

Health systems model for chronic disease secondary prevention in rural and remote areas – *Chronic disease: Road to health*

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ABSTRACT

Objectives. Cardiac rehabilitation (CR) provides evidence-based secondary prevention for people with heart disease (HD) (clients). Despite HD being the leading cause of mortality and morbidity, CR is under-utilised in Australia. This research investigated healthcare systems required to improve access to CR in rural and remote areas of North Queensland (NQ). **Methods.** A qualitatively dominant case study series to review management systems for CR in rural and remote areas of NQ was undertaken. Data collection was via semi-structured interviews in four tertiary hospitals and four rural or remote communities. An audit of discharge planning and CR referral, plus a review of community-based health services, was completed. An iterative and co-design process including consultation with healthcare staff and community members culminated in a systems-based model for improving access to CR in rural and remote areas. **Results.** Poorly organised CR systems, poor client/staff understanding of discharge planning and low referral rates for secondary prevention, resulted in the majority of clients not accessing secondary prevention, despite resources being available. Revised health systems and management processes were recommended for the proposed *Heart: Road to health* model, and given common chronic diseases risk factors it was recommended to be broadened into *Chronic disease: Road to health*. **Conclusion.** A *Chronic disease: Road to health* model could provide effective and efficient secondary prevention for people with chronic diseases in rural and remote areas. It is proposed that this approach could reduce gaps and duplication in current healthcare services and provide flexible, client-centred, holistic, culturally responsive services, and improve client outcomes.

Keywords: cardiac rehabilitation, client centred, culturally appropriate, health systems, management, remote, rural, secondary prevention, social determinants.

Introduction

Heart disease (HD) continues to be the leading cause of mortality in Australia¹ and is responsible for the highest burden of disease in every state except the Australian Capital Territory.² Furthermore, hospitalisation rates for cardiovascular disease are 45% higher for people from rural and remote areas, compared with metropolitan areas, with Aboriginal and Torres Strait Islander peoples having twice the rates of non-Indigenous Australians.³

Cardiac rehabilitation (CR) is a model for providing secondary prevention for people with HD. Services are predominantly provided through centre or home-based programs, including telephone or telehealth programs.⁴ CR is known to reduce mortality and morbidity, as well as improving quality of life through education, risk factor management, psychological support and medical care, culminating in client self-management.⁵ A cost-benefit analysis (2013) estimated that such benefits would save \$A86 million if CR referral rates were increased to 65%.⁶ Based on Reserve Bank of Australia inflation rates these savings are now estimated to be \$A100 million, as well as improving quality of life and providing a positive return on investment.^{5,7}

CR has traditionally been provided in three phases. Phase-1-CR provides in-patient education, discharge planning and referral to Phase-2-CR, which provides out-patient secondary prevention, risk factor management and medical care, finally proceeding to Phase-3-CR for maintenance and supported self-management.

Barriers to CR in rural and remote areas include low referrals (30%)⁸ and few centre-based CR services.⁹ Queensland Health provides a telephone support service, Self-Management of Chronic Conditions (SMOCC) (previously Coaching on Achieving Cardiovascular Health, COACH).¹⁰ However, referral and uptake are low (range 4–20%).¹⁰

To investigate barriers and enablers to improve access to CR/secondary prevention in rural and remote areas, and propose potential solutions, a case study series commencing in hospitals and concluding in local communities was undertaken. Hereon in, the term secondary prevention, rather than CR, is used when discussing matters related to risk factor management, including client education, psychosocial support and medical management.

Methods

A sequential case study series was completed, with Stage 1 investigating implementation of Phase-1-CR in two public and two private tertiary hospitals in North Queensland (NQ).¹¹

Stage 2 investigated the provision and access to post-discharge Phase-2-CR or secondary prevention in four rural and remote communities in NQ, including two designated Aboriginal and Torres Strait Islander communities.⁴ Predominant in both studies was investigation of awareness and understanding by staff and clients of:

- disease and treatment;
- receipt of documented discharge plan, including reference to risk factor management and/or referral for secondary prevention;
- system for holistic follow-up care.^{4,11,12}

