Original Article

AUStralian Indigenous Chronic Disease Optimisation Study (AUSI-CDS) Prospective Observational Cohort Study to Determine if an Established Chronic Disease Health Care Model can be Used to Deliver Better Heart Failure Care Among Remote Indigenous Australians: Proof of Concept—Study Rationale and Protocol

P. Iyngkaran, FRACP a,c,9, V. Majoni, RN b,1, K. Nadarajan, FRACP c,2, M. Haste, CCRN d, M. Battersby, PhD a,3, Marcus Ilton e,2 and M. Harris a,4

a Flinders Human Behaviour and Health Research Unit (FHBHRU), Margaret Tohn Centre, Flinders University, Bedford Park, SA 5042, Australia
b Royal Darwin Hospital, Division of Medicine, Level 7 Royal Darwin Hospital, Rocklands Drive, Tiwi, NT 0810, Australia
c Top End Heart Failure C&C, “Chronic Disease Coordination Unit | Department of Health”, Room 264, 2nd Floor, Block 4, Royal Darwin Hospital, Rocklands Drive, Tiwi, NT 0810, Australia
d Royal Darwin Hospital, NT Cardiac Services, Darwin Private Hospital, Tiwi, NT 0810, Australia

Background: The congestive heart failure syndrome has increased to epidemic proportions and is cause for significant morbidity and mortality. Indigenous patients suffer a greater prevalence with greater severity. Upon diagnosis patients require regular follow-up with medical and allied health services. Patients are prescribed life saving, disease modifying and symptom relieving therapies. This can be an overwhelming experience for patients. To compound this, remoteness, differences in conventional health care and services pose special problems for Indigenous clients in accessing care. Additional barriers of language, culture, socio-economic disadvantage, negative attitudes towards establishment, social stereotyping, stigma and discrimination act as barriers to improved care. Recent focus supported by clinical evidence support the role of chronic disease self-management programs. A patient focused, problem identification, goal setting

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Abbreviations: ASH, Alice Springs Hospital; BNE, Brain Natriuretic Peptide; CDSMP, chronic disease self management program; CCFM, Flinders Program of Chronic Condition Management; CHF, congestive heart failure; C&K, Care and Response; FMC, Flinders Medical Centre; FMSM, Flinders Model of Self Care; HE, heart failure; NT, Northern Territory; NT DHRCS, Northern Territory Department of Health and Families; PACIC, patient assessment and chronic illness care satisfaction questionnaire; P&G, Problems and Goals; PHC, primary health care records; PIH, Partners in Health; RDFH, Royal Darwin Hospital; 6MWVT, six minute walk test.

* Corresponding author. Tel.: +61 8 8920 6250.
E-mail addresses: balamyngkaran@hotmail.com (P. Iyngkaran), vongayi.vongayi@yahoo.co.uk (V. Majoni), kanganada@gmail.com (K. Nadarajan), malcolm.battersby@health.sa.gov.au (M. Battersby), marcus.ilton@gmail.com (M. Ilton), melania.harris204@flinders.edu.au (M. Harris).

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and psychosocial modification based program should in principal highlight these issues and help tailor a patient focused comprehensive care plan to complement guideline based care. At present there are no Indigenous focused chronic disease self-management programs. There is a need for research on ways to provide chronic disease management to this group. We therefore designed a study to assess a model of patient focussed comprehensive care for Indigenous Australians with heart failure.

**Study design:** ASUIC-CD5 is a prospective, cohort, observational study to evaluate the efficacy of the standard “Flinders Program of Chronic Condition Management” for Indigenous patients with chronic heart failure. Eligible patients will be Indigenous, suffering from chronic heart failure, in the Northern Territory. The primary end-point is the satisfaction score based on the PACIC. The study will recruit 20 patients and is expected to last 12 months.

**Summary:** The rationale and design of the ASUIC-CD5 using the Flinders Model is as follows.

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**Keywords:** Indigenous; Heart failure; Self-management; Protocol; Rural

**Background**

The Australian Indigenous community suffer a high prevalence of congestive heart failure (CHF). They also suffer greater disease severity, increased morbidity and mortality at younger ages and as a whole there are more treatment delays than for the Australian population as a whole. It is generally accepted that inadequate provision of usual therapies contributes to poorer outcomes. This picture of worse disease and poorer care delivery is particularly evident in the Northern Territory of Australia with a vast area serviced by two major public hospitals [1–13]. In excess of 70,000 Indigenous Australians live in the NT, 65% remotely, with 70 spoken languages. Specialist services reside at the tertiary hospitals. Satellite district hospitals in several smaller townships support a small number of visiting specialists and provide the medical needs for these communities [14,15]. Thus the NT with its unique socio-cultural-geographical factors, is in need of better tools to deliver heart failure best practice.

