



WCCHN Family Satisfaction Survey Results

2014 – 2015 Fiscal Year

About the Survey

The survey was first sent out to families in the Fall of 2012. The 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.

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.

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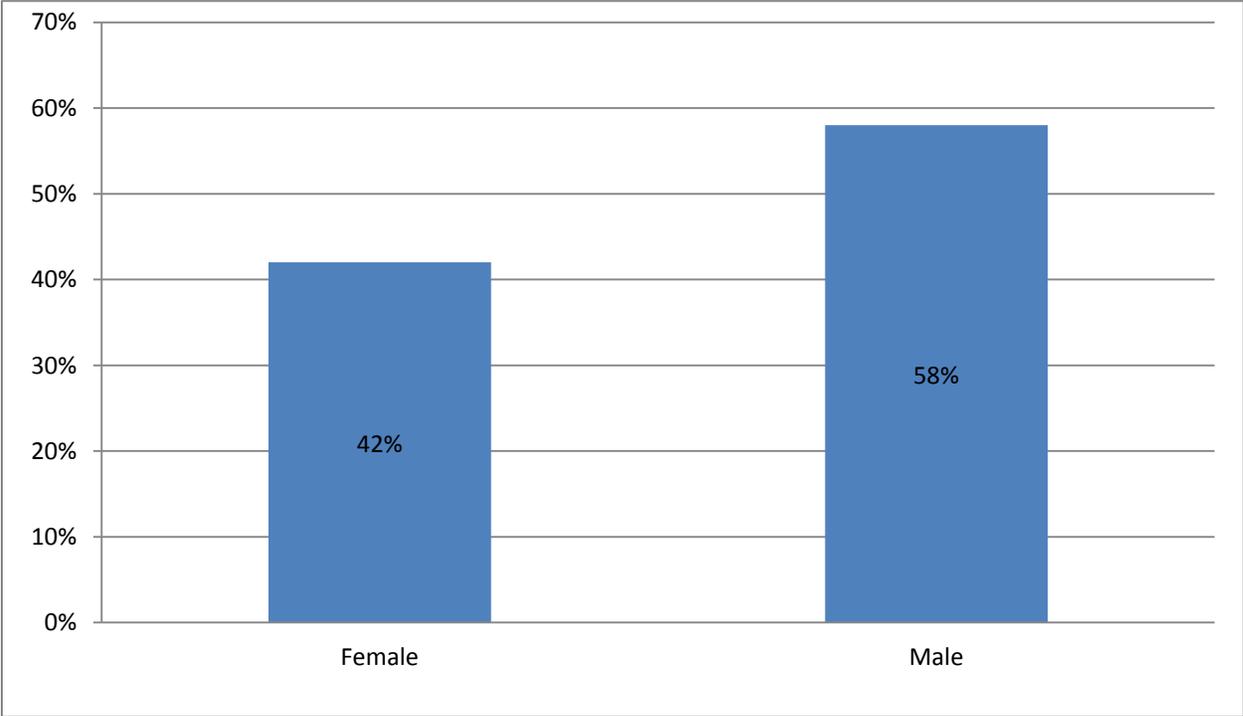
- General Questions About Your Family 3
- Before Your Child's Procedure 12
- During Your Child's Hospital Stay 30
- After Your Child's Procedure 45
- General Questions 49

Total surveys distributed: 570

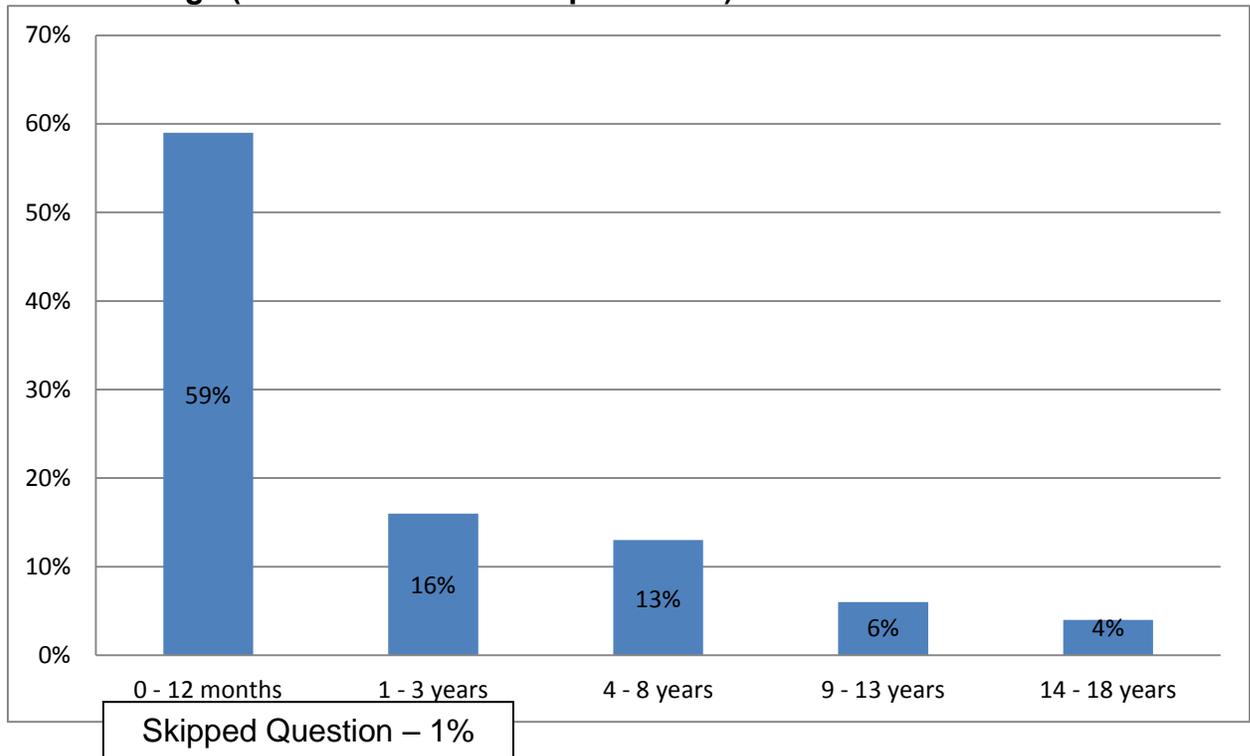
Total number of respondents: 142 (25%)

General Questions About Your Family

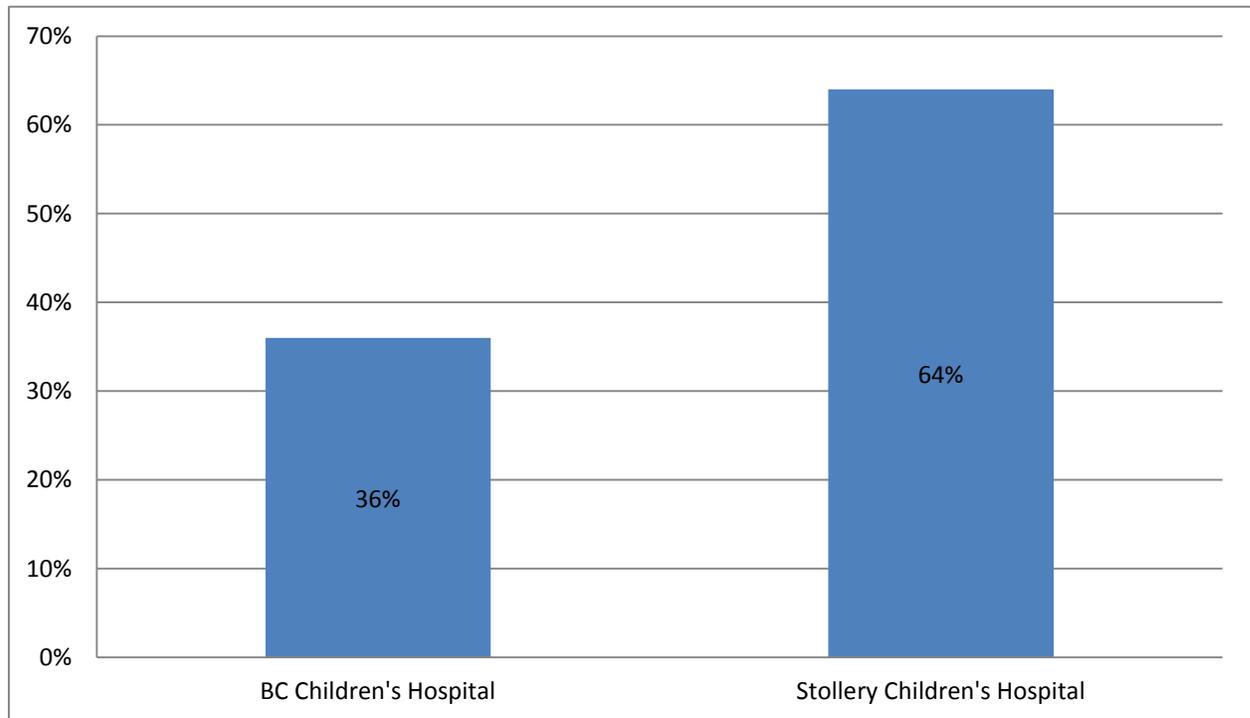
1. Child's Gender



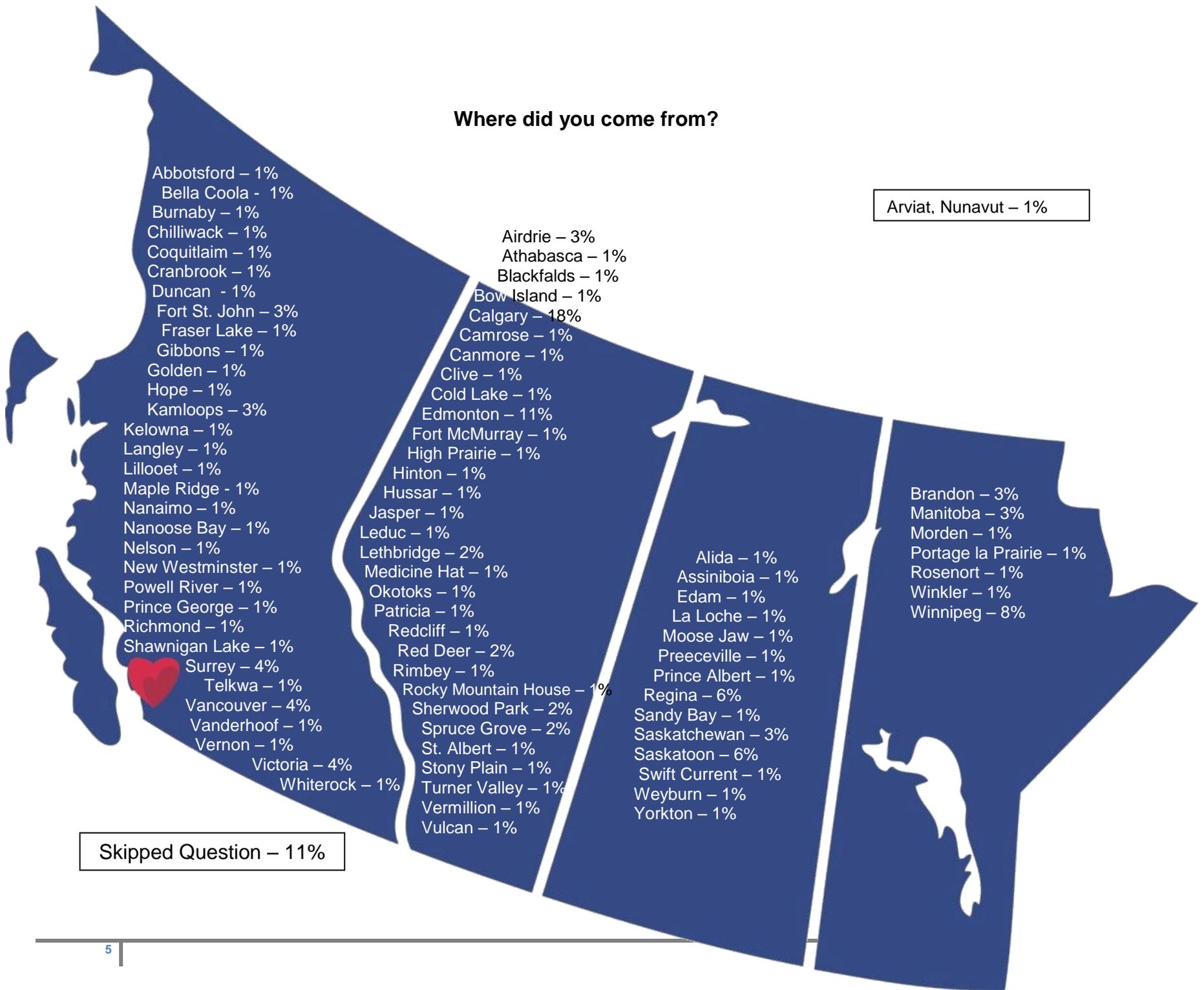
2. Child's age (at the time of cardiac procedure)



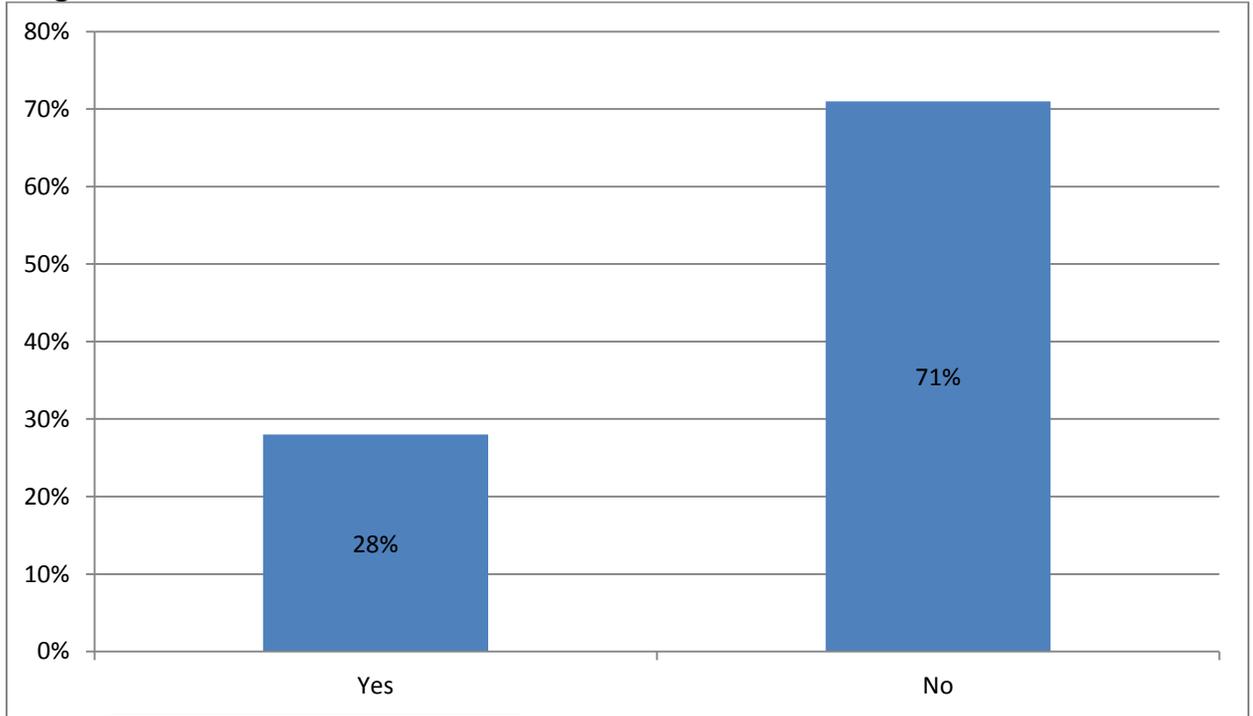
3. Where did you go for the cardiac procedure?



Where did you come from?

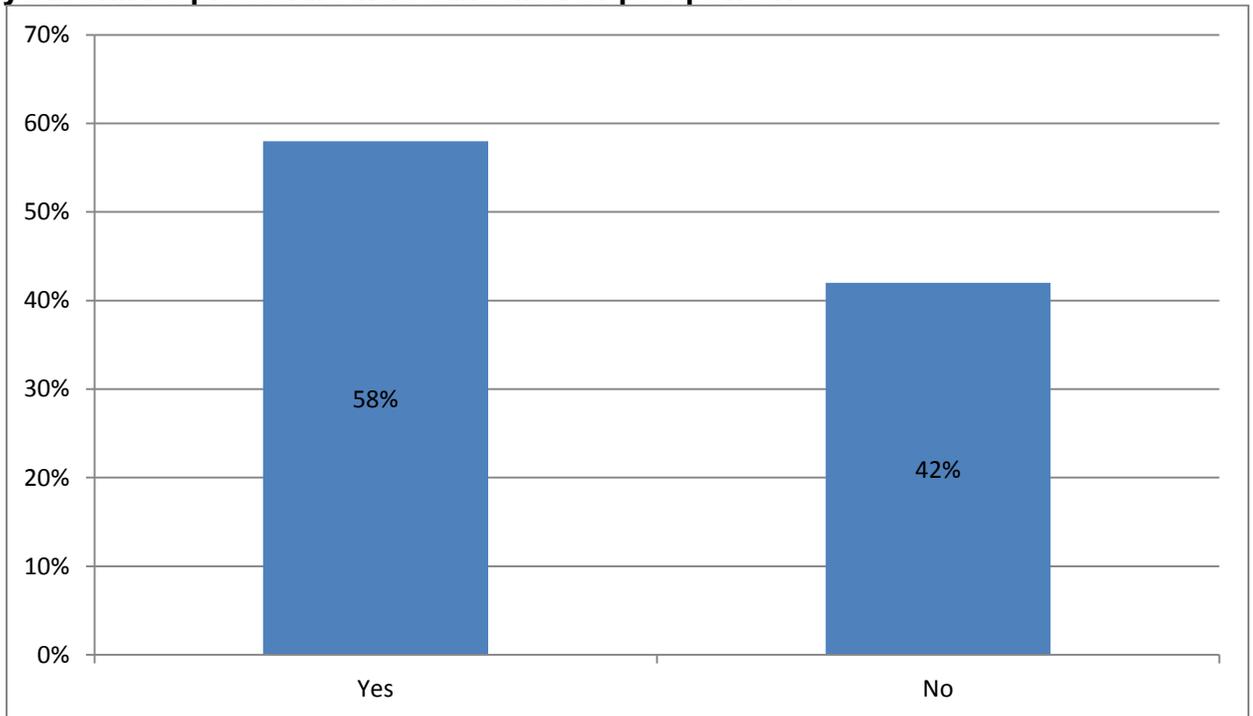


4. Was your child's current procedure ever cancelled or postponed by the surgical centre?



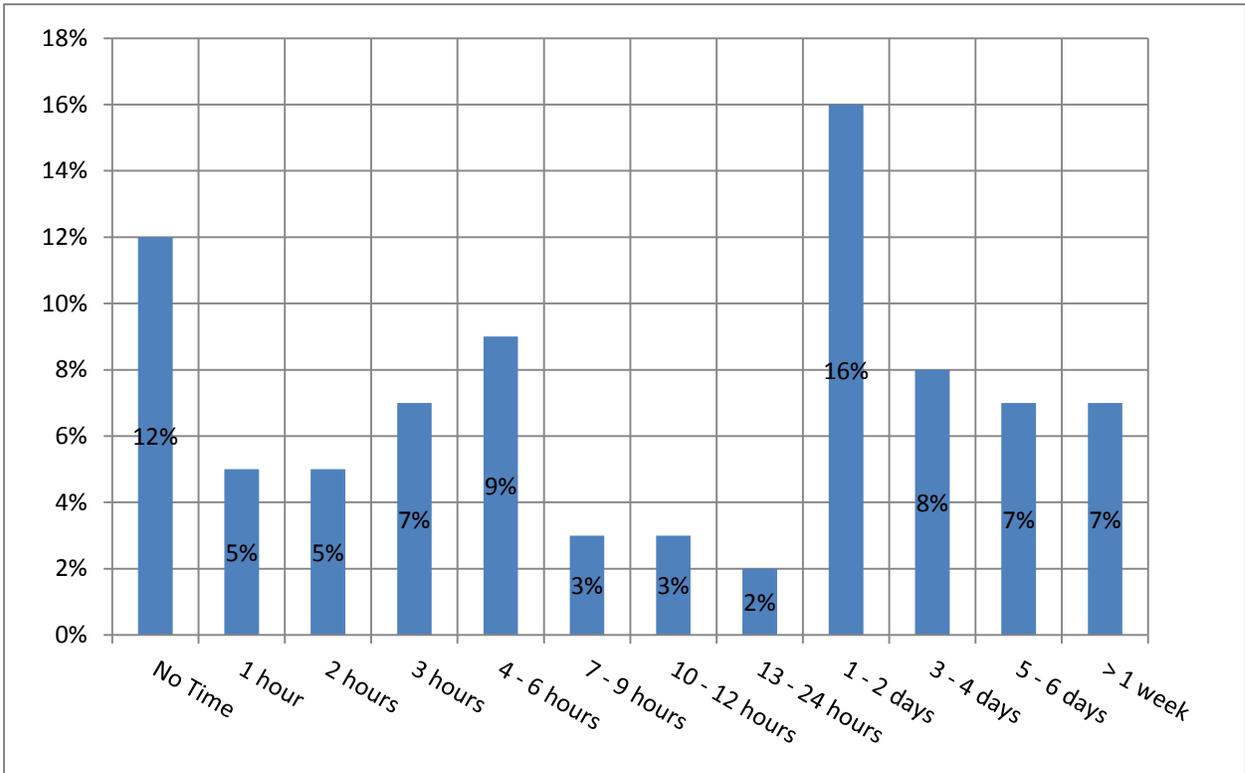
Skipped Question – 1%

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



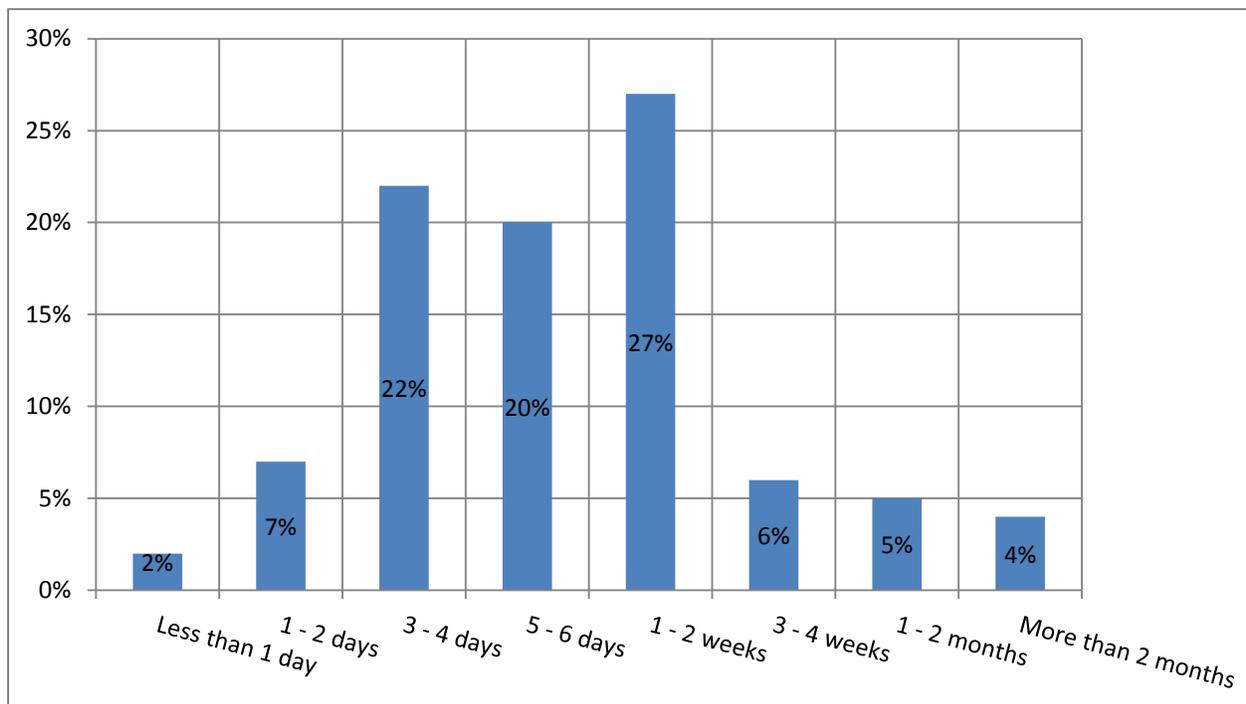
How long was your child's stay at the surgical centre:

