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Ethics / Law / Policy and the Supportive Smart Home
2022

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How to cite this document

Wallace, Bruce & Knoefel, Frank. Ethics, Law, Policy and the Supportive Smart Home (2022). AGE-WELL National Innovation Hub Sensors and Analytics for Monitoring Mobility and Memory (SAM3) and Advancing Policies and Practices in Technology and Aging (APPTA).

Introduction

A key decision facing many aging adults and their families/informal caregivers, is whether they are able to remain living independently. While the aging adult is at the center of this decision, many factors can influence the decision, including the ability of family to provide care giving support, the availability of appropriate communal care options, and the accessible financial resources (ability to supplement community provided care). Canada and AGE-WELL NCE Inc. are leaders in developing technology to support aging adults (AgeTech). The Supportive Smart Home, one that leverages technology to support the aging adult's desire to age in place, is an emerging AgeTech option to potentially delay the decision to enter institutional care. In this report, we introduce some of the research on Supportive Smart Homes and then address questions these systems raise around ethics, policy, and legal concerns; particularly as we move from the research setting into consumer settings or large scale deployments.

The Supportive Smart Home

Smart home technologies are commonplace and readily available within the retail sector. Homeowners widely use a range of smart home applications, such as home security systems, utilities automation, and home entertainment. These systems consist of sensors through-out the home which are connected to a hub device, and in most cases, are also connected to internet cloud services for added capabilities, such as messaging and controlling apps on smart phones.

Supportive Smart Homes take this one step further by using technology to assess the well-being of home occupants and to provide them with support and assistance. The Supportive Smart Home system shown in Figure 1 demonstrates a system that is currently in the research stage within hundreds of homes across North America. The system comprises sensors that are deployed through-out the house and in the homeowners' vehicles. In some cases, the sensors are also worn by the older adult. These sensors can include: door contact sensors to detect doors opening/closing; motion sensor to detect movement in an area; weight scale sensors to assess biometric information; or pill box sensors to monitor the taking of medication. Smart speakers connected to the system can allow for the system to communicate with the resident(s) of the home.
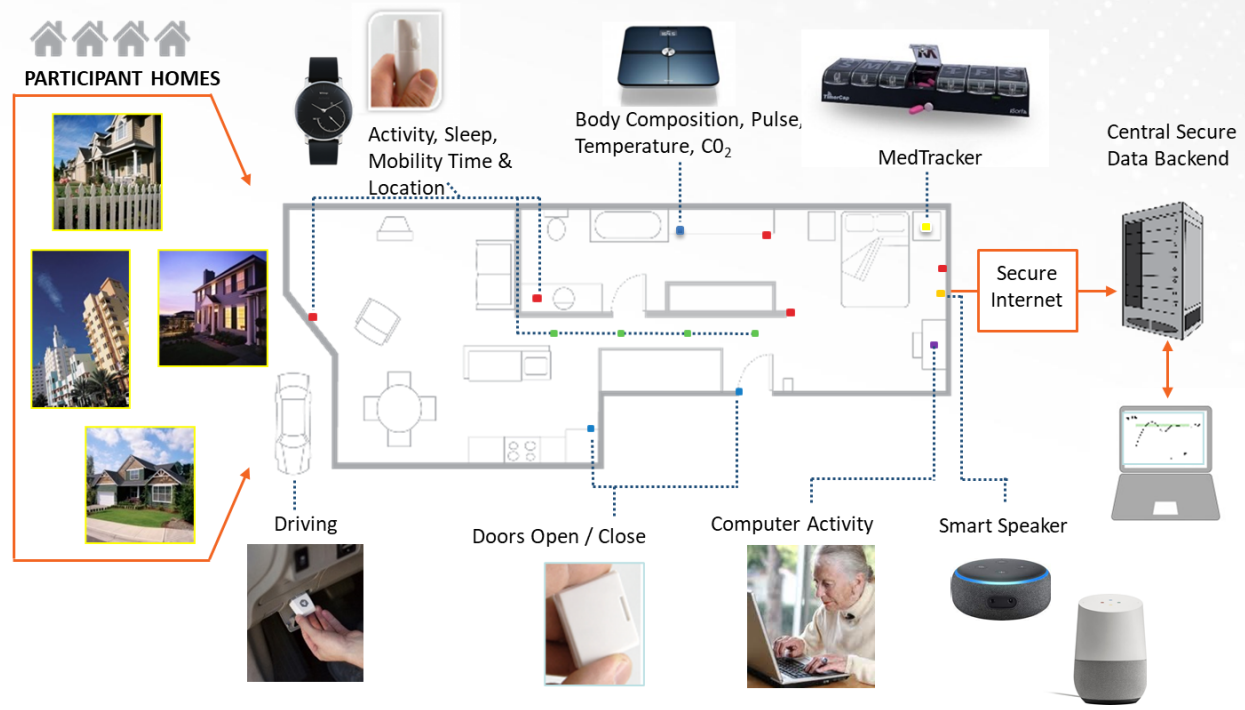
Figure 1 - Example Supportive Smart Home System

Broadly, a Supportive Smart Home is the newest example of products and systems which fall under the umbrella of AgeTech.

