

A THOUSAND VOICES
FOR WOMEN'S HEALTH
A PIONEERING STUDY | PART 2

A thousand ways to advance the health of women

A PIONEERING STUDY | PART 2





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CHAPTER 1

BACKGROUND

Listening to the voices of women

In 2010, **Women's College Hospital** asked a **thousand women** from across Canada what they want and need from their hospitals and their healthcare providers. **They told us what works and what doesn't work** when it comes to hospitals, to care and to services. They shared their stories and experiences, their fears and challenges and their vision **for a hospital they can call their own.**

And then Women's College Hospital (WCH) designed and built a new state-of-the-art hospital incorporating the feedback and ideas of these women. As Canada's only academic, ambulatory hospital focused on the health of women, we are serving a unique mandate. Our commitment is to deeply understand, through research, what women and girls need to prevent and manage diseases and conditions so they can live healthy, independent lives. And by training the healthcare professionals of the future we ensure they understand the unique and complex challenges that women face in managing their health. Our chosen mission is to be a champion of equitable access with an unrelenting commitment to advocating for and advancing the health of women from diverse cultures and backgrounds. For every single woman who walks through our doors and the women we touch in the many communities we serve outside our walls, we will ensure their needs are reflected in the care they receive.

Now, more than five years after our original report, Women's College Hospital has conducted a followup study and set out to learn **what has changed and how women's needs are being met today.** **Once again we asked more than 1,000 women** about their experiences and what they want from hospitals, healthcare programs and the care they receive. Using various methodologies, including quantitative surveys, online forums and face-to-face discussion groups, we listened to women from diverse cultural and socio-economic backgrounds and various life circumstances speak about their current healthcare experiences, and invited them to share their thoughts on how the healthcare system can be improved and how women can be better served.

In our original study we learned that women want an approach to care that focuses on all aspects of their lives, that focuses on prevention and enables them to be the drivers of their own health, and that gives them the option of being treated at home rather than being in hospital. We learned that they desire a healthcare facility that inspires health, healing and community. Above all, we learned that women want to be treated with dignity and respect. This year's study shows how those themes continue to prevail, how opinions have evolved and where gaps still exist.



Continuing a legacy of groundbreaking advances in the health of women

Looking at the world through a different lens and applying innovative thinking is nothing new to Women's College Hospital.

Since it began in 1911, Women's College has been dedicated to a single mission: groundbreaking advances and advocacy in women's health.

Our track record is legendary. We collaborated on the development of a simplified Pap test. We opened the first Cancer Detection Clinic in Ontario to screen healthy women for early signs of cancer. We were the first hospital in Ontario to use mammography and the first in Canada to have a Perinatal Intensive Care Unit. We began Ontario's first regional Sexual Assault Centre and delivered the nation's first test-tube quintuplets. We launched Canada's first Multidisciplinary Osteoporosis Program and established the country's first Women's Cardiovascular Health Initiative. And the list goes on.

The fact is, no one understands women's health better than Women's College Hospital. We have developed cutting-edge programs that deal with today's most pressing health issues and their particular impact on women's lives. We have the only research institute in a Canadian hospital devoted to advancing health for women and the only academic learning centre for training the health professionals of the future to work in ambulatory (or outpatient) facilities where most of today's healthcare is delivered. And we have world-renowned physicians, scientists and healthcare professionals who are leading the world in healthcare discoveries, treatments and interventions.

"Through this community engagement project and the publication of this report, Women's College Hospital can ensure that the voices of women are heard and their courageous stories are told. Our hope is that by disseminating our learning across Canada and sharing these rich insights with our health system partners and community stakeholders, we can all work together to close the gaps in our health system so we can continue to improve our health services and deliver on the healthcare promises we are all committed to." – Marilyn Emery, President and CEO, Women's College Hospital

Study methodology

In order to capture both **depth** and **breadth** of insights for this important initiative we adopted an iterative, **mixed methodology** approach for our 2016 study.

1. Quantitative Survey

We **first conducted a quantitative survey** among 1,260 Ontario women and girls over the age of 12, to examine their points of view on how healthcare was being delivered in Canada and also, importantly, to identify who is falling through the gaps. This quantitative survey was fielded in the summer of 2015 by Leger Canada.

Guided by learning from the quantitative study, we **then designed and conducted qualitative forums and face-to-face discussion**. This qualitative research, conducted by Strategic Navigator, was shaped by the **driving principle that we needed to invite women to share their stories in environments where they would feel comfortable and safe to share their personal experiences and the challenges they encounter**. To this end we engaged in two qualitative phases:



2. Qualitative Online Forums

In December 2015 we hosted online discussion forums over three days and among various communities of women. Each woman chose to participate in the group to which she felt the strongest sense of belonging.

The discussion groups were:

- Teen girls aged 16-17
- Women 18-64
- Senior women
- Women who are caregivers
- Women with disabilities
- Women with mental health issues
- LGBTQ women
- Caucasian women
- Women born in Canada
- Newcomers to Canada who have lived here more than five years
- Newcomers to Canada who arrived within the past five years
- Women who live in rural communities
- Black/African Canadian women
- Women of East Asian descent
- Women of European descent
- Women of South Asian descent
- Women with lower household incomes
- Women with higher household incomes

3. Qualitative Face-to-Face Discussion Groups

In January 2016 we selected a few communities where, according to the quantitative survey, women were falling through the gaps with respect to healthcare. We hosted eight face-to-face discussion groups with women from these communities. These discussion groups were held in the community in venues familiar to the women who participated and hosted by women from their communities. It is here that we developed true depth of understanding of the health gaps and the barriers some women face accessing the healthcare they need. It is also where we engaged in hope-filled conversations about how health services can be improved.

The eight discussion groups were:

- Teen girls aged 16-17
- Newcomers to Canada
- Indigenous women
- LGBTQ women
- Women with low income and/or education
- Senior women with chronic illness
- Women with physical disabilities
- Women who are caregivers



This report

There are three main sections to this report. The first is titled **Collective Voices**, and it pulls together the themes that resonated across the thousand women who shared their healthcare experiences and expectations. The section opens with a look at how this study's insights compare to those gathered in 2010 and examines women's views on their relationships with health. Then we delve into what women want. You will hear them describe their current healthcare experiences and contrast those with their ideas on what the best possible healthcare would be like. The final element of Collective Voices is an exploration of what our respondents expect from a hospital dedicated to women's health.

