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### Cultural Safety

*Aboriginal and Torres Strait Islander readers are advised that this publication may contain images and details of people who have passed away.*
Introduction

This publication contains three sponsored content articles produced by Croakey Professional Services and two editorial articles published by Croakey Health Media.

The Croakey team warmly thanks members of the Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) project and the Health Journey Mapping (HJM) project, based at the University of Adelaide, for inviting us to collaborate on these articles and produce this publication. We are honoured for the opportunity to help share the news about this important work.
Foreword

Associate Professor Shilpanjali Jesudason

This special Croakey report focuses on the journey, work and outcomes to date of the Aboriginal Kidney Care Together - Improving outcomes Now (AKCTION) program.

In a series of articles, you can learn how AKCTION began, the progress that has been made and their vision for the future. This report showcases what happens when passion and determination is supported by reversal of power structures, deep listening and reflection, opening of doors, sharing of seats at tables where decisions are made - and of course critical injections of funding.

Some years ago, when we first devised this acronym, AKCTION and the associated research and clinical teams were a diverse group of people finding a way to work together in collaboration and trust. These principles remain strong years down the track.

By breaking down the meaning of the acronym “AKCTION”, the key principles and goals emerge:

**Aboriginal** - Aboriginal leadership, ownership and governance over all AKCTION activities puts Aboriginal people and community in the driver’s seat. Leveraging an enormous breadth of lived experience, the AKCTION team of patient experts are now also NHMRC and MRFF Chief investigators, supported by Aboriginal project staff. Such self-determination is a super-power.

**Kidney Care** - The burden of kidney disease and the burden of treatment for kidney failure is immense for Aboriginal people. “Kidney care” is more than just treating biological illness - this means care of the whole person, their family and community.

**Together** - This single word defines ACKTION. AKCTION1 and 2 have brought together patients, community members, Aboriginal health practitioners and staff, doctors, nurses, allied health, researchers, students, professional organisations and health services to advance a common goal in a way that is unprecedented yet absolutely essential to progress.

**Improving Outcomes** - The pendulum must swing away from disastrous outcomes for Aboriginal people with kidney disease, towards equity in health and thriving. AKCTION and its team are motivated by what they see happening every day to patients, family and community members - improving outcomes is core business.

**Now** - The time is now for ACKTION. With many national and local activities and initiatives all occurring at the same time, the AKCTION team have become integral to everything from inaugural First Nations kidney care Guidelines to a national taskforce for improving kidney transplant access.

I strongly urge you to read this Croakey report, understand the stories of the AKCTION team members and be inspired. While there remains much to do, take a moment to reflect on how far this incredible team have come.
Introduction: A project that aims to transform Indigenous kidney health and healthcare is being led by Aboriginal kidney patients in a unique and trusting collaboration with doctors, nurses, researchers and healthcare providers.

The Adelaide-based Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) project is founded on long-term relationships, a shared determination for systemic change, and recognition of the need for Aboriginal and Torres Strait Islander leadership, autonomy and governance.

This article is sponsored by AKction, and edited by AKction chief investigators Dr Kim O’Donnell, a Malyangapa/Barkindji woman, and Kelli Owen, a Kaurna, Narungga and Ngarrindjeri woman.

Readers are advised this series mentions people who have passed; we publish their names and photos with permission, respect and acknowledgement of their legacy as kidney warriors.
Croakey Professional Services writes:

In a small room at the University of Adelaide, the key members of a ground-breaking kidney research project are meeting amid much emotion as they balance many long-term health issues and life stresses with the additional disruptions of the COVID-19 pandemic.

The eight Aboriginal patient experts coming together with their research colleagues are part of the reference team for the Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) project.

The team includes Inawinytji Williamson, a Pitjantjatjara/Yankunytjatjara Elder, renowned artist and Keeper of the Seven Sisters Dreaming story, and prominent Ngarrindjeri and Yorta Yorta health campaigner Nari Sinclair, known for “chasing down politicians” in her wheelchair.

They take turns to hold a message stick, designed by Kokatha and Mirning artist Micky Barlow, that is a crucial part of their research journey which began in this unique collaboration three years ago.

As they talk about what is going on in their lives, they laugh, cry, share artwork, joke and juggle babies.

Then, as always in these meetings, they hold a minute’s silence for those in their families and communities who have passed away, including Alice Abdulla and Matthew Hobbs, two members of their small team who passed from kidney disease since their work together began. They pay their respects also to other members who have passed (they do not have family’s consent to name them here).

“That minute’s silence reminds us why we’re doing this work…it keeps us grounded in our purpose,” says Dr Kim O’Donnell, a Malyangapa/Barkindji woman and health researcher who is leading the Adelaide-based Akction2 project.

“We have a lot of Sorry Business,” she says of the team. The photograph below includes the late Matthew Hobbs, who was a powerful advocate for kidney care and action. It is published with the permission of his family.
Window of opportunity

All of the Reference Team members, who range in age from three years old (accompanied by his mum) through teens to their early 70s, are either on dialysis, have had kidney transplants or are awaiting transplants.

But, as one of their research themes declares, we are all “much more than our disease” and are now playing key leadership roles in AKction, an action research project that is being hailed as a “game changer” for Aboriginal and Torres Strait Islander health research.

For O’Donnell, that regular minute of silence held at each meeting is also a reminder of the many competing drivers for the research which is being funded over the next four years by a $2 million Ideas Grant from the National Health and Medical Research Council.

On the one hand, she says, its work is driven by urgency: the critical need for better care for Aboriginal and Torres Strait Islander people, who suffer very high rates of chronic kidney disease and die from it at four times the rate of non-Indigenous Australians.

Adding to that is a sense that there is currently a “window of opportunity” for change in Aboriginal and Torres Strait Islander kidney health, so long needed, through the creation of the National Indigenous Kidney Transplantation Taskforce (NIKTT) and development of national guidelines for the management of chronic kidney disease for Indigenous people.

But O’Donnell is also driven by the need to create a culturally safe space, “a Blak space”, for the AKction Reference Team that provides connection and healing for its “patient experts” and re-empowers them to challenge and change the health system, with the support of trusted and respectful non-Indigenous allies and activists.

