

**The Human
Rights, Big Data
and Technology
Project**



A Digital Cage is Still a Cage*

**How can new and emerging digital
technologies advance, rather than put at
risk, the human rights of older people
who draw on social care?**

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* Title

The title to this report, 'A Digital Cage is Still a Cage' is inspired by the oft-cited statement by Lady Hale that a 'gilded cage is still a cage' in the UK Supreme Court case of *P v. Cheshire West and Chester Council and Another* [2014] UKSC 19 (19 March 2014), at paragraph 46.

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EXECUTIVE SUMMARY

In the field of social care, a range of new and emerging technologies are drawn upon by older people, their families, and state and independent care providers for different purposes, including to:

- monitor health and wellbeing, for example, by detecting a fall;
- provide companionship or to increase connectivity with friends and relatives;
- carry out discrete household tasks, such as vacuuming;
- stimulate long-term memory and set reminders for particular tasks, such as to take medicine;
- support decision-making by care providers;
- detect pain;
- monitor staff performance.
- provide a 'digital marketplace' to find, buy and sell social care.

Some of these technologies, such as smart assistants, are not designed or developed for the delivery of social care specifically or targeted at older people as a user group. However, they are used by older people, their families, or care providers as a tool in social care. Other technologies are aimed at older people, as reflected by a rapidly developing market for 'age tech'. Age tech encompasses technology with specific functions, such as to monitor for falls, and can integrate a range of technologies within customised smart homes, for example, smart homes designed specifically for people with dementia.

In many states, people largely draw on formal social care from private, voluntary and community sector provider organisations. This care may be commissioned by national or local government. However, in contexts in which publicly funded social care is limited, many individuals and families offer or arrange such care themselves, a challenge accentuated where families live far apart. Some care providers draw on digital technologies to maintain records and plan and monitor care delivery. They may also experiment with new and emerging technologies, often as alternatives to human care-workers, such as technologies



that are marketed as able to monitor the movement of residents in care homes or detect seizures as well as to assist in human caregiving, such as facial recognition technologies to help detect pain in people who are non-verbal, for example due to dementia or a stroke. Outside of or alongside formal care, older people and their families are also turning to new and emerging technologies not only as a means of communication but also as a safeguard, for example, to alert their family to a fall.

How New and Emerging Technologies can Advance or Deny Older People's Human Rights

New and emerging technologies already play a role in, or have great potential to feed into, and support the realisation of, a rights-based model of social care. Such a model is not about simply 'maintaining' a person or the transactional provision of food or medication. Rather, at its core are the underlying principles of human rights, namely human dignity, fairness, equality, inclusion, participation, and empowerment. A rights-based model of care underscores the agency of older people to make decisions about their care and to claim their human rights to choice and control over their lives. This not only requires a rights-based approach to health and care but also the fulfilment of the right to independent living, the foundations of which are autonomy and independence in decision-making, with support where appropriate; liberty and security of the person; and inclusion and participation in the life of the wider community on an equal basis with others. When used as part of a rights-based model of care, new and emerging technologies may give older people greater choice and control over daily life and the support they draw upon, rather than having decisions taken away from them, including by supporting people with cognitive impairments with memory, communication, and decision-making. These technologies may empower older people to live more autonomous lives, for example by postponing or avoiding altogether moving into residential and nursing care homes. They could help ensure that people are safe, without safety coming at a disproportionate cost to their liberty or privacy. New and emerging technologies may help to connect people with their families and local community. By delivering some of the more 'life and limb' dimensions of care, they could help reshape human



‘care-giving’ to focus on supporting people to achieve or maintain meaning, purpose, and relationships. Technology may also beneficially assist in the monitoring and regulation of services, both at the level of identifying good or poor practice, as well as, for example, harnessing data analytics to identify risks and to ensure the more equitable distribution and targeting of resources.

