Featured Article

Ethical adoption: A new imperative in the development of technology for dementia

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Abstract

Introduction: Technology interventions are showing promise to assist persons with dementia and their carers. However, low adoption rates for these technologies and ethical considerations have impeded the realization of their full potential.

Methods: Building on recent evidence and an iterative framework development process, we propose the concept of "ethical adoption": the deep integration of ethical principles into the design, development, deployment, and usage of technology.

Results: Ethical adoption is founded on five pillars, supported by empirical evidence: (1) inclusive participatory design; (2) emotional alignment; (3) adoption modelling; (4) ethical standards assessment; and (5) education and training. To close the gap between adoption research, ethics and practice, we propose a set of 18 practical recommendations based on these ethical adoption pillars.

Discussion: Through the implementation of these recommendations, researchers and technology developers alike will benefit from evidence-informed guidance to ensure their solution is adopted in a way that maximizes the benefits to people with dementia and their carers while minimizing possible harm.

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1. Introduction

In recent years, there has been much interest in the use of technology solutions to assist with symptom management and maintenance or improvement in quality of life for older adults with dementia and their carers. Based on the current literature, seven broad overlapping categories of technology-based solutions are currently available: (1) cognitive aids [1,2]; (2) care robots [3]; (3) physiological sensors [4]; (4) environmental sensors [5]; (5) surveillance devices [6]; (6) cognitive engagement and monitoring systems [7]; and (7) integrated systems, which draw data from a network of heterogeneous inputs from the previous categories and apply artificial intelligence to provide supervision, guidance, and feedback to users [8,9].

Taken together, these technologies are promising in their potential to compensate for cognitive and physical limitations of persons with dementia, reduce carer burden, promote independence and autonomy, manage safety risks in the environment, and reduce stress. Nevertheless, despite these potential benefits and significant development efforts over the last decade, assistive technologies for dementia remain mostly in the realm of research. A major challenge in the commercialization and use of these solutions is low technology adoption rates, despite concerted efforts in this area [10]. Recent evidence suggests technology adoption is closely linked to ethical considerations. The intersection of adoption and ethics can occur at a high level, for example,

when low adoption is due to a misalignment between the needs or values of end users and the benefits of technology solutions [11]. In other cases, specific ethics-related concerns such as conflict of interest or privacy issues impede widespread adoption.

Although ethical issues in technology for people with dementia have been extensively reviewed [12], it can be difficult for technology developers and researchers to implement ethics principles without specific practical guidance within the context of technology-based solutions for dementia [13]. To close the gap between adoption research, ethics, and practice, here we introduce the concept of "ethical adoption," which we define as the deep integration of ethical principles into the design, development, deployment, ongoing usage, and management of technology. Ethical adoption is aimed specifically at technology for dementia and as such is grounded in the theoretical foundation of the principles of biomedical ethics, the standard theoretical framework used to analyze issues at the intersection of ethics and medicine. In this article, we first explore the barriers and facilitators of technology adoption, then describe five pillars of ethical adoption and propose a set of 18 stepwise, practical, and evidence-based recommendations for the development of technology solutions for dementia research and care.

1.1. Determinants of technology adoption

When examining adoption and acceptance of assistive technologies, researchers often profile users based on their engagement or lack thereof with the technology [14,15]. This results in a matrix of adoption, describing whether the person will use the technology based on two factors: whether the technology is usable by the participant and whether they see a perceived utility in the solution.

It is becoming increasingly evident, however, that the likelihood of adoption is much more complex and multifaceted in nature than is described by this two-factor model. Perceptions of usability and usefulness may change over time as individuals change. More importantly, however, the likelihood of adoption spans factors that go beyond the physical design of the solution and individual characteristics of the person with dementia and their carer and also includes social settings and the channels through which the technology is delivered [16].

Several groups have examined factors that act as facilitators or determinants of technology adoption. In a 2014 systematic literature review, Peek et al. [17] found that technology acceptance, which is closely related to adoption, is influenced by 27 factors across six themes: concerns, expected benefits, need, availability of alternatives, social influence, and priorities. Using survey methodology, Lee and Coughlin [18] identified 10 key factors that influence technology adoption (Table 1), with some overlap with Peek et al.'s list.

Table 1
Factors that are considered as facilitators or determinants of technology adoption [18]

Factor	Description
Usefulness	Perception of usefulness and potential benefit
Usability	Perception of user friendliness and ease of learning
Affordability	Perception of potential cost savings
Accessibility	Knowledge of existence and availability in the market
Technical support	Availability and quality of professional assistance throughout use
Social support	Support from family, peers, and community
Emotion	Perception of emotional and psychological benefits
Independence	Perception of social visibility or how a technology makes them look to others
Experience	Relevance with their prior experiences and interactions
Confidence	Empowerment without anxiety or intimidation

In support of these factors, Cook et al. [10] examined the barriers and facilitators to adopting and continuing to use telehealth and telecare solutions by older adults. When analyzing the decision to use assistive technologies, the authors identified four themes: "acceptance of old age/health condition," "previous knowledge and awareness of the equipment available," "perceived usefulness of equipment," and "attitudes and perceptions toward assistive technology." When considering the continued engagement and usage of assistive technologies, four additional and related themes were identified; "usability," "usefulness of equipment," "functionality of equipment," and "threat to identity and independence." The authors highlighted the need for better communication with technology end users and availability of detailed information about the equipment. In addition, "hands-on" demonstrations with a discussion of patient expectations on the support they will need through using the service were deemed critical to support and encourage both adoption and sustained usage.

