

Extending dementia care into Indigenous communities

The University of Queensland's Centre for Online Health (COH) is an internationally regarded leader in the field of telehealth. In this article, **Anthony Smith** (COH Director) and members of his research team, **Helen Haydon, Emma Thomas, Centaine Snoswell** and **Liam Caffery** explain how telehealth is being used to connect dementia specialists to selected Aboriginal and Islander Community-Controlled Health Services in Queensland. These projects build on the skills of a strong local workforce, and help raise awareness of dementia within Aboriginal and Torres Strait Islander communities

The delivery of health services to people living in rural and remote areas is considerably more challenging than for those living in city locations. However, regardless of location, telehealth can increase access to care (Smith *et al* 2020).

Telehealth has been shown to be useful for people of all ages, for a broad range of conditions, and in a range of different settings. The benefits are not limited to rural or metropolitan populations. Telehealth services can be delivered in real-time (eg video consultations), asynchronously (eg email and patient portals), or through remote monitoring (eg use of a non-invasive technology to collect and transmit vital signs from a patient to a clinician).

Aboriginal and Torres Strait Islander people (for brevity, herein respectfully the term Indigenous Australians will be used) have a much higher level of risk and need for dementia services than the general population. The prevalence of dementia in Indigenous Australians is three to five times higher than their non-Indigenous counterparts (Flicker & Holdsworth 2014). The quality of care available to people with dementia in remote Australian Indigenous communities is considered poor (Smith *et al* 2010). Since nearly half of Indigenous Queenslanders live in outer regional or remote areas, we sought to explore opportunities where telehealth could be used to improve access to specialist care.

Dementia management

Whilst there is no specific cure for dementia, there are a range of therapeutic interventions which can help manage symptoms and slow the progression of the disease. This is why early detection is particularly important for dementia management. Lack of detection (or late-stage diagnosis) is a significant barrier to improving the lives



Badu Island, in the Torres Strait, Queensland, was one of the communities involved in the DREAMT telehealth trial. Photos: Centre for Online Health, The University of Queensland

of people with dementia, their families and carers (Strivens and Craig 2014). Dementia Australia estimates that for Indigenous Australians, the time between the onset of symptoms and dementia diagnosis often exceeds three years, which could potentially be reduced by increasing access to specialists by telehealth (Flicker & Holdsworth 2014).

The risk of developing dementia can also be reduced with appropriate community education and preventative healthcare (Livingstone *et al* 2020). Attention to cardiovascular risk factors, physical and cognitive leisure activities, and diet can improve cognitive function and/or reduce dementia risk. Indigenous Health Workers (IHWs) are considered an effective strategy to deliver risk-reduction programs and education

within local health services (Smith *et al* 2010).

Combining the management of dementia with health promotion programs has the potential to reduce the population prevalence of dementia and its associated social and clinical burden, and increase quality of life for Indigenous Australians.

Telehealth for dementia care

As many specialist services are concentrated in metropolitan areas, patients from rural and remote areas often need to travel to access care. Telehealth enables healthcare to be delivered to remote communities, which provides patients with a choice about how they access care. Additionally, a patient's out-of-pocket expenses associated with travel (eg transport,



Health workers and members of the DREAMT project. The project explored ways in which telehealth could be of value in improving access to specialist dementia services in Indigenous communities

accommodation, lost income) can be substantially reduced when they access care via telehealth (Bradford *et al* 2016; and Snoswell *et al* 2019). Telehealth models of care for dementia management can improve the timeliness and accuracy of detection which, in turn, can facilitate early intervention and management, leading to improved patient outcomes.

Indigenous communities

Recent reviews have demonstrated a broad range of benefits associated with the use of telehealth for people living in Indigenous communities. Telehealth services delivered to people in Aboriginal and Islander Community-Controlled Health Services (AICCHS), from a specialist located in tertiary hospitals, are thought to be the optimum telehealth-facilitated model of care for Indigenous people (Caffery *et al* 2018). Advantages of this telehealth model include: providing care in a familiar and culturally appropriate environment; reducing or eliminating the need for travel; reducing out-of-pocket expenses for the patient; engaging a salaried local workforce; and providing opportunities for Medicare funding, which improves the sustainability of the service.

Dementia care

The evidence regarding telehealth use for dementia care in remote Indigenous populations is quite limited. However, there is collateral evidence that supports the use of telehealth for dementia care. For instance, Indigenous-specific dementia screening tools (such as the Kimberley Indigenous Cognitive Assessment tool (KICA-Screen); LoGiudice *et al* 2006) have been validated for use by videoconference (Russell *et al* 2019). There is also evidence that

telehealth in non-dementia contexts was an effective way of delivering health services to remote Indigenous communities, with Indigenous Australians reporting positive experiences using telehealth. In a 2016 systematic review, we identified specific outcomes associated with the use of telehealth for the provision of healthcare to Indigenous Australians. These included: improved social and emotional wellbeing, clinical outcomes and access to health services (Caffery *et al* 2016).

