

Young Adults Program

Project Title: Kidney Health Australia – Young Adults Program.
Improving health outcomes post “transition” for adolescents and young adults with advanced kidney disease.

Applicant: Kidney Health Australia

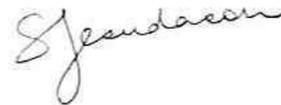
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KHA's ask for funding support

Kidney Health Australia (KHA), the only national body dedicated to assisting Australians living with kidney disease to improve their health outcomes and quality of life, seeks funding of \$1 million to establish and deliver a national peer support and education program for young people (15-24 years) with advanced kidney disease. Elements of this program would also deliver benefits to the carers of young people.

Funding will be directed to capacity building, to empower and leverage local communities, and to minimize the ongoing support costs.

This project will act as a pilot project which can then be transformed into similar projects for young adults with other chronic disease with the view of building awareness, self-management and resilience in this vulnerable group.

Patient population

Almost 700 young Australians (<25 years) are affected by kidney disease. Many of these young people are candidates for, or recipients of, a kidney transplant.

Cohort	Australians under the age of 25
Affected by kidney disease	<ul style="list-style-type: none"> <input type="checkbox"/> 156,000 have biomedical markers of kidney disease. (1). <input type="checkbox"/> Incidence of advanced kidney disease. (2). <ul style="list-style-type: none"> > 101 started renal replacement therapy (dialysis or transplant). <input type="checkbox"/> Prevalence of advanced kidney disease. (2) <ul style="list-style-type: none"> > 190 are receiving dialysis > 506 are living with a transplant.
Kidney transplant in 2015 (3)	74 young Australians (8% of all transplants).

Young people (aka "young adults") affected by kidney disease describes the group of patients aged 15-24 years of age (69% of prevalent patients under the age of 25 in 2016). This is the group in transition to adult care. They may be patients diagnosed when children or as young adults.

Issue

Transition to adult health care is challenging for young people, their families and health care workers. (4) Apart from the normal developmental factors influencing young people, there are additional factors associated with having a chronic disease including (5) anger and resentment, denial of severity of illness and/or questioning authority leading to rejecting medical advice and treatment. In addition, patients in the 15-24 age range have to cope with treatment in an adult clinic dominated by a significantly larger and older cohort with medical teams ill-equipped and under-resourced to tailor services to support younger patients.

These factors mark the transition from to adult care as high risk of non-adherence to medication (6, 7) and/or complex graft compliance regimes.

A regrettable consequence is that adolescent and young adult kidney transplant recipients have a worse graft outcomes than any other age group up to 70 years of age, with late acute rejection and reduced 5-year graft survival. (8).

The implications of this are significant in terms of health costs (transplantation and dialysis are expensive treatments – see note below*) and lost opportunity (many first grafts are donated by family). Poor transition can also affect a young adult’s transplant prospects: “well dialysed” is a pre-requisite.

Addressing the issue

To combat the problems of transition, three metropolitan hospitals have introduced specialist young adult transition clinics (Adelaide, Brisbane, Hobart). These clinics offer a dedicated young adult service that incorporates teenage patients transitioning from paediatric care and patients diagnosed as young adults presenting initially to adult care. (9).

*Kidney Health Australia research reported the following estimated annual costs for kidney transplantation and dialysis (2010 prices). Cass A, Chadban S, Craig J, Howard J, McDonald S, Salkeld G, White S. (2006) The Economic Impact of End-Stage Kidney Disease in Australia, Kidney Health Australia, Melbourne)

Kidney transplant	Year 1	Subsequent years
	\$81,549	\$11,770

Hospital dialysis	Satellite dialysis	Home haemodialysis	Peritoneal dialysis
\$79,072	\$65,315	\$49,137	\$53,112

A similar service in the UK led to a 67% reduction in transplant failure associated with transition. (10). Australia's first young adult kidney transition program in South Australia "graduated" 12 young adults in 2017 with new kidneys and no relapse. (11).

An important element of this model's success is peer support, typically provided by a youth worker attached to the clinic who:

- acts as a bridge between the young adult patient and the traditional medical team
- arranges peer support activities during the clinic.

Peer support, in conjunction with medical treatment, has an important impact on: (10, 11)

- readiness for transition, quality of life, and patient satisfaction
- graft outcomes and adherence.

While the value of specialist transition clinics is undisputed, current services provide:

- infrequent peer support – limited to the 3-4 sessions held each year
- limited geographical reach and in States whose combined young adult patient population represents about a third (28%) of prevalent patients aged 15-24 years.

