Towards an Ethical Framework for the Design and Development of Inclusive Home-based Smart Technology for Older Adults and People with Disabilities

Emma Murphy[1][a], Damian Gordon[1][b], Brian Keegan[1][c], Julie Doyle[2][d], Ioannis Stavrakakis[1][e] and Dympna O'Sullivan[1][f]
[1]*ASCNet Research Group, School of Computer Science, Technological University Dublin, Dublin 7, Ireland*
[2]*Netwell CASALA, Dundalk Institute of Technology, Dundalk, Co. Louth, Ireland*

Keywords: Digital Ethics, Digital Health, Older Adults, People with Disabilities, Human Centred Design, Co-creation.

Abstract: Unique ethical, privacy and safety implications arise for people who are reliant on home-based smart technology due to health conditions or disabilities. In this position paper we highlight a need for a reflective, inclusive ethical framework that encompasses the life cycle of smart home technology design. We present key ethical considerations in the design, development and deployment of smart home-based technology for older adults and people with disabilities. Using ethical theories, human-centred design and personas we explore how some of these critical issues can be addressed. Finally, 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 human-centred design and participatory techniques must form part of a larger multi stakeholder ethical framework for the design of inclusive smart spaces for older people and people with disabilities.

2 HOME-BASED SMART TECHNOLOGY

Home-based smart technology encourages independent living at home with the support of smart technologies. Specialised assistive devices,

[a] https://orcid.org/0000-0001-6738-3067
[b] https://orcid.org/0000-0002-3875-4065
[c] https://orcid.org/0000-0003-0445-108X
[d] https://orcid.org/0000-0003-4017-6329
[e] https://orcid.org/0000-0001-6127-3000
[f] https://orcid.org/0000-0003-2841-9738

Murphy, E., Gordon, D., Keegan, B., Doyle, J., Stavrakakis, I. and O'Sullivan, D.
Towards an Ethical Framework for the Design and Development of Inclusive Home-based Smart Technology for Older Adults and People with Disabilities.
DOI: 10.5220/0010879900003123
In *Proceedings of the 15th International Joint Conference on Biomedical Engineering Systems and Technologies (BIOSTEC 2022) - Volume 5: HEALTHINF*, pages 614-622
ISBN: 978-989-758-552-4; ISSN: 2184-4305

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 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 behavioural, 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; Elers, 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 and Trust.
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). 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.
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.

It is accepted that end users make trade-offs when using smart technology, for example, data privacy for functionality (Singh et al., 2016) or 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.

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. *Deontology* emphasises the intention to act in accordance with our duties (intentions), and believes the consequences of our actions have no ethical relevance. The *utilitarian* view is that everyone's interests have equal weight, and as form of consequentialism, 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" could be considered 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 is 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 Department for Digital, Culture, Media & Sport (2020) formulated an ethics framework in its National Data Strategy.

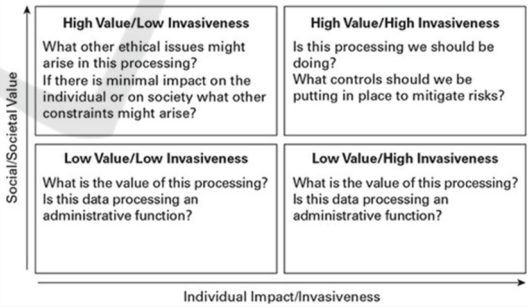

Figure 1: Framework to assess individual invasiveness of the outcome of data processing vs. societal value (O'Keefe and O'Brien, 2018).

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

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?

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 Madisetti, 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).

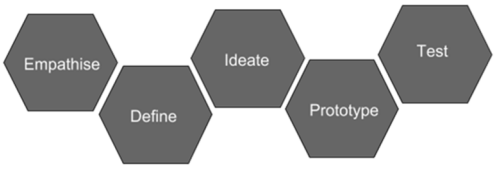

Figure 2: Five stages of Design Thinking (Hasso Plattner Institute of Design, 2010).

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 and Rosson, 2013). It should be acknowledged that some applications of participatory approaches to technology design have been critiqued as having 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 the 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. Furthermore human centred does not preclude innovative technology designs. For example recent state-of-the-art IoT environments have explored how systems can be more human centric by incorporating contextual elements that have meaning for users such as time and space based on 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.

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. 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.

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.

