient journey.

What could a patient journey look like in the future...?

Having, analysing and sharing ethical, robust and secure health & social care data will enable us to transform health & social care in Scotland with new insights and technologies:

- Elderly woman living alone has bad fall. Detected – or even predicted and prevented – by IoT wearables or sensors in her smart home. Home IoT calls 999 and notifies family or neighbours
- Nearest available ambulance is Connected and Autonomous Vehicle (CAV). Assigned rapidly by algorithm
- Paramedics have immediate (but permissions- and time-limited) access to patient's single, comprehensive digital health record via tablets. Informed of existing conditions, previous illnesses, allergies and other patient needs
- Paramedics collect patient. CAV ambulance is tracked. Tablets communicate information and data (e.g. condition, estimated arrival time) to A&E en route
- Hospital's AI system identifies and secures staff and resources required, ready for patient in A&E. Manages most productive division of labour
- Automated devices record and organise patient-doctor interactions in hospital. Removes need for notetaking. Automatically added to digital health record
- Two-way AI-powered language translation if required
- Scans, x-rays or tests enhanced with automated image interpretation using AI or informed by anonymised Big Data and patient's digital health record

cont/-

6 https://knowledge.wharton.upenn.edu/article/singapore-south_korea-taiwan-used-technology-combat-covid-19

- Emergency surgical procedures (or lab work) conducted with assistance of robotics
- Clinical judgements on most effective options for care and treatment informed by patient data and insights from anonymised, aggregated data
- Patient prescribed by doctors and pharmacists with more effective precision medicine shaped by AI-automated drug discovery, real-world data and randomised controlled trial evidence in laboratories locally and globally
- Patient discharged from hospital. Returns home after recovery. Community care and support delivered in-person by carers, via phone and digitally by video consultation.
- Automated collection of quantitative data (and remote monitoring of) on patient's recovery from smart housing and wearables
- Qualitative citizen-generated and clinician-generated data on patient's recovery, lived experience and quality of life collected in-person, via phone or digitally by video consultation with GP surgeries or community pharmacy
- All data added to digital health record. Patient (and doctor or carer) can access in real time online or via secure smartphone app. Data harnessed for prediction and prevention. Patient can choose to share her data with family
- Patient also goes online or uses smartphone app for supported self-care and self-management of long-term health. Accesses further advice or makes appointments

All these examples are technically feasible with today's proven and emerging technologies – and some have already become reality in health & social care in some parts of the world – with the collection, sharing and utilisation of the right data at the right time.

Data is critical for evidence-based public policy, enabling the identification and analysis of health inequalities to inform the design and delivery of more effective, targeted interventions. Health inequalities are significant and entrenched in Scotland between different communities on the basis of deprivation, gender, ethnicity and sexuality.[7]

Economic Gains

A healthy society is essential for a healthy economy. Workers who are less physically or mentally healthy are less productive. Learners who are less healthy achieve lower levels of education. A healthier population provides employers with access to a larger talent pool for their workforce. Ill-health can force individuals to leave the workforce and the labour market. Illness and injury therefore often result in lower household income and earnings potential, or higher living costs.

> *"Poverty is both a cause and a consequence of poor health. Poverty increases the chances of poor health. Poor health, in turn, traps communities in poverty."*
>
> **Health Poverty Action**

Scotland's public health is among the worst in Western Europe, contributing to:

- Lower levels of productivity and inclusive growth.
- Higher levels of economic inactivity and sickness absence.
- Unprecedented demand pressures and higher costs for the NHS and Scottish Exchequer.

Economic inactivity has historically been stubbornly high in Scotland, reducing employer access to the

7 www.gov.scot/collections/long-term-monitoring-of-health-inequalities

labour, skills and talent they need. Around a third of the economically inactive are not in work or looking for work due to long-term sickness, disability or temporary sickness or injury.[8]

The NHS alone has lost more than 1.3 million working days due to COVID-19.[9] The cost to employers of lost working days and weakened productivity due to the pandemic is expected to reach several billion pounds. Even in more normal times, an estimated 141.4 million working days were lost due to sickness or injury across the UK in 2018, representing an average of 4.4 days per worker or 2% of total working time. The sickness absence rate in Scotland is the highest of the nations and regions of the UK at 2.4%. The average cost to employers is around £570 per employee every year.[10]

Health is the single largest area of public spending in Scotland at over £15 billion. Since devolution in 1999, its proportion of the Scottish Budget has grown relentlessly. The Scottish Government now spends 42% of its total budget on the NHS.[11] This raises significant concerns and 'major risks' about its long-term financial sustainability, according to Audit Scotland. Health & social care spending will have to increase by to £20.6 billion in the next five years to meet the scale of rising demand in the face of an ageing population. A shortfall of £1.8 billion is forecast.[12] Reducing costs needs to be a priority to reinvest savings in staff and infrastructure, ease the fiscal burden on other public services and secure the long-term future of the NHS.

Research by Dell EMC estimates that better use of information and harnessing Big Data Analytics could reduce NHS costs across the UK by between £16 billion and £66 billion every year. Big Data could deliver between £1.3 billion and £5.4 billion in savings for NHS Scotland, a staggering 9% to 38% of its current total budget, which could be reinvested across health & social care.[13]

> *"The introduction of disciplines such as improvement science and process engineering based on modern data analytics rather than on the pursuit of targets, could transform Scotland's NHS into one of the most effective and efficient systems in the world."*
>
> **Prof. Sir Harry Burns**
> former Chief Medical Officer for Scotland

The value of the European data sector was over €300 billion in 2016 – of which a substantial proportion was directly or indirectly connected to health & social care – representing nearly 6.1 million jobs and 2% of Europe's GDP. The sector doubled in size to 4% of the continent's economy by the end of 2020.[14] The size of the potential prize for Scotland is immense if we can achieve world leader status and export our expertise and technological solutions across Europe and beyond.

Scotland has a narrow window of opportunity to establish itself as a world leader in Big Data in health & social care and in the global race for inward investment, jobs and inclusive growth to boost our economy. The conclusions of the Logan Review in 2020 underlined how far Scotland still must go to nurture a mature Scottish technology ecosystem.[15]

We need to learn from and keep pace with the progress of other leading countries, including those which have responded quickly and effectively to the challenges of COVID-19, including those in different contexts and with different political and health systems.

In Singapore, South Korea and Taiwan, dense testing networks have been deployed and a wide range of diverse data sources from across society utilised to track, trace and successfully suppress the

8 www.gov.scot/collections/labour-market-statistics
9 www.heraldscotland.com/news/national-news/18744789.1-3-million-nhs-working-days-lost-covid-england-figures-show
10 www.ons.gov.uk/employmentandlabourmarket/peopleinwork/labourproductivity/articles/sicknessabsenceinthelabourmarket/2018
11 www.gov.scot/budget
12 www.audit-scotland.gov.uk/report/nhs-in-scotland-2019
13 https://volterra.co.uk/wp-content/uploads/2014/09/Final-EMC-Volterra-Healthcare-report-web-version.pdf
14 https://ec.europa.eu/digital-single-market/en/news/final-results-european-data-market-study-measuring-size-and-trends-eu-data-economy
15 www.gov.scot/publications/scottish-technology-ecosystem-review

transmission of the virus.[16]

Estonia has developed a nationwide system of electronic patient records and handles 99% of prescriptions online.[17] Finland has created Findata, a single source for public health data, and a single regulatory authority for access to health & social care data for research and innovation open to patients, service users, health & social care professionals, academics and industry.[18]

Singapore is home to a dense network of health tech start-ups which are developing innovative new products and services and make the city-state South East Asia's Big Data hub.[19] Denmark is building a national register of the genomes of its entire population.[20] Canada and China are pioneering the first 'all-digital' hospitals.[21]

Scotland must therefore raise the level of its ambition, the scale of its investment and the urgency of its action to be a global leader. Investors, innovators and researchers will only be attracted to Scotland if we can demonstrate our status as a global first mover with a proposition unique in its maturity and opportunities. They will be attracted to wherever they can access high quality, consistent, aggregated and anonymised Big Data on a large scale and at a national level to discover new medicines, design better treatments, manufacture innovative products or test pioneering approaches. Scaling and sharing data is essential to developing a successful health data economy.[22]

Scotland can build on the progress being made and our existing strengths, which are considerable, as it designs and delivers its first-ever Data Strategy for Health & Social Care. NHS Scotland is in unique institution globally with its unrivalled ability to collect and harness Big Data. As the heart of a nationally integrated, publicly owned, universal system, it could provide a holistic picture of patient experiences and journeys by harnessing diverse data.

