From local realities to system reform:

Lessons from the Katherine Palliative Care Review

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Katherine Hospital, NT Health

Acknowledgements

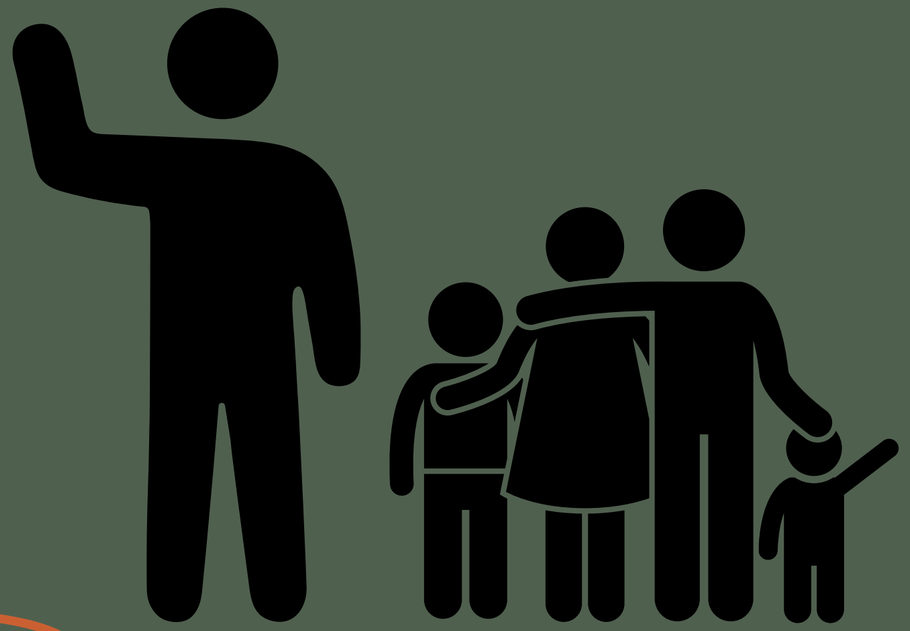
Vocabulary

- **Sorry Business** - mourning period following the death of an Aboriginal person, including ceremony and custom
- **Finish up** - to die
- **Mob** - your people group, your family, from a particular Country/place
- **Kumanjayi** - a name used to refer to someone who has died in Warlpiri culture

Outline

- **Orientation** - welcome to our region and our service
- **Case study** - meet Kumanjayi and his journey
- **Our Service** - strengths and gaps in our service
- **Learnings for the Future** - our plans for our service, and our hopes for others

