



New Zealand Clinical Network for Paediatric Tube Feeding
Clinical Reference Group



Paediatric Tube Feeding Consumer Survey 2017

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and mother of a teenage boy who has been tube fed seven years to date

New Zealand Clinical Network for Paediatric Tube Feeding Clinical Reference Group

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Why was this survey conducted?

This reference group was established in July 2015 to address current paediatric tube feeding services in New Zealand by the Paediatric Society in partnership with the Ministry of Health from a public petition signed by 4500 people made by Tube Wean NZ (now called Tube Feeding NZ) in 2014. Its mission being “..to support optimal management of tube fed children. Our goal is for each child to reach their maximum potential for oral feeding”.

It was initiated by a consumer and as the consumer representative on this group I feel a great deal of responsibility to gather and share information provided by consumers to inform and shape the guidelines developed. It is a two way process.

The prerogative falls under Objective 3 of the current Clinical Reference Group (CRG) work plan.

The Survey

This is the first national consumer survey to gain feedback. Responses reflect current access to, availability and experience of Paediatric Tube Feeding services in NZ.

- The survey was drafted between January-February 2017 and was a mix of 20 closed and open questions. Establishing age, region and current tube feeding status, experience so far and suggestions made to improve the experience of paediatric tube feeding services in NZ. (appendix: ref 1)
- First release 28th March (facebook groups)
- Rolled out over 3-4 stages
- Closed end of July 2017

The aim was to spend no more than 10 minutes answering questions.

- We have received 76 responses out of a potential 430 (at time of survey).
- 1 was rejected as it was outside the paediatric age range.

What did we have to offer the consumer?

A chance to be heard, share current experience, provide input on the needs they would like to be met and by whom, to a multidisciplinary clinical group who will offer guidelines and advice on the future national provision of services for paediatric tube feeding. Feedback to consumers would be via;

- newsletters (appendix: ref 2) following-up key points raised
- on the KidsHealth website
- and any other appropriate public forum (i.e. Tube Feeding NZ facebook page)
- Tips and tricks submitted to be published on KidsHealth.

Who are the consumers?

Parents and/or caregivers with children who have been tube feeding for 3 months or more. They are a diverse group nationally with varying health conditions. The one thing they have in common is tube feeding. They may only be in contact with their health provider, outreach team or condition specific organisation. This group also contains many who will not wean from tube feeding, something to remember when looking at the long term plan and support.

How were they reached?

Through specific facebook or websites these consumers visit. Through collegial groups and networks, directly from medical health providers and via national agencies and organisations. There is no guidebook for this kind of work. (appendix: ref 3)

It's important to gain input from consumers at their own discretion so responses are freely given. A medical environment can be an inhibiting and distracting factor so consumers were asked to complete the survey online in their own time. Alternative arrangements were made for those with no access to the internet or who might have difficulty with reading or writing.

I am humbled by the trust and generosity by which consumers have taken the time to add such useful information to the open text questions. They could have simply complained about the current service, or lack thereof.

However, the majority of comments were how we can improve and already these are influencing the procedures and guidelines the CRG will roll out nationally.

The age distribution graph looks very similar to Dr Timothy Jelleyman's Prevalence and Patterns of Enteral Feeding for NZ Children: A National Survey, demonstrating a good reflection of this survey's population sample.

Executive Summary

There have been several key themes to emerge from this survey.

The strongest message to emerge is the request for more holistic support for the families facing the challenges of not only having a child with a medical condition, but one that also requires prolonged tube feeding.

Parents and caregivers are having to learn how to keep their child alive with formulas, pumps, tubes, syringes and medicine schedules, all day, every day. In the early stages consumers comment this is often overwhelming.

There are a series of stages that follow on from this that consumers have clearly identified requiring more information and support.

Families need to have information presented to them and made available in a way that they understand.

When going home and back out into their community they need assistance with:

- Day to day management
- Ongoing care; including how to prepare for, identify when ready and support the weaning process
- Assistance educating those around them i.e. extended family, other caregivers, pre-school and school
- Hauora, wellbeing i.e. physical, emotional, social and spiritual
- Regional support for those living outside the main centres

A consideration our reference group discussed early on was the need to really think before you even start tube feeding; especially if some more time waiting or hospital days could avoid it.

If not, and a feeding tube is the correct path every DHB must provide the following:

- Appropriate Information
- Timely Plan
- Follow-up
- Oral Stimulation
- Skilled & resourced Multi Disciplinary Team (MDT)
- Support for the Family

The survey results have highlighted a number of areas and questions that need to be assessed and addressed by DHB's in New Zealand with tube fed children.

Author comments: Tube feeding helps keep our children alive.

Caring professionals such as this CRG ^(appendix: ref 5) are producing guidelines and advice to improve the experience of paediatric tube feeding services in NZ.

You - the specialists, registrars, nurses, dietitians, therapists & psychologists are part of that solution.

The education, experience and skills required in the MDTs are being identified. Support documentation is being written and ongoing access to a panel of experienced practitioners investigated by the CRG. This is particularly pertinent to regions where access to a complete MDT is unlikely.

The CRG's aim is to make everybody's journey easier.

1 in 7 consumers have made a valuable contribution to tell us exactly what the issues are, consumers offer a realistic sounding board, out of the box thinking and highlight priorities.

It is fitting that I conclude this summary with quotes from our generous responders.

“Make sure we are followed-up, checked on. Plan forward. Provide other agency information and how they fit in ongoing health support to improve the picture.”

“Wrap around plan especially if looking long term (short term not such an issue), access to up to date equipment, as relates to NZ.”

“Oral aversion - specialist awareness need to limit tube feeding to avoid oral aversion. More awareness is required.”

“Up to date strategies required to be effective, currently out of date and ineffective.”

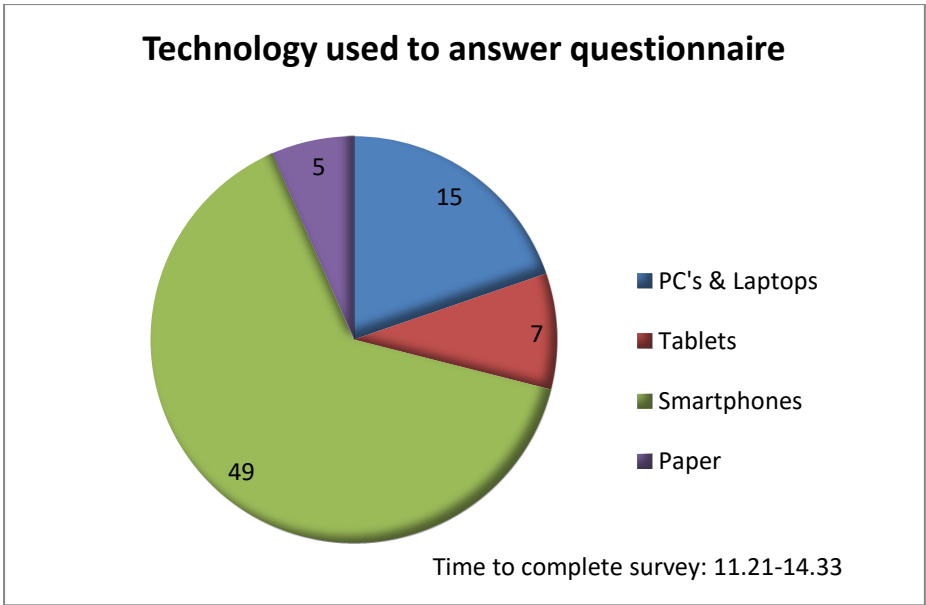
“Support is key. Parents know their children, trust them and support their choices. Encourage them, let them know how great they are. Tube weaning is the hard.”

Survey Results

* indicates a compulsory question.