Our world-class research universities have renowned life sciences expertise which is a critical part of the jigsaw.[23] Scotland's pharmaceutical industry contributes £2.5bn to the Scottish economy, 5,600 direct jobs and £575m in exports, with strong potential for further growth.[24] The Edinburgh and South East Scotland City Region Deal has an exceptional ambition and vision of Edinburgh as the 'data capital of Europe'.[25] The tech sector is worth £4.9 billion to the Scottish economy, with over 100,000 people employed as tech professionals across all sectors.[26] The health tech and data sector could be Scotland's next key growth sector to rival FinTech.

Building Trust, Meeting Expectations

The social and economic gains of Big Data must be clearly communicated to the public. Data saves lives, time and money, supporting our health and our wealth by attracting inward investment, creating jobs and fuelling inclusive growth.

The trust of citizens, patients and service users is essential to enabling the transformation of health & social care with Big Data. Public awareness of and sensitivity to data privacy and security issues has increased significantly in recent years after many high-profile scandals in which personal data has been misused or privacy violated by firms. Personal health & social care data must be ethical, secure and anonymised as far as possible with robust and transparent governance arrangements.

16 www.thelancet.com/journals/lanwpc/article/PIIS2666-6065(20)30044-4/fulltext
17 https://e-estonia.com/solutions/healthcare/e-health-record
18 www.findata.fi/en
19 www.edb.gov.sg/en/business-insights/market-and-industry-reports/the-singapore-healthtech-ecosystem.html
20 https://eng.ngc.dk
21 www.bouygues-es.com/buildings/humber-river-first-fully-digital-hospital-north-america
22 www.ncbi.nlm.nih.gov/pmc/articles/PMC6284141
23 www.gov.scot/binaries/content/documents/govscot/publications/research-and-analysis/2015/10/delivering-innovation-through-research-scottish-government-health-social-care-research/documents/00488082-pdf/00488082-pdf/govscot%3Adocument/00488082.pdf
24 www.abpi.org.uk/publications/the-economic-contribution-of-the-pharmaceuticals-sector-in-scotland
25 http://esescityregiondeal.org.uk
26 www.skillsdevelopmentscotland.co.uk/media/46258/scotlands-digital-technologies-summary-report.pdf

Nevertheless, patient expectations are changing and rising in the fifth wave of public health. Health & social care needs to recognise and respond to the needs, concerns and expectations of patients and service users. There is a growing movement across the UK which articulates the case for change and suggests increasing public support.

Patients in Scotland want to share their data and want to use technology [27]

- 77% support their data being shared
- 86% happy for their data to be shared across primary care team
- 61% happy for their data to be shared across whole NHS
- 79% would use wearable devices to monitor activity levels and blood pressures and allow information to be transmitted direct to GPs
- 90% want to use technology to order repeat prescriptions
- 82% want to make appointments online
- 76% would like to receive test results digitally
- 69% happy to have a telephone consultation and 52% by video call
- 82% want to use digital resources to access information.

There is a mandate for change. Levels of support for data sharing and digital approaches are high. Patients want to be able to access their data, schedule appointments and get more information or support online. Patients want to know that health & social care professionals are empowered with all the insights they need to make informed decisions.

use MY data

use MY data is an independent movement of patients, relatives and carers which is educating, amplifying and harnessing the patient voice – including through powerful patient testimonies – to use data to improve healthcare for everyone.
www.usemydata.org

Understanding Patient Data

Understanding Patient Data work to democratise knowledge about health data issues and opportunities among patients and clinicians, while pressing for a better and more systemic use of ethical and secure patient data across health and social care.
www.understandingpatientdata.org.uk

Patients and service users overwhelmingly support their data being shared ethically and securely for their benefit and for the benefit of others – in fact, they expect it and are often shocked to learn that it is not. Even basic data or information is not always shared by services or colleagues across health & social care or even within the NHS to the detriment of care and the damage of patients. Patients are often frustrated by having to repeat information or retell their stories to multiple professionals within the same organisation due to a failure to share appropriate data.

Human Rights Charter for Technology and Digital in Social Care

Scottish Care, the voice of Scotland's independent care sector, has developed a human rights-based charter to guide the sector's employers and employees as they respond to the ethical and practical issues raised by the Fourth Industrial Revolution.

The Charter is based on 17 principles and 5 values – **Participation; Accountability; Non-Discrimination; Empowerment; Legality** – to ensure consensual, ethical, secure and transparent use of data for the benefit of service users.

27 www.parliament.scot/parliamentarybusiness/CurrentCommittees/113038.aspx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CHAPTER 2
Strategy

Scotland's national strategy needs to deliver an ambitious, collaborative and innovative national approach to harnessing data to transform health & social care which maximises social and economic gains.

From Incrementalism to Innovation

Successful small nations are often noted for their ability to be more agile and responsive, and to unite behind a clear vision or a sense of national mission, due to their size. To compete and thrive on the global stage, small nations must be innovative; it is in their economic DNA.[1] It is therefore no coincidence that those nations who are currently leading the global health data revolution tend to have smaller populations, from Estonia to Finland to Singapore.

Scotland's size as a relatively small nation should give us a similar competitive advantage in innovation over some of our competitors, as well as the opportunity to develop greater flexibility and shared purpose. The national culture of experimentation and innovation across our economy and our society in response to the pandemic demonstrates the extraordinary things which we can achieve with ambition, collaboration and urgency.

The Muscatelli Report (2020) into the economic impact of universities importantly called for a national mission behind driving innovation in Scotland.[2] With a population of around five million people, Scotland is small enough to link and manage health & social care data together nationwide – and yet big enough to provide a demographic critical mass for research and insights.[3]

> *"The UK has some of the richest health data of anywhere in the world. With the NHS it is feasible to collect health data on a large and diverse population, and to make national-scale improvements to health and care. Combined with unique research expertise, outstanding talent in the NHS and universities, and a vibrant life sciences industry, the UK has an unprecedented opportunity to use data at scale to drive innovation, grow the UK industry base and improve the long-term health of the public."*
>
> **Health Data Research UK**

However, this will require a national strategy which sets strong ambitions for Scotland; incentivises and

1 www.nesta.org.uk/report/when-small-is-beautiful-lessons-from-highly-innovative-smaller-countries
2 www.gla.ac.uk/media/Media_700300_smxx.pdf
3 https://wellcome.org/sites/default/files/wtd038686_0.pdf

compels a joined-up, collaborative approach with coordinated action by all partners and stakeholders; and supports and accelerates innovation by reducing fragmentation, breaking down data silos and providing a pathway to national scale-up of approaches and solutions.

We therefore welcome the Scottish Government's commitment in the Programme for Government 2020/21 to 'create a dedicated data strategy for health & social care for the first time'.[4] It is essential that this strategy is developed and delivered in a timely way and in alignment with Scotland's multitude of related strategies for health & social care and the economy – see table below. They must be joined up to maximise the coherence and impact of policy, as well as to prevent duplication and inefficiencies.

Scotland's historic approach has tended to be one of incrementalism. While this has delivered some positive results in some parts of the country, it could be characterised as lacking the sense of ambition, vision and urgency which has been on full display during the COVID-19 crisis. The new Scottish approach for a post-pandemic world should learn the lessons of COVID-19 and focus on driving forward innovation at pace and at scale for the benefit of all.

Milestones & Strategies

2015	Scotland's **Economic Strategy** published
	Health & Social Care Research Strategy published
2016	**Integration of health & social care** begins
2018	**Digital Health and Care Strategy** published
	Scottish Government's **Data Scoping Taskforce** reports
2019	**Topol Review** published in England
February 2020	**Independent Care Review** published
April 2020	**Public Health Scotland** launches
	Research Data Scotland launches
May 2020	**Test and Protect** strategy for COVID-19 rolls out
August 2020	**Logan Review** published
September 2020	**Key Programme for Government 2020/21** commitments to: ➔ develop new Data Strategy for Health & Social Care ➔ boost acceleration and adoption of innovation in NHS to save lives and boost economy
	Protect Scotland app launches
November 2020	**Scottish National Investment Bank** opens
December 2020	**Life Sciences Scotland Recovery Plan** published
	Digital Approaches in Care Homes Action Plan published
January 2021	SCDI's ***Mind the Gap*** report published
2021	Independent **Review of Adult Social Care** to report
	New **Data Strategy for Health & Social Care** to be published
	Updated **Digital Strategy for Scotland** to be published
	New **AI Strategy for Scotland** to be published

4 www.gov.scot/programme-for-government

Reforming a Fragmented Landscape

The welcome creation of Public Health Scotland as an integrated national agency with a strategic focus on Data Driven Innovation represents an important opportunity for better alignment and whole systems thinking. It has faced a baptism of fire during the early stages of the pandemic. It is essential in future that Public Health Scotland's Data Driven Innovation Directorate is properly resourced to expand Scotland's capacity to act nationally. However, there will also remain a need to go further with strategic and structural reform across the wider health & social care sector.

