

Appendix A Vital Insights: A 10-Year Retrospective Review of the Women and Children's Health Research Institute

2014-2024



June 2024 (DRAFT)











Executive Summary

In this document, we provide a retrospective and comprehensive review of the Women and Children's Health Research Institute (WCHRI) over the last 10 years to supplement the Memorandum of Understanding Case for Collaboration, and provide context for our next renewal and goals for the next 10 years. We draw on a range of evaluative data to tell a story about WCHRI's qualitative and quantitative impact over the decade, and cover a number of key areas in describing WCHRI's advocacy and support for women and children's health research in Canada. These key areas are:

The Need

We briefly highlight the ways women and children continue to be vastly underrepresented in health research with significant detrimental consequences for their health and wellbeing. In doing so, we demonstrate the need for targeted research across perinatal health, children's health, and women's health as a matter of distributive justice.

The Women and Children's Health Research Institute (WCHRI)

We provide an overview of how WCHRI came to be, and the core work the institute engages in to stimulate and support high quality research in women and children's health. We detail the support offered to researchers through the platforms, funding, and capacity development opportunities. We also share information about WCHRI's involvement in the targeted recruitment of highly sought after scholars across Canada in the areas of acute care, chronic and developmental conditions, and preventative health and wellness, along with other strategic programs. Finally, we discuss the WCHRI research community, comprising over 400 members who conduct and translate high quality local and international research.

The Research

We highlight some of the research that was supported by WCHRI over the years. In child health and wellbeing, this includes research focused on early life and developmental trajectories, medical treatment and technologies, community research and precision health. In the area of women's health and wellbeing, we present research focused on pregnancy and maternal health, menopause and post-reproductive health, clinical research and unique gender-based projects. Through this presentation, we also highlight the academic members who make it all possible.

Reflections

Finally, we provide a reflection on the biggest contributions we feel WCHRI made over the last 10 years, creating a solid foundation for the next 10 years. Specifically, we focus on the impact of the trusting relationships built and nurtured between WCHRI, institutional partners, members, patients and community partners. In addition, we reflect on the development of reliable and adaptable infrastructure at WCHRI, creating a high level of dependability for partners and members while also being responsive to changing needs and trends over time.



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Introduction

As the title suggests, this document is a retrospective review of the Women and Children's Health Research Institute (WCHRI) over the last 10 years. It provides a detailed overview of the Institute's efforts in advocating for and supporting women and children's health research in Canada. We are grateful to have had the opportunity to reflect on our contributions over the years and take a moment to celebrate the dedicated staff and research community who make it all possible.

The document:

- **Provides an in-depth description of WCHRI:** Who we are as an institute, what we do on a day-to-day basis and who our members are.
- **Provides examples of the research areas supported:** The trajectory of research supported by WCHRI over the 10 years, demonstrating how the areas of research have changed over time in response to societal trends, the research environment, and partner priorities.
- **Reflects on the structural aspects of WCHRI that make all of it possible:** Trusting relationships and a dependable instructure.

We recognize this is a bit of a detailed document! Please engage with it as it makes sense for you. We have tried to present everything in a way that you can review it at a higher level or dive deeper into the content.

To supplement our learning and reflection, we included insights from our many evaluations over the years. We view evaluation as crucial to the continuous improvement of WCHRI and for capturing our impact, while committing to only collecting data that will be *used* to avoid burdening our research members and staff. The following evaluations informed the document:

- Grantee reporting
- Research platforms evaluation
- Member bibliometric analysis
- Strategic and operational programs reporting (quarterly)
- Staff impact evaluation



The Need for Research in Women and Children's Health

Women and children are vastly underrepresented in health research with significant detrimental consequences for their health and wellbeing. Health research has historically defaulted to adult males, which leads to a **lack of understanding of physiological and experiential differences** for women and children. Research specific to women and children across a wider spectrum of health conditions and experiences is a matter of **distributive justice** and essential to providing the highest quality, evidence-based healthcare.

Perinatal Health & Wellbeing

Developmental origins of health and disease (DOHaD) and the impacts of poor health events in both pregnancy and prenatal development is consistently shown to have potential **long-term effects** on women and children. Perinatal health, where women and children's health intersect, is therefore crucial at a societal level. Research plays a significant role in our understanding and facilitation of perinatal health, yet

Although perinatal mortality and morbidity rates have been declining in general, relative inequalities still exist within most countries and are not noticeably decreasing (van der Meer et al., 2022)

there is a lack of specific attention in this area. More research is needed to ensure **high-quality healthcare and supports** are made available to all women and their children, from preterm through birth and throughout a child's lifespan.

Children's Health & Wellbeing

Research involving children is a **moral duty** and is essential for providing **evidence-based care**. Despite this, children are **often not included** in research due a lack of funding sources, fewer

An estimated 50-80% of medications prescribed to children in Canada are given off-label (Gilpin et al., 2022) researchers working in this area, and the challenges associated with their involvement - such as difficulties recruiting and financial disincentives (Fernandez, 2008). As a result, many treatments have been developed either without sufficient evidence or

extrapolated from experience with male adults, with substantial adverse effects for children and adolescents (Field & Berman, 2004). More research is therefore needed

to ensure **high-quality health care** is made available to all children, from preterm through birth and throughout their lifespan.



Women's Health & Wellbeing

As with children, there is a scarcity of research relating to women's health. The limited data available has resulted in a drastic underestimation of the **prevalence** and **diagnosis** of health conditions for women (Ellingrud et al., 2024). This scarcity of data is reflective of a broader societal trend whereby **women's health research is undervalued** and there is a **lack of investment** in targeted health Since 2000, women in the United States have reported adverse events from approved medications 52% more frequently than men, and had serious or fatal events 36% more frequently (cited in Ellingrud et al., 2024)

technologies and treatments (Ellingrud et al., 2024). Many treatments have subsequently been adopted either without sufficient evidence or extrapolated from experience with men, with

A study in Denmark found that, across 21 years, women took two and a half more years than men to receive a cancer diagnosis and four more years for diabetes (University of Copenhagen, 2019) substantial adverse effects for women. In areas where health interventions have been developed for women, these technologies and treatments have focused predominantly on **mortality prevention and not disability**, with a 10-fold higher volume of new therapies in development for some of the most common women's cancers compared to more ubiquitous and debilitating gynecological conditions such as menopause,

premenstrual syndrome, endometriosis and polycystic ovary syndrome (Ellingrud et al., 2024). There is an urgent

need, not only for more research in the area of women's health, but for research that reflects the full breadth of health conditions and experiences women have throughout their lives.