Purposeful and convenience sampling were used to select clients and staff for data collection which was performed via semi-structured interviews, until data-saturation was reached.^{13,14} For the hospital studies, interviewees were drawn from cardiac services staff ($n = 50$) (nurses, medical officers and allied health professionals (AHPs) providing direct care) and in-patients treated for HD ($n = 46$).¹¹ For community studies, interviewees were local and visiting health staff ($n = 23$) and people discharged from hospital following treatment for HD in the past 5 years ($n = 44$).⁴ Primary themes were identified through deductive analysis based on an earlier integrative literature review.¹² Secondary themes were identified through thematic inductive analysis of transcribed recorded interviews.¹⁴ Furthermore, a medical

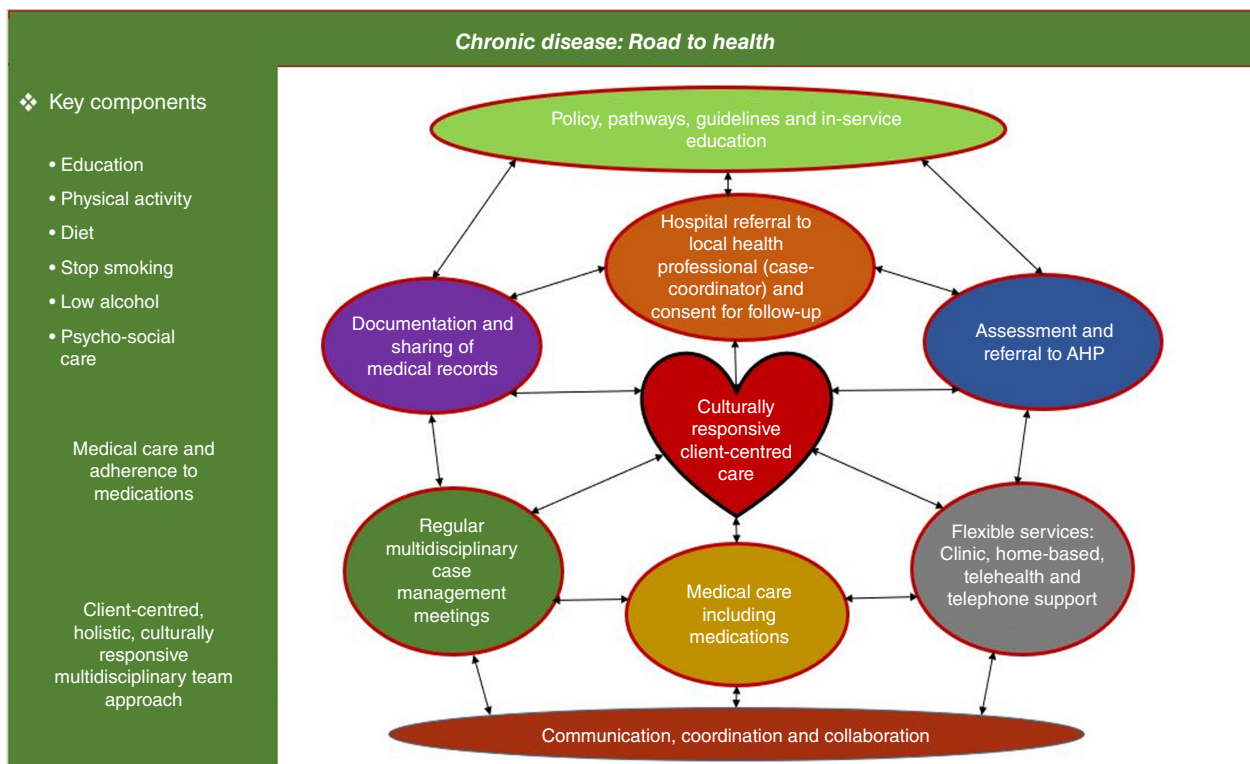


Fig. 1. Chronic disease: Road to health model.

Table 1. Ethics approval.

Study focus	Human research ethics committee (HREC)	Approval number
Stage 3: Hospital case studies on understanding and implementation of Phase-1-CR and impact on post-discharge care in rural and remote areas	(i) Townsville Hospital and Health Services Human Research Ethics Committee (HREC)	HREC/2018/QTHS/4360619/17
	(ii) Greenslopes Research and Ethics Committee	7/05/2019
	(iii) James Cook University HREC	H7737
Stage 4a and 4b: Community case studies on understanding and implementation of Phase-2-CR	(i) Townsville Hospital and Health Services HREC	HREC/2019/QTHS/5921
	(ii) James Cook University HREC	H8467

record discharge planning audit¹¹ and a review of community-based and visiting health professional services were completed.^{4,11} (See Project Protocol for details of community studies' research methodology.¹⁵) The data collection and analysis was facilitated by an iterative/co-design process that included feedback of findings, further consultation and discussion with healthcare staff, community members and leaders. Through this process the *Heart: Road to health* model of secondary prevention for HD in rural and remote areas was developed.^{4,15} Through an iterative process based on further information, consultation and discussion, the *Heart: Road to health* evolved into the *Chronic disease: Road to health* (Fig. 1). Ethics approval was granted for all studies (Table 1).

