

NACCHO Aboriginal Kidney Health #NIKTT #NIDTC2019 #ClosingTheGap #HaveYourSayCTG : Our CEO Pat Turner pays tribute to her Uncle Charlie Perkins in speech to the National Indigenous Dialysis and Transplantation Conference



2 days ago

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As I have described below, Danila Dilba and KAMS show you the proven capacity of

community control to deliver results and accelerate outcomes for people with chronic renal disease.

Both services have people sharing their experiences at this conference. Keep an eye out for their presentations.

*To our non-Indigenous supporters in the audience today, I believe these examples about **HOW** we want to work together will be inspiring. Please expand your discussions during the conference with a positive acknowledgement of community control, and the rights we have as Aboriginal and Torres Strait Islander peoples to shape our own destiny, to partner with you as equals in service delivery, and to be accountable. ”*

Pat Turner NACCHO CEO

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[Read all 160 Aboriginal Health and Diabetes articles published by NACCHO](#)

Before I begin, I acknowledge the Arrernte people and their country on which we meet today. As many of you may know, I am back home where I was born and feeling very much re-energised by the country that knows me so well, my family and friends.

This conference brings together both community and health care sectors. A hugely diverse audience! Your efforts at this conference will help shape a five-year *National Indigenous Kidney Transplantation Strategy* to be provided to the Commonwealth in 2020.

With this conference mandate, I hope you will permit me to reflect on the **WHY**, the **HOW** and the **WHEN** of what we are all trying to achieve together.

The **WHY** is both personal and professional for me.

At the time of his death in 2000 from renal complications, one of my uncles

had been the longest living Australian kidney transplant recipient.

And my uncle had been many other 'firsts' in his life. For example:

- The first Aboriginal person to graduate with a university degree
- The first Aboriginal person to play soccer at elite level

and

- The first Aboriginal person to be the permanent head of an Australian government department.

My uncle's name? Charlie Perkins.

His transplant in 1972 – the year he arrived in Canberra for the Tent Embassy – gave my uncle another 28 years of life.

Instead of dying at 36 years of age, he died nearly three decades later at 64.

Imagine if his life had been cut short at 36, which is what would have happened without his renal transplant.

In the words of then Senator Aiden Ridgeway in the Senate chamber in October 2000 about my uncle: “*we would not have had his contribution to the life of the nation*”.

Dying in his mid-thirties would have been a tragic loss for the country. BUT, it would ALSO have been a tragic personal loss for uncle's family, including me,

and his communities. It would have robbed us of someone we loved far too soon.

Every Aboriginal and Torres Strait Islander person whose life you save is just as important to their family and community as my uncle was to me and mine.

While each one may not have the same national profile as Charlie Perkins, each person has a life with meaning and importance.

The old man you treated last week could be a respected cultural boss, a law man, an esteemed knowledge holder in his own community.

The young woman you treat next week could be on her own journey to become a healer, an artist or elder in her own right, as her community ordains.

The next 20 year-old your efforts engage in renal health could be Australia's first Aboriginal Prime Minister, or the Chancellor of Australia's first Indigenous university or our 1000th Aboriginal doctor.

You never know. You must take the long view.

Every premature death from preventable renal disease inflicts a shortfall in community capacity and resilience: now and in the future.

Every funeral adds to our intergenerational trauma, our collective loss and our ... exhaustion! We have plenty of reserves — history shows my people always manage to bounce back. BUT the preventable toll of chronic renal disease must stop.

So there it is. The **WHY** is huge!

Because of this **WHY**, let me now share a few ideas about **HOW**.

My first example comes from Danila Dilba Health Service in Darwin.

Data points taken over a ten-year period provided Danila Dilba with unique

insights about the management and disease trajectory of people with chronic renal disease before and after the appointment of a Renal Case Manager to their team. Creating this Renal Case Manager position specifically aimed to delay progression of their clients to end-stage kidney disease.

Danila Dilba recruited this new position in early 2008. With this new role, all members of the primary healthcare team were to be supported through the provision of systematic patient monitoring, and access to the latest advice about evidence-based practice for very complex clinical challenges. As a learning organization, Danila Dilba also committed to an independent evaluation of these service changes.

