



Western Canadian
Children's Heart
Network

MEASURED IMPACT
BIENNIAL REPORT
2018-19 & 2019-20

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“ It is reassuring for families to know that there are medical experts across Western Canada collaborating on child patients in Saskatchewan, Alberta, BC, Manitoba. No need for a second opinion - you get multiple opinions.

Survey Respondent, 2018-19 Home Centre Survey, Saskatoon Saskatchewan

A partnership amongst:



BC
Children's
Hospital



BC Children's Hospital
4480 Oak Street
Vancouver, BC V6H 3V4



STOLLERY
CHILDREN'S
HOSPITAL



Stollery Children's Hospital
8440 112th Street NW
Edmonton, AB T6G 2B7



Alberta Children's Hospital



Alberta Children's Hospital
2888 Shaganappi Trail NW
Calgary, AB T3B 6A8



JIM PATTISON
CHILDREN'S
HOSPITAL



Jim Pattison Children's Hospital
103 Hospital Drive
Saskatoon, SK S7N 0W8



Children's Hospital
HSC
Winnipeg



Children's Hospital, HSC
685 Williams Avenue
Winnipeg, MB R3E 0Z2

Who We Are

The Western Canadian Children's Heart Network (WCCHN) links expertise between the five pediatric cardiac centres in western Canada and has successfully established inter-provincial cooperation and partnership. The WCCHN spans over 4-million square kilometres, and serves a population base greater than 11 million people. The WCCHN includes two pediatric cardiac surgical programs (British Columbia Children's Hospital in Vancouver and the Stollery Children's Hospital in Edmonton) and three referring centres (Alberta Children's Hospital in Calgary, Jim Pattison Children's Hospital in Saskatoon, and Children's Hospital – Health Sciences Centre in Winnipeg).

What We Do

The core function of the Network is to coordinate and integrate care for pediatric cardiac patients across the western provinces and territories. The WCCHN promotes cooperation in education and clinical practice, supports research efforts, and advocates for the continual improvement of service delivery. Collaboration among Network sites ensures that our patients have access to the highest standard of care available.

Mission

To offer a framework for which collaborative care is provided to children in the western provinces and territories.

Vision

Equitable and timely access to world class care for children with heart disease.

Values

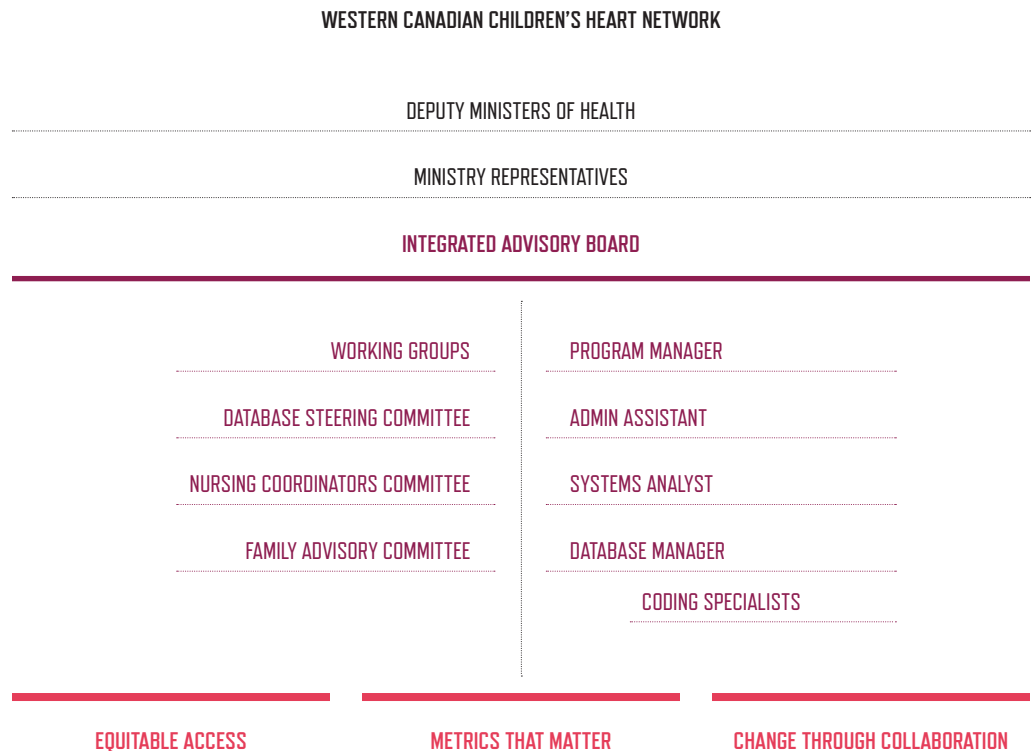
Collaboration | Quality | Collegiality | Respect | Transparency | Engagement

“ I commend the WCCHN for its work across the western provinces and collaborative approach to complex medical care. Collaboration is essential to meeting the challenges of building an exceptional health care system. Thank you for contributing to improved health outcomes for pediatric cardiac patients in the four western provinces and two territories.

Dean Screpnek, Assistant Deputy Minister, Health Standards, Quality and Performance Division, Alberta Health

Our Governance

In June 2019, the WCCHN merged their Clinical Operations and Steering Committees into a unified and expanded Integrated Advisory Board. The Integrated Advisory Board is designed to provide strategic guidance to the cross-province leadership and institutional members that form the Western Canadian Children's Heart Network. This Board integrates the expertise of leading physicians, senior hospital administrators, Ministry of Health representatives, frontline nurses, and patient and family advisors from all western provinces. Together they ensure that initiatives remain true to the Network's mission, vision, and values. The Integrated Advisory Board stands on three important pillars: Equitable Access to services and resources; Metrics that Matter; and Change through Collaboration.



“ I would like to thank the members, staff and stakeholders of the Western Canadian Children's Heart Network for the many years that I have been part of the WCCHN, participating as a parent representative from Manitoba. Being part of the WCCHN committees provided me with opportunity to create many amazing relationships over the years, take part in very valuable initiatives, while enabling me to give back to the Network that provides such excellent cardiac care to thousands of children in my province, including my own son. All of my experiences interacting with WCCHN will continue to hold a special place in my heart and I feel forever blessed.

Joni Wilson, Heart Mom and Former WCCHN Parent Partner, Winnipeg Manitoba

Annual Address



A Message from the WCCHN Program Manager

2019 has been a time of great renewal for the WCCHN. Not only has it been a chance to reset and recalibrate after 20 years of service, but it has also presented an invitation to re-imagine and recommit to the future that lies ahead. While the Network remains a large and productive group, the past twelve months have offered valuable opportunity to refresh strategy and approach. I have had the great privilege of working alongside some of our most senior leaders and administrators to drive our shared vision forward. Patients and families remain our first and highest priority. We remain committed to finding new ways of keeping heart patients and their families at the centre of all we do.

Elina Williams RN, BScN , PMP

Program Manager, Western Canadian Children's Heart Network



The WCCHN Welcomes Dr. Charissa Pockett as Interim Chair of the Integrated Advisory Board

Credentials: MD, FRCPC

Title: Faculty, Division Head Pediatric Cardiology, Department of Pediatrics, University of Saskatchewan

Clinical interests: Diagnostic and interventional cardiac catheterization, single ventricle physiology, medical education

Originally from Manitoba, Dr. Pockett studied and completed medical school at the University of Calgary in 2005. She completed her Pediatric residency at the Alberta Children's Hospital in Calgary in 2009 which included 6 months of training at the Mater Children's Hospital in Brisbane Australia. She went on to train in Pediatric Cardiology at the Stollery Children's Hospital in Edmonton from 2009 to 2012. In July of 2012 Dr. Pockett joined the division of Pediatric Cardiology at the Royal University Hospital in Saskatoon. A one year leave of absence in 2014 allowed her to pursue advanced training in Pediatric Interventional Cardiology at the Rady Children's Hospital in San Diego, California. Since 2015 Dr. Pockett has been a full time Interventional Cardiologist at the Royal University Hospital, now the Jim Pattison Children's Hospital in Saskatoon. She became Division Head for Pediatric Cardiology in December 2017. She is a member of the Children's Heart Healthy Camp in Saskatchewan (CHAMPS) research team at the University of Saskatchewan and is also currently studying the use of Robotic presence for remote murmur assessment. She became the interim Physician Lead at the Western Canadian Children's Heart Network in June 2019.

