



FemTechnology

Creating a Vision of Women-Centric Cancer Care (WCCC)

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Discussion Paper

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Table of Contents

<u>Table of Contents</u>	3
<u>Abstract</u>	4
<u>Definitions</u>	5
<u>I. Background</u>	6
<u>II. A Call to Action from the WCCC Workshop Participants</u>	8
<u>III. A Working Definition of Women-Centric Cancer Care (WCCC)</u>	8
<u>IV. The Cancer Experience for Women</u>	9
<u>V. The Core Steps of a Woman's Cancer Experience</u>	10
<u>VI. Commitment Statement and Call to Action to Deliver WCCC</u>	12
<u>VII. Stakeholder Actions and Advocacy Throughout a Woman's Cancer Experience</u>	12
<u>A. Caregivers</u>	12
<u>B. Researchers</u>	14
<u>C. Healthcare Providers</u>	16
<u>D. Innovators</u>	18
<u>E. Insurance Payers, Employers and Policymakers</u>	21
<u>Appendix 1: The Expanded WCCC Experience</u>	25
<u>Appendix 2: "How To Guide" for Each Actor</u>	28
<u>A. Caregivers</u>	28
<u>B. Researchers</u>	30
<u>C. Healthcare Providers</u>	33
<u>D. Innovators</u>	36
<u>E. Insurance Payers, Employers and Policymakers</u>	38
<u>Appendix 3: #MyStoryforChange: Her Lived Cancer Experience</u>	42

Abstract

The FemTechnology Summit focused on creating equitable and women-centric healthcare, convening a diverse group of stakeholders to address the sex and gender gap in healthcare. These included leaders from various sectors including women living with or surviving cancer, caregivers, healthcare providers, researchers, VCs, start-up founders, and other innovators.

Examination of cancer care data unveiled disparities in the experiences of women, shedding light on the urgent need for Women-Centric Cancer Care (WCCC). While summit stakeholders affirmed that patient-centric care leads to better outcomes, it was recognized that a woman's access to such care is often limited. In response, we are advocating for WCCC to improve the healthcare system to better meet the needs of women facing cancer.

WCCC focuses on the unique needs of women in cancer treatment and care and is a concrete step towards the call from the Lancet Commission on Women, Power and Cancer to advance a more women-centric approach to cancer. It also aligns with recent appeals to "Close the Gender Health Gap" and "Redesign Healthcare with Women in Mind" emanating from the World Economic Forum (WEF) Annual Meeting in January 2024.¹

We are calling on all healthcare community members to join this effort to provide comprehensive support for women with cancer, addressing their physical, social, and mental well-being needs. We believe that cooperation across different sectors is crucial to enhancing the overall cancer care experience for women. Through this collaborative effort, we aim to empower women to make informed decisions and to receive equitable access to cancer prevention and care.

To make WCCC a reality, in this discussion paper we are:

- **Defining WCCC:** Establishing a universally accepted definition.
- **Proposing Stakeholder Roles and Responsibilities:** Outlining the key actions and advocacy needed from each stakeholder throughout a woman's cancer experience, including:

Caregivers	<ul style="list-style-type: none"> ● Provide advocacy and support ● Maintain self-care
Researchers	<ul style="list-style-type: none"> ● Conduct sex- and gender-specific research ● Include women in studies and research leadership
Healthcare Providers	<ul style="list-style-type: none"> ● Tailor treatments and care ● Facilitate informed decisions based on active listening
Innovators	<ul style="list-style-type: none"> ● Develop women-centric solutions ● Engage in collaborative design
Insurance Payers & Employers	<ul style="list-style-type: none"> ● Reassess coverage policies ● Support comprehensive care
Policymakers	<ul style="list-style-type: none"> ● Implement women-centric health policies ● Allocate funds for women's health research

- **Illustrating the WCCC Experience:** Proposing an integrated experience that addresses a woman's needs at each step.
- **Formulating Key Questions:** Providing a "How To Guide" for each stakeholder to improve care and outcomes.

1. <https://www.thelancet.com/commissions/women-power-and-cancer;>
<https://www.mckinsey.com/mhi/our-insights/closing-the-womens-health-gap-a-1-trillion-dollar-opportunity-to-improve-lives-and-economies#/;>
<https://www.kearney.com/industry/health/redesigning-healthcare-with-women-in-mind/open-letter>

Definitions

The concept of gender in women's health has been a subject of discussion. For the necessity of alignment, this discussion paper utilizes the Cleveland Clinic's definition: "Women's health is for anyone who needs it, regardless of their sex at birth".²

Stakeholders across the ecosystem include:

Stakeholders	Groups Included
Caregivers	The families of women living with cancer and other caregivers.
Researchers	Academic researchers, institutes, public and private research organizations, and centers.
Healthcare Providers	Healthcare providers including nurses, nurse practitioners, doctors, pharmacists, and other allied health professionals.
Innovators	Start-up founders, entrepreneurs, small and medium-sized businesses, large pharma, biotech, and medical technology firms, and innovation ecosystem funders like venture capital (VC) firms.
Insurance Payers, Employers, and Policymakers	Groups that determine women's health benefits coverage and funding, including insurance companies, government payers, employers, and policymakers.

2. <https://health.clevelandclinic.org/what-is-womens-health>

I. Background

Cancer care is often considered a non-gendered experience. Yet, upon further examination, significant disparities in cancer care for women are evident. During the FemTechnology Summit in Basel, Switzerland, a cross-sector group assembled to consider emerging evidence of women's care gaps and the actions required to create a women-centric cancer care (WCCC) approach to bridge such gaps.

Research preceding the summit from the Lancet Commission on Women and Cancer in 2020 highlighted disparities in healthcare experiences between men and women.³ For example, women are 34% more likely to experience severe side effects from cancer treatments than men.⁴ Additionally, studies reveal a striking difference in the care focus provided to men and women. For instance, in a high-volume cancer center, 9 of 10 men undergoing brachytherapy for prostate cancer were asked about their sexual health, compared with 1 of 10 women having brachytherapy for cervical cancer.⁵

The group acknowledged that patient-centric care results in better outcomes and that women are less likely to receive tailored care. The group considered, debated, and confirmed that cancer treatment often fails to take into account the needs of women. A consensus arose that there is both an unmet need and opportunity for WCCC. The group agreed to act jointly, as a healthcare ecosystem, to shape the global understanding of what WCCC means and how it can be delivered to better serve women.

The broader societal impact of cancer on women was also considered, particularly their role as caregivers and the consequences for their families and children when a mother dies of cancer. The group confirmed a commitment to address questions related to social inequality, cancer risk, and women's status in society and a need for a gendered approach.

In the spirit of growing momentum to develop national Women's Health strategies and policies to enable WCCC, the group sought to create a clear, universally accepted definition and a vision for implementing and measuring WCCC in healthcare systems and private sector product development. The group continues to advocate for WCCC by identifying core actions that lead us toward a renewed health ecosystem that considers and improves the women's cancer care experience from pre-diagnosis through survivorship.

Also, at the FemTechnology Summit in Basel, a related workshop championed by Kearney focused on "Redesigning Healthcare with Women in Mind," leading to an open letter presented at the World Economic Forum (WEF) Annual Meeting in January 2024. The open letter urges stakeholders across the healthcare ecosystem to address gender inequalities and work towards a more equitable future in women's health.⁶ This discussion paper on WCCC is a significant step in the right direction. It outlines a vision for transforming cancer care for women and identifies key stakeholders needed to turn this vision into reality.

Further research that has emerged since the FemTechnology Summit reveals the enormous disparity women face and strengthens the call to action for advancing and investing in WCCC across healthcare systems globally:

3. [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)31479-3/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)31479-3/fulltext)

4. <https://www.cancer.gov/news-events/cancer-currents-blog/2022/cancer-treatment-women-severe-side-effects>

5. <https://www.astro.org/News-and-Publications/News-and-Media-Center/News-Releases/2022/Sexual-side-effects-of-cancer-treatment-often-unad>

6. <https://www.kearney.com/industry/health/redesigning-healthcare-with-women-in-mind/open-letter>

- The Lancet Commission on Women, Power, and Cancer report, released in September 2023, highlights that 2.3 million women die prematurely from cancer each year. The large majority of the mortality occurs in low and middle-income countries. Primary prevention and early detection/screening strategies could avert 1.5 million of these deaths. The additional 800,000 deaths could be prevented if all women everywhere could access optimal cancer care. The report also underscores that "patriarchy dominates cancer care, research, and policy-making. Those in positions of power decide what is prioritised, funded, and studied". This research reinforces the need for a women-centric approach to cancer and issues a call to action for all stakeholders to be a part of making this change.⁷
- The Economist and the APAC Women's Cancers Coalition report, released in August 2023, illuminates the case for investing in women's cancers in Asia-Pacific, noting that in 2020, almost half of all breast cancer in the world was in Asia (45%), and Asia represented 58% of all cervical cancer. The report advocates that "services and programs should be patient-centric and tailored to needs of affected populations in different settings." It also advocates for "considering integrated, holistic approaches to tackle resource and capacity challenges," bolstering the call for a women-centric, integrated, and holistic approach.⁸
- The WEF and McKinsey Health Institute report "Closing the Women's Health Gap: A \$1 Trillion Opportunity to Improve Lives and Economies," released in January 2024, outlines how addressing the women's health gap could significantly reduce women's time in poor health by nearly two-thirds, amounting to over 500 healthier days in a woman's life. The report emphasizes that 34% of the women's health gap is due to inadequate care delivery. By providing sex- and gender-specific healthcare, the global burden of women's health issues could be decreased by 25 million DALYs annually, equating to an average of 2.5 healthier days per woman each year.⁹
- "Hiding in Plain Sight: The Healthcare Gender Toll" by Deloitte, released in September 2023, examines the growing gender disparities in out-of-pocket healthcare costs in the United States. The report reveals that employed women pay an estimated \$15 billion more per year for healthcare compared to employed men, exacerbating the gender wage disparity. Key factors cited as driving the higher out-of-pocket costs for women related to cancer screening, including gynecological exams and the notably high costs associated with breast cancer imaging.¹⁰
- The Bill & Melinda Gates Foundation and National Institutes of Health (NIH) "Women's Health Innovation Opportunity Map," released in October 2023, identifies high-value opportunities to advance women's health R&D, including in data generation and analysis, research design, policy, and training. Some of the areas highlighted relating to WCCC include evaluating sex- and gender-related differences in outcomes and responses to cancer medications (e.g., chemoprevention, chemotherapy, immunotherapy, and targeted therapy) to inform the development of prevention strategies, screening and diagnostic tools, and treatments for lung, colorectal, and gynecological cancers.¹¹

As the mounting research underscores, there is a clear and urgent need for WCCC. In the face of stark disparities in care, it is our collective mission to ensure that WCCC becomes a standard part of our healthcare systems and also a beacon of change, guiding us towards a more equitable and effective approach to cancer care that recognizes and addresses the unique challenges faced by women.

7. <https://www.thelancet.com/commissions/women-power-and-cancer>

8. <https://impact.economist.com/perspectives/health/impact-and-opportunity-case-investing-womens-cancers-asia-pacific>

9. <https://www.mckinsey.com/mhi/our-insights/closing-the-womens-health-gap-a-1-trillion-dollar-opportunity-to-improve-lives-and-economies>

10. <https://www2.deloitte.com/content/dam/Deloitte/us/Documents/life-sciences-health-care/us-lshc-health-gender-gap.pdf>

11. https://orwh.od.nih.gov/sites/orwh/files/docs/womens-health-rnd-opportunity-map_2023_508.pdf

II. A Call to Action from the WCCC Workshop Participants

The group is committed to driving healthcare systems and women-focused entrepreneurial ventures to make this vision of WCCC a reality. Our commitment is to collaborate within and among each stakeholder's domain in cancer care in the spirit of driving more effective outcomes and more fulfilling lives for women living with cancer and women survivors of cancer. We envision leveraging this discussion paper to architect better risk assessment, prevention, diagnostic, treatment, product design, service design, research, clinical practice, and advocacy for healthcare financing for WCCC.

