



Care, Autonomy, and Technology Workshop Report

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'Digital technologies that help with care tasks are not only increasingly popular with consumers but are also becoming an integral part of welfare provision. For me, the workshop discussions highlighted the fact that technologies used in care are sociotechnical systems that often amplify and sometimes also create societal and within-household power imbalances as they get utilised in care provision.'

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'Having conducted many years of research relating to children's Internet experiences, it was fascinating to learn of the parallels experienced by older family members around the uses of technology for support, supervision and caring. Both older and younger generations are subject to complex judgments of trust, autonomy and wellbeing by their families and the state, it seems.'

Dr Victoria Nash

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'Coming at this workshop from my research into technology use among migrant families in China, it was enlightening to hear the lively discussions drawing on experiences of technology usage across a range of care settings in the UK and elsewhere in East Asia.'

Professor Rachel Murphy

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On September the 26th 2023 the Institute for Ethics in AI, University of Oxford hosted a one-day workshop on the topic of Care, Autonomy and Technology. Our workshop implicated different types of care: safety and wellbeing measures by guardians of children, adult social care provided at home by family and friends, and by carers in formal facilities like hospitals. This care work implicates different actors, dynamics, policies and indeed challenges. While we use the concept of care to understand the actions, services, and measures made to improve health and wellbeing for different populations, we highlight contestation and power imbalances that have the potential to cause harm to those receiving care. We summarise our key discussion points and insights below, referring to specific kinds of care dynamics as relevant.

- **Across different kinds of care relationships, technologies offer opportunities to assist care workers, family members and guardians involved in care with various tasks. Technologies also have the potential to allocate care resources more efficiently. However, these potential benefits are not guaranteed and even if they happen, they will not automatically translate to positive outcomes for those receiving care. Outcomes depend on careful implementation and the alignment of the technology usage with care priorities that can be contextual and vary between carers, those receiving care and other stakeholders.**

Our discussion highlighted that care priorities can be highly contested with interests and viewpoints varying significantly across stakeholders. Many participants questioned the hyper-focus on resource efficiency and cost savings, a particular focus of care-tech initiatives led by states. While this can undoubtedly be important, and necessary, the workshop discussed this lens as being overly narrow and restrictive. In some cases, positive outcomes and experiences can be compromised if technology is only mobilised in response to crisis or perceived risk. Instead, we should work towards an alignment of technologies that can support already established care standards and be sensitive to and work towards meeting the diverse goals of the stakeholders.

- **Several participants noted disagreements between the viewpoints of carers and priorities of state systems introducing technologies into care provision. These disagreements and the observed difficulties carers faced when trying to get their perspectives incorporated point to inequalities in the ability to shape care policy, priorities, and direction.**

We identified a significant challenge of participation around care-tech and a concerning power inequality where actors determining digital care routes often have little, if any, direct experience of being cared for using those technologies. At the higher level, state institutions make decisions around technology investment and procurement, dictating which technologies patients can access through government provided or subsidised care. State actors, however, tend to have the least amount of direct contact with those receiving that care. Carers, who could be employees in care facilities or family and friends, are more directly involved in care and may choose between a range of available technologies. This group, while often

more closely tied to the experiences and desires of those in care, are nonetheless constrained by state and institutional policies and resources and may not have direct channels to influence which technologies are made available in care. Finally, those receiving care tend to have the fewest routes to influence digitising care structures and, in some cases, are unable to choose or contest which technologies are used, and how, in their care.

In recent years, there has been stronger advocacy for communication and co-regulation of care technologies¹ that account for the voice of those with direct experience of being in care. This communication and co-regulation will look materially different depending on the care relationship in question. In the case of guardians, participants suggested that the use of parental monitoring technologies and tactics like limiting screen time, or location tracking, be decided upon in active conversation with children. In formal care facilities, this may look like providing alternative care options when there is discomfort with using particular technologies.

