

Passive collection of geolocation data by older people with cognitive impairment: Feasibility and user experiences for use in research

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Abstract

Background: The community mobility and engagement of older people is an important aspect of health and quality of life. Population studies and clinical trials are important for understanding ageing-related experiences, needs, and impacts of interventions. Passive collection of data through sensors could help to build the understanding of community lives, potentially without adding to participant burden or requiring an accurate recall. There are assumptions that technology-based data collection may not be feasible or acceptable for older people with cognitive impairment. Technology development and evaluation needs to engage with the direct perspectives of users with cognitive impairment to build an understanding of usability, acceptability, and ethical considerations.

Objective: To explore the feasibility, user experiences, and processes needed to support the smartphone-based collection of older people with cognitive impairment.

Method: An exploratory study, embedded within a longitudinal observational study, invited older adults to collect geolocation data for one week using smartphones and Bluetooth beacons. A process to support consent, transparency of data collection, and accessibility eredeveloped. Experiences and reflections on data collection were gathered via audio-recorded semi-structured interviews and field notes. Inductive content analysis was conducted.

Results: Eighteen older adults (15 with mild cognitive impairment, 3 with probable dementia; age M=86.7 years; 8 men) collected geolocation data. Most completed a week of data collection and considered it a positive experience. On average 161.5 hours (SD 31.7) of geolocation data were collected over a week. Reported user experiences included technical issues, consent and concerns, acceptability, and accessibility. Some support and reassurance were required, along with time to gain familiarity. Participants reportedly enjoyed engaging with their collected lifespan data.

Conclusion: Older adults with cognitive impairment were able to collect geolocation data following an accessible and ethical process. Future work may increase usability and engagement between participants and their data to build insights.

Keywords: smartphone, gerontology, mobility restriction, usability testing, community

INTRODUCTION

Monitoring of both individual and population-level outcomes has been a focus of gerontological and health studies for decades (Rojo-Perez & Fernandez-Mayoralas, 2021). Longitudinal studies of ageing have provided important insights

into the experiences and needs related to older people, informed community design and resource distribution, and led to the development of new policies and perspectives in relation to ageing (Kaiser, 2013; Rojo-Perez & Fernandez-Mayoralas, 2021). An international shift from a

focus on purely health and mortality to the inclusion of participation and quality of life outcomes, has marked an important advancement in the conceptualisation, monitoring, and supporting of active ageing and well-being in later life (Rojoperez & Fernandez-Majoral, 2021). This has been accompanied by the development of outcome measures that indicate aspects of quality of life and community participation across languages, cultures, and contexts (Harding et al., 2021; Harding & Reilly, 2021). For population-based studies, these need to be able to be measured at scale, have suitable psychometric properties (produce reliable and valid data), be able to be used with diverse populations and settings, and not be resource intensive (Harding & Reilly, 2021).

Outcome measures are also required to monitor individual outcomes related to health, ageing, and interventions (from individual clinical to community-wide). Quality of life and participation outcomes are key aspects of clinical trials, and observational research (Harding et al., 2021). A particular concern is paid to the meaningfulness, validity, and responsiveness of outcomes measured. Typically outcomes are measured at predefined time frames, giving insights into the current status of individuals and communities. In recognition of the historical trend of excluding older people and people with cognitive impairment from research (e.g. Pachana et al., 2015; O'Connor et al., 2021), there has been recent attention paid to their inclusion in research and the measurement of outcomes that are meaningful, valid and reliable for people with cognitive impairment (Harding et al., 2021). Many patient-reported outcomes have been criticised for relying on memory, being overly burdensome to complete, or requiring caregivers to provide insights, rather than directly including people living with dementia or cognitive impairment. There is therefore a need to develop, identify and explore the use of outcome measures that are meaningful in capturing the outcomes of older people with cognitive impairment (Harding & Reilly, 2021). These need to not rely on memory, not be complex to use, and be reliable in their data collection during community life.

