

# Assessing Local Needs

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**2<sup>nd</sup> Congress on Paediatric Palliative Care**

**A Global Gathering**



# Outline

- A global prospective
- Local prospective: New South Wales (NSW), Australia
- Case studies
- Summary

# What is the need?

- Around the world



Paediatric palliative care service provision challenges vary in different parts of the world

# What do we know?

*Pediatr Blood Cancer* 2011;57:361–368

## REVIEW

### Pediatric Palliative Care Provision Around the World: A Systematic Review

Caprice Knapp, PhD,<sup>1\*</sup> Lindsey Woodworth, BBA,<sup>1</sup> Michael Wright, PhD,<sup>2</sup> Julia Downing, MD,<sup>3</sup>  
Ross Drake, MD,<sup>4</sup> Sue Fowler-Kerry, PhD,<sup>5</sup> Richard Hain, MD,<sup>6</sup> and Joan Marston<sup>7</sup>

Pediatric palliative care is recommended by many organizations. Yet, there is no information available on the progress that has been made in providing this care or the gaps that still exist in provision around the world. We conducted a systematic review to address this gap in knowledge. The systematic review identified 117 peer-reviewed and non-peer reviewed resources. Based on this information, each country was assigned a level of provision; 65.6% of

countries had no known activities, 18.8% had capacity building activities, 9.9% had localized provision, and 5.7% had provision that was reaching mainstream providers. Understanding the geographic distribution in the level of provision is crucial for policy makers and funders. *Pediatr Blood Cancer* 2011;57:361–368.

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**Key words:** international; palliative care; pediatrics; provision; systematic review

~66% of countries have no known paediatric hospice-palliative care activity

5.7% of countries have integrated paediatric palliative care with mainstream service providers.

**Assessment of the Need for Palliative Care for Children**  
**Three Country Report: South Africa, Kenya and Zimbabwe**



November 2013



# The NSW Paediatric Palliative Care (PPC) Programme

To provide equitable access to specialist paediatric palliative care for every child in NSW and their family



