

HUMAN RIGHTS CHARTER FOR TECHNOLOGY AND DIGITAL IN SOCIAL CARE GUIDANCE DOCUMENT



SEPTEMBER 2019

INTRODUCTION

Over the last year Scottish Care and partners have been working on developing a human rights-based Charter for Technology and Digital in Social Care. This work has included developers and designers, providers and practitioners, residents and citizens who use social care supports. This Guidance reflects briefly on each of the 17 statements and suggests how they can be used to support the human rights of individuals and communities in the use of technology and digital in social care. They have been designed to foster discussion and to promote further reflection.

The overarching model both for the development of the Charter and these supporting notes has been the human rights-based model known as **PANEL**:

The **PANEL** principles are:

- **P**articipation – People should be involved in decisions that affect their rights
- **A**ccountability – There should be monitoring of how people's rights are being affected, as well as remedies when things go wrong
- **N**on-Discrimination – Nobody should be treated unfairly because of their age, gender, ethnicity, disability, religion or belief, sexual orientation or gender identity. People who face the biggest barriers to realising their rights should be prioritised when it comes to taking action
- **E**mpowerment – Everyone should understand their rights and be fully supported to take part in developing policy and practices which affect their lives
- **L**egality – Approaches should be grounded in the legal rights that are set out in domestic and/or international law.

An approach like this is about going beyond the minimum legal requirements and instead mainstreaming human rights in services, policies and practice to make them more effective for everyone. It is our contention that the rigorous use of 'PANEL' together with the use of a human rights-based assessment framework is now required to ensure that, as a society in general and for social care in particular, we are able to maximise the benefits of technological innovation, whilst ensuring public trust and confidence, and establishing appropriate safeguards, accountability and sustainability.

Before we go on to consider each of the individual 17 Principles in the Charter, we will briefly explore each of the PANEL themes to illustrate the potential of the 'PANEL' approach in elucidating questions and issues.

Participation – how do we enable people to participate if they have no access, no control and where that participation may be limited or manipulated by others? How is participation possible if there is a lack of digital skill and confidence even where access exists? It is clear that there are significant benefits to be garnered through the engagement and involvement of individuals from the point of initial conceptualisation and throughout a collaborative design process. It is equally clear that in the use of technologies the role of individuals as continuing co-designers and evaluators is primary.

Accountability – who is accountable in the use of technology and digital? There are very genuine fears around who has access to personal data; concerns over the emergence of Big Data without clear codes of behaviour and conduct; fears over the data that could be being gathered without consent and awareness by means of Artificial Intelligence (AI) and the Internet of Things (IoT). Are both leading to a growing public distrust or even aversion to new technologies? Who has oversight for the management and use of data? How can the citizen who uses social care services access, control and edit data held by others? Is the desire of the health and social care system to simplify and create consistency, antithetical to individual citizen control and access?

Non-discrimination – is technology appreciative of diversity and enabling of equality in social care? Is there a risk with AI and the IoT that software can serve to perpetuate discriminatory behaviours and attitudes? Is there a way in which technology can be truly built around the person and their unique identity without expecting personal identity to change to fit into the technology?

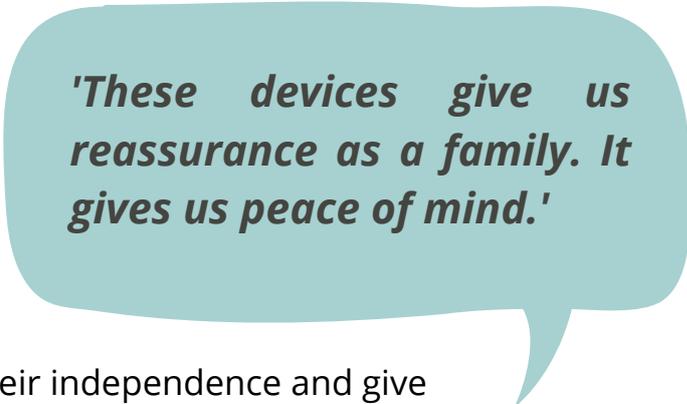
Empowerment – is the potential empowerment of individuals through the use of technology a democratisation of care or leading to even greater control? Does technology foster an increased dependency or is it enabling of personal independence? Is there are risk of a technological institutionalisation?

