

1,000 reasons
we're at the
forefront
of women's
health.



WOMEN'S COLLEGE HOSPITAL
Health care for women | REVOLUTIONIZED



Meet the women behind the future of women's health.

They spoke to us from across Ontario. They told us what they want and what they don't want when it comes to hospitals, to care and to services. They shared their stories and experiences, their fears and concerns, their hopes and dreams.

This research report is a distillation of the voices of 1,000 women. Women who cover the spectrum of racial, cultural and religious communities, demographic and socio-economic backgrounds, diverse sexual orientations and vulnerable life circumstances.

Women's College Hospital is building the hospital of the future – a state-of-the-art facility dedicated to women's health that delivers an entirely new model of care.

It is a hospital designed to keep people out of hospital. It is a hospital designed by the ideas of 1,000 women.

A THOUSAND VOICES
FOR WOMEN'S HEALTH

A PIONEERING STUDY

introduction

We asked Muslim women and homeless women. We asked South Asian women and Canadian-born women. We asked older women and women with addictions. We asked lesbian women and women with disabilities. We asked lower-income women and their wealthier counterparts. We asked young women and Aboriginal women.

For the past two years, Women's College Hospital has been engaged in an unprecedented study – entitled **A Thousand Voices for Women's Health** – to find out what women from diverse communities from across Ontario want from hospitals, from care, and from services.

Now their responses are informing the very design of our new, state-of-the-art facility, and will enhance the very way in which we serve our patients.

By 2015, Women's College will have a new hospital designed unlike any other – built not around in-patient wards and bedrooms, but around specialized clinics, centres and surgical suites that combine clinical care, research and education.

That's because an entirely new model of care requires a new facility. As Ontario's only ambulatory hospital focused on women's health, Women's College has a unique mandate: to help women and their families prevent and manage their diseases and conditions so that they can live healthier and more independent lives. All without in-patient hospitalization.

Nothing could be timelier. Women's health has changed and it goes far beyond reproduction. Today, women of every age are living with a complex range of health issues – like diabetes, cancer, heart disease, arthritis, osteoporosis and depression – that require ongoing support and care, education and disease management skills. Not hospitalization.

Welcome to another century of groundbreaking advances in women’s health.

Fortunately for us, innovation 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 in women’s health.

Our track record is legendary. We collaborated on the invention of the 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’ve got cutting-edge programs that deal with today’s most pressing health conditions – and their particular impact on women. We’ve got one of the few research institutes worldwide – and the only one at a Canadian hospital – devoted to women’s health. And we have world-renowned physicians, scientists and health-care professionals who are breaking new ground in discoveries, treatment and interventions in women’s health.

Most importantly, we’ve got a hospital that is designed to keep people out of hospital. **We’re calling it the Hospital of the Future.**

Our Methodology

In order to produce the richest data based on in-depth discussion and survey, four approaches were used to obtain information in this qualitative and quantitative study.

1) We conducted 25 focus groups with women from diverse communities who identified themselves as:

Seniors	Women with disabilities	Bengali women (translated)
Youth	Women living with HIV-AIDS	East African - Somali and
Lesbian and queer women	Street workers and	Swahili women (translated)
Lesbian and queer youth	women with mental health issues	Caribbean & African women
Transgendered	Lower income women	Mandarin-speaking women
Women with addictions	Lower income new immigrants	(translated)
Abused women	Recent immigrants	Health-care & community workers
Homeless women	Tamil women (translated)	

2) We conducted 35 online community forums, also with women from diverse communities. Each respondent identified her background, age, sexual orientation, life circumstance, etc.

Women aged 15 to 24	Women with no religious affiliation	Black women
Women aged 25 to 44	Muslim women	Filipino women
Women aged 45 to 64	Hindu women	Latin American women
Women aged 65 plus	Jewish women	Southeast Asian women
Lesbian & queer women	Buddhist women	Aboriginal women
Bisexual women	Sikh women	Higher income women
Transgender & transsexual women	Canadian women	Recent immigrants
Protestant women	Western European women	New citizens
Catholic women	Eastern European women	Established immigrants
Orthodox Christian women	East Indian women	Canadian-born citizens
Women who are Christians	Jamaican women	Women with disabilities
other than Catholic,	South Asian women	
Protestant or Orthodox Christian	Chinese women	

- 3) We asked for and received letters of perspective from community-based organizations and leaders.
- 4) We conducted 1,500 telephone and online surveys with a representative sample of women from across Ontario and Canada (only Ontario results are reported here). The qualitative results helped to inform the quantitative survey.

This Report

This report is presented in two parts. The first, entitled *What Women Want – From a Hospital, From Services, and From Care*, is a distillation of women’s responses to questions concerning their perceptions of and experiences with health care to date, and their sense of what an ideal hospital might be. The second section, *How We’re Responding*, is a brief overview of how Women’s College Hospital is addressing many of the issues raised.

A few things to note. First, where possible, quotes by women from focus groups and online surveys are provided. In most cases, we’ve also identified the background or group to which the particular woman belongs. However, due to length constraints, not all findings of all groups are reported here. Our goal is to be illustrative of major themes, not exhaustive.

Second, no question was asked about Women’s College Hospital specifically. Our sole purpose was to investigate women’s views in general with regard to health care. We did not seek feedback on particular hospitals or providers.

Finally, this report is in no way meant to be definitive, nor the final word on women’s needs. Rather, it is intended to begin the dialogue that is most necessary if providers are to respond to women’s health-care realities and priorities in a meaningful way. And it is just the start. In fact, we are asking women to provide continuous input and feedback through our dedicated site www.womenshealthmatters.ca/1000women.

Thank You

Many community-based organizations, representing women from diverse communities, were instrumental in connecting us with the women we wanted to speak with most. Without these community groups, this project would not have been possible. We owe a great deal of thanks for your help, your guidance, and your support.

We are indebted, of course, to the women who took the time to share their stories – their experiences and their perceptions, their anxieties and fears, their hopes and their dreams. These remarkable women offered honest, sometimes painful, often inspiring input that is invaluable for enabling us to create the patient experience that all women deserve.

