Consultation Response

vhs
voluntary health scotland

Renewing Scotland's full potential in a digital world
December 2020

Background

Voluntary Health Scotland (VHS) is the national intermediary and network for voluntary health organisations in Scotland. We work with our members and others to address health inequalities and to help people and communities live healthier and fairer lives.

It is important to point out that while VHS recognises that the consultation aims to develop the wider key principles and priorities of digital transformation in Scotland, we will aim to respond to the consultation by focussing on people's health and wellbeing as a central tenet of effective digital transformation. We understand that digital technology, infrastructure and implementation can both reduce *and* widen health inequalities and the underpinning social and economic inequalities that people face – it is therefore crucial that any overarching Digital Strategy is cognisant of its impact on people and the inequities they face.

The current pandemic has made it imperative that 'digital' is implemented equally and accessibly. An understanding of the digital challenges that organisations face across the health and voluntary health sectors, as well as the challenges facing those individuals who are most at risk, vulnerable or marginalised when it comes to health and care, must inform the strategic development of digital health.

VHS has been conducting research and monitoring the impacts of COVID-19 on people's health and wellbeing as well as the ability of the voluntary and community sector to continue to support people, since the beginning of lockdown. Our evidence shows that access to digital or digital exclusion emerged as one of the major issues alongside financial insecurity, food insecurity, mental health, and loneliness and social isolation. We heard of widespread digital exclusion whereby people do not have access to digital technology or access to the internet, mobile phones, or phone credit.

However, the research has also shone a light on the positive role digital has played in ensuring people are well supported and can access vital services as well as how digital has ensured organisations, their paid workforces and volunteers can continue to deliver their roles effectively and efficiently. We have also tracked the development of the discussion around digital and how this has progressed over the last 9 months from purely defining issues and opportunities to a more nuanced discussion around rights, co-production and an effective roll-out of digital infrastructure across sectors in a joined up manner.

VHS has used the findings of our initial survey[1] as well as the discussion from our online engagement events[2] [3] to help shape the VHS response to how the Scottish Government should define the priorities Scotland's digital future.

Introduction

The digital environment has always been fast paced, with a constant array of innovative technology, services and products being offered. However, the COVID-19 pandemic has further accelerated the rate of digital transformation, resulting in more widespread use of digital services, products and technology to work, play, stay connected and access vital services. This has also meant that digital is no longer in the domain of the 'tech' industry or large businesses but has transcended to other sectors: many small and local businesses have had to operate online, people are having to access healthcare appointments and services using a digital platform and many self-manage conditions using digital technology. Voluntary and community sector organisations have had to move online to continue to provide their suite of support and services. We are now finding ourselves in a situation where the adoption of digital is more a necessity than a choice. It is therefore timely and opportune to consult on the key principles that should guide digital transformation in Scotland.

Voluntary and community organisations were quick to pivot the support and services they provided to a number of online platforms, at the start of the March lockdown. For example, Scottish Families Affected by Drug and Alcohol offered a helpline, web-chat, bereavement and telehealth support services alongside a number of light-hearted, social ways for people to connect with each other. They quickly recognised that some families may be experiencing problems with substance use for the first time (where this may not have been the case before – due to lockdown and the strenuous social and economic situation). They therefore developed a range of new initiatives: Connecting Conversations[4], a 30 minute online zoom slot for people to have a cuppa and a chat, as well as Together in the Distance[5], a community arts initiative; Anonymous Pen Pals[6], a letter exchange project; and Voices Together[7], a virtual choir.

Parkinson's UK Scotland has been supporting working age people with Parkinson's with advice and support through a range of face-to-face initiatives. Due to the pandemic, it was no longer possible for people to come together in person and those with Parkinson's were feeling increasingly isolated. Parkinson's UK Scotland also identified that people were finding it harder to manage their Parkinson's symptoms – with many reporting worsening symptoms, including tremors, slow movement, pain and anxiety. This was happening in the backdrop of a number of NHS and community services being cancelled or postponed as well as group exercise and wellbeing sessions having to be suspended. Parkinson's UK Scotland pulled together a 12 day online programme[8] for those with Parkinson's and their families covering a range of topics and issues such as work, social security, hints and tips to self-

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[1] https://vhsscotland.org.uk/vhs-briefing-impact-of-covid-19-on-voluntary-health-organisations/
[2] https://vhsscotland.org.uk/key-messages-digitally-healthy-health-literacy-and-health-inequalities/
[3] https://vhsscotland.org.uk/key-messages-digitally-healthy-members-zoom-meeting/
[4] https://twitter.com/ScotFamADrugs/status/1251119488491311105
[5] https://www.sfad.org.uk/communities/together-in-the-distance
[6] https://www.sfad.org.uk/communities/connecting-families/anonymous-pen-pals
[7] https://www.surveymonkey.co.uk/r/VoicesTogetherChoir
[8] https://docs.google.com/document/d/1AI8DqXXZYF-DITQJJj-In-OH0W9-aIy18Og4Gm3CjxU/edit

manage, research, medication and treatment as well as navigating the health service. The events came to a close on 2nd of December 2020.