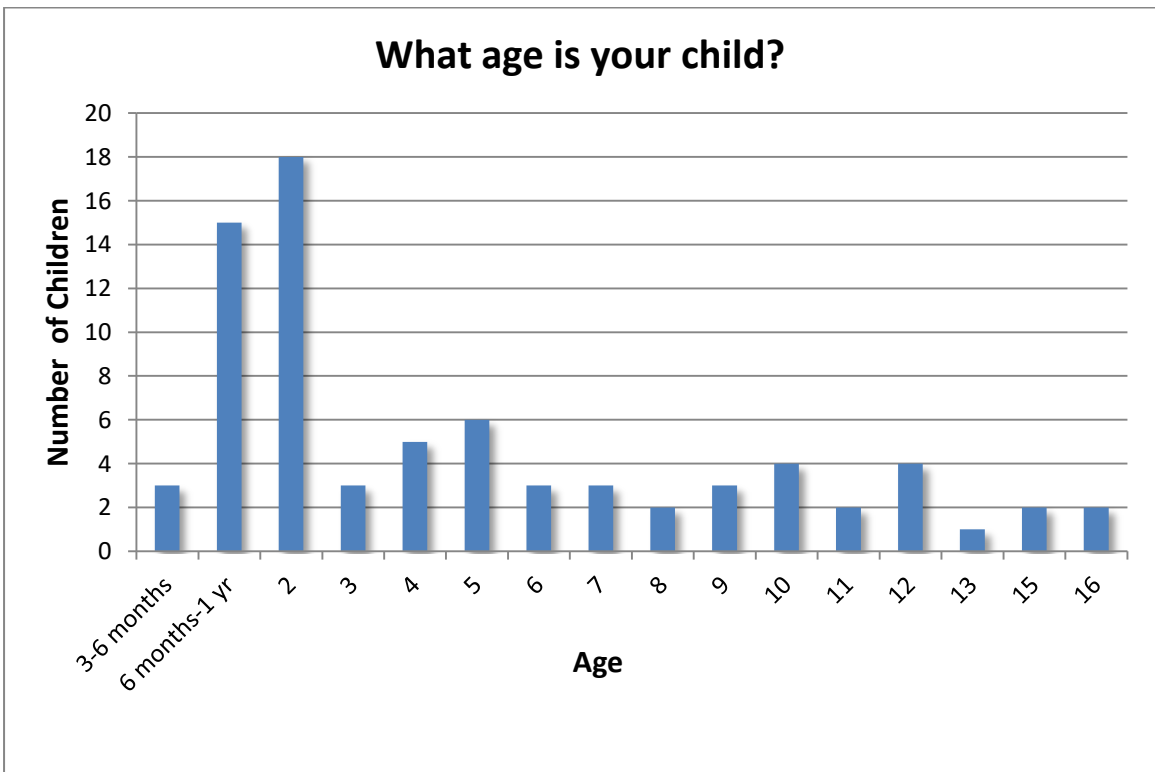
The following covers the questions asked and responses given.

Where themes are identified, selected *“Quotes in italics”* are provided as real comments made by consumers from the open questions.



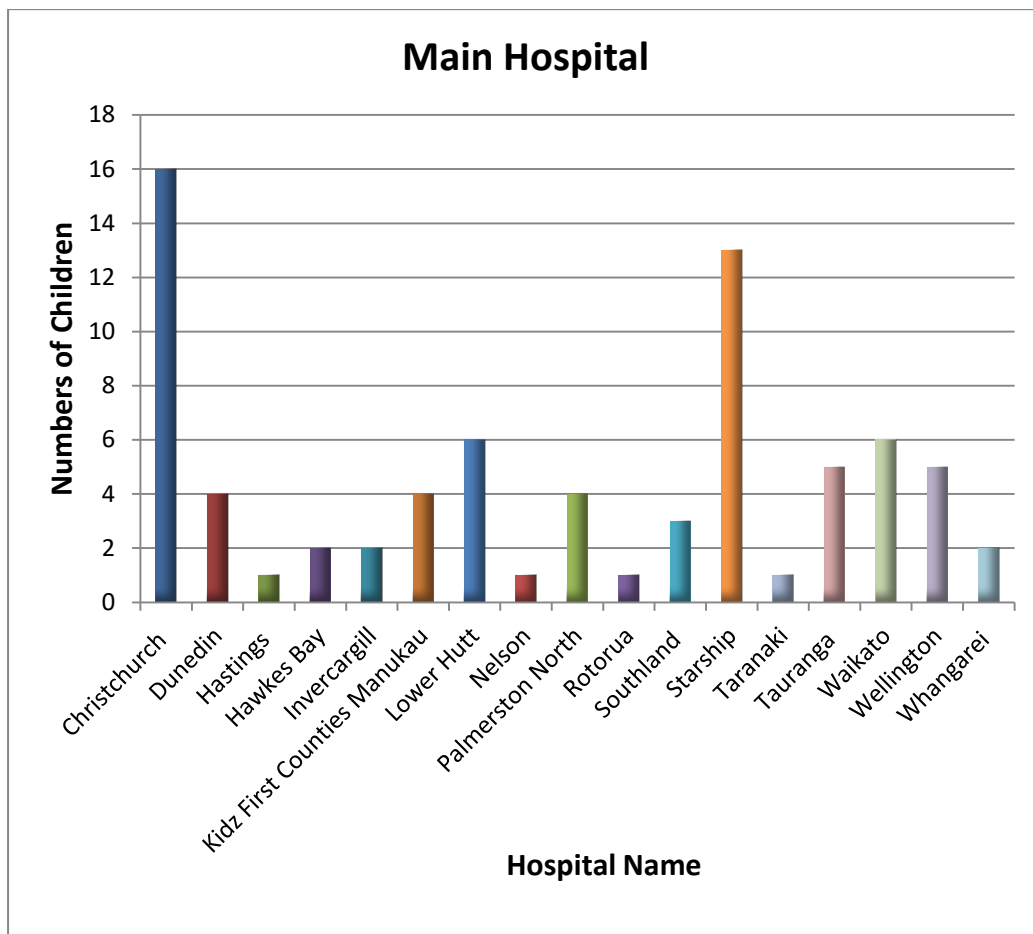
The technology used to answer the survey was an interesting reflection of how this group is communicating.

1. What age is your child? *



Though this shows an expected early peak in the preschool years (44 children), almost half are school aged children (32 children).

2. Which is the main hospital you go to? *



Author comment and questions: Consumers have to go to the nearest hospital that provides a tube feeding service. These are not only in the large metropolitan centres. **How are we going to provide consistent support and experience in all locations?**

If outside the larger centres in NZ then access to a multiple disciplinary team (MDT) is unlikely. Ongoing support is vital.

It is a big job if you only have one staff member allocated to tube fed children especially if considering weaning. And when staff are allocated, do they have the right skills? If not, how do you find them?

“ NZ needs tube weaning specialists with experience. We are relying on dieticians and nurses and this is such a small part of their workload, they just don't have the time to spend with us, and this process needs time.”

“Educating all medical staff that is involved in the care of your child about insertion of the tube so they know what they're doing.”

“Nurses on the ward were terrible at inserting the NG tube, and in the ED some nurses have never done this, we once had a nurse try and insert the wrong end of the tube!”

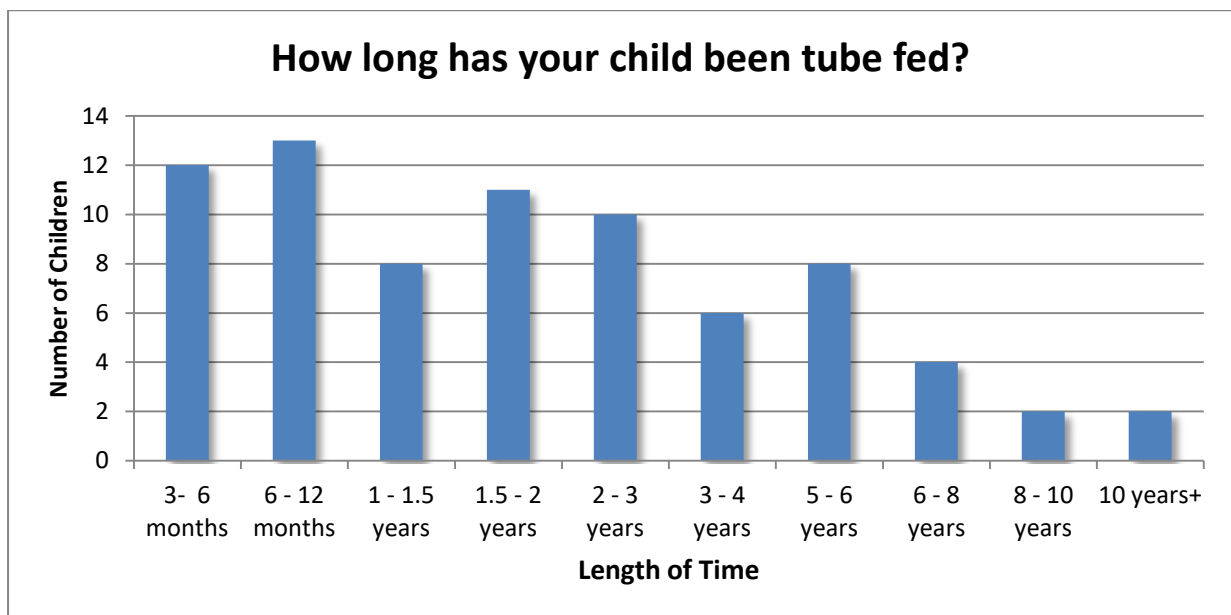
“Dietitians seem very busy with little time for each person. They seem unsure of how tube feeding or pumps work in daily life.”

“Why can’t dietitians offer other options for feeding other than clinical formula if appropriate.”

“Gain knowledge rather than opinion (conflicting across professionals).”

These are **national workforce questions to be addressed**; whether support is locally provided or by a larger centre and how, including the training required to adequately support a tube fed child.