“It does take time for relationships to build, and then sometimes there’s the voice inside your head saying, ‘we don’t have that time, our people are dying’,“ she says.

“You’re trying to get as much traction as you can but at the same time we have to hold that space, to ensure we do it our way,” she said, emphasising the need for shifts in power, to step away from “that top down approach to research” and into a deep sense of Indigenous “knowing, being and doing”.

“It has to be ethical, it has to ensure voices are heard...we have to bring back words like self-determination and sovereignty and be strong in bringing those words into the academic space and keeping them here.”

Celebrating resilience, kinship and the next generation.
Beginnings

AKction began in 2018, funded as a Health Translation SA (HTSA) project, led by non-Indigenous researcher Dr Janet Kelly at the University of Adelaide and supported by the Medical Research Future Fund (MRFF) Rapid Applied Research Translation initiative.

But it was already many years in the making, building on relationships formed over decades between Elders, community members, clinicians and researchers, many of them “movers and shakers” in their areas, and reuniting kidney patients with their specialist doctors and nurses, though this time all at the same table.

Kelly and O’Donnell met in 2005, became friends as students and have worked together on research projects since, including the Lowitja Institute funded Managing Two Worlds Together project. This started in 2008 to identify the challenges, distress and dislocation experienced by many Aboriginal patients in regional and remote areas who are forced to travel away from community and Country for biomedical health treatment. A set of patient journey mapping tools was co-developed to identify gaps in care and responsive strategies.

Those complex journeys continue to impact on Aboriginal and Torres Strait Islander people, Kelly said, noting that, at the first AKction stakeholder meeting in 2019, the Reference Group’s first set of priorities were not about clinical issues, but problems with transport and accommodation, and later on workforce.

The AKction team had mapped the patient journey issues graphically (see this map of distressing patient journey) for their colleague Alice Abdulla, who passed away just before the 2019 meeting.

Everyone was really feeling her loss and were determined to make sure this sort of journey doesn’t happen again,” Kelly remembered.

The main focus of AKction in its first phase was around bringing together community members, patient journey mapping, and conducting community consultations in Adelaide, Port Augusta and Ceduna that fed into the national Indigenous kidney care guidelines.

The team worked closely with Kidney Health Australia and NIKTT to drive national reform, while also feeding back into clinical practice within renal care in South Australia. That has included the establishment of two kidney dialysis chairs — which they hope to have named in memory of Alice Abdulla and Matthew Hobbs — set up at the Kanggawodli Aboriginal hostel, the only Aboriginal hostel in Australia to have dialysis treatment onsite.

Now its scope has expanded dramatically through the NHMRC funding for AKction2. As the team says, this “flipped” the Western research model and embedded “purposeful decolonisation”, self-determination, power shifting, and data sovereignty at its core.

Nari Sinclair and fellow Reference Team community members Kelli Owen and Rhanee Lester are now chief investigators, alongside O’Donnell and Kelly, non-Indigenous South Australian nephrologist Dr Samantha Bateman and Professor Josée Lavoie from the Indigenous Institute of Health and Healing at Canada’s University of Manitoba.

AKction 1’s clinicians and researchers, including non-Indigenous nephrologists Dr Stephen McDonald and Associate Professor Shilpa Jesudason, Torres Strait Islander senior researcher fellow Dr Odette Pearson, a health services and epidemiology researcher, and nurse academic Melissa Arnold-Chamney, have taken up support roles as associate investigators.
Address systemic racism

Jesudason is the former national clinical director at Kidney Health Australia and chair of the Clinical Research Group at the Royal Adelaide Hospital’s Central Northern Adelaide Renal and Transplant Service (CNARTS). She has been closely involved with the AKction team since before the project began, including as doctor to a number of the Reference Team members.

She sees the securing of the NHMRC Ideas Grant as “an extraordinary achievement by Kim and Janet and the team” in a cut-throat competitive research environment and recognition of AKction as an exciting model for embedding change in health services and systems.

Jesudason says the AKction community members may not all fit “the traditional Western definition of researchers, but of course they are researchers because they ask questions and they want answers and they can work with community to be able to provide those answers.”

“It gives their expertise the appropriate respect and recognition, it’s a game-changer for Aboriginal research,” she says.

From her perspective, AKction’s success and impact has been grown through “a lot of hard work, a lot of trust” by all involved in the project, through shared understanding of the importance of Aboriginal leadership, autonomy and governance and of learning that “it’s not up to non-Indigenous people to vet what is an important issue for Aboriginal people or not”.

Like other team members, Jesudason has long shared concerns that Aboriginal and Torres Strait Islander people are more at risk of chronic kidney disease, for a range of complex reasons including the long-term impacts of colonisation and racism, intergenerational trauma, low birth weights, diabetes, obesity, and high blood pressure.

Just as worrying is the lack of access to care for many complex reasons that include interpersonal and institutional racism. Aboriginal and Torres Strait Islander people have rates of dialysis five times the non-Indigenous rate, but they are ten times less likely than non-Indigenous patients to be added to the waiting list for a kidney donation transplant.
Aboriginal and Torres Strait Islander people are also too often “crash landing on dialysis”, says Jesudason — only diagnosed when they are already in kidney failure, rather than having access to early, long-term, preparatory care in the leadup to the need for dialysis.

That’s a shock in itself, but for many Aboriginal patients, it means they have to move away from their homes and communities “and sometimes never go back…a terrible outcome”.

And it leads to high mortality rates among young Aboriginal and Torres Strait Islander people that Jesudason says would be regarded as a “catastrophe” for non-Aboriginal people but is accepted in a healthcare system where the gaze is too often on whether patients are ‘compliant’ versus whether the system provides proper and culturally safe care.

**Both-ways accountability**

For O’Donnell, AKction 2 is “research activism at its core”, which ensures that its patient experts are paid and respected for their expertise and given a safe space in which to work.

As well, their issues and recommendations are “not left on a shelf”, as so often happens with research, but listened to and acted upon by allies who have power and influence in the system.

“We’re operating like a kinship family,” she said, describing the “continuous loop” between the Reference Team and the Research Team, so that when an issue is raised about care, a response can come immediately and be relayed back to the group.

