Connected Care

Care Coordination for Children with Complex Healthcare Needs

Lynne McKinlay
RACP Congress
May 2016

Children with Medical Complexity

1. chronic, severe health conditions
2. substantial health service needs
3. major functional limitations
4. high health resource utilization
   - › CMC likely represent less than 1% of all children
   - › account for more than 1/3 of paediatric health care costs
   - › inpatient care is responsible for as much as 80% of health care cost for CMC
   - › use of the hospital is increasing for CMC over time

» 0.4%- 0.7% all children based on literature (estimate a total of 3500-6000 children in Queensland)

Some quotes from families:

“It is important to voice your needs very loudly - which you should never have to do. It was not until I really put my foot down and made them listen that anything happened.”

“*The monitor doesn’t tell you the full story. It doesn’t tell you the full picture of the child. They don’t listen to parents. We feel like we were getting pushed aside like you don’t know what you’re talking about we know better and we’ll deal with it so you guys just shut up.”*

“It’s hard… and it shouldn’t be that hard.”

Benefits of Care Coordination

- “an individualised health plan has been shown to improve communication between health care providers, family goal setting and improved family experience”
- children … were hospitalized fewer times and their parents missed fewer days of work
- Importance of family buy-in – involved in design of program and reference committee
- Importance of physician leadership and engagement: leadership from physicians “committed to the idea that complex children could be cared for in the community, and … made a conscious decision that they wanted to improve their practices to accommodate children with complex problems”

Palfrey, 2004

SPECIAL REPORT

CHILDREN'S HOSPITAL ASSOCIATION

June 2013

The Landscape of Medical Care for Children with Medical Complexity

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This special report was supported by the Children's Hospital Association and is available online at www.childrenshospitals.net/cmclitreview.

http://www.childrenshospitals.net/cmclitreview

REPORT OF THE PAEDIATRIC COMPLEX CARE COORDINATION EXPERT PANEL

Peter Rosenbaum, MD
Expert Panel Chair

MAY 2008

https://www.sickkids.ca/pdfs/Paediatric-Medicine/34603-PCCC%20Expert%20Panel%20Report.pdf

Evidence Base

Stiles et al, August 2014

- Center for Children with Complex and Chronic Conditions (C5) established in 2008 (North Carolina, 13 hospitals)
- 2008 to 2010, 234 children enrolled with complex conditions
- Including: tracheostomies, gastrostomy tubes, ventilators, feeding pumps, cerebral palsy, intellectual disabilities, complex genetic syndromes

Model of Care Coordination (Stiles et al; August 2014)

Interventions:

- comprehensive assessment of patient and family needs
- care plan development
- referrals to community services
- patient and caretaker education
- collaboration with providers and caregivers to facilitate transitions in care.
- “warm handoff” to the community-based care coordinators in primary care practices
- provide link between the subspecialist team and primary care professionals
- care plans posted on a secure web-based provider portal

Stiles et al, August 2014

Benefits of Care Coordination

- 20% reduction in average inpatient length of stay for ventilator-dependent patients
- 36% reduction in readmissions during the first month after discharge
- 26% reduction in readmissions during the first year after initial discharge
- 55% reduction in overall re-hospitalizations
- 11% reduction in emergency department visits
- calculated savings total for 2008 to 2010 is over USD $6 million

