

Enhancing Enrollment and Adherence in Long-term Wearables Dementia Research: A Qualitative Synthesis from a Systematic Review

Colleen M. Peterson, Renée M. St. Louis, Carol A. Flannagan

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Abstract

Background: With the rapid expansion of wearable technologies, there is increased interest in their utility for passive data collection applications in aging research. Wearables can be specifically beneficial to research featuring people with dementia and their families who have burdens that can make both study participation and reliable data collection more difficult, especially as dementia progresses. However, population-specific issues affecting the success of wearables for data collection can include remembering to wear a device, fluctuating acceptance of the device or study participation, and reliance on strained caregivers. Better understanding of how research with wearables can address these and other issues is necessary to enhance participant buy-in and sustained wearing for better quality dementia research.

Objective: We undertook a systematic evaluation of contemporary wearables research to describe this population's wearables experiences, desired qualities, and protocol needs.

Methods: We used the PRISMA 2020 guide to systematic reviews and searched three scholarly databases using medical subject heading (MeSH) terms for papers published since 2018 featuring the use or discussion of wearable devices for persons with dementia. We screened 1757 abstracts and retained 58 for full-text review.

Results: We present synthesized preferences, barriers, and facilitators to wearables buy-in and adherence in dementia research. A total of 29 factors were categorized into four overarching categories aligned with study development: device selection, protocol considerations, enhancing recruitment, and promoting adherence.

Conclusions: These findings inform researcher guidelines for wearable device selection and protocol design to enhance the utility of wearables in future longitudinal research featuring persons with dementia and their caregivers.

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Original Manuscript

Enhancing Enrollment and Adherence in Long-term Wearables Dementia Research:

A Qualitative Synthesis from a Systematic Review

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Abstract

Background: With the rapid expansion of wearable technologies, there is increased interest in their utility for passive data collection applications in aging research. Wearables can be beneficial to research featuring people with dementia and their families who have burdens that can make both study participation and reliable data collection more difficult, especially as dementia progresses, but their use also has challenges. Population-specific issues affecting the success of wearables for data collection can include remembering to wear a device, fluctuating acceptance of the device or study participation, and reliance on already strained caregivers.

Objective: Better understanding of how research with wearables can address these and other issues is necessary to enhance participant buy-in and sustained wearing for better quality dementia research. We undertook a systematic evaluation of contemporary wearables research to describe this population's wearables experiences, desired qualities, and protocol needs.

Methods: We used the PRISMA 2020 guide to systematic reviews and searched three scholarly databases using medical subject heading (MeSH) terms for papers published since 2018 featuring the use or discussion of wearable devices for persons with dementia. We screened 1757 abstracts and retained 58 for full-text review.

Results: We present synthesized preferences, barriers, and facilitators to wearables buy-in and adherence in dementia research. A total of 29 factors were categorized into four overarching categories aligned with study development: device selection, protocol considerations, enhancing recruitment, and promoting adherence.

Conclusions: These findings inform researcher guidelines for wearable device selection and protocol design to enhance the utility of wearables in future longitudinal research featuring persons with dementia and their caregivers.

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Keywords: dementia; dementia care; Alzheimer's disease; caregivers; cognitive impairment; wearable electronic devices; wearables; systematic review



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Introduction**Background**

The growing prevalence of dementia and its substantial economic and social impacts has led to increased attention and funding allocations for research supporting persons living with dementia (PwD) and their caregivers as well as dementia prevention research [1]. Obtaining the perspective of PwD and their caregivers is critical to advancing our understanding of dementia to not only find effective treatments but to address burdens often associated with providing care to this population [2,3]. Engaging PwD and their caregivers in research studies can be challenging for many reasons, including the fluctuating cognitive capacities of individuals with dementia, the logistical and emotional demands placed on caregivers, and the need for research protocols that accommodate the specific needs and limitations of this population [3]. Innovative methods to increase meaningful engagement in research studies involving PwD and their caregivers are warranted.

Meeting researcher needs

Wearable technology is a non-invasive, passive way to collect a variety of data over long periods and offer potential benefit to enhance care and prevention efforts [e.g., 4,5,6]. Remote data collection such as that offered by wearable technology has many potential benefits, including reducing recall bias and decreasing the burden placed on participants due to frequent contact for research purposes. Identifying wearables and research protocols that meet both researcher and participant needs will help wearable technology be more effectively used in longitudinal dementia studies [7]. As the wearable technology market is expected to continue growing substantially [8], guidance for researchers to optimize selection of device(s) to enhance buy-in and adherence in their studies is necessary. Wearable devices and research strategies tailored to PwD and their care providers are crucial for optimizing long-term research with this

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population [9].

Currently, longitudinal dementia research with wearables faces three overarching challenges. First, the challenges particular to persons with dementia and their caregivers and/or health care professionals must be considered to gain long-term buy-in and use, especially as dementia progresses and caregiving burdens increase [10,11]. Population-specific issues include remembering to wear or charge the device, ethical informed consent [12], and privacy concerns [13,14] that may differ from cognitively intact older adults [e.g., 15,16]. Second, there is a multitude of wearables on the market with a variety of features and hardware forms at various costs that haven't been evaluated in terms of this population's usability and adherence factors. Third, wearables must also provide consistent, accurate, and useful data that meet researcher needs (e.g., activity monitors, GPS/location information), and have limited or easily resolvable technical problems, user-related issues, or data access factors [17].

To date, there has not been a systematic evaluation of wearables for research that holistically examines wearables to meet the needs of persons with dementia, their caregivers, and researchers to enhance participant buy-in and research utility. Moreover, with the rapid expansion and advancement of wearable technology in the last few years, new research on participant experiences and desires for wearables is necessary. Recent wearables research with this population has featured focus group discussion with limited representation of persons with dementia and their caregivers [10,18] to be compared to the experiences of non-dementia older adults [19]. Observational research that could inform wearable acceptance and adherence strategies has often been limited to very short-term evaluation time periods (typically up to 7 days) with a handful of activity monitoring devices [20-22]. Identifying factors related to wearables that are acceptable to PwD and their care providers as well as population-specific

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support systems is necessary to strengthen the quality of research requiring long-term adherence [7].

The objective of the current study is to conduct a systematic review of dementia-related preferences, barriers, and facilitators to using wearables in research studies to inform future study development, including device selection and participant support protocols.

