



WCCHN Family Satisfaction Survey Results

2016 – 201 Fiscal Year

About the Survey

This survey was developed to obtain feedback on a quarterly basis from the families regarding their experiences within the WCCHN centres' Pediatric Cardiology Departments. These surveys provide an opportunity to highlight the Network's successes and examine areas of improvement to the cardiac services provided to the children in Western Canada.

This report contains the results from the survey that was sent to families that had surgery at both BC Children's Hospital in Vancouver, and Stollery Children's Hospital in Edmonton between April 2016 and March 2017. A previous survey was completed from April 2014 and March 2015. Those results have been included in the report for comparison.

These are mailed out to families every quarter. The survey takes approximately 30 minutes to complete. Families are able to fill out the survey either electronically or by hard copy. The results are separated into which surgical centre the child had their procedure at. The survey is entirely voluntary. The care of children is not affected by the results of the survey. Individual surveys are only reviewed by the WCCHN office. This is a compilation of the results received during the reporting period.

Total surveys distributed: 606
Total number of respondents: 117
(19%)

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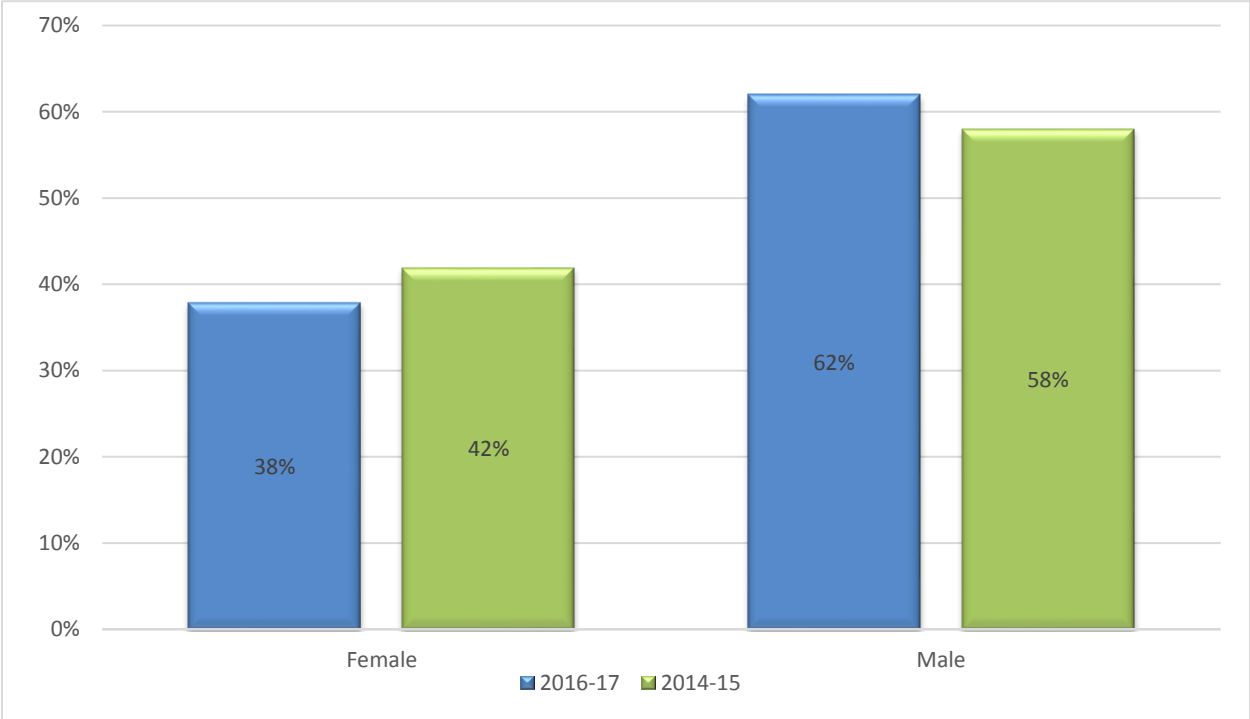
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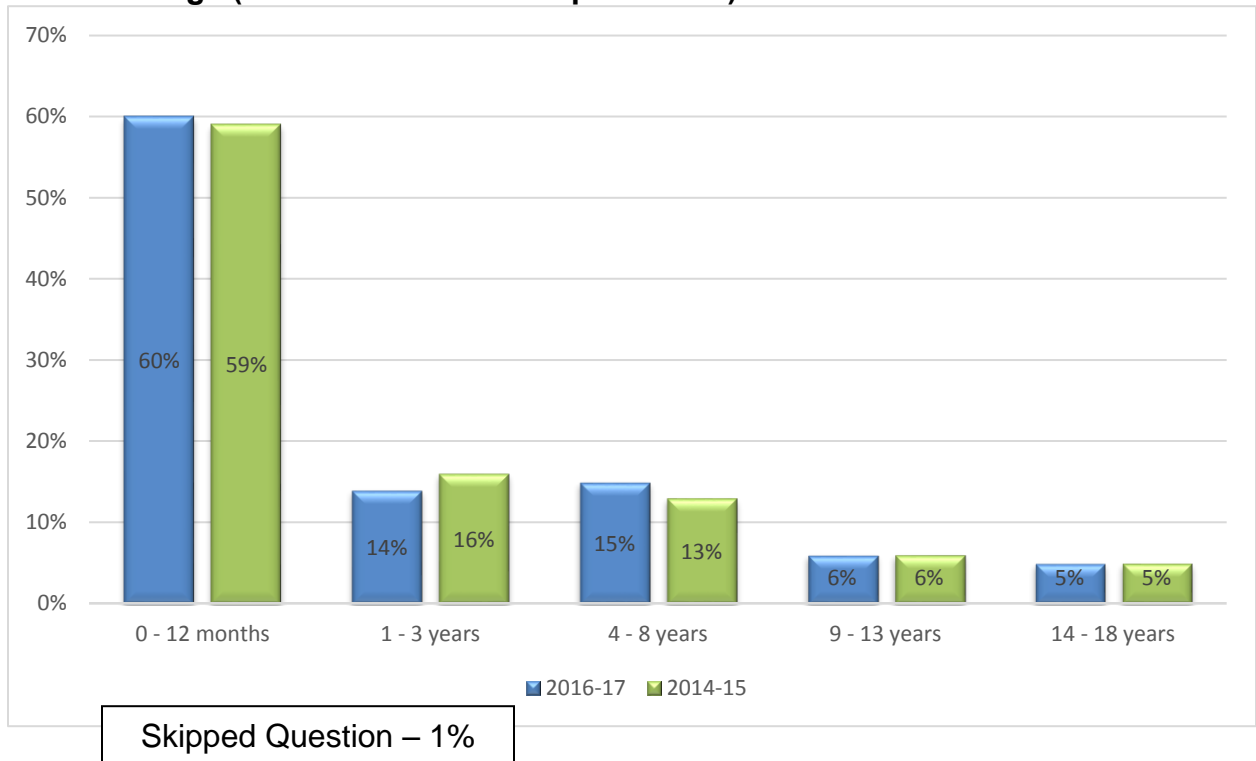
General Questions About Your Family

1. Child's Gender

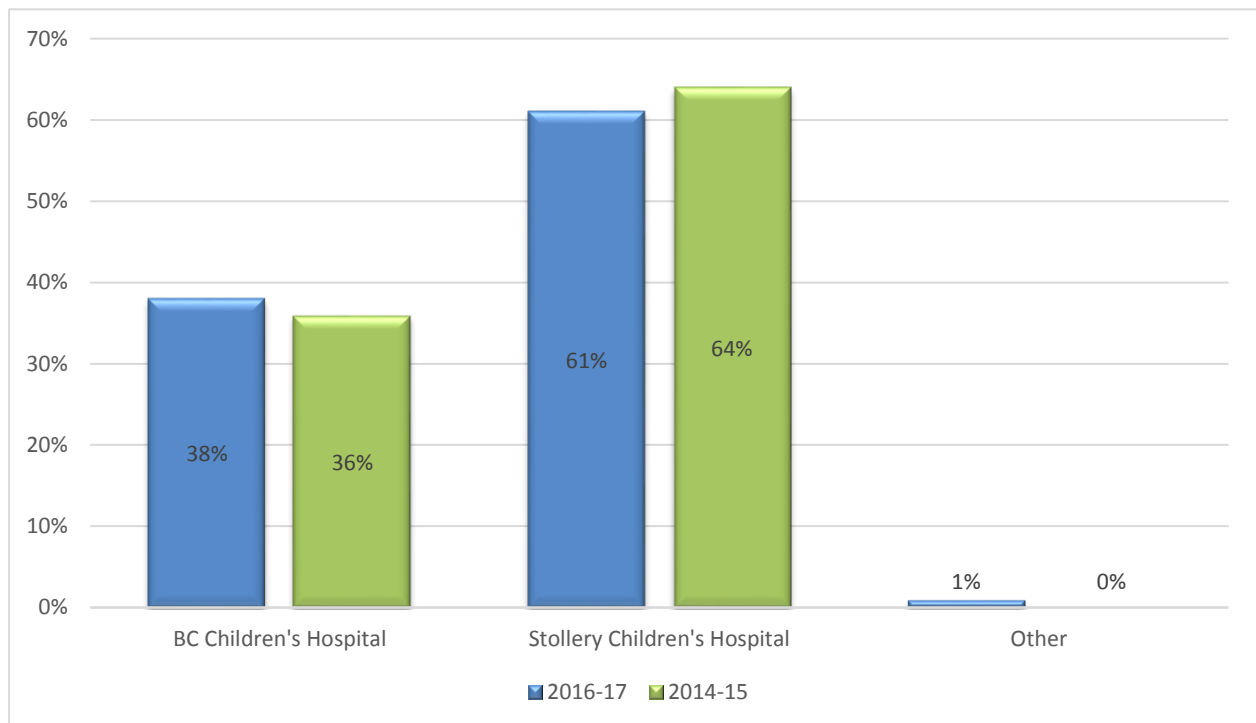


Skipped Question – 1%

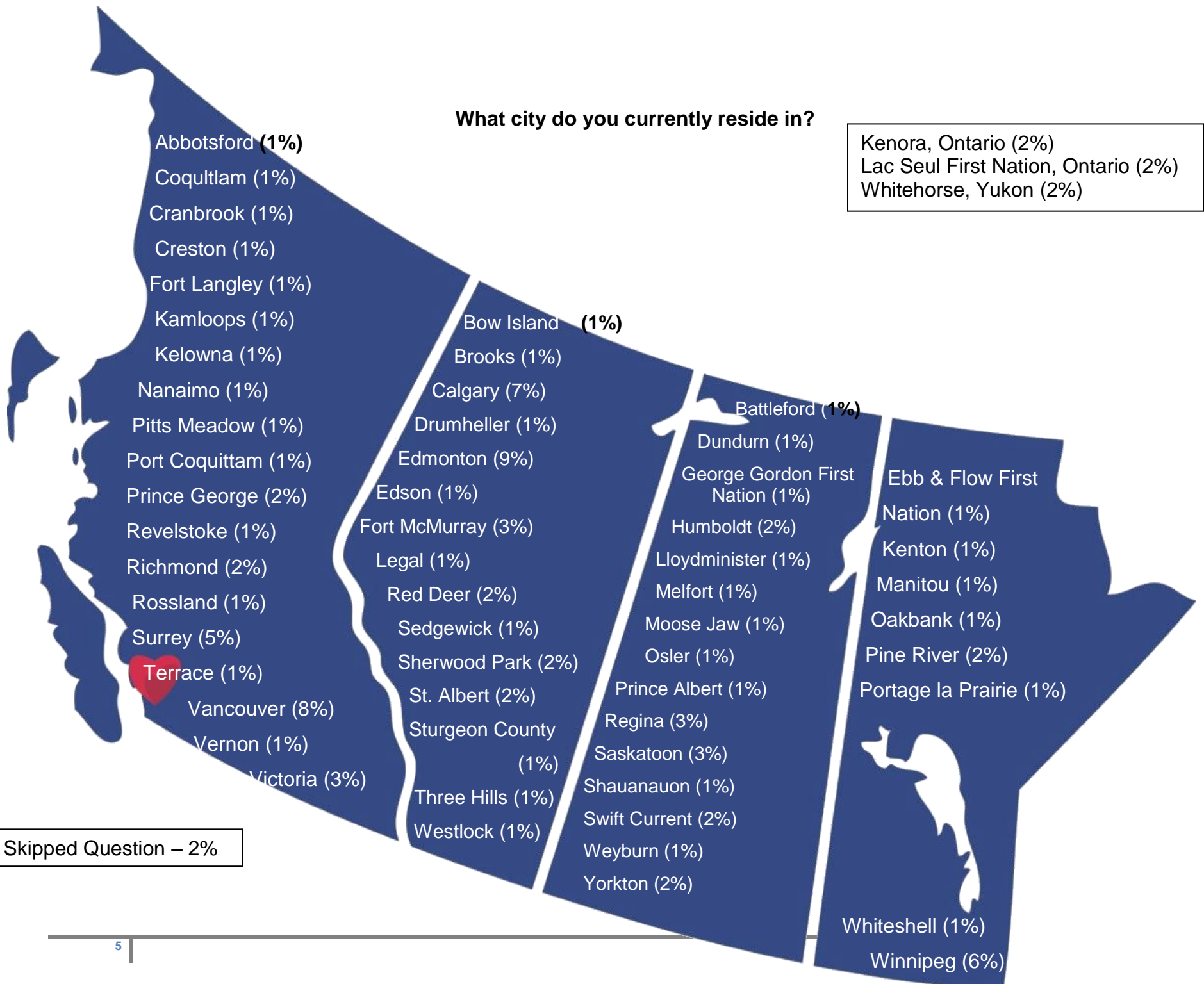
2. Child's age (at the time of cardiac procedure)



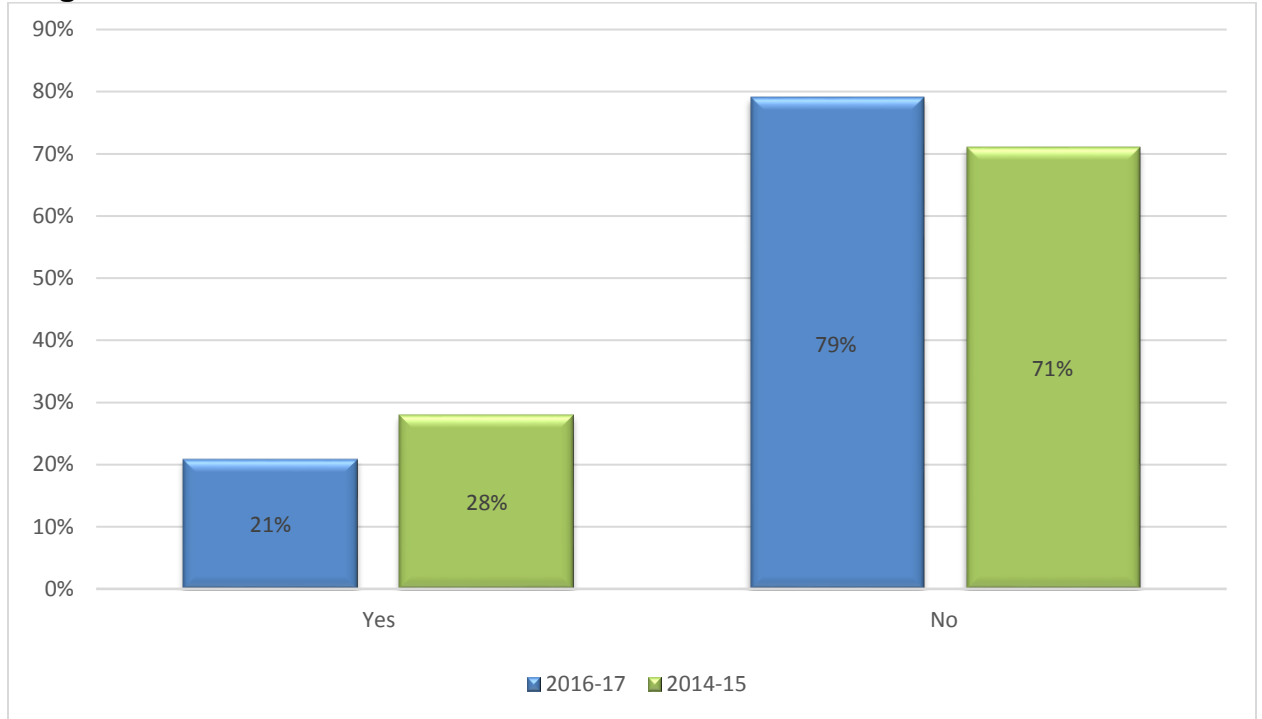
3. Where did you go for the cardiac procedure?



What city do you currently reside in?

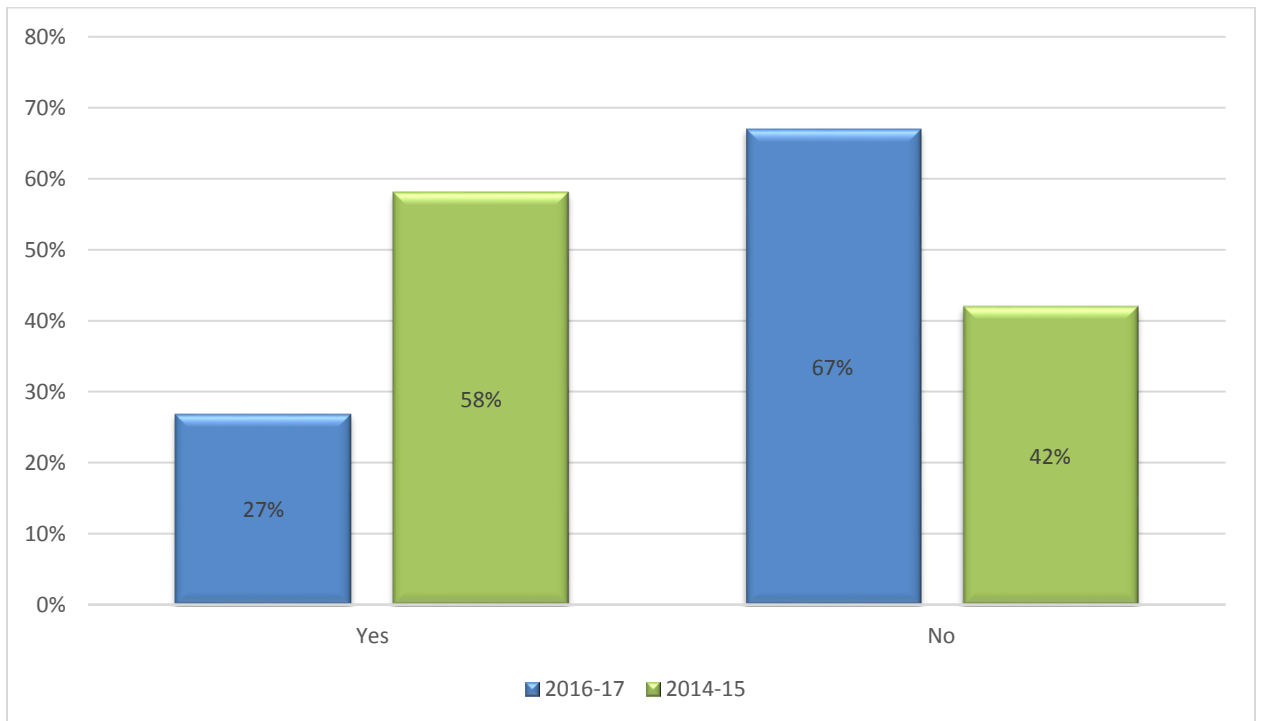


4. Was your child's current procedure ever cancelled or postponed by the surgical centre?

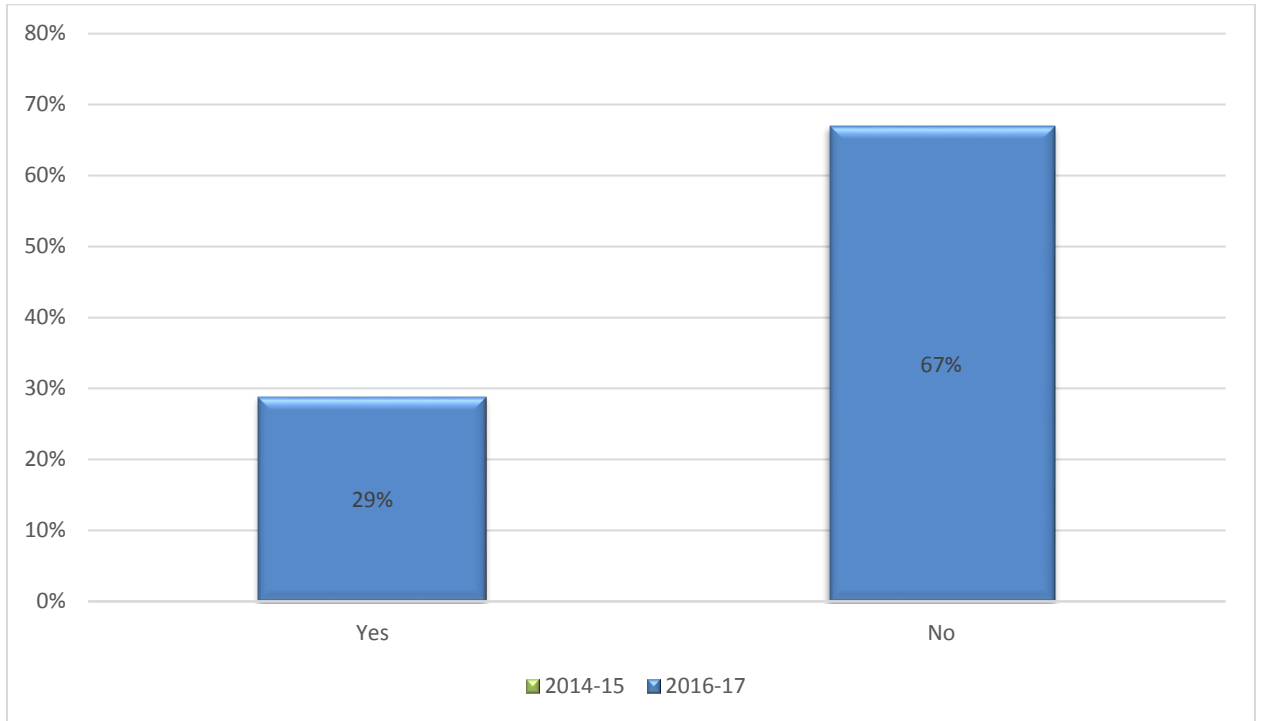


Skipped Question – 1%

If you answered yes: Had you already travelled to the surgical centre before your child's procedure was cancelled or postponed?



