Health, Social Care and Sport Committee

12th Meeting, 2021 (Session 6), Tuesday, 23 November 2021

Data and digital services in health and social care

Introduction

1. At its meeting today the Health, Social Care and Sport Committee will take evidence on data and digital services in health and social care from:

    - Scott Heald, Interim Director for Data Driven Innovation and Head of Profession for Statistics, Public Health Scotland; and
    - Ed Humpherson, Head of Office, Office for Statistics Regulation

and then from:

- Martyn Wallace, Chief Digital Officer, Local Government Digital Office;
- Christopher Wroath, Director, NES Technology;
- Jim Miller, Chief Executive, NHS24;
- Chaloner Chute, Chief Technology Officer, The Digital Health & Care Institute;
- Chris Mackie, Digital Hub and ALISS Programme Manager, the Health and Social Care Alliance; and
- Dr Steve Baguley, Clinical Director for eHealth, NHS Grampian and Chair, Clinical eHealth Leads, Scotland

Background

2. The Committee had an initial discussion about work programme priorities at its Business Planning Day on 30 August 2021. The Committee subsequently discussed its future work programme on 5 October 2021.

3. At this meeting the Committee agreed to undertake a number of one-off evidence sessions including one on data and digital services in health and social care.

4. Ahead of the evidence session the Committee agreed to write to the Cabinet Secretary for Health and Social Care seeking an update on the Scottish Government's Digital Health and Care Strategy which was originally published in 2018. A response was received from the Cabinet Secretary on 17 November. The full letter is available at Annexe A.

5. Several witnesses have provided written evidence ahead of the formal session. These are attached at Annexe B.

6. Evidence from today's first panel will focus on data in health and social care while the second panel will principally focus on digital services, including implementation of the Scottish Government's Digital Health and Care Strategy.

Clerks to the Committee

18 November 2021

Annexe A

Gillian Martin MSP
Convener, Health, Social Care and Sport Committee
The Scottish Parliament
Edinburgh
EH99 1SP

Via Email: hscs.committee@parliament.scot

17 November 2021

Dear Gillian,

Re: Scotland's Digital Health and Care Strategy

Thank you for your letter of 15 October 2021 seeking an update on progress with implementing the Digital Health and Care Strategy to help inform the Committee's planned session on data and digital services in health and social care.

As you are aware, in 2018, Scotland's first Digital Health and Care Strategy was published. It was a bold and ambitious strategy that recognised the health and wellbeing of the people of Scotland can, and should, be enhanced and transformed through the use of digital technology.

Key Outputs (pre-pandemic) include:

- The establishment of the Digital Health & Care Strategic Portfolio Board, which oversees the strategy implementation, has made significant progress thus far taking key decisions on national strategic projects such as the setup of the National Digital Services to deliver a national digital platform, and approving strategic contracts such as the replacement of the national Community Health Index (CHI) system and significant investment in Microsoft Windows 10 and Office 365.

- Creation of enhanced leadership, including within the Scottish Government with the appointment for the first time of a dedicated Director for Digital Health & Care.

- Information Governance, Assurance and Cyber Security – Establishment of the Scottish Health Competent Authority with regulatory responsibility for oversight and enforcement of standards across NHS Scotland Health Boards as part of the Security of Network and Information Systems Regulations.

- Service Transformation – Scale up of Near Me (Attend Anywhere) remote consultations and Blood pressure monitoring.

- Workforce – growing digital leadership through Scottish participation in the NHS Digital Academy and supporting Nursing, Midwifery and Allied Health professionals to acquire digital leadership skills through the NES delivered dNMAHP programme.

- National Digital Platform – initial steps in development of the key building blocks required for an interoperable digital echosystem.

- A completed Digital Maturity Assessment of health and social care organisations. Full responses received from all 14 territorial health boards, all 6 special health boards who were invited to take part as well as 22 of 32 local authorities/HSCP's. In 2019, this provided us with a solid evidence baseline of digital readiness and capabilities. A further assessment will be undertaken in 2022.

Refreshed Digital Health and Care Strategy

As well as requiring a degree of reprioritisation and a shifting of focus to support our pandemic response – not least in the areas of vaccine delivery and Test & Protect, the Covid-19 pandemic has significantly accelerated some of the ambitions we set out in 2018, while highlighting areas where we can do better. As part of the Programme for Government, a refreshed strategy was published on 27th October 2021. It draws on our learning since 2018, including the increased emphasis on digital as a priority area as a result of Covid-19. Digital health and care strategy - gov.scot (www.gov.scot)

As the pandemic has shown us, people now look to digital tools to access a multitude of services, and health and care is no different. People want and expect to have greater choice over how – and increasingly when – they access their care. This is backed up by the recent Seventh Citizens' Panel report (hisengage.scot) which looked at people's health and social care experience during the COVID19 pandemic and priorities for health and social care in the future.

I would also encourage the committee to read our recent update report - Scotland's Digital Health and Care Response to COVID-19 2021 (Attached as Annex A, also available at Coronavirus (COVID-19) digital health and care response: 2021 update - gov.scot (www.gov.scot)) – for a detailed overview of the significant progress made over the past 20 months, a large part of which relied on the foundations put in place for the National Digital Platform but in a way not previously envisaged.

As I previously set out to the Committee in my letter of 27 September 2021, a key output from this work to date is the creation and ongoing development of the National Clinical Data Store (NCDS), which is the single point of truth for all C-19 vaccination data. NCDS links to other digital products including the Turas Vaccination Management Tool (VMT), GP-IT, PHS and CHI. These core systems being interoperable are now allowing us to realise our ambitions of ensuring that information is available to staff when and where they need it. The National Digital Platform work, which is now under new leadership within NHS National Education for Scotland (NES) but should not be seen as a single entity hosted and managed by one organisation, is evolving into a collaborative and integrated approach, which pulls together the infrastructure, products and services which, together represents an evolution in how health and care technology is delivered, managed and experienced in Scotland. This work is being overseen by the Digital Health & Care Enabling Technology Board.

The need for this approach was a key finding from your previous enquiry into Technology & innovation, and I would like to assure you that your report from that and recent reports such as the Health & Sport

Committee's examination of the future of primary care, the Feeley review into adult social care and the Logan report into the technology sector have all been factored into our work over the past few years, and continue to be reflected in our refreshed strategy. We have noted that they all suggest the need to go further and faster. The specific recommendations within all these reports are considered and help form core elements of the refreshed strategy.

The principles of the original strategy (empowering citizens to better manage their health and wellbeing, and the underpinning architectural and information governance building blocks for the effective flow of information, to enable this) continues into the refreshed strategy. However, there is a a greater emphasis on data, ethics, human rights, digital maturity, workforce capacity and procurement.

The refreshed strategy, which once again is jointly owned with COSLA, focuses on six main areas:

Digital access

As the pandemic has shown us, people now look to digital tools to access a multitude of services, and health and care is no different. Just as digital technology was at the forefront of our response to the pandemic, it will be central to how we re-build and remobilise the NHS as part of recovery from Covid19, as outlined in the NHS Recovery Plan. We will build upon the successes that were accelerated as a result of Covid – Near Me video consulting; Microsoft Teams implemented across our NHS estate; information sharing barriers addressed at speed; digital capability increased in care homes; the increased remote monitoring and self-management of conditions from home.

Digital services

As part of the refreshed strategy and the Programme for Government, we will develop a Digital Front Door for Health & Care in Scotland. This reform of digital access offers the strategic vehicle to deliver our ambitions and to build on the good work, innovation and lessons from the pandemic. This work will look to provide citizens access to things like health records, being able to manage appointments and prescriptions online, allow for communication with services, self-management and the facility to update personal information and preferences. As we develop this digital service, which will include a safe, simple and secure digital App, we will also ensure that non-digital access and services remain available and we will be clear that the option to have a face to face consultation will always be available to those who need it. In addition, we also look at what has worked well and what hasn't in other parts of the UK and beyond in order to develop our approach.

We will involve people and staff in the design of tools, technologies and services that support them, as we know that designing services along with users is more likely to deliver meaningful and lasting change that improves outcomes. We are specifically

committed to engaging and consulting on the development of an App as outlined above.

Digital foundations

A core commitment in the last strategy was to develop a 'National Digital Platform' (NDP) and I have provided a short update on that above. you have also sought an update on this work in your letter. As I outlined core systems including GP-IT, PHS, CHI and the National Clinical Data Store (NCDS) are now allowing us to realise our ambitions of ensuring that information is available to those who need it and when they need it because they are interoperable. The NDP is not a single product but a collaborative and integrated approach to delivering cloud-based digital components and capabilities that will play a significant role in our digital health and care ecosystem now and in the long term. Therefore, the NDP is integrated throughout the refreshed strategy and is seen as the focus on new architecture, the development of a cloud strategy and Digital standards.

Beyond that, this section of the strategy focuses on the need for greater standard-based approaches to the development of products and services, with a strong focus on secure, authenticated access for staff and citizens – with a key reliance on the work of Digital Identity Scotland.

