The Application of Big Data and ICT-Based Systems to Support Older Adults: A Consensus Report

September, 2015

Aging Gracefully across Environments using Technology to Support Wellness, Engagement, and Long Life

Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

Preface

This report is based on the work of a planning group (advisory panel, workshop participants, other collaborators) funded by a Canadian Institutes for Health (CIHR) planning grant. It is a synthesis of discussions from a workshop held in April 2014. Every effort has been made to provide accurate information.

The views presented in this report are those of the planning group and do not necessarily represent the views of CIHR

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EXECUTIVE SUMMARY

The goal of this planning initiative is to explore the potential to exploit the research opportunities afforded by information and communications technologies (ICTs) through partnership with existing longitudinal studies, such as the Canadian Longitudinal Study on Aging (CLSA), to collect real-time data that includes both sensor and health data from the homes and communities of older people.

In April 2014 a group of experts convened to address the following key questions:

1) What are the benefits of conducting this type of research and extending the CLSA to include data from ICT systems?
2) What are the main research questions that could be explored and answered if this type of data existed? What are the main research questions that cannot be answered?
3) What data would need to be collected to answer these research questions?
4) What kind of technical infrastructure (sensors, networks, etc.) would be required to collect these data?
5) What are the strengths, weaknesses, opportunities, and threats in relation to the proposed initiative, including social and ethical concerns?
6) What are the pros and cons of linking this project to the CLSA? What are the pros and cons of harmonizing data sets and linking to other data sets?

At the end of the day and a half workshop, we identified a number of key themes related to conducting research on technology and aging. These clusters, which represent a focus for future discussions, are:

- **Research approaches** (questions, methodologies, population, etc.)
- **Data to be collected** (sensor and clinical data, annotation of data)
- **Infrastructure required** (sensors, logging, annotation, transmission, storage, access, processing and analytics, maintenance)
- **Harmonization and standardization** (CLSA or other partners, sensors)
- **Ethics, privacy, and security**

We completed a Strengths, Opportunities, Weaknesses and Threats (SWOT) analysis and also established a number of consensus statements:

1) The information that is generated using technology to monitor health and wellness, which may result from this type of data set, has the potential to improve the lives of older adults.
2) It is important to not lose sight of the clinical utility; we need to look beyond scientific inquiry to consider potential applications of the research and utilization of the technologies by the various stakeholders.

3) There are gaps in our understanding in many fields of aging that cannot be filled through traditional approaches and measurement tools; technology can be used to advance our understanding.
4) We need robust datasets for algorithm development in order to determine the reliability, specificity and sensitivity of the algorithms being developed and to generate the applications that can support older adults and aging research.
5) Standardization and harmonization of sensors and data collected is required.
6) Ethical standards governing the gathering and use of the data are of paramount importance.

This process enabled us to identify the possible types of data to be collected, how these data will be useful to the research community we are trying to serve through this initiative, and preliminary thoughts on how the next phases of research should proceed. This grant enabled us to bring together key stakeholders within this community to realize this work, including clinicians and caregivers, who play a critical role in the adoption and success of any new healthcare technology. Potential partnership with CLSA was explored, and requires further discussion as there may be other potential initiatives that could be leveraged.

Next steps in moving forward this planning initiative may involve the following:

- Establish priorities for research moving forward (i.e. articulate specific research questions, ranging from basic to complex)
- Determine research approach (i.e. population, sample size, and methods)
- Secure a study collaborator (CLSA or other longitudinal study, organization, entity)
- Establish funding (e.g., grant, industry)
- Identify guiding principles to help determine the types of real-time data to collect and the (population-specific) data that are already being collected or available indirectly (i.e., raw data [e.g., falls risk, way finding, medication use] being collected in home care, facilities) that could be used
- Identify specific data to be collected (clinical and sensor; outcomes and indicators)
- Specify the infrastructure needed to collect the data
- Develop a prospective harmonization plan, as appropriate
- Establish a plan to ensure utmost attention to ethics, privacy, and security

The vision of the overall this planning initiative is that it will result in the largest data set of smart home and ICT sensor data that will be accessible by the research community. In addition, this project will produce a data set that complements the CLSA (or other similar initiative). The data that we propose to collect will generate new knowledge to enhance the understanding of the everyday lives, activities and social participation of seniors and their relationship to personal (e.g. health and mobility) and situational (e.g. social context) factors.

1 INTRODUCTION

1.1 Goal and objectives

Aging populations in Canada and worldwide demand innovative approaches to ensure people can live and age well across and within societies [1]. Information and communications technologies (ICTs) have recently emerged as a potential solution to improve the health, safety and social participation of seniors [2]. These technologies utilize environmental and person-based (i.e. body-worn) sensors, and communications networks to provide important information on the health and care needs of seniors. As well as clinical applications, ICTs offer huge opportunities for gerontological research, particularly in respect to the collection of real-time data on the daily lives and health behaviours of older individuals.

The goal of this planning initiative is to exploit the research opportunities afforded by ICTs through a potential partnership with the Canadian Longitudinal Study on Aging (CLSA) [3] (or other similar group) to collect a longitudinal real-time data set that will include both sensor and health data from the homes and communities of older people. This data set will be collected, developed, and stored with the intention of it becoming part of the CLSA platform that researchers can use in their own research programs. The end result will be one of the most powerful health data sets available.

This initiative will be completed in three phases. The first phase will scope and plan the collection of ICT-based data through a process of consultation with stakeholders (as described below and the focus of this whitepaper). A second phase will develop a suitable ICT platform and develop a detailed protocol for data collection. The primary activity in this second phase will be to prepare the hardware (i.e. sensors) and software necessary to collect the data identified in phase one. A third and final phase will focus on the implementation of the ICT systems and the collection of data. The aim here will be to implement the ICT platform with a large sample of older people (e.g. n = 1000) who are already part of the CLSA or similar dataset.

1.2 Background

The CLSA is a large, national, longitudinal cohort study that will follow approximately 50,000 men and women between the ages of 45 and 85 for at least 20 years. The study collects information on the changing biological, medical, psychological, social, lifestyle and economic aspects of people's lives. These factors are being studied in order to understand how, individually and in combination, they have an impact in both maintaining health and in the development of disease and disability as people age [3]. This planning initiative will both **complement the existing CLSA (or other similar) dataset**, by providing additional data on a subset of the main sample and **afford new opportunities for longitudinal research** on health and aging.

There is significant research conducted on the development and application of ICTs to support and assist older people [4-6]. These systems have been used for a variety of purposes including: Monitoring patterns of daily living and mobility; providing assistance during common activities; automatically detecting adverse events such as falls or dangerous situations; monitoring health status; and enhancing social interaction and participation. For a system to be successful on the market it must be flexible and easily configurable, which can only be achieved by using open standard (non-proprietary) interfaces allowing high interoperability with other systems [7]. It must, of course, be acceptable to the users.

A key element of ICT systems is the collection of data about a person using a variety of devices and sensors, such as motion sensors, global positioning system (GPS), and switches, as well as body-worn devices (e.g. to measure bio-medical data) and the potential to link into exogenous data. Much of the research to date has focused on using sensors indoors, but more recent work has also begun to exploit the potential of mobile ICT networks outside the home.

The use of ICT systems affords opportunities for gerontological research, through the collection of real-time data. This would provide objective data on the physiological health mobility and activities of individuals in their everyday living situations, specify scope for collecting subjective data on mood and attitudes which may vary depending on personal and situational factors [8, 9] and also provide important data on user acceptability.

