



Transition and Transfer of Young People with Congenital Heart Disease

Hospital Name: The Royal Children's Hospital

**Presenters: Tracy Stanley – HeartKids, Evelyn Culnane – Transition Support Service
Manager and Dominique Davidson – RCH Consumer Participation Manager**

HRT 1603 Paediatric Improvement Group

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Melbourne



Key Problem

- Brief summary of the key problem. What was the situation before you implemented this innovation? What prompted you to undertake the project
- Research shows that a significant number of young people with congenital heart conditions are lost to medical services once leaving The Royal Children's Hospital (particularly within 24 months post transfer)
- Disjointed transition process which is confusing for patients and their families/carers
- Patient and parent/carer feedback

Aim of this innovation

- What were you aiming to achieve? What was the improvement you were seeking?
- Continuum of care – creating a transition and transfer process
- Quality of care, coordination and support provided during this period for patients and their parents/carers
- Reduction of ‘lost patients’
- Holistic transition approach

Baseline Data

- Please focus on changes that were implemented that contributed to the project's success.
- 1) Expansion of support provided to all CHD patients/families by the RCH Transition Support Service to include pathway development for all CHD (particularly with RMH). Previously (pre-2013) TSS working only with Htx & PH.
 - 2) RCH Transition Support Service taking the lead in the following initiatives:
 - VCCN & VPCN CHD Transition Project Stage 1 (Stage 2 in 2016 – creation of App &/or shared national database system)
 - ANZ Fontan transition NHMRC Grant (TSS providing consultation in development of transition pathway development & resourcing in major paed/adult CHD services across Australia & NZ)
 - RCH and RMH Transition Project: Evaluation study in development (for CHD and 5 other clinical disciplines)
 - Joint clinic pathway processes established – Heart Transplant (Alfred), Pulmonary Hypertension (Alfred) and CHD (RMH)

