How can access to cardiac rehabilitation in rural and remote areas of North Queensland be improved?

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Abstract

Mortality and morbidity of heart disease continue to be high in Australia, particularly in rural and remote areas, with Aboriginal and Torres Strait Islander people having the highest rates. Cardiac rehabilitation (CR) is a model of secondary prevention that is known to improve health and quality of life, and reduce mortality, morbidity, hospital readmission rates, healthcare and personal costs, of people with heart disease (clients). The aim of this research was to develop a revised model to improve access to CR for clients living independently in rural and remote areas of North Queensland, using four stage sequential, qualitatively dominant multiple method, design.

Health care resources including nurses, Aboriginal and Torres Strait Islander Health Workers, allied health professionals and medical officers, either resident or visiting, were identified in rural and remote communities, but secondary prevention for heart disease was seldom provided. Barriers were identified as inadequate healthcare systems, low CR referrals, discharge planning, and poor functional pathways from hospital to the client's home community.

To achieve holistic, multidisciplinary, culturally responsive healthcare, including secondary prevention, that is effective and efficient, communication, coordination and collaboration, between local and regional health organisations, alternative models of chronic disease management, and technology based programs is necessary. To achieve this, the revision of healthcare systems including policies, guidelines, in-service education, and referral pathways from hospital to local healthcare services, namely *Road to health* approach for people with heart disease, diabetes and renal disease is proposed.

Executive summary

Introduction

Heart disease continues to be the leading single disease cause of death with the highest burden of disease in Australia. The situation is worse in rural and remote (R&R) areas and for Aboriginal and Torres Strait Islander people, who have twice the rate of heart disease (HD) than non-Indigenous people. Cardiac rehabilitation (CR) as recommended by the National Heart Foundation of Australia (NHF) is a best-practice model for providing secondary prevention for adults with HD (clients). It is known to be effective in reducing mortality and morbidity, improving quality of life, and decreasing healthcare costs, mainly due to fewer hospital readmissions.

CR consists of three phases: Phase-1-CR is designed to provide client in-hospital education, discharge planning, and referral to out-patient Phase-2-CR for continuing education, risk factor management, clinical, and medical care. Phase-3-CR describes supported self-management, ongoing medical monitoring, in conjunction with community-based programs such as walking, social groups and gymnasiums. Queensland Health (QH) provides a home-based, Phase-2/Phase-3 secondary prevention telephone support program for chronic disease (Self-management of Chronic Conditions [SMOCC], previously called Coaching on Achieving Cardiovascular Health [COACH]). SMOCC/COACH is designed to provide secondary prevention for people who do not have access to centre-based CR, with other chronic disease programs, or who prefer to use a home-based service. This research uses the NHF definition of eligibility for CR, which includes all people with stable HD, including acute coronary syndrome and stents; arrhythmias and implantable devices such as pacemakers and automatic defibrillators; any cardiac surgery; heart failure; and risk factors such as hypertension, obesity, diabetes, hypercholesterolaemia, smoking and insufficient exercise.

Despite the known benefit of a CR, only approximately 30% of eligible people are referred across Australia, with less attending or completing the program. Therefore, it is important to understand the reasons for low referrals and attendance, and propose a way forward to address the barriers, build on the enablers, and plan a pathway for improved access to CR in R&R areas of Australia.

Aim

The aim of this research was to investigate access to CR and develop a revised CR model for clients living independently in R&R areas of North Queensland (NQ), with the overarching research question of: How can access to CR in R&R areas of NQ be improved?

Objectives

i. To identify barriers, enablers and pathways for CR in R&R areas of Australia and other developed countries and synthesise findings and lead to a new framework and perspectives. (integrative literature review).

ii. Describe rates of hospitalisation and COACH referral for Queensland adults with heart and related disease and make comparisons between Aboriginal and Torres Strait Islander people and non-Indigenous people in NQ (epidemiological study).

iii. Investigate the implementation of Phase-1-CR by staff and in-patients in cardiac services in two public and two private tertiary hospitals in Townsville and Cairns and consider the impact on post-discharge care in R&R areas of NQ (hospital case study series).

iv. Investigate barriers, enablers, and pathways for improved access to Phase-2-CR in selected R&R areas of NQ (community based case study series).

v. Informed by Objectives i–iv, develop a model of healthcare delivery that aims to improve access to CR in R&R areas of NQ. (iterative process: communication with residents and healthcare staff to develop a model for improved access to CR in R&R areas [*Road to health*]).

Methodology

Four stage sequential approach that included qualitatively dominant multiple method research was used in this research. A combined conceptual and theoretical framework was used to link reasons for the research, provide guidance, and build towards the achievement of the aims and objectives. Further, theories from public health, health promotion and primary healthcare provided direction within this framework. This approach enabled the integration of continuous quality improvement, co-design, health education and social determinants of health, to enable flexible, client-centred, community-based, culturally responsive, and collaborative processes, that culminated in developing a model to improve access to CR in R&R areas of NQ (*Heart: Road to health).* Ethics approval was obtained for each research study undertaken to achieve this outcome. (Chapter 3: 3.7)

An integrative literature review was completed as part of Stage 1 of the research (Objective i). Based on the review findings, and the combined experience of the research team, the methodology for the total research was developed. Stage 2 comprised an epidemiological study (Objective ii) to provide baseline information on rates of HD, hospitalisation, and referral to

COACH for Aboriginal and Torres Strait Islander and non-Indigenous people in Queensland. Stages 3 and 4 comprised qualitatively dominant multiple method case studies that focused on understanding, implementation, and client access for hospital-based Phase-1-CR (Stage 3), and community-based Phase-2-CR (Stage 4). Both studies included healthcare staff understanding and involvement in CR; availability of resources; and information, understanding, and support, received by clients in tertiary hospitals and local communities in R&R areas of NQ (Objectives iii and iv).

As a result of the sequential approach, each stage informed the next. In the final stage, (4b), the results of all stages were summarised and discussed with healthcare staff, community members and clients.

Results

Stage 1 (Objective i): An integrative literature review to identify barriers, enablers and pathways for access to CR in R&R areas of developed countries.

Results: Effective CR models reported in the literature included centre-based programs, usually attached to hospitals; home-based programs with intermittent health professional visits, and/or telephone support; and telephone apps. However, there was a general perception that CR refers to short term centre-based programs, usually run by hospitals. To counter this, the NHF uses the term ‘cardiac rehabilitation continuum’, or a ‘coordinated system of long-term care’ necessary for clients to achieve optimal health and well-being.

Barriers to CB programs included travel, costs, dislike of groups, poor program flexibility and work hours. Attendance was impacted by gender (women are less likely to attend), differing cultural needs, levels of education, socio-economic status, age (too old or too young), and multimorbidity. There was a common perception that CR was of no benefit particularly by clients and some healthcare staff. This often resulted in a lack of support from health professionals, including doctors. This implied poor understanding and/or under-valuing of CR.

An optimal multidisciplinary team approach to CR that includes a GP, cardiologist, nurse, physiotherapist, dietitian, psychologist, and an exercise physiologist was recommended by the NHF and Australian Cardiac Rehabilitation Association (2010). Such a multidisciplinary team is unlikely to be achieved in one place at one time in R&R areas. However resources are available with nurses and Aboriginal and Torres Strait Islander Health Workers (ATSIHW), at times GP, living and working in these areas, supported by visiting allied health professionals, medical officers and specialists.

Factors that impact on client's recovery included poor mental health, coping with change and competing priorities, plus costs for travel, medications, and health professional consultations. Poor cultural understanding by non-Indigenous staff, and low levels of involvement of ATSIHW in care of their own people, are also identified as important factors that need to be addressed to improve access and provision of CR for Aboriginal and Torres Strait Islander people. (Chapter 2: 2.2.1, Paper 1; Chapter 5: 5.3.1, Paper 6)

Stage 2 (Objective ii): A descriptive retrospective epidemiological analysis of QH Hospital Admitted Patient Data Collection: 2016–2017, and linked COACH referrals for all adults with HD 2012–2016.

Results: Queensland's Aboriginal and Torres Strait Islander people overall have non-significant higher rates of hospitalisation for heart and related disease (RR 1.1, range 0.56–2.23), but higher rates for NQ (relative risk range 1.3–2.23). Despite the demonstrated need for CR and lack of centre-based CR, Queensland's overall COACH referral rates were low (3.9%), with NQ rates ranging between 2.3% and 13% for non-Indigenous people in NQ, and between 4% and 20%, for Aboriginal and Torres Strait Islander people. Hospitalisation and COACH referral rates are unlikely to reflect the secondary prevention needs of Aboriginal and Torres Strait Islander people, especially in R&R areas, given their higher mortality and morbidity rates, likely under enumeration, and fewer services. (Chapter 4: 4.1, Paper 2)

Stage 3 (Objective iii): A qualitative case study series, augmented by a medical record audit, that focused on implementation of Phase-1-CR in two public and two private tertiary hospitals in NQ.

Results: Phase-1-CR was predominantly provided by cardiac educators (CE) who were employed by public hospitals. Implementation rates, staff and in-patient understanding, as well as multidisciplinary team involvement were low. The highest rates of Phase-1-CR were 74% (range 67–80%), for in-patients with a length of stay (LOS) $\geq$3 days in cardiac units with CE. Rates fell to 14% (range 6–26%) in cardiac units with no CE, and 9% (range 0–19%) for in-patients in all areas of all hospitals with LOS $\leq$2 days. Low Phase-1-CR implementation rates resulted in poor in-patient understanding about their disease, treatment, and post-discharge care. Further, medical discharge summaries rarely mentioned CR or risk factor management, 5% (range 3–6%), resulting in a lack of information on secondary prevention for post-discharge healthcare providers. This resulted in people from R&R areas being discharged with insufficient information to be proactive in achieving their holistic healthcare needs, and a lack of guidance for their healthcare providers. *(Paper 4 - Chapter 4: 4.2)*

Stage 4a (Objective iv): A case study series to investigate barriers, enablers and pathways for access to community-based Phase-2-CR in R&R areas of NQ.

Because of the complexity of undertaking research in R&R environments and with Aboriginal and Torres Strait Islander people, a project protocol was developed and published to guide stages 4a and 4b. (Chapter 3: 3.6, Paper 3)

Results: QH Multi-Purpose Health Services and Primary Health Care Centres, staffed by resident and visiting staff including nurses, ATSIHW, medical officers, and allied health professionals (AHPs), were identified in the four focus R&R communities of the study. Additional services were available through Aboriginal and Torres Strait Islander Community Controlled Health Organisations (ACCHO), the Royal Flying Doctor Service (RFDS), other contracting organisations and private practitioners. The contracting organisations generally provided visiting AHP services, and occasionally locum GP. As well as routine service provision, a range of mostly disease-specific initiatives that provided holistic, client centred multidisciplinary, disease management and secondary prevention programs, such as the Diabetes Education and Self-management, and Cape York Kidney Care, were identified. However, there is limited evidence of effective communication, coordination or collaboration between these alternative specialised programs and/or the standard established healthcare organisations such as QH, ACCHO and RFDS.

Barriers to CR included low referrals to community-based health professions by the discharging hospital and poorly defined referral pathways, compounded by lack of guidelines, staff support and in-service education. There were limited centre-based CR (secondary prevention) services and inadequate understanding of holistic, multidisciplinary CR by health staff, community participants, and leaders, as well as a lack of awareness or acceptance of telephone support services, that were at times also unreliable. These factors were compounded by the predominance of the Western medicalised approach and underutilisation of ATSIHW, which contributed to inadequate culturally responsive services.

The study concluded that to address the barriers to CR in R&R areas, healthcare systems revision, including development of referral pathways to local health professionals, secondary prevention guidelines and in-service education, are required to develop a model of secondary prevention: *Heart: Road to health.* The *Heart: Road to health* terminology was developed because of the need to address the common misunderstanding of the term ‘rehabilitation’, which was often related to treatment for people post orthopaedic surgery, stroke or for drug and alcohol rehabilitation. Given the common risk factors for many chronic diseases further consideration needs to be given to improved communication, coordination and collaboration

with current chronic disease initiatives that aims for one system for access to secondary prevention for people with HD, diabetes and renal disease, or a generic *Road to health* approach. (Paper 5: Chapter 4.3, Chapter 5: 5.3.2, Paper 7; 5.3)

Stage 4b (Objective v): Informed by Stages 1 to 4a, a collaborative and iterative process to propose the development of a model of healthcare delivery that aims to improve access to CR in R&R areas of NQ and ultimately health outcomes.

Results: It is proposed that an accessible and culturally responsive *Road for health* is achievable through reorientation and improved coordination of current healthcare resources. To achieve this, revised health systems, including pathways, guidelines and in-service education, which are developed, implemented, monitored and evaluated through continuous quality improvement (CQI), and utilisation of strategies for effective behaviour change, are recommended. Special consideration of healthcare provision for Aboriginal and Torres Strait Islander people including strengthening the role of ATSIHW, and systems of healthcare is also advocated. (Chapter 5: 5.3.1, Paper 6)

The total process encompasses communication, coordination and collaboration between healthcare providers, their managers and community participants to facilitate a continuous client-centred pathway, to ensure continuity of care from hospital to home, which has the potential to result in improved health status, health literacy, disease self-management, and quality of life.

Conclusion

A broad approach has been taken in this research to investigate the barriers, enablers and pathways to develop a model for improved access to secondary prevention for people with HD, diabetes and renal disease in R&R areas of NQ (*Road to health)*. It is proposed that through the development of effective systems and management, improved, community-based, flexible, client-centred, holistic, and culturally responsive care the *Road to health* in R&R areas could be realised. To achieve this, it is necessary to consider the client pathway that commences with Phase-1-CR and continues through to community-based secondary prevention (Phase-2-CR and Phase-3-CR). Continuous quality improvement and co-design have been identified to facilitate this process

There are examples of successful chronic disease initiatives that provide client-centred, holistic primary and secondary prevention for chronic diseases in Queensland, and other states of Australia. It is proposed that these could be adapted and coordinated to provide secondary prevention for heart and other chronic diseases. However, these programs are often research or

pilot projects that may not have recurrent funding and often focus on specific geographic areas. There needs to be further consideration of these initiatives with a view to developing a standardised healthcare model that is flexible, holistic, client-centred, and culturally responsive to fulfil the secondary prevention needs of people with chronic disease, including HD. Therefore, it is proposed that translational research, is undertaken to develop, coordinate and standardise a *Road to health* by building on successful current chronic disease initiatives. Such a system would facilitate efficient and effective healthcare that is available to improve access and health outcomes through secondary prevention for all people with chronic disease in R&R areas of Australia.

Keywords: cardiac rehabilitation; rural and remote areas; Aboriginal and Torres Strait Islander people; heart disease; chronic disease; barriers, enablers, and pathways

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Abbreviations

ACCHO	Aboriginal and Torres Strait Islander Community Controlled Health Organisation
ACRA	Australian Cardiovascular Health and Rehabilitation Association
AHP	allied health professional
ASGS-RA	Australian Statistical Geography Standard—Remoteness Areas
ATSIHW	Aboriginal and/or Torres Strait Islander Health Worker
CHD	coronary heart disease
CHHHS	Cairns and Hinterland Hospital and Health Services
COACH	Coaching on Achieving Cardiovascular Health
CR	cardiac rehabilitation
HD	heart disease
HHS	Hospital and Health Service
IR	integrated literature review
IRSAD	Index of Relative Socio-economic Advantage and Disadvantage
MPHS	Multi-Purpose Health Service
NQ	North Queensland
NWHHS	North West Hospital and Health Service
PHCC	Primary Health Care Centre
PHN	Primary Health Network
QH	Queensland Health
R&R	rural and remote
R&VR	rural and very remote as classified by ASGS-RA
SDoH	social determinants of health
SEIFA	Socio-Economic Indices for Areas
SMOCC	Self-Management of Chronic Conditions
TCHHS	Torres and Cape Hospital and Health Services
THHS	Townsville Hospital and Health Services
WHO	World Health Organization

Key definitions and terminology

Aboriginal and Torres Strait Islander Community Controlled Health Organisations (ACCHOs)	Organisations 'which allow the local Aboriginal community to be involved in its affairs in accordance with whatever protocols or procedures are determined by the Community'. https://www.naccho.org.au/acchos
Aboriginal and Torres Strait Islander people(s)[1]	Terminology as used in this research is according to the Federal Government *Style manual* 2022. https://www.stylemanual.gov.au/accessible-and-inclusive-content/inclusive-language/aboriginal-and-torres-strait-islander-peoples The term 'Indigenous' is used when referring to data sets and government documents in which this term is used, or in direct quotations.
Allied health professionals	Terminology as used in this research: Health professionals who are most commonly involved in cardiac rehabilitation programs, such as physiotherapists, exercise physiologist, social workers, or psychologist and dietitians.
Burden of disease	'Burden of disease is a measure of population health that aims to quantify the gap between the ideal of living to old age in good health, and the current situation where healthy life is shortened by illness, injury, disability and premature death'. https://www.health.qld.gov.au/research-reports/population-health/burden-disease
Cardiac rehabilitation	An effective method of secondary prevention for people with heart disease that includes coordinated activities to influence behaviour that contributes to risk factors for heart disease. This is achieved by providing the best possible physical, mental, and social conditions, so that through self-managed care, people with stable heart disease (clients) achieve optimal health and functioning in their community and slow or reverse progression of heart disease.[1]
Cardiovascular disease	Range of conditions that affect the heart and blood vessels, e.g. coronary heart disease, stroke and heart failure.[2]
Chronic disease	'Chronic diseases, non-communicable diseases or long-term health conditions, chronic conditions are generally characterised by their long-lasting and persistent effects'.[3] Commonly in this research the term chronic disease refers to heart, diabetes and renal disease. However, there are many instances in which the term could be interpreted more broadly, and to which the research is equally applicable.
Client	Terminology as used in this research: A person with stable heart disease living independently.
Coaching on Achieving Cardiovascular Health (COACH)	Home-based telephone support secondary prevention program for people with heart and other chronic diseases.[4] Rebranded in 2021 as Self-Management of Chronic Conditions (SMOCC).

Coronary heart disease	Coronary heart disease (CHD) or coronary artery disease occurs when a coronary artery clogs and narrows because of a build-up of plaque. https://www.heartfoundation.org.au/conditions/coronary-heart-disease. At times used as a proxy for all heart disease due to lack of specific data (Chapter 1: 1.1.1)
Culturally responsive care	Healthcare that is adaptable, acceptable, and effective for all people regardless of race, heritage, and socioeconomic status.
Direct care staff	A term developed in this research to describe hospital staff who provide day-to-day personal care, including clinical, medical, and nursing, as well as allied health specialties such as physical, dietary, psychosocial, cultural, and pharmacy.
Eligible clients	People with heart disease who are eligible to attend CR as per the National Heart Foundation of Australia and the Australian Cardiovascular Health Association recommendations.[1]
Guidelines	Documentation of specific activities required to ensure that clients have access to evidence-based healthcare that includes discharge planning, referral, clinical care, assessment, risk factor management and psychosocial support.[5]
Heart disease	All disease that relates to the heart, and dysfunction, including myocardial infarction (heart attack) angina, heart failure, valvular disease, arrhythmias, and infections.
Heart: Road to health	Terminology developed in this research as an alternative to the term 'cardiac rehabilitation' because of confusion over rehabilitation only being necessary for people who have had a stroke, orthopaedic procedures, or treatment for drug or alcohol misuse.
Road to health	Terminology developed in this research and used as an alternative to *Heart: Road to health,* to indicate access to secondary prevention for people with heart disease, diabetes and renal disease.
Holistic care	Terminology as used in this research: Treating the client as a whole person, considering mental and social factors and not just their illness.
In-patient	A person in hospital for treatment for heart disease.
Living independently	A person who does not permanently live in institutionalised care such as a nursing home.
Metropolitan areas	Major cities as classified by Australian Statistical Geography Standard—Remoteness Area (2016) (ASGS-RA1).[6]
Modified Monash Model	Classification of regional, rural, remote, and very remote areas, which as per the Australian Statistical Geography Standard—Remoteness Area framework, and further differentiates areas in Inner and Outer Regional Australia based on local town size. Modified Monash Model locator[7]

	Terminology as used in this research: Based on common usage, the term rural and remote (R&R) is used to encompass all areas classified as outer regional, rural, remote, and very remote.
Multimorbidity	Refers to a health state in which a person has more than one chronic disease. Commonly heart disease, diabetes and renal disease may occur concurrently.
Non-Indigenous Australians[1]	All people who do not identify as an Aboriginal and Torres Strait Islander person. At times also referred to as general populations.
Pathways	A process, commencing with effective hospital discharge planning including referral to coordinated community-based support (CR program or locally based secondary prevention) for clients on discharge from hospital.[5]
Phase-1-Cardiac Rehabilitation	Phase-1-CR that provides hospital in-patient education on heart disease and risk factors; discharge planning that includes referral to out-patient centre, or home-based Phase-2-CR.[1]
Phase-2-Cardiac Rehabilitation	Post-hospitalisation care that includes ongoing multidisciplinary, holistic (health and lifestyle) care that includes medical, continuing education, risk factor management and psychosocial support.[1]
Phase-3-CR	Ongoing holistic healthcare and risk factor maintenance, preferably utilising community-based programs.[1]
Primary prevention	'Primary prevention aims to prevent disease or injury before it ever occurs. This is done by preventing exposures to hazards that cause disease or injury, altering unhealthy or unsafe behaviours that can lead to disease or injury, and increasing resistance to disease or injury should exposure occur', e.g. education on healthy diets and exercise, use of seatbelts and bike helmets. https://www.iwh.on.ca/what-researchers-mean-by/primary-secondary-and-tertiary-prevention#:~.
Public health	The art and science of preventing disease, prolonging life and promoting health through the organised efforts of society. https://www.nhmrc.gov.au/health-advice/public-health
Secondary prevention	Provision of healthcare that aims to prevent reoccurrence of disease and enable optimal recovery through holistic medical care, including prescription of medications, risk factor management, such as smoking, obesity, hypertension, and lipid control.[8] These essential components of CR/secondary prevention are complemented by psychosocial care, education, and support for self-management, delivered in a variety of settings, through a holistic, multidisciplinary team approach.[9]
Self-Management of Chronic Conditions (SMOCC)	Home-based telephone support secondary prevention program for people with heart and other chronic diseases. Previously COACH.[4]

Social determinants of health	Access to healthcare and education, conditions of work and leisure, housing, location (rural, remote or metropolitan areas), linked to socioeconomic status, access to computers, and good nutrition.[10]
Socio-economic Indices for Areas (SEIFA):	Based on the 2016 Census, SEIFA ranks areas in Australia according to relative socioeconomic advantage and disadvantage and includes Index of Relative Socio-economic Advantage and Disadvantage (IRSAD).[7]
Tertiary healthcare	'Highly specialised medical care usually over an extended period of time that involves advanced and complex procedures and treatments performed by medical specialists in state-of-the-art facilities'. https://www.merriam-webster.com/dictionary/tertiary%20care
Yarning	Informal discussion via a dialogue circle[11] as a culturally sensitive approach for Aboriginal and/or Torres Strait Islander peoples.[12]

1 During the development of this research, every effort has been made to use terminology that is respectful to Aboriginal and Torres Strait Islander peoples. Over time, the terminology has changed. Any variations in terminology are explained in the relevant section of the research.

Statement of authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at James Cook University or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Statement of the contribution of others

Nature of assistance	Contribution	Names
Intellectual support	Proposal writing Technical support Data analysis Statistical support Editorial assistance	Prof. Richard Franklin, James Cook University (JCU), Townsville (Primary advisor) A/Prof. Ruth Barker, JCU, Cairns Prof. Ian Ring, AO, JCU Townsville Prof. Peter Leggat, AM, ADC, JCU, Townsville, (Advisor mentor) A/Prof. Karla Canuto, Flinders University, Darwin
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Data collection	Cardiac services staff and in-patients: Townsville Hospital; Mater Hospital and Health Services, Townsville; Cairns Hospital; Cairns Private Hospitals Hughenden community leaders, and people discharged from hospital following treatment for heart disease in the past five years. Multipurpose Health Services (MPHS) staff Cooktown community leaders, and people discharged from hospital following treatment for heart disease in the past five years. MPHS staff Hopetown community leaders and people discharged from hospital following treatment for heart disease in the past five years. Primary Health Care Centre (PHCC)staff and Aboriginal and Torres Strait Islander Community Controlled health organisation (ACCHO) staff Wujal Wujal community leaders and people discharged from hospital following treatment for heart disease in the past five years. PHCC, and ACCHO staff	
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Publications

1. **Field P**, Franklin R, Barker R, Ring I, Leggat, P. Cardiac rehabilitation for people living in rural and remote areas: An integrated review. International E-Journal of Rural and Remote Health. 2018. https://doi.org/10.22605/rrh4738
2. **Field P**, Franklin R, Barker R, Ring I, Canuto, K, Leggat P, Canuto K. Heart disease hospitalisation and COACH referral in Queensland. Australian Journal of Rural Health. 2020. https://doi:10.1111/ajr.12588
3. **Field P**, Franklin R, Barker R, Ring. I, Leggat P, Canuto K. Improving access to cardiac rehabilitation in rural and remote areas: a protocol for a community-based qualitative case study. International Journal of Therapy and Rehabilitation. 2021. http://doi:10.12968/ijtr.2020.0167
4. **Field P**, Franklin R, Barker R, Canuto K, Leggat P. Importance of cardiac rehabilitation in rural and remote areas of Australia. Australian Journal of Rural Health. 2021. https://doi:10.1111/ajr.12818
5. **Field P**, Franklin R, Barker R, Ring I, Leggat P. Improving access to cardiac rehabilitation in rural and remote areas: How well are we doing? Australian Journal of Rural Health. 2022. http://doi:10.1111/ajr.12861
6. **Field P**, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Improving access to cardiac rehabilitation (Heart: Road to health) for Aboriginal and Torres Strait Islander peoples in rural and remote areas of North Queensland. Australian Journal of Rural Health. 2022. http://doi:10.1111/ajr.12932
7. **Field P**, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Model for Heart: Road to health or Chronic disease: Road to health in rural and remote areas. Submitted for publication, October 2022.

All published or submitted papers were approved by the authors as listed at time of publication, and as required by the publisher.

Through the development of this thesis fifteen conferences were attended, at which either a paper or a poster were presented, as listed in Appendix 7.1.

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The completion of this thesis has been a long journey that has had its ups and downs, but through the unerring support from my expert advisory team, competently led by Prof Richard Franklin, supported by A/Prof Ruth Barker, Prof Ian Ring, Prof Peter Leggat and A/Prof Karla Canuto. Each member of the team contributed to all aspects of this research and were always ready to provide extra support.

Before I continue, I would like to explain why I am here now and what I hope to achieve. The idea for this PhD began approximately 25 years ago when I was working with the National Heart Foundation of Australia, considering heart disease and services for people in rural and remote (R&R) areas, including Aboriginal and Torres Islander people. During this time, it became evident that once people left hospital, there was poor access to cardiac rehabilitation (CR) in R&R areas, and it was common for people with heart disease to struggle mentally and physically following discharge from hospital. This had a lasting impact, and in 2016, I was encouraged by my long-time friend A/Prof Ruth Barker to undertake a PhD to investigate the barriers and identify enablers and pathways to improve access to CR in R&R areas in NQ, and early 2017 I began.

As well as my advisory team, I would like to thank the Cohort Doctoral Studies Program, particularly Prof Melissa Crowe, Dr Diana Mendez and Ms Christine Teitzel, for their support throughout my PhD. The program really enhanced my learning, and as an external student enabled me to link with a valuable peer group.

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Thesis structure

This thesis is by publication and is organised around four sequential stages. Each stage has at least one paper published or submitted. Figure 1 sets out the thesis chapters, related publications, and chapter position within the thesis, with the current chapter outlined in red.

Chapters		Content & publications
1. Introduction	⇨	Background, introduction & implications of the research
Stage 1 Research foundations		
2. Integrative literature review	⇨	Cardiac rehabilitation services for people in rural and remote areas: Integrative literature review (2007–2016). Published 2020 (Paper 1). Supplementary review (2018 – 2021)
3. Methodology and methods	⇨	Project protocol: Improving access to cardiac rehabilitation in rural and remote areas: A protocol for a community-based qualitative case study. International Journal of Therapy and Rehabilitation. Published 2021 (Paper 2)
Stage 2 Results: Heart disease, hospitalisation, and referral		
4. Results 4.1 Epidemiological study	⇨	Heart disease, hospitalisation, and referral: coaching to achieving cardiovascular health through cardiac rehabilitation in Queensland. Published 2020 (Paper 3)
Stage 3 Results: Hospital-based Phase-1-Cardiac Rehabilitation		
4.2 Hospital case study series	⇨	The importance of cardiac rehabilitation in rural and remote areas of Australia. Published 2021 (Paper 4)
Stage 4a Results: Community-based Phase-2-Cardiac Rehabilitation		
4.3 Community case study series	⇨	Improving access to cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing? Published 2022 (Paper 5)
Stage 4b Pathways to *Heart: Road to health*		
5. Discussion and conclusion	⇨	Discussion and conclusion
5.3.1 *Heart: Road to health* for Aboriginal and Torres Strait Islander people	⇨	Improving access to cardiac rehabilitation (Heart: Road to health) for Aboriginal and Torres Strait Islander peoples in rural and remote areas of North Queensland. Published 2022 (Paper 6)
5.3.2 Model for *Heart: Road to health*	⇨	Model for Heart: Road to health or Chronic disease: Road to health in rural and remote areas. Submitted for publication Oct 2022 (Paper 7)

Figure 1: Thesis structure

Chapter 1: Introduction

Chapter 1 provides the background and context of the research, clarifies terminology, and describes why the research was necessary. Combined with Chapter 2: Integrative literature review, information presented in this chapter informed the development of aims and objectives (1.5) and following stages of the research.

1.1 Background

This research focuses on improving access to cardiac rehabilitation (CR) for people in rural and remote (R&R) areas of North Queensland (NQ). WHO 1993, defined CR as:

> … the coordinated sum of activities required to influence favourably the underlying cause of cardiovascular disease, as well as to provide the best possible physical, mental and social conditions, so that the patients may, by their own efforts, preserve or resume optimal functioning in their community and through improved health behaviour, slow or reverse progression of disease.[13]

This definition is equally applicable today regardless of how or where CR is provided. Given that rates of heart disease (HD), and burden of disease continues to be high (Table 1), CR is an important component of optimal recovery and quality of life for people with HD (client[s]). Rates of coronary heart disease (CHD) are the most common rates of HD reported by the Australian Institute of Health and Welfare.[4] Due to paucity of accessible information about rates of the full range of HD, rates of CHD are used as a proxy for HD, in this research.

1.1.1 Coronary Heart disease

CHD includes heart attack and angina and is reported as the largest single disease cause of death in Australia (11%), contributing to significant illness, disability, poor quality of life, and high healthcare costs.[14, 15] Further, CHD resulted in 6.9% of the total burden of disease in Australia in 2018/19.[14] The rates of CHD by selected population groups, according to rurality and socioeconomic status, and compared with overall Australian rates are summarised in Table 1.

Table 1: Impact of coronary heart disease by selected population groups and multiples of the Australian population rate

Disease characteristics	Population groups		
	Indigenous/non-Indigenous	Rural and remote/major cities	Lowest/highest socioeconomic areas
Coronary heart disease (prevalence)	2.0x	0.9x	1.6x
Hospitalisations	2.1x	1.5x	1.3x
Mortality	2.0x	1.5x	1.6x
Burden of disease	2.3x[16]	1.4x	1.6x

Adapted from AIHW report on coronary heart disease – 2020[14, 17]

In R&R areas, there are higher rates of hospitalisations, mortality, and burden of disease from CHD, than in metropolitan areas.[14, 17] If data for the full range of HD, including CHD, rheumatic heart disease, heart failure, valvular disease, cardiac arrhythmias, cardiomyopathy, other infections, and risk factors, were available for R&R areas and for Aboriginal and Torres Strait Islander people, it is likely that these rates would be considerably higher especially for Aboriginal and Torres Strait Islander people. These rates have a considerable impact on the number of hospitalisations and range of services and support required when a client is discharged from hospital to their home community.

1.1.2 Cardiac rehabilitation: Terminology, eligibility, models and best practice

In this research, the term 'heart disease'(HD), which includes CHD, rheumatic heart disease, heart failure, valvular disease, cardiac arrhythmias, cardiomyopathy and infections, is used because it is inclusive and easily understood. CR is a model for delivery of evidence-based best practice secondary prevention, which includes provision of healthcare that aims to prevent reoccurrence of HD and enable optimal recovery through holistic medical care, including prescription of medications, and risk factor management, predominantly for smoking, obesity, hypertension, and lipid control.[8, 18] These essential components of CR/secondary prevention are complemented by psychosocial care, education, and support for self-management delivered in a variety of settings, through a holistic, multidisciplinary team approach,[9] and recommended for all clients.[19]

The terms CR and secondary prevention are used interchangeably, according to the context throughout the research. Initially CR is predominant, but as the research progresses terminology transitions to secondary prevention for people with HD. The terms, Phase-1-CR, Phase-2-CR and Phase-3-CR are predominantly used throughout, particularly when referring to structured

programs commonly provided by hospitals and urban community health centres or at times via telephone, telehealth and telephone apps. Best-practice CR begins in hospital with Phase-1-CR, continues to post-discharge with Phase-2-CR, through to Phase-3-CR for supported self-management.[20] Each phase of CR is essential in the continuum of care, to achieve optimal client recovery and quality of life. Phase-1-CR provides in-patient education on HD, medications, risk factors, together with discharge planning, which optimally includes referral to centre- or home-based Phase-2-CR, for ongoing support, education, risk factor and medical management. Finally, Phase-3-CR, through the health literacy gained from Phases-1 and 2, enables clients to transition to a supported self-management approach, preferably utilising local community-based programs such as walking and social groups.[8, 21, 22] Given the known dose-response effect,[8] it is important to provide optimal access to all Phases of CR to ensure maximum client participation.

Several factors influenced the transition from the term CR to secondary prevention. These included a general perception that CR could only be provided through a centred-based specialised facility, with little understanding of the concept that effective post-hospitalisation CR (secondary prevention) could be provided, in a community-based setting. Further, there was general confusion over the use of the term 'rehab', which was often perceived as referring to centre-based CR, or post-operative care for people following orthopaedic surgery or, on occasions, drug and alcohol, or stroke rehabilitation. Therefore, the term secondary prevention, with an explanation provided, for staff and clients to minimise further misunderstanding, evolved into *Heart: Road to health* and further to a generic *Road to health* as the preferred terminology for HD, diabetes and renal disease as common multimorbidity (Chapters 4: 4.3; 5: 5.1, 5.3.1, 5.3.2, 5.4).

Eligibility for CR is defined according to the Heart Foundation of Australia (NHF) and Australian Cardiovascular Health and Rehabilitation Association (ACRA) criteria, and includes people with stable acute coronary syndrome, cardiac arrhythmias, and implantable devices, valvular incompetence, heart failure, cardiomyopathy, and risk factors such as hypertension, obesity, elevated cholesterol, smoking and excessive alcohol.[1] CR is commonly provided via structured centre-based or home-based services, telephone support, telehealth or combined hybrid programs with the support of local healthcare providers,[23] and is known to reduce hospital readmissions, costs, mortality, morbidity, and improve health and quality of life.[1, 24, 25] CR needs to be a long-term, coordinated continuum of care from hospitals through to the client's home community to enable clients to self-manage their disease and realise an active,

satisfying life. [23, 26] To achieve this, a lifelong individual commitment to healthy lifestyle choices and adherence to medical advice with healthcare support is required.[27]

Despite the known effectiveness of CR, attendance rates in Australia are low, (range 10–30%),[28] especially in R&R areas, with Aboriginal and Torres Strait Islander people least likely to attend.[29] Much of NQ has vast R&R areas with no centre-based CR, (Figure 2). Queensland Health (QH) provides a home-based telephone support secondary prevention program, Self-Management of Chronic Conditions (SMOCC), previously called Coaching on Achieving Cardiovascular Health (COACH). SMOCC is available for people who are unable to attend centre-based services or prefer a home-based program.[30] A wide range of commercial smartphone apps are also available.[31]

NQ health status and demography is provided in 1.2.1 and Table 3.

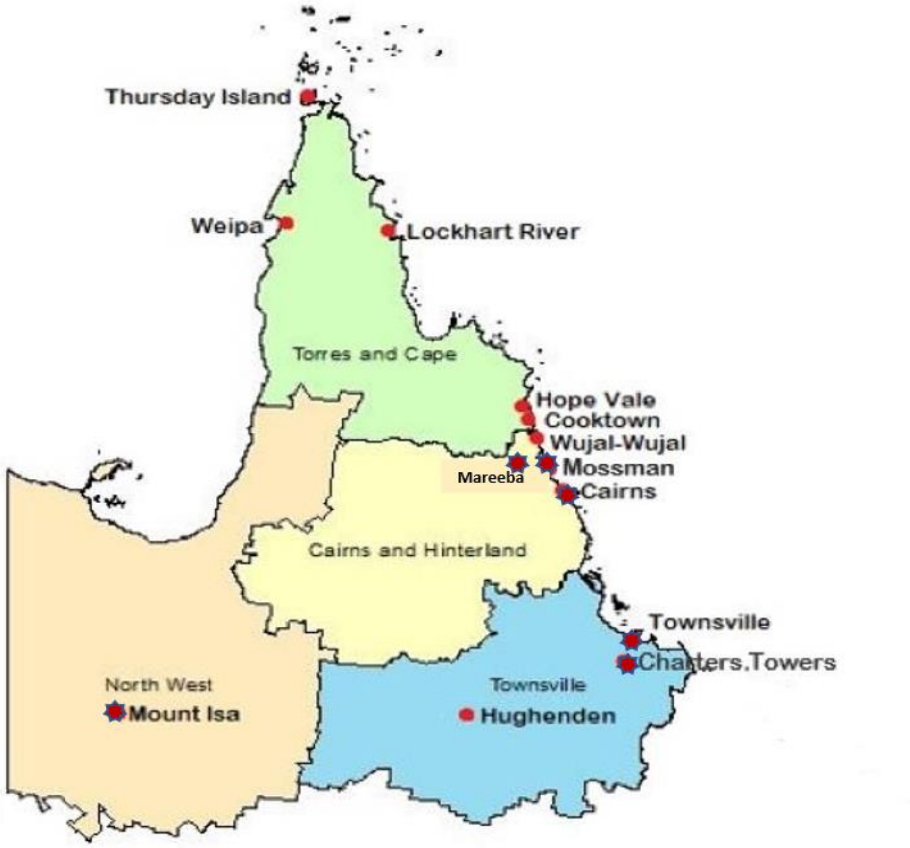

Figure 2: Map—North Queensland Hospital and Health Services and centre-based cardiac rehabilitation services

Adapted from map prepared by QH Statistical Reporting and Coordination, Statistical Services Branch 2018. Copyright permission QH March 2019. Scale 800km/5cm.

Torres and Cape indicates, Torres and Cape Hospital and Health Services (TCHHS); Cairns and Hinterland indicates, Cairns and Hinterland Hospital and Health Services (CHHHS); Townsville indicates, Townsville Hospital and Health Services (THHS); North West indicates, North West Hospitals and Health Services (NWHHS)

Location of centre-based cardiac rehabilitation in NQ.

1.1.3 Telehealth, telephone support and smartphone apps

Telehealth use in Australia is increasingly accepted by clients and health professionals, especially since the advent of the COVID-19 pandemic.[32] During this time, government funding and changes in managerial and medical culture combined to enhance service provision via telehealth services.[32] A recent study found that completion rates for CR presented by telehealth, in both metropolitan and rural areas, were higher than face-to-face programs, indicating client satisfaction with the medium.[33] Despite positive reports about the value of telehealth, some reservations were expressed by clients when bulk billing ceased.[32] Further, difficulties were encountered in R&R areas, due to unreliable telephone and internet connections.[34]

The development and utilisation of telephone apps is a fast evolving area with at times conflicting evidence. An assessment of apps in The United States of America, identified through Google or Apple Store searches, found that generally apps were of good quality.[31] However, a further study on patient preferences for CR programs found that 57% of participants preferred to attend a centre-based facility, and 43% preferred home-based programs with support of a health professional, rather than a telephone app.[35] A further study found that telephone apps are increasingly popular for people of all ages, including those 65 years and over, but that the quality was variable.[36]

Telephone apps are fast evolving and have the potential to augment secondary prevention services. However, caution is required prior to adopting apps as an alternative to face-to-face services, and further investigation is required especially in R&R areas and to gauge suitability particularly for Aboriginal and Torres Strait Islander people.

1.2 Context and factors for consideration in healthcare provision

The NQ focus areas of this research cover a wide range of R&R areas in the QH regions of THHS, NWHHS, CHHHS and TCHHS, (Figure 2). People who live in R&R areas of Australia are known to have higher levels of disease, shorter life expectancy, more injuries, poorer access to services, and lower use of primary healthcare centres, compared with metropolitan areas.[37] An underpinning principle of this research is that all adults who live independently, and have been treated in hospital for HD, should have access to post-discharge CR. This post-discharge care is required in a variety of settings, through a holistic, multidisciplinary approach that is culturally, geographically and technically accessible for all.[9] To achieve this in the environment of R&R NQ it is necessary to consider a range of factors that impact on health.

1.2.1 Demography and geography and impact on health in NQ

NQ is a large geographic region with extensive R&R areas, sparse services, and disparate populations.[37] The regions covered by Townsville Hospital and Health Services (THHS), and Cairns and Hinterland Hospital and Health Services (CHHHS), have the highest populations (Table 2), with the majority of people living in major metropolitan areas of Townsville and Cairns, where medical specialist services are commonly provided. This often results in hours, or days, of travel from a client's home in R&R areas, to essential services.[37, 38]

THHS and CHHHS have a higher proportion of people 65 years and over (Table 2).[37] This is likely to be due to higher social determinants of health (SDoH) in metropolitan areas, and subsequent migration of people from R&R to metropolitan areas, for improved access to services, particularly as they get older.[39] All NQ Hospital and Health Services (HHS) have higher rates of Aboriginal and Torres Strait Islander people (range 12–69%)compared with

Queensland overall (5%). The highest proportion being in the North West Hospital and Health Service (NWHHS) (31%) and Torres and Cape Hospital and Health Service (TCHHS) (69%), These HHS are the most remote, and also have the highest rates of potentially preventable hospitalisations (Table 2).

Table 2: North Queensland demographic population profile, and potentially preventable hospitalisations by hospital and health service [40]

Queensland Health Hospitals and Health Services 2019	Total population	Aboriginal and Torres Strait Islander population (%)	Percentage aged 65+	Potentially preventable hospitalisations (%)
All Queensland	5,094,510	5	16	7
Townsville	241,577	14	14	6
North West	27,512	31	8	8
Cairns and Hinterland	259,055	12	16	7
Torres and Cape	28,052	69	8	10

1.2.2 Social determinants of health

SDoH are factors that impact on health status and access to healthcare services, described by WHO as the 'social conditions in which people are born, live and work, and contribute to rates of disease and recovery'.[41] The importance of considering SDoH in healthcare provision is evident given that they are known to increase rates of HD by 30%.[15]

Examples of SDoH that influence health behaviour, and impact on health, include:

- income and social security
- education
- employment and job security
- working life conditions
- food security
- housing, basic amenities and the environment
- early childhood development
- social inclusion and non-discrimination
- culture
- conflict
- access to affordable, culturally responsive, good quality health services.
- distance to major centres
- telephone and internet services [10, 14, 37, 42, 43]

Aboriginal and Torres Strait Islander people have lower SDoH and higher rates of the populations in all the focus areas of this research, than Queensland overall, (Table 3). These factors have been given special consideration in the development of a model for improved access to CR for people in R&R areas of NQ. (5.3.1:Paper 6)

Table 3: Demography and sample social determinants of focus communities[44]

Community	Hughenden, Flinders Shire	Cooktown, Cook Shire	Wujal Wujal, Cook Shire[1]	Hope Vale, Cook Shire[1]	Queensland
Population	1,136	2,631	282	891	5.17×10^6
% Aboriginal and/or Torres Strait Islanders	8.2	14.5	91.5	98.7	4.0
Heart related hospital admissions per 1000/year	7.5	12.3	12.8	12.7	11.7
Age (medium, years)	44	44	30	25	37
Year 12 education (%)	14.9	10.5	12.3	8.9	16.5
Low income households < $650/week (%)	25.6	29	41.7	37.6	19.5
Internet access to dwelling (%)	68.7	70.8	66.2	70.3	83.7
Distance from tertiary hospital services (km)	383	328	346	372	N/A

[1] Designated Indigenous location.

A compounding factor for health status of Aboriginal and Torres Strait Islander people in R&R areas is that their housing overcrowding rates in very remote communities in Australia are 51% for, compared with 8% in inner regional areas.[45]

SDoH affect all aspects of people's life and health. Even if health services are available in the local community, a person's ability to access and benefit, are likely to be impacted by SDoH, such as literacy levels and/or cultural differences, which potentially create barriers to interacting with health professionals, and contribute to poor understanding and ability to follow healthcare advice. These barriers also impact on accessing health services via telephone, smartphone apps, and telehealth services.[46]

1.2.3 Aboriginal and Torres Strait Islander people: Culture and heritage

A major impact on the health and wellbeing for Aboriginal and Torres Strait Islander people is that all aspects of their life and culture have been disrupted by the consequences of colonialism.[47] Consequently, cultural aspects of healthcare need to be considered in health service planning and delivery.[48] Despite this, Western medicalised practices, which are known to be ineffectual in communicating with Aboriginal and Torres Strait Islander people,

predominate.[12] The provision of culturally responsive services is essential in all health service planning and delivery. Aboriginal and Torres Strait Islander Community Controlled Health Organisations (ACCHO) and Aboriginal and Torres Strait Islander Health Workers (ATSIHW) are known to provide culturally responsive services based on a holistic wellness model.[49] This model could be more broadly applied if ATSIHW, particularly those employed by QH, are utilised in roles that enable them to develop and fully utilise their skills, and provide support and further education for specialist areas such as CR.[50]

1.3 Health services, staffing and costs in rural and remote areas

In Queensland, QH is the major health service provider, responsible for leadership and healthcare provision through the state's public health system. Services are provided via regional Hospital and Health Services, in conjunction with the Commonwealth-funded Primary Health Networks and ACCHO. These services are supplemented by non-government organisations such as the Royal Flying Doctor Service (RFDS), and contracting organisations who provide allied health professional (AHP) services, and individual private health practitioners including GP.

In R&R areas, the majority of health services are provided by community-based and visiting health professional services via Primary Health Care Centres (PHCC) and Multi-Purpose Health Services (MPHS). These services comprise nurses, ATSIHW, GP, medical specialists, and AHP. QH priorities include '… Growing our regions: Help Queensland's regions grow by attracting clinical expertise and building capacity within our rural and remote health network … investing in skills [and] … backing our frontline services …'[51] QH has a focus on primary and secondary prevention strategies. These strategies include initiatives to address the risk factors of smoking, obesity, physical inactivity and poor diet, in order to combat high rates of heart and other chronic diseases.[52] Despite QH's predominantly Western medicalised approach, there are several examples of alternative, predominantly stand-alone programs that provide flexible, holistic, multidisciplinary, and culturally responsive client-centred models in NQ. For example:

- The Diabetes Education and Self-Management Program [53]
- Cape York Kidney Care (CYKC)[54]
- Older Persons Enablement and Rehabilitation for Complex Health Conditions (OPEN ARCH)[55]
- Healthcare In Your Home (HIYH) (TCCHHS, CN 6/2)
- Deadly Ears, Deadly Futures.[56]

Virtual Out-patient Integration for Chronic Disease (VOICeD) is a telehealth medical consultation program for people with HD, diabetes and renal disease. (TCHHS, CN14/2)[57]

1.3.1 Staffing, recruitment and retention

A multidisciplinary team approach consisting of a GP, nurse, physiotherapist, exercise physiologist, dietitian, and psychologist, and if possible a cardiologist, is recommended by the NHF and ACRA for CR programs.[1] These services are most commonly provided through metropolitan centre-based services.[1, 58] However, in R&R areas, this range of health professionals, while at times available through outreach services or telehealth, are rarely in one place at one time, resulting in the need for innovative approaches for CR in these areas.

