

AKAction

Aboriginal kidney care together -
improving outcomes now



THE UNIVERSITY
of ADELAIDE

Who Am I?

Nangka.

Ngai mityi Rhanee-nha.

Ngatyu Yura Mityi utyu Unakanha

Ngaityu Adnyamathanha Yurartu,

Ngatyu Yarta utyu Flinders Ranges Yarta

Ngai utyu Ararru artu.



Who Am I?

Hello, my name is Rhanee Lester. My ancestral ties are with the Adnyamathanha people of the Northern Flinders Ranges in South Australia and my moiety (or skin group) is Ararru, which is important to know because it helps me to understand how I relate to my people, nature, creation and all living things within. My Adnyamathanha name is Unakanha - which means 3rd born child who is female.



A shared project between patients, peer navigators and the nurses of the Port Augusta Renal Unit



Kerry & Doug

A Kidney Care Community led by First Nations Peer Navigators



Insert classification eg OFFICIAL, OFFICIAL: Sensitive//IMM if required.

Janet Kelly

Grew up on Kangaroo Island

German/English/Welsh background

Worked as community health nurse and researcher

- with Aboriginal community members and health professionals
- mapping journeys from country to city and return

Now

Research-teaching role

- University of Adelaide Nursing School (Assoc Prof)
- Co-lead AKction and Health Journey Mapping projects
- Co-teach nursing students Aboriginal Health Care and Cultural Safety





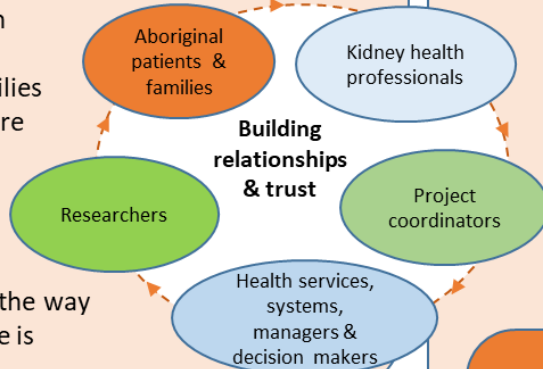
Aboriginal Kidney Care Together – Improving Outcomes Now: AKAction1 → AKAction2

- Community
- Health, Renal & support services:
CNARTS
CALHN
NALHN
- National Indigenous Kidney Transplant Taskforce
- SAHMRI
- Universities
- Aboriginal Chronic Disease Consortium
- Aboriginal Health Services
- Kidney Health Australia
- CARI guidelines
- Purple House

AKAction1

- Aboriginal Reference Group
- Community Consultations
- Patient journey mapping
- Stakeholder workshops
- Networking - local, NT, international
- New national clinical guidelines

Building relationships and trust between Aboriginal patients, families and health care professionals



Changing the way kidney care is provided

HTSA/MRFF Funding

Working with NIKTT: National Indigenous Kidney Transplant Taskforce

- IRG – Indigenous Reference Groups
- National Community Kidney Panel
- Peer navigators
- Cultural Bias report & policy document

AKAction2

Decolonising approaches & methodologies

Indigenous methods

Yarning – relaxed conversations
Dadirri – deep listening
Ganma – knowledge sharing

Interface – working in Brave Spaces

combining Indigenous and Western concepts
Co-design, collective decision making
Participatory Action Research
Look & Listen, Think & Discuss, Take Action Together

Western methods

Interviews, focus groups
Surveys, evaluation
Critical reflection

4 sub studies

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

What we want to achieve - our end goals

Patients & families

Better kidney care, dialysis & transplantation experiences & outcomes
Access, education & prevention
Peer support

Health professionals

Cultural safety training & tools
Effective partnerships with patients, families and communities
Increase Indigenous workforce

Health services and systems

Improved coordination of care - within and across health services & systems
Improvements in care processes and outcomes
Implementation of new guidelines & standards
Increased Indigenous workforce
Reducing racism

NHMRC Ideas Grant Funding



The AKtion Reference Team



Members with lived experience of kidney disease, dialysis and transplantation & family members

Back row: Ramon Gadd, Jared Katinyeri, Kelli Owen, Rhanee Tsetsakos,
Front row: Inawinytji Williamson, Nari Sinclair, Matthew Hobbs, Lily Neville
(photo shared with permission of Hobbs family)

