

Using Participatory Design to Develop Ethical DataSheets for the Research and Design of Ambient Assistive Living Technologies

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Abstract

By 2030, the Government of Canada predicts that over 9.5 million (23%) Canadians will be 65 years of age or older. For this growing demographic of older adults, intelligent home health technologies have been proposed as one beneficial avenue to support and maintain health and wellness as they begin experiencing ageing-related health effects. However, many ethical concerns have been raised regarding the design and deployment of these technologies in ageing-in-place settings such as long-term care and nursing homes.

This thesis aims to better understand the ethical concerns that long-term care stakeholders have with a subset of intelligent home health technologies known as Ambient Assistive Living (AAL) technology.

To obtain this understanding, a Systematic Literature Review (SLR) was conducted to gather the different ethical concerns that long-term care stakeholders have with AAL technology and to observe the various ethical design and engineering frameworks used to develop AAL technology for aging-in-place settings. 41 publications were analyzed to identify various ethical concerns held by ageing-in-place stakeholders and the different ethical design and engineering frameworks used to address these concerns. The findings from the SLR identified 17 ethical concerns that influenced how the research was conducted with long-term care facility stakeholders.

Following the SLR, a Participatory Design methodology in the form of workshops and interviews was developed and implemented with 30 long-term care facility stakeholders to understand their ethical concerns with two AAL devices: the Hexoskin ProShirt™ - a wearable device used to monitor and collect vital signs, and the AWS DeepLens™ camera - a machine-learning enabled video camera used to make predictions. Through data analysis, 35 topics were identified and grouped into 12 main ethical concerns for both devices.

Once a better understanding of long-term care stakeholders' ethical concerns with the two devices was gained, a prototype of an ethical design tool—the Ethical DataSheet—was proposed. An Ethical DataSheet is meant to support researchers, engineers, designers, and others in developing a better understanding of the ethical concerns they must consider when designing and developing AAL technology for ageing-in-place applications.

To create the Ethical DataSheet prototype, a snowball sampling literature review was conducted. By conducting the second literature review, inspiration from different ethical design tools was used to develop the prototype. The Ethical DataSheet prototype was then used to create Ethical DataSheets for the Hexoskin ProShirt™ and AWS DeepLens™, which present the top ethical concerns that were identified through the workshops and interviews with long-term care facility stakeholders.

The findings of this research will be shared with the PATH research community, who are dedicated to providing nationwide testing and services for home health technologies that will accelerate the availability of appropriate smart systems (i.e. AAL technologies) for seniors' and patients' home healthcare.

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1.0 Introduction

1.1 Background

Globally, life expectancies are increasing, and birth rates are decreasing, which has led to a generational shift in population distribution. The United Nations (UN) estimates that by 2050 one out of every five people globally will be over 60 years old (Ting et al., 2020). In 2014, the proportion of Canadians aged 55–64 surpassed those aged 15–24 for the first time since 1971 (Statistics Canada & Government of Canada, 2015). With the current demographic trends, in 2030, over 9.5 million Canadians will be over the age of 65 (Government of Canada, 2016a). Other countries, such as the United States, Britain, Germany, and Japan, are experiencing similar trends (Novitzky et al., 2015)

For Canada, this growing demographic of older adults poses demands for healthcare systems to provide a continuous high Quality of Life (QoL), health, and well-being for this group. However, the feasibility of these demands remains challenging, as novel techniques, technologies, and processes must be investigated to see if they can aid in achieving effective health system outcomes.

One approach that has been gaining interest in recent years is the use of Assistive Technology (AT). As defined by Fadrique et al., “AT refers to any item, piece of equipment, or product [...] that is used to increase, maintain, or improve the functional capabilities of [the user]” (2020, p. 1). AT aims to improve older adults’ quality of life by providing cognitive and physical support in everyday tasks while maintaining their dignity, autonomy, safety, security, and self-confidence. In addition, other stakeholders such as caregivers (family and friends) and healthcare professionals (HCPs) can use AT to provide additional support to the older adult end-user (Hlauschek et al., 2009; Ienca et al., 2018; Novitzky et al., 2015; Panico et al., 2020).

This thesis focuses on a subset of AT known as Ambient Assistive Living (AAL) technologies. AAL technologies blend AT with computational components such as Artificial Intelligence (AI) and/or Machine Learning (ML) (Di Napoli et al., 2021). Overall, AAL technology includes any device, software, or human-machine equipment that can aid older adults in everyday activities to live actively, healthy, and autonomously in their own homes, regardless of any physical, cognitive, or environmental impairments (Biermann et al., 2018; Panico et al., 2020).

While much research has been dedicated to AAL technologies for older adults with cognitive impairments such as dementia, it is important to note that these technologies can be used to support anyone “ageing-in-place.” The Government of Canada (2016b) and the Centers for Disease Control and Prevention (CDC) (2017) define ageing-in-place as: “*The ability to live in one’s own home, space, and community safely, independently, and comfortably, regardless of age, income, or ability level.*”

1.2 Ethical Concerns in the Context of Technology

Defining “ethical concerns” in relation to technology is challenging as it is a concept that is very open-ended and has a very loose boundary around it. Other authors have encountered this challenge, for example in the definition of Value Sensitive Design (VSD), which is a design framework intended to motivate designers to think more explicitly about values and ethics

(Friedman & Hendry, 2019). As with VSD, this work defines “ethical concerns” from the view that to consider ethical concerns in designing technology is to design a particular technology for what a broad set of stakeholders consider to be important in their lives with respect to their (potential) interactions, direct or indirect, with that technology (Friedman & Hendry, 2019). Put another way, a particular ethical concern with a technology's design points to an issue that conveys some sense of benefit or risk to a stakeholder, where the outcome of some design decision has an impact on what the stakeholder considers to be important in their life.

Ethical concerns in the design of technology can motivate, or lead to, design decisions, but what characterizes an ethical concern in design is an explicit focus on normative aspects that link the technology and its design to those benefits and risks to stakeholders. This means that when considering ethical concerns, those responsible for designing and developing technology are explicitly considering a broad set of questions about how they *should* design and develop a new technology with various benefits and risks (or permissibilities and impermissibilities) in mind, rather than designing and developing a new technology because they believe, for example, that a particular feature is what the user would want to do, or what the designer would want the user to do. Therefore, normative aspects of a technology would ask whether or not it is right (or permissible, justified, etc.) to design that feature. In using a normative lens to design and develop technology, ethical concerns, such as autonomy or privacy, are considered as a means of determining how to design a technology that is in line with what stakeholders consider to be important in their lives, and in line with what is more broadly justifiable on normative grounds. In using this mindset, considering ethical concerns can be “*useful no matter the particular sociotechnical context of stakeholders, values, tools and technologies*” (Friedman & Hendry, 2019, p. 5).

Therefore, just as with VSD, by understanding and designing for ethical concerns, engineers, researchers, and designers have the ability “*to make insightful investigations into technological innovation in ways that foreground the well-being of human beings and the natural world*” (Friedman & Hendry, 2019, p. 3).

1.3 Ethical Concerns with AAL Technology

With the increased adoption of AAL technologies, many ethical concerns have been raised regarding the design and development of this technology in ageing-in-place settings (Panico et al., 2020; Stahl & Coeckelbergh, 2016; Wangmo et al., 2019). Such ethical concerns include social isolation (Astell et al., 2020; Curumsing et al., 2019; Ienca et al., 2018) as AAL technology can be used to replace human assistance, and privacy (Biermann et al., 2018; Etemad-Sajadi & Dos Santos, 2019; Zwijsen et al., 2011) given the vast amounts of personal data required to develop AI and ML. As early as 2006, researchers such as Sparrow and Sparrow (2006) started to voice concerns long before many of these systems had been proposed. They argued that much of the research efforts towards robotics and AI for the healthcare industry—AAL technologies among them—were driven more by researchers’ interests and curiosity rather than any genuine concern for older adults’ needs, considerations, or desires (Sparrow & Sparrow, 2006).

Even though such concerns were raised almost two decades ago, the ethical questions and concerns regarding the use of technology to aid ageing-in-place, such as social isolation, privacy, autonomy, and dignity, have only grown due to the advancements that AI has made

over the years (Astell et al., 2020; Jiang et al., 2019; Panico et al., 2020; Sanchez et al., 2019; Schomakers & Ziefle, 2019; Skär & Söderberg, 2018; Wang et al., 2019)

1.4 AGE-WELL and the Program to Accelerate Technologies for Homecare (PATH)

AGE-WELL is a “*Canadian-based network that aims to bring people together to develop technologies and services for healthy aging*” (AGE-WELL, 2022a). In trying to achieve this goal, AGE-WELL has identified eight challenge areas that “*demand innovation and deployment of real-world solutions*” (AGE-WELL, 2022b). In establishing these areas, AGE-WELL has opened the door for researchers in academia and industry to suggest, research, innovate, and implement projects that attempt to provide solutions to the proposed challenges.

One project that has emerged to address AGE-WELL’s challenge area of ‘Supportive Homes and Communities’ is the *Program to Accelerate Technologies for Homecare (PATH)*. PATH’s mission is to provide a nationwide testing and optimization service for home health technologies that will accelerate the availability of appropriate smart systems (i.e. AAL technologies) for seniors’ and patients’ home healthcare. PATH’s unique program aims to provide an affordable open-access infrastructure for researchers across Canada to propose algorithms and test prototypes and concepts in real home environments while providing the opportunity for rapid market access through established distribution channels. Overall, PATH is meant to be a world-leading program that supports ageing-in-place by researching and developing technologies that benefit from AI methods to fuse data, increase sensitivity, eliminate false alarms, and do away with unnecessary data that is often a burden to caregivers or HCPs.

PATH is a research collaboration across several major Canadian universities, including the University of Toronto, the University of Alberta, the University of Ottawa, and the University of Waterloo. A critical component of PATH involves sharing data across university research sites to facilitate the development of AI algorithms for end-users (typically older adults), and also includes sharing that data with an industry partner, SmartONE, that is developing the data platform—the PATH Platform—and connected smart home technology. SmartONE is a Canadian-based technology company responsible for the infrastructure that connects environments (such as labs, apartments, or buildings), so that smart home data can be collected and stored on the PATH Platform. Additionally, each university partner is connected with a senior’s residence or Long-Term Care (LTC) centre in their community. By engaging with community partners at the project’s onset, PATH allows its researchers to interact with the people who will be impacted the most by any new technology that PATH suggests.

1.5 PATH devices

Launched in 2020, PATH is in its formative stages. Currently, PATH is in a testing phase, where each site (Edmonton, Ottawa, Toronto, and Waterloo) is installing and testing the devices for home health monitoring that were decided upon during the early stages of the project. The testing phase allows researchers to debug the devices to confirm they are working correctly, ensure that all data collected from the devices are correctly uploaded to the PATH Platform (the shared data repository), and to test different scenarios they may want to implement with their LTC partners.

Each university partner started with a suite of five devices provided by PATH. These devices include:

- The Fitbit Aria Air™ is a wireless smart body weight scale with bioimpedance. The scale tracks weight, body fat percentage, BMI, lean body mass, and body fat fluctuations of the user over time.
- The AWS DeepLens camera™ is a fully programmable video camera that utilizes deep learning (a Machine Learning technique) to make predictions through computer vision, algorithms, and AI models.
- The Empatica e4™ watch is a medical-grade smartwatch that monitors vital signs by measuring photoplethysmography signals, temperature, and Galvanic Skin Response.
- The Hexoskin ProShirt™ is a wearable device that uses textile sensors to monitor cardiac, respiratory, and movement activity and can collect 36,000 data points a minute.
- The Withings Sleep Mat™ is a pneumatic mat placed under a mattress to track sleep and snoring patterns.

Together, these devices, and any additional devices that researchers decide to add later, are designed to collect physiological and other data from users that can be stored and used to design and build AAL technology for ageing-in-place applications.

1.6 Research Objectives

This thesis has two primary objectives:

OBJ1: Investigate and understand how the ethical concerns raised by stakeholders, including older adults, caregivers (family and friends), and HCPs, have been, and should be addressed in the design and development of AAL technology.

OBJ2: Prototype an ethical engineering design tool that conveys stakeholders' ethical concerns with devices used in AAL technology.

The tool proposed in the second objective is meant to assist those responsible for designing and developing AAL technology to better understand the ethical issues and considerations they should keep in mind throughout the design and development process so that they might develop AAL technologies that better anticipate stakeholders' ethical expectations and requirements. For example, as the results of this thesis will be shared with the PATH community explained above, the tool should be used by PATH researchers, engineers, and designers to gain a better understanding of LTC stakeholders' ethical concerns with a device before it is integrated into more complex AAL technology. In using this tool, PATH researchers, engineers, and designers have a way to collect and understand LTC stakeholders' ethical concerns so that those concerns can be addressed throughout the design and development phases of new AAL technology, with the hope that LTC stakeholders will be more willing to accept and adopt the technology into their daily lives.

To address the two objectives discussed above, three research questions were developed:

To satisfy the first objective (OBJ1) of identifying the ethical concerns that stakeholders raise with AAL technology and how engineers and designers are addressing those concerns, the following research question was posed:

RQ1: How are ethical concerns voiced by long-term care stakeholders influencing the design, development, and implementation of AAL technology?

To answer this research question, a systematic literature review (SLR) was conducted, which first analyzed stakeholders' various ethical concerns towards AAL technology (See Chapter 2.0). The SLR identified and analyzed the different ethical design and engineering frameworks that have been used and are being proposed to identify and address ethical concerns in the development of AAL technology.

While many ethical design and engineering frameworks were identified from this SLR, it was found that Participatory Design (PD), a methodology where many relevant stakeholders that will be impacted by a proposed idea or solution are involved throughout the design process, can be a useful framework/methodology for identifying and addressing stakeholders' ethical concerns. Therefore, PD was chosen to address the second research objective (OBJ2).

The second objective of this thesis is to propose an ethical engineering design tool that effectively conveys the ethical concerns of stakeholders, such as older adults, caregivers, and HCPs. This way, those responsible for designing and developing new AAL technology can understand the concerns that stakeholders have with the devices used in the technology and are therefore able to accommodate the concerns so that stakeholders are more willing to accept and adopt the technology in the future.

Two devices from the original PATH suite were chosen to create the first versions of this ethical engineering design tool: the Hexoskin ProShirt™ and the AWS DeepLens™. These AAL devices were selected as they were the two devices anticipated to raise an interesting and broad set of ethical questions with long-term care facility (LTCF) stakeholders.

A PD methodology was deployed through workshops and interviews with LTCF stakeholders to gain the necessary insights to develop the ethical engineering design tool. Interactive workshops were held with LTCF *tenants* (older adults who live independently and require little to no additional assistance with everyday tasks). In addition, interviews were held with LTCF *residents* (older adults who need more intensive or around-the-clock care), *caregivers* (family members and friends), and LTCF HCPs. The goal of these workshops and interviews was to answer the second research question:

RQ2: How well does a Participatory Design methodology work to uncover the ethical concerns that long-term care facility stakeholders have regarding the Hexoskin ProShirt™ and the AWS DeepLens™?

Once all workshops and interviews were completed, the data was transcribed and analyzed to determine the significant ethical concerns LTCF stakeholders saw with the Hexoskin ProShirt™ and the AWS DeepLens™.

Once the data analysis was complete and findings were collected, a smaller literature review was conducted to get a clearer sense of what kinds of ethical design tools other academic and industry researchers have proposed to communicate ethical concerns regarding AI and ML technology. Inspired by what has been proposed in the past, and adding elements unique to PATH and the devices chosen for this research, this thesis presents a prototype for an ethical design tool called an Ethical DataSheet (EDS). The creation of this prototype goes towards answering the third and final research question:

RQ3: How can Ethical DataSheets be created to convey the ethical implications that must be considered before an AAL device is developed and deployed?

This third research question, and second objective of this thesis, are to propose a tool that PATH researchers, engineers, designers, and any other interested party, can use to identify the ethical concerns their LTCF stakeholders may have with devices used in AAL technology early in the design lifecycle. By anticipating these concerns, researchers, engineers, and designers have a better understanding of the ethical elements they must consider when designing and developing their AAL technology for ageing-in-place applications. Therefore, an EDS aims to translate applied ethics research into practical ethical engineering supports (Millar, 2020) so that critical ethical concerns that are already present or may arise with a particular device are highlighted.

For this thesis, the EDS prototype is presented first so that it is available for others to use upon completion of this research. The EDS prototype is also used to create EDS for the Hexoskin ProShirt™ and the AWS DeepLens™. The EDSs for the two devices are populated using the data collected from the workshops and interviews with LTCF stakeholders.

1.7 Scope and Outline

To achieve the research objectives outlined above, this thesis proceeds as follows.

Chapter 2.0 presents a Systematic Literature Review (SLR) that aims to answer the question: *Have ethical design and engineering frameworks been implemented in the development of Ambient Assistive Living technologies for ageing-in-place?* This SLR first presents the ethical concerns that LTC stakeholders, such as older adults, caregivers, and HCPs, have with AAL technology. The SLR also investigates the current landscape for ethical design and engineering frameworks that could be used to help address ethical concerns while designing and developing AAL technology.

Chapter 3.0 discusses the participatory design study that was conducted with LTCF stakeholders. This chapter details the purpose of the study, the methodology that was developed and followed, and the recruitment of participants. Finally, the outcomes of the workshops and interviews after qualitative analysis are presented, documenting the benefits and concerns LTCF stakeholders had with the Hexoskin ProShirt™ and the AWS DeepLens™.

Chapter 4.0 focuses on prototyping the Ethical Datasheet. This chapter starts with a snowball sampling literature review conducted to gather and analyze different ethical design tools that have been proposed. Elements from various tools were then used to develop an Ethical Datasheet prototype that can be used for other devices outside of this research. The

prototype is then used to create Ethical Datasheets for the Hexoskin ProShirt™ and the AWS DeepLens™.

Finally, Chapter 5.0 summarizes the overall project, the complications that arose during the research, the overall takeaways and insights that were gained, and the ideas for future work.

2.0 Review of Ethical and Responsible Assistive Technology Design and Development

Ambient Assistive Living (AAL) technologies, such as environmental and wearable sensors that monitor vital signs and activity patterns, can have many benefits for its users and other stakeholders; however, their practical deployment is challenging. Kong & Woods (2018) note that while, theoretically, AAL technology can enable independence and autonomy for older adults, in their application AAL technologies often raise many ethical concerns and are unable to yield tangible results. Of particular interest to this research, many questions and concerns voiced by long-term care (LTC) stakeholders (i.e. older adults, caregivers, and healthcare professionals (HCPs)) centre around ethical considerations and decisions taken when designing and developing AAL technology (Burmeister, 2016; Hlauschek et al., 2009; Hofmann, 2013; Ienca et al., 2018; Remmers, 2010; Sparrow & Sparrow, 2006; Stahl & Coeckelbergh, 2016; van Hoof et al., 2011; Wangmo et al., 2019; Zwijsen et al., 2011). Furthermore, the question of how ethical concerns with AAL technology voiced by stakeholders are addressed, remains open.

This chapter presents a Systematic Literature Review (SLR) conducted to identify LTC stakeholders' ethical concerns with AAL technology used in ageing-in-place environments. This SLR also maps the scholarly literature on methods and approaches employed during the design and development process of AAL technology to provide insight into the ethical design and engineering frameworks that are being used and developed to address stakeholders' concerns.

Based on OBJ1 and RQ1 from Chapter 1.0, this SLR aims to answer the question:

SLRQ: Have ethical design and engineering frameworks been implemented in the development of Ambient Assistive Living technologies for ageing-in-place?

For this SLR, “ethical design” and “engineering frameworks” refer to engineering frameworks that include ethical design elements throughout the framework.

2.1 Methodology

2.1.1 Initial Meta-analysis

To begin the process of conducting an SLR to answer the SLRQ, we reviewed the major SLRs available in the domains of “ambient intelligence”, “sensor technologies”, “assistive devices”, and “elderly care”. Specifically, we reviewed earlier SLRs that were peer-reviewed and published in scientific journals between 2010 – 2018. This initial meta-analysis provided a basic set of normative principles, ethical concepts and considerations, and practical opportunities and challenges of the relevant technologies. This set of principles and concepts informed the search syntax defined in the next section.

2.1.2 Defining the Search Syntax

Subgroups were then defined for the database search syntax, see Table 2-1, using terms from the initial meta-analysis to gather relevant publications. The searched databases excluded Google Scholar for reasons of questionable reproducibility of the search results (Gusenbauer &

Haddaway, 2020). Research suggests that search in full-text databases yields higher quality results (Lin, 2009). However, the tested databases with full-text search (ScienceDirect, Dimensions.ai) provided inconclusive results (the defined search syntax was too long for ScienceDirect; in Dimensions.ai, the full-text search with the defined syntax resulted in an error). For this reason, all our search queries were conducted with the defined syntax in Table 2-1 against the titles, abstracts, and keywords of the three database entries. Whenever needed, the search syntax was adjusted according to the specifications of the particular database, as shown in Table 2-2.

Table 2-1: Generic Syntax Query

Domain	Generic Syntax
Ethics	((ethical OR moral OR autonom*) AND (judgement? OR argument? OR reason* OR value? OR decision?)) OR (ethics OR morality OR normative) OR utilitarian* OR deontolog* OR virtue OR virtuous OR libertarian* OR communitarian* OR just* OR rightful* OR norm OR decision OR "policy guideline" OR "policy guidance" OR "policy recommendation" OR principl* OR regulation OR intent* OR (independen* OR dependen*) OR oversight OR accountab* OR liab* OR responsib* OR dignity OR "human right" OR ELSA OR ELSI OR "technology assessment")
Design and engineering of smart and assistive technologies	((("ambient assistive technology" OR "ambient assisted living" OR "active assistive technology" OR AAL OR telehealth OR (smart AND (environment OR home)) OR IoT OR sensor?technolog*) AND (design OR framework OR living?lab* OR fab?lab* OR ((participatory OR inclusive OR empathic OR emotional OR user?centred OR user?centered OR value-sensitive) AND design) OR (human?computer AND (interaction OR interference)) OR human?factor?))
Elderly care	("vulnerable person" OR "marginalized group" OR elderly OR ((long?term OR chronic) AND care) OR dementia OR PwD? OR resident OR frail OR ((cognitive OR physical) AND (impairment OR handicap OR frailty)) OR ageing?in?place OR aging?in?place)

Table 2-2: Database Adjusted Syntax Query

Database	Database-adjusted syntax
Web of Science URL: (https://clarivate.com)	<p>Set #1: TS=((ethical OR moral OR autonom*) AND (judgement? OR argument? OR reason* OR value? OR decision?))) OR (ethics OR morality OR normative) OR utilitarian* OR deontolog* OR virtue OR virtuous OR lib ertarian* OR communitarian* OR just* OR rightful* OR norm OR decision OR "policy guideline" OR "policy guidance" OR "policy recommendation " OR principl* OR regulation OR intent* OR (independen* OR dependen*) OR oversight OR accountab* OR liab* OR responsib* OR digni ty OR "human right" OR ELSA OR ELSI OR "technology assessment") Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=2018-2021</p> <p>Set #2: TS=((("ambient assistive technology" OR "ambient assisted living" OR " active assistive technology" OR AAL OR telehealth OR (smart AND (environment OR home)) OR IoT OR sensor?technolog*) AND (design OR framework OR living?lab* OR fab?lab* OR ((participatory OR inclusive OR empathic OR emotional OR user?centred OR user?centered OR value-sensitive) AND design) OR (human?computer AND (interaction OR interference)) OR human?factor?)) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=2018-2021</p> <p>Set #3: TS=("vulnerable person" OR "marginalized group" OR elderly OR ((long?</p>

	<p>term OR chronic) AND care) OR dementia OR PwD? OR resident OR frail OR ((cognitive OR physical) AND (impairment OR handicap OR frailty)) OR ageing?in?place OR aging?in?place) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=2018-2021 Set #4: Set #3 AND Set #2 AND Set #1 Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=2018-2021</p>
<p>Scopus URL: https://www.scopus.com/</p>	<p>TITLE-ABS-KEY (((ethical OR moral OR autonom*) AND (judgement? OR argument? OR reason* OR value? OR decision?)) OR (ethics OR morality OR normative) OR utilitarian* OR deontolog* OR virtue OR virtuous OR libertarian* OR communitarian* OR just* OR rightful* OR norm OR decision OR "policy guideline" OR "policy guidance" OR "policy recommendation" OR principl* OR regulation OR intent* OR (independen* OR dependen*) OR oversight OR accountab* OR liab* OR responsib* OR dignity OR "human right" OR ELSA OR ELSI OR "technology assessment") AND (("ambient assistive technology" OR "ambient assisted living" OR "active assistive technology" OR AAL OR telehealth OR (smart AND (environment OR home)) OR IoT OR sensor?technolog*) AND (design OR framework OR living?lab* OR fab?lab* OR ((participatory OR inclusive OR empathic OR emotional OR user?centred OR user?centered OR value-sensitive) AND design) OR (human?computer AND (interaction OR interference)) OR human?factor?)) AND ("vulnerable person" OR "marginalized group" OR elderly OR ((long?term OR chronic) AND care) OR dementia OR PwD? OR resident OR frail OR ((cognitive OR physical) AND (impairment OR handicap OR frailty)) OR ageing?in?place OR aging?in?place)) AND (LIMIT-TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018))</p>
<p>Dimensions.ai URL: https://app.dimensions.ai/discover/publication</p>	<p>(((ethical OR moral OR autonom*) AND (judgement? OR argument? OR reason* OR value? OR decision?)) OR (ethics OR morality OR normative) OR utilitarian* OR deontolog* OR virtue OR virtuous OR libertarian* OR communitarian* OR just* OR rightful* OR norm OR decision OR "policy guideline" OR "policy guidance" OR "policy recommendation" OR principl* OR regulation OR intent* OR (independen* OR dependen*) OR oversight OR accountab* OR liab* OR responsib* OR dignity OR "human right" OR ELSA OR ELSI OR "technology assessment") AND (("ambient assistive technology" OR "ambient assisted living" OR "active assistive technology" OR AAL OR telehealth OR (smart AND (environment OR home)) OR IoT OR sensor?technolog*) AND (design OR framework OR living?lab* OR fab?lab* OR ((participatory OR inclusive OR empathic OR emotional OR user?centred OR user?centered OR value-sensitive) AND design) OR (human?computer AND (interaction OR interference)) OR human?factor?)) AND ("vulnerable person" OR "marginalized group" OR elderly OR ((long?term OR chronic) AND care) OR dementia OR PwD? OR resident OR frail OR ((cognitive OR physical) AND (impairment OR handicap OR frailty)) OR ageing?in?place OR aging?in?place) Publication Year = 2018 OR 2019 OR 2020 OR 2021</p>

2.1.3 Selection Criteria

The resulting set of publications from the database search were evaluated, and primary studies were collected and used in this SLR based on the following criteria:

- *Type of publication:* The studies were published in internationally recognized peer-reviewed journals and conference proceedings, indexed in the search databases in **Error! Reference source not found.-2**. The search for relevant terms in full-text results is

a comprehensive overview of contemporary literature that goes beyond the metadata fields.

- *Date of publication*: The studies were either published or scheduled for publishing between 2018–2021 (including accepted and pre-print entries), as defined in Table 2-2 when conducting the search.
- *Relevance to the review question*: The title and abstract of the retrieved documents, following the syntax query containing the relevant search terms, were scrutinized based on the authors' relevance to the research question. A publication was deemed suitable if its text was in English and it referred to all of the following criteria: *a*) engineering and, or design application or system, *b*) elderly care (with or without any physical or cognitive impairments), and *c*) ethical or value-sensitive methodology, reflection, or evaluation of the system.
- *Relevance assessment*: The final relevance of the identified primary studies was established by reading the article. The main focus was whether and in what particular way ethical design has been implemented in the domain of assistive technologies for ageing-in-place and which engineering frameworks have been utilized during the development of such smart tools and environments.

2.2 Results

Based on the selection criteria defined above, the database queries yielded 731 publications (114 from dimensions.ai; 367 from Scopus; 250 from Web of Science). The results were qualitatively assessed following the selection criteria in two rounds, first, by checking their relevance based on the title (132 remaining items) and second, based on their abstract (44 remaining items). During this process, any duplicate items found were excluded. Three of the 44 relevant publications were unreachable with institutional access, leaving 41 relevant papers for in-depth analysis.

Figure 2.2.1 depicts the flow in which type of outlets the relevant publications are published. The highest proportion of publications target journals in the field of Computer Science, followed by Healthcare, and finally, Ageing. Most researchers represented a designer cohort, followed by healthcare professionals and computer scientists. Only a fraction of the author teams were multidisciplinary. Representatives from fields of human-computer interaction, humanities, and social sciences were in the minority. The relevant papers were concerned mainly with topics linked to older adults, followed by designers, caregivers, and HCPs.

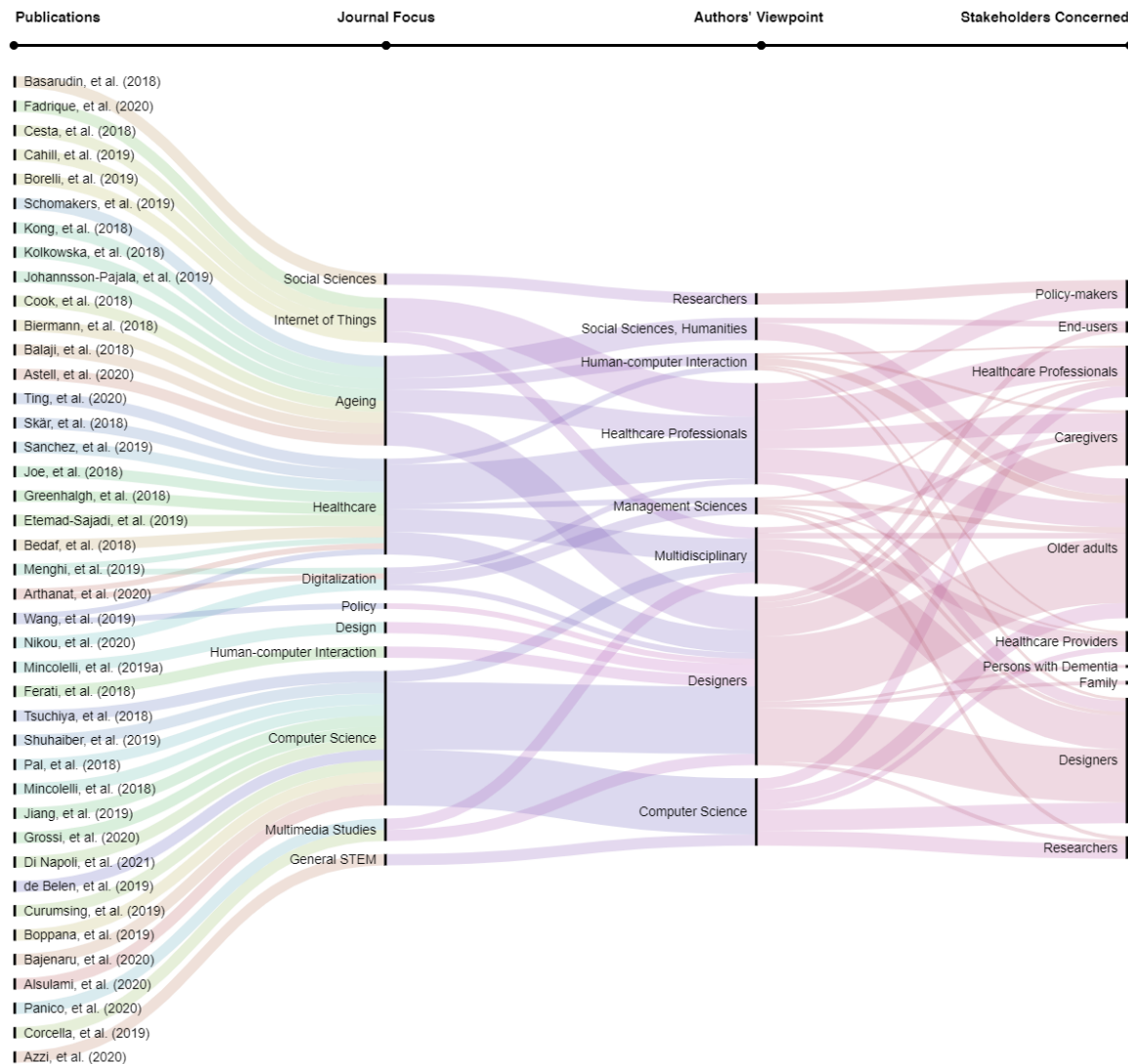


Figure 2.2.1: Alluvial Diagram of Relevant Publications, Journal Outlet Focus, Authors' Represented Viewpoint, and Targeted Stakeholders Concerned

Figure 2.2.1 also suggests that no major dedicated journal type is specific to where the respective authors from design and related fields target their publications. In addition, the stakeholders concerned are also spread throughout the various author teams and journal types, without preference for a specific stakeholder perspective or author viewpoint. Finally, while most of the papers focused their attention on designing and developing AAL technology for older adults, many of the publications focused on challenges associated with designers, caregivers, and HCPs, and not the older adult end users.

Figure 2.2.2 visualizes the occurrence of ethical concerns that emerged in the literature for AAL technology. Most of the ethical concerns in the analyzed literature are associated with social isolation and loneliness, followed by topics of autonomy, personal privacy, and

independence. A relatively high number of publications referred to data security and privacy as ethical challenges. However, a low proportion of articles mentioned informed consent, maintaining quality of life (QoL), or dignity as ethical concerns.

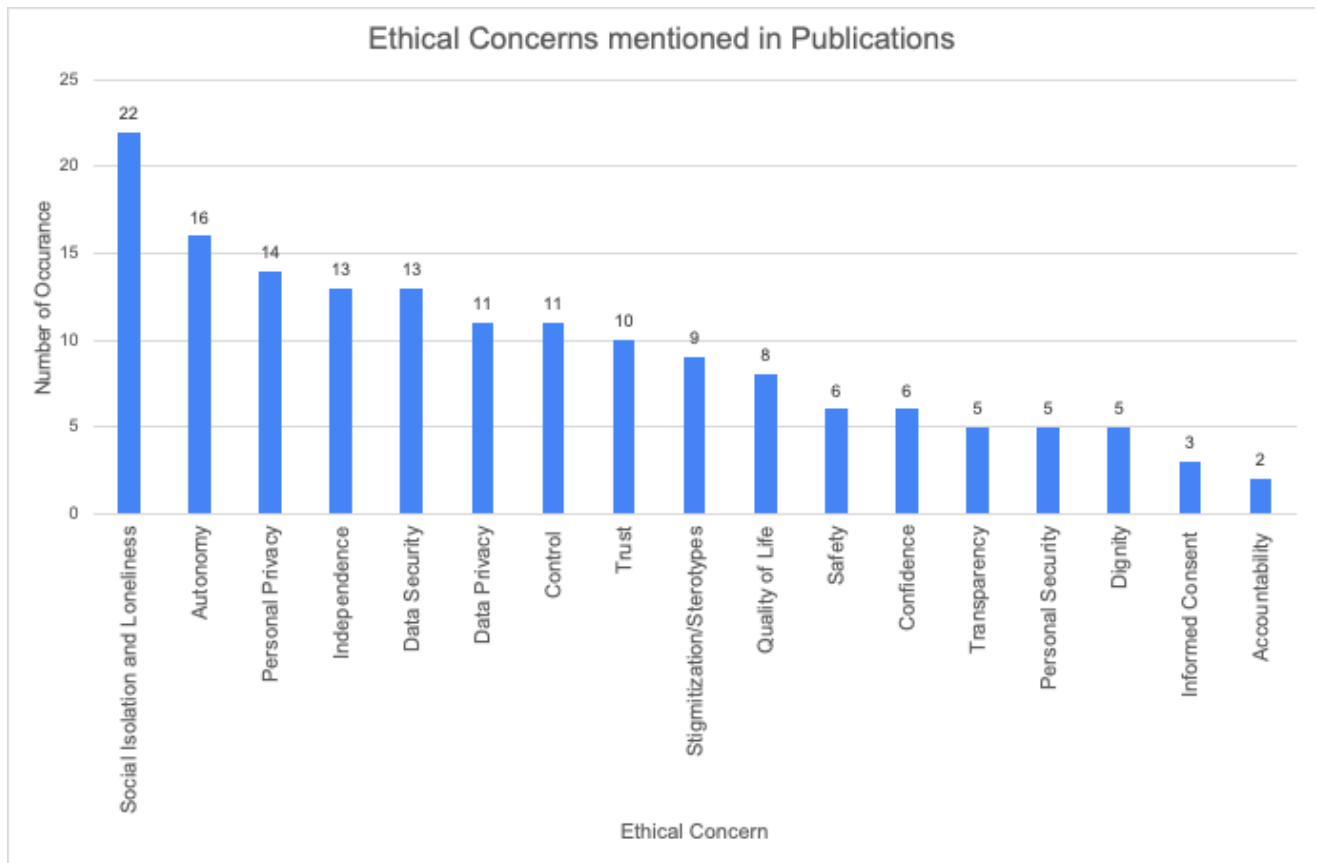


Figure 2.2.2: Clustered Column Chart showing the number of publications that mentioned different ethical concerns relating to AAL technology

2.2.1 Ethical Concerns and Findings

The reviewed literature listed multiple stakeholders’ concerns when considering AAL technology. While a large number of factors may influence a stakeholder’s reasons for adopting a technology or not (Figure 2.2.2), some authors suggest that due to the lack of user involvement throughout the design and development phases of AAL technology, many of the stakeholders’ concerns are not being understood or addressed (Fadrique et al., 2020; Kong & Woods, 2018). While AAL devices are proposed as a cost-effective and less resource-intensive approach to eldercare, Kong & Woods (2018) highlight that current technology is approached from technologists’ “*functionalist perspective*,” meaning that the critical conversation with older adults is missed, often leading to a considerable resistance against, or abandonment of, the devices when deployed.

2.2.1.1 Stereotyping

Many older adults worry that people will judge them based on their use of an assistive device, i.e., *stereotyping* (Astell et al., 2020; de Belen et al., 2019; Joe et al., 2018; Mincoletti,

Marchi, et al., 2019; Tsuchiya et al., 2018). Older adults are also fearful that by using AAL technology, such as a wearable fall detection monitor or a touchscreen health tool, they will be classified as ‘different,’ ‘dependent,’ ‘frail,’ ‘old,’ ‘weak,’ or will just look foolish when interacting with friends and loved ones (Astell et al., 2020). Such adjectives are not congruent to older adults’ self-image, as they wish to be perceived as ‘capable,’ ‘confident,’ ‘competent,’ ‘independent,’ and ‘self-reliant.’ Therefore, Astell et al. (2020), Curumsing et al. (2019), Fadrique et al. (2020), and Joe et al. (2018) point out that when a particular AAL device reinforces a stereotypical dependent ‘elderly person’ persona, older adults quickly and decisively reject the technology. This observation led Johansson-Pajala et al. (2019) to suggest that if such stereotypes manifest into crucial design decisions, AAL technology will only frustrate and upset the older adult. The research done by Joe et al. (2018) further underscored that older adults’ depictions of ideal AAL devices avoided common stereotypes. Instead, older adults desired devices that resembled inconspicuous everyday items rather than apparent health devices (Joe et al., 2018).

This finding also confirms that older adults are not fearful of technology—another common stereotype (Arthanat et al., 2020; Bedaf et al., 2018; Biermann, Hannah et al., 2018; de Belen et al., 2019; Joe et al., 2018; Sanchez et al., 2019). Older adults are not ‘too old’ or ‘too scared’ to use technology; instead, they are often eager to learn how to use it and what it could mean for the future of their care (Johansson-Pajala et al., 2019; Tsuchiya et al., 2018). Much of the hesitation that older adults have regarding AAL technology stems from a lack of confidence and experience (Biermann et al., 2018; Sanchez et al., 2019; Tsuchiya et al., 2018; Wang et al., 2019). Therefore, de Belen et al. (2019) suggest that for the successful adoption of an AAL device, it must be designed as “socially acceptable and even desirable” (p. 10) from the older adult’s perspective.

2.2.1.2 Privacy & Trust

Privacy was another commonly discussed concern among stakeholders, including older adults, caregivers, and HCPs. In general, privacy is the state of being free of observation or disruption (Merriam-Webster, n.d.). AAL devices impact privacy on two fronts, physically and digitally, and both concern older adults, caregivers, and HCPs.

Regarding *physical privacy*, stakeholders found themselves nervous and uncomfortable with the possibility of being observed or having their personal space monitored by an AAL smart camera device (Etemad-Sajadi & Dos Santos, 2019). Family members and healthcare professionals shared similar concerns when visiting the older adult (Cahill et al., 2019). The study from Biermann et al. (2018) confirmed that the placement of AAL devices significantly impacted older adults’ comfort with technology in their space. For example, devices placed in fixed locations, such as windows and light switches, were acceptable; however, devices placed in more intimate areas such as the bedroom or bathroom were rejected (Biermann et al., 2018). In the same study, older adults voiced that they preferred human monitoring to digital surveillance (Biermann et al., 2018). Similarly, Bedaf et al. (2018) found that older adults preferred interactions with a human caregiver over technology, especially for intimate tasks where privacy is often desired, such as showering or dressing.

AAL technology in ageing-in-place settings also significantly impacts *digital*, or *data*, privacy, which concerns capturing and storing personal, social, physical, and behavioural data

(Shuhaiber et al., 2019). Although eager to use the technology, many older adults are often unfamiliar with the technical terminology and capabilities of AAL devices (Shuhaiber et al., 2019). Common questions stemming from this unfamiliarity include *‘what is my data being used for?’* (Fadrique et al., 2020), *‘how is my data being stored?’*, *‘who can access my data?’* (Schomakers & Ziefle, 2019), and *‘what if someone uses my data in nefarious ways?’* (Biermann et al., 2018; Fadrique et al., 2020; Schomakers & Ziefle, 2019; Wang et al., 2019). Consequently, these concerns lead to feelings of anxiousness and discomfort with the device and the data collection, all resulting in the rejection of the technology (Shuhaiber et al., 2019).

Stakeholders’ concerns regarding trust in the technology were also reflected in privacy concerns. Both Etemad-Sajadi & Dos Santos (2019) and Pal et al. (2018) note that trust influences stakeholders’ acceptance and adoption of technology. For example, Pal et al. (2018) state that *“older adults are reluctant to share their private data with their close friends and family”*, and *“are extremely concerned and sensitive about the data that smart homes can collect...”* (p. 10). Pal et al. (2018) surmise that for stakeholders to trust the technology, they must be able to understand what is happening to the data the technology is collecting. Additionally, Etemad-Sajadi & Dos Santos (2019) discovered that the level of trust in a device impacts a stakeholder’s perception of usefulness and the degree of intrusion. For example, if older adults trust the device, they often find it very useful in their day-to-day lives and don’t find the technology intrusive. However, the opposite is true if the user considers the technology untrustworthy (Etemad-Sajadi & Dos Santos, 2019).

2.2.1.3 Autonomy & Control

Many older adults fear losing autonomy when conversations regarding AAL technology occur (Biermann et al., 2018; Cesta et al., 2018; de Belen et al., 2019; Mincolelli et al., 2018, 2019; Pal et al., 2018; Skär & Söderberg, 2018). Panico et al. (2020) describe autonomy as the ability human beings have to determine the course of their own lives. In the context of AAL technologies, *“autonomy means to ensure that the assistive devices developed for elderly care must not interfere with the will of the person they are caring for”* (Panico et al., 2020, p. 3). In Sanchez et al. (2019), older adult study participants were critical about who would make decisions regarding the technology if they were to become weaker or cognitively impaired. Participants also wondered if they would be forced to use AAL technology if their health declined, *“... sacrificing their autonomy to the economic interests of the municipality”* (Sanchez et al., 2019, p. 11). Similarly, from the study by Cook et al. (2018), some caregivers revealed that the main reason they suggested AAL technology to their older loved ones was for their own (i.e., caregiver’s) benefit, not the benefit of the older adult. Regardless if older adults use the technology due to outside influences or of their own volition, older adults are resolute that they have no qualms about rejecting AAL technology that does not maintain, improve, or respect their autonomy (Cahill et al., 2019; Corcella et al., 2019; Joe et al., 2018; Sanchez et al., 2019).

Kolkowska et al. (2018) highlight the relationship between autonomy and *control*. For AAL devices, control is seen as an empowering force and something that can quickly be taken away. Kolkowska et al. (2018) comment that AAL technology could help older adults regain or maintain control of their lives, e.g., stay on top of their health and, in doing so, have meaningful conversations with caregivers or HCPs. On the other hand, the technology could become

overwhelming, leading to older adults feeling insecure and vulnerable and as though their lives are out of their control (Tsuchiya et al., 2018). Similarly, in Biermann et al. (2018) and Curumsing et al. (2019), study participants expressed that they feared they would lose control of their lives if they became dependent on technology.

When it comes to AAL technology, older adults want the capability to make decisions about the devices, including when a device is on or off, what type of data a device is collecting, and what information is shared with other people (Biermann et al., 2018; Corcella et al., 2019; Schomakers & Ziefle, 2019). This also explains the findings from Schomakers & Zifle (2019) and Wang et al. (2019), where participants state that control is vital for their privacy preservation.

Just as with autonomy, older adults also want to maintain their independence. Panico et al. (2020) define independence in terms of AAL devices as *“the device supporting users in functioning socially and in solitude without constant intervention from other human carers”* (p. 3). Many older adults see independence as an influential factor in their QoL and consider it an essential facet of ageing well (Astell et al., 2020; Cesta et al., 2018; Nikou et al., 2020). In the literature, older adults expressed their desire to remain independent for as long as possible, avoiding becoming a burden on their family members or the healthcare system (Astell et al., 2020; Cesta et al., 2018; Nikou et al., 2020). In the study by Arthanat et al. (2020), the researchers conclude that independence and safety are correlated after finding that independence positively affects home safety. When investigated further, researchers discovered that the older adults who believed an AAL device could provide them with independence found their living spaces safer than devices that offered no independence or less independence than they previously had (Arthanat et al. 2020).

2.2.1.4 Isolation, Loneliness, Human Care

Finally, one of the most significant concerns noted throughout the literature was the social isolation and loneliness that could stem from using AAL technology in ageing-in-place settings. Curumsing et al. (2019) define social isolation as a *“lack of structural and functional support”* and loneliness as a *“perceived absence or loss of companionship”* (p. 10). The authors stress that while these terms are often interchangeable, they are not identical. Social isolation can be circumstantial or a chosen path, while loneliness is involuntary (Curumsing et al., 2019).

Some researchers propose that AAL technology can combat social isolation and loneliness for older adults. They do this by explaining that the technology may ease the burden and stress on caregivers and HCPs so that they can spend more time with their loved ones or patients (Arthanat et al., 2020; Etemad-Sajadi & Dos Santos, 2019; Joe et al., 2018; Johansson-Pajala et al., 2019; Nikou et al., 2020). Grossi et al. (2020) also note that social participation is a crucial element of ageing well. This was demonstrated by Bajenaru et al. (2020), who found that older adults with no social contact did little to no physical activity and were in a poor emotional state, likely leading to negative consequences they experienced with their health and QoL. The insight from Grossi et al. (2020) is even more important when considering a finding by Jiang et al. (2019), where the researchers discovered that as an older adult’s ability to participate in social events decreases, their desire to take part is often stronger than those who can participate.

Even though older adults and other stakeholders show interest and excitement for AAL devices, many still fear that the technology could cause social isolation and loneliness (de Belen

et al., 2019). From Cahill et al. (2019), all older adult participants shared the concern that introducing AAL technology into their lives could reduce human contact and promote an inferior quality of care. For many older adults described in the literature, the idea of technology replacing humans in their care was unpopular (Biermann et al., 2018; Cahill et al., 2019; Cesta et al., 2018; Corcella et al., 2019; Curumsing et al., 2019; de Belen et al., 2019; Sanchez et al., 2019; Tsuchiya et al., 2018). Both Cesta et al. (2018), and Sanchez et al. (2019), found that older adults much preferred the idea of human care to technological care. This finding caused Cesta et al. (2018) to recommend that *“technical solutions should not replace human contact, rather they should be seen as a means to foster and promote human communication and support”* (p. 8). In the study of Bedaf et al. (2018), while caregivers and half of the participants rejected the idea of a care robot attending to older adults, the remaining half of older adults surveyed said they preferred to receive support from the robot; the willingness of which increased with the likelihood of requiring more intensive care in future (Bedaf et al., 2018). Therefore, AAL technology should meet the communication need but not cut off all other avenues of contact between older adults and other stakeholders such as caregivers and HCPs.

2.2.1.5 Acceptability, Heterogeneity of Needs

All the concerns discussed above impact stakeholders' willingness to use, accept, and adopt AAL technology. For stakeholders, such as older adults, caregivers, and HCPs, the concerns listed above are only a fraction of what may impact their willingness to accept or adopt AAL technology into their lives. As Biermann et al. (2018) and Sanchez et al. (2019) discovered, older adults often decide to use assistive technology when they believe it's necessary for their health and safety. This reflects similar statements from Arthanat et al. (2020), Bedaf et al. (2018), Biermann et al. (2018), and Sanchez et al. (2019) that older adults see the value of assistive technology but want very little to do with it until it is necessary for them, likely due to many of the concerns mentioned above. Jiang et al. (2019) suggest that while older adults generally accept the idea of assistive technologies, they are more willing to try a device than adopt it. This led the researchers to note that *“designers should pay attention to the different attitudes of the different groups of older [adults] towards different assistive technologies and pay attention to distinguish [different] users”* (Jiang et al., 2019, p. 10). This quote highlights the idea that older adults are not homogeneous (Skär & Söderberg 2018).

In the same way that older adults have concerns about accepting and adopting AAL technology, other stakeholders (i.e. caregivers and HCPs) have concerns of their own. For instance, as discussed in Greenhalgh et al. (2018), for caregivers and HCPs an introduction of AAL technology into an older adult's life means not only will the family members or HCPs need to learn how to use the technology, but they may also have to accept changes in their identity as a primary caregiver. Some caregivers or HCPs may not see themselves as 'technology savvy' but now have to interact with technology regularly, or they may go from the primary caregiver who helped with every task to someone who is no longer required as a constant presence in the older adult's care (Greenhalgh et al., 2018). The technology may also stress caregivers and HCPs, change their care role, or, in the case of HCPs, threaten their jobs (Greenhalgh et al., 2018). As mentioned above, family members and HCPs can considerably influence older adults to use, accept, and adopt assistive technology. This means that just as designers and engineers

need to take in the considerations and concerns of older adults, they also must factor in the considerations and concerns of other stakeholders, like caregivers and HCPs.

As seen above, AAL technology raises many ethical concerns amongst stakeholders. Therefore, it is crucial to identify and address these concerns to enable stakeholders to be comfortable with AAL technology and consider using, accepting, and adopting it into their day-to-day lives with dignity.

2.2.2 Frameworks from the Literature Review

This section concentrates on the ethical design and engineering frameworks used and proposed to develop AAL technology. AAL technology has been developed for over a decade (Sparrow & Sparrow, 2006), and many framework proposals have been suggested to assist the design and development process. As such, ethical design and engineering frameworks for AAL technology are meant to guide engineers, computer scientists and designers to consider *“ethical recommendations as a standardization process to strengthen bridges between theory and practice”* (Panico et al., 2020, p. 10). Therefore, based on the SLRQ, this review aims to scrutinize suggested ethical design and engineering frameworks by learning more about their creation, implementation, and impact. In conducting this overview, contributions can be made by evaluating the current ethical design and engineering frameworks and providing insight for future development.

Figure 2.2.3 displays two charts. The pie chart on the left represents the number of publications that implemented ethical design and engineering frameworks for AAL technology. The stacked bar chart on the right breaks down the frameworks that were discussed in the publications. The bar on the left shows the number of existing frameworks (blue) compared to the number of new frameworks proposed in a publication (orange) that discussed designing and developing AAL technology. The bar on the right shows the number of existing frameworks (blue) compared to the number of newly proposed frameworks from a publication (orange) that were used to design and develop new AAL technology.

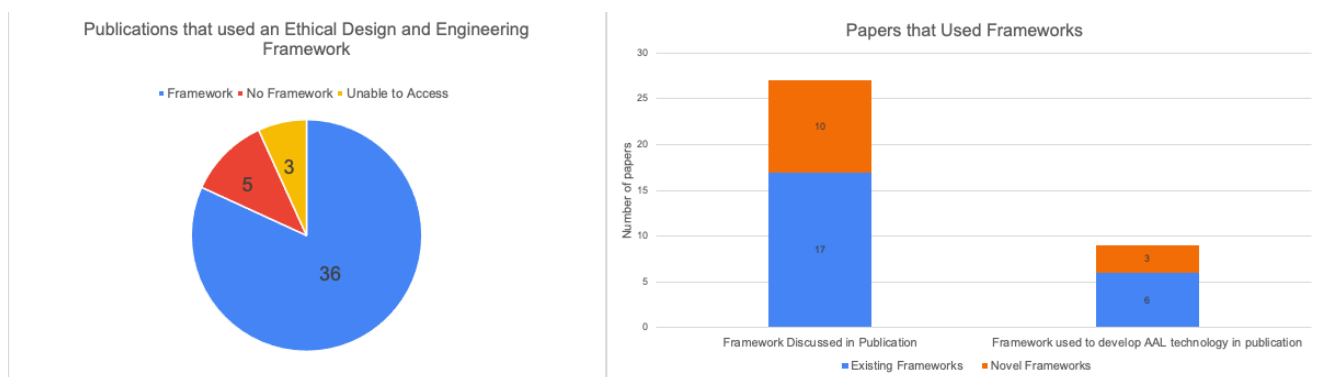


Figure 2.2.3: Pie Chart representing the number of publications that used and didn't use ethical design and engineering frameworks and a stacked bar chart showing the number of publications that discussed and used existing and novel frameworks to develop AAL technology

As seen in Figure 2.2.3, the collected literature breaks down into existing and novel frameworks discussed and used to develop new AAL technology. Many of the existing frameworks mentioned in the literature consist of User-Centered Design (UCD) (cited 6 times),

Participatory Design (PD) (5), the Technology Acceptance Model (TAM) (3), Co-Design and Person-Centred Design (2). In contrast, the remaining existing frameworks were discussed in one publication each. For novel frameworks, manipulations of UCD and PD along with the Quality Function Deployment (QFD) tool were the most popular, while the remaining novel frameworks were discussed in the publication they were proposed in. Of the 44 publications collected, 36 referenced one or more ethical design and engineering frameworks, where ten proposed novel frameworks and nine used a framework to develop new AAL technology (six using known frameworks and three using novel frameworks), as seen in Figure 2.2.3.

Though the papers proposing novel frameworks represent a relatively small percentage (23%), the shift towards developing new ethical design and engineering frameworks for AAL technology indicates that researchers are becoming increasingly aware of the high ethical rigour required for developing these technologies. It also shows that researchers are beginning to push the boundaries to ensure that future AAL technology is designed to meet stakeholders' ethical concerns. This was most noticeable in publications that proposed new frameworks by adapting or expanding on known frameworks, such as User-Centered Design (Kolkowska et al., 2018) and the Technology Acceptance Model (Etemad-Sajadi & Dos Santos, 2019; Kolkowska et al., 2018; Pal et al., 2018; Shuhaiber et al., 2019). Furthermore, the publications that modified known frameworks to propose novel frameworks did so in such a way that the frameworks were explicitly geared towards ageing-in-place stakeholders and AAL technology, rather than being a general use framework.

Appendix A presents a comprehensive analysis of each ethical design and engineering framework that was used in this SLR.

2.2.2.1 Existing Ethical Frameworks and Design Methodologies

2.2.2.1.1 User-Centered Design

From the literature collected, the most used ethical design and engineering framework for AAL technology for ageing-in-place settings is User-Centered Design (UCD). As defined by Bajenaru et al. (2020), a *"User-Centered methodology is used to gain an understanding of what the user really wants and needs, and which features can be accepted by"* the user, in this case older adults (p. 5). Once a user's needs are identified, they can be translated into *"development requirements for a technology"* (Bajenaru et al., 2020, p. 1). The UCD framework ensures the involvement of users in the design process, as *"User-Centered Design strives to develop technology-based on users' potential use, desires, or needs, rather than focusing on users to adapt their behaviour or needs according to the technology"* (Skär & Söderberg, 2018, p. 5). Johansson-Pajala et al. (2019) further highlight that *"early and ongoing user involvement has been recognized as one of the principles that is particularly important in healthcare technology"* (p.12). Additionally, Cesta et al. (2018) emphasize UCD's role for technology development, which can substantially impact usability and accessibility for older adults.

The UCD framework has three phases for gathering user needs and requirements: 1) identify and select users (e.g. older adults); 2) interact with users, so information about their needs can be obtained through workshops, surveys, questionnaires, or focus groups; 3) evaluation, where the user needs from phase two are transformed into design requirements for the technology (Bajenaru et al. 2020; Borelli et al. 2019).

However, UCD does present challenges. UCD relies on the idea that stakeholders share their needs and desires with researchers. If stakeholders share nothing, researchers may be at a loss regarding what stakeholders need or desire in AAL technology. Conversely, if they share too many or drastically different needs, it can be hard to accommodate everyone (Johansson-Pajala et al., 2019; Menghi et al., 2019). Furthermore, the needs of stakeholders are determined by the people participating in the conversation, which can lead to participant bias in the results. The needs and desires of the UCD participants may fail to address the needs and desires of an entire group of people that the technology will affect (Johansson-Pajala et al., 2019; Tsuchiya et al., 2018).

2.2.2.1.2 Participatory Design

The second most referenced framework from the literature is Participatory Design (PD), also called co-design. PD is *“a cooperative design process, with a focus on enabling different stakeholders with different perspectives and competencies to cooperate.”* (Ting et al. 2020, p.3). PD attempts to bridge the gap between technical- and human-oriented approaches to technology design as a way to consider and decide how best to include human-centered concerns in technology (Ferati et al., 2018). The PD approach highlights the idea that ATs should be looked at for more than just their technical functionality. Factors such as the user’s needs and the overall experience should be considered since many elements will influence technology acceptance and adoption (de Belen et al., 2019).

Rather than starting with a proposed solution, a PD framework requires researchers, engineers, and designers to start by engaging stakeholders as a means of uncovering their needs with the understanding that they are the people who will be most affected by the new AAL technology (Borelli et al., 2019; Curumsing et al., 2019; Mincoelli et al., 2019). The identified needs then feed into an iterative design and development cycle until a satisfactory prototype is achieved (de Belen et al., 2019). While ensuring active user involvement (Ting et al., 2020; Wang et al., 2019), this design process shifts away from designing *for* the users to designing *with* the users, making older adults and other stakeholders co-designers of the technology (Mincoelli et al., 2019; Ting et al., 2020).

PD methodologies can accommodate a variety of approaches during the R&D process, e.g. large group discussions (Corcella et al., 2019; de Belen et al., 2019; Ting et al., 2020) or visual exercises (Ferati et al., 2018; Joe et al., 2018). For example, Ferati et al. (2018) used cartographic mapping, future workshops, and cultural probes to have participants visualize interacting with proposed AAL devices in the future to elicit their needs and concerns. Similarly, Joe et al. (2018) used the 6-8-5 method to have participants work individually to generate 6–8 ideal AAL devices, before sharing them for 5 minutes with a larger group, then repeating the process, leading to rapid idea generation.

Of the publications that used PD to develop a technology (Bedaf et al., 2018; Corcella et al., 2019; Ferati et al., 2018; Joe et al., 2018; Ting et al., 2020), the majority of the feedback from stakeholders regarding the final product was positive. Ferati et al. (2018) note that PD helped the researchers learn that participant priorities and needs were mainly in the bathroom and kitchen areas. The researchers state that PD enabled them to work with participants to identify their issues and how they could be overcome with new AAL devices. Corcella et al. (2019) comment that after two rounds of iteration, participants saw value in the technology

and found it easy to use. Participants were also proud of the product they were able to co-create (Ting et al. 2020).

