Dialysis Models of Care
March 2017 Update

Joint Investigator-Stakeholder Meeting

The annual face to face Investigator meeting for this NHMRC funded partnership project was held on the 17th February) in Darwin. Members of the Policy Forum (representatives from government and non-government stakeholders) were also invited since this was the first presentation and discussion of the analysis of early data.

Aboriginal presenters

Lachlan Ross, Margaret Herffernan, Irene Nangala, Jacqueline Amagula and Gundamulk Marawilli, some of whom are DxMoC Project co-researchers, presented at the meeting and spoke very strongly about their work, their experience of renal disease and said how important the project is. They spoke of their different roles within research and in providing education and support within renal services and their communities. Lachlan, Jacqueline and Gundamulk work as *patient preceptors* helping dialysis patients and clinicians and supporting patients to deal with the changes of living in town and navigating the health system. Margaret and Irene are working as leaders in a research project developing cultural awareness with renal nurses. All five are members of their respective renal consumer groups and are contributing to the DxMoC through this groups.

Margaret Heffernan and Irene Nangala talk about the cultural awareness workshops

The project and team

The Project

The aim of the Dialysis Models of Care (DxMoC) project is to evaluate the costs and outcomes of different models of dialysis care in the NT – particularly for Indigenous people relocated for treatment. The project will consider the broader impact on government and non-government services as well as on patients, family and community.

Project Team

The project team have a wealth of experience in health services and have worked closely with renal clinicians and patients over many years. The project is led by Gillian Gorham, and coordinated by Kylie Tune. Samantha Togni leads the qualitative aspects working with Aboriginal community-based researchers with support from Georgia Robinson and Jeannie Devitt. Shamsir Ahmed and Mark Chatfield have recently joined the team and work closely with the AIs and CIs on the data analysis.

The team is based in Darwin and Alice Springs and are always interested in hearing from people who would like to contribute to the knowledge gathering for this project.

Key Contact:
Project Manager, Renal Team
Web: www.menzies.edu.au
E: gillian.gorham@menzies.edu.au
Ph: 08 89468529

Models of Care

The second part of the morning program covered the models of care framework, the type of data received so far and an early sample of analysis. There was animated discussion of the five distinct models of dialysis care selected to provide a framework for the research.

Attendees at the February Joint Investigator Stakeholder meeting

5 Dialysis models of Care:

1. **Urban satellite unit**- larger facilities in urban areas, provides maintenance haemodialysis; training and support for self-care therapies.
2. **Regional satellite unit** - Smaller distant facilities, often co-located with regional hospitals to access support services. Offers haemodialysis and some support for self-care patients in local community
3. **Rural/remote satellite unit**- Small unit distant from hub service, may co-locate with local primary health clinic to access services. Offers haemodialysis and some support for self-care therapies;
4. **Community-based dialysis** - Community controlled services providing permanent and respite haemodialysis in small remote facilities within program of social supports.
5. **Self-Care dialysis** - Multi-user facilities in remote areas for independent home haemodialysis. Single-user machines in private residences. Peritoneal dialysis carried out at home.

Data linkage and sample analysis

To date, researchers have only received linked data for health (hospitalisations) data and ANZDATA (Australia & New Zealand data registry for renal patients). A lot of information was presented, but two areas generated most discussion:

- comparisons of hospital collected information with that of ANZDATA reporting on incidence and prevalence;
- patterns of hospital utilisation by dialysis model of care.

The analysis shows (graph below) that the number of new patients commencing treatment each year (hospital data) is much higher than that reported by ANZDATA. The difference between the two systems is not yet clear and while not all of these patients will require long term dialysis, the higher number of patients would be a considerable draw on resources.
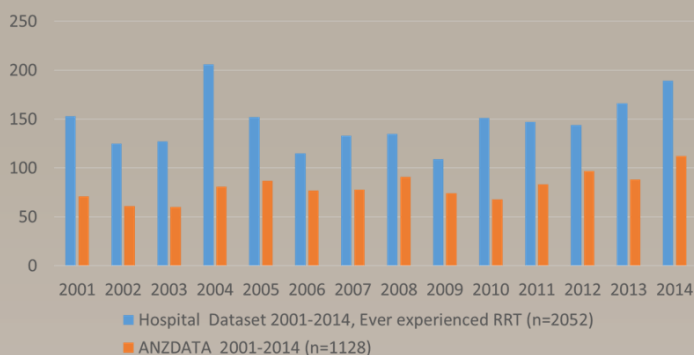
This early finding is significant since ANZDATA is a key reference in strategic and planning documents when discussing growth in prevalence and incidence, especially in comparisons with other jurisdictions.