Realising the vital role that technology now plays for access to information, keeping in touch with friends and family, as well as leisure, RNIB Scotland have launched a range of Technology for Life support services for people with sight loss. Those who are eligible for support can apply for a grant for equipment through the Technology Grants Programme[9]. They also host a resource centre[10] selling a wide range of aids and equipment.

These are just some of the creative examples through which the voluntary and community sector has adapted its services to and should provide useful lessons for public services about how to act at speed to develop and deliver new services. Whilst the range of digital voluntary and community initiatives have provided vital service and support there have been many people who have fallen through the gaps of provision, therefore it is important to carry out the ground work to ensure digital is inclusive, before the roll out of national digital reforms.

Inclusive – digital for all

Due to the fact that this is an overarching strategy that aims to set out the key principles for digital transformation across Scotland we recommend that the strategy clearly states the importance of access to digital as a human right for all. We would like to call for access to digital to be as equally as important as access to our basic utilities. We recommend the use of the PANEL principles[11] in order to operationalise a human rights based approach to digital transformation.

We welcome the inclusive language of the consultation paper and the first principle calling for, *'no one to be left behind'*. We particularly welcome the definition of this principle to include geography, background and ability as barriers that need to be tackled to ensure everyone can get online and benefit from digital technology. The strategy states that, *"We will work to ensure that moving government and other services online reduces inequalities and does not exclude the least advantaged in society from the services they may need the most. This will require us to build on the Connecting Scotland programme to provide equipment and data packages and digital skills training to those in greatest need"*.

This is a positive statement that recognises the role of inequalities as a barrier to digital adoption and progression for people in our society. However, we believe that this statement needs to go beyond just digital skills and there is a need for the strategy and the Scottish Government to be cognisant of the wider inequalities that can result in barriers to digital adoption.

These include tackling issues such as poverty, privacy concerns (including a lack of access to private space to use digital), as well as digital literacy and a lack of trust in digital technology. Throughout our engagement with member organisations we have been consistently hearing of individuals and groups that could not access support or services because of a lack of phone credit, or that their data or phone credit ran out mid-appointment and that they could not afford broadband or did not have a credit rating to secure broadband packages.

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[9] www.rnib.org.uk/information-everyday-living-benefits-and-concessions-grants/grants-rnib
[10] https://www.rnib.org.uk/advice/technology-useful-products/stores
[11] PANEL: Participation, Accountability, Non-Discrimination, Empowerment and Legality

Our evidence showed that real issues such as the 'heat or eat' dilemma where families are having to choose between eating or heating their home are coming to the forefront and for these families digital is not a priority. However, in not having access to digital they are further disadvantaged as they do not have the same level of access to services, support, information and opportunities as those who are digitally literate and connected. An organisation at one of VHS's digital health events commented that, 'In the process of social renewal, which we must have as a national response to the pandemic, we must eradicate income poverty to enable low income families access to universal basic services which includes digital.'

Through our evidence gathering we have also heard of people not having space or privacy at home to make calls or online appointments for services or support. We were made aware of vulnerable groups such as women affected by domestic abuse who lost out on vital support and services that they were receiving face to face due to a lack of space and privacy within their home. Replicating and expanding on the Health Hubs Initiative[12] in England is one idea to pursue. These are dedicated community locations with people on hand to support those who are socially and digitally excluded to improve their online skills and access relevant information and tools, both online and in their local area. It would be interesting to utilise this model within existing community venues such as community centres, community cafes as well as local libraries and provide extended time and private spaces for people to use the digital equipment and access services and support in a safe environment. This would also support those who rely on library facilities to access digital tools but are limited to 1 hour or often 30 minutes slots, which is often not sufficient.

We recognise this may not be in the realm of this strategy alone and that a more joined up approach across the work of the Scottish Government is required, whereby a cross-portfolio and multidisciplinary approach ensures the effective and inclusive roll-out of digital across Scotland. We envisage that a number of Scottish Government strategies and policies will have a role to play: for example, the Digital Health and Care Strategy; Health Literacy Action Plan[13]; Public Library Strategy[14]; Local Governance Review[15]; Volunteering for All, A National Framework; and A Connected Scotland[16], amongst others.

