

Human

Rights

Principles

for Digital Health and Social Care



Exploring the principles in practice

The Health and Social Care Alliance Scotland (the ALLIANCE), Scottish Care and VOX (Voices Of eXperience) are working together to support the development of rights based digital health and social care policy and practice across Scotland.

Over the summer of 2021, we explored a set of five principles for a human rights-based approach to digital health and social care:

People at the centre

Digital where it is best suited

Digital as a choice

Digital inclusion, not just widening access

Access and control of digital data



We developed these principles collaboratively, engaging with a range of individuals and stakeholders through online workshops and a survey.

We wanted this to extend beyond theory, to identify practice based examples where these principles are already at the heart of work being delivered. As a result, we listened to what people told us to share a series of case studies, presented in this paper. The case studies shared here are neither complete nor exhaustive. However, we hope they can help bring the principles to life and inspire others to apply them in their work.

In response to the pandemic, we have seen a great mobilisation of stakeholders in the area of digital and technology across Scotland. This materialised through various positive initiatives, such as the Connecting Scotland programme, the rapid roll out of Near Me and a coordination of local and national supports available to shielding individuals. However, pandemic responses have also removed certain rights and choices. Therefore, we need to ensure that we continue to build on what works and challenge what does not.

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the quick creation [of Near Me consultation options] and then almost immediate destruction of accessibility I had for a brief eight months [once lockdown ended and services went back to only offering face-to-face] was so jarring. It's clearly possible these things can be done for folk like me: it's just... nobody particularly wanted to.

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Principle 1: People at the centre

People should have access to inclusive and flexible digital services that meet their needs, rights, preferences and choices, with support if appropriate.

- Digital services should be focused on the best outcomes for the person, not the needs of the service or the health and social care system.

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I think it's worth acknowledging differences in needs for age groups. I have experience [...] supporting children and young people with cancer, and this is an age group who actively become more and more digitally confident and diverse. We must understand and utilise digital tech to best support them or we will be left behind.

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What this looks like in practice:

Throughout our engagement we heard of various **tools that allow people to be involved in the preparation and planning of the care and support they receive:**

- For example, **the Anticipatory Care Planning toolkit developed by the iHub** aims to support care providers to carry out conversations which provide ‘people with person-centred, coordinated care, focusing on goals and preferences, whilst offering opportunities to consider realistic treatment and care options.’
- Similarly, the **ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) form developed by the team at the NES Digital Service** is created through conversations between a person, their families, and their health and care professionals to understand what matters to them and to create personalised recommendations for their treatment in a future emergency.
- There are also examples of tools which can be created by individuals or their families. The **PAMIS Digital Passport** allows people with profound and multiple learning disabilities to tell their own story, giving unique insight into their lives, experiences, needs and character, all of which help to build positive interaction and truly person led communication.



Principle 2: Digital where it is best suited

People should be involved in deciding how, where and when digital is used in health and social care, and co-create rights based digital services to ensure they are appropriate and effective.

- Digital services are not always appropriate and should not automatically be the default health and social care service.

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I have had positive experiences in the use of Near Me which meant that it took less time out of my day to have an appointment, I didn't need to travel and as I live in a rural location and sometimes don't have access to a car this was important, and I was able to use a mix of video calling, emailing photographs and in person visits to the surgery that met my needs.

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Do not dictate what we need to us - let us tell you, and then you help us deliver it.

”

What this looks like in practice:

One of the key themes arising from our engagement was that of **relationship building through multiple channels**. It is important to consider existing and new relationships and how the introduction of digital or new tech will affect these.

- It was noted that simple solutions, such as sending appointment reminders, introductions or useful information by text can be highly beneficial. One example of this is the **SMS Shielding Service** developed in Scotland during the first wave of the COVID-19 pandemic to help those on the shielding list access urgent support and food deliveries. We also know that informal uses of text, email and even social media has been used by various charities and organisations for a long time to develop and maintain support relationships.

- Furthermore, some organisations have developed bespoke channels to support their audience's needs. **Versus Arthritis**, for example, have a virtual assistant service for basic Q&A style information linked to arthritis.
- Similarly, **Change Grow Live Forth Valley Recovery Service** have adapted their service delivery model in response to lockdown to include telephone and virtual options. They have different channels for different supports, depending on what proved to work best for their client group.

