Scottish Parliament Call for Views - Digital Health & Care
DHI Response

The Digital Health & Care Institute (DHI)

The DHI is one of Scotland's Innovation Centres - funded by the Scottish Government Health & Care Department and the Scottish Funding Council. DHI has spent the last four years (known as DHI Phase 1) facilitating and funding a large portfolio of digital health and care innovation projects that both support health and care service improvement, as well as capitalise on and drive value for Scottish digital industries. During this time, we:

1) Gathered significant evidence and experience as an organisation – informing a view of the digital health and care market, allowing us to see common barriers and opportunities for scale.
2) Connected with over a thousand innovators, creating an environment to bring diverse capabilities together and developing a mechanism to quickly access these when required.
3) Developed and then refined a co-design approach with citizens and professionals that could help the community explore and then define the preferred future care models required.
4) Due to (1) now have an insight into how to align digital health and care capabilities with the new agenda around citizen-centred, co-managed, integrated, and community based care. We can now develop new underpinning digital infrastructure that will help us move from the current, closed nature of data systems to new, open, distributed data systems. Scotland's care aspirations will not be met if the infrastructure does not evolve to support this.
5) Developed several digital products that would scale well with the right enablement (see 4), with several of these gaining valuable evidence for commercialisation, and others gaining enough traction to move on to develop the case for change at a national level.
6) Helped Scottish Government identify issues with the current overall innovation approach, allowing a DHI Phase 2 approach to emerge that was far more systemic and demand driven.

The DHI Phase 2 approach will now:

- prioritise based on national demand drivers to focus activity for the national benefit – with Scottish Government commissioning a small number of core challenges for DHI to address;
- scope and build whole system service models, clustering relevant technologies, rather than progressing individual technologies – product-focussed pilots are ineffective;
- incorporate co-design practices to help define the challenges being set and centre-solutions on the citizen;
- create a risk-free environment to simulate innovative service models, and the digital infrastructure they depend upon;
- involve the procurement/commissioning community early to ensure that "landing zones" are defined for successful innovations to be adopted and scale up in the health and care system;
- research both in Scotland and internationally to identify and target specific knowledge gaps such as in regulations and standards;
- use design approaches to articulate better the real requirements and define "preferable futures" rather than rushing to immediate (and not the right) solutions, and
- ensure that there is a focus on the skills gap in digital being addressed.

What do you consider have been the main successes of the existing Scottish Government's eHealth and telecare/telehealth strategies and why?

Linkage of SCI Diabetes to My Diabetes My Way (MDMW) – One of the first developments of its kind globally – this demonstrated how to unify a dataset for a citizen and then develop a set of data driven (and so semi-personalised) tools and educational resources to assist a citizen to self-manage. However, the model now needs to do two things to progress further:

1) **Appreciate complexity –** most notably the likelihood that someone with diabetes may have other health and care needs – which may create interdependencies that a single condition system like this cannot handle, disenfranchising the user. The ability to link this to other data sets to create more nuanced tools would be of great benefit.

2) **Break the tether –** this is still a service built by the NHS, within a clinical / education context. It is an example of a tethered Personal Health Record. While it allows access and even the ability to edit the record by contributing glucose readings – this is limited to one means of communication, using a PC software based uploader. The system is having problems breaking into widespread use because it is not built to be seamless and convenient for citizens who are consuming effortless digital technologies in all other walks of life. If MDMW can evolve to be more open and citizen-led, then there will be a much higher likelihood of adoption at scale. As will be noted later in this paper, MDMW should not have to build bespoke infrastructure to offer this openness and interoperability – instead some common, open and distributed infrastructure could be developed to help MDMW and other services that may emerge to do so quickly, cheaply and consistently.

Clinical Portal – this is a virtual electronic patient record that draws from existing patient record databases into one view, rather than centralising to create a national database. 'Single sign on' allows for seamless access to these disparate sources of information where previously a clinician would need to sign into multiple services simultaneously. This development aligns well with progressive approaches to data sharing and integration – it works on the principle of 'using what you have' in terms of existing infrastructure, and the principle of reuse of data / drawing from local databases rather than trying to centralise the stored data. However, note that this works best for clinical / service oriented requirements – the same 'single sign on', centralised approach cannot be easily applied to more diverse and personalised citizen facing services.

Creation of the DHI – the Scottish health and care community anticipated the emergence of the digital health and care market long before it accelerated to the scale it enjoys today. DHI was created by this community to act as a force that drives digital health and care progress forwards, breaking new ground and leveraging Scotland's broader capabilities to help health and care services transform. The 'arms-length' nature of the DHI as an Innovation Centre allows for scrutiny and critique (such as found in these papers) which help Scotland remain progressive in its approach to digital health and care.

What do you consider have been the main failures of the existing Scottish Government's eHealth and telecare/telehealth strategies and why?

- **Tensions between Operations and Innovation -** The eHealth Leads in Scotland have operational responsibility for maintaining a complex set of legacy systems that are increasingly taxed to deliver new or enlarged services they were not designed to satisfy. The strategies and development work around digital health and care place an unrealistic demand on this group to lead and progress next generation digital infrastructure, when they are barely resourced to maintain the status quo.

