



# **TECHRIGHTS**

## **HUMAN RIGHTS, TECHNOLOGY AND SOCIAL CARE**



# Contents

Foreword	3
Introduction	4
The developing debate	8
Particular ethical & human rights challenges with technology	15
Emerging practice	27
The developing story of policy	33
Human rights & ethics in policy & practice	40
The potential of human rights for technology in Scotland's social care	43
Final words & recommendations	46
References	52
Author details	59

# Foreword

Newspaper headlines like ‘*robots are coming*’ and most recently ‘*the robot will see you now*’ are becoming increasingly common and prompt mixed emotions of both fear and excitement around the role of technology in the context of health and social care.

This report is welcomed and timely in articulating and consolidating the existing knowledge about the complexities and sensitivities of the technological landscape in social care as well as producing dedicated insight into how we can adopt and uphold an ethical, rights-based approach when we consider the role of technology in this context. The report presents both the challenges and the opportunities of technology in social care but also shines light on the important, yet often uncomfortable questions that we need to dedicate further dialogue, debate, research and action to as technology continues to advance at an exponential rate.

Just as we see the paradigm shift in health and social care towards proactive, responsive and preventative models of care, we also need to be proactive rather than reactive in our approach towards how technology can be meaningfully integrated in social care. We have a responsibility to proactively drive technological development for the sector, supporting the voices who often remain unheard to be engaged and included across the design process to truly co-create care enabled by technology that is based on the experiences of both those receiving and providing care. We need to engage our ‘ethical imagination’ in determining how technology should be appropriately deployed to mediate future care interactions and experiences and in considering the resulting implications for policy and practice.

The complex and sensitive ethical and human rights issues discussed in this report are of critical importance as we continue to build our understanding of technology in the health and social care landscape. The perspectives offered in this report present us with the academic and industry insight on the human rights and technology debate as well as highlighting the changing political landscape. What is clear is that we are at the early stages of a cultural journey that needs to involve all actors in the social care sector and considers technology in relation to practice, mindset and behaviour in order to understand and situate how technology can meaningfully enhance and enable our care interactions and relationships. It is only by embracing these wider cultural, psychological and social processes that the benefits of technology can be realised and subsequently adopted with confidence by the sector.

The way in which we design and deploy technology in social care needs a collective approach and a national conversation to ensure that change is person-led and driven by needs, choice and aspirations for care. This report is a defining part of the journey and sets the path towards ensuring that we foreground human interactions and experience, create time for person to person care enabled by technology and ground this in an ethical and rights-based approach.

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# Introduction

One of the most persistent assumptions in debates around the future of social care and health service delivery in Scotland is that technology will play a critical and fundamentally important role in that future. Indeed in no small measure many social care providers in Scotland are in the vanguard of using technological products to address practice challenges. Despite this positive adoption and endorsement of technological solutions there has been a relatively limited debate in social care literature and policy around the role that technology might play in a re-designed and re-imagined service delivery. Specifically, despite an increasing narrative around the central role that human rights should play in health and social care service delivery and outcomes, there has been scant analysis of the inter-relationship between human rights, technology and their use within the social care environment.

This paper will focus on this largely neglected area of human rights as they relate to the use of technology in social care and in particular to the care of older persons.

We will firstly explore the overarching issues relating to the developing debate around technology, ethics and human rights in general, reflecting on both the potential benefits and challenges identified by commentators. In particular our focus within this work will be on AI (Artificial Intelligence), Big Data and the Internet of Things<sup>1</sup>. Thereafter we will consider what has been said about the specific issues of social care's use of technology both in a policy and in a practice context with a particular focus on Scotland. In the latter part of this study we will suggest the adoption of the widely accepted PANEL human rights model as an aid to assist the development of a set of ethical principles for technology and its use in social care, as well as proposing recommendations for the Scottish social care, technology and digital policy and practice context.

## A technological age? Definitions and context

The word 'technology' comes from the Greek word *tekhnologia* meaning 'systematic treatment', itself deriving from *tekhnē*, an 'art or craft'. It means '*the application of scientific knowledge for practical purposes, especially in industry*'.<sup>2</sup> In some senses since the first discovery of fire and the forging of metals we have lived in a technological age. However, the word gained specific meaning when technology became defined as 'advances in computer technology' largely in the 1950s and 1960s. Nevertheless, from the early 1700s the sense of technology being practical in purpose and being a craft in itself has been foremost. It is that practical, purposeful definition of technology which will be the focus of this paper.

Commentators have argued that we now live in a time of an especial and significant advance in the use of technology for practical purposes. This period has variously been described as a Fourth Industrial Age, a Third Wave or a Second Machine Age. Either way the times they are indeed 'a changing'! Modern Technology has, for at least the last seven decades, made a



dramatic change to the way in which human life is lived and human potential is achieved. There are now over 3 billion people using the internet every day – an increase of 2.3 billion since the year 2000.

As a young boy I attended a school which was situated within a university campus. That university was one of the leaders in Scotland's development of information technology and communication. As part of an exercise to stretch adolescent imagination we were invited along one afternoon to see what was, at that time, reputed to be the world's fastest computer. It was a whirring series of metal cupboards which literally filled a room with a standard screen and keyboard to operate them. This was well before the era of the 'mouse', so all instructions were laboriously typed in by complicated code. What struck me then was the sense of sheer wonder with which the technicians and scientists viewed their work and its creation. It filled me with both a lifelong fascination for, and indeed a fear of, the power and potential of technology to change the world I inhabit for good and ill. One of the men working on the computer at the time mentioned that when we had reached his age - an elderly 40 - the computer we saw that day would be the size of a cigarette packet. We laughed then. Nearly 40 years later after my flirtations with a BBC computer, an Amstrad, an enduring love affair from the earliest Apples, loads of floppy discs and CD-ROMs, I am no longer laughing. The truth of a processor 1000s of times faster and more powerful than the machine that filled that Glasgow room is in the laptop I carry every day and the smartphone whose presence is, reluctantly, my essential life tool.

## Technology has and is changing the world

The concept of the Fourth Industrial Revolution (4IR)<sup>3</sup> suggests that we are living in the fourth major industrial era since the initial Industrial Revolution of the 18th century. It is a time characterised by a fusion of technologies which is removing or blurring the lines between the physical, digital, and biological spheres.

The First Industrial Revolution used water and steam power to mechanise production. The Second used the power created by electricity to enable mass production. The Third used the advances of electronics and information technology to automate production not least in manufacturing industries. The Fourth Industrial Revolution is a direct product of the digital revolution of the last few decades but is uniquely fusing technologies. The rate, degree, speed and scope of current innovations have no historical precedent.

A similar concept which describes the rapid technological change we are living in is that of the *Third Wave*. This theory has been proposed by Paul R Daugherty and H James Wilson, in '*Human + Machine: reimagining work in the age of AI*.'<sup>4</sup> The authors suggest that we are about to enter a '*third wave*' of societal and workplace transformation. The first wave, they argue, was when people like Henry Ford introduced 'standardised' procedures. The second consisted of the automation of processes. The third, they suggest, is the 'missing middle' where humans and machines interact. In this space human and machines are not fighting each other for dominance

but are rather seeking to complement the role of the other. This does, however, require new skills and employee roles, a new understanding of team and management, and maybe even a new understanding of work.

It is indeed in the world of work that we evidence both the most dramatic possibilities and challenges of the modern technological era. Erik Brynjolfsson and Andrew McAfee<sup>5</sup> have coined the phrase the ‘second machine age.’ They argue that unlike the ‘first machine age’ of the Industrial Revolution where automation made labour and machine complementary, the recent advances in automation mean that a lot of cognitive tasks can now be undertaken by technology, consequently substituting human agency rather than complementing it. Theirs is an optimistic analysis, stating that once the androids start to do jobs, we don’t have to do them anymore, and we get freed up from ‘drudgery and toil.’ Is it that simple, especially for jobs demanding emotional and empathic connection?

When we consider these three new ‘ages’ within a social care context, we get to the heart of some of our contemporary debates. It is when we consider how we can enable some of our most vulnerable citizens to achieve their full human potential that there is both challenge and potential for the Fourth Industrial Revolution, the Third Wave and Second Machine Age. Our focus in what follows is upon the support and care of older persons. In that regard some of the most innovative technological developments have led to an emerging and increasingly influential field of academic and practical interest, namely the new concept of ‘gerontechnology’.

## Gerontechnology

Related to the period of technological advance described above, but this time linked to older people, has been the growth of the academic and professional discipline of ‘Gerontechnology’. Gerontechnology combines gerontology and technology. It is inclusive of both assistive technology and inclusive design and environmental approaches which support independent living and the social participation of older adults in good health and wellbeing. Gerontechnology includes the impacts of technology and its design in areas such as mobility, communication, housing, employment and the leisure of older people.

A recognised definition of gerontechnology states that:

*‘Gerontechnology is defined as “the study of technology and aging for ensuring good health, full social participation, and independent living through the entire life span.”<sup>6</sup>*

There is also an International Society for Gerontechnology<sup>7</sup> and more recently, what is perhaps more significant, is that Silicon Valley and its worldwide equivalents have discovered the burgeoning economic power of the older generation as purchasers as much as consumers of technological invention.<sup>8</sup> Presently, someone who is in their 70s was born in 1940s and may have first experienced some form of personalised technology in middle age or later, whilst an average fifty-year-old today is far more technology-friendly and confident. Thus, there will be a

growing interest and market for already available and maturing technologies to support physical, emotional, social, and mental wellbeing.

So in our consideration of what emerging and existent technologies have to say to the support and care of our older citizens, we would do well to remember that many of those who are older are both the co-designer, developers, users and innovators of the very technology we are about to explore. Whilst we will note that there are particular challenges in relation to digital and technological access for older citizens it would be both false and erroneous to create a dichotomy where technological and digital innovation were seen as the preserve of the young.<sup>9</sup>

Illustration of older citizens using technology



# Human rights and technology: the developing debate

## Technology as a human rights potential

Before we go on to consider in greater depth human rights as they relate to technology in the social care of older persons, it is useful to briefly explore what, if anything, has been said within the sphere of human rights about technological advances over the years.

Where do human rights fit within all this dramatic technological change? Are they fighting a rear-guard action to protect the individual *human in the machine* or does technology have a potential to enable the fulfilment and realisation of human rights? As with most things the answer is probably a mid-course, neither a vision of automaton hell and dystopia on the one hand, nor one of a rights utopia on the other. One thing is, however, clear and that is that technological innovation and advance offers both potential and challenge. It is never neutral.

In the year in which we are celebrating the 70th anniversary of the United Nations Universal Declaration of Human Rights (UDHR), it is worth noting that for most of its existence and that of its European sibling, the European Convention on Human Rights (ECHR), we have been living through a period of immense technological change and challenge. Ethical and moral decision making was at the heart of the earliest debates during and after the inception of the UDHR as the world faced up to the dawn and reality of a nuclear age. From 1948 onwards the courts and legislators have sought to keep up with the speed of technological innovation from in-vitro fertilisation through to the human genome, from data management to self-controlled automated cars. At times there has been a sense in which the Treaty frameworks of the 1940s and 1950s have been stretched to breaking point to accommodate new realities and there may be a debate to be had in earnest about whether developing case law alone is sufficient as a response to this latest technological ‘age of humanity.’ Indeed a growing number of commentators have suggested that the legal frameworks have been too slow to respond to new technological realities and that unless they do so as a matter of urgency then their future in a technological world is highly questionable. More of that later.

So what has been the experience of human rights organisations and interest groups with the new technologies that have been developed? This is worthy of a paper in its own right, but a brief summary is useful. Let us start with a series of positive perspectives which indicate that technology can support the realisation and fulfilment of human rights.

Organisations like Amnesty International have stated clearly that they believe that there are positive ways in which technological advances can assist the realisation of human rights. In recognising that existing legal frameworks have significantly advanced and kept to the fore the rights of millions across the world it cannot be denied that there are hundreds of millions who



are being daily denied their basic human rights. Technology can potentially assist in addressing that denial. Amnesty states:

*'Political, economic and technological changes can create risks and opportunities for human rights. In this era of unprecedented technological advances, those who work on technologies like artificial intelligence, robotics, and genetic engineering have a great responsibility to ensure not only that these technologies are safe and respect people's rights, but that they are part of the solution to today's human rights concerns.'*<sup>10</sup>

Amnesty suggests that there are highly practical ways in which technology and advances in AI could protect and advance rights. These might include, with appropriate safeguarding caveat; addressing harassment and threats of violence online, abuse against refugees and migrants, tracking pollution and environmental damage, and alerting people to risks to their health at an early stage.<sup>11</sup>

Other positive approaches to the human rights promise of technology can be found in the work of Gina Klein Jorasch who is currently Senior Advisor to the Center for Social Innovation at the Stanford Graduate School of Business. She argues that whilst it is relatively easy to recognise the ways in which social media has caused great discriminatory treatment there is also growing evidence of the ways in which social media platforms have been used to positively advance human rights. From the use of the web during the Arab Spring<sup>12</sup> to the more recent #metoo movement to address sexual harassment,<sup>13</sup> there are substantial grounds for her optimistic positivity towards technology.<sup>14</sup>

Another strong international voice arguing for a positive human rights response to technological innovation comes from Witness.<sup>15</sup> An international organisation, its primary purpose is to empower local people to document human rights violations in film. Indeed they have already had significant impact on the reduction of the voluntary recruitment of child soldiers in the Eastern Democratic Republic of Congo. Now working in over 100 countries, their focus is to identify critical situations and teach those affected by them the basics of video production, safe and ethical filming techniques and advocacy strategies arguing that with today's video and internet technologies, anyone can be a witness and documenter.

Nevertheless, despite all of the positivity outlined above, there were more than a few eyebrows raised when the United Nations Human Rights Office decided to enter into a formal partnership with one of the IT giants, Microsoft, when it signed a five-year partnership agreement in May 2017. As part of the agreement, Microsoft will provide a grant of USD 5 million to support the work of the UN Human Rights Office. This represents an unprecedented level of support from a private sector organisation. Not surprisingly some observers have asked whether such a massive donation came with any attached strings. The UNHRO, stated at the time that:

*'The new partnership builds on a long-standing relationship between the UN Human Rights Office and Microsoft that is based on two shared ideas. The first is a commitment to ensuring technology plays a positive role in helping to promote and protect human rights. The second is a recognition of the need for the private sector to play a bigger part in helping to advance the cause of human rights globally.'*<sup>16</sup>



The UNHRO almost as an afterthought in the face growing criticism, did acknowledge that ‘in some cases technology may contribute to human rights challenges.’ The partnership also sought to enable and promote a human rights-based approach and the promotion of responsible business conduct across the world, including the wider adoption of the United Nations Guiding Principles on Business and Human Rights. These Guiding Principles provide a global standard for preventing and addressing the risk of adverse impacts on human rights linked to business activity.

