



Digital Health  
& Care Scotland



# DIGITAL HEALTH & CARE IN SCOTLAND

REPORT OF THE EXTERNAL EXPERT PANEL



**Healthier  
Scotland**  
Scottish  
Government

## Foreword - Professor David W Bates MD MSc, Chair, External Expert Panel



At the invitation of the Cabinet Secretary for Health and Sport, Shona Robison MSP, an external, independent panel of UK and international experts was asked to advise the Scottish Government on how digital technology can support Scotland's aim for high quality health and social care services with a particular focus on prevention, early intervention and supported self-management. This is a timely request as Scotland has an opportunity to emerge as a global leader in using digital technology to improve health and social care delivery and outcomes.

Scotland has many advantages. It is an international leader in the policy drive to integrate health and social care, built around a single strategic 2020 Vision of shifting the balance of care from the acute to the community sector. Its size is sufficiently manageable yet large enough to demonstrate impact, and its leadership is suitably enlightened such that it is possible to reach cross-sectoral consensus in the national interest. A number of successes have been achieved in specific areas, including using technology enabled care (TEC) in prevention and early intervention (for example, in the management of hypertension); having a single patient identifier across health (the Community Health Index (CHI) number); the establishment of the Scottish Wide Area Network (SWAN) single broadband; the NHS National Services Scotland (NSS) Data Warehouse; and the Picture Archiving and Communications System (PACS) national radiology network. Also noteworthy is Scotland's evaluation of the impact of the smoking ban in public places, which has demonstrated to the world the considerable potential of interrogating routine national datasets to evaluate national public health policy decisions.

If Scotland is to become a true 'learning health and care system', digital technology and data science will be a key piece of the infrastructure. There are a number of places where progress is needed. For example, citizens do not routinely have online access to personal health and care records (PHCRs), and they cannot routinely make appointments electronically. While electronic health records (EHRs) are used in general practice, levels of adoption of EHRs in hospitals is patchy, and too many processes remain paper-based. In general practice, much of the technology is too old, and not all practices have high-speed internet connections. Practitioners need to use multiple systems to do their day-to-day work, which slows them unnecessarily and is frustrating, particularly where single sign-on is unavailable. Social care providers are generally not yet digitally connected. Social care users generally do not have access to personal records, and there is limited interoperability between electronic records from different providers or authorities. Despite the size of Scotland, significant local variation in the application of individual systems persists, with only a limited number of national applications. While the cloud is used for centralised hosting of national applications joined up by a common broadband network (SWAN) where that is available, it is not routinely used to house electronic data. Ensuring that the technical infrastructures in health and care provide robust security protection of information is a real and recognised challenge as we move towards greater use of digital and outward facing systems, for example with citizen portals and mobile apps.

We make a series of recommendations in this report regarding how Scotland can strategically move forward. In doing so, we build on working examples from other parts of the world that we believe can and should be considered for implementation in Scotland. These are described in detail later, but some of our key recommendations are to offer every citizen a personal health and care record, and to make it easier to carry out tasks like making appointments with any part of the 'system', which today is unnecessarily onerous. EHRs which work well should be the norm in primary, community and hospital services. Social care needs to be completely integrated into this and brought into the core digital exchange. To enable this broad data exchange, it will be critical to have a framework including nationally agreed standards. High-speed connections and use of the cloud will be critical. Issues of upgrades and security will need to be addressed. What is clear is that any effective strategy needs to be couched in terms of transforming services rather than digitising services, and needs to look beyond existing services provided by the NHS and by social care for answers.

### **So how might things work? Here is one example:**

*Isla MacCarthy is a 67 year-old woman with hypertension and diabetes. She lives alone with little family support but has a strong social network in her community. She has been managing her conditions together with her general practitioner (GP), and regularly checks her blood pressure and blood sugars. She has recently changed her diet and lost weight, and both of these have been much better than they were, in part because she has been tracking them through her PHCR, following suggestions she has received through her PHCR, and the home monitoring she carries out. Today, she has had a bad cold and has found that her blood pressure is much higher than it was the day before. Data from her monitors are regularly, automatically transmitted to her GP medical record. Instead of calling her general practice, she sends a text to her health coach at the practice, and quickly gets a call back; her coach finds out that she is taking a new over-the-counter cold medicine which likely caused the spike in her blood pressure. She stops it and instead of spending the afternoon waiting at the doctor's surgery, is able to go to pick up her grandchild after school. When her GP prescribes medications for her, the choice is guided by decision support related to her genome—which she has had sequenced—as well as her clinical characteristics. Her record is housed in the cloud and data exchange across providers and Health Boards has become the norm, which means that no matter whether she sees a specialist in Aberdeen or Glasgow, it will be available to them. She is also delighted to be participating in a Scotland-wide study of hypertension, and regularly communicates with a network of other patients with similar conditions which give her ideas about how to manage her diet among many other issues.*

In this document, we make a series of recommendations that will enable Scotland to achieve this vision, along with many other advances.

## Executive Summary

The goal of this report is to enable Scotland to capitalise on major developments in digital technology and data science to improve the health and social well-being of the Scottish population. We also seek to position Scotland as a world leader in digitally enabled health and care.

This will involve many categories and dimensions of health, including mental, physical, and social health to name a few. Scotland is already an international leader in patient safety and in technology enabled care (TEC), but our hope is that by following these recommendations it can also become an international leader in digital health and social care more broadly, in delivery of care and in service transformation among many other areas. This will involve health and social care and also public health.

In this report, we present seven key themes:

1. Supporting citizen engagement
2. Digital maturity
3. Leadership and workforce
4. Standards and interoperability
5. Resources and information governance
6. Technology enabled health and care, and
7. Digital innovation and research.

These can be mapped to four meta-themes, which are:

1. Infrastructure (citizen engagement and technology enabled health and care)
2. People and workforce (leadership and workforce)
3. Governance (digital maturity, standards and interoperability, resources and information governance), and
4. Research and innovation.

Within each we present the context, rationale and principles, specific recommendations, and external experience from other countries. We also present key milestones that we believe can be reached within a year, and also others which we think can be reached within three to five years.

We believe achieving these goals will be foundational in terms of Scotland's ability to realise the triple aim, i.e. 'the simultaneous pursuit of improving the citizen experience of care, improving the health and social care of populations, and reducing the per capita cost of health and social care' as well as becoming an international leader in digital health and care.

## **Introduction**

### **Rationale for the establishment of the External Expert Panel**

The External Expert Panel (The Panel) was set up to play a key role in advising the Scottish Government and the Strategic Oversight Group for the development of the Scottish Digital Health and Care Strategy (The Strategy) on how digital technology can support Scotland's aim for high quality health and social care services that have a focus on prevention, early intervention, and supported self-management. The purpose of The Panel was to help ensure that a broad evidence base and expert opinion was taken into account in the development of The Strategy. In particular, The Panel was asked to provide a national and international perspective on the types of digital infrastructure and capability Scotland will need in order to realise its ambition to transform services and support the creation of a national learning health and care system. This included advising on how culture, leadership and skills in the health and care sectors in Scotland might be developed in order to leverage digital technology and data science to transform care experiences and outcomes.

Leaders from the United States (US) and Europe, including England, Northern Ireland and Spain (including the Basque Country and Catalonia) were sought to participate because of the progress they have already made in this area.

The following criteria were used when identifying Panel members:

- Internationally renowned and recognised in their field.
- From both the UK and overseas.
- From across a breadth of backgrounds in health and social care.
- Ability to provide insight and experience from across a range of sectors, including government, care services, academia, industry, third sector and service users.
- Well-networked and connected with other sources of relevant knowledge and expertise.
- Ensuring a gender balance.
- Ability to act as a constructive, critical friend to Scotland.