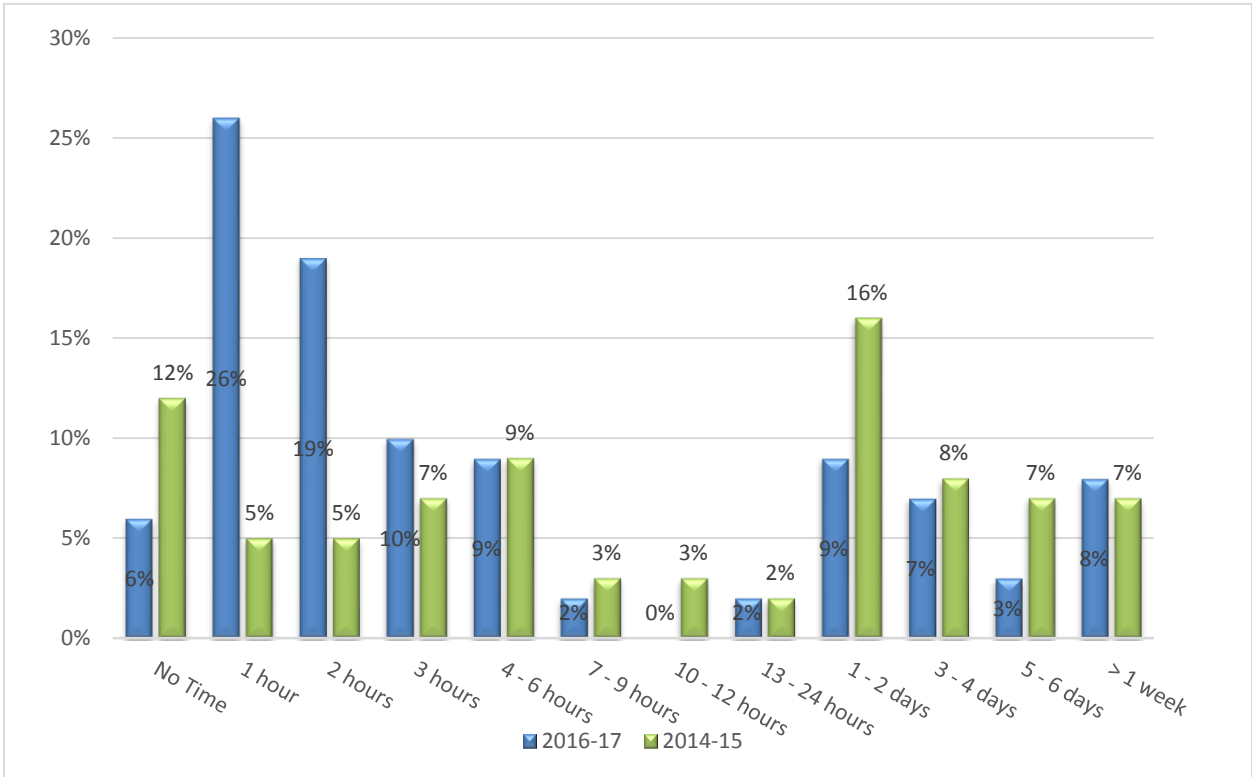
If you answered yes: Was the surgery postponed because your child was ill (ie. Had a cold, etc.)



**New question – no data from 2014-15 survey.*

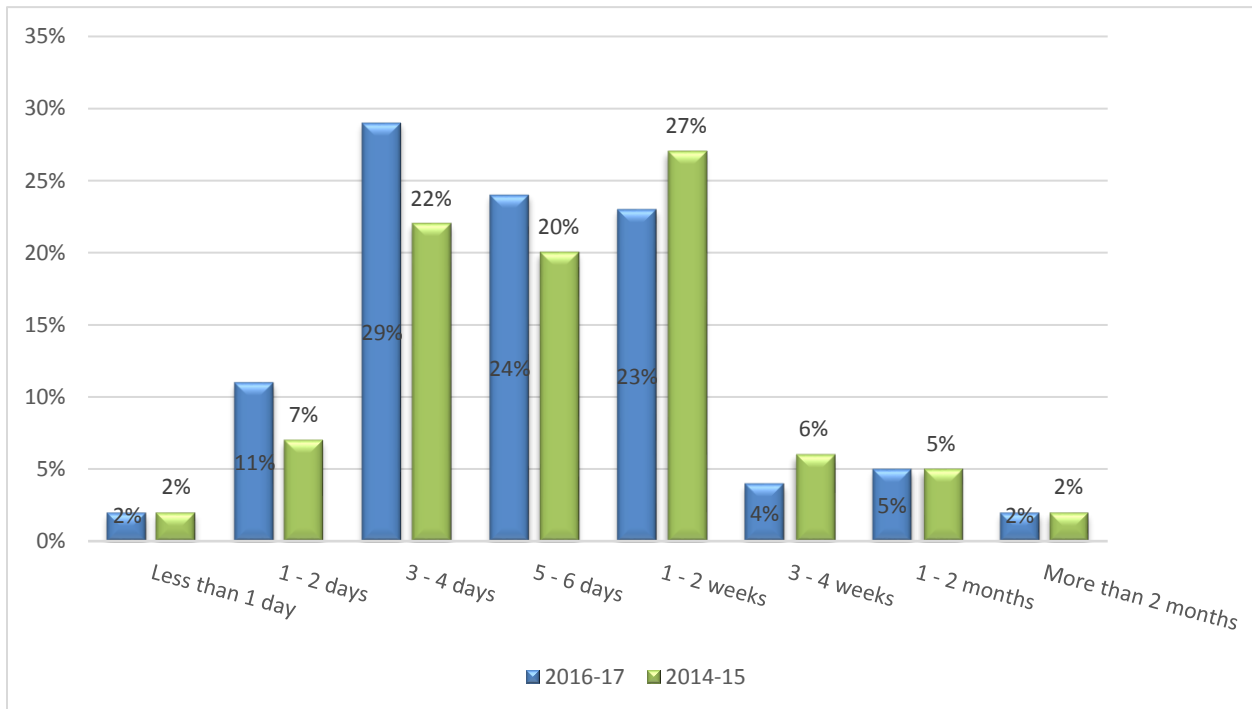
5. How long was your child's stay at the surgical centre:

Before they were taken to the OR:

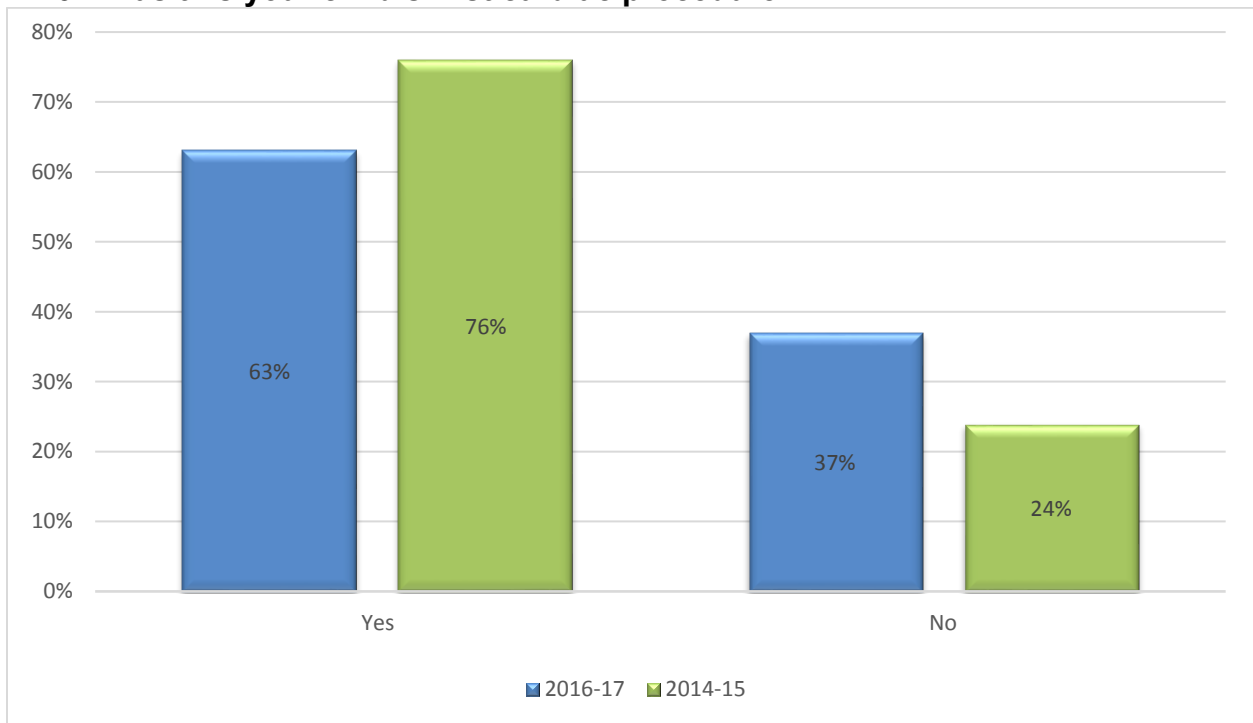


Skipped Question – 2%

After they had their procedure:



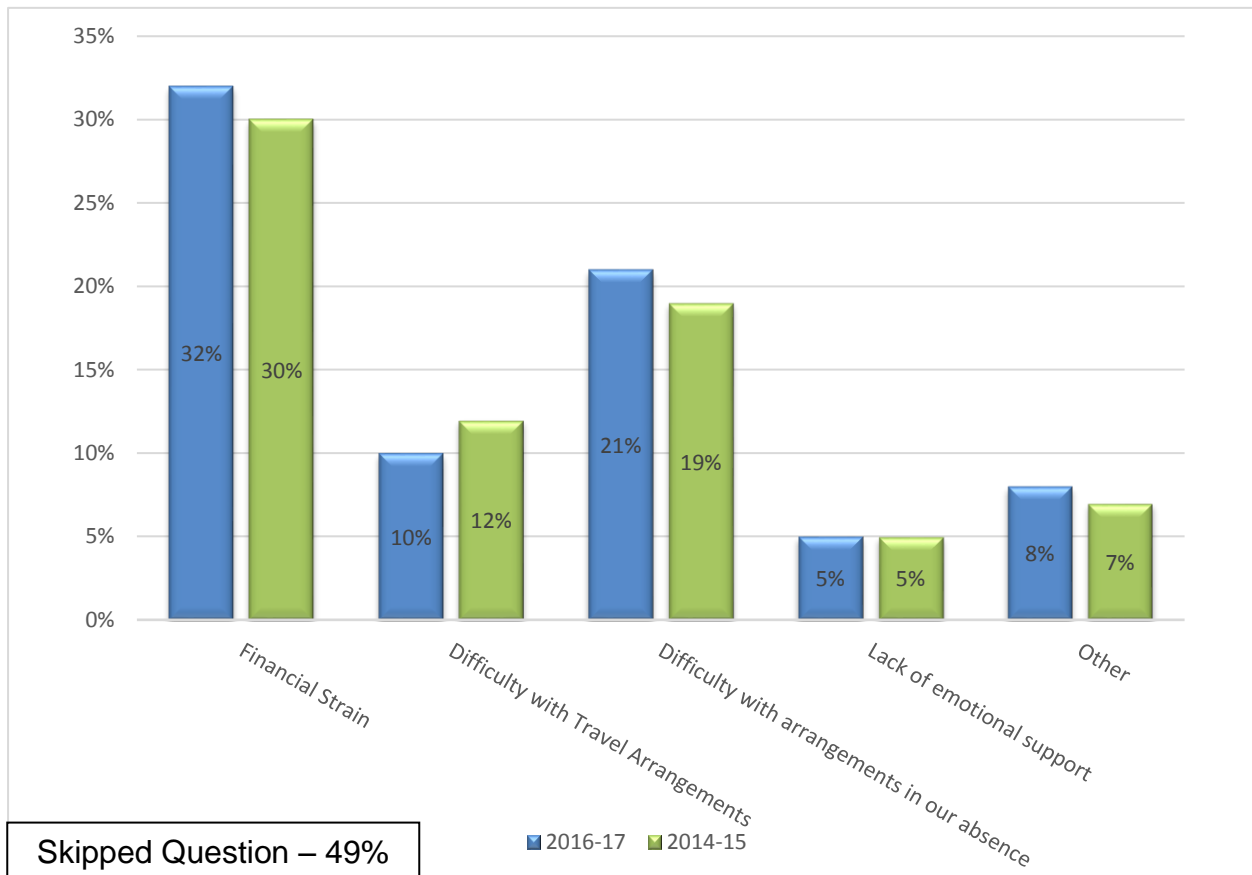
6. Was this your child's first cardiac procedure?



If your answer was no: How many previous cardiac procedures has your child had?

	2016-17	2014-15
Heart Catheterizations	37	61
Surgeries	49	96
Electrophysiology Procedures (ie. Pacemakers & Internal Defibrillators)	8	15

7. Did you experience any of the following when your child had his/her cardiac procedure? (please check all that apply)



“Other” responses:

- fear for my child’s life
- emotional challenges, re: not being able to plan
- work arrangements, relocation stress
- My grandmother passed away hours before his surgery.
- The Social Worker said they would get a note from the Doctors that my work required. When I followed up because I never received one, another Social Worker said we don’t do that. Ridiculous service from Social Work as that was the only thing the first Social Worker offered to do.
- being her caregiver (uncle), she was in need of her mom
- Always very stressful – not sure that can be avoided.
- my child’s final exam times

Comments:

- The first visit was unexpected. My son was born very ill. We never knew what to expect; things changed a lot. Some Doctors were a little pushy and made me feel uncomfortable.
- So very thankful for the Ronald McDonald House once we got in.
- We accessed funds from Kinsmen, plus two private fundraisers were arranged for us. We did not see anyone from the medical team between January 9, 2017, when it was decided our son needed open heart surgery and March 22, 2017, the day of his PAC. We did call when we had questions, but no one spoke to us about the risks of surgery until we saw the Surgeon an hour before surgery. We knew the risk were low, but not receiving any more detailed facts felt dismissive. We chose not to go on the internet as we trusted our care team and did not want horror stories. Secretly, we lived with the fear of losing our son in surgery but publically we could not express this because he "only" had an ASD - the most "straight-forward and uncomplicated procedure they perform".
- The biggest challenge for us was around timing. We were first told it would likely happen (once we were on the list) in a month or two. We expected late November/early December. As time got closer, I finally phoned to find out it may not happen until the New Year. I had been telling everyone that our family/at home supports (my parents) were leaving in the New Year for their vacation home. It was extremely stressful not knowing the timing and trying to plan. We did end up getting in late December, but it was very stressful. We had (unexpectedly) to have a cath procedure too that was almost another delay but they squeezed us in. The uncertainty of dates and timing was really stressful.
- The staff at the Stollery are truly amazing and made this difficult time calm and reassuring.
- We lived in Vancouver before our daughter was born only to find out surgery would likely have to take place in Edmonton after she's born, but no definitive plans were given. The Surgeon in Vancouver was planning a holiday around the time our daughter was expected to have surgery. After she was born, she was transferred to Edmonton (we got ~12 hours' notice) when she was 2 days old. We had to arrange travel to Edmonton (I went with my newborn daughter) for my other daughter, husband, my parents, and father-in-law (grandparents were there for support from Saskatchewan).

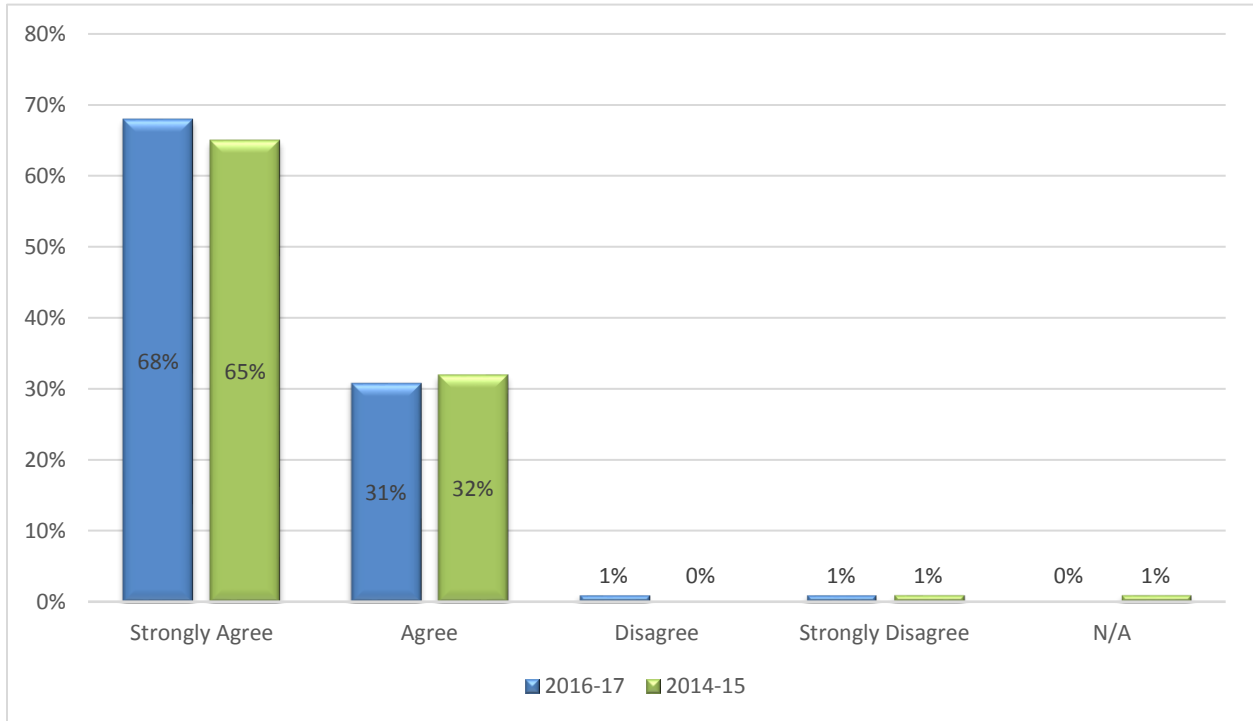
- We would have had financial strain if Telemiracle had not approved us for our grant. Family let us stay at their place while in Edmonton.
- We were unable to get into Ronald McDonald House (RMH) but were able to stay in two different hotels prior to the surgery and with a friend who lives close to the Stollery after his surgery. Hotel bookings were difficult because Edmonton was very busy at the time, but RMH helped us with the bookings, which was great!
- The parking for appointments, procedures, and hospital stays always present a financial strain; not going/being there isn't an option for us.
- Because we are foster parents, we were able to have all the financial pieces taken care of, which was instrumental in reducing our stress.
- Members of the PCICU became family.
- I have two other small children that needed to be looked after, and it was very difficult to find someone to watch the small children while we were away at the time of surgery.
- While the initial surgery date was cancelled, our son had bumped someone for his first surgery, so we can appreciate that the hospital has the needs of its patients as its highest priority.
- All staff were actually amazing. We were informed of basically every move before it was done. Recovery time was amazing.
- Difficulty upon our return. My son still needs lot of extra care and attention, so balancing him and his twin sister and his other brother is very difficult.
- I felt that the staff assumed I was prepared and aware of my son's situation ahead of time and I wasn't. I imagine most people are, but we were not. I had not researched his condition, I barely began to process it. I did not have baby blankets and sleepers with me, though I felt this was expected of me. On top of all this, I was dealing with the stress that comes with recovering from childbirth and being away from my other children for a period of time. I would appreciate if the staff didn't assume that we knew about the needed surgery ahead of time, and would provide comfort to people, like me, who come in in almost a state of shock and unprepared.
- Basically, every time she was in pain, she cried out for her mommy. It was very heartbreaking to experience such a thing.

- The staff at the Stollery are amazing. Both Doctors and Nurses took extremely good care of us.
- Although we did not experience financial strain, it was only because our family provided a gift of \$5,000 and my coworkers provided \$400. We did not qualify for any of the support programs due to our higher income, except for the Ronald McDonald House. We didn't stay at RMH in Edmonton but we did book through their affiliate hotel. Without the financial gifts we received, we would have taken the entire costs of travel and accommodations as debt.
- Everything before and after the procedures was going smooth as we were informed of his situations every step of the way. Also, the team from the hospital was extremely supportive, both physically and emotionally, for all family members. We were well prepared for what was coming.
- All the procedures that have been done to my baby were all good. The whole team is awesome. I pray that there will be more of them so that there will be more kids they can help. Thank you.
- Of course I experienced all sorts of stress and strain, however, most, if not quite all of the various people I met, from Surgeons to Volunteers, were awesome and did everything they could to help us.
- We were very fortunate not to encounter any of the above. Through Victoria General Hospital and the Cardiac centre at BC Children's, we were fully covered.
- Our experience with all pre- and post-op care was way beyond our expectations. All the Doctors and Nurses were gentle and caring with our daughter and informative and sensitive to us as parents. Thank you for turning this difficult experience into a positive and happy time.
- Our son had a complete AVSD and MDS (T21) that was missed by all Medical Professional until December 8, 2016. We travelled to Vancouver for a consult that led to surgery on December 14th. Our son spent 12 days in PICU, and another 10 in CHU. He missed Christmas, New Years, and we arrived home on his first birthday!
- We were treated with the utmost care and sensitivity by the entire surgical team. Our pre-op was smooth, quick, and as painless as possible, which was nice because we had to get home to prepare for surgery the following day.