# NSW Paediatric Palliative Care Programme

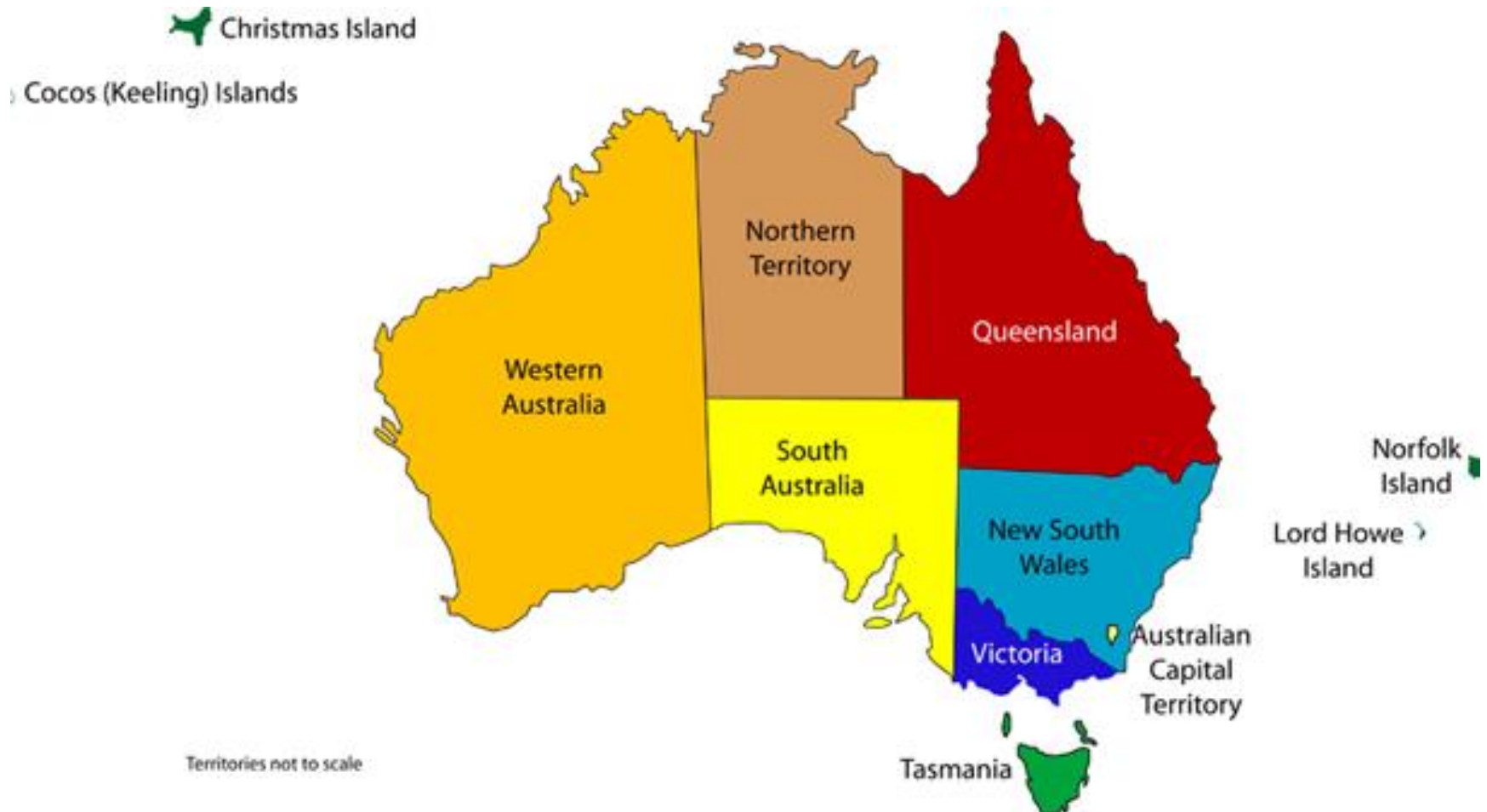
## Aim

to develop an improved model of care that identified enhanced care pathways for palliative care patients and their families

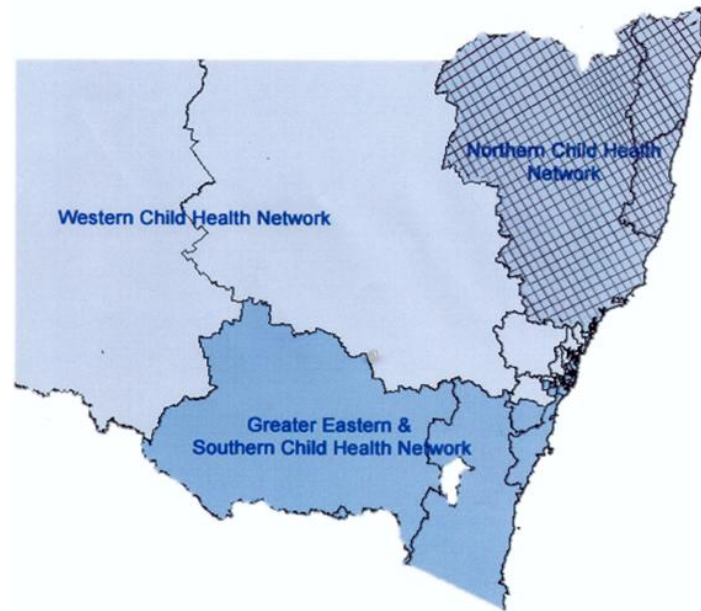




# The new models of care support local, rural, regional areas through POP UP Interventions



# Barriers to Accessing Specialist PPC in NSW





NSW Paediatric Palliative  
Care Programme

the  
children's  
hospital at Westmead



SYDNEY  
CHILDREN'S  
HOSPITAL  
RANDWICK



## NSW PPC Multidisciplinary Teams

- Medical
- Nursing
- Allied Health
  - Social Work
  - Occupational Therapy
  - Psychologist\*
  - Physiotherapy
  - Play therapist\*
  - Bereavement Co-ordinator
- Volunteer Co-ordinator
- Administrative Support



# The New Models of Care

- Pop Up interventions
- Education and In-Time training
- Tele-health (e.g. iPad technology, utilising videoconferencing equipment)