The second section is called **Seldom Heard Voices**. It is a deep-dive into often marginalized and disadvantaged communities that face specific issues accessing healthcare. This section features narratives from women who are not typically part of the debate over how healthcare professionals and hospitals can best serve patients. We try, where possible, to share these women's own voices, by using quotes from our conversations with each community.

The final section of the report, called **Responding To A Thousand Voices**, is an overview of how Women's College Hospital is addressing many of the issues raised by the various communities of women and girls it serves.

We would appreciate hearing your input and feedback, so please share your thoughts or questions on one of our social media channels, email us at 1000Voices@WCHospital.ca or visit our **Health Gap** campaign website to learn about the most prevalent gaps affecting the health of women at www.thehealthgap.ca. This report is also available online at www.wch1000voices.ca.

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 instagram.com/wchospital
 youtube.com/wchospital

A heartfelt thank you

We appreciate and offer our most sincere gratitude to **each of the community-based organizations** that connected us to the women who shared their voices in this study. You made this project possible by inviting us into your communities where we could have open and honest conversations. Thank you for your guidance and support.

To the women of A Thousand Voices, thank you for your courage, honesty and for trusting us with your stories. **Your voices have been heard.**

Take pride knowing that **Women's College Hospital is sharing your input and ideas with our health system partners** so that we can close the gaps and deliver the healthcare you deserve.

This is just one more step in our journey to advocate for and advance the health of women. Women's College Hospital will continue to reach out to our patients and the communities we serve and engage them in dialogue and consultation so that our hospital continues to be shaped by the voices of women and girls.



CHAPTER 2

COLLECTIVE VOICES

Much of what we learned in 2010 continues to hold true and so there are still areas that need to be addressed in allowing women to access the healthcare they need.

However, we were pleased to learn that some of the issues that surfaced before have shown considerable improvement. Women are more likely to feel their healthcare organizations or hospitals are **respecting diversity and creating inclusive environments**. They are also more likely to feel these institutions are taking a holistic approach to healthcare by **treating the whole person rather than just specific symptoms**.

But some shifts over the past few years concern us. In particular, personalization of care is a growing issue and many women now feel that their **healthcare should recognize and address a person's individual needs**. The bottom line is that almost half of women surveyed continue to say they are often **disappointed by the care they receive from the healthcare system**. Women's College Hospital is determined to change that statistic with our health sector partners.

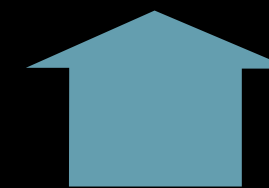
BY THE NUMBERS | SHIFTING ATTITUDES

Hospital or healthcare organization successfully...

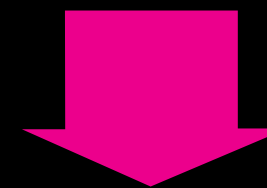
...respects diversity and creates an inclusive environment:
 2010 = 57%
 2015 = 67%



...treats the whole person rather than just the specific symptoms:
 2010 = 44%
 2015 = 51%



...recognizes and addresses patients' unique individual needs:
 2010 = 71%
 2015 = 61%



Women's relationship with health

Women's relationship with their health is an **impassioned** one, as evidenced by the language, emotions and stories shared throughout this community engagement initiative. By extension, their feelings toward clinicians, hospitals and healthcare facilities are also very passionate and emotional.

To understand the source of this passion, we realized we needed to explore more deeply the **relationship between women and their health**.

Being healthy is viewed **holistically**, involving body, mind and spirit. Women see their well-being as part of a broader context. In fact, a woman does not necessarily have to resolve her injury or illness to feel healthy.

Women told us that **energy** – physical, mental, emotional – is one of the key barometers of their health. Having the energy to live their lives to the fullest, to perform their work and to connect meaningfully with loved ones and friends is a major indicator of health. And lack of energy is often a sign of underlying health problems.

Because a woman so often holds primary responsibility for the well-being of others, she feels considerable pressure to be

seen as healthy. So she may **present a face of composure and wellness to the world that is not reflective of how she may be feeling** physically, emotionally or spiritually.

Being unhealthy is defined, at the most basic level, as **not being able to function normally during the day**. Given the tremendous load of responsibility shouldered by women, this can be discouraging, disruptive and at times debilitating. Women told us that they feel there is a stigma attached to not being strong, capable and self-sufficient.

“My doctor took the time...it felt like he was caring about me.”

To women, being healthy means not only feeling good for themselves, but also being able to fulfill their responsibilities to others.

Current healthcare experiences

Appreciating this relationship with health paves the way to understanding women's attitudes toward healthcare. It is encouraging to note that the majority of women told us their healthcare organization and/or hospital is **successful at providing care**. And, while the women who took part in this study report a variety of emotions when having to go to a hospital or healthcare centre, they are most likely to say they feel **taken care of** and **safe**. That's the good news.

“My doctor took the time...it felt like he was caring about me. He asked a lot of questions. He's like a friend.”

“They listen. They let you speak. The first thing she says is ‘How are you doing with your stress?’”

Unfortunately, negative emotions also prevail, with one-half of respondents agreeing that they experience a **high level of anxiety** when visiting hospitals, clinicians or healthcare centres. Underlying these concerns is a broad spectrum of issues, ranging from major systemic problems such as barriers to access, perceptions of racism, gender biases and cultural prejudices to enduring frustrations with wait times and a perceived lack of coordination among healthcare providers.

BY THE NUMBERS | THE GOOD NEWS

84%

feel their healthcare organization and/or hospital is successful at providing care

74%

feel taken care of when they go to a hospital or healthcare centre

70%

feel safe when they go to a hospital or healthcare centre

A transgender woman explained to us: “I have a lot of struggles in my life and I don't want to feel uncomfortable going to the doctor.”