The majority of community-based health professionals working in R&R areas are nurses and ATSIHW.[59] Nurses, in R&R areas of NQ, identified excessive working hours and high levels of responsibility which resulted in increased stress, particularly for inexperienced staff, who are unable to work to full capacity because of learning and coping with an unfamiliar environment.[59] These issues, together with inadequate information prior to recruitment, lack of ongoing education opportunities and career prospects, too few rural placements during undergraduate studies, poor work–life balance, and insufficient management support, all contribute to difficulties with recruitment and retention of health professionals in R&R areas.[59, 60]

While there are improvements in the number and range of multidisciplinary positions for health professionals in R&R areas, staff turnover continues to be high, and professional support, education and quality of life must be considered in health services planning and ongoing staff management.[59, 60]

1.3.2 Costs

Healthcare expenditure in Australia was $2.2 billion (2017–18).[14] In 2000–2001, hospital care accounted for 34% of this expenditure, which rose to 40% in 2017–18. Conversely, primary healthcare accounted for 37% in 2000–2001, and fell to 34% in 2017–18.[14] The lowest expenditure, 2% of the 15% allocation for primary healthcare, was spent on ‘allied health and other services’ (‘other services’ not defined), (Table 4). This low expenditure for AHP is potentially detrimental to effective CR services, for which AHP are an essential part.[15]

Table 4: Health expenditure for cardiovascular disease in Australia (2008-2009)[1]

Category	Expenditure (%)
Hospitals	69
Pharmaceutical Benefit Scheme	15
Primary healthcare[1]: GPs, medical specialists, medical imaging and pathology, allied health and other services[2]	15
Dental	1

source: AIHW, 2014. Health-care expenditure on cardiovascular disease in 2008-09

[1] No comparable breakdown in expenditure was found in later reports.

[2] Allied health and other services (undefined) account for 2% of the 15% primary healthcare expenditure.

In 2019/20 hospital expenditure was reported to have increase by 2.9%, primarily due to COVID-19. Primary health care, mainly comprising GP and pharmaceuticals increased by 0.6%, other health professionals and public health by 0.4%,[14] thus exacerbating the disparity between acute care and those services which have the potential to provide secondary prevention.

A cost–benefit analysis (2013), which included costs for CR programs, direct in-patient costs, burden of disease, informal care costs, and loss of productivity and earnings, estimated a net financial savings of $86.7 million per annum if CR referral rates increased to 65%.[24] These projected savings, based on Reserve Bank of Australia inflation rates are now estimated to be $100 million.[61] Included in these costs are drugs prescribed for lowering elevated cholesterol, which is a major risk factor for HD, accounted for the highest number of Pharmaceutical Benefits Scheme prescriptions.[62] In R&R areas, distance to health services further contributes to costs.[63]

1.4 Provision of cardiac rehabilitation in rural and remote areas

Overall, access to CR in R&R areas of NQ is negatively impacted by low referrals, large geographic regions, and inadequate availability of services including centre-based CR.[64-66]To address these deficits, there are a range of issues that need to be considered. These include:

- hospital in-patient preparation for post-discharge care (Phase-1-CR), including referral to Phase-2-CR (secondary prevention)[67]
- availability of culturally responsive, flexible, and accessible Phase-2-CR (secondary prevention) for all eligible clients[63]

- communication and pathways between hospital, client and local community healthcare providers, to ensure that post-discharge holistic support is provided[68]
- availability of education and support for hospital and community-based health staff[69]
- higher healthcare, socioeconomic and cultural needs of Aboriginal and Torres Strait Islander people[12]
- possible alternative methods of service delivery, including telehealth and telephone apps[70]
- coordination of services especially chronic diseases such as diabetes and renal disease[12]

In addition, health professionals' and clients' poor understanding of CR, and its potential benefits, also affect post-discharge CR attendance.[21, 71, 72] These factors are exacerbated by distance and costs,[63, 65, 73, 74] which could potentially be reduced through increased use of technology. The need for telephone or telehealth services to link with local healthcare providers warrants further consideration.[70] However, more research is required to investigate client's acceptance of telephone apps, and telehealth particularly in R&R areas where internet and phone coverage remain unreliable.[75]

To facilitate addressing these shortfalls, a combined primary healthcare/health promotion approach, consistent with Ottawa and Geneva Charters,[76, 77] and Declaration of Alma Ata,[78] were used to guide this research, (Chapter 3: 3.5.4). To achieve such an approach would require major revisions of current healthcare systems and services, led by management utilising continuous quality improvement (CQI) and co-design (Chapter 3: 3.5.6), to ensure inclusion of consumers, health service managers, and clinical health professionals.[79, 80]

1.5 Aim and objectives

A fresh approach to investigating barriers, enablers and pathways for access to CR in R&R areas of NQ was taken in this research. Much of the previous CR research considers one or two aspects of CR, rather than the whole picture, particularly in regard to access. The findings of this research resulted in an innovative model for CR in R&R areas of NQ: *Heart: Road to health.* This was achieved through a sequential approach in which each stage of the research provided information for the next, and cumulatively leading to the research findings. As part of the iterative process the research finding were summarised (Appendix 7.2), and discussed with community members, leaders and healthcare staff, clinicians and managers. Through ongoing discussion and follow-up, further information on chronic disease programs was gathered, and the transition to a generic: *Road to health* for HD, diabetes and renal disease began to emerge.

Aim: To investigate access to CR for all adults living independently in R&R areas of NQ, and develop a healthcare model for improved services, and answer the overarching research question: How can access to CR in R&R areas of NQ be improved?

The aim of the research was clear from the beginning, in line with the sequential approach (Chapter 3), the objectives were developed, based on the experience of the research team, and evidence-based information HD and CR, as well as the findings of the integrative literature review (IR) (Chapter 2). These synthesised findings informed the development of a framework for achieving the aim.

Objectives:

i. To identify barriers, enablers and pathways for CR in R&R areas of Australia and other developed countries and synthesise findings and lead to a new framework and perspectives. (integrative literature review). (Paper 1)

ii. Describe rates of hospitalisation and COACH referral for Queensland adults with heart and related disease and make comparisons between Aboriginal and Torres Strait Islander people and non-Indigenous people in NQ (epidemiological study). (Paper 2)

iii. Investigate the implementation of Phase-1-CR by staff and in-patients in cardiac services in two public and two private tertiary hospitals in Townsville and Cairns and consider the impact on post-discharge care in R&R areas of NQ (hospital case study series).

iv. Investigate barriers, enablers, and pathways for improved access to Phase-2-CR in selected R&R areas of NQ (community based case study series). (Papers 3 [project protocol] and 5)

v. Informed by Objectives i–iv, develop a model of healthcare delivery that aims to improve access to CR in R&R areas of NQ. (Papers 6 and 7)

Each objective was investigated through a specific study, with methods and methodology provided in Chapter 3, in each study, and provided in Chapter 4: 4.1, 4.2, 4.3; Chapter 5: 5.3.1, 5.3.2.

1.6 Implication of the research

Benefits of CR include reduced rates of hospital readmission, lower costs for clients and health services, lower burden of disease, and improved health and quality of life.[24, 58] Therefore, it is imperative that access and attendance to CR is improved in all areas, particularly in R&R areas where the situation is complex and services limited.[37, 38] Consequently, this research

focused on identifying barriers, enablers and pathways for CR in R&R areas of NQ, and was designed to contribute to the development and implementation of flexible, holistic, culturally responsive, effective services provided in a range of environments, through revised health systems and requiring minimal extra resources.

For healthcare planning of holistic, responsive services, it is necessary to consider a range of factors that affect health and welfare. These include geography, demography, socioeconomic and cultural aspects of services, and encompass SDoH, which are particularly important when seeking effective solutions, particularly in localities as complex and culturally diverse as R&R areas of NQ. If successful, the *Heart: Road to health* or generic *Road to health* based on revised healthcare systems has the potential to provide a model for holistic post-discharge care for HD, diabetes and renal disease.

1.7 Summary

All clients need support to achieve optimal recovery following hospitalisation for HD, regardless of their geographic location or culture. But access to face-to-face CR services continues to be limited in R&R areas.[81] A lack of adequate, flexible, culturally responsive CR services, and geographic isolation are known to affect access to CR in R&R areas. Further staff turnover is high which makes it difficult for staff to work to optimal capacity.[12, 28, 59, 60] Overall, the benefits of CR are poorly understood by staff and clients. Referrals are rarely made by hospital staff to staff in R&R areas for risk factor management and secondary prevention.[12, 58] To counteract these issues, strengthening of healthcare systems, and improved staff understanding of CR is required. This includes reinforcement that CR is simply a method for providing secondary prevention, which doesn't require expensive equipment and facilities, and is important to ensure effective post-discharge care in the client's local community. To achieve this a flexible, holistic (health and lifestyle) approach is necessary to ensure that each phase of CR is available for all eligible clients in all areas. Optimally, CR needs to be designed and delivered in a variety of settings, through a holistic, multidisciplinary team model of care.[9] However, given the low referral and attendance rates, it is clear that the current centre, and home-based Phase-2-CR programs are not meeting the needs of the majority of clients, in R&R areas of Australia.[24, 82]

1.8 Conclusion

The benefits of CR are already well described, but referral, access and attendance remain low. Before there can be any improvements, it is important that all steps in the client's pathway from hospital to home are investigated. This pathway was followed in this research, and identified barriers, enablers and pathways to CR in R&R areas of NQ. The research commenced with an

integrative literature review (Chapter 2), followed by an epidemiological study (Chapter 4: 4.1); a hospital case study series (Chapter 4: 4.2) and a R&R community case study series (Chapter 4: 4.3) that culminated in the development of a revised model of care, *Heart: Road to health* or generic *Road to health* (Chapter 4: 4.3; 5: 5.3.1, 5.3.2, 5.4).

Stage 1 Foundations

Chapters	Content & publications
1. Introduction ⇨	Background, introduction & implications of the research
Stage 1 Research foundations	
2. Integrative literature review ⇨	Cardiac rehabilitation services for people in rural and remote areas: Integrative literature review (2007–2016). Published 2020 (Paper 1). Supplementary review (2018 – 2021)
3. Methodology and methods ⇨	Project protocol: Improving access to cardiac rehabilitation in rural and remote areas: A protocol for a community-based qualitative case study. International Journal of Therapy and Rehabilitation. Published 2021 (Paper 2)
Stage 2 Results: Heart disease, hospitalisation, and referral	
4. Results 4.1 Epidemiological study ⇨	Heart disease, hospitalisation, and referral: coaching to achieving cardiovascular health through cardiac rehabilitation in Queensland. Published 2020 (Paper 3)
Stage 3 Results: Hospital-based Phase-1-Cardiac Rehabilitation	
4.2 Hospital case study series ⇨	The importance of cardiac rehabilitation in rural and remote areas of Australia. Published 2021 (Paper 4)
Stage 4a Results: Community-based Phase-2-Cardiac Rehabilitation	
4.3 Community case study series ⇨	Improving access to cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing? Published 2022 (Paper 5)
Stage 4b Pathways to *Heart: Road to health*	
5. Discussion and conclusion ⇨	Discussion and conclusion
5.3.1 *Heart: Road to health* for Aboriginal and Torres Strait Islander people ⇨	Improving access to cardiac rehabilitation (Heart: Road to health) for Aboriginal and Torres Strait Islander peoples in rural and remote areas of North Queensland. Published 2022 (Paper 6)
5.3.2 Model for *Heart: Road to health* ⇨	Model for Heart: Road to health or Chronic disease: Road to health in rural and remote areas. Submitted for publication Oct 2022 (Paper 7)

Chapter 2: Integrative literature review

2.1 Cardiac rehabilitation services for people in rural and remote areas: Integrative literature review

An integrative literature review (IR) was undertaken to better understand issues around access to cardiac rehabilitation (CR) in rural and remote (R&R) areas in Australia and developed countries, as a foundation on which to develop objectives for the sequential stages of the research.

Objective: To identify barriers, enablers and pathways for CR in R&R areas of Australia and other developed countries and synthesise findings and lead to a new framework and perspectives.[83]

This chapter is presented in two parts. Part A describes an IR of publications (2007–2016) that focused on access to CR for people in R&R areas.[83] Part B describes an updated IR for papers published 2017–2021 to ensure that relevant papers were identified and informed this research.

2.2 Part A: Cardiac rehabilitation services for people in rural and remote areas: Integrative literature review

In the initial IR, a systematic approach was used to identify and synthesise relevant publications and grey literature, to describe barriers, enablers and pathways to CR for adults living independently in R&R areas of developed countries, including Australia.

Table 5: Summary of database searches and findings (2017-21)

Data bases	Search 1: Search terms & results	Search 2: Search terms & results	Search 3: Search terms & results	Final result
	'cardiac rehabilitation' OR "secondary prevention."	(AND) rural OR remote OR Aborigin* OR 'Torres Strait Islanders' OR 'Indigenous' OR 'Oceanic ancestry groups' (Medline MeSH term)	(AND) barriers OR enablers. (Scopas, PsychInfo, Medline)	All terms
CINAHL	3,845	47,661	0	12
SCOPUS	11,152	12,019	254,905	36
Informit	45	21,806	0	7
PscyINFO	16,104	40.127	50,656	18
Medline (OVID)	16,776	63,492	83,216	24
			Total	97

Each search was done separately and combined with AND for final result. CINAHL and Informit showed zero results when barriers and enablers were added, so in these databases only search one and two were included. For completeness Table 5 with results of data base searches is included because this information is not provided in the following published paper that provides full details:

Field P, Franklin R, Barker R, Ring I, Leggat P. Cardiac rehabilitation services for people in rural and remote areas: An integrative literature review. Rural and Remote Health. 2018. http://doi.org/10.22605/RRH4738

(Sections of this paper have been replaced with final Word version of the paper because of poor legibility of reproduced tables in the published paper. Appendix 7.5 provides a copy of paper as published)

2.2.1 (Paper 1) Cardiac rehabilitation services for people in rural and remote areas: An integrative literature review

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REVIEW ARTICLE

Cardiac rehabilitation services for people in rural and remote areas: an integrative literature review

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Abstract

Introduction: Morbidity and mortality from heart disease continues to be high in Australia with cardiac rehabilitation (CR) recognised as best practice for people with heart disease. CR is known to reduce mortality, reoccurrence of heart disease, hospital readmissions and costs, and to improve quality of life. Australian Aboriginal and Torres Strait Islanders (Australian First Peoples or Indigenous) have a greater need for CR due to their higher burden of disease. However, CR referral, access and attendance remain low for all people who live in rural and remote areas. The aim of this integrative review was to identify barriers, enablers and pathways to CR for adults living independently in rural and remote areas of high-income countries, including Australia.

Methods: Studies were identified through five online data bases, plus reference lists of the selected studies. The studies focused on barriers and enablers of CR for adults in rural and remote areas of Australia and other high-income countries, in English peer-reviewed journals (2007–2016). A mix of qualitative, quantitative and mixed method studies were reviewed through a modified Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), followed by a critical review and thematic analysis.

Results: Sixteen studies were selected: seven qualitative, four quantitative and five mixed method. Five themes that influence CR attendance were identified: referral, health services pathways and planning; cultural and geographic factors necessitating alternative and flexible programs; professional roles and influence; knowing, valuing, and psychosocial factors; and financial costs – personal and health services. Factors identified that impact on referral and access to CR were hospital in-patient education programs on heart disease and risk factors; discharge processes including CR eligibility criteria and referral to ensure continuum and transition of care; need for improved accessibility of services, both geographically and through alternative programs, including home based with IT and/or telephone support. Also the need to ensure that health professionals understand, value and support CR; the impact of mental health, coping with change and competing priorities; costs including travel, medications and health professional consultations; as well as low levels of involvement of Australian First Peoples in their own care and poor cultural understanding by non-Australian First Peoples staff all negatively impact on CR access and attendance.

Conclusion: This study found weak systems with low referral rates and poor access to CR in rural and remote areas. Underlying factors include lack of health professional and public support, often based on poor perception of benefits of CR, compounded by scarce and inflexible services. Low levels of involvement of Australian First Peoples, as well as a lack of cultural understanding by non-Australian First Peoples staff, is evident. Overall, the findings demonstrate the need for improved models of referral and access, greater flexibility of programs and professional roles, with management support. Further, increased education and involvement of Australian First Peoples, including Indigenous Health Workers taking a lead in their own people's care, supported by improved education and greater cultural awareness of non-Australian First Peoples staff, is required.

Keywords: Aboriginal and Torres Strait Islanders, Australia, barriers, cardiac rehabilitation, enablers, First Peoples, indigenous, pathways.

Introduction

Heart disease is the largest single cause of death in Australia and contributes to significant illness, disability, poor quality of life and high healthcare costs[1,2]. Rates of heart disease in rural and remote areas are higher than in urban areas[1,3]. Whilst Australian Aboriginal and Torres Strait Islander First Peoples' (Australian First Peoples)[4] disease rates, including heart disease and complex multimorbidity, are higher, this only partially accounts for the disparity in health status between people in rural and remote and urban populations[3,5]. Disparity may be worse than reported due to people with poor health moving to urban areas for better services[5].

There is significant evidence that cardiac rehabilitation (CR) is best practice for people with heart disease[6-8]. However, despite this and known higher levels of heart disease of people living in rural and remote areas, referral and access to CR remain low, and access issues are exacerbated by geographic distance, fewer health services and staff[3,9], compounded by poor telephone and IT services to support alternative programs in rural and remote areas[5].

Cardiac rehabilitation

CR is known to reduce reoccurrence of hospital readmissions, mortality and morbidity from heart disease, and improve general health and quality of life[7,8,10]. WHO describes CR as including physical, mental and social conditions for people with heart disease, so that by their own efforts, together with support through medical or clinical management, they may preserve or resume optimal function[7,10,11]. The term 'cardiac rehabilitation continuum' is preferred by the Heart Foundation of Australia[7], due to the general perception that CR refers to short term, centre-based exercise and education programs, usually run by hospitals. The CR continuum is a 'coordinated system of long-term care' necessary to help people with heart disease return to an active and satisfying life, and to prevent the reoccurrence of heart disease or new cardiovascular conditions[7]. This indicates the need for a lifelong individual commitment to healthy lifestyle choices, and adherence to medical advice with health service support[7,11].

Costs and priority

Expenditure for hospital-admitted patient services for coronary heart disease, stroke and other cardiovascular diseases in 2008–09 was A$4460 million, and accounted for the highest level of healthcare sector spending, with coronary heart disease expenditure of A$1517 million[2]. Other costs associated with coronary heart disease were out-of-hospital medical expenses (A$223 million) and prescription pharmaceuticals (A$311 million). Costs of pharmaceuticals for males were nearly twice that of females, but comparatively similar for other out-of-hospital expenses[2]. Drugs prescribed for lowering cholesterol (statins) account for the highest number of Pharmaceutical Benefits Scheme prescriptions[12] and are major contributors to the cost of all pharmaceuticals. Despite evidence that CR reduces recurrence of heart disease and hospital readmissions and improves general health, it is estimated that only 30% of people hospitalised with heart disease are referred to CR in Australia[13]. A recent cost–benefit analysis that considered the impact of increased CR uptake to the internationally

acknowledged standard of 65%[13], and included costs for CR programs, direct in-patient costs, burden of disease, informal care costs, and loss of productivity and earnings, estimated a net financial saving of A$86.7 million per annum[6].

Multidisciplinary teams and staffing

A CR program based on a multidisciplinary team that includes a general practitioner, and if possible a cardiologist, nurse, physiotherapist, dietitian, psychologist and exercise physiologist, is recommended by the Heart Foundation of Australia and Australian Cardiac Rehabilitation Association[7,10]. Realistically, due to lack of resources, such a multidisciplinary team is only available in major centres[14].

A range of issues negatively impact on recruitment and retention of allied health professionals in rural and remote areas. These include a lack of or inadequate (i) information prior to recruitment, (ii) ongoing education opportunities, (iii) career prospects, (iv) rural placements during undergraduate studies, (v) work–life balance, (vi) management and support – which all contribute to high staff turnover[15]. Staffing difficulties have also been identified by nurses in Australia's rural and remote areas in northern Queensland such as excessive working hours, high levels of responsibility and resultant high staff turnover[14,15]. This leads to an increase in staff stress for inexperienced staff who are still learning, and unable to work to full capacity due to the unfamiliar environment[14]. Whilst the majority of health professionals working in these areas are nurses and Aboriginal health workers[14], it is likely that these issues impact on all health professionals and subsequently quality of services in rural and remote areas.

Major issues for cardiac rehabilitation services

Whilst it is estimated that throughout Australia only 30% of eligible people are referred to CR, and less attend[10,16], rates cannot be substantiated due to a lack of data[16,17]. Negative impact on service delivery and access to CR due to large geographic regions is significant[3,18,19]. This is compounded by health professionals and potential participants' poor understanding of the benefits of CR[20-22]. Distance and costs are identified as barriers to attendance in rural and remote areas[18,23-25]; however, with changing technology options these barriers may be more readily addressed. The major issues identified were limited and suboptimal CR services in rural and remote areas, with more information required to inform policy, management and organisation of CR for adults with heart disease living in rural and remote areas.

Methods

An integrative review is an established evidence based practice method for reviewing qualitative, quantitative and mixed method research[26,27]. The present integrative review was undertaken through systematic identification, analysis, critique and synthesis of selected peer-reviewed literature to facilitate the identification of a new framework and perspective[26-28] of barriers, enablers and pathways of CR in all adults with heart disease in rural and remote areas of high-income countries, with a focus on Australia.

Searches and selection criteria

Electronic database searches used to identify relevant studies included CINAHL, SCOPUS, Informit, PsycINFO and Medline (OVID).

Electronic searches were augmented by reviewing reference lists and citations of selected studies and professional networks (snowballing). Google Scholar was used in this process for forward searching of reference lists and citations to check for additional studies. The 107 articles identified through this process were due to a large meta-analysis[29], identified by the database search. However, the abstract review of these references revealed only 13 studies eligible for critical review and thematic analysis. Following the critical review and thematic analysis only two extra studies were included for further analysis.

Search terms used were 'cardiac rehabilitation' OR 'secondary prevention' AND 'rural' OR 'remote'; OR 'Aboriginal and Torres Strait Islanders' OR 'Indigenous' AND 'enablers' OR 'barriers'. These key words were varied for specific databases, for example Medline (OVID), which uses medical subject headings (MeSH), which required that the terms 'cardiac disease' OR 'coronary disease' OR 'heart disease' be expanded and combined with 'rehabilitation' to identify articles about CR. Also, the Medline MeSH term 'oceanic ancestry groups' is used for First Peoples. The term 'indigenous' was used as a generic term because it is in common use internationally. The database searches identified a comprehensive range of studies: Medline (OVID) for wide ranging studies, Informit for studies that focused on First Peoples, SCOPUS for international studies, PsycINFO for psychosocial and mental health and CINAHL for allied health. Limitations applied were studies in English, with human subjects and dated 1 January 2007 to 31 December 2016. Supplementary table 1 contains further information about the searches.

Inclusion criteria were:

- published in English in peer-reviewed journals from 1 January 2007 to 31 December 2016
- focusing on cardiac rehabilitation in rural and remote areas of Australia and high-income countries internationally; barriers, enablers and pathways to CR; or First Peoples, indigenous (Australian and global) and general populations.

Exclusion criteria were:

- effectiveness of centre-based and home based (technology-supported) CR due to available evidence of effectiveness[7,8,10,17,30,31]
- clinical cardiac procedures, acute treatment and interventions
- non-high-income countries are equated to developing countries, according to the 'List of developing countries as declared by the Minister of Foreign Affairs(2015)'[32]. This is because studies that focus on developing countries are considered to have little relevance in Australia, which is amongst the 10 largest advanced economies in the world, based on International Monetary Fund criteria[33].)
- programs that include only one component of CR (eg exercise), rather than having a holistic view
- outside the date limit, to ensure a contemporary basis due to rapid changes in technology that have had a large impact on possibilities for CR in rural and remote areas and due to the recent decentralisation of health services in Queensland, the establishment of primary health networks and their impact on health service delivery.

Whilst this study includes all adults living independently in rural and remote areas of Australia as well as high-income countries, because of the known poor health status of Australian First Peoples[1,3] studies were sought specifically for CR with Aboriginal and Torres Strait Islanders people and/or Indigenous people. Using this strategy, six studies with a primary focus on Australian First Peoples were identified. No international studies were identified specifically for Indigenous people.

Preliminary review and critical appraisal

Principles and processes of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Fig1) was used to describe the collection, review and identification of final studies for analysis[34].

Following screening of abstracts, a full text critical review to assess research quality, outcomes and eligibility was undertaken on the remaining 56 quantitative, qualitative and mixed method studies. A modified process, suitable for critical review of all research methods, was developed based on the premise that all research includes clearly focused research questions, constructs arguments, collects data from appropriate participants, speculates about outcomes of data analysis[35-37] and considers important outcomes and results[38-40]. To achieve this, McMaster's qualitative research guidelines[40], and the Critical Appraisal Skills Program quantitative review guidelines[38], were combined. Studies were assessed according to McMaster's guidelines for study design, type, methods, sampling and data collection[38] and Critical Appraisal Skills Program quantitative research guidelines to assess the research question, including appropriate sampling, equal treatment of all participants, chance minimisation and research rigor, with all results presented to ensure epidemiological and statistical strength[38]. The critical review was further strengthened by a thematic analysis in which key findings were coded and grouped to identify 'patterned responses' or 'themes', to enable extraction of further meaning[36].

Supplementary table 2 provides details of the critical review and thematic analysis carried out by the first author and peer reviewed by the other authors. This process of review and validation continued throughout.

Following the critical review and thematic analysis, a further analysis, evaluation and integration of findings from the 16 final studies that identified barriers, enablers and pathways was undertaken. These are synthesised in the results according to identified themes.

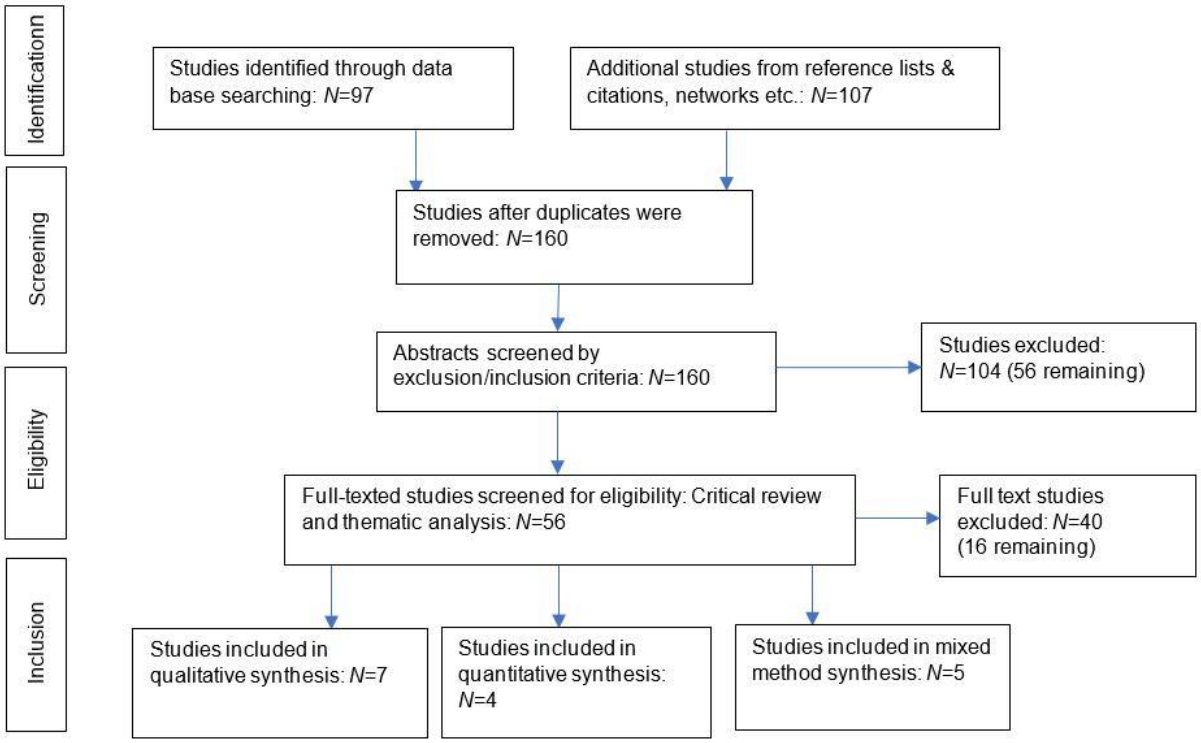

Figure 1: Modified PRISMA chart[34]: Integrative review of studies on cardiac rehabilitation for people in rural and remote areas

Results

The review and analytic process identified 16 studies, from which five themes emerged. Table 1 summarises the pertinent theses including factors that influence failure or success of CR. These factors provided the underpinning criteria for the emergent themes. The themes identified were referral, health service pathways and planning; cultural and geographic factors necessitating alternative and flexible programs; professional roles and influence; knowing, valuing, and psychosocial factors; and financial costs – personal and health services. Embedded in these themes are barriers, enablers and pathways for CR in rural and remote areas by general population and Australian First Peoples.

Table 1: Themes identified through critical analysis and underpinning thematic criteria

Themes	Criteria
Referral to cardiac rehabilitation and continuing along the health pathway	- Pathways for continuum of care; transition of care, referrals, eligibility - Framework or plan of care - Automatic referral, combined with patient education and information systems - Communication between health services and health professionals
Cultural and geographic factors necessitating alternate and flexible programs	- Distance from services - Poor culturally appropriate services with few First Peoples involved - Importance of 'yarning' and flexibility especially with First Peoples. - Need for alternate programs that include telephone, telehealth, written materials, structured support with flexible format - Poor IT access and skills - Need to include community activities e.g. walking groups, healthy cooking classes, using media to promote healthy behaviour, involve local gyms
Professional roles and influence	- Opportunistic casual minimal interventions in any environment e.g. supermarket, home visits - Involving ambulance officers in cardiac rehabilitation programs. - Involving all health professionals for ensuring referral and attendance - flexibility in professional roles - Staff judgemental attitude is a deterrent - Low value of cardiac rehabilitation and/or multidisciplinary team - Low health service standards
Knowing, valuing, psycho-social factors	- Depression, anxiety, denial, sadness, guilt, grief personal loss often resulting in poor motivation and non-completion of programs - Varying education levels and social vulnerability - Competing priorities including work and family responsibilities - Abandoning medical advice and using alternate therapies. - Difficulties in changing risky behaviour in home environments - E.g. families who continue to smoke, poor diet etc.
Financial Costs – personal and health services	- Travel, medication, health professional consultations, funding

Referral, health services pathways and planning

General populations: Low levels of referral are commonly identified as barriers to CR[18-21,23,24,41]. Education and information about heart disease risk factors and the benefits of CR are an important part of hospital discharge and referral processes[22-24]. A transition of care framework and care planning, together with systematic assessment to ensure that participants have appropriate, and if necessary, individualised programs, is recommended[21,23] (Table 2)

Table 2: Final analysis, evaluation and integration: General populations

Author/(Country)	Purpose	Study Design	Barriers	Enablers/Pathways
Beasley C, Dixon R.[20]. (New Zealand)	The perceptions and experiences of nurses involved with the delivery of CR in a rural health care setting in a Northland Region of New Zealand	**Qualitative** descriptive, exploratory study **Limitations:** not generalisable; only one meeting with Maori people weakens applicability for Maori people	Distance and travel; cost; work and family; client motivation; lack of role models and local attitudes not supporting cardiac rehabilitation (CR); lack of a co-ordinated multidisciplinary team (MDT) approach	Support groups; local knowledge: rapport with clients; need an effective HB alternative and better-informed health professionals on CR programs and benefits. **Pathways:** Need a clear transition of care, referral and framework or plan of care
Fernandez S, Davidson P, Griffiths R.[24]. (Australia)	To assess the perspective of CR coordinators regarding patient-related barriers to implementing the evidence-based guidelines after an acute cardiac event	**Qualitative**- interviews, focus groups and thematic analysis (TA) **Limitations:** not generalisable specific to the geographic regions; medical officers not included	Not accepting a diagnosis of heart disease or seriousness; cost, including medications, travel and visits to health professionals; using alternate therapies and not adhering to prescribed treatment; families continuing to smoke; taking time off work	Efforts directed to increase participation in CR and supporting behaviour change. Changes to health service policies that address identified barriers. **Pathways:** nil identified
Fernandez S. Davidson P. Griffiths R.[21]. (Australia)	To explore the strategies used by CR coordinators to overcome the obstacles to implementation of the evidence-based Reducing Risk in Heart Disease guidelines	**Qualitative-** interviews, focus groups and TA **Limitations**: not generalisable specific to the geographic regions; medical officers not included	Greater focus on acute care rather than health promotion; Lack of participation in CR is compounded by geographic location; and low-level referrals	Media; opportunistic casual minimal interventions; home visits; community activities e.g. walking, healthy cooking, lobby restaurants to provide healthy food choices; ambulance officers teach cardio-pulmonary resuscitation (CPR); involve local gyms; flexibility in roles and programs; communication with GPs **Pathways:** Develop automatic referral/information /education system
Fernandez S, Davidson P, Griffiths R.[41]. (Australia)	To explore the perceptions of CR coordinators relating to challenges, including guideline implementation for improving the delivery of CR services	**Qualitative**- interviews, focus groups and TA **Limitations:** not generalisable specific to the geographic regions; medical officers not included	Funding; distance; difficulty in accessing health professionals and their lack of knowledge of prioritisation of CR; poor communication within health services/ health professionals; slow and/or low rate of referrals. GPs consider themselves as a "one stop shop"; lack of planning	No enablers or pathways presented
Jackson M, McKinstry B,Gregory S.[19]. (Scotland)	To explore why people do not participate in CR and coronary heart disease self-help groups, and their rehabilitation experience without these resources	**Qualitative-** interviews, focus groups and TA. Scotland. Explored experiences of people recently hospitalised with coronary heart disease, and their "significant others", and non-use of CR and experiences of recovery with-out these resources. A demographic profile of the group was included	CR not offered; perception of no benefit; transport issues; dislike of groups; unnecessary; no benefit because of age and co-morbidities; not appropriate; work patterns; physical discomfort; judgmental staff; lack of motivational support for instigating or maintaining lifestyle changes; inadequate information and support for emotions e.g. uncertainty, anxiety, non-acceptance of MI and consequences, sadness, guilt; social vulnerability, depression, mood swings, irritability	'Heart Manual' home-based rehabilitation resource - increased confidence in recovery; encouraged independence; Initially people may feel they don't need support, however with education and opportunity this perception may change **Pathways:** nil identified
Brual J, Gravely S, Suskin N, et al.[18]. (Canada)	To assess whether clinical and geographic factors were related to use of either a CB or HB program, Ontario, Canada	**Quantitative:** Cross-sectional secondary analysis of clinical data extracted through a patient questionnaire which was repeated 9 months later **Limitations**: a high number of potential participants deemed ineligible, raising questions about referral practices	Geographic distance, lack of CR services and referral of higher risk patients to HB programs	High functioning clients more likely to complete either program **Pathways:** Nil identified

Table 2: Final analysis, evaluation and integration: General populations (continued)

Author/(Country)	Purpose	Study Design	Barriers	Enablers/Pathways
De Angelis C, Bunker S, Schoo A.[23]. (Australia)	(i) establish baseline data on CR programs in SW Victoria; (ii) identify local barriers and enablers for CR for both decliners and attendees (iii) explore preferred options	**Mixed method: Quantitative** descriptive statistics: Assessment of CR risk factors pre- and post-program (paired t-tests, $P < 0.05$) **Qualitative:** Focus groups and "yarning **Limitation:** Only one carer interviewed; CR decliners are likely to be under represented as lower than average; decliners completed the questionnaire and not interviewed. Geographically limited	Distance, transport, costs; lack of available alternative programs e.g. HB with telephone support; stoic self-reliant rural attitude; dislike of groups; anxiety and depression; difficulty in acknowledging the need for lifestyle changes; lack of information about CR; negative view from experience or misinformation; women's carer role and possible inability to drive	Health professionals and family supporting CR; alternative programs e.g. HB, telephone support; positive attitude, motivation, enjoy groups; welcoming staff; home visits; CR manual, and phone contacts. **Pathways:** Early referral and personal contact from the local GP and CR co-ordinator
Sangster J, Furber S, Phongsavan P'et al.[42]. (Australia)	Examines the risk profile and participation in CR of rural and urban residents with cardiac disease who enrolled in a telephone coaching program	**Quantitative** prospective descriptive data collection by telephone questionnaire **Limitations:** only 30% eligible were referred to CR and a "large proportion" (no number) declined to participate. Not generalisable as participants from 2 urban and 2 rural areas	Difficulties such as lack of affordable transport or not feeling well enough to attend a group program	Alternate methods of CR program delivery make CR more accessible to people who find it difficult to access outpatient CR and/or dislike group **Pathways:** Nil identified
Scane K, Alter D, Oh P.[43]. (Australia)	1. To compare adherence of patients in a CR home based with a CB program 2. To compare clinical and demographic profiles and changes in CV fitness	**Quantitative:** retrospective audit of patient files and data base for CB program and HB programs **Limitations:** non-experimental design; no random assignment, women under-represented; self-efficacy and motivation not considered	Geographic distance (30+ km) to CB programs; younger fitter, employed males less likely to attend CB programs	Home programs more acceptable for younger, fitter, employed; more time efficient; better for women with family responsibilities **Pathways:** Nil identified
Shanmugasegaram S, Oh P, Reid R.[22] (Canada)	To examine barriers to participation in CR by program type (CB/HB), and their links program participation and exercise behaviour. Ontario, Canada	**Quantitative:** Cross-sectional, in-hospital sociodemographic survey, based on clinical data from case notes. A follow-up survey one year later. **Limitations:** Low number of HB participants	CB programs: Distance, cost, weather. CB and HB: poor participant energy; other health problems; family responsibilities; Perception no need; no doctor doesn't support; too old; not aware of CR, referral too late and/or no follow-up	Minimal travel and costs. HB programs for people who prefer self-care and exercise programs that can be integrated into home routines **Pathways:** Early referral and follow up

It is known that there is a lack of data on CR referrals, attendance and completion of centre-based or home based programs[16]. At times the studies recommended that people 'eligible' for CR are referred by their treating doctor[18,42]. No eligibility criteria were identified in the selected studies. Many potential CR participants were deemed ineligible without explicit decision-making criteria[18,42]. Other barriers to CR include non-completion or delay in post-hospitalisation referrals, lack of information and prioritisation of CR[21,23,24,41] (Table 2). Table 2: Final analysis, evaluation and integration – general populations[18-24,41-43]

Australian First Peoples: Lack of data on referral rates and poor discharge planning were identified as barriers to CR for Australian First Peoples[43,44]. Lack of services, low levels of involvement of Australian First Peoples staff and culturally inappropriate services are identified as contributory factors to low rates of CR referral and access[43,45-47]. In one community in Western Australia, the number of people who attended CR was reported as being augmented by self-referral of people interested in learning more about health and risk factors rather than formal referrals or involvement in CR[46,47] (Table 3).

Table 3: Final analysis, evaluation and integration – Australian First Peoples[43-48]

Author	Purpose	Study Design	Barriers	Enablers/pathways
Taylor K, Smith J, Dimer L, Ali et al.[45].	To examine barriers to Australian First Peoples participation in CR. Western Australia	**Qualitative-** interviews, focus groups and TA **Limitation:** Small study of urban First Peoples limits generalisability. No impartial verification.	Family responsibilities; standard CR programs not culturally appropriate; programs connected with colonialism; younger First Peoples and health status have negative media statistics	Need for a shift in media and public health campaigns from "shock" headlines and statistics to a focus on strengths and successes, inspiring the groups involved and supporting them to make changes **Pathways:** Nil identified
Di Giacomo L. Thompson C. Smith S.[48].	To describe health professionals' perceptions of Australian First Peoples' access to CR services and the role of institutional barriers in implementing the NHMRC guidelines for *Strengthening CR and Secondary Prevention for Aboriginal people*	**Qualitative**- interviews, focus groups and TA **Limitations:** Health professionals' perspective only, no impartial verification	A lack of awareness of First Peoples' needs as patient; low level of cultural awareness training for health professionals	First Peoples' health staff to facilitate access for Australian First Peoples' patients; all staff to have an increased knowledge of the NHMRC Guidelines for *Strengthening CR and Secondary Prevention for Aboriginal people* **Pathways:** Nil identified
Davey M. Moore W. Walters J.[47].	To evaluate the uptake and effectiveness of a Tasmanian Aboriginal Centre CR and pulmonary rehabilitation program for Australian First Peoples with chronic heart or respiratory disease or at high risk	**Mixed method: Quantitative** descriptive and **Qualitative study:** interviews, focus groups and TA **Limitations:** No impartial verification	Established disease sufferers were less likely to attend than people with risk factors only. Transport was anticipated as being a barrier; 48% of participants used transport provided all the time and 15% sometimes	**Positives for Aboriginal Health Workers (AHWs)**: making a difference; concentrating on one program; part of MDT. **Positives for participants:** learning new skills; community interaction and comradeship. **Positive for non-Australian First Peoples' staff** gaining cultural insight, feeling valued and assisting people to improve skills and functioning **Pathways:** Word of mouth recommendations
Dimer L, Dowling T, Jones J.[46].	The initial purpose was to conduct a secondary prevention program. The high level of community interest in primary and secondary CV health information resulted in broadening the program to engage the family and broader community to address the burden of chronic disease in Australian First Peoples' populations through primary and secondary prevention. (WA)	**Mixed method**: **Quantitative** cross-sectional assessment of cardiovascular risk factors pre-and post-program (paired t-tests, $P < 0.05$). **Qualitative** interviews, focus groups and TA and "yarning" **Limitations:** Qualitative methodology not fully described; sufficient verbatim quotations provided to substantiate the conclusions	Western medical practices are ineffective in taking accurate medical histories of First Peoples; poor understanding of medication regimes and use of prescribed medications; reluctance to call an ambulance due to the possible costs; lack of CR services	Cultural security of Aboriginal Medical Services (AMS); cross cultural benefits; strong relationships and trust between staff and participants; engaging the family and broader community; including both primary and secondary prevention, flexibility and "yarning". **Pathways:** self-referral from word of mouth, with community elders being a strong referral source;
Thompson S, Di Giacomo M, Smith J.[43].	To describe health professionals' awareness, implementation, and perspectives of barriers to implementation of the NHMRC guidelines: Strengthening CR and Secondary Prevention for Aboriginal and Torres Strait Islander Peoples (2005)	**Mixed method:** predominantly **qualitative** study which included **quantitative** descriptive methods with quantifiable close-ended questions combined with semi-structured interviews, allowing for exploration of issues and thematic analysis **Limitations:** Small number of interviews. (average 1.4 per organisation), may not be representative of the whole organisation	Tensions between standard medical care and secondary prevention and the needs of First Peoples. discharge processes are lacking with Australian First Peoples often not identified, poor inter-health service communication	Implementation of NHMRC guidelines and recommendations i.e. integrated models of care including: Awareness, communication, co-ordination, involvement of AMS; post discharge estimated time of arrival; transportation; family commitments; the interplay between physical and mental concerns; social vulnerability; family links; community education; follow-up and support; strengthen cultural skills of non-Australian First Peoples' staff; management support for policy changes and practice; strategies to reduce staff turnover and subsequent staff shortages **Pathways:** nil identified
Hamilton S, Mills B, McRae S.[44].	To investigate the provision of CR and secondary prevention by AMSs in WA with a focus on rural, remote and Indigenous populations.	**Mixed method: Qualitative interviews**, focus groups and TA **Quantitative** descriptive methods reporting continuous and categorical data **Limitations:** Lack of verification of qualitative data, and lack of standard method of collection of quantitative data limits the ability to make direct comparisons between services and report inferential statistics. No data on non-referral of eligible patients	Lack of a minimum dataset to record and monitor CR and secondary prevention in WA to evaluate the quality and outcome of an individual's participation in the core components of CR	Revision of the current WA data set and a review of referral pathways could provide information that would identify possible barriers and enable these to be considered and if necessary modified. NB completion rates are high therefore need to ensure referrals are made and people attend the first session **Pathways:** a revised referral and data collection system

Cultural and geographic factors necessitating alternative and flexible programs

General populations: A range of studies identified that alternative approaches to CR are required due to low levels of geographic access in rural and remote communities[18,19,23,41,42,49]. It is known that distance from services impacts on access to CR[18,21,23]. Technological or personal support home based programs are identified as alternatives to centre-based programs[20,22,23]. There is a demonstrated need for flexible and individualised programs to accommodate factors related to employment, age and gender, supported by community involvement[19,20,42]. The use of a 'heart health' manual combined with home visits has been shown to be of benefit19. Innovative management policies are recommended to enable alternative and flexible models necessary to meet individual and local needs[23,24] (Table 2).

Australian First Peoples: Studies repeatedly found that First Peoples programs must be of high standard, culturally appropriate, holistic, flexible and include family and community[43,45,48]. Aboriginal health workers are identified as an essential part of the health service team, which needs strong relationships and trust within the team and program participants[46,48]. Strong links with mainstream health services are necessary whilst retaining flexibility and individuality, such as 'yarning' or storytelling to encourage attendance[43,46] (Table 3).

The barrier of distance from services is not identified by First Peoples to the same extent as for the general population[18-21,23-25,41](Table 2). In one Tasmanian study, transport was provided for participants. This was regularly used by 48% of the participants and by 15% 'some of the time'[47] (Table 3).

Professional roles and influence

General population and First Peoples: Medical officers and/or CR coordinators' personal involvement, accessibility and follow-up, together with supportive and non-judgemental attitudes, were found to be enablers for CR attendance[19,20,23]. Further enablers identified included health professionals' knowledge and prioritisation, their willingness to share information and work as part of a coordinated multidisciplinary team, as well as ensuring effective inter-health services communication[23,41] (Table 2).

There is evidence that professional relationships between Australian First Peoples and general population staff are strengthened when they are based on trust and respect, with Australian First Peoples in primary professional roles[43,46,48]. Improved cultural skills of general population staff are of primary importance in this process. These are identified as core components for effective CR and secondary prevention for Australian First Peoples[43,46]. Two studies involving Australian First Peoples also identified multidisciplinary teams as being important, together with flexibility of professional roles[45,48] (Table 3).

Knowing, valuing, and psychosocial factors

General population: Public perception generally demonstrated that CR is unnecessary for younger, fitter people[49], or not suitable for people with multimorbidity or advanced disease[24,42]. Lack of information, positive role models, negative local attitudes, experience or misinformation, and health professional support, have all been identified as limiting the perceived value[19,20]. It is also noted that people experience difficulty in acknowledging the need for lifestyle changes, especially if families continue with risky behaviour such as smoking[24]. People may opt to deny the need for risk modification, cease taking their prescribed

medications and seek alternative therapies[21] (Table 2). Depression, anxiety, denial, sadness, guilt, grief and personal loss have been found to result in poor motivation and non-completion of programs[23] (Table 2).