At the same time, new and emerging technologies could be used – intentionally or unintentionally – to adversely impact older people’s human rights and contribute to their segregation and isolation from wider community. The current design and use of many technologies pose acute risks to the right to privacy, which is particularly serious given that these technologies are deployed in people’s homes, including in bedrooms and bathrooms, and may be recording, processing and sharing data about the most intimate details of older people’s lives. These risks may increase as technologies become more sophisticated, and are able to interact, for example, within the context of a smart home.

At their most extreme, the use of new and emerging technologies could replicate the worst features of institutional care rather than facilitate independent living and inclusion within the community. People could find themselves subject to regimes of daily living either pre-programmed, or evolved through machine learning, that limit choice and involve coercion. This could include new and emerging technologies being programmed to lock doors should a person attempt to leave their home on their own or at an unscheduled time, potentially subjecting them to restrictions to their freedom of movement, and even de facto forms of deprivation of liberty, through techno-restrictions. Where humans are still involved in the delivery of care, they may be subject to management and monitoring by these technologies, deepening ‘time and task’ models of care delivery and denying them the opportunity to practice empathetic, relational care, and support. Some forms of new and emerging technologies may replicate modes of ‘substitute decision-making’ that have historically denied people with cognitive impairments their legal personhood and autonomy. They may be introduced without meaningful consent or the input of older people, resulting in technology being ‘done’ to them rather than at their direction. When framed as a solution to deal with



diminishing resources, there is also the risk that they accentuate existing challenges in social care, and potentially entrench isolation and feelings of loneliness where people live in, but become completely isolated from, the wider human community, interacting mainly with technologies.

Between these two extremes lie the same risks emphasised by Lady Hale in the UK Supreme Court case of *Cheshire West*.¹ She observed that if a person living in the community is denied the possibility of leaving their home without permission and is subject to close supervision, then, '[t]he fact that my living arrangements are comfortable, and indeed make my life as enjoyable as it could possibly be, should make no difference. A gilded cage is still a cage.'. Similarly, the use of new and emerging technologies in the lives of older people living in the community could offer the veneer of autonomy, liberty and inclusion, yet their human rights may still be compromised: a digital cage is still a cage.

All of these futures are possible, and indeed may co-exist; how these risks and opportunities manifest themselves depends on a range of factors. While not exhaustive, these factors include who decides whether particular technologies are used and for what purpose; the design and function of the technology; who decides upon who accesses and uses the data and for what purpose, raising the question of whether older people can meaningfully consent and control whether and how their data is collected, stored, deleted, shared, or sold and the data analytics applied to it; whether the technology replaces or complements services or decisions typically made by humans; and the safeguards in place to protect a person's dignity, autonomy, and human rights.

Our report sets out the current challenges and debates surrounding social care in general and maps the current technologies being used by local governments, independent care providers, individuals, and families to support social care. We show how, depending on their design and deployment, and the framework in place to protect human rights, new and

¹ P v. Cheshire West and Chester Council and Another [2014] UKSC 19 (19 March 2014).



emerging technologies can pose significant risks to older people's enjoyment of human rights or enhance their autonomy and dignity, supporting them to live independently and participate in the community, moving away from models of care based on residential and nursing homes.

Putting a Human Rights-Based Approach to the Use of New and Emerging Technologies on the Social Care Agenda

With some exceptions, there is relatively little literature on the ethical and human rights implications of the use of new and emerging technologies in the context of social care. Ethical and human rights considerations appear to play little part in the commissioning, design, or application of such technologies in social care. Yet, how new and emerging technologies are designed, regulated, and governed in the care sector has serious implications for whether they enhance or deny older people's human rights.

