

# **Creating innovative partnerships: establishing Paediatric Palliative Care in a geographically challenging area**

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# PPC in Australia

	<i>Paediatric Hospice</i>	<i>Shared care with adult PC</i>	<i>Rural outreach by PPC</i>	<i>Home-based care</i>	<i>All diagnoses catered for</i>
<b>QLD</b>	<b>X</b>	✓	TeleHealth	✓	<b>X</b> *
<b>NSW</b>	✓	✓	Some	✓	✓
<b>ACT</b>	<b>X</b>	✓	N/A	✓	<b>X</b>
<b>VIC</b>	✓	✓	✓	✓	✓
<b>TAS</b>	<b>X</b>	✓	<b>X</b>	✓	<b>X</b>
<b>SA</b>	<b>X</b>	✓	✓	✓	✓
<b>NT</b>	<b>X</b>	✓	Limited	Limited	<b>X</b>
<b>WA</b>	<b>X</b>	✓	✓	✓	✓

# Differences between Adult and Paediatric Palliative Care

- smaller patient numbers
- diversity of childhood conditions
  - rare diagnoses
  - genetic components (*siblings may be affected*)
  - 30-40% cancer / 60-70% non-cancer (*vs adult 80-90% cancer*)
- developmental issues (*ages and stages*)
- child-specific issues (*pharmacokinetics, drug licensing*)
- ethical and legal differences (*legal minor, parental decision making*)
- unclear transition from curative to palliative care
- parents preference for children to be at home
- impact of loss and grief on parents/siblings
- the impact of childhood death on communities

# Western Australia

- Area = 2.5 million km<sup>2</sup>  
30% mainland Australia
- Population = 2.5 million  
20% are 0-14yrs  
75% live in greater Perth

● = PPC patients  
(Non-oncology)



# Paediatric Palliative Care, WA

- State-wide service, liaising with services local to each patient
- Increased focus on non-oncology population
- Partnerships with parents, agencies and healthcare providers

# Funding

## 2008

- WA Cancer & Palliative Care Network
  - Federal funding to support paediatric PC
  - Project Worker (0.5 EFT)
- Charitable funds (PMH)
  - Staff
    - Clinical Nurse Consultant (1 EFT)
    - Medical Consultant (1 session/week)

## 2009 (July)

- WA Government Funding
  - Education/Equipment
  - Special Funds
  - Staff:
    - Clinical Nurse Consultants (1.3 EFT)
    - Medical Consultant (2 sessions/week)
    - Social Worker (0.4 EFT)
    - Clinical Psychologist (0.2 EFT)

# Non-oncology diagnoses

- **Perinatal**
  - congenital anomalies
  - complications of prematurity
  - birth asphyxia/HIE
- **Neurological**
  - neurodegenerative (Batten disease)
  - neuromuscular (muscular dystrophies, SMA)
  - Cerebral Palsy
- **Organ failure**
  - liver, heart, renal
- **Progressive metabolic disorders**
  - Hurler's, Niemann-Pick, Krabbe, Tay-Sachs
- **Chromosomal abnormalities**
  - Trisomy 13
  - Trisomy 18
- **Congenital anomalies**
  - cardiac, spina bifida, CNS, gastrointestinal, pulmonary
- **Respiratory**
  - Cystic Fibrosis, Bronchopulmonary Dysplasia
- **Infections**
  - HIV, TB

# Variable trajectories in non-oncology conditions

- May have periods of good health or plateau at a stable state
- May have many *near-death* episodes then stabilise
- May have slow deterioration with acute final stage

***This variability and uncertain prognosis leads to reluctance to refer to PPC programs***



# PPC Referral Criteria

Life-limiting Illness (LLI) / non-curative condition

**AND/OR**

Death in next 12 months would not be unexpected

**AND/OR**

DNR order in place

***ANYONE CAN REFER***

***No families have declined referral to PPC***

# PPC offers

- **24-hour phone support**
- **Care coordination**
- Assistance with decision-making
- Case meetings
- Practical support – equipment, respite etc
- Care plans
- End-Of-Life planning
- Bereavement support

# Care plans

- PPC care plans
- DNR/AND documentation
- Symptom management plans
- EOL plans

Increased staff satisfaction:

*“We knew what to do as there was clear documentation”*

# PPC - the first 14 months

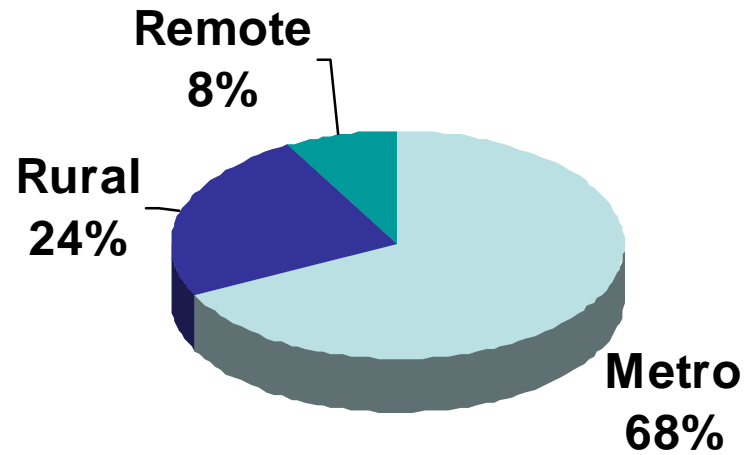
- 37 referrals
  - 3 families with 2 children affected
  - Most children are non-verbal (including infants) with significant medical co-morbidities and/or disabilities
  - Average 10 week stay with PPC  
(Range: 1/7 - 12/12)
- 9 terminal at referral
  - 17 deaths