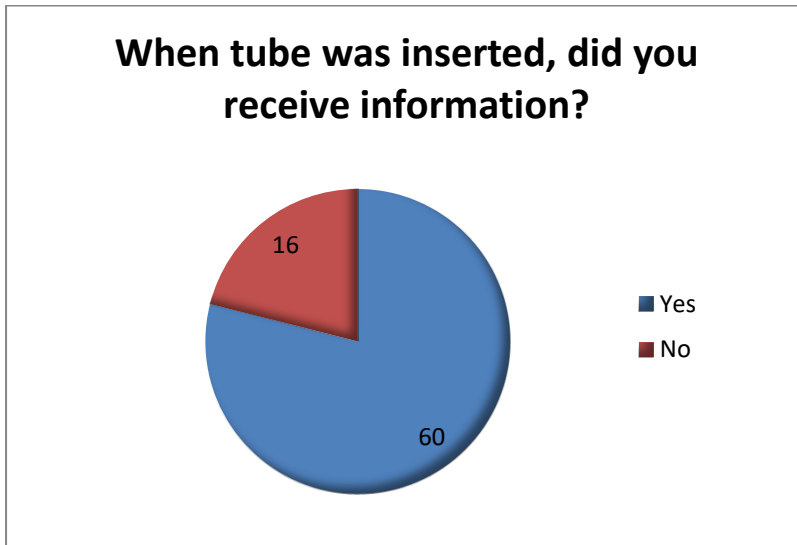
3. How long has your child been using a feeding tube? *



42% of children have been tube fed for more than 2 years.

Author comment: The survey reinforces the significant lack in timeliness and resource for weaning. This percentage of longer tube fed children should decrease as new guidelines and procedures are adopted nationally.

4. When the feeding tube was inserted, **did you receive any information about the tube and feeding?** *



Author comment: This is interesting, how come 16 families, that's 21%, said they didn't receive any information?

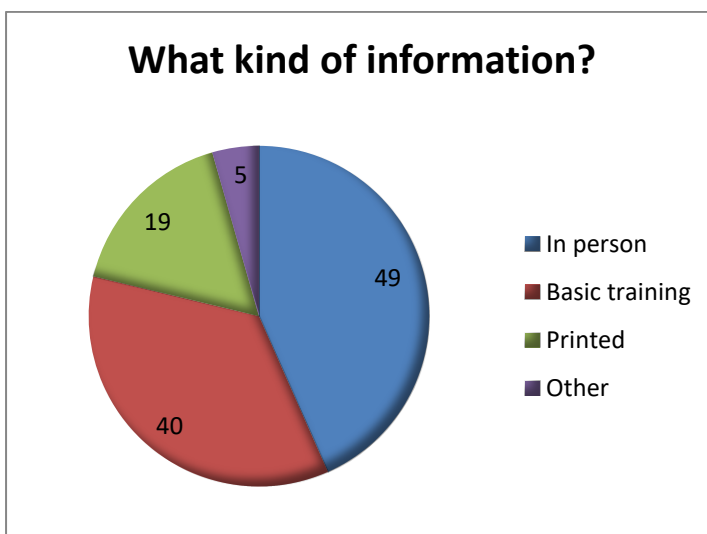
You might think, 'how could that happen? They were, but didn't remember'.

Even if that was the case, they weren't told or given information in a way that meant something to them so they would hear it and remember it.

Consider the different ways important information can be delivered and understood by different people; listening, watching, reading or a mix of all three.

5. If you said YES to the question above, **how did you receive that information?**

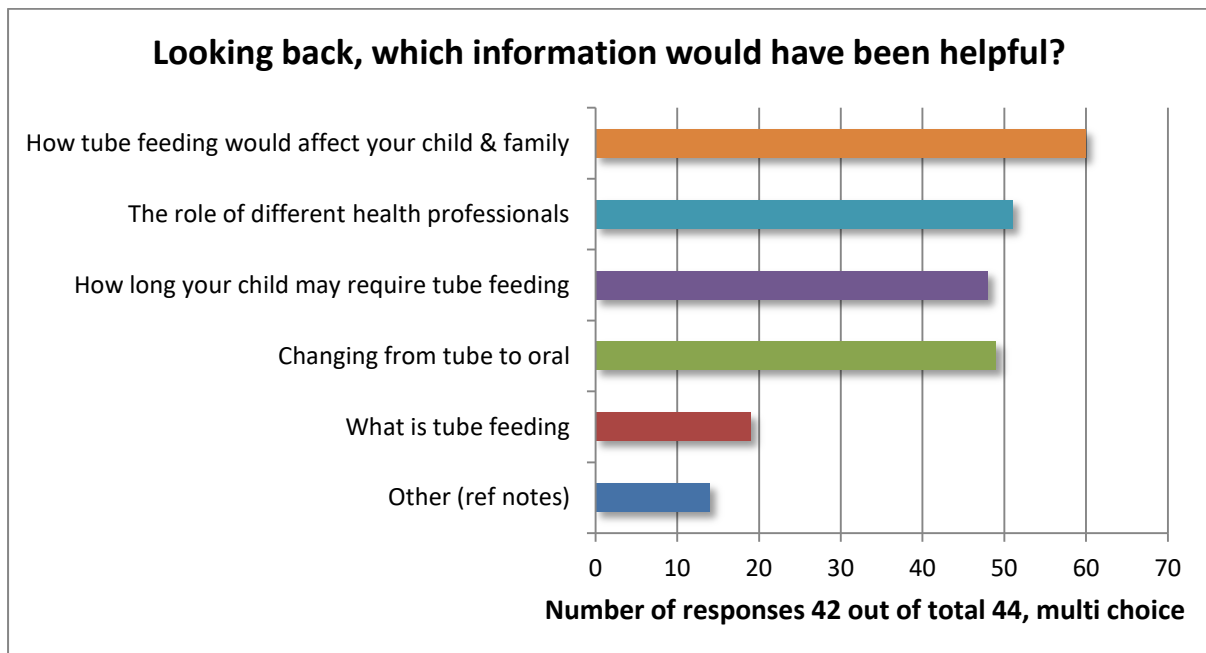
(tick and choose as many as you like)



Consumers indicated they would like suggestions for websites to visit for more information.

6. Looking back, which information about tube feeding would have been helpful to you and your family?

(tick and choose as many as you like)



This is the information consumers said would be have been most helpful, **how tube feeding would affect their child and family.**

- Tube feeding is **all day, every day.**
- **Food is not a choice.**
- **Food is everywhere**, it is ingrained in every social occasion, in happiness and sorrow, 3 plus times a day (if you can afford it) and culturally significant. Lack of sharing this basic necessity makes others feel uncomfortable.

Hauora - Wellbeing

Look at the social, psychological, physical, spiritual impact and support required for all family members.

This has become a key theme throughout consumer responses. The impact upon the child and family cannot be underestimated. Because this is such an important area to develop I will leave it to the consumers themselves to tell you what they need.

- Practical information e.g. how to cope with questions when you first take your child out.
- Information from hospital on emotional support for parents, links to facebook support groups.

- Talking to other mums who have tube fed children is often very valuable and can be a great source of information. Maybe connect with people in their area about tube feeding.
- How to help your child adjust being different from others.
- What will happen when your child starts school?
- How can we safely educate carers?
- Information about the long term impacts of tube feeding.
- Emotional and family support around the affects of tube feeding and tube dependency.
- Counselling available for family and/or caregiver and child.
- Talking to others about the future of lifelong tube feeding.
- A real and updated helpful information site on tube feeding.

“When I left the hospital for the first time with my daughter and feeding supplies/NG tube in I felt overwhelmed and very nervous about feeding her by myself at home. Information for first time tubies is important.. and also some sort of support person who could come into the hospital and talk to parents. It would have been nice to have talked to a mother in person about tube feeding just to see how they coped and what issues may arise etc when we were first starting our journey.”

“Information about the huge affect having a tube fed child has on someone's life; for spouse, family, friends that maybe don't quite understand what you're going through.”

“How to - manage at home, going out, dealing with family and friends, support when at school, mental health for whole family (huge).”