A 17-year-old girl tabled her concern: “I feel anxious. They will ask me about sexual activity in front of my dad.”

Another teen girl expressed privacy concerns: “Even though they said there's confidentiality, I don't know...something about them makes you feel like they are going to go tell your mom.”

And a newcomer to Canada spoke for her community: “As newcomers, with language barriers and no family, you need help but [you and the doctor] don't understand each other. I'm suffering.”

BY THE NUMBERS | NOT GOOD ENOUGH

82% of respondents cite feeling negative emotions when accessing hospitals or healthcare facilities

62% claim to face barriers accessing healthcare for themselves and/or their families

51% experience a high level of anxiety when visiting a hospital, doctor or health centre

47% are often disappointed by the healthcare they receive

The issues, of course, vary among different groups of women. But here's what really caught our attention: those who need the care most are too often the women who are falling through the gaps. Women who consider themselves in poor health are significantly less likely than those in good health to feel empowered or calm when accessing healthcare. In fact, they are more likely to feel afraid, anxious and frustrated.

With almost half of women surveyed claiming to be **disappointed by the healthcare they receive** and two-thirds of women saying they **face barriers when accessing healthcare**, it became important for us to gain a more in-depth understanding of **what women want** from their healthcare system.

What women want

Five broad themes emerged through our conversations with women:

1. Women want respectful, compassionate care.
2. Women want their healthcare personalized.
3. Women want integrated care.
4. Women want care that is accessible and seamless.
5. Women want their health organization to be a place of wellness, not illness.

Let's look more closely at what they told us.

1. Women want respectful, compassionate care

Almost all women say it is very important to them that their hospital or healthcare organization provide respectful, non-judgmental care, yet 25 per cent say hospitals and other healthcare facilities are not delivering this successfully.

This is a gap that needs to be addressed.

95% say it is important that their healthcare organization or hospital provide respectful, non-judgmental care

Yet **25%** feel their healthcare organizations or hospitals are not successful at doing so

A third of women surveyed often feel disrespected by the people providing their healthcare. This number is even higher among teens, caregivers, those with lower household incomes and those in poor health. How are they being disrespected? Perhaps more importantly, what does respect look like?

In their words:

Start from a place of compassion.

The women in our study expressed a strong belief that women are compassionate by nature. When an interaction lacks compassion a woman may feel less at ease and less trusting. She may be less inclined to share the very details needed to get the care she needs. The tremendous value

of compassionate care came through so clearly when one of the women in the “Newcomers to Canada” discussion group explained with a gentle smile: “When they talk nicely, half the disease is gone.”

Respect and reflect our wonderfully diverse population of women.

Respect is a very powerful tool for healthcare providers. A woman from a lower-income household who is highly satisfied with her healthcare experiences, encapsulated how she feels when she is treated with respect: “I have a doctor who makes me feel proud.”

More often than not, women feel their healthcare organization or hospital is successful at respecting diversity and creating an inclusive environment. But in a city filled with a wonderfully diverse population of women, and with several hospitals



and healthcare facilities, unfortunately this is not always the case, particularly for some groups of marginalized women. Lack of respect can hurt women and it can also be detrimental to delivering the care they need. Some of these women do not feel accepted or respected and as a result are not opening up to their healthcare providers. A 17-year-old girl articulated a concern felt by many: “What if she’s judging me?”

Women want to see visible signals of inclusiveness. “[I want to] see more diversity. Even the frontline reception. It sets the tone. Give staff ongoing training. Have a board that reflects the women you are serving.” Inclusivity should be evident the moment a patient walks through the door. A transgender woman explained that even the check-in process at some facilities can be intimidating because she is asked to choose from one of just two options – male or female. An indigenous woman told us, with a heavy heart, that she would not go to a hospital unless she had to crawl there.

Recognize and respect my role as nurturer and healer.

Many women may be reticent to seek medical attention because they are immersed in their roles managing the well-being of others. What do we do when the healer needs to be healed?

“We are the ones responsible for the health of our children, our husbands, our parents. You cannot tell me to go home and lie down for a week.”

“Today’s illness is not just physical. We need support for what is inside.”

2. Women want their healthcare personalized

Another concerning insight our study showed is that almost all women say it is very important to them that their hospital or healthcare organization recognize unique and individual needs, yet one-third say these institutions are not delivering this successfully.

Our research showed that 58 per cent of women often feel treated like a number rather than as an individual. And once again, this issue of personalized care is more pronounced among those in greatest need of care – women in disadvantaged communities and in poor health.

In their words:

See me as an individual, not a category.

Women feel they are too often defined by their illness or by the cultural biases of others rather than as individuals.

94% say it is important that their healthcare organization or hospital recognize and respect patients’ unique and individual needs

Yet only **61%** feel their healthcare organizations or hospitals are successful at doing so

“It all comes down to the doctors and their staff respecting all patients. Everyone’s needs are different and each person needs to be dealt with differently.”

Establish and sustain a meaningful personal connection in order to unlock my truth.

Many women suppress or withhold the very truths they need to share in order to be well. They do not share their physical or mental struggles because they often feel these thoughts are not welcomed by medical practitioners. In particular, the inextricable links between physical, mental and spiritual health are not tabled during visits to the hospital, doctor or healthcare facility.

“Today’s illness is not just physical. We need support for what is inside.”

Help me by listening, asking questions, assuming nothing.

Women typify a medical facility as a place where they are “told” and seldom one where they are “asked.” They often feel misunderstood and, in turn, vulnerable. They would prefer to be active participants in their quest for health. Sixty-five per cent of survey respondents felt there is more of a focus on moving them through the system as quickly as possible instead of hearing what they have to say about their situation and needs.

“I believe asking questions AND getting the answer to satisfy the patient’s understanding of what is going on is the key to promoting better care.”



“Better care for me is integrated and collaborative between me, my GP, my therapist and any other healthcare professional that I have to access.”