Delivery of CHF best practice is an important contributor to overall outcomes. In the OPTIMIZE-HF study simple measures alone significantly improved outcomes [16,17]. Among Indigenous patients the excess CHF mortality is most likely to be multifactorial in origin. Economic, social, physiological and educational disadvantage play an important role [5,17]. Other factors that variably affect outcomes include the impact of developing a new chronic illness, the impact of associated co-morbidities on the patient, family and community dynamic. There are numerous other factors that confound achieving the OPTIMIZE-HF goals, as highlighted by the CSANZ IHC writing group. Critical to this is acknowledging that "one shoe does not fit all" approach [4]. Chronic disease management models, with attention to comorbidities and social factors, including self-care models may have benefits in this area.

Chronic disease self-management programs have shown benefits in CHF [18,19]. Limitations include lack of programs with adequate reliability and validity [20], or sufficient flexibility to deal with co-morbidities and psychosocial factors [21]. To deliver chronic disease self-management models for Indigenous Australians understanding the socio-cultural beliefs is important [18,22]. A more flexible, regional and patient focussed model may have better outcomes for Indigenous patients. Previous work has also highlighted several key factors that need to be taken into account in the design of programs for this population:

1. Barriers in access and timing to appropriate, acceptable and evidence based medical care and uptake of preventative and post discharge measures [23–29].
2. A greater burden of rheumatic and non-ischaemic aetiology at younger ages [14].
3. A range of health, social and economic disadvantages compared to the whole population such as in life expectancy (62.6/68.3 years vs. 79.5/84.1 years), age 12 educational level (15.5% vs. 46%), labour force participation (49% vs. 70.5%), home ownership (13% vs. 72%), financial stress 67.2% vs. 31.3%), unable to fund basic living expenses (36.6% vs. 30%), reported good health (47% vs. 56%) and cigarette smoking (52.7% vs. 28.4%) [14,15].

The “Flinders Program of Chronic Condition Management (Flinders Program or CFPM)” is patient focused and allows flexibility [30] and therefore has the potential to address the factors listed above. It has been tested in a range of chronic conditions with benefit, and a study among Indigenous diabetics showed promising results [31–33]. Given the lack of existing data on appropriate models of care for Indigenous clients we aim to conduct a pilot study to assess the Flinders Program as a way to deliver heart failure care to Indigenous Australians living in remote areas of the Northern Territory. Study objectives are:

- to assess the feasibility of implementing the Flinders Program for Indigenous patients with CHF;
- to obtain critical feedback on the model and its application from Indigenous patients and Indigenous health care workers; model is described.
- to determine from the feedback if the current model is applicable or requires modification to achieve the required benefit;
- to use the information obtained to tailor an Indigenous specific chronic disease model to be trialed in a larger...
study that is powered to provide information on quality of life, readmission rates, cost-benefit and mortality.

Methods

Study Objectives and Measures

The key requirement for feasibility of an intervention, which supports self-management, is patient acceptance. Patient satisfaction will be measured using the validated patient assessment and chronic illness care satisfaction questionnaire (PACIC) (Fig. 1) [34]. The PACIC consists of a 20-item patient report instrument that allows clients to rate chronic illness care they received over a six-month period. The PACIC takes 2-5 min to complete, written format, or 7-8 min, telephone format. Five domains are covered including patient activation, delivery system design/decision support, goal setting, problem solving/contextual counselling and follow up/co-ordination. Across a range of chronic illness and client characteristics the PACIC showed satisfactory validity and internal consistency reliability with Chronbach’s alpha [35].