Methods

Data sources

This systematic review followed the PRISMA 2020 guide [23]. Primary, original research studies were identified from PubMed/MEDLINE, SCOPUS, CINAHL (all last consulted Jan. 2023), and Google Scholar (reviewed about 500 results to capture additional references since the 2023 search in March 2024). The search strategy included a combination of MeSH (Medical Subject Headings) terms and keywords. Categorized according to PICO (Population/Intervention/Comparison/Outcome), search terms were used in OR statements in combination for the population (“dementia”, “Alzheimer* Disease”, “memory loss”, and “cognitive impairment”) and the intervention/indicator (“wearable*”, “wearable sensor*”, “tracker*”, “biosensor*”, “Fitbit”, “wearable electronic*”, “remote monitoring”, “pedometer”). Comparison/Control: Inclusion criteria did not require intervention trials. Outcome: Inclusion criteria did not specify outcomes from the studies. Full text of the relevant articles was retrieved from Web of Science, Google Scholar, and library access from the University of Michigan. Articles were reviewed for additional related references.

Study selection

Selection criteria for the literature search included: 1) full-text data from primary peer reviewed journal articles, commentaries, and conference proceedings; 2) employed remote monitoring via electronic devices that captured data of persons; 3) enrolled or referred to

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populations living with Alzheimer disease, dementias, or chronic memory impairment/loss impairment; 4) published in English from January 2018 to March 2024; and 5) documented any preferences, barriers, or facilitators to wearables device use. Notably, research featuring Huntington's or Parkinson's disease could be included if participants were experiencing dementia-type impairment and otherwise met the inclusion criteria. Studies were excluded if: 1) they did not meet the criteria above; 2) the wearable was an implant or not used with the intention of data collection (e.g., hearing aids); or 3) papers reporting study protocols only or 4) they included no person-interaction (e.g., device development without consulting with the affected population). Dissertations, books, book chapters, other reviews, and single case studies were excluded.

Author CMP searched independently, and authors CMP and CAF reviewed titles and abstracts for relevance and subsequent full review. CMP manually searched reference sections of these full text articles and key reviews for additional citations for review. Author RMS independently reviewed the search criteria and list of full text articles for meeting eligibility criteria. The authors used EndNote, a bibliographic tool that allowed them to organize PDFs of articles by topic along with other data about each article.

Data extraction and analysis.

Data extracted (by CMP) from the full text of the eligible studies included, as available: publication details, study location, study design, study population, device type and location worn, and device-wearing duration. For the focus of this study, we extracted information related to the preferences, barriers, and facilitators of the use, adoption, maintenance, and adherence of wearable electronic devices by persons with dementia, including ideal device qualities and protocol needs for PwD and their caregivers. This information could come from the researchers

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(e.g., procedures and processes attempted), persons with dementia (e.g., reported preferences, difficulties inhibiting ongoing use), or persons caring for those living with dementia whether health professionals or informal family caregivers (e.g., getting persons to wear the device).

Extracted preferences, barriers, and facilitators qualitative data was reviewed and initially synthesized for each study by author CMP into a common factor coding structure using a grounded theory qualitative research approach [24]. This approach does not presuppose findings but relies on iterative (“constant”) comparison of collected data to develop codes and overarching themes. Author RMS reviewed the summaries and factor synthesis, which the authors CMP and RMS then independently assigned to each study. Factor assignments were reviewed, and discrepancies were adjudicated together. We report the descriptive frequencies of the factors identified and noted in at least 5 studies and provide a qualitative synthesis of their implications for optimizing long-term dementia research.

Results

The systematic review identified 1,757 studies through the databases as well as iterative and manual reference searches. After eligibility criteria were applied, 58 studies were retained for data extraction analysis (see for the PRISMA study inclusion flow diagram). Most of the studies were excluded based on the abstract review because the device evaluated was not a wearable or the population had some cognitive impairment but did not feature dementia specifically. Studies were primarily observational (e.g., feasibility studies) and qualitative (e.g., using interviews or focus groups), with only 11 featuring trial of some sort. Participants were most often PwD living in the community (as opposed to residential care), their informal family care partners, and paid dementia care health professionals. The duration PwD were asked to wear the study device ranged widely from multiple hours over a handful of days up to 12 months, though seven days was a common wear period. Information pertaining to the individual studies, including the type

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of wearable, are summarized in Supplemental Table A1.

Barriers, facilitators, and preferences from the 58 studies were qualitatively synthesized into a total of 29 factors that fit into four overarching themes. These themes are categorized by issues dementia researchers should attend to from study development to deployment: device selection, protocol considerations, enhancing recruitment, and promoting adherence. Although we categorized these factors by greatest relevance to a particular study section, it should be recognized that many of the factors are interconnected and related to one another. Frequency and proportion of studies featuring each factor are detailed in Error: Reference source not found. The factors present in each study and their cross-reference number are available in Supplemental Table A2. As we describe the factors in the results, we use the term caregivers inclusively to mean both informal (i.e., unpaid, often family) and paid caregivers (e.g., health professionals, residential care staff) and provide relevant quotes that capture participant experiences. In the discussion, we offer a synthesis of recommendations to researchers planning to conduct longitudinal research with dementia populations.

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Table 1 Counts and proportions of study-specific factors

Factor	Count	Percent
<i>Device selection</i>		
Easy to use	21	35.6%
Smaller size/weight	18	30.5%
Comfort	15	25.4%
Fits into routine	13	22.0%
Unobtrusive	12	20.3%
Tailorable	12	20.3%
Materials	10	16.9%
Aesthetics	8	13.6%
Easy to wear	7	11.9%
Water resistant	7	11.9%
<i>Protocol considerations</i>		
Privacy concerns	15	25.4%
Consent capacity	14	23.7%
Battery	13	22.0%
Adjustment period	10	16.9%
Task requirements	9	15.3%
<i>Enhancing recruitment</i>		
Technical anxiety	17	28.8%
Multifunctional	16	27.1%
Burden impact	16	27.1%
Stigma	13	22.0%
Caregivers buy-in	12	20.3%
Connectivity	10	16.9%
<i>Promoting adherence</i>		
Remote monitoring	19	32.2%
Provide health insight	18	30.5%
Technical support	17	28.8%
Caregiver support	14	23.7%
Safety	14	23.7%
Remembering the device	12	20.3%
Independence	10	16.9%
Self-removal	7	11.9%

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Device Selection***Easy to Use***

Given the care burden of family or paid caregivers in residential settings, a wearable's ease of use was paramount when asking caregivers to be involved in a study. It was the most frequently identified factor in studies with 21 of 58 studies (35.6%) mentioning it. The wearable device must be easy to use [25-32] with an intuitive interface and features [33-36]. The device should require little maintenance or technical support for everyday use and any interaction with the device required by the study should be simple [10,33,37-41]. Some studies explicitly noted that perceived ease of use was associated with more positive attitudes toward wearing the device and less effort or sense of inconvenience in participation [27,42-45]. As one PwD exclaimed in Gris et al. [44], "Older people need to use simple things!"