Results

Enablers for secondary prevention in rural and remote areas included a range of available healthcare resources. These provided community-based and visiting healthcare providers, such as nurses, Aboriginal and Torres Strait Islander Health Workers (ATSIHW), AHPs and medical officers, employed by Queensland Health (QH), Aboriginal Community Controlled Health Organisations (ACCHOs), the Royal Flying Doctors Service (RFDS), other contracting organisations and additional private health practitioners.⁴

Furthermore, a number of alternative models of successful primary health care and secondary prevention programs for chronic diseases or specific populations were identified (Table 2). The Cape York Kidney Care,¹⁶ Diabetes Education and Self-management Program^{17,18} and Older Persons Enablement and Rehabilitation for Complex Health Conditions (OPEN ARCH) aged care program¹⁹ demonstrated person-centred, multidisciplinary, culturally appropriate holistic care. Healthcare In Your Home^{20,21} and Deadly Kids, Deadly Futures²² are further examples of programs that are available in various areas of NQ. However, little or no communication, coordination or collaboration was found between programs⁴ (Table 2).

Barriers to access secondary prevention began with inadequate discharge planning or referral for risk factors management and secondary prevention. Apart from cardiac

educators, few staff demonstrated an understanding of Phase-1-CR and rarely engaged with systems for hospital discharge planning or referral to community-based secondary prevention.^{4,11} Subsequently only 27% of patients in hospital with cardiac educators were referred for Phase-2-CR and <9% in hospitals with no cardiac educators.¹⁴ Further, only 6% of discharge summaries, routinely sent to a GP, mentioned secondary prevention and risk factor management.^{4,11}

Staff in community health centres demonstrated poor understanding of secondary prevention and there was no system in place to ensure patients received risk factor management.⁴ Only one person interviewed received support through SMOCC.⁴ Overall there was inadequate communication, collaboration and cooperation between service providers resulting in limited effectiveness through service gaps and/or duplication of services.^{4,23,24}

A further barrier to post-discharge secondary prevention was that the term CR is not well understood. 'Rehab' or 'rehabilitation' were terms most often used for people post stroke, orthopaedic surgery or drug and alcohol misuse.⁴ This misconception is likely to result in clients not attending available services such as physiotherapists, exercise physiologists, dietitians, social workers or community and mental health nurses for secondary prevention of heart or other chronic diseases.⁴

To address the misconception of 'rehab' or 'rehabilitation' the term *Heart: Road to health* was adopted for the provision of secondary prevention of HD. The *Heart: Road to health* model was designed through the iterative co-design process that built on successful models such as the Diabetes Education and Self-management and Cape York Kidney Care programs (Table 2). For example, the Diabetes Education and Self-management program is a well-established primary health care and secondary prevention program, which ensures that people with diabetes are followed-up at home following hospitalisation for diabetes. The diabetes program is coordinated by regional credentialed diabetes educators (CDE) who work collaboratively with GPs. The GP or CDE receives post discharge referrals, with the CDE coordinating person-centred holistic, multidisciplinary clinical care and a secondary prevention program. This approach results in client-centred, holistic, collaborative and co-ordinated health care, in which the

Table 2. Examples of alternative healthcare programs in NQ.

