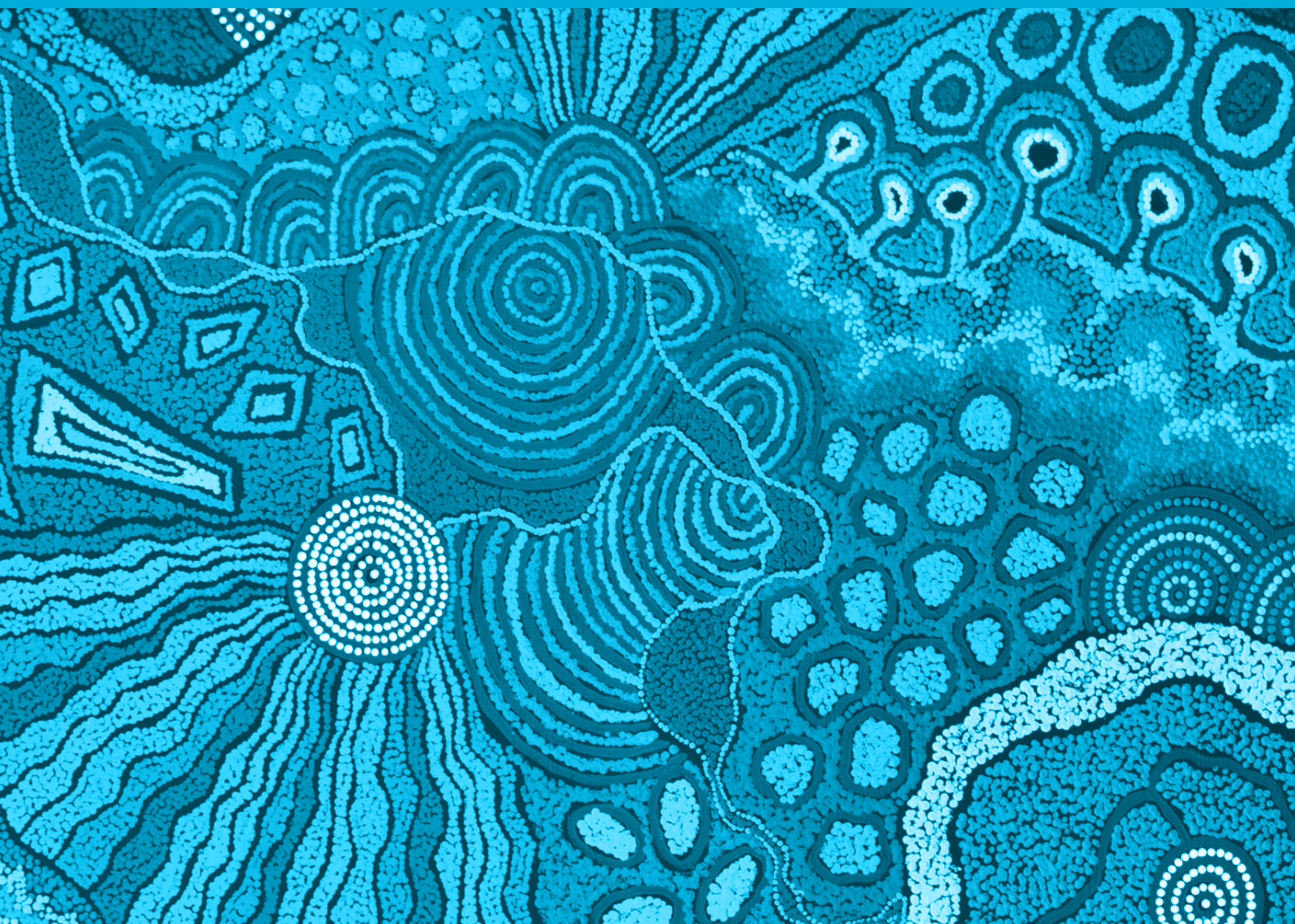# At home in Quandamooka

Scoping report for the feasibility and cultural safety of Smarter Safer Homes with Aboriginal and Torres Strait Islander people in Quandamooka Country

Acknowledgements

Winnam Aboriginal and Torres Strait Islander Corporation's board of directors and staff pay our respects to both the traditional owners of the land on which we live and work and to all Elders, past and present. We also appreciate that Aboriginal and Torres Strait Islander people continue to keep an ongoing cultural connection and care to Country.

This report features designs by Casey Coolwell. Casey is a Quandamooka, Nunukul woman from Minjerribah (North Stradbroke Island) with links to the Eulo and Biri people of Bowen.

ISLANDS: This artwork represents the connections between land and sea. The solid lined circles represent each island/community and the small gathered dots represent the waters connecting each place.

Cover image: Shutterstock

Figure 1: *Quandamooka Country Map*[1]

[1] Quandamooka Yoolooburrabee Aboriginal Corporation - ICN 7564; State Election 2017; Policy Questions to the Political Parties. Available at: http://www.qyac.net.au/docs/StateElection.pdf

Abstract

Background: Historical and contemporary experiences of colonisation and racism have contributed to disadvantage experienced by Aboriginal and Torres Strait Islander people. Difficulties accessing culturally safe health and aged care compound these challenges.

Emerging digital technologies have been developed to assist older Australians to live safely and independently in their homes or in aged care facilities. Researchers at the Australian e-Health Research Centre (AEHRC), CSIRO's digital health research program, have developed the Smarter, Safer Homes (SSH) platform which has been trialled in homes across Australia.

Methods:

A scoping study was conducted to consider the use of SSH and its cultural appropriateness for urban Aboriginal and Torres Strait Islander older people in partnership with the Winnam Aboriginal and Torres Strait Islander Corporation (WATSIC). Study approval from WATSIC Board was received in June 2019. The Winnam General Manager, staff of the Georgina Hostel and representatives from AEHRC arranged two meetings in November 2019. These sessions sought the perspectives of WATSIC Members and Georgina Hostel aged care staff on the feasibility to trial the SSH platform in Winnam's affordable houses and the Georgina Hostel.

Results:

A meeting held at the *Georgina Hostel* on 11 November 2019, included four AEHRC staff, two WATSIC staff and five Georgina Hostel staff.

Participant feedback demonstrated that staff were curious and receptive to the concept of the SSH platform and could see value in the collection of data that would support the health and safety of the residents. They did express concern about the residents' possible discomfort regarding privacy fears and this would need to be carefully addressed. However, their support for the SSH trial stemmed from the potential to lift communication with health care providers including General Practitioners (GPs). Additionally, there was a consensus that the long-term data collection could support decision making about level of care (need for transition) and contribute to preventative measures to better support residents.

A meeting with targeted *Winnam ATSIC* Members took place on 13 November 2019, with one AEHRC staff, two WATSIC staff and four Winnam Members.

Participant discussion emphasised the significance of their family connections, shared culture, historical impacts, their privacy and health which strongly influence their daily decisions. Participants were receptive to the SSH platform and noted the potential for data to support preventative health steps but did not believe the system was relevant to them individually (yet). Rather, the SSH platform would assist care and safety of older members of their community who relied on home care services. A trial must have a 'whole of community' approach and acknowledge the complexity of family situations and the historical experiences of many older Aboriginal and Torres Strait Islander people. Familiarity with devices and other forms of technology for those in the older generation may also be a challenge. Collaboration with other Quandamooka representatives, use of local language and artwork in the portal would strengthen the trial feasibility.

Recommendations:

Four key recommendations are made as a result of this collaborative scoping study.

1. Planning should proceed for a trial of the Smarter, Safer Homes platform at the Georgina Hostel (incorporating appropriate Human Research Ethics approval).

2. Planning should proceed for a trial of the Smarter, Safer Homes platform within the Winnam ATSIC community housing (incorporating appropriate Human Research Ethics approval).