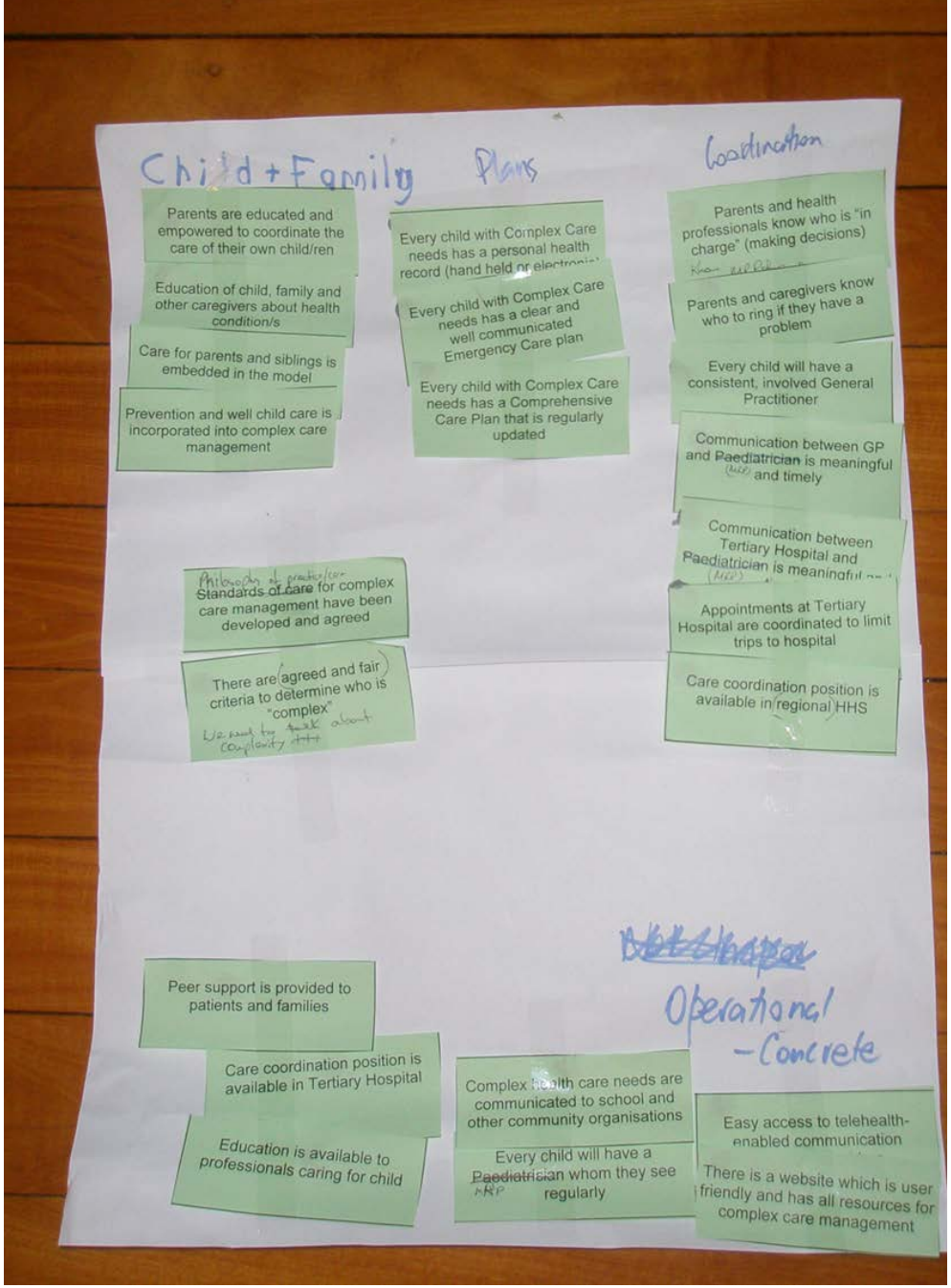
Stiles et al, August 2014

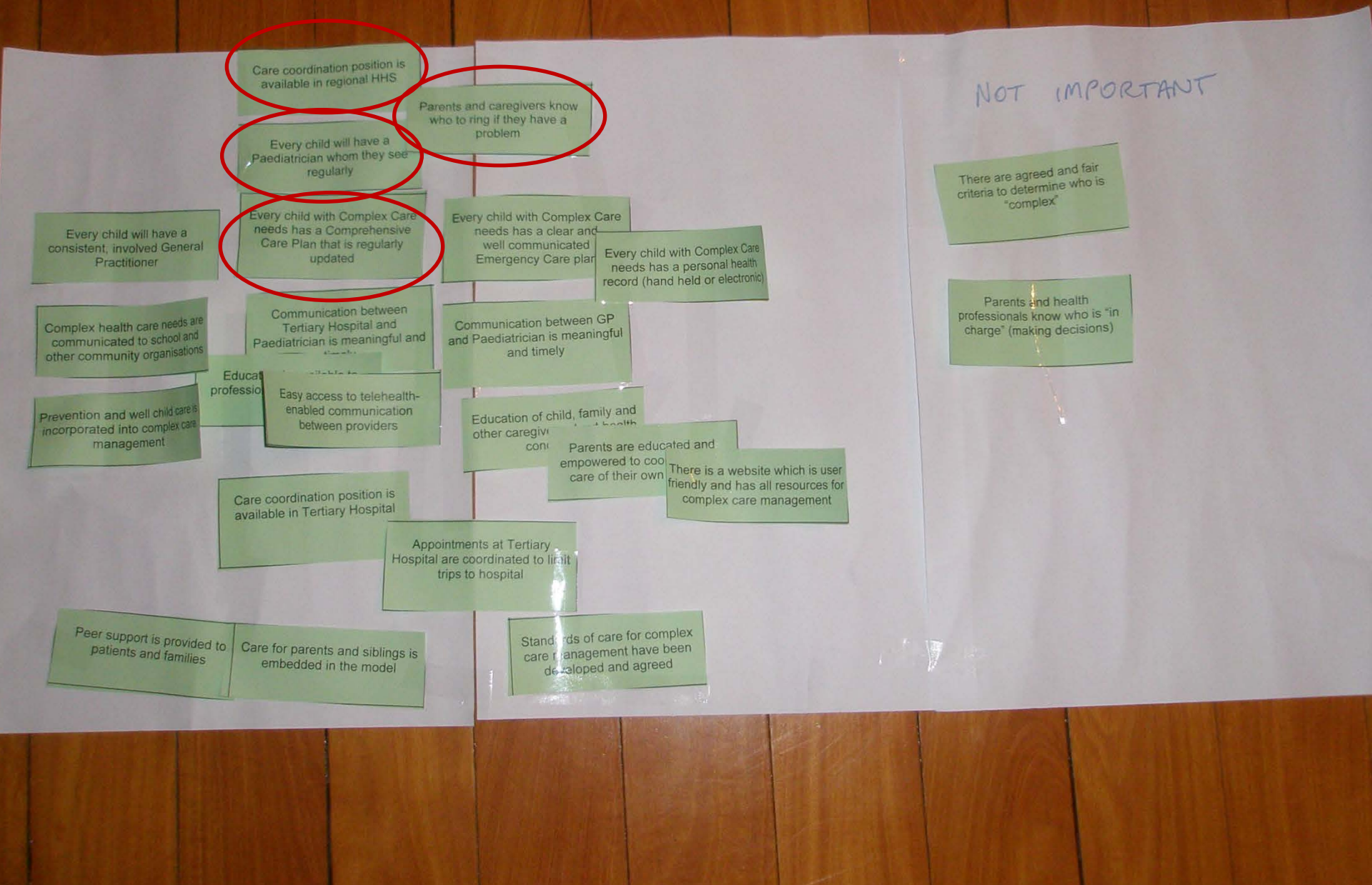
Statewide Consultation

All Directors of Paediatrics from QLD and Northern NSW came together at workshop.

Prioritisation of service goals

November 2013




Care coordination position is available in regional HHS
Parents and caregivers know who to ring if they have a problem
Every child will have a Paediatrician whom they see regularly
Every child with Complex Care needs has a Comprehensive Care Plan that is regularly updated
Every child will have a consistent, involved General Practitioner
Every child with Complex Care needs has a clear and well communicated Emergency Care plan
Every child with Complex Care needs has a personal health record (hand held or electronic)
Complex health care needs are communicated to school and other community organisations
Communication between Tertiary Hospital and Paediatrician is meaningful and
Communication between GP and Paediatrician is meaningful and timely
Easy access to telehealth-enabled communication between providers
Prevention and well child care is incorporated into complex care management
Education of child, family and other caregiv
Parents are educated and empowered to coo care of their own
There is a website which is user friendly and has all resources for complex care management
Care coordination position is available in Tertiary Hospital
Appointments at Tertiary Hospital are coordinated to limit trips to hospital
Peer support is provided to patients and families
Care for parents and siblings is embedded in the model
Stand rds of care for complex care management have been developed and agreed
NOT IMPORTANT
There are agreed and fair criteria to determine who is "complex"
Parents and health professionals know who is "in charge" (making decisions)

Queensland Connected Care Program

Evolution of Program

- Reference committee with family involvement
- Articulated vision, philosophy and partnerships
- Goal to move patients through the program and towards family enablement and independence
- Medical engagement
- Explicit medical and care coordinator roles
- Wide consultation
- Regionalisation of the model but centralisation of intake
- Use of allegory

Marine Pilot

- “A pilot is a mariner who guides ships through dangerous or congested waters, such as harbours or river mouths.
- Pilots are expert shiphandlers who possess detailed knowledge of local waterways …
- (however) the master has full responsibility for safe navigation of his vessel, even if a pilot is on board.”

To ensure a ship arrives in port safely, it needs:

Captain (parent)
Pilot (Care Coordinator)
Lighthouse (Hub)

