Kōrero mai: Patient,
family and whānau
escalation of care

Case study by Canterbury DHB

Context

A mother of a baby, admitted for the management of a broken limb, tried on a number of occasions to convey concern around their baby's breathing to clinical staff. While clinicians were reviewing her baby and interventions were being put into place, there was inadequate exploration of the mother's primary concern – the baby's breathing. The baby went on to acutely deteriorate, requiring respiratory support and admission to the intensive care unit. There it was discovered the baby had received two overdoses of morphine; the cause of their deteriorating condition. The mother's reflections of this experience was that she had raised the alarm as she knew something was not right, but felt not listened to and that the information she shared with clinicians was not valued.

This incident was the primary catalyst for the Canterbury District Health Board (CDHB) advocating to be a pilot site for the second worksteam of the National Patient Deterioration programme – patient, family and whānau escalation. Another driver was knowledge among some of our clinicians and other staff of the implementation of patient/family escalation systems internationally and the potential benefits for the CDHB to be involved.

Aim

At the start of the project our aim was to co-design, with consumers and staff, a process for patients/families/whānau to escalate care in circumstances where they had a concern or where they felt their condition was worsening from their perspective and that communication with their primary caregiver was not resulting in action. This included defining the role of staff in responding to this new element of escalating care and ensuring it worked with existing processes to respond to deteriorating patients. The solution needed to be simple to understand and easy to access/use from both the consumer and staff perspective.

We confess that some of us in the project team had a preconceived idea that what we would be designing was a pathway for consumers/families/whānau to escalate care, ending in a number for them to call for help. This was even before the start of the co-design process.

While the scope of the pilot project was within the paediatric speciality at Christchurch Hospital we planned to explore the applicability of any solutions to adult populations across the CDHB and, if deemed appropriate, move to testing. The intent was also to share the project learnings with the South Island Alliance as an enabler for others to implement a patient/family/whānau escalation system.

As the project unfolded it became increasingly apparent that our initial aim was an 'ambulance at the bottom of the cliff' strategy, only addressing the sharp end of the problem. As we moved through the capture and understand processes of the co-design journey there was a 'light bulb moment'; we uncovered a range of precursory communication issues from the beginning of the consumer/family/whānau journey and these provided an opportunity to proactively co-design solutions. Many of these are also reflected in the literature around patient/family escalation systems.

Image source: www.medium.com/@kevinyong/a-gp-perspective-on-healthy-living-f64c2faa6f1b

Engage

Learning point: What we would like to stress is the importance of not just an initial engagement but continued engagement with senior leaders, staff, consumers, family members and other key stakeholders as the project progresses. This reflects the true partnership approach of co-design; people are involved, feel informed, and are able to participate in providing feedback and new ideas throughout.

We completed a literature summary around implementing models of patient/family escalated care to determine the:

- benefits of and challenges to consumer experience
- impact such systems have on clinical workload and patient outcomes.

Learning point: Information extracted from the literature and the story from one mother was powerful when explaining the project to senior, medical and nursing leadership as well as paediatric clinicians.

Presentations

We included how this project can:

- improve consumer experience
- work with other strategies to identify patient deterioration, ie, early warning scores
- be achieved with only a small impact on clinical workload
- result in a fit-for-purpose system designed with consumers and clinicians.

Our approach appeared to connect with leadership and clinicians' hearts as well as their minds, calling them to action that implementing a patient/family/whānau escalation system is the right thing to do. While there were still a range of concerns which included the depth of literature currently available and how we might completely operationalise and communicate any new systems, overall the benefits to consumer experience were not questioned and the pilot was endorsed to go ahead.

We initially intended to include an adult population alongside the paediatric one as part of the pilot, but this was to result in a large group of different stakeholders. While it was encouraging to see this level of 'buy-in' from different areas/specialities we needed to redefine our scope and assured people that we would share the learning and plan to test and spread solutions to other areas.

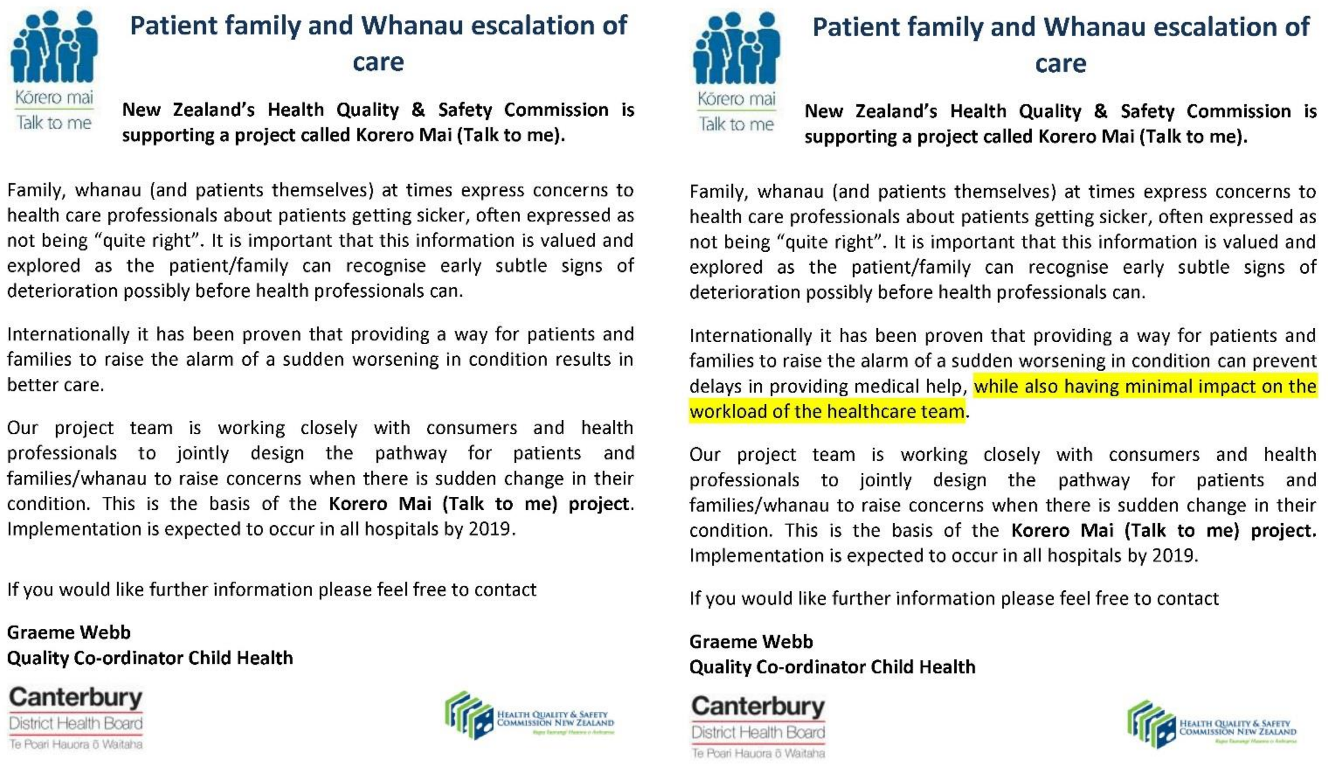
Learning point: It is important that the project communication strategy conveys that no one will 'miss out' being involved and that it is important to undergo small-scale testing and development first before the project spreads it wings and that they will be opportunities to shape solutions so they are fit for purpose for other populations/clinical environments. It is also important to have governance support to back the approach of 'Think big but start small'.

We also engaged with the South Island Child Health Alliance to gain their support and to set the scene to share the learnings of the pilot. The aim of this was to inspire them to move forward with the implementation of a patient/family/whānau escalation system at other locations across the South Island.

Elevator pitch

We developed two versions of an elevator pitch (Figure 1) which the core project group viewed as a script to share the project with staff and consumers in conversation, although in initial interactions with consumers a hard copy was also offered to them for reference. Other written information concerning the project designed for consumers by the Health Quality & Safety Commission was also used to engage with them. The version aimed at staff highlighted that systems implemented elsewhere have had minimal impact on workload.

Figure 1: **Elevator pitch**



Kōrero mai
Talk to me

Patient family and Whanau escalation of care

New Zealand's Health Quality & Safety Commission is supporting a project called Korero Mai (Talk to me).

Family, whanau (and patients themselves) at times express concerns to health care professionals about patients getting sicker, often expressed as not being "quite right". It is important that this information is valued and explored as the patient/family can recognise early subtle signs of deterioration possibly before health professionals can.

Internationally it has been proven that providing a way for patients and families to raise the alarm of a sudden worsening in condition results in better care.

Our project team is working closely with consumers and health professionals to jointly design the pathway for patients and families/whanau to raise concerns when there is sudden change in their condition. This is the basis of the **Korero Mai (Talk to me) project**. Implementation is expected to occur in all hospitals by 2019.

If you would like further information please feel free to contact

Graeme Webb
Quality Co-ordinator Child Health

Canterbury
District Health Board
Te Poari Hauora ō Waitaha

Health Quality & Safety Commission New Zealand

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We delivered the elevator pitch at both nursing handover sessions and in opportunistic conversations with paediatric medical staff, not only to inform/engage staff in the project but as a means of identifying individuals who may want to engage with us with a story to tell.