1.2. Ethical considerations

Technology adoption work has yielded key insights into the factors that promote and deter the adoption, widespread deployment, and sustained use of technology by older adults with and without dementia and their carers. Missing from this endeavor, however, has been the inclusion of ethics as a critical focus point in technology adoption. Technology adoption and technology ethics share many common elements, such as the consideration of risk versus benefit, the possibility of harm (e.g., privacy breach), and social pressure. As such, practical ethical considerations aimed at promoting adoption must inform the delicate balance between the interests of technology users and technology providers. A useful theoretical framework to apply in this context is the four principles of biomedical ethics, namely autonomy, beneficence, nonmaleficence, and justice [19]. Briefly, autonomy refers to the concept of making reasoned, informed decisions for ourselves. Beneficence considers the balance of benefits and risks of a given intervention and the

imperative to benefit the end user. Nonmaleficence relates to the avoidance of causing harm, and justice refers to the fair distribution of benefits, risks, and costs of the intervention across all end users [19]. Here, we build on previous work in technology adoption and on the theoretical foundation of the principles of biomedical ethics to introduce the concept of "ethical adoption" and describe its five pillars: (1) inclusive participatory design; (2) emotional alignment; (3) adoption modeling; (4) ethical standards assessment; and (5) education and training. The five pillars of ethical adoption are conceptualized as spanning the principles of biomedical ethics such that all principles are adhered to. Table 2 shows the relationship matrix giving the key features of each ethical adoption pillar as it relates to the principles of biomedical ethics. In the remainder of this article, we discuss each of the five pillars of ethical adoption in more detail, showing how these key features arise; and deliver a set of practical recommendations for the development of technology for dementia-related applications. As the five pillars are distributed across the process of technology development, from early design of technology solutions (e.g., inclusive participatory design) through product launch, testing, and use (e.g., education and training), the application of these recommendations should be considered as a stepwise system for researchers and technology developers to follow.

2. Five pillars of ethical adoption

2.1. Pillar 1: Inclusive participatory design

Key ethical features: ensures benefit to end users (beneficence), promotes engagement and meaningful self-direction (autonomy), and ensures usability across the population (justice).

Recommendation 1.1: Use a participatory, user-led design.

Improvements in technology adoption should be driven by the investigation of specific user needs. When asking end users to review or inform technology development, it is critical to ensure that the primary user has the capability to express his or her opinion in a reflected and autonomous manner. Researchers must also consider the bias in carers' ability to separate their needs from those of the primary users. To address these challenges, participatory design, the process of building technology that involves end users at every stage of the development process, can be used to assist with the early stages of design and provide a supportive environment in which participants feel included, engaged, and confident to provide critical feedback [20]. The utilization of a participatory approach is essential in assuring that solutions are usable, intuitive, meet the needs and expectations of the user, and consequently are more highly accepted. End-user input can assist in establishing the risk-benefit balance of a solution with an inherent ethical concern, such as surveillance technology to prevent falls or wandering. In this case example, participatory design can inform whether the right to privacy and dignity can be justifiably overridden for the sake of promoting health or safety and place boundaries on this trade-off. End-user input can also assist in directly addressing operational ethical dilemmas, for example, by providing researchers and developers insights on preferred mechanisms to provide consent as capacity declines.

Various participatory design methods and techniques are well known and widely used, both in academia and in the research community [21].

Recommendation 1.2: Consider the limitations of older adults (vision, hearing, motor, varying levels of computer knowledge) in design of visuals, instructions, and overall usability.

Recommendation 1.3: Consider cultural differences in technology adoption and use.

Conventional participatory design methods and techniques may be tailored to account for a diversity of user characteristics, languages, community cultures, environments, and motivations [22]. To ensure representative results are obtained, researchers should adapt participatory design methods to ensure they are relevant and feasible in the context of their target population, with close attention to

Table 2
The matrix of relationships between the five pillars of ethical adoption and the four principles of biomedical ethics

Ethical adoption pillars	Principles of biomedical ethics			
	Beneficence	Nonmaleficence	Justice	Autonomy
Participatory design	Ensures benefit to end users		Ensures usability across the population	Promotes engagement, meaningful self-direction
Emotional alignment		Minimizes emotional harms	Minimizes bias	
Adoption modeling	Reduces barriers to benefiting from solution		Enables outreach to specific populations	
Standards assessment		Minimizes overadoption Minimizes harms related to privacy and conflict of interest		Promotes informed use
Training and education	Ensures solution is used to full potential		Removes familiarity with technology as a prerequisite	Promotes independent use and understanding

cultural differences in engagement with technology. In particular, researchers must consider the needs and desires of people who are cared for in the community, many of whom require care for two or more different conditions and have complex care needs [23]. Developing multimodal solutions (in which multiple communication modes are used in a single device) is particularly important, given that the acuity of all sensory modalities declines with age. Assistive technology systems must be able to accommodate such holistic care plans and the wide range of formal and informal carers that manage them [24].