An Example – Nocturnal Wander Detection and Diversion (NWDD)

A Nocturnal Wander Detection and Diversion (NWDD) system, tested by AGE-WELL SAM[3], is one example of AgeTech that can be incorporated into a Supportive Smart Home [2], [3], [4]. This system was specially designed to support Persons Living with Dementia (PLWD) and their care partners: typically, a spouse or an adult child. One common set of symptoms of dementia is disorientation to time and/or place, and this can lead to a PLWD becoming confused, such as, when they wake during the night. From a time point of view, they may see 3:00 (AM) on the clock but think that it is the middle of the day and that they should take the dog for a walk. From a place point of view, they may not remember where they are and hence where the bathroom is. The care partner is also typically affected because they sleep poorly while worrying that the PLWD could wake and

leave the residence, potentially resulting in injury or death (especially during Canadian winters). Care partners, who experience a lack of sleep, can suffer from stress and potentially burn-out, which may result in less effective care giving, and possibly premature institutionalization of PLWD.

The NWDD Supportive Smart Home system flow model (Figure 2) uses sensors deployed in a home, along with speakers and other smart home technology. Like any other persons, PLWD may wake in the night to use the bathroom, therefore, the system incorporates a bed-sensor to determine if the PLWD has gotten out of bed and responds by turning on the bathroom light. This provides the PLWD with a visual cue in the direction that they likely need to go. If they go to bathroom and return to bed, the lights are then shut off for them. Should they go to a safe place elsewhere in the residence, a smart speaker will suggest that they should return to bed, typically using the care partner's voice. If they go somewhere unsafe, such as an exit door, the system will awaken the care partner using a customizable alert.
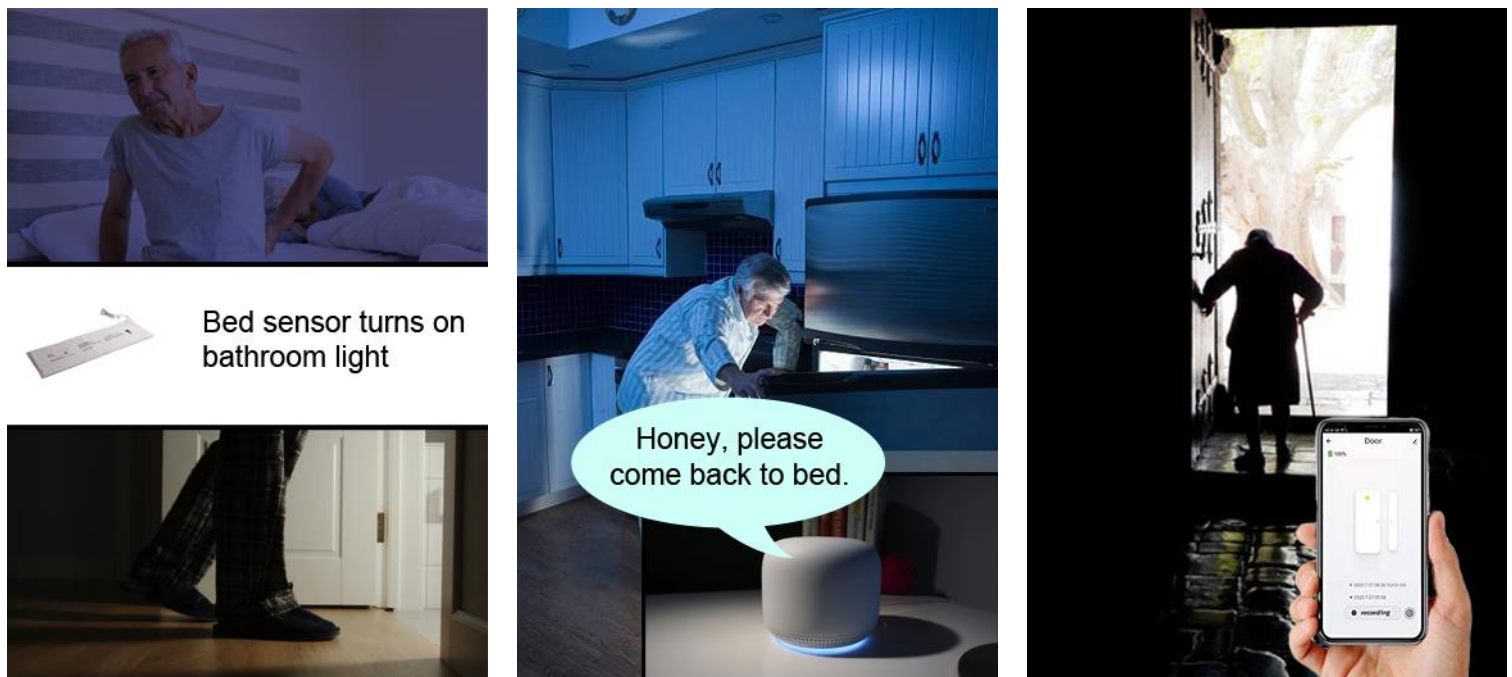
Figure 2 - Wandering Detection and Diversion Example