3. Engagement processes for these trials must ensure that all personnel involved in the trial are informed and acknowledge;

   a. the mission and values of the Winnam ATSIC community – strong connections and caring relationships; and

   b. the generational challenges that continue to impact the health and wellbeing opportunities for Aboriginal and Torres Strait Islander people.

4. Project planning will be strengthened by additional collaboration with established networks in the Quandamooka region.

List of Terms and Abbreviations/Acronyms

Abbreviation/Acronym	Meaning
AEHRC	The Australian e-Health Research Centre
ATSICCHO	Aboriginal and Torres Strait Islander Community Controlled Health Organisation
CSIRO	Commonwealth Scientific and Industrial Research Organisation
[The] Community	Residents and members of the Winnam Corporation and the Quandamooka regions
GP	General Practitioner
Georgina Hostel	Georgina Margaret Davidson Thompson Hostel (residential aged care facility in Morningside, Brisbane)
IUIH	Institute for Urban Indigenous Health
Members	Members of Winnam Aboriginal and Torres Strait Islander Corporation
NACCHO	National Aboriginal Community Controlled Health Organisation
Project Team	Project members from WATSIC, Georgina Hostel and CSIRO
QYAC	Quandamooka Yoolooburrabee Aboriginal Corporation
RACF	Residential Aged Care Facility
Residents	Residents of the Georgina Hostel (Aged care or Independent)
The Sector	Aboriginal and Torres Strait Islander Health Sector
The Study	The Scoping Study carried out by Winnam and CSIRO as reported in this document
Winnam or WATSIC	Winnam Aboriginal and Torres Strait Islander Corporation

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1 Introduction

An increasing proportion (~15%) of all Australians are aged 65 years and older (1). However, while Australians are living longer, many of them experience chronic conditions (2).

For Aboriginal and Torres Strait Islander people, ageing-related conditions are experienced at earlier ages than non-Indigenous Australians. Historical and contemporary experiences of colonialist policies and racism (direct and indirect) have contributed to this gap and have severely disadvantaged Aboriginal and Torres Strait Islander people, including those in urban areas (3,4).

Difficulties accessing culturally safe health and aged care compound the challenges faced by Aboriginal and Torres Strait Islander people. Solutions to support Aboriginal and Torres Strait people to live with autonomy and safety on Country are needed (5).

Emerging digital technologies have been developed by health and medical research to assist older Australians to live safely and independently (where possible) in their homes or in residential aged care facilities. Such technologies offer passive remote monitoring of the activities of daily living through sensors which feed activity data to a central portal. Family members and clinicians can view details of data to identify any gradual or sudden changes in the wellbeing of the resident, prompting contact to clarify the cause of changes. Resident feedback regarding the technology has been mixed, but overall, positive outcomes are reported (6). The Commonwealth Scientific and Industrial Research Organisation has developed Smarter, Safer Homes (SSH) which has been trialled in homes across Australia.

This report considers the use of the SSH technology and its cultural appropriateness for urban Aboriginal and Torres Strait Islander older people. It outlines the relevant literature, methods and results of a scoping study. The research sought the perspectives of Winnam residents and aged care staff of the feasibility for SSH technology to be trialled in Winnam's affordable houses and within an aged care Hostel.

2 Literature

2.1 Ageing population and policy responses

An increasing proportion (~15%) of all Australians are aged 65 years and older (1). A combination of factors including advances in medical treatments, health prevention programs and technology has enabled an increase in life-expectancy (7). However, while Australians are living longer, many of them experience chronic conditions (2). For Aboriginal and Torres Strait Islander people, ageing-related conditions are experienced at earlier ages than non-Indigenous Australians. The proportion of Aboriginal and Torres Strait Islander people aged 65 years represents approximately 5% of the national Aboriginal and Torres Strait Islander population (1).

The impact of this trend has been increasing pressure on health and social systems to enable and support healthy living and quality of life into the later years (1, 8). In anticipation of this shift, the Australia federal government has implemented changes to welfare and health system services in a move to assist people to 'age in place' (i.e. to live at home as long as they wish). A key policy designed to facilitate this is the Home Care Packages Program (9). Eligibility is determined by an assessment2, and once approved, consumers have the choice of what subsidised in-home services they need and which provider they prefer. Once a person is considered to require high-level personal care services, they may need to enter a residential aged care facility (RACF). Accommodation and services of RACFs are also funded, or co-funded by the Australian government to assist with affordability and accessibility (10).

Emerging digital technologies developed by health and medical research organisations plus commercial entities are also being used to assist older Australians to live safely and independently (where possible) in their homes or in RACFs. For example, diabetes care models are being optimised through remote monitoring via Bluetooth glucometer devices and data portals accessible by health professionals (11).

2.2 Healthy ageing

Accepted definitions of 'health' do not always represent the diversity of individuals and values of society. However, the concept of health usually means more than simply a lack of illness, but an ability to live with meaning and purpose through strength across physical, mental, social and spiritual dimensions (2). Aside from an individual's genetic makeup, health and wellbeing is determined by life context – also known as the 'social determinants of health' (e.g. housing, employment, policies) (2). The complex interaction of biomedical, social and cultural determinants will influence the opportunity for older Australians to experience health and quality of life (1).

2.3 Healthy ageing for Aboriginal and Torres Strait Islander people
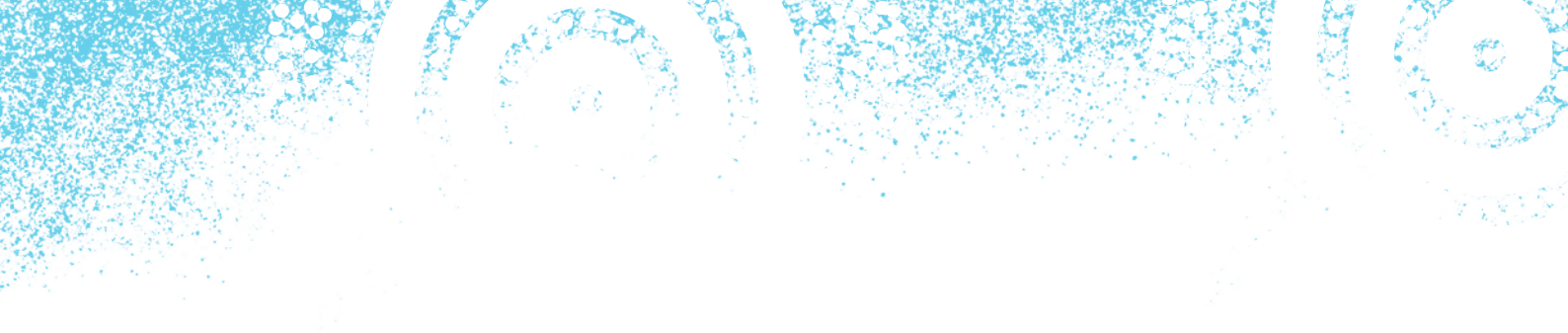
2.3.1 Health concepts

Aboriginal and Torres Strait Islander peoples' expression of health is a broad concept drawing on self and others, as a Community, in which the health and wellbeing of all is key. Health, therefore, is a holistic balance of physical, mental, emotional, cultural and spiritual well-being that includes strong connections to family, kin, Country and Community (12, 13). It does not have an individualistic emphasis, as it does for many non-Indigenous people (14). This is reflected in the constitution of the National Aboriginal Community Controlled Health Organisation (NACCHO) (15) as follows.

"Aboriginal health" means not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being thereby bringing about the total well-being of their Community. It is a whole of life view and includes the cyclical concept of life-death-life. (pg.5,6)

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2 This assessment is referred to as an ACAT (Aged Care Assessment) and is conducted by a government assigned assessor in the person's residence. For further information visit: https://www.myagedcare.gov.au/assessment

Aboriginal and Torres Strait Islander people express a number of key values that help them age well. For residents of South Western Sydney, engagement in meaningful activities that maintained connection to Community, their sense of identity, their family, their physical and mental health were vital (8).