As we moved through the capture phase of the project, engagement with paediatric clinical staff evolved to include two other patient stories that were thought to impact the heart of our clinicians. The first highlighted an 8-hour struggle a parent had, trying to communicate that she felt her non-verbal child was in pain. The parent was very distressed as she felt this information was ignored. Their situation resolved when a senior clinician, who knew the child well, intervened. This highlighted that the knowledge and information parents/family/whānau members have of their loved ones' 'norms' should be valued and explored by clinicians.

> 'I felt like I needed to walk out of the hospital and enter through the emergency department again to get what I knew my child needed – pain relief.'

The second patient story shared with clinicians highlighted a consumer experience which led to a high degree of satisfaction. The positive behaviours and attributes clinical staff demonstrated were presented to staff to illustrate what shaped this positive experience and as a 'blueprint' of how interactions with patients and staff should be.

The two consumer representatives who worked with us as core members of the project team had a lot of expertise to offer. This included one of them being involved in the first workstream of the patient deterioration programme and the second consumer having an existing relationship with the CDHB through their involvement in the Child Health Advisory Council (CHAC) – a consumer group supported by our organisation to provide input into the health services children/families/whānau receive.

Engagement with consumers who had or were having the experience of their child being in hospital took the form of one-on-one discussions through which we were able to gather valuable information that contributed to the capture phase of the project.

Ongoing communication is important for ongoing engagement. We are and will be continuing to inform the rest of the organisation of the pilot project learnings and next steps through the Chief Executive Officers (CEO) Update (see extract below in Figures 2 and 3). We have collaborated with our CDHB communications team to assist in developing a wider communications plan as learnings from the pilot emerge and can be shared with the wider organisation and the consumer community who have been involved.

Figure 2: CEO Update

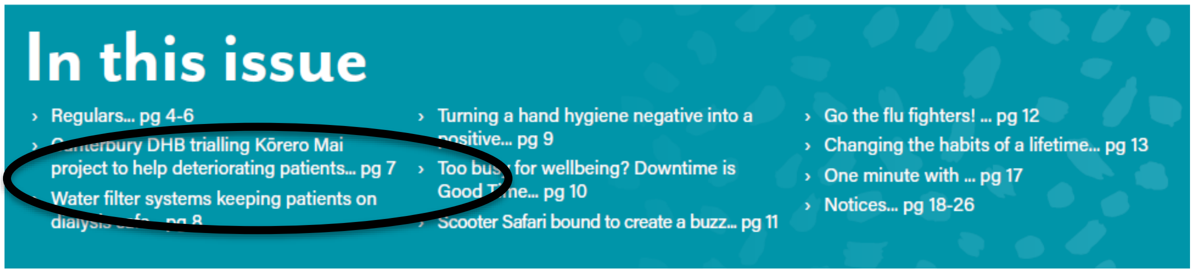

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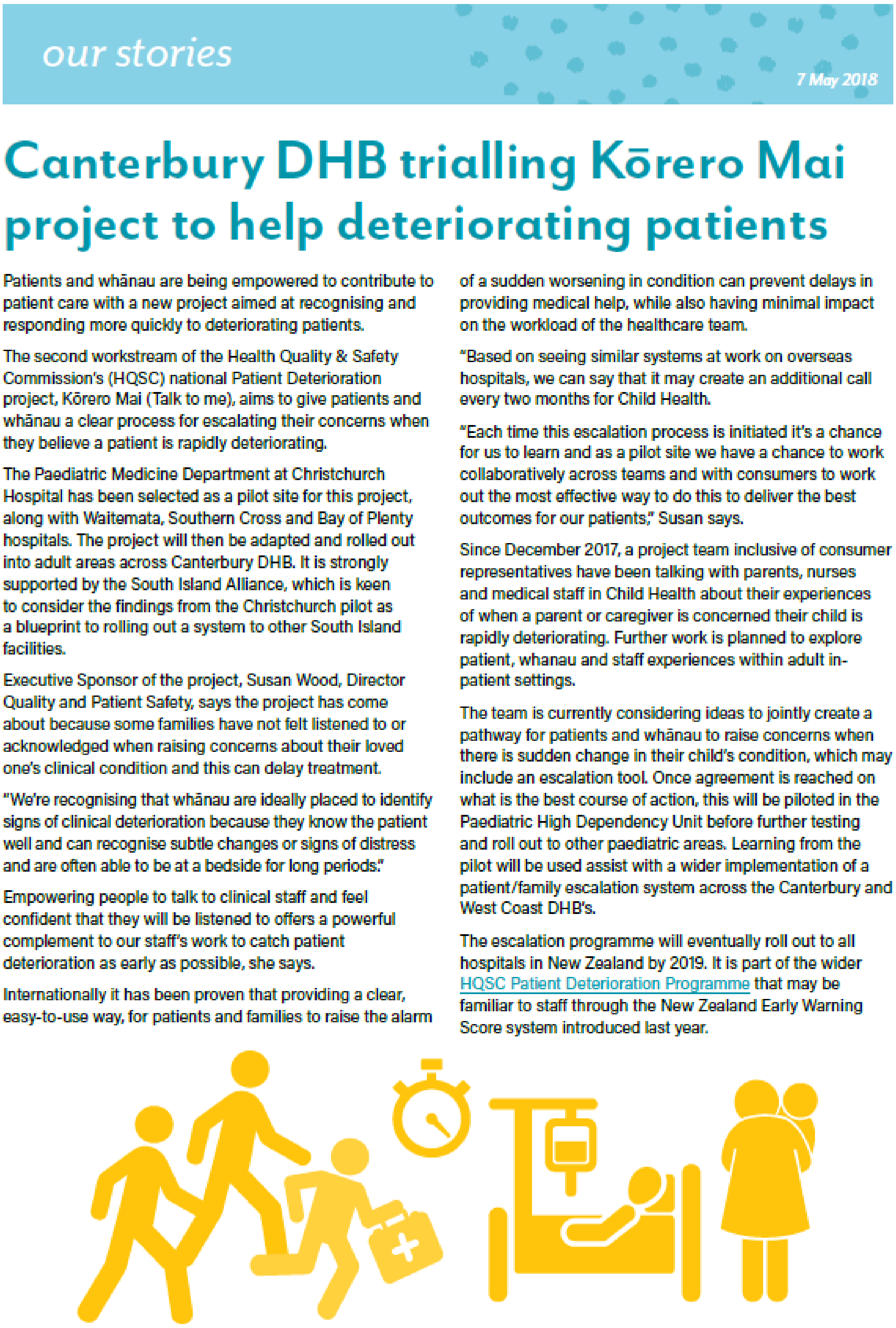
Figure 3 – CEO Update content



our stories

7 May 2018

Canterbury DHB trialling Kōrero Mai project to help deteriorating patients

Patients and whānau are being empowered to contribute to patient care with a new project aimed at recognising and responding more quickly to deteriorating patients.

The second workstream of the Health Quality & Safety Commission's (HQSC) national Patient Deterioration project, Kōrero Mai (Talk to me), aims to give patients and whānau a clear process for escalating their concerns when they believe a patient is rapidly deteriorating.

The Paediatric Medicine Department at Christchurch Hospital has been selected as a pilot site for this project, along with Waitemata, Southern Cross and Bay of Plenty hospitals. The project will then be adapted and rolled out into adult areas across Canterbury DHB. It is strongly supported by the South Island Alliance, which is keen to consider the findings from the Christchurch pilot as a blueprint to rolling out a system to other South Island facilities.

Executive Sponsor of the project, Susan Wood, Director Quality and Patient Safety, says the project has come about because some families have not felt listened to or acknowledged when raising concerns about their loved one's clinical condition and this can delay treatment.

"We're recognising that whānau are ideally placed to identify signs of clinical deterioration because they know the patient well and can recognise subtle changes or signs of distress and are often able to be at a bedside for long periods."

Empowering people to talk to clinical staff and feel confident that they will be listened to offers a powerful complement to our staff's work to catch patient deterioration as early as possible, she says.

Internationally it has been proven that providing a clear, easy-to-use way, for patients and families to raise the alarm of a sudden worsening in condition can prevent delays in providing medical help, while also having minimal impact on the workload of the healthcare team.

"Based on seeing similar systems at work on overseas hospitals, we can say that it may create an additional call every two months for Child Health.

"Each time this escalation process is initiated it's a chance for us to learn and as a pilot site we have a chance to work collaboratively across teams and with consumers to work out the most effective way to do this to deliver the best outcomes for our patients," Susan says.

Since December 2017, a project team inclusive of consumer representatives have been talking with parents, nurses and medical staff in Child Health about their experiences of when a parent or caregiver is concerned their child is rapidly deteriorating. Further work is planned to explore patient, whanau and staff experiences within adult in-patient settings.