Digital skills and leadership

The impact of Covid19 has led to the rapid increase and take-up of technology and has required the health and social care sectors to embrace change in practice at an unprecedented pace. The use of technology has affected many areas including new ways of working, productivity, connection and communication, the wellbeing of staff and the people we support and care for. Our digital response to Covid-19 has included supporting changes to the way our health and care staff work and deliver services by using digital as an enabler to provide staff with the best possible tools, flexibility and environment to ensure the right level of care to our patients and public. We focused on the digital facilitation of education, learning and access to information implementation of the solutions that were deployed at pace and scale including the Near Me Platform, Office 365, MS Teams and the required digital facilitation of education, learning and access to information about:

- Support for remote communications – competently using MS Teams and video consulting

- Support for Remote health monitoring - national Remote Health Pathways (RHP), InHealthcare vCreate Platform expansion from ICU to Care Homes

The Digitally-Enabled Workforce Steering Group chaired by NES has re-shaped the identified priorities previously identified pre pandemic to reflect the learning and work required during the last year and have produced a proposal with short and medium term priorities to address these known workforce skills gaps. This has now been approved by the Digital Health & Care Strategic Portfolio Board and will be funded from April 2021 to June 2023. This work will help to drive and support our primary aim of having a digitally enabled health and care workforce.

Digital futures

It is clear that the response to the coronavirus pandemic has accelerated the pace of change, whilst highlighting the challenges faced by people who find themselves excluded from the digital world. As we look to recovery, we now have an opportunity build on the progress that has been made to date and to take account of the changed landscape we now operate in. However, it is essential that we are prepared for what comes next and that we can influence some of these important developments in technology. The strategy can support the economy through a focus on innovation and furthermore digital technologies contribute to our effort to tackle climate change in many ways, such as a reduction in fuel use enabled by on-line appointments and technologies to monitor conditions at home. We will do this through collaborative working with industry and our innovation centres while taking the public with us.

Data-driven Services and Insight

Covid has also highlighted some gaps, most notably around how data is used and flows through the system for maximum public benefit. We have therefore committed to publishing a dedicated Data Strategy for Health & Social Care in Scotland for the first time, and development work on this is underway. This has to be developed with, and for, the people of Scotland who we recognise need to have complete trust in how their data is used, as well as develop greater understanding in the value of sharing their data for the benefit of the future of health & care delivery. This builds on work already undertaken with the likes of NESTA and their Data Dialogues programme of work (Data dialogues | Nesta). This work will progress into the summer of 2022 and will look to set out the strategic direction for resolving issues of lengthy waits to access data, opening up access to citizens, improve our security capabilities, and help individuals to take ownership of Information Governance.

Delivery Plan

The refreshed strategy will introduce a rolling three-year delivery plan that will be updated each year from April 2022 to ensure our commitments across our 6 areas of focus are progressed. The plan will clarify what our priorities for delivery are, what outcomes are expected to be achieved, who has been tasked with delivery, what budget has been allocated to the work and how success will be measured. Priorities will focus on programmes including Digital Care Homes, CHI, Social Care Management System, HEPMA, GP IT, Digital Appointments (DACS), Near Me, Remote Health Pathways, Digital Telecare, Office 365, Person Held Records and Digital Prescribing.

The plan will be developed alongside a clear approach to commissioning, benefits realisation and evaluation.

Conclusion

I trust this provides the Committee with an assurance that we continue to see the Digital agenda as a priority. A key aspect is how we embed digital into all programmes of work, recognising there is very little of our health & care services that are not already reliant on digital & data, and I anticipate all improvements and

activities going forward to have significant digital developments as a core part of the necessary work. I would welcome the Committee's consideration as to how it will assess the role of digital in all of its work going forward, and I would of course be happy to continue to provide updates as required.

I hope your session on data and digital services goes well.

Yours sincerely,

HUMZA YOUSAF

Annexe B

Office for Statistical Regulation written submission: Data and digital services in health and social care

Copy of a letter to Convener of the Health and Sport Committee dated 7 October 2021

Dear Ms Martin,

Today, the Office for Statistics Regulation (OSR) has published its review, *Improving health and social care statistics: lessons learned from the COVID-19 pandemic*[1]. I hope the findings and recommendations will be of interest to you and members of the Health, Social Care and Sport Committee.

The pandemic resulted in a huge public appetite for data and statistics. We have seen a remarkable response from producers of data and analysis to meet this demand, in many cases overcoming challenges which would previously have seemed insurmountable. The pandemic has also drawn attention to pre-existing challenges for health and social care statistics.

Statistics produced by Government and public bodies must command public confidence.

They must support public understanding of public health issues and the effectiveness of Government policy – to hold decision makers to account. Statistics and data are a public asset and should be valued as that.

I would hope that the recommendations from the OSR review will be considered and appropriately implemented by Government and that this work will also help the work of your Committee.

Yours sincerely,

Sir David Norgrove

Chair of the UK Statistics Authority

[1] *Improving health and social care statistics: lessons learned from the COVID-19 pandemic*, Office for Statistics Regulation, 7 October 2021

Public Health Scotland written submission: Data and digital services in health and social care

Background to Public Health Scotland

Public Health Scotland (PHS) is Scotland's lead national agency for improving and protecting the health and wellbeing of all of Scotland's citizens. The organisation's vision is for a Scotland where everybody thrives. Focusing on prevention and early intervention, their aim to increase healthy life expectancy and reduce premature mortality by responding to the wider determinants that affect people's health and wellbeing. To do this, they use data, intelligence and a place-based approach to lead and deliver improvement against

Scotland's public health priorities.

Health and social care statistics

1. Official statistics provider for the NHS in Scotland

1.1. PHS is the official statistics provider for the NHS in Scotland. Over 400 statistical outputs were published in 2020/21, covering a broad range of areas of health and social care including:

- population health
- conditions and diseases (including COVID-19)
- health services
- healthcare resources
- lifestyle and behaviours

1.2. Statistics are produced in line with the Official Statistics (Scotland) Order 2008, the Official Statistics (Scotland) Amendment Order 2019 and the Pre-release Access to Official Statistics (Scotland) Order 2008. This includes pre-announcing forthcoming publications online and providing pre-release access – access to the statistics in their final form prior to publication – to certain key stakeholders.

2. Statistical governance

2.1. The PHS Director of Data and Digital Innovation, Scott Heald, is the Head of Profession (HOP) for Statistics responsible for PHS statistics, and the official health and social care statistics produced by NHS National Services Scotland (NSS), the Scottish Ambulance Service (SAS), NHS 24, and NHS Education for Scotland (NES).

2.2. The HOP role is set out in the Framework for National Statistics 2000 and the UK Code of Practice for Statistics 2018 (COP). The HOP is professionally responsible to the UK National Statistician, Sir Ian Diamond, who is head of the UK Government Statistical Service and Chief Executive of the UK Statistics Authority. The regulatory arm of the Statistics Authority is the Office for Statistics Regulation, whose Director General is Ed Humpherson.

2.3. The HOP is responsible for implementing the provisions set out in the Statistics and Regulation Services Act 2007 and the COP. They have sole authority for statistical methods, standards, procedures and timing of statistical releases. This includes ensuring that all statistical publications comply with the three pillars within the COP:

trustworthiness, quality and public value. The HOP is supported by a statistical governance team.

3. COVID-19

3.1. PHS leads on daily reporting of case numbers and severe outcomes associated with COVID-19. This includes providing:

- public-facing data through an interactive dashboard
- a weekly statistical report including data on Test and Protect, vaccination, case numbers and deaths
- a daily high level dashboard of official statistics on the outbreak
- detailed epidemiological data in the form of management information to the Scottish Government and NHS Boards
- a weekly public-facing release focusing on data at a national level including
- an interactive dashboard analysing the wider impact of COVID
- one-off special reports including analysis of outcomes relating to Discharges from NHSScotland Hospitals to Care Homes between 1 March and 31 May 2020, analysis of uptake of the vaccine by ethnicity and deprivation, and analysis of COVID-19 outcomes by ethnic group

3.2. PHS has taken positive learning from the way the public has interacted with statistics over the course of the pandemic. The organisation's dashboards have been popular with the public and with professional stakeholders, leading to greater emphasis on this approach to sharing data. The public-facing dashboard has received almost 45 million hits since its launch in October 2020. The greater use of neighbourhood level data is a further positive legacy from the pandemic. PHS plans to review all statistical outputs to ensure digital innovations are used to best effect and impact across the organisation's suite of health and social care intelligence.

Digital technology

1. PHS Data and Digital Strategy

1.1. The PHS Digital Strategy sets out the organisation's ambition to maximise the power of digital and data to empower individuals, communities, partners and our staff.

1.2. The organisation's digital priorities are to:

- Engage and empowering the public by empowering individuals and communities to make better health and wellbeing decisions.

- Create actionable insight across the public health system by providing the public health network with rich insight which draws on health, care, education, social and economic data.

- Lead digital collaboration across the public health system by enabling processes and data to flow between local partners to drive collaboration and reduce health inequalities.

- Accelerate digital innovation for the public health system by maximising the intellectual and human capital of different sectors to support digital innovation to protect and improve health and wellbeing.

2. Digital Health and Care Strategy

2.1. PHS sits on the Digital Health and Care Data Strategy Working Group, working collaboratively with a range of organisations to further develop the data elements of Scottish Government's refreshed Digital Health and Care Strategy.

2.2. PHS fully supports the ambitions of the refreshed strategy and will work with partners to help realise its ambitions including health boards, local authorities, health and social care partnerships, housing organisations, industry, and third sector organisations.

3. COVID recovery

3.1. PHS is committed to ensuring that digital technology is central to re-building and remobilising the health and social care system – and wider public services – as part of the recovery from COVID. It is crucial that services are designed and delivered to drive better outcomes for the people of Scotland.

3.2. While it is critical that the gains achieved through accelerated deployment of data and digital solutions in response to COVID are maintained as the country recovers, it is also crucial that we ensure that the modernisation of public services does not increase inequalities.