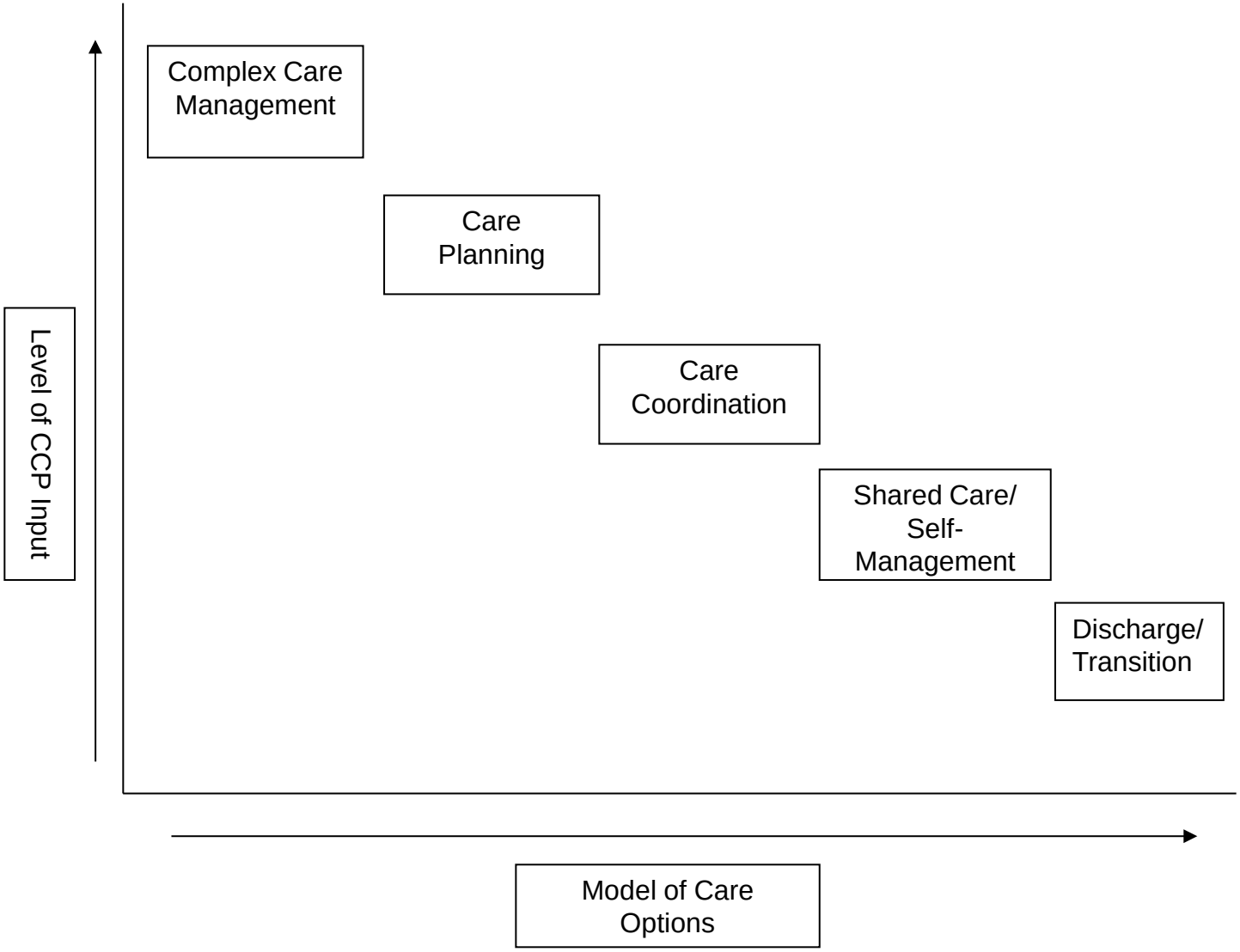
Connected Care Program

- State-wide Model
- a “Care Coordinator/team” for each child from within Connected Care Program.
- Partnership using a shared care model with other services throughout the state.
- a “Lead Specialist”
  - depends on health condition/s
  - region where family lives
  - will respect parental choice

Queensland Connected Care Program

A range of services depending on the level of support required.

- Appointment coordination
- Access to welfare support including complex travel needs
- Health Care Profile or Health Care Summary (“Care Plan”)
- Individualised Proactive management of identified health issues
- Support for Transition
- Identify and support parent goals
- For regional children admitted to LCCH, daily rounding and support partnership between LCCH and region
- Pharmacist support
- Allied Health Assistant program for inpatients


Complex Care Management
Care Planning
Care Coordination
Shared Care/ Self-Management
Discharge/ Transition
Level of CCP Input
Model of Care Options

Principles

- Family centred care
  - Family is the primary source of experience for a child
  - Families have the capacity to strengthen their capability to support their child
  - Work together to determine meaningful solutions to complex problems
- Shared Care
- Strengths- based approach – increase self-management
- Avoid duplication
- Add value to system

Health Care Profile / Summary

- Summary of conditions
- Current Management
- Care Team incl. GP
- Functional Assessment
- Emergency Care plan/s
- After Hours Action Plan
- Immunisation report
- Medication summary

http://qheps.health.qld.gov.au/childrenshealth/resources/clinforms/docs

Eligibility Criteria

Chronicity	Complexity	Fragility	Intensity of Care
Child's condition is expected to last at least 6 more months or is lifelong.	Involvement of, or anticipated need for, multiple medical specialists	The child has severe and/or life threatening disease	Child requires prolonged intravenous administration of nutritional substances or drugs
	Health care interventions delivered in multiple locations: • Home • Out of home care • School • Hospital	Failure of equipment or treatment places the child at immediate risk - including limitations to access to health care as a result of isolation.	Child has prolonged (>1 month) dependence on device-based support, eg: • tracheostomy tube care • suctioning • oxygen support or • tube feeding • Mechanical ventilation
	The child has had 10 or more medical specialist outpatient clinic visits in the past year	Short terms changes in the child's health status (eg. an intercurrent illness) put them at immediate serious health risk	Child has prolonged (>1 month) dependence on any other medical devices to compensate for vital bodily functions and requires daily or nearly daily nursing care eg. • apnea monitors • renal dialysis • urinary catheters/colostomy bags plus nursing care
	The child has had two or more prolonged admissions (LOS >10 days) to hospital in the past year	As a consequence of the child's illness, the child remains at significant risk of unpredictable life threatening deterioration, necessitating round-the-clock monitoring by a knowledgeable caregiver	Child is not technologically dependent but has any chronic condition that requires as great a level of care as the above group eg: 1. children who, as a consequence of their illness are completely dependent on others for activities of daily living at an age where they would not otherwise be so dependent 2. children who require constant medical or nursing supervision or monitoring, resulting from the complexity of their condition and/or the quantity of oral drugs and therapy they receive 3. children whose level of care is disproportionate to carer capacity, which may include families with multiple family members with high care needs
			Child is preparing for, undergoing or recovering from major surgery or other intervention which places them temporarily in the high intensity of care category – will be eligible for a time limited period, until return to baseline status, or referred to another service.