However, despite the emergence of viable technologies, ICT-based research has so far been very limited by the lack of sufficient data sets. While there have been several attempts to collect such data sets, these have only had small sample sizes over short periods of time, and within constrained environments. Research has also been project-specific, resulting in data not being available or useable within the wider research community. In addition, these data sets are often sparse with missing health data, and do not include any standardized approaches with respect to the type, frequency, or storage of data collected.

2 METHODS

2.1 Planning activities and approach

Preliminary discussions with various groups and researchers involved in the ICT field (e.g. Technology Professional Interest Area of the Alzheimer Association), gerontology researchers, and current members of the CLSA have indicated strong interest and support for the idea of this planning initiative. The aim of this process was to formally extend these initial consultations and to begin concrete planning of a major new Canada-wide research initiative that will have a global impact. Our planning activities were comprised of consultation with key stakeholders and members of the current research community on technology and aging in order to identify and reach a consensus on an optimum pathway for future research. Key questions (as agreed by stakeholders) explored were:

1) What are the benefits of conducting this type of research and extending the CLSA to include data from ICT systems?
2) What are the main research questions that could be explored and answered if this type of data existed? What are the main research questions that cannot be answered?
3) What data would need to be collected to answer these research questions?
4) What kind of technical infrastructure (sensors, networks, etc.) would be required to collect these data?
5) What are the strengths, weaknesses, opportunities, and threats in relation to the proposed initiative, including social and ethical concerns?
6) What are the pros and cons of linking this project to the CLSA? What are the pros and cons of harmonizing data sets and linking to other data sets?

To achieve these objectives, we applied a modified **consensus workshop approach**, specifically the CITRA (Cornell Institute for Translational Research on Aging) model that was developed by Sabir et al (2006). A consensus workshop model allows for the generation of common goals and outcomes from a range of diverse ideas that have been generated through brainstorming and clustering of ideas from experts and stakeholders in the specific field of interest [10]. This approach has been used successfully in setting of research and policy agendas and developing consensus documents on topics related to aging, such as fall prevention strategies [10]. Frontline clinicians and caregivers were included to ensure that solutions and plans are feasible and clinically useful and relevant. The CITRA consensus workshop model approach includes the following steps:

Preparation for the Research Planning Process (December 2013 – April 2014)
In this first step we assembled an advisory group of technology researchers (n = 6), current members of the CLSA (n = 2), and practitioners (n = 1) who were charged with further refining the goals and objectives of this planning initiative, including refining and expanding the initial research questions. This was conducted through teleconference meetings, with follow-up interactions online and offline as needed. (See Appendix 1 - Members of the Advisory Panel).

Convening a Panel of Experts (December 2013 – April 2014)

The project investigators identified and invited potential expert members and stakeholders (including trainees) to be involved in the planning process. In addition to the advisory group, we recruited another 21 members to be involved, for a total of 30 stakeholders, 23 of whom were current researchers within the field of technology and aging with specific interests in the use of sensors and ICT technologies; three were researchers involved with the CLSA; four were clinicians and/or caregivers; and one representative was from private industry. Of the experts who participated, four were from Europe, five from the United States, and 21 from Canada. See Appendix 2for a list of workshop participants and other collaborators. These experts provided input and guidance in selecting the literature that was reviewed and the proposed agenda for the workshop, and reviewed drafts of the resulting research and consensus documents.

Producing a Nontechnical Research Review (December 2013 – March 2014)

A major output of the process was a scoping review [11, 12] of the field's ICTs for older people, with specific emphasis on sensors and networks that have been used, data sets that have been developed, and associations that have been shown between ICT data and health indicators. The primary goal was to prepare an easily understandable summary document for all stakeholders that acted as a springboard for dialogue at the Consensus Workshop [10]. This summary was provided to the expert members for their review in advance of the workshop. The original representative advisory group, as well as other workshop participants, reviewed drafts of the document, and a manuscript was prepared for publication in a peer-review journal.

Convening a Stakeholder Consensus Workshop (April 2014)

A major milestone was a face-to-face workshop at the University of Toronto over the course of a day and a half. The goal was to emerge with a set of "clusters", or themes to answer our primary research questions and that would help us to prepare for Phases 2 and 3. The agenda is included in Appendix 3. The workshop began with an overview and presentation of the goals, objectives and research questions of this initiative, as well as an overview of the Research Review. The classic approach for a consensus workshop was used and included: 1) setting the context; 2) brainstorming; 3) clustering of ideas; and 4) naming the clusters [10]. Workshop activities consisted of a series of expert presentations on related topics, large group discussions, and small group sessions. The workshop was facilitated by one of the project investigators (AM), as well as an external facilitator, and was audio recorded for subsequent transcription, analysis and production of this consensus document.

Follow-up Roundtable (February 2015)

The consensus document resulting from the workshop was sent to workshop participants and the advisory group members for their feedback and comments. This was completed through a two-hour teleconference, which allowed all participants to have a final open discussion on the results and emerging themes and issues. This discussion was centred on the research questions and goals and next steps for subsequent work.

2.2 Outcomes of planning activities

The primary outcomes of our planning activities are the **research review** and this **consensus document**. The research review was intended as a discussion document for the workshop. The consensus document describes the types of data proposed to be collected through this planning initiative, the various options for developing an appropriate data collection platform, and a discussion of the types of networks, sensors and data storage that may be used to collect these data. The development of this Consensus Paper has been an iterative process, informed by the detailed knowledge (related to technology and aging) of the expert participants and collaborators, as well as the scoping review.

As a result of this effort, we have identified a number of key researchers, team members, and knowledge users, who will continue to be involved in this initiative through the facilitation of national and international collaborations. The promotion of a comparable study, with the same data collection (at least a subset) in other parts of the world (e.g., Europe) would certainly be beneficial. These documents will serve as a starting point to develop research protocols for the collection of a longitudinal real-time data set of both sensor and health data from the homes and communities of older people. They will be used in the planning of the next phase of this initiative, which will include the preparation of funding applications (e.g. CIHR Operating Grant, Canadian Foundation for Innovation, private industry) to help support the completion of phases 2 and 3. Long-term outcomes of this research include the development of a comprehensive data set of smart home and ICT sensor data that will be accessible by the research community. Such a study will possibly result in knowledge development for undertaking similar initiatives in the future, which may be harmonized synergistically with a resulting dataset.

3 FINDINGS

This section highlights key themes (clusters) arising from our exploration of the questions we sought to answer by engaging in this consensus process. During the workshop we summarized and discussed as a large group the priority items arising from the small group sessions. These statements became the named clusters and were further edited by the full group on the second day. A number of the items became the consensus statements listed later in this report. These issues, relevant to technology research in aging, will require careful consideration when developing hypotheses, collecting samples, making measurements, and interpreting results for the proposed study. The clusters were identified as follows:

- **Research approaches** (questions, methodologies, population, etc.)
- **Data to be collected** (sensor and clinical data, annotation of data)
- **Infrastructure required** (sensors, logging, annotation, transmission, storage, access, processing and analytics, maintenance)
- **Harmonization and standardization** (CLSA or another partner, sensors)
- **Ethics, privacy and security**

In discussing the clusters, it became evident that there are cautions to collecting data solely for the purpose of research or scientific inquiry. For this type of initiative, it is necessary to involve various stakeholders, including end-users (the people for whom gathering such data will be beneficial). Thus, it is essential that we consider how the production of data matches or aligns with clinical and therapeutic requirements and the needs of the population for whom this work is intended to benefit. This assessment and application cross-cuts all five of the delineated clusters, highlighting the notion of participants as agents – human beings with choices.