2.3.2 Historical considerations

Indigenous people from across the globe, including Aboriginal and Torres Strait Islander people have endured the generational impacts of colonisation and government policies (16). In the Australian context, these policies have included the following events (17).

- Separation of children from their families, the 'Stolen Generation'
- Separation from Country and sacred lands
- Forced housing in camps and missions
- Restrictions to use of language, cultural values and foods
- Wage theft and payment in-kind with drugs and other materials

Contemporary presence of colonisation is seen in racism and marginalisation of Aboriginal and Torres Strait Islander people and continued severance of their connections to Country, kinship, language and culture (18-20). Collectively, these historical and modern processes impact lifestyle opportunities for health and wellbeing of Aboriginal and Torres Strait Islander people (16, 21-23).

2.3.3 Social and economic changes and implications

Over three quarters of Australia's Aboriginal and Torres Strait Islander population live in metropolitan areas (4, 24). Historical events and policies have contributed to the urbanisation of Aboriginal and Torres Strait Islander people. Firstly, displacement from homelands during the Stolen Generation saw Aboriginal children being taken away from their families and placed in other locations (4). Secondly, the end of the Protection Act in 1969 meant Aboriginal and Torres Strait Islander people who had been forced onto missions were now permitted to go back to their homelands or move into the cities (4). Similar to trends of other Indigenous people across the globe, many Aboriginal and Torres Strait Islander people chose to remain in the cities because the cities were built on their traditional lands, and/or for access to opportunities such as employment and education (4). For the Quandamooka people, Brisbane City was built close to and on their traditional lands (3).

The historical and contemporary experiences described above have severely disadvantaged Aboriginal and Torres Strait Islander people. Many Aboriginal and Torres Strait Islander Elders have lived through the fight to end racist policies. Furthermore, those living in more urban and regional areas have lived through massive societal changes including significant population growth, commercial and industrial growth, birth of the technological age as well as global disruption (e.g. World War II). Quandamooka Elders have stood strong together throughout the past three to four decades to ensure the voices of and opportunities for Aboriginal and Torres Strait Islander people are heard and realised. This process has demanded persistence and determination, with challenges to education, resources and employment opportunities.

The 2016 monograph series by Brand, Bond & Shannon (3, 4) provides a comprehensive overview of the socio-economic factors that contribute to the poorer health and wellbeing outcomes of the urban Aboriginal and Torres Strait Islander population. While a portion of Aboriginal and Torres Strait Islander people have relatively more opportunities than their regional and remote counterparts, they remain at a disadvantage compared to non-Indigenous Australians. In fact, Brand et al. highlight a "challenging socioeconomic profile" (p.3) for Aboriginal and Torres Strait Islander people in urban areas. Aspects of disadvantage include housing, education and employment, which feed into poorer health and wellbeing outcomes (3).

2.3.4 Chronic illness outcomes for Aboriginal and Torres Strait Islander people

The disadvantage attributed to the complex interaction of racism, marginalisation and rapid social and economic change has translated to poorer health outcomes for Aboriginal and Torres Strait Islander people. This includes a current life-expectancy gap of 11.9 years, and an overrepresentation of Aboriginal and Torres Strait Islander people in chronic and geriatric diseases, such as diabetes, chronic respiratory disease and cardiovascular disease (4, 24, 25).

It is important to note that while life expectancy for Aboriginal and Torres Strait Islander people is up to 20 years less compared to non-Indigenous people, research shows (26) that only some diseases are early-onset and the gap in life expectancy decreases as people age. A recommendation of this study was for the Australian Government to focus on combatting those specific conditions for middle-aged people rather than applying blanket aged care services to middle-aged Aboriginal and Torres Strait Islander people (26).

2.3.5 Cultural identity

Another central theme reported by Waterworth et al. in 2016, was a lack of cultural identity that impedes healthy decision-making for urban Aboriginal and Torres Strait Islander people (27). Displacement from traditional lands and family is a significant contributor to loss of identity. This is due to the stolen generation and from having to move away from Country for employment and education. Living in an urban setting makes it difficult to stay in balance with both Aboriginal and Torres Strait Islander and Western cultures. The respondents believed that strong culture leads to strong personal identity, leading to confident decision-making in line with personal values that lead to better health outcomes (4, 27).

Although many Aboriginal and Torres Strait Islander people express a lack of cultural identity, a connection to culture is still prevalent for urban Aboriginal and Torres Strait Islander people. Cultural identity is central to expressions of healthy ageing by Aboriginal and Torres Strait Islander people. For example, many Aboriginal older people provide leadership, caring responsibilities for grandchildren and live in multiple generation households (8, 28). However, there is a reported decline in reciprocal caring by younger generations for Elders (8).

2.3.6 Access to services impact on health

The health challenges and disadvantage experienced by Aboriginal and Torres Strait Islander people are further compounded by difficulties in accessing culturally safe health care. The root cause of most barriers faced by Aboriginal and Torres Strait Islander people when seeking health system support in Australia, is racism (29, 30).
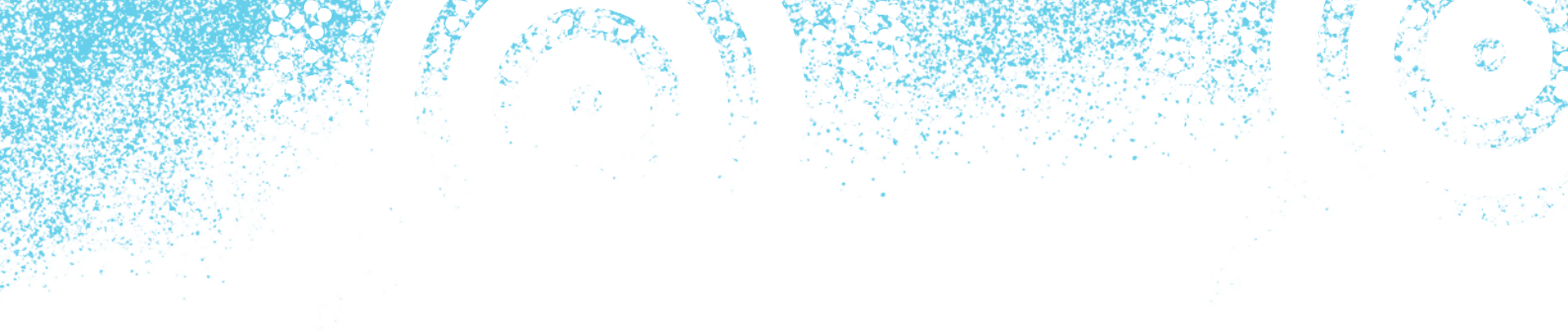
It is important to understand that racism is experienced not solely through deliberate acts of prejudice, but rather, more subtly by institutionalised practices (31, 32). Such practices include discrimination on account of the way a system is designed and operates which also can discourage further contact and help-seeking by older Aboriginal and Torres Strait Islander people.

2.3.7 Health care reach in South East Queensland

Prior to the creation of the Institute for Urban Indigenous Health (IUIH) in 2009, it was assumed that Aboriginal and Torres Strait Islander people living in Brisbane had ease of access to health care through mainstream services (3). However, Aboriginal and Torres Strait Islander people were not accessing these services, as evidenced by public health providers believing that urban Aboriginal and Torres Strait Islander populations were hard to reach (24).