The health & social care landscapes are highly complex and fragmented across a diverse array of institutions, organisations and businesses across the public, private and third sectors. The lack of an ambitious and comprehensive national strategy to date and a common approach to data issues generates several significant barriers to sharing data and to harnessing data to transform health & social care on a national scale.

Scotland's complex and fragmented health & social care landscapes [5]

- 14 regional and territorial NHS Boards
- 7 special NHS Boards
- 31 Health & Social Care Partnerships
- 32 local authorities
- 2,552 social care providers across public, private and voluntary sectors

There has been significant progress to date, particularly in the emergency response to the pandemic. There are great examples of pockets of innovation, and of local or regional pilots, across Scotland. However, these are rarely scaled-up nationally to deliver their potential social and economic gains for the benefit of all. Silos between institutions, organisations and businesses in the sector, and often within them, need to be broken down.[6]

It can be very challenging to navigate for potential innovators internally – such as health & social care professionals eager to support rollout of new practices or approaches in the NHS or social care – or externally – such as academic and industry partners seeking to support delivery of new ideas, innovations or inventions which can help close the Data Gap. NHS Boards, Health & Social Care Partnerships and local authorities have divergent approaches and data standards or governance. This differentiation is not beneficial for patients or service users and not supportive of innovation.

The public health emergency of COVID-19 has stimulated significant further progress in the wider and better use of technology across the sector. This must be deepened, strengthen and sustained. The national rollout of the 'Near Me' service is enabling remote consultations by video between GPs and patients. Prior to the pandemic, an average of 300 weekly patient consultations were conducted via Near Me. This has increased by over 5,000% to over 17,000 per week.[7] This demonstrates what can be delivered with ambition and urgency.

A Strategy for Scale-Up & Adoption

There is a need to better facilitate and incentivise the acceleration of scaling-up and joining-up data, digital and technological innovations across Scotland's NHS Boards and Health & Social Care Partnerships to help close the Data Gap. There needs to be a greater focus on evaluation of effectiveness and support for wider implementation.

Performance is currently assessed against fiscal measures and key treatment targets, such as waiting times. They are also focused on delivering care in their mandated territory, often taking decisions at this level which can make it more difficult to integrate with or support rollout across other regions or nationally. There is no assessment of progress in

5 https://data.sssc.uk.com/data-publications/22-workforce-data-report/239-scottish-social-service-sector-report-on-2019-workforce-data

6 Scottish Government's Data Scoping Taskforce (2018) Medicines Use and Digital Capabilities – Building capability to assess real-world benefits, risks and value of medicines: Towards a Scottish Medicines Intelligence Unit

7 www.gov.scot/news/support-for-gp-video-appointments

the adoption of innovations or their national scale-up.

There is also no clear pathway to national scale-up or rollout of pilots and innovations due to a lack of support for and investment in the adoption or implementation stage. Governance approaches are unaligned and data systems are unintegrated. The Scottish Government and NHS Scotland should explore how to integrate data, digital and technological innovation and national scale-up as a statutory responsibility or key performance measure linked to resourcing for NHS Boards and Health & Social Care Partnerships.

The Scottish Government should work in partnership with citizens, patients, service users, staff, industry and other stakeholders to design and deliver the new Data Strategy for Health & Social Care. It should comprehensively address the key issues raised in this report on Culture & Leadership, Skills and Infrastructure, mandating a national action plan across NHS Scotland and the wider health & social care sector. It should be backed by a Health & Social Care Transformation Fund which provides the necessary resources for successful and timely implementation.

It should emphasise the anticipated social and economic gains for patients, service users. staff and the public by articulating how data saves lives, time and money, delivers better outcomes for patients and value for the system and attracts inward investment, creates jobs and supports inclusive growth.

It should be an essential part of Scotland's recovery from COVID-19. It should build on the Digital Health and Social Care Strategy and the AI Strategy for Scotland. It should align with delivery of these strategies, as well as the implementation of the Logan Review, the missions of the Scottish National Investment Bank and the delivery of the Export Growth Plan. There are significant opportunities for Scotland to export our expertise and technological solutions in the growing global market for health & social care data innovation.

Many highly innovative and promising health tech start-ups are struggling to access the financing they need. There is a need for more accessible patient capital from government and its innovation and enterprise agencies, which can play a greater role in sharing the risks of early-stage innovation, as well as supporting scale-up and engagement with the NHS at a national level. There needs to be a clear innovation and adoption pathway which harnesses the potential role of Scotland's private sector, colleges and universities, innovation centres and the public and third sectors.

The newly operational Scottish National Investment Bank has a critical role to play in Scotland's recovery from the COVID-19 crisis. It will take a mission-orientated approach to patient capital, including supporting innovation which responds to public health and demographic challenges.

It should target its own funds and crowd-in private investment in data, digital and technological innovation in health & social care in recognition of the unmet demand for patient capital and the big social and economic gains which it can deliver.

We therefore welcome the proposed third mission for the Bank to 'harness innovation to enable our people to flourish' and 'invest in innovation and industries of the future for a healthier, more resilient and productive population'. Alongside the Bank, health & social care can play its part in the creation of a mature Scottish technology ecosystem as envisaged by the Logan Review, supporting the scale-up of talented health tech start-ups in Scotland.

Tackling asthma with IoT

Two-thirds of asthma attacks are preventable if patients take inhaler medication as and when prescribed by their doctors. Paisley-based QIoT have developed an IoT connected asthma ecosystem which monitors inhaler usage and provides patients and doctors with data analytics to help them better manage their condition, save lives and reduce costs.

CHAPTER 3
Culture & Leadership

Scotland's political and health & social care leadership need to drive change by building an ambitious and collaborative national culture of innovation in data, digital and technology.

Empowering Data Champions

A major issue which the new Big Data Strategy for Health & Social Care in Scotland will have to address is transforming data culture and empowering data leadership in the NHS and across the wider sector, because many of the existing barriers to progress are fundamentally cultural rather than technical.[8]

There is political will and a shared commitment from the Scottish Government, local authorities, industry and stakeholders to reform and modernise the NHS and the wider health & social care sector to ensure it is sustainable and fit for the future. This has been demonstrated by the increasing level of devolved spending committed to Health, the integration of health & social care and the establishment of Public Health Scotland, as well as the ongoing work to implement Hospital Electronic Prescribing and Medicines Administration by NHS Boards or build the National Digital Platform for health & social care data by NHS Education for Scotland.

Our health & social care workforce's response to the pandemic has only underlined the extraordinary lengths which many of those on the frontline go to help patients and service users and to improve public health. Large numbers of inspirational health & social care professionals and academics at all levels – Scotland's data champions – have been demonstrating leadership by driving change on data, digital and technology in their workplaces and organisations.

The valuable work they do every day to gather, utilise and enhance data is saving and improving lives across Scotland, whether that is educating colleagues about the opportunities of data or partnering with industry to test and drive forward innovations. Scotland's key workers and data champions need to be supported and empowered by political and organisational leadership to continue to drive behavioural and organisational change.

Resistance to Change

However, there has historically been resistance to change in parts of the NHS and the wider sector, with some scepticism or even opposition to the Big Data agenda. Clinicians, for example, have been

8 www.tsh.scot.nhs.uk/Safe/Docs/Learning%20from%20External%20Inquiry%20Reports/Sturrock%20Report%20-%20Apr%2019.pdf

accustomed to independent decision-making based principally on clinical judgement, rather than utilising data alongside it to inform and enhance decision-making. Health & social care lags most other sectors of the economy in the use and adoption of now basic technologies which increase efficiency and productivity. The openness to change or the pace of innovation can often be slow, although the significant progress made during the pandemic suggests ongoing cultural change and underlines what can be achieved.

Such issues can be exacerbated by the silos which have been allowed to become entrenched between organisations, but also within them whether on an occupational, structural or geographical basis. This is particularly true of NHS Scotland, which is a large, complex and diverse institution employing more than 163,000 people. The wider public health workforce broadly defined could be up to 2 million people.[9]

There can therefore be a sense of differentiation and protectionism or a perceived divide between, for example, managers and clinicians, or clinicians and other health & social care professionals, including data analysts and IT specialists. Silos are a major factor behind pockets of innovation or examples of best practice failing to spread beyond a localised context or achieve national scale-up.