We asked, and you answered. Now it is our job to listen. The good news is that we are already responding to women’s needs in very real and innovative ways. Yet there is always more to do. And while there are many questions, one thing is clear. Our goal is to fully integrate women’s diverse needs into every aspect of our hospital – from patient experience to cultural competencies, from staff training and education to appraisal and evaluation systems, from research and programming to knowledge translation and exchange.

It is a challenge we are proud to embark upon.



what women want

from a hospital, from services and from care.

Women have made it clear.

They want a holistic approach to care that focuses on prevention, that gives them the option of being treated at home, that enables them to be at the helm of their own health, and that focuses on all aspects of their lives.

Women want a health-care facility that inspires health, healing and community – and that is a hub of women's health.

But mostly, women want to be treated with dignity and respect. They want to be heard, they want to belong, and they want to see themselves represented by the staff who care for them and in the images and languages that surround them.

Here, by the numbers, is what women have to say.



“I want care
that gives
me control
over my own
health.”

It's not news that women want a holistic approach to care. But clearly, it's not what most women are experiencing.

Consider this: over 88 per cent of women say it is vital that health-care facilities provide a holistic approach to health that treats the whole person, not merely parts of the body. But only 43 per cent feel hospitals and health-care facilities are successful at it.

Yet for a huge number of women, well-being can only be seen in terms of the broader context of their lives. "Fix me," says one woman, "I am a mother." Holistic care is the connection between women's health and the lives they live every day – as parent, caregiver, worker and partner. Here is what holistic health means, according to the voices of 1,000 women:

It means prevention – rather than treatment:

Women lament that health care is reactive and solution-focused rather than proactive and preventive. As one woman puts it, the system is "responsive when you're really ill, but next to useless in helping me maintain good health." Another woman comments that there is too much focus on "fixing instead of preventing," and still another woman complains that the emphasis is on "episodic treatment, not health maintenance."

Most women want information, education and resources that can help them manage their own health. As one woman in the 45-64 age category says, we want "information on preventive measures for various illnesses and degenerative conditions, as well as stress management, pain management, weight management, psychological and hormonal changes." Still another woman says she would like "practical classes and workshops for self-improvement and emotional healing." One woman with HIV says that her emotional suffering sometimes caused her more pain than her physical condition, and that recognizing her psychosocial needs would improve her overall health.

"Fix me,"
says one woman,
"I am a mother."

It means delivering care in the context of women's lives:

Women want health-care professionals who acknowledge the connection between mind and body. Religion, family status, caregiving responsibilities, concurrent illnesses, medication interactions, and domestic and economic realities are just some of the

issues that women want doctors to consider when developing a health-care approach tailored to their specific needs. As one woman says, holistic care happens when "health and well-being, home situation and total care of body and mind are taken into account when considering treatment."

For some, holistic care might mean child care. “Women shouldn’t have to ignore their health-care needs because there is no one to care for their children for an hour,” says one woman. Other women simply want a space for children to play while mothers wait for appointments. Women who suffer abuse are in particular need of child care while they are tested, treated or take relevant classes and workshops.

For others, holistic care might mean accommodating religious custom and honouring belief. It might mean that health-care providers understand the importance of abstinence before marriage. Or it might mean access to religious clergy, a space for prayer and spiritual renewal, and visible evidence of the appropriate religious symbols.

Women who are abused identify particular needs for whole health. They want doctors who will listen to more than a single concern in one appointment. They want programs for weaning off medications. And they want the emotional aspects of their treatment addressed through access to mentors, support and counselling programs that can help relieve anxiety, give hope and present practical possibilities for improving their lives.

It means having the option of being treated at home:

Ninety per cent of women agree that should they require ongoing treatment, they would not want to be admitted to hospital as an in-patient. And close to 94 per cent of women say they want access to resources within their communities – like support groups, survivorship programs and workshops – to help them with recovery and maintain relationships developed through their health-care experiences.

It’s not surprising. For many women, remaining in their homes with their children and families is far preferable. As one woman puts it, “one always feels better in the comfort of their own environment surrounded by familiarity. Unless there are medical services that cannot be done at home, or the home environment is not tenable, I see no reason to be hospitalized.” Another woman says that a great advantage of outpatient care is that women are “able to help themselves and their families and still be able to live their lives.” And even when women are admitted to hospital, they want to maintain connections after they leave through community and/or Internet-based support groups.

Perhaps most interesting is that, for many women, being at home is empowering. As one woman says, “I can take care of my family, I can sleep better, and feel more empowered.” Another says, “I think if more people were to take control of their health and do things from home they may feel more in control of their condition instead of just being up in a bed in a hospital preparing to die.” For these women and others, being treated while living at home empowers them to be co-creators of their own recovery.

Nonetheless, some groups have reservations about being treated at home. Women with mobility challenges, women who live in situations of domestic violence, and those without sufficient support at home expressed concern about outpatient care.

Most women agreed, however, that “choice might be a better solution. Sometimes a decision is not best based on the nature of the health issue but on the basis of the patient’s ability to cope.”

The very definition of holistic care.

“My name is Josie.
Not HIV.”



It means enabling women to be the co-creators of their own health:

Amazingly, only 30 per cent of women feel empowered when it comes to their health and their health care. Yet the vast majority of women want to be at the helm of their own health. “Give me the options and let me decide what is best for me,” says one woman.

For many women, taking part in their own health means a health-care team that includes not only practitioners, but the patient herself. The ideal for one woman is to be “treated as the intelligent person I am, and really be listened to because I probably know more about my health issues than some of them do.” Another young woman says, “I want things clearly explained to me and my confirmation is needed that I’m happy to go ahead.” And still for other women, it means breaking down the “us versus them paradigm that can often exist within health-care environments.” According to many women, they are simply not given sufficient information or time to make important decisions.

For many women, acting as co-creator also means being empowered to manage prevention and recovery at home. It means being empowered to take control of their own health through knowledge and understanding of issues and treatments, and through supports and services provided by health professionals and health centres.

Playing an active role in their own care is not for all groups, however. Homeless women, for instance, say they lack confidence in looking after themselves. Some express feelings of insecurity and fear. Others feel poorly educated about their own health, and seem to have more of a desire to be cared for and guided by health-care experts. According to one woman, “we shouldn’t be the bosses of our own health” because “we don’t know what’s going on in our bodies.”