### **Panel engagement process**

The Panel met eight times between May 2017 and March 2018. Each meeting was carried out by videoconference. All meetings were chaired by Professor David Bates and supported by a secretariat appointed by the Scottish Government. At the first meeting, a prioritisation exercise was carried out to determine which topics would be covered by The Panel in detail before the interim report was produced in September 2017. For each meeting, papers were prepared by topic experts from the Scottish Government. These papers covered the current landscape in Scotland, and asked key questions of The Panel to assist in the development of the Strategy. After each Panel meeting, the key feedback from The Panel was relayed to the Scottish Digital Health and Care Strategic Oversight Panel for further discussion.

Following the production of the interim report and the stakeholder feedback session in September 2017, the final four meetings were devoted to honing the recommendations in light of the stakeholder feedback received, to produce the final report.

In June 2017, The Panel's chair, Professor David Bates, visited the Scottish Government to plan the work of The Panel in more detail. Meetings were held to discuss priorities for health and social care with both Shona Robison MSP, the Cabinet Secretary for Health and Sport, and with Paul Gray, Director General for Health and Social Care at the Scottish Government and Chief Executive of the NHS in Scotland. Professor Bates also made visits to a general practitioner within a Healthy Living Centre in Edinburgh and to the Royal Hospital for Sick Children in Edinburgh to see first-hand the use of different types of electronic records, and to get first-hand accounts of the priorities of clinicians. Finally, a presentation was given to key Scottish Government stakeholders (including leaders from local authorities and health boards) including examples of key international successes and opportunities for digital technologies in health and care.

The entire Panel was invited to a two day face-to-face meeting in Edinburgh in September 2017 to discuss the interim report amongst the Panel themselves, and also with the Cabinet Secretary for Health and Sport, senior leads from the Scottish Government, The Convention of Scottish Local Authorities (COSLA) the Scottish Local Government Digital Office, and with a wider group of stakeholders drawn from Scottish territorial and special Health Boards, Integration Joint Boards (IJBs), academia, patient groups, the third sector, housing associations, social work, and eHealth clinical leads. To ensure that participants had the opportunity to engage with the interim report, and to be able to influence the Panel's final report, five external stakeholder groups were set up and run twice over one day. Participants in the stakeholder groups were given the opportunity to feed back on the overall interim recommendations and then to focus on a facilitated discussion in one of the following domains:

1. Self-management
2. Infrastructure and architecture
3. Data analytics and service planning
4. Integrated service delivery, and
5. Scaling-up.

The Panel is willing to reconvene in approximately three years' time to assess progress against the recommendations, if that would be helpful to the Scottish Government.

### **Key opportunities for Scotland**

The Panel strongly believes that investment in this area will help the Scottish Government's stated goals, including better, less expensive health and social care, economic development, and will result in both value to people and value to care.

With the right strategy in place, and with the right implementation plan, the Panel's view of Digital Health and Care in five years' time looks like this:

1. For every Scottish citizen to have access to an online personal health and care record (PHCR) including electronic scheduling with health and care services, to have the right information on who they need to communicate with in relation to their health and social care needs, and to know where their data are going and how their data are being used.
2. For health and social care professionals to be able to access the data they need, when they need it, wherever they are; this will be achieved by an increase in digital maturity which allows data to be retrieved, in real or near-real time, from disparate providers.
3. Dedicated leadership including a Chief Clinical Information Officer (CCIO) and Chief Technology Officer (CTO) who, alongside the Scottish Government Digital Director and the Local Government Chief Digital Officer can promote and lead the digital health and care agenda. There is also the need for informatics and data science training for local chief information officers and health and social care staff to be available more broadly.
4. Single standards for all key domains of data, and a health and care data summary, as well as a move towards cloud-based approaches to facilitate broad exchange of health and care data. A 'Once for Scotland' approach being used to deliver health and social care, including a 'One Platform' agenda for a citizen-facing services platform, which is underpinned by a common approach to data integration and data sharing.
5. A Scottish-wide, national, consistent approach to Information Governance in which central and local government work together with the NHS to ensure that data can be accessed from and by health and social care providers, and that information can be provided to citizens, clients and their carers, and be used safely for the benefit of all Scottish citizens. This would be supported by a single national Open Platform which should use modern approaches such as support for open application programme interfaces (APIs), which will in turn enable integration of applications.
6. Evidence-based technology enabled care (TEC) should be more broadly implemented across Scotland, including a focus on digital products, information and services to help citizens' connections to public services and infrastructure and to support early intervention and self-management of health and well-being, with initial use cases including urgent care and management of common chronic conditions such as diabetes and hypertension.
7. The availability of a Scotland-wide data infrastructure to enable innovation, research and public health, and structured support for three to five digital innovation centres building on existing foundations.

## Recommendations

### Supporting Citizen Engagement

#### Context

Currently in Scotland, citizens can access their health data through condition-specific portals such as My Diabetes My Way and Renal Patient View. However, there is no widespread comprehensive access for citizens to their records in primary, community and secondary care or in social care. Communication with health and social care providers is not routinely facilitated digitally, which in general practice can lead to lengthy waits for access to reception staff to make appointments. To remedy this, the Scottish Government has already committed to producing a Health and Care citizen facing portal by 2020. This will give citizens and their carers access to a summary view of their own health and care data as well as the ability to contribute information to it. Enhancing this technical capability will lead to better citizen engagement in health and social care, facilitating follow-up from visits, uptake of services, reducing citizen uncertainty and enabling citizens and their health and care providers to have a clearer, shared understanding of their current status and their health and social care goals. Work is currently being carried out to design this portal with key features including the ability for two-way communication, as well as mechanisms for both electronic authentication and for consent management.

#### Rationale and Principles

Citizens who are more engaged in their care are generally happier, and have better outcomes <sup>(1)</sup>. A key foundation in enabling this is making access to their health and social information easily available online. Personal health and care records have been very positively received in many other countries <sup>(2)</sup>.

Principles include that:

- The personal health and care record (PHCR) should include functions that citizens find most valuable, such as making an appointment, requesting a repeat prescription, asking a question, and completing an assessment questionnaire.
- The PHCR should be truly personalised-so that it should eventually include features targeted to the individual and their conditions, such as hypertension or diabetes, to allow for greater self-management.
- Citizen involvement / co-design should be built into the design of all new citizen-facing digital services.



## Recommendations

The Panel recommends that:

- Every Scottish citizen should have a personalised view of their information which they can contribute to through a Personal Health Record (PHR) by 2020. The PHR should include access to laboratory tests, medical notes and care plans among other types of information with advice for the citizen on how to interpret these data. It should, in time, include both read and write access for citizens. The PHR should also allow citizens to upload data from vetted 'apps' from digital devices which can link into core systems used by health and care providers.
- A number of digital functions should be offered to all citizens such as booking appointments online and repeat prescribing, which are particularly high priorities given the limitations of the current processes.
- This PHR should be 'opt-out', that is, all citizens will be offered the PHR, but those not wishing to use it should be given the opportunity to opt-out.
- A firm commitment should be made to extending the PHR to social care information so that it ultimately becomes the PHCR.

### Exemplars

In Catalonia, La Meva Salut (LMS - which translates as 'My Health') is an online facility which lets all citizens access their health data and online health services securely and confidentially. It aims to promote self-care by improving quality of care and by increasing the co-ordination between different providers and professionals. In addition to giving access to data about diagnoses, clinical reports, test results and prescriptions, the Personal Health Channel also integrates data from mobile apps so that these data provide another resource to support a patient's treatment. In order to do this, apps are approved using an accreditation framework before they can be prescribed by healthcare providers.