Other study measures include assessment of participants’ clinical changes in heart failure and general well-being through the six-month CFPI score, NYHA class and 6MWT and plasma BNP. Health worker satisfaction questionnaire will be assessed using an internally designed and...
Figure 1: Study Design & Study Plan. Diagram A: Specific clinical outcomes and measures, 1. Data and study collection methods. Figure 2: Study Design & Study Plan. Diagram B: Specific clinical outcomes and measures, 2. Study Procedures and Interventions. Table 1: Study Design & Study Plan. Table 2: Study Design & Study Plan. Table 3: Study Design & Study Plan.
failure (echocardiographic EF <40%) or diastolic heart failure requiring admission with acute pulmonary oedema (echocardiographic EF >50%) with another chronic morbidity (as defined by medical or surgical complaint requiring ongoing specialist care for at least six months, e.g. chronic renal failure, hypertension, diabetes mellitus and others). All patients must agree and be willing to participate with the study protocol. Subjects will be excluded if concerns are raised by any medical staff, life expectancy of ≤6 months, receiving palliative or nursing home care. Cognitive status and dementia will not be a contraindication if there is consent from a caring relative or legal guardian and ability to complete the CFPI™.

STUDY POPULATION AND SETTING: Patients identified from the cardiology outpatient’s of the RDH and ASH will be referred to the study case manager at the presenting hospital. Once consent is obtained a time will be made to complete the CFPI™. Baseline demographics collected will include age, sex, primary residence, language and cultural group identified with, co-morbidities, medications, primary care physician, pharmacy, mode of travel, income and smoking and alcohol use. Baseline investigational tests as shown in Fig 2b, and baseline CFPI™ score (Fig 2c), will be recorded. All staff will be health care workers within Northern Territory Department of Health Alliance. The case manger is a new role in this hierarchy specifically acting as the patient advocate. Participants will be recruited over a six-month period, from February 2013 to July 2013 and followed for six months, ending January 2014.

INTERVENTION: All enrolled patients will receive routine medical care as per Heart Foundation guidelines 2006-2013. Additional investigations will be required from usual care. Clients will be able to choose the original CFPI™ or a version designed for people who use languages other than English. From the goals and issues raised in the CFPI™, a unique solution is arrived at and care is co-ordinated from this. Usual care may include a range of services including further workup for heart failure or associated co-morbidity, referral for cardiac rehabilitation, increased follow-up by primary physician and other allied services such as diabetes and diet education, podiatry, physiotherapy and occupational therapy. If the client requires care in another centre, this may be Flinders Medical Centre, South Australia; the case manager will contact the Indigenous social worker and heart failure nurse at that site. A discussion of patient focused concerns will be raised and solutions implemented. The study case-worker will contact the patient at day 30, 90 and 180. Additional contact at the behest of health staff or participant will be accepted and details of such contact recorded. At day 380 the client will be asked to complete the CFPI™, 6MWT and blood test for BNP (Fig 2a, b).

Data Collection and Study Management

DATA COLLECTION AND STORAGE: Data will be collected on a standardised case note extraction form which contains the details including demographics, clinical details, investigational results and questionnaires (Fig 3). The forms will be filled in by trained staffed. Additional information will be accessed through multiple sources including hospital records, primary health care clinic records, specialist databases, and record systems maintained by visiting district medical officers. The period of interest for data collection will be 1-6 months following the initial completion of CFPI™. Data definitions will be standardised and widely accepted case and outcome definitions as outlined in the ACC Clinical Data Standards.[37,38] A locally convened panel of the research team will review all cases that demonstrate ambiguity in data definitions or outcome data, and consensus sought. Only when two investigators agree will the data be recorded. All data will be de-identified when transferred for analysis, and subsequently will be stored within locked files at the Chronic Disease Management Research Office, RDH.

TRAINING AND STANDARDISATION: Staff conducting the study will receive training and relevant documentation and ongoing professional support from the Finders Human Behaviour & Health Research Unit. Staff delivering the CFPI™ will undergo an accreditation process and assessed competent against the current standard. In addition, this project requires access to data housed and maintained by NT DHCS and NT Cardiac Services, Hospital Separation Data; Hospital Records and PHC Records will be sought from NT DHCS and will be arranged through the principal investigators in Darwin (pending ethics approval). In the event that PHC records are housed within independent services (non-DHCS clinics) appropriate consultation will be undertaken as requested by the independent services themselves. Formalised consent processes as directed by Independent services will be followed. If they wish to perform the audit themselves, as a training and quality assurance process, appropriate training and support will be provided by the research team (PI and project coordinator). The quality or data recording is noted and will be standardised by training staff on the ICD-10 classification for heart failure and ACC/AHA guidelines for key performance indicators [38]. Areas of ambiguity will be discussed with at least two members of the steering committee and recorded if there is agreement from both parties.