- **Care is fundamentally relational, that is, a negotiation between multiple stakeholders' interests, values, and resources. In formal care settings, it is also transactional and often provided by private profit-making entities. As technologies continue to be introduced into care, practitioners will need to navigate new relationships and dynamics between stakeholders, including relationships with private sector technology companies that may be predominantly profit-oriented. Existing regulatory frameworks should be adaptable to these changing relationships and their implications.**

Care is relational. Relevant to our discussion of autonomy is understanding that care has always involved negotiation, for example, between labour rights of carers and the needs of those in care. We spent a significant amount of time during the workshop discussing emerging relationships to private sector technology developers as states integrate new technologies into care systems, and as guardians and carers integrate consumer technologies into their domestic care. Participants highlighted many cases where technologies utilised in care have been designed as consumer technologies, not regulated, or guided by medical or social care standards. In formal care settings, care is also transactional, where optimising the use of resources or saving professional's time may be viewed as a priority, over the demands of those in care. Here, practitioners and developers lack a common framework through which to discuss improvements and challenges around the use of these tools in care. Such a framework is necessary to safeguard high-quality relational aspects of care. Regulatory frameworks must remain adaptable to these emerging relationships.

¹ See Wisniewski, P., Ghosh, A. K., Xu, H., Rosson, M. B., & Carroll, J. M. (2017). Parental Control vs. Teen Self-Regulation: Is there a middle ground for mobile online safety? In Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing (pp. 51–69). Association for Computing Machinery. <https://doi.org/10.1145/2998181.2998352>

- **In the case of state-funded care, public participation remains a critical issue, particularly if we are looking to build a coherent understanding of autonomy that integrates evidence around the actual impact of technologies and experiences of autonomy by those in care.**

As care is relational, our workshop highlighted that autonomy too is relational, and situated. There will likely be no single standard for assessing independence and autonomy as every care relationship is different. In the case of guardian-child relationships, our workshop participants discussed the importance of public protections around childhood autonomy and safeguarding, while encouraging guardians to take a co-regulation approach to monitoring technologies. In the case of adult social care, which implicates state actors more directly, public participation is crucial. In particular, public feedback is necessary to think about the types of care technologies that should be endorsed and (part-)funded by state institutions, which technological care interventions are to take place, as well as regular post-implementation evaluations of care technologies by the carers and those cared for. Workshop participants broadly agreed that more evidence is needed to make conclusions around the actual impact of most care-tech interventions in adult social care. Critically, new definitions of success are also needed. How can we integrate standards of care outside resource efficiency into assessments? Similarly, how can we record and integrate the objections and questions of the public and those involved in technologically supported or mediated care?

In October 2023, the United Kingdom's Department of Health and Social care announced the £3 Million funding for four new projects through the government's Adult Social Care Technology Fund. The projects support the use of digital technology in social care, looking to improve the independence of adults in care and to reduce avoidable hospital admissions.² The projects explore the potential of different interventions: the embedding of technologies like sensors in homes to monitor daily activities, virtual care delivery programmes that improve health literacy and digital record systems to improve independence in taking medication.

Outside adult care, the use of tools like parental monitoring apps (colloquially referred to as parental control apps) have received similar interest and attention. Mobile devices have become ubiquitous in families, with virtually all UK children having a mobile phone by the age of 12 (Ofcom 2023)³. This has been accompanied by growing concern about children's safety online, as is evident from Ofcom survey data and the UK's Online Safety Act (2023). Against this background, parents are increasingly turning to their children's devices to monitor their activities through "parental control apps" provided by private vendors in mobile app stores. These tools claim to help parents supervise and guide their children's digital interactions, as well as helping parents ensure their children's safety offline through functionalities like location tracking.

In sum, both at the state level and within families, digital technologies are increasingly playing an important part in the delivery of care and caring relationships. Given the remit of these technologies in regulating and intervening in the personal lives of individuals, particularly vulnerable individuals, important questions of consent, trust, and independence have been raised.^{4,5} We maintain that these concerns are relevant across age groups and types of care situations. Stakeholders from government to medical practitioners, and the public, will need to grapple with difficult ethical questions around existing and emergent care technologies. It is in this context that The Institute for Ethics in AI, University of Oxford hosted a workshop on the topic of Care, Autonomy and Technology. Discussions focused on the need to foster positive experiences for adults and children, as well as individuals directly involved in adult care and childcare. We explored the place for technology to support this endeavour. Specifically, we were interested in the relationship between

