TE WAIORA Nelson Marlborough Health

DHB Office
Braemar Campus

Private Bag 18
Nelson, New Zealand

Phone: 03 546 1723

5 March 2019

[redacted]

Response to a request for official information

Dear [redacted]

Thank you for your request for official information received 10 January 2019 by Nelson Marlborough Health (NMH)[1], followed by the necessary extension of time 1 February 2019, where you seek the following information.

1. ***Your DHB's current core policy document on facilitating education access for inpatient and outpatient children and young clients (including tertiary age),***
   and/or
   Your DHB's current core policy document on the transition and monitoring of transition from paediatric to adult services. I am aware that at least one DHB has a formal transition process and joint management document for each patient.

NMH does not have a specific policy document on facilitating education access, however our transition programme to provide guidance for those caring for children and adolescents with a chronic illness is currently being worked on and near completion. The following four documents (as enclosed) reflect the work to date:

- DRAFT Health Pathway – *Transition: Moving into Adult Care*
- NMH HIA (Health Innovation Awards) 2018 Poster – *Mind the Gap Supportive Transition Education for Patients and Parents* (STEPP)
- NMH HIA 2018 Poster – *Turning Point; Making the Move to Adult Services*
- Entry Form NMH HIA (Health Innovation Awards) Poster – *Turning Point; Making the Move to Adult Services*

Individual staff names have been redacted under Section 9(2)(a) *'to protect the privacy of natural persons, including that of deceased natural persons'.* In the circumstances, the withholding of that information is not outweighed by other considerations which render it desirable, in the public interest, to make that information available.

[1] Nelson Marlborough District Health Board

2. ***Your DHB's current core policy document on transitions and/or co-management between:***
   a) genetic and paediatric services
   b) paediatric and other specialist services and
   c) genetic and adult services.
3. ***Please also advise me if you do not have a written policy on any/each of the above, and if these situations are covered in a general DHB policy, and please send a link/copy of these policies.***

NMH does not have a specific policy document on transition and co-management between services. The Ministry of Health provides a general guidance document for DHBs at this link *Service Coverage Schedule* where section 4.18 (page 82) summarises transition to adult care.

This response has been provided under the Official Information Act 1982. You have the right to seek an investigation by the Ombudsman of this decision. Information about how to make a complaint is available at www.ombudsman.parliament.nz or free phone 0800 802 602.

If you have any questions about this decision please feel free to email our OIA Coordinator OIArequest@nmdhb.govt.nz

Please note that this letter (with your personal information removed), or an edited version of this letter, may be published on the Nelson Marlborough Health website.

Yours sincerely

Jane Kinsey
Acting Chief Executive

cc: Ministry of Health via email: SectorOIAs@moh.govt.nz

Encl:
NMH DRAFT Health Pathway – *Transition: Moving into Adult Care* (8 pages)
NMH HIA 2018 Poster – Mind the Gap: Supportive Transition Education (1 page)
NMH HIA 2018 Poster – Turning Point: Making the Move to Adult Services (1 page)
Entry Form *for* NMH HIA Poster – Turning Point: Making the Move to Adult Services (5 pages)

Transition: Moving into Adult Care

Overview: It is recognised that adolescence is a developmental age during which time knowledge and skills are gained that will be needed for adulthood (WHO, 2014). With advances in technology, children with chronic illness are now surviving into adulthood. Since Paediatric services generally become inappropriate environments for this population, adolescents with a chronic illness move into an adult services between the ages of 16 and 18 years. In contrast to the Paediatric service which takes a family-centred approach, adult services are patient-centred where the parents and caregivers are seen as supports. Consequently, both the adolescent and parent/caregiver need education and assistance with preparing and adapting to the role and service changes that occur.

Background: NMH recognises that adolescents have specific needs as they move to adulthood and are working to make health services accessible and appropriate (NMH, 2017). At present, support and education for adolescents and their families falls short of bridging the gap between the two service approaches. As a result, adolescents fail to engage with adult services and have poor health outcomes (NMH, 2017).

Purpose: The purpose of this pathway is to provide guidance for those caring for children and adolescents with a chronic illness and their families in order that they experience a seamless move from Paediatric to Adult services.

Scope: All staff of Nelson Marlborough Health who provide care to adolescents with a chronic illness and their families.