Smaller Size and Weight

Almost without exception, participants desired smaller and lighter wearables or expressed discontent about the size and/or weight of the device they were asked to wear in the study [30,31,39-41,46-50]. The influence of a wearable's size and weight was the most frequent physical form factor, with 18 of 58 of studies (30.5%) having comments about it, and the fourth most common factor identified overall. While rare, there were some exceptions to participants desiring smaller devices overall. Some suggested enlarging certain facets of a device such as having a larger face/font to read [51] or larger buttons to interact with [27].

Comfort

The physical ease of wearing the device was important [33,36-38,44,47,49,52,53] with discomfort being specifically cited as a reason why participants removed the device in several studies [39,41,54]. *Comfort* was sometimes explicitly paired with *Unobtrusive* as qualities that

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went together [20,28,34]. Even so, prototype devices that were bulky or wearables with more invasive application (e.g., required taping to limbs or backs) were mostly tolerated in the short-term. However, simply put, “if residents would show discomfort related to the wearable, the wearable would not be used” [28].

Fits into Routine

Studies found that if a device type was already familiar or like what caregivers and PwD already used regularly, the wearable could be seen as convenient and more easily fit into a participants’ lifestyle [10,35,37,38,49,55,56]. Wristwatch forms were the most frequently cited as meeting these criteria [20,34,40,44,47,57]. At the same time, devices might also be removed if accessory removal is also part of their routine [20,37,47].

“To tackle such barriers [to using mHealth devices] will likewise require (informal) caregivers to change their attitudes towards using digital technologies and the integration of these technologies into routine care” [35]

Unobtrusive

A wearable that is not obvious or can be hidden was a distinct positive [25,34,40,44,56,58]. Having the ability to conceal a wearable alleviated some worry about a PwD being resistant to wearing the device or issues with the PwD removing the device (see *Self-Removal*), which could be especially pertinent in studies involving those with more advanced stages of dementia [28,41,50]. Unobtrusive devices were also seen as reducing the potential drawing attention to themselves or experiencing stigma associated with wearing a device [10,28,48] (see *Stigma*). Like *Fits into Routine*, wristwatches were commonly cited as an unobtrusive solution [10,20] but something that could be slipped onto a belt or into a shoe was also noted as a viable option [10,34].

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Tailorable

Having the option to use a wearable in a way that fit a person's particular style preferences was desired, from format (e.g., neck pedant, watch) to style (e.g., colors, design) [10,28,29,34,39,40,44,58] as some had a problem with the particular format that was in the study and desired a different way to wear it [26,36,50]. Alternative device forms can be inclusive of a spectrum of participants and their day-to-day presentations (e.g., gender, culture)[10,18]. Offering a wearable in several different forms could help a device suit the *Fits into Routine* factor but the *Tailorable* factor highlights that singular forms may not fit into everyone's routine equally.

"Several members in all four groups expressed a desire for more options in device styles...all groups asked if alternative styles could include a broach, belt clip, small bracelet, or ankle bracelet." [36]

Materials

Non-specific material concerns or durability were cited as important considerations for wearables to be satisfactory to participants and researchers alike [30,34,47]. Specific material issues such softness [30,39,41] and the need to make wearables safe for those with skin sensitivities or allergies were also mentioned [10,28,33,39]. Some participants stopped wearing the device altogether because the device they wore caused irritation [22] or even skin abrasions [59].

Aesthetics

The general appearance of the device design in its look and feel could be a barrier to everyday use and thus adherence [30,31,47,51,57]. Size, form, colors, and device material all play a role in the aesthetic attractiveness of a wearable [36,39,40]. For example, participants in

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Jacklin et al.'s [36] study were dissatisfied with the prototype wearable they were testing, calling it "big and clumsy looking" and "rubbery".

Easy to Wear

Diminishing PwD's fine motor skills made *Easy to Wear*, or how simply one can put on or take off the wearable, an issue for day-to-day use [10,29,32]. Wearables that were difficult for the wearer to put on or take off by themselves required caregiver support that could add stress to both the person living with dementia and their caregiver, creating participation burden and sense of a lack of independence [39,59]. Some wearables were slightly more complicated and required specific sensor placement, which was either difficult to affix in the first place or did not stay adhered [39,60,61].

Easy to Wear is distinct from *Easy to Use* and may not play a role if a wearable is designed to be worn continuously. For example, in one study a family caregiver reported that an accelerometer was "a little bit difficult to put on, so [the PwD] did do it but . . . it's not easy". The researchers echoed that "the wristband of the accelerometers could be difficult to fasten" but reported that afterwards, "the accelerometers were not burdensome to wear." [32]

Water Resistant

Water resistant or waterproof wearables were recommended [28,31,33] to minimize potential disruptions to data collection. Along with having to charge the device, a common point of non-compliance occurred when participants would forget to put a wearable back on after removing it bathing (see *Remembering the Device*) [34,39]. By selecting a waterproof device and asking participants not to remove the device, study protocols do not have to rely on PwD or their caregivers remembering to take off the device during bathing and therefore can reduce the number of study *Task Requirements* and related *Burden Impact* [30,52]. Indeed, Cruz-Sandoval

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et al. [34] suggested reducing the number of times when a device needs to be removed can also reduce times of PwD offering “resistance” and therefore waterproof devices “can ease some of the burden on caregivers” as well.

Protocol Considerations***Privacy Concerns***

Many studies noted privacy was an issue, with participants voicing concerns about data security and who had access to the wearable’s data [10,18,26,30,36,44,50,58]. For example, a caregiver’s spouse worried third-party breaches of her wearable data, explaining “privacy and security are important to his wife because ‘...she understands just how easily those systems can be hacked.’” [58]

At the same time, some PwD and their caregivers said explicitly that privacy concerns were outweighed by the personal or societal benefits of their study participation [25,38] or reported no privacy concerns [27]. Participants understood that sharing was often necessary to meet the goals of the study and privacy concerns were ameliorated when researchers established trust around data management: “Both informal caregivers and the nursing staff were not concerned about privacy issues regarding the wearable, as they consider biomedical variables as de-individualized values. The participants trusted the researchers and nursing home regarding good data handling, as they felt well-informed.” [28]

Researchers were able to build trust and attenuate privacy concerns through transparency about data access and security measures during informed consent processes and study duration as well [28,62]. Empowering participants to have control over privacy options (e.g., allowing collection of some, but not other data as able) and the ability to turn off or select data for monitoring helped as well [63,64].

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Consent Capacity

The ability of PwD to understand and actively affirm study participation is an ethical imperative but was specifically mentioned as a potential difficulty by several studies [44,58]. Especially in longer term studies, seeking ongoing consent to participate was highlighted as necessary, with suggestions to check-in regularly to assess the cognitive capacity of the PwD and their willingness to participate [20,63,65].