3.3. The implementation and use of digital technology and its infrastructure can both reduce and widen health inequalities and the underpinning social and economic inequalities that people face. Digital exclusion has emerged as a major issue through the course of the pandemic. Consideration must therefore be given to those that are currently digitally excluded, and have an unequal access to information and services. PHS fully endorses the 'No one is left behind' commitment in the Scottish Government's Digital Strategy. It is

important to ensure that options are available to people who do not have the equipment, data, skills, knowledge or desire to connect digitally. Those who may be most impacted by digital exclusion include older people, those living in poverty, those in overcrowded housing, ethnic minority groups, those experiencing homelessness and those living with domestic violence.

NHS Education for Scotland (NES) written submission: Data and digital services in health and social care

1. Key Messages:

    1.1 NES is the national health board with statutory functions for providing, co-ordinating, developing, funding and advising on education and training for the NHS and social care staff. NES is ambitious to drive change: it is innovative, collaborative and forward-thinking – working with NHS, local government, academia, professional organisations, regulators, social care organisations and a wide range of strategic partners across Scotland, and at UK and international levels. NES is a leader in digital solutions and cloud-based services. NES has built the TURAS platform integrating applications, data and intelligence making access to services and key information easier for users. It supports health and social care staff to work more efficiently with access to the information they need, when they need it, where they need it.

    1.2 NES has the demonstratable capacity to deliver the technology to underpin the outcomes of the Digital Health & Care Strategy 2018 and 2021 refresh. This is the same capability and technology that delivered the Covid-19 Vaccination Management Tool, designed, developed and live within eight weeks delivering to 4.3 million citizens, 9.8 million vaccination events by 31,000 vaccinators in 8,600 in different venues in every part of Scotland.

    1.3 NES has developed the technology (Turas Safety Huddle) to collect, link and then report in real time data on workforce in all 1012 adult Care Homes delivering statistical information to support the homes, the home providers, Integrated Joint Boards, Health Boards and SG directorates.

    1.4 The above was possible as a result of NES investment in public cloud technology and associated Agile delivery methodologies.

2. Submission:

    2.1 The key issue facing a “Once for Scotland” approach to health and care data is the current model of data created and managed within organisational (health board) and technology boundaries. While fit for the purpose of supporting delivery of services within a Health Board, current systems do not easily link within and across Board and sector boundaries.

    2.2 To achieve the strategic outcomes identified requires a shift in the underpinning technology being delivered to cloud base services. At the scale and affordability necessary for an enterprise such as health and care in Scotland, this has to be through public cloud. NES has the capability and experience to draw existing data into a central, logical space, removing barriers between individual data to achieve a holistic, digital citizen record.

2.3 The Covid-19 pandemic demanded response from health and care at national level, across organisational and sector boundaries at a pace and scale not required before, significantly increasing the understanding of public cloud technology and how it can underpin the delivery of the strategy. The mass vaccination programme is an exemplar; the requirement to deliver vaccinations in hundreds of different, public space environments, to capture consistent high-quality data as a national service, with citizen engagement from information to attendance could only be fulfilled by secure, scalable, available everywhere services that public cloud can deliver. Three clouds were deployed:

- for data capture: NES Vaccination Management Tool (VMT);
- for mass data storage and deployment: NES National Clinical Data Store (NCDS);
- for citizen scheduling and interface: NSS National Vaccinations Scheduling Service (NVSS).

2.4 This experience has increased the pace at which the aspiration of health and care data "where and when needed" can be delivered, and recognition that the definition of the National Digital Platform (NDP) should be expanded in support of national scale integration. The approach will be Application Programme Interface (API) led allowing for accessibility to existing data without significant developmental change.

2.5 A key component has been linking GP data into the NCDS, required to ensure all vaccination data was held in a single clinical space. This has supported NES in accelerating development of a single Clinical Data Repository (CDR) – the core of the NDP - leveraging 10 million+ records captured through VMT and GPIT.

2.6 The CDR is being designed and built by NES with citizen access at its heart. This work is drawing on the citizen feedback and engagements through the development of the Covid-19 Protect Scotland, vaccination certification and the status verification applications, all hosted on the NES public clouds.

2.7 To attract, train, develop and crucially retain the health and care workforce, we require the strategy to also deliver the same high quality, focused services that make our workforce feel valued and supported. The value of having near real time data was demonstrated by the NES Turas Safety Huddle, allowing for swift intervention by Health Boards when staffing numbers dropped below safe levels.

3. Conclusion:

3.1 NES's response to the Covid-19 pandemic demonstrates that we have the capacity, capability and opportunity to deliver the technology to underpin the outcomes of the Digital Health & Care Strategy 2018 and 2021 refresh.

3.2 The 2021 refresh takes into account the learning that the most effective way to deliver the outcomes quickly is to develop access to and share the existing data (and systems) that support current services. NES is already working with stakeholders on the technology to broker access to citizen's data through a single architecture that links systems together.

NHS24 written submission: Data and digital services in health and social care

1. INTRODUCTION

NHS 24 develops and delivers a range of digital services to support demand to NHS Scotland. In addition, as a national Board we also work with partners on shared data to improve public health outcomes, especially Public Health Scotland and Scottish Ambulance Service. NHS 24 also works collaboratively with partners to ensure that health information is available and accessible for all communities across Scotland.

2. DEVELOPMENT OF DIGITAL SERVICES

The focus over the last two years has been on supporting the COVID-19 response. Working alongside Scottish Government and partners, NHS 24 accelerated enhancement of its digital services including the heavily promoted use of *NHS inform* for all public and professional facing content related to COVID-19. This has enabled empowerment of citizens for self-supported care and signposting to relevant services.

Through the pandemic, NHS inform has become a national, trusted source of help and advice for the public. The table below provides a high level summary of digital related activity over the last 12 months, including COVID related demand:

Service	**Last 12 months demand (1 Oct 2020 – 31 Oct 2021)**
NHS inform views	87.8 million
NHS inform – COVID-19 page views	15.7 million
NHS Inform – Scotland's Service Directory accessed	1.8 million
COVID-19 chatbot sessions	Between 600-1000 per day

Accelerating and embedding digital developments

In response to the COVID-19 pandemic NHS 24 were able to accelerate already planned developments of digital channels to support broader access to COVID related content and services. Taking a user centred design approach where possible, the development of services has enabled a broader range of access to quality assured resources and services. NHS 24 currently delivers a range of digital services, summarised below:

NHS inform	NHS 24's key health and care digital platform, providing a wide range of clinically assured and accessible content, tools and advice across symptoms and conditions. This includes a range of hubs and micro-sites including COVID-19 hub, Ready Steady Baby, Flu Vaccination and content to support the Women's Health Plan. Content is provided in a variety of formats to support different user accessibility needs. Also available via NHS inform is Ask Inform chat bot, where users can ask natural language questions and be provided automatic answers, directed to web content or provided the option to chat live with an advisor via web chat.

	We are collaborating with a number of Health Boards on our service design activity. For example, we are working with NHS NSS on redesign of screening pathways, looking at how NHS inform can increase engagement with screening programmes and support delivery.
Scotland's Service Directory	A single directory for Scotland containing information on statutory services (GPs, Pharmacies, A&E, Dentists, Opticians, Sexual Health Clinics) plus full access to the ALISS directory which contains third sector, community and voluntary services (in partnership with Health & Social Care Alliance).
Self Help Guides	Accessed through NHS inform, these are symptom checkers, based on specific symptoms or conditions, which through a series of questions provide advice to users about what to do next e.g. contact GP, phone 111 or self-management advice. These are aligned with 111 clinical content.
GP.scot	In support of the 2018 GMS contract, NHS 24 provide a template website platform to GP practices, to enable them to provide access to their patients. This contains information directly from NHS inform, which provides consistency of content for patients, alongside links into related tools (Scotland's Service Directory and Self-Help Guides). Practices also have the ability to include and publish their own practice specific content.
SMS text	Used in various ways to support both internal and external communications. Provides users to the COVID 111 service follow up links to self-care and testing resources. In addition has been used to pro-actively contact previous users of the 111 service to highlight COVID related resources.
Care Information Scotland (CIS)	Delivers quality information on how to access care services, what you are entitled too, how to prepare for care needs in the future and guidance on financial needs for care. Work is underway to further integrate CIS with NHS inform content.

3. LEVERAGING THE USE OF SHARED DATA AND IMPROVED INTELLIGENCE TO ADDRESS PUBLIC HEALTH INEQUALITY

The response required of all health and care services to COVID-19 has introduced new ways of working collaboratively with partner organisations, including new relationships with the Public Health Scotland and its components including Health Protection, Maternal and Child Health, and Information Services Division.

This has included rapid update and joint governance of national clinical content, agreeing how NHS 24 data is presented nationally, and new data feeds to support national early warning systems for unscheduled care and respiratory illness. Mental Health will remain a strong focus of the approach.

The experience of COVID-19 has also highlighted the need to increase the pace of digital innovation and provide better access to nationally available data and standards, which can be used flexibly as circumstances change without the need for complex integrations.

In addition, the National Boards Collaborative have identified that there may be an opportunity for the National Boards to explore the benefits of collaboration to accelerate pace in addressing public health inequalities through shared data and improved intelligence.

CONCLUSION

In conclusion, NHS 24 is working closely with SG Digital Health and Care colleagues to explore how we can support the Delivery Plan that will support the refreshed Strategy. We are also working with National Board colleagues to progress specific areas of digital and data collaboration to also support development of the Strategy.