On the other hand, in a study conducted by Bedaf et al. (2018), where researchers introduced stakeholders to a service robot which performed tasks in a home environment, such as fetching a glass of water or turning off the light, stakeholders' opinions were more skewed. While stakeholders were positive about the idea of the service robot and had no complaints about its technical performance, it lacked critical interaction capabilities, such as being able to hold conversation. Caregivers also had concerns about social isolation for their loved ones (Bedaf et al. (2018). These remarks confirm the importance of involving stakeholders from the beginning of the design phase instead of mid-way through the design process.

PD's prominence in much of the literature is due to its benefits for everyone involved. The PD framework provides a way to "*explore the opportunities and challenges that are inherent to the development of an assistive technology*" (de Belen et al., 2019). PD provides a platform for older adults and other stakeholders, such as caregivers and HCPs, to have their voices heard and to generate collaborative discussions with other stakeholders (Bedaf et al., 2018; Corcella et al., 2019; de Belen et al., 2019; Ting et al., 2020). For those tasked with designing and developing AAL technology for ageing-in-place settings, PD offers an invaluable glimpse into a stakeholder's everyday life and how the technology will impact them.

PD has its own set of challenges. For PD, the research must be conducted in such a way as to elicit stakeholder thoughts, opinions, and concerns while still balancing technical capability. This may mean that value tensions, or an imbalance between two or more values, arise between what stakeholders ask for versus what technology can achieve (de Belen et al., 2019; Joe et al., 2018).

2.2.2.1.3 The Technology Acceptance Model and the Unified Theory of Acceptance and Use of Technology Model

Other known frameworks discussed in the literature are the Technology Acceptance Model (TAM) and the Unified Theory of Acceptance and Use of Technology (UTAUT) model. The TAM describes the two characteristics that influence a user's (behavioural) intention and attitude towards using technology: a) usefulness; and b) ease of use (Arthanat et al., 2020; Biermann et al., 2018; Etemad-Sajadi & Dos Santos, 2019). Biermann et al. (2018) was the only publication reviewed that used the TAM to develop a technology from the collected literature. Following the TAM, the authors developed a deep understanding of how participants—older adults—felt about using ultrasonic whistles in their environments. With the help of TAM, researchers uncovered user preferences for its use, subjective (dis)comfort about their desired placements of the technology, and factors influencing their intention to use these devices (Biermann et al., 2018). While the TAM and UTAUT model are prevalent and can be applied to various situations, they do face criticism that even though they address critical aspects of decision-making regarding technology adoption, the understanding as to why the rejection of technology still occurs is lacking (Astell et al., 2020). As is discussed with some of the novel frameworks down below, some researchers believe that the TAM and UTAUT model do not go far enough to investigate the various factors that influence technology acceptance, especially for older adults (Astell et al., 2020; Etemad-Sajadi & Dos Santos, 2019; Pal et al., 2018; Shuhaiber et al., 2019).

2.2.2.1.4 The Capabilities Approach

The final established framework present in the reviewed literature is the Capabilities Approach (CA). Just as with the TAM and UTAUT model, the CA can be applied to explain older adults' intention to use AAL technology (Nikou et al., 2020). The CA states that resources, such as AAL technology, give people the freedom to live their lives in ways that they find valuable, and capabilities refer to the opportunities, such as autonomy, that one is afforded by those resources (Nikou et al., 2020). Nikou et al. (2020) argue that older adults decide whether or not to use AAL technology by considering how the technology will enhance their capabilities to live their lives in ways that are valuable to them. The CA has similarities to both the TAM and UTAUT model as all three models have similar outcome expectations where they attempt to explain an older adult's intention to use AAL technology (Nikou et al., 2020). However, while the TAM and UTAUT model consider outcome expectations regarding whether the technology can enable specific tasks or activities to be performed, the outcome expectations for the CA focus on whether or not the technology will allow people to live their lives in ways that are meaningful to them (Nikou et al., 2020).

Just as with the frameworks and models before it, the CA faces its own set of challenges where, most notably, selecting relevant capabilities can be non-trivial and often involve normative assumptions that can lead to various outcomes (Nikou et al., 2020).

2.2.2.2 Novel Ethical Frameworks and Design Methodologies

Ten of the reviewed publications proposed their own ethical design and engineering frameworks. Many of these new frameworks build upon well-known frameworks mentioned above (Alsulami et al., 2020; Azzi et al., 2020; Etemad-Sajadi & Dos Santos, 2019; Pal et al., 2018; Shuhaiber et al., 2019).

Etemad-Sajadi & Dos Santos (2019) and Shuhaiber et al. (2019) propose modified versions of the TAM, while Pal et al. (2018) suggest a modified UTAUT model. In all three cases, the researchers add additional factors into the model that may influence a user's (behavioural) intention and should therefore be considered while developing AAL technologies. While Shuhaiber et al. (2019) took a more general approach to modify the TAM to include factors such as personalization, cost, and availability, both Etemad-Sajadi & Dos Santos (2019) and Pal et al. (2018) included factors that they believe are specific to the acceptance of AAL technologies for older adults. For example, in addition to the two TAM factors mentioned previously, Etemad-Sajadi & Dos Santos (2019) also incorporated the factors of social presence, trust, and the degree of intrusiveness. For the modified UTAUT model, Pal et al. (2018) suggest the original factors of performance and effort expectancy, social influence, and facilitating conditions are extended to include technology anxiety, perceived trust, perceived cost, and expert advice.

Both modified TAM proposals share trust and privacy as being vital for increasing the usefulness and ease of use of technology (Etemad-Sajadi & Dos Santos, 2019; Pal et al., 2018), stating that *"trust and privacy are central requirements for the implementation of such technology in private spaces"* (Etemad-Sajadi & Dos Santos 2019, p. 4). Additionally, Etemad-Sajadi & Dos Santos (2019) further highlight the degree of intrusiveness in their modified TAM, which, they note, is inversely related to trust.

Alsulami et al. (2020), also inspired by TAM, created a decision-making framework to help map the influences when adopting AAL technology. Their framework suggests 14 factors, grouped into four dimensions, that influence technology adoption. These factors with their respective dimensions are: a) Human (Training, User Acceptance, Awareness, Resistance, Motivation, Culture); b) Technology (Privacy, Security); c) Organization (Strategy, Processes, Infrastructure, Availability, and Lack of Information); and d) Business (Cost) (Alsulami et al. 2020).

In contrast, other studies suggest new frameworks based on ideas from previously mentioned frameworks, like UCD and TAM, but with different objectives (Di Napoli et al., 2021; Greenhalgh et al., 2018; Kolkowska et al., 2018). Di Napoli et al. (2021) propose the Normed-Quality of Service framework, which generates and suggests assistive technology personalized to specific groups of individuals rather than offering a general technology meant for everyone. Using this approach, the authors expect increased user satisfaction and technology acceptance (Di Napoli et al., 2021). Similarly, Greenhalgh et al. (2018) propose the Non-adoption or Abandonment of technology by individuals and difficulties achieving Scale-up, Spread and Sustainability (NASSS) framework. The NASSS framework was developed to help encourage complex thinking about technological innovations and their adoption by understanding domains such as technology, the health/care organization, and continuous adaptation over time (Greenhalgh et al., 2018).

Kolkowska et al. (2018) propose the User-Centered Ethical Assessment (UCEA) framework, developed to evaluate the ethical consequences of user-centered aspects of AAL technology. The authors of UCEA took inspiration from two previously proposed frameworks—the Norrlandicus method and the Ethical Value Matrix proposed by Nordgren (Kolkowska et al., 2018). The Norrlandicus method is an elderly-centered assessment method, while the Ethical Value Matrix supports identifying ethical, moral and practical values that are important stakeholders (Kolkowska et al., 2018). The resulting UCEA framework can be used to “*support the evaluation of the ethical consequences as a part of user-centred [sic] aspects*” (Kolkowska et al., 2018, p. 6). The authors also note that the addition of the Ethical Value Matrix makes it possible to record the favoured values of involved stakeholders to ensure that the resulting design and development process is in line with their core values. With the UCEA framework, Kolkowska et al. (2018) believe that techno-centric development can be prevented by seeing the system in relation to the stakeholders’ values and expected results. Furthermore, the UCEA framework allows for greater transparency and traceability, enabling developers to keep note of which values were realized or not, influencing decisions so that they can be made with a focus on the benefits for stakeholders. Even though Kolkowska et al. found many benefits with their framework, they also pointed out a limitation, noting that *value tensions* arose in some situations where “*some of the values were in conflict with each other*” (Kolkowska et al., 2018, p. 11). However, in response to this, the authors note that “*by being able to visualize the conflict, the developers are given an opportunity to find a solution to satisfy both values*” (Kolkowska et al., 2018, p. 11).

Three publications from the collected literature developed their own ethical design and engineering frameworks along with a technology based on the newly proposed framework. Two of these publications, by Borelli et al. (2019) and Mincoletti et al. (2019), discuss the framework

developed by a multi-group project (the HABITAT project¹) and the technologies that were developed using that framework. Using the new framework, HABITAT aimed to create five new AAL devices combining UCD, PD, and a decision-making tool called Quality Function Deployment (QFD) (Borelli et al., 2019; Mincoielli et al., 2019). The QFD tool *“compares the emotional and qualitative user needs with measurable characteristics of the product, identifying the most important technical parameters that must be used for the final product”* (Mincoielli et al., 2019). As the study participants completed activities that helped identify their needs concerning AAL technology, five QFD matrices were created for each proposed device to identify the significant needs for the device in question. The correlation between the selected needs and measurable product characteristics produced a technical assessment of the importance of every technical feature for each device (Mincoielli et al., 2019). The final results were then used to determine the design guidelines for each of the five device prototypes (Mincoielli et al., 2019). In all, by combining UCD, PD and the QFD tool, the researchers collected, analyzed, compared, and proposed design guidelines for proposed prototypes (Borelli et al., 2019; Mincoielli et al., 2019).

Of the five devices developed using the UCD, PD, and QFD framework, all personal evaluations of the devices were largely positive (Borelli et al., 2019; Mincoielli et al., 2019). Participants, consisting of 19 older adults, declared that they were satisfied with the devices, enjoyed interacting with them (Mincoielli et al., 2019), and had a high level of acceptance for using the devices in their day-to-day lives (Borelli et al., 2019). An interesting finding for one of the devices, a wearable recognition tag, was that while it was acceptable to participants, it was the least-favourable device out of the five. Participants commented that they found it bulky and noticeable (Borelli et al., 2019; Mincoielli et al., 2019). Through the collected literature, it was observed that older adults are reserved when it comes to wearable devices, a finding that is explored further in the discussion section of this chapter.

The publication by Curumsing et al. (2019) also proposes a new ethical design and engineering framework called the Emotion-Oriented Engineering framework. It describes a new technology called the SofiHub, an AAL platform for older adults, created using the novel framework. The Emotion-Oriented Engineering framework comprises three different models: a) the Role Model; b) the Emotional Model; and c) the Goal Model. The role model is meant to *“identify key user roles in the system”* (Curumsing et al., 2019, p. 4). Key user roles may include older adults, family members, healthcare professionals, etc. The emotional model *“captures the role’s pain points and translates them into threats and a set of functional, quality and emotional goals”* (Curumsing et al., 2019, p. 7). Functional goals look at the task at hand, quality goals look at how the task should fit into the role’s life, and emotional goals look at how the role should feel regarding the task. In this model, functional goals should be determined first once the threat has been identified, and quality and emotional goals are ascertained afterward (Curumsing et al., 2019). Finally, the Goal Model is a visual representation of the role and emotional models using different shapes and colours to identify the key users (the roles), the emotional threats the users see or anticipate in the system, and the functional, quality, and emotional goals that are meant to address the emotional threats.

¹ <http://www.eng.habitatproject.info/home>

Overall, the authors found that by using the Emotion-Oriented Engineering framework, SofiHub was successful with older adults who tested it over many weeks. Overall, *“SofiHub was shown to successfully address the target users’ key emotional goals. In particular, SofiHub made its users feel safe, supported, cared about, reassured, reduced their loneliness, and the technology integrated well into their lives”* (Curumsing et al., 2019, p. 10). In general, older adults were excited about having SofiHub installed in their homes and were confident in their ability to use the technology (Curumsing et al., 2019). Furthermore, they felt that as time went on, they were more comfortable with SofiHub in their space, so much so that some participants complained when it was time to remove the technology (Curumsing et al., 2019).

However, while the Emotional-Oriented Engineering framework was a success for older adults, the engineers and designers tasked with implementing the framework struggled, stating that *“the framework is insufficient in self-guiding through the design and development phases to ensure emotional goals are met”* (Curumsing et al., 2019, p. 13). This finding led the authors to suggest that the models in the Emotional-Oriented Engineering framework could be *“applied and further extended to create a set of design guidelines and heuristics to guide designers in their tasks”* (Curumsing et al., 2019, p. 13).

2.3 Discussion

The purpose of conducting this research was to provide insight into OBJ1 and RQ1 by answering the SLRQ, *“Have ethical design and engineering frameworks been implemented in the development of Ambient Assistive Living technologies for ageing-in-place?”* This research confirms that various established and novel ethical design and engineering frameworks are implemented in developing AAL technologies for ageing-in-place

Therefore, in the remainder of this section, we reflect on the most important recognitions and gaps in the literature that were identified during this analysis.

2.3.1 Notable findings for AAL technology and Older Adults

While many ethical concerns were identified through this research, an interesting finding that emerged was the concern older adults had about being stereotyped when using AAL technology. This concern was especially apparent when older adults discussed wearable AAL technology.

As noted above, wearable AAL devices raise interesting concerns for many older adult participants in some of the collected publications (Astell et al., 2020; Joe et al., 2018; Mincolelli, Marchi, et al., 2019). While many participants see the advantages of AAL devices, they have little desire to wear them if the device makes them look weak or dependent in front of family, friends, or acquaintances. Mincolelli et al. (2019) demonstrate this point in their study, where participants approved of the wearable recognition tag; however, it was ranked the least favourable out of the five devices presented. Much of the criticisms came from the fact that the device itself was noticeable—its large size would draw the eyes of onlookers and make the wearer feel uncomfortable or judged for wearing it. This finding made the study by Joe et al. (2018) especially relevant, where older adult participants were encouraged to imagine their ideal wearable AAL devices. The findings shared by Joe et al. (2018) showed that all the ideal

devices resembled inconspicuous everyday items (e.g., a watch, a lamp, a tablet) that would not indicate that the older adult had medical issues in their daily life.

These findings also relate to the study done by Astell et al. (2020), who note that older adults do not want to be seen as dependent or someone who needs help from technology to go about their daily lives. Instead, many older adults who require the assistance of AAL technology would prefer if it was something unassuming that would not draw attention to its use.

The concern that older adults have about being stereotyped when using AAL technology is interesting because it suggests that frameworks should be more detailed in their approach to understanding stakeholders' concerns with AAL technology. For example, a framework like the TAM, which looks at the usefulness and ease of use of technology, would likely be unable to identify stakeholders' stereotyping concerns. Therefore, ethical design and engineering frameworks that are proposed for the design and development of AAL technology should be able to uncover and address the ethical concerns that stakeholders have with a proposed technology, as their concerns will ultimately impact their decision to accept, and adopt, or reject the technology.

As one of the devices investigated in this research is a wearable device (the Hexoskin ProShirt™), it was important to explore older adults' concerns present in the literature, so that a better understanding of the concerns could shape the research conducted after the completion of the SLR (Chapters 3.0 and 4.0).

2.3.2 Incremental Need for Ethical Design and Engineering Frameworks

As seen in Figure 2.2.3, of the 41 papers reviewed, only five publications did not use an ethical design and engineering framework in their work. Moreover, almost 30% of the papers that discussed an ethical design and engineering framework proposed modified versions of existing frameworks specifically for AAL technology (Figure 2.2.3). This statistic indicates that researchers are becoming more aware of the ethical rigour that AAL technology requires if it is to be accepted and adopted by ageing-in-place stakeholders, including older adults, caregivers, and HCPs. It also suggests that design and engineering frameworks may benefit from customization to effectively capture and address the needs of particular stakeholders in particular use contexts, such as LTC or ageing-in-place. Moreover, this SLR identified 13 publications introducing novel ethical design and engineering frameworks for AAL technology. The introduction of these new frameworks also supports the idea that researchers are growing more aware of the ethical considerations that AAL technology requires for LTC or ageing-in-place settings.

2.3.3 Limited Testing and Lack of Standardized Comparative Measures of Efficacy

The result of this research shows that although many different research groups have proposed novel ethical design and engineering frameworks for ageing-in-place AAL technology over the decades, the frameworks receive little post-study attention. For example, from the collected literature, only one of the newly proposed ethical design and engineering frameworks has been investigated in a multi-centre setting—the reason was the researchers' membership in the same research consortium.

Once a framework is presented, there is little evidence that the framework is used in follow-up research to validate the initial claims, nor is there evidence to suggest that the framework is used to develop an AAL technology elsewhere to see if the new technology meets stakeholder needs and expectations. Therefore, this leads to unnecessary framework fragmentation, with few having anything to recommend them but the original author's claims.

Furthermore, this lack of follow-up validation makes it hard to ascertain the limitations of each framework as many authors will comment about what benefits the new framework brings rather than discussing its challenges or downsides. A notable exception to this is Curumsing et al. (2019), where a lengthy discussion section not only highlights the benefits that the newly proposed ethical design and engineering framework gave to the new AAL technology but also discussed the challenges and pitfalls the framework raised when developing the new technology.

This review did not find any large-scale studies in which AAL technologies were tested in clinical trials across larger cohorts (e.g. 1000+ participants). This research reveals that many of the frameworks and design approaches were explored by a small number of participants, leading to a small data collection, which may limit the potential findings for future AAL technology. While the small number of participants alludes to the fact that participant recruitment can be very challenging, especially with older adults, such studies are desirable considering the global societal challenge of ageing societies. Older adults are often keen to participate in research studies, which they perceive as an additional socializing opportunity, potentially alleviating their loneliness (Grönvall & Kyng, 2013). In addition, further studies may also shed light on questions of AAL technology efficacy, where there is a lack of more profound insights into the potential placebo effects of AAL technology (Novitzky et al., 2019).

2.4 Summary

This SLR provides an investigation into some of the concerns that ageing-in-place stakeholders' have with AAL technology. This SLR also investigated the ethical design and engineering frameworks that have been proposed to identify, understand, and address stakeholders' concerns through the design and development of AAL technology.

Throughout the collected literature, stakeholders expressed many ethical concerns regarding AAL technology. Overall, social isolation, autonomy, privacy (personal and digital), independence and control made up the top six most-discussed concerns among older adults, caregivers, and HCPs.

Therefore, these ethical concerns will be implemented in research with long-term care facility (LTCF) stakeholders in Chapter 3.0. This research will test these six ethical concerns to see if they are still concerns when evaluating two new AAL devices, the Hexoskin ProShirt™ and the AWS DeepLens™.

From the 44 publications collected and 41 publications reviewed, 36 publications (88%) discussed or proposed an ethical design and engineering framework in their research. Additionally, six publications used an ethical design and engineering framework to develop new AAL technology, and three publications developed a new ethical design and engineering framework and used the new framework to develop a new AAL technology. While small, the number of papers that use an ethical design and engineering framework to develop new AAL

technology shows that researchers are becoming aware of the ethical demands that AAL technology requires if it is to be accepted and adopted by ageing-in-place stakeholders.

However, a caveat to the number of new ethical design and engineering frameworks proposed for designing and developing AAL technology, is that while a framework may be introduced and explained in a publication, there seems to exist little follow-up research aimed at validating such frameworks. Additionally, participant cohorts tend to be quite small in the studies proposing a new framework, and/or developing new AAL technology based on it. This means that data collection is limited, and findings are hard to generalize.

Therefore, a PD methodology was chosen to conduct research with LTCF stakeholders in the next chapter as it is adaptable and has shown promising results with ageing-in-place stakeholders.

3.0 Investigating Additional Ethical Stakeholder Issues with Ambient Assistive Living (AAL) Technologies – A Participatory Design Approach

Conducting the Systematic Literature Review (SLR) presented in Chapter 2.0 provided a better understanding of the ethical concerns that Long-Term Care (LTC) stakeholders (i.e., older adults, caregivers, and healthcare professionals (HCPs)) have with current AAL technology. The SLR also introduced and investigated the various ethical design and engineering frameworks that are used to address stakeholders' ethical concerns with AAL technology during the design and development process.

In this chapter, I report on further investigations into ethical issues that LTC stakeholders have with AAL devices. As this research involves different groups of stakeholders, a Participatory Design (PD) methodology was chosen to conduct research with participants. This methodology was used to better understand participants' ethical concerns with the Hexoskin ProShirt™ and the AWS DeepLens™, two of the five AAL devices from the PATH device suite.

3.1 Purpose of the study

This research aimed to verify the ethical concerns identified from the SLR discussed in Chapter 2.0, as well as uncover additional ethical concerns that LTC stakeholders have with two AAL devices: the Hexoskin ProShirt™ and the AWS DeepLens™, seen in Figures 3.1.1 and 3.1.2, respectively. As introduced in Chapter 1.0, the Hexoskin ProShirt™ is a wearable device that collects the wearer's vital sign data, and the AWS DeepLens™ is a deep-learning enabled video camera.



Figure 3.1.1: Hexoskin ProShirt™ from Men (left) and Women (right)



Figure 3.1.2: Front (left), Side (middle), and Back (right) view of AWS DeepLens camera™

By having a better understanding of stakeholder concerns with the devices mentioned above, engineers and designers can develop AAL technology that addresses stakeholders' concerns so that they will have an easier time using, accepting, and adopting future AAL technology that uses these devices. Therefore, to better understand stakeholders' ethical concerns with the Hexoskin ProShirt™ and the AWS DeepLens™, a Participatory Design (PD) methodology was utilized to conduct workshops and interviews with different groups of stakeholders at a regional long-term care facility (LTCF).

As discussed in Chapter 2.0, PD is a cooperative, iterative design process that encourages stakeholders with different perspectives and abilities to work together on a task (de Belen et al., 2019; Ting et al., 2020). PD starts at the very beginning of the design and development process and shifts the narrative from 'designing *for* the users' to 'designing *with* the users' (Mincolelli, Imbesi, et al., 2019; Ting et al., 2020). In taking this approach, researchers, engineers, and designers have a much better understanding of stakeholders' thoughts, opinions, and concerns with the proposed technology (Borelli et al., 2019; Curumsing et al., 2019; Mincolelli, Imbesi, et al., 2019). Furthermore, PD can be implemented in many settings, from being used in group conversations (Corcella et al., 2019; Ting et al., 2020), to being used to develop group activities (Ferati et al., 2018; Joe et al., 2018). In this research, PD was used in workshop activities and interviews with LTCF stakeholders to elicit their ethical concerns with the Hexoskin ProShirt™ and the AWS DeepLens™.

The results of this study will be used to prototype and propose an ethical design tool called an Ethical DataSheet (EDS). The EDS is intended to be a tool for engineers, designers, or other interested parties, to use before developing new AAL technology so that they can understand the ethical concerns that LTC stakeholders have with a device before the device is

used in a more complicated technology. The process of researching and prototyping the EDS is explained in Chapter 4.0.

3.2 Study Participants

As explained in Chapter 1.0, this research is a part of an initiative to develop AAL technology for ageing-in-place settings. To do this, each PATH member institution collaborates with an LTCF in their region. Participants included in this study were from different stakeholder groups in the affiliated regional LTCF, who would be the most impacted by new AAL technology. The LTCF in this research offers two types of accommodations for older adults, apartments and LTC. The apartments are where *tenants* live. Tenants are older adults living at the facility who are relatively independent, meaning they require little additional assistance from the HCPs working at the LTCF. However, if tenants do require assistance, they have access to various features offered by the assisted living program at the facility, such as support with meals, personal care, house cleaning, and medications. Conversely, LTC is where *residents* live. Residents are older adults living in long-term care who require partial to total assistance from the LTCF HCPs. Tenants and residents comprise two of the four stakeholder groups who participated in this research.

The third stakeholder group included as a part of this research were caregivers. Caregivers are family members or close friends of residents or people living in LTC.

The final group included in this research was the LTCF HCPs. As the facility employs many different types of HCPs, this research focused HCPs whom the device would impact if a tenant or resident was to use it. Therefore, HCPs for this research consisted of nurses, registered practical nurses, therapists, and Personal Support Workers (PSWs).

3.3 Study Design and Methodology

It is well documented that working with an older adult population is challenging due to obstacles such as interest, availability and access, resident capacity and cognitive abilities, and time commitment (Beeson et al., 2014; Boaz et al., 2018). Therefore, to design the workshops and interviews with the identified stakeholder groups mentioned above, a Participatory Design approach was implemented from the beginning of the study design. PD was used to collaborate with the LTCF research coordinators to better understand the various stakeholder needs and requirements when conducting research with them. Through meeting with the LTCF research coordinators the decision was made to conduct interactive workshops with tenants, given that tenants are capable of more interactive participation. At the same time, individual interviews would be held with residents, caregivers, and HCPs. This decision was made based on guidance from the research coordinators about stakeholders' availabilities, attention span, cognitive abilities, mobility constraints, workload, and COVID-19 protocols. Based on recommendations, two one-hour workshops were held with tenants (one workshop per device), 20-minute interviews were held with residents and caregivers, and 5 to 10-minute interviews were held with HCPs. At the LTCF where this research took place, there are two buildings for tenants: Building A and B. To accommodate tenant interest, the workshop in Building A looked at the Hexoskin ProShirt™, while the workshop in Building B investigated the AWS DeepLens™.

In developing the study design, inspiration was obtained from a PD methodology (Ballard et al., 2019) titled *“Judgement Call The Game”* (referred to here as ‘Judgement Call’). This methodology aims to have participants think and reflect on the ethical considerations for an AI technology they are developing and how the technology will affect different stakeholders. This is done by roleplaying as a stakeholder who is directly or indirectly impacted by the technology in question, reflecting on their concerns by writing out a product review, and providing a rating of the technology as their stakeholder character. At the end of the round, participants are encouraged to converse with other participants who are roleplaying as different stakeholders. By the end of the game, multiple rounds will have occurred, allowing participants to have played as different stakeholders and to have considered various ethical principles in relation to their product and how the product may impact the stakeholder characters. As the authors note, *“Together, [the reviews] paint a more holistic picture by providing multiple perspectives on the same technology”* (Ballard et al., 2019, p. 3).

After reading through Judgement Call and playing through the methodology, similar elements were used to develop the methods used for this research. However, they were adapted to fit the purpose of this research. For example, in Judgement Call, the authors used ethical principles to investigate stakeholder concerns relating to a device. For this research, instead of using the principles identified in Judgement Call, six of the ethical concerns identified in the Systematic Literature Review (SLR) from Chapter 2.0 were used as a starting point to engage stakeholders in learning more about their ethical concerns with the Hexoskin ProShirt™ and the AWS DeepLens™.

The six concerns were meant to inspire conversation and questions from participants in the workshops and interviews that would lead to new insights or ethical concerns that participants had with the Hexoskin ProShirt™ and the AWS DeepLens™. The six ethical concerns are identified and described below:

1. Personal Privacy: the control one has over their physical self or space
2. Data Privacy: the control one has over information that is personal to them
3. Autonomy: the ability to make decisions for oneself
4. Independence: one’s ability to complete a task without help from others or technology
5. Social Connectedness: the experience of feeling close or connected to others; it is a sense of belonging to a social relationship
6. Comfort: the state of physical ease and relaxation

It should be noted that while comfort was not one of the top six ethical concerns identified in the SLR, I believed that for the two devices under study, comfort was an interesting ethical question. In the SLR, wearable devices and cameras were recurring topics of conversation and were not very popular with older adult participants. Therefore, the hope was that exploring comfort with LTCF stakeholders would provide more insight into why wearable devices and cameras were not as favoured by older adults compared to other AAL technology.

For the tenant workshops, each ethical concern was printed on a card (Figure 3.3.1), with questions on the back to help stakeholders facilitate conversation (Figure 3.3.2).



Figure 3.3.1: Examples of the ethical concern cards used in the workshops with tenants

For the interviews with residents, caregivers, and HCPs, the researchers followed a semi-structured interview format to ask participants questions about their thoughts on the ethical concerns in relation to the device.

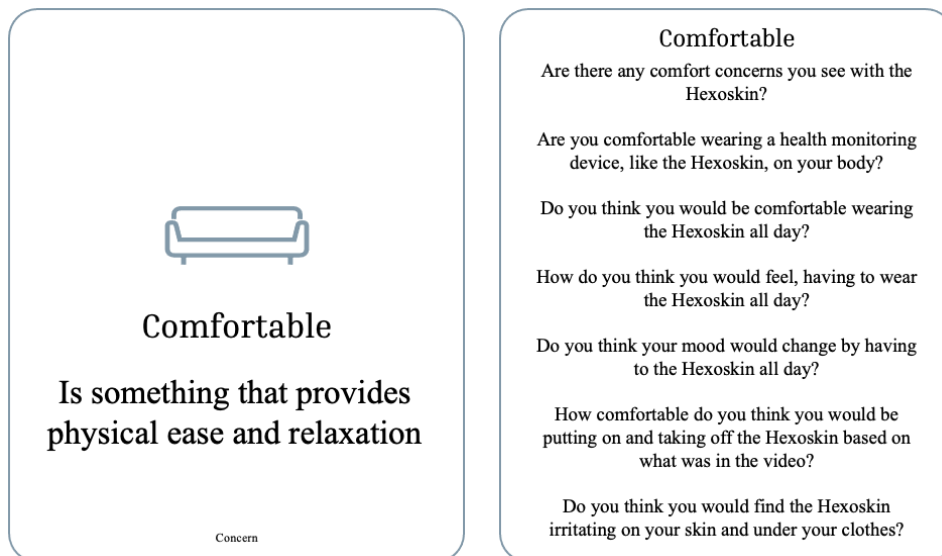


Figure 3.3.2: Front and back of the ethical concern card for Comfort for the Hexoskin ProShirt

To obtain a quantitative value of what participants thought of the device as a whole, while keeping in mind the ethical concerns that they had discussed, at the end of the workshops or interview, participants were asked to rate the device they looked at on a scale from 0, meaning the participant could see no redeeming qualities with the device, to 5, meaning participants would use the device immediately if they had the opportunity. For the workshops, tenants were asked to rate the device for each ethical concern card that they looked at, meaning there were six ratings per device from the workshops. The overall ratings for each device are examined later in this chapter (see Section 4.6.12) and are revisited in Chapter 4.0 when discussing the Ethical Datasheet Prototype.

3.4 Participant Recruitment

Tenant recruitment for this research began as soon as Research Ethics Board (REB) approval was received. Tenant recruitment was conducted in two stages in both apartment buildings (A and B). The first stage consisted of hanging posters around the tenant living quarters, drafting an email for the research coordinators to send to the tenant group email list, and posting an article in the monthly tenant newsletter. The second stage is when researchers visited tenants at the LTCF during their “coffee hour”—a social gathering held regularly during the week. During this visit, researchers went over the purpose of the research, described what tenants would be asked to do if they participated, and answered any questions the tenants had. During this visit, researchers also went through the Informed Consent Form approved by the REB and collected any signed documents from tenants willing to participate in the research. In total, 14 tenants were recruited: ten from Building A and four from Building B. Each workshop was scheduled to run for 1 hour.

To recruit residents and caregivers, the help of the LTCF research coordinators was needed. The recruitment of residents and caregivers was a joint effort between the LTCF coordinators and the researchers. Coordinators were responsible for identifying potential residents and caregivers who might be interested in participating in the research. Once identified, the researchers spoke to each resident and caregiver to give them an introduction to the study and what they would be asked to do if they were to participate. Following this, the lead researcher then went through the informed consent document with the resident or caregiver. In total, six residents and two caregivers were recruited. The two devices were split evenly among participants, meaning three residents participated in an interview about the Hexoskin ProShirt™, and three looked at the AWS DeepLens™. Similarly, one interview with a caregiver focused on the Hexoskin ProShirt™, and the other, the AWS DeepLens™. Each interview with residents and caregivers was scheduled for twenty minutes.

Finally, the recruitment of the LTCF HCPs ran similarly to the recruitment of tenants. Just as with tenants, recruitment was done in two stages. The first stage was to hang posters around the LTC side of the facility, as well as to draft an email that the LTCF research coordinators sent to the group HCP email. The second stage occurred when the researchers attended the HCP monthly meeting to inform HCPs about the research, let them know what they would be asked to do if they participated, and answer any questions the HCPs had about the study. In total, eight HCPs were interviewed, consisting of two RNs, one RPN, two therapists, and four PSWs. As with residents and caregivers, the two devices were split evenly among participants. Therefore, four HCPs participated in an interview about the Hexoskin ProShirt™, and the remaining four looked at the AWS DeepLens™. Each interview with an HCP was scheduled for no longer than 10 minutes, but it could be shorter if they needed to tend to something else.

3.5 Data Collection – Workshops and Interviews

In line with a PD methodology, it was decided that the best way to engage different stakeholders would be to hold interactive workshops with tenants, while residents, caregivers, and HCPs would participate in individual interviews.

The data collection process for the different stakeholder groups is described in the following three sections.

3.5.1 Data Collection Process for Tenants

To begin the workshops with tenants, participants were invited to have coffee and donuts as soon as they entered the room the workshop was held in. Once all tenants arrived, introductions were made. All participants and researchers were asked to introduce and share a fun fact about themselves. This small activity allowed tenants to settle in, familiarize themselves with participants they did not know, and become more comfortable with the researchers.

After the introductions, the researchers explained the workshop's purpose and what tenants would be asked to do during the workshop. Researchers also reminded tenants that they would be audio recorded throughout the workshop, as was explained in the Informed Consent Document. Following the instructions, tenants were shown a short video about the device their workshop would focus on (the Hexoskin ProShirt™ for Building A and the AWS DeepLens™ for Building B). As the physical devices were not available to bring into the LTCF, the video was meant to be a device showcase allowing tenants to see the device, learn more about its characteristics, and what it does when turned on. After the video finished, tenants were given a moment to ask any clarifying questions about the video or the device itself. After all questions were addressed, the researchers provided the tenants with the instructions for the interactive activity.

To start the activity, the researchers presented the tenants with a scenario of the device that was the focus of their workshop. The scenario was critical as the devices were entirely new for tenants, so the scenario was meant to give tenants an idea of how the device may fit into their lives if they were asked to use it for research purposes or if they were to adopt it into their daily routines. The scenarios used for this research can be found in Appendix B.

Once the researcher finished reading the scenario, the interactive activity began. For the Building A workshop, tenants were divided into two groups (5 people per group) due to the number of participants. Each group discussed three ethical concerns and how they saw the ethical concern relating to the Hexoskin ProShirt™. For Building B, since there was a smaller number of tenants participating, all tenants remained together and discussed each ethical concern card as it related to the AWS DeepLens™.

To start the interactivity activity, all ethical concern cards (Figure 3.3.1) were placed into a box. One participant was asked to draw a card for their group to discuss. This was done twice for building A, once for each sub-group, and once for building B. Participants were encouraged to use the questions on the back of the concern card (Figure 3.3.2) if they did not know how to start their conversation. Each group was also given blank cue cards and markers to write down concerns, ideas, thoughts, or opinions as they arose throughout the discussion. Additionally, the researchers were close by if the tenants had any questions.

After each discussion, each tenant was asked to provide a rating for their opinion of the ethical concern in relation to the device. Tenants were asked to rate the device for the ethical concern from 0, meaning they saw no positives with the device with regard to the ethical concern, to 5, meaning the tenants believed the device addressed the ethical concern completely. Once ratings were collected, a new tenant was asked to draw a new ethical concern card from the box, and the activity continued until all six cards were drawn and discussed by participants.

After the final ethical concern card was discussed, a small debrief session was held with all participants. This was an important element for the tenants in Building A because it allowed both groups to see the ethical concerns that the other group discussed and talk about commonalities between the two groups and any new insights or concerns that came out of the smaller group discussions.

To end the workshops, the researchers provided more detail about what the data collected from the workshops would be used for. In doing this, researchers introduced tenants to the concept of the ethical design tool that would be created using the data collected through the interactive activity. While explaining the ethical design tool, researchers also displayed all the cue cards that were used throughout the exercise (Figure 3.5.1.1), grouped by ethical concern, to give tenants an idea of how their comments, thoughts, opinions, and concerns would be utilized to create the EDS.

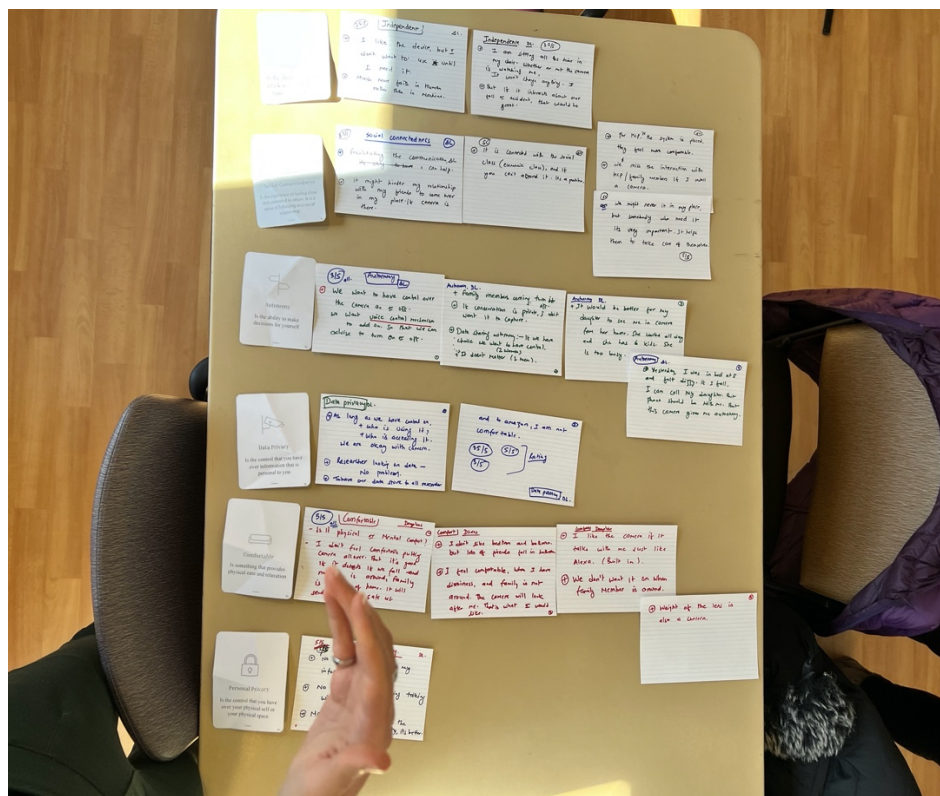


Figure 3.5.1.1: Cue Cards from tenants after AWS DeepLens Workshop

To finish the workshop, tenants were encouraged to comment their thoughts on the idea of the EDS, anything they believed should be included in such a tool, or to ask or share any remaining questions or opinions.

3.5.2 Data Collection Process for Residents and Caregivers

Interviews with residents and caregivers started similar to the workshops with tenants. To begin, the researchers provided a quick introduction to the research and its purpose. They also reminded the resident or caregiver that they would be audio recorded.

Researchers began by playing the video for the device that was the focus of the interview (the Hexoskin ProShirt™ or the AWS DeepLens™). Researchers then provided the residents or caregivers with a scenario so that they could picture the device as a feature in their lives. Following the scenario, the researchers began a semi-structured interview process. Using a semi-structured interview methodology allowed researchers to ask participants questions while also allowing residents and caregivers to ask their questions, bring in new thoughts or ideas, and voice any additional concerns with the device that had not been touched upon. The interview questions were the same questions found on the back of the ethical concern cards used for the workshops with tenants, each focusing on the identified ethical concerns from the SLR.

To conclude the interview, the researchers asked the residents and caregivers to provide a rating (from 0-5) for the device. Just as with tenants, this rating was meant to get residents and caregivers to reflect on the conversation and the ethical concerns that were discussed, and then provide a rating that reflected the benefits or concerns they could see with the device if it was introduced in their or their loved ones' lives.

3.5.3 Data Collection Process for Healthcare Professionals

The interviews with HCPs were similar to those with residents and caregivers, conducted in a shorter timeframe. To begin, researchers quickly reminded HCPs about the purpose of the research and that the interview would be audio recorded. The video for a device was played so HCPs could learn more about the device and its capabilities. The main difference between interviews with residents and caregivers and HCPs was that a scenario was not provided during the interviews with the HCPs, due to the nature of their profession and time constraints.

After the video finished, the researchers moved directly to the semi-structured interview, asking HCPs questions once again allowing the HCPs to ask questions and raise new thoughts, ideas, or concerns relating to the device.

To conclude the interview, HCPs were asked to provide an overall rating of their thoughts on the device, just as was done with residents and caregivers.

3.6 Data Analysis from Participatory Design workshops and Interviews

All collected data, i.e., the audio recordings and cue cards, were transcribed into text and uploaded into NVivo, a qualitative data analysis software. In NVivo, the data was prepared so that it was ready to be used for different data analysis methods.

A variation of the Grounded Theory approach was utilized throughout the data collection and analysis stages. The objective of using Grounded Theory in this research was to evaluate how stakeholders responded to the ethical concerns used in the workshops and interviews (i.e., deductive research), as well as to discover new ethical concerns that emerged from the conversations (i.e., inductive research) (Ruhi, 2021), (Corbin & Strauss, 1990). Thus, the focus of this qualitative work was not on developing a new theory about the technology or concerns, but rather on unearthing new thematic issues—ethical concerns that stakeholders expressed regarding the technologies. An essential element of Grounded Theory is how interconnected the data collection, and analysis stages are (Ruhi, 2021), (Corbin & Strauss, 1990). This means that data collected from the workshops and interviews were analyzed to

observe known or new findings (i.e. themes such as ethical issues or concerns). If new findings emerged through the analysis, they were tested in the next round of data collection to see if other stakeholders had similar thoughts or if the new findings were unique to specific stakeholder groups or people.

Additionally, two types of content analysis techniques were used: Direct Content Analysis and Emergent Content Analysis. Direct Content Analysis validates or extends hypotheses or existing theories, while Emergent Content Analysis allows new categories to flow from the collected data (Ruhi, 2021). Therefore, Direct Content Analysis was used to identify any data related to the six ethical concerns derived from the SLR, while Emergent Content Analysis was used to identify new concerns from the data.

Direct and Emergent Content Analysis were used across three stages of data coding: open coding, axial coding, and selective coding. During open coding, codes were created to label the transcribed data, such as 'cost,' 'fear of isolation,' and 'concerned about personal privacy.' During axial coding, key codes and concepts of interest were identified, and the data were grouped together into more substantial themes. In axial coding, phrases such as 'Control,' 'Device Characteristics,' and 'Use without Help' emerged. Finally, in selective coding, central concerns were created, and all existing codes were grouped under the new concerns. In selective coding, similar themes such as 'Personal Privacy,' 'Independence,' and 'Social Connectedness' re-emerged, along with new themes like 'Device Design' and 'Economic Distribution.'

The remainder of this section presents the selective and axial codes identified and created during the data analysis process using NVivo, along with the results of how tenants, residents, caregivers and HCPs from the LTCF felt about each code for each device. In total, 12 selective codes were created, and 35 axial codes were grouped into the selective codes for both the Hexoskin ProShirt™ and the AWS DeepLens™.

3.6.1 Autonomy

As defined above, autonomy is the ability to make decisions for oneself. Through the data analysis, autonomy was grouped into four axial codes: Behaviour, Caregiver or Institution Access, Control, and Informed Consent. These subcategories are defined in Table 3-1.

Table 3-1: Axial codes for autonomy concern

Axial codes for autonomy	Definition
Behaviour	Do the stakeholders believe that the device would change their actions
Caregiver or Institution Access	If the caregiver or institution had access to the data collected from the device, would that alter an older adult's actions (e.g. if the Hexoskin ProShirt™ notes that a person's heart rate is relatively high during their walk, their loved one might ask them to stop walking because it stresses their heart, or if the DeepLens™ records the end-user eating potato chips when they were advised to stop so the caregiver intervenes to prevent them from eating potato chips)
Control	Do stakeholders believe the device would impact the amount of choice or decisions older adults have in their life
Informed Consent	How stakeholders feel about what they know about the Hexoskin ProShirt™ or AWS DeepLens™ and their ability to make decisions regarding it

Each axial code was broken down further to identify stakeholders' benefits and concerns with each code (Figures 3.6.1.1.1 and 3.6.1.2.1).

3.6.1.1 Autonomy in relation to the Hexoskin ProShirt™

For the Hexoskin ProShirt™, the tenant and resident stakeholders had the most to say about the codes in autonomy (Figure 3.6.1.1.1).

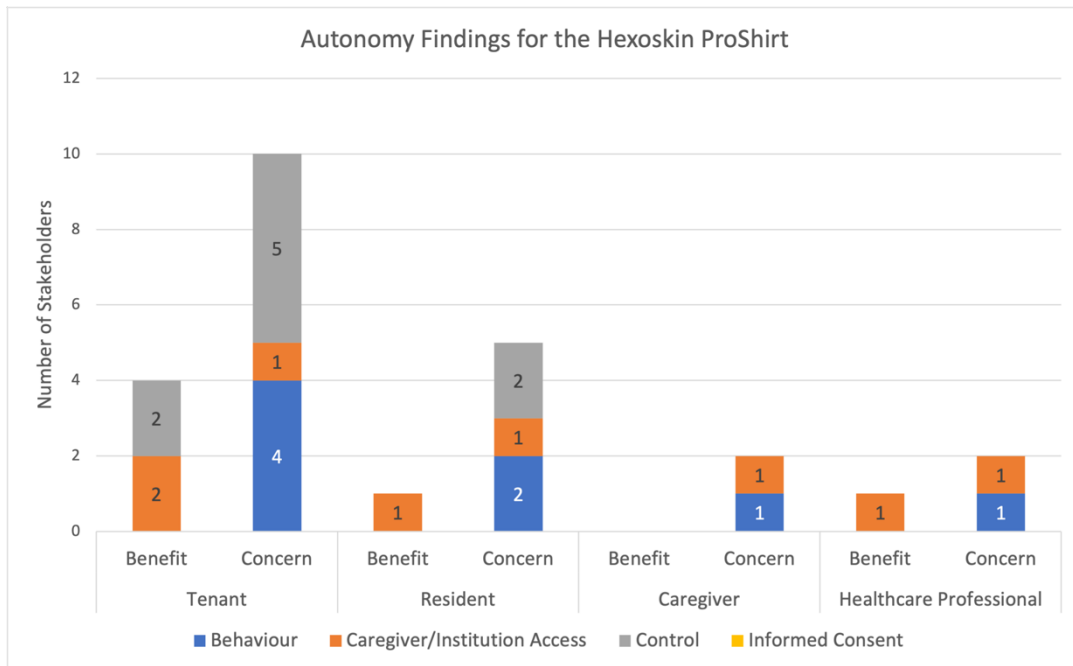


Figure 3.6.1.1.1: Autonomy subcategory benefits and concerns from tenants, residents, caregivers and HCPs for the Hexoskin ProShirt™

For tenants, benefits with the Hexoskin ProShirt™ for autonomy were seen in the Caregiver or Institution Access and Control codes. Two out of ten tenants in this group saw benefits with their caregivers or the LTCF having access to their data. For example, one tenant commented, *“your physician or the healthcare provider could have access to it to monitor it and see your data.”* Additionally, benefits were also seen for control, where two out of ten tenants saw the Hexoskin as a way to keep or bring control back into their lives. According to one tenant, *“If I had something like this, I could venture more outside and do more things.”* However, some tenants also had control concerns. Five out of ten tenants commented on how the shirt may negatively impact their control, with one tenant saying, *“It’s my information. I should have control over it.”* Similarly, concerns regarding how the shirt may negatively impact their behaviour were also noted, with fears that it may change their daily routines, with one tenant commenting, *“Well if you have to wash your clothes every day, it becomes a frustration.”*

Residents also had concerns that the Hexoskin ProShirt™ would impact their control. For example, two out of three residents commented about how the device might affect their control of their lives, *“It should be my choice to wear it to sleep or not.”* Additionally, two out of three residents also had concerns that their behaviour would have to change if they used the Hexoskin ProShirt™, with one resident voicing concerns like, *“Is it going to get caught on my elbow every day? Every time I move? Is it going to be there where I try and bend at the waist a little bit?”*

The caregiver had concerns about how the Hexoskin ProShirt™ may impact their loved one's behaviour and how they might impact their loved one they were given access to the data.

Similarly, two out of four HCPs also had concerns about the Hexoskin ProShirt™'s impact on behaviour and how the older adult might be impacted if caregivers or the LTCF were given access to the data collected by the shirt.

Interestingly, Informed Consent was not discussed among any of the stakeholder groups for the Hexoskin ProShirt™.

3.6.1.2 Autonomy in relation to the AWS DeepLens™

For the AWS DeepLens™, tenants, residents, and HCPs all had concerns regarding two or more of the axial codes for autonomy, as seen in Figure 3.6.1.2.1 below.

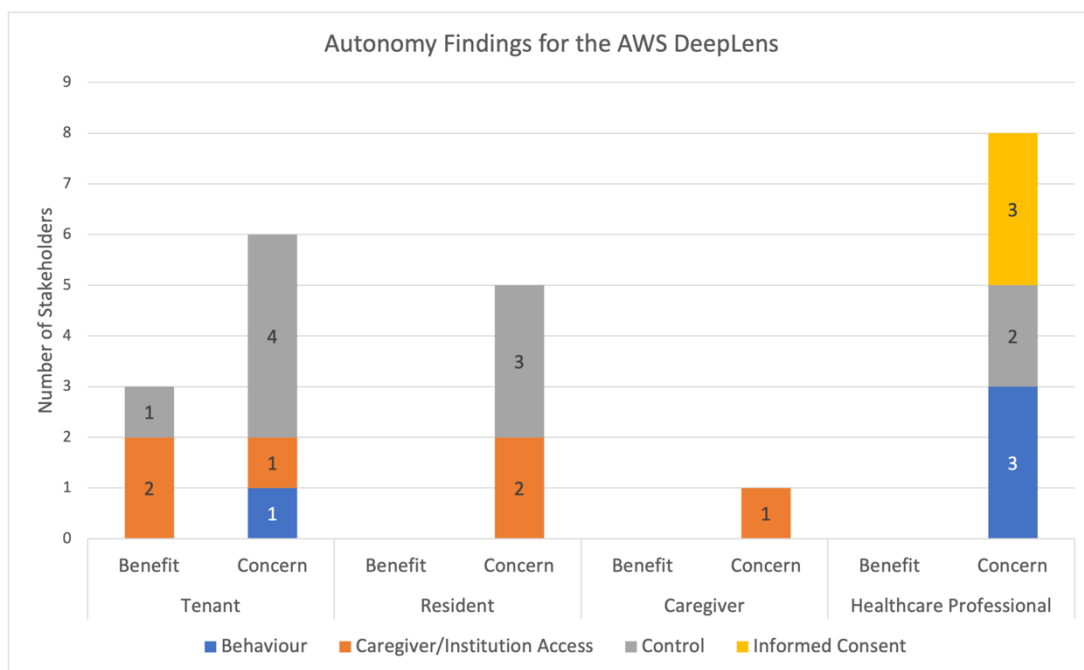


Figure 3.6.1.2.1: Autonomy subcategory benefits and concerns from tenants, residents, caregivers and HCPs for the AWS DeepLens™

For tenants, benefits and concerns were present for autonomy when considering the AWS DeepLens™. Two of four tenants saw benefits to sharing the data collected by the camera with their caregivers or with the LTCF. They believed that if their caregivers or the LTCF had access to the data collected, then the caregiver or the facility could check in on them to make sure that they were okay at any given time. In the words of one tenant, *“For my caregiver, who does things for me, it would be nice for them to see that I’m okay.”* Another tenant noted that their caregiver had a young child at home, so giving them access to the data would allow the caregiver to check-in and then focus back on other tasks. This comment is interesting because it supports a point discovered in the SLR- older adults do not want to impose or be a burden to their family or friends.

Conversely, tenants also had concerns regarding their autonomy and the AWS DeepLens™, with three out of four tenants raising concerns with the control subcategory. This

area of the conversation revolved around tenants wanting to be able to control the camera—from being able to turn it on or off, deciding what data could be collected and used, or being able to make the call whether or not events detected in their data required further investigation by a third party (e.g. a HCP or caregiver). Three out of four tenants indicated that they wanted to be able to control when the camera was on or off, as there were some events that they did not want the camera recording, such as taking care of personal needs in the bathroom. One tenant noted that even if they could turn the camera on or off, they still wanted to review all of the footage captured before it was used for research so that they could eliminate any additional data they did not want used. Another finding similar to the SLR was that one tenant noted that they wanted to be the one to decide what the camera did if something were to happen to them while the camera was recording. For instance, if the camera was running a fall detection model and the tenant fell while the camera was recording, the tenant wanted to control whether or not the camera followed through with its programming to contact their caregiver or the LTCF to say that they had fallen. In their explanation, the tenant said that if it wasn't a severe accident, they did not want to bother anyone, *"I'm on the Assisted Living program, but not that often, and I don't bother the girls, but I don't bother the girls unless something drastic happens."*

All residents interviewed about the AWS DeepLens™ had concerns with the control subcategory and their ability to choose when the camera was on or off at any given time. For example, residents did not want the camera catching certain moments in their daily routine, such as care with HCPs or when they were sleeping.

Overall, HCPs had the largest number of concerns for autonomy with the AWS DeepLens™. Three out of four HCPs showed concerns about informed consent with the camera, and three out of four HCPs also worried about changes in behaviour. For informed consent, HCPs noted that they should have to sign an informed consent document before helping any resident who would be using the AWS DeepLens™, as their faces would also be recorded due to the nature of the care that they provide. One HCP expressed this by saying, *"We should almost have a consent too, that we don't mind being on camera, or having our pictures stored in the cloud. I really don't want my face out there if I didn't give my consent to allow it to be out there."* For behaviour concerns, HCPs were worried that a camera might change how comfortable a resident would be in their own environment. Some HCPs also spoke about how they use elements of their own lives to build up trust with the residents they are caring for so that residents will hopefully open up to them and let HCPs know when they are uncomfortable or in pain throughout their care. But with the use of the camera, HCPs weren't sure how comfortable they would be sharing elements of their own lives if they were recorded. As one HCP commented, *"If there is a camera, I wouldn't be comfortable sharing all of these things about my life, trying to get the resident to open up to me."*

3.6.2 Comfort

As defined previously, comfort is the state of physical ease and relaxation. In the analysis, comfort was grouped by nine axial codes: Amount of Time, Big Brother (i.e., surveillance), Company Integrity, Convenience, Explaining the Device, Location, Mindset, Time of Day, and Wearing the Device. These codes are defined in Table 3-2.

Table 3-2: Axial codes for comfort concern

Axial codes for comfort	Definition
Amount of Time	How long stakeholders think the device should be running or collecting data
Big Brother	If stakeholders believe they would feel like someone was monitoring their every move with the device
Company Integrity	How comfortable stakeholders feel with the companies that produce the devices
Convenience	How easy stakeholders see the devices fitting into their lives
Explaining the Device	How comfortable stakeholders would feel if they had to explain why they were using the device to someone else
Location	How stakeholders feel about where the device is placed in their apartment or room (more for the AWS DeepLens™)
Mindset	If the devices would give stakeholders peace of mind (benefit) or anxiety (concern)
Time of Day	If stakeholders would prefer to use the devices at certain times during the day or year
Wearing the Device	How comfortable older adults would feel wearing the device (applicable to the Hexoskin ProShirt™)

The codes were broken down into benefits and concerns for each stakeholder group, as seen in Figure 3.6.2.1.1 and Figure 3.6.2.2.1.

3.6.2.1 Comfort in relation to the Hexoskin ProShirt™

Figure 3.6.2.1.1 illustrates that tenants expressed a variety of concerns for comfort when it comes to the Hexoskin ProShirt™, followed by concerns from HCPs, then residents, and finally caregivers. However, tenants and HCPs also expressed many comfort-related benefits with the Hexoskin ProShirt™.

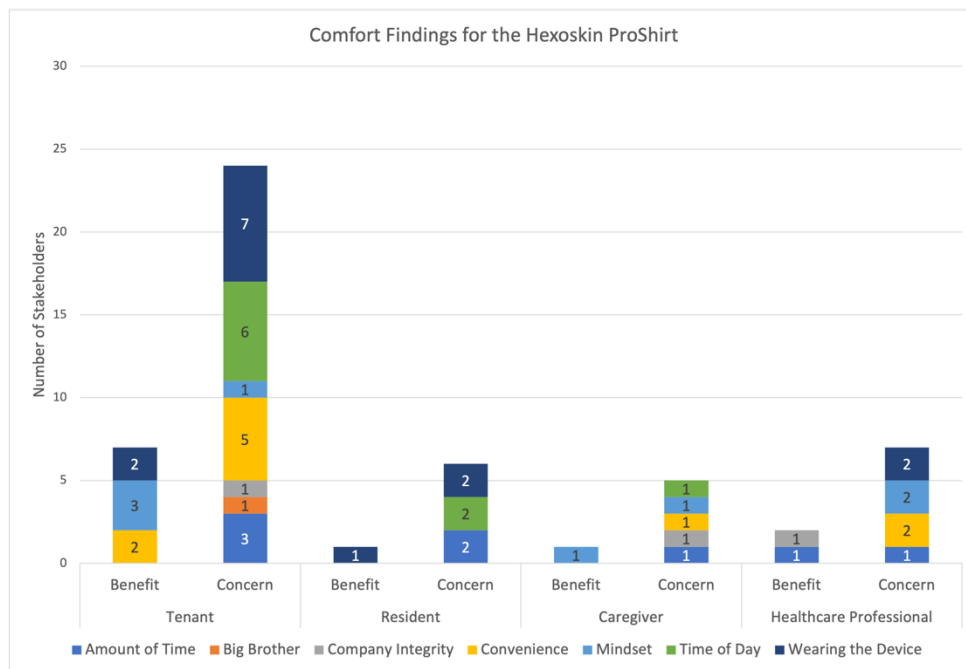


Figure 3.6.2.1.1: Comfort subcategory benefits and concerns from tenants, residents, caregivers and HCPs for the Hexoskin ProShirt™

For tenants, the most discussed concern within comfort was wearing the Hexoskin ProShirt™, with seven out of ten tenants making a note of it, with comments such as, *“I wouldn't want to wear a device like that all day. It's too cumbersome”* and *“I have very sensitive skin, and it gets irritated when I wear new things.”* Six out of ten tenants also had concerns about when they would have to wear the device, preferring not to wear it in warmer climates with one tenant commenting, *“The weather, you know, sometimes it's very cold and your bundled up, and other times it's so hot. So, I would think it gets too hot wearing this device.”* Along similar lines, one tenant said they did not want to wear the device in their home, *“We really don't need it inside [the home], do we?”* Additionally, five out of ten tenants also showed concerns about how convenient the Hexoskin ProShirt™ would be, with fears that it would impact their daily routines. As one tenant noted, *“If I'm wearing it all day and I want to take a shower, then I'd have to take it off and put it back on. That could get annoying.”* However, some tenants did see benefits with the shirt's comfort, with three out of ten tenants noting that wearing the Hexoskin ProShirt™ would give them peace of mind.

Residents voiced similar concerns, with two out of three raising concerns about wearing the device, when they would have to wear it, and how long they would have to wear it. Examples of such comments from two residents included, *“I could see some people not watching that because not wanting to feel something that close to them, that constricting, and*

there all of those restriction restrictive devices here, which is a big no-no” and “Well, if I wear it on a hot day, then I’m going to get hotter. Wearing something close to your skin like that, like all this, it gets warm, you’re going to get hot.”

The caregiver raised concerns with multiple different subcategories within comfort, including when the Hexoskin ProShirt™ would be worn, for how long, how convenient the device is, how the device might affect their loved one’s mindset, and the integrity of the company (Hexoskin) itself.