From Risk-Averse to Risk-Aware

There are also pervasive and valid concerns about access to and the sharing of personal health data, which often leads to a highly cautious, risk averse data culture and a lack of data leadership. The primary barrier to the sharing of data to help to close the Data Gap is not regulatory or legislative, or even in many cases about technological capacity.

Although legal and governance requirements around data privacy and data security are often cited as representing insurmountable barriers, this is in fact rarely the case. It is rather usually a reflection of misunderstanding or highly restrictive, conservative interpretations of regulations or legislation like the General Data Protection Legislation (GDPR).

Throughout the public sector, there is often a disproportionate assessment of risk or a disproportionate scepticism of potential gains. The diversity of approaches by Scotland's 21 NHS Boards, 31 Health & Social Care Partnerships, 32 local authorities and over 2,500 social care providers can also be unconducive to an ambitious and collaborative data culture.

In the emergency response to the pandemic, some attitudes and practices have changed, albeit in a limited and uneven way. Information governance rapid assessments have been devised and carried out to support the timely, ethical and secure sharing of data to save lives whilst maintaining due diligence.[10]

Progress must be deepened, strengthened and sustained on a systemic, national basis to deliver social and economic gains. Health & social care needs to permanently and collectively move from risk aversion to risk awareness. Leaders, staff or organisations generally fail to share data because of a fear the potential consequences or reputational costs of a breach of data privacy or data security. Data could be shared, and could save lives, if there was a strong commitment to do so from confident, directive and informed leadership.

Closing the Diversity Gap

The paradigm shift in culture & leadership which we are calling for will require a new approach to the attraction and retention of talent at all levels. This will be especially critical at managerial, leadership and Board levels where control over policy and resource lies.

There is extensive evidence globally that businesses and organisations which are more diverse in terms of gender, ethnicity and nationality, sexuality and gender identity, disability and class are more productive and more successful. By convening a

9 https://publichealthreform.scot/media/1471/lphwd-deliverable-4-customer-requirements-final-draft-040219.pdf
10 www.digihealthcare.scot/wp-content/uploads/2020/07/Scotlands-digital-health-and-care-response-to-Covid19_JUNE-2020.pdf

range of people and perspectives, diverse teams are more creative and challenging, more resilient to change and better understand their customers, partners and stakeholders.[11] Despite some progress towards greater equality in health & social care workplaces in recent years, challenges and inequalities remain. This acts as a drag on productivity and innovation.

Both personal and professional background matter. NHS Boards, for example, are largely dominated by men. They also often lack individuals with lived experience of health inequalities or technical expertise in data, digital or technology issues or experience in these sectors. Broader industry experience is highly valuable and critical to closing the Data Gap but is often limited or lacking. The diversity gap in Scottish public health limits understanding of the opportunities and challenges of Big Data among key leaders and decision-makers.

NHS Scotland therefore needs to adopt more innovative, inclusive recruitment practices and to widen progression opportunities with the strategic objective of increasing leadership diversity by both personal characteristics and sectoral expertise.

People-Led Solutions

We believe that the culture of NHS Scotland and the wider health & social care sector needs to change to a culture of innovation – and that the solutions will be and should be people-led, rather than tech-led.

The culture of NHS Scotland and the wider health & social care sector needs to legitimate and incentivise, rather than stigmatise or disincentivise, new ways of thinking and working. The culture needs to be one of openness to new ideas, innovations and technologies and of openness to transparent collaborations, partnerships and projects for the common good with other parts of the public sector, as well as with the private and third sectors.

Leaders needs to understand and articulate the social and economic gains which will benefit patients, service users, staff and Scotland as a whole. Leaders need to be role models and data champions. There is a need to encourage and nurture data leadership at all levels and in all areas of the sector, such as through leadership programmes and as an integral part of developmental training. The workforce needs to be supported and inspired to embrace change – and this should be driven by leadership.

Health & Care Leadership with University of Strathclyde

The University of Strathclyde has launched a new and innovative interdisciplinary Masters for aspiring and established senior leaders with a strong focus on data, culture, inequality and technology.
www.strath.ac.uk/courses/postgraduatetaught/healthcareleadership

In attempting to break down resistance to change, lessons need to be learnt from past efforts at cultural change and organisational transformation, both successful and unsuccessful. Scotland also needs to learn from best practice in other countries where high-quality public services are delivered with greater flexibility and innovation.[12]

However, there is a significant shortage of project management skills and cultural transformation capacity in the sector, which will be essential to managing and delivering change, for example, across an organisation as large, complex and diverse as the NHS. Closing this specific skills gap – while addressing wider leadership issues through broadening and deepening the impact of existing interventions like Project Lift – should be a strategic priority for the leadership of the NHS and the wider sector.

11 www.mckinsey.com/business-functions/organization/our-insights/delivering-through-diversity
12 www.inderscience.com/offer.php?id=46266

Project Lift

Project Lift is a new approach to recruit, retain, develop and manage talent within Health and Social Care in Scotland to ensure all leaders can reach their potential from entry roles to boardrooms. It is building communities of transformational leaders at all levels. The approach has four key strands in values-based recruitment, performance appraisal, talent management and leadership development. www.projectlift.scot

NHSX

NHSX was established in England in 2019 to bring together teams from the Department of Health and Social Care, NHS England and NHS Improvement into one unit to drive the digital transformation of health and social care, and lead policy, implementation and change. NHSX will invest £1 billion annually to realise its Tech Vision across innovation, technologies, procurement reform, cyber security and workforce skills.

Project Lift – Leadership Profile

National Culture of Innovation

It is essential that the Scottish Government, NHS Scotland and the wider sector makes a collective statement of intent that demonstrates powerfully to the public, patients, service users and staff domestically, as well as to potential industry partners, innovators and investors globally, that Scotland is serious about building a national culture of innovation across health & social care and is taking strong steps to do so. The creation of the Danish National Genome Centre, Findata and NHSX are powerful examples elsewhere.

Building a national culture of innovation which maximises the social and economic gains for Scotland will require leadership at all levels. It will require strong, joined-up leadership at a political level from the First Minister, the Cabinet Secretary for Finance, the Cabinet Secretary for Health and Sport and the Cabinet Secretary for Economy, Fair Work and Culture, with a joint position across their directorates. It will also require strong, joined-up leadership from NHS Scotland, NHS Boards, Health & Social Care Partnerships, local authorities and private and third sector providers.

Change will require increased commitment and higher levels of investment in innovation and service change, in addition to an accelerated shift in resources from a short-term focus on treatment towards a longer-term focus on innovation and prevention.

Public Health Scotland's Data Driven Innovation directorate could act as a hub for Scotland's drive towards a national culture of innovation across health & social care. It could have a role to support and invest in research and innovation; identify and accelerate best practice; and support, invest in or accelerate national scale-up. There should be increasingly close collaboration by existing organisations and assets, including NHS Scotland and Research Data Scotland, as well as Health Data Research UK, the Health & Care Futures initiative at the University of Strathclyde and the Usher Institute at the University of Edinburgh.

Usher Institute for Population Health Sciences and Informatics

The Usher Institute at the University of Edinburgh is a hub of world-leading expertise in health data learning and teaching, research, innovation and knowledge exchange, striving for the data-enabled transformation of health. It works with people, populations and their data to understand and advance public health through innovative collaborations in a global community.

