

Partners in Care – case study

‘Through the eyes of children’

Context

Nelson Marlborough Health (NMH) was one of three district health boards (DHBs) who were successful in receiving Ministry of Health (MOH) support to develop systems and processes to demonstrate how maternal and child health universal services can be better integrated and coordinated, in order to improve patient health outcomes and more efficient service provision.

The two-and-a-half-year project was based on the feedback received from adult consumers and from clinicians; however, it did not focus on gaining direct feedback from children themselves. The project team saw the co-design project as an opportunity to see if we could also get better at sourcing this feedback.

Aim

The aim of this project was to assist services involved in providing paediatrics health services to adopt strategies which would enable feedback to be received from children themselves.

The project team proposed to develop, facilitate and encourage the use of tools in our services and departments in order to gain a better understanding of how our services meet the needs of children.

Capturing data

This aspect of the project became the key focus and seemed to take the most time. The project concept was tabled and discussed at the MOH funded Maternal and Child Health Integration Project working group. The concept was strongly supported and several agencies volunteered their interest to be involved.

The concept was then tabled at the Paediatrics Services Meeting at NMH. This meeting has representatives from medicine, nursing, and Allied Health. It was immediately and strongly supported and encouraged. child development services and paediatrics outpatients were agreed to be the initial sites for this work. The concept of patient experience is one that is well accepted within paediatrics. They were receptive to the tools proposed.

The tools we used to gather information included:

- Child written surveys.
- Patient experience questionnaire.
- Narrative excerpts we had collated from both families and clinicians in the first part of the MOH funded project.

The paper surveys were designed specifically to appeal to children. The children needed to complete them and then post in a letter box for collection and collation. Every participating service was able to adapt the survey to address specific parts of their service. The options for the survey response included obtaining feedback from children by their responses. Depending on their age they could:

- draw a picture to describe the experience
- write a word
- write a story.

We also gathered information from patient experience questionnaires as well as from previously collected feedback from parents, families and clinicians.

One-to-one meetings with the charge nurse managers of both paediatric units, in Nelson and Wairau, followed. They were willing to assist with performing more in-depth interviews with children who have experience of the outpatients departments, using the patient experience questionnaire to prompt the discussion and to make the child surveys available on their wards. Unfortunately, much of this work occurred over the Christmas and summer period and staffing levels were such that participating in quality initiatives took a lower priority than we would have liked.

A key challenge for improvement projects including those focussed on co-design is the time taken to do this on-top of usual work demands and practices.

Surveys:

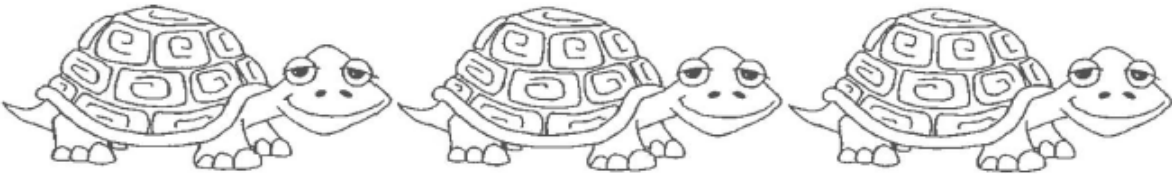
The survey we used was adapted from one designed in Invercargill – it looked like this:

KIDS... Tell Us What You Think

I am _____ years old

I think the best thing about XXXX has been

(Space to write or draw)



The children then completed the form and 'posted it' into a letter box set up in the outpatients department:



Patient experience questionnaire:

The patient experience questionnaires were adapted and used to gather deeper feedback:



EBD - Experience
paeds OPD.doc

Narrative excerpts:

Selections of narrative excerpts were chosen from those we had previously collated from families who access child health services. This feedback had been gathered from a combination of survey responses from families as well as from several focus groups held across the district.