The group examined the benefits of this research and agreed that there is a continuum or spectrum of pros and cons to conducting this type of research (i.e., a population based, longitudinal, naturalistic study looking at all aspects of aging). These advantages and disadvantages were further discussed in reference to researchers, the CLSA, consumers, and practitioners. It was noted that benefits to the consumers and practitioners would be realized further into the future than advantages for the other stakeholders (i.e., researchers, CLSA). Please see Table 1 for a summary of these advantages and disadvantages.

Table 1. Advantages and disadvantages of conducting this type of research and extending the CLSA to include data from ICT systems

Stakeholder Group	*Pros*	*Cons*
Researchers	More/better (valid, reliable) data (near real time monitoring, ability to repurpose data, develop different algorithms) Objective benchmark validation	Ground truth challenged Unstructured data (messy) Lack of standards with respect to collecting sensor based data
CLSA	More/better (valid, reliable) data (near real time monitoring, ability to repurpose data, develop different algorithms) Objective benchmark validation	Complexity Coordination
Consumers ***Industrial*** ***Users (patient, caregiver)***	Accurate and timely assessment and diagnosis of physical and mental conditions Degree of intrusiveness Independent living Privacy Ease of use and minimal effort Motivate activity and health management Altruism	Degree of intrusiveness Threat to privacy
Practitioners	Decision support Accurate and timely assessment and diagnosis of physical and mental conditions Motivate activity and health management	Too long term (future benefit)

3.1 Cluster 1: Research approaches

Early in the process we agreed to not be constrained by the notion of being aligned with the CLSA. We desired an ideal approach, agnostic to any particular dataset that allowed use of a variety of existing datasets, including the CLSA. We appreciated that our approach could significantly enhance the CLSA dataset, among others. After ample discussion, we arrived at the following inventory of considerations related to the proposed "Research Approach". Many items will require further discussion and future decisions as the research progresses:

- What sample sizes are needed?
- How much data would it actually take to achieve our goals? How long do we need to collect the data?
- What are the key research questions (impact on clinicians, cost savings to providers)?
- What measures/indicators will be used (costs, hospitalization)?
- What are the research goals (preventative care, clinical decision support)?
- What is the benefit for CLSA? We need to view the goals of this endeavour to not only be the creation of a dataset for algorithm development but also as the source of interventions that would benefit CLSA or a similar longitudinal study.
- Do we focus on a specific disease, chronic illness, etc. or the general aging of the population? Or is the focus on a population subset defined by geography, rather than disease? Perhaps the best approach at first is to look at the changes in specific disease/illness (e.g., movement disorders, cognitive, heart disease) with a relatively simple set of sensors.
- What is the correct starting point (with respect to the above point) for this initiative? This may be determined by what is possible from a technological/sensor perspective (i.e., the technology that is available to us).
- Why not just follow the general population to obtain a solid understanding of baseline conditions vs. a subset of (a 'diseased") population?
- What are the key areas of research in the field (e.g., fall detection, activity monitoring, cognitive decline, etc.), which will then help us to determine the target of the dataset and research conducted?

It was agreed that at this stage it was difficult to define specific research questions that could be answered if this type of data existed; it was agreed that this task is researcher and project dependent. However, four high-level topic areas (listed in no particular order) about which questions could be posed were suggested: 1) health and function, 2) ethics and policies, 3) user acceptance and usability, and 4) technology development.

1) *Health and function*

- How does *physical mobility, cognition, chronic disease, safety, aging in place, social inclusion, caregiving* change over time as people age?

- How do different trends in the data correspond to changes in *mobility, cognition, chronic disease*?
- What are the trends in *mobility, cognition, chronic disease* with respect to geographic areas, policy differences?
- How do *mobility, cognition, chronic disease* correspond to changes in the state of behaviour, disease condition, disease management of individual people?
- Can technology improve health outcomes? Hospitalization rates? Morbidity rates? Mortality rates?

2) *Ethics and policy*

- How does use of technology-based interventions impact the decision making of policymakers?
- What kinds of data are relevant for policymakers and how do we generate it?
- How do we ensure a phased approach to the research?
- What is the impact on privacy? Re-consent and ethics?

3) *User acceptance and usability* (users defined as clients/patients, caregivers, care providers)

- How do people use technology in their daily lives?
- What influences acceptance of devices/technology (i.e., age, passive vs. active use, urban vs. rural, level of cognition)?
- How do we understand key usability metrics (e.g., how well people use their smart phones, what they like about them, what they dislike about them, etc.)?
- Training and support – What are best practices?

4) *Technology development*

- What is the *efficacy, sensitivity, specificity, precision, accuracy* of key sensors?
- How are machine-learning algorithms generated?
- How can data collection be standardized for algorithm development and data sharing?
- What interfaces substitute for sensory losses of the users?
- What are the metrics in data mining and integrity of data sets?
- What is the size of data sets needed?
- What are the security considerations?
- What are the real-time applications? What is the desired number and location of wearable and environmental sensors (e.g., wrist watch, waist)?
- What are data acquisition storage characteristics?
- What is the minimum number and configuration of sensors necessary to maximize data collection?

Caution was expressed with respect to being overly ambitious by "putting the cart before the horse" or doing things in the "wrong" order. While clinical application was acknowledged to be the ultimate goal (i.e., an effective application to help older adults), it was cautioned that the research being proposed is very much in advance of the

application stage. Risk of failure is inevitable (and perhaps unethical), if we attempt to prematurely fulfill unrealistic expectations by moving directly to the application phase. The technologies and the problems we hope to address are too complex to develop solutions in a very short period of time. As with pharmaceutical studies, data acquisition in technology based studies takes time because of this complexity (i.e., complexity of technology, the nature of the problems being researched, cost, aging vs. disease process, life-stage, etc.). It was, however, noted that the clinical relevance of such an endeavour needs to be underscored for policy-makers, such that politicians might lend their ear if we propose interventional research, not just observational research. The self-funding of studies, as seen in the United States, by companies to validate the cost-savings aspect was noted as a way to communicate the importance of this type of research to politicians.

Lastly, there was mention of whether or not the measures that are chosen should be generic or specific (i.e., should the measures address multiple outcomes, and thus be applicable to a variety of research questions or should they focus on one particular variable). It was agreed that it would be ideal to apply generic measures to generate data to answer multiple questions. For example, some activities of daily living (ADL) may be assessed using passive infrared (PIR) sensors to measure feeding oneself, grip strength, eating alone or in the company of others. Bed sensors may provide a means to track changes in sleep that can translate to large shifts in cardiovascular data.

3.2 Cluster 2: Data to be collected (sensor and clinical)

It was agreed that to develop a longitudinal data set for aging and technology further consideration of the following would be necessary:

- How much data is needed (what is the minimum required to achieve maximum output)?
- How long is the data collection interval?
- What is the data sampling interval (frequency)?
- Should data collection be done on only a sub-set of (e.g., CLSA) participants? How would this subset be defined? (i.e., based on geography, population type, disease, age, living situation, etc.)
- What data will be annotated and how?
- What is the clinical relevance of the data?

A set of principles were suggested to help us determine the type of real-time data we want to collect and type of data already being collected or available indirectly in the health care system on our populations of interest that we will want to be able to access (e.g., what kinds of raw data are being collected in home care and facilities, such as falls risk, way finding, medication use) for secondary data analysis.