The DREAMT Project

DREAMT was derived from the words: Dementia, Regional and remote, Empowering Aboriginal and Torres Strait, Medicine and Telehealth. The project was funded through the Department of Aged Care Services (DACs) Fund, under the broad strategy of improving access to specialist dementia services in Indigenous communities. Engaging with

communities in the south-west region of Queensland (Cherbourg, Cunnamulla and Charleville) and up through the Torres Strait (Badu and Mabuiag Islands), we explored ways in which telehealth may be of value.

The DREAMT project (www.coh.centre.uq.edu.au/project/dreamt) ran from July 2017 to June 2020. Its main objectives were to:

- engage with Aboriginal and Torres Strait Islander communities, and better understand current impressions and awareness of dementia
- provide dementia education and training
- promote the use of a culturally sensitive routine dementia screening assessment (the Kimberley Indigenous Cognitive Assessment (KICA) tool) and,
- develop referral processes for telehealth consultations with a geriatric specialist.

Our funding allowed for the employment of a part-time IHW in each of the community health services in south-west Queensland (Cherbourg, Cunnamulla and Charleville). We were unable to employ any IHWs in the Torres Strait due to Queensland Health governance and approval processes. Instead, we developed educational videos which could be used to raise awareness of dementia and telehealth (covered in more detail below).

Supported by the 12-person DREAMT project team (comprising people from COH, the Princess Alexandra Hospital in Brisbane and Cairns Base Hospital), the health worker was the primary contact in each community, responsible for activities related to raising dementia awareness (education and training), promoting routine dementia assessment,



A DREAMT telehealth consultation conducted in Charleville, Queensland

and telehealth uptake (service development). The IHW selected by each community had varying levels of experience and qualifications. Most had a Certificate IV-level qualification. Some were working towards the qualification or very close to completion.

The teleconsultation process facilitates interaction between the IHW and geriatric specialist. This leads to increased knowledge in dementia management, and increased empowerment for the IHW, the community-controlled health service and/or aged care facility.

Health interventions for Indigenous Australians need to be tailored to the needs of the community. There's no such thing as one model suits all. This was apparent during our visits to each community, where valuable yarning sessions were held with local community members, elders, health workers, families and service managers.

Community yarning

The DREAMT project team learnt a lot thanks to the generosity of all communities involved in the project. The engagement process involved extensive travel around Queensland to some very remote locations; and priceless opportunities to hear from local community members and better understand everyone's impression of dementia, and how this affects life in each community. It's estimated that we had direct contact with at least 150 community members, including health service staff, health workers, local residents, government and council representatives and local elders.

Yarning opportunities happened in pre-planned meetings, but most often through ad-hoc conversations in supermarkets, on fishing jetties, in health centres and along local streets. This was the perfect opportunity to get to know one another, share stories and really begin to understand the needs of each community.

Everyone had a story about dementia – whether that involved a parent or grandparent, a neighbour, a work colleague, or just someone living in the community. Whilst most people had a general understanding of dementia, there were many different interpretations of exactly what it was, its causes and treatment options. In some cases there was acknowledgment about low awareness of strategies to treat dementia and factors which can reduce or slow the onset of dementia. Occasionally, stories would reflect an element of fear or stigmatisation, where one felt more



Thursday Island, in the Torres Strait, one of the communities involved in the DREAMT project

comfortable just pretending that everything was okay and that certain behaviours were just part of ageing.

Community members also shared their experience navigating a complex health system, where often they would not know how to get support and assistance when caring for someone living with dementia. Another interesting challenge was associated with the high degree of respect shown for Elders, and a reluctance by younger health workers to ask certain questions (during the dementia assessment), in fear of appearing disrespectful.

Community discussions revealed the needs of the communities to increase access to services. Specifically, the following themes were found:

- the need for increased access to specialist services
- positive experiences with telehealth
- the need for dementia education
- strategies to assist with different viewpoints about dementia (what it is, the causes, and how to deal with it), and
- the impact on families who are living with someone with dementia.

In response, some of the educational requirements were captured in two short DREAMT films which displayed the magical beauty of each region, and the process of engaging with health services and specialists by telehealth.