The UN High Commissioner for Human Rights, Zeid Ra’ad Al Hussein, expressed his belief that the deal was illustrative of the way in which private sector technology companies could make a critical difference to the achievement of human rights in the years to come.<sup>17</sup>

Is Al Hussein being overly optimistic? Some would contend the human rights challenges in relation to modern technology and its use are very significant and that partnering with one organisation, however dominant and global, does not reduce these challenges nor serve to address them.

Undoubtedly there is a potential for technology to support and further embed human rights and thus to foster improvement and change. Encryption and digital security tools *can* help curb harassment; social media tools *can* support activism and be a communicator of real public sentiment; Big Data *could* predict human rights crises and Blockchain<sup>18</sup> technology *can* foster a reduction in corruption by improving transparency by the means of indisputable records of transactions instantly. Within a social care context it is not too difficult to recognise the potential benefits of technology and its use to, for example, highlight changes in behaviour and frailty; to connect individuals who may suffer isolation and loneliness, to give assurance and transparency in caring for some of the most vulnerable. We will consider further human rights benefits later. These are but a few of the potential areas for human rights to be supported by technological innovation.

But are we being overly optimistic? Is technology the neutral paragon of positive human rights that some enthusiasts and ‘tech evangelists’ have suggested? Are there limits and constraints especially for those of us who work in social care? Are there health warnings for the use of technology and digital in the care and support of some of our most vulnerable citizens? In particular, are there challenges within the three dominant and inter-related fields of Artificial Intelligence (AI), Big Data and the Internet of Things (IoT)?

## Human rights concerns over technology

Despite the technological enthusiasts it has to be recognised that the majority of human rights commentary and narrative (such as has existed) over the last few decades have been suspicious of - if not downright hostile towards - technological advance. This is especially evident when one explores the somewhat limited jurisprudence in Europe and elsewhere. However, in exploring this perspective we may have to ask ourselves is this human rights critique misplaced, starting from the wrong basis or simply a failure to appreciate the inexorable advance of a technological age? Are we trying to judge the questions raised by technology by

using a rights and ethical paradigm which itself needs to be brought into a new age? Can the legal human rights frameworks which are so embedded in our culture and politics still speak to a very different age? In terms of social care, does it remain valid for us to continue to talk about human rights in relation to privacy, for instance, when we explore the use of smart technology and its gathering of data in an individual's home; or in giving citizens access to personal clinical data; or in considering the benefits of sharing or accessing individual data, for example, around Anticipatory Care Planning with a diverse group of health and social care professionals? Are human rights the right language and grammar for conversations in a new ethical environment?

We will return to these issues later, but for now it is worth noting that there are, nevertheless, a number of areas in which there has been a particularly focussed critique of technology within the human rights literature and community.

In 2017 BSR™ identified 10 key human rights risks for the ICT sector most of which, we would suggest, have relevance for social care, admittedly recognising that in each area of risk there is also potentially an opportunity.<sup>19</sup> The three key relevant areas for social care delivery which we will predominantly focus on within this work are:

## 1. Artificial Intelligence (AI) and Big Data Analytics

The creation of more powerful computing and the ability to use large and complex data sets has fed and enabled the related developments of AI and big data analytics. There is huge potential in this area, but there are also human rights risks of automated systems making discriminatory decisions without human influence, the impact of AI upon the labour workforce and associated rights, as well as the misuse of personal data and associated issues of ownership, management and access. Some of these issues have been highlighted in the developing capacity of machines to be autonomous without human intervention or influence.<sup>20</sup>

BSR™ argues that whilst technologies and services such as AI, big data analytics, and blockchain are shaping our future with all their potential for advance one of the ways to limit the potential risks and harm would be to develop a '*human rights by design*' approach which would build on existing 'privacy by design' methodologies to ensure that other human rights issues—such as freedom of expression, non-discrimination and child rights—are built in from the start. It could be suggested that such an approach needs to be centre stage for the ethical use and development of such technologies within the social care environment. We will explore this in more detail later, but already in some work, e.g. from the Glasgow School of Art, the concept of what it means to embed the person in technological design is well underway.

## 2. Internet of Things

There has been a developing narrative around a concept called the 'Internet of Things' which has a very direct relevance for the role of human rights within social care. It is perhaps in this realm that there is both potential and challenge for the social care support of older persons.

*‘The networking of objects, devices, people, and organisations to create the so-called ‘internet of things’ is enabling a wide range of new products, services, and solutions, such as smart cities, sustainable agriculture, self-driving cars, connected healthcare, and more efficient industrial processes. These opportunities are accompanied by new risks and challenges, such as the difficulty of obtaining informed consent from citizens for data use, or the need to establish privacy protocols for who has access to data, who controls data, and how data is used. These challenges form an important new social license to operate—without public trust, the Internet of Things is much less likely to become a commercial success.’*

In early 2018, Ruth Hickin from the World Economic Forum similarly identified - as we have above - three key trends in the world of technological innovation which were impacting upon human rights. She suggested that priority needed to be given to automation, the Internet of Things and how it related to freedom of expression, as well as the Internet of Things and the right to privacy.

She stated that experts estimated that by 2020, 85% of all customer interactions will be handled without a human agent, with support coming in the form of chatbots<sup>21</sup> and self-service technologies:

*‘A subset of AI, Machine Learning (ML), is expanding rapidly, unlocking pathways to increasingly efficient, accurate, and powerful processes ranging from diagnosing cancer to enabling self-driving cars. Data is the key ingredient that makes machine learning possible. Companies like HireVue use AI and facial analysis to measure tone and delivery, for example, to make the hiring process more efficient.’<sup>22</sup>*

But arguably not all data is neutral and there are risks of discrimination both in its use and in its sufficiency and lack of consistent availability. This is a particular challenge in a diverse and non-uniform context such as social care service delivery. As Hickin states: *‘In hiring practices, for example, algorithms mimic human decision-making, which can be based on bias.’<sup>23</sup>* How do we equality and human-rights ‘proof’ the algorithms?

Hickin also clearly articulates the issues relating to privacy and the Internet of Things:

*‘The Internet of Things is perforating domains that were previously private. As a result, the distinction between private and public spheres is blurring and the individual’s right to privacy is being threatened. Business Insider projects there will be 34 billion devices connected to the internet by 2020. All of those devices have the ability to interact with and track our personal data, from smart phone location tracking to motion sensors with inbuilt video cameras filming your movements.*

*Millions of us are giving away our private data without even realising, despite many of us valuing privacy more than ever. This has an impact on children as well as adults. There is a growing industry of ‘smart toys’ equipped with AI and speech recognition that can interact with children, learn and send data back to the manufacturers - potentially violating the privacy rights of the child.’<sup>24</sup>*

Alongside this growing body of research expressing concern for human rights in technological use, there is also the evidence of a somewhat ambiguous and, at times, antithetical approach seen in some recent human rights case law. We will return to this later.

## Human Rights legal frameworks as a critique of technology

Some of the commentators we have cited above identify apparent challenges in technological advances for the embedding and achievement of human rights. There are diverse ways of responding to such pressures. One is, as described above, to see the positive potential, another is to identify negative impacts without then attempting to seek remedy. Both can result in a recourse to the courts to protect and defend human rights or a desire through developing case law and other measures to redefine rights for a new and different age. We have already questioned above the robustness of the current legal frameworks in dealing with the questions posed by a technological age.

The international human rights system has been unfortunately very slow to adapt to technological change. Sherif Elsayed-Ali, Director, Global Issues at Amnesty International has written generally in the area of human rights law and the need for it to adapt. He has suggested the rights system has survived thus far because the pace of change has been gradual - but this is no longer the case.

*'What makes this period different is that the rate of technological advance is unlike anything we've seen before. It will take us by surprise, no matter how much we prepare for it. We tend to think linearly — when we project into the future, we imagine that in five years things around will be more or less as different as today is compared to five years ago. But a number of technologies are advancing exponentially — from artificial intelligence to robotics and additive manufacturing (3D printing) to synthetic biology — these will fundamentally change individual lives and societies. The international human rights framework, just like national legal and political systems, will have to adapt very fast, or become irrelevant.'* <sup>25</sup>

The case of changing understandings of privacy illustrates this point and has a particular resonance when it is considered within social care and in its use of smart technology.

Sherif Elsayed-Ali, suggests that:

*'The Internet of Things (IoT) will force us to rethink what privacy means. By 2020, it is estimated there will be 20–30 billion devices and possibly billions more sensors connected to the internet. Eventually, it will be the norm for any appliance, car, or gadget to collect information on its usage and its environment. Privacy is not dead, but it means different things for different people — we will always want ways to keep certain things private, but it will get harder.'* <sup>26</sup>





Faced with that reality, what will privacy and personal data mean in a social care context? We need to start having that debate more generally in Scotland, but in particular in relation to health and social care contexts. Who controls our data? What does privacy under Article 8 of the ECHR mean? There will soon be even more enormous volumes of data on individuals than exist at the current time. The control and management of that data by AI techniques raises significant issues, demanding not only robust legislation but encryption which is truly owned by the citizen rather than by other actors.

As Elsayed-Ali states:

*‘Privacy is usually thought of in the context of an individual’s private thoughts or actions or in relation to their interaction with other people, but people already entrust a lot of their private lives to their devices. The idea of devices such as smartphones being digital extensions of ourselves, and the dependency that comes with it, will deepen as artificial intelligence develops and human-machine interaction becomes more profound. Concepts of privacy should therefore also develop to encompass human-machine interaction — that is, privacy should not just exist in relation to one individual or between a defined set of individuals, but also as a fundamental part of the relationship between an individual and the devices they use. This is a critical test for the private sector: will companies build products and services that people trust enough to consider their interaction with them private?’<sup>27</sup>*



# Particular ethical and human rights challenges with technology

Having considered the wider human rights responses - both positive and negative - to the changes in technology, it will have become apparent that this is an enormous field of study. It is, therefore, not possible within the confines of this present paper to explore all the potential concerns relating to aspects of technology from a human rights perspective, never mind as they relate to social care for older persons. Therefore, as a starting point and for the purpose of this work we propose to explore Artificial Intelligence and the concerns raised by some key commentators, as well as - in somewhat less detail - two other related areas, namely Big Data and the Internet of Things, examining all as they relate to the social care of older persons.

## Artificial Intelligence and human rights

What is Artificial Intelligence?

There are numerous definitions of this term first coined by John McCarthy in 1956.<sup>28</sup> We will use a strict, albeit limited, dictionary definition which states that AI is:

*‘The theory and development of computer systems able to perform tasks normally requiring human intelligence, such as visual perception, speech recognition, decision-making, and translation between languages.’<sup>29</sup>*

For many individuals it is the world of AI that both threatens and yet proffers hope to humanity in the years to come. Our media - with almost weekly regularity - offers us stories of the development of AI which seem to stretch the imagination to breaking point. It is AI which has captured the popular imagination not least in dystopian nightmares like those depicted in movies like ‘Genesis’, ‘Terminator’ movies or ‘2001: A Space Odyssey.’

So is AI the panacea and hope-bearer of humanity or a threat? Or indeed, is the debate, especially as it relates to social care, much more nuanced?

There is a considerable ethical and human rights debate to be held around AI and unfortunately it is one which is at a relatively early stage in its articulation.

There are various strands within the debate on ethics, right and AI, some of which are directly relevant to an exploration of social care issues. Julia Bossmann<sup>30</sup> has identified nine top ethical issues relating to AI. These are unemployment; inequality - especially how we distribute wealth; humanity – how will machines affect our behaviour?; artificial stupidity – how can we guard against mistakes?; ‘racist’ robots – how do we eliminate AI bias?; security – how do we keep AI

free from adversaries?; ‘evil genies’ – how do we protect against unintended consequences?; singularity – how do we stay in control of a complicated system? and lastly, ‘robot rights’ – how do we define humane treatment of AI?

Two of the foremost AI scientists, Elon Musk<sup>31</sup> and the late Professor Stephen Hawking have raised significant concerns about the future use and developments of AI. Hawking’s critique was especially robust and worthy of comment in our exploration of the human rights basis of technology within social care.

Musk, CEO and lead designer at SpaceX and co-founder of Tesla, believes that it is highly likely that AI will be a threat to people. He suggests that there is only a slim chance that humans will be safe from such AI systems especially if they are controlled by a handful of major companies giving them “extreme” levels of power. He has called upon the key developers, especially Google, to slow down progress until there is a clear ethical and rights-based framework in place, arguing that the large companies hold more data upon us than we will ever be able to remember or recall.

The late Stephen Hawking’s critique is along similar veins but even more direct. In late 2014 he issued a warning that the development of full Artificial Intelligence could mean the end of the human race.<sup>32</sup> He was warning his fellow scientists of the inevitable moment when AI develops full intelligence beyond the threshold of human intelligence and potentially human control, a threshold dubbed the ‘*technological singularity*.’ Indeed in one of his last interviews, Hawking warned that such developments could result in new forms of life:

*“If people design computer viruses, someone will design AI that improves and replicates itself. This will be a new form of life that outperforms humans.”*

*“The real risk with AI isn’t malice but competence,” he said. “A super intelligent AI will be extremely good at accomplishing its goals, and if those goals aren’t aligned with ours, we’re in trouble.”*<sup>33</sup>

His challenge was that those who were non-scientists needed to work with the AI developers to prevent or reduce that threat. Two years later the creation of the Leverhulme Centre for the Future of Intelligence<sup>34</sup> at Cambridge University heralded the arrival of a dedicated Centre which focussed on the ethical dimension of AI. It includes within its staff philosophers, psychologists and ethicists as well as scientists and engineers.<sup>35</sup>

At its launch, Hawking stated his belief that:

*“I believe there is no deep difference between what can be achieved by a biological brain and what can be achieved by a computer. It therefore follows that computers can, in theory, emulate human intelligence — and exceed it.”*

*“In short, the rise of powerful AI will be either the best, or the worst thing, ever to happen to humanity. We do not yet know which.”*



So whilst diseases may be eradicated, climate change controlled and natural disasters anticipated, there is also a danger, as he suggested, of “*autonomous weapons, economic disruption and machines that developed a will of their own, in conflict with humanity.*”

All of this may, on the surface, be an interesting technological and human rights debate, but it might appear some light years from the practicalities of social care delivery. However it is not.