Program	Information
Diabetes Education and Self-management Program ¹⁷	Coordinated by a credentialed diabetes educator, nurse or AHP, who provides person-centred, holistic, culturally appropriate, multidisciplinary outreach services throughout Queensland. Well-established program. No formal evaluation was identified. ^{17,18}
Cape York Kidney Care (CYKC) ¹⁶	Coordinated by a renal disease nurse practitioner, CYKC provides person-centred, holistic culturally appropriate, multidisciplinary services for people with renal disease in Western Cape York. ATSIHWs are employed as part of the team. An unpublished evaluation demonstrated a reduction in unplanned hospital admissions, emergency evacuation and delay in commencement of dialysis. This resulted in cost savings and positive feedback from clients. The program is now at capacity. ¹⁶
Healthcare In Your Home (HIYH) ²⁰	Currently being established in NQ, where HIYH is designed to be coordinated by a nurse or AHP with less reliance on general practitioners than HIYH programs in other areas. In NQ, the client continues to be a patient of the hospital that provided their initial treatment. Through the HIYH program, ongoing outreach health care is provided by local providers in the client's home, with support of clinicians from the original hospital. Currently, no evaluation has been undertaken in Queensland, but similar programs funded by the Primary Health Network and involving GPs and ACCHO found that there was uncertainty about the program from clients, insufficient GPs participating, issues around GP payment and duplication of software programs. Overall ACCHO are supportive of the program but have difficulties with transient populations and staff turnover. Furthermore, it was recommended that more effort was required to publicise the program and recruit clients who were less motivated to attend. Efforts were being made to address these issues and the program had been extended for a further 12 months. ³³ The NQ program is currently being implemented. ²¹
OPEN ARCH ¹⁹	A community-based program that provides preventative, comprehensive person-centred, holistic culturally appropriate, multidisciplinary, service integrated care at the primary/secondary prevention interface. Evaluation found no significant difference in emergency department presentations or hospitalisations. However, stabilisations in presentation rates, and a trend towards lower hospitalisation rates, plus stabilisation of quality of life and absence of functional decline, were noted. ¹⁹
Deadly Ears ²²	Ear nose and throat program the prioritises children hearing, through capacity building, workforce development and collaboration between QH, ACCHO and non-government organisations. Health care is provided in local communities with support from a medical specialist in Brisbane. ²² The program is reported as being well received, but no formal evaluation was available.

client is supported to achieve improved health literacy and self-management.^{17,18} The Cape York Kidney Care program is another successful client-centred holistic, culturally appropriate multidisciplinary program that demonstrated delay in commencement of renal dialysis, fewer unplanned evacuations and improved quality of life through better managed care.¹⁶ However, the effectiveness of both programs is limited by their single disease focus. Given the common risk factors of HD, diabetes, renal disease, stroke and respiratory disease,²⁴ the *Chronic disease: Road to health* model is proposed. This model utilises the strengths of these programs (Table 2) while working collaboratively across a range of chronic diseases. The *Chronic disease: Road to health* will be achieved by involving managers, planners, community representatives and clinicians in developing healthcare systems and clinical algorithms for disease specific care, which will be delivered through a culturally appropriate, coordinated and collaborative approach in any environment (Figs 1 and 2).

To ensure optimal utilisation of current resources, continuous quality improvement (CQI)²⁵ and co-design, processes that involve multidisciplinary health staff, managers and community leaders are proposed. Both CQI and co-design support the delivery of effective and efficient health services to address barriers and build on enablers for

effective service delivery.^{25,26} This process has the potential to improve communication, working relationships and service coordination. Through this process *Chronic Disease: Road to health*, including appropriate policies, pathways, and guidelines, supported by in-service education, will be developed, implemented and evaluated.

Successful implementation of *Chronic disease: Road to health* will depend on a pathway from hospital to home, commencing with effective hospital discharge planning. This pathway, depicted in Fig. 2, includes referral to a community nurse and/or ATSIHW, who receive support and education to provide initial assessment and follow-up for secondary prevention, initiate referrals to AHPs for risk factor management and liaise with a medical officer, either locally, when visiting and/or via telehealth.²⁷

The aim of *Chronic disease: Road to health* is to ensure that all people with heart or other chronic diseases especially stroke, diabetes and respiratory disease in rural and remote areas have access to culturally responsive secondary prevention services.^{24,28} While conceptually simple, *Chronic disease: Road to health* includes aspects of health care and secondary prevention that may be unfamiliar to community-based health professionals.⁴ Thereby, staff education and support are essential, together with ongoing support, which could potentially be provided by centre-based CR