We also agreed that there are various potential objectives that will define our future data collection and how we should be thinking: 1) Standardization of methodology – researchers (and others) are collecting data on their own without standardization, which makes it difficult to share data; 2) Longitudinal study – using sensor technology as a methodology in its own right for collecting longitudinal data on people and engaging with those individuals to collect data on them over time; and, 3) Data curation – identifying ways to collect data sets and making them more acceptable, generally, and to maintain research data in the long-term such that it is available for reuse and preservation. Thus, it was agreed that we need to clarify our objectives.. How this becomes operationalized will be dependent on the goal(s) we hope to achieve. Given the scope of this work, we will not to be able to combine all objectives into a single study. Ultimately the decisions made regarding the choice of which data and how they are collected and the infrastructure required to manage them will be based on and adapted to these objectives or different approaches we could take.

Issues of who will be responsible to collect and maintain the data, how the sensor data will be annotated to enable interpretation and understanding, and who will perform this task (e.g., CLSA staff and then maintained by the data custodian) were discussed. It was noted that the role of caretaker of the data is a sensitive one. Not all stakeholders want to take on this role (for privacy reasons—i.e. “big brother” perceptions attached to the role, risk associated with responsibility to act based on the data). Nor do individuals want certain groups (e.g., police) to have this role. This individual or group needs to be conscientious and responsible, as this is not an inconsequential task. Responsibilities include data storage, distribution, and maintenance of access rights to scientists working

with the data. Inter-jurisdictional communication (as appropriate) will be necessary, including agreements related to data sharing with health professionals for clinical decision making and others. Furthermore, to "piggy-back" data collection on the CLSA (or other longitudinal study) will require adherence to its principles.

Participants noted that sensor studies often use single resident homes. However, with younger populations, other family members may also be present, which will complicate data collection. Some technologies cannot discriminate between individuals (e.g., infrared [IR]), while other types (e.g., Ultra-wideband [UWB] Radio Frequency Identification [RFID]), can do so but are much more expensive and require tagging (data annotation). Given the question of which sensors will allow data collection from an entire family unit, it was suggested to focus on the *environment* rather than the individual and investigate sensors that capture environmental data. This approach will address the issue of multiple people in the home. It will allow us to examine the family unit, as well as the individual (e.g., assess how movement patterns change as a function of family status, or eating alone [a measure of social isolation] or with others at home; use multiple bed sensors for different home residents; multiple sensors to capture gait and to assess how a person moves about in their home and outside - how do users use inside and outside space).

Data collected through sensor-based monitoring may be broadly classified as movement data (e.g., GPS, room occupancy), biometrics, device and utilities usage, and user-provided data (e.g., self-report questionnaire). Data to be collected may in part be determined on an individual sensor basis to assess the merits (see discussion in Cluster 3 on maturity of sensor technology), as well as based on an assessment of "What really matters to older people?" Figure 1 below summarizes the data required to be able to address the topic areas delineated in Section 3.1. This Figure may also serve as a starting point for discussion to further develop these priority research areas and the specific research questions. It is not intended that any of these data would work in isolation of each other; various measures would be combined to identify change. Data were grouped based on the following issues:

- User Acceptance/Usability (signified by large circle to symbolize its importance to all the other topic areas)
- Mobility and Function
- Safety and Detection
- Cognition
- Social Inclusion
- Chronic Disease Management
- Technology Development
- Aging in Place (in home)

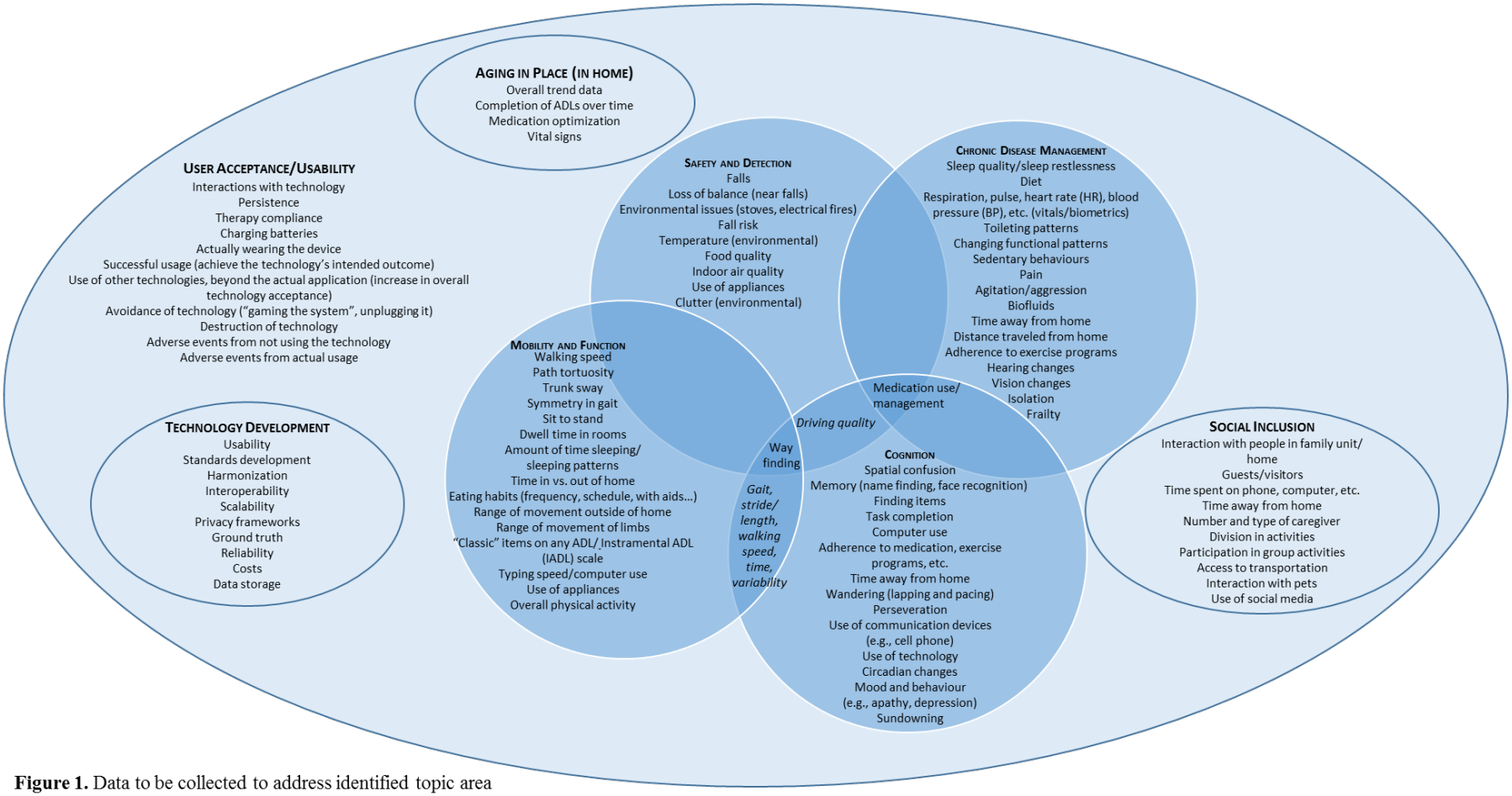

Figure 1. Data to be collected to address identified topic area

The topic of alerts (and addressing incidental findings in the data) – whether and how this will be done – raised a number of issues for further consideration:

- Dealing with false negative rates,
- Ensuring abnormal readings are relayed to a participant's physician (with consent) or to other health professional,
- Maintaining stability of systems over time,
- Collecting baseline data,
- Establishing guidelines re: critical mass of data before notification is required, and
- Knowing when it is appropriate to notify someone or call 911 and how to incorporate the sensor technology's knowledge into an alert system (interpretation).

