2023 EDITION

FEMTECHNOLOGY SUMMIT REPORTS

A blueprint for transformative change in women's health, tackling:

AI & THE GENDER HEALTH GAP

FINANCING INNOVATION IN WOMEN'S HEALTH

WOMEN-CENTRIC CANCER CARE

ESG ALIGNMENT ON WOMEN'S HEALTH

REDESIGNING HEALTHCARE WITH WOMEN IN MIND

ROLE OF THE MEDIA IN WOMEN'S HEALTH

IN COLLABORATION WITH Roche

2023 FEMTECHNOLOGY SUMMIT

Catalyze change

Connect actors for long-lasting partnerships

Solve collective pain points

Raise awareness for women's health

June 6 and 7, 2023

Roche-Turm (Bau 1), Basel, Switzerland

The 2023 edition of FemTechnology Summit brought together 150 expert innovators in women’s health— clinicians, researchers, femtech startups, corporates, VCs— to collapse silos and tackle collective pain-points in women’s health.

The reports that follow are the product of this generosity of spirit and collective expertise.

We hope these reports serve as both inspiration and a roadmap for the journey ahead.

The challenges we face are collective, but so too are the solutions.

Before each report we break down how these reports should be used and how (if the mission resonates) **you (yes, you!)** can contribute.

With much gratitude and excitement for the world we can build together,

Oriana
Founder, FemTechnology Summit

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AI & THE GENDER HEALTH GAP

Researchers found that a state of the art approach to AI used in hospitals has a **70% success rate in predicting liver disease** from blood tests

They also uncovered a **wide gender gap - with 44% of cases in women missed, compared with 23% cases among men**

Questions Tackled:

- Will AI perpetuate the gender data gap even further? Or can it accelerate women's health?
- Which crucial data sets in women's health should be prioritised?
- By which innovative means might they be collected?
- What are the most effective ways to incorporate these findings into research, clinical practice and corporate settings?

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FemTechnology Summit 2023

AI & THE GENDER HEALTH GAP

Featured at **AI House in Davos**
Panel on Harnessing AI To Bridge The Gender Data Health Gap

How You Can Get Involved:

We are piloting FemTechGuide, which collects quantitative and qualitative women's health data via a platform that centralizes best-in class women's health solutions to match women with a personalized health solution – creating a database to provide new data for research and innovation.

- If you are a Corporate or Clinician get in touch about what using FemTechGuide might look like for you.
- If you are a Researcher or Startup get in touch about how your work can be made accessible via FemTechGuide.

Contact: oriana@femtechnology.org

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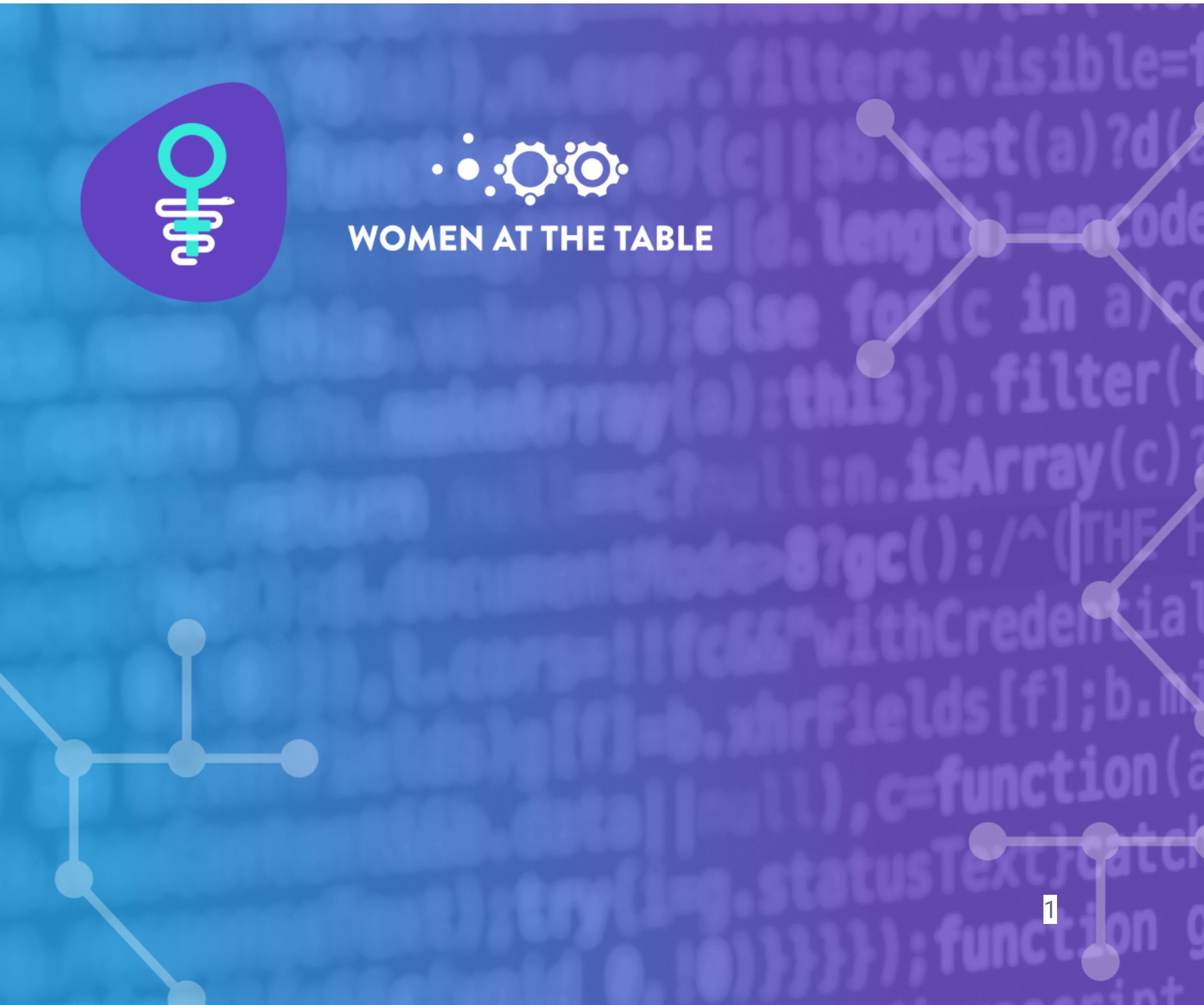
The Gender Data Health Gap:

Harnessing AI's Transformative Power to Bridge the Gender Health Data Divide

FemTechnology | Women At The Table
November 2023



The data we need for women's health in the 21st century is missing.

The digital age promises unparalleled advancements in healthcare through AI, but we stand at a crossroads. As we chart our path forward, we must confront the glaring void in women's health data. How can we steer AI's prodigious capabilities to not only recognize but also address this deficit? And more crucially, as we're on the brink of an AI-driven healthcare revolution, how can we redesign this future to be inclusive, ensuring women's health isn't relegated to the periphery?

The Problem

The foundation of contemporary women's health data is fractured:

- **Historical Exclusion:** Until 1993, women were not mandatorily included as subjects in clinical research in the US.[1] This startling omission spans critical areas: prescription drugs, vaccines, cancer research, cardiovascular health, mental well-being, Alzheimer's, and more.

- **The Impact of Time:** Even though women have been included for the last 30 years, there exists a lag of about 17 years from translational research to direct patient care.[2] Effectively, this means our actionable data on women's health is barely in its adolescence.

- **Ongoing Biases:** Fast forward to 2023, and a majority of biomedical research still relies predominantly on male mice,[3] perpetuating the cycle of gender-skewed data.

The Implications

The repercussions are profound:

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[1] Women's involvement in clinical trials: historical perspective and future implications - PMC

[2] The answer is 17 years, what is the question: understanding time lags in translational research - PMC

[3] Twenty years and still counting: including women as participants and studying sex and gender in biomedical research - PMC

- **Medicine's Gender Skew:** The diagnostic and treatment paradigms in place today largely reflect male-centric data, leading to potential misdiagnoses, suboptimal treatments, and inequitable health outcomes for women.[4]

- **AI's Magnifying Effect:** Existing AI models in healthcare are trained on these limited datasets. The swift adoption and reliance on AI, without rectifying these foundational gaps, threatens to perpetuate and even amplify these disparities at an unprecedented scale.

- **Global Ramifications:** With 90% of US hospitals marching forward with AI-centric strategies[5], the reverberations of these gaps aren't just national; they're global.[6] Part of this problem is structural, some is systemic, all will be amplified by the use of AI as we currently practise it.[7]

What is the Gender Data Health Gap?

> The Gender Data Health Gap is the difference in quality and quantity of health data both collected and analyzed between women and men.

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[4] Sex bias exists in basic science and translational surgical research

[5] 90% of Hospitals Have Artificial Intelligence Strategies in Place

[6] Closing the gender data gap in healthcare | McKinsey

[7] Raising awareness of sex and gender bias in artificial intelligence and health - PMC

Why does the Gender Data Health Gap matter?

> The Gender Data Health Gap (whether conscious or unconscious) is often a factor perpetuating the disparities that women and men experience in healthcare provision.

This can result in:

- **Delays in diagnosis:**
  Women wait an average of 4 years longer to receive a diagnosis for the same disease as men.[8]

  Many of the ways in which we diagnose diseases (e.g. 'cut-off' values, symptoms or even the instruments used) are overly reliant on the white male model of presenting. This results in women being underdiagnosed for diseases that are present in both sexes but manifest differently. [9]

- **Not being prescribed the appropriate treatment:**
  In a cohort study of adults with acute nontraumatic abdominal pain, women were 13% – 25% less likely to receive opioids in the emergency room for their pain despite presenting with the same pain scores.[10]

  Conversely, between January 2017 and December 2021, women in England were 59% more likely to be prescribed benzodiazepines (medication often used to combat anxiety and insomnia) [11] - better known by the brand names of Valium, Xanax and Temazepam - than men. In 2020, the FDA mandated that a "black box warning" be placed on benzodiazepines to inform patients that withdrawal from the drugs can be life-threatening.

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[8] Population-wide analysis of differences in disease progression patterns in men and women | Nature Communications

[9] Females with ADHD: An expert consensus statement taking a lifespan approach providing guidance for the identification and treatment of attention-deficit/ hyperactivity disorder in girls and women

[10] Gender disparity in analgesic treatment of emergency department patients with acute abdominal pain

[11] Hundreds of thousands more women than men prescribed powerful anti-anxiety drugs 'harder to come off than heroin'

- **Care that is not structured to take differences in account:**

In a high volume cancer centre:

9 out of 10 men Undergoing brachytheraypy for prostate cancer **were asked about their sexual health** **vs 1 out of 10 women** Having brachytherapy for cervical cancer	**Sexual function** was discussed with **89% of men** **vs 13% of women** At their initial radiation therapy consultation
81% of men With prostate cancer had their sexual health assessed using a patient-reported outcome tool	Compared to **0% of women**

Some research has indicated that women athletes are more susceptible to muscle and tendon injury during ovulation[12]. Female athletes may also be more susceptible to having concurrent issues like eating disorders, multiple stress fractures, gastrointestinal issues and mental health concerns. But the approach to these issues (although they are related) is fragmented. An interdisciplinary approach to these issues is not yet the norm.

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[12] Injury Incidence Across the Menstrual Cycle in International Footballers

Which parts of the healthcare ecosystem, and who is impacted by the Gender Data Health Gap?

> The Gender Data Health Gap is embedded in the workflow of each and every stakeholder in the healthcare ecosystem, whether they are conscious of it or not.

1. Physicians

- **Have a lack of training on how diseases may present differently in women or conditions that only impact women.**
  41% of UK universities do not have mandatory menopause education on the curriculum.[13] This situation results in: **1 in 3 women between 45 to 54 being given an incorrect diagnosis** before finding out their symptoms are related to menopause, according to a study that also revealed **32% of women feeling their doctor was not very knowledgeable about the topic**[14].

- **Structural bias in diagnostic tools.**
  - Heart Attack:
    - Cardiac troponin (cTn) test: Is used to measure the level of troponin (protein released by damaged heart muscle) in the blood. Higher levels of troponin are used as an evaluation parameter for more heart damage. The clinical threshold that signals a heart attack can differ between men and women, i.e. a woman could be having a heart attack but the troponin level would be below the level of detection.
    - Cardiac catheterization: is used to detect blockages in large arteries. Women are more likely than men to have plaque buildup in the smallest arteries due to inflammation, which could be better visualized with an MRI.

If the tools used for screening for heart attacks render 'invisible' the heart attacks women have, this can further contribute to misconceptions about what type of individual has a heart attack. This is a part of a reason (but not the only one) that **women have a 50% greater chance of misdiagnosis of a heart attack compared to men.**

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[13] Menopause knowledge and education in women under 40: Results from an online survey - PMC
[14] Nearly 1 in 3 Women Have Had Their Menopause Symptoms Misdiagnosed

- **Lack of treatment options to prescribe to patients.**
  There are only 2 FDA-approved treatments for female sexual dysfunction - which impacts approximately 40% of women in the world - **vs 27 treatment options for men.**[15]
  The first treatment option for sexual dysfunction for women was only approved in 2015 vs men's treatment options beginning in 1998. Furthermore, research investigating the interaction between alcohol and Addyi, one of the drugs developed for treating female sexual dysfunction, included 23 male participants and only 2 female participants.

- **Patient dismissal.**

Variability in national regulatory decision:

Medical abortion pill	**Oral contraceptive pill (birth control)**	**Sildenafil ("viagra") for erectile disfunction**
Time for approval by USA FDA:	Time for approval by Ministry of Health, Japan:	Time for approval, Japan & USA
4 years	**35 years**	**6 months**

84% of women
report **feeling dismissed by their GP** in the UK.[16]

Nearly 1 in 4 women
say they **do not feel their clinician takes their pain seriously** (versus 1 in 6 men). [17]

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2. Physicians

- **Lack of awareness around female-centric diseases,** which are diseases that disproportionately impact women or diseases that present differently in women result in:
    - Delays in diagnosis (from the patient side) as women are not aware that they should seek care, or that care is indeed available.