- **Guidance only goes so far -** While the eHealth community in Scotland cooperates strategically, benchmarks and enjoys some economies of scale, the health boards in Scotland are still fundamentally separate organisations and Scottish Government only acts as a guide and facilitator. This in turn means that the culture around data sharing has remained focused on point to point data sharing agreements and integrations between health boards. Some development have occurred across boards – such as the Emergency Care Summary or Key Information Summary. However, other governments have mandated and resourced more comprehensive common data exchange and integration approaches that have allowed them to accelerate beyond Scotland when it comes to realising the benefits of broader data sharing.

- **No recurrent funding for new developments –** a common problem across all digital development activities is that the funding is almost always only seed funding for initial proof of concept. In a best-case scenario, the new development proves successful. This then usually results in an already strained health board eHealth budget being required to stretch to cover the ongoing costs of the new digital capabilities. Often this cannot be achieved and new developments cease when the project funding finishes.

- **Decisions to invest –** There is no cohesive framework for how Scotland invests in new digital health and care services:
    - Due to the emerging nature of many of the digital capabilities, there is no easy way of benchmarking value – and so no one can clearly say what 'good' looks like.
    - There is an unrealistic expectation around the burden of proof for digital service investment – often requiring favourable cost / benefit in the short term as well as advanced levels of evidence around clinical outcomes and technical viability.
    - This misunderstands that these developments are not new 'treatments', but a new way of offering services – and that developments of this nature will require several iterations to get the service right, and it will only yield the required benefits if the service is scaled up and other non-digital services are decommissioned as a result.
    - This is linked to the issue of nonrecurrent funding for new developments. A pilot is really just deferral of a decision to invest. Instead we need to commit to a new way of working, plan for a phased development that iterates and replaces non-digital capabilities, and that has recurrent funding built in.
    - The first couple of years of a scaled digital service are unlikely to yield benefits, this must be planned for an improved upon as necessary until new ground is broken and the delivery channels are shifted.

- **Building for services, not designing for citizens –** While more recently there have been more efforts to design services with citizens, there is a still a default to building to improve clinical workflow and support service delivery. This is understandable given the successes achieved in this manner in the past. However, this has led to approaches that centralise and standardise interfaces and in general, apply thinking that has led to good gains for clinical users – but that are not necessarily engaging or intuitive for citizens.

- **Engaging SMEs –** the eHealth objective to engage better with Scottish SMEs is admirable but difficult to achieve in practice. DHI's experiences trying to broker these relationships highlight that most SMEs simply can't operate to the scale or deal with the rigour and governance required by eHealth development. Equally the public sector is still only just beginning to understand developmental procurement processes, and still has a hard time managing risk associated with smaller supplier relationships. There is no easy answer here. It will be damaging to retain this strategic objective if it continues to be a token commitment only.

How well does the Scottish Government's draft Digital Health and Social Care Vision 2017-2022 address the future requirements of the NHS and social care sector?

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Do you think there are any significant omissions in the Scottish Government's draft Digital Health and Social Care vision 2017-2022.

The draft vision is not definitive or strong enough in its wording – it has to address the core barriers and opportunities around data sharing to support real progress over the coming years. Please see the table below for comment.

As a citizen of Scotland:

Vision Statement	Comment	Alternative
I have access to the digital information, tools and services I need to help maintain and improve my health and wellbeing.	• This statement could be read very superficially and arguably NHS Inform already satisfies this aspiration. • A distinction should be made between access to generic information / tools vs access to your own records, treatment options, care plan and tools that leverage this data to offer personalised self-management options. • Access to information alone will not bring about significant improvements. A citizen should be able to both act on the information and contribute information into the record in turn. • If this is only delivered through state provided digital services in a 'Once for Scotland' approach, this will not offer the choice and personalisation required.	I can use widely available digital tools and services to manage my own health and wellbeing, knowing that these tools can use and contribute to my personal and official health and care records.
I expect my health and social care information to be captured electronically, integrated and shared securely to assist service staff and carers that need to see it,	• Capturing the information electronically could mean scanning letters and storing them as PDFs. It doesn't also make a commitment to ease of use and reduction in duplication. • The information is already being integrated – but saying how matters. The current approach is very onerous and based on point to point integration and data sharing agreements between organisations that can take two or more years to put in place or change. There are other ways of doing this. • This doesn't link into the broader digital public services agenda. • There is no mention of data ownership or consent. Nor does it offer transparency around data use for the citizen. There is an opportunity here to make a stronger statement to keep Scotland progressing in line with leading European approaches.	I expect my health and care information to be captured once only, and for this information to be made available to all relevant public services, and for any use of this information to be known to me and based on my consent.
and that digital technology and data will be used appropriately and innovatively to help plan and improve services, enable research and economic development	• Again, this happens today. It is not clear how this statement can drive change of any scale or ambition. Also, from a citizen's point of view is this important?	I expect to be able to consent to the use of my health and care information to support improvements in public services while also creating a market for the digital tools I need.