Recommendation 1.4: Design to deliver direct benefit to all potential users (persons with dementia, carers, health care professionals) and ensure this benefit is clear to all.

In addition to the complex care and functional needs of the primary user, assistive technologies must account for the needs of multiple stakeholders. These include direct end users and may also include family, friends, formal and informal carers, and health care professionals. For example, a system might remind all members of the household of an appointment or it might remind the user themselves to take their medication. In this example, stakeholders are defined as those who can directly or indirectly specify requirements and add, delete, or change the information the system produces. Assistive technologies should identify clear pathways for resolving any conflicts that might occur from involvement of several stakeholders with different needs and motivations. For example, if a user mutes or misses a reminder, it may be necessary to escalate a reminder to another stakeholder. These pathways must include explicit mechanisms for seeking user input and validating the selected options [24]. Assistive technologies for dementia should therefore use a participatory approach to incorporate needs and preferences and allow these preferences to be regularly reviewed, stored, and viewed by all stakeholders. To accommodate this approach, assistive technologies need to be highly modular, flexible, and easy to configure [24].

Recommendation 1.5: Allow for personalization of the solution to create a sense of ownership.

Providing individualized support and personalization of solutions, taking into account physical impairments (hearing, sight, cognition, dexterity), social and cultural differences, and technological experience, can ensure the full integration of technology within a person's routine [25]. This has been further acknowledged as a key driver of technology use in dementia [26,27]. It has also been noted that a standardized approach to both the design and delivery of general assistive technologies failed to account for individual's lived experiences, leading users and carers to reconfigure technologies to meet individual need [25,28].

2.2. Pillar 2: Emotional alignment

Key features: Minimizes emotional harms (nonmaleficence) and minimizes bias (justice).

Recommendation 2.1: When appropriate, ensure technology has inbuilt model of human emotion, including how to recognize emotion, how to track emotion dynamics, and how to map emotional signals to modulations of potential actions of the system.

Once technology solutions have been established to meet existing needs and lead to benefits through the application of recommendations under pillar 1, technology developers and researchers should consider a cornerstone of human interaction: emotional alignment [29]. Humans seek interactions in which their sense of self on an emotional level is respected and valued and conversely avoid those in which their sense of self is disrespected and devalued. For persons with dementia, this alignment is challenging due to an inability to maintain a consistent presentation of their self within a situational context [30]. Emotional signals from others are no longer perceived as consistent with a more uncertain and fluctuating self, and the resulting misalignment leads to uncertainty and stress. To promote adoption, emotional factors must be at the forefront of technology development otherwise technological solutions may be viewed with suspicion and mistrust and will be discarded more readily. As one example, prompts delivered in the context of assistive technologies for the completion of activities of daily living should match the emotional tone of the end user to minimize harms such as anxiety and ensure a positive relationship with the technology. As one example of methodology, identity modeling has been used successfully to integrate emotional alignment in health care technology [29,30].

Recommendation 2.2: Ensure technology does not propagate implicit biases through the inclusion of emotional modeling.

Recent work in affective computing has investigated how to best develop intelligent technologies that are emotionally aligned with end users. However, emotional alignment of users with technology can lead to the propagation of implicit biases. As one example, many mobile assistants (e.g., SIRI) can be viewed as promoting females in submissive roles. Without proper modeling of emotion, these biases can become a mainstay of applications that handle emotional situations. Therefore, careful affective modeling and reasonable checks and balances must be used to ensure that these biases are not enhanced by assistive technologies.

Moving forward, the modeling of affect in computerized intelligent systems for dementia applications will play an increasingly important role in ensuring assistive technologies align with the values of end users and with ethical principles in general. Many application areas (e.g., medical diagnosis, online medical information filters [31]) in health care broadly and in assistive technology for dementia specifically will benefit from advances in affective computing, as society moves toward a sociotechnical environment in which humans and technological artifacts play increasingly equal yet complementary roles.

2.3. Pillar 3: Adoption modeling

Key features: Reduces barriers to benefitting from intervention (beneficence) and enables outreach to specific populations (justice).

Recommendation 3.1: Understand factors that influence decisions and rights to disengage.

Adoption modeling has been put forward as a method to gain a more in-depth understanding of the factors associated with technology adoption [32]. An adoption model defines a function from a set of features that can be extracted from a technology-enhanced environment to a prediction of whether a user will adopt a technology or not in the future. Evidence suggests important benefits for this approach, most notably from having the ability to use the adoption models as screening tools for those who will or will not be able to use the technological solution [33]. Regression-based models have demonstrated the ability to identify, with high levels of precision, individuals who are likely to adopt technology-based solutions [15]. Input parameters to these models have ranged from details relating to education, living arrangements, prior technology experience, and medical history [15]. Data obtained from these models have allowed the characterization of end users who are less likely to adopt technology, thereby informing targeted efforts to reach these specific end users and promoting inclusivity in technology adoption, which aligns with the ethical principle of justice. For example, technology adoption modeling for a specific solution may uncover relationships between adoption of the emerging technology and socioeconomic status, which can in turn inform health economics assessments for this solution and drive innovative and targeted means to reduce costs. Overall, this additional knowledge-driven perspective has the potential to assist with the overarching aim of making models transferable to different users and applications.