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[15] A discussion about treatment options for women's sexual dysfunction
[16] Results of the 'Women's Health - Let's talk about it' survey - GOV.UK
[17] See My Pain | Nurofen

Doctors discussed **Sexual Health**

with **89% of men** compared to

13% of women

Women with Type 1 Diabetes

are **37% more likely to die**

from secondary complications than men

Women wait **4 years longer**

on average **to receive a diagnosis**

for the same disease as men

Women receive **Pain medication**

16 minutes later than men

in emergency settings

An incomplete picture of potential complications of the condition. For example, the link between PCOS (Polycystic Ovary Syndrome), which impacts an estimated 8-13% of reproductive aged women and cardiovascular disease studies suggest that women with PCOS have 2x risk of a future cardiovascular event, such as a heart attack or stroke.

3. Researchers

- **Lack of sex disaggregated data.**

  In COVID-19 vaccine trials, 28.3% of publications did not report sex distribution among participants. Only 8.8% of the studies provided sex-disaggregated Vaccine Effectiveness estimates.[18]

  Sex-disaggregated data is essential to understand whether there are increased side-effects in one sex or the other, and more generally to

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[18] Sex-disaggregated effectiveness data reporting in COVID-19 vaccine research: a systematic review - PMC

understand the distributions of risk, infection and disease in the population. For example, a study that looks at the impact of a new drug on pain relief might draw the overall conclusion that a drug is effective for both men and women.

Disaggregation would allow visibility into whether the drug works better in one sex than the other, as women and men may well have different mechanisms for experiencing pain[19]. Data disaggregated by sex also allows better visibility into how resources are allocated.

- **Non-representative numbers of females and males in studies.**

  A 2010 survey examining 2000 animal studies found that 80% included more males than females. As recently as 2016, 70% of biomedical experiments did not include sex as a biological variable, and of those that did include sex as a biological variable less than half of them included both males and females in their trials.

  Women's participation in clinical trials remains low, especially in phase I trials (around 22%). Pregnant and lactating women continue to be excluded from clinical trials - even in postmarket phases. This lack of evidence poses challenges for physicians when advising pregnant and breastfeeding women in need of medical treatment.[20]

  - Meaningful representation and analysis of outcomes by sex when it comes to clinical trials still falls short - for instance, the approval of emtricitabine/tenofovir alafenamide (Descovy) for HIV pre-exposure prophylaxis in the United States in 2019 was limited to men and transgender women, excluding individuals assigned female at birth. The manufacturer cited difficulties in recruitment, resource constraints, and uncertain expectations of achieving significant clinical outcomes as the reasons for this exclusion.

  Current guidelines suggest that women should be included in trials in proportion to their prevalence in specific health conditions, but this target is not met in serious disease areas like cardiovascular conditions and certain cancers. Out of the 40 medicines approved by the FDA in 2019 for conditions affecting both sexes, 16 had less than 50% representation of women.

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[19] Why the sexes don't feel pain the same way

[20] Gender bias in research: how does it affect evidence based medicine? - PMC

  - Focusing solely on prevalence fails to address sex differences in disease progression or mortality. For example, in the case of erdafitinib, which the FDA approved for a type of bladder cancer in 2019, only 21% of the participants were women. The justification for this skewed ratio was that men were affected at a significantly higher rate, even though women had poorer prognostic and survival outcomes, even with alternative treatments.

- **Not having visibility into where the gaps in women's health research exist**

  As an example, the NIH has not assigned a unique identifier code to menopause, unlike other conditions such as anorexia or prostate cancer. This means that anyone who wants to know how much funding the NIH has awarded for research on menopause must manually count the number of grants that mention "menopause" in their titles or descriptions.

4. FemTech Startups

- **Gender Data Health Gap**

Lack of consistent data surrounding prevalence, incidence, economic and quality of life burden of diseases in women's health impacts the ability of many FemTech Startups to craft more traditionally compelling businesses-cases. Without data the problem is often dismissed as too 'niche' or 'small' to offer solutions for their populations.

Lack of data also poses a problem from an investment perspective. It makes it difficult for startups to objectively quantify the specific problem they are solving, forced to rely instead on more general metrics such as the size of the 'FemTech' sector as a whole.

Furthermore, data often acts as a substitute for lived experience - which, in the FemTech sector, is vital, as those in decision making positions often have not experienced the problem themselves. For example, startups that tackle fertility and cancer treatment within FemTech are the ones that routinely raise the most money (these are also areas that male founders in FemTech are more involved in). **70% of femtech startups are founded by women, yet male-founded startups raise more capital. On average, female-founded femtech startups raise $4.6m, compared to $9.2m by those with all-male teams.**[21]

FemTech startups thus face an uphill battle, having to convince stakeholders of the need for their solution in the first place. If they are

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[21] https://sifted.eu/articles/even-in-femtech-it-still-pays-to-be-a-male-founder

successful in convincing stakeholders of the need and market opportunity for their solution, they are then confronted by the challenge of a lack of pre-existing data sets from which to base their solutions. It is *difficult* to develop diagnostic and/or therapeutic solutions for women's health conditions when much of the foundational data and basic translational science in the field has not yet been carried out.

As an example, we still have a *fundamental* lack of research and understanding of the pathophysiology of many 'common' women's health conditions such as Endometriosis (which impacts approx. 1 in 10 women, Uterine fibroids (which up to 77% of women during childbearing years experience), PCOS (which 1 in 10 women experience) or PMDD (which impacts between 1-12 and 1 in 20 women of childbearing age). Subsequently, all of the aforementioned conditions rely on imprecise diagnostic tools and none possess a cure.

- **Novel ways to collect data sets to tackle the Gender Data Health Gap in real time**

As we have noted, women's health is rife with information that has not been researched and data that have not yet been collected. FemTech start ups are uniquely poised to disrupt this by collecting novel women's health data sets in real time.

- **Patient Reported Outcomes**

  What is it that women want to know about their own health? Where are they looking for answers and consistently not finding solutions? How can we prioritise the problems women themselves want to be solved in order to identify the most pressing 'unmet needs'.

  - **Roche's #MyStoryForChange initiative:** The stories of 600 women across the globe were collected to better understand the interaction bias women experience with the medical system. A theme that emerged in healthcare settings is that many women feel as if they are not being listened to or that their experiences are not being taken seriously.

  There is a need to find alternative ways to access the healthcare experiences of women, to really learn what issues women are struggling with. We need qualitative as well as quantitative data.

  - **Clue, the #1 doctor-recommended free period tracker app** built in collaboration with top health researchers, is a good case study in the virtuous cycle of women being able to use their own data to advocate for themselves. In the words of Audrey Tsang, Co-Ceo, Clue: “We often hear users in our community say that ‘I just want to be taken seriously’. The world today doesn’t take their pain or their concerns that ‘something doesn’t feel right’ seriously. That’s why they track in Clue—so that their data can help them advocate for themselves and the care they need”

- **Reimagining care**

  Women are more likely to suffer from chronic conditions yet our current healthcare model is structured to service acute situations (and is episodic in how it engages patients).

  If we employ a more consistent, longitudinal means of engaging patients that would expand the type of information we are able to collect. For example, noticing patterns in depressive episodes that might be linked to hormonal fluctuations.

- **Collecting novel biomarkers and datasets via FemTech Startups:**

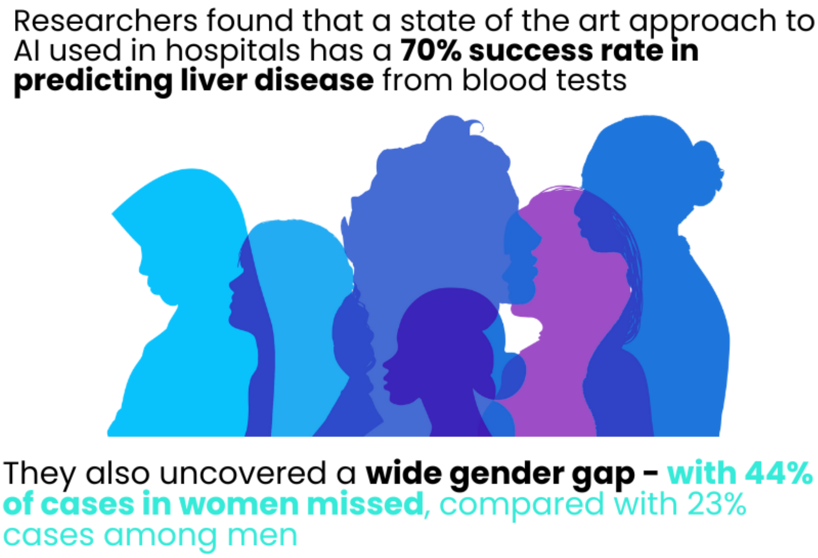
  FemTech startups are uniquely poised to collect data sets that have been previously neglected. Some participants in the 2023 FemTechnology Gender Data Health Gap Workshop doing this are:

  - **Impli:** Continuous hormone monitoring via an implantable device, which has the potential to assist fertility specialists in selecting the best treatment by understanding the patient's hormonal profile, or improve chances of successful fertilization and implantation by optimizing medication dosages and timing.
  - **Daye:** At-home vaginal microbiome screening, using a diagnostic tampon to check for infection-causing microbes and fungi, as well as levels of protective, good bacteria.
  - **TheBlood:** Analyzing menstrual blood for unique biomarkers in women’s health via an at home blood analysis kit for menstrual blood.
  - **Sanno:** Supporting patients with chronic conditions in gut and metabolic health, immunology and women’s health to connect them with clinical trials in the space.

The gender data gap is turbocharged by AI

In the context of continuing and widespread AI adoption in healthcare, we run the serious risk of structurally embedding biases and gaps. Without being aware. Again.

AI learns from the data it's trained on therefore if women are 'invisible' or misrepresented in that data, this can have lethal consequences.


Researchers found that a state of the art approach to AI used in hospitals has a **70% success rate in predicting liver disease** from blood tests

They also uncovered a **wide gender gap - with 44% of cases in women missed**, compared with 23% cases among men

Gender bias revealed in AI tools screening for liver disease[22].

What is algorithmic bias in a healthcare context?

Defined for the first time in 2019 in the Journal of Global Health as "the instances when the application of an algorithm compounds existing inequities in socioeconomic status, race, ethnic background, religion, gender, disability or sexual orientation to amplify them and adversely impact inequities in health systems."[23]

We are becoming more and more aware of how this nexus of missing data sets and our speed in deploying AI models with missing data will entrench inequities.

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[22] Gender bias revealed in AI tools screening for liver disease | UCL News - UCL – University College London

[23] Artificial intelligence and algorithmic bias: implications for health systems - PMC

How does bias enter into AI in health research?

Table: Examples of Types of Bias in Artificial Intelligence & their descriptions[24]

Type of Bias	Description
Inherent or Historical Bias	Even when data is **accurately collected and sampled**, models might yield **undesired results due to pre-existing societal biases** in the world. e.g. making the mistake of associating HIV primarily with gay and bisexual men because of its higher occurrence in this group.
Representation or Sampling Bias	When certain **segments of the data input are not adequately represented**. e.g. a large part of genomics research predominantly focuses on European male demographics, sidelining other ethnic groups.
Data Proxy Bias	When the data we collect serves as an **indirect measure for the desired attributes.** e.g. using various clinical, social, and cognitive indicators to identify early stages of schizophrenia, even though gender differences can influence the manifestation of these indicators and their related psychosis risk.
Generalization / Aggregation Bias	When a **universal model is applied** to groups that have **distinct underlying conditions.** e.g. despite diabetes' variable interpretations across different ethnicities and sexes. the widespread use of haemoglobin A1c (HbA1c) levels to diagnose and track the disease.
Evaluation or Benchmarking Bias	when the data used to test or benchmark an algorithm isn't a **good match for the intended audience.** e.g. the underwhelming performance of certain facial recognition technologies on individuals with darker skin tones, especially females, because most benchmark images are sourced from white males.
Modelling Bias	Bias can be inadvertently or deliberately embedded into an algorithm, **especially when relying on improvised solutions.** e.g., when a commercial health prediction algorithm used healthcare costs as an indicator for health condition without factoring in prevalent disparities in healthcare accessibility, it displayed considerable racial prejudice changing predictions of genuine need.

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[24] Sex and gender differences and biases in artificial intelligence for biomedicine and healthcare - PMC

Synthetic Data

As we wait to collect the much needed missing data sets on women's health there is a discussion about the use of synthetic data to augment data sets. This is a very promising approach on a number of levels but which has its own limitations if not thought through carefully.

Before using synthetic data to add to a dataset it must be noted that many patient cohorts had minimal participation in the original data.[25] **Statistics show that racial and ethnic minorities comprise 39% of the United States population but only account for 2% to 16% of clinical trial participants.**

Factors like age, biological sex, disabilities, chronic comorbidities, geographical location, gender identity, race, and ethnic background may influence how an individual reacts to a certain drug, medical device, or treatment plan. If patients in clinical trials do not represent the whole community, there is the risk that differences in drug metabolism, side effect profiles, and outcomes will be missed.

This also translates when using synthetic data. The lack of diversity in synthetic patient cohorts can result in AI models that perform poorly on real-world populations. As an example, generating data for 500 Black male patients and 500 Black female patients using a synthetic data generator trained on predominantly white medical records would not accurately reflect the true disease progression and outcomes experienced by Black patients.

To address this, **representative real-world data must be collected** first to ensure that AI models do not perpetuate healthcare disparities. Moreover, the synthetic data landscape in healthcare is fraught with ethical considerations. While synthetic data offers the potential to accelerate medical research, drug development, and personalized treatment strategies, it must be used with care to avoid reinforcing biases and ensuring patient privacy and consent.

The opportunities for bias to enter into the data and machine learning lifecycle occur at every stage from inception, to System Requirement definition, data discovery, selecting and developing a model, testing and interpreting outcomes, and post-deployment/ Impact & Audit.

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[25] https://aiequalitytoolbox.com/library/synthetic-data/

A multifaceted approach

Addressing gender data gaps in healthcare using AI requires a multifaceted approach, both in terms of technical solutions and systemic awareness. Here are some thoughts on a multi-dimensional strategy to fill these gaps, keeping the data limitations in mind:

- **Acknowledge the Limitations:** First and foremost, any AI solution should clearly communicate the limitations of the data it's trained on. Users should be aware that predictions or insights may have inherent biases and are not likely to be as accurate for underrepresented groups, particularly women.