One opportunity for measurement of outcomes of community life arises from the development of devices passively collecting outcomes via sensors. Passive collection of sensor data (automated sensor-based data collection that does not require direct involvement of participants) has been used as part of ambient assistive living approaches (distributed systems; smart homes) and specific assistive technologies (e.g. location tracking devices) (Grigorovich et al. 2021; Moyle, Murfield & Lion, 2021). In addition, there is a growing approach within gerontology and health research,

as well as care providers, to consider activity monitoring and other passively collected data to explore physical activity, patterns of daily activity, and health outcomes (De Silva et al., 2021; Gettel et al., 2021). With the development of mainstream and specialised technologies to collect data during regular community activities, there are opportunities to embed these approaches into outcome measurement in the longitudinal cohort and intervention studies. One approach is to convert existing constructs, typically measured through self-report in these studies to passively collected sensor data. This approach could contribute large amounts of data while not affecting community activity, increasing the burden, or requiring detailed memory for participants (Cosco et al., 2019; Liddle et al., 2014).

Lifespace is a measure of lived home and community mobility, indicating the geographic space in which an individual conducts their daily activities (Wettstein, Wahl & Schwenk, 2018). It has been identified as providing important insights into health, community participation, and well-being; as well as being predictive of key health and wellbeing outcomes, including quality of life, admission to residential care, and rate of cognitive decline (Taylor et al., 2019). Lifespace and community mobility, traditionally by self-report, are long established aspects of longitudinal ageing studies (e.g. Portegijs et al., 2016) and intervention studies (e.g. Fairhall et al., 2012). It is particularly relevant for older people and people with cognitive impairment as it is a clear indicator and predictor of community participation, quality of life, and support needs, reaching beyond traditional morbidity and mortality measures (Taylor, Buchan & Van der Veer, 2019). Global positioning system (GPS) data collected by specialised devices or smartphones have been used to establish lifespace in outdoor areas for some time (Liddle et al., 2014; Schenk et al, 2011). To include consideration of indoor areas, beacons or transmitters can be placed in regularly used spaces, which can be logged by devices (including trackers and smartphones) (Schenk et al. 2011). Reviews of lifespace in older people have identified that the technology for the passive measurement of the construct is emerging but with some existing usability and technical concerns. The future potential for this approach in monitoring individuals and the impact of interventions in a more holistic way was noted (Taylor et al., 2019).

Despite the availability of both mainstream and specialised technologies which allow the monitoring of location without specific input from the user, there are many identified gaps in current knowledge and practice. Research identifies particular concerns and need for research attention in relation to use by people with cognitive im-

pairment (Grigorivich et al., 2021). The consideration of privacy, surveillance, and other ethical requirements are particularly recommended as the technology develops and is adopted (Carter et al., 2015; Grigorivich et al., 2021). People with cognitive impairment may not be able to provide consent or assent for the ongoing collection of data, particularly if they are not aware of it happening within their environment (Carter et al., 2015; Leikas & Kulju, 2018). Importantly, technology researchers advocate for the direct discussion of these technologies with vulnerable users (Peeters, Shouten & Wouters, 2021; Thorstensen, 2019). In developing and evaluating technologies, a sociotechnical perspective, rather than one centring the technology is recommended, along with direct implementation and exploration of the technical, social, and contextual considerations, and the acceptability for users, and other people in their lives during the implementation (Peeters et al., 2021; Tsertsidis, 2021). As well as the importance of considering usability and ethical considerations, it is recommended that it is essential for the direct involvement of users in the design and evaluation of technology, to ensure usability and support future adoption (Leikas & Kulju, 2018; Leese et al., 2021).

Technology-based lifespace data collection requires further investigation. We require further exploration of the construct it measures, as well as usability, acceptability, and ethical implications (Liddle et al., 2014; Zhu et al., 2020). There are specific usability and acceptability considerations for users with cognitive impairment. Given geolocation data shares the actual location of participants, and could identify homes and other key locations, careful security and ethical considerations are required. The complexity of consent and usability requires direct input from users with cognitive impairment (Carter et al. 2015; Leikas & Kulji, 2018). The measurement of lifespace data passively in a research context also requires further consideration. Issues of consent, and not collecting ongoing or unneeded data are paramount to consider within the design of cohort and intervention studies. Unlike ambient assistive technologies or long-term use of commercial wearables, the technologies will not be continually used or continually sharing data. Ethical research outcome measurement will require intermittent engagement with the technology, which may not be familiar. It will also require transparent ways of providing consent and opting out of data collection at any time. In addition, it will be important to evaluate any burden or distress in relation to use, develop processes for obtaining consent and ongoing assent to use, and explore whether the process of collecting data is not directly assisting the user (Carter et al., 2015).

This study aimed to explore the experiences of passively collecting geolocation data of older adults with mild cognitive impairment (MCI) and dementia. It trialed and documented study processes for making the data collection ethical and accessible, including the direct perspectives of older people living with dementia and MCI.