Brand et al. (2016a) describes this as 'Indigenous invisibility', where urban Aboriginal and Torres Strait Islander people are ignored because they are spread across urban populations, not from distinct 'communities' that fit the stereotype of remote areas. This invisibility "…

ignores the strong family and kinship ties that characterise Indigenous communities in urban areas…" and diminishes the cultural appropriateness required for quality health care (Behrendt, 2009 in (3, p.14)). Combatting Aboriginal and Torres Strait Islander 'invisibility' was a part of the reason why IUIH was created.

Strategic work in the last decade by IUIH has responded to the growing population and Aboriginal and Torres Strait Islander invisibility by establishing a System of Care that facilitates access for Aboriginal and Torres Strait Islander people of South East Queensland. It covers a spectrum of Aboriginal and Torres Strait Islander services including primary health care, school, kindergartens, legal, housing and media services through various Aboriginal and Torres Strait Islander corporations. However, challenges remain regarding the continued population growth which impacts scale and access (4, 24).

2.3.8 Local considerations

As stated previously, the majority (79%) of Aboriginal and Torres Strait Islander people live in cities, meaning this is where the majority of the burden of disease exists (24). This highlights the increasing importance of accessible and culturally appropriate health and aged care services (4, 24-26).

In Brisbane, this is particularly relevant, since it is estimated that by 2031, the Aboriginal and Torres Strait Islander population in South East Queensland (SEQ) will increase to over 130,000 people (3). Current Census data report that 2,134 Aboriginal and Torres Strait Islander people aged 65 years and over live in the Brisbane region (33). This is an increase from 2011, whereby 1,630 Aboriginal and Torres Strait Islander people aged 65 and over were reported to be living in Brisbane (34).

Census data drawn from Wynnum-Manly, Capalaba and Cleveland-Stradbroke Statistical Area Level data[3] from the 2016 ABS Census, reported a total of 262 Aboriginal and Torres Strait Islander people aged 65 years and older living on Quandamooka Country.

It is important to note that resident numbers should be viewed as estimates rather than absolute, as Census data does not necessarily capture every individual in Australia. Aboriginal and Torres Strait Islander data is subject to adjustments by the Australian Bureau of Statistics. However, such data is valuable in needs assessment and service planning for regions.

2.4 Health technology to support healthy ageing in place

Research to explore the perspectives of people aged 65 and over regarding in-home wireless monitoring, have reported mixed themes (35, 36). While participants expressed concern over the safety of living alone (e.g. risk of falls), their value of independence and freedom from 'monitoring' by others was strong.

Focus groups with community-dwelling older persons, their family members and friends in the United States (35) reported perceived benefits for participants to include: possibility of earlier help when needed if something was wrong. Monitoring of physical health data (i.e. blood pressure, blood sugar etc.) was important to older people, whereas wellbeing measures (i.e. social outings, walking, general activity) was more important to family and friend participants. Similar research in Belgium, used a survey to summarise attitudes and perceptions of older adults to in-home monitoring. Acceptance of the system by participants was based on its capability to: support ageing in place by promoting safety and independence, but also the "…timely detection of emergency situations and gradually emerging health problems" (36, p.134).

However, in both studies, participants were not convinced that they needed monitoring, given they did not believe they had experienced any decline in capabilities yet. The systems would be useful in 'later life' (35, 36). They also wanted 'pragmatic justification' as to why it was necessary and wanted control over who would access the data, although were not overly

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[3] Estimates included data from Statistical Area Level 3 for the regions of Wynnum-Manly, Capalaba and Cleveland-Stradbroke. Source: 2016 Census: Aboriginal and/or Torres Strait Islander Peoples QuickStats, https://www.abs.gov.au/websitedbs/D3310114.nsf/Home/2016%20QuickStats

concerned about privacy. Participants noted the possibility of an overwhelming amount of data and the fact that doctors do/may not have time to analyse it. Older persons in one study noted that people physically checking up on each other keeps people in touch, and the introduction of monitoring may keep people at a distance (with risk of isolation) (35, 36).

Other concerns included: privacy, limitations of system regarding age-associated changes (e.g. hearing, sight or adjustments), possible stigmatisation by others or visitor concerns about the presence of the sensors (36).

Several references emphasise that self-reporting via a GP practice or other health professional is not necessarily a reliable indicator of older peoples' wellbeing. Factors such as self-awareness, cognitive decline or choice, pose challenges to identification of changes in health or self-care. As such, monitoring activity through in-home systems may offer assurance and be useful in predicting early cognitive (acute and gradual) changes in elderly people that require medical intervention (35-37).

2.5 Health technology to support healthy ageing on Country for Aboriginal and Torres Strait Islander people

2.5.1 Cultural appropriateness

Contemporary research by Parmenter et al. (2019), through focus groups highlight social emphasis as key factor in any health intervention with Aboriginal and Torres Strait Islander people. Other key elements include: prioritising relationships; encouraging empowerment; self-management; supporting staff training around cultural responsiveness and respectful support for priorities of Sorry Business, family needs and illness (38).

Important elements reported for primary- and aged-care services that support older Aboriginal and Torres Strait Islander people, include three main themes (12).

- "Maintaining Indigenous identities" – Family, Community and Country connections are kept strong; Traditional ways are maintained.

- "Promoting independence" – Recognition that person may not be "sick, I am just old"; Encouraging Elders to remain active and live life on their own terms; Ensure quality information for informed decisions; Enable ongoing contributions to Community.

- "Delivering culturally appropriate care" – Free from prejudice; Well-functioning; Allow Elders' contribution to design and delivery of services; Assistance and advocacy entitlements; Offering understanding when Sorry Business happens.

Central to participant engagement in health programs or use of a new technology is the need for acknowledgement by the whole project team of historical and societal influences on Aboriginal and Torres Strait Islander people. This awareness assists understanding about some Elders' mistrust of governments and institutionalised systems, fear of loss of language, and independence. It also emphasises the need for respectful, personal communication and right of choice (27).

Continuity for traditional ways and cultural practices, where possible, also supports a healthy lifestyle for Elders, for example, speaking in language and participating in 'traditional practices like bush tucker, drinking water, walking, better diet and exercise with the old ways.'

The cultural considerations of health programs and interventions is well summarised in a statement by Carteret (2010; in Parmenter et al. 2020, p.2).

"Culturally responsive care has been defined as "an extension of patient-centred care that includes paying particular attention to social and cultural factors in managing medical encounters with patients from very different social and cultural backgrounds."

2.6 Smarter, Safer Homes platform

The CSIRO Smarter Safer Homes (SSH) platform takes advantage of the latest wireless communication technologies in home and health monitoring sensors, to provide a smart home with consumer design interfaces and engagement of informal (e.g. family) support. This platform aggregates information from wireless sensors (Figure 2) placed in a person's living environment to infer an individual profile of functional and health status to enable support from family members or carers and clinicians (Figure 3).

2.6.1 Activities of daily living

To measure the functional and health status of older people in gerontology clinical settings, the Katz ADL scale (39) is widely adopted to quantitatively measure the ability of independent living for elderly people in clinical and home environments. Motivated by this, the SSH platform extracts activities correlated to the resident's functional and health status included in the Katz ADL scale (39), including mobility, meal preparation, dressing, hygiene and posture transfer. These activities will then be integrated as a unique indicator to the health and wellbeing of resident/s, i.e. the objective Activity of Daily Living index (oADL).

Compared to the Katz ADL that is based on the subjective assessment from clinical staff and self-reported responses of the elderly, the oADL is an objective measurement that continuously assesses everyday ADL of seniors in their own home environment to provide a long-term care and support. Furthermore, the oADL scale automatically aligns well with residents' individual activity performance and thus becomes a personalised scale that can best reflect individual's functional and health status. This enables the SSH platform to accurately monitor any adverse changes of independent living seniors' activity pattern and send alarms to family members or carers for prompt intervention when these changes are drastically away from normal patterns. The SSH platform development and trials have been extensively published (6, 40-46).

