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Towards an ethical framework for the design and development of inclusive home-based smart technology for smart spaces for older adults and people with disabilities

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Towards an ethical framework for the design and development of inclusive home-based smart technology for smart spaces for older adults and people with disabilities

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Abstract: Unique ethical, privacy and safety implications arise for people who are reliant on home-based smart technology due to health conditions or disabilities. As a result we need to carefully reflect on our approaches to ethical issues over the life cycle of smart home technology design and the wider living context for end users and relevant stakeholders. In this position paper we highlight a need for a reflective, inclusive ethical framework for the design of inclusive smart spaces. We present key ethical considerations in the design, development and deployment of smart home-based technology for older adults and people with disabilities. We propose a novel ethical framework for the development of inclusive home-based smart technology which combines these key considerations with existing models of design.

1 INTRODUCTION


The planning, design, development and implementation of home-based smart technology to enhance the quality of life of a particular individual is a complex and evolving challenge, and these complexities can be amplified when end users are older or have a disability. Unique ethical, privacy and safety implications arise for people who are reliant on technology due to health conditions or disabilities. The aim of home-based smart technology is to provide utility to an end user by enhancing their independence and improving quality of life, but if attention has not also been paid to ethical and privacy issues, the end user can have difficult and unfair choices to make.


While ethical approaches have been applied to particular aspects and phases of smart home-based technology design and evaluation there is a need for a practical ethical framework that spans the


technology life cycle and that can address the specific requirements of people with sensory, physical or cognitive impairments. In this position paper, we argue that co-design or participatory techniques must form part of a larger multi stakeholder ethical framework for the design of inclusive smart spaces for older people or people with disabilities.

2 HOME-BASED SMART TECHNOLOGY

Home-based smart technology encourages independent living at home with the support of smart technologies. Specialized assistive devices, smartphone or tablet based applications, on-body or passive sensing technology can be used to increase, maintain, or improve the functional capabilities of older adults or individuals with disabilities. Feedback and information from monitoring technology can be relayed to occupants or

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shared with informal caregivers to aid with decision making about a person's health and wellbeing.

Challenges in the development of inclusive smart technology include how to develop understandable and usable technologies so that they meet individual variations in needs and abilities so that they help to maintain autonomy, provide meaningful activities, address the emotional state of individuals and promote social inclusion (Nunes, 2015). Moreover, there is a great variety within these user groups, such as differences in demographics (e.g., socioeconomic status) and personality, but also due to the diversity of specific conditions, each with different behavioral, cognitive, and emotional consequences. It is, therefore, vital to have extensive insight into the dynamic needs, wishes, and abilities of these user groups and a reiterated theme in the literature is the essential requirement to involve older adults or individuals with disabilities in identifying which needs technologies should meet as well as in the development and evaluation of such technology (Jovanovic 2021, Mannheim 2019, Cesta 2018, Ellers 2018). A review of the literature has highlighted the following as ethical considerations when developing smart assistive technologies.

Informed consent

The pervasive nature of some smart devices raises issues of technological understanding and consent. In addition, older adults or persons with specific disabilities might have a reduced or even compromised ability to decide for themselves about the use of smart technology (O'Connor, 2017).

Privacy

Smart devices gather a broad spectrum of data about their users, ranging from in-application activity to communications to movement and location data. Combined with their pervasive nature, data can be collected and used in ways that are not always clear to end users (O'Connor, 2017, Gochoo 2021).

Security

Security in smart spaces refers to securing the IoT devices and the networks they're connected to. This involves physical security as well as security of the data from intrusion and cyber attacks. Users need to trust in these devices and that their data is secured (Karale 2021). Choosing the right technology to fit the requirements is crucial in avoiding over or unnecessary surveillance. For example when it comes to security, a motion sensing device may be sufficient in place of a camera to determine if a busy path is clear of traffic to ensure safe passage.

Autonomy

Technology should be designed to accommodate existing living patterns and should offer users control

and influence over their lives and well-being (FakhrHosseini 2019).