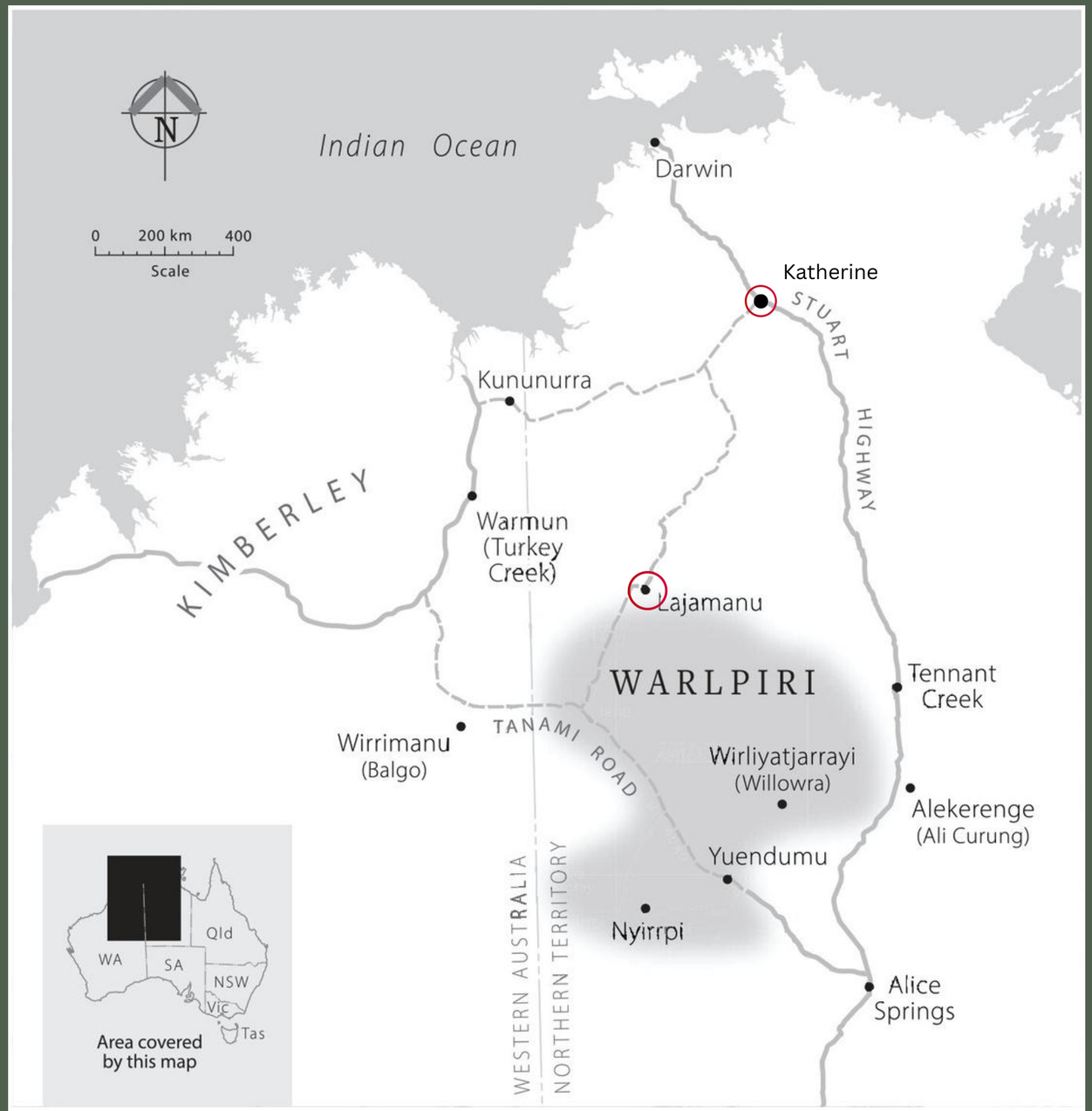
Kumanjayi

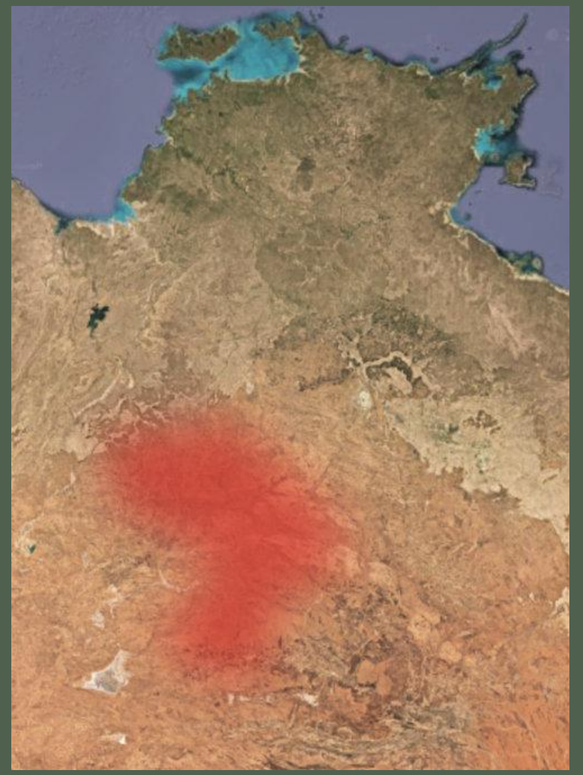


Lajamanu Community

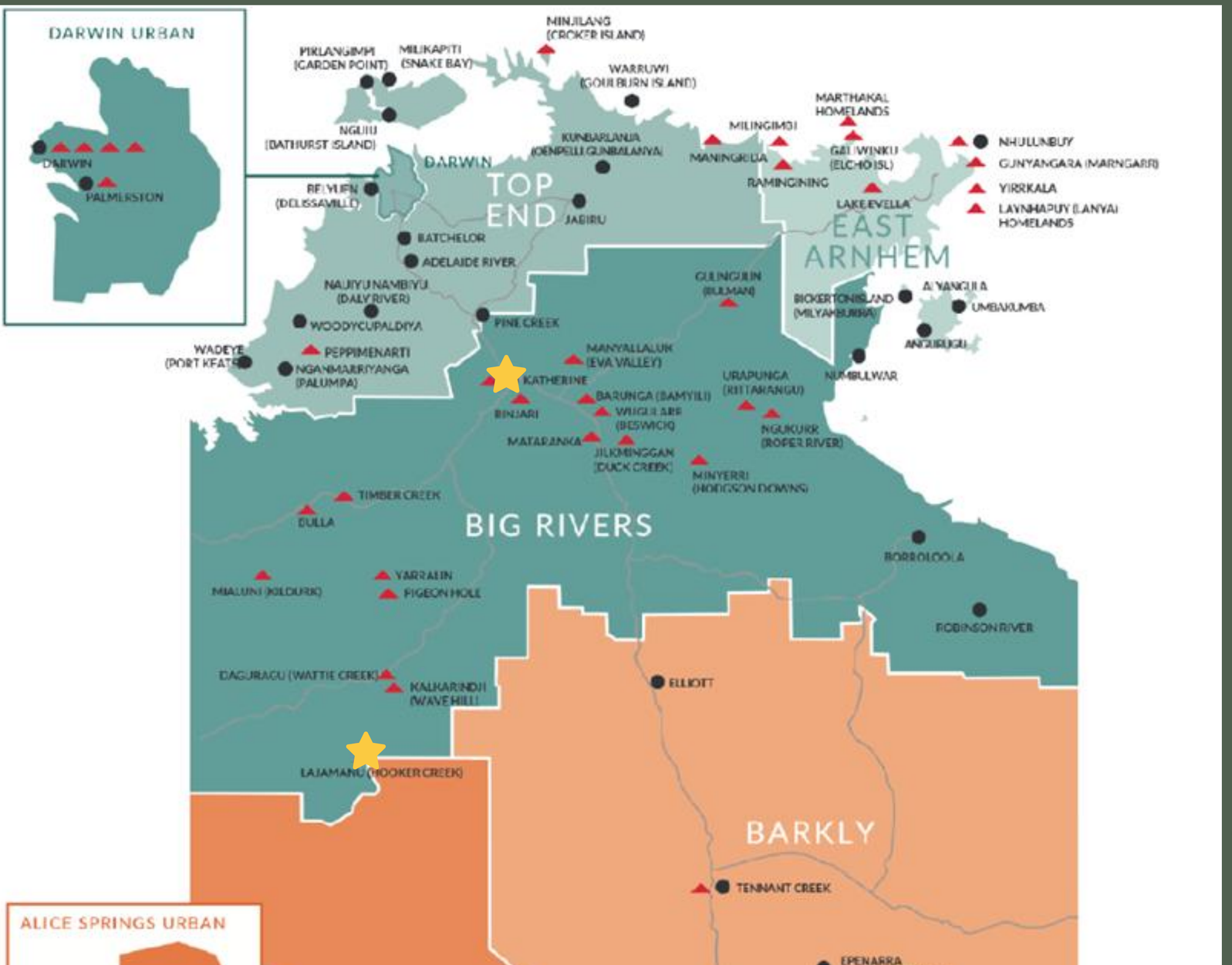
Photo courtesy of Central Desert Council