But their sights are higher than everyday care issues. O’Donnell wants to be able to hold hospitals and health services accountable for their care to Aboriginal and Torres Strait Islander people nationally by measuring them, for example, against a matrix for identifying, measuring and monitoring institutional racism within public hospitals and health services developed by Adrian Marrie and Professor Henrietta Marrie in 2014.

“In an initial audit of institutional racism, the nine geographic Local Health Networks in South Australia were assessed as having very high evidence of institutional racism, while the Women’s and Children’s Health Network was assessed as having moderate evidence of institutional racism,” she said.

O’Donnell makes the point that the project is called AKction “because that’s what the Reference Team wanted from the start.”

“When we approached them, they were very firm and said: ‘is this going to be another meeting or another project going nowhere, because we want action, we want to lead this work, and we want our time and our work to lead to real change for our people.’”

This article was written for Croakey Professional Services by Marie McInerney and edited by Croakey editor Melissa Sweet and AKction chief investigators Dr Kim O’Donnell, a Malyangapa/Barkindji woman and health researcher, and Kelli Owen, Kaurna, Narungga and Ngarrindjeri woman, the Community Engagement Coordinator for NIKTT.

The series was conceptualised and sponsored by the AKction project, which had final say over the content.

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Acknowledgement of Country

We know this land here is Ngarrindjeri land. When we tread we should think of the Ngarrindjeri people. Photo by Kelli Owen on morning of my 5th kidney anniversary.

Ngarrindjeri acknowledgement

Nankeri nanggi

Ngarni ngelun alyenik ruwi-elen Ngarrindjeri Ruwi
Ya:ral angan towun ngarni-idal Ngarrindjeri palak
Ngarrindjeri-ar watjun mulumi ngelerumi ruwald
Kar yamalai palak alyenik ruwald
Ngarnikung-un ngapald-ar, kaldowinyeri erai
Namawi nglelurumi elun piltenggi
Kunthun-ap Nguni kaylan
***

Good day,

We know this land here is Ngarrindjeri land
When we tread we should think of the Ngarrindjeri people
The Ngarrindjeri have sacred knowledge of the land
They are the first custodians of this land
We respect the Ngarrindjeri Elders of long ago
Our knowledge is strong
I’m glad you all are here
Dreaming big: building a movement in Aboriginal kidney healthcare

**Introduction:** Aboriginal kidney patients are leading a ground-breaking research project where their experiences, resilience and expertise are re-shaping kidney health research and clinical services and challenging health systems to do better.

This article is sponsored by the Adelaide-based *Aboriginal Kidney Care Together – Improving Outcomes Now (AKction)* project, and edited by AKction chief investigators Dr Kim O’Donnell, a Malyangapa/Barkindji woman, and Kelli Owen, a Kaurna, Narungga and Ngarrindjeri woman.

Readers are advised this series mentions people who have passed; we publish their names and photos with permission, respect and acknowledgement of their legacy as kidney warriors.
Croakey Professional Services writes:

The odds were against the call ever coming, so it was a shock that night in 2016 when Kelli Owen's phone rang just before midnight to tell her that, after three years on the kidney transplantation wait list and decades of chronic disease, a kidney had become available for transplant.

Owen, a 48-year-old Kaurna, Narungga and Ngarrindjeri woman, teacher and mother of five, rushed from her home in Murray Bridge, south-east of Adelaide, for the life-saving operation that took place the next day – May 26, National Sorry Day.

On the other end of the phone that night was Associate Professor Shilpa Jesudason, a Royal Adelaide Hospital nephrologist, who went on to be part of Owen’s transplant care team.

“Shilpa wanted to know whether I would accept the offer and I said, ‘hell yes, get me there!’,” Owen remembers. “I didn’t even have my bag packed because I didn’t think it was ever going to happen for me,” she said.

The pair next met three years later when Jesudason, by then the national clinical director of Kidney Health Australia, attended Owen’s keynote address to the World Congress of Nephrology’s (WCN) Satellite Symposia on First Nations Kidney Health in Naarm (Melbourne).

Soon after they were co-chairing the National Indigenous Kidney Transplantation Taskforce (NIKTT) Community Engagement Committee and working together in leadership roles on the ground-breaking Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) project in Adelaide.

Owen’s chances of being offered a kidney that night in 2016 were low because of a range of personal and clinical factors. But another critical reason is the systemic racism and lack of cultural safety in the health system that contributes to Aboriginal and Torres Strait Islander people with end-stage kidney disease being less likely to be wait-listed for transplantation and therefore up to ten times less likely to receive a kidney transplant.

This is despite disproportionately higher rates of end-stage kidney disease among Aboriginal and Torres Strait Islander people, compared with non-Indigenous Australians, particularly in remote areas, where the incidence is up to 18 to 20 times higher than in metropolitan areas.

“If we had peer or patient navigators to help my First Nations brothers and sisters navigate the system and culturally appropriate health services, it would be a different story,” Owen said.

Karrendi – rise up

It’s these terrible inequities that drive the work of the AKction project, now led by Dr Kim O’Donnell, a Malyangapa/Barkindji woman and health researcher, with non-Indigenous researcher Dr Janet Kelly.

Funded under a $2 million Ideas Grant from the National Health and Medical Research Council, the game-changing project is hailed for its Aboriginal and Torres Strait Islander leadership, autonomy and governance and the trusted relationships it has built with non-Indigenous clinicians and researchers.
Leading the work is a small group of Aboriginal patient experts, who are either on dialysis, have had kidney transplants or are waiting for transplants and form the AKction Reference Team, which is now being used as a model for similar bodies across Australia through NIKTT.

“We are leading those conversations, sitting at the same table with the academics and specialists who are able to open doors and change the way things are being done,” said Owen, who is a Reference Group member and a chief investigator.

“This will be our Brave Space together,” the AKction project declares, outlining four sub research themes that centre the voices of patient experts:

1. Indigenous governance: “We are more than our disease”
2. Kidney journey mapping: “No-one else should have to experience this”
3. Support for kidney patients: “We know what it is like”
4. Cultural safety in kidney care: “Sometimes they just don’t get it”

See this slide representing Karrendi – rise up.