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. 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 Rekall 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.

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.

Mary is enjoying taking part in the research 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.

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).

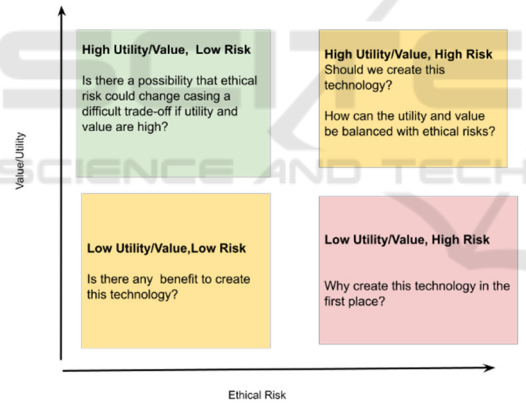

Figure 3: Considering the trade-off between utility and ethical risk that is particularly relevant to older adults and people with disabilities.

In the second persona we describe a 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 and controllable by the user, 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.

6 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 and relevant health domain i.e. clinicians, occupational therapists, physiotherapists etc.

In Appendices A and B we have presented two 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. The 5D Framework is as follows:

1. Discover
• In this stage the full Design Team must begin a two-way dialogue with the end-user (and other parties) in a thoughtful manner to understand their needs. If

they cannot locate any end-users, they should use personas such as those provided in Section 5.

- They may use techniques from Software Engineering, including Requirements Gathering and Knowledge Elicitation (Sommerville, 2015), and the IoT design methodology from Bahga and Madisetti (2014).
- They may use design and research techniques including interviews, ethnographical diarying, and shadowing (Creswell, 2021).
- From an ethics perspective, the three main ethical theories from Section 3 (Deontology, Utilitarianism, and Virtue ethics) need to be considered.
- 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

- 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. For the times they are not available, the personas can be used.
- They may use techniques from Software Engineering, including Use Case Diagrams and Data Flow Diagrams (Sommerville, 2015) and the IoT design methodology from Bahga and Madisetti (2014).
- 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, *et al*., 2020).
- From an ethics perspective, the O'Keefe and O'Brien (2018) Framework (looking at Dignity, Autonomy, Necessity, and Good)

3. Develop

- 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 "Wizard of Oz" Prototyping (Sommerville, 2015), as well as the two personas, and the IoT design methodology from Bahga and Madisetti (2014**)**
- They may use design techniques such as the Six Thinking Hats and Ishikawa Diagrams (Michalko, 2006).
- A research ethics review should be conducted 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

- In this stage the full Design Team are selecting a single potential solution from those developed in the previous stage, and it is vital that the end-user is asked and listened to, as well as using personas where needed.
- 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 (Hasso Plattner Institute of Design, 2010)
- The ethics 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

- 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 ethics 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.

7 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.

ACKNOWLEDGEMENTS

The authors gratefully acknowledge the support of the Erasmus+ programme of the European Union. The European Commission's support for the production of this publication does not constitute an endorsement of the contents, which reflect the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein. This material is based upon works supported by the Science Foundation Ireland under Grant No. 19/FFP/6917.

REFERENCES

Apiyanti, S. and Dewi, L., 2019, Design Thinking of the Inclusive Education Learning Strategy in the 5.0 Society Era". *4th International Conference on Education and Regional Development (ICERD)*, pp. 631-642.

Aramendi, AA, Weakley, A., Goenaga, AA., Schmitter-Edgecombe, M., Cook, DJ, (2018). Automatic assessment of functional health decline in older adults based on smart home data, *Journal of Biomedical Informatics*, 81: 119-130.

Bahga, A., & Madisetti, V., 2014, *Internet of Things: A hands-on approach*. Vijay Madisetti Publishers.

Bieker, F., Friedewald, M., Hansen, M., Obersteller, H. and Rost, M., 2016, September. A Process for Data Protection Impact Assessment under the European General Data Protection Regulation. In *Annual Privacy Forum* (pp. 21-37). Springer, Cham.

Brown S. (2019) *Consequence Scanning Manual Version 1*. London: Doteveryone.

Buffel, T., Phillipson, C.and Scharf, T. (2012) Ageing in urban environments: Developing 'age-friendly' cities. *Critical Social Policy*, 32: 597-617.