The Women and Children's Health Research Institute

Who We Are

The Women and Children's Health Research Institute (WCHRI) was developed in 2006 to

Our staff has grown from 25 to 56 in the last 10 years!

respond to the lack of representation of women and children in health research, with the specific goal to encourage, stimulate, and

support research to address the distinct and unique health needs of women and children. WCHRI is housed at the University of Alberta in the Faculty of Medicine and Dentistry and





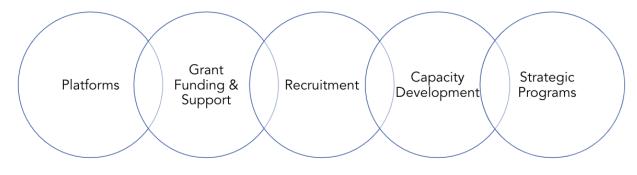
serves academics, trainees (undergraduate students, graduate students and postdoctoral fellows), service providers, patients, and communities. The institute operates on a membership structure through which support and resources are provided to members. Over the last 18 years, WCHRI developed into a leading institute at the U of A and continues to be Canada's only research institute dedicated to women's, children's and perinatal health. We have grown to have a staff of 56, reflecting the growth of the institute overall - in membership, partnerships, projects and requests for support.

What We Do

Research is at the forefront of human curiosity and progress. In this way, research plays a pivotal role in solving society's most complex problems. Our main goal at WCHRI is to stimulate and support high quality research that contributes to understanding and innovation in the field and practice of women and children's health. Through basic, applied, clinical and social research, knowledge advancement can:

- Address health disparities;
- Inform the development of new health technologies, therapies and interventions;
- Improve clinical policy and practice to better meet the needs of patients;
- Shape the implementation and improvement of community-based interventions.

Recognising the significant potential impacts of research for patients and communities, WCHRI supports knowledge generation and advancement in a number of ways. Our core areas of operation include:



Platforms¹

WCHRI's research platforms assist researchers by providing high-quality, affordable and comprehensive project consultation and implementation services throughout the entire research process. Platform staff members help researchers ensure their studies are properly

¹ An evaluation of the platforms was conducted in 2021. A full report of findings is available upon request.



designed, methodologically rigorous and meet ethical and regulatory requirements. They also help researchers gain a competitive edge in local, provincial and national grant competitions.

"The WCHRI platform staff are very knowledgeable and helpful. They are great collaborators and improve the quality and rigour of my team's research. It is comforting to know that we can access their support. The support is also vital to the research of the Ob/Gyn residents who have little in the way of methodological support. Without WCHRI methodologists to help them, many would struggle to design, carry out or complete their research projects." - WCHRI Member

Platform assistance is provided in the following areas: biostatistics, data coordination and

management (REDCap support), clinical trials support services, knowledge translation, qualitative research and evaluation, community and patient engagement, and clinical research support. Each of these areas is described briefly with a look to how the platform areas have changed over the last 10 years.

Biostatistics

Medical and health research studies often rely on biostatistics at various stages and many researchers require input from an expert statistician. The U of A **does not have enough statisticians to respond to this need**. To address the gap, WCHRI provides biostatistics support to its members. The WCHRI biostatistics team works with investigators to develop the concept of a study using the best methodology and statistical analysis plan to help them conduct **rigorous** research and to be as **competitive** as possible when applying for funding. The biostatistics platform has changed substantially over the years, moving from a focus on small local research projects, to developing expertise in clinical trials methodologies, allowing us to support and collaborate with a broader range of investigators within WCHRI and on a national level. Moving forward, we plan to continue this growth by

WCHRI research platform support to researchers doubled from 2015 to 2020

100% of researchers who accessed the platforms said they were satisfied with the support provided

74% of 2021 survey respondents said their project, with platform support, helped advance knowledge in the field of children and women's health

supporting WCHRI members as they collaborate and lead research on national and international level, expanding our involvement in clinical trials, and strengthening our support of academic researchers.

Qualitative and Engaged Research

Where biostatistics are necessary to understand large-scale trends across and between populations, qualitative





research is needed to understand the deeper meaning, experiences and perspectives of people on a smaller scale. As such, qualitative research in a health context provides an understanding of **the 'how' and 'why' underlying health behaviours, lived experiences and healthcare needs**. However, many people have little to no training in qualitative research and need support from the conceptualization of their project through to analysis. WCHRI has provided this support to researchers from its inception, developing over time to respond to the changing trends of research. As such, this platform now also supports engaged research projects, through which community members, patients and service providers are involved as equal partners throughout the research to generate **action-oriented knowledge**.

Pediatric Clinical Trials and Clinical Research Coordination

Clinical trials and clinical research are vital for testing new medical treatments, tests, or vaccines to determine if they are safe and effective for patients. Clinical trials for children are particularly crucial since most medications and treatments have historically been **extrapolated**

The pediatric clinical research coordination team currently supports over 200 clinical trials / studies annually. from research with male adults and/or are prescribed without sufficient evidence. This has had harmful, and sometimes fatal, consequences for children. WCHRI has seen an ever-increasing desire among child health researchers to provide access to promising new therapies, including through complex phase I trials (i.e. first in



human) in pediatric populations. To address the demand for assistance in this area, WCHRI developed state-of-the-art infrastructure and support services to expand and improve clinical research in children's health. Clinical trials, in particular, require specialized skills in a highly regulated environment and many investigators would not have the means to conduct clinical research without this help. Reflecting

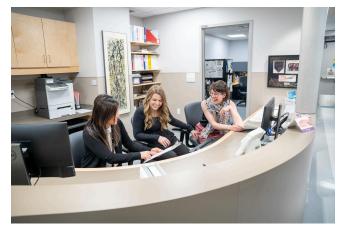
the need for support, and as **one of the only centres in Canada offering these services**, WCHRI's efforts in this area have grown exponentially over the years with no signs of slowing down. The WCHRI pediatric clinical trials and research coordination team currently has 12 full-time employees who work in close partnership with investigators, hospital staff, ethics boards, and industry to offer children and families the opportunity to participate safely in clinical trials and



research. Moving forward, the platform will continue to grow, providing mentorship and working collaboratively with investigators to fill gaps in care to improve health outcomes for children and their families.

Clinical Research Support in Women's Health

Women face unique health challenges related to their biology, hormones and gender roles that require targeted research. Conditions like breast cancer, cervical cancer, endometriosis and pregnancy-related complications predominantly or solely affect women. Translational research that **bridges the gap between research and clinical practice** is crucial for advancing women's health and



furthering the development of interventions and treatments that are tailored to their specific needs. WCHRI developed a platform to support this translational research at the Lois Hole Hospital for Women (LHHW) by *facilitating multidisciplinary collaboration* between academics, trainees and healthcare providers. Working out of the *Dale Sheard Centre for Solutions in Women's Health*, the platform supports the entire research process, with the goal of ensuring rigour and adherence to regulatory standards. The platform includes a team of research associates and coordinators from WCHRI and Alberta Health Services (AHS), with additional support provided by other WCHRI research platforms (e.g. qualitative research, knowledge translation and data coordination). Since 2018, *over 650 women participated in research and/or were recruited as research participants* through the centre. Moving forward, the platform would like to foster more authentic engagement with patient partners to improve the relevance, quality, and impact of research outcomes, ultimately leading to better health outcomes and healthcare delivery.