3. Women want integrated care

Throughout our study, women told us they want solutions for their overall health and not just for specific ailments or symptoms. They also want their care to be well coordinated because for many their care requires multiple visits to a variety of specialists and healthcare providers. Many feel that their physicians are not connected to one another and as a result are not sharing important information, which often leads to increased anxiety and poorer health.

In their words:

Align your approach with my holistic approach to healthcare.

For many of the women we spoke to, health of the body, mind and spirit can be inextricably linked. As such, women believe that illness in any one of these areas can affect the others and must be treated accordingly.

“I live with chronic pain and that takes its toll on my general health. I’m also dealing with some workplace and insurance company issues as well as looking after my daughter who has cancer and is the mother of two young children. Being clinically depressed is getting in the way of my being healthy.”

Give me better care by building bridges between GPs, specialists and non-traditional healers.

When being sent to a specialist, our participants’ expectations are not always well managed. They are often not prepared for long wait times for appointments. Conversely, some doctors’ offices are not accessible and some women feel there is a lack of cultural inclusivity training among staff.

“Better care for me is integrated and collaborative between me, my GP, my therapist and any other healthcare professional that I have to access. The care I want is also preventive – healthy lifestyle, proper knowledge of risks, etc.”

BY THE NUMBERS WOMEN WANT INTEGRATED CARE

94% feel it is important to treat the whole person and not just the symptoms

89% agree that while they want the healthcare system to treat their problem, they also want it to provide solutions to improve their overall health

69% expressed an interest in preventive health services to help them achieve the highest quality of life and/or health goals, such as nutrition, stress management or weight management
(this measure has seen a significant increase in importance since 2010)

“I believe asking questions AND getting the answer to satisfy the patient’s understanding of what is going on is the key to promoting better care.”

BY THE NUMBERS BARRIERS TO ACCESS

35% are not able to get an appointment soon enough

18% are not able to get to the doctor's office when it is open

17% are too busy with work or other commitments

4. Women want care that is accessible and seamless

While all of the carefully considered suggestions put forward by these women provide inspiration for better healthcare delivery, the issues will not be solved if women cannot get to their healthcare providers. The top barriers to accessing healthcare all relate to time, further highlighting that the overall healthcare system needs to be flexible and adaptive to meet the needs of today's women.

Busy schedules, multiple demands on her time, parking, transportation and childcare challenges all get in the way of a woman seeing her healthcare provider. While healthcare facilities must take steps to address these issues, there is also a strong desire among women for healthcare to come to them. Situations in which a healthcare provider has reached out to a woman in her home or community have had profound

impact. This gesture makes a woman feel that someone cares, it shows compassion, it demonstrates recognition of her as an individual and so much more.

5. Women want their health organization to be a place of wellness, not illness

To some, visiting a medical facility is a sign of weakness. Women don't always view doctors, hospitals and healthcare facilities as allies in their journey to being healthy. Instead visits to doctors and healthcare facilities can be seen as admissions of being in poor health and being weak. For women a positive healthcare environment is one that provides signals of wellness in her interactions with her health providers, in the attitude she encounters and in the physical environment itself.

"When you are actually a patient in a hospital, you feel like your body has failed you in some way so you feel out of control. You also have no control over how you get treated and what kind of attention you get, which makes you feel even more at the whim of the world. Better communication of what a patient should expect, the process that will be followed, and updates is key (if this is the preference of the patient)."



“I would have an instant surge of trust walking into a hospital dedicated to women.”

Expectations for a hospital dedicated to understanding women

Women want a hospital that serves their specific needs. **Seventy-four per cent of women** said that it's important to them that there is a hospital that specializes in women's health and that understands how women want to receive and experience their healthcare.

In their words: “I would have an instant surge of trust walking into a hospital dedicated to women, just as I would if I had cancer and walked into Princess Margaret Hospital.”

“[...] Being able to speak to someone that specializes in women's health would make broaching topics more comfortable and would give me peace of mind that the doctors I'm working with are familiar with the issues at hand.”

Women explained that the desire for a hospital specializing in women's health is driven by five perceived benefits or expectations:

- **Compassionate care** and a welcoming, comforting environment with patients being treated individually and as if they are the only ones seen that day.
- Better knowledge around and specialization in women's bodies and **female-specific health challenges**.
- **Research dedicated to the woman's body** and women's health challenges.
- **Hospital services streamlined** so that delivery of care is more efficient and better connected.
- **Hospital-facilitated community support groups and services** tailored to the unique challenges of those groups.

“[A hospital dedicated to women's health would have] more holistic and community-based care. More group type services. Drop-in services offered during the evenings and weekends. Women empowering women.”

BY THE NUMBERS EXPECTATIONS FOR A WOMEN'S HOSPITAL

86% feel it is important to act as a central hub for women's health

83% feel it is important to provide specialization in women's health

83% feel it is important to make women's health a research priority

“[A hospital dedicated to women's health would have] more holistic and community-based care.”



CHAPTER 3

SELDOM HEARD VOICES

As evidenced in the report up to this point, many insights regarding women and health are common across the broad population of women. But we also set out to explore unique themes among distinct communities of women.

We selected these groups with a goal of listening to those who live in marginalized communities and are not always engaged in the healthcare conversation. Within these communities there are unique opportunities for providing healthcare that meets – or exceeds – the expectations of our increasingly diverse Canadian society.

	Community	Healthcare-related issues
1	Senior women with chronic illness	More likely to feel negative emotions More likely to face barriers More likely to experience anxiety Low perceived success of healthcare organization/hospital at providing care
2	Teen girls aged 16-17	More likely to experience anxiety
3	Women who are primary caregivers	More likely to feel negative emotions More likely to face barriers More likely to experience anxiety More likely to feel disappointed Low perceived success of healthcare organization/hospital at providing care
4	Indigenous women	Struggling to access appropriate healthcare
5	Women with physical disabilities	More likely to face barriers Low perceived success of healthcare organization/hospital at providing care
6	Women with low income or education	More likely to feel negative emotions More likely to face barriers More likely to experience anxiety More likely to feel disappointed Low perceived success of healthcare organization/hospital at providing care
7	Women who are newcomers to Canada	More likely to feel negative emotions More likely to face barriers
8	LGBTQ women	More likely to feel negative emotions More likely to face barriers Low perceived success of healthcare organization/hospital at providing care

Our quantitative survey revealed specific communities where the health gaps are bigger and the needs are more urgent.