Buzan, T. and Griffiths, C., 2013. *Mind Maps for Business, Using the Ultimate Thinking Tool to Revolutionise How You Work*. 2nd Edition, Pearson.

Calderon, M. A., Delgadillo, S. E., & Garcia-Macias, J. A. (2016). A More Human-Centric Internet of Things with Temporal and Spatial Context. *Procedia Computer Science*, 83, 553-559.

Cannizzaro S, Procter R, Ma, S, Maple C (2020) Trust in the smart home: Findings from a nationally representative survey in the UK. *PLoS ONE* 15(5): e0231615.

Cappelen, B. and Andersson, A.P., (2021). Trans-Create–Co-Design with Persons with Severe Disabilities. In *Universal Design 2021: From Special to Mainstream Solutions* (pp. 87-101). IOS Press.

Carroll, J. and Rosson, M. (2013) Wild at Home: The Neighborhood as a Living Laboratory for HCI. *ACM Transactions in Computer Human Interaction* 20, 3, Article 16 (July 2013)

Cesta, A., Cortellessa, G., Fracasso, F., Orlandini, A., & Turno, M. (2018). User Needs and Preferences on AAL systems that Support Older Adults and their Carers. *Journal of Ambient Intelligence and Smart Environments*, 10(1), 49-70

Cook, A.M., Polgar, J.M., Encarnação, P., 2020, *Assistive Technologies: Principles and Practice*, 5th ed., Mosby.

Cooper, A., Reimann, R., Cronin, D. and Noessel, C., 2014. *About Face: The Essentials of Interaction Design*. John Wiley & Sons.

Creswell, J.W., 2021, *A Concise Introduction to Mixed Methods Research*, SAGE publications, ISBN-1544355750.

Dourish, P. (2006) Implications for design. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '06). Association for Computing Machinery, New York, NY, USA, 541–550.

Doyle, J., Caprani, N., Bond, B. (2015) Older adults' attitudes to self-management of health and wellness through smart home data, *2015 9th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth)*, pp. 129-136.

Elers, P., Hunter, I., Whiddett, D., Lockhart, C., Guesgen, H., & Singh, A. (2018). User Requirements for Technology to Assist Aging in Place: Qualitative Study of Older People and their Informal Support Networks. *JMIR mHealth and uHealth*, 6(6), e10741

FakhrHosseini M., Lee C., Coughlin J.F. (2019) Smarter Homes for Older Adults: Building a Framework Around Types and Levels of Autonomy. In: Zhou J., Salvendy G. (eds) Human Aspects of IT for the Aged Population. Social Media, Games and Assistive Environments. HCII 2019. *Lecture Notes in Computer Science*, vol 11593. Springer, Cham

Friedman, Batya, Peter H. Kahn, Alan Borning, and Alina Huldtgren. 2013. "Value Sensitive Design and Information Systems." In Early Engagement and New Technologies: Opening up the Laboratory, 59–95.

Gochoo, M.; Alnajjar, F.; Tan, T.-H.; Khalid, S. Towards Privacy-Preserved Aging in Place: A Systematic Review. *Sensors 2021*, 21, 3082.

Gordon, D., Fennell, A., O'Leary, C., O'Connor, J. (2013) "Persona-Based Teaching: A New Approach to Exploring the Dimensions of Universal Design using Personas and Scenarios", in *Proceedings of "Is*

Universal Design in Education Any of My Business?" AHEAD Conference, Dublin, Ireland, March 12th & 13th, 2013.

Gravells, A. and Simpson, S., 2014. *The Certificate in Education and Training*. Learning Matters Press.

Hasso Plattner Institute of Design (2010) An Introduction to Design Thinking: PROCESS GUIDE. Available: https://web.stanford.edu/~mshanks/MichaelShanks/files/509554.pdf

Howard, T.J., Culley, S.J. and Dekoninck, E., 2008. Describing the Creative Design Process by the Integration of Engineering Design and Cognitive Psychology Literature. *Design studies*, 29(2), pp.160-180.

Howard, T.W., 2015. Are Personas Really Usable?. *Communication Design Quarterly Review*, 3(2), pp.20-26.

Jovanovic, M & De Angeli, A& Mcneill, A & Coventry, L. (2021). User Requirements for Inclusive Technology for Older Adults. *Int J Hum-Comput Int*. 10.1080/10447318.2021.1921365.

