

Peace of mind: A community-industry-academic partnership to adapt dementia technology for Anishinaabe communities on Manitoulin Island

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Abstract

Introduction: Aging Technologies for Indigenous Communities in Ontario (ATICON) explores the technology needs of Anishinaabe older adults in the Manitoulin region of Northern Ontario. Our program of research addresses inequitable access to supportive technologies that may allow Indigenous older adults to successfully age in place.

Methods: Using Indigenous research methodologies (IRM) and community-based participatory research (CBPR) we explored the acceptability of CareBand - a wearable location and activity monitoring device for people living with dementia using a LoRaWAN, a low-power wide-area network technology. We conducted key informant consultations and focus groups with Anishinaabe Elders, formal and informal caregivers, and health care providers (n = 29) in four geographically distinct regions.

Results: Overall, participants agreed that CareBand would improve caregivers' peace of mind. Our results suggest refinement of the technology is necessary to address the challenges of the rural geography and winter weather; to reconsider aesthetics; address privacy and access; and to consider the unique characteristics of Anishinaabe culture and reserve life.

Conclusion: All three partners in this research, including the Indigenous communities, industry partner, and academic researchers, benefited from the use of CBPR and IRM. As CareBand is further developed, community input will be crucial for shaping a useful and valued device.

Keywords

Technology, dementia, aging, Indigenous, focus groups

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Introduction

The incidence of dementia continues to rise in Indigenous communities^{1,2} and Indigenous older adults have expressed interest in technological solutions to support aging-in-place.³ Thus far, there is no evidence in the literature of inclusion of Indigenous persons with dementia (PWD) or caregivers during the early stages of technology development.^{4–8} Developers engaging user or community input almost invariably include only urban settings and urban residents, often only within large metropolitan areas, and no one has reported targeting Indigenous persons with dementia.^{3,5,9–11} The development of aging-in-place technologies is further complicated by the fact that many

Indigenous people live in rural communities that often lack health care resources, connectivity, and mHealth tools designed to diagnose and treat cognitive impairment as people age.^{10,12,13}

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To examine these issues further, it is important to note that there are various health technology specialities including eHealth (e.g. electronic health records (EHR), patient portals into EHR), mHealth (e.g. ambulatory monitoring devices, health-related cellphone apps, etc.), and, more narrowly, surveillance technology systems. Surveillance tracking systems are electronic systems capable of identifying the location and travel of a person with dementia to ensure safety. Within mHealth technologies a handful of products have been developed within Indigenous or American Indian communities using community-based participatory research (CBPR) methodologies including breastfeeding, medication adherence, alcohol consumption during pregnancy, hypertension, and general healthy lifestyle support.^{14–20} While these are notably important health priorities, none of these medical conditions are related to dementia and aging-in-place. The general exploration of mHealth or eHealth applications among adults supports the feasibility and indicates a general interest in technologies, though economic and connectivity limitations in rural and remote areas are always a strong concern.^{15,21–23} None of the products reviewed in a recent systematic review of mHealth technologies who engaged Indigenous communities included products specific to issues of aging.²⁴ Finally, with dementia-specific surveillance technology research, not one of the surveillance technology products described in several systematic reviews reported the inclusion of Indigenous or American Indian communities.^{25,26} Indirect evidence from studies of perceived usefulness highlights the need to include non-majority, Indigenous end users in technology development. For example, high perceived usefulness of technology increases acceptance, and “usefulness” is noted to be context specific (e.g. specific to caregiver or person with dementia). In this work however, the ethnicity of participants was rarely identified in any of the cited studies, nor was culture considered as a driving force behind context.²⁶ Our research objective is the development of culturally safe and culturally designed technology capable of tracking an Indigenous older adult with declining cognitive health in rural and remote areas in such a way that their mobility and independence is not impaired, connection to cell towers or internet is not needed, and the information reported from the device is useful to families to facilitate aging-in-place.