Before this new role, there were clear gaps in care that needed improving. For example:

- Documentation in the electronic clinical record system. Only 60% of patients were identified with their diagnosis.
- Screening of 'at risk' patients was very low. Although there were over 500 patients with diabetes for example, few of these had been screened for chronic renal disease.
- There was underuse of the GP management plan. Only 63% of patients had a current plan. Only 14% of these contained self-management goals. Only 26% contained clinical goals.

Using the ten-year data, this independent evaluation documented convincing improvements. The evaluation showed that Danila Dilba increased screening and monitoring of people under their care with Stage 3 to 5 chronic renal disease.

Prompt access to expert knowledge at the tertiary level also increased the organisation's competence to recognise and effectively manage patients with chronic renal disease and associated complex comorbidities.

BUT the risk of tertiary renal services taking over the management of people to

the exclusion of their other health priorities was avoided.

There was a significant increase in the timely identification of people in Stage 3 rather than the later, more difficult stages of chronic renal disease. In fact, the patient numbers with Stage 3 grew from fifteen to 101 patients. The growth in the number of people in Stages 4 and 5 was less dramatic in absolute numbers, but a positive improvement was shown. There was an increase in clinic visits for people with more advanced disease and, overall, improved management of risk factors.

As a result of this initiative, those patients with both renal disease and diabetes were better managed in terms of meeting agreed evidence-based targets for diabetes control.

At Danila Dilba, the proportion of patients meeting specific clinical targets for their care has sat above 90% consistently since 2012. Indeed, management of patients with diabetes has been above average since these data audits commenced. There was a very welcome stabilization of diabetes control for those with Stage 5 renal disease. This is fantastic for the patient's wellbeing.

Of course, you'll also be asking whether this increased service output delayed progression of chronic renal disease!

Before the program, 50% of patients ended up with Stage 5 within two and half years of identification. After the program, progression had slowed down dramatically. Rather than two and half years, the time it took to progress had extended out to four years. This represents a significant delay in disease progression. I find these results very positive. In my mind, the rate of progression seems to have been nearly halved. My congratulations to the team.

Overall, this experience has helped shift Danila Dilba to a 'systems approach'. Their new service design, which also takes services close to home, has increased client access and increased client numbers. This is what

community-controlled primary health care is all about. Screening for chronic renal disease is embedded in annual health checks. Anyone with acute kidney injury is managed with clinical precision, until their kidney function returns to usual. Since 2014, there has also been a doubling of people with diabetes, so Danila Dilba staff are managing much more complexity.

As a result of these initiatives, those patients with both renal disease and diabetes are better managed in terms of meeting agreed evidence-based targets for diabetes control. The evidence is convincing. Danila Dilba's national KPIs are either AT or VERY CLOSE to their 2023 targets.

At Danila Dilba, there is a careful balance between 'siloed' technical expertise held by those with super-speciality knowledge about chronic kidney disease, and the need for care that looks at the whole person. As Dr Sarah Giles has said "We're not managing numbers, we are caring for people". Danila Dilba is preventing disease onset through effective risk factor management AND preparing people with serious renal disease and their families for choices, for a planned transition to dialysis.

I learned from the Transplant Society's Performance Report that Aboriginal Australians are less likely than other Australians to receive a kidney transplant primarily because they are less likely to be put on the waiting list. The need for culturally competent pre-transplant education is indisputable. What Danila Dilba shows is that this education cannot happen out-of-the-blue without an existing relationship between the person, their family AND a health service they trust. Expanding that waiting list is a clear role for community-controlled primary health care in concert with their tertiary service colleagues.

The second community-controlled example I'd like to share with you today is from the Kimberley region.

There, the Kimberley Aboriginal Medical Services known as KAMS has taken a pioneering step in becoming the first aboriginal community controlled renal

healthcare service in Australia. And quite possibly in the world. This service is known as Kimberley Renal Services, or KRS, a wholly owned subsidiary of KAMS. By running KRS itself, KAMS ensures a culturally appropriate renal healthcare service is available for Aboriginal people with chronic renal disease close to home.