The goal of this system is to support the PLWD to have increased independence while also reducing risks (e.g., should they try and exit the home) and additionally supports the care partner's ability to get the rest they need to support and care for the PLWD.

## But these systems can do so much more

The potential for Supportive Smart Home systems is vast. Recent research has explored well-being information assessed through bed sensing [5], assessment of physical activity such as gait [6], assessment of Activities of Daily Living [7] and overall activity within a home [8]. Because Supportive Smart Homes would potentially generate very significant amounts of data, cloud-based computing would be optimal. Research has started to look at the growing technical challenges associated with this, such as the communications between the home and cloud [9], the processing by the cloud [10] and the design of the communications between the Supportive Smart Home and residents [11].

The result is that Supportive Smart Homes have the potential to allow aging adults to have increased independence as they age by providing them with an option to manage the risk to themselves and potentially decrease the burden they place on their care partners. The potential of these systems suggests that wide scale adoption is more realistic than it has ever been.

Figure 3 shows one example of the well-being and activity that can be assessed from sensors within the NWDD system. In this figure, the two shades of blue indicate if the residents are in bed (both or only PLWD), while red indicates overnight activity in the bathroom. Green and yellow show activity levels during the day. This figure shows many weeks of consecutive data in concentric circles. There are some visible general patterns in the data such as a regular bedtime and rise time along with regular weekend episodes where the residents are away. It also shows exceptions to these patterns.

Cloud Computing

The Internet has introduced many new modes of communication and within these we find a way to support and enhance AgeTech. Each AgeTech system requires a computer to process complex sensor data into useful, understandable information. The notion of cloud computing is based on a model of sharing computing resources across the Internet. Instead of each home having a dedicated AgeTech computer, along with its associated costs, a few computers on the Internet can be shared across many hundreds or even thousands of homes.
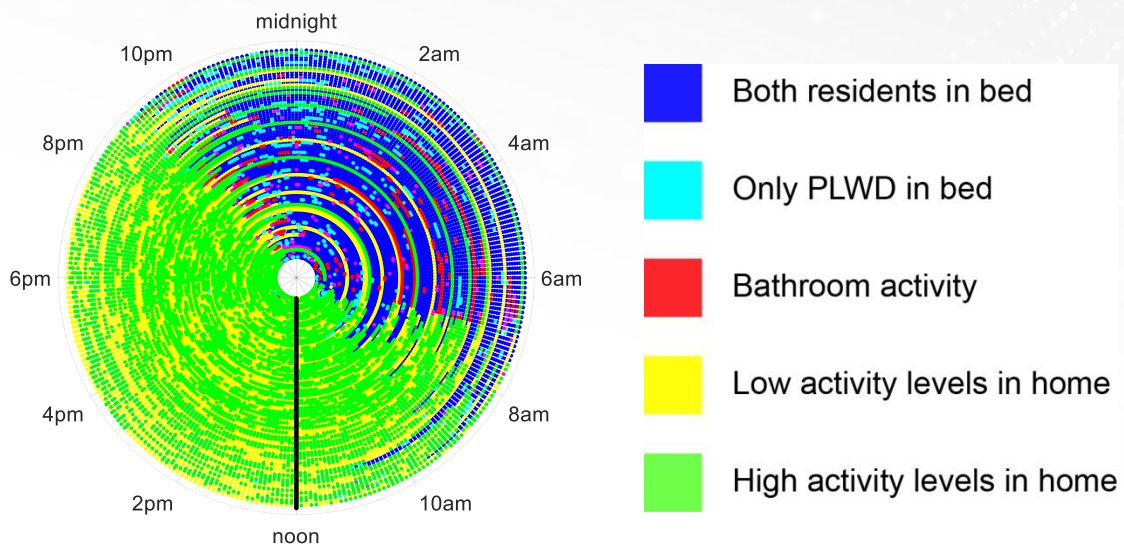
Figure 3 - Longitudinal data possible from Supportive Smart Home system