Our report concludes that significant work is needed to first understand, particularly from the perspective of older people as a diverse group, whether and how new and emerging technologies can improve later life, including in the context of social care. The development and deployment of individual technological applications and the wider regulation of the tech sector in a manner that is ethical and respects human rights will be critical to the protection of older people's human rights. However, the future direction of technology in this field will also depend on how social care is conceived. We find that the chances of new and emerging technologies contributing to the advancement and enjoyment of rights will be greatly enhanced if they are introduced into social care environments that assume a rights-based approach to care. We therefore suggest that securing a rights-based approach to care should be prioritised as part of a wider commitment to grounding the design, development, and deployment of new and emerging technologies in social care in human rights.

Accordingly, in this report we suggest that the role of technologies in older people's lives is inextricably linked to the wider vision, strategies, and policies for social care. If we choose a future in which care amounts to little more than maintenance, then it is more likely that technology will be designed and employed to help maintain people alive, but not living a life.



If we choose a future in which people are supported to live a life they have reason to value and in which they are included and able to fully participate in the wider community, then technology will be developed to support that goal.

Of equal importance, especially given the widespread consumption and deployment of digital technologies by private citizens to the ends of social care, is the adoption of a human rights-based approach to the design, development, and deployment of new and emerging technologies by states and private actors, including technology companies and care providers, taking into account the diverse and intersectional experiences, goals, and needs of older people. This includes reassessing existing data protection frameworks to ensure that they adequately protect older people from situations in which their access to low-cost or free internet or AI-enabled devices is conditioned on restrictive terms and conditions that allow their data to be collected, stored, analysed, and sold in ways that adversely affect their privacy and wider human rights, and contributes to structural inequalities. Moreover, where states and private care providers provide AI-enabled devices, the purposes for which they collect, store, analyse, share and sell data may need to be subject to specific regulation.

Within both frameworks, much more attention is needed to understand the extent and nature of current use of new and emerging technologies within social care and the experience of older people, their families, and caregivers of these technologies. This knowledge base and the meaningful participation of older people is critical in the shaping of normative and operational principles on the use of new and emerging technologies within a rights-based approach to social care and to prevent intersectional discrimination in the design and development of AI-enabled technologies and services and decision-making processes using such technologies. This would mean avoiding technology being ‘done to’ people and instead assessing the ways in which it can enable older people to people enjoy their rights to live independently, make autonomous decisions and participate in community life as set out in



the UN CRPD and to enhance the quality of later life without having to trade-off or give up other rights.²

Our report also recommends that:

1. Overcoming Digital Divides

If older people are to have the option of using new and emerging technologies as tools to advance their human rights, core baseline issues, such as overcoming the intersectional digital divides facing older people requires urgent attention, including to avoid the realisation of two digital futures, whereby some are able to enjoy the benefits of technology whereas others are excluded or subjected to technology being ‘done to them’.³ Digital divides continue to exist at multiple levels, such as ongoing barriers to the affordability and accessibility of the internet and new and emerging technologies more broadly, including for older people with visual, aural and cognitive impairments. Strengthening data and technology literacy is also a critical pre-condition to the exercise of meaningful consent to the use of new and emerging technologies in older people’s lives, as well as being able to fully utilise the different functionalities offered by particular technologies.

Developing effective strategies to overcome the digital divides experienced by older people and the inaccessibility of certain technologies requires prioritisation as an overall policy objective for states and technology designers and developers. However, it is important that it is not only treated as a contained policy objective on overcoming digital divides but also integrated within wider social care law and policy. For example, overcoming digital divides

² Council of the European Union, ‘Conclusions on Human Rights, Participation and Well-Being of Older Persons in the Era of Digitalisation’ (9 October 2020), at §27, <https://www.consilium.europa.eu/en/press/press-releases/2020/10/12/improving-the-well-being-of-older-persons-in-the-era-of-digitalisation-council-adopts-conclusions/>

³WHO, Decade of Healthy Ageing: Baseline Report (2020), 67, 126.



and the inaccessibility is inextricably linked to initiatives to increase connectivity as part of public health policies.

