Waitematā
District Health Board
Best Care for Everyone

Consumer Council

Wednesday

11 May 2022

2:00pm – 4:00pm

In person attendance with Zoom option available

CONSUMER COUNCIL
11 May 2022

In Person Attendance with Zoom Option
Time: 2:00pm – 4:00pm

Consumer Council Members	Ex-officio - Waitematā DHB staff members
Lorelle George (Consumer Council Chair) Ngozi Penson (Consumer Council Deputy Chair) Neli Alo Samuel Cho Alexa Forrest-Pain (Te Rūnanga o Ngāti Whātua) Maria Halligan (Te Whānau o Waipareira) Insik Kim Jeremiah Ramos Ravi Reddy Kaeti Rigarlsford Vivien Verheijen Eden Li (Student Representative)	Dr Dale Bramley – Chief Executive Officer Dr Judy McGregor - Board Chair, WDHB Samantha Dalwood – Disability Advisor Other Waitematā DHB Staff members Ravina Patel – Manager, Patient Experience Sarah Timmis – Charge Nurse Manager Sarah Murray - Complaints and Adverse Events Manager Elizabeth Maritz - Clinical Leader Paediatric Dietetics Paediatric Community Dietitian Matthew Knight – Project Director, Facilities Services Group Tamzin Brott – Covid-19 Executive Lead and Chief Allied Health, Scientific and Technical Professions Officer

APOLOGIES:

Dr Dale Bramley – Chief Executive Officer
Samantha Dalwood – Disability Advisor
Dr Judy McGregor - Board Chair, WDHB

AGENDA

Disclosure of Interests (see guidance)

- Does any member have an interest they have not previously disclosed?
- Does any member have an interest that might give rise to a conflict of interest with a matter on the agenda?

KARAKIA
WELCOME

	1.	**AGENDA ORDER AND TIMING**
	2.	**Welcome / Introduction / Karakia**
	3.	**CONFIRMATION OF MINUTES**
2.05pm	3.1	Confirmation of the Minutes of Meeting (09/02/22)
	3.2	Confirmation of the Minutes of Meeting (23/03/22)
	3.3	Actions Arising from Previous Meeting
	4.	**DISCUSSIONS**
2.10pm	4.1	Patient Experience Report
2.20pm	4.2	Complaints and Compliments
2.35pm	4.3	Discharge Process Update (Verbal)
2.45pm	4.4	Feeding Support Survey
3.00pm	4.5	Facilities Update (Verbal)
3.10pm		--- Break ---
	5.	**INFORMATION ITEMS**

3.15pm	5.1	COVID-19 update – Omicron (Verbal)
3.30pm	5.2	HQSC/Health NZ/MHA Updates
	6.	**ANY OTHER BUSINESS**
3:45pm	6.1	Community Concerns
3.50pm	6.2	Agenda items for next meeting
3.55pm	6.3	Meeting evaluation

Waitematā District Health Board
Consumer Council
Member Attendance Schedule 2022

NAME	Feb 2022	Mar 2022	May 2022	June 2022	July 2022	Sept 2022	Oct 2022	Dec 2022
Lorelle George (Chair)	✓	✓	✓					
Ngozi Penson (Deputy Chair)	✓	✓	✓					
Alexa Forrest-Pain	✓	✓	✓					
Neli Alo	✓	✓	✓					
Maria Halligan	✓	✓	✓					
Insik Kim	✓	✓	✓					
Samuel Cho	✓	✓	✓					
Jeremiah Ramos	✓	✓	✓					
Ravi Reddy	✓	✓	✓					
Kaeti Rigarlsford	✓	✓	✓					
Vivien Verheijen	✓	✓	✓					
+Dale Bramley	✓	✓	✓					
+Samantha Dalwood	✓	✓	✓					
Eden Li (Student representative)	✓	✓	✓					

✓	*attended*
×	*apologies*
*	*attended part of the meeting only*
^	*leave of absence*
+	*ex-officio member*

WAITEMATĀ DISTRICT HEALTH BOARD
CONSUMER COUNCIL

REGISTER OF INTERESTS

Board/Committee Member	Involvements with other organisations	Last Updated
Neli Alo	nil	24/09/19
Samuel Cho	Committee Member, Waitakere Health Link Member, Metro Auckland Asian and MELAA Primary Care Service Improvement Group (Auckland DHB and Waitematā DHB) Member, Asian Health Action and Advisory Group (Counties Manukau Health)	11/06/21
Alexa Forrest-Pain	Member, Auckland Council Youth Advisory Panel	17/03/21
Lorelle George (Chair)	Consumer Advocate – Harbour Hospice, Clinical Governance Committee	07/05/21
Maria Halligan	nil	13/10/21
Insik Kim	No declared interest	03/07/19
Ngozi Penson (Deputy Chair)	Member, Metro Auckland Clinical Governance Forum Member, Ethnic Advisory Group (EAG), English Language Partners, Northern Region Laboratory Network Point of Care Testing (POCT) Network Group	09/03/22
Jeremiah Ramos	nil	03/07/19
Ravi Reddy	Board Member – Hospice West Auckland Senior Lecturer – Massey University Honorary Academic – University of Auckland	19/02/20
Kaeti Rigarlsford	nil	03/07/19
Vivien Verheijen	Member, Consumer Advisory Committee - PHARMAC Board member, Companionship & Morning Activities for Seniors (CMA)	31/08/20
Eden Li (Student Representative)	nil	22/04/21

Conflicts of Interest Quick Reference Guide

Under the NZ Public Health and Disability Act 2000, a member of a DHB Board who is interested in a transaction of the DHB must, as soon as practicable after the relevant facts have come to the member's knowledge, disclose the nature of the interest to the Board.

A Board member is interested in a transaction of a DHB if the member is:

- a party to, or will derive a financial benefit from, the transaction; or
- has a financial interest in another party to the transaction; or
- is a director, member, official, partner, or trustee of another party to, or person who will or may derive a financial benefit from, the transaction, not being a party that is (i) the Crown; or (ii) a publicly-owned health and disability organisation; or (iii) a body that is wholly owned by 1 or more publicly-owned health and disability organisations; or
- is the parent, child, spouse or partner of another party to, or person who will or may derive a financial benefit from, the transaction; or
- is otherwise directly or indirectly interested in the transaction.

If the interest is so remote or insignificant that it cannot reasonably be regarded as likely to influence the Board member in carrying out responsibilities, then he or she may not be "interested in the transaction". The Board should generally make this decision, not the individual concerned.

A board member who makes a disclosure as outlined above must not:

- take part in any deliberation or decision of the Board relating to the transaction; or
- be included in the quorum required for any such deliberation or decision; or
- sign any document relating to the entry into a transaction or the initiation of the transaction.

The disclosure must be recorded in the minutes of the next meeting and entered into the interest register.

The member can take part in deliberations (but not any decision) of the Board in relation to the transaction if a majority of other members of the Board permit the member to do so. If this occurs, the minutes of the meeting must record the permission given and the majority's reasons for doing so, along with what the member said during any deliberation of the Board relating to the transaction concerned. Board members are expected to avoid using their official positions for personal gain, or solicit or accept gifts, rewards or benefits which might be perceived as inducement and which could compromise the Board's integrity.

IMPORTANT

Note that the best course, when there is any doubt, is to raise such matters of interest in the first instance with the Chair who will determine an appropriate course of action.

Ensure the nature of the interest is disclosed, not just the existence of the interest.

Note: This sheet provides summary information only.

2. Welcome and Introduction

3. CONFIRMATION OF MINUTES

3.1 Confirmation of the Minutes of Meeting 09/02/22

3.2 Confirmation of the Minutes of Meeting 23/03/22

3.3 Actions Arising from Previous Meeting

Minutes of the meeting of the Consumer Council of the Waitematā District Health Board

Wednesday, 9 February 2022

held by video conference
commencing at 2.04pm

CONSUMER COUNCIL MEMBERS PRESENT:

Neli Alo
Samuel Cho
Alexa Forrest-Pain (Te Rūnanga o Ngāti Whātua)
Lorelle George (Chair)
Maria Halligan
Insik Kim
Ngozi Penson (Deputy Chair)
Jeremiah Ramos
Ravi Reddy
Kaeti Rigarlsford
Vivien Verheijen
Eden Li

ALSO PRESENT:

Prof Judy McGregor (Waitematā DHB Board Chair)
Dr Dale Bramley (Waitematā DHB Chief Executive)
Samantha Dalwood (Disability Advisor)
Peta Molloy (Committee Secretary)
(Staff members who attended for a particular item are named at the start of the minute for that item.)

APOLOGIES:

An apology was received and accepted from Hannah Bjerga.

WELCOME:

The Consumer Council Chair welcomed everyone in the meeting and welcomed Mr Rob Campbell, CNZM (Health NZ, Chair.)
Introduction from David Lui (Waitematā DHB Board member and former Chair of the Waitematā DHB Consumer Council.)

DISCLOSURE OF INTERESTS

There were no additions or amendments to the Interest Register.

There were no interests declared that might involve a conflict of interest with an item on the agenda.

1 AGENDA ORDER AND TIMING

1.1 Items were discussed in a slightly different order than listed in the agenda.

1.2 David Lui noted the purpose and responsibilities of the Consumer Council highlighting the demand for its service and continuity upon the conclusion of upcoming reforms. Some of the duties mentioned were the Council's mission on maintaining diversity, consumer engagement, focus on patient experience and the implementation of a values programme across the DHBs. It was also noted the importance of holding the DHBs accountable for the practice of the adopted values and mission. In addition, the Council sees its role as an essential link between the Public Health system and the communities it serves in order to maintain a strong connection, to increase outreach of health services as well as bring awareness into the Committee on issues arising in the community that may not have the opportunity to be addressed otherwise.

Mr Rob Campbell acknowledged the important work and function of the Consumer Council and provided reassurance that it is the new entity's intention to continue to support the work of the Committee. Mr Campbell explained that although a clear strategy was not yet in place in view of a partnership, he asserted that it was in the organisation's best interest to maintain the Committee fully operational.

2 CONFIRMATION OF MINUTES

2.1 Confirmation of Minutes of the Consumer Council Meeting held on 1st December 2021

That the Minutes of the Consumer Council Meeting held on 1st December be approved.

Carried

3 DISCUSSIONS

3.1 End of Life Choice Act (Agenda pages 8-9)

Dr Jonathan Christiansen (Chief Medical Officer) joined by video conference for this item. He summarised the report noting the current process of patient care provided by the DHBs under the implementation of the aforementioned Act. In addition, he noted several issues with the current process that may be obstacles to patient's informed consent such as access to information of the services available.

Issues covered in the discussion and response to questions included:

- Eligibility criteria: information needs to be clear and emphasise that all elements of the criteria need to be met in order to qualify for the service; not just one
- Information needs to be available in other languages to accommodate culturally diverse populations
- Estimating prognosis may present an issue with clinicians overestimating projected outcomes
- Process for eligibility may take up to two/three weeks
- Assisted end of life service currently a primarily community based support but DHBs can facilitate the process if required
- Conflicting clauses between the Act stating that viability of the procedure can only be studied upon patient's initiative, is in contrast with the Rights Code stating that all options available should be presented to the patient for informed consent

The Consumer Council Chair acknowledged the input on the End of Life Choice Act subject and thanked Dr Jonathan for his time.

3.2 Youth Mental Health (agenda pages 10-23)

Petra, Selena, Julia and Jane joined by video conference for this item. The report was taken as read.

Matters covered in the discussion and response to questions included:

- Age definition was provided on age groups under the *young person* criteria, and the contexts these criteria may apply to qualify for mental health services
- Clarity was provided on routes of access for self-referral options for youth in need of mental health services: currently Duty Teams provide support through Health Point and Schools in additions to the professional referrals
- It was acknowledged Mental Health Services are running at full capacity and currently overwhelmed due lack of mental health practitioners' workforce, issue that's been aggravated by Covid-19 Omicron
- Several issues were raised regarding Mental Health Services unable to meet the public demands, standards of appropriate cultural competency, focus on partnerships with family for continuity of care for the young person, equity and accessibility
- It was collectively agreed that the discussion needs to continue in order to find a solution to the unmet and ever-increasing demands of the service
- Upcoming DBT programme to be launched on 10 schools for 30 weeks providing youth with tools to deal with crisis and overcome mental health issues

The Consumer Council Chair acknowledged the work of the team and thanked Petra, Selena, Julia and Jane for their time.

The session was adjourned for a short break from 3.25pm to 3.33pm.

3.3 Covid-19 Update – Omicron (Verbal update)

Dr Dale Bramley (Chief Executive) provided and update.

Matters covered in the discussion and response to questions included:

- An update on the COVID-19 vaccination roll-out: currently over 90% of eligible population have been vaccinated. This successful campaign focused on equity of health outcomes for Māori and Pacifica groups
- Message to the community: get the booster, prepare to isolate if in contact with the virus. Testing with Rats and Proc for staff members is available
- Recruit 500 campaign: aimed to recruiting new staff members as part of the Business Continuity Plan to buffer the effects of predicted 25% reduction of workforce during the pick of the Omicron spread
- Planned response to deal with increasing numbers of Covid-19 cases amongst the admitted patients, with focus in acute services and maintaining normal functioning of all services.
- Plan in place to extend services out to the community to people that may be home isolating unable to seek health services
- Plan in place to maintain operational testing sites

The Consumer Council acknowledged Dr Dale's update and thanked him for his time.

3.4 **Discussion on NZREX** (agenda pages 24-35)

Ngozi (Committee member) provided a summary of the report presented on NZREX Clinical pass rates and general registration figures. Ngozi noted the cost to the general population based on the low numbers of registrations granted in relation to the numbers of candidates that sat the examination.

Matters covered in the discussion and response to questions included:

- The process is raised by the Council to highlight the position in which International Medical Graduates (IMG) find themselves, due to the lack of PGY1 placements at District Health Boards, the only accredited training provider for pre-vocational training.
- As a consequence of this process, it has become impossible for those who successfully pass the NZREX clinical exam to complete an internship (hospital based) prior to entering general practice.
- This situation has resulted in a high number of unregistered practitioners being unable to apply for registration with the Medical Council, and continue to the next phase of securing meaningful work in New Zealand.
- The question of why these internships are exclusive to DHBs, and no longer available in the community, was raised.
- It was collectively agreed that Prof. Judy McGregor would bring this issue to the attention of the Health Workforce Advisory Board.

The Consumer Council acknowledged Ngozi's contribution to the discussion and thanked her for her time.

4 INFORMATION ITEM

4.1 **Patient Experience Report** (Agenda pages 37-40)

The Patient Experience Report was noted and a need to better understand the patient discharge process was raised and it was requested for the item to be added for discussion at the next meeting.

5 OTHER BUSINESS

Actions to note and to be followed up at next meeting:

- Mental Health discussion to be continued to resolve the shortage of mental health practitioners to increase capacity of the service
- It was agreed that Prof Judy McGregor will take the issue of shortage of Drs to the Health Workforce Advisory Group, Lorelle to email Judy with Ngozi's paper for the issue to be referred.
- Insik to email Lorelle regarding question on how items for discussion are decided to be on the on the agenda

The Chair thanked the members and attendees for their time.

The meeting closed with a Karakia.
The meeting adjourned at 4.00pm.

SIGNED AS A CORRECT RECORD OF THE MEETING OF THE WAITEMATĀ DISTRICT HEALTH BOARD – CONSUMER COUNCIL MEETING HELD ON 23 MARCH 2022.

_________________________________CHAIR

Draft Minutes of the meeting of the Consumer Council of the Waitematā District Health Board

Wednesday, 23 March 2022

held by video conference
commencing at 2.04pm

CONSUMER COUNCIL MEMBERS PRESENT:

Lorelle George (Chair)
Ngozi Penson (Deputy Chair)
Neli Alo
Samuel Cho
Alexa Forrest-Pain (Te Rūnanga o Ngāti Whātua)
Maria Halligan (Te Whānau o Waipareira)
Insik Kim
Jeremiah Ramos
Ravi Reddy
Kaeti Rigarlsford
Vivien Verheijen
Eden Li (student representative)

ALSO PRESENT:

Prof Judy McGregor (Ex-officio)
Dr Dale Bramley (Waitematā DHB Chief Executive Officer)
Samantha Dalwood (Disability Advisor)
Peta Molloy (Committee Secretary)
Ravina Patel (Manager, Patient Experience)
Johanne Egan (ED SMO/Clinical Lead People & Culture)
Cassie Khoo (Design Fellow)
Ivana Nakarada-Kordic (Human-Centred Design Specialist)
Janette Ng (Illustrator)

APOLOGIES:

No apologies were received.

WELCOME:

The Consumer Council Chair welcomed everyone in the meeting.

The meeting opened with a Karakia by Alexa Forrest-Pain

DISCLOSURE OF INTERESTS

It was noted that the Interest Register page needed to be updated to reflect changes for Lorelle George, Chair and Ngozi Penson, Deputy Chair.

There were no interests declared that might involve a conflict of interest with an item on the agenda.

1 AGENDA ORDER AND TIMING

1.1 Items were discussed in a slightly different order than listed in the agenda.

2 CONFIRMATION OF MINUTES

2.1 Confirmation of Minutes of the Consumer Council Meeting held on 9th February 2022

The minutes of the Consumer Council meeting, 9th February 2022 were not approved and the following amendments requested. The minutes would be resubmitted to the Council at its next scheduled meeting.

Amendments requested to the 9th February 2022 minutes:

- Section 3.4 'Discussion on NZREX' be updated to better reflect the discussion held.
- Noting the acknowledgement of Hannah Bjerga (Student Representative), who has had to step down from her position as a member of the Consumer Council and that a letter of gratitude for her membership and attendance has been provided to her on behalf of the Consumer Council.

2.2 Actions Arising from the previous meeting

i. It was noted, in relation to point **4.1** ***Patient Experience Report,*** that the discussion was to be continued at the next Consumer Council meeting in May. A better understanding of patients' discharge process was required.

ii. It was noted, in relation to point **3.2** ***Youth Mental Health,*** that perhaps a timeframe needed to be set to address the shortage of mental health practitioners in order to increase capacity of the service at a critical time.

iii. It was raised that further discussion with Mr Rob Campbell CNZM (Health NZ, Chair) was needed to establish links and expectations of a future partnership between Health NZ and the Consumer Council.

iv. It was acknowledged that the Transition Unit indicated that there was no decision made in how the Consumer Council would engage with the new entity at a local or regional level and that further clarity was needed.

v. Prof Judy McGregor provided an update on point ***3.4 Discussion on NZREX****.* The issue of shortage of Drs has been referred to the Health Workforce Advisory Board. Prof Judy McGregor will provide further updates once the Ministry of Health Workforce's directorate has briefed the Minister.

3 DISCUSSIONS

3.1 QSM Consumer Council paper approval (Agenda pages 12-15,79-88)

Samantha Dalwood (Disability Advisor) and Ravina Patel (Manager, Patient Experience) joined via videoconference for this item. The paper was taken as read.

Matters covered in the discussion and response to questions included:

- Positive change in three domains: increased score ratings from 2 to 3. The evidence supporting the overall ratings of 3 shows improvement in the last six months.
  Equity domain needs improvement with score of 2.
  It was acknowledged that different score categories in the iteration provided for WDHB to respond are not clearly differentiated.
  The aim is to address domains with scores of 2 to reflect improvement at the next QSM submission before the end of the year.
- Health Literacy training is now included in the six-monthly training schedule to all staff members to improve Patient Experience. Health Literacy training focuses on effective whanau involvement, communication, and language used ensuring accurate understanding of key information by the patient and whanau for better outcomes.
- Feeding Support Survey: data was collected from responses to surveys that were emailed out to selected patients. A total of 30 responses were received with very positive feedback. However, some areas for improvement were identified.
  The survey will be repeated and an updated report will be presented at the next meeting in May.
- It was noted that Health Quality and Safety have delayed the QSM report submission deadline to 31 May due to Covid-19. Also noted were changes to the Health Quality and Safety website (submission page and dashboard) due to upgrades.
- It was collectively agreed that the presented version of the QSM report was final and ready for submission in March.

The Consumer Council Chair acknowledged Samantha Dalwood's and Ravina Patel's input on the QSM Consumer Council paper and thanked them for their time.

3.2 ED Video Storyboard presentation and paper (Agenda pages 16-74)

Johanne Egan (ED SMO/Clinical Lead People & Culture), Cassie Khoo (Design Fellow), Ivana Nakarada-Kordic (Human-Centred Design Specialist) and Janette Ng (Illustrator) joined by video conference for this item.

Matters covered in the discussion and response to questions included:

- The ED video will supplement the ED Journey Map currently on display in the ED waiting rooms at both North Shore and Waitākere hospitals. The aim of the video is to provide general information and to be used across different Emergency Departments.
  Information includes: what to expect when coming to ED, what happens behind the scenes while patients wait, and what resources are available to support patients' ED journey and make them feel more comfortable
- Sections on specific areas of the patients' journey:
  - Different arrival points
  - Main point of contact upon arrival
    - Need to review current signage at the space itself to ensure information on main point of contact on arrival is clear and visible
  - Triaging of medical conditions
  - What happens behind the scenes
  - Language used
    - Some of the medical terms may need to be replaced with more accessible vocabulary; such as *resuscitation*
    - Discourse voice needs to be consistence throughout the entire video

        - Information could be a bit more specific rather than too general
        - Some of the dialogue, especially around waiting time, needs to be rephrased to avoid reinforcing negative stereotype around waiting time
    - Voucher for offsite emergency care providers in the community
        - Stages at which patients have access to the vouchers need to be clearly stated
        - A list of the locations where patients are able to use the vouchers for community urgent care services would be useful
        - Urgent community care centers: perhaps a specific section/shot with the specific location could be added to each individual video to make this information clearer to patients
        - Need to emphasise choice
    - Registration process
        - Need to identify at which stage patients are required to provide evidence of eligibility criteria
    - Interpreting services available 24/7
        - Need to ensure to replace word translator for interpreter
    - Additional visual aid with symbols could help patients identify the urgency of their condition
    - A small booklet on different languages would be useful while video versions in other languages are being developed
    - Additional support services information
        - Wi-Fi available: Need to ensure signs are visible
        - Cultural, access needs, care support: Need to ensure there is additional information in the space that is available to patients who may not know these services are available

The Consumer Council were invited to provide any further feedback directly to the team. A final iteration will be presented to the Council, which will be before the animation stage commences.

The Council Chair acknowledged the work of the team and thanked them for their time.

3.15pm to 3.20pm – the meeting adjourned for a short break from.

3.3 Patient Experience Report (Agenda pages 75-88)

Ravina Patel (Manager, Patient Experience) provided and update. The report was taken as read.

Matters covered in the discussion and response to questions included:

- Highlights of the report:
    - Friends and family health measures: overall performance score well above the target with 65%
    - Māori Health Measures: areas of improvements were identified with score of 60%
        - Feedback for this score shows further improvement is needed in areas of communication to effectively involve patients and their whanau, and on the information provided
        - Scores may have been impacted by the limited number of visitors due to Covid-19

- Areas of consideration when looking at the scores:
  - Volunteers haven't been working onsite. However, they have continued to provide sleep packs and care packs
- Patient Experience team has been supporting the Covid-19 response
  - Staff redeployment due to staff illness
  - Corporate team has been supporting the wards with non-clinical activities to maintain positive patient experience
- Food parcels demand has increased significantly in the last two months
  - Dec 2021: 32 food parcels were given across both sites
  - January 2022: 16
  - February 2022: 74
  - March 2022: 165-170
  - It is anticipated that there will be a decrease in demand in April-May
- A challenge in providing food parcels is trying to effectively manage stock whilst dealing with supply chain issues
- Volunteers to be reintroduced to their roles in the Orange Traffic Light setting
- Patient Experience data is being transferred to a new system over the coming months.
- Community organisation supply relationships:
  - PE provides patients with food parcels for 2-3 days upon discharge.
  - On discharge patients receive information from the social workers on where in the community they can access further support with food parcels if needed.

