

STANDARDS RESEARCH

Data Governance for Active Assisted Living Technologies Along the Continuum of Care

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Table of Contents

Executive Summary 4
1 Introduction 5
1.1 Background and Motivations 5
1.2 Research Aims and Objectives 6
2 Methods 7
3 Exploring AAL Systems 7
3.1 Survey of Existing Work 7
3.1.1 Examples of Similar Work 8
3.1.2 What We Learned 8
3.1.3 Gaps in the Canadian Context 9
3.1.4 Actors 10
3.1.4.1 Agents 10
3.1.4.2 Technologies 12
3.2 Modelling the Continuum of Care 12
3.3 The Data Governance Framework 13
3.3.1 Identify Independent, Intermediary, and Dependent Variables 15
3.3.2 Identify Agents, Social Norms, Collective Problems, and Internal Processes 16
3.3.3 Determine the Role of Agents and Transactions for Each Agent 16
3.4 Interviews of Selected Stakeholders 17
3.4.1 How the Use of AAL Data Can Improve Care 18
3.4.1.1 Monitoring and Alerts 18
3.4.1.2 Confidence in Aging in Place 19
3.4.1.3 Care Recipient Empowerment and Well-Being 19
3.4.2 Concerns Regarding the Use of Data in Care 20
3.4.3 Barriers to Use and Implementation 20
3.4.3.1 The Value Trade-Off 20
3.4.3.2 Oversight and Management of Devices 21
3.4.3.3 Managing Transitions 21
3.4.3.4 Governing Bodies 22
3.4.3.5 Use by Agents 22
3.4.3.6 Considering Equity 22
3.4.4 Current State of Data Flow 23
3.4.5 Desired Characteristics and Responsibilities of a Regulatory Body 24
3.4.5.1 Preference for a National Body 24
3.4.5.2 Responsibilities 24
4 Conclusions 25
References 28

Executive Summary

Active Assisted Living (AAL) technologies are systems designed to improve the quality of life, aid in independence, and create healthier lifestyles for those who need assistance at any stage of their lives. As the population of older adults in Canada grows, there is a pressing need for non-intrusive, continuous, adaptable, and reliable health monitoring tools to support aging in place and to reduce health care costs. AAL technologies have great potential to support these efforts with the wide variety of solutions currently available, including solutions for home automation, assistive devices, and remote monitoring. However, more effort is required to address the concerns of older adults and their care providers arising from the integration of AAL into care.

This research report explores the integration of AAL technologies and data into the clinical pathway (continuum of care) and provides a model for the continuum of care in the context of the AAL technology ecosystem. In addition, it maps data access and governance for AAL technologies, providing innovators in the space with guidance on how to implement these solutions in the Canadian context, while protecting the privacy and well-being of seniors using AAL technologies. Finally, it presents the findings of the research and the opportunities for standards and guidelines that emerged.

Exploration of the two objectives was done through four successive research phases:

1. Conducting a literature search to survey existing work in this area and identify lessons learned;
2. Developing a model for the continuum of care within the context of AAL technologies;
3. Adapting a framework for data governance to the AAL context; and
4. Conducting interviews with stakeholders to validate and explore the applicability of the research findings.

Recurring themes that emerged from these four phases include a need for greater consistency in language and technology requirements across Canada, better role definition regarding who may have access to the data, identifying who is responsible for taking action based on the gathered data, and the recognition of the privacy–utility trade-off inherent in using AAL technologies in care settings.



"The pandemic incentivized the commercialization of products that were not ready for market, increasing the need for guidelines and an ecosystem capable of accommodating new technologies as they become available."

1 Introduction

1.1 Background and Motivations

Canada has a growing aging population and a pressing need for non-intrusive, continuous, and reliable health monitoring tools to support aging in place [1], [2], [3] and to reduce health care costs [4]. One of the biggest challenges is supporting older adults so they can continue to age in their own homes and communities, even as they navigate an increased prevalence of chronic diseases [5]. The COVID-19 pandemic has accelerated the need for remote monitoring tools that enable clinicians to support their patients from a distance, without requiring clinic visits and hospital admissions [6], as well as preventing unnecessary exposure to COVID-19 [7]. It should be noted that the demand for services and technologies that support telehealth, Active Assisted Living (AAL), and the internet of things (IoT) for health was not being met during the COVID-19 pandemic, as many technologies were still in their infancy when the pandemic began [8]. Consequently, the pandemic incentivized the commercialization of products that were not ready for market, so the market was flooded with products of lower quality [8], increasing the need for guidelines and an ecosystem capable of accommodating new technologies as they become available [9]. Furthermore, there has been insufficient effort to address the concerns arising from the integration of AAL technologies and IoT into patient care. These concerns include privacy, care recipients' loss of control over their own information, and a feared loss of independence due to care providers acting on the data from the technologies or dependence on the technology itself.

Given this context, it is important to understand and model the continuum of the AAL technology ecosystem by exploring the integration of AAL technologies and data into the clinical pathway that seniors are often exposed to during their journey through different levels of senior living. The somewhat premature technological advancements and the increased availability of IoT technologies are not without their challenges. For example, very few building codes and guidelines exist for developers in the market that outline requirements for AAL and IoT for health technologies [10], resulting in new developments that may be inadequately prepared to incorporate AAL and health-IoT technologies [11] and installations of such technologies that are not fully integrated into the building infrastructure [12].

This report also presents the mapping of data access and governance for AAL technologies in Canada. One of the unintended consequences of structured standards and guidelines for new AAL developments is that novel technology is often deployed in the market with limited usefulness to health care providers [13]. In addition, data from AAL technologies often reside in data silos [13], [14] and are not fully adopted by health care providers [15]. Therefore, this research explored the development of guidelines and proposed opportunities for standards to help guide service and technology providers during the application and implementation of AAL services.

1.2 Research Aims and Objectives

The primary research aim was to work closely with care providers to help ensure that recommendations for system-service integrations aligned with the needs and capacity of the health care and allied health systems. Data from these technologies are not only frequently siloed, but they are also not sufficiently available to care providers or may lack user-friendly systems that provide easy access to health professionals [13], [16]. When available, extracting meaningful information and knowledge from the wealth of data collected can also be challenging, mainly due to the high volume of data and the nature of the data itself [11], [17].

The priority in the AAL technology ecosystem is to promote independent living and improve the quality of life for vulnerable individuals. This goes beyond the user's home environment, and includes services and data being collected at the community and city levels. As shown in Figure 1, smart homes and AAL technologies provide individual support for people living independently, focusing mainly on providing user feedback. AAL technologies have very limited integration with external services, especially community health services [13]. It is imperative to expand the integration of IoT and AAL technologies within the community and across the broader region by understanding the needs and challenges of integrating these technologies with the health system at the community level (e.g., paramedics, pharmacy, allied health professionals, medical clinics, and emergency services).

The following questions guided this research:

1. What are the needs of AAL users, beyond their homes, to remain healthy, improve their quality of life, and prevent future health problems?
2. How can the continuum of care be mapped as care recipients move between different care settings?
3. Who are the agents needed to support the patient throughout the continuum of care?
4. What are the governance requirements for ensuring the data collected by AAL technologies are kept safe, secure, and confidential, while providing the intended benefits to seniors and health care providers, and
5. Where are standards needed to guide the implementation of future smart homes and smart communities to help ensure that data from AAL and IoT devices can be used to inform patient care?

Figure 1: AAL Ecosystem and the Continuum of Care



2 Methods

Four methods were used to explore and model the objectives of this report:

1. A survey of existing work;
2. The development of a model to map AAL systems to the continuum of care;
3. The development and adaptation of a data governance framework; and
4. Interviews to validate the framework.

These methods were employed sequentially, with the work of each new phase building on the findings of the previous. At the end of this process, several opportunities for the development of standards and guidelines were identified and are detailed in the conclusion of this report.

A literature search was conducted for the survey of existing work. Academic literature (e.g., IEEE, Scopus, and PubMed) was primarily reviewed, along with some grey literature (e.g., web pages and media releases about projects and initiatives with goals similar to those of this research). The keywords included "AAL", "continuum of care", "older adults", "health technology", and "integrated care". When researching integrated care initiatives, particular attention was paid to what agents and technologies (collectively, the "actors" of the AAL system) were included. International examples were considered to provide different perspectives.

The results of the literature search were used to develop a model for the continuum of care. This process included creating categories of care recipients in different care settings and at different levels of care needs and then considering how they might be best served by an AAL system. For each category, a sample use case was created to explore the relationship between care recipients and agents.

The different agents involved in a care recipient's AAL system have different circumstances and priorities that influence their relationship with the data. With that in mind, a data governance framework was developed to consider the social norms, collective problems, and internal processes of agents. The interviews provided details about agents' experiences with the use of technology in elder care using a data governance framework that was intentionally broad (i.e., not AAL-specific).