The Digital Health & Care Institute written submission: Data and digital services in health and social care

1. Unmet Needs

The common user requirements DHI found across health and care services focus on how data is shared, and how a user can 'tell their story once' and use this digital story as a starting point for joined up care and support that meets their 'whole of life' needs (Figure 1). This 'story' needs to be shared across many domains (Figure 2).

Figure 1: Common User Requirements

Figure 2: Different Personal Data Domains

In this context, the National Digital Health and Care Platform (DH&CP) could act as an anchor infrastructure that could provide a 'single version of the clinical truth'. This is a good start, but this must be able to cooperate with a broader 'single version of the personal truth' that can move with the citizen between domains. This broader approach involves a citizen being able to login with a digital ID and take a copy of their data into their own personal data store. Then, when they login to a different service with this digital ID, they can then consent to use their data (their story) to auto-populate forms or prove things (e.g. age, financial status, clinical need) in a manner that is trusted by organisations needing to determine eligibility. This is the Scottish Government's Digital Identity Strategy and so should heavily influence the National DH&CP approach.

The DH&CP must provide the digital 'plumbing' that aggregates health and care data from a range of services, so that different teams can read and write to the same clinical story. A citizen should then be able to login to a digital health and care product (app) that allows them to manage data sharing permissions for the reuse their clinical data with other apps. Here they could also enable a Personal Data Store that allows them to port their data to other domains. The platform could also provide secondary infrastructure for common health and care transactions. For example a national appointments management service that standardises appointments administration. Many products (apps) could use this as a common 'engine' – creating

a consistent scheduling system for professionals but allowing a variety of appointment booking experiences for citizens.

The same 'plumbing' that joins up health and care data and enables citizen access could also be made available to academia and industry to drive the development and deployment of digital health and care products at scale. There are Scottish SMEs lining up with innovative digital products that could support service change right now – but there is no clear place to go to show what they can do and little flexible infrastructure to use to allow them to integrate effectively with health and care systems.

7. The National Digital Health and Care Platform (DH&CP)

DHI's experience of the National DH&CP development has not been positive. DHI and partners found:

1) The DH&CP team focused more on 'product' than on 'platform' – many developers can create products. We are missing platforms to help them integrate these products.
2) The DH&CP team did not recognise the value of existing digital infrastructure – choosing a 'clean slate' method that was unrealistic from an operational health / care delivery perspective.
3) The 'Once for Scotland' principle was misused and misunderstood – The platform was pitched as a 'solution' to help with many challenges overnight. People erroneously put their hopes on one 'mega product' to fix a diversity of problems. Other groups and platforms had funding withheld. This stopped progress in a wide range of areas while many waited for one solution.
4) The DH&CP team focused on their own goals, instead of enabling everyone else – The team did not seem capable of collaborating with other agencies. For example, DHI (the National Digital Health & Care Innovation Centre) submitted six collaboration proposals to the DH&CP team over a two-year period. Not a single formal response was forthcoming. To date we do not have a single collaborative project with the National DH&CP team.

The combined effect of these three elements is that:

- The National DH&CP team did not satisfy its brief, with little discernible platform in evidence.
- The progress already being made by other groups was delayed by up to three years.
- A wide range of innovators have not been accelerated as anticipated and have instead been disenfranchised by the mixture of undelivered promise and the closed, exclusive methods used.

8. Parallel Development

After the first year of inaction, DHI and partners (NHS GG&C, Lothian, Grampian, NSS, NES, Blackwood, two Scottish charities and eight Scottish SMEs) restarted their existing digital platform developments.

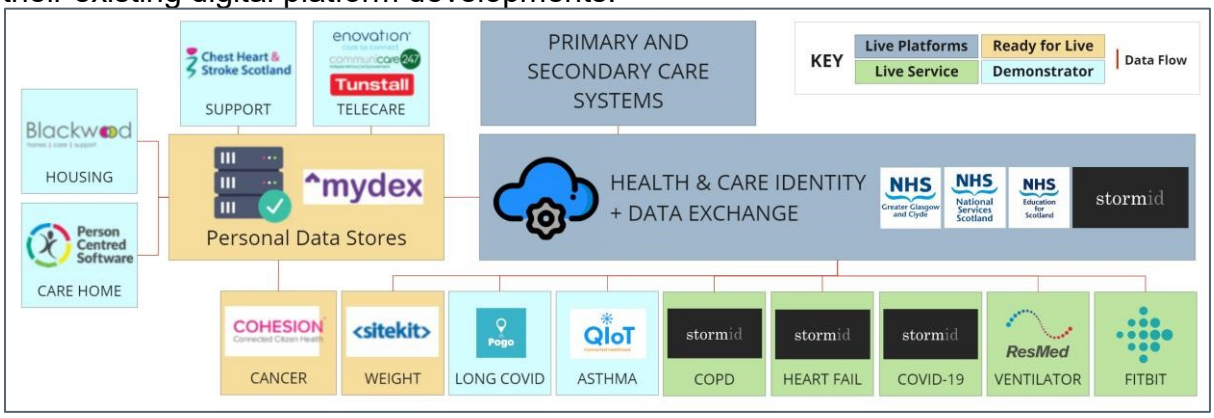


Figure 3: Digital Platform Development (DHI & Partners)

Figure 3 depicts the simple architecture resulting from this parallel programme of work. This involved:

1) Procurement and development of a common digital Identity and data exchange platform and then integrating this into existing clinical systems.
2) Providing a responsive innovation environment to support the integration of products from seven digital health suppliers. Five of these are complete with six services live in Scotland.
3) The live services are in use across eleven health boards with Greater Glasgow & Clyde, Lothian and Grampian deploying the most live service in their role as innovation testbeds.
4) The next year will see the integration with Personal Data Stores which will allow citizens to share data between health, care, telecare, third sector, housing, and care home services.

9. Moving Forwards

The central element of the National Digital Health & Care Platform development is the OpenEHR Clinical Data Repository (the 'single version of the clinical truth'). This will be a long running and complex development that replaces existing legacy healthcare data stores and integrates with primary and secondary care patient management systems. It needs to be a relatively inward facing development to put the NHS clinical records system onto a more flexible and sustainable footing.

In contrast, our approach focuses on immediate frontline service redesign, allowing a new generation of digital tools to be deployed in a way that lets users share data with legacy systems, but also gives the citizen a more active role and control over their data – presenting the possibility of citizen-controlled data sharing between the NHS and other domains like social care, third sector, housing, social security.

Our approach is also 'outward' focused - provides open, 'sandbox' innovation environments where innovators from across all sectors can come and show what they can do, using our person-centred data sharing infrastructure to join services up

better. This means we can activate a much larger group of contributors, including world leading Scottish universities and Scottish SME's looking for a route to market and a demonstration environment to support international exploitation.

We propose that the National DH&CP medium to long term capability is complimented by the more immediately impactful Data Exchange work carried out by DHI and health board / third sector / industry partners over the last four years.

DHI understands the NDP is under new management and so we stand ready to collaborate, offering our existing networks and assets to help relaunch the NDP capability to support more open, personcentred, and impactful innovation.

Audit Scotland written submission: Data and digital services in health and social care

Introduction

1. Audit Scotland welcomes the opportunity to provide the Committee with a short, written submission to support the evidence session regarding health and social care data. Our response highlights findings from our recent reports and sets out recurring themes around incomplete and poor quality health and social care data and the impact of poor data sharing.

Health and social care data

2. There are numerous indicators measuring access to acute care services, such as hospitals, but there is still little reliable and robust data about primary and community care, and very little about social care. A range of Audit Scotland reports have highlighted concerns about incomplete and poor quality data and the impact that this has both on decision making and planning and on the ability to demonstrate whether, and the extent to which, Government policies and initiatives are delivering improved outcomes. There have been significant delays in improving this situation.

3. Our 2018 report on Health and Social Care Integration highlighted several areas which need to further improve to help Integration Authorities (IAs) and their council and NHS board partners make better use of data. These include:

    - GP practices agreeing data-sharing arrangements with their IA;
    - IAs and (the then) Information Services Division (now part of Public Health Scotland) agreeing data-sharing protocols for using data in national databases;
    - IAs identifying gaps in data about primary, community and social care services and establishing how this information will be collected; and
    - improving consistency in IAs' data, making comparisons easier.

4. Sharing of information, including both health and performance information, is a vital part of providing effective care that is integrated from the point of view of the people who use services. It is also vital in helping to anticipate or prevent need. Throughout our work for the Health and Social care Integration report we were told of examples where this was not happening in practice, because of local legacy systems or behaviours.

5. Our 2018 report on Children and Young People's Mental Health highlighted that the scrutiny of children and young people's mental health services has focused on the waiting times for specialist CAMHS. Nationally, some wider performance data is published as part of the CAMHS balanced scorecard but the scorecard focuses on inputs and outputs rather than outcomes for children and young people and provides limited information about service quality.

6. There are also a number of current limitations with social care data, including:

- There is no social care record in the same way there is an NHS record for each member of society. This makes it difficult to assess whether social care is meeting the needs of people using social care support.

- No consistent method for recording unmet need. A person may be assessed as requiring social care support but may not meet the eligibility criteria in place. This makes it difficult to assess the level of need required to deliver a more person-centred, human rights approach to social care.

- No coordinated approach to anticipating future demand and costs of service delivery. Although some individual Health and Social Care Partnerships base their strategic plans on evidence of the prevalence of conditions in their area, e.g., heart disease, there is limited evidence of this being fed into budget decisions.