III. A Working Definition of Women-Centric Cancer Care (WCCC)

In 2022, over 130 stakeholders were surveyed on the need for WCCC and what it should encompass. The respondents included women living with cancer, caregivers, healthcare providers, policymakers, and payers from seven countries across Africa, Europe, the Middle East, North America, and South America. The insights shared highlighted a clear need and current gap, with consistent themes emerging about how women can effectively experience WCCC. Survey findings, workshop feedback, and subsequent discussions led to the development of the following definition:

Women-Centric Cancer Care improves the lives and health experiences of **all women**, regardless of where they live, by **empowering them to make informed decisions** and **providing them with evidence-based prevention and integrated healthcare** that is **innovative, accessible, affordable, equitable, tailored, and holistically delivered.**

To make this definition a reality, every stakeholder in the healthcare ecosystem must work toward comprehensive and inclusive care for women. Women-centric healthcare means enabling women to express their health needs, desires, and goals confidently. It also means ensuring women are heard, believed, respected, and supported by a dedicated healthcare team. Quick and easy access to tailored cancer prevention, screening, diagnosis, treatment, rehabilitation, survivorship support, and, if necessary, palliative care is crucial. Examples include streamlined screening processes and faster, more convenient therapies.

Additionally, as healthcare stakeholders do not operate in isolation, women require coordinated, personalized support throughout their journey, addressing their physical and psychological needs and daily life challenges. Cross-sectoral collaboration is essential for holistic care that aligns with broader personal needs, such as fertility consultations before treatment, resources for possible menopause transition due to treatment, and emotional support during the cancer experience.

IV. The Cancer Experience for Women

Understanding the baseline of a woman's cancer experience is fundamental to improving each step. The group mapped out the essential steps of this experience, the actions needed from specific healthcare system stakeholders along the path, and where enhanced cross-functional coordination is required.

Living with cancer is a complex and challenging experience for women, involving multiple stages and steps. Power imbalances, a tendency to prioritize others' needs over her own, and navigating a healthcare system not fully tailored to her unique needs exacerbate a woman's challenges.

The first step begins with listening to and empowering women to take behavioral preventive measures, including tobacco control, physical activity, eating a healthy diet, reducing alcohol consumption, getting vaccinated against HPV/HBV, being aware of early signs and symptoms of cancer, and getting screened based on their age and risk factors. Many women face challenges knowing their risk, getting screened, or seeking diagnosis and are dismissed due to age, race, socioeconomic status, or other intersectional factors. Barriers to prevention, screening, and diagnosis must be removed to support women.

Various stakeholders support a woman living with cancer, including medical professionals who assist in diagnosis and treatment and those providing care, support, and guidance. In addition, researchers and innovators create products and services to aid her at each step. Policymakers, payers, and employers determine whether she can access the healthcare she needs and at what associated costs.



Listening to Women: Stories for Change

The key to understanding and improving her experience is to listen to her lived story and tailor the support to her needs. No one can share the example better of the lived experience of a woman with cancer than the woman herself. Throughout this paper, we share the experiences of many women living with cancer and their caregivers through their own words that were submitted to F. Hoffmann-La Roche's #MyStoryForChange campaign (original text in [teal](#), translation in [white](#)).¹² Below, we highlight a woman's story and her hope for better support for women in their experience:

"El apoyo en el viaje del paciente es fundamental para transitarlo de la mejor forma. Lo constaté luego de mi diagnóstico de Cáncer de Mama. Fue un periodo en el que tuve vivir diferentes etapas de largas esperas e incertidumbre, donde hubiera sido muy importante contar con un acompañamiento en la institución para ayudarme a transitar los distintos momentos y dar respuesta a muchas interrogantes que me generaban ansiedad, angustia. Ojalá más mujeres cada día accedan a un diagnóstico temprano y puedan ser acompañadas en este camino."

"Support in the patient's journey is essential to make the best of it. I realised this after my diagnosis of breast cancer. It was a period in which I had to go through different stages of long waiting and uncertainty, where it would have been very important to have support in the institution to help me through the different moments and answer many questions that caused me anxiety and anguish. I hope that every day more women have access to an early diagnosis and can be accompanied along this path."

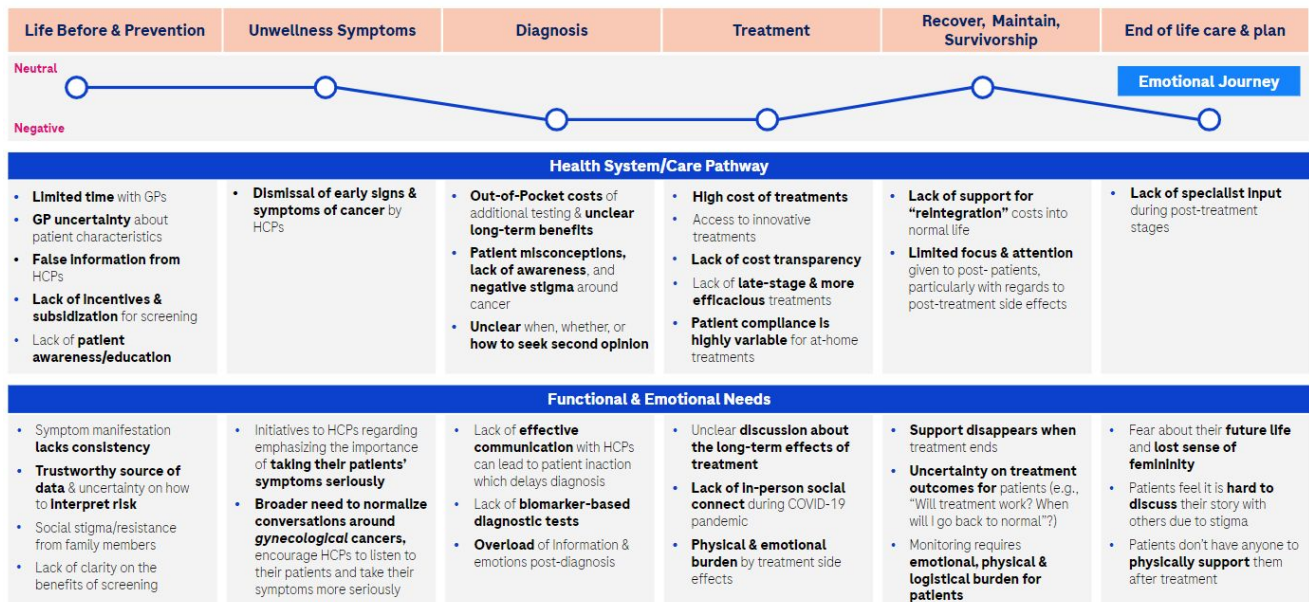
V. The Core Steps of a Woman's Cancer Experience

The graphic below presents a high-level base case of how a woman's experience flows from pre-diagnosis, prevention, diagnosis, treatment selection, and treatment to survivorship or end-of-life care.

A woman makes decisions along her journey typically based on insights from her healthcare provider(s), such as the type and stage of cancer, potential side effects, personal preferences, treatment goals, and aspirations for survivorship. Critical factors could include preserving fertility, quality of life, emotional well-being, support for possible menopause transition, and sexual health. Women are also increasingly turning to online sources and patient support groups for information to empower herself in decision making. Depending on where a woman lives and the breadth of universal health coverage available, another important factor in her decision-making is a clear understanding of what is financially accessible to her during and after her treatment experience. Keeping her preferences in constant consideration helps maintain her self-determination.

What dictates a fulfilling life for every woman living with cancer is a personal and often cultural collection of wants, needs, beliefs, and fears. Being clear about these preferences has implications in the treatment selection, follow-up, monitoring, and survivorship or end-of-life care. Women and their caregivers have expressed that listening is vital to honoring a woman's goals. [Appendix 1](#) expands on creating an integrated WCCC experience, shifting from the current paradigm to one that addresses a woman's needs at each step.

The Women's Cancer Experience: Pain Points and Concerns





Listening to Women: Stories for Change

Many women living with cancer and survivors are potent advocates for policy change. The experience of surviving cancer can bolster a woman's interest in raising her voice and advocating for increased funding, more equitable access, and better treatment options and guidelines for themselves and others as indicated by the following stories.¹³

The following quote from a woman living with cancer highlights the critical need for new screening guidelines based on her cancer diagnostic experience:

"It's time to lower the age of breast screening. Black women don't fall into the standardized age of 50 years old to begin breast screening. We are presenting with the disease at far younger ages (under 50), more aggressive subtypes and later stages. I was denied a mammogram at the age 40 and at 42 when I requested to begin my breast screening. The reason.. I wasn't 50 yet. Two years later at the age of 44, I discovered a lump and received a diagnosis of triple negative breast cancer. Thankfully I am here to tell my story and advocate."

Appropriate communication with women around cancer risk and the importance of screening is also vital, as emphasized by the following quote:

"I lost a maternal aunt to cervical cancer that was discovered late. Because I was around 14 years old, it did not occur to me until my 20s that she was very young when she died - around 32 years old. I also did not think that she would die. I did my first Pap in my early 20s, and I am now strict about doing so regularly, or (preferably) a HPV test. The reality is that still in Africa thousands of women of all ages die from this. Education about screening tends to end in urban areas or online, and many are not familiar with the latter."

The following personal account underscores the challenges that women can face in having their healthcare preferences acknowledged and respected:

"I was diagnosed with breast cancer and chose to have a double mastectomy, even though it was caught early. I had pre-cancerous formations on the unaffected side and felt it was a matter of time before I faced this battle again. Several providers questioned my "radical" decision and asked if my husband agreed with my choice. I told them it was my choice because it was my body and he knew I would make the choice that was right for me. There needs to be greater sensitivity from providers around bodily autonomy, regardless of one's marital status."

VI. Commitment Statement and Call to Action to Deliver WCCC

We, as leaders from across the healthcare system - representing women living with or surviving cancer, caregivers, healthcare providers, researchers, innovators, employers, insurance payers, and policymakers - pledge to advocate and collaborate within and across our fields to prioritize the needs of women living with cancer. We recognize that healthcare delivery for women relies on collective action rather than individual efforts. We commit to a shared focus and dedication to advancing Women-Centric Cancer Care (WCCC) to improve the lives and health experiences of women by empowering them to make educated decisions and delivering equitable and tailored cancer prevention, diagnosis, and care.

VII. Stakeholder Actions and Advocacy Throughout a Woman's Cancer Experience

Cross-sectoral collaboration and coordination throughout a woman's cancer experience is essential. Strengthening such collaboration requires all health system stakeholders to understand their roles clearly. Accordingly, this discussion paper outlines key questions and specific actions for each stakeholder to enable our shared vision of WCCC.

This cross-functional group of stakeholders has taken the first step to outline actions and our commitment in each of these domains:

- How women living with cancer and survivors interact with or are impacted by each stakeholder along her cancer experience.
- How ensuring WCCC is delivered can transform each stakeholder's role throughout the experience of women living with cancer and survivors.
- Core questions and actions each stakeholder must ask to enable WCCC to become a reality.

A. Caregivers

Caregivers are integral to WCCC, providing crucial emotional support, aiding decision-making, and ensuring the overall well-being of women living with cancer. This support network, including professional caregivers, spouses/partners, and family members, contributes significantly to the comfort and resilience of a woman living with cancer. Key roles for caregivers involve comprehensive support, effective communication facilitation, assistance with daily living, pain management decisions, advocacy for the needs of a woman living with cancer, fostering psychological and emotional well-being, and supporting the needs of the family so the woman can prioritize her care.

Caregivers may also play a key role in monitoring the condition of a woman living with cancer, encouraging treatment compliance, providing access to resources, assist in end-of-life care care decisions, considering cultural sensitivity, upholding her dignity and comfort, advocating for medical needs, ensuring continuity of care, and assisting in legal and financial decisions. Caregivers maintaining their self-care is also vital to prevent burnout.

Core questions are suggested to guide caregivers through these responsibilities. These include understanding family medical history, clarifying and understanding the treatment goals of a woman living with cancer, respecting her preferences, assessing emotional coping, identifying practical assistance needed, facilitating communication, supporting nutritional needs, providing social and emotional support, aiding in financial assistance, addressing cultural factors, guiding survivorship, contributing to community awareness and importantly, promoting caregiver self-care

Addressing these questions empowers caregivers to deliver more effective and compassionate care tailored to the unique needs and preferences of women living with cancer throughout their experience. Appendix 2 includes a [“How To Guide”](#) for caregivers to help make WCCC a reality, including key roles, questions to ask, and actions to take.