Legality – are we adhering to the articles of the current European Human Rights Convention or do we need to re-draw what we mean by concepts such as privacy to fit with a new technological age? Are we already, as citizens, remodelling what we mean by privacy by the way in which we share data on social media and the way in which we already use smart technology? Is the digital equipment in our hands an extension of our self? Is the essence of who we are for others now partly mechanistic?

THE SEVENTEEN PRINCIPLES:

1. **Technology** ...must be to the benefit of the individual and the common good

Technology has the potential to make a huge difference to the lives of people who use social care supports. However, the use of technological and digital interventions is not without risk and they are not always beneficial. A tracking wearable device might positively enable someone living with dementia to retain their independence and give assurance to family that the individual whilst autonomous is safe from harm, but it could equally (if misused) cause that person's ability to exercise their human right to freedom of movement to be restricted, limited and curtailed. In other words, even in the most beneficial technological aid there is the potential for harm and misuse.



'These devices give us reassurance as a family. It gives us peace of mind.'

Consideration also needs to be given to the extent that technology may impact upon fundamental components of human behaviour and relatedness. Whilst the use of a monitoring system in someone's own home might reduce or lessen the risk of a fall, and the use of a medication dispensing system may ensure greater accuracy and reduce pharmacological risk – what do either mean for human presence and relatedness? When so many individuals depend upon a professional and formal care worker as their sole point of human contact and interaction during a lonely day, what price the use of technology to replace that human encounter and visit?

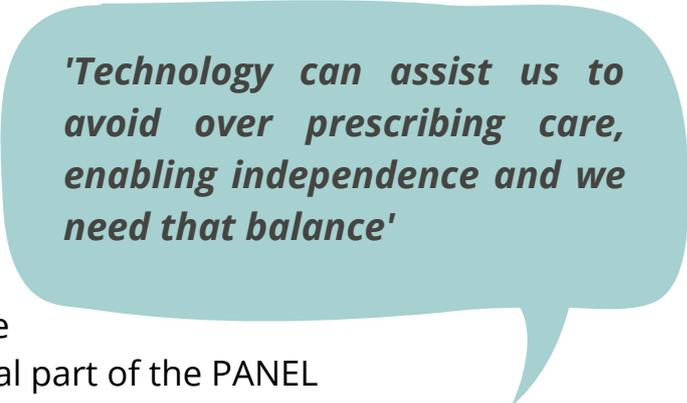
The use of any technological or digital intervention, must therefore, pass a high litmus test as to whether or not its use is enabling the realisation of an individual's human rights or limiting and restricting those. It is therefore important that an individual is able to participate at all times in the use and introduction of technology into their care and support; that there are safeguards which hold everyone to account; that all are treated equitably and that there is always an option open to someone to change their mind!

2. **Technology** ...cannot be used to restrict or remove any human right but should seek to enhance and fulfil human rights

The European Convention of Human Rights describes quite clearly the human rights that are intrinsic and fundamental to our humanity. There are some which are absolute such as the right to life and the right not to be treated in an inhumane or degrading manner. Others are limited or qualified rights, such as the right to privacy, family life and physical and psychological integrity; the right to freedom of expression or the right to free association. What is clear in the use of technology is that nothing should be used within a social care context which would illegally and unnecessarily prevent or limit an individual from exercising their full human rights. This is not an absolute position so for instance in terms of our Article 8 right to privacy it might be both reasonable and proportionate in order to achieve the legitimate aim of keeping a person safe from harm to use cameras in public areas of a care home. But a question would certainly need to be raised about whether the use of surveillance in a private or personal space was legitimate, proportionate and reasonable.