Safety

Ensuring the safety of older adults and persons with disabilities is crucial to their independence and quality of life. From a technology standpoint, safety and technological reliability are highly coupled and it is important that evaluations of smart technologies are not limited to testing in laboratory settings designed to simulate potential end user environments rather than more complex real world environments (Pigini 2017).

Data Accuracy

The accuracy of data collected in smart spaces depends on a number of factors including the reliability of the device, device configuration or placement, device misuse or misunderstanding. Smart sensors can also generate false positives and inferences, recommendations and predictions based on inaccurate data will contain errors (Aramendi 2019).

Data Sharing

Data collected via smart technologies is often shared with manufacturers and third parties. This can be for varied purposes, to help the manufacturer to improve the product or to aggregate data for analytics and insights. Older adults or persons with disabilities may wish to share data with formal or informal caregivers but they should have control over how and with whom their own data is shared (Doyle et al., 2015). Data management policies should be available and accessible (Mocrii 2018).

Transparency

Transparency enables end users to understand the smart system. It incorporates previous factors such as privacy and data management and ensuring that these are well understood by those using the system. Transparency is important at both the device and system levels (Yao 2019). Understanding how the data is stored and managed is essential for trust of system and data (Doyle et al., 2015)

Trust

To trust decisions computed by smart systems, users need to know how that system arrives at its conclusions and recommendations. Trust is related to data accuracy and transparency above and explanation below (Cannizzaro 2020).

Explanation

Existing approaches to explanations for smart systems are tailored more towards interpretations that are more suitable for modelers and less for technically inexperienced users. The majority of smart systems do not incorporate explanation capabilities (Nikou 2019).

Acceptability

It is accepted that end users make trade-offs when using smart technology, for example, data privacy for increased autonomy, security over privacy for better surveillance, increased functionality or better displays for less explanations or usability for complexity. We argue that these trade-offs should not be inevitable, particularly for persons who are reliant on technology. We posit that an ethical, user driven framework incorporating a design-driven approach can reduce or eliminate these trade-offs by better understanding the needs and requirements of end users.

Affordability

Immersive technology requires immersive data to understand the environment and the individual. This means allowing technology access to our personal spaces. This can be intrusive if not done correctly and tailored for the cohort. Passive, low impact, low visibility, low maintenance and high reliability should be considered as high priority requirements when dealing with older adults and people with disabilities. These requirements have a cost trade off over disposable low cost IoT devices.

3 ETHICS AND TECHNOLOGY

In terms of ethical frameworks, individual ethical theories place different weight on the importance of intentions versus outcomes in evaluating actions. The utilitarian view is that everyone's interests have equal weight. Deontology emphasises the intention to act in accordance with our duties (intentions), and believes the consequences of our actions have no ethical relevance. This is unlike consequentialism, which judges actions by their results or outcomes. Virtue ethics becomes increasingly popular in philosophy of technology. For example, Vallor (2016) has argued that virtue ethics with its focus on choices that aim at the 'good life' is ideally suited for managing complex, novel, and unpredictable moral landscapes, just the kind of landscape that today's emerging technologies present. *Value Sensitive Design* (Friedman, 2013), defined as "a theoretically grounded approach to the design of technology that accounts for human values in a principled and comprehensive manner throughout the design process" is an example of Vallor's (2016) application of virtue ethics to technology.

It is fair to say that the software engineering process has traditionally been driven by a more utilitarian approach by focusing on outcomes in terms of the development of commercial products or services. But a blind spot for intentions has led to

many high profile ethical technology failures where software has displayed unintended consequences (e.g. biases or privacy violations) or been used in a different and unethical manner from that for which it was originally designed (e.g. data harvesting applications embedded in social media or facial recognition technology used for commercial purposes when it had originally been developed for law and order purposes). The recent emphasis on data management and governance and high profile data breaches have led to high level data management frameworks incorporating ethics, for example the UK's Department for Digital, Culture, Media & Sport formulated an ethics framework in its National Data Strategy.