It means a focus on wellness, not illness:

For too many women, the medical world too often focuses on illness rather than healing, on disease rather than wellness and well-being. One lower-income woman suggests that a hospital must be “founded on the premise that health is more than just fixing a body’s illness; it’s about providing a sense of well-being – healing the body and spirit.”

For a great number of women, healing does not always equate to the fixing of a wound or an illness. Healing is about wholeness, and it is about living as a whole person. “My name is Josie. Not HIV,” says one woman. Josie cannot be cured, but that does not compromise her sense of healing because healing happens when body, heart, mind and soul are treated in concert.

BY THE NUMBERS:

WHAT WOMEN WANT FROM HOLISTIC CARE

Over **88%** say that health-care facilities must provide a holistic approach to health that treats the whole person, not merely parts of the body.

Only **43%** feel hospitals and health-care facilities are doing it well.

90% want the option of being treated as an outpatient.

94% want access to resources within their community to help them with recovery, yet only **70%** feel hospitals are successful at this.



“I want
patient care
that doesn't
assume that
I'm straight.”

Women want a physical space that inspires health, healing – and community.

“I feel so alone. And it gets worse and worse throughout the visit to the hospital. I walk in and no one looks at me. I don’t know where to go. My heart is pounding. I don’t know if anyone cares.” So says one woman over the age of 65.

The numbers cannot be ignored. Fifty-seven per cent of women feel afraid when they have to go to a hospital or health-care centre. Over three-quarters of women feel anxious. In fact, 47 per cent of women say they experience a high level of anxiety when they visit a hospital, doctor or health clinic. And 45 per cent of women feel isolated, 47 per cent feel confused, nearly 63 per cent feel frustrated and more than 28 per cent feel angry.

An ideal hospital, many women insist, is about “wellness and energy, a place of activity where we can feel women’s health happening.” It is a place that creates community and a sense of mutual support. It is a place that is “peaceful but alive, that alleviates anxiety, and that promotes self-improvement.” In this place, one woman says, “I am not scared.”

Women had many suggestions about how to make that happen. The entrance, recommends one woman, is a “hive of activity where patients are pulled into positive energy.” The grounds are welcoming and the lobby is warm with “smiling greeters who take time to connect.” There is a “private place to explain why I am here.” Reception desks are not too high and so do not create barriers. Sunlight streams through glass windows, and live flowers, plants, and sounds of water create a sense of calm. Washrooms are immediately visible. There are spacious waiting areas with “comfy chairs.” The moment a patient walks in, she feels immediately at home.

In this place,
one woman says,
“I am not scared.”

Throughout the building, there are fluid spaces with no hard edges. Windows are tall, modern and allow for natural lighting. There is “nothing too sharp, and not much metal.” There are private places to “relax and meditate, to read and listen to music,” and to engage in “intimate conversations and time with family.” For religious women, places of worship are essential. For Muslim, Hindu and other women, spaces that allow for privacy are imperative.

These kinds of spaces are integral to a sense of community. “While we want a hospital to recognize us as individuals,” says one woman, “we also want to be connected.” That kind of connectedness, say many women, happens when women have a venue for speaking with other women, for voicing their fears and anxieties, and for supporting one another. As one woman comments, “Women usually want to go to places where women are so they can talk about their issues without shame.” For many women, a place for children to play and families and friends to meet is fundamental to a sense of community.

Many women want décor, signage, artwork and magazines that represent the diversity of the patient population. They want wall murals that reflect various cultures and brochures produced in relevant languages. They want signage that is icon-based and easily understandable.

Safety too is a major issue for women, and for many, a safe environment is how a hospital generates trust. Clearly, safety goes beyond physical space and encompasses a whole range of measures. For some women, for instance, safety means not being treated by male clinicians because of religious belief, sexual orientation or past experience – and because, for many, a female health provider just “feels safer, more comfortable.” Other women define safety simply as being heard. But when it comes to the facility itself, women have distinct needs. For abused women, for instance, confidentiality and privacy are safety issues – and extremely pronounced. They want “a physical space in which they can feel emotionally safe, and can therefore express themselves without fear,” according to one woman. For transgender populations, outdoor lighting and security guards are essential to protect those who feel threatened in public.

For women with disabilities and some older women, accessibility cannot be overemphasized. Accessibility is directly related to dignity, respect and empowerment. Women with disabilities and those over 65 years of age, for instance, want adjustable equipment, such as mammograms that can be done “while I am still in my wheelchair.” They want better exam rooms with doors that can accommodate their wheelchairs and examination tables that can be reached. They want wider doorways that open automatically and wider hallways. They want accessible bathrooms and short distances between entrance and elevator. They want properly angled ramps and handlebars in hallways for those whose walking is impaired. They want light switches that can be reached by those in wheelchairs. “We need to be consulted when it comes to building design,” says one disabled woman. “The builder needs to videotape themselves going through the building in a wheelchair and prove that it can be done without any unnecessary detours or getting stuck in a space that’s too small to turn in. They should also have to go down the ramp themselves to prove that the slopes are gradual and not a theme park ride.”

And finally, food. For many women, food is fundamental to healing. Some say they want home-cooked local foods. Others want foods from diverse cultures that reflect their heritage. Food is particularly important for some groups of religious women. Many Muslim women follow Halal dietary laws and for many Jewish women, the food they eat must be Kosher. East Indian and Hindu women want vegetarian options. Chinese women want “fresh and authentic Chinese food that doesn’t taste frozen.”

BY THE NUMBERS :

WHEN IT COMES TO VISITING A HOSPITAL OR HEALTH-CARE CENTRE, HERE’S HOW WOMEN FEEL:

57% feel afraid

76% feel anxious

47% experience a high level of anxiety

45% feel isolated

47% feel confused

28% feel angry

63% feel frustrated

30% feel empowered



“As a Muslim woman, the kind of care I want begins with privacy.”

It's that simple. Women want dignity and respect.

Virtually all women – 96 per cent of them – want care that comes without judgment, categorization or preconceptions.