Before they were taken to the OR:



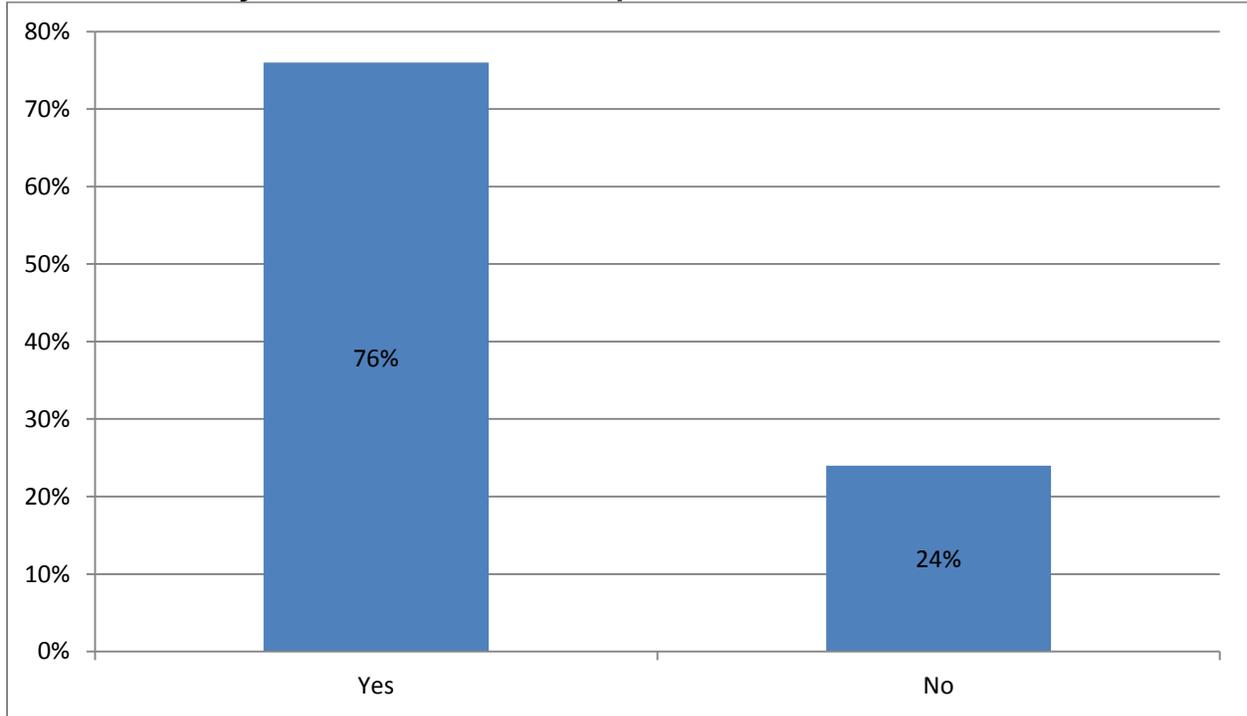
Skipped Question – 16%

After they had their procedure:



Skipped Question – 9%

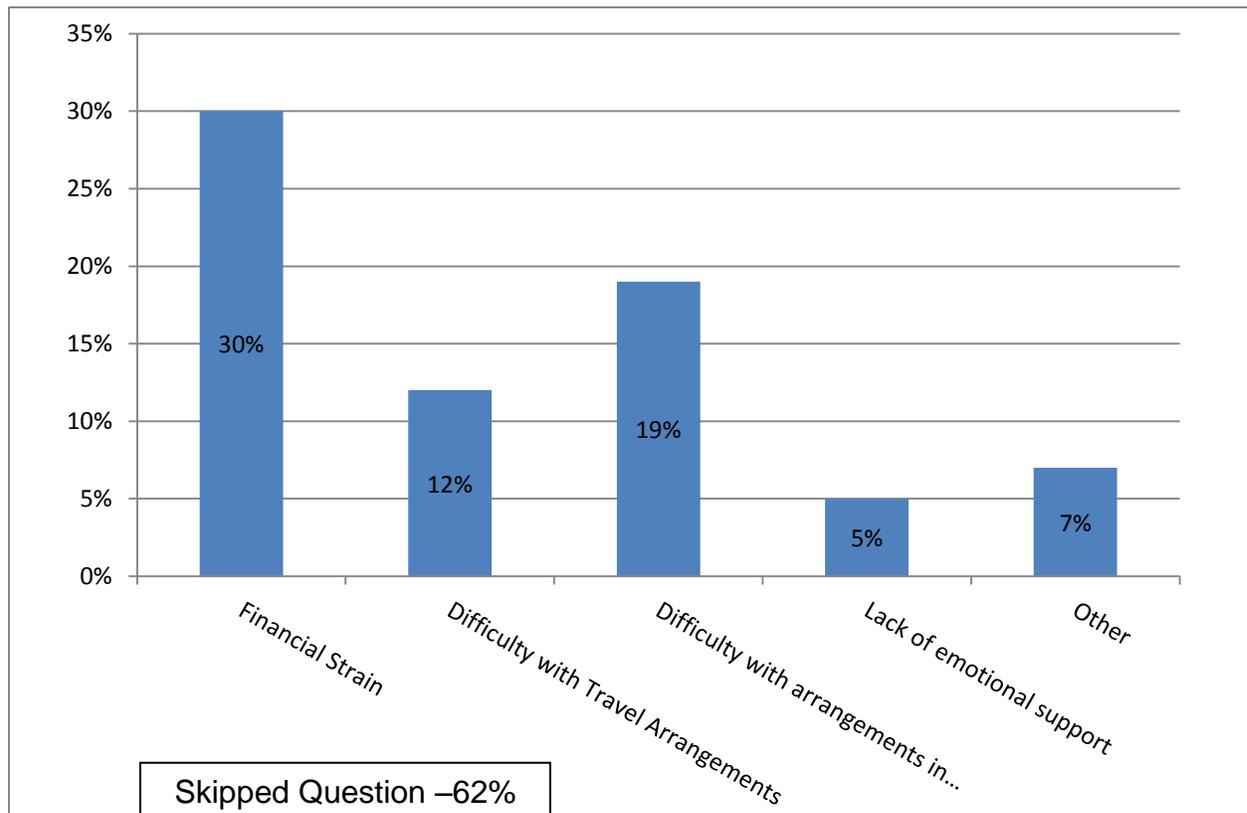
5. Was this your child's first cardiac procedure?



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

	Combined Results
Heart Catheterizations	61
Surgeries	96
Electrophysiology Procedures (ie. Pacemakers & Internal Defibrillators)	15

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



“Other” responses:

- Travel arrangements back to Winnipeg.
- The support we received in Edmonton far exceeded my expectations. Planning for our home, work, and everyday lives was very difficult as there were so many unknowns and no one was willing to estimate timeframes.
- Lack of emotional support and/or understanding by some staff. Emotional stress/distress.
- Not that it was anyone’s fault, but we were cancelled 3x so we went through a lot of emotional strain. But the staff were very helpful.
- Difficulty getting employer to allow time off from work.
- Misinformation.
- Social workers helped a lot.
- We were fortunate to have family in Edmonton to stay with. Had we not, it would have been more of a financial strain on our family.
- We had help with expenses from Kinsmen Telemiracle, so that was wonderful. We did have to give up our apartment in Saskatoon because we were told we would be in Edmonton for three months.
- Outpatient residence has a three month maximum stay. Ronald McDonald House was too far from the hospital and our baby.

- There was no room at the Ronald McDonald House. We had to rent an apartment.
- Financial strain was not too much due to child being on first nations.
- The support of the surgical centre is so well.
- We did have financial challenges as my husband had to close his business (he is self-employed) when our daughter had her surgery. However, the funding we received which covered the meals and groceries during our stay at the Children's Hospital, the option of staying at Ronald McDonald House for free, and the free ferry ride, was a huge help.

Comments:

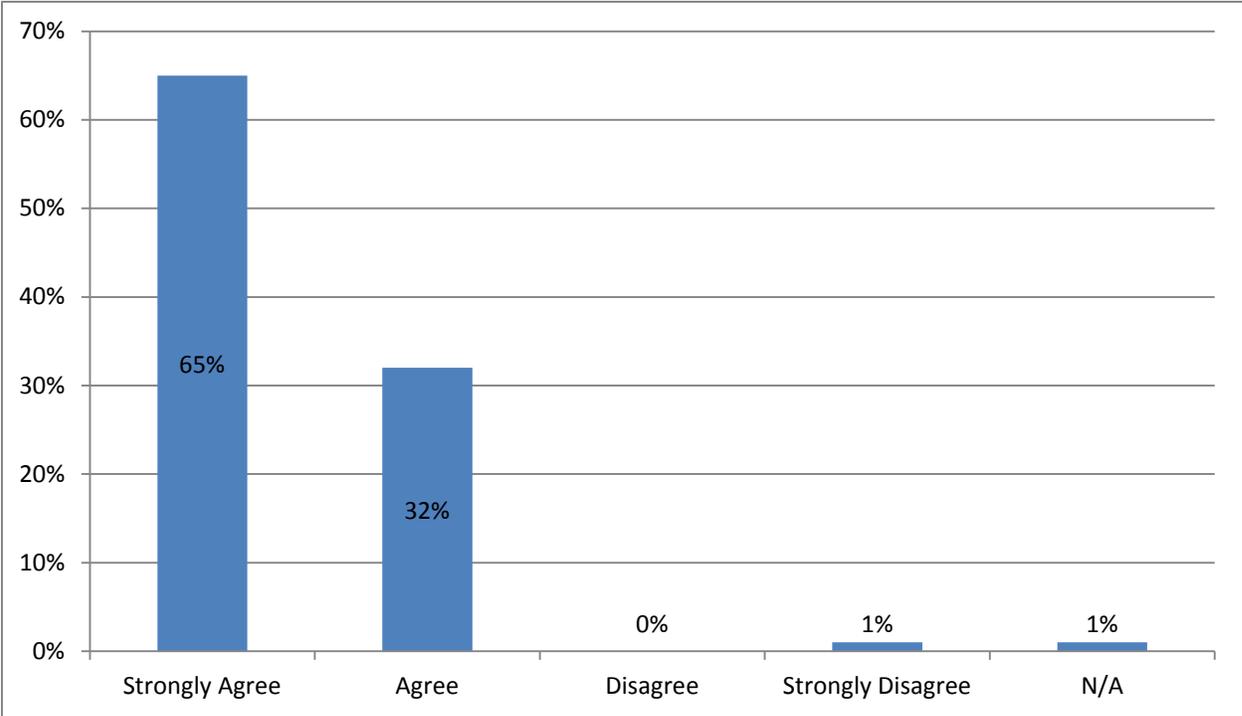
- Financial strain – alleviated by generous gifts from family and friends. Social worker did not inform about potential government financial help in a timely manner.
- Support could not have been better. Both baby and parents well supported.
- Limited amount of space at Ronald McDonald left us needing to find a hotel as the surgery was done at relatively short notice. As a low income family this was incredibly challenging.
- We were very blessed to have so much support from family and friends.
- We were lucky to have a place to stay for free. If we hadn't had that, there would have been financial strain.
- We felt very supported throughout our entire trip.
- The surgery was unexpected so we had a difficult time finding someone to watch our older child as we have no family in the area.
- Our stay was wonderful and satisfying.
- I wouldn't say "difficult", but we definitely had to make arrangements on a daily basis for child care for our daughter (2 years old) at home, as well as for our pets.
- Our daughter's stay was filled with complications – UTI, blood clot, ECMO.
- We had many great nurses and support staff but also many who lack the experience and compassion to deal with critically ill children.
- Our stay at the hospital in Edmonton was awesome. The nurses were so very happy, he had good service. Oh, I can't explain to you how great our stay was.
- We were very fortunate in that our son's surgery went very smoothly, and so we were home within a week. In addition, our parents live in Edmonton and so we were able to stay with them, which helped financially, as well as provided emotional support.
- We made it work. Mom stayed home with the other two kids (one in school) and Dad went with child to the hospital. Stayed at a relative's house.
- Support in hospital was amazing. All staff members were helpful and treated our son well.
- Luckily we are self-employed and had great family and friends help out. But we can understand how emotionally and financially straining this could be.

- Having our surgery postponed twice complicated our plans for staying with family in Edmonton, time off work and care of our pets.
- None. Stollery was amazing. The medical staff were exceptional. They were knowledgeable, reassuring, confident and compassionate. Everything you want and need in a time like that.
- Finding childcare for our other children was most difficult, as we do not have family close by.
- Child's health decreased quickly so hospital stay/surgical intervention this early was unexpected.
- My sister lived 5 minutes from the hospital which was lucky because the Ronald McDonald was full as were the host hotels.
- It was very difficult to be "house-bound" for 1 month before so we didn't get sick. And the surgery kept getting postponed so we had to wait longer.
- The team at the Stollery are fantastic. We are thankful for them.
- We were told by Winnipeg HSC that my son would travel back to Winnipeg via air ambulance and his clothes/car seat would not be needed. Edmonton released us to take a commercial flight. Edmonton did supply what we needed, but this added extra strain to our family. Also, when leaving, we were rushed and ended up missing our flight. It was also very difficult to get assistance with packing expressed milk to bring back home.
- It was our first experience at Stollery. Experience while there was fantastic.
- We travelled to Edmonton from home the day before our PAC appointment. The surgery was scheduled for two days later, but was postponed for another three days. Because of holiday/weekend, bad weather, and far distance from home, we ended up being in Edmonton for seven nights before our son's surgery. No one's fault. His surgery was postponed due to an emergency. Quite a bit of waiting in the hotel and extra hotel costs, but just a weird combination of timing/distance/emergency.
- My nanny and friends looked after my other twin. We were in touch by phone.
- We had bought a house and were moving at the time we went into the hospital. My husband had to take a leave without pay from work to be at home with my daughter.
- There is no extra coverage for follow up pacemaker appointments in Victoria. At least when we have to go to Vancouver, our ferry costs are covered.
- Staff were very supportive.
- We live in the Lower Mainland, BC. Travel accommodations, travel and support, both financially and emotionally are readily available.
- We were very blessed with help from our community, Kinsmen, family, and friends.
- The nurses were so very supportive and caring. This helped us emotionally to have wonderful support from the hospital.
- Before surgery, when we were booked to travel to come, I felt like we could have been informed better as to when we could go home. We had to guess when we would be going and it costs us extra because of it.

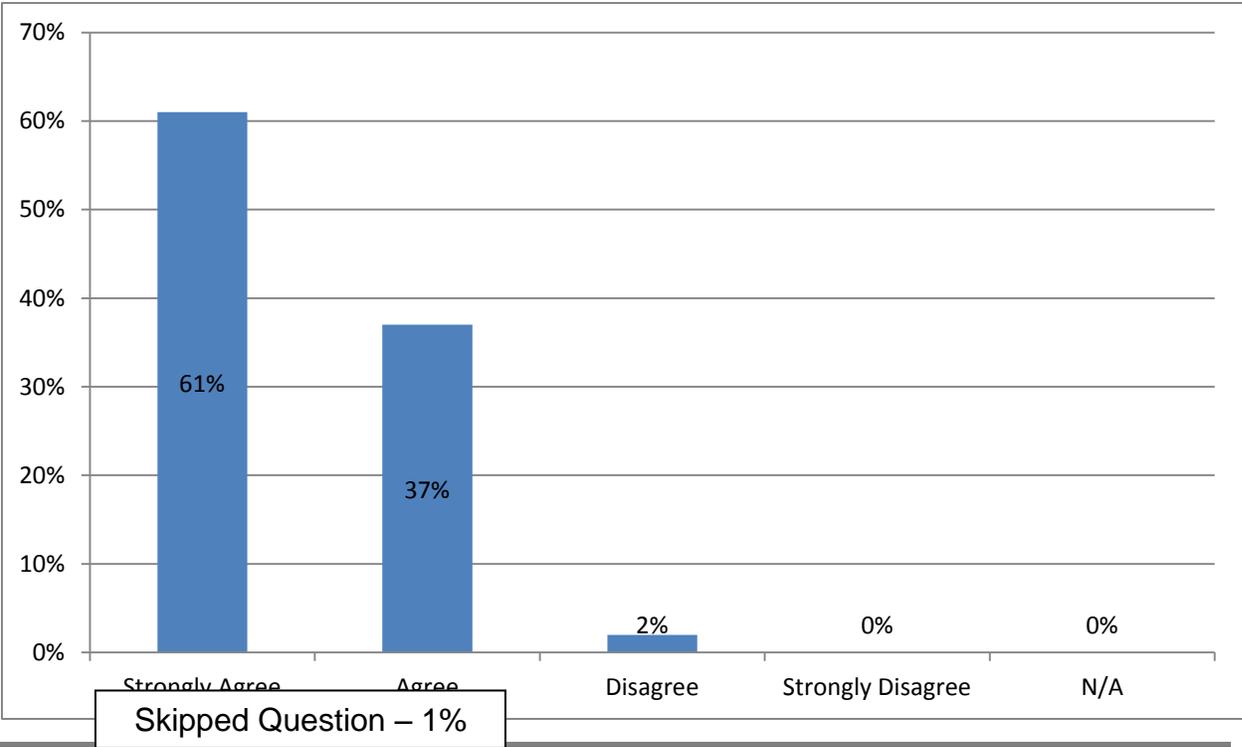
- The team at BCCH was amazing. Our surgeon gave daily updates to me and my family. It was really comforting and reassuring.
- PICU staff were extremely comforting and engaging during the process, ensuring we were aware and comfortable with goings on.
- Quick timeline made it challenging for our 3 daughters we left in Vernon. More of an emotional challenge.
- We were very impressed with the information we received prior to surgery. Staff were informative, clear, sympathetic and optimistic.
- Exceptional care throughout.
- We received help from the BC Family Residence Program, which paid for accommodations.
- No. We did not feel any of the aforementioned strains as we are fortunate enough to have a very strong family system. Our family support was available to us throughout the process.
- Thanks for all the help that we needed.
- Very helpful, pleasant, and kind staff. Especially the ICU staff.
- No. Great place, amazing staff/support.

Before Your Child's Procedure

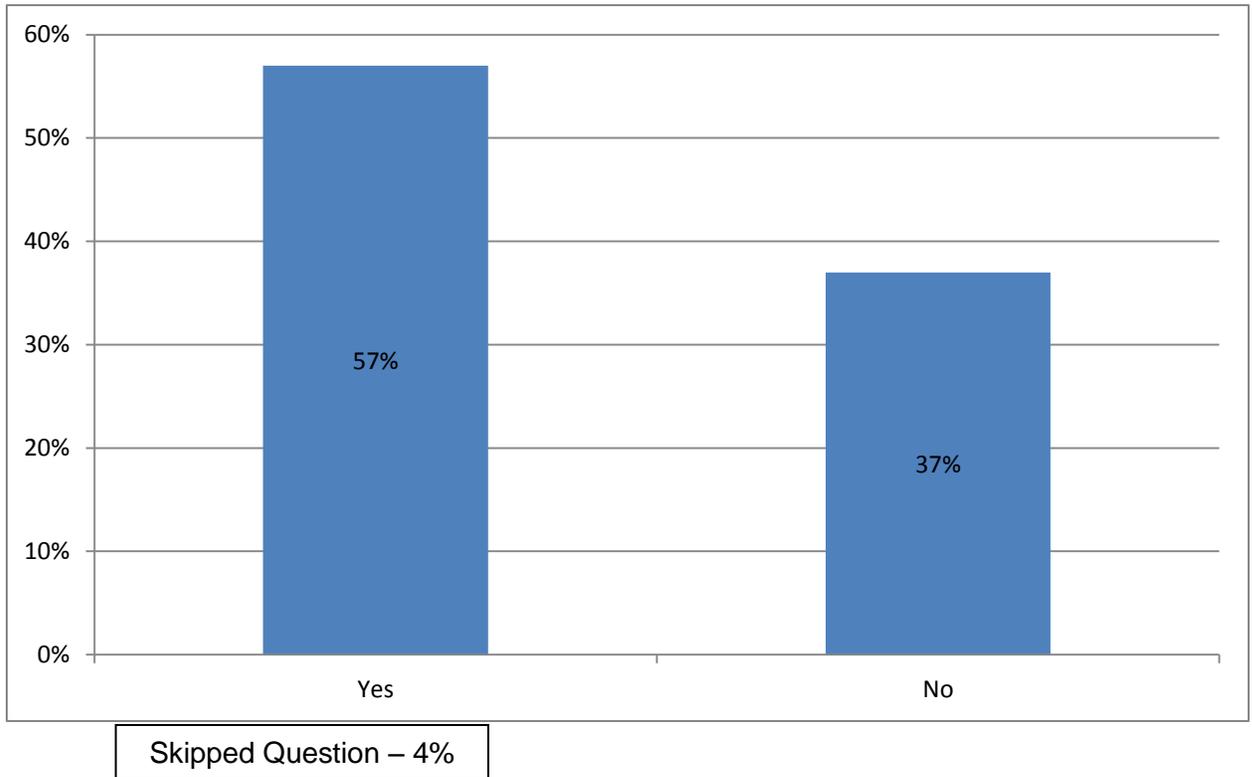
8. I felt I had a good understanding of my child's heart condition before the procedure.