Lastly, HCPs shared similar concerns as tenants and residents, with two out of four HCPs showing concern for end-users wearing the Hexoskin ProShirt™, with one HCP noting, “I could see a resident just being like this is too tight, because they like their clothes to be pretty loose fitting.” Other HCP concerns included the device's convenience and how the device could cause anxiety for end-users, caregivers, and HCPs.

3.6.2.2 Comfort in relation to the AWS DeepLens™

Figure 3.6.2.2.1 shows that while a few benefits are seen for comfort with the AWS DeepLens™, almost all stakeholder groups had concerns about two or more axial codes, with HCPs having the most concerns, followed by tenants and residents.

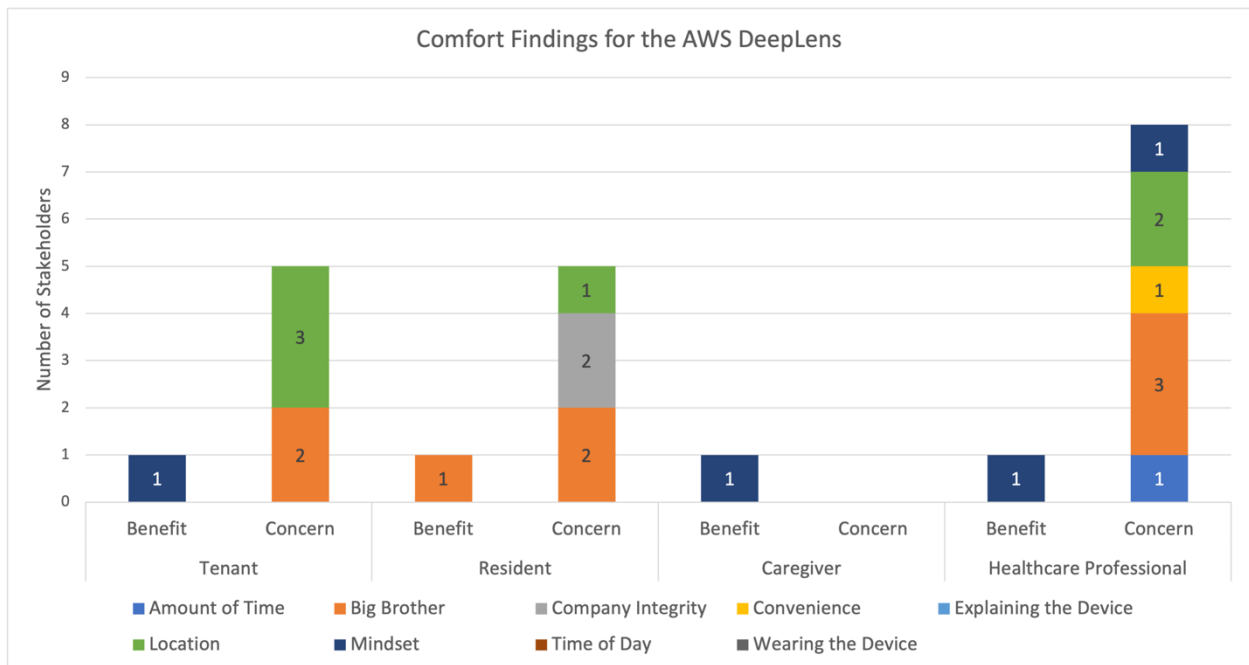


Figure 3.6.2.2.1: Comfort subcategory benefits and concerns from tenants, residents, caregivers and HCPs for the AWS DeepLens™

For tenants, the axial code that highlighted the biggest concern was the Location of the AWS DeepLens™. While three out of four tenants were unsure where the AWS DeepLens™ would go in their homes, they were firm that they would not want it in the bedroom or the bathroom. They were also worried that if they had only one camera in their home, they would be responsible for moving it around, depending on its purpose. Two tenants also raised

concerns for the Big Brother subcategory, where they felt as though the camera would be a constant presence watching over them.

Two of the three residents had similar concerns with the Big Brother subcategory. Interestingly, one resident compared the AWS DeepLens™ camera to cameras installed in the forest so that people can watch an animal's movement without it knowing that it's being observed. Two of the three residents also had concerns with company integrity. With a lot of media coverage involving Amazon, residents were on the fence about using a product from a company that they had unfavourable opinions towards, with one resident commenting, *"Well, we know what they've done in the past, don't we?"*

Unlike the other stakeholder groups, the caregiver saw a benefit for comfort of the AWS DeepLens™. The caregiver noted that if they were to use the AWS DeepLens™ with their loved one, it would bring them peace of mind. The caregiver saw the AWS DeepLens™ as something they could use to check in on their loved one to ensure they were doing okay throughout the day. The caregiver also thought that their loved one would have peace of mind using the device, knowing that they were visible to their caregiver at any time saying, *"I think that the residents would have more peace and contentment, knowing that there is a loved one within their reach."* However, this benefit was not shared by any of the interviewed residents.

One HCP also believed the AWS DeepLens™ would provide them peace of mind, as they would be able to check the camera to make sure the resident was safe instead of going into the resident's room continuously. On the other hand, HCPs had the largest number of comfort concerns, with three out of four HCPs commenting on concerns relating to the big brother code. For HCPs, they worried that staff might be uncomfortable knowing that they are on camera, and anything could be collected and potentially used against them. One HCP pointed out that this could even lead to more workload as an HCP would try to be especially careful in every interaction with a resident, to make sure they were doing everything perfectly. As one HCP described, *"When a personal support worker knows that there is a camera recording, we have to elaborate on our routine. So we have to tell them step by step what's happening, 'let's get dressed, let's put on your robe, okay now we're going to get a shower...', that can be really time-consuming rather than just talking with the resident casually and doing the steps at the same time."* Just as with tenants, two out of four HCPs also had concerns about the location of the AWS DeepLens™. One HCP pointed out that for a device like the DeepLens™, it would be important to keep it up high to ensure that the resident wouldn't play with it or break it.

3.6.3 Cost

The selective code of cost emerged through the workshops and interviews and was identified through emergent content analysis. Cost arose in different questions throughout the data, from stakeholders wondering how much the devices would cost, who would pay for the devices, and what would happen if the device were to break. The breakdown of benefits and concerns amongst stakeholders can be seen in Figure 3.6.3.1.1 and Figure 3.6.3.2.1.

3.6.3.1 Cost in relation to the Hexoskin ProShirt™

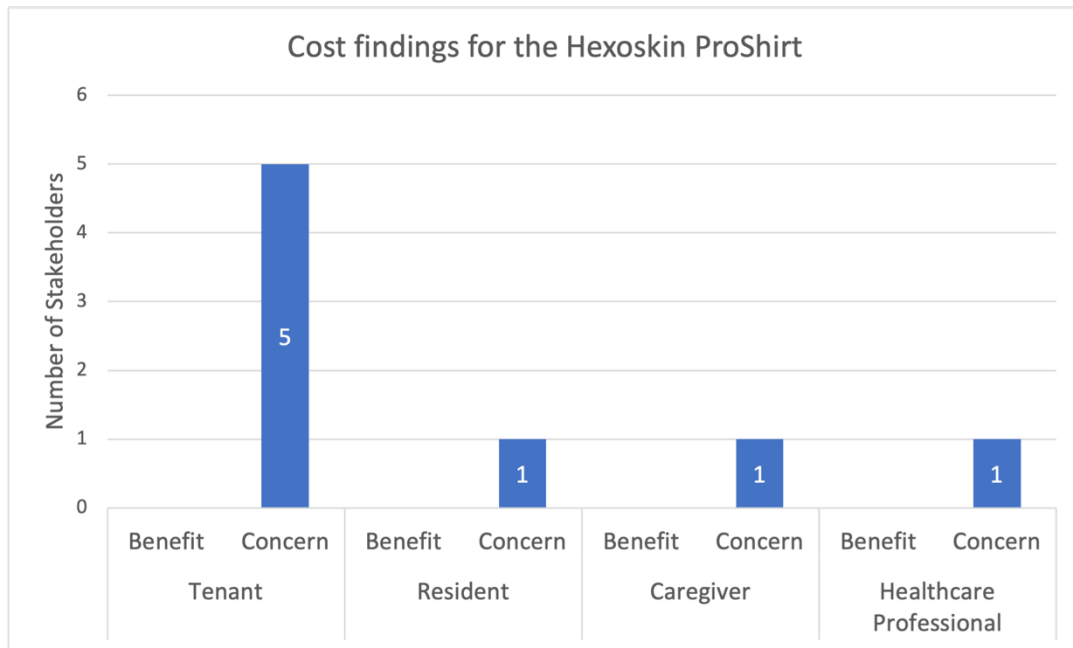


Figure 3.6.3.1.1: Cost subcategory benefits and concerns from tenants, residents, caregivers and HCPs for the Hexoskin ProShirt™

Tenants raised the most questions about the cost of the Hexoskin ProShirt™, with five out of ten tenants asking questions such as, “How much are they?” and “Who will have to pay for this device? Is it out of pocket or can OHIP pay?”

As for the residents, caregivers and HCPs, only one participant per stakeholder group asked about the cost of the Hexoskin ProShirt™, where the resident and caregiver were concerned about the price, while the HCP was worried that something could happen to the shirt and require a replacement.

3.6.3.2 Cost in relation to the AWS DeepLens™

For the cost of the AWS DeepLens™, only tenants and HCPs had concerns regarding the device's price, as seen in Figure 3.6.3.2.1

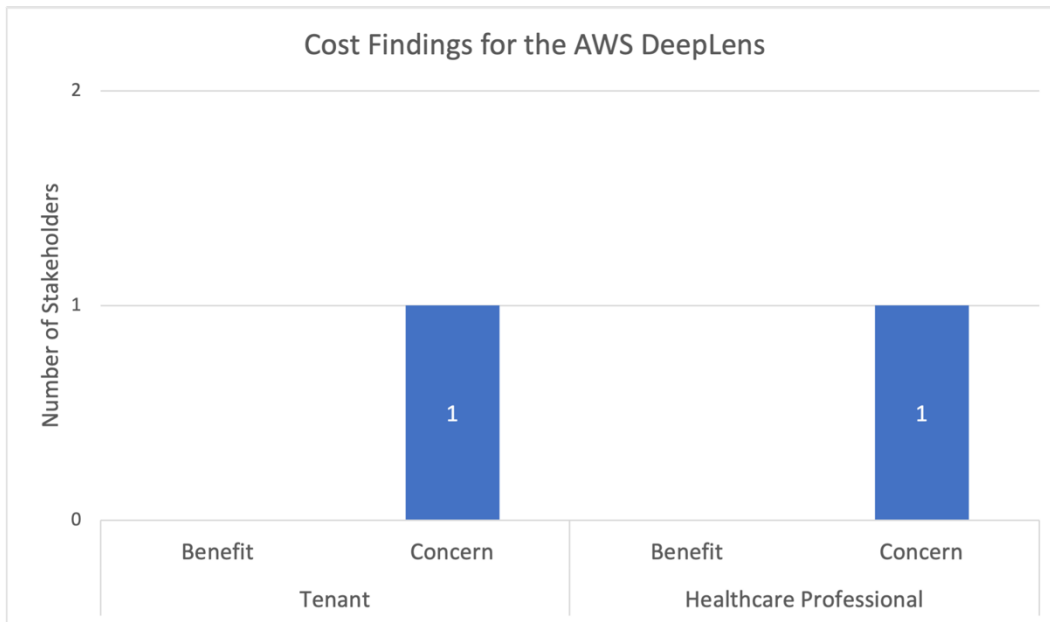


Figure 3.6.3.2.1: Cost subcategory benefits and concerns from tenants, residents, caregivers and HCPs for the AWS DeepLens™

For tenants, while there was interest in the device, they were concerned about the camera's price. However, they did admit that if the camera could prove to be a significant enough benefit, they would not mind paying a higher price.

For HCPs, the concern with cost centred around the fear that HCPs saw the camera as something that might be broken easily, similar to HCP fears with the Hexoskin ProShirt™. HCPs worried that replacing such a device would become very costly in the long run.

3.6.4 Data Privacy

As defined above, data privacy is the control one has over information that is personal to them. For the analysis, data privacy was grouped by five axial codes: Access to Data, Data Collection, Data Sharing, Data Storage, and the Use of Data. These codes are defined in Table 3-3.

Table 3-3: Axial codes for data privacy concern

Axial codes for data privacy	Definition
Access to Data	How stakeholders feel about who has access to the data that is collected
Data Collection	What stakeholders think about their data being collected by a device
Data Sharing	What stakeholders think about their data being shared with other parties, from other researchers to different companies, through the internet.
Data Storage	What stakeholders think of their data being kept by researchers or the companies that built the devices
The Use of Data	What stakeholders think about their data being used to further research or to build, train, or test Artificial Intelligence or Machine Learning models or systems.

Each axial code was broken down into benefits and concerns, so that a clear picture of what stakeholders think about each code is gained (Figures 3.6.4.1.1 and 3.6.4.2.1).

3.6.4.1 Data Privacy in relation to the Hexoskin ProShirt™

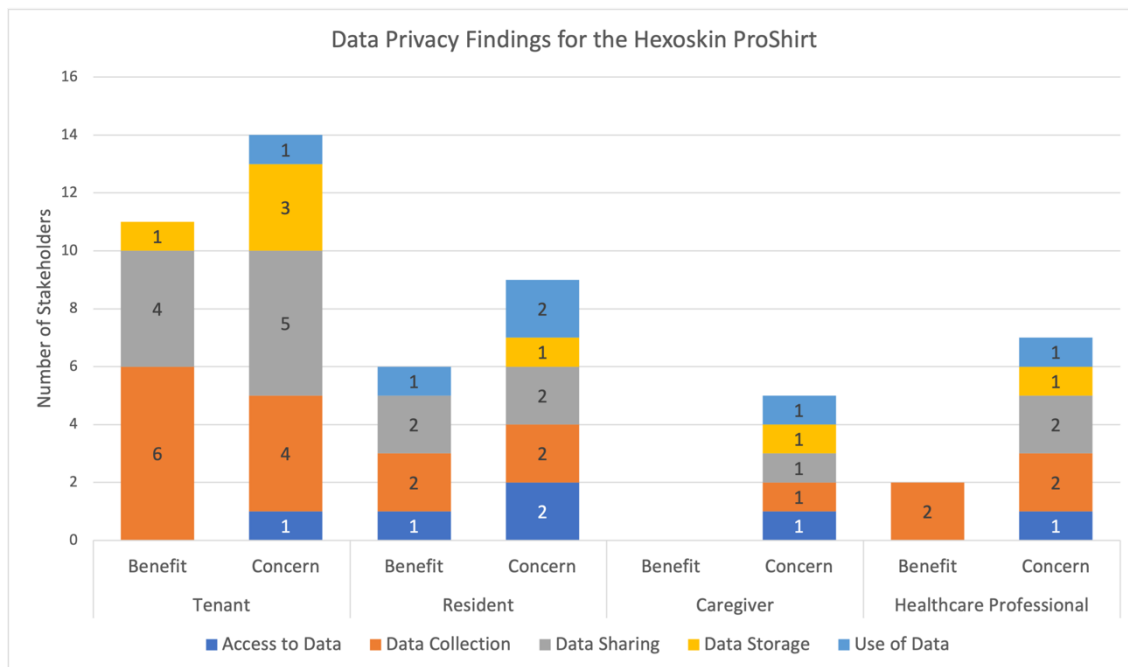


Figure 3.6.4.1.1: Data Privacy subcategory benefits and concerns from tenants, residents, caregivers and HCPs for the Hexoskin ProShirt™

As seen in Figure 3.6.4.1.1, six out of ten tenants saw benefits with the Hexoskin ProShirt™ collecting their data, and four out of ten were supportive of their data being shared with researchers, their physicians, or the LTCF. As discussed by one tenant, *“You’d have to let your doctor know! They are the ones that are going to prescribe or send you off for testing. There’s no point if they don’t know.”* Interestingly, five out of ten tenants had concerns about data sharing, with some stating that they were okay with their data being shared with researchers or physicians but against the data being shared with caregivers, as one tenant commented, *“My family physician, yes... but not... not with my family.”* The remaining four tenants shared similar concerns with the Hexoskin ProShirt™ collecting their data.

Residents were similar to tenants in that the overall number of benefits and concerns was almost equal, indicating that residents saw value in the data being collected and shared but still had reservations. While positive comments were made about data collection and data sharing, an equal number of concerns were raised about the same topics, along with concerns about access to data and its use.

The opposite was true for both the caregiver and the HCPs interviewed, as both groups of stakeholders showed greater concerns for data privacy than benefits. The caregiver raised concerns for each axial code, with no comment on benefits.

For HCPs, two out of four commented on the benefits of the Hexoskin ProShirt™ collecting data, with one HCP mentioning, *“It’s pretty neat that if someone isn’t feeling feel, or if they feel like they are short of breath, then they could see the data and see what’s going on.”* However, many more concerns were identified, with the most centred around data collection

and data sharing, with one HCP questioning, “Like what identifiers are they using, how are they storing the data, who sees the data?”

3.6.4.2 Data Privacy in relation to the AWS DeepLens™

Interestingly, across the board, stakeholders had fewer data privacy concerns with the AWS DeepLens™ than they did with the Hexoskin ProShirt™ (Figure 3.6.4.2.1).

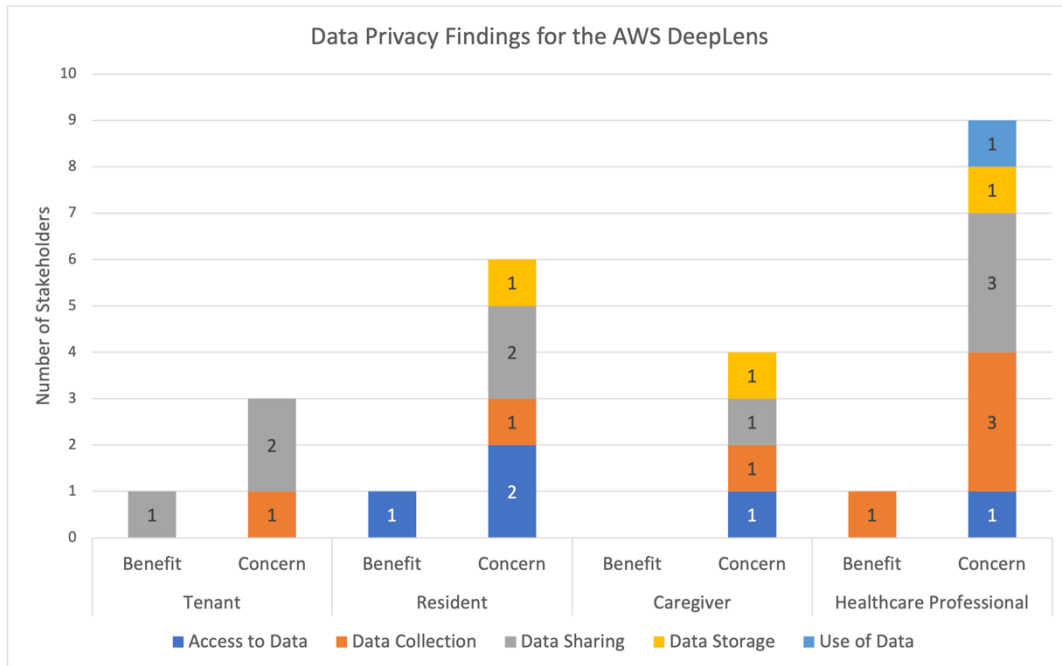


Figure 3.6.4.2.1: Data Privacy subcategory benefits and concerns from tenants, residents, caregivers and HCPs for the AWS DeepLens™

For tenants, one participant saw data sharing as a benefit, stating that as long as the information was used to help with research, it was okay to share, “I don’t have any problem with sharing, as long as it can help with the research.” However, two out of the four participants had concerns with sharing their data collected by the AWS DeepLens™. These concerns centred around specifics, with tenants wanting to know precisely who their data would be shared with, from the researchers to the company itself.

Two out of three residents had similar data sharing concerns, with questions about who their data would be shared with due to worry that someone else could use their data for projects in which they did not agree to participate. In discussing this topic, one resident brought up their distrust of Amazon and did not appreciate the idea of the company potentially having access to their data. Two out of three residents also had concerns with different people being able to access their data, with one resident adamant that they did not want the LTCF having access to data collected by the camera.

The caregiver interviewed raised concerns with four out of the five axial codes within Data Privacy. Using the Word Count feature in NVivo, the caregiver spoke most about the concerns with access to data and data sharing. The caregiver worried about what the camera might record on a day-to-day basis and who would be able to see the data. The caregiver noted

that some elements of care are very personal and should remain private. Therefore, they worried that the camera would record aspects of their loved one’s life that no one has any business looking at or using in research.

For HCPs, three out of four participants had concerns with data collection and data sharing. As was noted in the interview with the caregiver, HCPs also commented that much of the care done with residents is personal and is better kept private. However, HCPs did note that if residents were okay with having the camera in their room and agreed to its recording, the HCPs had no problems with it. For data sharing, HCPs had similar concerns with personal images being shared with different parties. Additionally, one HCP noted that they had concerns with data being shared with residents’ family members as it might erode the trust between residents and HCPs, *“Sometimes there are conversations between the resident and staff, because we have built up a relationship and they trust us. So, they might say things that happen in their family, happen in their past, and they share it with us. So, would I feel comfortable being recorded and that information shared with the family members or other people...? Not really.”*

3.6.5 Device Design

Device Design is a new category that emerged by conducting emergent content analysis. Throughout the data, all stakeholder groups made comments about device attributes for both the Hexoskin ProShirt™ and the AWS DeepLens™. This new selective code aims to uncover stakeholders' benefits and concerns with the device characteristics and how they might impact the end-user. The Device Design code was created by grouping six axial codes together, and are explained in Table 3-4.

Table 3-4: Axial codes for device design concern

Axial codes for device design	Definition
Colour Choice	What stakeholders think of the colour of the device (applies to Hexoskin ProShirt™)
Device Characteristics	What stakeholders think about the devices as they are (i.e., the layout of the Hexoskin ProShirt™, or the weight and movability of the AWS DeepLens™)
Health Aspects	Where stakeholders consider any health conditions they have or are aware of and how the device may benefit or impede the condition
Material	What stakeholders think about the fabric of the device (applies to Hexoskin ProShirt™)
Men and Women Style	What stakeholders think about the fit of the device for men and women (applies to the Hexoskin ProShirt™)
Putting Device On	What stakeholders think of having to put the device on (applies to the Hexoskin ProShirt™)

These codes were broken down further to identify stakeholders' benefits and concerns with each topic (Figures 3.6.5.1.1 and 3.6.5.2.1).

3.6.5.1 Device Design in relation to the Hexoskin ProShirt™

Across the board, all stakeholder groups had many more concerns regarding device design for the Hexoskin ProShirt™ than they did positives, as seen in Figure 3.6.5.1.1.

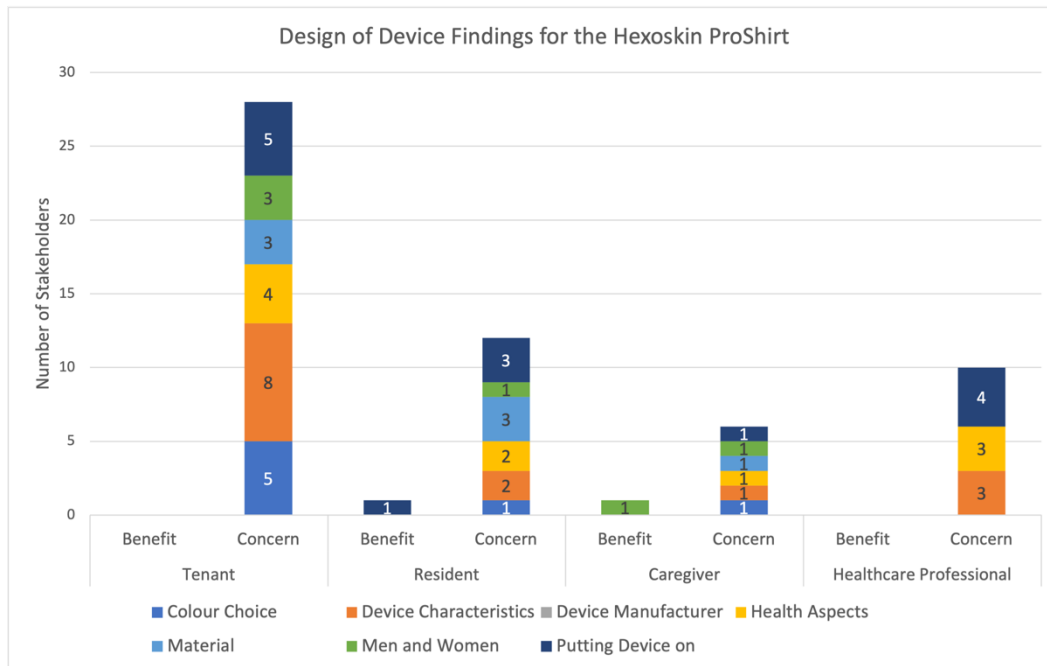


Figure 3.6.5.1.1: Device Design subcategory benefits and concerns from tenants, residents, caregivers, and HCPs for the Hexoskin ProShirt™

For tenants, the code with the most concerns from eight out of ten participants was the device characteristics of the Hexoskin ProShirt™. This means that many tenants had concerns about the Hexoskin ProShirt™ not having buttons or zippers to fasten it from the front or side and instead would have to pull it over their head if they were to wear the device. This was not a popular way to put on the device and is reflected by the five out of ten tenants who had concerns with the same code. This also impacts the Health Aspects category, where four tenants showed concerns that health conditions, such as arthritis and frozen shoulders, would prevent them from being able to pull the device on over their heads. Additionally, five out of ten tenants also had concerns regarding the colour of the Hexoskin ProShirt™. These tenants did not appreciate the device's dark colour, which would be noticeable under lighter-coloured clothing. This was especially true when tenants spoke about wearing the device in the summer when they preferred to wear light-coloured tops. Notably, the five tenants with these concerns were all female suggesting that the device's design expresses a gender bias.

All interviewed residents had concerns about having to put the Hexoskin ProShirt™ on and the material used for the shirt. Like tenants, residents noted that they would have trouble putting the device on with its current design and would likely need someone to help them. Residents also had concerns with the material used for the Hexoskin ProShirt™. Three residents

raised concerns that the material would be restricting and uncomfortable against their skin and feared that the material would make the device hot and uncomfortable under their other clothes.

The caregiver raised concerns in each axial code. Using the Word Count feature in NVivo, it was found that the caregiver had the most to say about their concerns with the Men and Women style of the Hexoskin ProShirt™ (90 words) and its characteristics (71 words). While the caregiver did see a benefit with the men’s and women’s style for the Hexoskin ProShirt™, in that they believed it was a good device for men to wear, the caregiver had concerns for women wearing the device. These concerns also translated to the device characteristics. The caregiver noted that many women would require support in the chest area but would likely need more support than the shirt would be able to give them. Additionally, the caregiver thought wearing a bra under the shirt would make the device and the wearer even more uncomfortable, further underscoring the device’s gender bias.

All HCPs had concerns with putting the device on code. As with tenants, HCPs worried about the health conditions that older adults have, which would make it nearly impossible to put on a device like the Hexoskin ProShirt™. Additionally, HCPs noted that their morning routines with residents allow only five minutes due to their typical caseload. Therefore, the idea of having to wet the sensors (as the manufacturer instructs), put the device on the resident, plug in the data recorder, and help the resident finish getting dressed, was very overwhelming to some of the HCPs.

3.6.5.2 Device Design in relation to the AWS DeepLens™

Compared to the Hexoskin ProShirt™, stakeholders did not have as many concerns with the design of the AWS DeepLens™. HCPs and tenants had the highest number of concerns, and the caregiver had no concerns, as seen in Figure 4.5.2.1.

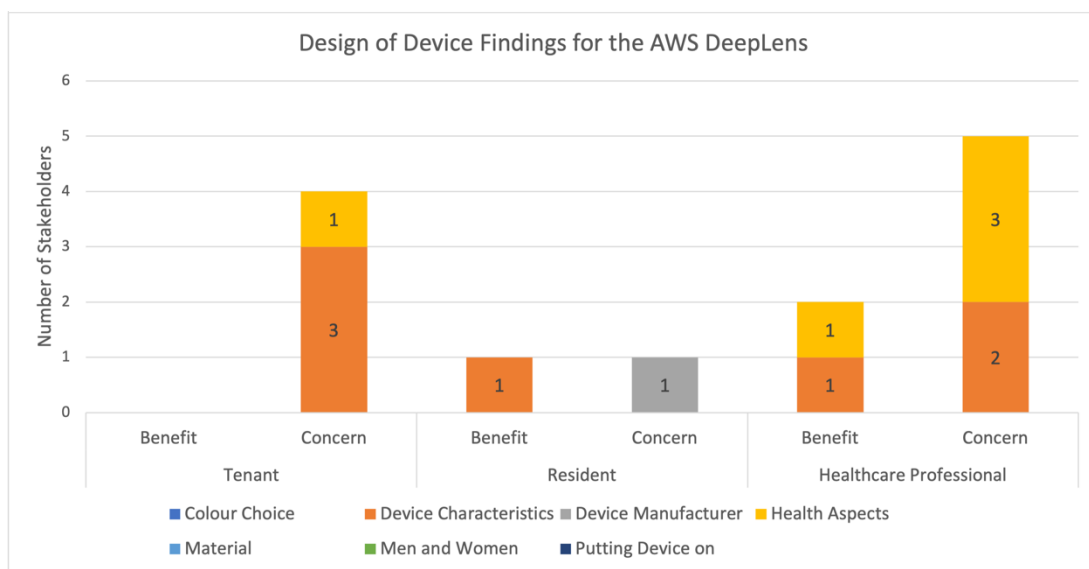


Figure 3.6.5.2.1: Device Design subcategory benefits and concerns from tenants, residents, caregivers, and HCPs for the AWS DeepLens™

For three out of four tenants the main concern with the AWS DeepLens™ was its weight. One tenant, who uses a wheelchair, worried that the camera would be too heavy for them if they needed to move or lift it. This point also relates to the health aspects concern seen in Figure 3.6.5.2.1. Due to the restriction of the wheelchair, the tenant feared that they would miss out on being able to use the camera due to their condition.

For residents, the only concern that emerged from one interview was about the device's manufacturer. As mentioned previously, some residents felt uncomfortable with Amazon potentially having access to their data, stemming from their discomfort with what they know of the company.

HCPs had the largest number of concerns, with three out of four worrying about certain health aspects and two out of four raising concerns about the camera itself. For the health aspects, HCPs feared that if the camera was used with residents who have dementia, the resident might play around with or accidentally break the camera as they might forget what it was used for. Conversely, one HCP noted that they saw the camera as a benefit for older adults with other behaviours, like fall risks, where the camera could be used to detect those changes. For device characteristics, two HCPs did raise concerns about charging the camera- if it needed to be continuously plugged in or if it would fall on the HCPs to be responsible for keeping an eye on the battery and plugging the camera in when needed. Interestingly, a common comment from all stakeholders was that they wanted the camera to also record audio. HCPs noted that if the camera recorded audio, they would block the video portion when conducting private care with residents. Therefore, it wouldn't be as big a deal if they forgot to uncover the camera because all the audio was still being recorded.

3.6.6 Economic Distribution

Economic distribution was another selective code found through emergent content analysis. While only mentioned during workshops and interviews for the AWS DeepLens™, it is an important code to explore and deserves consideration. The breakdown of the benefits and concerns for the different stakeholder groups can be seen in Figure 3.6.6.1.

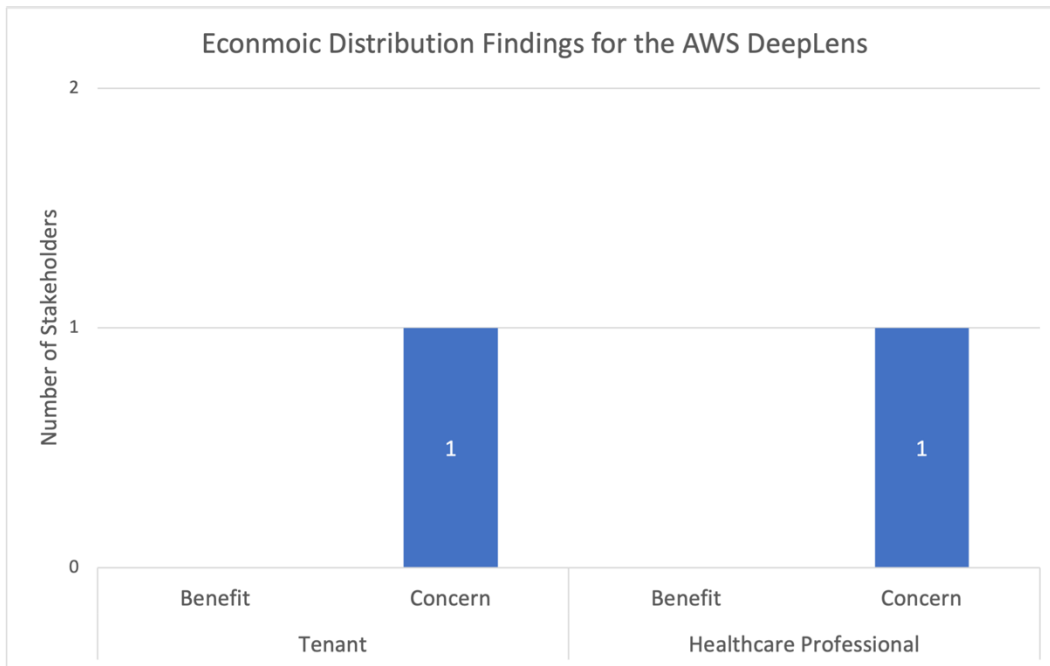


Figure 3.6.6.1: Economic Distribution subcategory benefits and concerns from tenants, residents, caregivers, and HCPs for the AWS DeepLens™

As seen in the figure above, one tenant and one HCP were the only two people to raise concerns about the impact that the AWS DeepLens™ might have on economic distribution. While the HCP found it unfair that some older adults, who could afford the device, would benefit, leaving others upset or underappreciated, the tenant went into far more detail. The tenant worried that the device might create a class imbalance between people who could afford the device and those who could not. The tenant feared that this imbalance would lead to friends growing apart and cause resentment to occur. This point resonated with the social connectedness category discussed below. If the device breaks apart friendships due to some people using it and not others, loneliness may become a problem.

3.6.7 Independence

As defined above, independence is one’s ability to complete a task without help from others or technology. From analyzing the data obtained from the workshops and interviews, two axial codes emerged and are defined in Table 3-5.

Table 3-5: Axial codes for independence concern

Axial codes for independence	Definition
Freedom	If the stakeholders believe that the device provides them with the ability to do things that they may not be able to do without the device
Use Without Help	If the stakeholders believe an older adult would be able to use the device without the assistance of another person

These codes were further broken down to identify stakeholders' benefits and concerns with each code (Figures 3.6.7.1.1 and 3.6.7.2.1).

3.6.7.1 Independence in relation to the Hexoskin ProShirt™

All stakeholders had concerns regarding an end user's ability to use the device without the assistance of another person and what that might mean for the end-user. The results of the data analysis for independence can be seen in Figure 3.6.7.1.1.

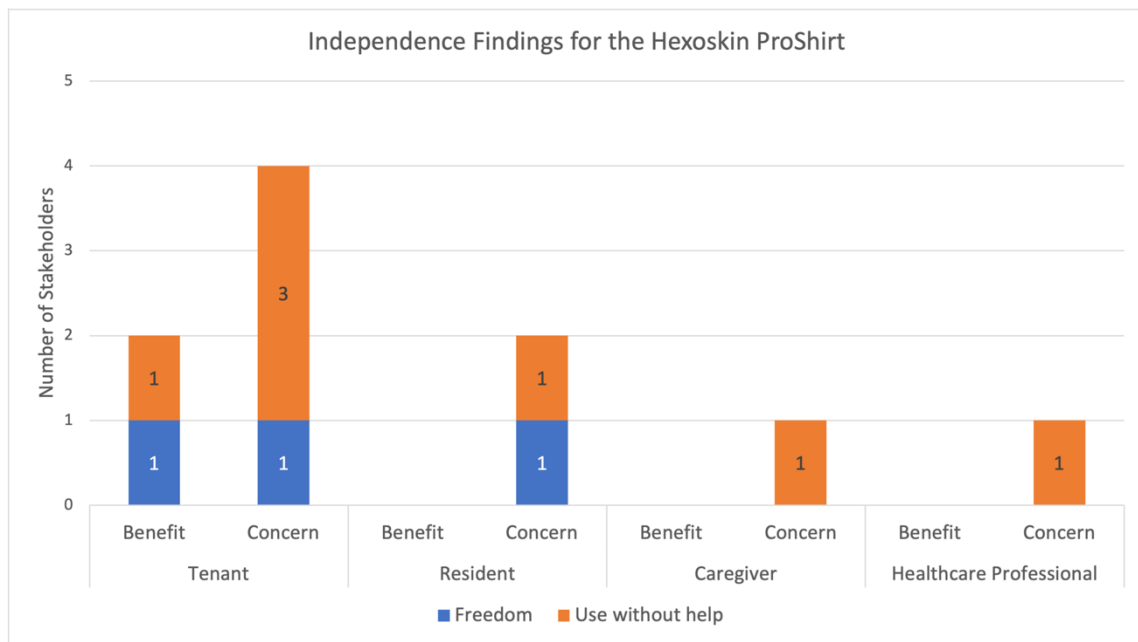


Figure 3.6.7.1.1: Independence subcategory benefits and concerns from tenants, residents, caregivers, and HCPs for the Hexoskin ProShirt™

For tenants, three out of ten had concerns about using the Hexoskin ProShirt™ without help from an additional person. As was discussed in the Health Aspects code of the Device Design theme, tenants and residents had concerns about not being able to put the device on due to ailments such as arthritis and frozen shoulders and would therefore require additional support if they were to wear the device. However, receiving help with putting the device on was not a popular idea, as the tenants voiced that they wouldn't want someone helping them dress. They expressed concerns that if they need help dressing, they might become dependent on another person, with one tenant commenting, *"I want something easier to put not, not someone to help me put it on. I want to put it on myself."* Additionally, they wouldn't want to ask someone for help when they need to put the device on or take it off, as one tenant explained, *"If you need help putting it on, that makes a great difference in terms of independence. You have to wait for the person to help you put it on."*

However, one tenant did see the Hexoskin ProShirt™ providing them with a great deal of freedom. They noted that by wearing the device, they would be able to go about their life, doing the things they enjoyed, and if something were to happen, the shirt would be able to

record the incident and potentially alert someone that something was wrong. The resident commented, *“If I had something like this, I could venture more outside, more independent.”*

Residents saw only concerns with the Hexoskin ProShirt™ with their independence. The resident who touched upon freedom was very concerned about their freedom of movement if they were to wear the device. This resident, who uses a wheelchair, believed that wearing the Hexoskin would negatively impact their mobility, as they were concerned that they would continuously bump into the data recorder or feel generally more restricted by wearing the device.

Both the caregiver and an HCP also had concerns about an older adult’s ability to use the device without help. For the caregiver, they noted it was inevitable that their loved one would require help if they were to wear the Hexoskin ProShirt™. Furthermore, the caregiver went on to say that asking an HCP to help an older adult put on the device would only increase the sizable workload that HCPs already undertake. The HCP noted that older adults want to remain as independent as possible for as long as possible. Therefore, they don’t want to ask for help unless necessary. This could lead to unintended negative consequences if older adults do not ask for help and therefore do not wear the device, or if the Hexoskin ProShirt™ is bothering them, but do not complain and the shirt could end up doing more harm than good.

3.6.7.2 Independence in relation to the AWS DeepLens

Concerns about independence for the AWS DeepLens™ were mentioned in each stakeholder group by at least one participant, as seen in Figure 3.6.7.2.1 below.

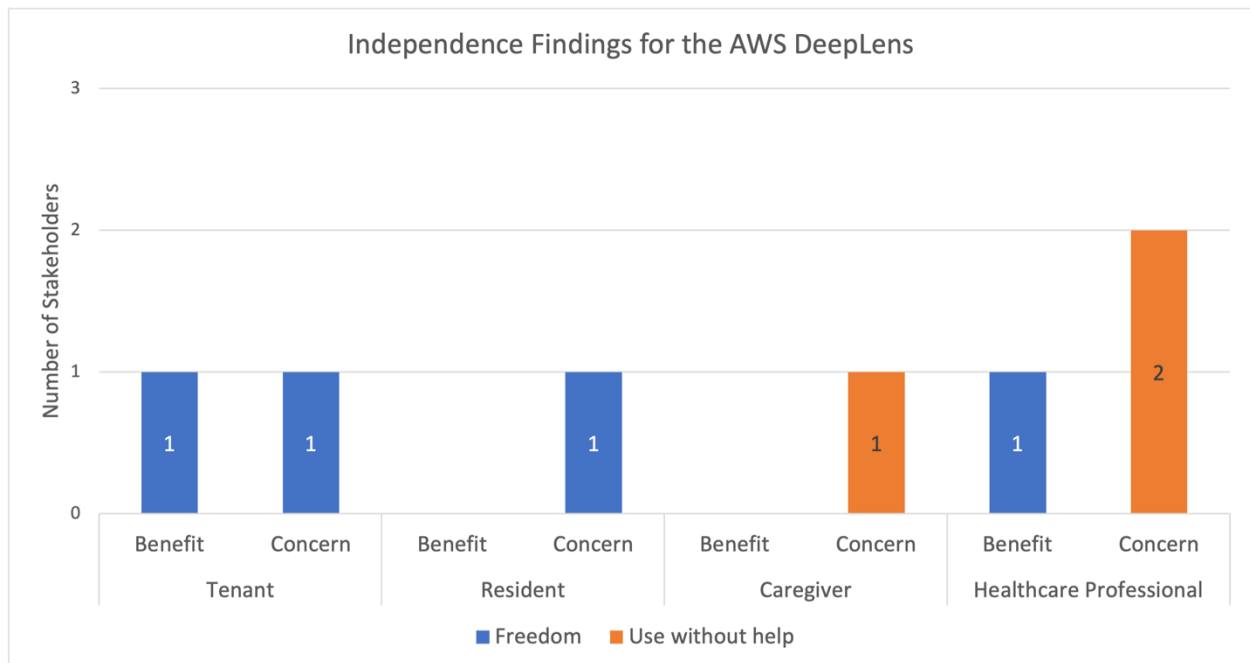


Figure 3.6.7.2.1: Independence subcategory benefits and concerns from tenants, residents, caregivers, and HCPs for the AWS DeepLens™

Tenants and residents shared similar concerns in that they found that the presence of the AWS DeepLens™ would make them feel more confined and observed in their own space.

For example, one tenant noted that if they wanted to eat a peanut butter and jelly sandwich for dinner one night, and the camera recorded it, their caregiver might find out and remind them that they shouldn't be eating peanut butter. This highlights another finding from the SLR, that older adults want the ability to choose and control their own lives, and the introduction of an AAL device like the AWS DeepLens™ could change that.

The caregiver and two of four HCPs had concerns about older adults being able to use the device themselves. The caregiver noted that older adults do their best not to ask other people for help. Instead, they would rather try to complete a task by themselves. This relates to the concerns of HCPs, who noted that some residents might forget what the camera was, what it was for, or what they would need to do if they needed to operate it. In response to this concern, one HCP suggested that if the residents were required to interact with the camera, clear and informative steps should be written out, telling the resident what they need to do with the device.

3.6.8 Personal Privacy

Personal privacy is defined as the control one has over their physical self or space. One axial code was found through data analysis about how stakeholders saw the devices impacting their personal privacy. The code is defined in Table 3-6.

Table 3-6: Axial codes for personal privacy concern

Axial codes for personal privacy	Definition
Feeling with the Device	If the stakeholder feels as though the device is a benefit or an intrusion in their personal space

The axial code was broken down further to identify the benefits and concerns that stakeholders had with the code (Figures 3.6.8.1.1 and 3.6.8.2.1).

3.6.8.1 Personal Privacy in relation to the Hexoskin ProShirt™

Across all stakeholder groups, personal privacy for the Hexoskin ProShirt™ was not a significant area of concern. HCPs had no benefits or concerns about personal privacy, and only one or two participants from the remaining stakeholder groups saw concerns, as seen in Figure 3.6.8.1.1.

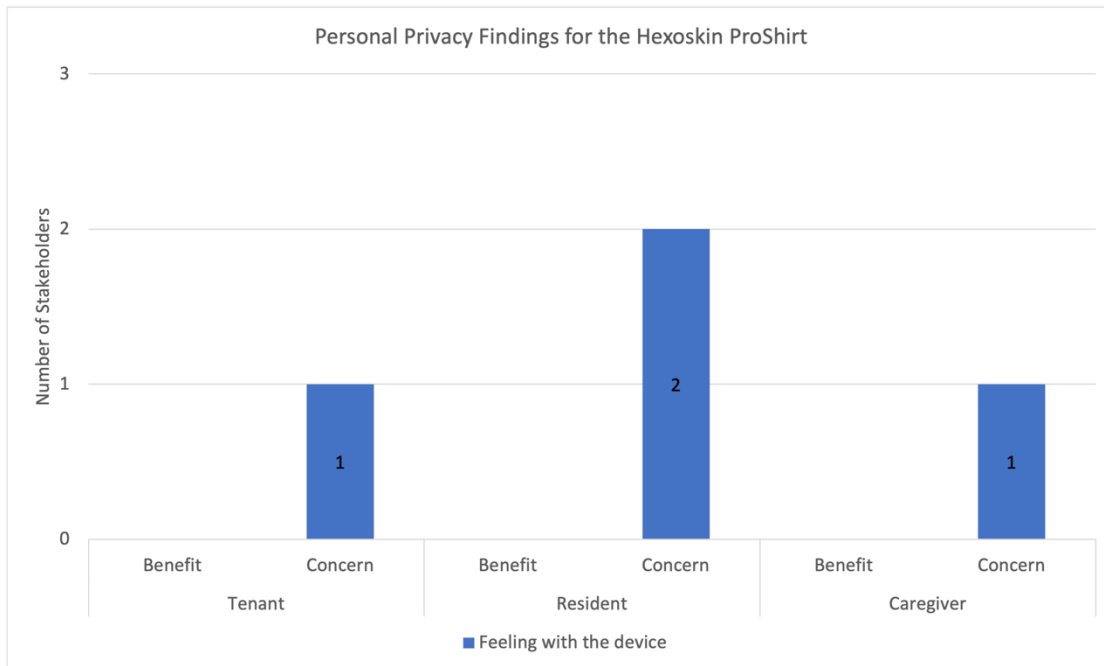


Figure 3.6.8.1.1: Personal Privacy subcategory benefits and concerns from tenants, residents, caregivers, and HCPs for the Hexoskin ProShirt™

For tenants, one tenant was concerned about how the device would make them feel in their own space and wondered if they would need to wear the device in their own home. This concern gives credit to the idea that while tenants may see the benefits of the Hexoskin ProShirt™, the idea of wearing it all day or when they are at home is not a popular one.

For two of three residents, concerns were voiced over their feelings about the Hexoskin ProShirt™. Both stated that wearing such an apparent monitor would make them uncomfortable in their own space, and even more so if they had to wear it continuously.

Lastly, the caregiver was concerned about how the device would make them feel in their own space. Interestingly, while they were okay with their loved one using the device, their concern stemmed from the device's name. The caregiver suggested that using a device called the 'Hexoskin ProShirt' made them feel like they were in "Star Wars" and were using technology well beyond their understanding.

3.6.8.2 Personal Privacy in relation to the AWS DeepLens™

Unsurprisingly, personal privacy with the AWS DeepLens™ was a popular topic with all stakeholder groups, with stakeholders voicing both benefits and concerns, as seen in Figure 3.6.8.2.1.

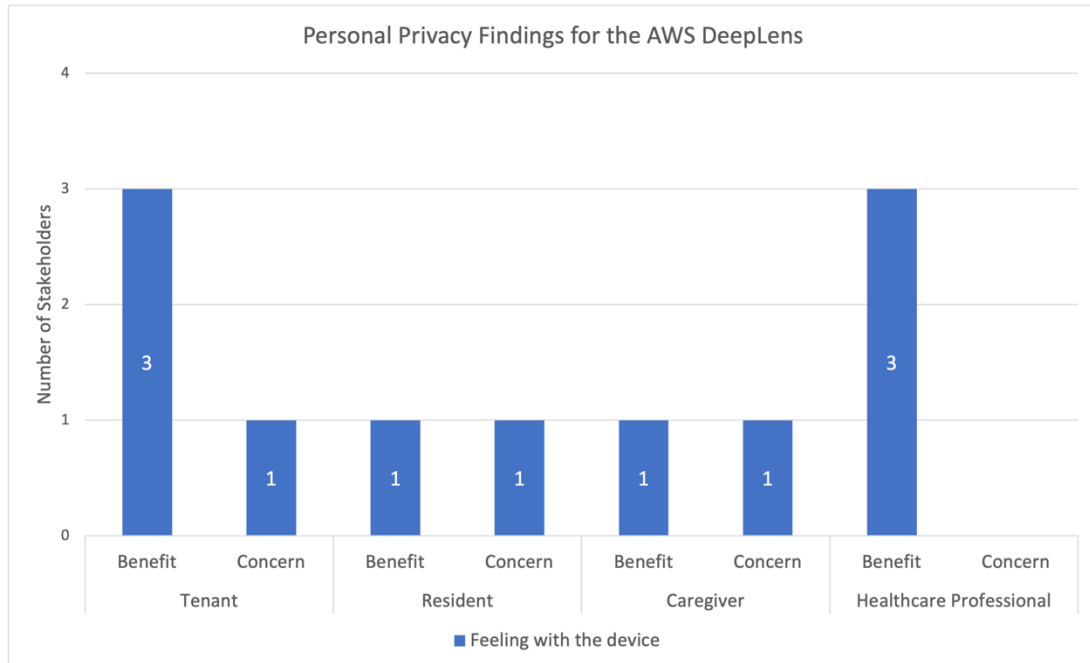


Figure 3.6.8.2.1: Personal Privacy subcategory benefits and concerns from tenants, residents, caregivers, and HCPs for the AWS DeepLens™

Overall, two out of the four stakeholder groups saw more benefits with personal privacy for the AWS DeepLens™, than they did concerns.

For tenants, three out of four participants had positive things to say about their feelings toward the device. Tenants commented that they thought the camera would be an added benefit in their lives. For the concern, even though tenants saw many benefits to the device, one tenant had reservations about it in their bedroom or bathroom, as discussed above.

For residents, participants raised both a benefit and a concern with the AWS DeepLens™. One resident was very against the idea of the camera in their space and said they would feel very uncomfortable with the camera recording them, especially when they were asleep. On the other hand, the resident who raised the benefit with the camera felt that the camera would bring positives, saying *“If I would have had one, oh gosh, I'd be happy.”*

Just as with the residents, the caregiver had a benefit and a concern for their feeling with the camera. They believed that their loved one would be uncomfortable with the device recording some aspects of their care. However, the caregiver noted if they were asked to use the device, they would have no problems with it due to its potential benefits.

Just as with tenants, HCPs saw more benefits than concerns about how they would feel with the AWS DeepLens™ in their space. HCPs commented that a camera in a resident's room would feel fine as it would have no impact on how they performed their required duties, with

one HCP commenting, “For me, personally, I don’t mind, because you just do what you need to do, and that’s the right thing to do.”

3.6.9 Safety

Safety is a selective code that was identified through emergent content analysis. Even though only a few stakeholders had comments in relation to this code, it was interesting to see how many stakeholders saw benefits with the devices in relation to their safety. The safety code was created by grouping two axial codes together, which are explained in Table 3-7.

Table 3-7: Axial codes for safety concern

Axial codes for safety	Definition
Safety	If the stakeholders think the device can keep them safe
Security	If the stakeholders feel as though the device provides them with a sense of security

The axial codes are broken down further to identify the benefits and concerns that stakeholders had with the codes (Figures 3.6.9.1.1 and 3.6.9.2.1).

3.6.9.1 Safety in relation to the Hexoskin ProShirt™

Safety for the Hexoskin ProShirt™ was not a concern for many of the stakeholders, with only one tenant seeing a benefit for their safety if they used the shirt, as seen in Figure 3.6.9.1.1.

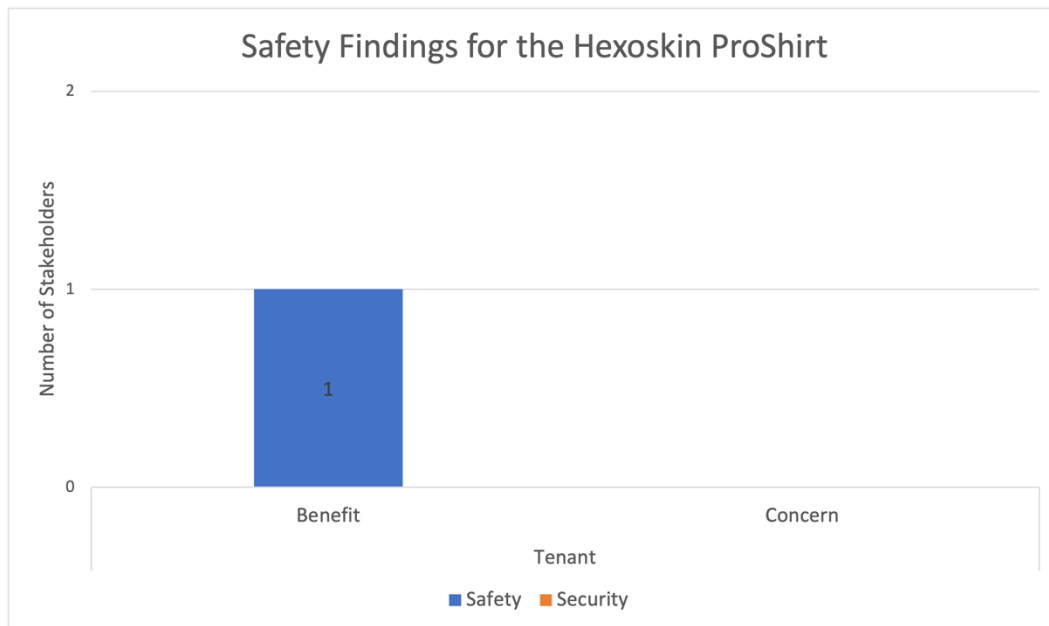


Figure 3.6.9.1.1: Safety subcategory benefits and concerns from tenants, residents, caregivers, and HCPs for the Hexoskin ProShirt™

The tenant who saw a benefit with the Hexoskin ProShirt™ for safety believed the shirt could help to keep them safe if they decided to leave the house. Tied to the freedom point explored in 3.6.7.1, the tenant believed that the device could be an additional safety measure if they ventured outside or became more independent.

3.6.9.2 Safety in relation to the AWS DeepLens™

Safety for the AWS DeepLens™ was a very positive conversation with stakeholders, with many stakeholders seeing more benefits with the camera than concerns, as seen in Figure 3.6.9.2.1.

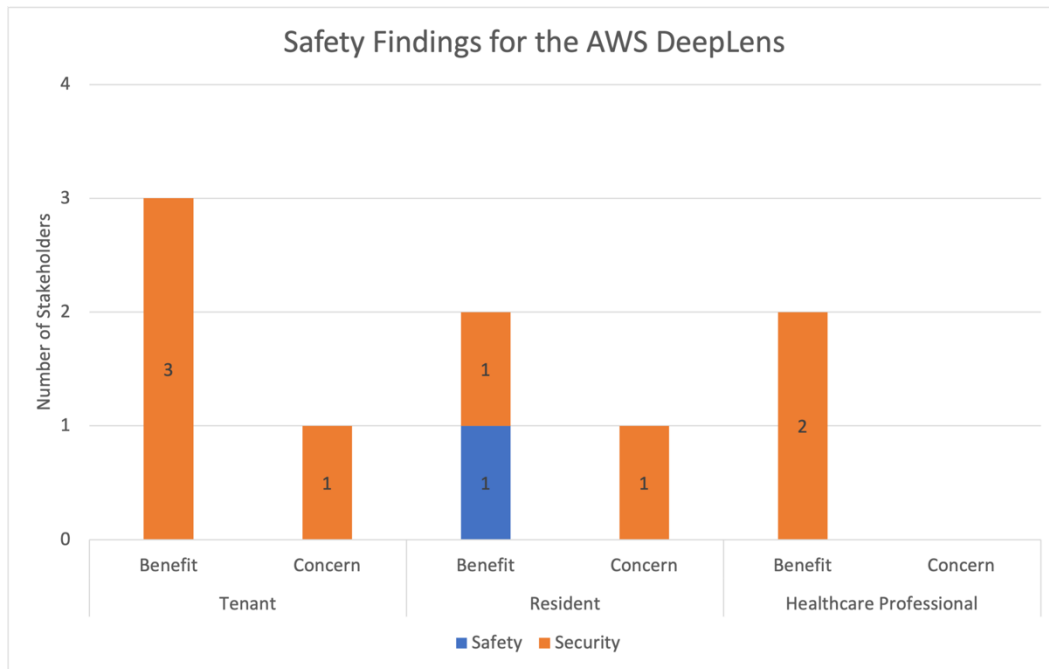


Figure 3.6.9.2.1: Safety subcategory benefits and concerns from tenants, residents, caregivers, and HCPs for the AWS DeepLens™

For tenants, three out of four participants had positive things to say about the sense of security the device would bring them. Tenants commented that they thought the camera would be an added benefit in their lives and an extra measure of security in their homes if something happened. One tenant commented, *“It would make me feel more secure.”* In addition, tenants suggested that their caregivers would also feel more secure with the camera, knowing that it was monitoring their loved ones.

For residents, at least one participant saw benefits with the AWS DeepLens™ for both codes. Like tenants, residents said they would welcome the device into their space as they could see its ability to aid in their safety and security. Interestingly, for security, the resident did not relate the security to themselves but saw the camera as something that could watch their room while they were gone if any other residents came in, like a security camera.

Just as with tenants, HCPs saw benefits with the AWS DeepLens™, with two out of four seeing security benefits. HCPs commented that the camera would not only be a security benefit for the residents, but also for themselves. As one HCPs noted, if anything did happen and their

practice was called into question, they would be able to go back through the data collected by the camera and find the truth, “...because that would help the protection for the resident and for ourselves, like for me, as a healthcare worker.”

3.6.10 Device Purpose

Device purpose is another selective code that was identified through emergent content analysis. In the data analysis, many questions and comments were found relating to what stakeholders thought the devices would be suitable for. In particular, stakeholders had concerns that all the devices would do is collect data with nothing given back in return. The breakdown of benefits and concerns relating to Device Purpose can be seen in Figure 3.6.10.1.1 and Figure 3.6.10.2.1.