- **Collaborate with Experts:** Collaborate with gender researchers, sociologists, and clinicians who have expertise in women's health. Their insights can guide data collection, feature engineering, and model evaluation.

- **Crowdsource & Citizen Science:** Engage the public, especially women, in collecting and contributing health data, including with wearables. Initiatives like Apple's Research Kit have shown how valuable citizen-contributed data can be for medical research.

- **Synthetic Data Augmentation:** Using synthetic data augmentation techniques to artificially increase the size of underrepresented datasets. As noted above, this doesn't replace real data, but it can help improve model performance by generating synthetic data based on existing patterns. With important caveats as ‘existing patterns’ can translate into perpetuating healthcare inequalities.

- **Transfer Learning:** Use models pre-trained on related tasks or datasets to benefit from their learned features. This can be particularly helpful if there are related areas of medicine where more diverse data is available.

- **Meta-analysis and Data Synthesis:** Conduct a meta-analysis of existing studies to derive broader insights. Even if individual studies are male-centric, combining results could help highlight patterns or trends that are relevant to women.

- **Inclusive Model Development:** Design models that explicitly account for gender and other demographic differences. For example, use multi-task learning where one task could be predicting a medical outcome, and another task could be predicting gender, making the model aware of gender differences.

- **Regular Model Evaluation and Audit:** Continuously evaluate and update the models as new data becomes available. This iterative approach ensures that AI solutions improve over time and remain relevant. If models 'go rogue' in the wild, retire them.

- **Ethical Oversight:** Establish an ethics committee or review board focused on AI in healthcare. This board can assess AI solutions for potential biases, ensuring that they meet ethical and inclusivity standards.

- **Feedback Mechanisms:** Implement feedback loops where clinicians and patients can provide input on AI predictions or insights. Over time, this can help in refining the model and making it more attuned to real-world nuances.

- **Education and Training:** Educate healthcare professionals on the limitations of AI tools, especially when they're based on historically biased data. This education ensures that they can make informed decisions and remain critical of AI outputs.

- **Push for Policy Change:** Advocate for policies that ensure more inclusive and diverse data collection in future clinical trials and studies. Over time, this will help in reducing the data gaps.

By embracing these strategies, AI can be a powerful tool to fill the data gaps in women's healthcare, while also ensuring that the solutions remain transparent, ethical, and continuously improve.

"If used carefully, this technology could improve performance in health care and potentially reduce inequities," says MIT Assistant Professor Marzyeh Ghassemi. "But if we're not actually careful, technology could worsen care."[26] [27]

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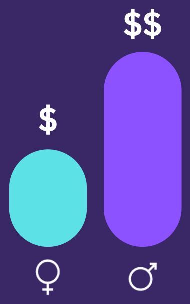
[26] The downside of machine learning in health care | MIT News | Massachusetts Institute of Technology
[27] In medicine, how do we machine learn anything real?: Patterns

FINANCING INNOVATION IN WOMEN'S HEALTH

The current funding patterns neglect Female Health Conditions

with only **4% of US healthcare R&D spending** going directly to **FEMALE HEALTH** of which only 1% goes for **DISEASES OUTSIDE OF ONCOLOGY**

if we invest
$300 MILLION
in women's health across just
3 diseases, we get
$13 BILLION
in returns to our economy



2x more funding
MALE PREVALENT DISEASES
vs female prevalent diseases

Questionst tackled:

- What strategies can be put in place to share the burden of development for novel innovative medicines in women’s health?
- How can multi-stakeholders come together and clearly outline hurdles to build new workable paths and innovate on endpoints in underserved women’s health conditions such as endometriosis, PCOS and fibroids?

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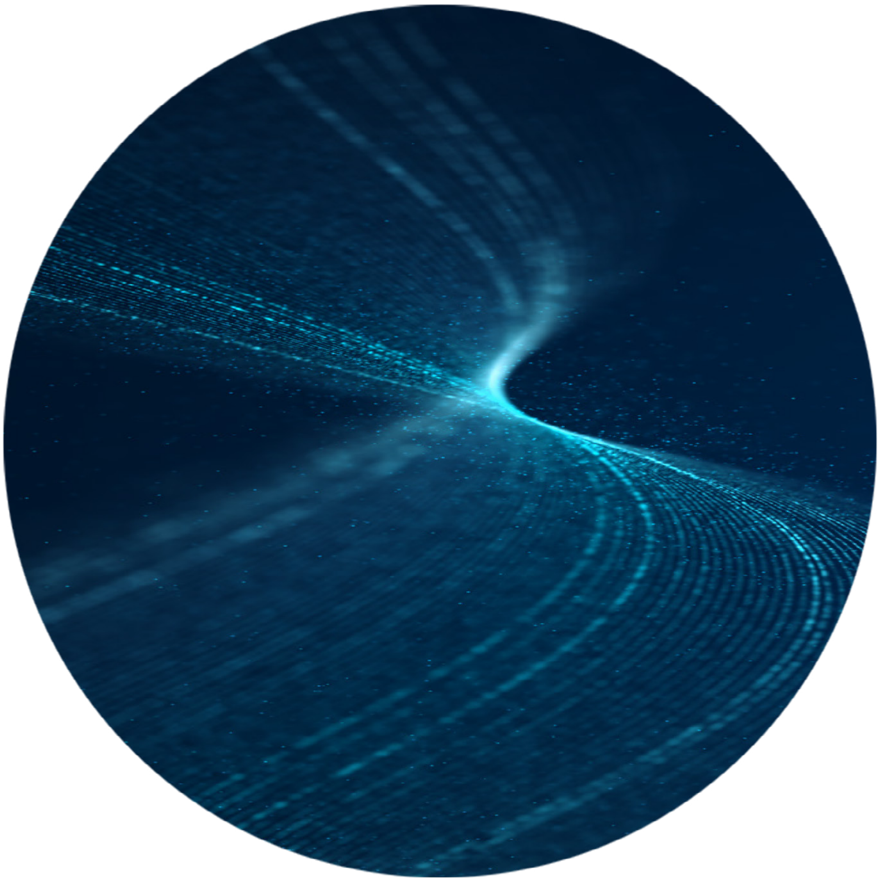

FINANCING INNOVATION IN WOMEN'S HEALTH

A PATH TO ADDRESSING DISPARITIES AND ACCELERATING INNOVATION

NOVEMBER 2023

Catenion

FINANCING INNOVATION IN WOMEN'S HEALTH

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This paper explores the challenges and opportunities in financing innovation in Women's Health. Despite significant unmet medical needs in female-associated diseases, funding research and development (R&D) in this area have been historically limited. To foster innovation, this paper proposes a comprehensive approach, including policy making, public investment, and collaborative efforts, inspired by successful models in other fields such as orphan drug development.

Disclaimer: Women's Health is a general term used to describe indications and diseases that affect uniquely, differently or disproportionally people with uteri, who may or may not identify as women.

NOVEMBER 2023

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FINANCING INNOVATION IN WOMEN'S HEALTH

1. Context

Women's Health encompasses a broad spectrum of diseases and conditions that may either:

01 be exclusive to females,

02 be more prevalent in females or

03 impact females differently and/or disproportionately;

The exact boundaries of this definition remain somewhat ambiguous, allowing for the inclusion of diverse medical indications and terms. Despite the significant unmet medical needs within this field, Women's Health (defined as above) has not received the attention obviously warranted in terms of research funding, for instance, accounting for only 10.8% of NIH funding[3]. Similarly, the biopharma industry has invested merely 4% of its resources, with the majority being directed towards cancer research[1]. Recognizing these critical shortcomings, and drawing parallels with other therapeutic areas, that produced innovative drugs that addressed significant unmet needs and also achieved commercial success is crucial.

To discuss an actionable roadmap forward, catalyze change and raise awareness for the Women's Health field, stakeholders spanning various sectors of the R&D value chain (including researchers, biotechs, pharmaceutical industry, and investors) convened on June 7, 2023 at the *FemTechnology* Summit in Basel, Switzerland. This paper presents the outcome of those deliberations as well as further discussions with Key Opinion Leaders, and outlines the proposed strategies for advancing research and development in Women's Health.

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2. Current status of Funding Innovation in Women’s Health

How relevant is the definition of Women’s Health to Leverage Biomarkers in Drug Development?

Properly defining Women’s Health can be a complex task. While reproductive system-associated diseases have been the obvious indications used to define Women’s Health (e.g., female infertility, Endometriosis, Polycystic Ovarian Syndrome) to date, the field now agrees that a true definition of Women’s Health should expand to indications more prevalent in females (e.g., Multiple Sclerosis, Alzheimer Disease). Nevertheless, there exists a substantially bigger set of indications that can be categorized under the Women’s Health umbrella. In essence, any condition in which women exhibit distinct symptoms and responses could be considered within the realm of Women’s Health, including diabetes and cardiovascular diseases, for example, which would in turn open a whole new perspective on possible disease/sex-specific biomarkers.

> *“The lack of funding in women’s health is why, even today, we still don’t have answers about so much of the basic physiology of 50% of the world’s population. For example, did you know that there are approximately 400 studies on menstrual effluent compared with 15’000 studies on semen? Or that in 2020, only 10.7% of the basic scientific research funding provided by the United States government went towards women’s health research? The lack of funding in women’s health has dire real-world consequences. If stories form a backbone for our society — how can we weave stories that incentivise – no, demands — innovation in women’s health? It requires a movement — and that movement starts with us.”*

Oriana Kraft
Founder, FemTechnology

In recent years, the field of personalized medicine and drug development has boomed, leading to higher Probability of Success (PoS) and blockbuster drugs. While identifying biomarkers can pose challenges, in this context, the most evident biomarker is biological sex. Quoting Dr. Marcus Altfeld, an immunologist at the Heinrich Pette Institute in Hamburg, Germany, “*Everyone is speaking about personalized medicine, having personalized approaches for every individual (…) I think having a step before there, maybe stratifying the population into male and female, and* *optimizing treatment strategies there, is an important step."*[7]. By recognizing the significance of biological sex as a logical biomarker in drug development, we can pave the way for tailored therapies that cater to the specific needs of female (and male) patients, ultimately leading to higher treatment efficacy and a greater PoS for drug developers. This approach also opens up the possibility of repurposing and tapping into previously unexplored diseases, as many drugs may have potential when tested separately in both sexes.

> *The opportunities that exist to improve therapeutic solutions for women and their economic impact are enormous. Replacing or delaying e.g. laparoscopies and hysterectomies with targeted non hormonal pharmaceutical treatments for endometriosis can lead to an increase of the quality of life of patients with endometriosis and a reduction of the current disease burden significantly.*

Liliane Brunner
Halbach Artemis Women's Health Foundation
Deputy Head Therapy Development Accelerator at the University of Zurich

Roots of Disparity: Funding and R&D Challenges

Women's Health has been historically underfunded[1,3] which has hindered innovation greatly both in diagnosis and treatment. This critical imbalance persists despite the widespread prevalence of conditions such as endometriosis, which afflicts an astonishing 10% of females worldwide, and represents a pressing need for more effective diagnostic and treatment options[6].

A stark disparity becomes evident when comparing Women's Health to other therapeutic areas within the biopharmaceutical industry. The market is dominated by generics, primarily hormone-targeting drugs, leading to fierce pricing competition. Additionally, regulatory guidance from FDA and EMA on several of these conditions remains conspicuously absent contributing to the already high R&D hurdles for clinical trial sponsors (e.g., lack of clinical trial endpoints, low recruitment rates, inadequate animal models). Furthermore, there is a profound lack of comprehension surrounding the underlying pathophysiology of these diseases, a deficiency in basic research that significantly constrains the development of novel mechanisms of action and/or bringing innovative treatments from other therapeutic areas into Women's Health.

Nevertheless, there is a growing number of initiatives aimed at supporting early-stage innovative developments. One example of a funding model that encourages transformative research is the BioInnovation Institute (BII). BII provides financial support for innovations that propel the

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creation of novel solutions, particularly by early-stage life science start-ups operating in diverse areas, including Women's Health. Another example is Repro Grants, which is a program that awards grants to scientists or academic institutions dedicated to the advancement of Women's Health research. While these initiatives undeniably play a pivotal role in propelling early-stage research aimed at unraveling the underlying pathophysiology of diseases, it is imperative to acknowledge that realizing substantial progress in this field will necessitate significantly larger investments.

3. Way forward to Financing Innovation in Women's Health

Irrespective of the therapeutic area, to increase interest of investors, pharmaceutical industry and other stakeholders, a positive business case needs to be established. In the context of Women's Health, which impacts over half of the global population, it is crucial to articulate both the broader economic rationale at the government level and the more focused investment perspective relevant to private investors with shorter timeframes.

At the governmental level, the 2021 WHAM report already demonstrated that funding Women's Health research can have a great economic impact (investing $300 million can save $13 billion to the US economy in the next 13 to 25 years)[2]. Regarding private investors, one could also argue that the current model of Venture Capital investment in biopharma may not be adapted to the field of Women's Health since VC incentives focus on the "*sprint*" commercialization, rather than the "*marathon*" of creating value and change. Changing such dynamic is a much broader Therapeutic Area-agnostic endeavor.

Investment in women's health will accelerate the transformation of dreams into innovation reality.