Data Coordination Centre (DCC)

Data management in research projects is critical for generating *high-quality, reliable and statistically sound data*. It can also drastically reduce the time between data collection and data use. Recognizing the significance of effective data coordination, while also noticing research teams often struggled to resource and manage study databases, WCHRI established the Data Coordinating Centre (DCC). The DCC provides data management, statistical support and

There are currently more than 1,000 projects active in REDCap with more than 2,000 active users. research consultancy to WCHRI members and collaborators across Canada. In the early years, the DCC had a staff of four and supported a few dozen new studies per year. In 2009 WCHRI became the *first institution in Canada to adopt the REDCap system* with huge



efficiencies. We now have a team of six data specialists and two statisticians, supporting more than **350 new research projects each year**. Building on this success we remain focussed on the needs of local researchers, however small, while also expanding the **support services we offer to** *large multi-site clinical trials*, including CIHR-funded collaborating groups and networks. This has significant impacts both locally and across Canada.

Knowledge Translation

Research is obsolete if the resulting knowledge is not shared. Knowledge translation is therefore primarily focused on the sharing of knowledge to inform decision making, change policy and practice, increase awareness of a particular condition or intervention, or to further build the knowledge base in a particular area. To support researchers in this crucial stage of their research, WCHRI developed a platform to specifically focus on knowledge translation, whether this occurs throughout the project or at the end. The intent of this translation is to make the knowledge generated through research *as widely accessible as possible*. Over time, many researchers responded to this call to democratize their research and started to expand their dissemination beyond academic audiences to include *community members, patients, service providers and policy makers*, using a range of strategies to do so.

Sex and Gender Based Analysis (SGBA+) and Equity, Diversity and Inclusion (EDI)

Discussions about the need for SGBA+ and EDI principles in research have increased substantially over recent years. With the majority of research historically conducted on males, there has been a call for studies that involve females with attention to the *biological variation across sexes*. Included in this call is a recognition that gender (along with the intersection of other identities and experiences) must also be considered to develop a more comprehensive understanding of the ways *biology and social/cultural factors are mutually influential*. In addition to SGBA+, researchers are also being asked to consider how EDI principles can be integrated into their projects, within their *team environments and in the research design*. As a new area, many researchers are unsure how to do this. As such, WCHRI developed a platform to support researchers in these areas, particularly in the conceptualization phase of their projects and increasing their ability to apply for and secure funding.

Grant Funding and Support

One of the essential ways we help our members advance their research is by offering

Through our operating grant reports we found that over 1500 publications were reported for WCHRI funded projects, with an average of 6 publications per researcher (per project) (accurate as of 2021) opportunities to apply for grants through the institute. These programs facilitate the

use of our resources in a way that maximizes impact and leverages funds from other partners and agencies. Our grants administration team processes and monitors over 300 grant awards annually (across all program types – operating and studentships) with annual grant funding commitments in excess of \$2m. Awards available to academic members include:



- Our Innovation Grant is a highly-competitive, highly sought after funding opportunity that provides up to \$60,000 in operating funds over two years. As WCHRI's premier grant program, the Innovation award provides members with important funding that assists researchers in gaining preliminary data, and supports staff salaries, in the hopes of leveraging this for additional research dollars. Since 2014 we have offered over \$10 million in Innovation awards and supported 203 projects.²
- Our Clinical/Community Research Integration Support Program (CRISP) was developed to bridge the gap between research and practice. Since its inception, the CRISP grant has supported the generation of action-oriented knowledge that can be integrated in community or clinical settings. The grant provides up to \$20,000 in operating funds to support collaborative clinical and/or community research that has the potential to directly improve health outcomes for women and/or children. Since 2016 we have offered over \$800,000 in CRISP awards and supported 47 projects.
- WCHRI offers a twelve-month Bridge Grant Program for CIHR applications that missed the funding cut-off. The Bridge Grant Program is intended to help sustain research momentum to support WCHRI members' successful reapplication to the following CIHR competition. Since 2014 we have offered over \$1.1 million in bridge funding and supported 40 projects.
- In 2021, WCHRI developed its new Grant Support Review Program to work directly with members and scientific experts from across Canada to ensure that submissions made to the <u>CIHR project grant program</u> (and potentially other national/international grant programs in the future) receive robust scientific review, feedback and support prior to CIHR submission. This program is an important evolution in our thinking about our internal funding, how to support research project development, bring together platforms and funding towards a common objective. Since 2021 we have supported 24 applications to CIHR through the Grant Support Review Program.

Recruitment

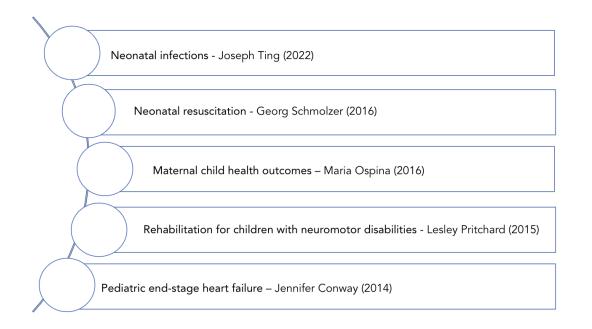
To advance research further, WCHRI supported a number of strategic recruitment opportunities at the U of A in partnership with faculties, departments and institutes. We welcomed 15 new researchers over the last 10 years as a result of this program. We have organized these recruits into three categories to show the breadth of research.

² Results only include funds actually provided to the award recipient as of April 30, 2024.



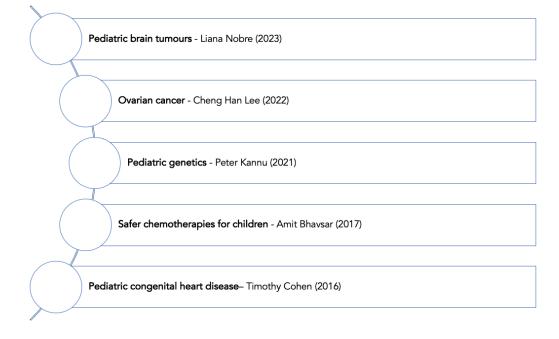
Acute Care

Promotive, preventive, curative, rehabilitative or palliative care



Chronic and Developmental Conditions

The care and management of long-term illnesses and conditions





Preventative/Wellness

Proactive care and supports to maintain health and prevent disease



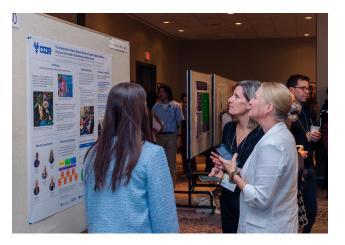
Capacity Development

WCHRI provides a range of capacity development opportunities to advance women and children's health research and support the next generation of researchers by providing funding, mentorship and learning opportunities. Some examples are listed below: WCHRI supported over 1,000 research trainees (accurate as of 2023)

Research Day

WCHRI Research Day brings our members and partners together to share common interests and research outputs on women's and children's health. It is an excellent venue for our trainees to communicate their recent work, discuss their research and network.