Procedure: There are 3 phases for the transition of care from Paediatric to Adult services:

1. Preparation
2. Transfer
3. Post-transition care

PHASE 1: PREPARATION:

A child with a long-term condition reaches

1. Age of 12 years:

    1. Consider extending the length of the usual appointment time to allow for discussion and education about transition.

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2. Offer cultural support to the child and family for the discussion(s) (eg. presence of Poukorowai Te Waka Hauora) during this phase.

3. The Paediatric team discusses transfer of care between the ages of 16 and 17 years with the child and family.

4. The Paediatric team provides the child and family with the appropriate patient and/or parent leaflet(s) (hyperlink(s) here).

5. The Paediatric team indicates to the child and family that after age 13, the adolescent will have the opportunity to meet alone with the Paediatric team for a short time at the beginning of the appointment. The parents/carers can join the consultation after this initial phase.

6. Add child's name to Transition Register.

2. Age of 13 years:

1. Consider extending the length of the usual appointment time to allow for discussion and education about transition.

2. Offer cultural support to the child and family/carers for discussions during this phase (eg. presence of Poukorowai Te Waka Hauora).

3. If appropriate, invite the adolescent to begin the appointment without parents/carers present.

4. Where appropriate, undertake a psychosocial assessment using HEeADSSS tool (Appendix 1).

5. Assessments using this format can be repeated at 6 to 12 month intervals until the adolescent is transferred to adult services. This process helps to identify the needs of the adolescent as well as evaluate the effectiveness of education and support previously.

6. Begin to empower adolescent by assisting with transfer of care from the parent/carer to the adolescent through education that increases health literacy and self-care for the adolescent.

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7. Update Transition Register.

3. Age of 14 years:

    1. Offer cultural support to the adolescent and family/carers for the initial discussion(s) during this stage (eg. presence of Poukorowai Te Waka Hauora).

    2. Provide the adolescent with a valid and reliable readiness tool for transition.
        i. Adolescents with diabetes: https://www.starship.org.nz/media/542935/transition-toolkit-preparation.pdf
        ii. Adolescents with other conditions: hyperlink here

    3. The readiness tool can be repeated in 12 to 18 months to evaluate the effectiveness of education and support.

    4. The results of the tool form the basis of education and support to be provided and included in a mutually agreed written plan (template hyperlink here).

    5. Identify and agree key professionals who need to be aware of the transition plan. In complex cases, consider naming one professional to act as a coordinator of the transition process in partnership with adolescent and family/carers.

    6. Include heading "Transition Plan" as well as a summary of goals in clinic letters to GP and other key professionals involved with the adolescent and family.

    7. Send a copy of clinic letters to the adolescent instead of/ in addition to the parents/carers.

    8. Review and revise the transition plan in partnership with the adolescent and family/carer at each encounter.

    9. Provide developmentally and cognitively appropriate resources, education, and support to the adolescent and their family/ carers in order to meet the goals agreed in the transition plan.

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10. Update Transition Register.

4. Age of 15 years:

    1. Offer cultural support to the adolescent and family/carers for the initial discussion(s) during this stage (eg. presence of Poukorowai Te Waka Hauora).

    2. Repeat Transition Readiness Tool.

    3. Review and revise "Transition Plan" in partnership with adolescent and family.

    4. Continue to include heading and summary of Transition Plan on correspondence.

    5. If adolescent requires further input from adult care in tertiary service, request referral from tertiary Paediatric service to tertiary adult service.

    6. Provide opportunity for tertiary adult service to meet adolescent and family. This may be face to face or via tele/videoconference.

    7. Include local adult service in referral letter and other correspondence.

    8. Approximately, 6 months prior to the estimated discharge date to the local adult service, send a referral letter to adult services.

    9. When discharge to adult services is confirmed, arrange final Paediatric appointment and invite adult professionals to a joint clinic visit.

    10. Update Transition Register.

PHASE 2: TRANSFER OF CARE:

Age of 16 to 17 years:

1. Offer cultural support to the adolescent and family/carers for the initial discussion(s) during this stage (eg. presence of Poukorowai Te Waka Hauora).

2.