In 2009, the Basque Government launched a health and digital transformation strategy within a new policy on chronic care. Since then, patients and families from the Basque Region (2.2 million) have access to their personal health records, can book appointments online, and electronic prescriptions can be renewed without a return visit to the GP. This is all implemented in the context of an EHR which is shared between hospitals and primary care.

Since 2015, Minhelse, has provided a Personal Health Record for citizens in Norway. This online system allows citizens to access their health data, information about appointments, referrals, prescriptions as well as tools to allow communication with caregivers.

In the US, Kaiser Permanente's My Health Manager allows registered patients to view their own health records and those of any dependents, to manage their appointments, to see laboratory results over time, to order new prescriptions and to email caregivers with non-urgent queries.

In Northeastern US, Partners Healthcare is a large integrated delivery system which offers a personal health record to all patients called 'Patient Gateway'. This record includes the patient's laboratory results, appointments, medications, and notes and gives patients the facility to ask questions, request medication refills, request appointments, and request

referrals. Over 600,000 patients are now enrolled in the Patient Gateway. While clinicians were initially worried that they would be bombarded with questions, this has not been the case. Indeed, in most practices, approximately 70% of questions can be dealt with by someone other than a doctor, but doctors can also be contacted when necessary. In terms of the 'digital divide', patients with low income and African American and Hispanic people were less likely to sign up, but after they signed up were as likely to use the patient portal, suggesting that a key factor is to get patients over the initial hurdle of signing up <sup>(3)</sup>.

## Digital Maturity

### Context

A survey of the technical infrastructure across NHS Scotland carried out in 2017 identified a pressing need for upgrade and additional investment. While there are national infrastructure upgrades in progress (for example, SWAN, GP IT), the availability of funding is a major barrier to increasing pace. Some parts of Scotland have limited connectivity, and many health and care settings are still without Wi-Fi. The plans to replace the current separate GP IT systems with the next generation of cloud-based software has identified a fundamental requirement to increase the speed and resilience of network connectivity to all GP practices. Furthermore, NHS Scotland has a wide range of legacy clinical applications, numbering in the mid-hundreds in every Health Board. Although NHS Scotland emerged relatively unscathed from the recent global WannaCry cyber security incident, this highlighted vulnerabilities that must be addressed and a need for increased focus on this growing area of risk. Within the social care setting, the formal statutory bodies have reasonably mature record management systems in place, but many of these tend to work in isolation from each other. Similarly, some third sector organisations (who, along with independent care organisations, provide more than 50% of all social care) use relatively sophisticated digital systems for direct service delivery, but these systems are all specific to each service provider. While 80% of people over the age of 65 in receipt of formal social care services use telecare to support their independence at home, there is a wide variability in both the maturity of telecare enabled pathways and their deployment into mainstream health and care services <sup>(4)</sup>.

A commitment to assessing the current levels of digital maturity has already been agreed by the Scottish Government with the aim of identifying opportunities for improvement and with support for making those improvements. This is complemented by work by [The Local Government Digital Office](#) which has also started assessing the digital maturity of local government and work by the Scottish Council for Voluntary Organisations (SCVO), which is supporting the development of digital across the entire third sector

## Rationale and Principles

Digital maturity is absolutely foundational for making progress. Both hardware and software need to be up to date to meet the time pressures associated with clinical care delivery. Wi-Fi is also foundational in clinical settings as is high-speed network connectivity. This is an area in which a "Once for Scotland" approach can help make sure that 'all the boats rise', as there has been too much variation at the Board level. In the future, citizen and professional surveys regarding issues around digital maturity, privacy and security might be valuable in guiding policy.

Principles include that:

- There need to be minimum standards in a variety of areas, including hardware, software, Wi-Fi and internet connectivity.
- The minimum standards need to be enforced; exceptions should not be allowed except in extreme circumstances.
- Recommendations should be forward-looking so they can support upcoming changes, such as the move to a cloud-based architecture.

## **Recommendations**

The Panel recommends that:

- All primary, community and hospital services and social care should offer access to all relevant services online (appointment booking, online information about services, and remote / virtual access to some services), with the first three being online by 2022.
- High speed connectivity to all service providers should be an investment priority.
- National minimum standards regarding upgrades should be put in place so that Boards do not lag behind.
- A periodic assessment of digital maturity (including reach, as well as availability of digital) using a single tool is carried out across all health and social care providers, including an independent assessment of whether improvements are being carried out.

## **Exemplars**

In the US, as a condition for receiving incentive payments for the adoption of EHRs under the 2009 HITECH Act, health professionals and hospitals had to demonstrate compliance with 'Meaningful use' requirements. They also had to use records that were certified by the federal government as capable of supporting those requirements. The intent was to increase the likelihood that patients and the healthcare system would realise value from the installation of EHRs. Recognising the challenge of acquiring, installing and mastering electronic health records, the Meaningful use program created three stages of performance with which users had to comply over time in order to continue to receive incentive payments - and later, to avoid financial penalties. The first stage of Meaningful use requirements emphasised the entry of data viewed as critical to patient care and quality measurement. Later stages were intended to be more demanding, and included providing electronic access for patients to their records, the use of decision support and some participation in health information exchange. Ultimately, the goal in Stage Three of Meaningful use was to ask users to demonstrate that they were employing electronic records to improve patient outcomes. Professionals and hospitals were responsible for collecting the data necessary to proving compliance with Meaningful use requirements, and were subject to audit to assure the accuracy of their attestations. This has resulted in widespread adoption of electronic records in both primary and secondary care. So far, it has been less successful with respect to interoperability, and quality has improved only modestly, although it is still early.

NHS England has developed online, self-assessment tools that are completed by individual organisations on a regular basis, to assess their digital maturity. These look at local readiness, infrastructure and capability availability and are used to provide a regular view as to progress being made in the uptake and utilisation of digital tools to support service transformation and delivery. They provide an ongoing measure of maturity that can be used locally to identify key strengths and gaps in the provision of digital services as well as providing insight into how well the country is progressing as a whole. Additionally, there is a more focussed tool that looks at the maturity of ePrescribing and Medicines Administration (EPMA) that is supporting work to optimise and develop system functionality.

## Leadership and Workforce

### Context

In terms of leadership, while a geographically representative group of clinicians across Scotland with a particular role in eHealth delivery currently exists, the group has not always been able to position itself at the forefront of digital health and care developments, and Board level commitment to the roles vary. Moreover, priorities and investments around data have historically been aligned to specific policy interests – often driven by management data needs, rather than taking a strategic system-wide approach. A Local Government Digital Office has been established in Scotland since 2016 with national leadership provided by a Chief Digital Officer and a Chief Technology Officer in relation to all aspects of local government, including social care.

There is now a need to develop a health and care leadership model which can drive forward the transformation and integration of services, support innovation and champion the use of digital and data to improve decision making and service provision at a strategic and local level.

A 2014 [survey](#) <sup>(5)</sup> found a need to develop digital capabilities for all staff in health and social care. These range from basic skills in accessing information online and use systems, through to advanced skills in using, sharing and exploiting digital knowledge and information to support person-centred care and self-management.