The Consumer Council acknowledged and thanked Ravina Patel for her work.

4 INFORMATION ITEMS

4.1 Covid-19 Update – Omicron (Verbal update)

Dr Dale Bramley (Chief Executive) provided an update on COVID-19 and the Omicron outbreak. It was also noted that the winter plan in place.

The Consumer Council acknowledged Dr Dale Bramley's update and thanked him for his time.

4.2 HQSC Code of Expectations submission update

Lorelle George (Chair) provided an update, noting the last document iteration was received being number 11. Feedback is required by Friday 25 March so that the document can then be submitted

4.3 Community concerns

Matters covered in the discussion and response to questions included:

i. Consumer Council Chair Lorelle George highlighted that all Consumer Council members are welcome to bring in relevant issues and concerns from the community and to propose agenda items for discussion.

ii. It was raised that Waitākere Hospital's master plan redevelopment project is awaiting approval and this has been deferred for decision to the new entity Health NZ. The community along with Waitākere Health Link have sent a letter to the local MP, and all three parties are expected to meet to address this issue. A petition will also be in circulation.

It was agreed that a letter would be sent to the Minister of Health related to the Council's concern around the delay of the Waitakere Hospital redevelopment plan.

5 OTHER BUSINESS

5.1 Agenda items for future meeting

- Agenda items
  - Follow up on previous meeting's actions and unresolved issues
  - Bring in community issues or concerns
- Members are encouraged to bring any community issues for discussion
- It was established that individual experiences with feedback in relation to complaints can be redirected to the appropriate channels through the feedback process
- Consumer Council has clarified that its primary role is to examine and address systemic and service issues that may come through individuals in the community
- Insik to reach out to Sam Dalwood regarding feedback from the community to be referred to the appropriate channel for resolution.

5.2 Meeting evaluation

The Consumer Council Chair Lorelle George invited all members to evaluate the meeting and provide feedback. It was agreed that the meeting addressed all issues discussed effectively.

The Chair thanked the members and attendees for their time.

The meeting closed at 4.00pm.

SIGNED AS A CORRECT RECORD OF THE MEETING OF THE WAITEMATĀ DISTRICT HEALTH BOARD – CONSUMER COUNCIL MEETING HELD ON 23 MARCH 2022.

________________________________CHAIR

4. DISCUSSION ITEMS

4.1 Patient Experience Report
4.2 Complaints and Compliments
4.3 Discharge Process Update (Verbal)
4.4 Feeding Support Survey
4.5 Facilities Update (Verbal)

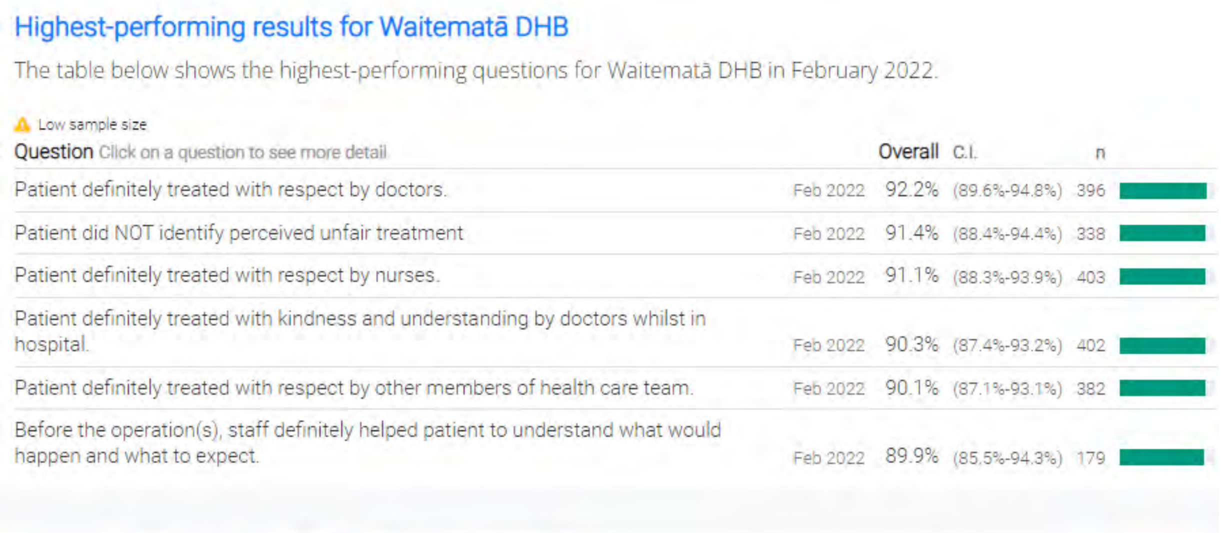
Patient Experience Feedback

1.0 National Inpatient Survey

Participation

- Patients discharged from Waitematā DHB hospitals from 31st January to 13th February 2022 were emailed the survey.
- Waitematā DHB sent out 1525 invitations to complete the survey and achieved 441 responses, a 29.5 % response rate. This is higher than the national response rate of 26.3%.
- Of the 441 responses, 32 responses were from Māori patients and 19 were from Pacific patients.

Performance



Highest-performing results for Waitematā DHB

The table below shows the highest-performing questions for Waitematā DHB in February 2022.

⚠ Low sample size

Question Click on a question to see more detail		Overall	C.I.	n
Patient definitely treated with respect by doctors.	Feb 2022	92.2%	(89.6%-94.8%)	396
Patient did NOT identify perceived unfair treatment	Feb 2022	91.4%	(88.4%-94.4%)	338
Patient definitely treated with respect by nurses.	Feb 2022	91.1%	(88.3%-93.9%)	403
Patient definitely treated with kindness and understanding by doctors whilst in hospital.	Feb 2022	90.3%	(87.4%-93.2%)	402
Patient definitely treated with respect by other members of health care team.	Feb 2022	90.1%	(87.1%-93.1%)	382
Before the operation(s), staff definitely helped patient to understand what would happen and what to expect.	Feb 2022	89.9%	(85.5%-94.3%)	179

Lowest-performing results for Waitematā DHB

The table below shows the lowest-performing questions for Waitematā DHB in February 2022.

⚠ Low sample size

Question Click on a question to see more detail		Overall	C.I.	n
Patient was definitely told the possible side effects of the medicine (or prescription for medicine) they left hospital with, in a way they could understand.	Feb 2022	57.1%	(51.6%-62.6%)	308
Hospital staff definitely included patient's family/whānau or someone close to patient in discussions about the care received during visit.	Feb 2022	58.6%	(52.8%-64.4%)	280
Hospital staff definitely talked with the patient about whether they would have the help they needed when they left the hospital.	Feb 2022	62.2%	(56.8%-67.6%)	307
Patient definitely had enough information about how to manage their condition or recovery after they left hospital.	Feb 2022	67.2%	(62.6%-71.8%)	405
Towards the end of the patient's visit, they were definitely kept informed as much as they wanted about what would happen and what to expect before they could leave the hospital.	Feb 2022	68.2%	(63.7%-72.7%)	406

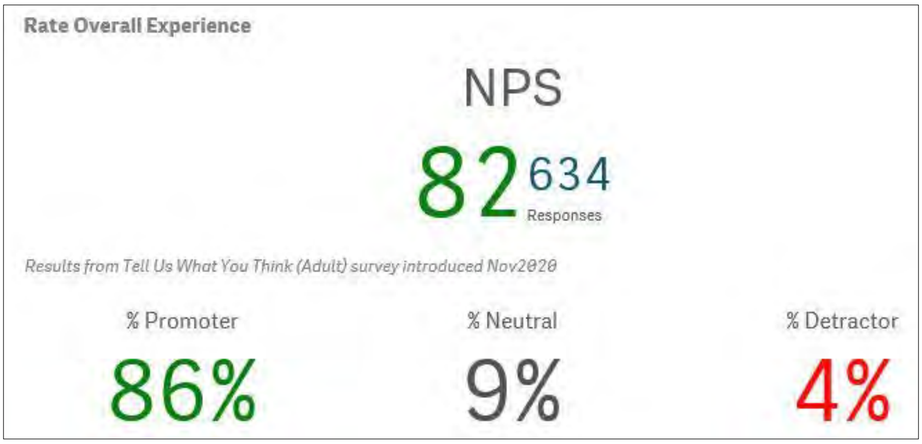
Patient Experience is working with the discharge planning team to ensure our patients are given the support they need to manage their recovery after they leave the hospital.

2.0 Friends and Family Test

2.1 Friends & Family Test Overall Results – Adult Survey

In March 2022 the Net Promoter Score (NPS) was 82 with feedback from 634 people. The NPS target has been revised and increased to 70. This month the NPS is up one point on the previous month and continues to score above the new target of 70. The number of responses is also up on the previous month however, it remains lower than usual due to the Omicron Covid-19 outbreak.

2.2 Friends & Family Test Overall Results



Rate Overall Experience

NPS

82 634 Responses

Results from Tell Us What You Think (Adult) survey introduced Nov2020

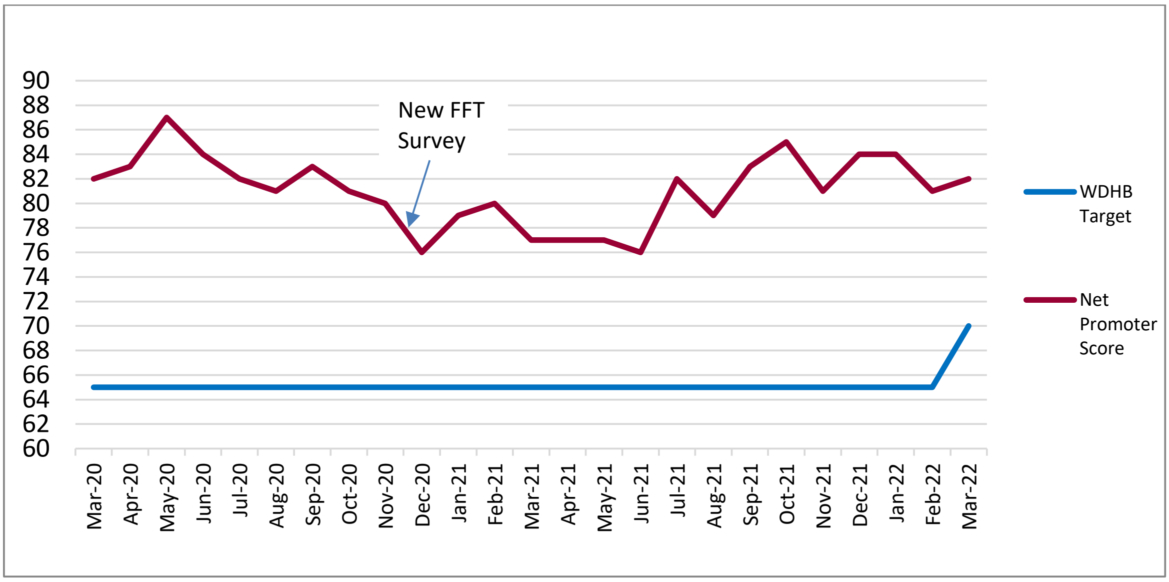
% Promoter	% Neutral	% Detractor
86%	9%	4%

Figure 1: Waitematā DHB overall NPS

Pt Experience by Service (Adult and Maternity)

Month & Year	Surveys	Rate Overall Experience	Welcoming and Friendly	Listened To	Treated with Compassion	Involved in Decision Making	Explained in a Way I Understood
Totals	634	82	89	87	88	79	87
Mar-2022	634	82	89	87	88	79	87

Table 1: Waitematā DHB overall FFT results



Graph 1: Waitemata DHB Net Promoter Score over time

The above chart shows the net promoter score over the last 2 years. A new Friends and Family Test was introduced in November 2020 changing the question from 'based on your experience would you recommend' to a general question asking about their overall experience. The scale was also changed from a five point scale to a more sensitive 11 point scale.

2.3 Total Responses and NPS to Friends and Family Test by ethnicity

March 2022	NZ European	Māori	Asian	Pacific	Other/ European
Responses	343	53	74	48	116
NPS	86	77	69	85	80

*Low base size, interpret with care

Table 2: NPS by ethnicity

In March, all ethnicities with the exception of Asian met the Waitemata DHB NPS target and scored above 70.

March 2022	NZ European	Māori	Asian	Pacific	Other/ European
Staff were welcoming and friendly	91	85	79	96	89
I was listened to	88	82	80	98	85
I was treated with compassion	91	84	77	96	86
I was involved in decision making	83	72	69	85	76
My condition/treatment was explained in a way that I understood	90	82	86	93	80

Table 3: NPS for all questions by ethnicity

This month, all measures score at or above the DHB target. NZ European recorded their highest score to date for 'treated with compassion', 'involved in decision making' and 'explained in a way that was understood'.

2.4 Patient Experience Highlights

- **Migration from InMoment to Qualtrics**

Waitematā DHB has begun the process of migrating our patient experience reporting system used for surveying and reporting patient experience, patient reported outcome measures (PROMs) and staff experience from our current provider 'InMoment' to 'Qualtrics'. The Qualtrics tool has increased functionality and provides a person-centric view of completed surveys and workflow management functions which will reduce the effort required to schedule and manage surveys. Key user groups, including Patient Experience, is undergoing intensive training prior to the go live date in June 2022.

- **Patient Feedback**

Once again, feedback this month has been positive with patients and whānau citing great care, professional, friendly and compassionate staff and good communication as some of the main reasons for an exceptional experience.

3.0 Volunteers

3.1 Volunteer Recruitment Statistics

Volunteer numbers are down by 36 on the previous month.

Green Coats Volunteers (Front of House) (A)	Other allocated Volunteers (B)	Volunteers on boarded awaiting allocation (C)	Total volunteers available (D) (A) + (B) + (C) =(D)
48	103	9	160

Table 4: Volunteers Recruitment

We continue to receive approximately 1-2 applications a month. Unfortunately, a number of volunteers have decided to resign for various reasons including relocation, Omicron concerns and change of circumstances.

3.2 Volunteer Highlights

Hospital Auxiliary

Waitakere and North Shore Auxiliary met in March to discuss ongoing demand for items that the North Shore team makes and sends to Waitakere. They have received many requests for baby items from Birthing Unit, Special Care Baby Unit, Maternity and Hine Ora and have compiled a comprehensive list of items requested regularly. In addition to the regular delivery to the wards at both sites, Hospital Auxiliary volunteers have provided four boxes of Sleep Packs and five sets of Discharge packs. Their latest project is 'twiddle mitts' and they have already made 15.

Return of volunteers

From Tuesday 19th April, our hospital volunteers will return to resume their roles. The introduction will be gradual with the focus initially on volunteers returning to non-blue stream areas such as Front of House and non-covid wards. Once these volunteers are settled into their roles, Patient Experience will work with Occupational Health and Safety to complete Vulnerable Worker Risk Assessments for any volunteers who wish to return to blue-stream covid areas. Nearly half of our volunteers have expressed that they are ready to return and excited to support the organisation once again.

Their absence has been felt greatly and staff are excited to see the volunteers return. "*Our volunteers bring another friendly and welcoming layer to the hospital environment and we have missed them in this crazy time" (Staff member)*

The Patient Experience team continues to engage regionally with other hospital volunteer leaders to align our approach to bringing back volunteers.

4.0 Consumer Council Update

The Consumer Council met on 23 March 2022. They discussed the following agenda items at their most recent meeting:

- **QSM Consumer Council paper approval** – Samantha Dalwood and Ravina Patel presented the consumer engagement quality and safety marker (QSM). This is measured by all District Health Boards biannually and needs to be endorsed by the Consumer Council members. The Consumer Council endorsed the scores and that these are submitted to the Health Quality and Safety Commission (HQSC).
- **ED Video Storyboard presentation**– Cassie Khoo, Design Fellow, and Johanne Egan, Clinical Lead, People & Culture, presented the storyboard for the Emergency Department information video. After creating the ED journey map in 2021, a recommendation was made for a video to be made to accompany the wall map. The Consumer Council members gave feedback on the video storyboard. Cassie and her team we invited to come back to the Council with the next iteration of the video.
- **COVID-19 update** – Omicron update from Dale Bramley, CEO. Dale told the meeting that there have been a large number of patients with COVID in the hospital and this has put some pressure on staff and services. Work is now happening to clear the backlog of operations that have been impacted by this. Dale encouraged people to get their booster and flu vaccination. He said that there has been virtually no flu in NZ for two years, but with the borders opening there is likely to be more this year. He said that the promotion of general good health measures is important, for example, wearing masks and washing hands as we continue to navigate COVID.
- **HQSC Code of Expectations submission** – update from Lorelle George, Consumer Council Chair. Lorelle updated the meeting on the submission that has been made the HQSC about the role of Consumer Councils in Health NZ and the Māori Health Authority. This work was led by CMDHB, with input from the three Auckland DHB Consumer Council Chairs.

Waitematā
District Health Board
Best Care for Everyone

Overview of Complaints Received by Waitematā District Health Board

The following information is provided to give the Consumer Council an understanding of the complaint activity and complaint themes at Waitematā District Health Board, since 2019, providing greater granularity for the last 12 months.

Complaints Management Process

All complaints are managed in line with the District Health Board's (DHB) Complaints Management policy. Complaints provide a means for consumers to have an input in the continuous improvement of the organisation.

Waitematā DHB has a target of responding to and resolving complaints within 14 days of receipt. Responses are usually in writing, however, we encourage staff to call the service user to discuss their concerns with the aim of resolving them at the earliest opportunity, if their concerns are serious the call is to be made either the same or next day. A timely response to any complaint is essential to effective complaint management and all services within the organisation are monitored on their complaint resolutions. **Appendix 1** shows how the Divisions have performed against the 14-day target since 2019.

Service users, patients, family and whānau can lodge a complaint with Waitematā DHB in a number of ways:

- Emailing Feedback@waitematadhb.govt.nz
- Telephoning the Feedback team on (09) 486 8920 extn 43153
- Completing a paper Feedback Form located in patient areas and in the main reception areas
- Completing the electronic Feedback Form on the DHB website
- Writing a letter
- Talking directly with a member of staff

Over recent years the Feedback Team have seen a notable decrease in the number of complaints received by letter and phone call. The majority of complaints are received via email and the Waitematā District Health Board's website 'contact us' section.

Regardless of the complaint method, the procedure for the management of the complaint is the same. The Consumer Feedback Administrator will log the details of the complaint onto the Feedback system. A unique reference number will be attributed to the complaint, a complaint severity and category will be assigned, and the appropriate Service or Divisional Manager identified, and the complaint sent to them.

Consent

If a complaint is received from a third party e.g. the patient's whānau or friend. In the interest of patient confidentiality and in line with the Health Information Privacy Code 2020, Waitematā District Health Board is unable to release information regarding a patient's care and treatment without the consent of the patient. When a third party raises a complaint on a patient's behalf, a 'Consent to Release Information' form will be sent to the patient receiving the care. If they are willing for information regarding their care and treatment, as it relates to the complaint, to be released to the person who has complained on their behalf they are asked to complete the form and return it to the Feedback Team. Consent from the patient is not required if the person who is raising the complaint is the patient's attorney specified in an Enduring Power of Attorney (EPoA) for care and welfare or welfare guardian appointed by a court order.

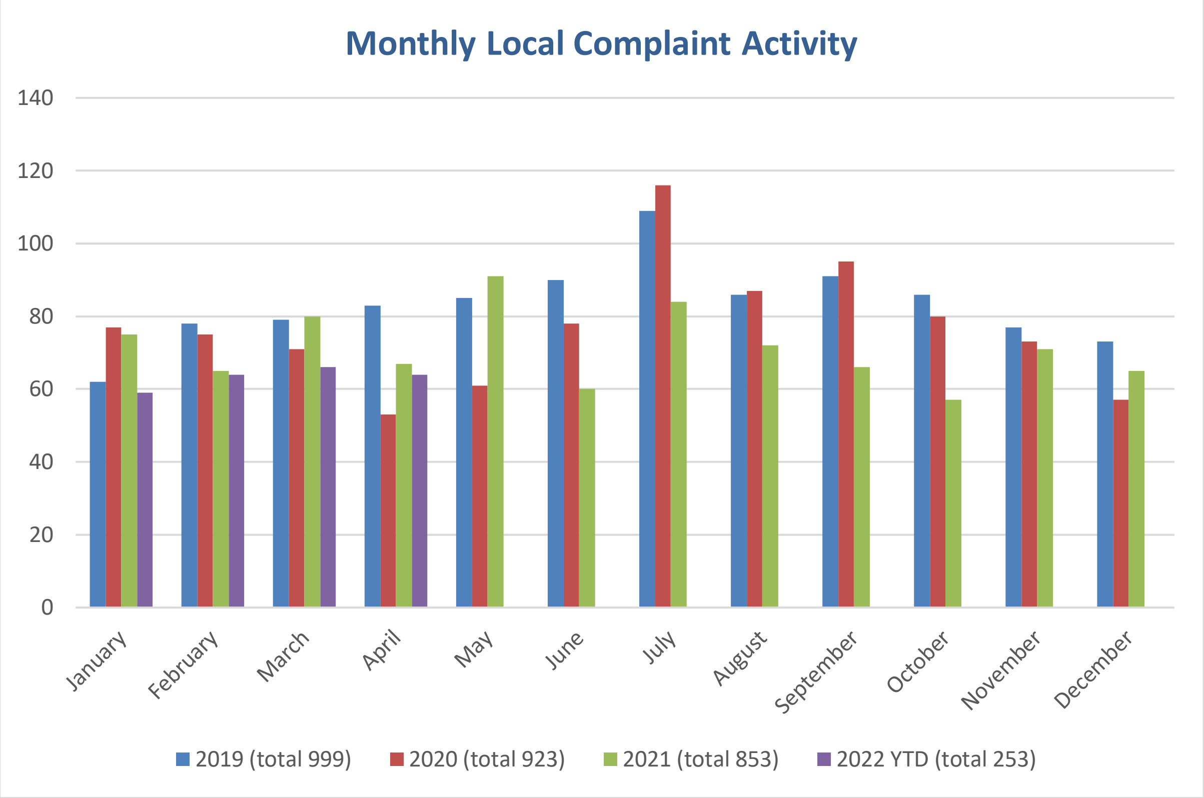
Where there is a patient safety concern, the Feedback Team will notify the relevant service of the issues raised in the complaint, whether consent has been obtained or not.