7. Health and social care workforce data is not as robust and reliable as it could be. In our 2019 report NHS workforce planning – part 2: The clinical workforce in general practice, we noted that the Scottish Government is working to improve primary care workforce data, but progress has been slow. There is a lack of national data on the current numbers in the workforce, workforce costs, activity, and demand. This makes it difficult to plan the workforce effectively or to monitor the impact of major policy changes, such as the new General Medical Services contract.

8. Ultimately, public services are about improving outcomes and it is critical that we are able measure the impact of financial decisions on people and communities. The new National Performance Framework, launched in June 2018, was a major step towards a greater focus on the delivery of outcomes. However, we have said for a number of years that monitoring and public reporting on the impact of health and social care needs to improve. Our 2019 Planning for outcomes report sets out the main factors that support planning for outcomes.

Data and the new Digital Health and Care Strategy

9. The Scottish Government published its refreshed Digital Health and Care Strategy on

   27 October 2021. The strategy commits to developing a *Data Strategy for Health and Social Care*. It acknowledges the impact of poor data sharing and access to health records can have on the delivery of care and continuity between services. Information governance, assurance and cyber security will be key elements of the data strategy as well.

The need for common data standards

10. Using common data standards and languages will make data quality and exchanging data easier. This should enable better analysis of different datasets, across sectors, to provide more in-depth insights for better decision making. This is seen as being key to delivering more personalised and preventative public services. Both the National digital strategy (March 2021) and Digital Health and Care Strategy aim to implement common data standards to achieve this.

11. The Scottish Government published its analysis of its consultation for Data standards in Scotland's public sector- framework for action on 21 October 2021. This highlighted a number of challenges which need to be addressed by the proposed framework: a lack of strategic leadership on public sector data; a fragmented landscape; limited learning or sharing of best practice; skills gaps; data quality (and data maturity); legacy systems; barriers to data sharing; and the investment required.

The Association of the British Pharmaceutical Industry (ABPI) written submission: Data and digital services in health and social care

Executive Summary

In September, the Life Sciences Scotland Industry Leadership Group requested a paper from this sub-group detailing the data priorities of the pharmaceutical industry in order to stimulate economic growth and investment. Through our own ABPI Scotland short-life working group on data we were able to identify the five recommendations from the 2018 Data Scoping Taskforce Report as both a starting point for this work and a key requirement for attracting global investment.

The five recommendations are as follows:

1. Capture medicines use for patients in all clinical settings
2. Include medicine indication in all prescribing systems
3. Create a national laboratory data resource
4. Improve recording of patient outcomes
5. Create a Scottish Medicines Intelligence Unit

Implementing these recommendations would make Scotland an attractive location for global companies looking to situate clinical trials, research and development projects and real-world evidence studies. Crucially, the recording of outcomes would also enable the creation of novel pricing arrangements which deliver innovation to patients and affordability to the NHS.[2]

The desire to understand what drives investment and how Scotland can improve its offer was recently communicated through the Scottish Government's inward investment plan. This strategy laid out the ambition to attract 50 global companies to Scotland and to increase investment from the current 50 largest investors. According to this blueprint it will be achieved through "a deeper understanding of their strategic direction and positioning the role Scotland can play to support those objectives."[3]

For the pharmaceutical industry our objective is clear. We want to research new treatments more efficiently and deliver innovative pricing arrangements which capture value more effectively. Better data collection is the only way to achieve progress in both, and a country which offers safe and secure access to large datasets will benefit from increased investment. As a result, this paper details not only the data asks from industry but also the steps required to realise them.

In order to draw out the wider picture, we assembled a steering group from across the healthcare sector, including patients, clinicians, pharmacists, data specialists, clinical research professionals and industry to submit their views on where we are and, importantly, where we should go. The role of the steering group was to provide guidance and oversight and without their wise counsel these recommendations would not carry the same weight.

[2] **National Institute for Healthcare Research, *How Clinical Research Benefits the UK Economy and NHS*, (October 2019)**

[3] **Scottish Government, *Scotland's Inward Investment Plan: Shaping Scotland's Economy*, (October 2020)**

In addition to this vital sounding board, we also commissioned a survey of key data stakeholders to understand their priorities. The results of this survey were independently analysed and coded to ensure full confidence in its conclusions.

Through both the stakeholder survey and the meeting of our steering group, we have been able to identify three key themes of which we have attached an immediate action for the Scottish Government to take.

From both the results of the stakeholder survey (appendix) and the wider conversations from within the steering group it became clear that three main themes would require action to deliver a data-driven NHS which attracts future pharmaceutical investment:

- Trust: Transparency is critical, and the public must be bought into the benefits of data sharing.
- Speed: The COVID-19 pandemic has demonstrated how quickly the NHS can adapt both technology and care when required. However, the economic opportunities offered through the better collection of data will not exist indefinitely and we need to move quickly in order to maximise them.
- Collaboration: Partnership between industry, academia and the NHS is required to exploit the triple helix.

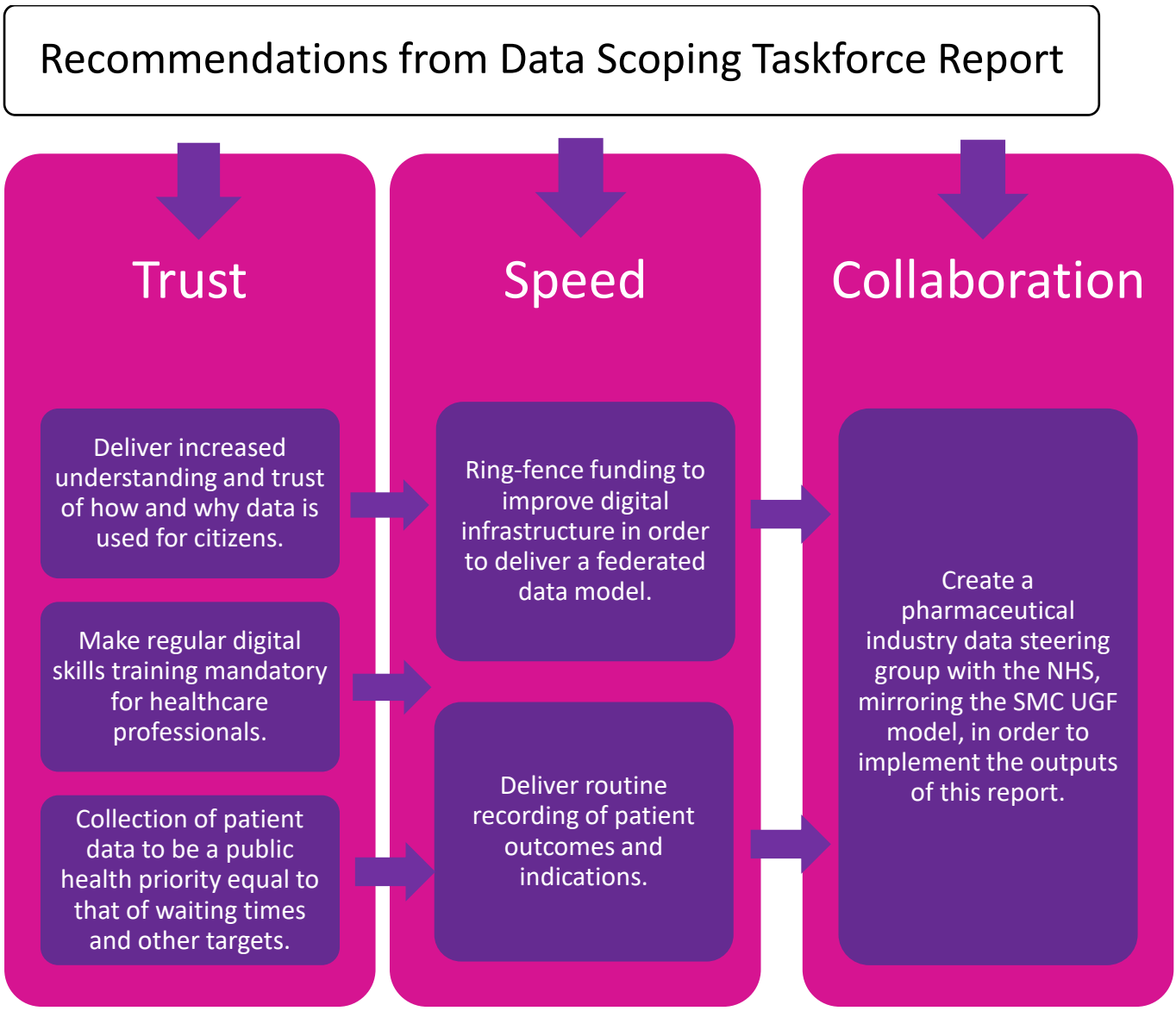


Figure 1: Flowchart of recommendations

Explanation of Recommendations

Trust

Patients need to have confidence that their data is being used appropriately, and they also need to understand, in greater detail, why it is being collected and how it can improve their care. Trust in the public sector to handle data is growing and more than three-quarters of those recently surveyed are comfortable for their data to be used as part of medical research efforts.[4] The uptake of the NHS Scotland Protect Scotland app underlines public willingness to help when the greater good is at stake.

[4] **Understanding Patient Data, Public Attitudes to patient data use: a summary of existing research, July 2018**

Recommendation: Deliver increased understanding and trust of how and why data is used for citizens.