### Rationale and Principles

Strong leadership and increasing the skill of the workforce will also be central to success. Countries which have made major progress in this area generally have a single individual as a leader, and this has been a high-level appointment in government. They generally need a team which can enable them to address the key areas. In addition, the workforce needs to be trained. This should address the training of IT leaders, but also of many individuals within the workforce, including those within Boards, IJBs and local authorities who are responsible for IT but also for clinical care, and this type of training is needed in all the major disciplines across health and social care. Much, but not all, of this training can be virtual. This effort can also leverage other developments, such as the NSS Digital Transformation Programme, and the identification of the Fellows of the [Faculty of Clinical Informatics](#), a new group which is drawn from across the UK, many of whom have substantial expertise which can be tapped.

Principles include that:

- Investment will be needed in digital transformation leadership across all levels within all organisations.
- Investment will also be needed to ensure that training about digital care is included for all types of health and care provider both as part of their initial studies, and their ongoing professional development.

## Recommendations

The Panel recommends that:

- A Chief Clinical Information Officer (CCIO) should be employed at a national level, to report to the Health and Social Care Management Board within the Scottish Government and to work closely with the Scottish Government's Chief Information Officer and the Local Government Chief Digital Officer. The CCIO should be a clinician and should have sufficient authority and resources to be successful in this role.
- A Chief Technology Officer (CTO), who would work closely with the CCIO, should also be employed at the national level.
- Chief Clinical Information Officers should be employed in clinical and social care domains across Scotland, including within Health and Social Care Partnerships.
- A programme of digital training should be implemented for those who would benefit from it, across all clinical and social care domains, across information technology professionals and data scientists at all skill levels. There should be mandatory training for all current and future health and social care professionals as a core part of workforce development.
- The CCIO should convene a citizens' panel to ensure that decisions are fully informed by the citizen view.

## **Exemplars**

Before the Bush administration, there was no central coordination of health IT in the US. This had many downsides: there was no agreement about standards for the key types of clinical data, adoption levels were low, data exchange did not occur except within organisations, and there was no agreement about what should be included in the clinical record, to name a few. The US has now had several national co-ordinators, and this area has been remarkably non-partisan: both major parties agree that health IT adoption is needed, that costs need to be reduced and care improved, and that health IT will be a key tool for achieving this. Under the leadership of the national coordinators, many clear-cut milestones have been achieved; among these are that there is a single standard for all the main types of clinical data, there are minimum criteria regarding what functionality all EHRs need to include and records need to be certified according to these criteria, adoption levels for EHRs have risen to 80-90% in both the inpatient and outpatient settings from levels of around 20%, electronic prescribing is routine in both the inpatient and outpatient settings, bar-coding of medicines is routine for inpatients, and there is a standard for data exchange called the continuity of care document (CCD) among providers, among others. Much remains to be done, but the national coordinators have played a key role in advancing progress.

NHS England has recently commissioned the NHS Digital Academy to develop a training and development programme to support, nurture and develop current leaders (Chief Clinical Information Officers and Chief Information Officers) as well as aspiring digital leaders who want to develop a career in informatics and executive change management. It is intended that in the long term, this programme will generate a network of leaders who will share best practice and intelligence in the longer term. The programme is being delivered by a partnership between Imperial College London, The University of Edinburgh and Harvard Medical School and has accepted its first participants, including digital leaders from Scotland, in the spring of 2018.

Work to build a digital ready workforce, including a focus on digital literacy; covering safety, wellbeing, security and identity is being developed by [NHS Health Education England](#).

## Standards and Interoperability

### Context

Scotland currently uses a small number of interoperable systems such as GP2GP, which transfers patients' medical records from one general practice to the next when a person changes GP, Scottish Care Information-Diabetes (SCI-Diabetes), which is a single shared patient record for people with diabetes, and Scottish Care Information Gateway (SCI Gateway), which handles all GP referrals. In addition, the national integration engine, Ensemble, is extensively used both locally and nationally for moving data between systems. However, while examples of both interoperability and support for working to standards exist, there are still challenges to their successful implementation.

Currently, national programmes each have their own Technical Design Authorities which have representation from NHS Boards and Scottish Government. There are a number of national governance and advisory bodies which provide strategic and technical expertise. The number of bodies, and their differing remits, compromises the ability for Scotland to have a truly country-wide strategic approach to digital integration for the future.

While some Scottish standards such as the national Clinical Document Naming and Indexing Standards and the Medications standard have been adopted at UK level and while Scotland is represented on the UK Professional Records Standards Body (PRSB), the continued use of Scottish standards does not enable it to drive the market or get the best deal from suppliers.

### Rationale and Principles

Standards are absolutely central to progress; without a single standard for the main types of clinical data, it will not be possible to achieve widespread exchange of clinical information which has many clinical benefits. Standards are not sufficient to ensure that interoperability will occur, but they are necessary. Another approach which can be useful in getting to data exchange is conformance testing, which is a type of evaluation in which messages are tested to ensure that they can be read; this complements standards, and is a helpful adjunct.

Principles include that:

- Guidance should be provided around the adoption of standards and evaluation of their use (linked to the digital maturity assessment) needs to be carried out.
- The adoption of standards should be guided from a national perspective, but allowing local discretion in order to get buy-in about what is happening at national level where that is appropriate.
- Standards should be open and international (or at least UK) level by default – when bespoke Scottish standards are considered they should be designed in such a way that they could become international.



## Recommendations

The Panel recommends that:

- An overarching national Design Authority be set up with a mandate to make architecture decisions for the whole service and enforce adherence, under the control of the CCIO alongside the Scottish Government's Chief Information Officer and the Local Government Chief Digital Officer for Scotland, which will promote efficiency throughout the health service.
- Standards should be adopted for technical infrastructure (including upgrades), which are pivotal for ensuring security and managing confidentiality.
- Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT), which is a systematic collection of medical terms, should be adopted for all key domains of clinical data, with the PRSB to be invited to develop a clinical summary standard which would be applicable in Scotland.
- Investment is made to ensure effective and efficient data exchange between primary, community and hospital services and social care, and across Scotland.
- Digital services (for example, integrated shared care records and data for population health management) should be provided within a secure International Organization for Standardization (ISO) compliant cloud.
- An approach to procurement is needed which supports the rationalisation of the management of vendors within a particular niche and supports a move away from bespoke solutions to leverage existing technology from the UK/internationally; this is central if interoperability is to be achieved.
- Clinical and care standards work should be led nationally (for example by National Services Scotland and the Care Inspectorate) and should be aligned with similar efforts in the rest of the UK.

## **Exemplars**

Standards are a key enabler for the secure exchange data among healthcare stakeholders. In the US, The Bush administration created the Health Information Technology Standards Panel in 2005 to select the best available standards and implementation guides to improve quality, safety and efficiency. The structure was a private/public partnership with no specific government mandates or funding. Foundational work was done selecting standards of summary data exchange (the Continuity of Care Document Architecture). In 2009, The Obama administration created the Health Information Technology Standards Committee to harmonise available standards with a special focus on privacy, use of controlled terminology, and patient/family engagement. The Health Information Technology for Economic and Clinical Health (HITECH) Act provided stimulus payments for standards adoption and penalties for lack of interoperability. For a summary of the standards selected, see the healthcare data standards advisory at <https://www.healthit.gov/isa/>.

In Denmark, a not for profit organisation called Medcom (funded by the Danish Ministry of Health service, the Danish Regions and local government), has set and monitored standards for the exchange of healthcare related data between hospitals, GPs, laboratories, and local authority care services etc. Many of these are internationally recognised standards which are adopted at the national level.

NHS England has adopted an Open Application Programming Interface (API) policy to allow for greater integration of systems, including the ability to link new developments with existing legacy systems.