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3. Once a tertiary adolescent or adult service has taken over care of the adolescent from a Paediatric tertiary service and the adolescent, family, and health care team (adult and Paediatric) agree that the care can to be transferred to local adult service, complete the referral process to the local adult service and invite adult professionals to a joint clinic visit. If the local adult service is a GP, please see the next paragraph.

4. For adolescents having care transferred to primary care, consider a joint visit with the Paediatrician and General Practitioner at a convenient location, such as the Practice, or via a secure video link.

5. When the adolescent and family/carers leave the last Paediatric appointment, they need an understand ing of when and where the next appointment will be. If the paediatric and adult services are co-located on the same site, the adolescent and family may wish to be shown where to go for the next appointment and meet staff within that area.

6. At this final Paediatric appointment, it is agreed in partnership between the health professionals and the adolescent and family, where the adolescent prefers to be admitted for acute treatment, especially if this occurs between the final Paediatric and first adult appointment.

7. At the final Paediatric appointment, the adolescent and family/carers require contact information for key professionals if they run into difficulty.

8. Provide reassurance to adolescent and family/carers that Paediatric health professionals are still available to provide support during the period between paediatric and adult care.

9. Update Transition Register.

PHASE 3: POST-TRANSFER OF CARE:

a. Offer cultural support to the adolescent and family/carers for the initial discussion(s) during this stage (eg. presence of Poukorowai Te Waka Hauora) regarding transition.

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2. Once the young person and family/carers have attended their first appointment in an adult service, they can then be considered discharged from Paediatrics.

3. The Paediatric team can, however, still be available for assistance if needed by the adolescent and family/carers.

4. After the initial six month period, the adolescent is considered to be in adult services. At this time, they can be offered the opportunity to evaluate their transition process. This evaluation is in the form of a questionnaire (Appendix 2).

Definitions:

Adolescence:	those aged between 10 and 19 years (WHO, 2014).
Transition Register	Database/spreadsheet with patients aged >12 years with long term conditions that indicates pathway status

References:

American Academy of Pediatrics. (2011). Clinical Report – Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home. doi:10.1542/peds.2011-0969

Nelson Marlborough Health [NMH]. (2017). Nelson Marlborough Health Annual Plan: Incorporating the Statement of Performance Expectation 2017/2018. Retrieved from https://www.nmdhb.govt.nz/assets/Uploads/NMDHB-Annual-Plan-2017-18-.pdf

World Health Organisation (2014). Recognizing adolescence. [Website]. Retrieved from http://apps.who.int/adolescent/second-decade/section2/page1/recognizing-adolescence.html

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Appendix 1: HEEADSSS Assessment Tool

H-Home

E-Education/employment

E-Eating

A-Activities (peer group)

D-Drugs and Alcohol

S-Sexuality

S-Suicide/depression

S-Safety

Reference: Goldenring, J.M. & Rosen, D.S. (2004). Getting into adolescent heads: An essential update. *Contemporary* Paediatrics, 2(1), 64-90.

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Appendix 2: Transition Evaluation Questionnaire

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Nelson Marlborough Health

Mind the Gap

Supportive Transition Education for Patients and Parents (STEPP)

BACKGROUND

Adolescence is a time of great change. Children with lifelong diseases are surviving into adulthood. By the age of 16 years, adolescents move from paediatric to adult services where they receive more suitable care, in appropriate environments. Prior to transfer, both the adolescent and family/whānau need preparation for the change of service.

Nelson Marlborough Health recognises that adolescents have specific needs (Nelson Marlborough Health, 2014), but adolescents and their family/whānau often struggle when moving from paediatric to adult services.

PROJECT REACH

Adolescents with a chronic illness, their families/whānau, and the professionals who deliver the services.

RESULTS:

1. Adolescents with chronic complex conditions and their family/whānau experience difficulty with coordination and navigation while in the Paediatric service.
2. Moving from paediatric to adult is discussed, not always documented.
3. Improve written communication between secondary and primary care.
4. Need to stagger change if tertiary Paediatric service involved.
5. Handover by multi-disciplinary team.
6. GP is from birth to death.

QUALITY IMPROVEMENT METHOD

Root cause analysis:

PROCEDURES
- No standard approach
- Paper-based communication

METHODS
- No standard approach
- Paediatrician to Physician/GP

Adolescent and family/whānau unprepared for move to adult services.

