A national quality of care collaboration to improve paediatric palliative care outcomes

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Delivering Education in Paediatric Palliative Care

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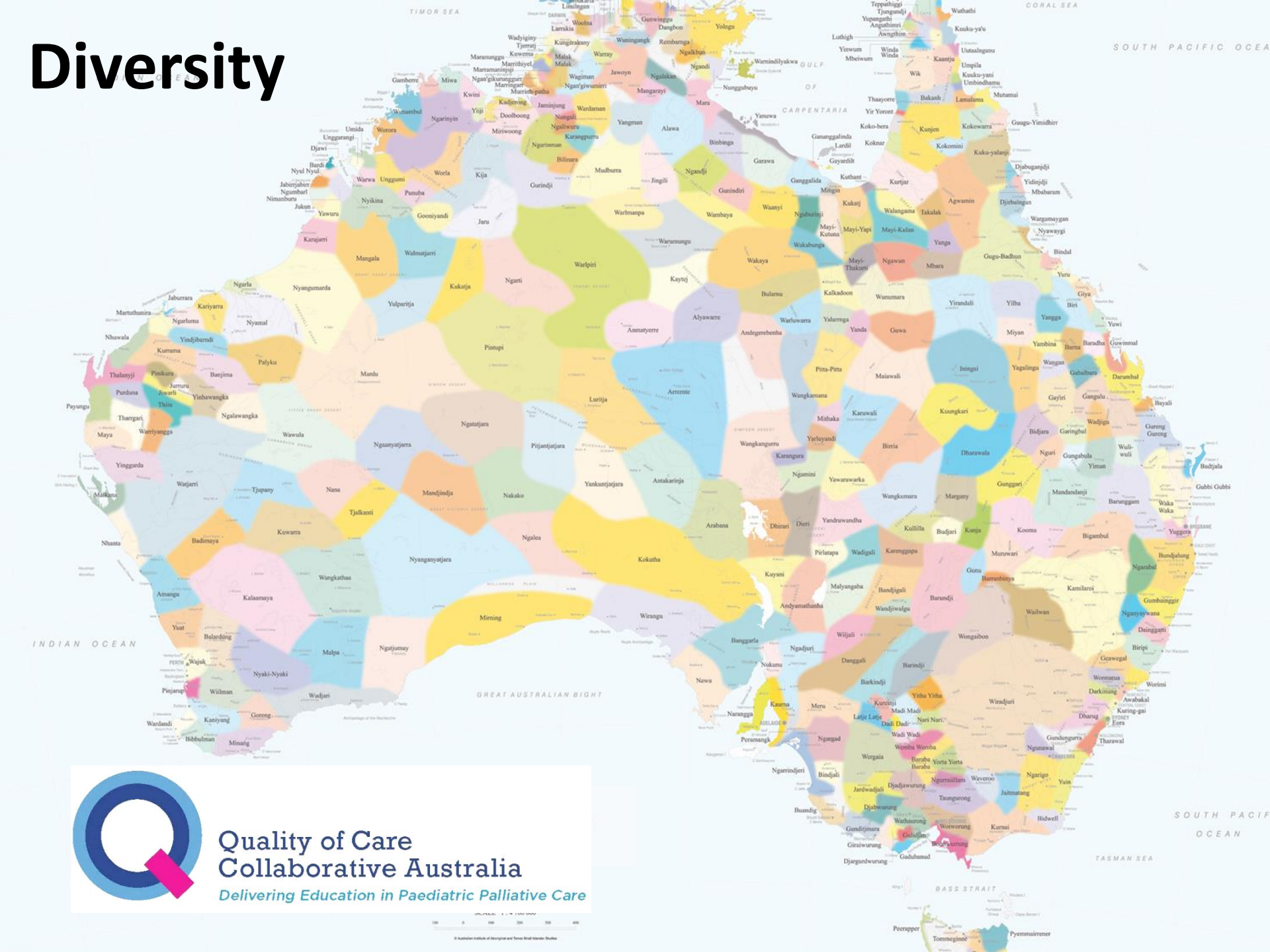
Diversity