3.3 Cluster 3: Infrastructure required

The group discussed the technical infrastructure (sensors, networks, etc.) that would be required to collect these data as described in Section 3.2, as well as technology maintenance and support. There are many technologies, systems, and conceptualizations that exist and/or can be further developed (e.g., e-health technologies [information and communication technologies used to provide health care], telehealth [remote vital signs monitoring], telecare [simple personal alarms to smart homes], remote monitoring technologies [RMTs] to monitor health status through remote interface and transmission of information to clinician for review]), as well as new infrastructure. It was suggested that infrastructure also encompasses user experience. Users include: researchers, IT professionals, health professionals, participants (clients/patients), and politicians. User involvement in technology design and data access will be important.

Infrastructure options to be considered for this initiative were summarized by the following categories, as elaborated in Table 2:

1. Sensors (e.g., fixed, mobile, wearable, passive, active, etc.)
2. Logging (local)
3. Annotation
4. Transmission
5. Storage (global) and access
6. Processing and analytics (online/offline)
7. Maintenance

Table 2. Infrastructure considerations and options

Type	Details
Sensors	Cameras (2D and 3D) Ultra wide-band (position) Motion (PIR) Visual Auditory RFID Thermal/Infrared cameras Binary sensors (on/off) Thermal arrays Force/load sensors Pneumatic sensors Hydraulic Radar Range finders Contact sensors/reed switch Ambient-based (temperature, light, etc.)

Type	Details
	Power line monitoring Water/power consumption Outdoor environment sensors Environmental sensor for pollution Experience/self-report Accelerometers HR monitors On-person (wearable) physiological sensors (e.g., HR, BP) Position transponders (GPS) Microphones Ultrasound Smart phones Smart watches Car sensors Computer/technology usage Olfactory
Logging (local)	Hard-drives (storage) Computers (what type) Wireless/network (local area network [LAN]) Middleware Security protocols Physical security Power/Power back-up (UPS)
Annotation	Ground truth to match Frequency Mechanism whereby people can easily annotate their data on a regular basis Crowd sourcing
Transmission	Internet (reliable) Plain Ordinary Telephone Service (POTS) Cellular network Satellite Stored forward (email) Portable drives/storage
Data storage (global) and access	Large-scale storage Silhouette data storage (e.g., vision data) Software development (e.g., cataloguing of needs, distribution of data) Bandwidth

Type	Details
	Scalable infrastructure (scale up to handle emergent technology) Storage in raw form and clean for specific purposes Raw data shipping off site vs. data pre-processed Tools Firewalls/security Cloud-based approaches Longevity of data Back-up systems Standard application program interface (API) Authentication/authorization Secure access
Processing and analytics	Visualization Post-processing algorithms Data scrubbing/cleaning Data analytics High-performance computing (HPC) resources Software development kits (SDKs)
Maintenance	Data collection (by whom, how) Equipment (including impact on users) Databases Cost implications Commercial partner and willingness to collaborate Introduction of new sensors over time Development and commercialization of product

While Table 3 identifies technology commonly used, areas in which the majority of algorithms have been developed, and promising new technology, we have not attempted to evaluate the options. Assessment of technology, vis-à-vis the challenges (e.g., challenges with harmonization), will need to be taken into account in future planning for this work.

We discussed the newness of sensor technology, which contrasts with the more mature technology that CLSA is employing to collect its data (e.g., validated instruments). Some sensors are well-developed (e.g., telemedicine to collect automated BP data in the home, with performance that is technologically equivalent to what would be used in the clinic or in the hospital setting, while others are less so (e.g. movement indicators using sensor data to measure social isolation). An objective of the project may be to use the sensor data to validate questionnaire (or other) data collected by CLSA (e.g., social isolation, user acceptance). It was also suggested that employing different kinds of sensing

modalities may complement each other. For example, a more mature technology could be used as a means of providing ground truth for new types of sensor modalities.

It was noted that we will need to iidentify a key partner(s) to provide infrastructure support, and to subsequently determine what this partner will be prepared to do. This will help to define the scope of the project. The infrastructure that is currently available and feasible may further dictate our starting point regarding what we can measure and also define parameters for data collection. For example, can all the data we need to gather be collected through existing technologies, or are new technologies needed? Maintaining equipment over time and integrating technology currently in use with emergent technology are important considerations (see section 3.4 on harmonization). We will need to be adaptable so that we can plan for the succession of methods and technologies over the long-term. Having a statement or philosophy regarding the adoption of technology (including new technology and new methods) in this initiative would be helpful. The content of this statement will vary depending on the nature of this initiatve and the ultimate research objectives (See previous discussion on objectives Section 3.2 – Cluster #2). For example, if we decide on a longitudinal study, choice of technology may need to be more conservative, while a standardization study will require greater adaptability

The question was raised concerning the extent to which the infrastructure should be permanent (a built-in installation) or more portable and flexible as to where and how the sensors can be installed based on the types of projects and research being conducted. We discussed middleware, at the heart of the infrastructure, and software to allow infrastructure flexibility in systems moving forward. For example, a universal middleware hardware adapter with a network connection to allow for integration of a variety of different types of sensors would permit us to run different studies in clusters, on individuals with different characteristics, which the investigators were interested in studying, as opposed to implementing a "one-size-fits-all" type of system. This is sensible, given that off-the-shelf sensors and tools are increasingly being used and gaining importance. One may think of these as toolkits to be easily deployed and then removed when data collection is no longer needed. We could also consider a logical sensor layer onto which physical sensors are mapped and subsequently related to higher-level clinically relevant parameters. This will permit a variety and new types of physical sensors and address the issue of harmonization across different technologies and new emerging sensors. We agreed that there needs to be consensus on how to accommodate new sensors and technologies as they become available.

Another question relates to the sophistication of the technology and whether an elaborate or higher-end sensor to obtain both complex and simpler, lower end data is preferable to one that offers less complex data but is useful for a number of different applications (e.g., PIR sensors will provide a limited view, whereas a more elaborate tracking system would provide much more information). Other issues to ponder include: an adaptable hub/interface port and relatively future proof standard means to connect sensors; bandwidth needed in the different locations and to transfer the data; and, inventory of infrastructure (local network access points) available in the various geographic (urban and rural) areas; audit of sensors and technologies already in people's homes or

environments (e.g., smart TV, X-boxes, smart phones, home security systems) as possible infrastructure to be leveraged, due to low installation demands and non-obtrusiveness, and may offer good user acceptability (they may not be thought of and sensors by the population at large). Smart phones, for example have great potential (e.g., GPS capability – people voluntarily give their whereabouts to numerous apps). It was noted that if we decide to use existing technology, we would need to take into account potential self-selection bias of the population in the study, particularly with older people who have varying levels of technological use.

3.4 Cluster 4: Harmonization and standardization

While this topic is presented as a separate cluster, harmonization and standardization seemed to be an underlying theme that intersected many of the clusters. Harmonizing cohort data to support collaborative research, whether with the CLSA or another entity, was a main topic of the workshop agenda. Harmonization refers to combining compatible data from multiple studies or multiple data sets into an integrated format resulting in a larger sample size, in doing so strengthening the information for the data user. In contrast, linkage implies adding information, or finding records in different data sets related to an individual and attaching that data to that person.

So why harmonize? Reasons presented were: 1) to obtain numbers and statistical power required to investigate less common events; 2) to better understand similarities and differences across studies or jurisdictions (thus harmonization is beneficial when comparing data across countries); and, 3) to extend the scientific impact of individual studies (optimize return on investment). A prospective harmonization arrangement is preferable to retrospective harmonization, which can pose challenges in attempting to "fit" fully developed studies together.