There are 124 people currently receiving lifesaving haemodialysis treatment cared for by KRS. KRS provides renal healthcare services within four renal health centres. These are located in the towns of Broome, Derby, Fitzroy Crossing and Kununurra. Another 18 patients have chosen Home Therapy. But there is a very large number of Kimberley people waiting in Perth to be able to come back home for dialysis. Perth is a long way from country.

After many years frustrated by a model that wasn't working for communities, KAMS secured significant funding for this service innovation which they have designed with absolute attention to cultural safety and clinical outcomes.

KRS has ensured a multi-disciplinary team approach is available to support people throughout their renal healthcare journey. Access to the renal health centres is provided 6 days a week Monday to Saturday all year round. The only days that the service is not available are Sunday's and Christmas Day.

In designing their own solution, our colleagues in KAMS thought it was important to emphasise health as a priority, not disease. So the decision was made to change from the previous term 'dialysis units' to the new term, 'renal health centres'. Anyone can engage with their renal health centre for advice, information and understanding.

There is a focus on local staff in each of these sites, learning and doing and caring for their families and communities in jobs vital for the community. These local KRS staff include Aboriginal Health Workers, Patient Care Assistants, Aboriginal care co-ordinators and Aboriginal nurses. KAMS is committed to Aboriginal employment. Currently, 36% of the staff employed in

KRS is Aboriginal. There is an affirmative Aboriginal employment policy and, because KRS is managed by KAMS, cultural values permeate the entire service. No patient is seen without an Aboriginal staff member. All non-Indigenous staff recognise that Aboriginal staff guide their practice.

As a matter of necessity, there are three “renal GPs” in the team. These are qualified GPs credentialed for independent practice who have also gained specific expertise in the nuanced management of chronic renal disease and other medical conditions affecting kidney function. In a region the size of Germany, this works in a shared care model.

KRS has also been designed to conduct scheduled outreach to communities. In doing so, this KRS multidisciplinary team does not cut across primary health care. Indeed, KRS has a shared care model that requires a strong foundation in primary health care to work. This partnership is best when there are common values, clear team arrangements and community control. Clinical medical records are shared. The renal team offers in-service training, both formal and informal, any time they are visiting a location for regular community outreach visits. There can be telephone enquiries about patients at any time.

Another part of this service addresses community engagement and life-saving prevention. There are approximately 2,800 people known to KRS who are in Stages 1 to 3 of chronic renal disease across the region. It is this commitment to prevention that will stem the tide of future incidence.

KAMS is looking outwards and wants to ensure none of these people in Stages 1, 2 or 3 progress to the more critical Stages 4 or 5. Currently, there are 138 people progressing to End Stage Kidney Disease. These patients will require haemodialysis within the next 12 to 18 months. This will more than double the caseload. With this projection, people are asking why the region does not yet have at least one full-time residential nephrologist. Addressing this unresolved aspect of medical workforce planning and distribution nationally is critical to successful chronic disease management, and achieving equity of

access to renal replacement therapy that our people deserve.

Having visited the Kimberley last week, I was most impressed by the commitment to evidence-based renal disease management through Australia's first community-controlled renal healthcare service. Speaking with staff and community, the best outcomes are coming through with community-controlled primary health care. Indeed, this KAMS model can't work unless there is a strong foundation of community-controlled primary health care.

I learned last week that some of the greatest frustrations occur when primary health care is understaffed, especially when members of the primary health care team are pulled off chronic disease management for a different priority, OR when locum staff don't handover properly and neglect to check critical pathology results. These "stop-start" dynamics in primary health care are seen in all settings across the country. They compromise shared care models. They are also unsafe for patient care.

For this reason, NACCHO is leading national projects to ensure that core services are fully funded in primary health care and deliver the outcomes our people deserve.

NACCHO supports statements by various governments to transition Aboriginal primary health care to community control. Successful transition of one local primary health care service in East Arnhem from government management to community control achieved a 400% (yes, FOUR hundred percent) increase in episodes of care within five years. This community engaged with an Aboriginal community-controlled primary health care service in a way that increased health checks beyond the national average. More babies were born with healthy weights. You, in the audience, know better than me the importance of healthy human development right from the beginning of conception to ensure healthy kidneys for life!