The same launch event also heard about more immediate concerns relating to the use of AI in the social care world. Professor Margaret Boden, who has over six decades of work in the field of computing and AI and is regarded as a seminal thinker in the history of cognitive science, was interviewed at the event by the BBC. In her interview she expressed specific concern on the impact of AI in the care of the elderly. Since then her warnings have become increasingly stark. In addressing the enthusiasm for the use of robots in the care of the elderly and the sick she has suggested that society needs to ask whether the use of robotic helpers is dehumanising.

After decades of research into AI, Professor Boden does not see robots replacing humans in functions which require empathy and emotional intelligence. However she contends that Artificial intelligence could soon offer governments the chance to cut growing bills for social care - but at a cost for those in need of help.<sup>36</sup>

The concerns of developers and others are increasingly reflected by the general public. A Nesta commissioned YouGov<sup>37</sup> survey in July 2018 revealed a deep public disquiet about artificial intelligence, with over 40% saying AI is an equal or bigger threat to mankind than nuclear weapons, and 52% supporting some sort of international regulation. A minority are happy for AI/robots to help with personal tasks like cleaning the home (40%). That means the majority remain sceptical or more negative.

## Care-bots, AI and social care

The last year has witnessed a growing debate in the social care of older persons around the use of robotic technology. One major care home group has adopted some of the technology which has been used for a few years in Japan. Advinia Health Care is taking part in a trial project from September 2018, as part of a £2.5m EU-funded partnership with the University of Bedfordshire. Dr Chris Papadopoulos, lecturer in public health at the University, said:

*“These robots are able to adapt, learn and tailor their conversations according to what they find out about an individual just as two people might do in a normal conversation... The software is in this way ground-breaking. We want to explore to what extent they might prevent loneliness and isolation, improve mental health and reduce family caregiver stress.”*

The 4ft tall robot, called Pepper, is designed by Softbank Robotics in Japan and Dr Sanjeev’s Kanoria, Chairman of Advinia Health Care and research partner in the study, said:

*“There is a pressing requirement for additional support in the social care of the elderly. Robots will not replace care workers, but such innovation could streamline processes such as medication delivery, setting reminders and providing access to technology and entertainment.*

*“This technology will not only improve care delivery, but also promote independent living and quality of life. Particularly for dementia patients, agitation can be reduced by offering culturally-appropriate care support.*

*“The robots do not have limbs, so they cannot carry out essential care tasks, but they have artificial intelligence which allows them to learn about the patients and residents and communicate this learning to the care workers enabling them to do their task better.”<sup>38</sup>*

There has been a mixed response even to this pilot. On the one hand there has been condemnation, with some individuals emphasising that it demeans the dignity of the human individuals involved and that technology cannot replace touch in the care of others. On the other hand some have reacted more positively, asking whether there are levels to which AI can assist in some of the tasks either in a care home or in someone’s own home? Are there ways in which the introduction of such models and approaches could utilise basic human rights-based assessment criteria to ensure that their use is both ethical as well as safe?

Writing recently in *The Telegraph*, the journalist Leyla Boulton enthused about the potential redemptory role of robotics in a stretched and challenged care home sector.<sup>39</sup>

However, as we have noted above, one of the long-term sharpest critics of an easy assumption that AI can automatically replicate the human person is Professor Boden<sup>40</sup> who has called for more work to be done on the ethical and responsible use of AI especially in the care of older persons.

Professor Boden has gone so far as to suggest that the use of robots (or care-bots) can be ‘dangerous’ in the care of the elderly or of children.<sup>41</sup> Speaking after the development of ‘Nadine’ in the University of Singapore - which is intended by its developers to eventually provide childcare and offer friendship to lonely pensioners - she declared:

*“Computer companions worry me very much...On the face of it, it could have conversations with an old person, and she can tell it her stories about her life, so it keeps her happy and if she tells it the same story it’s not going to be bothered. It could even collect her memories together and keep it in a diary.*

*“But think about that. If she tells it that her husband cheated on her with her best friend. That’s a betrayal a lack of loyalty and very very hurtful. These things are supposed to be able recognise her emotional state and to respond in an appropriate way.*

*“I suggest that the machine wouldn’t understand what we mean by a best friend, or loyalty. It is just too complex for it to understand and be simulated by an artificial computational system.*

*“I am very very worried about that. I think these things are very emotionally dangerous. And I think similar things used on children if they were over-used could seriously affect a child’s*



Boden has been spearheading the need to put the human dimension back into robotics and the way in which, as a society, we plan to use AI and robotics. There can be no sharper theatre for that ethical and human rights debate than in the care and support of some of our most vulnerable citizens. That is why this debate and intervention is one of such priority. We should resist the assumption that just because an action is technologically *possible* and economically beneficial that it is automatically desirable, necessary or allowable.

Boden extended her thoughts more recently when she stated, in a speech at the University College Dublin, that we have to question whether we should even consider giving to robots the responsibility to give solace to us or remove our fears. Boden acknowledges the advances in supercomputers beating humans at chess but is sceptical about the emergence of artificial general intelligence (AGI) and then artificial super intelligence (ASI) where machines are sufficiently intelligent to improve themselves.

*“I am sceptical about them having AGI, never mind ASI, within this century. Some people are saying 2030 [for AGI]. Do the maths: that is 13 years away. That is nonsense in my humble opinion. I don’t think people realise how hard the problem is and how rich and subtle human thinking is.”*

*“I cannot think of a single example of human activity that will not be touched in some way by AI, but there are huge dangers too even if you don’t believe there will be superhuman intelligence in 30 years... Fortunately, people have started to worry about it, to think about what the problems are and whether they could be regulated. So it is a hugely exciting, problematic and important area.”<sup>43</sup>*

As well as reflecting on the impact on the workforce (to which we will return below) Boden is most worried about situations where computers are being used where there should be one-on-one human relationships.

In a lecture in June 2018 Boden stated that the fundamental difference between AI systems and human beings is that computers can’t care. She suggests that it is our human needs that are the basis of our caring and our goals are accepted only in relation to our needs. She states that computers have no needs. Boden believes it is highly inappropriate for us to utilise AI systems in the context of inter-personal relationships.<sup>44</sup>

This is not just significant for older person care but has equal relevance for childcare. Mattel had announced its new childcare device, ‘Aristotle’ with considerable fanfare in January 2017. This was a robotic device which was designed to act as a child nanny and parent support. However following growing concerns over the ethics of using the device to parent for even a short time, combined with concerns over privacy and data gathering, it removed the launch and withdrew it from its strategic plans.<sup>45</sup> It would be reasonable to question if the use of AI is considered ethically unacceptable in childcare, is there a different moral or ethical paradigm at work in

relation to elderly care?

Notwithstanding the Mattel decision to postpone the 'Aristotle' project, Nanjing-based AvatarMind are continuing to argue and promote its belief that its iPal robot can give companionship to lonely children, is a great educational support and offers peace of mind to parents who can see and talk to their young ones remotely via mobile app.<sup>46</sup>

In addition a generation of Robo-pets are being presented as being able to offer companionship without the responsibility of usual pet ownership. Leading the way in this field is Sony's puppy-shaped 'aibo' whose latest version has sensors on its head, chin and back which respond to touch (in addition to voice), and a camera that helps it to fetch a bone.<sup>47</sup> Hasbro has also launched a companion Pet cat which is a cat-like figure that purrs authentically and responds to hugs, motion and petting. The company argue that their market research found that an interactive pet could alleviate risks associated with aging and improves relationships and communication with loved ones.<sup>48</sup>

A critical and related ethical consideration is the extent to which it is possible to form relationships with a robot. This may seem somewhat far-fetched but it is a key issue for a human rights and ethical base for social care's use of robotics both now and in the future. Professor Margaret Boden has made her stand on this issue very explicit. She has stated that without sharing the human (or even mammalian) condition, there is no ground for empathy and to suggest otherwise is deceptive. There are some who diverge from this view to a greater or lesser extent.

Dr Robert Clowes from the New University of Lisbon has argued that an ever-increasing segment of human social life is already influenced by AI.<sup>49</sup> One example is the Edgerank algorithm deployed by Facebook to manage which posts of which friends appear on our personal newsfeed, re-mediating and changing the structure of our social networks in the process. He has stated that AI technology such as the Amazon Alexa is already presenting us with immediate ethical challenges and choices. Indeed internet-based social technologies are likely to give us a snapshot of where social robotics will be going in the near future. As increasingly autonomous devices interact with us using detailed knowledge of our human social interactions and history, social AI technology will form the hidden inference basis for social robotics. He has highlighted the significant ethical and moral challenges and opportunities in what he and others have termed 'social robotics.' This whole dimension, in its infancy, is likely to be of particular significance for social care technology designers and practitioners.<sup>50</sup>

## AI and labour/workforce human rights concerns

One of the frequent comments made about technological advance has been the negative impact such innovation has on employment and workers' rights. The growth of the so-called *gig economy*<sup>51</sup> is illustrative of the disruptive effect of smart technology on employment and it is not just from high-profile examples such as Uber. There are now, and will in the future, be millions

who work, but not directly for an employer in the traditional sense. Social care is no different to other sectors in this regard.

Such changes impact upon worker rights and the ability of a flexible, dispersed workforce to collectively bargain and challenge employment practice. They also impact on the security of work and have an effect on emotional well-being. We have already seen instances where AI and automation has reduced the need for particular work activity, so we are already at a time where workers will increasingly compete with machines. This is happening in some surprising contexts. For example, the extent and abilities of Artificial Intelligence are having an impact even in the arguably dusty world of human rights jurisprudence. A study, which was conducted by researchers at University College London and the universities of Sheffield and Pennsylvania, showed that an AI system correctly predicted the verdicts in hundreds of cases heard at the European Court of Human Rights to an accuracy of 79%. Increasingly, law firms are turning to AI to help them wade through vast amounts of legal data, especially in fraud cases. In commenting on the research, Matt Jones, an analyst at data science consultancy Tessella, made an important observation about the restrictions of AI in human interactions. He said that such systems were not yet capable of ‘understanding nuance.’<sup>52</sup>

This is only the beginning.

The *Technological Change and the Scottish Labour Market* report from the Scottish Parliament in April 2018 summarises the issues well, in concluding:

*‘There is no consensus on the impact new technologies will have on labour demand; some tasks and occupations will be replaced but new jobs will be created, and it will not necessarily make economic sense to replace human labour even when technologically feasible to do so. This is especially true when there is weak wage growth and a global abundance of labour.*

*However there is a plausible case that the technological change in the 21st century could pose new and serious challenges in sustaining a labour market that supports broadly based prosperity.’*<sup>53</sup>

One leading commentator - Elsayed-Ali has reported that:

*‘The accelerating rate of automation will put a very large proportion of current jobs at risk across the world, with developing countries at greater risk. According to analysis by the University of Oxford and the World Bank, 35% of jobs in the UK could be replaced by automation...*

*Finally, pressure on jobs in the future will likely hurt gender equality. Progress towards equal pay and equal access to economic opportunities for women has been painfully slow. In a world with fewer jobs, there is a very real danger that we could see a reversal in the small gains that have been achieved. Serious policy action will be needed to avoid such an outcome.’*<sup>54</sup>

Not all commentators are as negative. A recent report from PricewaterhouseCoopers on the impact of AI on the workforce in Scotland, suggests that 544,000 jobs could be lost as a result

of automation, but that AI could create 558,000 Scottish posts by 2037 - resulting in a net increase of 14,000.<sup>55</sup> Indeed they argue that, the health and social care sectors could enjoy the greatest benefit with an increase of 1 million posts across the United Kingdom.

A further argument relates to a developing critique of the position which assumes that AI can be utilised to ‘complement’ or ‘collaborate’ with a human workforce. Boden argues that

AI cannot collaborate in the way in which humans can because it assumes a shared set of needs and goals which do not exist. Further she would suggest that, especially in a human care interaction, it is erroneous to assume that the exchange is primarily utilitarian and functional, but rather that there is an affective dimension and depth of emotional reciprocity which an AI system cannot ever achieve.<sup>56</sup>

In concluding this section we have two of the foremost proponents and developers of AI arguing for the need to develop a rights-based framework for its design, development and use. We have evidence of a potential dramatic impact on the workplace and on human interaction, and lastly, we have, in the work of Professor Boden, a specific identification of issues related to the use of AI in the care of older persons. What of ethical and human rights issues as they relate to Big Data and the Internet of Things?

## Big Data

Big Data doesn’t really have an agreed and accepted definition since its first usage in the 1990s, but in a general sense it is the term used to describe data sets which are of such a large size that traditional software tools cannot ‘capture, curate, manage and process data within a tolerable elapsed time...’

*‘Big data requires a set of techniques and technologies with new forms of integration to reveal insights from datasets that are diverse, complex, and of a massive scale.’*

*‘A 2016 definition states that “Big data represents the information assets characterised by such a high volume, velocity and variety to require specific technology and analytical methods for its transformation into value.”’<sup>57</sup>*

There have been developing ethical concerns over the capturing, analysis and exploitation of such data, especially as they impact on an individual’s right to privacy when data can be gathered either deliberately or otherwise. There are concerns over who owns the data and how that ownership is exercised; how an individual has access to and an ability to alter that data if required; what level of consent an individual may have over that data; the knowledge of an individual about data which may be held on them, and all of these are set against a backdrop of a changing understanding of privacy.