“ Many thanks for all your hard work to ensure the continued viability of WCCHN. Although the functioning of the Network is not visible to all, kids and families in western Canada benefit from it every day.

Deb Jordan, WCCHN Integrated Advisory Board Member

Executive Director, Connected Care Services Branch, Ministry of Health, Saskatchewan

By the Numbers

Annually (BASED ON 2018/19 DATA)

4

MILLION SQUARE
KILOMETRES

11

MILLION
POPULATION BASE

3

REFERRING
CENTRES

2

SURGICAL
CENTRES

4

TRAVELLING
SPECIALIST CLINICS

852

HEART
SURGERIES

699

CARDIAC
CATHETERIZATIONS

107

ELECTROPHYSIOLOGY
PROCEDURES

24,862

OUTPATIENT
CLINIC VISITS

3,066

OUTREACH
VISITS

108,246

TOTAL RECORDS
IN THE DATABASE

Our People

Know your WCCHN Office Staff



Elina Williams, Program Manager

- Partners with WCCHN leadership in strategic planning
- Manages and provides oversight for programming, staff, and strategic initiatives
- Manages stakeholder engagement and communications
- Supports vendor procurement and maintenance for third party contractors
- In her free time: Chases after two rambunctious kids aged 5 and 8



Vera Horobec, Database Manager

- Oversees routine operations for the database and registries
- Collaboratively establishes best practice, procedures, process guidelines, and reference materials as it pertains to the database
- Monitors and facilitates user access requests, onboarding, and training
- Fulfills data access requests
- Supports coding specialists at all five sites in training and continuing education
- Provides ongoing monitoring and quality control for database functionality
- In her free time: Dreams about her next travel destination



Mike Scott, Systems Analyst

- Provides technical support, maintenance, and application enhancements for the WCCHN and Centripetus databases
- Supports data access requests
- Engages both internal and external IT resources
- Monitors systems for stable operations and optimum performance
- In his free time: Likes to play with electronics and is always up for a new TV series to binge



Karen Lam, Administrative Assistant

- Works closely with all network committees, sites, and members for logistical planning, scheduling, and coordination
- Facilitates core office administration and operations
- Supports internal and external communications
- Manages office documentation and asset archive
- Participates in profiling activities
- In her free time: Likes to read a good science fiction novel and is learning French

Our People

Know your WCCHN Coding Specialists



TANIA GILMORE, BC CHILDREN'S HOSPITAL

Place of study: Douglas College

Year Graduated: 2000

CHIMA Certified: Yes

Length of Service with WCCHN: 13 years

Why do you do what you do?

I enjoy collecting and analyzing health information that is used to provide quality patient care.

What do you think makes the role of a Health Information Manager so important?

The information collected helps improve the quality of patient care.

What do you love about your job?

I am always learning something new.

Just for fun

Reading now: The Wives by Tarryn Fisher

Favourite place in the world:

Maui. I love the sun!

Hidden Talent: I play the piano

If you could be an animal,

what would you be: A horse!



JESSICA CHAGNON, ALBERTA CHILDREN'S HOSPITAL AND JIM PATTINSON CHILDREN'S HOSPITAL

Place of study: Alberta

CHIMA Certified: Yes

Length of Service with WCCHN: 10 years

Why do you do what you do?

I greatly enjoy this line of work and find it very interesting.

What do you think makes the role of a Health Information Manager so important?

It helps support resource and financial allocation, provides important statistics, aids in research studies, and provides support to physicians.

What do you love about your job?

The challenges, the application of my post-secondary education, the continuous education, and the importance of the work.

Just for fun

Reading now: Riding Between The Worlds by Linda Kohanov

Favourite place in the world: On the backs of horses, and anywhere where my family and the dogs are

Hidden Talent: Event planning

If you could be an animal, what would you be: Varies by day, location, environmental conditions, and other circumstances



KATHLEEN MCCARTHY, STOLLERY CHILDREN'S HOSPITAL

Place of study: Northern Alberta Institute of Technology

Year Graduated: 1996

CHIMA Certified: Yes

Length of Service with WCCHN: Since the beginning

Why do you do what you do?

I knew I wouldn't be comfortable being a frontline health professional, but my designation gave me an opportunity to use my 'attention to detail' skills and still be a part of healthcare.

What do you think makes the role of a Health Information Manager so important?

I believe, when it is done well, that it is beneficial for research projects, financial decisions, and also the area of epidemiology etc.

What do you love about your job?

I love the advances I've seen in Cardiology, watching procedures once only performed in an OR now being performed in a Cardiac Cath lab (Amplatz devices, valve replacements). I've loved watching the number of days a post-transplant patient stays in the hospital come down dramatically. It has also been amazing to watch our program grow from the time I began in 1997 when we performed 360 surgeries to 2019 when over 800 surgeries were performed - it's incredible.

Just for fun:

Reading now: Opening to Gratitude & Grace by Linda Joy

Favourite place in the world: United Kingdom, Edinburgh & Dublin

Hidden Talent: I'm fairly good at home decorating

Hobby: I love to walk around my city and discover new and interesting areas. (My highest number of steps to date in a day was just over 30k.)

If you could be an animal, what would you be: A cat



SHARMAINE APUYA, VARIETY CHILDREN'S HEART CENTRE, HEALTH SCIENCES CENTRE - WINNIPEG

Place of Study: Red River College

Year Graduated: 2018

CHIMA Certified: Yes

Length of Service with WCCHN: <1 year

Why do you do what you do?

Interacting with patients, indirectly, I am still able to provide patient care by performing data analysis of the information found within the health record to facilitate health care delivery, patient safety and decision support.

What do you think makes the role of a Health Information Manager so important?

They maintain the integrity and confidentiality of personal health information and are also responsible for collection of health care data as it is required for patient care, research, education, financial and management planning.

What do you love about your job?

As a new member of the Variety Children's Heart Centre and the WCCHN, it's great to come into a welcoming environment. I enjoy being able to connect with people outside of Manitoba.

Just for fun

Watching now: The Good Doctor

Favorite place in the world: Hawaii

Hobbies: Trying out new activities, food, and visiting new locations

If you could be an animal, what would you be: A Panda

Integrated Advisory Board Membership

AS OF NOVEMBER 2019

WCCHN

Dr. Charissa Pockett *Interim Board Chair and Divisional Director, Cardiology, Jim Pattison Children's Hospital*

Elina Williams *Program Manager, WCCHN*

British Columbia

Susan Schroeder *Senior Director, Medical/Surgical Ambulatory Patient Care Services, BC Children's Hospital*

Dr. Shubhayan Sanatani *Division Head, Cardiology, BC Children's Hospital*

Dr. Sanjiv Gandhi *Division Head, CV Surgery, BC Children's Hospital*

Lea Legge *Nurse Clinician, BC Children's Hospital*

Derek Rains *Director of Medical Services, Provincial Services Branch, BC Ministry of Health*

Alberta - Calgary

Patty Knox *Nurse Clinician, Division of Cardiology, Alberta Children's Hospital*

Dr. Robin Clegg *Staff Cardiologist, Division of Cardiology, Alberta Children's Hospital*

Renee Sholes *Patient Care Manager, CardioRespiratory, GI, Endocrine, PCWH and Ambulatory Care, Alberta Children's Hospital*

Alberta - Edmonton

Crystal Coroon *Discharge Coordinator, Cardiology and GI Services, Stollery Children's Hospital*

Dr. Michal Kantoch *Divisional Director, Cardiology, Stollery Children's Hospital*

Kristy Cunningham *Executive Director, Critical Care and Respiratory Therapy, Stollery Children's Hospital*

Dr. Mohammed Al Aklabi *Divisional Director, CV Surgery, Stollery Children's Hospital*

Saskatchewan

Lucia New *Director of Children's Acute and Subspecialty Children's Programs, Royal University Hospital*

Marie Penner *Nurse Clinician, Cardiology, Jim Pattison Children's Hospital*

Deb Jordan *Executive Director, Connected Care Services Branch, Ministry of Health, Saskatchewan*