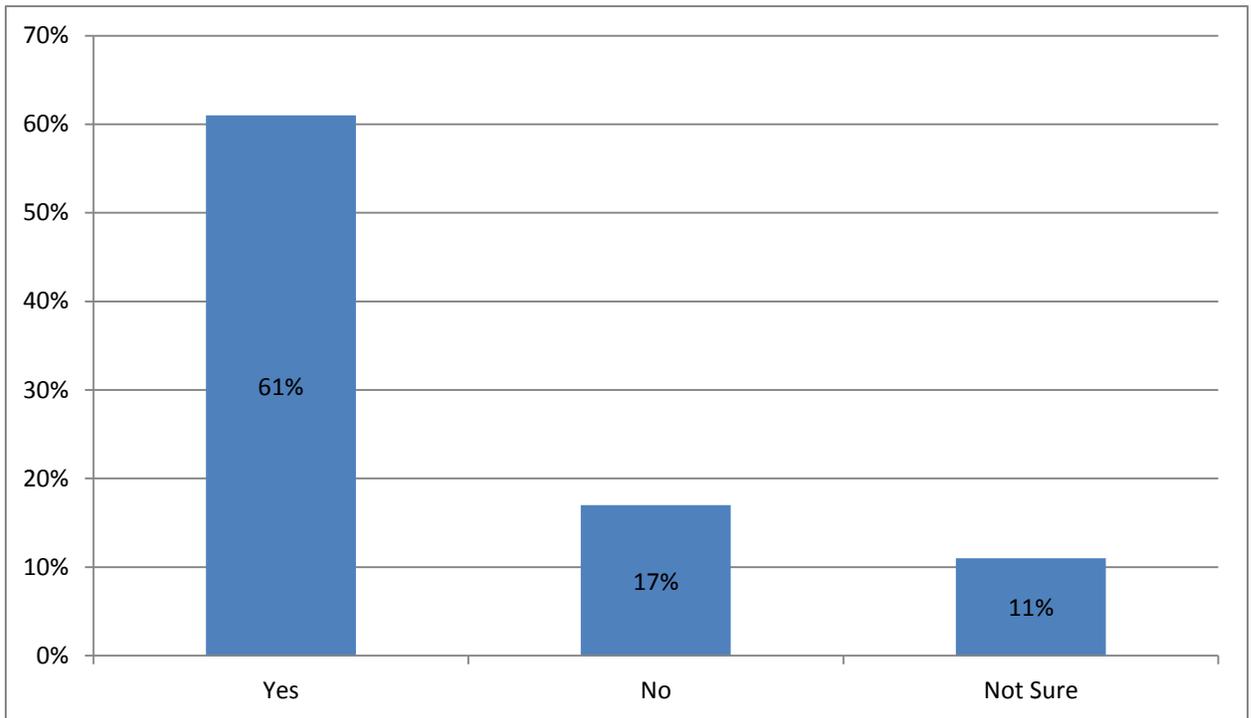
9. I had a good understanding of my child's procedure.



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?



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

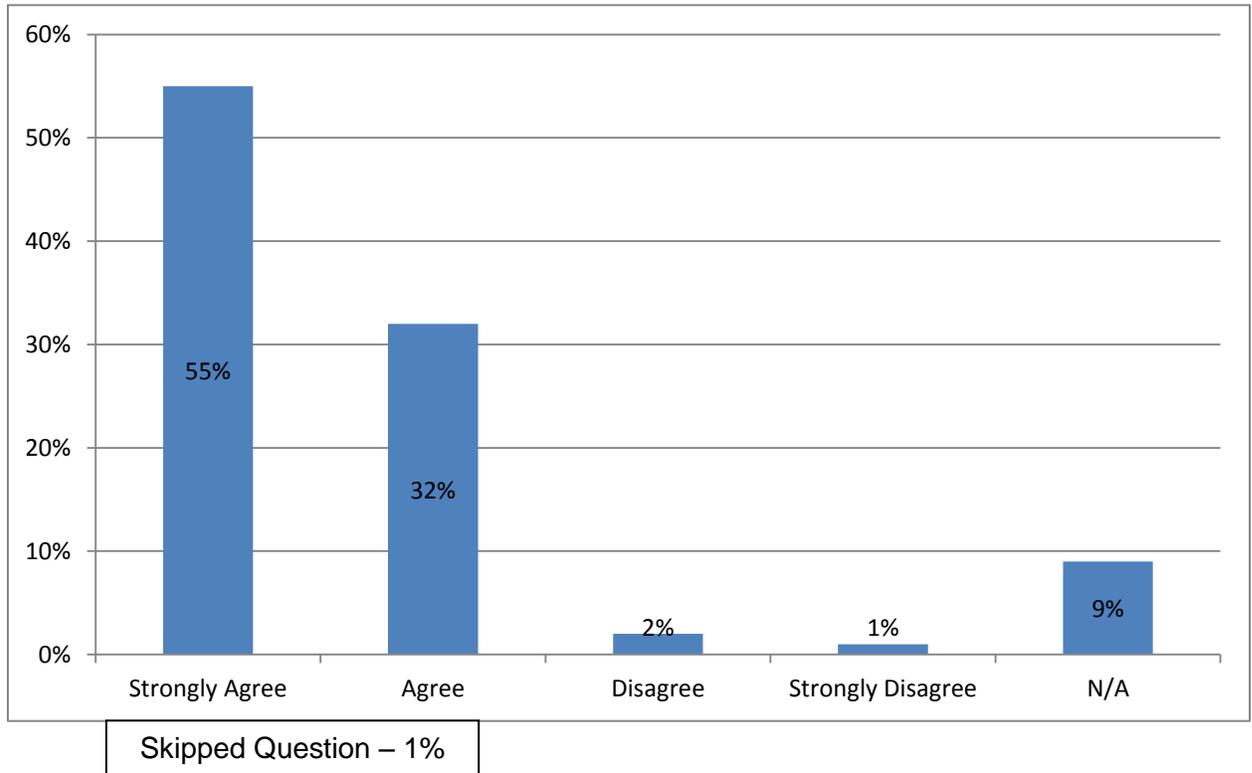


Skipped Question – 4%

If yes, who spoke to you?

	Combined Results
My child's cardiologist	120
One of the clinic nurses	46
Other:	-
Multidisciplinary video conference	2
Pediatrician	2
Other Physician/Cardiologist	5
Social Worker	1
Surgeon	6

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



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

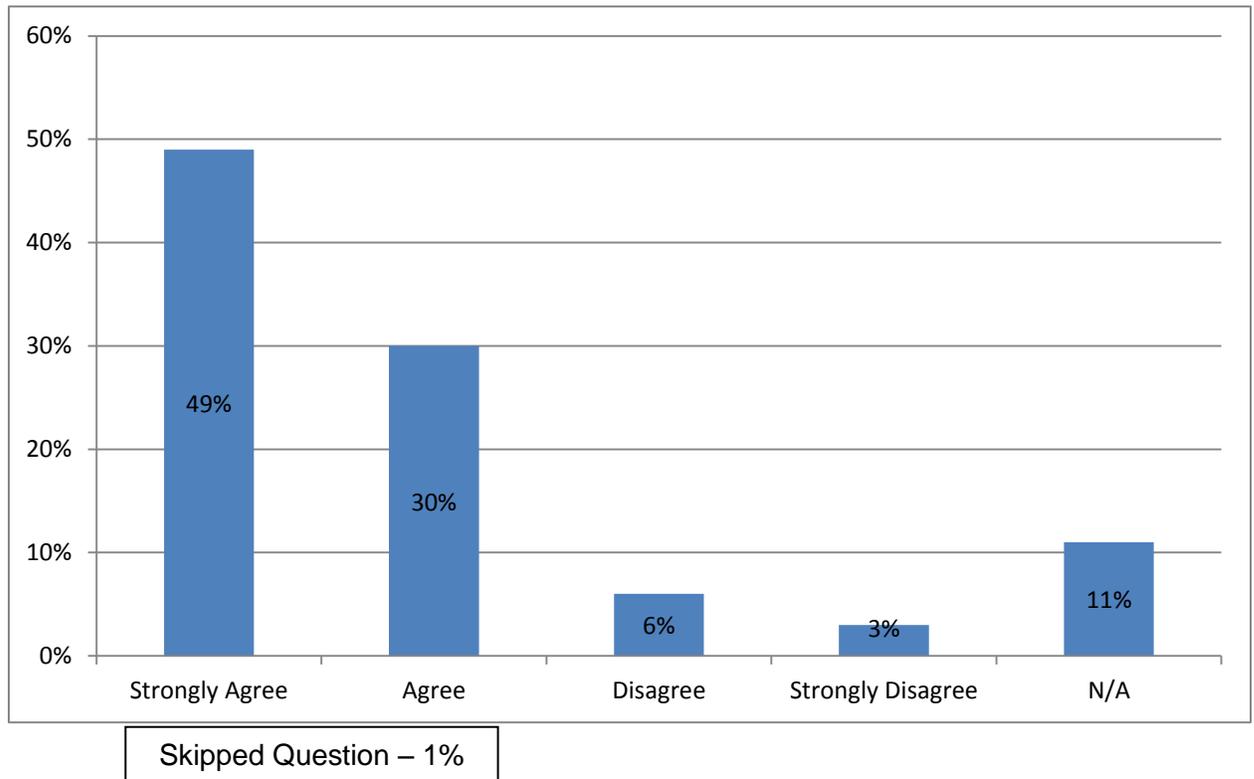
- Nothing. It all went smoothly.
- Stop cancelling her surgery and do a videoconference so I would understand more about my daughter's condition.
- Nothing. I think everything that was done was good enough.
- I believe that my child was as prepared for this given her age.
- Not sure – still difficult to explain at young age.
- Better notice before surgery.
- Nothing. We were very lucky.
- Nothing that I know of.
- All was good.
- I feel that everything was done excellently to prepare my little girl.
- Nothing as he was very young.
- Nothing. Everything was excellent.
- There was an error in the pre-admit clinic day. I was told to fast her for a different time. So she spent much longer being hungry than needed.
- Surgery being cancelled on three separate occasions slowed down recovery process and spending more time in hospital.
- Not one thing could have been better. I wouldn't change a single thing, everything went perfect.
- He was only 3 months old.
- Nothing.
- Nothing. Everyone prepared her and us as much as they could.
- Maybe a cartoon of what was going to take place so that the kids have a better understanding what the doctors are going to do. Our son was very nervous.
- She was only 3 months old – not much could be done to prepare her. The directions and advice we were given was excellent.
- A picture book.
- Everything is fantastic.
- Nothing. He was 2.5, he understood his heart had a hole and the doctor had to fix it.
- Waited for me (mother) to be present before doing certain procedures (ie. Taking blood, etc.). This was not always done or considered.
- Doctors and nurses in Edmonton/Saskatoon are the best. I wouldn't change a thing and we love them all for their hard work and dedication and the support they give. I'm speechless.
- Nothing. He was well prepared.

- I guess if the staff could try (as much as they could) to take note of fasting requirements when booking OR times and rescheduling.
- She's too young.
- He got best care possible in Alberta Children's Hospital.
- Nothing. Care was excellent.
- Nothing. He is 19 months old. It would have been scary regardless.
- He wasn't sure why he had to have a pacemaker. He thought the medications would be good enough. The doctor explained to him why he had this procedure.
- My son was given a doll from Child Life but we weren't told we could draw on and play with the doll as if it were my son.
- Several weeks before the procedure, we received a call from the surgical center describing when to hold his medications in the days prior to the surgery. A follow up email would have been appreciated describing when medications should be held would have helped, so we wouldn't have to rely on memory, or have the possibility of misplacing the paper which we wrote the information down.
- Knowing how long the wait times were before the procedure. Being made aware of postponed or longer wait times before having to ask.
- The worst part of the whole thing was fasting for the sedated echo in our PAC. If our son could have had his sedation/echo first thing prior to meeting with specialists and care team, he would not have thought he was starving and come completely unglued like a savage beast. That was the most exhausting morning of the whole experience for my spouse and I because our son was screaming, angry, and hungry, and we couldn't placate him. The quality of care from PAC to surgery to ward was so excellent. The worst part of open heart surgery was one morning of fasting.
- Nothing that I can think of.
- Absolutely nothing. We were very well informed before, during, and after her procedure.
- She was too small to understand. But she did miss her twin brother.
- Perhaps during pre-admission, there can be a discussion with the parents re: the amount of information and details told to the child about their procedure and lines/leads the child will have post-op and during the operation. My child was very overwhelmed with the amount of details/information told to him by the pre-admission nurse.
- Nothing comes to mind. My child needed the procedure as she was experiencing signs of heart failure.
- Nothing that I know of. He was well taken care of.

- Blood work done ahead or when he was sedated. It was hard to find a vein and he was quite uncomfortable.
- Updated children's book on what to expect. This book was copy written in 1990 – pictures and certain words created anxiety for my child. Need a book that is more up to date for 2015.
- My son was sent to Vancouver but they were unaware at the hospital that he was on oxygen. I informed them it was for pulmonary hypertension and was informed that was unlikely as a VSD and pulmonary hypertension typically do not go together. Thus leading them to do the cardio cath and angiogram.
- I think she was well taken care of. Child life came in and met her the day before and was there the morning of. We met with the Cardiologist and Surgeon the day before. It's a long day for a kid was the only problem with the tests, ultrasound and blood work.
- Not much seeing she had surgery 2 days after she was born.
- Updated photos for arthroscopic surgery instead of open heart.
- Everything was perfect regarding both procedures. BCCH was outstanding.
- Nothing. They were outstanding.
- He was well prepared.
- It is hard to answer this question as he was 3 ½ at the time and is very hard to prepare them for what was going to happen. He didn't quite get it.
- BC Children's Hospital took time and care and our son was prepared and had little anxiety. The length of time for the pre-assessment was a little too long for him and maybe too much information in regarding to the procedure - sometimes less is more if they aren't stressing about what is to come.
- Nothing. The staff (nurses and doctors) were great.
- My child underwent emergency heart surgery after being medevaced. There was very little the surgical centre could have done to prepare him or us for this. Also, he was too young to have any idea what was about to happen.
- My child was 2 ½ weeks old. Nothing further could have been done to my knowledge.
- Nothing. Child too young to understand.
- When baby grows up, it is important to give him emotional support.
- Nothing – only five months old.
- No. My child was newborn.
- Nothing. He was well prepared.

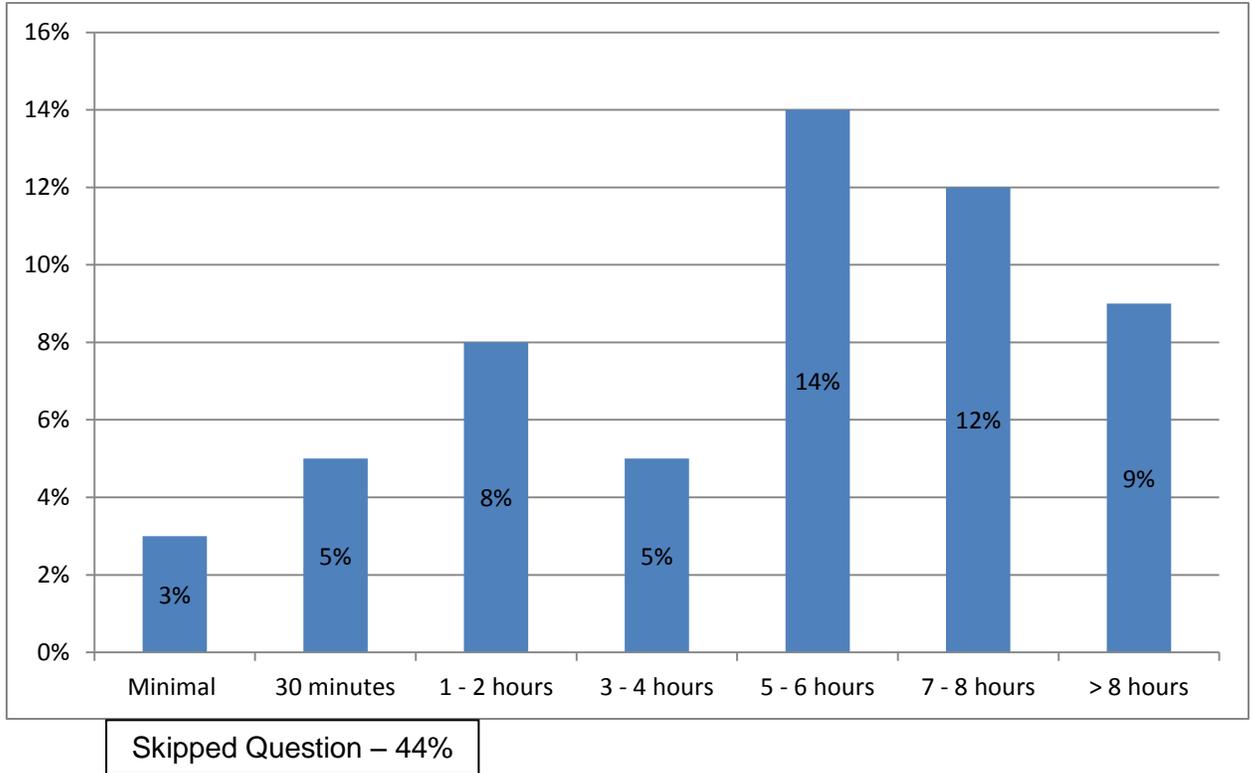
- Had the procedure been booked early in the morning and started on time. He was very upset and cried a lot before surgery due to being very hungry.
- Nothing.
- We tried to have my son meet/talk to another teen his age that had the procedure, but it couldn't be arranged. I think such a peer meeting would have helped alleviate some stress and anxiety for my son.
- Nothing.
- Nothing. Everyone was wonderful.
- Can't think of any.

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



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

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



b) Please comment on the pre-operative clinic environment:

- Clean, friendly, organized, and knowledgeable.
- My child was admitted early during the clinic.
- Mostly calm. The nurse showed pictures of what to expect. It took a long time but everyone was helpful.
- Everyone was very nice.
- The pre-operative clinic environment was very good despite the wait on all the people coming to speak with us and how many hours my daughter had to go without eating.
- Everyone was very nice and informative. The wait time was alright for us, just long for my child.
- Caring staff, clean, enough activities to keep the children entertained.
- Staff was very informative and caring. Things were pretty well coordinated.
- Quiet and very calm.
- Clinic was calm, but my child got very bored in between waiting for doctors and tests.
- It was good. The nurses were very nice and supportive.
- Clean, friendly/helpful nurses.
- Good staff.
- Nurses were very helpful.
- Uncomfortable, like we were in the way. The nurse that did his pre-op was extremely rude.
- Very good.
- Went well.
- The nurses were so good and I can't complain about anything.
- Everyone was wonderful. Long day but everyone did the best to provide fast, effective service and to help us get home as fast as we could.
- Was a comforting environment. Staff was very good with our son and our daughter who was also with us.
- Everything was booked in order so not to much waiting. The sedated ECHO was booked later than the letter stated so our daughter was fasting for much longer period then needed.
- Good.
- Pre-op was awesome.
- For the time we have to be there, there is nothing to do for the kids.

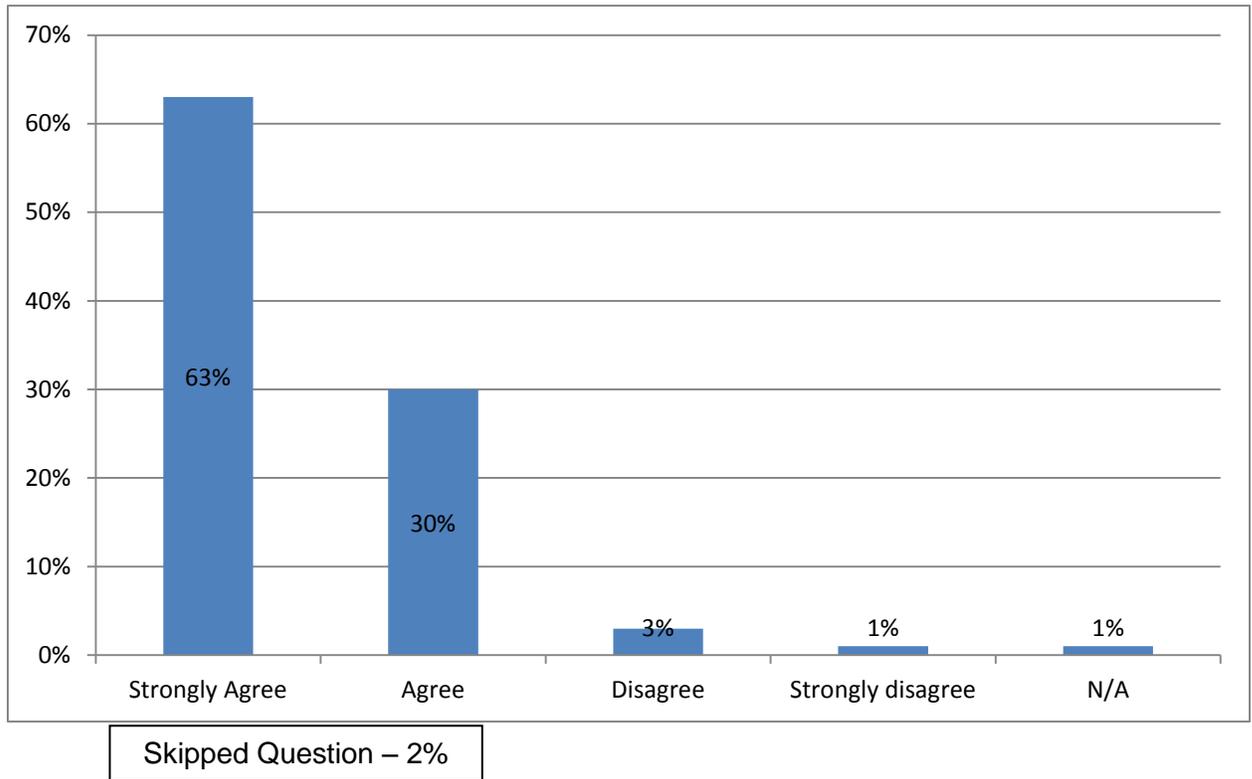
- We had an issue where they closed before we could collect our stuff at the end of the day and had to wait till the following day to pick it up. We wish we had known this would happen.
- The environment was very happy, relaxed, and positive.
- It was ok. The people were wonderfully supportive and helpful, but the clinic area itself was rather dated, uncomfortable, and impersonal.
- Very busy that day. There was hardly any room to sit down.
- Good.
- Busy; overburdened; too few staff; many families waiting; long wait times; kind and helpful staff.
- Professional, busy place – but still a calm environment with a friendly atmosphere. Very informative – a lot of info to take in.
- Friendly, informative, thorough.
- Was good.
- Need better prioritization of tests. For a 2.5 year old having an echo at 1pm when he should be napping was awful. Getting tests done that need more cooperation earlier in the day would be better for his age group.
- No major concerns.
- Everything is so great.
- Took long between appointments. Wait too long in Cardiology – he was seen by a resident for his ultrasound. It took more than 2 hours.
- I feel that the environment was good. The nurse we had was very caring and concerned. She took time to explain what to expect and the course of events.
- It was a nice and clean environment.
- Overall, it was quite, calm (having our own room while waiting was helpful).
- Environment was typical hospital – somewhat cold. But staff was great. Long wait to talk to surgeons, specialists, echo, etc.
- It was a long day but they did their best.
- Good.
- Best possible.
- My son was very anxious. The team was amazing. They got things done as quickly as possible.
- It was good. The staff explained everything as we went along through the clinic time and then had about 1.5 hours before surgery.

