

# Human Rights Principles for Digital Health and Social Care



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for Digital Health and Social Care



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# Background

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The Health and Social Care Alliance Scotland (the ALLIANCE), Scottish Care and VOX Scotland have been working together since 2021 to create a human rights based approach to digital health and social care. Collaboratively and independently, we have worked with partners and stakeholders across sectors to support services to maximise the capabilities of digital by embedding a human rights based approach to service design, delivery and improvement.

In 2025, The ALLIANCE engaged and reviewed our existing human rights principles for digital health and social care due to the continued pace, growth and diversity of digital innovations, technologies, and digital health and social care services. Reports from [Audit Scotland](#) and the [Good Things Foundation](#), continue to highlight ongoing barriers of digital exclusion, lack of privacy and issues relating to the equity/fairness of service models, highlighting the critical importance of this work.

This year, we engaged with a range of individuals and stakeholders via online and in person events/workshops. As a result, we listened to what people told us and, as well as reshaping the principles, we have also shared examples of good practice in action to show what digital health and social care services can look like when they embed the principles in practice.

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## Foreword

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Human rights are central to the work of the ALLIANCE, and I am delighted to see this refreshed version of the digital human rights principles launched. Since 2021, we have seen increased pace of change in the adoption of digital to support people's health and wellbeing. However, everyone in Scotland must see the benefits of digital transformation. These principles seek to describe what this means in practice. We hope that they provide a focal point for any organisation digitalising their services, as well as for people to understand and assert their human rights in this digital world that we all live in.

Chris Mackie, Director of Digital, The ALLIANCE



# Principle 1:

## Person led services with people at the centre

People should be involved in co-creating digital services, deciding how, where and when digital is used in health and social care. People should have access to inclusive and flexible digital services that meet their needs, rights, preferences and choices, with support if they need.

The review highlighted that although 'people at the centre' is a strong principle, it didn't emphasise sufficiently the need for people to be in the driving seat, rather than recipients of available services. Digital services are not always appropriate and should not automatically be the default. Service providers need to engage and enact existing service standards (e.g. the Digital Scotland Service Standard), in consideration of their use of digital as 'business as usual'. There is an array of guidance, principles and standards available to support and aid the service design process to ensure services meet people's needs - following this type of guidance must be viewed as compulsory regular practice, if we are to strive for quality services.

People who access health and social care services should be involved throughout the design process of developing digital services, contributing their lived experience and sharing their hopes and goals. Adopting a co-production approach ensures digital services are fit for purpose and meet the needs and choices of people, whilst capturing their aspirations and adopting a positive goal setting culture. Creating person-led services lets people identify what they need and be a part of the solution.



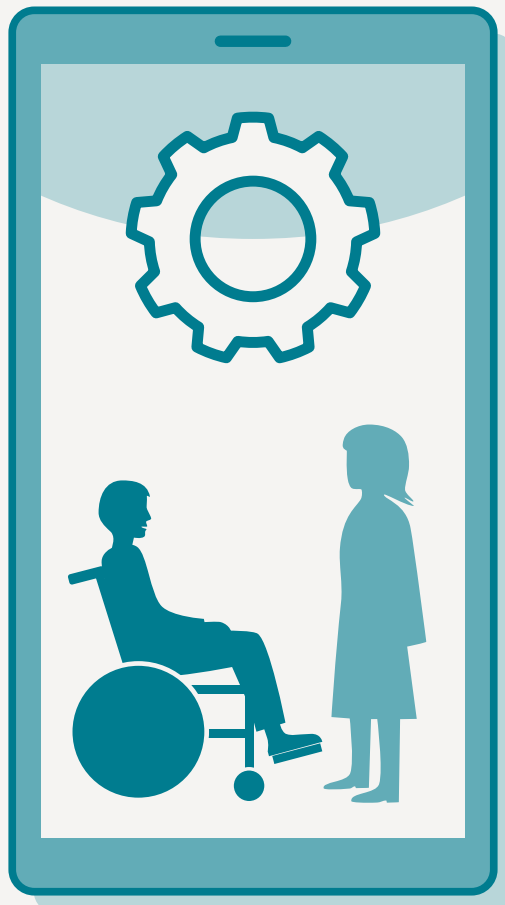
## Examples in action:

### **Epilepsy Self Management**

**Toolkit** – People across Scotland brought together their stories and experiences about living with epilepsy. Professionals, families and carers shared theirs too. They worked together to design a set of digital self management resources, which frames these stories and advice for others

**Digital Citizen Panel** – ensures that the seldom heard voices of lived experience are supported and encouraged to engage in the design and improvement of digital services, helping to shape and inform the development and delivery of digital health and care.

