Call for evidence - Technology and Innovation - from Mydex CIC

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

The main successes have involved collaboration, and when the citizen has been the focus and point of integration. Citizens seek trust, and to build relationships in health and care. There is a growing recognition (6 years after Christie) of person-centred services and citizen journeys within digital public services. Organisation-centred Health and Care services are struggling and may put security at risk. We need collaboration and some places in Scotland are beginning to look at new citizen journeys e.g. in Glasgow for cancer. Future strategies need to created trust to deliver meaningful outcomes for citizens, carers and staff.

One recent potential success to build on has been Derek Mackay MSP accepting that the previous NHS and other data sharing policies are in need of review, and starting the process again in a more person centred and collaborative way to rebuild trust with citizens. This is a significant opportunity for Scotland to take a distinctive position and lead on the implementation of genuine person-centred services. The citizen can then be the point of integration, and have personal choice over personal data e.g. in activating Scotland’s Dementia Strategy.

Scotland currently has many organisation-centred policies and processes in Health and Social Care. These need to change to a “new world” transparent approach, empowering citizens and carers in order to comply with General Data Protection Regulation (GDPR) coming in 2018. Citizens, families and carers and communities seek person-centred health and care services. When citizens are the point of integration, trust and confidence can be recreated in 2017.

Mr Mackay MSP wrote to Mr Crawford MSP, Chair of the Finance Committee announcing an important change in March 2017, and the letter is in the Scottish Parliament Information Centre (BiB number 58578). It is time the people of Scotland take control of their own identity online -

“Ministers do believe that it is desirable that a member of the public, who wants to access public services online, can be given the chance to demonstrate their identity easily – and be confident that appropriate safeguards are in place to protect their privacy. This becomes ever more important as the Scottish Government takes on new powers, prepares to deliver new services, and aims to make these services as convenient, accessible and user-centred as possible.”
The Nuffield Trust identified 7 keys to success in digital health and care that include culture change and transformation first. Empowering citizens is critical to enable trust.

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

Main failures include lack of dialogue, low trust and transparency and incorrect data architecture choices. Scottish Government (SG) strategy and Parliament’s legislation continue to take an organisation-centred approach to health and care. Unfortunately, this means it is difficult for trust to be developed. Citizens cannot participate equally or actively with their health and care needs. Two-way digital communication and trusted, person-centred data sharing have not happened.

Legacy ICT systems in Scotland’s health and care domain continue to exacerbate the problems by being disconnected and disparate. Professional NHS users may not always have the time to consider the benefits, and redesign person-centred services within their own schedules. There has been a failure to create ICT demonstration environments, and places for open, person-centred services to be designed for new Health & Care services. In turn these could create service and growth opportunities for citizens, SMEs and Third Sector in Scotland.

The current approach does not address the whole system. This is a cause of failure.

Scotland’s strategies need to become genuinely person-centred, to build trust, to design equality, to create better citizen journeys and to follow Christie principles. The needs of citizens, carers and families would be placed first if this happens. The Health & Sport Committee should also be considering the design, interoperability and person-centredness of the new Scottish Social Security System, as this will have a significant impact on around 2 million citizens and carers.

The Welfare Reform Committee advised in December 2015 the following key Recommendation: http://www.parliament.scot/parliamentarybusiness/CurrentCommittees/94823.aspx

14. The other major principle which we advise the Scottish Government to adopt is to make the new system person-centred. The current social security system often appears to be designed for bureaucratic convenience. The fact that a whole advocacy industry has grown up to support claimants through the process is an indication of how the system is not currently person-centred. Ultimately we would like to see a system where the need for advocacy and support disappears for the vast majority of claimants.

The Health and Social Care system in Scotland has not considered the needs of citizens, families and carers in a genuinely person-centred way. There has not been a democratic dialogue in the Scottish Parliament. Citizens, carers, families and the Third Sector are not currently active participants in Scotland’s health and care system. Citizens cannot share in the
design and delivery of services in order to feel empowered, have trust and confidence and to believe they can make a contribution to change and self manage.