- We were scheduled for 7:00am. We got in right away and everything seemed well planned out and scheduled appropriately. We left the hospital about 1:30pm. Long day but no complaints.
- It was good. They have plenty of toys and a TV and we were allowed to go out and walk around while we waited.
- Very positive. It had toys and a TV with kid's movies.
- Very good. All tests were scheduled and we were kept well informed of who we were going to see.
- It felt like we did a lot of waiting and had a very grumpy, hungry baby.
- We had two pre-admission appointments. One the day before the surgery date that was cancelled. Then had to go through it again the second time.
- It was comfortable but felt like we were waiting around a lot. I'm sure it was due to unexpected problems getting blood from my son. His veins are difficult to draw blood from.
- Typical hospital experience. Friendly staff.
- My child was in the PICU before and after the surgical procedure.
- We had a lovely nurse who cared for us immediately and thoroughly. PAC was quite and clean. Impressed that we met all of our son's team from PTs, Social Worker, Anesthetist, Surgeon, etc.
- Took a long time to get through all the tests. Lots of waiting.
- It was ok.
- It was a wonderful experience. They function like a well oiled machine. The staff are very professional and knowledgeable.
- I appreciated the multi-disciplinary approach (ie. Social work, physiotherapy, etc.)
- Very explanatory. However too long and my son became overwhelmed with all the detail.
- Kind, helpful, patient, caring.
- We stayed at the surgical daycare for about 6 hours prior to surgery.
- It was amazing. PAC Nurse was such a great person to work with. She made the day a little less hard.
- Very calming and supportive.
- NICU at Children's Hospital was good.
- Very quiet.
- Friendly nurses.
- It was good. The staff were helpful but the front desk people were not that personable as the staff doing the tests, etc.

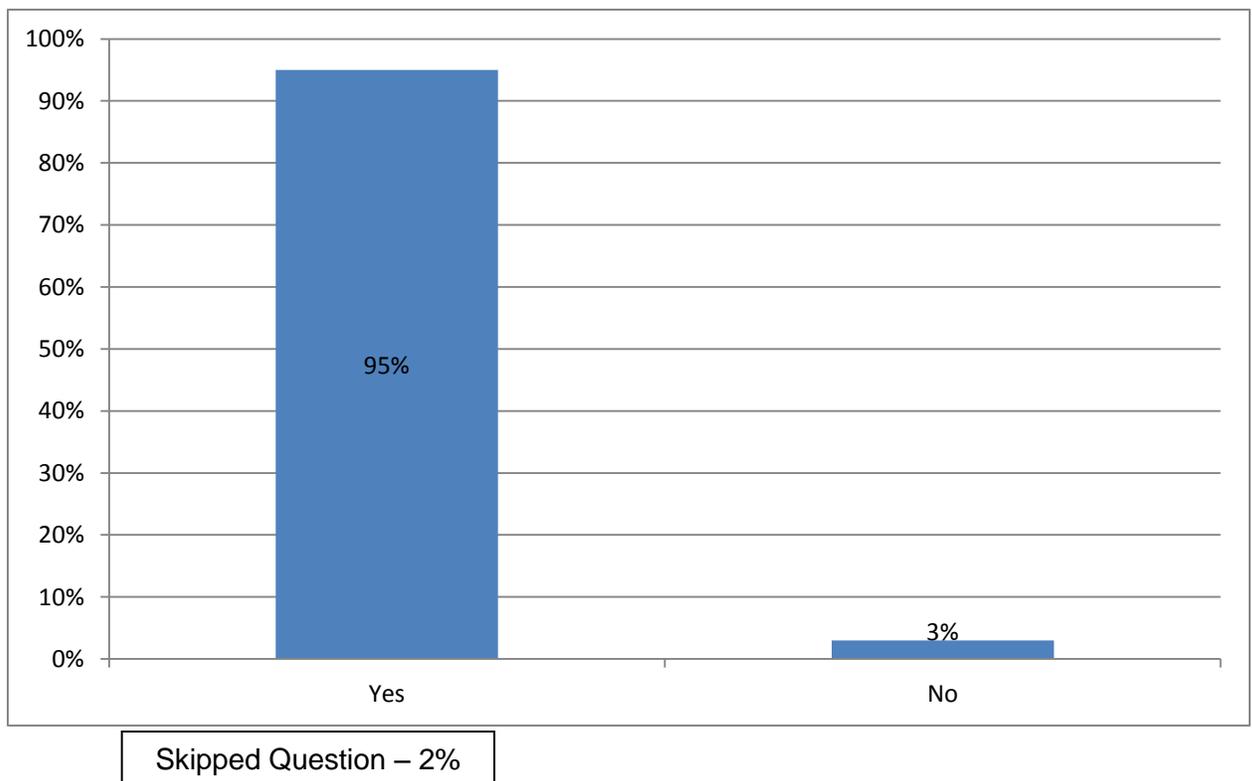
- They made sure we were fully aware of the procedure, gave us a tour of what the day involved. Very supportive and helped set our minds at ease.
- Well it was stressful for parents and long for kids but they give you lots of information on how it will be and to bring food and stuff to do for them. I don't see how they could make it any different. It's just a hard thing for a family to go through.
- Professional and child friendly.
- Very efficient and thorough – really helped my son. The nurses were excellent at explaining and helping. They did it as quick as possible.
- Very friendly, caring staff. Very comfortable environment. Lots of toys and movies for the kids. My daughter was even given a teddy bear and some toys to take home.
- The staff was very warm and comforting to patients and parents.
- Fine. Tablets for boys to make them not scared. It was pleasant.
- All appointments were prompt and thorough.
- It was a bit hectic having to run from one room to another but when you have pre-work done that is what happens I guess.
- Fine.
- Great.
- Very calm and the nurses were friendly.
- Long time between “stations”.
- Positive.
- Good.
- Positive and friendly with helpful nurses.
- Can't remember.
- It went very well.
- Very helpful, calm, informative, and reassuring.
- It is a very long day with lots of information. But the staff were very helpful.
- It was very informative. Nurse Practitioner was very thorough and helpful.
- Nice place with kind people.
- Clinical and professional.
- Friendly, caring, and knowledgeable.
- Everyone was informative and efficient. The only major wait was to meet with the surgeon, but that is understandable.

- Very long (hard with a baby who needs to nap). Too many different doctors and nurses asking the same questions we already answered – would be nice if it was all done at once.
- Pleasantly normal.
- The place is easy to find where everything is (ie. X-ray, surgical day centre, heart centre).
- Good explanations to parents.
- Clean, excellent, friendly, welcoming and warm staff.
- We saw pictures, met with nurses and surgeons. Everyone was amazing.
- It was friendly and fun for our daughter.
- Excellent experience.

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



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



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

Combined Results		Very Helpful	Helpful	Somewhat Helpful	Not Helpful	N/A	Skipped
	Cardiology Nurse	69%	14%	3%	1%	7%	6%
	Social Worker	37%	20%	11%	3%	18%	11%
	Cardiologist	75%	15%	2%	1%	2%	5%
	Other Families	16%	19%	7%	2%	36%	20%
	Local Family Support Group	8%	7%	4%	1%	58%	22%
	Child Life Specialist	14%	8%	5%	3%	50%	21%
	Website Resources / Internet	21%	20%	13%	2%	22%	22%

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

Alberta Children's Hospital	1
Alberta Health Services	1
Annals of Thoracic Surgery	1
Baby Centre	2
BC Children's Hospital	5
Boston Children's Hospital	5
Canadian Down Syndrome Society	1
Canadian Marfan Association	1
Can't Recall	5
Cincinnati Children's Hospital	3
Circle of Hearts	1
Edmonton Down Syndrome Society	1
Facebook Support Groups	6
Google / Various Websites	24
Heart Beats	2
Mayo Clinic	8
Medical Journals	5
Mended Little Hearts	1
Parent Blogs	2
Ronald McDonald House	3
Stanford Hospital	1
Stollery Children's Hospital	2
The Ups and Downs Society (Calgary)	1
Toronto Children's Hospital	1
WCCHN	1
WebMD	1
Website that the Doctor gave to us	1
Wikipedia	1
Williams Syndrome Association	1
YouTube (PAC Video)	7

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

- I feel that we had all the information we needed.
- Discussions regarding ECMO, full resuscitation, CPR, etc. should have taken place prior to surgery, not after.
- Nurses were very helpful and always willing to answer questions in Edmonton.
- More help on how to explain what was happening to my child.
- Had Skype call with a mother whose son had the same procedure done on him 6 months ago.
- More information on oxygen saturation parameters (what levels are safe, and what levels are not) and more discussion on potentially negative outcomes.
- Talking with Surgeon about surgery was helpful.
- We prepared ourselves as best we could. Not sure there could have been anything else.
- It would have been nice to speak with the surgeon and the real plan to know the reasons why before arriving in Edmonton.
- Speaking with other families through a Facebook page was extremely helpful.
- I wouldn't know. It was good.
- The staff here in Saskatoon prepared as much as possible.
- The Cardiologists explanation. The Neonatologists recommendation and assurance. From a family who had experienced the same as ours.
- DVD, booklet.
- We were well informed.
- More information regarding how pain management is handled for the patients after the operation.
- We visited with a family that we met through the Heart Beat Society in Calgary, which provided us a lot of support and comfort going into the procedure.
- That you would have been sharing a room with 10 other children. Been staying in a cooler room, with just an office chair (ICU). Heads up about that and what state your child could be in after the surgery.
- Resources regarding childcare around the hospital.
- More information on the drugs used and what heart and long bypass is, along with the risks to them. Also would have been nice to see the anesthesiologists to know how he does put them under.
- Knowing all the details of his recovery.
- More about procedures after surgery, such as breathing tube procedures.
- I wouldn't know where to begin to look for information.

- How common complications/human errors could occur.
- Talking to families who experienced the same procedure.
- We had a very short notice about the surgery – only 1 week. I would have liked to talk to other families about their experience.
- I would have liked to be prepared for the ICU and seeing my son post-surgery. I almost died when I saw him there in the bed for the first time. We felt so unprepared for that. So much time had been spent on him and the pre-op.
- Information from parents who have gone through the same was most helpful.
- The wealth of preparation the doctors, nurses, and the whole team gave me before the procedure.
- We were not made aware of potential family support groups. My husband and I felt emotionally drained, but did not know where to turn for support. Some social workers were helpful with respect to counseling while our son was an inpatient. When he was discharged however, we were not provided with any information regarding supports. We had to do our own research and came across the Children’s Heart Network.
- Nothing. I had all I needed.
- A meeting with the Cardiologist or Cardiac Nurse before I gave birth but after our diagnosis was made would have been useful.
- Was provided enough information.
- A website they requested to get information from.
- Nothing I can think of.
- Not sure.
- All was good.
- We felt very well informed.
- Warning signs of stroke.
- We felt very well informed.
- Maybe if they had recommended websites or even booklets about procedures (as I think a lot of heart problems are semi-standard). Then families wouldn’t have to seek out, sometimes overwhelming websites that aren’t always the right one for them.
- Not sure anymore would have helped as it was a crazy time getting my baby delivered and all the emotions that come with it. It was a feeling of “it-has-to-be-done-anyways-why-not-now”.
- My son really liked the photo album that showed the different stages. The props were very good – he was extremely upset / anxious before the second surgery and found actually seeing a real ICD helpful.

- I think any additional information would have been “overload”. It was perfectly presented.
- Not sure there is anything that can prepare you for surgery as they get older. I wish I knew more about the medications they were giving him and sometimes wished I pushed more to either get answers or get him off certain medications I knew he didn’t do well with.
- None. We were very well informed.
- We were unaware he had to have a blood transfusion until the day of pre-op.
- None.
- Really, everything was covered mostly by the Cardiology Nurse and Cardiologist.
- Support from a family friend who had a similar situation happen.
- None.
- The Ronald McDonald House provides all baby gear (ie. Strollers, car seats)
- Instructions given to parents by the Cardiology Nurse.
- Being able to meet the surgeon and other relevant Children’s Hospital Specialists in person sooner than two days before his surgery.

Other Comments:

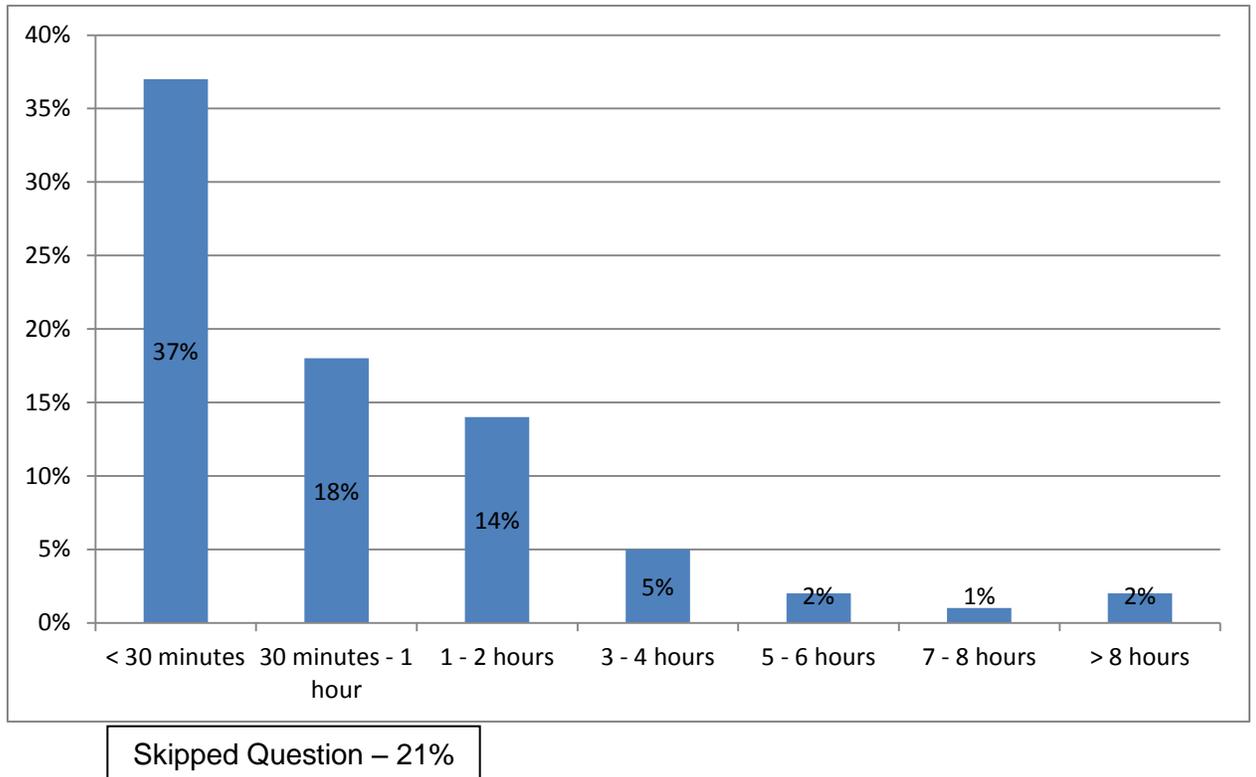
- Our pre-surgery Cardiologist focused on negatives of surgery and PICU recovery and did not give any encouragement before or during recovery. Other staff were very helpful and encouraging.
- Would be good if nurses talk with you about your child. I never knew my daughter was quarantined until 3 days later. Nurses need to be more helpful and make sure they are doing what they are supposed to before sitting down and chatting.
- We felt as parents we were prepared as we could be considering our child was diagnosed March 2014 and she had surgery April 2014.
- I believe parents should be involved in the videoconference or at least ask questions to the surgeon earlier, not just the day before.
- Being able to talk to other parents who have had similar procedures. (I do understand privacy rights).
- Everything went well. Our stay was awesome. We enjoyed every minute to the fullest.
- We were called in for a cancellation. We were phoned Friday and were to be there on Tuesday. The package they sent via mail to prepare us obviously did not make it to us in time. It could have been nice to have the package there for us on the Tuesday instead of mailed out to us.
- The Heart Transplant Coordinator and Cardiologist in Edmonton were both really helpful.
- All in all, for how busy everyone was, we were provided with a good amount of information.
- The information and resources we were provided were very helpful. Again, we experienced a best case scenario as we didn't have any mishaps leading up to surgery, and the surgery and recovery both went as well as could be hoped for. Had things gone differently, I could see that we would have sought out assistance from some of the other resources (social workers, etc.) on a much greater basis.
- I asked a lot of questions, otherwise some things may not have been told to us. (ie. Certain procedures).
- Damage was done to our son's heart while in surgery. Punctured left ventricle and damaged mitral valve, paralyzed diaphragm. This resulted in a longer stay.
- For pre-op clinic, it would have been easier if his sedated echo was first. It was last. He had to go all morning with no food or drink. He likely would have been happier.

- Photos of patients post-op in PCICU to help us anticipate what our son would look like immediately post-op.
- The experience was stressful of course but the nurses and hospital staff were great. My major complaint was that the resident covering the surgeon's case couldn't speak English well and gave us different information than we were prepared for (said they'd remove the old leads and there were significantly more risks). I asked to speak to the surgeon who said they'd leave them in. During a stressful situation it is important that the doctor speaks English
- The heart centre at BCCH was great. The staff, nurses and doctors were very helpful and very understanding.
- Overall, the staff at BC Children's Hospital were amazing, especially, our surgeon. It is hard to constructively comment on pre-surgery care as everything happened in a very short space of time.
- We were very happy with our experience overall. We were treated with respect, as was our daughter and we felt well informed about the procedure, recovery and problem.
- Our child had a stroke during or right after the surgery and showed many signs, but it went undetected.
- Child Life Specialists were supposed to be with our very anxious son before the 1st surgery - no one came. It turns out the specialist was with a different patient with a similar name. The second surgery, this was corrected but I think the trust was broken and it wasn't as helpful as it could have been.
- My entire life, I have had negative experiences around hospitals and medical professionals. Then I fathered a son with heart deformities. Everything about the journey through BCCH has been very positive.
- Idea of surgery was a shock – condition was to be stable for a number of years but there was a change in protocol.
- My daughter had emergency operation due to an ATV accident. Most of these questions were not applicable. I feel the hospital staff did an excellent job handling my daughter and her care.
- Everything was always explained very well.
- The process of the surgery itself with the patch and what the surgeon will do is not discussed in detail prior to departure for surgery. The number of hours the surgery actually was to take place was communicated differently from our Cardiologist and pre-op.
- I only believe Cardiologists because they know my kid's condition well. Most information on the internet is not suitable. Sometimes makes us scared and upset.
- Surgeon, Cardiologist, and Cardiology Nurse are excellent.

During Your Child's Hospital Stay

20. When your child went to the operating room pre-holding area for his/her procedure, please comment on the following:

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



b) Please comment on the surgical pre-holding environment:

- Quiet, calm and warm.
- The porter was very compassionate.
- Nicely decorated, “home-y” feel (in room), quiet, clean.
- Very nice people let me know what was going on.
- We were supposed to go in at 10, but due to other reasons, we were pushed back. Not the staff’s fault as a different surgery took longer. No concerns.
- Everyone was nice and helpful while we waited.
- Clean, sterile.
- Kind of small, but well organized. Wish we could go straight from pre-op clinic as waiting is a bit intimidating for a child.
- Busy. Seemed very rushed of an area.
- Not bad.
- Good.
- He was in the NICU.
- Very quiet.
- Calm atmosphere, friendly workers/staff.
- It could have been more private.
- Everyone was very nice.
- Comfortable.
- Felt like a prison.
- No concerns.
- Not much stress there.
- Not sure. She was wheeled after from the NICU and we didn’t see her for hours.
- I don’t really remember much about it.
- Don’t remember.
- Very calm.
- Information we got was easy to understand and very caring.
- Very friendly and comforting staff.
- We went straight from his room to the operating room.
- Environment was conducive. Staff were supporting.
- Our son was in the NICU when the anesthetist nurse and anesthesia tech came to pick him up and take him to the OR. Surgery was scheduled for 1250h and he didn’t get picked up until 1405h.
- Excellent.
- Very good.
- Quiet, clean good toys for distraction.
- NICU.