² Department of Health and Social Care and Helen Whately MP. (2023, October 5). Over £3 million to transform technology in adult social care. [News story]. GOV.UK. <https://www.gov.uk/government/news/over-3-million-to-transform-technology-in-adult-social-care>

³ Ofcom. (2023, March 29). Children and parents: media use and attitudes report 2023. [Report]. Ofcom. [https://www.ofcom.org.uk/research-and-data/media-literacy-research/childrens/children-and-parents-media-use-and-attitudes-report-2023#:~:text=Childrens%20Media%20Use%20and%20Attitudes%20Report%202023%20\(PDF%2C%208.2%20MB\)](https://www.ofcom.org.uk/research-and-data/media-literacy-research/childrens/children-and-parents-media-use-and-attitudes-report-2023#:~:text=Childrens%20Media%20Use%20and%20Attitudes%20Report%202023%20(PDF%2C%208.2%20MB))

⁴ Wang, G., Zhao, J., Van Kleek, M., & Shadbolt, N. (Year of publication). Protection or Punishment? Relating the Design Space of Parental Control Apps and Perceptions about Them to Support Parenting for Online Safety. *Proceedings of the ACM on Human-Computer Interaction*, 5(CSCW2), 1-26. [DOI: 10.1145/3476084]

⁵ Morley, J., Machado, C. C. V., Burr, C., Cowls, J., Joshi, I., Taddeo, M., & Floridi, L. (2020). The ethics of AI in health care: A mapping review. *Social Science & Medicine*, 260, 113172. [<https://doi.org/10.1016/j.socscimed.2020.113172>]

technology and experiences of autonomy in care. By autonomy we refer broadly to the right and ability to make informed decisions in line with one's own values, acknowledging that autonomy takes on multiple meanings and connotations across disciplines and contexts. Autonomy furthermore implicates related questions around consent, and the potentially conflicting rights and interests of different groups involved in care. The capacity for autonomy may change over time, with uses of digital technologies by carers expected perhaps to prolong the enjoyment of autonomy for older adults or to limit or enable autonomy for children and teenagers. These diverse perspectives and experiences were explored by bringing together expert stakeholders from across health, adult care, and child safety sectors. The workshop was thus concerned with several key questions, amongst them:

- What implications do digital tools and apps have for family relationships, particularly around trust and autonomy?
- How might trends towards digital monitoring reshape our assumptions about good parenting, or good family care?
- How is the ability to provide care remotely transforming care?
- What have been some of the most recent developments in different world regions with respect to how technology is deployed in the provision of care?
- Looking beyond public policy, do we need a broader societal conversation about the opportunities and risks of our evolving, digitally-enabled care practices?

Following Chatham House rules, the following report takes stock of the presentations and discussions throughout the workshop, as well as the future-facing questions raised by our diverse group of participants. While we do not name them, participants hailed from academia and the private and public sector, working locally in the UK as well as in international contexts. This report is structured as follows: we begin by providing a brief background to the issue of autonomy in digital care, followed by a discussion of key issues raised during the workshop. We close with open questions and calls for future research and action.

Workshop participants discussed technology interventions across multiple fields. From virtual care assistance that arose through the Covid-19 pandemic, to sensory monitoring that focuses on ageing in place initiatives, content moderation, managing children's online worlds as well as their offline interactions, there has been a steady integration of technologies in hospitals, schools, and cities. The technologies used across these interventions are themselves wide-ranging, from wearable devices to mobile apps on the user side, to AI and machine learning and 3D printing on the practitioners' side. This expanse implicates multiple stakeholders, policies, and audiences. Nonetheless, our workshop identified challenges that are common to many of these interventions and that are critical to our exploration of fostering autonomy in care. As is the case with all technological developments, leveraging the benefits of tech needs careful weighing against the accompanying risks.

Privacy and Security: many of these technologies are programmed to rely on a large amount of user data. Unauthorised access and data breaches are a cause for concern around sensitive data. More broadly, participants discussed wariness around the 'datafication' of care that can amount to intense surveillance of daily activities. Equating good care with the collection of massive data is incongruent as more data does not automatically mean better insight. Currently, individual users often lack the expertise and state institutions commissioning digital technologies to support care provision often lack the expertise and the manpower to engage with prospective providers on an equal footing.