Our proposal

KHA seeks funding to build and implement a national peer support and education program to engage the geographically dispersed population of about 500 young people (15-24 years) receiving renal replacement therapy (transplant or dialysis) and support better health outcomes.

Our national program will utilise virtual channels as well as face to face activities so peer support is readily available in a variety of ways outside the clinic setting. This will complement and broaden the peer support offered by current and future young adult transition clinics.

To supplement existing academic and clinical research about the unmet needs of young people with kidney disease and/or a chronic disease, KHA will undertake research, prior to and following implementation, to set a baseline for evaluation and ask young people with kidney about their:

- perceived needs and prioritization
- thoughts on utilising social and digital technologies to enhance support and education.

The expected outcomes of this program would be improved adherence and better patient outcomes through:

- reduced sense of isolation, increased sense of normality
- positive peer influence for study and employment
- body image
- dealing with independence for the first time.

KHA will collect baseline data and conduct follow up research to evaluate the impact of this program.

Program overview

Target group: small and geographically dispersed group of patients (as shown in figure 1) aged 15-24 years undertaking renal replacement therapy (dialysis or transplant).

Figure 1. Distribution of young adults by state – 2016 (2)

State	NT	NSW	VIC	QLD	SA	WA	TAS
Number (%)	7 (1%)	166 (34%)	126 (26%)	109 (22%)	27 (5%)	37 (7%)	7 (1%)

A national peer support and education program to engage the geographically dispersed population of about 500 young people (15-24 years) receiving renal replacement therapy (transplant or dialysis) and support better health outcomes.

Our national program will utilise virtual channels as well as face to face activities so peer support is readily available in a variety of ways outside the clinic setting. This will complement and broaden the peer support offered by current and future young adult transition clinics.

The program will be built and implemented over 2 years as follows:

- Research
- Augmenting/leveraging existing KHA resources and assets
- Developing and launching novel ways of engaging and educating young people with kidney disease.

Program element	Description	Costing comments ¹
Research	Undertake research through survey (questionnaire) and State based focus groups to set a baseline for the program and evaluate impact: <ul style="list-style-type: none"> with young people with the carers of young people Gather “user input” to inform engagement and education initiatives	<i>To be undertaken by the project officer and a research consultant</i> <ul style="list-style-type: none"> research and questionnaire development, analysis and evaluation Focus groups in each State – travel, accommodation, room hire, resources Utilise KHA state based Community Services Managers to record the event
Kidney Helpline - telephone support	Augment existing service by expanding the current team and training all team members on how to manage and support calls from young adults and/or their carers/family members	Cost of additional full time team member + training
Educational resources	Tailor existing resource and develop new ones, as required, in consultation with young adults <ul style="list-style-type: none"> with capacity to be delivered in a variety of formats including video and app 	<i>To be undertaken by the project officer in collaboration with KHA clinical education team</i> <ul style="list-style-type: none"> Consult young people to identify content needs and formats Development and production costs
On-line community	Establish a secure and safe online forum on KHA’s upgraded website (scheduled to be delivered in Q4 2018)	<i>To be undertaken by the project officer</i> Minor additional costs
Volunteer training	Draw on KHA’s existing networks and relationships to identify and train candidates to facilitate on-line and face to face peer support including: <ul style="list-style-type: none"> “graduates” of KHA’s Kidney Kids camp, a program for 7-17 year olds with kidney disease young adult transition clinics in Qld, SA and Tas Renal Society of Australia Transplant Society of Australia and New Zealand Transplant Australia Volunteer facilitators will be responsible for succession planning and training	<i>To be undertaken by the project officer</i> <ul style="list-style-type: none"> Develop and deliver training for volunteer facilitators (2-3 per State) and KHA Community Services Managers (1 per State) as coordinators and back up facilitators Convene a program “kick off” meeting for training and to foster strong networks
Face to face activities	Develop an annual program of low cost social activities (4 per year per State) to bring young adults together <ul style="list-style-type: none"> third party funder (eg Trust/Foundation) and/or user pays 	<i>To be undertaken by the project officer</i> Consult young people on activities

Note

In previous years, KHA provided an experienced youth worker to support young adult transition clinics in Hobart, Brisbane and Adelaide which deliver services to about 30% of the national population of young adults with advanced kidney disease. The model of care was based on the ‘Oxford Kidney Transplant Transition Program’. For equity and financial reasons, KHA was forced to withdraw this support in 2017

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