

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

**Cooper Pedy June 2021**

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# Acknowledgment of Country

*Pay respects to all  
involved in previous  
yarnings*

# What is CARI Guidelines?



Australian and New Zealand guideline developers in kidney disease



Based at The University of Sydney



We have been operating since 1999



30 Guidelines – mainly targeted at clinicians

- Chronic kidney disease
- Dialysis
- Transplantation



Increasing producing content for patients and carers

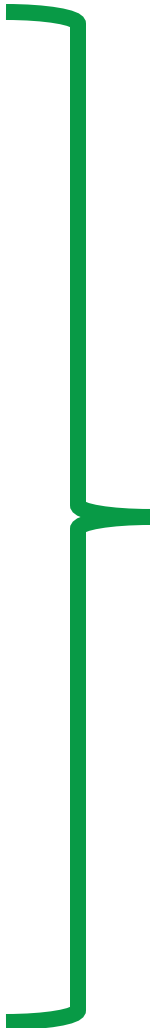
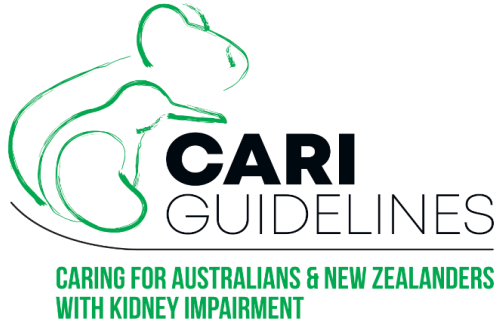


# Clinical practice guidelines

- 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



# Nationwide community consultation – *the issues facing Aboriginal and/or Torres Strait Islander kidney health*





*Prevent, Detect, Support.*



*Prevent, Detect, Support.*



## **Indigenous 'Yarning Kidneys'**

Report: Adelaide Consultation 2018

## **Indigenous 'Yarning Kidneys'**

Report: Port Augusta Consultation, February 2019



*Prevent, Detect, Support.*

## **Indigenous 'Yarning Kidneys'** **Report: Ceduna Consultation, June 2019**

Report available online at <https://kidney.org.au/get-involved/advocacy/yarning-kidney-consultations>

# KHA Yarning Kidneys AKction – 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

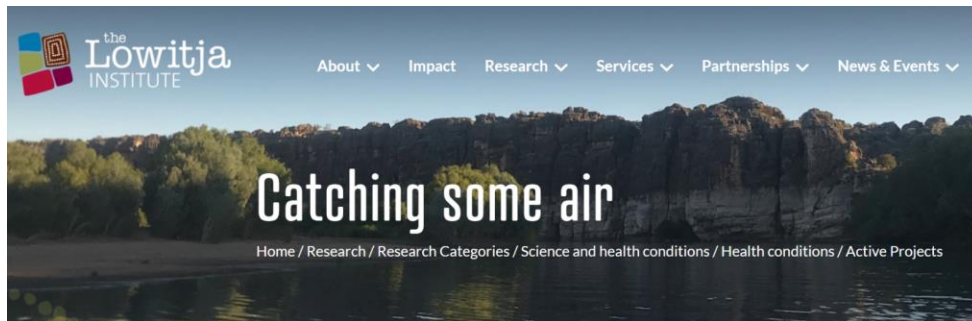
*“Transport should be available to all patients, and not only to Aboriginal patients – all of us need it.” (Adelaide participant)*

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



# Nationwide community consultation

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



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Racism is evident and common

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Increasing access to care on Country

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Current transport and accommodation inadequate

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Increased Aboriginal Health Workforce required

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

# Community voice is fundamental to guidelines

- Informed scope
- Community voice is underlying rationale for recommendations

## 4Cs framework

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

# 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**

# 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

# Preferences for the guidelines – terminology and dissemination

Guidelines have used terms

- First and Sovereign Peoples of Australia
  - First Nations Peoples
- **Are there terms that should not be used?**

**How** should the guidelines be disseminated?

- For health professionals
- For community-controlled health services
- For mainstream health services