Warlpiri nation





Big Rivers Region



360,000 square kilometres

24 communities + Katherine town

110 outstations/homelands

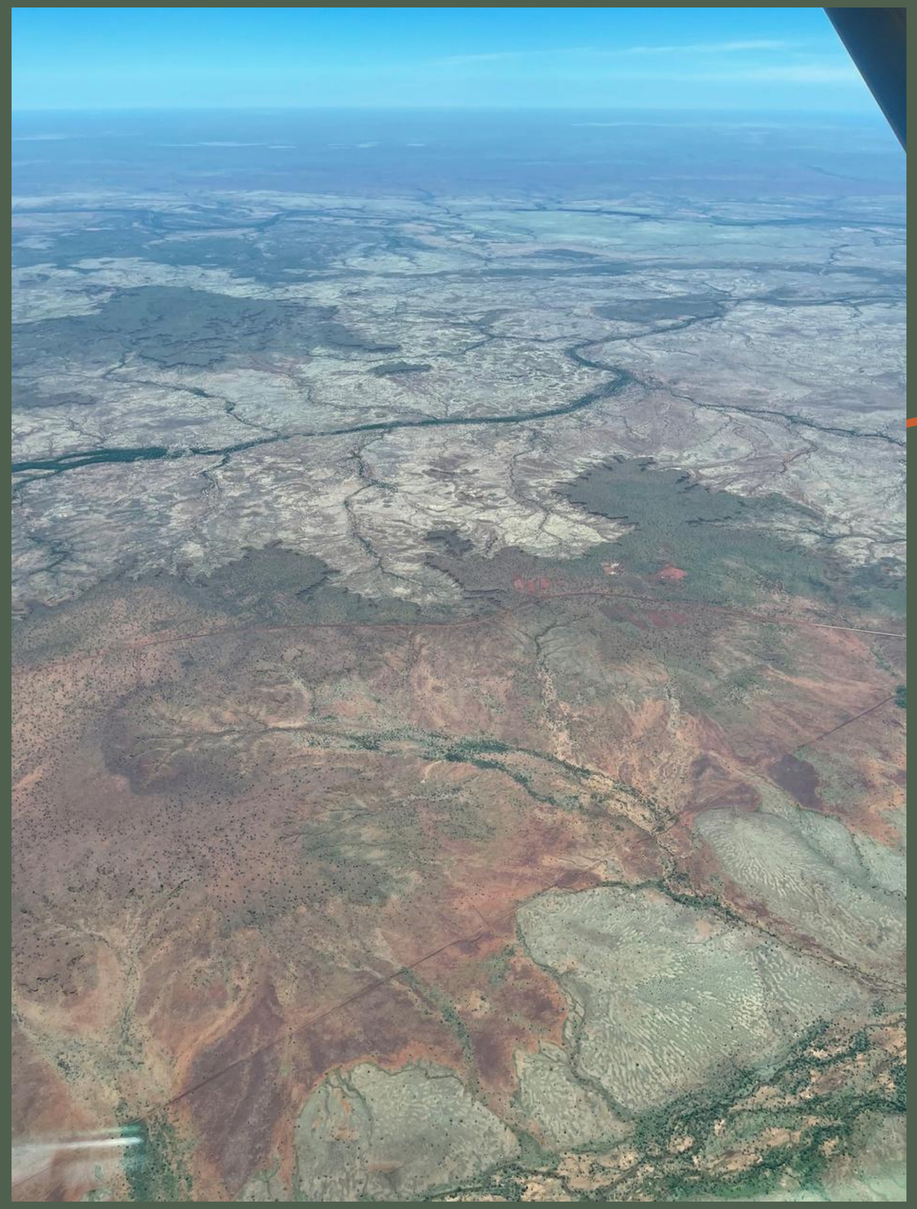
~30 language groups

105 cattle stations

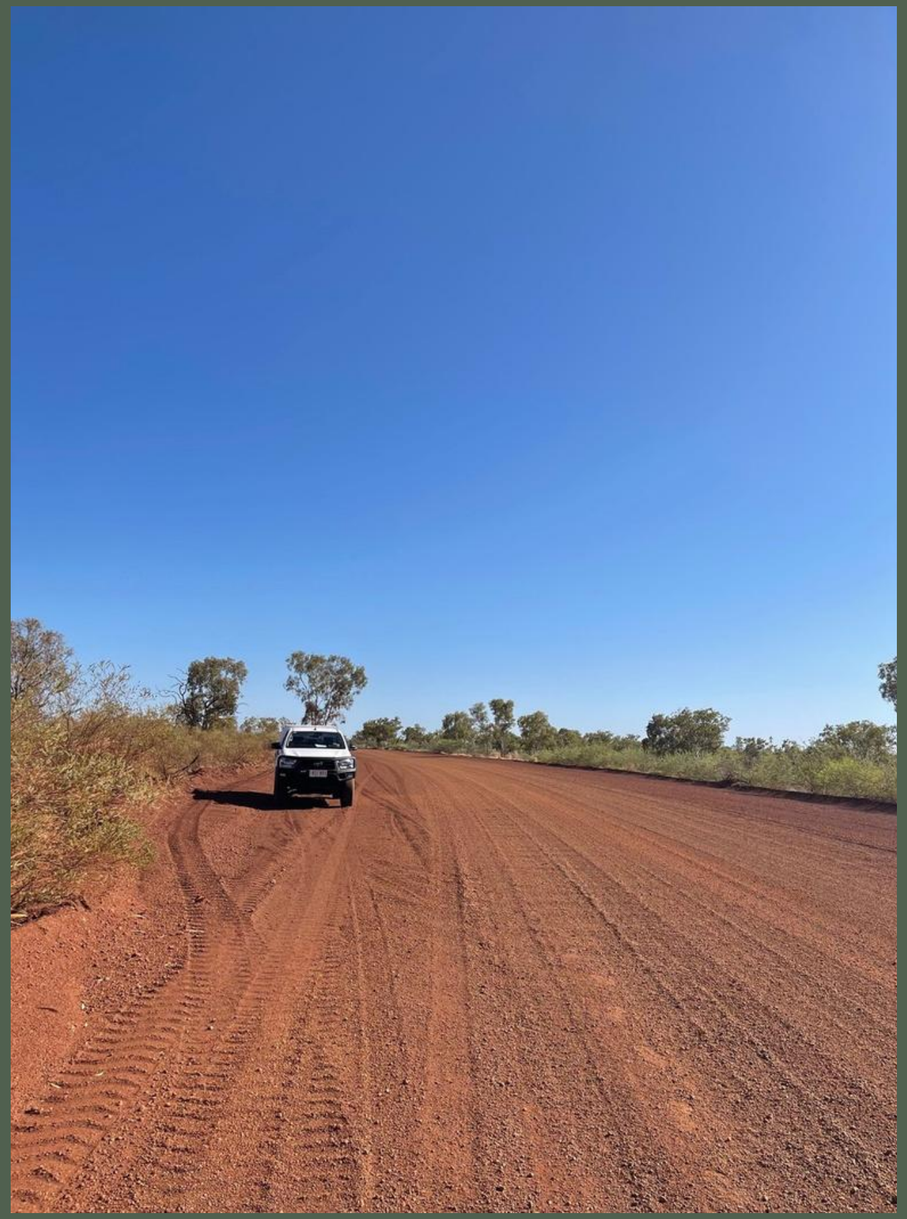
2x remote ACCHOs (+1 urban)

4x remote NT Gov clinics

Getting to Town



Getting to Town



Katherine

1x GP
1x ACCHO (urban)
3x physio private practices
1x SP and OT private practice
3x RACF
1x Community Nurse (wounds)
2x Child and Family Nurses