In most cases, they're getting it. Almost 70 per cent of women say they feel respected by those providing their care. And close to 80 per cent of women feel taken care of when they are accessing health-care services. Many women speak very highly of their experiences with quality care and a caring staff.

"Whenever I have been in need of any health care I have always received good care," says one woman over the age of 65. "At times there may have been a bit of a wait but never was there a time when I was in jeopardy." A woman with a physical disability says she has "only met kind and caring medical professionals who have a clear understanding of my disabilities, limitations and options." One Sikh woman describes staff as "compassionate, friendly and kind" and a Jamaican woman describes the care she received as "patient, accommodating and maternal." One Canadian-born woman contends that while "there have been hiccups, even those were dealt with in a caring way." A Chinese woman remarks that the care provided to her was "top-notch." And a Jewish woman says that the care "exceeded my expectations. The surgeon was personable and took time to talk to my spouse before and after surgery." She also says that "nursing was efficient and kind. I felt all hospital staff cared about me."

Yet that leaves nearly a third of women who say they often feel disrespected by health-care staff. According to findings, it is women across all ages, all racial and cultural backgrounds, vulnerable life circumstances, women with disabilities and women suffering from chronic illness who are most likely to report perceptions of inequity and feelings of exclusion.

Here are the issues women point to most:

"Don't judge me"

One young woman says she feels judged for "having a baby before what society feels is proper" and would have liked support from health-care professionals. A woman with HIV remarks, "I feel like I've committed a crime." Many bisexual women feel judged because of their choices or lifestyle. Women aged 15-24 ask for non-judgmental sexual health education, confidentiality, and emotional support – particularly around pregnancy. And still another woman says, "Don't assume who I am based on how I look or talk."

Women with addictions and those who suffer abuse fear being negatively labelled because of their presentation and circumstances (for instance, they might not have a permanent phone number or address and are poorly dressed). Women with HIV recount painful stories of physical and emotional isolation. "Don't put a stop sign on my door," says one woman with HIV, "and don't walk into waiting rooms and announce I have HIV." Another woman with

"Don't assume who I am based on how I look or talk."

HIV says, "Don't judge me. Know that I got here through horrible conditions of abuse, rape, war, poverty." One lesbian woman says that "I have had mostly negative experiences in hospitals, mainly with wait times and doctors not listening to me. As someone who has had a mental problem in the past, I feel they judge me immediately because of this and do not leave me a chance to explain myself."

Women in the Aboriginal, Chinese, Filipino, Southeast Asian, South Asian, East Indian, Eastern and Western European communities share similar sentiments. One Hindu woman, for example, says, “They tell you who you are. There is no such thing as your self-dignity.” An Aboriginal woman used a string of words to explain her feelings: “No power, condescending, sadness, fear.” A South Asian woman sums it up in a phrase. “What we need is to be treated equally.”

One Jamaican woman commented that, “We don’t want to feel like because we’re black we don’t matter.” And a Latin American woman puts it very succinctly: “No discrimination.”

“Diversity matters”

Eighty per cent of women want a hospital that is knowledgeable about the needs of women from diverse cultures, and puts practices in place to address those needs. But it’s not just those from diverse cultures who expressed those views. Women born in Canada believe that the health-care system already reflects their needs; they insist the focus be on women from diverse communities.

“Listen to me”

Feelings of disrespect are often rooted in the sense that women are not being heard. In fact, just two-thirds of women believe hospitals and health-care facilities offer collaborative communication to patients and families.

“I have a story,” says one woman. “Please listen to it.” The feeling among some women is that, too often, staff do not take the time to understand the patient and address her individual concerns. “Listen to what I’m telling you and give me the time to talk; don’t be hurried and dismissive,” says another woman. “Address me by name,” insists one woman. “Remember my history and don’t make me tell it to you over and over again,” says another. Still another says “look me in the eyes and talk to me like a human being.”

As one young woman says, “I’ve had a few fantastic doctors and a few not so fantastic. The non-fantastic ones I would describe as such because they didn’t take my needs seriously or didn’t listen very well.” A woman from the lesbian community claimed that she’s had both good and bad experiences. “The good experiences have been for the most part with doctors and other health-care professionals. The poor experiences have been predominantly from support staff and health-care tech (ultrasound, blood, x-rays).”

One woman says that though doctors are generally “good at the technical side of their jobs, they lack the personal skills necessary in dealing with their patients. There isn’t enough empathy. I feel like I’m just being pushed through the system.” Some other women agree. One Chinese woman laments that “most employees are nice and professional, but some just don’t care.” One Hindu woman remarks that “overall I have had OK experiences in a hospital or health clinic setting. There are of course some negative experiences as well but that has been as a result of a combination of bad client/customer service (not ending up with a health-care professional who I was satisfied with) versus overall health-care system flaws.”

“Make me feel safe”

Women from different communities tend to feel anxious and afraid for reasons specific to their backgrounds and life circumstances. Young women aged 15-24, for instance, claim to feel a tremendous amount of fear when it

“I have a story,”
says one woman.
“Please listen to it.”



“I want a hospital where the primary challenge isn't getting onto the exam table.”

comes to health issues – particularly those surrounding pregnancy, sexually transmitted diseases, and confidentiality. Transgender and transsexual women fear for their physical safety because of a history of being assaulted by men. Some are also afraid of procedures that they do not understand, like the Pap smear. Filipino women often do not feel safe enough to fully express their needs and ask questions, in large part because they can be “in awe of authority.” Recent immigrants can often feel unsafe because they have so little understanding of the health-care system. Some lower-income women don’t feel safe because they don’t feel equal to others. Women with HIV are extremely anxious because of misconceptions and myths surrounding their condition, and fear of being publicly humiliated. Homeless women describe a fragile sense of emotional safety because of low self-esteem and a deep embarrassment about their circumstances. Some lesbian and queer women express discomfort with men. “I don’t want to be put to sleep by a man,” says one woman.

“Give me privacy”

For many women, respect means privacy. Muslim and lesbian women, for instance, want the option of receiving care from an exclusively female staff. Muslim and Hindu women bemoan gowns that fail to cover them appropriately, and ask for head covers in the operating room. Lesbian and queer women want private spaces in which they can openly discuss their sexuality and sexual safety. Other women – particularly those from vulnerable groups – lament the lack of physical spaces in which to discuss their issues privately.