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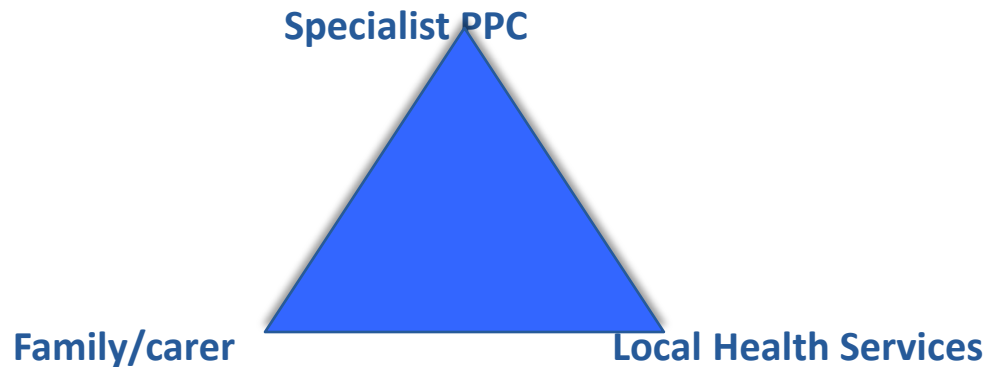
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RANDWICK



Kaleidoscope  
HUNTER CHILDREN'S HEALTH NETWORK

# The Pop Up Model of Care

- Specific intervention for care over & above care usually provided for a child & family
- Occurs when the specialist PPC service is building capacity within a child & family's local community & creating a paediatric network between the following triad:





NSW Paediatric Palliative  
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Hospitals Network



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# In time training

Is defined as specific, high level training around:

- Symptom management
- End of life care
- Physical aspects of patient care according to individualised need and diagnosis
- Psychosocial aspects of paediatric palliative care

# CASE STUDIES

## Palliative Care Pop Up Interventions



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the  
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## Case Study 1:

- 5 yr. boy with Menkes syndrome lives ~120km from Sydney.
- Other medical problems: - profound global developmental delay, seizures, severe gastroesophageal reflux, gastrostomy fed, recurrent urinary tract infection, and obstructive sleep apnoea.
- Staff: CHW- Clinical nurse consultant, palliative care fellow, Physiotherapist (PT), Occupational Therapist (OT). Local - Paediatrician, Paediatric Unit Nurse Manager
- Patient and family
- Reason: MDT review for symptom management and link to local services .
- Nature: face to face
- Outcome



## Case Study 2:

- 7 year old Pelizaeus-Merzbacher disease from ~ 280km from Sydney.
- Other medical problems: Refractory epilepsy, movement disorder, severe developmental delay, Sensorineural deafness, cortical blindness, feeding problems
- Staff CHW: Clinical Nurse Consultant, Staff Specialist, Physiotherapist (PT), Occupational Therapist (OT)
- Patient and parents
- Reason: Symptom management and equipment review
- Nature: Videoconference
- Outcome

## What do the health care providers need from Specialist PPC?

- **Patient related service provision/support**
  - Multidisciplinary management plans
  - Symptom management plans
  - Detailed medication information (e.g. supply, dosing & delivery techniques)
  - Access to clinical support/advice
- **Education/resources with a multidisciplinary focus**



# Achievements of the NSW PPC Programme

- Resource development (Brochures/Factsheets)
- NSW PPC Bereavement Model of Care
- NSW PPC Programme website (Collaboratively with Care Search)  
<http://www.nswppcprogramme.com.au/>
- Mapping of NSW PPC equipment services\*
- Minimum Data Set developed for intake and referrals\*
- Development of PPC education modules in progress
- Medical NSW PPC after hours on call service
- Review of PPC pharmacy services
- Tele-health working group
- NSW PPC Consumer Engagement group



# Impact on patients

The NSW PPCP is assisting health professionals to identify and address any problems patients have with:

- Health system and information (e.g. information, access to services, resources, treatment centre environment)
- Patient care and support (e.g. choice of specialist & hospital, reassurance, prompt attention to needs).
- Identifying and addressing issues as they arise



# Impact on Service Utilisation and Referral

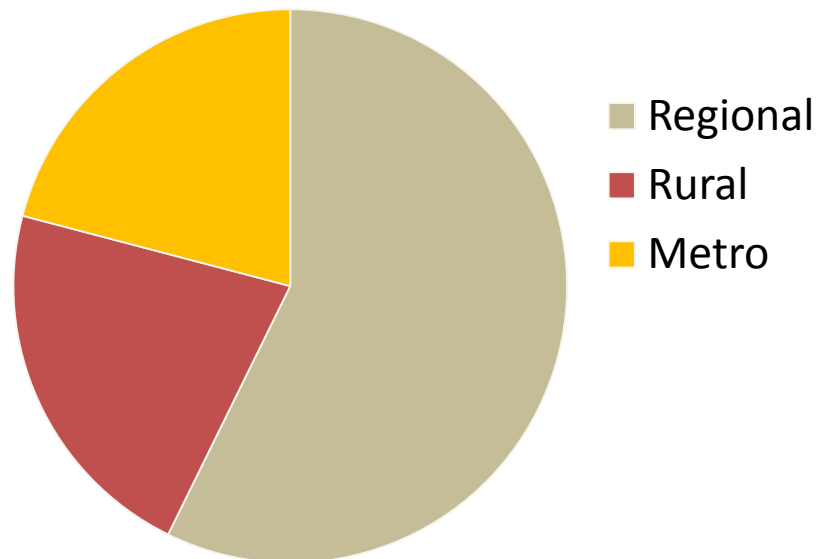
- Assisting busy clinicians to efficiently identify issues of concern, particularly in areas that are not routinely well addressed such as psychosocial issues.
- Our involvement does not create additional burden in terms of consultation length.