‘My Kidney Journey’ - Inawinytji Williamson Elder mentor

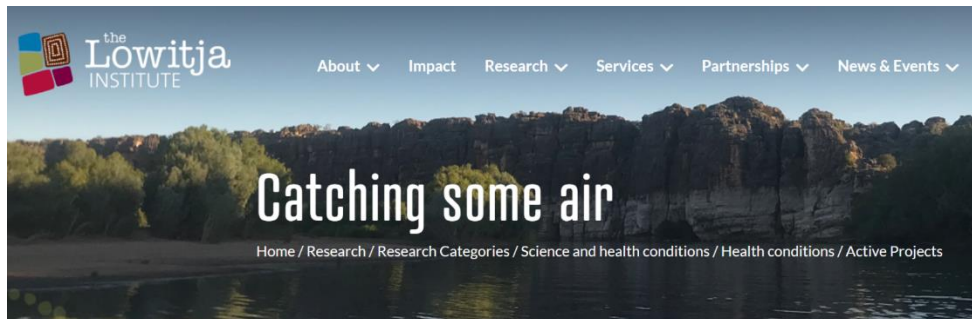
The white circles in the centre represent all Aboriginal kidney patients coming together to have a yarn about kidney health with doctors and nurses, talking about the plans for the future and sharing what they want to see happening to improve kidney health for their people.

The outside circles represent patients on dialysis to help cleaning their body to keep healthy. There are two footpaths that represent the journey of Aboriginal kidney patients. Wild flowers and grass are represented by purple, white, black, orange and green dots.”



Nationwide community consultation

- Guidelines **must address** important issues and topics to community



Racism is evident and common

Increasing access to care on Country

Current transport and accommodation inadequate

Increased Aboriginal Health Workforce required

Education, detection, and care needs to be led by community for community

KHA Yarning Kidneys AKtion – findings



Prevention & early detection

“We don’t know when it is best to get further information or a ‘kidney health check’, or even how to do this” (Port Augusta participant)

“There are materials in Italian, Greek and other languages, but there is nothing in our languages – yet we are the Traditional owners of the land” (Adelaide participant)

- Early detection is necessary - People are shocked when diagnosed
- Encourage periodic kidney checks for early detection
- Education about lifestyle risk factors and how to manage is required

Culturally safe education and health promotion

“Getting into schools, raising awareness and getting kids thinking about their kidneys and how to keep them healthy” (Port Augusta participant)

“We have to stop this dependence on other people to solve problems, people need to be empowered” (Ceduna participant).

- At the community level – urban, rural, remote.
- Collaboration with Aboriginal communities in mainstream healthcare services and schools
- Incorporate storytelling and intergenerational learning
- Include Aboriginal patients and educators

KHA Yarning Kidneys AKtion – findings



Availability of Aboriginal patient experts

“The hospital should employ [Aboriginal experience kidney patient] to explain Aboriginal people about dialysis and what is a kidney transplant, and what are the consequences of these treatments.” (Adelaide participant)

- Support Aboriginal health workforce and people with kidney disease

Improving access to cultural safe care

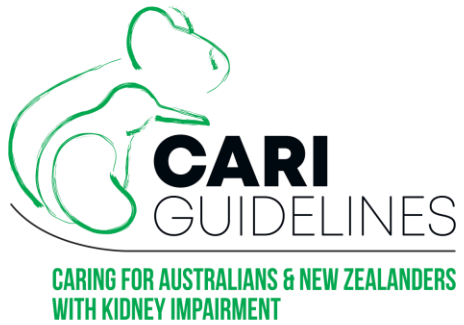
• *“Going back to the bush is good for the heart and the mind” (Ceduna participant)*

- Effective cultural safety training for staff – incorporating Aboriginal knowledge and methods
- Increased capacity and access to Aboriginal health workforce, including translators
- Care should be delivered in collaboration with Aboriginal communities
- Increase support for family who relocate
- Increased reliable transport to dialysis services and accommodation

Improving access to transplantation

“Transport should be available to all patients, and not only to Aboriginal patients – all of us need it.” (Adelaide participant)

- Increased reliable transport to transplant services
- Increase services pre and post-transplant