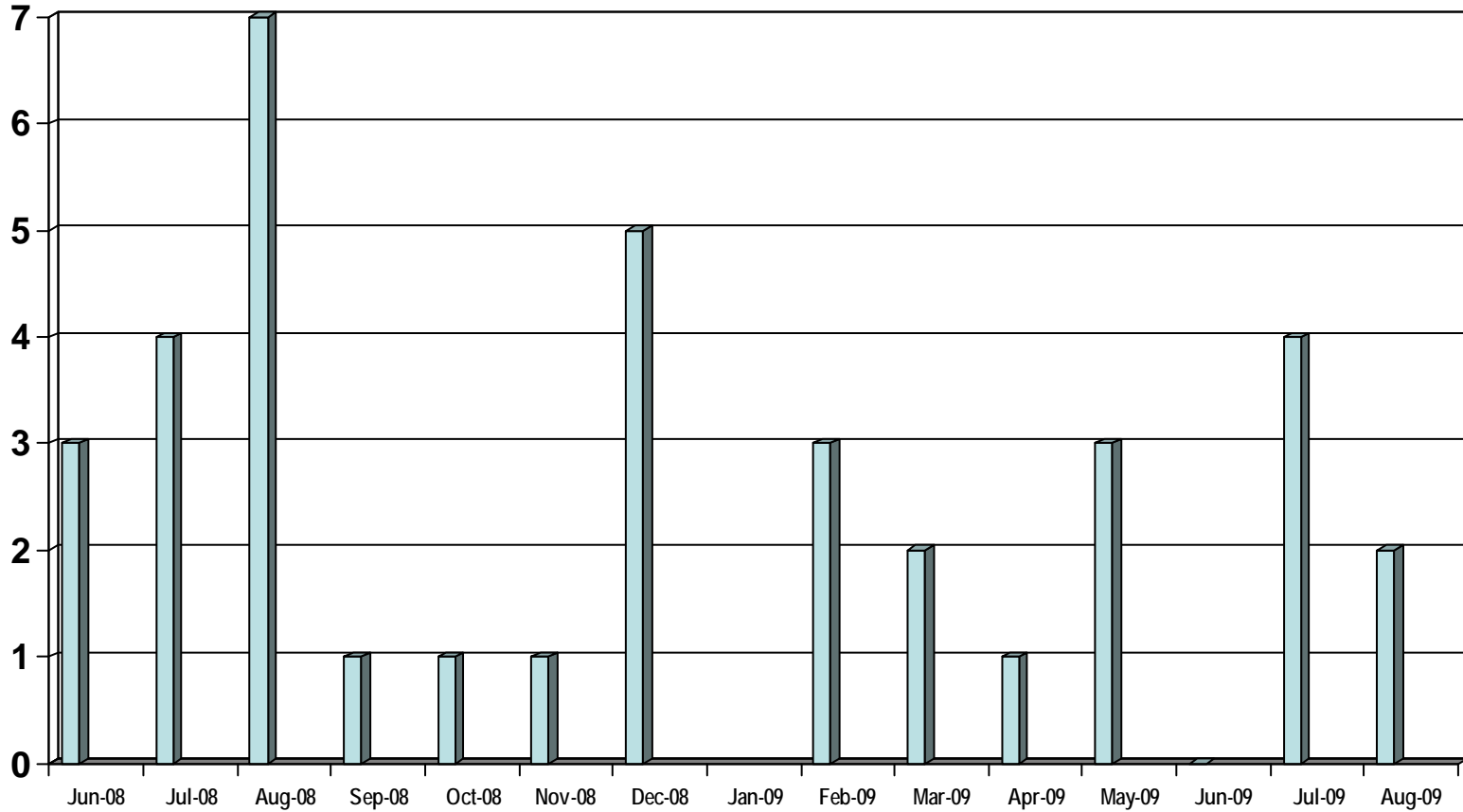
# PPC referrals

	Neurological	Metabolic / Chromosome	Organ failure	Neonatal	TOTAL
Subtotal	19	3	3	12	<b>37</b>
Alive	14	1	3	2	<b>20</b>
Deceased	5	2	0	10	<b>17</b>
Discharged	4	0	0	0	<b>4</b>
Male	7	1	2	6	<b>16</b>
Female	12	2	1	6	<b>21</b>
Aboriginal/TSI	1	0	1	2	<b>(4)</b>
Age at referral	2mo - 16yr	4yr - 13yr	8mo - 16yr	2d - 6mo	