For the interviews, participants were recruited from the following four groups:

1. **Care delivery.** Stakeholders working for organizations directly involved in care delivery (e.g., retirement communities, long-term care (LTC) homes, and community care organizations);
2. **Tech developers.** Stakeholders working for companies or groups involved in the development or manufacturing of AAL technologies;
3. **Tech integrators.** Stakeholders working for companies or groups involved in the integration of AAL technologies into care; and
4. **Reception.** Care recipients and patient advocates.

Interviews were conducted over Zoom and began with a brief presentation to explain the data governance framework and contextualize the project. Following the presentation, questions were posed using a semi-structured interview guide, which allowed for the questions to be adapted to each participant's context. A basic version of the interview guide was shared with participants prior to the interview to give them time to consider the questions (see Appendix A). Whenever possible, interviews were conducted with groups of participants who worked in different positions within the same organization in order to gather diverse perspectives. A thematic analysis of the interview transcripts was then conducted by summarizing the benefits, concerns, and barriers regarding the use of AAL data in elder care, and providing descriptions of the current state of data flow in the context of AAL technologies and the responsibilities of a hypothetical oversight body.

3 Exploring AAL Systems

3.1 Survey of Existing Work

The research literature identified for this report related to care for older adults living in a range of contexts, from those living independently at home to those living in LTC with full-time support. Ultimately, the use of AAL in the continuum of care aims to support integrated care [18]. Integrated care involves seamless transitions

between care services and settings, coordinated care that delivers quick access, effective treatment, self-care support, respect for patient preferences, and appropriate involvement of family members and other informal caregivers [18], [19]. Simple solutions to smooth these transitions and improve continuity include accurate contact information for care providers and discharge information that is clear and tailored to the patient [20], [21]. The use of AAL offers the opportunity to further expand on this, bridging the gap between actors and providing more opportunities for integrated care.

3.1.1 Examples of Similar Work

The literature search examined how different actors come together to support the provision of integrated care. One example of such integration is the ElderHelp Concierge Club [22], a program based in San Diego, California that provides integrated, community-based care. Services offered include personal and environmental assessment, multilevel care coordination, access to a mix of professional and volunteer service providers, and an income-adjusted fee model. The "concierge" acts as a service coordinator, facilitating access to agents such as intake specialists, care managers, volunteer liaisons and volunteers, and the "Preferred Provider Network" that provides health care to members at a discounted rate. After a phone screening, members are sorted into three potential tiers of service, with receiving information and a referral being the lowest and full care management being the highest. This example provided a valuable user case for bringing community care into the home and an example of how agents may be broadly grouped into two categories: agents who provide medical care services and agents who provide support on the level of a highly involved family member or other informal caregiver. It also provided an example of how the services for care recipients could be divided based on needs level, which was essential for creating the continuum of care model.

Regarding the use of AAL systems in the care of older adults, two examples were identified in the literature: GatorTech Smart Home in Florida and Whyndyke Garden Village in the UK [23]. The GatorTech Smart Home was a pilot study that explored how to make a smart, AAL-enabled home that is adaptive and can be easily updated over time to support the care recipient as their needs change. This pilot study raised a number of practical considerations for the building of smart homes, the most prominent one being issues of scalability. In making and expanding the functions of smart homes, a large portion of development time and budget must be dedicated to integrating devices that work collaboratively and are interoperable. The more devices that are added to smart homes, the more difficult and time-consuming this process becomes. In addition, when the integration of these new devices is not planned in advance, it can lead to increased difficulty when changing or managing installations. Looking to the future, the Whyndyke Garden Village is a planned development that will provide an example of the practical considerations involved in the development of a larger-scale smart community. Plans for the Village include a computer in each home connected to a secure and scalable cloud tenancy, and a variety of health kiosks, such as Alexa-style conversational kiosks at home, self-operated kiosks around the town centre, and large pharmacy-operated kiosks linking to nearby clinics.

3.1.2 What We Learned

The literature search and survey of past projects led to the identification of several considerations regarding the implementation and use of AAL systems. Fundamentally, the degree of technology use among older adults is influenced by six major themes:

1. Challenges of independent living;
2. Availability of behavioural options to cope with challenges;
3. Personal thoughts on technology use;
4. Influence of their social networks;
5. Influence of organizations; and
6. The role of the physical environment.

Many of these themes are associated with the trade-off of technology; that is, evidence must be provided to the older adult to demonstrate how life with AAL technology may be safer or better than life without it [24]. In other words, the advantages (i.e., better support for maintaining independence, reducing dependence on others, or navigating the physical environment of their home or care setting) must be greater than those that could be achieved through simple modification of behaviour, making it worth the effort to learn how

to use the technology and to allow one's data to be collected and used [24], [25].

In considering this, it is important to note the impact of context and the different needs of care recipients living in different settings (i.e., at home or in some form of assisted living facility) and receiving different levels of care from different providers. Past research has shown that this context significantly impacts how AAL technologies are perceived and evaluated [26]. On the care recipient side, the level of care required may heavily influence their judgment of the trade-offs described above. If an older adult is already dependent on others, for example, they might see value in technology to help improve their independence. Alternatively, depending on their cognitive state, digital literacy, or other factors, the care recipient may not be the one making decisions regarding what technologies are used. In this case, the privacy trade-off may be minimized if the caregivers want the option of more comprehensive monitoring [27]. On the care provider side, the utility of different types of gathered data may be perceived very differently. For example, those working in geriatric care contexts tend to approve the gathering of sleep data more than those working in non-geriatric-focused medical contexts. Understanding these differences, while avoiding prescriptive, one-size-fits-all solutions, is critical for the acceptance and implementation of AAL technology.

Barriers to the implementation of AAL technology by care providers are wide-ranging and include factors such as the level of training and technical support available, the potential impact of a new technology on workflow, and the extent of care providers' discomfort with the intended purpose of the technology [28]. However, implementation can be considered a success when the following three goals are met: (a) older adults' needs and wishes have been prioritized during the technology's development and deployment, (b) the technology has been accepted by older adults for use in their care, and (c) the technology has provided benefits to the older adults [29].

During the literature search, several recommendations were identified for increasing the use of AAL technology in care. Although the recommendations were written specifically for the LTC context outside of Canada, some are included here due to their potential for facilitating a more continuous system overall within Canada [30]:

- "Create international and national digital authorities to promote use of meta-national datasets to increase coherence, equivalence and standardization of IT use and impact across the continuum of care."
- "Create partnerships across the care continuum, enabling meaningful interoperable Health Information Exchange (HIE) tailored to the needs of all stakeholders."
- "Encourage stakeholders to leverage emerging technologies, expand health intelligence, change provider relationships, and optimize coordination services."
- "Identify caregivers, clinicians, service workers, administrative and support staff, and executives connected to people, processes, and information used in the health system."
- "Leverage technology innovations to enhance workflow and care delivery for improved outcomes."

3.1.3 Gaps in the Canadian Context

Several challenges specific to the Canadian context limit care recipients' access to AAL technologies, including [31]:

- There are multiple definitions for "assistive technologies" (including AAL), which vary within and between provinces and territories. Consequently, there is confusion about what they are and whether procurement of specific technologies is covered under government funded programs.
- There is an increased need for assistive technologies due to factors such as an aging population and both the prevalence and burden of chronic disease on caregivers and the broader health care system.
- There is inconsistent access to assistive technologies, and none of the 50 priority assistive technologies identified by the World Health Organization's Global Cooperation on Assistive Technology (GATE) initiative[1] are available across all federal, provincial, and territorial programs, and some technologies do not receive any public funding.

1 Full list is available at https://apps.who.int/iris/handle/10665/207694.



"Across different settings and different levels of governance, the eligibility for funding through government programs specifying which technologies are funded and for whom is highly variable."

- There are system-level factors that can make it complicated to access assistive technologies, such as government, financial, and delivery arrangements.

These challenges are related to the decentralized nature of funding and care delivery in Canada's health care system. Across different settings and different levels of governance, the eligibility for funding through government programs specifying which technologies are funded and for whom is highly variable [31]. Furthermore, there is not a single program that funds and oversees the provision of AAL technologies and is responsive to the needs of different cases and care recipients. Nor are there established procurement policies and regulatory arrangements to govern the rapidly expanding market for AAL technologies and corresponding user demand. As a result, many older adults in Canada who would benefit from AAL technologies cannot access them.

This question of access leads to the issue of equity. In the AAL context, equity means that regardless of their circumstances or ability to pay, all care recipients and providers have access to reliable information and technologies and, depending on what side of the care interaction they are on, may receive or provide integrated and coordinated care stemming from the collaboration among the care recipients, their health care providers, organizations, and the AAL technologies [31]. The challenges described above create barriers to equity, where a care recipient's access to AAL technologies is limited by where they live, and if they live in a jurisdiction where government funding for a required solution is unavailable, whether they can finance it in some other way. Because care providers in Canada face wage disparities depending on the context in which they work (e.g., personal support workers [PSWs] in LTC are typically paid more than those working in community settings), it limits the ability for provincial/territorial health agencies, regional health authorities, care networks, or other governing bodies to consolidate services and may create a differential in the time devoted to training on a new technology [32].