In 2023, Research Day had 450 attendees, 119 member volunteers (as judges, session chairs, etc.), and 26.7K impressions on social media.





"Seeing the work that has been done by students was inspiring. I hope stakeholders were able to get a sense of the broad range of excellent work that they have supported." ³ - Research Day Attendee

Trainee Awards

Undergraduate Students

• The Summer Studentship Award supports a new generation of talented, engaged young researchers to pursue careers in women's and/or children's health. Students receive direct experience working on specific research projects under the guidance of WCHRI academic members for three or four months between May and August. Funding of up to \$1,300 per month is offered. Since 2014, we have offered over \$1.1 million in Summer Studentship Awards and supported 242 student projects.

Graduate Students

- Our Graduate Studentship Award is a foundational program at WCHRI that attracts the best talent and propels knowledge generation in important areas of children's and women's health. The program directly supports students engaged in a full-time, thesis-based graduate level program of study at the U of A. The award is valued at up to \$18,000 per year for up to two years and allows these students hands-on experience in a research program. Since 2014 we have offered over \$5.75 million in Graduate Student awards and supported 166 trainees.
- WCHRI's Patient and Community Engagement Training Program (PaCET) aims to support and build the capacity of trainees who are conducting engaged research because we recognize the challenges of using an engaged research approach that involves community members or patients as equal partners. In addition to \$8,000 funding, WCHRI PaCET participants, along with a WCHRI facilitator, form



³ WCHRI Research Day evaluation



a "community of practice" over 8 months to learn from one another as engaged researchers. Since 2015 we have offered over \$250,000 in PaCET awards and supported 36 trainees.

"I think of the Patient and Community Engaged Research Training (PaCET) as a milestone in my career. Not only did I learn a lot about doing research with communities but also about personally coping with research that can be difficult and trigger all sorts of emotions for the researcher." - PaCET Awardee

Postdoctoral Fellows

 WCHRI's Postdoctoral Fellowship (PDF) Program was created in September 2018 to support outstanding postdoctoral candidates who are training under the supervision of WCHRI academic members. This program provides \$40,000 / year for two years to help support those keen to continue a research path focused on advancing women and/or children's health. Since 2018 we have offered over \$2 million in PDF awards and supported 28 trainees.

Strategic Programs

WCHRI developed several strategic programs over the last 10 years. These *research catalyst programs* were aimed at building capacity. Some of these are described here:

Stollery Science Lab Distinguished Researchers: Established Investigators

 The <u>Stollery Science Lab Distinguished Researchers program</u> was created to support established researchers to take their research programs to the next level, for example by training learners, securing additional competitive peer-reviewed funding, producing high-impact publications, or engaging stakeholders through innovative and integrated knowledge translation. Awardees actively engaged with partners from the Stollery Children's Hospital (STO) and Stollery Children's Hospital Foundation (SCHF) as research ambassadors; promoted child health research; and received the named title, "Distinguished Researchers, Stollery Science Lab". This program supported 7 distinguished researchers from across Pediatrics, Nursing and Public Health.

Emerging Team Grants: Interdisciplinary Teams

• The Emerging Team Grant program was designed to support the development of new competitive research teams that could, over time, demonstrate a potential to leverage additional multidisciplinary funding and tackle complex health challenges. The program



provided a 3-year award to five teams focused on different research challenges including youth mental health, effects of diet on pregnancy and infant outcomes, pediatric weight management, improving diagnosis and management of pediatric respiratory diseases, and optimizing hospital and community based maternity care for immigrant and minority women in Alberta. This program supported 5 teams by cultivating leadership, increasing participants' ability to secure future grants, and significantly contributed to the training of the next generation of research personnel.

Research Capacity Building Program: Hospital/Clinic Programs

The Research Capacity Building Program was aimed at supporting the development of multidisciplinary child health research teams integrated in clinical care. The program was implemented as a 5-year award and provided teams with salary support for dedicated research coordination. Teams conducted multiple local studies and were able to participate in national/international initiatives as a result, leading to increased research team growth and sustainability. Teams explored topics such as noise levels in PICU, impact of physical activity on children with single ventricles, off-label medication use in children with inflammatory bowel disease, and the most reliable way to measure fever in babies, just to name a few. This program supported 4 teams across several pediatric units and specialities - emergency department, critical care unit, gastroenterology and cardiology.





The WCHRI Community

WCHRI supports an impressive community of academics, trainees, clinical service providers and community members who conduct research in the areas of women and children's health. Although not all are academic members, these individuals can access a range of resources through WCHRI to support their research.

WCHRI Members

WCHRI attracts new members every month to consistently maintain a membership of approximately 400 academics and clinical researchers⁴. A breakdown of members and their research areas are provided below to show the breadth of interdisciplinary knowledge being generated in women and children's health.



⁴ Doesn't include trainees and patients/community members who are numerous and also part of the research community. In addition, many of these researchers do research across disciplines, reflected in the "Areas of Research" diagram.



Advancing Knowledge

One of the ways we are able to understand how knowledge is being advanced in women and children's health research is through publication data—assessing publication outputs, citation analyses and co-authorship. While these data have their limitations and do not represent the full scope of knowledge generated or shared, they are often reasonable indicators of research impact and can help us understand the reach of research conducted by WCHRI members.

Outputs

As seen in the chart below, WCHRI members have high annual publication output, averaging over 1300 publications annually.

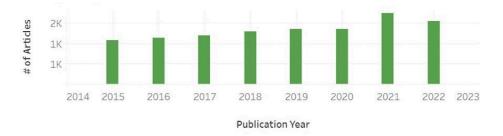
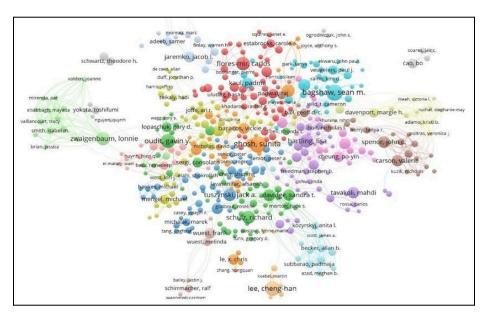


Figure 1: WCHRI members' annual publications (Courtesy of U of A, College of Health Sciences)

Local and International Collaboration

We have also learned over the years that WCHRI members are extremely collaborative. Over 60% of publications were those in which WCHRI members had collaborated with other WCHRI



members. Figure 2 provides a visual representation of this internal collaboration, with each "bubble" representing an author, the lines representing co-authorship, and colours indicating clusters of researchers who work closely together. Overall this map illustrates a high degree of collaboration within WCHRI.

Figure 2: WCHRI members' co-authorship map 2021 (courtesy of University of Alberta Library)



In addition to this internal collaboration, nearly 40% of all WCHRI research publications indicated that WCHRI members had engaged in collaboration with scholars around the world⁵. Figure 3

provides a visual representation of these collaborations, with the colour of each "bubble" representing the magnitude of international collaborations (darker colours indicate more collaborations).