Complaints data

Complaints sent directly to the DHB

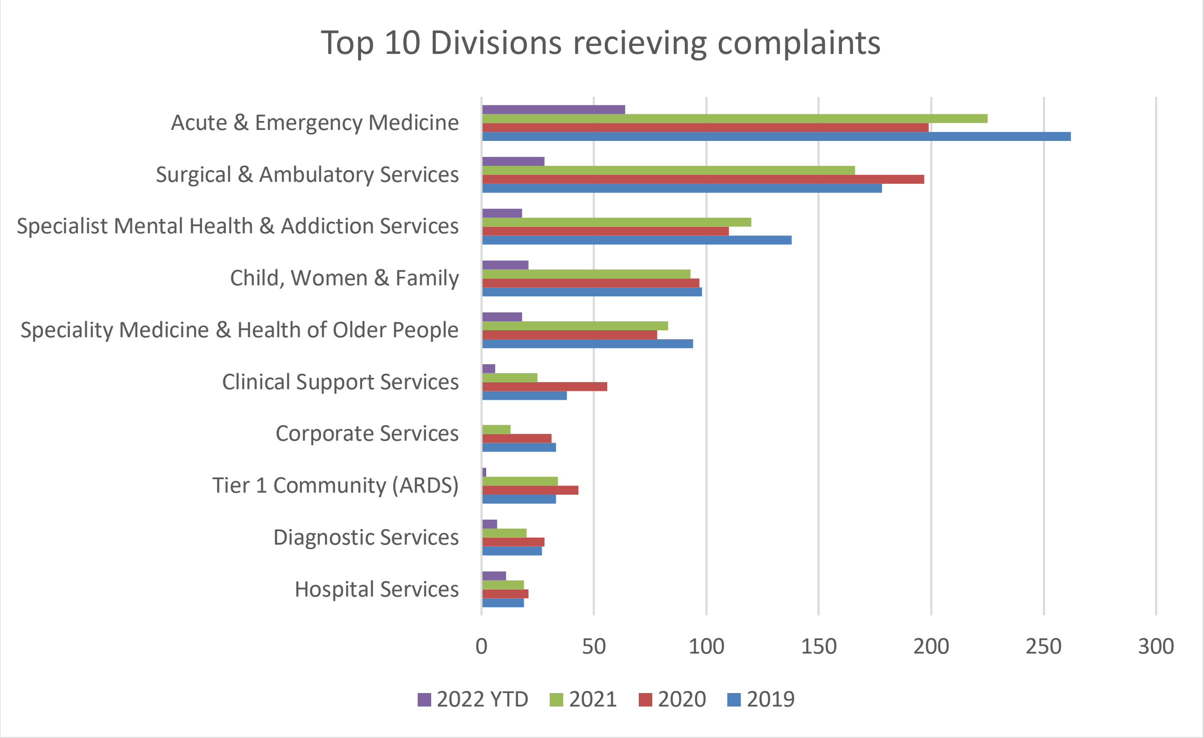
The following table details monthly local complaint activity in the period January 2019 to March 2022 (YTD) which demonstrate a general decrease in local complaints over the period. This trend of a decrease in local complaints received is noted for the Divisions who have received the highest number of complaints in the period January 2019 to March 2022 (*note*: this is likely to be linked to the level of activity / patient interactions and possible impact of COVID-19 restrictions and so does not necessarily indicate areas of concern).

Monthly Waitematā DHB Local Complaint Activity: January 2019 – March 2022 (YTD)



All complaints received by the Feedback team are logged against a Division. The following table shows the Divisions receiving the most complaints since January 2019 to March 2022 (YTD).

Complaint numbers[1] by Waitematā DHB Division - January 2019 – March 2022



Complaints are logged against primary and secondary complaint categories. The list of complaint categories used by Waitematā DHB has been added at **Appendix 2**. The number of categories allocated cannot be correlated with the number of complaints received, as one complaint may be allocated several primary and secondary categories.

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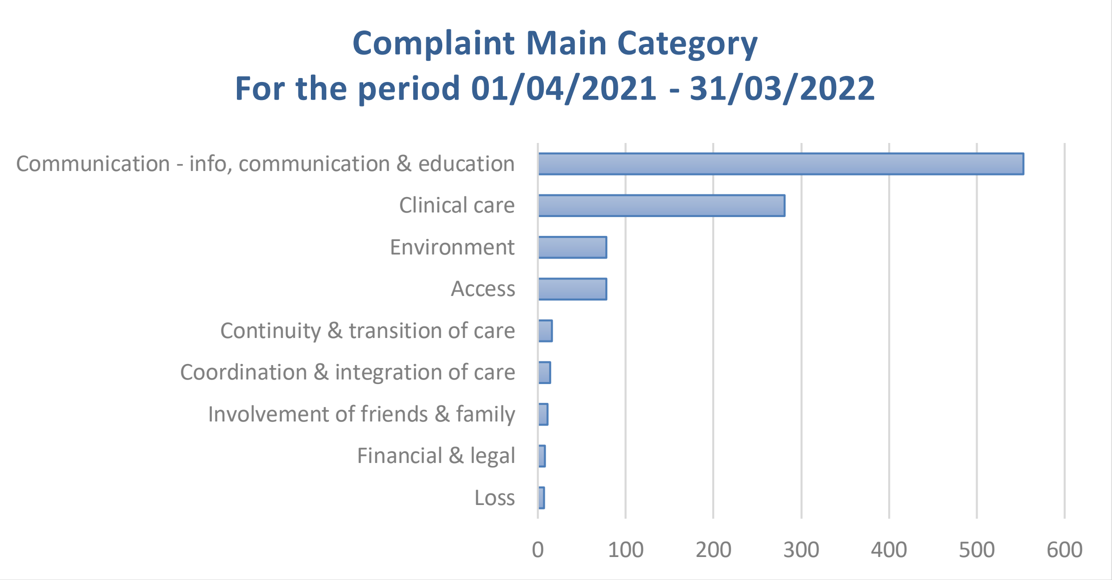
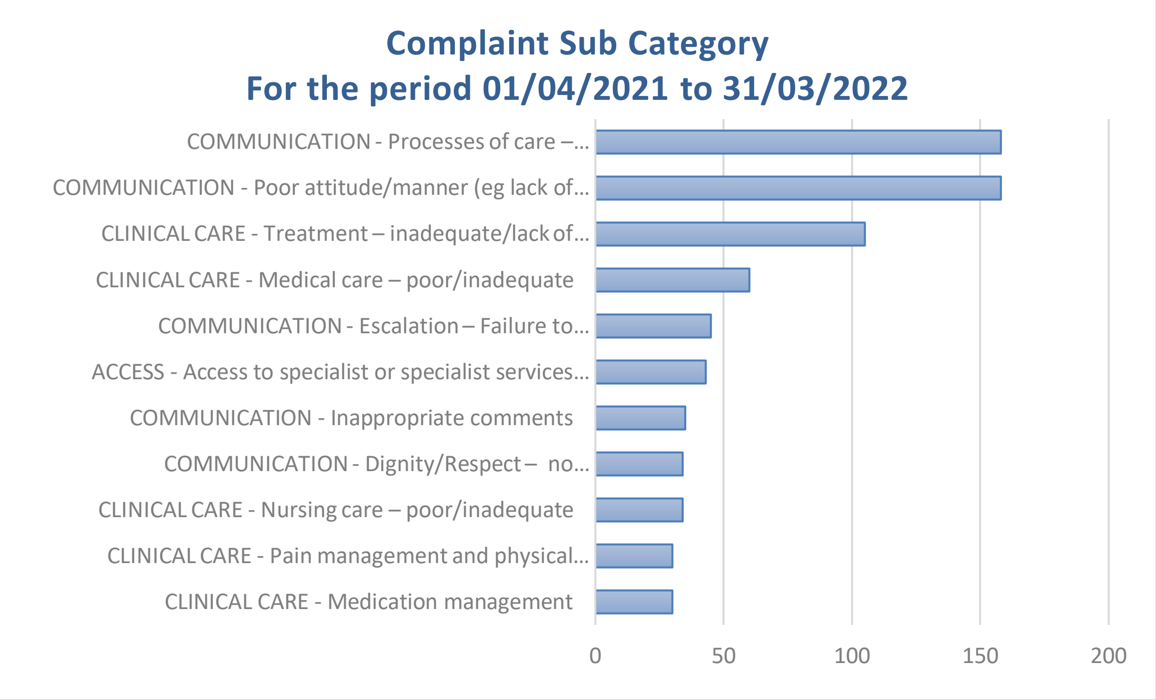
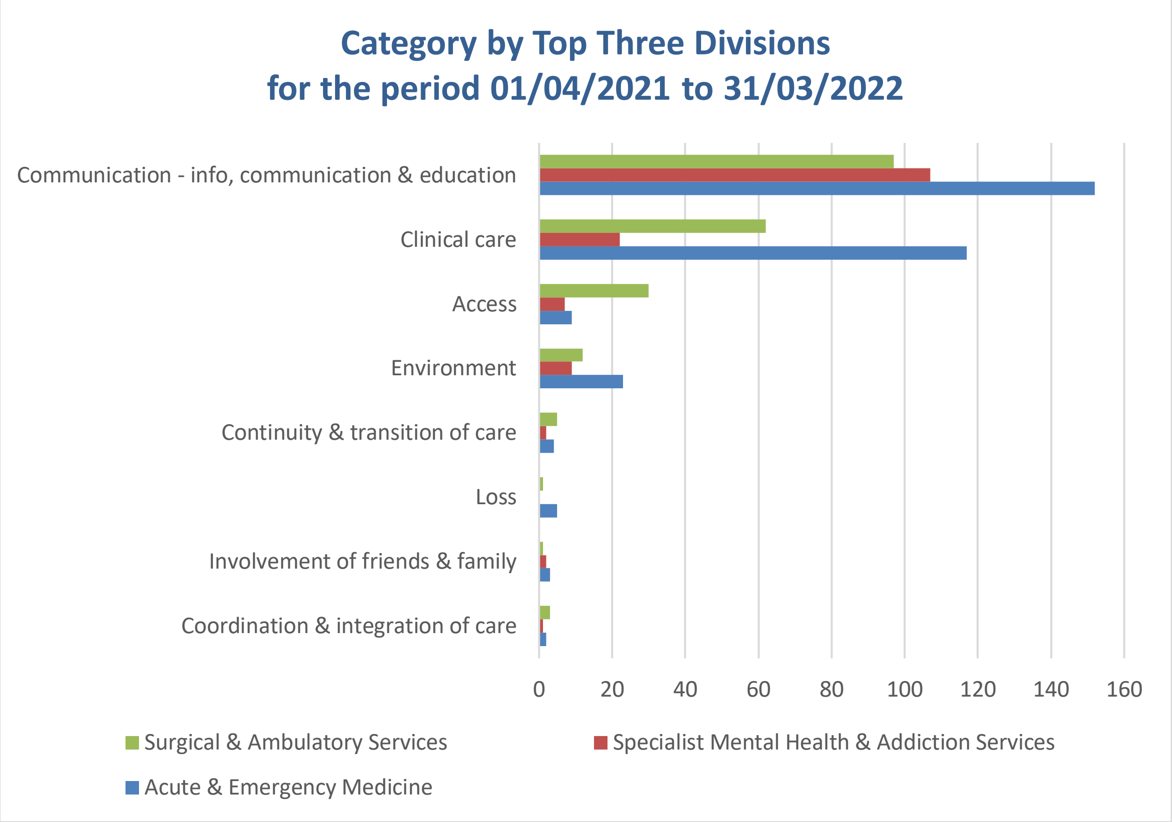
[1] Excluding Health Disability Commissioner complaints





The following chart shows the complaint categories within the top three Divisions receiving the most complaints where communication is the most common issue across these Divisions.



Category by Top Three Divisions
for the period 01/04/2021 to 31/03/2022

<u>Complaints sent directly to the Health and Disability Commissioner (HDC)</u>

The Health Disability Commissioner (HDC)[2] Analysis 2021, national data shows a similar picture regarding the Divisions / Services receiving the highest number of complaints – Surgery, Mental Health and Medicine.

<u>1 January to 30 June 2020</u>

<u>1 July to 31 December 2020</u>

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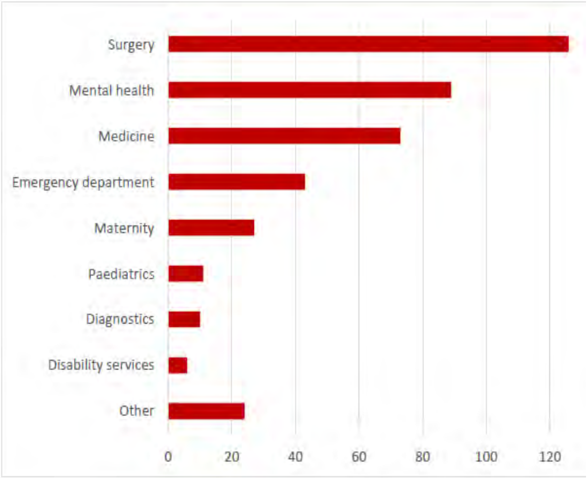
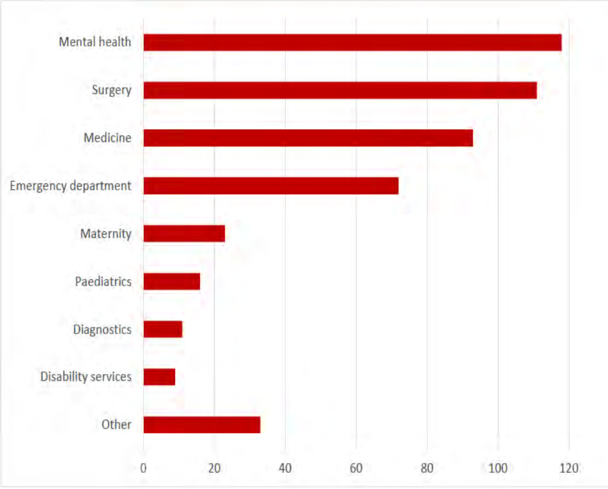
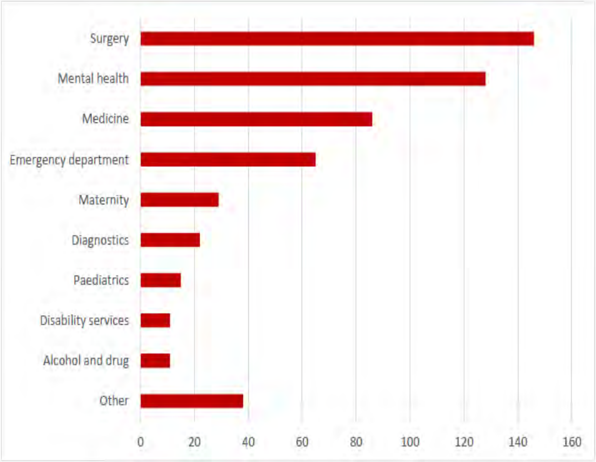
[2] Complaints to HDC involving District Health Boards - Report and Analysis for period 1 January to 30 June 2020
Complaints to HDC involving District Health Boards - Report and Analysis for period 1 July to 31 December 2020
Complaints to HDC involving District Health Boards – Report and Analysis for period 1 January to 30 June 2021





1 January to 30 June 2021



The DHB has slightly different complaint categories than the HDC, however, we are able to do a high-level comparison. When looking at the 2021 National HDC data it shows that nationally the top primary complaint category for 2021 is Care/Treatment followed by Access/Funding, whilst the HDC analysis of **all specific issues** identified in complaints specifically about Waitematā DHB, Communication is the most common issue.

Nationally, the primary issues identified in complaints received by the HDC Analysis have remained consistent between January 2020 and June 2021 as listed below.

1 January to 30 June 2020

- The most common primary issue categories were:
    - Care/treatment (43%)
    - Access/funding (20%)
    - Consent/information (11%)
    - Communication (9%)

1 July to 31 December 2020

- The most common primary issue categories were:
    - Care/treatment (46%)
    - Access/funding (16%)
    - Consent/information (11%)
    - Communication (7%)

- The most common specific primary issues complained about were:
  - Lack of access to services (12%)
  - Missed/incorrect/delayed diagnosis (10%)
  - Unexpected treatment outcome (8%)
  - Waiting list/prioritisation issue (7%)
  - Inadequate/inappropriate treatment (5%)

- The most common specific primary issues complained about were:
  - Missed/incorrect/delayed diagnosis (13%)
  - Lack of access to services (8%)
  - Unexpected treatment outcome (7%)
  - Waiting list/prioritisation issue (7%)
  - Inadequate/inappropriate treatment (6%)

1 January 2021 to 30 June 2021

- The most common primary issue categories were:
  - Care/treatment (48%)
  - Access/funding (16%)
  - Consent/information (11%)
  - Communication (7%)

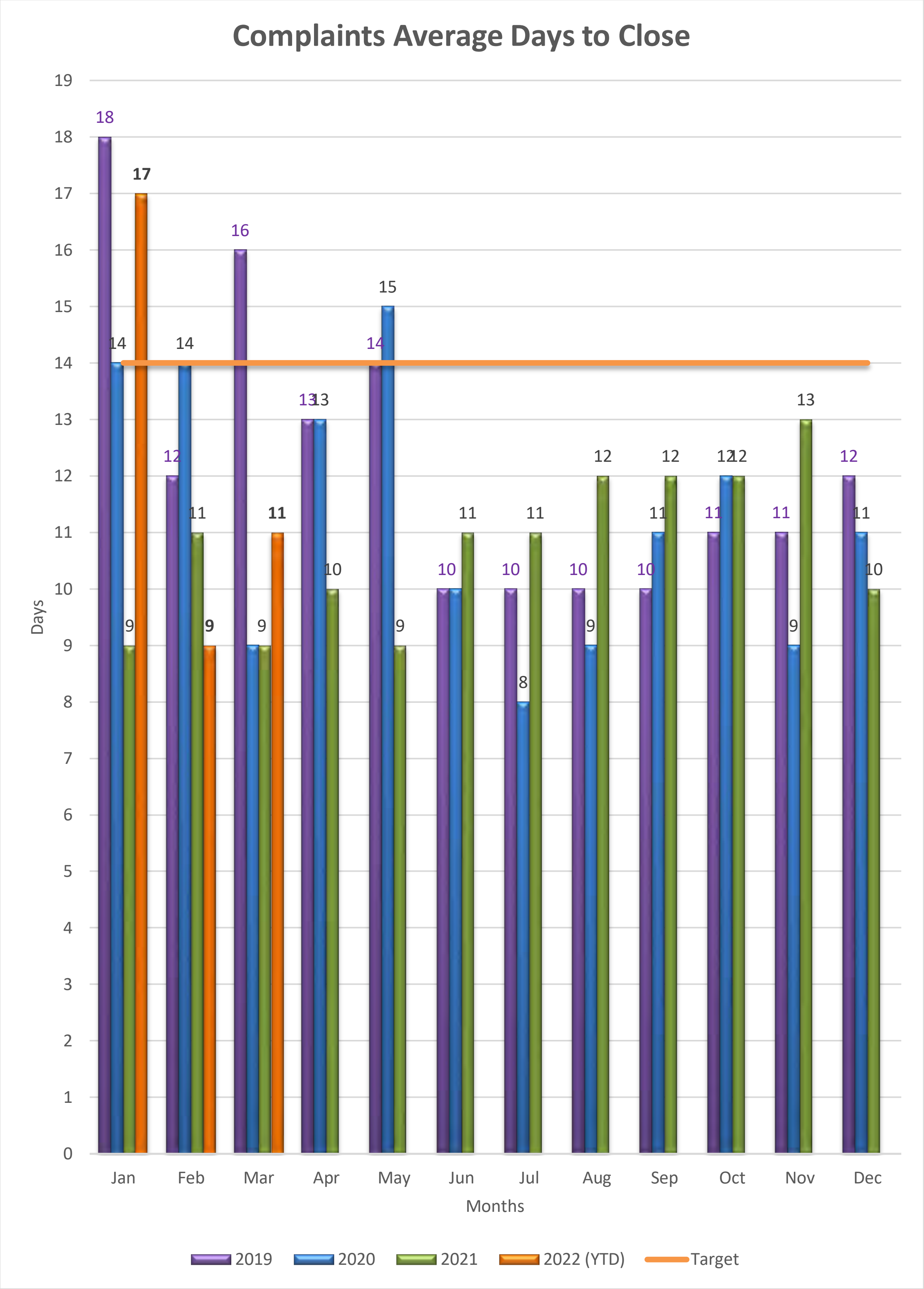
- The most common specific primary issues complained about were:
  - Missed/incorrect/delayed diagnosis (11%)
  - Unexpected treatment outcome (8%)
  - Lack of access to services (6%)
  - Inadequate/inappropriate treatment (6%)

The HDC also provide data in their analysis specifically related to complaints they receive where Waitematā DHB was identified as a provider by the complainant or was subsequently identified by HDC as a party. The most common primary issues complained about for Waitematā DHB for the period January 2021 to July 2021 were Care/treatment (27.9%), Consent/information (14%) and Access/funding (11.6%) which is comparable to the national data.

Comments and observations from the Consumer Council are welcomed on the above information.

Sarah Murray
Complaints and Adverse Events Manager
4 May 2022

Appendix 1


Complaints Average Days to Close
Days
19
18
17
16
15
14
13
12
11
10
9
8
7
6
5
4
3
2
1
0
Jan: 18, 14, 9, 17
Feb: 12, 14, 11, 9
Mar: 16, 9, 9, 11
Apr: 13, 13, 10
May: 14, 15, 9
Jun: 10, 10, 11
Jul: 10, 8, 11
Aug: 10, 9, 12
Sep: 10, 11, 12
Oct: 11, 12, 12
Nov: 11, 9, 13
Dec: 12, 11, 10
Months
2019
2020
2021
2022 (YTD)
Target

Appendix 2: Waitematā DHB Complaint Categories

CATEGORY	SUBCATEGORY
ACCESS	• Access to specialists or specialist services when a referral is made • Access to the location of hospitals & clinics • Appointments – ease of scheduling an appointment • Appointments - availability of appointments when needed • Availability of transportation • Inequitable service provision due to consumer's disability • Referrals - clear instructions provided on when and how to get referrals
CLINICAL CARE	• Allied Health care – poor/inadequate • Diagnosis – delay/lack of diagnosis • Inequitable service provision due to consumer's disability • Medical care – poor/inadequate • Medication management • Nursing care – poor/inadequate • Pain management and physical comfort – inadequate/lack of • Treatment –inadequate/lack of treatment • Wound management
COMMUNICATION **(INFORMATION, COMMUNICATION & EDUCATION)**	• Incorrect information – may require amendment • Clinical status, progress & prognosis - inadequate/lack of information • Communication - methods not appropriate due to consumer's disability • Dignity/Respect – no respect/sensitive to patient/family's cultural values, language, discrimination • Discharge - inadequate/lack of information regarding medications, physical limitations, dietary needs, social & physical support etc. after discharge • Discrimination – due to; age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, or sexual orientation • Escalation – Failure to respond/listen to concerns raised by patients, families and whānau • Inappropriate behaviour / harassment • Inappropriate comments • Informed consent - informed & shared decision making – no respect of patient preferences/lack of • Poor attitude/manner (eg lack of kindness, courtesy, empathy, helpfulness; responsiveness; not listen etc.) • Privacy / Confidentiality - Breach • Processes of care – inadequate/lack of information
CONTINUITY & TRANSITION OF CARE	• Discharge planning - inadequate/lack of • Discharge summary – not provided or inadequate • Inequitable service provision due to consumer's disability • Ongoing treatment & services after discharge - inadequate/lack of
COORDINATION & INTEGRATION OF CARE	• Coordination of clinical care - inadequate/lack of • Inequitable service provision due to consumer's disability • Integration of ancillary & support services - inadequate/lack of

CATEGORY	SUBCATEGORY
ENVIRONMENT	• Access / Environment – arrangements not suitable due to consumer's disability • Access for family & friends - inadequate/lack of • Equipment - inadequate/lack of • Hygiene – (inadequate/lack of) patient areas/hospital not clean • Nutrition/food/café facilities - inadequate/lack of • Parking • Physical comfort for family & friends - inadequate/lack of • Physical comfort for patient - Inadequate/lack of • Privacy - inadequate/lack of • Safety & Security – inadequate / lack of • Safety & Security – not feeling safe / feeling vulnerable • Signage - inadequate/lack of • Smoking • Telephonist services - inadequate/lack of
FINANCIAL & LEGAL	• Funding of health services • Inequity due to consumer's disability • Patient eligibility & invoicing
INVOLVEMENT OF FRIENDS & FAMILY	• Family & friends - inadequate/lack of accommodation by clinicians & caregivers of family & friends to whom patient relies on for emotional & social support • Family & Friends – failure to recognise consumer's required/specific support needs due to their disability • Family & friends - inadequate/lack of recognition of their needs • Family & friends as caregivers - inadequate/lack of support for them
LOSS	• Accidental loss • Alleged Theft

4.4 **Discussion:** Patient Experience Feeding Support Survey

Recommendations:

The recommendations are that you:

Please specify what you wish to achieve or questions that you wish to ask the Council (see sample below)

a)	Review the Family and Whānau-Centred Tube-Feeding and Weaning Closure Report for more background (Attached)	**Yes**
b)	Review the Patient Experience Feeding Support Survey - Summary Report 12/07/2021 (Attached)	**Yes**
c)	Provide your feedback and recommendations	**Yes**

Background

The feedback received in this survey helps us understand how we can improve patient experience of our services to families and whānau with children with feeding difficulties requiring tube-feeding and weaning support.