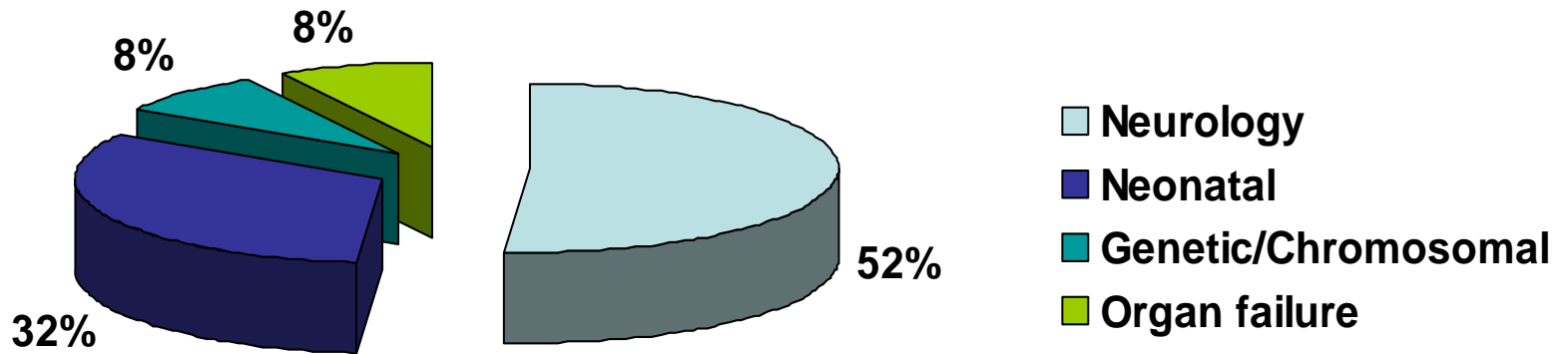
# Location of patients



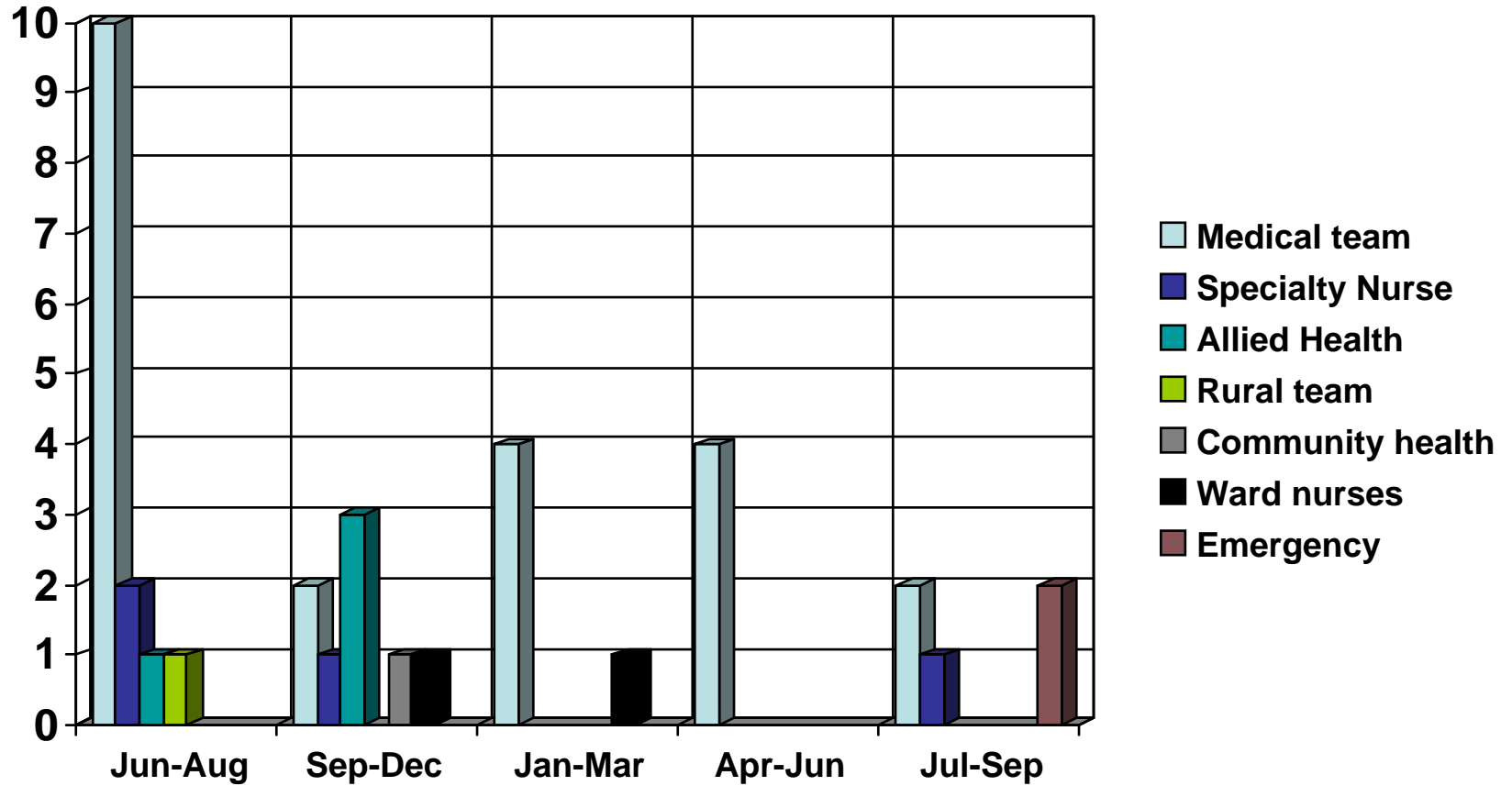
# Referrals per month



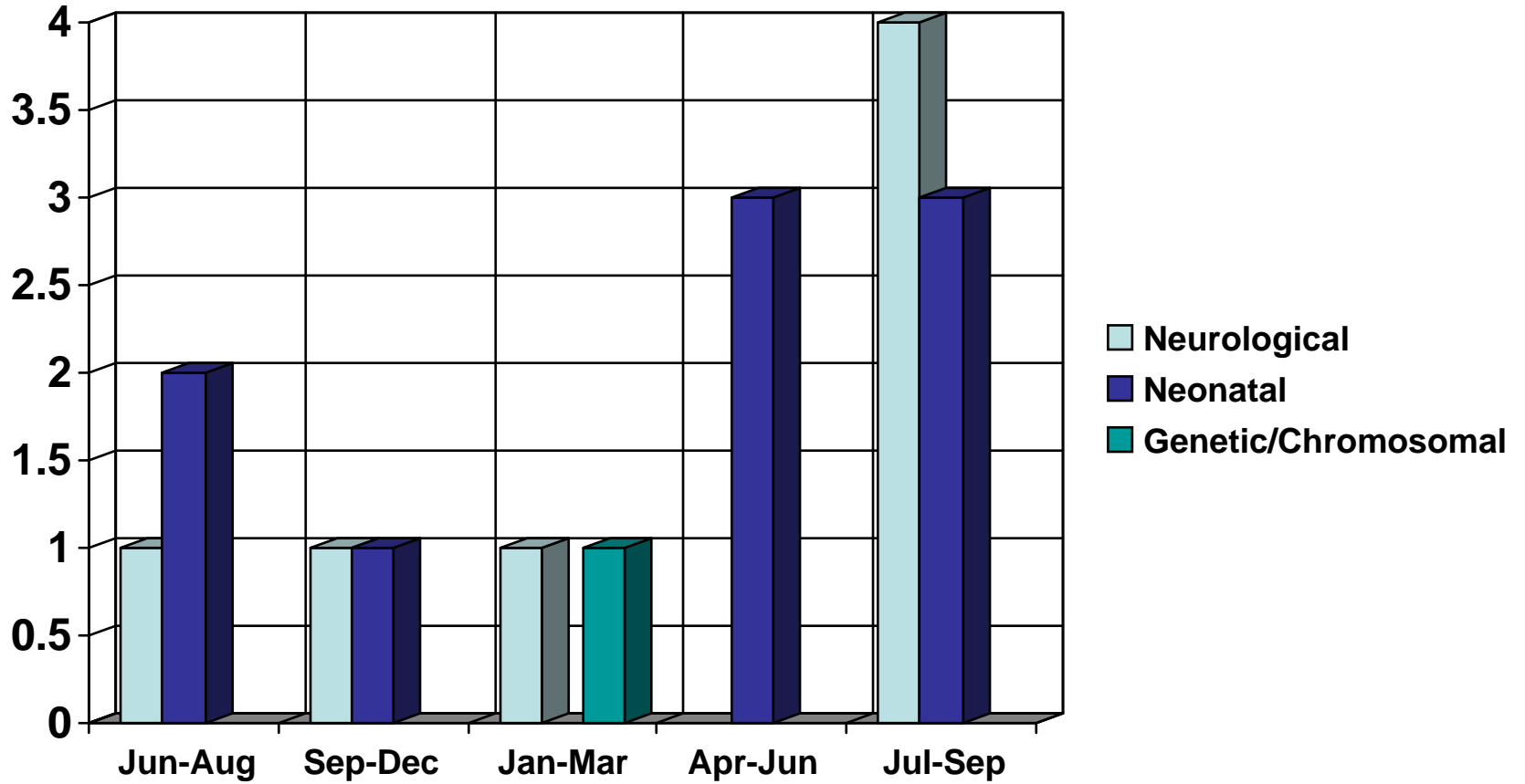
# Referrals by diagnosis



# Referral source