Patient journeys

Owen’s negative experiences of healthcare began when she contracted tuberculosis as a young girl. She was put on a “cocktail of meds” and ended up hating hospitals and nurses. When she was told, at 19 years of age and with few symptoms, that she had kidney disease, she “didn’t want to know”.

The group photographed in 2021: Amy Graham, Nari Sinclair, Dr Kim O’Donnell, Kelli Owen, Kuranye Owen, Dr Samantha Bateman, Melissa Arnold-Chamney, Jared Kartinyeri, Kynesha Temple Varcoe, Dr Shilpa Jesudason, Dr Janet Kelly
A decade later Owen was told her kidneys were functioning at just 30 percent of capacity and that she needed acute care. Handed a bunch of DVDs and pamphlets to explain her condition, the gaps in education and support for Aboriginal and Torres Strait Islander patients were clear for the then primary school teacher.

“I didn’t see myself in any of that pre-education,” she said. “There were no Aboriginal people there, despite our people making up such high numbers in chronic kidney disease.”

Later, living back on Country in Murray Bridge, the stresses of her illness hit hard. She travelled to Adelaide three times a week for dialysis, cutting into her work hours and disrupting family life. The transport costs alone were “astronomical”.

“I started to think, ‘if this is happening to me from a country area, what is happening to my First Nations brothers and sisters in remote areas?’ Lots of questions started to formulate in my head while I was sitting on that dialysis machine.”

Those questions continued after her transplant, needing to live with relatives in Adelaide while completing weeks of daily clinical checks, cared for by her teenage son.

She began to ask who should be held accountable for such poor healthcare for her people and why she had rarely seen Aboriginal or Torres Strait Islander health professionals in her journey. “I was thinking, ‘our people are smart, where are they, where are the career pathways?”

Then this year the ground shifted again, when her 17-year-old son Kuranye (a Kaurna word meaning rainbow) was diagnosed with the same kidney condition – Alport syndrome – that she has.

While his diagnosis is heart-breaking for the family, Owen is hopeful that, despite the many gaps she is already seeing in care for young Aboriginal and Torres Strait Islander kidney patients, his kidney journey will be better than hers.

“Knowing the questions to ask puts me in a different position now,” she says.
Time to thrive

Rhanee Lester, another Reference Team member and chief investigator, talks about chronic kidney disease as a “constant rollercoaster”, physically, socially, emotionally.

The 35-year-old former youth worker and children’s book author says the disease is often very isolating. “You feel alone, like you’re in your own little bubble.”

An Adnyamathanha woman from Port Augusta, more than 300 kilometres north of Adelaide, Lester knows well the burdens faced by many Aboriginal and Torres Strait Islander patients, with 78 percent having to relocate to cities for dialysis, away from Country and community, often with devastating impacts on their wellbeing and that of their families.

Many, she says, are Elders or others with cultural, family and financial responsibilities, “doing a lot of caring of other people”. These obligations “almost take precedence over their own health” — something few health services or professionals factor in when they talk about treatment ‘compliance’.

Lester remembers vividly getting the results of her first kidney function test in 2004. She was told to rush to hospital, where she was led straight to the high dependency unit. At first she thought this was because there were not enough beds in the general wards, until the seriousness of the diagnosis sank in.

Despite the shock and stress, it was a relief to finally know what was wrong: “I thought, ‘okay, this is what I’ve got, what do I have to do to survive?’ I went into survival mode.”

Now she wants more for herself and other Aboriginal and Torres Strait Islander kidney patients, to not just survive but “to thrive” — which is what makes the AKction2 project so full of promise and strength for everyone involved.

“We’ve been asked to dream big,” Lester says, inspired to be part of a team with the power to make change, to sit at decision-making tables in a process that feels safe and respectful and that acknowledges the strength and resilience of its patient experts.

Owen talks about the relief and comfort she felt at the first meeting in 2019 of the AKction Reference Group. Its members were able to yarn, with no pressure from a constrained agenda. Their ‘terms of reference’ was renamed ‘the way we work together’.

“I just felt like I was at home with my people,” she said.

Owen laughs that in the early days she did not understand the differences in research roles. But AKction has since opened her eyes to decolonising methods, of “how important research is for us, doing it our way, with our people”, after a history where “we haven’t been a part of the research, we’ve just been the research, talked to and talked at”.

“Now we’ve flipped that,” she says, talking about AKction as a “movement” where “it feels like the wheels are all moving together”.

Dreaming big: building a movement in Aboriginal kidney healthcare | #KidneyCareTogether
Shifting Gears

That shift is driving real change in care in South Australia and informing national clinical guidelines.

Kanggawodli (meaning Caring House in Kaurna), an Aboriginal-managed SA Health hostel in the inner northern Adelaide suburb of Dudley Park is now home to some of that powerful change.

In response to AKction’s advocacy, two dialysis machines were installed in the hostel that provides primary healthcare as well as accommodation for patients from regional and remote areas— a first for an Aboriginal hostel in Australia. This means remote and regional community members staying there can have dialysis in familiar and culturally safe ways, without needing to travel to the more ‘unfriendly’ environment of a metropolitan hospital.

Kanggawodli represents a breakthrough in better care, according to Dr Stephen McDonald, senior nephrologist at the Royal Adelaide Hospital and long-time Clinical Director of Renal Services for the Country Health SA, who has also been part of AKction since its early days and has worked alongside Kelly and O’Donnell.
McDonald had a “light bulb moment” nearly a decade ago when a mobile dialysis ‘bus’ was introduced in the APY lands and he saw what it meant for patients to go back on Country for short periods of time. They were able to fulfil cultural commitments, to be part of their own communities, and to undergo dialysis surrounded by kids and grandkids.

McDonald later co-authored a research paper on the initiative, describing the “grief and loss” many patients felt from having to travel far from home for treatment in a clinical environment.

It was a “tipping point” for him in developing a better understanding of culturally safe care and the need to turn a critical gaze on the system when individuals or communities struggled to access healthcare or did poorly in seemingly high quality facilities.