The team is currently considering ideas to jointly create a pathway for patients and whānau to raise concerns when there is sudden change in their child's condition, which may include an escalation tool. Once agreement is reached on what is the best course of action, this will be piloted in the Paediatric High Dependency Unit before further testing and roll out to other paediatric areas. Learning from the pilot will be used assist with a wider implementation of a patient/family escalation system across the Canterbury and West Coast DHB's.

The escalation programme will eventually roll out to all hospitals in New Zealand by 2019. It is part of the wider HQSC Patient Deterioration Programme that may be familiar to staff through the New Zealand Early Warning Score system introduced last year.

Capture

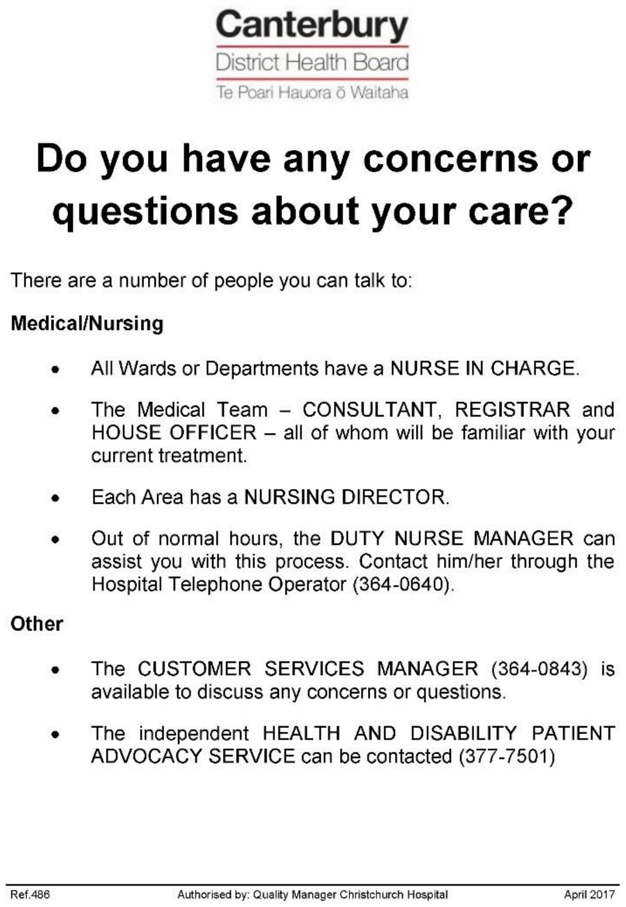
This aspect of the project became a focal point and consumed a lot of time. Initially baseline data was gathered by reviewing the consumer feedback collated for the years 2016–17. This was done as a means of helping to define the problem and aim statement for the project, as well as establishing one of many future metrics around the success of a patient/family/whānau escalation system. Formal complaint data was scanned looking for key words within the descriptors to identify those that possibly met one or more of the following criteria:

- Multiple presentations/communication of progressive symptoms but no action taken.
- An adverse event or outcome following multiple attempts to raise concern.
- The complaint explicitly mentioned they felt they were not listened to concerning the patient/family member's condition.

Those meeting the criteria led to the full original complaint being reviewed. These were then summarised to extract both the cause and effect story and associated emotions expressed by the complainants. Additionally we reviewed informal complaint data and compliments for the same period to identify comments stories which exemplified a positive/timely response to a deteriorating patient and/or behaviours/attributes described by families indicating they felt listened too or opportunities to improve (see Figure 7).

Learning point: As part of our baseline data collection we explored if any systems were currently in place to communicate or encourage families to escalate concerns around care their loved one was receiving.

Figure 4



Canterbury
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Do you have any concerns or questions about your care?

There are a number of people you can talk to:

Medical/Nursing

- All Wards or Departments have a NURSE IN CHARGE.
- The Medical Team – CONSULTANT, REGISTRAR and HOUSE OFFICER – all of whom will be familiar with your current treatment.
- Each Area has a NURSING DIRECTOR.
- Out of normal hours, the DUTY NURSE MANAGER can assist you with this process. Contact him/her through the Hospital Telephone Operator (364-0640).

Other

- The CUSTOMER SERVICES MANAGER (364-0843) is available to discuss any concerns or questions.
- The independent HEALTH AND DISABILITY PATIENT ADVOCACY SERVICE can be contacted (377-7501)

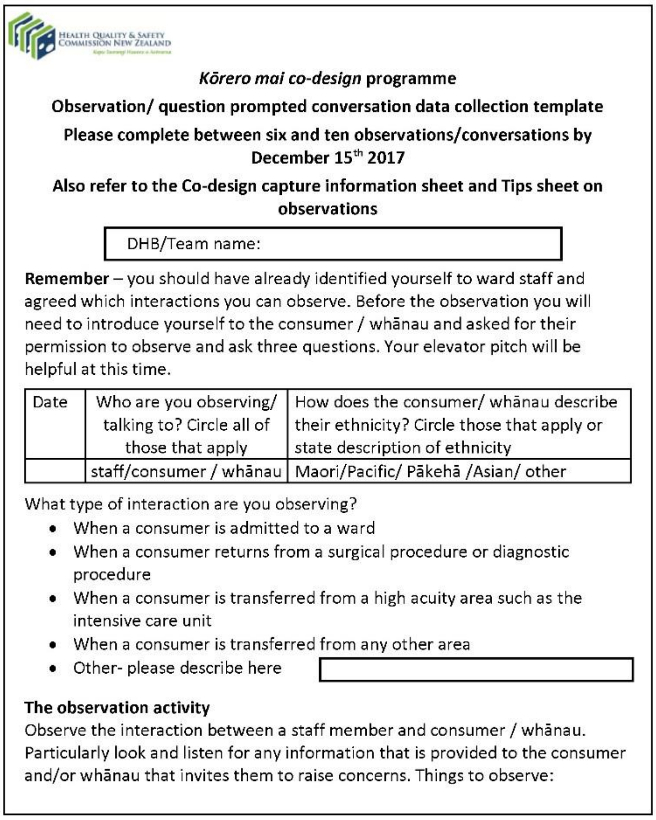
Ref.486 Authorised by: Quality Manager Christchurch Hospital April 2017

It was felt it was critical to understand the ‘current state’, learning how these systems work and of the positive and negative attributes of these.

Through this process we identified the existence of posters within the Christchurch Hospital campus which were often located near lift access. These provide guidance for consumers about who they could ‘talk to’ should they have any concerns or questions about their care (see Figure 4).

We surveyed a small sample of paediatric nursing staff (four charge nurse managers and five staff nurses) about their knowledge of these posters and anything else they knew was used to encourage parents to raise issues or concerns they may have about their child’s care.
The majority of clinicians surveyed, namely nursing staff, were unaware of the posters and there did not appear to be any data about frequency or nature of use of the ‘call’ number.

Figure 5



Health Quality & Safety Commission New Zealand

Kōrero mai co-design programme

Observation/ question prompted conversation data collection template

Please complete between six and ten observations/conversations by December 15th 2017

Also refer to the Co-design capture information sheet and Tips sheet on observations

DHB/Team name:

Remember – you should have already identified yourself to ward staff and agreed which interactions you can observe. Before the observation you will need to introduce yourself to the consumer / whānau and asked for their permission to observe and ask three questions. Your elevator pitch will be helpful at this time.

Date	Who are you observing/ talking to? Circle all of those that apply	How does the consumer/ whānau describe their ethnicity? Circle those that apply or state description of ethnicity
	staff/consumer / whānau	Maori/Pacific/ Pākehā /Asian/ other

What type of interaction are you observing?

- When a consumer is admitted to a ward
- When a consumer returns from a surgical procedure or diagnostic procedure
- When a consumer is transferred from a high acuity area such as the intensive care unit
- When a consumer is transferred from any other area
- Other- please describe here

The observation activity

Observe the interaction between a staff member and consumer / whānau. Particularly look and listen for any information that is provided to the consumer and/or whānau that invites them to raise concerns. Things to observe:

Observation and individual and group interviews were the mechanisms through which we captured experiences from consumers and staff; this also led us to gather some patient stories.

Firstly we used an observational tool developed by the Commission. The focus was to observe interactions between clinicians and parents/caregivers within the paediatric medical ward at defined touchpoints highlighted in Figure 5. We noted if the clinician introduced themselves, observed their body language and if there was any specific information or instruction given on what to do if patients and/or parents have a concern, eg, ‘if you are worried please use the call bell’.

After gaining consumers’ consent we asked them the following questions, recording answers feelings and any other information they wanted to share.

- If you felt that you were getting sicker, or were worried about your condition, what would you do to get help?
- If you felt that your ‘family member’ was getting sicker, or you were worried about their condition, what would you do to get help?
- How would you feel having to raise a concern? or How would you feel about ringing the call bell?
- What do you think would make that (even) better?
- Do you have any ideas that we could use to make improvements?

Through this process we identified the aforementioned story of the parent who had a distressing journey to obtain pain relief for their non-verbal child. This parent’s powerful experience was later capture in depth on video.

After completion of this initial exercise it became apparent we needed to capture more information from consumers, particularly ‘emotion’ words around raising concerns about the condition of their child, barriers to this and what they believed would improve things.