Recommendation 3.2: Consider evidence from adoption modeling when targeting intervention to specific end-user groups.

The adoption models developed will need to be updated to reflect (1) changes in a user's behavior over time; (2) changes in a user's level of technology familiarity over time; and (3) application areas across technology types and health conditions. With regard to dementia specifically, models will need to be dynamic to be responsive to the changing behavior of users as their disease progresses. Over the course of the disease, dementia can cause changes in personality, cognition, and ability to engage in social interactions, all of which need to be accommodated for a successful, inclusive, and ethical technology adoption process. For example, a technology must be removed from use when a person with dementia ceases to be able to use it, such that the stress of not being able to benefit from or use it is reduced. A related, equally difficult challenge is how to integrate changes in a user's level of technology familiarity. Although many efforts have been undertaken within this domain broadly, little work has been directed toward development of transferability functions to allow models to be deployed in the context of more than one technology-based solution. This introduces a limitation in the extent to which adoption modeling can be used outside the specific use case for which a given model has been designed.

As an extension to adoption, the modeling process should be broadened to support users after the point at which they have decided to adopt the solution. This falls in the realm of behavioral science where goal-motivated interventions are required to motivate a continued usage pattern and avoid deteriorations in usage of the target solution [34]. As such, the ability to detect a decline in usage and intervene when possible is the key.

Advances in adoption modeling hold the potential to yield critical evidence to inform the promotion of adoption for diverse end-user groups, with a focus on inclusivity and justice. Future work in this field will allow for an in-depth characterization of technology users over time as well as within the use of a specific application, yielding further insight for the customization of user experience and the promotion of ethical adoption.

2.4. Pillar 4: Ethical standards assessment

Key features: Minimizes overadoption, minimizes harms related to privacy, conflict of interest (nonmaleficence) and promotes informed use (autonomy).

The development of technology for dementia must include the consideration and evaluation of key standard ethical factors surrounding privacy, confidentiality, and informed consent before their launch and continued use. Most academic research is bound by ethical requirements from Institutional Research Ethics Boards, which govern aspects of the research process such as the use of human subjects and oversee adherence to norms and requirements around recruitment methods, privacy and confidentiality of participant information, and informed consent procedures. Although these requirements are critical during the development and testing phases of new technologies, developers and researchers must think beyond what is strictly required by Institutional Research Ethics Boards and consider the broader ethical dimensions of the finished products and the impact of the technology on eventual end users.

Recommendation 4.1: Include a clear, effective, and tested consent mechanism.

Informed consent is critical in ensuring that users fully understand the benefits and risks of technology solutions. Obtaining meaningful consent has been identified as a problematic process in existing technologies [35], and cognitive impairment adds complexity to this endeavor. When designing the informed consent process for emerging technologies, efforts should be made to involve end users, including persons with dementia, as much as possible. When end users lack capacity to consent and surrogate consent must be obtained, ensuring the best interests of the person with dementia should be the priority. This can be challenging in the case of surveillance technologies, for example, where a balance must be struck between preserving autonomy and reducing stigma on the one hand and ensuring safety on the other [34,36–38]. Inclusive participatory design (pillar 1) can inform end-user preferences such as methods for obtaining consent (e.g., one time vs ongoing). The standard assessment phase of technology development should include testing of the effectiveness of the consent process and the inclusion of mechanisms to address the issue of capacity when applicable.

Recommendation 4.2: Meet the highest standards for the protection of users' personal information.

The issue of privacy has been raised with a range of technology solutions, including telecare interventions and both portable and environmental *in situ* health monitoring [36,37]. Design recommendations have been put forward to enhance user independence and privacy [36], such as encryption and secure storage [37]. As the market for these technologies expands and an increasing number of commercial options become available, it is critical to ensure that the promotion of adoption, for example, by designing simple, uncluttered user interfaces, or by harnessing cloud storage, is not carried out at the cost of adherence to ethical norms.

Recommendation 4.3: Clearly state the funding sources and real and perceived conflicts of interest.

Ethical assessments of at-home technologies, such as online resources about dementia, have been conducted with concerning results [38–40]. Freely accessible online self-assessments for dementia, for example, have been shown to fail to adhere to standard ethical norms such as disclosure of conflicts of interest, informed consent, and the safeguard of privacy and confidentiality [39]. Predatory marketing strategies are often disguised as health information or services, a critical concern given that older adults experience more difficulty in discerning trustworthy online information and may be more susceptible to fraud [35,41]. Technology developers and researchers should ensure transparency as a guiding principle in all communications about their solution.

Recommendation 4.4: Ensure claims about the solution are accurate and clearly state the limitations of the solution.

Recommendation 4.5: Ensure all information within the solution is evidence based.