Some of these concerns and ethical questions were brought sharply to the fore for many individuals in early 2018, following what has become known as the ‘Cambridge Analytica Scandal’. The data analytics firm is alleged to have used personal information harvested from more than 50 million Facebook profiles without the permission of the account holders, in order to build a system that could be used to target US voters with personalised political advertisements based on their psychological profile. The scandal broke when Christopher Wylie, a former Cambridge Analytica contractor who helped build the algorithm, went public.<sup>58</sup>

For the general public, Big Data and issues of ethical oversight are very much in the news and of the moment. However, some have questioned whether or not it is already too late to establish an ethical framework for the use of Big Data:

*‘the tide in the world of big data and AI research seems to have turned decidedly against the notion of outside ethical review. Instead of asking what questions we should be asking that would better human society, data scientists today all-too-often ask what questions are possible with the data and tools at hand and especially what questions would generate the most attention (and hence publication prestige and grant funding).’*<sup>59</sup>

The same author, Leetaru, cogently argues that data scientists are becoming a universal discipline, crossing traditional academic and research boundaries, paying lip-service to ethical and research codes and systems of ethical review, and working across diverse domains and fields of study and research.

Over and against this pessimism, there are no shortage of codes and principles being developed around the use of Big Data, some of these are governmental, some academic and others originating from the AI and technology sector itself. One such is the Bloomberg, BrightHive, and Data for Democracy Launch initiative to develop a Data Science Code of Ethics.<sup>60</sup> Another is the recently published Google ‘AI Principles’ which we will consider more fully below. But are these doomed to failure, already running far behind the actual science?

The development of an ethical and human rights-based framework or paradigm for the ethical use of data is a major issue for those of us working in a social care context. The issues of ownership, consent, transparency and access are critical to building trust which would enable the benefits of Big Data and AI to be maximised for the positive enablement of individuals rather than for the narrower benefits of developers and designers. Trust is fundamental to such a process and yet it is only achievable within an ethical dimension where conditions exist to enable its establishment. The problem is that there is evidence that trust, in data or more accurately its use, is something which is significantly lacking, and that was even before the Cambridge Analytica Scandal.

Research by the Royal Statistical Society has indicated that there is a ‘data trust deficit’ where the public have lower levels of trust in institutions to use their data appropriately, when compared to their general levels of trust in that organisation.<sup>61</sup> The Society held a symposium





in late 2015 to explore ‘*The Opportunities and Ethics of Big Data.*’ Their report<sup>62</sup> is a helpful summary of some of the issues and it clearly highlights the operational gaps in the United Kingdom.

*‘In the United States, the National Science Foundation helped to set up a Council for Big Data, Ethics and Society. There is no equivalent in the UK. Do existing ethical, regulatory and legal frameworks need to change, or can they accommodate big data? Do professional bodies need to change their professional codes in light of the changing nature of data? How can we use the increasing amounts of data in society for public good and with public support?’*

These concerns around Big Data indicate a considerable lack of understanding amongst the general public about how data is held and controlled. This has been alleviated more recently by the introduction of General Data Protection Regulations (GDPR)<sup>63</sup> but only, it would be suggested, to a marginal extent. A Wellcome Trust report<sup>64</sup> found that just one third of people in Britain have heard a fair amount (or more) about how the NHS is using health data. We have already stressed the fundamental role data will play in the future, not least in the delivery of health and social care services. There is a clear need for greater awareness raising and education at all life-stages about data, how it is used, and how the citizen in their health and care can access and control that data.

These are fundamental concerns which go to the heart of how Big Data can or should be used in a social care context. In the next sections we will explore some of the policy and practice landscape within Scotland and how these are, or are indeed are not, being addressed. However, firstly a brief exploration of the ethical issues relating to the last of our three areas of examination, the Internet of Things.

## Internet of Things (IoT)

Matthew Evans from techUK defines the Internet of Things (IoT):

*‘In the broadest sense, the term IoT encompasses everything connected to the internet, but it is increasingly being used to define objects that "talk" to each other. "Simply, the Internet of Things is made up of devices – from simple sensors to smartphones and wearables – connected together.”’*<sup>65</sup>

Alongside AI and Big Data, there is again a growing desire to develop or support an ethical and a human rights framework around the current and future use and development of IoT. Clearly, and perhaps most especially for IoT, there is a connection with the device and the data gathered and their attendant ethical issues. This is of particular interest in a social care environment where we are witnessing a significant growth in the domestic use of devices which are often collectively termed as ‘telecare.’

Whilst IoT may be in its infancy, the number of smart devices in the domestic environment

from smart meters, phones, toasters, televisions to motion sensors, lightbulbs and switches evidence that this is becoming a dominant part of everyday domestic life. Some might argue that devices do not need to be connected to the internet, but the arguments evidencing efficiency and benefit seem to be overcoming such a proposition. However there are understandable concerns in relation to security, as all such devices, are potentially ‘hackable’.

By late 2017 there were over 20 million Amazon Echo devices in circulation alongside millions of similar smart devices like the Google Home or Apple Homepod. More recently, there have been some negative stories emerging relating to smart devices; from ‘Alexa’ devices starting to speak in creepy voices<sup>66</sup> to an admission from Amazon.com Inc. that a series of miscues picked up by one of its voice-activated Echo speakers during an Oregon couple’s private conversation resulted in the chat being recorded and sent to one of their acquaintances without their knowledge.<sup>67</sup>

In 2017, Francine Berman, a computer-science professor at Rensselaer Polytechnic Institute, and Vinton Cerf, an engineer considered one of the fathers of the internet, wrote about the need for an ethical system for the IoT. In particular, they suggested that we needed to develop policy for IoT safety, security and privacy, in order to advance and protect individual rights, data security, and trust; a legal framework for determining appropriate behaviour of autonomous IoT entities, and:

*‘[a] focus on human rights and ethical behaviour in the IoT, including a sense of how these would be enforced. This gets to the heart of the need for the IoT to promote human well-being and contribute to the advancement of society.’<sup>68</sup>*

Berman has also argued elsewhere that the success of the IoT will be assessed on the basis that the social revolution which it has the potential to herald, is built on a trust-established, rights-based environment where the citizen has a degree of control and ownership and where his or her rights are advanced and fulfilled. Engaging and involving individuals from the point of design, in order to create a valued social contract is central to this. Berman states:

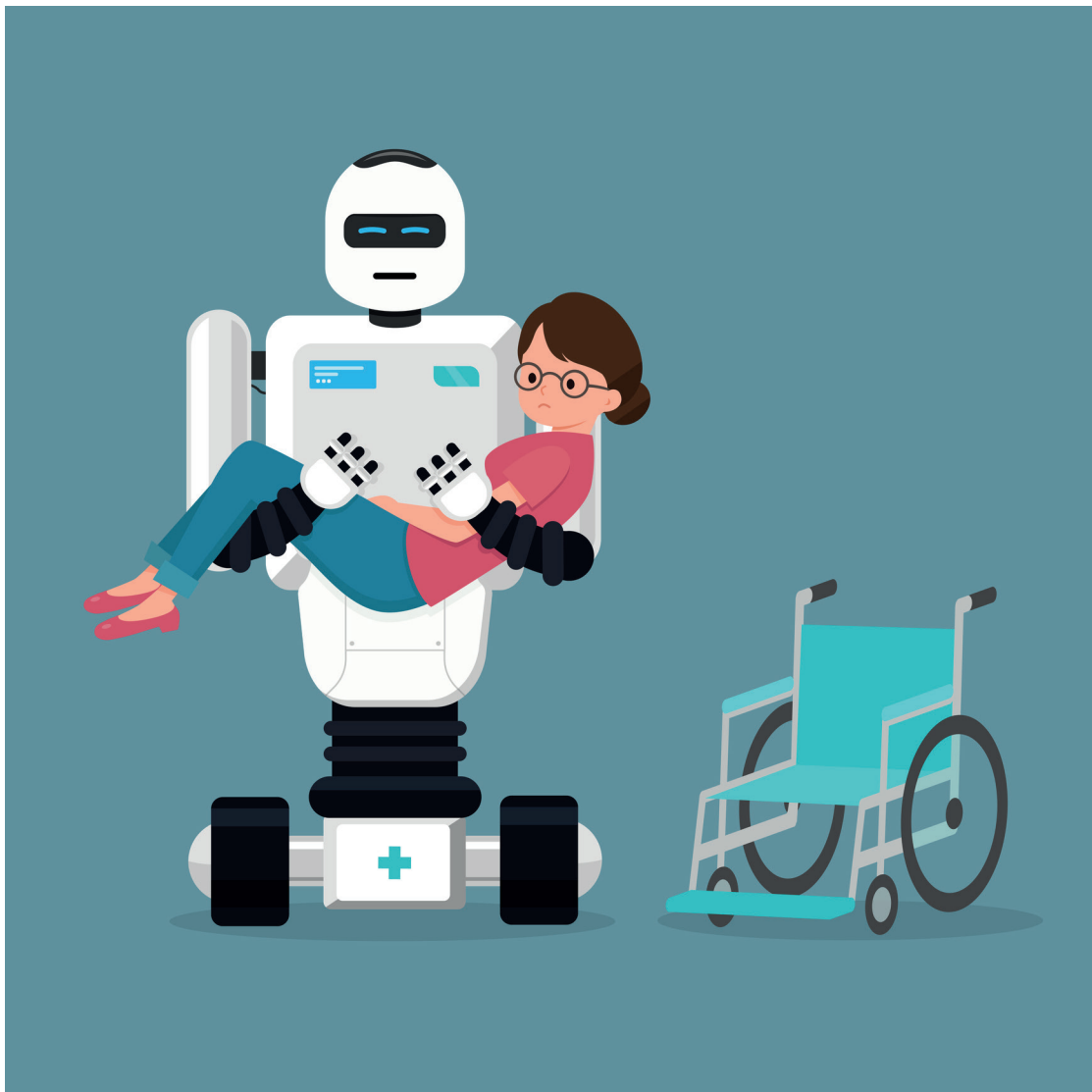
*‘Think about designing a car. I want to design it so it’s safe, and so that the opportunity to hack my car is minimized. If I design Internet of Things systems that are effective, provide me a lot of opportunities, and are adaptive, but I only worry about really important things like security and privacy and safety afterwards, it’s much less effective than designing them with those things in mind.*

*We can lessen the number of unintended consequences if we start thinking from the design stage and the innovation stage how we’re going to use these technologies. Then, we put into place the corresponding social framework.’<sup>69</sup>*

It is this social dimension at the heart of design and development which is of particular resonance within a social care context. So how do we develop an interactive environment with AI, Big Data and the Internet of Things rooted in a social dimension, purposeful and rights-

based, and ultimately secure from malign use and intent, whilst also being accessible and personal yet private?

We will now turn to examine social care practice as it relates to technology, with particular reference to Scotland, before considering the policy, ethical and human rights context.



# Technology and social care in Scotland: emerging practice

## Care and technology: a growing reality

To date in this study we have rather presumed an understanding of what social care is and the nature of the relationships engaged in its practice. Before we go on to consider the use of specific technological interventions already happening in Scotland, it might be worthwhile pausing to reflect on what social care within a rights based technological environment might look like.

Scottish Care has argued in many of its recent research publications for the creation of a dynamic, trust-based, relational model of care which is time-flexible, person-led and oriented around self-management and prevention.<sup>70</sup> Social care is a human interaction which goes far beyond the carrying out of particular functional tasks. It is not solely about the maintenance of health, but rather the fullest achievement possible of individual potential in a manner which is holistic. The relationship dynamic involved is one which is mutual, reciprocal and trust-based.

The care relationship is often portrayed as a passive exchange between the ‘carer’ and the ‘cared for.’ This is to wholly misunderstand the potential for effective and affective care to enable the achievement of full humanity and human potential. A good care relationship is one where there is a mutuality of power, a recognition of diverse contribution, and where autonomy and control is in the hands of the supported person not the ‘professional carer.’ Person-centred, and what we would want today to describe as person-led care, is rooted in the fundamental human rights principles of autonomy, control, dignity and individual choice. Care is much more than a set of transactional functional tasks carried out by one person ‘upon’ or ‘on’ another; it is rather the growth and fostering of a relationship of trust, reciprocity and joint-action.

The question arises of what role technology can or should play in such a dynamic? At one level technology and technological interventions are perceived as substantiating a functionalist, task-focussed, tick-box oriented approach to care. Indeed, some of the ways in which technology has been utilised, especially within a risk-averse clinical environment, have added weight to such suspicions. For many involved in social care delivery the way in which technology has been used of late in Scotland to contract monitor and manage homecare providers has left some frontline workers feeling dis-empowered,<sup>71</sup> lacking autonomy and respect, and effectively feeling as if they were continually under surveillance. Technology in such environments is unsurprisingly not viewed positively.

The failure to build trust and to engage and involve citizens when technology has been introduced into social care settings - whether as a monitoring tool for workers or as a support system for individuals - further risks the perception that technology is being used as a replacement or substitute for human interaction, rather than as an enabler of even better and

deeper human presence and relationship.

We have witnessed this most recently in the rather public discussions around the use of technological interventions within overnight support. Some parts of the media have reported a backlash in Glasgow City against the replacement of overnight staff by technological supports.<sup>72</sup>

In such situations, technology is often perceived as an infringement upon - and as a barrier to - human communication and contact. Anecdotes abound about professional individuals who, during an assessment interview, are so concerned with accurately inputting data into their iPad that they fail to give eye contact or pick up on the subtle nuances of human bodily communication, all of which results in the technology becoming a block to encounter rather than an enabler of deeper communication, dialogue and care.

One of the ways this negative perception needs to be and can be challenged is through the engagement and involvement of individuals in the development and design of new technologies within care pathways. Recent work undertaken by the School of Innovation at the Glasgow School of Art is illustrative of this potential. This innovative approach to design has highlighted the extent to which the designer is a co-collaborator alongside the person who is being cared for and the person doing the caring. It is evidence of the profound significance of having a clear design 'ethic' where the emphasis is upon trust, relationship, dignity and empathy. At its best, designing around technology in a social care environment is a fully participative process, utilising the lived experience and expertise of those who are supported alongside the insights of other 'professionals.' The design journey is purposed around making a human difference, enabling better and deeper relationships, rather than achieving greater functional outcomes or technical excellence as a primary motivation. Effective technological design which is fully inclusive is trust-enabled rather than risk averse.<sup>73</sup>

This participatory approach to democratic co-design of technology in social care ties in with the direction of travel for care and support in Scotland, not least with the new National Health and Care Standards<sup>74</sup> which state that people receiving care should be involved in all decisions regarding their care and support. Underpinned by the principles of dignity and respect, compassion, inclusion, responsive care and support and wellbeing, the new standards are reflective of legislation such as the Social Care (Self-directed Support) Scotland Act 2013 with its emphasis on co-production, collaboration, participation, involvement and informed choice. The latter, with its emphasis on creating new models of support, has huge untapped potential to utilise person-led, ethically designed technological solutions.