These include: Quality care provision; Psychosocial support as required for improved outcomes; Consistent approach as close as home as possible; Productive communication between the multi-disciplinary team and Whānau; Facilitate processes for quality improvement.

Key Issues

- Timeframe for feedback from families: The responses received were far less than expected in this survey. I would suggest we repeat this exact survey again after the recommended interventions were made and allow 3-4 weeks' timeframe for feedback Reasoning for this recommendation: This is not an easy survey to complete due to the complexity, psychologically or emotionally experienced within each child's journey. Parents might need to get their 'head around' thinking/remembering their journey and then find the time to do it.
- Feedback received however highlighted important themes that is still gaps in the service, including meeting whānau expectations for the timing of tube weaning.
- Feedback required on empowering families and whānau in this journey with their child and managing their expectations around tube feeding and weaning.
- Any other comments or recommendations are valued.

Please specify key issues and questions to guide the discussions

Contacts for further discussion (if required)

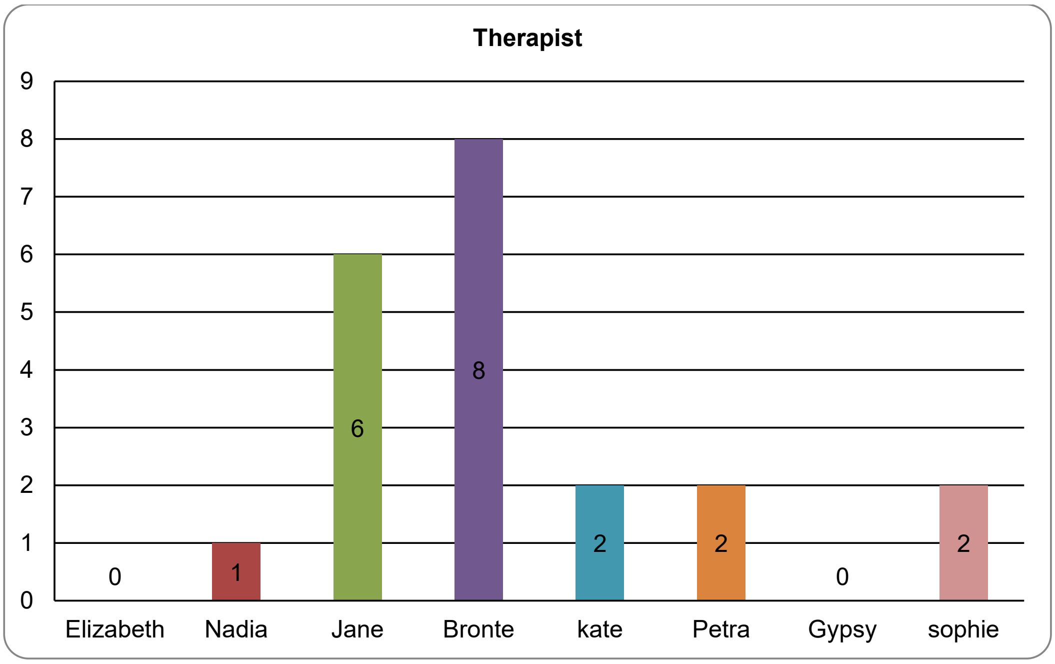
Name	Position	Telephone	Suggested first contact
Todd Warner	**Paediatrician**	021323857	✓

Feeding Support Survey
Summary Report
12/07/2021

Therapist

Response Rate: **100% (N=21)** Question Type: **Choose one** Tag: **Therapist**

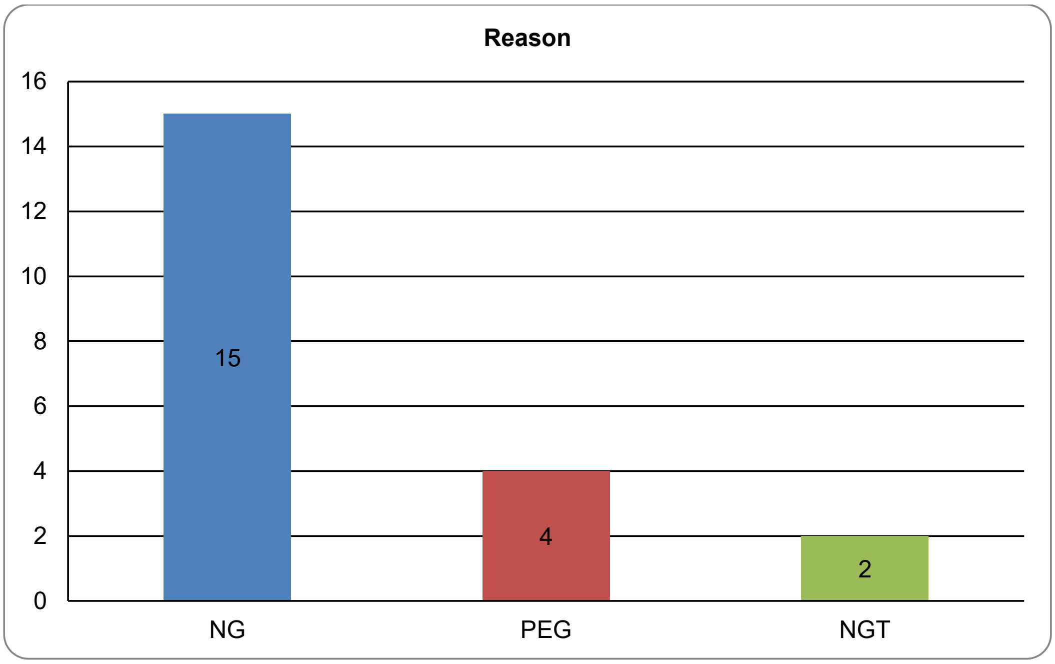
Elizabeth	**0**
Nadia	**1**
Jane	**6**
Bronte	**8**
kate	**2**
Petra	**2**
Gypsy	**0**
sophie	**2**
Total Responses	**21**



Reason

Response Rate: **100% (N=21)** Question Type: **Text** Tag: **Reason**

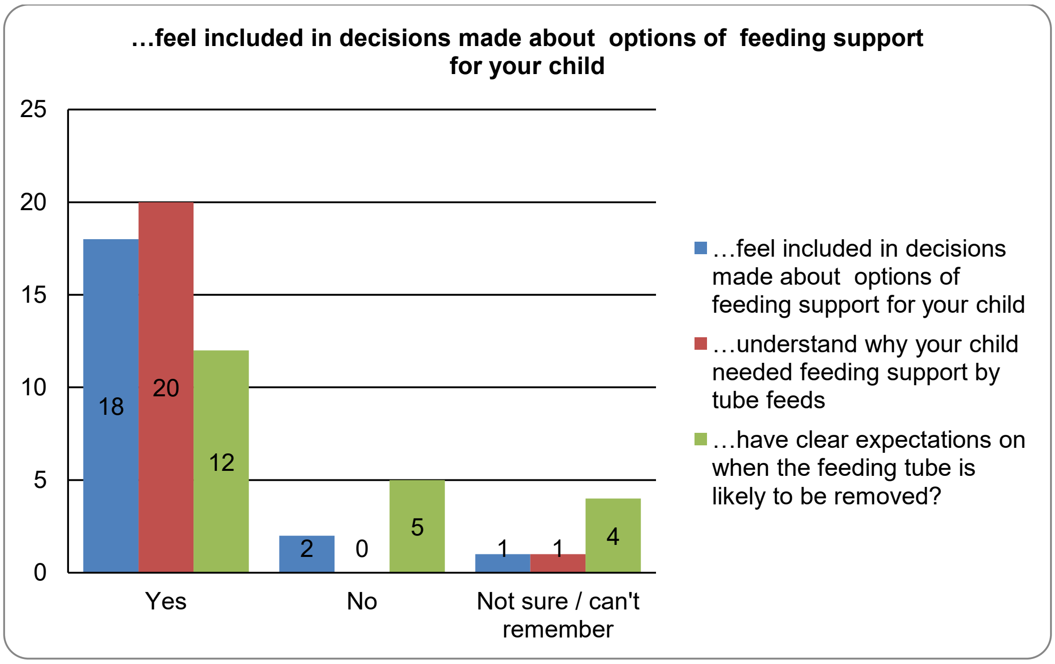
NG	**15**
PEG	**4**
NGT	**2**
Total Responses	**21**



1. Before leaving the hospital, did staff help you to …? Answer Group 1

Question Type: **Choose one**

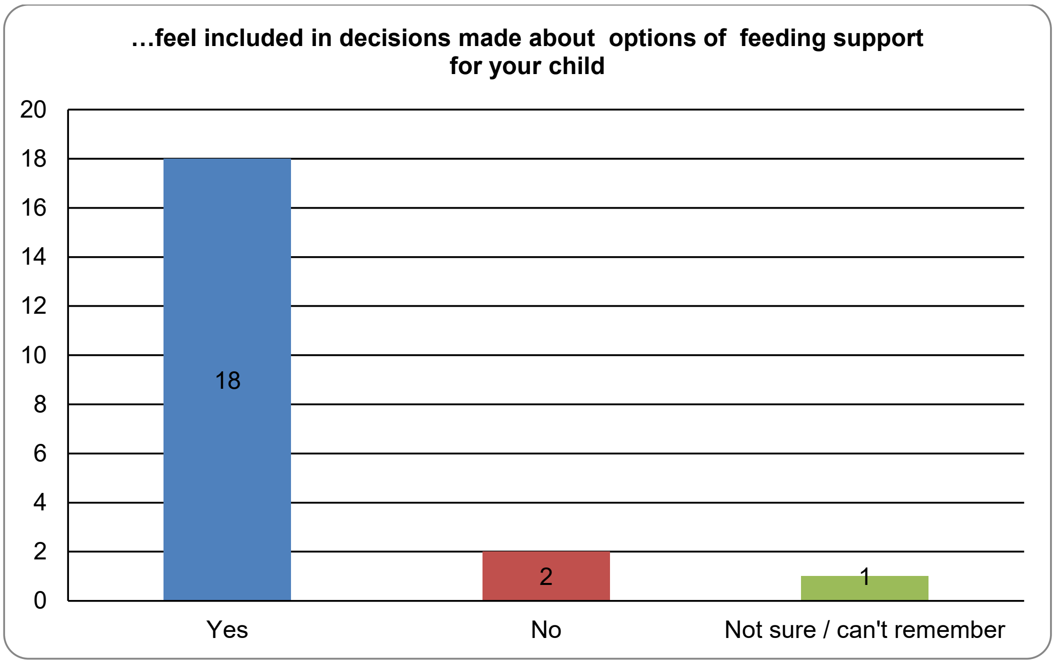
	Yes	No	Not sure / can't remember	**Total Responses**
…feel included in decisions made about options of feeding support for your child	18 86%	2 10%	1 5%	**21**
…understand why your child needed feeding support by tube feeds	20 95%	0 0%	1 5%	**21**
…have clear expectations on when the feeding tube is likely to be removed?	12 57%	5 24%	4 19%	**21**
Total Responses	**50**	**7**	**6**	**63**



…feel included in decisions made about options of feeding support for your child

Response Rate: **100% (N=21)** Question Type: **Choose one**

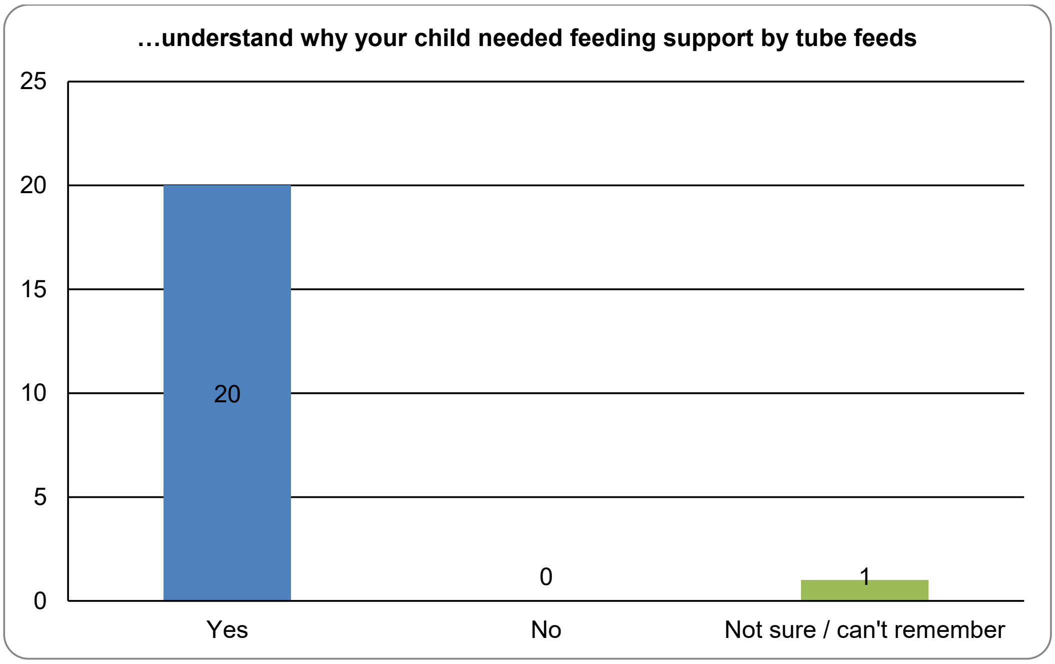
Yes	**18**
No	**2**
Not sure / can't remember	**1**
Total Responses	**21**



…understand why your child needed feeding support by tube feeds

Response Rate: **100% (N=21)** Question Type: **Choose one**

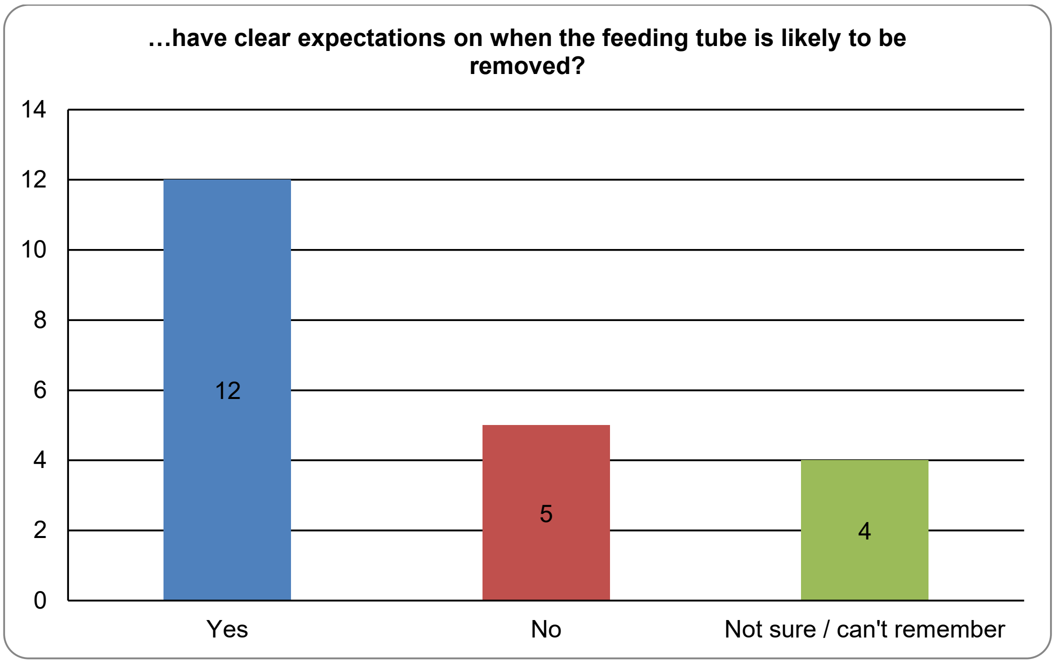
Yes	**20**
No	**0**
Not sure / can't remember	**1**
Total Responses	**21**



…have clear expectations on when the feeding tube is likely to be removed?

Response Rate: **100% (N=21)** Question Type: **Choose one**

Yes	**12**
No	**5**
Not sure / can't remember	**4**
Total Responses	**21**

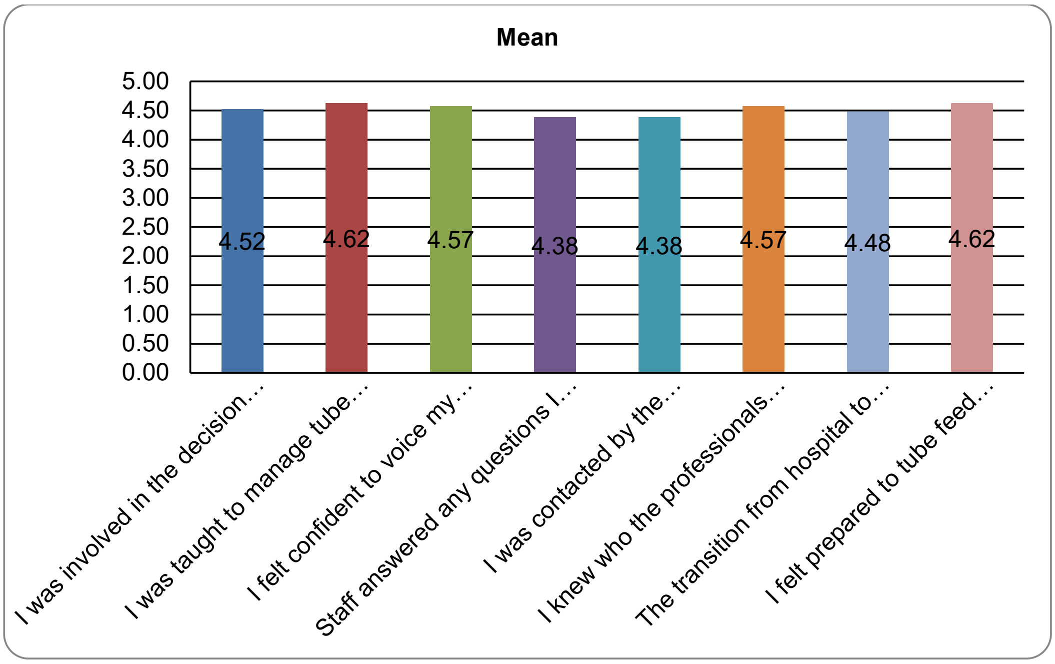


2. How would you rate the transition process from the Special Care Baby Unit (SCBU) to your home for the following…?

Answer Group 1

Question Type: **Choose one**

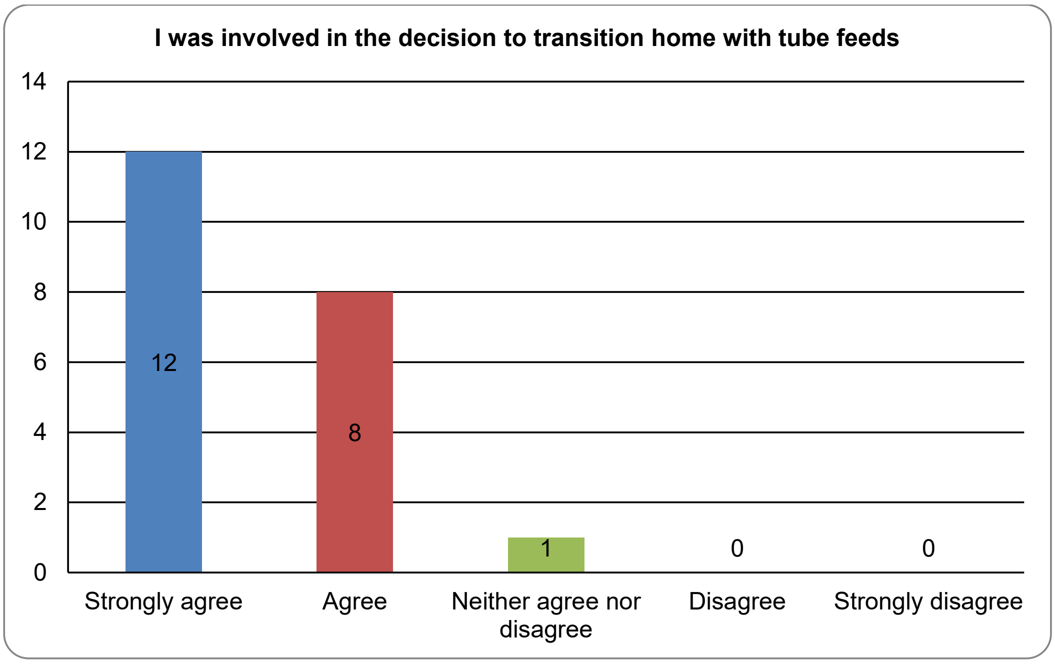
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	**Total Responses**	Mean
I was involved in the decision to transition home with tube feeds	12 57%	8 38%	1 5%	0 0%	0 0%	**21**	4.52
I was taught to manage tube feeds for my baby before discharge	13 62%	8 38%	0 0%	0 0%	0 0%	**21**	4.62
I felt confident to voice my concerns with staff	13 62%	7 33%	1 5%	0 0%	0 0%	**21**	4.57
Staff answered any questions I had	13 62%	4 19%	3 14%	1 5%	0 0%	**21**	4.38
I was contacted by the community team whilst in hospital or the first day after discharge	10 48%	9 43%	2 10%	0 0%	0 0%	**21**	4.38
I knew who the professionals involved were and their roles in both the hospital and in the community	14 67%	5 24%	2 10%	0 0%	0 0%	**21**	4.57
The transition from hospital to home went smoothly	11 52%	9 43%	1 5%	0 0%	0 0%	**21**	4.48
I felt prepared to tube feed when I got home	13 62%	8 38%	0 0%	0 0%	0 0%	**21**	4.62
Total Responses	**99**	**58**	**10**	**1**	**0**	**168**	


Mean
5.00
4.50
4.00
3.50
3.00
2.50
2.00
1.50
1.00
0.50
0.00
4.52
4.62
4.57
4.38
4.38
4.57
4.48
4.62
I was involved in the decision…
I was taught to manage tube…
I felt confident to voice my…
Staff answered any questions I…
I was contacted by the…
I knew who the professionals…
The transition from hospital to…
I felt prepared to tube feed…