Dementia on the big screen

The DREAMT films showcased an Aboriginal community in south-west

Queensland and a Torres Strait Island community which allowed the uniqueness of each community to shine through. Aiming to increase dementia awareness at a community level, the films target IHWs, people with younger-onset dementia and their families, and are freely available. They have been actively shared in public places (such as airports, hospitals and community health centres) and universities around Australia. These films were shortlisted for the 2019 Australian Teachers of Media (ATOM) Awards, which recognise film and media excellence in education and industry. Links to the videos are available here: www.coh.centre.uq.edu.au/project/dreamt.

Project findings

The delivery of the DREAMT project within a two-year period was a challenging task, mainly due to the time needed for proper community engagement. For our project, two years included site visits and engagement; service planning; service implementation and some evaluation to better understand community perspectives, the uptake of routine dementia screening and the use of telehealth. What we appreciated was the significance of working with community, understanding community requirements, and the importance of tailoring services based on community needs.

Our team of Indigenous Health Workers were extremely passionate about their role in the DREAMT project but, on a day-to-day basis, were also

managing multiple roles and responsibilities in the community health service. Health workers wore many hats – and when one of these hats involved leading dementia training or organising an assessment, there was always the risk that other competing activities would get in the way. Prioritising dementia care in a community with so many other health and social challenges is difficult.

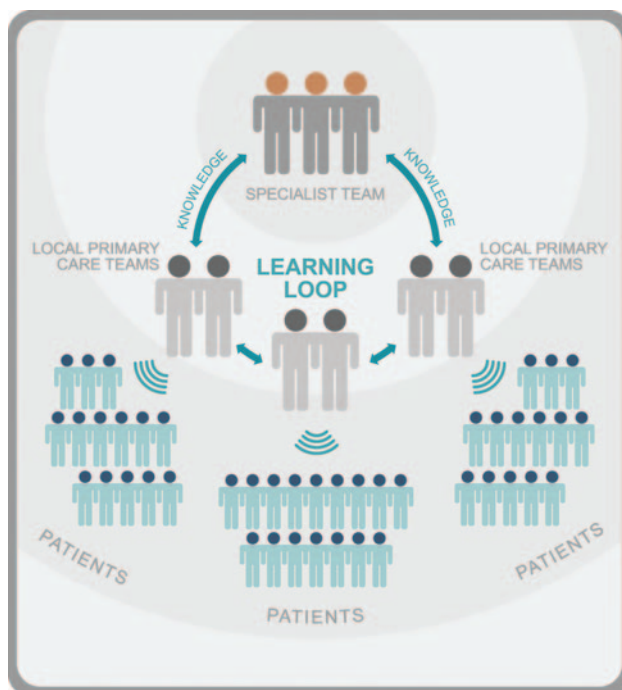
The introduction of routine screening processes for dementia as part of the project meant some changes to the usual assessment tools used by the health workers, and increased burden of time due to additional questions and concerns which needed to be addressed. These responsibilities were supported by specific training services provided by Dementia Australia and the COH during the course of the DREAMT project.

This training included tailored workshops on dementia assessment and management, and how to support people living with dementia. These workshops also gave participants the opportunity to use a dementia virtual reality tool called EDIE (Educational Dementia Immersive Experience) – which allows participants to see and experience the world through the eyes of a person living with dementia (Dementia Australia 2020).

Workforce training and support is important to ensure local health workers and other clinicians are familiar with evidence-based approaches to dementia care; and are confident delivering these as part of routine practice. To help with the coordination of the DREAMT program, we also developed practical guidelines to simplify the steps involved in screening documentation, prioritisation of patients, patient education, telehealth referral processes and billing procedures.

The uptake of telehealth was slow during the project. Of the first 20 KICA assessments done during the project, only six patients (30%) required a telehealth appointment with the geriatrician. We attributed the low numbers of patients screened during the project to delays in establishing routine dementia screening services, the availability of health workers to complete the assessments, as well as the competing health priorities mentioned above.

While funding allowed for the employment of an IHW in each community for the duration of the project, we have managed to maintain ongoing access to telehealth services for those



Stage 2 of the project is Dementia ECHO, based on the Project ECHO model which uses hub and spoke knowledge-sharing networks to create a learning loop (above)

communities. We have a geriatrician who runs a telehealth clinic every week. Sites involved in the DREAMT project can continue to refer patients to the geriatrician for assessment and management advice. The same geriatrician will be involved in our next project, Dementia ECHO (described below), as the medical specialist on the panel.

Future directions

The focus of the DREAMT project was mainly on Indigenous Health Workers who were employed to act as the local dementia contact – responsible for screening, community and patient education and referral to specialists. In hindsight, we believe that a more productive approach would be to engage the wider primary care team – including GPs, nurses, allied health staff and IHWs. Developing new systems or services which promote closer engagement between these primary care service providers and dementia specialists may be what is needed to encourage the translation of expert knowledge into local services.