“Speak my language”

Women across the board are intensely aware of the barriers to care, even when those barriers do not personally impact them. Cultural barriers are one example. For instance, when English is not a first language, translation services and cultural interpreters are identified as a primary need. Western and eastern European, Aboriginal, Latin, recent immigrant, Filipino, Jamaican, East Indian, Southeast Asian and South Asian women – all request not only interpreters, but posters and pamphlets that are language- and culture-specific, décor that reflects various backgrounds, and clinicians who speak their language.

Access to language goes beyond mere practicality. The failure to understand, and be understood, is central to feelings of anxiety, isolation and confusion. As one new immigrant remarked, “Going to the doctor in this country is very stressful. No one helps us. We are nervous about what they will tell us.”

Similarly, a Chinese woman comments that “communication between the doctor and patient may be one of the major issues, not only with the Chinese community but with other ethnic groups. With the lack of understanding, the patient will not possess the knowledge required to make sound decisions or have enough confidence to ask questions.”

One Aboriginal woman points out that, at times, elders in her community are afraid to admit to their language difficulties and could benefit from translators. One eastern European woman says because those in her community often have thick accents, “people tend to get quickly frustrated.” Another Latin woman stresses, “having doctors that can communicate with you in your own language helps so much (I can speak for my mom!).”

One South East Asian woman describes both the frustration of a language barrier and the feelings that result from it. She complains that health-care providers do not always take the extra time to hear her stories, or listen to what she has to say. “Because we have caution on our minds. We have to make our sentences first. Then explain it. They have to have the mind to listen to us. To realize we are afraid.”

As one woman sums up, “we feel safe when we are listened to. You feel like you can let your guard down.”

“Understand where I come from”

Here’s the good news: 60 per cent of women say that health-care facilities and hospitals are indeed knowledgeable about cultural sensitivities and have put practices into place to help address these sensitivities.

Yet for many, this isn’t happening enough. Women 65 and over report ageist attitudes characterized by inappropriate comments. As one woman says, “I feel that women 65 and older are being swept under the carpet as people that have lived long enough and should expect these types of illnesses at this age. In other words, put out to pasture!”

How well staff understand cultural and economic diversity – in terms of realities, customs and practices – is a major priority for women. One black woman, for instance, says she wants health-care providers to understand racial issues and poverty. Some Chinese women want staff to know important Chinese holidays. And many transgender and transsexual women want their health-care providers to understand that their identification might not reflect their gender. As one lower-income woman says, in an ideal hospital “all the staff would be fully educated about women’s concerns including same-sex relationships, poverty, and single parenting.”

“Know my diseases”

Women from diverse groups want health professionals who understand diseases and conditions that are unique to or disproportionately individual cultures and groups – and are able to diagnose, treat and educate women about them. Aboriginal women, for instance, want clinicians to understand diabetes, alcoholism, and depression. Jamaican women want preventive approaches to sickle cell anemia. Women with HIV want physicians who understand neuropathy and specific drug interactions and their side-effects. Transgender communities (both male to female and female to male) want care providers to have expertise in hepatitis C and hormone therapies.

“Queer friendly
doesn’t just mean
a rainbow sticker.”

“Let me belong”

For many women, belonging means being reflected in the health-care system. For a great number of women from racially and culturally diverse communities, food, décor, reading materials and staffing models are indicative of how well women are represented in the system. As one black woman says, her ideal hospital would be a place where “members of staff are black so they can relate to my concerns.” Similarly, Aboriginal women agree that representation in staffing models is very important to their community.

Lesbian and queer women want a hospital that does not assume heterosexuality. One woman says she gets “sick and tired of having to come out everywhere I go and having to worry about how I might be treated by doctors.” Some want health professionals to use language like “spouse and partner rather than husband.” And still others want diverse staff that reflects their community. Mostly, women want acceptance that runs deep and to the core of culture and operations. “Queer friendly,” says one woman, “doesn’t just mean a rainbow sticker.” It means same-sex partners treated the same way as family members. It means privacy to openly discuss sexuality. It means staff at every level is educated about how to best communicate with women from this community.



“I feel like a number, not a person”

Almost 65 per cent of women say they often feel like a number rather than an individual, and nearly 70 per cent believe there is more of a focus on moving them through the system as quickly as possible – instead of really hearing what they have to say.

As one black woman put it, “They don’t see the whole person. I am just a walking symptom.” A Canadian-born woman claims she feels “treated like a piece of meat with no feelings and just a dumb obese woman.” Still another woman complained of “assembly line service. I did not get the feeling the physician sincerely cared. I was being rushed through.” And one disabled woman complained that “doctors and nurses are very abrupt and in a hurry and don’t take the time to explain your symptoms and problems and the treatment thoroughly.”

In fact, a good number of women with disabilities feel that, except for their physical limitations, they go unseen. As one woman says, “We’re not asking for much: eye contact, hi, how are you? That’s what we need the most.” Many women with disabilities feel they are often not consulted or spoken to directly. Still others say that their sense of self is often diminished. “Treat me like I have a brain,” remarks one woman, “and don’t talk about me as if I wasn’t there.”

Women aged 35–44 are far more likely to feel they are treated as a number (almost 77 per cent), as are women with children. Both groups are significantly more likely to say that their individual needs go unheard, and to feel that hospitals and health-care facilities are not successful in recognizing life stresses such as caregiving responsibilities and concurrent illnesses.

Interestingly, less than 50 per cent of women aged 65 and over say they feel treated like a number. At the same time, many say they feel dismissed or patronized because of their age. Women in this group want to be treated as valued and complete individuals – not “as elderly or decrepit,” as one woman says. As such, they want knowledge so they can make appropriate treatment decisions. They want to “forbid phrases such as ‘at your age you can expect...’” and they want their concerns acknowledged – not ignored as age-related inevitabilities. They also want physical supports to help with mobility so that they can be as independent as possible.

BY THE NUMBERS :

WOMEN WANT DIGNITY AND RESPECT

96% want care that comes without judgment, categorization, or preconceptions.