- Good. Calming.
- He went straight from NICU to OR. He was in NICU for 7 days in Edmonton before surgery.
- Quiet, relaxing.
- Seemed like a long wait – but probably wasn't.
- People were so friendly and explained all what will happen.
- Our 4 month old had not eaten since 1:00 am and our surgery was booked for 7:00 am. We got bumped, which I completely understand, but instead of waiting in that tiny room with a screaming, almost passing out from exhaustion baby, they should have let us come back the next day. It was too hard on all of us. Also, if they expect parents to wait there for so long, get chairs that recline so we can lie down and get some rest.
- Staff were supportive.
- He stayed in NICU; it was an on call schedule.
- Organized
- A lot of helpful nurses came to talk to us and made us feel comfortable. Asked us constantly if he had any questions.
- Was very quiet, a couple of nurses. No other parents. One nurse did ask my child to pick his favorite parent to take him into the operating room. This, I felt was inappropriate, and I did tell her off to the side by herself as we have a split family and it was very obvious.
- Welcoming.
- The environment was good and they take good care of the children.
- Quiet. Peaceful.
- Our son went straight from the Stollery NICU to Surgery.
- Not much to say. We were scared and it wasn't fun.
- It was fine. Quiet.
- Long wait and my child was very hyper and irritated from meds.
- Fantastic.
- Awesome. It was a blessing to have the toys to distract our son (and ourselves). The nurses were so patient and kind and truly made an impact on me (a very emotional and pregnant scared mom).
- Ok. No major concerns. Nurses were supportive and kind.
- It was good/confidential.
- We waited 1 hour and 15 minutes in pre-admission clinic and 45 minutes for the surgery.
- Very caring and understanding staff.
- Clean, quiet, and nice environment.
- Very quiet as we were the only ones there.

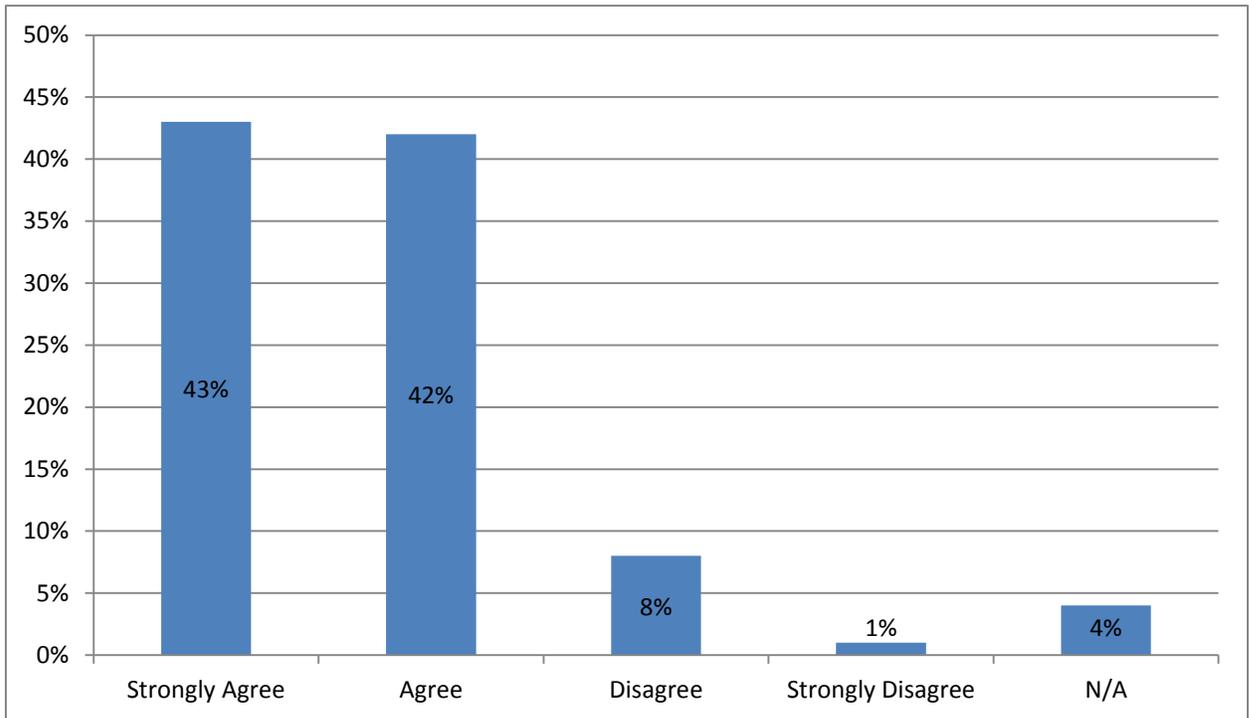
- Pleasant. Toys and books for kids with couch for parents. It was comfortable.
- PICU – kept very up to date on timeline.
- It all happened so fast.
- Comfortable with toys and books for kids.
- Quiet and comfortable seating area.
- Clean, quiet. Calm environment, friendly staff.
- Comfortable but scary.
- We were given a pager at his procedure was postponed due to lack of beds. We waited 6 hours before they were able to take him in.
- Went straight to OR.
- Good private space.
- They had problems with a new born baby.
- It was ok. There were things to occupy child while waiting.
- It was comfortable enough, but had a very large window into the nurse's station – which just meant it wasn't very private. I suppose on the one-hand that forced us to try to keep our emotions in check as we prepared to hand our son over for surgery, but on the other, it would have been nice to have more privacy. Apart from that it was just fine.
- Honestly, we didn't notice as we were very emotional and nervous about our sons operation.
- Lots of toys. Very comfortable.
- Quiet, clean.
- Clean, quiet, calm.
- Was not with him.
- My son fell asleep on me before surgery but the room looked comforting with toys.
- Stayed in the same Pre-admission room as we were in the previous day in our PAC consultation. Cardiac nurse was present to answer any questions.
- It was nice, private, and comfortable.
- Very cold type of area. Not a comforting place to wait.
- It was comfortable. We were updated on OR status periodically.
- Calm. Supportive.
- Talk to Anesthesiologist while waiting. Great rapport and comfortable environment.
- My child was in PICU from the day she was born and about a week post-surgery. Then about a week in NICU, then a week in recovery.
- Excellent for family.
- Excellent.
- Very clean and organized.

- It was ok.
- They were friendly and helpful.
- Friendly staff. Private room was appreciated.
- My child was in the NICU for 2.5 months prior to procedure. She was not home after birth before this procedure.
- Clean, quiet. I was grateful I could stay with him there.
- I found the room to be a little small, but it was ok.
- Clean and accommodating.
- Efficient, supportive.
- Comfortable, activities for kids a good distraction.
- She was in ICU transferred from ARH.
- Clean, quiet.
- Good and can be better.
- They seemed a little unorganized. We were put in the wrong room and our nurse couldn't find us. May have taken 30 minutes too long.
- I was losing my mind at the time, so don't really recall much about the environment.
- Very quiet and calming.
- Good.
- NICU, then to pre-op, then to surgery. All very quick.
- Organized.
- Stuffy.
- Warm, friendly, calming.
- It was good. They were kind.
- They welcomed all our family to come in.
- I have been there twice. Both times I found it to be busy, but caring with a bunch of stressed parents and kids (sometimes) all looking around wondering what the others are there for. Overall, I think it is fine. The busyness takes your mind off for a minute or two.
- I was not in it. My child was taken from PICU.
- Went straight from the PICU to the OR.
- Tense, peaceful, strange, apprehensive, and sad – all at once. Anyone who works and has been in PICUs know this feeling all too well.
- It is stressful for everyone there. You focus on what is going to happen soon, not really on the environment of the area.
- Friendly.
- Same as pre-op, very warm caring professionals making things very comfortable for the patient. Lovely atmosphere all around.

- Very friendly staff. A nurse came in with a tablet and let my daughter play on it, then asked what her favorite movie was and brought her a TV with the movie. They are very good at making sure our daughter is comfortable the whole time.
- Pleasant.
- No complaints.
- Again, it was similar to the pre-op instructions. I was especially impressed with the counselor who stayed with our son throughout the pre-holding experience. She made us all more comfortable – loved the iPad games she played with him.
- It was very busy. All kids getting any type of surgery were all in there – some ok, some freaking out. Hard to control emotions of children which causes additional stress when they see other kids very upset.
- Fine.
- Great.
- Son went directly to the OR.
- Excellent.
- Everything
- Very clean and isolated.
- No concerns. Was given information.
- No complaints. Everyone was very helpful.
- Baby was in PICU after birth until surgery. Baby monitored 24 hours.
- Calm. Life Support Worker arrived with iPad.
- This was the most difficult time for us by far. It was not very private and only a curtain separates patients and families next to you. This was very emotional, and was hard to show all emotions knowing someone was watching you, but I don't think we were prepared for this moment.
- Everything was well synchronized. It did not take them very long to get our son prepared for surgery and take him to the OR.
- It's nice. The nurses are quite patient and helpful.
- Clinical, staff very professional.
- Took him in for PICU when ready.
- It was quiet and inviting. Very friendly nurses.
- Was ok. Front staff was not aware that our surgeon had changed and instead of listening to us, she was adamant she was right and we were wrong. Nurses and anesthesiologist was great.
- Quiet.
- Great.
- The environment is easy to get use to.

- Excellent.
- Excellent care.
- It was early in the morning. Our daughter slept on our shoulder for most of it. It was a very relaxed environment.
- Empty and quiet.
- Our son was hospitalized before both procedures.
- Good.
- Could be more child friendly.

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



Skipped Question – 2%

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

- Nope.
- There was not enough beds in the ward, so we stayed in the PCICU almost a week longer.
- Hospital staff did not recognize drug reaction/aggravation. Overall, excellent patient/parent centered care but lots of room for improvement. Parental input regarding feeding needs to be respected more. More access to written and digital charts.
- Nurses not slacking in the isolation room and the last stage. NICU was amazing.
- Staff in Edmonton were very much interested in parent's observations and helping parents understand charts and monitors. Less so in Winnipeg.
- Wish there was a private room.
- Staff to be more friendly.
- The staff at the Stollery were amazing. We felt we were in good hands and had lots of support.
- Child Life could have been more involved.
- More beds available outside the PICU.
- More communication.
- No. I think everyone was doing the best they could. I think our hospital experience was as good as it could be, but I wouldn't say it was what we expected just because our child had unexpected complications following surgery. She is doing great now, and we are thankful for everything the medical team did, but at the time, it was very stressful.
- It would have been nice to have had a recliner to sleep on in my child's room for the parent.
- It was a pleasant experience in what was a very stressful time for us.
- At that point, I was ok with staff and care.
- I couldn't say.
- Hospital staff was amazing. Couldn't imagine the strain we would have been feeling if things were not the way we experienced.
- We had to wait a very long time for her to have an echo. She had been released from the hospital and no one seemed too concerned about the 14 hour drive.
- An update on your child's procedure would be nice. After 8 hours a parent gets very worried.
- Better informed social workers with more accurate support programs.
- No. Absolutely not.

- Like I said, rather than making us wait all day, let us leave, feed our baby and come back the next day. It might be easier for older kids but you can't explain to a baby why she is starving.
- There was a nurse in Cardiology NICU who seems new at her job and while our nurse was on break, I asked her to check on my baby, she was not in a great mood. Our baby had lots of bleeding to the point where it was leaking from the bandages from her chest tube. She was rude to the point where I was crying and asking her to check the bandage. Finally, I asked her to get her supervisor and she was very nice and changed her bandages and put me at ease. During these vulnerable time when we as parents of the baby, we need more patient and caring staff! Especially in the middle of the night when everyone is tired.
- I was really tired having been up all night the night before so I went to have a nap while the Heart Transplant was happening. I was so disappointed no one called me once our daughter was out of surgery. I woke up and went to PICU to find out she had already been there for 45 minutes. Because I wasn't there, I never got to talk to the Surgeon to find out how it went, and the nurse that was in the room just happened to be filling in for the nurse so she wasn't friendly at all and seemed to just want to ignore me, wouldn't answer my questions. I was so disappointed and felt so terrible I wasn't there for our little girl when she came back to PICU. It was the worse. I didn't have anyone to talk to or celebrate with because my wife was in Saskatoon. So glad the surgery went well that's the main thing! And the nurse was really great that came back on later. A big blessing. So thankful it all worked out and our daughter came through it wonderfully!
- The outpatient rooms in the hospital could have a TV.
- Better food for our daughter. It wasn't nutritious at all.
- Nothing. Everyone was excellent.
- No cancelling. More beds. PCICU nurses and staff are amazing.
- It was fantastic.
- Our stay at 4C3 was less than ideal. I found the nurses we had cared little about dealing with my son and easily frustrated by a 2-year-old who wouldn't let them get a BP or assessment done.
- More consideration of all the procedures/medicine my child was getting. Child was woken frequently by various staff and often not able to rest, which caused more stress on child, my husband and I.
- Can't complain.
- No. A room where we can rest close to the ICU. There is one for NICU, not ICU.

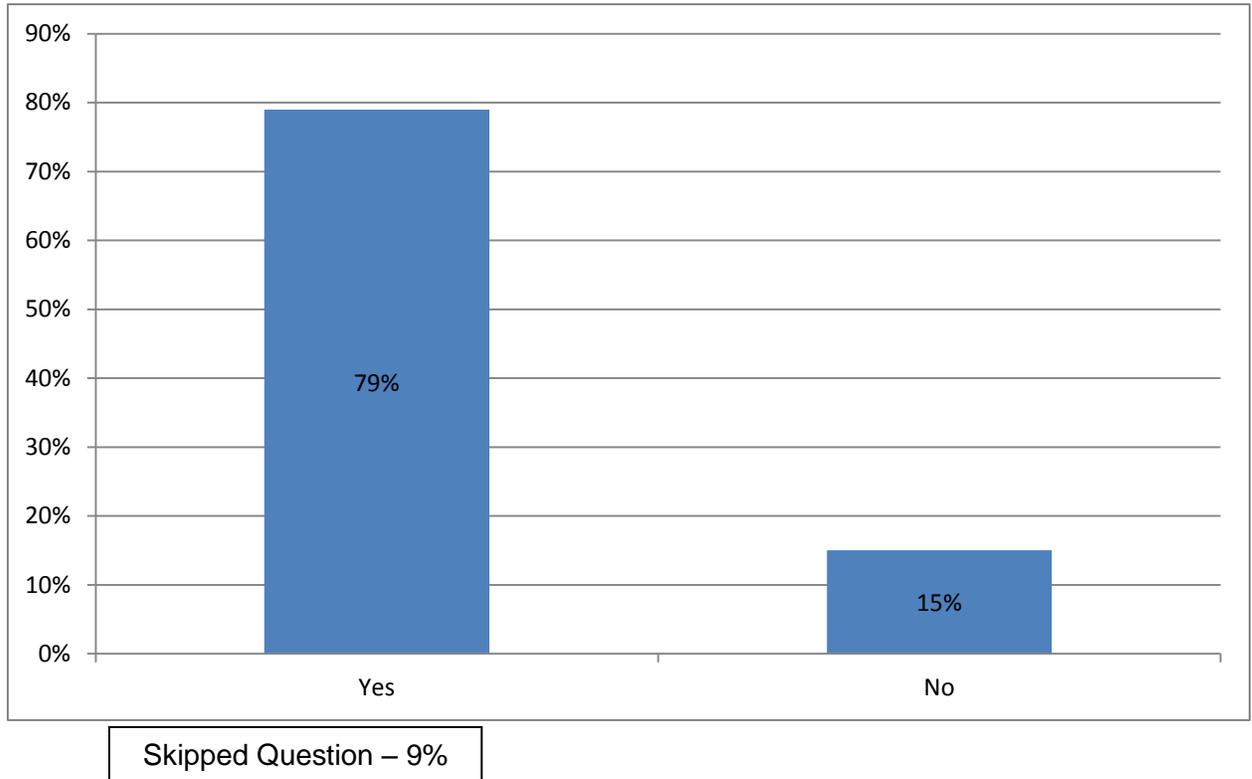
- Just more accommodations and food available to families that didn't get a spot in the Ronald McDonald House.
- No. The centre, staff, and Physicians were excellent.
- Better social work support. We did not see the Social Worker at least for 5 days after the procedure.
- Better room arrangements. Our child was not able to get the proper rest due to the other person in the room being very loud. We got moved twice, and finally the third room we were moved to, she was able to get her rest to recover. I understand that is not always possible, but that was one of our only downfalls of our stay.
- Felt a little rushed to be discharged before Christmas. Fluid issues were not adequately addressed before being sent home.
- Not really, everyone was exceptional. We really appreciated the lengths that everyone went to.
- Clearer line of communication between parents and specialists.
- Help with bottle feeding to post surgery. We had met with OT prior to surgery but not after. We had to use the NG tube for 2.5 months post-surgery.
- I wish there could have been a sleeping area near the PCICU for parents.
- More consistency with nurses. No communication between NICU and PICU. Some nurses did not feel certain things were as important as others.
- The only thing I can comment on was the lack of a freezer in CCICU. I was pumping and storing milk for my son and the nurses to put into his tube feed. I had to take it to the Cardiac Unit as the freezer in PICU was full. My milk went missing and was never found.
- Pain management and communication to parents after the operation. If we didn't ask questions, we were left with vague or no information about our sons recovery.
- I was still breastfeeding our son during this time, and I was disappointed that there wasn't a better set-up to pump. There was just one room for nursing in the PICU area, and it was often being used, and was not very clean or private (there was no lock on the door). I was very surprised at the lack of a better space for pumping, especially given how breast milk is known to be such a positive for infants.
- No, it was fine.
- Parking!
- Ran out of heart pillows unfortunately.
- More communication as far as when procedures were completed so we could return. A few times they forgot to call and we were worried.

- A little more understanding from nurses on how a stress-free environment is needed when trying to pump breast milk.
- Better information regarding support groups for parents of children with Congenital Heart Defects.
- No. It was ok. The staff were wonderful.
- Arrived on a weekend, staff was sparse. Things were not as organized as regular weekday staff.
- Our baby shared a room with an older child, and this caused issues with sleeping for both children.
- No. We were satisfied.
- Care we received far exceeded our expectations. Janitors to Anesthetists to Nurses to Surgeons were so compassionate and even remembered our son's name after a brief meeting.
- Could have been a bit cleaner.
- Nothing at all.
- Everything was alright.
- There are many different opinions among Nurses and Doctors. We were often told different things that would happen during her stay in the NICU, depending on the staff working any given day.
- Communication. We didn't see the Surgeon for days after we arrived. It wasn't clearly communicated that the Surgeon would meet with us before starting the procedure. The only person on the medical team who would come when we requested information was the NP. We weren't made aware of any resources available.
- No. Everyone was very helpful.
- No. For having an unexpected heart surgery at 6-days-old, our "stay" was fine.
- We were very pleased overall.
- More comfortable cots for parent sleeping in room. Less loud chatter at nurse's station. Close door when leaving so light/noise doesn't wake child.
- I couldn't ask for anything different.
- The wait at the surgical daycare was longer than expected. But I guess this was due to unexpected events at the OR.
- Individual rooms in PICU like Surrey Memorial Hospital.
- Provide parents meals. In a stressful situation, it is hard to find the time for parents to prepare their own meals.
- The Surgeon was to send a message to our beeper but it never went off. Surgeon did say he sent us a message so the beeper was not working correctly.

- Pediatric care and Cardiology was good. Neonatal care in my opinion was mostly good, however, could use some improving, mostly in regard to communication, attentiveness to past documentation more than 12 hours pre-nurse changeover. The bedside manner with some nurses definitely need attention.
- Our son didn't receive pain management after moving from PICU to 3M. He had a full week of being very uncomfortable and not sleeping. It was a nightmare to watch and left me so exhausted I couldn't see straight. The jump from PICU to 3M is too big. You go from constant help to little.
- After surgery, when you go up to the ward. I do find what the Surgeon says and what the nurses do or will do are two different things. With pain management with the nurses, your kid is always about to get discharged so they won't give the meds that the Doctor or Surgeons says they can have cause they can't be discharged on them. As a parent, it is very frustrating.
- No.
- Nothing as it was our child's reasons to why we stayed longer than expected.
- Yes! The beds for parents/guardians in the room post-op are utterly atrocious! I had a c-section and lying on those cots did not offer any rest. This was my first baby and staying up with a newborn and trying to rest and also dealing with my own post-op, I broke down. Too overwhelming and I don't usually complain about things. It wasn't until the third night that one of the nurses offered to roll in an actual patient bed that I was able to get some resemblance of sleep. I was alone at the time and I found it very hard and overwhelming, I broke down because I knew I was going to not sleep on an awfully, "pokey", extremely uncomfortable cot.
- We were so impressed with the care our little girl received. The nurses were exceptional and they were amazing with her. The only negative experience we had was when we were ready to go home, we asked for a wheelchair, because we parked really far away and she did walk, but she still got tired quickly. Being only 3 days after her ASD repair. The resident told us she doesn't need a wheelchair and that we should let her walk, that it will be good for her. We were a little upset about that. We didn't like her attitude and the way she spoke to us. We realize it's good for them to start moving right away, but we also realized she is not ready to walk that far.
- Better explanation of options for food services (done really well at second surgery). The Sunshine Bundle reps were very pushy and rude.

- Only one little thing had a bad experience with the social worker but so was the hospital staff. I believe she was terminated at this point. This event did not affect my son's experience.
- Wish Children's stay could have been more comfortable with video games.
- It was very accommodating.
- No.
- Parent beds are terrible.
- The beds in the rooms were uncomfortable. I had to stay in the room with my baby.
- Nope. Nurses and Doctors were excellent.
- Enough.
- The room to go after you were paged that the surgery was complete was not labeled well or we did not know where to go to at this point. We were shown the hallway to ICU but got a bit confused of what room to go into to meet the Surgeon.
- No.
- Everything was done very well. We were fortunate to have found the team we did. They were professionals who preformed their job very well.
- I believe we were rushed out of PICU too soon, which resulted in us going back to the PICU for many weeks after our child coded on the ward. Less rush would be our suggestion.
- Better cots (more comfortable) for mother to sleep on in pediatric ward.
- Not having to pay for parking.
- Was not expecting to be there. Better cots for parents overnight stay or beds made for both parents. More rocking chairs (not wood). Better setup for parents to stay in PICU longer.
- No. It was a very pleasant experience under the circumstances.
- No.
- Can't think of any.