Management of chronic kidney disease among Aboriginal and/or Torres Strait Islander Peoples

Cooper Pedy June 2021

 www.cariguideines.org

 @cariguideines

Clinical practice guidelines

- Statements that include recommendations, intended to improve care, that are informed by a scientific literature – balance of benefits and harms of treatment
- Clinical practice guidelines can improve patient outcomes and the quality of care.
- Traditionally guidelines have been written by clinicians for clinicians
- CARl increasingly involving people with lived experience and producing content for them



Community voice is fundamental to guidelines

- Informed scope
- Community voice is underlying rationale for recommendations

4Cs framework

Domain	Description
Community voice	<ul style="list-style-type: none">• Prioritise and needs identified in community consultations• Any other feedback from community
Cultural considerations	<ul style="list-style-type: none">• Other cultural issues not raised in the consultations• Cultural safety considerations
Clinical evidence	<ul style="list-style-type: none">• Scientific evidence on the - balance of benefits and harms• Certainty of the evidence – assessment of confidence on the data
Costs, capacity, equity and other resources	<ul style="list-style-type: none">• Cost-effectiveness data if available• Costs implications to individual, health systems and organisations – including increasing capacity• Equity issues – Rural and remote, socioeconomic status.

Themes of the guidelines



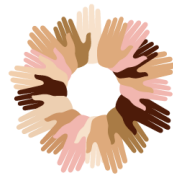
Driven by the community

Address issues raised in community consultation & use as justification



Outcome driven

Focused on improving health care services



Increased community control

Community control and co-design from public awareness to health services



Combat bias

Formal evaluation of racism and educating clinicians



Increased services

More kidney services in the community

INDIGENOUS GUIDELINES

MANAGEMENT OF CHRONIC KIDNEY DISEASE AMONG ABORIGINAL AND/OR TORRES STRAIT ISLANDER PEOPLES



- 1**
 - INSTITUTIONAL RACISM
 - CULTURAL SAFETY
- 2**
 - COMMUNITY AND FAMILY INVOLVEMENT
- 3**
 - TRANSPORTATION
 - ACCOMMODATION NEEDS
- 4**
 - ABORIGINAL AND/OR TORRES STRAIT ISLANDER HEALTH WORK FORCE
- 5**
 - RISK FACTORS
 - SCREENING
 - REFERRAL
- 6**
 - PUBLIC AWARENESS
 - EDUCATION
 - SELF MANAGEMENT
- 7**
 - MODELS OF CARE
 - PRE-DIALYSIS
 - KIDNEY-FAILURE,
 - TRANSPLANTATION

