Human Rights Principles
in Digital Health and Social Care

Introduction

This paper proposes a set of principles for a human rights based approach to digital health and social care. The Health and Social Care Alliance Scotland (the ALLIANCE), Scottish Care and VOX (Voices Of eXperience) want to engage with people and organisations to refine the principles and collectively develop practice-based scenarios to illustrate their application in health and social care. Our aim is to support the development of rights based digital health and social care policy and practice across Scotland.

Digital developments and human rights

COVID-19 has increased the pace of digital technology's use in health and social care. For example, the "use of video consultations direct from people's homes" as highlighted in the Digital Health and Care Strategy[1], has been supercharged by the nature of the pandemic and the importance of social distancing to preventing the spread of the virus.

The evaluation of the extension of Near Me during the pandemic[2] and the People at the Centre Engagement Programme[3] both highlighted a range of benefits, including improved access and convenience for some

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[1] https://www.gov.scot/publications/scotlands-digital-health-care-strategy-enabling-connecting-empowering/
[2] https://tec.scot/wp-content/uploads/2020/09/Near-Me-public-engagement-Full-Report.pdf
[3] https://www.alliance-scotland.org.uk/wp-content/uploads/2021/02/Health-Wellbeing-and-the-COVID-19-Pandemic-Final-Report.pdf

users. However, barriers were also reported, including digital exclusion and lack of privacy for health and care conversations in people's homes. Concerns have also been raised about the equity and fairness of different types of services. For example, if it is possible to get a quicker digital appointment than a face to face appointment, what does this twin track system mean for people who have no access to – or desire to use – technology?

Digital technology can be an enabler of human rights, offering individuals the opportunity to be more empowered and better informed.[4] But its unquestionable benefits should not lead to us ignoring the risks it presents – particularly when we are transforming our ways of working at speed. Actions must be taken alongside technological change to ensure that we do not widen the digital divide and to ensure that choice remains paramount in our interactions with health and social care services.

With the refresh of Scotland's Digital Strategy recently published[5] and that of the Digital Health and Care strategy on the horizon, the ALLIANCE, Scottish Care and VOX believe it is important to propose some founding principles to influence these key policy developments.

Human rights principles for digital health and social care

We welcome the statement by the Cabinet Secretary for Health and Sport that digital consultations should not be a replacement for face to face.[6] Extending beyond consultations, we believe that people accessing services and support should have free, meaningful and active choice over the use of digital technology in their care and support. This should underpin any future digital strategies, including digital health and care, and support a human rights based approach to the future of health and social care.

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[4] https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25158&LangID=E;
https://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/DigitalTechnologiesandHR.aspx
[5] https://www.gov.scot/publications/a-changing-nation-how-scotland-will-thrive-in-a-digital-world/
[6] https://bit.ly/3lfgoea

Scottish Care launched a co-produced Human Rights Charter for Technology and Digital in Social Care in September 2019[7]. This charter seeks to place the development and use of technology and digital in social care within a human rights and ethical perspective, and is the first of its kind to be developed in Scotland. We believe that its principles are cross cutting and could be practically adopted across health and social care. Building on the charter, that incorporated the rights based PANEL Principles, we propose the following human rights principles that should be embedded into digital health and care developments at all levels.
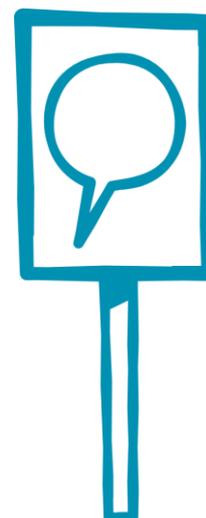
1. **People at the centre**. Any digital experience needs to be flexible around individual needs, preferences and choice.

2. **Human rights foundations.** All digital services need to respect and protect human rights, whilst also seeking to enhance and fulfil individuals' ability to exercise their rights.

3. **Digital as ongoing choice**. 'Digital first' approaches can risk alienating or disadvantaging those who are currently excluded from accessing digital services. Instead, there should be 'digital choice'. People should have equal access to services on equal terms, regardless of their circumstances. Moreover, we need to recognise that circumstances change, and that people might want to switch between digital and analogue service provision seamlessly, in a way that suits them.

4. **Digital where it is best suited**. Digital service provision lends itself better to some outcomes and processes (i.e. updating preferences online, transactional services) than others (i.e. tailored support, relational services). We need to be aware of this and build digital capacity where it is most impactful and appropriate, whilst also keeping in mind that digital does not resolve everything and should not replace face to face services.

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[7] https://scottishcare.org/wp-content/uploads/2019/10/Tech-charter.pdf

5. **Digital inclusion, not just widening access**. For digital to achieve its potential of delivering better outcomes for people, it needs to be truly inclusive of all members of society, including those most at risk of exclusion or harm. While widening access initiatives are a welcome step forward, digital exclusion needs to be tackled at all levels in the community through person-centred rather than system-available responses. Digital skills, confidence and literacy need to be at the heart of digital inclusion activities going forward.

6. **Personal ownership of digital data.** The move to digital services will come with increased amounts of digital personal data being created, shared and used across systems. In line with Data Protection regulations, we believe that citizens should have ownership over their personal information and be in control with regards to its use.

Putting the principles into practice

While the growing policy focus on human rights in digital health and social care is welcomed, practical implementation remains a concern. We believe that the use of human rights principles will lead to a more equitable, meaningful use of technology and realise benefits for citizens as well as policy makers and service providers.

During 2021, we will work with stakeholders to collectively develop practice-based scenarios that illustrate the application of these principles across health and social care. We aim to share best practice and offer practical steps and examples that health and social care providers can use to develop frameworks that enhance their rights based work. This will include examples of rights based monitoring and evaluation of the use of digital technology in health and social care.

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