ENVIRONMENT
- No adolescent clinics
- Separation of paediatric and adult services.

PEOPLE
- No coordinator
- Reliance on adolescent/ family/ whānau
- No tracking system.

RECOMMENDATIONS:

Apply "Core Elements for Transition":
(Center for Health Care Transition, 2014)

Core Element	Local Application
Transition Policy	Clinical Pathway
Transition Tracking and Monitoring	Transition Register
Transition Readiness	Use of valid tool
Transition Planning	Clinical Pathway
Transfer of Care	Clinical Pathway
Transfer Completion	Clinical Pathway

REFERENCES:

Nelson Marlborough Health. (2017). *Nelson Marlborough Annual Plan*. Nelson, NZ: Author.

Center for Health Care Transition. (2014). *Transitioning youth to an adult health care provider: Six core elements of health care transition 2.0*. Retrieved from

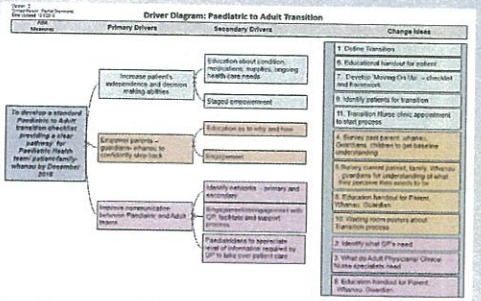
Turning Point:
Making the Move to Adult Services

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QI Health Quality & Innovation Awards

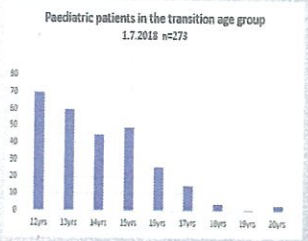
A GAP IN OUR SERVICE

- Identified need for transition process to be developed.
- Recent report: 'All DHBs should develop clear processes for transition of paediatric patients to adult medical services where it is clear or likely that a young person will require ongoing specialist care at secondary level as they move towards adulthood'



QUALITY IMPROVEMENT METHODS

- Research existing transition programmes
- Discuss and gain feedback from: Primary care; adult secondary service; local Paediatric team; former patients/family/whanau.
- Samples of transition documentation given to current patient/family/ whanau.
- Identify patients numbers within transition age group
- Compile feedback data
- Make recommendations to NMH Paediatric Service



RESULTS

Patients/family/whanau:

- Are keen for a transition process
- Need information to be concise, simple language, clear headings, bullet points
- Say colour and font important
- Like checklists and grids
- Identified key pages to include

Feedback from Patients and Family/Whanau

0 No comment, 1 Poor, 2 Average, 3 Good /Easy

UK	Christchurch	Starship	Australia
3	3	3	0
3	3	3	2
2	3	1	3
3	2	2	1
3	3	2	2
3	3	2	2
3-	2	2	2
3	3	3	3
23	**22**	**18**	**15**

NEXT STEPS

- Continue moving forward
- Team decision on documentation to be used
- Trial use of documentation with teen diabetes cohort for 6 months
- Discuss/engage with primary care; adult secondary services
- Review, change, develop
- Implement



Acknowledgements: Thank you to former and current patients/family/whanau who provided feedback on transition documentation, and encouraged the development of a transition process. Thank you to mentor Fran Mitchell for her support and guidance both during and beyond the QI Champs Secondment.

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HIA Health Innovation Awards

Nelson Marlborough Health Innovation Awards 2018

ENTRY FORM

PROJECT TITLE

Turning Point: Making the Move to Adult Services

CATEGORY

Child & Adolescents

PROJECT TEAM

	Name	Role	Email address	Location/organisation
Project Lead		Paediatric Outreach Nurse	nmhs.govt.nz	Nelson Hospital
Project contact person		Paediatric Outreach Nurse	nmhs.govt.nz	Nelson Hospital
Proposed presenter		Paediatric Outreach Nurse	@nmhs.govt.nz	Nelson Hospital
Members		Charge Nurse Manager	nmhs.govt.nz	Nelson Hospital
		Paediatrician	nmhs.govt.nz	Nelson Hospital
		Paediatric Outreach Nurse	@nmdhb.govt.nz	Nelson Hospital
		Clinical Nurse Educator	@nmhs.govt.nz	Wairau Hospital
		QI Champs mentor	@nmdhb.govt.nz	Nelson
		QI Champs mentor	@nmdhb.govt.nz	Nelson