**The Real Toolkit** – A digital leaving care resource for STaf, Scotland's national membership organisation for all those involved in the lives of people leaving care. The Real Toolkit was created by the Real Advisory Group through genuine coproduction, meaning that both people with care experience and the workforce are equal partners and stakeholders in this work.



## Principle 2:

### Digital as an informed, meaningful, ongoing choice

People should be able to make an informed choice between using digital and 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 advised on the array of support services available to them, including information about any digital options to be considered, and the non-digital alternatives. We heard from people that often they are unaware of what digital tools are available and feel apprehensive about accessing digital services without some initial support and reassurance. We have also heard that it is often family support that initiates the use of preventative digital solutions, which are often not shared by professionals until it is part of a formal diagnosis, after a crisis intervention or as part of a treatment plan.

For *meaningful* choice, this needs to be prioritised as part of the design or implementation of digital services to ensure there are no negative consequences or inequalities when choosing a non-digital service journey.



## Examples in action:

**Age Scotland By Your Side** - Age Scotland have advisers who provide holistic multi-issue advice and low-level advocacy service and support older people to overcome barriers, like digital exclusion to access the services they need. It has a helpline that helps over 50s with energy, finances, social security etc. and an in-person service in a few areas.

**National Galleries Scotland** offer a Visual Impaired Programme, a free, relaxed and sociable art sessions that take place online or live in the gallery.

**Care Connectors – enabling choice and confidence** - In North Ayrshire, Care Connectors are working alongside adults with learning disabilities to enable informed and ongoing choice in how they access support and community life. Connectors help people and families explore both digital and non-digital options, offering reassurance and practical support so that technology is introduced at the right time and in the right way. By building trusted relationships, Care Connectors ensure people are aware of what is available, can try digital tools without pressure, and can move between digital and non-digital services without compromising their experience of services. This project is a collaboration between SCLD, North Ayrshire Learning Disability Service and Scottish Care.



## Principle 3:

### Digital Inclusion: embedding safety, skills and confidence

Everyone has the access, skills and confidence to utilise digital services if they choose to do so, regardless of their socioeconomic background, location or ability.

We know that people can experience digital exclusion for a number of reasons, and the consequences and effects are likely to increase as the digitalisation of health and social care delivery expands. Digital inclusion is not static, it is fluid and complex, influenced by a range of different factors and can change over the course of our lives as circumstances and situations change. There are economic requirements (cost of devices and data) as well as skills, confidence and learning implications.

Digital inclusion is key to basic citizenship, and some communities are more at risk than others of being affected by digital exclusion, with over two thirds of those with no basic skills having an impairment or seeing themselves as disabled (Rural Service Network, 2025). Ongoing access to digital skills training is necessary to ensure people have the confidence to access services and stay safe whilst online.



## Examples in action:

### **The ALLIANCE - Discover Digital**

Discover Digital is a project to raise awareness of digital tools which promote health and wellbeing. It offers free roadshows and tailored training workshops on digital health and social care tools for community groups, third sector organisations and communities.

### **Simon Community Scotland- Get Digital Scotland**

The Get Connected has connected over 1600 people experiencing homelessness to the digital world. The Get Connected model combines the provision of a device, unlimited data, support from their own support worker (trained in digital inclusion) and a learning framework of digital skills.

**Ability Net** supports a wide range of users; from older or disabled people looking for help with their technology to digital professionals advocating for accessibility and inclusion best practices within their organisation.



## Principle 4:

## Quality digital experiences - rights and system responsibilities

Digital services should be accessible, trustworthy and inclusive, providing a high quality digital experience for people who use them. Services should be accompanied by supportive initiatives to provide tailored support, coaching and practical resources to assist those who might be experiencing digital inequality.

We know that people continue to experience barriers when it comes to accessing digital services and service providers must make it easier for people to access digital tools and supports, with simplistic functions which can be navigated with ease. The Good Things Foundation reports that one third of those offline say it's difficult to use council and government services and 31% of UK adults don't access health services online. Co-produced digital solutions should result in a reduced demand for digital support, as they are made by people for people rather than 'made for' and 'done to'.

The Pillars for Digital Inclusion framework (SCVO, 2023) includes an explicit focus on 'inclusive design' as key to enabling digital inclusion, switching the narrative from an individual journey to a shared responsibility where services embed digital inclusion and accessibility as a core part of digital transformation. The paper is recommended to anyone working in any sector across health, social care or wider services who are designing or developing digital services or supports. A person should be able to use digital services without requiring advanced 'digital skills', they should be accessible, functional and pleasant to use.