Due to ongoing impacts of colonisation

NOT due to ethnicity

Increased burden of kidney disease

Scoring Matrix as tool

Is present

Should be monitored & acted upon



First Nations Reference Groups

Address power imbalances

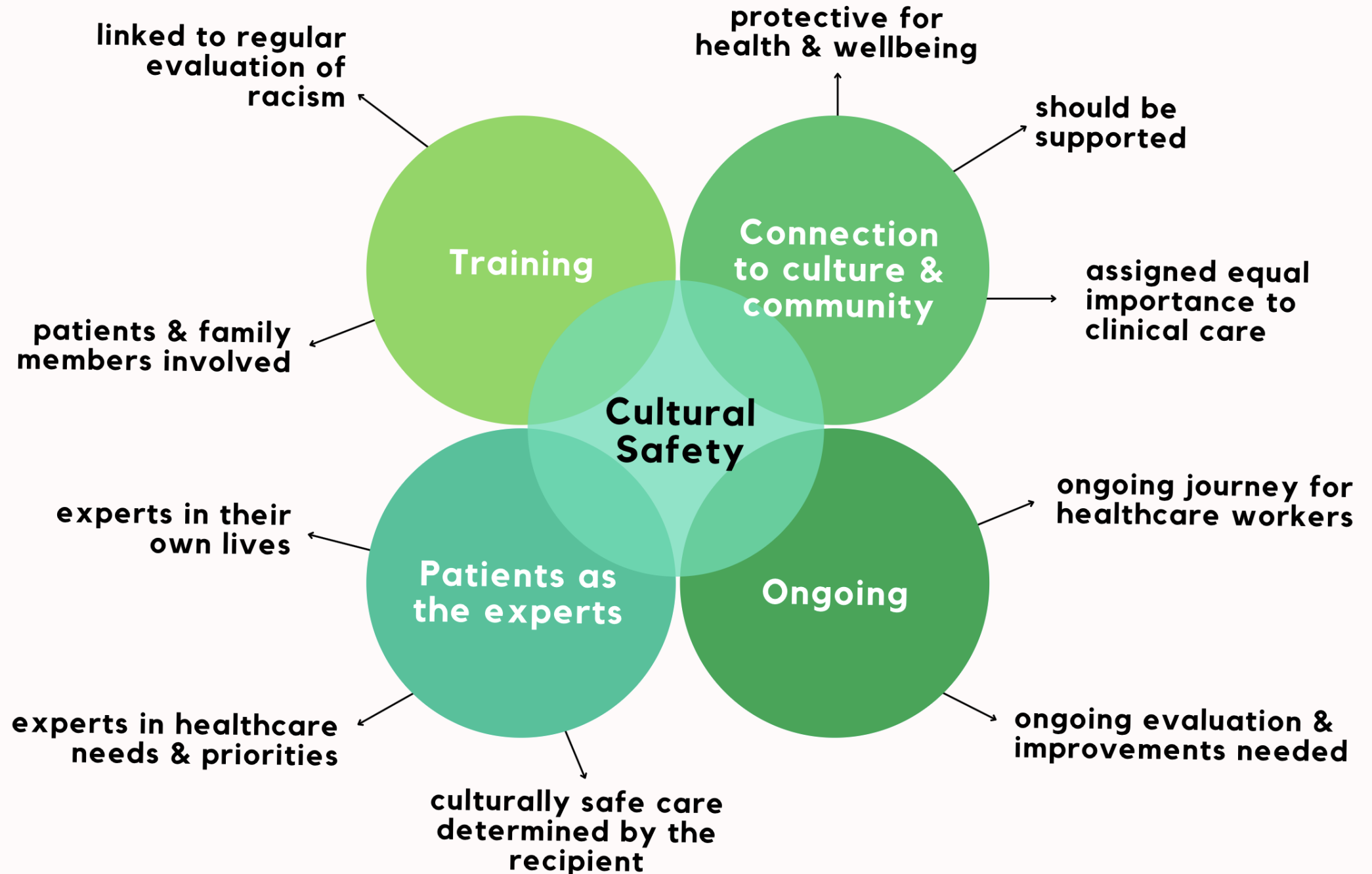
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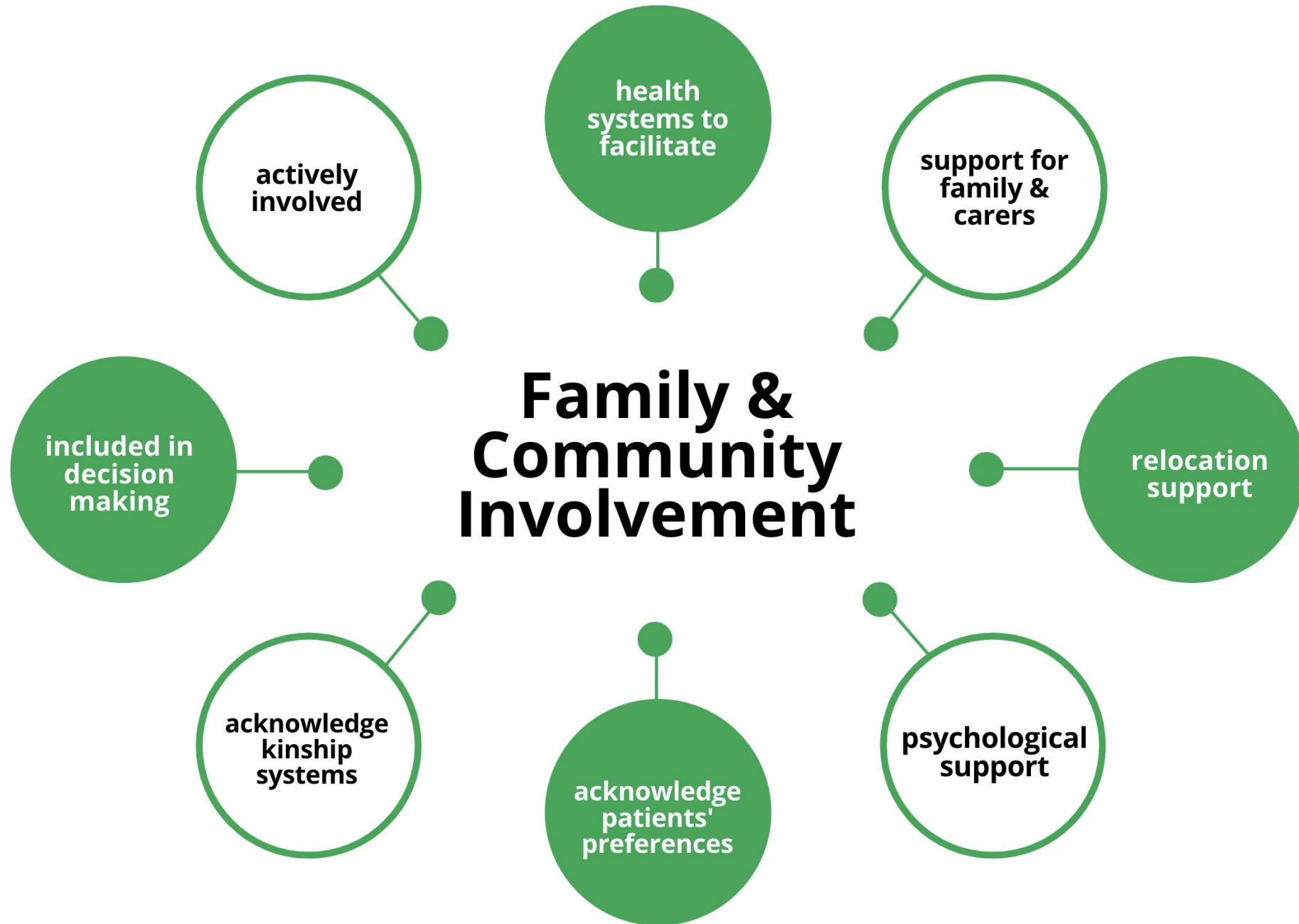
Decolonise health systems