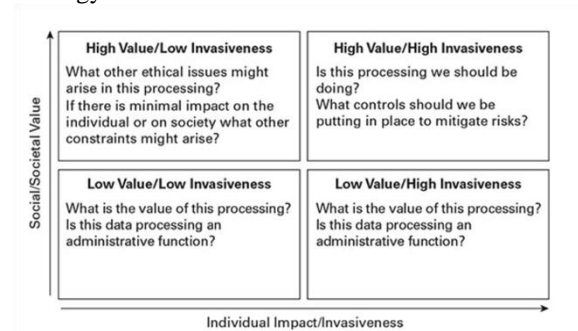


Figure 1 Framework to assess individual invasiveness of the outcome of data processing vs. societal value (O'Keefe and O'Brien, 2018).

Table 1 First Principles Ethical Test (O'Keefe and O'Brien, 2018)

First Principles Ethical Test:
"Does the outcome of your design/algorithm/process outcome contribute positively to 'the good', or positive preservation of human rights?" (O'Keefe and O'Brien, 2018)
Does it preserve or enhance human dignity?
Does it preserve the autonomy of the human?
Is the processing necessary and proportionate?
Does it uphold the common good?

At lower levels, frameworks such as that by O'Keefe and O'Brien (2018) (Figure 1 and Table 1) offer organisations a practical guide to implementing data ethics. These frameworks have tended to follow the traditional trajectory in software engineering by focusing more on outcomes than intentions. Recent welcome developments have shifted the emphasis from outcomes to intentions to reduce blind spots in technology development, for example Consequence Scanning is an Agile approach that fits within an iterative development cycle and encourages organisations to consider the potential consequences

of their product or service on people, communities and the planet (Brown 2019).

Research projects involving human participants undergo ethical assessments and more recently data protection impact assessments that are built on some of the outcome-focused ethical frameworks presented above but typically these occur at the end of the technology design phase. This point of ethical evaluation is usually late in the development of the technology or research project and focus on the impact of the system as designed on the research participants. At this point, it is arguably too late for researchers to consider questions such as “should this technology ever have been developed in the first place?”. We argue that a framework is required that allows us to reflect on ethical issues - those related to both intentions and outcomes - at challenge points throughout the technology life cycle.

4 HUMAN CENTRED DESIGN

Most technology lifecycle models involve a user requirements phase, for example the incorporation of use cases as part of purpose and process specifications within a practical IoT design methodology (Bahga and Madiseti, 2021). However it can be difficult to capture the complex requirements involved in designing home-based smart technology for older adults and people with disabilities without involving them directly in the process.

Human-centred participatory approaches to technology that involve end users at every stage of the design process from requirements gathering to prototype design and iterative development are not novel. Design thinking, first proposed in 1969 (Simon, 1969) as a three step process is most commonly applied to technology using the five stage user centred, iterative design model developed by the Hasso-Plattner Institute of Design at Stanford University (see figure 2)

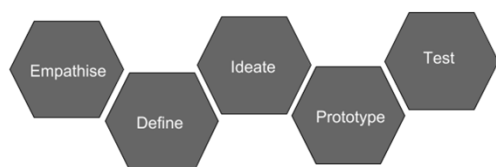


Figure 2 Five stages of Design Thinking (Plattner, 2010)

However, we need to acknowledge that even when a user-centred approach such as design thinking is adopted, designs can still be technology-led or driven by researchers rather than end users (Rogers and Marsden, 2013) due to practical constraints such as meeting requirements of funders or commercial technology partners involved in the design. The tensions between the requirements of relevant stakeholders and a genuine user centred approach are important to acknowledge for a holistic ethical approach to design.


There are multiple stakeholders involved in the creation, implementation and deployment of home-based smart technology for health and wellbeing. Social models of research and care for older adults and people with disabilities have progressed participatory approaches to technology design and have led to more inclusive approaches to the entire research process. There is a growing body of research exploring ethnographic methodologies for a co-researcher approach in the areas of developing age-friendly concepts, (Buffel, 2015; Egan et al., 2014) and disability research (Cappelen, and Andersson, 2021). Rather than passively taking part in a task or design phase, research participants can be viewed as partners in the entire research lifecycle, with a focus on conceptual issues of identity, participation and support networks (Carroll, 2013). It should be acknowledged that some applications of participatory approaches to technology design have been critiqued as a narrow interpretation of ethnographic methods as a requirements gathering exercise and have ignored core insights of ethnographic inquiry, such as the relationship between researcher and subject (Dourish, 2006). An honest understanding of the relationship is crucial to being able to evaluate ethical risk through the entire design lifecycle.