## Information Governance, National Governance and Resources

### Context

Information about citizens is currently gathered and recorded by many systems and care functions. This information exists in different places, is bound by health and care organisational boundaries and most citizens do not have electronic access to any part of it (although some citizens have access to aspects of it through disease-specific portals as described in Section 2.1 above). Despite over 50% of social care being delivered by non-statutory bodies, delivery organisations have little or no access to individual care records, so have to create additional in-house records. There are therefore multiple owners of parts of the information (effectively the data controllers) with no one profession, professional or sector responsible for its overall management. This is compounded by the fact that the information governance landscape in Scotland is complex and involves a number of key decision makers including Caldicott Guardians, Information Governance leads and Senior Information Risk Officers, whose roles overlap significantly. Access to data, whether for clinical, care, administrative or research purposes is therefore challenged by the location of data, the difficulty in moving data between organisations, and the diverse mechanisms for accessing these data. In managing these processes, the citizen's perception of how their information is used, accessed and kept secure is crucial.

### Rationale and Principles

Having a robust information governance structure is of central importance both for achieving transformational change and maintaining citizen trust; this will be especially important for social care, which is, as described above, less advanced than healthcare. Scotland has not had a coherent national approach in this area.

Stronger national governance is also critical. The current approach has led to a great deal of variation across Scotland which creates a number of issues, in particular impeding interoperability and data exchange.

For this effort to achieve the desired ends, a key will be allocating sufficient resources to ensure success. In most information-intensive industries, such as banking, the spend on information technology (IT) is approximately 6-10% of gross revenue. In the US, the average spend on IT within healthcare has been 3-4% of revenues. In England and Scotland, these figures have been much lower, typically around 2%, which is a bare minimum. Some initial spend will be needed at the beginning just to get to basic levels, and then on-going funding beyond the 2% minimum to enable the sector to build from there. Exact decisions should be made in the context of a defined financial plan for the sector which would justify additional spend in terms of value for money.

Principles include that:

- A 'Once for Scotland' approach is taken to develop standards in relation to information governance in order to improve data exchange across health boards, across health and social care and within social care. This sharing has to occur in real time, and cover many types of data.

- The entire sector would benefit from the development of a single national platform, which would support open integration standards.
- Scaling-up good practice can only occur when funding is sustained beyond pilot projects.

## Recommendations

The Panel recommends that:

- The Community Health Index (CHI) Number should be extended for use within social care.
- A national financial plan for IT in health and social care should be developed, and resources should be allocated based on its estimates.
- Adequate resources should be dedicated to this effort. Some initial spending will be required to bring infrastructure up to standards. On an ongoing basis, allocation should be determined and justified based on the financial plan described above. The panel suggests that 2% of gross revenues on an ongoing basis would be a bare minimum as above, it is likely that a higher amount will be needed, probably at least in the 3-4% range.
- A single open platform be implemented by health and social care which utilises open standards such as open APIs.
- A comprehensive approach to data use is made, thereby including data from social care, public health and the third sector and that health data should include data from sensors, robotics and data derived from appropriate data from technology enabled care.
- An extensive public engagement exercise is carried out to inform the public about the plan for moving forward including sharing data across Health Boards and IJB boundaries.

### Exemplar

In **Catalonia**, an Inter-Ministerial Plan for Integrated care (PIAISS) has been set up with a focus on incorporating Information and Communication Technologies (ICT) to fulfil its strategic objectives and guidelines. This has led to the setup of a national governance body which has identified three key areas of interest: 1. exchange between healthcare and specialised social care providers (residential facilities, daily care); 2. exchange between healthcare and the social affairs central repositories (disability and dependency legal assessment); and 3. exchange between healthcare and primary social services provided by local authorities such as social work, home care, and telecare. Work has started on the third area with a project integrating data between healthcare and social care in Barcelona using the EHR (called HC3) as an exchange platform. Citizen identification is via the Unique Personal Health Identification number stored centrally by the Health Authority and used as the first trigger for the data exchange. Health data and social care data are stored in separate servers; healthcare professionals are able to consult social care services information authorized from the Professional Viewfinder and social care professionals are able to access certain information via HC3. Citizens must give consent (and can withdraw that consent) for professionals to view either the health or social care data. Further work is being carried out to improve this system by allowing better collaboration between different health and care providers, and to include safe messaging to improve inter-professional communication.

## Technology-enabling health and care services

### Context

The Scottish TEC Programme has been set up to promote the use of home and mobile health monitoring (HMHM), to expand the take up of telecare, to expand the use of video-consulting, and to create a national digital platform providing digital information and services for citizens. Since the outset of the programme in April 2015, an additional 62,000 people have benefitted from use of TEC. Ten thousand people are now on HMHM from a baseline of 200 people two years ago. This is already demonstrating benefits following the evidence provided by Scottish randomised controlled trials in hypertension <sup>(6)</sup> and diabetes <sup>(7)</sup>, so that HMHM is now being used to help over almost 4,000 people in Lothian. People in Ayrshire and Lanarkshire manage their hypertension at home, and more generally via the application of telecare to allow more people to remain safely at home. While the TEC Programme has demonstrated the contribution of technology to improvements in health and care services, there is now a need to integrate these opportunities in a more effective and sustained way. In order to do this, digital technology now needs to transform the way in which health, housing and social care services are provided, empowering people to self-manage and live more independently thereby reducing demand on services (including pressures on the workforce) and improving outcomes and quality of life. In particular, evidence-based and scalable approaches are needed to be adopted at a national level, so that local health and care systems can focus on using digital technology for upstream prevention, self-management and greater independent living.

### Rationale and Principles

In the future, much more care will be delivered through virtual approaches. This will span a wide range of services, from urgent care, to care and support of citizens with chronic conditions at home, to remote consultation for citizens in small hospitals and care homes, to electronic and virtual management of intensive care unit (ICU) care, to name a few. This should be much more efficient in the long run and is likely to be more convenient for citizens.

Principles include that:

- TEC should involve co-design and development of solutions which support the management and delivery of citizens' own health and wellbeing, with a particular focus on addressing health inequalities;
- TEC should facilitate flexible solutions which expand choice, control, coverage and accessibility;
- TEC should build on existing and familiar technologies, with the adoption of simple, low cost approaches which can be tailored to the individual;
- TEC should support service redesign to integrate new ways of working into mainstream service provision and pathways, including a focus on prevention and anticipatory care.

## Recommendations

The Panel recommends that

- Evidence-based technology enabled health and care (TEC, including telehealth), be more broadly implemented at scale across Scotland, supporting people to live well, safely at home and support self-management, building on work already underway on next generation telecare and telehealth.
- Initial use cases should include care and management of common chronic conditions such as diabetes and hypertension; building upon the substantial success of these latter two which is already starting to emerge across the country.
- Another use case will be delivery of care for urgent health and care needs outside the hospital.

### Exemplar

The US Veterans Administration (VA) is a pioneer in using telehealth for mental health, behavioural health prevention and treatment. VetsPrevail is a VA online programme backed by the National Science Foundation, which helps more than 30,000 US veterans. Their website provides veterans with depression with interactive psychoeducation. This includes services of online self-assessment, peer coaching, online communities, personalised and interactive lessons and a gaming environment. Built in partnership with the National Science Foundation, VetsPrevail programmes have been shown in multiple clinical trials <sup>(8)</sup> to deliver clinical results similar to face-to-face interventions at a tiny fraction of the cost.

The California Health Network, Kaiser Permanente (KP) provides telehealth as part of an integrated care programme for preventive care and the management of long-term conditions as well as for one-off health requirements. This approach is becoming more popular with users, with KP reporting that in 2016, more than half of consultations (52%) were conducted remotely: either by smart phone app, by telephone, email or videoconference or through online portals. As of 2017, over 20% of primary care visits are conducted by telephone consultations between patient and clinician. This demonstrates that the impact of using different workflows around existing technologies can make a big difference.