3.1.4 Actors

In an AAL system, an actor refers to an entity that communicates and interacts in the system, including persons, technical components, software applications, systems, databases, and other bodies that play a role in the system. When reviewing the literature on how AAL systems could map to the continuum of care, we considered which actors had been a part of these systems and how they often worked together. To summarize these findings, this section is divided into human actors (agents) and nonhuman actors (technologies).

3.1.4.1 Agents

In an AAL system, an agent refers to any person interacting with the system or interacting with the care recipient along the continuum of care, who is not themselves the care recipient. From the literature search, four groups of agents emerged:

1. Traditional health care provider users;
2. Allied health professionals;
3. Informal caregivers; and
4. Paraprofessionals.

These four groups and examples of the types of agents in them are outlined in Figure 2, with agents typically associated with health care settings or for whom established funding structures exist within the Canadian health care system on the right branches, and others on the left branches.

"Traditional health care providers" are "traditional" in the sense that, in addition to being naturally associated with the term "health care providers," past pilot projects that have sought to integrate data from AAL technologies into care typically first seek to include them. This group includes doctors, nurses, pharmacists, and social workers. Those working in additional roles associated with elder care, such as transition care coordinators or geriatric care managers, are included here if they perform these tasks in the context of their work as a nurse or social worker.

"Allied health professionals" refers to agents who work in the health care context and are paid through public funding but have not commonly been included in past pilot projects of integrated AAL systems. Agents in this group can still benefit from the data obtained from AAL systems (e.g., movement, room temperature, and use of tracked or RFID-tagged items) if it is properly interpreted and targeted to their work. Examples of agents in this group include physical therapists, occupational therapists, patient navigators, community health workers, and PSWs.

"Informal caregivers" refers to agents who are not compensated for the care they provide and are involved in the continuum of care due to their personal relationship with the care recipient. These are usually family members and close friends, and in some cases may act as the legal guardian or substitute decision-maker (SDM) if the care recipient has a high degree of impairment. Informal caregivers who live with the care recipient, such as a spouse or other cohabitant, are in a unique situation with regards to the AAL system because they also live in the smart living environment, so devices collecting data on the care recipient may also collect data on them. This raises the need to consider how the AAL system manages different needs, consents, and data sources.

"Paraprofessionals" refers to agents who directly impact quality of life but are unlikely to directly interact with AAL technologies. Examples include agents hired for home maintenance, meal delivery, transportation, housekeeping, or volunteers who provide similar

Figure 2: Agents Interacting with the AAL System



services. These agents could potentially receive their instructions through an intermediary who does have access to AAL data, such as a care manager, community manager, or "concierge" as described in the San Diego pilot study. The AAL data relevant to the functions of some paraprofessionals may not be immediately apparent and may require some interpretation. As such, part of the role of the intermediary may be to examine available data to determine what services are necessary and whether care recipients' needs are changing. While provincial governments may fund some programs that employ these agents, either partially or in full (i.e., Meals on Wheels or tax rebates for installing assistive devices in the home), it is not consistent across the country, and these agents may not be fully integrated into the continuum of care.

3.1.4.2 Technologies

Technologies in AAL systems include those designed to improve quality of life, aid in independence, and create healthier lifestyles for those who need assistance at any stage of their lives. These are typically IoT devices and include assistive devices for individuals with disabilities that aim to increase, maintain, or improve functional capabilities. Other technologies include those for the purposes of monitoring parameters associated with health (e.g., step tracking or heart-rate monitoring), monitoring the care recipient in case of decline or an emergency (e.g., ambient sensors or cameras), and providing entertainment or improving quality of life. These purposes are not mutually exclusive, with some devices potentially serving a range of purposes.

In discussing assistive devices and technologies, it is important to distinguish between two broad groups [33]:

- **Regulated:** Technologies regulated under Health Canada's Medical Devices Regulations as medical devices. This group includes most devices used in home or hospital care (e.g., blood pressure monitors, CPAP machines, etc.).
- **Unregulated:** Technologies that are not regulated by Health Canada as a medical device, although they may still fall under the purview of consumer safety legislation (e.g., the Canada Consumer Product Safety Act) [34]. This group includes most consumer-grade technologies (i.e., smart home devices, thermostat monitoring, etc.).

An AAL system may include both regulated and unregulated technologies. An important distinction between the two is that regulated medical devices typically have established processes for integrating the resulting data into clinical practice and care coordination, whereas unregulated devices do not. While data from both regulated and unregulated technologies have the potential for painting a holistic view of a care recipient's health and well-being, additional work is necessary to leverage their potential.

3.2 Modelling the Continuum of Care

The survey of existing work informed the next phase of the research, which was modelling the continuum of care within the context of AAL technologies. In this model, care recipients were classified into three levels of needs:

1. **Low needs:** Care recipients require little to no assistance in their day-to-day lives and manage their own care with the assistance of relevant health care providers.
2. **Medium needs:** Care recipients are generally able to care for themselves but benefit from assistance managing care or performing the instrumental activities of daily living (e.g., meal preparation, home maintenance, financial management, etc.).
3. **High needs:** Care recipients are partially or entirely reliant on the assistance of formal and informal caregivers in their day-to-day lives.

Care recipients may move between these levels during their lives, such as when their conditions worsen or as they recover from an episode of acute care. As they move between levels, their requirements from their AAL system may change and, consequently, so may the actors involved in their care. In general, actors were considered to stack from low needs to high. In the case of agents, for example, a low needs care recipient would benefit from or require a basic subset of agents involved in their care, such as health care providers or family members. A medium-needs care recipient would benefit from certain additional agents, such as a patient navigator and service coordinator. A high-needs care recipient might benefit from additional agents beyond that, such as a PSW, while

still receiving potential benefits from the same agents as care recipients in the lower levels. Figure 3 provides additional examples of the different types of agents that might be required at the different needs levels.

Given how care settings affect care recipients' requirements from the AAL system, the three needs levels were further subdivided by living situation to create a needs matrix, which is provided in Table 1 and includes some example characteristics of care recipients in each category. Medium and low needs care recipients living in LTC are not described as part of the needs matrix, as care recipients at those levels are unlikely to live in LTC homes.

3.3 The Data Governance Framework

As the applications of AAL systems expand, the systems will also expand in complexity as more actors and interactions are added. As such, a data governance framework is necessary to manage this growing complexity and outline how data is managed and utilized. In this context, a data governance framework uses care recipient data generated from AAL devices and IoT technologies for clinical care applications. The initial framework developed for research applications was based on the Governance Analytical Framework [35] and was further adapted in this research project for the AAL and clinical care context, with consideration given to the following questions:

Figure 3: Bullseye Diagram of Agents

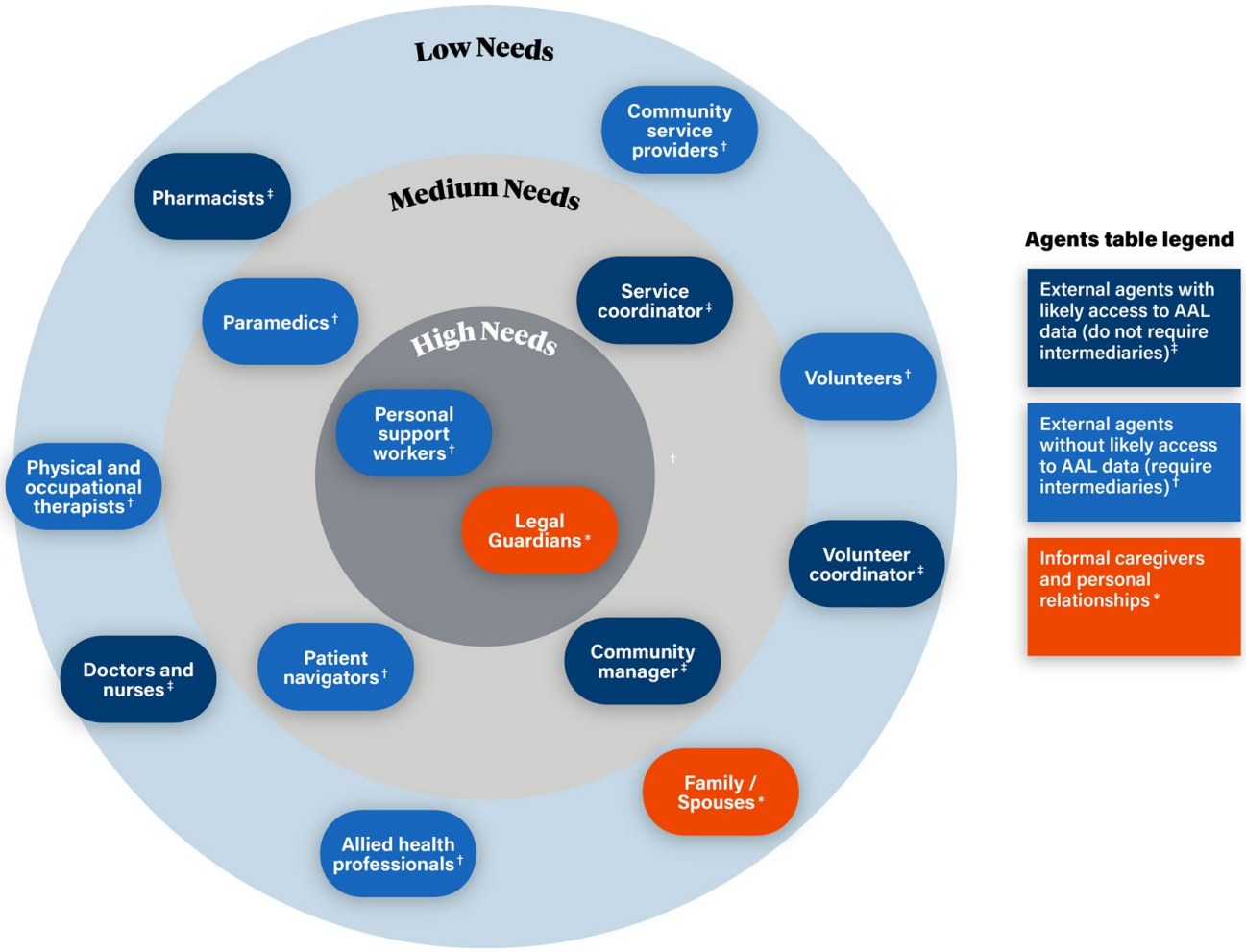


Table 1: AAL Needs Matrix

Living Situation / Needs Level	Low	Medium	High
Home and community	▪ Utilize off-the-shelf devices, such as smart home devices ▪ May utilize community services but do not need help to access	▪ Require family member support ▪ Utilize home grade medical devices ▪ Utilize community services but need help to access	▪ Likely receive care from a live-in caregiver, PSW, or home care nurse ▪ User of regulated medical devices or medical furniture
Paid retirement	▪ Live in a retirement community by choice, rarely use medical services	▪ Mostly independent but strongly benefit from community's on-site services	▪ Similar to high-needs living at home, but more utilization of on-site services
Long-term care (LTC)			▪ Receive care from institutional PSW ▪ Possible SDM

PSW = Personal support worker; **SDM** = Substitute decision-maker

1. What are the data flow requirements of the system and its actors?
2. What regulated and unregulated technologies are needed?
3. How do these requirements change the involvement of additional agents who interact with the system or make decisions on behalf of the care recipient?

Answering these questions and adapting the framework required three steps: (a) identify the independent and dependent variables with regards to the AAL system; (b) identify the actors and their shared collective problems, internal processes, and social norms; and (c) determine the role of these actors and their transactions with other actors in the AAL system.

Two fictional use cases representing care recipients in different squares of the needs matrix were used to consider the practical application of the data governance framework. The first use case is Renée, a medium-needs care recipient living in a paid retirement community. The second is Burt, a high needs care recipient living at home. Further details on these use cases are provided in the callout boxes and additional use cases are described in Appendix B.



Renée – Medium needs / Paid retirement

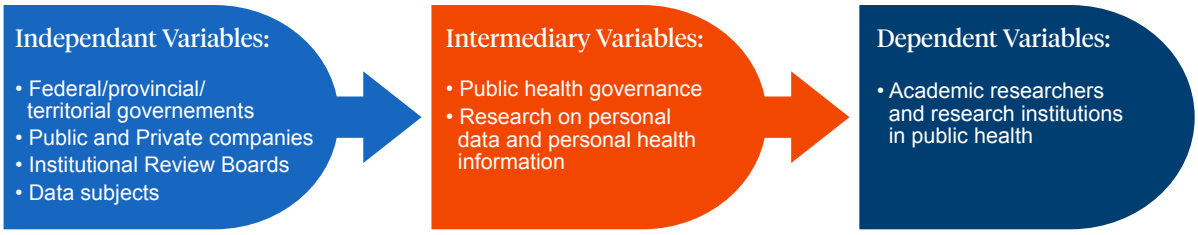
Renée moved into an Ontario retirement community five years ago, when her vision and mobility issues made it difficult for her to access the services she needs. She has difficulty walking and has high blood pressure, which has already begun to affect her eyesight. Renée is concerned with how her current health conditions will lead to greater issues in the future.



Burt – High needs / Home and community

Burt lives with his adult son in a house in a suburban community in Manitoba. His son is his primary caregiver and works closely with a home care nurse to manage Burt's health needs. Burt has advanced dementia and often forgets to bathe or eat if he does not have support. He also has osteoporosis, and his son worries about Burt getting injured when he is by himself.

Figure 4: Data Governance Variables



3.3.1 Identify Independent, Intermediary, and Dependent Variables

Data flow variables within AAL systems fall under three categories: independent, intermediary, and dependent. Which category variables fall under is a function of how they relate to the context: that is, whether the variable shapes it, refines it, or results from it. Figure 4 illustrates what these variables might be in a typical public health research case, however for AAL contexts, these variables will change depending on the particular circumstances of each care recipient. As such, both Renée and Burt will be considered.

Independent variables provide the context for data use. Note that data here does not refer to clinical data, but the data generated by AAL devices. Independent variables are the variables involved in the decision-making processes at different levels (federal, provincial, municipal) and the key actors that aid in decision-making. For both Renée and Burt, this would include federal and provincial governments, insurance companies, hospital ethics committees, and themselves. While Burt's son manages his care, he is doing so based on Burt's care needs and preferences and is therefore not an independent variable. However, he may act as a proxy for Burt as an independent variable.

Intermediary variables refine the context for data use. These variables influence the decisions being made and can sometimes be the source of the problem. Governance is an intermediary variable. It consists of the problems, agents, interactions between agents, social norms, surveillance, and personal data collected via AAL technology. An example of this would be any information privacy policies applicable in the jurisdictions where care recipients live. In Renée's case, her health information is protected under Ontario's Personal Health Information Protection Act (PHIPA) [36]. For non-health information, as in non-medical devices, governance is less clearly defined beyond basic consumer protection.

Dependent variables measure the extent of the problem. These variables identify the interactions among actors and characterize their relationships to see the effect of these interactions on the problem. While the original framework, as presented in Figure 4, focused on researchers as the dependent variables in a public health research context, it is more ambiguous within a continuum of care context. For care recipients like Renée and Burt, the dependent variables would theoretically be those working or making decisions based on the data from the AAL system. In some cases, the data from AAL systems goes back to decision-makers, such as community care services and hospital management, making this a circular system.

Within the AAL context there is the added question of where to classify AAL technology manufacturers and developers. If guidance for the use of technology in the care of older adults is defined by regulatory bodies, then manufacturers and developers would be considered dependent variables. However, this is not accurate in the current landscape of AAL technology use in Canada. In the absence of established, top-down guidelines and standards, the onus has been put on manufacturers and developers to establish these themselves. As such, they are currently classified as independent variables.

Table 2: Example of Analytical Tools Applied to AAL for Health Care Providers

Social Norms	Collective Problems	Internal Processes
▪ Royal College of Physicians and Surgeons of Canada ▪ College of Physicians and Surgeons of Ontario ▪ Regulated Health Professionals Act ▪ Medicine Act ▪ Procedural Code ▪ Code of Conduct	▪ Access to collected patient data ▪ Low incentive to check AAL data due invalidated tools ▪ Lack of integrated systems that limit access to data collected ▪ Differences in presentation of data and analytics	▪ Ensuring safe, quality care for patients based on collected data ▪ Working toward increased system efficiency (with accompanying changes to best practices) ▪ Fostering collaborative care ▪ Protecting patient privacy

3.3.2 Identify Agents, Social Norms, Collective Problems, and Internal Processes

Agents[2] lead to the formulation of social norms in data governance. This may be done by any agent described in Section 3.1.4.1, as well as any governing organization or technology company. For each agent, their social norms, collective problems, and internal processes will shape how they interact with the data-rich environment. Renée and Burt have some types of agents in common, such as the traditional health care providers listed in Figure 2 (doctors, pharmacists, etc.). Any technology integrators of AAL systems would also be considered agents. Additionally, Renée has a community manager and various service providers that she interacts with regularly, whereas Burt has his son and home care nurse, and the occasional aid of paramedics. All of these agents have different social norms, collective problems, and internal processes that shape their relationship to AAL data. Given the ubiquity of health care providers as agents, health care providers are used as the example for the application of these analytical tools in Table 2.

Social norms are used to guide, prescribe, and sanction collective and individual behaviour. In the AAL context, this includes the guidelines for practice set by regulatory bodies and legislation to protect privacy and oversee the management of health information.

Collective problems are a set of interrelated issues that are typical or inherent. In a sense, the lack of integration in the health care system overall is a collective problem. Furthermore, different agents will have collective problems that are more unique to their contexts and social norms.

Lastly, **internal processes** are complex interactions that occur over time without external interference. In the AAL context, this includes descriptions of where systems can be leveraged for more continuous care.