Kathrin Schoenborn

Advisor | Business Angel | Non-executive Director | Diversity enthusiast

In the current financing setup, when economic incentives for biopharma are lacking, it becomes necessary to establish new ones. There are two main paths to create such incentives. One possible path is to launch a Women's Health moonshot initiative with substantial grants for both basic and clinical research, including sex-specific biomarker discovery thus de-risking private investment. However, in the absence of such substantial investment, the foundational step should involve Policy Making & Regulatory support. In Figure 1, we present this potential pathway to achieve financing innovation in Women's Health. Once a foundation of Policy Making & Regulatory Support and/or sufficient Public investment is in place, the next step is to build a solid foundation of basic research. Thorough preclinical studies are essential, allowing us to better understand pathophysiology, a vital component on our journey toward financing innovation. Clinical Proof of Concept (PoC) takes the stage next (Step 4). This phase relies on research partnerships and the generation of clinical PoC data by biopharma to create compelling value propositions (Step 5) that can attract the investment needed to drive innovation in Women's Health (Step 6). It is important to recognize that this journey towards financing innovation in Women's Health will

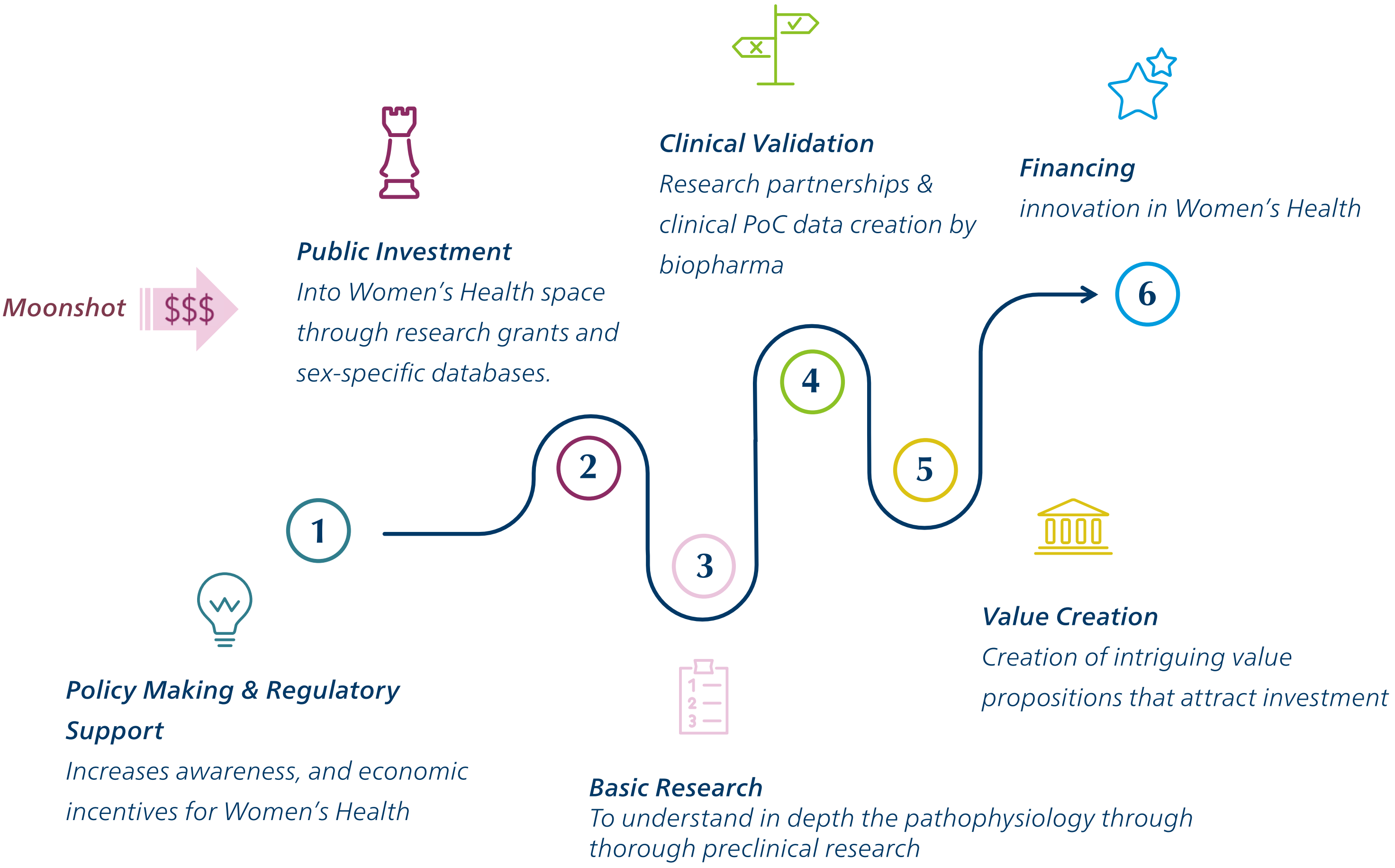

Figure 1 | *Achieving the goal of financing innovation in Women's Health starting from a moonshot investment in research or, in the absence of it, from effective policy making & regulatory support. Source: Catenion* not be a swift one, as basic research, for example, cannot yield immediate results and requires significant time and effort – a reality that may currently pose challenges to venture capital timelines that prioritize rapid PoC and quick exits.

4. Drawing Parallels with Orphan Drug Development:

Women's Health would not be the first example of policy making and regulatory change driving innovation. Historically, orphan diseases were an area in which for many years biotechnology and pharmaceutical companies refrained from developing drugs due to low expected commercial returns. This changed upon the efforts of patient organizations that led to the Orphan Drug Act (Figure 2)[4,5]. Learning from the success of the Orphan Drug Act, which transformed rare disease research, we can apply similar principles to Women's Health. Policy makers, regulators,

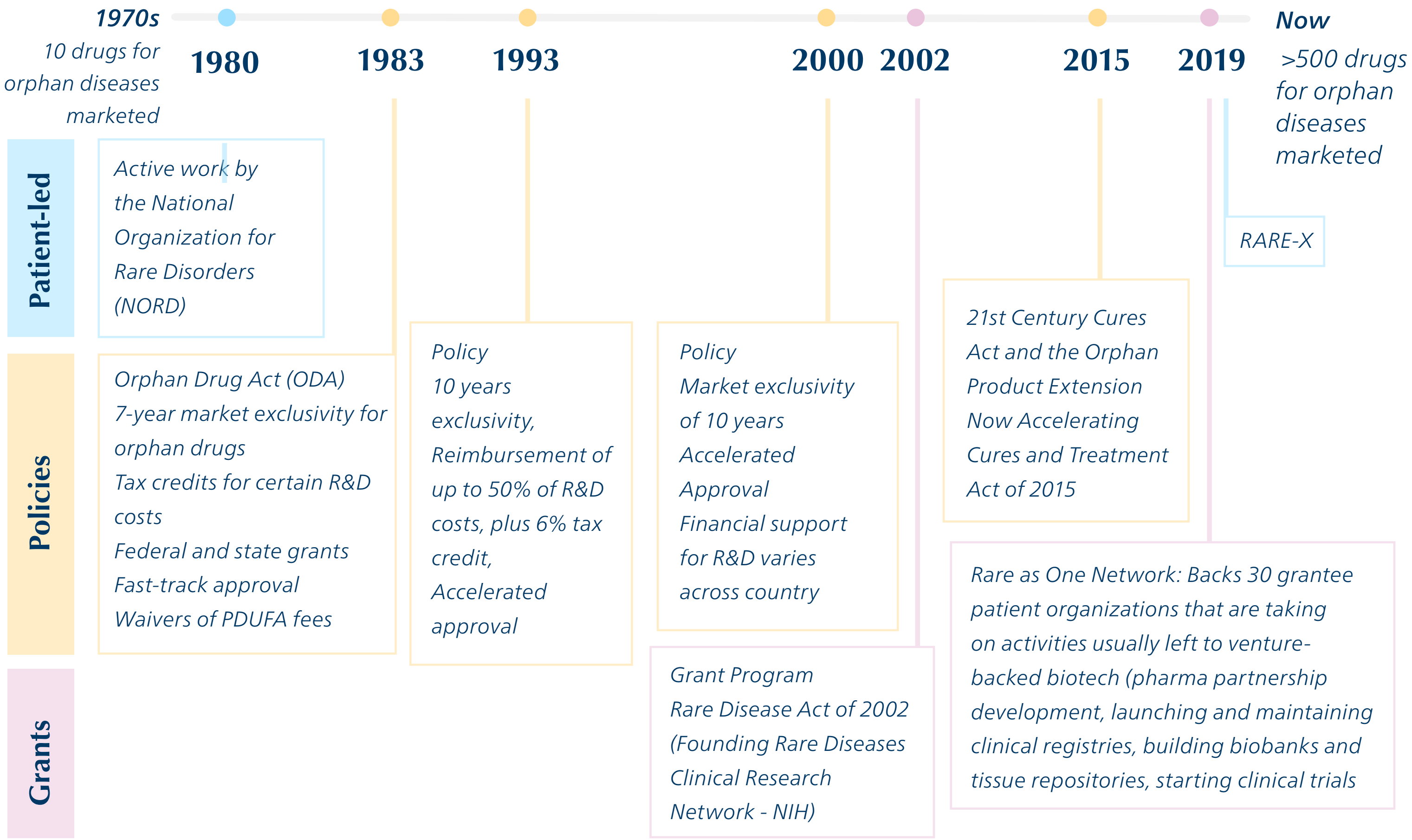

Figure 2 | *Orphan Drugs: From empty pipelines to >500 drugs marketed. Sources: Catenion analysis; FDA.gov; NORD "Impact of the Orphan Drug Tax Credit on treatments for rare diseases" 2015*

patient organizations, and public funding agencies played a pivotal role in incentivizing drug development for rare diseases. A positive business case was created by addressing pricing issues, encouraging investment, and improving patient access. Similarly, for Women's Health, a collaborative effort is necessary to encourage investment and research to initiate the steps towards investment in the field.

The same is true for other fields such as Pediatrics, in which there are clear differences in responses to drugs between children and adults, including different dosages and unique pediatric adverse events. Therefore the Best Pharmaceuticals for Children Act (BPCA) in 2002 and the Pediatric Research Equity Act (PREA) in 2003, driven by the United States Congress, were established for similar reasons that we observe for females today: safety and effectiveness differences (out of the 668 drugs used for the 20 most frequent treatment regimens in the US, 86 show significant sex differences in pharmacokinetics in females[8]). Even cases that are also far from being addressed, such as Racial and Ethical Representation in clinical trials, had legislative acts by the FDA (FDA Amendments Act of 2007 (FDAAA), Prescription Drug User Fee Act (PDUFA) 2016, 2021 FDA's guidance on Enhancing the Diversity of Clinical Trial Populations) in order to encourage development of drugs that address health disparities. These health disparities are also true for females who are underrepresented in preclinical studies & clinical trials. (e.g., Cardiovascular Diseases are the #1 reason of death in females, but in clinical trials, only a quarter of participants are females[9]).

5. Policy Making for Women's Health Innovation:

Given the importance of policy making to drive innovation forward and increase financial incentives to the Women's Health field, Catenion discussed the current state of the Women's Health with 3 experts from United States (US) and 2 from Europe (EU) (policy maker experts from EU and US, and pharmaceutical, medical device and regulatory experts from the EMA and FDA).

Across the spectrum of experts, a consensus emerges highlighting low awareness and limited interest in the Women's Health arena. However, there are differences in sentiment when contemplating the trajectory of this field over the next 5 to 10 years. While a majority of experts exhibit optimism by anticipating the formulation and implementation of policies aimed at fostering innovation in Women's Health within the next 5 years, and quite possibly extending into the subsequent decade, it is worth noting that some remain cautiously skeptical about the likelihood of substantial transformation during this period. All experts concur that ongoing discussions about reproductive rights have heightened interest in Women's Health as a field. However, the challenge of expanding beyond this narrow definition of Women's Health remains substantial. Notably, some experts believe that as a new generation of policymakers assumes positions of influence and leadership teams in regulatory bodies undergo changes, their unique experiences and insights into the healthcare system will bring about different expectations and catalyze change within the field.

Education of the General Public and Policy Makers is Vital to Raise Awareness and Interest in innovation for Women's Health

Women's Health currently receives insufficient recognition from both policymakers and regulators. This is evident in the inadequate funding allocated to researchers and entrepreneurs in the field, resulting in a limited understanding of the underlying pathophysiological processes of related diseases. As elaborated earlier, there's a pressing need for increased incentives on the regulatory front, similar to those granted to orphan diseases. While the FDA and EMA review and approve novel pharmaceuticals and medical devices, these agencies function solely as regulatory bodies, adhering to decisions made by healthcare policymakers (the US congress and the European Commission, respectively). Although they consult policy making, they lack the autonomy to offer incentives independently. Therefore, it becomes imperative to raise policymakers' awareness about the current state of Women's Health and the areas that require enhancement.

One of the primary policy challenges encountered is the lack of a comprehensive understanding of Women's Health. Today, many policymakers and policies in this domain narrowly focus on reproductive health. As voiced by an interviewed US policymaking expert, "*…the important thing is going to be trying to point out that there's a lot more to Women's Health… All their [policymakers'] focus is on access to abortion and domestic violence and that's it. There is more to Women's Health than just pregnancy. There's a way to leverage concern over reproductive health. But to point out that reproductive health is just a small part of the unique needs of women.*".

To alter this narrative effectively, establishing a solid business case for Women's Health is critical. This entails identifying all needs, including but not limited to reproductive health, quantifying their impact on healthcare costs, and showcasing how resolving these issues can lead to long-term healthcare cost savings. Only then advocating rooted in data for policy changes can be done. In recent years there have been noticeable shifts in the field. In addition to WHAM's efforts to highlight the economic aspects of investing in Women's Health, ongoing initiatives led by the NHS Confederation in England are working on a report to highlight the business case of investing in Women's Health. This report will quantify the intrinsic links between investment in women's health and wider economic growth to make the case to the UK government that women's health, the NHS, and the wider economy cannot continue to be viewed as separate concerns, and the most basic needs of 51% of the population should be prioritized.

The Pivotal Role of Patient Advocacy Groups in Shaping Policy

Experts unanimously affirmed the pivotal role of effective policymaking in driving incentives within the Women's Health field. To engage policymakers effectively, experts stressed the significance of leveraging patient advocacy groups and the influence these groups can exert. To ensure productive discussions with tangible outcomes, it is vital to approach policymakers with specific indications that exhibit high unmet medical needs, rather than approaching Women's Health as an entity. Supporting these discussions with patient stories and empirical data, demonstrating unmet medical needs and the economic benefits of improving current treatment options is imperative. For instance, highlighting the needs of the growing number of women entering menopause with limited options to enhance their quality of life, which can result in prolonged participation in the workforce. A recent study by Mayo Clinic supported this by showcasing that menopausal symptoms costs American women an estimated $1.8 billion in lost working time per year[10].

Empowering women's health innovation is not just a choice; it's a responsibility we all share. Let's invest in a healthier and equal future.