BACKGROUND

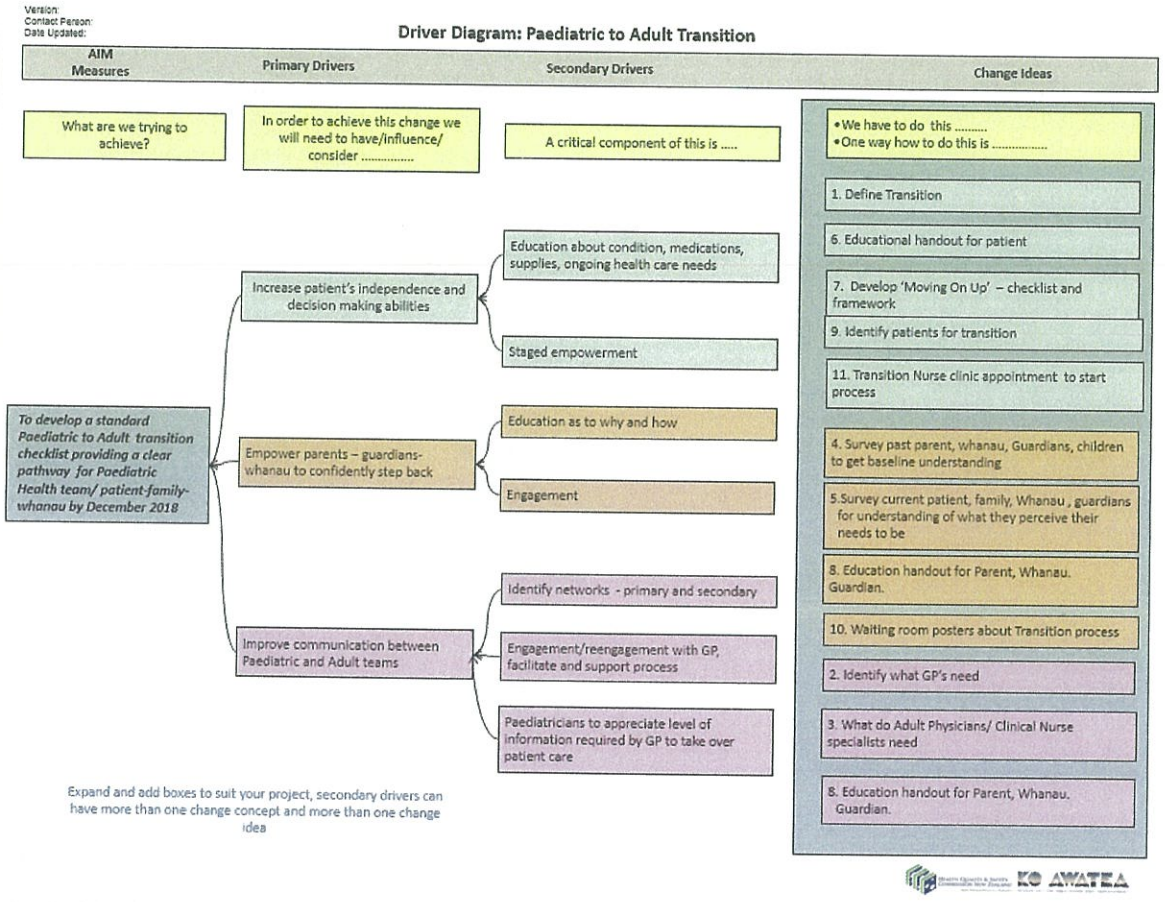
In 2015 the Nelson Marlborough Paediatrics Service identified a gap in our service in the way we were discharging and transferring our Paediatric patients, at around 16 years old, to adult care. We recognised that patients, family and whanau were unprepared for the significant changes that occurred when moving from holistic paediatric care to a specialty focused adult service with GP support. This discharge and transfer often impacted on the quality of care/treatment they received as young adults and into adulthood. The team began district wide discussions around developing a transition process but it never got beyond this point due to the lack of resources available to work on the process. It was put on hold with the hope that at some time in the future it would somehow be actioned.