Learning point: Ensure whatever tools you use there is a focus on teasing out/documenting the emotions the consumer has experienced and determine if this relates to any particular points along the patient’s journey or a hospital process.

We designed a couple of sets of cue questions to use in interviews and ending up using both of these. We interviewed parents whose children were admitted to the paediatric progressive care/high dependency unit as this was the area accommodating children who were thought to be more acutely unwell compared to others in the ward environment.

Figure 6: Parent interview cue questions

Set 1	Set 2
Do you know who your child’s primary nurse is today? Did staff tell you how you could raise any concerns you had about your/child’s condition if you thought they were getting sicker? Who would you be most likely to raise concerns with? Do you feel listened to when you raise concerns? Did you feel invited to speak up? If you didn’t speak up – why not? Are there any barriers to raising concerns with staff?	What did you notice about your child that concerned you? What did you do next? How did you do it? What did you say? Did you get a response/what happened? What did you do next? How could we do this better? Is there anything else you would like to share about that experience? Important to tease out what made the experience good and bad and the associated behaviours to assist with design process. Also capture the emotional component so important to ask how this made them feel at each step.

We used the same question development technique for interviewing nursing and medical staff. Again there were several sets of questions developed with changes/additions coming on board as we moved through the process (see below). While we interviewed staff who worked within the paediatric progressive care/high dependency unit we extended this to capture information from other paediatric nursing areas.

1. How frequently do patients, family and whānau help recognise clinical deterioration?
2. How does family and whānau concerns about clinical deterioration influence your clinical decision-making?
3. How supportive are colleagues of your decision to escalate care?
4. What are the challenges you face when you decide you need to escalate care? How does this make you feel?
5. Have you ever been asked to review a child whose parent thinks they are getting worse? Tell us about that experience.
6. What language do you use when interacting with parents to explore health problems?
7. Can you think of a time when escalating care went well? What did that look and feel like?
8. Can you think of a time when this didn’t go so well, or you had a different level of concern to the parent? What happened, what did you do? How did this make you feel?
9. Do patient, family and whānau concerns about clinical deterioration influence your clinical decision-making?
10. Have you or a family member been hospitalised previously and can you describe what your experience was like and how this may have impacted you raising concerns about your/their condition?

11. How frequently do you document patient, family and whānau concerns about clinical deterioration?
12. How would you feel about the implementation of a patient/whanau-initiated clinical deterioration call system? (Give Cincinnati Children’s Hospital example.)

Understand

We collated all of the information we had gathered, including the compliments and complaints data (Figure 7) to extract themes, identify positive and negative attributes associated with experiences by consumers and staff and see if we could map this to touchpoints within the patient’s journey.

We found the latter challenging and were unable to clearly map emotions/events to certain processes, such as admission, ward rounds or handovers. However we felt that there was an overall theme:

Aspects of communication and interaction between clinicians and consumers can define the overall experience and this can occur at any point along the journey.

We grouped information captured from consumers/parents/whānau into inexperienced and high users of hospital services to see if there were differences between these groups. Eighteen parents were interviewed. Five were high users of health care services and were interviewed outside of an admission episode by one of our consumer representatives. It is perhaps not surprising that those parents of children who repeatedly used hospital services provided the most in-depth information around good and bad experiences they had in the context of their child becoming more unwell.

We also compared information gathered from nursing staff working in different paediatric areas. Information from medical staff was grouped into registrar and consultant levels. Overall we interviewed 10 nursing staff across five different paediatric clinical areas, eight registrars and three paediatricians.

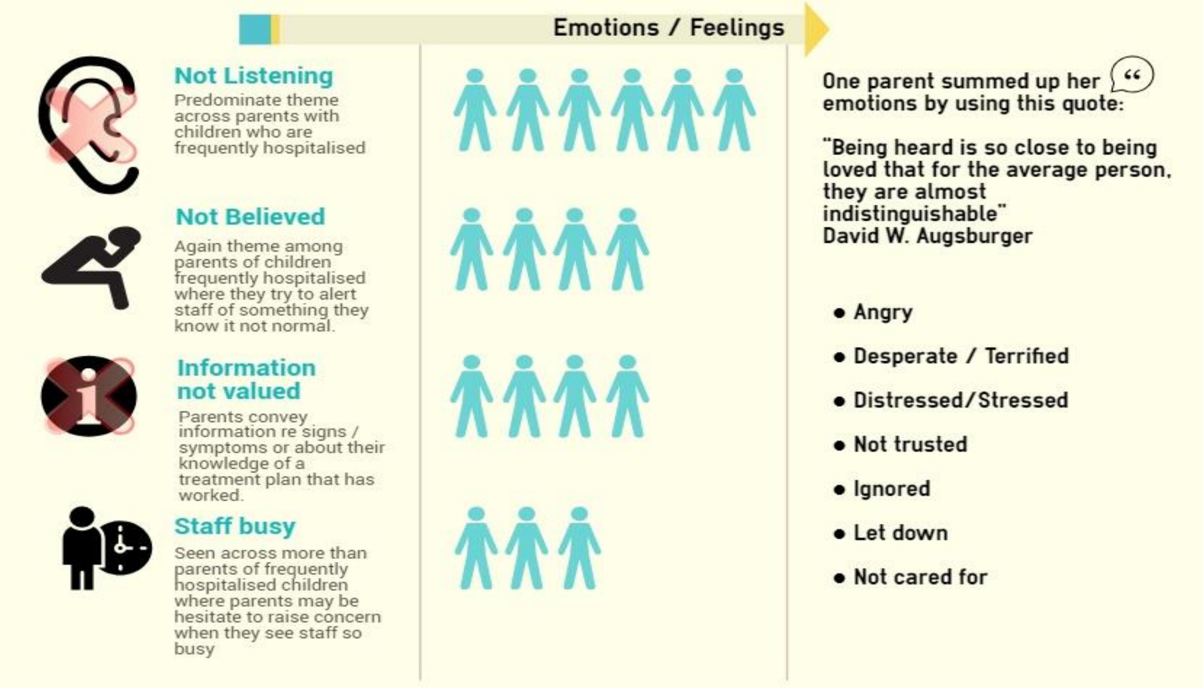
Figure 7 – Complaint/compliment data

Not listening to the concerns of consumers was the overwhelming negative theme to emerge from both the complaints data (see Figure 7) as well interviews with consumers (see Figure 8). Consumers feeling like the information they provide clinicians about their child was not valued or even believed was also a strong theme. These themes emerged from the high health care consumer group. Another theme to emerge was the hesitation of parents to interrupt busy staff to bring something to their attention. This was across both the naïve and high user group.

A key point that we kept coming back to was the importance of both listening to the concerns of parents/consumers and valuing their knowledge of what they consider is ‘normal’ and ‘not normal’ in terms of their health. Additionally from the data we determined that parents would like to be invited by clinicians to express concerns and feel comfortable doing so.

Feelings of frustration and helplessness when trying to convey concerns about a deteriorating child were not exclusive to parents. Some clinicians too expressed these feelings when they had tried to escalate care to other disciplines or services and additionally like some of the parents felt they too were not being listened to, or the information they were conveying to others was not acknowledged. Additionally some staff provided accounts of when they were a family member having to try to advocate for their family member when they were hospitalised. These staff could empathise with those parents’ stories where they felt no one was listening.

Figure 8: Overall themes – consumers



Not Listening
Predominate theme across parents with children who are frequently hospitalised

Not Believed
Again theme among parents of children frequently hospitalised where they try to alert staff of something they know it not normal.

Information not valued
Parents convey information re signs / symptoms or about their knowledge of a treatment plan that has worked.

Staff busy
Seen across more than parents of frequently hospitalised children where parents may be hesitate to raise concern when they see staff so busy

One parent summed up her emotions by using this quote:

“Being heard is so close to being loved that for the average person, they are almost indistinguishable”
David W. Augsburger

- Angry
- Desperate / Terrified
- Distressed/Stressed
- Not trusted
- Ignored
- Let down
- Not cared for

The project group reflected on the themes of the baseline data and started to use this too collectively to define how both consumers and clinicians would like to feel and experience raising concerns, as shown in Figure 9.