3.6.10.1 Device Purpose in relation to the Hexoskin ProShirt™

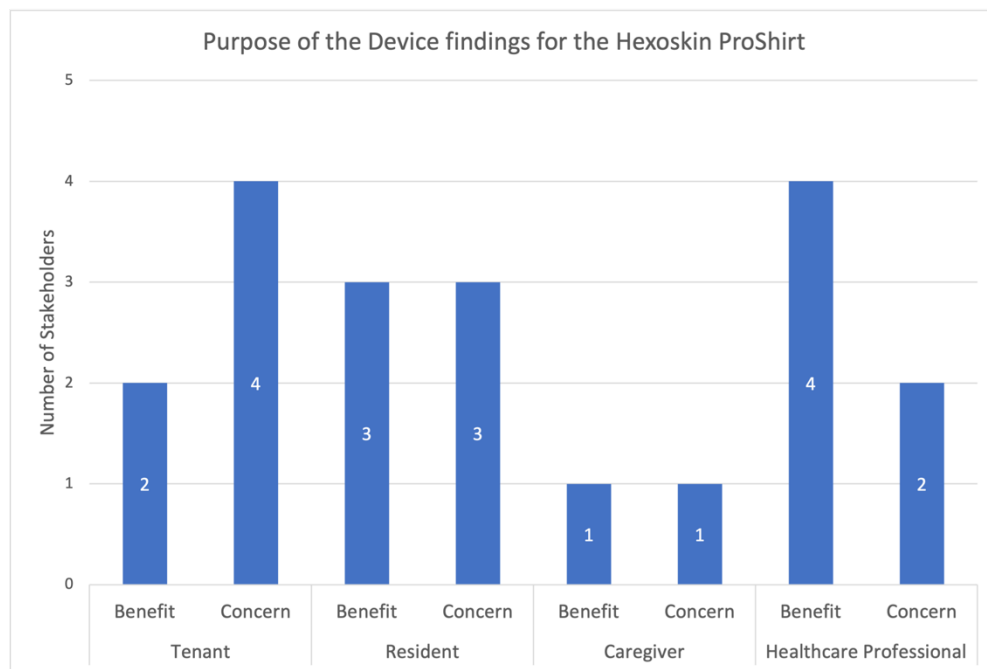


Figure 3.6.10.1.1: Purpose of the Device benefits and concerns from tenants, residents, caregivers, and HCPs for the Hexoskin ProShirt™

Four out of ten tenants had concerns regarding what the Hexoskin ProShirt™ would be used for. Similar to findings from the SLR, while tenants saw the benefits that the device might bring, many of them stated that they did not need such a device at this time in their lives, with multiple tenants saying similar lines like, “I have a high rating for the product, but necessity is not needed at this time.” This conversation inspired comments from tenants that if they were asked to use the device, they would need a convincing reason to do so, as one tenant stated, “Yeah, I would need a reason. I’m not going to wear it just because.” Conversely, two tenants believed that the Hexoskin ProShirt™ would be a benefit because it could monitor their vital signals while doing the things they enjoyed, and if something happened, the shirt would record the event. Additionally, one tenant commented that depending on how sophisticated the shirt’s

sensors are, it might be able to detect underlying or unknown health conditions, which they saw as a convincing factor.

For residents, each one could see benefits and concerns with the Hexoskin ProShirt™. Residents stated that if the device was monitoring for something specific, there would be a purpose for wearing it, with all residents saying similar lines like, *“If I was having an issue like if I had coronary history or thrombosis history or something like that, I might be convinced to wear it.”* However, each resident vehemently stressed that to wear the shirt, they would need a reason, saying lines like, *“You gotta convince me that it’s going to be to my advantage,”* and *“For me, it would all come from the ‘why I’m wearing the shirt.’”* One resident went as far as to state that if the device did not serve a purpose, then it was “useless.”

The caregiver had a similar view to the residents, where they could see benefits and concerns with the device's purpose. They stated that if the device had a goal, then wearing it would be a benefit, *“If it were being used as a monitoring device and was used as some kind of alert system or early warning system, I would think that would be the value of it. You know, if a person is going to have a heart attack or blood pressure drops, then you might want to dash in there and take a look.”* However, the caregiver suggested that with the current model of the Hexoskin ProShirt™, they would need a lot of convincing that the device would be beneficial for their loved one, *“I mean, it would have to be a really good sell job to convince me that the wearability of it, and the convenience of it, that it’s worth it. Right now, I don’t see it.”*

Interestingly, the benefits and concerns for the HCPs were reversed from the tenants, with four HCPs seeing benefits with the Hexoskin ProShirt™'s purpose and two having concerns. HCPs that commented on benefits thought that it was good the device could monitor an older adult's vital signs and could therefore warn staff if something went wrong, with one HCP commenting, *“I can see the importance of having the monitor, especially for things for people who have high blood pressure, or if you’re trying to mitigate any further complications going forward.”* However, two of the four HCPs that noted benefits with the shirt also pointed out concerns regarding the device's purpose, stating that the shirt would likely be better for either a younger generation or older adults who are still active in their day-to-day lives. This finding suggests that both HCPs did not see a purpose for the Hexoskin ProShirt™ in Long Term Care, with one HCP saying, *“I feel like this machine, this device, would be easier to implement in a younger population,”* and *“It would be good on some people who have cardiac problems, but in Long Term Care? I don’t think so.”*

3.6.10.2 Device Purpose in relation to the AWS DeepLens™

Stakeholders who participated in a workshop or interview for the AWS DeepLens™ saw many more benefits than concerns, as see in Figure 3.6.10.2.1.

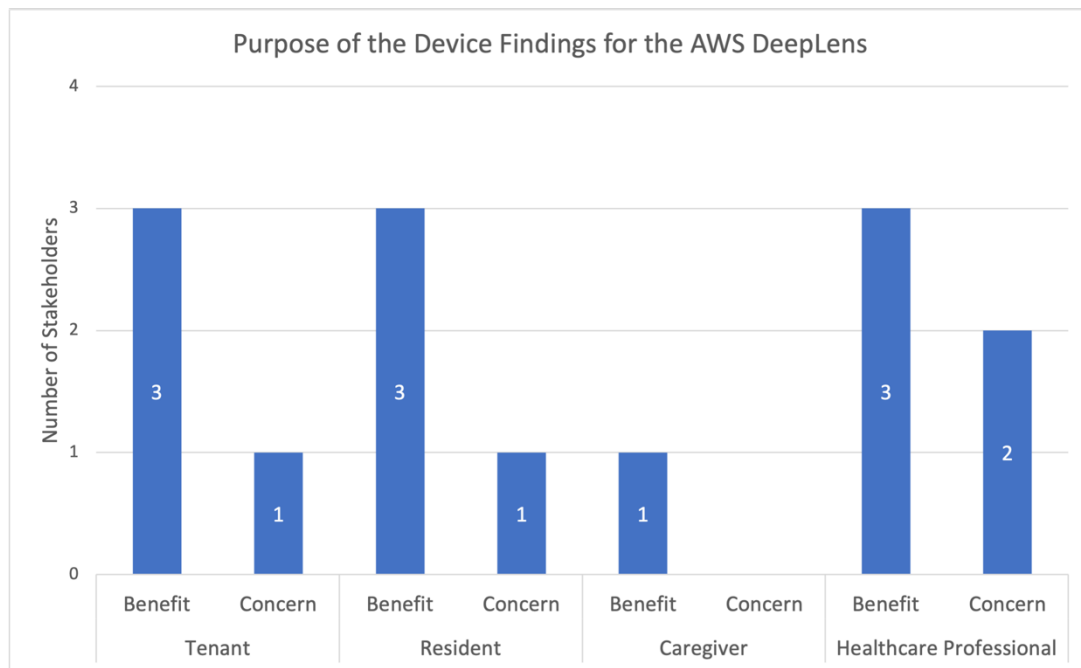


Figure 3.6.10.2.1: Purpose of the Device benefits and concerns from tenants, residents, caregivers, and HCPs for the AWS DeepLens™

Three out of four tenants commented on the benefits that they believed the AWS DeepLens™ could have in their lives. The tenants who lived on their own noted that the device would have a clear advantage for them, as it could record and potentially alert a caregiver or the LTCF that something had happened. Furthermore, although some residents were against using the camera in some spaces, they did acknowledge that many accidents occur in the bathroom, such as slipping or falling, so having the camera there might be an advantage. Overall, tenants agreed that the AWS DeepLens™ would be a welcome addition to other systems, with one tenant saying, *“It would be an additional system. I have this [points to button around neck], I have my phone. If I fall on my phone, I can’t access these things, so maybe the camera would catch something, and maybe alert somebody else.”*

For residents, all participants acknowledged that they saw benefits with the camera; two out of the three told the researchers how much more beneficial the device would have been when they were younger and working. These stories made it clear that the residents saw the camera’s benefit in situations when they were working but did not see a precise application at the LTCF. This was touched on above when it was mentioned that one resident saw the AWS DeepLens™ as a security camera. However, the same resident noted that if the camera could act as a reminder system to drink water or take their pill, they would find that very beneficial. Another resident commented that if HCPs could use the camera at night to check in on the resident instead of opening their door while they were sleeping, that would be an advantage.

The caregiver saw many different applications for which the AWS DeepLens™ could be used. The application that they were particularly concerned about for their loved one was the risk of choking, mentioning that it would be a great benefit if the camera could detect and alert an HCP that someone was choking.

Three out of four HCPs saw benefits with the AWS DeepLens™, while two had concerns. Just as with the Hexoskin ProShirt™, some HCPs wanted to be clear on what the data collected by the AWS DeepLens™ is used for, i.e., they wanted to understand the purpose of the device before they jumped into using it and letting it record them. On the other hand, the HCPs who saw benefits with the camera saw it as a helpful tool to aid them in their duties. For example, one HCP saw a clear advantage for residents who wake up at night. The HCP noted that many accidents happen overnight because it is dark, and the older adult does not want to bother anyone, so they try and get out of bed themselves. Therefore, the HCP noted that if the device could detect a resident trying to get up from their bed, the HCPs could be alerted and help the resident before an accident happens. Other HCPs noted similar benefits, where the device might be able to detect behaviours that would alert HCPs to go check on a resident.

3.6.11 Social Connectedness

Social Connectedness was defined above as the experience of feeling close or connected to others and is the sense of belonging to a social relationship. By conducting the data analysis on the workshops and interviews with stakeholders, six axial codes emerged relating to Social Connectedness and are defined in Table 3-8.

Table 3-8: Axial codes for social connectedness concern

Axial codes for social connectedness	Definition
Having People Over	How stakeholders would feel if they invited people into their space while using the device (tenants or residents) or how the stakeholder would feel visiting a room where the device was being used (caregivers or HCPs)
Human Contact	If stakeholders believe the device would increase or decrease the amount of contact they have with other people
Lone Wolf	An expression that looks to see how stakeholders would feel if they were the only ones using the device (i.e., none of their friends were using the device) (applies to tenants and residents)
Loneliness	If stakeholders believe the device would improve or propagate loneliness
Other People Knowing	Investigates how stakeholders would feel if other people were to find out that they were using the device if they were not informed beforehand (applies to tenants and residents)
Reporting on Findings	Stakeholders want researchers to use the devices as a means of facilitating communication between stakeholders and researchers

The axial codes were broken down further to identify the stakeholders' benefits and concerns with each code (Figures 3.6.11.1.1 and 3.6.11.2.1).

3.6.11.1 Social Connectedness in relation to the Hexoskin ProShirt™

Tenants and residents expressed most of the concerns about social connectedness related to the Hexoskin ProShirt™. At the same time, the caregiver had very little to say, and nothing was noted by HCP participants. Overall, very few benefits were seen, with only two tenants and one resident commenting on positive aspects. The breakdown of the benefits and concerns for the axial codes can be seen in Figure 3.6.11.1.1.

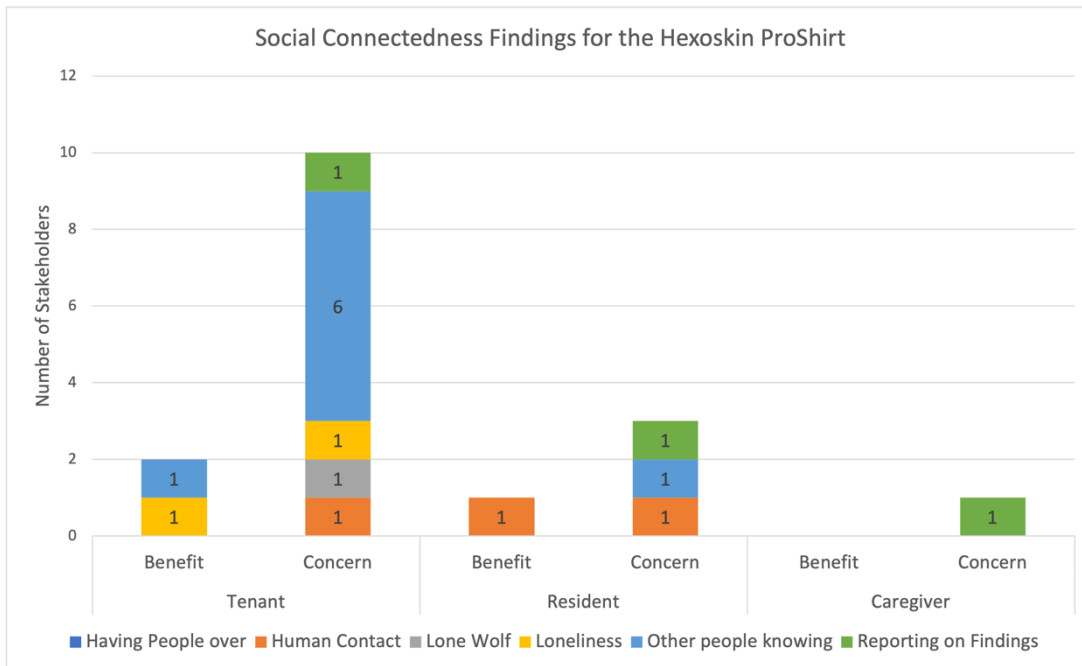


Figure 3.6.11.1.1: Social Connectedness subcategory benefits and concerns from tenants, residents, caregivers, and HCPs for the Hexoskin ProShirt™

For tenants, the axial code with six out of ten concerns was other people finding out that they were wearing the Hexoskin ProShirt™. Similar findings were noticed in the SLR presented in Chapter 2, where older adults fear that if people find they are using an assistive device, people will stereotype them as ‘needing help’ or ‘frail,’ which is not how older adults want to be perceived. This was demonstrated in a comment from a tenant who said, “By not telling them, they might think that you have a health issue.” Many of the tenants believed that it was no one else’s business if they were wearing a device or not, and preferred to keep it to themselves. This conversation led back to the debate about colour, where some tenants remarked that the darker colour of the shirt would be more noticeable and might cause other people to question what they were wearing, as one tenant noted, “If they want you to wear it in the summertime, can they make it in white, so it’s not so obvious”.

For residents, at least one participant had concerns with each axial code. Using NVivo’s Word Count feature, reporting on findings was the most discussed concern at 66 words, followed by human contact at 56 words, and having people over at 43 words. For the resident concerned about reporting on findings, they expressed that if they wore the Hexoskin ProShirt™ they would want researchers coming to talk to them about the device and the data it was collecting. That way, the resident could be engaged in what the device is doing and an active participant in their own health. In the words of the resident, “I would hope that by virtue of me wearing it, and affording somebody the data that I would end up either having someone come and talk to me.”

The caregiver had similar feelings to the resident and went on to say that often when participants learn that feedback is not given as a result of a study, they don’t participate. In the caregiver’s own words, “Most people are very upset if in fact they say, well we didn’t actually plan on sharing [the data]. So, then it turns into an okay, goodbye.” Here, the caregiver was

speaking about studies that have been conducted at the LTCF in the past. However, the caregiver was trying to express that if open communication does not exist between the users and engineers or designers, then tenants and residents are less likely to be interested in any future AAL technology that is presented.

3.6.11.2 Social Connectedness in relation to the AWS DeepLens™

For social connectedness, most stakeholder groups showed more concerns than benefits with the AWS DeepLens™, as seen in Figure 3.6.11.2.1.

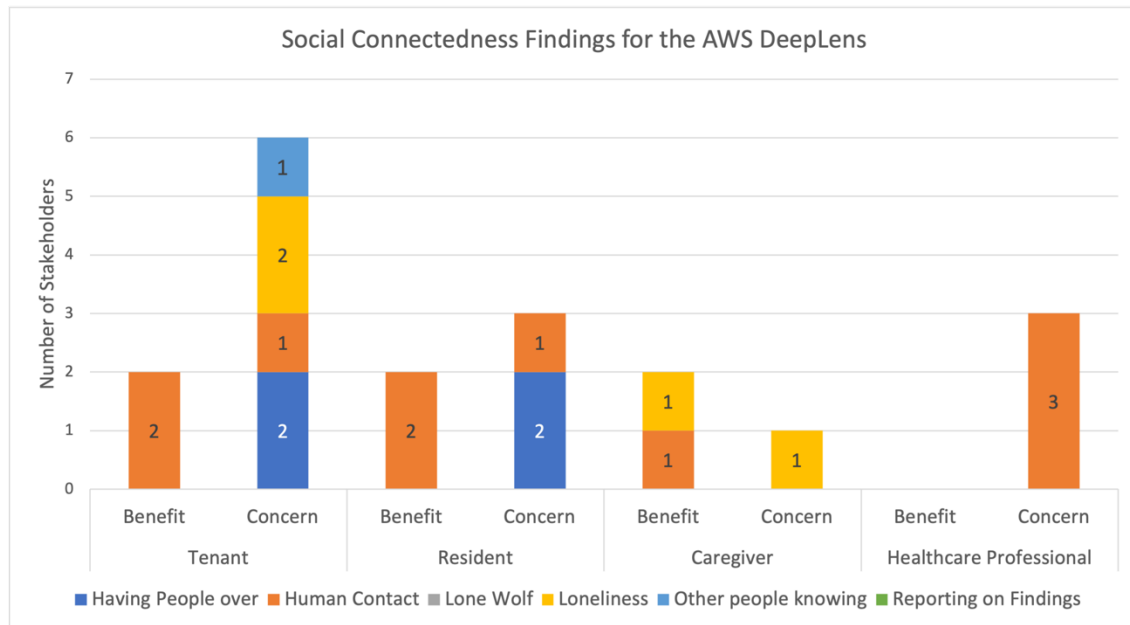


Figure 3.6.11.2.1: Social Connectedness subcategory benefits and concerns from tenants, residents, caregivers, and HCPs for the AWS DeepLens™

Two out of four tenants had concerns with the axial codes of having people over and loneliness. Tenants indicated that if they had guests over, they would want to turn off the AWS DeepLens™ so that it wouldn't record their interactions with family members, caregivers, or friends. Tenants also had loneliness concerns, fearing that caregivers might become reliant on the camera and use it to check in on them rather than coming in person to see them. This concern also fed into the human contact concern voiced by one tenant, who indicated they would miss the caregiver if they stopped coming by because of the camera, *"You'd miss the person that you've been used to having to help you."* However, tenants noted that if the camera could speak to them, or their loved ones or caregivers could use the camera to communicate with them, the camera could bring people together, with one tenant surmising that the camera could see loneliness, *"I guess more for facilitating conversations because, if you are by yourself, and unless you go to sit outside or come to coffee, you're not with anybody. So, if it could bring people together, that would be ideal."*

Residents had similar concerns to tenants about the axial codes of having people over and a loss of human contact. Just as with tenants, two out of three residents indicated that they would turn the AWS DeepLens™ off if they had visitors, preferring that the camera did not

record those interactions. One resident also stated a concern with a loss of human contact, fearing that they would have no one to talk to if they used the camera, *"...Because there aren't too many people that you can talk to, and I like to chit chat."* The resident also noted that the camera is no replacement for a human being.

The caregiver was the only stakeholder group to see more benefits with the AWS DeepLens™ for Social Connectedness than concerns. The caregiver noted that loneliness is a significant factor among older adults, especially in LTC. Therefore, the caregiver believed that residents would feel more connected and at peace, knowing that their loved ones or caregivers could watch them through the camera, *"...I think that the residents would have more peace and contentment, knowing that there is a loved one within their reach, where they know that someone is looking after them."*

While HCPs noted no benefits for social connectedness for the AWS DeepLens™, three out of four participants did have concerns about a loss of human contact. HCPs were worried that a camera would impact their relationship with residents, with one HCP stating, *"It can also take away the one-on-one relationship, and the trust between the resident and the staff."* As one HCP put it, to build up trust between the HCP and the resident, they need to build a positive, friendly, and trusting relationship, and they worried that the camera might change that dynamic, *"So I think the device might limit the openness that the resident and staff have if everything is being recorded. There are more barriers. Like, I better not be chatty, or being too friendly with this resident"* Another HCP pointed out that if their attention was always focused on the camera, then less time could be spent with the resident, and that could also have negative implications, *"If we're paying attention to that, then we're taking away time to actually go talk to the resident. Even though they might not be able to answer you, but still they'd could have that feeling of somebody being there, and that's important that they know that we're there."*

3.6.12 Workload

Workload was the last selective code that was identified through our emergent content analysis. Workload emerged due to stakeholder's comments on how the devices may relieve or add to the strenuous workload that HCPs are responsible for. The breakdown of benefits and concerns for each device by each stakeholder group for workload can be seen in Figure 3.6.12.1.1 and Figure 3.6.12.2.1.

3.6.12.1 Workload in relation to the Hexoskin ProShirt™

The breakdown of benefits and concerns for workload for the Hexoskin ProShirt™ can be seen in Figure 3.6.12.1.1, where HCPs have the largest number of concerns, and residents did not comment.

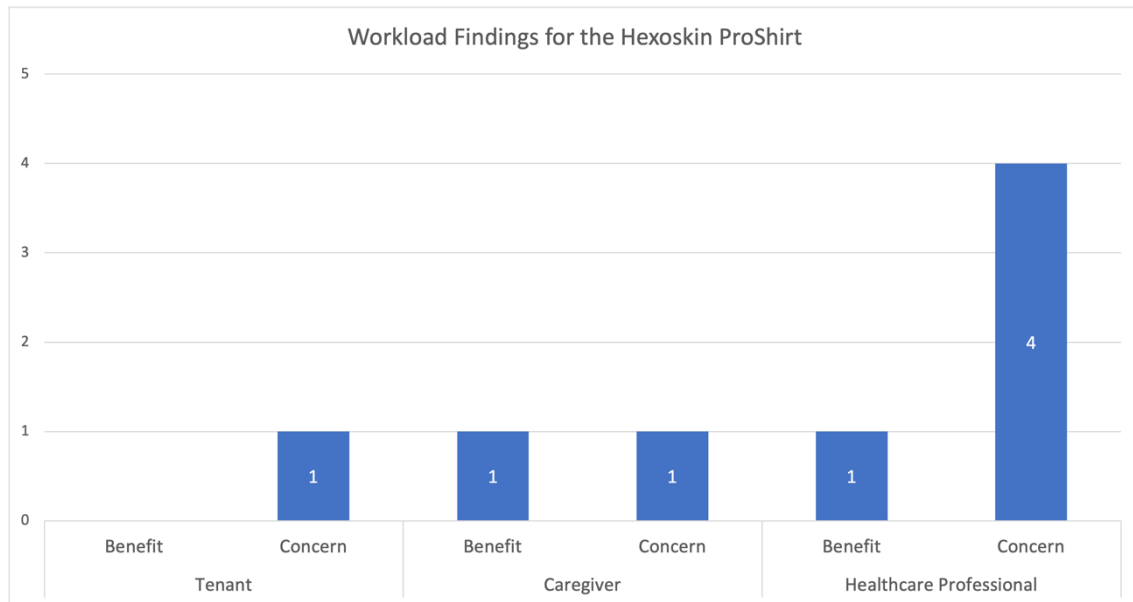


Figure 3.6.12.1.1: Workload benefits and concerns from tenants, residents, caregivers, and HCPs for the Hexoskin ProShirt™

For the tenant and caregiver who expressed concern over workload, they saw the Hexoskin ProShirt™ as something that would add additional load to an HCP’s day, with wearers being uncomfortable, waiting to take the device off, needing help putting the device on, or asking for interpretations of the data coming from the shirt, with the caregiver stating, *“It’s just another task that HCPs really don’t need”*. The caregiver also noted that if the Hexoskin ProShirt™ were to be implemented and used at the LTCF, it would mean a change in the entire structure of the centre.

For HCPs, many more concerns about workload were noted than benefits. For example, four out of four HCPs interviewed about the Hexoskin ProShirt™ stated concerns with the device, while two also noted the benefits. The concerns HCPs had regarding the Hexoskin ProShirt™ were wide-ranging, from who would be responsible for the well-being of the device, miscommunications that might happen between shift changes or the number of steps it would take to get the device on. Furthermore, HCPs may require additional training to know how to use the device or interpret the data coming out of it, with one HCP pointing out, *“You have to have these special courses to read ECGs, it’s not everyone who can read them.”* Therefore, if HCPs were expected to be able to interpret data from the shirt and provide feedback to the wearer or the wearer’s caregivers, then additional training and coursework would be required. However, on the opposite side of the spectrum, some HCPs noted that even though there would be an increased amount of workload, if the device could show that their care was working, the extra workload would be worth it, as one HCP noted, *“If it could really help an*

aspect of my work, knowing that there is a bit more work at first to get accustomed to it, I'd probably still be willing to put it in place.”

3.6.12.2 Workload in relation to the AWS DeepLens™

HCPs were the only stakeholder group to raise both benefits and concerns with the workload for the AWS DeepLens™, as seen in Figure 3.6.12.2.1.



Figure 3.6.12.2.1: Workload benefits and concerns from tenants, residents, caregivers, and HCPs for the AWS DeepLens™

Three out of four HCPs pointed out benefits that they saw the AWS DeepLens™ achieving with workload. However, each HCP interviewed also raised concerns about workload. For benefits, HCPs saw the camera as something that could be used to check in on the residents so that HCPs could have time to complete other tasks they needed to get done instead of going door to door to ensure all of the residents were doing okay. However, all HCPs interviewed also spoke about the added workload the AWS DeepLens™ would create, from making sure the camera was charged to ensuring that they were conducting care in a manner that would block aspects the resident did not want recorded. One HCP noted that with the pandemic, HCPs in LTC facilities are already stretched thin, so bringing in another device that would add more work to their plate would be a challenge, “...you might be asking too much of the PSWs, especially with the pandemic going on right now. And we work so hard anyways, and our workload keeps increasing.” One HCP also commented that due to the additional time it would take to make sure they were explaining everything to the resident so that nothing could be called into question at a later date, the HCP was worried that they would fall behind with other residents or with other work, “... the disadvantage is that you have to be extra, or more careful,

because you'd have to say all of the extra details about what you're going to do, which would take more time."

3.6.13 Device Ratings

As discussed earlier in this chapter, to conclude each workshop or interview, participants were asked how they would rate the device in terms of the conversation during the workshop or interview. The rating is meant to be a quantitative value of what participants think of the device as a whole while keeping in mind the ethical concerns they discussed. Participants were asked to rate the device on a scale from 0-to 5, where 0 means the device does nothing to address the ethical concern(s) and they want nothing to do with it, while 5 means the device fully addresses the ethical concern(s) and they would be willing to use it as soon as possible. For the workshops, tenants rated the device according to each discussed ethical concern, while residents, caregivers, and HCPs were asked to give an overall rating of the device at the end of the interview. Therefore, to obtain an overall rating from tenants, the averages of each ethical concern were calculated, and those averages were averaged to obtain an overall rating for the device.

The overall ratings for the Hexoskin ProShirt™ and AWS DeepLens™ can be seen in Figures 3.6.13.1.1 and 3.6.13.2.1, respectively.

3.6.13.1 Overall Device Rating for the Hexoskin ProShirt™

Looking at Figure 3.6.13.1.1, all stakeholder groups provided high ratings for the Hexoskin ProShirt™, with tenants and the caregiver rating the device a 4/5, while residents and HCPs gave the Hexoskin ProShirt™ a 3.5/5.

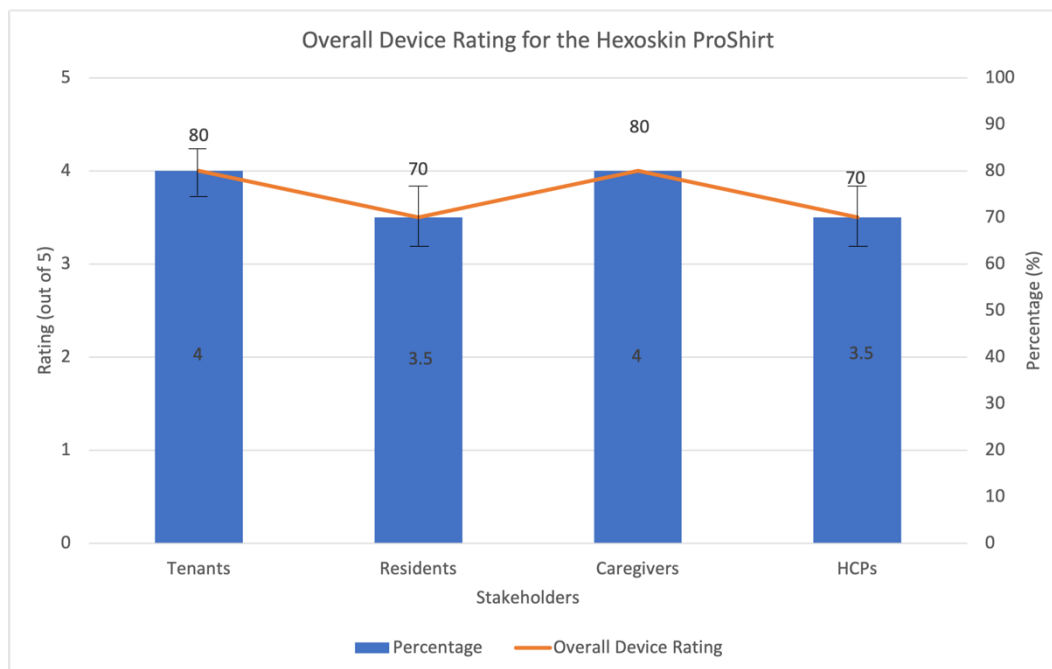


Figure 3.6.13.1.1: Overall Device Rating and Percentage from tenants, residents, caregivers, and HCPs for the Hexoskin ProShirt™

Since multiple tenants, residents, and HCPs participated in workshops and interviews with the Hexoskin ProShirt™, Standard Deviation (S.D) was calculated for each stakeholder rating of the shirt. The S.D for calculated for tenants is ± 0.47 , ± 0.62 for residents and ± 0.65 for HCPs.

3.6.13.2 Overall Device Rating for the AWS DeepLens™

The ratings for the AWS DeepLens™ were more spread out compared to the Hexoskin PorShirt™, as can be seen in Figure 3.6.13.2.1. Both tenants and HCPs gave the camera rating of 4/5, residents gave the camera a 3.5/5 rating, and the caregiver gave the AWS DeepLens™ a 5/5 rating.

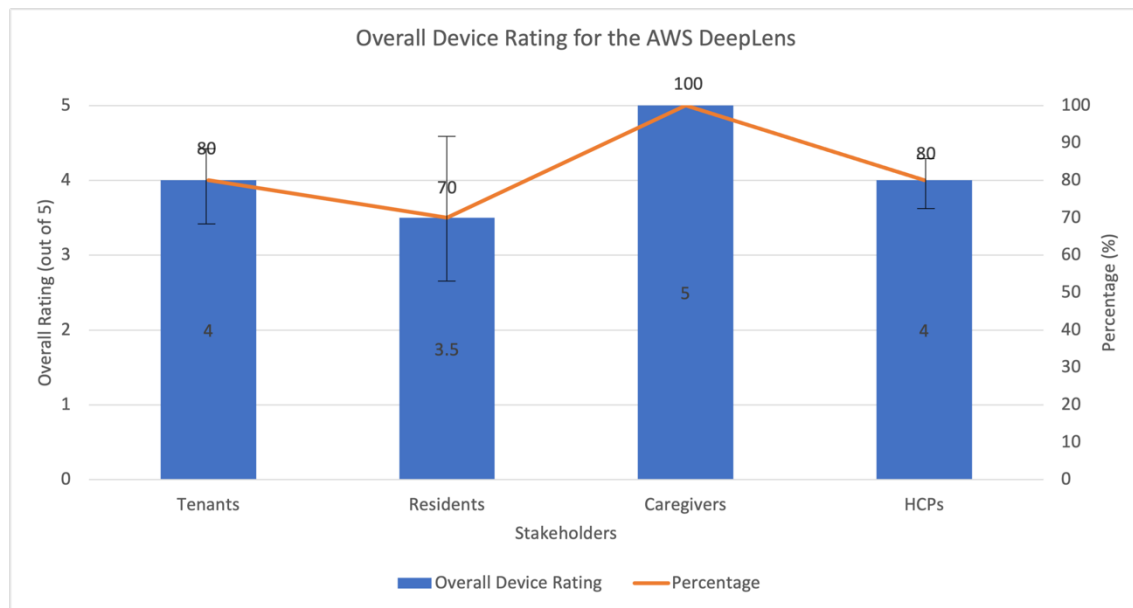


Figure 3.6.13.2.1: Overall Device Rating and Percentage from tenants, residents, caregivers, and HCPs for the AWS DeepLens™

Just as with the Hexoskin ProShirt™, S.D was calculated for the device ratings of the AWS DeepLens™ for each stakeholder group. The S.D for calculated for tenants is ± 0.77 , ± 1.45 for residents and ± 0.99 for HCPs.

3.7 Summary

The purpose of this chapter was twofold: 1) to present a detailed explanation of the study design used to conduct research with LTCF stakeholders, including tenants, residents, caregivers, and HCPs; and 2) to report the findings from the PD workshops and interviews conducted to investigate LTCF stakeholders' ethical thoughts regarding two AAL devices

The findings from the SLR presented in Chapter 2.0 provided a starting point for conducting research with the LTCF stakeholders. The SLR identified the initial ethical concerns and provided the groundwork for the topics that would be explored with participants for the Hexoskin ProShirt™ and the AWS DeepLens™. In the workshops with tenants, participants were actively involved, communicating with each other to discuss their thoughts on ethical

concerns relating to a device. These discussions raised new ethical concerns for both devices and were explored further in the remaining interviews. In the interviews with residents, caregivers, and HCPs, a semi-structured approach was used to ask participants their thoughts on a device while still allowing them to ask questions of their own.

By using the modified Grounded Theory approach, not only were the original ethical concerns investigated with participants, but new concerns were also identified and explored throughout the workshops and interviews. Direct and emergent content analysis was also utilized to code the transcribed data, creating a series of open, axial, and selective codes. At the end of the coding stages, 12 selective codes, or ethical concerns, were identified, and 35 axial codes, or ethical concern subcategories, were created. Six of the 12 ethical concerns were identified through emergent content analysis, meaning they are new ethical concerns that stakeholders brought up and discussed in the workshops and interviews and are uniquely tied to the Hexoskin ProShirt™ or the AWS DeepLens™.

Each ethical concern was investigated for each device based on its subcategories for each stakeholder group in terms of benefits and concerns. The findings are presented so that it is clear how many participants saw benefits or concerns with each subcategory that makes up an ethical concern for each device. Overall, stakeholders had the highest concerns with comfort, data privacy, device design, and social connectedness for the Hexoskin ProShirt™. For the AWS DeepLens™, stakeholders had the greatest number of concerns with autonomy, data privacy, device design, and social connectedness.

Finally, in section 3.6.12, the overall ratings for each device are presented for each stakeholder group. Tenants and caregivers rated both devices highly, with tenants giving a 4/5 (80%) to both devices and caregivers giving a 4/5 (80%) and a 5/5 (100%) for the Hexoskin ProShirt™ and the AWS DeepLens™, respectively. Residents and HCPs provided lower ratings for both devices, with residents providing a rating of 3.5/5 (70%) for both devices and HCPs giving a rating of 3.5/5 (70%) for the Hexoskin ProShirt™ and a 4/5 (80%) for the AWS DeepLens™. The lower ratings suggest that more will need to be done to address resident and HCP concerns before they use and adopt the devices or any AAL technology that implements them.

4.0 Prototyping the Ethical DataSheet

Artificial Intelligence (AI), and Machine Learning (ML) in particular, are rapidly evolving technologies that, despite the clear benefits they promise, have begun to raise serious ethical issues in the past several years. AI and ML (AI/ML) promise many benefits to various sectors, such as helping to mitigate climate change (Huntingford et al., 2019), optimizing business operations (Tarafdar et al., 2019), and developing cancer prognosis and prediction tools (Kourou et al., 2015). However, as AI/ML technologies advance, understanding how they work and/or how they generate results becomes more difficult. This lack of understanding of the underlying technological components, which has contributed to many of the ethical controversies surrounding AI/ML systems recently, is multi-faceted. For example, it can stem from a lack of transparency in how AI/ML systems are created (Ross & Swetlitz, 2017), or from complicated biases contained in the data on which the AI/ML models are trained (Buolamwini & Gebru, 2018), or from the complex sociotechnical systems in which they operate once deployed (Chopra & Singh, 2018).

These AI/ML knowledge gaps have opened fields of research over the past decade. High-profile examples motivating those fields have emerged, such as Google's infamous photo classification application that mistakenly labelled some black people as "gorillas" in photos (Simonite, 2018), or Microsoft's chatbot—named Tay—that exhibited misogynistic and racist tendencies after only 24 hours of being exposed to Twitter (Vincent, 2016), or the machine translation system that exhibited discriminatory behaviour against some genders (Mohammad, 2022). Such examples have led to heavy criticism of AI/ML systems and often raise uncomfortable questions for AI/ML researchers, developers, and other stakeholders involved in designing or developing such systems (Mohammad, 2022).

To help AI/ML developers anticipate some of the ethical issues that could arise throughout the design and development process of new AI/ML technology researchers in both academia (Bender & Friedman, 2018; Chmielinski et al., 2020; Holland et al., 2018; Yang et al., 2018) and industry (Gebru et al., 2021; Mitchell et al., 2019; Procope et al., 2022; Richards et al., 2020) have suggested and developed ethical design tools (EDTs) that are meant to highlight and address the many ethical issues that an AI/ML system can raise in specific contexts, such as healthcare. Such details could include why an AI or ML system was created, the data collected and used to train the system or the intended use cases for such a system. Of the examples found in the literature, some propose documentation intended for use by developers of AI and ML systems (Bender & Friedman, 2018; Chmielinski et al., 2020; Gebru et al., 2021; Holland et al., 2018; Mitchell et al., 2019; Mohammad, 2022; Richards et al., 2020), while others propose documentation meant for end-users or stakeholders who were directly impacted by these systems (Procope et al., 2022; Yang et al., 2018).

This chapter aims to accomplish two objectives: 1) to review the existing literature to find different types of EDTs that have been proposed for various AI/ML systems, and 2) to propose a prototype design tool that can be used to communicate the particular ethical concerns LTCF stakeholders have with AAL devices (from Chapters 2.0 and 3.0). The prototype developed in this chapter is meant to help engineers, designers, researchers, policymakers, healthcare professionals (HCPs), caregivers, and other LTCF stakeholders responsible for

developing and deploying new AAL technology, better anticipate the ethical concerns they may need to address in their projects.

4.1 A Review of Existing Ethical Design Tools for AI and ML systems

A snowball sampling literature review was conducted to find different EDTs for AI/ML systems in the literature. To begin the snowball sampling process, Gebru et al. (2021) was used to identify other publications that proposed EDTs for AI/ML systems. When a new publication was identified, that publication was read through to identify additional publications that proposed EDTs. To be considered viable for this research, the publication needed to introduce an ethical design tool for AI or ML and be written in the past five years (2018-2022).

Using this methodology with the inclusion criteria described above, ten publications were identified. Upon collection of the publications, the full text was read to determine if the publication proposed an EDT for AI or ML, and if any references used in the text, identified new EDTs. After reading through the ten publications, eight were retained for this literature review as two publications did not propose new EDTs. A brief summary of each tool identified and used in this research is seen in Table 4-1.

Table 4-1: Summary table of each Ethical Design Tool used in this research

Ethical Design Tool (EDT)	Author(s) and Year	Summary of EDT
Datasheets for Datasets	(Gebru et al., 2021)	Datasheets for Datasets aims to provide a standardized process for documenting machine learning datasets
AI Factsheets	(Richards et al., 2020)	AI Factsheets summarize information for use for a variety of stakeholders about how an AI model or service was developed and deployed
Data Statements for Natural Language Processing	(Bender & Friedman, 2018)	A data statement is a characterization of a dataset that informs readers of how the software should be deployed, how results might generalize, and the limitations present in the dataset when created
Data Nutrition Label	(Chmielinski et al., 2020; Holland et al., 2018)	The Dataset Nutrition Label is a framework that provides a comprehensive overview of the “ingredients” that make up a dataset, so that a reader is aware of the components before using the dataset

Ranking Facts	(Yang et al., 2018)	Ranking Facts uses the idea of a nutrition label to explain the elements that make up ranking and scoring systems
Model Cards for Model Reporting	(Mitchell et al., 2019)	Model Cards report details of datasets, such as intended use cases and possible outcomes, that are used to train and test ML models
System Cards	(Procope et al., 2022)	System Cards provide insight into ML system architecture to help explain how a system operates
Ethics Sheets for AI Tasks	(Mohammad, 2022)	Ethics Sheets are used to identify the assumptions and ethical considerations hidden in how an AI or ML task is framed and the decisions that are made regarding the data and evaluation process

By researching each tool through this literature review, an understanding for each tool was obtained, and different design elements were explored and considered for the proposed tool introduced later in this chapter. A summary of the eight identified tools is presented in section 4.2.3, and a full analysis of each tool is presented in Appendix C.

4.2 Prototyping the Ethical DataSheet

By conducting the snowball sampling literature review summarized in Table 4-1 and presented in Appendix C, different tools were used to document the intricacies and considerations of AI/ ML models and systems. This exploration uncovered that while many different tools look at different elements of an AI or ML system, each tool has the same goal of getting readers to think about the model or system they are creating or using. Taking inspiration from the above tools, this research proposes a tool, called an Ethical DataSheet (EDS), that attempts to get engineers and designers responsible for the development of AAL devices like the Hexoskin ProShirt™ and the AWS DeepLens™, to consider the ethical concerns that LTCF stakeholders may have with these types of devices.

To begin this section, I present the EDS prototype providing rationales for the different components. I then incorporate the findings discussed in Chapter 3.0 into the EDS prototype to show EDSs for the Hexoskin ProShirt™ and the AWS DeepLens™. Finally, I present a summary of the challenges and limitations associated with the prototype EDS.

4.2.1 Inspiration for the Ethical DataSheet Prototype

The Ethical DataSheet (EDS) prototype draws inspiration from various elements from the above tools. In introducing Datasheets for Datasets, Gebru et al. (2021) made the analogy that just as the simplest electronic components come with documentation explaining how they work and what they should be used for, datasets should have similar documentation to tell people more about the dataset and how it should be used. This analogy holds just as accurate with the EDSs for the devices to which it is applied. The purpose of developing an EDS prototype is so that engineers, designers, researchers, policymakers, and other affiliated stakeholders can use the tool to understand the concerns that LTCF stakeholders (such as older adults, caregivers, and HCPs) have with AAL devices before the devices are incorporated into more complex AAL technology.

In presenting EDSs in this manner, there are similarities to Ethics Sheets for AI Tasks proposed by Mohammad (2022). Just as done when creating Ethics Sheets, instead of looking at what the devices can do, this research aimed to understand the ethical concerns that LTCF stakeholders have with the devices individually before they are integrated into a more complex technology. Therefore, just like Ethics Sheets, EDSs are meant to preview the task ahead, to help engineers, designers, and other stakeholders understand LTCF stakeholders' concerns with the devices and find ways to address those concerns.

EDSs also share similarities with the Data Nutrition Label in how they are designed to resemble a familiar tool. The EDS prototype was designed to resemble a Material Safety Data Sheet (MSDS). An MSDS is a commonplace document in workplaces. It is of the utmost importance as it documents every known hazardous property of a material (e.g. hydrochloric acid), how safely to handle it, possible outcomes that could happen with the product if something goes wrong, and ways to mitigate harm or injury. Therefore, designing the EDS prototype to resemble an MSDS signals to the reader that the EDS should be read through and understood before working with the device, just as an MSDS should be reviewed before working with a chemical or a hazardous material. Like an MSDS, the EDS documents the properties of a device in a way that links them to the ethical concerns LTCF stakeholders have with the devices.

Even though EDSs share similarities to Datasheets for Datasets (Gebru et al., 2021), Ethics Sheets for AI Tasks (Mohammad, 2022), and MSDSs, EDSs differ in their presentation. Datasheets, Ethics Sheets, and MSDSs are all text-heavy, using questions or statements to communicate their information. EDSs, on the other hand, follow a presentation similar to tools like the Data Nutrition Label, Ranking Facts, and System Cards, using a mix of text and graphic elements to communicate important information. EDSs are meant to be a concise, consumable tool for engineers and designers to better understand LTCF stakeholders' ethical concerns with a device. Therefore, instead of using just text to communicate important information that readers should know, a mix of iconography, graphs, and bullet-point information is used to share important findings and provide a visually pleasing tool for the reader. In using both representations, the reader can either look through the images to take in the information or read through the text.

Additionally, by representing the information in two formats—text and visuals—EDSs have the potential to be represented in two versions, similar to long- and short-form Data Statements (Bender & Friedman, 2018). A short-form EDS could convey the information using

standardized pictures, graphs, and icons to deliver the essential material concisely. In contrast, a long-form EDS could use images and text to convey critical information with additional text to supply any supplemental information a reader might want to know.

Taking inspiration from the tools examined in Appendix C, the EDS prototype was developed for engineers, designers, researchers, and other stakeholders to read before the device is used for or integrated into a new AAL technology or intervention for LTC. The EDS is a tool that provides the reader with insight into the ethical concerns that different LTCF stakeholders have with a device, and that may arise if the device is used in AAL technology in LTC settings. Therefore, the EDS for a device identifies these ethical concerns for the different LTCF stakeholders so that engineers, designers, and other readers are aware of the ethical concerns they will need to keep in mind and address when developing AAL technology, or interventions using the technology.

Details about the development of the EDS prototype are presented in the following sections, along with EDSs for the Hexoskin ProShirt™ and the AWS DeepLens™. To develop the EDSs for the two devices, data from Chapter 3.0 was translated into the EDS prototype to present the ethical concerns that the LTCF stakeholders expressed through the workshops and interviews with the Hexoskin ProShirt™ and the AWS DeepLens™.

4.2.2 The Ethical DataSheet Prototype

The EDS prototype can be used by anyone who wants to make their own EDS for a device that could be used for AAL technology in LTC settings. The first page of the prototype provides an overall look at the device in question, providing a device description along with device specifics and characteristics. Following the first page, the prototype is separated into sections for each stakeholder group that is considered. In each section, a description of the stakeholder is given and then the stakeholder's top three ethical concerns are presented and explained along with the rating that the stakeholder group gave the device.

In order to provide guidance for someone who is creating their own EDS for a device, comments and notes were left throughout the prototype to help guide the creator in elements that they may want to consider when creating their own EDS, as seen in Figures 4.2.2.1 – 4.2.2.3.

As briefly described above, the first page of the EDS is meant to be an introduction to the device itself, similar to how a System Card or an MSDS are presented, providing the reader with a brief description of the product, its purpose, and additional information. The first page of the EDS prototype, seen in Figure 4.2.2.1, provides basic information that a reader should know about the device and the EDS itself. This means that the creator or company that developed the EDS should feature prominently in the top left-hand corner with contact information if the reader has questions or concerns about the EDS. In the top right-hand corner, information about when the EDS was created, and its revision dates, should be present. As discussed above, many of these tools are constantly changing as new information is obtained. Therefore, by providing creation and revision dates, the reader is aware of how often stakeholders' opinions change with the device or if the reader should consider conducting their own study if revisions have not been made in some time. The remainder of the first page for the EDS consists of device-specific information, including the name of the device and identification and characteristics sections that the creator of the EDS will fill out. By providing information about

the characteristic information of the device, the reader is aware of what the device is, what it might be used for, the contexts the device should be used in, and how stakeholders may interact with it. By providing this information on the EDS's front page, the reader is able to understand some of the ethical concerns LTCF stakeholders have with the device. The last element on the front page of the EDS is a space to include a picture of the device being discussed. By providing a picture of the device, the reader is immediately familiar with the device being discussed.

It is important to note that the information found in an EDS will change depending on the device for which the EDS is being created and the context in which it is being used (e.g. AAL in an LTCF). For example, depending on the device, the first page of the EDS may have different labels in the Device Characteristic section. For instance, in Figure 4.2.2.1, there is a 'Putting the Device On' label in the Device Characteristic section. However, for the AWS DeepLens™, this label doesn't make sense and, therefore, wouldn't be present on the AWS DeepLens™ EDS.

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**Be sure to add who created the EDS, so that people are aware and have contact information in case they have questions*

Creation Date: DD/MM/YYYY
 Revision Date: DD/MM/YYYY
**important to show the revision date so the reader has a sense as to how often the concerns change*

Ethical DataSheet

**add a picture of the device*

Device Name: **Name of the device goes here*

Device Identification **list the basic information someone should know about the device from the start*

Device Name: <i>*Name of Device</i>	Device Purpose: <i>*Provide an overview of what the device does so the reader has an understanding</i>
Device Type: <i>*What kind of device is this? (Wearable, camera?)</i>	Context of Use: <i>*Provide an overview of the contexts the device should be used in for acceptance</i>
Device Manufacturer: <i>*Who created the device?</i>	

Device Characteristics **these are subject to change based on the device*

Weight:	Device Components: <i>*Sensors? Attachments? External components?</i>
Colour:	Type of Data Collected: <i>*Biological? Images? Video?</i>
Size:	Data Storage Location: <i>*Where is the data collected, stored?</i>
Cost:	
Putting Device On:	

1

Figure 4.2.2.1: First Page of Ethical DataSheet Prototype

The remaining pages of the EDS—the Stakeholder Sections—follow a similar layout but are grouped by different stakeholders. For example, for this research, the LTCF stakeholders involved included tenants, residents, caregivers, and HCPs. Therefore, the EDSs for this research have four stakeholder sections, each specific to the ethical concerns that a particular

stakeholder group had with the device. By designing the prototype in this manner, the EDS follows a modular design, meaning that engineers and researchers can reference the relevant pages for their work if they design only for one or two stakeholder groups.

As the remaining pages of the EDS are identical except for the stakeholder group they are being used for, the tenant portion of the EDS will be used to explain the layout of the remaining pages.

Each section dedicated to a stakeholder group starts by providing the reader with a description of who the stakeholders are, as seen in Figure 4.2.2.2. This is important because before a device is used or incorporated into technology, engineers, designers, and other readers should have an idea of the people for whom they are designing. This description can be as long or short as the creators want to make it, with the description communicating to the reader the most important things they should know about the stakeholder group.

Following the stakeholder description, the overall device rating obtained during the research (workshops and interviews for this research) is displayed. While the ratings collected from the research ranged from 0 – 5, for the prototype, the overall rating is presented as a percentage. As described in Chapter 3.0, the rating is meant to provide the reader with an understanding of how positively or negatively the stakeholder group sees the device knowing the ethical concerns that were discussed during the research.

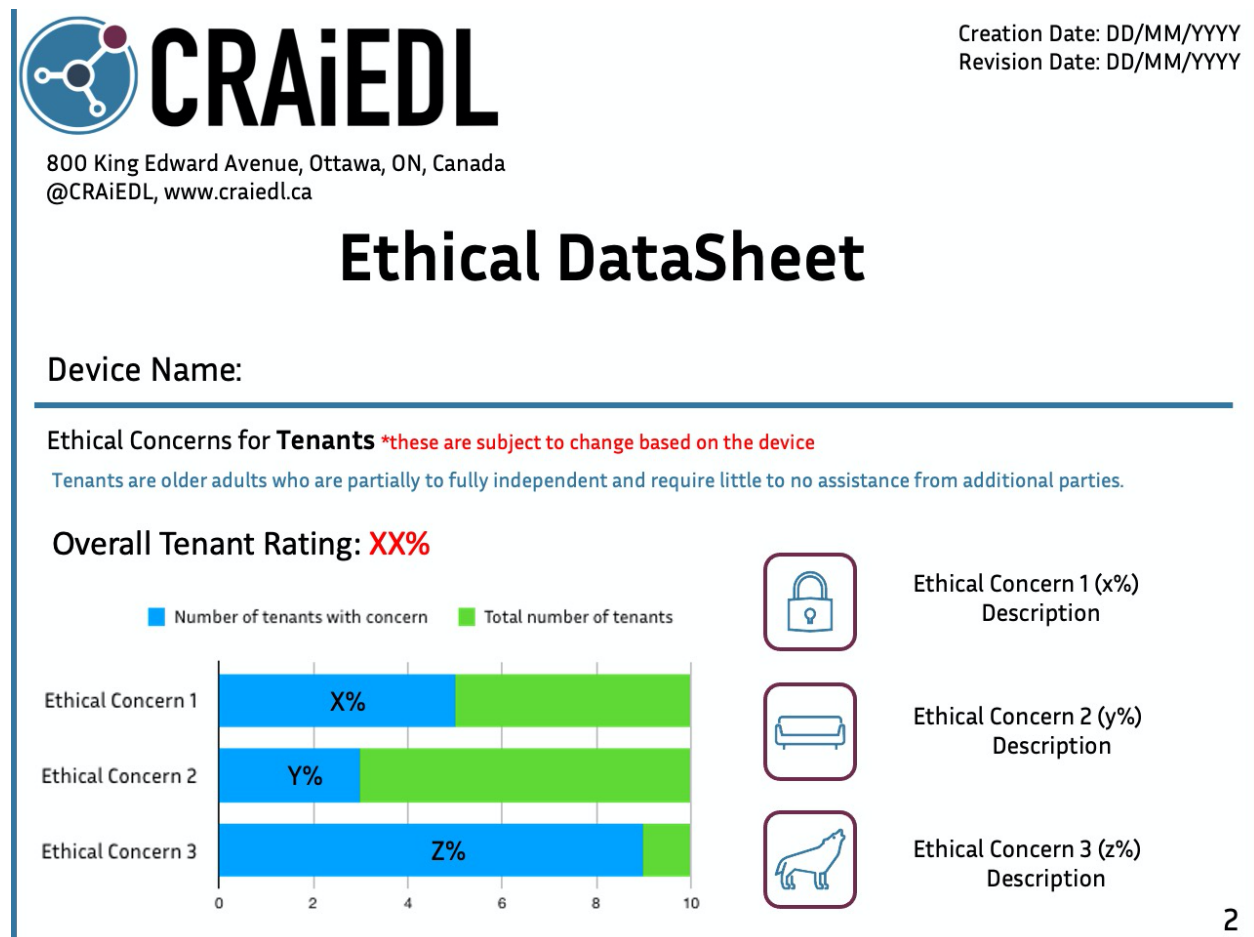


Figure 4.2.2.2: First page of the Tenant Section of the EDS




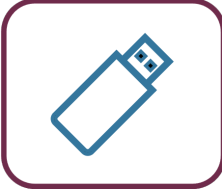

The graph on the left-hand side of the page represents the top three ethical concerns raised when talking with the stakeholder group about the device. The graph also represents the number of stakeholders who had concerns out of the total number of participants. The graph is meant to give the reader a snapshot of the most significant concerns that the stakeholder group raised throughout the research. It is also used to give the reader a distribution of how many stakeholders had concerns versus the overall number of participants. By presenting the information in this format, as opposed to just the percentage of stakeholders who had concerns, the reader is made aware of the other stakeholders who participated but didn't have the same concerns or didn't express their concerns as vocally as other stakeholders. Therefore, the reader is presented with an overall picture of the concerns, and how strongly they resonated with the stakeholder group that participated in the research. Overall, the graph is meant to provide the reader with a better understanding of the concerns they will need to keep in mind and address as they design and develop new AAL technology for LTC settings, but it also provides a breakdown of which concerns resonated with stakeholders the most.




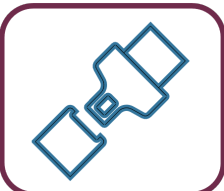

To the right of the graph, icons are used to represent the ethical concerns, along with overall percentages for the number of stakeholders who had those concerns. Using iconography in EDSs is meant to resemble the use of icons in an MSDS. In an MSDS, icons represent the Workplace Hazardous Materials Information System (WHMIS), which is Canada's national Hazard communication system (Health Canada, 2022). When used in an MSDS, WHMIS symbols indicate the hazards and, therefore, the precautions that must be taken when handling the chemical or product that the MSDS is referencing. In the same way, literal and metaphoric icons were developed to act as metaphors for the ethical concerns (Leta Jones & Millar, 2017), as seen in Table 4-2. For this research, literal icons are an exact representation of the ethical concern, while metaphoric icons are conceptual representations of the ethical concern (Saul & Rodier, 2021). To ensure that readers associate the icon with the correct ethical concern on the EDS, the ethical concern is written beside the image, as seen in Figure 4.2.2.2. However, if EDSs become more commonplace, the goal would be for readers to recognize the icon and be able to associate it with the ethical concern without the concern beside the picture (similar to WHMIS symbols and their hazards).



Overall, by developing and using icons in the EDSs, another representation of the ethical concerns are presented to the reader so that they can understand the ethical concerns they will need to address with the device when designing and developing their AAL technology.

For this research, as 12 ethical concerns were identified, 12 icons were developed to represent the various concerns, as seen in Table 4-2 below.

Table 4-2: Explanation of the different icons used to represent the ethical concerns in the EDSs

Ethical Concern	Explanation of Ethical Concern	Icon	Explanation of Icon
Autonomy	The ability to make decisions for oneself		<p>Since autonomy is the ability to make decisions for oneself, the two flags going in different directions are meant to represent the choices people have to choose their own path</p>
Comfort	The state of physical ease and relaxation		<p>Oftentimes, couches are used to not only be a comfortable seat but also to set people at ease so they can relax in different environments</p>
Cost	The amount of money required to obtain the device		<p>In North America, the Dollar Sign is used to represent the price of an object</p>
Data Privacy	The control one has over information that is personal to them		<p>The USB stick is used to represent the large amounts of data that are being collected. In presenting this concern as a USB stick, it signifies the control that a person has over their own data.</p>
Device Design	The characteristics and elements that make up the device		<p>Many stages happening when designing a device. Therefore, the person at a drafting table icon is meant to represent the</p>

			drafting stage when engineers and designers are still considering all of the elements that will make up a device
Economic Distribution	How the devices are distributed based on economic status		This icon represents how wealth may be distributed and the disparities that can result from it
Independence	One's ability to complete a task without help from others or technology		Often, someone who completes tasks without help from others is described as a lone wolf which is the icon used for this concern
Personal Privacy	The control one has over their physical self or space		To keep things private, locks are used as a method of protection. Therefore, a lock is used to represent this concern.
Safety	Is the feeling of being protected or away from danger		Safety is about being protected from danger, and in a car, a seatbelt is meant to do exactly that for the passengers
Device Purpose	Is the reason why the device is created or used		Stakeholders want to know exactly what the device will be used for- therefore, the bullseye is meant to represent the need for a precise explanation of the device

Social Connectedness	The experience of feeling close or connected to others; it is a sense of belonging to a social relationship		As social connectedness is about feeling close or connected to others, when the opposite happens, it can be very lonely and isolating, which can be pictured as being alone on a desert island
Workload	The amount of work that has to be done		When so many things are happening at once, each one demanding attention, it can feel like a juggling act

The second page of each stakeholder section provides more details about the stakeholder group’s ethical concerns, as seen in Figure 4.2.2.3. The ethical concerns are broken down further on this page so readers understand which elements concern the stakeholder group the most. These sub-categories are meant to be the axial codes identified using emergent content analysis from Chapter 3.0. Examples of how the page looks when completed can be seen in sections 4.3 and 4.4 for the Hexoskin ProShirt™ and the AWS DeepLens™, respectively, while the Full EDSs for the Hexoskin ProShirt™ and the AWS DeepLens™ can be found in Appendices D and E. The icons and percentages are also included to provide a visual element and remind the reader of the percentage of stakeholders that had worries about the ethical concerns for the device.

Section 3: Ethical Concerns for Tenants (Continued) *these are subject to change based on the device



X%

Ethical Concern #1 (List the subcategories and their descriptions that raised the largest concerns)

- Subcategory 1: Description
- Subcategory 2: Description



Y%

Ethical Concern #2 (List the subcategories and their descriptions that raised the largest concerns)

- Subcategory 1: Description
- Subcategory 2: Description



W%

Ethical Concern #3 (List the subcategories and their descriptions that raised the largest concerns)

- Subcategory 1: Description
- Subcategory 2: Description

Other notable concerns include: ethical concern #4, ethical concern #5, ethical concern #6

3

Figure 4.2.2.3: Second Page of the Tenant Section of the EDS

At the bottom of the page, space is left for other notable concerns that stakeholders have, which readers should be aware of when planning to implement the device in particular context-specific purposes (e.g. AAL in LTCF). If more than three concerns need to be displayed for a stakeholder group, the EDS should be adapted to present all information relevant to the reader. This can be done by decreasing the icons' size and not being as detailed with the subcategories for each concern.