Caregivers' Perspectives

Since caregivers have a front-row seat and access to the woman living with cancer during her experience, they will often have detailed knowledge of her progress and symptoms and can be advocates for treatment intervention. The following are stories from two caregivers about their mother's cancer experience:¹⁴

“Mi madre empezó a tener sangrados muy fuertes, cólicos e inflamación constante, iba una y otra vez al doctor y siempre le decían lo mismo “colitis” nunca le hicieron más estudios a pesar que ella los pedía directamente decían que estaba loca, fue con un ginecólogo especialista y le dijo que tenía cáncer cérvico uterino en tercera etapa, que estaba a nada de ser terminal, mi madre murió después de 5 años de lucha y me preguntó que hubiera pasado si una de esas tantas veces le hubieran hecho un estudio.”

“My mother began to have very heavy bleeding, cramps and constant inflammation, she went to the doctor again and again and they always told her the same thing “colitis” they never did any more tests even though she asked for them they said she was crazy, she went to a specialist gynecologist and he told her she had stage 3 cervical uterine cancer, that she was close to being terminal, my mother died after 5 years of struggle and I wondered what would have happened if one of those many times they had done a test.”

“Vou contar a historia da minha mãe! Ela começou a sentir dificuldade de respirar, cansaço e dores nas costas, procuramos o médico, recebemos o diagnostico de uma bronquite e começamos o tratamento, mais em dois meses ela piorou muito e procuramos outro médico e ele analisando o raio X feito dois meses antes disse que minha mãe tinha uma massa no pulmão de 10 milímetros e precisávamos investigar, quando foi refeito o exame a massa já tinha tomado todo o seu pulmão, ou seja minha mãe tinha um câncer super agressivo e veio a falecer em 2 meses.”

“I will tell you my mother's story! She began to feel difficulty breathing, tiredness, and back pain, we went to the doctor, received a diagnosis of bronchitis and started treatment, but in two months she got much worse and we went to another doctor and he analyzing the X-ray done two months before said that my mother had a mass in her lung of 10 millimeters and we needed to investigate, when the exam was redone the mass had already taken all her lung, that is, my mother had a super aggressive cancer and died in 2 months.”



Caregivers - Key Takeaways:

- **Provide Advocacy and Support:** Act as advocates for the needs and preferences of the women they care for. Offer emotional and practical support in decision-making, daily care routines, and addressing family needs.
- **Maintain Self-Care:** Prioritize self-care to avoid caregiver burnout.

B. Researchers

There is growing recognition that healthcare research traditionally has not adequately considered the needs of women living with cancer, leading to gaps in understanding and treatment. Developing more inclusive and beneficial healthcare strategies for women will require researchers' commitment to rectify this oversight. A critical step is fostering a diverse workforce inclusive of women investigators and scientists in key research leadership roles.

As noted in the Lancet Commission 2023 report, "sex-related biological differences in cancer biology and treatment effects can affect treatment outcomes but remain poorly understood and under-researched."¹⁵ Investigating and understanding women's genetic backgrounds and other sex- and gender-specific differences are essential parts of a personalized, effective, and WCCC approach.

Every stage of research, from pre-clinical through real-world evidence generation, should utilize female subjects, animal models, and women living with cancer to comprehend gender-specific responses and recognize sex as a crucial biological variable. Clinical trial design should also incorporate a comprehensive analysis of the broader ecosystem, considering biological, social, economic, and cultural factors. Also, research and development is still mostly limited to high income countries, and within these countries racial and ethnic minorities in addition to women, are often underrepresented. It is essential to expand clinical and implementation research across diverse demographics including sex, race and ethnicity and also to low and middle income countries; only then will the treatments women need be understood, developed, and delivered.

Understanding women's preferences is vital, as is developing methodologies for measuring potential gender-specific differences in outcomes and health experiences, such as pain and well-being. One mechanism to support the inclusion of women's perspectives is collaborating with advocacy organizations during research and study design to ensure the prioritization of the outcomes women value. Such collaboration also includes involving women in identifying the aspects most meaningful to them, such as side effects, possible tradeoffs, and treatment convenience.

Important examples of how researchers can ensure WCCC is delivered include considering women-specific approaches to researching and treating cancer typically not considered "women's cancers", including lung cancer, colorectal cancer, and beyond. In addition, many gynecological cancers like endometrial and ovarian cancer are historically under-researched and in need of new diagnostic and treatment approaches.

15. <https://www.thelancet.com/commissions/women-power-and-cancer>



Researchers can uncover important learnings by developing sex-specific disease models and reporting results by sex and gender. Research funders can foster such insights by including sex and gender metrics in grant requirements. In addition, integrating behavioral science into research methodologies can address psychosocial aspects of care, ensuring the delivery of holistic, women-centric care.

Key questions researchers can ask to advance WCCC include:

- Is the study population appropriately representative of women?
- What sex or gender-specific biomarkers should be included?
- Has sex been included as a biological variable?¹⁶
- Are appropriate behavioral, psychosocial, and social determinants of health aspects included in the trial design?
- Have women living with or survivors of cancer been involved in the development review process to ensure their input is considered and communication is clear?
- Have consideration been given to intersectional dimensions that could compound sex or gender differences?
- Are there design elements that can be incorporated to enable participation by women?
- What impact will trial design have on the accessibility of the treatment to women?

Appendix 2 includes a ["How To Guide"](#) for researchers to help make WCCC a reality, including key roles, questions to ask, and actions to take.



Researchers' Perspectives

Researchers are at the forefront of developing groundbreaking, women-centric innovations in healthcare, tackling overlooked challenges. Though fraught with uncertainty and risk, their work is vital in pioneering new therapies, diagnostics, digital solutions, devices, and care models. These advancements hold the promise of transforming care for all women, including those living with cancer, by specifically addressing their unique health needs.

The following quotes from contributing authors in the Research sector underscore their dedication and commitment to enhancing women's health. The quotes reflect the ongoing research efforts and highlight the critical need to incorporate sex as a biological variable in scientific studies, ensuring more equitable healthcare outcomes.

"At Magee-Womens Research Institute, we have hundreds of world-class researchers devoted to advancing the health of women across their lifetime - from nine months in utero to 90+ years of health and wellness. Our focus is to improve women's lives by learning more about the various conditions and diseases from which they suffer. We are fighters for more women in clinical trials and more research dedicated to women's health and reproductive biology, and we are changemakers by transforming women's lives to create a better future for us all." - Michael Annichine, CEO of Magee-Womens Research Institute

"Cancer research must evolve beyond focusing solely on Progression-Free Survival (PFS) and Overall Survival (OS) to include sex as a biological variable, ensuring equal efficacy and post-cancer quality of life for both sexes. This involves establishing guidelines for researching sex-specific differences in treatments, side effects, and long-term health impacts, including fertility and sexual health. Investing in preventive measures, earlier diagnostics, and addressing long-term effects predominantly experienced by women, like fatigue and lymphedema, is crucial for a balanced approach to cancer survivorship." - Liliane Brunner Halbach, University of Zurich and Artemis Women's Health Foundation

¹⁶<https://orwh.od.nih.gov/sex-gender/orwh-mission-area-sex-gender-in-research/nih-policy-on-sex-as-biological-variable>



Researchers - Key Takeaways:

- **Conduct Sex- and Gender-Specific Research:** Conduct research that uncovers and addresses differences in cancer biology and treatment relating to sex and gender.
- **Include Women in Studies and Research Leadership:** Ensure clinical trials represent a broad spectrum of women and support women investigators and scientists in key research leadership roles.

C. Healthcare Providers

In the realm of WCCC, healthcare providers play a pivotal role in making crucial decisions tailored to individual needs, diagnosis, stage of cancer, and overall health.

Healthcare providers' key decisions include determining cancer type and stage, assessing treatment options, helping to set treatment goals, deciding on the treatment plan inclusive of clinical trials when relevant, addressing fertility preservation, planning follow-ups, and managing pain. Healthcare providers can also support a woman by ensuring psychological and emotional support is available and provided, addressing the possible transition to menopause due to cancer treatment, suggesting complementary therapies, and discussing end-of-life care if necessary.

Upholding women-centric care involves aligning decisions with the woman's values, preferences, and goals and fostering and empowering shared decision-making. The emotional intelligence of healthcare providers is critical, given the complexity and sensitivity of the cancer experience for women. Healthcare providers should also act as or identify a connector across the multi-disciplinary team, championing communication and coordination among the individuals providing her care. This shared goal ensures she is aware of and connected to all resources and services available to support her care.

A set of core questions is proposed to guide healthcare professionals in designing solutions for women living with cancer. These questions cover medical history, aids for early detection, details about the cancer, available treatments, and gender-specific considerations. The questions also address the woman's preferences, collaboration within the healthcare team, psychological support, assistance for both the woman and her caregivers, technology use, a supportive environment considering social and cultural aspects, and understanding long-term care requirements.

Asking these questions ensures a structured and woman-focused approach throughout the cancer experience, which prioritizes her voice and preferences. By asking the right questions at the right time, the healthcare team can ascertain important insights from a woman living with cancer, including her wishes, concerns, symptoms, and side effects.

Appendix 2 includes a ["How To Guide"](#) for healthcare providers to help make WCCC a reality, including key roles, questions to ask, and actions to take.



Healthcare Providers' Perspectives

Healthcare providers are instrumental in delivering WCCC, transcending traditional medical care by recognizing the myriad of physical, emotional, psychological, and social challenges women face during their cancer journey. The following insights from medical and clinical professionals underscore the importance of this holistic approach, highlighting the need for personalized care, gender-specific research, and active patient involvement in treatment planning:

"Providing holistic, woman-centric care in cancer treatment is essential as it encompasses the full spectrum of challenges women face, including physical, emotional, psychological, and social factors. By attentively listening and responding to a woman's unique needs, we can tailor our care to address not only the disease but also its impact on their overall quality of life. This approach is about empowering each woman, respecting her voice, and supporting her comprehensively, and most effectively, on her journey towards healing." - Mitzi Krockover, MD, Internist and (former) Founding Medical Director, Iris Cantor - UCLA Women's Health Center

"Every individual is different, and more so men and women when it comes to diagnostics and therapy. Large, randomized controlled studies are essential to understand the full scope of these differences. However, these studies should be designed from the outset to address individual variations. Over decades, we've learned the importance of gender-specific research; therefore, there's a pressing need for more female-focused randomized controlled studies. Furthermore, individual differences must be respected as we dive into single individual counseling and advice for care and treatment, especially for female (or male) cancer patients." - Tina Buchholz, MD, Assistant Professor, Obstetrics, Gynecology, Human Genetics, Reproductive Medicine

"Cancer is a long-term journey from diagnosis, which differs from conditions with single-intervention therapies such as in trauma. Clinically, 70% of diagnoses are made from the history the woman brings to the physicians. Excluding patients from the therapy decision-making has shown low adherence to the treatment plans. For example, the 5-year plan of adjuvant hormonal therapy in HR+ breast cancer is more successful if the patient has bought into it and is actively involved in treatment planning. In the last three decades, most cancers diagnosed early are considered 'chronic diseases'. Due to the vital importance of quality of life in chronic disease, the desires of the patient and her definition of quality of life are critical for the healthcare provider to understand and honor." - Paul Chilwesa, MD FCRO, Clinical Oncologist and Global Population Health Impact Leader, Roche



Healthcare Providers - Key Takeaways:

- **Tailor Treatments and Care:** Customize cancer care and treatment plans to address each woman's unique needs.
- **Facilitate Informed Decisions Based on Active Listening:** Listen to, educate, and empower women to make informed choices about their care.

D. Innovators

Innovators play a vital role in shaping products, services, and digital solutions that support women throughout their cancer experience, from diagnosis to survivorship or end-of-life care. Building from personal experience, cancer survivors and caregivers often find purpose in launching businesses to support women living with cancer.