We set out to better understand these women's unique challenges, needs and desires.

We sat down with groups of women from each of these communities and listened to their stories. The compassion in the room was palpable. We promised to share their stories.

“[I feel] anxious. They will ask about drugs and sexual activity... It would be easier if they were friendly.”

Key Themes among Senior Women with Chronic Illness

Fact: 50 per cent of women in our quantitative survey have at least one chronic illness. This number is even higher among seniors and among those with lower household incomes. The most common chronic illnesses among these women are arthritis, hypertension, asthma, mental illness and diabetes.

- **These women need outreach as their health issues can become all-consuming and at times isolating.** Healthcare providers should encourage social interaction and exercise and inform them about workshops and opportunities to boost efforts to be healthy.
- They seek preventive care and holistic solutions, often regretting not having embraced these earlier in life. **Many are exasperated with prescriptions being the only solution offered.**
- Wait times for specialists are discouraging. **Health issues often evolve or compound in the time these women wait to see a specialist.** Plus, many are spending a significant number of hours every week in waiting rooms.
- **They want the medical community to show patience** – explain medical issues, treatment, prevention more clearly and slowly. Write it down.

“Living is getting a little complicated these days. They wait till you have diabetes to teach you about prevention.”

Key Themes among Teen Girls aged 16-17

This is often their first foray into tabling highly personal issues with a relative stranger. They feel judged. They assume healthcare providers won't relate to them. **They yearn for connection yet the experience does not feel personal.** They feel that personal connection can be achieved by smiling, looking at the patient, asking the patient about herself, what she would like to discuss, what she thinks about the health diagnosis and treatment.

- Confidentiality concerns are notable barriers to sharing medical questions and concerns. **Girls are concerned that their parents/guardians may find out** or that their parents/guardians will speak for them during appointments, dominating conversations with healthcare providers.
- Teens are often poorly informed about health and medical-related issues. **They may not know what is important to ask or to share.** They may have a fear of the unknown and/or of being different. For this reason, they need encouragement to open up, and to the degree possible, they want their situation normalized.

“[I feel] anxious. They will ask about drugs and sexual activity...It would be easier if they were friendly.”



“Living is getting a little complicated these days. They wait till you have diabetes to teach you about prevention.”

Key Themes among Women who are Caregivers

Fact: 33 per cent of women in our quantitative survey are the person most responsible for ongoing care for an adult, such as a spouse, partner, parent, relative, neighbour, or friend.

- **Many caregivers feel isolated handling this burden.** A desire for financial support, social support and personal/community support was expressed by many of the women in this group.
- **The health needs of the individuals they care for often receive priority over the caregivers' own health needs.** The responsibility of caring for another can be so great there is little time/energy left for these women to take care of themselves.
- **Needing to make multiple appointments in multiple locations** for those they care for is an issue that many of these women found to be exhausting and extremely stressful.
- Wait times for appointments and wait times at healthcare facilities can be a nuisance. This challenge is **exacerbated by the fact that these women tend to use the healthcare system frequently.**

“I think that women who become caregivers for their parents (or spouses or adult children) should have access to care in facilities that are all-encompassing. It is so difficult to take elderly (or physically challenged) individuals to multiple trips to the doctor, hospital, clinic, laboratory.”

Key Themes among Indigenous Women

- **Healing is fundamental to their role as women.** It is very difficult for an indigenous woman to abdicate this responsibility to professionals, put herself first and seek healthcare.
- **Many are balancing traditional and western medical care** and as a result neither is being fully realized.
- There is an issue of trust; a belief that **the medical community is not confronting the anti-indigenous racism that exists.** In turn, the indigenous community is not trusting medical practitioners to provide the best care.
- **Addiction and mental health** are complicated issues. There is a stigma attached to indigenous women which can lead to these women not seeking appropriate care. Those with addiction and/or mental health issues may have a fear of being prescribed medications that could interfere with their intentions to be clean.

“We only go in there if we have to crawl there. There should be an aboriginal advocate.”





Key Themes among Women with Physical Disabilities

- They regularly encounter disrespect, disregard and underestimation from medical professionals. **Providers need to talk to the patient directly and take the time to listen; not assume she doesn't know her own body.**
- Participants felt there is often inflexibility in the medical community to doing things in new or different ways to accommodate special needs. **Providers need to understand the individual's specific situation and needs.**
- **Family physicians must consider accessibility and attitudes of specialists before making referrals.** Ideally the family practitioner would give a briefing or hand-off form to specialists, advising them that the patient has a disability, special needs, requires accommodations, etc.

- **There are issues of trust.** Medical professionals must appreciate that the patient may be trying her very best – against many odds – to be healthy and support her in that journey.

“I was so impressed with [my provider's] focus on my needs. Look at the person individually and what their special needs are... the doctor needs to be a good person.”

Key Themes among Women with Lower Household Income and/or Low Education

- Many of these women are carrying very heavy loads, holding together jobs, families, etc. Just getting to the healthcare provider is a challenge and so **they may not be inclined to put their own health first.**
- Societal experiences with discrimination and stigma have often led to shame or low sense of self worth. They may have an ingrained fear of rejection. This in turn inhibits willingness to share “secrets.” **These women want healthcare providers to make them feel proud. To give them dignity, respect and love.**
- **They often have limited access to exercise and nutrition classes unless they are seniors.** This issue is particularly acute for women in their 50s who are beginning to face health problems but don't yet qualify for the seniors' healthcare benefits.
- Some are dogged by communication barriers, **experiencing difficulty finding the words to express medical and mental health challenges.**

“The doctor is talking in medical terms but we need support for what is inside. Today's illness is not just physical.”

- **Healthcare providers must tease out barriers to accessing care;** ask about the barriers to being healthy beyond the presented condition.