Manitoba

Pam Wiebe *Nurse Clinician, Cardiology, Variety Children's Heart Centre*

Dr. Reeni Soni *Divisional Director, Cardiology, Children's Hospital HSC Winnipeg*

Monika Warren *Program Director, Child Health, HSC Winnipeg*

Sonia Busca Owczar *Senior Policy Analyst, Quality and Citizen Experience Branch, Department of Health, Seniors and Active Living, Manitoba Health*

Crystal Maslin *Patient and Family Advisor*



Metrics that Matter

CLINIC RESOURCING

SUMMARY OF PEDIATRIC CARDIOLOGY CLINIC RESOURCING INFORMATION

SOURCE: WCCHN CENTRES, SOURCED FROM LOCAL ADMINISTRATIVE SYSTEMS
WAIT TIME IS FOR NON-URGENT NEW REFERRALS

WCCHN Centre	Pediatric Cardiologists	Average Wait Time for Clinic Appt	Clinic Nurses (FTE)	Echo-sonographers (FTE)	Dietician Support (FTE)	Social Work Support (FTE)
BC CHILDREN'S HOSPITAL VANCOUVER	8	1-6 months	5.4	6.8	0.2 unfunded	0
STOLLERY CHILDREN'S HOSPITAL EDMONTON	16 2 Locums	3-4 months	8.6 RN 1.0 LPN	11.9	1.0	1.0
ALBERTA CHILDREN'S HOSPITAL CALGARY	8	3-6 months	2.1 RN 1.0 LPN	4.4	0.5	0.75
JIM PATTISON CHILDREN'S HOSPITAL SASKATOON	4	> 48 months	2.0	2.0	0.5	0.5
CHILDREN'S HOSPITAL HSC WINNIPEG	4	6-8 weeks	2.5	3.8	0	1.0

“ We would like to thank everyone who helped us especially during the hard times, the doctors, specialist, nurses and everybody involved - thank you so much. You’ve given my daughter a chance to live and to be with us.

Survey Respondent, 2018-19 Home Centre Survey

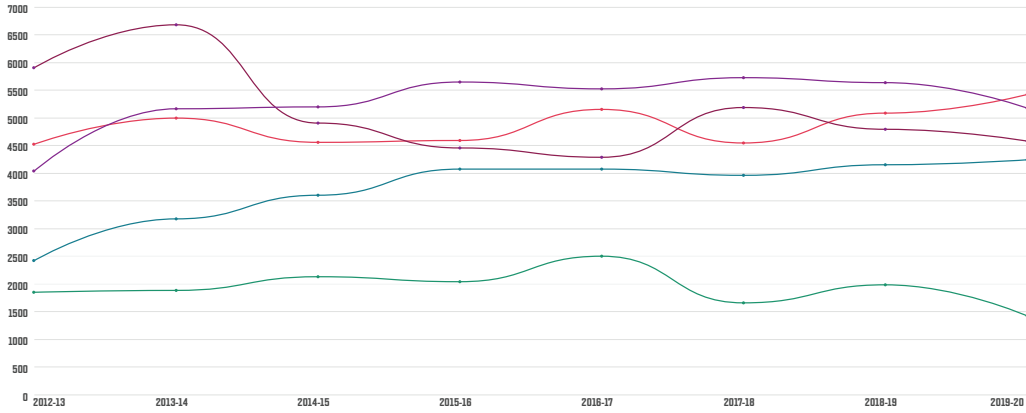


Metrics that Matter

CLINIC VOLUMES AND OUTREACH METRICS

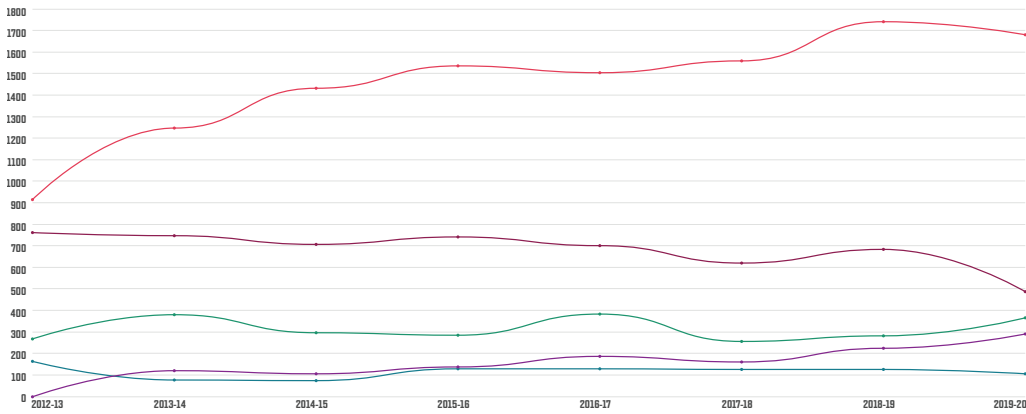
WCCHN CLINIC VISITS BY CENTRE

SOURCE: WCCHN CENTRES, SOURCED FROM LOCAL ADMINISTRATIVE SYSTEMS
EXCLUDES PARTNERSHIP/OUTREACH VISITS, ECHO ONLY, NURSING ONLY, AND RESIDENT CLINICS



WCCHN PARTNERSHIP/OUTREACH VISITS

SOURCE: WCCHN CENTRES, EXCLUDES CLINIC VISITS AT WCCHN CENTRES



- BC CHILDREN'S HOSPITAL, VANCOUVER
- STOLLERY CHILDREN'S HOSPITAL, EDMONTON
- ALBERTA CHILDREN'S HOSPITAL, CALGARY
- ROYAL UNIVERSITY HOSPITAL, SASKATOON
- HEALTH SCIENCES CENTRE, WINNIPEG