Data shows that WCHRI members also advanced knowledge through the acquisition of external research revenue. Through the



Figure 3: WCHRI members' international collaborations 2023 (courtesy of University of Calgary, One Child Every Child Program)

chart below, we can see the diversity of funding sources being accessed by WCHRI members in order to conduct women and children's health research.

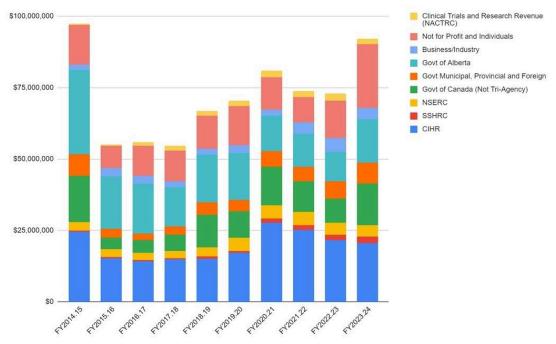


Figure 4: WCHRI members external research revenue (courtesy of University of Alberta, College of Health Sciences)

⁵ Data obtained from WCHRI's <u>Bibliometric Report, 2021</u>

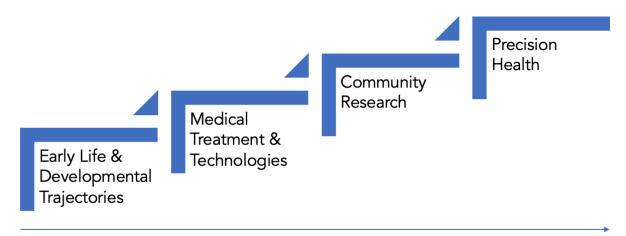


Research Supported Over the Previous 10 Years

WCHRI has supported a vast number of research projects over the past decade. We have attempted to organize these projects into core themes to provide examples of the research conducted in children and women's health, while recognizing that these categorizations will never be exhaustive or representative of the full breadth of research WCHRI supported since 2014. We included perinatal and pregnancy health research within the broader categories to showcase how this research integrates with and across women and children's health. The following sections of this report will attempt to illustrate some of this research and its importance, along with the tangible support provided by WCHRI to enhance or enable this research.

Child Health and Wellbeing

Health in the earliest years — which starts before a woman becomes pregnant — strengthens developing biological systems that enable children to thrive and grow up to be healthy adults. Positive early experiences provide children with a foundation for building sturdy brain architecture, which supports a broad range of skills and learning capacities throughout the lifespan. WCHRI assisted a large number of research projects in the area of child health and wellbeing through our funding programs and platform support. We selected four areas of research that we felt best reflect the trajectory of WCHRI supported research over the last 10 years, and chose to present several projects within each area. These areas and projects are not fully representative of all the research happening in the WCHRI research community, but rather provide some examples to highlight the interdisciplinary nature and impact of the work. In addition, these areas are not 'complete' and are continuing areas of research.





2024



Early Life and Developmental Trajectories

The study of early life and developmental trajectories is essential to understand the life course of a child, from preconception into adulthood. This research enables researchers and clinicians to identify the role that development plays in the origin of particular conditions and behaviours, while also considering the complexity of numerous interactions between personal and environmental factors. For example, the family context and parenting have a major influence on preschoolers' emotional and behavioural functioning with long term consequences across the life course. The ultimate goal of this research is to inform the development and implementation of suitable interventions (e.g., programs, education, parent supports) to facilitate a full life. Examples projects within this topical area include:

- **Premature birth** remains the main cause of child-related mortality in the developed world. Infants who are born preterm will also experience a higher incidence of health problems in their lives, including obesity, diabetes, behavioural problems and cardiovascular and inflammatory diseases. There are currently limited means for predicting when preterm labour will occur, affecting early intervention and the development of new drugs to delay labour and prolong pregnancy. Through research, David Olson, professor of obstetrics and gynecology and an international team consisting of clinicians, scientists and biostatisticians, set out to develop a blood test to identify pregnant women at risk of delivering babies prematurely. They collected blood from pregnant women at 17 weeks and at 27 weeks to examine gene expression, profiling and bioinformatics. When coupled with a patient's clinical history, they discovered they could predict whether or not a woman would deliver prematurely. By identifying women who are at risk of premature birth early in their pregnancies, clinicians are more able to prevent preterm birth using tailored approaches. *WCHRI support:* Innovation Grant.
- Autism is a neurodevelopmental condition defined by differences in communication and social interaction style, as well as by intense interests, preference for routine and reactions to the sensory environment. Autism manifests across the lifespan and can present and evolve in diverse ways. Lonnie Zwaigenbaum, developmental pediatrician and the Stollery Children's Hospital Foundation Chair in Autism, is working on groundbreaking early





detection and intervention tools to improve outcomes for children with autism spectrum disorder. *WCHRI support:* Stollery Science Lab Distinguished Researcher Award.

Indigenous healthy life trajectories is an approach to research that takes into consideration the Developmental Origins of Health and Disease (DOHaD) by exploring the ways environmental factors— e.g., poverty, racism, intergenerational trauma, housing, geography, etc.—interact with an Indigenous child's genes during conception, fetal life and infancy/early childhood, and the effects on health later in life. Rhonda Bell, a professor in nutrition alongside Richard Oster, Scientific Director of the Indigenous Wellness Core of AHS, are working with community members in Maskwacîs to support maternal and infant nutrition and health and improve outcomes for Indigenous families .
WCHRI support: WCHRI leveraged partnership award, Qualitative Platform support.

Medical Treatment & Technologies

A large number of children are born every year in Canada with medical conditions that can negatively affect the longevity and quality of their lives.

Advancements in medication and technologies are needed to address both the underlying causes, symptoms, and treatment of these conditions and research is fundamental to this process. Example projects within this topical area include:

Over 150 children gained access to novel drug therapies and over 1400 children had the opportunity to participate in other types of interventional and observational research as a result of WCHRI-supported site-based studies (accurate as of 2021)

• **Cystic fibrosis:** It is estimated that one in every 3,600 children born in Canada have cystic

fibrosis, a genetic disorder that affects the lungs, pancreas, and other organs. In the lungs, the mucus clogs the airways and traps germs, like bacteria, leading to infections, inflammation, respiratory failure, and other complications. Before new medications can be made fully available to all patients, they need to be tested across the various disease mutations. Research is therefore needed to approve these medications for broader use. WCHRI members, Tamizan Kherani and Winnie Leung, are currently doing just that by

"If you ask me again in 20 years, we will see patients living with less cystic fibrosis complications, fewer lung transplants, with longer lifespans. These drugs are drastically changing care for patients with cystic fibrosis." - WCHRI Staff Member testing medications that target the cause of cystic fibrosis rather than the symptoms. As a result of clinical research such as this, along with collective advocacy efforts, provincial funding was granted for the medications so that patients with cystic fibrosis in Alberta who meet the criteria for the mutations have access to this life-changing drug. **WCHRI support:** Clinical Research Coordination.