Cristina Vilarmau
Innovation Manager at MiMARK

Leveraging Established Consortia to Enhance Credibility

While patient advocacy groups provide essential real-world examples of the impact of diseases

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on individuals, they require scientific validation from the industry. To accomplish this effectively, experts emphasize the importance of establishing consortia that bring together researchers, drug developers, and physicians to address critical gaps and define objectives aimed at resolving these issues. Given that approximately 80% of healthcare professionals in the US & EU are female[11,12], it is reasonable to assume that the industry would be keen to form such consortia. While newly formed consortia, particularly those focused on specific Women's Health indications, are crucial in the field, enhancing the credibility of discussions with policymakers may necessitate engaging with more established consortia such as The American College of Obstetricians and Gynecologists (ACOG) or The European Board & College Of Obstetrics And Gynecology (EBCOG).

6. Supporting Innovation in Women's Health – a Roadmap:

Based on the research and perspectives by Catenion, insightful discussions held during the *FemTechnology* Summit workshop "Financing Innovation in Women's Health" with various industry stakeholders, and in-depth interviews with policy makers and regulatory experts, a roadmap has been put together. The goal of this roadmap is to serve as a valuable guide to steer efforts and as a foundation for discussions regarding the necessary actions to be taken in both the short term and as we shape our long-term strategies.

01

Short-term (~2y)

Identify successful companies and indications with high unmet medical need in Women's Health through systematic assessment, **triggering enthusiasm and interest**. This would allow the field to be portrayed as a successful business case. Start **engaging with regulators and policy makers** to develop mid and long term goals.

02

Mid-term (~4y)

Develop a **health economics model** to **demonstrate the positive business case** for investing in Women's Health, supporting funding decisions using two perspectives:

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- Business Case for governmental entities (mostly in US and EU) focusing on return on investing in Women’s Health research by healthcare savings and economic gains (e.g., working days gained). An example is the current effort by the NHS Confederation for England’s Women Health initiative (more info in the next section). This effort requires a concerted approach and an injection of substantial capital into Women’s Health (such as the *NIH Cancer moonshot* which authorized \$1.8bn to cancer research over a 7 year period);
- Business Case for private investors focusing on return on investment for Women’s Health, emphasizing the potential return on investment and the reduced risk associated with this therapeutic area when substantial government backing mirror practices in other domains.

03

Long-term (~7y)

1. **Break the silos** through a collaborative effort to direct existing and further funding, bridging gaps between basic and applied research in Women’s Health. Such consortia should involve not only pharmaceutical industry by also patient advocacy groups, regulators, policy makers, researchers, translational scientists, etc.

2. **Regulatory Incentives**: Advocate for regulatory incentives through established consortia to promote development and innovation, learning from successful models in other therapeutic areas (e.g., orphan drugs and pediatrics). Engage in education efforts of regulators regarding the key challenges of drug developers in the field of Women’s Health and how a reward based incentive (e.g., longer exclusivity, accelerated development path,) could lead to more innovation for these patients with high unmet medical needs.

7. Call to Action

To follow this roadmap, different actionable strategies can be applied. The relevance of these strategies can differ based on your role and perspective as a reader. Whether you are a patient, a Woman's Health founder, a pharmaceutical executive, a medical doctor, a politician, a health economist, or simply an engaged citizen who values equitable healthcare, these approaches offer various ways for you to get involved and make a positive impact.

It is evident that a collaborative effort is essential to construct a compelling business case for governmental entities to fund Women's Health and help de-risk investment for private investors. To this end, we invite you to consider engaging with and supporting this field as it moves forward.

Below, we enumerate various strategies in which you can actively participate:

- ***Educate and Raise Awareness***
  Launch targeted awareness campaigns, raise your voice on social media to shed light on the wide-ranging health needs of women that go beyond reproductive issues. Share information, stories, and statistics on the existing gaps and challenges in Women's Health (e.g., *XProjet from Roche*, *FemTechnology*). As professionals within healthcare organizations, advocate internally for a stronger commitment to research and investment in areas pertinent to Women's Health from an R&D perspective (e.g., The Wyss Institute's Women's Health Catalyst at Harvard University).

- ***Empower Patient Advocacy***
  Collaborate with patient advocacy groups, participate if you are a patient, or initiate one if needed. Share real-life stories and empirical data that illustrate the unmet medical needs in Women's Health, emphasizing the profound impact on women's lives and the economy (e.g., *The National Polycystic Ovary Syndrome Association*, *The Endometriosis Association*, *The Endometriosis Foundation of America*). Help policymakers and politicians understand the urgency of these issues.

- ***Build Credibility Through Collaborations***
  There is a need for diverse perspectives and interdisciplinary collaboration in Women's

Health innovation. Discuss and collaborate with healthcare professionals, researchers, tech experts, entrepreneurs, etc. to foster more comprehensive solutions. Engage with established organizations such as ACOG and EBCOG to enhance credibility when advocating for policy changes (e.g., *The Lancet Commission on Women, Power and Cancer*).

- ***Establish a Business Case for Women's Health***
  Support organizations and initiatives dedicated to crafting a compelling business case that attracts investment. An excellent illustration of this approach is the "*Women's Health Access Matter*" initiative in the United States. Similarly, in England, the NHS Confederation Initiative is aiming to demonstrate the economic benefits of investing in Women's Health to not only advance the country's Women's Health strategy and secure sustainable funding but also to highlight the broader value of investment beyond the NHS (reach out to *Bridget Gorham* for more information). If you are in a position to contribute to these initiatives, you can do so by donating or by actively participating in the creation and provision of the data required.

- ***Participate in Clinical Trials***
  If you are eligible and interested, consider participating in clinical trials related to Women's Health. The involvement can contribute to vital research and will also provide valuable data that can drive innovation.

- ***Support Nonprofits and Research Organizations***
  Numerous nonprofit organizations and research institutes are dedicated to advancing Women's Health (e.g., *WHAM*, *SWHR*). Consider donating to these organizations, participating in their events, or volunteering.

- ***Advocate for Regulatory Support & Engage with Policy Makers***
  Use your voice to advocate for regulatory incentives similar to those granted to orphan diseases, for example. These incentives can kickstart much-needed research and innovation in Women's Health. Write letters, make phone calls, or meet with local representatives to emphasize the significance of Women's Health and the need for financial support. Or, if you can, collaborate with regulatory agencies such as the FDA and EMA to highlight the

unique challenges and opportunities within this field, by discussing some of the following points:

- Mandatory public reporting of preclinical and clinical trials results segregated by sex
- Increase funding for basic research and for biobanks with segregated data by sex
- Simplified FDA/EMA submissions (develop as the example from ODA)
- Expedite pathways for innovative treatments and diagnostics in Women's Health
- Extended patent life for products launched in highly genericized indications with no innovation in the last 10 years and high unmet medical need

- ***Showcase Success and Solutions***
  Highlight successful Women's Health initiatives and innovations that have effectively addressed unmet medical needs.

> *"These can feel like overwhelming challenges but I get excited about it because you can actually go out in the world and see some really exciting things that are happening on the ground and you know there's the potential to make this look very different. In the same way that many of these things have changed in our lifetimes, my hope is that still in our lifetime we'll see more change happen. (...) Given the amount of treatments that we (Roche) have that can actually impact women's health, I believe we have a very unique, important and urgent role to play in getting this dialogue about women's health more out there."*
>
> ***Teresa Graham***
> *CEO Roche Pharmaceuticals*

Geopgraphical Implications:

While the focus of this report predominantly centers on innovation in women's health within the United States and the United Kingdom, it is worth noting the potential significance of this geographical emphasis. One could speculate that these countries are featured prominently due to their more advanced policies and research environments pertaining to women's health. Nevertheless, it raises an intriguing point about the potential for Europe to become a pioneering force in this domain. With increasing politicization of women's health and reproductive rights in the United States, an opportunity may exist for Europe to establish itself as a cutting-edge hub for innovation in women's health. If Europe or other regions, like Asia, were to implement attractive policies and incentives, they could position themselves as frontrunners in this critical field, ultimately fostering positive global impact.

"… we are playing catchup up. Not only do we have to create knowledge for the future, we actually have to create awareness and advocacy for right now to continue to make sure that dollars get channeled into the women' health category."

Michael Annichine
CEO at Magee-Womens Research Institute and Foundation

8. Conclusion

The path to financing innovation in Women's Health requires a strategic and concerted effort driven by policy making, public investment, and collaboration. Drawing from successful models and supported by a compelling business case to attract investment to R&D, access to effective treatments in Women's Health can be created. However, it is important to acknowledge that venturing beyond the scope of reproductive health will require a longer and more challenging journey. Overall, financing innovation in Women's Health is an imperative for improving the well-being of females worldwide as well as a strategic opportunity for the pharmaceutical industry to develop novel solutions and address dire unmet medical needs.

Any market-player who ignores the needs of women, will be losing out.

Stephanie Sassman
Portfolio Leader Women's Health at Roche

Catenion

Catenion is a management consulting firm devoted to helping pharmaceutical and biotech companies implement more innovative and effective strategies. Catenion works across multiple therapeutic areas for the global biopharma industry including Women's Health.

Authors

Pascal Joly

Partner

Ana Rita da Costa

Manager

Ilkin Nehls

Manager

For further enquiries please email ana.costa@catenion.com

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Sources

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NOVEMBER 2023

WOMEN-CENTRIC CANCER CARE

Women are 34% more likely than men to experience severe side effects from cancer treatments

9 out of 10 men undergoing brachytherapy for prostate cancer were asked about their sexual health vs 1 in 10 women for cervical cancer.

Question Tackled:

Cancer treatment often fails to take into account the personal needs women - in order to improve support and recovery, the holistic (and unique) needs of women must be taken into account. How can we go about shaping this during treatment and after the fact?

IN COLLABORATION WITH Roche

WOMEN CENTRIC CANCER CARE

Featured at **the US Chamber of Commerce**
Panel on How Employers Can Better Support Their Female Employees With Cancer

How You Can Get Involved:

We are looking to showcase case studies of how Women Centric Cancer Care can be implemented in the real world. If you are a Corporate, Clinician, Researcher or Startup with data or a case study for us to highlight - please get in touch at: contact@femtechnology.org

IN COLLABORATION WITH Roche

FemTechnology

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

FemTechnology Summit 2023
Discussion Paper

Authors and Contributors:

Michael Annichine	Magee-Womens Research Institute
Yasmin Baba	Amilis
Shaan Bassi	Inizio Engage XD
Jennifer Cain Birkmose	VivaValet
Amy Bruhn	F. Hoffmann-La Roche
Tina Buchholz	Gyn-Gen-Lehel MVZ, Munich Germany
Maria Louise Cascabel	VivaValet
Paul Chilwesa	F. Hoffmann-La Roche
Aline Clauss	F. Hoffmann-La Roche
Anne Rohinsky Clement	GE HealthCare
Linda DaSilva	Deloitte
Marissa Fayer	HERhealthEQ & DeepLook Medical
Alex Fisher	AOA Dx
Wendy Gerhardt	Deloitte
Rachael Griffin	Patient Advocate
Angela Honegger	UE LifeSciences
Bruno Jolain	F. Hoffmann-La Roche
Farah Hassanbhai Kapoor	Thomas Jefferson University Hospital Women's Board - Executive Committee
Antje Knöll	F. Hoffmann-La Roche
Ece Kozlu	Kadir Has University
Oriana Kraft	FemTechnology Summit
Mitzi Krockover	WomanCentered, LLC and former Founding Medical Director, Iris Cantor-UCLA Women's Health Center
Emanuela Kufel	Prosoma Digital Therapeutics
Liliane Brunner Halbach	University of Zurich & Artemis Women's Health Foundation
Nicola Marcon	F. Hoffmann-La Roche

Caroline Mitterdorfer	Levy Health
Czuee Morey	Xena Dx
Melinda Morimoto	Genentech, Inc., A Member of the Roche Group
Claudia Navarro Padilla	Deloitte
Gilbert Ogbewele	F. Hoffmann-La Roche
Eva Poggio	RoX Health
Margaret Punch	Deloitte
Aahuti Rai	Four Points Health | Conduit Connect (UK)
Emma Ricci-De Lucca	Dartmouth College and ROGUE Innovation + Design
Stephanie Sassman	F. Hoffmann-La Roche
Maike Schmitz	RoX Health
Bharati Shivalkar	Cardiologist (Delta Hospital, Brussels, Belgium); Pfizer
Michelle Snowden	F. Hoffmann-La Roche
Kyle Srinivasan	F. Hoffmann-La Roche
Eva Sum	F. Hoffmann-La Roche
Blessing Tawari	F. Hoffmann-La Roche
Andreas Ullrich	Charité Universitätsmedizin Berlin/Germany Department of Gynaecology
Bettina Zimmerman	F. Hoffmann-La Roche

Members of:
Magee-Womens Research Institute,
UPMC Magee-Womens Hospital,
UPMC Hillman Cancer Center, and
UPMC Health Plan

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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	• Provide advocacy and support • Maintain self-care
Researchers	• Conduct sex- and gender-specific research • Include women in studies and research leadership
Healthcare Providers	• Tailor treatments and care • Facilitate informed decisions based on active listening
Innovators	• Develop women-centric solutions • Engage in collaborative design
Insurance Payers & Employers	• Reassess coverage policies • Support comprehensive care
Policymakers	• 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.

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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.

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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:

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3. 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.

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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."