**What** information and **how** should information reach **the community**

- For people living with kidney disease, carers, families

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

**Racism in healthcare**

First Nations Reference Groups

Address power imbalances

**IMPROVE**

Decolonise health systems

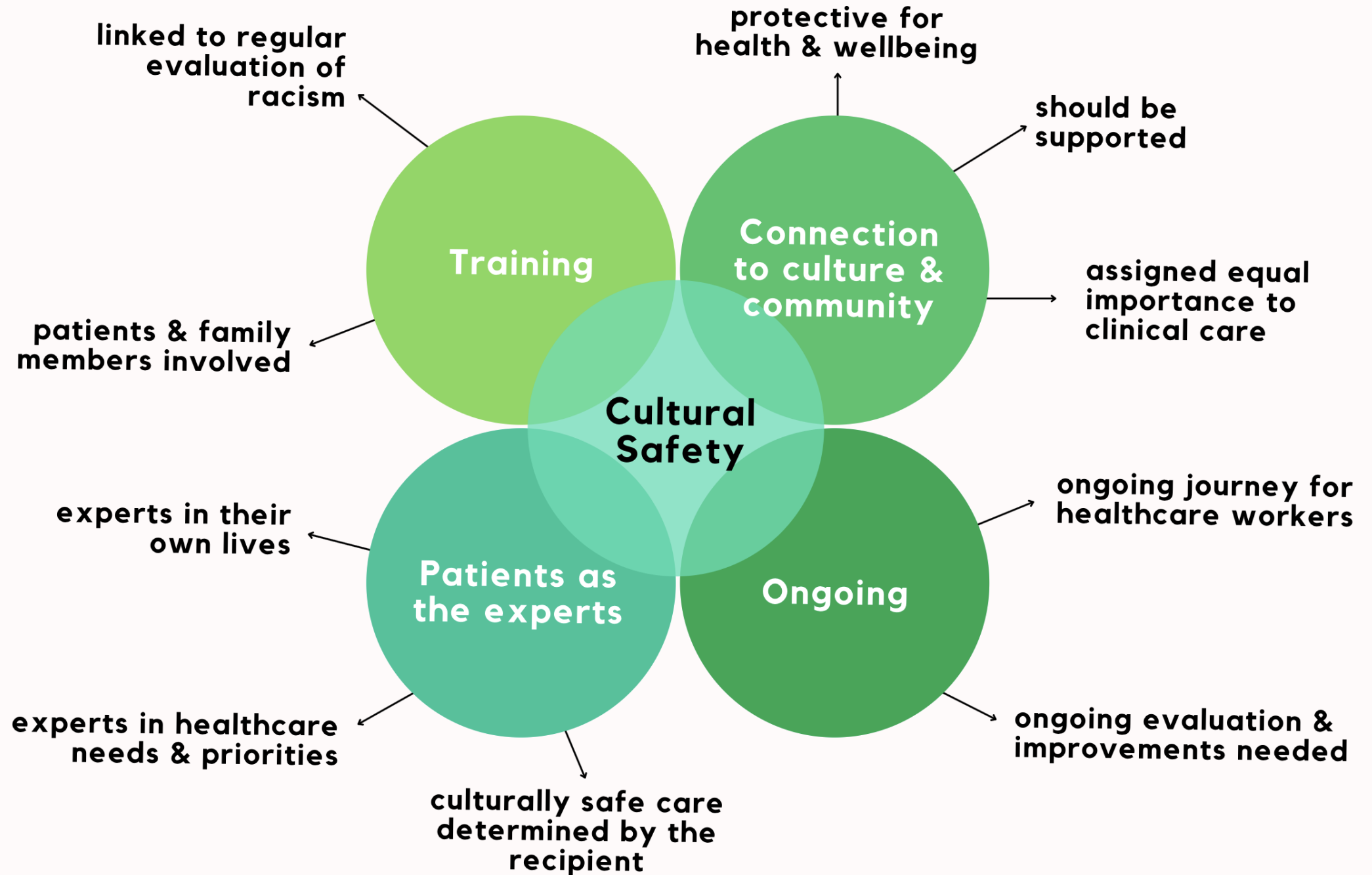
two-way communication

culturally-shaped care

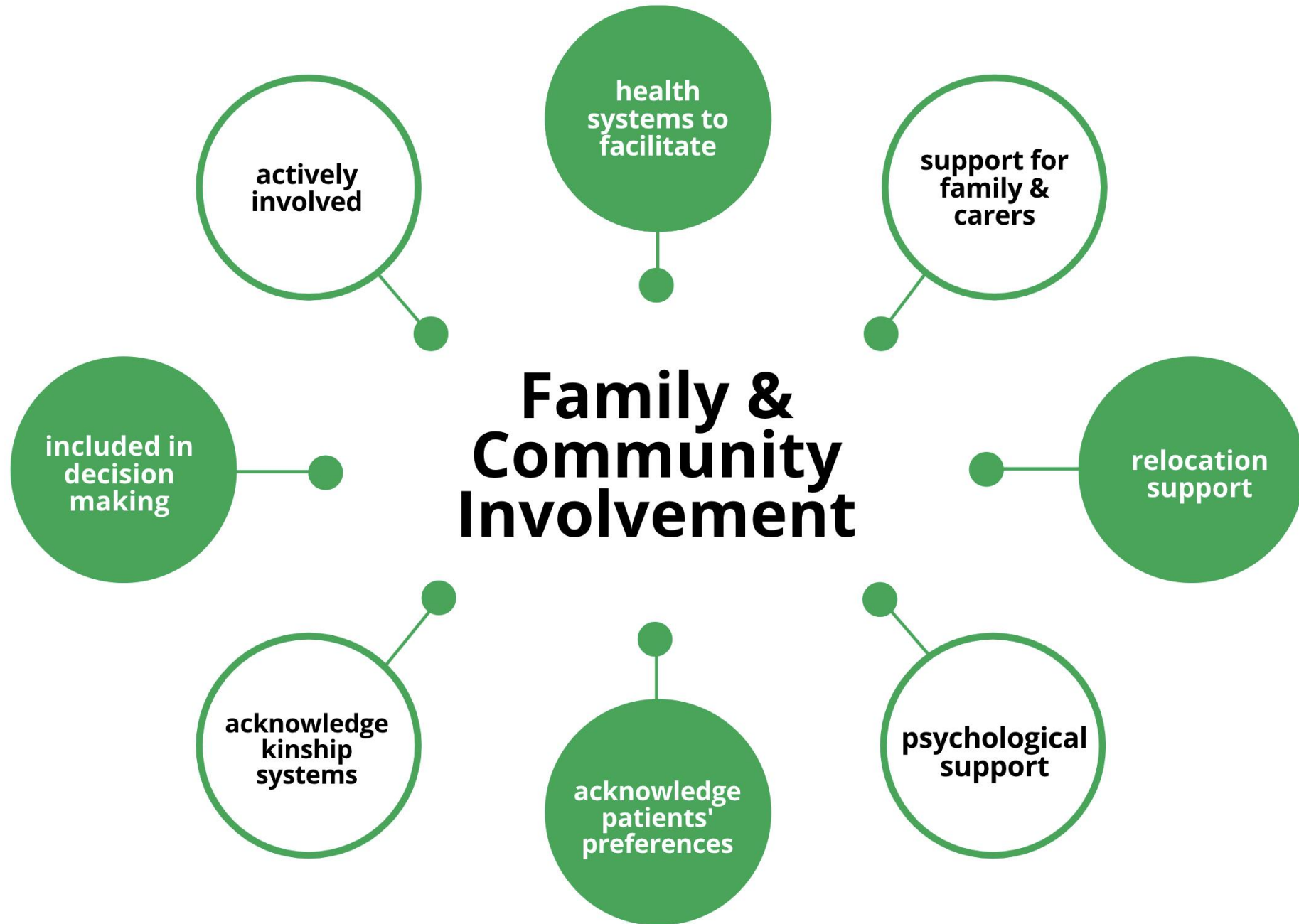
confidential complaints process

**Table 1.** Scoring matrix

Domain	Key Indicators and Criteria
Participation in organisation leadership/governance	• Legal visibility in relevant legislation
	• Representation at board level
	• Representation at Executive Management level
Policy implementation	• Closing the Gap health outcomes
	• Community engagement
	• Public Reporting and Accountability
Service delivery	• Aboriginal and Torres Strait Islander Health Service Plan
	• Cultural competence
	• Health Service Performance Indicators
Recruitment and employment	• Aboriginal and Torres Strait Islander Health workforce development
	• Aboriginal and Torres Strait Islander participation in health workforce
Financial Accountability and Reporting: Closing the Gap Funding	• Commonwealth contribution
	• State/Territory contribution