Low-quality technology solutions or inaccurate claims about the benefits of these solutions can have a significant impact on health care variables, including the patient-physician relationship [42] and the demand for health care services [43]. Furthermore, some solutions such as online self-assessments or interactive online resources may directly impact the health of end-users, for example, by fueling health anxiety [44] or through complications from self-medication with substances obtained online [45]. Unfounded claims about the benefits of technology for dementia or about the evidence supporting these benefits have ethical implications not only for the end users but also the developers, as was seen in recent Federal Trade Commission rulings on unfounded claims about the benefits of mobile brain-training applications [46]. As older adults have been shown to be more optimistic about certain types of technology solutions than their younger counterparts [47], technology researchers and developers should be mindful to ground their solutions in empirical evidence and avoid misleading claims about potential benefits to ensure end-user expectations match outcomes.

Recommendation 4.6: Avoid design features that encourage adoption or use beyond what is required to derive maximum benefit or in a way that would impair well-being across other domains of life (e.g., social interaction, exercise).

A large variety of online resources that are not aimed specifically at older adults but are used by this demographic, such as popular social networking sites and mobile games, are designed to elicit compulsive and repetitive behaviors, with features such as variable rewards and infinite scrolling. These features can lead to adoption that is overly successful, by engaging users beyond what is appropriate to derive maximum benefit from the technology. Efforts to design technology in a way that promotes adoption must not supersede the development of an ethical product.

Taken together, these ethical considerations highlight the need for high-quality standards and the promotion of ethical adoption of everyday technologies ranging in complexity from simple websites containing health information to pervasive or ubiquitous health monitoring systems.

2.5. Pillar 5: Education and training

Key features: Ensures intervention is used to full potential (beneficence) and removes familiarity with technology as a prerequisite (justice).

Recommendation 5.1: Consider using familiar objects (e.g., clocks, mirrors) that are unobtrusive and minimize the need for training.

Previous research suggests older adults are willing to use advances in technology in many cases, particularly when they perceive its potential benefit. In addition, it has been found that people with dementia can continue to use well-known everyday technologies (TV, phone, etc.) with simple adaptions to compensate for memory deficits [26].

Recommendation 5.2: Optimize options for direct support in the use or maintenance of a technology.

Many older adults report a lack of knowledge with regard to emerging technologies, both in terms of what technologies are available and how to use them [25]. When coupled with interfaces that have been inadequately designed, this can lead to reduced interaction and elevate existing feelings of technical isolation and inadequacy [48]. In addition, many of these assistive technologies still suffer from stigma attached to their use. Therefore, care must be taken to ensure the technologies appropriate to the needs of the person and are designed effectively to negate feelings of inadequacy. This can also be achieved through the use of effective training and communication strategies to highlight the benefits of the technology.

Boyd et al. [49] demonstrated the potential of training older people to use online social networking to help alleviate the problem of social isolation. By providing special training and consideration to usability in technology design, tailored specifically to the needs of the older user, the authors found that it was possible to increase adoption of the solution.

Where appropriate, training and education initiatives should be supplemented by a technical support service, to provide assistance for purchase, installation, learning, operation, and maintenance [18].

Recommendation 5.3: Create opportunities for the development of social ties between technology users.

In addition, social support is essential to overcome barriers of adoption. Key stakeholders within older adult's social circles, including family, friends, and community members play an important role in advocating technology, fostering improved awareness of technology and its benefits, as well as promoting use and providing guidance and assistance [Lee Coughlin]. Facilitating better communication between these groups is essential in both initiating and sustaining adoption of assistive technology.

These findings, along with those of others [49], support education and training strategies both as key factors in technology adoption and as ethical imperatives to promote autonomy and informed decision-making in the adoption of assistive technology.

3. Recommendations and future directions

Structured and unstructured instruments have been developed to assist with the ethical evaluation of health-related technologies, for example, as part of health

technology assessments [50]. However, these methods are often limited in scope and their interpretation and application remain variable [50]. Other initiatives have attempted to integrate ethical evaluation together with technology assessment, to address the issue of health technology assessment in itself being a value-laden process [51]. These types of instruments can be useful when evaluating existing technologies but offer little practical guidance specifically for technology developers and researchers.

Outside the context of formal health technology assessments, practical instruments have been designed to evaluate the quality of online health information, many of which incorporate some ethical criteria such as the presence of conflict of interest [38,50–53]. Nevertheless, both quality evaluation tools and the ethical criteria checklists described previously are limited in their scope of application and do not capture all features that are unique to technologies for dementia. As such, there is a need for a set of simple guidelines that can be easily applied to a broad range of technologies for people with dementia and their carers.

In light of the evidence across all five pillars of ethical adoption and to close the gap between adoption research, ethics, and practice, we summarize in Table 3 the set of 18 recommendations to guide the development of technology for dementia with successful and ethical adoption as an end goal. These recommendations span the timeline of the technology development process, and their application should be considered as a stepwise system. In the earliest stages of design, technology researchers and developers should consider pillar 1 recommendations and include end users in a participatory fashion to ensure the solutions meet existing needs and lead to measurable benefits. Once the solution has taken form, considering recommendations under Pillar 2 will ensure the technology is delivered in a way that aligns with end-user values and minimizes potential harms. Once benefits and harms have been addressed, following recommendations under pillar 3 will assist in promoting adoption. Before launch, a careful review of ethical standards such as informed consent (pillar 4) is necessary. Finally, recommendations under pillar 5 are critical during user testing, launch, and continued use to ensure end users are adequately trained and supported in using the solution. Applied as a whole, the set of ethical adoption recommendations has the potential to resolve key issues at the intersection of adoption and ethics through multiple channels, ensuring redundancy in addressing challenges and the maximization of benefits for end users. Taking informed consent as an example, the inclusive participatory design can inform the preferred modality of consent, emotional alignment can ensure the consent is delivered in a way that aligns with end-user values, and standard assessment can ensure the consent process is