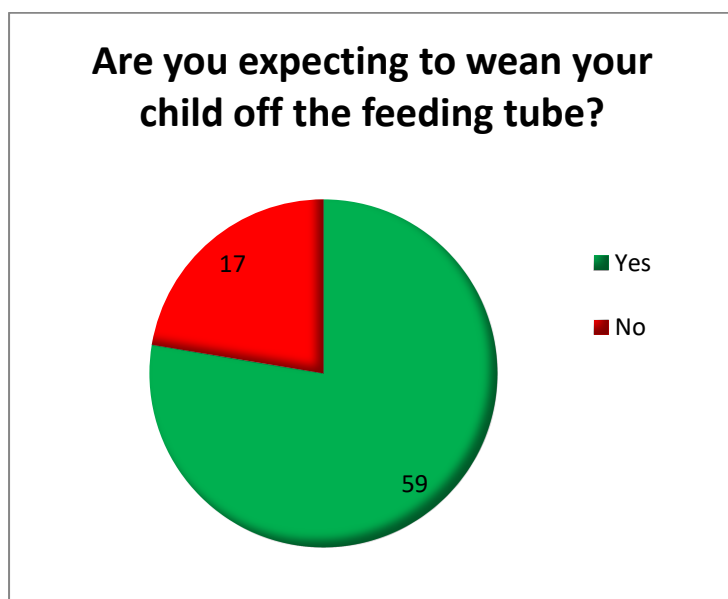
Other information consumers would like to know:

- Information about tube weaning, bottle aversion, individualised information about volumes to feed, strategies for mixed feeding
- Long term plan for feeding
- What are the signs your child is ready to wean?
- What oral skills does my child need in order to attempt weaning?
- How to wean off a tube
- Support tube weaning earlier
- Blended diets
- Ongoing support
- What might the future hold

“Challenges and future considerations and how we could prepare ahead of time for successful weaning, or practising oral skills.”

“The roles. Any help or support we could get would've been helpful, we often discovered things were available by accident months or years afterwards.”

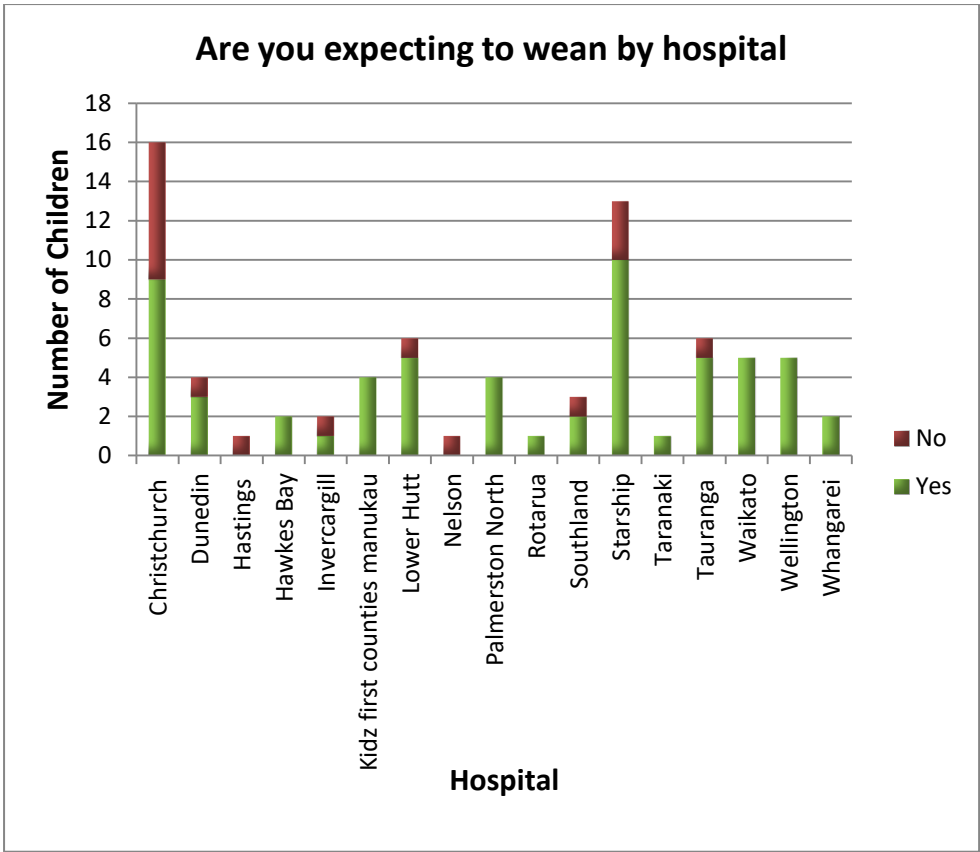
7. Are you **expecting to wean** your child off the feeding tube? *



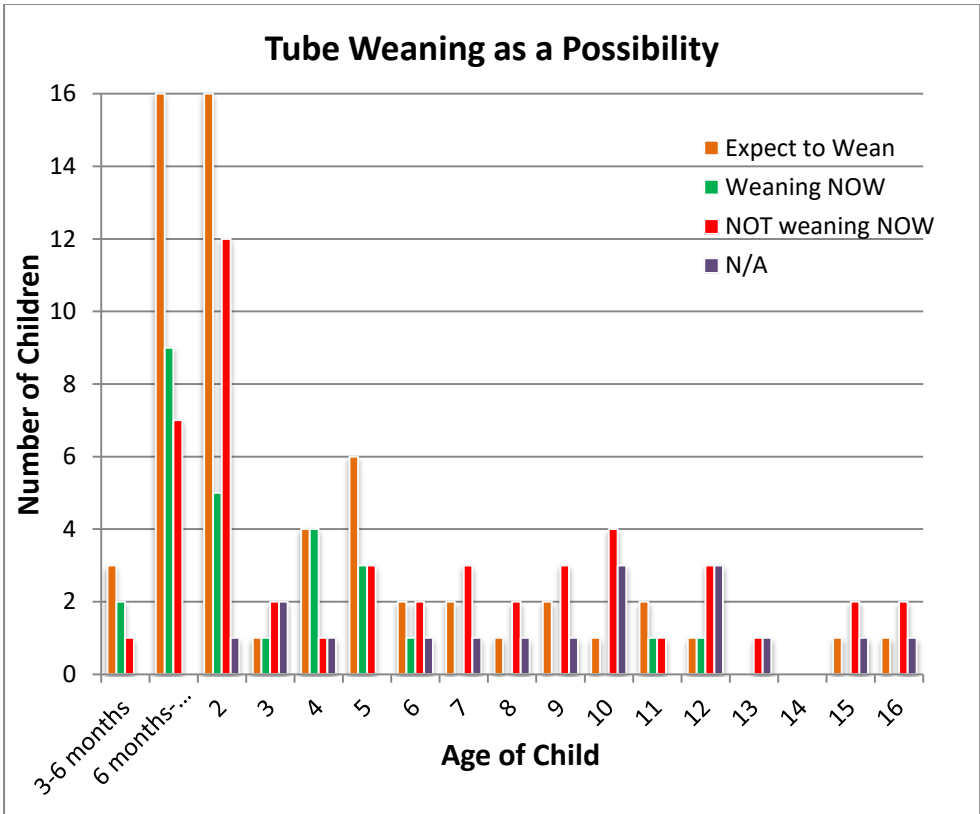
Author comment and questions: Using existing data it seemed worthwhile to get an indication as to where the potential tube wean child's main hospital was located.

Questions to consider are:

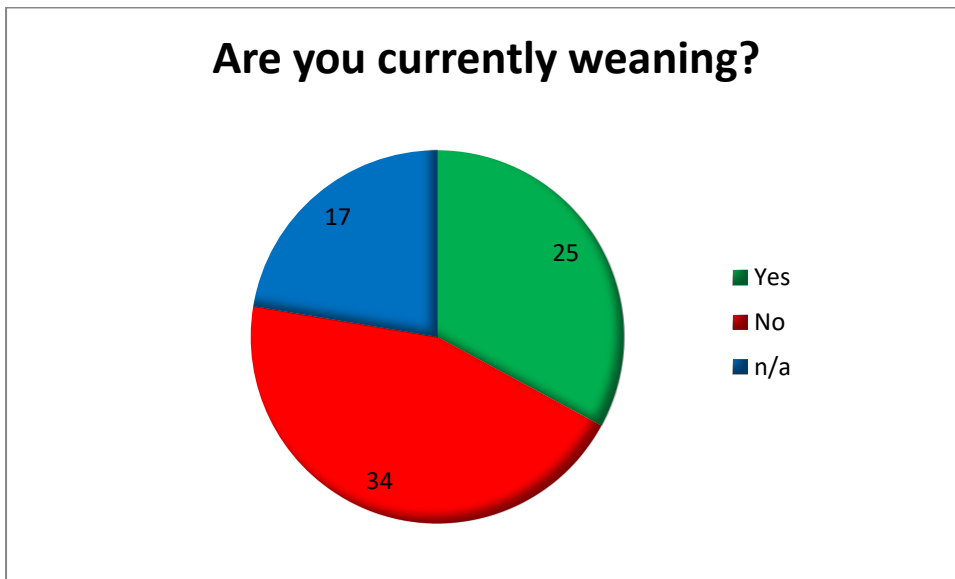
- Do you have a current record of tube fed children in your hospital that is regularly reviewed?
- Do you have a plan that includes oral stimulation and a timeline for the reintroduction of food with weaning support?
- Are consumers involved in the planning?
- Does your service provide the level of support required by these consumers?
- Do you require more resources and/or staff education to be able to tube wean more effectively? If not, then what is put in place to meet this need?