To this end, CareBand Inc. sought to work with Aging Technologies for Indigenous Communities in Ontario (ATICON) and Anishinaabe residents of the Manitoulin region of Northern Ontario (Figure 1). With ATICON’s support, CareBand representatives visited First Nations on Manitoulin to learn how to work in a culturally appropriate way and to understand

the rural and remote environmental, social, infrastructure, and health care needs of the Anishinaabe of the Manitoulin region. Working with Indigenous communities around health research requires a different orientation to research and careful attention to the methodological approach.²⁷ The concept of “ethical adoption” as it relates to technology development for dementia requires the inclusion of targeted users in the early stages of technology development. During this early technology development stage producers and engineers benefit from hearing the reactions end users have of prototypes and the thoughts and wishes for potentially new features or uses, and this is especially important in dementia care technologies.^{28,29} Decades of research ethics violations and distrust within Indigenous communities has resulted in a shift to using CBPR and IRM approaches in which all research partners, in this case academics, industry leaders, and Indigenous communities, hold mutual respect and equitable involvement in all phases of research development. Through a university – community – industry partnership, a study was designed based on CBPR approaches, utilizing Indigenous Research Methodologies.^{3,30,31} The current project highlights the partnership between academic researchers, Indigenous communities, and industry representatives. The contributions and characteristics of each of these 3 partners are described in turn. Note that the organization of the three partners as “academic”, “Indigenous”, and “industry” must be understood as a convenient way to introduce the partners, but meaningful cross-overs exist. For example, Indigenous researchers were based (employed) in both the academic (MB) and Indigenous communities (KP). Strong collaborative bonds, open and constant communications, and teamwork are the norm for this partnership, which makes a brief description difficult. Though artificial, the following description is organized by each professional affiliation partner.

Academic researchers

KJ and WW, both anthropologists, have worked closely with First Nations communities on Manitoulin Island for over 20 years. Their work addresses Indigenous dementia evaluation and care,^{1,32–34} rural health equity and social accountability,^{35,36} diabetes among Indigenous communities,^{37–39} and the development of innovative CBPR methodologies within Indigenous communities.^{40–43} KJ leads ATICON and is an internationally recognized expert in cultural understandings of Indigenous dementia. WW has conducted research on several approaches including telemedicine and online training formats for professionals in rural and remote areas.^{7,44} KJ and WW use a CPBR