3.3.3 Determine the Role of Agents and Transactions for Each Agent

The roles and transactions of agents in AAL systems may differ but may also periodically overlap. Not only are there different transactions related to the access and sharing of data when the data subjects (care recipients), private companies, and public entities interact, but there are also challenges and opportunities (see Figure 5). The data subject's role is to provide or deny informed consent to users, while private companies and public entities are the custodians of data belonging to, in our scenario, patients. For example, doctors and other regulated health care providers obtain public health information (PHI) and patient data (PD) and therefore interact and transact with private companies and public entities. Federal and provincial governments provide laws and regulations for PHI and PD sharing. All these parties engage in four types of transactions: negotiation transactions, directive transactions, distribution transactions, and reciprocity transactions. Descriptions of these transactions are provided below along with

2 In literature on the Governance Analytical Framework [35], the term "actor" is typically used here. As this report is focused on the AAL context, the term "agent" is used instead for consistency and to reflect AAL nomenclature.

examples. Note that these transactions may apply to a care recipient at any square of the needs matrix. Examples where a care recipient is specified are for illustrative purposes only.

- **Negotiation Transactions** determine collective rules for transfer of ownership. It is assumed that there is equality of power among the agents.

  Example: Burt has fallen, been injured and needs to be taken to the hospital. Information about Burt's health is shared by his home care nurse and the paramedics with hospital staff.

- **Directive Transactions** operate in a hierarchy where goods and services are produced, and work relations are overseen using predetermined structures. It is assumed that there is inequality of power among the agents, where one issues the orders and the other complies, according to the set rules.

  Example: Based on information gathered from AAL devices in Renée's suite, a service coordinator directs volunteers to provide certain services to Renée.

- **Distributive Transactions** organize the relationships and distribution of wealth and knowledge according to rules from the government and authorities. It is assumed that there is inequality of power among the agents, where decisions made by authorities are backed and enforced by laws and regulations.

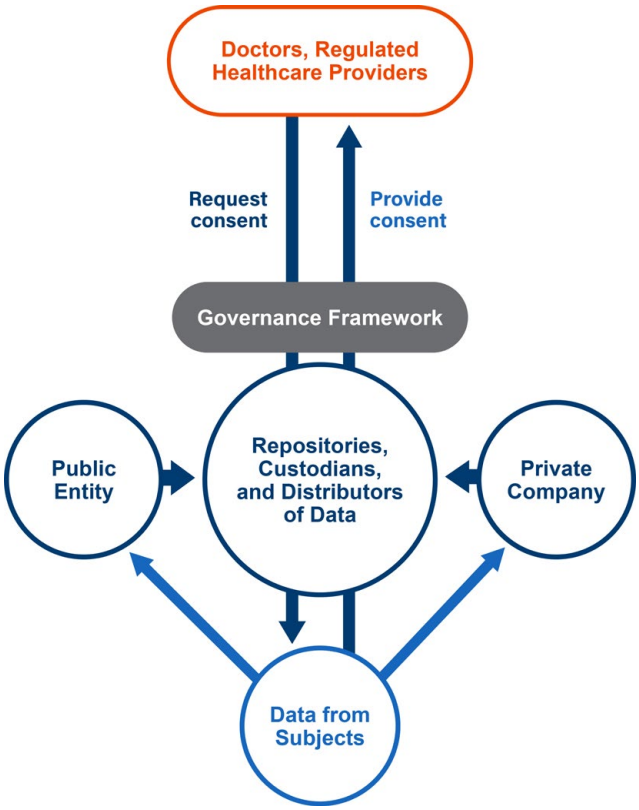
  Example: Care providers must act in accordance with guidelines set by regulatory bodies.

- **Reciprocity Transactions** are mutually beneficial exchanges between agents where, although a gift incurs a moral debt, it helps to reinforce social relationships. It is assumed that there is relative equality of power among the agents, in so far as the gift is received and the giver will reap some social benefit.

  Example: Renée agrees to participate in a trial in order to receive a new smart thermostat in her unit.

The implications of data governance on these transactions are that the flow of data will be accompanied by data accuracy, reliability, compliance, and security, while the rules, policies, and procedures will provide consistency and replication when agents transact.

Figure 5: Data Flow Diagram



3.4 Interviews of Selected Stakeholders

The fourth phase of this research project involved interviews with a group of selected stakeholders, and the main findings from the interviews are presented in this section. Section 3.4.1 reviews the benefits participants identified regarding the use of AAL technologies and their data for care applications. Sections 3.4.2 and 3.4.3 describe the concerns and barriers raised during the interviews around the use and implementation of these technologies. Section 3.4.4 describes the currently disparate nature of data flow in the continuum of care, and Section 3.4.5 outlines what a theoretical governing body overseeing the use of AAL systems might look like based on the preferences and projections described during the interviews.

Eighteen interviews were held, each including one to three participants from the same organization. Six interviews were with stakeholders who work for care



"The most frequently cited benefit was the potential for sensors and other monitoring technologies to predict and alert care providers and caregivers to incidents where the care recipient is at risk, such as injury or illness."

delivery organizations (care delivery), four were with developers or manufacturers of health technologies (tech developers), three were with integrators of health technologies (tech integrators), and five were with potential care recipients and patient advocates (reception).

3.4.1 How the Use of AAL Data Can Improve Care

3.4.1.1 Monitoring and Alerts

Participants outlined several benefits that AAL can provide to senior care, both at home and in higher levels of assisted living, as older adults move through the continuum of care. The most frequently cited benefit was the potential for sensors and other monitoring technologies to predict and alert care providers and caregivers to incidents where the care recipient is at risk, such as injury or illness. This is especially important in the case of older adults with chronic conditions, as continuous monitoring could potentially detect when a care recipient is experiencing a decline or if there are deviations or abnormalities from their typical parameters. One participant (from the tech developers group) described the value of their technology:

> *"Most senior people have some chronic condition or multiple chronic conditions, and with good electronic devices, we can collect data on a daily basis so that we can monitor their general health condition and identify problems early, right, before they become a big issue."*

Monitoring often takes one of two forms: (a) tracking of a regularly measured parameter to examine if it has exhibited a recent change (typically one measured by a regulated medical technology, such as blood pressure), or (b) a more sophisticated option wherein machine learning is used to identify the usual behaviours and patterns of the care recipient to establish a baseline for daily functioning. Such tracking by the AAL system can be used by health care providers to inform adjustments of the care plan. Two interviews from the tech developers group included members of organizations that were developing technologies that would allow health care providers to remotely monitor their patients at home.

Providers who use these systems are alerted if an incident occurs. More importantly, there is continuous monitoring of data available for them to accurately determine changes in the health of their patients, which can then be used to adjust patient care plans as needed. Such systems are particularly desirable as they take some of the burden off the care recipient to identify and report potentially relevant information, and are even more beneficial for care recipients who cannot report on their own well-being due to cognitive or language difficulties.

Example of AAL Technology Application

One of the health care provider participants shared the example of a care recipient with advanced Parkinson's disease. The care recipient consistently experienced freezing episodes at a certain time of day, which suggested they were more susceptible at this time as

their dopamine levels tended to get lower, which could be ameliorated with an adjustment to their medication. However, they may have struggled to recognize and report this pattern as advanced degrees of parkinsonism are associated with declining cognitive function. If this care recipient had a wearable device that tracked these freezing episodes, the health care provider could have been alerted that the adjustment was necessary, circumventing the problem of lack of reporting.

It is important to acknowledge that the use of data and, critically, systems that facilitate the sharing and interpretation of that data, may vary between different settings with different priorities and needs. For example, most participants from the care delivery group were involved with large live-in facilities where different staff members work together to provide care, and the priority was having consistent data flow throughout the facility. However, one participant (care delivery) working in home care and community care pointed out that agents in these settings often do not directly interact with each other, coming into the care recipient's home at different times and from separate home offices. In this case, benefits are seen when there is effective inter-organizational communication between the different agents.

3.4.1.2 Confidence in Aging in Place

Another benefit of AAL described by participants is greater confidence in aging in place for both care recipients and the various caregivers, or agents, who have input on their living situation. Participants remarked on the potential of technological supports to prevent premature moves into assisted care settings, keeping the older adult in their preferred space. Beyond the safety and convenience AAL technologies can provide, they can also help with peace of mind for caregivers. One participant (tech integrators) described how caregivers can benefit:

> *"For a family member or caregiver, being able to actually see the information around daily activities or movement, if the house is at the right temperature, can provide some of that peace of mind and more information to them just to be reassured. I see that playing an important role in elder care so that they can better understand in a little bit more holistic picture of what's happening with their family member, because oftentimes (...) the individual older adult living in their home doesn't want to share everything that's happening, they don't want to tell them about if they had a fall or if they've been feeling ill and staying in bed much longer than usual."*

If there is an issue, there is an opportunity to reduce the burden of reporting by care recipients, who may not want to share information that they think they will worry their loved ones or make them seem unwell. In contrast, if all is well, the caregiver may feel more comfortable not intervening. Any technologies brought into the home, however, for monitoring purposes or otherwise, must be appropriate for the care recipient's needs and must consider their preferences for the level of personal privacy and independence they want to maintain.