As well as by age.



8. Are you currently weaning your child off the feeding tube?

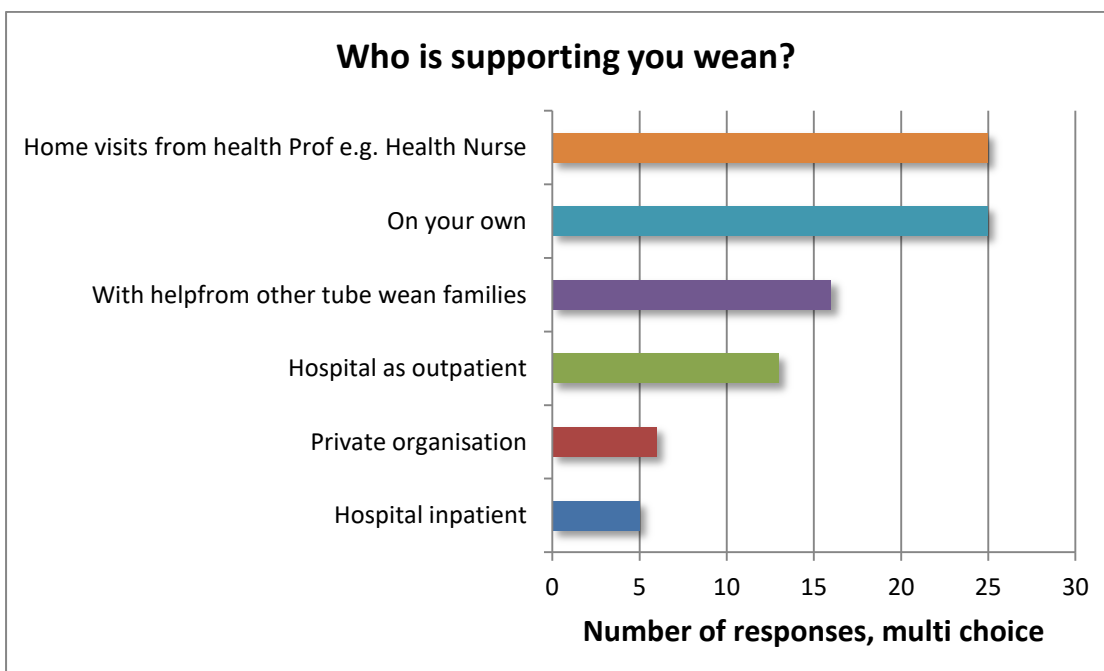


Author comment: There are many reasons why weaning will not become an option (n/a). These consumers and caregivers may require more intensive and diverse support by multiple health departments, agencies and government ministries. Your role will be key in helping point them in the right direction, with support and documentation.

What are we doing to meet the needs of these families?

9. Who is supporting you wean your child off tube feeds?

(tick and choose as many as you like)



Author comment: This answer is within the current 'what is available' service, not 'what is possible'. **The rise in private agencies providing tube weaning advice and services has noticeably grown as the need has overtaken what is provided in the public health sector.**

Services range in cost from the hundreds to the thousands of dollars. These services are not only provided by overseas agencies but by a growing number of New Zealand practices who have seen the opportunity to monetise this gap in service.

"..... in Hamilton is great but still not a lot of tube weaning experience."

"The help I have received is from a sole person from an institution outside the Public Health Services."

"When wanting to wean off the tube no one knew what to do, we ended up paying for a private psychologist from overseas to support us."

Taken together 'on your own' and 'with help from other tube wean families' is 46% of the total. It is important to recognise what consumers are doing 'out of the system'.

What consumers would like is:

- More information regarding what to expect, realistic expectations about weaning.
- Guidelines and basic plans on weaning.
- What are the signs you need to seek assistance while weaning?
- Prevention or recovery from sensory aversion.
- Developing oral skills.
- How to support your child to feed.
- More one on one or at home support.

"More experienced tube weaning specialists so needed!"

"There is no help or support about weaning from the tube. I have no idea how we are going to do it and am so desperate for help. The constant vomiting and tape changes is just a nightmare. We tried ourselves and our daughter just lost weight and we got more stressed. Where are the expertise in this area?"

"Due to our child's physical disability it has become too difficult now to wean but more support early on would have helped."

"If weaning is a possibility then it should be discussed and information given right from the start so that goal is always in mind for medical professionals and hopefully limit dependency on the tube."

In service comments:

“We participated in a pilot programme at Starship. Made some progress but support and intervention needs to be ongoing. It is too hard to replicate the program solo.”

“A tube feeding and weaning specialist programme and centre. A psychologist would also be great, as it's very challenging.”

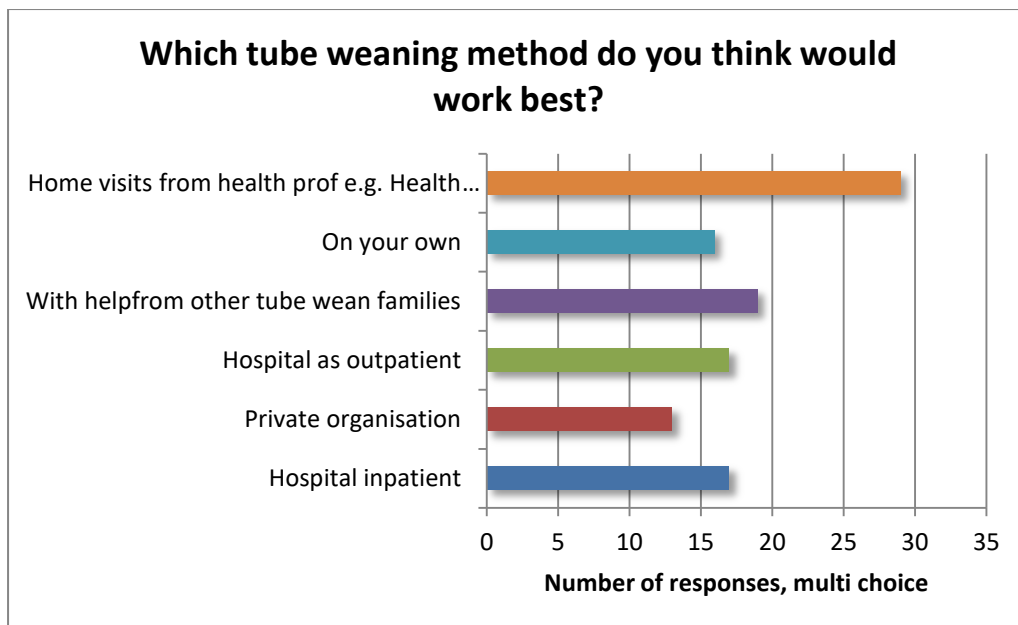
“A centre where you live in for up to 3 weeks. Somewhere that has recipes for allergy children, room for family if needed, children of various ages. At the centre I would want support to guide a wean.”

“In the weeks post tube weaning to have more support as they can go backwards. People to pop in to check you're okay. Someone you can call and seek advice from. Weight checks for at least 6 weeks post tube wean. I found this time very stressful and had no support. It's really taken a toll on our family.”

“We went to the Wilson Rehab Centre for 2 months after the end of the treatment, and this was where our child was weaned. They held multi-disciplinary meetings (Dietician, Nurse, Physiotherapist etc) and all came from a slightly different angle, with the Specialist Doctor making the final call on “the plan”. I believe this was a superior way to wean.”

