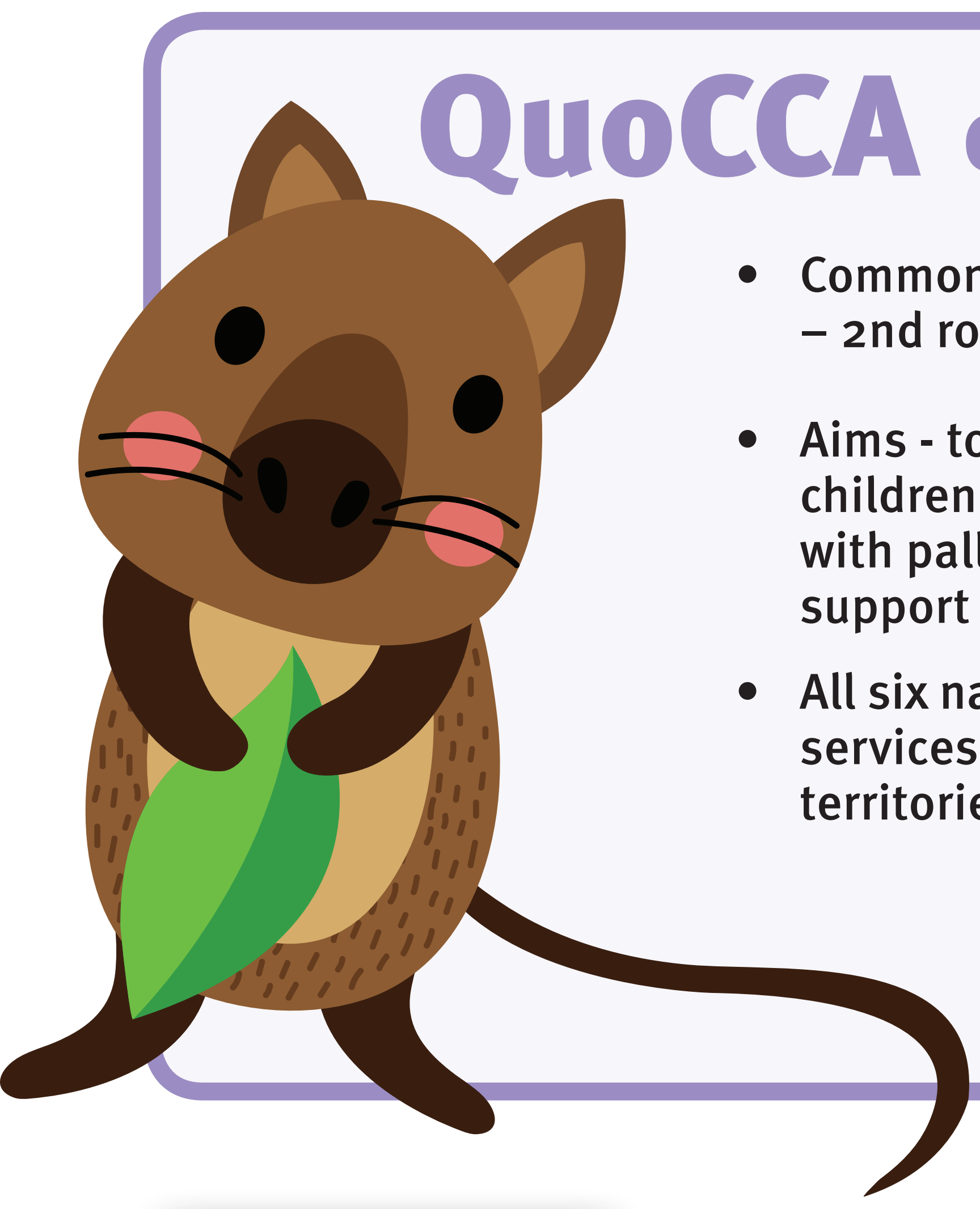
Making a difference

A Pop-up model for Paediatric Palliative Care

Lee-anne Pedersen, Nurse Practitioner. Queensland Children’s Hospital , Brisbane



QuoCCA Quality of Care Collaborative Australia

- Commonwealth Health and Aging grant – 2nd round until mid 2020
- Aims - to improve care provided to infants/ children/teenagers who have a life limiting illness with palliative care needs- focus on education/ support of local teams.
- All six national specialist paediatric palliative care services working together to reach all states and territories
- The project includes pop up and scheduled visits , as well incidental sessions in the teams’ hospitals and community settings
- Reaching indigenous communities, supporting detention centres, visiting rural/ remote, regional and metropolitan locations of all states and territories of Australia
- Results have reported increased confidence for those involved in providing care to children with palliative care needs

What is a pop up?

- A creative way for the specialist paediatric palliative care teams to support local teams
- In time education, peer support, clinical handover/ teaching, co ordinate resources, identify 24 hr support plan for family, strengthen communication strategies and an opportunity for professional growth

How does it work?

- Palliative care team liaise with local teams and care providers
- The QuoCCA team is ‘invited’ to the location
- Discussion with QuoCCA educator, clinical teams , palliative team – logistics and needs

Data to date

	2017-2018	QuoCCA 2
State	**Pop-ups**	**Scheduled**
WA	7	8
SA (Inc NT)	10	15
Vic (Inc Tas)	6	5
Qld (Inc NSW)	19	13
National total	**42**	**41**

Case study

A 12 year old with devastating neurological complication secondary to bone marrow transplant is facing only days of life. Her care needs are very complex with high symptom burden and required extensive skin care.

Family are wanting to be home to country as soon as possible once this have become clear.

Local team is very small rural hospital with minimal resources and limited capacity to care for sick children as an in patient. However the team are keen to support transfer and try to meet families wishes.

Child transferred home via RFDS

The nurse practitioner from the paediatric palliative care team and the bone marrow transplant specialist nurse went ahead to the local destination by commercial flight to meet the RFDS plane carrying the young person.