It is important to stress that the EDS prototype is meant to be adaptable depending on the device it is being created for and the stakeholders that are involved. Therefore, creators of new EDSs must decide the information they want to convey to the reader about the device and what ethical concerns, for the different stakeholders, they want to share with the reader. Just as was discussed with AI Factsheets, EDSs are not a *'one size fits all'* tool. Each EDS for a device will have differences, from the design characteristics of the device to the ethical concerns each stakeholder group has with the device.

Once the EDS prototype was finalized, it was used to develop EDSs for the Hexoskin ProShirt™ and the AWS DeepLens™. The EDSs for both devices are in the following two sections. All of the data used to populate the EDSs for both devices is from Chapter Three, where the findings from the workshops and interviews with LTCF stakeholders were discussed.

4.3 Ethical Datasheet for the Hexoskin ProShirt™

The EDS for the Hexoskin ProShirt™ was developed using the prototype presented above, along with the data that was presented and discussed in Chapter 3.0. This section presents the first page of the EDS for the Hexoskin ProShirt™, along with the Resident Section. The full EDS for the Hexoskin ProShirt™ can be seen in Appendix E.

The first page of the Hexoskin ProShirt™ EDS provides the reader with device information and characteristics, as seen in Figure 4.3.1. The features are unique to the Hexoskin ProShirt™ and give the reader more background about the device.




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Creation Date: 02/07/2022
Revision Date: DD/MM/YYYY

Ethical DataSheet



Device Name: Hexoskin ProShirt

<p>Device Identification</p> <p>Device Name: Hexoskin ProShirt Device Type: Vest (wearable device) Device Manufacturer: Hexoskin Manufacturer Origin: Canada</p>	<p>Device Purpose: Used to monitor vital signs including cardiac, respiratory, and movement</p> <p>Context of Use: Should be used when the wearer is out and about- not as popular for home usage</p>
<p>Device Characteristics</p> <p>Weight: 80g (3.02 oz) Colour: Dark Blue Size: 2XS – 4XL Cost: \$648.00 USD Putting Device On: Over the head</p>	<p>Device Components: Five internal sensors, one external sensor (data recorder)</p> <p>Type of Data Collected: Vital (heart and breathing) and activity (movement)</p> <p>Data Storage Location: 3 locations (Locally in the data recorder, on Hexoskin servers, or the PATH database) 1</p>

Figure 4.3.1: First page of the EDS for the Hexoskin ProShirt™

Following the first page of the EDS, the Stakeholder Sections for Tenants, Residents, Caregivers, and HCPs present the three most discussed ethical concerns from each stakeholder group. The Tenants, Caregivers, and HCPs sections for the Hexoskin ProShirt™ can be seen in Appendix D, while the Residents Section is presented in Figures 4.3.2 and 4.3.3 below.

89

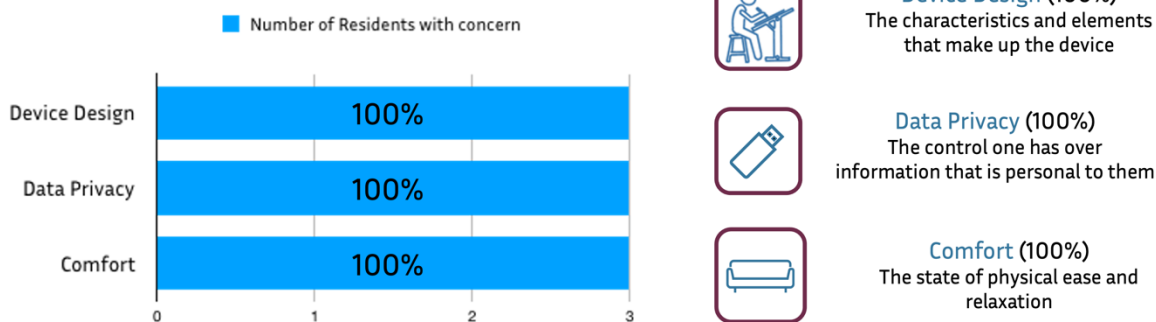
Ethical DataSheet

Device Name: **Hexoskin ProShirt**

Section 3: Ethical Concerns for Residents

Residents are older adults who are living in Long Term Care and require additional to around-the-clock care from healthcare professionals

Overall Resident Rating: **70%**



4

Figure 4.3.2: First page of the Residents Section in the Hexoskin ProShirt™ EDS

In Figure 4.3.2, the three most discussed concerns for residents that participated in the study with the Hexoskin ProShirt™ were Device Design, Data Privacy, and Comfort, with all three residents raising points for each concern during their interviews. The overall rating of how residents view the Hexoskin ProShirt™ in relation to the ethical concerns discussed is also prominently displayed on the EDS.

To provide more detail about residents' concerns, the second page of the EDS is meant to provide the reader with more information to help them understand the background for each concern, as seen in Figure 4.3.3.

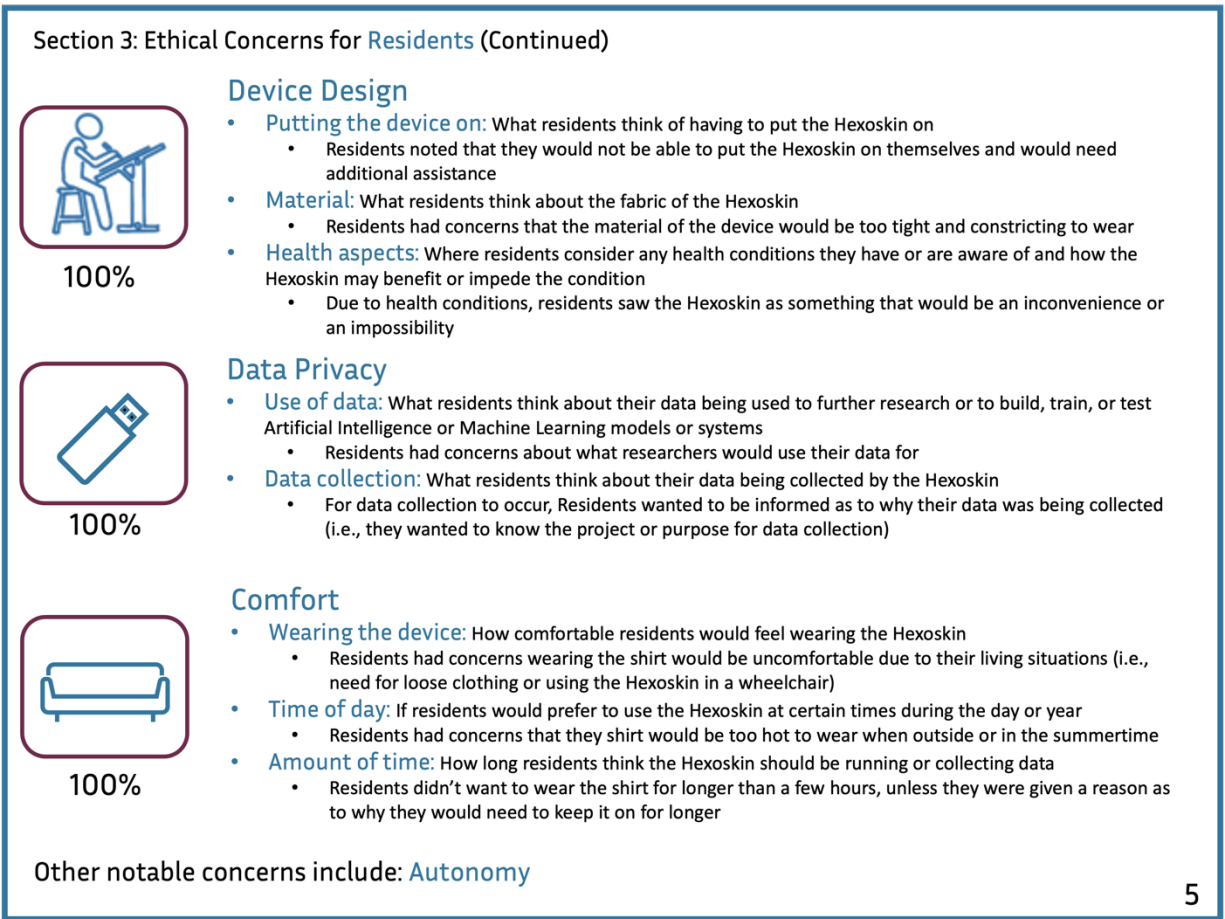


Figure 4.3.3: Second page of the Residents Section in the Hexoskin ProShirt™ EDS

To provide more detail on the top three ethical concerns, axial codes, presented in Chapter 3.0, are defined and used to provide the reader with more insight into what topics made the ethical concerns worrisome to the stakeholder group. Therefore, the second page of the Residents Section in the EDS provides more information about why residents had concerns with Device Design, Data Privacy, and Comfort when considering the Hexoskin ProShirt™.

4.4 Ethical Datasheet for the AWS DeepLens™

Just as with the Hexoskin ProShirt™ EDS, the EDS for the AWS DeepLens™ was developed using the prototype presented above, along with the data that was presented and discussed in Chapter 3.0. This section presents the first page of the EDS for the AWS DeepLens™ along with the Tenant Section. The full EDS for the AWS DeepLens™ can be seen in Appendix F.

Like the EDS for the Hexoskin ProShirt™ presented above, the first page of the AWS DeepLens™ EDS provides the reader with device information and characteristics, as seen in Figure 4.4.1. Since the AWS DeepLens™ and the Hexoskin ProShirt™ are different devices, the first page of each EDS will reflect this and provide the reader with different information for the different devices.

Ethical DataSheet



Device Name: AWS DeepLens

Device Identification

Device Name: AWS DeepLens
Device Type: Camera
Device Manufacturer: Amazon Web Services (a subsidiary of Amazon)

Device Purpose: Captures photo and video data to perform Deep Learning capabilities

Context of Use: Preference to be used in public spaces and not private ones (i.e., bedroom or bathroom)

Device Characteristics

Weight: 296.5 g (10.5 oz)
Colour: White
Size: 47x94x168 mm
Cost: \$249.00 USD

Device Components: AWS DeepLens camera, Micro SD card, Power Supply

Type of Data Collected: Photo and video data

Data Storage Location: 3 Locations (locally on the Micro SD card, the AWS Cloud, or the PATH Database) 1

Figure 4.4.1: First page of the EDS for the AWS DeepLens™

Again, following the first page of the EDS, the Stakeholder Sections for Tenants, Residents, Caregivers, and HCPs present the three most discussed ethical concerns from each stakeholder group. The Residents, Caregivers, and HCPs sections can be seen in Appendix E, while the Tenants Section is presented in Figures 4.4.2 and 4.4.3 below.

Ethical DataSheet

Device Name: AWS DeepLens

Ethical Concerns for Tenants

Tenants are older adults who are partially to fully independent and require little to no assistance from additional parties.

Overall Tenant Rating: **80%**

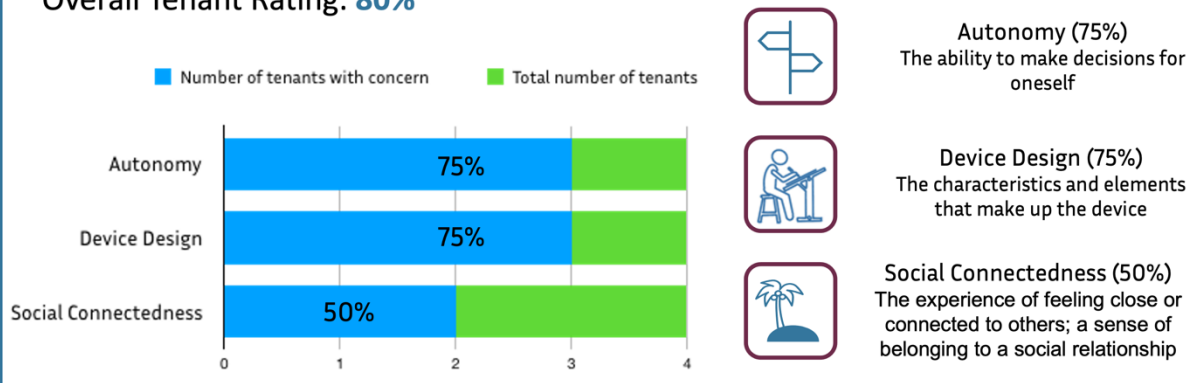


Figure 4.4.2: First page of the Tenants Section in the AWS DeepLens™ EDS

Just as with the Residents section for the Hexoskin ProShirt™ EDS, the Tenants Section for the AWS DeepLens™ EDS presents the top three ethical concerns that were the most discussed through the workshop with tenants, with three out of four tenants raising concerns with Autonomy and Device Design for the AWS DeepLens™, while two out of four tenants had concerns with Social Connectedness. Visual elements and text are used to communicate these findings to the reader. Again, the overall rating of how tenants view the AWS DeepLens™ in relation to the ethical concerns discussed is also prominently displayed on the EDS.

As done above, to provide more context to tenants' top three most discussed ethical concerns, the second page of the Tenants Section uses axial codes to offer more details on what elements concerned tenants the most.

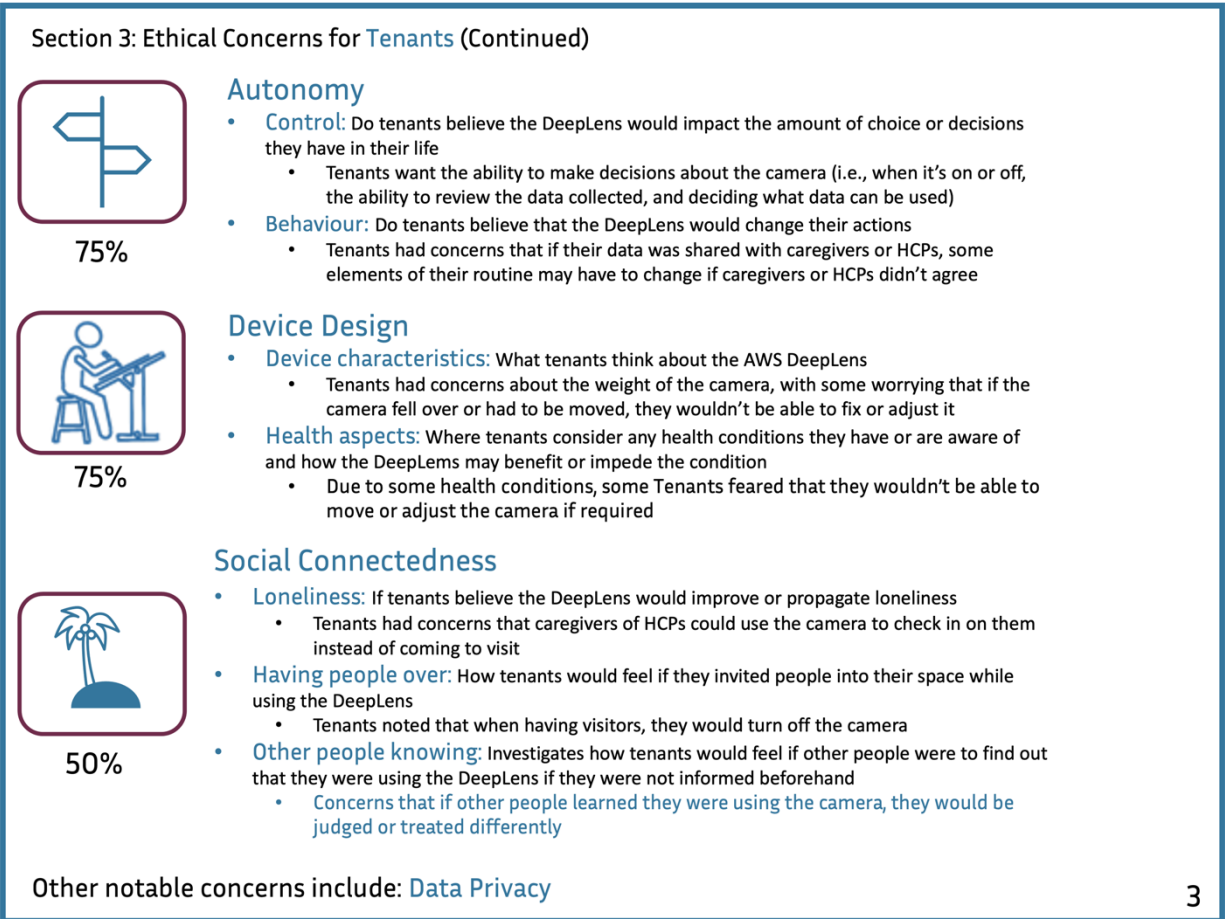


Figure 4.4.3: Second page of the Tenants Section in the AWS DeepLens™ EDS

As seen in Figure 4.4.3, the second page of the Tenant Section for the AWS DeepLens™ EDS uses different axial codes to provide more context as to why tenants found Autonomy, Device Design and Social Connectedness the most worrisome ethical concerns throughout the discussion regarding the AWS DeepLens™.

4.5 Challenges with the Ethical DataSheet

The EDS was developed as a communication tool meant to translate LTCF stakeholders' concerns with a device to engineers, designers, and researchers, and anyone attempting to address the ethical concerns in future AAL applications that implement the device in LTC facilities. However, as with the tools described above, EDSs have challenges.

First, even though this tool outlines the ethical concerns that LTCF stakeholders have with the device, there is no guarantee that engineers, designers, or other potential EDS users will use the EDSs in their work. This may be especially true if addressing the concerns appear to hesitant users as monumental tasks, which could easily be the case if engineers and designers are unsure how to move forward with the information. Therefore, it is essential that to evolve EDSs the next step is to prototype the design tool with engineers, designers, and other similar stakeholders to understand the limitations specific to those EDS stakeholders. By involving as many stakeholders as possible, more thoughts and opinions can be gained on how the EDSs

should look, the type of information they should present, and what would make the EDSs more practical overall.

Second, depending on the technology being developed and who the technology and device may impact, an EDS could grow to be very long. If many impacted stakeholders are identified, and each stakeholder group has different concerns, EDSs could grow to be overwhelmingly long. If this were to happen, the tool may be ignored due to its length and complexity. However, by implementing an idea similar to Data Statements (Bender and Friedman, 2018), there could be long- and short-form EDSs. This obstacle may be overcome so that the most important information is conveyed in a short, digestible manner, while an accompanying longer document could provide additional information if required.

Lastly, collecting the ratings with LTCF stakeholders proved to be difficult as many stakeholders did not enjoy providing ratings for either device without seeing them, or trying them for themselves. Therefore, depending on how future iterations of the EDSs are developed, new methods to obtain LTCF stakeholders' overall approval of a device should be investigated.

Just as with the tools presented above, EDSs will not solve all of the concerns that LTCF stakeholders have with AAL devices. However, EDSs are the first step in identifying LTCF stakeholders' concerns and making engineers and designers aware of those concerns so that they can attempt to address them through the design and development process of new AAL technology. Therefore, in addressing these concerns, stakeholders may be more inclined to use, accept, and adopt the technology in their day-to-day lives.

4.6 Summary

This chapter presented several design tools that aim to bring ethical considerations to the forefront of AI/ML model and system development. By investigating these tools, elements of each were ascertained and used to influence the development of the EDS prototype and, therefore, the EDSs for the Hexoskin ProShirt™ and the AWS DeepLens™.

The EDS prototype was developed using different elements from the various tools investigated in Appendix C. Meant to resemble an MSDS, the EDS is designed for engineers, designers, and any other interested party to understand the ethical concerns that LTCF stakeholders have with a device before the device is incorporated into a more complex technology, such as AAL technology. Just like an MSDS, the EDS for a device is meant to be read before using the device so that the reader has a better understanding of the stakeholders they are designing for and the concerns those stakeholders have with the device. In knowing more about stakeholders' concerns, engineers and designers can address and accommodate the concerns when developing technology that uses the device in question.

The EDS prototype was developed first, as this research aims to provide a tool that other researchers can use to explore and present the ethical concerns that LTCF stakeholders have with a device. Once the prototype was developed, it was used to create sample EDSs for the Hexoskin ProShirt™ and the AWS DeepLens™. By conducting this research and using the prototype to present the findings, LTCF stakeholders' concerns with the devices are available in an easy-to-read, digestible format.

However, as with the tools that have come before the EDS, some questions will need to be addressed as the EDS progresses. For example, two important questions arise now that the

EDS has been proposed. The first is to see if this tool is helpful to engineers and designers who are tasked with developing AAL technology that implements the device the EDS was created for. The second question is, if EDSs are used to develop AAL technology, do LTCF stakeholders feel their concerns were adequately addressed in the resulting technology.

These questions open up new opportunities and research to explore the future of EDSs, from prototyping the tool further with engineers, designers, and LTCF stakeholders, to using the tool to develop AAL technology to see the outcome and receive feedback from LTCF stakeholders.

Overall, just as with the tools that have come before it, EDSs are meant as a design tool to help the reader understand the ethical implications their work will have, whether it's working with AI or ML models, systems, devices, or technology. For EDSs, they offer an invaluable opportunity to identify, understand, and address end-users concerns with a device so that end-users are more open to using, accepting, and adopting the device and any related technology in their day-to-day lives.

5.0 Conclusions and Future Work

This research had two objectives:

OBJ1: Investigate and understand how the ethical concerns raised by stakeholders, including older adults, caregivers (family and friends), and HCPs, have been, and should be addressed in the design and development of AAL technology.

OBJ2: Prototype an ethical engineering design tool that conveys stakeholders' ethical concerns with devices used in AAL technology.

To meet these two objectives, this research set out to answer three research questions:

RQ1: How are ethical concerns voiced by long-term care stakeholders influencing the design, development, and implementation of AAL technology?

RQ2: How well does a Participatory Design methodology work to uncover the ethical concerns that long-term care facility stakeholders have regarding the Hexoskin ProShirt™ and the AWS DeepLens™?

RQ3: How can Ethical DataSheets be created to convey the ethical implications that must be considered before an AAL device is developed and deployed?

To answer these questions, different research strategies were used. To answer RQ1, a systematic literature review (SLR) was conducted to investigate the ethical concerns that LTC stakeholders have had with AAL technology. The SLR also explored the different ethical design and engineering frameworks that have been proposed or used to address stakeholders' concerns when designing and developing new AAL technology. Next, using a Participatory Design (PD) Methodology, PD workshops and interviews were conducted with long-term care facility (LTCF) stakeholders to elicit their ethical concerns with two AAL devices from the PATH project: the Hexoskin ProShirt™ and the AWS DeepLens™. Findings from the SLR influenced how the research with LTCF stakeholders was conducted, from the ethical concerns that were explored to the questions that were developed and asked.

When analyzing the data, direct and emergent content analysis strategies were used through open, axial, and selective coding to identify the ethical concerns that LTCF stakeholders saw with the two devices. Finally, a snowball sampling literature review was conducted to identify and investigate different ethical design tools in order to prototype a new ethical design tool for this research. To propose this tool (called an Ethical DataSheet or EDS), elements from the tools explored in the literature review were used to develop an EDS prototype, and then the prototype was used to create EDSs for the Hexoskin ProShirt™ and the AWS DeepLens™. The purpose of an EDS is so that engineers and designers can use the tool to gain a better understanding of the ethical concerns that LTC stakeholders have with a device. Furthermore, by identifying these concerns, engineers and designers are better equipped to address stakeholders' ethical concerns when designing and developing new AAL technology.

5.1 How are Ethical Concerns Voiced by Long-Term Care Stakeholders Influencing the Design, Development, and Implementation of AAL Technology?

To answer the first research question, two interrelated research areas were explored through the Systematic Literature Review presented in Chapter 2.0. The first area was to identify the different ethical concerns that ageing-in-place stakeholders (i.e., older adults, caregivers, and HCPs) had with AAL technology. The second was to explore the different ethical design and engineering frameworks used or proposed to address stakeholder concerns.

In total, 44 publications were deemed acceptable to use, and 41 out of the 44 publications were accessible. By conducting the SLR, 17 ethical concerns were identified across the 41 publications, with the six most popular ethical concerns with respect to AAL technology being Social Isolation, Autonomy, Privacy (personal and data), Independence, and Control. Overall, social isolation was mentioned in over half of the collected publications, while control was mentioned in a quarter of the publications. The top six ethical concerns were then used to develop the Participatory Design methodology for the workshops and interviews conducted with LTCF stakeholders.

Of the 41 publications that were used for this research, 36 used or discussed an ethical design and engineering framework in their publication. Of the 36 papers that discussed an ethical design and engineering framework, nine used a framework to design and develop AAL technology. Of the nine publications that used a framework to develop new AAL technology, six used well-known, documented frameworks to develop their technology, while the remaining three publications used novel frameworks. Therefore, this addresses the above SLR research question regarding the use of ethical design and engineering frameworks to design and develop AAL technology.

Interestingly, of the 21 ethical design and engineering frameworks identified from the literature, ten were well-known frameworks that have been documented in other literature (such as User-Centered Design and Participatory Design). In contrast, the remaining 11 frameworks were new frameworks that were proposed through the publication. These numbers indicate that researchers are growing aware of the ethical concerns and challenges that AAL technology in ageing-in-place settings poses and are trying to address those concerns by developing and proposing new ethical design and engineering frameworks. As mentioned in Chapter 2.0, even though 11 new frameworks were proposed, many took inspiration from other well-known frameworks. These adaptations of old frameworks are another indication that researchers are identifying the challenges that AAL technology poses for ageing-in-place and are trying to adapt well-known frameworks to fit specific situations.

Moreover, from the collected literature, when an ethical design and engineering framework was used to produce an AAL technology, ageing-in-place stakeholders regarded it highly. When asked what stakeholders thought about the new technologies, many believed that the technology could meet their needs and fit into their, their loved ones, or their patient's lifestyle: a promising sign of acceptance and adoption.

However, one caveat is that even though new frameworks are being proposed to identify and address ageing-in-place stakeholders' ethical concerns with AAL technology, aside from one, each new framework has not been used by outside researchers (i.e., researchers who did not propose the framework). While proposing new frameworks is important, frameworks that have already been suggested should be implemented to understand their success and what needs to

be changed in the future. It is fair to say that one framework cannot be the catch-all, especially for ageing-in-place circumstances; however, it is also important to iterate and improve on the work that has already been proposed. In this way, new findings and research questions may emerge.

5.2 How well does a Participatory Design Methodology work to Uncover the Ethical Concerns that Long-Term Care Facility Stakeholders Have Regarding the Hexoskin ProShirt™ and the AWS DeepLens™?

For this research, conducting workshops and interviews using a PD methodology with LTCF stakeholders was successful. Overall, 30 LTCF stakeholders participated in workshops and interviews, where they discussed their thoughts, opinions, and concerns with the Hexoskin ProShirt™ and the AWS DeepLens™. Tenants participated in interactive workshops where they discussed a device among themselves, while residents, caregivers, and HCPs participated in semi-structured interviews where they discussed their thoughts about a device with the researchers.

Overall, many of the concerns identified through the SLR resonated with the LTCF stakeholders for the Hexoskin ProShirt™ and the AWS DeepLens™. However, by following a PD methodology, stakeholders were able to identify new ethical concerns not identified through the SLR and that were unique to the two devices discussed. Therefore, following a PD methodology enabled the verification of findings from the SLR while also allowing new themes and discoveries to emerge.

Some findings from SLR were verified by conducting research with LTCF stakeholders. For example, LTCF stakeholders raised many concerns regarding their autonomy, privacy (personal and data), and fears about social isolation for both devices. Therefore, these findings may suggest that some ethical concerns apply to many devices used in AAL technology and should be considered when integrating any new device into future AAL technology.

On the other hand, some findings from the SLR contradicted the findings from the PD workshops and interviews. For example, many papers in the SLR commented that while LTC stakeholders saw value in AAL technology, they did not want to use it until needed. From the workshops and interviews with LTCF stakeholders, many saw benefits with the two devices (as seen in Figures 3.6.9.1.1 and 3.6.9.2.1). Most LTCF stakeholders were eager to use the devices sooner rather than later because they saw them either as a way to take back control of their lives or as an additional safety measure that they could implement.

One finding that was interesting was the limited discussion around equity in relation to the devices. Both the Hexoskin ProShirt™ and the AWS DeepLens™ come with high price tags, which not all potential beneficiaries will be able to afford. Therefore, it is worth noting that if this study were redone cost, economic distribution, or other equity considerations may emerge as a more prominent focal point depending on the stakeholders involved.

Observing the differences between the SLR findings and research with LTCF stakeholders cements the fact that stakeholders will have different thoughts, opinions, and concerns for different devices. Therefore, the differences found show the importance of this type of research. Even though similar groups of stakeholders were used for the SLR and the PD workshops and interviews, stakeholders have different thoughts, opinions, and concerns

regarding AAL devices and technology. Therefore, AAL technology cannot be a one-size-fits-all solution - stakeholders will have different needs and concerns that should be identified and understood before engineers and designers take on the task of developing new AAL technology.

It should be noted that conducting PD research with LTCF stakeholders was challenging, requiring considerable preparatory work. For example, recruiting participants was a very long process and required the assistance of the LTCF research coordinators. While many potential participants showed interest in the research during recruitment, getting stakeholders to sign consent forms was difficult. Therefore, in reference to a comment made in Chapter 2.0 where many publications had small participant numbers, it is not hard to understand why the SLR publications that conducted face-to-face research with participants had a much smaller turnout than studies that were conducted using surveys or questionnaires.

Therefore, this research has explored the importance of liaising with LTCF research coordinators, or people in similar roles, before conducting a study. That way, researchers gain a better understanding of how the facility works, the best ways to conduct research within the facility, the stakeholders who live in the LTCF, and stakeholders who may be more willing to participate in the research. By taking these steps, it is possible that the research becomes more inviting and exciting to potential participants and encourages more people to participate in the research.

5.3 How can Ethical DataSheets be Created to Convey the Ethical Implications that must be Considered before an AAL Device is Developed and Deployed?

Before the Ethical Data Sheet (EDS) was prototyped, a snowball sampling literature review was conducted to better understand the different ethical design tools that academic and industry researchers have proposed. Each of these tools, discussed in Chapter 4.0, aims to communicate the ethical concerns or the questions the reader should be thinking about before, during, and after the design and development of an Artificially Intelligent model or system. By learning more about tools that have been proposed in the past- where they have succeeded and struggled, the EDS was prototyped by integrating elements of the various tools to create an ethical design tool for AAL devices and technology used in LTC settings.

The purpose of an EDS is to communicate the ethical concerns that LTC stakeholders have with a device to the engineers, designers, or anyone else involved in developing AAL technology using the device. This way, engineers, designers, and other readers have a better understanding of the concerns they will need to address throughout the design and development process.

For this research, the EDS prototype was developed first and then used to develop model EDSs for the Hexoskin ProShirt™ and the AWS DeepLens™. The purpose of creating and presenting the prototype for the EDS was to allow other researchers interested in creating their own EDSs for a device to take their findings from their research and format them into the prototype. The prototype was inspired by a Material Safety Data Sheet (MSDS). MSDSs are found in many science and engineering laboratories and should be read and understood before interacting with a product or chemical. In the same way, EDSs are meant to be reviewed and understood before someone uses the device to develop new AAL technology. Similar to MSDS, EDSs use visuals and text to communicate important information to the reader. In presenting

information this way, the reader can gain a complete but simple and digestible snapshot of stakeholders' concerns with the device in question. Additionally, by offering information in multiple formats, future variations of the EDS have more possibilities.

5.4 Future Work

This research presents many avenues for future work, with opportunities to explore the idea of the EDS further. In this research, a prototype of the EDS was presented as a possible way of sharing information from stakeholders with engineers, designers, and other stakeholders wishing to use AAL in LTCFs.

The prototype has many elements, from the device identification and characteristic sections to the various stakeholder sections that present the ethical concerns for each stakeholder group using text and icons and their overall device ratings. Each of these elements has room for future improvements. For example, more detail can be added to the device identification and characteristics sections to personalize the EDS to the device it has been created for. Additionally, the icons proposed for the EDS prototype are one interpretation of literal and metaphoric metaphors. Therefore, future work could involve creating a standardized set of icons for each ethical concern that would be recognizable to all users, just as WHMIS symbols are recognizable and well-known to many. Finally, different methods for presenting overall device opinions should be explored. As discussed in section 4.5, LTCF stakeholders, especially tenants and residents, found it difficult to rate the devices on a scale as they were not comfortable giving ratings. Therefore, different methods to collect and convey this information would be worth exploring to truly understand how LTC stakeholders view such devices.

As discussed in Chapter 4.0, the prototype was used to develop EDSs for two devices that may be used in future AAL technology in LTC settings. The EDS presented in this thesis is a concept, and for EDSs to progress further, they must be tested by engineers and designers and iterated upon until they become a tool that is useful and usable for everyone involved.

Testing the EDSs with engineers and designers will provide insight into whether this ethical design tool is a viable way to communicate LTCF stakeholders' ethical concerns with a device to the engineers and designers who will be using the device to develop AAL technology. If engineers and designers are unable to understand how the tool is a benefit to them or unable to understand the concerns that are being presented, more research will need to be done to prototype EDSs so that they are seen as a beneficial and insightful tool by engineers and designers. Like the Data Nutrition Label discussed in Chapter 4.0, which went through different iterations with different stakeholders before it was deemed a valuable tool, EDSs will need to face the same process.

As this research is associated with the PATH project, which is composed of researchers, engineers, designers, and computer scientists, PATH members could be asked to participate in interviews or workshops to provide their feedback on the EDSs so that further prototyping with the tool could be conducted. In this way, the tool would not only communicate stakeholders' concerns with a device but would also be seen as a helpful tool by engineers and designers when they begin designing and developing AAL technology for LTC applications.

In theory, EDSs alert engineers and designers to the ethical concerns LTCF stakeholders have with a device. However, it remains to be seen if identifying and alerting engineers and designers to these concerns translates into an AAL technology that takes the concerns into account. Therefore, to know if EDSs are a helpful tool in identifying and addressing ethical concerns in AAL technology, the EDSs will have to be used during the design and development process for an AAL technology. To do this, the EDS prototype and the EDSs for the Hexoskin ProShirt™ and the AWS DeepLens™ will be shared with the broader PATH community that is developing AAL technology using the original suite of devices mentioned in Chapter 1.0. If EDSs are used to develop the technology, more research will have to be conducted with LTCF stakeholders after the fact to see if their concerns were addressed and how willing they are to accept and adopt the new technology into their lives. If positive feedback is received, it would provide credibility for the EDSs. However, if the opposite is true, more research and prototyping will need to be conducted to determine what else an EDS can do to identify LTCF stakeholders' concerns while presenting the information in a way that engineers and designers can understand and be able to address in their technology.

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Appendix A: Detailed Review of Ethical Design and Engineering Frameworks Collected from the Systematic Literature Review

Appendix A presents a visual representation of the data collected from the Systematic Literature Review (SLR) in Chapter 2.0. In collecting various ethical design and engineering frameworks, we decided to present and analyze each one, as seen in this table.

Table A-1: A table presenting the different ethical engineering and design frameworks that were used for the Systematic Literature Review presented in Chapter 2.0

	Author	Design method/ Framework	Type of Study	Study Participant Size	Benefits	Shortcomings
Previously Used Ethical Design and Engineering Frameworks (n = 17)	Nikou et al., 2020	Capabilities Approach	Focus Groups and Interviews	71 Participants (59 interviewees and 12 focus group members)	<ul style="list-style-type: none"> Explains how resources give people the freedom to their lives in ways they find valuable Can be used to create a model to understand technology acceptance where the model considers outcomes in terms of enabling people to live their lives in ways they find valuable Decouples the ownership and usage of digital technologies Encourages designers to look beyond direct activities or tasks that their offerings support Encourages multi-stakeholder collaboration 	<ul style="list-style-type: none"> Does not consider all personal characteristics as conversion factors Selecting relevant capabilities can be non-trivial and often involves normative assumptions Focusing on functionings rather than capabilities may lead to different outcomes How broad or narrow the capability set that is used will influence the outcome Capabilities may come into conflict with each other, which made lead to undesirable trade-offs
	Wang et al., 2019	Co-Design	Survey and Focus Groups	31 older adults	<ul style="list-style-type: none"> Enables stakeholders to collaborate and share thoughts and ideas in design Users are asked to assume roles that are traditionally intended for developers An iterative process that allows stakeholders to voice their opinions throughout the design lifecycle 	<ul style="list-style-type: none"> It can be challenging to ensure that technology is designed in such a way that allows stakeholders to be effectively included

					<ul style="list-style-type: none"> Enables users to reveal untapped areas for improvement 	
	Kong & Woods, 2018	Human-centred Design	Literature Review	N/A	<ul style="list-style-type: none"> Is centred on the exploration of new forms of living in, and through, technologies that give primacy to human actors, their values and their activities Focuses on how to support, develop, and extend people's capabilities through the latest technological developments Considers the fundamental needs and concerns of the ones at the center of the investigation 	<ul style="list-style-type: none"> Found to lack precision and tries to accommodate all, and therefore accommodates very few Focuses on present solutions to problems, not future ones Doesn't push the boundaries of available technology
	Astell et al., 2020	Identity Theory	Literature Review	N/A	<ul style="list-style-type: none"> Seeks to explain how people's identities influence their behaviour, thoughts, feelings, or emotions Specifically looks at the influence that identity has on a person's behaviour. Provides a useful framework for understanding the role of self-image in people's decision-making about technology 	<ul style="list-style-type: none"> Theory suggests that people employ multiple identities as they operate in the world, therefore if someone is being dishonest with their identity, desired results will likely not be achieved
	De Belen et al., 2019	Participatory Design	Workshops and Interviews	12 Participants	<ul style="list-style-type: none"> Encourages the active involvement of stakeholders in the research, design, and 	<ul style="list-style-type: none"> It can be challenging for participants to talk about their thoughts or opinions, so Participatory Design must be

					<p>commercialization of new technologies</p> <ul style="list-style-type: none"> • Explores elements of user experience and acceptance which is important for successful adoption • Bridges the gap between technical orientation and human-oriented approaches • Can be integrated in different ways to achieve active user engagement • Focuses on enabling different stakeholders with different perspectives and competencies to cooperate • Comprises active user involvement and participation in the design of IT artifacts and systems 	<p>used correctly to elicit stakeholder views</p> <ul style="list-style-type: none"> • Can be hard to find a balance between user's desires and technical feasibility • Hard to create generalizable results, as everyone can have different opinions
	Sanchez et al., 2019	Person-centred Design	Interviews	9 Participants	<ul style="list-style-type: none"> • Keeps individuals' values central to decision-making • Emphasizes the necessity of respecting the individual • Seeks to study how technology influences relationships and how it contributes or diminishes humanistic values 	<ul style="list-style-type: none"> • Very generalized approach • Tries to accommodate a large group of people
	Grossi et al., 2020	Positive Technology Paradigm	Literature Review	N/A	<ul style="list-style-type: none"> • Technology is consciously designed to foster well-being in older adults 	<ul style="list-style-type: none"> • Paradigm doesn't help to address the lack of cross-fertilization when developing

					<ul style="list-style-type: none"> • Technology is developed to induce positive and pleasant experiences • Supports individuals in reaching engaging and self-actualizing experiences • Supports and improves social integration and connectedness 	<p>AAL technology among disciplines</p> <ul style="list-style-type: none"> • Doesn't help to address technology acceptance for older adults • No long-term data to know how effective the paradigm is in creating technology that older adults will continue to use • Doesn't address how technology should preserve and protect user's privacy
	Cahill et al., 2019	SCRUM/AGILE Frameworks	Interviews	78 Participants	<ul style="list-style-type: none"> • Lightweight, iterative, and incremental framework for product development • Promotes sustainable development • Satisfies the customer through early and continuous development delivery 	<ul style="list-style-type: none"> • Can be very time consuming as many iterations may need to take place before the final prototype is reached
	Arthanat et al., 2020	Technology Acceptance Model (TAM)	Survey	447 participants	<ul style="list-style-type: none"> • Plays a part in understanding technology acceptance amongst users • Used to explain or predict factors that influence or determine the attitude towards accepting new technologies • Highlights the interactions of inherent behavioural traits with the adoption of technology 	<ul style="list-style-type: none"> • Even though this model addresses critical aspects of decision-making regarding technology adoption, the understanding as to why technology is still rejected is lacking • Considers behavioural traits but leaves out other characteristics such as demographics of users- therefore not providing the complete picture to what influences technology acceptance
	Jiang et al., 2019		Questionnaires and interviews	119 Participants		
	Bajenaru et al., 2020	User-centred Design	Survey	124 participants	<ul style="list-style-type: none"> • Identifies needs and translates them into 	<ul style="list-style-type: none"> • Can lead to value tensions

	Cesta et al., 2018		Survey and Focus Groups	155 participants (105 for survey and 20 for focus group)	<ul style="list-style-type: none"> development requirements for technology Used to gain an understanding of what a user wants and needs, and which features will be accepted by users 	<ul style="list-style-type: none"> Identification of value tensions may lead to malicious trade-offs Participants can have significant differences that can be hard to accommodate Results depend on participants that are involved in the conversation but may not necessarily represent a majority of users Can be hard for users to voice their needs
	Johannsson-Pajala et al., 2019		Group Discussions and Focus Groups	24 Participants		
	Menghi et al., 2019		Focus Groups	Unspecified number		
	Mincolelli et al., 2018		Survey, Interviews, Focus groups	Unspecified number		
	Schomakers et al., 2019		Questionnaire and Focus Groups	112 participants (107 for questionnaire and 15 for focus group)		
	Tsuchiya et al., 2018		Focus Groups	10 Participants		
Novel frameworks (n=10)	Alsulami et al., 2020	Decision-making framework for using AAL by healthcare providers	Community Practice Study	4 Participants	<ul style="list-style-type: none"> Creates a theoretical foundation to build a better understanding of the factors that are essential in boosting the usage of technology in improving elderly health in Saudi Arabia 	<ul style="list-style-type: none"> Very specific to a particular group of people (people living in Saudi Arabia)
	Azzi et al., 2020	Extended Expanded Chronic Care Model	Systematic Literature Review	N/A	<p>Extended Expanded Chronic Care Model</p> <ul style="list-style-type: none"> Helps integrate diverse AIA technologies around patient needs in various healthcare contexts Emphasizes the use of advanced patient-centric IT using prequalified, evidence-based knowledge repertoires to validate and reuse care pathways 	<p>Expanded Chronic Care Model</p> <ul style="list-style-type: none"> Not tested in a large healthcare context to understand the quality, safety, and efficiency effects of technology

	Etemad-Sajadi & Dos Santos, 2019	Extended Technology Acceptance Model	Surveys	213 Participants	<ul style="list-style-type: none"> Incorporates additional factors into the TAM to better understand technology acceptance 	<ul style="list-style-type: none"> Model is specific to AAL technology Even though more factors are identified, there are still additional variables that may influence technology acceptance Model is based on the assumption that stakeholders have little knowledge of technology
	Balaji et al., 2018	Framework for Pervasive and Ubiquitous Geriatric Monitoring	Literature Review and Experimentation	N/A	<ul style="list-style-type: none"> Shows similarities to User-Centred Design as the framework is designed to cater to a larger number of older adults Framework aims to follow the design philosophies of: extensibility, efficiency, availability, security, easy integration, usability, and scalability 	<ul style="list-style-type: none"> Framework doesn't take into account how to handle the trade-offs between data acquisition, the level of intrusiveness and precision
	Basarudin et al., 2018	Framework for Smarthome Housing Developments	Literature Review	N/A	<ul style="list-style-type: none"> A robust, regulatory housing framework, focused mainly for the regulation of standards in Smart Home Assisted Living for the Elderly 	<ul style="list-style-type: none"> Developed for use in Malaysia
	Shuhaiber et al., 2019	Modified Technology Acceptance Model (TAM)	Questionnaire	267 Participants	<ul style="list-style-type: none"> Captures the specifics of smart homes by examining smart home attributes as external factors Adds additional factors to the TAM to better understand user acceptance 	<ul style="list-style-type: none"> Remains unknown if the additional factors influence smart home acceptance
	Pal et al., 2018	Modified Theory of Acceptance and Use of	Online Survey	254 Participants	<ul style="list-style-type: none"> Framework is meant to determine the care 	<ul style="list-style-type: none"> Customized for an Asian healthcare context

		Technology (UTAUT) Model			<ul style="list-style-type: none"> factors that can affect an elderly users' acceptance of smart home services for healthcare Provides insight into more factors that influence user acceptance of healthcare technology 	<ul style="list-style-type: none"> Framework was created based on a healthcare tool that is not available for commercial scale, meaning that more research would need to be done to know if the same factors still hold the same weight More threat factors should be identified and analyzed
	Greenhalgh et al., 2018	Non-adoption or Abandonment of technology by individuals and difficulties achieving Scale-up, Spread and Sustainability (NASSS) Framework	Ethnographic Observation and Interviews	165 Participants	<ul style="list-style-type: none"> Developed to encourage complex thinking about technological innovations in healthcare Helps explain non-adoption or abandonment of technology Observes multiple domains to understand their complexity and how everything together influences non-adoption or abandonment 	<ul style="list-style-type: none"> When there is complexity across multiple domains, outcomes become less predictable, less controllable and less amenable to conventional planning and implementation logic
	Di Napoli et al., 2021	Service-Oriented Approach with Normative Reasoning Framework	Literature Review and Experimentation	N/A	<ul style="list-style-type: none"> Automatically generates and proposes assistive plans that are personalized to specific individuals or groups of individuals to increase user satisfaction and acceptance Reduces complexity of generating assistive plans Easily Adaptable 	<ul style="list-style-type: none"> May lead to stakeholders becoming dependent on technology, as technology is providing all of the necessary alerts and messages throughout the day May lead to social isolation
	Kolkowska et al., 2018	User-centred Ethical Assessment (UCEA) Framework	Iterative Design Workshops	11 Participants	<ul style="list-style-type: none"> Used to address the gap that exists between ethical consequences for AAL technology and the 	<ul style="list-style-type: none"> Values may come into tension with each other and can not be satisfied

					<p>dignity of life and well-being of an individual</p> <ul style="list-style-type: none"> • Avoids techno-centric development by highlighting system functionality in terms of values and expected results • Stakeholder values can be used to make informed decisions to benefit users 	<ul style="list-style-type: none"> • Even though values are voiced by stakeholders, there is a sense of supervision (or gate-keeping) by developers
Development of new AAL technology with existing frameworks (n=6)	Corcella et al., 2019	Co-design	Interviews	Unspecified number	Described Above	Described Above
	Bedaf et al., 2018	Multi-Perspective Evaluation	Workshops	28 Participants	<ul style="list-style-type: none"> • Allows different stakeholders, with different roles, to confront their points of view, which gives birth to a rich and complex set of data insights for the development of the next generation of the technology 	<ul style="list-style-type: none"> • Used once a technology has already been prototyped, and then stakeholders are asked to participate in the Multi-perspective evaluation-meaning that any problems stakeholders have with the technology will have to go through another round of iteration instead of identifying any concerns from the start • In the beginning, more focus is placed on the technology than stakeholder needs or wants
	Ferati et al., 2018	Participatory Design	Workshop using techniques such as: Cartographic mapping, future thinking and cultural probes	6 Participants	Described Above	Described Above
	Joe et al., 2018		Focus Groups	43 Participants		
Ting et al., 2020	Iterative Design Workshops (Living Lab approach)		5 Participants			

	Biermann et al., 2018	User-Centered Design & Technology Acceptance Model	Interviews and Scenario-based Planning activities	9 Participants	<ul style="list-style-type: none"> • Able to uncover intentions to use and accept technology • Can be used to expose Value Tensions 	<ul style="list-style-type: none"> • Two-step framework (User-centred design and participatory design) can reveal a disparity between assessment results • Some factors are more context-sensitive than others and must be considered as such • Results can vary depending on experimental conditions • Results may be biased as participants can respond differently to match presumed expectations
Development of new AAL technology with novel frameworks (n=3)	Curumsing et al., 2019	Emotion-Oriented Engineering	User-based Trials	10 older adults	<ul style="list-style-type: none"> • Framework that attempts to account for emotion • Identifies user requirements to help the iterative design and evaluation process • Addresses target users' key emotional goals 	<ul style="list-style-type: none"> • No formal process to communicate to make sure technology is being designed following the identified emotional goals • Hard to develop emotional goals to satisfy everyone • Incorporating users' emotional goals without a well-established methodology is challenging • Even though the framework provides a clear picture of user's needs, the framework is insufficient in guiding the design and implementation process to ensure emotional goals are met
	Borelli et al., 2019	User-centred Design (UCD), Participatory Design (PD) and the Quality Function Deployment QFD Tool	Paper outlining the project and deliverables	N/A	<ul style="list-style-type: none"> • Utilized to analyze and process user needs • QFD Matrix helps to identify the most important user needs 	<ul style="list-style-type: none"> • Due to comparisons with other characteristics, final prototypes do not always meet stakeholder expectations or desires

	Mincoelli et al., 2019		Questionnaire	100 Participants	<p>that are then compared to product characteristics to provide a technical assessment</p> <ul style="list-style-type: none"> • Results of the tool can be used to determine design guidelines for prototypes • Can help to identify other solutions or ideas to needs 	
			Workshop	12 families		
			Usability Testing	19 participants		

Appendix B: Scenarios used in the Workshops and Interviews with Long-Term Care Facility Stakeholders for the Hexoskin ProShirt™ and the AWS DeepLens™

Appendix B presents the scenarios that were during the study presented in Chapter 3.0: Prototyping the Ethical DataSheet, to help LTCF stakeholders visualize themselves interacting with the Hexoskin ProShirt™ or the AWS DeepLens™.

Table B-1 – Scenarios used for LTCF stakeholders for the Hexoskin ProShirt™

Stakeholder Group	Scenario
Tenants	<p>Imagine that you are just waking up from a good night’s rest, and you are lying in your bed before you get up and start your day. As you are lying there, you start thinking about everything you have planned for the day ahead- you want to go out for a walk, you need to stop at the store to pick up groceries, and then you have dinner plans at a nice restaurant with close friends in the evening. Once you’ve thought through your day, you decide that it’s time to get out of bed and get going.</p> <p>When you stand up, you remember that you’ve agreed to participate in a trial with the Hexoskin ProShirt™, where you have been asked to wear the device from the moment you wake up to the moment you go to sleep each evening so that the data recorder can collect your heart rate, breathing rate, and your activity throughout the day. Next, you remember that the Hexoskin ProShirt™ must have contact with your skin, so it must go under your clothing, and it must be as tight as comfortable. Then, once you have the shirt on, you must plug in the data recorder and tuck it into the side of the shirt before you can continue getting dressed.</p> <p>You get to work putting the Hexoskin ProShirt™ on, and once you are finished getting dressed, you walk out of your home and start your day.</p>

<p style="text-align: center;">Residents</p>	<p>Imagine that you've just woken up from a good night's rest and you are lying in bed. As you wake up, you smile remembering one of your friends is planning to visit you later in the afternoon, and you are looking forward to seeing them.</p> <p>As you sit up in your bed, you hear a knock on the door and you look to see it's one of the healthcare professionals that works on your floor. They tell you that they are there to help you put on the Hexoskin ProShirt for the day ahead. You nod, and as they come into the room, you think back to agreeing to use the Hexoskin ProShirt™, letting the device collect your vital signs like heart and breathing rate, and your activity, as you wear it.</p> <p>The healthcare professional gets you situated on the bed so that they can assist you with putting the Hexoskin ProShirt on.</p>
<p style="text-align: center;">Caregivers</p>	<p>I'd like you to imagine that you are heading to your loved one's room to visit them in the morning. You knock, and when they welcome you in, you see the Hexoskin ProShirt™, on the back of the chair. You pick up the shirt on your way in and ask if they need your help putting the device on. They nod, and as they sit up, you think back to when your loved one agreed to use the Hexoskin ProShirt™ to collect their vital signals, such as their heart rate, breathing rate and their activity.</p> <p>As they sit up, you stand beside them, and help them put on the Hexoskin ProShirt™ for their day ahead.</p>

Table B-2 – Scenarios used for LTCF stakeholders for the AWS DeepLens™

Stakeholder Group	Scenario
<p style="text-align: center;">Tenants</p>	<p>Imagine that it's mid-morning, and you are excited to start your day because you remember that some of your friends are stopping by your home later in the afternoon. You haven't seen them in a while, so you are excited to see them.</p> <p>As you make your way out of your bedroom, your eyes pass over the small white camera sitting on your counter. You then realize that your camera can see much of your living space from its placement in your home. In thinking about the camera, you recall you agreed to try the AWS DeepLens™ as a fall detection monitor as it was programmed to detect any concerning signs by analyzing your movements and contacting emergency contacts if you were to fall. You remember that the camera is continuously recording, and the collected data is stored in the cloud.</p> <p>As you stand in the kitchen, you realize that you haven't told your friends that you are using the AWS DeepLens™, so when the visit, they will also be on camera.</p>
<p style="text-align: center;">Residents</p>	<p>It's mid-afternoon on a chilly November day in Ottawa. You are sitting in bed watching TV when you hear a knock at your door. You turn to look to see that it's a good friend of yours and they have stopped by to visit you. You smile at them and welcome them inside your room.</p> <p>As you turn off the TV, the blue light from the AWS DeepLens™ camera, positioned across the room, catches your attention. You remember agreeing to use the AWS DeepLens camera, where the camera will take pictures of your space every 30 seconds. The collected images will be used to develop an Artificial Intelligence model to look for unusual behaviour that might cause a healthcare professional to check in on you.</p>

	<p>You are unsure if your friend is comfortable having their picture taken; however, you know that it's too cold to go outside, and the social rooms on your floor are being used for an event.</p>
<p>Caregivers</p>	<p>You are visiting your loved one on a cold November afternoon in Ottawa. You knock on their door, and they welcome you inside their space. They smile at you, and as you go to sit down beside them, your eyes catch on the blue light from the AWS DeepLens™ across the room. You remember that your loved one agreed to use the camera, allowing it to take pictures every 30 seconds with the plan to use the photos to develop an Artificial Intelligence model that will learn their behaviour, and flag any unusual behaviour to the healthcare professionals working on the floor.</p> <p>As you go to sit, you realize that the camera will be recording your entire interaction with your loved one, and it's too cold to sit outside and there is an event going on in the social rooms.</p>

Appendix C: Ethical Design Tools

Appendix C presents the full analysis of each Ethical Design Tool referenced in Chapter 4.0: Prototyping the Ethical DataSheet.

C.1 Datasheets for Datasets

Geburu et al. (2021) introduce Datasheets for Datasets ('Datasheets') that are meant to accompany datasets used to train AI and ML models. The authors state that the purpose of this tool is, *"to bring the conversation regarding data provenance to the machine learning community"* (Geburu et al., 2021, p. 1). At the time of publication of this paper, there was no standardized process for documenting machine learning datasets. Explaining the concept of a datasheet, the authors make an analogy to electrical components, which, regardless of complexity, come with accompanying documentation that explains there, *"operating characteristics, test results, recommended usage, and other [important] information..."* (Geburu et al., 2021, p. 2). The authors propose that Datasheets accompany AI/ML datasets to provide information on the dataset's, *"motivation, composition, collection process, recommended uses, and so on."* (Geburu et al., 2021, p. 2).

The datasheet itself is split into seven sections that align with the critical stages of the dataset lifecycle (i.e., Motivation, Composition, Collection Process, Preprocessing/Cleaning/Labeling, Uses, Distribution, and Maintenance). Each section is populated with questions, Figures C-1 and C-2, that dataset creators (the intended authors of the Datasheets) should answer as the dataset lifecycle progresses. The questions that populate each section are intentionally worded to avoid 'Yes' or 'No' answers and instead are meant to cause dataset creators to reflect more deeply (i.e. in more detail) on what is being asked. Once completed, the Datasheets should be shared with intended users (dataset consumers) to ensure they have the information they need to make informed decisions about using the dataset to train AI/ML models (Geburu et al., 2021). A full version of a Datasheet can be seen in Appendix D.

Figure C-1 - Figure 4.1.1.1: Motivation Section for Polarity Dataset Datasheet. From Gebru et al., 2021

Motivation
<p>For what purpose was the dataset created? Was there a specific task in mind? Was there a specific gap that needed to be filled? Please provide a description.</p> <p>The dataset was created to enable research on predicting sentiment polarity—i.e., given a piece of English text, predict whether it has a positive or negative affect—or stance—toward its topic. The dataset was created intentionally with that task in mind, focusing on movie reviews as a place where affect/sentiment is frequently expressed.¹</p>
<p>Who created the dataset (e.g., which team, research group) and on behalf of which entity (e.g., company, institution, organization)?</p> <p>The dataset was created by Bo Pang and Lillian Lee at Cornell University.</p>
<p>Who funded the creation of the dataset? If there is an associated grant, please provide the name of the grantor and the grant name and number.</p> <p>Funding was provided from five distinct sources: the National Science Foundation, the Department of the Interior, the National Business Center, Cornell University, and the Sloan Foundation.</p>
<p>Any other comments?</p> <p>None.</p>

Figure C-2 - Distribution Section for Polarity Dataset Datasheet. From Gebru et al., 2021

Distribution
<p>Will the dataset be distributed to third parties outside of the entity (e.g., company, institution, organization) on behalf of which the dataset was created? If so, please provide a description.</p> <p>Yes, the dataset is publicly available on the internet.</p>
<p>How will the dataset will be distributed (e.g., tarball on website, API, GitHub)? Does the dataset have a digital object identifier (DOI)?</p> <p>The dataset is distributed on Bo Pang’s webpage at Cornell: http://www.cs.cornell.edu/people/pabo/movie-review-data. The dataset does not have a DOI and there is no redundant archive.</p>
<p>When will the dataset be distributed?</p> <p>The dataset was first released in 2002.</p>
<p>Will the dataset be distributed under a copyright or other intellectual property (IP) license, and/or under applicable terms of use (ToU)? If so, please describe this license and/or ToU, and provide a link or other access point to, or otherwise reproduce, any relevant licensing terms or ToU, as well as any fees associated with these restrictions.</p> <p>The crawled data copyright belongs to the authors of the reviews unless otherwise stated. There is no license, but there is a request to cite the corresponding paper if the dataset is used: <i>Thumbs up? Sentiment classification using machine learning techniques</i>. Bo Pang, Lillian Lee, and Shivakumar Vaithyanathan. Proceedings of EMNLP, 2002.</p>

However, as promising as Datasheets sound, the authors note that they are not a definitive solution to address all problems with AI/ML systems like the ones stated above. For example, datasheets do not provide a complete solution to “*mitigating unwanted societal biases or potential risks or harms*” (Gebru et al., 2021, p. 11) as Datasheet creators cannot account for all possible uses of a dataset and, therefore, cannot account for all potential risks or harms that may arise from using the dataset (Gebru et al., 2021). Another limitation of Datasheets is the dynamic nature of datasets; if changes are made to the dataset, those changes should be reflected in the Datasheet. This implies that continual maintenance of the Datasheet will need to occur as long as the dataset keeps changing. Even though the authors provide a template for what a Datasheet may look like and what questions should be asked, ultimately each datasheet created will be different (Gebru et al., 2021). Dataset creators will be responsible for personalizing the Datasheet as they see fit for their datasets.

Despite the challenges, the authors believe that the benefits Datasheets can bring to the AI/ML community outweigh the costs. In other words, “*datasheets provide an opportunity for dataset creators to distinguish themselves as prioritizing transparency and accountability.*” (Gebru et al., 2021, p. 11).