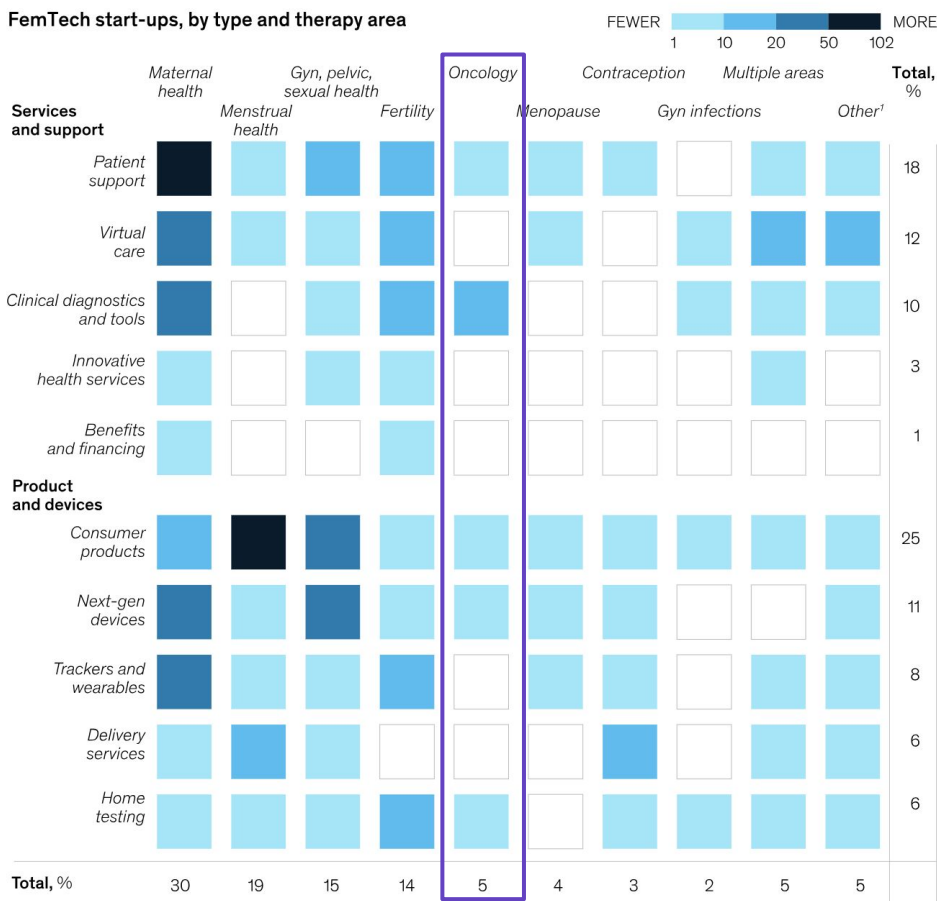
Designing new products and solutions requires a meticulous understanding of women's specific needs and challenges. Cancer survivors or their caregivers often find purpose by applying this lived experience to starting businesses.

This deep understanding is equally crucial for established researchers and pharmaceutical companies. A commitment to patient-centricity throughout the product development process is essential, ensuring maximal value for women, regardless of where they are in their cancer experience.

Critical decisions during product design include determining the product type and purpose, considering the cancer type and stage it targets, and prioritizing user-centric design with input from women living with cancer and caregivers. The first and most important decision is to listen to a woman to garner trust and understand her experience and aspirations.

Research by McKinsey indicates considerable unmet need and white space for innovation by Femtech start-ups in Oncology, as depicted in the chart below:¹⁷

FemTech start-ups are proliferating, but meaningful white space remains.



17. <https://www.mckinsey.com/industries/healthcare/our-insights/the-dawn-of-the-femtech-revolution>

Taking a concept from idea to product delivery requires iterative collaboration with women living with cancer, researchers, healthcare providers, and caregivers. Such approaches assure alignment with medical standards, emphasizing ease of use, comfort, and well-being for women.

To embody a woman-focused approach, innovators need to pose core questions during the design phase, including understanding the specific cancer type, common challenges a woman may face during her experience, psychological and emotional impacts throughout, early detection strategies, remote healthcare options, and supportive community care are crucial. Additional paramount considerations include privacy, accessibility, inclusivity, support for fertility preservation, the transition to menopause, and emotional and psychological well-being.

Innovators must also navigate regulatory compliance, conduct thorough prototyping and testing, plan effective marketing strategies, and offer support resources. Affordability, ethical considerations, and sustainability are key factors, alongside continuous improvement based on user feedback. Finally, product design must empower women through education, ensuring privacy and comfort in healthcare facilities, community-based care, and the family unit. In summary, innovators are essential in delivering WCCC by advancing new products, services, and technologies for each stage of the experience, from cancer prevention to survivorship or end-of-life care. Innovators can also promote women's quality of life during and beyond cancer by designing solutions for the unique experiences of women living with cancer.

Appendix 2 includes a ["How To Guide"](#) for innovators to help make WCCC a reality, including key roles, questions to ask, and actions to take.



Innovators' Perspectives

In the journey to enhance women's cancer care, innovators play a pivotal role in uncovering new opportunities and developing groundbreaking solutions. From improving the quality of life for patients to advancing cancer detection technologies to supporting fertility preservation, the impact of innovation is far-reaching. Let's hear from innovators who are at the forefront of these transformative efforts:

The story of the founding of the startup LebensHeldin in Germany demonstrates a caregiver's experience that led her to create a startup:¹⁸

"Qualvolle Todesfälle in meiner Familie haben mich wachgerüttelt. Krebs ist eine Familienkrankheit - doch keiner spricht darüber, wie groß der Schmerz, Angst und Leid der Angehörigen ist und welche seelischen Narben bleiben. Frauen nach Brustkrebs kämpfen mit ihrem Identitätsverlust, fühlen sich in ihrer Weiblichkeit verletzt, fallen nach der Therapie oft in ein tiefes Loch und fühlen sich allein gelassen. Deshalb habe ich LebensHeldin! e.V. gegründet, um diese Lücke im Gesundheitssystem zu füllen: in jeder Frau steckt eine LebensHeldin!"

"Agonizing deaths in my family have shaken me awake. Cancer is a family disease - but no one talks about how great the pain, fear and suffering of the relatives are and what emotional scars remain. Women after breast cancer struggle with their loss of identity, feel violated in their femininity, often fall into a deep hole after therapy, and feel left alone. That's why I have founded LebensHeldin! e.V. to fill this gap in the healthcare system: in every woman, there is a LebensHeldin!" (translated from German, LebensHeldin means "Heroine of Life" - Silke Linsenmaier, Founder, LebensHeldin



DeepLook Medical was inspired to improve the cancer screening process, giving women a better opportunity for early detection:

"At DeepLook Medical, we are committed to ensuring radiologists and oncologists have the best visual tools to help their patients. Ensuring better visualization of dense tissue, especially breast tissue, which affects 45% of all women globally, is our focus to ensure a suspicious mass isn't missed in screening mammograms. As dense breasts disproportionately affect Black, Asian, and Jewish women, this is also an equity imperative to ensure ALL women have access to the best quality images in breast cancer screening. Enabling the reduction of anxiety also has significant health benefits, knowing that all of your breast tissue was visualized, not only the non-dense areas." - Marissa Fayer, CEO of DeepLook Medical

Levy Health is driven to support access to reproductive healthcare, a topic often not adequately discussed with women facing cancer:

"We at Levy Health are committed to advancing innovation in fertility because many women and couples still lack access to reproductive healthcare. What is particularly disheartening is the low number of women who receive education and access to fertility preservation before undergoing cancer treatment. By observing communities that set a positive example, it is evident that collaboration and impeccable time management could make significant differences here for many affected individuals with relatively minimal medical effort. Innovation does not always have to be about technology; sometimes an open mindset is all that is needed." - Caroline Mitterdorfer, CEO and Founder of Levy Health



Innovators - Key Takeaways:

- **Develop Women-Centric Solutions:** Create products and services focusing on the specific needs of women with cancer.
- **Engage in Collaborative Design:** Involve women living with cancer in the development and design process.

E. Insurance Payers, Employers, and Policymakers

Insurance payers, employers, and policymakers play pivotal roles in shaping the landscape for and access to women's cancer prevention and care. A recent Deloitte publication emphasizes businesses, insurance providers, and policymakers need to reassess benefit coverage to mitigate the higher out-of-pocket burden on female employees.¹⁹

Policymakers at Ministries of Health, the United Nations (UN), and Development Agencies shape healthcare policies crucial for women's cancer care. In 2018, the World Health Organization (WHO) introduced the Cervical Cancer Elimination Initiative, which was adopted in 2020 by the World Health Assembly (WHA). The initiative calls for 90-70-90 targets for:

- Prevention: 90% of girls to be fully vaccinated for HPV by age 15,
- Early detection: 70% of women to be screened using a high-performance test [HPV DNA-based testing] by age 35 and again by age 45, and
- Treatment: 90% of women identified with cervical disease receive treatment.²⁰

In 2021, the WHO introduced the Global Breast Cancer Initiative (GBCI), aiming to reduce breast cancer mortality by 2.5% per year, which over a 20-year period would save 2.5 million lives. The GBCI calls for:

- Early detection: >60% of invasive cancers are stage I or II at diagnosis,
- Timely diagnostics: Diagnostic evaluation, imaging, tissue sampling, and pathology within 60 days, and
- Comprehensive cancer management: >80% of patients undergo multimodality treatment without abandonment.²¹

The WHO's efforts in tackling women's cancers are creating significant momentum in accelerating development and increasing access to equitable cancer prevention, early detection, and treatment for all women, regardless of where they live. Achieving these objectives necessitates strengthening healthcare systems and offers a chance to fund comprehensive, integrated care systems that facilitate WCCC delivery. For example, in 2023, the WHO AFRO launched a pilot project integrating the breast and cervical cancer initiatives and other non-communicable diseases (NCDs), focusing on creating convenience in how women access these critical services.²²

National policymakers set national targets to reduce mortality and morbidity and drive incentives into the healthcare system to improve the quality and outcomes of care. Following these international health priorities and agreed national priorities, they direct resources toward research funding, determine screening and prevention program scope, and enhance access to care, particularly for underserved populations.

In addition, insurance payers and employers make critical decisions regarding financial coverage depth, ranging from diagnostic tests to supportive services. Choices include provider network selection, prior authorization guidelines, and clinical review processes. They determine access to specialized care, clinical trial support, drug formulary, fertility preservation coverage, menopause support, mental well-being services, and palliative care. Moreover, insurance payers, and employers decide on cost-sharing structures and financial assistance options, with the goal of mitigating the hurdles faced by women living with cancer.

19. <https://www2.deloitte.com/content/dam/Deloitte/us/Documents/life-sciences-health-care/us-lshc-health-gender-gap.pdf>

20. <https://www.who.int/news/item/19-08-2020-world-health-assembly-adopts-global-strategy-to-accelerate-cervical-cancer-elimination>

21. <https://www.who.int/initiatives/global-breast-cancer-initiative>,
<https://iris.who.int/bitstream/handle/10665/365784/9789240067134-eng.pdf>

22. <https://www.afro.who.int/countries/cote-divoire/news/three-african-countries-pilot-initiative-boost-cervical-and-breast-cancer-care>

Innovative options like microinsurance have grown in recent years to address insurance gaps, with over 250 million people in emerging markets covered by various microinsurance policies. However, most policies for women focus only on maternal care and there is a significant opportunity to better tailor policies in areas like women's cancer care, including prevention, screening, early diagnosis, and treatment.²³

Collectively, concerted efforts by insurance payers, employers, and policymakers to ensure comprehensive and equitable coverage and access decisions can better support the unique needs of women facing cancer. A holistic strategy to improve women's cancer care outcomes requires a commitment to addressing barriers, promoting prevention and education, supporting treatment and coverage, and advancing research.

Appendix 2 includes a "[How To Guide](#)" for insurance payers, employers, and policymakers to help make WCCC a reality, including key roles, questions to ask, and actions to take.