This now raises questions about the ethical use of these systems, the policies and legal models associated with their use, especially since these are novel applications of technology. The assessment and support of well-being were never contemplated by commercial vendors of technology devices or internet / cloud services. The balance of this report, using ethics, policy, and legal lenses, will consider and address the implications of a Supportive Smart Home. For the purposes of this discussion, we have created a fictional persona and a fictional product.

Persona

Mrs. Murray is an 82-year-old widowed female living alone in an apartment. She takes medication for blood pressure, has arthritis, and some balance problems. Over the last month she has fallen once a week. So far, when she fell, twice she was able to get up by herself, and the third time she was able to drag herself to the phone to call her daughter. Her daughter lives at the other end of town and takes about 30 minutes to reach Mrs. Murray's home by car.

AgeTech

FallsAlerts is an AgeTech company that produces home sensors. FallsAlerts sensor data are collected by a home-installed hub and the information is transmitted to the cloud. Using cloud computing, algorithms determine the probability that a fall has happened in the home. If the algorithm assesses the data as a high likelihood that a fall has occurred, the software sends an urgent message to a person's phone. It could be the phone of the older adult themselves, an informal caregiver (family member, friend, neighbour), or a formal caregiver (home care nurse, doctor's office).

Ethical Considerations

This report will initially focus on the ethical considerations for the system and through this analysis some of the policy- and legal- related issues will necessarily surface. The primary focus of this discussion will be on the aging adult in which the AgeTech system is supporting, but it will also consider others (e.g. care partners, health care providers) as they may also be involved with the system.

Beneficence

The principle of beneficence requires that a Supportive Smart Home system benefit the welfare/well-being of the aging adult. An AgeTech system provides the possibility to benefit the aging adult by supporting their independence in physical, cognitive, emotional, or social areas. This leads to an important question: Will the AgeTech benefit a care partner equally or more than the participant? In the case of Mrs. Murray, the technology is designed to get her help as quickly as possible after her fall, with the goal of reducing morbidity. However, Mrs. Murray may not want to have technology "watching her mobility" in her home, because it makes her feel "even older." Yet, because of her last three falls, her daughter is worried, and would be reassured if her mom had the FallsAlerts system in her apartment. In this case, if the system is installed, is it really a benefit to Mrs. Murray?

Nonmaleficence

The principle of nonmaleficence requires that AgeTech not harm (side effects, unintended consequences) the aging adult. This may appear obvious, but nonmalefience requires that we examine the design of these systems at a much deeper level, one which considers how the technology could potentially cause harm physically, cognitively, emotionally or socially. For example, a wire connecting the system could be a tripping hazard, or a smart speaker using a synthetic voice could scare an older adult. As mentioned, visible technology aids (e.g. walkers) can be equated with loss of autonomy, leading to embarrassment in their use. If the FallsAlerts system uses motion sensors, which have small red lights that blink when there is motion in the room, Mrs. Murray may be embarrassed if her friends ask her about the blinking lights. In turn, this could lead to her decreasing social activities in her home so no one else will see her "assistive device." If Mrs. Murray stops seeing her friends would this not be harmful?

Autonomy

Autonomy would refer to the aging adult's ability to make an informed, uncoerced decision in the use of AgeTech to support their independence and/or reduce risks they are concerned about. Many older adults think AgeTech is great for someone they know, but they won't need it for many more years themselves. The reality is AgeTech can support the care partners as well. This may lead to a conflict between the aging adult choosing the amount of risk they are willing to accept, and their care partner wanting them to be safe. In the case of Mrs. Murray, there are several areas of autonomy which can be considered. First, the autonomy to make decisions. In principle, assuming Mrs. Murray has no cognitive impairment, it would be up to her alone to decide to sign up for FallsAlerts. Of course, she could choose to involve her daughter in the decision-making as well. Secondly, if we consider autonomy in the larger sense, then autonomy might mean her ability to decide to remain living in her apartment. If she were to fall and did not have the system in place, she may remain helpless on the floor for hours. This could lead to muscle breakdown, which could then result in her not being able to return home after receiving care, and ultimately, a loss of autonomy. Consequently, Mrs. Murray might give up some autonomy in terms of a monitoring presence in her home, in exchange for the increased autonomy that comes from living independently in her apartment for a longer time; a choice that the AgeTech makes possible.