TIMOR SEA
CORAL SEA
SOUTH PACIFIC OCEA
GULF OF CARPENTARIA
INDIAN OCEAN
GREAT AUSTRALIAN BIGHT
SOUTH PACIF OCEAN
TASMAN SEA
BASS STRAIT
Gunwinggu
Dangbon
Yolngu
Larrakia
Woolna
Limilngan
Wuthathi
Kuuku-ya'u
Teppathiggi
Tjungundji
Yupungathi
Angathimiri
Awngthim
Luthigh
Ymwum
Mbeiwum
Winda
Uutaalngamu
Umpila
Kuuku-yani
Uenbindhamu
Mutumui
Lamalama
Bakanh
Thaayorre
Yir Yoront
Koko-bera
Kunjen
Kokowarra
Guugu-Yimidhirr
Kokomini
Kuku-yalanji
Djabuganjdji
Yidinjdji
Mbabaram
Djirbalngan
Agwamin
Wargamaygan
Nyawaygi
Bindal
Gugu-Badhun
Yuru
Giya
Biri
Yiwi
Yangga
Yilba
Yirandali
Wunumara
Kalkadoon
Bularnu
Kaytetj
Gawa
Yanda
Yalarrnga
Warluwarra
Andegerebenha
Alyawarre
Anmatyerre
Pintupi
Luritja
Arrernte
Pitta-Pitta
Iningai
Yagalingu
Wangan
Gahalbara
Darumbal
Gayiri
Gangulu
Hayali
Gureng Gureng
Wadjigu
Garingbal
Bidjara
Karuwali
Kuungkari
Mithaka
Wangkamana
Maiawali
Wangkangurru
Yarluyandi
Birria
Karangura
Dharawala
Nguri
Gungabula
Yiman
Wuli-wuli
Badtjala
Gubbi Gubbi
Waka
Barunggam
Mandandanji
Margany
Gunggari
Wangkumara
Ngamini
Yawarawarka
Yankuntjatjara
Antakarinja
Ngaanyatjarra
Pitjantjatjara
Ngatatjara
Mardu
Wawula
Ngalawangka
Tjupany
Nana
Mandjindja
Nakako
Tjalkanti
Kuwarra
Badimaya
Watjarri
Yinggarda
Thargari
Warriyangga
Maya
Payungu
Thiin
Purduna
Jiwarli
Yinhawangka
Thalanyji
Pinikura
Banjima
Kurrama
Yindjibarndi
Nhuwala
Ngarluma
Martuthunira
Jaburrara
Kariyarra
Nyamal
Palyku
Ngarla
Nyangumarda
Yulparitja
Kukatja
Ngarti
Warlpiri
Mangala
Walmatjarri
Karajarri
Jaru
Warlmanpa
Warumungu
Wambaya
Waanyi
Ngaliwurru
Karanggurru
Ngarinman
Bilinara
Mudburra
Jingili
Ngandji
Gurindji
Nyikina
Gooniyandi
Worla
Kija
Warwa
Unggumi
Punuba
Jukun
Yawuru
Nyul Nyul
Bardi
Djawi
Jabirrjabirr
Ngumbarl
Nimanburru
Unggarangi
Umida
Worora
Wunambul
Ngarinyin
Miriwoong
Gamberre
Miwa
Kwini
Yiji
Kadjerong
Doolboong
Jaminjung
Wardaman
Nungali
Yangman
Alawa
Binbinga
Garawa
Ganggalida
Kuthant
Kurtjar
Mitngin
Gunindiri
Kukatj
Ngaliwurru
Mayi-Kutuna
Mayi-Yapi
Mayi-Kaitan
Walangama
Takalak
Wakabunga
Yanga
Mbara
Ngawun
Mayi-Thakurti
Gananggalinda
Lardil
Koknar
Gayardilt
Yaanyuwa
Nunggubuyu
Warnindilyakwa
Wik
Kaantju
Thaayorre
Bakanh
Lamalama
Mutumui

Diversity of Families

Diversity of Children

	As an illness progresses the emphasis gradually shifts from curative to palliative treatment. E.g. cancer
	Highly technical invasive treatments may be used to both prolong life and improve quality of life alongside palliative care, each becoming dominant at different stages of the disease e.g. Duchenne's Muscular Dystrophy or Spinal Muscular Atrophy. (many children diagnosed with Duchenne's survive to adulthood also)
	No cure is possible and care is palliative from the time of diagnosis e.g. Neurodegenerative conditions
	At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation comes e.g. cerebral palsy