I was involved in the decision to transition home with tube feeds

Response Rate: **100% (N=21)** Question Type: **Choose one**

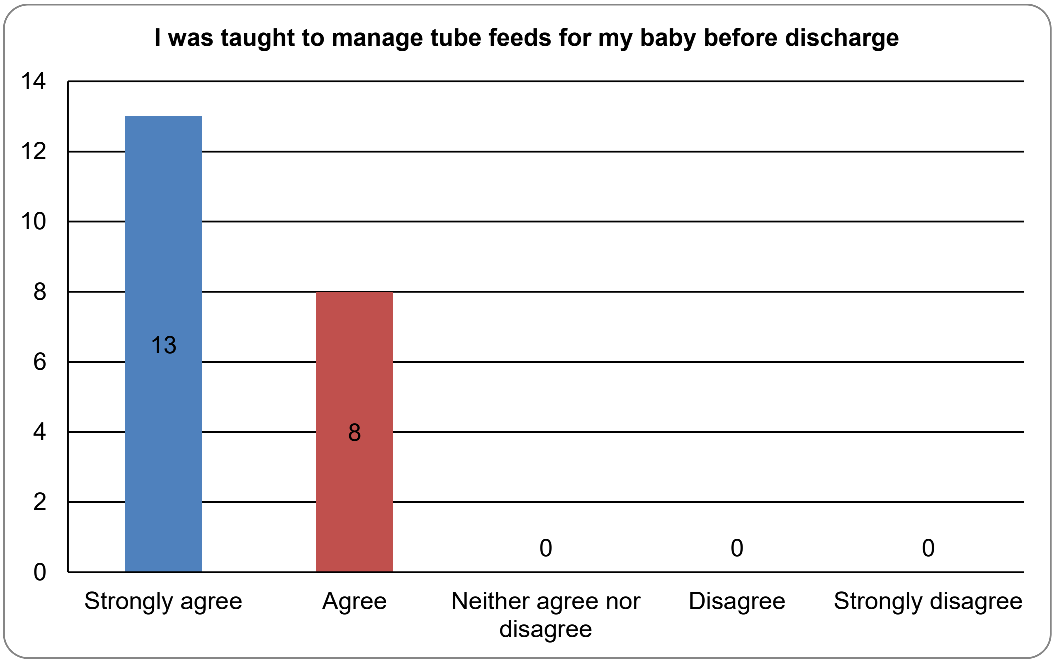
Strongly agree	**12**
Agree	**8**
Neither agree nor disagree	**1**
Disagree	**0**
Strongly disagree	**0**
Total Responses	**21**



I was taught to manage tube feeds for my baby before discharge

Response Rate: **100% (N=21)** Question Type: **Choose one**

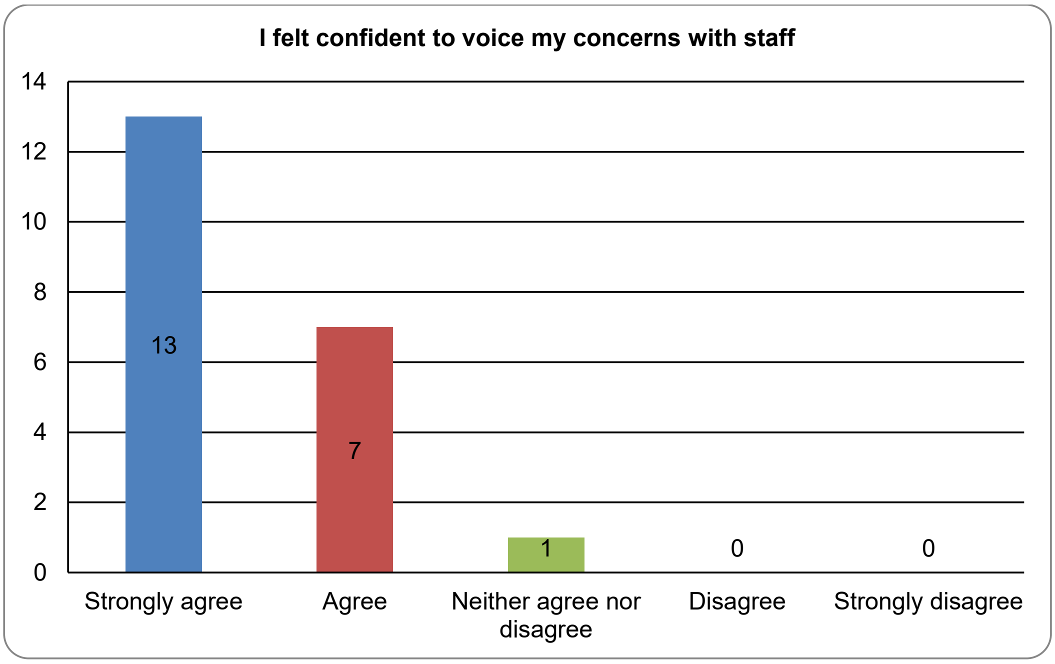
Strongly agree	**13**
Agree	**8**
Neither agree nor disagree	**0**
Disagree	**0**
Strongly disagree	**0**
Total Responses	**21**



I felt confident to voice my concerns with staff

Response Rate: **100% (N=21)** Question Type: **Choose one**

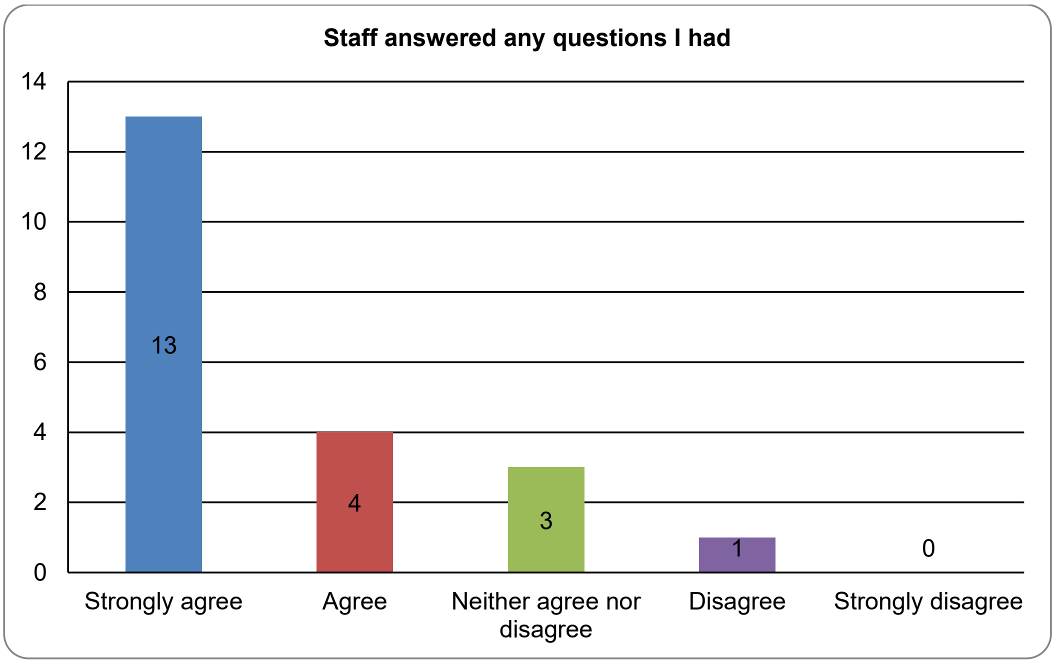
Strongly agree	**13**
Agree	**7**
Neither agree nor disagree	**1**
Disagree	**0**
Strongly disagree	**0**
Total Responses	**21**



Staff answered any questions I had

Response Rate: **100% (N=21)** Question Type: **Choose one**

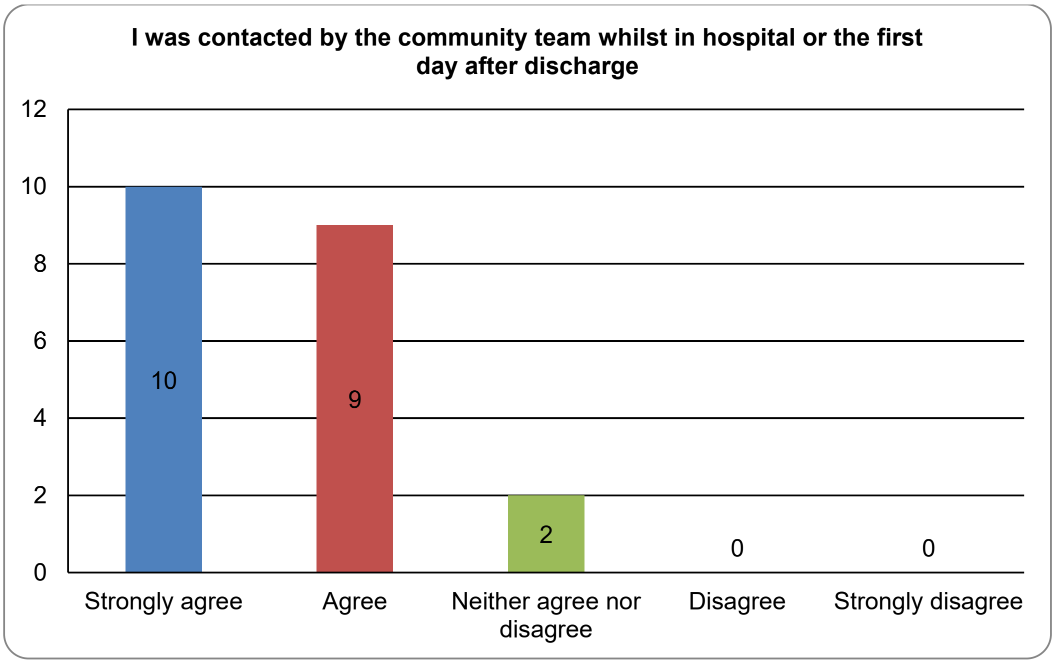
Strongly agree	**13**
Agree	**4**
Neither agree nor disagree	**3**
Disagree	**1**
Strongly disagree	**0**
Total Responses	**21**



I was contacted by the community team whilst in hospital or the first day after discharge

Response Rate: **100% (N=21)** Question Type: **Choose one**

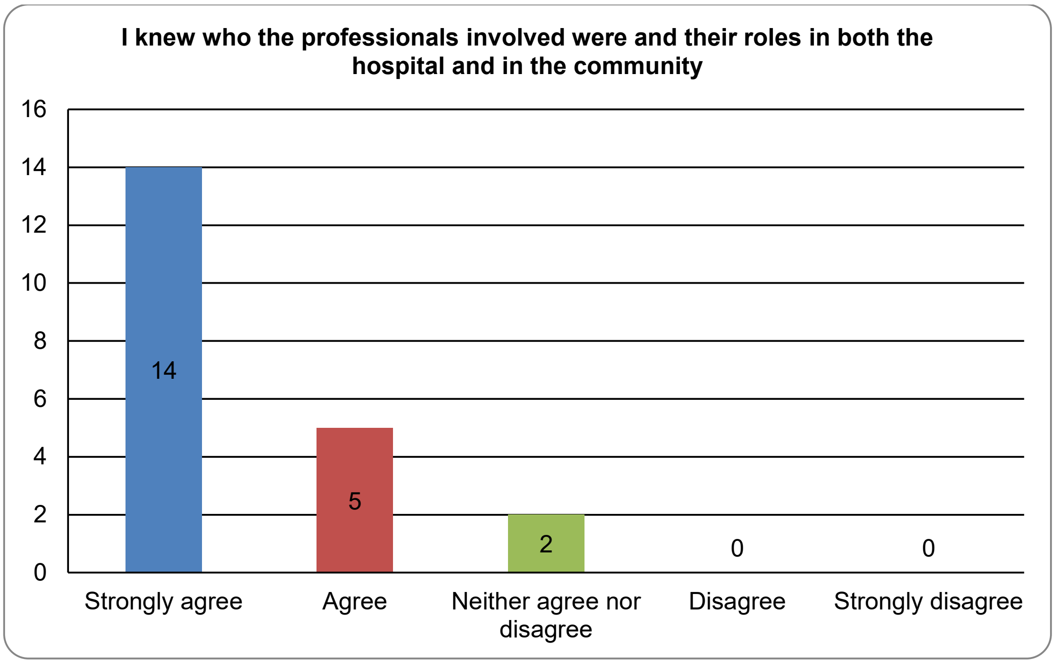
Strongly agree	**10**
Agree	**9**
Neither agree nor disagree	**2**
Disagree	**0**
Strongly disagree	**0**
Total Responses	**21**



I knew who the professionals involved were and their roles in both the hospital and in the community

Response Rate: **100% (N=21)** Question Type: **Choose one**

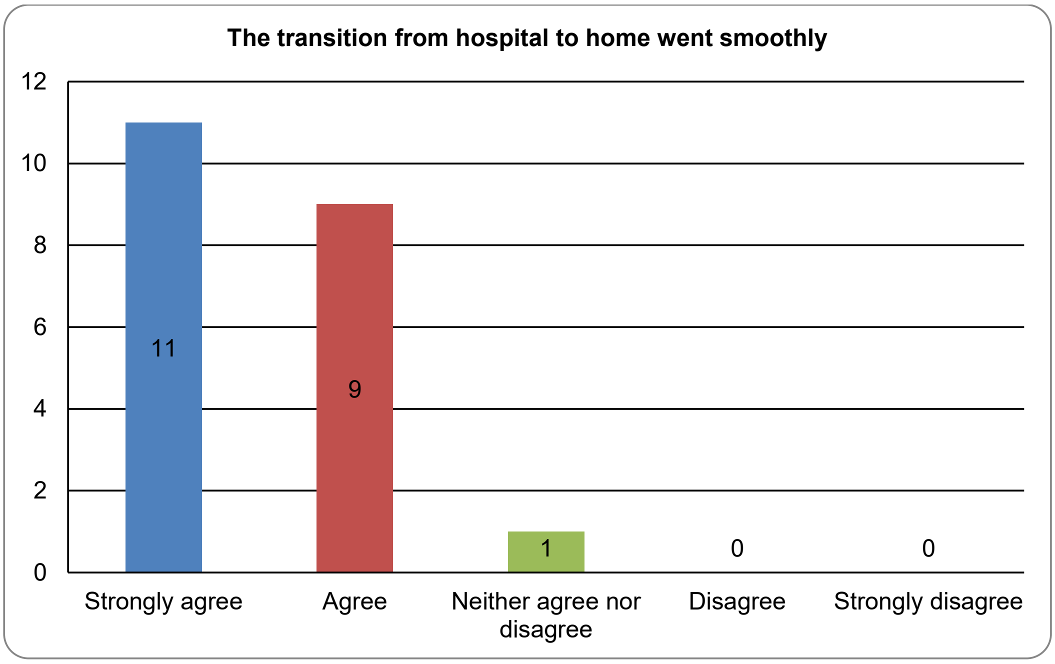
Strongly agree	**14**
Agree	**5**
Neither agree nor disagree	**2**
Disagree	**0**
Strongly disagree	**0**
Total Responses	**21**



The transition from hospital to home went smoothly

Response Rate: **100% (N=21)** Question Type: **Choose one**

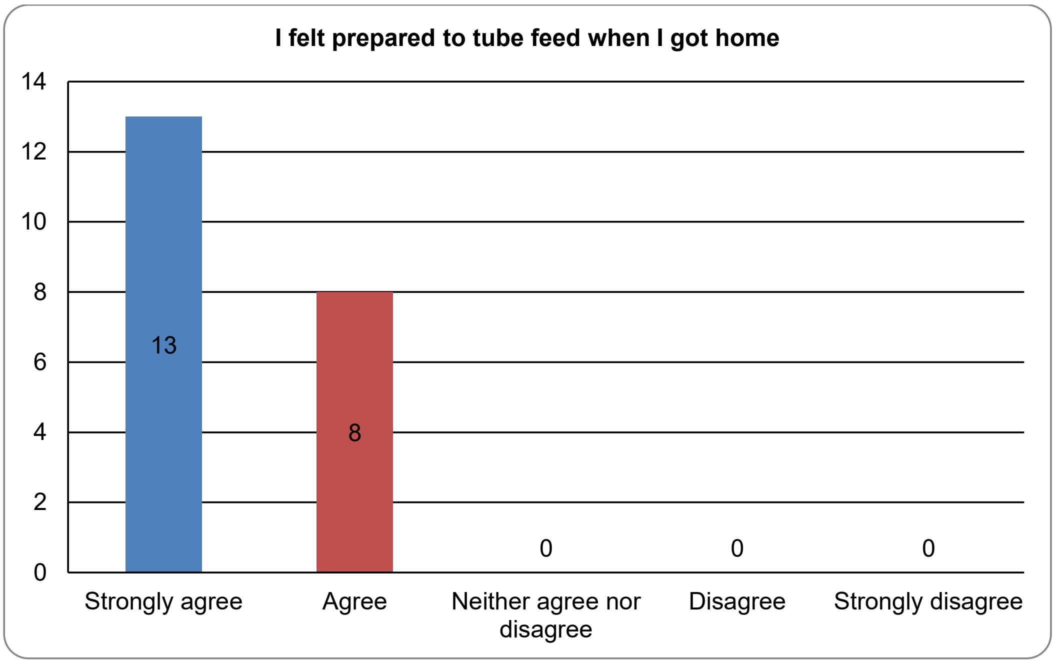
Strongly agree	**11**
Agree	**9**
Neither agree nor disagree	**1**
Disagree	**0**
Strongly disagree	**0**
Total Responses	**21**



I felt prepared to tube feed when I got home

Response Rate: **100% (N=21)** Question Type: **Choose one**

Strongly agree	**13**
Agree	**8**
Neither agree nor disagree	**0**
Disagree	**0**
Strongly disagree	**0**
Total Responses	**21**



3. Could we have done anything else to prepare you to go home?

Response Rate: **48% (N=10)**Question Type: **Paragraph**

More contact information for local team. I always get answer phones and they are so busy they never get the chance to get back to us. Daughter came off nasal feeds and we are still waiting to hear back from local team. Understandable during lock down but even level 3 nothing. I feel you need more staff.

No, we had a great transition and it had been a very long time and we're so ready to be home. I think maybe we left a couple of days before the dr would have liked but baby was more than 100 days old and I was feeling very confident and had bees doing all cares and feeds for a while. I feel like the staff supported me and it was a very smooth transition.

No. Everything was supplied, materials needed for baby, health education, contact details in emergency, etc. The whole multidisciplinary team helped me and my family.

To provide a clear understanding of how much feed volume a child can tolerate especially when they have severe GERD and are Hypotonic.

The preparation did discharge was adequate however once home the path to wean from the tube was vague. The approach was watchful waiting. In the end we sought private support to wean from the tube. The transition from hospital to community is disjointed. There is continuity of care in so much that some of the team members are the same, but the approach in the community is less weight gain and feed quantity focused. It would be better to have an end to end pathway for tube feeding from insertion to removal.

I actually gave birth at Auckland hospital. So this hospital based feedback is not relevant for Waitakere hospital.

More practice re-inserting NG tube whilst in SCBU would have made the transition to managing that at home easier. As would the advice that tape changes are possible while baby sleeps meaning that tube doesn't need to be reinserted etc to minimise the trial and error isolated at home. As well as any nurses tips relating to taping removal and replacement tips and tricks.

I was very happy with the guidance and resources i was given, it made the transition so much easier than I could have hoped

Better idea of when the tube can come out and the strategies such as an "ideal" timeline. I found that we were still tube feeding for quite some time once home as baby was not waking to breastfeed at night. Only much much later did I learn about dreamfeed (through other online resources I sought for myself). Then only were we able to come off the tube feeds since I learnt to dream feed him. I also thought there was no issue with baby having the tube feeds so didn't rush into looking at other resources. When a different nurse visited, she then gave me the impression that the tube should have been a much bigger prior to focus on as it can have long term developmental issues. Which is why I then tried to night feed in order to remove the tube. Had I known to prioritise this and work towards it as opposed to “waiting for baby to be ready”, perhaps he would have come off the tube earlier and we could have worked in bottle feeding earlier. Baby still doesn’t take a bottle now.

none

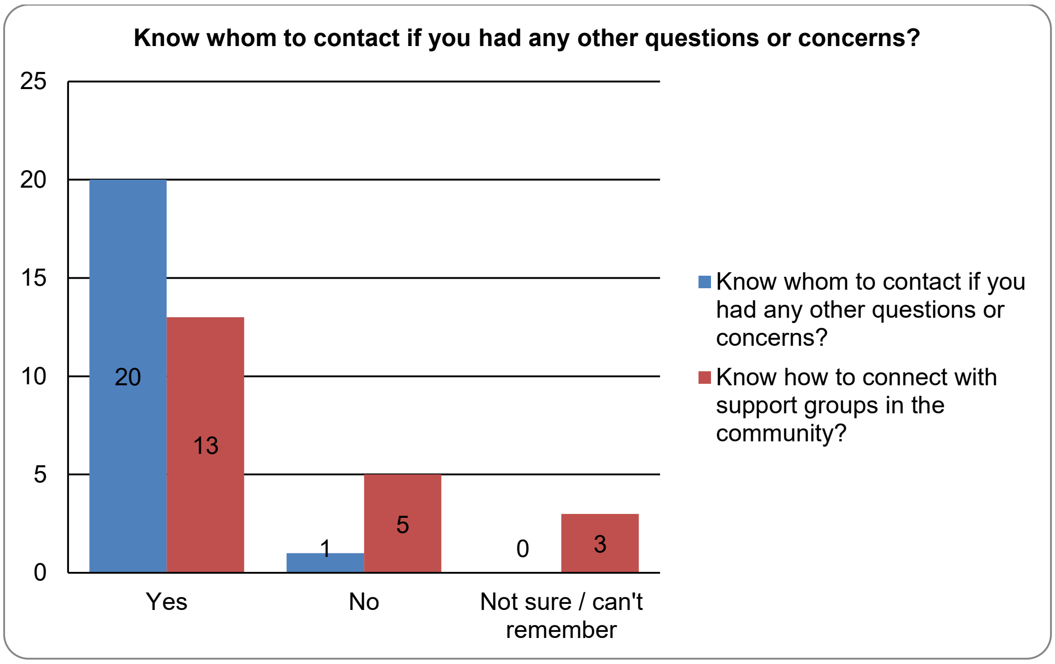
Total Responses: 10

4. At home, did you…?

Answer Group 1

Question Type: **Choose one**

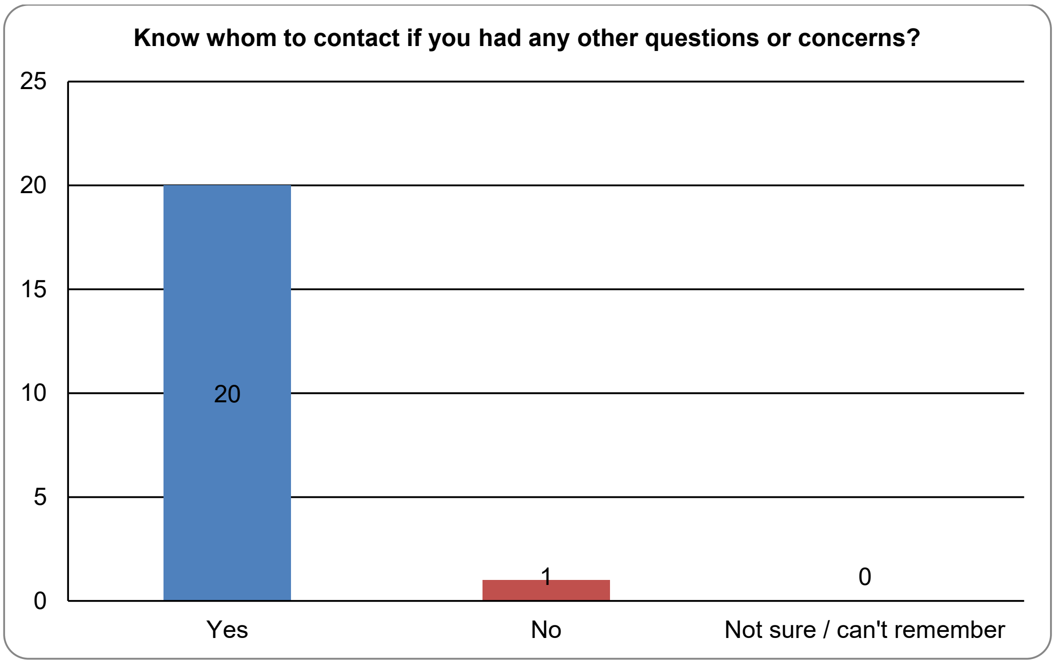
	Yes	No	Not sure / can't remember	**Total Responses**
Know whom to contact if you had any other questions or concerns?	20 95%	1 5%	0 0%	**21**
Know how to connect with support groups in the community?	13 62%	5 24%	3 14%	**21**
Total Responses	**33**	**6**	**3**	**42**



Know whom to contact if you had any other questions or concerns?