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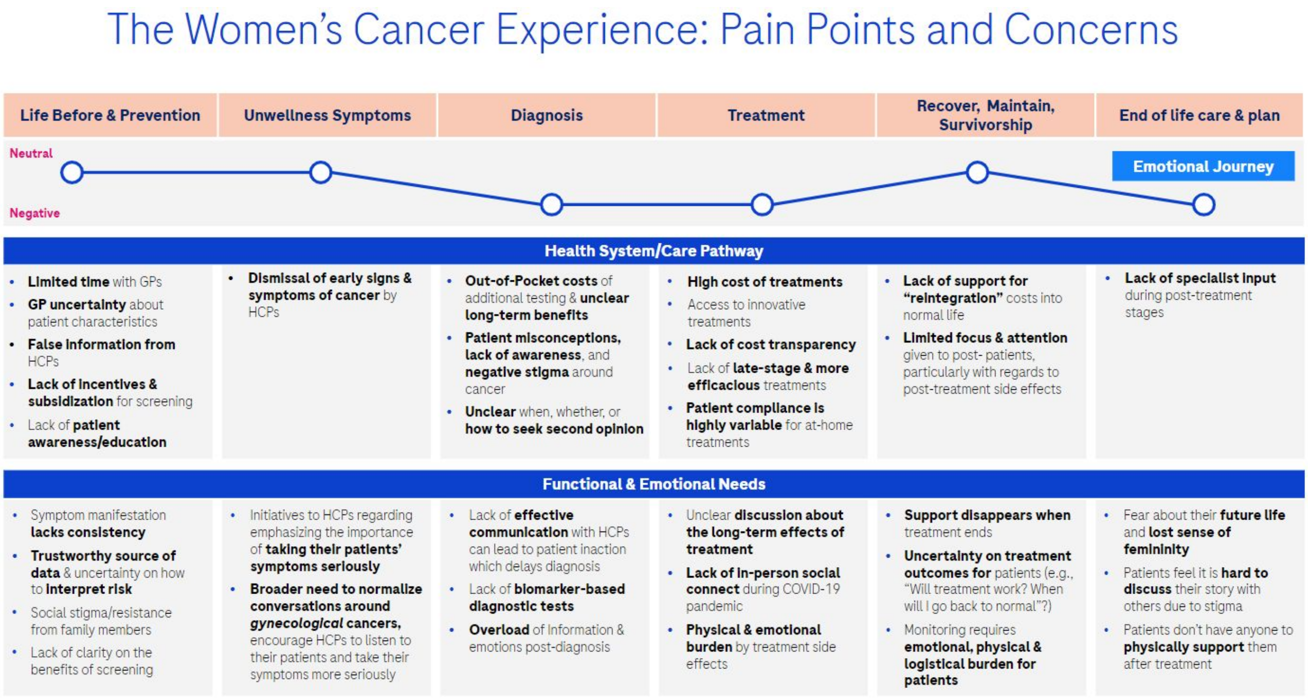
[12] Roche - My Stories for Change: https://www.roche.com/xproject/xstories

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

	Life Before & Prevention	Unwellness Symptoms	Diagnosis	Treatment	Recover, Maintain, Survivorship	End of life care & plan
Health System/Care Pathway	- **Limited time** with GPs - **GP uncertainty** about patient characteristics - **False information from** HCPs - **Lack of incentives & subsidization** for screening - Lack of **patient awareness/education**	- **Dismissal of early signs & symptoms of cancer** by HCPs	- **Out-of-Pocket costs** of additional testing & **unclear long-term benefits** - **Patient misconceptions, lack of awareness**, and **negative stigma** around cancer - **Unclear** when, whether, or **how to seek second opinion**	- **High cost of treatments** - Access to innovative treatments - **Lack of cost transparency** - Lack of **late-stage & more efficacious** treatments - **Patient compliance is highly variable** for at-home treatments	- **Lack of support for "reintegration"** costs into normal life - **Limited focus & attention** given to post- patients, particularly with regards to post-treatment side effects	- **Lack of specialist input** during post-treatment stages
Functional & Emotional Needs	- Symptom manifestation **lacks consistency** - **Trustworthy source of data** & uncertainty on how to **interpret risk** - Social stigma/resistance from family members - Lack of clarity on the benefits of screening	- Initiatives to HCPs regarding emphasizing the importance of **taking their patients' symptoms seriously** - **Broader need to normalize conversations around *gynecological* cancers,** encourage HCPs to listen to their patients and take their symptoms more seriously	- Lack of **effective communication** with HCPs can lead to patient inaction which delays diagnosis - Lack of **biomarker-based diagnostic tests** - **Overload** of Information & emotions post-diagnosis	- Unclear **discussion about the long-term effects of treatment** - **Lack of in-person social connect** during COVID-19 pandemic - **Physical & emotional burden** by treatment side effects	- **Support disappears when** treatment ends - **Uncertainty on treatment outcomes for** patients (e.g., "Will treatment work? When will I go back to normal"?) - Monitoring requires **emotional, physical & logistical burden for patients**	- Fear about their **future life** and **lost sense of femininity** - Patients feel it is **hard to discuss** their story with others due to stigma - Patients don't have anyone to **physically support** them after treatment

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."

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[13] F. Hoffmann-La Roche #MyStoryForChange: https://www.roche.com/xproject/xstories

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 studio."

"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."

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[14] Roche - F. Hoffmann-La Roche #MyStoryForChange https://www.roche.com/xproject/xstories

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.

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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

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[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.

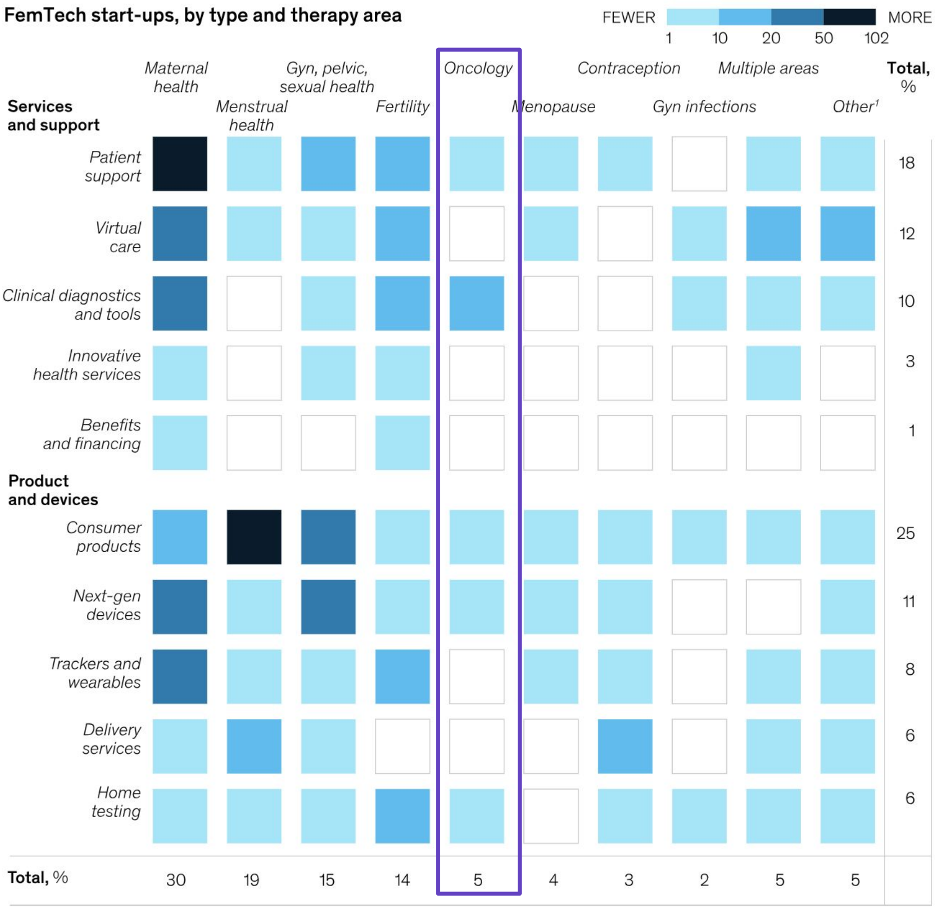
Designing new products and solutions requires a meticulous understanding of women's specific needs and challenges. Cancer survivors or their caregivers often find purpose by applying this lived experience to starting businesses.

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.



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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 haber 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

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[18] F. Hoffmann-La Roche #MyStoryForChange: https://www.roche.com/xproject/xstories

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.

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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

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[23] https://microinsurancenetwork.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 asesoramiento 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."

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24. F. Hoffmann-La Roche #MyStoryForChange: https://www.roche.com/xproject/xstories

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 recommendations[25], 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.

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[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.

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[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]

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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.

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[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?

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[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.

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[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]

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[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://bciu.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.

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[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 Act[37] 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

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[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 #MyStoryForChange[39]. 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 diagnostico 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 perdida 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."

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[39] F. Hoffmann-La Roche #MyStoryForChange: https://www.roche.com/xproject/xstories

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 checkeos genecológicos 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."

ESG ALIGNMENT FOR WOMEN'S HEALTH

WHAT WE DON'T MEASURE, WE CAN'T SEE

How can we track the performance of public companies committed to disclosing their efforts to support women's health?

WOMEN ARE UNDER-REPRESENTED IN THE BOARDROOM

Questions Tackled: :

How can we make women’s health a priority in ESG frameworks? Ever since ESG became a governmental priority, people have increasingly started thinking about the under-representation of women in business, science and clinical trials.
How can this be leveraged to make women’s health a priority within governance and provision frameworks?

IN COLLABORATION WITH Roche

Urgency in Addressing Women's Health: Breaking Barriers and Promoting Equity

FemTechnology (FemTech) Summit 2023: Environmental, Social, and Governance alignment on women’s health

Published: September 2023

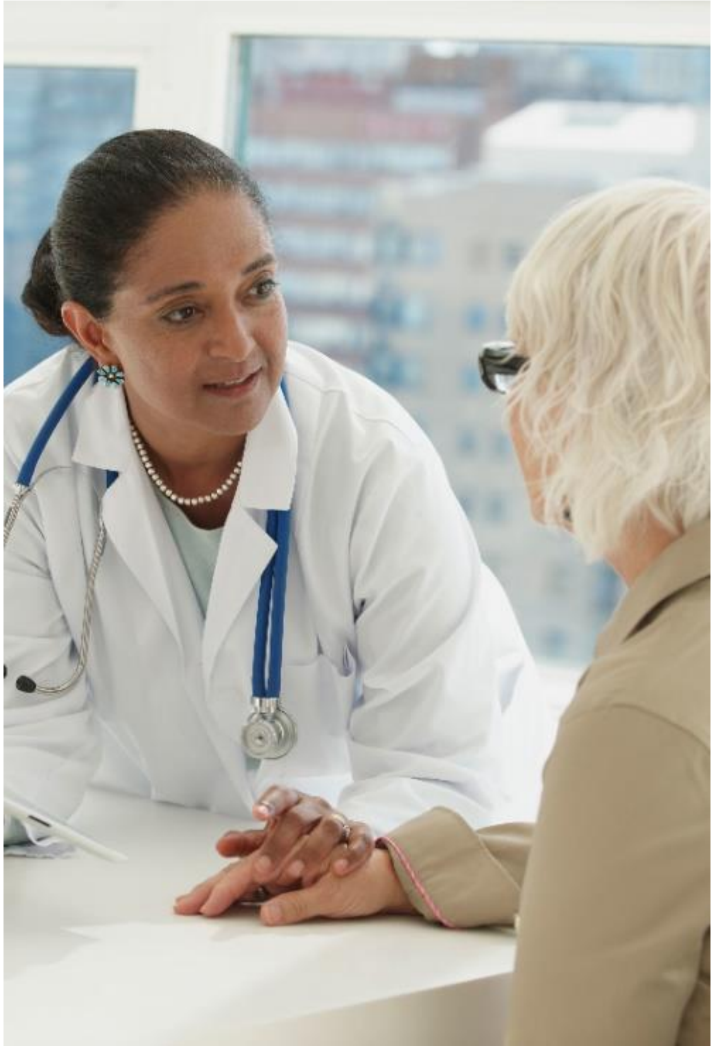
MAKING AN
IMPACT THAT
MATTERS
since 1845

Women's Health: From Historical Oversights to Present-Day Priorities

“We hear a lot about personalized medicine, but we cannot even understand sex-specific care yet” – Oriana Kraft, FemTech Summit Founder

Introduction

Women's health has historically been overlooked and continues to be under-addressed, characterized by disparities and challenges in health care that demand immediate attention. Despite some progress in recent years, significant gaps persist. The FemTechnology (FemTech) Summit, founded by Oriana Kraft, serves as an integrated platform for women's health, bringing together academic researchers, clinicians, FemTech entrepreneurs, investors, and leaders from government and industry. FemTechnology refers to technology focused on improving women's health and well-being[1]. It includes products like wearables, apps, and medical devices and services such as telehealth, digital platforms to improve or support women's health. As a community of experts at the frontier of women's health and digital technologies, the summit sought to disrupt conventional norms and inspire groundbreaking progress in promoting health equity for women. Taking place on June 7th, 2023, in Basel, Switzerland, the FemTech Summit witnessed the participation of over 150 delegates[2] . This global event addressed various interconnected issues, including gender bias, improved health outcomes, the gender data gap, financing innovation for women's health, the role of media in women's health, and the development of women-centric treatments across all health care domains.



During the summit, Deloitte led a workshop aimed at identifying key environmental, social, and governance (ESG) actions that would significantly advance women's health and well-being[3]. This workshop marked the beginning of an ongoing discussion on how FemTech, as a key stakeholder in the health care ecosystem, could accelerate advancements towards reaching health equity for women and sustainably improve health outcomes through appropriate investments.

At the summit, vibrant discussions emerged, highlighting the essential challenges and misconceptions associated with women's health care across various global regions. Attendees emphasized the need for transparent impact measurement and identified three priority areas: awareness, data-driven insights, and affordability.

"The FemTech Summit aims to challenge the status quo and foster innovation in advancing women's health equity. Taking place on June 7th, 2023, in Basel, Switzerland, the FemTech Summit witnessed the participation of over 150 delegates."

1. Increase AWARENESS of female health: Incorporate female-specific content into health care education systems to challenge outdated gender biases and stereotypes.

☆ Challenges

Knowledge on women's health is significantly lacking, resulting in limited understanding of the impact of diseases affecting women beyond those related to reproductive and sexual health[4-7].

Persistent gaps in awareness and prevalent gender bias contribute to misconceptions surrounding women's health. One prevailing misconception is that women's health pertains only to sexual and reproductive aspects. However, women's health encompasses their overall well-being. As an example, the leading cause of death for women worldwide is cardiovascular disease (CVD) and more women die from CVD than all types of cancer combined[8]. In contrast, the number of awareness campaigns and charities dedicated to breast cancer is much more than that of CVD for women, and it sends a wrong image that breast cancer is the leading cause of death for women in developing countries[9].