Australian First Peoples: Inequities in First Peoples health services are compounded by 'Western' medical practices reported to be ineffective in taking accurate medical histories[43,46] and to mirror a 'power inequity that resembles colonialism'[42,47,48]. The need for flexible and innovative programs that consider all aspects of chronic disease risk factor minimisation, with a possible focus on primary and secondary prevention and consideration of mental as well as physical health, has been identified to address these barriers[43] (Table 3).

Financial costs – personal and health services

General populations: On a personal level, travel costs, medications, visits to health professionals and potential loss of income due to work commitments are identified as significant barriers to CR[19,21-23] (Table 2).

Australian First Peoples: Current studies do not identify the same financial issues for First Peoples, who largely attend local Aboriginal medical services or government health services, which, whilst accessible, provide few CR or secondary prevention services[43,46] (Table 3).

Limitations

The methodological quality of articles was assessed and demonstrated validity in research methods, with some limitations (Tables 2,3). The majority of qualitative and mixed method studies used purposive sampling and semi-structured interviews[19-21,24,41,43,44,46-48], with data analysed and themes identified using NVivo software. However, many studies were limited in their generalisability due to specific geographic location of data collection[19,20,23,41]. Other limitations were non-inclusion of essential representatives (eg medical officers, carers and local indigenous people (Māori of New Zealand)[20,23,24,41,49], and lack of data verification[45,47]. Three quantitative studies were limited by lack of exclusion criteria (CR eligibility)[18,43,50], with one sample not randomised[45]. One mixed method study relied on a small and possibly non-representative sample[43].

Results are assimilated according to themes, barriers, enablers and pathways to provide information as a basis for developing a revised framework and perspective for CR referral and access models that will ultimately improve health and quality of life for all people with heart disease in rural and remote areas (Tables 4, 5).

Table 4: Themes, barriers, enablers and pathways – general populations[18-25,41,42,49]

Themes	Barriers	Enablers	Pathways
Referral: health service pathways and planning	- low level referrals[18,20,23,24,41] - not aware of CR[24] - CR not offered[19]	- develop automatic referral/information /education system[24] - early referral and personal contact from the local GP and CR coordinator[19,24]	Need a clear transition of care, referral and framework or plan of care[21]
Cultural and geographic factors necessitating alternate and flexible programs	- Distance, and lack of, CR services [18,19,23,24 41,42,49] - poor participant energy; family responsibilities[22] - taking time off work[19,21] - stoic self-reliant rural attitude; dislike of groups; anxiety and depression[23] - women's carer role and possible inability to drive[23]	- support groups; local knowledge: need an effective HB alternative[23,24]. - media; opportunistic casual minimal interventions; home visits community activities e.g. walking, healthy cooking, lobby restaurants to provide healthy food choices[24] - family support[23] - range of alternative programs e.g. HB, telephone support; positive attitude, motivation, groups for people who enjoy; welcoming staff; home visits; CR manual, and phone contact/support[23] - HB programs are time efficient and more acceptable for younger, fitter and employed people and those who have family responsibilities[49]	Nil identified
Professional roles and influence	- lack of a co-ordinated MDT approach[20] - poor support from health professionals[21,24,41] - GP's consider themselves 'one stop shop'[41]	- better-informed health professionals on CR programs and benefits[20] - rapport with clients; a supporting behaviour change[20,24] - ambulance officers teach cardio-pulmonary resuscitation (CPR); involve local gyms: flexibility in Programs and roles; communication with GPs and health professionals[21]	Directing efforts at increasing participation in CR. Changes to health service policies that address identified barriers e.g. extended and flexible roles[21]
Knowing, valuing, psycho-social factors	- lack of role models and local attitudes not supporting CR[20] - no benefit, too old; other health problems[19,22] - using alternate therapies and not adhering to prescribed treatment; families continuing to smoke[24] - younger fitter, employed males less likely to attend CB programs[49] - lack of information about CR; negative view from experience or misinformation[23] - difficulty in acknowledging the need for lifestyle changes[23] - depression, anxiety, denial, sadness, guilt, grief personal loss often resulting in poor motivation and non-completion of programs[23,22]	- Heart Manual HB rehabilitation resource - increased confidence in recovery and provided encouragement to manage independently[19]. - home programs more acceptable for younger, fitter, employed and requiring HB more time efficient also better for women who have family responsibilities[49] - alternate methods of CR program delivery make CR more accessible to people who find it difficult to access outpatient CR and/or dislike groups[23,42]	Nil identified
Financial costs – personal and health services	- costs - transport, time off work, cost of health professional visit and medications.[19,20,41,42] - varying education levels and social vulnerability[19] - competing priorities including work and family responsibilities[20-23, 25,49]	- home based and alternate, flexible, individualised programs[23,49]	

Table 5: Themes, barriers, enablers and pathways – Australian First Peoples43[-48]

Themes	Barriers	Enablers	Pathways
Referral: health service pathways and planning	- discharge processes are lacking with Australian First Peoples often not identified as such[43] - lack of a minimum dataset to record and monitor CR referrals and outcomes in WA[44]	. revision of the current WA data set and a review of referral pathways[44] - high completion rates indicate the need to ensure people are referred and attend the first session[44]	- word of mouth recommendations, and self-referral[46,47]
Cultural and geographic factors necessitating alternate and flexible programs	- not culturally appropriate, programs connected with colonialism[48] - family responsibilities and commitments[43,45] - Western medical practices are ineffective in taking accurate medical histories of Australian First Peoples[46]] - negative perceptions and media of Australian First Peoples[45] - the interplay between physical and mental concerns[43] - lack of services[46]	- cultural security of AMS[43,46], - cross cultural benefits[47] - engaging the family and broader community; including both primary and secondary prevention, flexibility and "yarning"[46] - community education, follow-up and support[43] - strengthen cultural skills of Non-Australian First Peoples[43] - management support for policy changes and practice[43]	- revised referral and data collection system.[49] - develop more services[47]
Professional roles and influence	- low level of cultural awareness training for health professionals[47,48] - Western medical practices are ineffective in taking accurate medical histories of Australian First Peoples[46] - tensions between standard medical care and secondary prevention and the needs of Indigenous people[43]	- AHWs part of MDT and involvement of AMS[43,46,47] - increased knowledge of the NHMRC Guidelines for *Strengthening CR and Secondary Prevention for Aboriginal people*[43] - non-Australian First Peoples' staff gaining cultural insight, feeling valued and assisting people to improve skills and functioning[47] - strong relationships and trust between staff and participants[46]	- management support for policy changes and practice[43] - strategies to reduce staff turnover and subsequent staff shortages[43]
Knowing, valuing, psycho-social factors	- established disease suffers were less likely to attend than people with risk factors only[47] - poor understanding of medication regimes and correct use of prescribed medications; reluctance to call an ambulance due to the possible costs[46] - varying education levels and social vulnerability[43] - family commitments[43,46]	- participants learning new skills; community interaction and comradeship[47] - strengthen the cultural skills of non-Australian First Peoples' staff[43,47] - family involvement[43,46]	
Financial costs – personal and health services	- nil identified in the studies reviewed for Australian First Peoples		

Discussion

CR is known to be effective in improving quality of life, reducing mortality, morbidity and hospital readmissions[7,8,10], and consequently reducing costs for hospital treatment for heart disease[,7-10,51,52]. The true value of CR is not realised in rural and remote areas due to poor access and/or attendance to CR services[18-21,23,24,41]. Whilst this integrative review provides information on barriers, enablers and pathways to models of referral and access to CR, there remain many unanswered questions, including why referral and attendance rates continue to be low despite the significant evidence of CR effectiveness.

One study in Victoria, Australia found that only 11.9% of people eligible for CR attend[53]. Whilst the reason for this is not completely understood, contributing factors identified in the selected studies include poor understanding of the benefits of CR by health professionals and potential attendees, compounded by low levels of referral[19,21,23,24,42]. Whilst some pathways of referral and transition of care planning are reported, referral rates are not known in many areas of Australia.

Early results of a recently instituted Queensland Health CR database are insufficient to draw conclusions about referral rates in Queensland. It is anticipated that as data collection increases, this information will become available[16,53].

Australian First Peoples experience many of the same barriers as the general population, compounded by cultural issues, lower socioeconomic and educational levels, and greater geographic isolation[1,3]. However, they have a greater need for CR, primary and secondary prevention due to higher levels of heart disease and multimorbidity[1,54,55]. To provide Australian First Peoples adequate and effective CR, their increased involvement, together with non-Australian First Peoples' improved cultural awareness, mutual trust, respect and two-way learning is required, as well as improved support and access to specialist services[43,46-48]. Many of these issues are not well investigated and described.

Costs associated with recurring heart disease are high and it is known that these costs can be reduced with improved systems that facilitate referral, accessibility and CR attendance[6]. To improve services, more information is required about hospital discharge and CR referral processes, including eligibility, in-patient education, perceived benefit and meeting participant needs.

The current situation demonstrates weak or poorly implemented systems. These include models of health services delivery, referral processes as well as inconsistent knowledge and value by health professionals and potential participants[14,15,19,23,40,48], plus a range barriers to access and appropriateness of services. Many of the issues identified are common to health service provision and access to services in rural and remote areas of Australia[56]. As such, findings of this integrative review potentially have broad applications. To address the deficits, the following priorities need to be considered.

Referral, health services, pathways and planning

A systematic referral process based on well-defined criteria, individualisation of CR, personal contact, trust, information and support from health professionals[13,22-24,46,49] needs further investigation. The systematic referral process, based on eligibility criteria, education on heart disease and risk factors, needs to commence prior to hospital discharge[20,22,57].

Cultural and geographic factors necessitating alternative and flexible programs

Flexibility in CR is essential because of the diversity of demographic profiles, geographic location and health status in rural and remote areas[23,41,47,48]. Alternative models of CR, including home based programs with telephone support, such as Queensland Health's Coaching Patients on Achieving Cardiovascular Health (COACH)[17], telehealth, purpose designed apps and community involvement, are all known enablers for CR[31,41]. However, attendance rates remain low[10,16,17]. In Australia there is little evidence of CR being provided by Aboriginal medical services, compounding poor access to CR by Australian First Peoples who live in

remote area communities. This highlights the need for further advocacy and a review of systems of health care for Australian First Peoples in remote area communities. In line with a holistic and culturally appropriate approach and scarcity of resources, consideration of an integrated, flexible primary and secondary prevention model that is appropriate for Australian First Peoples as well as the general population needs further investigation.

Professional roles and influence

Key issues identified include ongoing staff shortages[14,15], indicating the need for increased professional role flexibility and modified multidisciplinary team models, supported by appropriate management policy[15,43]. A further priority is including a primary role in CR, supported by further education, for Aboriginal health workers working with Australian First Peoples[43,45,47]. These are all key issues that need further consideration to work towards optimal effectiveness of CR in rural and remote areas.

Knowing, valuing, and psychosocial factors

Poor understanding of the concepts and benefits of CR contributes to low attendance rates[19,21,23,25,41,58]. This is exacerbated by the general perception that acute care health services are of greater importance than primary and secondary prevention services[24]. Lack of knowledge and negative perceptions of CR need to be addressed. Mental as well as physical health issues are of primary importance and currently not prioritised in many CR programs[19,21,43]. A holistic approach to CR, primary and secondary risk factor prevention and use of resources need further consideration[46].

Financial costs – personal and health services

Through effective CR it is known that healthcare costs can be significantly reduced through a reduction in reoccurrence of heart disease and hospital readmissions[6]. To achieve increased CR participation, improved professional understanding and support is essential[41]. The cost factors for general populations include travel, loss of work, cost of health services, professional consultations and medications[19,23,24,42]. It is also reported by James Cook University, Cairns and Apunipima Indigenous health Services (unpublished internal report, 2016) that Australian First Peoples are faced with financial costs, practical and cultural barriers when attending centralised specialist services that require them to travel and stay away from their families and community. The overall low level of health services in rural and remote areas results in poor access and overloaded services, and resultant staff turnover and cost implications[14,15,42,59,60,60]. Reconsideration of the system, current health services and resource allocation is required.

Limitations

Due to the predominantly qualitative or mixed method research the results are not outcome focused and have limited generalisability due to the specific geographic areas and small purposive contextual samples of the studies. Therefore, conclusions drawn by this integrative review on health service systems and services are based in part on selected studies' discussions, findings and conclusions, and subject to the limitations of the study. No northern Queensland or Northern Territory studies on CR were identified in this integrative review. These are extensive regions of Australia with large rural and remote areas. This and the overall low number of studies indicate the need for further research to improve information that will

facilitate decision making and identify further CR enablers and pathways and minimise barriers specific to rural and remote areas of Australia, so that service improvements can be achieved.

Conclusion

The purpose of this integrative review was to explore barriers, enablers and pathways for access to CR, with the aim of optimising services, improving health and quality of life for all people living independently in rural and remote areas. The review indicates that CR services are fragmented and lack a systematic policy driven approach, with resultant low levels of referral and access. Even when alternative services are offered in Australia (eg COACH), attendance rates remain low.

To address this, the following elements for improved referral and access to CR need further investigation and development:

- referral systems and eligibility criteria
- availability and access to flexible centre-based and **home-based** CR programs including telephone/personal support and technology based programs via telephone apps, with distance support
- education/awareness/training on CR for providers and potential participants, family/significant others
- information systems for CR referral and access
- improved education and training for general populations staff on Australian First Peoples' cultural issues
- improved workplace support and education for Aboriginal health workers
- greater flexibility and extended professional roles supported by management policy and protocols
- consideration of combined CR primary, secondary prevention and risk factor management
- improved funding.

CR works to improve health status and reduce costs, and there are a range of ways to provide effective services for more people. These include a systematic, policy driven approach that includes referral, eligibility and access. This is necessary if CR is to fulfil its role as a valuable tool in substantially lowering coronary heart disease morbidity and mortality. Understanding and addressing these factors has the potential to reduce costs, through reduced cardiac events and hospital readmissions as well as improved quality of life and contribute to improved CR and/or secondary prevention services and ultimately health outcomes for all people living independently in rural and remote areas of Australia.

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End of paper

2.3 Part B: Supplementary integrative literature review: Cardiac rehabilitation in rural and remote areas

A supplementary IR was undertaken on 28 December 2021 (Table 5), to ensure that relevant peer-reviewed publications from 2017 to 2022 were considered in the context of this research.

2.3.1 Methods

Initially, IR keywords and search terms of the original study were used for database searches, but no additional papers were identified. Following this, a broader approach was taken to ensure that relevant studies were identified, and the search terms 'cardiac rehabilitation', 'secondary prevention', 'rural', 'remote' (including health services and communities) used for the search. While the original IR included both peer-reviewed and grey literature, the supplementary review included only peer-reviewed literature, due to high levels of ongoing consultation with healthcare providers, conference attendance, together with follow-up discussion and clarification with QH Community Advisory Networks[52] who served as reference groups for the study (Chapter 4: 4.3) (member checking).[84] Through this process, government documents and organisational webpages, continuously informed the research. No relevant papers were identified through a review of selected papers' reference lists.

A summary of database searches is provided (Table 6), followed by a modified 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' (PRISMA),[85] in Figure 3, which reports on the process of the collection, identification, review, inclusion/exclusion of papers.

Table 6: Summary of database searches and findings (2017-21)

Databases	Search 1: Results	Search 2: Results	Final results
Search terms	'Cardiac rehabilitation' or 'secondary prevention'	[and] rural [or] remote	All terms
CINAHL	8,522	24,574	71
SCOPUS	8,503	987,455	2
Informit	35	36,695	4
PsycINFO	2,064	54,767	7
Medline (OVID)	7,891	183,744	27
Total	27,015	1,287,235	111

Limits were English language, peer-reviewed, humans and years: 2017–2021.
Each search was done separately and combined with 'AND' for the final result. Duplicates were removed, titles and abstracts reviewed, for final inclusion/exclusion (PRISMA Figure 3).

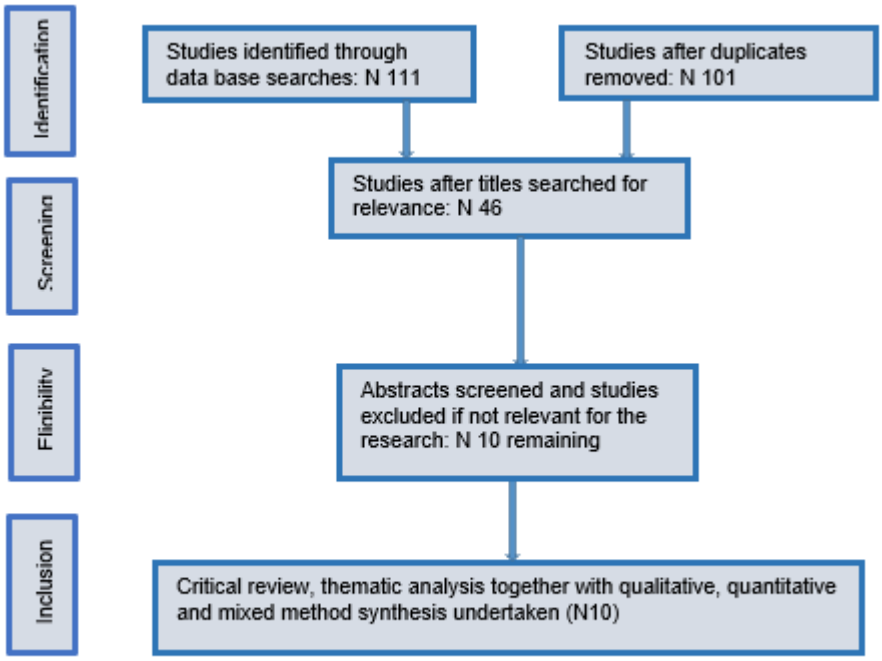

Figure 3: Modified PRISMA Chart[85]: Integrative review of studies on cardiac rehabilitation for people in rural and remote areas

The 10 selected papers were critically reviewed, and a thematic analysis undertaken using the same deductive process as the initial IR.

Table 7: Critical review and thematic analysis of improving access to cardiac rehabilitation in rural and remote areas of North Queensland (N=10)

Author	Title	Year	Study design	Population & environment	Findings	Inclusion/exclusion	Themes
O'Bertos SE, Holmberg D, Shields CA, Matheson LP	Partners' attachment styles and overprotective support as predictors of patient outcomes in cardiac rehabilitation.	2020	Self-report questionnaires - n 69 patient partner dyads. **Strengths & limitations:** Self-reporting without member checking or triangulation weakens validity and generalisability of findings.	Regional hospital - no geographic location provided	Attachment insecurity as a potential risk factor for offering overprotective support in a cardiac rehabilitation context; demonstrates that partners' attachment styles are associated with their use of support strategies, which in turn are associated with important patient outcomes.	Relevant for CR programs in R&R areas that involve family support	- Knowing, valuing, and psychosocial factors
Wilson TM, Peng Z, Clark RA, Tirimacco R	Cardiac rehabilitation and secondary prevention: Assessing patient satisfaction	2018	Patient survey. **Strengths & limitations:** Important observations about effectiveness of telehealth, being effective for completion of CR in R&R and metropolitan areas.	Metropolitan and rural areas of UK and Australia	Overall satisfaction was high, with completion rates noted to be greater in the telehealth group compared with face-to-face models. But access continues to be low and requires further investigation.	Relevant for CR programs in R&R areas because of satisfaction with telehealth	- Cultural and geographic factors necessitating alternate and flexible programs
Choshi, Mosima G (Thesis)	Self-care behaviours of rural women post-invasive coronary interventions	2017	Qualitative description design. Purposeful sampling. Data collection face-to-face semi-structured interviews. Sample size n=10. Strength and limitation: Small sample size. Data saturation not discussed.	Rural women in Arizona, USA. Many parallels with women in R&R areas of NQ	Women resumed normal activities such as walking and cleaning as soon as they felt physically able. Some reported lack of fruit and vegetables due to isolation. None reported any support apart from family and medical e.g., scripts for medication. They were also lacking knowledge as to what constituted ' heart health' behaviour.	Relevant because of environment and need for self-care	- Cultural and geographic factors necessitating alternate and flexible programs - Knowing, valuing, and psychosocial factors
Freier C, Heintze C, Herrmann W	Prescribing and medical non-adherence after myocardial infarction: Qualitative interviews with general practitioners in Germany	2020	Qualitative interview study. Episodic interviews (n=16) with 16 general practitioners from rural and urban surgeries in Germany. Framework analysis with focus on general practitioners' prescribing and patients' non-adherence was performed. **Strengths & limitations:** Triangulation was achieved through exploring 'narrative episodic and semantic knowledge' and reframing the questions. No data saturation described.	Rural and urban medical surgeries in Germany	GP would often administer medication according to the hospital's discharge summary rather than according to best-practice guidelines. GPs described patients as having an 'indifference to health' but patients' indifference has not been reflected in other studies. GPs stated that they would use messages about the negative consequences of not taking medication with low to moderate use of motivational interviewing techniques during individual risk counselling. No evidence of utilising allied health professionals for risk factor management.	Relevant as an example of non-holistic and instructing approach of GP rather than holistic care, supported by motivational interviewing	- Referral, health services' pathways and planning - Professional roles and influence

Author	Title	Year	Study design	Population & environment	Findings	Inclusion/exclusion	Themes
Valaker I, Råholm M-B, Norekvål TM, Rotevatn S, Fridlund B, Nordrehaug JE	Continuity of care after percutaneous coronary intervention (PCI): The patient's perspective across secondary and primary care settings	2017	Qualitative content analysis with inductive exploratory design. Purposeful sampling, in-depth interviews of 22 patients at 6–8 weeks after PCI. Nine were women and 13 were men; 13 were older than 67 years of age. Eight lived remotely from the percutaneous intervention centre. **Strengths and limitations:** Interviews continued until sufficient sample size that included sufficient richness, experiences and relatedness to the research questions was reached. Limited to PCI; therefore, generalisability to other forms of heart disease is limited.	People who lived remotely from the percutaneous coronary interventions centre in Norway.	Post-procedure care was described as rushed with little time allocated to preparation for discharge. Information provided for GPs was often incomplete and GPs were not up to date with hospital treatment and patients had insufficient information. Difficulty in accessing CR. Would have preferred home support. Nurses checked blood pressure, electrocardiogram and pulse many times during the patients' stays in hospital, but these patients could not remember the nurses talking about discharge preparation. (Falun, N. F., Fridlund) Nurse-led initiatives to improve continuity of care involve a range of interventions at different levels of the healthcare system.	Relevant because of similar problems with discharge and follow-up and access to CR experienced in R&R areas of NQ	- Referral, health services' pathways and planning
Walters R, Leslie SJ, Sixsmith J, Gorely T	Health literacy for cardiac rehabilitation: An examination of associated illness perceptions, self-efficacy, motivation and physical activity	2020	Self-administered postal questionnaire. 282 patients completed the questionnaire out of 617 who were eligible (45.7% response rate). **Strengths and limitations:** Responders were predominantly male and from more affluent areas (bias)	Remote and rural Highlands region of Scotland	People with lower health literacy were less physically active and had poorer health, and more distressing illness perceptions. Results did not show an association between health literacy and cardiac rehabilitation attendance, but those with the lowest literacy were significantly less likely to be aware they had been referred to cardiac rehabilitation.	Relevant because of health literacy being an important factor in overall health and understanding of factors that affect health.	- Knowing, valuing, and psychosocial factors
Kohler AK, Jaarsma T, Tingstrom P, Nilsson S	The effect of problem-based learning after coronary heart disease—A randomised study in primary health care (COR-PRIM)	2020	Mixed method including randomised control trial. Patients (N=157) randomly assigned problem-based learning or home-sent patient information. Questionaries and follow-up interviews used to collection information about satisfaction and benefit with the intervention. **Strength and limitations:** Highly empowered participants recruited for the study. High dropout rate mainly due to the perception that CR is unnecessary.	SE Sweden	Patient involved in the problem-solving group, supported by a nurse who was trained to support the participants, versus those sent information in the post, had a positive outcome on weight loss, BMI, and HDL cholesterol.	Relevant because of importance of appropriate support and education.	- Cultural and geographic factors necessitating alternate and flexible programs - Knowing, valuing, and psychosocial factors
Barnason S, Zimmerman L, Schulz P,	Weight management telehealth intervention for overweight and	2019	A randomised clinical trial used a repeated measures experimental design to examine the impact of a 12-week telehealth weight management intervention.	Rural areas of USA	This study demonstrated the feasibility of implementing a specific weight management intervention program component for CR participants that could be implemented in conjunction with standard CR in response to the	Relevant because of focus on benefits of support for weight management in	- Cultural and geographic factors necessitating

Pullen C, Schuelke S	obese rural cardiac rehabilitation participants: A randomised trial		Purposeful sampling, adults after coronary artery bypass surgery or percutaneous intervention **Strength and limitations:** Demonstrated benefits of weight management intervention that could be delivered by telehealth, making it accessible for people in R&R areas. Weight management intervention was not linked with local health service providers or CR program.		national guidelines to use behavioural interventions to promote adherence and self-management skills in weight management. Telehealth delivery provided access to the intervention by CR participants regardless of location in urban or rural communities.	conjunction with CR and linking with telehealth.	alternate and flexible programs
Quirk J, Parfitt G, Ferrar K, Davison K, Dollman J	Predictors of physical activity among rural adults following cardiac rehabilitation	2018	The aim of this study was to investigate the personal, social, and environmental level predictors of post-cardiac rehabilitation physical activity in rural adults. As the focus of the study was the post-CR period, the study prioritised psychological attributes known to predict physical activity maintenance beyond intervention. Random questionnaire of eligible population (people previously referred to CR). 128/340 questionaries returned (40%), 73% males. **Strengths and limitations:** Good return rate. Predominance of males responded. Self-administered questionnaire largely precludes illiterate people from participation, creating bias.	R&R areas of South Australia	Regular physical activity among rural adults post CR was low. Overall, these results confirm previous reports that, although access to CR is critically important, access or even participation does not guarantee favourable longer-term changes in behaviour or subsequent health status. Robust predictors of long-term physical activity participation predominantly emanated from the psychological domain. For CR programs to be effective, emphasis must be placed on providing patients with 'tailored, contextually appropriate strategies to improve self-efficacy and self-regulation'.	Relevant in the holistic approach to CR in R&R areas. More research is required to establish suitability for lower socioeconomic groups, including Aboriginal and Torres Strait Islander people.	- Knowing, valuing, and psychosocial factors - Cultural and geographic factors necessitating alternate and flexible programs
Dechaine C, Merighi J, O'Keefe T	Healing the heart: A qualitative study of challenges and motivations to cardiac rehabilitation attendance and completion among women and men	2017	Qualitative study explored the treatment experiences of 20 women and 20 men at urban and rural rehabilitation clinics in Minnesota. Participants were equally divided based on the number of CR sessions completed (>18 years). The study's primary aim was to articulate similarities and differences in the CR treatment experiences by gender. **Strengths & limitations:** The study findings can help inform the design of rehabilitation programs and strengthen patient-centred interventions to enhance participation in treatment. Purposeful sampling equal numbers of males & females with similar demographic profile. interviews were limited by number of participants rather than continuing until data saturation	Minnesota USA	Women demonstrate sense of partnership manifested as an obligation to staff and a concern that they do not want to let down the staff by not participating in CR to the best of their ability. In contrast, men focused less on relationship building and more on framing their CR treatment as a task that can be mastered.	Relevant because of appreciating the different approaches of male and female participants to CR. Limited by not proceeding to data saturation.	- Knowing, valuing, and psychosocial factors - Cultural and geographic factors necessitating alternate and flexible programs

2.3.2 Results

Through critical review and thematic analysis, themes were identified, and findings synthesised. The themes and findings are the same as those of the original IR, except for 'financial costs—personal and health services'. However, elements within each theme vary.

Themes:

Referral, health services pathways and planning

Little time was allocated in hospitals for discharge planning, and post-discharge plans were not routinely discussed with in-patients by direct care staff. Further, inadequate information was provided for follow-up care, in particular for GPs or community nurses.[86, 87] One study recommended nurse-led initiatives to improve continuity of care that involves a range of interventions at various levels of the healthcare system.[87]

Knowing, valuing, and psychosocial factors

Studies focused on various aspects of the provision of effective CR. Overall, people with higher levels of health literacy, and utilised in a problem-solving approach, had better health outcomes.[88, 89] Further, the patient's partner/carer influenced the patient's recovery (positively and negatively), indicating the need for an inclusive family-focused approach.[90] Another study found that healthcare services need to be contextually appropriate for improved outcomes.[91]

Professional roles and influence

GPs are known to be key post-discharge service providers, and are influential in CR attendance.[21, 63, 86] However, one study found that GPs regularly neglected to follow best-practice guidelines, inaccurately described people with HD (clients) as being indifferent to their health, used negative messages about consequences of failure to adhere to medical advice, and failed to use motivational interviewing techniques, or utilise AHPs for holistic care.[92]

Cultural and geographic factors necessitating alternate and flexible programs

Studies reported positive feedback on telehealth programs but lacked information on the acceptance and participation rates in R&R areas.[33, 93] Women in R&R areas demonstrated resilience and returned to their routine activities as soon as they felt well enough. However, the women also described barriers to regaining their health, as a lack of information and holistic support, together with inability to access fresh fruit and vegetables in R&R areas.[33] Further, the need for clients to receive support from a local nurse who is trained in the role

was identified.[89] Overall, an individualised, holistic, culturally responsive, and environmentally appropriate approach that included psychosocial factors was identified as being required for effective CR programs.[91, 94]

2.3.3 Conclusion

The findings of this supplementary IR demonstrated inadequate implementation of Phase-1-CR, including in-patient education, discharge planning, and referral to Phase-2-CR. Further, GPs need to be more engaged with CR, together with better utilisation of nurses and AHPs. Overall, the need for modified health systems; alternate models of CR, including telehealth; and holistic multidisciplinary care to improve the effectiveness of CR for R&R areas was identified. This provided new information that contributed to the discussion and development of models of care to improve access to CR in R&R areas.

End of supplementary IR

2.4 Conclusion

The supplementary IR reinforced many of the findings of the original IR, with an increased focus on telehealth, and were congruent with many of the findings of the studies undertaken during the development of the research. This reaffirmed the need for a comprehensive revised model for secondary prevention in R&R areas.

The objectives were developed from the findings of the initial IR and provided the foundation and direction for the total research. Chapter 3 describes the methodology and methods used to address each objective and proposes important factors to be considered in the development of efficient and effective delivery of CR services in R&R areas of Australia.

Stage 1 Foundations (continued)

Chapters	Content & publications
1. Introduction ⇨	Background, introduction & implications of the research
Stage 1 Research foundations	
2. Integrative literature review ⇨	Cardiac rehabilitation services for people in rural and remote areas: Integrative literature review (2007–2016). Published 2020 (Paper 1). Supplementary review (2018 – 2021)
3. Methodology and methods ⇨	Project protocol: Improving access to cardiac rehabilitation in rural and remote areas: A protocol for a community-based qualitative case study. International Journal of Therapy and Rehabilitation. Published 2021 (Paper 2)
Stage 2 Results: Heart disease, hospitalisation, and referral	
4. Results 4.1 Epidemiological study ⇨	Heart disease, hospitalisation, and referral: coaching to achieving cardiovascular health through cardiac rehabilitation in Queensland. Published 2020 (Paper 3)
Stage 3 Results: Hospital-based Phase-1-Cardiac Rehabilitation	
4.2 Hospital case study series ⇨	The importance of cardiac rehabilitation in rural and remote areas of Australia. Published 2021 (Paper 4)
Stage 4a Results: Community-based Phase-2-Cardiac Rehabilitation	
4.3 Community case study series ⇨	Improving access to cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing? Published 2022 (Paper 5)
Stage 4b Pathways to *Heart: Road to health*	
5. Discussion and conclusion ⇨	Discussion and conclusion
5.3.1 *Heart: Road to health* for Aboriginal and Torres Strait Islander people ⇨	Improving access to cardiac rehabilitation (Heart: Road to health) for Aboriginal and Torres Strait Islander peoples in rural and remote areas of North Queensland. Published 2022 (Paper 6)
5.3.2 Model for *Heart: Road to health* ⇨	Model for Heart: Road to health or Chronic disease: Road to health in rural and remote areas. Submitted for publication Oct 2022 (Paper 7)

Chapter 3: Methodology and methods

3.1 Introduction

This research used a sequential approach in which each stage of the research informed the next, using various sources of data, with each study's findings providing the basis for collection of the next data set.[95] The sequential, multiple method, qualitatively dominant methodology, provided flexibility for this research which required a range of studies to answer the overarching research question: How can access to cardiac rehabilitation (CR) in R&R areas of NQ be improved? The studies undertaken included: a integrative literature review on barriers, enablers and pathway to CR in rural and remote areas (R&R) areas; an epidemiological study on rates of cardiac hospitalisation in Queensland, and referrals to Coaching on Achieving Cardiovascular Health (COACH); a hospital-based case study series on implementation of Phase-1-CR; followed by a community-based case study series on implementation of Phase-2-CR; and finally an iterative process that included information sharing and ongoing community consultation, in the development of a model for improved access to CR in R&R areas of NQ.

The sequential process ensured that the findings from one study informed the next, until completion. The overall research was guided by combined conceptual and theoretical frameworks,[96, 97] and theories of public health, health promotion, and primary healthcare as discussed in section, 5.4 Design and methods.[76, 77] These concepts and theories, complemented by appropriate methods, provided the basis to investigate access to cardiac rehabilitation (CR) in rural and remote areas (R&R) areas of NQ, and was designed to address each study's objectives through four sequential stages, (Figure 4), all of which were undertaken with an overarching consultative approach.

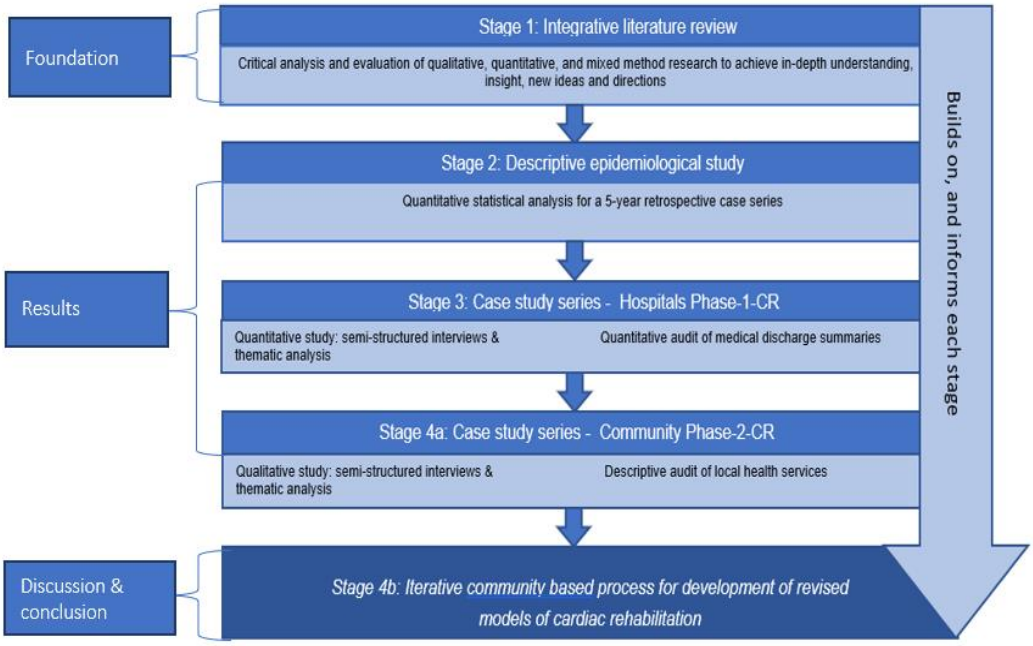

Figure 4: Sequential approach for stages of the research

The research was carried out in line with the stages in Figure 4. The following sections of this chapter provides information on my background as the coordinating primary investigator, an overview of the research focus areas, and key factors that need to be considered when undertaking research in R&R areas, followed by the theoretical underpinnings. This provides the context for the sequential stages, that are described in more detail in Section 3.5 Design and Methods.

3.2 My Background

This research is underpinned by my nursing career that spanned many years, and included working in clinical, management, and capacity building roles in R&R areas of Australia, the Pacific region, and Asia. Throughout my career, I backed up my practical experience with ongoing education. Following my registered nurse training, I completed a Grad. Dip. in Extension (Social Communication), B. Administration (Nursing) and Master of Public Health. I have predominantly lived and worked in R&R areas, including Alice Springs, where I worked as a health services manager and clinician for The Centre for Remote Health. From here I joined the National Heart Foundation of Australia (NHF) in a role that focussed on primary and secondary prevention of heart disease (HD) for rural, remote and Aboriginal and Torres Strait Islander populations. During this time, the disparity in healthcare services between R&R and metropolitan areas was highlighted.[37] My practical experience, supported by academic qualifications, strengthened my ability to work collaboratively with

health staff and people in R&R communities, as well as undertake research to inform interventions that could potentially reduce these disparities.

As coordinating primary investigator in this research, I drew on my previous experience as a registered nurse in the provision of healthcare services in R&R areas of Australia, and the NHF. Both roles involved healthcare provision for Aboriginal and Torres Strait Islander and non-Indigenous populations. During this time, it became evident that there was poor access to CR for people with stable HD (clients) in R&R areas. As a result, the aim of this research was designed to develop a model of healthcare to improve access to CR for people living independently in R&R areas in NQ. The first stage of this research was an IR, which focused on barriers, enablers and pathways to CR in R&R areas (Chapter 2). The objectives were based on the findings of the IR, and the research team's experience.

Because of my role as coordinating primary investigator, it was important that my situation in the research was considered, possible bias minimised, and steps taken to ensure research rigour. Full details of how this was addressed are provided in Chapter 3: 3.6 Validity and rigour.

3.3 Research focus areas

For successful research in complex environments such as R&R areas of NQ, it is important that the focus areas for data collection represent a cross section of communities, social determinants of health (SDoH), geographic and demographic factors.

This research is set in NQ, which has geographically diverse areas, with sparce and disparate populations as well as major metropolitan centres. Generally R&R areas have poorer SDoH, with a high proportion of Aboriginal and Torres Strait Islander people, who have poorer health than non-Indigenous people. [38, 98] To address this complexity and facilitate validity and rigour of data collection, six focus areas were selected that provide a diversity of R&R and metropolitan locations. These areas are metropolitan centres of Townsville and Cairns, and R&R communities of Hughenden, Cooktown, Wujal Wujal and Hope Vale (Figure 5). Healthcare in the focus areas is provided by a diversity of organisations including tertiary hospitals, Multi-Purpose Health Centres (MPHS), Primary Health Care Centres (PHCC), and Aboriginal and Torres Strait Islander Community Controlled Health Services (ACCHO). The services are augmented by Royal Flying Doctor Service (RFDS), contracting organisations and individual private health practitioners.

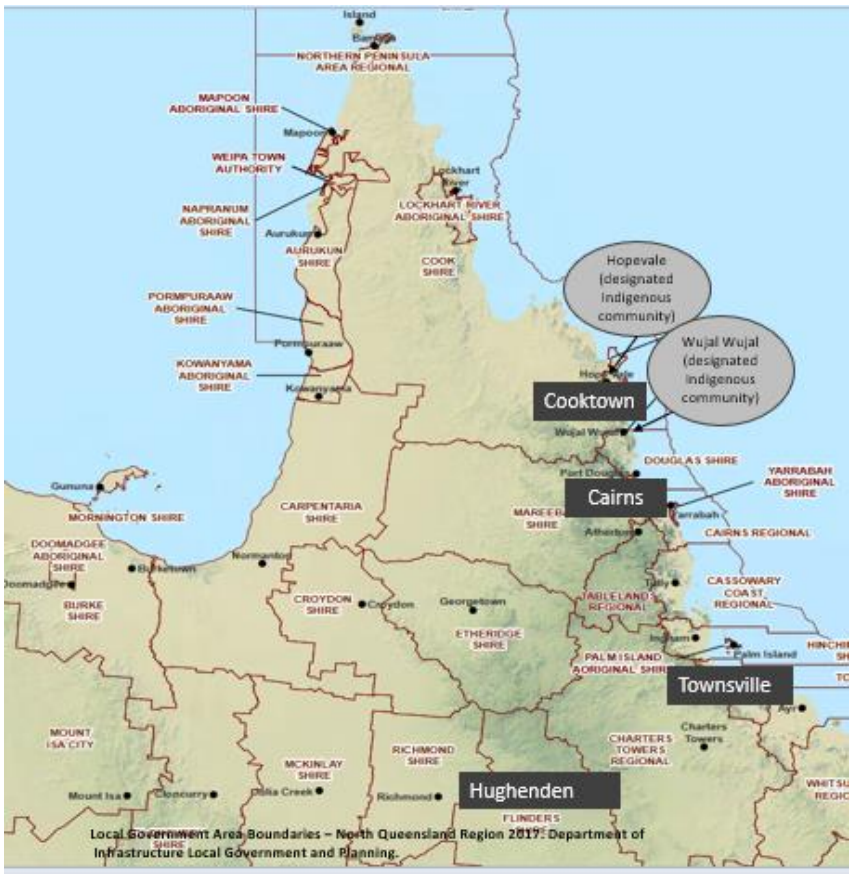

Figure 5: Research focus areas—Townsville, Cairns, Hughenden, Cooktown, Wujal Wujal and Hope Vale [99]

Townsville and Cairns are major regional metropolitan areas and are hubs for service provision in NQ, with industries and services including tourism, defence, local government, education and training, health, small business, retail, professional services, public administration, construction, manufacturing, shipping, fishing, and wharf facilities.[100, 101] Tertiary health services in both Townsville and Cairns are provided through two major public and two private hospitals, with primary/secondary healthcare provided through PHCC, Community Health Centres, MPHS, Aboriginal and Torres Strait Islander Health Community Controlled Health Organisations (ACCHO), Royal Flying Doctor Service (RFDS), other healthcare contractor and private practitioners, including GP.[102]

Hughenden and Cooktown are remote areas hubs, with a range of industries including farming, tourism, retail, professional and service industries, local government, and infrastructure development. Hughenden also has solar and wind farms, and Cooktown, reef fishing, and prawn and lobster industries.[103, 104] Both towns are healthcare hubs that provide outreach services for surrounding areas. Primary and secondary healthcare is provided predominantly through Queensland Health (QH) MPHS, staffed mainly by nursing and Aboriginal and Torres Strait Islander Health Workers (ATSIHW) supported by

administrative and support service staff, plus onsite or visiting medical officers and allied health professionals (AHP). These services are augmented by telehealth or telephone support services such as Coaching on Achieving Cardiovascular Health (COACH), now rebranded as Self-Management of Chronic Conditions (SMOCC).[4] QH services are supported by ACCHO, Royal Flying Doctor Service (RFDS), contracting organisations, and individual private health practitioners, who deliver onsite and visiting services. Contracting organisations often provide visiting AHP services, which are usually contracted by state or federal organisations such as QH and North Queensland Primary Health Care Network (NQPHN).[102]

Wujal Wujal and Hope Vale are designated Aboriginal and Torres Strait Islander peoples' communities, also known as 'Aboriginal or Indigenous Shires'[99] (Figure 5). Each community has basic infrastructure such as a local council, justice centre, general store, police station, primary school, sports ground and recreation centre, QH PHCC, and community housing services. PHCC are staffed by nurses and ATSIHW, supported by administrative staff, visiting medical officers and AHP.[102]

The diversity of geographic, climate, populations, culture, and SDoH result in a challenging environment for health service provision and are considered throughout this research.

3.3.1 Validity and rigour

As coordinating primary investigator, I led each stage of the research. Thereby, my personal background, and the theoretical perspective of the research, affects all interactions, approaches to data collection, and analysis.[105, 106] The research team and I have broad experience in a range of healthcare environments especially in R&R areas, working with Aboriginal and Torres Strait Islander peoples, and other Indigenous populations in the Pacific, (Chapter 3: 3.2). This experience influenced our approach to this research based on our understanding of the need for effective communication and collaboration with local communities and healthcare providers.[86] My previous experience also enhanced understanding and communication with hospital and community health/primary healthcare service providers. This greatly facilitated communication on healthcare and professional issues. My approach to research, healthcare planning, and delivery of health services is underpinned by public health, health promotion and primary healthcare theoretical and personal perspectives. Thereby, my focus is on improved access and equity for healthcare provision that is equitable, holistic, client focussed, culturally responsive and delivered by a multidisciplinary health team.

Through my experience in remote area health services, I understand that the development of networks is necessary to build trust with local communities, and that this is best achieved through personal communication, listening to ideas, flexibility and collaboration. Finally, my previous experience with the NHF provided the direction for this research in line with the conceptual/theoretical framework of this study, (Chapter 3: 3.5.3).

Possible bias and preconceived ideas due to past experience, and public health training, were minimised using a framework for data collection and analysis,[107] characterised against NHF and Australian Cardiovascular Health Association (ACRA) guidelines,[1, 58] together with principles of public health, health promotion, and findings of previous and contemporary research.[76-78]

To ensure validity and rigour in the data analysis of all studies, I undertook the initial analysis, which was checked by the primary investigator and subsequently the full research team, to ensure that the themes were reasonable, logical and obvious.[107] For the qualitative studies, this included reviewing, audio recordings, interview texts and field notes.

Building and consolidating trust, community consultation, information sharing and collaboration with the focus communities of Hughenden, Cooktown, Wujal Wujal and Hope Vale continued throughout the research. This was achieved through community leaders and members, healthcare staff and managers, in conjunction with Community Advisory Networks, which provided reference groups for the development of ideas, member checking and clarification.[84] This qualitative consultative process, augmented by medical record, and health service audits, plus an epidemiological study, (Figure 4) ensured data was collected from a variety of sources thereby enabling triangulation.[84]

3.4 Design and methods

A separate study was undertaken for each stage of the research. (Figure 6). Full details of methods are provided in each study, and in line with the sequential approach, each stage builds on, and informs, the next.

3.4.1 Methods

Qualitatively dominant multiple method research[108] was used in the four sequential stages of the research. These methods provided information collected from a range of sources that included interviews and audits, together with an epidemiological study, (Chapter 4.1). This led to the development of a comprehensive picture of pathways and support available, or required, on the pathway from hospital to home for people with HD (clients), regardless of

where they live and finally the development of a model for improved access to CR for people in R&R areas of NQ.

3.4.2 Conceptual and theoretical frameworks

In line with the sequential approach, conceptual and theoretical frameworks were used to link reasons for the importance of the research, provide guidance, and enable building towards the achievement of the aim and objectives.[96] These frameworks provided a structure to answer the overarching research question: How can access to CR in R&R areas of NQ be improved?

The conceptual framework guided the collection, analysis, and investigation of data, as well as ensuring that methods were appropriate and rigorous.[96] The theoretical framework describes concepts and relationships of a particular phenomenon, and provides a map for qualitative investigation, that is built inductively from previous experience, research, existing theories, or literature.[97] In line with the theoretical framework, this research was initiated by real life experience of myself, and the research team, combined with barriers, enablers and pathways to access to CR in R&R areas, identified in the integrative literature review, (Chapter 2: Integrative literature review). Further, due to the variety of environments and potentially large quantity of data, the theoretical framework assisted in guiding data collection towards the primary area of interest, and combined with a conceptual framework provided a sound structure for the research.[96, 97]

The frameworks used in this research, while predominantly used for qualitative research, are flexible enough to include quantitative methods that provide additional information from different perspectives. The process of using multiple methods and frameworks facilitates triangulation, accuracy and rigour.[84, 109] A diagrammatic representation of the process by which each stage was guided, and builds on the findings of the previous stage, culminating in the development of a proposed model for CR that is suitable for all clients in R&R areas of NQ is provided in Figure 6.