C.2 AI FactSheets

Similar to Datasheets for Datasets, AI FactSheets (‘FactSheets’) proposed by IBM researchers was, at the time of publication, “*the first work to describe a methodology for creating a form of AI documentation*” (Richards et al., 2020, p. 1). FactSheets were proposed when the authors discovered that while proposals for AI documentation to uncover ethical and legal concerns were emerging, there was little published work to describe how to create such documentation. Therefore, FactSheets are the outcome of following a proposed methodology that defines how to capture essential details of how an AI model or service is developed and tested in order to increase transparency for the reader. Additionally, to ensure transparency and understanding, FactSheets are tailored to the AI model or service that is under study as well as the needs of the target audience who would be interacting with the AI model or service. Therefore, FactSheets for the same AI model or service may vary in content or format so that the FactSheet presents comprehensive, consumable information to the reader, regardless of their role (e.g., end-user, developer, engineer).

Like the Datasheets examined above, FactSheets follow a 7-step process for construction (i.e., Know your FactSheet consumers, Know your FactSheets Producers, Create a FactSheet template, Fill in FactSheet template, Have producers create a FactSheet, Evaluate created FactSheet with consumers, Devise other templates for other audiences and purposes). Throughout the process, FactSheet stakeholders’ needs are identified, a FactSheet template is created, the template is populated with relevant information for the AI model or service that is being evaluated, and finally, the FactSheet is tested with different impacted stakeholders, such as producers and consumers.

FactSheet development is highly iterative when involving different stakeholders. The authors note that iteration usually creates a psychological barrier to adoption, due to the perceived amount of work involved. However, they emphasize the importance of iteration when using such a tool by saying, “*that while creating a FactSheet may seem like a lot of work, ..., failing to perform these steps will incur an ongoing price in poor documentation, repeated*

requests between team members for missing information, insufficient testing based on faulty assumptions about data or model structure, ..., and exposure to unnecessary risk.” (Richards et al., 2020, p. 6).

By completing this process, FactSheets are developed for different AI models and services for different stakeholders. Examples of some sections for a developed FactSheet can be seen in Figures C-3 to C-5, and a full FactSheet can be found in Appendix D.

Figure C-3 - Overview, Purpose, and Intended Domain sections of an Object Detector FactSheet. From Richards et al., 2020

Object Detector

Overview

This document is a FactSheet accompanying the [Object Detector](#) model on IBM Developer [Model Asset eXchange](#). FactSheets aim at increasing trust in AI services through supplier's declarations of conformity and this FactSheet documents the process of training the Object Detector model as well as its expected results and appropriate use.

Purpose

Detect multiple objects within an image, with bounding boxes. The model is trained to recognize 80 different classes of objects in the COCO Dataset. The model consists of a deep convolutional net base model for image feature extraction, together with additional convolutional layers specialized for the task of object detection, that was trained on the COCO data set. It is based on SSD MobileNetV1 using the TensorFlow framework.

What is a bounding box?

A bounding box is used to describe the detected object location. The bounding box is a rectangular box that is identified by the x and y coordinates in the upper-left corner and the x and y axis coordinates in the lower-right corner of the rectangle.

Intended Domain

The model is designed for the computer vision domain. It can detect 80 different classes of objects like person, bicycle, car, etc. Details about the objects that the model can detect can be found [here](#).

Note: only the "thing" category is included. "Thing" categories include objects for which individual instances may be easily labeled (person, chair, car).

Like Datasheets, FactSheets use questions to explain how an AI model or service was developed and deployed (Richards et al., 2020). However, what separates FactSheets and Datasheets is that FactSheets are intended for use by various stakeholders. The methodology used to develop FactSheets was influenced by User-Centered Design principles to garner input from multiple stakeholders to inform the final design of the FactSheet. In explaining this process, the authors recognize this approach leads to an extended development period but state, *“although there is a strong desire to create a standard template for all FactSheets, we believe this diversity illustrates that for FactSheets, one size does not fit all.”* (Richards et al., 2020, p. 2).

Figure C-4 - Model Information and Input and Output sections of an Object Detector FactSheet. Adapted from Richards et al., 2020

Model Information

The model is based on the [SSD MobileNet V1 for TensorFlow](#). Pre-trained model weights for the model can be found [here](#). SSD stands for Single Shot Detector and a detailed explanation about this architecture can be found [here](#). MobileNet is used as a base network for feature extraction and its architectural details can be found [here](#).


Inputs and Outputs

The **input** to the model is an image and a threshold value. The threshold value is the probability threshold for including a detected object in the response, in the range [0, 1] (default: 0.7). Lowering the threshold includes objects the model is less certain about.

The **output** of the model is a JSON object that includes a list of all the predictions.

A sample input and output are shown below.

Input:



Output:

```
{
  "status": "ok",
  "predictions": [
    {
      "label_id": "88",
      "label": "teddy bear",
      "probability": 0.9896332025527954,
      "detection_box": [
        0.27832502126693726,
        0.5611844862805176,
        0.643224835395813,
        0.8432191610336304
      ]
    },
    {
      "label_id": "1",
      "label": "person",
      "probability": 0.9879012107849121,
      "detection_box": [
        0.24251864850521088,
        0.26926857233847485,
        0.6558930277824402,
        0.5768759846687317
      ]
    }
  ]
}
```

Output description:

- status: Response status message
- predictions: Predicted class labels, probabilities and bounding box for each detected object.
- label_id: Class (Object) label identifier
- label: Class label
- probability: Predicted probability for the class label
- detection_box: Coordinates of the bounding box for detected object. Format is an array of normalized coordinates (ranging from 0 to 1) in the form [ymin, xmin, ymax, xmax].

Figure C-5 - Bias section of an Object Detector FactSheet. From Richards et al., 2020

Bias

The training data set for this model was evaluated for evidence of gender based bias in image captioning in a study reported in this [paper](#). The authors note that image captioning models tend to exaggerate biases present in training data. Images labeled with human annotations to indicate gender were tested and found to make incorrect gender labels in some cases. Concerns about potential for bias in image captioning applications might be present in the simpler image class identification label that is an output of this model. Therefore careful attention should be paid if this model will be used for applications where incorrect gender classification is sensitive or harmful.

We note that a full evaluation of bias along other dimensions of the data beyond gender has not been made. Therefore we caution consumers of the model to include bias testing sensitive to groups who may have traditionally experienced bias in applications of this model.

In addition to other mechanisms, the authors are hopeful that FactSheets can “lead to better understanding and transparency and more effective mitigation of any harm or safety issues in the system, such as bias, vulnerabilities to adversarial attacks, or other undesirable impacts” (Richards et al., 2020, p. 7).

C.3 Data Statements for Natural Language Processing

Natural Language Processing (NLP) is a form of AI/ML that has been criticized in recent years due to some NLP systems failing to work for specific subpopulations, such as different genders (Mohammad, 2022) and different cultures (Bender & Friedman, 2018). Furthermore, some NLP systems have also been found to reinforce biases present in the data on which the system was trained, such as a *“resume-review system that ranks female candidates less qualified for computer programming jobs because of biases present in the training text”* (Bender & Friedman, 2018, p. 1). Bender & Friedman (2018) note, *“the linguistic data we use will always include pre-existing biases, and because it is not possible to build an NLP system in such a way that is immune to emergent bias...”*, there are *“open and urgent questions of how we integrate ethical considerations into the everyday practice of [NLP]”* (2018, p. 1). And while there are no simple answers to such questions, the authors imply that a *“constellation of multi-faceted solutions”* should be used instead (Bender & Friedman, 2018, p. 1).

Suggesting one such solution, Bender & Friedman utilized a value-sensitive design methodology to propose Data Statements to *“mitigate the scientific and ethical shortcomings that follow from imperfect datasets”* (2018, p. 1). As explained by the authors:

“A data statement is a characterization of a dataset that provides context to allow developers and users to better understand how experimental results might generalize how software might be appropriately deployed, and what biases might be reflected in systems built by the software” (Bender & Friedman, 2018, p. 1).

The suggestion here is that Data Statements have the potential to bring about *“improvements in engineering and scientific outcomes while enabling more ethically responsive NLP technology”* (Bender & Friedman, 2018, p. 1).

Inspired by publication practices in psychology and medicine, where standardized information is often required for describing study populations, Data Statements are meant for use in academic and other writing on NLP. This includes papers presenting new datasets, reports documenting new work with datasets, and documents for NLP systems. Bender & Friedman thus propose two versions of Data Statements: long-form and short-form. The reasoning behind the two variants is to try and keep data statements detailed but as concise as possible. Therefore, long-form Data Statements are meant to be included in academic papers presenting a dataset or within the system documentation. Long-form Data Statements should be written at, or close to, the time of the dataset’s creation and should include details about curation rationale, language variety, speaker and annotator demographic, text characteristics, and recording quality. Conversely, short-form Data Statements should be no more than 100 words summarizing the essential elements found in the long-form statement and should be included in publications that use the dataset for training, tuning, or testing a system.

Just as with DataSheets and FactSheets, the authors note that Data Statements are one piece of the puzzle when addressing the scientific and ethical questions that arise when considering integrating AI/ML into people’s everyday lives. However, the authors comment on the advantages they believe Data Statements may provide to the field. Firstly, the authors point out that Data Statements can be *“instrumental in the diagnosis (and thus mitigation) of pre-existing biases”* and that *“when a system is paired with data statement(s) for the data it’s*

trained on, those deploying it are empowered to assess potential gaps between the speaker populations and the populations whose language the system will be working with” (Bender & Friedman, 2018, p. 8).

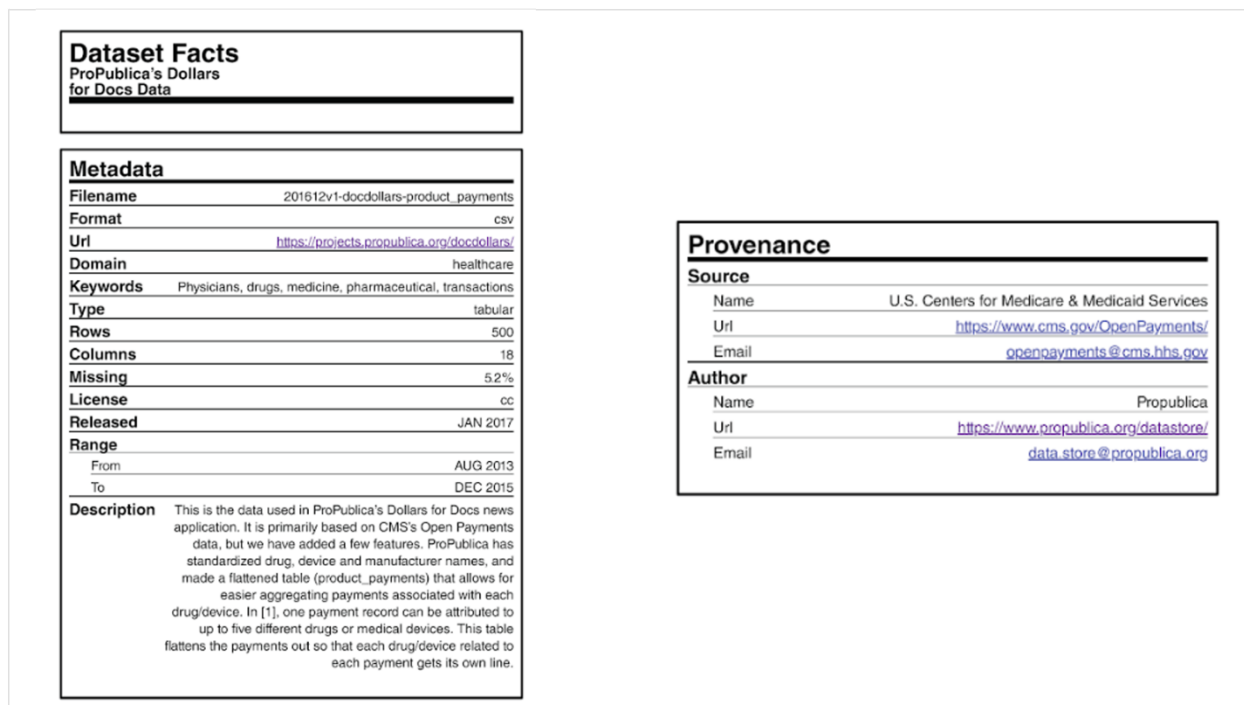
C.4 Data Nutrition Labels

The Dataset Nutrition Label (Chmielinski et al., 2020; Holland et al., 2018) has similar elements to the tools mentioned previously. Drawing inspiration from standard food nutrition labels, the sort found on food packaging, it aims to address the harms that AI and ML systems can propagate, with a specific focus on the data used in algorithmic decision-making systems (ADS). Unlike the tools mentioned above that use questions to convey information, the Data Nutrition Label is presented in a visual and very familiar manner.

Before suggesting such a tool, the researchers conducted an anonymous online survey within the data science community to understand current data analysis practices prior to model development. Based on the results, the researchers discovered that just under half of the respondents said they analyzed their data before using it in their models (Holland et al., 2018). Furthermore, almost 75% of the participants indicated that their companies did not have explicit best practices for data analysis and just under 60% of respondents admitted they relied on experience and self-directed learning to inform their data analysis practices (Holland et al., 2018). After analyzing the results of the survey, the authors concluded that data scientists should have a tool enabling them to *“more quickly assess the viability and fitness of datasets, and more easily find and use better quality data to train their models”* (Holland et al., 2018, p. 3). The results of this survey heavily influenced the creation of their tool, known as the Data Nutrition Label.

In the first iteration of the tool by Holland et al. (2018), the authors utilized the idea of a nutrition label, as is seen in Figures C-6 and C-7. The reason behind this, aside from being an easily recognizable icon, is that according to a report done by the International Food Information Council, *“more than 80% of consumers reported that they looked at the “Nutrition Facts” label when deciding what foods to purchase or consume, and only 4% reported never using the label”* (Holland et al., 2018, p. 4). Additionally, five years after the “Nutrition Label” was mandated by Congress, the Food Marketing Institute reported, *“that one-third of consumers stopped buying food because of what they read on the label”* (Holland et al., 2018, p. 4). Therefore, hoping to achieve the same results for the importance of data interrogation before model creation, the authors decided to represent their tool in a manner resembling the food Nutrition Label. A complete example of the Data Nutrition Label proposed by Holland et al. (2018) can be seen in Appendix D.

Figure C-6 - Metadata and Provenance sections from the First iteration of the Data Nutrition Label for the ProPublica’s Dollars for Docs dataset. Adapted from Holland et al., 2018




The label is meant to act as a *“diagnostic framework that aims to lower the barrier to standardized data analysis by providing a distilled yet comprehensive overview of dataset ‘ingredients,’ before AI model development.”* (Holland et al., 2018, p. 1). Therefore, the primary audience for this tool is the data science and AI/ML developer community, who are responsible for building AI models.

The first iteration of the Data Nutrition Label was designed to introduce the concept of a tool to expedite decision-making without sacrificing the quality or thoughtfulness of data interrogation (Holland et al., 2018). The tool’s second and most recent iteration, called the Dataset Nutrition Label, amalgamates the feedback from data scientists, analysts, and others to solidify a tool that is another step toward building and deploying trustworthy AI (Chmielinski et al., 2020).

In soliciting feedback for the first iteration of the label from the data science community, the authors of the second iteration note that many of the responses suggest there is a shift toward the *“‘contextualization’ of artificial intelligence and the need for frameworks that are ‘personalized’”* (Chmielinski et al., 2020, p. 2). This same idea was reflected in the Systematic Literature Review presented in Chapter 2.0 and discussed in Section 4.1.2 with the AI FactSheets; while general frameworks and EDTs may be able to identify some of the concerns that stakeholders have with AI/ML models, devices, or systems, frameworks and EDTs that are personalized stand a much better chance of being able to identify and address specific concerns that stakeholders have with AI/ML technology. Therefore, considering the feedback and suggestions that the authors received, the second iteration of the Dataset Nutrition Label, seen in Figures C-7 and C-8, is presented in an interactive, web-based GUI that aims to give

general information about the dataset alongside known issues and relevant information for a particular use case (Chmielinski et al., 2020). A full version of the second iteration of the Data Nutrition Label can be found in Appendix D.

Figure C-7 - About, Use Cases, and Alert Count sections of the Second Version of the Dataset Nutrition Label for the TaxBillsNYC dataset. Adapted from Chmielinski et al., 2020


Dataset Nutrition Label
TaxBills NYC Dataset (joined.csv)

About

This dataset was created to make information about NYC's rent stabilized apartments more accessible to the public. Currently, information on rent stabilization in NYC is only published in aggregate by borough, leaving little information about specific buildings available. By parsing tax bill data about buildings contained in Notice of Property Value (NoPV) documents, which are available publicly in pdf format, this dataset is able to get a building-by-building count of rent stabilized units in NYC. **See more about why this dataset was created here.**

Data Creation Range: January, 2015 - Present
Created By: John Krauss
Content: Tabular (csv, JSON)
Source: <https://github.com/talos/nyc-stabilization-unit-counts>

Use Cases

Potential real-world applications of the dataset


- 1 How many rent stabilized units are in a particular building?
- 2 Has a building lost rent stabilized units?
- 3 Is there a pattern of deregulation in a building?
- 4 Is there a pattern of deregulation for a specific landlord?
- 5 Where might there be abuse of tax abatements? Is the landlord breaking the rules of the abatements?
- 6 Where is gentrification happening?

Alert Count	4*
Completeness	0
Provenance	1
Misrepresentation	1
Collection	2
Socioeconomic Bias	1
Inaccurate Prediction	1
Description	0
Composition	1
Racial bias	1

* Please refer to the Objectives and Alerts section for more details

By presenting information relevant to a specific use case, the current version of the Dataset Nutrition Label sets itself apart from other tools that have been analyzed thus far. Instead of creating a general tool or creating a tool for a specific stakeholder, the creators of the Dataset Nutrition Label focus on how the dataset may be used, the possible problems that may arise from the use case, and potential mitigation techniques that the user could implement to avoid undesirable outcomes (Chmielinski et al., 2020), as seen in Figure C-9. Lastly, due to its web-based interface, the Data Nutrition Label focuses on usability to ensure it is actionable and immediately useful to its user (Chmielinski et al., 2020).

Figure C-8 - Objectives and Alerts section of the Second Version of the Data Nutrition Label for the TaxBillsNYC dataset. Adapted from Chmielinski et al., 2020



Objectives & Alerts

Selector

Click on a modeling objective to filter relevant alerts.

Modeling Objectives:
What is the objective?

- Predict change in % of stabilized units for a building
- Predict change in % of stabilized units for a community district
- Predict change in % of stabilized units for a zip code
- Predict change in % of stabilized units for an owner (name)
- Predict building deregulation based on owner patterns
- Predict building deregulation based on community district patterns
- Predict building deregulation based on zip code patterns
- Classify owners into categories based on rate of stabilization
- Classify zip codes based on rate of stabilization

3 Alerts

Click on the arrow next to an alert to see more information.

Alerts FYIs

MITIGATION POSSIBLE: ■ 0 No ■ 1 Maybe ■ 2 Yes

FILTER: All ▼

- Some stabilized unit counts are estimates ▼
- Owner listed is not always the true person/company that owns the lot ▼
- Zipcode is highly correlated with racial demographics in the US ▼

Figure C-9 - Mitigation Suggestions from Alerts section of the Second Version of the Data Nutrition Label for the TaxBillsNYC dataset. From Chmielinski et al., 2020

■ Some stabilized unit counts are estimates ▲

Mitigation Possible: **Yes**
 Category: **Collection**
 Potential for Harm: **Socioeconomic Bias Inaccurate Prediction**

From <https://github.com/talos/nyc-stabilization-unit-counts#caveats>: "The combination of self-reporting stabilization counts and occasionally missing tax bills means that a significant percentage of buildings miss reporting for some years.

In order to compensate, all output files contain some estimated counts. You can exclude these estimates in your own aggregations by replacing those unit counts with 0. If there is no stabilized unit count for a building that had one the previous year, the previous year's number is used in any of the following cases: 1) The bill without a unit count had a SCRIE or DRIE abatement, indicating the continued presence of regulated units. 2) The bill without a unit count maintained the same abatements as the previous year (for example 421a or J51) indicating that restrictions mandating affordability remained in effect. 3) The building appeared on HCR's stabilized building list for the year without a unit count, indicating that it was in fact still stabilized."

Possible Mitigations:
 Dataset Provides A Mitigation By Marking These In The Data, So That Dataset Users Can Account For Them In Calculations

Even though the second iteration of the Dataset Nutrition Label is an improvement on the first, the second generation poses its own challenges. These challenges include adapting the label when the dataset changes, third-party access for label creation, balancing the amount of qualitative and quantitative data represented on the label (Chmielinski et al., 2020), and identifying all possible use cases for the dataset. Knowing these challenges exist, the authors state that they are committed to advancing the Dataset Nutrition Label *“through well designed, carefully vetted, and context-aware [methods] that help mitigate harm while improving public understanding of the risks and opportunities of working with ADS, and with particular focus on their underlying data”* (Chmielinski et al., 2020, p. 4).

C.5 Ranking Facts (A Nutrition Label for Rankings)

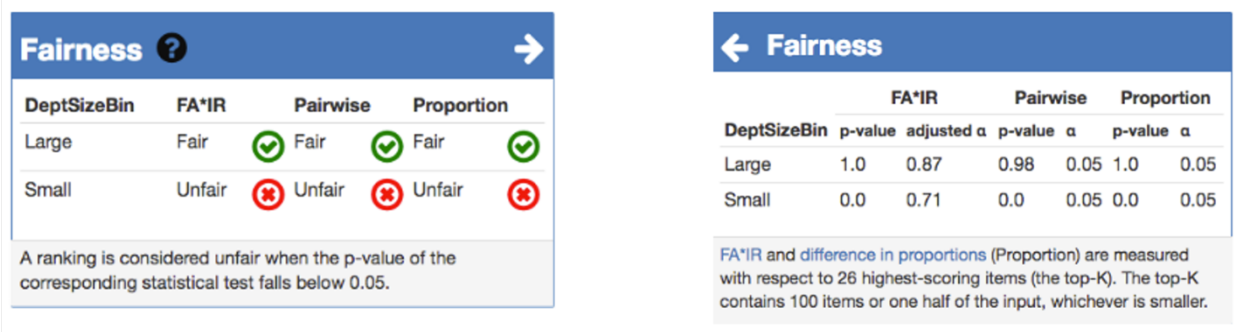
Ranking Facts is a tool meant to communicate to the end-user the intricate details of algorithmic decision-making systems (ADS), specifically ranking and scoring algorithms, such as creditworthiness systems or dating compatibility apps (Yang et al., 2018). While similar to Dataset Nutrition Labels, which focus on the datasets that ADS use (Holland et al., 2018), Ranking Facts focuses on the specifics of how ranking and scoring algorithms produce their results (Yang et al., 2018). Using visual widgets, Ranking Facts presents the reader with the ranking or scoring algorithm in terms of the algorithm’s fairness, stability, and transparency. In presenting the readers with the information, Yang et al. (2018) aim to promote the *“development of interpretability and transparency tools”* (p.1) by providing the reader with a tool that they can use to determine the ‘fitness of use’ for a given model or dataset and to assess the methodology that was used to produce the model or dataset.

Ranking Facts comprises six visual widgets (Recipe, Ingredients, Overall Diversity, Diversity at Top-10, Stability, and Fairness) that address aspects of transparency and interpretability and are meant to show the results of the system’s ‘recipe’ or the description of the algorithm, as seen in Figure C-10. While the widgets that are presented on the Ranking Facts sheet are meant to be overviews of the findings for each category, some widgets can also be expanded out to provide more information so that readers can understand the information that is available on the overview widget, as seen in Figure C-11. A full version of the Ranking Facts sheet can be found in Appendix D.

Figure C-10 - Ranking Facts for a Computer Science Department Dataset. From Yang et al., 2018



Figure C-11 - Expanded Fairness Widget for Ranking Facts for a Computer Science Department Dataset. Adapted from Yang et al., 2018



Like the Data Nutrition Label, Ranking Facts attempt to provide transparency to ADS results by providing the reader with insight into the complex processes that are used in ADS, the assumptions made, and the diversity, stability and fairness factors that exist within the results.

C.6 Model Cards (for model reporting)

When “*Model Cards for Model Reporting*” (Mitchell et al., 2019) was published, the authors stated that there were “*no standardized procedures to communicate the performance characteristics of trained machine learning (ML) and Artificial Intelligence (AI) models*” (2019, p. 1). As with similar tools analyzed above, this lack of documentation raises alarms when AI/ML models are used in high-stakes contexts that can severely impact people’s lives, such as in employment (e.g. hiring and firing decisions), healthcare (e.g. diagnostics), or the criminal justice system (e.g. sentencing recommendations) (Mitchell et al., 2019). However, even if documentation accompanies an AI or ML model, it often supplies very little information regarding the model, its performance characteristics, intended use cases or pitfalls, or any other additional information someone would need to decide whether or not to use the model for their purposes (Mitchell et al., 2019). For the authors, the growing number of concerns about poorly documented AI/ML models prompted the creation of a tool that could capture a trained machine learning model’s metrics, bias, fairness, and inclusion characteristics.

Model Cards for model reporting (Model Cards hereafter) is a tool intended to accompany new machine learning models as a one or two-page description describing the model, its characteristics and intricacies, and its use cases (Mitchell et al., 2019). To present this description, Model Cards are presented through nine different sections (Model Details, Intended Use, Factors, Metrics, Evaluation Data, Training Data, Quantitative Analyses, Ethical Considerations, and Caveats and Recommendations), as seen in Figure C-12.

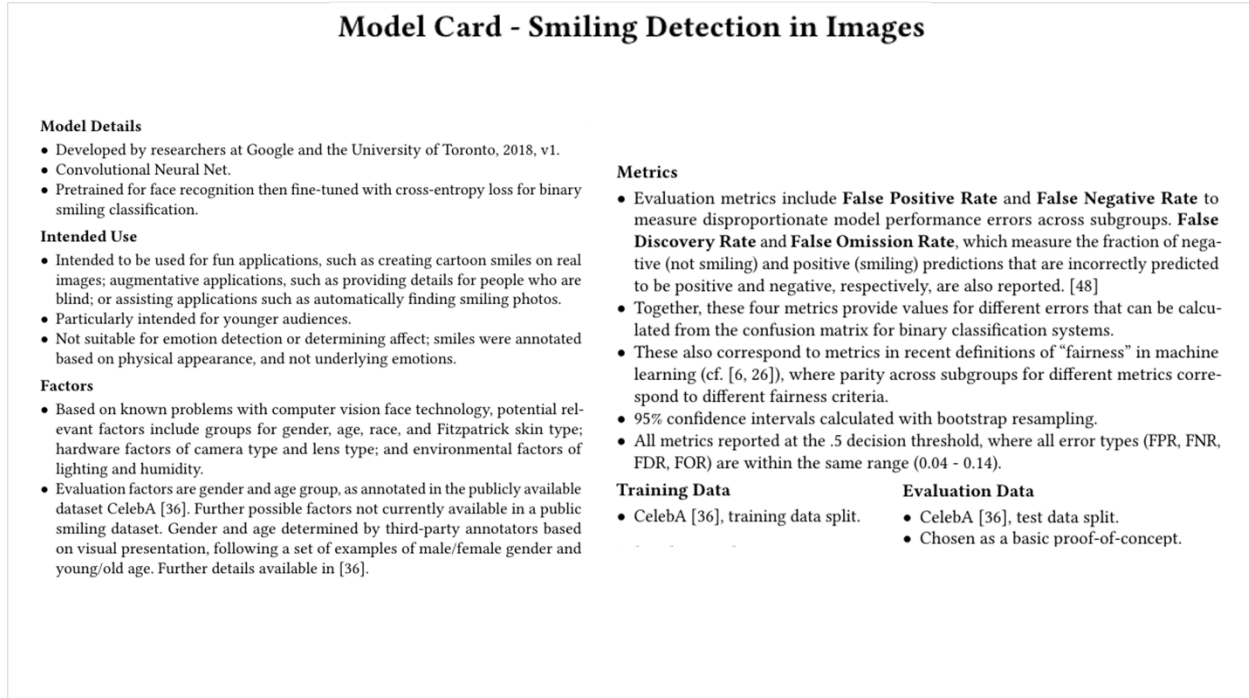
Model Cards are meant as an accompaniment to Datasheets for Datasets (Gebru et al., 2021), where Datasheets are responsible for reporting the details of the dataset being fed into the model, while Model Cards focus on explaining details regarding the ML model that will use the dataset (Mitchell et al., 2019). Additionally, each Model Card could also be accompanied by Dataset Nutrition Labels (Chmielinski et al., 2020; Holland et al., 2018), Data Statements (Bender & Friedman, 2018), or AI FactSheets (Richards et al., 2020), as each pertains to the dataset that the model is trained or evaluated on, and is therefore important to include when discussing the model itself. Sections of a developed Model Card are pictured in Figures C-13 and C-14, and the Model Card can be found in Appendix D.

Figure C-12 - Summary of Model Card sections and prompts to consider for each. Adapted from Mitchell et al., 2019

Model Card	
<ul style="list-style-type: none"> • Model Details. Basic information about the model. <ul style="list-style-type: none"> - Person or organization developing model - Model date - Model version - Model type - Information about training algorithms, parameters, fairness constraints or other applied approaches, and features - Paper or other resource for more information - Citation details - License - Where to send questions or comments about the model • Intended Use. Use cases that were envisioned during development. <ul style="list-style-type: none"> - Primary intended uses - Primary intended users - Out-of-scope use cases 	<ul style="list-style-type: none"> • Factors. Factors could include demographic or phenotypic groups, environmental conditions, technical attributes, or others listed in Section 4.3. <ul style="list-style-type: none"> - Relevant factors - Evaluation factors • Metrics. Metrics should be chosen to reflect potential real-world impacts of the model. <ul style="list-style-type: none"> - Model performance measures - Decision thresholds - Variation approaches • Evaluation Data. Details on the dataset(s) used for the quantitative analyses in the card. <ul style="list-style-type: none"> - Datasets - Motivation - Preprocessing
	<ul style="list-style-type: none"> • Training Data. May not be possible to provide in practice. When possible, this section should mirror Evaluation Data. If such detail is not possible, minimal allowable information should be provided here, such as details of the distribution over various factors in the training datasets. • Quantitative Analyses <ul style="list-style-type: none"> - Unitary results - Intersectional results • Ethical Considerations • Caveats and Recommendations

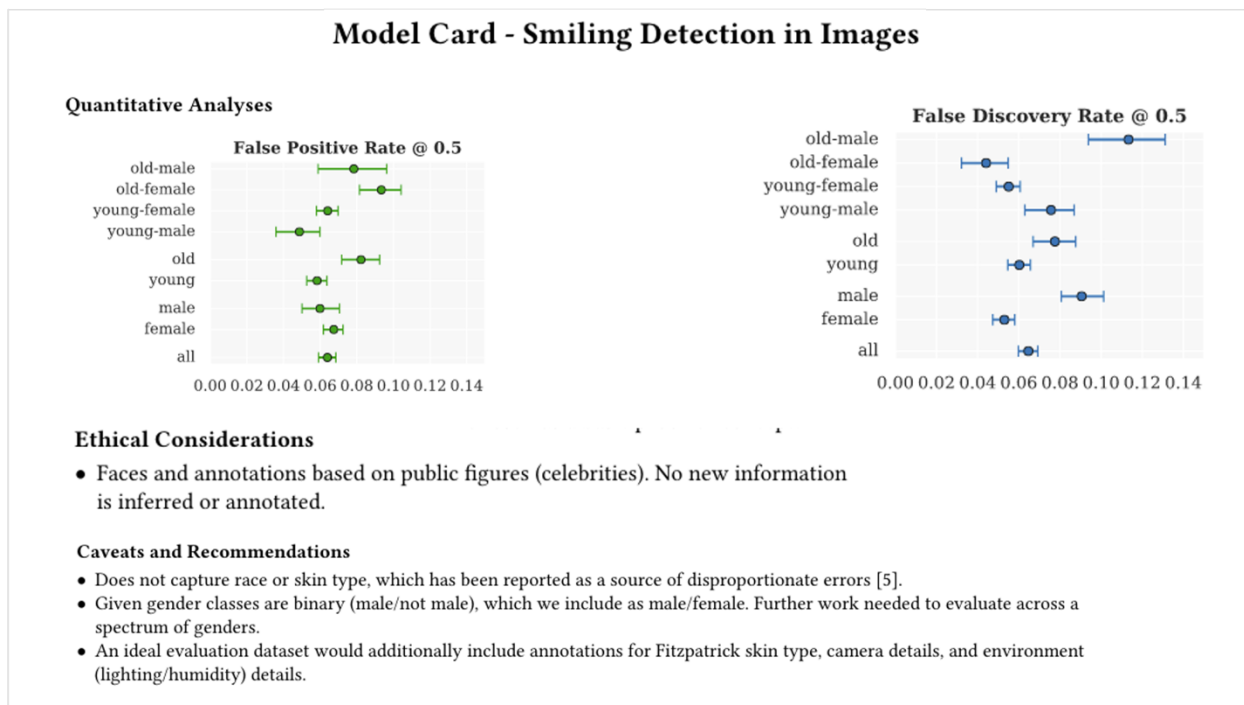
Model Cards are an attempt to “provide a way to inform users about what machine learning systems can and cannot do, the types of errors they can make, and additional steps that could create more fair and inclusive outcomes with the technology” (Mitchell et al., 2019, p. 2). The motivation behind Model Cards is to “standardize ethical practice and reporting—allowing stakeholders to compare candidate models for deployment across not only traditional evaluation metrics but also along the axes of ethical, inclusive, and fair considerations” (Mitchell et al., 2019, p. 2). This motivation will hold a different meaning for different users. While Model Cards are intended for AI and ML practitioners and model and software developers, the tool can also have insights and significance for law and policymakers, ML-knowledgeable individuals, and other impacted stakeholders (Mitchell et al., 2019).

Figure C-13 - Sections of Model Card for Smiling Detection in Images Model. Adapted from Mitchell et al., 2019



Just as with the Dataset Nutrition Label (Chmielinski et al., 2020; Holland et al., 2018) and the Nutrition Label for Rankings (Yang et al., 2018), Model Cards include visual elements to communicate information to the reader. Model Cards are divided into different sections, Figures C-12 and 13, that collectively relay how a model was built, the assumptions made during its development, how the model may behave when using datasets with different cultural, demographic, or phenotypic populations, and how well the model will perform concerning those groups (Mitchell et al., 2019).

Figure C-14 - Remaining sections of Model Card for Smiling Detection in Images Model. Adapted from Mitchell et al., 2019



As with tools mentioned previously, such as Datasheets for Datasets (Gebru et al., 2021), Model Cards do not identify all of the ethical issues that arise with AI/ML models and their use. As Mitchell et al. (2019) note, “*ethical analysis does not always lead to precise solutions*” (p.6). Therefore, the idea that Model Cards will be standardized to a point where all ethical concerns are addressed and misleading representation for the AI or ML model or results of the model are eliminated seems unlikely (Mitchell et al., 2019). Regardless, the authors do see the potential for Model Cards, used in combination with other processes such as algorithmic auditing, adversarial testing, and user feedback mechanisms, to contribute to the future of responsible (i.e. ethical) AI/ML work stating, “*the process of ethical contemplation is worthwhile to inform on responsible practices and next steps for future work*” (Mitchell et al., 2019, p. 6).

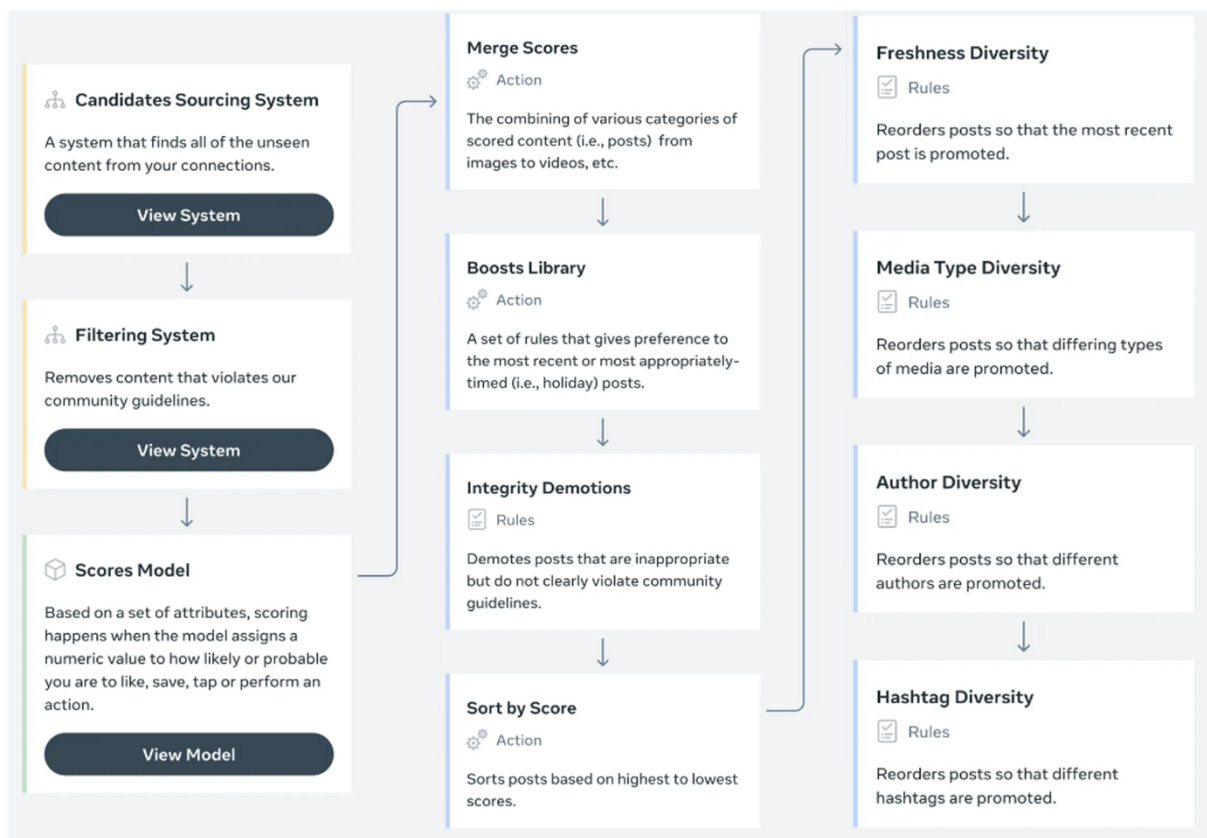
C.7 System Cards

Though they share many similarities to previously discussed tools, System Cards differ from the tools mentioned above in that System Cards are concerned with an entire ML system, or the combination of many ML models working together to produce a result (Procope et al., 2022). Instead of communicating key facts about individual models, as is done by Model Cards (Mitchell et al., 2019), or focusing on various details regarding the datasets that ML models are trained on, as with Datasheets for Datasets (Gebru et al., 2021), AI FactSheets (Richards et al., 2020), or the Dataset Nutrition Label (Chmielinski et al., 2020; Holland et al., 2018), System Cards aim to “*provide insight into how an ensemble of models work together to make systems*”

(Procope et al., 2022, p. 3). An example of such a system would be the ranking and recommending ML system that Instagram employs on their explore page (Procope et al., 2022).

Similar to Dataset Nutrition Labels (Chmielinski et al., 2020; Holland et al., 2018) and Model Cards (Mitchell et al., 2019), System Cards use visual elements to communicate with the reader. A System Card starts with a page that briefly describes the system, its purpose, and information about version type and authors. This page also includes a high-level diagram of the system (Figure C-15), its components, and how each component is used to achieve a desired functionality and result. Interestingly, if users want to explore a specific model included in the system outlined in the System Card, they can access that model’s Model Card to learn more (Procope et al., 2022).

Figure C-15 - An Overview of a Content Ranking System. From Procope et al., 2022



Even though System Cards build upon the ideas of their predecessors, the authors still note many challenges with creating “usable and valuable documentation artifacts” for AI/ML models and systems (Procope et al., 2022, p. 4). A major challenge includes scalability: it is questionable whether System Card creation can be automated, or if it requires manual creation, compounded by the continual maintenance that System Cards require as AI and ML models and systems continuously change (Procope et al., 2022).

C.8 Ethics Sheets for AI Tasks

In analyzing the previous seven tools, one commonality seen is that the tool is either created during creation or after finalizing the dataset, model, or system. Ethics Sheets for AI Tasks (Ethics Sheets) is a tool that takes the opposite approach, in more ways than one (Mohammad, 2022). Unlike tools that have been discussed above, where the reason for creating the tool is to document a dataset, an AI or ML model, or an overall AI or ML system, Ethics Sheets focus on the AI task for which the dataset, model, or system is being created (Mohammad, 2022). Mohammed (2022) explains that an AI task *“is some task that we want to automate using AI techniques, [while] an AI system is a particular AI model built for the task”* (p. 2). While there are ethical considerations that datasets and individual AI/ML models face, those ethical considerations usually stem from the AI or ML task itself (Mohammad, 2022). Take, for example, the task of alerting a family member if their loved one falls at home. Before we consider an AI or ML system to implement this task, we ought to consider questions that the task raises: How will the person feel about being monitored? Do they want someone to be alerted if they fall? Could this system be misused in some way? Is there enough evidence to support going forward with this idea? From the author’s perspective, if someone wants to propose and create a new AI task, it is essential to have *“a document that substantively engages with the ethical issues relevant to that task; going beyond individual systems and datasets, drawing on a body of relevant work”* (Mohammad, 2022, p. 3).

To facilitate the proposal and creation of a new AI or ML task, the author proposes Ethics Sheets as a way to *“flesh out the assumptions and ethical considerations hidden in how an [AI or ML] task is commonly framed and in the choices we make regarding the data, method and evaluation”* (Mohammad, 2022, p. 1). To do this, the author proposes four sections of the Ethics Sheet to uncover assumptions hidden in task framing, present ethical considerations that are relevant to the task, discuss choice points and trade-offs for different stakeholders, outline the risks, and go through mitigations that can be taken as an attempt to avoid undesirable outcomes (Mohammad, 2022). The author notes that thinking about the questions presented in the Ethics Sheets enables people to *“break away from the current paradigm of building things that are divisive (that work well for some and poorly for others) and instead move towards building systems that treat human diversity and variability as a feature (not a bug)”* (Mohammad, 2022, p. 3).

As discussed with similar tools, Ethics Sheets are not meant to be the ‘golden ticket’ that makes everything perfect, leads to easy solutions, or the *“thing that solves ethics”* (Mohammad, 2022, p. 4). Instead, ethics sheets provide thoughts on AI or ML tasks’ ethical considerations and societal impacts while also encouraging best practices and inspiring new ideas for responsible research and innovation (Mohammad, 2022). Ethics Sheets are also not meant to be a stand-alone tool. The author comments that Ethics Sheets should be used to facilitate the creation of tools like Datasheets and Model Cards (Mohammad, 2022), and the tools should complement each other. For example, tools like Datasheets and Model Cards would be used as post-production documents, while Ethics Sheets are meant to be a preview for the task ahead.

Like all tools that have come before it, Ethics Sheets have limitations. One such limitation is that maintaining Ethics Sheets is a perpetual task. Since Ethics Sheets are created manually, a task’s list of ethical considerations is not static. It is almost impossible to predict

every potential outcome or harm of an AI or ML task, meaning that Ethics Sheets require periodic or constant visitation and updating (Mohammad, 2022). Acknowledging this, the author states, *“Ethics Sheets will always be incomplete and require revision..., but that should not stop us from creating a document that will be useful to others, ..., [so] we are better placed to anticipate issues for the future”* (Mohammad, 2022, p. 11).

Appendix D: Ethical Design Tools

Appendix D presents the Ethical Design Tools discussed in Chapter 4.0: Prototyping the Ethical DataSheet.

Figure D-1 – DataSheet for Datasets EDT: Movie Review Polarity DataSheet- Page 1 (Gebru et al., 2021)

Movie Review Polarity	Thumbs Up? Sentiment Classification using Machine Learning Techniques
<div data-bbox="412 541 527 567" style="text-align: center;">Motivation</div> <p>For what purpose was the dataset created? Was there a specific task in mind? Was there a specific gap that needed to be filled? Please provide a description.</p> <p>The dataset was created to enable research on predicting sentiment polarity—i.e., given a piece of English text, predict whether it has a positive or negative affect—or stance—toward its topic. The dataset was created intentionally with that task in mind, focusing on movie reviews as a place where affect/sentiment is frequently expressed.¹</p> <p>Who created the dataset (e.g., which team, research group) and on behalf of which entity (e.g., company, institution, organization)?</p> <p>The dataset was created by Bo Pang and Lillian Lee at Cornell University.</p> <p>Who funded the creation of the dataset? If there is an associated grant, please provide the name of the grantor and the grant name and number.</p> <p>Funding was provided from five distinct sources: the National Science Foundation, the Department of the Interior, the National Business Center, Cornell University, and the Sloan Foundation.</p> <p>Any other comments?</p> <p>None.</p>	<div data-bbox="776 541 1269 682" style="border: 1px solid black; padding: 5px;"><p>these are words that could be used to describe the emotions of john sayles' characters in his latest , limbo . but no , i use them to describe myself after sitting through his latest little exercise in indie egomania . i can forgive many things . but using some hackneyed , whacked-out , screwed-up * non * -ending on a movie is unforgivable . i walked a half-mile in the rain and sat through two hours of typical , plodding sayles melodrama to get cheated by a complete and total copout finale . does sayles think he's roger corman ?</p></div>
<div data-bbox="396 1108 544 1134" style="text-align: center;">Composition</div> <p>What do the instances that comprise the dataset represent (e.g., documents, photos, people, countries)? Are there multiple types of instances (e.g., movies, users, and ratings; people and interactions between them; nodes and edges)? Please provide a description.</p> <p>The instances are movie reviews extracted from newsgroup postings, together with a sentiment polarity rating for whether the text corresponds to a review with a rating that is either strongly positive (high number of stars) or strongly negative (low number of stars). The sentiment polarity rating is binary {positive, negative}. An example instance is shown in figure 1.</p> <p>How many instances are there in total (of each type, if appropriate)?</p> <p>There are 1,400 instances in total in the original (v1.x versions) and 2,000 instances in total in v2.0 (from 2014).</p> <p>Does the dataset contain all possible instances or is it a sample (not necessarily random) of instances from a larger set? If the dataset is a sample, then what is the larger set? Is the sample representative of the larger set (e.g., geographic coverage)? If so, please describe how this representativeness was validated/verified. If it is not representative of the larger set, please describe why not (e.g., to cover a more diverse range of instances, because instances were withheld or unavailable).</p> <p>The dataset is a sample of instances. It is intended to be a random sample of movie reviews from newsgroup postings, with the</p>	<p>Figure 1. An example “negative polarity” instance, taken from the file <code>neg/cv452.tok-18656.txt</code>.</p> <p>exception that no more than 40 posts by a single author were included (see “Collection Process” below). No tests were run to determine representativeness.</p> <p>What data does each instance consist of? “Raw” data (e.g., unprocessed text or images) or features? In either case, please provide a description.</p> <p>Each instance consists of the text associated with the review, with obvious ratings information removed from that text (some errors were found and later fixed). The text was down-cased and HTML tags were removed. Boilerplate newsgroup header/footer text was removed. Some additional unspecified automatic filtering was done. Each instance also has an associated target value: a positive (+1) or negative (-1) sentiment polarity rating based on the number of stars that that review gave (details on the mapping from number of stars to polarity is given below in “Data Preprocessing”).</p> <p>Is there a label or target associated with each instance? If so, please provide a description.</p> <p>The label is the positive/negative sentiment polarity rating derived from the star rating, as described above.</p> <p>Is any information missing from individual instances? If so, please provide a description, explaining why this information is missing (e.g., because it was unavailable). This does not include intentionally removed information, but might include, e.g., redacted text.</p> <p>Everything is included. No data is missing.</p> <p>Are relationships between individual instances made explicit (e.g., users' movie ratings, social network links)? If so, please describe how these relationships are made explicit.</p> <p>None explicitly, though the original newsgroup postings include poster name and email address, so some information (such as threads, replies, or posts by the same author) could be extracted if needed.</p> <p>Are there recommended data splits (e.g., training, development/validation, testing)? If so, please provide a description of these splits, explaining the rationale behind them.</p> <p>The instances come with a “cross-validation tag” to enable replication of cross-validation experiments; results are measured in classification accuracy.</p> <p>Are there any errors, sources of noise, or redundancies in the dataset? If so, please provide a description.</p> <p>See preprocessing below.</p> <p>Is the dataset self-contained, or does it link to or otherwise rely on external resources (e.g., websites, tweets, other datasets)? If it links</p>

¹All information in this datasheet is taken from one of the following five sources; any errors that were introduced are the fault of the authors of the datasheet: <http://www.cs.cornell.edu/people/pabo/movie-review-data/>; <http://xxx.lanl.gov/pdf/cs/0409058v1>; <http://www.cs.cornell.edu/people/pabo/movie-review-data/rt-polaritydata.README.1.0.txt>; <http://www.cs.cornell.edu/people/pabo/movie-review-data/poldata.README.2.0.txt>.

Figure D-2 – DataSheet for Datasets EDT: Movie Review Polarity DataSheet- Page 2 (Geburu et al., 2021)

Movie Review Polarity

Thumbs Up? Sentiment Classification using Machine Learning Techniques

to or relies on external resources, a) are there guarantees that they will exist, and remain constant, over time; b) are there official archival versions of the complete dataset (i.e., including the external resources as they existed at the time the dataset was created); c) are there any restrictions (e.g., licenses, fees) associated with any of the external resources that might apply to a dataset consumer? Please provide descriptions of all external resources and any restrictions associated with them, as well as links or other access points, as appropriate.

The dataset is entirely self-contained.

Does the dataset contain data that might be considered confidential (e.g., data that is protected by legal privilege or by doctor–patient confidentiality, data that includes the content of individuals’ non-public communications)? If so, please provide a description.

Unknown to the authors of the datasheet.

Does the dataset contain data that, if viewed directly, might be offensive, insulting, threatening, or might otherwise cause anxiety? If so, please describe why.

Some movie reviews might contain moderately inappropriate or offensive language, but we do not expect this to be the norm.

Does the dataset identify any subpopulations (e.g., by age, gender)? If so, please describe how these subpopulations are identified and provide a description of their respective distributions within the dataset.

No.

Is it possible to identify individuals (i.e., one or more natural persons), either directly or indirectly (i.e., in combination with other data) from the dataset? If so, please describe how.

Some personal information is retained from the newsgroup posting in the “raw form” of the dataset (as opposed to the “preprocessed” version, in which these are automatically removed), including the name and email address the author posted under (note that these are already public on the internet newsgroup archive).

Does the dataset contain data that might be considered sensitive in any way (e.g., data that reveals race or ethnic origins, sexual orientations, religious beliefs, political opinions or union memberships, or locations; financial or health data; biometric or genetic data; forms of government identification, such as social security numbers; criminal history)? If so, please provide a description.

Aside from the aforementioned name/email addresses, no.

Any other comments?

None.

Collection Process

How was the data associated with each instance acquired? Was the data directly observable (e.g., raw text, movie ratings), reported by subjects (e.g., survey responses), or indirectly inferred/derived from other data (e.g., part-of-speech tags, model-based guesses for age or language)? If the data was reported by subjects or indirectly inferred/derived from other data, was the data validated/verified? If so, please describe how.

The data was mostly observable as raw text, except that the labels were extracted by the process described below. The data was collected by downloading reviews from the IMDb archive of the `rec.arts.movies.reviews` newsgroup, at <http://reviews.imdb.com/Reviews>.

What mechanisms or procedures were used to collect the data (e.g., hardware apparatuses or sensors, manual human curation, software

programs, software APIs)? How were these mechanisms or procedures validated?

Unknown to the authors of the datasheet.

If the dataset is a sample from a larger set, what was the sampling strategy (e.g., deterministic, probabilistic with specific sampling probabilities)?

The sample of instances collected is English movie reviews from the `rec.arts.movies.reviews` newsgroup, from which a “number of stars” rating could be extracted. The sample is limited to forty reviews per unique author in order to achieve broader coverage by authorship. Beyond that, the sample is arbitrary.

Who was involved in the data collection process (e.g., students, crowdworkers, contractors) and how were they compensated (e.g., how much were crowdworkers paid)?

Unknown to the authors of the datasheet.

Over what timeframe was the data collected? Does this timeframe match the creation timeframe of the data associated with the instances (e.g., recent crawl of old news articles)? If not, please describe the timeframe in which the data associated with the instances was created.

Unknown to the authors of the datasheet.

Were any ethical review processes conducted (e.g., by an institutional review board)? If so, please provide a description of these review processes, including the outcomes, as well as a link or other access point to any supporting documentation.

Unknown to the authors of the datasheet.

Did you collect the data from the individuals in question directly, or obtain it via third parties or other sources (e.g., websites)?

As described above, the data was collected from newsgroups.

Were the individuals in question notified about the data collection? If so, please describe (or show with screenshots or other information) how notice was provided, and provide a link or other access point to, or otherwise reproduce, the exact language of the notification itself.

No. The data was crawled from public web sources, and the authors of the posts presumably knew that their posts would be public, but the authors were not explicitly informed that their posts were to be used in this way.

Did the individuals in question consent to the collection and use of their data? If so, please describe (or show with screenshots or other information) how consent was requested and provided, and provide a link or other access point to, or otherwise reproduce, the exact language to which the individuals consented.

No (see previous question).

If consent was obtained, were the consenting individuals provided with a mechanism to revoke their consent in the future or for certain uses? If so, please provide a description, as well as a link or other access point to the mechanism (if appropriate).

N/A.

Has an analysis of the potential impact of the dataset and its use on data subjects (e.g., a data protection impact analysis) been conducted? If so, please provide a description of this analysis, including the outcomes, as well as a link or other access point to any supporting documentation.

N/A.

Any other comments?

Figure D-3 – DataSheet for Datasets EDT: Movie Review Polarity DataSheet- Page 3 (Gebru et al., 2021)

None.

Preprocessing/cleaning/labeling

Was any preprocessing/cleaning/labeling of the data done (e.g., discretization or bucketing, tokenization, part-of-speech tagging, SIFT feature extraction, removal of instances, processing of missing values)? If so, please provide a description. If not, you may skip the remaining questions in this section.

Instances for which an explicit rating could not be found were discarded. Also only instances with strongly-positive or strongly-negative ratings were retained. Star ratings were extracted by automatically looking for text like “**** out of *****” in the review, using that as a label, and then removing the corresponding text. When the star rating was out of five stars, anything at least four was considered positive and anything at most two negative; when out of four, three and up is considered positive, and one or less is considered negative. Occasionally half stars are missed which affects the labeling of negative examples. Everything in the middle was discarded. In order to ensure that sufficiently many authors are represented, at most 20 reviews (per positive/negative label) per author are included.

In a later version of the dataset (v1.1), non-English reviews were also removed.

Some preprocessing errors were caught in later versions. The following fixes were made: (1) Some reviews had rating information in several places that was missed by the initial filters; these are removed. (2) Some reviews had unexpected/unparsed ranges and these were fixed. (3) Sometimes the boilerplate removal removed too much of the text.

Was the “raw” data saved in addition to the preprocessed/cleaned/labeled data (e.g., to support unanticipated future uses)? If so, please provide a link or other access point to the “raw” data.

Yes. The dataset itself contains all the raw data.

Is the software that was used to preprocess/clean/label the data available? If so, please provide a link or other access point.

No.

Any other comments?

None.

Uses

Has the dataset been used for any tasks already? If so, please provide a description.

At the time of publication, only the original paper (<http://xxx.lanl.gov/pdf/cs/0409058v1>). Between then and 2012, a collection of papers that used this dataset was maintained at <http://www.cs.cornell.edu/people/pabo/movie%2Dreview%2Ddata/otherexperiments.html>.

Is there a repository that links to any or all papers or systems that use the dataset? If so, please provide a link or other access point.

There is a repository, maintained by Pang/Lee through April 2012, at <http://www.cs.cornell.edu/people/pabo/movie%2Dreview%2Ddata/otherexperiments.html>.

What (other) tasks could the dataset be used for?

The dataset could be used for anything related to modeling or understanding movie reviews. For instance, one may induce a lexicon of words/phrases that are highly indicative of sentiment polarity, or learn to automatically generate movie reviews.

Is there anything about the composition of the dataset or the way it was collected and preprocessed/cleaned/labeled that might impact future uses? For example, is there anything that a dataset consumer might need to know to avoid uses that could result in unfair treatment of individuals or groups (e.g., stereotyping, quality of service issues) or other risks or harms (e.g., legal risks, financial harms)? If so, please provide a description. Is there anything a dataset consumer could do to mitigate these risks or harms?

There is minimal risk for harm: the data was already public, and in the preprocessed version, names and email addresses were removed.

Are there tasks for which the dataset should not be used? If so, please provide a description.

This data is collected solely in the movie review domain, so systems trained on it may or may not generalize to other sentiment prediction tasks. Consequently, such systems should not—without additional verification—be used to make consequential decisions about people.

Any other comments?

None.

Distribution

Will the dataset be distributed to third parties outside of the entity (e.g., company, institution, organization) on behalf of which the dataset was created? If so, please provide a description.

Yes, the dataset is publicly available on the internet.

How will the dataset will be distributed (e.g., tarball on website, API, GitHub)? Does the dataset have a digital object identifier (DOI)?

The dataset is distributed on Bo Pang’s webpage at Cornell: <http://www.cs.cornell.edu/people/pabo/movie-review-data>. The dataset does not have a DOI and there is no redundant archive.

When will the dataset be distributed?

The dataset was first released in 2002.

Will the dataset be distributed under a copyright or other intellectual property (IP) license, and/or under applicable terms of use (ToU)? If so, please describe this license and/or ToU, and provide a link or other access point to, or otherwise reproduce, any relevant licensing terms or ToU, as well as any fees associated with these restrictions.

The crawled data copyright belongs to the authors of the reviews unless otherwise stated. There is no license, but there is a request to cite the corresponding paper if the dataset is used: *Thumbs up? Sentiment classification using machine learning techniques*. Bo Pang, Lillian Lee, and Shivakumar Vaithyanathan. Proceedings of EMNLP, 2002.

Figure D-4 – DataSheet for Datasets EDT: Movie Review Polarity DataSheet- Page 4 (Gebru et al., 2021)

Movie Review Polarity

Thumbs Up? Sentiment Classification using Machine Learning Techniques

Have any third parties imposed IP-based or other restrictions on the data associated with the instances? If so, please describe these restrictions, and provide a link or other access point to, or otherwise reproduce, any relevant licensing terms, as well as any fees associated with these restrictions.

No.

Do any export controls or other regulatory restrictions apply to the dataset or to individual instances? If so, please describe these restrictions, and provide a link or other access point to, or otherwise reproduce, any supporting documentation.

Unknown to authors of the datasheet.

Any other comments?

None.

tion. Will these contributions be validated/verified? If so, please describe how. If not, why not? Is there a process for communicating/distributing these contributions to dataset consumers? If so, please provide a description.

Others may do so and should contact the original authors about incorporating fixes/extensions.

Any other comments?

None.

Maintenance

Who will be supporting/hosting/maintaining the dataset?

Bo Pang is supporting/maintaining the dataset.

How can the owner/curator/manager of the dataset be contacted (e.g., email address)?

The curators of the dataset, Bo Pang and Lillian Lee, can be contacted at <https://sites.google.com/site/bopang42/> and <http://www.cs.cornell.edu/home/lee>, respectively.

Is there an erratum? If so, please provide a link or other access point. Since its initial release (v0.9) there have been three later releases (v1.0, v1.1, and v2.0). There is not an explicit erratum, but updates and known errors are specified in higher version README and `diff` files. There are several versions of these: v1.0: <http://www.cs.cornell.edu/people/pabo/movie-review-data/README;>

v1.1: <http://www.cs.cornell.edu/people/pabo/movie%2Dreview%2Ddata/README.1.1> and <http://www.cs.cornell.edu/people/pabo/movie-review-data/diff.txt>; v2.0: <http://www.cs.cornell.edu/people/pabo/movie%2Dreview%2Ddata/poldata.README.2.0.txt>. Updates are listed on the dataset web page. (This datasheet largely summarizes these sources.)