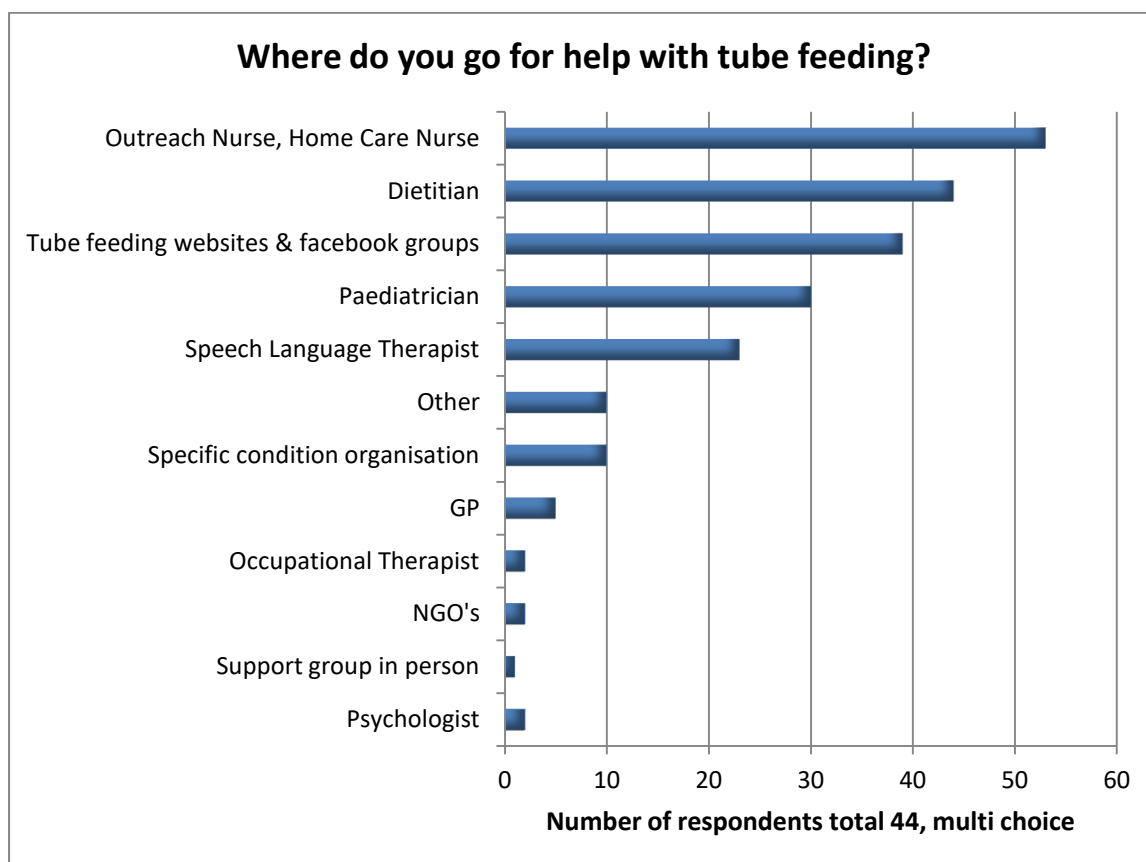
10. Which tube weaning method do you think would work best for you and your child?

(tick and choose as many as you like)



11. Where do you go for help with tube feeding? *

(tick and choose as many as you like)



Author comment: Consumers can only answer from what they know is available. With an appropriate plan in place and MDTs more visible the chart distribution will change. The call for and use of psychologists is an area that will increase as well as SLTs and OTs.

12. What or who has been most/least helpful?

(4 of the options were compulsory to answer)

Again the view is from what is currently available. We wanted to know not only where did consumers go for help but how helpful they found these health professionals or groups.

Out of 11 options it was good to see that the most helpful was also the most utilised i.e. the Outreach or Home Care Nurse. The GP was seen as the least helpful.

Tube feeding websites and facebook groups were a close second with dietitians and paediatricians mid way. SLT's and support groups in person followed.

This list will change as MDTs develop providing a service that meets the needs of the tube fed child in partnership with their caregivers.

13. What did consumers think would help?

The majority of the comments made by consumers have been placed in the relevant sections above to provide a more complete picture of the current issues, additional constructive comments and emerging themes are:

General

- A holistic approach from the beginning, instead of the short term goal of getting the child out of a hospital bed.
- Consistency between DHB's. Booklet with tips and tricks i.e. hand priming the giving set, best ways to tape tubes at home, explanation of terminology, equipment and supplies.
- Education, just what tube feeding means and how to get the child back to eating.
- Practical advice for every day e.g. how to prevent alarms going off, getting out and about, what to do at school, home and help.

“Understanding the psychological impacts, the process, the issues about vomiting and having to reinsert a NG tube, techniques for the best process for insertion. Really the whole area needs an overhaul from a psychological point of view and this varies between age groups.”

- Make sure patients are followed-up and checked on.
- Plan forward.
- Health professionals need up to date and accurate training about tube weaning.

“I could have done without the laughing and joking the dietitian and some nurses did at the time was very unhelpful and when we asked questions we were made to feel stupid!”

“In terms of educating carers for our children - all left to us. There are no helpful resources supplied to give to other carers, to explain the typical issues with these tubes and to assist with trouble shooting. I feel like there is a huge gap, where I am writing up resources to be able to have someone safely look after my child. I'm tired, stressed, thinking through each single step and possible issue is cumbersome and I often miss things - not safe when hoping for respite and needing to train new carers.”

“We are researching to find ways to avoid tube feeding pitfalls. Why don't you know these?”

“If you go to the internet or facebook for more support there truly is a problem.”

Timing

“There's no long term plan in place for my baby with regard to tube feeding and weaning. I would like a timeline and specific goals and milestones we can work toward.”

Equipment

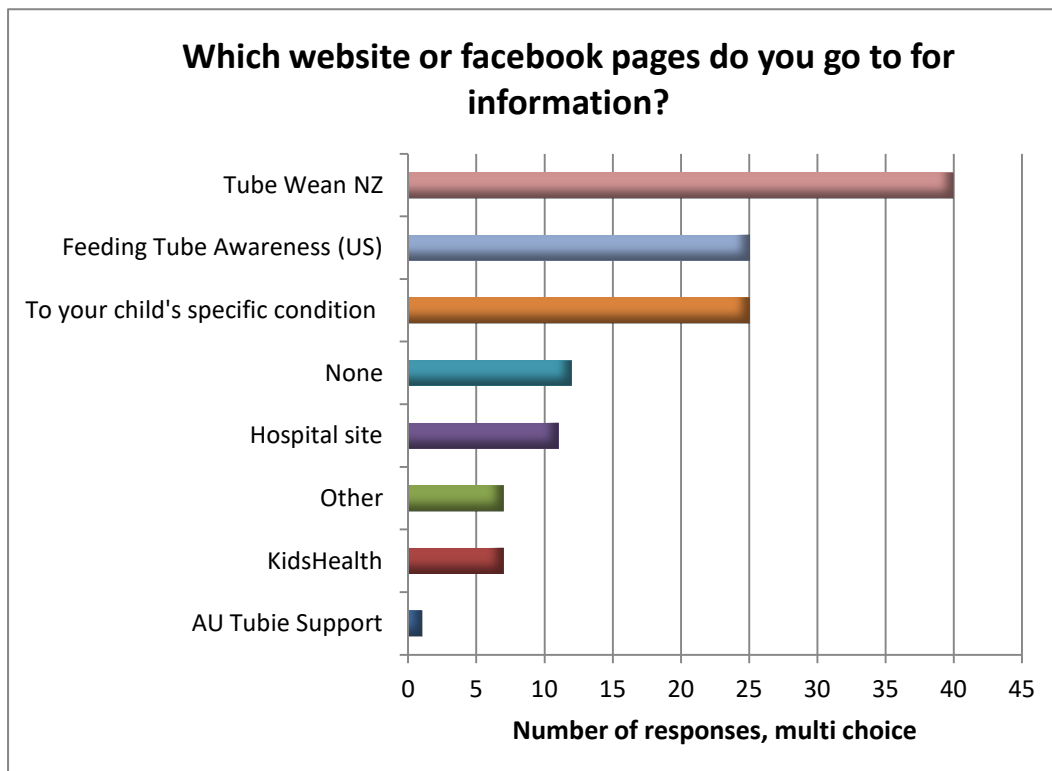
- Child lock on the pump, child proofing the tube, e.g. chew proofing
- Equipment needs assessed and provided
- OT would be useful for equipment needed such as bed wedges and button protectors.

Medical

“I would love if everyone involved in my son’s care was on the same page and had the same plan. I think it also comes down to the medical professionals respecting other medical professionals opinions.”