Response Rate: **100% (N=21)** Question Type: **Choose one**

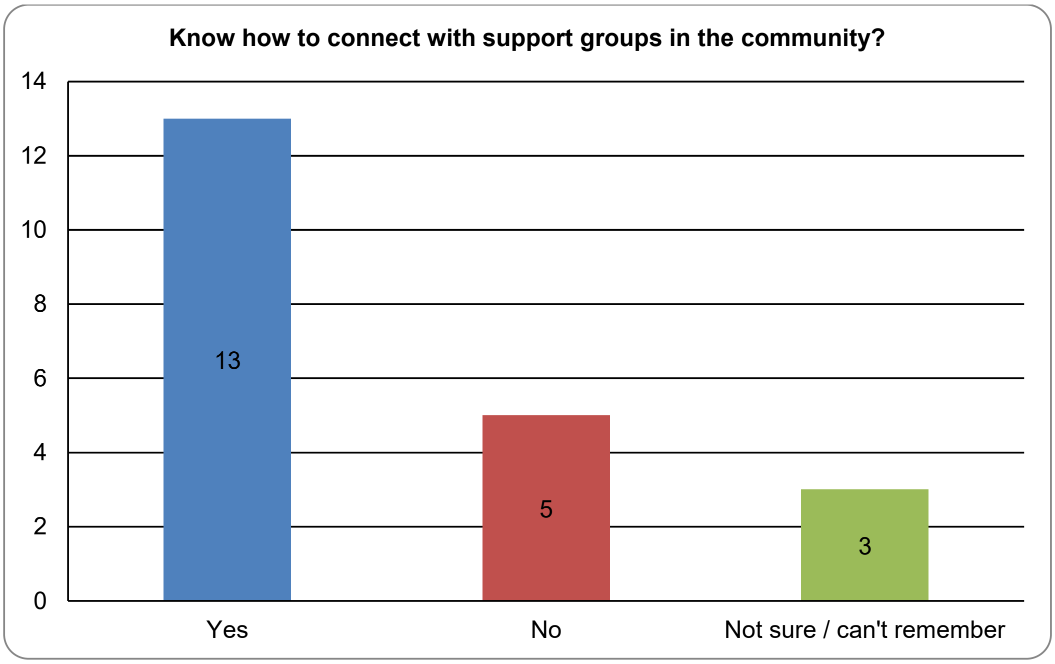
Yes	**20**
No	**1**
Not sure / can't remember	**0**
Total Responses	**21**



Know how to connect with support groups in the community?

Response Rate: **100% (N=21)** Question Type: **Choose one**

Yes	**13**
No	**5**
Not sure / can't remember	**3**
Total Responses	**21**



5. Did you experience any challenges or difficulties with tube feeding at home?

Response Rate: **76% (N=16)** Question Type: **Paragraph**

No

Not really, it took some time to get into a new routine with another child at home and setting up in a way that suited us best but we managed with the help of our homecare team.

No

No

No.

The syringes the home care nurses have are not compatible with the feeding tube so we have to get adapters, it is frustrating that different dHB shave different syringes and such a waste of tax payer money buying adapters when they could just order the same type of syringe

At times I couldn’t get an aspirate, but community nurses had helped

Management of his skin integrity under the tape to secure the NG tube was a constant challenge

Yes. The feeding tube led to reflux which meant we were unable to put our baby down at night

No, we only needed them for 1 week

We found it stressful and upsetting emotionally because it came as a shock. Tube feeding our baby was very hard when he would be screaming and upset. I also found it hard when he would pull the tube out I asked the community nurse to teach me how yo reinsert it so we didn't need to go to A and E. This made a huge difference.

Baby was already full and sometimes spilling but I still had to give a certain amount of feed through the tube.

Yes. We have experienced getting ph reading challenges. Placing the tube to deep into the stomach>bile vomits and unable to get aspirate back. Reinserting tube is very stressful and reinforces oral aversion setting back all of the work done with SLT to desensitise. It is crushing to see. Tube feeding takes hours and makes reflux and vomiting much worse.

No

No. Eventually I felt pretty confident in putting the tube in, which at first was quite daunting.

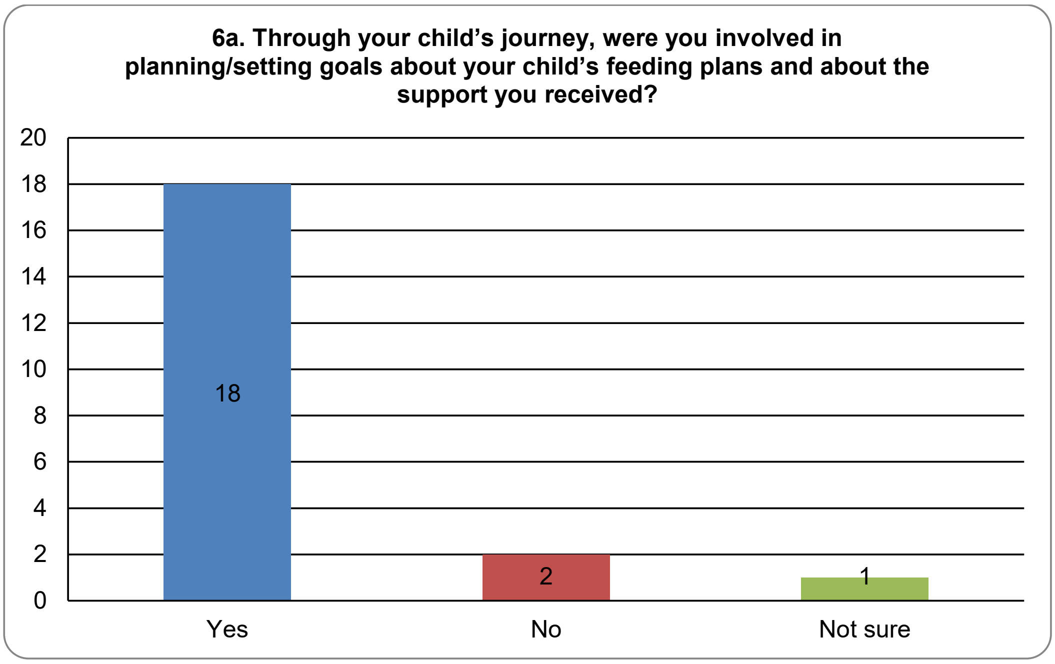
none

Total Responses: 16

6a. Through your child's journey, were you involved in planning/setting goals about your child's feeding plans and about the support you received?

Response Rate: **100% (N=21)** Question Type: **Choose one**

Yes	**18**
No	**2**
Not sure	**1**
Total Responses	**21**



6b. Please can you tell us more about your involvement in setting goals for your child, specifically related to feeding plans and any other support you required?

Response Rate: **62% (N=13)**Question Type: **Paragraph**

I get heard and consulted the whole way through. I was able to help choose which reflux meds to try and had been consulted on the use of calogen (which was decided against) amongst other things. I was given a stand to get used to at SCBU before heading home
Feeding plans were discussed with the dietitian based on my son’s weight gain
We had a plan in place however both my babies had their tubes out within a week of coming home as they had established themselves with breast/bottle feeding by then
I am involved with my child’s insertion of tube, volume of feeding, how often. Due to having medical background I am able to comprehend and put my skills into caring for my baby with NGT feeding.
Worked with Dietican and regularly monitored weight, growth, height to make sure our son began to grow and thrive again
The goal was presumably to remove the tube however I am not sure this was documented or what the agreed process was to move towards the goal
We wanted to try feeding without tubes after a week and the community health nurse and dietitian supported us with this plan
Overall, the community team was absolutely amazing. They always made sure we were at the centre of any plan and always asked us what we wanted and needed.
When baby accidentally pulled out the tube, I wanted to try different options before reinserting the tube. The team gave me choices and were supportive.
Good input with dietician around calorie addition etc and flexibility around trying different things. Our goal has been to try and establish oral feeding. The team approach appears to be baby led rather than hunger driven and thus far not successful. I note that another baby with similar feeding difficulties was discharged to ADHB catchment and they used hunger based approach and that baby established oral feeding and was tube weaned at home. The baby led approach does leave you feeling like it is a wait, see and hope for the best without actually having a plan in place.
I would regularly discuss my child's feeding with all the team (community nurse, dietitian, SLT) and we would make adjustments as needed
Overall goal of coming out of feeding tube was set. This involved breastfeeding as much

as possible during the day. At night however, he would not wake to feed so I had to rely on tube feeding. (Until I learned about night feeds).

Helping my child to eat/drink only a very small portion of food and drinks without using the tube

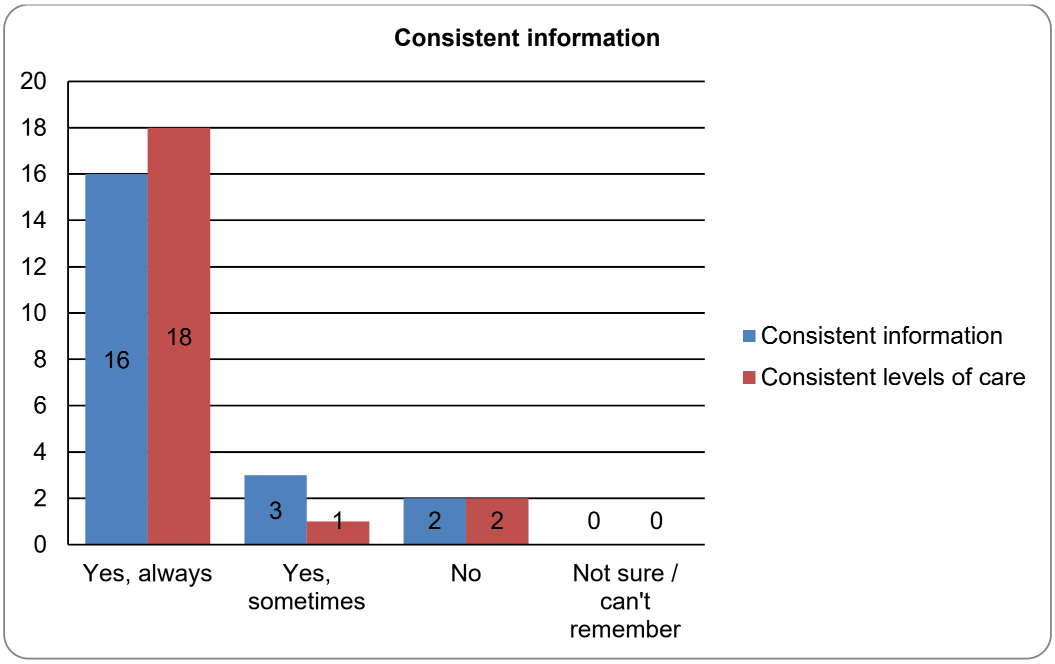
Total Responses: 13

7. Did the in-patient and community team members within Waitematā District Health Board, provide you with…?

Answer Group 1

Question Type: **Choose one**

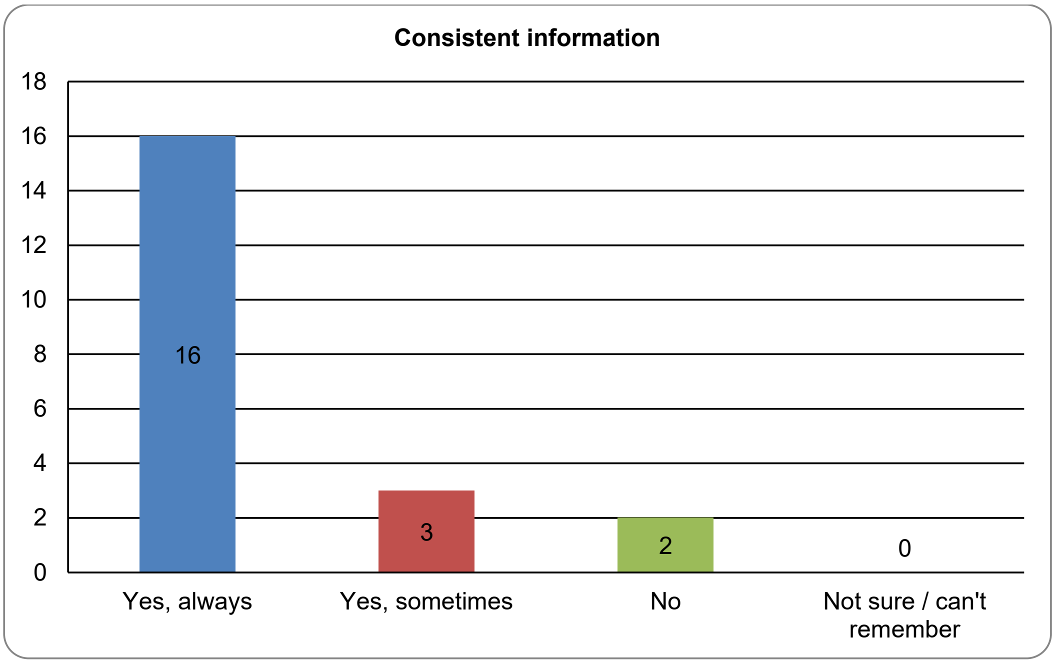
	Yes, always	Yes, sometimes	No	Not sure / can't remember	**Total Responses**
Consistent information	16 76%	3 14%	2 10%	0 0%	**21**
Consistent levels of care	18 86%	1 5%	2 10%	0 0%	**21**
Total Responses	**34**	**4**	**4**	**0**	**42**



Consistent information

Response Rate: **100% (N=21)** Question Type: **Choose one**

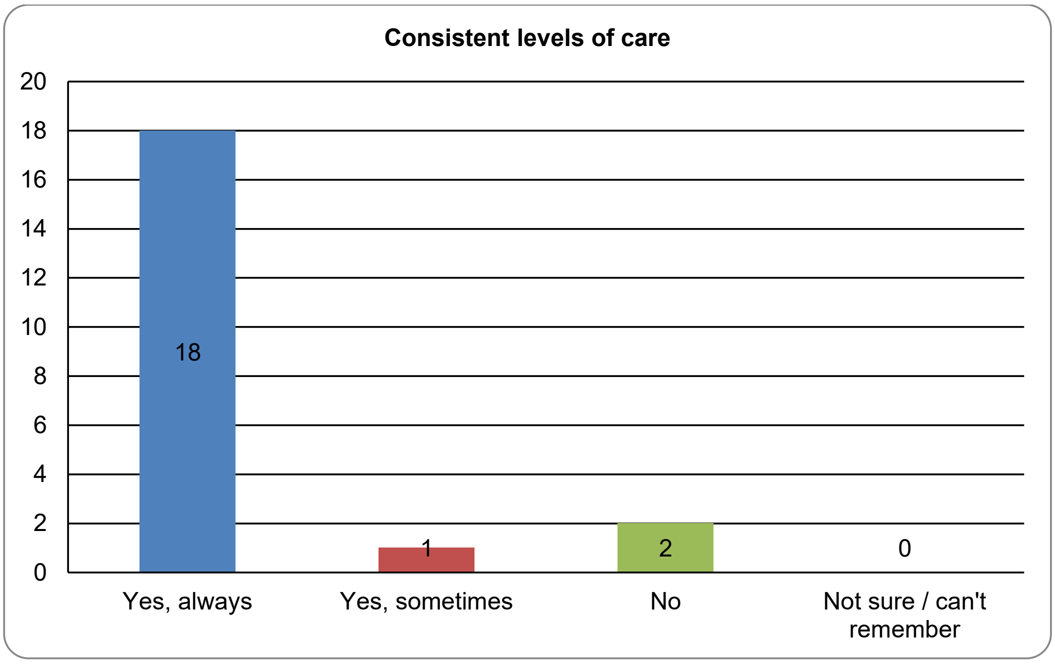
Yes, always	**16**
Yes, sometimes	**3**
No	**2**
Not sure / can't remember	**0**
Total Responses	**21**



Consistent levels of care

Response Rate: **100% (N=21)** Question Type: **Choose one**

Yes, always	**18**
Yes, sometimes	**1**
No	**2**
Not sure / can't remember	**0**
Total Responses	**21**



8. Do you have any other feedback or suggestions?

Response Rate: **52% (N=11)** Question Type: **Paragraph**

Yes more staff

No, for me and my whānau it was a smooth transition home. The teams in SCBU were amazing and supportive and our homecare team were so fantastic! I had a LOT of questions and was always treated with respect and included in decision making. I cried when our homecare nurse moved to another city! They all made such a very stressful, frightening and unknown time so much easier to deal with for me and I will forever be grateful!

The SCBU unit could do with being bigger. We have been in both NICU in akl and Waitakere SCBU and the NSH site needs an upgrade

Get the same syringes as the Auckland dHB to save money, time and effort for everyone

Having a child rely on a tube for their sole source of nutrition is a whole world to wrap your head around. It can be very scary and intimidating at times. Support to make decisions in all aspects is crucial, I feel we were lucky to have the team supporting us at the time but if we had a lesser experience I can only imagine how hard that would have made it!! Training and compassion are key. Remembering go remind parents this was not a part of anyone's plan but having to roll with it is the only way forward.

We were given varying advice by multiple team members. It felt like too many people were involved especially as we ended up involving someone else privately who did help us to remove the tube. The approach from the team was watchful waiting which felt too passive - especially once our baby was struggling with reflux

There is apparently a website where we should be able to see info about our babies' health and professionals working with them but we have no idea how to access that. Other than that though, the community health nurses, paediatrician (Kay Lyn Wong) and other visiting health professionals have all been fantastic. Really amazing level of support

I found the community nurses utterly fantastic. They were so kind, caring and supportive. I was disappointed with the dietician as she rarely responded to my messages regarding feeding and I felt she didn't offer much support or advice at all really. We eventually found another dietician privately who made great simple suggestions which eventually helped us get our baby off the tube and fully feeding orally.

I very much like the MDT team both inpatient and community but I do wonder if WDHB has the correct approach for supporting infants from tube feeding to oral feeding. Are WDHB reviewing what other DHB's are doing and how their success rates compare to WDHB with discharge home on the NG tube from the hospital and duration of time before oral feeding is established. Has WDHB got the correct protocol and guidelines in place to support the staff working for on the ground to transition babies to feed orally? Is WDHB's baby led approach successful?

Overall pretty happy with the level of service and care. Perhaps would have appreciated earlier intervention around bottle feeding (at an appropriate time). We were breastfeeding our baby but there is a window where you can introduce a bottle whilst avoiding nipple aversion. Which would have been good to implement. We unfortunately seemed to have missed that window.

Every Waitemata Health Board staffs were all nice and kind, I am really pleased with all your support. Thank you

Total Responses: 11

Waitemata
District Health Board

Best Care for Everyone

i3

Family and Whānau-Centred Tube Feeding and Weaning Closure Report

Prepared By:	Olivia Anstis, Innovation and Improvement Project Manager Institute for Innovation and Improvement Elizabeth Maritz, Clinical Lead Paediatric Dietetics, Waitemata District Health Board
Input Provided By:	Penny Andrew, Director, i3 Kelly Bohot, Care Redesign Programme Lead, i3
Approval required from:	Susan Peters, Head of Division, Allied Health Child Women and Family Service
Document changes:	0.1 (18.12.17) 0.2 (26.02.18) 0.3 (07.08.18) 0.4 (04.10.18) 0.5 (10.10.18)

Contents

1. Opportunity

Nutrition support, to treat or prevent malnutrition where the usual eating habits are not sustained, can be administered via tube feeding. Placement of feeding tubes is relatively common amongst premature neonates; children with disabilities; and can also occur in children with behavioural issues around food. Family and whānau are sometimes discharged into the community following tube placement, without knowing how long the feeding tube will be needed for, and what indicators to observe that may indicate that the child is ready to be weaned. The weaning process itself may be complex, and require specialist support.

A Blitz project undertaken at Waitemata DHB in 2016 undertook a review of clinical processes when making a decision for and supporting tube feeding in the adult and paediatric populations (see Appendix A). Two clinical process maps were produced to review paediatric in-patients and community services. As result of the review recommendations were made to support paediatric tube feeding and weaning management by clinicians, including:

- Support parents by working closely with MDT prior to putting the tube in or taking it out
- Develop a clearer framework/policy regarding the role of the MDT and the process involved
- Increased MDT discussion/review of cases on a regular basis
- Consider longer length of stay the enable intensive weaning process before discharge
- Clearer interdisciplinary pathway for tube weaning in the community
- Access to psychologist for managing behavioural and emotional effects on both child and family
- Access and support for inpatient tube weaning
- Up skilling of all staff regarding tube management (including education based support)
- Review outcomes for school aged children with nasogastric tube

As a result of these recommendations, it was decided to progress with a family and whānau-centred tube feeding and weaning co-design project, focused on understanding the psychosocial support needs of families living with tube feeding and in most cases requiring tube weaning. The aim was to co-design a family and whānau-centred paediatric tube feeding and weaning multidisciplinary pathway of care to overlay the clinical process maps.

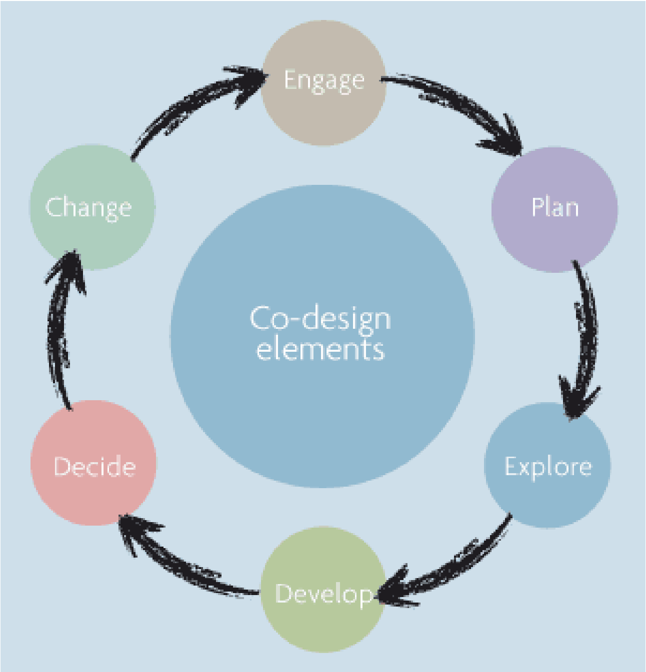
2. Project Overview

This project aimed to co-design a family and whānau-centred paediatric tube feeding and weaning multidisciplinary pathway of care. The first objective was to map the experience of patients/family/whānau affected by tube feeding and weaning across the tube feeding and weaning management clinical process maps, and secondly, to co-design solutions for areas of unmet need.