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



Comments:

- The transfer from PCICU to 4C2 did not go smoothly. Medications were messed up – PRNs not transferred, plan of care was not transferred. It felt like a different hospital! Communication between doctors regarding plan of care was often lacking between week and weekend shifts.
- Yes, very helpful and genuine concern.
- Nurses on 4C are excellent.
- Very well kept together, quiet, not a rush.
- We spent 3 days longer in the PICU due to no beds being available on the wards.
- I would say that there was one nurse who maybe shouldn't be working in pediatrics. The rest of our nurses were great.
- Social Workers were easy to find. The rest we didn't look for.
- Stollery Clinic is an absolutely amazing hospital, doing amazing things. All the staff were wonderful, from the doctors to the nurses, all the way to the food servers and cleaning staff.
- Care was excellent.
- Social worker there at initial pre-op day and came by in the PCICU. Once admitted to unit, no one came by to explain or offer services/area to use.
- It took a few days to connect with social worker but eventually we did. She is great.
- Overall, we felt that we had the best of care! ICU would benefit from having more privacy such as curtains. It was very difficult to leave our daughter when the ICU was closed for procedures on other children.
- Three days after our son's heart surgery, he was moving to the Recovery Floor on the 4th from the PICU on the 3rd floor. For 17 hours that day he was not given any pain medication.
- As a parent struggling with having to be the person to physically restrain by child for procedure (CT removal/pacing wire removal, etc.). He was hysterical with fear and pain and instead of being able to comfort him, I had to hold him down. This is where the unit staff should have stepped in and allowed me to be a parent and them "the bad guys".
- Very stressful. Discharge plan could have been handled better – with more understanding of my child, my husbands and my stress and lack of sleep. Most staff were helpful when requested.
- I don't mean to sound negative, but I remember asking a couple of nurses on different occasions if there was an exercise room for parents. It would be nice to have one for parents to utilize, so it can take some pressure off while at hospital stay.

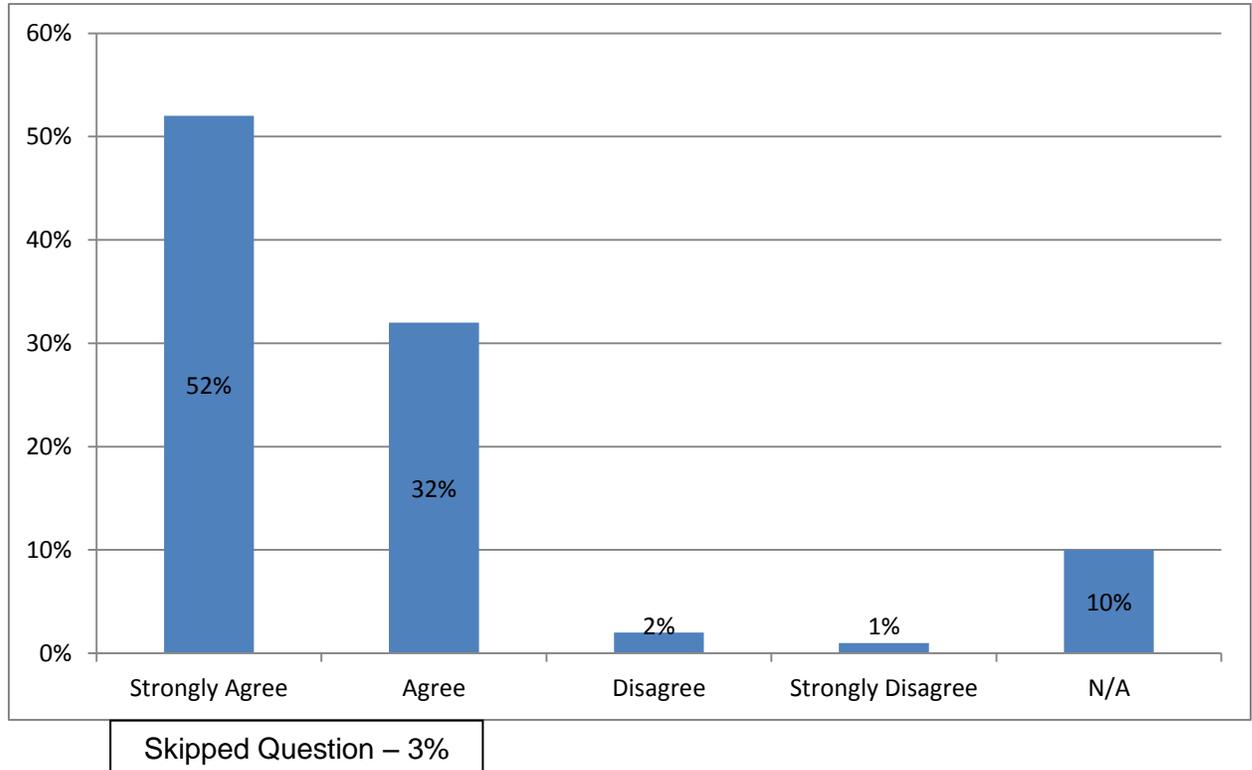
- We loved our nurses in CCICU. They are amazing and took very good care of us and our son. Also the Intensivist and residents were very knowledgeable and took time to explain things to us in a manner we could understand. We are very grateful.
- Our nurses and doctors especially in PCICU were amazing.
- We stayed at ACH for two weeks prior to surgery – care was fantastic in Ward/Unit 2. Nurses and Doctors very informative on care plan. Stollery Ward 3 and post-surgery was subpar. No information on care plan. We felt like a burden to some nurses.
- I felt we left so soon – four days after.
- Wonderful staff, felt cared for and listened to.
- Weekday Social Worker easy to find. Weekend Social Worker not easy to connect with. Also different parts of the hospital had different Social Workers so felt tossed around and information not passed to the next part of the hospital (ie. NICU to PICU).
- I am not sure if the difference would be equipment, training, or something else, but the Lab Technicians used to take blood in the Stollery consistently have trouble finding and getting a vein, and a few times stopped drawing blood too early, requiring a follow-up poke as the Lab was not able to run necessary tests on the sample. Lab Techs at ACH have never had any trouble drawing blood.
- The team at the Stollery are exceptional as are the team at RUH, but I was surprised how little information was transferred between sites.
- Hard to meet Doctors for rounds because times vary or they round outside of patients rooms.
- Nursing was awesome.
- I felt unnecessarily pressured to stay overnight and care for my child. What purposes do the nurses serve if I'm expected to stay overnight?
- This was not a planned surgery. We went to the Emergency due to his falling and banging his head. We had no idea he had an issue with his heart therefore we were not prepared for any of this and everyone we dealt with was very helpful.
- Lucky to live close by and not have to use all resources available. Close to not use hospital resources to stay overnight as to keep those beds open for out-of-town parents.
- Nurses in Neonatal care should pay extra support and care when communicating with mothers, for they themselves more so than fathers are going through that much extra stress post-pregnancy.
- Suggestions would be for nurses to do a stroke screening on all cardiac patients after surgery, more nurses on during the night shift (especially for parents just brought up to 3M), a “comfort analysis” done on the child each day to make sure they are as comfortable as possible.

- We did not know about these options to these groups.
- I was not aware a social worker was available to assist us. She did contact us right after surgery (day 2 or 3). She was very helpful in guiding us to a clean place to stay (Ronald McDonald House).
- I do feel and think that kids are rushed out of there sometimes too soon. People that live in remote places (ie. Up north) have no health care like hospitals equated to deal with the medical conditions post-op in cases of complications. Most of us only have a G.P. or nothing at all.
- We had an amazing experience. Wonderful staff and environment.
- As first time parents, it was a lot to take in. Having a newborn is hard enough, but a newborn with a CHD is harder. I don't know what you guys could do differently, but I know the nurses in PICU are amazing in helping you and not only your child.
- Overall, the staff was fantastic, supporting and friendly. The only issue we had was with the Sunshine Bundle Rep that was rude and tried to push us to pay extra for services we didn't need (we stayed at Ronald McDonald House so already had free parking). After we said no, returned to ask to check our TV for a moment. We say sure, she hits some dials and turned off all the channels as we were watching the news – no explanation, then walked out the room. Our concern wasn't turning off channels since we needed to pay, but it was the sneaky and rude way it was done with no explanation.
- Everyone communicated well with each other.
- Doctors and nurses at BC Women's have always been top notch.
- We had a great experience.
- Parent waiting area for OR patients is limited. More rooms for parents would be very helpful.
- The Surgeon and medical team that did our son's surgery were very professional and helped answer any questions that we had. Travelling to BCCH was a good experience and we are very grateful for the care we were provided.
- Our stay was nothing like what we expected due to unforeseen health challenges.
- The nurses were amazing.
- The staff were very helpful and friendly throughout our experience from pre-surgery consultations to after surgery care. Very pleased with the quality and care that our son received.
- Thank you to all the staff that helped my son get better! Especially to the Surgeon.

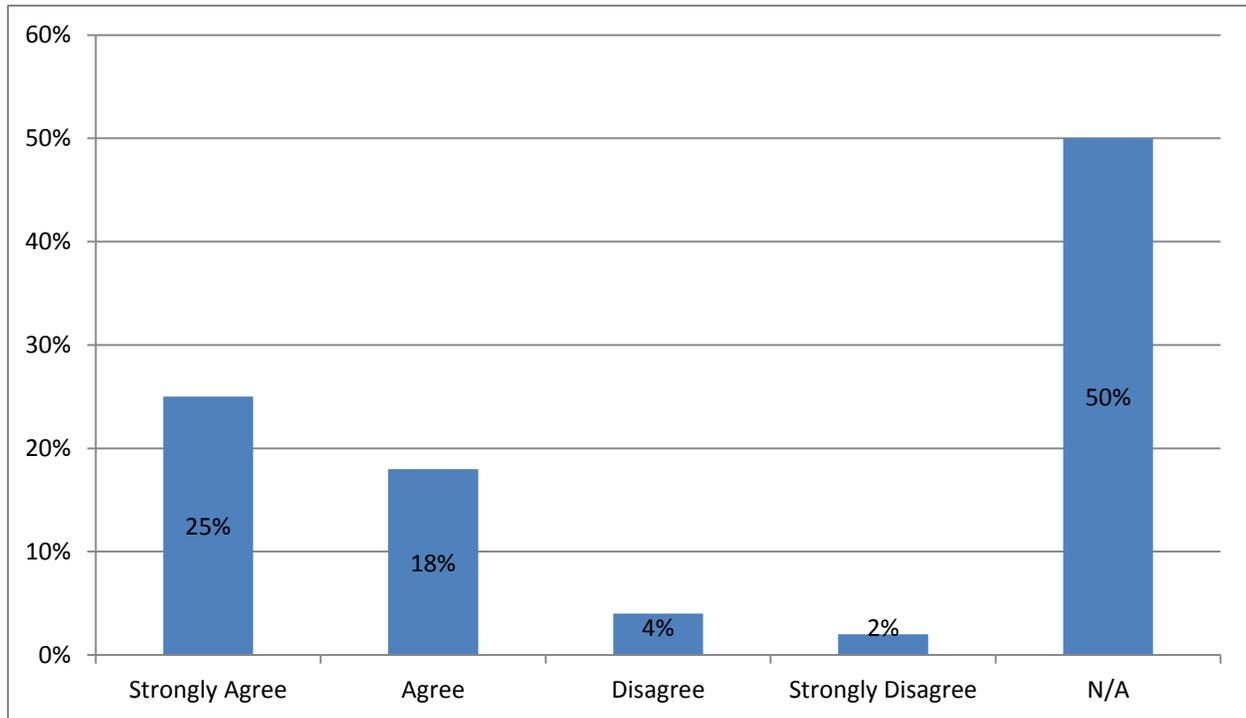
After Your Child's Procedure

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.