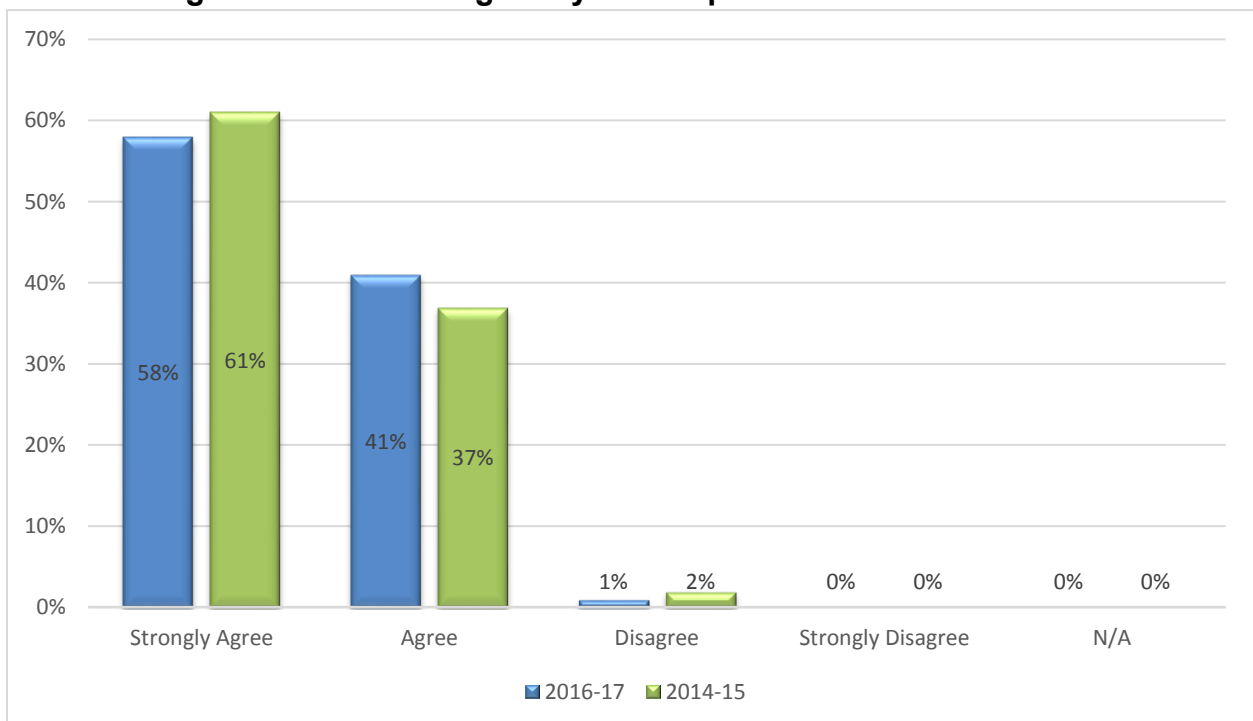
- The hospital staff were fantastic. The financial strain was due to our quick appointment, leaving us minimal time to put money for our stay/travel together.
- I did have staff ask if we were planning on taking EI benefits. The strain was not in those regards but that parking is expensive at the hospital. I found out later through friends that there is free parking in limited spots around outer areas. It would have been nice to know simple things like that or even not to pay on the day of surgery.

Before Your Child's Procedure

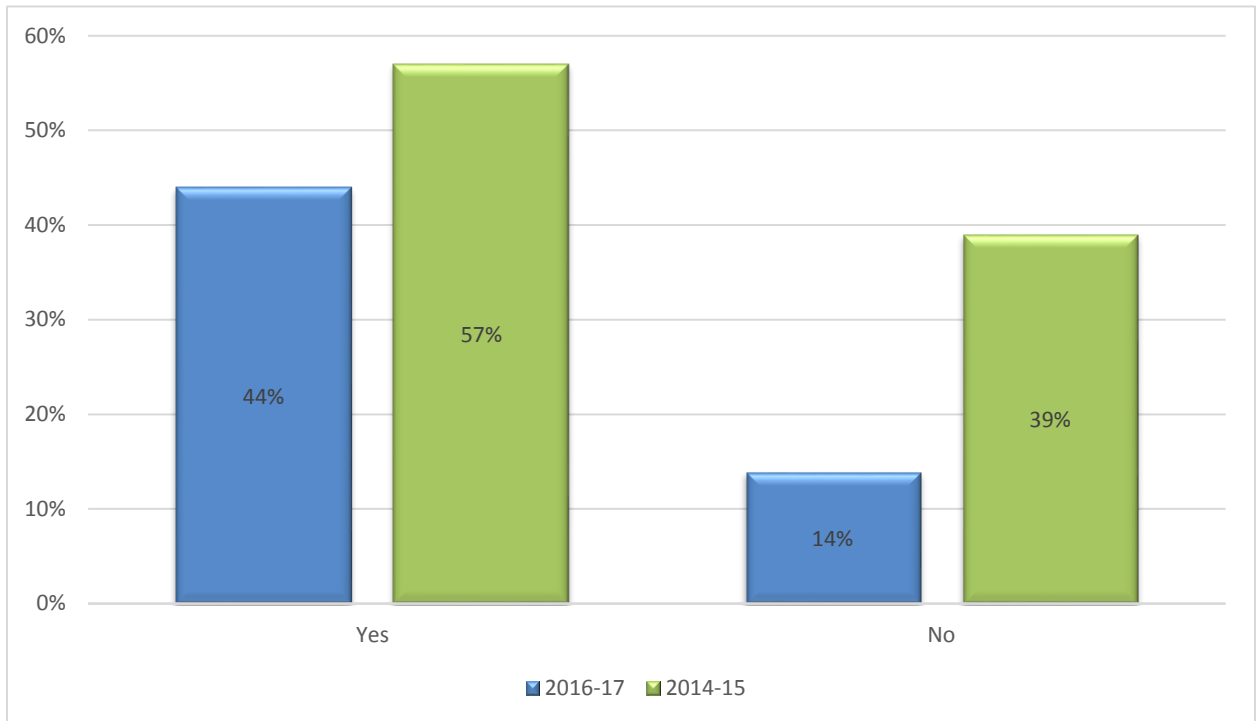
8. I felt I had a good understanding of my child's heart condition before the procedure.



9. I had a good understanding of my child's procedure.

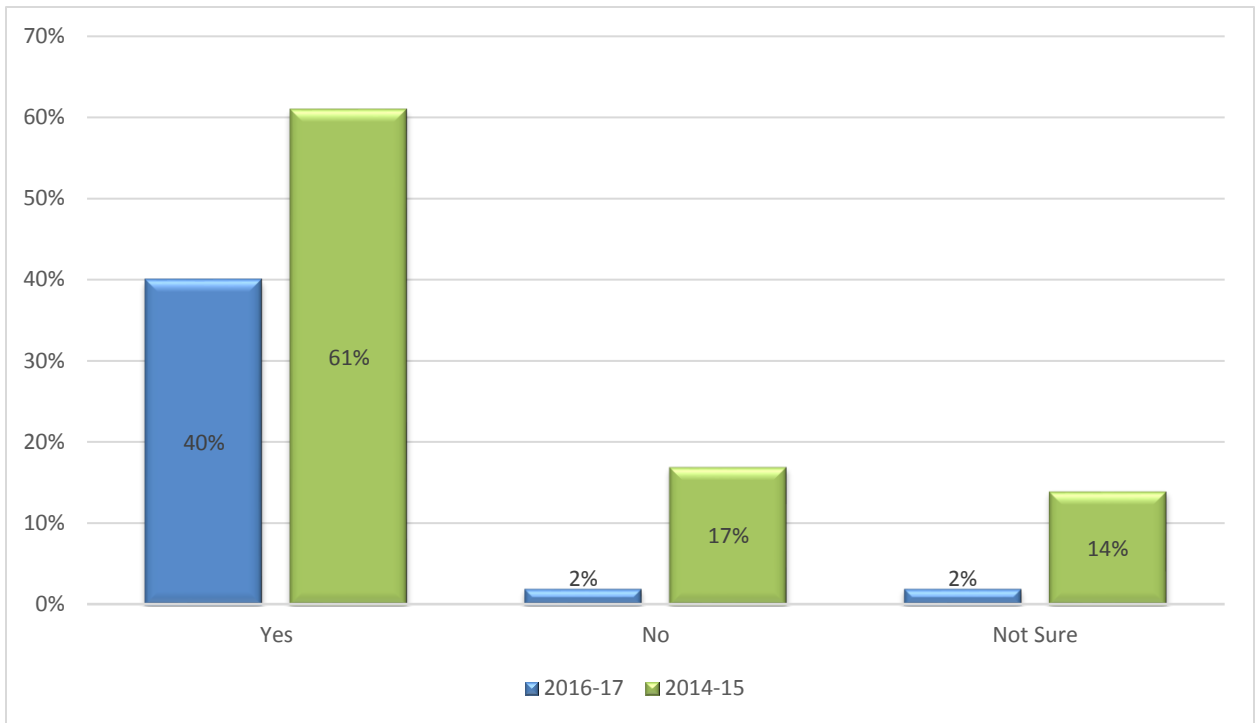


10. Before you were booked for your procedure, did you know that a videoconference about your child's case took place between your centre and the one you were going to?



Skipped Question – 42%

Did someone speak with you following the videoconference to discuss the plan of treatment determined for your child?

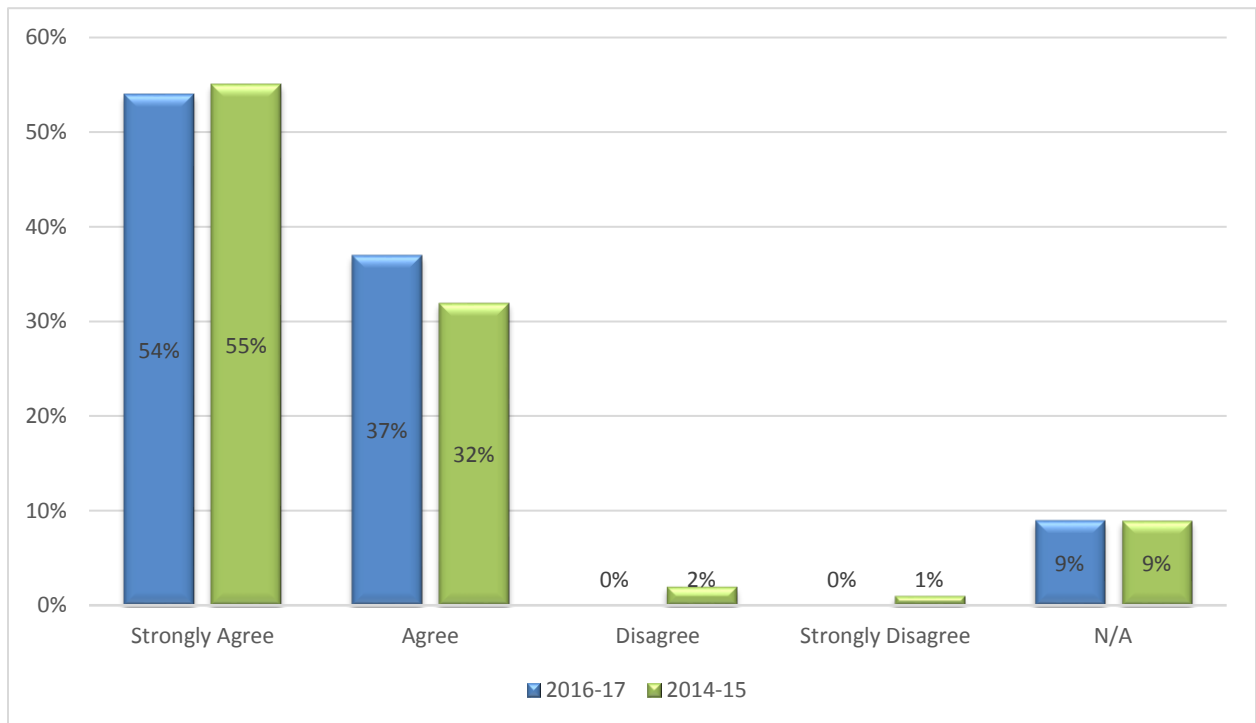


Skipped Question – 73%

If yes, who spoke to you?

	2016-17	2014-15
My child’s cardiologist	43	120
One of the clinic Nurses	11	46
One of the Surgeons	9	6
Other:	-	-
Multidisciplinary video conference	-	2
Other Physician/Cardiologist	-	5
Pediatrician	-	2
Preadmission Head Nurse	1	-
Social Worker	-	1

11. I felt that my child was prepared appropriately for his/her age.



12. What could have been done better to prepare your child for his/her procedure?

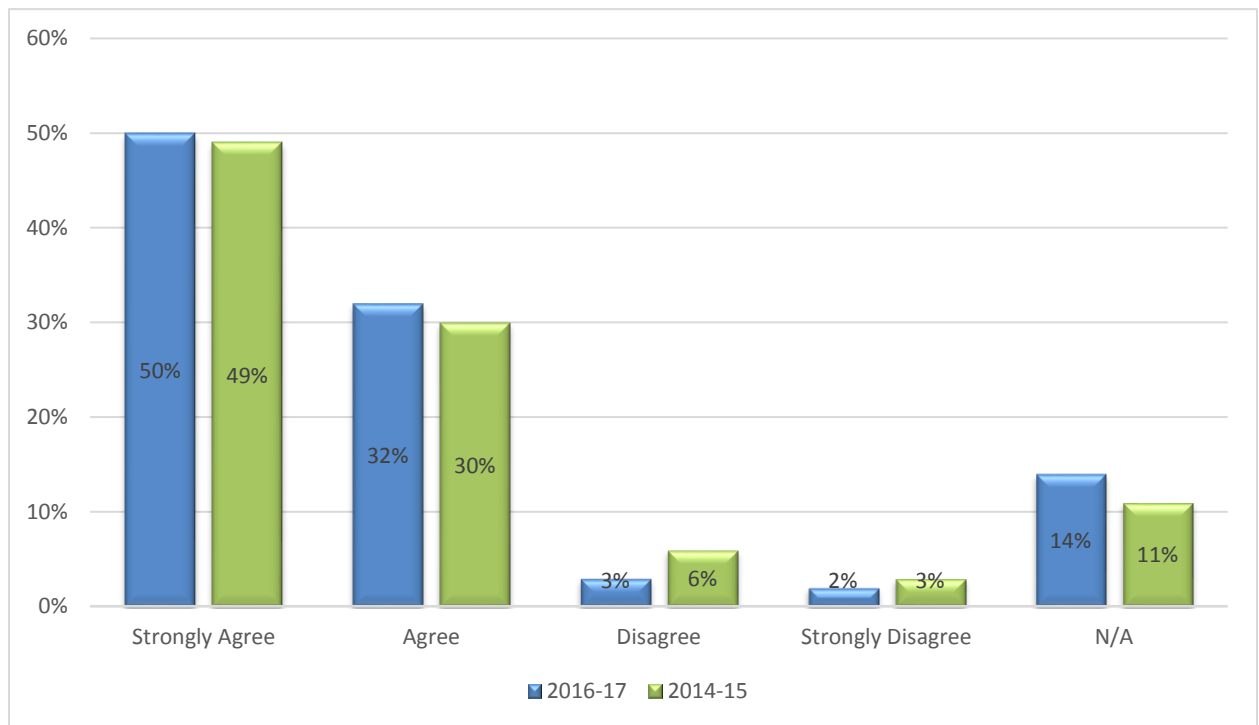
- I believe everything was done accordingly for my child to be prepared. He was five months old.
- The only thing I was not prepared for is having to do a cath procedure before surgery. No one told us this might be a possibility, so it was a big surprise when we went to Pre-Admission Clinic and they called to say we needed the cath. It would have been nice to know that was a possibility.
- The instructions we had were very straight forward and the Pre-Admission Clinic provided us with everything (handout information, sterile wash, formula, and sugar water/Pedialyte).
- Taking care that she doesn't get a cold and eat new stuff so she doesn't get sick or intoxicate for the different flavours. Give her a regular amount of formula every three hours except the breakfast and dinner with soup strong with vitamins.
- Nothing. He was two weeks at first surgery and five months old at his second surgery.

- My son is traumatized to this day, maybe a chance to visit before surgery.
- He was only five months old so he had no idea what was happening. He enjoyed wearing his surgical gown!
- We felt well prepared before our daughter's surgery. We met with our daughter's Cardiologist in Calgary a few weeks before and she along with the Nurse in the Cardiology Clinic were very helpful in answering any last minute questions and concerns we had. The Nurse had recently had a child who had surgery at the Stollery and was able to give us great information from a parent's perspective.
- Maybe more heart support for the ambulance ride from Prince Albert to Saskatoon or from Saskatoon to the airport.
- I don't feel that anything else could have been done.
- Instruct Nurses to be prepared when a child is intubated with no sedation that BP will rise and child will wake up. This would prevent parents from holding him down which was traumatic for my wife. This happened twice until I said you are pulling the tube or else sedating him properly.
- Child Life Specialist was amazing.
- We didn't inform our child (he was four years old at the time of the procedure) about the surgery until after the procedure. I tried to explain to him but when I was started telling him about the surgery, he asked me immediately if he is going to die? He said, Mommy, I do not want to die, then I stopped telling him about it and switched the topic to something else. He was very brave and very cooperative about the procedure.
- Making sure she/he is ready for it. Weight, healthy and good conditions to do it.
- Nothing. He was too young to understand.
- Nothing, at this age, four years old is hard to explain things to.
- Nothing more than was done.
- I think it went as smooth as possible.
- Nothing. He was an infant.
- Nothing.

- Our son was initially prepared for a heart cath, but was pushed out of OR because the diagnosis was corrected by the Surgeon at the time of ultrasound. Then he was prepped for surgical repair instead. We were hoping to have known his condition more precisely to be more emotionally prepared, but everything turned out to be better for him in the long run. Thankful for the team.
- The Nurse gave the cream inside the nostril, because they said the nose must be clean before the surgery. Also, there was something needed to put for the heart area, to make sure it was clean before surgery.
- Everything possible was done. I was somewhat in denial.
- We were lucky to have some time with the Child Life Specialists - their play and explanations were invaluable.
- I don't know what could have been done to prepare a six-month-old child.
- It was all very sudden.
- I think it would have been nice if she was already sleeping when they took her from me. She was fussing and that made it harder for me. They had given her some sedative already but she was fighting it.
- Everything the hospital did was perfect.
- More time for notice of travel and surgery. We had a days' notice (less than a day's notice to leave ON to BC). Prep time was chaotic.
- Updated pictures or a cartoon video about the surgery. (We have been taking pictures and will give them to the Nurses so they can use them if they want).
- The week before surgery we met with Nurse/staff who spent a lot of time with us. Their care and compassion were very supportive. For our own reasons, we did not join the family network prior so my son didn't have any conversations with kids to alleviate fears. I think having short video clips of teens who have gone there would be helpful. Some kids will initiate conversations and some are just too fearful.
- At an early age, I started to explain the condition of her heart and I know she understands. One good thing also is how the Nurse, Doctor (Cardiologist) and Child Life Specialist explained clearly the procedure before surgery without fear.

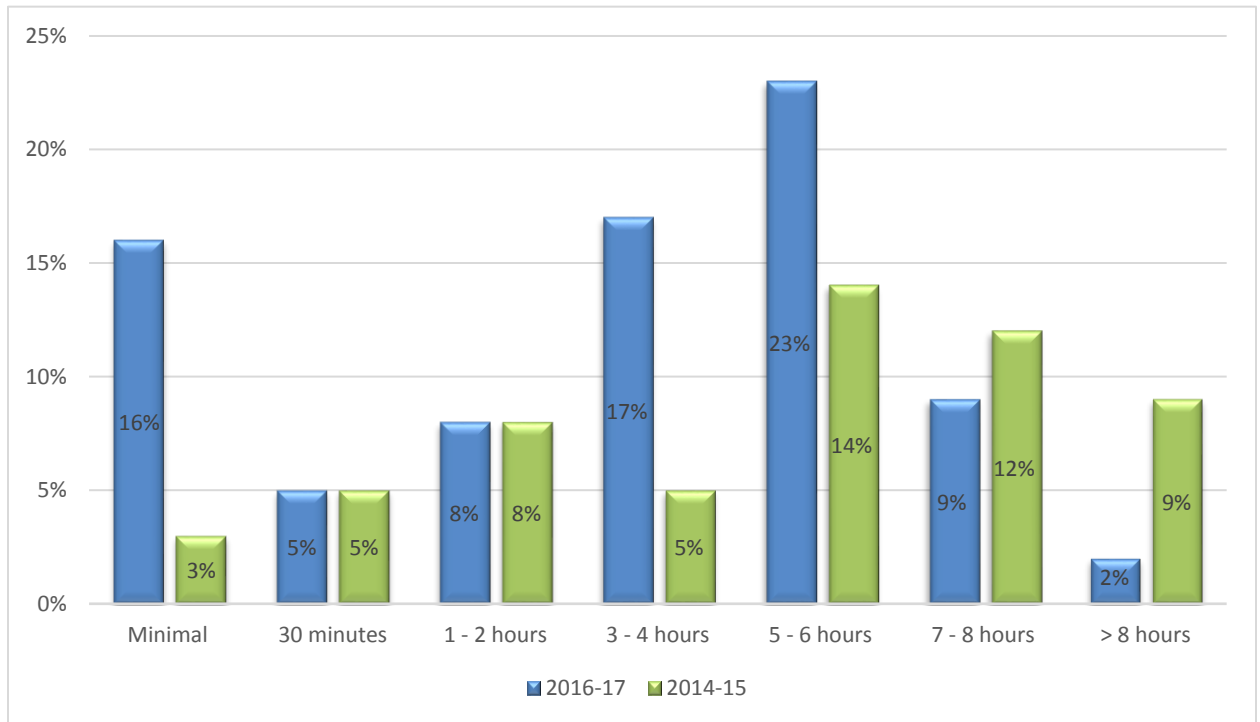
- They fully prepared my son for the procedure.
- We got advice in advance from a friend who is a Child Life Specialist and found that very helpful. If not for our friend, it would have been great to have a CLS from the hospital talk to us.
- Still a baby. Most of the explaining was done to his older sibling.