Table 3
Ethical adoption recommendations

Recommendations			
Number	Pillar	Keywords	Description
1	Inclusive participatory design		
1.1		User engagement	Use a participatory, user-led design
1.2		Usability	Consider the limitations of older adults in design (vision, hearing, motor, varying levels of computer knowledge) of visuals, instructions, and overall usability
1.3		Culture	Consider cultural differences in technology adoption and use
1.4		Benefit	Design to deliver direct benefit to both person with dementia and caregiver and ensure this benefit is clear to both
1.5		Customization	Allow for personalization of the solution to create a sense of ownership
2	Emotional alignment		
2.1		Emotion	Ensure technology has inbuilt model of human emotion, including how to recognize emotion, how to track emotion dynamics, and how to map emotional signals to modulations of potential actions of the system
2.2		Implicit bias	Ensure technology does not propagate implicit biases through the inclusion of emotional modeling
3	Adoption modeling		
3.1		Barriers and facilitators	Understand factors that influence decisions and rights to disengage
3.2		Data	Consider evidence from adoption modeling when targeting intervention to specific end-user groups
4	Ethics		
4.1		Consent	Include a clear, effective, and tested consent mechanism
4.2		Privacy and confidentiality	Meet the highest standards for the protection of users' personal information
4.3		Conflict of interest	Clearly state the funding sources and real and perceived conflict of interest
4.4		Accuracy	Ensure claims about the solution are accurate and clearly state the limitations of the solution
4.5		Evidence	Ensure all information within the solution is evidence based
4.6		Responsible use	Avoid design features that encourage adoption or use beyond what is required to derive maximum benefit or in a way that would impair well-being across other domains of life (e.g., social interaction, exercise)
5	Training and education		
5.1		Intuition	Consider using familiar objects (e.g., clocks, mirrors) that are unobtrusive and minimize the need for training
5.2		Training courses	Optimize options for direct support in the use or maintenance of a technology
5.3		Social support	Create opportunities for the development of social ties between technology users

effective. Thus, ethical adoption allows this challenge to be tackled through multiple channels rather than providing a one-size-fits-all, prescriptive solution that may not be broadly applicable.

Although each of the recommendations in the ethical adoption model is based on empirical evidence, a limitation of the concept is the absence of evidence about the application of the set of recommendations as a whole. Future directions will include the measurement of outcomes as a result of the application of the recommendations in technology development.

Through the implementation of the ethical adoption recommendations at all stages of technology development, researchers and technology developers alike will benefit from evidence-informed guidance to ensure their solution is successfully adopted in a way that maximizes the benefits to people with dementia and their carers while minimizing possible harms and that ensures accessibility to the widest possible range of persons in need and that allows engagement with full determination, comprehension, and consent. This is a difficult equilibrium to achieve, and the ethical adoption recommendations are meant to guide the development of dementia technology toward optimal solutions in the long term.

RESEARCH IN CONTEXT

1. Systematic review: The authors reviewed the literature using academic and medical databases (PubMed, Google Scholar, Cochrane Library, Medline) and identified a lack of practical guidance for the development of technology for dementia specifically to promote adoption.

2. Interpretation: To fill this gap, the authors propose a framework of ethical adoption, based on five pillars supported by recent empirical evidence: (1) inclusive participatory design; (2) emotional alignment; (3) adoption modelling; (4) ethical standards assessment; and (5) education and training.

3. Future directions: Future work will explore the implementation of the framework in diverse technology development contexts (e.g., academia, industry) as well as investigate the impact of the framework on technology adoption and on the balance of benefits and harms of technology applications.

References

[1] Kerssens C, Kumar R, Adams AE, Knott CC, Matalenas L, Sanford JA, et al. Personalized technology to support older adults with and without cognitive impairment living at home. Am J Alzheimers Dis Other Demen 2015;30:85–97.

[2] O'Neill SA, McClean SI, Donnelly MD, Nugent CD, Galway L, Cleland I, et al. Development of a technology adoption and usage prediction tool for assistive technology for people with dementia. Interact Comput 2014;26:169–76.

[3] Robinson H, MacDonald B, Broadbent E. The role of healthcare robots for older people at home: a review. Int J Soc Robot 2014; 6:575–91.

[4] Patel S, Park H, Bonato P, Chan L, Rodgers M. A review of wearable sensors and systems with application in rehabilitation. J Neuroengineering Rehabil 2012;9:21.

[5] Sprint G, Cook DJ, Fritz R, Schmitter-Edgecombe M. Using smart homes to detect and analyze health events. Computer 2016; 49:29–37.

[6] Teipel S, Babiloni C, Hoey J, Kaye J, Kirste T, Burmeister OK. Information and communication technology solutions for outdoor navigation in dementia. Alzheimers Dement 2016;12:695–707.