# Progress

## April to September 2014

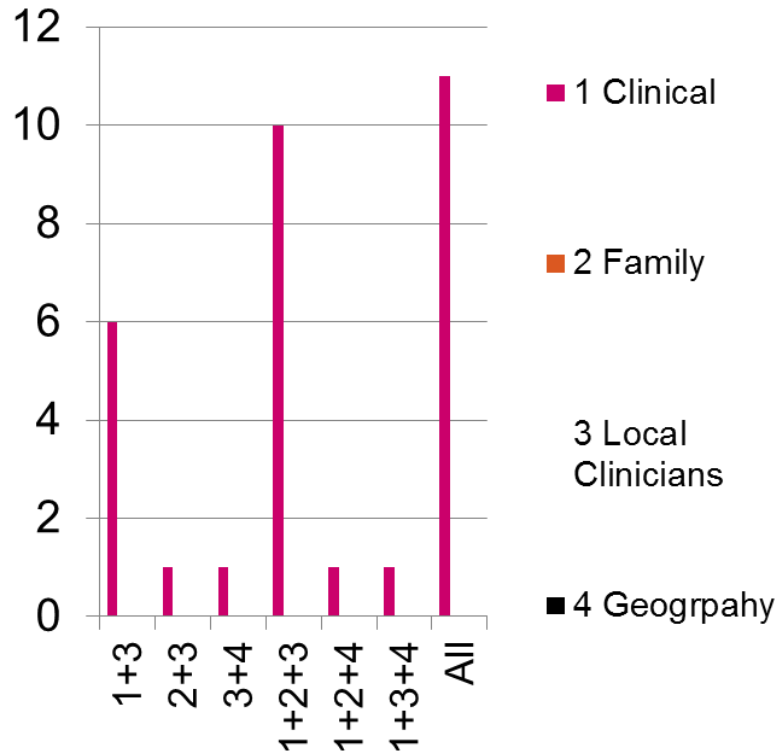
- 79 new referrals
- 31 Pop up interventions
- 31 In time training