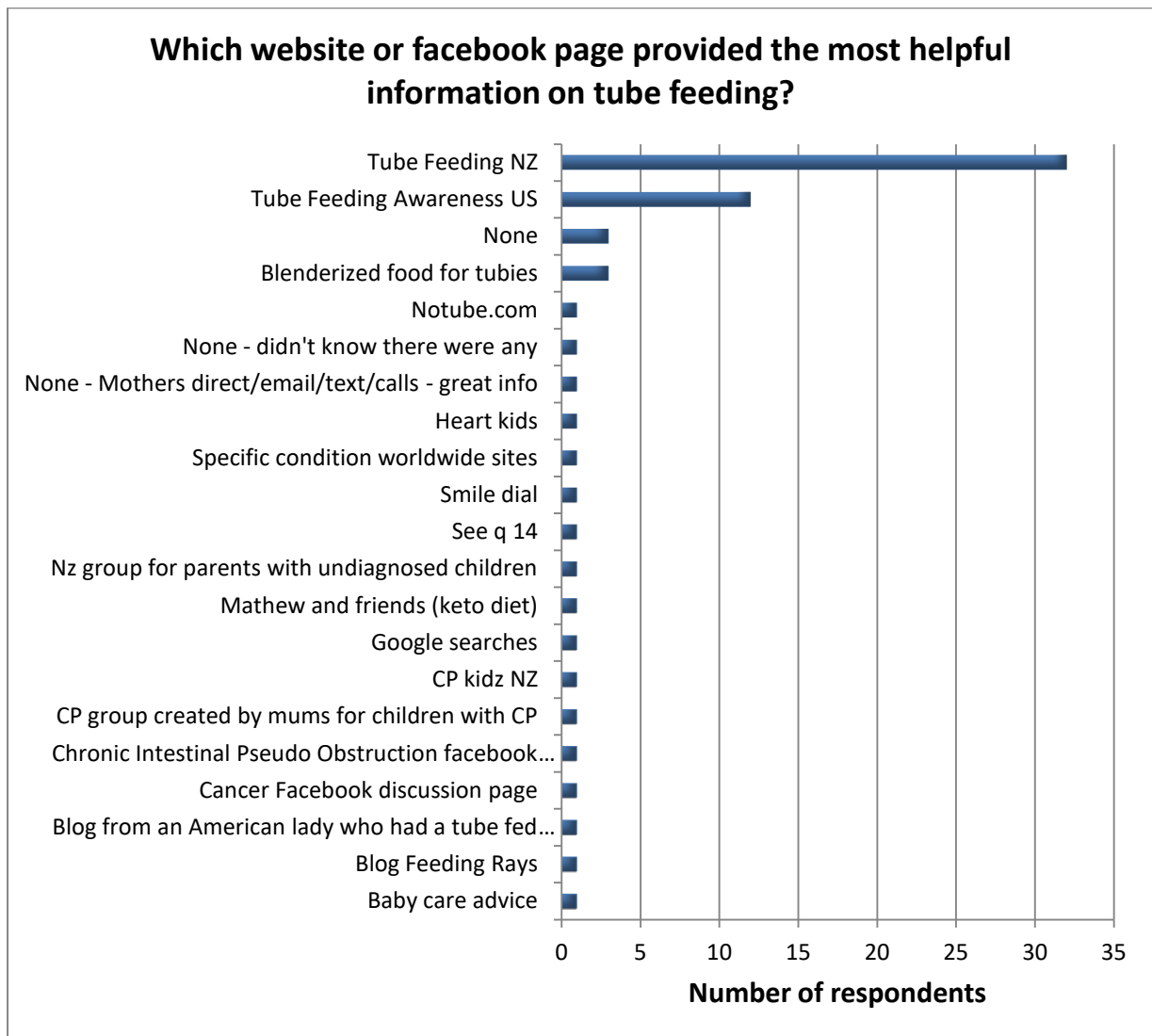
14. Which **website or facebook** pages do you go to for information? *

(tick and choose as many as you like)



Other facebook and websites mentioned ^(appendix: ref 4) included Multiples with Special Needs, Blenderised Feeding for Tubies and other blended diet groups, Markus Wilken and NoTube.

15. Which website or facebook page provided the most helpful information on tube feeding?



It doesn't take long to want more information and support as families face new challenges.

Author comment: Consumers have chosen Tube Feeding NZ as their 'go to' facebook support, they have over 520 members (430 at time of survey). They offer a connection to consumers for immediate support, issues & questions raised around tube feeding.

However, many questions being asked and issues being raised are health service or system ones. Answers to these questions need to be addressed within the service.

An open channel of communication should be available for information. If not provided directly by the service, then elsewhere i.e. KidsHealth.

The Tube Feeding Awareness Foundation (.org) US is also an excellent website for guidance and resources.

16. What information would you like to get on tube feeding?

Here are some outstanding questions which have not been included under another topic heading. Some may seem quite obvious and may have been provided. The key here is to acknowledge that the information has not reached the consumer in a way they remember it. Keeping in mind that at different stages, different challenges are presented and questions raised.

General:

What medical conditions require tubes and why?

Health risks to other organs when long term tube feeding; effect on nutrition, delivery and absorption of other medications.

Maximising the child's health and wellbeing

What are the rights as parents of a tube fed child?

What can caregivers do if they have problems with people involved in our child's care?

Tube / Button:

How do you clean the tubes?

How to keep a tube from blocking and how to unblock it when it does get blocked?

How often do you change the tube how many mls do you put in Mic-Key button balloons?

What sort of tape is best to use?

How do you secure the tube to your child's clothes?

Mickey care - risks associated with long term placement.

How to you teach a child to eat orally with an NG in?

What can and can't your child do when they have an NG tube?

Types of tubes, changing from one type to another and why?

How long do you have an NG tube in before changing to a peg?

Aspiration information and support.

Feeding:

What are essential supplies to have when tube feeding?

What formulas are available to try?

Bolus versus pump feeds?

Feed volumes and safety at room temp and time.

How to reduce vomiting.

When doing the pH test, what number should you get on the strips? If the child is also on reflux meds it changes the test. There can be a big range of numbers at different times, 0-6. What is the ideal number when testing?

Feeding real food and nutrition.

Trouble shooting around how to teach a non orally averse child that they're not allowed to eat anything. How to explain to a child so they understand that they need to do this for their own wellbeing.

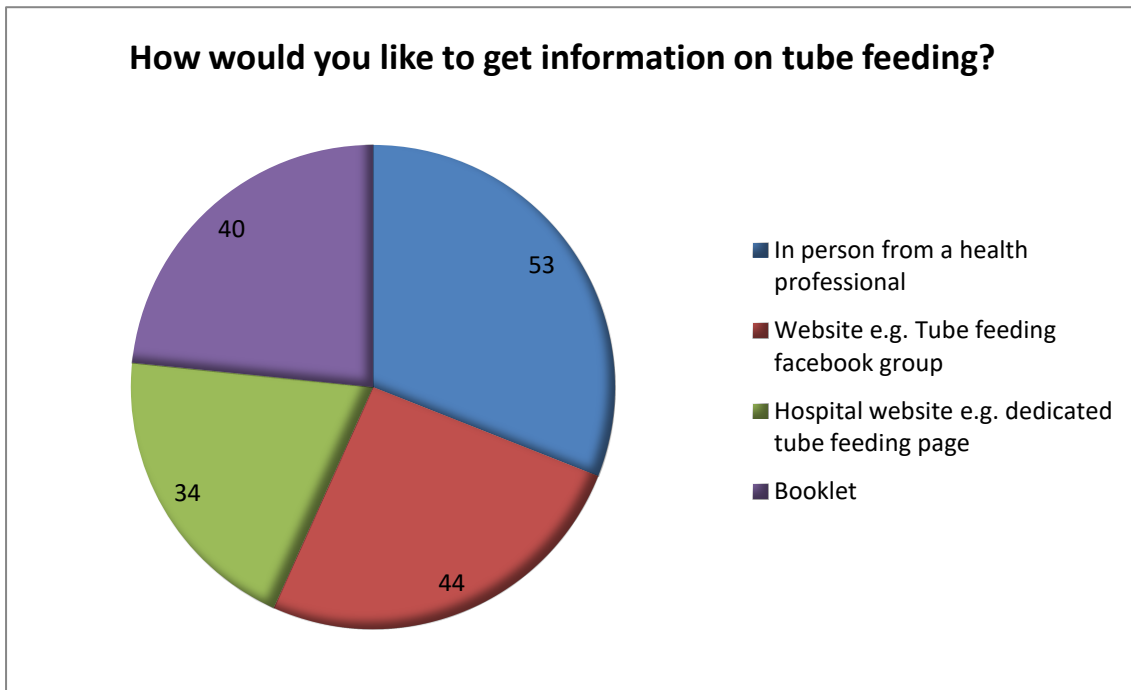
Support:

Wrap around plan especially if looking long term.

Just having a regular catch up with an expert to be able to ask questions - the questions you have as a parent change over time.

17. How would you like to get information on tube feeding?

(tick and choose as many as you like)