Figure 2: *Wireless sensors placed in a two-bedroom residence*
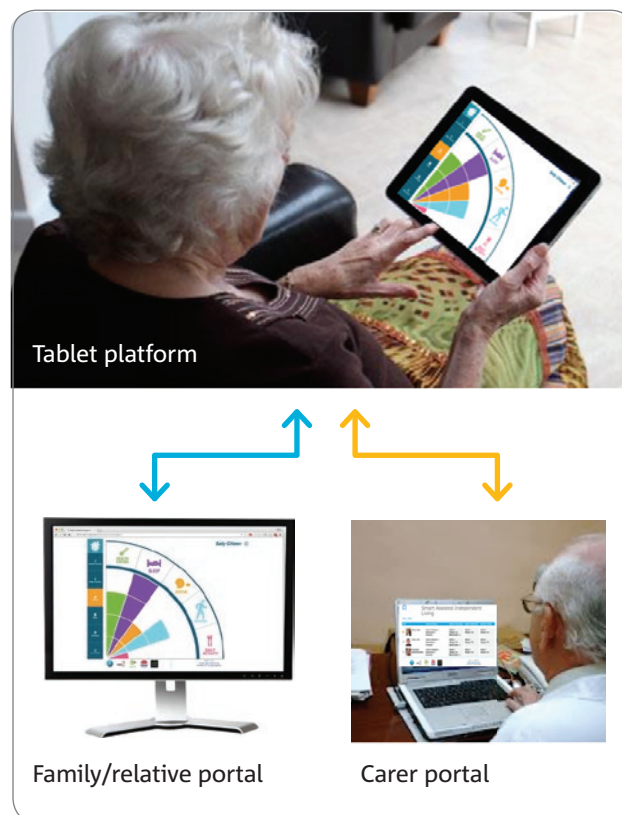
Figure 3: *Smarter, Safer Homes architecture with portals for resident, family and clinician*

2.6.2 Participant perceptions

Resident feedback from the trials of the SSH platform have included the following outcomes.

Positives:

- After a period of adjustment, residents did not find the system interfered with their lifestyle or routines (41).

- Overall usefulness of the system reported by residents and their families, particularly when frailty increased (41).

- After initial lack of confidence with iPad technology (portal), residents became more comfortable and benefited from guidance by grandchildren (41).

Concerns:

- Despite the knowledge that sensors did not include cameras or audio recording, some residents expressed hesitations about private and personal activities (41).

- Other feedback included negative interpretations of a residents' routine e.g. judgement about skipping some daily activities like changing clothes (41).

- Annoyance with the iPad and some of the sensors (41).

3 Methods

3.1 Study rationale and parameters

This collaborative project between the Winnam Aboriginal and Torres Strait Islander Corporation (WATSIC) and the Australian eHealth Research Centre (AEHRC) aims to support older Aboriginal and Torres Strait Islander people to live happy and well on Quandamooka country. The "At Home in Quandamooka" project aims to make the SSH technology useful and culturally appropriate for urban Aboriginal and Torres Strait Islander older people. The scoping phase of the project sought perspectives on healthy ageing, factors that impact ageing such as: geography, language, culture, mental health, social and emotional wellbeing, health literacy, chronic disease, childhood adversity and trauma, removal and social exclusion, social economic status and attitudinal change in the lifespan. The study also aimed to determine attitudes towards home monitoring and co-design of health monitoring systems that allow freedom of cultural expression in a health supported home environment, with the potential to delay or prevent the need for institutionalised residential care. It does not represent a formal research project and consultation was undertaken accordingly. Where further investigation is identified as an outcome of the findings, it is envisaged that a research framework including relevant ethical approval would be commissioned.

3.2 Objectives

This Study aims to explore the perspectives of the Winnam ATSIC Members on the feasibility and cultural appropriateness of this emerging technology, to support Aboriginal and Torres Strait Islander people to age well on Country.

3.3 Study partners

3.3.1 Commonwealth Scientific and Industrial Research Organisation

The Commonwealth Scientific and Industrial Research Organisation (CSIRO) is Australia's largest scientific research organisation. The AEHRC is a business group within CSIRO, based at the Royal Women's and Brisbane Hospital in Queensland. AEHRC started as a joint venture between CSIRO and the Queensland Government over 14 years ago and has delivered considerable impact within the e-Health space at both state and national levels. AEHRC undertakes research in a number of e-Health areas including Medical Imaging, Medical Text Analysis, Health Services research (including, remote and mobile health), Health Informatics, specifically in the field of data interoperability (e.g. Snomed CT, FHIR an HL7 architecture development) and Health Data Analytics.

3.3.2 Winnam Aboriginal and Torres Strait Islander Corporation

WATSIC is an enterprising community organisation that is a holistic service provider for the Aboriginal and Torres Strait Islander community in the Wynnum and Bayside Suburbs of Brisbane. These are within the boundaries of the Quandamooka country where the pandanus palm once grew in abundance. Winnam takes its name from the Aboriginal word for pandanus palm.

WATSIC is a 100 per cent community-based and controlled, not-for-profit corporation. It uses all its income to extend or improve services for local Aboriginal and Torres Strait Islander people. Winnam was incorporated in 1990 by local Aboriginal and Torres Strait Islander volunteers and now has approximately 40 properties in the local Bayside area that are used to provide affordable housing to local Aboriginal and Torres Strait Islander people. Winnam is a safe and trusted backstop for people in the community providing safe, affordable housing options for members of the community who face economic and social hardship, such as unstable employment, low income and discrimination.

Figure 4: *Georgina Margaret Davidson Thompson Hostel - known as Georgina Hostel in Morningside, Brisbane*
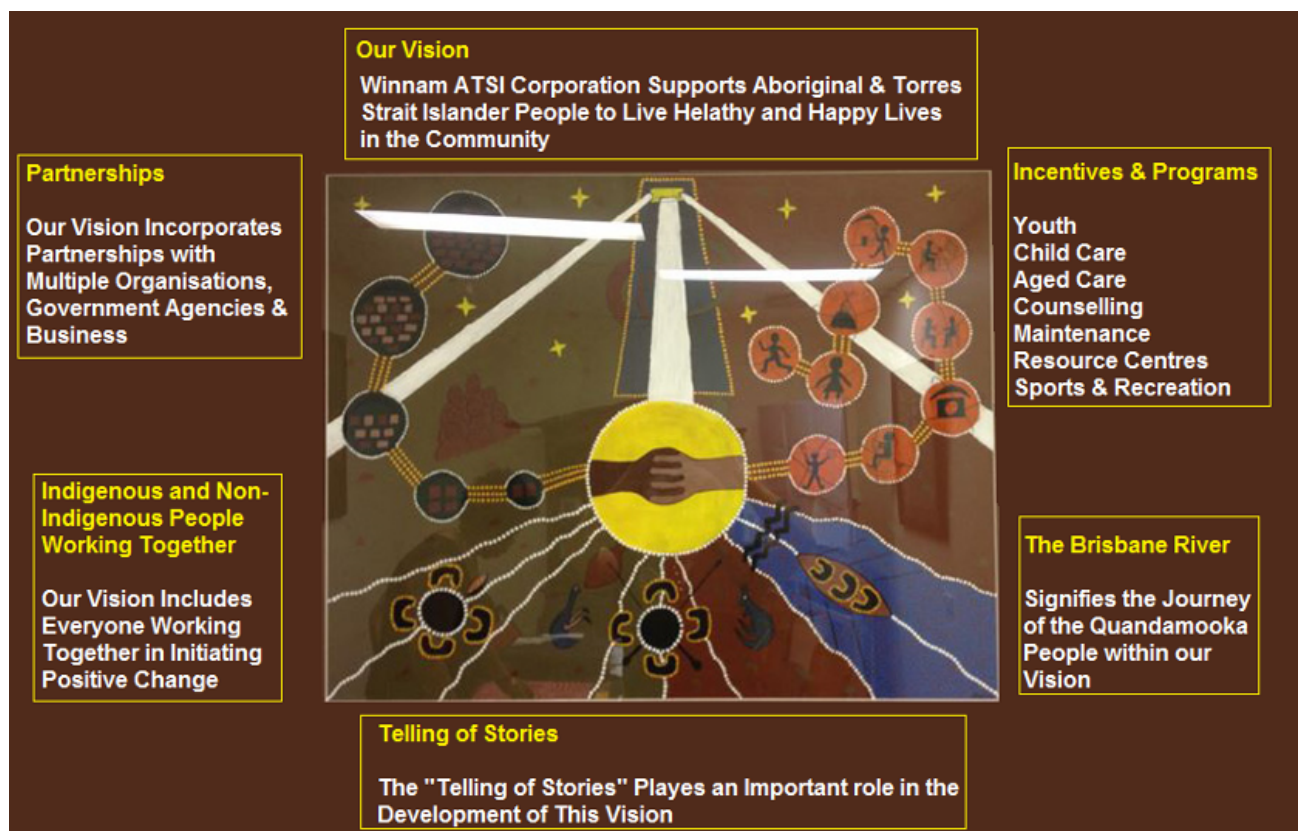
Figure 5: *"Keeping our people together" Winnam Aboriginal and Torres Strait Islander Corporation vision statements*