7x Schools
1x Supermarket

Katherine Hospital (KH)

Katherine Hospital... in March 2026

KH - Challenges

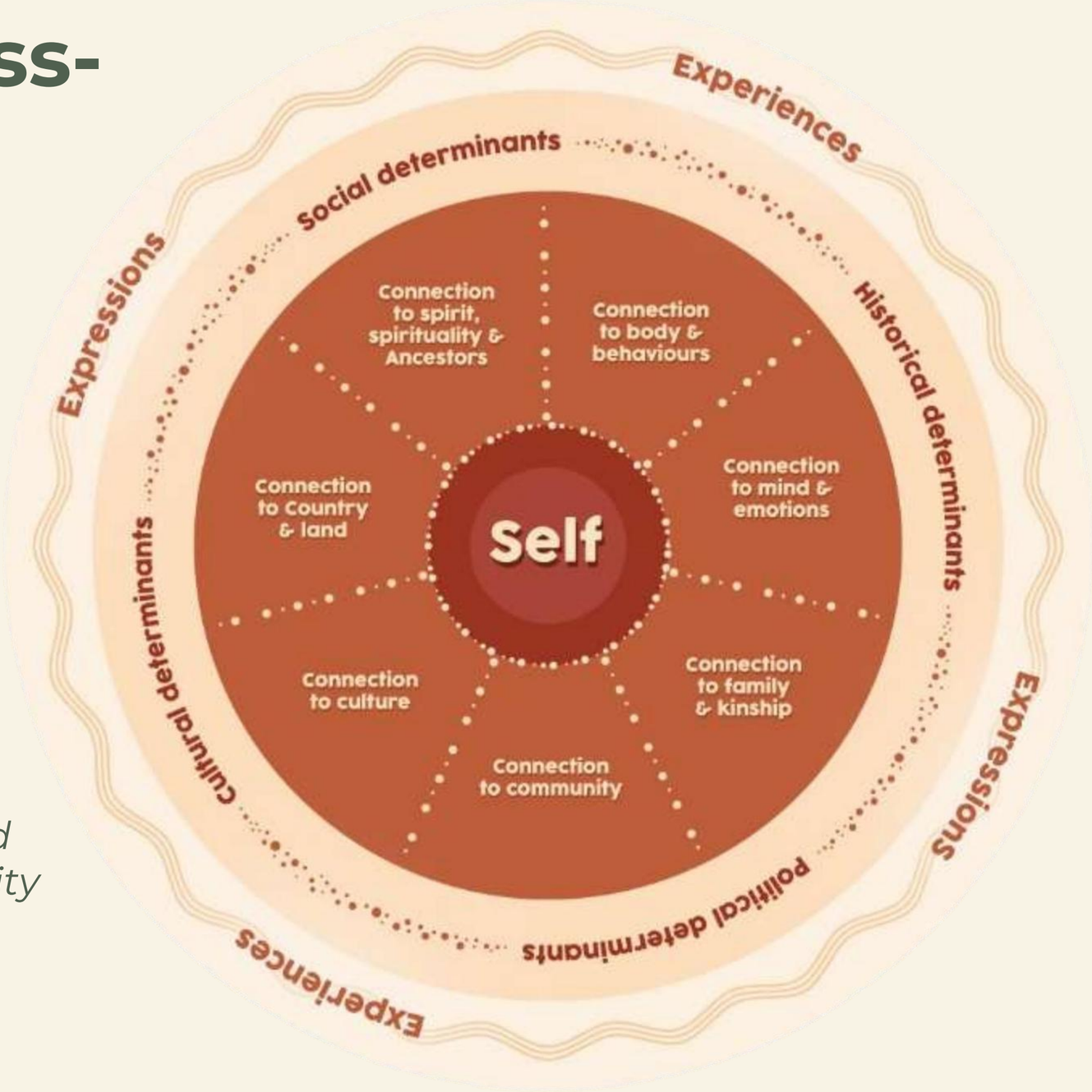
- **Geography** - travel, distance, climate
- **Services** - limited community services, no ‘safety nets’
- **Staffing** - turnover, reliance on agency, investment
- ***System and Resource Gaps cause:***
  - **Communication challenges** - cross-cultural, across services, assumptions
- **Determinants of Health** - social, political, economic, historical