Technological design is a critical primary first step and component in the constructing of a human-rights based approach to technology and its use in social care environments. Further design of technological interventions will increasingly take place in an already fertile environment.



## Technological diversity in practice

There is a real diversity of practice in Scotland, albeit that the level of uptake of new technologies has been significantly impacted by fiscal austerity and challenges to organisational sustainability caused by resource drain and sustainability issues.

Across the UK as a whole social care is one of the emerging fields to utilise AI, maximise the benefits of Big Data and the Internet of Things. It is estimated that the number of monitoring devices currently capturing data from patients and social care users for AI purposes such as predictive analytics will increase exponentially. A recent US report<sup>75</sup> noted that at present in the US there were 53,000 such devices in use as of 2017, and there will be 3.1 million as of 2021. Although social care has been slower to engage within the United Kingdom, the rise is likely to be equally exponential.

An exploration of the diverse ways in which technological innovation is occurring would be a work in its own right. For our purposes, it is worth highlighting just a few areas which are illustrative of some of the emerging issues and ethical questions which we have focussed upon thus far in this study.

Some of the benefits of AI in enabling independence and for home-based preventive care solutions are already well under way in terms of their adoption by the supported housing and housing with care sector in Scotland. Assistive technology is the technology and apparatus that enables people with disability and limited mobility to stay living longer in their own home.

This includes the 'FitHome' models, developed by Albion Housing Society and NHS Highland,<sup>76</sup> which use data-gathering equipment and artificial intelligence to support independent living for young people with disabilities.

In Dumfries and Galloway, Loreburn Housing Association has utilised smart waterproof wristband monitors which detect the wearer's vital health signs 24 hours a day in a programme to prevent falls and reduce costs to the NHS. Known as ARMED (Advanced Risk Modelling for Early Detection), the system was developed by care management technology company CM2000. The wearable device detects early indicators of frailty, such as low grip strength, muscle mass, hydration levels, low heart rate and heart rate variability. Detecting early signs of frailty and change in behaviour to enable intervention is key to maximising the benefits of AI and thus predictive analytics modelling is key to much AI development.<sup>77</sup>

The contribution of accessible technology utilising cost-effective software such as Xbox technology in order to keep older people safe and independent is increasingly being explored. There are particular challenges associated with older people using wearable technology, so building in 'monitoring' technology at the design and construction phase of new buildings is well under way in some locations.<sup>78</sup>

Blackwood is another Scottish provider spearheading the use of digital and technology to enhance the experience of those receiving care and support in their own home. They have developed a bespoke digital system called 'CleverCogs' which is a digital system where customers are provided with a touch screen home hub tablet device. They enable people to stay in touch with friends and family; discover subjects of interest; access information they want to see and receive convenient reminders of any appointments, care visits or medication they need to take. It enables the development of a personalised care package around the individual considering both formal and informal care needs.

Blackwood have also developed a Blackwood House in Dundee to deliver housing with care. The homes come equipped with pocket doors - electric doors that slide open and shut at the touch of a button; electric blinds that can be controlled from an app to suit a range of scenarios are installed in each room; underfloor heating throughout and temperature control in each room; rise and fall kitchen surfaces and cupboards and fully adapted bathrooms.<sup>79</sup>

There are a whole range of Scottish providers seeking to offer whole system solutions to promote independent living. The diverse range of technologies on show at the Scottish Care event in August 2018<sup>80</sup> is illustrative of the wide spectrum of organisations who are increasingly working to bring technological solutions to the social care environment.

Some of the most innovative developments have related to the challenges facing recruitment, retention and maximising the autonomy and independence of the social care workforce. A growing number of Tech start-ups are focussing on the challenges faced by social care and health providers. 'Cera',<sup>81</sup> created by former doctor Ben Maruthappu and Marek Sacha, has developed an "Uber for carers" model with a marketplace that matches care workers to clients and their families. It also digitises care records so carers can log information about clients using their smartphone. This information is then being fed into an AI platform, which will eventually predict the health of their clients.<sup>82</sup>

The Scottish Government has invested a significant resource in creating technology and digital as a strategic priority in health and social care. In 2014 they announced a £30million fund and established the Technology Enabled Care Programme. Increasingly there has been a greater appreciation of the challenges of embedding technology and digital within a diverse social care market and environment. There has also been a re-orientation in focus with the change from 'technology' to 'care' as evident in the journey of the Scottish Government programme on 'Technology Enabled Care:'

*'With the advances already made in the introduction of technology opportunities within our health and care system in Scotland, it is now appropriate to shift our focus from 'technology' itself to 'care, supported by technology'. To support this transition, the Scottish Government has adopted "Technology Enabled Care" (or TEC) as a simpler and broader term ...the emphasis needs to be on enabling care using the most up-to-date methods, and not on the technology – i.e., any change needs to be service led and outcomes driven, not technology led.'*<sup>83</sup>

The TEC Programme also developed a core set of principles:

- *‘Citizen-centred: work with citizens, users and patients to co-design and develop solutions which support the management and delivery of their own health and wellbeing, with a particular focus on addressing health inequalities;*
- *Flexible: facilitate flexible solutions which expand choice, control, coverage and accessibility;*
- *Familiar: build on existing and increasingly familiar technologies and favour the adoption of simple, low cost approaches which can be tailored to the individual, utilising users’ own technologies where and when practical to do so;*
- *Facilitative: Support service redesign to integrate new ways of working into mainstream service provision and pathways;*
- *Innovative: secure continued investment in innovation to ensure a pipeline of ‘next generation’ solutions for the benefit of our citizens and our economy, and work with national procurement bodies to ensure supportive procurement frameworks;*
- *Efficient: optimise efficiencies through significantly scaling up the application and use of TEC in home and community settings, and enabling our specialist health and care resources to be targeted in the most effective ways.’<sup>84</sup>*

Technology is already having an impact on many lives across Scotland. However the need for a robust framework around consent, data management, and individual control and choice is becoming increasingly evident.

Writing in a recent edition of Inside Housing, Harriet Bosnell, suggested a Checklist for Assistive Technology:

- *‘Technology needs to be utterly reliable with swift and ring-fenced connectivity in an emergency*
- *It needs to be attractive, sleek and good looking enough for all of us to want to have it in our home. It needs to look like I’m worth it*
- *Technology must connect me to my friends and family, wherever they are in the world*
- *I want technology to be non-intrusive, easy and intuitive to use, so I don’t feel patronised by the technology I’ve allowed into my home*
- *I should be cost-effective and have different price points*
- *I don’t want to be tracked by my children via sensors, so they know how long I’ve been in the bathroom and I don’t want to talk to a robot instead of a human.’<sup>85</sup>*

Both this Charter and the TEC Principles are a useful starting point for our later discussion on what an ethical and human rights-based framework and set of principles might look like. We will return to this below.

## Older people and digital technology

One theme we have not reflected on thus far and which is often noted in discussions on technology, digital and social care, is the extent to which older individuals actually access technology. There is a divergence in the research literature about what the actual experience of older people is both in relation to digital access and its use. On the one hand there is growing evidence that access to technology and digital formats are of particular benefit to older persons serving to increase connectedness and reduce isolation, regardless of whether in the community or in a care home.<sup>86</sup> On the other hand the physical ability to access such opportunities remains challenging for many.

A study published by the UK Centre for Ageing Better<sup>87</sup> in May 2018, states that people over 55 make up 94 per cent of non-users of the internet, but digital-inclusion approaches tend not to cater for them. It argued that 4.8 million people over the age of 55 are not online. They are a group likely to be poorer, less healthy and less well educated than their peers, the report says.

It also argues that many existing approaches to digital inclusion fail to effectively target these people. It advocates for the need to move away from basic digital skills in favour of enabling people to do more specific things they need, such as gaining access to information and services or cheaper goods.

It is perhaps surprising that it has taken so long for digital inclusion agencies to discover the basic principles of ‘andragogy’ as described by Michael Knowles in the 1960s, i.e. that adults learn differently to children and targeting learning on individual outcomes, tasks and needs works best.

This latest work builds on a major study in 2013 from Age UK<sup>88</sup> which stated that over two thirds of all digital exclusion is among those aged 65 and over (66.79%) and over 82 per cent are aged 55+.

Despite efforts, there remains a major issue which is less about access, but more significantly about use and digital confidence. So virtually everything we are alluding to in terms of the potential of digital and technology within a social care context is predicated on us improving both digital access and use by older individuals. Arguably to date this has not received sufficient Governmental attention and focus.

# Technology and social care in Scotland: the developing story of policy

## Strategies, plans and programmes

Before we go on to explore what a human rights-based framework might look like in practical terms, it is worth spending some time exploring in greater depth the policy and governmental environment to date.

As has been suggested above, in the last decade there has been an astonishing diversity of development in technology and digital usage and in software and hardware development in the health and social care sectors across the United Kingdom. A similar pattern of development can be evidenced at a policy and governmental level.

In recent years Scotland has forged ahead in the realm of technology and digital in health and social care policy, producing numerous strategies and action plans. These have recently been considered and reviewed by the Health and Sport Committee of the Scottish Parliament. In its 2017-18 *Inquiry into Technology and Innovation in Health and Social Care*,<sup>89</sup> the Committee examined a wide range of policy documentation and plans and took evidence from a considerable number of stakeholders, including Scottish Care. The report is extensive in its coverage of how technology and digital has, and is likely to, impact on the delivery of health and care services, albeit that it is somewhat weak on the social care side of things which is itself reflective of the health dominance within both the policy and implementation context in Scotland.<sup>90</sup>

The Committee report provided an opportunity for a range of bodies to raise some of the issues we have highlighted above in relation to data access, management, security and privacy, co-design and co-production, although there was less on issues relating to AI and the Internet of Things.

For our purposes, one of the key issues the Committee explored was the extent to which data would be managed and controlled and especially the person-centred nature of that control.

The Report states that:

*‘medConfidential and the Open Rights Group (said) that the vision statements (of the Draft Digital Strategy) fail to position the individual at the centre of the NHS. They believe that a truly person-centred approach would be to empower patients to control their own information.’<sup>91</sup>*

It is unlikely that many would find fault with the overarching aim of the Scottish Government’s





*Digital Health and Care Strategy*<sup>92</sup> to place the individual at the centre, but what does that practically mean, especially in light of what we have said above about our ability to have ownership, access and control over increasingly complex data? In their evidence to the Committee, medConfidential and the Open Rights Group<sup>93</sup> rightly stated that statements of intent need to be followed through with action. Co-design and co-production of technological and digital solutions need to involve the user of social care and health services. They state that this necessitates a commitment to work on ‘privacy-by-design principles’.

*‘Placing the patient at the centre and building systems where the patient is able to understand they are at the centre and control their data. This includes knowing who has access to their data and being in a position to decide who can access that data.’*

*Placing the individual at the centre of this process can improve patient experience... Ultimately this would allow the individual to remove their data from being processed or being held by certain providers, whether that is specific GPs or initiatives, or services. Data portability would improve privacy and health outcomes by rewarding those who act responsibly with patient’s data and punishing those who fail to respect the privacy of their patients.’*<sup>94</sup>

They rightly postulate the belief that the current *Digital Health and Care Strategy* does not go far enough in giving the control to the individual citizen. Indeed we would argue that in terms of data control we should move away from a narrative around patient-centred or user-controlled to one that is person-led and controlled.

It is clearly possible for models to be developed that would allow the social care user to access data held about them by health and social care actors. What is needed is a consistent set of practice principles and models to evidence how this can be achieved on the basis of upholding and advancing the human rights of an individual. Indeed some of these already exist.

Chaloner Chute from the Digital Health and Care Institute, in his evidence, indicated how individuals can retain control, individuality and power over their data and yet still share it when appropriate by means of a data ‘bridge’.

*‘In Estonia it is called X-Road, and DigitalHealth.London has done it across all the trusts in London; there is one bridge, to which everyone connects. That includes patients—the patient can connect to the bridge, see who is looking at their data and withdraw consent if they feel that someone is misusing their data or using it in a way that is not in line with their wishes. That is the patient empowerment, citizen rights and data protection win.’*<sup>95</sup>

There is a considerable desire, both within the Scottish Government’s *Digital Health and Care Strategy* and in practice, to share data effectively utilising a single data platform or central spine. The principles of creating data once and giving autonomy and control to the individual citizen are an example of the potential for a rights-based approach to lie at the heart of technological solutions and interventions.<sup>96</sup> Regrettably, much of the focus to date in Scotland has been health and clinically dominated rather than utilising and accessing social care. It is to be hoped that this

will change as it is fundamental to building the contextual trust we and others have noted above as being critical.

Recently in England an initiative has been launched to ensure private and independent healthcare and social care data is recorded in the same way as NHS data in England, with the aim of improving consistency across the system. This initiative, called the Acute Data Alignment Programme (ADAPt), aims to integrate diverse data under a standard protocol system.<sup>97</sup>

## Scottish Digital Health and Care Strategy

The primary focus of the Scottish Parliament's Health and Sport Committee's Inquiry was the draft *Digital Health and Care Strategy* which was later published in its final format in the summer of 2018. In defining its aim, the *Scottish Digital Health and Care Strategy* states that:

*'The strategic aim for Health and Social Care is that Scotland offers high quality services, with a focus on prevention, early intervention, supported self-management, day surgery as the norm, and – when hospital stays are required – for people to be discharged as swiftly as it is safe to do so.'*

*'This strategy focuses on how digital can support this aim whereby, as a citizen of Scotland:*

- 'I have access to the digital information, tools and services I need to help maintain and improve my health and wellbeing*
- I expect my health and social care information to be captured electronically, integrated and shared securely to assist service staff and carers that need to see it...*

*...and that digital technology and data will be used appropriately and innovatively:*

- to help plan and improve health and care services*
- enable research and economic development*
- and ultimately improve outcomes for everyone.'*<sup>98</sup>

It is self-evident that there is potential for this Strategy to be firmly rooted in a core set of human rights-based and ethical principles which address some of the concerns and ethical challenges we have highlighted above. The fact that it fails to directly mention these issues is profoundly regrettable and disappointing. There is quite rightly an appropriate list of expectations, but little delineation of the rights-basis for their fulfilment and the ethical and legal recourse available should they not be addressed or met.