13.I received useful information (by phone and/or by mail) from the surgical centre before my child's procedure.



14. If your child had an appointment in the pre-operative clinic prior to his/her procedure, please comment on the following:

How long was your wait/stay in the pre-operative clinic?



Skipped Question – 20%

Please comment on the pre-operative clinic environment:

- Nice and quiet - calm. Great Nurses.
- I'm really thankful for all the Nurses, for their work, for being so kind.
- It was a child-friendly clinic. All of the staff were approachable. They always asked if we need something or we had any questions.
- Everyone was very friendly and informative. We didn't have a long wait in between people we had to meet with throughout the day.
- Long, but good.
- Great - everyone/staff were awesome. It was good to meet with Surgeon in advance on that day.
- Clean, quite noisy (every now and then).

- The Surgical Fellow came to see us in place of the Surgeon who was not there the day of our PAC. He wrote some notes, asked if we had any questions and left without any word of explanation or smile. It matters! We didn't ask him any of our questions as he was disinterested and as we mostly needed reassurance, he was not the right person to ask.
- These set of appointments were really helpful. It did seem overwhelming and didn't quite make sense until the day of the surgery. Thank you for everything.
- Staff were very friendly and worked quickly but efficiently to get us the info we needed so we were able to go home. We met the Surgeon, Physiotherapist, Social Worker, Anesthesiologist, and were able to tour the PCICU as well as the PICU.
- The tv/movies were a great distraction.
- I was pretty nervous about everything but was very happy everyone was so gentle and helpful.
- fine
- It was very nice, friendly, and understanding.
- The PICU at BC Children's Hospital and NICU at Stollery Hospital were both very supportive environments and we were kept well in the loop about our daughter's condition. Our daughter's case was unique as there was some uncertainty in how to proceed surgically (there was disagreement between specialists and Surgeons) which led to delay in her surgery until she became very ill and required PICU care at the Stollery prior to surgery,
- The staff were knowledgeable and friendly. The staff did their best to get us through in a timely manner. It was really nice that we got to speak to the Doctors beforehand.
- Was as quick as anticipated, thankfully everyone we had to see was on schedule.
- Could have more activities and toys for the children.
- The Nurses in the Pre-op Clinic were very kind, helpful, and willing to answer any questions we had.
- The Pre-op Clinic was clean, quiet, and well organized. Comfortable.
- Very good staff. Hard to arrange other disciplines to come meet with us.

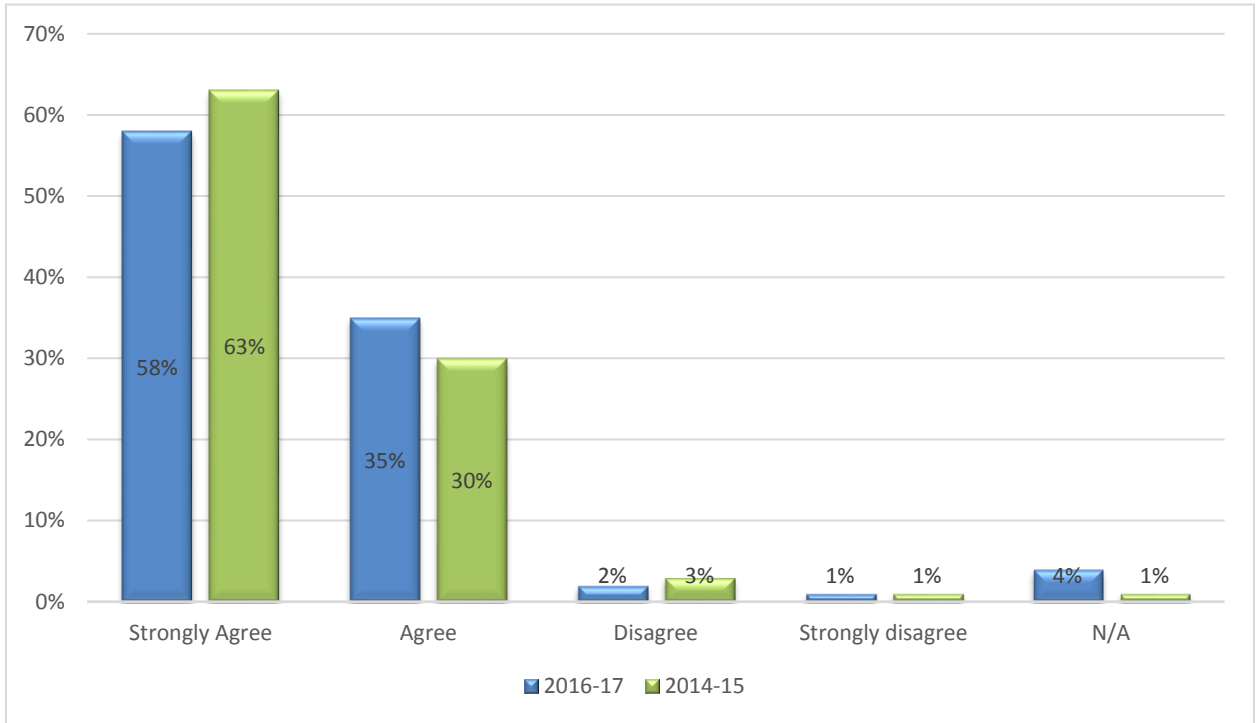
- Very long day for a three-year-old.
- I think it really helped my son understand the procedure better.
- One of the Specialists was obviously sick with a cold and was not covering or washing his hands. The Cardiology team post-op was wondering if she caught something prior to surgery that caused complications and I had to stay home shortly after because of being sick. Proper hygiene is expected from the Doctors!
- The staff were wonderful. Our Nurse. She had an amazing bedside manner.
- Lots of waiting between procedures (CT, X-ray) and Doctors (Surgeon visits) but was all handled well by staff. Friendly.
- It was very good, all the people involved in the procedure went and had a talk with us including the Surgeon.
- They do an amazing job with the kids and the parents.
- Wonderful! They explained everything that was going to happen. Made sure we were emotionally supported when needed and also gave us breaks so that our son wasn't going stir crazy.
- Would have been nice to have things arranged better. I asked to have ECG done while we waited for the Cardiologist to look at Echo to ensure a thorough assessment was done. We ended up waiting 1.5-2 hours for the Echo.
- Everyone was very friendly and explained everything she was going to have done and what would be next and why they were doing it.
- Pre-operative Clinic is good. Too many different cases, many different kids. Very friendly staff. Excellent services.
- It was busy. We were never left for very long when a Nurse/test was ready for him.
- Too much wait time, especially since the child is a baby and couldn't eat.
- It was a very long day for such a young age.
- Very clean/friendly.

- Ok. Nurses were experienced when not to change a baby or when to take BP to keep baby happy.
- Good, informative, and efficient.
- The clinic was clean and very well organized. The Clinic Nurse was very helpful and tried to make the appointment run as smoothly and efficiently as possible when dealing with so many disciplines.
- Excellent. They got us in quickly and explained the procedure appropriately.
- It was pleasant. The Nurses were very nice, they went above and beyond to make my girl comfortable.
- The Pre-op Clinic Staff were not aware of his sedated Echo time that was given to me by the clinic but once I told them of it they confirmed it and there were no problems. Otherwise, everyone was very knowledgeable and helpful.
- During the Echo, they couldn't get the pictures they needed. Then we had to wait an hour and a half for a Cardiologist to review the images. It would have been nice if we could have continued with the rest of the required tests (i.e. EKG, blood work, etc.) and come back up to the Echo if required.
- I was frustrated that he required another poke for his blood tests because they did not cross check his name.
- Our daughter went straight from an outpatient Echo to the ICU for pre-op.
- We were surprised that the clinic was well prepared as we adults received detailed information regarding all the steps of our son's operation. They understood it was very hard for adults to hear it all, but their positive and professional attitudes have been the calm factors which made us well informed and well-prepared at the end of the clinic.
- It was a good place. All the things that I expect to be there was there.
- We didn't have this in Toronto, only Vancouver.
- Coming from out of town, it is good to have the Pre-op clinic in one day. It is also appreciated that there is a day between the Pre-op clinic and the surgery day with nothing booked.
- Kind, knowledgeable Pre-op Nurses. Very supportive.

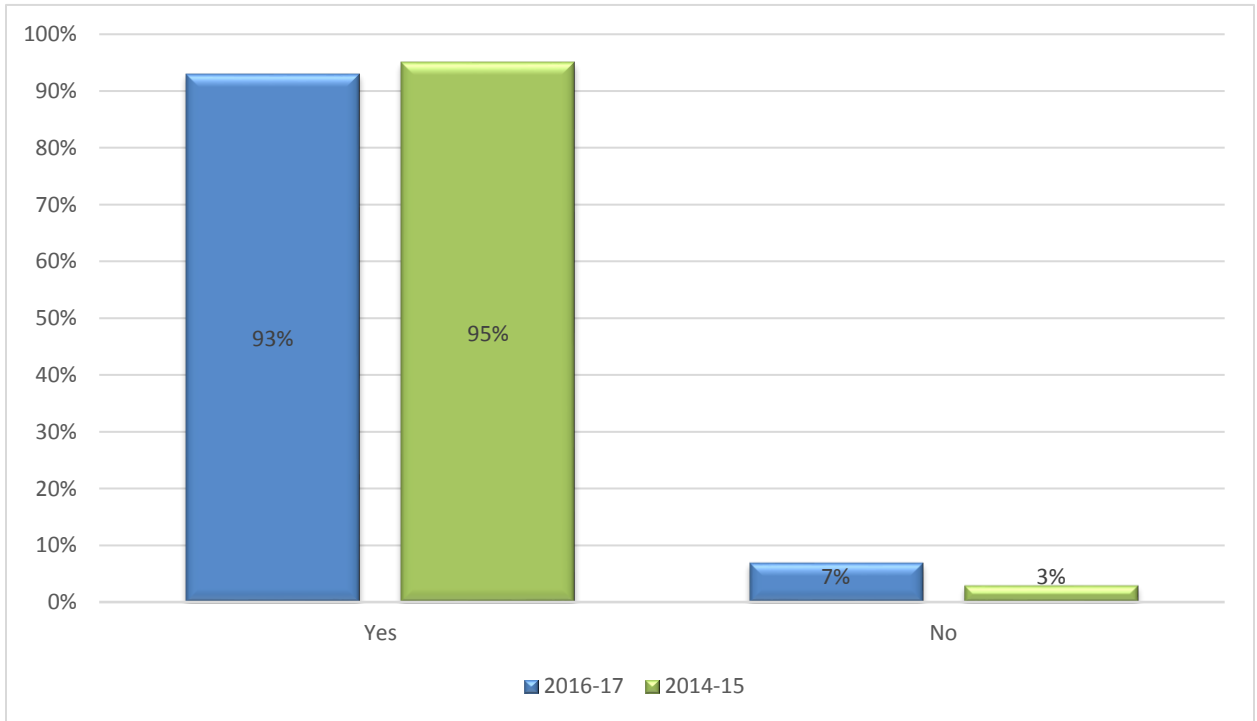
- There was no problem with the Pre-op clinic. Everybody was assisting us with the Pre-op. However, there had been a delay in the registration unit of the BC Children's Hospital before they had issued the card containing our information. Apparently, they have not been updated that Pre-op was advanced one day from the original date.
- The Preoperative environment was hectic but everyone seemed to know what they were doing. It was a long day of different tests but someone was always updating us if we were waiting and all were very caring.
- Great. The toys were helpful (the ones they had there). Staff were very friendly and checked up to make sure we were doing ok.
- We had a constant team of Specialists coming in to introduce themselves and explain their role in the operation, we appreciated this. The clinic was clean and nice to have privacy with the curtains. Our daughter was comforted by the Child Life Specialist.
- friendly and prompt
- Amazing staff - they made the worst time in our lives bearable.
- We felt very comfortable. The staff were very friendly.
- fairly quiet and organized
- Everyone was so helpful and informative.
- well scheduled
- didn't go to it
- Very fast. Lots of information to process but very thorough. Great staff/team.
- The Nurses were amazing. Super friendly, knowledgeable, accommodating, and professional and they always had a smile. They were just amazing.
- good, friendly, informative
- Hectic. We are from out of town & all the tests were crammed into one day (X-ray, Echo, two Ultrasounds & CT-scan) which left very little time in the clinic. Most stuff was just rushed over. We didn't get any of the planned tours etc. to make the next day less confusing. Would have rather spent another night in town & spread it over two days.

- They are compassionate, caring, in tune, and did a great job. They thoroughly go through everything to address any questions. Although we didn't feel the need for the heart network before, we certainly felt a need to connect with someone going through the similar experience and I believe a video would be helpful because it meets us at our needs. At this point, we don't need long standing relationships but it would have been helpful to hear of similar surgery experiences.
- It was a scheduled day - well organized.
- nice and good
- They were very cooperative.
- It took a while for the Pre-op because they explained it well and made us fully aware of things that were going to be happening during the surgery. We were scared and so was my son of course, but they made us feel strong and positive. I really salute the services they had, particularly the Nurse.
- was a busy place
- not much privacy

15. I knew where I could stay during my child's hospital stay.



16. I knew who to contact if I had questions.



17. Did you use any of the following information sources before your child's procedure?

			Very Helpful	Helpful	Somewhat Helpful	Not Helpful	N/A	Skipped
Combined Data	Cardiology Nurse	2016-17	63%	16%	4%	1%	9%	6%
		2014-15	69%	14%	3%	1%	7%	6%
	Social Worker	2016-17	46%	15%	4%	2%	27%	6%
		2014-15	37%	20%	11%	3%	18%	11%
	Cardiologist	2016-17	74%	14%	3%	2%	3%	4%
		2014-15	75%	15%	2%	1%	2%	5%
	Other Families	2016-17	20%	11%	12%	0%	45%	15%
		2014-15	16%	19%	7%	2%	36%	20%
	Local Family Support Group	2016-17	9%	4%	9%	0%	57%	15%
		2014-15	8%	7%	4%	1%	58%	22%
	Child Life Specialist	2016-17	17%	10%	4%	4%	51%	4%
		2014-15	14%	8%	5%	3%	50%	21%
	Website Resources / Internet	2016-17	27%	18%	13%	1%	30%	3%
		2014-15	21%	20%	13%	2%	22%	22%

If you were using the internet, please list most helpful websites you looked at:

	2016-17	2014-2015
Alberta Children's Hospital	-	1
Alberta Health Services	3	1
American Heart Association	2	-
Annals of Thoracic Surgery	-	1
Baby Centre	-	2
BC Children's Hospital	2	5
Boston Children's Hospital	-	5
British Heart Foundation	1	-
Canadian Down Syndrome Society	-	1
Canadian Marfan Association	-	1
Can't Recall	-	5
Centers for Disease Control & Prevention	2	-
Children's Heart Clinic	1	-
Children's Heart Network (Vancouver)	2	-
Cincinnati Children's Hospital	4	3
Circle of Hearts	-	1
Cover Point Foundation	1	-
Edmonton Down Syndrome Society	-	1
Facebook Support Groups	3	6
Google / Various Websites	7	24
Heart Beats (Calgary)	1	2
HeartPedia (App)	1	-
Heart & Stroke	1	-
Heart.org	1	-
JACC – American College of Cardiology	1	-
John Hopskin's	1	-
Kids Health	2	-
Mayo Clinic	3	8
Medical Journals	-	5

	2016-17	2014-2015
Medicine Net	1	-
Mended Little Hearts	-	1
Parent Blogs	2	2
Pediatric Cardiothoracic Surgery, University of California	1	-
Philadelphia Children's Hospital	2	-
Ronald McDonald House	-	3
Royal Children's Hospital Melbourne	1	-
Stanford Hospital	2	1
Stollery Children's Hospital	1	2
Surgery Encyclopedia	1	-
The Ups and Downs Society (Calgary)	-	1
University of California	1	-
WCCHN	1	1
WebMD	3	1
Website that the Doctor gave to us	-	1
Wikipedia	1	1
Williams Syndrome Association	-	1
YouTube	5	7

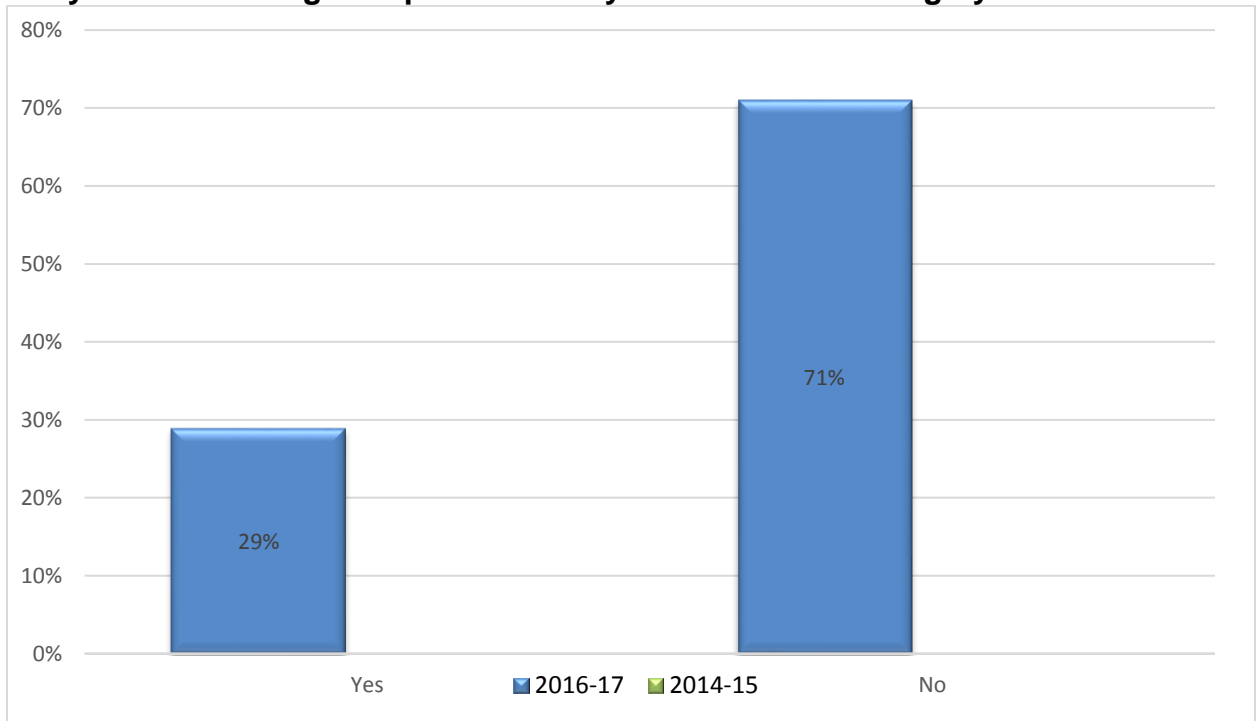
18. What other information would you have found helpful before you went for the cardiac procedure?

- I found out that a prayer to God was the most helpful thing that I could do before I went to the cardiac procedure.
- Just the Pre-Operation procedure mailed to us is a big help to prepare our child for the procedure itself.
- Not much more could be helpful. Everything is very straight forward.
- A handout with a brief explanation of the surgery and risks.
- The booklet we received was really great and useful. One thing I did is a blog of our journey in the hospital. I am keeping it up so, through the Edmonton Down Syndrome Society, they can share with other families. I think I would have enjoyed or benefited from reading about other families journeys before I went with our daughter.
- This was our son's second surgery so we knew what to expect.
- Information about how to deal with your child post-surgery, about the first day/night at home, some items we should have had at home (like shower seat, propping up the head of the bed, etc.).
- We thought the surgery was going to be the hardest part but it was our stay in the PCICU. It's just a very intense environment with some critical children. We weren't prepared to see our baby hooked up to a million lines and machines and to be so sedated. When we toured the PCICU we just stood in the doorway as it was busy and very small with so many staff, beds, and patients, so we weren't able to get the full picture of where we would spend five long days.
- Speaking to a parent that went through the same thing with their baby.
- Success rates between hospitals for Norwood Procedure and Aortic Repair. At one point, our Vancouver Surgeon was back from holidays, and offered for us to transfer back from Edmonton and we had to decide between Vancouver and Edmonton for surgery. We chose to stay in Edmonton to avoid further delay. It would have also been nice to be informed of potential infections in the OR by Mycobacterium due to OR machinery - we heard about this in the news several weeks later.
- We were well informed about the procedure.