Informed Consent and Capacity

A core principle in the use of any AgeTech, is that the aging adult purchasing/using the system, has a complete understanding of its potential benefits and potential negative effects. This information is required to make an informed decision (i.e. informed consent). All technology is vulnerable to security breaches; hence, the aging adult needs to understand and consider the potential for loss of privacy when using AgeTech, in addition to the benefit(s) the system provides. This leads to questions surrounding how system providers communicate these risks to purchasers/users. Anyone who has tried to communicate potential side effects of medication to an older adult will understand the challenges of balancing useful information with over-selling a product and under-emphasizing possible negative outcomes. In the case of Mrs. Murray, how does one communicate the balance between (1) the chance of loss of private information (depending on type of sensor) with (2) the potential medium-term benefits to physical health?

Central to any decision surrounding AgeTech should be the aging adult's right to make their own informed decision on the use or non-use of a solution. Capacity is rarely an "all" or "nothing" situation where an aging adult goes from being fully capable of making informed decisions to totally incapable. Capacity to make informed decisions typically declines slowly through the effects of illness or aging. How does one assess ability to make decisions for oneself regarding technology? How much of an understanding of technology does one need to be considered capable? If the person is incapable to consent, there remains the question of the ability to provide assent. How does one handle the case if Mrs. Murray is not able to make a decision and her daughter consents to the installation of the FallsAlerts system. Yet every time the installer comes to her house, she refuses to let the "strangers" in? In this context would it be ethical to take her to lunch and have small, almost invisible sensors installed while she is away?

Privacy

Privacy can be defined as the ability of an individual to withhold information about themselves from others. In the case of AgeTech, privacy could include the aging adult not allowing care partners or even healthcare providers to have access to Supportive Smart Home data. This suggests AgeTech be designed in a way that allows the aging adult to easily determine what information is shared with others. This issue is complicated, for example, by the fact that different types of sensors can provide different levels of information. A simple door sensor, which can only indicate if a door is open or closed, will only create a "loss of privacy" if the information transmitted includes a home address and

a location of the sensor – which is not usually the case. This is in stark contrast to moving images transmitted from a video camera deployed at the front door to see who enters and exits the home.

Honesty

Honesty has been associated with integrity, truthfulness, and straightforwardness, while being the opposite of lying and cheating. For AgeTech, this directly focuses on the paradox between a need/desire to "sell" an intervention and an ethical obligation to be honest about the benefits and risks of the intervention. Honesty brings together many of the previously discussed ethical aspects, as it forces open and honest discourse on the benefits and risks of an intervention, and thereby allows the aging adult to make their own decision on a system. Honesty provides the baseline from which the aging adult can balance their understanding of the benefit(s) and reduced risks the system can provide them along with the new risks associated with the technology itself. In the case of Mrs. Murray, how does one balance (1) selling the risks of falls being undetected and the older adult not being able to get up from the floor, with (2) the risk of strangers being able to obtain private information by hacking into the AgeTech system?

Trade-off

The concept of 'trade-off' can be extrapolated using the notion that you can only spend $100 once. If you buy a new shirt, that money can't be used for food, rent, or other clothing. In the personal decisions around the use of AgeTech by older adults living off a small pension, the decision may come down to: Which do I pay for – the monthly subscription to AgeTech or the co-payment for my medication? The trade-off can also be between domains: for instance, giving up some aspects of privacy (my daughter will be notified if I fall) in return for gains in medium-term independence (I will be helped sooner after a fall and will be able to remain at home for longer).

Data Ownership

Identifiable data at the individual level

When a system is installed, data collected can provide highly personal and potentially rich knowledge about the activity and well-being of the aging adult. The aging adult needs to have direct ability to control and manage who is able to see information (care partners, healthcare providers) and control what information those individuals are able to see (complete data, subsets, highly summarized, etc.). This challenge is now incumbent on the providers of AgeTech to make these features available and easy to use.