Another systemic challenge to awareness is the lack of communication associated with negative stigmas surrounding diseases of aging women like menopause. Despite its impact on virtually all women, menopause is rarely discussed openly at home, in the workplace, or at clinics. A survey in the US revealed that 20% of women wait for more than a year before seeking medical advice for menopausal symptoms, and 34% have never been diagnosed[10]. This underdiagnosis leads to other preventable areas of mental and physical health deteriorating and worsening the overall quality of life for women. As of now, initiatives to address the gender health disparities during menopause and perimenopause have been minimal, highlighting a pressing need for more comprehensive strategies and actions[11].

> "A survey in the US revealed that 20% of women wait for more than a year before seeking medical advice for menopausal symptoms, and 34% have never been diagnosed."

Actions

To address the challenges in women's health, it is crucial to increase awareness and educate the general public as well as health care providers with gender-specific content. Providing a comprehensive view of women's health will also override outdated biases and stereotypes. Impactful actions highlighted during the discussion to address the awareness challenges include:

01 Update medical education curricula to include comprehensive gender-specific medical information. By covering a wide range of conditions beyond reproductive health and providing continuing education on women's health, including gender-sensitive care and communication skills, we can bridge the gap and promote gender equity in health care[4, 12]. Using latest technologies including AI, FemTech can revolutionize medical education, improving patient outcomes. (*social/governance aspects of ESG)*

02 Foster interdisciplinary collaboration among health care stakeholders to ensure comprehensive FemTech investment and continuous growth to innovate women's health. Give priority to patient education and empowerment through the creation of precise and easily accessible resources, while encouraging open dialogues with patients. (*social aspects of ESG)*

03 Raise awareness by implementing United Nation's sustainable development goals and initiatives into corporate strategy[13]. Measure progress to bridge health care gaps and promote equity. For instance, partner with influential figures to raise awareness about women's health, sharing their experiences, and advocating for policy changes. (*social/governance aspects of ESG)*

04 Monitor the percentage of women in leadership roles. Develop plans to sustain gender parity at the highest levels while advocating for women's health advancement[14]. The representation of women in executive committees across the health care sector needs improvement to help progress on health equity. Every institution could advance their governance and gender parity agenda by addressing this call for action. (*social/governance aspects of ESG)*

Metrics

Potential metrics to evaluate the impact of efforts to raise awareness and support for women's health are:

- Ranking of medical universities: Assessing the inclusion of women's health in medical education curricula through university rankings.
- Reporting the amount of financial investment made by venture firms specifically in FemTech startups, indicating active financial contribution towards achieving health equity for women.
- Tracking and reporting the number of initiatives implemented by organizations to raise awareness on women's health. The report can be part of the annual report.
- Under the ESG or corporate social responsibility section to raise awareness and to foster an equitable society.
- Percentage of female leaders at the highest level of decision-making bodies within health care ecosystems including government, NGOs, and industry.

2. DATA-DRIVEN insights and actions: Improve understanding of diseases in women by collecting the right data.

Challenges

There is currently not enough comprehensive data collected on women's health, despite comprising approximately 50% of the global population, leading to underdiagnosis and lack of early intervention. This need has been overlooked in society and medicine and is evident in various aspects, such as:

- Research funding for diseases affecting mostly women is significantly lower compared to those prevalent in men[15].
- Fewer women participate in clinical trials, hindering our understanding of gender-specific symptoms, side effects and treatment options. Subsequently biased conclusions can arise from the use of primarily male subjects, animals, and cell lines[16].
- Women often feel their health care concerns are dismissed due to societal gender biases on what should be tolerated by a woman versus a man, therefore symptoms experienced are not captured as a data point for diagnosis and treatment consideration[17,18].

> “Women often feel their health care concerns are dismissed due to societal gender biases on what should be tolerated by a woman versus a man...”

Actions

01

Ensure fair distribution of research and development funding. This requires unbiased decision-making within funding organizations, where neither men's nor women's health are given preferential treatment. A study found that a $300 million investment into women’s health research could yield $13 billion in returns to the economy by reducing health care costs, improving quality of life, and returning years of productivity to the workforce[19]. (*social/governance aspects of ESG)*

02

Include more female subjects, female-specific animal models, and female-derived cell lines in medical research to enhance the understanding of disease conditions in women. Health authorities and pharmaceutical companies have already initiated measures to increase gender diversity in clinical trials and aggregate data[20, 21]. These efforts enable the analysis of data based on gender, race, and ethnicity, thereby improving health outcomes for all individuals. (*social aspects of ESG)*

03

Provide incentives to enforce diversity in clinical trials. Health authorities and relevant stakeholders can implement policies to promote clinical trial diversity. A breakthrough designation has been implemented to accelerate access to medicine for patients with life-threatening diseases. Such an accelerated approval path can also be applied to medicines that greatly improves health equity for underserved populations including women. (social/*governance aspects of ESG)*

04

Implement a centralized and publicly accessible data repository of disease prevalence with gender-specific information. While such information is partially already available online data clustering by gender, race, and ethnicity can be further improved. It allows for a better monitoring of disease occurrence, identifying contributing factors and symptoms unique to women, and establishing evidence-based interventions and policies. It democratizes data and promotes informed decision-making. FemTech could be an enabling partner for building data solutions. (*social/governance aspects of ESG)*

Metrics

Potential metrics to measure the impact of better understanding women's health include:

- Disclosure of the allocation of research funding to women's health by funding agencies, research institutions, and biopharma companies is a crucial metric that will help identify and adjust disproportionate distribution of investment at innovation stage.
- Percentage of female-specific animal models used and female subjects in a clinical trial study to promote clinical trial diversity.
- Evaluation of the incentives and their impact on gender balance in research studies.
- Data-driven insights inform health investment decisions both in public and private health care systems and lead to collaborative initiatives to improve health outcomes for women across all disease domains. The number of times a data source is referenced in approved business cases for health investment could be an indicator of equitable attention.

3. Improve the quality, accessibility, and AFFORDABILITY of health care for women.

Challenges

Social and economic disparities ingrained in our society, worsened by taboo perceptions around women’s health issues, greatly hinder access to quality care. According to a report of the World Health Organization, 2 billion people struggle to pay for health care service out of pocket, including women in marginalized communities, leading to preventable health complications and mortality[22]. The apparent lack of information, consideration of women’s access and affordability challenges when developing new care models and innovative treatment is essentially depriving half of the world’s population of their basic right to equitable health care.

> “Social and economic disparities ingrained in our society, worsened by taboo perceptions around women’s health issues, greatly hinder access to quality care.”

Actions

To address these challenges, the following actions can be taken:

01 Leverage innovative methods like telehealth, drone deliveries, and mobile clinics to improve accessibility and reduce geographical barriers in health care. These solutions not only offer better societal outcomes but are also environmentally sustainable [23]. Utilizing Femtech apps and wearables, patient data can be shared electronically to health care professional and in return receive diagnosis and prescription without going into a clinic. Mobile clinics and drone delivery bring health care directly to underserved communities, minimizing the need for patients to travel long distance. COVID was the most recent accelerator that led to an increased leverage of these health care access channels[23]. Furthermore, this sustainable approach aligns with environmental conservation goals thereby preserving a healthy planet for a healthy population. (*social/environmental aspects of ESG)*

02 Adopt affordable health care models to enhance patient outcomes and ease the health care system's load. Comprehensive health insurance plans, combined with preventative care initiatives could both ensure affordable care for women while also contributing to better lifestyle choices and early diagnosis. (*social/governance aspects of ESG)*

03 Enhance timely access to accurate data by implementing system-wide electronic health records and interoperable systems, allowing access to medical history, and enabling timely and accurate diagnoses at all clinics. FemTech could leverage data science and Generative AI to develop personalized health care solutions for women[23]. (*social/governance aspects of ESG)*

04 Equip pharmacists with the facilities to conduct private consultations for women’s ailments that can be treated by non-prescription medications, thereby discussing symptoms in privacy, and providing affordable treatments in time (e.g., urinary tract infection medicine, morning-after pill). (*social/governance aspects of ESG)*

05 Reinforce collaboration among policymakers, academics, health care organizations, insurance providers, and technology stakeholders. Collaborative research and development among them will reveal evidence-based solutions to provide more accessible, affordable, and accurate medical care and eradicate health inequity in health care. This Femtech Summit is an example of such a collaboration, and we need to continue building this ecosystem. *(social/governance aspects of ESG)*

Metrics

Potential metrics to consider in measuring progress include:

- Number of patients reached through telehealth who would otherwise not have consulted a physician or received treatment.
- Ranking of health insurance offerings that promote preventive and monitoring care for women can provide insights into the level of support and focus on women's health care within the insurance industry.
- Savings in health care costs resulting from early diagnosis.
- Increase in quality-adjusted life year rates for diseases prevalent in women.
- Reduction in disease-adjusted life rates through affordable treatment and improved adherence.
- List and number of local pharmacies per region that are capable of triaging women’s health issues.

Conclusions

Upon the conclusion of our workshops, it is abundantly clear that we stand at the precipice of change. Through our diverse organizations, each of us possess an extraordinary capacity to ignite this transformation in women's health care and drive change forward, utilising the myriad of resources at our disposal.

To drive impactful change, forging strong alliances across the health care ecosystem is critical. We need to create a sustainable 'community for change' underpinned by collaboration with Femtech stakeholder to turn the tide in favour of women's health equity.

Importantly, in all our endeavours, let's align our actions with Environmental, Social, and Governance (ESG) priorities. Let's strive to articulate a narrative promoting an equitable governance structure that serves as a vital lever for driving meaningful social impact through women's health equity.

Let's continue to campaign for improving women's health equity which has far-reaching implications. It will not only influence women but society at large. With an urgent and united approach, we can activate our collective strength, fostering a healthier and more equitable future.

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Health Equity Team

Patricia Gee
Swiss Health Equity Lead
pgee@deloitte.ch

Rekha Jacob
Swiss Health Equity Team
rjjacob@deloitte.ch

Elizabeth Hampson
European Health Equity Lead
ehampson@deloitte.co.uk

Agathe Grisard
Swiss Health Equity Team
agrisard@deloitte.ch

Linda DaSilva
Vice President, Sales Executive
lidasilva@deloitte.com

Dr Shafagh Dastjani Farahani
European Health Equity Team
sdastjanifarahani@deloitte.de

Dr Helena Klipan
ESG and Health Equity
hklipan@deloitte.ch

Dr Sonoko Kanai
Swiss Health Equity Team
skanai@deloitte.ch

Deloitte.

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REDESIGNING HEALTHCARE WITH WOMEN IN MIND

Doctors discussed **SEXUAL HEALTH** with **89% of men** compared to **13% of women**

Women receive **PAIN MEDICATION** **16 minutes later** than men **IN EMERGENCY SETTINGS**

Women wait **4 years longer** on average **TO RECEIVE A DIAGNOSIS** for the same disease as men

WOMEN WITH TYPE 1 DIABETES are **37% more likely to die** from secondary complications than men

Questions Tackled:

Modern medicine was not designed with women in mind.
A notable example: women's reproductive health - puberty, pregnancy, menopause and beyond - is often treated in isolation from other organ systems and conditions with problematic implications.
How can we ensure these monumental transitions are better integrated?

The prevalence and manifestation of diseases differs between men and women - how should that shape the diagnostic tools that are used, how care is accessed, what is considered a 'vital sign', what our definition of the baseline is in what we screen for?

IN COLLABORATION WITH Roche

REDESIGNING HEALTHCARE WITH WOMEN IN MIND

Open Letter Launched at the **World Economic Forum** As Part Of The Women's Health Global Alliance

How You Can Get Involved:

Sign The Open Letter to Join The List of 60+ Signatories From Across The Healthcare Value Chain Who Have Committed To Collaborating And Taking Collective Action To Redesign Healthcare With Women In Mind.

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Photo by Kearney

Redesigning healthcare with women in mind

FemTechnology

KEARNEY

Foreword

For many years, there was an overlooked inequity at the heart of the global healthcare industry: one that continues to have potentially devastating—if not deadly—consequences for half of the population. What is it? A decades-long history of inadequate awareness, underinvestment, missed opportunities, and institutional bias in women's health.

In today's world, health equity is by no means a given, and recently, the penny has started to drop that change is not only necessary, but long overdue. More and more evidence has come to light, showing that women spend a greater part of their lives in ill health and disability compared with men and are more likely to have their concerns dismissed, misdiagnosed, or missed altogether when they do seek help.

In response, high-profile programs such as the World Economic Forum's Women's Health Initiative and UNFPA's 2030 Equity Alliance have started to give the issue more consideration, while large corporations such as Roche, UCB, Philips, Hologic, and GE Healthcare have picked up the baton in the private sector. Now more than ever, health outcomes for women and girls are being specifically addressed.

The digital and data revolution has also enabled some huge leaps forward. Femtech, the branch of technology innovation designed to support and advance women's health, has given many women control over their menstrual cycles and hygiene; fertility, pregnancy, and postpartum treatment; reproductive, sexual, and family health; preventive care; and more. The femtech industry is forecast to be a trillion-dollar sector by 2027. Similarly, digital health companies such as Owkin and Huma and tech giants such as Microsoft have turned their attention toward advancing women's health in particular, contributing to addressing a significant data gap.

But at the same time, a dizzying array of statistics tell us that biological sex and gender continue to form deep fault lines in healthcare provision, which negatively and disproportionately impact people who are biologically assigned female at birth and those who identify as women.

While most theories of health communication, public health, and medical education currently do not consider issues of gender or identity, we believe not widening out this lens has the potential to worsen inequalities within the system. In this report, we examine the nature of care required and the experience of care for individuals across biological sex and gender. For the purpose of simplicity, we will use the words "woman" and "women" to apply to anyone who fits either category, unless we are talking specifically about the female sex or sex-based differences in healthcare.

This isn't the first time these issues have been presented. The causes are complex, varied, and often buried under layers of historical norms and bias. However, in our view, it's time for practical solutions and fixes and a lasting commitment to regenerating women's health. It is also our view that, like raising a child, closing the women's health gap will take a village: companies acting alone will certainly have an impact, but the step-change required will only come from cross-sector collaborations and partnerships.

That's why this movement, backed by this report, was born. To create a cross-sector community, representatives from the healthcare industry, education, government, the medical profession, financial investors, and all other parties have committed to come together to shape a more equitable future for women's health. We are committed to change things for the better, together.