97% feel it is important that hospitals or health-care facilities recognize their individual needs.

36% often feel disrespected by the people providing their care.

Close to **80%** feel taken care of by health-care providers.

65% believe that hospitals and health-care facilities offer collaborative communication to patients and families.

80% want a hospital that is knowledgeable about the needs of women from diverse cultures, and puts practices in place to address those needs.

60% say that health-care facilities and hospitals are knowledgeable about cultural sensitivities and have put practices into place to help address these sensitivities.



“I don’t want
to be
dismissed
because I’m
too old to
matter.”

Women want a health-care facility that is an expert in women's health.

It's unequivocal: More than 8 out of 10 women want a hospital that specializes in women's health – and that understands how women want to receive and experience their care (nearly 82 per cent of women with chronic illness believe a facility of this kind is very important). What exactly does that mean to women? Here's what they had to say:

It's all about the care:

According to most women, superior knowledge in women's health means better prevention and treatment and better standards of care – and it equips staff to ask the right questions that lead to the right diagnoses. As one woman puts it, a facility that specializes in women's health means “there is likely a better understanding of what I'm going through and a staff that sees it more often and can offer relevant advice.”

It's life-long:

Many women indicate the need for a hospital that can support them through the many stages of their lives. As one woman remarked, a hospital must accommodate women in various phases and circumstances of their lives – “single or married, in childbirth, taking care of a parent and child, work stress, sex and peri-menopause.” Others agree. Those who are nearing menopause, for instance, want guidance and understanding as they deal with what can often be a very difficult time in a woman's life. “Once past the fertile period,” says one woman, “help us understand the changes our bodies are going through as we age.”

“Help me understand where all the resources are so I don't always end up in emerg.”

It's about a “one-stop shop”:

A full 90 per cent of women say they want a hospital that acts as a hub of women's health and that includes testing, diagnosis, treatment, followup and support. For most, a one-stop shop ensures more comprehensive health care because everyone talks to one another – and that saves time for the patient, money for the system, and missed days of work. As one woman puts it, “We need a health-care team that comes from a variety of disciplines in

one clinic that can work collectively to resolve a woman's health issues.” One older woman says that she misses having “someone with experience with joints and bones, a cardiac specialist, a lung specialist, a dietitian and exercise instructor...” – all under one roof.

Moreover, women see a women's facility as a “safe haven where they can express the full extent of their needs.” One woman underscores the point. “I've struggled with fertility problems and have been bounced around from one office to another, seeing a variety of doctors, none of whom looks at me as a whole person. A health-care facility specifically designed for women provides a much-needed model of comprehensive care.”

It's cutting-edge technology and women-centred research:

Access to the full range of women's health services isn't enough on its own, say the majority of women. They also want leading-edge technology and research that ensure best practice and that generate confidence. Eighty-seven per cent of women, in fact, believe that women's medical issues must be in the foreground of the institution's research. Yet only 56 per cent feel health-care facilities are doing a good job at it.

It's convenient:

Women want satellite clinics operated by the hospital in communities. They want access to community support for recovery. "Help me understand where all the resources are so I don't always end up in emerg," says one woman. And women want followup once the patient leaves the hospital.

BY THE NUMBERS:

WOMEN WANT A WOMEN-FOCUSED HEALTH-CARE FACILITY

83% want a hospital that specializes in women's health – and that understands how women want to receive and experience their care.

82% of women with chronic illness believe a facility of this kind is very important.

90% want a hospital that acts as a hub of women's health and that includes testing, diagnosis, treatment, followup and support.

87% believe that women's medical issues must be in the foreground of the institution's research. Only **56%** feel health-care facilities are doing a good job at it.



“Respecting
my Aboriginal
culture makes
a world of
difference when
it comes to my
health care.”



WOMEN'S COLLEGE HOSPITAL

How we're responding

at Women's College Hospital.

The breadth and depth of information, insight and ideas shared by these remarkable 1000 women are helping us create a hospital that is even more responsive to women's needs, circumstances and realities than we have always been.

The findings have been invaluable in telling us what we are doing right. They have been equally essential for identifying gaps that need to be addressed. This section provides a very brief overview of just some of our thinking when it comes to building the hospital of the future.

For Ontario's only ambulatory hospital dedicated to women's health, this is just the beginning.

Create a hospital that keeps women out of hospital

There is a new health reality out there.

Women's health today goes far beyond reproduction. Now, women are living longer than ever before, but many are doing so with a complex array of diseases and conditions – like cancers, diabetes, heart disease, arthritis and mental health issues – that need ongoing support and care, not in-patient hospitalization.

That means women need prevention, education and disease management strategies and tools that they can use to manage their own health – at home, while they're living their everyday lives. Programs like the Women's Cardiovascular Health Initiative do exactly that. As Canada's only cardiac prevention and rehabilitation program designed exclusively for women, it helps women at risk of heart disease and teaches those who already have it how to manage this chronic disease.

Then there is the After Cancer Treatment Transitional (ACTT) Care Clinic, Canada's first program of its kind developed by Women's College Hospital and Princess Margaret Hospital. It treats the unique health-care needs of cancer survivors – physical, psychological and social – to keep them out of hospital.

Programs like these empower women to take an active and leading role in their own health. They enable women to remain at home, where most say they want to be. And they promote linkages with community-based programs, where women can access care and other health resources.

There are opportunities for so many more programs of this kind. For instance, Women's College is now looking to address the pre- and postnatal care needs of specialized populations, such as Aboriginal women. Our surgery department is working to reduce length of stay for breast reconstruction patients by instituting new guidelines and procedures in hospital care and preparation. We are developing a new and fully integrated approach to sport care with a major focus on women. And, our chief of medicine Dr. Gillian Hawker, is heading a task force to develop the ambulatory care capacity needed for new models of care and education for the department of medicine, University of Toronto.

Women want a hospital that is focused on wellness, not illness.

Build a state-of-the-art facility based on what women expect from a hospital

The message came loud and clear. Women want a hospital that inspires health, healing and community. That is focused on wellness, not illness. That represents all women, and all of their distinct needs.