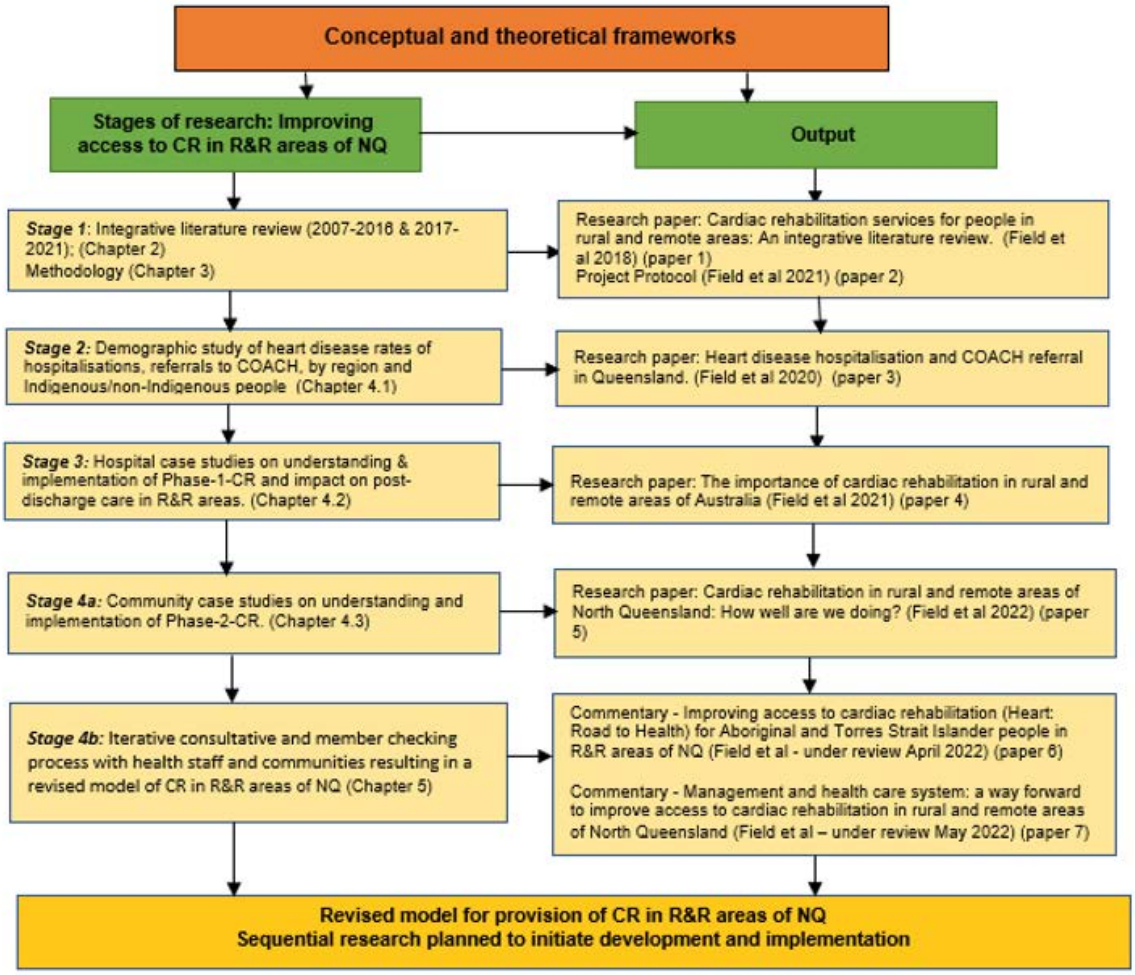

Figure 6: Conceptual and theoretical frameworks

3.4.3 Public health, primary healthcare and health promotion theories

Health promotion is a primary component of public health and together with primary healthcare, are inextricably linked.[76-78] Together they provide a theory-based approach and direction for this research, within the conceptual and theoretical framework. This approach integrates health education, and supports client-centred, community-based, culturally responsive and collaborative processes. Such processes include continuous quality improvement (CQI) and co-design, that encompass health education and behaviour change, necessary for effective problem solving and identification of suitable solutions, through the involvement of community participants, healthcare staff and managers.[79, 80]**.** These methods facilitate equity and access to efficient and effective health services that meet the needs of local people and health staff.[10, 43]

The seminal theories of public health, health promotion and primary healthcare are described by the Ottawa Charter 1986,[76] and subsequent Geneva Charter 2021,[77] for health promotion and public health; with primary healthcare described by the Declaration of Alma

Ata (1978), affirmed by WHO (2022).[78] The diagram of the principles of health promotion encompasses the holistic approach that provides the necessary components for an effective model for improving access to all healthcare services (Figure 7). These principles are also reflected in theories of public health and primary healthcare,[76-78] and are essential principles of this research.

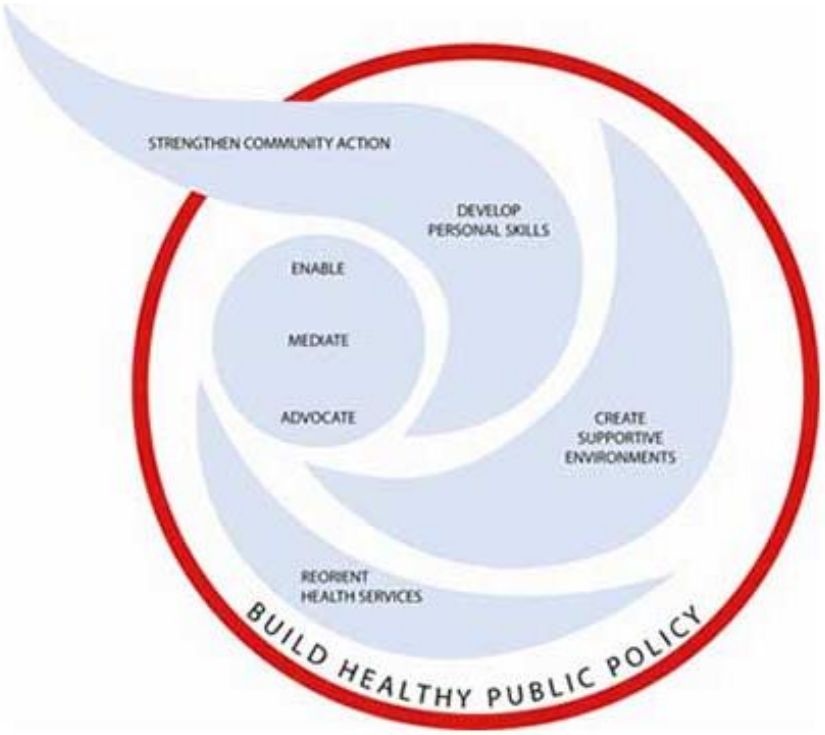

Figure 7: Principles of health promotion Ottawa Charter (adapted from Ottawa charter WHO 1986)[76] (Published under creative commons licence)

Public health was originally defined as the consideration of 'individual, population and/or physical and environmental risks for disease prevention'.[110] New public health has emerged that focuses on the impact of lifestyles, and living conditions, in determining health status.[110] These factors lead to the need to mobilise resources, invest in policies, programs and services, that 'create, maintain and protect health by supporting healthy lifestyles and creating supportive environments for health'.[110] Given the public health focus on environment and lifestyle, it is implicit that effective change can best be made by integrating public health and health promotion into primary and secondary healthcare services.

Health promotion is a social and political process that aims to strengthen individuals' skills and abilities, as well as effecting social, environmental and economic change to lessen the impact on public health, and enable people to increase control over, and improve, their own health.[78, 110] Community and individual participation, together with support for people to

increase their control over SDoH, are primary components of health promotion. (Figure 7).[78, 110]

Furthermore, a critical component is cultural responsiveness of healthcare provision, which is essential, particularly for Aboriginal and Torres Strait Islander people.[111] Canuto, citing Arabena, 2014, pointed out that 'health promotion [or secondary prevention] programs that are developed specifically or primarily for Aboriginal and Torres Strait Islander peoples and consider historical, cultural, socioeconomic and political dimensions could contribute to a much greater reduction in the burden of disease and thus life expectancy gap'.[111]

Primary healthcare is defined as 'essential health care made accessible at a cost a country and community can afford, with methods that are practical, scientifically sound and socially acceptable'.[78, 110] Key principles of primary healthcare are that it should be universally available, affordable, accessible, and ensure equity, community participation, intersectoral collaboration, and appropriate use of technology.[78, 110] Health education is a key component of primary healthcare, and important for improved health literacy and behaviour change, necessary for any improvements in health.[112, 113]

Public health, health promotion and primary healthcare are inextricably linked and inclusive of SDOH, which need to be considered for effective and appropriate healthcare provision and ultimately improved health outcomes.[10] Key principles of these theories are embedded in the development of the revised model for improving access to CR in R&R areas in this research.

3.5 Iterative process, continuous quality improvement and co-design

The final stage of the research (4b) was an iterative consultative process, which comprised a dynamic spiral design,[114] and included ongoing sharing of information, discussion and consultation, with the local community members, leaders and healthcare staff. This process commenced with the development of a plain English summary of findings and recommendations of the previous stages (Appendix 7.2). This summary was discussed with various community groups, ideas further developed and documented, leading to the development of the model for improving access to CR in R&R areas or NQ.

Local communities and health staff's involvement in planning, implementation, monitoring and evaluation of all aspects of healthcare, is based on the combined public health, health promotion and primary healthcare theoretical approach.[115] In this research such a process ensured the consideration of context, culture, societal norms and involvement of stakeholders, including a range of government, non-government organisations, and community groups,

which is congruent with continuous quality improvement (CQI)[79] and co-design[80] and key for effective design of tailored healthcare models most likely to succeed.[113]

3.8.1 Continuous quality improvement and co-design

CQI and co-design, are advocated to facilitate health systems' reform throughout this research. Together or individually these concepts are recommended as the preferred method for working collaboratively with those most closely involved in circumstances that require improvement. CQI is a cyclical process that is suitable for involving healthcare providers and recipients in a process that identifies problems and possible solutions, leading to the development, implementation, monitoring and evaluation of revised health systems and models of care.[79] Co-design is described as a participatory approach in which healthcare staff, community members and leaders work together to develop solutions to local problems.[80] Whilst the processes have similar concepts this research proposes that CQI is suitable for healthcare systems review especially due to the ongoing cyclical nature, and co-design more appropriate for community-based consultations, which can also be revisited and reviewed in the future.

3.6 Project protocol

Given the complexity of the environment for this research, and as part of the pre-research planning for the community-based studies (Chapter 4: 4.3), a project protocol that provided details of methodology and methods for these studies was developed and published.[86] In this paper and throughout the research, the importance of being aware of SDoH and cultural sensitivities, particularly for Aboriginal and Torres Strait Islander people, is discussed.[86] Overall, the paper emphasises the importance of developing networks and trust with the local community prior to data collection, and the importance of a flexible approach to conducting interviews.[86] According to the participant's preference important factors that need to be considered include family support, agreeing on a suitable venue for interviews, and allowing for variation in data collection methods, such as yarning rather than audio recording of interviews.[11]. In this way, some of the barriers that occur because of inequities in SDoH are respected, and likely to be reduced, thereby potentially improving accuracy in data collection. The full project protocol is inserted as published:

Field P, Franklin R, Barker R, Ring. I, Leggat P, Canuto K. Improving access to cardiac rehabilitation in rural and remote areas: A protocol for a community-based qualitative case study. International Journal of Therapy and Rehabilitation. 2021. https://doi.org/10.12968/ijtr.2020.0167

3.6.1 (Paper 2) Improving access to cardiac rehabilitation in rural and remote areas: A protocol for a community-based qualitative case study

IJTR

PROTOCOL

Improving access to cardiac rehabilitation in rural and remote areas: a protocol for a community-based qualitative case study

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Abstract

Background/Aims Heart disease is the largest single cause of death and contributes to poor quality of life and high healthcare costs in Australia. There are higher rates of heart disease in rural and remote areas, with the highest rates in Aboriginal and Torres Strait Islander people. Cardiac rehabilitation is known to improve health outcomes for people with heart disease but referral rates remain low (30.2% overall and 46% following acute coronary syndrome) in Australia. Further, access to cardiac rehabilitation in rural and remote areas is affected by there being few centre-based services, and poor use of home-based services. The aim of this protocol is to investigate: (i) understanding of cardiac rehabilitation by health staff, community leaders and community participants discharged from hospital following treatment for heart disease; (ii) access and support for cardiac rehabilitation in rural and remote areas via health service availability in each community.

Methods A qualitative case study methodology, using an interpretive descriptive framework, will be used together with content analysis that will encompass identification of themes through a deductive/inductive process.

Conclusions To improve access to services and health outcomes in rural and remote areas, a strong evidence base is essential. To achieve this, as well as having appropriate methodology, it is necessary to build relationships and trust with local communities and healthcare providers. This research protocol describes a qualitative community-based case study, together with processes to build sound relationships required for effective data collection through semi-structured interviews or focus groups. Each step of the pre-research planning data collection and analysis is described in detail for the guidance of future researchers.

Key words: Cardiac rehabilitation; Community consultation; Qualitative research protocol; Rural and remote

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Introduction

Cardiac rehabilitation is recognised as post hospitalisation best practice for people with heart disease (Woodruffe et al, 2015), but referral rates in Australia remain low (30.2% overall and 46% following acute coronary syndrome; Gallagher et al, 2020). This is well below the recommended international referral rate of 65% (De Gruyter et al, 2014). Heart disease continues to be the largest single cause of death and contributes to significant illness, disability, poor quality of life and high healthcare costs in Australia (Australian Institute of Health and Welfare, 2014a, b). Rates of heart disease are higher in rural and remote areas, with the highest rates in Aboriginal and Torres Strait Islander people (Australian Institute of Health and Welfare, 2014c). Poor social determinants of health, such as lower incomes and levels of education, high cost of food, and long distances to services, contribute to these higher rates (Heart Foundation of Australia, 2017a).

Barriers to access to cardiac rehabilitation in rural and remote areas include fewer health services including centre-based phase 2 cardiac rehabilitation (supervised ambulatory outpatient programme), per capita (Australian Cardiovascular Health and Rehabilitation Association, 2018; Australian Institute of Health and Welfare, 2019) and increased costs, largely as a result of distance and staff turnover (De Angelis et al, 2008; Birk et al, 2010;

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Brual et al, 2012; Beatty et al, 2013). A study of inpatient cardiac rehabilitation in four major regional hospitals in North Queensland found that discharge planning was fragmented, with cardiac rehabilitation referral rates of 31% (range: 6–53%) for patients admitted for ≥3 days, and 9% (range: 0–19) for patients admitted for ≤2 days (Field et al, 2021). Enablers for cardiac rehabilitation participation include numbers of referrals and service availability (Field et al, 2018), medical practitioner support and involvement of family and/or significant others (Sherwood and Povey, 2011; Jackson et al, 2012), as well as ensuring that programmes are appropriate for diverse populations including Aboriginal and Torres Strait Islander people (Hamilton et al, 2016; Field et al, 2018).

In the absence of centre-based phase 2 cardiac rehabilitation, or if people prefer home-based programmes, there are several phone support programmes available. These include two no cost programmes: Queensland Health's Coaching on Achieving Cardiovascular Health (Ski et al, 2015; Health Support Queensland, 2018) and Heart Foundation of Australia's My Heart My Life (Heart Foundation of Australia, 2017b) and several commercial programmes, including Cardihab (Cardihab.com) (Varnfield et al, 2014). Despite limited centre-based outpatient cardiac rehabilitation, referrals to Coaching on Achieving Cardiovascular Health are low (range 4.1–20.3%) for residents of North Queensland (Field et al, 2020).

Given the known barriers to cardiac rehabilitation, healthcare system changes are required to improve access to cardiac rehabilitation, especially in rural and remote areas of Australia. Flexibility and inclusiveness (Fernandez et al, 2008) are known to be necessary components to achieve sound results based on strong relationships and trust with local communities. These relationships and trust need to be established in pre-research planning. For this study, the pre-research planning will include engaging with four communities in isolated locations of rural and remote Australia with a population range of 500–3500. These communities comprise a range of individuals and families, with various occupations, generally disadvantaged by socioeconomic status and social determinants of health, including limited general services and healthcare provision (Heart Foundation of Australia, 2017a), as well as a higher proportion of Aboriginal and Torres Strait Islander people than Queensland overall.

Further, to address population diversity and provide a culturally sensitive approach for data collection especially for Aboriginal and/or Torres Strait Islander people (Dimer et al, 2013), it will be necessary to adapt data collection processes. Simple English is necessary for written and verbal communication and collaborative yarning (dialogue circle) will be offered as an alternative to audio recording for data collection. Yarning is a process by which data is collected using a 'storyboards' technique, where text is written by the researchers during and after the yarning discussion, and regularly checked with the participants to ensure accuracy (Shay, 2021).

This research protocol builds on previous research and investigates factors that need to be addressed to improve access to cardiac rehabilitation in rural and remote areas of Australia, including previously completed studies that aim to improve access to cardiac rehabilitation in rural and remote areas of Australia (Field et al, 2018, 2020). These studies informed the direction, development and framework (Table 1) of this research protocol.

Aims

The aim of this study will be to investigate:

- Understanding of cardiac rehabilitation by health staff, community leaders and community participants discharged from hospital following treatment for heart disease
- Access and support for cardiac rehabilitation in rural and remote areas via health service availability in each community.

Methods

Qualitative case study methodology with an interpretive descriptive framework will be used to provide direction and focus on the practical aspects of knowledge, in a logical systematic manner, so that the researchers' engagement with the data makes it possible to interpret the

Table 1. Framework for data collection to improve access to phase 2 cardiac rehabilitation in rural and remote areas

Primary questions and area of interest
Post discharge and referral plan:
■ Community participants' understanding and suggestions
■ Staff role and suggestions
Cardiac rehabilitation: service availability and access
■ Community participants' understanding and suggestions
■ Staff role and suggestions
Improving cardiac rehabilitation:
■ Community participants' understanding and suggestions
■ Staff role and suggestions
The way forward:
■ Community participants and staff: assimilating information into revised cardiac rehabilitation models for improving access to cardiac rehabilitation in rural and remote areas of Australia

content beyond the obvious (Denzin and Lincoln, 2011; Teodoro et al, 2018). Based on an integrative literature review on barriers, enablers and pathways to cardiac rehabilitation in rural and remote areas (Field et al, 2018), initial primary themes and areas of interest were identified (deductive analysis) (Clarke et al, 2015) (Table 1). This preliminary analysis also provided the framework for the study and guided the development of semi-structured conversational interviews that will be used for data collation via purposefully sampled interviewees or focus groups members.

The analysis, including identification of secondary themes (induction), will be guided by the six steps identified by Clarke and Braun (Clarke et al, 2015), and conducted according to consolidative criteria for reporting qualitative research (COREQ) (Tong et al, 2007).

Inclusion criteria

Participants will be included if they meet the following criteria:

- Community participants:
  - Adults ≥18 years
  - Men and women including Aboriginal and/or Torres Strait Islander peoples, discharged from hospital following treatment for heart disease in the past 2 years, who live independently and are eligible for cardiac rehabilitation according to National Heart Foundation of Australia and Australian Cardiac Rehabilitation Association (2004) recommendations (Woodruffe et al, 2015)
- Local and visiting health centre staff including nurses, doctors, allied health professionals, health service managers
- Community leaders employed in leadership positions or recognised as leaders by the local community.

Exclusion criteria

People with a medical diagnosis of mental impairment, or who are unable to comprehend the process despite assistance of a support person or interpreter and thereby do not fulfil the requirements of informed consent as per NHMRC research guidelines (National Health and Medical Research Council et al, 2018) will be excluded from the study.

Ethical approval

Ethical approval has been granted from the Townsville Hospital and Health Services (HREC/2019/QTHS/59212; JCU Ethics Committee acknowledgement: H8467). All participants will be required to sign an informed consent form.

Settings

The focus of this research will be four communities in rural and remote Australia. Each community has contrasting demographic profiles that include farming, tourism, small industry, mining, commercial and government services. All communities have a higher proportion of Aboriginal and/or Torres Strait Islander people than Queensland (4%) (Australian Bureau of Statistics, 2016). Two communities include a proportion of Aboriginal and/or Torres Strait Islander people (8% and 16%), who are part of the larger community, and two communities are designated communities with majority of Aboriginal and/or Torres Strait Islander people (91% and 99%) (Australian Bureau of Statistics, 2018).

Pre-research planning

Community focused pre-research planning is required in preparation for the research. It is important that networks include local government, community organisations, education, health, transport and social services (Woods, 2006). The coordinating primary investigator made three visits to each community to develop networks and build trust with community members and health staff.

The proposed research was discussed at meetings with local organisations. Ideas were sought and education on heart disease and risk factors was provided. Follow-up notes were sent by email and between community visits further email and phone updates were provided. This process resulted in sound networks in each community that will provide a nexus for ongoing consultation, and recruitment of community participants and health staff.

Recruitment and consent

Recruitment and interviewing of community members and health staff will be undertaken over a 2–6-week period as per best practice for community consultations (Department of Prime Minister and Cabinet, 2016). Community participants will include both people who participated in cardiac rehabilitation, or did not participate or complete the programme, thus providing important insights into barriers to attending cardiac rehabilitation as well as an opportunity to explore the reasons why they did or did not attend. Community leaders and staff will be recruited according to the inclusion and exclusion criteria.

Information about the research, process of data collection, including confidentiality and withdrawal if required, will be explained as part of the recruitment process (National Health and Medical Research Council et al, 2018). Recruitment of community participants will be through health staff, or community organisation members, who will be briefed about the project, and asked to contact potential participants.

A simple English brochure describing the project and contact details (Appendix 1) will be provided so that potential participants may contact the coordinating primary investigator, or leave their contact details. Health staff, including nurses, medical officers, Aboriginal and/or Torres Strait Islander Health workers and local and visiting allied health professionals will be recruited through routine staff meetings. Community leaders will be recruited through regular meetings and ongoing liaison with community organisations.

During the first meeting between the participant and coordinating primary investigator, further verbal and written information about the project will be reiterated. Before obtaining written consent, the choice of audio recording or yarning with note taking (Shay, 2021), and use of information for the development of revised models of cardiac rehabilitation, will be discussed. Every effort will be made to ensure proportionate representation of men and women, with a specific effort made to over-recruit Aboriginal and/or Torres Strait Islander people, given their rates of heart disease in rural and remote areas are twice that of the general population (Australian Institute of Health and Welfare, 2016). To help ensure good communication with Aboriginal and Torres Strait Islander people, an Aboriginal and/or Torres Strait Islander health worker, Aboriginal and/or Torres Strait Islander liaison officer or a participant's family member will assist with communication and language interpretation as required (National Health and Medical Research Council et al, 2018; National Health and Medical Research Council, 2018).

In recognition of their expertise and contribution, community participants will be given a AUD$50.00 voucher for the local store. Transport to attend interviews or focus groups and refreshments will also be provided as required. The location of interviews or focus

groups will be discussed with the potential participant to ensure that they are comfortable with the environment. However, should it become difficult to carry out interviews or focus groups in the communities, for example because of COVID-19 restrictions, it will be possible to conduct the discussion using an online application such as Zoom. It is reported that relationship-based face-to-face discussion is preferred by populations in rural and remote areas, particularly Aboriginal and Torres Strait Islander people (Dimer et al, 2013). Poor quality internet can also result in difficulty with using online communication. This reinforces the need to develop sound community relationships before recruitment and data collection. If transport is required, distances are not great within rural and remote communities because of small populations. If networks and trust have been developed, transport can be negotiated through the local council or health services with payment of expenses, or hire, as necessary.

Sample size

People will be individually interviewed and/or focus groups undertaken until data saturation has been reached (Patton, 1990). This will be confirmed when repeated themes emerge, thereby ensuring research questions can be answered and further data collection is redundant (Patton, 1990). Based on previous qualitative community studies, it is anticipated that this will be achieved through 10–15 interviews or focus groups lasting 15–25 minutes for individual interviews, and 1–2 hours for focus groups (White et al, 2009; Van Gelderen et al, 2017; Nyumba et al, 2018). Longer times have been allowed for focus groups, as it is anticipated that several people will generate more discussion, and refreshments will be provided. The number of participants for focus groups are anticipated to be between three and six participants (Nyumba et al, 2018), but will be expanded as required.

Data collection and validation

Data collection will be through semi-structured conversational interviews or focus groups involving information-rich participants (health staff and community participants). Participants will be purposefully selected, according to the inclusion criteria.

As the populations are small, there may be fewer potential participants for the study. If there are insufficient community participants who have been discharged from hospital in the previous 2 years, the recruitment timeframe will be extended. If this happens, recall bias will need to be considered as there is a reported 20% loss of recall over 12 months and 50% for more extended periods (Hassan, 2006). However, recall will be assisted because heart disease represents a significant event in people's lives, and this is known to improve people's recollection of major events (Smith et al, 2003; Heart Research Australia, 2016). Clear open-ended interview questions (Mason, 2010) (Table 2) that explore issues by asking the same question in different ways and checking for correlation will assist with validation and triangulation (Denzin and Lincoln, 2011).

Triangulation will also be assisted by collecting data from different sources (staff and community participants) as well as follow-up clarification meetings to address questions that may arise from the initial interviews. This process will provide a depth of information, as well as increasing credibility and validity of findings (Denzin and Lincoln, 2011). Prompts are included in the interview schedules because of the conversational semi-structured interview format, thereby ensuring required data is collected.

Both community participants and staff questions will be tested through pilot interviews and adjusted as required. Should adjustment be necessary, an amendment will be submitted to the approving human research ethics committee. All interviews and group discussions will be conversational and exploratory to gain a rich description of community participants and health staff's experience of cardiac rehabilitation and support services.

During the interview process, requests for further information on attending cardiac rehabilitation or the need to emotional support may arise. To address this support can be arranged a through the local health centre, GP, mental health services, and/or the telephone support home-based programmes Coaching on Achieving Cardiovascular Health (Health Support Queensland, 2018) or My Heart My Life (Heart Foundation of Australia, 2017b).

Demographic data

Before the interviews and focus groups, participants will be asked to complete a voluntary questionnaire (Appendix 2). Data collection is not mandatory, and non-completion will not preclude participation. Staff data collection will be as per Appendix 3; health staff data collection will follow the same process.

Table 2. Open-ended questions for patients and staff

Patients	Staff
When you were discharged from hospital, what information were you provided with about your health care when you got home? Prompts: Were you referred to a centre or home-based cardiac rehabilitation* programme or a community nurse or allied health professional? What follow-up medical appointments did you have? Did you receive medication on discharge form hospital? Did you and your doctor receive information about your ongoing care from the hospital (medical discharge summaries)? When did these arrive, and do you know what they advised for your ongoing care?	Can you tell me your role in providing support for people in the community and/or health care? Prompts: Do you understand what is meant by cardiac rehabilitation? Are you aware of the COACH home-based cardiac rehabilitation programme?
Can you tell me about any difficulties or what made it easy for you to get health care or cardiac rehabilitation when you went home from hospital having been treated for heart disease? Prompts: Did anybody phone or visit you to see if you needed any support?	What do you think are the most important aspects of post-discharge care for people with heart disease and how will this be able to be achieved in your area?
When you got home, who did you contact, or who contacted you about your follow-up care?	What do you think are the main factors that prevent people from attending cardiac rehabilitation or seeking post discharge health care?
Out of all the health care that you received after coming home from hospital what do you think helped you most?	Do you have any guidelines for providing care for people recently discharge from hospital after treatment for heart disease (eg insertion of stents, coronary artery bypass graft surgery or myocardial infarction)? (health staff only)
Can you tell me if anybody discussed things that you could do to improve you overall health? Prompts: Were you given any brochures?	What do you think that people need to understand about their ongoing care and health plan once they have returned home after in-hospital treatment for heart disease?
What information was most helpful?	How do you make sure these people get the information that they need, and how will this be done? (health staff only)
What things do you think could have been done that you think would have made a difference to your recovery?	Can you describe any cardiac rehabilitation services that are available locally? Prompts: What about visiting and local health professionals and related services, such as gymnasiums and support groups? Any further comments or suggestions?
Since your first hospital admission for heart disease have you had to go back for further treatment? If so can you tell me about it?	Can you tell me about the COACH or any other home-based cardiac rehabilitation programme available for people in this area? Prompts: Any comments or suggestions?
What is worrying you most about your heart problem? Do you need somebody to talk with somebody about this?	Who is responsible for organising essential post hospitalisation follow-up and care? Prompts: How do you think that this can be improved?
Any other comments that you would like to make?	What do your think could be done to improve provision of cardiac rehabilitation and follow-up?
	Any other comments that you would like to make?

Analysis

Audio interviews will be professionally transcribed verbatim and NVivo-12 software will be used to facilitate thematic analysis of participants' responses, as distinct units of meaning with headings (nodes), and subheadings developed through reflective induction (Grbich, 2013). This process will enable confirmation and clarification of the primary questions/areas of interest (Table 1), and the development of secondary themes that capture 'levels of patterned responses of meaning' (Braun and Clarke, 2006). Further, consistency will be considered with quotations from transcripts used to illustrate primary themes or areas of interest and secondary themes. The same process will be used for documented records of yarning discussions. Overall a flexible approach that includes researcher interpretation and judgement will be used (Braun and Clarke, 2006).

Community participant demographic data will be stratified by age, sex, Aboriginal and/or Torres Strait Islander peoples, general population and heart disease. Staff data will be stratified by professional classification and role, whether community based or visiting service providers and working with Aboriginal and/or Torres Strait Islander Peoples or the general population.

Reflexivity and rigour

The analysis will be undertaken by the coordinating primary investigator, reviewed by the primary investigator and discussed with the research team to ensure reflexivity, rigour, clarification and verification (Daws et al, 2014). Reflexivity includes considering the researcher's situation in the research, based on self-critique of personal experience (Patnaik, 2013).

Possible bias and preconceived ideas will be minimised by using:

- Australian Cardiovascular Health and Rehabilitation Association (ACRA) core components of cardiovascular disease secondary prevention and cardiac rehabilitation (Woodruffe et al, 2015)
- Findings of the previous integrative literature review (Field et al, 2018)
- Demographic study of heart disease, hospitalisation and referral to Coaching on Achieving Cardiovascular Health in Queensland (Field et al, 2020).

These guidelines and studies provided an objective basis for data collection and analysis. Following data collection, emergent themes will be discussed with a community reference group (face to face or via teleconference), thereby providing opportunities for member checking to ensure accuracy and clarification (Denzin and Lincoln, 2011), as well as ensuring an iterative process that will review and build ideas towards the ultimate goal of improving access to cardiac rehabilitation for rural and remote areas of North Queensland. Individual community participant interviews will not be confirmed or clarified, as a previous research study demonstrated that interviewees may have concerns or feel uncomfortable about how they sounded or what they said in their interviews, rather than inaccuracy (Mero-Jaffe, 2011). Every effort will be made to minimise bias in data collection through adherence to rigorous qualitative methods including ensuring data satuation (no new information forthcoming) is achieved, and ensure findings are reviewed by a community reference group.

Strengths and limitations

Of primary importance in this project protocol is the pre-research planning, consultation, and development of trusting relationships in rural and remote communities. Qualitative research needs to be attuned for various environments and the authors propose that this project protocol for research in rural and remote communities including Aboriginal and/or Torres Strait Islander people will provide a template that can be adapted to a range of environments.

Significance

Ultimately, this proposed research aims to identify factors (barriers and enablers), that need to be addressed in order to develop model(s) that improve access to cardiac rehabilitation and/or locally based support for people discharged from hospital with heart disease in rural and remote areas of Australia. It is proposed that information gathered in this research, in combination with the final stages of the full research project, will lead to realising the

Key points

- Referral and access to cardiac rehabilitation remain sub-optimal overall, with lower levels in rural and remote areas.
- Further research is required to develop new approaches (models) to improve access to cardiac rehabilitation in rural and remote areas.
- Developing sound community relationships requires extensive pre-research planning to ensure trust, which is necessary for effective research.
- This protocol for a qualitative community-based case study will inform and guide future research to improve health outcomes and could be applied in a range of locations.
- Improving access to cardiac rehabilitation in rural and remote areas has implications for other environments and chronic disease risk factor management.

benefits identified through access and subsequent cardiac rehabilitation attendance (De Gruyter et al, 2016; Heart Foundation of Australia, 2017c). The initial awareness raising, and improved understanding of cardiac rehabilitation, including management of risk factors for chronic disease, will be initiated through community consultation. Should participants wish to make lifestyle changes they will be linked into appropriate health care and/or support organisations.

Conclusions

To improve access to services and health outcomes in rural and remote areas, a strong evidence base is essential. To achieve this, as well as having appropriate methodology, it is necessary to build relationships and trust with local communities and health care providers This research protocol describes a qualitative community-based case study, together with processes to build sound relationships required for effective data collection through semi-structured interviews or focus groups. Each step of the pre-research planning data collection and analysis is described in detail for the guidance of future researchers.

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Conflicts of interest

There are no conflicts of interest to declare.

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Appendix 1

How can you talk to the research team?

If you would like more information you can contact:

Pat Field: 0409 778 489

email: patricia.field1@my.jcu.edu.au

or ask any staff member who will make sure that Pat gets the message.

I look forward to meeting you and having a chat!

Who are we?

We are from James Cook University trying to find out how much health care and support is available for people who have returned home after treatment in hospital for a heart problem.

We are working closely with the hospital and health centre staff who are happy to assist

Happy heart – happy life

What do we need to know?

Many people everywhere, get heart problems and sometimes need hospital care, and health services support when they go home.

We would like to hear the story of people when they come home from hospital after treatment for heart sickness.

How will we find out?

Pat Field is a JCU researcher, and would like you to tell your story about what happened to you after you got home from hospital. Pat would like to know if you knew what to do, when you got home. Things like how much walking is best, what sort of food is good, when you next see your doctor. Who told you this? How did you get on as time went by? Did you feel sad and did anybody help you with this?

Do you want to chat?

If you want to have a chat with Pat, please let one of the hospital staff members know and they will introduce Pat, who will tell you how you can help and will arrange a time to meet with you in private. Before you tell your story you will be asked to sign a form to let us know that you understand your part in the project and you are happy to tell your story.

Only the researchers will know what you have told us, unless you take part in a group discussion. If this happens all people are asked not to talk about what is said at the meeting to other people.

If you decide that you no longer want to take part you can leave at any time.

End of paper

3.7 Ethics approval

Each study undertaken in the research required ethics approval, apart from the IR. (Table 8)

Table 8: Ethics approval by study

Study focus	Human research ethics committee (HREC)	Approval number	Chapter
Stage 2: Demographic study of heart disease rates of hospitalisations, referrals to COACH, by region and Indigenous/non-Indigenous people	i) Townsville Hospital and Health Services HREC ii) James Cook University	HREC/18/QTHS/35 H7343	(4.1) Heart disease hospitalisation and COACH referral in Queensland. (Field et al 2020).
Stage 3: Hospital case studies on understanding & implementation of Phase-1-CR and impact on post-discharge care in R&R areas	i)Townsville Hospital and Health Services HREC ii) Greenslopes Research and Ethics Committee: iii) James Cook University HREC	HREC/2018/QTHS/436 0619/17 7/05/2019 H7737	(4.2) The importance of cardiac rehabilitation in rural and remote areas of Australia (Field et al 2021)
Stage 4a & 4b: Community case studies on understanding and implementation of Phase-2-CR	i)Townsville Hospital and Health Services HREC ii) James Cook University HREC	HREC/2019/QTHS/592 1 H8467	(4.3) Cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing? (Field et al 2022)

3.8 Results and publications

At least one paper has been published for each stage of the research (Figure 6), with a further paper, submitted for publication in October 2022. These papers provide details of methods for each study included in the research and are summarised as follows:

Stage 1 (Objective i): An integrative literature review provided the foundation and direction for research objectives, and subsequent stages of the research (Chapter 2).

Field P, Franklin R, Barker R, Ring I, Leggat P. Cardiac rehabilitation services for people in rural and remote areas: An integrative literature review. Rural and Remote health 2018. https://doi.org/10.22605/RRH4738.

Stage 2 (Objective ii): An epidemiological study focused on rates of hospitalisation for Aboriginal and Torres Strait Islander and non-Indigenous people, and referral to home-based CR (Coaching on Achieving Cardiovascular Health, [COACH]) in the context of geographic, socioeconomic and SDoH (Chapter 4: 4.1).

Field P, Franklin R, Barker R, Ring I, Leggat P, Canuto K. Heart disease hospitalisation and COACH referral in Queensland. Australian Journal of Rural Health 2020 .https://doi.org/10.1111/ajr.12588

Stage 3 (Objective iii): A case study series investigated the implementation of Phase-1-CR by hospital staff, and in-patients understanding of their disease, discharge plan and referrals for

Phase-2-CR, in cardiac services of two public and two private tertiary hospitals in Townsville and Cairns, and the impact on post-discharge care in R&R areas (Chapter 4: 4.2).

Field P, Franklin RC, Barker R, Ring I, Leggat P, Canuto K. Importance of cardiac rehabilitation in rural and remote areas of Australia. Australian Journal of Rural Health 2021. https://doi.org/10.1111/ajr.12818

Prior to commencing the community based case study series, a project protocol was developed to guide the pre-research planning and undertaking the research of stages 4a and 4b (Chapter 3: 3.4).

Field P, Franklin R, Barker R, Ring. I, Leggat P, Canuto K. Improving access to cardiac rehabilitation in rural and remote areas: A protocol for a community-based qualitative case study. International Journal of Therapy and Rehabilitation 2021. https://doi.org/10.12968/ijtr.2020.0167

Stage 4a (Objective iv): A case study series investigated barriers, enablers, and pathways for access to community-based Phase-2-CR in R&R areas of NQ (Chapter 4: 4.3).

Field P, Franklin RC, Barker R, Ring I, Leggat PA. Cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing? Australian Journal of Rural Health 2022. https://doi.org/https://doi.org/10.1111/ajr12861

Stage 4b informed by Stages 1–4a, (Objective v): A collaborative and iterative process that involved health education, information sharing and discussion of the findings of the previous stages, resulting in the development of a model of healthcare delivery that aims to improve access to CR in R&R areas of NQ (Chapter 5: 5.3.1).

Field P, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Improving access to cardiac rehabilitation (Heart: Road to health) for Aboriginal and Torres Strait Islander peoples in rural and remote areas of North Queensland. Australian Journal of Rural Health. https://doi.org/10.1111/ajr.12932

Field P, Franklin R, Barker R, Ring I, Canuto K. Article—Management and healthcare systems: Aa way forward for to improve access for secondary prevention in R&R areas. Submitted for publication, October 2022.

3.9 Conclusion

Overall, the methodology in the research was designed to ensure that data collection methods and analysis are relevant and rigorous, to ensure that findings provided a basis for improvements in access to CR in R&R areas of NQ. Full details of methodology, methods,

findings, and recommendations are provided in subsequent chapters, all of which include published studies.

Stage 2 Results: Heart disease, hospitalisation, and referral

Chapters	Content & publications
1. Introduction ⇨	Background, introduction & implications of the research
Stage 1 Research foundations	
2. Integrative literature review ⇨	Cardiac rehabilitation services for people in rural and remote areas: Integrative literature review (2007–2016). Published 2020 (Paper 1). Supplementary review (2018 – 2021)
3. Methodology and methods ⇨	Project protocol: Improving access to cardiac rehabilitation in rural and remote areas: A protocol for a community-based qualitative case study. International Journal of Therapy and Rehabilitation. Published 2021 (Paper 2)
Stage 2 Results: Heart disease, hospitalisation, and referral	
4. Results 4.1 Epidemiological study ⇨	Heart disease, hospitalisation, and referral: coaching to achieving cardiovascular health through cardiac rehabilitation in Queensland. Published 2020 (Paper 3)
Stage 3 Results: Hospital-based Phase-1-Cardiac Rehabilitation	
4.2 Hospital case study series ⇨	The importance of cardiac rehabilitation in rural and remote areas of Australia. Published 2021 (Paper 4)
Stage 4a Results: Community-based Phase-2-Cardiac Rehabilitation	
4.3 Community case study series ⇨	Improving access to cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing? Published 2022 (Paper 5)
Stage 4b Pathways to *Heart: Road to health*	
5. Discussion and conclusion ⇨	Discussion and conclusion
5.3.1 *Heart: Road to health* for Aboriginal and Torres Strait Islander people ⇨	Improving access to cardiac rehabilitation (Heart: Road to health) for Aboriginal and Torres Strait Islander peoples in rural and remote areas of North Queensland. Published 2022 (Paper 6)
5.3.2 Model for *Heart: Road to health* ⇨	Model for Heart: Road to health or Chronic disease: Road to health in rural and remote areas. Submitted for publication Oct 2022 (Paper 7)

Chapter 4: Results

4.1 Epidemiological study: Heart disease, hospitalisation, and referral

In line with sequential approach, and informed by Stage 1 a descriptive retrospective epidemiological study[116] was undertaken to address research objective ii:

> To describe rates of hospitalisation and Coaching on Achieving Cardiovascular Health (COACH) referral for Queensland adults with heart and related disease, and comparisons between Aboriginal and Torres Strait Islander people and non-Indigenous people in NQ.

4.1.1 Summary

This epidemiological study provided a profile of adults in Queensland with heart disease (HD) and those referred to home-based CR (COACH), according to geographic area. An age-standardised risk ratio was used to investigate variations in hospitalisation and referral to COACH for Aboriginal and Torres Strait Islander and non-Indigenous people. The study found that overall referrals to COACH were inadequate, and rates of hospitalisation were unlikely to meet the needs of Aboriginal and Torres strait Islander people in R&R areas of NQ. Full details are provided in the paper inserted as published:

Field P, Franklin R, Barker R, Ring I, Leggat P, Canuto K. Heart disease hospitalisation and COACH referral in Queensland. Australian Journal of Rural Health [Internet]. 2020. https://doi.org/10.1111/ajr.12588

4.1.2 (Paper 3) Heart disease, hospitalisation and referral: Coaching to Achieving Cardiovascular Health through cardiac rehabilitation in Queensland

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DOI: 10.1111/ajr.12588

ORIGINAL RESEARCH

WILEY

Heart disease, hospitalisation and referral: Coaching to Achieving Cardiovascular Health through cardiac rehabilitation in Queensland

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Abstract

Objectives: To describe rates of hospitalisation and Coaching on Achieving Cardiovascular Health referral, for Queensland's adults with heart and related disease, and comparisons between Aboriginal and Torres Strait Islander and non-Indigenous peoples in northern Queensland.

Design: Descriptive retrospective epidemiological study of Queensland Health Patient Admission Data Collection for adults with heart and related disease, and Coaching on Achieving Cardiovascular Health referral data. Relative risk and age standardisation were calculated for Aboriginal and Torres Strait Islander and non-Indigenous peoples.

Participants: Queensland's adults ≥20 years, hospitalised with heart and related disease (1 January 2012-31 December 2016).

Setting: Queensland, Australia.

Main outcome measures: Queensland Health Hospital and Health Services' hospitalisation and Coaching on Achieving Cardiovascular Health referral rates for heart and related disease.

Results: Queensland's Aboriginal and Torres Strait Islander peoples have a higher hospitalisation rate for heart and related disease, with higher rates for northern Queensland. Queensland's overall Coaching on Achieving Cardiovascular Health referral rates were low, but higher for Aboriginal and Torres Strait Islander peoples. Deficiencies in documentation of Aboriginal and Torres Strait Islander people's status affected results in some areas.

Conclusion: Queensland's Aboriginal and Torres Strait Islander peoples were more likely to be admitted to hospital for heart and related disease and referred to Coaching on Achieving Cardiovascular Health than non-Indigenous peoples. However, hospitalisation and Coaching on Achieving Cardiovascular Health referral rates are unlikely to reflect the needs of Aboriginal and Torres Strait Islander peoples especially in rural and very remote areas given their higher mortality and morbidity rates and fewer services.

KEYWORDS

Aboriginal and Torres Strait Islander, cardiac rehabilitation, heart disease, Indigenous, referral, remote

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4.1.3 Conclusion

As described in this study, there are very few centre-based CR services in NQ, and inadequate referrals to the QH home-based telephone program, COACH. However, it is not clear whether Aboriginal and Torres Strait Islander people access services at a rate that reflects their higher

rates of HD, and if not, why not? In line with the sequential approach, the findings of this study are further considered in the hospital-based case study series, which investigated the implementation of Phase-1-CR in hospitals in NQ, and how well people with HD are prepared for discharge, including referral to Phase-2-CR, (Chapter 4: 4.2).

Stage 3 Results: Hospital-based Phase-1-Cardiac Rehabilitation

Chapters		Content & publications
1. Introduction	⇨	Background, introduction & implications of the research
Stage 1 Research foundations		
2. Integrative literature review	⇨	Cardiac rehabilitation services for people in rural and remote areas: Integrative literature review (2007–2016). Published 2020 (Paper 1). Supplementary review (2018 – 2021)
3. Methodology and methods	⇨	Project protocol: Improving access to cardiac rehabilitation in rural and remote areas: A protocol for a community-based qualitative case study. International Journal of Therapy and Rehabilitation. Published 2021 (Paper 2)
Stage 2 Results: Cardiac disease, hospitalisation, and referral		
4. Results 4.1 Epidemiological study	⇨	Heart disease, hospitalisation, and referral: coaching to achieving cardiovascular health through cardiac rehabilitation in Queensland. Published 2020 (Paper 3)
Stage 3 Results: Hospital-based Phase-1-Cardiac Rehabilitation		
4.2 Hospital case study series	⇨	The importance of cardiac rehabilitation in rural and remote areas of Australia. Published 2021 (Paper 4)
Stage 4a Results: Community-based Phase-2-Cardiac Rehabilitation		
4.3 Community case study series	⇨	Improving access to cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing? Published 2022 (Paper 5)
Stage 4b Pathways to *Heart: Road to health*		
5. Discussion and conclusion	⇨	Discussion and conclusion
5.3.1 *Heart: Road to health* for Aboriginal and Torres Strait Islander people	⇨	Improving access to cardiac rehabilitation (Heart: Road to health) for Aboriginal and Torres Strait Islander peoples in rural and remote areas of North Queensland. Published 2022 (Paper 6)
5.3.2 Model for *Heart: Road to health*	⇨	Model for Heart: Road to health or Chronic disease: Road to health in rural and remote areas. Submitted for publication Oct 2022 (Paper 7)

4.2 Hospital case study series: Hospital in-patient cardiac rehabilitation

This qualitative case study series, augmented by a medical record audit, that builds on the findings of the previous stages of the research, to address objective iii:

> To investigate the implementation of Phase-1-CR by staff and in-patients in cardiac services in two public and two private tertiary hospitals in Townsville and Cairns and the impact on post-discharge care in rural and remote areas of NQ.

4.2.1 Summary

Main findings were poor understanding of Phase-1-CR and Phase-2-CR by in-patients and staff, low rates of referrals to Phase-2-CR, with medical discharge summaries rarely mentioning CR, secondary prevention or risk factor management. This inadequate implementation of Phase-1-CR, including discharge planning resulted in the majority of people with heart disease (HD) being discharged from hospital without referral to any form of secondary prevention.

Full details of this study, are provided in the paper, inserted as published:

Field P, Franklin RC, Barker R, Ring I, Leggat P, Canuto K. Importance of cardiac rehabilitation in rural and remote areas of Australia. Aust J Rural Health. 2021. Available from: https://doi.org/10.1111/ajr.12818

4.2.2 (Paper 4) Importance of cardiac rehabilitation in rural and remote areas of Australia

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ORIGINAL RESEARCH

AJRH National Rural Health Alliance WILEY

Importance of cardiac rehabilitation in rural and remote areas of Australia

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Funding information
This work was supported by Far North Queensland Hospital Foundation Research Grant: JCU-QLD-837551—2019

Abstract

Objective: To assess implementation of in-patient cardiac rehabilitation (Phase-1-cardiac rehabilitation), impact on people in rural and remote areas of Australia and potential methods for addressing identified weaknesses.