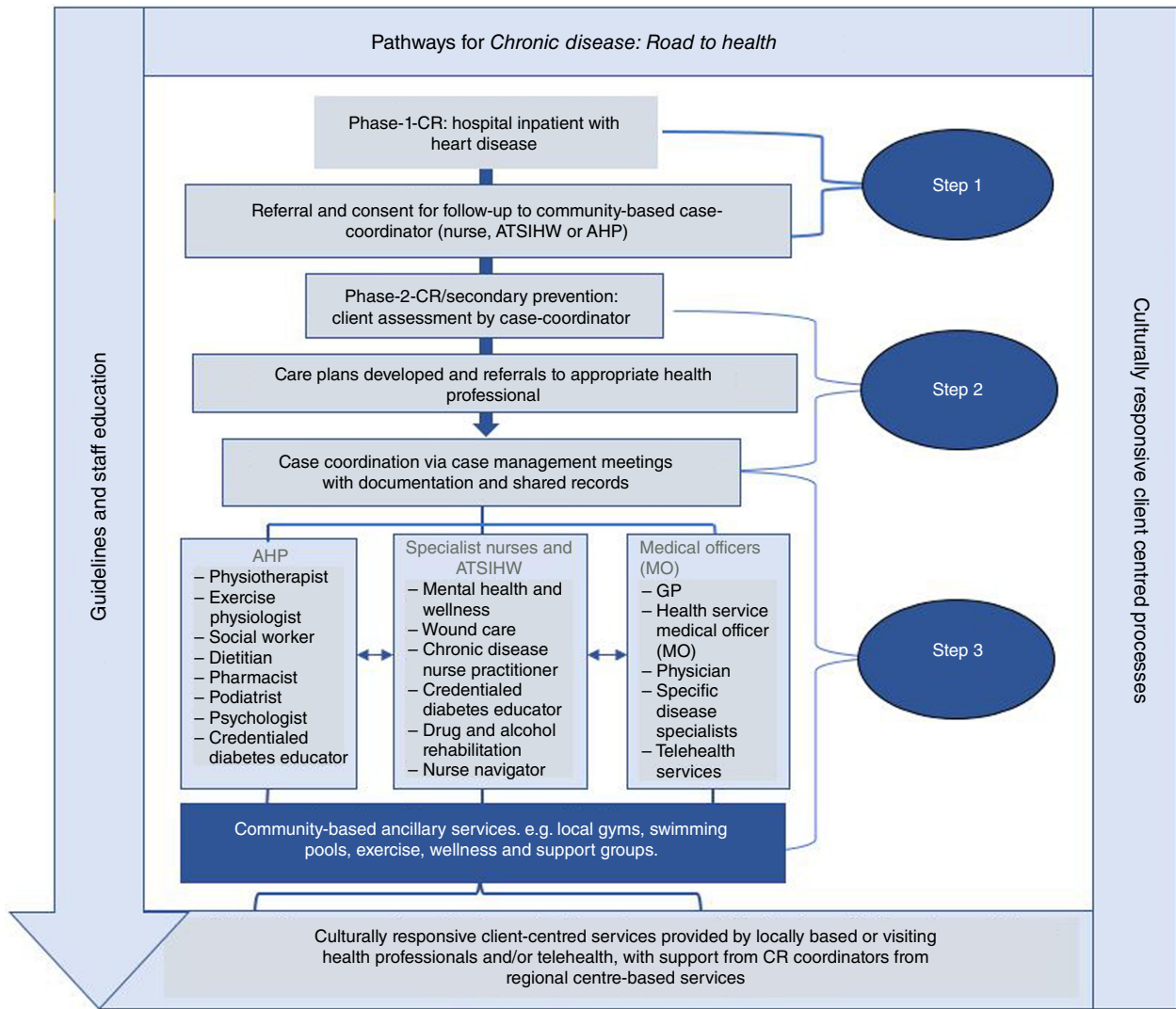


Fig. 2. Pathway for Chronic Disease: Road to health.

coordinators and/or established chronic disease programs, via telehealth or telephone.⁴

Discussion

Barriers to secondary prevention were identified as poor hospital discharge planning and communication with local health carer providers. Overall, in-patients and staff (hospital and community-based) had a poor understanding of secondary prevention, and systems for ensuring that people with HD receive secondary prevention following discharge from hospital were weak or not adhered to.

Enablers included the range of available services and willingness of local staff and community members to improve healthcare services. However, effective use of resources was limited by poor communication, coordination and collaboration. It is proposed that improved healthcare

systems, including effective communication, collaboration and cooperation, could ensure that improved secondary prevention for people with chronic disease could be achieved through implementation of the model *Chronic disease: Road to health* (Figs 1 and 2).