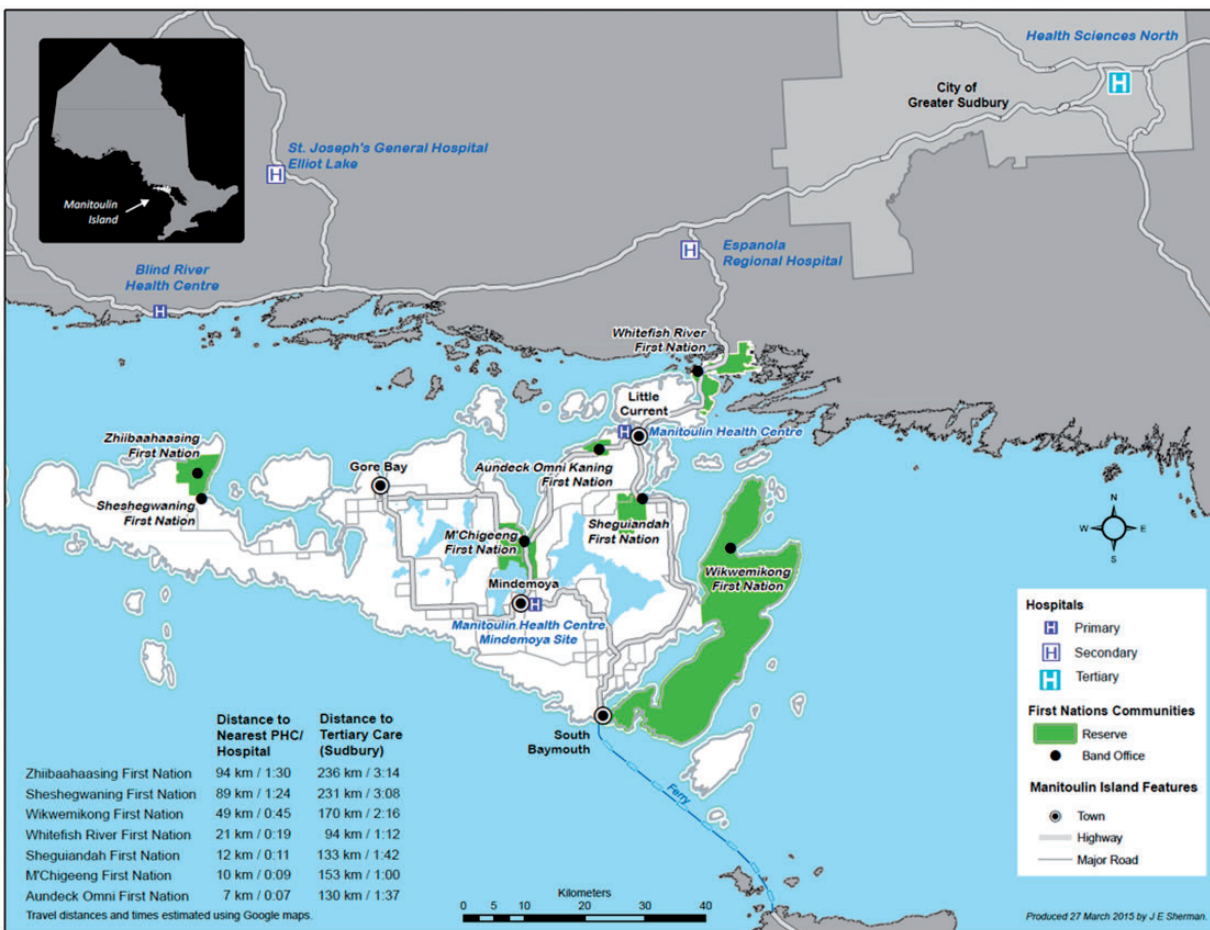


Figure 1. Map of Manitoulin Island, Ontario, Canada.

approach and work closely with a community researcher (KP) and a senior research associate (MB) to facilitate the research at the community level.

Indigenous communities

The Manitoulin region in Ontario, Canada, is home to seven First Nations communities, three First Nations Health Authorities (FNHA), and an Aboriginal Health Access Centre (AHAC). All research that involves Indigenous people or Indigenous health data on Manitoulin Island must be supported by the local leadership and undergo review by Manitoulin Anishinaabek Research Review Committee (MARRC). The MAARC is a local research ethics board (REB), that reviews proposals to ensure the research benefits communities in a culturally safe and ethical manner.⁴⁵ KP lives on Manitoulin Island where she coordinates community projects and conducts research in these communities in partnership with KJ, WW, and MB.

Industry partner

CareBand, Inc. is a new research partner to the long-standing academic – Indigenous community partnership described above. Their Chief Executive Officer (CEO; AS) began developing a wristband technology designed to enable people living with dementia to live safely in their own home and community in the least restrictive way possible. There are 4 active patents on the device (see below), and in 2017, CareBand was named in the “Top 10 Healthcare Tech Startups to Watch” by TechRepublic. CareBand’s CEO (AS) has also received accommodations in 2018 from the American Medical Directors Association. He began working with the academic researchers (WW, KJ) in 2018. CareBand is a wristband system (Figure 2) for monitoring the ambulation and position of persons with dementia. The innovation and characteristics that make CareBand well suited for rural and remote communities are found in the unique combination of Bluetooth Low Energy (BLE), GPS, and Internet of



Figure 2. The CareBand device.

Things (IoT) wireless technology called LoRa to track indoor and outdoor location. CareBand's use of LoRa allows the device to reach distances up to 5–10 miles with optimal power, location, and height of antenna systems. The CareBand wristband communicates first through location beacons placed within the home to the LoRa system of wireless technology. LoRa technology greatest value comes from its versatility to further enable CareBand to function in hard to reach regions without requiring access to traditional forms of Internet access such as cellular towers or WiFi network. It can be worn continuously for three days before requiring a thirty-minute recharge, and also features a locking clasp that requires two hands to remove. CareBand has the capability of capturing and quantifying movement-related behaviours (falls, wandering, agitation, etc.) that are informative to caregivers and clinically relevant to geriatric and dementia professionals. Caregivers can access this information through the CareBand dashboard on their computer or mobile device.

Methods

Community based participatory research (CBPR) approaches and Indigenous research methodologies (IRM)

We utilize a CBPR approach ensuring the communities are actively involved throughout the research process and are confident in claiming ownership over the

research outcomes.^{40,46,47} This approach includes working closely with a local community researcher who is a trusted member of the community, a fluent Anishinaabemwin speaker, and acts as a liaison between the academic and Indigenous partners. KP, an Anishinaabe community researcher and Registered Nurse from Wikwemikong Unceded Territory, has over 14 years research experience, and 30 years of nursing experience on Manitoulin Island. The research team also works closely with a Community Advisory Council (CAC), composed of Anishinaabe language experts, caregivers, Elders, and health care providers representative of the seven First Nations, who are well known and respected throughout their communities. The CAC is involved in every aspect of the research from conception through to knowledge translation and exchange activities.