Another recurrent theme was that of **mixed approaches to service delivery which include both digital and non-digital options.**

- We heard from care home representatives from across Scotland who were involved in **the Digital Approaches in Care Homes programme**, which provided iPads to help care home residents stay connected with friends and relatives and support their health remotely. Care homes were able to provide new ways of socialising, exercising and attending health consultations for their residents. Some even took into consideration families that were less digitally connected and emailed them videos of their loved ones if they weren't able to link in with them live.
- We also heard personal examples from participants in our workshops, some of whom were able to link in with NHS specialists remotely through a range of channels, including **Near Me**, WhatsApp and face to face. **Online triage options pre-consultation** were seen as a potentially good way to ensure that people were accessing the most relevant support in person.
- A need for digitally-connected private spaces across local communities, where people could go to access digital support or virtual appointments, was acknowledged across our engagement. Initiatives of this sort are already being developed across Scotland, with one example being provided by the DVVA Technology Enabled Care Team and Brooksbank Centre in Dundee, who have opened **a hub to allow residents in the East End of Dundee to access online medical and welfare appointments.**

Here are some further ideas for how this principle might be fulfilled in the future.

What if...

- There was flexibility built within services, so that people accessing services could seamlessly switch between online, telephone or face to face appointments according to their needs at a specific moment in time?





Principle 3: Digital as a choice

People should be able to make an informed choice between using digital or non-digital health and social care services – and to switch between them at any time – without compromising the quality of care they experience.

- People should be fully involved in decisions made about their care. This should include information about any digital options being considered, and the non-digital alternatives.

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the choice I would make is to have someone paired with me who doesn't find technology a struggle, who can mark a preference (much like we do now for whether someone wants a specialist of a certain gender).

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“

We also need to factor in here that people's circumstances can change, they may develop other conditions that affect their ability to participate, or their confidence levels.

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What this looks like in practice:

In order to meet the needs of people they aim to help, services must **adapt their offering to ensure it meets the abilities of people accessing support and allows choice.**

- The Food Train worked to deliver groceries to people throughout Scotland during pandemic and shop for older people who weren't able to do it themselves. Due to infection concerns, there was a drive at the start of the pandemic to get people paying for this service by direct debit. However, the charity acknowledged the fact that some individuals prefer cash and some have family managing their accounts, so they adapted their processes to allow for wider choice.

We also heard about the need to embed more **awareness of why some people might choose digital or non-digital options, including embedding trauma-informed practices** to ensure people can access services safely.

- For example, digital attendance options can be empowering and provide more safety or comfort to certain groups, as it allows people to contribute in various ways (verbally or in writing), put their cameras off, join or leave on short notice. But we must also acknowledge that for others digital can be a triggering medium which will not suit their support needs. Some organisations, such as **Health in Mind, developed their support pathways in light of the COVID-19 pandemic to ensure they were offering both online and telephone options, according to need and preference.**

Here are some further ideas for how this principle might be fulfilled in the future.

What if...

- Services were better able to provide information around what their access and engagement options are, as well as guidance for interaction which sets out how the different options can be used and why people may prefer some options over others?





Principle 4: Digital inclusion, not just widening access

People should have access to free training and support to develop the skills, confidence and digital literacy they require to make a meaningful choice whether to access digital health and social care services.

- Digital services should be accessible, trustworthy and inclusive.

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we need to make sure that digital skills training, confidence and literacy is provided to both service user and those giving the care.

”

“

the use of digital devices that do not require any 'digital skills' to operate them should be included when options are considered in relation to digital inclusion and digital services.

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What this looks like in practice:

In response to the rapid uptake of digital technology during the pandemic, many organisations stepped in to provide **accessibility support**.

- The Glasgow Disability Alliance responded to the COVID-19 situation by setting up peer support teams, distributing tech and providing bespoke training. Their **GDA Connects** service also includes specialist support for visually impaired people and those who don't speak English as a first language.
- **AbilityNet** supports anyone living with any disability or impairment to use technology to achieve their goals at home, at work and in education.

Furthermore, some initiatives were developed to provide **tailored support, coaching and practical resources to those who might be digitally excluded.**

- **Connecting Scotland** is a Scottish Government initiative set up in response to coronavirus. Its aim is to help get every citizen in Scotland online by providing helpful resources for friends and family to help people get online, and by managing a funded programme to support the most vulnerable citizens get online through access to devices, connectivity and digital skills support.
- **Friends of the Centre for Integrative Care** developed an online version of their self-management Cognitive Behavioural Therapy course, aimed at individuals with no previous digital skills or who were previously digitally excluded and didn't have equipment or digital connectivity. Individuals were supported to access this course and develop skills.