The statement in the document that *'digital technology is key to transforming health and social care services so that care can become more person-centred'* is both truthful and illusory. It is truthful in that technology has a potential to enable more person-centred care, but it is illusory unless the care is person-led and democratic and thus the technology is there to empower the individual at the heart of care.

## Wider UK policy

Outside Scotland there has been more focussed attention on dealing with issues relating to Artificial Intelligence. Recently there has been a robust and thought-provoking report on AI produced by the House of Lords, *'AI in the UK? Ready, willing and able?'*,<sup>99</sup> although despite hearing from a number of witnesses in its deliberations, they have made only tangential comment on the concerns identified by Hawking and others about extreme forms of AI.

Nevertheless, in their recommendations they have provided a solid analysis of what the main ethical issues are and how these can be handled. In comparison, the Scottish Health and Sport Committee Report and the Digital Strategy are relatively weak in this regard.<sup>100</sup>

The House of Lords Report recognises that although there have been significant developments over time in relation to AI, it is only in the last decade that these advances have gained significant speed. The time is right, therefore, it suggests, for embedding the best possible ethical and practical regimes around further development. This means that we are in an environment with as much risk as potential, not least over who has access to the increasingly vast data which already exists and which will exist in the future.

They summarise the main human rights and ethical issues as:

- *'Large companies with control over vast quantities of data should not be allowed to dominate. Competition authorities should be tasked with a proactive review of the potential monopolisation of data. Innovative companies of all sizes, and research organisations, should be able to access data on fair and reasonable terms.'*
- *'Greater visibility and control for individuals and better protection for privacy. Individuals should know when and how AI is being used to make decisions about them. Datasets should be audited to reduce the risk of prejudice against groups in society.'*
- *'Clarity around legal liability if AI systems malfunction or cause harm through poor decision-making, ideally through a Law Commission review.'*

The Committee heard from experts across industry and academia. The active approach of businesses like DeepMind and Prowler.io in engaging with the ethical issues is recognised in the report.

A core recommendation within the House of Lords Report is for a cross-sector AI Code embodying five principles, that might form the basis of an international consensus:

- *Artificial intelligence should be developed for the common good and benefit of humanity*
- *Artificial intelligence should operate on principles of intelligibility and fairness*
- *Artificial intelligence should not be used to diminish the data rights or privacy of individuals, families or communities*

- *All citizens should have the right to be educated to enable them to flourish mentally, emotionally and economically alongside artificial intelligence*
- *The autonomous power to hurt, destroy or deceive human beings should never be vested in artificial intelligence.*<sup>101</sup>

There is considerable merit in the adoption of such an AI Code not least in contexts where social care is involved and where the capacity of individuals may be reduced, diminished or otherwise affected and where AI may impact upon the lives of individuals who may be vulnerable. We will offer our own principles later in this paper.

Writing in *Computer Weekly*, the tech commentator Brian McKenna has considered the AI report's suggestion that the UK should find itself a specialist niche, putting forward the ethics of AI as its preferred candidate.<sup>102</sup> The Report states: (sections 392-403):

*'In January 2018, the Prime Minister said at the World Economic Forum in Davos that she wanted to establish 'the rules and standards that can make the most of artificial intelligence in a responsible way, and emphasised that the [UK's] Centre for Data Ethics and Innovation would work with international partners on this project, and that the UK would be joining the World Economic Forum's new council on artificial intelligence, which aims to help shape global governance in the area.*

*'We believe it is very much in the UK's interest to take a lead in steering the development and application of AI in a more co-operative direction, and away from this riskier and ultimately less beneficial vision of a global 'arms race'. The kind of AI-powered future we end up with will ultimately be determined by many countries, whether by collaboration or competition, and whatever the UK decides for itself will ultimately be for naught if the rest of the world moves in a different direction. It is therefore imperative that the Government, and its many internationally-respected institutions, facilitate this global discussion and put forward its own practical ideas for the ethical development and use of AI.'*<sup>103</sup>

The House of Lords Committee has called on the UK Government to convene a global summit in London by the end of 2019, with the aim of establishing a common framework for the ethical development and deployment of artificial intelligence systems.

In progressing this, the UK Government has opened a consultation on the aims and priorities of its Centre for Data Ethics and Innovation which had been announced by the Chancellor at the Autumn Budget 2017.<sup>104</sup>

There is an emerging groundswell of opinion that we need to develop ethical standards for the use of AI, Big Data and the Internet of Things. Even during the period of writing this paper there have been almost daily media articles on the emerging role of ethics in technology.<sup>105</sup> This is to be welcomed, but as we will suggest below, such an ethical process has to be rooted in a participative and enabling human rights framework.

One positive recent contribution, that we mentioned earlier, has come from Google's chief executive, Sundar Pichai, who has published a set of AI principles. They include an emphasis on ideas that the technology should be socially beneficial, should avoid creating or reinforcing unfair bias, be built and tested for safety and be accountable, should include privacy by design and uphold high scientific standards. Some of these principles make for a set of very aspirational commitments:

### **'1. Be socially beneficial**

*... As we consider potential development and uses of AI technologies, we will take into account a broad range of social and economic factors and will proceed where we believe that the overall likely benefits substantially exceed the foreseeable risks and downsides.*

### **2. Avoid creating or reinforcing unfair bias**

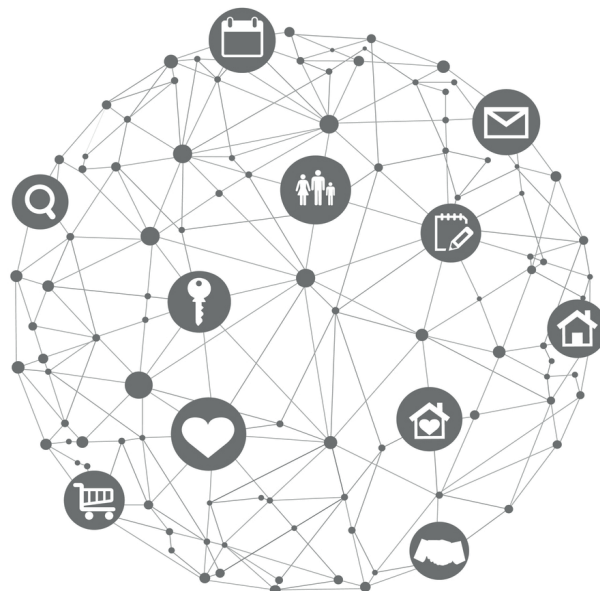
*AI algorithms and datasets can reflect, reinforce, or reduce unfair biases. We recognize that distinguishing fair from unfair biases is not always simple and differs across cultures and societies. We will seek to avoid unjust impacts on people, particularly those related to sensitive characteristics such as race, ethnicity, gender, nationality, income, sexual orientation, ability, and political or religious belief..*

### **4. Be accountable to people**

*We will design AI systems that provide appropriate opportunities for feedback, relevant explanations, and appeal. Our AI technologies will be subject to appropriate human direction and control.*

### **5. Incorporate privacy design principles**

*We will incorporate our privacy principles in the development and use of our AI technologies. We will give opportunity for notice and consent, encourage architectures with privacy safeguards, and provide appropriate transparency and control over the use of data.'* <sup>106</sup>





# Technology and social care in Scotland: human rights and ethics in policy and practice

## A strange human rights silence.

We have no shortage, therefore, of a rich policy and strategic landscape relating to technology and digital in the United Kingdom and in Scotland specifically. However if you explore many of the documents and strategies noted above there is scant reference to human rights and the ethical challenges raised by new technologies, especially the three areas we have focussed on.

For the purposes of this current paper we will explore the extent to which the policy, implementation and evaluative work in Scotland is reflective of a human rights and ethical debate.

There is a complete dearth, with some notable exceptions, of an exploration of the human rights dimension of technology and care within work to date in Scotland. This is troubling if we are concerned in rooting the further development and implementation of rapid technological change in a rights-based and ethical grounding. The latest Scottish Government *Digital Health and Care Strategy*<sup>107</sup> makes no explicit mention of human rights nor did its two predecessors, and only passing reference is made to issues of ethics, choice and individual control.

A fully rights-based model for technological development and implementation has to be based on more than a tangential reference or occasional passing comment. It requires a robust appreciation of the complexities of a human rights-based approach and therefore of its potential in fostering public assurance and enabling confidence and trust.

It is the central proposition of this work that the concerns raised to date, for example, on the use of AI as referenced above; the fears over the impact of technology upon the workforce; the issues relating to the handling of Big Data and the ethical challenges highlighted by the Internet of Things - all need to be dealt with by a developing and robust human rights framework and methodology. This process needs to be evidenced in a rights-based pathway from design to development, through implementation to review and re-articulation.

This paper is arguing that there is every reason why there should be - at both a theoretical and empirical level - a close connection between human rights tenets and the development, use and enablement of technology in the social care of the individual in Scotland. We are arguing that for technological intervention to be effective and ethical within a modern human-rights based society we need to develop human-rights based approaches to technology.

Scottish Care in its own evidence to the Health and Sport Committee Inquiry on Technology and innovation stated that:

*‘Scottish Care believes that technology offers and is already delivering real benefits to the care and support of individuals across Scotland. We would like work to be undertaken as we come to adopt the National Health and Care Standards on the development of a Human Rights Charter for Technology in Care so that those who procure, commission, deliver, work in and receive care and support have their rights and dignity upheld through and by the use of technology.’<sup>108</sup>*

Before we move to outlining what such a human rights-based framework might look like, it is worth exploring some of the positive work that *has* already taken place, albeit outside official policy and governmental strategies. We have noted the Westminster work on AI above, but in Scotland there have also been significant contributions to embedding rights in technological practice.

## Positive ethical and rights-based modelling

The *Alzheimer Scotland Technology Charter* for people living with dementia, launched in late 2015, was described as a call to action:

*‘calling for the delivery of health and social care to people with dementia to incorporate and promote the use of technology; helping people with the condition to live healthier, safer, more active and more confident lives as valued citizens. It also seeks to raise public and professional awareness of how technology can enhance lives, promote independent living and assist and complement care and support.’<sup>109</sup>*

It was, and is, a positive endorsement for the potential of technology to advance choice, enable greater control and promote independence for people living with dementia and their families.

The Technology Charter has six key values:

- *‘Practice and service provision is rights based, personalised and free from discrimination*
- *Unpaid carers and families are recognised and valued as equal partners in care.*
- *Information and advice about technology is available in clear everyday language and in a variety of formats*
- *Routes and access to technology are ethical, equitable, simple, understandable and user-friendly*
- *Consideration of technology is embedded at all key points in the integrated dementia care pathway*
- *Technology augments - but does not replace - human intervention.’*

This is an excellent and solid basis and framework of key principles. It roots some of the key concepts we have explored thus far in relation to human rights and technology; namely, individual ownership, personalisation, non-discrimination, co-design, access, transparency and proportionality.

Yet its suppositions demand further embedding and articulation in the implementation of technology in wider social care settings. What does it mean practically for the use of technology to be 'rights based and free from discrimination'? In what ways is access to technology currently equitable and ethical? Is the use of technology in care today in Scotland personalised and enabling of care? What about issues of data control, access and management? How confident are we that the introduction of robotics into the Scottish care context is going to add value rather than reflect austerity?

A further positive piece of work has been undertaken by the Mental Welfare Commission for Scotland.

Scotland's Mental Welfare Commission report '*Decisions about Technology*' seeks to offer principles and guidance on good practice when considering the use of telecare and assistive technology for people with dementia, learning disabilities and related disorders. The Commission makes it clear that there are clear, rights-enhancing benefits of technological intervention to support individuals, but that this is not always the case, and that each individual must be dealt with in a unique and person-centred manner. They comment on the human rights' dimension thus:

*'It is easy to see the potential benefits of technology for individuals, but care needs to be taken to ensure it never stigmatises, and it should never fully replace direct contact with care-givers.'*

*A particular technology for one person could be the difference between feeling isolated and vulnerable in their own home or continuing to be engaged in their local community and usual activities. The same technology used for someone else could be viewed by them and their carers as intrusive and demeaning.*

*'There is also the potential for telecare and assistive technology to stigmatise and be degrading for the user and potential for it to place limits on the personal freedom of the individual if not used discreetly. This is why we believe a rights-based approach to decision making is required.'*

110

In referring to their earlier Guidance, '*Rights, Risks and Limits to Freedom*,'<sup>111</sup> the Commission indicates that the use of technology and telecare in some instances could constitute restraint, even in someone's own home.<sup>112</sup> They suggest that this is especially the case in the use of wandering technology and video surveillance. They make it clear that the care of an individual is best achieved through human interaction and that use of technology must be undertaken only when certain core human rights standards and principles have been met. These principles are at the heart of social care legislation in Scotland as well as in the Human Rights Act. We will consider them in more depth below.

The last exemplar of best practice we will consider is the work undertaken by the Scottish

In March 2018 the '*Independent Advisory Group on the Use of Biometric Data in Scotland*' published their Report.<sup>113</sup> Whilst this deals with the use and retention of biometric data in policing, it also sought to establish an ethical and human rights-based framework which could be applied to existing, emerging and future biometrics in what is an important and fast-moving area of technology. It is this section, developed by Diego Quiroz from the Scottish Human Rights Commission, which has a particular relevance to the work we are considering here, especially in its articulation of key principles and human rights considerations.

It is clear that the introduction of new technologies should fully take account of the inherent dignity of the individual. '*The Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data*'<sup>114</sup> is a binding international instrument which protects the individual against abuses which may accompany the collection and processing of personal data and which seeks to regulate at the same time the trans-frontier flow of personal data.