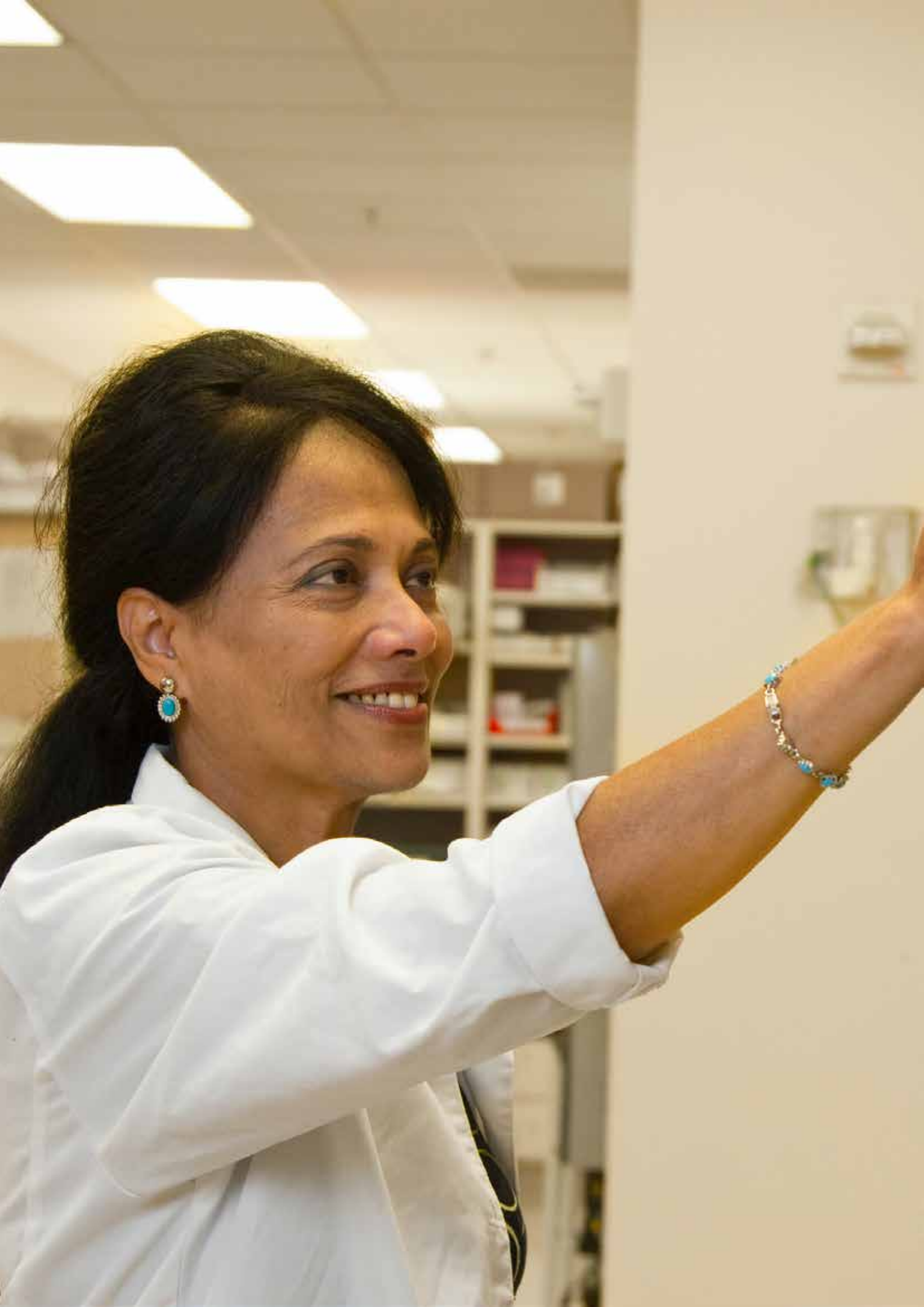
The Data Lab Innovation Centre

The Data Lab is Scotland's innovation centre for data and AI. Its mission is to help Scotland maximise value from data and lead the world to a data-powered future by fuelling innovation through collaboration, building skills and growing talent, and strengthening Scotland's thriving data science community. Health & social care is a key sector where The Data Lab has ambitions to support a Scotland wide community to innovate with data and AI.

Engaging with or navigating the NHS is often complex and challenging for potential partners, especially start-ups. NHS Scotland needs to be more open, collaborative and flexible to support and accelerate innovation which closes the Data Gap. It must be open to working fairly and transparently for the common good with external partners in academia, industry and beyond.

In this spirit, NHS Scotland should create the role of NHS Navigator to support external researchers, innovators, entrepreneurs and industry as part of a national network for all of Scotland. NHS Navigators could act as single points of contact and relationship managers to provide signposting, access and advice, especially for SMEs and start-ups, with a mission to support the national culture of innovation.

NHS Scotland could learn from the model operating in England through Digital Health London, which is developing a similar network for the capital, or from the focused model which already exists for local clinical trials in NHS Grampian. It could also learn from the Interface model for facilitating partnerships in Scotland between academia and industry.



CHAPTER 4
Skills

Scotland needs to invest in reskilling, upskilling and lifelong learning to develop a health & social care workforce better equipped to harness data, digital and technology.

Technological Disruption

From pandemics to politics, we are in a new era of disruption for the global economy. The Fourth Industrial Revolution is fundamentally transforming the world of work and the future of skills. Its technologies – from Big Data and AI to IoT and nanotechnology – are already disrupting labour markets, business models and learning approaches across the world.

Technological disruption and the use of Big Data will impact all sectors of our economy, including health & social care, as recognised by the Scottish Government's Digital Health and Care Strategy (2018)[1] and the Topol Review (2019)[2]. New innovations are already creating new opportunities for the health & social care workforce to improve productivity and the delivery of care. There is a new human-machine frontier to which all workers will have to be supported to adapt, developing existing and learning new skills to work alongside and get the best out of data, digital and technology and close Scotland's Data Gap.

Some human labour will be swiftly or gradually replaced by technology. Many routine, repetitive, manual or administrative tasks will be automated or semi-automated. Meanwhile, other human skills will be enhanced by the complementary use of technology and demand for entirely new skills will also be generated. There will be an increasingly close, symbiotic relationship between humans and machines, although solutions should remain people-led, rather than tech-led.[3]

Changing World of Work

Work will not disappear, but it will change. Many new jobs – even entirely new sectors of the economy – will be created. New kinds of jobs will be created which we cannot even imagine now. Not long ago, it would have been impossible to anticipate that our labour market would feature Big Data Analysts, Drone Pilots or Social Media Managers.[4]

Most jobs will remain but will be transformed by new technologies as individual tasks are automated

1 www.gov.scot/publications/scotlands-digital-health-care-strategy-enabling-connecting-empowering
2 https://topol.hee.nhs.uk
3 Carl Benedikt Frey (2019) The Technology Trap: Capital, Labour and Power in the Age of Automation
4 www.cognizant.com/jobs-of-the-future-index

away or more closely integrated with AI. There will be significant opportunities to deliver productivity gains for all workers. Automation will focus largely on tasks, rather than jobs.

The right care at the right time

NHS Lothian is working with Deloitte to automate the clinical triage process for a cohort of urgent-suspected-cancer GP referrals. The project is already delivering reductions in administrative workloads, less variation in referral triage and shorter referral waiting times for patients.

Nonetheless, it is also likely that some jobs which are largely or wholly composed of automatable tasks will be displaced, including in health & social care.[6] Technology replacing people is not new and has been a feature of every previous industrial revolution, as we change the way we live and work. This will be a challenge for all sectors of the economy.

Those affected will need support and learning opportunities to transition into new jobs that offer secure, meaningful and rewarding employment.[7] However, the nature of the health & social care sector and its workforce means that health & social care jobs are likely to be strongly resilient to being replaced by technology.

Jobs in health & social care are often a particularly complex mix of tasks which involve different kinds of cognitive, emotional, social and physical labour. Fourth Industrial Revolution technologies can expose specific tasks within jobs to the risk of automation, but not necessarily the complex mix of skills which comprise a single job. Technology can typically be applied to many physical or some cognitive tasks, but less so to emotional or social tasks which are so crucial in health & social care.[8]

For a GP or surgeon, while AI can be adept at completing structured cognitive processes, it struggles with social interactions with humans, creative or strategic thinking and innovative problem-solving.

For a nurse or carer, while Big Data Analytics and the Internet of Things can be utilised to collect and analyse large amounts of rich quantitative data about patients, service users or clients, these technologies can struggle to assess qualitative information, interpret insights to redesign care or provide emotional solidarity and support.

For a hospital cleaner or porter, while automated machines can effectively replace repetitive, simple but strenuous physical tasks from mass production to lifting of parts, it struggles with highly dexterous or delicate tasks in varied or unstructured environments beyond regimentally consistent environments.

Skills for the Future

Scotland has world-leading strengths in skills and education in health & social care. Our colleges and universities are centres of global expertise, hubs for pioneering learning and engines of innovation and growth. We have a highly educated population and a highly skilled health & social care workforce, which has proven extraordinarily adaptable, flexible and resilient in its admirable response to the pandemic.