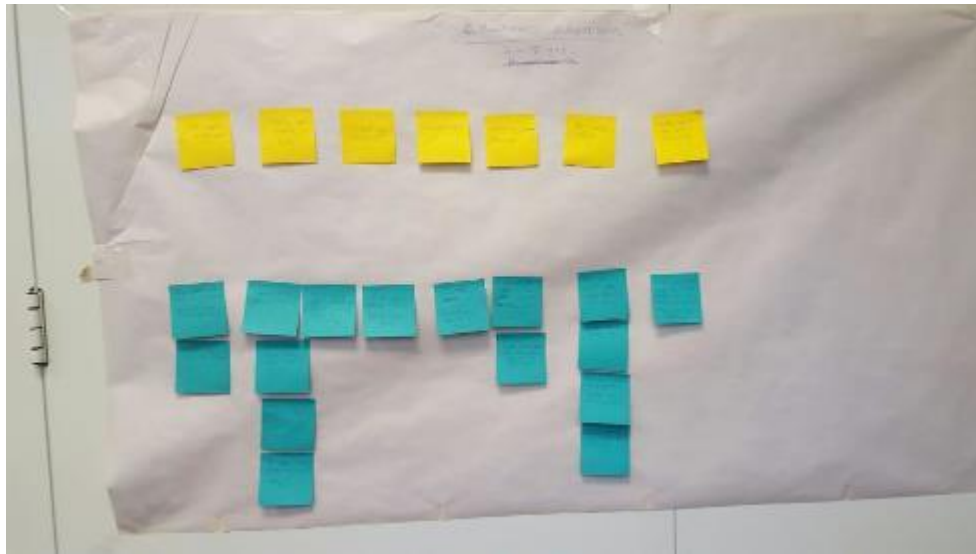
Touch points

The pathway that a family must navigate can be quite complex, to ensure their family can access the services they are eligible for. It often does involve contact with multiple providers at different times at different ages and stages.

As this can potentially involve a large number of contact points our group agreed to focus on three key 'touch points'. The touch points for the purpose of mapping were identified as:

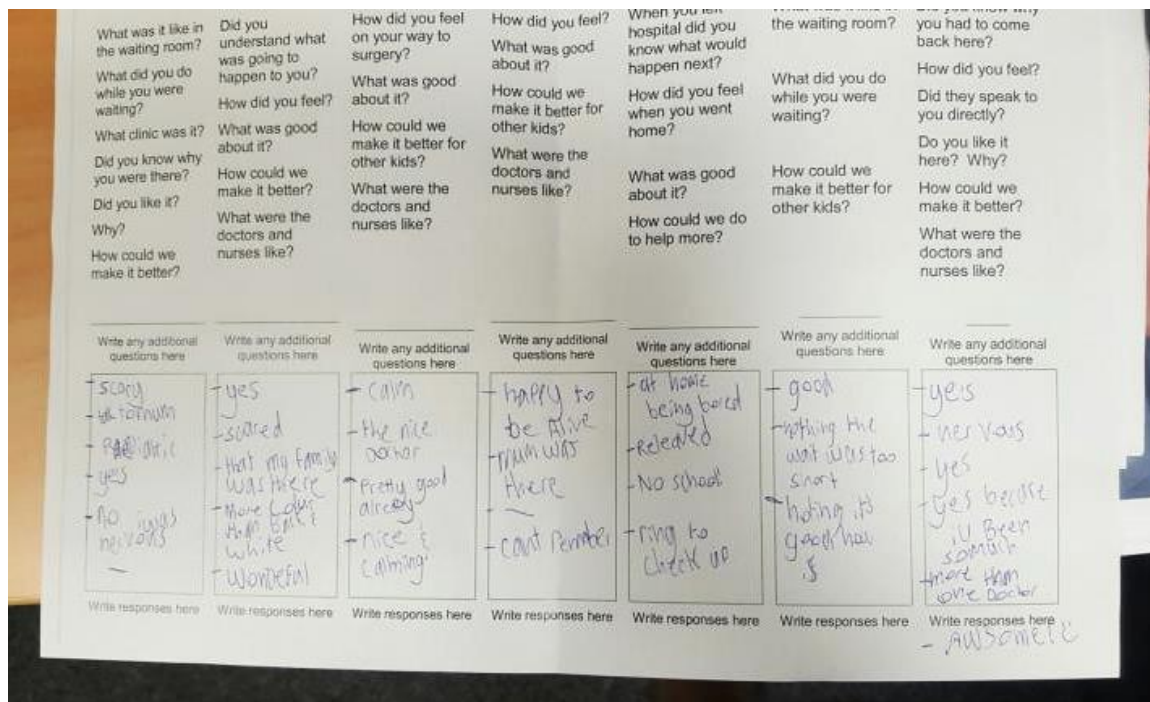
- First point of contact/primary care.