WATSIC also owns and operates (with Federal Government funding assistance) the Georgina Margaret Davidson Thompson Hostel (known as Georgina Hostel) in Morningside. Although Georgina Hostel is open to everyone (Aboriginal and Torres Strait Islander people and non-Indigenous people) it is the only residential aged-care facility in Brisbane that caters specifically for Aboriginal and Torres Strait Islander people.
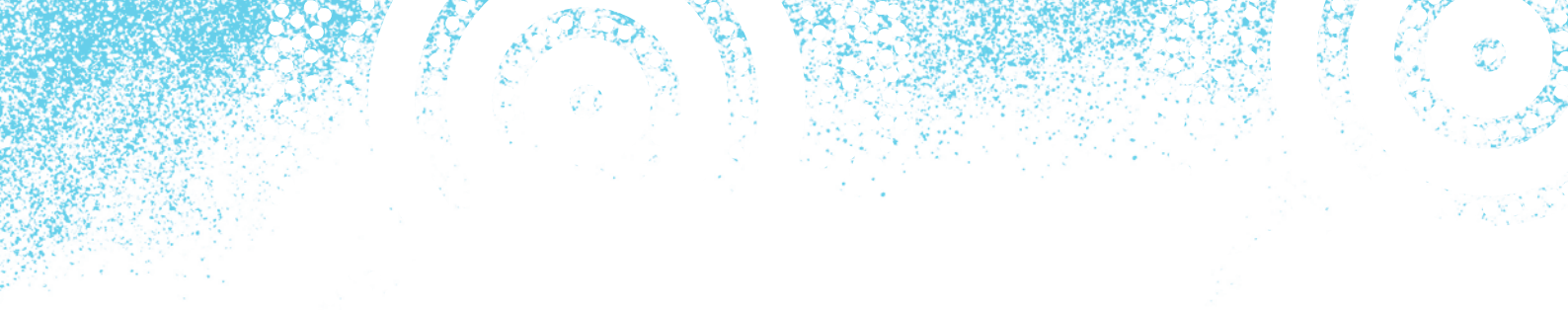
WATSIC also runs a wide range of events for the community, including cultural activities for non-Indigenous people. For many Aboriginal and Torres Strait Islander people, Winnam is the first place they contact for advice and support. They know they'll receive guidance in any number of areas, from social justice issues to referrals for employment, education and training, health care and a range of accommodation options.

The corporation's motto 'keeping our people together' is well known to members and refers to Winnam's connection to the community and to the Bayside area. Its principal purpose is providing a network of support and a meeting place for local Aboriginal and Torres Strait Islander people.

3.4 Study design/plans

3.4.1 Community engagement processes, permissions

Approval for the scoping work with CSIRO was provided by the Winnam Board Directors in June 2019 with a presentation by Dr Ray Mahoney about the project background and opportunity. Board members endorsed the project on 17 June 2019.

3.4.2 Sampling, sites and background information

Participant recruitment relied on convenience and snowball sampling. Two sites in the Quandamooka region were selected as consultation venues.

An onsite meeting was arranged for November 2019, to bring together staff and management of the Georgina Hostel, in Morningside to discuss their feedback about a potential trial of the SSH platform.

Many of the Georgina Hostel residents live with medical and cognitive conditions, and as such, are considered a vulnerable population. For this reason, the initial consultation process did not seek to recruit residents. The project team has not ruled out future opportunity to consult with residents about their acceptance of the system, perhaps through the proxy voice of family members.

In November 2019, nine Winnam ATSIC Members were contacted by telephone to gauge interest in participating in an informal meeting in Wynnum. Participants were selected by Winnam staff as those who would be the most receptive to the technology, aware of their own health and have a good understanding of community needs. The gathering provided opportunity for Winnam ATSIC Members to give feedback about the SSH project being piloted in community-owned houses. Consideration of cultural appropriateness was of particular interest to the project team.

Background documents were mailed to each prospective Winnam ATSIC Member participant, describing SSH technology, participant information, and information about a larger pilot trial underway in South East Queensland.

3.4.3 Engagement

Both meetings opened with a welcome and an acknowledgement of Country. Semi-structured discussions led by project staff were then held with participants of both sessions. Further explanation of the SSH platform was given by project staff to build on the project documents that had been provided to participants in advance

Data collection and analysis

Details of attendees, feedback and discussion outcomes were documented in notes by project member, with further detail noted in follow-up reflection on the meetings.

Meetings were not recorded. Notes and verbal reflections were transcribed from the meetings and reviewed to identify themes contained in the participant feedback. Descriptive analysis of the themes and recommendations was an iterative process involving various project staff.

4 Results

4.1 Engagement with Georgina Hostel

4.1.1 Details

The engagement session at Georgina Hostel took place on 11 November 2019 from 9-11am. Attendees included management, nursing and activity staff of Georgina Hostel, CSIRO scientists, project managers and technical staff. The General Manager of Winnam and a research assistant were also in attendance. Consultation with the representatives of Georgina Hostel included several technical explanations of the system components and portal by CSIRO staff. This provided attendees with opportunity to better understand the capabilities of the system and how a proposed pilot would work in the aged care facility.

4.1.2 Participant feedback

Themes from the consultation of staff and management of the Georgina Hostel (Meeting 1) are presented as Facilitators, Challenges, Opportunities and Recommendations.

Facilitators

Staff receptiveness and curiosity: A significant contributor to the feasibility of an SSH pilot at this site was the interest and engagement demonstrated by all staff participants in the system. For example, staff expressed high interest in the bed-sensor functionality for managing care of the aged care residents. Currently, resident monitoring relies on visual checks, notes and sensor mats which alert staff to movement in the rooms. Staff were positive about the value of the SSH system and its data could add to the health and safety of their residents.

Challenges

Technology presence and privacy: Staff were concerned that residents may feel uncomfortable or upset about the presence of the sensors in their room. There could, understandably, be some confusion about the sensors' appearance to be cameras filming resident movements, or audio recording devices, which would invade their privacy. Some residents may take steps to remove the devices if they are not consulted or informed (where possible), or where steps are not taken to reduce their visibility.

Opportunities

The positive approach observed in staff members' attitudes led way to discussions around the value that the SSH system could add to the Georgina Hostel environment. Some of the opportunities identified and discussed by the meeting participants included:

- The potential for improving communication and data sharing with GPs. For example, provision of summary data through the interactive SSH portal would enable hostel staff and GPs to be up to date with patient mobility and other activities of daily living.

