

Human Rights Principles in Digital Health and Social Care



Scottish Care
Voice of the independent care sector



The Next Iteration!

Background

[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. We are exploring a set of principles for a human rights-based approach to digital health and social care.

Between June-August 2021, we carried out engagement to seek a wide variety of views on our [draft principles](#) and how useful they might be. We talked to people who used digital services, those who provided services and support workers who engaged with digitally excluded groups.



We have now refined the principles based on what people told us. These 'new' principles still follow the same themes but are more concise and practical in nature. We will use these principles to campaign for the better implementation of human rights principles in digital health and social care. We will also work to identify practice-based examples of how they can be applied in real life scenarios.

Human Rights Principles for Digital Health and Social Care

Providers must ensure that all digital health and social care services are based on firm human rights foundations. They must respect, protect and fulfil human rights, and embed a human rights based approach using the **PANEL Principles** (Participation, Accountability, Non-discrimination and equality, Empowerment, Legality).

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.

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.

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.

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.

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.

August 2021

Definitions



Digital health and social care use a wide and ever-expanding range of services, tools and resources. This can include apps, wearables, websites, sensors, or tele-monitoring tools. For a more comprehensive definition, please see www.dhi-scotland.com/about/what-is-digital-health-and-care.



Health and social care services are all services provided by the NHS, care homes, housing associations, local authorities and other care at home, community, third and independent sector organisations that promote people's health and wellbeing.

Examples of digital health and social care services people might be familiar with are: booking a GP appointment online, attending a Near Me video consultation or having a telecare panic button installed at home.



By digital health and social care data we mean information about people and their health that is stored digitally on different systems: on health records and care plans, on information systems managed by local authorities and wider support services, or even on personal phones. To understand more about data please see www.alliance-scotland.org.uk/digital/tools-and-materials/data.

Contact

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

Carmen Paputa-Dutu - Digital Health and Care National Lead, the ALLIANCE

✉ carmen.paputadutu@alliance-scotland.org.uk

Gordon Johnston - Director, Voices Of eXperience (VOX)

✉ G_Johnston@btinternet.com

Communications - Scottish Care

✉ comms@scottishcare.org