Every which way you look at renal disease in Aboriginal people, the only solutions that will work in the long term are those that are Aboriginal-led, culturally responsive, located in Aboriginal organisations and evaluated through an Aboriginal lens.

As I have described, Danila Dilba and KAMS show you the proven capacity of community control to deliver results and accelerate outcomes for people with chronic renal disease. Both services have people sharing their experiences at this conference. Keep an eye out for their presentations.

To our non-Indigenous supporters in the audience today, I believe these examples about **HOW** we want to work together will be inspiring. Please expand your discussions during the conference with a positive acknowledgement of community control, and the rights we have as Aboriginal and Torres Strait Islander peoples to shape our own destiny, to partner with you as equals in service delivery, and to be accountable.

So that covers the **WHY** and the **HOW**.

I want to talk about **WHEN**.

WHEN should we start working differently together?

The answer is right now.

An historic Partnership Agreement on Closing the Gap has been signed between COAG and the national Coalition of Peak Aboriginal and Torres Strait Islander Organisations. Now, for the first time, Aboriginal and Torres Strait Islander people through their peak representatives will **share decision making with governments** on Closing the Gap.

This Partnership Agreement has created a high-level COAG Joint Council for Indigenous Affairs.

This Joint Council is made up of 22 members. That means a Minister from the

Commonwealth Government, a Minister from each State and Territory Governments, and a representative from local government. This makes up ten members.

What about the other twelve?

The Coalition of Aboriginal Peak Bodies has ensured that the majority of members on this Joint Council are Aboriginal or Torres Strait Islander representatives. Chosen by us, in the majority, working for our mobs.

The Joint Council has three reform priorities. These are:

1. Establishing shared formal decision making between Australian governments and Aboriginal and Torres Strait Islander people at the State/Territory, regional and local level to embed ownership, responsibility and expertise on Closing the Gap.
2. Building and strengthening Aboriginal and Torres Strait Islander community-controlled organisations to deliver services and programs in priority areas.
3. Ensuring all mainstream government agencies and institutions undertake systemic and structural transformation to contribute to Closing the Gap.

This commitment to equal partnership through COAG has brought us to the table. There's no going back.

The Joint Council also agreed to the Coalition of Peaks leading engagements with Aboriginal and Torres Strait Islander people to ensure others can have a say on the National Agreement on Closing the Gap. Surveys are out now and can be submitted anytime by Friday 25 October.

So to close my presentation to you today, a final reflection.

I am mindful that the Bulletin of the World Health Organization recently carried an article stating that kidney disease is '**THE most neglected chronic disease**'.

..... but neglected by whom?

Certainly **NOT** by anyone in THIS audience!

I applaud your dedication and your hard work. By being here in Alice Springs, your commitment to better health for Aboriginal and Torres Strait Islander peoples in Australia is visible and much appreciated.

I know this issue is complex and no doubt frustrating. Occasionally, you must feel completely demoralized in your work. The Society's Performance Report recognizes there is '*no easy fix*'.

But please be strengthened by the **WHY**, the **HOW** and the **WHEN** I have described today.

Working together, we can achieve even more than my uncle ever imagined.

National : Closing the Gap / Have your say CTG deadline extended to Friday, 8 November 2019.

The engagements are now in full swing across Australia and this is generating more interest than we had anticipated in our survey on Closing the Gap.

The Coalition of Peaks has had requests from a number of organisations across Australia seeking, some Coalition of Peak members and some governments for more time to promote and complete the survey.

We want to make sure everyone has the opportunity to have their say on what should be included in a new agreement on Closing the Gap so it is agreed to extend the deadline for the survey to Friday, 8 November 2019.

This will help build further understanding and support for the new agreement and will not impact our timeframes for negotiating with government as we were advised at the most recent Partnership Working Group meeting that COAG will not meet until early 2020.

There is a [discussion booklet](#) that has background information on Closing the Gap and sets out what will be talked about in the survey.

The survey will take a little bit of time to complete. It would be great if you can answer all the questions, but you can also just focus on the issues that you care about most.

To help you prepare your answers, you can look at a [full copy here](#)

The survey is open to everyone and can be accessed here:

<https://www.naccho.org.au/programmes/coalition-of-peaks/have-your-say/>

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