## Digital Innovation and Research

### Context

There is a clear and unambiguous commitment to innovation across Scotland – particularly *health* innovation. There has been investment in Scotland's innovation capacity and expertise, whilst building on strong foundations of academic excellence. Within health specifically, Scotland can point to a great deal of innovative activity across academia, NHS and industry. Within academia, [The Farr Institute @Scotland](#) has brought together NHS National Services Scotland with six universities to improve the health of the Scottish population and place Scotland as a global leader in health informatics research. Authorised researchers can use the national safe haven and a federation of four federated regional safe havens with access to routinely collected healthcare and cross-sectoral health-related data linkable via the CHI number. From 2018, [Health Data Research UK](#) will include a Scottish substantive site to take this work forward. Despite this key infrastructure being in place, challenges remain, particularly in relation to accessing data from multiple data controllers and accessing near real-time data. Scotland currently has three innovation centres to develop digital health: [the Data Lab](#), [The Digital Health and Care Institute](#) and [Stratified Medicine Scotland](#). While investment in innovation has translated well into support for more traditional industries such as pharma, medical technology etc. within the NHS, supporting innovation in digital health – particularly stemming from small and medium-sized enterprises (SMEs) is still at an early stage. The approach to date has largely focused on the needs of the NHS in particular, rather than the broader societal needs of wellbeing, or integrated care and social care more specifically, and the infrastructure has developed over time to reflect that. In addition, much of the formal 'innovation' activity has focused on supporting *product* innovation rather than *service* innovation. To date, the translation of innovative developments into implementation of service improvement and service change, with a few exceptions, has been challenging.

### Rationale and Principles

Getting many of the desired long-term benefits will require that Scotland becomes a leader in digital innovation, and that it more readily enables research on the data produced by clinical systems, where it has the opportunity to be one of the top nations in the world. Digital innovation, especially in healthcare, is one of the most fast-paced industrial sectors worldwide. Scotland has the opportunity to become a focal point for this type of innovation, which is likely to come from both small and large companies. Small companies should be able to access data through approaches such as APIs, and the barriers to entry for them should be made low. With large companies, collaborations will be more the rule, and Scotland should make efforts to engage several of the large companies in making Scotland a test bed and helping it advance.

In addition, the opportunities for research are huge. Care improvement is one obvious target: the Panel recommends leveraging the 'Once for Scotland' effort in order to innovate and promote service redesign and population health and care. But the opportunities go well beyond this; it should be possible to leverage data to enable new evaluations of epidemiology, genetics, genomics, health services research and public health and the use of radiological and pathological data, to name just a few. Because of its modest size, it is possible to obtain relatively complete data for almost the entire Scottish population <sup>(9)</sup>, which is likely to result in

many opportunities to improve health and social care and to take forward a data driven approach to public health that is unlikely to have been attempted at a national scale internationally.

Principles include that:

- Innovation should be recognised as a core organisational function, including a willingness to accept risk and failure.
- A focused pipeline should be created to support innovation from start-up to the rapid national scale-up of interventions which have been proven to be successful.

## **Recommendations**

The Panel recommends that:

- The further development of three to five digital innovation centres, which are complementary to the existing centres.
- Scotland-wide data infrastructure for research, including access to data about the care of the entire Scottish population who agree to participate, should be set up with appropriate governance, under the leadership of the new CCIO for Scotland.
- Investment should be made in health and social care applications that enable health and care professionals to capture data at the point-of-care so that these data can be used in near real time to understand how health and care systems operate at a population level in order to support service planning, redesign and innovation.



## Exemplars

Other countries have been very successful in encouraging innovation in this sector. Israel is a notable example with key steps taken in relation to infrastructure such as establishing innovation zones and creating specific space dedicated for start-ups near engineering departments, as well as incentivising innovation with tax advantages and competitive funding programmes.

One approach that has been highly beneficial in terms of improving value has been targeted approaches to high-risk populations. In Scotland, 2% of the population consumes 50% of the health and social care costs, so identifying this group and intervening can be very useful. In Scotland, this is done through a programme run by ISD which identifies 'High Health Gain Individuals'. At Partners Healthcare in the Northeastern US, a programme has been developed called the Integrated Care Management Program (ICMP) which identifies this group using previous utilisation data. Then, each patient is assigned a care coordinator with particular attention focused on their mental and social care needs, which often drive the high costs. Intervening in this way has reduced hospitalisation rates and the costs for this important group <sup>(10)</sup>.

A digital personal health record that includes not only subsets of medical care reports but also allows for daily, in the moment capture of health-related behaviours such as meals, socialisation and sleeping and even information about upcoming clinical trials could be a real boon to people with rare diseases. Around the world, people with rare diseases, in part because they are not well-served by a health care system that focuses on well-identified conditions, have created their own learning communities, sharing self-management and personal observations of symptoms and responses to illnesses. From [PatientsLikeMe](#), a web-based integrator of self-tracking observations from thousands of people to [FasterCures](#), an industry-tech innovator-health care research partnership to [Eurodis](#) which includes a searchable map of services for people with rare diseases, electronic tools not only allow clinicians to monitor patients between office visits, but also afford an entirely new approach to understanding disease, creating social networks of support, and leveraging peer-to-peer wisdom and support in managing complex health challenges.

## **Future vision**

Advances in the technological infrastructure for health and social care will first and foremost improve the health and care of individuals, the ability of the care delivery system to provide efficient care, make the best use of professional resources and improve public health efforts across the country. Decision makers will have in addition a robust, interoperable health and social care information system which will offer unprecedented opportunities for research, innovation and quality improvement. Improvements in genotype-phenotype-sociotype assessment-enabled precision medicine and precision public health, comparative effectiveness of therapies, and more-complete understanding of the natural history of disease will all be accelerated through such access.

Any uses of data collected in the course of health and social care for the purposes of research and quality improvement will require assurances that proper privacy considerations are met. In addition, it is important to recognise that electronic records allow closer scrutiny of professional practice patterns; in many cases this level of observation may be helpful (e.g. for identifying best practices in addictions medicine) but in some cases it may inadvertently reveal aspects of practice (for example response time, institutional behaviours) that have previously gone unobserved. Such increased awareness will be of greatest value if there is transparency and engagement of citizens and professionals in decision making.

## Conclusions

These recommendations are for a health and care system which is supported by digital, rather than a digital system *per se* and therefore the opportunities offered by the Scottish Digital Health and Care Strategy should be viewed as a transformation programme rather than as a technology project. We are proposing a core system which allows agility and innovation. We strongly encourage that this integrates with the public health informatics reform that is planned as many of the opportunities and challenges are common, and synergising efforts offers considerable added value and efficiency gains.

Within a year, the Panel proposes that the following actions could be taken:

- Appointment of a national CCIO, CTO and local CCIOs.
- National approach agreed in regards to Information Governance.
- A national financial plan for IT in health and social care will have been developed.
- Infrastructure plan in place looking at key infrastructure developments to aid implementation.
- The CHI number to be standardised across Scotland.
- Digital maturity assessment completed across health and social care services.
- Develop a public awareness plan as well as a short summary of the strategy targeted to people who are not fully aware of the on-going work.