METHODS

An existing longitudinal study (Sachdev et al., 2010) was supplemented with a mixed-methods observational study. Participants in the study were classified as having a mild cognitive impairment or probable dementia (based on a clinical panel and series of assessments measuring memory, language, attention and processing speed, visuospatial and executive functioning; Dementia was defined by DSM-IV criteria. Mild cognitive impairment defined as 1.5 standard deviations below matched normative scores in at least one domain), was invited to participate in an additional data collection involving technology. Participant numbers and design of data collection and analysis were consistent with the mixed methods feasibility approach was undertaken (Baldeh et al., 2020; Orsmond et al., 2015; Tashakkori, Johnson & Teddlie, 2021). The study received approvals from relevant Human Research Ethics Committees including University of New South Wales (HC14332) and University of Queensland (2015000100). Written consent for the additional study was obtained. Details of the longitudinal study, cognitive impairment assessments, and the lifespace study have been reported elsewhere (Liddle et al., 2021).

Procedure for geolocation data collection and user experience

An accessible and ethical process for passive data collection was developed by a multidisciplinary team. This was based on prior work developing remote monitoring technologies with guidance from people with Parkinson's disease (Chenery et al., 2014), clinical experience, technology accessibility, and data security standards and ethical guidelines (e.g. Carter et al., 2015).

The choice of smartphones as the data collection device was based on earlier work and adapted to technology, ageing, and health researchers. There were also pragmatic considerations for a study involving one-off data collection within the homes and communities of older people living with dementia and mild cognitive impairment. Key considerations that led to the choice were potential familiarity and lack of stigma of a smartphone, adequate battery life for full-day use, availability of multiple sensors within a safe commercial device, ability to deploy a custom app with required security and functionality, and avoidance of sharing of data with a third party



Figure 1. Study Android smartphone and custom low energy Bluetooth beacon

entity. It was important that the device was visible to the users allowing them to be reminded of consent and the ability to opt-out.

Participants were visited at home where written consent was obtained. Participants were shown the study equipment (smartphone, smartphone charger, low-energy Bluetooth beacons) (Figure 1) along with some brief information about the equipment and phone numbers for assistance. The participants selected a comfortable case for wearing or carrying the smartphone and identified a suitable place to plug in the charger. Participants were asked to carry the phone around with them during their waking hours and charge it each night for a one-week period. Three to five low-energy blue tooth beacons were placed around the house in locations agreed upon as suitable with the participants. The researcher recorded the locations on a sketch of the house plan.

Accessible information about how to opt out of data collection (switch off or leave phone; switch off beacons) was provided verbally and in the simple written form placed with the equipment. Clear information about what the devices were collecting (location of the phone only) was provided. The research team provided assistance, reassurance, and support as needed to participants during data collection, keeping field notes. One week later, the research team member returned, collected the equipment, and conducted an audio-recorded, semi-structured interview about the experience of monitoring their mobility using technology and their community mobility. Heatmaps, simple visualisations laid out over

a map of the area, indicating the data collected were shown to the participant at this time.

Outcome measures

Geolocation data (in the form of longitude and latitude coordinates via GPS recording) were collected in five-second increments through a custom app on the Android smartphone, provided as part of participation in the project. Locations of the smartphone in relation to beacons were also collected during the period. The data were streamed to a secure portal and metrics were calculated at the completion of data collection. The portal was accessible to the research team who could check during data collection whether data were present. Missing data could represent times when people deliberately opted out of data collection, being in a location without GPS coverage, or a technical issue (including running out of battery, or problems with the phone). Visualisations including heatmaps were automatically created on the portal and were shared with participants on the return visit. Any interaction with participants about their use of the technology was noted by research staff and included in content analysis.

Analysis

Development of metrics from lifespace data has been documented elsewhere (Liddle et al., 2021). Data checking/verification of the metrics included plotting and visually checking data, examination of the metrics in relation to the key aspects of participant-reported activity and generation, and showing heatmaps overlaying a map (Figure 2). Inductive content analysis (Elo & Kyngas, 2008) of interview data and researchers' logs were conducted to generate key aspects and considerations of the experience. These findings were discussed and verified by members of the research team involved in data collection.