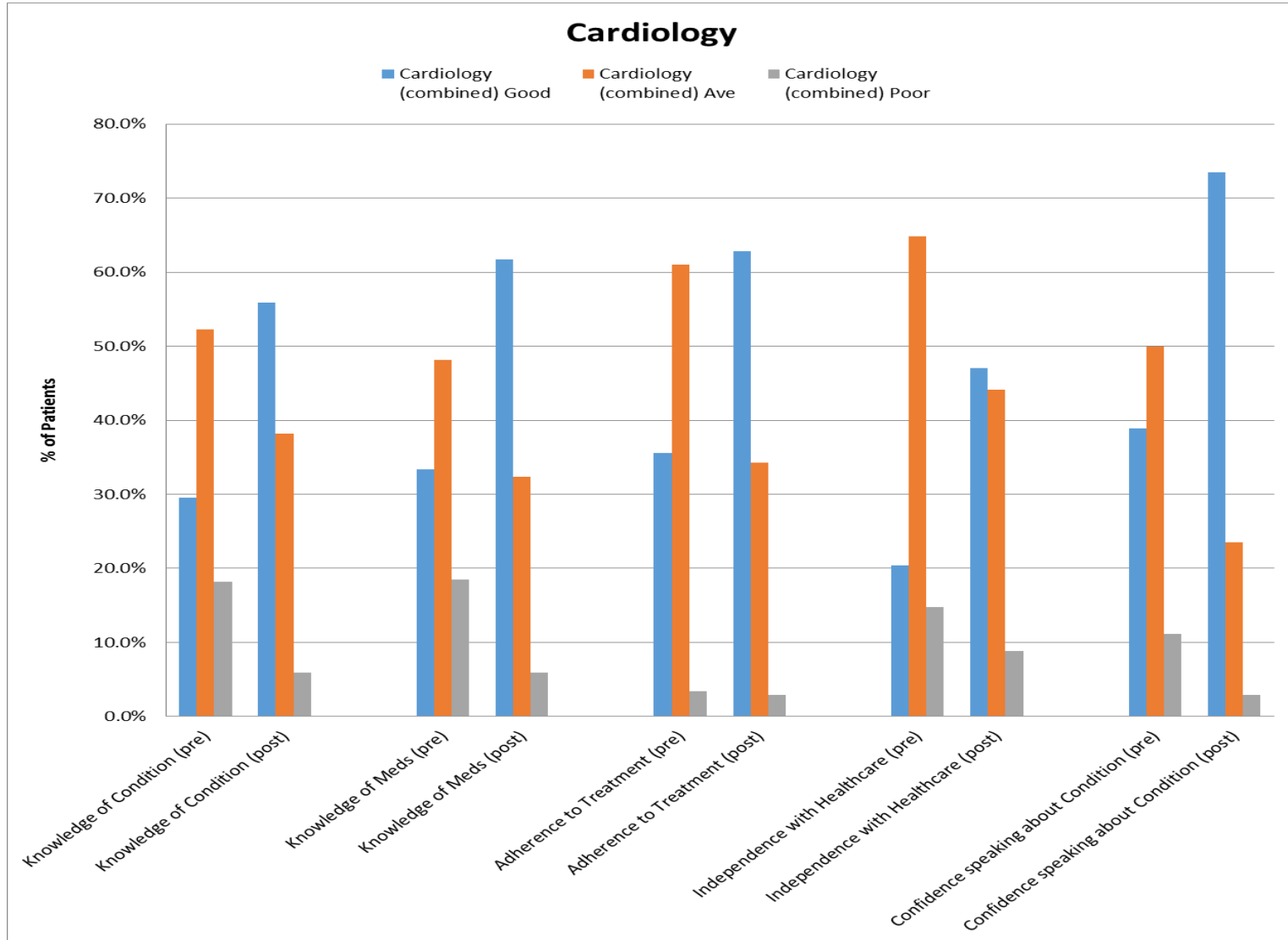
Key Changes Implemented

- Brief summary of the key problem. What was the situation before you implemented this innovation? What prompted you to undertake the project
- Fontan, Htx, PH and other CHD – transition clinic support provided by Transition Support Service for patients from 15+ years (includes cardiac transition youth mentor)
- Transition from RCH to RMH: annual CHD joint transition information forum
- Transition from RCH to Alfred (Htx from 2013 & PH from 2015)
- Youth Mentorship (HeartKids)
- Transfer pathway process developed for all CHD to RMH
- Transfer pathway process developed for complex patients including CHD
- Development of transition resources including - Healthcare Transition Plan, Transfer to adult services passport, Cardiology Transition Brochure, RMH Transition flyer

Outcomes so far

- Please focus on real results and provide evidence that the changes have made an improvement eg control charts, data from before and after
- Quality Data
 1. RCH Transition Support Service Clinic Data for Cardiology 2013-15 (includes Heart Transplant, Fontan, Pulmonary Hypertension and some general CHD):
 - Knowledge of condition
 - Knowledge of medications/treatment
 - Adherence to medications/treatment
 - Independence with healthcare management
 - Confidence/competency speaking about their cardiac condition
 2. CHD Transition Project data: Patient knowledge of cardiac conditions 2015
 3. RCH Cardiology Patient Transfer Data 2010-14

RCH Transition Support Service Clinic Data 2013-15 (n=63)



CHD Transition Project – Stage 1 (2015)

Survey responses from Young People 15+ yrs

What is your Heart Condition?

Out of the 50 participants that answered this question:

16% are unaware of their heart condition

78% have had cardiac surgery

If someone asked you what type of heart surgery you had, do you think you could explain it to them?

Out of the 41 participants that answered this question:

55% said yes they could explain the type of heart surgery they had

32% said not very well they could explain the type of heart surgery they had

13% said no they could not explain the type of heart surgery they had

Needs Improvement:

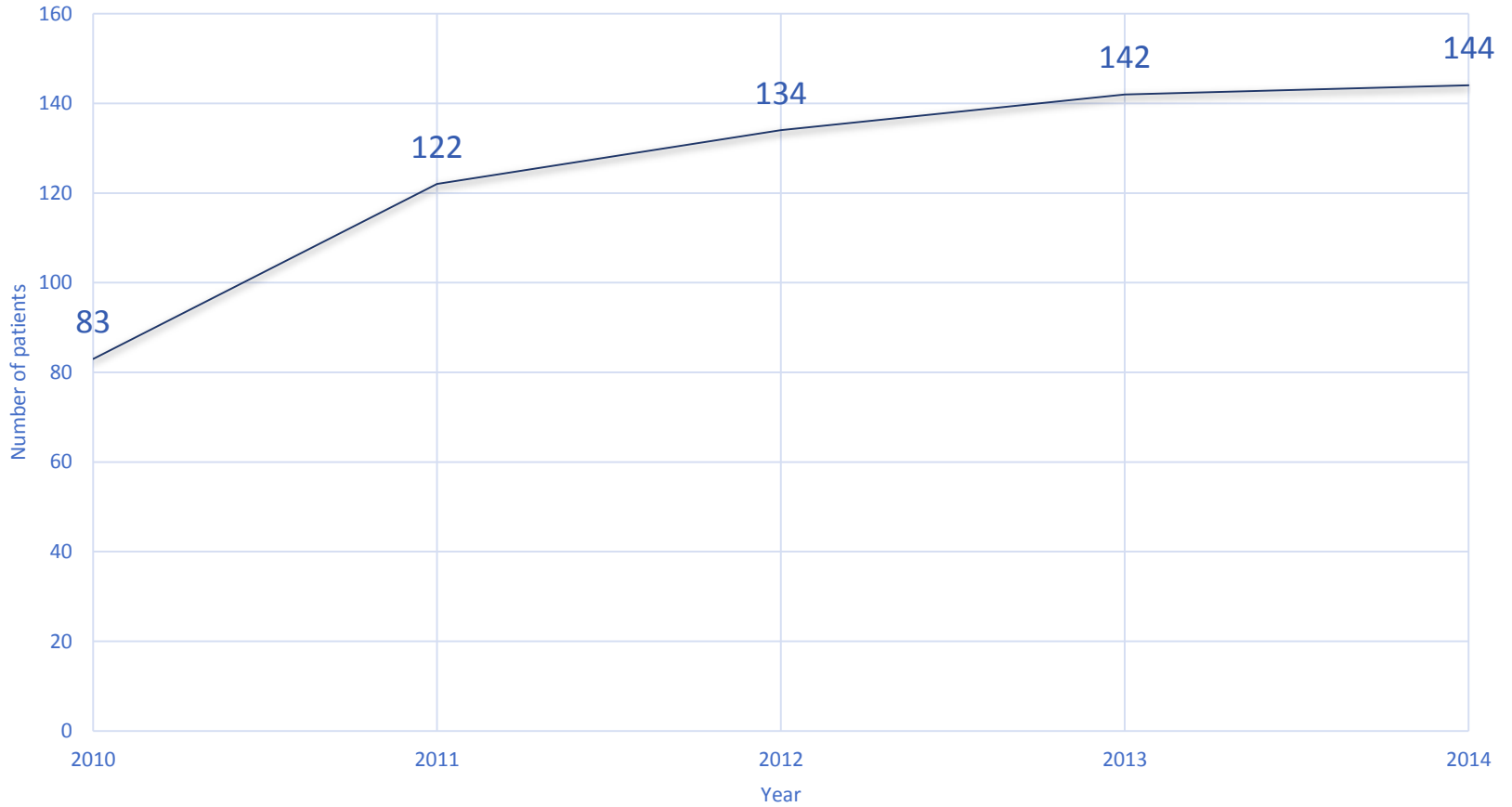
"They put poles in my chest to help the blood flow" (16 years –Hypoplastic right heart)

"Open Heart surgery to put plastic arteries in to pump blood through my heart" (19yr old (Post Fontan)

"I don't know (16yr TAPVD repair)"

RCH CHD Patient Transfer Data 2010-14

RCH Patient Transfer Numbers 2010 - 2014



Outcomes so far (continued...)

- Annual Education forums to support all young people with Chronic Health Conditions/Disabilities navigate the senior years of secondary school and beyond – next one is 21/6/16
- Person dependent – reliant on clinician expertise, co-expertise in the continuum of care
- Development of knowledge and expertise with Paediatricians running clinics in adult services
- Acknowledgement and sharing of how paediatric services differ to adult services eg. Congenital vs coronary care
- There are many different models of transition across Healthcare
- Increased acknowledgement that transition preparation is just as important as the transfer pathway process – leading to a successful transition to adult care

Lessons Learnt

- What have you learned from the project? What would you recommend to other organisations?
- 360° education is required
- There are always challenges
- It's all about relationships and building of trust
- Successful transition requires a transition 'lead' or 'champion' in every site
- Early planning and preparation is essential to engender personal responsibility
- Sharing of care and expertise is critical
- A good GP is important
- Make it easy for the patient – transition appointments easy to attend, in line with clinic appointments
- Engagement with patients and families is key
- For more information Contact: Evelyn Culnane, Manager Transition Support Service, RCH
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