Key:
Curative Palliative

NSW PC Programme/ ICPCN

Diversity of Health Professionals

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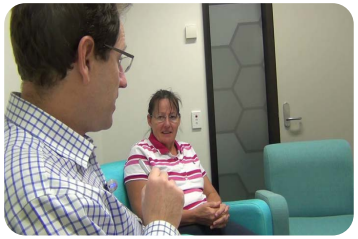
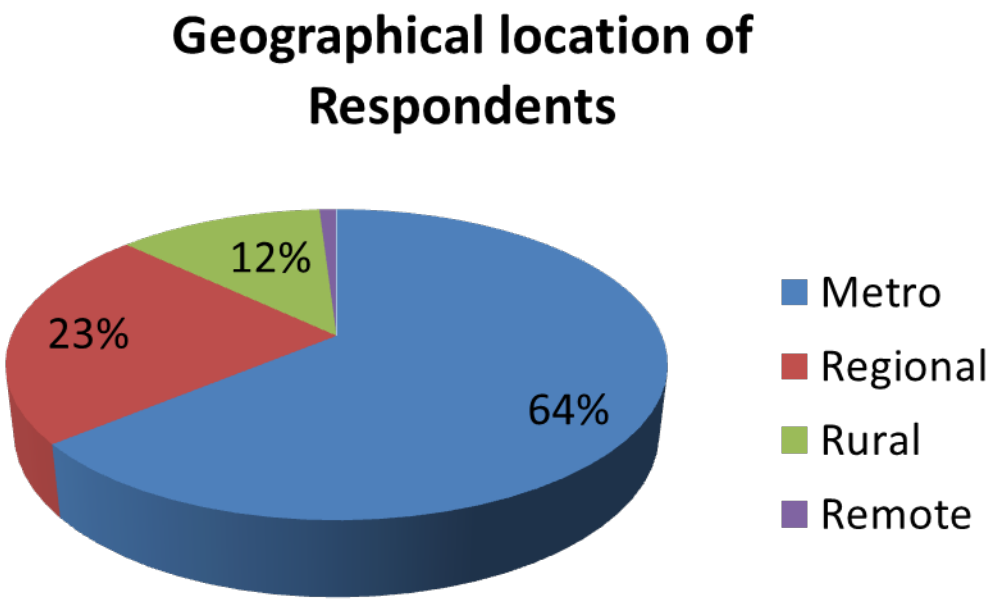
Research Arms



LNA-Baseline	Impacts Pop-up MOC Scheduled Incidental	Perspectives DI Fam-CARE-2

Learning Needs Analysis Data



Profession Type	Responses (%)
Nursing	54%
Allied Health	24.5%
Medical	19%
Aboriginal & Torres Strait Islander Health Practitioner	0.6%

44% described minimal – no experience working in PPC
14% reported no PPC education

Top 12 Identified Learning Needs

1. Preparing families for the death of their child (4.28)
2. Palliative Care resources (4.25)
3. Management of the dying child (4.16)
4. Communication skills (4.14)
5. Pain management (4.14)
6. Other symptom mx (4.12)
7. Bereavement Care (4.02)
8. Emotional Supports (4.02)
9. Practical support (4)
10. Grief and loss (3.95)
11. Self-care (3.87)
12. Management of Non-Oncology cases (3.86)

Challenges

Communication

Who, what, where, when, why & how??

*Knowing the **language** to speak - **being able to ask** the questions required without being insensitive I guess. As this area is very new to me I am finding it **difficult** to know exactly **how much to say/what to say/what not to say**!*

Clinical Nurse, less than two years experience of PPC

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Uniqueness of each child and family

*I would like to think **every child and their families** are **unique** in every way. There lies the challenge. Every child and their families are in a position **of our own worst nightmare**. Challenges include emotions of the child and his family which **change daily**. The challenge for me would be to **try to tune in as much as possible** to better understand what is happening on that day at that time.*