[7] Owen AM, Hampshire A, Grahn JA, Stenton R, Dajani S, Burns AS, et al. Putting brain training to the test. Nature 2010;465:775–8.

[8] Stavropoulos TG, Meditskos G, Kontopoulos E, Kompatsiaris I. Multi-sensing monitoring and knowledge-driven analysis for dementia assessment. Int J E-Health Med Commun 2015;6:77–92.

[9] Lyons BE, Austin D, Seelye A, Petersen J, Yeargers J, Riley T, et al. Pervasive computing technologies to continuously assess Alzheimer's disease progression and intervention efficacy. Front Aging Neurosci 2015;7.

[10] Cook EJ, Randhawa G, Sharp C, Ali N, Guppy A, Barton G, et al. Exploring the factors that influence the decision to adopt and engage with an integrated assistive telehealth and telecare service in Cambridgeshire, UK: a nested qualitative study of patient "users" and "non-users". BMC Health Serv Res 2016;16:137.

[11] Bharucha AJ, Anand V, Forlizzi J, Dew MA, Reynolds CF, Stevens S, et al. Intelligent assistive technology applications to dementia care: current capabilities, limitations, and future challenges. Am J Geriatr Psychiatry 2009;17:88–104.

[12] Novitzky P, Smeaton AF, Chen C, Irving K, Jacquemard T, O'Brolcháin F, et al. A Review of contemporary work on the ethics of ambient assisted living technologies for people with dementia. Sci Eng Ethics 2015;21:707–65.

[13] Ienca M, Wangmo T, Jotterand F, Kressig RW, Elger B. Ethical design of intelligent assistive technologies for dementia: a descriptive review. Sci Eng Ethics 2017:1–21. https://doi.org/10.1007/s11948-017-9976-1.

[14] Thorpe JR, Rønn-Andersen KVH, Bień P, Özkil AG, Forchhammer BH, Maier AM. Pervasive assistive technology for people with dementia: a UCD case. Healthc Technol Lett 2016; 3:297–302.

[15] Chaurasia P, McClean SI, Nugent CD, Cleland I, Zhang S, Donnelly MP, et al. Modelling assistive technology adoption for people with dementia. J Biomed Inform 2016;63:235–48.

[16] Fritz RL, Corbett CL, Vandermause R, Cook D. The influence of culture on older adults' adoption of smart home monitoring. Gerontechnology 2016;14:146–56.

[17] Peek STM, Wouters EJM, van Hoof J, Luijkx KG, Boeije HR, Vrijhoef HJM. Factors influencing acceptance of technology for aging in place: a systematic review. Int J Med Inf 2014;83:235–48.

[18] Lee C, Coughlin JF. PERSPECTIVE: older adults' adoption of technology: an integrated approach to identifying determinants and barriers. J Prod Innov Manag 2015;32:747–59.

[19] Beauchamp TL, Childress JF. Principles of Biomedical Ethics 2001. New York: Oxford University Press; 2001.

[20] Czarnuch S, Ricciardelli R, Mihailidis A. Predicting the role of assistive technologies in the lives of people with dementia using objective care recipient factors. BMC Geriatr 2016;16.

[21] Stawarz K, Cox AL, Blandford A. Don'T Forget Your Pill!: Designing Effective Medication Reminder Apps That Support Users' Daily Routines. Proc. 32nd Annu. ACM Conf. Hum. Factors Comput. Syst. 2014. New York, NY, USA: ACM; 2014. p. 2269–78

[22] Stojmenova E, Imperl B, Žohar T, Dinevski D. Adapted user-centered design: a strategy for the higher user acceptance of innovative e-Health services. Future Internet 2012;4:776–87.

[23] Hendriks N, Huybrechts L, Wilkinson A, Slegers K. Challenges in Doing Participatory Design With People With Dementia. Proc. 13th Particip. Des. Conf. Short Pap. Ind. Cases Workshop Descr. Dr. Consort. Pap. Keynote Abstr. - Vol. 2 2014. New York, NY, USA: ACM; 2014. p. 33–6.

[24] McGee-Lennon MR, Wolters MK, Brewster S. User-centred Multimodal Reminders for Assistive Living. Proc. SIGCHI Conf. Hum. Factors Comput. Syst. 2011. New York, NY, USA: ACM; 2011. p. 2105–14

[25] Gibson G, Dickinson C, Brittain K, Robinson L. The everyday use of assistive technology by people with dementia and their family carers: a qualitative study. BMC Geriatr 2015;15:89.

[26] Astell AJ, Malone B, Williams G, Hwang F, Ellis MP. Leveraging everyday technology for people living with dementia: a case study. J Assist Technol 2014;8:164–76.

[27] Nygård L, Starkhammar S. The use of everyday technology by people with dementia living alone: mapping out the difficulties. Aging Ment Health 2007;11:144–55.

[28] Greenhalgh T, Wherton J, Sugarhood P, Hinder S, Procter R, Stones R. What matters to older people with assisted living needs? A phenomenological analysis of the use and non-use of telehealth and telecare. Soc Sci Med 2013;93:86–94.

[29] Damasio A. Descartes' Error: Emotion, Reason, and the Human Brain. Reprint edition 2005. London: Penguin Books; 2005.