Challenges Cont.: Cross-Cultural Healthcare

Aboriginal Model of Wellbeing

Gee et al., 2014

**This conception of self is grounded within a collectivist perspective that views the self as inseparable from, and embedded within, family and community*



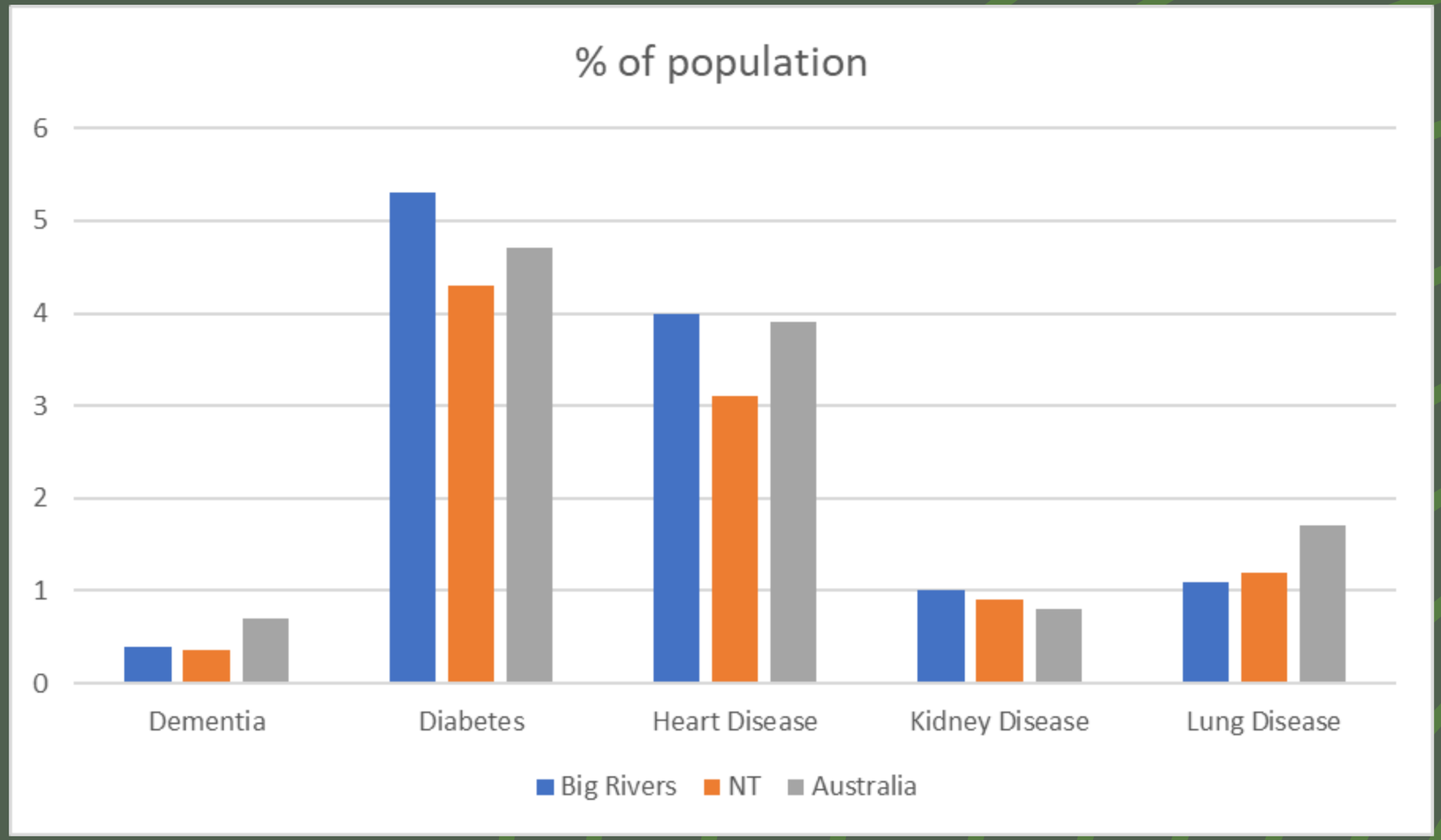
SEWB Diagram adapted from Gee et al., (2014)

2025: Palliative Care Service

“If anybody is sick, they just send them to Katherine or Darwin. That many family who have passed in Katherine Hospital in palliative care. If they send them to Darwin and then they realise there is nothing more they can do—if they are from Beswick, Barunga, Bulman… they bring them to Katherine. That is the closest they can get to their home.”