Here are some further ideas for how this principle might be fulfilled in the future.

What if...

- the same principles and support applied to the workforce too, to ensure we support the development of a skilled workforce which can in turn better support people?





Principle 5: Access and control of digital data

People should have access to data held about them by health and social care services and have control over this data and how it is used.

- People should give free, prior and informed consent to the use and sharing of their data, particularly outside health and social care.
- If consent is given, sharing should allow people to avoid 're-telling their story', be straightforward for all involved, and maintain the highest possible security before, during and after sharing.

“

As someone with multiple long-term conditions, I am sick and tired of having to repeat everything umpteen times to different departments/services, and to have medical personnel ignore my other problems, simply concentrating on their own specialty. Hopefully, data sharing can lead to a more holistic approach, but I absolutely agree that the individual should have ultimate control over what is and is not shared.”

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What this looks like in practice:

We heard that there are some **services which provide open access to people's clinical data**, which was seen as a great benefit by our participants.

- **My Diabetes My Way** is an interactive website developed by NHS Scotland, which aims to help support people who have diabetes and their family and friends. It provides various information about diabetes, but also up-to-date diabetes clinic results, to help individuals manage their condition more effectively and to set their own goals.

We also heard about informal examples of where **biographical or personal information is provided by the individual to support of the care they receive.**

- One participant was happy to share emails with their consultant in advance of their care sessions, in order to provide more context to their consultation. That allowed opportunities for better understanding and more efficient time use within the actual consultation.

Here are some further ideas for how this principle might be fulfilled in the future.

What if...

- we viewed access and control over our own personal data as a human right, and worked with people to empower them to understand and exercise this right within services?
- We all had a secure personal data store, containing our health and wellbeing information, that we could add to and share all or part with others
- We were able to provide information digitally before interacting with a service or engaging in a consultation, to help have a meaningful and high quality conversation?



Next steps

As mentioned in the introduction, we are aware that there are many more examples of good work founded on human rights principles taking place across Scotland. The ALLIANCE, Scottish Care and VOX would like to invite others with an interest in this work to get in touch to share knowledge and explore the following questions:

- How can we raise awareness of further good practice examples across Scotland?
- How can we embed human rights approaches within the design, delivery and evaluation of digital services?



Contact

For more information and to discuss this work, please contact:

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About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims. We seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

About Scottish Care

Scottish Care represents over 400 organisations, which totals almost 900 individual services, delivering residential care, nursing care, day care, care at home and housing support services.

Our membership covers private, not for profit and charitable provider organisations. It includes organisations of varying types and sizes, amongst them single providers, small and medium sized groups, national providers and voluntary organisations and associations.

Our members deliver a wide range of registered services for older people and those with long term conditions, learning disabilities, physical disabilities, dementia or mental health problems.

Our vision is to shape the environment in which care services can deliver and develop the high quality care that communities require and deserve.

Scottish Care is committed to supporting a quality orientated, independent sector that offers real choice and value for money. Our aim is to create an environment in which care providers can continue to deliver and develop the high quality care that communities require and deserve.

<https://scottishcare.org>



About VOX

VOX Scotland is Scotland's national voice on mental health – we represent our members' views to Scotland's politicians and health professionals to make sure Scotland's laws and mental health services reflect service user needs and interests. VOX is Scotland's only national mental health advocacy organisation run by people with lived experience for people with lived experience.

VOX stands for Voices of eXperience, and VOX was formed to ensure that the voices of people with a lived experience of mental illness can actively:

- Shape Scotland's laws
- Influence service design and delivery
- Promote a better understanding of mental illness in wider society
- Advance the general interests of people with mental health issues.

VOX provides collective advocacy at the Scottish national level – representing groups and communities with a lived experience of mental illness – and we also support individuals to form their own groups to express their experiences in their own words.

In some ways, VOX acts as an intermediary between the people, Scotland's Government and health and social care services. We try to promote a good 'fit' between mental health services and laws to ensure that everyone benefits and public money is spent wisely.

We don't provide individual advocacy, counselling, home support or care services – we exist to represent our members' views at the national level to health professionals and politicians. We don't have a vested interest in service provision and this enables us to represent our members' views without referring to financial considerations or a political agenda.

VOX represents at the national level across all mental health issues and works in partnership with local/ regional groups and other specialist mental health organisations. We don't compete with local groups and encourage all our members to think about joining local groups and organisations.

<https://voxscotland.org.uk>



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