3.4.1.3 Care Recipient Empowerment and Well-Being

On the care recipient side, some participants described how the use of AAL technologies could contribute to greater access and empowerment. Rather than needing to go to a different care setting for assessment and adjustments, care recipients could do so in the comfort of their homes, in the background of their daily activities, and in real time. Care recipients could access information about their own well-being in a timely way and ideally, in a way that is compatible with their health literacy levels. Furthermore, as one participant (tech integrators) indicated, care recipients who are more comfortable with technology and its use would likely utilize it to become more goal-oriented as they observe their metrics improve, such as setting a greater daily step count. It is important to acknowledge, however, that access comes with a significant qualifier of equity and affordability. Further information is provided in Section 3.4.3.

Lastly, another benefit raised by interview participants was the potential of AAL technologies to not only aid in the management of care, but to also enrich care recipients' lives. Participants in the care provider and tech integrators groups who worked with several technologies discussed their potential to provide entertainment, connection, or to otherwise help the care recipient work toward something they are motivated for. This application of AAL systems

encourages an expansion of the definition of wellness, by considering how to help the care recipient continue doing what they enjoy between episodes of medical intervention.

3.4.2 Concerns Regarding the Use of Data in Care

When asked about their concerns regarding the current use of data from AAL technologies in care, almost all participants raised two questions that are at the core of the data governance framework: (a) who owns and stores the data, and (b) what they are doing with it. Participants from the care provider and tech developers groups indicated that these questions were often the first ones asked when a new technology was proposed for use by the care organization.[3] One participant (tech integrators) suggested that part of this phenomenon was due to health care providers' discomfort with using cloud infrastructure to store patient information. Traditionally, data in hospitals and large care settings is kept on a local server or hard copies are stored on-site, so trusting that this data would be more secure in another location may require some adjustment. Regarding how the data is used, the same participant noted that signing a user agreement for many consumer devices involves signing away the rights for the data to be used in algorithm development. As this does not provide direct benefit to the care recipient, the participant suggested this might not be something the user would naturally agree to if they were aware of the terms.

However, this concern was not universally shared: patient advocates in the reception group shared that, in their experience, most older adults are happy to share their de-identified data to improve services, support public health efforts, and help others. Their more pressing concern is how the data is being monetized, as they are less comfortable with the idea of their data being used to generate profit for a company. A different tech integrator agreed, adding that in their experience, maintaining reasonable privacy from caregivers was more of a concern than privacy in data collection. In the view of care providers and patient advocates, the ideal situation would be a learning environment where there is mutual benefit by all parties and information is shared in a *"positive manner",* meaning that the intention is to benefit others and not for financial gain. Participants acknowledged that this ideal state was not necessarily realistic, and instead suggested that what is needed in Canada is more explicit legislation to encourage large companies to disclose secondary uses of data.

Another concern raised by participants (care delivery and reception) was regarding accountability and legal responsibility. This concern stemmed from the fact that as more actors with different focuses were added into a system, it would become more difficult to determine who was at fault if an incident were to occur. Furthermore, with alerting systems, there is the question of whether care providers could be held responsible for an incident resulting from a false positive (e.g., a resident in a facility being labeled as aggressive when they are not) or a false negative (e.g., failure to predict an impending medical event) flagged in their system.

3.4.3 Barriers to Use and Implementation

3.4.3.1 The Value Trade-Off

During the interviews, participants discussed a range of barriers to the use and implementation of AAL systems and how these can vary based on the living situation of the care recipient. One of the barriers discussed was a value trade-off where, in order for an AAL system to be acceptable to its users, the benefits must justify (a) the encroachment, real or perceived, on the care recipients' privacy, and (b) the resources required to procure, implement, and learn to use the system. Some participants (tech integrators and patient advocates) described how some older adults indicated that they felt someone was *"spying on them"* when using the technology. The participants suggested that this may be due to a lack of understanding of how the technologies work. Therefore, it would be beneficial to better inform care recipients of the benefits of collecting data, both for them and others, as well as of their own rights to choose and refuse the technology as desired. That choice includes which agents — particularly informal caregivers — have access to the data from the technology.

3 In Ontario, compliance with PHIPA is crucial for health data gathered by devices, although for devices that gather non-health data, this may be more ambiguous [36].

The second part of the challenge includes the perceived value of the technology. Participants in the care delivery and tech integrators groups described the question of value as a common issue, stating how in their own discussions and experiences with older adults, the older adults did not feel that the systems were sufficiently necessary and did not see enough benefit in the technological solutions. The cost of technologies, in terms of financing, time, and resources, was also identified as an issue. As one participant (tech integrators) pointed out:

> *"Technology is not provided in the form of a prescription. Therefore, there's no pay model described, so who pays for it is always a big question."*

The financial cost of procuring and installing AAL technologies is a large burden for individuals and care organizations. Given the lack of consistent government funding and reimbursement programs, cost can be a major barrier to entry. Even if the resources are available and the technology is procured, it is still necessary to take the time to learn how to use it and to allow care providers to integrate it into their workflow. While this may be a nuisance for care recipients, the extra time is critical for care providers, and includes time to learn how to use the new technology, time to adjust to a new workflow, and "slack time" to deal with issues. This needed extra time often does not exist or is not budgeted for during the implementation of the AAL system, which can impose challenges. Furthermore, AAL systems come with certain prerequisites that many homes and care organizations lack. For example, Wi-Fi access is not guaranteed in facilities, and many do not have a strong IT team [37].

3.4.3.2 Oversight and Management of Devices

Care facilities must also contend with the fact that they do not necessarily have control or oversight over all the technologies in their facilities, as some devices might be brought in by the care recipients and their families. Care delivery participants described how there is some advantage to this model as it is often not feasible to bulk-purchase these devices at the facility level, either to give or lend out to residents, and care recipients are more likely to agree with the use of a technology that either they or their caregiver have brought in themselves. However, as the facility is not involved with these devices, if there is an issue or failure of some sort (e.g., a depleted battery) they may not be aware or able to help, and there may not be a way for the data from these devices to be integrated into the facility's own alerting systems or recordkeeping unless a staff member makes a note of it.

One group of participants (tech integrators) raised concerns about the issues caregivers may run into when they have to manage "jerry-rigged" systems (i.e., improvised systems with components not intended to work together) with no support. These participants described how caregivers often attempt to construct their own solutions from several different components, but then must put significant time and effort into maintaining these solutions remotely. Not only is this a lot of effort but it can also be very frustrating for caregivers and may not be sustainable over the long-term. Participants in the tech integrators, care delivery, and reception groups also raised the concern of who is the "expert" for these systems, as they see part of the reason for the confusion behind management of systems being a lack of best practices to help care facility staff, caregivers, and care recipients determine which of the many devices available on the market are best suited to the care recipient's needs.

3.4.3.3 Managing Transitions

Another barrier described by care facility teams trying to implement AAL systems is the difficulty of dealing with care transitions, such as when care recipients move to a different care context. One dimension is the lack of interoperability between AAL and health information systems, as well as between AAL systems following the guidelines set by different manufacturers. If an entirely new system is needed, the data from old devices may not necessarily transfer. Furthermore, suites with several technologies take a lot of time to plan and set up. Participants who work for an organization that has such suites (care delivery) described the following situation:

> *"Sometimes we get the calls that [an independent living resident] can be released from the hospital, but they need these mechanisms in place, so we need to be able to pivot and set up a unit within hours and sometimes less to be able to accommodate that. There's some devices that do seven out of eight of the check boxes, but they also take two or three weeks to set up. It's great if you can put them in every room beforehand, but that's not always the case."*

The more comprehensive or detailed a solution is, the more effort there is in setting it up. However, when transitions happen very rapidly, this is not always feasible.

3.4.3.4 Governing Bodies

Another issue concerns managing the expectations and regulations of governing bodies, including unions. A recurring theme in the interviews was that health care providers are already heavily regulated, to the point where regulations can get in the way of care. Participants (tech developers and reception) described how the strictness of existing protocols makes it so there is no room for new technologies, as they would only add to the workload rather than creating efficiencies. An example raised by one participant (tech developers) was that in LTC facilities, nurses must visit each room once every two hours, and this is a very well-established protocol that is difficult to change. As such, even if a monitoring system was implemented that allowed these check-ins to be done from the nurses' station, it would add to the existing workflow rather than integrate into it, creating more work. Another participant (reception) emphasized that if something is being introduced to the workflow, then governing bodies must consider what can be taken away to simplify procedure. Inversely, if the integration of a technology creates so much efficiency that the jobs of staff members could potentially be redundant, their unions might object. Generally, governing bodies will have necessary and valid concerns upon the suggested integration of any new system that must be addressed, such as compliance with regulations, budget concerns, and privacy concerns.