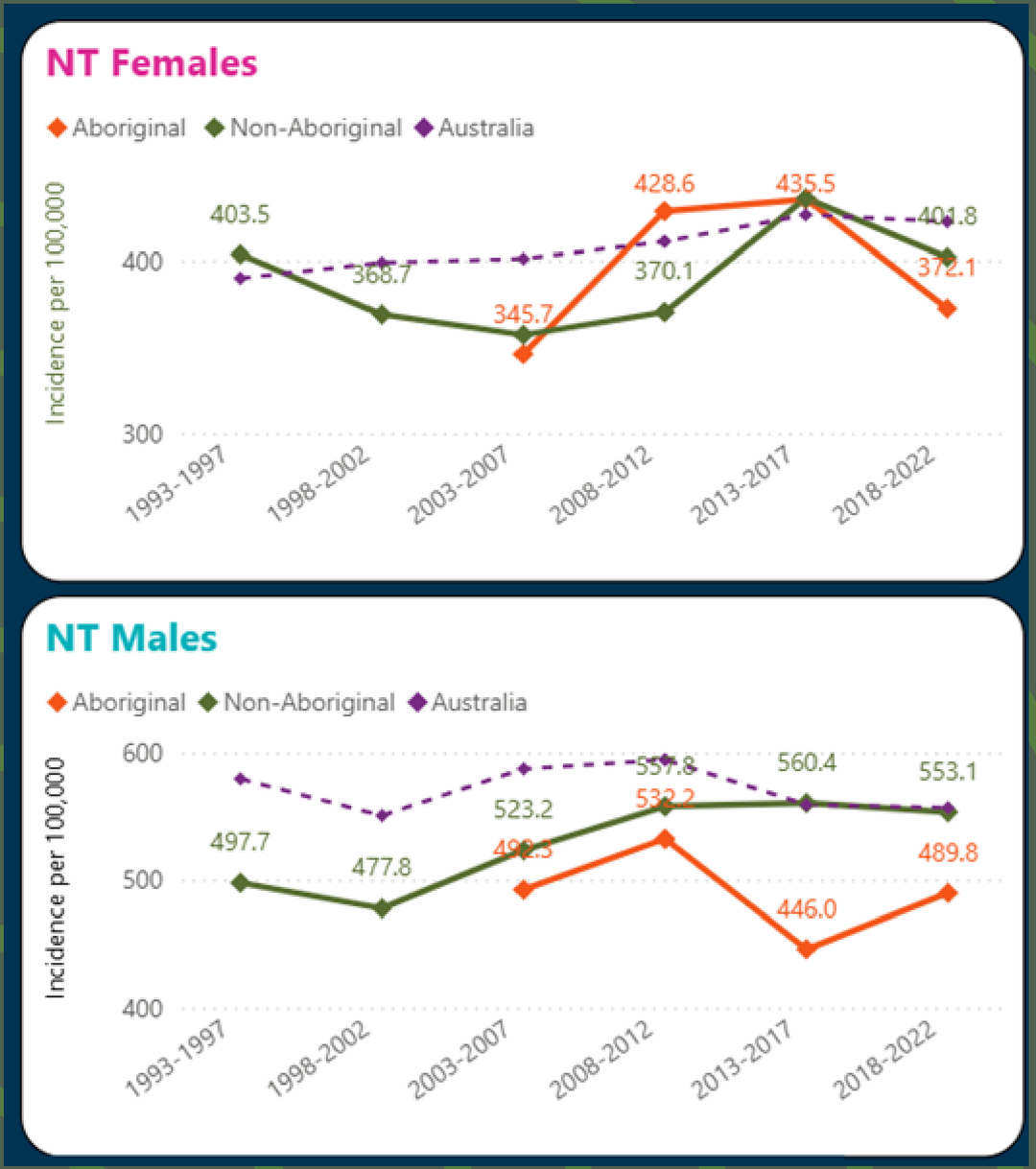
(Legislative Assembly of the Northern Territory, 2025)