Insurance Payers, Employers and Policymakers Perspectives

Insurance payers, employers, and policymakers play a vital role in shaping WCCC. Their collaborations and innovative approaches are crucial in providing accessible, comprehensive care for women, early detection, providing affordable and holistic care options, and supporting women throughout the cancer experience. Below are insights from key representatives in these groups:

"UPMC Health Plan, headquartered in Pittsburgh, Pennsylvania, is among the United States fastest-growing health plans and being owned by the University of Pittsburgh Medical Center (UPMC), we are part of an integrated healthcare delivery system committed to providing our members with better health and the peace of mind they deserve. Led by Diane Holder, our President and Chief Executive Officer, our goal is to improve the health of our members, including the many women we serve. We launched a podcast called 'Good Health, Better World,' and in our most recent season we talk about supporting women's health—body and mind—across generations, populations, and stages of life. The series includes topics on providing comprehensive care to women, the complexities of chronic disease in women, prevention as self-care, disparities in diagnosing and treating breast cancer, and new research frontiers in women's health equity." - Ellen Beckjord, Vice President, Population Health and Clinical Optimization, UPMC Health Plan

"Achieving women-centric cancer care (WCCC) requires the joint intersectoral collaboration of governments, academia, non-governmental organizations such as patient organizations, public and private insurance agencies, and the private healthcare sector. Most of the stakeholders are still working in silos, and fragmentation of healthcare is the consequence. It is essential to establish national or regional multi-stakeholder platforms. There is a huge chance to move forward with WCCC principles and values with the overarching goal of reducing suffering and improving the survival and quality of life of the women affected." - Andreas Ullrich, Department of Gynaecology and Gynae Oncology, Charité Universitätsmedizin and former Adviser to the Assistant Director General Noncommunicable Diseases and Mental Health (NMH cluster) with the World Health Organization (WHO) at WHO Headquarters Geneva

23. <https://microinsurancenet.org/resources/resource-13621>, <https://www.rgare.com/knowledge-center/article/closing-the-gender-gap-the-role-of-inclusive-insurance-in-empowering-women-around-the-world>



"Our venture, YuBuntu, tackles female cancers (breast, cervical, and ovarian) for its members through prevention (vaccines, diagnostics, screenings, and education), which drives down incidence rates and catches cancers early. This unlocks affordable insurance coverage at a level that funds some of the latest immunotherapies and innovative treatments. APA Femina Plus, powered by YuBuntu, is priced to cater to women in the 'missing middle' in Kenya, those with lower-middle incomes for whom healthcare access is limited. Our holistic solution for women's cancer care aims to empower and inspire more women to take charge of their health and well-being." - Dan White, CEO, ARK Venture Studio, which is incubating the YuBuntu venture

"We recognize the importance of an early diagnosis and want to remove barriers to our women taking care of themselves. This includes no age restrictions for cancer screenings, expanded preventive care benefits to include breast MRI/ultrasound at no cost, and financial incentives for our employees and spouses/partners to get preventive screenings. And if she faces a cancer diagnosis, we want her to have peace of mind in our expansive coverage including biomarker testing, free remote expert medical reviews, fully paid time off, and robust mental health support - all personalized to her health care needs with the support of her dedicated oncology nurse who walks the journey with her." - Melinda Morimoto, Senior Benefits Director, Genentech



Insurance Payers & Employers - Key Takeaways:

- **Reassess Coverage Policies:** Modify insurance policies and offerings to make cancer care pathways comprehensive, affordable, and accessible for women.
- **Support Comprehensive Care:** Ensure coverage includes a wide range of cancer care services, including screening, fertility preservation, rehabilitation and occupational therapy, menopause, and mental well-being support.



Policymakers - Key Takeaways:

- **Implement Women-Centric Health Policies:** Develop and enforce policies and targets that prioritize women's health needs in cancer care.
- **Allocate Funds for Women's Health Research:** Increase funding for inclusive research focused on women's health and cancer care across demographics including race and ethnicity and in low, middle, and high income countries.



Listening to Women: Stories for Change

In developing this discussion paper, the stories of women calling for change have been our primary source of inspiration. Here, we share more stories emphasizing the urgent need for WCCC.²⁴

The following quote illuminates two key challenges women face in getting a diagnosis—the fact that women tend to put their own health needs behind the needs of others and the fact that when women do seek help, their concerns are often dismissed:

“When I was 15 my mom spent months in pain, and because it was ingrained in her that women should endure the discomfort and because she lacked help to leave her children at home and take care of her health, she was reluctant to go to the doctor. When she did, multiple doctor dismissed her symptoms as a migraine and sinus infections. It wasn't until 2 full months later, when she was in agonising pain and could not handle it anymore, that she was diagnosed with a form of rare cancer that is even rarer in women. She passed away 2 years later.”

During the experience of cancer, women face many challenges that are often not adequately discussed, leading to uncertainty, confusion, and pain. The following stories highlight two such critical areas—the desire for fertility preservation and the transition to menopause:

“A los 17 años me diagnosticaron de un fibrosarcoma facial. He tenido 3 recidivas locales y metástasis pulmonar. Me he hecho quimioterapia y radioterapia. Hace 7 años que terminé los tratamientos y me hago controles cada 4 meses. Afortunadamente el cáncer cesó. Pero mis posibilidades de ser madre también . Los tratamientos para la congelación de óvulos son costosos y después de recibir tratamientos oncológicos la sanidad pública no los cubre. Hubiera marcado la diferencia contar con 6mas asesamiento sobre las alternativas disponibles.”

“At the age of 17 I was diagnosed with a facial fibrosarcoma. I have had 3 local recurrences and pulmonary metastasis. I have undergone chemotherapy and radiotherapy. I finished the treatments 7 years ago and I have check-ups every 4 months. Fortunately, the cancer stopped. But so have my chances of becoming a mother. Egg-freezing treatments are expensive; after receiving oncological treatments, the public health system does not cover them. It would have made a difference to have more advice on the alternatives available.”

“At 37, I was diagnosed with breast cancer. Pushed into menopause, I had operations, chemo, antibody, and hormone therapies. The focus was on treating my cancer, not talking about menopause and my mental health suffered. 49.7% of today's population has, is, or will go through menopause, yet doctors still lack education, failing to recognize, diagnose and treat its symptoms. While society continues to treat menopause as a taboo, women will continue to suffer from preventable hormone loss, and workplaces will continue to lose exceptional talent.”

Appendix 1: The Expanded WCCC Experience

1. Pre-Diagnosis:

Risk Assessment: This stage begins with identifying risk factors, such as family history, lifestyle choices, cancer history, genetic predispositions, and environmental and occupational factors. In the world of health-tracking wearables, Innovators who are developing self-monitoring tools, apps, and trackers have a voice in early detection as their prospective data collection can have early indications of pre-clinical disease.

2. Preventive Measures:

Preventive measures include vaccinations (e.g., HPV), regular and focused screenings (e.g., breast cancer, cervical cancer with high-performance test [HPV DNA-based testing] according to WHO recommendations²⁵, colorectal cancer, and lung cancer based on eligibility criteria), and adopting a healthy lifestyle. Many women face challenges accessing these measures due to financial, cultural, logistical, and educational hurdles. Partnership with healthcare providers and researchers is key to shortening the time between early signals and diagnostic testing.

3. Diagnosis:

a. Symptom Recognition:

Women, their partners, and families are often the first to notice symptoms, prompting them to seek medical attention. Screening programs or health-tracking apps may also raise an alert. Symptoms and changes include: lumps, pain, discomfort, mood shifts, demeanor changes, or unusual bleeding.

b. Medical Evaluation:

This phase includes consultations, physical examinations, and diagnostic tests (biopsies, imaging, blood tests, biomarker testing) to confirm the presence and type of cancer. The role of researchers is vital in developing tests that comprehensively review women's specific symptomatology. A skilled diagnostic team aids decision-making and fast action by coordinating closely with healthcare providers.

c. Staging:

Determining the extent and stage of cancer is crucial for treatment planning.

4. Treatment Experience:

a. Shared Decision-Making, Palliative Care and Treatment Goals:

After diagnosis, women and their healthcare team discuss and evaluate the available treatment options, which may include surgery, chemotherapy, radiation therapy, immunotherapy, targeted therapy, fertility-preservation options or hormonal therapy. Also at this time, they will consider treatment convenience including faster administration and flexible dosing and/or decentralized care.

25. <https://www.who.int/europe/news/item/11-09-2021-who-recommends-dna-testing-as-a-first-choice-screening-method-for-cervical-cancer-prevention>



b. Treatment Options and Choice:

After diagnosis, women and their healthcare team discuss and evaluate the available treatment options, which may include surgery, chemotherapy, radiation therapy, immunotherapy, targeted therapy, fertility-preservation options, hormonal therapy, and genetic testing. Consideration should be given to treatment convenience, including faster administration, flexible dosing, and decentralized care. Additionally, the appropriateness of palliative care should be assessed given it "improves the quality of life of patients and their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social, or spiritual".²⁶

c. Second Opinions:

Following an initial diagnosis, women may seek second opinions to ensure the chosen treatment plan is appropriate and aligned with their needs.

d. Treatment Commencement:

Women begin the chosen treatment, which may involve multiple modalities.

e. Management of Side Effects:

Coping with treatment-related side effects and symptoms, like chemo-induced menopause, requires support and management strategies. Vigilance is necessary among the care team, the woman living with cancer, and caregivers to monitor side effects and take timely action. Digital monitoring can provide more seamless side effect management.

f. Care Team Collaboration:

Effective communication and collaboration are essential among healthcare providers, the woman living with cancer, her family, and caregivers to manage care and side effects and monitor the quality of life from treatment through survivorship.

5. Remission and Post-Treatment:

a. Response Assessment:

Regular check-ups, scans, and tests monitor the response to treatment. Achieving remission or a reduction in the disease's presence is a key goal for survivorship. Other important aspects include preserving sexual health, sexual function, mental well-being, quality of life, and outlook.

b. Follow-Up Care:

Women continue to receive follow-up care and surveillance for rehabilitation to detect any signs of recurrence or complications.

c. Psychological and Emotional Support:

Managing the emotional experience is critical throughout diagnosis, treatment, and post-treatment, including anxiety, depression, and fears of recurrence.

6. Survivorship:

a. Life Beyond Cancer:

As time passes, many women transition into the survivorship phase, focusing on living a fulfilling life beyond cancer, which may require adjustment as it is not a return to business as usual in the case of long term impacts such as peripheral neuropathy, treatment-induced menopause, body image issues, after-effects of surgery, cardiovascular concerns, the potential for permanent hair loss, and the myriad of other issues that can result from cancer treatment. For example, women who decide to start a family post-cancer need ongoing support to navigate fertility options and possible implications for their long term hormone therapy treatment.

26. <https://www.who.int/europe/news-room/fact-sheets/item/palliative-care>



b. Ongoing Health Maintenance:

Regular follow-up appointments, health screenings, and lifestyle choices are essential for maintaining overall health.

c. Support and Advocacy:

Survivors and caregivers often become advocates by sharing their stories, supporting others, and raising cancer awareness. It is not uncommon for survivors and caregivers to launch their own entrepreneurial ventures and policy advocacy efforts. Partnering with women-centric funding agencies, venture capitalists, and private equity is vital to transform these ideas into viable businesses, especially Femtech ventures. Policy advocacy can drive change and funding to support better healthcare for women.

7. Planning End-of-Life Care:

a. Shift Focus of Care:

When the healthcare team determines her cancer can no longer be controlled, care is still critical, though it shifts to a focus on quality of life and making her comfortable instead of treatment with curative intent. It is imperative to listen to her during this time as everyone experiences end-of-life very differently and with unique needs, as may her loved ones.²⁷

b. Advance Directives:

Since every woman has different needs and wishes, communication with her and her family is essential to ensure decision-making and end-of-life decisions are aligned with her values. Encouraging the woman living with cancer to have an advance directive in place is highly recommended.

c. Preparing Affairs:

Beyond advanced directives, it's important to ensure key paperwork and documents are in place, including wills and healthcare power of attorney, and that financial documents and beneficiaries are updated. It is a very individual choice, though some women may want to be involved in decisions such as funeral planning and organ donation.²⁸

d. Hospice Care and the Final Days:

Consider how she desires to spend her final days, including the potential for hospice care, which can start six months before death is anticipated. Often, people who are dying have a fear of being a burden, being abandoned, or concerns regarding loss of dignity or control. It is important to respect her wishes and spirituality and continue to listen and communicate with her honestly and respectfully - reassuring her that her advance directives will be honored. It is also critical for caregivers to take care of themselves and be open to asking for help from others, as this is an emotionally and physically exhausting time.²⁹

27. <https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/care-fact-sheet>

28. <https://www.usaa.com/inet/wc/advice-retirement-terminally-ill-checklist>

29. <https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/care-fact-sheet>

Appendix 2: “How To Guide” for Each Stakeholder

Following, we provide a “How to Guide” organized by stakeholders to make WCCC a reality, including key roles, questions to ask, and actions to take.