“Fluctuating cognition can be a significant barrier to the remote monitoring of isolated patients as forgetting about one’s motivations to be monitored can lead to anxiety and agitation for being watched and, consequently, the disablement or destruction of equipment.” [65]

At odds with fully informed consent was PwD’s general awareness of their participation and/or the device [37,51]. At this level of impairment, consent from a caregiver or another proxy for the PwD was sometimes sought instead, which could be a(n appropriate) barrier to inclusion [22,53,56]. Another major challenge is reconciling what to do when PwD desires conflict with caregiver desire for PwD to engage in the study and wear the device [10,50]. Under consideration is the issue of dignity, respect for autonomy, and how ignoring these or not obtaining assent could and lead to agitation.

“In one case, [study staff] visited the participant after he had refused to wear it on his wrist, saying his wife was tagging him 'like a dog.'” [50]

“[My husband] would have never given his consent even at the beginning – he liked the independence of making his own decisions and doing what he wanted. And I would have had to do it without his consent.” [10]

It was recommended that, as able, researchers and the PwD caregivers and their proxies should attend to their care recipient’s wishes, whether from an explicit advanced directive [64] or

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knowledge of their comfort with similar technology [35].

Battery

Longevity of battery life and ease of charging were concerns for researchers and participants alike [9,30,31,33,44,66]. Wearables with a battery life of at least several days were ideal [30,33,34,67], decreasing the need for participants to remember to charge the device [9,10,62](i.e., simplifying *Task Requirements*), which also minimized data collection interruptions for researchers. Low battery warnings from the device or study staff were seen a useful tool to ensure adequate charge of the battery [10,37,50]. Necessarily, the burden of charging was exacerbated if a caregiver was not on site to physically assist or the charging mechanism was difficult to implement [40].

Adjustment Period

Participants may need time to acclimate to wearing the device (e.g., establish wearing routines) and to work out technical issues before consistent adherence and therefore consistent data quality, as adherence tended to improve after an initial time period [9,28,34,37,38,47,68]. On the other hand, some studies found better compliance earlier in a study period [32,48,69] perhaps due to novelty. Adjustment periods featuring cognitive aids such as instructional pamphlets and study staff check-ins provide early troubleshooting and time to build in new routines [9,34,38].

Task Requirements

Cognitive impairment and caregiving burden was a barrier to protocol adherence when participants were asked to do more than simply wear the device [65,66,70,71]. When a study protocol required additional activity from either the PwD or a caregiver, such as completing bedtime and wake-up event markers, they were less likely to remember or be able to comply

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[9,61,62,72].

Enhancing Recruitment***Technical Anxiety***

Although many interacted with the study wearables and related technology platforms successfully, participant sense of a lack of technical proficiency and negative attitudes about technology was a perceived barrier to enrollment [10,18,27,43,44,47,58] and to adherence once in a study [29,34,68]. Caregivers and PwDs alike worried about the complexity or technical know-how needed to operate the wearables [30,34,42,65,68]. Technical anxiety could present in worrying about damaging or losing the device [20,34,39]. Level of technical anxiety and attitudes toward the technology were related to age qualitatively and statistically [10,27,29,44,68] and previous experience with devices [42,55,73]. In one study, participants rated themselves as less technologically proficient at the end of the study due to difficulty with the wearable [48].

Multifunctional

Participants saw the potential for the device and platform to offer more information or other uses to the wearer as a benefit of being involved in the research [27,58]. Being able to track their health and activity, signal health events or emergencies (e.g., wandering or fall alerts), provide directions or offer location services, amongst others, were cited as desirable features [10,25,27,30,31,34-36,39,49,65]. Simpler functions such as information about time, date, and alarm capacity were also ideal wearable facets [10,30,37,40,47,67].

“Participants with dementia indicated that multiple purposes for the locator device, such as being able to measure heart rate, blood pressure and activity level, is advantageous as it would streamline the number of devices that they and their caregivers must contend with.” [10]

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“Feedback suggested that some people with dementia may be more willing to accept technology that supports them in their daily functioning, in addition to assessing it.” [30]

Burden Impact

Caregivers especially liked the potential the wearables offered in terms of supporting their caregiving role and tasks, which in turn, reduced related burden and stress [27,31,37,45,53]. Factors such as a wearable’s capacity for *Remote Monitoring* and *Providing Health Insights* could improve quality of life or provide peace of mind [30,38,45,49,62]. However, when the wearable was technically difficult to use (*Easy to Use*) or researchers required additional time or study activity (see *Task Requirements*), being involved in the study was perceived as a cause of additional burden and a deterrent to both enrollment and continued participation [28,34,37,38,56,65,74,75]. Notably, participants in several studies reported experiencing a mix of both reduced and heightened burden, which varied according to specific facets of the research or from using the wearable [32,37,38,53].

“The nursing staff indicated that they did not want to spend valuable care-time if the foreseen benefit of the wearable for the specific resident was not evident to them. Likewise, also informal caregivers found it important to know the potential individual benefits, before deciding whether to bother the resident with the wearable, as they anticipated some level of resistance to wearing the wristband by the residents.” [28]

Stigma

Caregivers and the PwD worried about the stigma associated with the wearable and the wearable identifying their care recipient (or themselves) as affected by the hidden disability [10,18,31,35]. There was worry about social acceptance and the visibility of the device, and perceptions or comments that it might engender (e.g., they are under surveillance or need to be

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monitored) [28,38,39,62]. On the other hand, “social influence” was often a positive, with care providers or fellow PwD offering positive comments or encouraging the use of the wearable [34,43,45,73].

Families and professional care providers alike are sensitive to the negative connotation that some wearables might cause. An Alzheimer Society staff member reported that some families might avoid a MedicAlert bracelet in their care management plans because “it’s a signifier or something that’s perceived to bring stigma – [the PwD] don’t want to be out there clearly marked in some way, that there’s something wrong with them. Nor does the family” [18].

Caregiver Buy-in

Caregiver buy-in underlies many facets of wearable studies featuring PwD as many studies relied on caregiver commitment and coordination with the researchers to do study activities (see *Caregiver Support*) [20,28,42,56,72]. Moreover, they played significant roles in facilitating understanding of the study to the PwD [34,57] and encouraging PwD to wear the device [45,47]. Some studies specifically cited the need for caregivers to have perceived usefulness or reasons to commit to reduce perceived potential burden or risks to enroll themselves and/or their care recipient in the study [28,62,73]. Gaining caregiver buy-in could be enhanced through reducing participation burdens (e.g., fewer *Task Requirements*, *Easy to Use* devices, offering ongoing *Technical Support*) and experiencing personal benefit from the study (e.g., *Remote Monitoring*, *Providing Health Insights*).