One potential concern of governing bodies is technological capability, which leads to another barrier raised by participants: digital health literacy among care recipients and agents. Participants (tech integrators) expressed concern that eagerness to implement more technologically advanced and smart solutions has led to *"[skipping] this whole section of basic tech."* They argued that groups trying to implement AAL systems tend to use language older adults are not familiar with and assume a level of competency that is not realistic. One participant (tech developers) presented an opposing viewpoint, arguing that assuming older adults cannot use technologies is ageist and that older adults are highly capable if the technology is designed with their use in mind. However, several participants (tech integrators and reception) indicated that the technologies are rarely designed for care recipients' use or are able to accommodate the technological limitations of seniors with cognitive or dexterity issues. Rather, the assumption is that informal caregivers, who may themselves not have a very high degree of digital literacy, will need to manage the AAL system.

3.4.3.5 Use by Agents

Lastly, there is the question of how care providers are expected to use the information from AAL systems. AAL systems can generate a very high volume of data, leading to concerns by interview participants about how that data can actually be used to improve care and coordination. Specific concerns included how to prevent alert fatigue and how to interpret the data in a way that is personal to the care of the care recipient. One participant (reception) suggested the following gold standard characteristics for interpretation of AAL data: *"actionable, simple to understand, reliable, and novel."* Interpreting the data with these goals in mind could then produce alerts for care providers that they understand, trust, and act on to improve the health or well-being of a care recipient.

3.4.3.6 Considering Equity

One advocacy participant emphasized the importance of the equity perspective. They suggested that thinking from the perspective of barriers is not necessarily helpful because it implies that the factors that interfere with use exist on the same plane as the technology. However, external influences will guide the development of technologies at large. The participant cited as an example the venture capitalist system that incentivizes technology companies to develop particular types of health technologies depending on what is most likely to be funded, rather than on an evidence-informed need. In this process, there may be exclusionary design practices in which certain imagined users are not accounted for, particularly those belonging to racialized and otherwise oppressed communities (e.g., a light sensor on a wearable device that is less effective on individuals with darker skin, or lack of effort to address groups with justified mistrust in health technologies).



"In general, participants described data flow as being good within care organizations and facilities, but poorer between facilities, or between facilities and external agents."

The same participant also cautioned against assuming all care recipients have the same resources available to them as *"a high-income, white, semi-urban community in Ontario where lots of people have pensions and retirement funds and have supportive family who maybe live in a different city in southern Ontario and it's simply a question of having a family member or paid support come to show how to use the technology."* If the challenges of adoption and use for care recipients in this group are the only ones considered, then the benefits will accrue for them only and further enhance health disparities for those who cannot afford the technologies. The participant concluded with the following:

> *"I want to raise the profile of attention to the publicly-funded system of care that serves the majority of Ontarians and Canadians, and the subset of those people who have no or very limited access to the technology, which is probably a bigger proportion than one might expect."*

3.4.4 Current State of Data Flow

When asked about how data currently flows in older adult care settings, the most frequent answer was that it was inconsistent. Management of care recipient data varies greatly based on organizational structure, established workflows, and strength of leadership. In LTC and retirement facilities, this may be managed by remote head offices that make decisions but are not necessarily involved in the day-to-day management of care. However, this issue is not universal, as some participants described fragmentation of data flow between facilities managed by the same head office.

When asked to describe how they see information flow within their own facilities, care delivery participants tended to answer in terms of which agents are responsible for managing privacy agreements or responding to alerts, typically nurses or community coordinators. In some cases, management of more sophisticated or prevention-type systems were outsourced to external IT companies.

In general, participants described data flow as being good within care organizations and facilities, but poorer between facilities, or between facilities and external agents. In one interview, participants (tech integrators) described that among facilities that operate under one large umbrella organization or brand, each facility (or even each building within a facility) may operate under its own governance structure. They suggested that better defining roles in order to have consistent rules for who has access to the data could be a potential solution. Certain organizations already have a key advantage if they have several types of living communities operating under one, well-established governance structure. In these organizations, a care recipient brings all their data from one care setting with them, as one participant (care delivery) described:

> *"If they move from one kind of continuing care to another (...) all that information comes with them, as opposed to coming from [other organization], or going to [other organization], we only send a small amount of information. Across [own organization] it's nice because we can see everything. We would be able to share all of that information and have access to all of that resident data, so overall they're going to get better care. When*

they move from one health care system to another, there is that gap. Not everything is shared and people forget about stuff."

Several participants described cases in which the care recipient's adult children, trusted friends, or neighbours are the ones who make decisions regarding which technologies are used or what data is collected, stating that this is very common. Reasons for this include a lack of digital literacy on the care recipient's part, lack of comfort making decisions pertaining to technology use in their care, and declining health or cognitive abilities. Thinking from a care continuum perspective, one participant (tech integrators) raised the question of when it is permissible to allow caregivers to be the driving force in these decisions:

"If the older adult is fully functional, independent, may have some comorbidities but they're still taking care of themselves, I assume the data will still be owned by the older adults. I think the other question is, when does a switch happen?"

3.4.5 Desired Characteristics and Responsibilities of a Regulatory Body

3.4.5.1 Preference for a National Body

During the interviews, participants were asked how they would like to see the data from AAL devices being regulated and what the ideal functions of a theoretical regulatory body would be. Almost universally, the first thing participants said was that they would want any regulations or regulatory bodies to be national and apply Canada-wide. Participants offered a number of reasons for this. Care delivery and reception participants referred to the fact that dispersal of funds in the Canadian health care system mostly occurs at the provincial level, resulting in separate systems and inconsistencies. Participants felt that a national body would be better equipped to support continuous data flow through the system, as well as sustain an expensive AAL ecosystem. Tech developers participants were concerned with how the structure of a regulatory body would impact their operations and sales. They described how having one national body could simplify matters, providing one set of standards to follow in order to be compliant with requirements and to reach care recipients across the country. As one participant pointed out:

"No one just sells in one province. It's a whole country-wide thing."

Tech integrator participants identified similar reasons to tech developers for preferring a national body. In one interview, participants pointed to the ideological differences regarding technology between provinces as a complication, saying that finding a way to consolidate these differences of opinion and establish common ground is "step number one." After that, future discussions with interprovincial stakeholders may be less fraught.

3.4.5.2 Responsibilities

Regarding the specific responsibilities of a regulatory body, participants (tech integrators and reception) described a need to determine how to navigate privacy of information for data that is both consumer and health. One advocacy participant pointed to the differences in policy between Canada and the European Union, and how the European General Data Protection Regulation (GDPR) has moved from a source-based definition toward a use-based one, meaning that regardless of their position, any agent that collects data that can be used to generate insights about health is bound to a higher standard of rigor when it comes to governing and making decisions about using that data. Canada currently has a much stricter separation between the two, adding complexity.

In addition to determining how to manage consumer health information, some participants described a need to establish certification regarding what counts as a consumer health product, and whether that product is achieving its intent. One participant (tech integrators) suggested that this could be addressed by first developing a framework for what is needed and encouraging manufacturers to develop technologies within those verticals. Alternatively, a different participant (tech developers) indicated that what is needed is an *"industry independent certification organization"* to provide certificates to appropriate devices.

Participants indicated that any regulatory body should better define the role of data in care and the roles of the agents who have access to data. In interviews

with two participants working in smaller health start-ups (two different tech developers), they mentioned that they do not see a strong understanding of how technologies are developed on the government side. While they saw regulations as important, they also emphasized the need to avoid implementing policies that make it *"impossible"* to develop new technologies. Another participant (tech integrators) described the practical purpose of role definition:

> *"Assuming this is a perfect world and nobody has any ill intentions around the data itself, I think the most important thing is defining the roles that should have access to the data and then defining the data and then building a response plan to their data."*

In other words, better-defined guidelines for who has access to the data, their role, and how they should respond to findings based on the data is necessary for more coordinated care.

Participants also suggested that a regulatory body might help navigate some controversial topics such as the ethics of data collection, use, and monetization. Having better guidelines and an enforcing body in place to outline what agents can and cannot do, as well as what care recipients and their caregivers can expect, could potentially reduce conflicts. Of particular concern, especially to care recipients, is what specifically can be monetized. Participants suggested that guidelines for monetization, or at the very least transparency, could aid in developing user trust.