RESULTS

Eighteen participants with mild cognitive impairment ($n=15$) or probable dementia ($n=3$) (10 male, age $M= 82.86$ years, $SD = 3.74$) collected geolocation data. The level and type of recorded cognitive impairment at the closest data collection to their participation in the substudy are as follows (probable dementia 3 (16.7%); Nonamnestic single domain MCI 6 (33.3%); Amnestic multiple domain MCI 4 (22.2%); Nonamnestic multiple domain MCI 1 (5.6%) Nonamnestic MCI without subjective complaints 1 (5.6%)) Participants collected between 105 and 240 hours of geolocation data ($M = 161.5$ hours, $SD = 31.7$). All participated in an interview following lifespace data collection.

Data collection experiences

Most participants did not experience difficulties after a careful explanation, demonstration, and consent process, where written information and

User experience smartphone lifespaces



Example heatmap A (participant living with dementia)



Example heatmap B (participant living with MCI)

Figure 2. Example Heatmaps of lifespaces data (the location of data collected has been shifted to preserve anonymity of participants)

how to get help were clearly displayed. The majority of participants collected a full week of data, with some exceeding this length of time and continuing to collect data until the device was retrieved. Where this occurred, the first full 168 hours of geolocation data collected by the participants were used in calculating lifespaces metrics.

The technology set-up process where participants chose charging points, locations for beacon, and a case for carrying the phone seemed to assist in clarifying the processes and bringing concerns or questions to the foreground. "Participant reported not having used a mobile phone previously, nor computer so handling technology like this was new to her. We thoroughly went through and practiced the charging and turning on and off procedures, and she seemed relatively comfortable" [field notes- Participant G]. These could generally be addressed at the time, or through later checking with the technology team. Issues that arose during data collection seemed more commonly related to a lack of familiarity and confidence with technology than diagnostic groups. Some issues arose during the study for both participants living with dementia and with MCI. Checking in about concerns, providing reassurance, and gaining familiarity and confidence seemed to address issues experienced. Once confidence had been gained, some participants requested a longer or repeated data collection period. "She was disappointed she had not participated fully, and said she had been really keen and now that she felt comfortable with the phone,

would like to have another go at the week of data collection [field notes- Participant B].

Technical issues

During the data collection period, an incompatibility between the Android operating system and the presence of Apple beacons with revolving MAC (media access control) addresses in public areas occurred. This resulted in the app being unable to function. This was diagnosed and was remedied through Android addressing the issue in an operating system update. Other technical issues were specific to individual participants and included experiencing areas without GPS/internet coverage.

While missing data was identified as a potential issue in earlier work, a novel error in geolocation data was also identified during data analysis. For one participant, a single data point was generated in error. This appeared to be the result of an interruption when writing a single data point to a file on the mobile device. The mobile app then resumed transmission of the latitude/longitude data which resulted in an amalgamated number that corresponded to a real location in another country. This meant that one data point out of 12245 for that participant was incorrect. This error was not visible in plots or heatmaps but affected metrics. It was identified with manual checking of datapoints after unexpectedly large metrics.

Consent and concerns

The nature of passive data collection, unlike actively entering data or responding to a question, posed ethical issues (e.g. where participants may be unaware they were still sharing locations). Therefore, clear indications of participation and easy opt-out processes were used. Participants were reminded that the location of the phone (not them) was being recorded and turning off (at the labelled physical button) or leaving the phone was an easy way to opt-out. Custom-built beacons also had clearly marked on/off switches and beacons were designed to be visible. All participants indicated that they understood this information in the introductory session and were willing to participate. Three participants subsequently reported confusion or concern about the technology. "She rang a few hours after the visit, very concerned that she had "stuffed up" the phone. ...Found the phone appeared to have simply been turned off. Apparently, the screen had gone to sleep not long after I had left, and she thought it meant the phone wasn't working" [Field notes – Participant E] This was generally resolved with a repeat explanation or troubleshooting. During the data collection, two participants expressed concerns in relation to messages received on the phone (operating system update requests). One accidentally turned off the phone

and was unable to turn it back on. One had concerns about the cost of charging the phone for the week of usage and another asked to repeat data collection once they became used to charging and carrying the phone. One participant reported family members had chastised her for participating as she *“is no good at technology”* (Participant D). Only one participant had incomplete data due to opting out. She turned off and packed up the beacons due to (unrelated) alarms from other devices in her house after a power outage in a storm.