Design: Exploratory case study methodology using qualitative and quantitative methods. Qualitative data collection via semi-structured interviews, using thematic analysis, augmented by quantitative data collection via a medical record audit.

Setting: Four regional hospitals (2 Queensland Health and 2 private) providing tertiary health care.

Participants: (a) Hospital in-patients with heart disease ≥18 years. (b) Staff responsible for their care.

Outcome Measures: Implementation of Phase-1-cardiac rehabilitation in tertiary hosptials in North Queensland and the impact on in-patients discharge planning and post discharge care. Recommentations and implications for practice are proposed to address deficits.

Results: Phase-1-cardiac rehabilitation implementation rates, in-patient understanding and multidisciplinary team involvement were low. The highest rates of Phase-1-cardiac rehabilitation were for in-patients with a length of stay three days or more in cardiac units with cardiac educators. Rates were lower in cardiac units with no cardiac educators, and lowest for in-patients in all areas of all hospitals with length of stay of two days or less days. Low Phase-1-cardiac rehabilitation implementation rates resulted in poor in-patient understanding about their disease, treatment and post-discharge care. Further, medical discharge summaries rarely mentioned cardiac rehabilitation/secondary prevention or risk factor management resulting in a lack of information for health care providers on cardiac rehabilitation and holistic health care.

Conclusion: Implementation of Phase-1-cardiac rehabilitation in regional hospitals in this study fell short of recommended best practice, resulting in patients' poor preparation for discharge, and insufficient information on holistic care for health care providers in rural and remote areas. These factors potentially impact on holistic care for people returning home following treatment for heart disease.

KEYWORDS
cardiac rehabilitation, health systems, rural and remote, secondary prevention

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4.2.3 Conclusion

The findings of this hospital-based case study series clearly indicated that Phase-1-CR was often inadequate. This resulted in many people being discharged from hospital with little understanding of their post-discharge care including CR available in their local community. An underlying factor that influenced the poor implementation of Phase-1-CR was that it was not possible for cardiac educators to see all people with HD in all areas of the hospital. Also, the majority of nurses who provided direct in-patient care demonstrated poor knowledge of Phase-1-CR or Phase-2-CR. This resulted in little, or no Phase-1-CR being provided in the absence of cardiac educators. This was a significant deficit for the provision of Phase-1-CR in public hospitals, particularly after-hours and on public holidays. This deficit was greater in private hospitals that did not employ cardiac educators.

To facilitate addressing these deficits, an individual report with recommendations was sent to each participating hospital, (Recommendations Chapter 5: 5.4.1). The coordinating primary investigator also met with hospital staff who participated in the study, to provide feedback and discuss the findings. To date, no further feedback has been received.

In line with the sequential approach this case study series, together with findings of Chapters 2, 3 & 4 (4.1), informs Stages 4a and 4b.

Stage 4a Results: Community-based Phase-2-Cardiac Rehabilitation

Chapters		Content & publications
1. Introduction	⇨	Background, introduction & implications of the research
Stage 1 Research foundations		
2. Integrative literature review	⇨	Cardiac rehabilitation services for people in rural and remote areas: Integrative literature review (2007–2016). Published 2020 (Paper 1). Supplementary review (2018 – 2021)
3. Methodology and methods	⇨	Project protocol: Improving access to cardiac rehabilitation in rural and remote areas: A protocol for a community-based qualitative case study. International Journal of Therapy and Rehabilitation. Published 2021 (Paper 2)
Stage 2 Results: Heart disease, hospitalisation, and referral		
4. Results 4.1 Epidemiological study	⇨	Heart disease, hospitalisation, and referral: coaching to achieving cardiovascular health through cardiac rehabilitation in Queensland. Published 2020 (Paper 3)
Stage 3 Results: Hospital-based Phase-1-Cardiac Rehabilitation		
4.2 Hospital case study series	⇨	The importance of cardiac rehabilitation in rural and remote areas of Australia. Published 2021 (Paper 4)
Stage 4a Results: Community-based Phase-2-Cardiac Rehabilitation		
4.3 Community case study series	⇨	Improving access to cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing? Published 2022 (Paper 5)
Stage 4b Pathways to *Heart: Road to health*		
5. Discussion and conclusion	⇨	Discussion and conclusion
5.3.1 *Heart: Road to health* for Aboriginal and Torres Strait Islander people	⇨	Improving access to cardiac rehabilitation (Heart: Road to health) for Aboriginal and Torres Strait Islander peoples in rural and remote areas of North Queensland. Published 2022 (Paper 6)
5.3.2 Model for *Heart: Road to health*	⇨	Model for Heart: Road to health or Chronic disease: Road to health in rural and remote areas. Submitted for publication Oct 2022 (Paper 7)

4.3 Community case study series

Community case studies continued to build on the information from previous stages of the research and undertake further investigation to address objective iv:

> To investigate barriers, enablers and pathways for improved access to Phase-2-CR in selected R&R areas of NQ.

4.3.1 Summary

This study identified a wide range of community-based, visiting, telephone or telehealth services available in R&R areas, but understanding of CR by staff and people with HD (clients) was often poor. Staff were predominantly focused on clinical care, and clients were seldom referred to alternative models of secondary prevention, such as Self-Management of Chronic Conditions, or allied health professionals (AHP), for community-based secondary prevention. Medical discharge summaries (MDS) were often late, rarely provided information on secondary prevention, including risk factor management.[117] QH employees could access MDS but AHP employed by contracting organisations did not have access. This was a major barrier to co-ordinated collaborative healthcare provision. Commonly staff were not aware that a client had returned to the community until the client presented to the health centre for post-discharge care.

Full details of this study are provided in the paper inserted as published:

Field P, Franklin R, Barker R, Ring I, Leggat P. Improving access to cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing? Australian Journal of Rural Health. 2022. https://doi-10.1111/ajr.12861

4.3.2 (Paper 5) Improving access to cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing?

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ORIGINAL RESEARCH

AJRH National Rural Health Alliance WILEY

Cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing?

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Abstract

Objective: To address access to cardiac rehabilitation (CR) for people in R&R areas, this research aimed to investigate: (1) post discharge systems and support for people returning home from hospital following treatment for heart disease (HD). (2) propose changes to improve access to CR in R&R areas of NQ.

Setting: Four focus communities in R&R areas of NQ.

Participants: Focus communities' health staff (resident/visiting) (57), community leaders (10) and community residents (44), discharged from hospital in past 5 years following treatment for heart disease (purposeful sampling).

Design: A qualitative descriptive case study, with data collection via semi-structured interviews. Inductive/deductive thematic analysis was used to identify primary and secondary themes. Health service audit of selected communities.

Results: Health services in the focus communities included multipurpose health services, and primary health care centres staffed by resident and visiting staff that included nurses, Aboriginal and Torres Strait Islander Health Workers, medical officers, and allied health professionals. Post-discharge health care for people with HD was predominantly clinical. Barriers to CR included low referrals to community-based health professions by discharging hospitals; poorly defined referral pathways; lack of guidelines; inadequate understanding of holistic, multidisciplinary CR by health staff, community participants and leaders; limited centre-based CR services; lack of awareness, or acceptance of telephone support services.

Conclusion: To address barriers identified for CR in R&R areas, health care systems' revision, including development of referral pathways to local health professionals, CR guidelines and in-service education, is required to developing a model of care that focuses on self-management and education: Heart: Road to Health.

KEYWORDS

Aboriginal and Torres Strait Islanders people, cardiac rehabilitation, holistic, multidisciplinary, remote, rural, secondary prevention

1 | INTRODUCTION

Cardiac rehabilitation (CR) is evidence based best practice for people with heart disease (HD),[1-3] which continues to be the largest single cause of death in Australia and contributes to significant illness, disability, poor quality of life and higher health care costs.[4] CR is important in improving health and quality of life for people with HD, especially for people in rural and remote (R&R) areas, where rates of HD were higher than the national average, and highest for Aboriginal and Torres Strait Islander peoples.[5] Despite high rates of HD, and demonstrated benefits of CR, referrals in Australia were only 45%,[6] with less attending (10%–30%), and R&R populations underrepresented.[7] Aboriginal and Torres Strait Islander peoples were least likely to attend, which may be due, in part, to cultural inappropriateness of many programs.[8]

Cardiac rehabilitation is defined by The World Health Organisation as a range of co-ordinated activities to address risk factors for cardiovascular disease, including physical, mental and social conditions, that enable patients to achieve optimal functioning.[9] Three phases of CR are recommended for people with a broad range of stable HD including acute coronary syndrome, stents, stable heart failure, cardiomyopathy, valvular surgery, implantable devices, heart transplant, risk factors, arrhythmias and stable heart failure.[1,2] CR is a component of secondary prevention (SP) that includes medical care, risk factors management, psychosocial care, education and support for self-management, delivered in a variety of settings, through a holistic (health and lifestyle), multidisciplinary team approach.[10] Phase-1-CR provides in hospital education on disease, risk factors, discharge planning and referral to out-patient, centre-based or home-based CR (Phase-2-CR). Phase-2-CR provides continuing education, risk factor management, psychosocial support and medical care. Phase-3-CR involves community-based ongoing health care and risk factor maintenance, which includes linkages to community programs.[1,2]

Health services in Australia are provided through network or government and private health care organisations and health professionals, who deliver a wide range of services throughout Australia.[11] It is well documented that services in R&R areas are sparse and difficult to access, in part due to low populations living in vast geographic areas.[12] Further disadvantages in R&R areas is noted due to poor social determinants of health,[13] including limited health, education, recreational and social services; fewer healthy food choices, higher living costs, greater distances to major centres and unreliable internet.[5] A major barrier to CR is distance to centre-based CR in R&R areas of NQ, with Mt Isa providing the only centre-based service west of Townsville (904 km), Mossman, the furthest service north of Cairns (76 km) (Figure 1), resulting in no centre-based services in Cape York and Torres Strait.[14]

What is known about the subject:

- There is a scarcity of health care services, including cardiac rehabilitation (CR), in rural and remote (R&R) areas of Australia
- There is inadequate discharge planning and referrals to CR for people treated in tertiary hospitals in North Queensland for heart disease
- There are few centre-based outpatients Phase-2-CR services in R&R areas, and few referrals to home-based telephone support service services
- Barriers to CR in R&R areas include, geographic distance from centre-based services, a perception that CR is not necessary, programs only available in working hours, lack of culturally appropriate services and flexibility to reach out to people at home
- A perception that CR is provided through centre-based services

What the paper adds:

- Overview of available health services in R&R areas of NQ
- Improved understanding of barriers to CR in R&R areas of NQ, including poor understanding of CR, no referrals to locally based health care providers in absence of centre based CR and lack of a holistic multidisciplinary team approach
- Suggests a way forward to locally based services through a model of education and self-management: Heart: Road to Health

Queensland Health (QH) home-based telephone CR program, Coaching patients on Achieving Cardiovascular Health (COACH) is available throughout Queensland to cover this shortfall, as well as offering an alternative program for people who prefer a home-based service.[15] However, COACH referral rates in NQ are low (range 4%–20%),[16] with fewer people participating (64%).[17] The Heart Foundation (HF) of Australia also offers a home-based telephone support program, My Heart, My Life (MHML), that focusses on SP for people with acute coronary syndrome.[18] As well as MHML, the HF offers a smartphone App that includes generic information on HD, SP and risk factor management.[19] COACH, MHML and HF Apps are available at no charge to the consumer. Both programs have been evaluated and demonstrated to be beneficial.[18,20] MHML continues to be rolled out, but due to low

FIGURE 1 Map of research focus areas in North Queensland

numbers, a full assessment is not available. Cardihab® is a commercial CR smartphone App that has been demonstrated to be effective,[21] but no information is published on access by people in R&R areas.

To address the issues around access to CR for people in R&R areas, this research aimed to investigate:

1. post-discharge systems and support for people returning home from hospital following treatment for HD,
2. propose changes to improve access to CR in R&R areas of NQ.

2 | METHODS

Descriptive case study methodology[22] was used, with a qualitative interpretive framework.[23] This approach was suitable for multiple sites[24] and allowed for the description of 'an intervention or phenomenon in a real-life context' (the case), in order to 'develop theory, evaluate programs and develop interventions.'[22] The initial direction and framework of the study were guided by the findings of (i) an integrative literature review on barriers, enablers and pathways to CR in R&R areas[25]; (ii) a demographic study of hospitalisations for HD and referrals to COACH in NQ[26] and (iii) a case study on implementation of Phase-1-CR in tertiary hospitals in NQ and impact in R&R areas.[27] Drawing on this research, deductive analysis was used to identify primary themes/areas of interest, together with the development of semi-structured interview guidelines (Appendix S2 and S3) for data collection via purposeful information rich samples.[28]

Participants were defined by:

2.1 | Inclusion criteria

- *Community participants*: Adults ≥18 years: males and females, discharged from hospital following treatment for HD in the past five years, who lived independently, and were eligible for CR, according to HF and Australian Cardiovascular Health and Rehabilitation Association (ACRA) recommendations.[1,2]
- *Community leaders*: Long-term residents of the community who held leadership positions or were recognised by the local community as leaders.

- *Health staff*: Local and visiting health professionals potentially involved in Phase-2-CR, and their managers.

2.2 | Exclusion criteria

People with a medical diagnosis of mental impairment, or who despite assistance of a support person/interpreter, were unable to comprehend the process and thereby did not fulfil the requirements of informed consent as per NHMRC guidelines.[29]

Major steps of thematic analysis as identified by Braun and Clarke[30] (Figure 2) were used to guide the inductive data analysis and identification of secondary themes. The initial analysis and review of the secondary themes was undertaken by the coordinating primary investigator (CPI) and checked by the primary investigator (PI) against interview text and field notes to ensure that the themes were reasonable, logical and obvious.[31] Finally, the results were reviewed by the research advisory team.

All processes were conducted according to consolidative criteria for reporting qualitative research (Hyperlink; COREQ)[32] https://cloudstor.aarnet.edu.au/plus/s/vPzk3RuIpwv3yQJ

To investigate factors that impacted on access to CR in R&R areas, the environment and context (settings), in which people lived, and availability of health services were explored. This was achieved thorough meetings with a local, regional and state health professionals/managers, bureaucrats, community leaders and members of community organisations. This process continued throughout the study and included accessing reports and websites from each organisation providing services in the focus areas, thereby, ensuring accuracy of information gathered (member checking).[28]

2.3 | Settings

The four focus communities were Hughenden, Cooktown, Wujal Wujal and Hope Vale, located in R&R areas of NQ Australia (Figure 1). These communities were selected as they provided differing demographic profiles (Table1) and employment opportunities including farming, tourism, small industry, mining, commercial and government services, and they were geographically accessible but remote (at least four hours from a major centre), with higher proportion of Aboriginal and Torres Strait Islander peoples compared to Queensland overall. To confirm participation by the community and local health services, pre-research planning visits were carried out, during which commitment to be involve was established.

All focus communities had higher proportions of Aboriginal and Torres Strait Islander peoples, lower rates of year twelve education, more low income households (<$650/week) and were less likely to have internet access at home, compared with Queensland overall.[13] Rates of hospitalisation for HD in Cooktown, Wujal Wujal and Hope Vale were also higher, except Hughenden that had lower rates (Table 1), with no explanation identified.

2.4 | Data collection and recruitment

Recruitment of community participants, health staff and community leaders, and data collection, were undertaken over 6 weeks in Hughenden and Cooktown, and 2 weeks in smaller communities of Hope Vale and Wujal Wujal, in line with advice of the Department of Prime Minister and Cabinet, best practice for community consultations.[33] Community participants were recruited through health staff or community groups, with whom the CPI discussed the project and provided simple English language brochures that described the project, and provided research team contact details (Appendix S1). Potential participants either contacted the CPI or consented for the CPI to contact them. The recruitment of health staff was via routine staff meetings, with community leaders identified through local councils and community groups. Prior to interviews, the CPI provided each community or health staff participant, comprehensive verbal and written information about the project purpose, confidentiality and withdrawal at any time. Participant information sheets: Staff; community participants and leaders) https://cloudstor.aarnet.edu.au/plus/s/9k7wDYQuINtYCYr

One locum GP and one community participant, declined to be interviewed because they perceived that the research was not relevant for them. Two pilot interviews were conducted for each category, with no changes made, and these interviews were included as data in the study.

In line with NHMRC ethical research guidelines for Aboriginal and Torres Strait Islander peoples, an Aboriginal

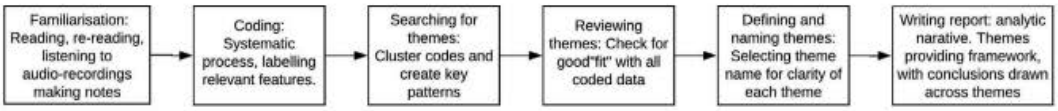

FIGURE 2 Summary: six steps of thematic analysis[30]

were not checked with participants, due to a previous research study that demonstrated interviewees may have concerns about how they sounded or what they said in their interviews due to feeling uncomfortable, rather than inaccuracy.[37] At times, member checking and clarification was also required on matters identified during interviews (e.g., referral systems and electronic medical records). Queries were discussed with staff, community leaders and regional managers of Torres Cape Hospital and Health Service (TCHHS), Townsville Hospital and Health Service (THHS), QH Central Office, Brisbane, Apunipima and Royal Flying Doctor Service (RFDS). Responses were recorded in field notes and coded as clarification notes (CN).

2.7 | Analysis

Data from each focus community was analysed separately with findings interpreted against the research objectives and integrated to form one case.[38] Audio interviews were professionally transcribed verbatim. All transcriptions and field notes were analysed thematically, through a process that identified headings (nodes), and subheadings, through reflective induction.[30] To ensure confidentiality, coding was used for community participants (CP), community leaders (CL) and health staff (S), with numbers used for focus communities (1–4). This inductive analysis took a flexible approach in which researcher interpretation and judgement was used to identify 'underlying ideas, assumptions, conceptualisations and ideologies.'[30] This process was facilitated by NVivo-12,[39] and enabled confirmation and clarification of the primary themes/areas of interest and development of secondary themes that capture 'levels of patterned responses of meaning.[30]

Triangulation[28] occurred by collecting data from three different participant groups (CP,CL and S) in four separate communities. This data was augmented by web pages, emails, and field notes taken at follow-up and clarification meetings. This process was systematic, rigorous, and resulted in data that was illustrative of the objectives of the case under study.[40]

The following section presents findings from the integrated case to identify factors that impacted on access to CR in R&R areas of NQ.

3 | RESULTS

In line with case study methodology, the results of the analysis are presented as a summary of synthesised data in order to 'build towards a more integrated understanding of events, processes and interactions'[22] as follows:

1. Overview of health services in focus communities.
2. Factors which impacted on access to CR (post-discharge care).
3. The way forward.

3.1 | Overview of health services in focus communities

Hughenden, and Cooktown Multi-Purpose Health Services (MPHS), together with Hope Vale and Wujal Wujal Primary Health Care Centres (PHCC), provided health services for people in their local community and surrounding areas. Both of them provided accident and emergency, in-patient acute, chronic disease, and long-term aged, outpatient mental health, allied health and community health services and health care support for Aboriginal and Torres Strait Islander peoples.

Onsite health care at Hughenden MPHS is predominantly provided by nurses, supported by visiting AHP, GP and an Aboriginal or Torres Strait Islander Liaison Officer. AHP provides services predominantly through contracts with NQ Primary Health Network (NQPHN) and QH. The local GP is also the MPHS medical director and provides on-call emergency care.[S1/1] The majority of specialist medical, and occasionally AHP consultations, are provided by telehealth.[THHSCN7/1] The Heart of Australia truck visits Hughenden four-to-six weekly for one-to-three days and provides cardiac diagnostic and monitoring services on referral from a medical officer. Bulk billing is available for people with a health care card.[S14/1]

Onsite health professionals in Cooktown include a medical director, staff doctors (number depending on availability due to recruitment difficulties), a number of ATSIHW, AHP and nurses. Cooktown MPHS is a hub that provides outreach services in the southern Torres and Cape region, extending to the Lockhart River and Weipa (Figure 1). Wujal Wujal and Hope Vale are provided visiting services by Cooktown. Medical care for HD is provided by cardiologists who visit Cooktown approximately five times a year, and a general physician who provides specialist medical care for people with chronic diseases in Cooktown, Wujal Wujal and Hopevale through four-six weekly visits.[S6/3] People also travel to Cooktown or Cairns for consultations or attended by telehealth in their local PHCC.[TCCN 23/2]

Wujal Wujal and Hope Vale PHCC, provide primary clinical, men's, women's, children's health, chronic disease management and emergency services. Staff included community-based nurses and ATSIHW, supported by administrative and operational service officers. Medical officers and AHP from Cooktown provide visiting services one-to-three days a week. Primary health care, alcohol,

tobacco, other drugs interventions and social wellbeing services were provided onsite by resident staff, or by one-to-two weekly visits by Apunipima Cape York Community Controlled Health Service (Apunipima). Royal Flying Doctor Service provided similar visiting services, often in areas not serviced by QH or Apunipima. [S9/4, S11/3, TCCN3/2]

PHCC are open Monday to Friday (apart from public holidays), business hours, with nurses and ATSIHW providing on call after hours emergency care, that included triage, stabilisation and if necessary transport to Cooktown by ambulance.[CL1/2]

Overall health service provision in R&R areas is predominantly funded by a mix of Australian Government (federal) and QH (state) funding arrangements:

- Federal: GP, Medicare, NQPHN, Apunipima, RFDS,
- State: MPHS, PHCC, Apunipima, RFDS, Heart of Australia (commercial organisation subsidised by QH [S14/1]).[11]

All services provided by MPHS, PHCC, RFDS, Apunipima, QH and NQPHN contractors had no direct cost for consumers. Both Hughenden and Cooktown GP services bulk billed people with a health care card, and Aboriginal and Torres Strait Islander people through the Federal Government 'Closing the Gap' scheme.[CN1/1, S14/4]

3.2 | Factors that impact on access to CR (Primary and secondary themes)

Factors that impact on access to CR are presented according to primary and secondary themes, (Table 3) with verbatim responses of community participants, community leaders and health staff, to illustrate CR access, understanding, post-discharge referrals, and if holistic health care for people with HD was provided and finally, a way forward.

3.2.1 | Theme 1: Post-discharge plan understanding, referrals and support

Overall, this study found that community participants and health care staff demonstrated poor understanding of post-discharge care. Discharge plans from the treating hospital were often delayed, and staff lacked the knowledge to provide holistic care. Subsequently, post-discharge care provided was predominantly clinical:

> ...our information and focus is clinical. We get the people in clinically and it might not trigger in the nurse when we're taking the blood pressure or talking about the medications in heading further down the track and sending a referral onto physios or dietitians and any of those type of things...and I do think a lot of that probably gets missed[S2/2]; and...clinic provides Webster pack medication, does medical check, people advised to go home and rest[CP4/2]; ...my GP generally only prescribed medication[CP 6/4].

Community participants were not referred to AHP for risk factor management for HD:

> ...[if] patients with heart disease are referred to physiotherapist, mostly it's back pain foot pain

TABLE 3 Primary themes/areas of interest and secondary themes (community participants, community leaders and health staff)

Primary themes/area of interest (community participants, community leaders and staff)	Secondary themes
Post-discharge understanding, referrals, and support for cardiac rehabilitation in rural and remote areas of North Queensland	• Access to services and systems of health care. • Allied/ancillary health role and holistic care. • Communication, co-ordination and referrals. • Home-based and alternative care. • The way forward.
CR understanding and access in rural and remote areas of North Queensland	• Access to health services, CR/secondary prevention (SP) and systems of health care. • Allied/ancillary health role and holistic care. • Communication, co-ordination and referrals. • Home-based and alternative CR. • The way forward.
The way forward to improving access to CR in rural and remote areas of North Queensland	• What can be done to improve access to CR in R&R areas of NQ?

> and knee pain[S1/2]; and ...so in the time that I've been here in this position [AHP], which is 10 months, I haven't had any referrals for cardiac patients;[S23/1]; ...you were speaking about cardiac rehab and it's tricky,... we're [AHP] not getting the referrals. It doesn't mean they're not out there. Obviously, the stats say that they[people with HD] are but we're literally just not getting them.[S23/1]

Staff lacked information and guidance from the discharging hospital about ongoing care:

> ... a lot of the time the patient comes home from a cardiac intervention and the discharge summary is not completed,[S2/2]

> ...so, I think there's a lack of knowledge and from our perspective of knowing what is expected when a patient has a stent or has open by-pass surgery or things like that. So what is expected in that rehabilitation phase? [S2/2]

3.2.2 | Theme 2: CR understanding and access

There were no centre-based Phase-2-CR programs in the focus communities, and community participants were generally referred to the GP who provided clinical care:

> When I left hospital, all I basically knew was, that I had another visit in, I think was three months. And that was it. There was no follow up out here whatsoever. No physio. Nothing. So, I was groping in the dark. And, it was really quite scary for me, mentally. I ended up asking the doctor for some tablets...Antidepressants. [partner added] ... and he's still doing it. He goes every two weeks [to GP] for bloods, nothing else suggested. No referrals. [CP13/1]

CR was available via COACH or MHML, but only one community participant was referred to COACH:

> ...the only thing I had was a phone call from COACH, they call themselves, and the girl, she was very nice. Yeah, we probably spoke for an hour on the phone. Other than that, I had to make an appointment to see the local GP here, who did blood tests, and that was about it.[CP10/1] [no further follow-up from COACH after 3 months]

COACH was rarely mentioned by health staff, community participants or leaders, and when prompted, doubt was expressed about its suitability for people in R&R areas especially for Aboriginal and Torres Strait Islander peoples:

> ...COACH I think out here, especially with Indigenous people, face-to-face is better. And the more that I see of one person, the ease of access or talking to them and building that sort of rapport with them[improves].[S6/1]

> ... face-to-face is always better in Indigenous health and people do pretty good with Telehealth these days[S1/2], and...it doesn't work for lots of people in remote areas, with poor mobile phone coverage, no reception, don't want to talk to a stranger on a phone. So, some of the Indigenous communities, this wouldn't work at all. But they need a person there to talk to. S9/4

AHP and nurses who had previous experience in CR demonstrated sound understanding, and potential for participation in CR. One nurse with previous experience in CR explained:

> So physiotherapy would be the main one, but you'd also look at the factors that put them into that situation in the first place. So if they were a big drinker, a big smoker, a big drug user, you'd start to get some counselling around that. There's also a bit of a syndrome, I believe, after people have had major heart surgery where they have a depression afterwards. Very high risk for depression. So, I'd be looking at a mental health report, if the patient wanted it, of course, and also review. [S4/2]

AHP also demonstrated a holistic approach:

> Health promotion is a real passion of mine as well, but we don't really do anything with heart disease[S11/4]...but our plan, myself and [another AHP], is to actually do a separate cardiac rehab exercise group at the club[S4/4].

3.2.3 | Theme 3—The way forward

Suggestions by community participants, community leaders and health staff on improving access to CR in R&R areas, included improved co-ordination of services,

utilisation of telehealth, appropriate referrals, guidelines and information from the discharging hospital to local staff, and linking people with local groups and programs:

Discharge plans and notification of discharge: *There's no automatic system to tell us [that someone has returned to the community post-discharge] except for a letter showing up in the mail many, many weeks later.*[S2/2]

> It's finding them pathways for that. [referral from the discharging hospital, linking people into services post-discharge] and then if they've consented for [a community nurse or local health service provider] to contact them, I ring them and say, I've just got your discharge paper consent form. Would you like an appointment? How are you going?[S3/1]

> Or even if they just—a bit like when you come home after a baby. ...They used to come and visit you maybe once or twice. Then from then on you just used to go to the clinic. [CP5/1]

Reaching out and providing holistic care supported by guidelines to ensure that staff have the knowledge to provide holistic post discharge care was proposed:

> Yeah, just someone, or a program,...You need someone there to still monitor them, and know the steps, [guidelines for post discharge care and CR], and something that people can go to. Because it helps people get out of the house,[CP3/1] and to support locally provided holistic care a...framework [or]guidelines for standard care—e.g., what everyone with heart disease needs: Physical activity; dietary advice; psychosocial support—needs to be provided in conjunction with Apunipima who focus on a wellness model.[S2/2]

Staff and community leaders advocated for better coordination of services and use of telehealth:

> If we can get all the service providers to link into the community and provide some outcomes as a joint community session, then we'd probably come up with better things... to link people into different, groups and programs;[CL2/4] and...We thought that if we could have the service providers working together and linking in to each other, it would probably provide overall a much better service, and there would be transitions from one to the other.[CL2/4]

> Telehealth could help with group discussions to discuss risk factors, diet, walking and smoking. This would be better than COACH because people prefer visual, 'seeing is better.'[S3/3]

> ...I think moving forward, when we were designing our model of care, I really think that COVID has changed how we do care with technology, and I think that will be a big part of care moving forward...Videoconferencing technology isn't for everyone, but we've had some really good responses. It just depends on how good the technology is.[S9/4]

The insights of community participants, staff and community leaders on understanding and access to CR rehabilitation, provided direction for improving access to CR in R&R areas of NQ.

4 | DISCUSSION

Effective healthcare systems are required to ensure that people in R&R areas have access to CR. Health staff, community leaders and community participants with HD identified the need for more information about CR, improvements in referral services and local holistic, multidisciplinary care. AHP and health staff who had previously been involved in CR programs demonstrated a sound understanding of CR.[S4/4, S3/4, S6/4, S16/1, S19/1, S23/1] Otherwise, community participants, leaders and health staff had low understanding, and discharge plans failed to provide adequate guidance.[S4/2, 3/1, 2/2] Despite AHP understanding and willingness to provide CR, their opportunity to deliver these services was limited, due to a lack of referrals for people with HD, together with an absence of pathways or guidelines.[S4/4, S3/4, S19/1] AHP reduced ability to be utilised to their full potential, which is also reflected previous research that described AHP's diminished role in holistic health care, and SP.[41,42] Further, post-discharge care for people with HD was found to be predominantly clinical,[2/2] with medical discharge summaries often delayed and rarely mentioning CR or risk factor management,[S2/2] confirming findings of a previous Phase-1-CR implementation study.[27]

Access to CR was impeded due to limited availability of centre-based CR services in R&R areas of NQ,[14] combined with a perception that centre-based facilities were

necessary for provision of CR[CL1/1]. This was compounded by home-based telephone support programs, such as COACH and MHML being seldom used. A range of factors impacted on utilisation of these programs, including low referrals,[16] unreliable internet and mobile phone services, and Aboriginal and Torres Strait Islander peoples' preference for face to face communication. [CN1/2&2/2]

Health systems' weaknesses further impacted on Phase-2-CR attendance, including inadequate implementation of Phase-1-CR, in tertiary hospitals in NQ.[27] This shortfall resulted in patients' poor understanding of their disease, post-discharge care and low referrals to Phase-2-CR.[27] QH Chronic Disease Manual recommends referral to CR or local health services to ensure continuity of care for all people with stable HD,[43] but no evidence of implementation of this recommendation, including guidelines or pathways, were found.[QHCN4/1]

To improve access to CR in R&R areas, a multifaceted systems approach that includes pathways and guidelines is required. Such an approach needs to commence prior to discharge from hospital and link patients to local health care providers to ensure CR is provided in their local community. There are examples of effective community based programs that provide holistic patient-centred care. These include the diabetes model of education and self-management,[44] and community-based post-natal care,[CP5/1,S3/1] in which referrals, patient consent for follow-up, and guidance for post discharge holistic care are sent by the discharging hospital to locally based community nurses, ATSIHW, AHP, diabetes educators and/or GP. It is proposed that CR services could be implemented through a similar community-based system. Such a system would include initial assessment, coordination and referral of community-based/visiting health care providers for ongoing health care, risk factor management and psycho-social support, augmented by telehealth and telephone CR. To ensure successful system changes, pathways, guidelines and ongoing staff education, are essential particularly in R&R areas due to high staff turnover.[45] An example of a tool that addresses these issues is the Western Australia Department of Health's guidelines and pathways for CR[46] that could be adapted for Queensland.

As part of the development and implementation of revised CR services in R&R areas that are accessible to all, it is important that terminology reflects a common understanding and clear purpose of CR, and dispels the perception that CR programs are centre-based and often linked to hospitals.[14] Thereby, the term Heart: Road to Health (HRH) proposed. Heart: Road to Health aims for post hospitalisation improved health and quality of life for people with HD, through a process that includes flexible, holistic multidisciplinary health care and risk management in all settings.[9]

Given the generally poor understanding of CR, it is unsurprising that there are deficiencies in holistic multidisciplinary CR or SP provided in a range of environments.[10] This study found that the majority of populated areas of NQ had access to community-based or visiting health care services that included ATSIHW, nurses, AHP and medical staff.[47] Therefore, it is proposed that it is possible to develop a HRH, that utilises local health resources, supported by pathways and guidelines. This model of care needs to be further developed and implemented to ensure that HRH is available for all.

4.1 | Strengths and limitations

The environment of this study is prone to rapid changes due to high staff turnover and occurred during a time of rapid change associated with the COVID-19 pandemic. Hence, information provided is as accurate as possible at the time of data collection. To mitigate this, follow-up has been undertaken to check for any significant changes prior to submission of this paper. Qualitative research was used for this study, and while a large number of interviews were carried out that demonstrated consistent findings, this does not necessarily account for the views of all health staff, and caution should be taken with applying the findings more broadly. However, it is also possible that findings may have broader applicability beyond NQ, and given the potential for CR to have a significant impact on HD mortality and morbidity, it would be desirable to replicate the study in other parts of Australia and beyond. When discussing health services, we did not include organisations that provide social support such as woman's and child care groups, or sport and recreation. These groups are considered highly important for the health and well-being of the community and were only omitted due to constraints on the length of the paper.

5 | CONCLUSION

Systems for CR in R&R areas were inadequate, resulting in limited understanding and access to CR, demonstrated by an absence of holistic, multidisciplinary, coordinated post-discharge care for people with HD. To counteract the common perception that centre-based facilities are required for CR, a change of terminology to *Heart: Road to Health (HRH)* to indicate a pathway for

improved health outcomes and quality of life is recommended. To implement HRH, a systems approach that includes guidelines and in-service education would be required. Healthcare system changes would also be a pre-requisite to develop a model of care that focus on self-management and education. To achieve this, post-discharge referrals to a case-coordinator to manage a process that includes co-ordinated holistic, multidisciplinary health care that utilises local/visiting health professionals would be required.

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CONFLICTS OF INTEREST

There are no conflicts of interest to declare.

AUTHOR CONTRIBUTION

PEF: conceptualization; data curation; formal analysis; funding acquisition; investigation; methodology; project administration; validation; visualization; writing – original draft; writing – review & editing. RCF: conceptualization; data curation; formal analysis; funding acquisition; investigation; methodology; supervision; validation; visualization; writing – review & editing. RB: conceptualization; formal analysis; supervision; validation; visualization; writing – review & editing. IR: conceptualization; supervision; validation; writing – review & editing. PAL: supervision; validation; writing – review & editing.

ETHICAL APPROVAL

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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4.3.3 Conclusion

There is a pressing need for systems changes to address the barriers and build on the enablers and develop pathways to improve access to secondary prevention in R&R areas of NQ. The way forward has been identified through the model of *Heart: Road to health*. This model encompasses the theories of public health, health promotion and primary healthcare in the revision of healthcare systems including the development of guidelines and pathways to ensure that all people in R&R areas of NQ receive the post-discharge secondary prevention that they require. Of particular importance are the needs of Aboriginal and Torres Strait Islander people, who are the most disadvantaged because of high rates of disease and poor social determinants of health (SDoH), which are barriers to optimal health, health literacy and disease self-management.[10] Thereby, to develop client-centred, holistic, efficient, and effective, culturally responsive secondary prevention programs, it is necessary to consider the needs of community members, local staff and health service managers. To achieve this, continuous quality improvement and co-design processes are proposed, (Chapter 5: 5.3.2). These considerations, contributed to an iterative process that included further discussion and consultation with healthcare staff, community members and leaders, (Stage 4b) resulting in the model for *Heart: Road to health*, and subsequently *Road to health*, for HD, diabetes and renal disease as discussed in Chapter 5.

Stage 4b Pathways to Heart: Road to health

Chapters		Content & publications
1. Introduction	⇨	Background, introduction & implications of the research
Stage 1 Research foundations		
2. Integrative literature review	⇨	Cardiac rehabilitation services for people in rural and remote areas: Integrative literature review (2007–2016). Published 2020 (Paper 1). Supplementary review (2018 – 2021)
3. Methodology and methods	⇨	Project protocol: Improving access to cardiac rehabilitation in rural and remote areas: A protocol for a community-based qualitative case study. International Journal of Therapy and Rehabilitation. Published 2021 (Paper 2)
Stage 2 Results: Heart disease, hospitalisation, and referral		
4. Results 4.1 Epidemiological study	⇨	Heart disease, hospitalisation, and referral: coaching to achieving cardiovascular health through cardiac rehabilitation in Queensland. Published 2020 (Paper 3)
Stage 3 Results: Hospital-based Phase-1-Cardiac Rehabilitation		
4.2 Hospital case study series	⇨	The importance of cardiac rehabilitation in rural and remote areas of Australia. Published 2021 (Paper 4)
Stage 4a Results: Community-based Phase-2-Cardiac Rehabilitation		
4.3 Community case study series	⇨	Improving access to cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing? Published 2022 (Paper 5)
Stage 4b Pathways to *Heart: Road to health*		
5. Discussion and conclusion	⇨	Discussion and conclusion
5.3.1 *Heart: Road to health* for Aboriginal and Torres Strait Islander people	⇨	Improving access to cardiac rehabilitation (Heart: Road to health) for Aboriginal and Torres Strait Islander peoples in rural and remote areas of North Queensland. Published 2022 (Paper 6)
5.3.2 Model for *Heart: Road to health*	⇨	Model for Heart: Road to health or Chronic disease: Road to health in rural and remote areas. Submitted for publication Oct 2022 (Paper 7)

Chapter 5: Discussion and conclusion

5.1 Introduction

Cardiac rehabilitation (CR) is a successful method of secondary prevention that results in improved health outcomes for people with heart disease (HD).[70, 118, 119] Despite this, CR is poorly attended.[24, 102] This research identified a range of barriers for access to CR in rural and remote (R&R) areas of NQ. These included poor implementation of hospital in-patient Phase-1-CR, low referrals and access to various models of post-discharge Phase-2-CR, such as centre-based CR programs, telephone support, telephone apps and telehealth.[102, 120] Notably, people with HD, as well as healthcare staff in hospitals and R&R communities, have poor understanding of CR and subsequent benefits.[83]

CR programs are rarely available in R&R areas of NQ, and existing programs often lack flexibility and cultural responsiveness. Further uptake of home-based telephone services continues to be poor.[102, 121] Barriers to access are further compounded by poor social determinants of health (SDoH), including education, socio-economic factors, access to services and costs (5.3.3).[122] Enablers include a range of existing resources which could be better utilised to enable more effective provision of CR, together with improved use of telehealth. There are also a range of alternate chronic disease and aged care programs which provide holistic, client centred, culturally appropriate services (Table 10). This thesis proposes that these resources could be better utilised through improved communication, coordination and collaboration for effective healthcare provision, including secondary prevention (5.3.3).[122]

To address the barriers and develop the enablers and pathways the model of *Heart: Road to health,* (5.3.1: Figure 1; 5.3.2: Figures 1 & 2) was developed to improve access to CR in R&R areas of NQ, and ultimately result in improved health outcomes.[102, 120] This model is based on revision of current health services to ensure a client centred, holistic, multidisciplinary, culturally response approach.

Prior to this research, no comprehensive research of CR that follows the pathway of clients from hospital to home had been undertaken in R&R areas of Australia. While undertaking this research it was clear that terminology was important, as a lack of knowledge about CR was common. CR was often perceived as applying to centre-based programs, and ‘rehab’ for people post orthopaedic surgery and stroke, or linked to drug and alcohol programs.[102] In an effort to address these misconceptions the terms secondary prevention and *Heart: Road to*

health were increasingly introduced, and explained during the discussions with community-based healthcare staff, clients, their families and community groups.[102, 122]

As risk factor management is equally as applicable for a range chronic diseases, including heart, diabetes and renal disease, it is important to ensure a wider understanding of these in the community when implementing CR.[123] Common risk factor modifications for chronic diseases include exercise, balanced diet, not smoking, low alcohol, and medication monitoring.[124] A chronic disease, rather than a disease specific approach, is supported by Queensland Health (QH) and North Queensland Primary Health Care Network (NQPHN) (Appendix 7.4).[51] Thereby it is proposed that the model developed for *Heart: Road to health* be considered as a generic *Road to health* which includes HD and/or chronic diseases such as diabetes and renal disease.

Whilst risk factors for chronic diseases are common, medical treatments and specific client needs vary widely, and require specialist medical, nursing, allied health professional (AHP) and Aboriginal and Torres Strait Islander Health Worker support for comprehensive secondary prevention.[58] The following sections of this chapter relate to this transition from *Heart: Road to health* to a generic *Road to health* approach.

5.2 Research summary and synthesis

To investigate barriers, enablers and pathways for all adults living independently in R&R areas of NQ and develop a model for *Heart: Road to health,* a sequential approach was taken across four stages. The methodology called upon conceptual and theoretical frameworks,[96, 97] integrated with public health, health promotion and primary healthcare theories, linked to a highly consultative approach.[76, 77] A summary of the stages are as follows:

Stage 1: An integrative literature review that identified barriers, enablers and pathways for access to CR in R&R areas of Australia and other developed countries.[83] The initial review was published in 2018, and updated in 2021 (Chapter 2).[83]

Key results: The importance of healthcare staff, especially doctors, in promoting CR was identified.[66, 71] Overall understanding of CR was low, and at times, considered unnecessary for younger and fitter people.[125] To provide CR in R&R areas flexibility was identified as important due to disparate and diverse populations.[68, 126, 127] The need to provide improved workplace education on secondary prevention and cultural matters, for all healthcare staff was identified as important, due to clear knowledge deficits and inadequate culturally responsive healthcare services, together with the influence of the dominant western medicalised model.[12, 29] Some examples of individual culturally responsive programs for

Aboriginal and Torres Strait Islander people were found, but these were not widely available.[12, 29, 126] However, flexibility, client centred approaches and the involvement of ATISHW, together with cultural training for non-Indigenous staff, was found to improve access and acceptability of CR programs for Aboriginal and Torres Strait Islander people.[12, 126]

Barriers to centre-based programs included travel, costs, dislike of groups, poor program flexibility and work hours. Attendance was impacted by gender (women are less likely to attend), differing cultural needs, levels of education, socio-economic status, age (too old or too young), mental health and multi-morbidities.[63, 65, 66, 68, 69, 125] An optimal multidisciplinary team approach to CR that includes a GP, cardiologist, nurse, physiotherapist, dietitian, psychologist, and an exercise physiologist is recommended by the National Heart Foundation of Australia (NHF) and Australian Cardiac Rehabilitation Association, (ACRA).[1, 58] This is unlikely to be achievable in R&R areas of NQ. Enablers, included early referrals, the need for flexible, culturally response client centred care, including home visits, telephone/telehealth programs.[63, 72]

Overall, weak or poorly implemented healthcare systems, inadequate referrals and provision of secondary prevention were identified, as well as inconsistent knowledge and valuing of secondary prevention, by people with HD (clients), and health professionals.[59, 63, 66, 127, 128] The information clearly demonstrated the need for further research, to address the barriers, build on the enablers, and revise pathways, to improve access to secondary prevention in R&R areas. The findings of the integrative literature review provided the foundation for the following stages, of this research. Prior to commencing more specific studies on Phase-1-CR in hospital, and access to Phase-2-CR or secondary prevention R&R areas, it was decided that it was important to have a clear understanding of rates of hospitalisation for people with heart disease in Queensland, and referral rates to QH home-based secondary prevention program, Coaching on achieving cardiovascular health (COACH). (Stage 2)

Stage 2: An epidemiological study undertaken to investigate variations in hospitalisation and referral to COACH for Aboriginal and Torres Strait Islander and non-Indigenous people, (Chapter 4: 4.1).[121]

Key results: In R&R areas of NQ overall rates of hospitalisations, mortality, and burden of disease from CHD are higher, with poorer access to services, than in metropolitan areas, (Chapter 1: 1.1.1, Table 1; 4: 4.1).[14, 17] Queensland's Aboriginal and Torres Strait Islander

people have higher rates of hospitalisation (relative risk 1.1, range 0.56–2.23) for heart and related disease compared with non-Indigenous people. These rates are unlikely to reflect the needs of Aboriginal and Torres Strait Islander people in R&R areas given the prevalence of coronary heart disease (CHD) disease in Aboriginal and Torres Strait Islander people is twice that of non-Indigenous people in Australia[14]

COACH referral rates ranged between 2.3% and 13% for non-Indigenous people in NQ, and between 4% and 20%, for Aboriginal and Torres Strait Islander people. Given that the vast majority of the NQ Hospital and Health Services (HHS) have no centred-based CR services outside metropolitan areas (Chapter 1.1.1: Figure 2), these referral rates are also likely to be inadequate.[121] Deficiencies in identification and possible under enumeration of Aboriginal and Torres Strait Islander people's status could have affected results in some areas, (Chapter 4: 4.1).[121] This study confirmed that further investigation of factors that influence referral and access for post-hospitalisation secondary prevention. These issues are further investigated in (Stages 3 and 4a)

Stage 3: A case study series that focused on cardiac in-patient facilities in two public and two private tertiary hospitals in Townsville and Cairns. The study investigated:

i. healthcare professionals' understanding and implementation of Phase-1-CR
ii. in-patients education and understanding of their disease, treatment, and importance of CR
iii. discharge planning, and referrals to Phase-2-CR.
iv. possible impact of these factors on post-discharge secondary prevention in R&R areas of NQ. (Chapter 4: 4.2).[120]

Key results: Across all hospitals, Phase-1-CR was provided for 31% (range 6–53%) of in-patients with a length of stay (LOS) $\geq$3 days. This rate increased to 74% (range 67–80%) in cardiac services with cardiac educators. For cardiac services with no cardiac educators, and LOS $\geq$3 days the rate fell to 14% (range 6-26%). For LOS $\leq$2 days the rate was to14% (range 6–39%), for patients admitted to cardiac services with cardiac educators and 9% (range 0–19%) for in-patients in all areas of all hospitals.[120] Involvement of direct care staff in the provision of Phase-1-CR, and in-patient understanding of their disease and discharge plan, and referral to CR, were low. Finally, only 5% (range 3-6%) of medical discharge summaries, which were the primary communication tool from tertiary hospitals to R&R healthcare providers, mentioned risk factor management, CR or secondary prevention.[120]

Overall, levels of Phase-1-CR in tertiary hospitals in NQ fell well short of recommended best practice.[1] This resulted in clients from R&R areas being discharged with little or no secondary prevention follow-up, and apart from a predominantly clinically focussed discharge plan that was commonly delayed, and usually sent to a local GP if available. These factors resulted in insufficient information for clients to be proactive in achieving their holistic healthcare requirements, and community-based staff to support this process (Chapter 4: 4.2).[120] This study identified the need to improve Phase-1-CR and that more information was required to establish the support available for the provision of secondary prevention in communities in R&R areas of NQ. (Stage 4a)

S*tage 4a:* A case study series that investigated barriers, enablers and pathways for improving access to Phase-2-CR (secondary prevention) in Hughenden, Cooktown, Wujal Wujal and Hope Vale (focus communities), (Chapter 4: 4.3).[102]

Key results: In the focus communities the majority of healthcare in R&R was provided by QH Multi-Purpose Health Services (MPHS) and Primary Health Care Centres (PHCC). These facilities were staffed by resident healthcare staff, predominantly nurses, Aboriginal and Torres Strait Islander Health workers (ATSIHW), supported by visiting staff, including medical officers, and allied health professionals (AHP). Other service providers were Aboriginal Community Controlled Health Services (ACCHO), Royal Flying Doctor Service (RFDS), contracting organisations, and individual private health practitioners. There was no routine systems for communication or coordination of services and collaboration was lacking between these organisations. As a result services were often fragmented with resultant duplication and gaps in client care.[102]

Barriers to secondary prevention included poorly defined referral pathways and low referrals by hospitals to community-based health professionals, who also demonstrated a poor understanding of secondary prevention. Post-discharge care was predominantly clinical, and lacked client-centred, holistic, multidisciplinary, and culturally responsive secondary prevention. These deficits were compounded by underutilisation of ATSIHW, which impacted on low provision of culturally responsive care for Aboriginal and Torres Strait Islander people.