Respondents to our stakeholder survey agreed that open and transparent communication with the public was the most important action to build trust. This conclusion was also supported by comments made by patient representatives on our steering group. We believe it would be beneficial for the Scottish Government to support this work through a high-level statement which would communicate the benefits of anonymised data access for researching, developing and dispensing medicine.

Recommendation: Make regular digital skills training mandatory for healthcare professionals.

The oftentimes complex, clunky and outdated digital infrastructure the NHS uses was cited as a barrier to better data collection and so too was a skills deficit in those tasked with capturing this information. Our stakeholder survey highlighted that a lack of digital skills was one of six barriers in preventing the NHS from curating data more seamlessly. At its core digital solutions and the collection of data should be a resource to help clinicians rather than a burden which requires time-consuming compliance. As a result, healthcare professionals should benefit from regular, mandatory training on how to improve their digital skills.

Recommendation: Collection of patient data to be a public health priority equal to that of waiting times and other targets.

Nearly every respondent in our survey agreed that the better collection and use of data will improve care and outcomes for patients. Survey respondents believed that the use of data could:

- Reduce inappropriate prescribing;
- Ensure treatments are better matched to patients;
- Deliver value for money;
- Reduce wastage;
- Enable more effective prescribing.

Given the significant improvements in care associated with the improved collection of data, the NHS needs to invest in the technological solutions to make this a reality. By moving to a prevention mindset, where the collection of patient data is given equal to priority to other statutory targets, the NHS can be more efficient whilst simultaneously building public trust.

Speed

Recommendation: Ring-fence funding to improve digital infrastructure in order to deliver a federated data model.

Health and social care lags behind other sectors in the use and adoption of basic digital infrastructure. Much of the system is burdened with archaic, inadequate or obsolete technologies and equipment. Our stakeholder survey identified the quality of

digital infrastructure as the second largest barrier to the NHS curating and using data more seamlessly.

Therefore, the NHS estate and Scotland's wider health and social care sector urgently requires investment to upgrade, modernise and standardise (platform/cloud/block chain) IT equipment. Through our steering group we have heard anecdotal tales of computers taking 15 minutes to load and it being more convenient to use paper than digital solutions. This cannot continue, and whilst we are aware of the current budgetary pressures, funding for this should be ring-fenced.

Investing in digital/data infrastructure has the potential to be revenue neutral given that savings can be realised later through increased clinical research funding, better population health and the greater use of flexible commercial arrangements. Furthermore, the collection of accurate data can also help refine patient pathways, which not only improves patient outcomes but also delivers efficiencies and savings for the health service. This part of the story is critical if the NHS is to take on an "invest now, save tomorrow" mindset.

Standardising the way data is collected and accessed across different systems would go some way to ensuring future digital platforms can be truly interoperable. We recommend that a coordinated approach is taken to curate, define, simplify access and encourage the use of existing regional data. Our aim should be to move away from the per-project preparation of datasets to a model of pre-linked data against a shared population spine. Doing so will drive research, improve patient care and reduce healthcare inequalities across the country.

Recommendation: Deliver routine recording of patient outcomes and indications.

Our steering group and stakeholder survey was able to prioritise three of the five recommendations from the Data Scoping Taskforce Report in the following order:

1. Improve recording of patient outcomes
2. Capture medicines use for patients in all clinical settings
3. Include medicine indication in all prescribing systems

A significant 50% of respondents highlighted the collection of patient outcomes as the most important recommendation and one that is most time critical. This view was furthered in the open question responses where respondents highlighted the importance of understanding patient outcomes in the context of COVID-19.

Despite these clear benefits, the Cabinet Secretary for Health, Jeane Freeman MSP, recently stated "there is little provision in existing NHS IT systems to collect information about the purposes for which medicines are prescribed and the outcomes achieved by particular medicines." This should change and work needs to take place immediately to make this ambition a reality.

Collaboration

Recommendation: Create a pharmaceutical industry data steering group with the NHS, mirroring the SMC UGF model, in order to implement the outputs of this report.

COVID-19 has shown what is possible when industry, academia and the NHS collaborate. The speed at which therapeutics and vaccines have been developed should serve as an example of what we can achieve when the collective endeavour of the whole system is committed to a shared goal.

However, according to our stakeholder survey, only one in five respondents thought Scotland, in comparison to other nations, was leading when it comes to the use of healthcare data. Pessimism was highest among industry respondents but well over a third of healthcare professionals, patient groups and third sector organisations believe we are lagging behind.

Despite this apparent lack of progress, 98% of respondents agreed that improving the data landscape would be beneficial to patient care, and crucially nearly nine in ten agree that developing good quality data can positively impact Scotland's economic recovery.

To tackle this challenge and to create a culture of innovation, the Scottish government needs to bring in new skills and perspectives through a pharmaceutical industry data steering group with the NHS which would be responsible for brokering co-produced solutions to implement the outputs of this report.

We envisage that this group will follow the model set by the Scottish Medicines User Group Forum. The SMC UGF enables company participants to engage constructively and productively with SMC officials to shape all relevant aspects of the new medicines Healthcare Technology Assessment (HTA) process in Scotland. This partnership model provides an opportunity for the pharmaceutical industry to work collaboratively with SMC to address technical and process issues, supporting their continuous process improvement, in order to keep SMC at the forefront of global HTA[5].

LSSILG Next Steps

The Sub-Group on Data Priorities for the Pharmaceutical industry request that the Scottish Government considers these recommendations with a view to providing an update on their feasibility by February 2021.

Steering Group Membership

- Chair of the Group- Fiona Hamill (Government & Policy Manager, Janssen)
- Alison Culpan (Scotland Director, ABPI)
- Analysis and report writing – Graeme Rose (Public Affairs Manager, ABPI)
- Secretariat- Claire Headspeath (Team Co-ordinator, ABPI)
- Bryan Deane (New Medicines and Policy Director, ABPI)
- Dr Sam Patel – (Clinical Lead, NES Digital Services)
- Matt Barclay – (Director of Operations, Community Pharmacy Scotland)
- Irene Oldfather – (Programme Director, The Alliance)

[5] **Scottish Medicines Consortium, SMC User Group Forum Terms of Reference, available at: https://www.scottishmedicines.org.uk/media/5496/smc-ugf-tor-final-october-2020.pdf (accessed October 2020)**

- Colan Mehaffey – (Edinburgh University, COO for the Health & Social Care Sector of the DDI Programme)
- Stuart McTaggart – (Principle Pharmacist, Public Health Scotland)
- Dr Steven Burke- (Associate Director, Site Collaborations, PPD)

Appendix:

Summary of Stakeholder Survey

Attached below are the key findings from the stakeholder survey. The composition of respondents is as follows:

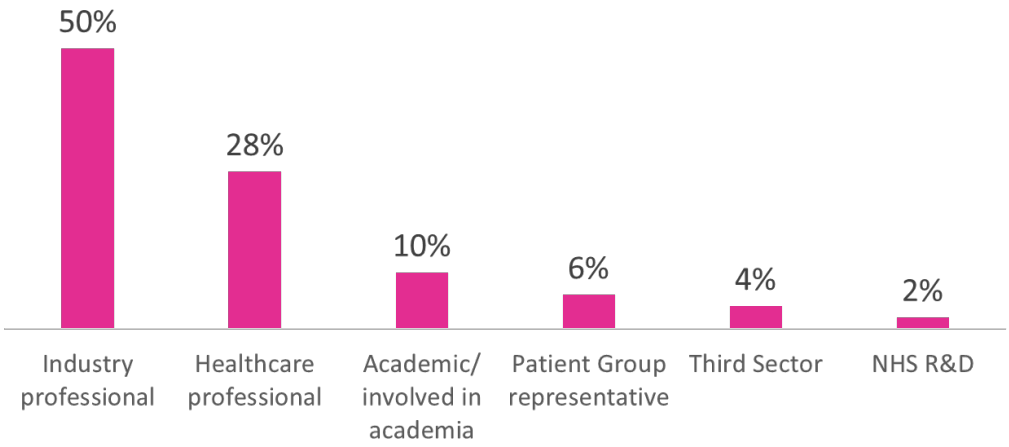


Figure 2. Analysis of survey respondents

When asked to rate how well Scotland was performing in this field only 1 in 5 of respondents think Scotland is a leader in use of healthcare data in comparison with other countries.

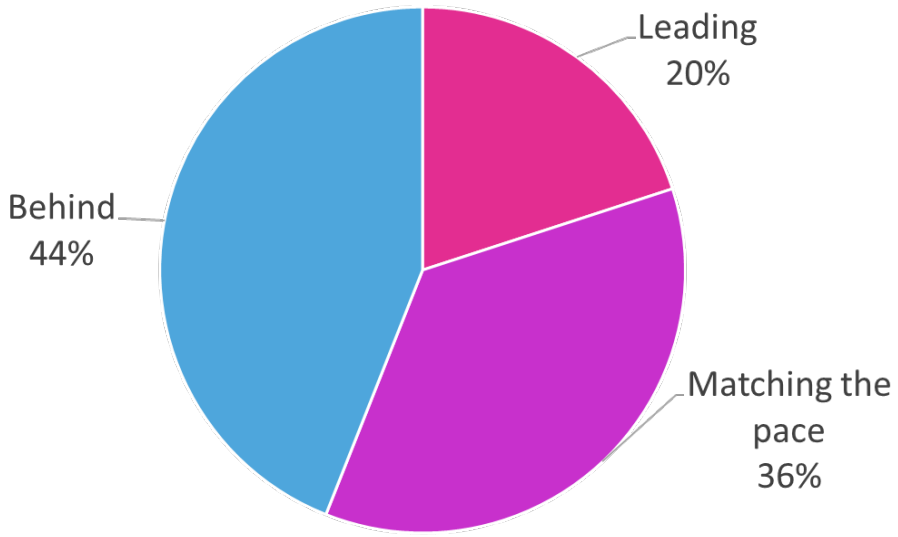


Figure 3. Scotland performance

A plank of this work has been to understand awareness of the recommendations from the Data Scoping Taskforce report. According to the survey 1 in 5 are not aware of the report and less than 1 in 10 know a lot about it. Of the respondents, industry professionals have the highest awareness levels.