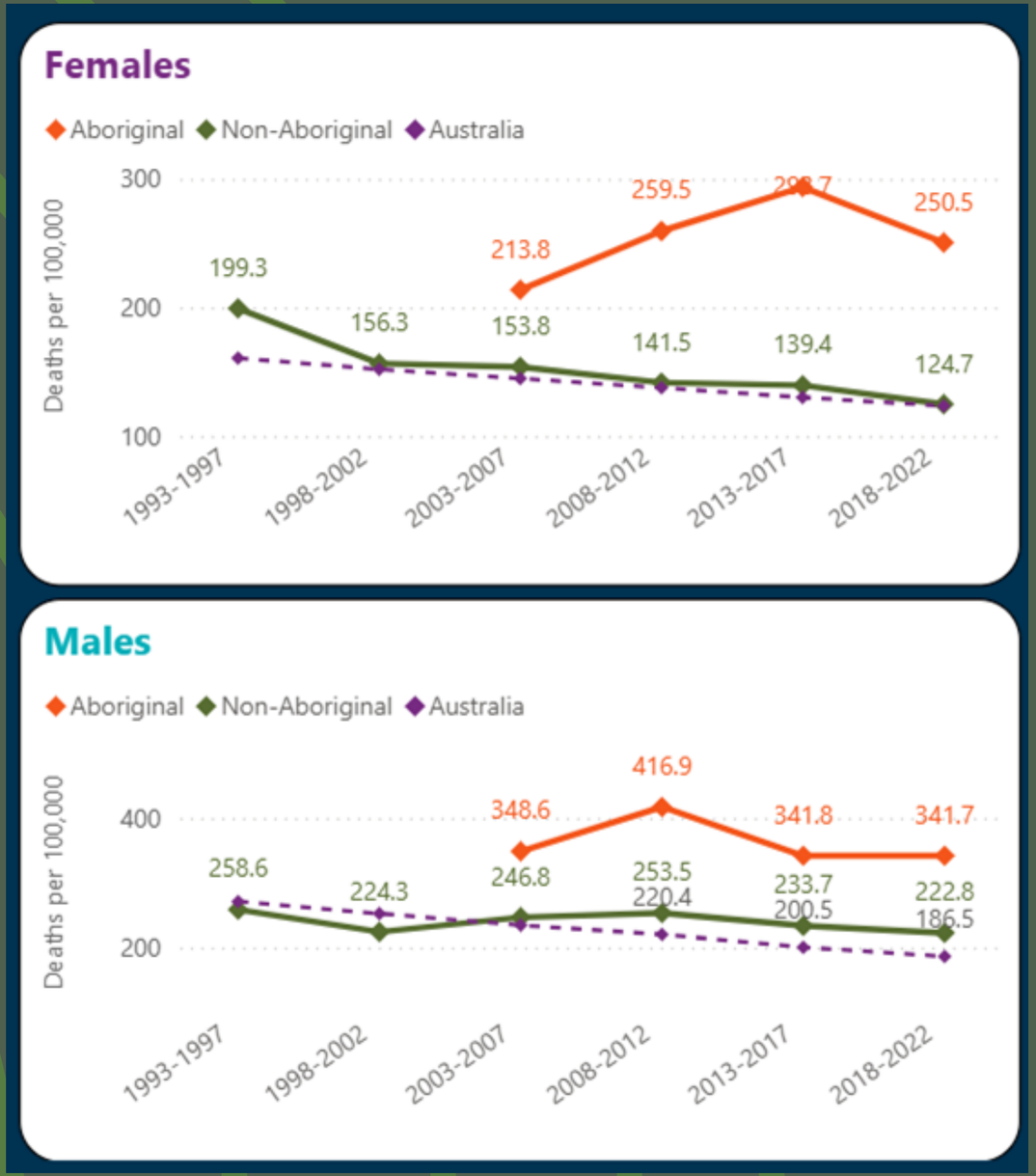
Our Service - Data



Data from Australian Bureau of Statistics Health Conditions Prevalence, 2022

Our Service - Data





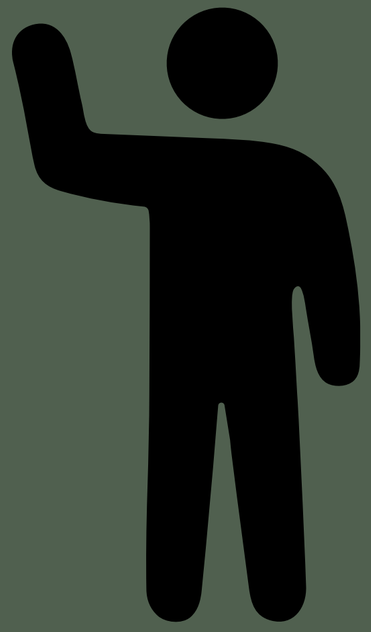
Data from NT Health and Health Roundtable

Our Service - Qualitative Data

- **Health Care Worker (HCW) Knowledge** - staff and community knowledgeable and invested in palliative care, and aware of demographics and needs

- **HCW Confidence** - dependent on relationships and interactions with CNC, and length of time in region

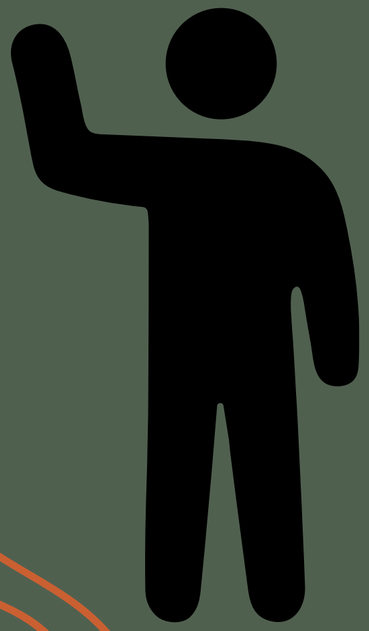
- **HCW Perception of Health System** - gaps in clear and accessible governance, resourcing, timely referral, community palliation and staff wellbeing



Kumanjayi - Wishes

From Advanced Personal Plan in Oct 2023:

- Being with family and being at home in Lajamanu
- Wanted palliative care, but at home only
- Wanted to participate in cultural ceremonies
- Wanted CPR, tube feeding, etc.
- Body to be in Lajamanu



Kumanjayi - Diagnosis

August 2023 - Royal Darwin Hospital

- Ulcerated left lateral tongue SCC with METs above and below diaphragm
- SCC 6 cm with epicentre over oropharyngeal tongue
- Limited chemotherapy

June 2024 - Royal Darwin Hospital

- Emergency tracheostomy for obstruction

July 2024 - Katherine Hospital

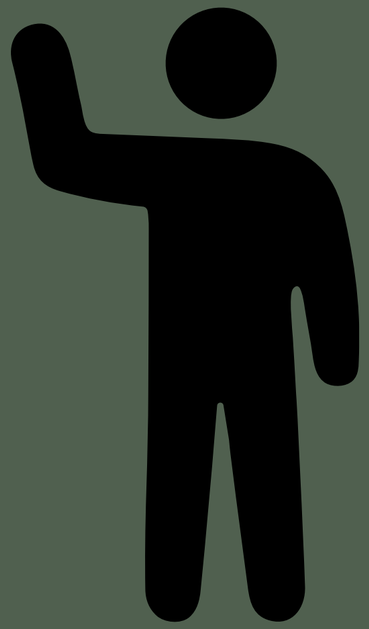
- Transferred to KH, aiming for palliative immunotherapy

What did we have?

- CNC and generalist Speech Path
- Palliative Care bed
- Some consumables
- Relationships

What didn't we have?

- Most consumables
- Relevant and practical guidelines, policies and procedures
- The right family member
- Regular access to the right interpreter
- Skillset across staff
- Specialists
- Pastoral care
- After-hours service
- Community service
- Appropriate AAC
- and so on...