[30] König A, Francis LE, Joshi J, Robillard JM, Hoey J. Qualitative study of affective identities in dementia patients for the design of

cognitive assistive technologies. J Rehabil Assist Technol Eng 2017;
4:2055668316685038.

[31] Robillard JM, Alhothali A, Varma S, Hoey J. Intelligent and Affectively
Aligned Evaluation of Online Health Information for Older Adults.
Workshop Thirty-First AAAI Conf. Artif. Intell.; 2017.

[32] Renaud K, van Biljon J. Predicting Technology Acceptance and
Adoption by the Elderly: A Qualitative Study. Proc. 2008 Annu. Res.
Conf. South Afr. Inst. Comput. Sci. Inf. Technol. IT Res. Dev. Ctries.
Rid. Wave Technol. 2008. New York, NY, USA: ACM; 2008. p. 210–9

[33] Zhang S, McClean SI, Nugent CD, Donnelly MP, Galway L,
Scotney BW, et al. A predictive model for assistive technology
adoption for people with dementia. IEEE J Biomed Health Inform
2014;18:375–83.

[34] Bhattacherjee A. Understanding information systems continuance: an
expectation-confirmation model. MIS Q 2001;25:351–70.

[35] Castle E, Eisenberger NI, Seeman TE, Moons WG, Boggero IA,
Grinblatt MS, et al. Neural and behavioral bases of age differences
in perceptions of trust. Proc Natl Acad Sci U S A 2012;109:20848–52.

[36] Sorell T, Draper H. Telecare, surveillance, and the welfare state. Am J
Bioeth 2012;12:36–44.

[37] Kang HG, Mahoney DF, Hoenig H, Hirth VA, Bonato P, Hajjar I, et al.
In situ monitoring of health in older adults: technologies and issues.
J Am Geriatr Soc 2010;58:1579–86.

[38] Robillard JM, Feng TL. Health advice in a digital world: quality and
content of online information about the prevention of Alzheimer's
disease. J Alzheimers Dis 2017;55:219–29.

[39] Robillard JM, Illes J, Arcand M, Beattie BL, Hayden S, Lawrence P,
et al. Scientific and ethical features of English-language online tests
for Alzheimer's disease. Alzheimers Dement Diagn Assess Dis Monit
2015;1:281–8.

[40] Palmour N, Vanderbyl BL, Zimmerman E, Gauthier S, Racine E.
Alzheimer's disease dietary supplements in websites. HEC Forum
2013;25:361–82.

[41] Illes J, Kann D, Karetsky K, Letourneau P, Raffin TA, Schraedley-
Desmond P, et al. Advertising, patient decision making, and
self-referral for computed tomographic and magnetic resonance
imaging. Arch Intern Med 2004;164:2415–9.

[42] McMullan M. Patients using the Internet to obtain health information:
how this affects the patient–health professional relationship. Patient
Educ Couns 2006;63:24–8.

[43] Suziedelyte A. How does searching for health information on the
Internet affect individuals' demand for health care services? Soc Sci
Med 2012;75:1828–35.

[44] Muse K, McManus F, Leung C, Meghreblian B, Williams JMG.
Cyberchondriasis: fact or fiction? A preliminary examination of the
relationship between health anxiety and searching for health
information on the Internet. J Anxiety Disord 2012;26:189–96.

[45] Hainer MI, Tsai N, Komura ST, Chiu CL. Fatal hepatorenal failure
associated with hydrazine sulfate. Ann Intern Med 2000;133:877–80.

[46] Charness N, Boot WR. Aging and Information Technology Use:
Potential and Barriers. Curr Dir Psychol Sci 2009;18:253–8.

[47] Boyd K, Nugent C, Donnelly M, Sterritt R, Bond R, Lavery-Bowen L.
EasiSocial: An Innovative Way of Increasing Adoption of Social
Media in Older People. Smart Homes Health Telemat 2014. Cham:
Springer; 2014. p. 21–8.

[48] Hofmann B, Droste S, Oortwijn W, Cleemput I, Sacchini D.
Harmonization of ethics in health technology assessment: a revi-
sion of the Socratic approach. Int J Technol Assess Health Care
2014;30:3–9.

[49] Saarni SI, Hofmann B, Lampe K, Lühmann D, Mäkelä M, Velasco-
Garrido M, et al. Ethical analysis to improve decision-making on
health technologies. Bull World Health Organ 2008;86:617–23.

[50] Seidman JJ, Steinwachs D, Rubin HR. Design and testing of a tool for
evaluating the quality of diabetes consumer-information web sites.
J Med Internet Res 2003;5:e30.

[51] Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instru-
ment for judging the quality of written consumer health information on
treatment choices. J Epidemiol Community Health 1999;53:105–11.

[52] Chumber S, Huber J, Ghezzi P. A methodology to analyze the quality
of health information on the Internet: the example of diabetic
neuropathy. Diabetes Educ 2015;41:95–105.

[53] Silberg W, Lundberg G, Musacchio R. Assessing, controlling, and
assuring the quality of medical information on the Internet: caveat lector
et viewor—let the reader and viewer beware. JAMA 1997;277:1244–5.