A. Caregivers

1. Caregivers - Key Roles During a Woman's Cancer Experience

Caregivers play a crucial role in decision-making and facilitating physical and emotional comfort for women living with cancer. They comprise a network of professional caregivers, nurses, spouses/partners, older children, and family members who support a woman throughout her experience.

Caregivers are typically the closest link to the woman living with cancer (often a family member or spouse). They will have unique insights into her preferences, as well as a front-row seat to how she is tolerating the treatments and cancer care. Such insights can assist decision-making and care, facilitating her comfort and emotional support.

The key roles we see in caregiving that will enable WCCC

a. Advocacy and Decision-Making:

Advocate for her medical needs, seek second opinions when necessary, and ask questions to ensure a thorough understanding of the treatment plan. Determine when and how to advocate for her needs and preferences to make her voice heard in medical decisions. For example, prioritize asking questions around topics such as pain management and fertility preservation and assisting the woman living with cancer in exploring these choices.

b. Communication:

Determine how to facilitate clear and effective communication between the woman living with cancer, her healthcare providers, and the care team. Such communication includes advocating for the needs of a woman living with cancer and ensuring a common understanding among the woman and her care team.

c. Emotional Support:

Decide how to provide emotional support and be attentive to the woman's emotional needs during treatment. Such support includes identifying when professional counseling may be necessary.

d. Assistance with Daily Living:

Decide how to assist with daily living activities such as personal care, household chores, transportation to medical appointments, and meal preparation, depending on the needs of a woman living with cancer.

e. Monitoring and Reporting:

Decide how to monitor her condition, including tracking symptoms and side effects and communicating any changes to the healthcare team.



f. Access to Resources Including Financial and Legal Support:

Help access resources and services supporting her care, such as transportation services, home healthcare, and support groups. Such support could also include assisting in legal and financial decisions, including health directives, power of attorney, and insurance matters.

g. Dignity, Comfort, and Cultural Sensitivity:

Ensure that her dignity, privacy, and comfort are respected in all aspects of care, from hospital stays to in-home care. Consider her cultural and religious beliefs and make decisions that respect and accommodate these values in the care provided.

h. Comprehensive Care Planning:

Encourage and assist her in adhering to the prescribed treatment plan, including taking medications and attending medical appointments.

Decide how to ensure continuity of care, including transitioning from active treatment to survivorship and supporting her long-term well-being.

If the condition of a woman living with cancer becomes terminal, caregivers may need to help make decisions regarding advanced care, planning hospice care, and end-of-life preferences.

i. Balance with Self-Care:

Make decisions about personal self-care and ensure that the caregiver maintains their own physical and emotional well-being to prevent caregiver burnout.

2. Caregivers – Core Questions and Actions to Take During a Woman's Cancer Experience

When a loved one's treatment begins, the process can be overwhelming for everyone, including the caregiver. For this section, we narrow the definition to family members as caregivers. The following questions aid caregivers in increasing support for their loved one during the cancer experience:

- a. Given the treatment plan of the woman living with cancer, what are the potential side effects and recovery expectations? Can you help her make her goals clear for her treatment team?
- b. What is her family medical history and other existing health conditions that must be considered in her care? Has genetic screening and associated counseling been done? Are there implications for other family members or children to be considered?
- c. Can you support her in clarifying her personal preferences and goals for care, and how can these preferences be respected and honored?
- d. How is she emotionally and psychologically coping with her cancer diagnosis and treatment? What signs of distress should be looked for, and how can emotional support be provided?
- e. What practical assistance does she need in her daily life, such as help with personal care, household tasks, or transportation to medical appointments? Identifying specific areas where support is needed is essential.
- f. What role can you as a caregiver play in facilitating communication between her and her healthcare providers? What is that role that she prefers you to have? How can you help with medical decision-making and advocacy?

- g. How can you as the caregiver support her nutritional needs and dietary preferences during treatment and recovery? What are the unique cultural, social, and personal factors that may influence her cancer experience?
- h. What can you do to provide social and emotional support and how can you help her engage with her support network of family and friends?
- i. How can you help her navigate her care's financial and insurance aspects, including managing medical bills and paperwork?
- j. How can you support her transition to life beyond cancer treatment? Providing guidance for life beyond cancer is essential.

By addressing these questions, caregivers can design and provide more effective and compassionate care for women living with cancer, ensuring that their unique needs and preferences are met during their cancer experience.

Not to be forgotten is the experience of the caregiver. The caregiver must also consider strategies to maintain their physical and emotional well-being while caring for their loved one.

B. Researchers

1. Researcher's Key Roles During a Woman's Cancer Experience

Healthcare researchers play a crucial role in bridging the gap in cancer research between women's and men's cancer experiences, which generate the clinical data that paves the way to implement WCCC. Researchers' decisions in study design, data analysis, and interpretation contribute to a more nuanced understanding of gender-specific responses to cancer and inform the development of tailored and effective treatments for women.

Here are key roles and decisions healthcare researchers can take to ensure women's unique needs are comprehensively addressed in cancer research:

a. Inclusive Study Designs:

Researchers must adopt inclusive study designs that prioritize the participation of women across diverse age groups, ethnicities, and socioeconomic backgrounds. By actively recruiting a representative sample, studies can capture the full spectrum of experiences of women with cancer, providing insights into potential variations and disparities. Study designs should consider a woman's preferences, including endpoints and outcomes. For example: Does the study consider the daily course of life she encounters? Will the data collected demonstrate the impact of the treatment on relevant aspects of her quality of life?

b. Sex-Specific Biomarkers:

Identifying sex-specific biomarkers is critical for understanding how cancer manifests differently in women, enabling the development of targeted diagnostic tools and therapies. Researchers need to explore and validate biomarkers that are indicative of cancer risk, progression, and treatment response, specifically in females living with cancer.



c. Integration of Sex as a Biological Variable (SABV):

Researchers should consistently integrate sex as a biological variable (SABV) in their analyses. By acknowledging the biological distinctions between males and females, researchers can identify sex-specific factors influencing cancer susceptibility, progression, and treatment outcomes. This integrative approach ensures that gender-related differences are systematically considered in the research process.

d. Diversity in Clinical Trial Enrollment:

Encouraging diversity in clinical trial enrollment is crucial for generating findings that apply to a broad range of women. Researchers must actively address barriers to participation, considering factors such as transportation, childcare, and cultural sensitivities. This approach ensures that clinical trial outcomes are relevant and representative of the diverse population of women affected by cancer.

e. Behavioral and Psychosocial Research:

Incorporating behavioral and psychosocial research methodologies is essential for understanding the holistic impact of cancer on women. Researchers should explore the psychosocial aspects of cancer, including emotional well-being, coping mechanisms, and social support networks. This information contributes to the development of interventions that address the unique psychological challenges faced by women during their cancer experience.

f. Analysis of Treatment Variations:

Researchers need to analyze variations in treatment responses between women and men rigorously. Such analysis includes evaluating the efficacy and side effects of different treatment modalities, specifically in female populations. Understanding these variations is fundamental to tailoring treatment plans that optimize outcomes for women with cancer.

g. Long-Term Survivorship Research:

Long-term survivorship research is essential for understanding the unique challenges and health needs of women who have completed cancer treatment. Researchers should investigate survivorship's physical, emotional, and social aspects, offering insights into effective post-treatment care and support.

h. Communication and Education Research:

Researchers should conduct studies on effective communication and educational strategies tailored to women. Such strategies include exploring the most impactful channels for disseminating cancer prevention, early detection, and treatment information. Culturally sensitive and easily accessible communication strategies are crucial for empowering women to make informed decisions about their health.

i. Intersectional Analyses:

Researchers should employ analyses that consider the intersections of gender with other social determinants such as race, ethnicity, and socioeconomic status. Such intersectional analyses unveil the compounded effects of multiple identities on cancer experiences, ensuring that research outcomes reflect the diverse realities of women.

j. Advocacy for Policy Changes:

Researchers can contribute to WCCC by advocating for policy changes prioritizing gender-specific health research. Engaging with policymakers to emphasize the importance of funding and supporting research addressing women's unique needs is crucial for driving systemic change.

In summary, healthcare researchers are pivotal in promoting WCCC by making informed research design, analysis, and advocacy decisions. These decisions collectively contribute to a comprehensive understanding of gender-specific factors in cancer, fostering the development of tailored and effective interventions for women throughout their cancer experience.

2. Researcher's – Core Questions and Actions to Take During a Woman's Cancer Experience

When designing cancer research and clinical trials, healthcare researchers must ask critical questions to ensure the incorporation of women's perspectives in cancer prevention, screening, and care. These core questions guide the research process and contribute to a comprehensive understanding of how cancer affects women, enabling the development of tailored interventions.

Here are key questions healthcare researchers should address:

a. Population Representation:

Is the study population representative of the diverse demographics of women affected by cancer? Ensuring diversity in the study population is crucial for generating findings applicable across various age groups, ethnicities, socioeconomic backgrounds, and geographical locations.

b. Inclusion of Sex-Specific Biomarkers:

Can biomarkers specific to females be included to provide insights into sex-specific responses to cancer? Identifying and validating sex and gender-specific biomarkers contributes to a more nuanced understanding of how cancer manifests in women. This information is vital for tailoring diagnostic tools and treatment strategies.

c. Sex as a Biological Variable (SABV):

How is sex as a biological variable (SABV) integrated into the study design and analyses? Recognizing sex-specific differences at the biological level is essential for uncovering gender-specific factors that influence cancer susceptibility, progression, and response to treatment. A systematic integration of SABV ensures a comprehensive examination of these distinctions.

d. Behavioral and Psychosocial Dimensions:

How are behavioral and psychosocial aspects considered in the research, reflecting the holistic impact of cancer on women? Incorporating behavioral and psychosocial research methodologies provides insights into the emotional well-being, coping mechanisms, and support networks of women facing cancer. Understanding these dimensions is prioritizing holistic and patient-centered interventions.

e. Impact of Social Determinants:

What social determinants of health are considered, and how do they intersect with the experience of women's cancer? Addressing the impact of social determinants, such as race, ethnicity, socioeconomic status, and cultural factors, is essential for recognizing disparities and tailoring interventions to the unique circumstances of diverse groups of women.

f. Representation in Clinical Trials:

Is there a proactive effort to enhance the representation of women in clinical trials? Inclusive representation ensures research findings translate into effective treatments for all women. Overcoming barriers to participation is essential for equitable inclusion.

g. Communication and Educational Strategies:

How are communication and educational strategies tailored to effectively convey information to women about cancer prevention, early detection, and treatment options? Designing communication strategies that resonate with women's preferences and information needs is vital for empowering them to make informed decisions about their health. Culturally sensitive and accessible approaches enhance engagement.

h. Long-Term Survivorship Research:

Are there plans to research the long-term survivorship experiences of women post-cancer treatment? Investigating the long-term physical, emotional, and social aspects of survivorship offers insights into the unique challenges faced by women after completing cancer treatment. This research informs post-treatment care and support.

i. Intersectional Analyses:

How are intersectional analyses applied to account for the compounded effects of gender with other social determinants? Considering the intersections of gender with race, ethnicity, and socioeconomic status reveals nuanced insights into the diverse realities of women facing cancer. Intersectional analyses ensure a more comprehensive understanding.

j. Community Engagement and Advocacy:

Has the community been engaged to advocate for WCCC? Community engagement fosters collaboration, builds trust, and ensures that research priorities align with the needs of women. Advocacy initiatives contribute to policy changes that prioritize gender and sex-specific health research.

By systematically addressing these core questions, healthcare researchers can design studies and clinical trials that holistically incorporate the perspective of women's cancer care. This approach advances WCCC by generating evidence-based insights and interventions tailored to women's unique needs and experiences throughout their cancer experience.

C. Healthcare Providers

1. Healthcare Providers- Key Roles During a Woman's Cancer Experience

When treating a woman living with cancer, healthcare professionals— such as doctors, nurse practitioners, nurses, pharmacists, and laboratory clinicians—must make critical decisions tailored to the woman's diagnosis, stage of cancer, overall health, and preferences. Given the complexity and sensitivity of the cancer experience for women, the emotional intelligence of these providers is critical in ensuring compassionate and effective care. Often acting as the central coordinators of the care continuum, healthcare providers require swift access to diagnostic data for treatment decision support.