- Migraines: Migraines are a neurological disorder of sensory processing involving nerves and vessels of the head. Throbbing headaches, often accompanied by nausea, vomiting and sensitivity to light, can occur upwards of 15 days per month for those who experience chronic migraines. The condition affects close to seven per cent of children that translates to about two or three kids in every child's classroom and is considered one of the world's most disabling maladies. For a long time, treatment was haphazard, with doctors prescribing everything from anti-seizure meds to antidepressants in an attempt to try and treat them. Thilinie Rajapakse is a migraine specialist testing two ground-breaking new migraine drugs with children and between the ages of six and 17. The medications Eptinezumab and Atogepant are what she calls a "revolution" in migraine treatment because they are designed specifically to prevent migraines by inhibiting the actions of a specific molecule. Through her clinical trial research she hopes to significantly improve quality of life for children and youth. WCHRI support: Clinical Research Coordination, Qualitative Platform Support.
- Non-invasive ventilation: Children with complex respiratory illnesses and their families often experience various stressors while children undergo non-invasive ventilation (NIV) therapy. As a technology used to treat breathing difficulties and potentially prolong life, the use of NIV has increased exponentially for children with life-limiting conditions. While previous quantitative data is important in understanding some of the challenges, there

"The hope is for parents to be part of discussions and decisions with clinicians regarding NIV; to see themselves in the research and to honour their child's life." - Dr. Maria Castro Codesal, Pediatric Respirologist and WCHRI member

remains a limited understanding of how NIV technology influences the life and death experiences of children with life-limiting, complex respiratory illnesses and their families. In particular, there has been a lack of attention paid to the experiences of NIV for children and their caregivers. A clinical team including <u>Maria Castro Codesal</u> (Pediatric Respirologist), Deb Olmstead (Pediatric Nurse Practitioner) and Hayley Turnball (Physician with ASSIST) is conducting research to explore caregivers' experiences of non-invasive ventilation through the progression of their child's illness towards and during end of life. The immediate impact of the project has been an increased awareness among clinician-researchers to inform clinical practice and policy to better meet the needs of families. *WCHRI support:* CRISP Grant, Qualitative Platform Support.

Community Research

To support the health of children and youth, there is a need for research that is situated in the community. Such research seeks to generate knowledge that is meaningful, practically relevant and immediately actionable by involving those affected by the issue as partners throughout the research process. In doing so, children, youth, families and/or service providers are involved in the research from the development of a research question through to knowledge mobilization.



Such research is intended to facilitate positive social change by reducing structural barriers and/or strengthening community services or programs for particular populations. WCHRI assisted various community research projects over the years via funding and platform support. Example projects within include:

- Fetal Alcohol Spectrum Disorders (FASDs) are a group of conditions that can occur in a person who was exposed to alcohol before birth. Alcohol can interfere with the growth and development of all fetal body systems but especially the developing central nervous system. The effects can include physical, mental, behavioural, and/or learning disabilities with lifelong implications. Early and appropriate support can have a positive impact and improve outcomes for individuals with FASD. Neuro-psychologist Jacqueline Pei's mission is to identify barriers that prevent kids with FASD from accessing mental health services. Pei and her counterpart Carly McMorris, at Calgary's Alberta Children's Hospital Research Institute, are working with front-line health professionals from all over Alberta to brainstorm strategies to mitigate these barriers. WCHRI support: Innovation Grant.
- Sexual and reproductive health: Young people between the ages of 10 and 19 years experience many biological changes, have an increased sense of maturity, and become curious about human relationships. Importantly, this developmental phase, marked by physiological and emotional change, is a critical time to establish and adopt lifelong healthy behaviours. However, immigrant youth tend to receive limited sexual and reproductive health education and rarely access services in Canada. Specific supports are needed to achieve healthy behaviours that adequately navigate their cultural identities, migration contexts, family expectations, and emerging attitudes developed within the Canadian context. Salima Meherali's research program involves community-based participatory projects that actively engage immigrant youth to evaluate their mental health and sexual and reproductive health needs. Her aim is to inform the development and scaling of evidence-based interventions in community settings to improve the health of youth. *WCHRI support:* Innovation Grant and CRISP Grant.
- Supportive housing and mental health services: Teen parents face a range of structural challenges due to social and economic disparities that exist before they become pregnant. These often contribute to the struggles they face afterwards with obvious impacts on these parents and their children. Teen parents are also at high risk for postpartum, general clinical depression, and in some cases, post-traumatic stress disorder resulting from trauma and family violence. Responding to these issues, <u>Melissa</u> <u>Tremblay</u> has conducted a number of research and evaluation projects to improve services for teen families, including the use of photovoice and other methods to develop and improve a model of supportive housing. The program provides long-term, affordable,



independent housing for families in combination with flexible, individualized, and accessible support. A more recent project has sought to build on this community-based research by looking at how to improve mental health services for parents. **WCHRI** support: Innovation Grant, CRISP Grant, PaCET supervisor and awardee.

Precision Health

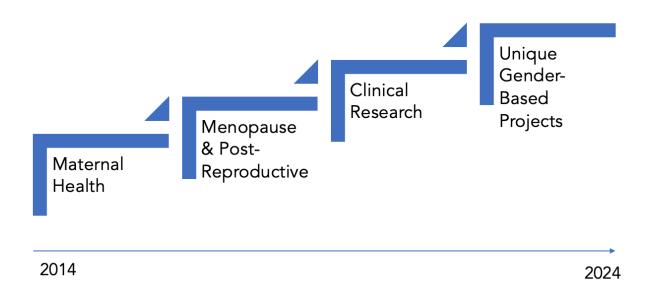
Over the years, our ability to prevent, diagnose and manage complex diseases was limited by the technologies available. This generally led to a "one size fits all" approach which doesn't always mean patients receive the best care. Precision health is an emerging approach to health and wellness that has the potential to reshape healthcare through advances in genomics, proteomics, microbiomics and metabolomics, biomedical engineering, and informatics. With an improved ability to generate and use data, *healthcare can be tailored* specifically to each individual patient.

WCHRI has been involved in a number of initiatives at the U of A to support precision health, including becoming host to the *Translational Genomics Hub (TGH)*, a research platform designed to help families affected by undiagnosed diseases with a rare genetic cause. TGH is designed to enable the application of cutting edge research approaches by removing barriers for clinical investigators by supporting ethics requirements, enrollment processes, sample collection, logistics and tracking, and by facilitating access to local scientists and funding. *WCHRI support:* Clinical Research Coordination, Strategic Partnership funding.