Access and acceptability

All participants were able to participate in choosing locations and a case during the setup, expressing preferences and discussing how the data collection would fit in with their daily life. Some participants had limited prior technology experience but had volunteered for a study using technology. Some participants indicated that they found the heatmaps generated from their data and being involved in the research to be interesting. *“It’s been absolutely delightful. It’s fascinating. I still get excited when I see the maps”* (Participant C). Some noted that just carrying the phone was preferable to be asked to write down their travel patterns or remember them in an interview. Most participants described finding the experience to fit in with daily life *“Interviewer: How did you feel carrying that around? Participant E: Oh I didn’t mind in the least, I just stuck it in my thing [carrier] here”* and to represent *“no problem”* (Participant F), although one participant found the charging connector (micro-USB) difficult to orientate and plug in and two worried about the potential damage to the phone by taking it out of the house to community locations (like the pub) and required reassurance and confirmation of how to use the phone.

DISCUSSION

This study indicated that people with MCI and dementia can collect geolocation data using smartphones in a study context. This work has potential implications for people considering using passive outcome measurement with this population, including the reported processes used, experiences of use, and user perspectives. Given the importance of monitoring the quality of life and participation in understanding population and individual ageing and well-being experiences (Rojo-Perez & Fernandez-Mayoralas, 2021), this can help to build understanding towards accessible and ethical approaches for technology-enabled outcome measurement. Accessible and acceptable technologies for measuring these outcomes could support the inclusion of people living with dementia in trials and studies where they may have been excluded (or reverting to proxy measures) due to difficulty with recording

and reporting such outcomes. Processes to support access, use, management of expressed concerns, and consideration of ethics were required and have been described.

Supportive orientation to the technology, choice of how to wear and charge, and easily opt out seemed important and useful, however, support and reassurance were still required for some people. Some people may benefit from an initial orientation or trial period or a longer data collection period to build familiarity. Unanticipated technical errors indicated the importance of technology investigators being involved in the deployment, monitoring, and troubleshooting during the trial. In addition, hearing direct user feedback about experiences and acceptability helped to build an understanding of the issues in passive data collection and may support future technology uptake, if applied (Peeters et al., 2021). Some participants continued to collect data beyond the requested week or requested additional data collection time once familiarity was built. This could be considered in designing research protocols, with the inclusion of time for familiarity or supported repeated data collection. It may also have implications for deploying passive outcome measurement on people’s own devices, particularly considering the ethical importance of not collecting data beyond that required for the defined purpose.

Considerations for improving future processes were uncovered. It may be possible to increase ease of use through custom-built devices, rather than using smartphones which introduced some complexity outside of the control of the research team (charging, operating system updates, interaction with unrelated beacons within the environment, concern about loss). There are some benefits of using smartphones (familiar form, could get assistance from others). The feedback from participants also indicated the value of sharing the data collected in an accessible form (heatmaps) with participants. This may enable adding additional self-report and reflective insights (Liddle et al., 2017). The steps taken to improve accessibility also seemed to support transparency of data collection processes (choosing locations of beacons and chargers and choosing a wearable case), reminding participants that they were sharing this information (Carter et al., 2015). Data-checking processes need to consider the potential for falsely generated data points.

Limitations and future directions

This was a small study, focused on the use of technology for outcome measurement in a research study, conducted with people who expressed interest in participating in a study involving technology. Findings cannot be extrapolated to people

who are less willing to engage with technology. It can also not provide specific insights into the use of geolocation technology as assistive or care technologies. As technology is shifting rapidly, the broad nature of findings, rather than specifics may help support further research and development as devices and background technologies change rapidly. Future research may engage people collecting geolocation data over longer periods of time, support direct access to the online data portal or other mechanisms of sharing data, and directly explore lived perspectives using generated maps. The potential for passively collecting these insights into community lives, and then scaffolding and potentially enriching reflections of people with cognitive impairment, may help to further

enrich our understandings and approaches to support people in later life (Taylor et al., 2019).

Conclusions

People with mild cognitive impairment and dementia can successfully engage in passive geolocation data collection using smartphones and beacons. Careful processes to ensure ongoing awareness of and assent to data collection can be embedded within research processes. Engaging directly with older users with cognitive impairment, and considering their experiences will support the careful development and deployment of may support more holistic, inclusive, and accurate data collection in future research.

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Conflict of interest declaration

PS is an Advisory committee member for Biogen Australia. HB is an advisory board member or consultant for Biogen, Nutricia, Roche and Skin2Neuron. The other authors declare they have no conflicts of interests.

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