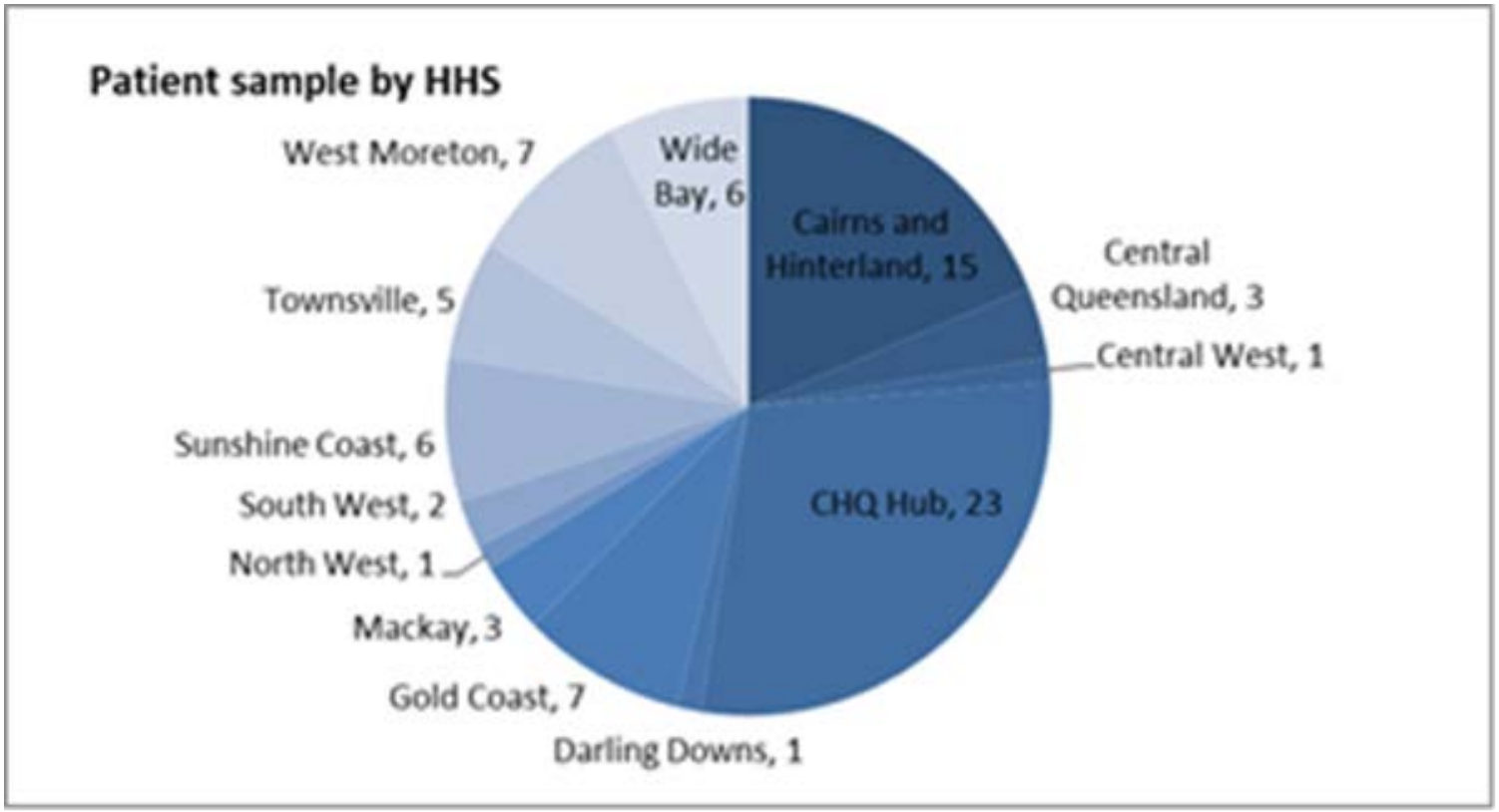
Connected Care Program Evaluation

- Current patient caseload = 655 patients across Qld and Northern NSW
- This evaluation performed on sample of first 80 patients
- Enrolled on the program for a minimum of twelve months
- Sample mix of patients from metropolitan, regional and rural health services
- Pre-enrolment activity compared with clinical service utilisation and measures in first 12 months post-enrolment