Women's Health and Wellbeing

Although women⁶ make up more than half the population in Canada, inequities in the healthcare process remain significant. Women's unique health needs therefore continue to be misdiagnosed, misrepresented and misunderstood. The efforts of women's health advocates who have exposed inequities in medical research have led to a broadened research agenda. We selected four areas of research that we felt best reflect the trajectory of WCHRI supported research over the last 10 years, and chose to present several projects within each area. These areas and projects are not fully representative of all the research happening in the WCHRI research community, but rather provide some examples to highlight the interdisciplinary nature and impact of the work. In addition, these areas are not 'complete' and are continuing areas of research.



Pregnancy and Maternal Health

Early life events, such as pregnancy complications, can increase health risks for both the mother and her child. Research is needed to understand how to minimize pregnancy complication rates, optimize infant outcomes, and develop early intervention and prevention strategies to improve the lives of women, children and their families. Example projects within this topical area include:

⁶ Although we use the terms "women" and "mother" throughout this document, we recognize that transgender men and non-binary people are affected by these same health issues and may not identify with either of these terms. We therefore use the terms "women" and "mother" to broadly include anyone experiencing pregnancy and/or maternal health needs.



- Houseless pregnant women: In recent years, the number of women without stable housing increased significantly. Houseless women often experience complex health issues that are exacerbated by a range of intersecting barriers that prevent access to adequate care, including the relationship with healthcare providers. A better understanding of the health care providers who provide care is therefore needed. Innovation and CRISP grant awardee <u>Vera Caine</u>, conducted a number of community-based research projects examining housing interventions and healthcare for pregnant or early parenting women who are precariously housed in Alberta. One such project examined the experiences and perceptions of health care providers in an acute care setting delivering care to pregnant women who are experiencing houselessness. Interviews with health care providers indicated that care practices are shaped by complex personal, interpersonal, and institutional factors. *WCHRI support:* Innovation Grant and CRISP Grant.
- Exercise during pregnancy. High-risk complications during pregnancy, such as gestational diabetes, high blood pressure or preeclampsia, affect about 20 percent of all pregnant women. This increases their risk of developing cardiovascular disease in just a few decades. Exercise has significant cardiovascular and metabolic benefits in non-pregnant populations. However, whether exercise during pregnancy can prevent or reduce maternal vascular dysfunction is unknown, although early evidence suggests that exercise programs initiated prior to conception or early in the first trimester may minimize potential adverse fetal outcomes. Margie Davenport, professor in Kinesiology, Sport and Recreation, developed a research program focused on understanding whether exercise can play a role in the prevention of risk transmission, and the effects of exercise on maternal-fetal health. Her aim through this research is to increase understanding around these mechanisms so that they may assist in the long-term prevention of chronic disease. *WCHRI support:* Innovation Grant.
- Malfunctioning placentas the failure of the placenta to form and function properly are linked to complications like preeclampsia and intrauterine growth restriction, threatening the health of mothers and their babies in the short and long term. By identifying the factors that cause abnormal development, doors could open for new diagnostic tools and medical interventions. <u>Meghan Riddell</u>, an assistant professor in the Departments of Obstetrics & Gynaecology and Physiology, is growing placentas in a dish to understand how the human placenta forms and functions. Ultimately, she hopes to develop a greater understanding of pregnancy complications to reduce the risk of lifelong health problems. *WCHRI support:* Innovation Grant and Recruitment Start-Up funding.



Menopause Transition and Post-Reproductive Health Concerns

When it exists at all, interest in women's health is largely focused on reproductive health while ignoring other significant life periods. Substantial gaps therefore remain in our understanding of the genetic, biological and environmental factors that influence women's health beyond reproductive age. This lack of research leads to late diagnoses and delayed treatment for conditions such as the menopause transition, which can last as long as 14 years. More research is essential to improve quality of life for all women and ensure they receive the care they deserve. WCHRI concertedly focuses on mature women's health to fill the research gaps in this area and provide women with the resources they need; with the appointment of two Cavarzan Chairs in Mature Women's Health Research since 2011 ensuring substantial progress. Example projects include:

- Menopause is a major transitional period for women, when they are often going through many other changes in their lives. In addition to physical problems such as night sweats, as many as one-half of menopausal women suffer from mood swings, irritability, anxiety, depression and an inability to concentrate. The first Cavarzan Chair in Mature Women's Health Research, <u>Sue Ross</u> conducted focus groups with menopausal patients and found that women who were able to get into a menopause clinic there is a 14-month waiting list at the LHHW reported clear improvement in their symptoms and quality of life. She also worked for five years in Maskwacis, collaborating with women and Elders to explore the experiences and needs of Indigenous menopausal women. After a series of discussions and community workshops, the group (Sohkitehew or Strong Heart) developed an informational pamphlet for women going through menopause and another for families on how they can help. *WCHRI support:* Cavarzan Chair in Mature Women's Health Research, PaCET Supervisor, Qualitative Platform Support.
- Connections between menopause and other health concerns: For too long, researchers and clinicians have ignored the connection between perimenopause, menopause and postmenopause with other health concerns. There is a need to examine the full life cycle of women to understand the multitude of factors that influence health. Colleen Norris, Cavarzan Chair in Mature Women's Health Research, registered nurse, and professor in the Faculty of Nursing, works closely with AHS, the Department of Obstetrics & Gynecology and the WCHRI team at the Dale Sheard Centre for Solutions in Women's Health to promote interdisciplinary and collaborative women's health research; provide mentorship that promotes the development of junior faculty in women's research; develops collaborations in mature women's health research locally, nationally and internationally; and acts as an ambassador and champion to actively link research with practice for the benefit of women and the communities in which they live. WCHRI support: Cavarzan Chair in Mature Women's Health Research, Clinical Research Support in Women's Health.



 Early surgical menopause: Although hormone therapy is one of the best options for managing menopause symptoms for those who undergo an induced menopause, only about a third of those patients take advantage of the treatment. There is similar reluctance among the larger group of women going through regular perimenopause or menopause, even if they are suffering from serious physical and mental health issues. In a WCHRI-supported project, <u>Nese Yuksel</u> – professor in the Faculty of Pharmacy & Pharmaceutical Sciences and team member at the LHHW menopause clinic – and her team conducted focus groups with women who had gone through early surgical menopause to discuss their physical and mental-health experiences. Out of those focus groups, they developed a patient decision aid called <u>SheEmpowers</u> to help women make informed decisions about hormone therapy. *WCHRI support:* PaCET Supervisor.