The co-design process involved staff from the multidisciplinary pathway of care, patients, and family/whānau affected by tube feeding and weaning in the Waitemata DHB catchment area. This involved co-design methodology as outlined below:

Co-Design Methodology

Co-Design is a process where the experiences and beliefs of service users (patients, family and whānau) and staff are captured and participants work together to redesign the services they use or deliver. Here, parents of tube fed children worked with staff at Waitemata District Health Board to uncover experiences and gaps in care, and co-designed solutions together, utilising the following elements:



Engage: *Stakeholders are identified and on-boarded as advisors, project team members, and as participants.*

We identified staff groups who were responsible for the delivery of multidisciplinary care (paediatricians, dietitians, nurses, speech language therapists, pharmacists, psychologists, midwives, lactation consultants) and approached individuals to join a co-design working party, and take part in staff workshops.

We identified patient groups that would best represent the tube feeding experience, and approached families/whānau who met the following criteria to take part:

1. Tube in SCBU, removed before discharge
2. Tube placed, discharged with tube, removed in community
3. Discharged with or without tube, long-term condition
4. Disability with tube
5. Older children with tube

Plan: *Working together to set our goals for the project, and understanding our approach.*

We worked with staff and service users to set goals for the project. The goal was to understand the user experience of tube feeding and weaning, and to complete a set of recommendations for service redesign.

Explore. *Understanding service users' experiences, and identifying gaps in care. Working on solutions together.*

To understand experiences and beliefs, several methods were used to capture data in this project:

Involvement	***Description***	***Number completed***
'Shadowing'	*'Shadowing' is a co-design method where an investigator on the project sits with a service user during an appointment or consultation. The purpose of this is to listen to and observe the interactions that occur during the consultation.*	*2*
1:1 Interviews	*An investigator sits with a service user and asks questions about their experiences with tube feeding and weaning. Transcriptions made of interviews.*	*10*
Videos	*An investigator films a service user about their experiences with tube feeding and weaning. The video can be used to promote the current project, raise awareness of the issues faced by those who tube feed and wean, and to create a sense of solidarity with other service users who are going through the same experience. In this case, three videos were filmed and shown at the Family-Centred, Multi-Disciplinary Tube Feeding to Weaning Management Symposium' held on 26th October 2017, Waitemata DHB.*	*3*
Staff Workshops	*Staff attends workshops to understand what is working well and what could be improved in the services they represent.*	*2*
Co-design Working Party	*Staff was actively involved in the project from start to finish, attending regular meetings, receiving updates,and contributing to identify recommendations for service redesign.*	*Biweekly over the course of the project*
Symposium	*A full-day 'Family-Centred, Multi-Disciplinary Tube Feeding to Weaning Management Symposium' was held on 26th October 2017 attended by service users and staff locally regionally and nationally representing 18 DHB's via video conference facilities at Whenua Pupuke, North Shore Hospital to share the results of previous 1:1 interviews, videos and staff workshops and to allow service providers to view patient experience through the lens of families. Staff and consumers presented their experiences and expertise in tube feeding and weaning. Feedback surveys were also administered.*	*1*
Co-design	*A workshop was held with service users and staff to present the*	*1*

consumer and staff workshop	*results of previous 1:1 interviews, videos and staff workshops.*	
Surveys	*Feedback surveys were given to attendees at the Tube Feeding and Weaning Symposium, and results were collated into themes.*	2

Develop: *Staff worked in partnership with service users to co-design solutions to areas of unmet need.*

We worked with service users to understand what a family and whānau-centred tube feeding and weaning pathway might look like, and which service improvements might make a difference. To do this we held a staff and consumer co-design workshop where we presented the results of previous 1:1 interviews, videos and staff workshops, tested the resultant themes, and overlaid the service user experience over the existing clinical process maps. We then worked on solutions to gaps in care by using a 'what if we tried' tool.

Decide: *The process of deciding on what solutions will be invested in as an improvement idea*

Results of the engage and develop phase were fed back to discipline-specific staff groups at North Shore and Waitakere Hospitals, for their reactions and suggestions on what solutions to focus on. A meeting was also held with a paediatrician experienced with clinical ePathway development, to test feasibility of turning the family and whānau-centred tube feeding and weaning management pathway into an electronic tool.

Change: *Implementation of our solutions.*

Implementation of change ideas, as result of recommendations made in this report, is dependent on service specific timelines. Quality developments, driven by the multidisciplinary teams involved in tube feeding and weaning management is expected to be initiated and incorporated in service delivery throughout 2018-2019.

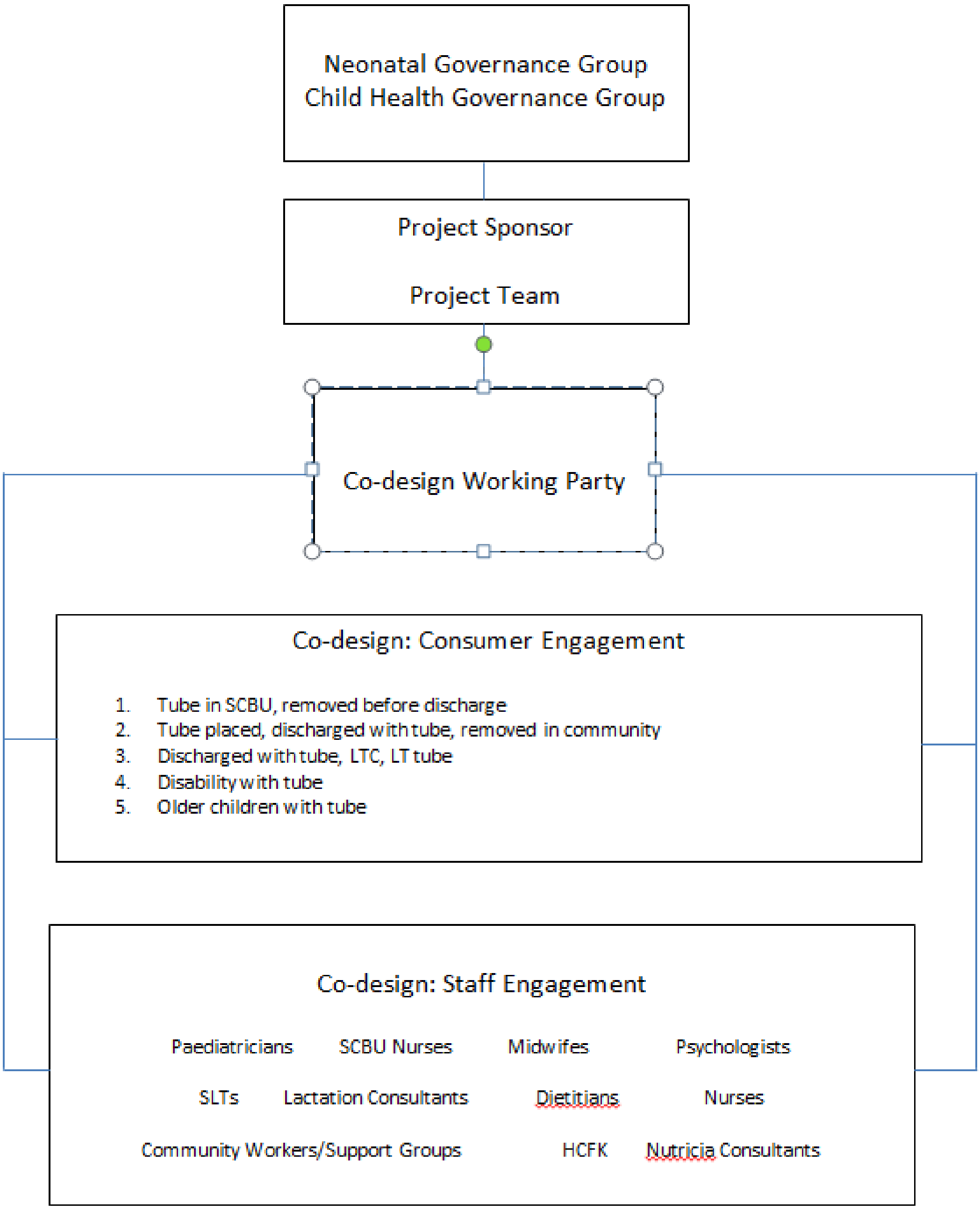
We anticipated the following timeframes:

Activity	Jun 17	Jul 17	Aug 17	Sept 17	Oct 17	Nov 17	Dec 17	Feb 18
Project scoping	■	■						
Stakeholder engagement - staff	■	■	■	■	■			
Staff Workshops	■	■						
Terms of Reference		■	■					
Governance Meetings			■	■	■	■	■	■
Symposium				■	■	■		
Co-Design Working Party meetings			■	■	■	■	■	

Consumer Interviews				🟧	🟧	🟧		
Thematic analysis						🟧	🟧	🟧
Co-Design Workshop						🟧		
Discipline-Specific Feedback						🟧	🟧	🟧
Results and Recommendations								🟧

The timeframes were met throughout the course of the project.

The Structure of the project is illustrated in the organogram below:



Project staff membership consisted of:

Governance	Project Team	Co-Design Working Party	
Chair and members of the: Neonatal Governance Group; and Child Health Governance Group	**Susan Peters** Head of Division, Allied Health Child Women and Family Service Project Sponsor **Elizabeth Maritz** • Clinical Lead, Paediatric Dietetics **Olivia Anstis** • Innovation and Improvement Project Manager & Health Psychologist, i3	Andrea Herron	Paediatric Dietitian WHT, Senior Allied Health Practitioner
		Carmen Haines	Paediatric Nurse Educator Child & Family West
		Carol Banks	Wilson Centre Nurse Educator
		Elizabeth Maritz	Dietetics Clinical Leader CW&F
		Gabrielle Noble-Campbell	Patient Experience CW&F
		Jane Carmine	Dietitian Community Child Health West
		Janet Hanson	Clinical Nurse Educator WDHB Child Health
		Jenny Crawford	Paediatric Pharmacist
		Kaajal Vashani	Speech-Language Therapist CCH West
		Karen Boyle	Charge Nurse Manager SCBU NSH
		Kelly Curreen	Occupational Therapist Clinical Lead CW&F
		Kerri Sheehan	Social Worker CW&F
		Kerryn Shaw	Nurse Educator Child and Family
		Lorraine Torrance	Paediatric Nurse Rangatira ward
		Nicola Parkin	Paediatric Psychologist CW&F
		Olivia Anstis	Project Manager, i3
		Sarah Timmis	Charge Nurse Manager Rangatira Ward
		Sian Lyness	Social Work Clinical Leader CW&F
		Teresa Stanbrook	Professional Clinical Leader Dietetics

3. Project outcomes

The expected benefits of the project included:
- Understanding service use from the family/whānau perspective,
- Identifying gaps in care, and
- Co-designing solutions together with staff that would result in the service being person-centred.

Perceived benefits are in line with the focus on people-centred healthcare delivery, outlined by the World Health Organisation (WHO), particularly their first strategy of 'engaging and empowering people and communities'.

The key themes reported by families throughout the project were as follows:

Experiences in SCBU	Being prepared to go home	Expectations and timelines	At home	How we're treated at hospital
Dads/Supporters	Connecting with others	Perception of tube changes over time	Weaning: No sense of urgency	Stigma in the community
Shared Decision Making	Don't assume we know what to do	Emotional needs & Self Care	Cultural influences	Where to go for help
	Access to childcare	Inter-sectorial care	Bonding	

1 Experiences in SCBU and/or in the wards

- Parents reported feeling overwhelmed and highly anxious being in the unit
- They felt staff were attentive, however there was a sense of 'resignation' once the tube was in
- More attention to non-nutritional feeding and skin-to-skin care would be appreciated.
- Assumptions were made that mothers would know what to do with their babies. This was particularly difficult for first-time mothers.
- Parents found the focus on weight frustrating. Suggested reducing the focus on weight and talk about other positive milestones

> "You wouldn't believe… my child wasn't bathed for seven weeks… because they thought, the mum knows.. no one noticed… they said "Haven't you been taught?" [STP2]

2 Being prepared to go home

- Parents are unsure of timelines – how long will the tube be in for, and what do they need to do to get home? This created uncertainty, anxiety and ultimately frustration.
- Lack of information before going home about:
    a. Tube pulling – how likely it is that the baby will pull the tube out, and what this is like.
    b. Tube problem-solving, e.g. tube coming out of the mouth – being prepared that it can happen and can look quite frightening. What to do.
    c. Time commitment – many families commented on how time consuming tube feeding can be and impact on family life.
    d. Social isolation. Families reported feeling isolated due to the time and practical commitment required to tube feed, not wanting to go out due to others' reactions, and not having anyone in their social circle to talk to who genuinely understood their situation.

> "Coming home at first was very, very terrifying. Especially having the tube in… how do we do this? What do we do?" [STP1]

> "But SLT was like, oh we have a stand that you guys can borrow and we were like, yes please! The first couple of months we didn't have anything so it was a lot of me just holding her and trying to adjust… " [STPC1]

e. Not quite ready for managing at home at time of discharge
f. Practical solutions, e.g. Carrying pumps and/or syringes around is cumbersome. Parents found ways around this such as using a selfie stick to hold the feeds, or eventually getting access to a stand through the hospital.
g. Reinserting the tube. This theme came through very strongly for all families. Most felt unprepared to reinsert the tube at home, and would prefer to be trained in this before they go home.
h. Skin care. Families were distressed at the skin damage on their babies' faces from the tape and were looking for ways to better manage this. It is also a motivation to move towards weaning.

> "Pulling it [the tube] out constantly, having to put it back down… that's one of the worst things I think. It is very stressful hearing her cry…" [STP1]

3 Expectations and Timelines

- Many families remarked they just didn't know what to expect
- Perhaps there was a high expectation on them from staff
- Knowing what to expect, they felt, would make a positive difference
- Timelines - having an incorrect timeline is better than no timeframe at all
- No timelines leave families floating in no-man's land with no way to plan, and they can lose hope
- Anger, frustration

> "Maybe it would have helped if someone told us, "okay this is what we are going to do first, if this doesn't work we will go to this and this and this" [STB1]

> "we have had trouble with the tube and I felt alone with that" [LTD2]

4 At home

- Feeling 'in the dark' about weaning
- There is no 'sense of urgency' about getting the tube out
    a. some resort to pulling the tube out themselves
- Social support is very much needed, particularly connecting with other families in the same situation
- Problem solving is part of managing a tube – ask parents about this and share ways other families have found solutions to common problems
- Having no-one to talk to who *really* understands
- Empower with resources – know where to go, who to talk to at critical times

> "..the other thing was that I was over the number of times I was putting the tube back in, it was emotionally affecting me and I was telling [name], "I can't do this anymore, I don't want him to have this tube"." [STB1]

5 How we're treated by healthcare providers

- Talk to my child, interact with her. I can help you communicate with her.
- Remember that it is her body. Tell her what you are doing and why. Reassure her and be kind.
- Don't give up hope. There is always hope that things might improve, or new technologies could help us.
- The tube might be working, but eating is really important to us – keep the energy up for the potential to wean.

> "He just saw disability before he saw child and you do come up against doctors like that… when you find the doctors that see the child first, then you're happier to go back to them" [LTD2]

6 Dads/Supporters

- They need support too

> "…going back even to the NICU stuff, it is very mum focussed. I mean there's obvious reasons why.. but you do sometimes sort of feel a bit on the outside as a dad… there's not as many people who say, how are you doing?" [STPC]

- Many are working full time, attending the hospital, and keeping the home running while mum/baby is in hospital.
- ‘It is exhausting’
- Often feel out of the loop in terms of communication and decision making.

“There was no explanation of long term complications or things like that” [STB1]

“They were very supportive and I have nothing to complain about them but I think at the same time we probably did not let them know how we were feeling emotionally… maybe ask how we were, whether I was coping emotionally” [STB1]

7 Connecting with others

- Nobody *really* understands what it’s like. I need to talk with others in the same situation
- No knowledge of existing support groups
- Online support preferred
- Healthcare professionals can facilitate support, but not always proactive in asking or offering

Nobody understands. That’s what is really hard. My sisters don’t understand, my friends don’t understand, my mum doesn’t get it. I don’t’ even get the sense that really the healthcare professionals really understand what it is like having to tube feed your baby” [STP3]

8 Perception of tube changes over time

- NG Tubes:
    - **Initially:** Lifesaving, ‘no-brainer’
    - **Mid-term: ‘**Are staff getting complacent?’
    - **Longer-term:** ‘Highly distressing’. Great urgency to wean, and urgency not always perceived to be shared by staff
- PEG:
    - **Initially:** A big decision, scary, some resistance
    - **Mid-term:** Waiting for surgery is an anxious time
    - **Longer-term:** The benefits outweigh the costs. It can make going out easier, you have to be very prepared all of the time.

“ I think it would have been useful to have

“Its [PEG] more like kind of a medical problem you know so it’s just a little bit more scary” [LTP1]

“The wait was very frustrating… its like come on, come on. And then you having too push for it and follow it up all the while spending time in hospital because this child’s refluxed and aspirated” [LTD1]

9 Weaning

- No sense of urgency
- No ‘game plan’
- No knowledge of available options/eligibility
- Parents spontaneously wean out of frustration
- Seek information/solutions online
- Highly distressing
- Recommended to build staff confidence/competence

“Because the hospital did not have a plan… they did not have a plan how to wean my child off… I just pulled it [the tube] out [STP2]

‘I say that in a way because I felt a real sense of urgency as I have just said to get this tube out and start normalising feeding. I do not get that sense of urgency from anyone else.” [STP3]

10 Stigma in the Community

- People stare
- Children ask questions
- Use it as an opportunity to educate
- Childcare centres label children ‘disabled’

“We just have our own version of normal… every now and then it will bug me when you have some little kid going “oh look at the baby” …the parents who just don’t see that as an opportunity to educate their kids” [LTD2]

11 Shared Decision Making

- Time is not always on our side

- Cost : Benefit ratio can change over time – tubes seen as advantageous in the short term, but can become difficult and stressful when weaning is desired but not actioned or achieved.
- Understanding of true impact/long term consequences

12 Don't assume we know what to do

New mothers and parents who are also healthcare professionals felt:

- There were lots of assumptions about how much they knew, or that they would just 'know what to do'.
- Staff were more hands off
- Parents received less information or active support
- Increased worry and anxiety

> "[staff] knew we were from medical backgrounds… there wasn't much explanation. It looked like we should know. I'm talking about assumption… we were not in the right frame of mind. We were stressed." [STB1]

13 Emotional Needs

- Stress, anxiety and depression reported throughout
- Stress and anxiety in particular interrupted with information retention in the hospital
- Parents were incredibly resilient, finding solutions to their practical problems
- The real impact of tube feeding left some feeling exhausted, depressed, isolated, and/or angry
- Some remained accepting of the situation
- Recommendations for staff:
  - Repeat important information
  - Write it down
  - Health literate resources
  - Go back to information provided – don't assume parents will read it

> "It is not just grief… I feel really angry… there was no safety net in place [to stop tube dependency]" [STP3]

> "I started getting sick. My mental health suffered… but I needed to look after me cos I was getting sick with would have killed me… I've got this child that I'm going to have to be a mum to for the rest of her life" [STD1]

14 Cultural influences

- Some cultures react differently to 'disability' when families are out in the community. It can be difficult to know how to respond without causing upset to either party.
- Some cultures have a different perception towards 'tube feeding'
- Information gathering may be hampered when working with some migrants or former refugee families due to their language or cultural barriers. Advised to use a trained interpreter if needed.
- Further investigation into:
  - Whānau-based care
  - Tapu/Noa and maintaining tube feeds at home

> "Because sometimes disability is hidden [other cultures] are not used to seeing a child profoundly disabled" LTD2]

15 Where to go to for help

- Knowing who to contact, especially if out of the service for some time
- The valued role of the psychologist. That there is a funding gap for Applied Behavioural Analysis Psychologists

> "The psychologist… when she came in she came in with full force and to make it work, was that we both collaborated together really well.. we were aiming for the same thing… it was awesome." [STB2]

to assist children with weaning. These skills were highly valued for their efficacy by parents.

- More support for childcare centres to manage tube feeds

16 Access to childcare

- Families living in the community had difficulty finding childcare
- Some who had a tube inserted after attending daycare were asked to leave
- Children with tube feeding labelled 'disabled' by childcare centres – distressing and stigmatising

"It is the saddest thing that can ever happen. Imagine, you see her, she is full of life, and you know being termed as disabled just because she doesn't like to eat is not nice" [STP2]

17 Inter-Sectorial Care

- There was feedback to have schools, health sector and private care providers share the same messages. There appeared to be confusing and contradictory messages provided across various service providers.
- Recommendation to provide a collaborative service across services:
    - Hospital services
    - Community Care
    - Schools
    - Wilson Centre

"What would make this more whānau-focused for me is having the school, together with the health sector, together with the medical staff, with my family to give support … we can work together… we're a family.. we're one" [STB2]

18 Bonding

- Bonding with an infant is difficult through absence of breastfeeding
- Being able to 'cuddle' baby is limited if child has to sit upright to be fed, and parent also has to hold the pump
- Trauma experienced at birth, and shock of having a 'disabled' child can affect bonding and adjustment

"That is one of the hardest aspects of it because as a mother feeding your baby… is so instinctive.. it is huge emotionally. It is a way of connecting… I grieve for what I have lost but I also grieve for what she has lost out on" [STP3]

4. Project recommendations

Recommendations from the above themes are captured below, including possible solutions that were generated in the co-design workshop with consumers and staff.