Workforce/User Adaptation: participants highlighted the intrinsically relational nature of care. Care involves negotiation and interaction between those in care, and those doing the caring. The integration of technology in care impacts the social dynamics and relationships that make care possible. Our discussions identified this as an under-researched element of care and technology, and one that is crucial to understanding whether technology promotes or undermines individual autonomy. We encourage a more relational understanding of autonomy that involves thinking about changing dynamics of care through and with technology.

Health Inequities: technologies are rapidly evolving and can require significant investment in infrastructure, training, and implementation. Our workshop discussed the ways that the capacity to adapt are different globally but also locally in the UK. We also discussed how, in some cases in the UK context path dependency plays a significant role in provision-related decisions. Relatedly, participants highlight how inequalities intersect with race, gender, and other socio-economic identities that mean differentiated access to care, but also the ability to advocate for autonomy and independence in care. There remain serious concerns around the potential of technologies to exacerbate existing health inequalities or introduce new ones.

In the case of state-led care, narrow definitions of success in current care-tech initiatives can restrict the potential of technologies. The effectiveness of technologies needs to be assessed not assumed.

Technologies offer opportunities to increase the quality of life in care, assist care workers with various tasks, and improve the resource efficiency of care systems. However, opportunities may not translate to positive outcomes for those receiving care. Outcomes are dependent on careful implementation and alignment with care priorities that can be contextual and varied. Our discussion highlighted that care priorities can be highly contested with interests and viewpoints varying significantly across stakeholders. In the case of adult social care provision, where institutions play a direct role, such as in health care, many participants questioned the hyper-focus on resource efficiency and cost saving that is at the centre of many care-tech initiatives, the short-hand of economy, efficiency, and effectiveness. While this can undoubtedly be important, and necessary, the workshop discussed this lens as being narrow and restrictive. When technologies have their origin in managing risk rather than in promoting wellbeing, positive health outcomes and experiences can be comprised.

Furthermore, there is little consensus around assessing what effective care looks like. Workshop participants highlighted throughout the discussions that there is no 'typical' family; intimate, or domestic structures differ significantly within populations. Yet guidelines around care-tech tend to be prescriptive and normative. One participant highlighted a tension around 'performing' good parenthood by using technologies and tools even when their benefit is unclear. When good parenting is equated with using digital technologies parents may not want to be seen as depriving their children of opportunities or protection. Technology then can end up being adopted and used for its potential, and its success, if measured at all, is an afterthought. This contributes to the common practice of intense collection of personal data and surveillance of those being 'cared for' preceding an assessment of how that data can be used to solve problems. In response to this tendency, one participant argued that we need to think instead: what is the least amount of data we need to collect to address a recognised problem? We should work towards an alignment of technologies that can support already established care standards and ensure that adopted technologies are regularly evaluated for the benefits they deliver after implementation and that these evaluations involve carers and those receiving care mediated by these technologies.

Evolving relationship between tech and care systems implicate new relationships, new dynamics in the healthcare system. New dependencies complicate our understanding of autonomy.

As has been emphasised, care is fundamentally relational. As technologies continue to be introduced into care, practitioners will need to navigate new relationships and dynamics, as well as the shifting locale of work. As virtual care is rolled out, new boundaries and relationships emerge that bring about their own challenges. One participant pointed to a contradiction in viewing virtual care through the framing of

connection. While virtual care can facilitate remote interactions is also can mean that the recipients of remote care are restricted to their homes without contact to the broader society.

Interdependencies inherent in care networks complicate how we understand autonomy. One participant highlighted the fact that care has always involved a degree of negotiation, for example, between practitioners and patients that entail compromise between labour rights and rights to care. Indeed, as one participant expressed, the assumption that technology creates efficiencies is not straightforward. In some cases, the introduction of robotics in healthcare has increased the workload for carers, distracting workers from caring for patients as these social workers need to make sure the newly adopted robots are functional. Rather than technology replacing care, currently it is more accurate to say that human care can be augmented when technologies work, and care is diminished when they don't. In formal care settings (to a much larger extent than in informal care), care is also transactional, focusing on optimising financial resources or saving a professional's time rather than responding to the demands of those in care. Workers who value autonomy in their work may be constrained by the need to manage and use technologies, which can restrict the patients' own autonomy in the negotiation of care.

