

The FAMILIES Pilot Trial - Family engagement in Chronic Disease Care

Background:

Chronic diseases remain the most important contributor to health disparities experienced by Aboriginal and Torres Strait Islander people and can have profound effects on emotional, mental and physical functioning in patients, their family and community.

Our exploratory research within Aboriginal and Torres Strait Islander communities has identified significant barriers to health services across the continuum of care for patients with Chronic Disease (CD). As a solution, patients have identified the need to a) improve access to outreach services; b) enhance health education and awareness of treatment options; and c) directly involve their families in the long-term management of their condition.

Indigenous people place great importance in the well-being of their family as a critical determinant of their own health, and acknowledge the important role that family play in supporting recovery of individuals experiencing life-threatening illness. However, little research has focused on family-centred interventions in chronic disease prevention.

The FAMILIES Pilot Trial aims to develop and trial (in two primary care sites) a culturally appropriate, integrated family based chronic disease management (CDM) program. We aim to determine if:

Aboriginal and Torres Strait Islander people with chronic disease, and their families, participating in an integrated, multidisciplinary outreach chronic disease prevention program will have improved delivery of evidence-based care, improved health outcomes and improved satisfaction with their CD care.

This trial will target people with chronic disease and use outreach assessment and integration with the primary health care annual health checks to implement gold-standard therapy.

Given the pilot nature of this trial, we also seek to determine:

1. Is a family based, outreach model of chronic disease care acceptable and feasible to Aboriginal and Torres Strait Islander peoples with chronic disease, their families, and their primary health care providers?
2. Can a multi-disciplinary care plan be developed that is based on the assessment of a patient's and their families' social, emotional and health needs?

3. Does implementation of the care plan improve access to, and delivery of, multi-disciplinary health and related services?
4. Does this model of care improve the quality of care, the achievement of clinical targets and improve family members' engagement with Primary Health Care services?

The integrated family based Chronic Disease Management program will have the following key components:

1. **Taking control of your health**
Engaging and empowering families in the management and prevention of chronic disease
2. **What do you need to be healthy?**
Comprehensive needs assessment that encompasses family health, social situation and needs, physical health care needs and social and emotional wellbeing
3. **Making the system work for you**
Facilitate integration of health and health related care delivery to patients and their families to improve health outcomes

The intervention will be coordinated by the study outreach case managers in consultation with multi-disciplinary health service staff. These case managers will facilitate the implementation of the individualised care plans, with aim of improving access to, and delivery of, multi-disciplinary health and related services. The aim of these care plans is to improve the achievement of clinical targets and patient identified goals for chronic disease management.

Given that this is a pilot trial we are keen to trial this project in two sites only. Once we have learnt from this field work, we seek to develop a more comprehensive project outline and will seek funding to run a multi-site family based chronic disease management program in the future.



**Centre for
Research Excellence**
Intervention Research in Chronic Disease
Kanyini Vascular Collaboration



Kanyini Vascular Collaboration Centre for Research Excellence

The Kanyini Vascular Collaboration (KVC) represents a network of leading Indigenous and non-Indigenous researchers, Aboriginal Medical Services (AMSs), community members and policy-advisors. Our key aim is to improve outcomes for Indigenous people with chronic disease (CD). Formed in 2006, KVC has received funding through the Australian Primary Health Care Research Institute (APHCRI) to establish a Centre for Research Excellence (CRE) in Indigenous primary health care (PHC) intervention research in CD (2011-2014).

Baker IDI Heart and Diabetes Institute (Alice Springs) and The George Institute for Global Health (Sydney) lead the work of KVC in partnership with 12 Indigenous controlled health services and health sector organisations. KVC responds directly to the significant and unequal burden of CD experienced by Aboriginal and Torres Strait Islander people through conducting research across several jurisdictions with partner PHC services in urban, rural and remote New South Wales, Western Australia, Queensland, South Australia and the Northern Territory. This research includes several inter-related component studies framed around equipping PHC with the necessary systems and skills to identify, manage and prevent chronic conditions in their communities.

The KVC CRE consolidates our innovative primary care research network at a time of significant health system reform and CD policy development. With an increased focus on interventions, the CRE has the following key objectives:

1. To improve the quality of care, quality of life and outcomes of chronic disease.
2. Examine the impact, utility and effectiveness of the Australian Government's 'Closing the Gap' chronic disease package elements within partner primary care services, with a view to maximising benefit for patients and informing policy development.
3. Develop Indigenous primary care researchers with the skills and support to contribute to their communities needs in chronic disease into the future.

These objectives will be achieved through explicit capacity development strategies, delivered within the context of three key research activities:

- A. Developing a model of CD care for Indigenous Australians – [The Kanyini Chronic Care Model](#).
- B. Building better systems of CD care involving innovative trials in [family-based chronic disease prevention and care](#).
- C. Extending our emerging yet pioneering research on the interplay between [psychosocial factors such as chronic stress and depression on the burden and management of CD](#) in Indigenous communities in order to develop future interventions in co-morbid chronic disease.

The KVC network is also progressing a number of innovative trials in CD management, including continuation of the Kanyini GAP Study and a newly established electronic decision support project (TORPEDO Study).

The KVC CRE employs an integrated approach to capacity building and knowledge translation into policy and practice, working across all levels of the KVC to develop and implement two way learning opportunities. The KVC CRE is committed to employing and supporting the development of Indigenous Research Fellows as key knowledge brokers embedded in our partner health services and organisations.

To find out more about the KVC CRE please visit www.kvc.org.au or contact the Project Coordinators at the George Institute (+61 2 8507 2503) or Baker IDI (+61 8 8959 0100).



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