3. **Technology** ...should enable and foster personal independence if so desired

One of the core principles behind the development of social care and supports is that of independent living, the right of an individual to be supported to be independent and autonomous without an automatic recourse to institutionalised care and support. Being able to participate in decisions about oneself is a fundamental part of the PANEL principles and there can be no greater decision than the ability to determine where you live and with whom you reside. However, being independent is not the same as living on your own. It is possible to retain, maintain and even increase independence whilst living in a group or communal environment. The question has to be continually asked as to whether or not a technological intervention is restricting the independence and autonomy of an individual or fostering, furthering and nurturing it.



'Technology can assist us to avoid over prescribing care, enabling independence and we need that balance'

4. Technology ... has to take account of the unique character and individuality of the person, including characteristics of gender, race and ethnicity, disability, sexual orientation, religion and belief, and age etc.

At the heart of all human rights frameworks is the recognition that each human being is distinctive and unique. Alongside this there is the recognition that dignity is inalienable to the essence of being human. Any technological or digital usage has to be appreciative of the distinctive characteristics which comprise personal human identity. In that sense there cannot be a one-size fits-all approach to the use of technology. We are increasingly aware that the way that we respond to technology, are open to its use, and comfortable with it are all highly individual in nature. The use of technology has to be sensitive to all the characteristics of identity that form to make the person and individual as a unique being.

5. Technology ...should always be non-discriminatory in implementation and usage

One of the core tenets of human rights practice is that rights should not be altered or diminished because of individual characteristics or associations. Whilst some human rights may be curtailed or limited because of actions an individual may have perpetrated (convicted criminals may have their right to freedom of movement restricted) this does not mean that all rights should be restricted or limited. Further we also have to be aware that the implementation of technological interventions should be as equal as possible and should not be impacted by factors such as the socio-economic group, or ethnic identity, or gender that an individual may have as part of their life or identity. Poverty or wealth should not be factors in the use of technology in the social care of an individual.



6. **Technology** ...should be accessible, understandable and transparent

Accessibility comes in many different forms. At one level access is about possessing the resources at both a personal and societal level to gain from the benefits of technology. At another level access has to do with comprehension, knowledge and understanding. Designers and developers should be seeking to create technologies which are easy to use, simple to navigate and clearly beneficial to the citizen. There has to be an appreciation of those who because of a hearing or visual impairment require to have reasonable adjustments made in order for them to access technology and its benefits in an equal manner. In addition, appreciation needs to be made of those who have other communication and access needs because of the nature of their physical or learning disability. There is little value in something which is technological advanced if its day to day application is obtuse and challenging.

'Some of these things are impossible for me to see or use because I have arthritis and macular degeneration'

7. **Technology** ...should use data in a manner which respects privacy, transparency and accountability to the individual

One of the many fears which people express over the Internet of Things (IoT) and smart devices in specific is the sheer amount of data that is gathered upon them by devices and over which they believe they have no control or access. A core principle for the use of data in the lives of those accessing social care services and supports has to be the right of the citizen to own, manage, edit and access their own data. It is their data after all. It is therefore important that the citizen is supported to understand the data held upon them, and on their care and support, to be able to change or edit that data, and to control who sees and has access to that data. This level of constructive enabling will have a positive impact on the ability of services to wrap support around an individual in an integrated and cohesive manner whilst retaining the citizen's right of data control. This is participation at its best. This in

'New systems of technology for care planning allows us to have shared information that is live and up to date'

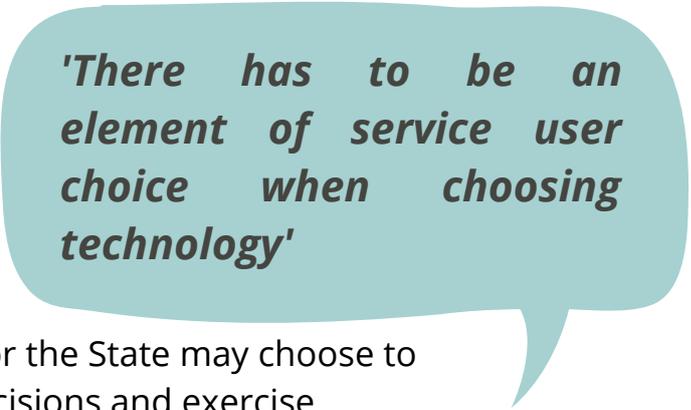
essence is empowerment. Being able to retain and exercise privacy is a fundamental part of Article 8 of the ECHR and data privacy is critical to achieving this for the whole of a person's life in the new technological age. This also includes instances when living in a group environment or accessing services in a shared setting. The citizen should have the right to determine (unless for reasons of legal capacity) who has knowledge of them and their information. There should not be an automatic presumption that once told all know.