# Transport and accommodation services

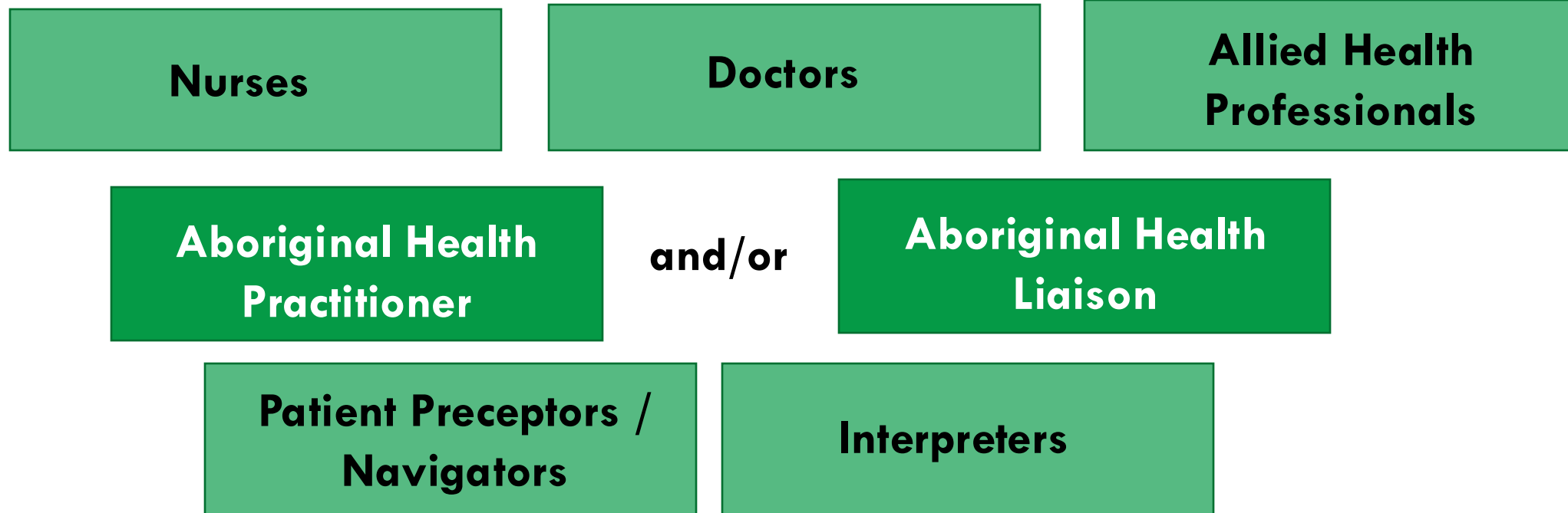
- g. Transport and accommodation should be **provided** for patients and their family members **for all appointments**
- Current services are **inadequate, difficult to access** and **not suitable** for Aboriginal and/or Torres Strait Islander Peoples with kidney disease