- I don't believe much was missed.
- I was so overwhelmed I had no idea where I needed to go. More signage. A map in the package.
- We felt very well informed going into his cardiac procedure. Everything went as expected.
- I feel we were well-informed about the reasons for the procedure and what was to follow.
- pictures
- For Social Work to know if they can get a note from Doctors and do not say you are going to and then not have any more contact.
- A contact number for PICU to see when she was ready to be seen.
- None. We were well informed.
- Better communication skills from a Cardiologist. His communication skills are awful.
- risks involved in procedure
- My husband's explanation helped me understand the whole procedure as a Surgeon himself and now on Family Medicine. I rely on him more than any information available online.
- Nothing. Everything is on the internet. Too much is on the internet. Any additional questions or concerns we had we asked directly to our son's Cardiologist.
- Experience from other parents.
- As terrifying as it was to send my daughter in to surgery, I felt that everyone did a very good job in preparing and tell us what to expect. We didn't have any surprises.
- It was an unprepared emergency situation, so we feel we didn't need anymore information than we received.
- Surgery booklet & Heart & Soul booklet were very helpful. Websites tended to fill in the rest.

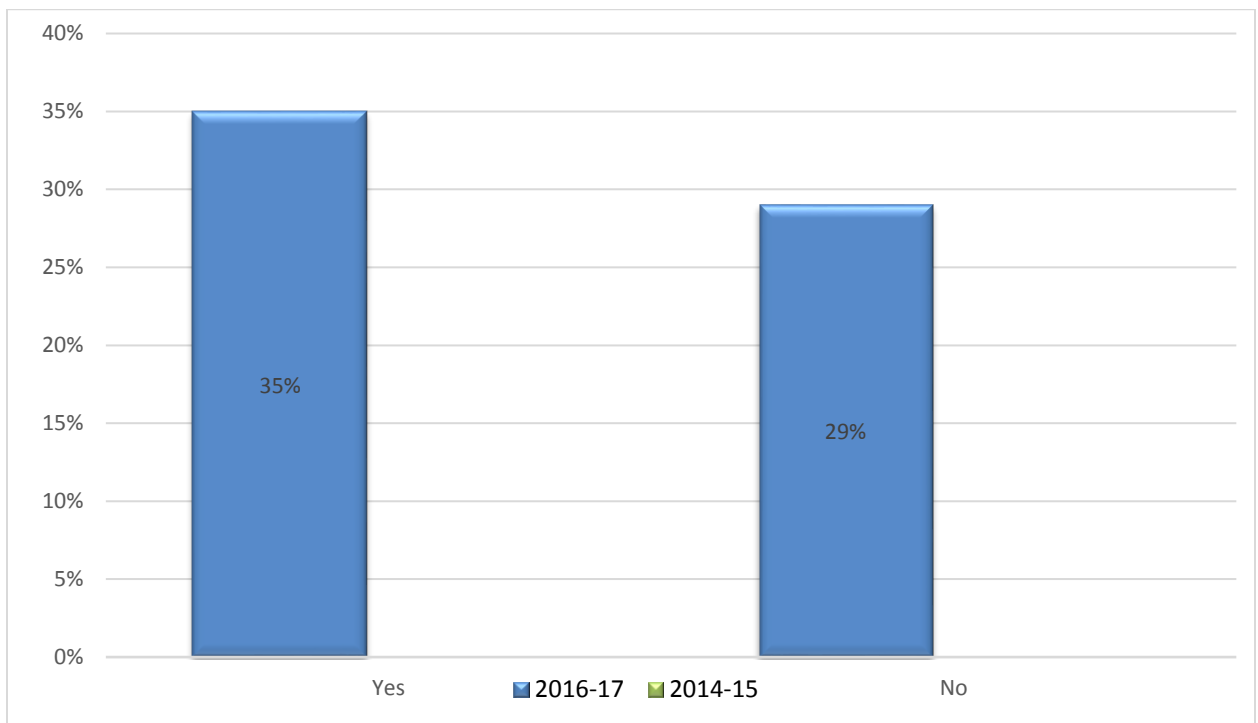
- The pictures of other babies with Trisomy-21 that had the same procedure as my son was extremely helpful and I would be willing to share pictures of my son for other parents to see. I was very prepared when I saw him in the PCICU and not overwhelmed by all the lines and tubes.
- Nothing we could ask for more since all the team members had provided every detail we should have received. We felt we were very well prepared by the hospital.
- I asked other people who have the same diagnosis as my baby who are already done with the surgery, that at this time, science has already evolved. Having cardiac surgery is not that scary to think about anymore.
- Nothing, I could only take in so much at a time.
- Cardiac Nurse and Surgeon provided all information that we needed.
- The results of the genetic testing - it was hard to be worrying about them in addition to the surgical procedure.
- None I can think of.
- N/A - this being caught during an ultrasound or by our GP.
- Everything supplied was very helpful, wouldn't change a thing.
- The fact that there was nowhere to really sleep while my baby was in ICU. I was told that the waiting room was not for sleeping by one person, but then encouraged to sleep there by another person.
- Speaking with other families in my community about heart surgery.
- I think they were excellent/great.
- The booklet given by Child Life Specialist/BC Children's Hospital that would tell me about the operation.
- people surrounding us (hospital staff)
- All was given by Nurse.
- More Child Life Specialist support before the procedure or a pamphlet covering issues of preparing our child in advance would be good. The Child Life Specialist support on the day of and after the procedure was very good.

19. Did you receive surgical updates while your child was in surgery?



**New question – no data from 2014-15 survey.*

Would you have liked to have received updates while your child was in surgery?



**New question – no data from 2014-15 survey.*

Other Comments:

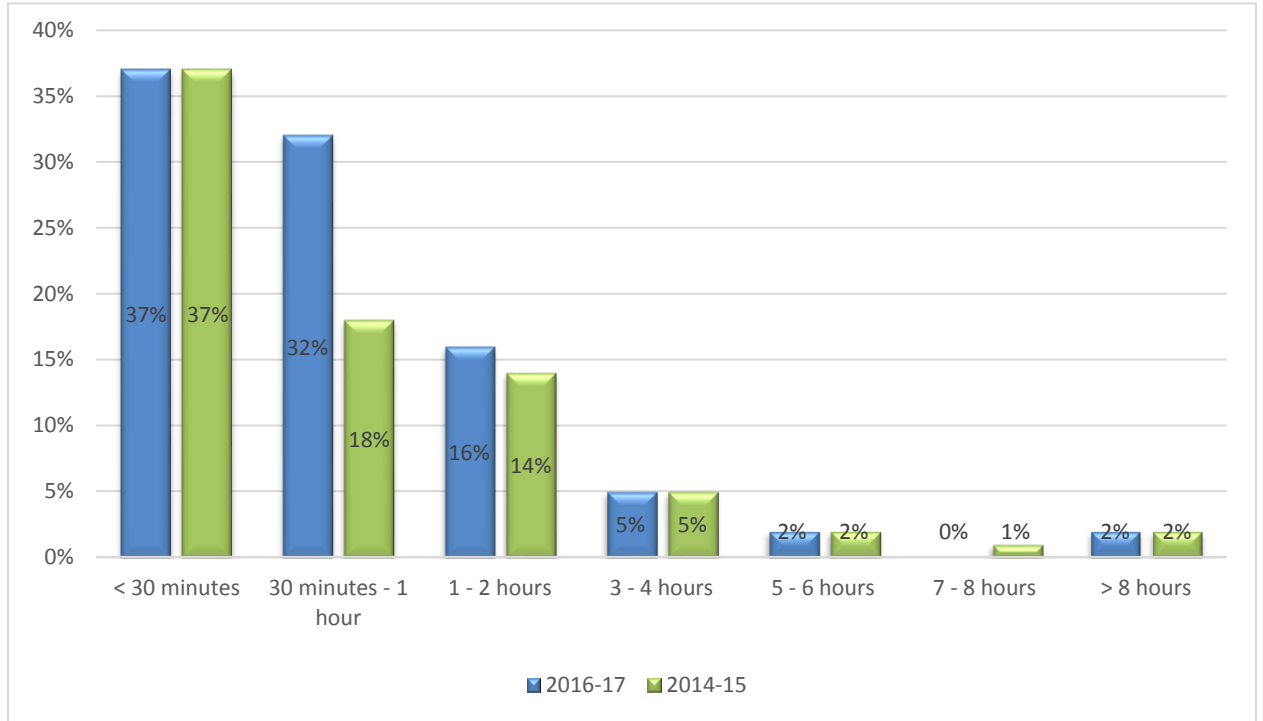
- Although the grandparents were at the hospital, the Surgeon gave updates to them. I thought updates were only supposed to go to parents. The Surgeon said it was supposed to take 4.5 hours, but it only took two hours. Since I was in another hospital recovering from a C-section and tired, we were going to arrive half way through. The surgery was finished before I even got there.
- This was managed very well. The Surgeon came out to update us right after he was done. We knew approximately how long it would be and when and where to be there for the update.
- Not too sure. I was just so thankful it was a success.
- The entire time your child is in surgery is so stressful, you can't relax until you hear from the Surgeon that he's out and everything went perfectly and he's doing great. A few updates may have eased our anxieties, or maybe made them worse.
- One or two updates would have been reassuring.
- Yes and no. He had some complications so in some ways not knowing was likely better or I would have fallen apart.
- We waited five hours during surgery and would have liked an update to reassure us she was doing ok during the procedure.
- His surgery went well, they didn't run into any problems so there was no need to give us updates. If something unexpected happened, then I would have wanted to know about it.
- The operation took several hours longer than expected. No updates made the waiting even more painful and stressful.
- I was happy to be able to accompany my toddler to the Pre-Operative area and then to wait in the waiting area (by the fish tank).
- The surgeon was unbelievable. He was excellent, made numerous contact throughout the stay.
- No one came to get us/contacted us after her surgery. We stayed in the unit room for one to two hours after she was already settled in PICU. Her Cardiologist finally noticed we were there and brought us in.

- Was wonderful to hear after surgery a thorough explanation of what all went on.
- I trust everyone inside the OR, and they know what they were doing. I do not want to bother them while my son was in a procedure.
- We were prepared for what to expect post-op by one of the NICU Nurses which was very helpful. It seems to just be based on which Nurses you get as I spoke to other parents who were less prepared for what their child would look like post-surgery.
- I said no to the updates in surgery, but if there was something that needed our attention, or if there were reasons for long delays I would want to know. But if everything was going as planned I wouldn't expect an update.
- I had faith in her Doctors. He told us he would come speak to us as soon as it was done and he did.
- Our Surgeon did come out to talk to us after the 3D Echo was complete to give us an update on his plan, but that was the only update until he came out to talk to us after surgery.
- I was so nervous I just waited the four hours walking around the hospital and back and forth to our hotel room.
- We met with the Surgeon right after he was done.
- At the time, when they had informed that we could check for updates, we had asked the Nurse to call the OR. We heard everything was going very well and even faster than we expected. We were very grateful they have provided us with that service.
- We waited for almost three hours for his surgery. If the Nurse can report to us every hour about his situation that will help us to worry less.
- Yes, updates would be nice if they don't interfere with my son's care.
- Staff would have given an update if we had asked, that was very clear. We would've liked an update but didn't know when to ask. Possibly more information on how timing works in OR. We saw the Surgeon after to get a report but it was so long after that report before we saw our daughter.
- Surgery went better than anticipated & was quicker than expected. We knew we could call for an update if we needed one.

- We did have to wait quite a while to see our son after he had his surgery. There were not enough Nurses on at the time so he did not go to the NICU right away like he was supposed to and had to stay in recovery. When they did move him to the NICU, we were not contacted right away due to forgetfulness, or that was what we were told. That was the only part I was not happy with because, by the time we got to our son, he was not sedated and was obviously scared with a whole bunch of strangers around him.
- I asked about counselling while our baby was in the ICU but there was none available. I would have found talking to a counsellor helpful. A Spiritual Counsellor was provided but that was not helpful as we do not follow a religion.
- We had to chase someone down to find out what happened and how he was doing. It was frustrating as we heard nothing from 0800h until 1700h.
- The internet in the BCCH is terrible. We are still paying off our cellphone bill.
- We were about to ask for an update but the surgery was already completed.
- It would be great to get updates as long as it doesn't disturb the Surgeon and Nurses (last priority).
- We were paged an hour before the Surgeon came in to see us. We thought something had gone wrong as we were told 10 - 20 minutes. That was a lot of unnecessary stress. I phoned the Nurse about 45 minutes after being paged and she got back to me 20 minutes later saying they were still in the OR. By that time, the Surgeon had already come to see us.
- The Nurse gave me the name of the surgery to be performed and although scary, it was informative for me, especially the necessity of it. Everything was prepared. The Nurses, Doctors, and Child Life Specialists explained everything very well to us and they are very patient and, most of all, sympathetic like a family. This is really how I felt when talking with the Nurse. We were emotionally prepared because of her, even after surgery. I am thankful for having her.
- Our experience has been nothing but positive!! Everyone was so helpful and pleasant to deal with!!

During Your Child's Hospital Stay

20. How long did your child wait in the pre-holding area before going into the operating room?



Skipped Question – 7%

21. Please comment on the surgical pre-holding environment:

- Helpful Nurses, calm, organized.
- The Nurse was friendly and prepped our son quickly and efficiently.
- It was good, but our Pre-op Nurse had no bedside manner. It was very unnerving before surgery.
- My child was pre admitted into hospital two days beforehand.
- private, pleasant
- No specific comments. We were hardly there. Was comfortable and was nice to have a separate room for the kids.
- clean
- Pre-holding Environment was good, a Nurse comes to chat and see how you are doing and if you need anything. Very friendly.
- Fine because I got to hold my little guy right until they put him under.
- It was very clean, bright, and quiet. We were the first case of the day. The Nurses were so comforting and tried to ease our anxieties. The Anesthesiologist came and explained what he would be administering and doing and asked if we wanted to come in until our child was put under. We spent 20 minutes in the Pre-Holding Area.
- Baby went straight from NICU.
- Staff were friendly. They brought me Kleenex when I was crying. Maybe a TV would have been distracting.
- very good thanks
- Not sure. We weren't in the Pre-Holding Environment. Perhaps that was because our son was in NICU.
- No issues. We had a private room to discuss our case with the Surgeon (they had a last minute opening so they put her in - we got one-hour notice of her surgery).
- Very calm and quiet.
- He was in NICU, they had taken our son off his meds and were waiting on the surgical team to come take him in.

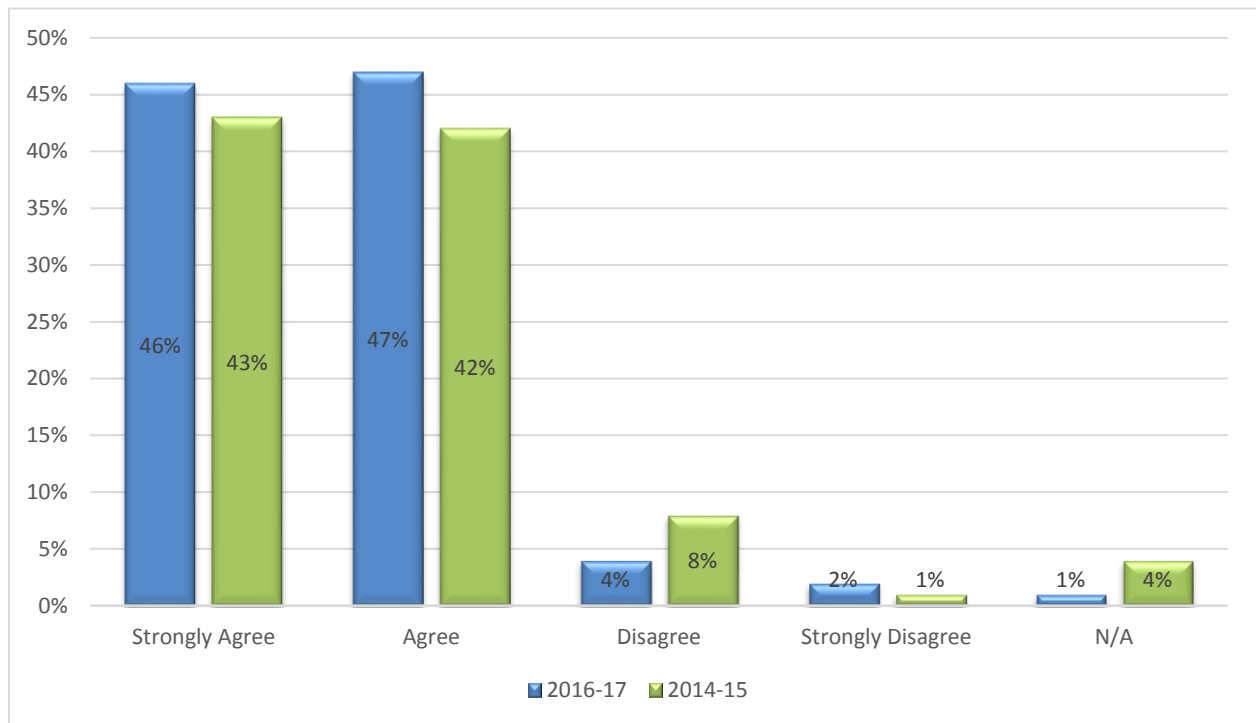
- great
- I don't remember much, just that I was really scared and the amount of time with him prior to surgery just didn't feel long enough. I was scared that I wouldn't ever hold him again. I got to hold and be wheeled up to the OR area with him and cuddle him prior to so I really appreciated that. I would have loved to take him into the Operating Room, but I understand why I couldn't but honestly it would have helped to see and to know the environment in there. If given the option to view the procedure from another room, I would have greatly appreciated that.
- Our son was put in the PCICU before his surgery. The staff were kind and answered all of our questions. They gave our son excellent care. Our son was scheduled to have a Balloon Dilation, but ended up needing surgery. Staff in the PCICU were reassuring and explained everything to us which helped settle our nerves while we waited for surgery.
- It was quiet, calm, and the staff there were considerate of my wishes (re: staying with my daughter or leaving before anesthetic).
- Waited for approximately seven hours until we found out surgery would happen. That was very hard on a child.
- Very good. Very relaxing for the circumstances.
- Good. We were nervous but the staff were amazing.
- Very quiet and private.
- Very helpful and accommodative.
- I think they do a great job keeping things calm and positive, especially in a stressful environment.
- It was calming and had toys to keep our son occupied.
- Staff were great. The Nurse was fantastic. We were the first case to Pre-Operative Holding area. Was quiet.
- Wonderful, everyone was warm and friendly.
- Hard and stressful time been in this zone for parents, but no complaints - good staff.

- It was busy. Very happy to see that we were not sitting most of the time. Everything seemed very organized and lots of information.
- Nice to have a little room for the family to wait in.
- clean, friendly
- Our baby left in a good mood in one of the Doctor's hands. However, I feel like he was upset when they started the procedure (like putting the mask on him), maybe if they kept doing things that would calm the baby down. I wish I could be around.
- calming
- He was comfortable in the NICU.
- It was quiet and accommodating to our family as we had a large group. They were very organized and well prepared to make a very stressful morning run smoothly.
- Great. They were quick and kind.
- It was so fast. Everything happened very quickly.
- We met with the Anesthetist, RN, and a Resident. Everyone was comforting and reassuring that they would take good care of my son.
- We were the first case and so Pre-Op Holding was empty. The staff that we met there were fantastic. They made us feel a little more at ease. We were also able to meet the Anesthetist here and discussed our (my) ability to come into the OR without our son to be with him while was put under.
- Our daughter was in NICU for a couple hours.
- Waiting was the hardest part during the whole hospital visit. I believe the members understood, so we felt the waiting time before OR was perfect as the family members were well prepared emotionally.
- It's a good place to stay, especially if you want to be in a private area.
- I am not sure how to improve the Pre-holding area. So many families in one space with children expressing their levels of stress and hunger. The children respond to seeing other children distressed and parents always feel pressured to ease their child but feel all eyes are on them.

- Standard hospital environment. Nurses who looked after us were very nice. We met the Anesthesiologist, Surgeon and Cardiac Nurses there.
- I was able to speak to the Nurses, Cardiologist and Anaesthetist prior to the procedure and they explained to me what will happen in the procedure and what to expect after. They answered my questions.
- The Pre-holding area was fine, we had to wait a lot longer due to short staffing.
- This was the only part of our 15 day stay we were upset with. We showed up on time and after we were taken in the Nurse asked why we were so early. Someone failed to tell us they moved our time back by almost two hours. Being in Pre-op was the beginning of a very stressful day, we didn't need to be there any longer than necessary. It's also very difficult to keep a one year old happy for hours when they have to stay in bed. That also meant that we could have fed him hours later than we did. Obviously, we were upset that he went hungry for so long and it wasn't necessary.
- There was another child crying hysterically which made it more difficult to let go of our baby. Other than that it was private and peaceful.
- We appreciated having a constant team of Specialists coming in to introduce themselves and explain their role in the operation. The clinic was clean and nice to have privacy with the curtains. Our daughter was comforted by the Child Life Specialist.
- It went well for us. Everyone was in a good mood.
- Hospital environment with friendly and caring staff.
- It was quiet and effective.
- Everybody was really nice and trying to make my child comfortable.
- Nurses were great.
- Very quiet and organized. Nurses and staff were very helpful.
- Well organized.
- It was good, private, and we had a Spiritual Care Worker come and talk to us and bring us to a private waiting area during her procedure, which was beyond helpful. She distracted us just enough from what was happening while remaining very sensitive to our frame of mind.