In 2017 a 'serious event review' report for Nelson Marlborough Health stated: 'All DHBs should develop clear processes for the transition of paediatric patients to adult medical services where it is clear or likely that a young person will require ongoing specialist care at secondary level as they move towards adulthood'. Simultaneously the Nelson Marlborough Paediatric Services District Wide Annual Planning for 2018 day highlighted this topic for discussion as it was still on hold.

Also around this time Clinical Governance offered a secondment for 6 months to work on a Quality Project and after submitting my proposal I was invited to join this programme which commenced in March 2018.

APPROACH

I initially developed my Project Charter and refined the project goal. 'To develop a staged checklist that will support our patients developing independence in managing their own health care starting when they are over 11 years old and completing it at by their 17th birthday when they will be transitioned from Paediatric care back to their GP +/- adult secondary services.' The time frame for completion being December 2018. I also spent time developing a Driver Diagram which has enabled me to stay focussed on this project working through many of the change ideas over the 6 months secondment.



What is Transition? There are many good but varying definitions including this one: "A purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child centred to adult- oriented health care systems"

Primary Care/Adult Secondary Services: I spent time meeting with both medical and nursing representatives from GP practices and Nelson Hospital to inform them of my project and engage in some dialogue about it plus ask them what it was they felt was missing/could be done better when we transferred a patient to them following discharge from Paediatrics.

Interviewing former patients/ family/whanau: It was informative to meet and chat with previous clients of our service and hear from them what they found their issues were when being discharged from our Paediatric service and trying to navigate into the adult service with no support.

Research existing transition programmes: I researched existing transitions programmes both in New Zealand and internationally finding some extensive work had already been done developing tools for this very purpose. I chose the documentation from two NZ and two International hospitals, emailing for permission to use their work. From here I developed folders containing samples of these documents as there were significant differences in the layout, language, use of colour, styles of presentation and information. Then I asked a cross section of nine current patient/family/whanau groups to review the documentation and provide feedback on it including an explanation of my project and feedback form with a guideline of the type of information I would find helpful.

Identify patient's numbers within transition age group: To have an idea of the numbers of patients we are potentially working with in Nelson I requested a print out of all Paediatric Patients who were aged 12 years and over as of 1st July, 2018. While these are raw figures and will not be the true number of patients requiring a transition programme it is an indicator of a large group of patients that we need to assess for need.

Compilation of feedback data: The feedback provided from the nine patient/family/whanau was compiled and scored providing a clear indication that the transition documentation of the UK Ready, Steady, Go programme met the expectations of the reviewers. A close second was the Canterbury District Health Board transition documentation however, this is not as complete as the Ready, Steady, Go programme.

Make recommendations to NMH Paediatric Service: This information is due to be presented to the NMH Paediatric service and in consultation with them a decision will be made as to which documentation we will go forward with.

PROJECT REACH

While the current Paediatric patients are the clear benefactors of this transition tool, the benefits are not limited to only them.

The Paediatric care team (medical and nursing) will have a clear process as to how and when to start the transition process with an identified patient/family/whanau following the patients 12th birthday, after which it will be strategically rolled out to the over the following 4 years.

The young person over this 4 year period learns about their chronic health condition and medication and the relevance of both for maintaining good health; will learn to take the lead in clinical appointments talking to the clinician themselves rather than through their parent; will learn to make appointments independently and obtain prescriptions and supplies; and generally taking responsibility for themselves. They will also get to meet with the adult team taking over their care prior to their final appointment in Paediatrics.

The family/whanau will get to learn their new role of taking a step back and encouraging their young person to take on the lead role for their own care while still being able to provide much needed support to them.

The adult health teams, both in secondary services and primary care, will receive patients into their care who have been prepared for transition and have an understanding of their health needs; who have learnt to talk with the clinician at appointment; who are responsible for making appointments, obtaining prescriptions, and requesting supplies as needed.

RESULTS

The feedback from conversations with former patients/ family/whanau helped to identify problem areas to look at. Discussions with Primary Care elicited problems with clinic letters being sent out to GP's and their inability to find the information they required easily. This has been addressed separately. From the Practice Nurses I learned how we can work together to re-engage patients with their primary care provider before they are transitioned back to their care.