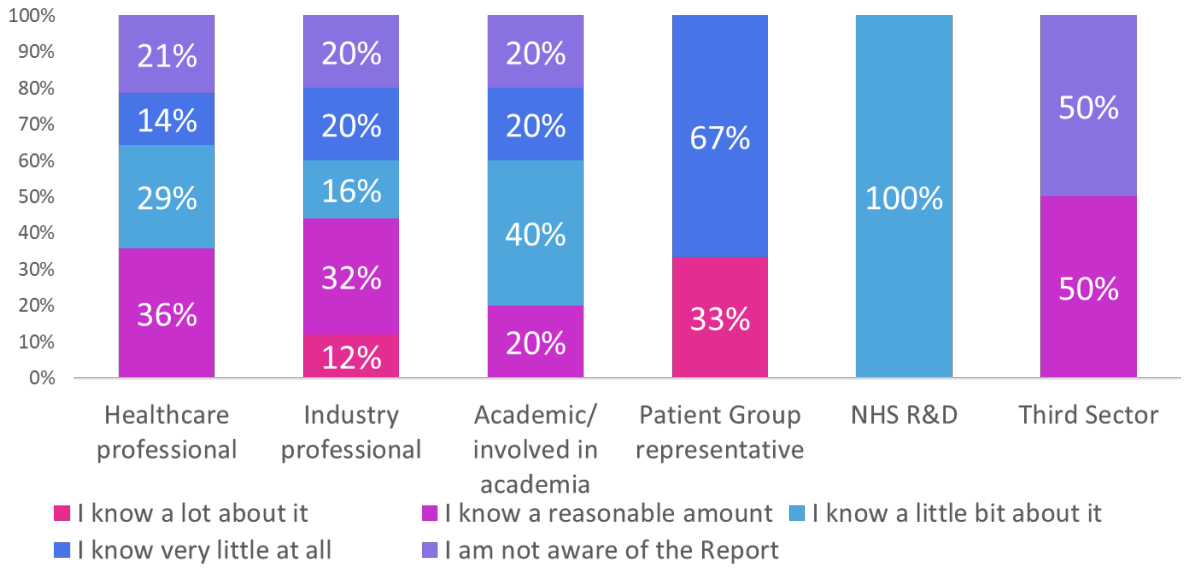


Figure 4. Awareness of Data Scoping Taskforce Report.

However, when asked to rank in order the recommendations from the report respondents overwhelmingly chose “improving recording of patient outcomes”. It is never placed last in anyone’s priority order, and three clear priorities emerged from the five recommendations.

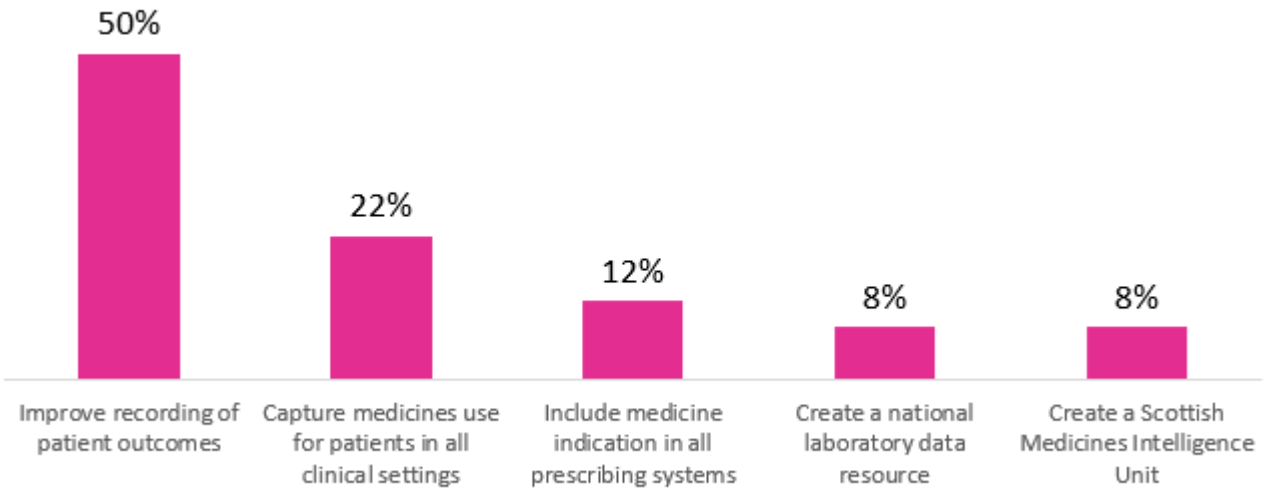


Figure 5. Data Scoping Taskforce priorities.

Nearly every respondent agreed that better data collection/use will improve care and outcomes for patients. Guiding this thinking was that it will drive a better understanding of medicine / interventions/outcomes which will in turn foster better research and more personalised treatments for patients.

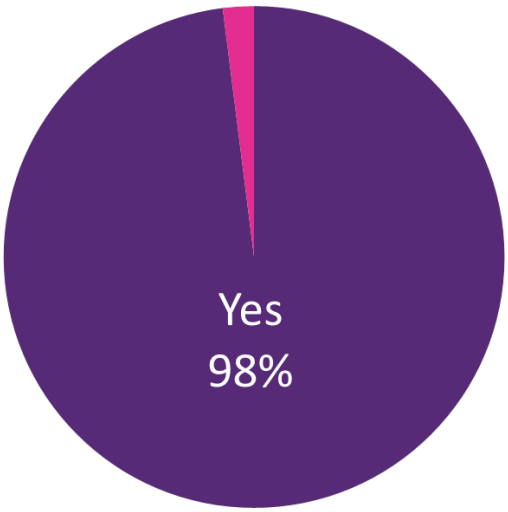


Figure 6. Importance of collecting/using data.

When asked to identify the most significant barrier to the NHS curating and using data more seamlessly from a list of five, two key barriers are most frequently cited, these are leadership (selected by more than 1 in 3) and quality of digital infrastructure, (selected by 1 in 4).

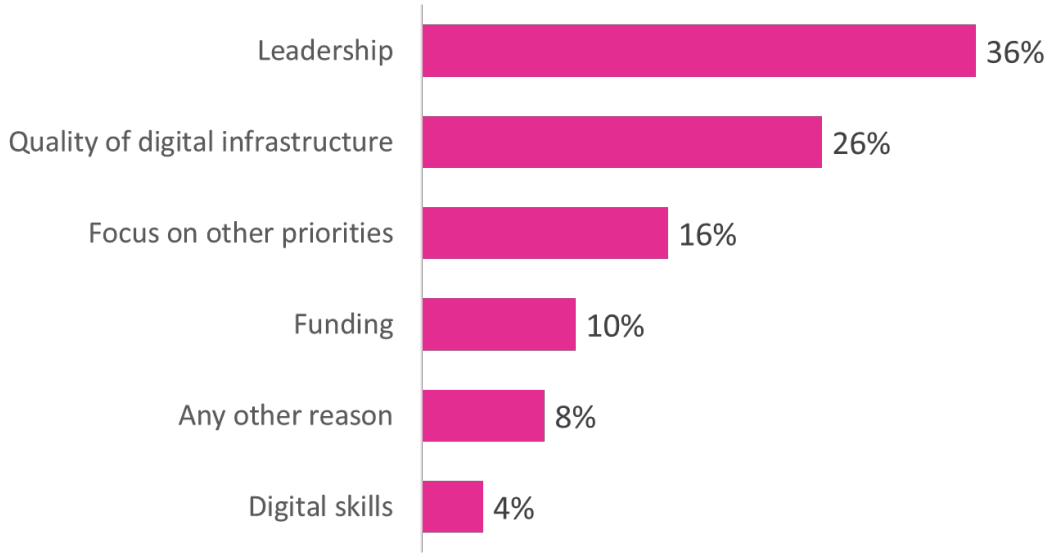


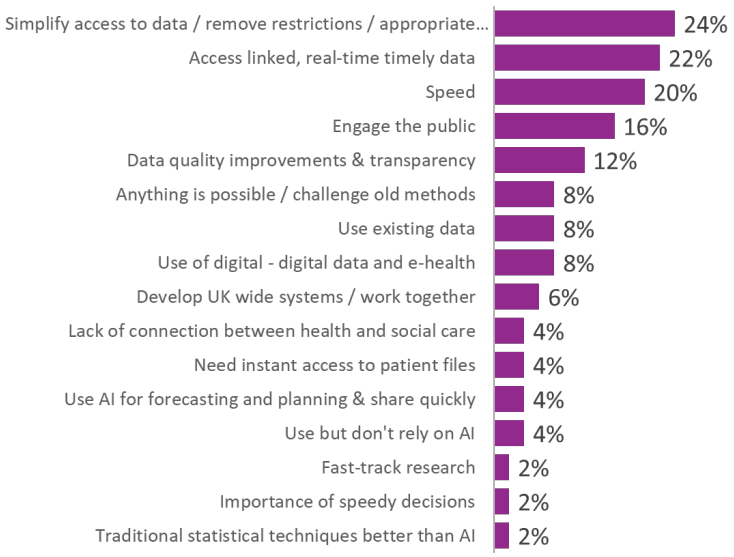
Figure 7. Barriers to data collection and use.