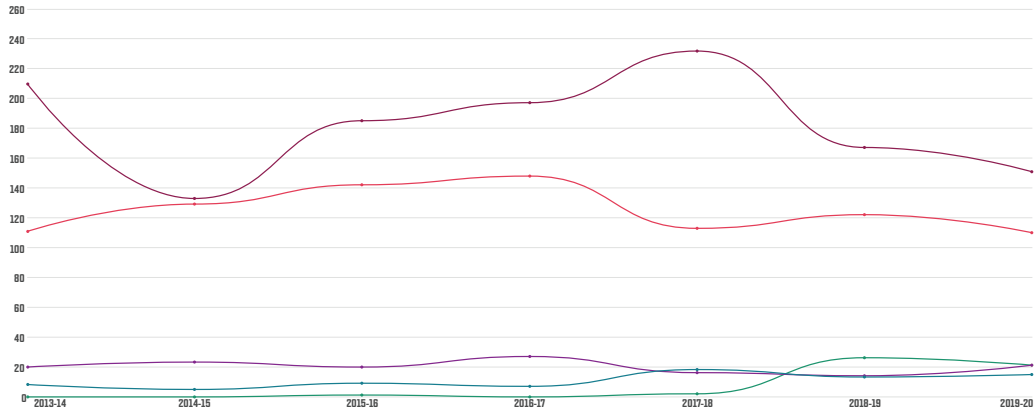


Metrics that Matter

CARDIAC CATHETERIZATION AND EP METRICS

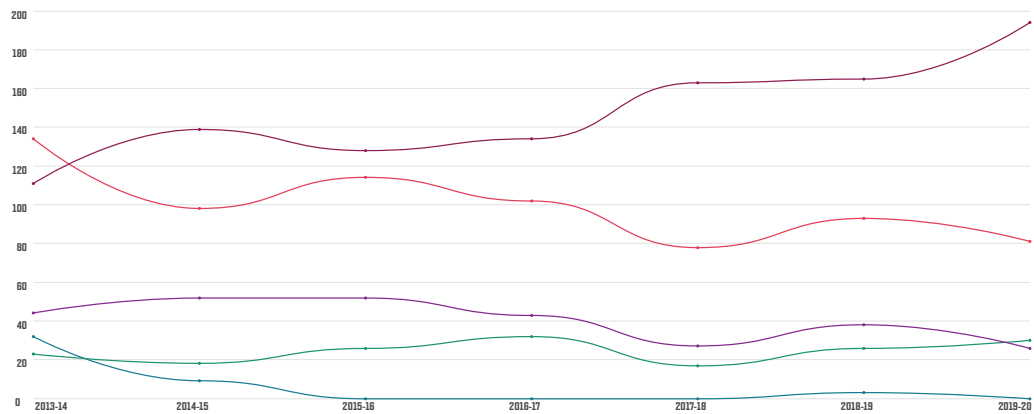
INTERVENTIONAL CARDIAC CATHETERIZATIONS

INCLUDES PEDIATRIC PATIENTS ≤ 17.99 YEARS AT TIME OF PROCEDURE
SOURCE: WCCHN DATABASE



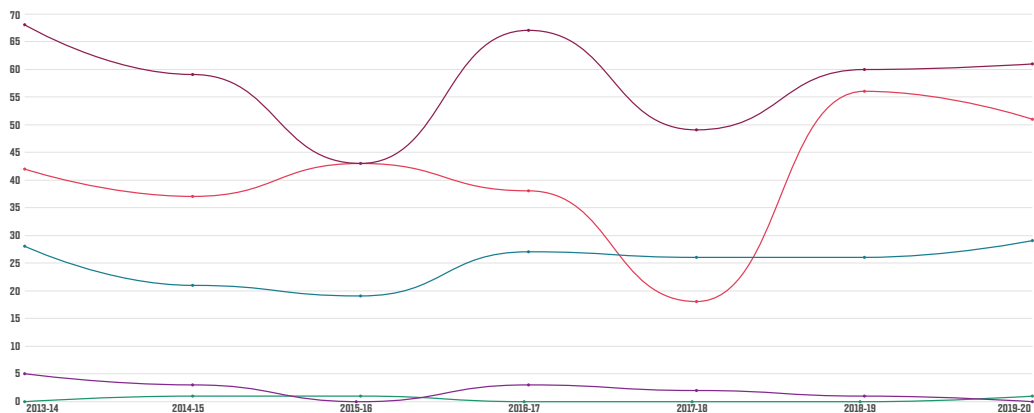
DIAGNOSTIC CARDIAC CATHETERIZATIONS

INCLUDES PEDIATRIC PATIENTS ≤ 17.99 YEARS AT TIME OF PROCEDURE
SOURCE: WCCHN DATABASE



ELECTROPHYSIOLOGY STUDIES/RADIO FREQUENCY ABLATION

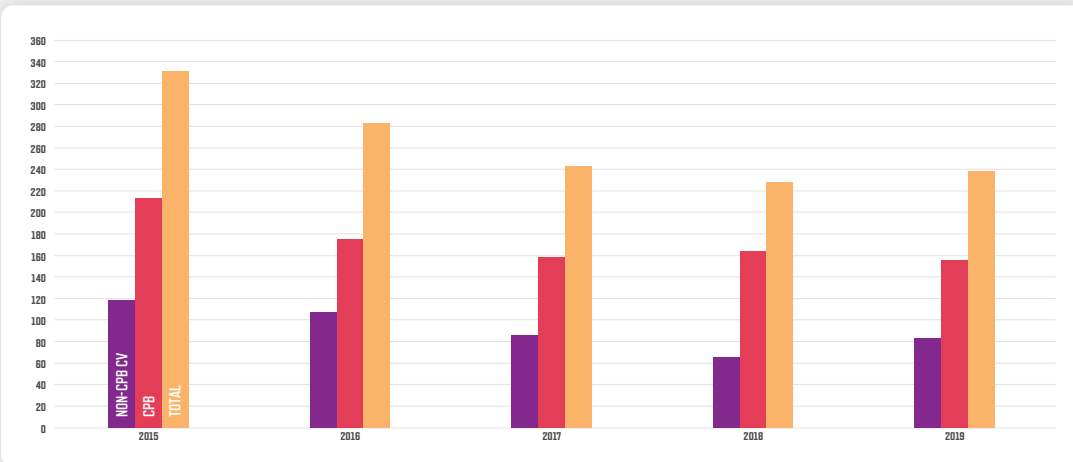
INCLUDES PEDIATRIC PATIENTS ≤ 17.99 YEARS AT TIME OF PROCEDURE
SOURCE: WCCHN DATABASE



SURGERY AT BC CHILDREN'S HOSPITAL

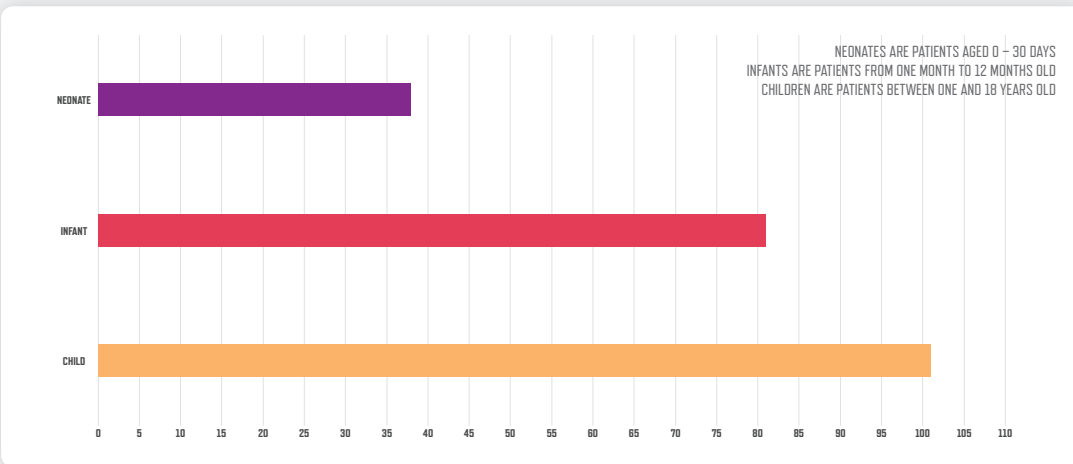
CASE VOLUME AND OPERATION TYPE BY YEAR

CPB — OPERATIONS WHERE CARDIOPULMONARY BYPASS WAS USED. NON-CPB CV — OPERATIONS WHERE CARDIOPULMONARY BYPASS WAS NOT USED. SOURCE: STS CONGENITAL DATABASE



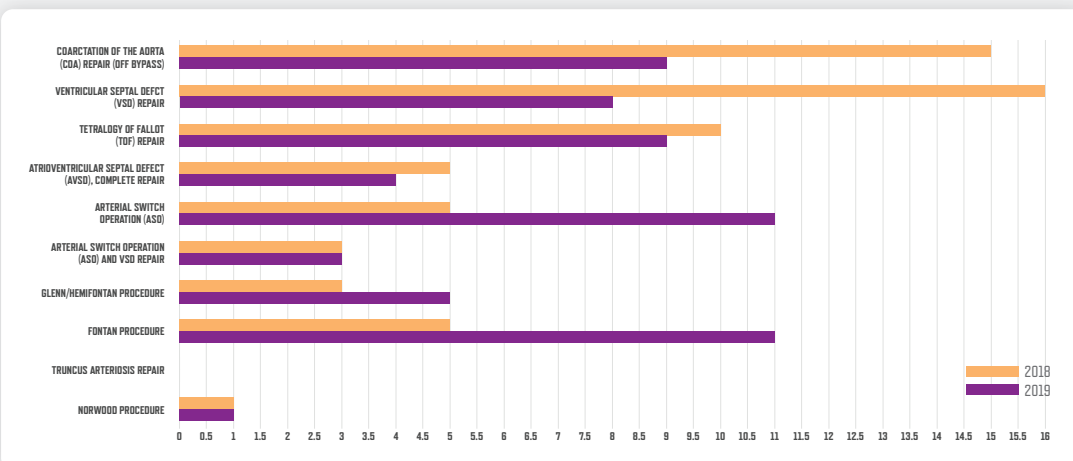
2018 CASE VOLUME BY AGE

SOURCE: TABLE 7, THE SOCIETY OF THORACIC SURGEONS (STS) AUGUST 2019 DATA HARVEST REPORT FOR THE PERIOD ENDING DECEMBER 2018