Clinical Nurse Team Leader, 6-10 years of PPC

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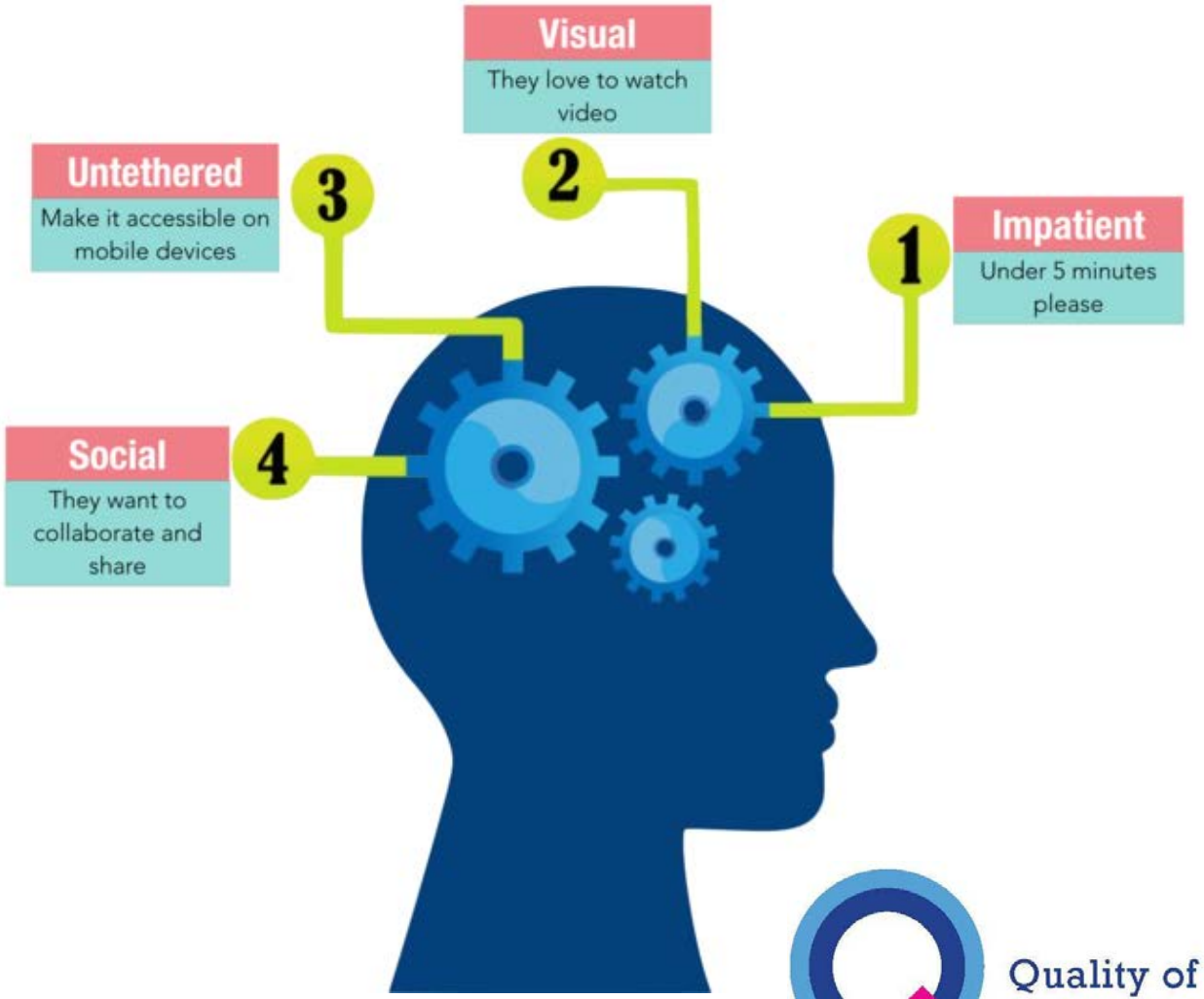
Modern Learner