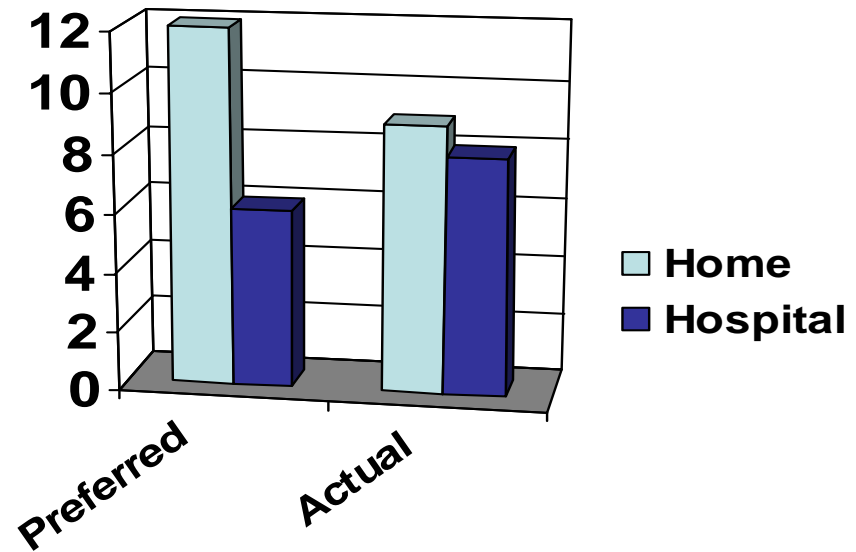
# Deaths



# Place of death

## Why not preferred POD?

- Time of death unexpected (1)
- Rapid death following treatment withdrawal (1)
- Unable to be D/C for legal reasons (1)