CASE DISTRIBUTION BY BENCHMARK PROCEDURE

SOURCE: STS CONGENITAL DATABASE



SURVIVAL RATES AND LENGTHS OF STAY BY BENCHMARK PROCEDURE, LAST FOUR YEARS

	Case Volume	Hospital Survival Rate (%)	STS Benchmark (%)	Hospital LOS (days)	STS Benchmark (days)
Coarctation of the Aorta (COA) repair (off bypass)	65	98.5	98.8	3.0	12.1
Ventricular Septal Defect (VSD) repair	102	100.0	99.5	3.0	9.2
Tetralogy of Fallot (TOF) repair	48	100.0	98.9	5.0	11.7
Atrioventricular Septal Defect (AVSD), complete repair	30	96.7	97.9	5.5	17.9
Arterial Switch Operation (ASO)	25	100.0	97.9	5.0	17.4
Glenn/Hemifontan Procedure	33	97.0	98.0	4.0	14.2
Fontan Procedure	32	100.0	99.0	7.0	13.3
Truncus Arteriosis repair	4	75.0	91.0	11.0	29.7
Norwood Procedure	7	71.4	85.5	9.0	48.4

FOR THE PERIOD COVERING JANUARY 2015 - DECEMBER 2018. LENGTH OF STAY (LOS) REFERS TO THE LENGTH OF TIME A POST-OPERATIVE PATIENT STAYS IN THE HOSPITAL. MEDIAN LENGTHS OF STAY ARE REFLECTED. SOURCE: TABLE 18, THE SOCIETY OF THORACIC SURGEONS (STS) AUGUST 2019 DATA HARVEST REPORT FOR JANUARY 2015 TO DECEMBER 2018

2018 SURVIVAL RATES BY STAT CATEGORY

Primary Procedure	Total Volume	Discharge Mortalities	Operative Mortality Rate (%)	STS Benchmark (%)
STAT 1	94	0	0.0	0.4
STAT 2	53	1	1.9	1.4
STAT 3	17	1	5.9	1.9
STAT 4	41	2	4.9	5.8
STAT 5	2	0	0.0	10.8

CONGENITAL HEART OPERATIONS ARE GROUPED BY THE COMPLEXITY OF THE PROCEDURE INTO WHAT ARE KNOWN AS STAT CATEGORIES. STAT CATEGORY 1 INCLUDES THE LEAST COMPLEX OPERATIONS, WHICH ARE ASSOCIATED WITH THE LOWEST RISK OF MORTALITY, AND STAT CATEGORY 5 INCLUDES THE MOST COMPLEX OPERATIONS, WHICH ARE ASSOCIATED WITH THE HIGHEST RISK OF MORTALITY. STAT MORTALITY CATEGORIES WERE DEVELOPED BY STS IN COLLABORATION WITH THE EUROPEAN ASSOCIATION FOR CARDIOTHORACIC SURGERY (EACTS).

OPERATIVE MORTALITY IS DEFINED AS A DEATH THAT OCCURS DURING THE HOSPITAL STAY IN WHICH THE PROCEDURE WAS PERFORMED NO MATTER HOW LONG THE PATIENT REMAINS IN HOSPITAL AFTER THE OPERATION; AT ANOTHER HOSPITAL BECAUSE THE PATIENT WAS TRANSFERRED BUT WAS NEVER DISCHARGED; OR WITHIN 30 DAYS OF THE OPERATION EVEN IF THE PATIENT IS DISCHARGED HOME.

SOURCE: TABLE 1, THE SOCIETY OF THORACIC SURGEONS (STS) AUGUST 2019 DATA HARVEST REPORT FOR THE PERIOD ENDING DECEMBER 2018

“ Given my daughter’s CHD (hypoplastic left heart syndrome), the team was excellent in preparing me for her surgery. Parents can only be so prepared for their child’s heart surgery, and BC Children’s Hospital did an outstanding job before, during, and after surgery.

Survey Respondent, 2018-19 Home Centre Survey, Vancouver BC

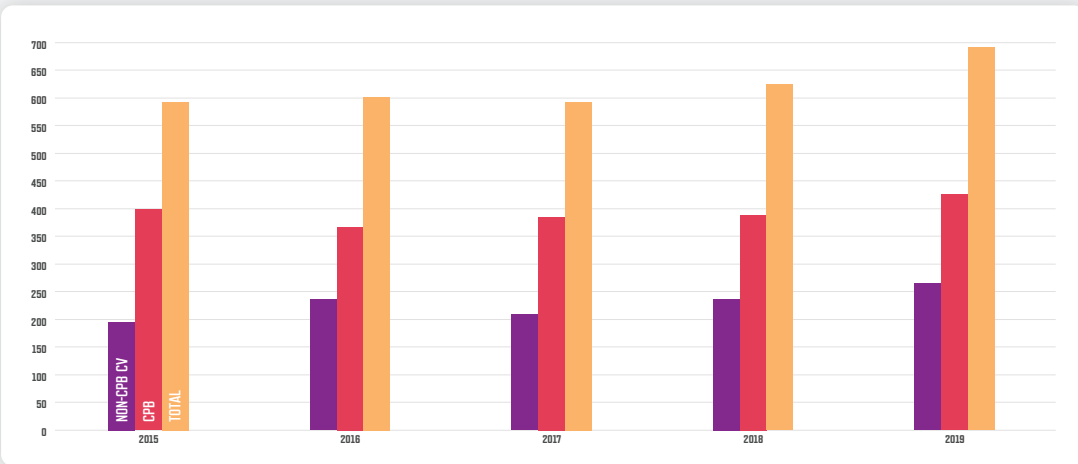
“ Overall fantastic care, great support by everyone involved. We were lucky enough to live a short walk away from BC Children’s and had a very strong family support network available at home. We could not wish for a better team of professionals taking care of our newborn boy’s heart. Huge Thank YOU!

Survey Respondent, 2018-19 Home Centre Survey, Vancouver BC

SURGERY AT THE STOLLERY CHILDREN'S HOSPITAL

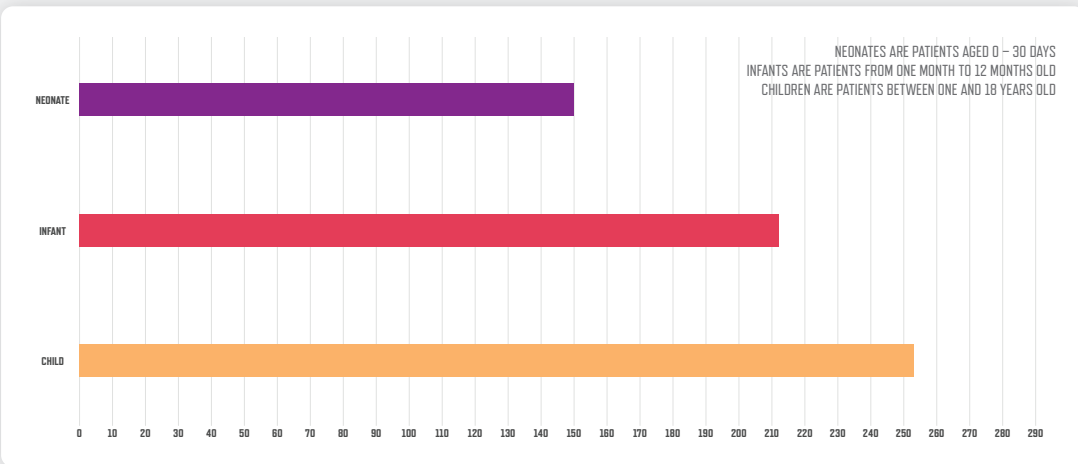
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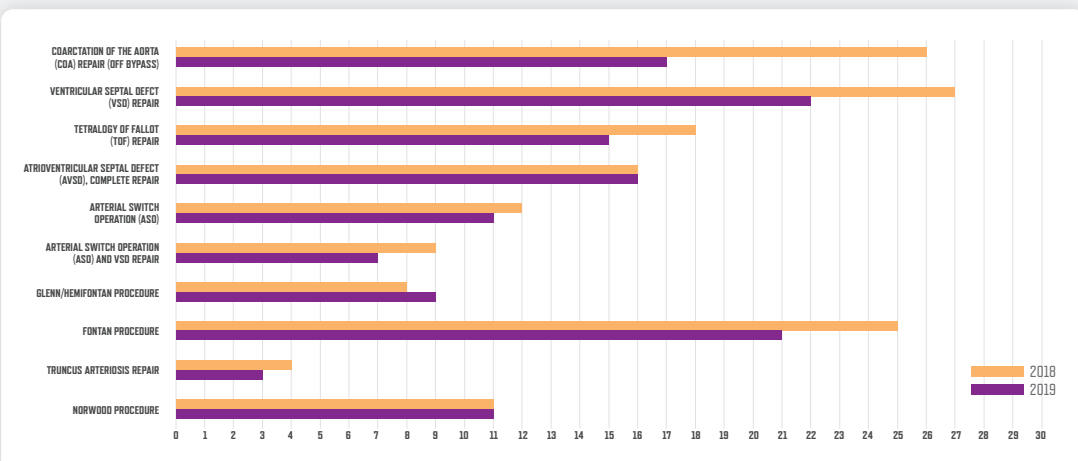
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SOURCE: STS CONGENITAL DATABASE