- Calming. Everyone was extremely friendly and helpful.
- Scary. Mickey Mouse window decals don't help... sorry.
- The Nurse was very knowledgeable. Interacted with our son, a Child Life Specialist brought to us. Overall, great experience leading up to the procedure.
- We were to be in isolation but the Nurses forgot. It wasn't critical as we were in the corner. Nurses were great and professional.
- efficient, friendly, well organized
- clean, friendly, helpful
- It was fine - friendly and calm environment.
- very cooperative
- We didn't wait so long. After weight, height, temp, and warming bed, he was asked to go to surgical room.
- Good overall. Everyone was calm & seemed competent.
- It was a long wait due to waiting for the OR to be ready. Pre-holding was not adequate for the length of time we were there. However, if we had gotten into surgery on time it would have been fine.
- Unsure the difference between Pre-holding and Pre-op.

22. Overall, your hospital experience was close to what you expected?



23. Is there anything that could have been done better during your hospital stay?

- No, everything was good.
- all is perfect
- I wish that the NICU at Stollery was closer to the Alex or that there was a bus/trolley that could have driven me. Would have liked if my son could have used the breast milk donor clinic if there was any available.
- A day after discharge, the stitch holding his chest drain tube hole closed broke and it was wide open. We went to emergency at 0900h and asked if we should go to cardiology. They kept us in emergency where we waited until the afternoon before being sent to Cardiology, missing the Surgeon and having to come back the next morning. After five minutes with the Surgeon, we were given supplies to bandage it and were ready to go. We stayed in Edmonton an extra day because of this. I assume there could be better communication with Emergency and Cardiology to make issues like this inconsequential.
- No. The team/staff were amazing and helpful.

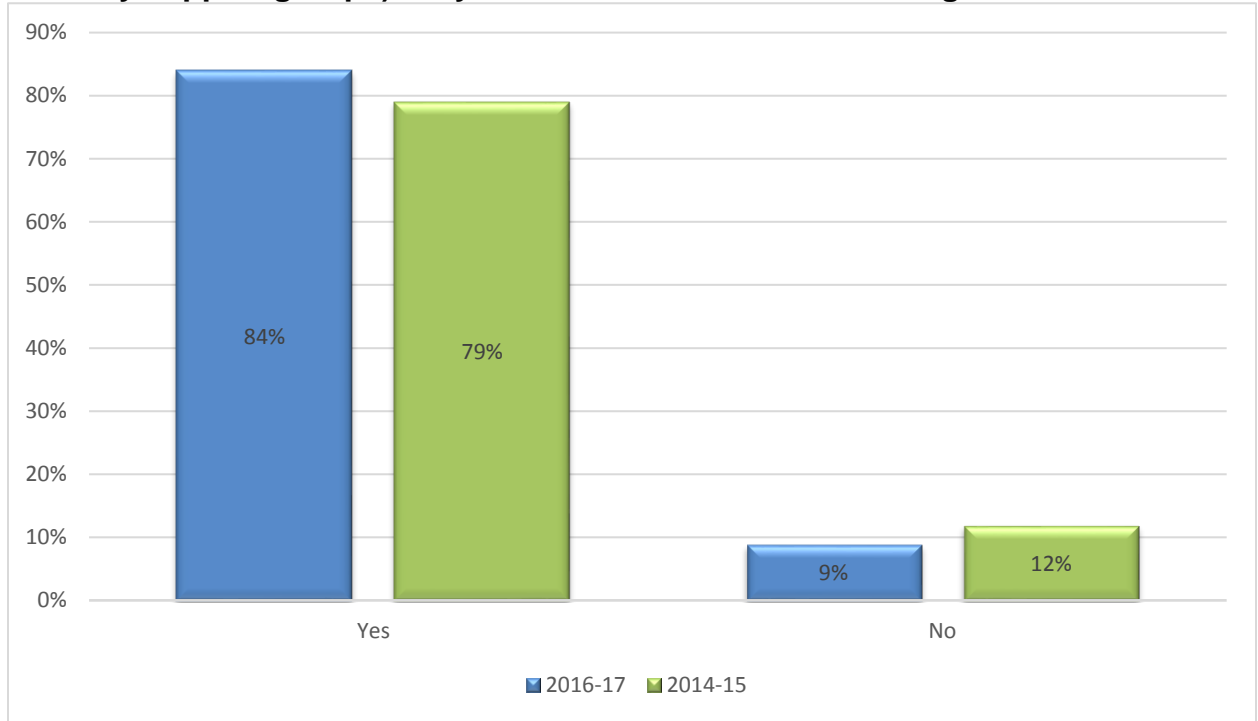
- As mentioned before, we felt we could have had more info about his care at home for him. We did receive information about wound care and that he required follow up with regular Cardiologist but lacked info about the possible experiences at home.
- We expected there would be no hiccups or setbacks and we should be home in five days. We stayed for 10 days. We spent five days in the PCICU, three days in the PICU, one night in the ICE room as there were no beds available in the day ward, then one night in the Pediatric Day Ward.
- More comfortable sleeping arrangements for bedside support in the ICE room.
- not really
- Our stay was way better than I could have imagined. Everyone was so kind and caring. Down to earth people make you feel at home and comfortable.
- It would have been nice to have been given more notice of a potential fit in surgery so that we could plan better. The day of her surgery we were given one-hour notice only. We arrived to visit, with no plans for food/drinks or activities for us to wait at the hospital for five hours.
- We were more than happy with our experience.
- Nurses and Doctors should listen to parents more. Parents are more aware of changes in their child.
- At the end of the day, when I or my spouse had to leave, we were torn. Would like to see both parents having the option to stay over night.
- Our son spent a lot of time in the "ICE" room in 4C. There was no bed available for my husband or I to sleep on, so it was hard to stay the night. One day they took our son for an X-ray early in the morning before we arrived. I wish they had called us and let us know. Instead, we showed up and were worried to see his bed in 4C empty.
- Find a way to monitor heart rates without having wires attached to a 16-month-old (lol). I think she pulled them off 800 times.
- Have a place for parents to shower rather than having to use the sink in the disabled bathroom. Have a place for a parent to sleep for a few hours.
- not that I could think of

- My foster daughter has FASD (and processes differently than other children). After I mentioned this, I only had one Nurse ask for my opinion on how to handle her (i.e. needles or tests). Her reaction was much better after this Nurse listened.
- Overall good, there were one or two individuals that could have done better at their job.
- Food coupons or something. Allowing both my husband and I to stay.
- There was an accidental over sedation during a procedure which resulted in 20-minute cardiac arrest.
- I knew it may cost a lot of money, but I hope each patient who has surgery would have their own room. My son shared a room with an infant who constantly cried during our stay in the room with him and no parents/relatives with him. Only Nurses on duty. It was very stressful for my son, that there was a time that he covers his ears and even cry because of the noise.
- Sometimes the communication between the different departments could be better, but I can't imagine the level of care getting any better.
- The ICU was hard to have both parents in. I think having chairs for the parents in there would make things a little less stressful. It was the only time my head was really spinning and when I felt like I was going to pass out, there wasn't really a place for me to just sit and take some deep breaths.
- It was so much better. Terrific care and if someone did not know an answer they found it out.
- No. All staff were exceptionally helpful.
- Private rooms for recovery so patients and parents can get more uninterrupted sleep.
- Once my child was on the cardiac floor, we felt the Nurses sometimes didn't check on her enough. She is well but is not a baby who will cry for her needs so you have to be present to read cues.
- I know it all comes down to finances, but would be nice for each child to have a separate room as every child has different schedule/routines. A couple times we had older patients in next bed; they were interfering with sleep and post-surgical recovery times for my baby.

- Our hospital experience was actually much better than I expected.
- I would have loved to go to West Edmonton Mall maybe before the surgery, just because we never have been and it would have been a great memory.
- A private room for my son for his whole stay.
- Having a private room on the fourth floor after being discharged from the NICU. I had just given birth two weeks earlier and was pumping every three hours in the night after each breastfeeding attempt. The times between when I could finally sleep, I was awakened by our eight-year-old roommate who would cry and scream during meds or tests or assessments. I was exhausted trying to care for my child. My husband was looking after our other children and I had no one else around to relieve me.
- No, we just wish we could have done more to show our appreciation to all the team members involved in our son's care.
- I can't say anything except continue with the kind of service you have because it helps us a lot.
- No. Services provided were outstanding.
- Specifically, one Nurse (on the 3rd floor, not ICU) was extremely loud and disruptive during nighttime checks. We understand it's her job to check our son every couple hours but she didn't need to loudly throw the door open and then announce her presence and purposely wake him. A little more respect for a sleeping baby who just had heart surgery would have been appreciated. His other Nurses were quiet and never tried to wake him or us. They quietly came in and did what they had to.
- Our son to not encounter so many medical challenges but that mostly was not the fault of the medical team. No one expected his outcome.
- Lack of preparation and orientation to 3M unit where he was moved from ICU. I had to ask for a place to sleep.
- Our time on the CHU was disappointing. We missed being part of rounds like we were in the PICU. Hot water in our bathroom would have been nice. Christmas was made as Christmas-y as possible. The kindness and support from Volunteers were so heartwarming.
- We didn't like our ICU Nurse. She coughed a lot into her hands and didn't wash often.

- As an exclusively breastfeeding mother, I feel that I should have been immediately and automatically hooked up with a Lactation Consultant in the hospital. I had no idea the challenges that lay ahead for us upon returning home, and having the right support in place could have made all the difference in the world. It also would have been nice to have been directed to the showers that we didn't realize were there until another parent told us on day five.
- ICU waiting area. Moms and Dads are desperate to be close to their kids. The waiting room is nice, but parents need a place to sleep. It doesn't make sense to not have cots (obviously not at the bedside).
- Sunshine Bundle Representative did not come to our room after we were told they would. I called and asked and she came by right away.
- No, BC Children's Hospital is the best hospital I've been to. Great team, great communication.
- It was all perfect. They helped us more than I expected. The Surgeon showed expertise's in his field and made me feel confident that everything goes well. Nurses were so amazing.
- A more comfortable parent bed in 3M would be nice. The mat on the floor was better than the cot I slept on two years ago.
- We were never really shown where anything was, so it was quite confusing at times to find the appropriate place to wait or put our food, etc. Minor really, but just made a stressful situation that more stressful.
- I was surprised that our child was not cleaned up from surgery before we were discharged and we were not told what or how to clean him properly. ICU was understaffed the night our child was there.

24. Were family support resources (family resource centre, social worker, family support groups) easy to find/connect with at the Surgical Centre?



Skipped Question – 7%

Comments:

- I felt that all the staff cared about me, they all tried to help me and encourage me.
- Loved the NICU family overnight rooms that I could start breastfeeding overnight.
- Loved how clean the hospital is. The cafeteria could have a change. Overall everything went well.
- We were very pleased with the care and had positive experiences with the care team at each point in our stay.
- The Social Worker is really nice. She helps us a lot.
- We became like a family with the staff. They're truly remarkable and do whatever it takes to get your child home. The care and service we received was truly top notch and are so grateful.
- The NICU Social Worker was extremely helpful and responded to all questions in a timely manner.
- I would refer the Stollery Hospital to anyone in need.
- NICU was a great and supportive environment to pump breast milk (a specific room and supplies) but the PICU room had no supplies - both of these were at the Stollery.
- Overall, we were very impressed with the care our son received.
- I always find the Stollery to be a welcoming and supportive environment. I appreciate the staff's tolerance and understanding.
- The foosball table was in need of repair. Overall, we were happy with how everything went - stay, communication.
- Nurses were all reliable.
- The Doctors and Nurses do an amazing job of explaining everything to us and keeping us involved. We have always felt the upmost confidence in everyone that has been around our son. They also do an amazing job of preparing us to go home and making sure that we are comfortable.
- Our Social Worker in PICU was awesome.

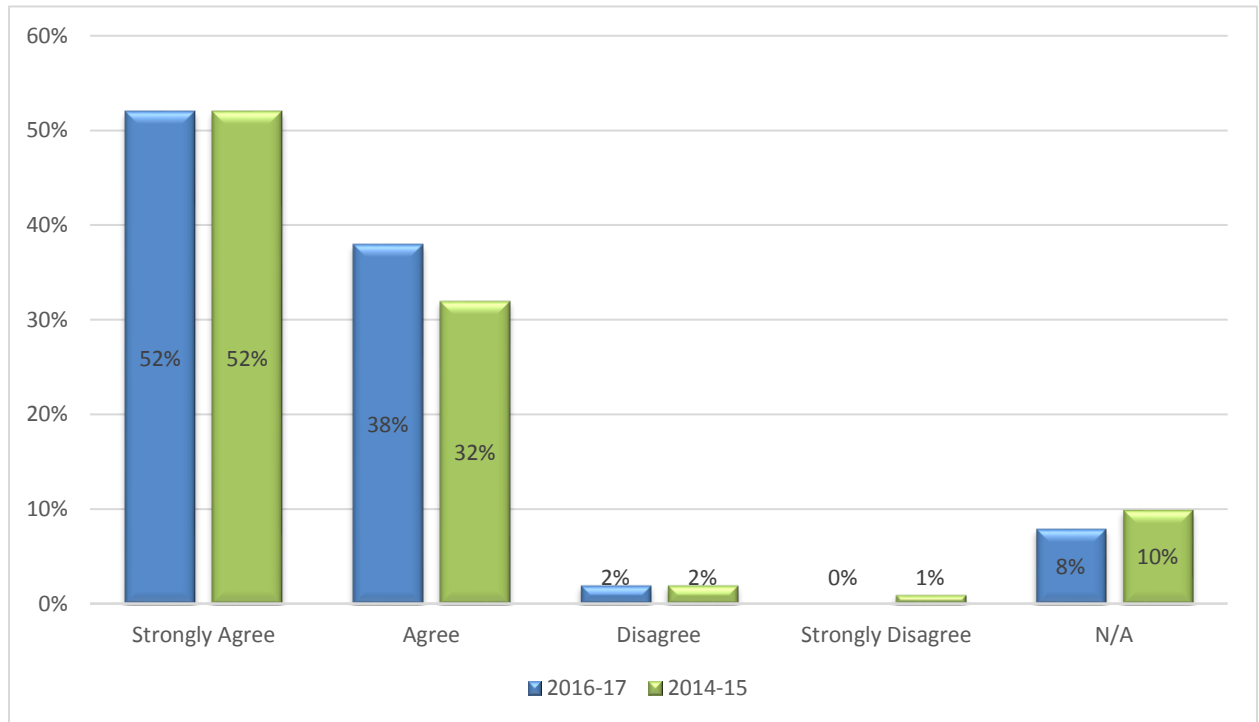
- There should be individual rooms for patients, or put babies with babies.
- The Doctors and Nurses were amazing. We would have never remained so calm. They are the ones who continued to make sure we were getting questions answered and fully understood what was about to happen during the open heart surgery.
- The only thing was when our baby had her Glenn surgery; they gave her three bottles of milk formula when they knew she was allergic to milk. We just don't want it to happen again with other patients.
- Needs improvement: separate rooms for each patient; during quiet times, Nurses need to be quieter when she comes to see the patient in the next bed; some (not all) need to be more approachable to babies.
- The care my daughter received was absolutely amazing! From the Surgeon, to the PCICU team we could not have asked for better. This is truly a world class program and we are so thankful for everything.
- Everyone was very helpful, especially the Nurses and Social Workers.
- I was very thankful for the rooms in the hospital. I stayed in one when my son was very ill for a few days so that I could be close.
- The NICU Social Worker was very helpful.
- The staff in the PCICU were fantastic. The staff we had on the ward were very good too.
- The cot in Ward 4C was fantastic. It was wonderful to know we were welcome to stay.
- It was a good stay knowing that my baby received all the care she needed.
- Did not use any of above groups. We just focused on the surgery as it was overwhelming.
- Social Worker was an amazing asset! She took care of us and our financial concerns, EI forms, housing issues while in Vancouver for surgery, etc. She championed for us!
- Lack of Wi-Fi was such a disappointment given our stay period.
- excellent care
- The playrooms are great.

- I cannot say any negatives, even a small one. Everything is perfect! From Nurses who showed emotional support and very comprehensive information to us, to our Doctor and Surgeon. Thanks to you.
- Nurses were amazing. The ICU Nurses happily answered our questions and encouraged us to come visit or call for updates. The medical floor Nurses were great as well, very patient. Kind of confusing that we don't have someone to follow us from the beginning (Pre-op clinic) to the end, a consistent contact or resource - kind of a liaison.
- I hate to complain about anything as I'm really grateful for the care we received. But there needs to be better accommodation for parents. As we live in Surrey we were too close to put in Ronald McDonald, but no way should a mother be expected to leave her four-month-old and go an hour away when they've had open heart surgery. I slept alternately in a chair beside her in the PICU or on the couch if I could grab a spot, for four nights. Then on a foam pad up on 3M for two nights, my husband and I alternatively sleeping. Plus there was no hot water in the room in 3M - a little disappointing to see a shower after five days and have it be cold. I mostly just feel really bad for parents who have to stay there even longer. We were lucky.
- Fabulous service, professional and friendly Doctors and Nurses. Extremely thoughtful Child Life Team. Excellent experience overall.
- excellent
- Our Ward Nurse was excellent. As was our Surgeon. All Ward Staff and ICU staff and other hospital staff were excellent. They made this stressful time bearable for us and our family.
- Everyone was just fantastic!
- Lasix's were given in the evening. Discharge had my son taken in the evening which means he had to get up to go to the bathroom during the night. Definitely not good.
- No. Very thankful for taking good care of my son.

After Your Child's Procedure

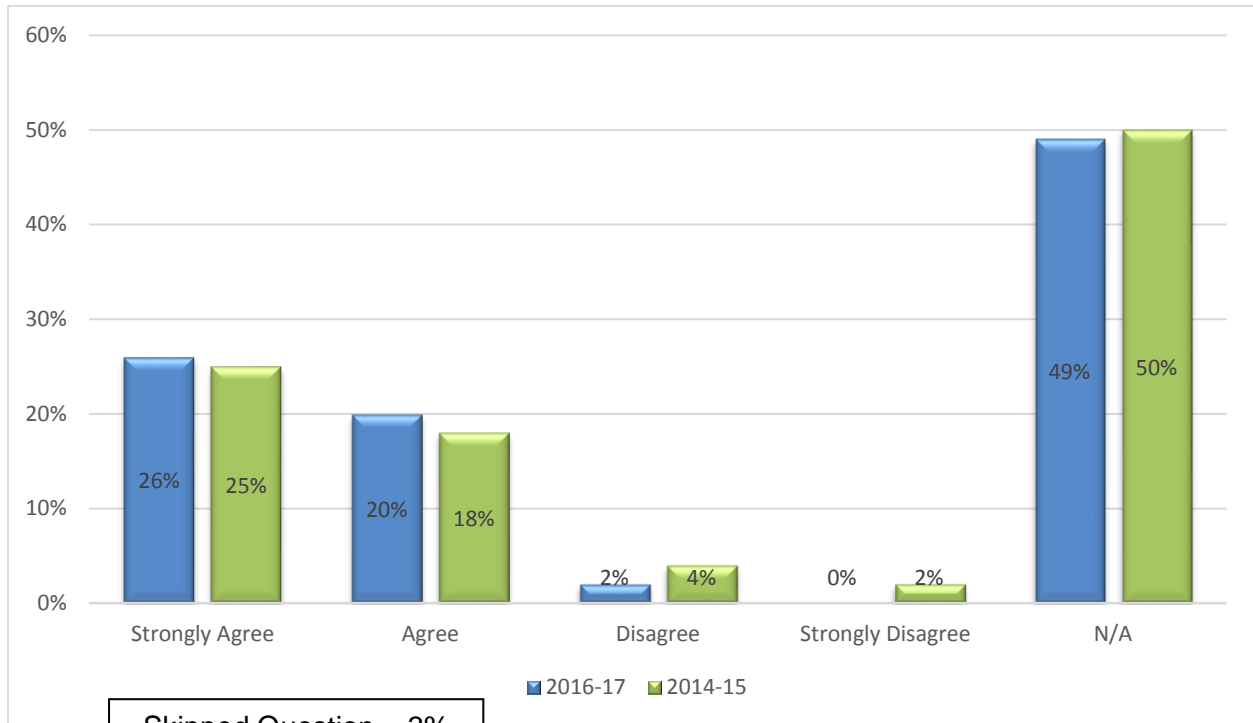
Some children go home after a surgery or procedure; other children are transferred to a hospital in their home community first. Please answer the following according to your experience.