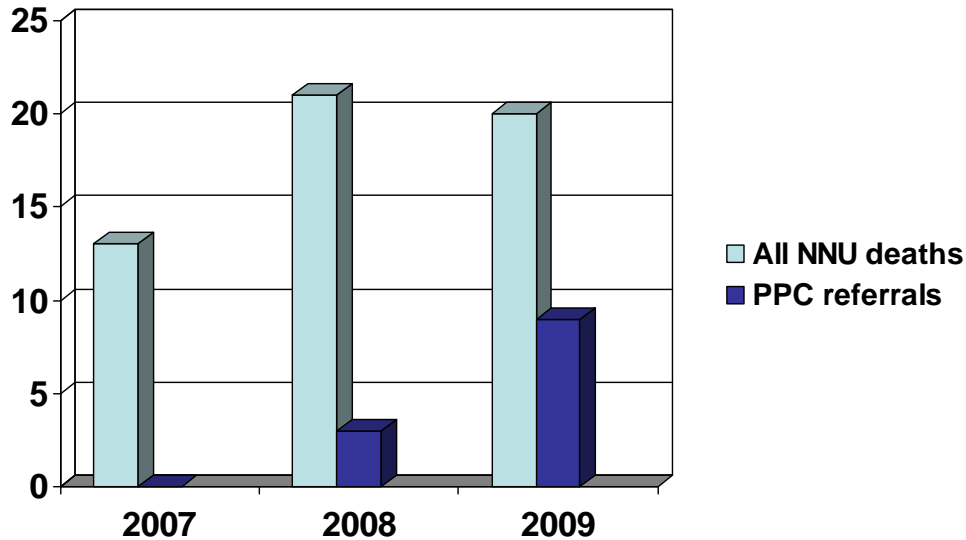
# Preference of POD

Of the current PPC patients:

- 6 parents want their child to die at home
- 2 parents want their child to die in hospital
- 12 parents are **undecided**, but the majority of care is home-based

**POD choices evolve over time and vary due to many factors...**

# Neonates referred to PPC



## 2008 referrals (3)

*Preferred POD:*

Home 2 Hospital 1

*Actual POD:*

Home 1 Hospital 2

## 2009 referrals (9)

*Preferred POD:*

**Home 9** Hospital 0

*Actual POD:*

**Home 6** Hospital 1

2 still living (at home)

# Creating PPC teams

## Community:

- General Practitioner
- Community Palliative Care team
- VMO - Palliative Care Consultants
- Community Paediatrician
- Pharmacist
- Disability coordinator (LAC)
- Respite facilities
- Home help (HACC)
- In-home respite workers
- Community Allied Health
- Department of Child Protection
- Teacher / School Principal
- School Nurses
- Integration Aides
- Child Health Nurses
- Regional Cancer coordinator
- Regional Specialty nurses
- Midwife

- Aboriginal Health Service/AHWs
- Regional +/- Local hospital
- Emergency departments
- Funding agencies
- BOC (Oxygen supplies)
- Medical equipment supplies
- Counselling services

## Tertiary Hospital

- Primary consultant/team
- Paediatric Palliative Care
- Ambulatory Care programs (**24hr phone**)
- Other consultants/teams
- Allied Health (PT, OT, SpTh, Dietitian, SW)
- Pharmacy
- Aboriginal Liaison Officer
- Pastoral Care
- Hospital In the Home (HiTH)
- Medical Equipment supplies
- Emergency Dept / Ward staff

# Case study 1

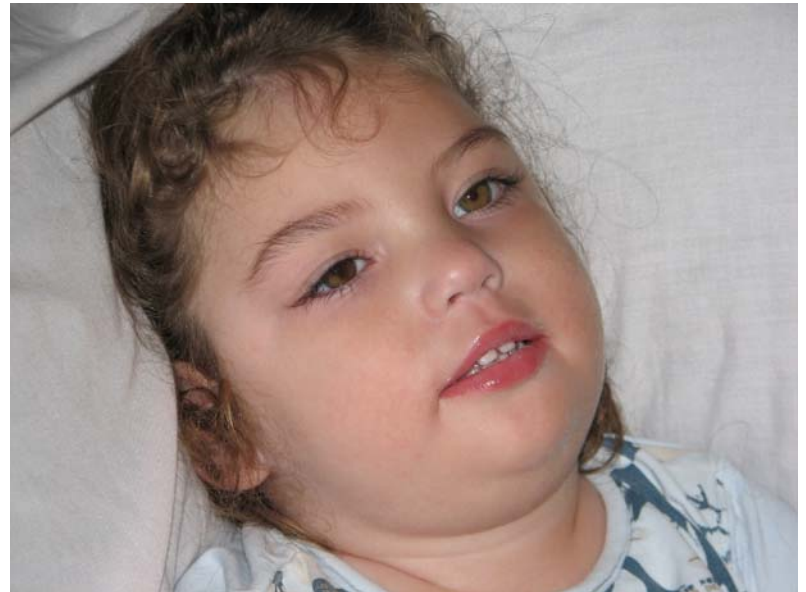
- Infant referred to rural town (Pop 2300)  
*(No Palliative Care service in this area)*  
**PPC TEAM CREATED:**
  - Midwife
  - Child Health nurse
  - Rural hospital Nurse Manager
  - General Practitioner
  - Regional Cancer nurse
  - Community nurse