We are delivering. Our new, state-of-the-art facility will be more than a hospital. It will be a beacon for women's health.

In fact, our new 600,000-square-ft. building will be a hospital designed like no other. It will embody and express the very hallmarks of Women's College Hospital – leading-edge care and unparalleled caring built on the inextricable link between clinical care research and education.

In the lobby, volunteers at a hotel-like reception desk will welcome visitors immediately and check their names on discreet computer screens to ensure privacy. Light pouring through glass will create a space that is soothing and uplifting. Curved walls will promote calm and comfort. Different seating arrangements throughout the main floor will be varied to meet all sorts of needs. Individual chairs, well removed from the fray, will allow for contemplative time. Groupings of seats will enable families and friends to engage in private conversation. Kids' areas – with size-appropriate tables and chairs – will be available on every floor. A café with diverse food options will contribute to the hive of activity that will pulsate throughout.

Off the lobby will be a spiritual room with a labyrinth in its centre. Its walls will be imprinted with massive images of textured leaves, just a small way of bringing nature in. Spaces throughout the lobby will be available for public art, events, storytelling and cultural displays. A massive wall, one of the major focal points, will incorporate images of diversity.

Each of the floors will be 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, centres and surgical suites will combine clinical care, research and education to ensure that patients are well-supported to manage their own health. Equipment monitors and private exam rooms will be as easily viewed by patients as by physicians so that patients can play an integral role in their own health. A supervised and enclosed child care space will be available in the Women’s Mental Health Program, so that patients can get the care they need without worrying unnecessarily.

Accessibility is a major priority at Women’s College. So our exam rooms will have ample room for interpreters and cultural translators. Barrier-free washrooms and change rooms will be easily accessible. Handrails will be evident throughout. Exam tables will be adjustable for patients in wheelchairs. Light switches will be within reach of everyone.

Privacy is no less important. Nature-inspired barriers between desks will allow for private conversations between patient and staff. Self check-in kiosks will enable patients to register for appointments without being overheard. A privacy/patient relations officer will be situated next door to the spiritual room, readily available to discuss patient concerns.

Safety is also an imperative. Well-disguised cameras will be placed throughout the hospital to ensure patient protection. There will be no isolated spaces and there will be clear sightlines for staff. There will be visual supervision of elevators and entrances. And importantly, destinations will be easily and quickly reachable with clearly marked signage, and staff and volunteers who will help people get where they need to go.

Our new hospital will be a wonderful combination of whimsy and functionality, of warmth and best practice, of vitality and cutting-edge care. Perhaps exemplifying this best will be a unique architectural construction at the centre of the facility – a pink glass cube that will be home to community and professional gatherings. This structure will provide a sense of openness and transparency on the one hand, and strength and certainty on the other. Very much like the women it will serve.

Bright. Soothing. Bustling. Energizing. A hospital that makes people feel calm and cared for, confident and empowered.

Women’s College Hospital – 2015.

When it comes to women’s health, start by recognizing they’re not men

Sounds obvious. But traditionally, most medical research has been conducted on men and findings extrapolated to women. Yet it’s well-known today that symptoms, treatments, diagnoses and prevention strategies are simply not the same for women and men.

Eight-five per cent of women believe women’s medical issues must be in the foreground of the institution’s research. At the Women’s College Research Institute, they are.

WCRI is one of the few research institutes worldwide – and the only one at a Canadian hospital – devoted to women’s health. Our scientists ask questions that are unique to women’s lives. Why do too few women with

Our scientists ask questions that are unique to women’s lives.

diabetes breastfeed? Why aren't women having joint replacement surgery as often as men – even though they are three times more likely to need it? Why are lower-income women more apt to die from diabetes than their wealthier counterparts? How can older women manage multiple medications more safely? How can women with HIV who want to have families find the support and care they need? How do poverty, violence and discrimination affect women's health and access to care?

Our research is dedicated to understanding women's unique health needs at every stage of their lives and to exploring their complex health needs in the context of their lives.

Yet it's not enough. We need to know more. More about why conditions – like depression or multiple sclerosis – affect women more frequently than men. More about how conditions – like arthritis or heart disease – affect women differently than men. More about how those conditions impact women at all stages of their lives.

Create cutting-edge programs that respond to women's needs

Women made clear to us what they want most. Programs that are “one-stop.” Programs that put women at the centre of their own health. Programs that treat women throughout their lives. Programs that are convenient and accessible. Programs that, at their core, address the mind as well as body. And above all, programs that are based on leading-edge technology and best practice.

Canada's first-ever Multidisciplinary Osteoporosis Program is a case in point. It's a one-stop approach to care for women who want to slow down the progress of the disease, and for those who want to reduce their chances of developing it. It takes into account the priorities, needs and choices of each patient and offers them access to a full team of specially trained professionals all at the same time. Physicians, pharmacists, physical therapists, occupational therapists, dietitians and clinical nurse specialists, along with the patient, collaboratively develop a personalized program. In other words, the program exemplifies an interprofessional model of care that puts the patient at the centre, respects her treatment decisions, and provides choice. Our renowned Bay Centre for Birth Control also has one-stop care, and invites all women with or without health cards.

Then there is our diabetes program. It's the only one in Canada that prevents and treats diabetes at every stage of a woman's life. That might mean specialized treatment for pregnant women with Type 1 diabetes. Or education for women with gestational diabetes, because the statistics tell the story: almost 20 per cent of women who get diabetes while they're pregnant will go on to develop Type 2 diabetes. And we have a Mid-Life Program that helps women with Type 2 diabetes manage the disease as their bodies change. Now we're developing a diabetes prevention program for women with polycystic ovarian syndrome.

We're also increasingly focusing on convenience. In order to address our Trauma Therapy Program wait list, for instance, we established an orientation meeting for new referrals. An interdisciplinary therapist team delivers a psycho-educational presentation about trauma therapy and helps clients determine their readiness for the program based on past therapy experiences, support and stability. Information about community resources is also provided so that clients can reach out to other support systems while on the wait list. This initiative is proving essential for helping women determine if Trauma Therapy is right for them, and in preventing time wasted if it isn't.