The basic steps that were presented for harmonization are:

- Define the research questions and objectives (why do you want to harmonize and what do you want to harmonize?)
- Ensure appropriate knowledge and understanding of each study
- Select the variables that will serve as reference for harmonization and determine the potential to create these variables (what are the primary and secondary variables?)
- As appropriate, process data under a common format
- Analyze participant data (conduct pooled [data transferred to a central server and combined for analysis] or federated analysis [centralized analysis with individual-level participant data remaining on local servers])

Achieving data harmonization and integration is time intensive and necessitates substantial collaboration. Collaborative research across heterogeneous studies requires access to high quality data and samples. Other considerations are: rigorous methodological approaches; harmonization guidelines; open-source software (e.g., Data SHaPER, Onyx, Opa, Mica, Data Shield) to support data cataloguing and data harmonization, processing and integration; and, web-based study catalogues and harmonization platforms. Formal harmonization frameworks are not mandatory, but will promote standard documentation (catalogues, list of variables, algorithms, etc.) and increase quality, efficiency and reproducibility of the results generated.
Beyond harmonizing the clinical data, harmonization will be needed across sensors when additional sensors are added or as new technologies are developed. As noted in the previous section, being able to support additional sensors as the study goes forward, to benefit from emergent technologies and the new kinds of data that can be collected, will be important. The discussion related to harmonization of sensor types (i.e., standard

requirements in terms of sensors being used) and sensor data (i.e., so new data are compatible with old data) gave rise to recognition of the difference between standardization and harmonization. It was noted that standardization implies sameness, while harmonization involves a mechanism or strategy to combine data for comparison purposes. The specific question of standardization for this project related to whether we would want to "enforce" sensor type or sensor data, which would be possible within this initiative, rather than at the level of the research field. "Conceptual sensors" – an intermediate layer between the physical sensor and data collected/clinical outcome (similar to a middleware) – were posed as a means of harmonizing across different types of sensor data and sensor modalities. Middleware was also considered one way to help achieve harmonization by enabling transfer of a system into new environments with low effort. Middleware was noted to achieve several standards, especially for hardware-abstraction, to allow interoperability and extendibility. To promote harmonization, it was reiterated that the outcome of interest will determine the necessary characteristics of the sensors engaged. Careful selection of sensors to adequately gather the data desired will help minimize missing data, a challenge when developing algorithms and also improve harmonization.

Establishing guidelines related to harmonization and standardization for the project will assist us in knowing how best to add sensors to collect new data or augment existing data collection and validate self-report or other data. It was also acknowledged that successful harmonization will require an interdisciplinary approach involving (not only) engineers and computer scientists who would be involved in the whole data collection process.

In tandem with our discussion on harmonization, we debated the benefits and constraints of linking this initiative to the CLSA. Although there was no firm resolution that a formal partnership with CLSA will evolve, there are definitely synergies on which we could build and messages we can learn from the CLSA. CLSA currently gathers a large amount of data (e.g., clinical and physical data on 13 chronic conditions, such as depression, osteoarthritis, cardiovascular conditions, diabetes; timed up and go (TUG), grip strength, self-reported ADL, nutrition, physical activity, wealth and assets cognitive evaluation - reaction times and other measures; biological samples; oral health assessment, hearing assessments, visual assessments; medication; air quality monitoring; brain imaging [on subset]; bone density; sleep). It will be worthwhile exploring what could be added with sensors to augment these data.

We did not restrict our thinking to leveraging a partnership with only CLSA, however, as we thought it would be important to first identify what data we will collect (big picture thinking). Then we will map our requirements onto CLSA (as a possible platform for linkage), or identify other potential national or international cohorts or sensor studies with which to collaborate. The research questions and key outcomes and measures we are most interested in exploring need to be further debated. This will then drive the decision with respect to most appropriate platform or longitudinal study or organization and the technology to be used to collect high quality data.

The advantages and disadvantages of partnering with CLSA were highlighted as follows:

Pros

- Standardized, centralized process
- Access participants in their homes (n=30,000)
- Sample design and selection already completed
- Consent is ongoing
- Random recruitment
- A large amount of clinical data already exists
- Additional contextual factors also exists
- Linkage to administrative databases (e.g., individual level administrative provincial health databases; disease registries; population level databases of community characteristics, climate, pollution; individual level economic characteristics)
- Archiving system for data exists (plug into it to have access to the data)
- Framework for accessing data already exists
- Little missing data
- Issues around central research ethics board (REB) have been sorted out (for the most part); coordinated process
- Already a "buzz" and credibility around the CLSA
- Heterogeneity of data
- Ability to choose specific types of participants based on selection criteria
- Ability to select a sub-group from the CLSA to conduct smaller, more extensive pilot study
- Provides a larger set of participants to test the applications developed based on data collected from the sub-set
- Has gone through the (long) process of developing the project and has learned many applicable lessons
- Has a strong advisory council that we can piggyback on
- Similar messages to communicate related to the importance of the initiative

Cons

- Rigidity of existing study structure/infrastructure
- Heterogeneity of data could be difficult to work with
- Follow-up periods may not be ideal (every 18 months, three years, etc.)
- May not capture populations with whom we would like to work (e.g., dementia, Aboriginals, caregivers, non-English/French speakers)
- Significant effort required to label the data (a separate infrastructure would be required to do this)
- Competing interests/agendas (including administrative structures, bureaucracies)
- Does it provide sufficient ground truth (especially looking at population-based data)
- May not allow depth of data collection we would like

- Participants (and resources) are very disperse across the country; therefore, difficult to install, maintain, and support infrastructure
- Does not provide consistent context (e.g., different types of homes, multiple occupants, etc.); although this may be overcome based on inclusion criteria
- Lack of intervention data (treatment incidences, etc.)
- Burden on existing participants
- Potential compromise to CLSA study
- Will not work for all technologies (e.g., not all participants have access to the Internet or are technology savvy/knowledgeable)

3.5 Cluster 5: Ethics, privacy, and security

A number of issues arose relating to: *ethics* (right and wrong conduct), *privacy* (of participants with respect to data collection, storage, distribution and access, and protection of personal information), and *security* (as related to the technology, safe storage of the data, and protection from unauthorized access).

Informed consent to participate

We discussed the CLSA informed consent process, which gave rise to a question of how to ethically obtain informed consent from participants (including individuals and other members of a family unit, such as spouses and children) in a longitudinal study when the future, long-term risks are unknown and if participants do not know how the data may be used. It was agreed that, for this planning iniative, there may need to be an ongoing consent process, such that participants are re-consented as the sensors/technology changes. Consideration will need to be given to proxy consent processes, for those individuals personally unable to provide consent, and on how to assess the capacity of individual from whom consent is being obtained. Questions include: Do we reassess capacity each time we gather consent; at what junctures do we obtain consent or re-consent – with each technological change, every time the older adult changes, etc.? We raised a concern related to sensors needing to be replaced (e.g., breaking down, installation of emergent sensors), as this may become a nuisance for participants and affect ongoing participation in the study. Furthermore, if technicians need to go into to the home to install, repair, or replace sensors, it was noted that this may affect participants' privacy. This will require a plan to handle participant and data withdrawal that is part of the informed consent process.