We also think that Social Security Scotland can support people not only financially but through embodying principles such as offering a choice of methods to fill out applications, rather than the methods being digital by default. We suggest that the Scottish Government evaluate their existing and upcoming strategies and policies for their impact on tackling barriers to digital adoption, as well as to identify opportunities to help support this. This whole Government approach would also align well with the National Performance Framework.

Digital Literacy

The language of No one Left Behind is derived from the 2030 Sustainable Development Goals which focus on the relationship between digital, health inequalities and health literacy. In order to reduce inequalities within our society we need to ensure that the systems in place

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[12] https://digital-health-lab.org/health-hubs
[13] https://www.gov.scot/publications/making-easier-health-literacy-action-plan-scotland-2017-2025/
[14] https://scottishlibraries.org/advice-guidance/national-strategies/new-public-library-strategy-in-development/
[15] https://www.gov.scot/policies/improving-public-services/local-governance-review/
[16] https://www.gov.scot/publications/connected-scotland-strategy-tackling-social-isolation-loneliness-building-stronger-social-connections/

are health-literate and make healthy choices the easiest choice. The recent information revolution has allowed more people to have access to the most up-to-date information; however, inequities in access still persist. The onset of the Covid-19 pandemic highlighted how many people had access to up-to-date information via social media and other digital platforms; however, those without access to digital had to wait for accessible and timely information and in some cases struggled to get this at all. It is therefore imperative that all digital infrastructure and systems are focussed on individual and societal needs and aim to tackle inequalities.

To use the language of healthcare, digital should be *person centred* and support individuals to access what they think is important for their health and wellbeing ('What Matters to Me') and fully benefit from it as a result. As highlighted at the Shanghai Global Conference on Health Promotion, 'health is a political choice that requires investment in people and systems. We must ensure that people are part of the solution, and that no one is left behind, as we embark on this collective journey to transform our world for the better by 2030'.[17]

Digital technology is often created with the biases of those that create it so there is a need for a more diverse group of people to be involved in the creation of technology and for the acknowledgment that imperfections need to be fixed from the outset. So rather than technological development being purely within the domain of those specialist knowledge there is a need to make technology simpler to engage with.

The design of technology and associated service design needs to have responsiveness to barriers, challenges and needs at its very centre. This can be achieved through cross-sectoral working with the public, voluntary, community and private sectors to ensure technology and service design meet people's needs and narrow the inequalities gap rather than widen it. Those with lived experience of poor health, disability, long term conditions, social inequalities and poverty must be voices that are heard and involved throughout the design stage. The principles of co-production and engagement at the earliest opportunity need to be embedded with in all digital services and systems and the strategy needs to clearly state how it will engage with a wide range of voices, including those deemed hard to reach.

This engagement needs to be ongoing. Utilising a similar approach to that applied by the Social Security Scotland Experience Panels[18] may prove useful for continued engagement. This will result in better systems and better technology that is fit for purpose and widely accepted.

The Scottish Government discussion document says, *'We will make design decisions through the lenses of inclusion and offer clearly signposted alternative ways to accessing services for those who cannot, or do not want to, use digital routes'*. This is an area where the third sector has a role to play - we can be that lens and help ensure that people with medical needs, long term conditions or disabilities are involved in shaping this digital future, not just benefitting from it being delivered to them as an end product. Likewise, we can use our reach and the trust people often place in us, to help ensure highly marginalised groups including asylum seekers and street homeless people have a say in how public services are designed and delivered.

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[17] https://www.sustainablegoals.org.uk/health-literacy-and-the-sdgs/
[18] https://www.gov.scot/collections/social-security-experience-panels-publications/

We are also aware of the fact that care and assurance hasn't been mirrored in digital technology and this is something that needs to be designed into the services and products that are offered digitally. For example, there is less opportunity for care and assurance through a self-health management tool than there is in a face to face consultation with a healthcare professional. It is therefore important that people can have access to both.

Not digital by default

It is crucial that services that utilise digital technology offer people choice and a blended approach to appropriately meet people's needs. Digital technology should be utilised so that resources can be freed up to provide personalised "high touch" services for those falling through the gaps of digital provision. The digital services and products should be designed using Equalities Impact Assessments to ensure they meet people's needs as best as possible.

We urge that the Scottish Government should give proper consideration to issues such as choice, privacy, human rights, sustainability, and fully understand the impact of poverty and other social and health inequalities on people's capacity to embrace digital.