8. Technology ...should be fair and equal in its treatment and use

As has been stated above the application and use of technology in the support and care of a person should be without discrimination and should be equal. This principle also applies to those who deliver services and supports. So, for instance, the frontline worker has the right to ensure that technology does not limit their dignity and creates systems where fair work principles are enhanced and advanced rather than reduced or put at risk. This would apply to instances where call monitoring systems are used or where there is the introduction of cameras into either an individual's own home or a residential or nursing home facility. Inclusion, engagement, participation and involvement are essential to ensure fair and equal treatment.

9. Technology ...should only restrict individual choice and autonomy to a degree which is proportionate and rights-abiding

There are clear principles within mental capacity and adult protection legislation which seek to protect and advance the human rights' principles of control, choice, autonomy and capacity. It is only in specific, defined and limited circumstances where another individual or the State may choose to restrict the ability of a person to make decisions and exercise personal choice. There are some such instances where technology or digital



'There has to be an element of service user choice when choosing technology'

interventions may be used to limit or restrict certain human rights which a person might have. This Charter is stating that such restrictions should only ever be in accordance with clearly defined legal principles which themselves are rooted in proportionate restriction with reasonable justification and for the achieving of legitimate outcomes. So, for instance someone who is at risk of significant self-harm may have their movement restricted for a period of time through the use of technology. Such restrictions should always be proportionate, time-limited and subject to regular review.

10. Technology ...should enable an individual to flourish and achieve their full potential

Technology and the use of digital in social care supports is primarily about enabling the person to achieve the highest degree of autonomy and control that they can possibly achieve. It is not about maintenance or risk aversion; it should always be about enabling the person to achieve the fullness of life possible to them until the end of their life. At all times technological or digital intervention should be about the flourishing of the person, not the maintenance of the individual. This is a core component of what PANEL describes as empowering an individual through the exercising of their rights. At its best technological intervention in social care is human rights enhancing and a key modern tool in the realisation of human rights at a personal and community level.

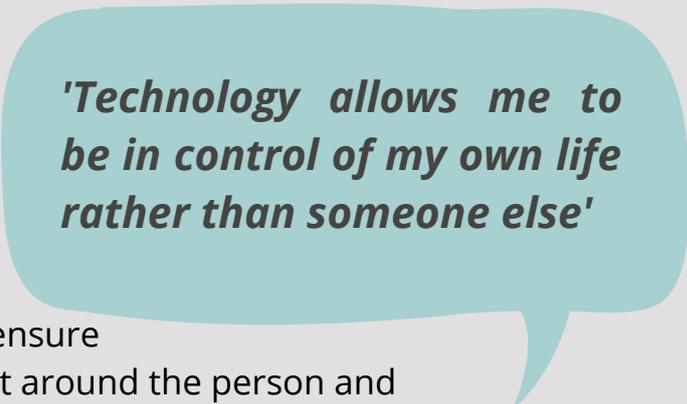
'Technology "keeps people living with dementia in their own homes longer"

11. Technology ...should be used with the consent of the individual and in accordance with the previously articulated wishes and views of the person

Sometimes such as in instances where neurological decline advances in conditions like dementia it is not always possible to gain the consent of an individual when it is proposed or becomes necessary to introduce a technological support. In such instances the wishes of the individual which have been previously articulated, and the views and feelings of close allies, friends and family should always be taken into account. This highlights the importance of ensuring that advanced care planning includes gaining personal views on the potential use of technology and digital in the care and support of an individual in the later stages of an illness or condition.