# Case study 2

- Child referred to rural town (Pop 4500)  
*(Palliative Care service in the region)*  
**PPC TEAM CREATED:**
  - Child Health nurse
  - Aboriginal Health Service
  - Regional hospital Paediatrician
  - Rural hospital Nurse Manager
  - Regional Palliative Care nurse
  - VMO Palliative Care

# Technology

- Telephone
- Mobile phone (Hands free)
- SMS
- Fax
- Email
- Videoconference
- Teleconference
- Internet



# Key PPC issues so far

- Communication around medical treatment options
- Medical complexity of patients
  - high level of medical technology
- DCP involvement with **10%** of referrals
- Complex ethical issues
- Low level of understanding of PPC
- Need for excellent interagency cooperation
- Need for education about PPC
- Parental interest in tissue donation

# Non-clinical

- Education

- 59 PPC education sessions (1000+ participants)
- 1-day PPC seminar
- 2 conferences

- Staff support

- Post-death debrief x 8
- Patient discussion x 8

# Research & Evaluation

- Statewide PPC Model of Care (WACPCN)
- Database (WACPCN)
- Death of a Child (PMH guidelines / state-wide template)
  - Post Grad Students projects (Clinical pathway for guidelines)
- Evaluation (WACPCN)
  - Satisfaction survey (Adapted existing USA PPC tools)
    - Staff
    - Families
- Research (WACPCN) (in progress)
  - Respite services for PPC patients in WA
  - Bereavement services for families in WA

# Staff satisfaction survey

- 55 HCWs involved with PPC patients (Most 3-5 PPC pts)
- **54%** response rate (12/19 Dr; 12/28 RN; 5/7 SW; 1 AH)
- 22/30 would definitely refer another patient to PPC
- **Most useful aspects:**
  - EOL plans; symptom management plans; dedicated PPC role; increase in staff confidence; EOL issues discussed early; 24hr phone support
- **Areas for improvement:**
  - Communication
- **Education needs identified:**
  - Communicating diagnoses; options for care; symptom management; decision making; ethical issues

# Staff feedback

*“Personally I have had few children in the PPC Program. It’s been fantastic for the families. This Program also relieves a lot of pressure from our clinical practice, which I think is very beneficial.”*

# Parent satisfaction survey

- 4/12 current PPC pts (Posted survey, no reminders)
- 5/7 bereaved PPC pts (Invited by telephone, posted survey if agreed)
- **47%** response rate
- **Very/extremely helpful:**
  - symptom management; decision making; care coordination; 24hr phone support; improved communication with primary team; case conferences; practical help; emotional support; care plans; Journey's folder
- **Areas for improvement:**
  - more options for emotional support for families; opportunities for contact with other PPC families

# Parent feedback

*“Navigating the hospital system became so much easier”*

*“We felt more confident about making the right decisions”*

*“It helped us feel we had a team supporting us - we were not alone”*

*“It eliminated all additional stress on our family”*

*“My child was back in control of her body. The CPAP was removed and life began”*

# Challenges



- Service growth within financial constraints
- Complexity and variability of different patients
- Urgency of discharges (especially neonates)
- Creating services where little exists

# Lessons learned

- OK to start small
- Get as much ready as possible before you start taking patients
- Get **DATA** to justify the service for the administrators
- Be creative, open to challenges and flexible
- Look after yourself!

# Future aims



# Thank you!!

- Marnie Chellew-Hawley  
(PPC Project Worker, WACPCN)
- Helen Walker  
(Palliative Care Program Coordinator, WACPCN)
- PMH PPC Reference Group