two-way communication

culturally-shaped care

confidential complaints process







Transport and accommodation services

Transport and accommodation should be **provided** for patients and their family members **for all appointments**

- Current services are **inadequate, difficult to access** and **not suitable** for Aboriginal and/or Torres Strait Islander Peoples with kidney disease

Aboriginal and/or Torres Strait Islander Health Workforce



First Nations Peoples with CKD should have access to

- **Aboriginal and/or Torres Strait Islander**

Nurses

Doctors

**Allied Health
Professionals**

**Aboriginal Health
Practitioner**

and/or

**Aboriginal Health
Liaison**

**Patient Preceptors /
Navigators**

Interpreters

- Health Practitioners should be **trained** in the management of CKD.
- **Financial investment** and **strategic commitment** to community-based First Nations health workforce is required.

Risk factors, screening, and referral for CKD

Risk factors for CKD

Traditional risk factors



Diabetes



High blood pressure



Obesity



Smoking



Heart disease



Acute kidney injury

Other risk factors



Low birthweight



Previous kidney infection damage



Social disadvantage



- **Remoteness**



- **Lower socioeconomic status**



- **Lower education**

- **Insecure housing**

Screening and early detection of CKD



i. Screening for CKD should be led and designed by the community



j. First Nations Peoples 30 years of age and older should receive an annual kidney health check and include tests for