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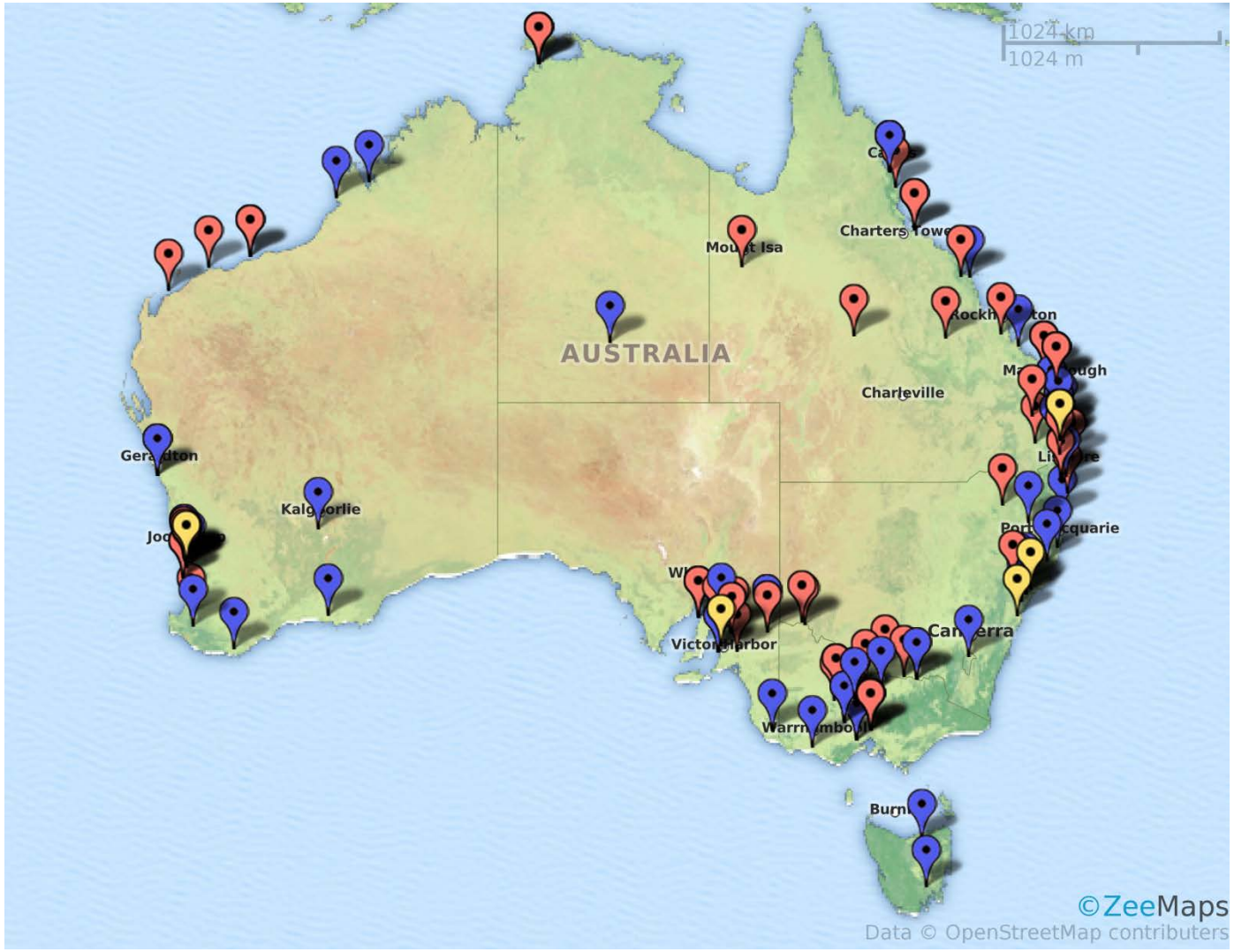
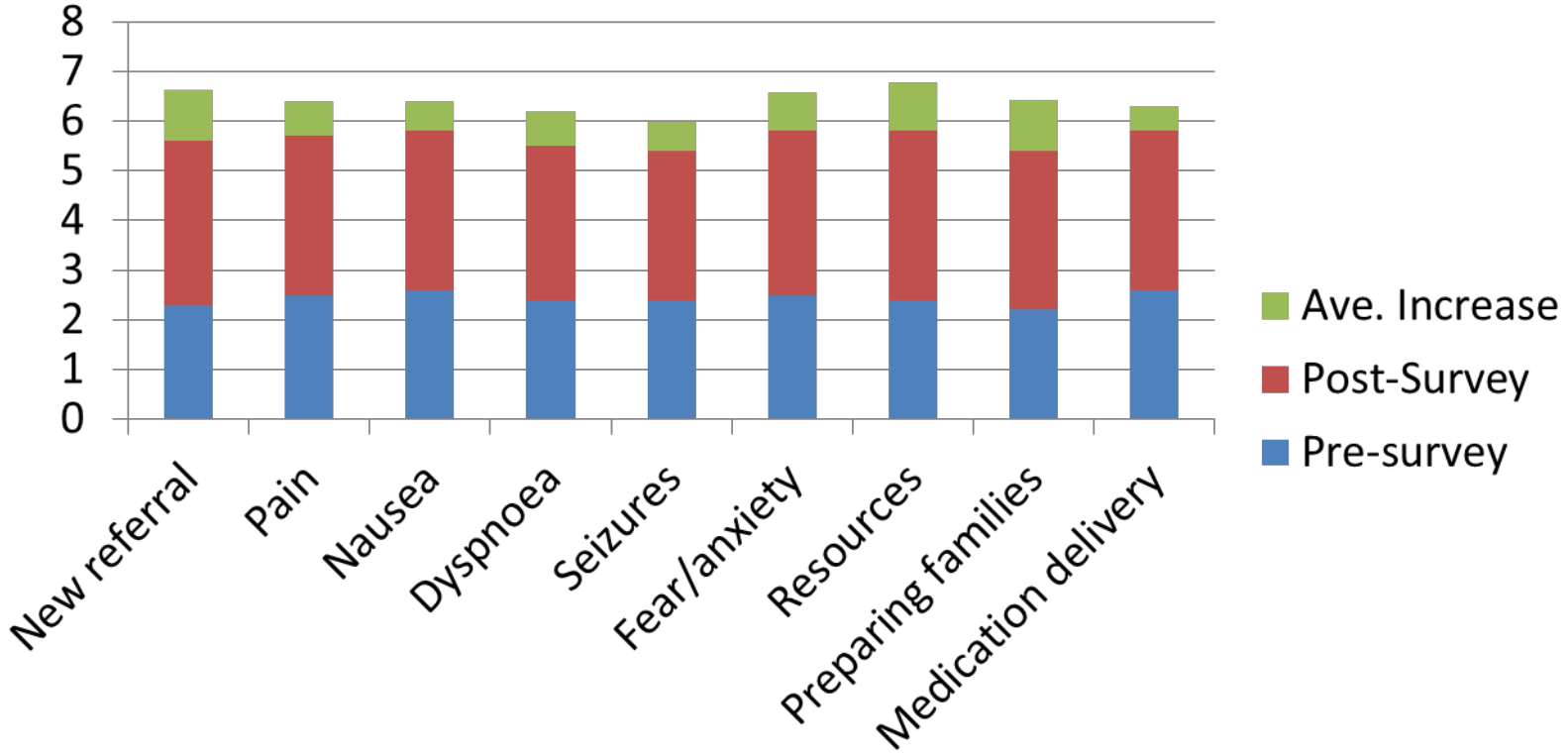
QuoCCA Impacts



Average Responses- paired surveys (n= 504)



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Comments in surveys – what participants learnt

- **Fantastic overview** of the holistic care given for paediatric pall care & excellent tools in communicating with families & patients, so as to **empowe**r them in their choices

- **Importance of self care & formal and informal approaches**. Approach to **personal grief versus professional behaviour.**

- I really enjoyed the **communication** component & case studies, real life experience & discussion, on the **importance of reflection & having an authentic relationship**

- **Increased confidence with awareness of PPCS** & **collaborative** role of medical, nursing and allied health

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Lessons Learnt

- Ethics processes
- On-line access
- Cultural appropriateness

- Pop-up model
- Flexible, MDT & interactive workshops

Future Plans

- Data collection & analysis - Consumers
- CareSearch/QuoCCA website release
  www.Caresearch.com.au
- Continued collaborations with other projects/organisations:
  PEPA, PCC4U, RedKite, universities and PPC networks

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QuoCCA Collaborators & Educators

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Thank-You

Metamorphosis: Judy Prosser