Kanggawodli, which has its dialysis chairs in the middle of the hostel’s dining room, is “absolutely the next development in that”.

“If we truly want to change what happens and improve services, we have to change what we do,” McDonald said.

“AKction has changed the way we are thinking about how we provide services, how we talk, and how we refer to and approach problems.”

AKction2 Working Together Agreement

- A living document
- Shared vision, and principles to guide the work we do together over the next five years
- Our way of knowing, being and doing
- Defines teams within AKction
- Helps create a culturally safe space to work in for all
- Collaborative model for working giving power to the Indigenous voice
- Importance of Niunga space “our campfire in the city”
- Creating a space where we can speak, our voices are heard, and purposeful action is made
- Agreed upon by all about how we work and who we are
This article was written for Croakey Professional Services by Marie McInerney and edited by Croakey editor Melissa Sweet and AKction chief investigators Dr Kim O'Donnell, a Malyangapa/ Barkindji woman and health researcher, and Kelli Owen, Kaurna, Narungga and Ngarrindjeri woman, the Community Engagement Coordinator for NIKTT.

The series was conceptualised and sponsored by the AKction project, which had final say over the content.

More than a patient: cultural and clinical knowledge on a healing journey

Introduction: This article is sponsored by the Adelaide-based Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) project.

It is edited by AKction chief investigators Dr Kim O’Donnell, a Malyangapa/Barkindji academic and public health researcher, and Kelli Owen, a Kaurna, Narungga and Ngarrindjeri woman, with Amy Graham, a Kaurna Narungga woman and AKction Research Coordinator.

Croakey Professional Services writes:

In 2018, a funding cut put an end to a free shuttle bus that took Aboriginal patients in Adelaide to and from their dialysis treatments. Nari Sinclair, a Ngarrindjeri and Yorta Yorta woman, was furious about the implications, for herself and others.

Reliant on a wheelchair because both her legs have been amputated, Nari is unable to drive, catch public transport or take a standard taxi, and faced significant inconvenience and costs as a result of the funding cut. She knew of other kidney patients who were also hit hard.
Determined to fight the decision, Nari joined forces with Pitjantjatjara/Yankunytjatjara Elder Inawinytji (Ina) Williamson, a renowned artist who was forced more than a decade ago to move to Adelaide, away from Country, family and friends, for dialysis treatment that cannot be accessed in the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands.

They got together for a yarn about how the complex clinical, cultural and social determinants impact Aboriginal people, families and communities affected by chronic kidney disease. For too long, says Nari, they have been poor cousins in healthcare – “shoved in one corner and forgotten”.

Nari and Ina were invited to a meeting with Kidney Health Australia and University of Adelaide researcher Dr Janet Kelly, who was working with kidney health professionals on a project to improve the quality and cultural safety of Aboriginal and Torres Strait Islander people's healthcare journeys, particularly for those from remote communities.

“And it’s gone from there,” Nari says of how she, Ina and Janet worked with others to launch what would become the landmark Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) project. It is transforming kidney health research and care from its base in Adelaide, on Kaurna country (read more in these two previous articles at Croakey).

Nari, 45, is now a Chief Investigator for AKction2, a project that has “flipped” the Western research model and recognises the cultural and clinical knowledge held by Aboriginal and Torres Strait Islander ‘patient experts’. Ina holds a position as Elder and mentor.

Dr Kim O’Donnell, a Malyangapa/Barkindji academic and public health researcher who is leading AKction2, says Nari and Ina have long been the epitome of this year’s NAIIDOC theme – Get up! Stand up! Show up!

“It’s about speaking up … having the fire in their bellies to make a difference for others coming through,” says Kim. “That’s what Nari and Ina do.”

Thanks to that work, Ina Williamson, 69, is now able to do dialysis three times a week at Kanggawodli (meaning Caring House in Kaurna language), an Aboriginal-managed SA Health hostel in Adelaide.

A yarn, a laugh, a cup of tea

In response to AKction’s early advocacy, Kanggawodli now has two dialysis chairs so Aboriginal patients from regional and remote areas can have their treatment in a culturally safe environment, the only Aboriginal hostel in Australia to have dialysis treatment onsite.

A cleansing fire burns in a central pit in the courtyard, wafting the scent of eucalyptus through the hostel. The dialysis chairs are not hidden away in sterile clinical surrounds but are positioned in the living area of the hostel.

Ina loves it, contrasting it with dialysis in a mainstream clinical setting where it “can be lonely, with no-one to talk to”.

“You see lots of people, lots of families,” she says. “You have a yarn, a laugh, a cup of tea, you can speak in Language.” Many of the staff are Aboriginal health professionals or non-Indigenous nurses and doctors who have spent time in remote areas, like Fregon, 1,100 kilometres north of Adelaide, where Ina is from. Coming to dialysis is a social outing as well as a treatment.

Ina was one of the first people from the APY Lands to start dialysis in Adelaide, and is a source of comfort and wisdom for the many who have come since, says Amy Graham, a Kaurna Narungga woman and AKction Research Coordinator.
You can view Croakey's coverage of the series here.

“A lot of people will go to Ina and ask for advice … there is a lot of respect for her as a woman and Elder, they have big trust in her knowledge,” Amy says.

The AKction team brings together Ina and Nari and other Aboriginal kidney patient experts with Indigenous and non-Indigenous clinicians and researchers.

Together they are working for change in kidney care, in line with the National Aboriginal and Torres Strait Islander Health Care Plan 2013-2023 and inaugural National Aboriginal and Torres Strait Islander renal clinical guidelines. The project is funded over five years by a $2 million Ideas Grant from the National Health and Medical Research Council.

AKction’s four sub studies – Indigenous Governance, Kidney Journey Mapping, Patient Support Needs and Cultural Safety in Kidney Care – speak to the big system changes they envisage, based on the lived reality and priorities of Aboriginal kidney patients and their families, and the challenges for renal services in providing holistic, culturally safe care.

From back L: Amy Graham, Dr Kim O'Donnell, Kelli Owen, Ina Williamson

**Yarning up**

Over at the AKction office in Adelaide University, Nari Sinclair is meeting with fellow AKction Reference Group member Jared Kartinyeri, 34, a Ngarrindjeri and Wiradjuri man whose life also has been changed by kidney disease and transformed by the project.