- Waiting room and reception experience.
- Appointment with doctor or nurse they had been referred to.



We set about gathering information that related to these touch points. Feedback was gathered from our three key sources – child surveys, patient experience interviews and excerpts from the previous report. The feedback was compiled according to the three touch points of the journey, that is from primary point of contact, waiting room and reception experience, as well as seeing the doctor or nurse at the referred clinic.

Arriving at clinic	Attending pre-admission	Surgery	Recovery	At home	Outpatients Waiting room	Outpatients appointment
What was it like in the waiting room? What did you do while you were waiting? What clinic was it? Did you know why you were there? Did you like it? Why? How could we make it better?	Did you understand what was going to happen to you? How did you feel? What was good about it? How could we make it better? What were the doctors and nurses like?	How did you feel on your way to surgery? What was good about it? How could we make it better for other kids? What were the doctors and nurses like?	How did you feel? What was good about it? How could we make it better for other kids? What were the doctors and nurses like?	When you left hospital did you know what would happen next? How did you feel when you went home? What was good about it? How could we do to help more?	What was it like in the waiting room? What did you do while you were waiting? How could we make it better for other kids?	Did you know why you had to come back here? How did you feel? Did they speak to you directly? Do you like it here? Why? How could we make it better? What were the doctors and nurses like?
Write any additional questions here It was ok! Read a book. Dr Bradley to get my jabbery off. Yes! Books & top. Penicillin!	Write any additional questions here Yes! Off! Right! The docs and nurses were really nice.	Write any additional questions here Ok. The stickers and my bunny came with me and got a hot and slippers too. The docs and nurses were kind.	Write any additional questions here I couldn't open my eyes! I was sleepy. It was nice to see Mum. Everyone was so nice to me!	Write any additional questions here Yes, but I knew it would be sore. Happy to have some food!	Write any additional questions here Fun. Filled out this form!	Write any additional questions here Yes, to check on my neck. Fine. Yes. Yes, it's friendly.
Write responses here	Write responses here	Write responses here	Write responses here	Write responses here	Write responses here	Write responses here



Narrative excerpts for each stage:

Primary care appointment – Primarily General Practice teams, Well Child providers or Lead Maternity Carers.

'GP is different every time. Having to explain every time. Can be a different doctor even in the same day. Has been worse over the last 6 months.'

'The nurse was 'attacking' - the way they provided advice; if you don't fit their 'normal' they weren't so welcoming; I felt harassed, berated; I felt judged because of my age; I didn't like having to stick to the guidelines.'

'I felt judged because of my age; felt judged because I couldn't breastfeed; I felt judged even when it was my second baby and I knew what to do.'

'Sometimes I need to explain 10 times which is frustrating with different people and I feel like I need convince them rather than just getting advice. It may be documented but GPs don't read and want me to retell my story again.'

'GP was good but they wouldn't see one of my children (she had a mouth abscess aged seven) because of my bill with them. I did have a payment plan with them but got behind because I didn't get onto it quickly enough.'