12. Technology ...should always be person-centred and focused in its intention and implementation

Technology is not an end in itself – it is there to serve the purpose of advancing the care and support of the individual. In the design and development of technological solutions and products it is important that the person most impacted by their use is centrally involved. This will ensure that the systems and technologies are built around the person and not that the person is expected to fit into the software requirements or the needs of the technology. The essence of all person-centred planning and working is where the person (the citizen) is at the centre and everything else (including technology) is changed and moulded to fit the needs and support required by the person.



'Technology allows me to be in control of my own life rather than someone else'

13. Technology ...should as far as possible be co-designed with the individual end user's engagement and involvement

The criticality of having the voice of lived experience at the start of design through development and into implementation should be self-evident. This is at the heart of ensuring the maintenance of human rights and the principles of participation, accountability and empowerment within the PANEL model. There have been too many instances in the past where technological supports have been designed in the laboratory without ever having engaged with those whose lives are impacted by their use.

14. Technology ...should seek to involve those important to an individual in the use of technology, include family members, informal carers and paid carers

PANEL recognises that in any support or care context there are a multiplicity of actors at a human rights level. There are those who are both rights-holders and rights-bearers, those who exercise their human rights and those responsible for ensuring that citizens are able to have those rights upheld and realised. In any care context, there are not only the human rights of the individual being supported to take into account, but of their family and friends, of the worker and carer, of other

residents and neighbours and so on. The benefit of a human rights approach is the recognition that rights are held in balance and in relationship; their realisation can only ever be achieved within relationship and by dialogue, discussion, encounter and exchange. There is a real sense of mutuality and co-responsibility in the implementation of a human rights-based approach to the use of technology as well as in social care itself.

15. Technology ...should be accountable to the individual whose data is held and enable them to check, edit and control that data

We have articulated above the central importance that data should be controlled by the citizen. This is important in upholding the rights of an individual but also in ensuring the consistency of care and its coordination when an individual comes into contact both with health and social care services and supports. But PANEL would also argue that within a legal framework it is necessary for this to be exercised in a manner which empowers the individual in the control and management of their data. This involves significant investment of time and resource in equipping and upskilling citizens to be their own data controllers. This is where real accountability comes to bear.



'I want to be in charge of what's in my house and what's done with it'

16. Technology ...should not be used to harm, destroy or diminish another

In a social care context, it is perhaps self-evident to state that the use of technology should not cause harm or hurt to an individual. But whilst intentional harm may never be at the centre of the use of technology or digital it may nevertheless occur. In order to avoid instances where the use of technology diminishes another, perhaps through, restricting choice, limiting personal decision-making and autonomy, removing the ability to exercise self-control or simply resulting in over-protection, it is important that the use of technology in social care is regularly and independently reviewed. It is equally important, we would argue, that the implementation of any technological or digital support should only ever be undertaken after a clear 'human rights' audit of the unique circumstances of each situation and the specific support needs of an individual. A human rights based social care assessment for the introduction of technology would be a good starting point for this.

17. Technology ...should enable and augment human presence rather than wholly replace it

It has always been a deep fear of any significant technological advance that the role of the human will be diminished and marginalised. From the First Industrial Revolution up till this so-called Fourth there has been a fear and suspicion of the automation and especially of the robotic. Without dwelling on the merits or otherwise of such fears, it is fundamental to the human interaction and essence of social care and support that technology is seen as being in place to enhance and deepen the nature of human presence rather than replace it. There may be instances where less staff are needed as a result of technological advance, but it is the spirit of this Charter and those involved in its development that technology in social care should primarily be about adding value to the essential human relationship which is care and support.

'In the end of the day I don't want all these gadgets, I want someone to sit with me and have a cuppa'

Technology frees up staff from the more repetitive and mundane tasks in order for them to spend time in human dialogue and relationship; technology can support an individual with routine and predictive behaviour and can greatly add value to interactions and dialogue. What the Charter declares is that ultimately, and perhaps especially, at the most intense and profound moments of palliative and end of life care, that the human remains essential. Technology is there to enhance and augment, to add value and deepen the quality of the care experience and environment.



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