Blood pressure



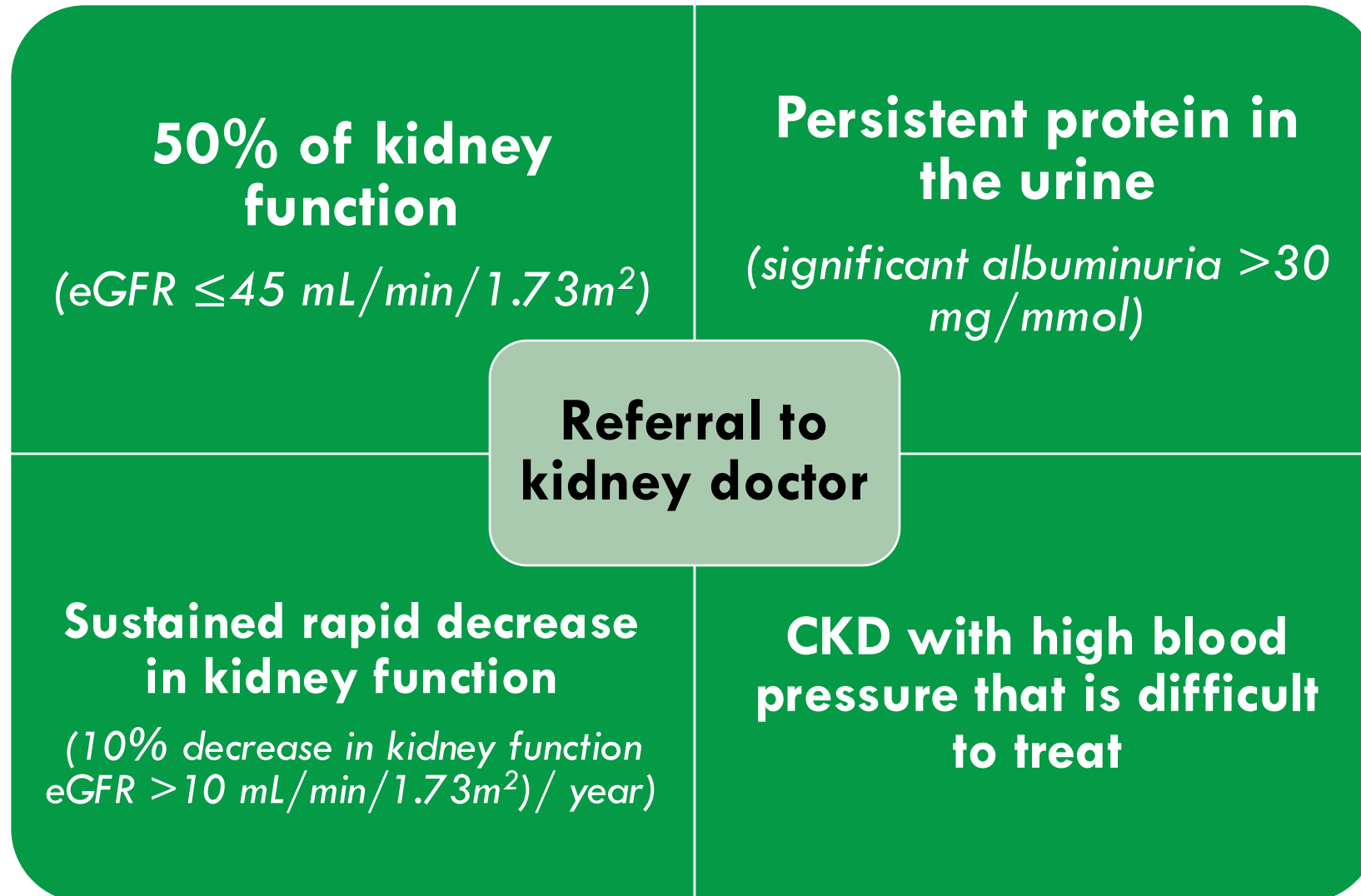
Kidney function
(eGFR)



Protein in urine
(urine albumin: creatinine ratio (ACR))

- First morning urine tests are preferred, but a *random “spot” urine* specimen can be used to check for protein in the urine.
- Repeated (1-2) checks to confirm protein in the urine should occur over three months

Referral practices



Public awareness, education, and self- management

Public awareness & education about kidney disease

- Should be should be **co-designed** with **Aboriginal and/or Torres Strait Islander Peoples**
- **Public awareness should incorporate Indigenous knowledge and methods**



Education resources and programmes should be **interpreted to local languages**

Use elements such as:



Involve Elders
People with lived experience



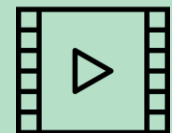
Cooking and shopping classes



Yarning Circles
Storytelling



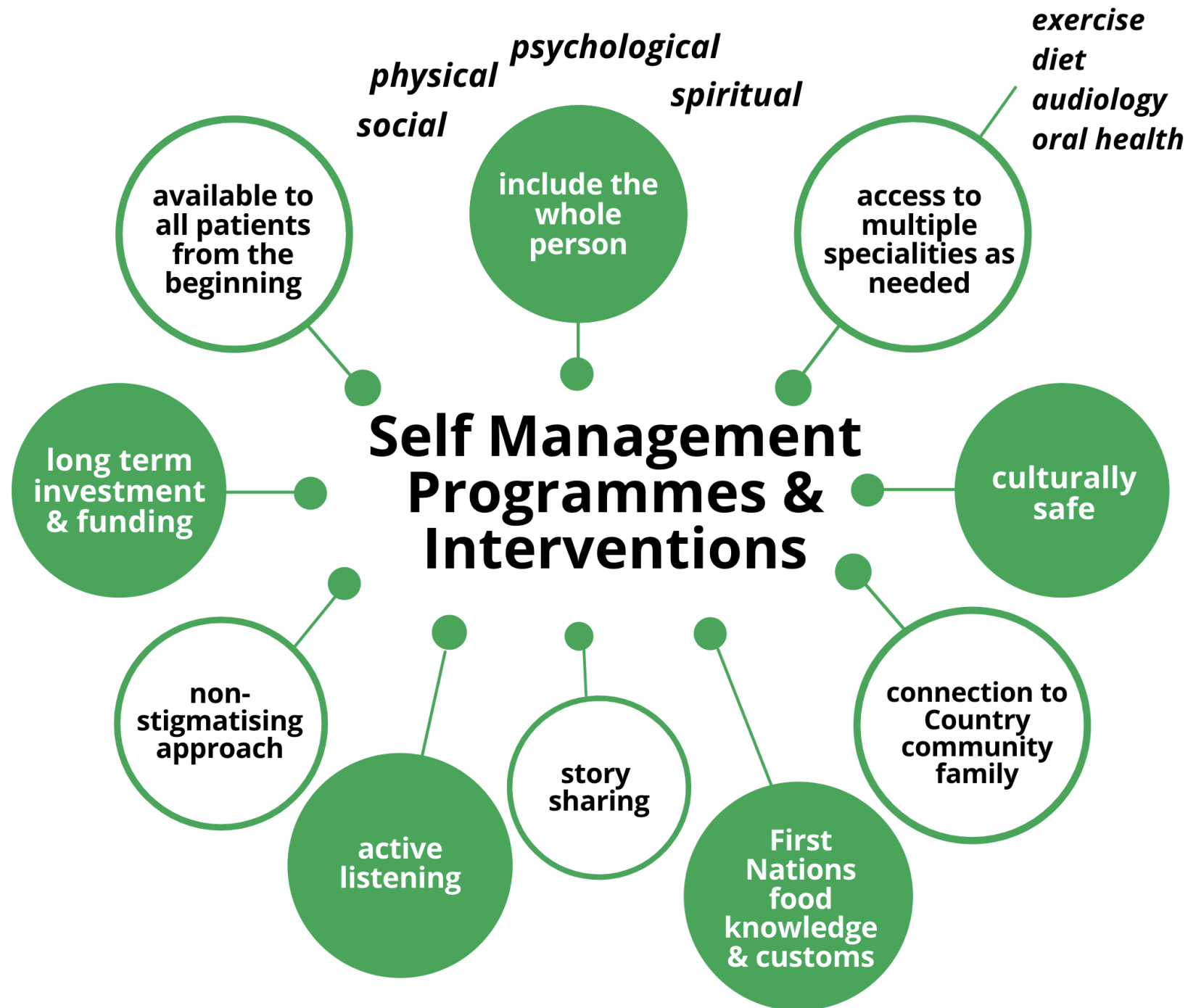
Community gardens



Interactive lectures & videos



Art
Music



How clinical care should be delivered

Models of Care

Chronic Kidney Disease (pre-dialysis)



CO-DESIGN & GOVERNANCE

with Aboriginal and/or Torres Strait Islander Peoples
Be conducted within **community-controlled health services**
Adhere to **data sovereignty principles**



CULTURALLY SAFE & TAILORED TO COMMUNITY NEEDS

Include education and nephrology services using **Telehealth services** (if appropriate)



IDENTIFY & ADDRESS BARRIERS TO CARE

Institutional racism, geography, transport, out-of-pocket costs to patients and families

Thankyou

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