Within three to five years, the Panel proposes that the following actions could be taken:

- Every Scottish citizen will have a near real-time personalised view of their information to which they can contribute.
- Online booking of appointments should be in place.
- All primary, community, hospital, and social services should offer access a citizen-facing services platform which is underpinned by a common approach to data integration/ sharing.
- All CCIOs will have had specific digital training.
- Standards will be in place for all key types of health data.
- There will be agreement around a clinical data summary which can be exchanged among Health Boards and IJBs.
- Half of encounters for chronic conditions and acute complaints in the outpatient setting will be, if the patients so desire this, virtual.
- Multiple digital innovation centres will be in place in Scotland with clear evidence that innovation has been catalysed.
- A Scotland-wide infrastructure for research will be in place that is closely aligned with the needs of the NHS, social care and public health, and which will enable researchers to make queries across the entire Scottish population among those who have opted to participate in near real-time.

## **Summary of Recommendations**

### **Supporting Citizen Engagement**

The Panel recommends that:

- Every Scottish citizen should have a personalised view of their information which they can contribute to through a Personal Health Record (PHR) by 2020. The PHR should include access to laboratory tests, medical notes and care plans among other types of information with advice for the citizen on how to interpret these data. It should, in time, include both read and write access for citizens. The PHR should also allow citizens to upload data from vetted 'apps' from digital devices which can link into core systems used by health and care providers.
- A number of digital functions should be offered to all citizens such as booking appointments online and repeat prescribing, which are particularly high priorities given the limitations of the current processes.
- This PHR should be 'opt-out', that is, all citizens will be offered the PHR, but those not wishing to use it should be given the opportunity to opt-out.
- A firm commitment should be made to extending the PHR to social care information so that it ultimately becomes the PHCR.

### **Digital Maturity**

The Panel recommends that:

- All primary, community and hospital services and social care should offer access to all relevant services online (appointment booking, online information about services, and remote / virtual access to some services), with the first three being online by 2022.
- High speed connectivity to all service providers should be an investment priority.
- National minimum standards regarding upgrades should be put in place so that Boards do not lag behind.
- A periodic assessment of digital maturity (including reach, as well as availability of digital) using a single tool is carried out across all health and social care providers, including an independent assessment of whether improvements are being carried out.

### **Leadership and Workforce**

The Panel recommends that:

- A Chief Clinical Information Officer (CCIO) should be employed at a national level, to report to the Health and Social Care Management Board within the Scottish Government and to work closely with the Scottish Government's Chief Information Officer and the Local Government Chief Digital Officer. The

CCIO should be a clinician and should have sufficient authority and resources to be successful in this role.

- A Chief Technology Officer (CTO), who would work closely with the CCIO, should also be employed at the national level.
- Chief Clinical Information Officers should be employed in clinical and social care domains across Scotland, including within Health and Social Care Partnerships.
- A programme of digital training should be implemented for those who would benefit from it, across all clinical and social care domains, across information technology professionals and data scientists at all skill levels. There should be mandatory training for all current and future health and social care professionals as a core part of workforce development.
- The CCIO should convene a citizens' panel to ensure that decisions are fully informed by the citizen view.

## **Standards and Interoperability**

The Panel recommends that:

- An overarching national Design Authority be set up with a mandate to make architecture decisions for the whole service and enforce adherence under the control of the CCIO alongside the Scottish Government's Chief Information Officer and the Local Government Chief Digital Officer for Scotland.
- Standards should be adopted for technical infrastructure (including upgrades), which are pivotal for ensuring security and managing confidentiality.
- Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT), which is a collection of medical terms, should be adopted for all key domains of clinical data, with the PRSB to be invited to develop a clinical summary standard which would be applicable in Scotland.
- Investment is made to ensure effective and efficient data exchange between primary, community and hospital services and social care, and across Scotland.
- Digital services (for example, integrated shared care records and data for population health management) should be provided within a secure International Organization for Standardization (ISO) compliant cloud.
- An approach to procurement is needed which focuses on dealing with a smaller number of vendors within a particular niche and a move away from bespoke solutions to leverage existing technology from the UK/internationally; this is central if interoperability is to be achieved.
- Clinical and care standards work should be led nationally (for example by National Services Scotland and the Care Inspectorate) and should be aligned with similar efforts in the rest of the UK.

## **Information Governance and Resources**

### **Recommendations**

The Panel recommends that:

- The Community Health Index (CHI) Number should be extended for use within social care.
- A national financial plan for IT in health and social care should be developed, and resources should be allocated based on its estimates.
- Adequate resources should be dedicated to this effort. Some initial spending will be required to bring infrastructure up to standards. On an ongoing basis, allocation should be determined and justified based on the financial plan described above. The panel suggests that 2% of gross revenues on an ongoing basis would be a bare minimum as above, it is likely that a higher amount will be needed, probably at least in the 3-4% range.
- A single open platform be implemented by the health and social care which utilises open standards such as open APIs.
- A comprehensive approach to data use is made, thereby including data from social care, public health and the third sector and that health data should include data from sensors, robotics and data derived from appropriate data from technology enabled care.
- An extensive public engagement exercise is carried out to inform the public about the plan for moving forward including sharing data across Health Boards and IJB boundaries.

## **Technology-enabling health and care services**

### **Recommendations**

The Panel recommends that:

- Evidence-based technology enabled health and care (TEC, including telehealth), be more broadly implemented at scale across Scotland, supporting people to live well, safely at home and support self-management, building on work already underway on next generation telecare and telehealth.
- Initial use cases should include care and management of common chronic conditions such as diabetes and hypertension; building upon the substantial success of these latter two which is already starting to emerge across the country.
- Another use case will be delivery of care for urgent health and care needs outside the hospital.

## **Digital Innovation and Research**

### **Recommendations**

The Panel recommends that:

- The further development of three to five digital innovation centres, which are complementary to the existing centres.
- Scotland-wide data infrastructure for research including access to data about the care of the entire Scottish population who agree to participate should be set up with appropriate governance, under the leadership of the new CCIO for Scotland.
- Investment should be made in health and social care applications that enable health and care professionals to capture data at the point-of-care so that these data can be used in near real time to understand how health and care systems operate at a population level in order to support service planning, redesign and innovation.

## Glossary

|  |   |
|--|---|
| API  | Application Programming Interface.  |
| Cabinet Secretary                                | A cabinet secretary is a senior member of the Cabinet of the Scottish Government.   |
| Caldicott Guardians                              | A Caldicott Guardian is a senior person within a health board or local authority who has responsibility for the confidentiality of health and care data.  |
| CHI number                                       | A unique number which is used to identify patients in Scotland.   |
| Convention of Scottish Local Authorities (COSLA) | COSLA is an organisation which represents most Scottish Local Authorities and provides political leadership on national issues, works with councils to improve local services and strengthen local democracy. |
| Genome   | Genetic material  |
| Health Information Technology (HIT)              | HIT includes different types of technology to store, transmit and analyse health information.   |
| Home and mobile health monitoring                | The use of technology to allow citizens to monitor, store, record, receive and transmit information relevant to their health and care.  |
| Hypertension                                     | High blood pressure   |
| Interoperability                                 | The ability to exchange information   |
| ISO  | International Organization for Standardization  |



|                                 |   |
|---------------------------------|---|
| Meaningful use                  | Meaningful use is a term used in the US to refer to using certified electronic health record (EHR) technology to: Improve quality, safety, efficiency, and reduce health disparities, engage patients and family, improve care coordination, and population and public health and maintain privacy and security of patient health information |
| MSP                             | Member of Scottish Parliament   |
| Once for Scotland               | An approach by NHS Scotland where services (where appropriate) will be managed on a Scotland-wide basis and will be delivered in a consistent way, unless there is a very good reason for variation.  |
| personal health and care record | A record of a citizen's health and care data which the citizen as well as their health and care professionals, can access.  |
| randomised controlled trial     | A type of research study where participants are randomly (like the toss of a coin) split into two or more groups and given different interventions. The results from the different groups are then compared to see if there are any differences.  |
| SNOMED CT                       | A structured clinical vocabulary for use in an electronic health record.  |
| technology enabled care         | Care using the application of technology as an integral part of quality cost-effective care and support.  |
| Telehealth                      | The use of telecommunications to receive and transmit information for health and care.  |
| Veterans                        | Servicemen and servicewomen   |

## **Appendix 1 External Panel Terms of Reference**

### **Digital Health and Care Strategy External Expert Panel Terms of Reference**

#### **Overview**

The External Expert Panel will play a key role in advising the Scottish Government and the steering group for the development of the strategy, the Strategic Oversight Group on how digital technology can support Scotland's aim for high quality health and social care services that have a focus on prevention, early intervention and supported self-management.