25. I was included in my child's plan of care for transfer/discharge.

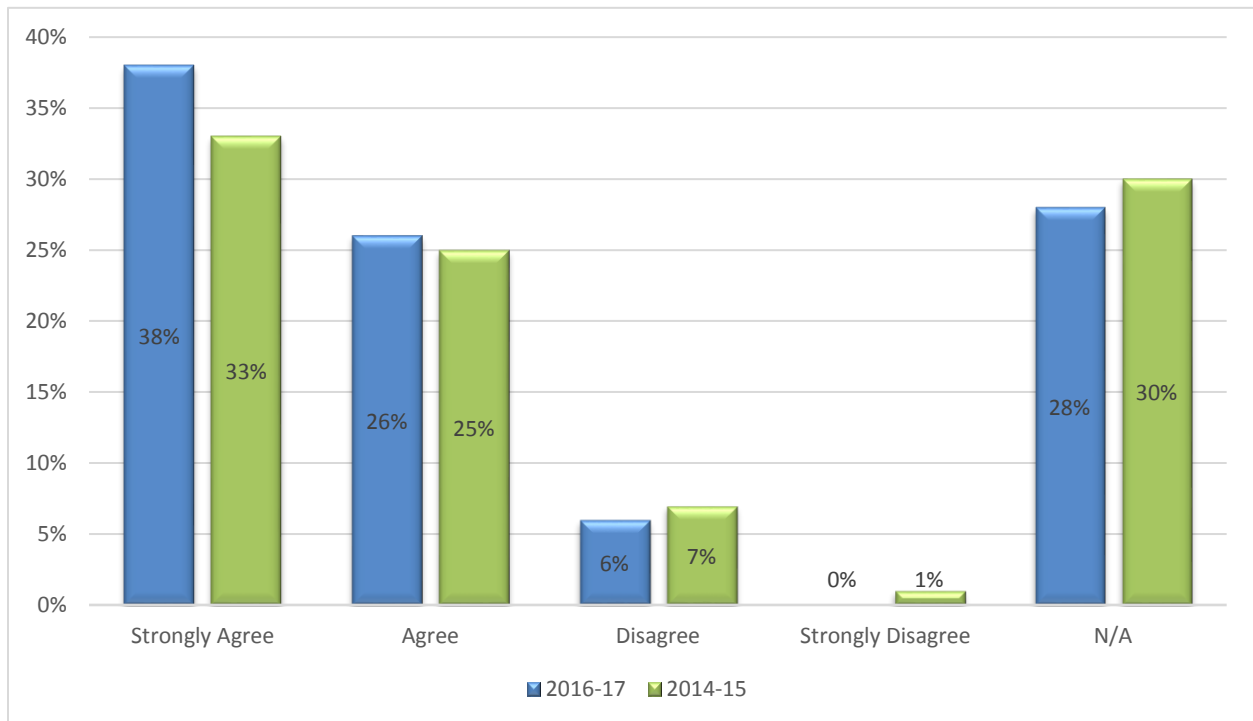


Skipped Question – 1%

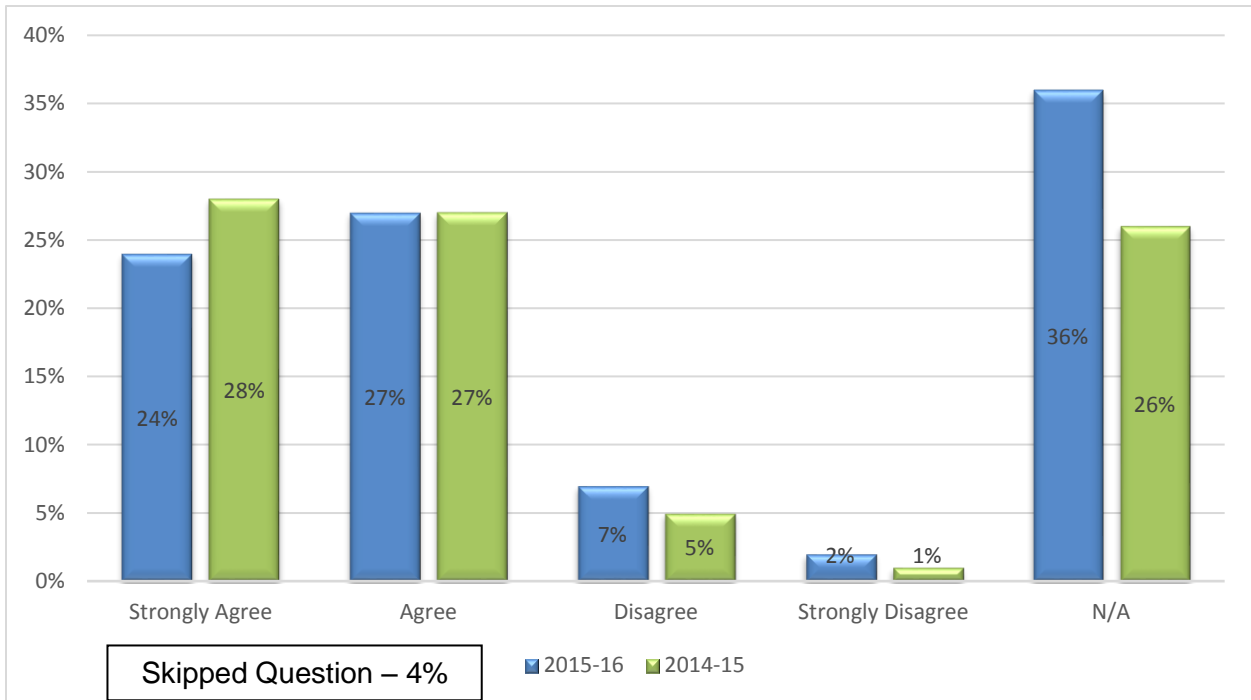
26. I felt well prepared for my child's transfer back to my home hospital.



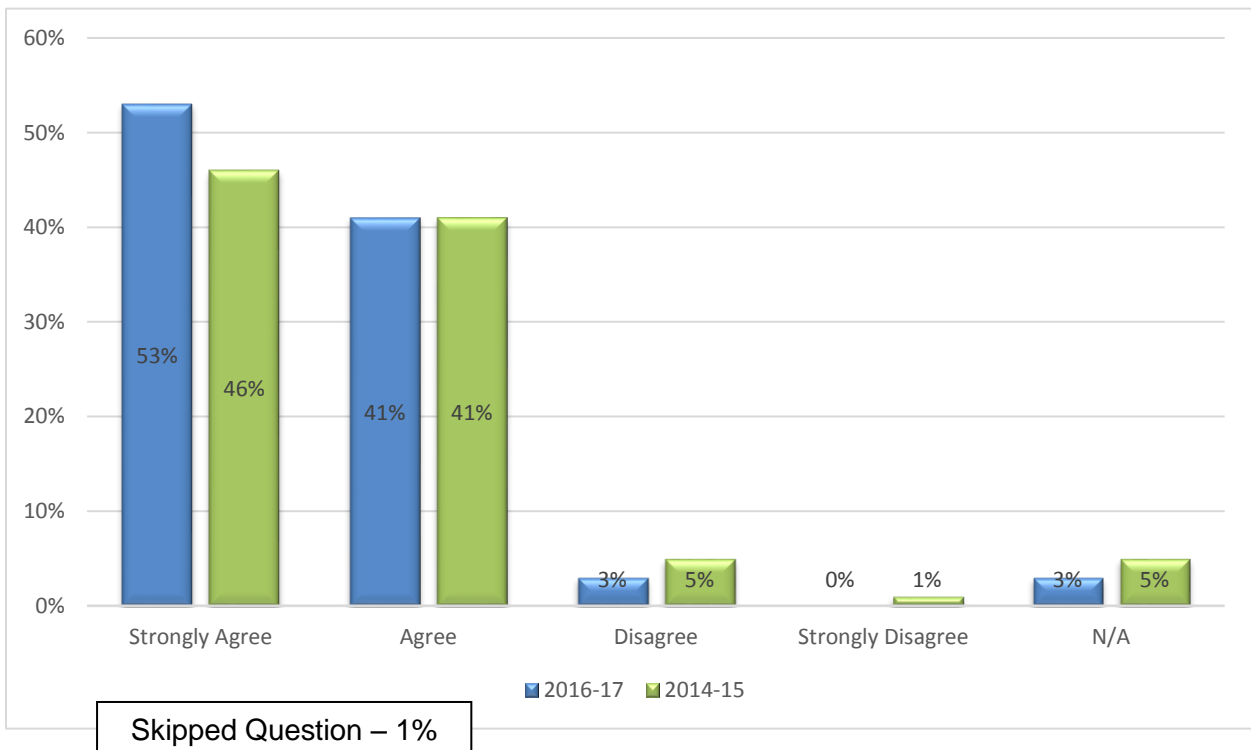
27. When I returned to my home centre, I felt enough information about my child had been communicated from the surgical/procedure centre.



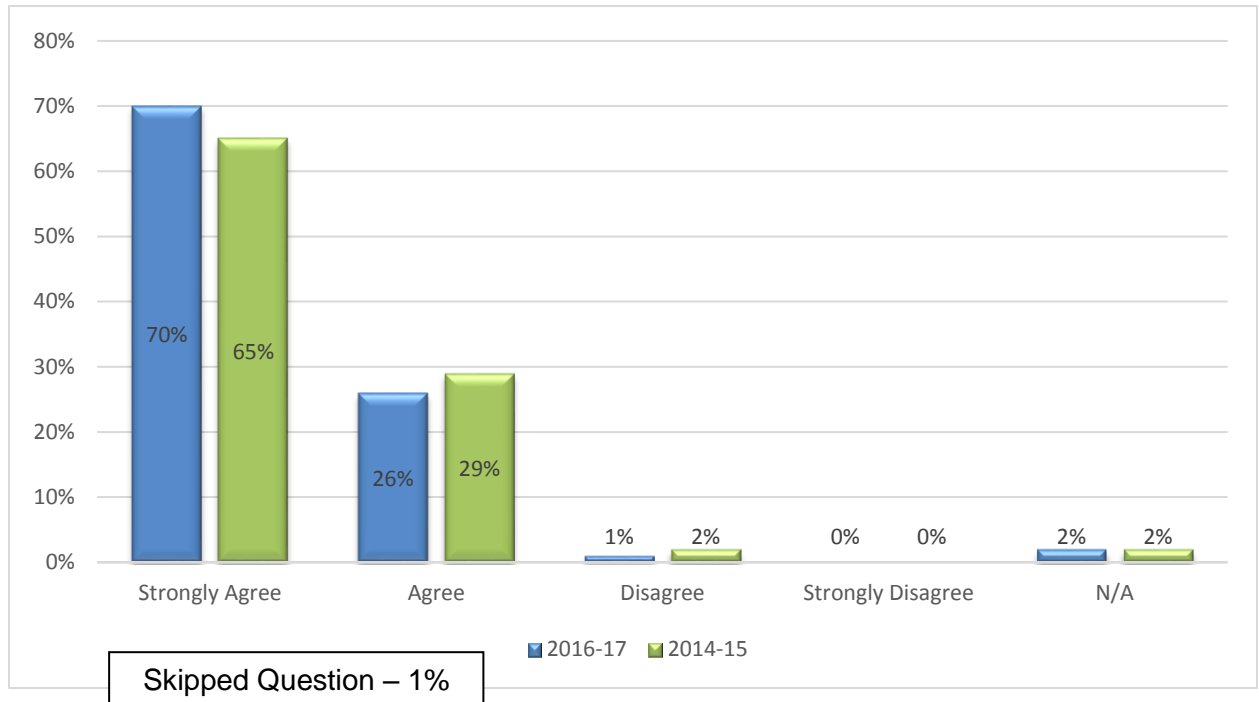
28. I was given the same information about my child's condition at my home centre as I was at the surgical/procedure centre.



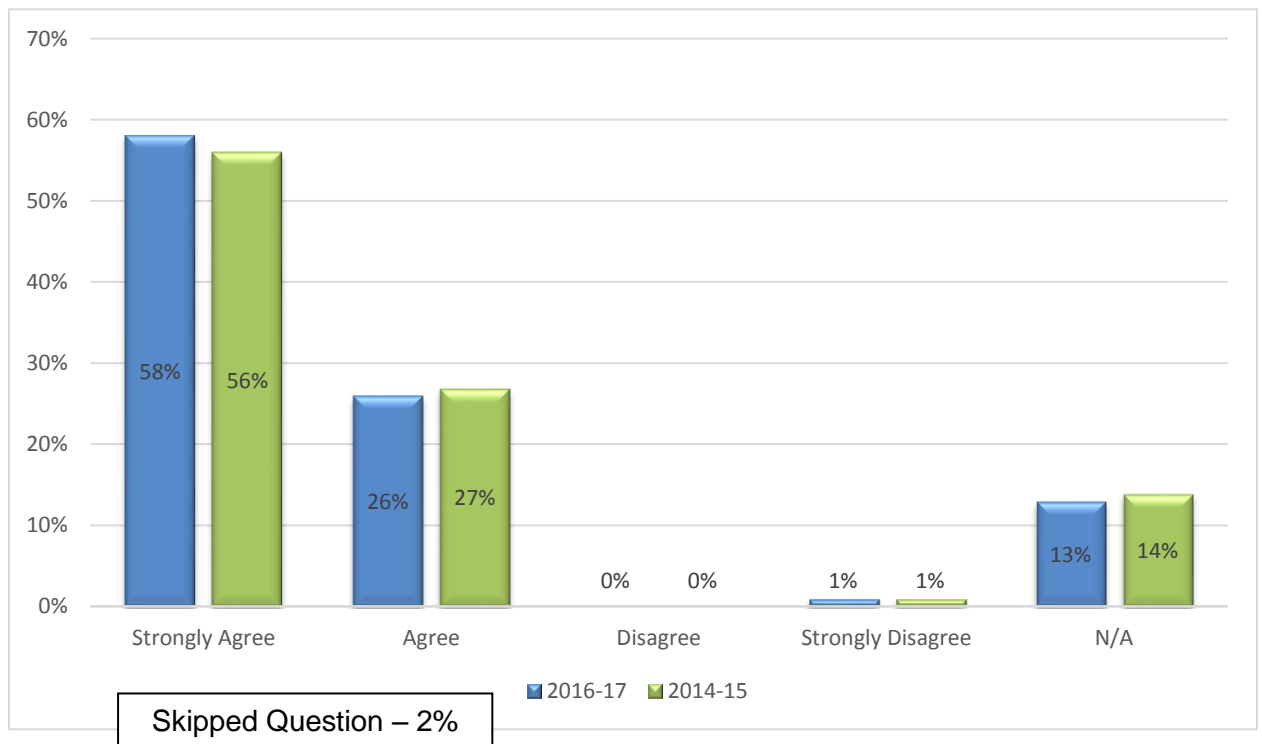
29. I felt well prepared for my child's discharge home.



30. When I returned home, I knew who to call if I had concerns about my child's condition.

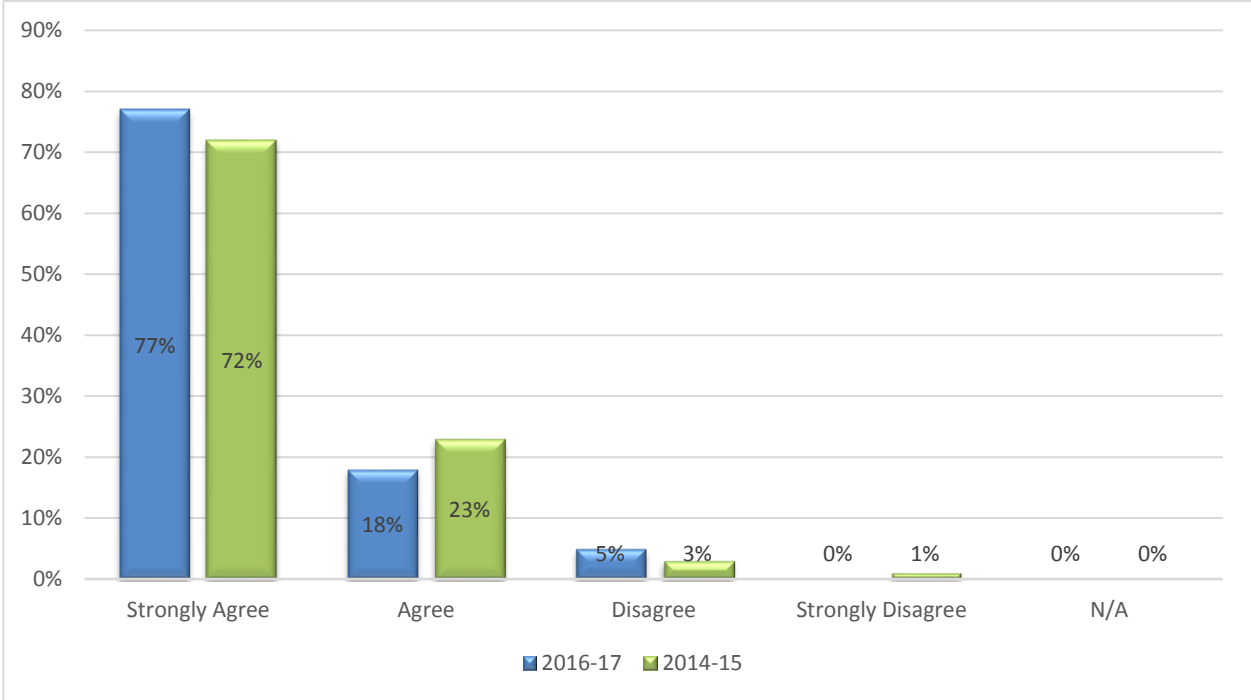


31. After discharge, I was able to get appointments at my home centre as recommended.



General Questions

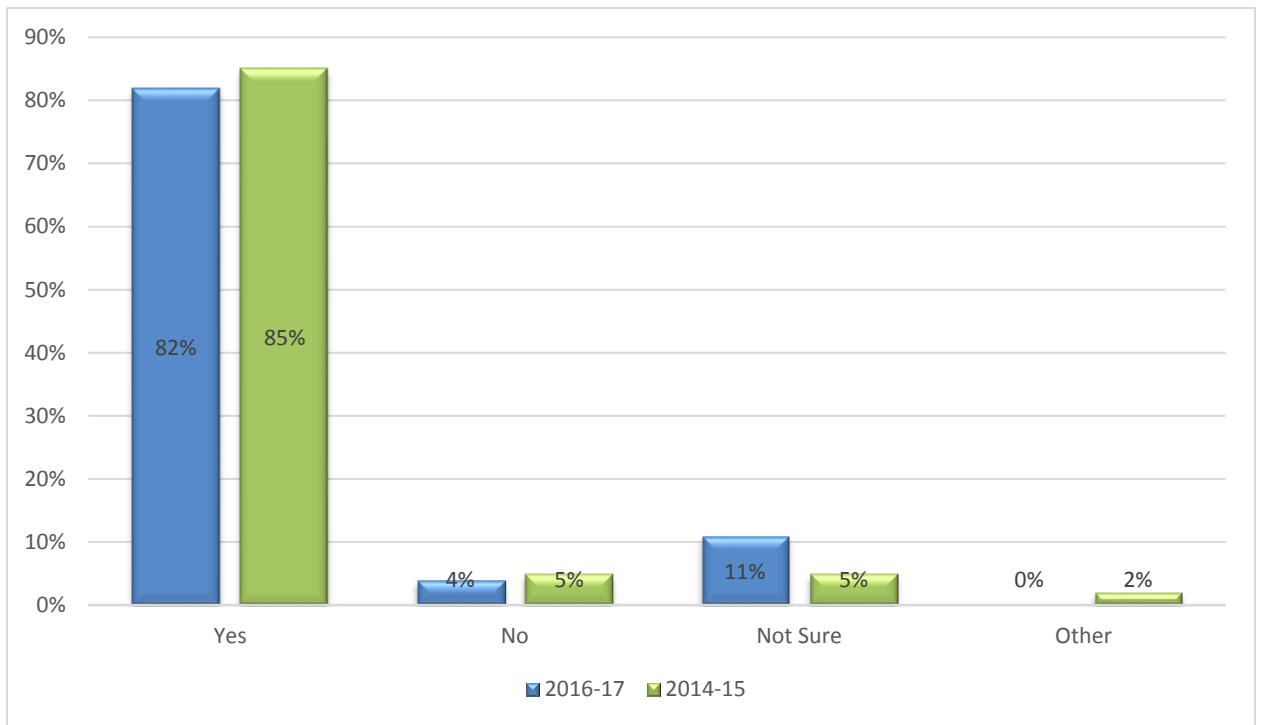
32. Do you feel you are getting the best possible medical care for your child's heart condition?