Geographical Distribution

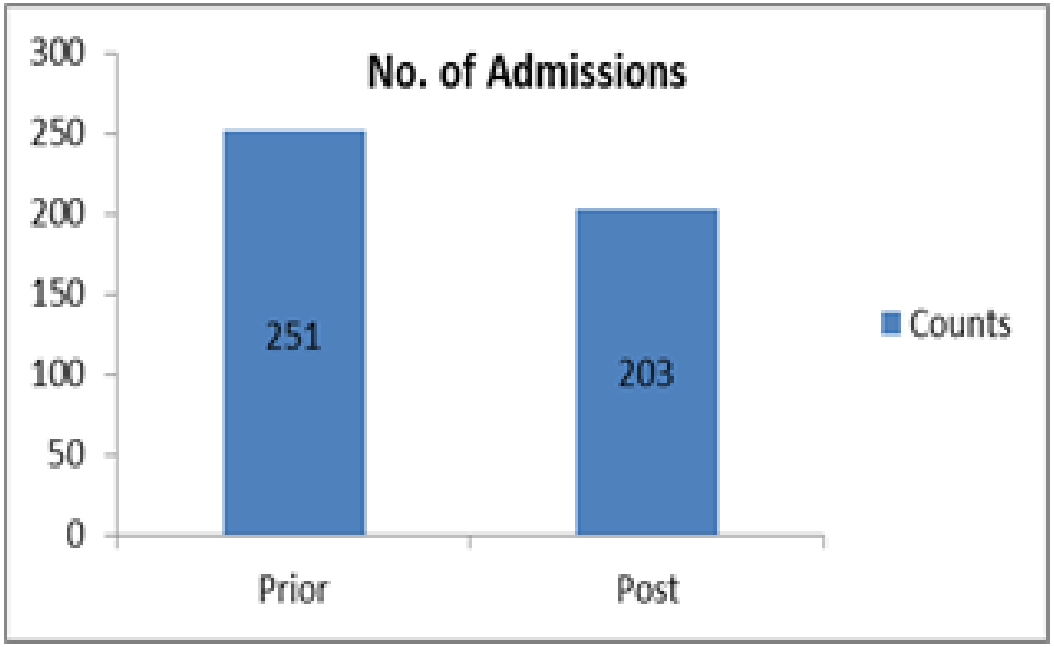
- Cairns & Cape York (CBH) - **45**
- Townsville (TTH) - **22**
- Mackay (MBH) - **7**
- Wide Bay : Bundaberg – **28;** Hervey Bay **- 9**
- Central Queensland (Rockhampton) – **46**
- Darling Downs (Toowoomba) - **37**
- Gold Coast - **44**
- Sunshine Coast - **45**
- North West (Mt Isa) – **18**
- South West – **11**
- Central West - **2**
- West Moreton (Ipswich) – **51**
- Greater Brisbane - **268**
- Northern NSW – **22**
- Northern Territory - **2**