Kumanjayi - Wishes vs Reality

Wish	Outcome
Being with family in Lajamanu	Facetimed family from hospital, saw some family towards the end, and died in PCU
Wanted palliative care at home only	Received Palliative Care in hospital
Wanted to participate in cultural Ceremonies	Unable to
Wanted CPR, tube feeding, etc.	Unable to continue immunotherapy due to bleeds, decided to decline CPR
Body to be in Lajamanu	Body returned to Lajamanu

Strengths - Kumanjayi’s Case

- **Skills and adaptability** - meeting changing needs in changing circumstances
- **Family meetings** - listening, understanding and communicating
- **Advocacy** - for both staff, Kumanjayi, family, community and clinic
- **Time** - dedicated time to sit and *be*, including overtime

Strengths - Our Service

- **Skills and adaptability**
- **Focus on Relationship**
- **Advocacy for all**

“We didn’t want for anything. When we did ask for something, it just happened with no effort… it was easy”

“[interstate was] very hospital-directed. I wouldn’t have even felt I was in a position to ask [for what I needed].”

“Compassion, understanding and empathy at every level”

~mother of palliative care patient

Steps We've Taken

2026

- Care in community for Katherine town
- Strong data

2026

- Guidelines and formal pathways
- Draft Practice Manual

2026

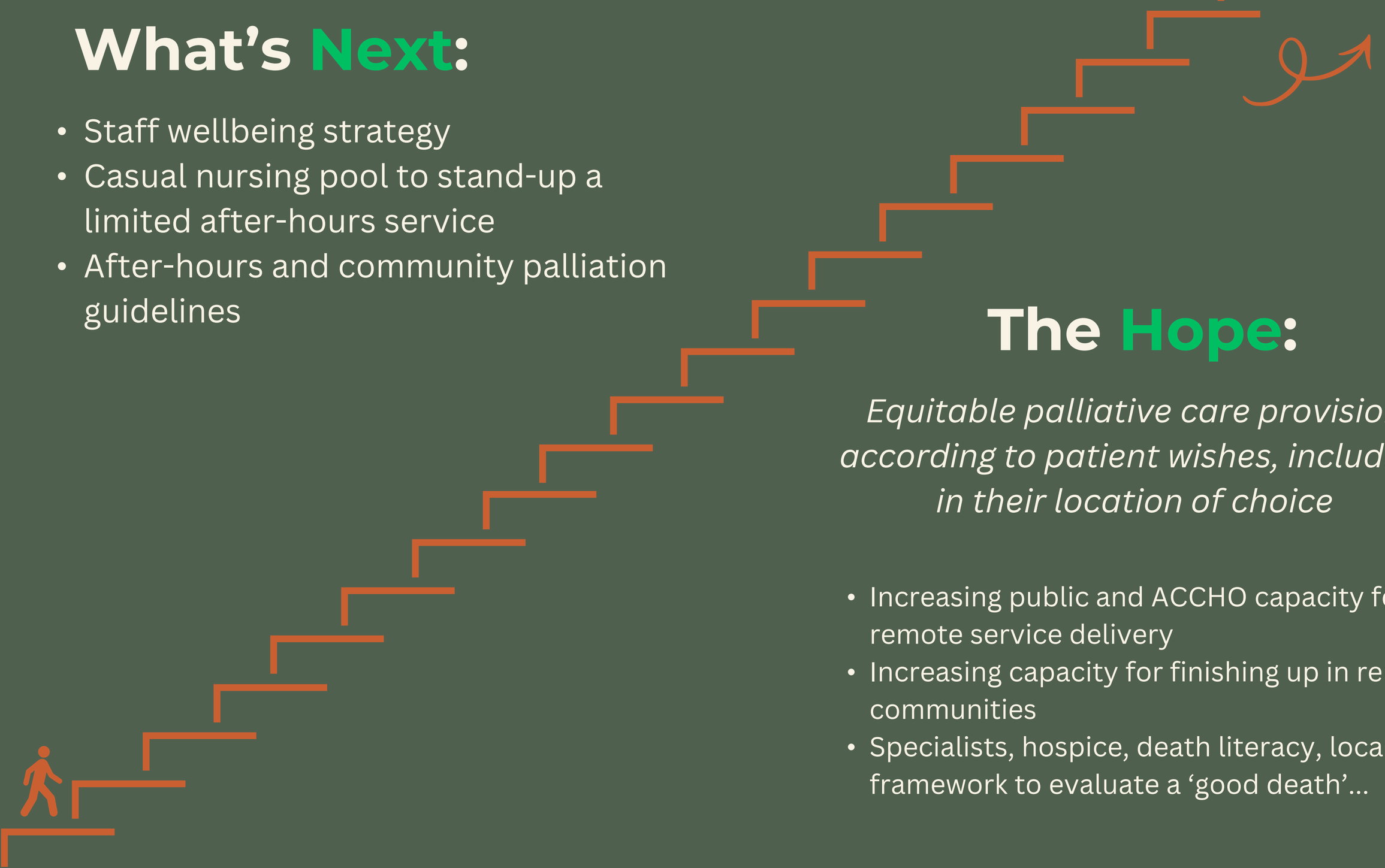
- 1.0 FTE CNC
- 0.4 FTE Rural Generalist Trainee

2021-2025

- ~0.5 FTE CNC
- PCU
- Outpatient service from mid-

What's Next:

- Staff wellbeing strategy
- Casual nursing pool to stand-up a limited after-hours service
- After-hours and community palliation guidelines



The Hope:

Equitable palliative care provision according to patient wishes, including in their location of choice

- Increasing public and ACCHO capacity for remote service delivery
- Increasing capacity for finishing up in remote communities
- Specialists, hospice, death literacy, local framework to evaluate a 'good death'...

What can we all do?

- **Put Relationships First** - understand **yourself** and your patient, and allow your patient to understand **you**
- **Listen and Ask** - acknowledge the authority of patients and families, and the knowledge and skills of the receiving service
- **Review your Governance** - do your documents focus on the patient, their wishes, and relationship-centred culturally responsive care?

Thank You

Questions?

References and Thanks

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