Digital transformation brings value and benefits across health and social care services, but there is also a cost and a responsibility in terms of equitable access. Health and social care organisations and providers need to embrace responsibilities to minimise inequality.

**Across our projects we heard the following recurring themes which we shared with the Digital Citizen Panel for further exploration and deeper understanding:**

- People are keen to learn the skills and develop confidence to access digital services and support but feel overwhelmed at the array of services available and are unsure who can help support them to embark on a digital journey and to stay safe.
- People want choice to access health and social care support in a way which is appropriate to them - which can alter and change across services over time (e.g., switching from non-digital to digital options and vice versa).
- People want a simple system to allow information and data to be shared between themselves and health and social care providers. People strive for digital to make life 'easier', 'save time' and 'reduce repetition' (see principle five).

When thinking of the benefits of digital inclusion and quality of those experiences, there should be equal focus given to both the benefits of service efficiency and to the personal benefits - to families and people, those who are at the core of health and social care. The ALLIANCE's Digital Learning Series published a paper '[Benefits and outcomes of digital in the context of health and social care](#)' in 2025 which highlighted how accessing support digitally improved an individual's health or care experience.

## Examples in action:

**Carers UK - Jointly app for carers** an innovative mobile and online app that's designed by carers for carers, developed by Carers UK. Carers UK constantly update the app in line with users' feedback.

**ALISS- A Local Information System for Scotland** a coproduced national digital service enabling people and health and social care providers to find and share information on health and wellbeing resources, services, groups, and support in their local communities and online. In 2025, ALISS refreshed its '[Our Health, Our Place, Our Voice](#)' Toolkit to meet the changing needs of today's young people and the evolving educational landscape, reflecting the importance of having young people's voices heard.



## Principle 5:

## Secure access and control of personal 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.

If people give prior and informed consent to digital information sharing between people and across service providers, it should and could avoid people 'retelling their story' and provide opportunities for better understanding and more efficient use of in person, human interaction during care, support and interventions.

The ability for people to have secure access and control of their personal data also helps a partnership approach to health and social care, where individuals are informed equals and can be proactive in taking a self management approach to their care, setting their own goals; integrating across services that can also be more proactive in how they support and respond to individual needs.

We know that remote monitoring has brought many benefits to both individuals and service providers, and it is now possible to build a personal data store that is safe, secure, and scalable, which can result in personal, social and economic benefits.



## Examples in action:

**My Diabetes My Way** - an interactive website developed by NHS Scotland, which aims to support people who have diabetes and their family and friends. It provides information, up to date clinic results, self management tips and allows people to set their own goals. clinic results, self management tips and allows people to set their own goals.

**PAMIS Digital Passport** - a simple, easy to use, flick-through e-book that can be created and displayed on tablet devices, computers and phones. Each PAMIS passport contains information about one person and uses video, photography, sound and text to help that person express their needs. The passport, uniquely, is owned by the individual and is shared with those they choose to share it with.

**Community Connections** - is a research programme which is exploring with the community better ways for people to find and share local resources to help people live well. The programme is funded by UK government through the Moray Growth Deal which aims to support the remobilisation of health and care services and the economic recovery of the Moray region, by investing in research and innovation activities aligned to the digital health and care agenda.



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# Contacts

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

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# Acknowledgements

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# About the ALLIANCE

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The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector membership organisation for the health and social care sector. We bring together over 3,500 people and organisations dedicated to achieving our vision of a Scotland where everyone has a strong voice and enjoys the right to live well, with dignity and respect. Our members are essential in creating a society in which we all can thrive, and we believe that by working together, our voice is stronger.

We work to improve the wellbeing of people and communities across Scotland by supporting change in health, social care and other public services so they better meet the needs of everyone in Scotland. We do this by bringing together the expertise of people with lived experience, the third sector, and organisations across health and social care to shape better services and support positive change.

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## The ALLIANCE has three core aims.

### We seek to:

- **Empower people with lived experience:** we ensure disabled people, people with long term conditions, and unpaid carers are heard and that their needs remain at the heart of the services and communities.
  - **Support positive change:** we work within communities to promote co-production, self management, human rights, and independent living.
  - **Champion the third sector:** we work with, support and encourage co-operation between the third sector and health and social care organisations.
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The ALLIANCE is committed to upholding human rights. We embed lived experience in our work and aim to ensure people are meaningfully involved at every level of decision-making.

Working together creates positive, long-lasting impact. We work in partnership with the Scottish Government, NHS Boards, universities, and other key organisations within health, social care, housing, and digital technology to manage funding and develop successful projects. Together, our voice is stronger, and we can create meaningful change.



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