We need to fully recognise, reward and value their contributions. We cannot achieve our vision of the future of health & social care and Big Data in Scotland without them. They need and deserve our support to recover and renew.[9]

5 www2.deloitte.com/uk/en/pages/consulting/articles/nhs-lothian.html

6 www.mckinsey.com/~/media/mckinsey/featured%20insights/Future%20of%20Organizations/What%20the%20future%20of%20work%20will%20mean%20for%20jobs%20skills%20and%20wages/MGI-Jobs-Lost-Jobs-Gained-Report-December-6-2017.ashx

7 www3.weforum.org/docs/WEF_Future_of_Jobs_2018.pdf

8 https://topol.hee.nhs.uk

9 www2.deloitte.com/content/dam/Deloitte/uk/Documents/life-sciences-health-care/deloitte-uk-time-to-care-health-care-workforce.pdf

META-SKILLS

Self-management	Social intelligence	Innovation
Taking responsibility for own behaviour and wellbeing	*Navigating and negotiating relationships and feelings, needs and concerns of others*	*Defining and creating positive change*
Focusing	Communicating	Curiosity
Integrity	Feeling	Creativity
Adapting	Collaborating	Sense making
Initiative	Leading	Critical thinking

Skills Development Scotland (2018) Skills 4.0

Due to the unprecedented scale and pace of change – as SCDI's Upskilling Scotland (2020) report argued – Scotland needs to act now to respond and to ensure that our people have the skills they need for the future.[10] Scotland will therefore need to raise investment in our health & social care workforce to support all staff to:

- **Meta-Skills:**
  Strengthen and deepen truly human skills of self-management, social intelligence and innovation as fundamental to cognitive but especially emotional and social labour, known as 'Meta-Skills'.[11]

- **Reskilling, Upskilling & Lifelong Learning:**
  Reskill and upskill throughout all stages of their lives and careers to utilise and harness data, digital and technology, keep pace with change and maximise opportunities to increase productivity, enhance care and improve outcomes.

Reskilling vs. Upskilling

Reskilling = Learning new skills to retrain, change job or career or transition into a new sector

Upskilling = Developing or enhancing existing skills to progress up the workforce value chain and increase productivity

Data- and Digital-Ready Workforce

The health & social care workforce has proven extraordinarily adaptable, flexible and resilient in its emergency response to the crisis. The health & social care workforce of the future will also need to be data- and digital-ready to play its part in closing the Data Gap. The Topol Review forecast that 90% of all NHS jobs will require digital skills by 2040.[12]

Staff will need to be flexible, adaptable and resilient, facing the future with confidence, prepared for change and ready to embrace it. They will need to

10 www.scdi.org.uk/policy/skillsleadershipgroup
11 www.skillsdevelopmentscotland.co.uk/media/44684/skills-40_a-skills-model.pdf
12 https://topol.hee.nhs.uk

be empowered to manage disruption and harness innovation. They will need to be lifelong learners, supported by government, employers, educators and colleagues to reskill and upskill in response to new technologies and emerging trends.[13]

Employers and educators will have to keep pace with change and refresh curricula more frequently and more quickly. The knowledge and skills which the workforce will need will continue to expand and evolve alongside technological and scientific progress, as identified by the Workforce 2020 Vision for NHS Scotland.[14]

The development of Meta-Skills is already fundamental to the training and education of the health & social care workforce across all professions and positions in Scotland. The importance of social intelligence in communicating with and caring for patients or service users is recognised as integral to the role of doctors, nurses, carers, counsellors and others.

However, all learning opportunities – from degree curricula to workplace training programmes to continuous professional development – will have to be revised and modernised to ensure that the workforce's data, digital and technology skills are fit for purpose and keep pace with change. The whole workforce needs to be included in the building of a culture of lifelong learning. Everyone needs to be brought on a reskilling and upskilling journey.

Data and digital literacy will be core skills for all, including the health & social care workforce, in the Fourth Industrial Revolution. Health & social care professionals will need to know how to access and interpret data, as well as understand data ethics issues and comply with data privacy and cyber security legislation, regulations and procedures to manage and share it appropriately. They will need to be informed about how to recognise and collect consistent, reliable and high-quality patient data.

Although data collection will be largely automated in the future through the IoT in particular, most staff will need practical skills in the servicing, maintenance and protection of IoT assets and infrastructure. The interpretation of Big Data to gain insights and deliver applied intelligence which enhances care and improves outcomes – translating information into action – will be a highly valuable skill, especially for health & social care professionals to inform and enhance decision-making. It will be key to avoid 'data overload' or 'cognitive overload', discerning what it important, reliable or useful from what is not.

Developing fundamental knowledge and core skills in data, digital and technology, and exploring related ethical and safety issues, should be a core part of all health & social care learning, including undergraduate and postgraduate degrees in Medicine, Nursing and Pharmacy and other professional qualifications. Some progress has already been made – the University of Edinburgh, for example, offers a Data Science module as part of its six-year Bachelor of Medicine and Surgery degree. However, this needs to be expanded, embedded and mainstreamed across Scottish higher and further education from MOOC to PhD. It should be an integral and mandatory part of pathways into and lifelong learning journeys through health & social care.

In addition, it will also be increasingly important for data, digital and technology reskilling and upskilling to be tailored to the health & social care sector and accessible to all through learning opportunities which are flexible, modular and bitesize. The Scottish Funding Council's Upskilling Fund has supported universities to develop short courses for the health & social care workforce in areas like data science, informatics and statistics.

13 www2.deloitte.com/content/dam/Deloitte/uk/Documents/life-sciences-health-care/deloitte-uk-time-to-care-health-care-workforce.pdf
14 www.workforcevision.scot.nhs.uk/vision-development

Free Online Upskilling with The Data Lab

Data Science in Stratified Healthcare and Precision Medicine

Learn about some of the different types of data and computational methods involved in stratified healthcare and precision medicine.

The Power of Data Science in the Health and Care Sector

Teaching health and care practitioners and project and change managers how to make the most of data, understanding issues of value, governance and strategy in data.

www.thedatalab.com/skills-talent/online-learning

Tackling Labour Shortages and Skills Gaps

Scotland already faces several critical labour shortages and skills gaps in key areas of health & social care, which need to be addressed as national and strategic priorities.

According to Audit Scotland, the Scottish Government and NHS Boards 'have not planned their NHS workforce effectively for the long term'.[15] It is anticipated that the implementation of the first Integrated Health and Social Care Workforce Plan for Scotland (2019) from COSLA and NHS Scotland – in addition to the Health and Care (Staffing) (Scotland) Act 2019 – will address some of the key issues in a joined-up way and deliver improvements to workforce planning across health & social care, alongside the Scottish Social Services Council as national lead for workforce planning in the social care sector. National, regional and local planning needs to be better coordinated.

NHS Scotland spending on agency staff to plug gaps has continued to rise significantly in recent years. Workforce planning challenges are only likely to increase in the coming years as immigration rules change, demand for services continues to rise and staff turnover accelerates. Nearly 1 in 5 nurses and midwives are set to retire over the next decade[16], while 1 in 3 GPs are aged 50 or over.[17]

There is a significant shortage of project management and cultural transformation skills in the sector, which will be essential to managing and delivering change across a sector as large, complex and diverse as health & social care, as highlighted in Chapter 3.

There is a need for Scotland to increase gender diversity in STEM and for the public sector to be as competitive as possible to attract and retain the key talent which we need to manage and deliver transformation. The large-scale nationwide integration of data, digital and technology systems across Scotland's health & social care sector will require a high level of skills in supercomputing, IT architecture, software development and so on. These skills are highly sought-after by the world's leading financial services and technology firms in London and across Europe, North America and East Asia, whose major cities often secure a large proportion of our best IT graduates.[18]

Investing in Informatics

Health & social care in Scotland faces a lack of data scientists and data analysts. It is clear from our conversations across the sector – which reflect the conclusions of the Digital Health & Care Institute's Our Time to Shine (2019) report – that Scotland's informatics workforce is significantly under-prioritised at present across health & social care, despite growing demand for their critical skills and their importance in managing and delivering data, digital and technology transformation. Big Data Analytics capacity is currently restricted by a

15 www.audit-scotland.gov.uk/report/nhs-workforce-planning
16 https://rcni.com/nursing-standard/newsroom/news/scotland-facing-nursing-retirement-boom-59161
17 www.telegraph.co.uk/news/2016/12/13/third-scottish-gps-plan-retire-next-five-years
18 www.gov.scot/publications/scottish-technology-ecosystem-review

relatively small workforce with limited capacity.[19] The pandemic has underlined the urgent need for investment to increase capacity.

The workforce is widely perceived as an administrative function of lower skilled roles with a subsequent lack of prestige, low and uncompetitive pay and a lack of progression opportunities or career and education pathways. They are often restricted in small silos within their larger organisations, preventing a greater degree of empowerment and innovation.