- The portal would serve as a key preventative resource, enabling health professionals and hostel staff to promptly identify changes from patient baseline data. The ability to detect these subtle changes could help fast-track health or safety concerns and follow-up treatment.

- Longer-term data monitoring was also identified by staff as a valuable addition to staff interactions and decision-making about when a resident may need to move from low- to high-care arrangements.

- Staff also highlighted the new electronic care system "CareLink" (Civica Group) used within the Georgina Hostel, and whether there was potential for the two systems to be integrated.

Recommendations

Staff offered some key recommendations for the SSH and Winnam project group to consider. These included:

- Having an initial pilot for a small group of low-care Residents at the Georgina Hostel to 'get the kinks out of the system'. That is, to test how best to modify the technology in the aged care setting.

- Ensuring all stakeholders of the hostel were able to gain a solid understanding of the project.

- It would be crucial to involve the Residents themselves, so that their opinions are heard. For example, allowing opportunity for Residents to contribute to the placement of the sensors.

- Engagement and education of family members would also be a key factor in a pilot intervention.

- Privacy concerns of all stakeholders must also be addressed.

- Potential for the SSH information to feed into the Carelink software would be valued by staff to increase efficiency.

4.2 Engagement with Winnam ATSIC Members

4.2.1 Details

The meeting at Wynnum included four Winnam ATSIC Members and was held on 13th November 2019. The Winnam General Manager, research assistant, and a CSIRO project officer were also in attendance. Other invited Winnam ATSIC Members were unable to attend the meeting because of scheduling conflicts, illness and family commitments. One Winnam ATSIC Member provided their feedback via email to the research assistant. Their feedback has been incorporated into the following sections.

4.2.2 Participant Feedback

Consultation with participants generated content about the appropriateness of an SSH pilot in selected Winnam Community-owned residences. Feedback was analysed through discussion and theming by the project team. These themes included Values, Facilitators, Challenges, Opportunities and Recommendations. Iterative reflection by the project team allowed meanings to be clarified and confirmed.

Values

Participant feedback revealed the importance of certain aspects of their lives and their considerations for people in community who may benefit from this technology. These underline the cultural values and give context to the practical comments shared by the participants.

- Family connection – participants value and care for family members, not just immediate, but those in wider circles of the community, and within other local groups from the Quandamooka area. This value is a reflection of the Winnam motto which expresses a desire to keep people together and to care for one another and the strong connection between participants who were long-standing members of the Winnam Corporation.

- Shared culture – Language and art, relevance, accessibility for all ages.

- History – participants ask that those in the wider community and the project staff (including installation technicians) are aware, educated and respectful regarding the historical context of Aboriginal and Torres Strait Islander people in Australia. Impacts of intergenerational trauma in the lives of Aboriginal and Torres Strait Islander people have included Stolen Generations; slavery and wage theft; lack of recognition as Australian citizens; denial of language and tradition; removal from Country etc. These experiences have caused ongoing trauma which flows into disadvantage and harm to all dimensions of health (mental, physical, spiritual and social).

- Privacy – participants expressed the importance of privacy to themselves and their older Elders. The impact of government policies regarding surveillance and restrictions on Aboriginal and Torres Strait Islander people may understandably cause reservation to new technology or sensor systems.

- Health – Keeping healthy. Particular concern for health of older Elders.

Facilitators

Participants receptiveness: Discussions at this session indicated a strong interest in the SSH system. Participants could see value in the ability of the system to support community members 'living alone and/or away from their family'. However, an important learning was the participants did not feel the SSH system would be relevant to them (yet) as they did not currently rely on home care services. They believed the system pilot would be best suited to their Elders, 'older persons' in the preceding generation (persons approximately 80 years and older). For example, participants were very interested in the sleep sensors. They stated that this would offer 'rich and valuable data'. Overall, there was a positive engagement and discussion regarding the system.

This positivity was expressed in the following statements by participants.

- 'Love the diary function' for being able to let people (doctors and family) see how they are going, especially for persons who live away from family.

- 'Love the sleep sensors' as they would offer rich data which would be valuable to carers and health professionals.

- '[We all] use phones every day', so are familiar with technology.

Aspects of preventative health were also discussed by the group.

- '[We are] healthy because of [our] regular physical activity, [we] listen to doctors, eat well, drink lots of water, look after grandchildren and are keep involved in the community.'

- '[We stay connected] to family through phones and regular visits.'
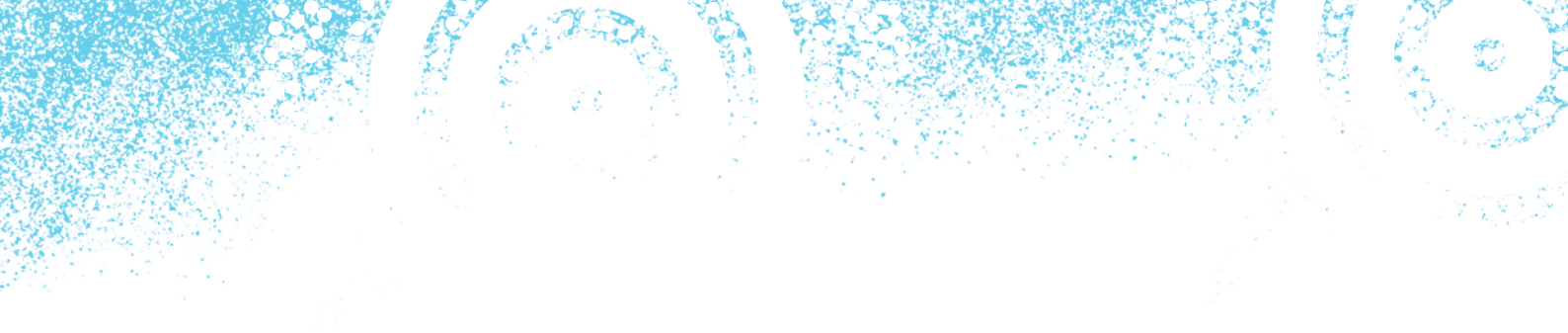
Challenges

The participants discussion identified barriers that would need serious consideration prior to a pilot. They reflect the Community values of strong caring relationships and acknowledge generational challenges that have impacted their people.

- The project team and the process of establishing a pilot 'must take into account that everyone has complex families and history'

- Participants expressed that many senior Elders of the Winnam Community may experience challenges to being healthy because of:

  – 'social isolation, especially kids not having interactions with older people', where generational care may no longer take place

  – 'physical conditions'

  – 'looking after the homes', with the physical demands of housework and maintenance

  – 'emotional' health challenges where people have a lot to deal with e.g. past trauma, Elder abuse

- Whilst the participants expressed their familiarity with technology e.g. smartphones, the senior Elders would 'have trouble' negotiating new systems and devices.

Opportunities

Despite the challenges, participants expressed ideas and creative solutions to increase the feasibility of a pilot trial using the SSH system.

- Use of language and art in the design and promotion of the SSH system. For example, including familiar terms from local language would help with generational language loss. Not necessarily a full translation, but perhaps several conversational terms that are immediately familiar to Community. Winnam logo would also be a valuable addition to the project resources including promotion materials, portal interface, information sheets, etc.

- A suggestion was made to connect with other Quandamooka organisations including Minjerribah Elders, Nareeba Moopi Moopi Pa Aged Care Hostel, North Stradbroke Island Housing Co-op, and Yulu-Burri-Ba (Wynnum, Capalaba, Dunwich). This could facilitate expansion of the study and build good connections on Country. Winnam Elders could facilitate the permissions and engagement of these organisations.

- Participants expressed interest in the ability to integrate the monitoring of chronic health conditions (e.g. diabetes) into the SSH portal.