The research is grounded in IRM in terms of privileging Indigenous knowledge and ways of knowing, following Indigenous protocols, and adhering to the 4Rs of research: respect, reciprocity, relevance, responsibility.^{48–51} Respect is demonstrated through meaningful engagement and research partnerships that address power imbalances that exist within western institutions. The research team acknowledges the local history, culture, traditions, and factors that contribute to social, mental, physical, and spiritual well-being.⁵² The community researcher and CAC guide the research process to ensure the project is relevant and inclusive of the communities they serve. All research findings and publications are vetted through the community researcher and CAC and shared back to the communities and Indigenous partners through multiple formats that are accessible and understandable. Another key component of IRM is the responsibility of the research team to uphold the ethical obligations and expectations outlined at the community level, in addition to those through educational institutions or funding agencies. For our research, this included outlining how the Seven Grandfather Teachings would be respected throughout the entire research process.⁵³

Community and ethical approvals

Prior to entering into a partnership with CareBand, exploratory discussions were brought forward to the CAC. The CAC expressed interest in the wearable technology and approved of the research team pursuing a research relationship with CareBand. Additional approvals were obtained from First Nations Health Directors, and ethical approval was obtained from the Manitoulin Anishinaabek Research Review Committee (MARRC Certificate #2018-15), and the Laurentian University Research Ethics Board (File Number 6008342).

Data collection procedures

CAC meetings. Five CAC meetings took place between August 2018 and September 2019 for review of the CareBand and focus group planning. During the first two meetings, the CAC brought forward questions around aesthetic design, concerns regarding safety and privacy, as well as geographical concerns and GPS functions of the CareBand. The research team worked with CareBand via Google Docs to ask and answer questions about the device. These questions and resulting discussions were used to design the research protocol and questions for the focus groups, which were reviewed and approved in the third meeting. During the fourth meeting, CareBand CEO (AS) and a previous Research Manager, met with the CAC on Manitoulin Island. The meeting began with an opening ceremony welcoming the research relationship and the sharing of traditional teachings as to why the research needs to be conducted in “a good way”.⁵⁴ CareBand answered additional questions relating to cost of the device, monthly fees, and device transferability within the family or community. The CAC also asked questions related to required power source and charging of the device, as well as GPS function, and the caregiver alerts for when the device is removed or irregular movement is detected. Meeting minutes and notes were recorded by the research team (MB, KJ, KP) and used to develop focus group protocols, facilitated by KP. A fifth meeting was conducted after the focus groups were completed to share the research findings back with the CAC as a form of member checking.

Focus groups. Focus groups were conducted in four geographically distinct areas on Manitoulin Island, Ontario, in May and June 2019. Areas were chosen in relation to population size and degree of geographic remoteness. The community researcher and CAC worked with Health Directors, Program Managers, Home Care workers, and Community Health Representatives to recruit focus group participants from six out of the seven First Nations. Targeted recruitment efforts were aimed at Indigenous men and women aged 45 years and older who are natural helpers (people who help Indigenous older adults in their community, regardless of monetary compensation or familial relationship) or caregivers to Indigenous older adults and people with dementia, and Indigenous health care providers aged 18 and older who work with Indigenous older adult populations and people with dementia. Adults meeting these criteria were first suggested by the CAC, health care directors, or community health representatives from each region. Potential participants who expressed interest in

participating in a focus group were contacted by the community researcher for additional information.

Focus group methodology requires unanimous verbal or written consent in order to allow digital recording, any dissenting participant results in prohibiting the recording of the session in favor of handwritten notes. In this project, one group denied the use of digital recording. Participants were encouraged to share their thoughts, feelings, and ideas for use of the CareBand in the language they were most comfortable with (Anishinaabemwin or English). Videos introducing the CareBand system were shown to each group and participants had the opportunity to try on a sample CareBand. Participants were also shown an initial smartphone interface. A total of 29 adults participated in the focus groups. Participants were provided with a meal, refreshments, and an honorarium in acknowledgment of their sharing of knowledge and time. Focus groups were facilitated by the community researcher, with assistance by a research assistant and solicited feedback on the CareBand prototype from Elders, formal and informal caregivers, and health care providers. Questions focused on the look and feel of the device, geographical usability in rural and remote locations, affordability, security needs, and general comfort in using technology, as well adaptations needed to address culture and lifestyle. The topics were not restricted by time, and each community was allowed to distribute their time on any one question in any way they saw fit. The four focus group meetings ranged from 33 to 67 minutes. Following each focus group, the community researcher and research assistant debriefed and recorded participant reactions, observations, and any issues that arose during the focus groups in a narrative summary to assist with the analysis.

