

Dialysis Models of Care Project Update

General

This NHMRC funded partnership project aims to provide a rigorous cost-effectiveness analysis of the different dialysis services (Models of Care) available in the NT. Relocation for dialysis treatment has profound health, social and economic consequences. The project aims to describe the impact of relocating for treatment, inclusive of health, housing, education and social service utilisation, as well as describing the impact on the patient, their family and community.

The project was awarded in November 2014 with the first few months of 2015 focussed on establishing a project team and attaining ethics approval. Final Ethics approval from both the Human Research Ethics Committee of Northern Territory Department of Health and Menzies School of Health Research (HREC 2015-2334) and Central Australia Human Research Ethics Committee (CAHREC-15-283) were received in March 2015.

Progress

The first face-to-face Investigator Steering Committee meeting was held on April 1st, with Investigators flying in from New South Wales, South Australia and Central Australia to exchange ideas, strategy and direction for the project. The Investigators determined the governance and organisational structures including the creation of specific working groups and subsequently approved Terms of Reference for the meeting committees. The establishment of an Executive Committee has enabled decisions to be enacted promptly while still receiving overall guidance and input from the Investigator group. Individual working groups for each project component means that we can receive relevant and specific input from experts in each of the component fields.

The project team has worked with the Menzies Communications team to create an online web presence. The web space enables information and updates to be shared with the general public as well as provide a feedback mechanism for comments and questions to be sent to the Investigators via the project manager. The web portal has an Investigators login page allowing the team to communicate and share documents with the Investigators and steering committees, providing greater accessibility and a more efficient and effective communication pathway.

A Policy Forum meeting has been established and membership currently includes senior staff from government and non-government partner organisations as well as political representatives. The intent of the meeting is to feed early and progressive findings to key and influential stakeholders with the aim of informing current and future service delivery policies and strategies. The first meeting of this group is planned for early 2016.

The team will also have made substantial progress in the service mapping component of the project including a summary of findings for dissemination, commencement of patient and clinician interviews and have received full data custodian approval for the data linkage component. Please see below for further information on the progress of each component of the project, to date.

Dialysis Models of Care Project Update

Data Linkage

Project Team

The data linkage will be managed by SA NT Datalink, based at the University of South Australia, and will follow standard ethical systems and protocols. Data sets from the Department of Health, Department of Housing, Department of Education, ANZDATA and NT Births, Deaths & Marriages will be linked utilising a predetermined cohort as the patient spine. SA NT Datalink will de-identify all individuals and attach linkage 'keys' which will enable researchers to link up data from different departments to the same individual without being able to identify that individual.

These data will directly inform the service use estimates and cost estimates that will be employed to estimate whole of system costs and will allow us to undertake economic evaluations with a societal perspective. We intend to document and quantify health service use beyond that for dialysis delivery only and investigate the use of other services including housing and education. Ascertaining the level of demand, type of accommodation required (single, couple or family), length of stay and related transient homelessness is of planning benefit to both accommodation providers and the Department of Health. Understanding the impact on educational outcomes of children of patients, particularly those accompanying relocated patients, will increase the evidence base on the impact of dislocation for patients and families.

The complex data linkage application is now complete and is awaiting the signatures of only three data custodians before the final application can be submitted to SA/NT Datalink. The researchers will then await SA/NT Datalink to provide linkage keys to the data custodians and for each department to supply the requested data. It is anticipated that the research team will receive the data by July 2016. When all data has been received, the economists and epidemiologists will commence analysis and the comprehensive cost-effectiveness evaluation.

Dialysis Models of Care Project Update

Service Mapping

Project Team

The service mapping component of the Dialysis Models of Care Project intends to describe the service delivery models in the NT and how these have changed since 2000. The mapping will describe the dialysis models of care available in the Northern Territory between 2000 and 2014 in a visual outline noting connections and relationships with other services. This process aims to understand how funding and policy have influenced the infrastructure and capacity of dialysis services. This process is important in determining a main outcome of the project: that is to identify how health service utilisation differs for each model of dialysis care and how differing levels of utilisation impact other health and housing services. This impact will be evident when overlaid on the data collected by the data linkage component of the project.

Service mapping has commenced with the collection and collation of existing service information from publicly available documents. Much of this information was outdated due to the expansion and growth of services over recent years. The project team subsequently met with relevant staff in both the Top End and Central Australia to gain an understanding of the historical structure of services and important dates for expansion and/or development of new services.

A draft discussion paper has been prepared for circulation to stakeholders to ensure the researcher's interpretations are accurate and reflective of the models of dialysis care.

Dialysis Models of Care Project Update

Qualitative Research

Samantha Togni

The qualitative research component of the Dialysis Models of Care project focuses on capturing and understanding the experiences of people having dialysis treatment and their family and community members across the five dialysis models. The research aims to understand the impact of the different models of dialysis on the social, emotional, financial and cultural aspects of people's lives. This component of the project will also capture the perspectives of renal and other health professionals, social and human service providers and community-based service providers relating to the delivery and impact of the five models of dialysis care.

The initial stage of the qualitative research has focussed on engaging with the renal consumer groups in the Top End and Central Australia and establishing relationships with these key stakeholders. In April, the researchers were invited to present at each of the consumer group meetings, providing an opportunity to discuss the project and discuss how the consumer groups wanted to engage with the project and the researchers. It was important that the consumer group members articulated what they wanted to gain from their participation in the project, understanding the reality that the translation into practice of the research findings will be several years off. There was great interaction and engagement from members at these meetings, establishing a solid basis from which to progress the project.

Ongoing discussions with these groups and the voluntary staff who support them, has focussed on how the project can contribute to strengthening these groups and developing their capacity to advocate for people on dialysis. An idea that is being pursued is for the project to support advocacy training for the consumer group members.

Through the connections with the consumer groups, the project is engaging Aboriginal community researchers to work on aspects of the qualitative research. This will strengthen the engagement and cultural safety of Aboriginal participants in the research and enhance the integrity of the interpretation of the qualitative data. Research capacity development for the Aboriginal researchers employed is a priority for the project.

Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation, who is a partner in the project, has been instrumental in facilitating the connections between the consumer groups and people on dialysis with the researchers. This highlights the strength of undertaking Aboriginal health research in genuine collaboration with key community stakeholders.

Over the next six months, the researchers will commence interviews with people on dialysis, family members, community members, health professionals and other service providers.