#### **Purpose**

The purpose of the Panel is to help ensure that a broad knowledge and evidence base is taken into account in the development of the new Strategy, which will be published at the end of this year. In particular, the Panel will be asked to provide a national and international perspective on the types of digital infrastructure or capability Scotland will need to realise its ambition to transform services and support a learning health system. This will include advising on how we might develop the culture, leadership and skills in the health and care sectors in Scotland in order to embrace digital.

#### **Panel Criteria**

- Renowned and recognised in their field.
- From both national and international countries.
- From across a breadth of backgrounds in health and social care.
- Ability to provide insight and experience from across a range of different sectors (Government, Care services, Academia, Industry, Third sector, Service user).
- Gender balance.
- Ability to act in a critical friend role.
- Well-networked and connected with other sources of relevant knowledge and expertise.

#### **Proposed format and operation**

We propose that the Panel:

- Is assigned a small number of key priority areas by the Strategic Oversight Group, and that the Panel works with the Scottish Government to articulate specific deliverables in these areas.
- Performs a 'critical friend' role on the development of the new Digital Health and Social Care Strategy. Panel members will offer advice and insight on relevant national and international good practice, evidence and studies.

- Membership and designated Chair will be personally appointed by the Cabinet Secretary for Health and Sport for a specific period of time and will be non-remunerated.
- Will conduct the majority of its work virtually, meeting through use of teleconference or videoconference on a monthly basis, but may meet occasionally in person as is appropriate. In those cases, travel and subsistence costs will be reimbursed by the Scottish Government.

In order to ensure that the areas and issues of most pressing concern or challenge in Scotland are addressed, we propose that the Panel:

**Make recommendations for the key types of digital infrastructure or capability required to support a learning healthcare system in Scotland, based upon national and international experience, and an understanding of the Scottish context and progress made to-date.**

Specifically, it will be expected that the Panel's work will consider the following areas:

- Quality
- Safety
- Efficiency
- Population health
- Innovation (scaling)
- Workforce and capacity building
- Underpinning enabling infrastructure

The Panel will be expected to produce interim findings in September that will feed in to the production of a draft Digital Health and Care Strategy for Scotland. A final report will be expected by December in order to support and coincide with the publication of the final Strategy.

## **Appendix 2 External Panel Members**

**David W Bates (Chair)** Chief of General Internal Medicine, Brigham and Women's Hospital; Medical Director of Clinical and Quality Analysis, Partners Healthcare, Professor of Medicine, Harvard University, Boston, MA, USA

**Rafael Bengoa** Co -Director Institute for Health & Strategy (SI Health) Bilbao. Spain

**David Blumenthal** President of the Commonwealth Fund, New York, NY USA

**Patti Brennan** Director of the National Library of Medicine, Bethesda, MD USA

**John Halamka** Chief Information Officer and Dean for Technology at Harvard Medical School, Boston MA, USA)

**Mary McKenna** Director, Elemental Software

**Nóirín O'Neill** Patient Advocate

**Ester Sarquella** Business Development Director for Digital Health and Care, Tunstall Healthcare, Southern Europe, and previously, Member of the Operational Committee of the Inter-Ministerial Plan for Integrated Care, Government of Catalonia, Spain

**Nirav Shah** Adjunct Professor, Department of Medicine, Stanford University, CA USA

**Aziz Sheikh** Director of the Usher Institute, Edinburgh University

**Ann Slee** ePrescribing Lead, NHS England

**Joanne Westwood** Head of Social Work, University of Salford, Manchester

### Appendix 3 References

- (1) Taylor SJC, Pinnock H, Epiphaniou E, Pearce G, Parke HL, Schwappach A, et al. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic Review of Self-Management Support for long-term conditions. Southampton (UK): NIHR Journals Library; 2014 Dec.
- (2) Mold F, de Lusignan S, Sheikh A, Majeed A, Wyatt JC, Quinn T, Cavill M, Franco C, Chauhan U, Blakey H, Kataria N, Arvanitis TN, Ellis B. Patients' online access to their electronic health records and linked online services: a systematic review in primary care. *Br J Gen Pract.* 2015 Mar;65(632):e141-51.
- (3) Yamin CK, Emani S, Williams DH, Lipsitz SR, Karson AS, Wald JS, Bates DW. The digital divide in adoption and use of a personal health record. *Arch Intern Med.* 2011 Mar 28;171(6):568-74. doi: 10.1001/archinternmed.2011.34.
- (4) The Scottish Government. A National Service Model for Home and Mobile Health Monitoring. May 2017. Available from <https://sctt.org.uk/wp-content/uploads/2017/05/A-National-Service-Model-for-HMHM-v1.1.pdf> [accessed 12 March 2018]
- (5) NHS Education for Scotland. Supporting Scotland's Workforce - Technology Enabled Care Research Report November 2017. Available from <http://www.nes.scot.nhs.uk/newsroom/media-releases/supporting-scotlands-workforce.aspx> [accessed 20 December 2017]
- (6) McKinstry B, Hanley J, Wild S, Pagliari C, Paterson M, Lewis S, Sheikh A, Krishan A, Stoddart A, Padfield P. Telemonitoring based service redesign for the management of uncontrolled hypertension: multicentre randomised controlled trial. *BMJ.* 2013 May 24;346:f3030. doi: 10.1136/bmj.f3030.
- (7) Wild SH, Hanley J, Lewis SC, McKnight JA, McCloughan LB, Padfield PL, et al. Supported Telemonitoring and Glycemic Control in People with Type 2 Diabetes: The Telescot Diabetes Pragmatic Multicenter Randomized Controlled Trial. *PLoS Med.* 2016 Jul 26;13(7):e1002098.
- (8) Hobfoll SE, Blais RK, Stevens NR, Walt L, Gengler R. Vets prevail online intervention reduces PTSD and depression in veterans with mild-to-moderate symptoms. *J Consult Clin Psychol.* 2016 Jan;84(1):31-42. doi: 10.1037/ccp0000041. Epub 2015 Aug 31.
- (9) Bhopal RS, Gruer L, Cezard G, Douglas A, Steiner MFC, Millard A, et al. Mortality, ethnicity, and country of birth on a national scale, 2001-2013: A retrospective cohort (Scottish Health and Ethnicity Linkage Study). *PLoS Med.* 2018 Mar 1;15(3):e1002515.
- (10) Hsu J, Price M, Vogeli C, Brand R, Chernew ME, Chaguturu SK, Weil E, Ferris TG. Bending The Spending Curve By Altering Care Delivery Patterns: The Role Of Care Management Within A Pioneer ACO. *Health Aff (Millwood).* 2017 May 1;36(5):876-884. doi: 10.1377/hlthaff.2016.0922.



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