What key opportunities exist for the use of technology in health and social care over the next 10 years?

The answer to this question is intricately linked to the need to share information more effectively – the answer to both questions is summarised below. For more detail please see the accompanying paper "Advancing Digital Health & Care: Exploring the infrastructure required for citizen-centred services".

What actions are needed to improve the accessibility and sharing of the electronic patient record?

To answer this question the DHI proposes to first answer a more fundamental one: **Why is data not shared more consistently for more effective and accessible digital public services?**

The UK is ranked highly (6th) for digital progress overall, but relatively poorly (19th) for accessibility and use of digital public services. This pattern extends to digital health and care services. Note there are no rankings for Scotland separately and so it is assumed that Scotland broadly follows the rest of the UK – with solid digital progress that doesn't necessarily translate into easily accessible digital public services.

In the UK, like many European countries, there are successful infrastructures that have improved service delivery from a systems perspective – such as Electronic Health Records (EHRs) and Clinical Portals. These worked very well in a system in which the NHS was expected to control the dialogue and optimise clinical outcomes for citizens. As care is shifted towards more distributed, citizen-centred, and community based models, these systems – which are largely centralised - can no longer handle the complexity and diversity involved in integrated and personalised care.

Health and care systems have attempted to remedy this through 'Patient Portal' platforms by giving citizens access to their EHR and by digitising transactions such as appointment and repeat prescription booking. This has had some positive impact from an administrative and workflow point of view but has as yet shown very poor uptake and retention of use and has shown no improvements in health outcomes for citizens. This is largely because this approach reflects only small changes within the existing patriarchal model of healthcare system and medical control, offering citizens only a small access point into the healthcare system as it already exists, rather than meaningful co-management functionality.

To learn from those countries topping the European digital public services accessibility and use rankings – Finland and Estonia – they have more radical approaches to citizen empowerment. Thinking holistically and with citizen access and empowerment in mind, these countries share common components around national identification, enforced database interoperability and consent driven, transparent control of data flows by the citizen. This simplifies access and builds trust in data sharing, which in turn creates a more seamless citizen experience. They are both also developing genuinely personally held data capabilities that can adjoin the statutory record to personalise services more effectively. This approach is based on a national dialogue led at the highest levels politically and organisationally.

Scotland currently has taken a more cautious route. The forcefulness of the mandated change around identity, privacy, citizen control and data sharing is difficult to commit to politically, and the benefits of doing so are not necessarily clear.

To close the gap between Scotland and the European leaders, it is recommended that, at a minimum there is a national dialogue initiated around a Scottish e-society – focusing on effective delivery of citizen centred digital public services and therefore concerning identity, privacy and transparency in the context of effective public service provision. Currently development is moving slowly because the public sector does not have a clear mandate from its citizens to transform services.

It is crucial to note that this is not a debate about national identity schemes and whether we follow the more extreme example set by the European leaders. However, there are a number of principles that have significantly empowered citizens in these countries that we must learn from.

Realistic Medicine, as espoused by the Chief Medical Officer, can be achieved by enhancing our ability to share data in a consent driven fashion, allowing more seamless and personalised services, with diversity for citizen but built on a consistent core infrastructure and standards base. Key to this are three interlinked concepts:

1) If the citizen is to be empowered, then they must own their own data, must see the data held by others about them and must be able to limit how data is shared effortlessly and directly.
2) Care is distributed – so the digital infrastructure must not centralise power and access. If citizens feel they genuinely have this control and choice, then trust in the system increases and data begins to flow more effectively.
3) Personalisation is more than just customisation of generic services - permission-less innovation must flourish near the citizen, but within a governed set of standards and norms to protect quality of care.

A distributed care system supported by a distributed, but standards based digital infrastructure, is exactly what the Scottish digital health and care marketplace needs to flourish. The leading e-societies of Europe are now capitalising economically on their open, distributed, data rich systems. Businesses are able to add value significantly quicker with far fewer barriers, and can demonstrate benefits directly to citizens. This in turn then allows them to engage with global markets that are increasingly working to the same consumer focused, distributed delivery models.

So, in conclusion, it is recommended that Scotland begins with citizen-centred co-design activity to understand how to empower citizens in a digital era and then build a distributed digital infrastructure that can then allow innovation to flourish in response to these diverse needs.

DHI can provide materials on request that highlights:

1) More detail of the leading approaches in Europe.
2) Case studies from co-design activity with Scottish citizens demonstrating their interest and need for this type of ownership and empowerment around data sharing.
3) Tangible next steps that could be taken to gently begin a broader dialogue around citizen empowerment and data sharing.

What are the barriers to innovation in health and social care?

There are multiple barriers – but DHI identifies the data sharing issues raised above as the most significant by far. Additional comments:

- Digital innovation is largely regarded as a pre-commercial procurement activity that depends on the initiative and energy of a small number of individual enthusiasts, rather than a strategic activity require to keep services sustainable.
- Key decisions need to be made about the system level change required for sustainability of public services. From this, new digital services need to be created and acknowledged as the 'new normal' – not asked to justify benefits in isolation as discrete projects.