They yarn about how tough chronic kidney disease can be, living it 24/7, effectively tied to a dialysis machine, often debilitated. Nari says it can sometimes become too hard, but her three children and two grandchildren keep her fighting, for her own health and that of broader Aboriginal and Torres Strait Islander communities.

Nari and Jared talk about family and community members, many in their early teens, who are terrified about the prospect of dialysis, “scared they’re going to die”. Jared says they are in desperate need of culturally appropriate information that is “given to us in a way that we understand, that we can take away and talk to our families about”.
They worry about the loneliness and isolation that Aboriginal people can feel in the mainstream services, particularly people from remote areas who “get lost in the system and in the city”, often falling between the cracks, missing dialysis and ending up being taken to hospital via ambulance, or the Royal Flying Doctors Service if they’ve headed back home.

Jared knows the risks, talking about the shock and dislocation of his own diagnosis in 2017. He had been feeling sick for two weeks and thought he had a stomach bug. He finally went to a doctor and within 24 hours was on dialysis.

“It was pretty quick and pretty serious,” he remembers. “My [creatinine] levels were so high that doctors and nurses were saying ‘how are you still living?’

“I’m still amazed I survived.”

But the treatment journey was also difficult. He felt alone and confused, sitting by himself day after day in a dialysis room. It was an uphill battle getting used to dialysis and the medication and then later managing the complexity of a kidney transplant.

“It was a pretty lonely experience there for a while,” he says. “I was pretty miserable.”

Then he was introduced to AKction and it has changed his life, connecting him with peers and clinicians, a community that has “widened my thoughts and vision of kidney health”.

In meetings with Ina, Nari and the rest of the team, Jared says that at first he was “very quiet, very shy”. “Now I’m very loud,” he laughs.

He has opened up, welcoming the role and responsibilities, planning to take AKction on the road to communities and to health and education expos. He loves being involved in an AKction project with fellow researcher Rhanee Lester, using recycled dialysis unit materials to make artwork that was gifted on World Kidney Day 2022 for display at Kanggawodli as well as at other renal facilities in Adelaide.

“I feel confident,” he says. “It’s the joy of being in AKction. Having the AKction team is really a safe space. It’s like a family.”

Wade Allan, Jared Kartinyeri, Kurt Towers and Rhanee Lester with the artwork presented at Kanggawodli
Making an impact

Amy Graham gets tears in her eyes hearing Nari and Jared talking about their roles and ambitions. She is moved by their humility given the huge impact of their work already.

Amy talks about first joining the project last year and seeing the Reference Group members sitting with leading non-Indigenous clinicians and researchers, “suddenly equal”.

“There was no hierarchy,” she says, comparing it to most other clinical settings she worked in as an Aboriginal Health Practitioner and Aboriginal Maternal Infant Health Care worker, where behaviour so often changes according to the status of the people in the room, and engagement with Aboriginal and Torres Strait Islander people is too often tokenistic.

“There’s none of that in AKction,” she says. “This is different, this is meaningful, this is actually going to make an impact, that’s what I love about it.”

Janet is also inspired by the positive difference that the eight Reference Group members have made as their confidence, sense of agency and authority have grown through collective action.

“We talk a lot in research about ethics and risk, but AKction is showing us how being involved in the right kind of decolonising research can be positive and healing, and how important it is for us all to counter past negative experiences that many Aboriginal and Torres Strait Islander people have of research,” Janet says.

“Instead of being subjects of research, these incredible, strong community members are now leading research, and taking it where it needs to go.”

Decolonising project

That recognition is at the heart of AKction’s governance and process, embedded recently in its position descriptions for the project’s Chief Investigators.

They state upfront that AKction is a decolonising project that recognises strengths and embeds Indigenous ways of knowing, being and doing, where Aboriginal people are acknowledged as experts of their own journeys, actively supported in priority setting, analysis and decision making.

Unheard of in most Western work contracts is a focus on self-care. Responsibilities for Chief Investigators include “caring for self and families”. They are urged to:

• take time for reflection and checking in
• acknowledge and make space for self-care
• keep spirit strong (“take Doona days when needed”)  
• focus on humour and having fun – “our super power”
• undertaking critical reflection, and
• “celebrate your journey”.

Ina, Nari and Jared are celebrating what they have achieved so far in AKction but have big ambitions still.
They want more Aboriginal and Torres Strait Islander people in the kidney care workforce and envision Kanggawodli as a model of care for other areas. They would love to see it evolve into a centre of wraparound care for Aboriginal kidney patients, providing culturally safe housing, transport, podiatry, dental and eye care, all critical components of good kidney care.

They also want to address the complex reasons, including interpersonal and institutional racism, behind why Aboriginal and Torres Strait Islander people have rates of dialysis five times the rate of non-Indigenous people, but are ten times less likely than non-Indigenous patients to be added to the waiting list for a kidney donation transplant.

Nari reflects that, when she and Ina first joined forces a few years ago, she did not expect to become a researcher, much less a Chief Investigator on a major national research project looking to transform kidney care.

But she welcomes the authority the research role brings to her interactions with Western systems.

“I’m not just a pretty face sitting on dialysis,” she laughs. “I am someone who has got some knowledge.

“A nurse or doctor can say ‘I know how you feel’ – but they don’t know how we feel. Chronic kidney disease is a complicated disease, it’s more than clinical. It’s cultural, social, mental, spiritual. That’s where we come in.”

This article was written for Croakey Professional Services by Marie McInerney and edited by AKction chief investigators Dr Kim O’Donnell, a Malyangapa/Barkindji academic and public health researcher, and Kelli Owen, Kaurna, Narungga and Ngarrindjeri woman, the Community Engagement Coordinator for NIKTT, and Croakey editor Dr Melissa Sweet.

The series was conceptualised and sponsored by the AKction project, which had final say over the content.

Health Journey Mapping: having a yarn about health

Families are an important part of health journeys. The co-author Amy Graham, a Kaurna/Narungga woman, with her family. Photo supplied by authors.