Clinical Research

As mentioned, women are significantly more likely than men to experience longer wait times for diagnosis and misdiagnosis, leading to delays in treatment. The goal of clinical research is to better prevent, diagnose and treat illness to improve the health and quality of life of patients. As such, this research tends to have a direct impact on healthcare policy and practice. Example research areas targeted by WCHRI members include:

- **Gynecologic cancers** are those that start in the female reproductive system. They include cervical, ovarian, uterine, vaginal, vulvar and fallopian tube cancers. Of all the gynecologic cancers, only cervical cancer has screening tests that can find this cancer early, when treatment can be most effective. Since there is no simple and reliable way to screen for any gynecologic cancers except cervical cancer, it is especially important to recognize warning signs, and learn if there are things you can do to reduce your risk. Sawin-Baldwin Chair in Ovarian Cancer and consultant pathologist, <u>Cheng-Han Lee</u>, conducts clinical research that has a diagnostic focus on gynecologic cancer, particularly ovarian cancer and cancers of the fallopian tube and uterus, which are among the most common cancers that affect women. By devoting his research to the study of these aggressive cancers, Lee has improved the lives of patients by changing the way these cancer types are diagnosed clinically. He also hopes to make further therapeutic advances to match the most effective treatment to patients with the most susceptible cancer. *WCHRI support*: Sawin-Baldwin Chair in Ovarian Cancer.
- **Pelvic floor disorders** are extremely common, affecting more than one-third of adult women of all ages. They occur when the muscles or connective tissues of the pelvic area weaken or are injured. These disorders can increase the risk of pelvic pain, sexual difficulties, pelvic organ prolapse, and urinary and fecal incontinence, substantially lowering quality of life while additionally carrying significant social stigmas. Despite their prevalence, seeking information about treatment can be a frustrating process, making



timely treatment far less likely. Alberta Women's Health Foundation Chair in Women's

Health Research and urogynecologist, Jane Schulz, has dedicated her career to innovations in clinical care and quality improvement. Her research has led to positive changes to clinical flow and care provision through direct



knowledge translation. *WCHRI support:* Innovation Grant, CRISP Grant, Clinical Research Support in Women's Health, Qualitative Platform Support, Alberta Women's Health Foundation Chair in Women's Health Research.

Unique Gender-Based Projects

- Family violence is a serious public health issue in Alberta, which consistently has the third-highest rate of domestic violence reported to police among Canadian provinces. Exposure to family violence in children can have social, behavioural, emotional and cognitive impacts over a lifetime. Primary Health Care is an important setting for the early detection and prevention of family violence and for facilitating access to specialist care and support. However, implementation of family violence responses in primary health care practices have been slow. Canada Research Chair and professor in the School of Public Health, <u>Stephanie Montesanti</u>, is engaging with communities, health service providers, decision-makers, and patients to inform the development of culturally-appropriate interventions and an integrated health system that can better address family violence, particularly for Indigenous families. *WCHRI support:* Innovation Grant, CRISP Grant, PaCET supervisor.
- Mental health access: Women are twice as likely as men to suffer from a mental health disorder. Pregnancy and new motherhood can prove to be especially stressful for many women. One U.K. study found that one in four women suffers from anxiety, depression or other mental-health challenges during pregnancy. For more than half of these women,



the problems continue beyond the one-year postpartum period, sometimes for life. Continued care for women is therefore essential across the life course. <u>Dawn Kingston</u>, Lois Hole Hospital for Women Cross-Provincial Chair in Women's Mental Health Research, aims to improve the perinatal mental health of women through research and education. Her team developed a digital tool to screen expectant mothers for mental illness when they visit their obstetrician or family physician. The <u>Hope Digital Platform</u>, initially funded through a WCHRI grant, also offers online therapies, referral options and access to a coach. It has been used by more than 4,000 women in more than 40 primary care clinics across Alberta. The tool will ultimately offer mental-health screening and support to women at all stages of life, with the hope that such strategies become embedded as part of all regular care for all women. **WCHRI support:** Innovation Grant, Lois Hole Hospital for Women Cross-Provincial Chair in Women's Mental Health Research.



Reflecting On the Last 10 Years

This final section provides an overview of the biggest contributions we feel we made over the last 10 years at WCHRI. These reflections were developed through conversations with WCHRI leadership, and provide a place from which to look forward to the next 10 years.

"The epitome of WCHRI is the people. The funding comes and allows us to do what we do, but in the end, our success comes from the dedicated staff and WCHRI members. Everybody believes in and has a passion for women and children's health."

- Sandra Davidge, WCHRI Executive Director

Trusting Relationships

One of the greatest impacts WCHRI has had over the last 10 years was in building trusting relationships to create a community of researchers dedicated to women and children's health. WCHRI has trusted relationships with our institutional partners (AHS and the U of A) and our funding partners (Stollery Children's Hospital Foundation and the Alberta Women's Health Research Foundation), with research viewed by all partners as essential to the improvement of health outcomes for women and children. WCHRI staff members have also developed strong relationships with academic and clinical members, patients and community members, to ensure the research is as rigorous and ethical as possible. We view these relationships as foundational to the work we are able to do at WCHRI, and will continue to nurture and grow these relationships over the coming years.

"...we sit with families for hours and get their life stories. Some of our families have a lot of layers of medical trauma from when their children were first diagnosed, misdiagnosed, or mistreated with the wrong medications or medications that didn't work for them. [With] a lot of families we see those layers of trauma that we have to work through and we do our best to do that. Because we have the time and the resources, we get to work with our partners in the healthcare system to help build a safer place for families to come."⁷

- Cheri Copithorne, WCHRI Pediatric Clinical Research Support

⁷ Quote taken from our 2022 WCHRI staff evaluation report



Reliable and Adaptable Infrastructure

Because of, and reinforcing, the trusting relationships built across the women and children's health research community, WCHRI has developed a research infrastructure that is both stable and dependable, while also being adaptable to changing needs over time. Built from the ground up, WCHRI's early years were characterized by a responsiveness to immediate needs in the areas of women and children's health. While maintaining this responsiveness, WCHRI now has a well-defined mandate and operating principles that guide decision making. As such, WCHRI has become a truly cohesive organization that staff members and researchers want to be connected to, enabling the institute's sustainability and continuous growth. Contributing to this sustainability and growth has been the WCHRI communications team, which has grown to include three full-time staff members and expanded their scope to include stewardship, events, and marketing, in addition to communications.

Reflecting this work, WCHRI has received **10 local and international awards for communications management, publications, web development, and notably, a "Best of the Best" global award** for the <u>2021-2022 Annual Report, Curious Minds</u>. Through these, and many other organizational efforts, WCHRI has developed a high level of accountability that reflects a commitment to our partners and members, and ultimately, to the cause of improving women and children's health.

"Stewardship has become a key component of our efforts, to provide our core partners/associated donors with the opportunity to see the impact of their philanthropy and show that the funds provided by our Foundations are invested with the highest standard of care."

- Breanne Sampson, WCHRI Communications

Summary

WCHRI has seen a lot of growth over the last 10 years in both the interest and commitment to women and children's health research, and WCHRI's support of this research. Foremost, we believe the creation of a research community, held together by authentic and mutually beneficial relationships, has been the biggest achievement since WCHRI's inception. As a result of these relationships, along with strong leadership throughout the organization, WCHRI has become a leading research institute at the U of A, the Stollery Children's Hospital, the Lois Hole Hospital for Women and, more broadly, across Canada. We will ensure this continues moving forward, and will push ourselves even further in our mission to foster the brightest minds to discover, innovate, and transform the health of children and women by supporting research excellence.



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