A further criticism of Human Centred Design has been the perception that latest technology advancements may not be utilised with a user driven approach (Norman, 2005). This critique highlights the need to involve multistakeholder design teams that involve technology experts co-designing with end users so that technological capabilities are well matched to user needs. The use of iterative prototyping models used in Design Thinking also complement this form of multistakeholder design approach and can lead to state-of-the-art IoT environments that consider spatial configuration by using human-centric proxemic interactions (Calderon, et al., 2016).

5 PERSONAS AND ETHICS

Personas are a useful tool in a human centred design approach to understand and communicate user needs and requirements. If designers want to test potential solutions, but don't have continuous access to the end-users, they can create fictional characters that can be used to represent a collection of the kinds of people who could be using that potential solution, called *personas* (Cooper, *et al.*, 2014). Although some researchers have criticised the use of personas by pointing out that real customers are preferable to the use of personas, there are many cases where this is not possible, so personas are an effective, if somewhat inferior, alternative (Salminen, *et al.*, 2018). Studies such as Long (2009) have shown that personas can result in many benefits, including: more usable designs, more user-centred discussions, and more effective communication in design teams.

In this case, we have developed personas for this process for design ideation to help create stories that bring to life the existing data, theory and literature (Gordon, *et al.*, 2013) to help to understand and communicate the key ethical issues presented above. The two personas are as follows:

John Neat	
	John is a software developer and has a good understanding of data flow and privacy issues. John has low vision and is a wheelchair user.
<p>John relies on various smart devices for daily activities. He has concerns regarding the data management for some of the commercial devices that he uses. As a software developer he is well aware that even if the creator of an application is very scrupulous about their own data management, the application will invariably use third-party libraries whose data management policies may be impossible to determine.</p> <p>For example he is concerned with how his voice recordings for his voice assistant are stored and shared with third party companies. However despite his concerns, this is the only device that is accessible and so he needs to make a difficult decision between his daily activities and his personal privacy.</p>	

John is married to Judy, and they have two teenage children, Gloria and Edward, who also use the family smart speaker, which again, John is concerned that this data will be shared, and that marketing companies will have an extensive profile about his children before they even become adults.

Mary Noble	
	Mary is a retired Mathematics teacher, and keeps up to date with the national maths curriculum so that she can try to take the state exams each year, she feels this helps her to monitor her cognitive functions.
<p>Mary has been diagnosed with a Mild Cognitive Impairment that may be the early stages of dementia. She has high blood pressure, high cholesterol and type II diabetes that she manages with medication.</p> <p>Mary has an old fashioned large keyed flip phone that she uses for making calls. Her children recently gave her an iPad which gathered dust for a while but her neighbour Kathleen showed her how to use a great app called ReCall that has a collection of puzzles, a diarying feature that she uses with her neighbour, and a calendar feature that reminds her of key events during the day, and during the week.</p> <p>Mary has recently joined a research project that involves her using a prototype of a smart pill box that helps her to manage her complex medication routine and is linked to an app on her iPad and alerts her when something is wrong in relation to her medication dosage, timing or frequency. Her daughter and neighbour Kathleen are also sent alerts. Her pharmacist is also part of the study and the system updates him when she needs a medication refill.</p> <p>Mary is enjoying taking part in the research project and while she finds the technology useful, she does not fully understand how her data is used in the project. She enjoys the regular meetings with the research team when they call to her house to interview her about the technology. She is anxious that she will not be able to answer their questions or use the technology if her memory deteriorates.</p>	

In the first persona, John Neat, we have tried to synthesise the unique ethical and privacy implications that arise for people who are reliant on a device or technology due to health conditions or disabilities. Accessibility requirements can generate unique challenges and lack of choice that can pose difficult choices for individuals and create an unfair trade-off between personal ethical concerns with benefits to health and everyday quality of life. In this persona, John has to balance his independence through the use of a voice assistant and the risk to privacy of his family. We have tried to visualise this trade-off using a matrix based on the O’Keefe and O’Brien (2018) model presented in figure 1 but this time considering the utility of a technology vs. the ethical risk posed (see figure 3).