Connectivity

Passive, remote monitoring is the defining advantage of wearable device studies. However, technical connectivity requirements can be a barrier to enrollment [10,28,36,53,65] and create logistical problems for data transmission [18,36,71,76]. For example, requiring faster

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Wi-Fi or consistent Bluetooth linkage with a smartphone for more frequent data uploads [49,66,76] may bias recruitment to higher socioeconomic status and to those already technically inclined.

“The lack of internet connection in patient homes and of funding for caregivers and family member to purchase assistive or communication devices are frequently coupled with skepticism or low abilities to engage with digital products.” [65]

Promoting Adherence***Remote Monitoring***

Remote monitoring was the top factor mentioned as desirable and useful (mentioned in 19 of 58 studies, or 32.2%) when engaging in a wearable study with dementia populations [10,25,27,28,39,53,73,75]. Remote monitoring through geolocation services allows caregivers the ability to monitor the movement of PwD when not in their presence, including tracking movement outside the home. Remote monitoring was also seen as a way to know about the well-being of the PwD, for example through identification of agitated movement or interrupted sleep [37,46,76]. Remote monitoring enhanced the *Independence* of the person living with dementia [27,30,44] while creating some peace of mind for informal caregivers about PwD’s safety (e.g., reduces *Burden Impact*) [30,31,49,55,62].

For some participants, the utility of the benefits of geolocation services conclusively outweighed potential *Privacy Concerns* [25,48]. However, for others introducing the idea of being monitored could be seen as an infringement on autonomy and privacy [25,36], such as when “some participants feared that proud Anishinaabe older adults would be offended by the idea that their movements would be tracked.” [36]

Provide Health Insight

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Providing health insight to the participants was one of the top factors mentioned as a benefit to ongoing participation and use of a study's wearable. Paralleling the *Multifunctional* factor as an aid to enrollment incentives, health insights included, for example, information on blood pressure, heart rate, sleep quality, and steps. Having ongoing access to this health data motivated participants' personal activity, helped caregivers monitor for health crises, and provided more general insight to PwD's well-being [10,25,27,28,30,34,37,38,44,53,65,68,69,74,76]. Additionally, they appreciated that this health information could be useful to residential staff and physicians to inform care decisions [25,27,28,31,37,39,53]. A caregiver in the study by Lazarou et al. [25] said with the information from the wearable, "we could monitor her daily activity and communicate any problems to the doctors. It helped us a lot to understand what is going on."

Technical Support

As *Technical Anxiety* was a barrier, providing initial technical training and ongoing technical support was identified as a complementary facilitator [20,26,43-45,61,65]. The availability of staff to provide wearable training at enrollment, through an *Adjustment Period*, and being available as needed during the study enhanced adherence [34,38,76]. Standalone instructional materials and cognitive aids were useful to participants seeking to troubleshoot issues on their own [9,10,41,57]. Along with data monitoring, regular proactive check-ins with participants made (or would have made) staff aware of technical problems and helped maintain better compliance [34,50,54,68,76].

As an example, Gelonch et al. [38] provided caregivers with initial training and ongoing technical assistance and they, in turn, supported their care recipient's use of a lifelogging camera: "the [PwD] said that the support and supervision provided by their caregiver in certain tasks or

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actions, such as connecting and loading the camera, were also key for them continuing with the experiment”.

Even with apprehension about using the technology (see *Technical Anxiety*), participants commonly showed a readiness to learn how to operate the wearable devices and follow study protocol. As recounted by [42], “Many were not necessarily technologically proficient caregivers, but they wanted to be useful. None of the caregivers implied that the research should not continue to be refined.”

Caregiver Support

While the importance of *Caregiver Buy-in* was highlighted in recruitment, here we underscore the importance of caregivers and their investment in the study for continued wearables adherence [42,45,58,76]. Many research protocols required caregiver activity to accomplish their goals, by having them be the primary study participant or helping PwD complete study tasks [34,52] and importantly, charging the wearable [40,76]. Many other factors are directed at or rely on the caregiver, such as caregivers helping PwD with *Remembering the Device* [20,47] put on the device (see *Easy to Wear*) [39,59] or otherwise understanding how to operate the wearable [38]. Additionally, caregivers could be instrumental in explaining facets of the study, and in other ways facilitating communicating research needs to their care recipient throughout the study [34,50].

Notably, relying on caregiver support can be a major ask (i.e., increase *Burden Impact*): “The caregivers were able to be present almost all the time. They demonstrated personal investment in the care that the person living with dementia received. Their willingness to participate in, work with researchers, and use technology 24 hours a day for 30-60 days was a significant commitment” [42].

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Safety

Broadly speaking, wearable technologies were seen as an instrument to enhancing the safety of the PwD [54,55,58,62]. This potential positive was specifically identified as an ongoing benefit, often in tandem or implied within *Remote Monitoring* and *Providing Health Insight*. Wearables offer a sense of security to PwD and their care providers that could aid aging in place, such as alerting caregivers to life events or potential crises (e.g., elopement, fall detector) and changes in health or behavioral patterns [33,36,39,75]. On rare occasions, the device itself was harmful, such as when an over-ear device caused skin abrasions [59] or participants desired different product/sensor design for safety reasons [53]. In opposition to other participants in their study, one caregiver in the study by Snyder et al. [58] explained that they felt the wearable, an emergency response pedant, gave a false sense of security, saying “My reluctance is that it doesn’t seem. . .It can’t stop something from happening to her. It just alerts you maybe if something does.”

Remembering the Device

Adherence in wearable studies was affected by PwD’s ongoing ability to remember what the device was for [22,34,48]. Not remembering the purpose of the device could also result in “confusion and agitation” [51]. Frequently though, PwD would simply forget to wear the device [10,20,30,66]. After removal for bathing (not *Water Resistant*) or for sleep sometimes coincided with forgetting to put the device back on [32,39]. Better adherence was reported earlier in the day [68,76] potentially due to sundowning.

“Due to memory impairment participants had to be constantly reminded to wear the device and they could change their opinion from one day to the other. Activities that made wearing the device more salient, such as the need to take it off to charge it or bathing, proved

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challenging with some participants.” [20]

Independence

Whether the device provided geolocating, physical activity monitoring, or health alerts, participants, especially caregivers, saw these devices and platform features as enhancing PwD’s independence and autonomy [10,27,30,45,49,58]. Participants’ ongoing access to the data and ability to turn off data collection at their discretion contributed to a sense of agency within the study itself [38,44]. Similar to the potential harms of *Remote Monitoring*, Synder et al. [58] framed this positive as part of the “conundrum between the benefits of having peace of mind, a sense of self-efficacy, and greater independence versus perceiving [remote monitoring technologies] as an invasion of privacy, a security risk, a false sense of security, and a distraction.”