Will the dataset be updated (e.g., to correct labeling errors, add new instances, delete instances)? If so, please describe how often, by whom, and how updates will be communicated to dataset consumers (e.g., mailing list, GitHub)?

This will be posted on the dataset webpage.

If the dataset relates to people, are there applicable limits on the retention of the data associated with the instances (e.g., were the individuals in question told that their data would be retained for a fixed period of time and then deleted)? If so, please describe these limits and explain how they will be enforced.

N/A.

Will older versions of the dataset continue to be supported/hosted/maintained? If so, please describe how. If not, please describe how its obsolescence will be communicated to dataset consumers.

The dataset has already been updated; older versions are kept around for consistency.

If others want to extend/augment/build on/contribute to the dataset, is there a mechanism for them to do so? If so, please provide a descrip-

Figure D-5 – AI FactSheets EDT: Object Detector FactSheet- Page 1 (Richards et al., 2020)

Object Detector

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Overview

This document is a FactSheet accompanying the [Object Detector](#) model on IBM Developer [Model Asset eXchange](#). FactSheets aim at increasing trust in AI services through supplier's declarations of conformity and this FactSheet documents the process of training the Object Detector model as well as its expected results and appropriate use.

Purpose

Detect multiple objects within an image, with bounding boxes. The model is trained to recognize 80 different classes of objects in the COCO Dataset. The model consists of a deep convolutional net base model for image feature extraction, together with additional convolutional layers specialized for the task of object detection, that was trained on the COCO data set. It is based on SSD MobileNetV1 using the TensorFlow framework.

What is a bounding box?

A bounding box is used to describe the detected object location. The bounding box is a rectangular box that is identified by the x and y coordinates in the upper-left corner and the x and y axis coordinates in the lower-right corner of the rectangle.

Intended Domain

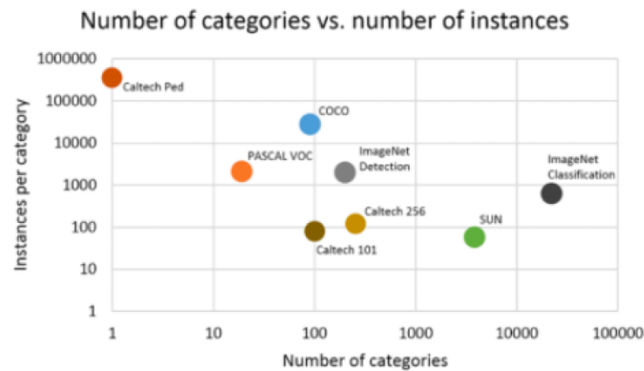
The model is designed for the computer vision domain. It can detect 80 different classes of objects like person, bicycle, car, etc. Details about the objects that the model can detect can be found [here](#).

Note: only the "thing" category is included. "Thing" categories include objects for which individual instances may be easily labeled (person, chair, car).

Training Data

The model is trained on the [COCO dataset](#). The dataset used in training the model was released in 2015.

The number of object categories and the number of instances per category of the MS COCO dataset in comparison with other popular datasets like [ImageNet](#), [PASCAL VOC 2012](#), and [SUN](#) are shown below (the chart uses a logarithmic scale).



MS COCO has fewer categories than ImageNet and SUN but has more instances per category which will be useful for learning complex models capable of precise localization. In comparison to PASCAL VOC, MS COCO has both more categories and instances. More information about the dataset statistics, process of data collection and annotation can be found [here](#).

Figure D-6 – AI FactSheets EDT: Object Detector FactSheet- Page 2 (Richards et al., 2020)

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Model Information

The model is based on the [SSD MobileNet V1 for TensorFlow](#). Pre-trained model weights for the model can be found [here](#). SSD stands for Single Shot Detector and a detailed explanation about this architecture can be found [here](#). MobileNet is used as a base network for feature extraction and its architectural details can be found [here](#).

Inputs and Outputs

The **input** to the model is an image and a threshold value. The threshold value is the probability threshold for including a detected object in the response, in the range [0, 1] (default: 0.7). Lowering the threshold includes objects the model is less certain about.

The **output** of the model is a JSON object that includes a list of all the predictions.

A sample input and output are shown below.

Input:



Output:

```
{
  "status": "ok",
  "predictions": [
    {
      "label_id": "88",
      "label": "teddy bear",
      "probability": 0.9896332025527954,
      "detection_box": [
        0.27832502126693726,
        0.5611844062805176,
        0.643224835395813,
        0.8432191610336304
      ]
    },
    {
      "label_id": "1",
      "label": "person",
      "probability": 0.9879012107849121,
      "detection_box": [
        0.24251864850521088,
        0.26926857233047485,
        0.6558930277824402,
        0.5768759846687317
      ]
    }
  ]
}
```

Output description:

- status: Response status message
- predictions: Predicted class labels, probabilities and bounding box for each detected object.
 - label_id: Class (Object) label identifier
 - label: Class label
 - probability: Predicted probability for the class label
 - detection_box: Coordinates of the bounding box for detected object. Format is an array of normalized coordinates (ranging from 0 to 1) in the form [ymin, xmin, ymax, xmax].

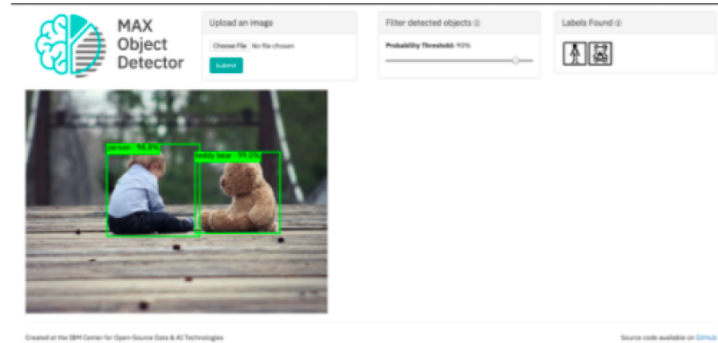
Figure D-7 – AI FactSheets EDT: Object Detector FactSheet- Page 3 (Richards et al., 2020)

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The model's Long Running Instance (LRI) can be found [here](#).

A [WebApp](#) version is also available for better Visualization of the results.

Sample output of the WebApp:



Performance Metrics

Metric	Value
Mean Average Precision	21 mAP Why mAP for Object Detection? This metric has become an accepted way to evaluate object detector competitions like PASCAL VOC, ImageNet and COCO challenges. This application is a combination of both classification and localization. Therefore, we need a metric that can evaluate both. Simple accuracy metrics can introduce bias as there will be many classes and their distribution can be non-uniform (e.g. there might be more cat images than dog images). It is also important to assess the risk of misclassifications. Thus, there is the need to associate a 'confidence score' or model score with each bounding box detected and to assess the model at various level of confidence. More information about this metric can be found here: link 1 , link 2 , and link 3 .
Model Speed	30 msec Running time is reported in msec per 600x600 image (including all pre- and post-processing). Running time is highly dependent on one's specific hardware configuration (these timings were performed using a NvidiaGeForce GTX TITAN X card) and should be treated more as relative timings in many cases. Also note that desktop GPU timing does not always reflect mobile run time. For example, MobileNetV2 is faster on mobile devices than MobileNetV1 but is slightly slower on desktop GPU. Additional notes from the repo .

Bias

The training data set for this model was evaluated for evidence of gender based bias in image captioning in a study reported in this [paper](#). The authors note that image captioning models tend to exaggerate biases present in training data. Images labeled with human annotations to indicate gender were tested and found to make incorrect gender labels in some cases. Concerns about potential for bias in image captioning applications might be present in the simpler image class identification label that is an output of this model. Therefore careful attention should be paid if this model will be used for applications where incorrect gender classification is sensitive or harmful.

We note that a full evaluation of bias along other dimensions of the data beyond gender has not been made. Therefore we caution consumers of the model to include bias testing sensitive to groups who may have traditionally experienced bias in applications of this model.

Figure D-8 – AI FactSheets EDT: Object Detector FactSheet- Page 4 (Richards et al., 2020)

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Robustness

Robustness to Image Transformations

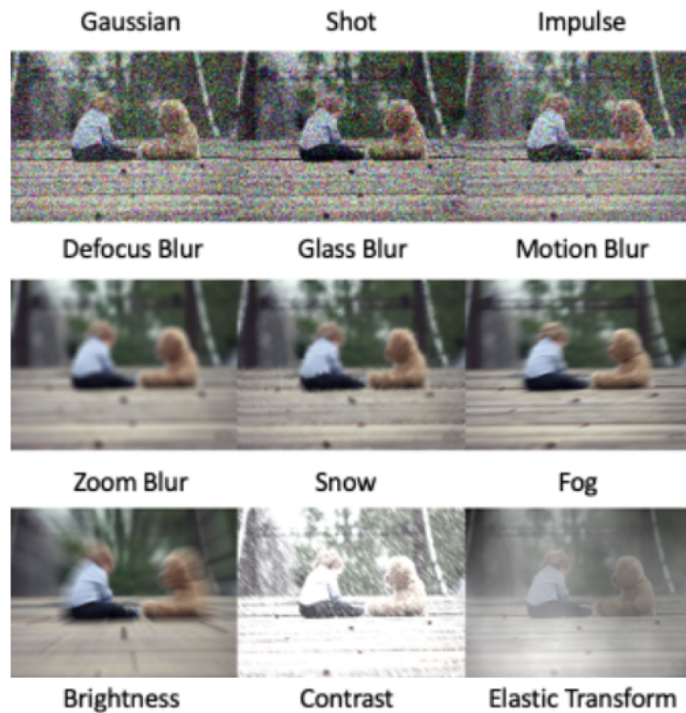
AI and ML models should perform normally even in the face of naturally occurring noise where the output should remain consistent in both the object labels and the bounding box predictions. These tests apply a variety of common image transformations in increasing severity (more noise) and measure the stability of the model to a wide range of image transformations.

More specifically, the stability of a model prediction is represented by three metrics:

1. Do the number of bounding box predictions change? (Detection Stability)
2. Do the set of unique object labels change? (Set Stability)
3. Do the locations and size of the bounding boxes change? (Bounding Box Stability)

Details

For these tests, we use the image corruptions from the image corruption benchmark (<https://github.com/hendrycks/robustness>). Given a set of N (100) randomly selected, class-distinct evaluation samples from the 2017 MS-COCO Eval Dataset (<http://cocodataset.org/>), we apply the following corruptions:



(additional corruptions omitted here to conserve space)

For each corruption, we generate 5 sets of corruption evaluation samples, each with a different severity level. The above images are examples of the highest severity level.

Figure D-9 – AI FactSheets EDT: Object Detector FactSheet- Page 5 (Richards et al., 2020)

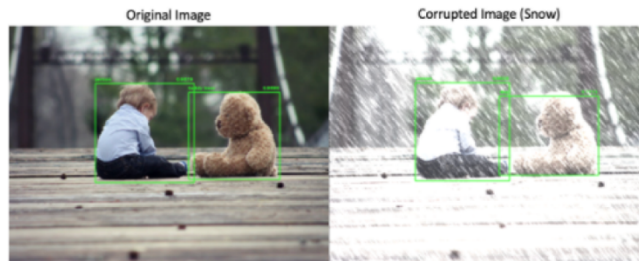
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Evaluation Metrics

For each image in the corrupted image set, we obtain the following statistics:

1. Detection stability: Measured by the number of corrupted images, which have the same number of output predictions as the original source image, divided by the total number of evaluation images (N)
2. Set Stability: Measured by the Intersection over Union (IOU) between the set of object labels in the corrupted image and the set of labels in the original source image.
3. Bounding Box Stability: Measured by the Intersection over Union (IOU) between the bounding box area in the corrupted image and the original source image

Ideally, we want each of these metrics to be as close to 1 as possible.



For the above image pair:

1. Detection Stability - 1
 - The original image has 2 predictions. The corrupted image has 2 predictions. Since they are equal, despite the different in the bounding box label, we consider it stable.
2. Set Stability - 0.33 (1 / 3)
 - The original image has 2 unique labels: [person, teddy bear]. The corrupted image has 2 unique labels: [person, dog]
 - The intersection of the two sets would be [person] as this is the only label they share in common
 - The union of the two sets would be [person, teddy bear, dog] as these are all of the unique labels.
3. Bounding Box Stability - 0.94
 - For each of the above images, we only count the area enclosed by a bounding box.
 - The intersection counts the number of common pixels enclosed by a bounding box in both the original image and the corrupted image (Red area in the image below)
 - The union counts the number of common pixels enclosed by at least one bounding box in either the original image or the corrupted image (Green area in the image below)

Intersection/Union



Figure D-10 – AI FactSheets EDT: Object Detector FactSheet- Page 6 (Richards et al., 2020)

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Results

Each of the graphs below shows the stability results for each type of image transformation noise. On the x-axis, we have the severity level for the image transformation. 1 is the lowest severity level and 5 is the highest severity level. On the y-axis, we have the stability as a measure between 0 and 1, with 1 representing the "best" performance with respect to the noise, meaning that performance was unaffected by noise.

In general, the results seem to reflect a model that has been trained to perform well with respect to a normal data distribution, but its performance on noisy data seems quite poor. We see that adding noise, which does not significantly change the macro features of the objects (shape, color, appearance, etc), still greatly affect the stability of the model. At severity level 1, adding random noise (gaussian, shot, impulse) or an image blur (glass, defocus, zoom) results in reducing the stability of the model's output to 50% with respect to the original predictions. As the severity level increases, the model's stability decreases across all three stability metrics as we might expect. Ideally, we'd prefer to see a model with much higher stability for the smaller severity levels.

The fact that the model performs poorly with respect to most of the image transformations suggest that the model may not be robust to adversarial noise. Existing research identified that models that perform well on adversarial noise also perform well with respect to some of the image transformations used in our evaluation (<https://arxiv.org/pdf/1903.12261.pdf>, <https://arxiv.org/abs/1901.10513>, <https://arxiv.org/abs/1902.02918>).

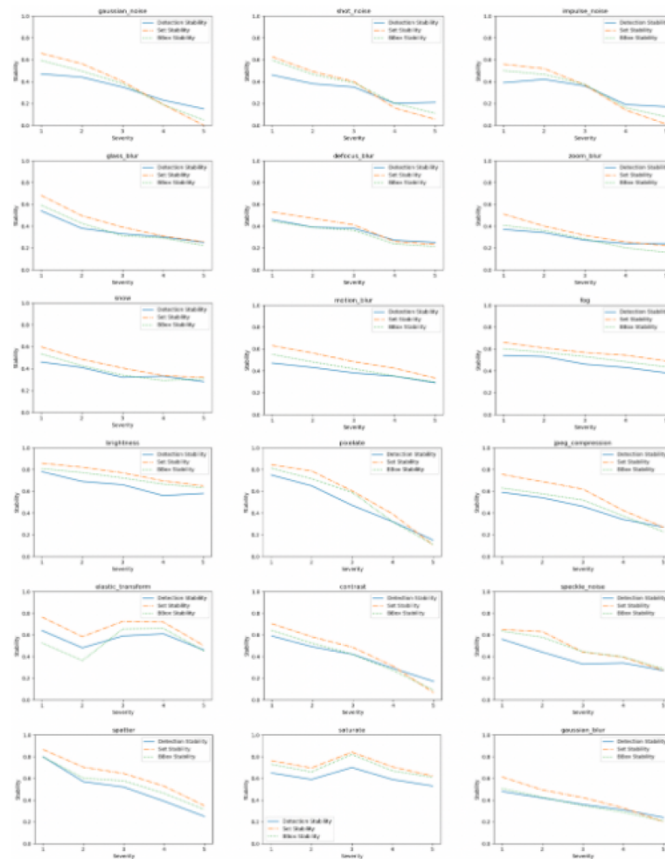


Figure D-11 – AI FactSheets EDT: Object Detector FactSheet- Page 7 (Richards et al., 2020)

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Robustness to Adversarial Attacks

AI and ML models are susceptible to adversarial attacks where the output can be altered by the addition of a small amount of noise, often imperceptible to a human, or such that a human would still classify the input correctly. These tests measure the vulnerability of the model to such attacks.

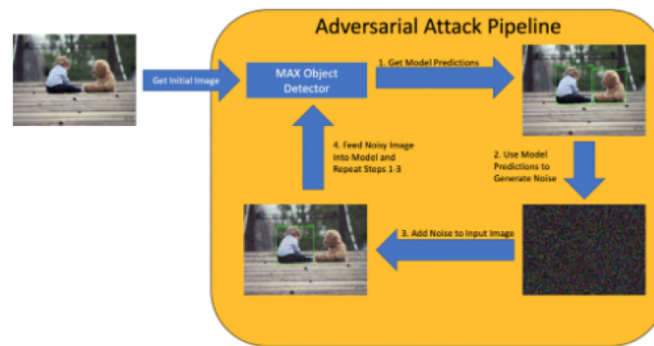
These attacks attempt to cause the model to:

1. Fail to identify an object
 - Localization attack: no bounding box drawn for the object
2. Mislabel a detected object
 - Classification attack: bounding box is drawn, but the incorrect label is written

Details

This model includes non-differentiable model components that prevents whitebox evaluation, so an empirical evaluation was performed using blackbox attacks to measure the end-to-end performance. This test leverages the Project Gradient Descent (PGD) (https://en.wikipedia.org/wiki/Gradient_descent) attack with the NES approximation for the loss gradient.

Attack Method: We use the following attack pipeline (link to a more in-depth explanation of each step)



1. Get Model Prediction
 - Following the NES approximation, we obtain multiple model predictions for the input image.
2. Use Model Predictions to Generate Noise
 - Using the most probable object label for each of the model predictions from step 1, we estimate the cross entropy loss gradient. We take a step in the opposite direction of the estimated loss gradient to generate adversarial noise.
3. Add Noise to the Input Image
 - We add the adversarial noise to the input image. From step 2, this noise should reduce the likelihood of the correct bounding box prediction and class. (Note that there is only one bounding box after adding noise)
4. Feed the Noisy Image into Model and Repeat Steps 1-3
 - We use the newly generated noisy image as an input to the model and repeat steps 1-3. The attack pipeline is repeated for some number of iterations. The final noisy image after these iterations is the final output the model is evaluated on for robustness. - In this particular eval, we performed a single step PGD attack, steps 1-3 were not repeated due to time constraints. Note that repeating the steps can increase the success rate of the attack or refine the noise to be less noticeable.

Figure D-12 – AI FactSheets EDT: Object Detector FactSheet- Page 8 (Richards et al., 2020)

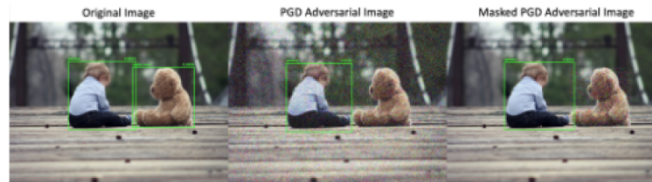
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Attack Parameters:

- **Number of Evaluation Images: 100**
 - Evaluation image are randomly selected from the MSCOCO 2017 eval dataset
- **Type of Attack: PGD L_{∞} attack**
 - The maximum absolute change to any a single pixel channel is limited by E (epsilon).
 - **E values: [10, 20, 30, 40, 50]**
 - Each pixel in a color image has 3 channels (R, G, B) and can be a value in the range [0,255]
- **Attack Iterations: 1**
 - This is the number of times the attack pipeline runs. In this case, we are doing a single step PGD
- **E Step: [10, 20, 30, 40, 50]**
 - As we are doing a single-step PGD, we add the maximum amount of noise based on the value of E in the computed direction.
- **Gradient Approximation Method: NES**
 - This method generates several noisy samples from a single sample, obtains model predictions for each sample, and then approximates a gradient.
 - **Number of Estimates: 15**
 - Number of samples to generate and provide to the target model for gradient estimation
- **Sigma: 2**
 - A scale factor for the generated noise. The noise is generated from a standard normal distribution (zero mean, unit variance)

Exact Objective

The objective is cause the model to either fail to detect a previously detected object or mislabel a previously detected object by adding noise to the image. If the area the noise can be added is restricted to a portion of the image, we refer to it as a masked attack. These attacks are done in an untargeted fashion. That is to say, we attempt to cause any misclassification or removal of bounding box.



Evaluation Metrics

We express the robustness of a model to these objects by the:

1. **Detection stability** - Measured by the number of adversarial images, which have at least the same number of output predictions as the original source image, divided by the total number of evaluation images (N)
2. **Set Stability** - Measured number of adversarial images, which have at least the set of unique labels in the original image box. We are not concerned with new unique labels that are present due to the added adversarial noise.

Note that these are calculated differently than the measures in the image transformation robustness section. Remember, we are concerned with if the adversarial noise causes the original predictions to be removed.

Figure D-13 – AI FactSheets EDT: Object Detector FactSheet- Page 9 (Richards et al., 2020)

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For the PGD Adversarial Image example:

- Detection Stability - 0
 - The number of predictions in the original image is 2. The number of predictions in the adversarial image is 1. Since the adversarial noise caused a prediction to vanish, the model's output is not stable in this example.
- Set Stability - 0
 - The original image has 2 unique labels: [person, teddy bear]. The adversarial image has 1 unique labels: [person]. Since the adversarial noise caused a unique label to vanish, the model's output is not stable in this example.

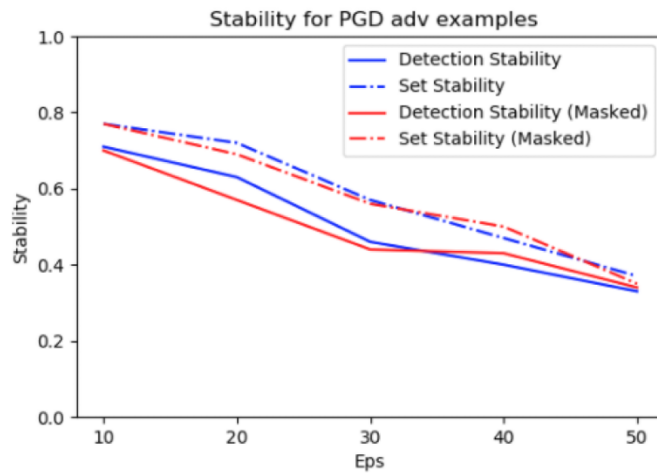
L-Inf PGD Attack Results

This is a plot of the model's stability with respect to a single step PGD attack. Recall that the evaluation only measures if the adversarial noise removed output information that was present in the original prediction on the unmodified input sample. On the x-axis, we have the value of epsilon, the maximum absolute amount of change allowed to any single pixel channel. On the y-axis, we have the stability of the model for its respective metric.

We see from the plot that the model is not very robust against a black-box single-step PGD attack. As we expect, as the maximum amount of noise is increased, the success rate of the attack increases, which is reflected by the decreased model stability at each point. As these results were generated using a black box single-step PGD attack, we expect that the model stability would drop even further if:

- The attack had access to the exact loss gradients for any given input - Whitebox attack
- The attack was run with more iterations - Multi-step PGD

To improve the model's stability to such attacks, we recommend using some data augmentation techniques such as randomized smoothing or adversarial training as a preliminary step if improved adversarial robustness is desired.



Certification using Randomized Smoothing

No certification has been performed on this model. More information on this type of certification can be found at <https://arxiv.org/abs/1902.02918>

Figure D-14 – AI FactSheets EDT: Object Detector FactSheet- Page 10 (Richards et al., 2020)

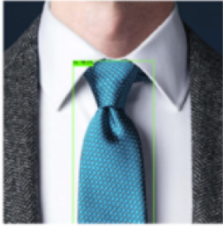
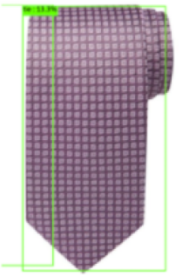
<p>Overview</p> <p>Purpose</p> <p>Intended Domain</p> <p>Training Data</p> <p>Model Information</p> <p>Inputs and Outputs</p> <p>Performance Metrics</p> <p>Bias</p> <p>Robustness</p> <p>Domain Shift</p> <p>Test Data</p> <p>Optimal Conditions</p> <p>Poor Conditions</p> <p>Explanation</p> <p>Contact Information</p>	<p>Other possible attacks:</p> <p>These are other effects of adversarial attacks that the models should be robust to, but were not measured in this section. (consider adding a link)</p> <ol style="list-style-type: none">1. Targeted Mislabeling Attack - Adversarial attacks can add noise to cause the model to mislabel an object(s) into a specific wrong object class2. Targeted Vanishing Attack - Adversarial attacks can add noise to cause the model to mislabel or fail to label objects belonging to a specific object class.3. Fake Object Detections - Adversarial attacks can add noise to cause the model to output a prediction for an object, which doesn't exist in the input. <p>Domain Shift</p> <p>No domain shift evaluation occurred.</p> <p>Test Data</p> <p>Test data was a subset of the COCO Validation dataset.</p> <p>Optimal Conditions</p> <ul style="list-style-type: none">• Inputs similar to the training dataset.• Images with good resolution and lighting. <p>Poor Conditions</p> <ul style="list-style-type: none">• Input from a different distribution than what the model is trained on. For example, the model might have been trained for specific tie patterns but providing input that is different from training data leads to a poor result. <div style="display: flex; justify-content: space-around; align-items: center;"></div> <ul style="list-style-type: none">• Model not trained for specific type of objects. If the model is trained to detect cars but if a truck is an input, it will either detect it as a car with low confidence score or it will go undetected.• Images with poor resolution and lighting.• Partially truncated objects. <p>Explanation</p> <p>The model is essentially a black box and does not provide explanations of its predictions.</p> <p>Contact Information</p> <p>Any queries related to the operation of the MAX Object Detector model can be addressed on the model GitHub repo.</p> <p>Additional information is also available on the model landing page.</p> <p>Queries about the general Model Asset Exchange project or this FactSheet can be raised on the MAX central GitHub repo or Slack workspace.</p>
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Figure D-15 – The Dataset Nutrition Label EDT: ProPublica’s Dollars for Docs Data- Page 1 (Holland et al., 2018)

Dataset Facts
 ProPublica’s Dollars
 for Docs Data

Metadata

Filename	201612v1-docdollars-product_payments
Format	csv
Url	https://projects.propublica.org/docdollars/
Domain	healthcare
Keywords	Physicians, drugs, medicine, pharmaceutical, transactions
Type	tabular
Rows	500
Columns	18
Missing	5.2%
License	cc
Released	JAN 2017
Range	
From	AUG 2013
To	DEC 2015
Description	This is the data used in ProPublica’s Dollars for Docs news application. It is primarily based on CMS’s Open Payments data, but we have added a few features. ProPublica has standardized drug, device and manufacturer names, and made a flattened table (product_payments) that allows for easier aggregating payments associated with each drug/device. In [1], one payment record can be attributed to up to five different drugs or medical devices. This table flattens the payments out so that each drug/device related to each payment gets its own line.

Provenance

Source	
Name	U.S. Centers for Medicare & Medicaid Services
Url	https://www.cms.gov/OpenPayments/
Email	openpayments@cms.hhs.gov
Author	
Name	ProPublica
Url	https://www.propublica.org/datastore/
Email	data.store@propublica.org

Variables

Id	A unique ID number for this payment & product combination. This is assigned by ProPublica for internal use
Applicable_manufacturer_or_applicable_gpo_making_payment_id	ID of the applicable manufacturer or submitting applicable GPO making payment or other transfer of value
Date_of_payment	If a singular payment, then this is the actual date the payment was issued; if a series of payments or an aggregated set of payments, this is the date of the first payment to the covered recipient in this program year
General_transaction_id	System-assigned identifier to the general transaction at the time of submission
Program_year	The calendar year for which the payment is reported in Open Payments
Product_name	Derived from the 'name_of_associated_covered_drug_or_biologicalX' field (for drugs) or 'name_of_associated_covered_device_or_medical_supplyX' field (for medical devices). Where possible, multiple versions of the same product are converted to the same product_name (i.e. records for 'Zorvolex 65mg' and 'Zorvolex 35mg' will be converted to 'Zorvolex'). The original value is contained in original_product_name
Original_product_name	A copy of the original name_of_associated_covered_drug_or_biologicalX field (for drugs) or 'name_of_associated_covered_device_or_medical_supplyX' field (for medical devices)
Product_ndc	If the product is a drug, this a copy of the original 'ndc_of_associated_covered_drug_or_biologicalX' field
Product_is_drug	't' if the product is a drug (contained in a 'name_of_associated_covered_drug_or_biologicalX' field). 'f' if the product is a medical device (contained in a 'name_of_associated_covered_device_or_medical_supplyX' field)
Payment_has_many	't' if the original payment record included data on more than one drug or device, i.e. 'name_of_associated_covered_drug_or_biologicalal1' and 'name_of_associated_covered_drug_or_biologicalal2', 'name_of_associated_covered_device_or_medical_supply1' and 'name_of_associated_covered_device_or_medical_supply2', etc;
Teaching_hospital_id	Open Payments system-generated unique identifier of the teaching hospital receiving the payment or other transfer of value
Physician_profile_id	ID of the physician receiving the payment or other transfer of value
Recipient_state	The state or territory abbreviation of the primary business address of the physician or teaching hospital or non-covered recipient entity receiving the payment or other transfer of value if the primary business address is in the United States
Applicable_manufacturer_or_applicable_gpo_making_payment_name	Textual proper name of the applicable manufacturer or applicable GPO making the payment or other transfer of value. This field has been standardized to eliminate different names attributable solely to punctuation
Teaching_hospital_ccn	A unique identifying number (CMS Certification Number) of the Teaching Hospital receiving the payment or other transfer of value
Product_slug	Used internally at ProPublica for web display on the Dollars for Docs app. You can pull up the corresponding Dollars for Docs page for a product by appending product_slug to https://projects.propublica.org/docdollars/products/ , i.e. https://projects.propublica.org/docdollars/products/device-dental-cabinetry
Total_amount_of_payment_usdollars	U.S. dollar amount of payment or other transfer of value to recipient (manufacturer must convert to dollar currency if necessary)
Number_of_payments_included_in_total_amount	The number of discrete payments being reported in the 'Total Amount of Payment' data element

Figure D-16 – The Dataset Nutrition Label EDT: ProPublica’s Dollars for Docs Data- Page 2 (Holland et al., 2018)

Statistics						
Ordinal						
name	type	count	uniqueEntries	mostFrequent	leastFrequent	missing
id	number	500	488 including mi...	missing value (13)	multiple detected	2.60%
applicable_man...	number	500	4	100000000232 (...)	multiple detected	0%
date_of_payment	date	500	213 including mi...	missing value (27)	multiple detected	5.40%
general_transac...	number	500	467 including mi...	missing value (34)	multiple detected	6.80%
program_year	number	500	2 including missi...	2014 (495)	missing value (5)	1.00%

Nominal						
name	type	count	uniqueEntries	mostFrequent	leastFrequent	missing
product_name	string	500	16 including mis...	Xarelto (200)	Aciphex (1)	3.20%
original_product...	string	500	15	Xarelto (212)	Aciphex (1)	0%
product_ndc	number	500	21 including mis...	5045857810 (201)	multiple detected	5.00%
product_is_drug	boolean	500	2 including missi...	t (492)	missing value (8)	1.60%
payment_has_m...	boolean	500	3 including missi...	f (267)	missing value (29)	5.80%
teaching_hospit...	number	500	2 including missi...	0 (464)	missing value (36)	7.20%
physician_profile...	number	500	230 including mi...	missing value (32)	multiple detected	6.40%
recipient_state	string	500	40	CA (56)	multiple detected	0%
applicable_man...	string	500	5 including missi...	Janssen Pharm...	multiple detected	7.00%
teaching_hospit...	number	500	2 including missi...	0 (481)	missing value (19)	3.80%
product_slug	string	500	15 including mis...	drug-xarelto (196)	drug-aciphex (1)	8.20%

Continuous									
name	type	count	min	median	max	mean	standardD...	missing	zeros
total_amo...	number	500	0.14	14.00	5000	134.21	501.99	9.40%	0%

Discrete									
name	type	count	min	median	max	mean	standardD...	missing	zeros
number_o...	number	500	1	1.00	1	1.00	0.00	4.80%	0%

Figure D-17 – The Data Nutrition Label (2nd Gen) EDT: TaxBills NYC Dataset- Page 1 (Chmielinski et al., 2020)

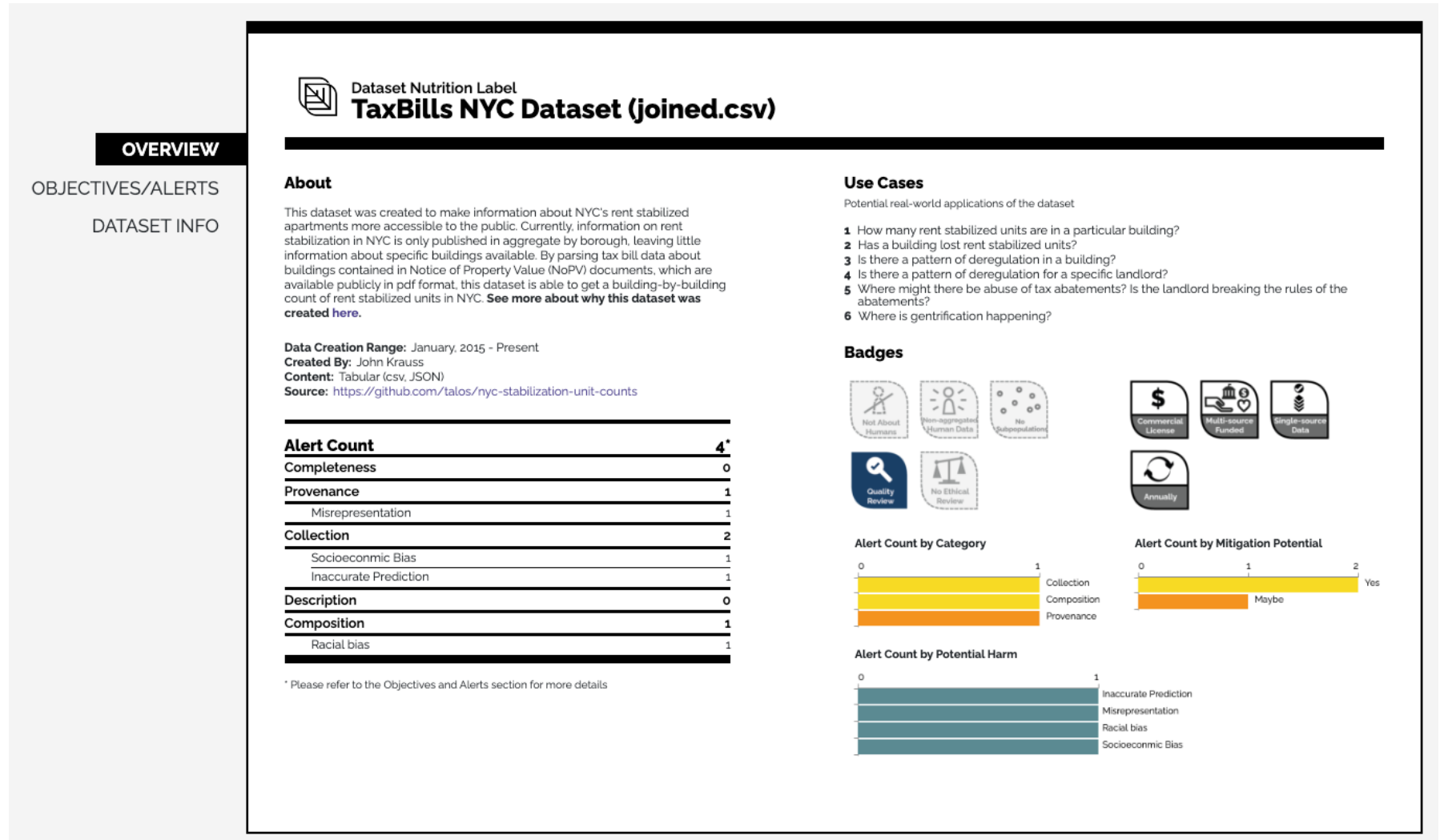


Figure D-18 – The Data Nutrition Label (2nd Gen) EDT: TaxBills NYC Dataset- Page 2 (Chmielinski et al., 2020)


OVERVIEW

OBJECTIVES/ALERTS

Selector

Alerts

DATASET INFO



Dataset Nutrition Label

TaxBills NYC Dataset (joined.csv)

Objectives & Alerts

About Relevant alerts for data practitioners who intend to use this dataset for specific use cases (types of analyses).

Selector

Modeling Objectives:
What is the objective?

Click on a modeling objective to filter relevant alerts.

- Predict change in % of stabilized units for a building
- Predict change in % of stabilized units for a community district
- Predict change in % of stabilized units for a zip code
- Predict change in % of stabilized units for an owner (name)
- Predict building deregulation based on owner patterns
- Predict building deregulation based on community district patterns
- Predict building deregulation based on zip code patterns
- Classify owners into categories based on rate of stabilization
- Classify zip codes based on rate of stabilization

3 Alerts

Click on the arrow next to an alert to see more information.

Alerts

FYIs


MITIGATION POSSIBLE: ■ 0 No ■ 1 Maybe ■ 2 Yes

FILTER: All ▼

- Some stabilized unit counts are estimates ▼
- Owner listed is not always the true person/company that owns the lot ▼
- Zipcode is highly correlated with racial demographics in the US ▼

Figure D-19 – The Data Nutrition Label (2nd Gen) EDT: TaxBills NYC Dataset- Page 3 (Chmielinski et al., 2020)

OVERVIEW
OBJECTIVES/ALERTS
DATASET INFO
Description
Composition
Provenance
Collection
Management



Dataset Nutrition Label
TaxBills NYC Dataset (joined.csv)

Dataset Information

Information about the ongoing management of the dataset, such as how the data will be maintained, updated, and the best contact for further inquiries.

The categories and questions that comprise this section are drawn from the terrific work of many teams; we have drawn heavily on the work of [Datasheets for Datasets](#), and supplemented that with work by [AI Global](#), [data.world](#), and [DrivenData](#). We further refined this section based on feedback from colleagues at the Department of Education, AI Global, and Memorial Sloan Kettering.

Description

1. TELL US ABOUT THIS DATASET.

This dataset was created to make information about NYC’s rent stabilized apartments more accessible to the public. Currently, information on rent stabilization in NYC is only published in aggregate by borough, leaving little information about specific buildings available. By parsing tax bill data about buildings contained in Notice of Property Value (NoPV) documents, which are available publicly in pdf format, this dataset is able to get a building-by-building count of rent stabilized units in NYC. **See more about why this dataset was created [here](#).**

2. IS THERE AN INTENDED PURPOSE FOR THE DATASET? WHAT DOMAIN WAS IT DESIGNED FOR?

See [here](#) for information on intended purposes from the dataset creator. Some intended purposes include:

1. Seeing loss of rent stabilized units over time in a building
2. Seeing loss of rent stabilized units over time in many buildings

3. WHAT IS THE LICENSE UNDER WHICH THE DATASET IS MADE AVAILABLE?

Creative Commons Attribution Share-Alike

4. ARE THERE ANY ADDITIONAL RESTRICTIONS UNDER WHICH THE DATASET IS MADE AVAILABLE? ARE THERE ANY LEGISLATION, CODES OF PRACTICE OR GUIDANCE FROM THE JURISDICTION OR DOMAIN IN WHICH THE DATA WAS COLLECTED ABOUT THE USE OF THIS DATA? ARE THERE TASKS FOR WHICH THE DATASET CANNOT BE USED? PLEASE PROVIDE A DESCRIPTION OR GUIDANCE.

No

5. ARE THERE TASKS FOR WHICH THE DATASET WOULD BE CAUTIONED AGAINST BEING USED? IF SO, PLEASE PROVIDE A DESCRIPTION.

No

Figure D-20 – The Data Nutrition Label (2nd Gen) EDT: TaxBills NYC Dataset- Page 4 (Chmielinski et al., 2020)

Composition

1. DOES THE DATASET HAVE A METADATA REPOSITORY OR DATA DICTIONARY? IF YES, PLEASE PROVIDE THE LINK AND IF NOT, PLEASE EXPLAIN WHAT EACH FIELD MEANS.

See the [github repository](#) for this dataset for a data dictionary, which is contained in its readme.

2. IN THE CASE OF EXPLICITLY RELATED INSTANCES, ARE THESE RELATIONSHIPS INDICATED? (E.G., RELATING AN INSTANCE ABOUT A USER TO INSTANCES ABOUT THEIR POSTS)

No

3. WHAT DATA DOES EACH INSTANCE CONSIST OF? FOR EXAMPLE, DOES IT CONSIST OF RAW DATA (E.G., UNPROCESSED TEXT OR IMAGES) OR FEATURES? IN EITHER CASE, PLEASE PROVIDE A DESCRIPTION.

This data contains features that were extracted from another dataset of raw, unprocessed file images. This process is described on the dataset's [github repository](#), where you can also find source code for how that data is extracted.

4. HOW MANY INSTANCES ARE THERE IN TOTAL (OF EACH TYPE, IF APPROPRIATE)?

46,462 instances in this dataset.

5. IS THERE A LABEL OR TARGET ASSOCIATED WITH EACH INSTANCE?

From <https://github.com/talos/nyc-stabilization-unit-counts#caveats>: "The combination of self-reporting stabilization counts and occasionally missing tax bills means that a significant percentage of buildings miss reporting for some years. In order to compensate, all output files contain some estimated counts..."

6. IS ANY INFORMATION MISSING FROM INDIVIDUAL INSTANCES? IF SO, WHAT IS MISSING AND WHY?

Landlords are not required to register stabilized apartments as part of their tax bills reporting, so in some cases this part of an instance's data is estimated. Estimated instances are marked as such in a column labeled `2007est`.

7. IS YOUR DATASET A SAMPLE? IF SO, WHAT WAS THE SAMPLING STRATEGY USED (E.G. DETERMINISTIC, PROBABILISTIC WITH SPECIFIC SAMPLING PROBABILITIES), AND DOES IT ACCURATELY REPRESENTS THE INTENDED OUTPUT?

No

8. WAS ANY PREPROCESSING/CLEANING/LABELING OF THE DATA DONE? IF SO, PLEASE PROVIDE A DESCRIPTION.

Data was scraped from its original source, and estimated values were added where original data was lacking. See <https://github.com/talos/nyc-stabilization-unit-counts#caveats> for more detail.

9. IF THE DATA WAS PROCESSED, WAS THE RAW DATA SAVED IN ADDITION TO THE PREPROCESSED/CLEANED/LABELED DATA? IF YES, PLEASE PROVIDE A LINK TO THE RAW DATA.

Data from the original PDFs is available with the github repository.

Figure D-21 – The Data Nutrition Label (2nd Gen) EDT: TaxBills NYC Dataset- Page 5 (Chmielinski et al., 2020)

Provenance

1. WHO CREATED THE DATASET AND ON BEHALF OF WHICH ENTITY?

This dataset was scraped by individuals as part of a volunteer effort led by John Krauss <http://blog.johnkrauss.com/>. The people involved are anti-displacement activists who did this without funding or direction of a specific entity.

2. HOW IS / WAS THE COLLECTION AND MANAGEMENT OF THIS DATASET FUNDED?

This dataset was scraped by individuals as part of a volunteer effort led by John Krauss <http://blog.johnkrauss.com/>. The people involved are anti-displacement activists who did this without funding or direction of a specific entity.

Collection

1. OVER WHAT TIMEFRAME WAS THE DATA COLLECTED? IF THE DATA CONTINUES TO BE UPDATED, PLEASE INDICATE.

The dataset collects yearly information, and is therefore updated yearly. It has records for each instance dating back to 2008.

2. WHAT MECHANISMS OR PROCEDURES WERE USED TO COLLECT THE DATA?

See the [github repository](#) for the dataset for more information. The scraper which goes through the original tax bills (Notice of Property Value PDFs) is contained within that repository.

3. WHAT IS THE RELATIONSHIP BETWEEN THE DATASET COLLECTOR AND OWNERS OR MANAGERS OF THE DATASET?

The original dataset is a set of tax documents published by a government agency. That data has been preprocessed and cleaned by the volunteers who have made this dataset.

4. IF INDIVIDUALS' DATA IS INCLUDED IN THIS DATASET, DID THOSE INDIVIDUALS CONSENT TO THE COLLECTION AND USE OF THEIR DATA? IF SO, PLEASE DESCRIBE CONSENT PROCEDURE.

N/A

5. IF INDIVIDUALS' DATA IS INCLUDED IN THIS DATASET, WAS THIS DATA ALTERED TO ENSURE HIGHER LEVELS OF PRIVACY? IF YES, PLEASE DESCRIBE ANY PRIVACY PROCEDURES FOLLOWED WITH REGARDS TO THIS DATASET (ANONYMIZATION EFFORTS, PRIVACY PROTOCOLS, SUPPRESSION TECHNIQUES, ETC).

N/A

6. HAS THE DATA BEEN REVIEWED FOR QUALITY?

Yes, data has been reviewed by internal team

Figure D-22 – The Data Nutrition Label (2nd Gen) EDT: TaxBills NYC Dataset- Page 6 (Chmielinski et al., 2020)

Management

1. HOW IS THE DATA BEING MANAGED AT REST AND IN TRANSIT?

Through a third-party data service, terms and conditions ensure users data should be protected from theft, misuse, or data corruption

2. HOW CAN THE DATA BE ACCESSED? IF THIS IS GOING TO CHANGE OVER TIME, PLEASE INDICATE THIS.

Data can be accessed at <http://taxbills.nyc/>, or on github at <https://github.com/talos/nyc-stabilization-unit-counts>.

3. WILL THE DATASET BE DISTRIBUTED TO ANY OTHER INDIVIDUALS/THIRD PARTIES (E.G. COMPANIES, INSTITUTIONS, ORGANIZATIONS)? IF YES, WHEN WILL THE DATASET BE DISTRIBUTED AND HOW WILL THE DATASET BE DISTRIBUTED (E.G. GITHUB, TARBALL ON THE WEBSITE, ETC)?

No

4. WILL THE DATASET BE UPDATED (E.G., TO CORRECT LABELING ERRORS, ADD NEW INSTANCES, DELETE INSTANCES)? IF SO, PLEASE DESCRIBE HOW OFTEN, BY WHOM, AND HOW UPDATES WILL BE COMMUNICATED TO USERS (E.G., MAILING LIST, GITHUB)?

Data is updated yearly. Date of update is unknown.

5. IS THERE A MECHANISM THROUGH WHICH AN INDIVIDUAL CAN REQUEST THEIR PERSONAL INFORMATION BE REMOVED?

N/A

Figure D-23 – Ranking Facts EDT: CS Department Dataset (Yang et al., 2018)

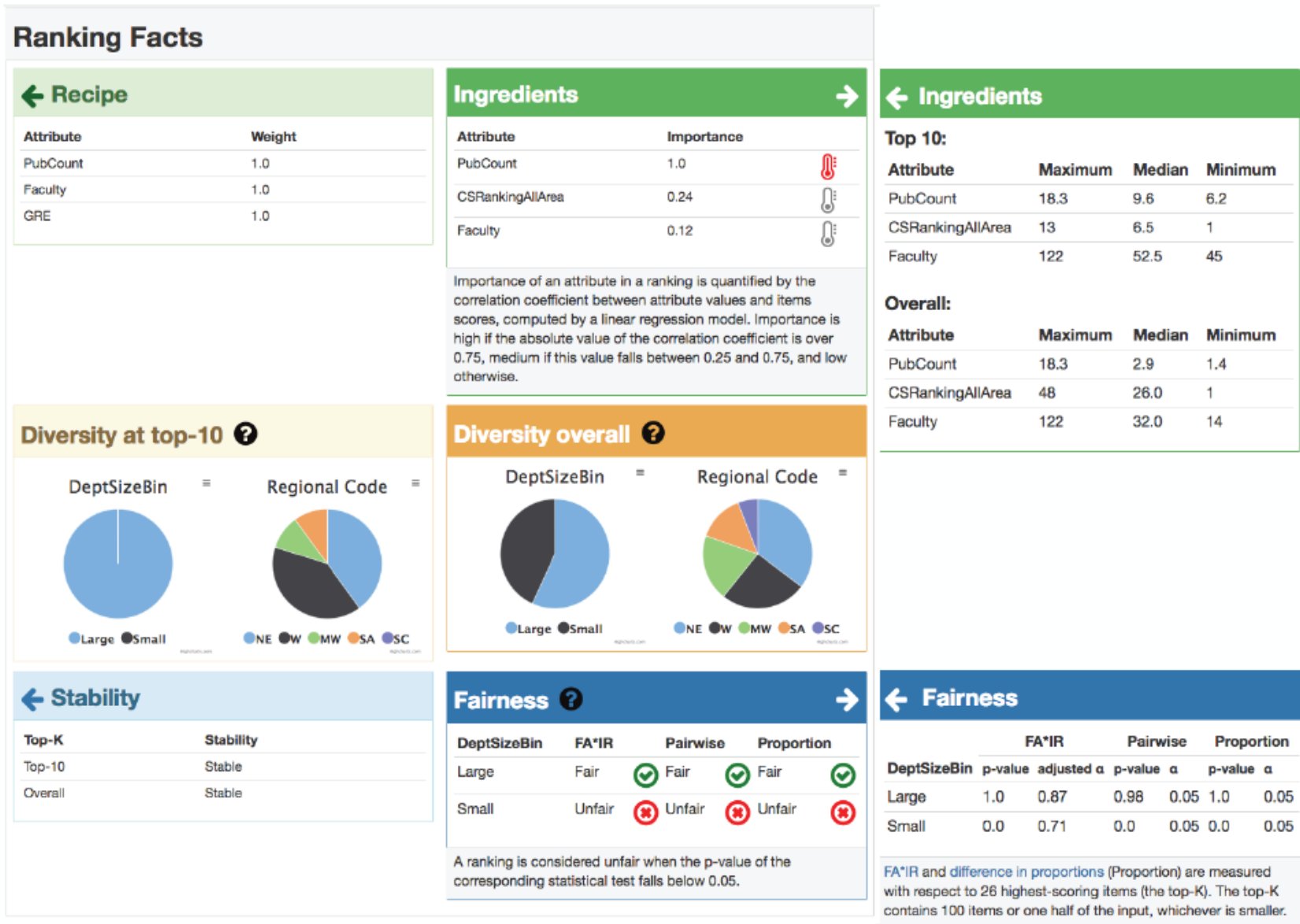


Figure D-24 – Model Cards for Model Reporting EDT: Summary of Model Card Sections and Suggested Prompts (Mitchell et al., 2019)

Model Card
<ul style="list-style-type: none">● Model Details. Basic information about the model.<ul style="list-style-type: none">– Person or organization developing model– Model date– Model version– Model type– Information about training algorithms, parameters, fairness constraints or other applied approaches, and features– Paper or other resource for more information– Citation details– License– Where to send questions or comments about the model● Intended Use. Use cases that were envisioned during development.<ul style="list-style-type: none">– Primary intended uses– Primary intended users– Out-of-scope use cases● Factors. Factors could include demographic or phenotypic groups, environmental conditions, technical attributes, or others listed in Section 4.3.<ul style="list-style-type: none">– Relevant factors– Evaluation factors● Metrics. Metrics should be chosen to reflect potential real-world impacts of the model.<ul style="list-style-type: none">– Model performance measures– Decision thresholds– Variation approaches● Evaluation Data. Details on the dataset(s) used for the quantitative analyses in the card.<ul style="list-style-type: none">– Datasets– Motivation– Preprocessing● Training Data. May not be possible to provide in practice. When possible, this section should mirror Evaluation Data. If such detail is not possible, minimal allowable information should be provided here, such as details of the distribution over various factors in the training datasets.● Quantitative Analyses<ul style="list-style-type: none">– Unitary results– Intersectional results● Ethical Considerations● Caveats and Recommendations

Figure D-25 – Model Cards for Model Reporting EDT: Model Card for Smile Detector (Mitchell et al., 2019)

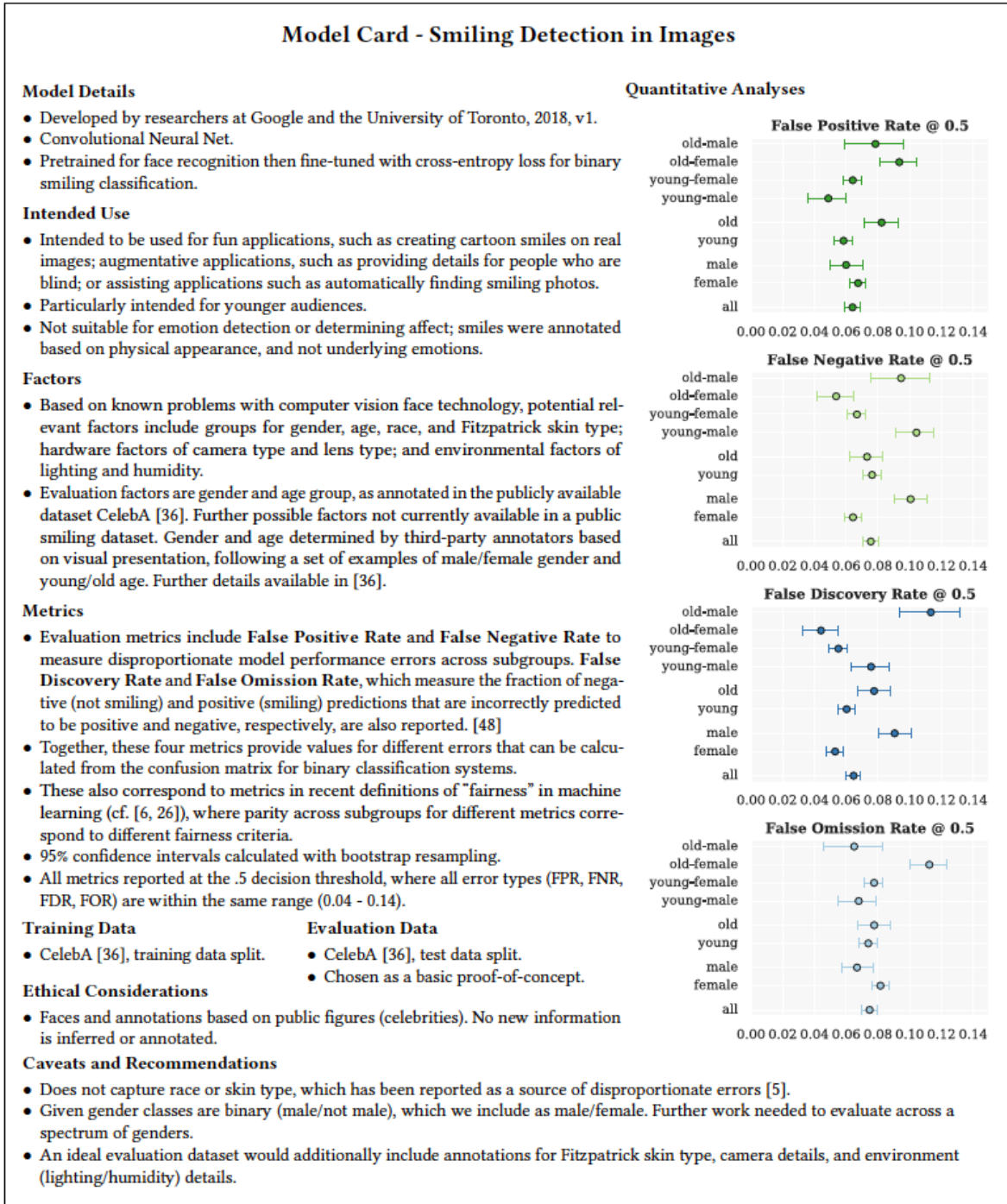
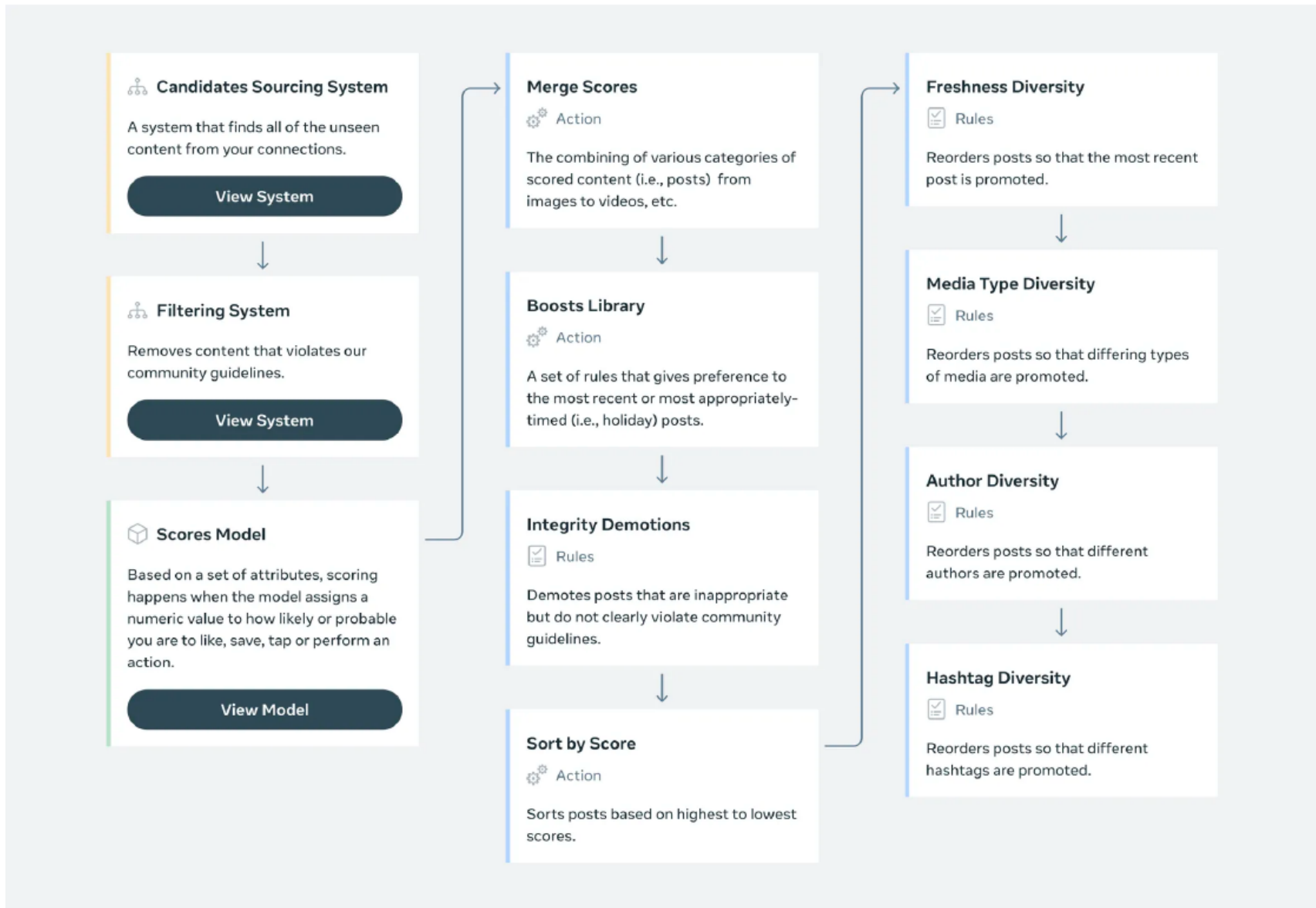



Figure D-26 – System Card EDT: System Card for an archetypal content ranking System (Procope et al., 2022)



Appendix E: Ethical DataSheet for the Hexoskin ProShirt™

Appendix E presents the Ethical DataSheet that was designed and developed for the Hexoskin ProShirt™ using the Ethical DataSheet prototype presented in Chapter 4.0: Prototyping the Ethical DataSheet.