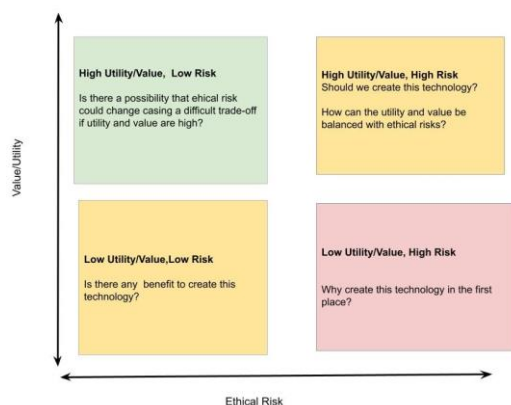


Figure 3 Considering the trade-off between utility and ethical risk that is particularly relevant to older adults and people with disabilities.

In the second persona we describe a relatively simple smart pill dispenser that sends alerts to the end user and their network of care. We tried to highlight in this persona the challenges that need to be addressed when a research participant has low digital literacy which will affect her use of the devices but her understanding of the data flow and data management within the research project. If these are not accessible, there are ethical risks around autonomy and consent for the research and related technology. Mary also has a cognitive impairment that may worsen over time and this also highlights that there can be ethical risks for the sustainability of a system that is designed to support a person at a point in time but may become redundant if their situation, health or capabilities change. Finally, we tried to illustrate the importance of the relationship between a researcher and participants in studies that deploy home-based smart technologies. Participants like Mary may enjoy the social aspects of being part of a research project and

the effects of this need to be considered after the technology is withdrawn and a study ends. The relationships between participants, their networks of care, researchers, technology designers need to be considered in the design of any research project that involves home-based smart technology.

5 PROPOSED 5D FRAMEWORK

This research proposes a new ethical framework, that we have entitled the *5D Framework*, for the development of inclusive home-based smart technology by combining the research presented above with aspects of the five-phase design thinking model proposed by the Hasso-Plattner Institute of Design (d.school), at Stanford, USA (Apiyanti and Dewi, 2019), as well as elements of the UK Design Council’s Double Diamond Model (Howard, *et al.*, 2008).

Crucially, the Framework emphasises that the user is at the heart of the entire framework - they must be the co-designers of the system; in combination with the O’Keefe and O’Brien ethics model and the practical application of ethics in value-sensitive design (Friedman, 2013), these two dimensions are present in all five stages of the framework. The Design Team are a team of participants that include the end-user, as well as experts in technology, medicine, therapy and rehabilitation. Presented in Appendices A and B are a pair of checksheets that can be used as prompts for system developers with some of the key ethics issues that are important for these systems, echoing themes identified in Section 2, as well as the O’Keefe and O’Brien (2018) Framework and in value-sensitive design (Friedman, 2013). The checksheet in Appendix A focuses on data-level ethical considerations, and the one in Appendix B focuses on system-level issues.

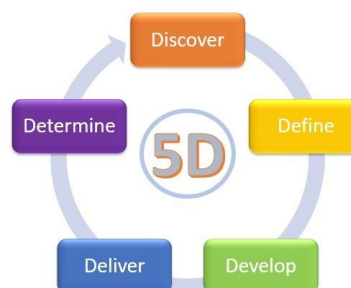


Figure 4 The 5D Framework

The 5D Framework is as follows:

1. Discover
<ul style="list-style-type: none"> In this stage the full Design Team are trying to understand the needs of the end-user of the system. They, therefore, will speak to the end-user in a thoughtful and solicitous manner, as well as other parties that may provide useful insights. The end-user is also asking questions. They may use techniques from Software Engineering, including Requirements Gathering and Knowledge Elicitation (Sommerville, 2015). They may use design and research techniques including interviews, ethnographical diaring, and shadowing (Creswell, 2021). From an ethics perspective, the O’Keefe and O’Brien (2018) Framework (looking at Dignity, Autonomy, Necessity, and Good). Assess potential benefit and harm for every stakeholder group as proposed in (Friedman, 2013) Basic research ethics protocols must also be used, adhering to standard policies and codes, and it would be expected to undergo a formal ethics approval.
2. Define
<ul style="list-style-type: none"> In this stage the full Design Team are trying to encapsulate their findings from the Discover Stage into a series of models, noting key challenges (pinch points and pain points) as well as existing affordances. Again, the end-user is a core member of the Design Team, and they are both the subject of the design, and the architect of the solutions. They may use techniques from Software Engineering, including Use Case Diagrams and Data Flow Diagrams (Sommerville, 2015). They may use design techniques such as MindMaps (or Spider Diagrams) and Gap Analysis to help clarify their thinking (Buzan and Griffiths, 2013). They may also refer to Assistive Technology models such as the HAAT (Human, Activity, Assistive Technology) and the TAM (Technology Acceptance Model) (Cook, <i>et al.</i>, 2020). From an ethics perspective, the O’Keefe and O’Brien (2018) Framework (looking at Dignity, Autonomy, Necessity, and Good)
3. Develop
<ul style="list-style-type: none"> In this stage the full Design Team are working on identifying a range of potential approaches to addressing the issues identified in the two previous stages. Again, the end-user will be a vital force in the stage. They may use techniques from Software Engineering including Paper Prototyping and

<p>“Wizard of Oz” Prototyping (Sommerville, 2015).</p> <ul style="list-style-type: none"> They may use design techniques such as the Six Thinking Hats and Ishikawa Diagrams (Michalko., 2006). A research ethics review should be done at this point to ensure that none of the proposed solutions diverge significantly from the formal ethics approval. This is likely to be the most iterative and cyclical stage.
4. Deliver
<ul style="list-style-type: none"> In this stage the full Design Team are selecting a single potential solution from those developed in the previous stage. In this stage it is vital that the end-user is asked and listened to. They may use techniques from Software Engineering including Vertical and Horizontal Prototyping (Sommerville, 2015). They may use design techniques including User Stories and Storyboards (Sommerville, 2015), Personas, Empathy Maps (add ref) The checksheets in Appendices A and B should be discussed in meetings, and reflected on carefully. The team may also consider undertaking a Data Protection Impact Assessment at this stage (Bieker, 2016).
5. Determine
<ul style="list-style-type: none"> In this stage the full Design Team are testing the effectiveness of their solution. The system is deployed and the team are determining what aspects of the system work well, and which are not fully serving their purpose. This section includes considerations relating to maintenance and sustainability. They may use techniques from Software Engineering including User Acceptance Testing and Performance Testing (Sommerville, 2015). They may use design techniques such as group-based roleplay and the Think-Aloud Protocol (Norman, 1986). They may use educational techniques such as Reflective Practice and Metacognitive Strategies (Gravells and Simpson, 2014). The checksheets in Appendices A and B are crucial at this stage of the process. They must also consider undertaking a Data Protection Impact Assessment at this stage (Bieker, 2016) as well as the O’Keefe and O’Brien (2018) First Principle Test. A research ethics review should also be done at this point to make sure no research ethics violations have occurred. All team members must consider if there are any lingering ethical issues that need to be addressed.

4 CONCLUSIONS

The development of inclusive, home-based smart technology presents many unique ethical challenges, and when this is allied with these systems being developed for older adults and people with disabilities, the ethical concerns and considerations grow significantly. In this paper we have outlined a framework for navigating some of these ethical issues using a range of techniques from Software Engineering, Education, and Research Methods to produce a coherent new ethics driven approach that we have entitled “The 5D Framework” that puts the user at the heart of the process.

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If any, should be placed before the references section without numbering.

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APPENDIX

Appendix A: SmartTech Data-Level Ethics Checksheet. Available: <http://www.damiantgordon.com/CheckSheets/Checksheet-Data.pdf>

Appendix B: SmartTech System-Level Ethics Checksheet. Available: <http://www.damiantgordon.com/CheckSheets/Checksheet-Smart-Devices.pdf>