# Aboriginal and/or Torres Strait Islander Health Workforce



## h. First Nations Peoples with CKD should have access to

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



- 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**



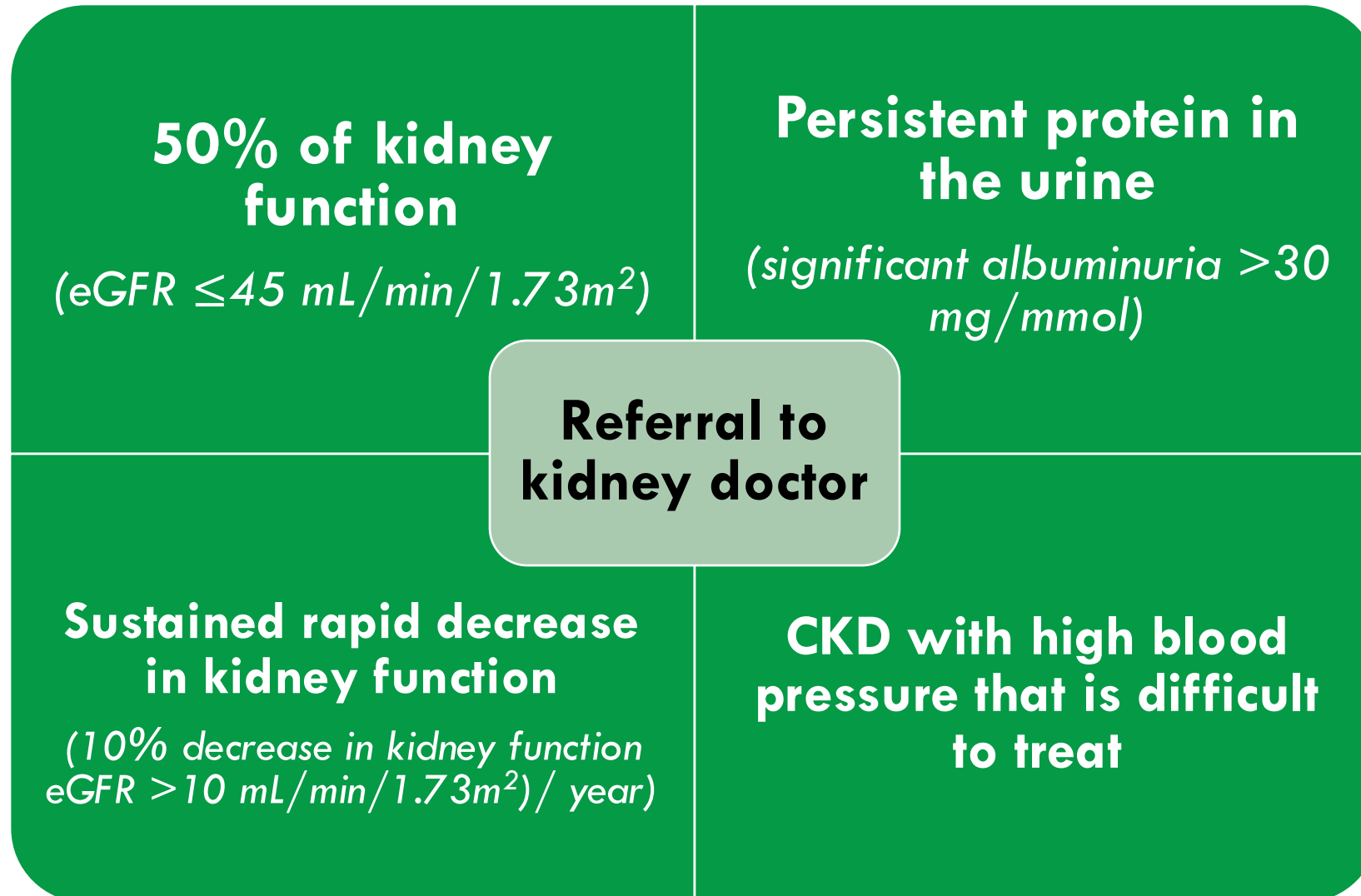
**Kidney function**  
(eGFR)