Self-removal

Taking off the device when not instructed to be an issue in several studies [52,77]. This was potentially temporary such as during bathing or because of routine such a taking accessories off for sleeping [37,62] or longer-term because they were agitated (possibly related to sundowning) and found it uncomfortable [22,37,41]. Some researchers and care providers suggested or chose to put the wearable out of reach to avoid PwD self-removal (e.g., on their back) [28,77].

Discussion

This review identified barriers, facilitators, and preferences that could improve the quality of research studies featuring wearable devices and PwD. The review included studies encompassing a variety of study designs and perspectives from researchers, PwD, and their caregivers (both unpaid family and paid professionals), ensuring broad inclusion of research experiences. We offer a qualitative synthesis of these findings to enhance enrollment and adherence in long-term

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wearable research featuring PwD. Recommendations for future research fall within three main categories: device selection, ethical study design, and technical and data management plans.

Device Selection***Dementia Impairment Level Requires Different Devices***

We identified the importance of selecting multifunctional devices with capacity for participants to monitor their or their care recipient's data, whether on the device itself or via a dedicated platform. **However**, what PwD and their caregivers preferred in terms of devices was sometimes different depending on advancement of dementia in their target population. In earlier stages, the PwD themselves were more engaged and desired more interactive, multifunctional devices that provided benefit to them personally. However, persons with more severe dementia, from their perspective and caregivers' perspectives, desired or interacted with only simpler wearable form factor and features [e.g., just used the clock feature; 76]. Even less obtrusive devices or ones out of reach may also be warranted if they may be more likely to remove the device themselves as dementia progresses.

The growing ubiquity of remote monitoring and wearable devices for everyday use likely makes stigma less of a concern as we move into the future because an older adult will not stand out when wearing something like it, especially if it is unobtrusive or looks like an everyday wristwatch. The availability of the devices likely also drives expectations of what participants will personally gain from being in a research study as people are more familiar with what kinds of information gathering is theoretically possible and participants expect to have access to that information too.

Wristwatch Form Fits into Routine but Could Also be Problematic

Wristwatch form wearables were highly recommended as they are part of normal wear

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for many and offer different levels of multifunctionality. Additionally, their unobtrusiveness can reduce stigma [e.g., 10]. However, habitual device removal during sleep and bathing often conflicted with the research protocols requiring participants to wear the devices all the time [37,47]. Waterproof forms along with clear instructions to the caregiver and/or PwD to avoid removal in these situations are useful. Researchers should understand that adjustment periods may be warranted with proactive reminders, as participants acclimate to the newer routine and have fewer persistent issues [e.g., 47].

Ethical Study Design***Attend to Fluctuating PwD Consent Capacity***

Persons living with dementia feel actively engaged in the research and empowered over their health status when they can see their health data and decide when to engage in the study. However, progressive impairment can mean a person living with dementia may experience fluctuating consent and understanding of protocol for a long-term study. Researchers in longer-term studies should establish ongoing communication to monitor possible changes in device preferences or needs. Advanced cognitive decline from dementia can mean decision-making and consent ability are totally compromised for the person living with dementia. Reliance on a caregiver or another surrogate for consent is common, but studies emphasized that if the person living with dementia has given their thoughts on similar situations before, those preferences should be prioritized. Respecting participants' agency is paramount; recognizing and responding to the issues of ongoing consent with this population is key to conducting an ethical study. Actively checking-in with participants on a regular basis in long-term studies to gain assent or consent for continued data collection is ethical and may also be required by Institutional Review Boards given expected cognitive changes.

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Promote Inclusivity with Wearable and Protocol Choices

Researchers should be aware of how their study protocol and wearable device requirements may impact who can or would enroll in their study. A couple studies, such as Cohen et al. [68], suggested screening participants for technical knowledge and ability as a way of ensuring compliant participants are enrolled. However, this is not inclusive and could result in some biases in recruitment. Instead, preexisting technology and connectivity needs (e.g., stable Wi-Fi) should be minimized or eliminated to enhance distributive justice [64,78] and increase the representativeness of the study results. Researchers can reduce burden and increase equity by not requiring constant wireless connectivity or by supplying the technology to participants. However, intermittent data collection may be at odds with proactive data monitoring for troubleshooting purposes. Staff phone calls or other lower-tech check-ins are recommended in this case.

If possible, offer different formats and styles (e.g., watch versus pendant, watchband options) that are familiar and fit participant personal, cultural, and gender preferences [79]. Consider, though, the balance between participant style and form preferences and the meaningful data that can be collected from different formats [e.g., 39]. As evidenced by this review and other research efforts, user-centered, co-development of a wearables with PwD for research purposes is feasible [e.g., 44,80] and should continue to be explored to enhance recruitment and adherence in longitudinal studies featuring PwD.

Data Management***Implement Data Management Plans***

We categorized a total of 29 factors into four categories that aligned with study development (device selection, protocol considerations, enhancing recruitment, and promoting adherence). However, a fifth category - data management – was largely left uncommented on as

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studies were primarily focused on the needs and preferences of the participants rather than the researchers. Participants may report ongoing adherence, but making sure a wearable is not only worn but also collecting data is paramount to quality longitudinal research.

Researchers' data management plans should comprise data collection, storage, and processing for analysis [34,64]. As one point, researchers conducting long-term studies should know how long their device batteries will last under their protocol and have procedures in place to limit both data loss and participant burden (e.g., reminders to participants to charge their devices). By regularly checking data for completeness, researchers can identify technical problems and offer troubleshooting to resolve missing data issues. Researchers should also have a loss prevention plan for the wearable to reduce missing or inactive devices and resulting data loss.

As an example, Cruz-Sandoval et al. [34] had a comprehensive data management plan for a wearable study in an assisted living setting. They combined weekly program visits with battery charging, data collection (i.e., upload and synchronization with the study server), and addressed technical troubleshooting needs. They also reviewed the uploaded data for abnormal data patterns and double checked with caregivers "as soon as possible" to understand if the abnormal data was valid or if they should flag it for deletion. As a loss prevention plan, the researchers also asked the caregiver on staff to report on the location of the device at the end of each work shift. Particular data management plans could also influence device options; Muurling et al. [81] recommended that real time participant access to device data could both increase adherence and help alert researchers to data issues in close to real time.

Collective Data Management Efforts Could Better Support Wearables Research

To reduce researcher data burden in individual studies, research groups could build

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infrastructure and codebases to share collectively in an open-access format (e.g., on GitHub). Although, researcher perspectives on the use of the devices and subsequent data management were generally missing in the studies, one study reported that their experience organizing, cleaning, and analyzing Fitbit data was “onerous and time consuming” and recommended others use automated data management software [76]. Researchers should be aware that many commercial, proprietary wearables may not offer researchers access to the raw data which may limit secondary utility and increase reliance on the original developers for measure validation. Other collective data enhancements include setting standard definitions or ideal compliance goals, which varied across studies or were not reported at all. Clear, agreed-upon definitions for adherence and reporting standards is critical for improving long-term dementia research with wearable devices [9,57]. Indeed, a lack of specific, consistent adherence and attrition data from many studies made quantitative comparisons related to the factors impossible. Paired with real-time data monitoring, shared data expertise could also help researchers understand whether seemingly incoherent data is due to technical difficulties and address those readily [81] or shifting cognitive abilities and life contexts as dementia worsens [82].