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

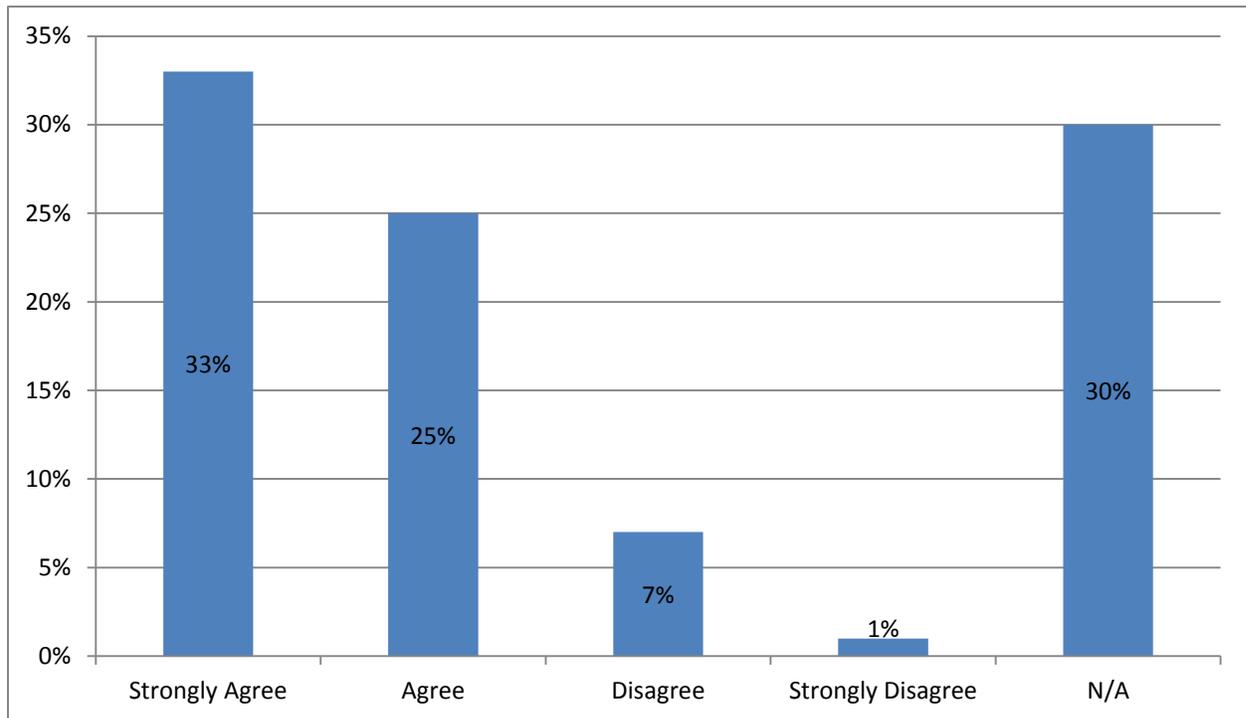


25. I felt well prepared for my child's transfer back to my home hospital.



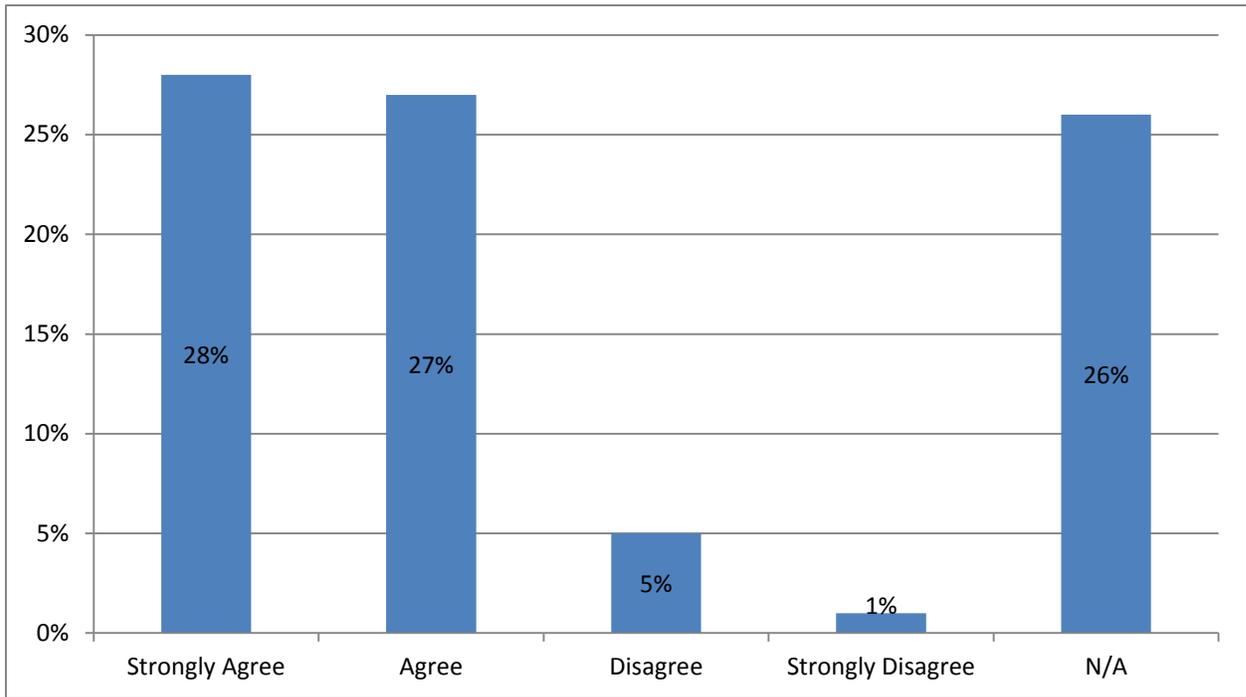
Skipped Question – 3%

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



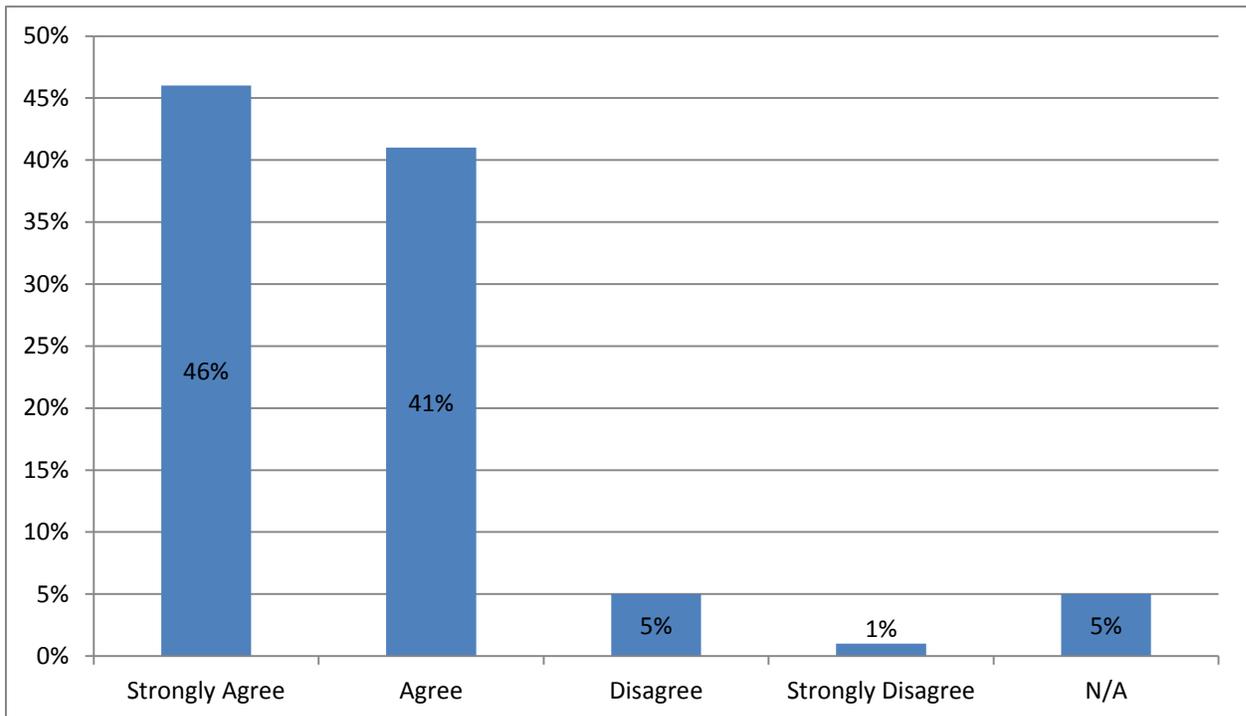
Skipped Question – 4%

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



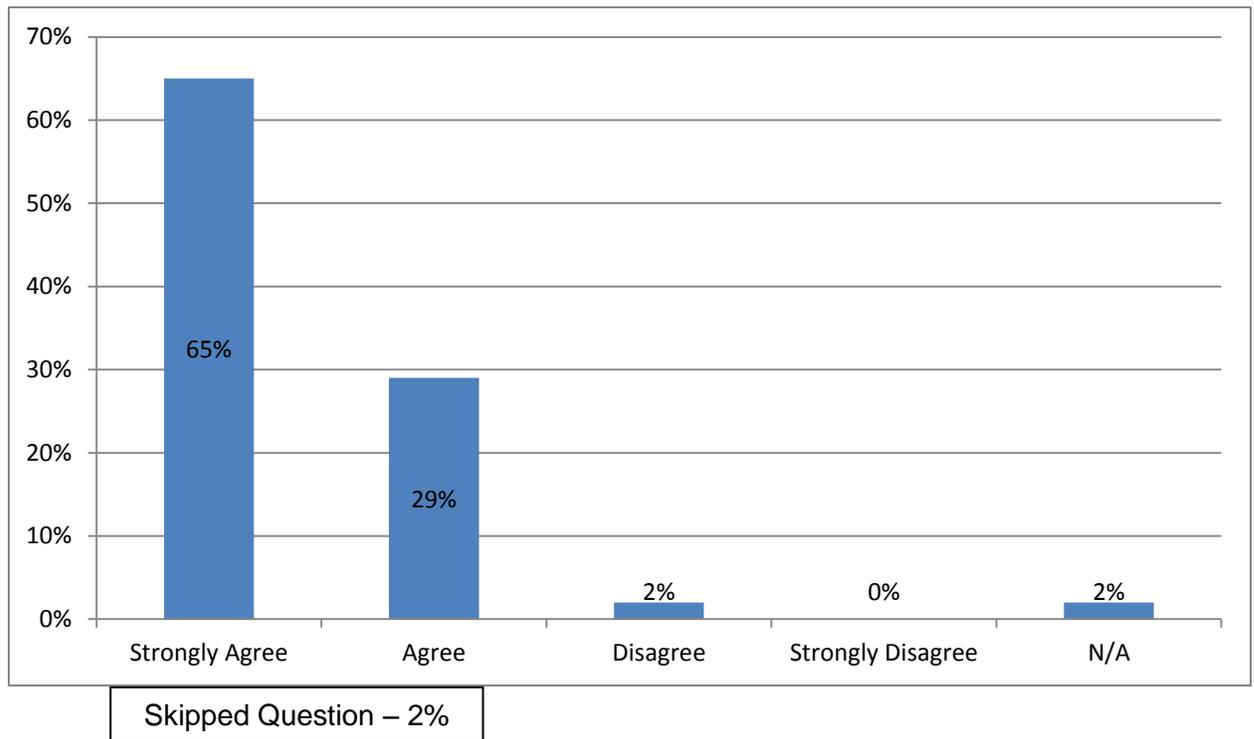
Skipped Question – 13%

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

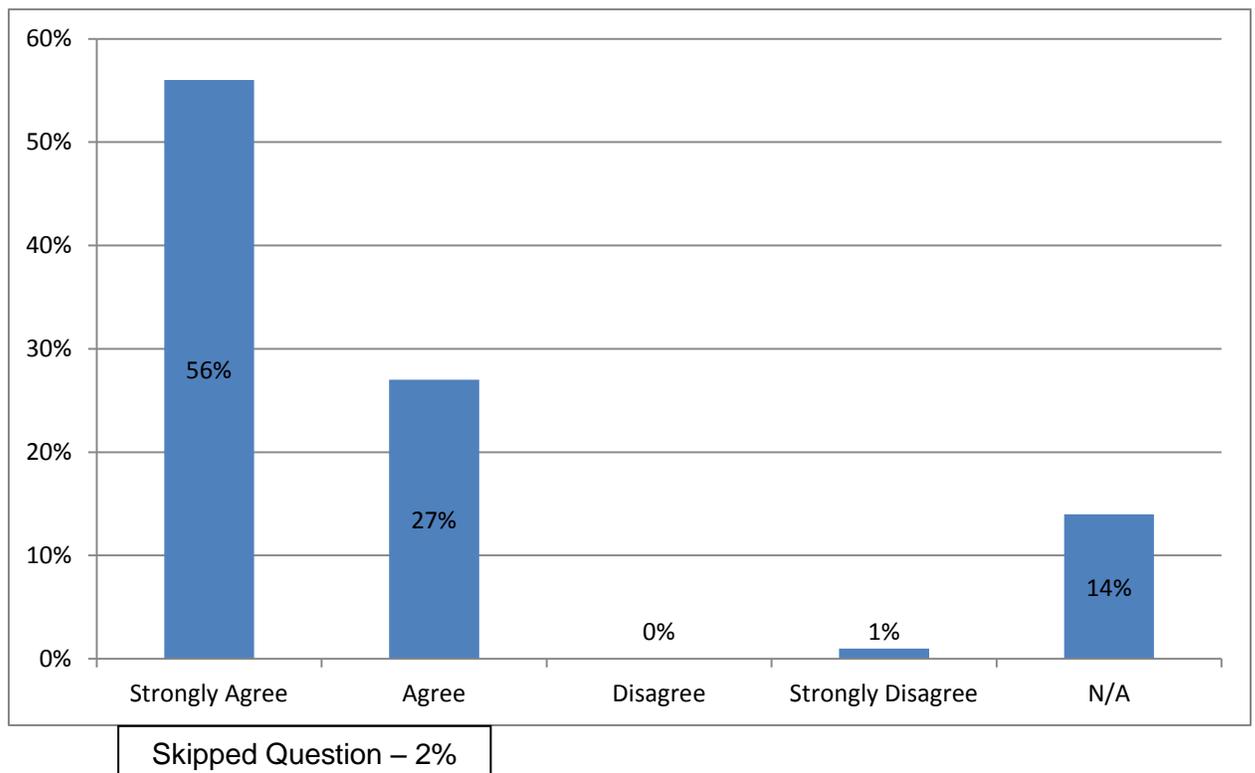


Skipped Question – 2%

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

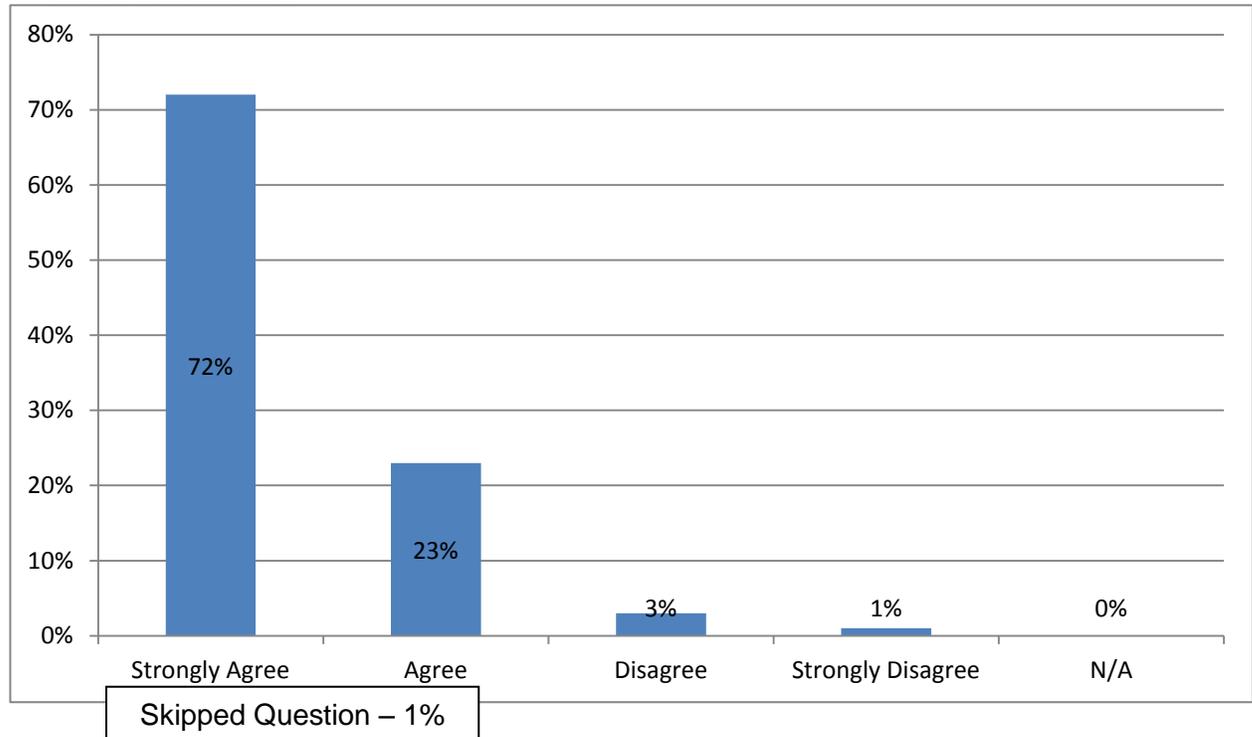


30. After discharge, I was able to get appointments at my home centre as recommended.



General Questions

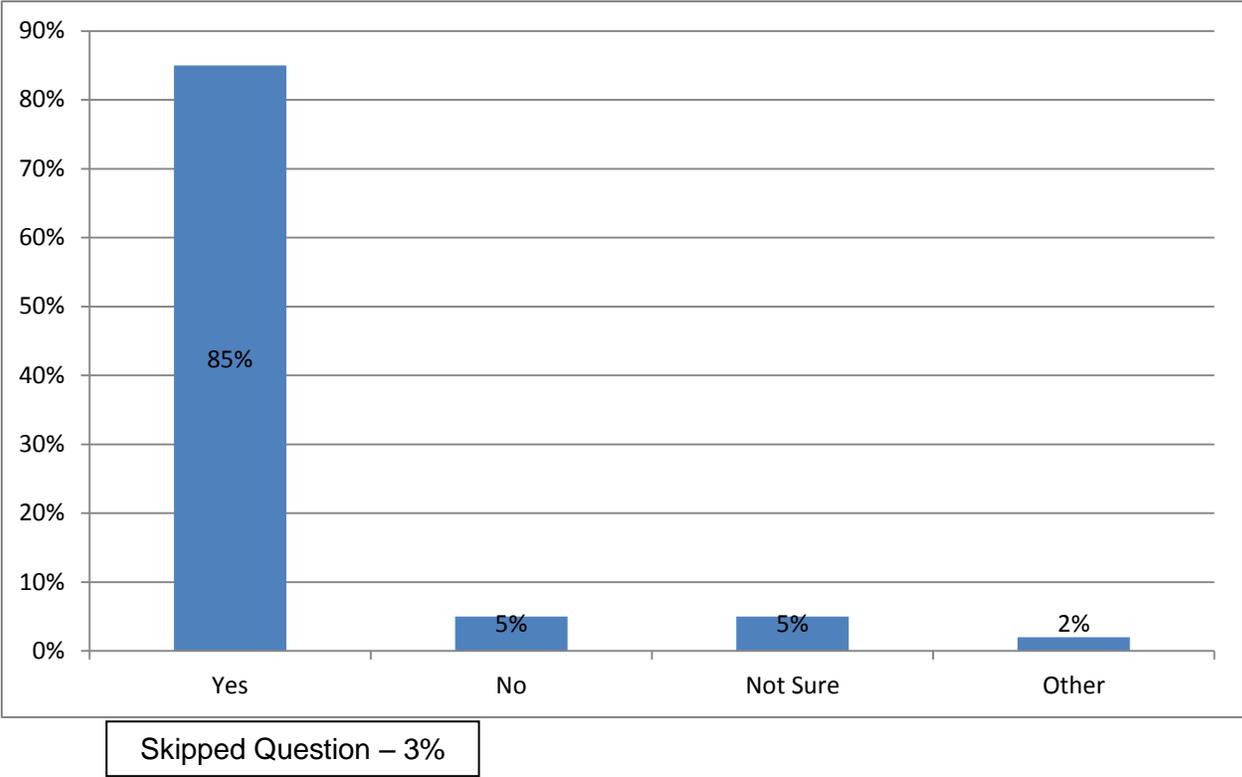
31. Do you feel you are getting the best possible medical care for your child's heart condition?



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

	Combined Results
I don't have confidence in my child's cardiologist	1
My child's cardiologist doesn't take the time to address my concerns	0
I have to travel too long a distance to see my child's cardiologist	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

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



Other:

- Very helpful before. Now that heart is fixed, the healthcare team is routine now.
- We live too far from her healthcare team.
- The Stollery has the best Cardiac team.
- It is an emotional and intense journey and they are advocates for our child and family.
- Having down syndrome, all medical professionals have been a wealth of information and help to us.

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

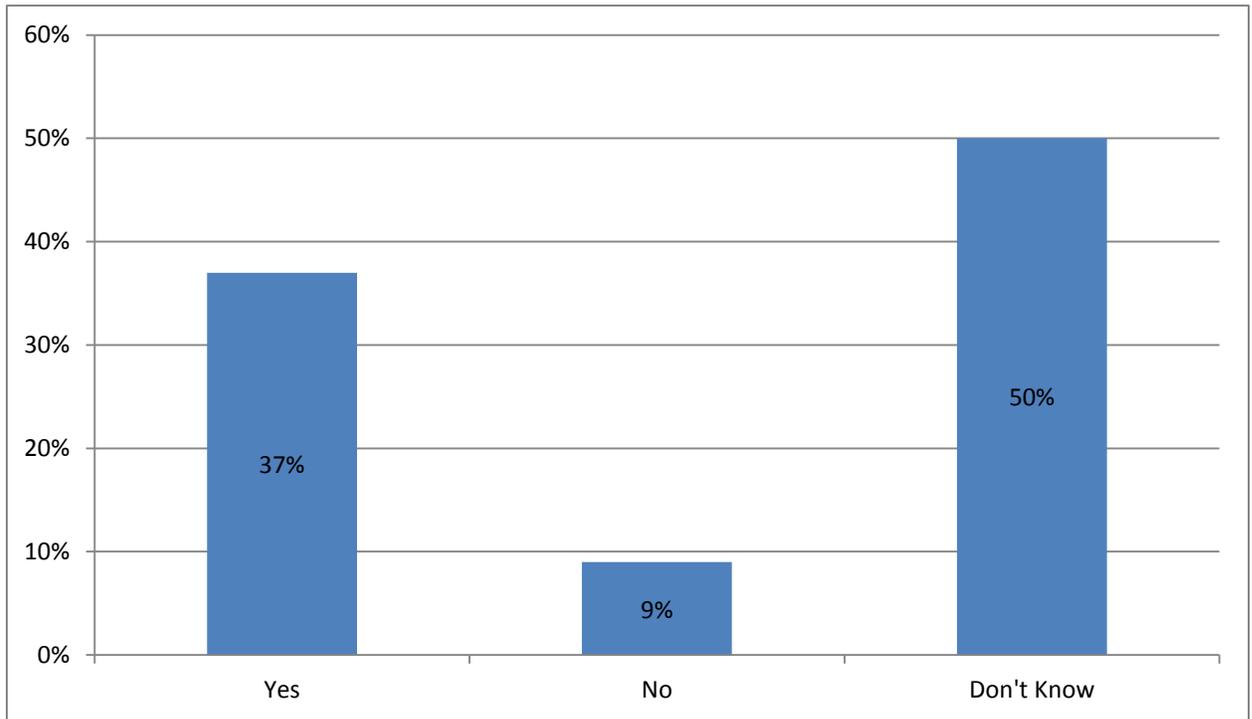
- If something isn't working, my dietician just wanted to keep changing instead of figuring if she was sick or give her a bit to settle.
- It would be nice if there was a pediatric cardiology clinic and cardiologist closer to our home. However, we do appreciate the cardiac team in Winnipeg. Have been well looked after by the same.
- Care has been fantastic.
- More frequent follow-up doctor appointments in regards to development.
- Doctors in our home town could help my child.
- Nothing, we are so thankful for the care we received.
- Impossible to make routine appointments with cardiology booking staff. Typically have to phone five or more times to get the appointment that the cardiologist wanted.
- Being contacted quicker about upcoming appointments. We live in Regina and are to go to Saskatoon for our appointments. We called last time a month before the time that they wanted us to come back, had we not called, we aren't sure when they would have booked us.
- No changes at this time.
- Find a good pediatrician that dealt with such a kind of disease.
- Coordination of appointments between different doctors.
- The central booking office at the Stollery is very hard to deal with. We had a follow up echo 8 weeks after procedure and no appointment was made for us. The follow up ended up being 12 weeks after. Knowing who/where to call to make appointments is hard.
- When I am concerned about O2 levels or fluid leaks, I would like to have someone local know how to assess our daughter. I have to drive 2 hours to the Winnipeg Children's ER.
- We have to travel to see our Cardiologist. Would be nice if we didn't have to.
- My son's team was wonderful. Nothing needs to change other than more staff.
- Make an EKG part of every child's first year care.
- More information on what kind of appointment to expect after discharge home. More information on immune deficiency and her syndrome she was diagnosed with.
- More frequent and more in-depth follow-up
- A medical facility with cardiology equipment and cardiologists in the south end of Calgary.

- Nothing. Everyone is great.
- Perhaps more training on the emotional distress children and families go through when in hospital and ways to provide support and/or show understanding.
- Nothing. They are the best.
- I am very happy with the care my son is receiving.
- In reference to question “I feel well prepared for my child’s discharge home”: I only felt unprepared because we were not given an adequate supply or understanding of how we could obtain our child’s medication. We were discharged around the holidays and if we didn’t know a pharmacist, we wouldn’t have any of her medications for an entire weekend.
- Better line of communication between health care professionals; more information provided to local health care providers.
- I wish he was seen more often.
- There really has been great communication between everyone involved in our son’s care. Especially in communicating with us, and making us feel comfortable with the path ahead.
- No. Great team.
- Nothing! We are so thankful for his surgeon and cardiologist/family doctor.
- Better organization and communication to us within the different parts of the hospital.
- Free medical prescriptions.
- There was talk on Wednesday (chest tube only pulled Tuesday) that our son might be discharged Thursday. We were worried because his care team wanted to discharge our son on Thursday after surgery on Monday. It seemed so soon and we were really nervous because our son was not back around to himself. We also live 2.5 hours from Saskatoon (in case of emergency). “Fortunately”, his O2 stats dropped overnight and he needed nasal O2 so wasn’t discharged until Friday. By this time he was well analgesic and we felt very comfy taking him home.
- Nothing.
- Give appointments or make appointments when the child is at the clinic for the next appointment so that we don’t need to call for appointments and be told “oh! We don’t have an opening”.
- Consistency in doctor/patient care. A different doctor/nurse each day often makes it frustrating when trying to provide care for our child. Different doctors/nurses do things differently.
- I wish he didn’t need it in the first place.
- Waiting list.

- I wish his condition has been better explained. I was under the impression there was only one large VSD and several small VSDs. It wasn't until a month after surgery we learned there was 2 large VSDs and several small ones.
- I don't feel comfortable going to an MD; rather I wish it was easier to see our pediatrician on a regular (6 month) basis.
- Absolutely nothing to change.
- Our son has heterodoxy which effects him head to toe. It is a rare condition and I don't feel educated on the full spectrum. I understand we are managing his heart condition first to stabilize him, but his stomach, lungs and other organs are all affected and I am interested in learning more.
- With my child's third open heart surgery, I felt very rushed out of the hospital. She ended up having complications that, had we flew home right away, wouldn't have been able to be diagnosed or dealt with at home. As it was, we ended up having to go back to deal with them.
- It's hard to describe over the phone. We were in and out of the doctors in town, because something was wrong with her, but every time they described her symptoms, it's just her waiting for heart surgery. But they didn't describe, or cardiology didn't listen, because when I went down to BCCH (IH Transfer), they asked about her symptoms as if they were new. It's hard in a small town to communicate between them and BCCH. Maybe video conferencing should be available so they can actually see the child.
- Nothing. We feel thankful and blessed with the wonderful care our child received.
- I would like the local BC Government Health Centre to stop pestering me and my wife to have our son immunized. No means no.
- Health care team in home city not involved due to no one being trained.
- I would like it to be easier to get a hold of the provincial Cardiology team, as they can sometimes be challenging to get in contact with, but they do cover a lot of people.
- A more consistent dietician who follows up regularly. The current dietician is very random in contacting us.
- I wish there was more specialists closer to home, for example, in Weyburn. Cardio and lung specialists in Regina, instead of just Saskatoon or any other baby specialist/surgeon in the province.
- Paying for parking.
- Nothing at all.
- Feel very fortunate to have such an amazing group look after our child.
- None so far.

- There was an RSV shot she could have received before surgery that no one told us about. This may have prevented her surgery from being postponed.
- I think it would be beneficial to have a Cardiac Ward in Winnipeg for when patients are in the hospital due to heart complications.

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



Skipped Question – 4%

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

- Being discharged on Saturday was difficult, due to being late in the day, finding a pharmacy to fill the prescription. He was on morphine wean and only certain places would fill the prescription. We ended up driving half way across the city to find a place. Otherwise, we would not have been able to leave.
- One unpleasant experience was an extremely bad headache after surgery. If possible, that would be something to avoid. And to understand what caused it, or do different, or what to do to avoid it. Otherwise, Stollery is recommended by us; we are grateful for the same.
- We appreciated the doctors, nurses, and pharmacists who respected us as parents and listened to our input, even if they diagnosed – it made such a difference! Snickers and eye rolling at rounds in response to parental wishes should never happen (but it did once). Better process for matching specific nurses' requests (primary care team) would be great. Nurses said the system doesn't work very well either. There wasn't enough time to communicate with the surgeon in the days after surgery. The world-class reputation of the Stollery (and among other parents) was reassuring. Thank you for listening.
- Overall, staff were kind and consistent with providing care. Everyone on my sons health care team was engaged, willing, and wanting to participate in providing the best care possible. We, the parents, were included every step of the way. Everyone worked as a team with a specific goal. We felt welcome. When he had questions, the team had answers. Our event was sudden and very emotional and stressful. We are very thankful for the excellent care our son received.
- Media feeds a steady stream of Health Care gone wrong stories, so one is concerned and very apprehensive entering the system. I can honestly say that at every point on our journey we felt as though we were in a very well managed program staffed by the best. If we could have taken our boy anywhere in the world, we would have not changed anything and had him looked after by the same amazing people. We can only say thank you for truly saving our boys life.
- Thank you for everything. Great support, loving, passionate team.
- We couldn't have been happier as to how everything was executed. From the moment our daughter was diagnosed, to the end surgery procedure. Knowing how much everyone truly cared about what we as a family were going through and to have all the support for all her doctors.
- We are very happy. Thank you very much.
- Our overall experience has been good.

- There is an opportunity to improve information for discharge to Saskatoon. Doctors at the Stollery are not very familiar with what care be given in Regina. Our daughter was discharged to Saskatoon when discharged to Regina ward, would be able to look after her health needs.
- Everyone went out of their way to make the experience as positive as possible, considering the circumstances.
- Conditions in the hospital were perfect, as comparison with other international hospitals. Was thankful letting me to stay even overnight with my baby. The staff was amazing. I wish nobody had such experience, but I knew my baby is in the right hands. Thanks.
- Our experience at the Stollery was fantastic! Everyone was very helpful, caring and great to work with. We stayed at the Ronald McDonald House and are so grateful for the love and support we received. For the stress we went through with our daughter, we couldn't have asked for a better experience. Thank you so much.
- Our experience as you know was hard mentally and emotionally. How we were treated by Doctors/Nurses and all other staff is greatly valued and cherished. Our son had great caregivers as well by the amazing staff at the hospital. We are only foster parents of this child and having to go through this with such a positive experience that if we ever had this presented again with a different child your staff has made me feel nothing more than the utmost confidence and relief that all will be okay. All the staff once again is truly amazing and I hold onto all the amazing things you all have done.
- The surgery was unexpected for us as we had no idea about our son's condition. We were always treated with great compassion and respect. We never felt like any of our questions were silly. We were so impressed with the team at the Stollery.
- As parents, we are strongly satisfied with the experience. We are enjoying having our child in very good condition and we have a great medical, social team around us. We hope that things will continue to go in the right direction.
- Post-op, I found some of the nurses on the cardiac unit to be less sensitive than what we had previously experienced in the NICU, especially the nurse practitioner who I found to be very cold and insensitive when it came to my baby and myself. The staff should be sensitive to the parents and families and understand that even though they themselves deal with this on a daily basis that the parents and families do not and that this is a new experience.