“There is a soul inside that hurts. The doctor is talking in medical terms but we need support for what is inside. It's non-clinical. You should be able to go deep inside. Today's illness is not just physical.”



“It’s **non-clinical**. You should be able to **go deep inside**. Today’s illness is **not just physical**.”

Key Themes among Women who are Newcomers to Canada

- **Newcomers desire personal connection**, which could serve as a proxy for having a mother or sister by her side. It makes her feel someone cares for her, which is particularly important when in a new country and disconnected from loved ones.
- They seek **signals of respect for their culture**.
- Newcomers look for signs of professionalism in the healthcare facility... **Professionalism is a signal of being in good hands** – a heightened need when you come from a country where professionalism cannot be assumed.

“[The provider] gave me half an hour, explained the Canadian system... called me after. Knew my name. Said, ‘you come and visit me.’ She comforted me a lot.”

“You can notice that things are – you know – disciplined and in order, and people [look] professional. And neatness.”

“Be understanding. Particularly with trans clients. Your protocol needs to be updated.”

Key Themes among LGBTQ Women

- This is a tight knit community often alienated from the broader female population so they have learned to take care of their own. **Healthcare environments need representation from this community to demonstrate acceptance.**
- Many of these women have been hurt by assumptions, misrepresentations and judgment. **They want to be asked questions and given the opportunity to clarify in order to get the care they need.** There needs to be the opportunity for each woman to explain how she identifies and where she is on her own very personal journey.
- **Acceptance needs to come from every corner of the hospital.** Admittance, security staff, nurses, practitioners... Everyone needs cultural inclusivity training.

“Be understanding. Particularly with trans clients. Your protocol needs to be updated... it will make your space more welcoming. My doctor can be part of my hormonal relationship.”





CHAPTER 4

RESPONDING TO A THOUSAND VOICES

Women spoke and we listened and then we built a hospital that reflects their needs and desires. The architect took the input from the voices of a thousand women and worked with the Women's College Hospital team to build a hospital designed specifically for them. A place that makes them feel welcomed and included, and inspires health, healing and community. Where every single person who walks through its doors is treated with dignity and respect and everyone who works here promises to deliver care that comes without judgment, categorization or prejudice. A place that delivers the physical space and emotional environment that makes our patients feel comfortable and cared for. We created a space that can be called "Women's."

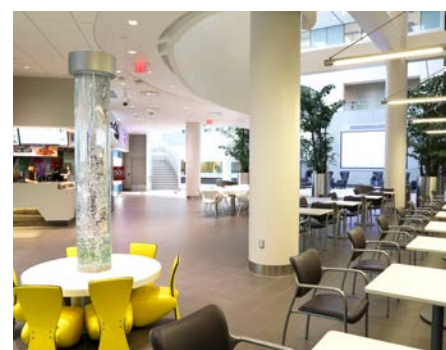
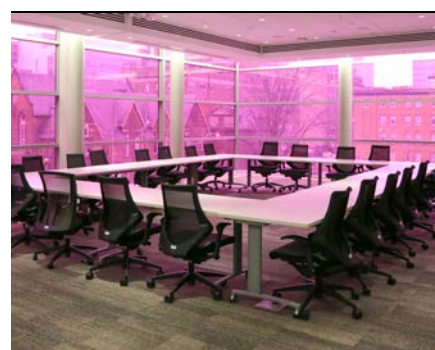
Our new, state-of-the-art facility is a hospital designed like no other. It's a beacon for women's health and it embodies the hallmarks of Women's College Hospital – leading-edge care and unparalleled caring.

Women asked us to create a place that is welcoming and bright. So in the lobby, volunteers at a reception desk welcome patients, wayfinding is intuitive and you can see the elevators from the front door. The space is filled with natural light and curved walls, creating an atmosphere that is calm, comfortable and uplifting. There are different seating arrangements throughout the main floor with individual chairs that allow quiet contemplation and groupings of seats that enable families and friends to engage in private conversation. We designed an open staircase with glass walls that starts in our main lobby and connects to our various clinical floors to address women's concerns about safety and anxiety about being in enclosed elevators. And kids' areas – with kid-size tables and chairs – are available on every floor. A food court offers various options with food appealing to different cultures and communities.

Women told us they want a hospital that is focused on wellness, not illness. So, in the main atrium there is a spiritual room with a labyrinth in its centre and walls imprinted with images of textured leaves. Throughout the building there are trees and plants and images of greenery that bring nature into the building. And artwork portraying diverse women and cultures is displayed on each floor.

To ensure the most efficient and accessible care, each floor is arranged in "clinical neighbourhoods" where patients can see all the health professionals they need – doctors, nurses, dietitians, therapists and others – in one place at one time. Specialized clinics, programs and surgical suites combine clinical care, research and education to ensure that patients are well-supported to manage their health. Our exam rooms have ample room for interpreters and cultural translators, exam tables that are adjustable for patients with mobility issues and light switches that are within reach of everyone. Individual, barrier-free washrooms and change rooms are easily accessible throughout the building.

We know that the more we discover and understand about the health of women, the better we are able to improve healthcare for all and deliver the highest quality care for all our patients. So one of our building's unique features is the iconic pink cube at its centre: a bright, open space forming part of a conference centre that serves as a hub of collaboration in research, clinical care and education. This bold architectural feature is the physical and philosophical heart of Women's College Hospital. It is a symbol of our dedication to advancing the health and well-being of women – a place for them to be inspired, empowered and healed.



Women's College Hospital's models of care have been developed to answer many of the barriers that women identified. Respect for time was one of the major concerns, so we have implemented processes and practices that ensure our patients wait no more than 20 minutes to see their provider. Also, for many patients undergoing breast imaging, apprehension and anxiety peak while they are waiting for their results, which often takes days or even weeks. In an effort to minimize this apprehension, the breast imaging team at Women's College redesigned their workflow to facilitate the sharing of real-time results with patients before they leave their appointment. Our teams work together to review the images immediately and share the results with the patient within one hour.