The essence of delivering WCCC lies in the multidisciplinary coordination of care with a central point of contact within the team. This approach always prioritizes the woman's experience and preferences at the heart of all medical decisions, integrating both clinical and emotional aspects of treatment and care.

Some key decisions healthcare providers may make include:

a. Clinical Team Collaboration:

Collaborating with a multidisciplinary clinical team, including specialists, nurses, and supportive care providers, to ensure communication and coordination across the team to provide the woman living with cancer comprehensive and integrated care.

b. Genetic testing and counseling:

Consider if genetic testing (which helps estimate the risk of developing cancer in a lifetime) is appropriate based on personal or family history. If appropriate, ensure counseling happens with the woman before and after the testing. Discussions about the implications of findings for her family members should also occur as relevant. Genetic testing is a personal decision to be made by the woman after she has weighed the risks and benefits with her clinical team.³⁰

c. Diagnosis and Staging:

Determine the specific type of cancer and its stage based on diagnostic tests, such as biopsies, imaging scans, biomarker testing, and blood work.

d. Shared Decision-Making, Palliative Care, and Treatment Goals:

As part of palliative care, collaborate with the woman living with cancer to set treatment goals (including curative intent) and improve her quality of life (including symptom management) based on the stage and nature of the cancer. Ensure that decisions throughout care align with her values, preferences, and goals and involve her in shared decision-making.

e. Treatment Plan:

Assess the available treatment options, which may include surgery, chemotherapy, radiation therapy, immunotherapy, targeted therapy, hormonal therapy, or a combination of these.

- **Clinical Trials:**

Consider whether the woman living with cancer is eligible for participation in clinical trials that may offer innovative treatments.

- **Surgical Decisions:**

If surgery is part of the treatment plan, the doctor will determine the type of surgery (e.g., lumpectomy, mastectomy, reconstruction) and the extent of surgical removal.

- **Treatment Options:**

Chemotherapy and radiation therapy, hormonal or targeted therapies, complementary and integrative therapies, palliative care or end-of-life care

- **Timing and Sequence:**

Determine the sequence of treatments (e.g., neoadjuvant or adjuvant therapy) and the timing of follow-up tests and scans.

- **Treatment Convenience:**

When available, provide options for more convenient treatment modalities that may provide faster administration of therapies or in a more convenient location such as closer to or at home.

- **Follow-Up and Surveillance:**

Develop a plan for regular follow-up visits, surveillance tests, and scans to monitor the woman's response to treatment and potential recurrence.

f. Fertility Preservation:

Address fertility concerns and discuss options for fertility preservation before starting cancer treatment, if relevant to the woman living with cancer. Additionally, providing support for fertility treatment post-cancer treatment and consideration of options open to the woman if preservation is not successful.

³⁰ <https://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/genetic-testing-cancer-risk#:~:text=Reasons%20to%20consider%20genetic%20testing%20for%20cancer&text=A%20personal%20or%20family%20history,steps%20to%20lower%20your%20risk>



g. Menopause Transition Support:

Address the potential transition to menopause due to cancer treatment and associated support to manage the multitude of symptoms, for example: hot flashes, vaginal dryness, mood swings, sleep disturbances, fatigue, decreased libido, cognitive changes, bone density loss, weight gain, thinning hair, and dry skin.

h. Psychological and Emotional Support:

Identify the need for psychological support, counseling, or mental well-being services to help the woman living with cancer cope with the emotional impact of the diagnosis and treatment. Using yoga techniques to improve muscle tone and pranayama (breathing techniques) to help balance the parasympathetic and sympathetic nervous systems. Meditation is a good tool for healing.³¹

i. End-of-Life Care and Symptom Management:

Continue her care with a focus on quality of life and making her comfortable instead of treatment with curative intent if the healthcare team determines her cancer can no longer be controlled. Since every woman is different in terms of needs and wishes, communication with her and her family is essential to ensure decision-making and end-of-life decisions are aligned with her values. Encouraging the woman living with cancer to have an advance directive in place is highly recommended.³²

j. Education and Communication:

Providing clear and informative communication to the woman living with cancer and her family throughout her experience to ensure she is empowered to make the best decisions for her and her family - a critical part of WCCC.

Keeping the woman's experience at the core of these decisions is essential to delivering WCCC. By doing this, along with taking into account the unique circumstances and needs of each woman living with cancer, the healthcare provider can provide the best possible care and improve the quality of life of a woman living with cancer.

2. Healthcare Providers – Core Questions and Actions to Take During a Woman's Cancer Experience

When healthcare professionals design solutions for women living with cancer, we advise that they consider a comprehensive set of questions to ensure they tailor care and treatments to meet the unique needs of women.

Here are some core questions they should ask:

- a. What type of cancer does she have, what biomarkers is she expressing, and what stage is her cancer?
- b. Given her medical history and diagnosis, what are the treatment options, potential side effects, and risks? What are gender-specific considerations that will impact treatment and care?
- c. What are her personal preferences and goals for treatment and care?
- d. What psychological and emotional challenges is she facing, and how can we provide psychological support and counseling?

31. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8191226/>

32. <https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/care-fact-sheet>



- e. What support can we offer to help the woman living with cancer and her family or caregivers through the cancer experience?
- f. What resources, information, and delivery channels can be provided to a woman and her family to better understand and manage her condition and treatment? In some instances, women prefer digital channels, and others prefer face-to-face.
- g. What role can technology and digital tools play in enhancing communication, monitoring, and support for women living with cancer? Leveraging technology for women-centric care is important.
- h. How can we create a supportive environment in healthcare facilities, ensuring privacy, dignity, and comfort for women living with cancer?
- i. What are the social, cultural, and socioeconomic factors that may influence a woman's cancer experience, and how can they be addressed?
- j. What are her long-term care and survivorship needs following treatment?

Asking these questions can offer essential insights for healthcare professionals to remain WCCC-focused. Such questions also provide structure to check in with the woman with cancer as she navigates her experience, maintaining her self-determination and vision for her life beyond treatment.

D. Innovators

1. Innovators - Key Roles During a Woman's Cancer Experience

Designing products for women living with cancer requires carefully considering their specific needs and challenges. Innovators play a critical role in designing products and services that can support a woman undergoing cancer screening and treatment. Also relevant is the role of venture and private equity funds to fund innovation from series A through, if relevant, IPO. Understanding the user experience is critical in the design phase to ensure women-centricity and maximal value to potential customers who are women.

Often, innovators are cancer survivors or family members of survivors. Although they bring a rich lived experience, they still must listen to the market and the experiences of women living with cancer. Regardless of the innovator's size, women-centricity in all aspects of product development is critical to advancing WCCC.

Innovators must make several key decisions to design and develop products that address women's cancer prevention and care needs, including:

a. User-Centric Design:

Prioritize user-centric design by involving women living with cancer and caregivers in the prototyping and development process to enhance her preferences and ease the caregiver burden. Input from women and caregivers is invaluable for creating inclusive, ethical products that address women's preferences, facilitating ease of use.

b. Medical Expertise:

Collaborate with healthcare providers, oncologists, and other experts to ensure that the product's purpose and type align with medical and regulatory standards and is safe for women living with cancer.



c. Cancer Type and Stage:

Consider the type and stage of cancer for which the product is intended. Different cancers and treatment phases may require unique solutions.

d. Emotional and Psychological Support:

Consider how the physical or digital product can provide emotional support, boost self-esteem, or help users cope with the psychological challenges of cancer while seamlessly integrating with blended care models incorporating health coaches, emotional support animals, and clinicians in the care continuum.³³

e. Ease of Use:

Design products that are easy to use and require minimal effort, especially if users may experience fatigue, weakness, or cognitive challenges due to treatment.

f. Treatment-Specific Features:

Tailor the product to address treatment-specific needs, such as skin care products for managing skin changes during chemotherapy or post-surgery recovery garments.

g. Privacy and Dignity:

Respect the privacy and dignity of women living with cancer. Products should be discreet and sensitive to the user's emotional well-being.

h. Comfort and Well-Being:

Consider the comfort and well-being of women living with cancer. Products should be comfortable, non-irritating, and enhance the user's overall quality of life.

i. Regulatory Compliance:

Ensure the product complies with relevant regulations, reliable data sources, education, and safety standards for medical devices or healthcare products.

j. Support and Resources:

Consider support resources, such as user guides, educational materials, or helplines, to enable women living with cancer to use the product effectively.

k. Cost and Affordability:

Evaluate the cost of the product and explore options for affordability, such as partnerships with insurance providers, patient organizations, NGOs, and charities, as well as healthcare facilities.

By addressing these key decisions, innovators can develop products that provide valuable, trusted support and solutions for women living with cancer, contributing to improved quality of life and well-being during their cancer experience. To ensure trust, including her voice is critical along all of these phases, essentially to embody the sentiment that no decisions are made about her without her.

2. Innovators – Core Questions and Actions to Take When Designing Products and Services to Support a Woman's Cancer Experience

Innovators play a vital role in designing products and services that can support a woman undergoing cancer treatment. Understanding the user experience is critical in the design phase to ensure women-centricity and maximal value to potential customers who are women. Though innovators often come with rich experience from having had cancer themselves or caregiving for loved ones, they still must listen into the market, including the experiences of women living with cancer.

33. <https://www.healthline.com/health/cancer/yoga-poses-for-cancer>



Whether through qualitative or quantitative research, here are some core questions to ask:

- a. Do you fully understand the type of cancer you wish to design a solution around, e.g. breast cancer? lung cancer? Are there gender-specific risk factors or considerations for this type of cancer?
- b. What is the psychological and emotional impact of cancer on women, and how can we provide emotional support?
- c. How can we improve early detection and diagnosis for women with this type of cancer?
- d. How can access to care and treatment for women in underserved or remote areas be enhanced? Are there remote, digital, or telehealth options available?
- e. What technologies and digital tools can facilitate communication, education, and support for women living with cancer?
- f. How can we create a supportive community and peer network for women facing cancer?
- g. What are the most effective ways to educate and empower women about cancer prevention and self-examination? Empowering women with knowledge can be a crucial strategy.
- h. How can we ensure privacy, dignity, and comfort in healthcare facilities for women with cancer? Creating a supportive environment is essential.
- i. How can we promote survivorship and life beyond cancer for women who have completed treatment? How is life different for them? Can solutions be designed to support this transition into the next phase of life?

E. Insurance Payers, Employers, and Policymakers

1. Insurance Payers, Employers, and Policymakers - Key Roles During a Woman's Cancer Experience

Insurance payers, employers, and policymakers play crucial roles in determining women's access to cancer screening and treatment. The decisions taken by these stakeholders will determine whether a woman living with cancer has insurance coverage as well as the estimated out-of-pocket cost that will impact her and her family. Such decisions significantly influence women's access to necessary treatments and support services and reduce catastrophic expenditure by out-of-pocket payments for health care.

Insurance payers and employers must balance the need to provide comprehensive financial coverage for women living with cancers to manage costs and ensure the quality and appropriateness of care. This responsibility has been highlighted in the Deloitte publication 'Hiding in Plain Sight: The Healthcare Gender Toll' suggesting that employers reassess benefit coverage to reduce the higher out-of-pocket healthcare costs for female employees.³⁴

Policymakers can improve access and outcomes by shaping healthcare policies to meet the unique needs of women for cancer prevention, screening, and treatment. While policymakers face the challenge of balancing public health investments within fixed budgets, determining access eligibility, duration, and cost capping, it is essential to see WCCC as a population-based investment, not a cost. It has been well described that a woman's health is connected to her economic power.³⁵

34. <https://www2.deloitte.com/content/dam/Deloitte/us/Documents/life-sciences-health-care/us-lshc-health-gender-gap.pdf>

35. <https://www.gatesfoundation.org/ideas/articles/womens-health-economic-power>;

<https://bcju.org/womens-health-is-wealth-how-investing-in-womens-health-directly-improves-economic-outcomes-in-developed-and-developing-markets/>



Investing in WCCC approaches will add not only life years but also the quality of life that will enable a woman to return to her role in society, supporting not only the woman but also the economy. For example, the APAC Women's Cancers Coalition report highlighted that "expanding prevention and screening for breast and cervical cancer is of paramount importance given the demonstrable positive impact in terms of mortality, economic and productivity gains, and the social impact for women, their families, and society."³⁶

At every turn, these stakeholders make pivotal decisions that shape the scope of access to cancer care, affecting the quality and affordability of treatment, prevention, and outcomes.