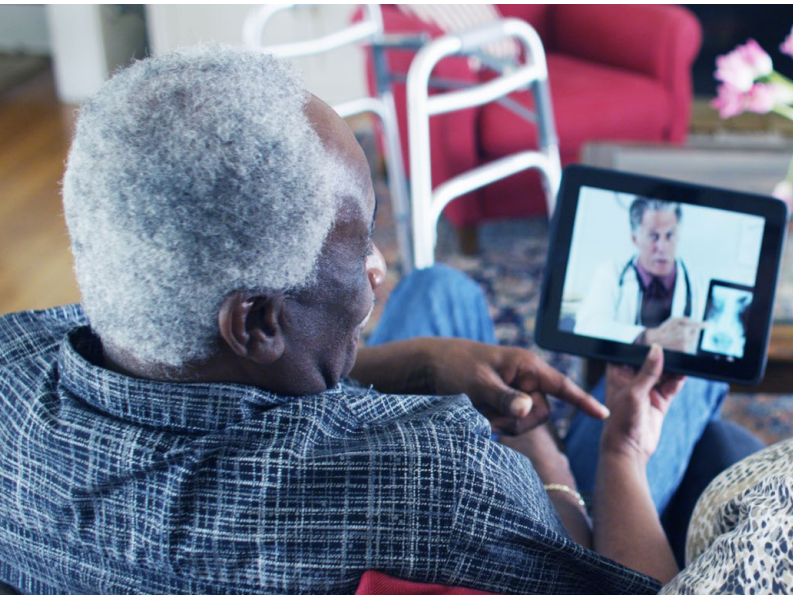
Lastly, participants (care delivery and tech developers) said that they would like to see a regulatory body setting requirements for interoperability. One participant (tech developers) described how, ideally, various care organizations could connect their technology to allow information to be passed seamlessly between settings. However, a care delivery participant indicated that the issue is that vendors do not consider the space of technology integrations enough. With a central body guiding how technologies could work together, it may be possible for different groups to work and share data in a more coordinated way.

4 Conclusions

The capacity of AAL systems and devices to improve lives can be leveraged to support Canada's growing aging population, especially for older adults with high care needs or those who wish to maintain their independence and remain in their homes as they age. However, the current lack of standards or guidelines surrounding the integration of these technologies into the continuum of care and the secure use of data has left this potential mostly untapped.

The literature search identified several considerations related to the implementation and utilization of AAL systems. First, it was important to acknowledge the trade-off inherent in the integration of AAL systems into care, that the advantages offered by the technology must be worth the effort of adoption and the potential loss of privacy. Furthermore, implementations must be sensitive to the context of care and, therefore, the needs and preferences of the care recipient and the agents involved in the AAL system. Inconsistencies in regulations and available resources across the Canadian health care system have led to many barriers to adoption, including difficulties in establishing training programs and what technologies are needed, and in determining whether procurement of AAL technologies is covered under government funding. The literature search also identified the four groups of agents (health care providers, allied health professionals, informal caregivers, and paraprofessionals) and the different ways they may interact with the AAL system and use regulated and unregulated health technologies.

The findings of the literature search led to the development of two models to help visually conceptualize the continuum of care and data governance and assess how they operate together. The model for the continuum of care divided care recipients into three needs levels: high, medium, and low. The agents and services necessary at each needs level accumulate, with high-needs individuals potentially benefiting from the actors involved in lower needs levels in addition to their own. The needs levels form one dimension of the model, and when further subdivided by the care recipient's living situation,



"The capacity of AAL systems and devices to improve lives can be leveraged to support Canada's growing aging population, especially for older adults with high care needs or those who wish to maintain their independence and remain in their homes as they age."

create a needs matrix. The needs matrix provides potential use cases for what different care recipients' needs might be with the understanding that one's position in the matrix is not static. Because needs evolve, there must be continuity in data flow between actors and settings to contend with changing needs. To manage the continuity within this changing context, a data governance framework for AAL data is necessary.

The data governance framework developed for this research adapted the Governance Analytical Framework to the AAL context, with consideration of the unique requirements and issues of integrating AAL systems into the continuum of care. Adaptation of the framework began by considering who the independent, intermediary, and dependent variables were, that is, who was setting the context for the use of the data, what the resulting context was, and who was using the data within that context. The who in this case referred to actors, which within this framework were the people and groups in the system. These actors, guided by the social norms they created and participated in, shared a number of collective problems that made it difficult for them to leverage AAL data for internal processes. Actors also interacted with each other in the AAL system, leading to actual data exchange. Finally, the social norms, collective problems, and internal processes of different actors shaped their relationships to the data, and therefore, their interactions and transactions with each other.

Following the development of these models, semi-structured interviews were conducted with industry stakeholders to validate the model's relevance and obtain a real-world perspective of the challenges and goals of AAL use and adoption. During the interviews, participants described how the use of AAL data can improve care and benefit care recipients, what their concerns are regarding the use of AAL data, the barriers to the use and implementation of technologies, the inconsistencies in data flow across the Canadian health care system, and any characteristics or responsibilities they would attribute to a hypothetical regulatory body to oversee AAL use in care. A recurring theme in the interviews was the need for better role definition regarding who can access the data and who is responsible for taking action based on the gathered data, as well as a greater sensitivity to the data privacy concerns of care recipients and caregivers.

Upon completion of these four phases of research, standardization needs and other opportunities for standard development were identified, including the following five key standardization needs:

1. Developing standardization and best practices for terminology and use of metadata. The current lack of guidance for AAL technologies has led to the lack of a common language for addressing the needs of care recipients, limiting discussion around AAL use. Furthermore, the uses of metadata available from AAL devices (e.g., the time of specific device actions) require established best practices to leverage their use in care.

2. Defining roles of different agents and expectations for data use. Agents should have a clear understanding of what the expectations are for the use of AAL data, and what their personal responsibilities are for responding to certain parameters.
3. Training formal and informal caregivers to use data from AAL systems, including updating the training of new health care providers to include use of technology. The development of this training curriculum must be done with an awareness of current regulations for care provision and established workflows, and how the introduction of AAL systems affects them.
4. Establishing interoperability for system scalability. This includes establishing ways of sharing information gathered from AAL technologies (e.g., movement, activity) with care recipients, caregivers, and health care providers. Interoperability should also consider the needs of health care transitions, and how these can be supported by AAL systems.
5. Defining a "consumer health product" and use of "consumer health data". These definitions require a shift from the current source-based definition of health data to a more flexible use-based definition.

Other opportunities for standard development include areas that are not necessarily a priority for the integration of AAL into the continuum of care but would nonetheless provide value, such as:

1. Developing data interpretation guidelines that are "actionable, simple to understand, reliable, and novel."
2. Developing clearer guidance for the use of consumer health data, including best practices for monetization and algorithm development.
3. Managing data collection from agents who are not the care recipient, such as spouses, caregivers, or other cohabitants.
4. Developing recommendations for clinical or care coordination uses of data from unregulated technologies in AAL systems.
5. Developing categorization or standardization of agents involved in the continuum of care.
6. Defining the collective problems that the data governance framework aims to tackle in the AAL landscape.

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Appendix A: Interview Guide Used in Consultations

Questions were omitted or modified as appropriate for the type of organization or the participant's background.

1. What kinds of health technology does your organization use to support care recipients and their health?
2. What are the barriers to using technology to provide care to care recipients?
3. How is the flow of information in retirement communities being handled today?
4. Who is involved in making decisions on behalf of care recipients regarding their data?
5. In what ways do you see health data from electronic devices playing an important role in elder care?
6. In your experience, how do you see health information being regulated?
7. What do you think of when I say "continuum of care"?
8. How do you see technology in elder care evolving in the next 5 years to support the continuum of care for seniors?
9. What types of living communities (e.g., LTCs, retirement, independent living) do you think have the most to gain from AAL? What communities are currently using it well?
10. What types of agents (e.g., doctors, pharmacists, nurses, non-clinical staff) have the most to gain from AAL? What agents are currently using it well?
11. What are some current regulatory challenges with the implementation or user acceptance of a new health technology in your organization?
12. What data security concerns or questions do you have when a new technology is proposed for use in your organization?
13. If you could wave a magic wand and change one thing in how information flows or is managed in senior care, what would it be?
14. We know the main goal is always to help the recipient of care. However, when it comes to health information, how can we bring the family into this process?
15. Who do you expect will be the trusted body or agency to oversee data governance in the AAL context?
16. Is there anything else you want to add/discuss?

Appendix B: Additional Continuum of Care Use Cases

Along with Burt and Renée, these fictional use cases enhanced the development of this report in considering the different circumstances that inform the level of care required by potential users and recipients of AAL systems. While only Burt and Renée were used in the main text to provide illustrative examples of the circumstances shaping data governance, the remaining cases may also offer unique considerations.

Use Case 1: Judy



Judy – High needs / LTC

Judy has been living in a LTC facility in Nova Scotia for two years. Following a stroke, Judy was hospitalized and lived in a temporary residential care facility. After being discharged, it became apparent that it was not safe for Judy to live at home, at which point she was moved into LTC. Her niece acts as her legal guardian and power of attorney.

Use Case 2: Irfan



Irfan – Low needs / Paid retirement

Irfan recently moved into a retirement community in British Columbia with his wife. They did so on the recommendation of their long-time friends, who also live there and enjoy the offered services. Irfan is active and social, and mostly uses services for his or his wife's personal convenience. He has type 2 diabetes, which he manages with the support of his doctor.

Use Case 3: Ludmilla



Ludmilla – Low needs / Home and community

Ludmilla lives alone in an apartment in the Montreal, Quebec. She has a few family members living about 3 hours away by car. Ludmilla is generally healthy and active. However, she has recently discovered she has breast cancer and is concerned about managing her care, as well as what supports will be available to her during treatment.

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