We all arrived at the hospital and the two QuoCCA staff stayed on site for the three shifts – teaching in real time – the cares, the medications, the palliative care elements, supporting the family as they got to know this team, liaising with the local indigenous elders .

We saw all the staff – even the cook – answered questions, decreased the anxiety , clariid myths, addressed fears , reassured, debriefed, laughed, cried, planned, plotted, charted, and eat great baking.

The QuoCCA team left after 48 hours and drove to the next town to catch a flight home

The family kept a supported bedside vidgil for the next 2 days

Sadly the young one died , very peacefully , surrounded by family

The cultural elders were then able to guide the team post death

Feedback

“Increased confidence to care for these cases.”

“Good discussion and questions about supporting women with incompatible life pregnancies to birth in their home town, and how to support children and their families with LLC.“

“Great to combine the education session with joint home visit.”

“We felt very valued as the city team (PPCS) came to us here, and we felt the local team had our back after that.”

“Learning to go at the families’ pace.”

“Joint family visit on the ward in combination with an education session for staff is fantastic way to do a pop up.”

“Extremely relevant for final semester nursing students doing a rural health unit. Being able to explain the benefits of the QuoCCA project to health care professionals who will be working in rural health was extremely valuable and necessary.”

“They enjoyed the case study - got them thinking everything is not just black/white and how to manage their own personal beliefs when they are different to the family they are caring for.”

“Thank you for coming to see and support us. Face to face at least once is extremely necessary and rewarding.”

“Some practitioners that work in adult Pall care are quite adverse to PPC because of the fear and depth of emotion around the death of a child. After discussion around the topic, this opened many up to considering PPC within the scope of their work.”

“A better of understanding of the behind the scenes support available.“

What now?

- Sustainability
- Creative funding models
- Focus on ‘ pop up ‘ style education and support
- Continued national collaboration
- Write up journal articles

References:

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Acknowledgements to QuoCCA members

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Quality of Care Collaborative Australia
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