Levels of vacancies are substantial in some areas. Audits to identify and resolve issues or gaps in the quality of data across NHS Boards receive limited attention and funding, despite their relatively low cost but significant return in terms of supporting robust research and innovation to take place.

There is a need to address the lack of a national approach to developing their skills, and their uneven distribution across the country and NHS Boards, to ensure that the informatics is recognised as a strategic priority for leadership to commit appropriate resource. Over half of the current workforce is based in the Public Health and Intelligence Unit of
NHS National Services Scotland, with small numbers distributed across NHS Boards and local authorities.

The historic underappreciation of the informatics workforce may have been partly due to a lack of expertise and experience in data, digital and technology at senior level. This should be addressed through learning opportunities, in addition to taking action to increase the diversity of NHS Boards and leaders, managers and decision-makers more widely, as outlined in Chapter 3.

Informed Patients, Informed Consent

Support from the public, patients and service users for data, digital and technology approaches and solutions in health & social care are high, as noted in Chapter 1. However, some concerns and misunderstandings remain pervasive, especially around data privacy and cyber security issues in relation to partnerships with industry.

High-profile controversies about the misuse of personal data also threaten to undermine trust. Few patients are aware of the Charter of Patient Rights and Responsibilities. Appropriate governance arrangements and strong safeguards are already in place and being further developed, but there needs to be much better communication with the public to ensure trust and understanding to support informed patients.

This raises significant ethical and strategic questions around whether informed consent has been secured from informed patients and service users. Do patients and service users in Scotland know what health & social care data is held about them? Do they know how it might be shared or how it could deliver social and economic gains? Are the ways in which we operate now, and our ambitions for the future, accessible, clear and transparent?

Public and patient engagement and education on data has not been viewed as a core part of their remit by the NHS or by other service providers. As a result, it has been largely left to a small number of external charitable or activist groups with limited collective capacity, such as Understanding Patient Data and Use MY Data, to try to democratise knowledge about data challenges and opportunities.

NHS Scotland and Public Health Scotland, in partnership with industry, researchers and others who generate or use health & social care data, should recognise their collective responsibility to engage with and educate the public, patients and service users on data-, digital- and technology-related issues of privacy, security and safety. By articulating the social and economic gains and equipping citizens with basic knowledge and skills, we can support public dialogue which strengthens trust and builds confidence. Data must be trusted and trustworthy.

19 strathprints.strath.ac.uk/69331/7/DHI_2019_Empowering_the_data_information_and_knowledge_workforce_as_a_driving_force_for_digital_health_and_care.pdf

CHAPTER 5
Infrastructure

Scotland needs to modernise and upgrade health & social care infrastructure to build a single national data architecture which integrates systems, enables ethical data sharing and creates secure digital health records.

Modernising and Upgrading Infrastructure

Health & social care has tended to lag other sectors in the adoption of basic digital infrastructure, complicating and impeding efforts to close Scotland's Data Gap. It has acted as a serious drag on workforce productivity and a significant barrier to transforming health & social care with Big Data, undoubtedly hindering the speed and effectiveness of our response to the pandemic in comparison with other countries.[1]

Much of the health & social care sector is burdened with archaic, inadequate or obsolete technologies and equipment. Many processes which it is technically feasible to digitise, automate or semi-automate to save lives, time and money are still highly inefficient, time-consuming and labour-intensive manual or paper-based processes.

Many hospitals, surgeries, pharmacies and care homes face a severe lack of basic digital software or hardware, particularly PCs and other similar devices. Many also struggle with poor connectivity, which is a fundamental building block of building smart and digitally connected health & social care. A lack of digital literacy or reliable internet access can often be a barrier to patients' accessing and staff delivering digital health & social care products and services – like NearMe, smartphone apps or smart housing – especially in rural, isolated and island communities or for those in 'digital poverty'.[2]

The COVID-19 crisis has only added to and underlined these challenges, putting unprecedented strain on the infrastructure of our NHS to deliver the highest quality care for all.

The NHS estate and Scotland's wider health & social care sector therefore urgently requires significant investment to modernise and upgrade its infrastructure to ensure it is fit for its digital future and empowered to close the Data Gap.

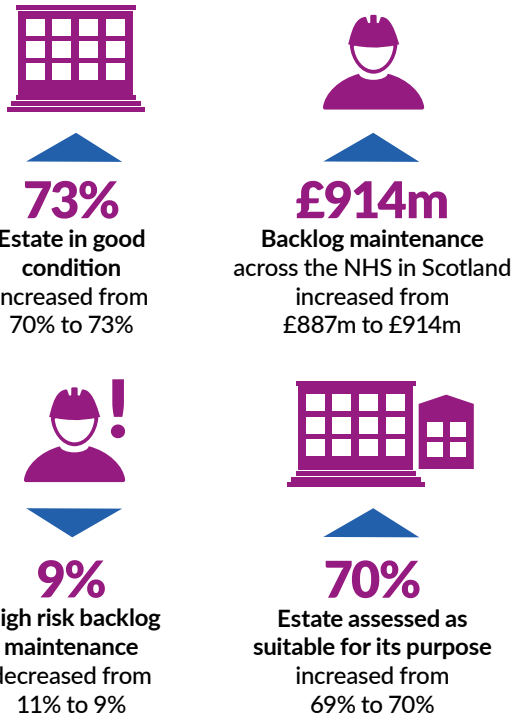
NHS Scotland's capital budget has decreased by 63% over the past decade and there is a backlog of maintenance of £914 million.[3] Raising capital investment in digital technologies and infrastructure will provide a critical platform for the sector to deliver the new Data Strategy, transform culture and

1 https://knowledge.wharton.upenn.edu/article/singapore-south_korea-taiwan-used-technology-combat-covid-19
2 www.audit-scotland.gov.uk/report/nhs-in-scotland-2019
3 www.audit-scotland.gov.uk/report/nhs-in-scotland-2019

NHS Estate

The condition of the NHS estate 2016 to 2018.

The condition of the NHS estate has increased slightly over the last three years, but the level of backlog maintenance increased.



Source: Scottish Government 2019

leadership and harness the skills of its workforce, as discussed in Chapters 2, 3 and 4. In the context of limited resources, key infrastructure needs and gaps will have to be identified with investment prioritised accordingly. There is a need to get the basics right, while also unlocking opportunities to prepare for an accelerated transition to a high-tech future.

The aim of the new Action Plan for Digital Approaches in Care Homes is that 'all care homes in Scotland become digitally enabled'. It outlines investment priorities in digital connectivity; capacity for data collection, analytics and sharing; new digital services.[4] Meanwhile, NHS Lanarkshire plans to replace Monklands Hospital in Airdrie, which has been declared not fit for purpose, with 'Scotland's first digital hospital' at a new site that could provide a national blueprint. The design has been inspired and informed by lessons learned from the world-leading Humber River Hospital in Canada.[5]

The Scottish Government will publish Scotland's first plan for attracting private capital investment in Spring 2021. It will set out how it intends to mobilise private investment alongside public investment with the health & social care, life sciences and digital sectors identified as priorities.