Karale A. The Challenges of IoT Addressing Security, Ethics, Privacy, and Laws, *Internet of Things*, 2021, 15:100420

Long, F., 2009, Real or Imaginary: The Effectiveness of Using Personas in Product Design. In *Proceedings of the Irish Ergonomics Society annual conference* (Vol. 14, pp. 1-10).

Mannheim, I., Schwartz, E., Xi, W., Buttigieg, S. C., McDonnell-Naughton, M., Wouters, E., & van Zaalen, Y. (2019). Inclusion of Older Adults in the Research and Design of Digital Technology. *Int J Environ Res Public Health*, 16(19), 3718.

Michalko, M., 2006. *Thinkertoys: A Handbook of Creative-Thinking Techniques*. Random House Digital, Inc.

Mocrii, D., Chen, Y., Musilek, P. (2018) IoT-based Smart Homes: A Review of System Architecture, Software, Communications, Privacy and Security ,*Internet of Things*, 1–2:81-98.

Nikou S. (2019) Factors driving the adoption of smart home technology: An empirical assessment, *Telematics and Informatics*, 45:e10128.

Norman, D.A., 1986. *User centered system design: New perspectives on human-computer interaction*. CRC Press.

Norman, D.A.,. 2005. Human-Centered Design Considered Harmful. *Interactions* 12(4), 14–19.

Nunes F, Verdezoto N, Fitzpatrick G, Kyng M, Grönvall E, Storni C (2015). Self-care technologies in HCI: Trends, tensions, and opportunities. *ACM Trans Comput Interact* 22, 33:1–33:45

O'Connor, Y., Rowan, W., Lynch, L., & Heavin C. (2017)Privacy by Design: Informed Consent and Internet of Things for Smart Health, *Procedia Computer Science*,113:653-658.

O'Keefe K. and O. Brien, D. (2018). *Ethical Data and Information Management: Concepts, Tools and Methods* (1st. ed.). Kogan Page Ltd., GBR.

Pigini, L., Bovi, G., Panzarino, C., Gower, V., Ferratini, M., Andreoni, G., Sassi, R., Rivolta, M.W., Ferrarin, M. (2017). Pilot test of a new personal health system integrating environmental and wearable sensors for telemonitoring and care of elderly people at home (SMARTA project). *Gerontology*, 63: 281-286

Rogers, Y. and Marsden, G. (2013) Does he take sugar?: moving beyond the rhetoric of compassion. interactions 20, 4 (July 2013), 48-57.

Salminen, J., Jansen, B.J., An, J., Kwak, H. and Jung, S.G., 2018. Are Personas Done? Evaluating their Usefulness in the Age of Digital Analytics. *Persona Studies*, 4(2), pp.47-65.

Simon, H (1969) *The Sciences of the Artificial* (3rd Edition, 1996), MIT Press.

Singh,R., Cassell, B. Keshav,S. and Brecht, T. (2018) TussleOS: managing privacy versus functionality trade-offs on IoT devices. SIGCOMM Comput. Commun. Rev. 46, 3, Article 3

Sommerville, I., 2015. *Software Engineering 10th Edition*. Pearson, ISBN-9781292096131.

Vallor S (2016) *Technology and the Virtues*. Oxford University Press, New York.

Yao, Y., Basdeo, J. R., Kaushik, S., & Wang, Y. (2019). Defending my castle: A co-design study of privacy mechanisms for smart homes. In CHI 2019 - *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (Conference on Human Factors in Computing Systems - Proceedings)*. ACM.

Zajicek, M. (2001). Interface design for older adults. In R. Heller, J. Jorge, and R. Guedj (Eds.), *Proceedings of the 2001 EC/NSF workshop on Universal accessibility of ubiquitous*

Moore, R., Lopes, J. (1999). Paper templates. In *TEMPLATE'06, 1st International Conference on Template Production*. SCITEPRESS.

Smith, J. (1998). *The book*, The publishing company. London, 2nd edition.

UK Department for Digital, Culture, Media & Sport (2020) National Data Strategy. Available: https://www.gov.uk/government/publications/uk-national-data-strategy/national-data-strategy

APPENDIX

Appendix A: SmartTech Data-Level Ethics Checksheet. Available: https://tinyurl.com/ynd3274e

Appendix B: SmartTech System-Level Ethics Checksheet. Available: https://tinyurl.com/388zhper