Our workshop devoted a significant amount of time discussing emerging and evolving power relations with private care technologies developers and vendors. Workshop participants highlighted many cases where care technologies have been designed as consumer technologies, not regulated, or guided by the standards of medical or social care. Here, practitioners and developers lack a common framework through which to discuss improvements and challenges around the use of these tools in care. This issue is relevant to guardians who use consumer technologies like parental control apps to provide care for their children, as well as for state actors who interface with private companies to plan and procure technologies for care systems.

More evidence is needed around the efficacy of tech in care, and we need ways of integrating stakeholder participation to build a more comprehensive understanding of autonomy.

We identified a significant challenge of stakeholder participation around technology in care. Both in adult care and in childcare those buying or utilising care-tech are often not the people who are being monitored or receiving care. We identified a significant challenge of participation around care-tech and a concerning power inequality where actors determining digital care routes often have the least direct experience of being cared for using those technologies. At the higher level, state institutions make decisions around technology investment and procurement, dictating which technologies patients can access through government-provided or subsidised care. Carers, who could be employees in care facilities or family and friends, are more directly involved in care and may choose between a range of available technologies. This group, while often more closely tied to the experiences and desires of those in care, are nonetheless constrained by state and institutional policies and resources and may not have direct channels to influence which technologies are made available in care. Finally, those receiving care tend to have the fewest routes to influence digitising care

structures and, in some cases, are unable to choose or contest which technologies are used in their care and how.

Workshop participants brought attention to the fact that non-consent to the use of technologies in care can be conveyed in non-verbal ways, such as hacking parental monitoring tools or breaking care sensors. Carers should have an expansive understanding of consent, remaining sensitive to recipients verbal and non-verbal interactions with care technologies, particularly as there may be power differentials between carer and recipient. There has been stronger advocacy for communication and co-regulation of monitoring technologies by children and guardians as one way to support autonomy rather than top-down decision making in the context of childcare, but there remain concerns around opting out to care-tech. Should those who are recipients of care not wish to consent to options like home sensors, will the state provide alternative measures? UK participants say alternatives have been unclear, leaving many to feel like they cannot make decisions around their care. Even with consent, serious questions remain around the datafication of care, and the privacy risks that this entails that are difficult to foresee at the individual level. Participants raised concerns about AI technologies changing the landscape of autonomy and consent as decision-making by the private companies developing those technologies can be opaque.

Public participation is, therefore, critical if we are looking to build a coherent understanding of autonomy that is relational and situated. This is particularly relevant in the case of adult social care, where the state plays a more direct role in deciding care options, compared to the more readily available and potentially more often exercised option of discussion and co-regulation between guardians and children. We need to build evidence around the actual impact of technologies if we are to build equitable metrics and definitions of success. There will likely be no single standard for assessing independence. Instead, contextualised guidance can foster autonomy in relationships of care. Workshop participants broadly agreed that more evidence is needed to make conclusions around the actual impact of most care-tech interventions across a broader group of people and in different contexts.

To conclude this report, we review prompts and questions left unanswered through our workshop that could provide guidance for future research.

- As technological capabilities are always shifting, we need to assume that while some principles of care and autonomy remain, there will be a need for care systems to continually adapt to challenges and opportunities when new technologies are introduced into care. How can we build participation to be part and parcel of our tech in care initiatives?
- In the same vein, can we think of a sustainable approach to the integration of technologies that does not mean always focusing on the latest or most advanced technologies? This can be costly in terms of resources, but also time and effort in re-skilling.
- There is the need to address the commercialisation of tech in care. Our discussion highlighted that the public sector is becoming more focused on private companies to 'plug the resource gaps'. How can the commercialisation in care technologies be reconciled with public/carers' interests?
- We need to address discourses around care and technology that shame or pressure people into the use of technologies when they express valid concerns and questions around their efficacy.

We extend our heartfelt thanks to all those who played a pivotal role in making this workshop a success. We would like to express our sincere thanks to all our panellists, whose valuable perspectives and insights shaped the workshop and, subsequently, this summary report. Their input and participation were instrumental in informing the findings and recommendations presented herein. The usual disclaimers apply.

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