ADVERSE EVENTS: We do not anticipate any adverse events from this study. All procedures are in place as per local institutions guidelines to address issues relating to client dissatisfaction or concerns. Any medical complication will be addressed by the treating physician/institution as part or standard care.

Statistical Aspects and Data Analysis

This being a feasibility study we will identify appropriate parameters to determine sample size calculations for future studies involving a controlled design. Initial data analysis will investigate the distribution characteristics of each primary and secondary outcome measure and to determine either a parametric or semi-parametric approach to main data analysis. If continuous outcome data is approximately normally distributed then Linear Mixed Models (LMM) will be used to examine change over
Immediate Challenges within the Health System

(1) What model of health care delivery is most appropriate?
(2) Who should deliver health care and what are the workforce requirements?
(3) What support systems and infrastructure are required?
(4) How can primary care and secondary specialist services be effectively integrated?
(5) Description and understanding of causality;
(6) Policy protection for health care standards.

Worldwide Training
(a) Defining workforce needs for primary and specialist care of cardiovascular disease according to relevant national and international standards and population needs.
(b) Publicising opportunities to contribute to Indigenous cardiovascular health care and establishing a register of health-care professionals willing to commit to regular and periodic support of provision of Indigenous health care.
(c) Describing standards for qualification for provision of cardiovascular health care and providing opportunities for skills improvements for the spectrum of health care professionals.
(d) Development and dissemination of relevant continuing education tools.

Improving Access to Care
- Importance of Primary Care and Socio-economic Status
- Co-ordinating Access to Specialist Care
- Reducing Travel and Bringing Care to Communities
- System Roadblocks – direct referral to specialists without primary care referral
- Reducing travel and bringing care to communities
- Point of Care tests to communities

Implementing a New Reporting Framework
- Development of national key performance indicators for primary health care services and their inclusion in a web-based reporting tool.
- Improved reporting back to service providers.
- Support for services to implement the new system.
- Voluntary performance indicators for continuous quality improvement.
- Improved Patient Information Recall System infrastructure.

Potential Initiatives
(a) Working with appropriate professional bodies to develop training curricula for medical, paramedical and nursing professionals engaged in Indigenous cardiovascular care.
(b) Development of appropriate cultural awareness training elements in consultation with Indigenous stakeholders for inclusion in professional training curricula.
(c) Reaching out to schools to encourage Indigenous children to consider health-care careers and also science careers, including video programs and educational materials, in partnership with local communities.

Avenues to Close the Gap
- Sustainable access to key medicines.
- Workforce Limitations.
- Lack of relevant Infrastructure.
- Language barriers.
- Cultural barriers.
- Poverty.
- Geographic isolation.

Discussion
Recent international research findings provide lessons for the design of programs for Indigenous Australians. Combining overseas experience with consensus statements from local leaders, "The panel of experts on the provision of chronic cardiovascular health care for Indigenous populations in Australia and New Zealand", we can isolate the common salient issues surrounding Indigenous health (Fig. S).
In CHF combining the strength of the existing evidence base and delivering this with cultural competence are important considerations [20,21]. However using such programs for clients from diverse/lower educational and socioeconomic backgrounds may be challenging but it is important that we do not relegate these programs to the “too hard” basket. In addition the stretch on available resources is now in the public and political spotlight in conjunction with health disparities. It would seem incongruous that maintaining or diminishing health budgets could be associated with improved health outcomes. On this basis it is important attempts are made to utilise existing experience to improve existing CDSMP for a wider audience.

A criticism of CDSMP is delivery among varying educational levels. Surprisingly in a randomised controlled trial of 317 CHF patients followed for 12 months, the authors noted patients with a lower educational level benefitted more than those with higher education, raising a counterargument to traditional beliefs of CDSMP [19]. There are, however, some concerns over CDSMP. While these programs have had significant benefits for diabetes and hypertension, attempts to integrate the Stanford University chronic disease self-management program in the National Health Service, UK (NHS–UK–CDSMP) met with limited success. Looking at this more closely, this was partly due to poor engagement of health care professionals especially general practitioners [40]. Diversity and applicability of such programs for ethnic minorities and socially deprived groups have also been limited. Individual programs are also rigid in structure and do not incorporate flexibility in delivery of intervention. Flexible delivery and CDSMP as conducted within the Australian Sharing Health Care Initiative had the greatest health impact [41]. Lessons from the UK experience suggest that any benefits of CDSMP are likely to be determined by how such a program is delivered at the individual client level and engagement of primary care. We have thus tried to incorporate the recommendations of the CSANZ BHC, NHS–UK–CDSMP and recent works by Liaw and Cameron [3,6,20,21]. This approach places the patient at the apex of the health pyramid team (Fig. 4). We have intentionally adopted a flexible exploratory approach, in the hope through observation, we may generate further hypotheses that will lead to a more focused approach.