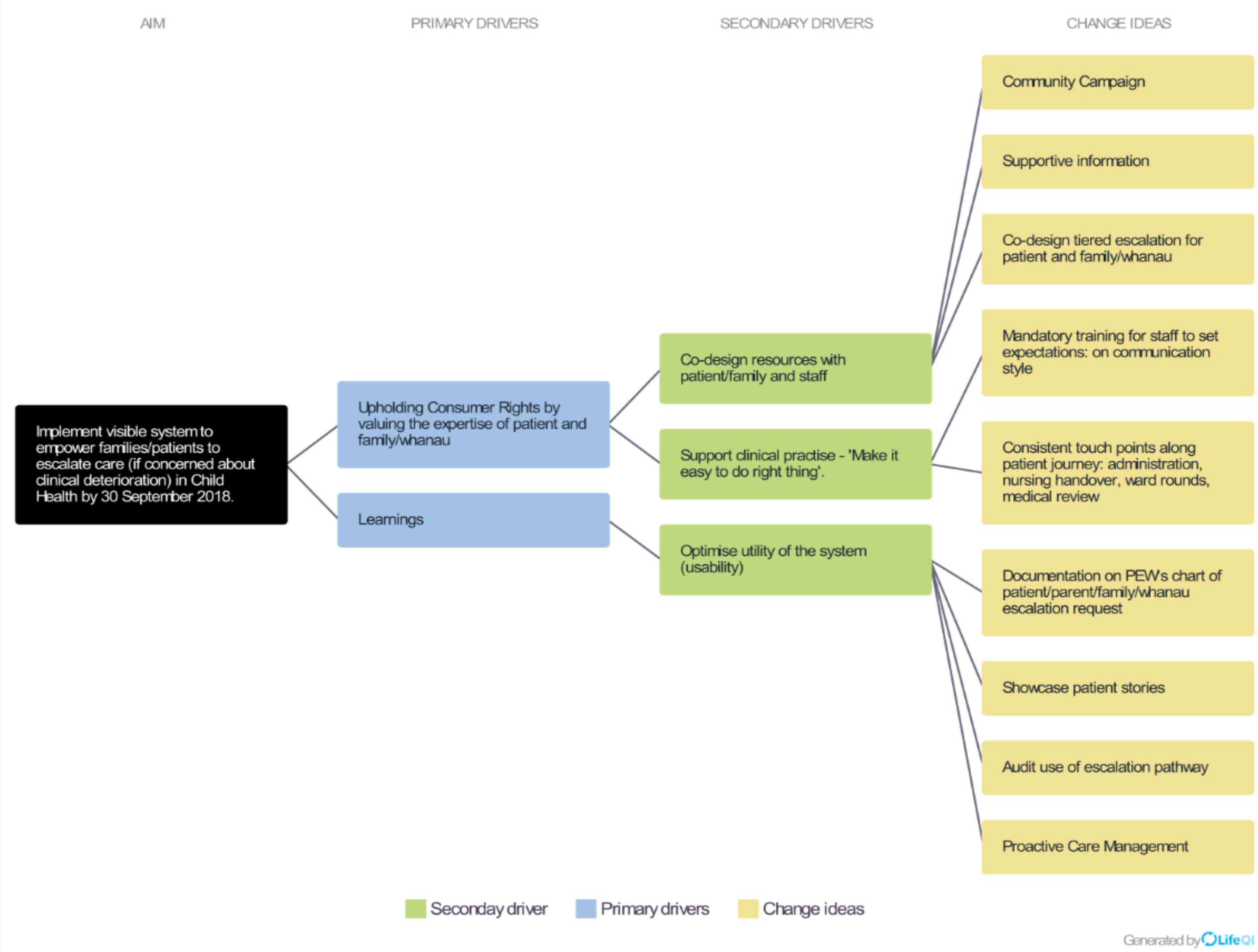
Figure 9: How a solution should look and feel

How consumers want to feel and experience when escalating care:	Consumers do not want to feel:	How clinicians want to feel and experience when escalating care:
• Heard • Information is valued and they feel a part of the team • Clinicians have experience and knowledge but acknowledge when they don't • Clinician values child as individual • Clinician demonstrates caring towards parent/family member (compassionate care) • Knowledge of how to get help • Trust system • Clinicians' conversations 'don't beat around the bush' • Clinician communication demonstrates a we're-in-this-together 'level' of communication	• Undervalued • Not acknowledged • Not believed • Patronised • Excluded from care planning • Concerns/test information is 'written off' without explanation • Busyness is seen as a barrier to voice concern. Particularly busyness on the ward and they don't want to feel like they are interrupting • Repeat themselves unnecessarily • Powerlessness	• Respected for their knowledge and skill • Listened to • Their concern re a child is acknowledge and action and support will be provided • Not threatened when trying to advocate for a sick child

Improve/implementation

As part of our process to design solutions we developed a driver diagram (Figure 10). This together with our initial design principles (Figure 11) and the information we collated around how staff and consumers wanted solutions to look and feel (Figure 9) formed the foundation for creating change ideas and designing solutions to test.

Figure 10: CDHB patient and family/whānau escalation of care driver diagram



Initially two solutions were put forward for testing, which turned into three. The first solution developed was a conversational prompt designed for clinicians to invite and encourage parents to express any concerns they may have regarding their child's condition. One PDSA cycle has been completed of this solution. The solution also incorporated the need for a clear response to acknowledge and address any concerns raised. Clinicians were provided education and training on how to interject 'the invitation' during key clinical touchpoints/conversations with parents as well as the 'why'. The 'why' incorporated patient stories and the major themes that we extracted during the 'Understanding' phase of the project captured from consumers and staff.

Despite not being able to connect consumer feelings to touch points in our health care system we did see admission, handover, ward rounds, etc, as opportunities where clinicians could use the conversational prompt. These clearly defined points where clinicians interact with consumers were seen as an aide memoir cueing clinicians to engage in using the prompt.

The expectation of clinicians was that, at a minimum, parents were invited to express their concerns:

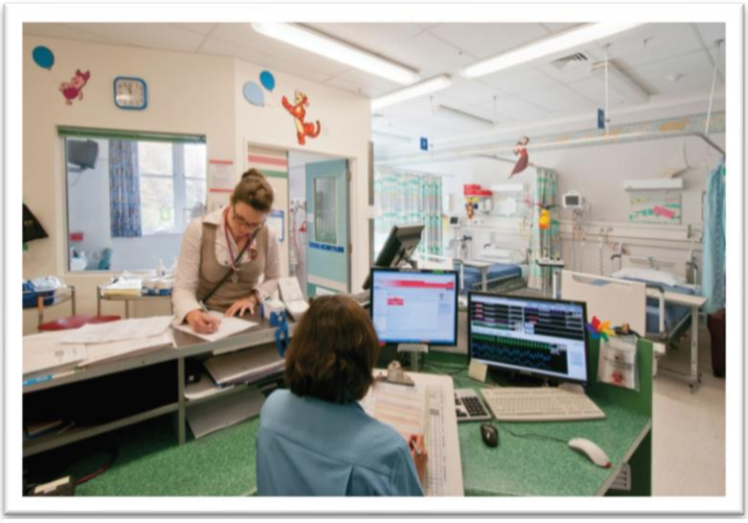
- at the point of nursing/paediatric medical admission
- at nursing handover
- during medical ward rounds
- at any time a physician is requested to review a child.

It was also made clear in the education and training that consumers viewed being asked, ‘Do you have any questions?’ different to that of being invited to express any concerns they may have and for clinicians to separate out the two.

Figure 11: Design principles

1. Make it easy for patients, families and whānau to use	6. Understandable to patients and families.
2. Supports a patient centred model of care	7. Can be transferable across all hospitals
3. Considers both the contributing factors and causal factors associated with communication breakdown in the context of the deteriorating patient	8. Easy to monitor in practice
4. Acceptable to patients, families	9. No harmful unintended consequences
5. Acceptable to full multi-professional health care team	

See Figure 12 for an example of how to use the conversational prompt which was used as part of education and training. There were some concerns from the project group that this solution may be viewed by some as too basic and ‘something we always do’. We felt that this would be managed by incorporating the findings from our capture phase around parent’s feelings around the need to be invited to express concerns and how they viewed this as different to having any questions. We engaged with the clinical nurse specialist and paediatric nursing educators to assist with delivering the education to nursing staff – they were great advocates. Medical staff were provided education by members of the project team.



The paediatric high dependency unit at Christchurch Hospital

We entered into the first PDSA cycle with the hypothesis that this communication strategy would empower parents to express concern at any time throughout their child’s health care journey.

The paediatric progressive care/high dependency unit was identified as the area to complete the first PDSA cycle, namely because the area accommodates children more unwell and more likely to deteriorate than those admitted to other inpatient areas. With the size of the unit being only eight beds, it was felt this was the ideal area to conduct small-scale testing.

Figure 12: Using the conversational prompt invite concerns of parents

- ✓ Introduction of #hello my name is… self and/or the team
- ✓ Engagement with the child/parent/s/caregivers
- ✓ Usual mechanisms to acknowledge/engage with both child and parent, play, etc
- ✓ Invite health history, emphasis on asking about any 'concerns' the parent/s/caregiver has
- ✓ Acknowledge and explore concerns further if more information required
- ✓ Provide information of possible causes, investigations, treatment that may be required and for what reason, ensure concerns are addressed at this point.
- ✓ Provide the opportunity for the parent/s/caregiver or where appropriate the child to ask questions regarding the information discussed and answer accordingly
- ✓ Invite the parent/s/caregiver to raise any further concerns, acknowledge these and discuss plan to address these
- ✓ Encourage the parent/s/caregiver to express concern re deterioration of their child at any time through alerting nursing staff verbally or through using the call bell. Not to delay this communication even if it appears the staff are busy.

'What concerns do you have about your child's condition?' or 'Do you have any specific concerns about your child's condition?' were given as examples of how clinicians could utilise the conversation prompt.