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Fontan Procedure	73	97.3	99.0	10.0	13.3
Truncus Arteriosis repair	13	84.6	91.0	23.0	29.7
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2018 SURVIVAL RATES BY STAT CATEGORY

Primary Procedure	Total Volume	Discharge Mortalities	Operative Mortality Rate (%)	STS Benchmark (%)
STAT 1	147	0	0.0	0.4
STAT 2	154	2	1.3	1.4
STAT 3	44	1	2.3	1.9
STAT 4	83	4	4.8	5.8
STAT 5	13	1	7.7	10.8

CONGENITAL HEART OPERATIONS ARE GROUPED BY THE COMPLEXITY OF THE PROCEDURE INTO WHAT ARE KNOWN AS STAT CATEGORIES. STAT CATEGORY 1 INCLUDES THE LEAST COMPLEX OPERATIONS, WHICH ARE ASSOCIATED WITH THE LOWEST RISK OF MORTALITY, AND STAT CATEGORY 5 INCLUDES THE MOST COMPLEX OPERATIONS, WHICH ARE ASSOCIATED WITH THE HIGHEST RISK OF MORTALITY. STAT MORTALITY CATEGORIES WERE DEVELOPED BY STS IN COLLABORATION WITH THE EUROPEAN ASSOCIATION FOR CARDIOTHORACIC SURGERY (EACTS).

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SOURCE: TABLE 1, THE SOCIETY OF THORACIC SURGEONS (STS) AUGUST 2019 DATA HARVEST REPORT FOR JANUARY 2015 TO DECEMBER 2018

“ Stollery Children’s Hospital was amazing in all kinds of ways - Good health care, excellent doctors & nurses & surgeons. We spent a lot of time in the Stollery from birth & on. We felt welcomed & involved in our daughters care. Nothing but amazing.

Survey Respondent, 2018-19 Home Centre Survey, Regina SK

“ The care at the Stollery was outstanding. I felt well informed that my child would be well taken care of, and that the best possible care was in place for us. Thank you to the staff, doctors, and nurses who helped the two of us get through the procedure and took care of us when we were worried, sad or scared. I am forever grateful.

Survey Respondent, 2018-19 Home Centre Survey, Calgary AB



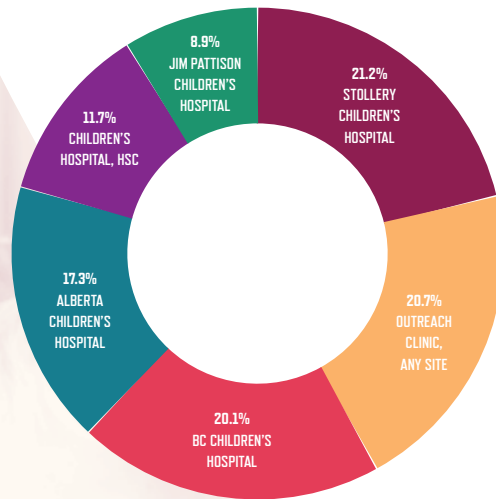
HOME CENTRE

Family Satisfaction

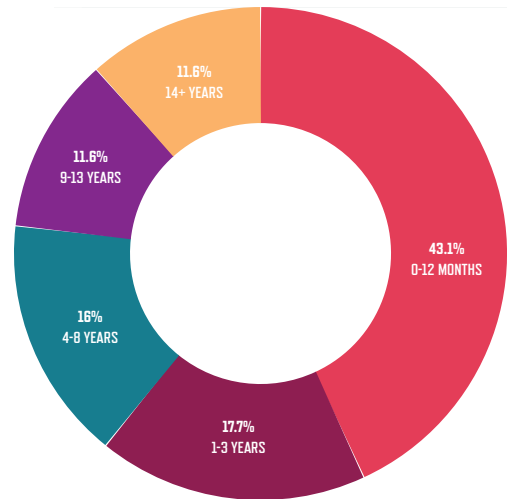
Home Centre Survey Results

In 2018-19, the WCCHN Nursing Coordinators Committee ran a fifth year of their Family Satisfaction Survey. This year's survey focused on delivering meaningful data back to "Home Centres" where patients are seen for their regular cardiac appointments. By capturing information about the patient and family perspective of receiving services at their home centre, the WCCHN hopes to learn more about whether or not patient and family needs and expectations are being met. This allows us to continue improving the quality of service delivery. Surveys were distributed quarterly to any family receiving a surgical procedure or cardiac catheterization in that survey year. 1117 surveys were distributed and 182 were returned (response rate 16.3%).

WHERE DO YOU TAKE YOUR CHILD FOR THEIR REGULAR CARDIAC APPOINTMENTS? (N=179)



YOUR CHILD'S AGE AT THE TIME OF THEIR CARDIAC PROCEDURE (N=181)



50%

HALF OF FAMILIES TRAVEL FROM A DIFFERENT CITY TO THEIR HOME CENTRE FOR THEIR REGULAR CARDIAC APPOINTMENTS

> 1HR

AVERAGE TRAVEL TIME TO HOME CENTRE

96.9%

OF FAMILIES WHO ARE SEEN IN AN OUTREACH CLINIC PREFER THIS OVER TRAVELLING TO THE NEAREST REFERRAL CENTRE



TRAVEL

Travelling for a Heart Procedure

- Half the survey respondents indicated their child had never received a heart procedure (surgery or cardiac catheterization) before
- Almost three quarters of families were aware that their child's case may have been reviewed by many specialists across western Canada at Surgical Case Conference. Knowing that their child's case had been discussed at surgical conference did not impact overall satisfaction scores ($p=0.0006$)
- 60% were required to travel to a different centre for their child's procedure
- Those who drove (vs air travel) were more likely to be satisfied overall ($p<.0001$)
- Average distance travelled to a procedure centre was 575.8 km
- Travelling less than 500 kms for a medical procedure was correlated with higher satisfaction scores ($p=0.0005$)

60%

WERE REQUIRED
TO TRAVEL TO A
DIFFERENT CENTRE

2/3

DROVE TO THE
PROCEDURE CENTRE

1/3

FLEW BY PLANE

16

AVERAGE TIME
AWAY IN DAYS

95%

FELT READY TO GO

Preparing to Go

- 95% felt well prepared by their home centre to go. Those who felt their child was prepared well for their age gave higher satisfaction ratings ($p<.0001$)
- 97.2% felt prepared for the routine pre-procedure tests like ECG or ECHO
- 96% felt their home centre helped them to have a good understanding of their heart condition before going. Those who understood their condition tended to give higher overall satisfaction ratings ($p<.0001$)
- 92.8% felt their home centre helped them to have a good understanding of the procedure before going
- 68% received a teaching session at their home centre before going. When receiving a teaching session, 98.3% agreed it was helpful and 93% said it helped them to prepare for the real experience. Those who found the teaching sessions helpful were more satisfied overall ($p<.0001$). Those who felt the teaching sessions prepared them for the real experience were more satisfied overall ($p=0.0279$)
- 96% knew who to contact if they had questions

“ We were very thankful about the cardiac care that my child received. When we went to BC Children's Hospital for her heart surgery everything, every detail has been taken care of. Our social worker, the nursing staff and cardiologist from our home centre and the cardiologist in BC were very accommodating and helpful. We had an awesome experience! Thank you!!!