The Flinders Program is patient centred and allows for flexible delivery to meet cultural requirements. The development of the program started as a Federal Government initiative to help reduce the burden of chronic diseases. The completed tool is structured to assess a client’s capacity to self manage, identify gaps in knowledge and self-management capacity and identify priorities in chronic diseases from a client’s perspectives. The program provides a generic set of tools and a structured process that enables health workers and patients to collaboratively assess self-management behaviours, identify problems, set goals, and develop individual care plans covering key self-care, medical, psycho-social and carer issues. Based on cognitive behaviour therapy and motivational interviewing, the tools include:

(1) The Partners in Health Scale (PIH).
(2) Cue and Response Interview (C&RI).
(3) Problem and Goals assessment (P&G).

The PIH is a self-rated questionnaire for the patient to assess their self-management knowledge, attitudes, behaviours and impacts of their chronic condition. The health worker administered C&R explores the same questions as the PIH via open-ended questions with responses, rated from the health provider’s perspective, shared with the patient. The P&G is a health worker administered tool based on behavioural psychotherapy and uses open-ended questions to determine patient-identified problems and formulate goals to address those problems. These behavioural changes are written down, scored, monitored and progressively implemented at the pace of the patient. Strengths, barriers and priorities identified through collaborative discussion of PIH, C&R and P&G are incorporated into a fully negotiated care plan. The care plan includes health worker and patient identified issues, management aims, agreed interventions, responsibilities and review dates. All tools use Likert-type scales (a 10 point rating scale), which allow change and progress to be measured and recorded during reviews. As the Flinders Program care plan tailors a range of possible self-management interventions (such as disease-specific patient education programs or lay-led programs) to the individual, it is compatible with both disease-specific and

Figure 4. Project management team. Upon diagnosis of heart failure, referral is made to indigenous social worker and study case manager (Red dotted arrows). Cultural and language issues are raised. Creating a patient focused CDSMP becomes the main goal. A suitable time is organised to complete the Flinders Model. The loop restarts and the patient now becomes the focus and leads the management team (Orange continuous arrows). The physician provides best available evidenced care. Issues raised via CDSMP are the basis for determining allied health and other measures that appear as barriers to this care. All communications and investigations concerning the patients will be provided to the case manager, and filed, who acts as the patients advocate to the CDSMP (Concept from Ref [40]). (For interpretation of the references to color in this figure legend, the reader is referred to the web version of the article.)
lay-led programs rather than an alternative stand-alone approach. The Flinders care plan is provided to the patient and all health professionals involved in the patient's care and can be incorporated into the patient's overall medical care plan. Recent data have supported good validity and internal consistency, while the four domains of self-management provide a valid measure of patient competencies with respect to self-management of their chronic conditions [36,33].

Several measurement instruments were assessed for this study, acknowledging there may exist a gradient of educational and social differentials. Liaw et al. presents some basic concepts on Indigenous perceptions on health and ill health [16]. At present there are no Indigenous specific CDSPM and only one published study of CDSPM in use [32]. Among 14 CHF self-care instruments only the European Heart Failure self-care Behaviour Scale (EHFScBS) and Self-care Heart Failure Index (SCHFI) shown adequate reliability and validity, although the programs appear to reduce CHF hospitalisations [41,42]. However neither the EHFScBS nor the SCHFI adequately address co-morbidities, provide a client focused solution or are flexible enough to incorporate the recommendations of the CSANZ IHC recommendations. The spirit and reasoning of the federal government initiated CFP™ accommodates this; however we accept translational gaps still exist. This was the main justification for determining a subjective primary outcome within a pilot study framework. The various formats of the CFP™ are a direct translation of the original document. This document is in progress. It will undergo scrutiny by feedback from various Indigenous groups comparing the original document and the translation version. As such we do not anticipate an additional confounder by allowing the clients or their guardian to choose the template to complete.