**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

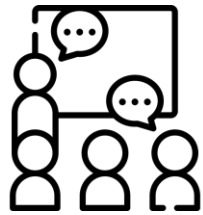


# Public awareness, education, and self- management



# 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**



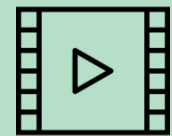
**Cooking and shopping classes**



**Yarning Circles**  
**Storytelling**



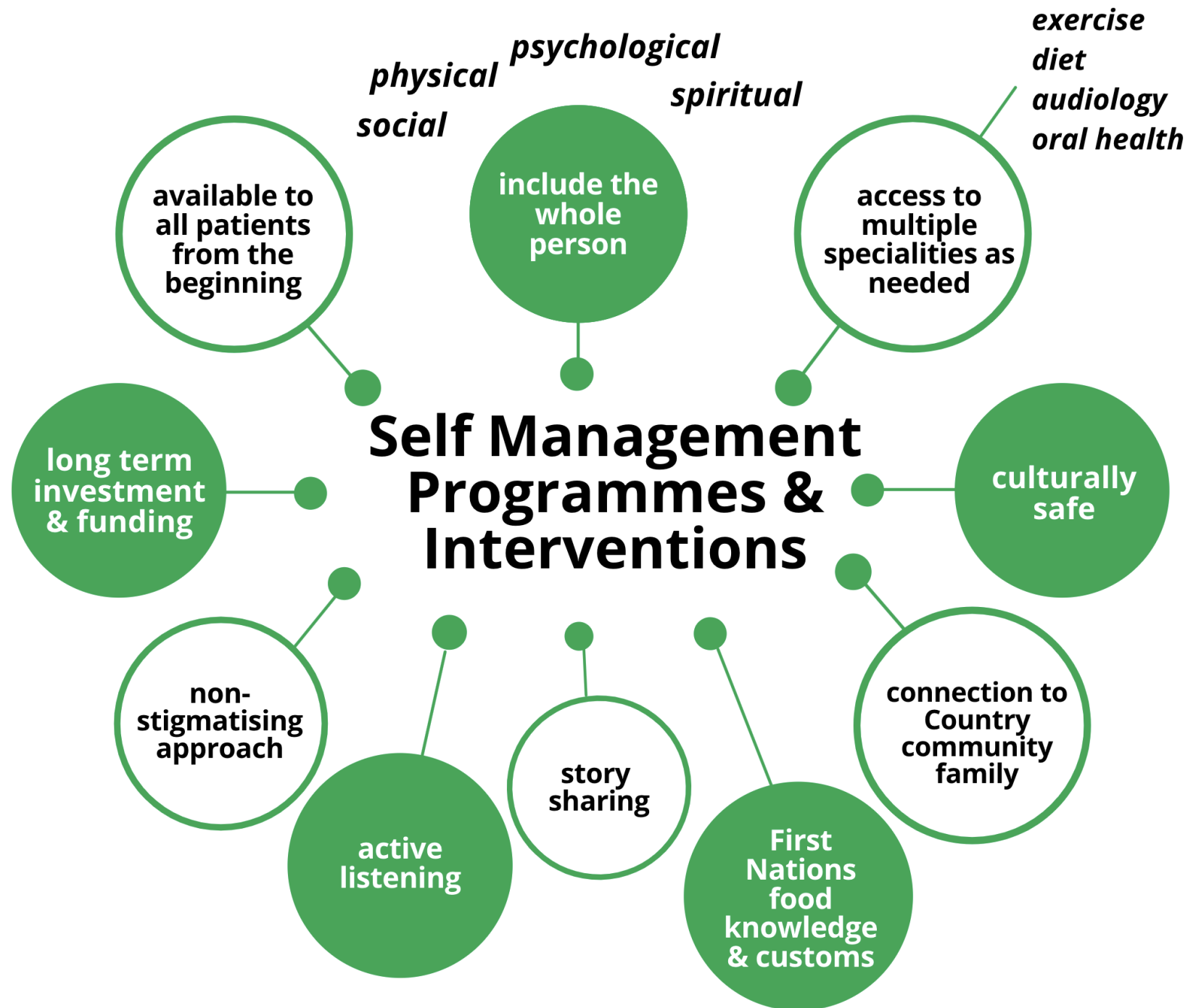
**Community gardens**



**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

# Models of Care - CKD (kidney failure) & Transplantation



- u. **Community-controlled nurse and Aboriginal Health Practitioner supported dialysis on Country** in partnership with Aboriginal Community-controlled health organisations
- v. **Mobile dialysis service** for respite dialysis on Country.
- w. **Co-designed programmes to address the social and emotional wellbeing**
- x. **Access to dedicated Aboriginal and/or Torres Strait Islander healthcare teams**
  - (Doctors and nurses, Aboriginal Liaison Officers, Aboriginal Health Practitioners and/or Aboriginal peer navigators)
- y. **Support community-based home dialysis models**
- z. **Kidney health primary-care services to use telehealth/video link models for those living in and having dialysis in regional and remote areas**
  - **Kidney transplantation** considered as treatment option for all Aboriginal and/or Torres Strait Islander Peoples with CKD
  - Important studies on the best models of care for transplantation are ongoing and guidelines will be written in future

# Draft guideline messages – for consumers?

## **Kidney health should be a part of an annual health check**

Including measuring

- Blood pressure
- Kidney function (via a blood test)
- Protein in the urine

To measure protein in the urine, the first part of your wee (20 mLs) in the morning is preferred, but a repeated random (“spot”) urine samples can be used

## **First Nations Peoples should be referred to kidney doctors**

- Kidney function  $\leq 50\%$
- Persistent and significant protein in the urine (albuminuria  $>30$  mg/mmol)
- Rapid and sustained decrease in kidney function over a year
- High blood pressure that cannot be controlled

# Draft guideline messages – for clinicians and healthcare system

Being Indigenous is **not** a risk factor for CKD, but First Nations Peoples are an at-risk group due to social determinants of health

Hospitals and healthcare facilities need to evaluate monitor, and respond to institutional racism to improve the care for First and Sovereign Peoples in Australia

Involving your family and community may help in clinical decisions to improve your kidney health

Transport and accommodation should be provided for all clinical interactions