Understanding the psychological aspect of medical conditions is another priority. That's why a team of psychiatrists and social workers treat women living in the community – women who have diabetes, HIV, endocrinological disorders, chronic pain conditions and chronic illnesses. Now we're looking at web-based support groups to address the mental health needs of these women.

While programs like these have proven integral to helping women live healthier and more independent lives, they are no by means available enough. Our next step must be to disseminate findings across the province so all women can benefit.

And, teaching the next generation of health-care providers is no less essential. So we are establishing, in partnership with the University of Toronto, Canada's first Centre for Ambulatory Care Education. While most health care happens in ambulatory settings, students are now primarily trained in in-patient hospitals. No longer. Providers will now learn how to deliver care in new ways – where and how patients need it most.

Deliver an entirely new model of care

The numbers bear it out. Almost 80 per cent of Ontarians over age 45 have at least one chronic illness. Nearly three-quarters of women over the age of 60 have at least one chronic condition, and nearly half are reporting two or more. And younger women are not exempt. Arthritis and rheumatism, cancers and asthma, depression and migraine, diabetes and addictions are increasingly affecting them – in major numbers.

Chronic conditions are increasing at unprecedented rates. What's more, women are far more likely to have chronic conditions and more likely to have multiple conditions than men.

No doubt traditional hospital care is still needed. But it is clearly not the best way to address many of the challenges associated with a changing health-care reality in a sustainable way. Because the fact is most care happens in the community.

Since 2006, Women's College has been delivering an entirely new model of care, one aimed at preventing and managing diseases so that patients can live healthier and more independent lives – without in-patient hospitalization.

This ambulatory model of care is working and it's giving women what they want from their health-care services: convenient treatment at home, in their communities, and in the context of their lives. So we provide ongoing phone consultations for our patients. And our Telehealth video conferencing program provides medical consultation to patients outside of Toronto who need our Multidisciplinary Osteoporosis Program.

We also work in partnership with community organizations to deliver services. For example at Women's Health in Women's Hands (WHIWH), we place a senior resident in psychiatry (under the supervision of our own staff psychiatrist) at the organization to provide direct patient care, case consultation, and education to centre staff. As a result, WHIWH mental health expenditures have decreased dramatically and the need to send patients to psychiatric emergency services has been virtually eliminated.

Ambulatory care reaches into our communities and focuses on prevention, healthy living and survivorship – as much as it does on medical and surgical intervention. It adapts to the needs of marginalized communities and those who don't have equal access to care. It integrates the breadth of health resources currently available – hospitals, community agencies, family health-care centres, home care providers and long-term care facilities. It is accessible and interactive.

Worldwide, models of ambulatory have a long way to go, and we're working on it every day. Our scientists are developing evidence-based research that pinpoints the qualities of successful ambulatory programs so that they can be implemented in other centres. They are also working closely with our clinical colleagues to generate ideas that focus on improvements to programs and service delivery.

This ambulatory model of care is working and it's giving women what they want.

Make inclusion, responsiveness and economic equity centrepieces of care

The findings are clear: all women want care that is responsive to and that respects individual identities, cultures and social circumstances and that is non-judgemental.

That comes down to forging a culture and climate of equity that is core to who we are.

Equity at Women's College Hospital is an abiding priority. So it's no wonder then that we recently won the Diversity in Governance Award from the Maytree Foundation and the Toronto City Summit Alliance.

Our Equity Vision guides everything we do. In order to meet the needs of lesbian and queer women, for instance, we have dedicated clinics at our Bay Centre for Birth Control to ensure privacy and confidentiality. And we've recently launched an awareness campaign in conjunction with the Queer Women's Health Initiative to create a shift in consciousness around the importance of annual Pap tests for women who have sex with women, and trans men with a cervix.

For those women who are uninsured and without identification (often due to homelessness), we're heading an initiative to establish standard protocols for ourselves that can influence all hospitals in the GTA so that uninsured and undocumented women can access the care they need. We've just developed the first-ever national HIV pregnancy planning guidelines so that women with HIV can have families safely. And we are home to the first hospital-based Sexual Assault and Domestic Violence Care Centre in Ontario. It offers services in over nine languages.

For women who are victims of domestic violence, we've created the first online program to educate emergency health-care providers – often the first point of intervention – about the signs of abuse. So they treat not just the physical wounds, but the emotional ones as well. We've adapted the program for family physicians so they can identify potential perpetrators of abuse based on key risk factors. We've recently created the RBC Learning Centre for Nursing. A key component of its curriculum is education about care that is sensitive to and knowledgeable about the beliefs, values and social issues facing our diverse patient population. And, we're now building a specialty clinic in ethno/cultural dermatology.

In research, world-renowned scientist Dr. Steven Narod looks to determine whether risk of inherited breast and ovarian cancers is more prevalent in certain sub-populations – and what can be done about it. He's giving hope to people around the world by establishing genetic testing centres in Poland, Pakistan, Philippines, Brazil and Cuba. He's also conducted the largest-ever study on Ashkenazi Jewish women to determine if their likelihood of inheriting breast and ovarian cancers is greater than the general population.

Annual patient satisfaction surveys tell us we're doing well. Nearly 95 per cent of patients rated our overall quality of care in the top categories. As importantly, 91 per cent of respondents said they were treated with dignity and respect. Over 80 per cent said the care they received paid great attention to individual family needs and situations. A full 95 per cent said their health care met personal, cultural and spiritual needs. Nearly all respondents agreed that health-care providers talked in lay language.

It's a good start. But there is so much more to be done. We need evidence-based data about what works and what doesn't when it comes to equitable practices. We need more staff education (in fact, based on the findings of *A Thousand Voices for Women's Health*, we are implementing education and awareness programs across the organization to ensure that our services and providers deliver culturally competent care). We need more educational materials in more languages, and we need them to meet both the language and cultural needs of diverse populations. We need human resource initiatives that ensure staff adequately reflect our patient composition. And we need to partner with more community-based organizations so that we can learn from their expertise and collaboratively care for women from diverse backgrounds.

If you want to tell us what you expect
when it comes to women's health care

visit www.womenshealthmatters.ca/1000women

A THOUSAND VOICES
FOR WOMEN'S HEALTH

A PIONEERING STUDY



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