Geographical distribution of 80 patients



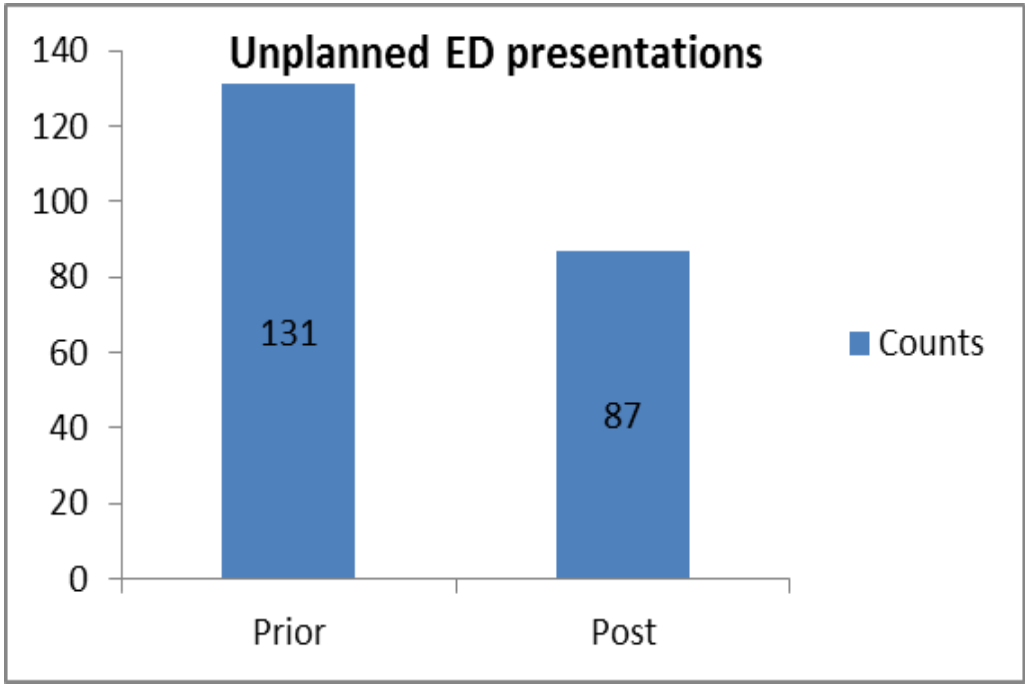
Successful outcomes – first 80 patients

» Reduced Admissions in 12 months after compared with12 months pre-enrolment



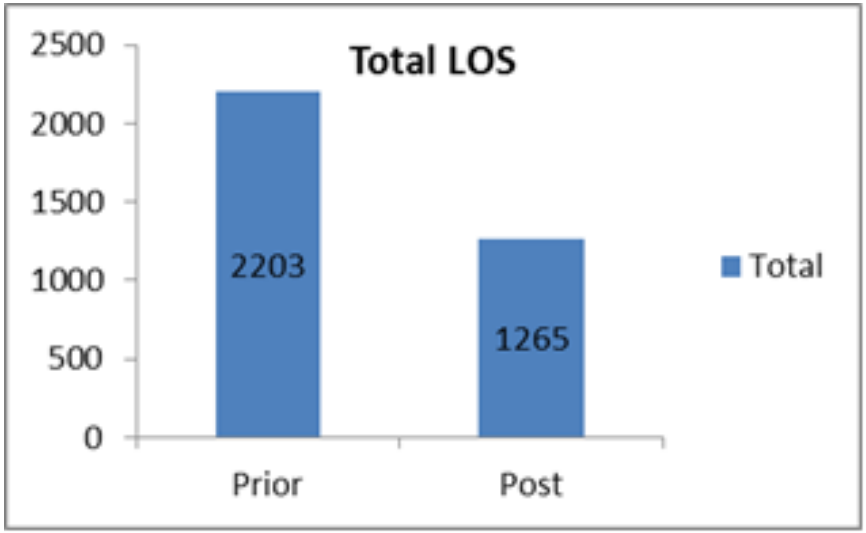
Successful outcomes – first 80 patients

» Reduced Emergency presentations in 12 months after compared with 12 months pre-enrolment