Women's College Hospital is an extraordinary place and the care and services that are delivered within it are equally unique. Here are a few examples of our innovative programs that meet the needs of our diverse communities of women and girls and help to close the health gaps they experience:

Creating Community Bridges

We know women face barriers to accessing healthcare services and that these barriers are even greater for women who live in marginalized communities. To help break down some of these barriers to care, Women's College Hospital has developed programs to care for women in their own communities and services within the hospital that make accessing care easier.

- Women's College Hospital physicians provide primary healthcare services, in collaboration with YWCA caseworkers and addiction support case workers from the Jean Tweed Centre, to the more than 300 women living at the **YWCA Elm Centre**, many of whom are struggling with significant substance use issues and mental health concerns. The ultimate goal of the program is to connect the women back to family practice at the hospital through the **PATH (Promoting Access to Team-based Healthcare)** program, a centralized intake model that brings complex patients without a primary care doctor into the hospital's family practice.
- For parents, sometimes just accessing care and attending appointments can be a battle. Finding childcare can be not only time-consuming, but also very costly. To make sure these challenges do not become barriers to accessing care, **Stella's Playroom** offers a short-stay, supervised "play zone" for children to have fun and relax. As a free service that can be booked based on availability, the room is filled with games, puzzles and toys to inspire imaginative play. A tremendous success, the room welcomed over 800 visitors in 2015.
- For many refugees fleeing their home countries and arriving in Canada, feelings of fear, anxiety and apprehension are not uncommon. They have many new systems to navigate and for most a new language to learn, all while looking



for housing, employment and schools for their children. This list of competing priorities sometimes means accessing healthcare is another daunting task that gets overlooked. To make arrival transitions smoother and to ensure that newcomers to Canada have access to the care they need, in 2012, WCH opened the doors of the **Crossroads** clinic, Toronto's only hospital-based clinic dedicated solely to refugee healthcare. Crossroads offers comprehensive primary care services to patients new to Canada, and after two years links them with community healthcare providers.

- More and more seniors are living independently in their homes. **The Wellness for Independent Seniors (WISE)** program helps improve access to the information that they need to stay well in their own community. The program provides links to social support services, information on health and wellness and even helps with coping related to the changes that come along with aging. WISE works with patients who are 60 years of age or older and offers access to a team of professionals including an occupational therapist, physiotherapist, dietitian, social worker and psychiatrist. When a patient joins the program, they meet with each of the team members to talk about their concerns. Program staff use their expertise to identify any other issues that patients may be dealing with, from nutritional concerns, home health and safety, to cognitive impairment and caregiver stress.
- WCH is part of a **community collaboration to improve service access for women vulnerable to human trafficking**. This consortium of community services, researchers and agencies is developing a coordinated response as they work with women with precarious immigration status who are also vulnerable to trafficking. The consortium includes Barbara Schlifer Clinic, Thorncliffe Neighborhood Office, Access Alliance Community Health Centre, FCG Refugee Centre, YWCA with funding by the Canadian Women's Foundation. The women we work with may have intersecting difficulties with labour migration, may have experienced gender-based violence, and may become vulnerable to trafficking. Due to their precarious status they may experience isolation and a lack of access to supports, such as primary health and prevention services, counselling, and housing and legal information. Through a combination of research, outreach, education and practical supports, WCH and our community partners are working together with these women to improve access and key social determinants of health for a population experiencing multiple levels of marginalization and exploitation.



Managing Complex Chronic Conditions

For patients with complex chronic conditions navigating the health system can be challenging. They often require care from a variety of specialists and healthcare providers to manage their illnesses and provide them with proactive preventive advice to help them be at their healthiest. With this in mind, WCH takes a multidisciplinary approach to caring for patients with chronic conditions.

- The hospital's **Complex Care Clinic (CCC)** was created to help patients manage their chronic health conditions. The goal is to stabilize and optimize chronic medical conditions and support patients to improve their health. A comprehensive team of healthcare professionals coordinate and provide the complete care patients need. The make-up of a patient's care team differs based on their unique needs but could include physicians, nurses, social workers, physiotherapists and pharmacists. To ensure the continuum of care, the team also works directly with the patient's primary care physician to keep them up-to-date on the patient's appointments and progress.
- At the **Centre for Osteoporosis and Bone Health**, our program draws on the expertise of a multidisciplinary team. Physicians, a clinical nurse specialist, pharmacist, physical therapist, occupational therapist, registered dietitian and bone densitometry technologist work together to ensure that patients stay well. Patients also have access to a range of resources including self-management support programs, decision aids, exercise tips from MyHealthMatters.ca and nutrition information. All of these resources are geared to improving access to care both inside and outside of the hospital's walls.
- For patients with Type 1 or Type 2 diabetes, managing care on their own can be a challenge. The hospital's **Centre for Integrated Diabetes Care** takes a holistic approach to diabetes health, providing patients with access to a team of experts including physician specialists, clinical nurse specialists, a registered dietitian and a social worker at one of three specialized diabetes clinics. The **Young Adult Program** supports access to a team specializing in Type 1 diabetes care for those aged 18-25 years. The **Integrated Diabetes Care Clinic** is led by a nurse practitioner and focuses on patients with complex Type 2 diabetes and decompensated glucose control. The **General Endocrinology Clinic** is led by a multidisciplinary team focused on helping patients manage their general health needs.

Women's Mental Health

Women suffer from mental health conditions like depression, anxiety and trauma significantly more than men. We also know that they experience more barriers to care than men do. To help close this gap and address the needs of women, WCH's mental health program has unique services and treatment models designed specifically for women. **The Reproductive Life Stages** program provides assessment and short-term treatment for women experiencing new or recurrent mental health problems, including anxiety, depression, mania and psychosis during the reproductive life stages such as menstrual cycle, pregnancy, postpartum and the menopausal transition. The program includes two child psychiatrists who provide care to children of mothers with mental health issues, and one addiction psychiatrist who provides consultation for women who have addictions in addition to their mental health challenges. For new moms who cannot come to the hospital for treatment but are in need of support, WCH developed the **Mother Matters online program** – a 10-week online support group where confidential discussion boards provide the opportunity for new moms to share their thoughts, feelings, and experiences, while learning from and supporting other mothers. Each week a new topic is explored, relating to issues that commonly emerge during the first year of life with a new baby. **The Trauma Therapy Program** offers confidential psychotherapy to women who have survived childhood interpersonal trauma which may include sexual, physical or emotional violence and neglect. The program works with a feminist anti-oppressive framework in which the client and team of health professionals work collaboratively around the issues brought to therapy.