Databases, such as the ICES (formerly Institute for Clinical Evaluative Sciences) database of Ontario's health-related data (healthcare system use), have allowed researchers to study health system use by the population. The data collected by AgeTech systems could enable a new domain of research, both using the new database alone and using it in conjunction with the health system use data. The benefits of this new research are difficult to quantify and predict in advance, but it is clear that the users of AgeTech need to be able to manage if and how their data is used.

Policy Considerations

Potential benefits of AgeTech systems should not be limited to only the residents of urban areas or those with higher socio-economic status. Meaning, considerations on the adoption of AgeTech, needs also consider how these solutions can and should benefit all demographics of our society.

Justice (social & procedural)

At the core of this principal, is 'people receive what they deserve;' which may include equitable distribution of resources (social) and fair and honest approaches to an intervention (procedural). Considering AgeTech, social justice includes the ability of the AgeTech solution(s) to be accessible to anyone that needs it. This poses problems when the AgeTech solution is cost prohibitive to people with low income or in circumstances where the technology requires high-speed internet access which are not widely available in some rural and Northern communities. There also needs to be considerations placed on AgeTech solutions which are culturally appropriate for First Nations people and immigrants.

Who Pays for AgeTech?

As an extension to the above social justice matters, an important question arises: When and how will AgeTech fit within publicly funded healthcare, if at all? AgeTech can help a person age in place and reduce the burden on the health system, resulting in a benefit to society in addition to the aging adult. AgeTech can also reduce the burden placed on the care partners, hence improving their well-being through reduced stress. Additionally, if the care partner is working, this increased well-being allows them to continue working and contributing to the family income and overall economy. AgeTech would then potentially reduce demands on the public health system – raising the question:

Should it be part of the public payor system? This is especially important, as a public payor system could address concerns over inequitable access to the technology because of cost.

Automated Health Data

If an AgeTech system provides well-being assessments on the aging adult to healthcare providers, this raises both a technical and policy related challenge. If we have thousands of older adults generating well-being data in their homes that is shared with the members of their healthcare team, already busy team members could be flooded with patient data. This becomes a needle in the haystack problem where the data from the massive set of aging adults who are otherwise stable needs to be processed to find the one person with issues. A major technical challenge is how to process this new well-being information to find the significant events that need to be highlighted to the healthcare team. These systems will likely not be perfect and healthcare providers will need additional time to process this new information. This leads to concerns regarding the accountability for an AgeTech system's processing of errors and for the healthcare teams required to review AgeTech reports.

Legal Considerations
Privacy and Privacy Law

Canada has highly differing legal frameworks for privacy: federally and within each province/territory. These include varying privacy considerations for "Health/Medical data". One of the challenges for AgeTech is that the data/knowledge within the system may or may not be "Health/Medical data". For example, a smart home system used for home security is clearly not "Health/Medical data", but, the same sensors and system being used to measure residents' activity levels leading to measures of well-being, is one step closer to "Health/Medical data". If the system now includes more "personal" measures, such as toilet use or measures of health events such as apnea, or heart rate, this data comes even closer to "Health/Medical data" and subject to the relevant provisions of information privacy, especially for information shared with the healthcare team. Essentially, we are left with the question: When does AgeTech data become Health/Medical data?

Is AgeTech a Medical Device?

There are clear regulations that govern medical devices, but, building on the previous discussion, the key question is whether some AgeTech solutions are medical devices, or even within the AgeTech solution, what aspects are considered medical devices? We see this case already, where a fingertip pulse oximeter purchased from a pharmacy is considered a medical device, yet a watch or smart phone app doing the same technical assessment is not considered a medical device, but rather, is marketed as a "fitness monitor". Therefore, as AgeTech systems evolve and provide more complex assessments of well-being, the line between these two cases needs to be clear as registration and compliance as a medical device carries both incremental cost for this regulatory requirement and also a higher standard for the accuracy of the assessment done by the device.

Summary

The Supportive Smart Home of the future has massive potential to enable all of us to live in our homes as we age and possibly help all of us as we become aging adults. It can provide us with the option to use systems to manage the risks to our well-being and reduce the burden we place on our families. AgeTech systems have the potential to delay entry to institutional care and support us in a more independent and active lifestyle. We are now seeing early examples entering the commercial marketplace from small and large technology providers.

These systems provide new options, but they are not without their challenges; many of these systems introduce new concepts or models that are beyond the previously established ethical, legal and policy frameworks. Essentially, work needs to be done to ensure that these frameworks evolve to encapsulate new AgeTech challenges.

Acknowledgements

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