~ Survey Respondent, 2018-19 Home Centre Survey



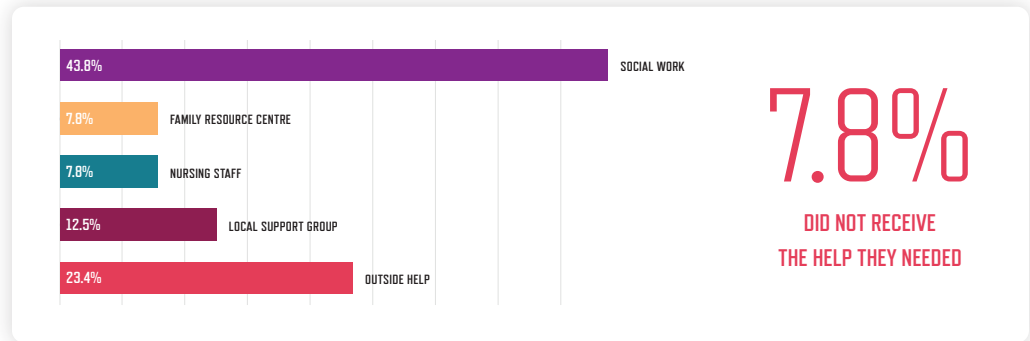
DIFFICULTIES

Difficulties Encountered

Financial Strain

1/3 of families experienced financial strain when travelling to another centre for their child's procedure. The experience of financial strain was likely to impact overall satisfaction scores (p=0.0154).

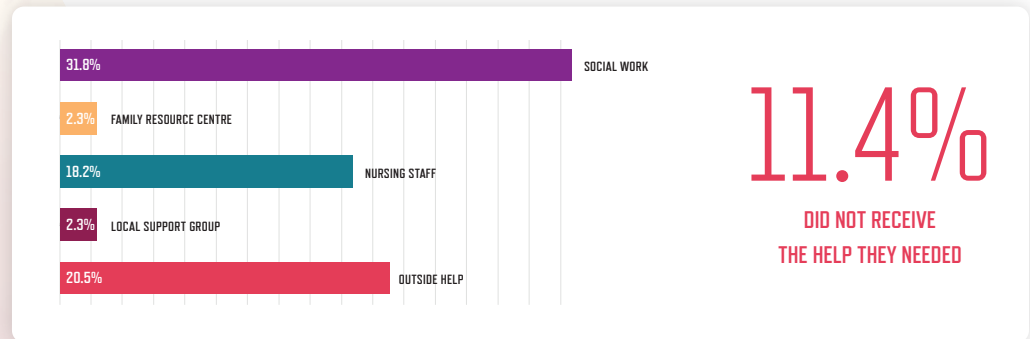
WHEN ADDRESSING FINANCIAL STRAIN, HELP WAS RECEIVED FROM:



Difficulty Making Travel Arrangements

One in four families experienced difficulty making travel arrangements. Difficulty making travel arrangements may impact overall satisfaction scores (p=0.0888).

WHEN ADDRESSING TRAVEL DIFFICULTIES, HELP WAS RECEIVED FROM:



97.2%

OF FAMILIES BELIEVE THEY ARE RECEIVING THE BEST MEDICAL CARE AVAILABLE FOR THEIR HEART CONDITION AT THEIR HOME CENTRE

92.2%

OF FAMILIES FEEL THEY PARTNER WITH THEIR MEDICAL TEAM IN THE PLANNING AND DECISION MAKING PROCESS FOR THEIR CHILD'S CARE

↑ 50%

OF FAMILIES ARE UNSURE OF WHETHER OR NOT THERE IS A FAMILY SUPPORT GROUP AVAILABLE TO THEM IN THE CITY OF THEIR HOME CENTRE

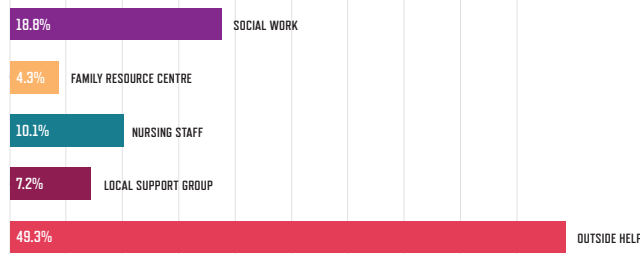


DIFFICULTIES

Difficulty Making Arrangements at Home

37.9% of families had trouble making arrangements at home when preparing to leave for the procedure centre. Although more than one third of families experienced difficulty making arrangements at home, the difficulty encountered did not impact overall satisfaction (p=0.9720).

WHEN ADDRESSING HOME ARRANGEMENTS, HELP WAS RECEIVED FROM:



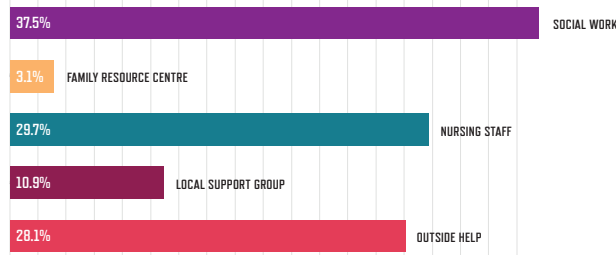
1 IN 10

DID NOT RECEIVE
THE HELP THEY NEEDED

Difficulty Accessing Emotional Support

35.2% of families had difficulty accessing the emotional support they felt they needed when travelling to another site for their heart procedure. Provision of emotional supports while preparing was correlated with a higher degree of overall satisfaction (p=0.0502).

WHEN SEEKING EMOTIONAL SUPPORT, HELP WAS RECEIVED FROM:



6.3%

DID NOT RECEIVE
THE HELP THEY NEEDED

92.8%

FELT THEIR HOME CENTRE
HELPED THEM TO HAVE A
GOOD UNDERSTANDING OF THE
PROCEDURE BEFORE GOING

575KM

AVERAGE DISTANCE TRAVELLED TO A
PROCEDURE CENTRE WAS 575.8 KM

96%

KNEW WHO TO CONTACT
IF THEY HAD QUESTIONS



RETURNING HOME

Returning Home

- When patients reported feeling prepared to return home, overall satisfaction scores were higher ($p=0.0397$)
- After returning home, 97% of patients were able to get the follow up appointments at their home centre on the timeframe recommended by the procedure centre
- 92% said the information they received from their home centre after the procedure was the same as what the procedure centre had told them. When families felt the information between the two centres was the same, they tended to report higher overall satisfaction ($p=0.0024$)
- One in ten families felt the communication between the two centres could have been better

97%

OF PATIENTS WERE ABLE TO GET THE FOLLOW UP APPOINTMENTS AT THEIR HOME CENTRE ON THE TIMEFRAME RECOMMENDED

92%

SAID THE INFORMATION RECEIVED FROM THEIR HOME CENTRE AFTER THE PROCEDURE MATCHED THE INFORMATION FROM THE PROCEDURE CENTRE

10%

ONE IN TEN FAMILIES FELT THE COMMUNICATION BETWEEN THE TWO CENTRES COULD HAVE BEEN BETTER

“ The care we have received in our home centre and surgical centre have been outstanding. The staff are thorough, informative, accommodating and compassionate. We feel fortunate to have received such world class care for our daughter so close to home.

Survey Respondent, 2018-19 Home Centre Survey

“ The Drs and nurses were professional, compassionate and empathetic. They thoroughly explained everything to me in fine detail. I never felt confused, or lost in anything.

Survey Respondent, 2018-19 Home Centre Survey

“ [Our surgical centre] was amazing. The nurses were well trained and cared for our child. The surgeon was friendly, knowledgeable and did a great job in the surgery. We felt comfortable and trusted the surgical team. When arriving at [our home centre], our cardiologist provided the care our child needed. She answered our questions and followed up on care. She was cautious with diagnosing and followed through on findings. We are so lucky to be at both centres.