Qualitative data analysis

Four senior researchers, with extensive qualitative research experience, engaged in a thematic analysis of the focus group transcripts, narrative summaries and meeting notes (WW, KJ, MB & KP). The focus group transcripts were organized by question and compared across sites through a data table in a word document by MB and KP. Hand coding of the transcripts, as opposed to using a qualitative software program, such as NVivo, was selected due to the small number of focus groups conducted. The narrative summaries from the focus groups were reviewed and any supplementary information included in the data table. The senior authors (WW & KJ) further reviewed the data and identified major themes. These themes were shared back with the CAC and reviewed and approved as a form of member-checking.

Results

The key themes produced by the attending participants were related to the following 6 areas: product aesthetics and comfort; needs associated with rural or remote life; the cost and affordability of the CareBand; issues of security, safety, and privacy; issues related to on-reserve infrastructure; and cultural considerations. Each of these key themes will be discussed in turn.

Product aesthetics and comfort

Several members in all four groups expressed a desire for more options in device styles. The prototype model was called “big and clumsy looking” and “rubbery.” Participants suggested the CareBand might “get caught on something” and all groups asked if alternative styles could include a broach, belt clip, small bracelet, or ankle bracelet. Several groups also expressed concern over the perceived roughness of the fabric and fear that it could irritate the skin of an older adult with thin, fragile skin. The prototype had a patent pending locking clasp that requires two hands to remove. This was liked by some, but others felt that it would induce frustration when people with dementia (PWD) tried to remove the CareBand.

Rural and remote life

A common theme across all groups were concerns related to the stability of the Island’s electric grid and recharging the CareBand. Manitoulin Island can experience frequent power outages during harsh weather, particularly the winter. There was concern that thunderstorms and lightning could affect the CareBand. Generators are used by some on Manitoulin Island and concerns about the CareBand’s ability to recharge using a generator were expressed. There was also concern by some about people who are reportedly unable to wear watches due to accelerated draining of the battery. Participants speculated that this was related to a person’s individual energy field which in some cases was believed to interfere with electronics. While the device does not require WiFi access, participants also expressed concern that using a cellphone interface as a method of monitoring the PWD might be limiting. The CareBand itself does not require WiFi or cellular access to record movement, but a caregiver uses a cellphone to review past movement (e.g. movement within and outside of the home) and behaviors (e.g. falls). Most liked the potential for electronic tracking of the PWD outside the home, but participants questioned what would happen if a wearer moved outside the range of LoRa signal: would the CareBand shut off, what if the PWD visited on the mainland beyond signal range, was the connectivity portable to allow visiting beyond signal

range? Tracking the battery life in an easy way (percent remaining) was also a desired feature. Finally, the effects of extreme temperature variation were questioned. For example, external LoRa hardware (radio bridge sensors) must be installed on phone polls or other tall towers similar to cellular technologies. Whether this hardware is capable of withstanding extremes of weather and temperature ($-30^{\circ}\text{C}/-22^{\circ}\text{F}$, with wind chills gusting to $-40^{\circ}\text{C}/-40^{\circ}\text{F}$) common in this region of Canada remains to be seen.

Cost and affordability

The current estimated cost ($\sim\$30$ monthly fee) was a controversial issue. While some felt that “that is basically a dollar a day, which is a lot of peace of mind for a dollar a day”, others felt the cost was prohibitive, a deterrent, and too much for those on a limited income. Some expressed the hope that subsidies might be available from Indian Affairs or other governmental programs for aging and dementia. The option to rent was also desirable and it was pointed out that other safety monitors are both available to rent and could be subsidized through government programs. Some participants noted that other systems for tracking movement in PWD exist and are subsidized by the government. Features of those products (satellite connectivity, fall detection, monthly fees and subsidies, caregiver safety alerts, etc.) were compared to the promise of the CareBand but uncertainty on what the final model will feature limited this discussion.