Privacy

Anonymity and confidentiality are no less important, even if there is a robust informed consent process. A trade-off was identified between having a more expansive consent process to allow for wider data collection across many variables and/or multiple participants (e.g., individual, spouse, children), versus gathering a limited dataset using a consent process that would restrict data collection in favour of promoting more privacy. Understanding how best to manage and protect research data, including personal information is not only ethical, but also has legal implications. Attention is required regarding privacy of data being collected, and how this changes across different sensor types (e.g., GPS vs. motion sensors) and invasiveness of data collection procedures. Also, who will have access to the data and ownership of the data? Other privacy considerations are third party (industry) storage of the data, de-identification protocols, and sharing personal information with third parties for purpose of sensor installation. While industry has expressed interest in being involved (and their involvement as one stakeholder is important), these are issues that will need to be clarified as we move forward. In addition to data confidentiality and anonymity, it is additionally important to note that we need to be cognizant of the potentially disruptive effect that surveillance technologies may have on an individual's lifestyle (e.g., during installation, maintenance in the home by

engineers). The process of "being watched" can have a significant impact on the lives and behaviours of people.

Adverse events (incidental findings)

The group discussed the implications of an adverse event (incidental finding) being captured in the data. This is more so related to the application being developed, as opposed to the data set being collected. It was agreed that if something happens (e.g., fall is noted in the data), participants need to be made aware in advance that they may not be helped or rescued as it would not be known when someone has fallen until the data are actually being interpreted at some point in the future. If an individual is being monitored continuously, that person may make an erroneous assumption that if something happens to them that the monitoring is some of the benefit (i.e., an alert will be made). This needs to be discussed carefully during the informed consent process.

Risk

The concept of risk (e.g., security, acceptance of research, acceptable level of risk in this work) was explored. Hackers have become sophisticated, and with seemingly minimal effort, can break into computer systems. Also, participants may be worried about risk of theft if they believe the raw sensor data are stored in their home. One possible way to mitigate risk is to collect only the information we really need to answer the research questions (e.g., with a GPS, track only distance traveled). However, this may be challenging and may not even be possible, given the multiplicity of purposes assigned to the various sensors that may be employed. Peripheral or ancillary data are a by-product that we might not be able to avoid (e,g., while monitoring mobility we may obtain information that relates to an individual's cognitive ability). For informed consent, we will need to clearly communicate to research participants that, in the process of collecting one type of data, data on another aspect of their life may also be recorded. This initiative will likely need to conduct a risk analysis for different types of sensors and data that are being collected as related to these issues, which will help in the informed consent process. Decisions about risk will be guided by existing privacy legislation and institutional (REB) guidelines and requirements.

Access and data ownership

We discussed questions such as *who can access the data*, *how do researchers/others have access to the data once it is collected*; *how will the data be made available, in what format*; and, *what will be the cost to access the data*. Specific discussion focused on the kind of access which industry (e.g. a partner on this project) may have to the data and test platform being developed. For example, in the CLSA one of the requirements in terms of accessing data is that it has to be utilized for research. Commercial enterprise are allowed to be part of the research team but they cannot access the data individually for commercial gain. A discussion related to commercialization will be essential. Definition of intellectual property (IP) guidelines are also relevant here. In the CLSA the IP rests with the individual investigators, so there is no CLSA-based IP.

3.6 Strengths Opportunities Weaknesses and Threats (SWOT) analysis

Table 3 represents a SWOT analysis to guide thinking about the important ethical considerations and to assist with making decisions about how to proceed with the next steps of this initiative:

Table 3. SWOT analysis

	Helpful to achieving the objective	**Harmful** to achieving the objective
Internal Origin (attributes of the environment)	**Strengths** • High participation rate with CLSA • If dovetailed to CLSA, people are consented in regular intervals so consent can be included (increases participation) • Good methodology in the CLSA - randomized sample • Unique range of functionalities may be proposed • Potential benefits to older adults • Committed collaborators • Involvement by various user groups (researchers, clinicians, industry) • 24/7 real time monitoring of the individual to collect data provides a value-added dimension to longitudinal data • Extends data collection beyond the current maximum of three years	**Weaknesses** • Ethical issues • Ethical review with CLSA might slow progress because CLSA is such a huge project • CLSA goes up to 85 years, but there are many older adults that won't be captured over age 85 (i.e., miss older cohorts) • Level of intrusion on participants over many years may be too high • Perception of intrusion of technology in home for so many years, and benefit from the intrusion • Responsibility of technology for the user (Who would be responsible for maintenance? What amount of compensation is worthwhile?) • Technology maintenance (What about new models - Who will switch out the technology?) • Rapidity of change in technology • Multiple sites - huge scale requires effort in terms of installation, maintenance, data collection, to be able to collect data from individuals using sensor networks • Cost • Long timeline • Unstructured data • How to harmonize data that are in many different formats • Lack of standards with regards to collecting this kind of sensor based data • Data storage and access rights • Ground truth – what do you know? • Efficacy (there is little evidence to suggest that the use of sensors in the homes to monitor people have any sort clinical efficacy) • Multiple occupants • Missing data • False alarms

	Opportunities	Threats
External Origin (attributes of the environment)	• Development of better fine grain technology to collect data • Chance to learn about what education is needed to obtain consent from older adults, and how to best explain the benefits of such research (and level of intrusion) • Possibility to split cohorts (e.g., ages 45 to 85 years - early vs. late) to understand consent practices and what technology is more acceptable in an older cohort • Potential change societal practice (i.e., creation of profiles of people to change policy) • Possibility to leverage existing investments and resources for sustainability • Growing research community in sensor-based research • Interest of external funders in this topic (e.g., private industry, NIH, other government) • Framing issue in plain language for benefit of policy-makers • Alignment with CLSA represents good synergy	• Perceptions of monitoring and intrusiveness • Acceptance of devices by participants • Inappropriate research design • Competitive funding environment • Amount of monitoring required • Custodian of the data • Inter-jurisdictional communication • Privacy legislation • Changing definitions of subject matter (e.g., categories of ethnicity) • Administrative structures and bureaucracies • Lack of understanding of timeline and research process to get to application stage (expectations)

3.7 Future directions

At the end of this exercise we were left with some unanswered questions or issues to explore in moving forward with this initiative, many of which related to the value and market for our proposed product:

- How do we garner political will or support to move this initiative forward?
- Have we fully established the need and value for progressing to the next stages? This will require a huge amount of work and needs convincing justification.
- Are the people who might benefit from the data sufficiently expert to truly understand and appreciate it (e.g., health researchers who are comfortable with their own types of data, but would find this work very foreign)?
- Or would we involve a very specific group of researchers who might be more comfortable with working with real-time sensor and health data collected from the homes and communities of older people; if so, is the current group large enough to warrant the effort required to do this?
- How are CLSA data currently used? What sort of research is being done? What would the real-time sensor and health data contribute?
- Have we outlined the various options about how real-time sensor and health data gathered from the homes and communities of older people could be linked to CLSA (or other longitudinal study) data?
- Are there other possible collaborators who can provide detailed feedback on the technical aspects of this kind of research?
- How can we provide input into AGE-WELL, a pan-Canadian network conducting research on technologies and services that benefit older adults?

There was a sense that we need to materialize on things that are readily available and easily implemented, so as to not lose momentum. Incremental steps can be mapped out, identifying the low hanging fruit, and our most basic needs, and subsequently identify how to then ramp up over time to get to where we see ourselves in the ideal world. One straightforward option of obtaining the types of data we discussed is to develop an easy to use smartphone 'app' (low bandwidth, low power consumption) to gather information that individuals would make available to the project volitionally. Having participants use their own phones, and own internet access as a means to gather the information longitudinally. This approach would require minimal effort, thus facilitating widespread application, and would be easier than building a physical infrastructure or placing sensors in people's homes. We can "bootstrap" the project by the least expensive means first, until we achieve enough momentum to start moving into areas requiring significant capital support. An advantage of this approach is that it can be done in parallel with the CLSA, with data being shared with the CLSA; the CLSA can brand this as part of its activities. This approach can also be relatively inexpensive way to gather data on a subset of pertinent variables. This approach speaks to the broad longitudinal study objective or purpose mentioned earlier in this report.