Introduction: Aboriginal and Torres Strait Islander peoples should have access to healthcare journeys that are culturally safe, responsive to their needs and of high quality – yet for too many they are complex, challenging and often unsafe.

In response to those risks, the Health Journey Mapping (HJM) project, based at the University of Adelaide, has created a range of tools and resources to improve the quality and cultural safety of Aboriginal and Torres Strait Islander people’s healthcare journeys.

Emerging from the Managing Two Worlds Together project (2008-2015), led by Dr Janet Kelly and funded by the Lowitja Institute, the HJM project was conducted by members of the Adelaide-based Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) project which aims to transform Aboriginal and Torres Strait Islander kidney health and healthcare.

Adelaide University project coordinator Amy Graham, a Kaurna/Narungga woman, and research assistant Alyssa Cormick, a Dutch/Irish/British woman, outline in the article below how HJM and its tools are based on underlying principles of equity, safety, and partnership.
Amy Graham and Alyssa Cormick write:

Imagine you are a healthcare worker in a busy clinic. An Aboriginal patient called Mrs Brown comes to see you, and you recognise that her healthcare needs are not being met. You want to sit down and talk with her to identify what is happening in her health and life, and how you can best support her.

But there are other patients to see, and you are in a rush. What can you do?

We are a part of a team of First Nations and non-Indigenous women from a range of research, education, and healthcare backgrounds who have collaboratively created a set of Health Journey Mapping (HJM) resources for use in healthcare settings.

These tools and resources can be used for all patients to better understand their journeys in the healthcare system, and particularly for patients with specific cultural, communication and healthcare needs. HJM resources allow healthcare workers to gather information about an individual's health journey in the context of their life.

They justify taking time to have conversations, collect individuals’ truths, and can inform delivery of responsive and appropriate care. See the video below:

What are the current gaps in care?

Many people working within hospitals and health services strive to identify and respond to clinical and cultural safety needs to improve overall quality and coordination of care.

However, this is often difficult in current healthcare systems, which are underpinned by colonial and biomedical concepts and priorities. Current healthcare structures, policies and resources emphasise the needs of the dominant culture, failing to identify biased care, racist and stereotypical assumptions, and recognise and respond to the diverse needs of First Nations peoples.

A health practitioner told us: “We know many healthcare workers are striving to improve the care they deliver, but current systems are failing to meet patient’s complex needs.”
**What is holistic health?**

First Nations definitions of health are inclusive of social, historical, and political determinants which impact health. These holistic perceptions focus on all aspects of an individual’s life, identifying the interconnected relationships of all factors that affect health and wellbeing.

These full patient experiences are rarely captured in colonial and biomedical systems focusing on presence or absence of disease, disconnecting people from spirit, family, culture, community, and Country. We believe it is essential for healthcare to look at this broader picture of someone’s life, as it enables greater understanding of patients’ lived experiences.

![Diagram of holistic health](image)

*Source: National Strategic Framework for Aboriginal and Torres Strait Islander Peoples’ Mental Health and Social and Emotional Wellbeing 2017-2023*

**Equitable healthcare**

Due to significant inequities that still exist in healthcare, First Nations peoples experience disparities in health outcomes. It is important to move beyond providing the same care for all Australians, to ensuring equitable outcomes as not everyone enters health systems with the same resources, experiences, and health status.

There is subsequently a need to rehumanise the healthcare system, by focusing on individual patient’s needs. This can be achieved by taking time to listen to patients, understanding their stories, and building upon their existing strengths and resources, which we believe the HJM resource does.
What is health journey mapping?

Health journey mapping involves recording stages of a patient’s journey. Our HJM resource applies a culturally appropriate method for this, by mapping a patient’s holistic and biomedical health needs. This provides a structured way to listen to patients’ journeys, identify strengths and gaps in care, and develop the best strategies to improve patient/carer family responsibilities and situations.

Dr Janet Kelly, Project Lead, RN, says: “In health we record single episodes of care rather than a patient’s journey through the health system. It can be quite difficult to record or look for a written record of a patient’s life outside of healthcare. These mapping tools enable both a patient’s biomedical story, life story and priorities to be recorded and responded to.”

A simplified version of a journey map

Returning to the example of Mrs Brown, as you speak to her, you can use the HJM tools to identify that she is an Aboriginal Elder who has been diagnosed with kidney disease requiring her to move off Country to access dialysis and undergo hospital admissions in the city.

Using the tools, you can legitimise having this conversation, record what is happening in her life, identify strengths and gaps in her healthcare, and plan and take actions to support her situation. A simplified map of her journey could look like this. (next page)
The tools

During the project we developed three different tools. These can each map journeys like Mrs Brown’s in different ways and for different purposes.

You are not limited to mapping journeys with only one tool. The three tools have different uses, and can complement each other. By mapping an individual’s journey with one tool, you may identify different areas that require focus and the need to use another HJM tool.

HINT: If unsure, try starting with the clinical tool to get a quick snapshot of what is happening and to identify areas of focus or stages that may need to be mapped in greater detail with the other tools.
How to access

These HJM tools are currently available to the Lowitja Institute Members Community via their online Learning and Development Hub. It is free to join and gain access to the three mapping tools, educational resources and worked examples.

Access the tools here.

A truth telling tool

By recording health journeys from individual’s own perspective, their truths can be told. This enables patient’s lived experiences to be recorded and understood and can provide evidence of what is actually happening in their health journeys.

As Amy Graham says:

“HJM has been designed with Aboriginal patients, families and their communities in mind, it centres us as the central stream of knowledge about who we are and what we need in our own healthcare, it gives us a voice and it provides health professionals with a tool to record our voices and incorporate what we say within their assessments and diagnosis.”
Sharing vibrant, productive and creative journeys to improve kidney care for First Peoples

The Adelaide-based Aboriginal Kidney Care Together – Improving Outcomes Now (AKction) project aims to transform Indigenous kidney health and healthcare. It is founded on long-term relationships, a shared determination for systemic change, and recognition of the need for Aboriginal and Torres Strait Islander leadership, autonomy and governance.