- Working with local health workers, who are known and trusted by Community Members would significantly enhance the potential of the trial i.e Yulu- Burri-Ba (Wynnum, Capalaba, Dunwich). In contrast, new staff or directives to make contact with new GPs or home care services would inhibit engagement.

Recommendations

The key messages of this engagement session again reflect the values and strong connections within the Winnam Community.

- The importance of involving established networks of people that are known by Members. This would include health workers and doctors but also wider Aboriginal and Torres Strait Islander services in the region, enabling participants to consult with a trusted person about their participation.

- Education for all participants, wider family and carers is key to the project. A 'good understanding about the technology and its benefits would make people more inclined to use it'. In addition, understanding of the context of health challenges faced by Aboriginal and Torres Strait Elders is necessary for respectful interactions and engagement in a trial.

- Privacy is also crucial, and all parties must have their concerns addressed.

5 Discussion and conclusions

The review of literature has highlighted the considerations and challenges experienced by many Aboriginal and Torres Strait Islander people living in urban areas. Brand et al. (3, 4) provide a comprehensive outline of the challenges in regard to education, employment and housing etc. which are relevant to the Aboriginal and Torres Strait Islander people of Quandamooka Country, including older adults. These social determinants, resulting from historical and contemporary racism and colonialist policies, further limit the health and wellbeing opportunities for Quandamooka people. Voices of the Members in the Community meeting reflected these realities. With an increasing proportion of older Australians (1, 2), solutions to support Aboriginal and Torres Strait people to live with autonomy and safety on Country are needed (5).

The growth and presence of ATSICCHOs, such as Yulu-Burri-Ba (Wynnum, Capalaba, Dunwich), has improved access and continuity of support for Aboriginal and Torres Strait Islander communities in Brisbane and Bayside. However, older person's help-seeking is not necessarily a reliable process for detecting health concerns (37). This may be due to past negative experiences with health care or government organisations. Winnam Members expressed the complexity of life and relationships that may be associated with Elders' ability to stay healthy.

Innovations in digital technologies are being trialled for their prospect of supporting older Australians to live independently in their own homes. CSIRO have developed SSH and trialled it in homes throughout Australia (40, 41). Using wireless sensors paired with secure data storage, a resident's activities of daily living are objectively monitored. Aggregated data presented in user-friendly software portals on a desktop computer or tablet allows for detection of changes from the individual's usual pattern of activity.
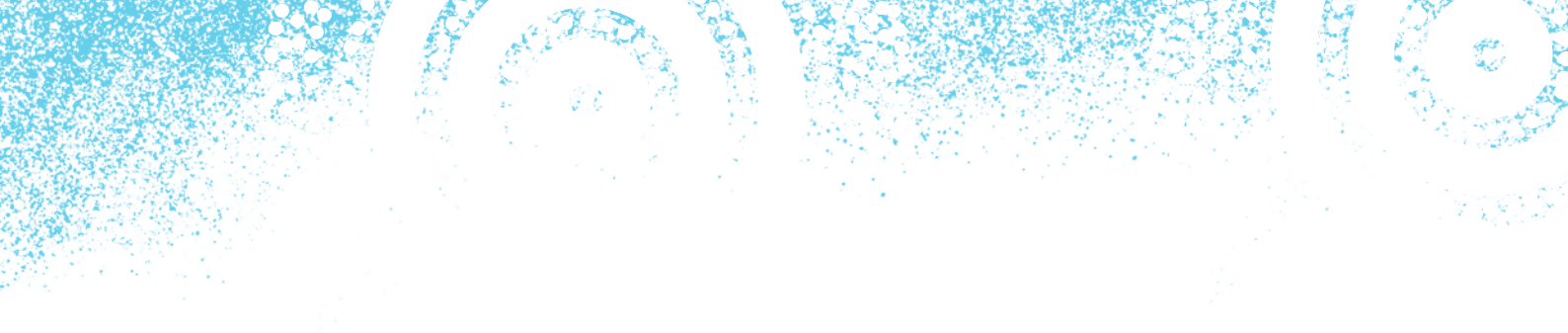
The "At Home in Quandamooka" project aims to make the SSH technology useful and culturally appropriate for urban Aboriginal and Torres Strait Islander older people. This scoping phase sought Winnam ATSIC Members' and Georgina Hostel Staff perspectives on healthy ageing and attitudes towards home/hostel monitoring and co-design of a tailored SSH system to allow freedom of cultural expression in a health supported home environment, with the potential to delay or prevent the need for institutionalised residential care.

Feedback reported from the Community meetings were not dissimilar to that expressed by previous participants in trials of in-home monitoring. For example, both Winnam ATSIC Members and Georgina staff expressed concern for residents' privacy with a possible fear that the system would be 'watching them', despite there being no audio or visual recording. Both Winnam meetings revealed strong interest and perceived value of the aggregated data to support independent living. Collectively, participants could see the potential for SSH in early detection of health concerns and/or information to support decision-making about independence. Support and enthusiasm for further research was evident.

Whilst it was understood that a pilot-trial with Aboriginal and Torres Strait Islander people in the Winnam region would be designed to support and facilitate autonomy and healthy lifestyles, there are important cultural and social factors that must be respectfully acknowledged and considered. The key recommendations of both meetings for the proposed study in the Winnam region include the following:

1. Engagement – It is vital that all stakeholders are engaged in the process of tailoring the SSH platform to be trialled with Aboriginal and Torres Strait Islander people in the area. For Georgina Hostel, this must include all staff, residents, families and visiting health professionals (GPs, allied health, etc.). For residents of Winnam ATSIC Community houses, this will include residents, family members, caregiver agencies and local ATSICCHO personnel. Engagement will need to consider installation, maintenance,

technology literacy, cultural aspects of the portal, relationships with in-home and health workers, etc.

2. Privacy – Georgina Hostel staff and Winnam ATSIC Members emphasised the need to address the privacy concerns held by participants and stakeholders of the trial.

3. Target audience – Clarification is needed about the proposed versus actual participant profile for a trial. Winnam ATSIC Members expressed a lack of relevance for the SSH system for themselves, but viewed it as more beneficial for their older Elders.

4. Established networks – Winnam ATSIC Members were clear that the project's feasibility and reach will be significantly strengthened by working with established networks in the Quandamooka region. This would include reaching out to gain permission and seek collaboration with Minjerribah Elders, Nareeba Moopi Moopi Pa Aged Care Hostel, North Stradbroke Island Housing Co-op, and Yulu-Burri-Ba (Wynnum, Capalaba, Dunwich). Furthermore, working with ATSICCHOs, GPs and health workers known to residents will build trust, understanding and engagement in the trial.

5. Education – All members of the project teams should ensure they have a contemporary understanding of the Winnam ATSIC Community values of strong caring relationships and also to acknowledge generational challenges that have impacted Aboriginal and Torres Strait Islander people. In particular, Winnam ATSIC Members requested that the project team (including installation personnel) 'must take into account that everyone has complex families and history'.

6 Recommendations

Four key recommendations are made as a result of this collaborative scoping study by the Winnam Aboriginal and Torres Strait Islander Corporation and the Australian eHealth Research Centre.

1. Planning should proceed for a trial of the Smarter, Safer Homes platform at the Georgina Hostel (incorporating appropriate Human Research Ethics approval).

2. Planning should proceed for a trial of the Smarter, Safer Homes platform within the Winnam ATSIC community housing (incorporating appropriate Human Research Ethics approval).

3. Engagement processes for these trials must ensure that all personnel involved in the trial are informed and acknowledge;

   a. the mission and values of the Winnam ATSIC community – strong connections and caring relationships; and

   b. the generational challenges that continue to impact the health and wellbeing opportunities for Aboriginal and Torres Strait Islander people.

4. Project planning will be strengthened by additional collaboration with established networks in the Quandamooka region.

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