Sustainability and investment

The discussion paper says the government wants to see that third sector partners *'are supported to develop their digital capabilities and introduce new digital models'.* Welcome as this is, we would stress that while other sectors may be able to invest in and adopt complete digital transformation this may not be possible for the voluntary and community sector, either for financial reasons (because digital changes so fast that there are recurring investment costs) or because digital may not be the most appropriate way to meet all of the needs of their beneficiaries. However, we obviously welcome the aim for '*third sector partners to be supported to develop their digital capabilities and introduce new digital business models'.* We strongly urge that this support is sustainable in the long term and takes into account the changing and ever updating nature of digital technology, and the often fragile and stretched nature of the third sector in terms of capacity.

We welcome the commitment to build on the Connecting Scotland programme which aims to provide equipment and data packages as well as digital skills training to those in greatest need. Our evidence shows that there was great demand for the initial funding and support available which meant that at a local level organisations had to make tough decisions regarding who they were able to support, as the level of resource they received was either limited or they lacked capacity regarding implementation.

We would be very interested to know how the Connecting Scotland roll-out has landed with organisations working with particularly vulnerable groups. One of our smaller member organisations works to support very elderly, isolated people to stay active and socially connected within their community. They told us this week, *"We are having huge challenges making this work. Giving older people 7th generation iPads then trying to tell them how to use them over the phone with volunteers who do not have the same model of iPad is not easy…there appear to have been some very big assumptions made about how this would work and we just got an email asking if we would like to take more iPads so goodness knows how many were purchased or why the most expensive devices. Also, when they were delivered, complete with 12 months WiFi for each, the 12 month had been activated on distribution so they are running down before we can get people through the basic set up".*

The discussion paper asserts that, *'collaboration can achieve powerful results',* which means we must dismantle barriers that exclude the third sector from working in digital partnership with public sector services where these are unnecessary and simply a matter of

bureaucracy, for example, the exclusion of key service providers from access to public sector systems and data. We would challenge exactly how the stated ambition to *'promote common standards and technologies'* across the third sector in order to *'promote interoperability with public sector partners'* is to be realised.

We are aware that, far too frequently, health and care charities find barriers put in place by their public sector partners regarding common standards and technologies, not the other way round. Early in 2021 VHS is facilitating engagement between a group of Scotland's largest health charities and the Scottish Government's Digital Health division, with a view to exploring exactly these kinds of questions and ambitions.

However, if we consider the overall size and diversity of the third sector, this ambition sounds rather like rhetoric. Taking registered charities alone, there are 4,448 charities directly involved in the advancement of health across Scotland, i.e. supporting people's health and wellbeing through a variety of services and support, but the vast majority are small and local, so there is a mountain to climb if common standards and technologies, integrated with public sector partners' systems, are to become the norm.

Conclusions

The coronavirus crisis has demonstrated to health organisations that working digitally is more important than ever before, whether they are in the public, private or third sector. The crisis has driven fundamental changes in how services and support have had to be delivered, some of which may become permanent, or part of a blended offer. Organisations in the third and community sectors were arguably the fastest off the starting blocks at the start of the March lockdown in terms of moving support and services on-line wherever they could.

The challenge now is to ensure that Scotland's fast developing national and local digital strategies will protect and enhance people's health and wellbeing going forward and that digital is not seen as a simple, one size fits all solution to people's very individual needs. Above all, these strategies must avoid exacerbating existing health inequalities or creating new ones.

The ambition for a Digital Scotland where, '*wellbeing is both safeguarded and enhanced through the greater use of digital technology'* is not a simple question of creating equality of access to digital, it requires proper consideration of questions concerning choice, privacy, human rights, sustainability and trust. It requires a real grasp of the impact of poverty and other inequalities on people's capacity to embrace digital. It requires understanding and compassion in relation to those people whose health conditions may be so complex – e.g. advanced dementia – that only very tailored digital solutions will ever be an option. A country where there is '*universal Digital Citizenship, with world-leading levels of digital inclusion, participation in community and democracy, accessible by all'* will only come about if all of the above is taken into account.

The language and culture of co-production, person-centredness, health literacy, ethics, clinical governance, self-management and lived experience, common in the world of health and social care, do not feature greatly in the discussion document. Nor does the language of compassion, kindness or humanity figure anywhere, but these are essential components of our health and care services, whether delivered by the public, third or private sectors or by unpaid carers. Rather, the language and culture of universal digital citizenship, digital skills training, broadband coverage for all and joined-up digital services figure strongly throughout the paper.

We need to bridge the language and culture gap as much as bridging the technological gap, if we are to collaborate and work to ensure digital will truly deliver for health and wellbeing and that literally no one is left behind.

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