2. Identifying Red Lines in the Design, Development or Deployment of New and Emerging Technologies for Social Care

Within the wider tech and human rights field, over 15 US cities have introduced bans on the use of facial recognition technologies by law enforcement⁴ and civil society organisations have instituted wider campaigns to ‘Ban the Scan’⁵ and ‘Reclaim your Face’.⁶ The draft EU AI Act also prohibits the use of AI-enabled technologies categorised as ‘unacceptable’. To date, debates and policy initiatives on possible ‘AI red-lines’ have not closely examined whether certain types of technology or use cases in the field of social care should be prohibited. However, given that new and emerging technologies are likely to be used in older people’s homes and for their care and support, this report highlights the critical importance of further analysis of whether AI red-lines should be applied to the use of new and emerging technologies in social care and support.

Clear examples emerging from this report include where new and emerging technologies are used within the community to deprive older people of their liberty or to replicate the control and coercion associated with institutions, even if implemented within their own homes. Article 5(a) of the draft EU AI Act is of relevance to the field of social care in prohibiting, ‘the placing on the market, putting into service or use of an AI system that deploys subliminal techniques beyond a person’s consciousness in order to materially distort a person’s behaviour in a manner that causes or is likely to cause that person or another person physical or psychological harm’. Article 5(b) also prohibits ‘the placing on the market, putting into service

⁴ Nathan Sheard and Adam Schwartz, ‘The Movement to Ban Government Use of Face Recognition’ *Electronic Frontier Foundation* (5 May 2022).

⁵ Amnesty International, Ban the Scan Campaign, <https://www.amnesty.org/en/petition/ban-the-scan-petition/>

⁶ EDRI, Reclaim Your Face Campaign, <https://reclaimyourface.eu>.



or use of an AI system that exploits any of the vulnerabilities of a specific group of persons due to their age, physical or mental disability, in order to materially distort the behaviour of a person pertaining to that group in a manner that causes or is likely to cause that person or another person physical or psychological harm'. Much greater analysis and discussion is required into the implications of these draft prohibitions and whether they are sufficient or require extension in the field of social care, particularly with regard to instances in which the use of new and emerging technologies inhibits choice and control, restricts cognitive autonomy or results in a new form of substitute decision-making.⁷

For other technologies, such as so-called 'companion' robots, their use or provision by states or private care organisations may not be subject to an outright ban, but may be conditional on their integration with wider strategies and policies aimed at preventing isolation and segregation and increasing connectivity and inclusion within the community, and never as a replacement to fostering human connection.

3. The Establishment of Clear Safeguards

Beyond AI red-lines, the development of clear safeguards is needed in both the decision-making process to introduce new and emerging technologies into social care as well as the establishment of effective oversight and monitoring systems and complaint processes. As we have recommended in previous research by the Human Rights, Big Data and Technology Project, such an approach should be informed by international human rights standards and norms and ensure the meaningful participation of older people.

(a) Meaningful consent

Where technologies are used in older peoples' lives, this report underscores that it must be with their meaningful consent and not at the direction of others, even if with a benevolent

⁷ European Commission, 'Proposal for a Regulation of the European Parliament and of the Council Laying Down Harmonised Rules on Artificial Intelligence (Artificial Intelligence Act) and Amending Certain Union Legislative Acts, COM/2021/206 final (21 April 2021).

purpose, such as to increase security or safety. Meaningful consent cannot be given if the person does not have detailed but accessible information on the benefits and functionalities of the technology as well as the full risks. If in the context of formal care, technology cannot be presented by state or private caregivers as an ‘either/or’ situation, meaning that older people must also be provided with a non-technological alternative. They must also always have the opportunity to change their mind and decide they no longer want the technology within their lives, without any adverse consequences to their care and support.