In a social care context faced with the prospect of enormous Big Data, this human rights-based provision is fundamental. This is especially true in the case of sensitive personal care and health data. The Convention outlaws the processing of sensitive data on a person's race, politics, health, religion, sexual life, etc., in the absence of proper legal safeguards. The Convention also enshrines the individual's right to know that information is stored on him or her and, if necessary, to have it corrected. This is of considerable import given the increasing numbers of non-statutory actors engaged in the handling of sensitive personal data within a social care context.<sup>115</sup> The '*Independent Advisory Group on the Use of Biometric Data in Scotland*' report highlights some general principles and the guidance on implementation is of benefit for our discussion on human rights-based principles for technology. Included amongst them is an emphasis on:

- *'impartiality – procedures should be applied without bias or unfair discrimination;*
- *proportionality – balancing individual rights, public safety and the public good*
- *effectiveness;*
- *openness and transparency;*
- *minimal intrusion needed to achieve outcome;*
- *the need for assurance in relation to the quality of the system;*
- *the need for public accountability;*
- *the need for independent oversight where appropriate;*
- *the need to provide adequate information and, where appropriate, to obtain consent from those from whom data (or samples) are sought or retained, or from some other appropriate individual where the individual cannot consent'* <sup>116</sup>

# The potential of human rights for technology in Scotland's social care

Human rights are the rights that we are all entitled to, simply by being human. These rights guarantee the dignity and worth of all human beings; the autonomy to make our own choices; the freedom to live without discrimination and the support to participate equally in society. Human rights are universal, in that they belong to every individual regardless of nation, location, religion, race, age or any other status. They have clearly, therefore, as we have argued above, a fundamental role to play in a technological and digital age.

There are differing conceptions as to what constitutes a human-rights based approach (HRBA), but in essence it is an approach which seeks to promote and protect human rights-based on agreed international human rights standards and principles. The approach seeks to work alongside groups and people whose rights are at risk of being or have been violated, understand why certain people are unable to enjoy their rights and redress unjust distributions of power that impede progress. In this sense it identifies rights-holders and their entitlements and corresponding duty-bearers and their obligations and works to strengthen the capacity of duty bearers to comply with their obligations and right holders to claim and exercise their rights. This is an approach that assumes partnership, collaboration and co-production. It is the contention of this paper that given the emerging desire to develop ethical frameworks and principles for the three technological themes we are exploring, a human-rights based approach from design through to implementation has a fundamental contribution to make.

The fulfilment of human rights are both the goal and guiding principles of all social care support. Human rights criteria (availability, accessibility, quality, affordability, acceptability) and principles (non-discrimination, participation, access to information, accountability and sustainability) should be considered throughout the process of technological design, development and use. It is clear from the above that these are amongst the core areas where there have been particular ethical and public concerns around the use of AI, Big Data and the IoT. A human rights-based approach has real value in addressing the accepted ethical challenges and in fulfilling the potential which technological and digital innovation offers in the world of social care.

A human rights-based approach seeks to ensure that individual rights are actively promoted and embedded in technological, health and social care policy and practice. It serves to underline the legal and moral commitment that every person has the right to be treated with dignity, respect and without discrimination.

With some clear exceptions, as we have argued above, there is a concerning silence in both debate and research in relation to human rights, technology and social care. There is undoubtedly an acceptance and a growing awareness that there is an ethical dimension to the use of new technologies and the impact they are having, and will have, upon society. There is an almost '*en passant*' acceptance that these issues need to be held in mind and acknowledged. There is, however, an astonishing lack of evidence to suggest that issues of





practical ethics *are* being considered in the day to day use of many technological interventions in social care. Whilst the emergence of ethical debate has grown significantly in the last few months and weeks, other than some robust academic papers there is little evidence of human rights issues impacting on policy development at a local or national level in Scotland, or indeed elsewhere in Europe. This is a glaring and concerning omission. A human rights-based approach to technology would go some way to address that gap.

## PANEL in a digital and technological age

Many human rights-based approaches have adopted the ‘PANEL’ principles as a mechanism to determine the extent to which human rights have been embedded in practice. ‘PANEL’ stands for Participation, Accountability, Non-Discrimination, Empowerment and Legality.

### What that means is:

- Participation – People should be involved in decisions that affect their rights
- Accountability – There should be monitoring of how people’s rights are being affected, as well as remedies when things go wrong
- Non-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
- Empowerment – Everyone should understand their rights and be fully supported to take part in developing policy and practices which affect their lives
- Legality – Approaches should be grounded in the legal rights that are set out in domestic and/or international law.<sup>117</sup>

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 maximize the benefits of technological innovation, whilst ensuring public trust and confidence, and establishing appropriate safeguards, accountability and sustainability.

In what follows we will briefly explore each of these themes to illustrate the potential of the ‘PANEL’ approach in elucidating questions and issues before turning to make some practical recommendations.

**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 AI and the IoT. Are both leading to a growing public distrust or even aversion to the 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 EHRC 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?



# Final words and recommendations

This paper has sought to paint, in the broadest brushstrokes, the emerging potential and challenges which technology presents to society in general and for the social care sector in Scotland in particular. It has explored some of the main areas of positivity and potential threat from the perspective of an ethical and human rights analysis. Its primary purpose is to promote a conversation within the social care and technology sectors in Scotland which recognises the fundamental role which an ethical and human rights-based approach could contribute to both sectors. It has presented a central proposition that for the potential of the three technologies of AI, Big Data and the Internet of Things to be maximised, a foundation of public trust needs to be built, which establishes a core set of ethical and human rights principles within which design and developments, the implementation and the use of technology can take place.

But an ethical framework for AI and technology has to be more than just about privacy and even human rights as we know them within the current legal frameworks. Human well-being and human purposes and goals have to be at the intrinsic heart of an ethical framework for the development and use of AI. We need to have a societal discourse about what are the fundamental needs and goals of being 'human'. Should it be a 'human right' to be cared for ultimately by a human being rather than an artificial machine, however developed its drive and intelligence? This work would argue that needs to be the case especially in the care of our older persons.

Scotland has a potential for not only digital and technological advance and innovation, but to root and earth that forward dynamic in a set of positive and enabling human rights-based ethical principles.

The pace and prospect of technology in the social care of older persons is huge. Modern communication enables not only the supported individual to have better and more immediate access, but potentially fosters the ability for the social care workforce to be more autonomous, responsive and preventative in their role. In an era of Big Data the promise is that if we can unify and create common data platforms and singular access points then we can unleash huge potential for person-led and citizen-informed data control and management of services and supports, which enables a more integrated, cohesive, consistent, multi-disciplinary care response. Artificial Intelligence offers non-intrusive monitoring which could be hugely beneficial in terms of, for example, the prevention of falls, dehydration, UTIs to name but a few outcomes and is altogether potentially enabling of a more positive life experience for the individual. Robotics proffers the opportunity of giving non-human but nevertheless important 'presence' to individuals living isolated and dislocated lives, of streamlining basic tasks thus freeing up the workforce to engage in time-rich relational care.

Technology need not be seen as antithetical to human contact, touch and presence. There is little disagreement that it should never be used to ultimately replace presence, but it can be utilised to enable, deepen and enrich that human presence. It would be unfortunate if a resistance to the 'non-human' nature of technology resulted in us failing to maximise its potential and unleash its possibilities. That is why, fundamentally, there is a necessity to construct trust-based, person-led, human-rights centred models of design, development and implementation.

The following recommendations are offered as a basis on which to build that human rights-based approach to technology within social care in Scotland.

## **Recommendation one:**

### **The creation of a human-rights based Ethical Charter for Technology and Digital in Scotland.**

There are no simple answers to the PANEL questions we noted above, but it is suggested that the PANEL model offers a good starting point for the establishment of a code of human rights-based Ethics and Principles for Technology in Social Care in Scotland.

This is not to assume that we are working here upon barren territory. As has already been alluded to above, we have had a core set of human rights principles at the heart of social care legislation in Scotland since the creation of the Scottish Parliament in 1999. What is required now is either by means of primary legislation or Statutory Guidance, the articulation of a human-rights Charter or Framework for Technology. Such a set of principles should hold both those who seek to design and develop, those who would commission and procure, those who would use and implement, those who are workers and supported persons within health and social care services and supports, to all collectively work under a consistent rights-based standard for conduct and behaviour in their use of technology.

As well as the Charters, Principles, Codes and Guidance mentioned above, we already have some core-principles to inform such a process. There is a need, however, for clarity and consistency or we risk a plethora of standards, charters and principles to work with. This is not to limit or relegate the work of Technology Enabled Care, or Google, or Alzheimer Scotland, or the Mental Welfare Commission to name but a few, but it is a call to encourage the Scottish Government, the Scottish Human Rights Commission and other stakeholders to seize a unique opportunity. Scotland has a rich and developing tradition of focussing on human rights principles in practice, (our new 'Care Standards' are illustrative of this), the creation of a set of human rights-based Ethics and Principles for Technology would offer much to our nation and our international partners. Social care is an excellent starting point.

In general terms, any charter has to respect human rights and would need to comply with the law and relevant care regulations.<sup>118</sup> The following principles are offered as an illustration (by no means exhaustive) of what such a Charter might incorporate. The use of technology:

- must be to the benefit of the individual and the common good
- cannot be used to restrict or remove any human right but should seek to enhance and achieve the human rights of the individual
- should enable and foster independence if so desired
- has to take account of the unique character and individuality of the person, including characteristics of sex, race and ethnicity, disability, sexual orientation and age etc.,



- should always be non-discriminatory
- should be accessible, understandable and transparent
- should be fair and equal in its treatment and use
- should enable an individual to flourish and achieve their full potential
- should be with the consent of the individual and accord with the previously articulated wishes and views of the person
- should be accountable to the individual whose data is held and enable them to check, edit and control that data
- should not be used to harm, destroy or diminish another
- should enable and augment human presence rather than wholly replace it

## **Recommendation two:**

### **Establish a Scottish Centre for Human Rights and Ethics in Technology**

The existence of the Leverhulme Centre for the Future of Intelligence is an exemplar of a multi-disciplinary and specialist academy which provides the environment for much of the ethical considerations that we have considered in this paper. It is suggested that a Scottish university should give serious consideration to the establishment of a Centre for Human Rights and Ethics in Technology. Such a multi-disciplinary, multi-sectoral body would help to embed the standards we have reflected upon above, to ensure ongoing appreciation of emerging issues and to become a specialist support to statutory, private, governmental and other actors.

## **Recommendation three:**

### **Develop a national awareness and information strategy around the positive use of technology for social care**

It has been suggested above that there is a danger that as scandals like ‘Cambridge Analytica’ catch the public imagination, the benefits of Big Data and indeed AI might be diminished as a result of growing public discomfort and unease. The existence of a ‘trust deficit’ requires a concerted approach to build public awareness and public confidence. Confidence comes from appropriate knowledge, informed consent and the ability to influence. A recent Nesta report has highlighted the importance of rebuilding trust around an ethical framework.<sup>119</sup> This is further articulated in a very important Nesta report on the need to build public engagement in the use of AI in the health sector.<sup>120</sup> There is a real opportunity for the Scottish Government, along with other stakeholders in the technology and digital sector, to invest in ensuring that as a nation our aspirations for technology are wholly achieved by means of developing an informed and aware public. Such a process of confidence building starts in our schools but should also be inclusive of all ages and individuals. It is not unreasonable to expect that a duty should be placed upon those who develop and use technologies to be educators and informers of those upon whom its impact is most immediately felt.



## **Recommendation four:**

### **Develop a technology strategy for the social care workforce which embeds practical skills to enable today's workforce to be innovators and co-designers**

The re-design of the social care workforce is a fundamental priority given the changing nature of care and contact which will be demanded as the care home, homecare and housing support sectors continue to develop and change under the influence of technology. Scottish Government and Local Authorities should give serious consideration to establishing a fund which will enable the specific learning and development of existing and new social care staff to become technologically confident rather than just aware. Specific targeting of health and social care professionals to embed knowledge about technology, confidence in its use, and awareness of its appropriateness in diverse settings should be seen as a workforce priority.<sup>121</sup>

## **Recommendation five:**

### **Prioritise the preventative potential of technology in social care**

Scottish Care has argued for some time that preventative care needs to be recognised as a fundamental priority in the integration of health and social care.<sup>122</sup> The financial and personal benefits of such an approach are incalculable. We should be working as hard as we can to invest in models and approaches which prevent decline and deterioration, delay the loss of independence and provide speedy support to individuals when that is required. There is a huge potential in such approaches and technological innovation is a key agent for fostering the success of prevention in the community. However, preventative approaches have to be undertaken alongside the maintenance of the existing delivery of care. This has frequently been the problem. There is a need for Integrated Joint Boards, Scottish Government and providers of care to work together in each geographical area and prioritise a proportion of the annual budget to the delivery of bespoke preventative models which utilise technological innovation.

## **Recommendation six:**

Self-directed Support (SDS) is the main mechanism by which citizens should be accessing social care supports. The report 'Self-Directed Support: Your Choice, Your Right'<sup>123</sup> has highlighted the shortcomings in the implementation of SDS. There is a real potential to maximise the benefits of SDS to enable technology to be much better used to enable the creativity which the legislation intended. In order for this to be achieved the Scottish Government, COSLA and Integrated Joint Boards, together with other stakeholders, need to review the use of traditionalist approaches to procurement which do not often offer scope for more non-bespoke innovative and creative packages containing technological intervention. The development of a set of case studies would assist in this regard.



## Recommendation seven:

The report has highlighted the existence of digital poverty and challenges relating to the capacity building of older adults. Traditional models of digital skills development have tended not to be successful for older adults. It is recommended that the Scottish Government, Skills Development Scotland and other stakeholders work with older people groups to identify learning models and practice which would focus on practical skills development around technology and digital use.

## Recommendation eight:

Recognising that work already under way to improve the access to, robustness and nature of social care data through the Scottish Government Information Services Division, it is recommended that social care providers be fully included in the further development of work to create a single data platform. Social care providers share with health colleagues the desire to share data effectively, utilising a single data platform or central spine. The principles of creating data once and giving autonomy and control to the individual citizen are an example of the potential for a human rights-based approach. The evidence of positive outcomes through full involvement and inclusion are self-evident (not least from Estonia). Scotland can ill afford the exclusion of third and independent sector providers from involvement in and equal partnership in this process.

## Recommendation nine:

Recently in England, NHS Digital has established a £1 million fund to award projects that support forward-thinking uses of digital technology in the design and delivery of adult social care.<sup>124</sup> A similar fund in Scotland could be used to attract innovation in the social care sector and would be hugely valuable. Another English model, *The Care Innovation Challenge*,<sup>125</sup> enabled young students to live and work alongside both users of and workers in social care settings to identify potential areas for technological innovation and design; support their early stage development and seed fund those with the best ideas. Scotland is full of innovation and feeding that technological spark would be hugely beneficial.