Overall, major barriers to access to CR in R&R areas of NQ was limited centre-based CR services; low awareness, referrals, and acceptance of telephone support services; inadequate or absent community-based models for secondary prevention.[102] Generally, clients received low levels of holistic care and lacked the health literacy to be proactive in their own disease

management. Enablers, included the range of available resources, which through revised healthcare systems, supported by policies, pathways, guidelines, and in-service education, have the potential to improve provision and access to secondary prevention, in R&R areas of NQ[102] (Stage 4b)

Stage 4b: In line with the sequential approach, Stages 1–4a informed the development of a model of healthcare, *Heart: Road to health,* designed to improve access to secondary prevention in R&R areas of NQ. To achieve this, an iterative process was used for further consultation and discussion on the findings of the research. This process included local community members and leaders, plus local and regional healthcare staff and managers. To facilitate the discussion, an information paper was developed (Appendix 7.2). This paper identified the lack of a comprehensive system for secondary prevention as the central issue, and the need to improve access to secondary prevention in R&R areas, through a flexible, client-centred, holistic, multidisciplinary, culturally responsive model of care (*Heart: Road to health*), (5.3.2 Figure 1). It is proposed that such a model could be achievable through reorientation of healthcare services, including improved communication, coordination and collaboration, between the range of currently available healthcare providers, supported by policies, pathways, guidelines and in-service education.[102] Continuous quality improvement (CQI) and co-design are recommended to address these issues and develop the *Heart: Road to health,* (5.3.2).

The *Heart: Road to health* model continued to be developed in cooperation with Hughenden and Cooktown Community Advisory Networks. Further, a forum, *Heart or Chronic disease: Road to Health* was convened in August 2022 and attended by health service providers and stakeholders including QH, NQPHN, Apunipima and NQ HHS representatives.

Each stage of this research has informed following sections, including the discussion and conclusion of the thesis. This sequential approach led to the development of *Heart: Road to health* and further the transition to a generic *Road to health* approach. The *Road to health* is proposed as a healthcare approach for people with HD, diabetes and renal disease, that could potentially improve access to secondary prevention, and ultimately improve health outcomes for people in R&R areas of NQ.

5.2.2 Barriers, enablers and pathways for improving access to secondary prevention in R&R areas of Australia.

In the development of *Road to health*, there are important factors that need to be considered. To assist this process a summary of barriers and enablers for access to secondary prevention

and holistic, multidisciplinary, client centred care are provided in Table 9.

Table 9: Summary of barriers and enablers for access to secondary prevention, and holistic, multidisciplinary, client centred care in R&R areas of NQ

Barriers	Enablers
• Inadequate discharge planning resulted in a lack of understanding of their disease and post-discharge care.[117] (Chapter 4: 4.2) • Low CR referral rates, including home-based telephone support secondary prevention programs.[102, 120] (Chapter 4: 4.2, 4.3) • Lack of centre-based CR and poor uptake of home-based telephone support programs.[102, 121] (Chapter 4: 4.1, 4.3) • Poor communication and referrals from hospital to local health professionals.[102, 120] (Chapter 4: 4.2, 4.3, 5.3.1; Chapter 5:5.3.2) • Predominantly clinical post-discharge care.[102] (Chapter 4: 4.3; 5.3.1; Chapter 5: 5.3.2) • Lack of holistic lifestyle approach partly due to underutilisation of AHPs.[102] (Chapter 4: 4.3; Chapter 5: 5.3.1, 5.3.2) • Generally low understanding of CR by staff, clients, and community members.[102, 120] (Chapter 4: 4.3, Chapter 5: 5.3.1, 5.3.2) • No follow-up system, pathway or guidelines for referral to community nurses, ATSIHW, or AHP, e.g., physiotherapists, dietitians, social workers, pharmacists, and psychologists, together with mental health nurses, nurse practitioners and educators.[102, 120] (Chapter 4: 4.3; Chapter 5: 5.3.1, 5.3.2) Poor utilisation of ATSIHW in holistic and culturally responsive care.[102] (Chapter 5: 5.3.1, 5.3.2) • Non-sharing of medical records, resulting in poor communication between various health professionals and organisations outside Queensland Health.[102] (Chapter 4: 4.3; Chapter 5: 5.3.1, 5.3.2)	• A range of multidisciplinary health professionals available, including nurses, ATSIHW, AHP and doctors.[102] (Chapter 4: 4.3; Chapter 5: 5.3, 5.4) • AHPs have a sound understanding of secondary prevention.[102] (Chapter 4: 4.3) • Improved uptake of telehealth and telephone support services since COVID.[32] (This has not been evaluated in R&R areas).[102] (Chapter 4: 4.3) • Several relevant multidisciplinary, holistic, person-centred models of care are currently being provided in NQ. These include: - Diabetes education and self-management (Diabetes model)[53] [102] (1.3, 4.3, 5.3.2, 5.2.4) - Cape York Kidney Care (CYKC)[54, 102] (Chapter 1: 1.3; Chapter 5: 5.3.4) - Older Persons Enablement and Rehabilitation for Complex Health Conditions (OPEN ARCH)[55] (Chapter 1: 1.3) - Healthcare In Your Home (HIYH)[129] (TCCHHS -CN6/2) (Chapter 1: 1.3; Chapter 5: 5.3.4) - Ear, Nose and throat program - Deadly ears[56] (Chapter 1: 1.3; Chapter 5: 5.3.4) • Country Heart Attack Prevention Project (CHAP) in South Australia is an example of a holistic client-centred model of care provided through a combination of local face-to-face and telehealth services.[130] (Chapter 5: 5.3.4) • Virtual Out-patient Integration for Chronic Disease (VOICeD)[57]: Medical telehealth consultations for HD, diabetes and kidney disease. (Chapter 1: 1.3; Chapter 5: 5.3.4)

Barriers (Table 9) identify key factors that need to be considered in the development of *Road to health* approach. *Enablers* are examples of factors and programs that demonstrate holistic, multidisciplinary, client centred, culturally response services currently being provided in Queensland and South Australia. VOICeD program is a medically focussed program that coordinated disease focussed care. [57] No evidence was found of a culturally response approach, although it is reported to be popular due to reduction in the client's need to travel,(TCCHHS, CN14/2).

Pathways for *Road to health* include the need for the development of comprehensive regional systems for secondary prevention based on coordination of services for people with HD, diabetes and renal disease. Coordinated healthcare systems for secondary prevention need to commence through improved communication and referral from tertiary hospitals to local

community nurses and/or ATSIHW for post-discharge case-management, (5.3.1, 5.3.2, 5.4).[102, 117] To achieve this, automatic hospital referrals systems and pathways to a locally based case coordinator, supported by guidelines and in-service education need to be established, (Chapter 4: 4.3; 5.3.1, 5.4).[102] To ensure that effective system changes are achieved, CQI and co-design that facilitate high levels of communication, bottom-up problem solving, and planning, in conjunction with community members, leaders, healthcare staff and managers is proposed. (5.3.1, 5.3.2, 5.4).[80, 102, 117]

5.2.3 Resources and translational research for Road to health

A range of community-based and regional resources for healthcare provision in R&R areas of NQ have been identified. These include healthcare resources available in R&R communities,[102] supported by regional resources such as QH Chronic Disease Centres. These Centres predominantly provide services for people with diabetes and renal disease.[40] It is proposed that the role for Chronic Disease Centres could include the development and implementation of a generic *Road to health* that facilitates a coordinated approach to holistic, multidisciplinary service provision, that includes secondary prevention for HD, diabetes and renal disease. This extended role may need extra resources but the combined focus on chronic disease, rather than a specific disease focus should achieve economies of scale.[131]

In recent years regional resources have increased to include QH nurse navigators and chronic disease nurse practitioners, whose roles are complemented by strengthening of the ATSIHW role.[51] However, healthcare systems that ensure effective and appropriate post-hospitalisation secondary prevention for heart and other chronic diseases were found to be ineffectual, and likely to result in less than optimal improvements in healthcare delivery and health outcomes.[102, 120, 122]

The importance of broadening the focus from *Heart: Road to health* to generic *Road to health* multi-morbidity is highlighted in the following quotation:

> …Many chronic conditions share common risk factors that are largely preventable or treatable, for example: tobacco smoking, insufficient physical inactivity, poor diet, overweight and obesity and other biomedical risk factors such as high blood pressure. Preventing or modifying these risk factors can reduce the risk of developing a chronic condition and result in large population and individual health gains by reducing illness and rates of death. As with chronic conditions, these risk factors tend to be

more prevalent in the lowest socioeconomic areas and in regional and remote areas.[123]

Because of chronic disease multimorbidity and common risk factors it makes sense that a generic *Road to health* approach is taken to minimise duplications in services, and multiple appointments for clients. For optimal effectiveness it is also proposed that regional and outreach services work cooperatively and collaboratively with local healthcare providers and provide capacity building for local staff. To achieve a successful outcome, translational research which is described as translating research into practice, by ensuring that new research knowledge reaches the populations for whom it is intended, and implemented correctly,[132]is necessary. This research would consider all levels of healthcare systems to facilitate the provision of the right care, provided by the right people, at the right time.

Essential to the *Road to health* approach is that local staff need to retain the case-coordination role because of their knowledge and understanding of local people and communities. Further, the range of existing alternative models of care provide information and lessons that need to be considered in the further development and implementation of *Road to health*, (Chapter 4: 4.3; 5.3, 5.2.4).[102, 122]

5.3 Discussion

This research has demonstrated that there is a need to improve access to secondary prevention for clients with HD in R&R areas of NQ. Whilst it is proposed that it may be appropriate to consider a generic *Road to health* that includes chronic disease, especially diabetes and renal disease, this discussion initially focusses on *Heart: Road to health* in line with the overarching research question*,* 'How can access to CR in R&R areas of NQ be improved?*'* To achieve this, it is proposed that a whole systems approach that considers barriers, enablers and pathways for a flexible, culturally responsive *Heart: Road to health,* is developed. Such a model would need to be provided by a multidisciplinary team who deliver client-centred, holistic, culturally responsive healthcare. Improved inter and intra-organisational communication, coordination and collaboration are crucial for this process, (5.3.1, Figure 1).[102, 122]

An important consideration discussed throughout this research is that Aboriginal and Torres Strait Islander people who live in R&R areas of NQ, have high rates of HD and multimorbidity,[3] and together with poor SDoH.[10] Therefore special consideration is required when developing and implementing healthcare services including secondary prevention. Accordingly, this research has investigated barriers, enablers and pathways

specifically for Aboriginal and Torres Strait Islander people, and proposes a way forward that includes inclusive, culturally responsive, collaborative development and implementation processes. Through this approach, it is important that the needs of the local staff and community, together with health service managers are considered.

Two papers that focus on healthcare systems for improving access to *Heart: Road to health* are inserted below. The first, (5.3.1, Paper 6), considers factors that are required, to improve access to *Heart: Road to health* for Aboriginal and Torres Strait Islander people.

The second paper, (5.3.2, Paper 7) focusses on health systems, and factors such as SDoH that need to be considered to achieve change necessary for improved access to *Heart: Road to health* in R&R areas.

5.3.1 (Paper 6) Improving access to cardiac rehabilitation (Heart: Road to health) for Aboriginal and Torres Strait Islander people in rural and remote areas of North Queensland

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COMMENTARY

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Commentary: Improving access to cardiac rehabilitation (Heart: Road for health) for Aboriginal and Torres Strait Islander peoples in rural and remote areas of North Queensland

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Abstract

Aims: To focus on the needs, challenges and opportunities to improve access to cardiac rehabilitation (CR) (Heart: Road to health [HRH]) for Aboriginal and Torres Strait Islander peoples in rural and remote (R&R) areas of North Queensland.

Context: It is known that there is insufficient access to HRH for Aboriginal and Torres Strait Islander peoples in R&R areas of NQ, who have the highest rates of heart disease and socioeconomic disadvantage mainly due to poor social determinants of health. However, at least in part due to the impact of colonialism and predominantly western medicalised approach to health care, few gains have been made.

Approach: This commentary draws on recent research and literature and reflects on cultural issues that impact on improving access to an HRH for Aboriginal and Torres Strait Islander peoples in R&R areas. The underutilisation of the skills of Aboriginal and Torres Strait Islander Health Workers (ATSIHW) and a lack of a defined process to ensure access to culturally responsive HRH are discussed. Finally, a way forward is proposed that includes the development of policies, pathways and guidelines to ensure that appropriate support is available in the client's home community.

Conclusion: It is proposed that culturally responsive, accessible and effective HRH is achievable through the reorientation of current health systems that include a continuous client-centred pathway from hospital to home. In this model, ATSIHW will take a lead or partnership role in which their clinical, cultural brokerage and health promotion skills are fully utilised.

Improving access to cardiac rehabilitation (Heart: Road to health) for Aboriginal and Torres Strait Islander peoples in rural and remote areas of North Queensland.

KEYWORDS
Aboriginal Health, access issues, community based rehabilitation, communication, policy

1 | BACKGROUND

There is a need for effective health care for Aboriginal and Torres Strait Islander people, who have the highest heart disease (HD) rates in rural and remote (R&R) areas of Australia.[1] These rates of disease are compounded by socioeconomic disadvantage, due to poor social determinants of health (SDoH), which include low levels of education, income, inadequate housing, poor security and disempowerment due to the impact of colonialism.[2,3]

HD contributes to significant illness, disability, poor quality of life and high health care costs in Australia.[1] CR is an evidence-based model of secondary prevention that provides coordinated activities including education, medical care and physical, mental and social support for self-management to address risk factors for cardiovascular disease.[4] This process results in reduced mortality and morbidity, improved quality of life and optimal functioning, together with reduced client and health care costs.[4,5] Ideally, CR is provided through a holistic (health and well-being), multidisciplinary approach that is delivered in a variety of settings, which includes hospital inpatient Phase-1-CR and outpatient Phase-2-CR.[6] Despite known benefits, CR referrals and attendance are low (30.2%),[7] predominantly due to inadequate Phase-1-CR[8]; a scarcity of centre-based services in R&R areas; inadequate culturally responsive care for Aboriginal and Torres Strait Islander people; and poor acceptance of telephone support programs.[9,10]

Aboriginal and Torres Strait Islander peoples have more than 65 000 years of continuous culture,[11] disrupted by the effects of colonialism. Therefore, cultural aspects of health care are an essential component of health service planning and delivery.[12] Culturally responsive care is provided by Aboriginal and Torres Strait Islander Community Controlled Health Organisations (ACCHO) and Aboriginal and Torres Strait Islander Health Workers (ATSIHW), who offer a holistic approach, which is reported to reduce the effects of colonisation and structural racism.[12]

Changes are required to address deficits in the provision of health care and improve access to CR for Aboriginal and Torres Strait Islander peoples. Currently, on discharge from hospital, people with HD (clients) are usually advised to see their general practitioner (GP), or in areas serviced by Primary Health Care Centres (PHCC), to consult a clinic nurse. During this process, holistic multidisciplinary postdischarge care is compromised by a range of factors including:

(i) medical discharge summaries being delayed, predominantly clinical and rarely mentioning CR, holistic, multidisciplinary care or risk factor management[8];
(ii) poor understanding of CR by health staff and clients[8,9];
(iii) poor interhealth service communication[8] including non-sharing of medical records by different health care organisations[9];
(iv) use of predominantly western medical practices that are known to be ineffectual in treating Aboriginal and Torres Strait Islander people.[13]

2 | HOW TO IMPROVE ACCESS TO CARDIAC REHABILITATION FOR PEOPLE IN RURAL AND REMOTE AREAS

Several recent research studies contribute to, and provide recommendations, for improving access and attendance to CR for people who live in R&R areas.[8,9,14] These studies include an integrative literature review that demonstrates a lack of understanding of CR, inflexible services, low referrals and attendance,[8] all underpinned by a weak systematic policy-driven approach. To address these shortfalls, there is a need for policy-driven, flexible, culturally responsive holistic programs, delivered by a multidisciplinary health team, with management support.[8] An epidemiological study found that Aboriginal and Torres Strait Islander peoples in North Queensland (NQ) were more likely to be hospitalised for HD than non-Indigenous Australians, (relative risk 1.27–1.98), but rates were lower than expected given Indigenous rates of HD are twice that of non-Indigenous Australians.[15] Also, referral rates to home-based telephone support CR (Coaching on Achieving Cardiovascular Health [COACH]) were found to be low in NQ: 4%–20%.[16] To compound this, a community study on provision and access to CR in R&R areas of NQ demonstrated that Aboriginal and Torres Strait Islander peoples prefer face-to-face communication with someone they trust.[9] Also, the term CR was found to be confusing as it was linked to centre-based care including gym, learning to walk poststroke, or hip replacement, or drug and alcohol programs.[9] To improve clarity and

understanding of CR, it is recommended that the term Heart: Road to health (HRH) is used.[9]

It is considered essential that the proposed HRH includes a pathway that commences with Phase-1-CR that includes education, discharge planning and referral to outpatient, community-based Phase-2-CR, taking a flexible client-centred approach. In this paper, the term pathway describes the process, commencing with effective hospital discharge planning, through a coordinated progression to community-based HRH. Guidelines refer to specific activities that are required for an evidence-based HRH, which includes clinical care, assessment, risk factor management and psychosocial support.[17]

Based on recent research,[8,9,14] the following pathway to HRH has been developed. The aim being to improve communication, coordination and collaboration between health care providers, centre or home-based CR services, leading to improved client outcomes (Table 1).

This proposed pathway is based on the utilisation and reorientation of available health resources, with or without a specialist HRH coordinator. Currently, all clients are seen by local health services, and we contend that improved coordination of services will result in more efficient and effective service and lead to improved health outcomes. To achieve this, it is proposed that the local community-based HRH coordinator will be a community nurse and/or ATSIHW who will undertake the initial assessment, develop a care plan, refer to AHP for risk factor management and/or arrange telehealth support. These locally based health professionals, either solely or in combination, will coordinate local secondary prevention services as outlined in Table 1. In line with recommended flexible services (Figure 1), this assessment may be at the local health centre or in the client's home as negotiated with the client. In the majority of cases, it is possible for people who live in the immediate community served by the local health centre. However, in areas where the client may live very remotely the assessment will need to be negotiated either via phone or computer link, with face-to-face conducted when the client visits the local centre for farm supplies or groceries.[9] Collaborative and consultative interorganisational policies, procedures, education

TABLE 1 Pathway to heart: road to health

Step	Activity	Responsibility
1.	Inpatient Phase-1-CR to ensure that clients: (i) understand their disease, postdischarge plan, and the need for a continuous HRH (ii) are referred to a CR service and/or a local HRH case coordinator (community nurse/ATSIHW) (iii) consent for follow-up	Hospital management and clinical staff
2.	In the client's home community, on receipt of a postdischarge referral and consent for follow-up, the HRH case coordinator contacts the client and organises a face-to-face meeting. This meeting may be at the client's home, with their family, or health centre, depending on the client's preference	Community nurse and/or ATSIHW
3.	During the initial meeting, the HRH coordinator will attend to immediate health care needs such as medications, blood pressure check and wound care (as required) and complete an assessment as per National Heart Foundation criteria[18]	Community nurse and/or ATSIHW
4.	The HRH coordinator will consult with a designated CR specialist, who may be based at a nominated CR centre, or a designated cardiac educator[a] to develop a HRH plan	Community nurse and/or ATSIHW & CR specialist
5.	Depending on the findings of step 3 & 4 referrals that include medical, nursing, ATSIHW, and allied health professional (AHP) care will be organised for follow-up and provision of secondary prevention services	Community nurse and/or ATSIHW
6.	Progress will be monitored and coordinated by the HRH coordinator, through a multidisciplinary case conference that includes all health care providers involved in the client's care	Multidisciplinary team
7.	Outputs from multidisciplinary case conferences will be documented and arrangements made for sharing information, when care is provided by a range of organisations	Multidisciplinary team
8.	The HRH case coordinator will stay in contact with the client and continue to coordinate care until the client is deemed able to self-manage	Community nurse and/or ATSIHW

[a]Currently, cardiac educators are not available in R&R areas of NQ.

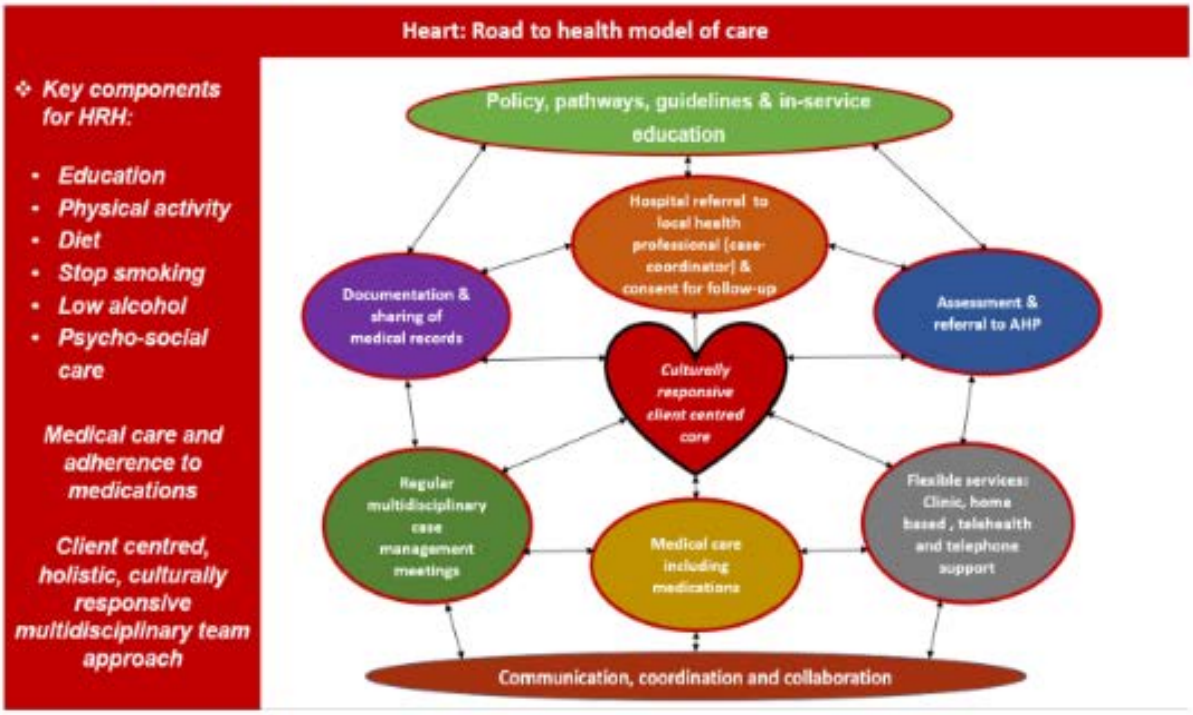

FIGURE 1 Heart: road to health model of care

and guidelines need to be developed to support all these processes.[9]

3 | CHALLENGES FOR HEART: ROAD TO HEALTH FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES IN RURAL AND REMOTE AREAS

Prior to improving access to CR for Aboriginal and Torres Strait Islander people, it is important to consider factors that impact on people's health, including culture, SDoH,[2] and the need for '…theory-based behaviour change intervention…'.[19] It is essential that clients and health staff have a better understanding of secondary prevention, cultural aspects of care and effective behaviour change strategies, in the context of the local culture, environment and SDoH.[9]

The western biomedical approach to health care is known to be a barrier to effective health care for Aboriginal and Torres Strait Islander peoples. To minimise this, ACCHO use a holistic wellness-based model.[13] Queensland Health (QH) continues to predominantly use the western biomedical approach to provide services for all people either solely,[9] or in collaboration with ACCHO or Royal Flying Doctor Service (RFDS).[9] However, the working relationship between QH and ACCHO, at times, lacks the collaboration necessary for holistic multidisciplinary care, and locally based ACCHO are not available in all R&R areas. The National Health and Medical Research Council guidelines provide information on culturally responsive programs for Aboriginal and Torres Strait Islander peoples.[20] These guidelines are supported by the recommendation of Taylor et al.[21] as pathways to culturally responsive, flexible CR in which ATSIHW play a key role.[21]

There are examples of successful CR programs for Aboriginal and Torres Strait Islander people in Western Australia (WA)[13] and Tasmania,[22] but no evidence of their systematic implementation,[10,13,21,23,24] in other areas of Australia.[25] Overall, there is a history of neglect for improving access to CR, especially for Aboriginal and Torres Strait Islander people in R&R areas, that is exacerbated by inadequate health information systems and communication, resulting in inadequate pathways for CR from hospital to home.[24]

Before access to CR for Aboriginal and Torres Strait Islander people can be improved, a whole of systems approach is required to ensure that there is adequate post-discharge information about secondary prevention and clinical management that is received in a timely manner by local health staff.[8,9] Staff education and support to provide client-centred culturally responsive care is essential as depicted in the HRH: Model of care (Figure 1).[9]

This model integrates the NHMRC guidelines[20] and the findings of previous research[8–10,13,16,21–24] depicting a

model for implementation in a range of environments for a range of diseases. It is argued that should this model be fully implemented, supported by necessary policies, pathways, guidelines and in-service education, with ongoing monitoring and evaluation, effective health provision should be realised. This process needs to be tested, but based on the known effectiveness of CR, it is expected that improved access to CR will result in improved health outcomes for people with heart and potentially other chronic diseases, with subsequent cost savings.[5]

4 | ROLE OF ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH WORKERS IN PROVIDING HRH

The range of health services available in R&R areas of NQ provides opportunities for a culturally responsive HRH. An essential component of these services is ATSIHW, whose skills include health promotion, cultural brokerage and clinical care.[26] Their involvement is essential in achieving improvements in HRH. Despite ATSIHW promoting home visits that were valued by clients, these were seldom supported by health systems or managers, resulting in, at times, ATSIHW being used as transport or administration officers.[9] Whilst there are weaknesses that need to be addressed, there are also examples of effective collaboration between QH and ACCHO, which can be built upon.[9]

The primary role of ATSIHW and variations in service delivery of available health services are key factors that need to be addressed in the delivery of appropriate and effective culturally responsive health services.[12]

5 | HEALTH SERVICE PROVISION AND OPPORTUNITIES FOR PROVIDING HRH IN RURAL AND REMOTE AREAS

Health services in R&R areas of NQ are provided by QH, ACCHO, RFDS and a range of contracting organisations. Services are provided either autonomously or through collaborative service provision,[9] by a range of community-based or visiting health professionals, including nurses, ATSIHW, doctors and AHP, augmented by telehealth services.[9] As discussed, it is proposed that community-based HRH could be provided by utilising these services. To achieve this, there is a need for improved working relationships between current health service providers, with ATSIHW taking a lead, or partnership role,[9,13,23,25,27] thus strengthening service provision and reducing health care costs through the reduction in hospital readmissions.[5] Before sustainable gains can be made, there is a need to ensure that:

1. communication, coordination and collaboration between QH, ACCHO, RFDS and health service contractors are improved;
2. client-centred, holistic, multidisciplinary health care is provided[9];
3. health staff are provided in-service education and support to ensure that they are equipped to provide HRH;
4. ATSIHW are supported in a lead role.

The involvement of ACCHO and ATSIHW is essential to facilitate holistic culturally responsive services that are congruent with the HRH. This approach would strengthen HRH from a cultural perspective and diminish systemic racism that has been identified in government health services.[12]

6 | THE WAY FORWARD

To enable the provision of an appropriate HRH for Aboriginal and Torres Strait Islander peoples, culturally, holistic, multidisciplinary, client-centred services, delivered by ACCHO and ATSIHW in conjunction with the other health care organisations such as QH, RFDS and health service contractors, are necessary. To achieve this, strong relationships between these organisations and individual service providers are essential. The first step in this process is the development of a pathway from hospital to the client's home community, supported by guidelines, and in-service education, with frequent updates, due to high staff turnover.[14]

In summary: A systems-based approach is required to ensure a culturally responsive effective HRH. To achieve this, all health care providers need to work collaboratively, supported by policies, procedures, a pathway and guidelines which ensure:

- improved support for ATSIHW to enable them to include health promotion, cultural brokerage and clinical care in their role;
- in-service education is provided for all health staff at regular intervals;
- improved coordination and utilisation of local/visiting staff (especially AHP), in conjunction with telehealth and home-based telephone support programs;

- improved communication from discharging hospitals to locally based and visiting health care providers that comprises:

  - referrals to local health care providers, for example, community nurses and/or ATSIHW,
  - medical discharge summaries that are timely and provide guidance and support for CR, secondary prevention and risk factor management,
  - sharing of medical records between health care organisations and individual health care providers.
- resources to revise and develop health care systems to support the implementation of the HRH;
- coordination and accountability at a regional level;
- continuous quality improvement cycle that includes development, monitoring and evaluation of health systems and delivery of HRH.

To assist with this process, there are examples of pathways and guidelines for a holistic multidisciplinary CR/HRH. These include Western Australian[28] and National Heart Foundation pathways.[18]

Whilst the development of health care systems is considered essential for improving access to culturally responsive HRH in R&R areas, it is unlikely that the desired impact will be achieved unless there is an overall, cooperative trusting relationship between health care providers and the communities for whom they care.[12] Clearly, utilisation of ATSIHW would strengthen relationships and facilitate the provision of health care in Indigenous communities. This, combined with previous research, strengthens the proposition that ATSIHW and ACCHO have a primary role in the provision of health care for Aboriginal and Torres Strait Islander peoples.[10,13]

There are further examples of successful patient-centred, culturally responsive, holistic, multidisciplinary models in which ATSIHW are key team members. These could provide a way forward for the development of HRH and include the Cape York Kidney Care program,[29] and diabetes client-centred model of education and self-management.[30] Both programs include routine home visits, and a coordinated plan of care, developed in conjunction with clients and their family. These models are built on a multidisciplinary team approach that includes medical care (GP and specialist), diabetic educators/renal nurse practitioners, ATSIHW and AHP, all of whom work collaboratively to provide patient-centred care.[9,29] Telehealth and telephone support programs are services available to augment HRH, but further investigation is required into their suitability given a lack of information on effectiveness with culturally and linguistically diverse populations, especially in R&R areas.

7 | CONCLUSION

It has been demonstrated that implementation of a culturally responsive, accessible and effective HRH is feasible in R&R areas of NQ and could be implemented through reorientation of current health systems, which includes a continuous client-centred pathway from hospital to home. To achieve this, revision of current health systems to include improved communication, coordination and collaboration between health care providers, with ATSIHW taking the lead role, or at least working in partnership with community-based health professionals is necessary. Further development of these ideas and pilot studies on the implementation of revised models are essential next steps for an effective Heart: Road to health or chronic diseases for Aboriginal and Torres Strait Islander peoples in R&R areas of NQ.

AUTHOR CONTRIBUTIONS

PEF: conceptualization; funding acquisition; project administration; resources; validation; visualization; writing – review and editing. RCF: conceptualization; funding acquisition; project administration; resources; supervision; validation; visualization; writing – review and editing. RB: conceptualization; supervision; validation; visualization; writing – review and editing. IR: conceptualization; supervision; validation; visualization; writing – review and editing. PAL: conceptualization; supervision; validation; visualization; writing – review and editing. KC: conceptualization; supervision; validation; visualization; writing – review and editing.

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CONFLICT OF INTEREST

There are no conflicts of interest to declare.

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5.3.2 (Paper 7) Healthcare systems and management

Many of the factors that need to be considered for improving access to secondary prevention for Aboriginal and Torres Strait Islander people are equally applicable for all secondary prevention services for all people in R&R areas of Australia. To achieve improved access to secondary prevention there are specific healthcare and management systems necessary to facilitate effective implementation of the proposed *Heart: Road to health.* These are discussed in the paper inserted as submitted for publication:

Field P, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Model for Heart: Road to health or Chronic disease: Road to health in rural and remote areas. Submitted for publication, October 2022.

Short communication: *Model for Heart: Road to health or Chronic disease: Road to health in rural and remote areas.*

Abstract:

Introduction

Heart disease (HD) is the leading cause of mortality and morbidity in Australia. Secondary prevention (SP) is recommended for people with HD (clients) through cardiac rehabilitation (CR) programs commencing in hospitals (Phase-1-CR) and continuing post-discharge (Phase-2-CR). SP is known to improve health and quality of life, but CR/SP referral and attendance rates are low (referral 45%; attendance 30%). In rural and remote (R&R) areas, there are few centre-based programs, and home-support telehealth or telephone services are poorly utilised (referral range 4-20%), with no adequate systematic approach to SP for heart or other chronic diseases. This research focusses on improving access to SP in R&R areas. As the research progressed it became obvious that given common risk factors for many chronic diseases, improved communication, coordination, or collaboration between organisations providing healthcare for people with heart and other chronic diseases in R&R areas is required.

Methods

A qualitatively dominant case study series was used to explore access to SP in R&R areas. Data collection was via semi-structured interviews, in four tertiary hospitals and four rural or remote communities, plus an audit of in-patient medical records (hospital study), and an audit of community-based healthcare services. Primary themes were identified through deductive analysis based on an integrative literature review, and secondary themes through an inductive thematic analysis. The findings were discussed with managers, health professionals, community members and leaders, using an iterative process to develop a revised model of SP for people with HD, *Heart: Road to Health*.

Results

Barriers included poor discharge planning, low referrals to centre-based, telephone and/or community-based health professionals for SP, together with poor client and staff understanding, and inadequate provision of SP in hospitals, primary health care settings and R&R communities. Aboriginal Community Controlled Health Organisations provided a 'wellness' model of healthcare, otherwise healthcare was generally provided through a western medicalised model which lacked a client-centred, holistic, multidisciplinary, culturally responsive approach. The *Heart: Road to health* was designed to address these issues and improve access to SP through revised health systems and management processes. Continuous quality improvement (CQI) and co-design, which are inclusive and effective methods for systems review and improvement, are proposed to ensure healthcare staff and community involvement in the development of policies, pathways, guidelines, and management processes, necessary for *Heart: Road to health.*

Given that risk factors for HD, such as obesity, smoking, inactivity, poor diet, and excessive alcohol are common for many chronic diseases, it is proposed that the *Heart: Road to health* would be suitable for people with chronic diseases (*Chronic disease: Road to health),* which, through improved access to SP could lead to improved health outcomes and quality of life.

Conclusion

The *Heart: Road to health* or *Chronic disease: Road to health* developed through this research has the potential to provide effective and efficient SP for people with chronic diseases in R&R areas. Translational research is required to develop, implement, monitor, and evaluate this healthcare model that includes improved communication, coordination and collaboration. This approach has the potential to reduce gaps and duplication in healthcare provision and provide flexible, client-centre, holistic, culturally responsive services.

Introduction

Heart disease (HD) continues to be the leading cause of mortality in Australia,[1] and is responsible for the highest burden of disease in every state except the ACT.[2] In R&R areas, hospitalisation rates for cardio-vascular disease are 45% higher than metropolitan areas, with Aboriginal and Torres Strait Islander people having rates that are double those of non-Indigenous Australians[3].

Cardiac rehabilitation (CR) is a model for providing secondary prevention (SP) of HD, predominantly through centre or home-based telephone or telehealth programs, and is known to reduce mortality and morbidity, as well as improving quality of life[4]. SP for people with HD (clients) includes education, risk factor and medical management, together with psychological support[5].

Barriers to SP in R&R of NQ areas, include few centre-based CR services and low referrals (30%)[6], compounded by even lower referrals for home-based SP services in North Queensland (NQ) (range 4%-20%)[7]. Further, health professionals often demonstrate a lack of understanding of the need for SP. To further investigate these barriers and propose potential solutions, in tertiary hospitals and R&R communities of North Queensland a case study series was undertaken to better understand factors relevant to client access to SP in R&R areas.

Methods

Sequential case study series was undertaken. Stage 1 focussed on implementation of Phase-1-CR including in-patient education, discharge planning and referral to Phase-2-CR for post-discharge SP. Stage 2 investigated the provision and access to post-discharge SP in four R&R communities. Purposeful sampling was used to select clients and staff for data collection via semi-structured interviews[8]. Primary themes were identified from the results of an integrative literature review (inductive analysis) and secondary themes through thematic data analysis (deductive analysis)[9]. Qualitative research was augmented by a medical record audit in the hospital study, and a review of current health services in the community-based study. An iterative process that included further consultation and discussion with healthcare staff, community members and leaders, was used to develop the *Heart: Road to health* model of SP for HD in R&R areas. Ethics approval was granted for all studies (Table 1)

Table 1: Ethics approvals

Hospital studies	i) Townsville Hospital and Health Services HREC	HREC/2018/QTHS/4360619/17
	ii) Greenslopes Research and Ethics Committee	7/05/2019
	iii) James Cook University Ethics Committee	H7737
Community studies	i) Townsville Hospital and Health Services HREC	HREC/2019/QTHS/5921
	ii)) James Cook University Ethics Committee	H8467

Results

A range of healthcare resources for post-discharge SP were identified in R&R areas. These resources included community-based, and visiting healthcare providers comprising nurses, Aboriginal and Torres Strait Islander Health Workers (ATSIHW), allied health professionals (AHP), and medical officers, employed by Queensland (QH), Aboriginal Community Controlled Health Organisations (ACCHO), Royal Flying Doctors service (RFDS), other contracting organisations and private health practitioners[4]. Inadequate communication, collaboration and cooperation between these organisations was identified as a barrier to healthcare provision[4, 10]. A number of alternative models for primary health care and secondary prevention of chronic diseases, and specific population groups such as aged care, were identified. Apart from cardiac educators, healthcare staff, both in hospitals and R&R communities, mainly demonstrated poor understanding of SP and systems for hospital discharge planning, and referral to community-based SP, were inadequate[4, 11].

In addition, the term CR is not well understood, with 'rehab' or 'rehabilitation' often perceived to be for people post stroke, orthopaedic surgery, or drug and alcohol misuse[4]. It is likely that due to this misconception, no examples were found of clients being referred to physiotherapists, exercise physiologists, dietitians, social workers, or community and mental health nurses for SP[4]. Therefore, the term *Heart: Road to health* was adopted.

The *Heart: Road to health* was based on a comprehensive revision of h*ealth systems* designed to address barriers, build on enablers, and develop pathways for SP for all clients, regardless of location, socio-economic status, education, and culture[12, 13]. (Figure 1)

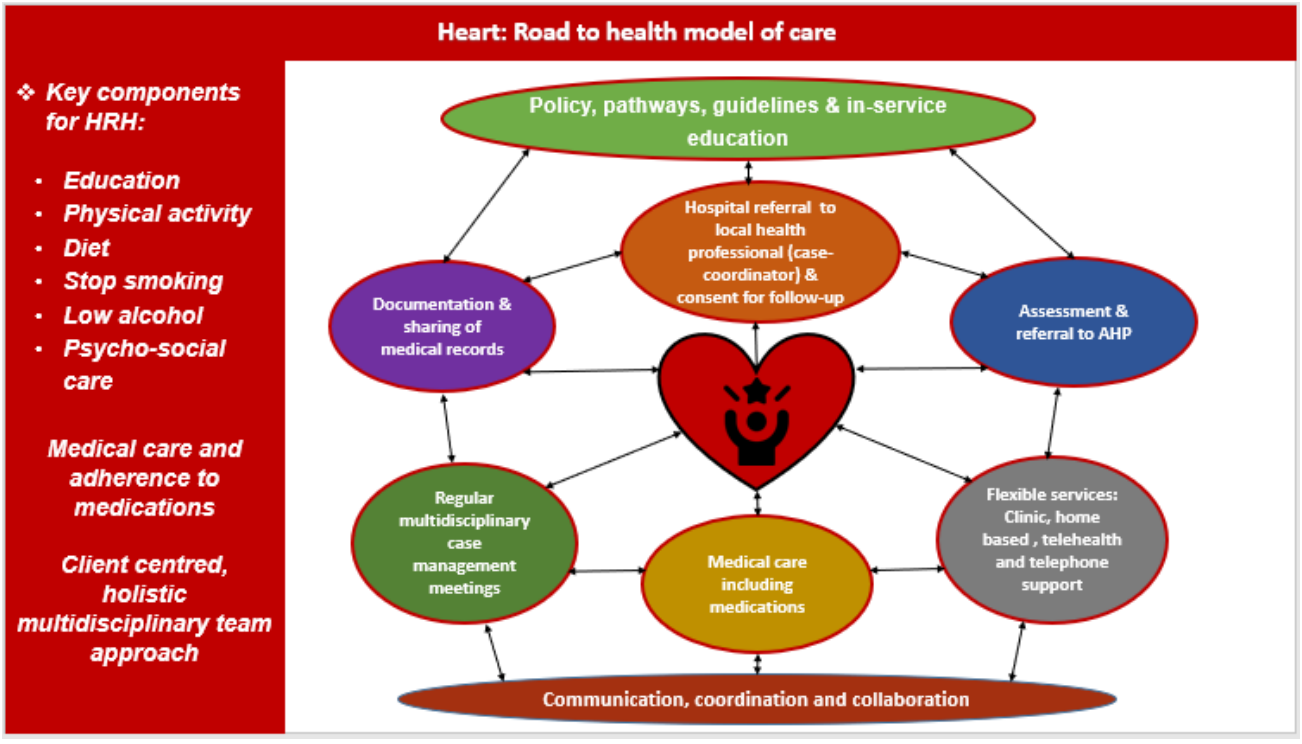

Figure 1: Heart: Road to health model

It is proposed that Heart: Road to health be implemented through revised healthcare systems that maximises use of current resources. To achieve this, interdisciplinary and interorganisational process based on continuous quality improvement (CQI) and co-design, which involve health staff and managers, in consultation with community leaders, is proposed. Such a process would include development, implementation, monitoring and evaluation of policies, pathways, and guidelines, supported by in-service education for provision of SP in R&R areas[4]. Both CQI and co-design have the potential to improve communication, working relationships, and service coordination, necessary for effective healthcare services that ultimately lead to improved health outcomes and quality of life[4, 14].

The pathway for the *Heart: Road to health* commences with in-patient education and discharge planning (Phase-1-CR) and is recommended to include automatic referrals to post-discharge CR programs and/or community-based SP (Phase-2-CR)[11]. Referral to community-based SP would also require consent for follow-up and assessment, by a community-based case-coordinator such as an ATSIHW and/or community nurse, who could initiate referrals to AHP for risk factor management and liaison with the medical officer. (Figure 2)

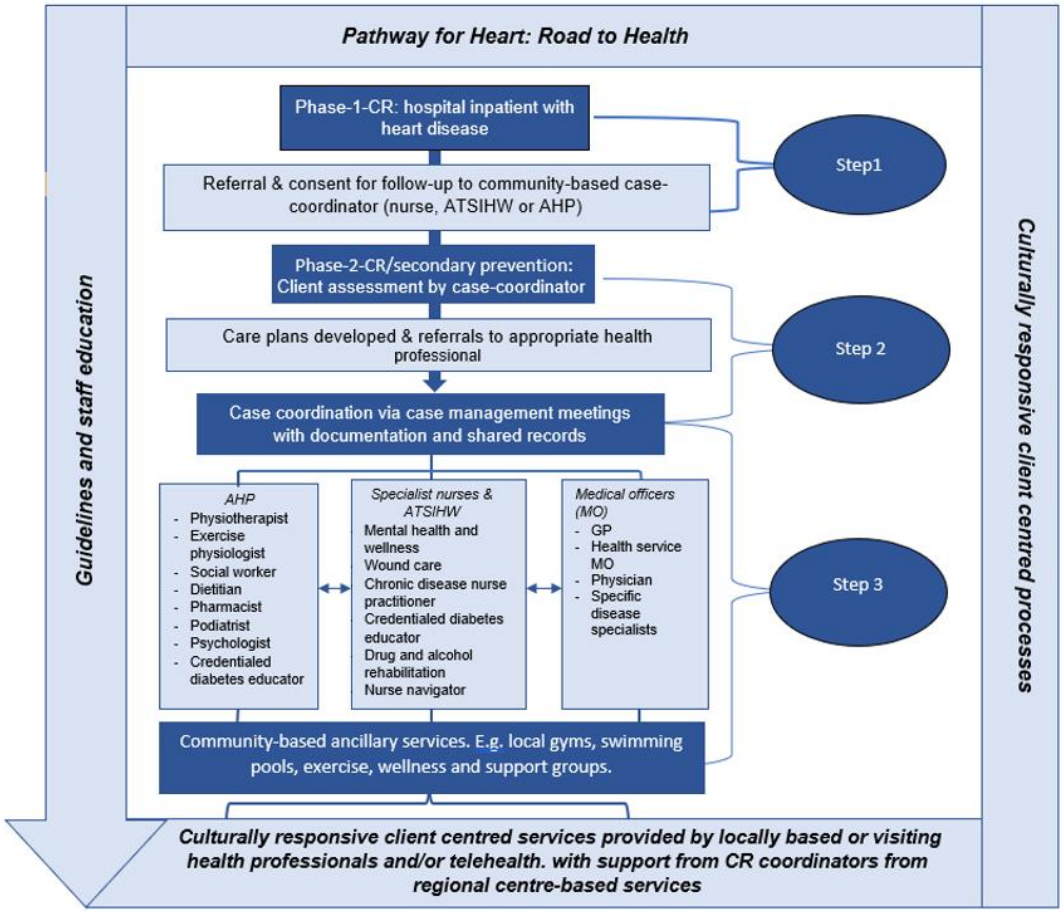

Figure 2: Pathway for Heart: Road to health

The aim of *Heart: Road to health* is to ensure that all clients in R&R areas have access to culturally responsive SP services. [10, 15]. Whilst conceptually simple, *Heart: Road to health* includes aspects of healthcare and SP that may be unfamiliar to community-based health professionals.[4]

Thereby, staff education and support are essential, together with ongoing technical support provided by centre-based CR coordinators and/or established chronic disease programs, via telehealth or telephone[4].

Discussion

Through this research the complexity of environmental, cultural, economic, and social issues became apparent, including cultural factors and social determinants of health (SDoH).

Poor SDoH include employment, income, education, healthy food choices, housing, climate, telephone, internet services, distance to services, and colonisation, and are known to negatively impact on health literacy, access and effectiveness of health services, and health outcomes. Therefore, SDoH must be considered when planning and implementing accessible and effective services in R&R areas. [16-19].

Everyone's culture is based on 'beliefs, customs, values, and activities' which are influenced by family, environment and relationships, that impact on all facets of life.[20]. These cultural factors make it impossible for a person from one culture, to fully understand all aspects of another culture. Therefore, for effective culturally responsive healthcare it is essential that ATSIHW are primary members of the team that provides services for Aboriginal and Torres Strait Islander people.[21] To achieve this, cultural training is essential to improve the understanding of non-Indigenous staff.