The information received from current patients/family/whanau proved to be very helpful in selecting which material to recommend to the Paediatric services. Families were keen to participate in this and some expressed a keenness to see this project completed after some were initially quite teary eyed and emotional when I broached the subject asking them to participate in providing feedback. One parent has already changed the way in which she and her daughter share information in clinic appointments from just reading the information. She now allows and encourages her 15 year old daughter to talk to the clinician and only speaks if the daughter looks to her for support.

Examples of comments from Patient/family/whanau

Christchurch	Starship	UK
Well presented, looks better than Starship one for colour, layout clearer. Easy layout to follow, liked bullet points on p 2. Informative, right amount of info, definitely no wordier, no longer. Like the generic 'transition framework' – good visuals with bullet points. Reads clearly and looks good but information could be better (e.g. Starship).	Easy to follow, informative. Like 'What is Transition' page but prefer CHCH layout, use of font and colour. Really like 'Main differences between Child and Adult services' grid – is very good, great to include, a quick, easy insight into the main differences between services. My daughter wants to know practical stuff e.g. room set ups, appts, wards etc. Like the Parent checklist. Child checklist really good – appeals to my daughter who likes to tick off jobs.	Very informative, great layout, heading, bullet points – similar to CHCH. Liked checklists – similar to Starship and Melbourne. Liked colour, font and layout.

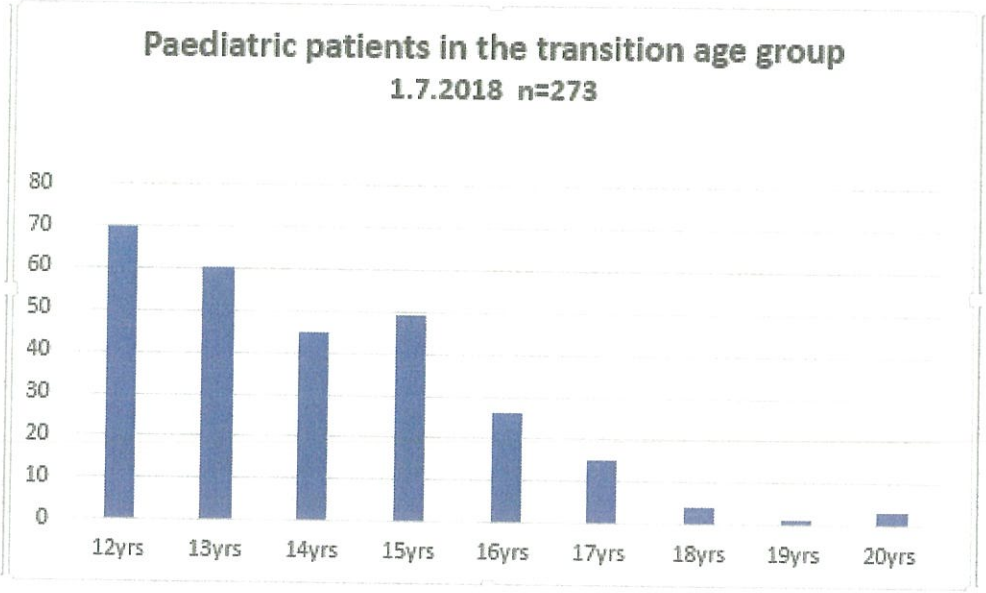
Scoring by Patients/family/whanau

Eight patients/family/whanau scored each template based on a 3 for very good, 2 for average and 1 for least liked. The table below shows the totals with the UK template being the most liked.

UK	Christchurch	Starship	Australia
23	22	18	15

LEARNING and SHARING

The graph below shows that we have a large number of young people within the transition age group who will benefit from a transition process being established. Therefore our next step is to test the transition tool on a small cohort of patients to ensure it has a correct fit for them before planning a wider roll out of the process to other patients. The group we have selected for our trial are Teenage Diabetes patients and we plan to initiate this in early 2019.



We continue to have on going networking with both adult secondary services and Primary Care to keep them informed of our progress with the transition tool and process encouraging their continued engagement with us.

Submit your entry to quality@nmdhb.govt.nz **(Closing date 31st October 2018)**