Waiting room and reception experience

'It takes half a day for us to get to an appointment at the hospital and come home. Sometimes they don't take into account that it takes an hour each way for us to travel in there when making appointment times.'

'I had to travel to Nelson with one of my children, the service was good but I had to pay for petrol and then be reimbursed. Would have been good to have the money upfront to be able to pay for the petrol.'

'I called (after hours) and was put on hold for six minutes and hung up on three times, to then receive an appointment for two hours later. My daughter had a split ear and needed treatment. It would of been quicker going to Nelson.'

'I had to call (dental services) to make an appointment. Was told they are six to eight months behind with three-year-old checks. Service was good when we got there. Nice and friendly and okay with child meltdowns.'

'Yes, we sometimes have to wait months for things and we have to follow up on them. At the moment we are waiting for dental care still and with a four-year-old in pain we feel it should have been addressed sooner as it has been four months already.'

Seeing referred doctor or nurse

'We don't think all of our needs are met all the time with the hospital services. There is a lot of passing on to different people but no real outcome. There seems to be a lack of communication between everyone involved and sometimes we don't hear back for weeks.'

'I went to the emergency department. It was quick being greeted and then was put in a room for two hours before someone came to see us – my son had breathing difficulties. Someone else came in the room after the two hours and then said someone will be in five minutes to take his weight and we waited another hour.'

'Feel that information is not shared – would like to know more information. Asked too many questions which we have already answered. I was treated like I didn't know anything.'

'One woman described her experience getting help for her child in secondary services. They were passed between different services and had to tell their story each time.'

We then simply captured the feedback then fed it into a wordle in order to get an overall feel for the experience at each touch point.

Seeing the referred Doctor and Nurse

The strongest words being doctors, nurses and like which is generally positive, however it is of note that judged is a strong negatively framed word.



Improvement ideas

Developing the wordle brings the words to life and makes them a lot more user friendly. We have found people are more interested in getting this feedback about the services as it seems to be presented in a more balanced way with the negative and positive at the same time. The group analysed this feedback and identified key issues at each of the touch points that we would like to understand further:

A) Primary care appointment – mostly GP or Well Child or Lead Maternity Carer

- The feeling of being judged.
- Frustration throughout the process.
- Barriers to access, such as finance.

B) Wait room and reception experience

- Waiting time.
- Travel and time considerations.

C) Seeing referred doctor or nurse

- Lack of communication between services.
- Peoples feeling of being judged.
- Long wait times.

The group intends to present this at a paediatrics service meeting and commit to ongoing work on how to address this. We are committed to involving consumers in any work to improve the current situation. Ideally we will give a quarterly update to the service meeting and repeat the wordles on a quarterly basis with the aim that over time the strong words become more positive.

Working as a co-design team

The group has appreciated the support to facilitate co-design with consumers. We are keen to have a think about funding dedicated time for staff to achieve this in the first instance. The thought of doing it is more daunting than the reality as the collation of data took longer than we first thought and initially it would have been good to have some time ring fenced to begin with.

Next steps

There is still work to do. The paediatrics department has committed to embracing this co-design approach and the service meeting will continue to monitor and support this. The key issues identified through this process will be tabled regularly and a plan to address each will be developed. A monitoring process will be established to achieve progress and to ensure consumers are involved in the co-design process as we progress.

Ideally this exercise is repeated over time and the strong words can be compared over time. It will also be a good measure of buy-in from staff if they continue to want this feedback. It really has emphasised the importance of focussing on the emotional experience of children and families when thinking about how services are provided.

NMH has utilised the patient experience survey for another project, incentivising smoking cessation for pregnant women. The patient experience questionnaire has proven to be a very useful tool to get good feedback from consumers, who are often very difficult to reach, in order to influence planning solutions. This questionnaire was able to be used over the phone which made women feel more comfortable than a face to face approach.

Names, email addresses, organisation and DHB of team members

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