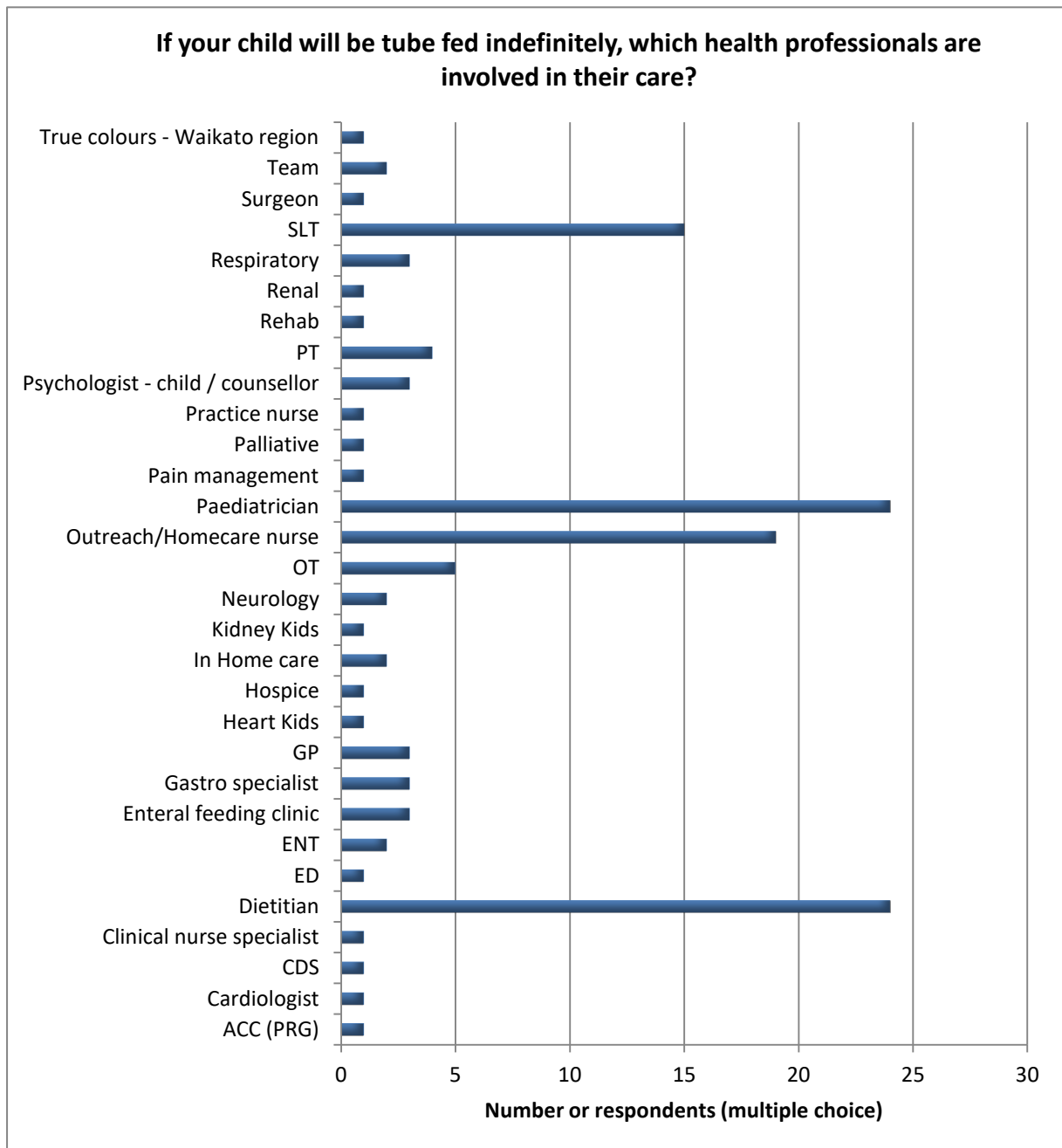


Author comment: As you can see there is not an obvious choice for consumers. This reflects the multiple platforms required to provide information.

At the beginning of their tube feeding journey the personal approach is more useful as the hands on training takes place and first week nerves and technical glitches are experienced for the first time, e.g. alarms going off, blocked tubes, stoma infections.

As the family/caregiver become more experienced and they venture out into the community at large, the need for and type of information changes. This is when websites and support sites or groups become more prominent.

18. If your child will be **tube fed indefinitely**, which health professionals are involved in your child's care?



Thirty different health professionals or organisations were mentioned, the most referred to were:

- Dietitian = Paediatrician
- Outreach / Home care nurse
- Speech Language Therapist

Author question: As a follow-up to Question 8, have we asked what these indefinite tube feeders need? What other support will be required as they age?

19. Is there anything else you would like to add?

These comments have been amalgamated into the relevant sections above.

20. Please write down your tip or trick.

This is where we wanted to be able to give something back to the responders. It was a vehicle by which we could gather up consumer experience of having a child with a feeding tube, the obstacles they come across on a daily basis and often creative solutions found. These tips and tricks will be shared amongst the wider tube feeding community via facebook and websites.

Appendix

Ref 1. Survey vehicle:

Initially started with Survey Monkey but found their free options too limiting. I therefore had to identify another free of charge method which would allow; closed and open questions, a place for free text, exporting of data gathered and ease of use. Typeform met these needs. This process and initial questions were drafted through January and February 2017.

Testing the questionnaire: the questionnaire was sent to the administrator of Tube Feeding NZ (also the MoH petitioner), to several consumers who had children that had been weaned, looking at weaning and would not wean. Also sent to the CGR. All to proof read and identify any gaps or revisions.

Following the feedback:

- Revisions were made and the survey launched on Tube Feeding NZ facebook 28th March 2017.
- Then to the CRG on 3rd April 2017 (delay due to completion of paper copy, suitable return address and promotional flyer).

Ref 2. Newsletter to consumers:

When and how needs to be clarified. We may find website and facebook links meet this need.

Ref 3. Consumer reach:

It is important to point out that there were no guidelines as to how to reach and speak with other consumers. Who is the CRG to them to ask for their precious time? There had to be some leaders. Within the DHBs this came from an introductory and supporting letter from the Clinical Lead Dr Timothy Jelleyman. This gave staff some background and permission to suggest and ask consumers if they would like to participate. Collegial networks were

provided by existing CRG members promoting the questionnaire to their tube fed clients i.e. paediatricians, dieticians. Not only do members of the CRG represent different disciplines they come from different regions of NZ.

An A5 paper flyer promoting the survey site was also made available to DHB staff to hand to affected families.

I approached the administrators of Tube Feeding NZ facebook site to introduce myself, provide information and talk about the survey so they would be happy to support it when published. This was a community based approach.

For national agencies and organisations I initially made contact with the local representative, then if appropriate the national representative by telephone, followed by an email to request they reach out to consumers who might be affected within their network.

There was one more group to consider, those without the technology to access the survey or who required assistance reading the questions and writing the answers down. A paper copy was provided to enable staff to assist or encourage consumers to have their say. A stamped addressed envelope was also provided.

List of contacts made and timeline

Date	Organisation name	Region
20.2.2017	Testing x 2	
28.3.2017	Tube Feeding NZ (prev. Tube Wean NZ)	National
avail 3.4.2017	Dietitians NZ	National
	Paediatricians	National
	Occupational Therapists	National
	Speech Language Therapists	National
	Psychologists	National
5.4.2017	Conductive Education Canterbury	National network reached
6.4.2017	CCS Canterbury/WC	National network reached
6.4.2017	CHAC - child health advisory council	Regional
6.4.2017	Montreal House	
6.4.2017	Outreach/ Home Care Nurses	
18.4.2017	Champion Centre	
3.5.2017	Cerebral Palsy	National
	VNT - visiting neural therapists	
3.5.2017	Kidney Kids	
3.5.2017	Child Cancer	National release 25.5.2017
16.5.2017	Specific Condition facebook	National

resend / reminder before close off date

16.11.2017 Presentation by Sarah Vane, Families tell us about tube-feeding: Current status, challenges and ideas (the good, the bad and the ugly) at the Paediatric Society of New Zealand 69th Annual Scientific Meeting 2017 in Christchurch.

Ref 4. Some websites you might like to visit:

<http://www.kidshealth.org.nz/tube-feeding>

<https://web.facebook.com/groups/177124695794208/> (Tube Feeding NZ)

<http://www.feedingtubeawareness.org/>

Ref 5. The New Zealand Clinical Network for Paediatric Tube Feeding:

- Dr Timothy Jelleyman (Clinical Chair), Paediatrician
- Mari Komp (Clinical Facilitator), Dietitian
- Peaario Bradbeer, Speciality Clinical Nurse
- Linda Chard, Clinical Psychologist
- Dr Alison Daniell, Paediatrician
- Jennifer Douglas, Dietitian
- Mandy Henderson, Paediatric Speech-and-Language Therapist
- Emily Jones, Paediatric Speech-and-Language Therapist
- Sarah Leadley, Psychologist
- Mary McNab, Paediatric Dietitian
- Elizabeth Maritz, Dietitian
- Sarah Vane, Consumer Representative
- Catherine Wheeler, Paediatric Dietitian

Consumer representative comments:

Survey design: This is a skill, how to ask the right question to gain the information we wanted. Survey content, testing and feedback is crucial. This may be the only chance we get to ask these questions.

Survey content: We need to be able to ask questions and offer options outside the limits of the institution we represent to get a true reflection of where and what tube feed families are accessing for information and assistance.

Survey feedback: Needs to be timely. Avoid amending survey content after release as this will effect data integrity and collation.

Cold calling national agencies & organisations: Why should they listen to someone they have never heard of before on a CRG they don't know exists to ask their clients to participate in a survey? Some credentials or reference would have been extremely helpful. Maybe assign appropriate colleagues to reach out to specific NGO's.

This is a new area and learning process for all parties. It is important to raise and discuss consumer involvement if we (the consumers) are to be seen as important participants and contributors in moving forward health practices in New Zealand.

The issues faced by Prolonged Paediatric Tube Feeding families are close to my heart and I am very encouraged by the commitment and care each CRG member brings to make much needed changes in these services in the near future.