Examples of key decisions taken by Insurance Payers and Employers are as follows:

a. Wellness and Prevention:

Support by funding and listing as a benefit preventive measures, such as vaccination (e.g., HPV), cancer screenings (e.g., breast cancer screening and DNA-based testing for HPV), and wellness programs to promote early detection and healthy lifestyles.

b. Coverage Decisions:

Determining the extent, scope, and sequencing of insurance/financial coverage for cancer-related care, including diagnostic tests, genetic testing, treatments, second opinions, medications (drug formulary), specialized care and supportive services, physical therapy, rehabilitation, and reconstruction. Coverage also includes the location to receive care and/or the network of healthcare providers and facilities that are in-network and can provide care to the woman.

c. Clinical Review and Case Management:

Implement clinical review processes and case management strategies to assess the medical necessity of treatment plans, coordinate care, and monitor her progress.

d. Mental Well-Being and Support Services:

Determine coverage for mental well-being support, counseling, and support services to help women cope with the psychological aspects of cancer.

e. Palliative Care and Hospice:

Establish coverage for palliative care and hospice services for women with advanced or terminal cancer.

f. Continuity of Care:

Plan for continuity of care, including the transition from active treatment to survivorship and the ongoing monitoring of survivorship-related needs.

g. Cost-Sharing and Financial Assistance:

Decide on cost-sharing structures, co-pays, and deductibles, and explore options for financial assistance or support for women facing financial challenges. Where possible, work with national policymakers to address equity challenges to create incentives for healthcare payers.

Examples of key decision areas for policymakers at various levels of policymaking are as follows:

a. At the international and national levels, the creation of treatment guidelines:

Develop clinical guidelines and pathways that outline evidence-based treatment options for specific cancer types and stages and help ensure the most appropriate care for women. These international treatment guidelines bring together evidence-based recommendations for the treatment of cancer, for example, the World Health Organization (WHO), European Society for Medical Oncology (ESMO), and National Comprehensive Cancer Care Network® (NCCN), among others. At the national level, these guidelines are taken up by policymakers formulating national public health and disease area guidelines, which are translated into funding priorities for national and private insurance providers to enable localization in clinical practice.

36. <https://impact.economist.com/perspectives/health/impact-and-opportunity-case-investing-womens-cancers-asia-pacific>



- b. **At the national level, the development of public health priorities that include women's perspectives:**
In the formulation of national targets for the reduction of morbidity and mortality with targeted disease funding within the Ministries of Health or in the case of government funding toward the health sector arising from the Ministry of Defense.
- c. **At the national level, coordination with government and private insurance Programs:**
Ensure coordination with government-funded and private insurance programs to provide comprehensive coverage to eligible women, ensuring that the gaps between coverage are managed with an eye for minimizing out-of-pocket expenditure.
- d. **At the national and international policy-making and advocacy arena, support advocacy and educational programs for women living with cancer:**
Offer resources and information to help women and their caregivers better understand their equitable insurance coverage, make informed decisions, and navigate the healthcare system.

2. Insurance Payers, Employers, and Policymakers - Key Questions to Pose When Designing WCCC Coverage

Insurance payers, employers, and policymakers play a significant role in shaping the healthcare landscape for women living with cancer. When designing solutions to ensure women-centric policies, quality care, coverage, employee benefit selection, and patient support, they should consider several core questions, all of which touch on each area of policy, funding, and coverage:

- a. **Access to Care:**
Are there barriers to accessing cancer screening, diagnosis, and treatment for women, both geographical as well as comprehensive access to insurance coverage and how can barriers be removed? Is there adequate coverage for cancer-related care, including screenings, diagnostic tests, and treatments? For example, can a policymaker create incentives to minimize the dispersion of health centers through the use of digital health tools? Can a payer fund an integrated pathway of preferred providers? In the case of an employer, can they select coverage networks that allow for ease of access relative to working location?
- b. **Prevention and Education:**
How can cancer prevention and early detection strategies, such as access to vaccines and screenings, be promoted to women? Can a policymaker create disease screening awareness months (e.g., breast cancer awareness month in October)? In the workplace: What educational initiatives can be implemented to raise awareness of risk factors, symptoms, and preventive measures?
- c. **Supportive Care:**
What support services can be provided to women living with cancer, such as mental well-being support, counseling, and palliative care? Are complementary and alternative therapies covered and accessible? At the national policy level, can laws be passed to extend family leave to support women undergoing cancer treatment as has been created in the Family & Medical Leave Act³⁷ that supports the care of young children and elders?
- d. **Survivorship Care:**
How can the long-term care and survivorship needs of women who have completed cancer treatment be addressed? What support is available for managing post-treatment side effects and transitioning back to life? At the policy level, can commercial incentives be created to support firms that employ or are founded by women cancer survivors, as has been applied in Kenya for Hemophilia patients?³⁸ For insurance providers and employers, are these policies

37. <https://www.dol.gov/agencies/whd/fmla>

38. <https://borgenproject.org/hemophilia>



e. **Genetic Testing and Counseling:**

For policymakers, are national policy incentives written into the public health guidelines that open the funding pathway for patients with cancer and their families?

For insurers and employers, does coverage include genetic testing for cancer risk, and if so, for whom and under what circumstances? What genetic counseling services are available and accessible for women and their families?

f. **Fertility Preservation:**

Is there coverage and support for fertility preservation options for women who wish to have children after cancer treatment?

If national policy incentives exist to incentivize births, how can this be extended to women surviving cancer? At the insurance level, are funding options available for women who wish to freeze eggs before cancer treatments?

g. **Menopause Support:**

Is there coverage and support for treatments to manage symptoms of menopause that arise from cancer treatment? Are these policies currently funded by insurers and offered in employee benefit plans?

h. **Financial Assistance:**

How can the financial burden of cancer treatment for women, including addressing out-of-pocket costs and copays, be alleviated?

Are there national policies and insurance policies in place to protect women from financial hardship due to cancer treatment in the case of catastrophic expenditure?

i. **Care Coordination:**

How can care coordination between healthcare providers be improved to ensure that women receive comprehensive, integrated cancer care? How can the fragmentation of care delivery for women living with cancer be reduced through a well-designed public and private health insurance system with information sharing, ease of movement, and coordination through different layers of care?

j. **Research and Innovation:**

How can research into gender-specific cancer treatments and therapies be encouraged? What funding and support can be provided to encourage innovation in cancer care for women? Is gender-specific data to understand the unique needs and outcomes of women living with cancer being collected? How can research and data analysis inform policy decisions to improve care for women?

k. **Health Disparities:**

What public health and disease area policies can be implemented to address disparities in cancer outcomes among different demographic groups of women? How can we ensure that care is equitable for all women, regardless of their socio-economic status or geographical location? Based on these priorities to mitigate disparities, how can insurance providers allocate funds to targeted populations to ensure access to screening, diagnosis, and treatment programs?

By addressing these core questions, insurance payers, employers, and policymakers can design comprehensive and equitable solutions that prioritize the needs of women living with cancer, improve access to care, and promote better health outcomes.

Appendix 3: #MyStoryForChange: Her Lived Cancer Experience

Below, we include more stories submitted by women who have experienced cancer and their caregivers to F. Hoffmann-La Roche's #MyStoryForChange³⁹. These testimonials, shared by women and their caregivers who have bravely faced cancer, are not just inspiring stories. They are crucial narratives that underscore the urgency of advancing WCCC. Each story adds a vital perspective to our understanding and enhances our collective commitment to this important cause. The original submitted story always appears first in its native language in [teal](#), followed by, if relevant, its English translation in [white](#).



Navigating insurance payers:

“En mi experiencia con diagnóstico de cáncer de mama hay 2 grandes obstáculos en los sistemas de salud costarricense. 1. Nunca vas a estar preparado para una noticia de cáncer sin embargo no existe apoyo emocional y mental desde el diagnóstico hasta tratamiento. Tomemos en cuenta que la mayoría de doctores en este espacio son hombres, y ellos no están preparados para entender, empatizar, he informar desde la perspectiva femenina, algo tan sencillo como que te preparen con visuales de cómo se va a ver después de la operación y como se verá 8 meses después de reconstrucción, información es poder por lo que tener la pintura entera es importante y además contar con herramientas de para normalizar mis etapas de pérdida y como navegar mejor cada etapa. 2. La complejidad excesiva de los seguros de salud genera enorme frustración y estrés innecesario para las familias pasando por estos momentos.”

“In my experience with a breast cancer diagnosis there are 2 major obstacles in the Costa Rican healthcare system. 1. You are never going to be prepared for the news of cancer but there is no emotional and mental support from diagnosis to treatment. Take into account that most doctors in this space are men, and they are not prepared to understand, empathize, and inform from the female perspective, something as simple as being prepared with visuals of how it will look after the operation and how it will look 8 months after reconstruction, information is power so having the whole picture is important and also have tools to normalize my stages of loss and how to better navigate each stage. 2. The excessive complexity of health insurance creates enormous frustration and unnecessary stress for families going through this time.”



The importance of self-advocacy:

“I received a Stage 3, triple positive breast cancer diagnosis in 2017, Valentine's Day. I am not the type to joke with my health. My body was giving signals. Unfortunately, my doctors did not know what to do prior to the diagnosis. According to them, I was too young, my OB-doctor's SBE 6 months prior ruled out any lumps. 6 months later I was receiving a diagnosis. Stage 3, metastatic to the lymph nodes. Today I am 6 years free. However, I choose to be an advocate. I encourage others to be body aware, and know how to advocate for themselves.”



Fighting to be believed:

"After two years of my mom being cancer free, I found a lump on my right breast. I immediately called my gynaecologist and she sent me to a special clinic right away to get further tests.

The first doctor said 'It's probably just a cyst' and that I should come back in a month. So I came back a month later to see a different doctor. She told me I was 'paranoid' and that I wasted her time - that I was 'way too young' to have breast cancer. Half a year later, 2 weeks before my 26th birthday, I got my breast cancer diagnosis, it had already spread."



Proving that strong is beautiful:

"When suggesting options for post-cancer reconstruction, the surgeon was very concerned about aesthetics and I just wanted to have function. He suggested using my lat muscle on one side to build a mound for a new breast. He said I would still be able to lift a bag of groceries. I now lift weights for my health and shake my head at the thought of destroying my back muscles so I could have a bigger looking breast. Would a female surgeon have suggested something so preposterous?"



Living with the emotional toll of a cancer diagnosis:

"Debido a la pandemia dejé de hacerme los chequeos ginecológicos que anualmente solía realizar. Pasó el tiempo y este año retomé mi rutina. Los resultados fueron saliendo y me detectaron HPV y posibilidad de cáncer al útero. Cuando te dan esta noticia pasan dos cosas: la primera es que el miedo se apodera de ti porque temes que todo vaya mal. La segunda, es saber que tienes la privilegio y la fortuna de poder realizarte los exámenes para diagnosticar a tiempo y que muchas mujeres no tienen el mismo acceso a la salud."

"Due to the pandemic I stopped having the gynecological check-ups I used to do every year. Time passed and this year I resumed my routine. The results came back and they detected HPV and the possibility of cervical cancer. When you get this news, two things happen: the first is that fear takes over you because you are afraid that everything is going to go wrong. The second is knowing that you have the privilege and fortune of being able to have the tests to diagnose in time and that many women do not have the same access to healthcare."



A daughter struggling to make her mother's wishes heard:

"My mother battled end stage Leiomyosarcoma a couple years ago. The physicians & hospital staff would look to our male relatives to make medical decisions on her behalf. At first it was puzzling for us, however very soon we made it clear that we her daughters were her next of kin and responsible for input on medical decisions if she was unable to make them. In many cultures female next of kin are still undermined when in the presence of male relatives. We can play a key role in education, bringing change and giving them a voice."



The ongoing need for new research and innovation:

"My mother died of ovarian cancer in the 1970s. She noticed a 'lump' in her vagina that would appear during her period; but no doctor would examine her during menstruation. When she stopped bleeding, the lump would recede into her uterus. Finally, she found a doctor that would examine her during bleeding. He was horrified and immediately scheduled her for surgery. She went on hormones and it bloated her up terribly. She died. 35 years later, my good friend was put on the same hormones, with the same effect. She died. Treatment has not progressed."