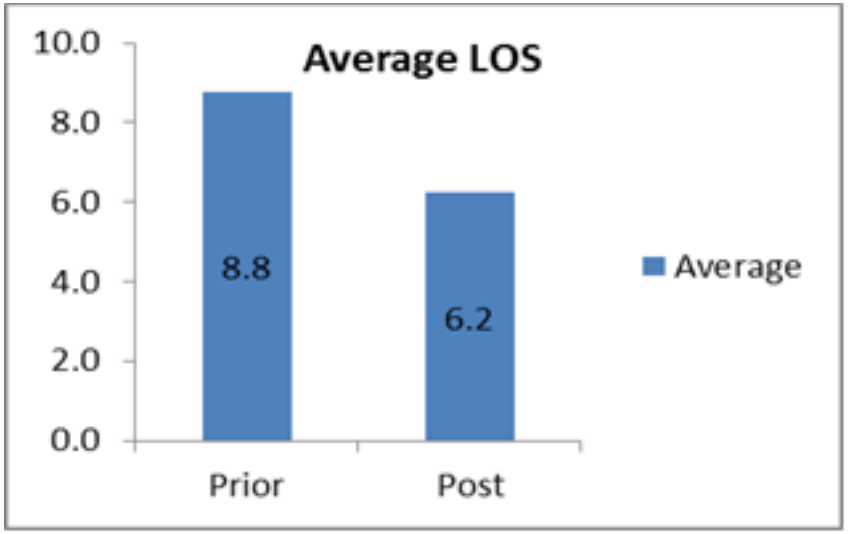


Fewer days spent in hospital

Total days in hospital

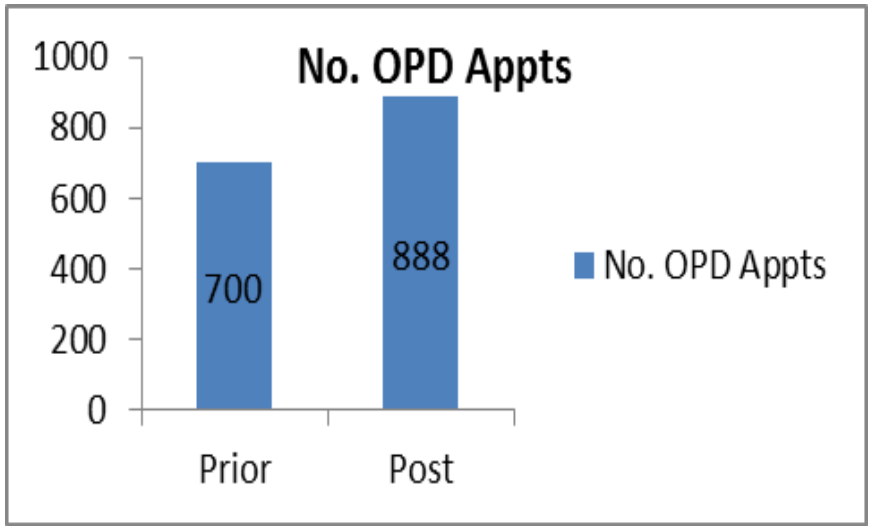


Average Length of Stay

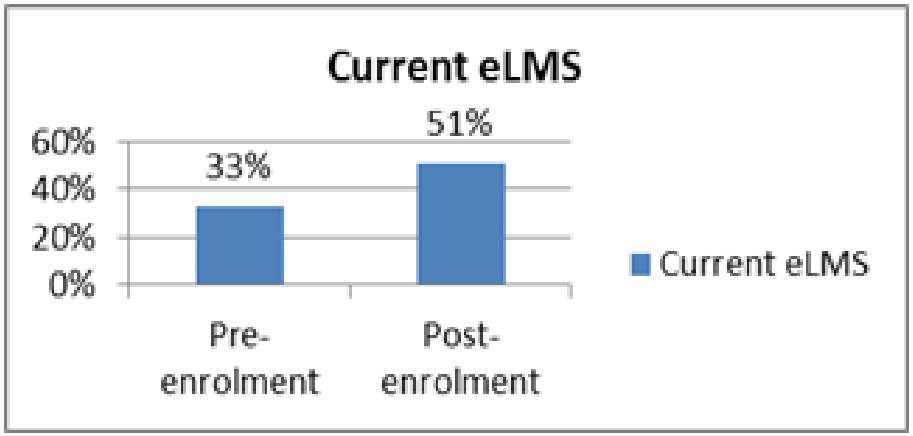


Other outcomes of note

Increase in ambulatory service use



Improved pharmacist-prepared electronic medication summary



Challenges

» Statewide consistency

» Determining resources

» Pharmacy support

» Psychosocial resources

» Support for care coordinators

» Enable families

» Emergency management

Opportunities

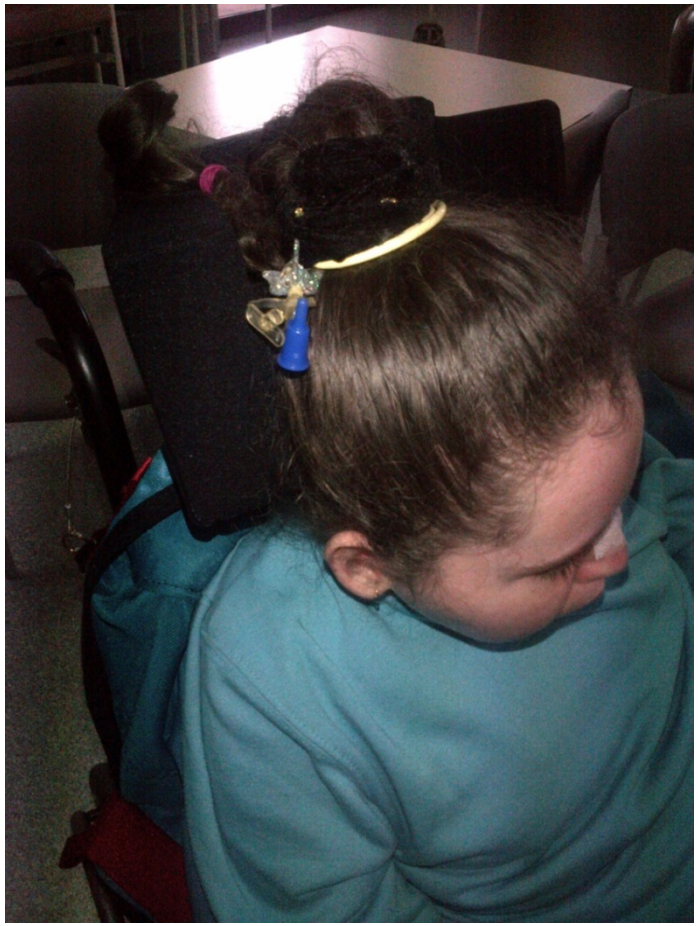
- ❑ Special Interest Group
- ❑ Electronic record
- ❑ Nurse Navigators
- ❑ Research

Allegory

- Literary device - a story, poem, or picture which can be interpreted to reveal a hidden meaning, typically a moral or political one
- A memorable illustration of the vision

Acknowledgements

- Connected Care Program statewide team
- Project and program support provided by Perrin Moss
- Collegiate sharing by other jurisdictions
- Children's Healthcare Australasia for support of Complex Care SIG
- Families and children who teach us and encourage us to do better.



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