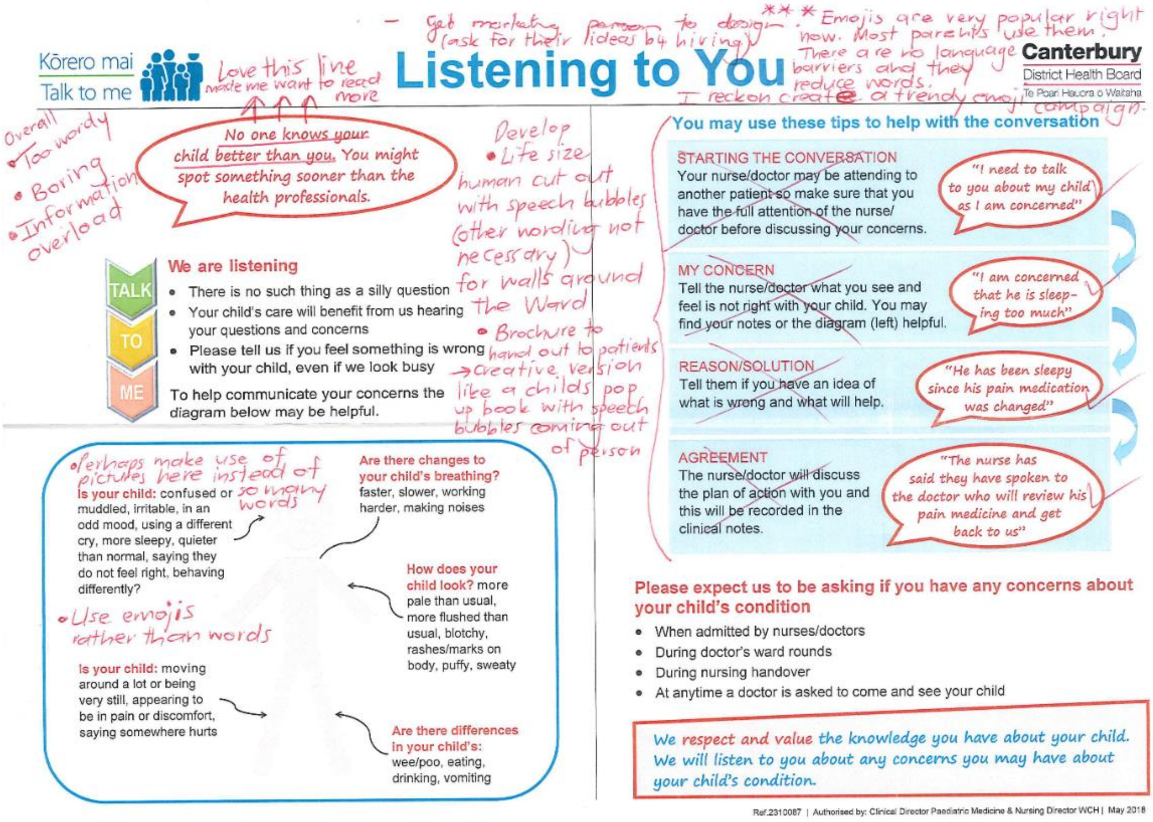
In addition to the conversational prompt, the project group felt that the invitation to parents to express concerns required some context and explanation. We needed to communicate that; we do value their knowledge of their child's 'norms' and flags that indicate they are unwell, that they know their child best and that clinicians will listen to them.

Staff nurse listens to parent after sharing information leaflet with them

An information leaflet (Figure 13) became the second solution we did not initially foresee we needed to create. The leaflet went through a number of iterations as we consulted staff and consumers about the content. We must credit the Birmingham Children's Hospital Trust in the UK for our inspiration, as they had developed a leaflet which we felt contained the key messages we wanted to convey to parents which formed the basis of our version. The intent was that this leaflet would be handed to parents during the admission process by nursing staff. We felt that it was important that parents knew from the 'get-go' of the hospital journey that our expectation of ourselves was to listen to, acknowledge and respond to family and patients' concerns.

Through the education and training process we asked clinicians if an aide memoir in the form of a lanyard card or another format would assist them in remembering to ask parents about concerns. Their thoughts were that this was not required, partially because they felt they were already communicating with families in this way. They felt that having the parent's handout in a poster format located above patient's beds adjacent to existing bedside boards (pictured right) would be enough of a prompt.

Figure 13: Listening to you consumer information leaflet – parent feedback



- Get marketing person to design. (ask for their ideas b4 hiring)

Kōrero mai
Talk to me

Listening to You

Love this line
made me want to read more

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*** Emojis are very popular right now. Most parents use them. There are no language barriers and they reduce words. I reckon create a trendy emoji campaign.

Overall
- Too wordy
- Boring
- Information overload

No one knows your child better than you. You might spot something sooner than the health professionals.

Develop
- Life size human cut out with speech bubbles (other wording not necessary) for walls around the Ward
- Brochure to hand out to patients → creative version like a childs pop up book with speech bubbles coming out of person

We are listening

TALK TO ME

- There is no such thing as a silly question
- Your child's care will benefit from us hearing your questions and concerns
- Please tell us if you feel something is wrong with your child, even if we look busy

To help communicate your concerns the diagram below may be helpful.

- Perhaps make use of pictures here instead of so many words

Is your child: confused or muddled, irritable, in an odd mood, using a different cry, more sleepy, quieter than normal, saying they do not feel right, behaving differently?

Are there changes to your child's breathing? faster, slower, working harder, making noises

How does your child look? more pale than usual, more flushed than usual, blotchy, rashes/marks on body, puffy, sweaty

- Use emojis rather than words

Is your child: moving around a lot or being very still, appearing to be in pain or discomfort, saying somewhere hurts

Are there differences in your child's: wee/poo, eating, drinking, vomiting

You may use these tips to help with the conversation

~~STARTING THE CONVERSATION~~
~~Your nurse/doctor may be attending to another patient so make sure that you have the full attention of the nurse/doctor before discussing your concerns.~~

"I need to talk to you about my child as I am concerned"

~~MY CONCERN~~
~~Tell the nurse/doctor what you see and feel is not right with your child. You may find your notes or the diagram (left) helpful.~~

"I am concerned that he is sleeping too much"

~~REASON/SOLUTION~~
~~Tell them if you have an idea of what is wrong and what will help.~~

"He has been sleepy since his pain medication was changed"

~~AGREEMENT~~
~~The nurse/doctor will discuss the plan of action with you and this will be recorded in the clinical notes.~~

"The nurse has said they have spoken to the doctor who will review his pain medicine and get back to us"

Please expect us to be asking if you have any concerns about your child's condition

- When admitted by nurses/doctors
- During doctor's ward rounds
- During nursing handover
- At anytime a doctor is asked to come and see your child

We respect and value the knowledge you have about your child. We will listen to you about any concerns you may have about your child's condition.

Ref.2310087 | Authorised by: Clinical Director Paediatric Medicine & Nursing Director WCH | May 2018

Figure 14

Are you **concerned**

that your **child** is getting **sicker**

or

Are you **concerned** about **their:**

- **breathing**
- **heartbeat**
- **colour**
- **sleepiness**
- **restlessness**
- **pain**

Follow these steps

STEP 1

Speak to your nurse or the nurse-in-charge right away.
Tell them why you're concerned and ask them to look at your child.

STEP 2

If you are still concerned and want a doctor to look at your child,
ask your nurse to call for an urgent 'doctor review'.

STEP 3

If the doctor has seen your child but you're still very concerned your child is getting sicker,
you can call 0800 ______________ 24 hours a day.

If you have feedback or a complaint, please speak with the nurse in charge or ask for a feedback form