Main failures -

- In Health and Social Care, there is not enough trust and relationships with citizens to make nation-wide changes, so that citizens can use and benefit from technology
- Health literacy and realistic medicine have not been aligned with citizens’ needs and the use of technology. There have been no demonstration environments for tests.
- The citizen is not currently the point of integration for data about them, has no identity, and the health & care System is not able to function properly. Citizen journeys between hospitals, Boards, charities and Social Care are unworkable due to disparate data and lack of interoperability and data portability. This can cause issues for patient safety and for planning, as the citizen, their carers and families do not know what is happening.
- There has been no consideration of genuine person-centred services that enable citizens to take seamless “citizen journeys” through the NHS, Local Authority and other parts of the whole Scotland system including social care, housing, transport and employability in a holistic, whole system approach.
- As a result, citizens find they have to repeat themselves and their stories; Carers have to perform tasks over and over again; Clinicians and nurses have to cope with duplication, re-starts and a broken infrastructure; GPs rely on paper trails and do not know what has happened to their patient; delayed discharge is not improving.
- There has been very limited genuine involvement of patients, carers, Third Sector and citizens in the strategy for Scotland’s health and care. The Strategy needs to be for all citizens, and the whole system founded on human rights and person-centred services.
- Self Directed Support is not succeeding, as citizens cannot actively obtain services.

3. 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?

The Scottish Government’s draft vision does not address the future requirements, as it is not a whole system approach. The SG draft vision is not person-centred and the vision does not include the human rights and needs of citizens, carers or families in ways that empower them to self-manage and to work with the NHS, Social Care, Third Sector to build a better Scotland.

The current vision is organisation-centred. It does not enable the citizens of Scotland to live their lives in the way they might wish, and to build trust, relationships and confidence with service providers, carers and staff. This leads to disappointment and disincentives and the System is then gamed and broken. Scotland’s health and social care system is currently organisation-centred and will not be sustainable until it changes and becomes person-centred. This change needs to be genuine, open, human rights based, transparent, earn trust and be collaborative in order to have any lasting and sustainable impact for the people of Scotland.
A system predicated on person-centred design, where the individual controls and manages their own data, is able to make it accessible to the necessary parties at the right time, is essential to improve healthcare outcomes in Scotland. With the current vision, systems will continue to work disparately and will not have access to the information needed to provide improved, seamless digital journeys for citizens, families and carers. Recognising the need to involve the individual citizen, and their information, in enabling of health, care and wellbeing services is a vital step to building the trusted, effective digital solutions of Scotland’s future.


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

There are a number of omissions (see Question 2 above). The latest vision repeats the mistakes of earlier visions, as it does not focus on citizens, families, the whole system, human rights and person-centred services and so the draft vision will lead to the same challenges, lack of implementation, missed targets and greater financial pressures on services.

Citizens, families and carers could make more impact, if they could work with Scottish SMEs, Third Sector and public sector to redesign the whole system. There have been some examples of innovation, although not as many as hoped and there could be more in the emerging Digital Health and Care Institute (DHI). The approach of the DHI is organic, person-centred, open and collaborative and it enables person-centred services and demonstrations.

Health and social care systems are an opportunity for Scotland to create sustainable economic growth and cross sector innovation through a genuine person centred approach. This needs a collaborative approach with all Scotland involved, and not just be a public sector vision. The latter omits citizens, carers and communities and the third sector and staff.

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

The key opportunities exist across a number of areas. The whole system must be person-centred. The citizen must be the point of integration, or the opportunities for the use of technology in communities will not happen as the system will ignore people. Scotland needs -

- Citizens - the individual participates in a digital Scotland system that includes a privacy protecting, portable, independent identity; consent management services; trusted, person-centred, data attribute exchange. This approach creates trust and confidence.
- Carers - this resource is largely ignored by visions and strategies, possibly even more than citizens, and yet they are critical to Scotland’s future.
● Citizen journeys - a person-centred approach; genuine re-design and plans; diagnosis, interaction, 2 way communication, clusters of organisations, data flow and trust.

● Future Data architecture - include independent identity layer; independent communications layer; data management layer; citizen journeys; demonstration environments and safe, secure digital places to test; consent; a Trust Framework.

● Identity - privacy friendly, portable, independent identity to enable the citizen to be the point of integration and to create trust and confidence as Christie recommends.