Survey Respondent, 2018-19 Home Centre Survey



SATISFACTION

Factors most likely to influence overall satisfaction:

TRAVEL TIME

DISTANCE TRAVELLED

MODE OF TRANSPORTATION

PROVISION OF FAMILY CENTRED CARE

AWARENESS OF LOCAL SUPPORT GROUPS

PREPARATION BEFORE GOING

UNDERSTANDING OF DIAGNOSIS

RECEIVING TEACHING SESSIONS THAT WERE HELPFUL IN PREPARING THEM FOR THE EXPERIENCE

FINANCIAL STRAIN

ACCESS TO EMOTIONAL SUPPORTS WHILE PREPARING

DISCHARGE PREPARATION BEFORE RETURNING

CONSISTENT INFORMATION BETWEEN SITES

UNIVARIATE DESCRIPTIVE ANALYSIS PROVIDED BY DR. G. HANSEN, ROYAL UNIVERSITY HOSPITAL, SASKATOON, SASKATCHEWAN
 BIVARIATE STRATIFIED ANALYSIS USING CHI-SQUARE PROVIDED BY AHS DATA INTEGRATION, MEASUREMENT & REPORTING (DATA & ANALYTICS), EDMONTON, ALBERTA

“ Overall very pleased! We feel very fortunate to live where we do and have the care that we have.

Survey Respondent, 2018-19 Home Centre Survey

“ We have always had amazing care @ both our centres. We always know what's ahead.

Survey Respondent, 2018-19 Home Centre Survey



Our History

GROWING IMPACT

OUR HISTORY

1992

PEDIATRIC CARDIAC SERVICES OPERATE INDEPENDENTLY AND IN ISOLATION

4 SURGICAL PROGRAMS ACROSS THE WESTERN PROVINCES

WESTERN CANADIAN PROVINCES RECOGNIZE A NEED TO ENGAGE INTERPROVINCIAL COLLABORATION WHERE SURGICAL VOLUMES ARE LOW AND THE POPULATION IS WIDELY DISPERSED

1994

PUBLIC EVENTS REGARDING SURGICAL MORTALITY IN WESTERN CANADA LEAD TO A PEDIATRIC CARDIAC INQUEST AND THE EVENTUAL CLOSURE OF SMALLER SURGICAL PROGRAMS

A RECOMMENDATION IS PUT FORTH FOR REGIONALIZATION OF PEDIATRIC CARDIAC SURGICAL CARE, DRIVING VOLUMES TO THE LARGER CENTRES IN THE WESTERN PROVINCES

1997

WESTERN DEPUTY MINISTERS OF HEALTH PROPOSE THE CONCEPT OF THE WCCHN

PEDIATRIC CARDIAC SERVICES COMMITTEE DEVELOPS A REGIONAL APPROACH TO THE DELIVERY OF SERVICE AND RECOMMENDS THE ESTABLISHMENT OF THE WESTERN CANADIAN CHILDREN'S HEART NETWORK

2000

FINAL REPORT OF THE IMPLEMENTATION COMMITTEE IS ISSUED

AFFILIATION OF THE FIVE PEDIATRIC CARDIAC CENTRES IS FORMALIZED

CORE FUNCTIONS ARE IDENTIFIED

20 STRATEGY RECOMMENDATIONS EMERGE

2001

KPMG CONSULTANTS ISSUES WCCHN IMPLEMENTATION FRAMEWORK

A COMMON DATABASE IS DISCUSSED

WCCHN TERMS OF REFERENCE ARE DEVELOPED

2003

THE WCCHN OFFICE IS ESTABLISHED WITHIN CAPITAL HEALTH (NOW ALBERTA HEALTH SERVICES)

FIRST COORDINATOR IS HIRED

2004

GOVERNANCE COMMITTEES BEGIN MEETING ON A REGULAR BASIS

WCCHN DATABASE PROJECT IS INITIATED

OFFICE TEAM GROWS WITH ADDITION OF ADMINISTRATIVE SUPPORT AND A TEMPORARY DATA QUALITY ANALYST TO TRAIN CODING SPECIALISTS ACROSS ALL SITES

2006

WCCHN DATABASE IS IMPLEMENTED AND GOES LIVE IN EACH OF THE FIVE CENTRES

PERMANENT DATABASE MANAGER IS RECRUITED AND HIRED

INFORMATION MANAGEMENT AGREEMENT IS FULLY EXECUTED

2011

OFFICE TEAM EXPANDS WITH ADDITION OF IT SYSTEMS ANALYST

CARDIOACCESS GOES LIVE

SURGICAL DATA IS SUBMITTED TO THE SOCIETY OF THORACIC SURGEONS AND REGULAR BENCHMARKING BEINGS

2014

CARDIOACCESS IS UPGRADED TO CENTRIPETUS

CORE DATABASE TRANSITIONS FROM HONOS DIAGNOSIS/PROCEDURE CODING TO IPCCC CODING NOMENCLATURE

2018

FIRST SITE GOES LIVE WITH ACC IMPACT REGISTRY

(2019) CLINICAL OPERATIONS COMMITTEE AND STEERING COMMITTEE ARE AMALGAMATED INTO A UNIFIED INTEGRATED ADVISORY BOARD

WCCHN Supports Knowledge Dissemination

Helping Siblings Cope

Parents know their children best. Brothers and sisters can be anxious, too. This brochure helps families balance the needs of siblings affected by Congenital Heart Disease in their family. Order your copies by contacting our office.

Fetal Cardiology Resource and Education

Developed and designed by the Stollery Children's Hospital with WCCHN member-site consultation, this handbook prepares families referred to Stollery for services following prenatal diagnosis of Congenital Heart Disease. WCCHN is happy to produce these handbooks for our Saskatoon and Winnipeg sites.

Pediatric Heart Transplant Management: Clinical Practice Guidelines

Used by more than 20 centres around the world including Germany, Boston, Stanford, and Toronto, WCCHN is pleased to sponsor print production of the collaboratively developed Pediatric Heart Transplant Guidelines.

Prepaid access to PedHeart Resource

The most comprehensive site of its kind, PedHeart Resource is devoted exclusively to congenital heart disease education. Including detailed defect and treatment descriptions, in depth tutorials, a searchable image library, and collections of patient handouts, our staff tell us this resource is useful for both patient consultation and continuing education. In the past two years, we have had 448 new accounts registered using the WCCHN corporate subscription, a value equivalent to > \$46k USD! Prepaid access to this resource is available to all cardiac staff at any WCCHN member site.

WCCHN's Nursing Coordinators Committee (NCC) Literature Review

Parental Experience of PTSD Following Pediatric Cardiac Surgery

Clinical Considerations and Implications for Cannabis use in the Pediatric Cardiac Population

Jordan's Principle Info Session for the WCCHN Integrated Advisory Board

Hosted by the First Nations and Inuit Health Branch (FNIHB), Indigenous Services Canada, this session addressed topics including equity of access, substantive equality, and provision of culturally appropriate services for ensuring that First Nations children have access to the services they need.

Financial Statements

STATEMENT OF OPERATIONS AS AT MARCH 31, 2020

GOVERNMENT FUNDING BY PROVINCE	2018/19	2019/20
British Columbia	229,125	233,707
Alberta	305,500	311,610
Saskatchewan	76,375	77,902
Manitoba	152,750	155,805
Total Revenue Received	763,750	779,024
Deficit/Surplus Carry Forward	128,725	155,915

STATEMENT OF RESULTS AS AT MARCH 31, 2020

EXPENDITURES	2018/19	2019/20
Operating Costs	15,130	20,802
Patient and Family Centred Care	3,332	2,469
Travel and Meetings	10,000	8,811
Data Platform	87,581	47,290
Contracted Services	212,723	188,690
Salary and Benefits	407,794	400,627
Integrated Advisory Board Series	n/a	45,326
Total Expenditure	736,560	714,015

Western Canadian Children's Heart Network

Alberta Children's Hospital
2888 Shaganappi Trail NW
Calgary, AB T3B 6A8

Phone: 403-955-7562

Fax: 403-668-2168

Email: WCCHN@ahs.ca

wcchn.ca

A partnership amongst:



BC Children's Hospital
4480 Oak Street
Vancouver, BC V6H 3V4



Stollery Children's Hospital
8440 112th Street NW
Edmonton, AB T6G 2B7

Alberta Children's Hospital



Alberta Children's Hospital
2888 Shaganappi Trail NW
Calgary, AB T3B 6A8



Jim Pattison Children's Hospital
103 Hospital Drive
Saskatoon, SK S7N 0W8



Children's Hospital, HSC
685 Williams Avenue
Winnipeg, MB R3E 0Z2