Informing Wearable Technology Adoption and Use Models

The present systematic review evaluated preferences, barriers, and facilitators to wearables in a study setting, so everyday technology adoption measures may not be entirely applicable. Indeed, caregivers and PwD may endure adjustment periods, committing themselves to using difficult technologies if the knowledge gained will advance dementia prevention efforts or benefit other caregivers [82]. Even so, because of the lack of consistent quantitative data, we could not assess factor relationships quantitatively with wearable technology adoption and use models such as the Unified Theory of Acceptance and Use of Technology Model [UTAUT; 83], its extended version [UTAUT2; 43], the Wearable

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Acceptance in Health Care model [WTAH; 84], or the Technology Acceptance Model 3 [TAM3; 85]. These measures may also need to be updated as perceptions of technology change and use becomes more ubiquitous, even among older adults. Surveys and other marketing research indicate that although fewer older adults use wearables compared to other age demographics, about 25% of U.S. adults 65 and older were using wearables in 2023 [86], a rapid increase even in just the last few years [87]. Moreover, these measures relate to technology acceptance in general, while motivations underlying intentions and actual use of wearables may be different, especially as noted within research contexts. A research-specific technology acceptance questionnaire could help researchers understand perceptions directly related to their needs and identify additional barriers to recruitment and adherence.

There is also utility for more systematic assessment of wearable device qualities themselves and how they relate to adherence. The use of measures like the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) 2.0 can simplify device comparisons and inform future wearable choice or commercial development. Future reviews could also benefit from standard reporting of why particular devices were chosen in original studies.

Clinical Implications

We have reviewed and identified factors related to the use of wearables in long-term dementia research. However, wearables are also a potentially viable way to gather data for clinical decision-making since they can offer a way for clinicians to proactively monitor health data and circumvent some of the challenges around gathering a patient history from someone with dementia [31,88]. Supporting this potential, a large cohort study of cognitively healthy participants showed changes in long-term 24-h activity patterns were associated with elevated

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risk for onset of Alzheimer's disease, Parkinson's disease, and cognitive decline [89]. Moreover, as wearable devices are being used more by the general population, clinicians are experiencing patients coming in with questions about what they have learned from their own wearable devices. Improving research in this area can help clinicians think about how they can interpret and use wearable data in a meaningful way (e.g., personalized medicine). Clinicians could use the results of the current paper to guide a conversation with their patients about selecting a wearable that is beneficial for meeting the needs of both the patient and their health care team, which could also enhance adherence.

Limitations and strengths

Our findings are generally agnostic of cognitive impairment status or degree of dementia, reflective of the participant mix seen in the studies, which also often did not disambiguate by severity or type of dementia (e.g., Alzheimer's Disease, Lewy Body Disease), which may influence findings as well as generalizability of findings. Because our analysis was not limited to specific device types or study goals (e.g., physical activity, dementia prevention), not all factors may be applicable to all future research applications. We did not perform a formal risk-of-bias assessment due to the heterogeneity of the study types included and note that many studies may be considered high risk of bias due to smaller sample sizes. However, considering the outcomes of interest for this study were qualitative in nature, the samples were sufficient.

Because our extraction captured all reported barriers and facilitators regardless of their origin, we identified holistic perspective of researchers, persons living dementia, and their care providers, including unpaid family or paid health professionals. We systematically coded barriers, facilitators, and perspectives using a grounded, qualitative approach, which did not presuppose expected outcomes, allowing for new or unexpected insights. We offer a

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comprehensive synthesis of multiple types of studies featuring many wearables and outcomes of interest, identifying overarching themes core to long-term wearable research featuring dementia populations.

Conclusion

We described factors critical to enhancing dementia study recruitment and wearable adherence, emphasizing how those factors should be considered collectively in an ethical context to meet both researcher needs and participant desires. Organized by study design order and literature prevalence, dementia researchers can use the findings of this systematic review to thoughtfully design quality long-term wearables studies. The incorporation of wearable technology in dementia research presents a promising pathway to surmount traditional challenges associated with studying PwD and their caregivers. By leveraging these non-invasive tools, researchers can obtain continuous, objective data for use in advancing treatment, care, and prevention efforts. The results of this evaluation will facilitate quality improvement in ongoing research efforts and contribute to a more person-centered approach to develop effective interventions and prevention strategies.

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Conflicts of Interest

No conflicts to disclose.