## Last byte

The potential of information and technology to facilitate change is clear, and there are already many examples of innovative practice leading to better outcomes for people. There is a huge opportunity for us to create a technological and digital social care environment rooted in a human-rights and ethical foundation. On an optimistic and positive note there is a prospect and a promise that AI might lead to the valuing of the distinctively unique aspects of humanity, such as giving care, enabling dignity, building trust, sharing goals and addressing inter-personal needs.

iThe *Digital Health and Care Strategy* states clearly that:

*‘This is a joint strategy for Scotland across national government, local government and the NHS. Similarly, delivery of the strategy needs to be a partnership endeavour, where we harness not only the collective skills, talents and capacity that exists within our public services, but also those of industry, academia, the third and independent care sectors and the wider public.’<sup>126</sup>*

The need to work closer together has been recognised. This paper has argued that there is an urgent need to collectively develop an ethical and human rights-based foundation for the future design, development, implementation and use of technology within social care, and indeed, more generally in Scottish society. Without such a foundation and the establishment of clear human rights principles there is a very real possibility that the opportunities of the Fourth Industrial Revolution, the Third Wave and the Second Machine Age will remain untapped. Let us create that technological ethical and human rights future together.

We conclude with some salutary words from one of the originators of modern artificial intelligence, Joseph Weizenbaum, who in *‘Computer Power and Human Reason’* wrote:–

*‘to substitute a computer system for a human function that involves interpersonal respect, understanding and love, is simply obscene.’*



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Researchers at the University of the Highlands and Islands will research proof of concept with financial support from the Digital Health and Care Institute. The Data Lab – the Scottish Innovation Centre charged with generating economic, social and scientific value from big data – is also supporting the project by funding research into predicting falls, which is being led by Professor Susan Craw, an Artificial Intelligence expert at Robert Gordon University.

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79 See <https://www.blackwoodgroup.org.uk/innovation>

80 ‘*Tech Care:” Care Tech*’ an event for technology and digital in social care in Scotland. Exhibitors include StoriiCare, <https://storiicare.com/> ; Qintil, <https://www.qintil.com> ; Bruin Biometrics, <http://www.bruinbiometrics.com/en/>; Sekoia, <https://www.sekoia-care.co.uk>; Skedulo, <https://www.skedulo.co> ; Person Centred Software, <https://personcentredsoftware.com>; and CogniHealth <https://cognihealth.uk> to name but a few of those attending.

81 See <https://ceracare.co.uk>

82 There are a whole host of companies, including OnCare <http://www.weareoncare.com>, Kraydel, <http://kraydel.com> , Pickashift, <http://pickashiftapp.com> and the Nesta Lab funded TrustonTap, <https://www.trustontap.com> to name but a few.

83 Page 2, ‘*Supporting & Empowering Scotland’s Citizens: National Action Plan for Technology Enabled Care*’, August 2016, <http://www.gov.scot/Publications/2016/10/3839>

For examples of innovation in social care see <https://sctt.org.uk/drafts/technology-enabled-care-programme/>

84 Page 4-5, ‘*Supporting & Empowering Scotland’s Citizens: National Action Plan for Technology Enabled Care*’, August 2016, <http://www.gov.scot/Publications/2016/10/3839>

85 Heather Bosnell is the *director of health, care, and support*, Curo

<https://www.insidehousing.co.uk/comment/a-checklist-for-assisted-living-technology-57154>

86 See <https://myageingparent.com/technology/communication/digital-inclusion-older-people/> . For benefits of connectivity in care homes see <https://wifinity.co.uk/importance-inclusion-elderly/>

87 *The Digital Age: New Approaches to Supporting People in Later Life Get Online*. <https://www.ageing-better.org.uk/sites/default/files/2018-05/The-digital-age.pdf>

88 [https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/active-communities/rb\\_sept13\\_age\\_uk\\_digital\\_inclusion\\_evidence\\_review.pdf](https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/active-communities/rb_sept13_age_uk_digital_inclusion_evidence_review.pdf)

89 The Inquiry Report ‘*Technology and Innovation in Health and Social Care*’ can be accessed at [http://www.parliament.scot/S5\\_HealthandSportCommittee/Reports/HSS052018R01.pdf](http://www.parliament.scot/S5_HealthandSportCommittee/Reports/HSS052018R01.pdf)

90 Scottish Care has been especially critical about the failure to engage the independent social care sector in the development of the latest Strategy. See <http://www.scottishcare.org/scottish-care-news/scottish-care-criticises-new-digital-health-care-strategy/>

91 See page 15, Health and Sport Committee Report, *Technology and innovation in health and social*

care, February 2018, [http://www.parliament.scot/S5\\_HealthandSportCommittee/Reports/HSS052018R01.pdf](http://www.parliament.scot/S5_HealthandSportCommittee/Reports/HSS052018R01.pdf)

92 *Scotland's Digital Health and Care Strategy*, <http://www.digihealthcare.scot/wp-content/uploads/2018/04/25-April-2018-SCOTLANDS-DIGITAL-HEALTH-AND-CARE-STRATEGY-published.pdf> ,

93 See [http://www.parliament.scot/S5\\_HealthandSportCommittee/Inquiries/TINN020\\_medConfidential\\_and\\_ORG\(1\).pdf](http://www.parliament.scot/S5_HealthandSportCommittee/Inquiries/TINN020_medConfidential_and_ORG(1).pdf)

94 Page 3 [http://www.parliament.scot/S5\\_HealthandSportCommittee/Inquiries/TINN020\\_medConfidential\\_and\\_ORG\(1\).pdf](http://www.parliament.scot/S5_HealthandSportCommittee/Inquiries/TINN020_medConfidential_and_ORG(1).pdf)

95 See evidence at <http://www.parliament.scot/parliamentarybusiness/report.aspx?r=11166&c=2034707>

96 See some of the evidence given by Digital Health and Care Institute [http://www.parliament.scot/S5\\_HealthandSportCommittee/Inquiries/TINN057\\_Digital\\_Health\\_and\\_Care\\_Institute.pdf](http://www.parliament.scot/S5_HealthandSportCommittee/Inquiries/TINN057_Digital_Health_and_Care_Institute.pdf)

97 The programme is being jointly led by NHS Digital and the Private Healthcare Information Network (PHIN), the CMA-approved information organisation, in partnership with the Department of Health and Social Care, NHS England, NHS Improvement, and the Care Quality Commission (CQC). For more detail see <https://digital.nhs.uk/news-and-events/latest-news/adapt-programme-initiative-launched-to-capture-private-data-in-nhs-systems>

98 *Scotland's Digital Health and Care Strategy*, <http://www.digihealthcare.scot/wp-content/uploads/2018/04/25-April-2018-SCOTLANDS-DIGITAL-HEALTH-AND-CARE-STRATEGY-published.pdf> , page 5.

99 See 'AI in the UK? Ready, willing and able?' Select Committee on Artificial Intelligence, Report of Session 2017-19, House of Lords, <https://publications.parliament.uk/pa/ld201719/ldselect/ldai/100/100.pdf>

100 'Professor Christoph Thuemmler noted "one of the biggest shortcomings of the national strategy is the neglect of future technologies, such as the use of the Industrial Internet of Things, 5G technology, Precision Medicine (Smart Pharmaceuticals and Population Health Management)" ...This view was reinforced by BMA Scotland. PA Consulting noted the focus should be on: secure N3 connected cloud hosting services, Agile software development, Software as a Service and Big Data (TINN002).' (page 7) [http://www.parliament.scot/S5\\_HealthandSportCommittee/Inquiries/Digital\\_Summary\\_of\\_Evidence.pdf](http://www.parliament.scot/S5_HealthandSportCommittee/Inquiries/Digital_Summary_of_Evidence.pdf)

101 Ibid, page 125

102 See Brian McKenna, *Is AI ethics enough of a niche for the UK's economic strategy?* <https://www.computerweekly.com/blog/Data-Matters/Is-AI-ethics-enough-of-a-niche-for-the-UKs-economic-strategy>

103 Page 118, section 395. See also sections 392-403: <https://publications.parliament.uk/pa/ld201719/ldselect/ldai/100/100.pdf>

104 See Consultation at [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/715760/CDEI\\_consultation\\_\\_1\\_.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/715760/CDEI_consultation__1_.pdf)

105 A helpful summary of this emerging trend is provided by SA Mathieson in Computer Weekly, July 2018, see <https://www.computerweekly.com/feature/Ethical-AI-requires-collaboration-and-framework-development>

106 Sundar Pichai, *AI at Google: our principles*, June 2018, <https://blog.google/technology/ai/ai-principles/>

107 *Scotland's Digital Health and Care Strategy*, <http://www.digihealthcare.scot/wp-content/uploads/2018/04/25-April-2018-SCOTLANDS-DIGITAL-HEALTH-AND-CARE-STRATEGY-published.pdf> ,

108 Scottish Care evidence to Scottish Parliament Health and Sport Committee Inquiry, 2017, page 3.

109 See [https://www.alzscot.org/news\\_and\\_community/news/3494\\_first\\_technology\\_charter\\_for\\_](https://www.alzscot.org/news_and_community/news/3494_first_technology_charter_for_)

people\_with\_dementia\_in\_scotland\_launched

110 From *'Decisions about Technology'* (Mental Welfare Commission, 2015), page 3 [https://www.mwscot.org.uk/media/241012/decisions\\_about\\_technology.pdf](https://www.mwscot.org.uk/media/241012/decisions_about_technology.pdf)

111 Important issues are raised in *'Rights, Risks and Limits to Freedom'*, MWC, 2013, [https://www.mwscot.org.uk/media/125247/rights\\_risks\\_2013\\_edition\\_web\\_version.pdf](https://www.mwscot.org.uk/media/125247/rights_risks_2013_edition_web_version.pdf)

112 The definition of restraint is significant here. It is *'Restraint is taking place when the planned or unplanned, conscious or unconscious actions of care staff prevent a resident or patient from doing what he or she wishes to do and as a result are placing limits on his or her freedom.'*

113 See <https://www.gov.scot/Resource/0053/00533063.pdf>

114 For the text of the Convention see <https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/108>

115 Importantly such actors should be accountable under both the Convention and also the UN Guiding Principle on Business and Human Rights. [http://www.ohchr.org/Documents/Publications/GuidingPrinciplesBusinessHR\\_EN.pdf](http://www.ohchr.org/Documents/Publications/GuidingPrinciplesBusinessHR_EN.pdf).

116 Page 54-55, *Independent Advisory Group on the Use of Biometric Data in Scotland*, March 2018, <https://www.gov.scot/Resource/0053/00533063.pdf>

117 See <http://www.scottishhumanrights.com/rights-in-practice/human-rights-based-approach/>

118 Most especially The Human Rights Act, 1998; The Adults with Incapacity (Scotland) Act 2000; The Mental Health (Care and Treatment) (Scotland) Act 2003; The Adult Support and Protection (Scotland) Act 2007; and The Social Care (Self-directed Support ) Act 2013.

119 The Nesta report, *'Reclaiming the Smart City: Personal Data, Trust and the New Commons.'* <https://www.nesta.org.uk/report/reclaiming-smart-city-personal-data-trust-and-new-commons/> is an important contribution. Amongst its many recommendations two are of particular note. *'Build consensus around clear ethical principles and translate them into practical policies.'* and *'Train public sector staff in how to assess the benefits and risks of smart technologies.'*

120 See *'Confronting Dr Robot: Creating a people-powered future for AI in health.'* Nesta, May 2018 <https://www.nesta.org.uk/report/confronting-dr-robot/> , In recognising that AI could become a critical front door to the health system the Nesta report highlights the challenge that to succeed *'we need to maximise benefits and minimise risks [and that] means engaging patients, disciplined testing in real world conditions, shaping the market, and increasing understanding of the technology.'*

121 *'The Future of Care'* project in 2018 undertaken by the Glasgow School of Art for Scottish Care has developed three new roles for the future homecare workforce. One of these is the 'care technologist'. This would be a good starting point for this recommendation. <https://www.futurehealthandwellbeing.org/future-of-care-at-home/>

122 See *'Prevention is the best cure: the potential of prevention'* at <http://www.scottishcare.org/scottish-care-news/sector-news/prevention-is-the-best-care-latest-blog-from-our-ceo/>

123 *'Self-Directed Support: Your Choice, Your Right'* (Centre for Welfare Reform, 2017). <http://www.centreforwelfarereform.org/uploads/attachment/579/selfdirected-support-your-choice-your-right.pdf>

124 See <https://www.digitalhealth.net/2018/05/adult-social-care-digital-innovations-funding/>

125 See <https://careinnovationchallenge.com>

126 *Scotland's Digital Health and Care Strategy*, <http://www.digihealthcare.scot/wp-content/uploads/2018/04/25-April-2018-SCOTLANDS-DIGITAL-HEALTH-AND-CARE-STRATEGY-published.pdf> , page 9.

# About the author

Dr Donald Macaskill has worked for many years in the health and social care sectors across the United Kingdom, specialising in learning disability and older people's work.

A particular professional focus has been issues related to bereavement, palliative care and individual rights. For thirteen years he ran an equality and human rights consultancy focusing on adult protection, risk and personalisation. Previously he worked in the early development of patient focus and public involvement work, the development of Self-directed Support and before that worked in higher education.

Donald was appointed Chief Executive of Scottish Care in April 2016.

# About Scottish Care

Scottish Care is a membership organisation and the representative body for independent social care services in Scotland.

Our vision is to shape the environment in which care services can deliver and develop the high quality care that communities require and deserve.

Scottish Care represents over 400 organisations, which totals almost 1000 individual services, delivering residential care, nursing care, day care, care at home and housing support.

Our membership covers both private and voluntary sector provider organisations. It includes organisations of varying sizes, amongst them single providers, small and medium sized groups, national providers and not-for-profit voluntary organisations and associations.

Our members deliver a wide range of registered services for older people as well as those with long term conditions, learning disabilities, physical disabilities, dementia or mental health issues.

The Scottish independent social care sector contributes to:

- The employment of over 100,000 people
- The provision of 85% of care home places
- The delivery of over 50% of home care hours for older people

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