- No one likes to hear that their child is sick and needs open heart surgery, but if they must, I can't think of enough good things to say about the Stollery clinic. Our experience was amazing.
- We were not informed of our baby's hospital transfer back home, as the decision and organization happened so fast and prior to us getting to the hospital that day. We were happy with the news of the transfer, but weren't at all prepared for our baby to be transferred. However, the transfer went quick and smooth. We felt it was planned and organized just as it needed to be.
- Our child's cardiac procedure was an emergency as she unexpectedly went into cardiac arrest as a result from SVT. Many of these questions do not apply as her procedure was not scheduled.
- The Edmonton team we had was amazing. Any questions we had were answered promptly. If they didn't have the answer, they contacted other resources and found it for us. We were always kept in the loop with everything. Our son was well taken care of.
- Our daughter's surgery was long, complicated and the surgeon did the best for her. The level of care from the Stollery to the Children's Hospital was a big shock to me and my family. Our daughter's transfer was done quickly but without a parent going along. By the time we got to Winnipeg, our daughter had not been fed for 6 hours. Before surgery the cardiology team or nurses lead us to believe that she did not need surgery for months and this was not true. I feel there is a lack of communication between Edmonton, Winnipeg, and parents.
- We spent a total of 6 months between hospitals, NICU Royal Alex and U of A/Stollery. We found some nurse practitioners at RAH to be unprofessional and had little regard for families' privacy and confidentiality. NICU at Stollery was great and during recovery, we were sent to 5G which children who require high attention and needs should "never" be placed. We had issues with feeds, missing in-hospital appointments and overall care.
- If I had to do it over, I wouldn't change a thing.
- Overall, the experience was good. We are very satisfied with the care Stollery hospital provided to our child. Everything went very well.
- We are so thankful to everyone we encountered pre-, during, and post-operatively. We had a great outcome, and have a healthy and happy child. Thank you, thank you, thank you.
- I was amazed how things went from start to end and things couldn't have been one bit better. We really really enjoyed our stay in Edmonton; it was a break away from home.

- Our son has HLHS and although I had 2, 20-week ultrasounds, they never found anything wrong with his heart. He was diagnosed at 3 days old after being at home. It was the most terrifying life experience, he almost died. I knew nothing about HLHS or CHDs. We flew to Edmonton the next day and were so unprepared for everything. We had to leave our 2-year old behind. It was the most depressing time of our lives that we thought our baby was healthy, then in hours found out he's critically ill. I'd like radiologists to look better. Half a heart should be easy to see when measuring at 20-weeks. Other than that everyone was helpful. We're blessed to have our 4 month old baby boy.
- Our last trip to Edmonton, our son experienced what I think was an overdose in medication. He was given Ketamine to pull out a chest tube – and about an hour and a half later, he was given Delodid for pain. His SATS instantly went down and his breaths per minute were so shallow that the machine wasn't picking them up. It was extremely scary and he didn't wake up for almost 5 hours. Maybe nurses could be reminded of possible side effects of mixing narcotics or double checking what he has already had if there has been a change in nurse. It was handled well, but could have possibly had a different outcome if the research was done.
- Overall, things went well. The nurses (especially in PCICU) were great, the surgeon fantastic. The only things I would have like to see done differently were waiting times during fasting (like, this tiny baby hasn't eaten since "xyz", let's get moving) and when she was moved to the final unit before going home I felt like if we as parents weren't there with her for an hour, we were terrible people. The doctor was rude and not helpful, rushed out daughter out and actually asked us where we were when we left to get dinner. We stayed with our daughter probably 19 hours out of 24 hours the whole time, and yet "got in trouble" (when we weren't there – we needed a break too!) And as I mentioned, we said we weren't comfortable taking her home that day and asked if she could stay just one more night – didn't happen.
- My experience was very stressful, but I have faith in God. Because of the dedicated and helpful doctors and nurses my baby was able to make it through. I want to tell them thank you for the great care.
- Our daughter was overdosed on morphine in PICU. She may have had 5 times the amount for 6-8 hours. We were very angry. The ward was lovely and the care there was great.
- The staff were amazing in Edmonton. Our medical team in Calgary is also great. They are able to answer all my concerns and questions.

- Overall our experience was good. We had an excellent doctor/team in PCICU. The Intensivist did bedside teaching and included us. During stay in PCICU (4 days), I was pumping breast milk. I found the spaces available unacceptable. I had to go to PICU if I wanted to have a private room to pump in and then go clean supplies in NICU where there wasn't an option to have a private pumping area (ie. Separated by a curtain). I found this very stressful. I had to spend more time going back and forth between rooms when I could be at child's bedside. I also found that not having a private area to pump in stressful which also contributed to lower milk supply.
- It has been great.
- We felt like our daughter left Edmonton a bit too soon, and kind of alone in Saskatoon to start with because the nurses didn't seem to have gotten the proper instructions for giving the meds – timing and which ones were supposed to be given in mouth and not by feeding tubes. We couldn't always be there and when we were for the first few weeks we had to keep explaining why it had to be done on time and a certain way. It seemed like the cardiologists in Saskatoon were too vague in their orders, but they did listen and eventually write up more specific orders after a few weeks when it wasn't being resolved.
- I would have felt better about our discharge from the hospital if I had more written instructions on things like how to care for a scar, medication list with doses and how long to take it for would have been helpful as there was a miscommunication for us with this issue. When a parent goes through this experience they have trouble remembering everything that is said so, I think it would be helpful to have these conversations along with it in writing for when you're at home.
- Overall our stay in hospital was fantastic. Everybody was helpful. They did more than we expected. We were very satisfied.
- After the surgery, NICU staff were very good/attentive. Doctors were great and most nurses very good.
- Everyone and everything is always so well organized. Putting off surgery for a couple of hours is all right with us, if there is someone whose in emergency care that has to be before my child. I understand that, other than that, everyone is great and always on top of things. I love Edmonton hospital.
- Thanks to all the teams in ICU. They are great, understanding. This scary/stressful experience was fantastic because of them. Nurses, doctors were great thanks to them.

- Overall, we had a fabulous experience. Our son had an ASD repair. Though a “simple” procedure, we were terrified of what “could” happen. Our surgeon was great. Our PCICU experience was exceptional. Our nurse was so kind and gently – she nurses us as much as our child. As a nurse myself, I struggled with the nursing care we received on 4C3. I felt our assigned nurses cared only about getting meds in/vitals done and otherwise were not present. I did not have confidence that they could even react appropriately if a medical emergency occurred. Our discharge nurse was wonderful. She made me feel confident that our child was safe and ready to go home and had a strong knowledge base. Our social worker was beyond comforting. She instead, never rushed me and went above and beyond. The pre-op clinic nurses are 5 stars.
- Thank you.
- We would like to thank you for all your help and support that was given to us during our son’s cardiac procedure. We were treated very well.
- Would have liked to know about more quiet places like Zen garden. Overall we felt our son received amazing care by the doctors and nurses. We knew they wanted to see our son get better just as much as we did. They also supported us and tried to get us to feel at ease when we left for the night.
- We are just so grateful that her condition was discovered and treated in such a short period of time. She is thriving.
- We are beyond pleased with the cardio team at ACH. They are very concerned about our daughter and the care is fantastic. Thank you! I would have appreciated some sort of document explaining, the plan for surgery. Given the emotional state during pre-op, it was hard to absorb and keep track of all that was being discussed. By 2 weeks post discharge visit with home cardiologist, no information had been sent to the clinic. I had to inform the cardiology team about the surgery, complications, etc.
- The staff at the Stollery in the PCICU were phenomenal and could not be more blessed. However, our community home care team was not provided with the proper information to understand our daughter’s specific condition.
- We are grateful for the care he was given, although this CHD he was born with and his DCRV came back. I would like to have him seen more often.
- This has been an eye opening experience, something that we never thought about. We are so grateful to live in a country where there is such a high level of healthcare available.

- The staff have been great but there is an obvious and significant lack of funding for healthcare as evidenced by staff shortages, long waits, and lack of beds available.
- Our experience with our daughter's surgery was stress-free. But the doctors/surgeons/nurses and everyone else did the best just they could to keep us informed. Our experience was life changing and to see how well everyone works was phenomenal. We are forever grateful to everyone there.
- The only problem we had seemed was the communication between the 2 hospitals when my son was transferred. They both use completely different equipment, IVs, everything. So when we arrived after the transfer, everything was a stressful mess trying to move it over, switch it out, find what's compatible, etc. Seems silly that everything is so different. They didn't carry the same nutrition even, so they were in a panic to find the alternative or similar thing to feed him (ie. Lipistart). I think this should have been communicated and ordered or set up before they transferred him. It really made us uneasy to leave his side the first few nights. Short from that, everything was great. One more suggestion, in regards to dialysis, post-op nurses were getting two-minute training on it in front of us and then making tons of mistakes. This isn't acceptable. If they don't know it, they should be caring for the patient. I believe for this reason, our son had to go through unnecessary pain. For the most part, the experience was wonderful, informative, supportive, and very well organized. Thank you!
- The nursing staff in pre-op Pediatric ICU, and the 4C3 units were absolutely excellent. The worst experience for our daughter was pulling the chest drain tubes, both for the cardiac procedure and for the pneumothorax. In our daughter's words "I could handle all of the rest of the procedure, but the chest tube was the worst!"
- Our surgeon was really good with my son. We need more doctors that really take the time to make a difference. We were very blessed with the staff we have in the ICU. Very helpful.
- I would have to say that our entire experience, from being diagnosed with a heart defect at 18-weeks into our pregnancy, through our son's birth, and then onto his heart surgery at four-months, has been excellent. The care, support, and attention by the Cardiologists, Nurses, NICU, and PICU teams really were beyond our expectations, and we feel very fortunate.
- Doctors, surgeons, and nurses provide exceptional care. Information on supports in the community is definitely lacking. We had no clue where to turn for emotional / social support.

- Our experience at the Stollery was great, especially the PCICU. Saskatoon demanded to do things their way when we arrived home, which included putting him in an isolate with heat (he needed no heat in Edmonton), put him back on SiPAP although he was on high flow in Edmonton. It was 5 days behind where we had gotten in Edmonton and was a frustrating way to come home.
- Three days after our sons heart surgery, he was being moved from the PICU to the Recovery floor. The morning nurse mentioned to us when we got back from lunch that our son threw up after she fed him around lunch. We assumed that she looked into the reason why he vomited after he ate since he hadn't vomited until that moment (abnormal behavior for our son). Our son was moved to the recovery floor around 4:00pm. When we arrived there, I fed our son. Immediately after he ate, he threw up again. I was so scared, that I asked the nurse why he would be doing that. She wasn't sure since he just arrived to her floor and hadn't been given any verbal information and hadn't had a chance to check his medical binder. I asked if my son would be going through morphine withdrawal and she said probably not since he wasn't on it long enough. Our nurse then called for the Cardiologist to help us understand why he was throwing up after eating that day. It took until 7:30pm before the Cardiologist finally seen us. She confirmed that it was morphine withdrawal but wasn't sure what was causing the vomiting. So I asked when the last time he received morphine, after about 10 minutes, both the Nurse and Cardiologist told us our son wasn't given any pain medication for 17-hours. No Tylenol, Advil, or Morphine. The Cardiologist immediately gave him pain medication. By the next day, he was starting to act like himself. We were so upset that our son sat in pain for 17-hours and no one did anything for him until I started asking questions. I met with the head nurse in Recovery and felt heard and understood. She was going to communicate with the head nurse from the PICU. The PICU Head Nurse was supposed to tell me how my son sat in her department for so long without any pain medication. I know that the doctors are supposed to sign off on any pain medications given to patients. I'm still waiting to hear back with information on how this happened so that no other child or parent has to go through this awful experience. As a result, our son's right lung started collapsing. We are very disappointed that no one had provided us with any information yet. I've tried contacting the PICU and no one has given us any answers. It's very disappointing when the beginning of our experience was so wonderful and the end experience so awful. We would love to know what went wrong with our sons after care (in writing).

- The Stollery is amazing. We feel incredibly grateful our son receives his care there. It's like a second home to us.
- Heart surgery for anyone is stressful: for the patient and the family. We were informed at all times of what to expect. Any questions were answered without hesitation and there were no dumb questions. Satisfied with my experience and my son is doing excellent.
- Big thank you to the operating team and a huge thank you to the excellent nurses who cared for my son before and after surgery.
- The nurses were amazing and helpful. Easy to talk to.
- We are grateful for the care we receive from WCCHN.
- Even though it was very emotional, I would highly recommend the Stollery. ICU Nurses were so awesome. We didn't want to leave there. They really made our visit a memorable one. We even saw one of them at the Tim Horton's across the road and felt compelled to buy her a coffee. The Children's Hospital in Calgary is where we go all the time to see our cardiologist. Love her to pieces. Will be a sad day when our son out grows ACH.
- Our experience at the Stollery Children's Hospital was positive. The doctors, nurses, surgeon, and other staff were very informative and involved us as often as they could. It's truly remarkable what they do every day. They made our stay as easy and comfortable as it could have been.
- Unfortunately, a nurse in the ICU was rather rude and abrupt with my 17 year old son the afternoon of his surgery. He was sitting in a chair and had asked to lie down a few times. The nurse stood in the doorway and yelled across the room that 80-year-old-patients were able to sit up for an hour and at his age he could as well. "Do not look at your mother; she's not in charge here. We are!" It was 5:20pm, he has been asked to sit up for another 10 minutes. The nurse again yelled "Now you are going to sit up till 6 o'clock". With that statement, she turned and left. Discussed the matter with the cardiologist but have not heard back. Abuse of staff is not tolerated, neither should abuse of patient or family be. The discharge video was inappropriate for a 17 year old as it dealt with older people and their activities/lifestyle. I don't think he needed to hear when he could resume sexual relations.
- This was our first procedure at the Stollery and we feel and have been told the care is exceptional. Our daughter was 9-months when she had her procedure and the NICU and PICU nurses were amazing. We never felt her care was compromised for anyone else's and we were kept informed.

- We are overall extremely satisfied with the health care provided for our daughter. Everyone we encountered during our stay was very pleasant and professional.
- Family Support Group in Saskatoon (too far away to be possible logistically, although a Facebook Group exists). The quality of care was really world class and that is because of the world class people providing it.
- Yes, the ICU recyclables need to be cleaned more often. I accidentally dropped my pen. When I put my hand inside, I found a used tissue, food, etc. I did show the nurse. He told me I should not have put my hand in. In the ward, the air vents had cobwebs and Nurses and Nursing Students leave syringes and caps on the bedsides. Some nurses did not introduce themselves by name. Other than that, the care was very good.
- I am grateful for all the care and support and pacemaker wireless transmitter we use instead of making extra trips to Vancouver. Amazing group of healthcare professionals. We always feel cared for.
- Our surgeon and all of the supportive at the BC Children's Hospital were amazing and we became very close to all of them in such a short stay. This says a lot. We are so grateful. Thank you so much.
- I felt the doctors were very capable. The nurses were fantastic. My baby was well taken care of.
- Our son was born with VSD, it was a difficult time for me, but the Doctors and Nurses made it easy for me. He was taken care of. I could call anytime to talk to the nurse and ask questions. Easy to get an appointment. Our surgeon was awesome, did a really good job. Overall, what can I say about the doctors, surgeon, nurses and all the staff are guardian angels walking on earth. They are doing a great job.
- PDA Ligation was performed at bedside in the BC Women's NICU. I was well informed about the procedure and possible complications. The doctors and nurses were excellent.
- Parking is expensive.
- Many of the questions didn't apply to us, as our son was 5 days old at surgery. He was not in a 'pre-holding' area and we went straight from BCCH to home afterwards. The staff were absolutely amazing and we received so much support.
- We were very impressed with the whole process. Very professional, especially in Vancouver.
- Our surgeon was amazing. Leslie in the pre-op counsel session was so great and helpful. She made a scary day a little less hard (pre-op clinic).

- We are incredibly grateful to the staff at BC Children’s Hospital. They did everything they could and it is hard to comment on a lot of things due to the procedure being carried out on an emergency basis. My only comment/complaint would be related to the medical in the weeks or months before medevaced (and not related to the surgical centre or staff there). We felt our child’s issue was not being taken seriously by his GP, particularly when we were trying to address the issue of a child with a heart murmur, collapsing and passing out, and were told it was “weird” and probably not related to his heart.
- I found it was very upsetting that my ex-husband (who rarely sees my son) was able to use Ronald McDonald House, and I, who have financial hardship (and live 5 blocks too close to the hospital) was not able to use these resources. This caused a lot of financial strain on me.
- Our surgeon was fabulous! Very approachable and informative. Our experience with Children’s Hospital was excellent - top notch care.
- We are very happy that there is a new Ronald McDonald House. We stayed 20 minutes away in order to accommodate our whole family which made things difficult.
- We were able to stay at the new Ronald McDonald House which was very nice and the staff helpful. Because it was so new, the cab drivers did not know where it was and we for some reason did not have an address given to us. We were dropped at the hospital and had to find our way there, with our luggage and child. We know this happened to another lady and her infant as well. Other than that, I feel we were well taken care of and the care our son received was top notch.
- Can’t thank Children’s Hospital enough for the care and support they gave. Our cardiac nurse was more than amazing. All the nurses kept good care of her and ensuring the best for her. The support and resources were so much appreciated to help us through the difficult time. Thank you, thank you. Keep up the wonderful job you do for families.
- Just that she operated fast and supported me the whole time. I never felt strange asking questions. I feel very fortunate and lucky to have my daughter with me today. She would have passed on if she didn’t have her operation for TAPVR. The hospital was fast, efficient, caring, compassionate and amazing. So fortunate to receive continuing treatment there.
- I have nothing but good things to say about BC Children’s Hospital. They made a very scary difficult time a lot easier. So thankful we have such an amazing hospital.

- Our surgeon was very informative and accommodating as we had come urgently from out of town. Our displacement from our 2-year-old son at home, along with our youngest sons need for care was talked about at time of discharge to get us home as soon as it was felt they were comfortable with the recovery process. It seemed people were willing to go out of their way to ensure we were taken care of, and informed of what to expect in the coming weeks/months. A thank you to our pediatrician for catching the original condition, transferring us to our cardiologist who moved us on to our surgeon and his team at BC Children's.
- We cannot speak highly enough about the team at Children's Hospital in Vancouver. The reason for our 8-hour delay was the fact that Dr. Gandhi was doing an emergency heart transplant on a baby. The care we were given and the professional manner in which it was delivered was fabulous. Our surgeon is the best surgeon you could ever ask for. Our daughter's surgery was Wednesday 3:30pm. We were going home by Friday 5:00pm. Amazing!
- BC Children's Hospital is amazing.
- The Cardiology team is excellent at Children's. If we have any concerns or worries at home, our phone calls are always returned by Dr. Sanatani himself within an hour or so (very quickly). They truly care and try to make my son feel comfortable and well informed. Connie is amazing and has been an invaluable source of support for our family. We wouldn't have emotionally made it through the two surgeries without her kindness, information and support.
- Ultrasound had showed our baby had TOF but at that point could not determine how bad it was. We had enlisted the BC midwives to assist with the birth. Ended up having (birthing) the baby at home unassisted. This was not a choice we made, it happened that fast. Back to BC midwives... the chief midwife treated us, in my opinion, terrible. But that's another story. I cannot praise BCCH Cardiology enough. Our son had two procedures and both events, looking back now, might as well been a skinned knee. Two times, two weeks, and back at home. Now our son is 13 months and even more vital than a few of my friends born with good hearts. Just amazing.
- Twin boys both have Marfan. One boy had pediatrician in ICU turn off external pacemaker on two occasions causing him to flat line to "test" if it was working. It was emotionally difficult to handle.
- Thank you so much.
- Overall my stay at the BCCH was a very positive experience. All the staff were kind and helpful.

- We were so impressed with the level of care our son received. Once he was diagnosed, he was treated as an individual and I was so happy with the way the information was delivered to him. We are fortunate because we live in the area and we have a strong family support system. My biggest complaint would be the cost of parking at BC Children's. Our son is thriving. He climbed the Grouse Grind 6-weeks post-op with many employees (and mom and dad) and is fully back to his active routine (plays soccer 6 days a week, basketball and baseball). I am optimistic that the level of care will continue. I thank the staff of Children's Hospital for their professional, informative, sympathetic and thorough treatment of our son, and involvement of us, his parents.
- BC Women's Heart Centre, Doctors, Nurses and all other workers are amazing and I feel so much more confident in my child's heart care knowing that there are professionals who care and do a great job day in and day out.
- It was devastating finding out my son's surgery was cancelled.
- Thank you for all the work that the BC Children's Hospital had done for my child.
- The ICU nurses were amazing.
- We were pleased with our experience and the quality of care our son received at BC Children's Hospital. We felt prepared and had regular appointments with our son's cardiologist.
- Everyone was wonderful and I am happy about the surgeries that were done. Thank you Vancouver.
- We were very grateful for the wonderful experience and care our daughter received.
- We found each and every doctor and nurse very helpful and committed and could not have wished for better care for our son. Very thankful to everyone at BCCH.
- Our son's cardiac ailment came on rather suddenly. It was a big shock for our family. However, we couldn't have asked for better care. Our pediatric Cardiologist in Victoria was phenomenal and took care to ensure we felt confident. The pre-op team, life support workers, and nurse physicians also took great care to ensure we were clear of the procedure before/after and were very reassuring. Our cardiac surgical team came by twice a day to check on us for our entire stay. We felt so confident about the surgery and post-op care. The nurses in the ICU and the cardiac ward were also very kind and attentive. We couldn't have asked for any more support. Thank you for looking after us so well.

- The nursing staff in the PICU were some of the most supportive and amazing women I have ever had the pleasure of meeting. They took phenomenal care of our baby boy and made sure we were well informed and felt comfortable as well.
- We have been very fortunate to have found the team of professionals we did. They took care of us very well. We can never truly thank the surgeon and his team of nurses for providing our son with a second chance at life.
- No information had been relayed to our pediatrician. All the information with history was relayed by me until the records showed up on the computer.
- Thanks a lot to the team work at Children's Hospital. The experienced doctors and nurses gave my kid a second life and new chance. They did a wonderful job. Thanks for the service and supports. Thanks for your organization. Hope every family like us can be better because of your help.
- We are grateful for our daughter's quality of care and being able to have had her life-saving surgery. She is with us today because of it and thriving. Thank you, thank you.
- My wife and I had high expectations for our son pre/post surgery centre in Vancouver. Our expectations were surpassed and we have only great things to say about the BC Children's Hospital. Thank you all for the great experience during a note so great time in our, and our sons life.
- Our surgeon was amazing pre- and post-operation. All staff at BC Children's were equally helpful and informative.
- Everyone was really great and helpful.
- It was really scary and hard for me and my family, but I learned to accept it from all the help we had in Winnipeg!
- The nurses in Cardiology and in the ICU were incredible. They made us feel like we were (or our son was) their only patient.
- All doctors and care staff are very helpful. Thanks to all the staff.
- BC Children's Hospital nurses and staff were excellent with round the clock care for my son. We are so grateful and thankful for our healthcare in BC and Canada.
- I couldn't have asked for a better cardiologist. Our cardiologist is very informative and always available for questions or concerns. He choose, who I believe, is the best surgeon for my son's heart defect. The clinic nurse was always very helpful and patient with us.