Another possibility is to investigate data collection that has already been done and conduct harmonization across these existing data. The ability to share data among different groups of researchers is a key step forward to facilitate the creation of algorithms to address the various problems. This would aim to address standardization and data curation objectives.

3.8 Conclusions and consensus statements

There is no doubt that large data sets and longitudinal studies are an essential research tool for attaining a better understanding of technology and aging and aging in place. Nonetheless, large cohort studies are costly and complex, and, therefore, any research effort should focus on leveraging and linking to research initiatives in which data and research platforms already exist. The CLSA provides one such possibility, but this initiative should not limit its thinking regarding possible collaborators or research opportunities. Potential partnership with CLSA requires further discussion.

Besides the five clusters identified to guide our future decisions (*research approaches*; *data to be collected*; *infrastructure required*; *harmonization and standardization*; and, *ethics, privacy, and security*), five consensus statements evolved from our discussions:

1) The information that is generated using technology to monitor health and wellness, which may result from this type of data set, has the potential to improve the lives of older adults.
2) It is important to not lose sight of the clinical utility; we need to look beyond scientific inquiry to consider potential applications of the research and utilization of the technologies by the various stakeholders.
3) There are gaps in our understanding in many fields of aging that cannot be filled through traditional approaches and measurement tools; technology can be used to advance our understanding.
4) We need robust datasets for algorithm development in order to determine the reliability, specificity and sensitivity of the algorithms being developed and to generate the applications that can support older adults and aging research.
5) Standardization and harmonization of sensors and data collected is required.
6) Ethical standards governing the gathering and use of the data are of paramount importance.

This process enabled us to identify the possible types of data to be collected, how these data will be useful to the research community we are trying to serve through this initiative, and preliminary thoughts on how the next phases of research should proceed. This grant enabled us to bring together key stakeholders within this community to realize this work, including clinicians and caregivers, who play a critical role in the adoption and success of any new healthcare technology. Next steps in moving forward with this initiative may involve the following:

- Establish priorities for research moving forward (i.e. articulate specific research questions, ranging from basic to complex)
- Determine research approach (i.e., population, sample size, and methods)
- Secure a study collaborator (CLSA or other longitudinal study, organization, entity)
- Establish funding (e.g., grant, industry)

- Identify guiding principles to help determine the types of real-time data to collect and the (population-specific) data that are already being collected or available indirectly (i.e., raw data [e.g., falls risk, way finding, medication use] being collected in home care, facilities) that could be used
- Identify specific data to be collected (clinical and sensor; outcomes and indicators)
- Specify the infrastructure needed to collect the data
- Develop a prospective harmonization plan, as appropriate
- Establish a plan to ensure utmost attention to ethics, privacy, and security

This overall planning initiative will result in the largest data set of smart home and ICT sensor data that will be accessible by the research community who are involved in the development and testing of healthcare technologies. In addition, this project will result in a data set that complements the CLSA (other similar initiative). The data that we propose to collect can provide new data to enhance the understanding of the everyday lives, activities and social participation of seniors and their relationship to personal (e.g. health and mobility) and situational (e.g. social context) factors.. This grant allowed us to bring together a collaborative group of experts with whom we will be able to realize our future goal to establish one of the most powerful health data sets available. We have commitment from many to move forward with these ideas and will continue to leverage support from the clinical community, technology researchers, and industry to help us to achieve a more independent senior population.

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Appendix 3. Workshop Agenda

CLSA – TECH Project

Workshop Agenda

April 14 & 15, 2014

Room 132, 500 University Ave., Toronto, ON, Canada

DAY 1	Topic	Presenter
8:45 – 9:00	*Continental breakfast*	
9:00 – 9:10	Welcome and introduction of project investigators	
9:10 – 9:30	Introduction and overview of expert members	
9:30 – 9:55	Presentation of the planning initiative, objectives for workshop and preliminary Q&A	Alex Mihailidis
9:55 – 10:15	Presentation on the US Experience	Jeffrey Kaye
10:15 – 10:35	Presentation of overview paper developed and discussion	Andrew Sixsmith
10:35 – 10:55	*Break*	
10:55 – 11:05	Presentation of planning goals and explanation of breakout sessions	Andrea Duncan
11:05 – 11:45	Break out session 1	
11:45 – 12:30	Break out session 1 presentation and discussion	
12:30 – 1:30	*Lunch*	
1:30 – 2:10	Break out session 2	
2:10 – 2:55	Break out session 2 presentation and discussion	
2:55 – 3:15	*Break*	
3:15 – 4:00	Introduce clusters and begin naming of clusters – Large Group Discussion	
4:00 – 4:30	Presentation on Harmonization	Isabel Fortier
4:30 – 5:00	Summary of day and findings and assigning of "homework"	

DAY 2	Topic	Presenter
8:45 – 9:00	*Continental breakfast*	
9:00 – 9:15	Overview of goals of Day 2	
9:15 – 9:45	Presentation on CLSA	Parminder Raina and Susan Kirkland
9:45 – 10:30	Discussion of each cluster and action items for each one	
10:30 – 10:45	*Break*	
10:45 – 11:30	Continue discussion of each cluster and action items	
11:30 – 11:45	Discussion and preliminary planning of resulting consensus document	
11:45 – 12:00	Summary of workshop and next steps	
12:00 – 12:15	Concluding remarks	
12:15 –	*Lunch to go*	

Key questions

Break Out Session #1

What are the benefits of conducting this type of research and extending the CLSA to include data from ICT systems? • For researchers • For CLSA • For consumers/users • For practitioners • Locally (Canada) • Globally
What are the main research questions that could be explored and answered if this type of data existed? • What health issues could be addressed? (e.g., falls, dementia, Parkinson's disease, CHD)
What data would be needed to be collected to answer these research questions? • Individual/Environmental • Who collects the data? • Will there be alerts? Who responds to?

Break out Session #2

What kind of technical infrastructure (sensors, networks, etc.) would be required to collect these data?

- Auditory, Visual, Motion
- Body worn vs. environmental vs. those that require the older adult to take his/her own readings)
- What would the system architecture look like (i.e., home hub delivered to central system).
- What type of computers? Software?
- How should users be involved? Design of the technology, seeing their own data, etc.
- How will data be transmitted? To where? Via what?
- How will the data be stored?
- What are the implications for existing technology vs. need for new technology (i.e., can all these data be collected through existing technologies, or are new technologies needed)

What are the strengths, weaknesses, opportunities, and threats in relation to the proposed initiative, including social and ethical concerns?

- What is the impact on privacy? Re-consent and ethics?
- Who owns the data?
- Who can access the data?
- How are the data maintained? (including all data collection procedures, equipment and database maintenance) What are the cost implications of maintenance?
- How do researchers/others have access to the data once collected?
- How will data be made available? In what format will data be available?
- What will be the cost to access the data?

What are the pros and cons of linking this project to the CLSA?

- What are the constraints of linking this initiative to the CLSA?
- What are the benefits of linking this initiative to the CLSA?
- What other cohorts exist that could be used—nationally, internationally?
- What other sensor studies, nationally and internationally, can the data be harmonized with?