Family and Whānau-Centred Experience	Driving Themes/Issues	Recommendation for person-centred care	Values: What we would like to see developed
Adjustment and Competence (Factors supporting or negating parental adjustment and feelings of competence with the tube)	• Experiences in SCBU and on the ward • Being prepared to go home • Expectations and Timelines • Don't assume we know what to do • Bonding	Improved care In SCBU: • Improve orientation to SCBU from NICU – demonstrate the differences e.g. with equipment. • Early education about bonding • Kangaroo care – natural feeding development for gestational age • Rework the agreed discharge checklist and incorporate into quality policies – include what parents and /or other caregivers (e.g. grandparents in some Asian families) can take charge of (e.g. tube feeds, flush); normal developmental milestones; trouble shooting/problem solving; how to connect with other parents and/or caregivers; descriptions of who is in their team/when they are available. Presented in a health literate format e.g. patient journey. • Involving and up skilling parents and/or other caregivers in all aspects of care • Encourage non-nutritional feeding	- **Better Best Brilliant** Positive and safe – We can make a difference. Uses best practice to deliver the best outcomes Best practice should also include responsiveness to patient/parental experience and how their experience of treatment can be improved - **With compassion** Compassion for your suffering – put self in other's shoes Prevent psychological harm by responding to these experiences, and implement recommendations from parents

		• Train parents and/or other caregivers to reinsert a tube before discharge with tube in situ • Setting realistic expectations and timelines before discharge • Access to helpful links / service specific website development for parents and/or other caregivers	
Anxiety and Uncertainty	• Weaning: No sense of urgency • Timelines	Creating a sense of urgency around weaning, Provide families with approximate timelines may help reduce feelings of anxiety and uncertainty. Consider staff competence and confidence in weaning	- **Better Best Brilliant** Positive and safe – We can make a difference. Uses best practice to deliver the best outcomes Improve services and ourselves – reviews performance and evidence to look for better ways to do things Efficient and organised – stays responsive to patients and colleagues when under pressure. Provide timely services
Day-to-Day Coping (How parents feel day to day and cope with adverse emotions)	• Emotional Needs & Self Care • Connecting with others • Lack of access to a psychologist • Where to go to for help • 'Chronic	The emotional impact of tube feeding could be reduced by normalising parents' experiences and reactions; by sharing other parents' stories. Anxiety/uncertainty could be reduced through provision of timelines and keeping the energy up for weaning (where possible). Connection with other parents	- **With compassion** Compassion for your suffering – put self in other's shoes Attentive and helpful – proactively offers to help Protects dignity – support privacy of patients and value

	Sorrow' resulting in lower thresholds for stressful events	can be achieved through: • Staff facilitation • Sharing details of the New Zealand Tube Feeding group on Facebook / website development • Encourage sourcing/searching for support groups (online or face to face) for other ethnic groups Self-care should be promoted by staff: • Taking time out • Engaging in exercise/relaxing activities • Neonatal coffee groups encouraged Improving access to social workers or Infant and Maternal Mental Health Services when applicable / indicated: • Provide a list of available community resources. • Refer to relevant services if needed (As some Asian people may be very reluctant to ask for a help from psychologists because of cultural belief and stereotype)	patients at all times Reassuringly professional – remain calm under pressure - **Connected** Communicate keep people informed Explain – clearly and follow up to check they have understood Teamwork/partnership with patients/ whanau and colleagues - to stay involved and make informed decisions about child's care Feedback – encourages feedback from service users
Family Whānau-Centred care in the hospital and in the community	How we're treated by healthcare professionals	Reminders to clinicians about respectful ways to treat a non-verbal or disabled child Communication courses for staff working with families Cultural Responsiveness included in Family and Whanau centred care provision CALD training for staff and consultation with Cultural Case Workers when working with	- **Everyone matters** Welcoming and friendly – makes everyone feel positively welcomed and valued Respect each individual – welcomes different views and cultures

		culturally and linguistically diverse patients. Family meeting and education session to all main carers before discharge. Make sure interpreting service/cultural support are provided as needed. (Many Asian grandparents are involved in grandchildren`s care , or sometimes they themselves are the main carer of these children. It is important if they can also get all information directly from clinicians.)		Listen and make time to understand others views and feelings Speak up for others
Continuity of care/Family Whānau care standards	At home	Develop an ePathway overlaying the parental experience on the clinical process maps Clinicians to follow a set of family/whānau-centred care standards Make list of available resources/services in community. Education about the impact of tube feeding journey for staff/family whanau Ensure staff is trained in active listening. Remember that families live with this all day every day – importance of access to family journeys. Support development for Waitemata DHB app for tube feeding management in the community	-	**Best Better Brilliant** Positive and safe – We can make a difference. Uses best practice to deliver the best outcomes Improve services and ourselves – reviews performance and evidence to look for better ways to do things Efficient and organised – stays responsive to patients and colleagues when under pressure. Provide timely services
Feelings of progress/ success	• Expectations and timelines • Experiences	Reduce the focus on weight and include other measures of developmental success, e.g. visual timeline of developmental	-	**Best Better Brilliant** Positive and safe – We can make a

	in SCBU • At home	milestones Celebrate successes, big and small	difference. Uses best practice to deliver the best outcomes Improve services and ourselves – reviews performance and evidence to look for better ways to do things Efficient and organised – stays responsive to patients and colleagues when under pressure. Provide timely services
Weaning	• Timelines and Expectations • Lack of urgency to wean	ABA (Applied Behavioural Analysis) Psychologists are highly valued and efficacious with their approach. There is currently no funding for these positions, yet families highly value the care they provide due to their success with weaning. Keep a timeline running for weaning at all times. Plan to wean should be discussed on day of tube insertion (where possible) Include a checklist of everything that can affect weaning – a way of seeing and monitoring progress Include other measurements than weight. Reinforce and reassure that every family is different Share other (de-identified) stories to normalise and reassure Many families are striving for	- **Best Better Brilliant** Positive and safe – We can make a difference. Uses best practice to deliver the best outcomes Improve services and ourselves – reviews performance and evidence to look for better ways to do things Efficient and organised – stays responsive to patients and colleagues when under pressure. Provide timely services

		normality and the tube is the last thing standing in their way. Develop a standardised approach tube weaning National Weaning tool (under development) Non-oral feeding and weaning development: ‘Readiness to wean tool’ Give indication of duration of NGT and options for PEG early too	
Staff competence	Building rapport, giving reassurance	Encourage staff training in communication skills such as active listening, normalising and validating. Providing family centred training to staff Using ‘Hello my name is…’ in the hospital and the home (explaining who you are, what your role is, and why you are there) Community MDT reach in to ward before discharge Health literacy – understanding what it is and using it in context Staff to access to eCALD training for better working with CALD (culturally & linguistically diverse) clients and families. Further investigation into: - Whānau-based care - Tapu/Noa and maintaining tube feeds at home	- **Best Better Brilliant** Positive and safe – We can make a difference. Uses best practice to deliver the best outcomes Improve services and ourselves – reviews performance and evidence to look for better ways to do things Efficient and organised – stays responsive to patients and colleagues when under pressure. Provide timely services
I’m not at the centre of care	Dads/Supporters or Partners	Include Dads/Supporters or partners in shared decision making Ask how they are doing	- **Everyone Matters** Welcoming and friendly – makes everyone feel positively

	Ask if they’d like to meet up with another dad/supporter or partner in the same situation Encourage connection between Dads/supporters or partners in NICU/SCBU	welcomed and valued Respect each individual – welcomes different views and cultures Listen and make time to understand others views and feelings Speak up for others and be encouraging

5. Celebrations

- ✓ Project accepted into i3 for co-design and innovative service development
- ✓ Staff and stakeholders across divisions wanting to be involved in this project and committing to provide feedback at various stages throughout the project
- ✓ Staff had fed back that the opportunity to co-design solutions to service delivery with consumers was positive, with many stating it had been valuable to have concerns of their own confirmed by families. They also felt motivated that something positive was being done to resolve these concerns. *“The feedback you gave re your interviews was really well summed up in themes and quite overwhelming and motivating”* – staff member
- ✓ Very successful ‘Family and Whanau centred tube feeding and weaning management’ symposium with networking across the region and nationally to discuss services (public, private and schools) for this population of children
- ✓ Families’ commitment to participate and share their journeys in 1:1 interviews and video recordings
- ✓ Feedback from staff of all levels, including governance groups and discipline specific meetings
- ✓ Future and current quality service development initiatives based on feedback from this co-design report
- ✓ Attending the ‘Let’s Talk Conference’ and learning more about co-design of quality healthcare services

5. Challenges

With such a wide and varied multidisciplinary team spread throughout both hospital sites and the community, stakeholder engagement was sometimes a challenge. Attendance at meetings was difficult for many due to workloads, working hours and conflicting demands on time. Lessons learnt for future MDT co-design work will focus on appropriate and acceptable communication channels for staff to participate remotely.

6. Next steps

Implementation of key recommendations (current @ 10 Oct 2018):

- Project Report presented to Governance Groups **– in process**
- Work request with i3 **- pending**
    - Education module for staff on Family-Centred Care and Communication
    - A family/whānau booklet and webpage containing stories, support for dads/supporters, expectations, and patient journeys.
    - Overlay of the ePathway of Care with prompts for family-centred care.
- Family and Whānau-Centred Clinical ePathway of Care for CeDDS **– under development**
- National Patient-Led Discharge Planning Tool **- under development**
- A2D Planner Redesign, SCBU **– under development**
- Māori and Pacific Health Teams Review **- requested**
- Asian Health Review **- complete**

7. Appendix A

Supporting documents:

..\Family Centered Tube Feeding Management\Recommended Change of Process for Feeding Tube Management V1 16May16.docx

..\Family Centered Tube Feeding Management\Paediatric Feeding Tube Process Map v1.41 4May16.pdf

Consumer Council Meeting

Patient Experience Survey:

Feeding Support

11 May 2022

Elizabeth Maritz
Clinical Leader Peadiatric Dietitians
Community Child Health Service

Waitemata
District Health Board
Best Care for Everyone

Pathway Development Timeline

2016
Blitz-project (i3)

2017
Co-design with family & staff

2017
Tube Feeding to Weaning Management Symposium

Dec 2019
Publishing Feeding Support ePathway

Nov 2021
Patient Experience survey

Waitemata
District Health Board
Best Care for Everyone

Reason for the feeding support survey

- To hear about family whānau's experience of receiving tube feeding support for their child.

- What we are doing well, and how we can improve our services to provide a positive experience.

Did the feeding support pathway make an impact on the services we offer families?

Waitemata
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Best Care for Everyone

Survey designed around Family/Whānau Themes

- Experiences in SCBU
- Expectations and timelines
- Being prepared to go home
- At home
- How we're treated at hospital
- Dads/Supporters
- Connecting with others
- Perception of tube changes over time
- Weaning: No sense of urgency
- Stigma in the community
- Shared Decision Making
- Don't assume we know what to do
- Emotional needs & Self Care
- Cultural influences
- Where to go for help
- Access to childcare
- Inter-sectorial care
- Bonding

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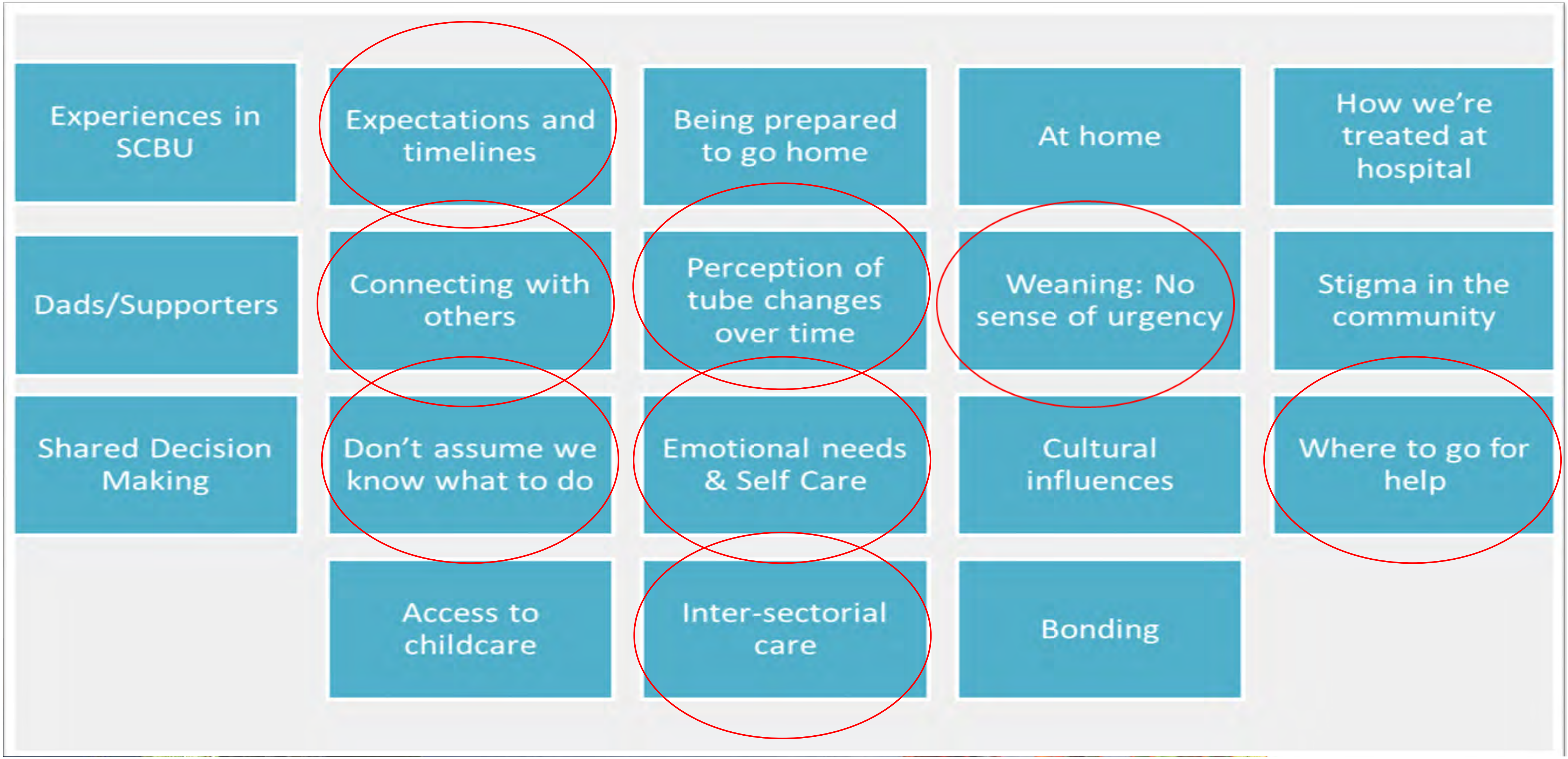
Co-design Themes 2017 & survey results 2021



Experiences in SCBU

Expectations and timelines

Being prepared to go home

At home

How we're treated at hospital

Dads/Supporters

Connecting with others

Perception of tube changes over time

Weaning: No sense of urgency

Stigma in the community

Shared Decision Making

Don't assume we know what to do

Emotional needs & Self Care

Cultural influences

Where to go for help

Access to childcare

Inter-sectorial care

Bonding

Next steps

- Raise awareness of family's experience with current feeding support offered.
- Coordinate and consolidate information about tube feeding:

  Upskill staff to ensure the feeding support pathway and resources are being used as a guideline in clinical practice
- Seamless flow through the service, including transitions from in-patient wards to community

Waitemata District Health Board

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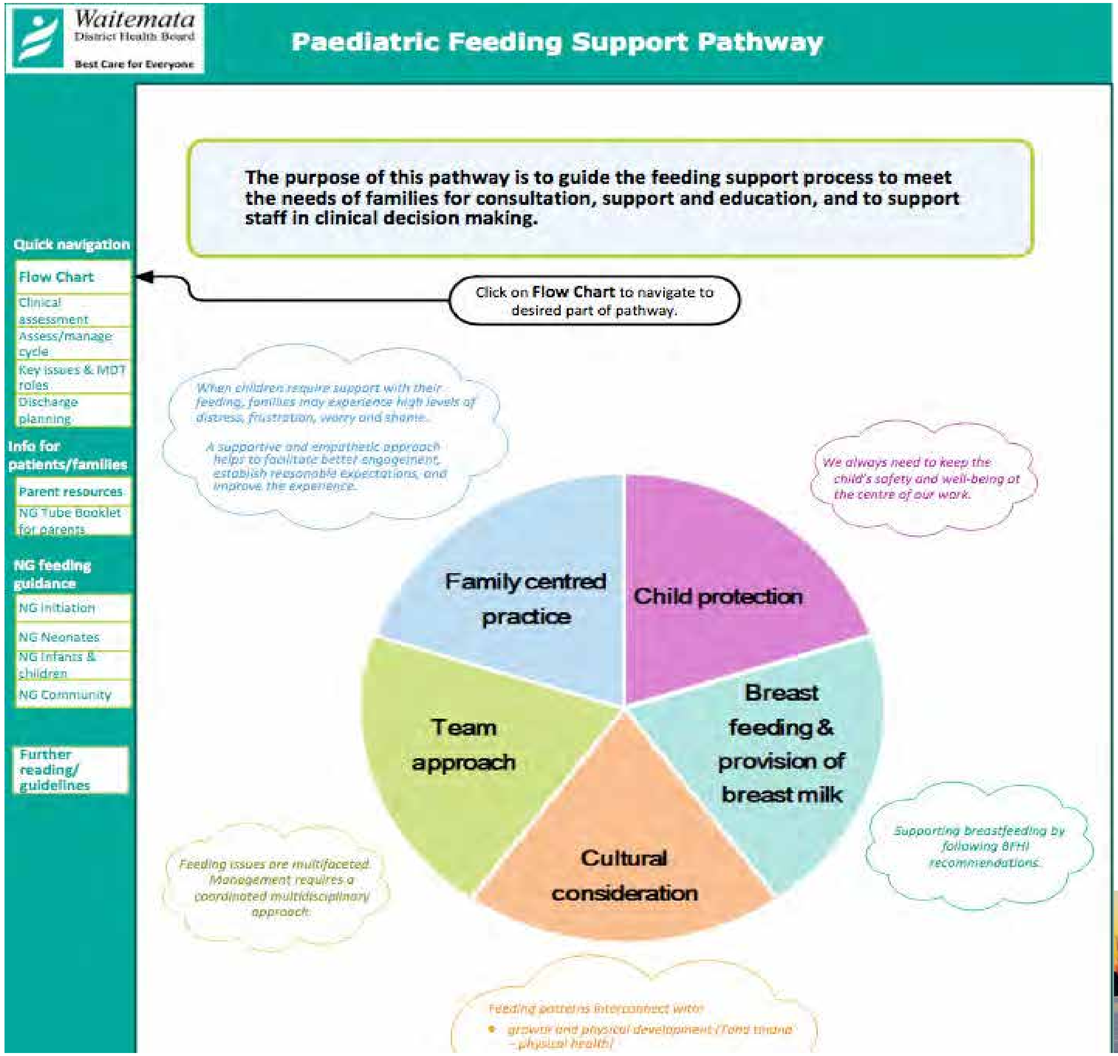
HOW? are we going to do it



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Paediatric Feeding Support Pathway

The purpose of this pathway is to guide the feeding support process to meet the needs of families for consultation, support and education, and to support staff in clinical decision making.

Quick navigation

- Flow Chart
- Clinical assessment
- Assess/manage cycle
- Key issues & MDT roles
- Discharge planning

Info for patients/families

- Parent resources
- NG Tube Booklet for parents

NG feeding guidance

- NG Initiation
- NG Neonates
- NG Infants & children
- NG Community

- Further reading/ guidelines

Click on **Flow Chart** to navigate to desired part of pathway.

When children require support with their feeding, families may experience high levels of distress, frustration, worry and shame.

A supportive and empathetic approach helps to facilitate better engagement, establish reasonable expectations, and improve the experience.

We always need to keep the child's safety and well-being at the centre of our work.

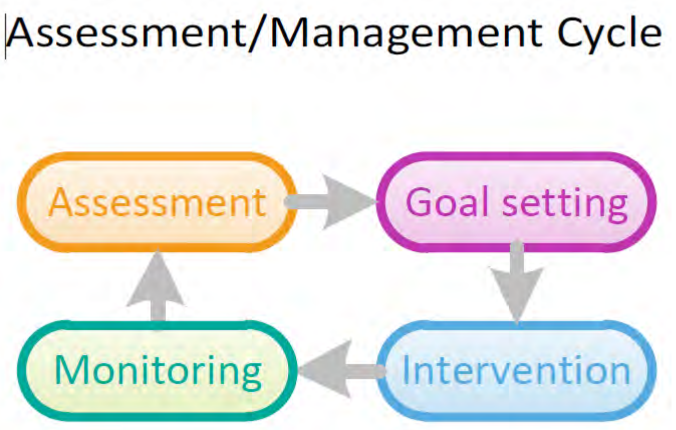
Supporting breastfeeding by following BFHI recommendations.

Feeding issues are multifaceted. Management requires a coordinated multidisciplinary approach.

Feeding patterns interconnect with:

- *growth and physical development (Taha tinana – physical health)*

✓ Facilitate a consistent family whanau-centred approach



Assessment/Management Cycle

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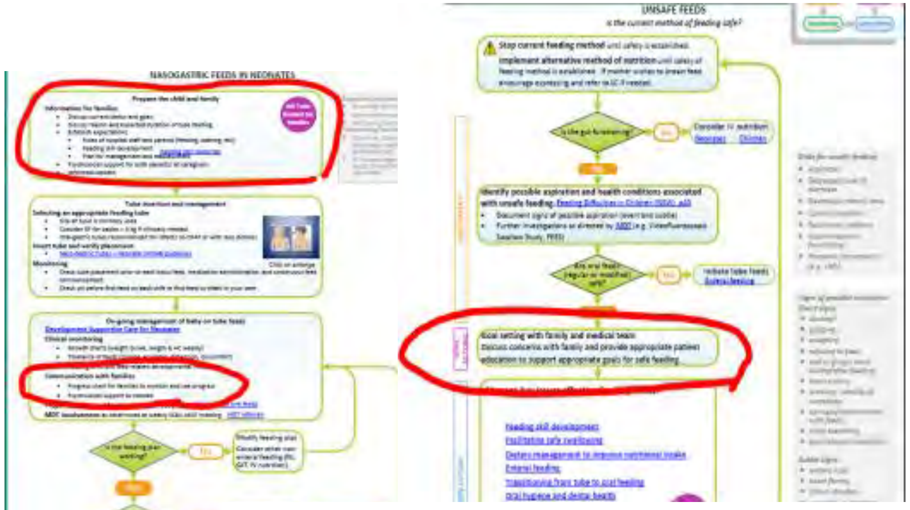
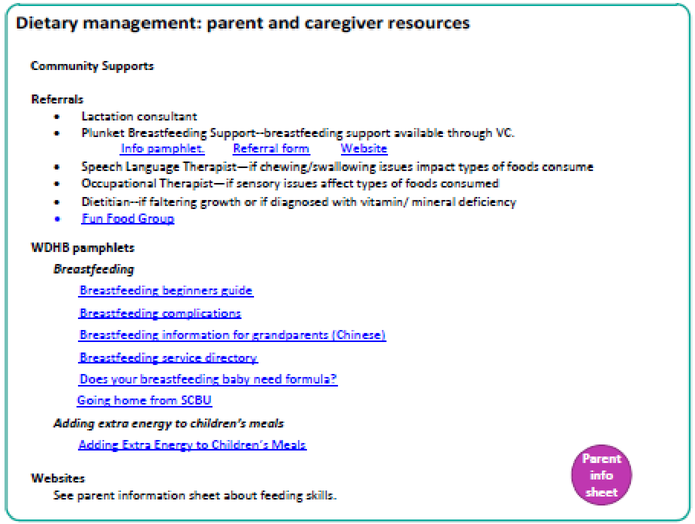
Patient & Family/Whānau experience

- **Early discussion, goal-setting, education and support** with the family at each step.
- **Resources and supports** for families highlighted for each key issue





Dietary management: parent and caregiver resources

Community Supports

Referrals

- Lactation consultant
- Plunket Breastfeeding Support--breastfeeding support available through VC.
  Info pamphlet Referral form Website
- Speech Language Therapist—if chewing/swallowing issues impact types of foods consume
- Occupational Therapist—if sensory issues affect types of foods consumed
- Dietitian--if faltering growth or if diagnosed with vitamin/ mineral deficiency
- Fun Food Group

WDHB pamphlets

Breastfeeding

Breastfeeding beginners guide
Breastfeeding complications
Breastfeeding information for grandparents (Chinese)
Breastfeeding service directory
Does your breastfeeding baby need formula?
Going home from SCBU

Adding extra energy to children's meals

Adding Extra Energy to Children's Meals

Websites

See parent information sheet about feeding skills.

Discussion invited: How to use the survey results

HOW? .. Managing families' expectations:

- Empowering families and whānau in this journey with their child and managing their expectations around tube feeding and weaning.
- Any other comments or recommendations are valued.

Questions/ comments

5. INFORMATION ITEMS

5.1 COVID-19 Update – Omicron - Verbal
5.2 HQSC/Health NZ/MHA Updates

6. OTHER BUSINESS

6.1 Community Concerns

6.2 Agenda for the next meeting

6.3 Meeting evaluation