Security, safety, and privacy

This topic consumed the most time during the focus groups. The security the device provided caregivers was appreciated by most, particularly as the island affords many safety risks related to geography and the remoteness of the island. Many hoped that the tracking feature alone would enable aging-in-place. The ability to receive alerts and track a loved one who wanders, particularly to protect against drowning, was frequently mentioned as a positive feature. It was also noted, however, that the current model did not appear to have a way for a PWD or older adult to send their own signal that they might have fallen or are confused, lost, or hurt. The timeline for alerts to caregivers was also questioned. All four focus groups also expressed a desire to have a built-in feature for fall detection. Security and privacy of the data collected by the device was also a topic of concern for all four groups. Participants both voiced their concerns regarding access to the data generated and breaches of privacy, while supporting the sharing of data with specific third parties (homecare services, emergency

and rescue services, police, etc.). Not surprisingly given the mistrust of mainstream institutions and researchers, several participants wanted to know how the CareBand Inc. intended to use the data. Finally, the most remote site suggested that the CareBand could be used to monitor the speed the PWD is travelling and send an alert to the caregiver if the PWD is in a moving vehicle when they are not supposed to be – either as a passenger or a driver.

On-reserve infrastructure

In this key theme, participants contrasted on-reserve homes and long-term care facilities. Several participants noted that the homes on-reserve were quite small, possibly so small that only one beacon would be needed within the home. The CareBand was viewed as potentially very helpful in long-term care facilities. Questions were asked about how CareBand would work within a nursing home and what care staff might learn about a resident from the device. The potential within a facility to track visits to the bathroom as a potential signal of urinary tract infections or assistance in resident monitoring during staffing shortages was also seen as a benefit of the CareBand. Having a device such as CareBand could allow programs to more securely bring a PWD out of the community or neighborhood for outings without fear of losing them. Or, in small and remote communities a lack of resources may necessitate bringing a PWD along on trips to larger metropolitan areas. This, in turn, may affect dementia behaviors such as wandering, confusion, and risk of becoming lost. In this situation as well, the availability of surveillance technology may be of particular value.

Cultural considerations

Several participants indicated that the device and app should be uncomplicated and friendly to use by an Anishinaabe older adult or caregiver. The desire for the device messaging feature and related materials to be in Anishinaabemwin was expressed. Some participants feared that proud Anishinaabe older adults would be offended by the idea that their movements would be tracked. As with the key theme of security, safety, and privacy, participants thought the possibility for sharing alerts with multiple friends, neighbors, informal caregivers, or family members was desirable. Focus group participants speculated that the CareBand would help give peace of mind to family who work off-reserve or off-island. In cases where family members are not available, other community members or natural helpers seamlessly step in to assist PWD in a way that is consistent with traditional Anishinaabe values.

Given this, participants saw potential benefit in giving multiple people permission to review surveillance technology alerts. Range was discussed in relation to cultural activities and a desire to ensure the PWD could continue to participate in land-based activities – the possibility of a mobile tracking box for group outings was well received. It was also noted it would be important that the device could include a way to signal for help if the PWD fell in the bush.

Results summary

This review of key themes and behavioral observations during the focus group sessions indicates that the six Manitoulin Island Anishinaabek communities saw both positives and negatives related to the use of this technology. The industry partner was offered several ways in which the aesthetics of the CareBand and its functionality could be improved both in general (size, style, incorporation of additional dementia-related symptoms, cost model) and specific to Indigenous culture and rural life (environmental hardening of the hardware, language in messaging, support land-based activities, wide support network, subsidies by Indigenous and Northern Affairs, or Health Canada). The increased incidence in dementia in Indigenous communities over the past decade^{1,2} has encouraged Indigenous communities to seek out new approaches to manage and treat these conditions in culturally appropriate ways. From the perspective of an industry partnership, the opportunity to receive direct feedback from Indigenous community members on a prototype and to hear their thoughts and wishes for further product development represents the goal of high quality co-designing of products for dementia care.^{28,29}