Canada's All-Digital Hospital

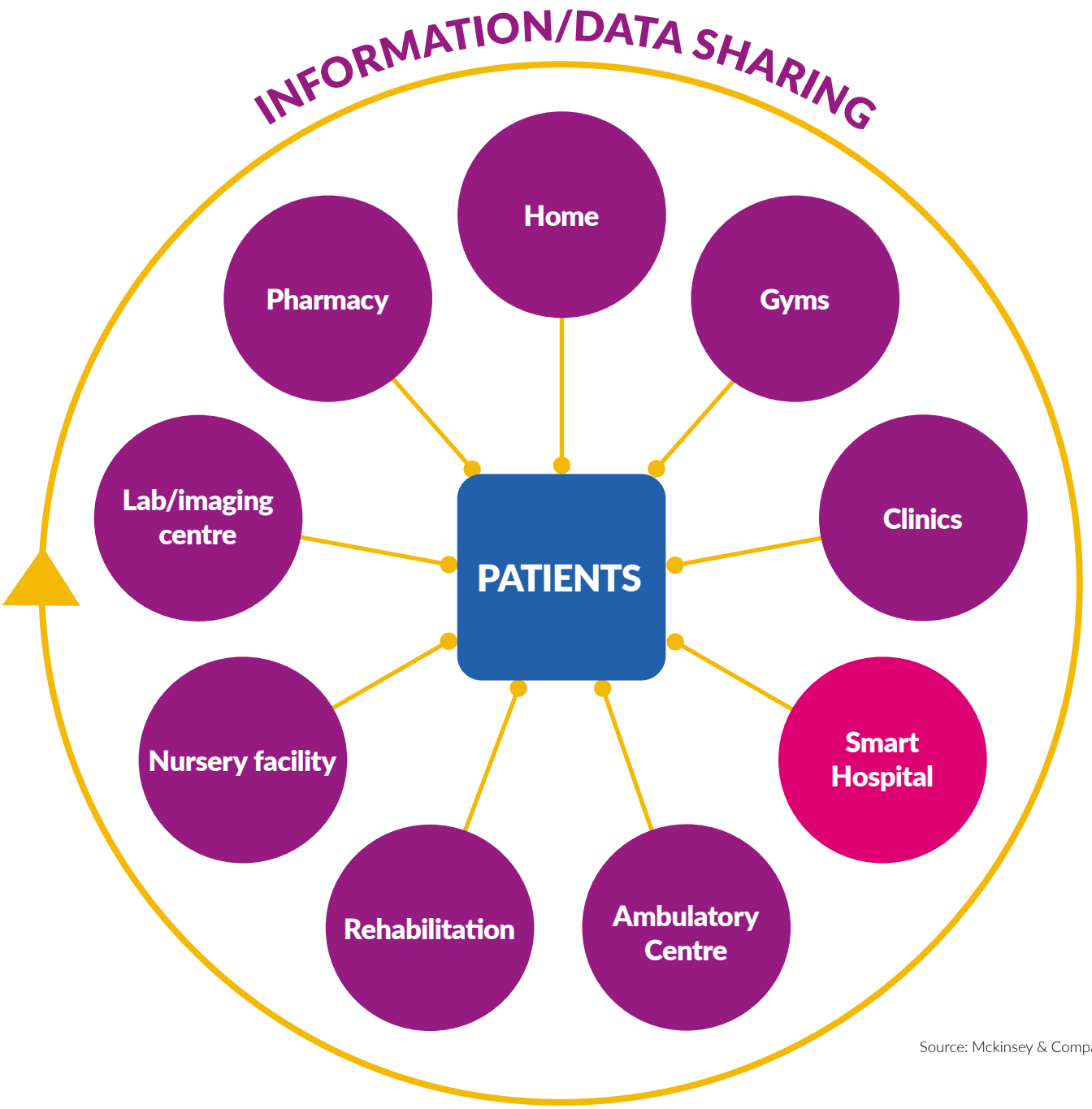
Humber River Hospital in Toronto was hailed at its opening in 2016 as 'North America's first all-digital hospital'. Technology has been utilised to enhance patient experience, increase workforce productivity and improve outcomes. Mobile apps provide information, guidance and review. AI systems schedule appointments and detect diseases. IoT tracks staff and monitors patients. Autonomous vehicles deliver meals and manage medicine storage.

Over 75% of 'back-hospital' functions – from administration, laundry and food delivery, to pharmacy, data collection and data analysis – have been automated. Hospital staff have been liberated from often mundane or repetitive tasks, often with higher rates of human error, to spend more time caring for patients rather than dealing with paperwork.

Danish National Genome Centre

The Danish National Genome Centre established in 2019 will support the collection and integration of, ultimately, the heterogenous biological data of the whole Danish population. By understanding the differences between individuals' genomes, and developing closer profiles of individuals, clinicians will be empowered with data and analysis to improve diagnoses of diseases and to enhance design of personalised, targeted treatment and care.

4 https://tec.scot/wp-content/uploads/2021/01/Digital-Approches-in-Care-Homes-Action-Plan-Final.pdf
5 www.nhslanarkshire.scot.nhs.uk/a-vision-for-lanarkshire-scotlands-first-digital-hospital



Source: Mckinsey & Company

Data Integration and Interoperability

The digital landscapes of health & social care are highly complex and fragmented. The NHS alone has thousands of different systems which do not link to or communicate with each other and prevent the ethical and secure sharing of information and data between patients, GPs, doctors, pharmacists and other professionals or facilities. This can exacerbate issues with a lack of consistency and interoperability of data across the system.

The number of siloed systems has continued to proliferate since the dawn of the digital age and the advance of the internet – creating various challenges and some confusion, not least for the workforce in securely managing access. NHS Boards, Health & Social Care Partnerships, local authorities and manufacturers or service providers in the private and third sectors also all have divergent, and often

incompatible, approaches.[6]

The openness, integration and interoperability of data sets and systems to create a single national data architecture will facilitate ethical and secure data sharing at a national level and the creation of a single, comprehensive digital health record for everyone in Scotland across primary, secondary, tertiary and social care. This will be challenging, but it is possible.

Ethical and secure data sharing needs to be underpinned by integrated systems and common data standards which bridge the technological and cultural divide between organisations and sectors. For example, the approaches and understandings between health & social care can differ significantly due to each sector's different history, culture, educational pathways and legislative or regulatory environment.

The Scottish Government and the public sector should agree a single ethical and secure data sharing agreement for all public bodies with a target date for implementation.

A single national data architecture underpinned by common data standards should facilitate ethical and secure data sharing whenever appropriate to empower staff across health & social care to improve care and outcomes for individuals – while also contributing to the development of aggregated, anonymised Big Data at a national level which can be accessed by academia and industry to support research and gain insights for the benefit of all.

The ambitious project by NHS Education for Scotland (NES) to build a National Digital Platform for health & social care is progressing this important work. The National Digital Platform will help improve care by providing a set of digital services across Scotland and directly supporting a range of scalable programmes and reusable data components.

Throughout the past year, it has been instrumental in supporting various programmes, including COVID-19 vaccinations, an electronic patient record for eyecare services and COVID-19 data flow integrations between national and local systems for test results and care assessment reports. It will provide an important resource for research and help facilitate national scale-up of innovation as a host of new products and services. Building the platform at pace could be a critical and positive part of Scotland's long-term recovery from COVID-19.

Integrated Joint Boards for Health & Social Care, the Care Inspectorate and Healthcare Improvement Scotland should agree common ethical and secure data standards with a target date for implementation and, once it is operational, develop integrated and interoperable data sets and systems through the National Digital Platform.

6 Scottish Government's Data Scoping Taskforce (2018) Medicines Use and Digital Capabilities – Building capability to assess real-world benefits, risks and value of medicines: Towards a Scottish Medicines Intelligence Unit

CONCLUSION
Our Key Recommendation

This report has explained why closing Scotland's Data Gap matters and how we can do it. Ethical, robust and secure data offers immense opportunities to transform health & social care and to harness digital and technology, but also significant challenges.

The social and economic gains in wellbeing and quality of life, employment, productivity and inclusive growth are potentially transformative. By closing the Data Gap, we can establish Scotland as a world leader and improve our public health to among the best in Western Europe by 2040.

Achieving our vision needs ambition, investment and urgency. It needs a coherent plan and coordinated action to strengthen each of the four pillars identified in this report.

We welcome the Scottish Government's commitment in the Programme for Government 2020/21 to create a first-ever Data Strategy for Health & Social Care. We believe that when this new Data Strategy is published later in 2021, it should be backed by a Health & Social Care Transformation Fund which invests in:

- **Strategy**
  Delivering an ambitious, collaborative and innovative national approach to harnessing data to transform health & social care which maximises social and economic gains.

- **Culture & Leadership**
  Empowering leaders to drive change by building an ambitious and collaborative national culture of innovation in data, digital and technology.

- **Skills**
  Investing in reskilling, upskilling and lifelong learning to develop a health & social care workforce better equipped to harness data, digital and technology.

- **Infrastructure**
  Modernising and upgrading health & social care infrastructure to build a single national data architecture which integrates systems, enables ethical data sharing and creates secure digital health records.

The new Data Strategy and the Transformation Fund should be designed and delivered in partnership with the diversity of partners and stakeholders across the sector – especially citizens, patients and service users, and including the voice of staff and industry – to build understanding, trust, support and agency across our society and our economy. It should be implemented at pace and with ambition, supporting action, collaboration and innovation across the public, private and third sectors.

Together, we have made significant progress closing Scotland's Data Gap in our emergency response to the pandemic. But there is much more still to do.

As we look to recover and build resilience from COVID-19, harnessing data, digital and technology for a healthy society and a healthy economy has never been more important.

Our Key Recommendation

The Scottish Government's new Data Strategy for Health & Social Care should be backed by a Health & Social Care Transformation Fund which invests in Strategy, Culture & Leadership, Skills and Infrastructure to close Scotland's Data Gap.

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Our Partners

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The views and conclusions in the report are those of SCDI and should be attributed to SCDI. SCDI takes full responsibility for the content of the report and associated publications.

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