Figure E-1 – Hexoskin ProShirt™ EDS- Device Identification and Characteristics




CRAiEDL

800 King Edward Avenue, Ottawa, ON, Canada K1N
@CRAiEDL, www.craiedl.ca

Creation Date: 02/07/2022
Revision Date: DD/MM/YYYY

Ethical DataSheet

Device Name: Hexoskin ProShirt



Device Identification

Device Name: Hexoskin ProShirt
Device Type: Vest (wearable device)
Device Manufacturer: Hexoskin
Manufacturer Origin: Canada

Device Purpose: Used to monitor vital signs including cardiac, respiratory, and movement

Context of Use: Should be used when the wearer is out and about- not as popular for home usage

Device Characteristics

Weight: 80g (3.02 oz)
Colour: Dark Blue
Size: 2XS – 4XL
Cost: \$648.00 USD
Putting Device On: Over the head

Device Components: Five internal sensors, one external sensor (data recorder)

Type of Data Collected: Vital (heart and breathing) and activity (movement)

Data Storage Location: 3 locations (Locally in the data recorder, on Hexoskin servers, or the PATH database)

1

173

Figure E-2 – Hexoskin ProShirt™ EDS- Tenants Section

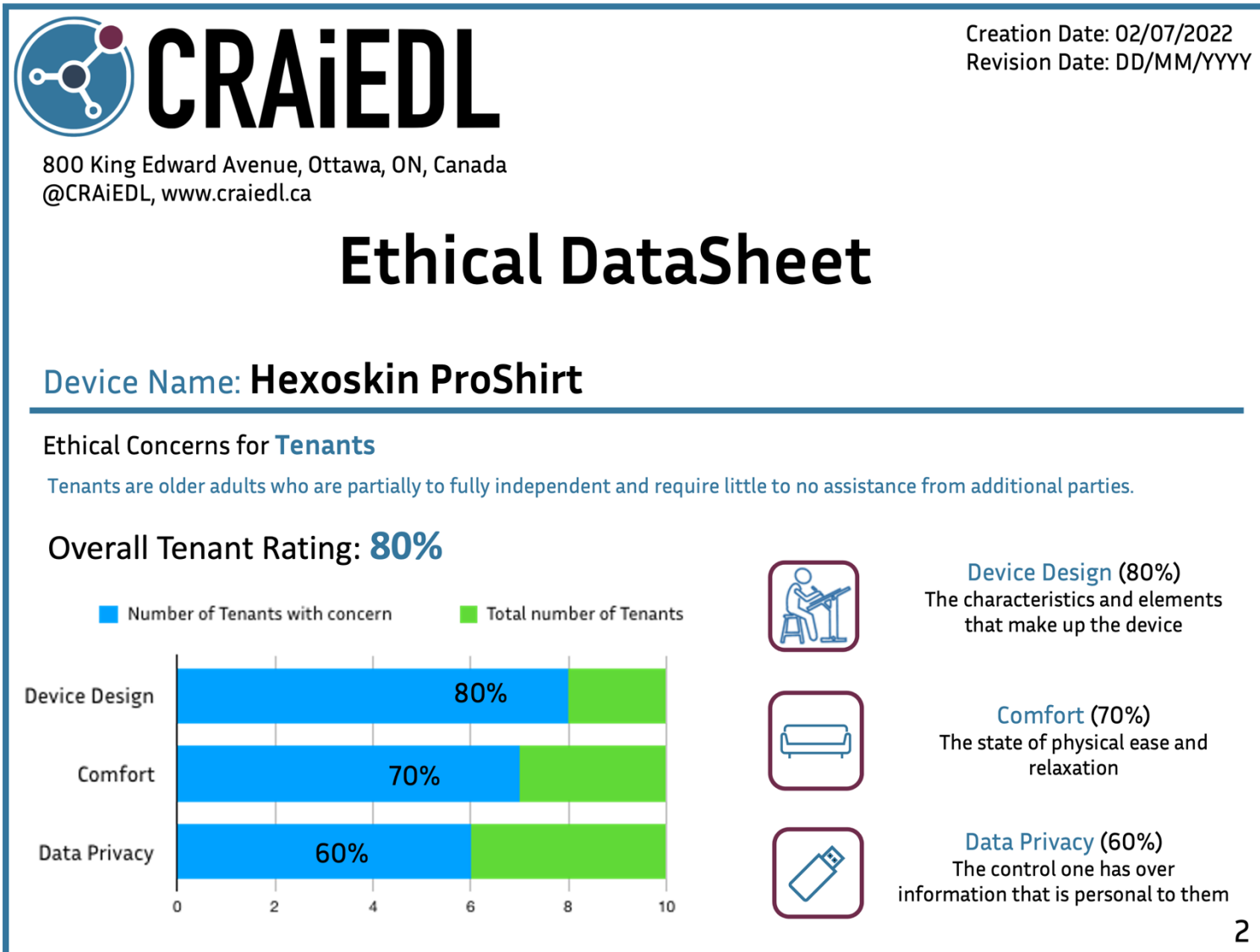


Figure E-3 – Hexoskin ProShirt™ EDS- Tenants Section Continued

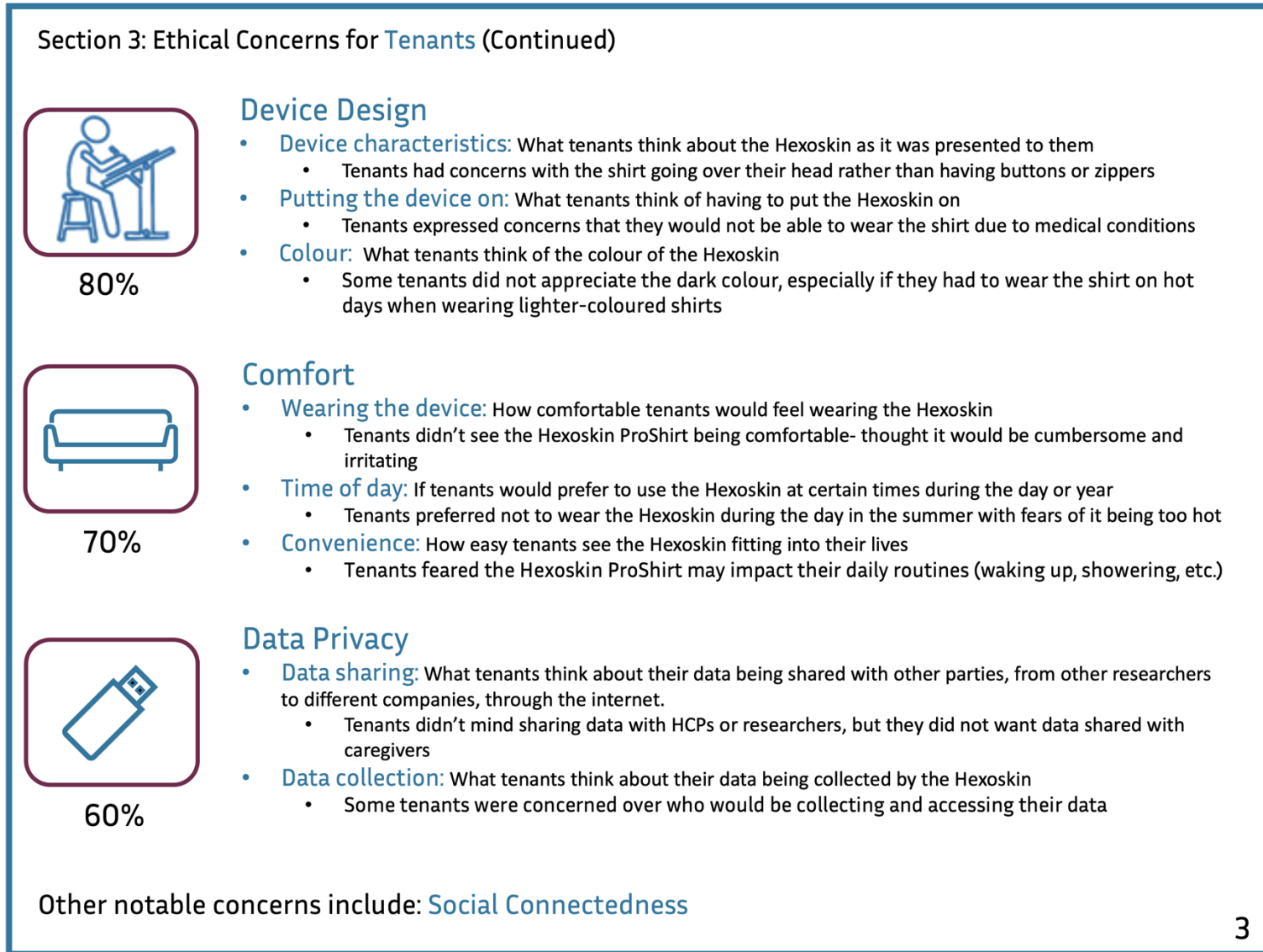


Figure E-4 – Hexoskin ProShirt™ EDS- Residents Section

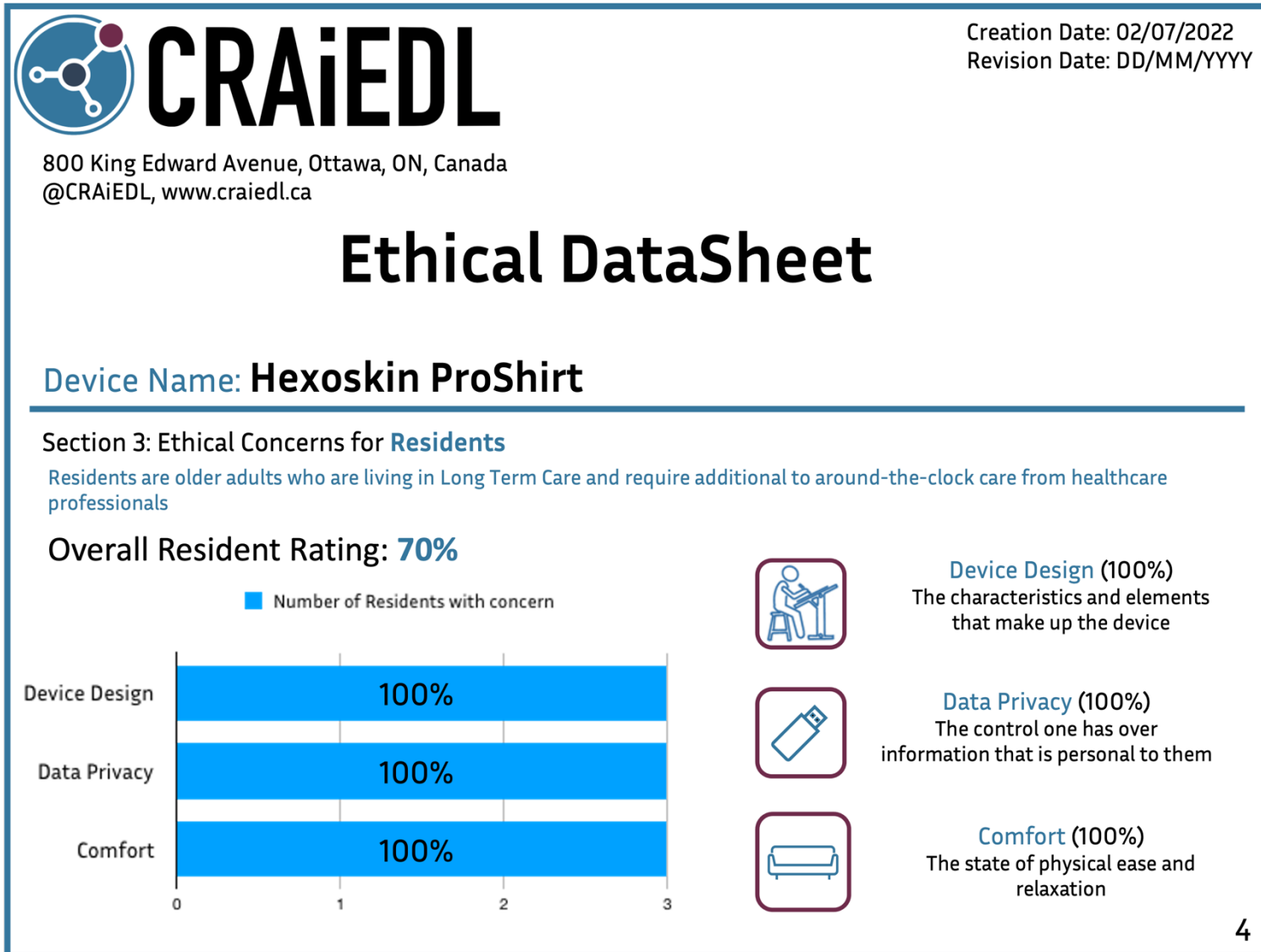


Figure E-5 – Hexoskin ProShirt™ EDS- Residents Section Continued

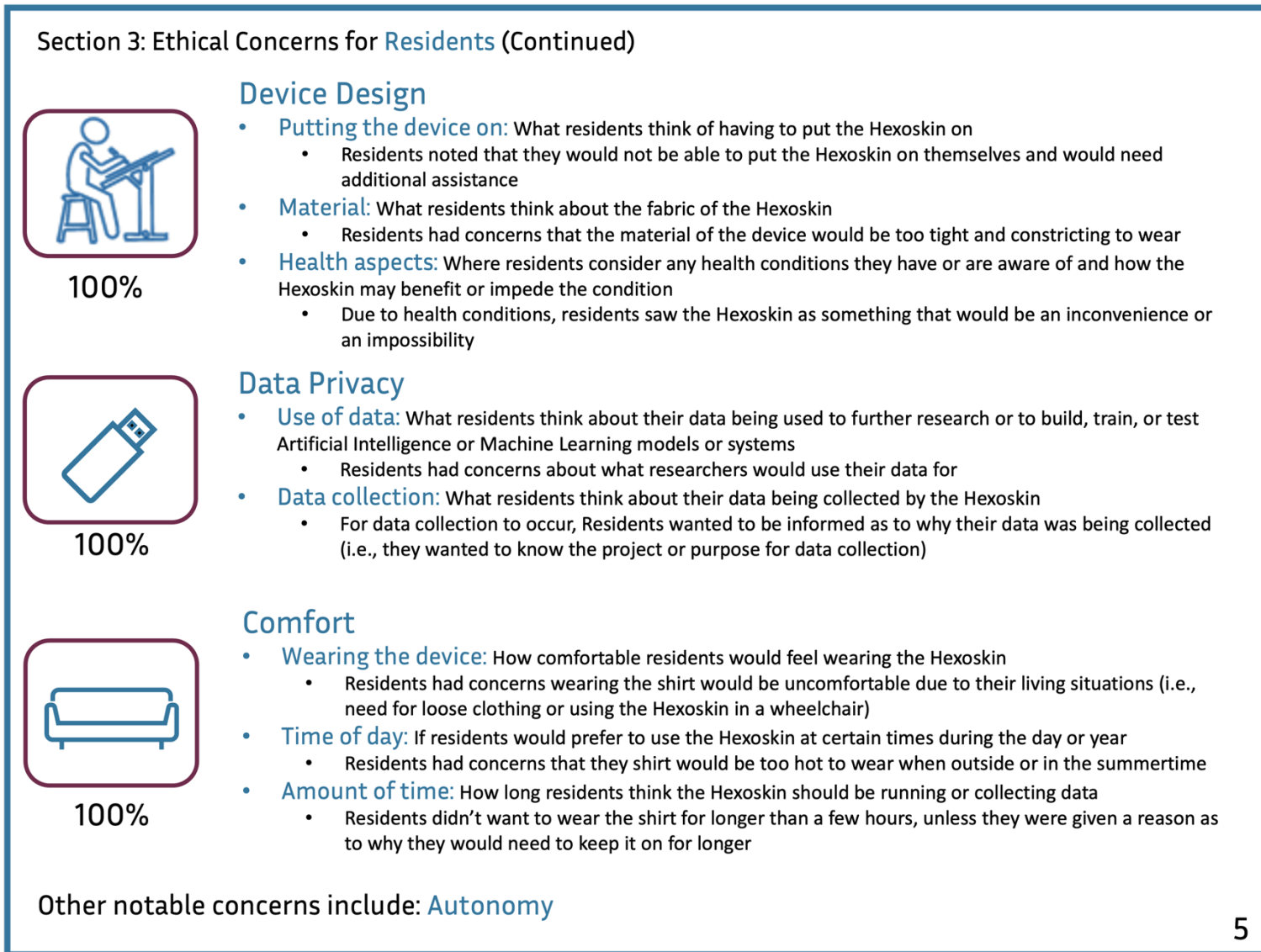


Figure E-6 – Hexoskin ProShirt™ EDS- Caregivers Section

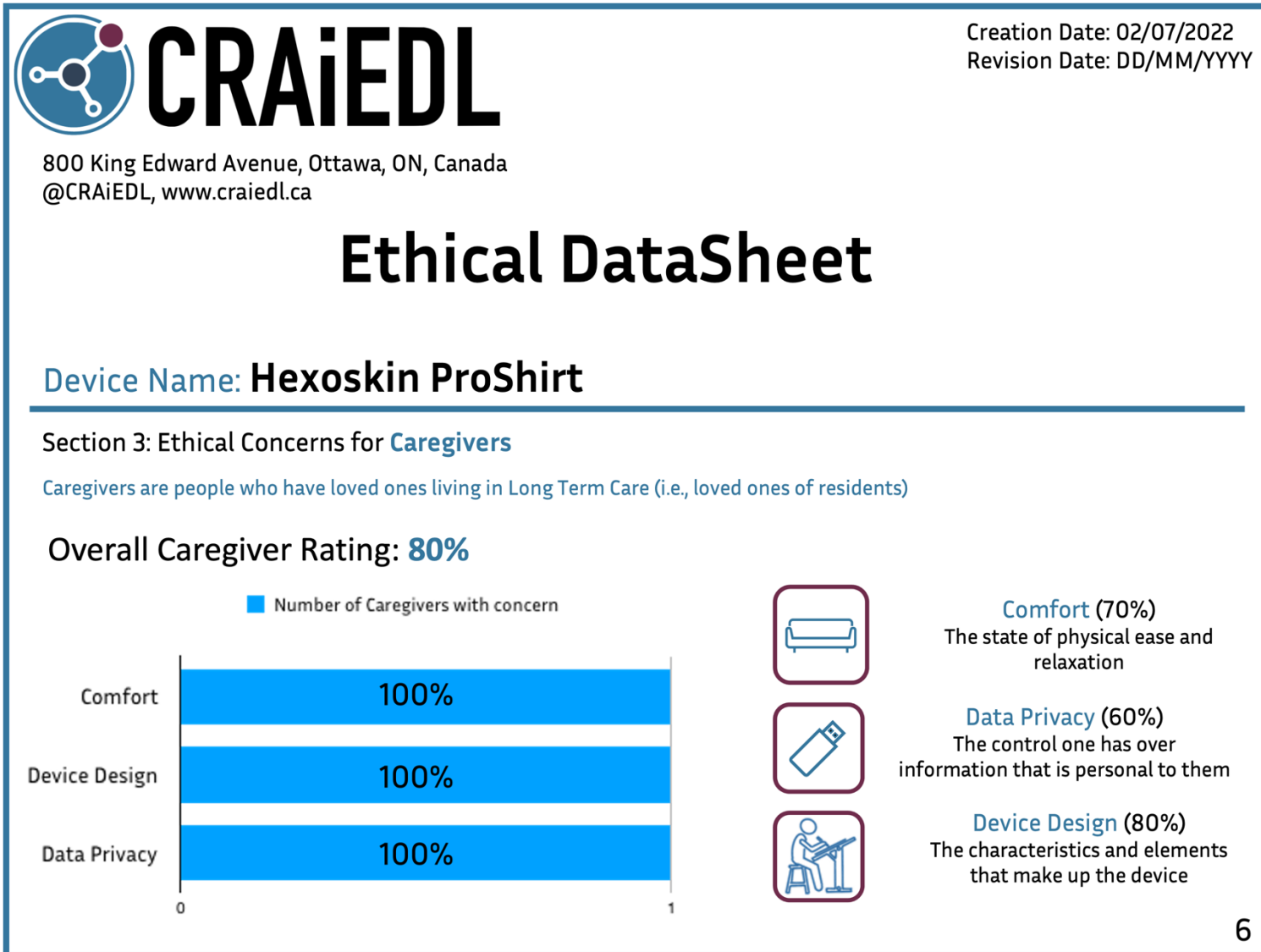


Figure E-7 – Hexoskin ProShirt™ EDS- Caregivers Section Continued

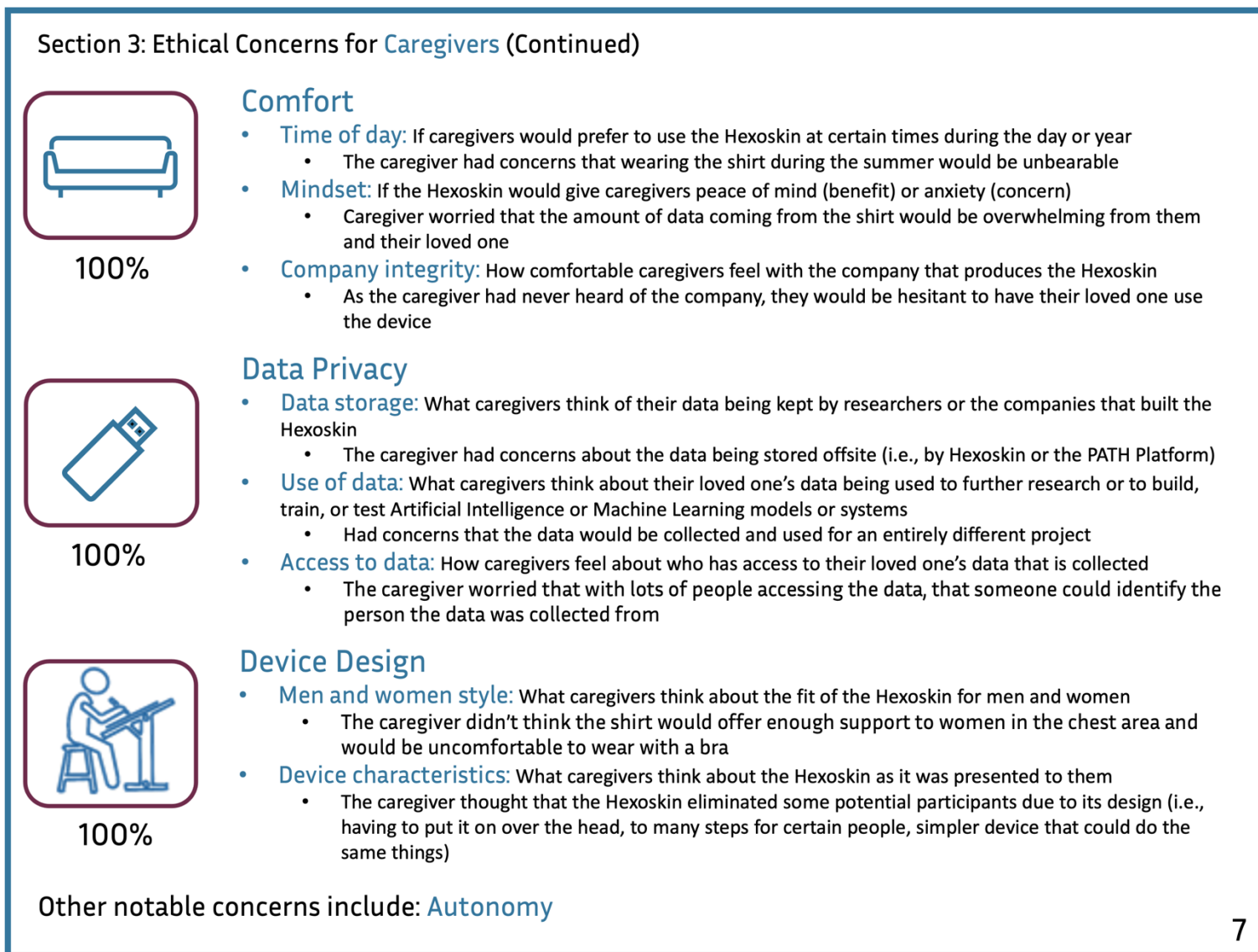


Figure E-8 – Hexoskin ProShirt™ EDS- Healthcare Professionals Section

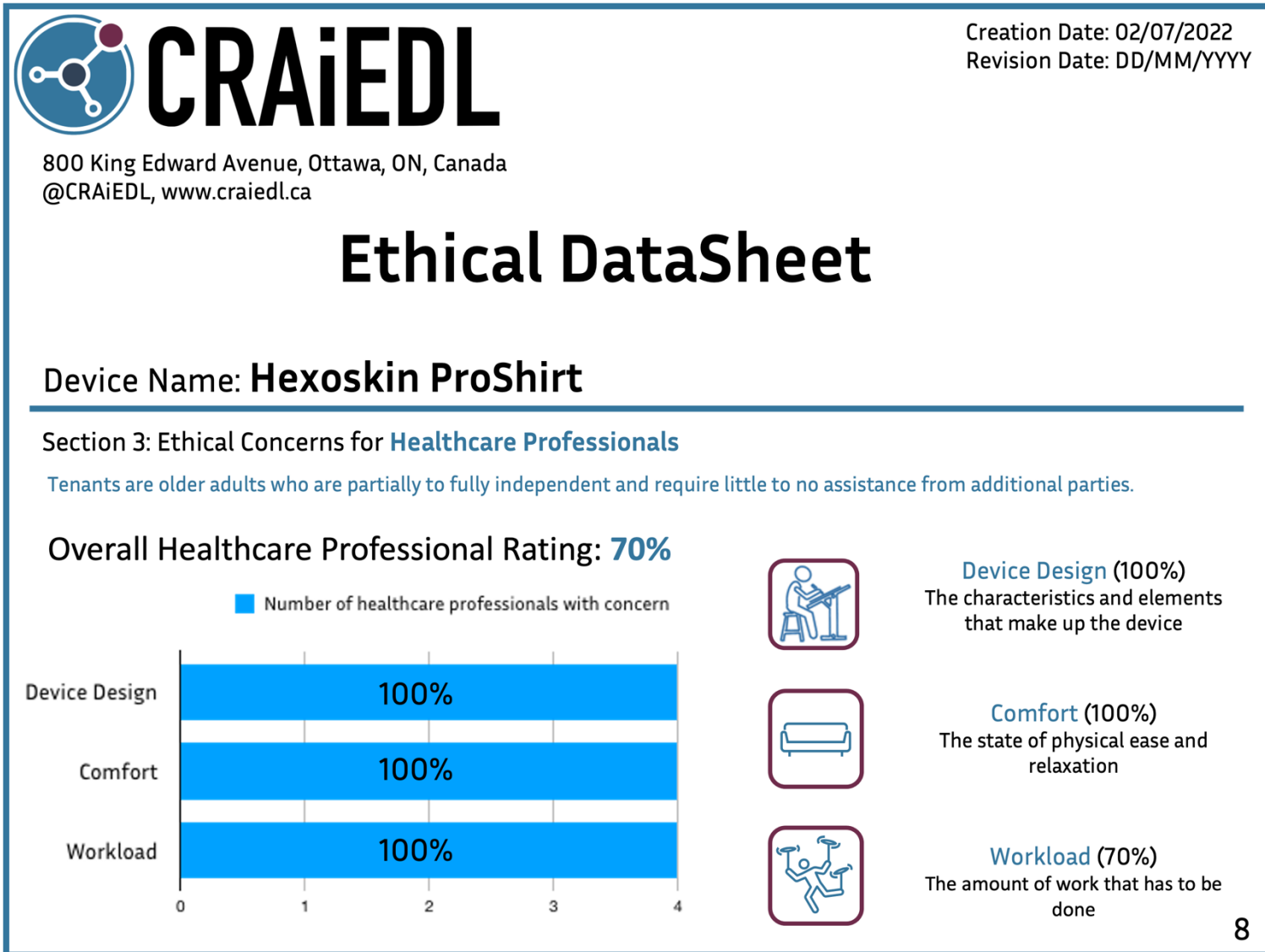
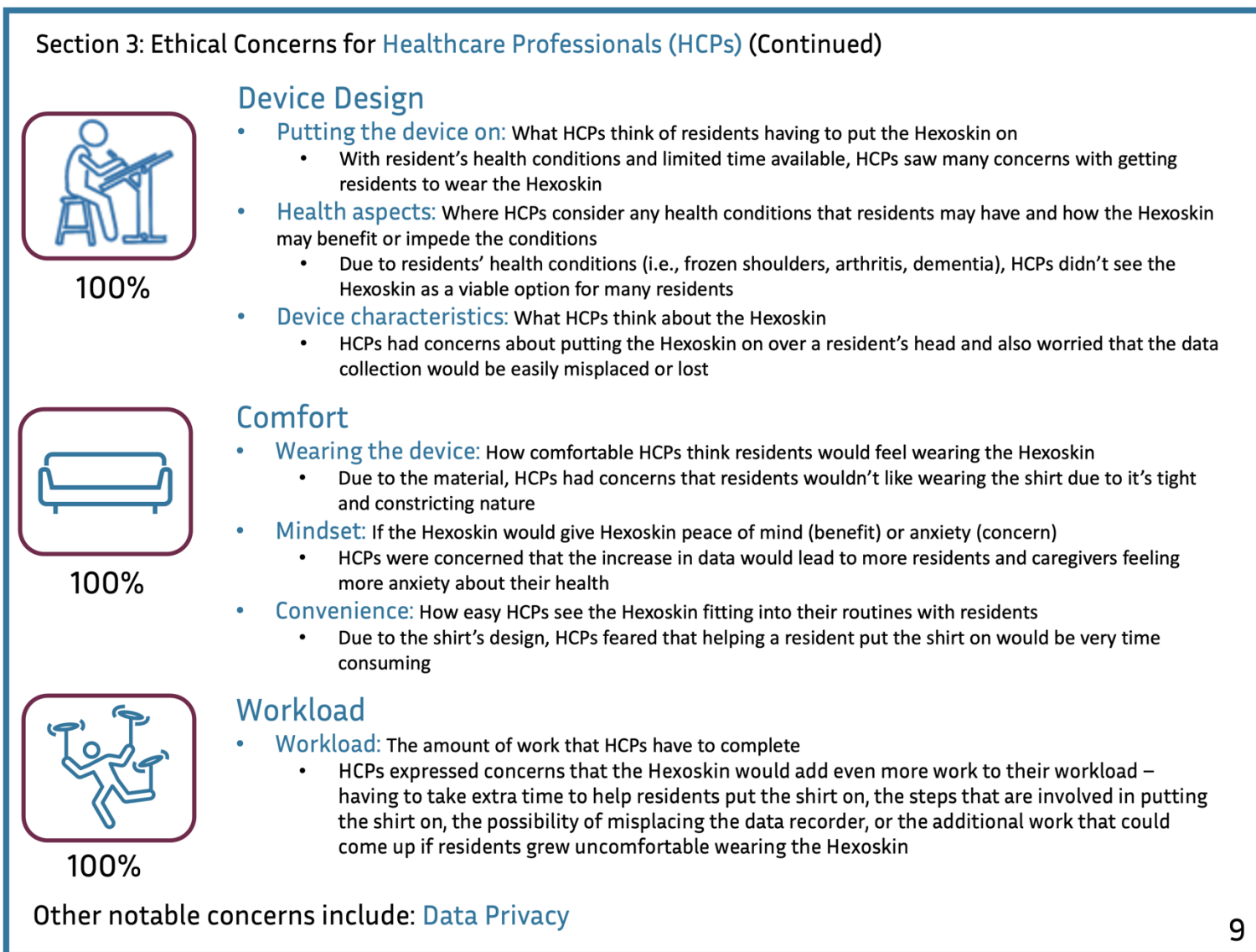



Figure E-9 – Hexoskin ProShirt™ EDS- Healthcare Professionals Section Continued



Appendix F: Ethical DataSheet for the AWS DeepLens™

Appendix F presents the Ethical DataSheet that was designed and developed for the AWS DeepLens™ using the Ethical DataSheet prototype presented in Chapter 4.0: Prototyping the Ethical DataSheet.

Figure F-1 – AWS DeepLens™ EDS- Device Identification and Characteristics




CRAiEDL

800 King Edward Avenue, Ottawa, ON, Canada K1N
@CRAiEDL, www.craiedl.ca

Creation Date: 03/07/2022
Revision Date: DD/MM/YYYY

Ethical DataSheet

Device Name: AWS DeepLens



Device Identification

Device Name: AWS DeepLens
Device Type: Camera
Device Manufacturer: Amazon Web Services (a subsidiary of Amazon)

Device Purpose: Captures photo and video data to perform Deep Learning capabilities

Context of Use: Preference to be used in public spaces and not private ones (i.e., bedroom or bathroom)

Device Characteristics

Weight: 296.5 g (10.5 oz)
Colour: White
Size: 47x94x168 mm
Cost: \$249.00 USD

Device Components: AWS DeepLens camera, Micro SD card, Power Supply

Type of Data Collected: Photo and video data

Data Storage Location: 3 Locations (locally on the Micro SD card, the AWS Cloud, or the PATH Database)

1

183

Figure F-2 – AWS DeepLens™ EDS - Tenants Section

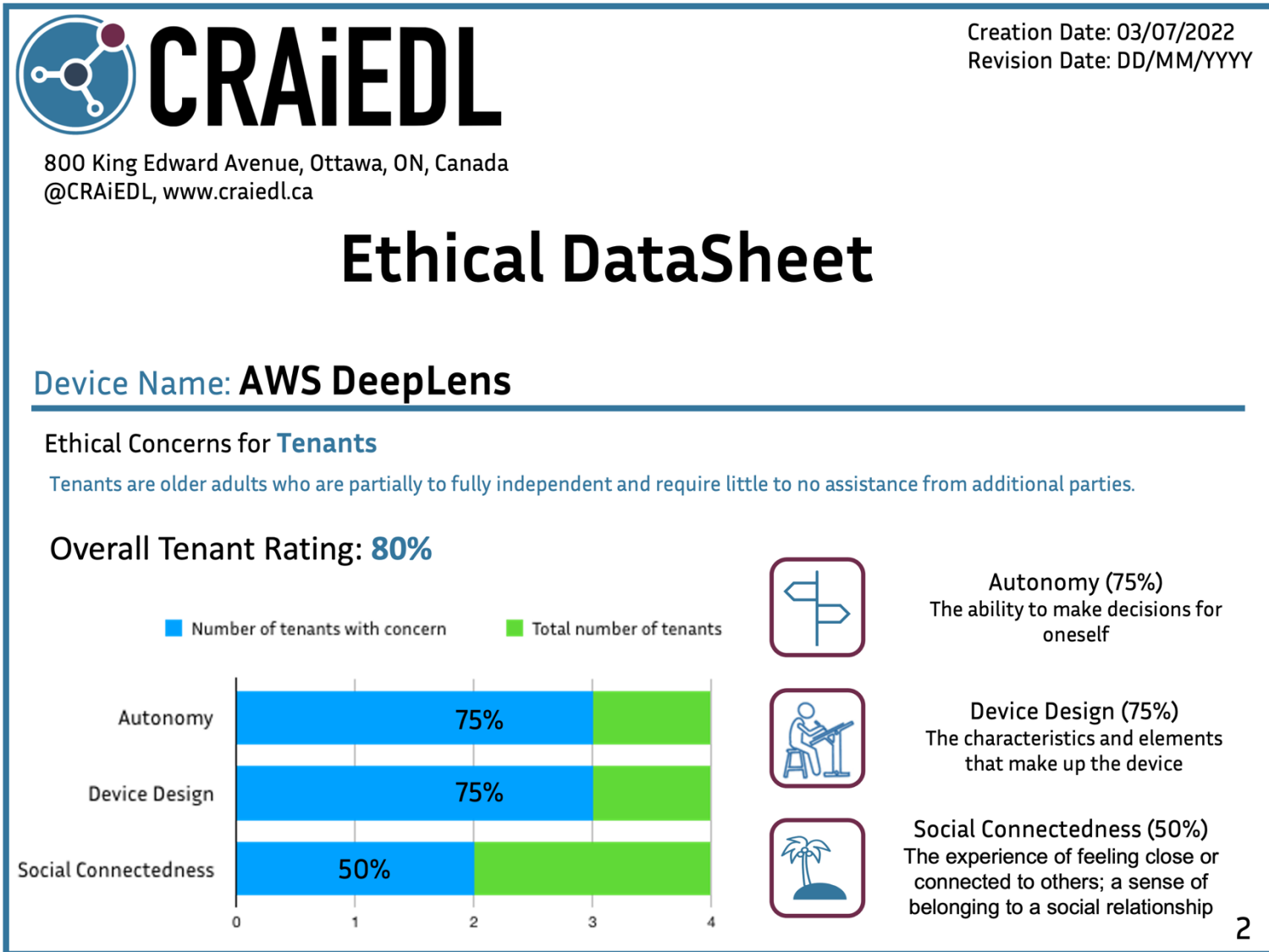


Figure F-3 – AWS DeepLens™ EDS - Tenants Section Continued

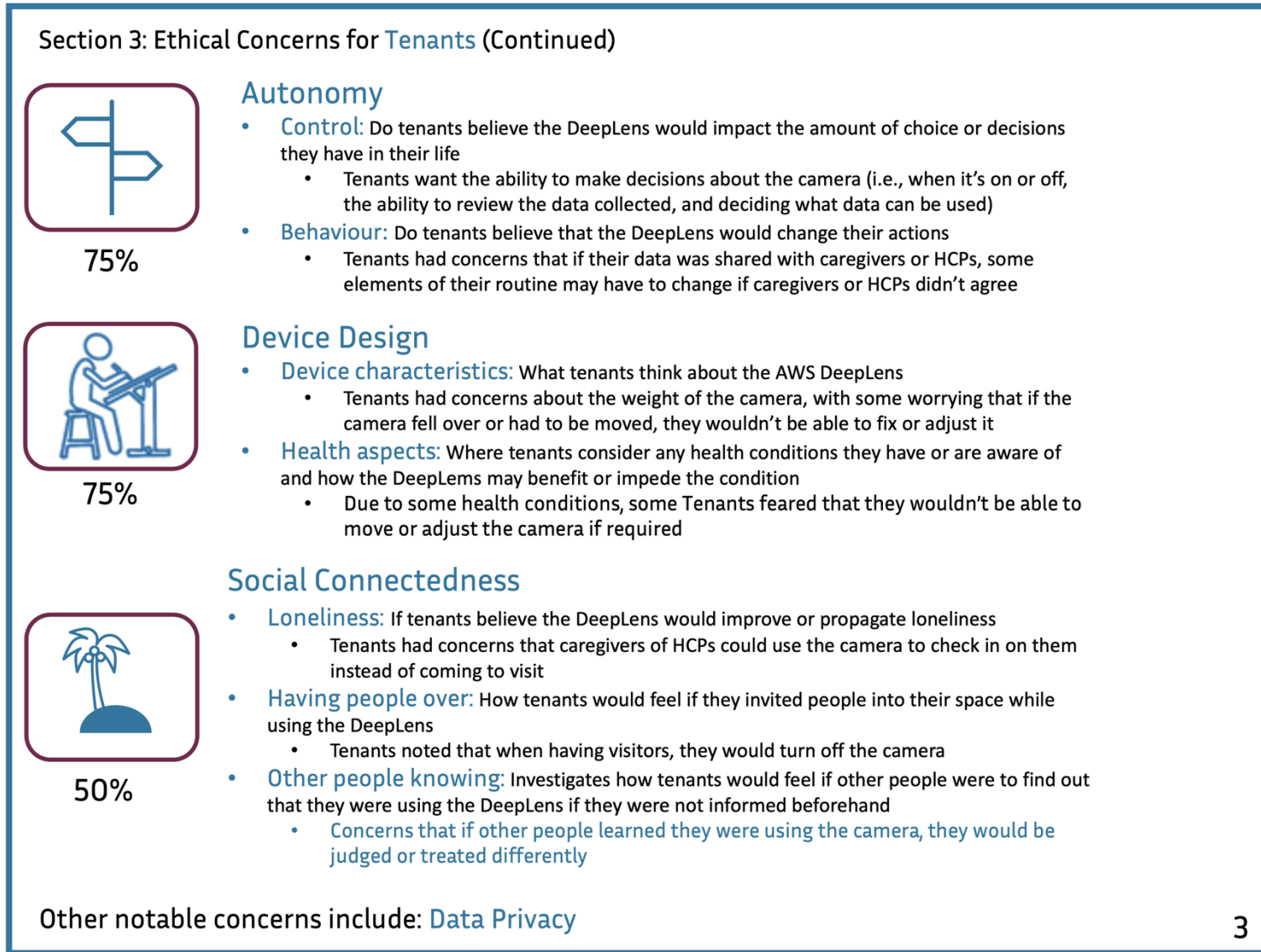


Figure F-4 – AWS DeepLens™ EDS - Residents Section

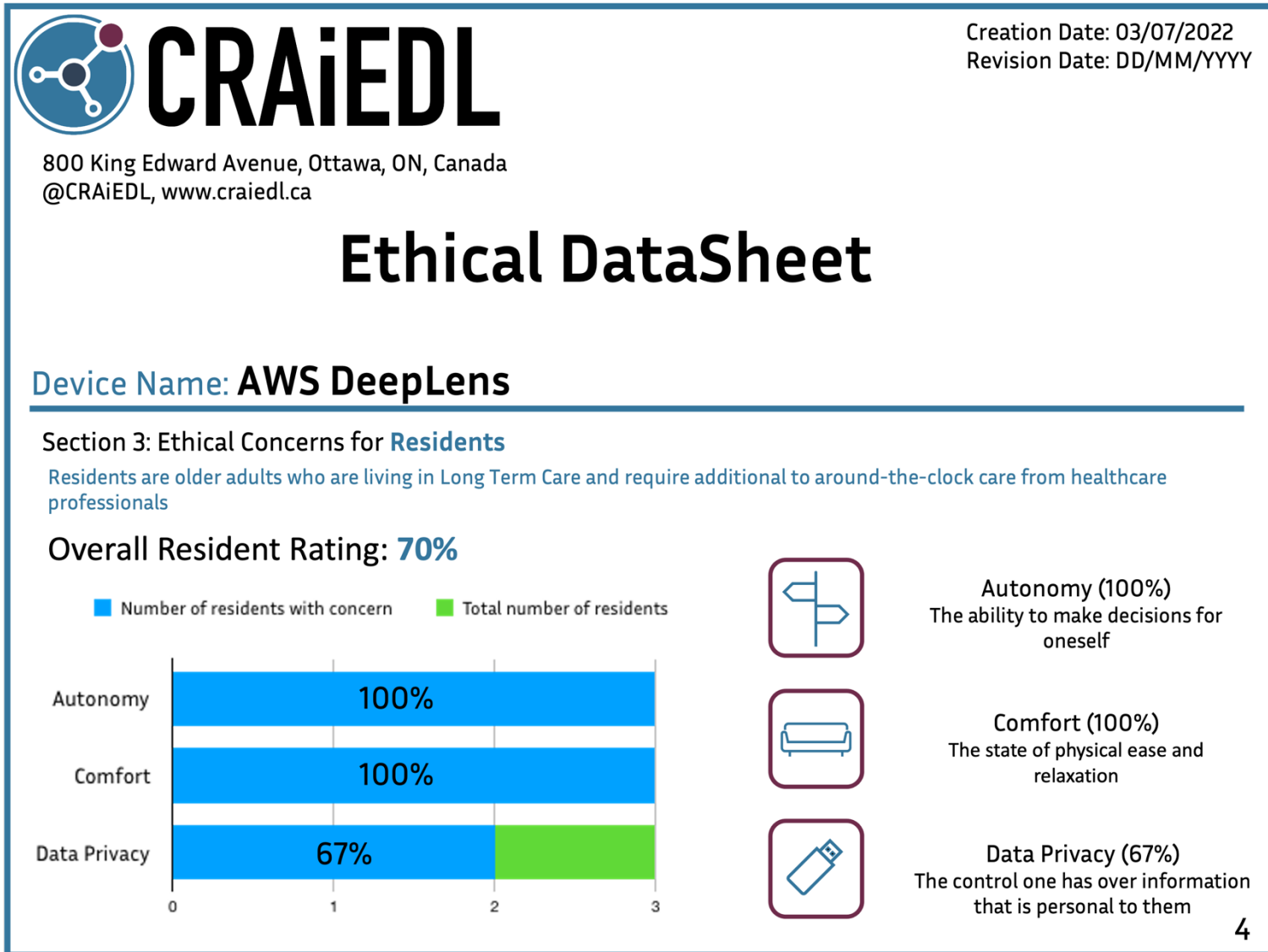


Figure F-5 – AWS DeepLens™ EDS - Residents Section Continued

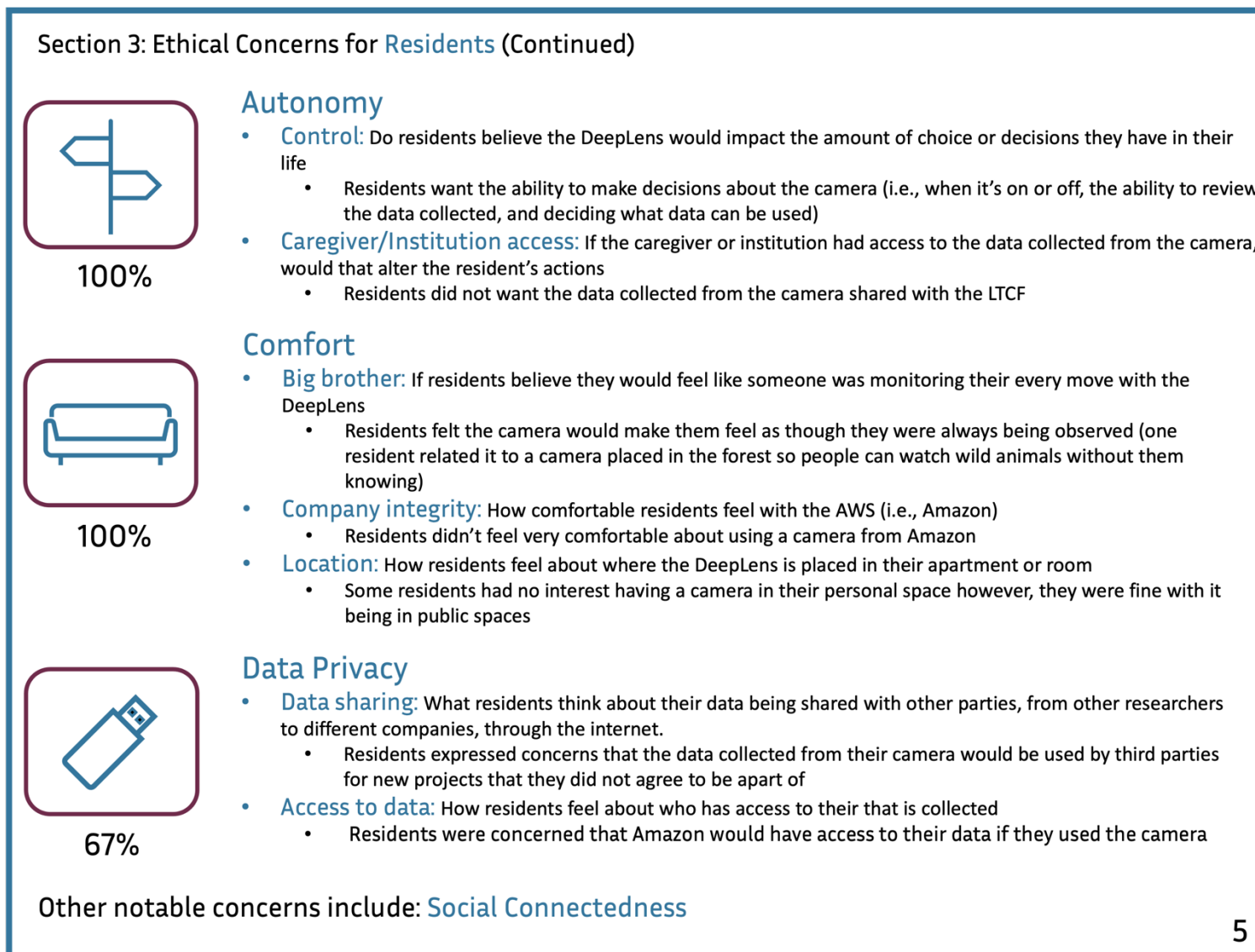


Figure F-6 – AWS DeepLens™ EDS - Caregivers Section

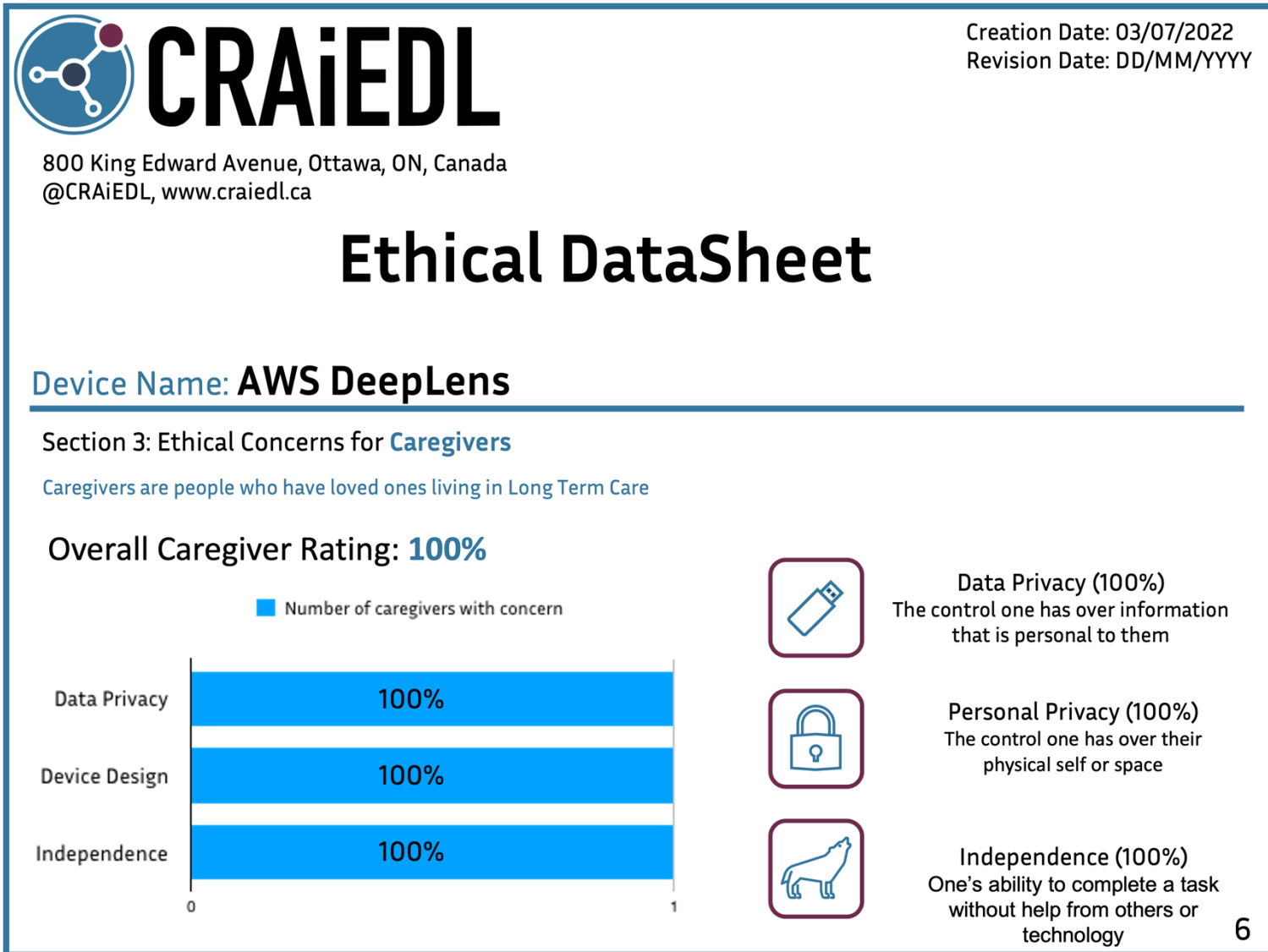


Figure F-7 – AWS DeepLens™ EDS - Caregivers Section Continued

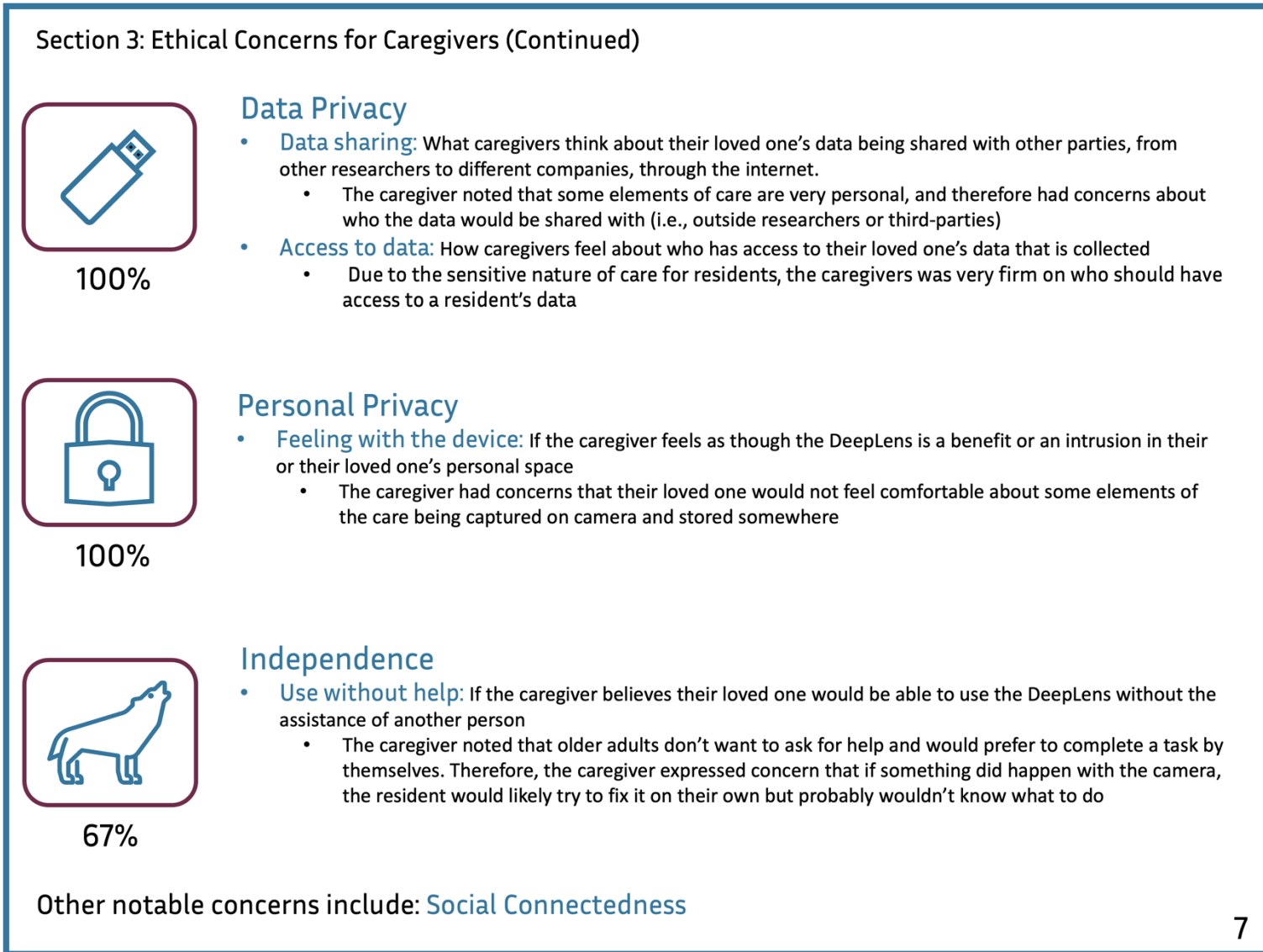


Figure F-8 – AWS DeepLens™ EDS - Healthcare Professionals Section

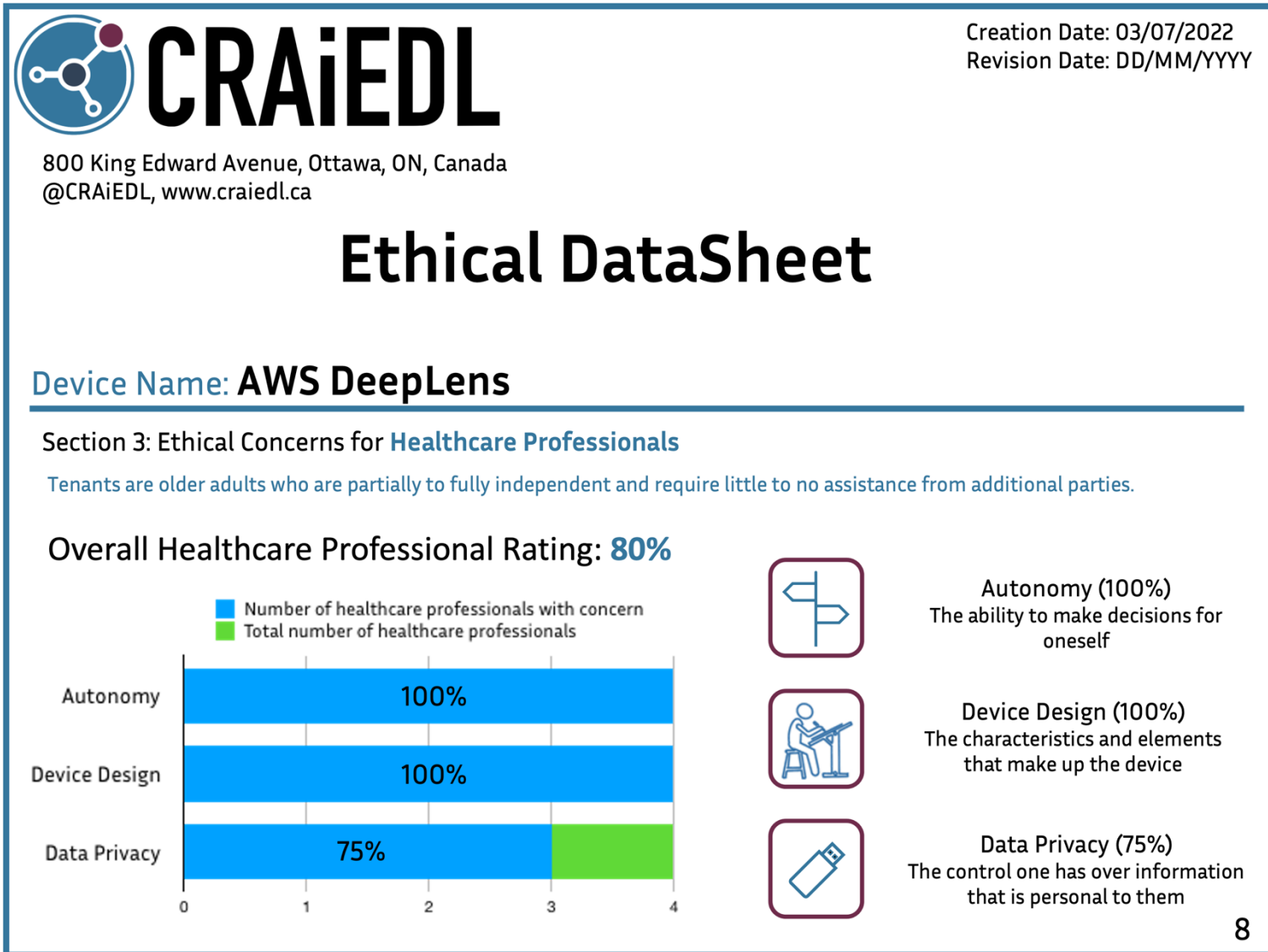


Figure F-9 – AWS DeepLens™ EDS - Healthcare Professionals Section Continued