To guide the development of revised healthcare systems for *Heart: Road to health,* there are examples of culturally responsive, holistic, multidisciplinary programs, that involve ATSIHW and ACCHOs in the provision of SP for Aboriginal and Torres Strait Islander people.[22, 23] These provide models that we can learn from by demonstrating state health and ACCHO working collaboratively, and thereby facilitating strong relationships and trust.[24]

The well-established and successful diabetes self-management program is coordinated by regional credentialled diabetes educators (CDE).[25] The diabetes model includes in-patient referrals made to CDE, and/or GP, who routinely link with the CDE. The program provides coordinated of person-centred holistic, multidisciplinary SP, that includes referrals to AHP, and liaison with local healthcare providers. This approach results in a collaborative and co-ordinated health care in which the client is supported to achieve improved health literacy, and self-management.[25] Further, Cape York Kidney Care is a client-centred holistic, multidisciplinary program that has been successful in delaying commencement of renal dialysis, reducing unplanned evacuations and improving patient's quality of life.[26] A further benefit from improved healthcare systems such as *Heart: Road to health,* is that fewer unscheduled consultations, and emergency evacuations would eventuate due to better managed care, thereby reducing stress for clients, their family, and staff, and subsequently staff turnover and healthcare costs. For optimal benefits from individual disease focussed programs, a collaborative/coordinated process for healthcare provision between QH, ACCHO, RFDS, contracting organisations, private practitioners and local research programs is required.

Overall, there is a pressing need for a comprehensive, flexible, client-centred, holistic, multidisciplinary systems approach for provision of SP for heart and other chronic diseases in R&R areas of Australia. The *Heart: Road to health* includes pathways from hospital to home, and healthcare systems that utilise current staff through revised systems, supported by appropriate management, policies, guidelines and in-service education. It is important that lessons learnt from successful SP models are integrated into the *Heart: Road for health*[4]. Furthermore, due to common risk factors for a range of chronic diseases, including heart, diabetes, and renal disease,[1] there are gains to be made by utilising the model for *Heart: Road to health* or *Chronic disease: Road to health* as depicted in Figures 1 & 2. Thereby a collaborative approach, possibly coordinated through QH Chronic Disease Centres is proposed.

Conclusion

Heart: Road to health or *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 a systems approach, that includes development of comprehensive policies, pathways, guidelines, and in-service education using CQI or co-design is proposed. Such processes could provide a continuous framework for improved communication, coordination and collaboration between all healthcare providers in R&R areas and potentially lead to improved health outcomes.

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5.3.3 Development of a Road to health approach

The studies completed in this research, led to the development of the model *Heart: Road to health*, which is designed to improve access and provision to secondary prevention for people with HD in R&R areas of NQ. However, it is proposed that an inclusive, rather than a disease-specific model is required for the provision of efficient and effective secondary prevention in R&R areas. In line with this collaborative approach the broadening of the focus from *Heart: Road to health* to a *Chronic disease: Road to health,* or to simplify, *Road to health* approach, is proposed. To achieve this the main factors identified by this research were:

- poor implementation of hospital in-patient Phase-1-CR that resulted in poor in-patient understanding of their disease and treatment, inadequate discharge planning and referrals to Phase-2-CR;[120]
- inadequate access to secondary prevention in R&R areas of NQ;[102, 117, 121]

- greater needs of people in R&R areas, including high rates of HD and multi-morbidities, and impact of SDoH especially for Aboriginal and Torres Strait Islander people;[122]
- a range of healthcare resources that could be potentially utilised for the provision of secondary prevention for people with heart or other chronic diseases are available;
- weak or non-existent systems to ensure access to secondary prevention in R&R areas of NQ;(5.2.3)[102]
- Holistic, client centred, multidisciplinary, culturally responsive approach that improves access to secondary prevention for people with heart and other chronic disease, in particular diabetes and renal disease is required (5.2.3) ([122]
- Translational research is required to establish if the proposed *Road to health* approach, is a feasible option.

As this research progressed, alternative models of holistic, multidisciplinary, client-centred healthcare initiatives were identified, (Table 10) and it is proposed that there is potential to develop a generic model for secondary prevention for heart and related chronic diseases such as diabetes and renal disease. (*Road to health)* These alternative models of care provide information on strengths and weaknesses of a range of programs.

The NQ Cape York Kidney Care program (CYKC), (Table 10) is a prime example of an alternative client-centred holistic, multidisciplinary, culturally responsive, healthcare program that demonstrates improved service delivery, efficiency, and health outcomes.[54] The CYKC programs works closely with local healthcare providers, but overall there is scant evidence of communication, coordination and collaboration between any of the programs currently being provided in NQ, (Table 10). For alternative healthcare programs to have maximum potential, it is important that the local community and healthcare staff, are engaged with, and provided education, capacity building and support.[54] Further investigation is required to establish if this is integral to all alternative programs. This investigation could be included in the comprehensive inventory of current services, and a gap analysis, that is required as part of translational research (5.3.4).

Through revised healthcare systems, including improved communication, coordination and collaboration, it is asserted that gaps or duplications in service delivery could potentially be minimised, and an effective *Road to health* achieved (5.3.2, Paper 7). Since COVID-19 telephone and telehealth services are more acceptable, with improved utilisation.[32] Thereby,

these services are increasingly important in the provision of alternative models of secondary prevention and/or as an adjunct to routine healthcare provision.[32] Conversely, unreliable internet and telephone services, plus staff and community members' continued preference for face-to-face communication, limit usage and potential benefits of these services in R&R areas and need further investigation.[34, 102, 133, 134]

It is advocated that services such as QH's Self-Management of Chronic Conditions (SMOCC) would be more acceptable in R&R areas if there were increased inclusion of local healthcare providers and community-based organisations, such as local gyms, sporting facilities, libraries, educational and community service organisations. Linking clients with local service providers, including community nurses and ATSIHW, as well as a GP (if available), would provide a connection with the local community, and potentially increase uptake and effectiveness of any technology-based program.

On occasions poor working relationships between QH and ACCHO continue to be a barrier to effective and culturally responsive healthcare. [102] However, this varies from place to place, and there are also examples of sound working relationships that could inform the development and implementation of a *Road to health*.[102] Examples of current programs that were identified throughout the research are summarised in Table 10, noting that there is a need to evaluate these programs and consider how a *Road to health* approach could be achieved in conjunction with these programs and routine healthcare delivery.

As described throughout this research, there is a network of healthcare services provided by QH, ACCHO, RFDS, contracting organisations and individual private health practitioners, throughout R&R areas of NQ.[102] These services are augmented by telephone support and apps, as well as telehealth. Apart from these established services, QH, NQ Primary Health Networks, and National Health Medical and Research Council (NHMRC) provide grants, to support a number of client-centred, holistic, multidisciplinary, culturally responsive models of healthcare, such as the diabetes education and self-management model,[135] and OPEN ARCH.[55] These programs focus on a specific chronic disease, or purpose, such as aged care, (Table 10).

Table 10: Examples of alternative healthcare programs in NQ

Program	Information
*Diabetes education & self-management model[135]	Coordinated by a credentialled Diabetes Educator, nurse or AHP, who provide outreach services throughout Queensland. Well-established program. No formal evaluation was identified.[135]
*Cape York Kidney Care (CYKC)[54]	Coordinated by a Renal Disease Nurse Practitioner, CYKC provides services for people with renal disease in Western Cape York.[54] ATSIHW are employed as part of the team. 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. (TCHHS,CN8/2)
*Healthcare In Your Home (HIYH)[129]	Currently being established in NQ, where HIYH is designed to be coordinated by a nurse or AHP with less reliance on GP 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 healthcare 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 ACCHOs found that there was uncertainty about the program from clients, insufficient GPs participated, 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. Further, it was recommended that more effort was required to publicise the program and recruit clients who were less motivated to attend. Efforts are being made to address these issues and the program has been extended for a further 12 months.[136] The NQ program is currently being implemented.[129]
*OPEN ARCH[55]	A community-based program that provides preventative, comprehensive integrated care at the primary/secondary prevention interface. Evaluation found no significant difference in emergency department presentations or hospitalisations. But stabilisations in presentation rates, and a trend towards lower hospitalisation rates, plus stabilisation of quality of life and absence of functional decline, were noted.[55]
Deadly Ears[56]	Ear nose and throat program the prioritises children hearing, through capacity building, workforce development, and collaboration between QH, ACCHOs and non-government organisations. Healthcare is provided in local communities with support from a medical specialist in Brisbane.[56] The program is reported as being well received, (TCHHS, CN8/2) but no formal evaluation was available.
Virtual Out-patient Integration for Chronic Disease VOICeD[57]	This program focuses on integrated medical specialist teleconferencing for heart, renal disease, and diabetes. Anecdotally, the program is well received but no formal evaluation was available.[57] (TCCHHS, CN14/2)[57]

Note: The programs indicated with an asterisk* were showcased at a recent *Heart: Road to health* or *Chronic disease: Road to health* forum in NQ. This forum provided examples of flexible, holistic, client-centred and culturally responsive programs being delivered in NQ and interstate. (Appendices: 7.3 Forum invitation; 7.4 Forum report).

Apart from the medical telehealth program VOICeD, all programs in Table 10 are community-based, with healthcare provided predominantly by nurses and ATSIHW, usually supported by medical officers and AHP or via teleconferencing through QH PHCC, MPHS, together with ACCHO and the RFDS.[54-56, 129, 135] Not all these programs have been evaluated, and there is no overall coordinated approach, or published plan, for implementation more broadly. Thereby, it is not possible to gauge overall effectiveness. However it is clear that resources and expertise in the areas of chronic disease and secondary prevention are available and arguably could be more effectively utilised.

It is advocated that through health services revision, supported by appropriate policies, guidelines, pathways, and in-service education, the *Road to health* approach is possible. Such a model of care would utilise local health resources, supported by visiting and telehealth specialists. It is important to note that whilst risk factors are common through a range of chronic diseases, medical management varies widely, and there will always be a need for specialist medical management, that is provided in conjunction with a broad, holistic multidisciplinary team approach. It is also proposed that community-based services such as women's, men's, and children's programs, plus local sport, recreation and educational organisations, are linked into support, exercise and education programs for people with heart disease, diabetes and renal disease.[69] Overall, it is proposed that collaborative working relationships, facilitated by improved staff capacity, could enable a *Road to health* approach, that could result in increased client health literacy, improved health outcomes, and quality of life.[137]

5.3.4 Implications for practice and policy

Effective service provision in R&R areas needs to be flexible, client-centred, holistic, and culturally responsive. To achieve this, revised healthcare systems that are developed through CQI and co-design, that enable consideration of SDoH, are required.[102, 122]

The iterative process that has continued through to the completion of this thesis indicates that there are relevant resources available in R&R areas of NQ. However, based on previous research in the Northern Territory which demonstrated that adequate resourcing and careful supervision are critical success factors for treatment of chronic diseases,[138] resources need careful consideration. Further, whilst this research has identified regional and community resources, plus alternative programs that provide services in NQ, a comprehensive inventory of current services, and a gap analysis, is required as part of translational research. Further, for comprehensive and effective change, a regional approach that includes healthcare providers,

managers and policymakers is proposed to inform the development of a revised model of coordinated and collaborative care for heart and common multimorbidity such as diabetes and renal disease (*Road to health* approach).

5.3.5 The way forward

To bring *Road to health* to fruition in R&R areas there are a range of complexities, including SDoH, environmental and geographic factors, availability of resources, and disparate and sparse populations, that need to be considered. The combined public health, health promotion and primary healthcare theories that underpinned this research ensured a bottom-up approach, in which local community members and healthcare providers are involved. This involvement continues and is essential as we move forward.

Apart from the factors necessary for the implementation of the *Road to health,* (5.3.1, 5.3.2), it is clear that there needs to be a shift away from the clinical Western medicalised model of healthcare, to enable holistic, client-centred and culturally responsive care to be achieved.[12, 122] A further barrier that needs to be addressed is the development of a system for sharing of medical records between the alternative programs, and routine healthcare organisations.[102] Without this, client-centred coordinated care will be diminished in areas with multiple healthcare providers, with gaps and/or duplication in service provision likely.[102, 113]

A blueprint for reform for secondary prevention of heart disease in Australia was developed by Redfern and Chow (2013).[19] Recommendations ii, iv, v. are congruent with the concepts of the *Road to health,* (Chapter 5: 5.3.1, 5.3.2) and the remaining recommendations continue to be relevant at a national level.

i. Develop and implement a national approach that is inherently adaptable to available resources and individual in-patient[/client] needs and values, and includes structured initial assessment, risk factor modification, follow-up and reassessment.

ii. Bridge the gap between hospital and primary health care and provide connected care by using a case-management approach, improved communication, and greater provider education relating to secondary prevention, behaviour change techniques and self-management strategies.

iii. Increase awareness, cohesion, and utilisation of existing services (by in-patients/clients) through creation of a national inventory or “map” of secondary prevention initiatives.

iv. Develop a system for monitoring and maintaining performance in secondary prevention.

v. Implement a communication strategy that links and engages state and federal government, Medicare Locals, [Primary Health Networks] consumers and private health funders to facilitate sustainability.

vi. Establish a national secondary prevention task force to implement the recommendations resulting from the secondary prevention consensus meeting.[19]

Apart from a database providing information on secondary prevention services,[81] no evidence of implementation of these recommendations was found. Therefore, a process to revitalise, in conjunction with the development and implementation of a *Road to health* is pertinent.

It is important that there is a sound and structured process around the development and implementation of the changes necessary for a *Road to health.* CQI combined with a co-design process, would facilitate the provision of locally provided secondary prevention that meets the communities' needs, (5.3.2).[80, 122] This approach would also facilitate consideration of SDoH and potentially result in programs that are responsive to specific populations and environments, (5.3.2).[79, 122] Ultimately this process could lead to appropriate, culturally responsive, efficient and effective *Road to health*.[76, 78]

It is acknowledged that it is difficult to implement revised healthcare systems without increased resources. This research has demonstrated that even when resources are available, healthcare systems are weak, and it is unlikely that optimal benefit is being achieved. The currently available community-based, visiting and regional resources are all playing an important part is provision and coordination of regional services. Through revised healthcare systems and improved communication, coordination and collaboration these resources in conjunction with alternative programs and augmented by technological services, have the potential to enable the implementation of the *Road to health* (Table 10),.

It is notable that in this research no staff member expressed that they were unwilling to provide secondary prevention due to a lack of resources.[102] However, their willingness to provide secondary prevention was hampered by delayed referrals,[102] with little post-discharge information provided on secondary prevention, and their own generally low understanding of holistic healthcare and risk factor management.[120] Therefore, it is proposed that through revised health systems revision, with regional support from Chronic

Disease and CR centres, together with nurse navigators, and nurse practitioners the implementation of *Road to health* is possible.

It can always be argued that significantly more resources are always required. However, this thesis proposes that a *Road to health* approach could be sustainable with careful planning and implementation of revised healthcare systems with little extra resources, especially where a holistic, well planned, collaborative approach is taken.

5.4 Recommendations

These recommendations are drawn from the studies presented in this research and compiled to provide recommended changes for health service revision required to improve access to secondary prevention for people with HD in R&R areas of NQ. In line with the *Road to health* approach the same recommendations could be applied for people with HD, diabetes or renal disease.

5.4.1 Implementation of Phase-1-secondary prevention and impact on post-discharge care in R&R areas

For provision of Phase-1-secondary prevention it is recommended that:

- a multidisciplinary team approach is integrated into day-to-day in-patient care, supported with appropriate protocols and processes guided by in-service education led by cardiac educators;
- an information sheet that includes priorities of Phase-1-secondary prevention, such as discharge planning and referral to Phase-2-secondary prevention, and is available within in-patient folders for staff reference;
- Phase-1-secondary prevention and Phase-2-secondary prevention information packs are available for people discharged after-hours and for short-stay in-patients;
- eligibility criteria as per National Heart Foundation of Australia (NHF) and Australia Cardiovascular Health Association (ACRA) recommendations are used to ensure that all in-patients are referred to Phase-2-secondary prevention programs and/or community-based healthcare providers for secondary prevention;
- a system for automatic referrals, and consent for follow-up for all eligible clients, with copies of referrals sent to community health nurses, ATSIHS and GP;
- specific cardiac services, and medical discharge summaries, are prepared prior to discharge, sent to the local community nurse, ATSIHW and GP as appropriate, with a copy given to the in-patient, prior to discharge;
- Information included in the discharge summaries need to include:

- information on risk factor mitigation, exercise regime, wound care and precautions (as applicable), medications, medical review, follow-up appointments, referral to centre-based secondary prevention programs, and/or telephone/telehealth and community-based secondary prevention services;

5.4.2 Implementation and improved access to secondary prevention (Phase-2-secondary prevention) in R&R communities and Road to health

As discussed to achieve a *Road to health*, systems need to be revised to ensure that all clients receive the support and secondary prevention services necessary, both in hospital and on return home. QH policies, strategies, and clinical pathways for treatment of HD are currently available. These include statements about discharge planning and follow-up care, plus the need for referrals to Phase-2- secondary prevention.[52, 139-142] However, there is no evidence of these policies being implemented.[102, 120] Therefore to achieve a *Road to health* it is recommended that by utilising CQI and co-design:

- policies, pathways and guidelines to guide the client's pathway, beginning in hospital with Phase-1-secondary prevention, in their home community with Phase-2 secondary prevention, and finally supported healthcare maintenance, and client self-management (Phase-3- secondary prevention) are developed. Each of these phases need to consider the following aspects of healthcare delivery to improve coordination, communication and collaboration and client centred care for implementation of *Road to health.* To achieve this it is recommended that through translational research the following are implemented through a pilot study:
  - terminology is changed from CR to secondary prevention and includes *Heart : Road to health* or *Road to health* for people with chronic disease especially diabetes and renal disease;
  - *Road to health* approach that utilises local health resources, supported by visiting and telehealth specialists according to pathways, guidelines and in-service education;
  - a system by which in-patients are referred to the local community nurse and/or ATSIHW for assessment, case-management, and referral to local or visiting AHP for secondary prevention;
  - a weekly multidisciplinary case-management meeting that is documented and decisions shared with all healthcare providers involved in a client's care.

- a system for sharing medical records with all organisations; and individual private health practitioners involved in a client's care;
- a review of existing Chronic Disease Centres to have a greater focus on secondary prevention for HD, and improved coordinated healthcare delivery of specific disease focussed programs;

It is important to reiterate that whilst risk factor for chronic disease are common across a range of disease, treatments vary widely and need to be considered by appropriate medical specialists. To achieve this, and as part of translational research, guidelines need to be developed for community-based staff to enable follow-up which links with specialised treatments for specific diseases.[143]

- a process is commenced to revitalise the recommendations of Redfern and Chow (2013), (5.3.5), to strengthen secondary prevention in Australia.

5.4.3 Improving access to cardiac rehabilitation (Heart: Road to health or Road to health) for Aboriginal and Torres Strait Islander people in R&R areas of NQ

To improve access to *Road to health* for Aboriginal and Torres Strait Islander people it is recommended that:

- flexible, client-focused, culturally responsive services such as those provided by the ACCHO Wellness model,[49] in which ATSIHW either take the lead role or at least work in partnership with community-based health professionals such as nurses, are provided;
- cross-cultural education is included as part of the in-service education for *Heart: Road to health* within the chronic disease area;
- flexible, client-centred, culturally responsive *Road to health* is accessible for Aboriginal and Torres Strait Islander people in R&R areas of NQ, achieved through:
  - improved communication, coordination and collaboration processes and revised healthcare systems provided by QH, ACCHO, RFDS, contracting organisations, and individual private health practitioners, together with successful alternative healthcare programs, (Table 10).[122]

Whilst this section specifically refers to appropriate and effective services for Aboriginal and Torres Strait Islander people the recommendations are equally as applicable for all people in all areas.

5.4.4 Implementation of recommendations

It is important that a process is developed to consider and implement the recommendations of this research. This process would be part of translational research, which could include a pilot study, initiated through health service managers and include healthcare providers, as well as community representatives. The CQI cycle is proposed for instituting effective organisational change and co-design would facilitate engaging community members and leaders with healthcare staff in finding solutions for access to secondary prevention, (Chapter3: 3.8.1; 5.3.2).[79, 80, 122] This approach would potentially facilitate an ongoing process through which programs could continue to grow, develop and meet the needs of people for whom services are designed.

5.5 Strengths and limitations

This research has taken a unique approach to investigating access to secondary prevention in R&R areas of NQ. The in-patient/client journey is followed from hospital to home and proposes a pathway to optimal health. The sequential research studies resulted in a sound understanding of the issues faced by healthcare staff, and clients, in the provision and access to comprehensive, holistic, post-discharge secondary prevention in R&R areas of NQ. Based on this understanding, the final iterative process that included communication and discussion with community members, leaders, healthcare providers and managers, resulted in the proposed *Road to health.* (5.3.2).

Extensive pre-research planning was undertaken in the community case studies, (Chapter 3: 3.4),[86] and up to four weeks was allowed for data collection in each site, during which time as coordinating primary investigator, I stayed in the vicinity. This facilitated the development of networks and relationships with local people and healthcare staff and allowed time to arrange meetings at a time and place that was acceptable to the participants.[86] I also made regular follow-up visits for further discussion, and checking of data, (member checking).[84] Overall, data collection and methods were rigorous and accurate at the time of collection. However, there is often rapid change in healthcare services in NQ, predominantly due to high staff turnover[59] and changing government strategic plans,[51] now compounded by the COVID-19 pandemic.[144]To minimise the impact of these factors, follow-up with health service managers, staff, strategic planners, community members and leaders, both individually and through the local Community Advisory Networks has continued following the completion of community-based studies.

Whilst Stage 4a of this research included a review of healthcare services.[102] Further investigation is required to accurately establish current availability. It is clear that even when resources are available, systems are weak and the available resources not well utilised. At this stage no economic analysis or pilot study has been undertaken. Therefore whether the *Road to health* is achievable, and ultimately results in effective and efficient healthcare services, cannot be established until translational research, is undertaken.

Finally, while a large number of interviews were carried out and consistent themes identified from the data, the findings of this research do not necessarily account for the views of all health staff, or community participants. While caution should be taken in generalising from this research, there was a high degree of agreement on barriers, enablers and pathways for the provision of healthcare and secondary prevention in R&R areas throughout Australia.

This research focused on a small part of rural Australia (NQ), however we note that these issues are not unique to NQ, nor Australia .[28, 86, 94]The literature review, (Chapter2: 2.1;2.3),[83] highlighted similar challenges faced across the globe,[65, 66, 71, 133] and the need for programs that meet local needs within a wider health system. Therefore the findings from this study may be applicable to other national and international healthcare systems. Prior to broader implementation it is important that translational research, including a pilot study and evaluation of the proposed model for *Road to health,* is undertaken.

5.6 Future research

This research provides evidence that there is potential to improve access to secondary prevention via the *Road to health* approach. We know that we can make a difference,[143] when adequate resources and systems are focussed on addressing multimorbidity and take a holistic, culturally appropriate community-based approach to healthcare delivery. However, as we have discussed, before this can be achieved, translational research is required to develop, implement, monitor and evaluate *Road to health.* It is proposed that community-based co-design and CQI, is used for health systems revision, and ensuring inclusion of community-based issues and initiatives,(5.3.2).[80, 122]

If a pilot study demonstrates that the *Road to health* is feasible in R&R areas in Australia, it is likely that such a model would be relevant in R&R areas of other countries that face similar issues. This needs further investigation.

5.7 Conclusion

The findings of this research led to the development of a model for *Heart: Road to health*, which is proposed to be expanded to a generic *Road to health* that has the potential to

improve access to secondary prevention for people with HD, diabetes and renal disease, in R&R areas in NQ. The pathway to *Road to health* needs to commence with improved hospital in-patient education, discharge planning and referral for secondary prevention, and continue through to improved access to effective and appropriate secondary prevention in the clients' home community, until supported self-management is achieved. A broad range of healthcare organisations, resident or visiting health professionals, alternative chronic disease and aged care programs, telephone and telehealth secondary prevention services, are available in R&R areas of NQ. However, communication, coordination and collaboration between these services remain inadequate.

It is proposed that translational research considers a collaborative way forward for the development, implementation, monitoring and evaluation of a *Road to health*. To achieve this, it will be necessary to move away from individual disease-focused programs and broaden service provision to generic programs that provide flexible and client-centred, culturally responsive, secondary prevention services. Should this be realised, the *Road to health* approach has the potential to address deficits in the provision of secondary prevention for HD, diabetes and renal disease, and if successful to improve health outcomes and quality of life, as well as reduce gaps or duplication in services, hospitalisations and costs.

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Appendices

Appendix 7.1 Conferences

Field P, Franklin R, Barker R, Ring I, Leggat, P. Cardiac rehabilitation services for people living in rural and remote areas: An integrative literature review. Paper presented at: Australian Cardiac Rehabilitation Association. 3 August 2018. Brisbane.

Field P, Franklin R, Barker R, Ring I, Leggat, P. Cardiac rehabilitation services for people living in rural and remote areas: An integrative literature review. Paper presented at: Are You Remotely Interested? 25 July 2018. Mt Isa.

Field P, Franklin R, Barker R, Ring I, Leggat P, Canuto K. Heart disease hospitalisation and COACH referral in Queensland. Paper presented at: Australian Cardiac Rehabilitation Association Conference. 7 August 2019. Sydney

Field P, Franklin R, Barker R, Ring I, Leggat P, Canuto K. Implementation of Phase 1 Cardiac Rehabilitation in major hospitals in North Queensland. Paper presented at: Far North Queensland Research Symposium. 16 October 2019. Cairns.

Field P, Franklin R, Barker R, Ring, I Canuto K, Leggat P. Improving access to cardiac rehabilitation in rural and remote areas: Early research findings. Paper presented at: College of Public Health, Medical and Veterinary Science seminar series. September 2020. JCU, Townsville.

Field P, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Improving access to cardiac rehabilitation in rural and remote areas: Client and staff perspective. Paper presented at: College of Public Health, Medical and Veterinary Science seminar series. April 2021. JCU, Townsville.

Field P, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Cardiac rehabilitation in rural and remote areas: How well are we doing? Paper presented at: JCU Cohort 10th Anniversary conference. 9 September 2021. JCU, Townsville.

Field P, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Cardiac rehabilitation in rural and remote areas: How well are we doing? Paper presented at: Townsville Health Research showcase. 12 October 2021. Townsville.

Field P, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Cardiac rehabilitation in rural and remote areas: How well are we doing? Poster presented at: Cairns Research and Innovation Symposium 2021. 6 October 2021. Cairns.

Field P, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Cardiac rehabilitation in rural and remote areas: How well are we doing? Paper presented at: NRHA 8th Rural and Remote Scientific Symposium. 7 October 2021. Canberra. (virtual)

Field P, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Access to cardiac rehabilitation in rural and remote areas of North Queensland: How well are we doing? Virtual poster presentation at: ACRA SA/NT showcase. 28 May 2022. Adelaide.

Field P, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Improving access to cardiac rehabilitation in rural and remote areas of NQ. Poster presented at: Queensland Cardiovascular Research Network Symposium. 8 November 2021. Sunshine Coast University Hospital, Qld, Sunshine Coast.

Field P, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Cardiac rehabilitation in rural and remote areas: Improved models of care. Paper presented at: National Rural Health Alliance (NRHA) Rural and Remote Health Conference. 2–4 August 2022. Brisbane.

Field P, Franklin R, Barker R, Ring I, Canuto K, Leggat P. Cardiac rehabilitation in rural and remote areas: Improved models of care. Poster presented at: Australia Cardiovascular Health and Rehabilitation Association (ACRA) Annual Scientific Conference. 8–10 August 2022. Gold Coast.

Appendix 7.2 Community information briefing sheet

23rd October 2021

Community information briefing sheet:

Improving access to cardiac rehabilitation in rural and remote areas of North Queensland - Heart: Road to Health

Background

It is known that rates of heart disease are high in rural and remote (R&R) areas of NQ and highest in Aboriginal and Torres Strait Islander populations. People with heart disease often need hospital treatment, and when they return home from hospital they need extra support to help them to fully recover and improve their general health (cardiac rehabilitation [CR]). When people leave hospital most don't know what to do. For example, how far they can walk; what they should eat and drink; if they are smokers and/or drink a lot of alcohol, how to stop. People are often very worried about their future health, life, and how they will manage. They need help with all these things, and this can be done through CR or the Heart: Road to Health (HRH). CR or HRH includes medical care, education, exercise, healthy diet, stop smoking, low alcohol, and mental health support, to help people recover from their recent treatment and improve their overall health. The HRH can support them to make the necessary lifestyle changes to achieve improved health and a good life.

Research

Since 2017 I have been working with a JCU research team towards improving access to CR in R&R areas of NQ. During this time I have met with, and interviewed many people from local communities, including those with heart disease, as well as health professionals and managers from Queensland Health, Aboriginal and Torres Strait Islander Health Services and Royal Flying Doctor Service.

By doing this we have been able to get a clear picture of what support is available for people in R&R areas when they return home from hospital after treatment for heart disease, and how well these services are used.

What did we find?

Weaknesses:

- Poor preparation of in-patients, prior to discharge from hospital, resulted in a lack of understanding of their disease and follow-up care.
- Poor communication between the treating hospital and local health professionals.
- Predominantly clinical post-discharge care.
- Lack of lifestyle approach through Allied Health Professionals (AHP).

- Low CR referral rates, including home-based telephone support secondary prevention (COACH).
- Generally low understanding by staff and community members of CR, other than those who have had previous involvement, in particular (AHP).
- No follow-up system or guidelines for referral to community nurses, Aboriginal and/or Torres Strait Islander Health Workers (ATSIHW), or AHP e.g. physiotherapists, dietitians, psychologists as well as mental health nurses, nurse practitioners and educators.
- Non-sharing of medical records resulting in poor communication between various health professionals and organisations outside Queensland Health. Torres and Cape Hospital and Health Services has introduced an electronic system to facilitate sharing of medical records, Regional Information Via Electronic Records (RIVeR). Currently this has mixed feedback on effectiveness and acceptability for various health service providers who need to access the records. We are not aware of any further systems to improve communication between various health service providers.

Strengths:

- A range of multidisciplinary team (MDT) services are available – Including nurses, Aboriginal and/or Torres Strait Islander Health Workers, AHP & doctors.
- AHP have a sound understanding of CR/secondary prevention.
- There is a functional model of care for people with diabetes including:
  - referral to diabetes educators who provide education, support and disease management
  - ongoing case management & referrals to AHP

The way forward:

- Improving communication and referrals to nurses, Aboriginal and Torres Strait Islander Health Workers & AHP, for case management on discharge from the treating hospital.
- Considering the model of diabetes care as a template for revising systems to improve linkages and MDT support for people in R&R areas with heart disease.
- Reorientating health systems to include referral pathways to a locally based case-coordinator, developing guidelines and providing education and support, for current health staff.
- Ensuring that services are culturally responsive for Aboriginal and Torres Strait Islander people
- Developing a system for sharing of medical records
- A successful model of 'Road to Health' could be utilised for secondary prevention for a range of chronic diseases.

Thank you for your contribution to this research and I am happy to discuss further.

Pat Field

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Townsville.
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Appendix 7.3 Invitation to Forum for Heart: Road to health or Chronic disease: Road to health

HEART OR CHRONIC DISEASE: ROAD TO HEALTH

INVITATION: You are invited to a forum to assist in the development of health care systems to improve access to cardiac rehabilitation(CR) or chronic disease in rural and remote (R&R) areas of North Queensland (NQ): *Heart or Chronic disease– Road to Health*

CONVENED BY: James Cook University, in collaboration with Tropical Australia Academic Health Centre; Queensland Cardiovascular Health Association; and Queensland Cardiovascular Research Network

PURPOSE: To hear from participants about current health care projects and develop a way forward to ensure that all people discharged from hospital receive holistic multidisciplinary care in their local community.

The best people to address any challenge in health service delivery are community members, health service providers, and managers from the local area. As such we strongly encourage you to participate so that we can develop a systems-based action plan for improved in *Heart or Chronic disease – Road to Health* in R&R areas.

DATE: 18th August 2022

TIME: 8am – 12md: Information sharing, scene setting identification of challenges

1pm – 4.30pm: Developing a way forward

VENUE: James Cook University Building 039, Room 252

OR via Zoom (link to be organised)|

Morning, afternoon tea and lunch provided

PLEASE RSVP or contact Pat Field with any queries.

Mobile Email: Patricia.field1@my.jcu.edu.au

Research team & convenors: Pat Field, PhD Candidate; Prof. Richard Franklin; A/Prof. Ruth Barker; Prof. Ian Ring; Dr Karla Canuto; Prof. Peter Leggat

With acknowledgement of support provided by Queensland Health and Tropical Australia Academic Health Centre (TAAHC) throughout the research

Report on Forum - Heart: Road to health or Chronic disease: Road to health in rural and remote areas

18th August 2022

Background

Cardiac rehabilitation (CR) is a successful method of secondary prevention that results in improved health outcomes for people with heart disease.[1-3] Despite this, CR is poorly attended,[4, 5] especially in rural and remote (R&R) areas of Australia. Barriers identified include inadequate implementation of hospital in-patient Phase-1-CR including discharge planning and referrals to Phase-2-CR (30%),[6]; poor understanding of the purpose, and benefits and weak healthcare systems to ensure flexible, client-centred, holistic multidisciplinary, culturally responsive, secondary prevention services for all people with heart or chronic disease (clients) in R&R areas,[5, 7]

The research on *Improving access to cardiac rehabilitation in R&R areas of NQ* identified that resources are available to potentially address the shortfalls. These include a network of Queensland Health (QH) multipurpose health services, (MPHS); primary health care centres (PHCC); Aboriginal Community Controlled Health Services (ACCHOs); and Royal Flying Doctor Service (RFDS). Further, there are a range of chronic disease, aged care, hospital extension programs and research, funded on a grant or contractual basis through North Queensland Primary Health Networks (NQPHN), Commonwealth or QH. However, there is little evidence of effective communication, collaboration and co-ordination between service providers or researchers. This information combined with data collected from hospital and community health staff, and people treated for heart disease together with ongoing community/health staff consultation, led to the development of the model for ***Heart: Road to health***. Due to the common risk factors between heart and other chronic diseases the focus of the model was broaden to ***Heart: Road to health or Chronic disease: Road to health*** (Figure 1).[5, 8]

Process

As per the ***Heart: Road to health or Chronic disease: Road to health ,*** improved communication, coordination and collaboration between the range of service delivery, strategic planning and research programs are required. Before this can be achieved it is necessary to understand strategic directions and service delivery of government organisations, ACCHOs, RFDS, healthcare departments, programs, and research in R&R areas. Accordingly, representatives from these organisations were invited to the ***Heart: Road to health or Chronic disease: Road to health*** forum to share information about their work and discuss interorganisational linkages. The aim was to initiate a collaborative and coordinated process, for improving access to secondary prevention for heart and chronic diseases in R&R areas, through healthcare systems that support an integrated approach to provision of healthcare services.

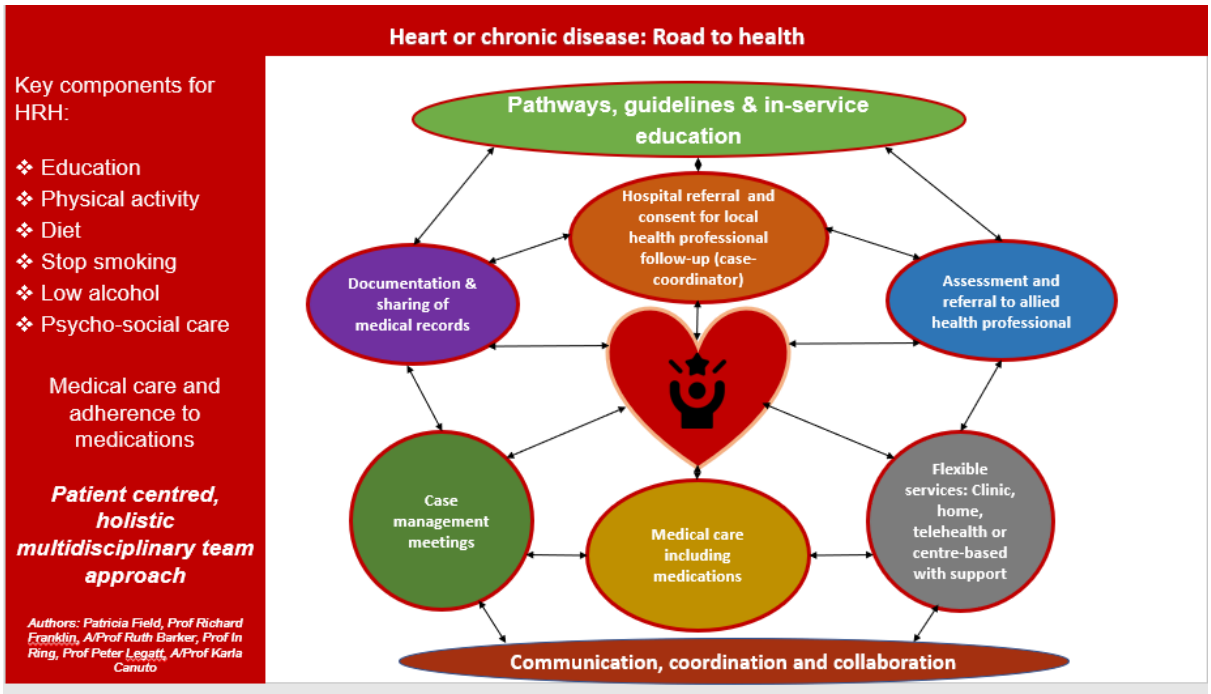

Figure 1 – Heart: Road to health or Chronic disease: Road to health

The ***Heart: Road to health or Chronic disease: Road to health*** forum provided and opportunity for a range of healthcare leaders, managers, clinicians, and researchers to present information on their current programs or organisational directions (Speakers and Attendees lists: Appendix 1 & 2), followed by a plenary discussion. It is envisaged that the forum could be the first stage in a process to achieve a ***Heart: Road to health or Chronic disease: Road to health .***

Results

Based on the presentation and plenary discussion the following themes and recommendation were developed.

Table 1: Summary primary themes, description, comments and recommendations

Primary themes	*Description*	*Comments/recommendations*
Current strategic planning for chronic conditions	*Focus on chronic conditions leading to client empowerment and self-management is increasing with planning processes underway through QH and NQPHN aiming at an integrated strategic approach.*	*Strategies include a collaborative process and community consultation. If not already part of the process communication and collaboration between QH and NQPHN is required to ensure complementary outcomes. All plans and strategies need to include a process that is implemented, monitored and evaluated. Principles of Continuous Quality Improvement (CQI) could facilitate this process[9]*
Communication, coordination & collaboration	*There is little evidence of communication, coordination, collaboration and between healthcare programs presented*	*This deficit needs to be addressed through the QH and North Queensland Primary Health Network (NQPHN) strategic planning processes.*

Primary themes	*Description*	*Comments/recommendations*
Multidisciplinary client-centred approach	*Multidisciplinary client-centred approach was consistently demonstrated in healthcare programs presented, but there is a lack of coordination and collaboration* *Diabetes outreach program provides an example of such a well-established effective program and support structure that is funded and coordinated through chronic disease centres e.g. North Cairns*	*The well-developed diabetes education and self-management program provides an example for other systems of chronic disease secondary prevention.* *Consideration is given for combining the diabetes program with other chronic diseases, managed through chronic disease centres utilising the model of the* ***Heart: Road to health or Chronic disease: Road to health***
Capacity building and liaison with local staff	*Cape York Kidney Care(CYKC), Older Persons Enablement And Rehabilitation for Complex Health conditions (OPEN ARCH) and Healthcare in Your Home(HIYH) are examples of programs that work closely with locally based healthcare providers to build their skills and contribute to the program*	*Capacity building and liaison with community based staff is an important part of service provision in R&R communities. . This approach facilitates multidisciplinary, client-centred, holistic care, and leads to improved skills for local staff*
Culturally responsive programs	*Successful culturally responsive programs such as CYKC[10] and OPEN ARCH[11] and Diabetes education and self-management[12] provide examples multidisciplinary, culturally responsive programs. CYKC includes heart disease & diabetes, with renal disease[10] Programs include home visits, flexibility of appointments, service provision, increased usage of Aboriginal and Torres Strait Islander Health Workers (ATSIHW), who are core to service provision. Two way capacity building is possible through this approach*	*The need for support and education for staff to be culturally aware in their interaction with Aboriginal and Torres* *Strait Islander clients and NHMRC guidelines for Strengthening cardiac rehabilitation and secondary prevention for Aboriginal and Torres Strait Islander People to be implemented.[13]* *Despite only focussing on one disease the diabetes program reported having difficulty in providing services for the number of people with diabetes requiring secondary prevention. Therefore, a coordinated multidisciplinary team approach is necessary to enable locally based staff to provide secondary prevention through support and education provided by the visiting expert diabetes team. This is relevant for all disease based approaches, and provision of Phase-1-CR in hospitals.[8]*

Primary themes	*Description*	*Comments/recommendations*
Telehealth services – virtual hub and spoke model	*Examples i.e. Country Heart Attack Program (CHAP) [14]and digital transition care solution[15] provide information on models for secondary prevention that include building local capacity, and referral pathways*	*Telehealth is beneficial in provision of secondary prevention especially using hybrid model and needs to be considered as a component of* **Heart: Road to health or Chronic disease: Road to health**
Referrals to local community health care providers	*There is a lack of a consistent approach with no guidelines, pathways for referrals to community-based healthcare staff for secondary prevention of chronic conditions*	*Standard systems supported by guidelines, pathways and in-service education are required.[5, 8]*
Discharge planning, medical discharge summaries	*Generally low quality. Inadequate multidisciplinary approach*	*Standard systems supported by guidelines, pathways and in-service education as per* **Heart: Road to health or Chronic disease: Road to health** *are required.[5, 8]*
Sharing of medical records and progress notes	*In major hospitals in QH integrated electronic medical records have been introduced. A summary of the record is able to be accessed through Viewer by QH staff in R&R areas and GP who subscribe to this service. There have been examples of contractual agreements to enable sharing of records, but no comprehensive system is available for all healthcare providers.*	*This is a serious issue that needs to be solved. Currently the inability to share medical records has the potential to result in duplication or gaps in services and is clearly detrimental to coordinated multidisciplinary, holistic client-centred care and needs to be considered in the NQPHN and QH strategic planning process.[5, 8]*
Predominantly clinical/medical focus of post-hospitalisation care. Underutilisation of allied health professionals (AHP)	*Many of the programs focussed on clinical/medical care post-hospitalisation with inadequate focus on secondary prevention and underutilisation of AHP*	*Resources such as nurses, ATSIHW, AHP, AHP assistants (AHA), medical officers are available through resident and visiting community services. Also available are a range of stand-alone disease/aged care programs in selected R&R areas.*

Healthcare services

As discussed at the forum healthcare services are provided through a range of organisations, adjunct programs, and telehealth. However, there is limited evidence of communication, collaboration or coordination of services. The following strengths, weaknesses were identified as a basis for developing a more efficient and effective approach to secondary prevention in R&R areas.

Strengths

A range of organisations are providing chronic disease programs, funded by QH or NQPHN, in conjunction with federally funded ACCHOs. These services are predominantly focussed on clinical/medical primary health care. However, there are examples of healthcare programs that also provide secondary prevention in R&R areas.[1] These include:

- Diabetes outreach education and self-management program
- Centre-based CR (predominantly available on the eastern seaboard)
- Self-management of Chronic Conditions (SMOCC) telephone support secondary prevention for heart and other chronic conditions.
- Older Persons Enablement And Rehabilitation for Complex Health conditions *(OPEN ARCH)* Healthcare in your home (HIYH)
- Cape York Kidney Care (CYKC)
- Apunipima Cape York Health Council and Townsville Aboriginal and Torres Strait Islander Community Controlled Health Organisation: health and wellness model
- Deadly Ears Deadly Futures (not represented at Heart: Road to health or Chronic disease: Road to health forum)

QH, RFDS and ACCHOs' healthcare services are provided through a community-based or visiting services via PHCC and MPHS throughout Queensland.[5, 8] ACCHOs base their services on a health and wellness model of care which includes primary and secondary prevention.[5]Virtual telehealth cardiopulmonary rehabilitation to be piloted in South-West, Central West and Northern regions. (four years funding provided) [16]

Weaknesses

- Lack of communication, coordination and collaboration between various health care providers
- Non-sharing of medical records
- Poor discharge planning and lack of referrals to community-based health professionals for secondary health care programs
- Generally, QH primary health care centres and multipurpose health services are not structured, nor have health systems in place, to provide client-centred holistic, flexible culturally responsive services.
- Poor understanding or engagement in Phase 1, 2, 3 CR/secondary prevention by the majority hospital and community-based health staff.
- Hospital and community-based staff were often unaware of COACH/SMOCC, and clients, even if referred, rarely accessed due to poor mobile phone reception and a preference for face-to-face

[1] The organisations listed only represent those organisations identified through the process of convening **Heart: Road to health** research and refer to but are not a comprehensive list of all services available in R&R areas of NQ

communication.[5, 8] Currently SMOCC liaises with GPs, however, due to a shortage of GPs in R&R areas GPs, linkages with community nurses or Aboriginal and Torres Strait Health Workers need to be established.

- Inadequate systematic approach to post-hospitalisation referrals to community-based services for risk factor management and secondary prevention in R&R communities [5, 8]
- Telehealth CR was discontinued during COVID but there are plans to re-establish through a pilot cardio-pulmonary program.[16] However barriers such as poor internet and Wi-Fi coverage as well as reported preference for face-to-face communication continue to be an issue.[5]

Discussion

The ***Heart: Road to health or Chronic disease: Road to health*** forum demonstrated that there are a range of healthcare services in R&R areas. However, the rates of chronic diseases, resultant mortality, morbidity, and costs continue to rise.[17] To address this, revised healthcare systems that ensure efficient, effective, coordinated and collaborative service provision in R&R areas of Australia are necessary.

As presented at the forum and there is a network of QH, ACCHO, RFDS, contracting organisations and individual private health practitioners available throughout Queensland. Additionally, there are a range of specialist services including diabetes, renal, aged care, ear, sexual health and HIYH. However, provision of these services is patchy, with no evidence of a strategic coordinated approach or funding equity. Furthermore, contracts are often short-term leading to uncertainty and demands on time and expertise for preparation of funding applications. Despite the availability of resources there is no comprehensive approach to a flexible client-centred, holistic, multidisciplinary culturally responsive secondary prevention for clients in R&R areas.

The ***Heart: Road to health or Chronic disease: Road to health*** proposes such a model of care that utilises current locally based health care providers, supported by chronic disease centres with expertise provided via expert health personnel. Currently expert services are available via diabetes education and self-management program, CYKC, OPEN ARCH, SMOCC, telehealth CR, HIYH programs, together with support services such as nurse navigators and central referral systems.[18] However, there is little coordination or collaboration between these services. Through ***Heart: Road to health or Chronic disease: Road to health*** specialist medical and clinical services for specific chronic conditions will be part of the coordinated multidisciplinary approach, that will include liaising and capacity building for locally based staff. This is a shift from expert staff attempting to personally see all people needing support for a specific disease. By liaising with local staff and building their capacity in secondary prevention for chronic disease and implementing the model for ***Heart: Road to health or Chronic disease: Road to health*** it is far less likely that clients will fall through the gaps in health care provision.[5, 8]

The way forward

It is proposed that ***Heart: Road to health or Chronic disease: Road to health*** is used as a model for

chronic disease secondary prevention in R&R areas through a more coordinated, holistic, client-centred, multidisciplinary, culturally responsive strategic approach to secondary prevention that includes collaboration between:

- NQPHN Health Priorities, including chronic disease
- QH strategic program development including:
    - Health promotion and secondary prevention – Advanced Health promotion strategies, systems approach to chronic disease prevention, including co-design and continuous quality improvement
    - Strategy, planning partnership, policy and reform
    - Health service planning
    - Preventative strategy
- Apunipima Cape York Health Council and Townsville Aboriginal and Torres Strait Islander Community Controlled Health Organisation
- NQPHN Far North Queensland Connect: Connecting people connecting care (rehabilitation services);
- National Heart Foundation of Australia and Australian Cardiovascular Health Association support and best-practice guidelines for CR/secondary prevention.