As there is little existing research on outcome tools for Indigenous Australians, choice of measures for this study was based on previous internal research at FHBBRU. On this basis we choose two tools for each outcome, as there has been internal comparison. The second criterion used was simplicity to allow for the language barrier and from our experience clients find this more acceptable. The large distances covered to arrive at clinics leading to patient fatigue physically and mentally are factors that affect participation and performance in studies. Specifically several publications have highlighted a small gradient with KCCQ, CHQ, LHFQ leading from SF-12, NYHA, 6-minute walk test (6MWT). As the CFP™ incorporates questions on well-being, we felt the combination of NYHA, 6MWT, BNP and clinical details from physician consult provide an adequate coverage on the sense of CHF well-being [43,44]. Fig. 4 summarises these tools and clinical benefits. Staff satisfaction was assessed using one scale only. The PACIC scale, which is validated, will be used to determine the six-month satisfaction scale. It covers a range of issues and is deemed the most suitable, reliable and reproducible measure for chronic disease outcome determinants [38]. Clinical investigational tools will be correlated with existing laboratory reference ranges. Specific data for the Indigenous community is lacking. However, they have been validated across a diverse range of communities [36,45].

The inclusion and exclusion criteria were intentionally flexible to reflect the existing demographics and to allow broad and general feedback that would reflect living with CHF in the NT. The Royal Darwin hospital is a good setting for assessment of a CDSPM. Unlike the other Australian states, the NT has the lowest cardiologist to patient ratio, no heart failure clinical service and only recently several dedicated cardiac nurse co-ordinators. The population is also largely spread in diverse communities with non-Indigenous communities concentrating in urban areas, while the Indigenous clients live both in the urban areas as well as remote townships with significant distances from the treating centres. The diversity of language and culture makes it impossible to design a uniform worded document as an appropriate surrogate for CFP™. As the hospital structures are, however, well established a patient focused team management approach as suggested by Ciccone et al. will be implemented through the co-ordination of the study case manager [46]. We have also made significant efforts to engage, and have received support from, the hospital Aboriginal Liaisons services, Remote Health Services, Chronic Conditions Strategy Unit NT Health, and primary care.

Studies such as this one are consistent with and can contribute to international trends in research for Indigenous health interventions. Much of present day research places significant emphasis on a structured approach with very clear translation of their guidelines. An extensive literature review using the key words “heart failure, chronic heart failure, congestive heart failure, cardiac failure, congestive cardiac failure” and “Aboriginal, Aboriginal and Torres Strait Islander, Indigenous, Koori, Native, First Nation”, revealed four articles, all presenting positive observational data with the themes of cultural sensitivity, patient centred care, creating specific policies for disparity, emphasis on accuracy and detail of information, engaging extended families, providing tools to facilitate health providers-patient relationship within the larger socio-cultural system [44-50]. Specific interventions for heart failure for Indigenous communities were not identified, however, seven interventions among African American and minorities in the US have noted that while the prevalence of heart failure is greater than for Caucasians, this is less attributable to race once hypertension and other risk factors are controlled for. Positive findings include not all studies showing disparity of CHF care between races and an evolving understanding for optimal care across races [53]. Clearly as more studies and policies are implemented, “no matter how small”, should add to changing the paradigm by creating positive values and are good steps in “Closing the Gap”.

Limitations
We highlight several limitations with the study design including that the study is hypothesis generating and results may reflect a degree of subjectivity. Generalisability of results will not be answered from this study; standardising training of study case workers, if they should
be from different allied health backgrounds, that may bring a different perspective for health provision; no background data to draw from in determining sample size and ensuring validity and reliability of the qualitative tools including PACIC and PHF scales. Finally the level of engagement with the wider Indigenous communities has also been limited at this stage. This will however be addressed when there are working hypotheses and a basic understanding in the area is increased, and should contribute to the design of a larger more focused study.

Conclusion
A proof of concept trial of chronic disease self-management is detailed. The burden of chronic heart failure among Indigenous Australians is significant. Remote communities continue to do worse due to infrastructure and non-traditional factors. Chronic disease self-management programs addressing patient focused goals could highlight barriers to improved care and a tailored patient focused solution could help bridge the divide between patient needs, health resources and clinical outcomes.

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References