When asked 'What lessons can be taken from the current COVID-19 pandemic on the practical use of data and Artificial Intelligence in healthcare?' three main reply groupings emerged:

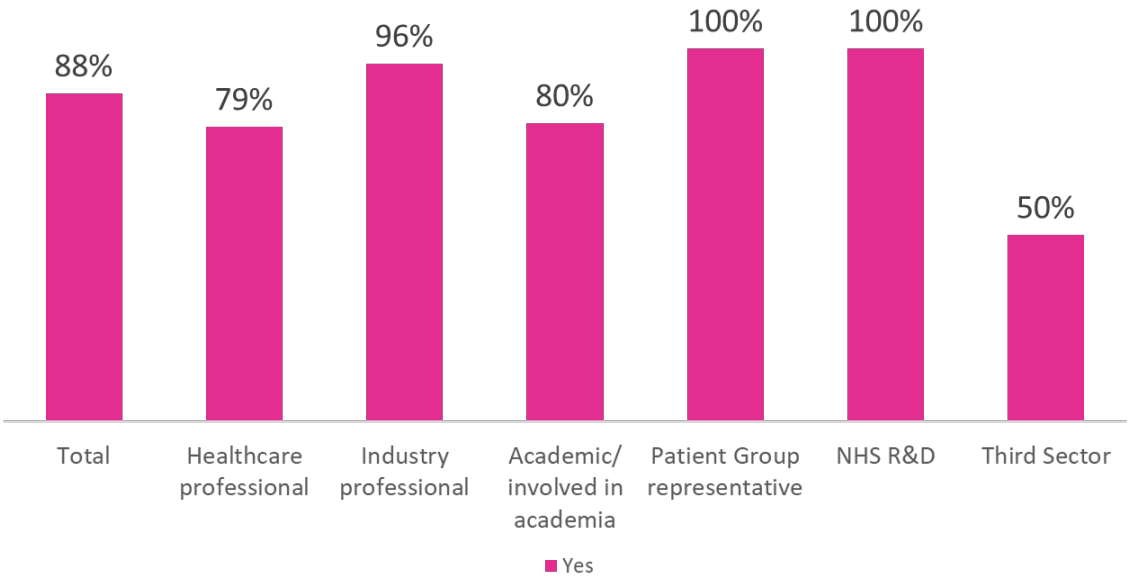
- Simplifying data access
- Real-time access to linked data
- Speed

A regrouping of the replies identifies five themes:

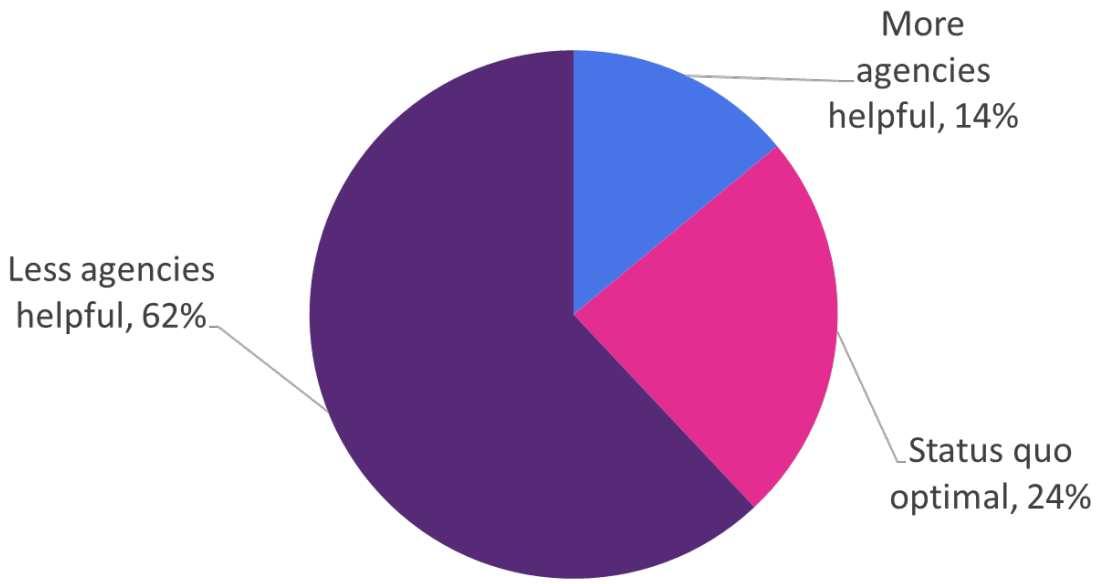
- Access to data
- System changes
- Speed
- Engagement
- Artificial Intelligence



Nearly 9 out of 10 think developing good quality healthcare data can positively contribute to Scotland's economic recovery. Attached in the graph below is a breakdown of this by respondent type.

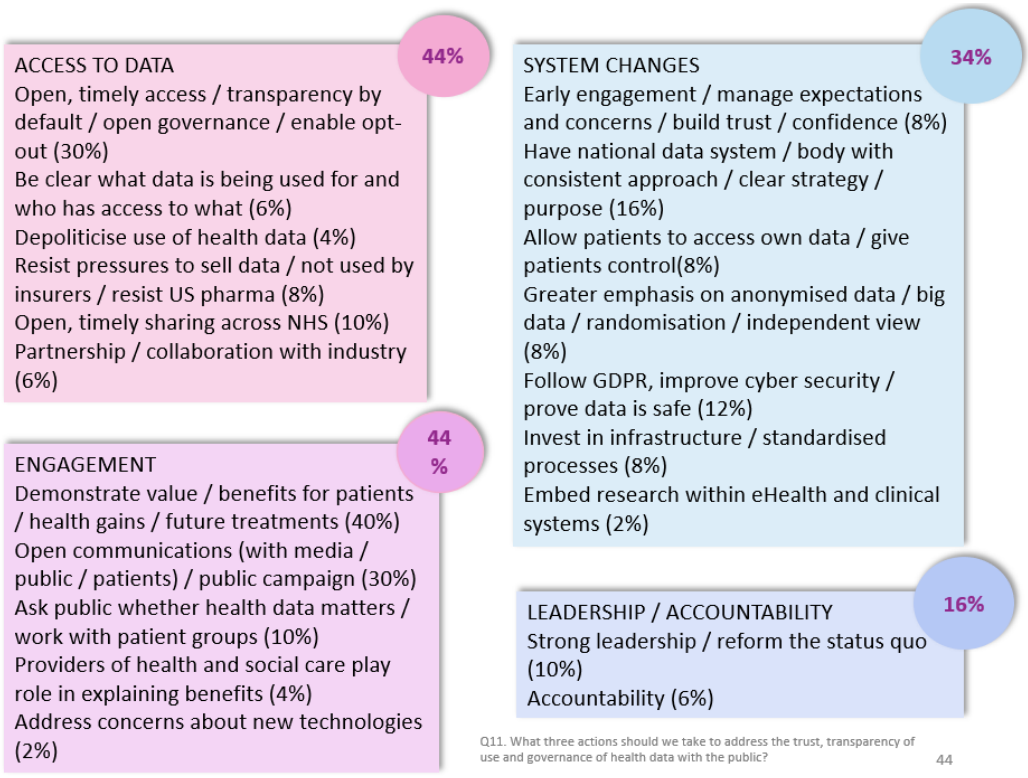


When asked their view on how many agencies should be involved in transforming the use of healthcare data, a little over three-fifths think that having less agencies involved in transforming healthcare would be helpful.



And finally, when asked about engendering greater patient trust in the use of healthcare data Seven out of ten respondents indicated up to three actions to address the trust, transparency of use and governance of health data with the public. The three most frequent replies are:

- To demonstrate value / benefits for patients
- Have open communications with the public
- Give open, timely access to data.


44%
ACCESS TO DATA
Open, timely access / transparency by default / open governance / enable opt-out (30%)
Be clear what data is being used for and who has access to what (6%)
Depoliticise use of health data (4%)
Resist pressures to sell data / not used by insurers / resist US pharma (8%)
Open, timely sharing across NHS (10%)
Partnership / collaboration with industry (6%)
34%
SYSTEM CHANGES
Early engagement / manage expectations and concerns / build trust / confidence (8%)
Have national data system / body with consistent approach / clear strategy / purpose (16%)
Allow patients to access own data / give patients control(8%)
Greater emphasis on anonymised data / big data / randomisation / independent view (8%)
Follow GDPR, improve cyber security / prove data is safe (12%)
Invest in infrastructure / standardised processes (8%)
Embed research within eHealth and clinical systems (2%)
44 %
ENGAGEMENT
Demonstrate value / benefits for patients / health gains / future treatments (40%)
Open communications (with media / public / patients) / public campaign (30%)
Ask public whether health data matters / work with patient groups (10%)
Providers of health and social care play role in explaining benefits (4%)
Address concerns about new technologies (2%)
16%
LEADERSHIP / ACCOUNTABILITY
Strong leadership / reform the status quo (10%)
Accountability (6%)
Q11. What three actions should we take to address the trust, transparency of use and governance of health data with the public?
44