Following the development of *Chronic disease: Road to health*, transitional research is required (i.e. translating research into practice by ensuring that new research knowledge reaches the populations for whom it is intended and implemented correctly²⁹). Such research will include a pilot study to trial and evaluate the proposed model. Co-design and CQI, including the involvement of community leaders and local, visiting and regional staff will ensure that implementation of the model will be appropriate.²⁶ For *Chronic disease: Road to health*, translational research should consider all levels of healthcare systems to facilitate the provision of the right care, provided by the right people, at the right time.

Through the development of *Chronic disease: Road to health*, the complexity and impact of environmental, cultural, economic and social issues, including cultural factors and social determinants of health (SDOH), became apparent. Poor SDOH include: low employment, income and education; poor healthy food choices and housing; extreme climate; inadequate telephone and internet services; excessive distance to services; and colonisation, particularly for Aboriginal and Torres Strait Islander peoples.^{30–33} All these factors negatively impact on health literacy, access and effectiveness of health services and health outcomes.³⁰ Therefore, SDOH must be considered when planning and implementing accessible and effective services in rural and remote areas, and need to be considered in the co-design process.^{30–33} Importantly, cultural protocols need to be respected in the planning and provision of effective services.²⁸

Everyone's culture is based on 'beliefs, customs, values, and activities' which are influenced by family, environment and relationships that has consequences on all facets of life.³⁴ These cultural factors make it impossible for a person from one culture to fully understand all aspects of another culture. Thereby, to address cultural requirements for Aboriginal and Torres Strait Islander peoples, it is essential that ATSIHW are primary members of the team that provides services in order to bridge this cultural gap.^{23,24,27} To guide the development of revised healthcare systems for *Chronic disease: Road to health*, there are examples of culturally responsive, holistic, multidisciplinary programs that involve ATSIHW and ACCHO in the provision of secondary prevention for Aboriginal and Torres Strait Islander peoples.^{23,24,27} These models provide examples of programs that are flexible and provide effective health care in a supportive and trusting environment that could be utilised in all environments and cultures.^{28,35,36} The programs showcased in Table 2 largely demonstrate a holistic client-centred approach. For optimal benefits a CQI/co-design process to facilitate healthcare provision between QH, ACCHO, RFDS, contracting organisations, private practitioners and local research programs is required. Such a process would aim to improve communication, coordination and collaboration, reduce duplication, fill service gaps and develop algorithms for the individual clinical requirements for specific chronic conditions and common risk factors. A similar approach was attempted by previous research in the Northern Territory that aimed to provide cost-effective services to lower mortality for renal disease.³⁷ However, the project proved to be unsustainable when research funding was completed.³⁸ Despite this, it is proposed that, due to currently improved levels of resources, including visiting services and telehealth,^{4,24,27} and by using co-design, it could be possible to develop an effective and sustainable *Chronic disease: Road to health* model within current resources. Such a model could potentially result in fewer unscheduled consultations and emergency evacuations, reduced stress for

clients, their family and healthcare staff and reduce staff turnover and healthcare costs.

Overall, there is a pressing need for a comprehensive, flexible, client-centred, holistic, multidisciplinary systems-based approach for provision of secondary prevention for heart and related chronic diseases in rural and remote Australia. The implementation of the *Chronic disease: Road to health* model (Fig. 1) is depicted in Fig. 2 and includes pathways from hospital to home, built on revised healthcare systems that utilise current staff supported by appropriate management, policies, guidelines and in-service education. It is important that lessons learnt from successful secondary prevention models are integrated into the *Chronic disease: Road to health* model, including for Aboriginal and Torres Strait Islander peoples.^{4,16–19,24,28,35,36} To test these premises, translational research is required.

Conclusion

Chronic disease: Road to health provides an opportunity to improve healthcare delivery and health outcomes for people with a range of chronic diseases. To achieve this, organised area and regional healthcare systems, including the development of comprehensive policies, pathways, guidelines and in-service education, through CQI and co-design, is proposed. Such processes could result in improved communication, coordination and collaboration between all healthcare providers in rural and remote areas and potentially lead to flexible, client-centred, holistic, culturally responsive, efficient and effective healthcare services and improved client outcomes.

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Data availability. The data that support this study will be shared upon reasonable request to the corresponding author.

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