In some communities, the connection between primary- and tertiary-level care is fragmented. The next stage of our project is called Dementia ECHO and involves the development of a Queensland-wide education and telementoring program. The project, which started in July 2020 and runs to June 2022, will use the Project ECHO

(Extension for Community Healthcare Outcomes) guided practice model (www.hsc.unm.edu/echo/) to deliver an innovative ‘hub-and-spoke’ telementoring service where expert teams lead virtual clinics.

Dementia ECHO

Based on what we have learnt from the DREAMT project, the COH will establish, manage and evaluate a telementoring program for dementia services. Supported by funding from the Australian Government (Indigenous Australians Health Program), Dementia ECHO will be available to selected AICCHS in Queensland. The main aims are to: build up local skills, enable easier access to specialist services normally only available in city locations, and encourage regular communication between specialists and primary care

teams responsible for the delivery of health services to Indigenous Australians.

The service will link a Dementia ECHO panel (medical, nursing and allied health) with AICCHS staff. The monthly videoconference sessions, scheduled to begin in February 2021, will include a short 10-minute didactic lecture on a dementia topic and discussion of a case put forward by an AICCHS clinician. Case conferences will involve the presentation of de-identified cases and discussion with the expert members.

The process is designed to encourage closer collaboration between primary care and specialist services; increase clinical peer support between communities and increase the capabilities of local health services. Dementia ECHO topics will relate to dementia knowledge, dementia assessment, telehealth case preparation, telehealth coordination, and community education.

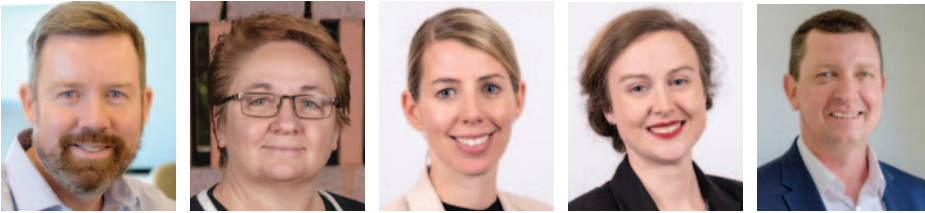
To assist with the promotion of the project and its delivery throughout Queensland, the COH is partnering with the Queensland Aboriginal and Islander Health Council (QAIHC). ■

For further information about the Dementia ECHO program, contact The University of Queensland's Centre for Online Health (COH) (Dr Helen Haydon) by email: h.haydon@uq.edu.au

For more information about the DREAMT project and the work of the COH, visit www.coh.centre.uq.edu.au

Acknowledgments

The Centre for Online Health acknowledges the Traditional Custodians of the land, and pays respect to Elders past, present and future and acknowledges Aboriginal and Torres Strait



From left: Anthony Smith, Helen Haydon, Emma Thomas, Centaine Snoswell and Liam Caffery

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Islander people's relationship with Country, and their cultural and spiritual beliefs.

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Dementia and changed behaviours

NPS MedicineWise has launched a new national education program focusing on the care of people living with dementia, which aims to reduce unnecessary use of antipsychotics and benzodiazepines and to improve the use of non-pharmacological techniques to support people with dementia who are experiencing changed or responsive behaviours. The program – **Dementia and Changed Behaviours: A Person-Centred Approach** – is aimed at GPs, pharmacists and nurses who care for people living with dementia in the community and in residential aged care facilities, as well as people living with dementia and family carers.

NPS MedicineWise says the program's key elements include educational visits to individual GPs and small groups in general practices who work in the aged care sector; a multimodal educational program for aged care facilities aimed at supporting champion nurses and pharmacists working in the sector; webinars for GPs, pharmacists and nurses; and online resources for consumers and GPs. Two webinars are already available to view on demand: 'Working together to enhance transitions of care for people with dementia', and 'Dementia: a multi-disciplinary approach to caring for people with changed behaviours'.

According to NPS MedicineWise medical adviser and GP Dr Anna Samecki, the program's main focus is on the importance of person-centred care.

"Antipsychotics and benzodiazepines have a limited role and they should not be used first line. If they are needed, the program highlights the importance of collaboration between the person or carer and the healthcare team in management decisions, which includes obtaining informed consent. These medicines should be used at the lowest possible dose, with a plan in place to review, wean and stop," says Dr Samecki.

The program has been developed in consultation with key stakeholders in aged care including Dementia Training Australia (DTA); Ellie Newman, Dr Andrew Stafford, Dr Margaret Winbolt and Dr Allan Shell from DTA have been part of multidisciplinary panels within the program's webinars. The program has also collated a collection of guidelines and resources relating to the topic which is available on NPS MedicineWise's website.

For more information on the program, go to <https://bit.ly/33fH5IT>