If you answered “Disagree” or “Strongly Disagree”, please provide some additional information:

	2016-17	2014-15
I don't have confidence in my child's cardiologist	1	1
My child's cardiologist doesn't take the time to address my concerns	2	0
I have to travel too long a distance to see my child's cardiologist	2	5
Other	-	-
More time in appointments for longer discussion	-	1
No Cardiology Doctors in home town	-	2
I don't think micro-preemies should travel between RAH to UofA for PDA Surgery	-	1
5 months seems so long to wait in between appointments	-	1
He is still in the hospital. The Nurses don't pay attention to him and allow him to cry for long periods of time.	-	1
My Cardiologist makes me feel that we are wasting her time	1	-
Often we feel that our lifestyle/family matters/distance to hospital aren't taken into consideration when making decisions for our child	1	-
Need better post-op support in Victoria	1	-
Not much confidence in nursing staff	1	-

33. Do you feel that your child's healthcare team plays an important role in your life, besides just routine care?



Skipped Question – 3%

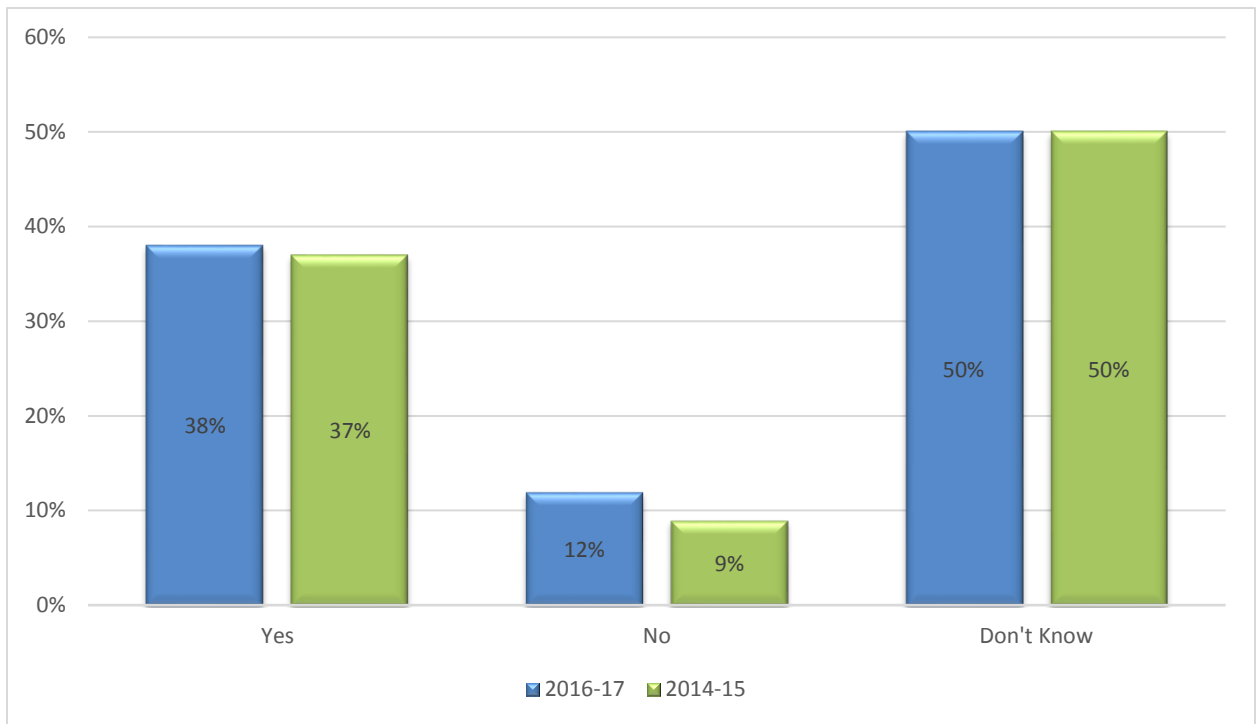
34. Please list anything you would like to change about your child's healthcare:

- Pediatricians could be closer to home. It is 2.5hrs away.
- I want a pediatrician Doctor to see him instead of the family Doctor.
- Yes, many times I have reached out to those amazing Doctors and Support Team with various and what I thought were silly questions. Every time they have helped and reassured me as a parent. Thank you!
- We received first class care and our best interest of our child's well-being and care was always a priority.
- They saved my child's life. Forever grateful!
- We were transferred back to Vancouver from Edmonton too soon, and then discharged much too quickly from the hospital in Vancouver (after three days) back home in Victoria. They forgot to connect Nursing with us before we left for home - we were supposed to get a weight scale and oximeter to check our daughter. This led to a delay in weight measurements to ensure weight gain and lack of O² checks at home which may have made a difference. Our daughter died of a chest infection one week after discharge home. The changes in her were too subtle for us as parents to realize. She saw her Pediatric Cardiologist four days after discharge and died three days after that as there was no follow-up over the weekend. We were checked by the Public Health Nurse but they didn't check her incision. We really need more Specialized Cardiac Nurses to do daily follow-ups after such a quick post-op discharge. Our Cardiologist was out of town when our daughter was taken to the ER by us in medical distress and died in PICU.
- I wish the Children's Hospital in Calgary was equipped to do heart surgeries so we didn't have to travel to Edmonton. But we're thankful that Edmonton isn't too far and we really believe he receives the best care there.
- We are very pleased with our daughter's care.
- Not to have Pediatrician call the house saying 'your son should not have been discharged. There was some paperwork missed - can you please get some more tests done.' This happened previous approx. 1.5 years before surgery when we found out about possible heart defect.
- We were transferred home to a Saskatchewan hospital. I wish very much that we would have stayed at the Stollery. The level of care we received at home doesn't begin to compare to Stollery.

- The KidClot came in to give us instructions for her injections but while she was next to me. I missed half of it, because of her meltdown and had lots of trouble at home. Would have preferred to have it explained to me first. Some documentation explaining her side effects of medication (i.e. warfarin) for the school would have been helpful.
- Wish there was a child Cardiologist in Regina, whether for emergency, etc. Cardiologist team in Regina. Surgical team in Saskatchewan.
- We would like a better communicating Cardiologist. Our Surgeon was phenomenal.
- nothing
- Currently in Fort McMurray, we do not have a Cardiologist for children and that would be very helpful here since we are four hours away from the Stollery.
- The whole team has been wonderful and are part of our family. The Cardiology Nurses in Saskatoon are amazing. Our Cardiologist - there are no words. She is an angel.
- It was quite nice.
- access/easier access to feeding support
- wait times at the clinic
- I'm just thankful. They are so informative and careful, really a blessing.
- I wish there was a health professional solely dedicated to my sons overall diagnosis of 22Q11 deletion syndrome.
- Nothing, but I wish there was more support from the general public to see how well the system runs and how it has a huge impact on people (or children). Unfortunately, I could only feel the importance when we needed the service but not before. We extremely feel grateful.
- While in ICU environment, it would be helpful to have Doctors/Interns/Residents/etc. introduce themselves every time they come to the bedside with name and position. It would be helpful to understand from what perspective someone is coming from, especially in regards to diagnosis. Normally a parent might remember, but in the high-stress environment our son was in for weeks, we couldn't retain that information.

- No. The team at BCCH were amazing. The PICU Nurses always went above and beyond. The Doctors were outstanding. They always made time to include us and answer our questions.
- We feel fortunate to receive such excellent care.
- We felt pressured and quite discouraged at our two-week Post-op appointment about her weight loss after the surgery. We didn't really realize that she shouldn't have lost as much as she did. She is exclusively breastfed and rather than getting the support we needed right away to continue that, we were told she had so many days to gain or she would be put on an NG tube. This caused much stress and turmoil which didn't help with supply for breastfeeding. It wasn't until I pressed much harder to be connected to a Lactation Consultant that I got the support I needed to continue nursing her. We now see an awesome feeding team at Surrey Memorial and progress has been slow but steady. I had asked a Nurse in the PICU for a Lactation Consultant and it was glossed over, and I asked the Surgical Nurse upon our two week appointment for one and we were told that a) a Lactation Consultant wouldn't be able to help unless it was a "supply issue" and b) all the Lactation Consultants were booked right up, even for inpatients, so we would never get one as an outpatient. I addressed both these issues with the Lactation Team at Children's, and with the Cardiac Nurses (who hooked me up with the support we so needed).
- Everyone was great, did a good job, and seemed to care. But sometimes I didn't feel listened to.
- No. Just continue helping.
- A bit more pre-surgery prep would be helpful. For the earlier procedures, this wasn't a big deal but now at three-and-a-half, pre-surgery advice is much more important. I'm referring to things like - how long before surgery should we start to discuss it with our daughter, how much detail to give, useful toys to get to familiarize her with medical gizmos etc.

35. Is there a family support group available to you in your home centre?



36. Is there anything else you would like to tell us about your experience?

- The only odd thing I experienced was I had to ask the Nurse if there was a different way to give my daughter Benadryl (via IV) instead of oral - which she disliked very much. I had to get creative as opposed to an experienced Nurse knowing and suggesting an alternative.
- everything went well
- The hospital is perfect and as expected the Nurses are friendly, the facility is best. All the information that we needed was told to us ahead of time.
- The staff in the PCICU in the Stollery were the most amazing. Kept us well informed and made us feel very cared about. Everyone was great throughout our journey. The PCICU in Edmonton blew everyone else out of the water. We are so thankful for the amazing Doctors and Nurses there.
- Overall, everyone at the Stollery were wonderful and very caring. Great care given to my son.
- Too many transfers between units at RUH which means many hand offs between Physicians and Nurses and things are getting missed.
- Our experience at the Stollery was excellent.
- I felt that there should have been better communication between my OB and the healthcare Cardiologist. My OB had no idea that they wanted the baby out on my due date and not after. Also, there was no room on the wards for my son to go to, so I was discharged from the NICU. I wish I had one to two days on the ward to acclimate.
- I feel Doctors (prenatal) should send expecting moms to have their babies hearts looked at. My son was born and almost died in my arms. No one knew he was sick.
- We are really thankful my daughter can have open heart surgery at the Stollery Children's Hospital. They have a great support team, medical team, and surgery team.
- My only concern was in the ICU at the Stollery. I was exhausted and needed sleep and the Nurse on duty felt that I should stay all night. Also, when I was in the ICU, the Nurse flocked around chit chatting like she was on a holiday. I needed her help and I was ignored.

- Our child is 12. We should have maybe provided him with counselling before and after, especially after his surgery. After being on restrictions for so long prior to, being able to do things without being scared was hard for him. He was scared that by running he could still have a heart attack. We have since been able to find him a Social Worker locally, but support for children with these types of conditions in a small town is hard to find. We will forever, as a family be grateful for the hospital saving our son's life!
- We received first class care from all the staff at the Stollery. The staff are remarkably trained and do everything to help your child succeed but they are also very aware of how emotional and anxious the parents are. So good at explaining everything until you understand and are aware and sensitive with the parents as they know what the parents are going through is extremely emotional and stressful. We will never be able to thank all the staff enough for the care and concern they showed to us and our son. We are forever grateful and feel so blessed to live in an amazing country, province, and city with such outstanding care and services. Thank you Stollery.
- Overall experience was good. Everyone in the hospital were very friendly and accommodating. During our stay, we felt comfortable with the Nurses and Doctors. We are so thankful to everyone for taking good care of my son during and after the surgery. We are very happy with the outcome of the surgery. No words can explain how thankful we are for all the help you gave to us. Thank you so much.
- Apart from a few negative instances, great job. Thank you so much.
- We were surprised to find out that the Doctor who was supposed to do our son's heart cath (according to Variety Heart Center in Winnipeg) hadn't worked at Stollery Children's Hospital for over a year. Although we were not concerned about the change in Doctors, we wondered about the level of communication between the two centers, and that was slightly concerning to us. We questioned how well the two centers discussed our son's case.
- We're so thankful to all the Doctors, Surgeons, and Nurses at the Stollery. They are amazing and gave our family such a precious gift - a happy, healthier baby boy!
- I feel very happy with the care he had. From the Cardiologist to the Surgeon and back home were amazing.
- No one wants to hear their child needs heart surgery, but if they do, we had the best team for the job. They care for your child as if they are their own.

- There were so many resources used to try and give our daughter a chance of life, but due to poor post-op follow up/post discharge follow up, we lost our precious daughter at five weeks of age to a preventable cause - infection. Please increase funding and support. Edmonton was an excellent centre for cardiac care. Our Cardiac Nurse and Pediatric Cardiologist are excellent but we need more of them as I believe they are stretched too thin. We as parents were relied on too much (without specific instructions) to see changes in our daughter that were subtle until it was too late - perhaps a cardiac trained professional would have been able to realize this earlier (i.e. the night she died, she had good color, tone, no fever, had been feeding and gaining weight - she was only a bit irritable). Now we suffer every day - our loss is insurmountable.
- We were in the hospital at the Stollery for five months and it was the PCICU team that made the stay easier. They saved our daughters life countless times and became like our family away from home. There is absolutely nothing that team could have improved upon during our stay.
- Overall we had a very positive experience at the Stollery. It is a world-class facility and we were very impressed with the quality of care from Doctors, Surgeons, Nurses and other Health Care Professionals. Everyone was very willing to include us in our child's care and shared information openly with us, which was very important to us and helped us feel more at ease. We are very thankful that our son was able to have his heart surgery in such an excellent facility; we knew he was in the best possible place and we are so happy with how well he is doing as a result of many wonderful people who took care of him before, during and after his surgery. One criticism we have though, is regarding the communication between the Stollery and our home hospital. We found that although everyone told us they trusted and communicated with each other, their actions did not illustrate that. Both hospitals have excellent medical teams, however, we were surprised by their somewhat negative opinions of each other and lack of trust in each other. There were tests repeated for no particular reason (other than for each hospital to have their own results), care plans changed and information was not shared (it was up to us as parents to ensure our home hospital had all the facts about our son's condition and medications when we returned to our home hospital). I feel that there needs to be more of a true team approach among the different hospitals, in order to provide consistent and effective care to the children.
- We are grateful for the Stollery. The Cardiologists, Nurses, etc. are all so caring and thorough.

- Our experience at the Stollery Children's Hospital was as comfortable as we could have wanted. The staff both in the PICU and the PCICU was excellent. All the Cardiologists we dealt with were good at explaining everything they were doing or planning and involved our family in the team discussions. They were open to our questions and concerns. We couldn't say enough about the excellent care that our daughter received from her Surgeon. He had an excellent bedside manner and came to talk to us and our daughter at numerous occasions to keep us well informed. He took our questions and concerns very seriously and had great compassion for us as well as our daughter. He made our daughter feel very comfortable in a stressful situation. Along with our Surgeon, we could not have been more impressed with her Anaesthetist. She was very thorough to explain everything to us and our daughter. She was compassionate and had a great bedside manner. She came to see how our daughter was on more than one occasion on the unit. We felt both the Surgeon and Anesthetist went above and beyond what we were expecting. We are very grateful for their care and compassion.
- We were really scared in the beginning but the Doctors assured us everything would be great, warned us of anything that could happen and let us know his outcome was very good.
- We appreciate everyone's compassion and understanding and patience for/with us during a difficult time. All staff deserves a huge kudos and hug for everything they do. We feel informed and cared for. Thank you.
- Edmonton's Stollery Hospital was fantastic. Ronald McDonald House was a wonderful blessing and place to stay.
- Treasure beads are wonderful! We very much appreciated the discounted hotel rates because of the WCCHN.
- Overall, our daughter's surgery/experience was very, very positive. Pre-op was lengthy with a fasting baby but we were very pleased that we had confidence in the people providing such critical care.
- I cannot express how thankful we are to have had the team we did looking after our daughter.
- Great experience. Our Cardiologist and Surgeon were fantastic.
- Staff, Doctors, Nurses were great. We felt the care our son received was exceptional.

- When our baby was born, we were uncertain if we could hold him due to his condition. We didn't hold him until he was much older until one Nurse offered to us to hold our baby. We wished to hold him when he was one-day old but no one offered that to us.
- Just to say how truly grateful we are to have a place like this so close to home. This place and the people that work here gave us our son back and we couldn't be more grateful. Thank you!
- The entire team was amazing. They helped us a lot, made us feel comfortable as possible. They were so kind and pleasant, especially the Nurses made us feel so special and welcome. Big thanks and hugs to all the team involved.
- Thank you for the excellent care - we were well prepared for this, from the point when I was 24 weeks pregnant and advised of my son's heart defect and that he would require surgery.
- We were unsure about going ahead with my son's surgery and when the Surgeon found out, he immediately cancelled this surgery. I'm so thankful for this Surgeon. He was extremely professional and took the time to answer our questions on multiple occasions. We were scared and unsure and he was compassionate and understanding and patient. We rescheduled our son's surgery and the Surgeon saved our sons life. We will always be thankful to Mohammed for how he treated us and his skills as a Surgeon. Even after surgery, when Specialists were unsure how our son was doing (this made us uneasy), Our Surgeon reassured us multiple times that our son just needed time (and this calmed us).
- Coming from the Regina NICU to the Stollery NICU was a bit of a shock. Space was limited in Edmonton, but that really can't be changed. The biggest concern for me was the hand washing and cell phone policy in the NICU. In Regina, cell phones are only allowed for pictures then need to be put away. At the Stollery, many parents are on the internet on their phones for hours at their child's bedside in spite of the warning given when entering how it could affect the equipment. The other concern was hand washing and germs. Being a cardiac focused NICU I was shocked to see how lax the Stollery was compared to Regina. In Regina, we had to use a special scrub for 2 minutes, elbows down. Visitors were limited to parents, grandparents, and children once. Staff don't wear street clothes, the scrubs stay and get cleaned at the hospital. I was concerned at the Stollery how many visitors wouldn't do a good job at hand washing, and many of the staff wore street clothes.

- Our experience was amazing, and difficult, but we easily coped with the help of our family here and abroad, and coworkers. We as workers dealing with patient care directly (my husband is a Doctor and I am a Clinic Manager) it's not easy to find out about our son's medical condition, because our job is to help patients and their family dealing with a medical condition. At first, we felt really bad about the fact that our son's condition was not good. Eventually, we managed to cope and face the fact that things happens for a reason. My sons is doing great after the surgery, and now he wants to follow his dad's and sister's footsteps, to become a Doctor, and "to help people to feel better". After the surgery, he never complained of any tiredness, tummy pain, and dizziness etc. He really understood that the surgery helped him a lot to feel better and that was with the help of Surgeons and Doctors. I would like to thank everyone who's been involved in my son's care. We salute you all!
- Excellent aftercare follow-up with Nurses. Well done to all!
- Everyone was amazing. Thank you all so much.
- We thank you for the rest of our lives. Every part, every member, and every service is appreciated. Thank you for taking my child's condition seriously and carefully.
- I really appreciated the Cardiologists and the Nurse. They are very sincere and kind. They told us all the steps of the surgery and prepared my son and us facing this surgery. My son had no worry in facing the surgery and the skills of the Doctors were very good. The scar is small. Thanks for the BC Children's Hospital.
- I really appreciated the quality of care my child received from the whole cardiology team. One of the Nurse Practitioners made remarks about the pain tolerance of my child and did not address her fear of pain and I did not appreciate that. As a child going through a heart operation, I did not want her to remember it as a traumatic experience.
- I would just like to say thank you for everything. I know my baby still needs to undergo another procedure but as long as I know that she will be with the Doctors at BC Children's Hospital, everything will be fine. Keep up the good work.
- We wouldn't have made it through this without so much love, support, and kindness, which we experienced all around us at all the hospitals we were at. Thank you!

- We really appreciated the family centered approach at BC Children's Hospital and the team approach makes us feel that many very smart, experienced and educated people are putting "their heads together" for the best possible care for our daughter and are making the best possible decisions for her as well. The hardest part of her medical issues is that medicine is more unknown than known. No one has a magic answer or procedure that will fix everything once and for all.
- Our time at BCCH was very difficult. All the staff we encountered were amazing, knowledgeable, kind and patient with us. From the Pre-op clinic to discharge we were taken care of. We can't say enough times how thankful we are for everyone at BCCH.
- All the Medical Practitioners have been most helpful to us from Winnipeg to Vancouver. Even the accommodation at the Ronald McDonald House had been taken care of. We are extremely happy and grateful that the surgery went well. Thank you Western Canadian Children's Heart Network.
- Overall very satisfied with the level of care we experienced, and both the professionalism and humanity we felt from the medical team. They handled tough situations very well.
- We are so appreciative of all the help, support, and most importantly the successful surgery! Thank you.
- I am so grateful to all of the wonderful, incredibly smart, efficient Doctors and Nurses at Children's, especially the Surgeon who is saving our little girl's life. All other things aside, we are extremely impressed with BC Children's and feel unbelievably lucky to be in their care.
- It was more than what we expected. The care of my child went great and every staff member was very helpful. The cardiac team worked so hard for my child. All staff, Doctors, Social Workers and Nurses worked very well and they were very understanding and caring.
- This experience at BC Children's was made so simple. The confidence in our surgical team and the Doctors and Nurses in general went a great deal towards putting our minds at ease. Friendly and supportive environment. Special thanks to: our Surgeon and our Cardiologist.
- We were well taken care of and well informed on all areas. Thank you to all staff and Volunteers who we came into contact with.

- The Spiritual Leader was an amazing support to our family. I will never forget how she took the time to help us prepare and how caring she was. I believe she is an essential part of the team. She made a huge difference to us. Please pass that message on to her. She really helped us keep it together when we were falling apart.
- The staff was overwhelmingly caring, attentive, diligent and competent.
- We had a great, positive experience. We weren't sure, since leaving Winnipeg to travel made us a little nervous but everyone was great! From our pre-op, where the Nurse explained everything in great detail - Child Life Specialist - Nurse Practitioner were amazing! Our ICU Nurses and Nurses on 3M. We cannot express how great the whole experience was even though the circumstances. Our son is doing great. Thanks so much!
- We tried to make it as easy on our son as possible so made it a little bit of a holiday. It will be great to have some information on what we can do in Vancouver, who has a wheelchair to borrow or access for one, maybe they can offer a discount to children coming from the hospital. But all in all the team was amazing and I cannot thank them enough.
- Please minimize waste of unused materials like soothers, recyclable materials.
- We are grateful to have such good medical care of our baby girl.
- Thank you so much for everything you've done to my son.
- We are very impressed with everyone at the BC hospital!! Thanks for saving our baby boy!!
- We feel we received absolutely world class medical service at Children's. Overall, we are very satisfied. All of the Doctors we interacted with were great. Of particular note, beyond his role in the OR, the Surgeon was remarkable for his attentiveness and involvement in all aspects of our daughter's hospital experience. He was in the ICU and on 3M daily, available to answer questions. Much more present and involved than other Surgeons we've interacted with.

- Suggestion: A pharmacy inside the hospital that is open during the weekend. In my experience, I brought my daughter to the emergency with pneumonia on a Sunday. The pharmacy inside the hospital was closed and at that time I didn't have any relatives with me (me and my daughter only) so I didn't have a choice but to find one outside the hospital to buy medicine even if my daughter is not feeling better and very weak at that time. I would like to take the opportunity to thank all the people behind the success of my child's heart operation: from the Surgeon for being a great Surgeon and saving my daughter's life; to all the Nurses; and all the Child Life Specialists and all the medical team at BC Children's Hospital. All of you did an awesome job. And of course, thank you very much also to the staff and medical team at Winnipeg Children's Hospital – our Cardiologist, the Nurse, and the Social Worker who did our travel booking and hospital appointments. An excellent job to all of you. May God bless you all. And to Western Canadian Children's Heart Network (WCCHN). More power and thank you very much.
- My experience at BC Children's Hospital was awesome! From my son's Cardiologist, who helped and diagnosed efficiently, to my son's need for surgery. To the Nurse, who helped us in understanding everything, with patience and sympathy enabled us to accept the situation in a positive perspective point of view. To the expert Heart Surgeon. Thank you. Everyone at BC Children's Hospital were all perfect. Thank you and may God bless you all. I'm so happy.
- Overall it's been an extremely positive experience. One thing we encountered is we were encouraged to email a Nurse with questions but we never received a reply. It was a little disconcerting, so we would follow up our emails with a phone call. We understand the Nurses have a large workload but it made us feel like we were bothering them with our questions when we had to keep pursuing them for answers. It made us less inclined to reach out with concerns as well.