● Place of care setting - the place of care cannot change until Government, NHS, Local Authority and citizen agree fundamental underlying principles e.g. identity; consent management; data exchange; personal data stores.

● There is currently no mechanism and no infrastructure for effective 2 way communication between the citizen and the NHS / Local Authority.

● Digital identity - citizens cannot participate in a health and care ecosystem when they do not have a privacy protecting, portable, digital identity that the citizen trusts and controls.

● Pharmacies - again, 2 way communication with person-centred, trusted attribute exchange and portable, privacy protecting identity is needed.

● Digital spaces - the Digital Health and Care Institute and demonstrations.

● NHS staff and Clinicians - the participation by staff and clinicians to innovate.

● Design Equality - digital is a means to enable equality to be designed into the whole system based on choices about data architecture, principles and values.

None of these will happen sustainably unless citizens, government, organisations and staff agree values, principles and data architecture for a person centred approach. The Third Sector and civic society an offer innovation and support. Key opportunities are building a trusted, lifelong relationship between citizens, carers and staff that enables citizens to self manage and to self direct their digital interaction and support for health and care. Communities, families and carers also have a vital role in creating trust and building confidence for 2 way communication.

Clinicians and other people in the Health and Social Care system will achieve more if they are willing to share power, and take appropriate risks to design trusted, person-centred, collaborative services. The citizen is the point of integration.

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

Again, there has been no dialogue here and no consent or transparency with citizens and carers. Trust is a challenge. There is no such record as the definitive and complete electronic patient record (EPR). An EPR record is not ever complete, as it is currently NHS and medical specific. The EPR has no sustainable personal input or contribution from the citizen, carer or GP. NHS and Local Authorities must change their attitudes to the way the citizen participates; to their identity and role; and to the whole health and social care system for use and sharing of an EPR.
The NHS may never wish to share the EPR that it holds (i.e. the Tethered Record) beyond the NHS firewall. A NHS EPR is only a partial record, and an incomplete one. The NHS cannot always share an EPR within hospitals, and so a wide dialogue is needed about this architecture. An EPR could for example have 2, 3, 4 or 19 different digital parts, and many more data attributes. Its design, function and contribution to Scotland’s person-centred services and human rights has not been part of a dialogue with citizens, and carers, and how their needs can be placed first. The Scottish Parliament should investigate these critical issues.

Other initiatives have also not worked out as planned. The Anticipatory Care Plan (ACP) was first mooted in 2007 and guidance appeared in 2010. The ACP has not been able to achieve consistency, because it is organisation-centred and there is no effective digital application in Scotland for this service 10 years later. This demonstrates the challenges in Health and Social Care sectors, and the problems that citizens, carers and staff face in our broken System.

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

The Health and Social Care system in Scotland is not the parent of innovation. There are too many constraints for the H&SC system in keeping the day to day services going. It cannot really innovate as there are not resources, open values and infrastructure in place to enable innovation.

The landscape in which to enable innovation is cluttered. Scotland has focused on targets in H&SC and not worked to redesign “citizen journeys”, with person-centred services for citizens, carers and the citizen’s genuine participation and evidence. The Scotland approach is not currently equal and collaborative. There is low trust and no genuine equality, as citizens and Third Sector are not equal partners. Scottish Government will not succeed like this as citizens don’t appreciate the attitude e.g. the SG seeks to “tell” people - *We are developing a patient portal enabling citizens to easily access many of the digital health and care services on offer.*

Citizens do not trust being told. Scotland can remove barriers by taking a new, whole system, person-centred approach, building on human rights, trust and relationships among participants. These are human behaviours and characteristics. This involves digital demonstrators and tests such as Digital Health and Care Institute. Citizens, carers and families can simulate citizen journeys with organisations in digital services in a whole Scotland System Demonstrator.

Scotland needs citizens empowered with privacy friendly, portable identity; consent management services; and trusted, person-centred, data attribute exchange. It is time for people in Scotland to take control of their identity, the evidence that underpins it and their entitlements. Empowered citizens will be more likely to self manage, self direct and work with services based on trust. This is a personal data and digital ecosystem as a platform for the future of the Scottish economy and public services (e.g. Health and Social Care; the new Scottish Social Security System), adding value for individuals and organisations.