Conclusions

Multiple models of aging-in-place technology are available that include continuous monitoring (AKA surveillance technology) within the community⁵⁵ and cognitive stimulation or tracking of cognitive change;^{56,57} but the current study is the first to use CBPR to engage rural North American Indigenous communities in the early stages of a dementia care product development. While other countries have made a concerted effort to engage Indigenous older adults, particularly in Australia,^{23,57,58} North America has lagged behind. Studies of assistive technology in Indigenous communities have been conducted,^{59,60} but these technologies were low technology devices (canes, prosthetics, walkers, etc.) and not dementia specific. In fact, recent systematic reviews of community engagement in the development of dementia care technology^{25,26} show that the omission of ethnicity and

rurality as variables, has been common in this field. In the present study, intentionally engaging six rural Indigenous communities in Canada led to firmware and hardware design issues that might not have otherwise been evident among urban participants or contexts. Most notable is the request by participants that a wide range of people be included in the contact list for the PWD. This may contrast with the typical urban, dominant culture focus group feedback where privacy and identifying one designee as primary caregiver or power of attorney is more common. So too is the recognition by these rural participants that certain geographic features pose heightened risk may be less relevant in large urban settings (e.g. bodies of water or forests as opposed to street traffic or unfamiliar neighborhoods). Community partners provided the CareBand representatives with multiple suggestions for product improvement and the inclusion of features previously not considered. For example, the suggestion to include detection of unusually high rate of movement (driving speeds) and alerts if indicated by care needs (driving license revoked) could significantly increase caregiver peace of mind and safety for the PWD. While not needed by all users, future study of the feasibility and programming of such a feature as an option is within the capabilities of this device. CareBand and academic researchers learned about Indigenous understandings of dementia and culturally-based care practices. Rural communities will also benefit from a product capable of providing safety monitoring of their loved ones that is free of the typical burdens related to limited internet and cellular connectivity. The inclusion of Indigenous older adults who provide formal or informal dementia care helps to ensure that the final product is culturally safe, useful to the community, and valued by the community as an important tool for aging-in-place. Future projects should address design issues for caregiver feedback of behaviors tracked by the system.

Despite the lack of inclusion of Indigenous communities early in product development by technology producers and creators, Indigenous communities have not sat idly by but have instead embraced mobile technology in unique and creative ways.³ As indicated earlier, there are several examples of quality research programs using community-based, culturally safe approaches to technology development,^{18,61,62} though there remains severe limitations in studies conducted within the area of dementia care for Indigenous communities. Although generalizing from one Indigenous community to another is fraught with problems, the current results show that caregivers of persons with dementia and professionals are eager to participate in technology development, they provide unique problems for industry to solve, and using their local knowledge of

dementia care within the culture, they can provide potential solutions that will enhance eventual marketability of wearable technology for dementia care. This research partnership involved technology that had already been conceived and held the potential to respond to an identified behavioural issue related to a dementia diagnosis – namely wandering. The community partners approached the project with caution but also with great interest as they understood the potential benefits. The already established research relationship between the academic partners and the community partners likely played some role in the initial acceptance of the project. The application of the CBPR and IRM to this technology development research were also crucial. As is the case for any research involving Indigenous populations, it is imperative that Indigenous knowledge and ways of knowing are prominent in the process. This project confirmed what an earlier literature review found that partnership approaches that are respectful of Indigenous methodologies hold the greatest potential for success.³ This project revealed some more specific elements of the process that can help guide others seeking to work with Indigenous partners: chose a research topic that addresses a community priority; engage with communities early; seek formal community approvals before you begin any research activities; hire and train local community researchers who understand the culture and community context; work with a community advisory group or advisors; govern, plan and implement the project jointly; and seek continual feedback and approvals at each stage.⁶³

As with all studies, the current study has several limitations that need to be acknowledged. In our focus group work with Manitoulin Island, we did not have an active wear period. Although this was intentional to allow for feedback prior to beta testing newer models on the island, it is clear that actual wear of the CareBand would greatly enhance the range and quality of feedback that caregivers and professionals are able to provide. In addition, we limited this first study to one geographic region in Canada. Expanding this work to other Canadian or North American communities would greatly enhance the depth of knowledge gleaned from other rural Indigenous communities and provide important tests of the generalizability of some of these findings. Given these two observations, future directions for this work would be to expand to other Great Lakes Anishinaabe communities or beyond for further qualitative analysis, to provide an extended wear period for firmware development, and to engage Indigenous caregivers, PWD, and professionals in the design and development of dementia-related software in a wearable technology format.

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Contributorship

KP, MB, AS, KJ and WW conceived the study. KP, MB, KJ and WW developed the protocol along with the CAC, gained ethical approvals, recruited participants and conducted the data analysis. All authors researched the literature. AML wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

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