## POP UP Interventions

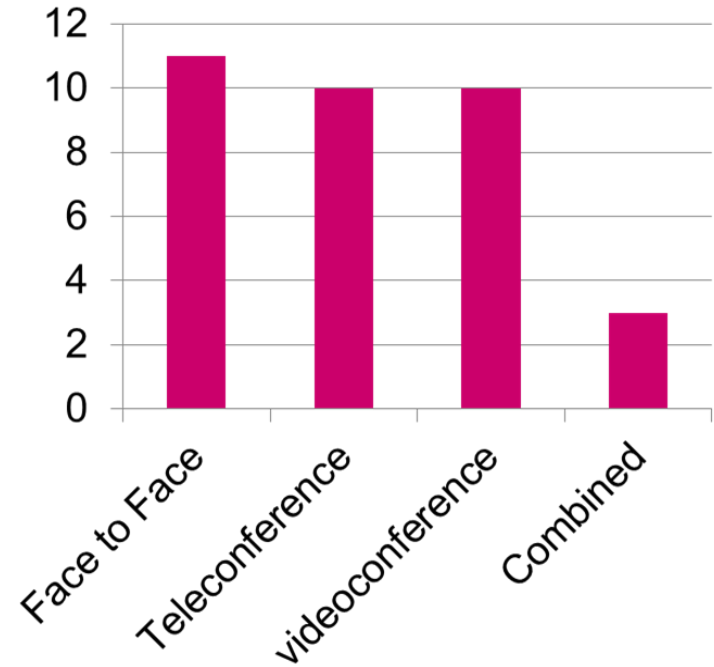


# Pop Up Interventions

## Pop Up triage



## Modality of training





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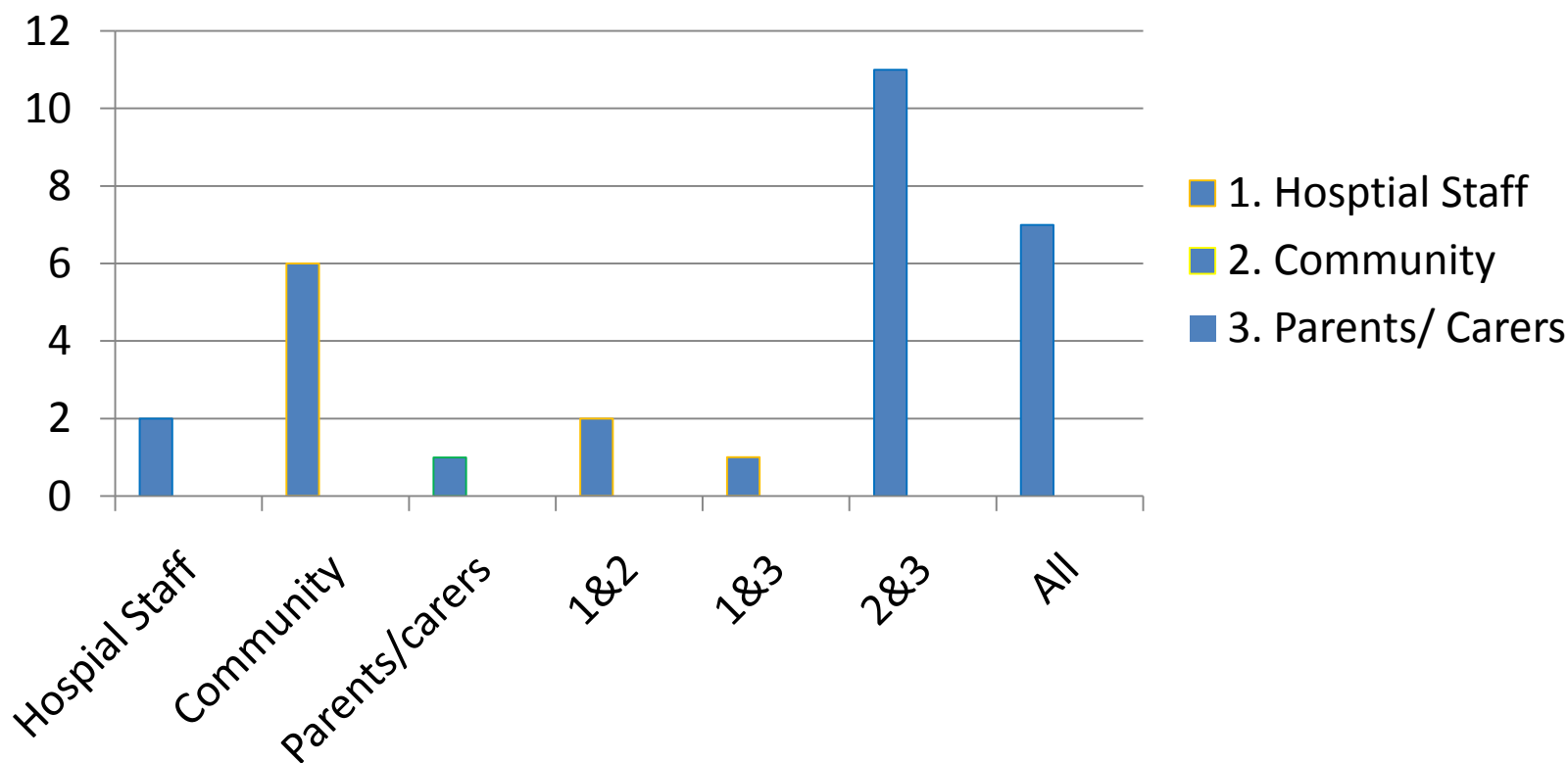
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# In Time Training







# Summary

- Assessing local palliative care needs is essential for the advancement and improvement of paediatric palliative care
- Education remains an integral part in disseminating the need for palliative care in children
- Barriers can be addressed by adapting new models of care and working collaboratively as discussed.



# Acknowledgements

- A/Prof John Collins: CHW Department Head, for his leadership and guidance for the development of the NSWPPC Programme
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*Thank you!*