For more information, speak with your nurse

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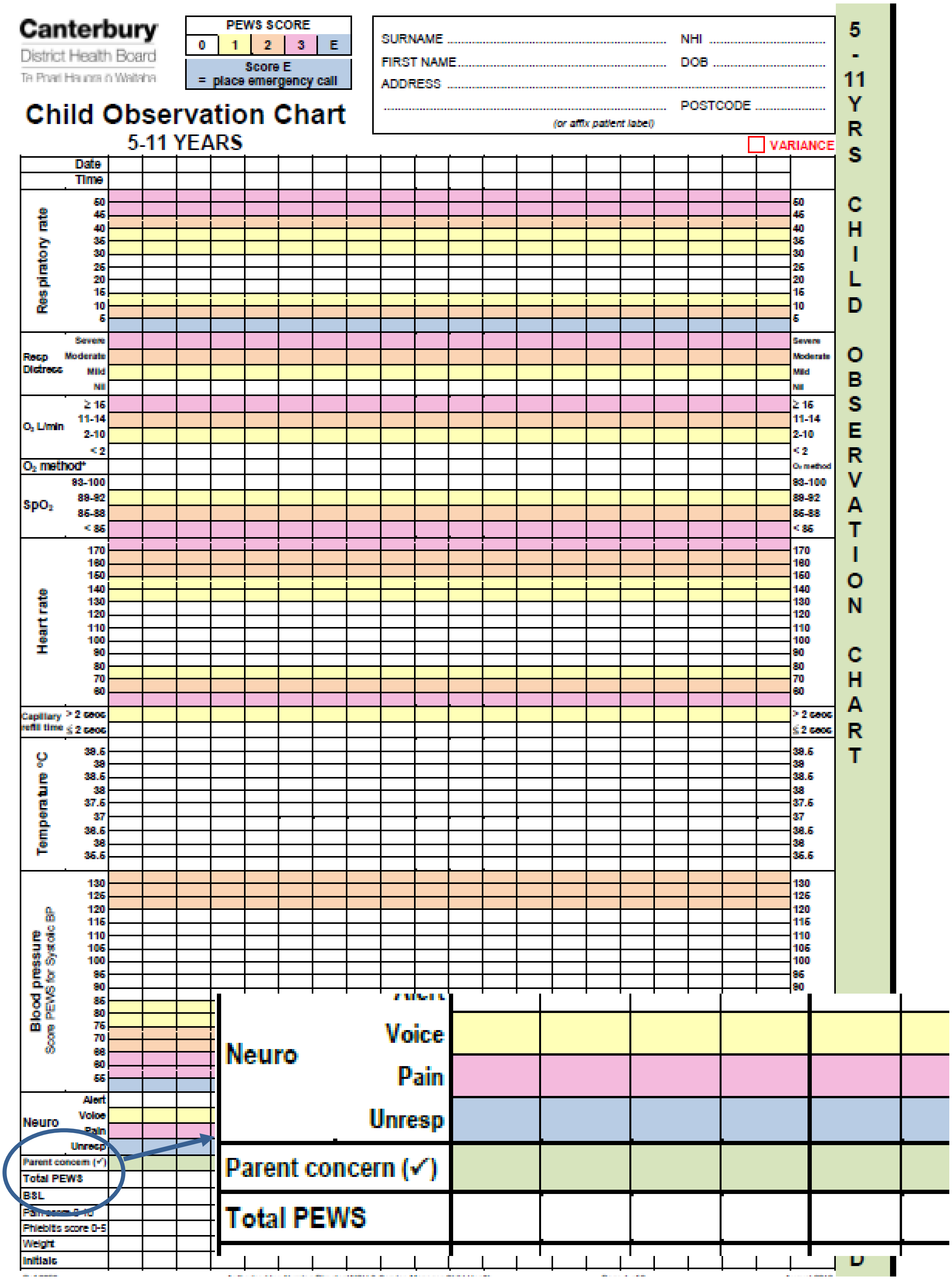
The **third solution** put forward for testing was a stepped process (see Figure 14) for parents to obtain a 'fresh look' or second opinion around their child's condition if they continued to have concerns after communication with the immediate treating team. This solution is reflective of other family escalation systems such as **Ryan's Rule** and **Call 4 Concern** implemented internationally. These systems usually employ the services of a team, originating out of the intensive care unit, who respond to a call from a concerned parent. Part of this solution was also to incorporate parental concern within our existing paediatric early warning score observation charts (PEWS) so **Step 2** could be formally recorded (see Figure 15).

Time constraints and availability to bring key stakeholders together to discuss how this could be operationalised meant the testing of this solution has been delayed. This also meant that the section of the parent information leaflet that covered this had to be removed for the first PDSA cycle. As there has been support at many levels for this proposed solution we are confident that will begin testing by September 2018.

Figure 15: Example of a PEWS chart



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PEWS SCORE
0 | 1 | 2 | 3 | E
Score E = place emergency call

Child Observation Chart
5-11 YEARS

SURNAME .... NHI ....
FIRST NAME .... DOB ....
ADDRESS ....
.... POSTCODE ....
(or affix patient label)

☐ VARIANCE

Date
Time
Respiratory rate: 50, 45, 40, 35, 30, 25, 20, 15, 10, 5
Resp Distress: Severe, Moderate, Mild, Nil
O_2 L/min: ≥ 15, 11-14, 2-10, < 2
O_2 method*
SpO_2: 93-100, 89-92, 85-88, < 85
Heart rate: 170, 160, 150, 140, 130, 120, 110, 100, 90, 80, 70, 60
Capillary refill time: > 2 secs, ≤ 2 secs
Temperature °C: 39.5, 39, 38.5, 38, 37.5, 37, 36.5, 36, 35.5
Blood pressure (Score PEWS for Systolic BP): 130, 125, 120, 115, 110, 105, 100, 95, 90, 85, 80, 75, 70, 65, 60, 55
Neuro: Alert, Voice, Pain, Unresp
Parent concern (✓)
Total PEWS
BSL
Pain score 0-10
Phlebitis score 0-5
Weight
Initials

5 - 11 YRS CHILD OBSERVATION CHART

Neuro: Voice, Pain, Unresp
Parent concern (✓)
Total PEWS

Measure

Observation of staff interactions with parents and their sick child, along with interviews with both parties were the mechanisms through which we measured the impact of the clinical conversation prompt and consumer information leaflet.

Parents:

- Apart from measuring if parents were asked/encouraged by staff to express their concerns re any deterioration in their child's condition, we also wanted to determine if this would lead them to confidently raise concerns at any time. If they did raise concerns, we wanted to determine if staff adequately addressed these and explore how a positive or negative experience made them feel and what were the characteristics of each.
- We also measured the utility of the consumer information leaflet from the parents' perspective to determine if the document added value to parents and if this too gave them confidence to raise concerns at any time.

Staff:

- We focused on measuring if staff had a positive experience using the script and expressed willingness to continue to adopt the script as part of everyday communication with families and if they felt it added value and how. Through observation we aimed to measure the numbers of staff who used the script, explore its utility and the level of comfort of those using the script and how they responded during their interactions with parents in terms of attentiveness and listening and acknowledging information parents shared.

The project team recognised that the data collection that took place did not adequately explore the consumer experience/views of Māori, Pasifika or ethnic groups such as Asian and Indian, of patient deterioration and any perceived barriers they may have around raising concerns to clinicians about their child's condition. With repeated testing of the family escalation solutions we will aim to capture more information from these groups.

Some of our findings are summarised in Figure 16. Perhaps the most powerful quote to come from a parent during the trial was:

> 'Continue to focus on having the conversation with families rather than focus on written material. We appreciate the discussion rather than a poster or piece of paper.'

This same parent also expressed appreciation for the conversation staff had with them about being encouraged to express concerns at any time re either their child's condition or the plan of care, so much so, they went on to submit a formal compliment to the nurse for this to the general manager. This message was reflected by another parent and others felt that the written information may have been too much for parents to process when worrying and caring for a sick child.

Some parents who were given the leaflet did not read it, expressing they were already confident enough to raise concerns but did state they saw benefit around others receiving it who did not have the same level of confidence. When discussing this with one mother whose child has had multiple hospitalisations over a number of years they stated they would have 'loved to have had something like this when they had started their journey', that over time she had developed ‘the speaking up’ and advocacy skill required for her and her child to ‘survive’ in the system.

One parent expressed concern over being asked if they had any concerns on a regular basis – wondering if there was something wrong. While clinicians were using the clinical conversation prompt they had not provided context around why we would be encouraging/inviting them to express any concerns either verbally or through providing the leaflet.

The feedback on the content/presentation of the information on the leaflet was split 50/50 with some saying that the information was useful in the format presented and others saying it was ‘too wordy’.

We obtained feedback from nine nursing staff, two registrars and three paediatricians about their experience with the conversation prompt and consumer information. The main themes to emerge were:

Easy

Staff thought that it was easy to ask parents if they had any concerns at points along their child’s inpatient journey. Some staff did combined in the same sentence asking about concerns with asking if they have any questions which was also noted during some of the interactions observed. Further work to reiterate to staff they need to be separated will be taken into the next testing round.

Self-awareness

Staff discussed how the conversational prompt made them more self-aware of the language they use, how parents feel and their needs in addition to their child’s. Moreover some staff also recognised the importance of ensuring you allow time for a family to say they have concerns and that the question is just not asked ‘on the fly’. Others mentioned the power of harnessing and acknowledging parents as ‘another set of eyes’.

No specific examples could be given by staff where they felt they perhaps gained more information from parents by asking them if they had any concerns but all staff interviewed believed this added value and it may also provide a gauge for potential concerns parents may have so these may be proactively managed.

Overall staff shared enthusiasm to continue using the wording re asking about concerns parents may have. One senior medical officer communicated they are spreading the use of the prompt into the outpatient clinic setting.

Suggestions for improvement

Across staff and consumers involved in the pilot, a number of suggestions were put forward to embed the conversational prompt into practice to ensure sustainability. There were also suggestions for the consumer information leaflet put forward – two parents provided feedback directly on the leaflet. See Figure 13 for one example. Simplifying the language and messages were the main themes.

Nursing staff felt it would be useful to incorporate in both new staff orientation and within yearly core educational updates, the importance of using the prompt, to show it is an important expectation but also provides a way of continuing nurses to believe in its value through presenting it alongside patient stories. Some felt an online learning component would also be useful.