Systems approach

A systems approach needs to underpin all healthcare reform commencing in hospitals with greater emphasis on preparing in-patients for discharge including:

- In-service education to improve understanding and involvement of discharge planning by hospital-based direct care nurses, allied health professionals, medical officers, Aboriginal and Torres Strait Islanders Health Workers and Liaison officers, to ensure that all health professionals are equipped to take advantage of teachable moments for provision of brief interventions.[19-21]
- Utilise continuous quality improvement for development, implementation, monitoring and evaluation of heart or chronic disease pathways, guidelines and in-service education to ensure that:
    - hospital clients receive a discharge summary that includes referral information for community-based health professionals such as community nurses and/or Aboriginal and Torres Strait Islander Health Workers, for assessment and ongoing holistic client-centred secondary prevention.[5, 8]
    - community-based healthcare provision is supported by pathways, guidelines and in-service education to ensure that local staff understand secondary prevention, and are equipped to undertake client assessment, refer to AHP and ensure GP follow-up for risk factor management and medical care.

Heart: Road to health or Chronic disease: Road to health provides a template into which components

of successful programs can be inserted thereby providing a standardised approach to clients' secondary prevention

Conclusion

The findings of this forum and ***Heart: Road to health or Chronic disease: Road to health*** provide a basis for secondary prevention services to move away from fragmented clinical silos-based approach. If effective and efficient services are to be provided for people with chronic conditions in R&R areas, it is essential that there is improved communication, coordination, and collaboration for the provision of secondary prevention for all chronic conditions. This requires a systems approach to facilitate working together for better results for both clients and staff.

Thank you for your attendance and participation in the forum.

Pat Field
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Acronyms

ACCHO	*Aboriginal and Torres Strait Islander Community Controlled Health Organisation*
COACH	*Coaching on Achieving Cardiovascular Health*
CR	*cardiac rehabilitation*
CYKC	*Cape York Kidney Care*
HIYH	*Healthcare in your home*
MPHS	*Multipurpose health service*
NQPHN	*North Queensland Primary Health Network*
OPEN ARCH	*Older Persons Enablement And Rehabilitation for Complex Health conditions*
PHCC	*Primary health care centre*
QH	*Queensland Health*
R&R	*rural and remote*
RFDS	*Royal Flying Doctor Service*
SMOCC	*Self-management of chronic conditions*

Appendix1 – Program for Heart: Road to health or Chronic disease: Road to health

Session/Speaker	***Topic***
Lisa Archer *NQPHN Health Priorities*	*Role of Primary Care in early intervention secondary prevention and management in* **Heart: Road to health or Chronic disease: Road to health .**
Dr Vicki Gedge *QH Advanced Health Promotion Officer*	*Linking* **Heart: Road to health or Chronic disease: Road to health** *with Chronic disease prevention*
Dr Ruth Barker – *Assoc. Prof. Rehabilitation, James Cook University*	*Linking* **Heart: Road to health or Chronic disease: Road to health** *Far North Queensland Connect: Connecting people connecting care*
Janet Struber *- Program Advisor Chronic Conditions Strategy Apunipima Cape York Health Council*	*Linking* **Heart: Road to health or Chronic disease: Road to health** *with Apunipima Chronic Disease Strategy*
Leanne Murray *– Primary health care nurse, Royal Flying Doctor Service (RFDS)*	*RFDS linking with* **Heart: Road to health or Chronic disease: Road to health**
Kylie McKenna *- Nurse Unit Manager, Office of Rural and Remote Health, NQ*	*Linking Office of Rural and Remote Health, NQ with* **Heart: Road to health or Chronic disease: Road to health**
Amy Frame – *Townsville Hospital and health Service (THHS) Nurse Manager Complex Chronic Nurse Navigator Service*	*Role of Nurse Navigator and possible involvement in* **Heart: Road to health or Chronic disease: Road to health**
Samara Phillips *- Queensland CR Program Adviser*	*Role of Queensland CR program and possible involvement with* **Heart: Road to health or Chronic disease: Road to health**
Melissa Moore *– THHS Heart Failure outpatient/outreach support*	*Role of Heart Failure outpatient/outreach support and linking with* **Heart: Road to health or Chronic disease: Road to health**
Dr Susie Cartledge *Heart Foundation Postdoctoral Fellow, Senior Research Fellow, Monash University, Honorary Senior Research Fellow, University of Sydney*	*Research project digital transition of care solution to support patients and families after a short inpatient stay following a cardiac event*
Dr Jennifer Mann *- Coordinator and Clinical Lead, Healthcare Improvement Unit, Queensland Health*	*Older Persons Enablement And Rehabilitation for Complex Health conditions (OPEN ARCH)*
Dr Leanne Brown *– Nurse Practitioner Cape York Kidney Care*	*Cape York Kidney Care Program*

Session/Speaker	***Topic***
Bernadette Sellwood– Diabetes Educator, Cairns North Community Care	*Diabetes outreach and self-management Program*
Dr Alline Beleigoli – Senior Research Fellow, Flinders University, SA.	*Country Heart Attach Prevention (CHAP) Heart Health for Life.*
Ben Houghton – Occupational Therapist, Cooktown. Torres and Cape Hospital and Health Service (TCHHS)	*Healthcare in your home (HIYH)*
Dr Alice Cairns - Senior Research Fellow *Centre for Rural & Remote Health. JCU.*	*Community rehabilitation services for Cape York communities: Feasibility and acceptability*
Samantha Squires & Leanne Heilbronn *Clinical nurse QH Self-Management of Chronic Conditions (SMOCC) program (previously Coaching on achieving Cardiovascular health. [COACH])*	*Self-Management of Chronic Conditions (SMOCC)*
Katie Panaretto – Public Health Physician, QH	*QH Public health services*

Attendees for Improving co-ordination and collaboration of services for people with heart or chronic disease post hospital discharge – Heart: Road to health or Chronic disease: Road to health

Name	***Position***	***Topic***
Alice Cairns (Dr)	*Research fellow Centre for Rural and Remote Health, James Cook University.*	*Linking student led rehabilitation in Western Cape with* **Heart: Road to health or Chronic disease: Road to health**
Alison Read	*Community nurse, Hughenden*	*What do Community nurses need to improve support for people with heart disease post-discharge from tertiary Hospital. for* **Heart: Road to health or Chronic disease: Road to health**
Alline Beleigoli (Dr)	*Snr Research Fellow,, Flinders Uni, SA*	*Country heart attack prevention (CHAP) Heart Health for Life*
Amanda Rojek	*Director Strategy, Planning and Partnerships* *Strategy, Policy and Reform*	*QH – Strategy planning and policy*
Amy Frame	*Nurse Manager Complex Chronic Nurse Navigator Service.*	*Role of Nurse Navigator and possible involvement in* **Heart: Road to health or Chronic disease: Road to health**
Ashley Horton	*Heart Failure, Clinical nurse*	*Linking* **Heart: Road to health or Chronic disease: Road to health** *with Heart Failure outpatient/outreach program*
Barbara Smith	*Flinders Council - Health*	*Hughenden community advisory network representation*
Ben Houghton	*Occ. Therapist. Torres and Cape Hospital and Health Service (TCHHS)*	*Linking Healthcare in your home with* **Heart: Road to health or Chronic disease: Road to health**
Carlie Smith	*Heart Foundation project officer*	*Linking Heart Foundation with* **Heart: Road to health or Chronic disease: Road to health**
Casey McKenzie	*Exercise Physiologist - Body Fix*	*Linking Body-Fix with* **Heart: Road to health or Chronic disease: Road to health**

Name	***Position***	***Topic***
Chloe Truesdale	*Snr Healthcare Programs Officer*	*Linking Heart Foundation in* **Heart: Road to health or Chronic disease: Road to health**
Chris Rissel (Prof)	*A/Prof Flinders University (Darwin)*	*Yolgnu CR research and* **Healthy Heart for life>**
Christine Kwong	*Cardihab – Customer support specialist*	*Role of CardiHab in* **Heart: Road to health or Chronic disease: Road to health**
Deb Smith (Dr)	*Research coordinator, Place Based Planning, Hughenden*	*Research into Place based Planning and possible links to* **Heart: Road to health or Chronic disease: Road to health**
Donna Richmond	*QH Executive Director, Health Services Planning*	*Health Services Planning possible links to* **Heart: Road to health or Chronic disease: Road to health**
Helen McLean	*Snr Healthcare program Officer. Equity (WA. Heart Foundation)*	*Linking Heart Foundation with* **Heart: Road to health or Chronic disease: Road to health**
Ian Ring (Dr)	**Professor, Tropical Health & Medicine,** **James Cook University**	*Research team Heart: Road to health*
Ian Wronski (Dr)	*Chair TAAHC*	*Opening address. Translating research into action*
Jacinta Bonaventura	*Alliance Rehab. – Exercise Physiologist*	*Linking allied health and an exercise physiologist in* **Heart: Road to health or Chronic disease: Road to health**
Jane McNamara	*Mayor – Flinders Council*	*Flinders Council Mayor*
Janet Struber	*Program Advisor Chronic Conditions Strategy Apunipima Cape York Health Council*	*Linking* **Heart: Road to health or Chronic disease: Road to health** *with Apunipima Chronic Disease Strategy*
Jenny Mann (Dr)	*Aged care project*	*Linking OPEN ARCH with* **Heart: Road to health or Chronic disease: Road to health**
Karen Carlisle	*Snr Research Fellow, School of Medicine, Dentistry*	*Linking proposed development of revised framework for operational*

Name	*Position*	*Topic*
		and implementational research in health and disease control programs, and possible linkages with **Heart or Chronic disease : Road to health**
Katie Panaretto (Dr)	*Public Health Physician QH*	*Linking QH public health services with* **Heart: Road to health or Chronic disease: Road to health**
Katina Corones-Watkins (Dr)	*Lecturer & Early Career Researcher Postgraduate Program Advisor: Critical Care & Emergency*	*Linking emergency and critical care services with* **Heart: Road to health or Chronic disease: Road to health**
Kaz Johnston (Dr)	*Senior Research Officer/Data Manager* *Integrating Health Care Planning in North Queensland Project*	*Integrating Health Care Planning in North Queensland Project with* **Heart or Chronic disease, Road to health**
Kylie McKenna	*Nurse Unit Manager, Office of Rural Health (TCHHS)*	*Linking Office of Rural and Remote Health with* **Heart: Road to health or Chronic disease: Road to health**
Leanna Murray	*PHC Nurse*	*RFDS Linking with* **Heart: Road to health or Chronic disease: Road to health**
Leanne Brown (Dr)	*Nurse Practitioner Cape York Kidney Care*	*Linking Cape York Kidney Care with* **Heart: Road to health or Chronic disease: Road to health**
Leanne Heilbronn & Samantha Squires	*Self-management of Chronic conditions (SMOCC)*	*Linking SMOCC with* **Heart: Road to health or Chronic disease: Road to health**
Lisa Archer	*NQPHN priorities (Chronic disease)*	*Linking NQPHN chronic disease and secondary prevention with* **Heart: Road to health or Chronic disease: Road to health**
Matthew Bryant (Dr)	*Public Health Medical Officer, Rural Hospital Services Group*	*Linking Rural Hospital Services Group with* **Heart: Road to health or Chronic disease: Road to health**
Melissa Moore	*Heart Failure, Nurse Practitioner*	*Linking* **Heart: Road to health or Chronic disease: Road to health**

Name	***Position***	***Topic***
		with Heart Failure outpatient/outreach program
Meryl Churchill	*Cohort program*	*Cohort program – translational research*
Michael Newman	*Chronic disease nurse practitioner*	*Linking* **Heart: Road to health or Chronic disease: Road to health** *with THHS chronic disease management*
Nadia Nestor	*Project lead, State wide Pulmonary Rehabilitation Project. Healthcare Excellence and Innovation*	*Linking Pulmonary Rehabilitation with* **Heart: Road to health or Chronic disease: Road to health**
Peter Leggat (Dr)	Professor Public Health	*Research team Heart: Road to health*
Peter Malouf (Dr) *(keynote speaker)*	*Associate Professor/CEO Townsville Aboriginal and Torres Strait Islander Community Control health Service (TAIHS)*	*Linking TAIHS with* **Heart: Road to health or Chronic disease: Road to health**
Richard Franklin (Dr)	Professor Public Health	*Research team Heart: Road to health*
Ruth Barker (Dr)	*A/ Professor Rehabilitation*	*Research team Heart: Road to health*
Samara Phillips	*Queensland CR program adviser*	*Queensland CR program linking with* **Heart: Road to health or Chronic disease: Road to health**
Bernadette Sellwood	*Diabetes Educator, Cairns North Community Care*	*Linking Diabetes program with* **Heart: Road to health or Chronic disease: Road to health**
Simone Braithwaite	*QH Manager preventive strategy*	*QH Preventive strategy*
Snezana Stolic (Dr)	*ACRA Qld. University of Southern Queensland.*	*Linking* **Heart: Road to health or Chronic disease: Road to health** *throughout Queensland*
Sue Devine (Dr)	*A/Prof. and Academic Head, Public Health and Tropical Medicine. College of Public Health, Medical and Veterinary Sciences. James Cook University*	*Linking JCU Public Health with* **Heart: Road to health or Chronic disease: Road to health**

Name	***Position***	***Topic***
Susie Cartledge (Dr)	*Heart Foundation Postdoctoral Fellow, Senior Research Fellow*	*Linking digital transition of care solution to support patients and families after a short inpatient stay following a cardiac event with* ***Heart: Road to health or Chronic disease: Road to health***
Vicki Gedge (Dr)	*QH Advanced Health Promotion Officer*	*Linking* ***Heart: Road to health or Chronic disease: Road to health*** *with Chronic disease prevention*
Wendy Ah-Chin,	*Executive Director, Aboriginal and Torres Strait Islander Health - TUH*	*Linking* ***Heart: Road to health or Chronic disease: Road to health*** *with Aboriginal and Torres Strait Islander clients*

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Appendix 7.5 Cardiac rehabilitation services for people in rural and remote areas: an integrative literature review (published paper)

Field P, Franklin R, Barker R, Ring I, Leggat P. Cardiac rehabilitation services for people in rural and remote areas: An integrative literature review. Rural and Remote Health. 2018. http://doi.org/10.22605/RRH4738

REVIEW ARTICLE

Cardiac rehabilitation services for people in rural and remote areas: an integrative literature review

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ETHICS APPROVAL: Nil ethics approval required

ABSTRACT:

Introduction: Morbidity and mortality from heart disease continues to be high in Australia with cardiac rehabilitation (CR) recognised as best practice for people with heart disease. CR is known to reduce mortality, reoccurrence of heart disease, hospital readmissions and costs, and to improve quality of life. Australian Aboriginal and Torres Strait Islanders (Australian First Peoples or Indigenous peoples) have a greater need for CR due to their higher burden of disease. However, CR referral, access and attendance remain low for all people who live in rural and remote areas. The aim of this integrative review was to identify barriers, enablers and pathways to CR for adults living independently in rural and remote areas of high-income countries, including Australia.

Methods: Studies were identified through five online data bases, plus reference lists of the selected studies. The studies focused on barriers and enablers of CR for adults in rural and remote areas of Australia and other high-income countries, in English peer-reviewed journals (2007–2016). A mix of qualitative, quantitative and mixed method studies were reviewed through a modified Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), followed by a critical review and thematic analysis.

Results: Sixteen studies were selected: seven qualitative, four quantitative and five mixed method. Five themes that influence CR attendance were identified: referral, health services pathways and planning; cultural and geographic factors necessitating alternative and flexible programs; professional roles and influence; knowing, valuing, and psychosocial factors; and financial costs – personal and health services. Factors identified that impact on referral and access to CR were hospital inpatient education programs on heart disease and risk factors; discharge processes including CR eligibility criteria and referral to ensure continuum and transition of care; need for improved accessibility of services, both geographically and through alternative programs, including home based with IT and/or telephone support. Also, the need to ensure that health professionals understand, value and support CR; the impact of mental health, coping with change and competing priorities; costs including travel, medications and health professional consultations; as well as low levels of involvement of Australian First Peoples in their own care and poor cultural understanding by non-Australian First Peoples staff all negatively impact on CR access and attendance.

Conclusion: This study found weak systems with low referral rates and poor access to CR in rural and remote areas. Underlying factors include lack of health professional and public support, often based on poor perception of benefits of CR, compounded by scarce and inflexible services. Low levels of involvement of Australian First Peoples, as well as a lack of cultural understanding by non-Australian First Peoples staff, is evident. Overall, the findings demonstrate the need for improved models of referral and access, greater flexibility of programs and professional roles, with management support. Further, increased education and involvement of Australian First Peoples, including Indigenous health workers taking a lead in their own people's care, supported by improved education and greater cultural awareness of non-Australian First Peoples staff, is required.

Keywords:

Aboriginal and Torres Strait Islanders, Australia, barriers, cardiac rehabilitation, enablers, First Peoples, indigenous, pathways.

FULL ARTICLE:

Introduction

Heart disease is the largest single cause of death in Australia and contributes to significant illness, disability, poor quality of life and high healthcare costs[1,2]. Rates of heart disease in rural and remote areas are higher than in urban areas[1,3]. Whilst Australian Aboriginal and Torres Strait Islander First Peoples' (Australian First Peoples/Indigenous peoples)[4] disease rates, including heart disease and complex comorbidities, are higher, this only partially accounts for the disparity in health status between people in rural and remote and urban populations[3,5]. Disparity may be worse than reported due to people with poor health moving to urban areas for better services[5].

There is significant evidence that cardiac rehabilitation (CR) is best practice for people with heart disease[6–8]. However, despite this and known higher levels of heart disease of people living in rural and remote areas, referral and access to CR remain low, and access issues are exacerbated by geographic distance, fewer health services and staff[3,9], compounded by poor telephone and IT services to support alternative programs in rural and remote areas[5].

Cardiac rehabilitation

CR is known to reduce reoccurrence of hospital readmissions, mortality and morbidity from heart disease, and improve general health and quality of life[7,8,10]. WHO describes CR as including physical, mental and social conditions for people with heart disease, so that by their own efforts, together with support through medical or clinical management, they may preserve or resume optimal function[7,10,11]. The term 'cardiac rehabilitation continuum' is preferred by the Heart Foundation of Australia[7], due to the general perception that CR refers to short term, centre based exercise and education programs, usually run by hospitals. The CR continuum is a 'coordinated system of long-term care' necessary to help people with heart disease return to an active and satisfying life, and to prevent the reoccurrence of heart disease or new cardiovascular conditions[7]. This indicates the need for a lifelong individual commitment to healthy lifestyle choices, and adherence to medical advice with health service support[7,11].

Costs and priority

Expenditure for hospital-admitted patient services for coronary

ABSTRACT:

Introduction: Morbidity and mortality from heart disease continues to be high in Australia with cardiac rehabilitation (CR) recognised as best practice for people with heart disease. CR is known to reduce mortality, reoccurrence of heart disease, hospital readmissions and costs, and to improve quality of life. Australian Aboriginal and Torres Strait Islanders (Australian First Peoples or Indigenous peoples) have a greater need for CR due to their higher burden of disease. However, CR referral, access and attendance remain low for all people who live in rural and remote areas. The aim of this integrative review was to identify barriers, enablers and pathways to CR for adults living independently in rural and remote areas of high-income countries, including Australia.

Methods: Studies were identified through five online data bases, plus reference lists of the selected studies. The studies focused on barriers and enablers of CR for adults in rural and remote areas of Australia and other high-income countries, in English peer-reviewed journals (2007–2016). A mix of qualitative, quantitative and mixed method studies were reviewed through a modified Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), followed by a critical review and thematic analysis.

Results: Sixteen studies were selected: seven qualitative, four quantitative and five mixed method. Five themes that influence CR attendance were identified: referral, health services pathways and planning; cultural and geographic factors necessitating alternative and flexible programs; professional roles and influence; knowing, valuing, and psychosocial factors; and financial costs – personal and health services. Factors identified that impact on referral and access to CR were hospital inpatient education programs on heart disease and risk factors; discharge processes including CR eligibility criteria and referral to ensure continuum and transition of care; need for improved accessibility of services, both geographically and through alternative programs, including home based with IT and/or telephone support. Also, the need to ensure that health professionals understand, value and support CR; the impact of mental health, coping with change and competing priorities; costs including travel, medications and health professional consultations; as well as low levels of involvement of Australian First Peoples in their own care and poor cultural understanding by non-Australian First Peoples staff all negatively impact on CR access and attendance.

Conclusion: This study found weak systems with low referral rates and poor access to CR in rural and remote areas. Underlying factors include lack of health professional and public support, often based on poor perception of benefits of CR, compounded by scarce and inflexible services. Low levels of involvement of Australian First Peoples, as well as a lack of cultural understanding by non-Australian First Peoples staff, is evident. Overall, the findings demonstrate the need for improved models of referral and access, greater flexibility of programs and professional roles, with management support. Further, increased education and involvement of Australian First Peoples, including Indigenous health workers taking a lead in their own people's care, supported by improved education and greater cultural awareness of non-Australian First Peoples staff, is required.

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FULL ARTICLE:

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Costs and priority

Expenditure for hospital-admitted patient services for coronary

- published in English in peer-reviewed journals from 1 January 2007 to 31 December 2016
- focusing on cardiac rehabilitation in rural and remote areas of Australia and high-income countries internationally; barriers, enablers and pathways to CR; or First Peoples, indigenous (Australian and global) and general populations.

Exclusion criteria were:

- effectiveness of centre based and home based (technology-supported) CR due to available evidence of effectiveness[7,8,10,17,30,31]
- clinical cardiac procedures, acute treatment and interventions
- non-high-income countries are equated to developing countries, according to the 'List of developing countries as declared by the Minister of Foreign Affairs(2015)'[32]. This is because studies that focus on developing countries are considered to have little relevance in Australia, which is amongst the 10 largest advanced economies in the world, based on International Monetary Fund criteria[33].)
    - programs that include only one component of CR (eg exercise), rather than having a holistic view
    - outside the date limit, to ensure a contemporary basis due to rapid changes in technology that have had a large impact on possibilities for CR in rural and remote areas and due to the recent decentralisation of health services in Queensland, the establishment of primary health networks and their impact on health service delivery.

Whilst this study includes all adults living independently in rural and remote areas of Australia as well as high-income countries, because of the known poor health status of Australian First Peoples[1,3] studies were sought specifically for CR with Aboriginal and Torres Strait Islanders people and/or Indigenous people. Using this strategy, six studies with a primary focus on Australian First Peoples were identified. No international studies were identified specifically for Indigenous people.

Preliminary review and critical appraisal

Principles and processes of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Fig1) was used to describe the collection, review and identification of final studies for analysis[34].

Following screening of abstracts, a full text critical review to assess research quality, outcomes and eligibility was undertaken on the remaining 56 quantitative, qualitative and mixed method studies. A modified process, suitable for critical review of all research methods, was developed based on the premise that all research includes clearly focused research questions, constructs arguments, collects data from appropriate participants, speculates about outcomes of data analysis[35-37] and considers important outcomes and results[38-40]. To achieve this, McMaster's qualitative research guidelines[40], and the Critical Appraisal Skills Program quantitative review guidelines[38], were combined. Studies were assessed according to McMaster's guidelines for study design, type, methods, sampling and data collection[38] and Critical Appraisal Skills Program quantitative research guidelines to assess the research question, including appropriate sampling, equal treatment of all participants, chance minimisation and research rigor, with all results presented to ensure epidemiological and statistical strength[38]. The critical review was further strengthened by a thematic analysis in which key findings were coded and grouped to identify 'patterned responses' or 'themes', to enable extraction of further meaning[36].

Supplementary table 2 provides details of the critical review and thematic analysis carried out by the first author and peer reviewed by the other authors. This process of review and validation continued throughout.

Following the critical review and thematic analysis, a further analysis, evaluation and integration of findings from the 16 final studies that identified barriers, enablers and pathways was undertaken. These are synthesised in the results according to identified themes.

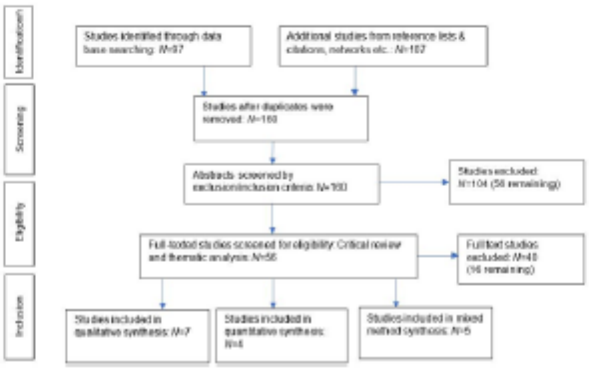


Figure 1: Modified PRISMA chart[34]: Integrative review of studies on cardiac rehabilitation for people in rural and remote areas

Results

The review and analytic process identified 16 studies, from which five themes emerged. Table 1 summarises the pertinent themes including factors that influence failure or success of CR. These factors provided the underpinning criteria for the emergent themes. The themes identified were referral, health service pathways and planning; cultural and geographic factors necessitating alternative and flexible programs; professional roles and influence; knowing, valuing, and psychosocial factors; and financial costs – personal and health services. Embedded in these themes are barriers, enablers and pathways for CR in rural and remote areas by general population and Australian First Peoples.

Table 1: Themes identified through critical analysis and underpinning thematic criteria

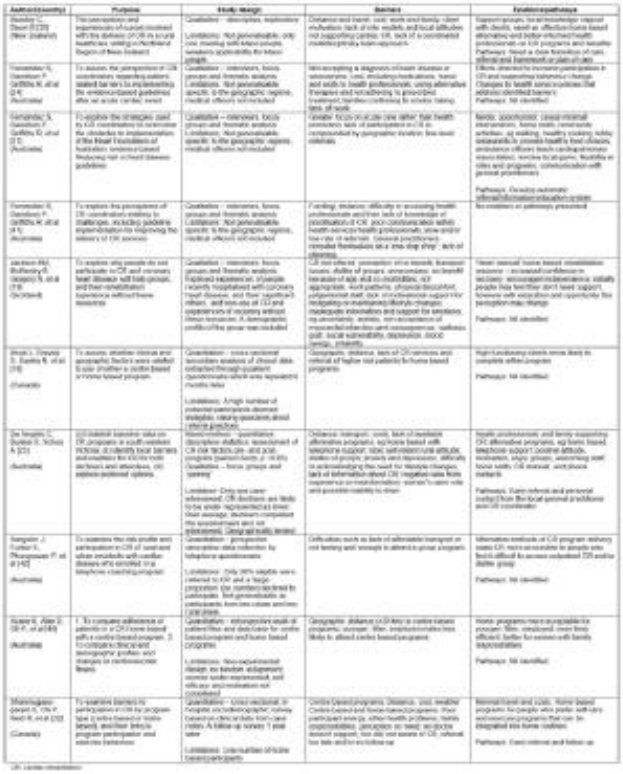
Theme	Criteria
Referral to cardiac rehabilitation and continuing along the health pathway	Pathways for continuum of care, transition of care, referrals, eligibility Framework or plan of care Automatic referral, combined with patient education and information systems Communication between health services and health professionals
Cultural and geographic factors necessitating alternative and flexible programs	Distance from services Poor culturally appropriate services with few First Peoples involved Importance of 'yarning' and flexibility especially with First Peoples Need for alternative programs that include telephone, telehealth, written materials, structured support with flexible format Poor IT access and skills Need to include community activities, eg walking groups, healthy cooking classes, using media to promote healthy behaviour, involve local gyms
Professional roles and influence	Opportunistic casual minimal interventions in any environment, eg supermarket, home visits Involving ambulance officers in cardiac rehabilitation programs Involving all health professionals for ensuring referral and attendance Flexibility in professional roles Staff judgmental attitude is a deterrent Low value of cardiac rehabilitation and/or multidisciplinary team Low health service standards
Knowing, valuing, and psychosocial factors	Depression, anxiety, denial, sadness, guilt, grief personal loss often resulting in poor motivation and non-completion of programs Varying education levels and social vulnerability Competing priorities including work and family responsibilities Abandoning medical advice and using alternative therapies Difficulties in changing risky behaviour in home environments (eg families who continue to smoke, poor diet, etc)
Financial costs – personal and health services	Travel, medication, health professional consultations, funding

Referral, health services pathways and planning

General populations: Low levels of referral are commonly identified as barriers to CR[18-21,23,24,41]. Education and information about heart disease risk factors and the benefits of CR are an important part of hospital discharge and referral processes[22-24]. A transition of care framework and care planning, together with systematic assessment to ensure that participants have appropriate, and if necessary, individualised programs, is recommended[21,23] (Table 2).

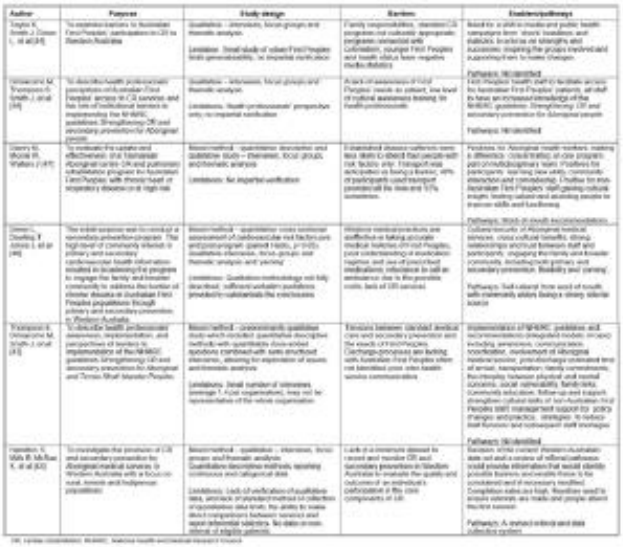
It is known that there is a lack of data on CR referrals, attendance and completion of centre based or home based programs[16]. At times the studies recommended that people 'eligible' for CR are referred by their treating doctor[18,42]. No eligibility criteria were identified in the selected studies. Many potential CR participants were deemed ineligible without explicit decision-making criteria[18,42]. Other barriers to CR include non-completion or delay in post-hospitalisation referrals, lack of information and prioritisation of CR[21,23,24,41] (Table 2).

Table 2: Final analysis, evaluation and integration – general populations[18-24,41-43]



Australian First Peoples: Lack of data on referral rates and poor discharge planning were identified as barriers to CR for Australian First Peoples[43,44]. Lack of services, low levels of involvement of Australian First Peoples staff and culturally inappropriate services are identified as contributory factors to low rates of CR referral and access[43,45-47]. In one community in Western Australia, the number of people who attended CR was reported as being augmented by self-referral of people interested in learning more about health and risk factors rather than formal referrals or involvement in CR[46,47] (Table 3).

Table 3: Final analysis, evaluation and integration – Australian First Peoples[43-48]



Cultural and geographic factors necessitating alternative and flexible programs

General populations: A range of studies identified that alternative approaches to CR are required due to low levels of geographic access in rural and remote communities[18,19,23,41,42,49]. It is known that distance from services impacts on access to CR[18,21,23]. Technological or personal support home based programs are identified as alternatives to centre based programs[20,22,23]. There is a demonstrated need for flexible and individualised programs to accommodate factors related to employment, age and gender, supported by community involvement[19,20,24]. The use of a 'heart health' manual combined with home visits has been shown to be of benefit[19]. Innovative management policies are recommended to enable alternative and flexible models necessary to meet individual and local needs[23,24] (Table 2).

Australian First Peoples: Studies repeatedly found that First Peoples programs must be of high standard, culturally appropriate, holistic, flexible and include family and community[43,45,48]. Indigenous health workers are identified as an essential part of the health service team, which needs strong relationships and trust within the team and program participants[46,48]. Strong links with mainstream health services are necessary whilst retaining flexibility and individuality, such as 'yarning' or storytelling to encourage attendance[43,46] (Table 3).

The barrier of distance from services is not identified by First Peoples to the same extent as for the general population[18-23,23-25,41] (Table 2). In one Tasmanian First Peoples study, transport was provided for participants. This was regularly used by 48% of the participants and by 15% 'some of the time'[47] (Table 3).

Professional roles and influence

General population and First Peoples: Medical officers and/or CR coordinators' personal involvement, accessibility and follow-up, together with supportive and non-judgemental attitudes, were found to be enablers for CR attendance[19,20,23]. Further enablers identified included health professionals' knowledge and prioritisation, their willingness to share information and work as part of a coordinated multidisciplinary team, as well as ensuring effective interhealth services communication[47] (Table 2).

There is evidence that professional relationships between Australian First Peoples and general population staff are strengthened when they are based on trust and respect, with Australian First Peoples in primary professional roles[43,46,48]. Improved cultural skills of general population staff are of primary importance in this process. These are identified as core components for effective CR and secondary prevention for Australian First Peoples[43,46]. Two studies involving Australian First Peoples also identified multidisciplinary teams as being important, together with flexibility of professional roles[45,48] (Table 3).

Knowing, valuing, and psychosocial factors

General population: Public perception generally demonstrated that CR is unnecessary for younger, fitter people[49], or not suitable for people with comorbidities or advanced disease[24,42]. Lack of information, few positive role models, negative local attitudes, poor experience or misinformation, and insufficient health professional support, have all been identified as limiting the perceived value[19,20]. It is also noted that people experience difficulty in acknowledging the need for lifestyle changes, especially if families continue with risky behaviour such as smoking[24]. People may opt to deny the need for risk modification, cease taking their prescribed medications and seek alternative therapies[21] (Table 2). Depression, anxiety, denial, sadness, guilt, grief and personal loss have been found to result in poor motivation and non-completion of programs[23] (Table 2).

Australian First Peoples: Inequities in First Peoples health services are compounded by 'Western' medical practices reported to be ineffective in taking accurate medical histories[43,46] and to mirror a 'power inequity that resembles colonialism'[42,47,48]. The need for flexible and innovative programs that consider all aspects of chronic disease risk factor minimisation, with a possible focus on primary and secondary prevention and consideration of mental as well as physical health, to address these barriers has been identified[43] (Table 3).

Financial costs – personal and health services

General populations: On a personal level, travel costs, medications, visits to health professionals and potential loss of income due to work commitments are identified as significant barriers to CR[19,21-23] (Table 2).

Australian First Peoples: Current studies do not identify the same financial issues for First Peoples, who largely attend local Indigenous medical services or government health services, which, whilst accessible, provide few CR or secondary prevention services[43,46] (Table 3).

Limitations

The methodological quality of articles was assessed and demonstrated validity in research methods, with some limitations (Tables 2,3). The majority of qualitative and mixed method studies used purposive sampling and semi-structured interviews[19-21,24,41,43,44,46-48], with data analysed and themes identified using NVivo software. However, many studies were limited in their generalisability due to specific geographic location of data collection[19,20,23,41]. Other limitations were non-inclusion of essential representatives (eg medical officers, carers and local indigenous people (Maori of New Zealand) [20,23,24,41,49]), and lack of data verification[45,47]. Three quantitative studies were limited by lack of exclusion criteria (CR eligibility)[18,43,50], with one sample not randomised[45]. One mixed method study relied on a small and possibly non-representative sample[43].

Results are assimilated according to themes, barriers, enablers and pathways to provide information as a basis for developing a

revised framework and perspective for CR referral and access models that will ultimately improve health and quality of life for all people with heart disease in rural and remote areas (Tables 4,5).

Table 4: Themes, barriers, enablers and pathways – general populations[18-25,41,42,49]

Theme	Barriers	Enablers	Pathways
Referral/ health service pathways and planning	Low level referrals [18,20,22,24,41] Not aware of CR [24] CR not offered [18]	Develop automatic referral/information/education system [24] Early referral and personal contact from the local general practitioner and CR coordinator [18,24]	Need a clear transition of care, referral and framework or plan of care [21]
Cultural and geographic factors necessitating alternative and flexible programs	Distance and lack of CR services [18,19,23,24,41,42,49] Poor participant synergy, family responsibilities [20] Taking time off work [19,21] Strong self-reliant rural attitude, dislike of groups, anxiety and depression [22] Women's career role and possible inability to drive [23]	Support groups, local knowledge, need an effective home based alternative [23,24] Media, opportunistic casual 'reminder' awareness, home visits community activities eg walking, healthy cooking, lobby restaurants to provide healthy food choices [24] Family support [23] Range of alternative programs eg home based, telephone support, positive attitude, motivation, groups for people who enjoy, welcoming staff, home visits, GP reminder, and phone contact/support [21] Home based programs are time efficient and more acceptable for younger, fitter and employed people and those who have family responsibilities [49]	Not identified
Professional roles and influence	Lack of a coordinated multi disciplinary team approach [20] Poor support from health professionals [21,24,41] General practitioners consider themselves 'one stop shop' [41]	Better informed health professionals on CR programs and benefits [24] Support with client's, a supporting behaviour change [21,24] Ambulance officers teach cardiopulmonary resuscitation, involve local carers; flexibility in programs and roles; communication with general practitioners and health professionals [21]	Directing efforts at increasing participation in CR. Changes to health service policies that address identified barriers, eg extended and flexible roles [21]
Knowing, valuing, and psychosocial factors	Lack of role models and local attitudes not supporting CR [20] No benefit, too old, other health problems [18,22] Using alternative therapies and not adhering to prescribed treatment, families continuing to smoke [24] Younger, fitter, employed males less likely to attend centre based programs [49] Lack of information about CR, negative view from experience or misinformation [23] Difficulty in acknowledging the need for lifestyle changes [23] Depression, anxiety, denial, sadness, guilt, grief, personal loss, often resulting in poor motivation and non-completion of programs [22,23]	Heart trust and home based rehabilitation systems – increased confidence in recovery and provided encouragement to manage independently [18] Home programs more acceptable for younger, fitter, employed and requiring home based; more time efficient, also better for women who have family responsibilities [49] Alternative methods of CR program delivery make CR more accessible to people who find it difficult to access outpatient CR and/or who decline groups [23,42]	Not identified
Financial costs – personal and health services	Costs – transport, time off work, cost of health professional visit and medications [19,20,41,49] Varying education levels and social vulnerability [19] Competing priorities including work and family responsibilities [20,23,25,49]	Home based and alternative, flexible, individualised programs [23,49]	

CR: cardiac rehabilitation

Table 5: Themes, barriers, enablers and pathways – Australian First Peoples[43-48]

Theme	Barriers	Enablers	Pathways
Referral/ health service pathways and planning	Discharge processes are lacking, with Australian First Peoples often not identified as such [43] Lack of a minimum dataset to record and monitor CR referrals and outcomes in Western Australia [48]	Reviews of the current Western Australian data set and a review of referral pathways [44] High completion rates indicate the need to ensure people are referred and attend the first session [44]	Word of mouth recommendations, and self-referral [46,47]
Cultural and geographic factors necessitating alternative and flexible programs	Not culturally appropriate, programs connected with colonisation [46] Family responsibilities and commitments [43,45] Western medical practices are ineffective in taking accurate medical histories of Australian First Peoples [46] Negative perceptions and media of Australian First Peoples [43] Interplay between physical and mental concerns [43] Lack of services [46]	Cultural security of Aboriginal medical services [43,46] Cross-cultural benefits [47] Engaging the family and broader community; including both primary and secondary prevention; flexibility and 'yarning' [46] Community education, follow-up and support [43] Strengthen cultural skills of non-Australian First Peoples [43] Management support for policy changes and practice [45]	Revised referral and data collection system [48] Develop more services [47]
Professional roles and influence	Low level of cultural awareness training for health professionals [47,48] Western medical practices are ineffective in taking accurate medical histories of australian first peoples [46] Tensions between standard medical care and secondary prevention and the views of Indigenous people [43]	Aboriginal health workers part of multidisciplinary team and involvement of Aboriginal medical services [43,46,47] Increased knowledge of the NHMRC guidelines *Strengthening CR and secondary prevention for Aboriginal people* [43] Non-Australian First Peoples staff gaining cultural insight, feeling valued and assisting people to improve skills and functioning [47] Strong relationships and trust between staff and participants [46]	Management support for policy changes and practice [43] Strategies to reduce staff turnover and subsequent staff shortages [43]
Knowing, valuing, and psychosocial factors	Established diseases authors were less likely to attend than people with risk factors only [47] Poor understanding of medication regimes and correct use of prescribed medications; reluctance to call an ambulance due to the possible costs [46] Varying education levels and social vulnerability [43] Family commitments [43,46]	Participants learning new skills; community interaction and comradeship [47] Strengthen the cultural skills of non-Australian First Peoples staff [43,47] Family involvement [43,46]	
Financial costs – personal and health services	Nil identified in the studies reviewed for Australian First Peoples		

CR: cardiac rehabilitation; NHMRC: National Health and Medical Research Council

Discussion

CR is known to be effective in improving quality of life, reducing mortality, morbidity and hospital readmissions[7,8,10], and consequently reducing costs for hospital treatment for heart disease[7-10,51,52]. The true value of CR is not realised in rural and remote areas due to poor access and/or attendance to CR services[18-21,23,24,41]. Whilst this integrative review provides information on barriers, enablers and pathways to models of referral and access to CR, there remain many unanswered questions, including why referral and attendance rates continue to be low despite the significant evidence of CR effectiveness. Whilst the reason for this is not completely understood, contributing factors identified in the selected studies include poor understanding of the benefits of CR by health professionals and potential attendees, compounded by low levels of referral[19,21,23,24,42]. Whilst some pathways of referral and transition of care planning are reported, referral rates are not known in many areas of Australia.

Early results of a recently instituted Queensland Health CR database are insufficient to draw conclusions about referral rates in

Queensland. It is anticipated that as data collection increases, this information will become available[16,53].

Australian First Peoples experience many of the same barriers as the general population, compounded by cultural issues, lower socioeconomic and educational levels, and greater geographic isolation[1,3]. However, they have a greater need for CR, primary and secondary prevention due to higher levels of heart disease and comorbidities[1,54,55]. To provide Australian First Peoples adequate and effective CR, their increased involvement, together with non-Australian First Peoples' improved cultural awareness, mutual trust, respect and two-way learning is required, as well as improved support and access to specialist services[43,46-48]. Many of these issues are not well investigated and described.

Costs associated with recurring heart disease are high and it is known that these costs can be reduced with improved systems that facilitate referral, accessibility and CR attendance[6]. To improve services, more information is required about hospital discharge and CR referral processes, including eligibility, inpatient education, perceived benefit and meeting participant needs.

The current situation demonstrates weak or poorly implemented systems. These include models of health services delivery, referral processes as well as inconsistent knowledge and value by health professionals and potential participants[14,15,19,23,40,48], plus a range barriers to access and appropriateness of services. Many of the issues identified are common to health service provision and access to services in rural and remote areas of Australia[56]. As such, findings of this integrative review potentially have broad applications. To address the deficits, the following priorities need to be considered.

Referral, health services, pathways and planning

A systematic referral process based on well-defined criteria, individualisation of CR, personal contact, trust, information and support from health professionals[13,22-24,46,49] needs further investigation. The systematic referral process, based on eligibility criteria, education on heart disease and risk factors, needs to commence prior to hospital discharge[20,22,57].

Cultural and geographic factors necessitating alternative and flexible programs

Flexibility in CR is essential because of the diversity of demographic profiles, geographic location and health status in rural and remote areas[23,41,47,48]. Alternative models of CR, including home based programs with telephone support, such as Queensland Health's Coaching Patients on Achieving Cardiovascular Health (COACH)[17], telehealth, purpose designed apps and community involvement, are all known enablers for CR[31,41]. However, attendance rates remain low[10,16,17]. In Australia there is little evidence of CR being provided by Aboriginal/Indigenous medical services, compounding poor access to CR by Australian First Peoples who live in remote area communities. This highlights the need for further advocacy and a review of systems of health care for Australian First Peoples in remote area communities. In line with a holistic and culturally appropriate approach and scarcity of resources, consideration of an integrated, flexible primary and secondary prevention model that is appropriate for Australian First Peoples as well as the general population needs further investigation.

Professional roles and influence

Key issues identified include ongoing staff shortages[14,15], indicating the need for increased professional role flexibility and modified multidisciplinary team models, supported by appropriate management policy[15,43]. A further priority is including a primary role in CR, supported by further education, for Indigenousl health workers working with Australian First Peoples[43,45,47]. These are all key issues that need further consideration to work towards optimal effectiveness of CR in rural and remote areas.

Knowing, valuing, and psychosocial factors

Poor understanding of the concepts and benefits of CR contributes to low attendance rates[19,21,23,25,41,57,58]. This is exacerbated by the general perception that acute care health services are of greater importance than primary and secondary prevention services[24]. Lack of knowledge and negative perceptions of CR need to be addressed. Mental as well as physical health issues are of primary importance and currently not prioritised in many CR programs[19,21,23]. A holistic approach to CR, primary and secondary risk factor prevention and use of resources need further consideration[46].

Financial costs – personal and health services

Through effective CR it is known that healthcare costs can be significantly reduced through a reduction in reoccurrence of heart disease and hospital readmissions[6]. To achieve increased CR participation, improved professional understanding and support is essential[41]. The cost factors for general populations include travel, loss of work, cost of health services, professional consultations and medications[19,23,24,42]. It is also reported by James Cook University, Cairns and Apunipima Indigenous health services (unpublished internal report, 2016) that Australian First Peoples are faced with financial costs, practical and cultural barriers when attending centralised specialist services that require them to travel and stay away from their families and community. The overall low level of health services in rural and remote areas results in poor access and overloaded services, and resultant staff turnover and cost implications[14,15,42,59]. Reconsideration of the system, current health services and resource allocation is required.

Limitations

Due to the predominantly qualitative or mixed method research the results are not outcome focused and have limited generalisability due to the specific geographic areas and small purposive contextual samples of the studies. Therefore, conclusions drawn by this integrative review on health service systems and services are based in part on selected studies' discussions, findings and conclusions, and subject to the limitations of the study. No northern Queensland or Northern

Territory studies on CR were identified in this integrative review. These are extensive regions of Australia with large rural and remote areas. This and the overall low number of studies indicate the need for further research to improve information that will facilitate decision making and identify further CR enablers and pathways and minimise barriers specific to rural and remote areas of Australia, so that service improvements can be achieved.

Conclusion

The purpose of this integrative review was to explore barriers, enablers and pathways for access to CR, with the aim of optimising services, improving health and quality of life for all people living independently in rural and remote areas. The review indicates that CR services are fragmented and lack a systematic policy driven approach, with resultant low levels of referral and access. Even when alternative services are offered in Australia (eg COACH), attendance rates remain low.

To address this, the following elements for improved referral and access to CR need further investigation and development:

- referral systems and eligibility criteria
- availability and access to flexible centre based and home based CR programs including telephone/personal support and technology based programs via telephone apps, with distance support
- education/awareness/training on CR for providers and potential participants, family/significant others
- information systems for CR referral and access
- improved education and training for general populations staff on Australian First Peoples' cultural issues
- improved workplace support and education for Indigenous health workers
- greater flexibility and extended professional roles supported by management policy and protocols
- consideration of combined CR primary, secondary prevention and risk factor management
- improved funding.

CR works to improve health status and reduce costs, and there are a range of ways to provide effective services for more people. These include a systematic, policy driven approach that includes referral, eligibility and access. This is necessary if CR is to fulfil its role as a valuable tool in substantially lowering coronary heart disease morbidity and mortality. Understanding and addressing these factors has the potential to reduce costs, through reduced cardiac events and hospital readmissions as well as improved quality of life and contribute to improved CR and/or secondary prevention services and ultimately health outcomes for all people living independently in rural and remote areas of Australia.

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End of thesis