Women's Cardiovascular Health Initiative

Women's Cardiovascular Health Initiative (WCHI) is Canada's first and only comprehensive assessment and lifestyle program for women with existing or potential heart problems. The program opened its doors in 1996 to provide cardiac rehabilitation for women. The evidence-based cardiac rehabilitation program is designed to meet the unique needs of women living with, or at risk for, heart disease – the leading cause of death among women. Cardiac rehabilitation has been shown to improve quality of life and ability to maintain activity. A multidisciplinary healthcare team provides risk factor modification counselling services and education sessions, and participants are offered enrollment into a women's exercise training program. Our program also conducts innovative research focused on women and heart disease.

Hereditary Women's Cancers

Cancer is a leading cause of illness and death among Canadian women. While some cancers affect both men and women, there are some common cancers that affect women at a higher rate like breast, ovarian and uterine cancers. The risk for developing these cancers is higher for women who have a genetic predisposition. The WCH **Familial Breast Cancer Research Unit** is a world leader in the prevention and diagnosis of genetic breast and ovarian cancer. Leading scientists at WCRI have discovered genetic mutations like BRCA that have a direct effect on a woman's risk of developing these cancers. This discovery has led to generations of families being saved from cancer's devastating impact.



Ambulatory Surgery

As Canada's leading academic ambulatory hospital, WCH has developed surgical models of care that allow women to receive the treatment they require without inpatient hospital admission or overnight hospital stays. For example, surgeons at WCH pioneered a surgical technique that enables a woman to have both a mastectomy and breast reconstruction in one surgery and go home the same day to recover in the comfort of her own home. And patients report higher patient satisfaction, better treatment outcomes and improved pain management. WCH's ambulatory surgery model is also applied to thyroid surgery and some orthopedic surgeries.

Substance Use Network (SUN) and Addictions Treatment

Substance use affects women differently than men. Women tend to progress more quickly from using an addictive substance to being dependant on it; they also experience the medical and social consequences of addiction faster than men, find it more difficult to quit using addictive substances, and are more susceptible to relapse. Many treatment programs require inpatient hospital admissions that can limit a woman's ability to participate because of her role in society. The WCH **Substance Use Network (SUN)** engages an interprofessional care team, combining addictions services with family medicine, psychiatry and social work. It also offers an ambulatory detox program which allows patients to avoid hospital admissions and return home or to their work and family responsibilities while undergoing detox.



“To the women of
A Thousand Voices,
 thank you for your
 courage and
 honesty, and for
 trusting us with
 your stories.
 Your voices have
 been heard.”

– Marilyn Emery, President and CEO, Women’s College Hospital

Sexual Assault/Domestic Violence Care Centre (SA/DVCC)

As one of the most commonly experienced forms of violence against women, domestic violence and sexual assault can have a profound, long-lasting, negative physical and psychological impact. Many victims are reluctant to seek help due to shame and embarrassment or even fear about how others, including healthcare providers, will react. Led by a team of highly trained, specialized nurses, the Sexual Assault/Domestic Violence Care Centre (SA/DVCC) at Women’s College Hospital is a comprehensive service that assists the victims at every point of their experience, from offering acute care and crisis support to followup and counselling.

Trans Health

As demand increases for transgender surgeries, Women’s College Hospital is working to increase access, capacity and expertise for trans health in Ontario. WCH will offer transition-related surgeries in an ambulatory environment and integrated programming supports in partnership with our acute care and community partners. Competent pre- and post-operative care services and expertise will be developed to ensure that trans people have access to trained, welcoming healthcare providers both for transition-related and general health issues.

Women’s College Research Institute (WCRI)

Our commitment to advocating for and advancing the health of all women and girls is at the centre of everything we do. This extends to our Research Institute whose central focus is research on the health of women and the integration of sex and gender-based analysis into all our research. Our researchers and scientists continue to seek answers to better understand health conditions that uniquely affect women and how women are affected by our current health system. Our research is integral to designing effective prevention and treatment strategies, addressing gaps in care and developing health system solutions that improve patient experiences and outcomes not only for the patients at our hospital but for women across Canada and around the world.



WCRI’S AREAS OF RESEARCH FOCUS ARE:

- Detection and prevention of hereditary women’s cancers
- Mental health during pregnancy and the postpartum period
- Prevention and care for women with diabetes
- Health challenges of older women with multiple chronic conditions
- The impact of gender-based violence and abuse on women’s health
- The complex relationship between mental health, obesity and eating disorders
- Improvements in women’s reproductive health
- Prevention and treatment of cardiovascular disease in women
- Improving the health of women with HIV
- Treatment and access to care for women with osteoarthritis

Thank you to the following individuals and organizations for supporting us in the creation of this report:

The women of *A Thousand Voices*

Leger Canada

Strategic Navigator

Alpha Abebe Photography

Orangecap Visual Thinking

First Copy

Our partner community organizations:

Youth Centre at Thorncliffe Neighbourhood Office

YWCA Girls' Centre

Toronto Birth Centre

The 519 Community Centre

Women's Health in Women's Hands

Anne Johnston Health Station

Community Living Toronto

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WCH Connect – our hospital newsletter with news, events & updates from WCH

Women's Health Matters – a monthly health and wellness newsletter from www.WomensHealthMatters.ca

WCRI IMPACT – a quarterly newsletter with news and information about the work of our researchers and scientists

For media inquiries please email media@wchospital.ca or call 416-323-6400 ext. 4054.

A THOUSAND VOICES
FOR WOMEN'S HEALTH

A PIONEERING STUDY | PART 2

www.wch1000voices.ca



Women's College Hospital
76 Grenville Street, Toronto ON M5S 1B2
416.323.6400
info@wchospital.ca