> *Some staff felt they were actually gaining more direct positive feedback around the care they were providing than before they were using the prompt – no doubt incentive to continuing using it.*

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About Me

Canterbury District Health Board
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Name :

Parents/Whanau Names :

Nil by mouth from :

Food allergy :

Diet Information :

Individual needs :

Mobility

☐ I am at risk of falling

Other

My schedule today :

Nurse :

Lead Doctor :

○ Child is
○ Parent/ caregiver is
Visually impaired

○ Child is
○ Parent/ caregiver is
Hearing impaired

○ Child is
○ Parent/ caregiver is
Communication impaired

What matters to me :

Questions we have :

I plan to go home on :

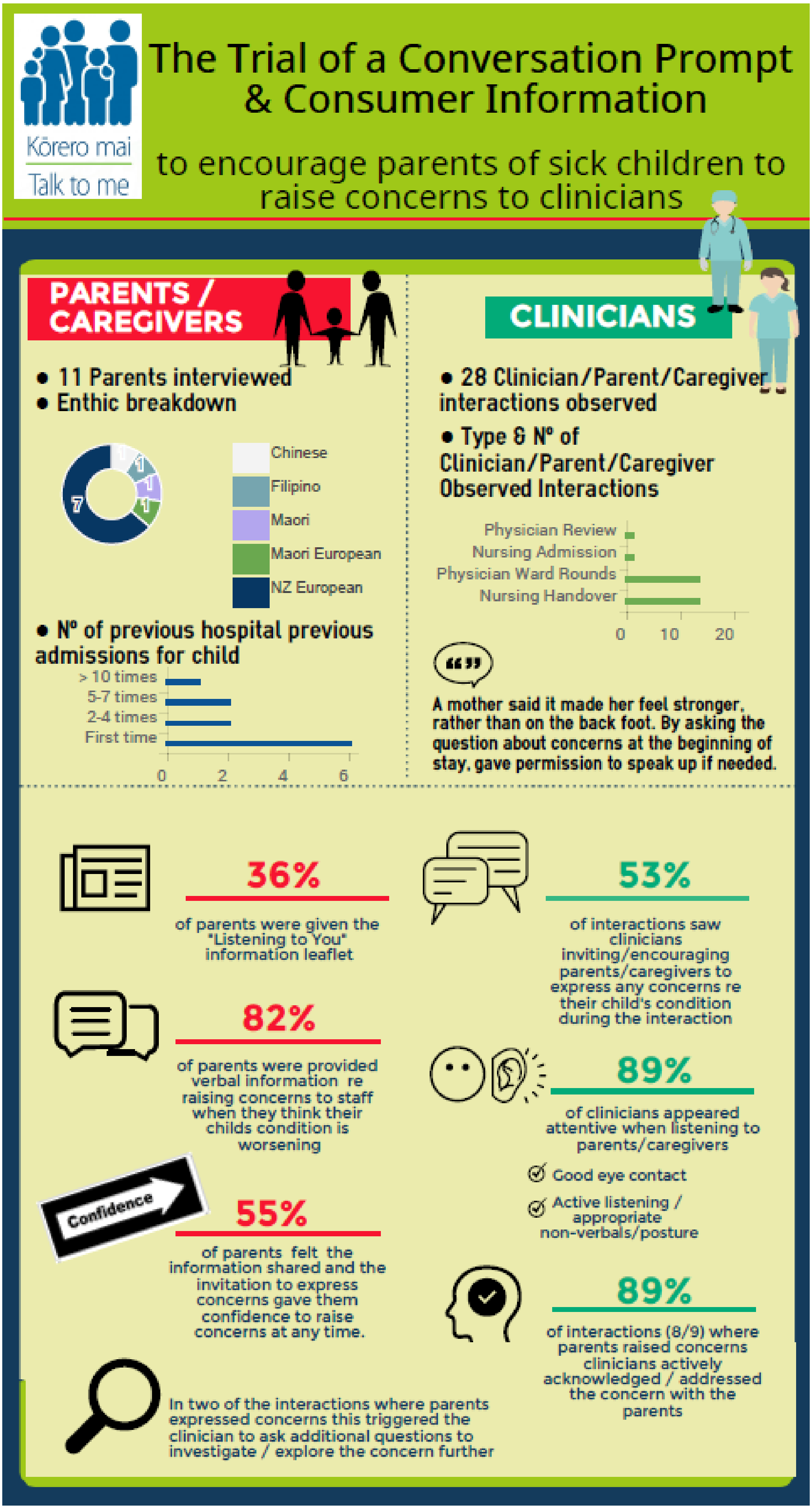
Updated

Some staff put forward other ideas which could act as an aide memoir for staff to use the prompt every day such as adding a visual cue in the nursing care plan, within the observation chart or incorporating it as part of shift by shift safety checks.

Additionally it was suggested to incorporate key messages into the bedside boards used by parents and the health care team. Somehow weaving in both the messages from the consumer leaflet and the tiered escalation pathway for parents to follow was seen as a way the information could always be ‘front and centre’ for both staff and families. All considerations for the next round of testing.

Finally it was suggested that future testing involve the wider health care team, ie, allied health professionals, in the initiative, which is certainly our plan.

Figure 16



Kōrero mai
Talk to me

The Trial of a Conversation Prompt & Consumer Information

to encourage parents of sick children to raise concerns to clinicians

PARENTS / CAREGIVERS

- 11 Parents interviewed
- Enthic breakdown

- Nº of previous hospital previous admissions for child

CLINICIANS

- 28 Clinician/Parent/Caregiver interactions observed
- Type & Nº of Clinician/Parent/Caregiver Observed Interactions

A mother said it made her feel stronger, rather than on the back foot. By asking the question about concerns at the beginning of stay, gave permission to speak up if needed.

36%

of parents were given the "Listening to You" information leaflet

82%

of parents were provided verbal information re raising concerns to staff when they think their childs condition is worsening

55%

of parents felt the information shared and the invitation to express concerns gave them confidence to raise concerns at any time.

53%

of interactions saw clinicians inviting/encouraging parents/caregivers to express any concerns re their child's condition during the interaction

89%

of clinicians appeared attentive when listening to parents/caregivers

- ✓ Good eye contact
- ✓ Active listening / appropriate non-verbals/posture

89%

of interactions (8/9) where parents raised concerns clinicians actively acknowledged / addressed the concern with the parents

In two of the interactions where parents expressed concerns this triggered the clinician to ask additional questions to investigate / explore the concern further

Working as a co-design team

The English architect Cameron Sinclair is quoted as saying:

‘A true architect is not an artist but an optimistic realist. They take a diverse number of stakeholders, extract needs, concerns, and dreams, then create a beautiful yet tangible solution that is loved by the users…’

This is in essence what our team view co-design to be. The chance to hear the perspective of those who care and of those who are cared for, develop a common understanding of issues and a way forward – solutions. The project consumer representatives stated they ‘felt like staff in this group truly understood the principles of co-design, and our inclusion felt far from token’. Overall the group felt like there was a flat structure where everyone’s voice was heard. We always found ourselves inviting improvement ideas from the paediatric staff we were working with, as overall they, together with consumers, were seen by the group to be in the best position to put forward practical solutions that would be easily adopted and be sustained over time. The co-design process really extended both the groups’ thinking beyond their own individual knowledge, thoughts and the options for solutions needing to be explored.

There was certainly realisation of the benefits of co-design beyond the usual – design a solution and expect everyone to ‘get on board’ – however the time and resource constraints around the project created tension. This tension has left us feeling like we could have better engaged with more staff and consumers; bringing them together using focus groups, so they too could see each other’s perspectives and co-developed solutions. We will certainly explore this as we move through other PDSA cycles.

Our lessons for future projects would be to enable even more consumer involvement in the process through the development of a contracting model for consumers and appropriate remuneration for their time. While staff in the core group encouraged consumers to be as involved as possible, there were some limitations around consumers interacting directly with staff and patients within the hospital through both the data collection and pilot phases and being more actively involved in the writing-up of documents required by the Commission.

Names, e-mail addresses, organisation of team members

Names of team members	**Role**	**E-mail address**	**Organisation DHB**
Rob Earle	Consumer representative		
Haley Nielsen	Consumer representative		
Neil Davidson	Intensive care consultant		CDHB
Donna Galloway	Charge nurse manager, adult medical		CDHB
Chrissy Bond	Project manager		CDHB
Rosalie Waghorn	nurse manager		West Coast DHB
Amanda Van Asperen	Nurse educator, Ashburton Hospital		CDHB
Wikitoria Crofts	Ngā Pūkenga Atawhai		CDHB
Michelle Morland-Mcrae	Quality facilitator corporate	Michelle.Morland-Mcrae@cdhb.health.nz	CDHB
Graeme Webb	Quality coordinator, child health	Graeme.webb@cdhb.health.nz	CDHB

Kōrero mai is a Health Quality & Safety Commission initiative in partnership with participating DHBs. This case study is reproduced with permission of Canterbury DHB. The Commission would like to thank the co-design team involved for sharing their example.

Health Quality & Safety Commission New Zealand
Kupu Taurangi Hauora o Aotearoa

New Zealand Government

We would also like to thank our partner, Ko Awatea, for its support:

KO AWATEA
HEALTH SYSTEM INNOVATION AND IMPROVEMENT