In June 2022, the @AKction2 team took the reins of Croakey’s rotated Twitter account @WePublicHealth and shared knowledge, language and insights into the cultural determinants of health, plus photos from the recent Renal Society of Australasian conference, as reported below. Don’t miss the fantastic map of the AKction research journey.
#AKtioinInAction @WePublicHealth · Jun 27

We’ll be sharing our journey of sending community members to decolonise conferences & teaching you about our project that’s improving chronic kidney disease (CKD) care for First Peoples in Australia

#AKtioinInAction

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#AKtioinInAction @WePublicHealth · Jun 29

#CKD is complex affecting all aspects of peoples’ lives. There are minimal symptoms early on and many don’t know they have it until they have end stage kidney disease #ESKD requiring renal replacement therapies #RRT like dialysis or a transplant @ANZDATARegistry #AKtioinInAction

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#AKtioinInAction @WePublicHealth · Jun 29

Conducting research with First Peoples living with #CKD means we often experience unexpected life events, health issues, and sorry business. What unexpected factors do you face in your work or research?

#AKtioinInAction

samuseum.ca.gov.au/wangayarta

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#AKtioinInAction @WePublicHealth · Jun 29

Members of our deadly @AKtioin2 team helped develop the cultural bias report with the @LowitjaInstitute for @NIKTTaskforce, which identifies 14 recommendations for improving kidney care and services for First Peoples

#AKtioinInAction #CKD #uturabilities

lowitja.org.au/fooment/1image/

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You can view Croakey's coverage of the series here.

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TREATMENT OF KIDNEY FAILURE FOR ABORIGINAL &
TORRES STRAIT ISLANDER PEOPLES OF AUSTRALIA

A summary based on a literature review by Australian government people and healthcare workers and Indigenous people

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A summary of 2020

- 31% of people were recorded again in the annual survey (prevalent patients).
- They were treated with haemodialysis (HD), peritoneal dialysis (PD) and renal transplantation (RTR)
- Diabetes was the cause of kidney failure for 63% in 100 patients during 2010-2020
- Cardiovascular disease caused most of the 271 deaths in 2020

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#31 kidney failure treatment among Aboriginal and Torres Strait Islander people

- 16% reporting HD
- 45% PD
- 8% RTR

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61 in 100 Aboriginal and Torres Strait Islander people (10%) died on a dialysis catheter at the first haemodialysis.

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26 in 100 Aboriginal and Torres Strait Islander people received care close to home as part of End Stage Renal Disease (ESRD) or transplant.

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# AKtioinInAction @WePublicHealth · Jun 29

Kaya

Hello in Noongar WA.

After a couple nczups and late-night phone calls, Nari and @JaredKarts3 arrived in Lanska country Damini #AKtioinInAction

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Sharing vibrant, productive and creative journeys to improve kidney care for First Peoples

#KidneyCareTogether

CROAKEY HEALTH MEDIA

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You can view Croakey’s coverage of the series here.

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You can view Croakey's coverage of the series here.
To respond to the disparities in #CKD outcomes for First Peoples, @Aktion2 has helped conduct nationwide consultations with community to develop @cariguidelines. These aim to improve cultural safety, responsive care, detection, management and outcomes.

#AktioninAction @WePublicHealth - Jun 30

Nganyi
A greeting from Barkindji Western NSW. While at the RISA Conference, Shani and Jared presented a poster alongside Aktion2 researcher and renal nurse Melissa.

#AktioninAction #DecolonisingConferences

In #Aktion2, we like to flip research on its head, challenging and changing typical colonial hierarchies and ways things are done. For example, we send community members to conferences to amplify their voices and knowledge.

#AktioninAction

Peer Navigation (a First Nations kidney care model) is where those with lived experience support others on their #CKD journey. With funding and support by @NRRTtaskforce & @SAHealth this decolonises current healthcare structures and enables culturally safe care.

#AktioninAction @WePublicHealth - Jul 2

At the @RISAconference Jared and Nari connected with Panuku mob from Purple House - who help First Peoples manage their #CKD, aiming to get people back home to have dialysis on country.

#KidneyCareTogether
You can view Croakey’s coverage of the series here.

#AKtioninAction @WePublicHealth - Jul 2
Nari and Jared said connecting with Paruku mob at the #RSAconference was like sitting around an open camp fire, having a yarn. We got to share our kidney journeys, what actions we have been doing in community, and have a laugh #AKtioninAction

#AKtioninAction @WePublicHealth - Jul 3
Besides the hiccups it was a really good trip. The #RSAconference was cool as I got to see what others are doing. It was great talking to fella’s on their country and I was so excited to see the new dialysis machine, it was like seeing a new iphone! - Jared #AKtioninAction

#AKtioninAction @WePublicHealth - Jul 4
Recording what we do is important, helping us identify what worked and what didn’t so we can learn for next time. This is especially important in healthcare, and can be used as a tool to strengthen and inform culturally safe health journeys #AKtioninAction

#AKtioninAction @WePublicHealth - Jul 3
After the #RSAconference the team made time for fun, and sight seeing. #CKD affects individuals’ social and emotional health and wellbeing, so we know the importance of having fun and connecting with others to make the journey easier #AKtioninAction #BMI

#AKtioninAction @WePublicHealth - Jul 3
I’m an expert and live with #CKD but it was good to learn about the clinical side of things at the #RSAconference. I enjoyed finding out what Purple House have done, how many units they have opened, and seeing what others are doing differently - Nari

#AKtioninAction @WePublicHealth - Jul 4
For this reason, @AKton2 collaboratively developed a resource with Aboriginal patients, families, and community, researchers, healthcare staff and academics to map health journeys. #AKtioninAction #HUM
croakey.org/health-journey...
lowtja.org.au/page/services/

croakey.org
Health Journey Mapping: having a yarn about health
Introduction: Aboriginal and Torres Strait Islander peoples should have access to healthcare journeys that are culturally safe, responsive to ...

Sharing vibrant, productive and creative journeys to improve kidney care for First Peoples #KidneyCareTogether
You can view Croakey's coverage of the series here.
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Sharing vibrant, productive and creative journeys to improve kidney care for First Peoples

#KidneyCareTogether

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