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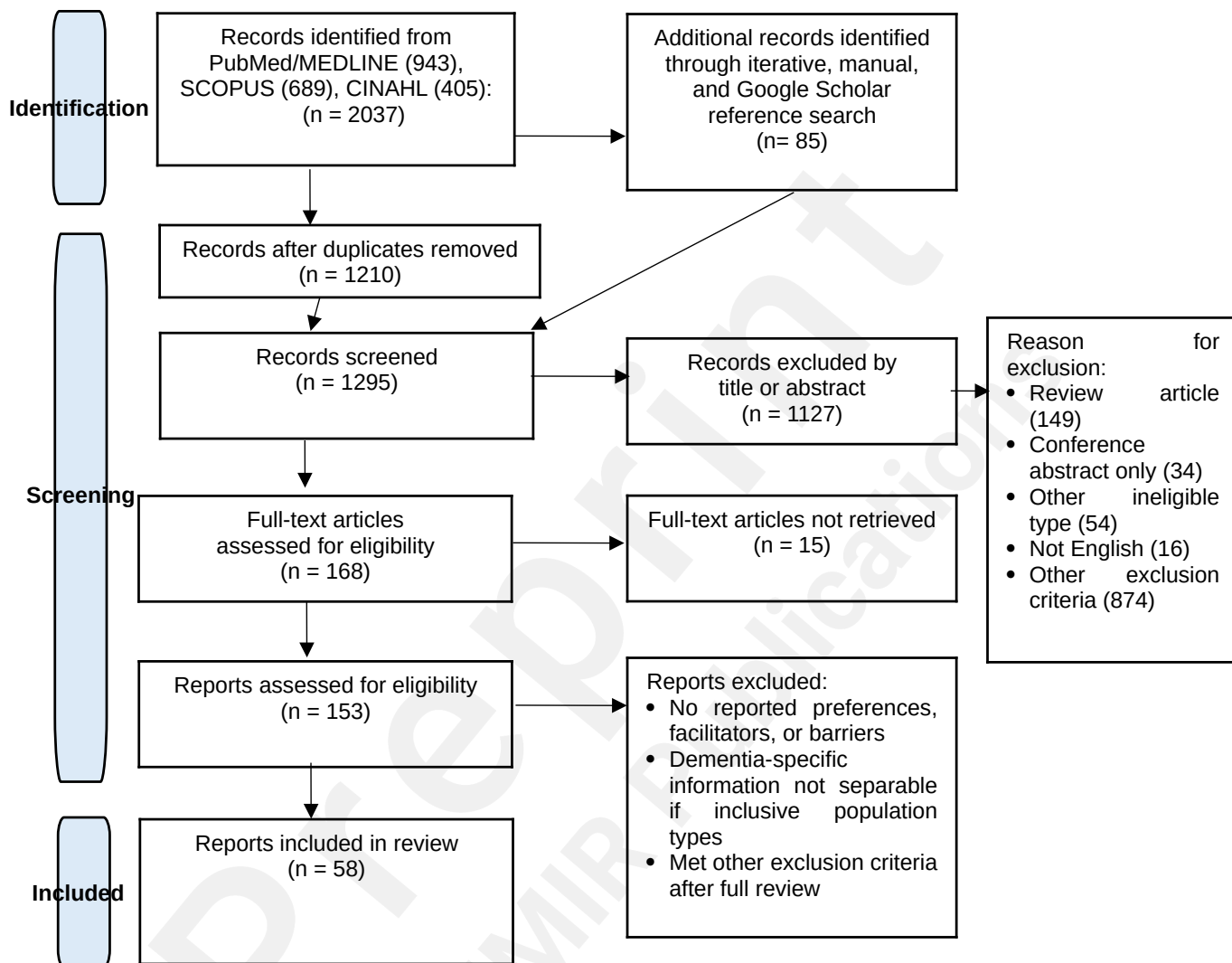
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Figure 1 PRISMA 2020 flow diagram for wearables in dementia research systematic review



Adapted from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

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List of Abbreviations

PRISMA: Preferred Reporting Items for Systematic reviews and Meta-Analyses

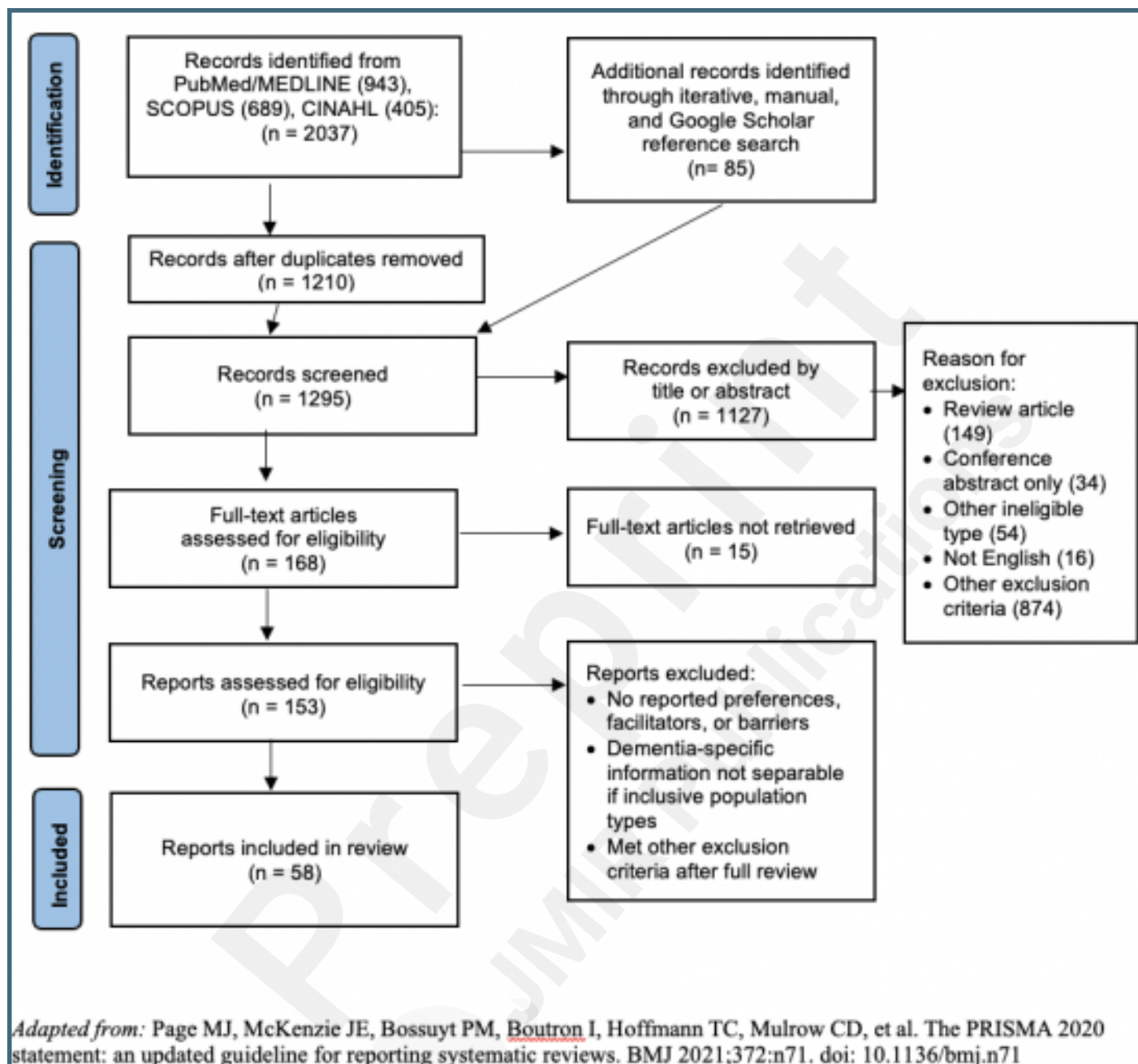
PwD: People with Dementia



Supplementary Files

Figures

PRISMA 2020 flow diagram for wearables in dementia research systematic review.



Multimedia Appendixes

Included wearable research with dementia populations study summaries.

URL: <http://asset.jmir.pub/assets/bff14be6048dbf7e34c21578dd94568e.docx>

Factor presence and counts by wearable research with dementia populations study.

URL: <http://asset.jmir.pub/assets/25eed786341e161cbcd114943b31e96b.docx>



CONSORT (or other) checklists

PRISMA checklist for standardized reporting of published studies. From Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71. Page numbers will be updated prior to publication; Presence of items noted for now.
URL: <http://asset.jmir.pub/assets/a7fa510bdb8035f463cd0c0c2b26472e.pdf>