Where individuals are deemed to ‘lack’ legal capacity, they must be supported in their decision-making about the role of technologies in their lives rather than having their decision-making capacity removed from them through substituted decision-making. Moreover, it is possible that some individuals consent to the role of new and emerging technologies in their lives within advanced care directives. In this regard, much more work is needed to examine the specificity that would be required within such directives, particularly as the nature and intrusiveness of specific technologies vary depending on factors such as the model used, the actor implementing it, and the governance and regulatory framework. Moreover, technologies are constantly evolving.

(b) Transparency and Safeguards by Companies Designing, Developing and Selling ‘Ageing Tech’

This report highlights that new and emerging technologies may be purposefully developed for older people, often referred to as ‘age tech’, or used as part of care and support, even if not marketed for that specific purpose. In both cases, this report cites research finding that older people feel excluded from the conceptualisation and design of these technologies with the result that they may not be fully and effectively designed and developed to enable them to live high-quality lives. In this regard, a key recommendation of this report is for both ‘age tech’ and technology companies more broadly to involve diverse groups of older people in the conceptualisation and design of new and emerging technologies to ensure that they are developed to maximise their goals, needs and interests and adverse human rights impacts are identified and addressed at an early stage.



The report also highlights the need to create opportunities to test new and emerging technologies and the provision of detailed but clear and usable information on how to use the technology to its full extent and protect human rights, in easy to read and accessible formats in order to enhance the prospects of such technologies advancing, and not harming, human rights. Help desks staffed by humans would also facilitate the accessibility and useability of such technologies.

(c) Transparency and Safeguards by Private and State Care Providers

At the stage at which local government or private care providers are considering offering new and emerging technologies, the reasons for such a proposal should be publicly documented, making clear whether the proposals are to meet objectives such as cost-reductions, and whether they are aimed at replacing an existing service or as additions to the care and support already offered. An impact assessment should also be carried out to assess the potential impact the technology could have on the safety, security, and human rights of older people and other people who come into contact with that person, such as family members, friends and care workers or informal carers. The design of impact assessments should involve older people and their advocates to ensure the tailoring of the assessment to the human rights of older people.

The impact assessment should not refer to the type of technology generically, such as acoustic listening, but the actual product or model being considered. It should include a comparison with the features of other technologies capable of carrying out a certain function, such as monitoring for falls, in order to see the range of technological options available and their advantages and disadvantages. It should also include assessments of whether specific features, such as collection of data, or the use of cameras or facial recognition, are the only way in which to meet a particular goal and whether they are necessary for the technology to function or an additional feature for commercial benefit or to feed into other goals of the state.

Where the technology will be offered by a private company, as is often the case, the human rights of older people should feature centrally in the procurement process and a risk



assessment into that company carried out from this perspective. Consideration should be given to whether any data gathered should be accessible, shared, and usable by the care provider, any other state actors or third-party actors, or the company providing the technology. Such assessments should not simply be between the care provider and the technology provider but should involve meaningful stakeholder consultation, particularly with those who are to use the technology, or have it used in their lives.⁸ As noted above, the use of the technology in an individual's life will require separate meaningful consent and include the right to refuse the use of technology in their lives or to require its removal, without consequence or to the detriment of their care.

Local government and independent care providers should also have ongoing monitoring and oversight practices in place, including for independent regulatory bodies, such as national human rights commissions, care commissions, national preventive mechanisms and independent monitoring mechanisms under the Convention on the Rights of Persons with Disabilities to ensure that the use of technologies complies with human rights, alongside effective and accessible complaints mechanisms.

The establishment of such safeguards is a minimum requirement to protect older people's human rights. If new and emerging technologies are to play a role in enhancing or securing the enjoyment of human rights, much greater attention is needed into the types of processes required to ensure that older people are effectively supported, where necessary, to make autonomous decisions about the use of new and emerging technologies in their lives and to exercise meaningful choice.

⁸ UNHRC, 'UN Guiding Principles on Business and Human Rights' (2011) UN Doc A/HRC/17/31 (UNGPs), Principle 18, https://www.ohchr.org/documents/publications/guidingprinciplesbusinesshr_en.pdf



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