Will you join us?

Paula Bellostas Muguerza
Senior Partner and European Healthcare and Life Sciences Practice Co-Lead, Kearney

Oriana Kraft
Founder and Producer, FemTechnology Summit

A tale of two halves

In 2012, four Berlin-based entrepreneurs co-developed an app called Clue, one of the world's first technology tools for tracking menstrual cycles and their side effects. It proved popular and grew quickly, gaining three million active monthly users in just two years. Fast forward to 2022, and Clue had been joined by many similar solutions, pushing the global menstrual health app market to a valuation of $1.2 billion.

Even as the demand for and provision of women-specific healthcare initiatives and tools is on the rise, policy changes that adversely affect women's health are still being enacted, and critical issues remain unaddressed, as the UK government's recent rejection of mandatory menopause training for general practitioners (GPs) demonstrates.

This illustrates both the critical need for—and precarious state of—women's health today, and it's just one example of the myriad ways in which women's lives and well-being are fundamentally disadvantaged by a lack of understanding, lack of data, lack of investment, and far too often a lack of interest in their specific health issues and needs.

Women's health: where is the care?

Several reports have already identified what has been referred to as a gender gap in healthcare. It's undeniable that the socially constructed norms, attitudes, and behaviors around what comprises different genders and identities holds sway over how people are regarded within the healthcare system, what they experience when they participate in it, and how this influences their health outcomes. It's also true that sex-based differences (in other words, the biological and anatomical differences between those assigned male or female at birth) have a huge influence on all these factors. In this report, we examine the specific impacts on those assigned female at birth and those who identify as women.

Biological sex impacts health

Most people assigned female at birth experience reproductive health events exclusive to their sex, namely menstruation, pregnancy, and menopause. These come with a wide variety of associated conditions, such as endometriosis, which is thought to affect 10 percent of reproductive females globally; perinatal mood and anxiety disorders, which affect around 15 to 21 percent during or after pregnancy; pelvic floor disorder, thought to afflict up to a third of adult females; and menopausal symptoms such as hot flashes, night sweats, insomnia, and "brain fog," which have been reported as causing one in three women to face problems coping at work. Interestingly, it was these topics, along with mental health, that most respondents to the UK government's consultation on its Women's Health Strategy for England wanted to see prioritized.

But the repercussions go far beyond the reproductive cycle.

Hormonal influences are also at play in conditions such as osteoporosis, which is four times more common in females age 50 and above than in males. If you're a member of the female sex, you also are two to three times more likely to suffer from migraines, are twice as likely to experience depression and anxiety or develop Alzheimer's disease, and have up to a four times higher risk of autoimmune diseases including lupus and rheumatoid arthritis. What's more, within five years of having a heart attack, almost one in two (47 percent) females will die, develop heart failure, or have a stroke, compared with 36 percent of males. Overall, while female life expectancy is generally longer than that of the male sex across geographies (83 years versus 78 years in the European Union, for example), females consistently report poorer health throughout their lives and spend longer in poor health.

Clearly, there is limited awareness of—and/or willingness to explore how—female health conditions as well as general health conditions that affect both sexes, impact females specifically.

On the other side of the coin are issues related to gender, which can be trickier to uncover and root out, given their importance in shaping identity at all levels of society and the many biases and stereotypes that come in their wake.

> **“The history of medicine, of illness, is every bit as social and cultural as it is scientific.”**
>
> **Elinor Cleghorn, *Time* magazine**

> **“Dementia disproportionately affects women, both as patients and as primary caregivers. This double burden underscores a critical need for redesigning healthcare with a female-centric approach.”**
>
> **Carl R. Hanna, PhD, CEO/Co-Founder, Evva Health**

Gender norms and biases also impact health

The great double bind in women’s health today is that, on the one hand, women are routinely treated differently from men because of the sex-based, biological differences between males and females, and on the other, they are treated as an “average male” because medicine hasn’t yet interrogated these differences sufficiently. What impact does this have?

There’s a persistent stigma around female and women’s health topics

This is particularly the case when it comes to menstruation, sexual and reproductive health, and mental well-being (hysteria, coming from the Greek word for uterus, being routinely used to explain many of the symptoms reported by women historically).

Even today, almost one in two women (42 percent) have experienced period shaming, while according to a Public Health England report, less than half of those experiencing severe reproductive symptoms have sought help.

In many ways, whether due to a lack of understanding, social taboos, or a combination of these and other factors, so-called “women’s issues” such as heavy bleeding, period pain, menopause symptoms, contraceptive side effects, and even birth damage have become normalized.

It’s not difficult to see why women feel hard done by in this respect if we look at some other statistics. For example, in one 2022 women’s health survey, almost 30 percent of participants said that their concerns had been dismissed by a healthcare provider, while 15 percent said their provider didn’t believe they were telling the truth. Elsewhere, women attending emergency departments are less likely to be taken seriously and wait longer for opioid painkillers when reporting acute pain. This is despite the fact that women are more likely to seek out healthcare than men, a fact that could be problematic in itself. Sixty-two percent of people with autoimmune disease (a population dominated by women) have been labeled “chronic complainers” by doctors.

Women-specific conditions are under-researched, under-represented, and under-funded

Something that might have escaped many people's attention is women's exclusion from clinical trials following the thalidomide scandal, which led to babies being damaged in the womb. In truth, they have been routinely excluded for years on the basis that hormonal fluctuations could skew results. It wasn't until 1993 that the United States National Institutes of Health (NIH) mandated women's inclusion in trials, meaning that 30 to 40 years of progress was almost entirely devoted to the male body—justified by a belief that what would work for one sex would work for the other.

The repercussions of this are still being felt today. For example, although women account for 70 percent of chronic pain patients, 80 percent of pain medication has been tested only on men or male mice. Going back to heart failure, which we know is more prevalent in women following a heart attack, the NIH reported in 2022 that the proportion of women enrolled in clinical trials for the condition had remained stagnant at around 20 to 30 percent since the 1980s.

When it comes to investment, even government health agencies such as the NIH are now revealing a huge funding gap in women's health research, with conditions that have been found to disproportionately affect women (such as mental illness, headaches, migraine, and anxiety disorders) receiving significantly lower funding relative to their burden on the population compared with those that affect males. As an example, The WHAM Report found that women account for 78 percent of autoimmune disease patients in the United States, yet only 7 percent of NIH funding for rheumatoid arthritis goes to women-focused research. In the UK, only a few years ago, less than 2.5 percent of publicly funded research was dedicated to reproductive health, although one in three women will suffer from reproductive health issues during their lifetime. Looking farther afield, women's digital health start-ups accounted for only 3 percent of global digital health funding in 2020.

> **"There has been a shocking lack of investment in understanding the biology of conditions that disproportionately affect women and girls. ... In nearly three-quarters of the cases where a disease has affected primarily one gender, NIH funding has favored males."**
>
> **Bill & Melinda Gates Foundation, Women's Health Innovations program**

Perhaps none of this is surprising when we consider medical education, which has an equally long history of male dominance, and of differentiating women primarily based on the reproductive system. The Reference Man—white, age 20 to 30, five feet seven inches tall, and weighing 154 pounds—was first developed in the 1970s to understand safe levels of radiation. It is still used in anatomy classes, a staple part of the medical curriculum, and as a standard for transplant organ sizes. Until 1991, it was also used (with reproductive organs added) to represent women, who were effectively treated as "small men."

This approach has not only limited many doctors' ability to recognize potential symptoms relating to female-specific health conditions and sex-specific differences in others; it has also had the trickle-down effect of preventing patients from acting as informed advocates for their own care. In 2021, a Freedom of Information Act request submitted to the UK's medical schools found that 41 percent did not have mandatory menopause education on the curriculum, the expectation being that students would gain this knowledge on GP training placements.

On the patient side of the equation, research by University College London recently revealed that nine in 10 women were never taught about menopause at school and that more than 60 percent only started looking for information about it once they started to experience symptoms. Fewer than 20 percent of UK women feel they have adequate information on a range of gynecological conditions from menstrual well-being to gynecological cancers, menopause, specialist services for victims of gender-based violence, fibrosis, and endometriosis.

What's more, none of these findings have delved into the specific issues that are experienced by transgender women. In a letter to the editor of the *Medical Education* journal, two then-student doctors stated that issues regarding transgender patients were often missing from their program of studies, "even in genitourinary medicine and sexual health, where this is vitally important."

Taking an even broader view, social factors such as income, education, employment, and living environment, along with other characterizations including race, class, and sexuality, also play a huge role in determining women's health outcomes. Often, these add additional layers of inequity.

Just as a few examples, we know that 95 percent of maternal deaths occur in low and lower middle-income countries, that LGBTQ+ individuals suffer poorer mental health and have a higher suicide risk than their heterosexual counterparts, and that Black women face higher rates of certain chronic conditions such as anemia, cardiovascular disease, and obesity, leading to excess mortality compared to other women in the United States.

Data is patchy, at best

All of these issues and more continue to contribute to a massive, woman-shaped gap in medical data, with blind spots in exactly the places they are needed to drive decisions on everything from research topics and funding to treatment development, education programs, resource allocation, and public awareness.

Like every other sector, healthcare has benefited enormously from the digital revolution in recent years, with the result that more data is being produced than ever before. However, women's health is still in catch-up mode. Whether from a lack of common understanding about the issues that fall under this umbrella, gaps in reported data when women do interact with the healthcare system, national reporting systems that lump everyone together (even the World Health Organization's global health statistics have only been categorized by sex since 2019, indicating the scale of the challenge here), or analysis that doesn't accurately reflect the experience of women, the problems they face at every stage of the healthcare process, as we will see in the next section, only compound the problem.

Like every other sector, healthcare has benefited enormously from the digital revolution in recent years. However, women's health is still in catch-up mode.

Worse outcomes for women, across the board

If we look at women's experience of the current health system on this basis, we can see that they suffer from worse health outcomes throughout the healthcare process, from pre-diagnosis to ongoing care.

Pre-diagnosis

As we have discussed, women are more likely than men to have their conditions downplayed or ascribed to mental health issues, especially when it comes to chronic pain and autoimmune disease, which often lead to anxiety, depression, or even suicidal thoughts. As a result, they face lingering conditions with worsening symptoms that are poorly managed. On top of this, there are too many stories to mention of women having to persistently advocate for themselves to secure a diagnosis, often over multiple visits, months, or years.

Diagnosis

There's also plenty of evidence that women face delayed or inaccurate diagnoses as a result of healthcare practitioners' lack of detailed insight into female-specific conditions or how general health conditions present differently in women:

- One study including data from the entire Danish population found that women wait four years longer on average than men to receive a diagnosis across a range of more than 700 diseases.
- Women are seven times more likely to have a heart condition misdiagnosed or be discharged during a heart attack, according to a report by the World Economic Forum.
- Even as female-specific diseases such as endometriosis are becoming better understood, the same report indicates it takes 10 years on average for the condition to be diagnosed, a situation that is only compounded by a lack of non-invasive diagnostic tools.
- Despite sexual function issues being a common side effect of cancer treatment, female patients are asked about their sexual health 41 percent less often than men.

The specialized nature of medicine that allows patients to see particular healthcare providers for different conditions also means that vital information can slip between the cracks, meaning missed opportunities to connect symptoms and provide accurate and timely diagnoses.

One prime example for women is data collection during and after pregnancy, which could be used to identify indicators of future health. If we consider the fact that women with gestational diabetes are more likely to develop type 2 diabetes at a later stage or that those who develop pre-eclampsia or hypertension during pregnancy are more likely to experience a stroke or cardiovascular disease at another point in their life, the case for breaking down these barriers becomes even clearer.

Treatment

"Reference Man" syndrome rears its head again at the treatment stage, a spillover from research approaches designed around men and male animals. Respondents to a UK government consultation on women's health called out limited discussion of treatment options and the risks associated with these, and treatment preferences being ignored as examples of not being listened to by healthcare professionals. For example, it's been found that women are half as likely as men to receive treatment for cardiovascular disease, and many women with chronic illnesses are required to stop taking essential medication during pregnancy due to drugs not having been tested during gestation.

Since 2000, women have reported 52 percent more frequent adverse effects from drugs than men, and of the 10 prescription drugs taken off the market by the United States Food and Drug Administration (FDA) between 1997 and 2000 because of serious adverse effects, eight of these caused greater health risks in women.

Post-treatment

This is often limited. Four in 10 of the women who responded to the UK government's consultation on women's health reported not being listened to when discussing follow-up care. Many of the poor experiences cited related to the period following childbirth or baby loss, while a smaller number felt this was lacking when they needed help with medication side effects.

Evidence also points to women experiencing additional complications and comorbidities compared with men, which is not surprising given the focus on how diseases and treatments affect the male body. For example, a woman with type 1 diabetes is 37 percent more likely to die from a stroke than a man with the same condition and 44 percent more likely to die from kidney disease. Another study found that women were consistently less likely to stick to the prescribed regimens for diabetes and cardiovascular disease, for example, which could potentially be linked to the fact that they experience more side effects.

Clearly, so long as the medical and healthcare professions continue to prioritize the Reference Man, women will continue to face poorer treatment and long-term care options.

> **"Women fare more poorly compared with men in relation to disease prevalence, access to healthcare, and outcomes after treatment."**
>
> **Neena Modi, The British Medical Association**

Of course, there are knock-on effects from this experience of care that affect women both psychologically and economically.

In addition to experiencing stigma, shame, and judgment on the basis of sex or gender, many women feel sidelined, unsupported, and even patronized by the medical profession. As a result, their experience is minimized, and they often disengage from the care process or fail to adhere to their treatment programs. As one paper that addresses male dominance in medical education describes, there is congruence between what we think, say, and do, and "part of empathy involves placing primacy on the patient's experiences and expertise, allowing practitioners to set aside their own expectations of medical omnipotence."

Ultimately, if trust is lost in the healthcare system, individuals are less likely to listen to experts or engage in maintaining their own health.

From an economic perspective, lower productivity at work is often the first casualty of poor health outcomes for women. For example, according to a study published in the *British Medical Journal*, while 13.8 percent of women reported being absent from work during their period, a massive 80.7 percent said that they attended but were less productive as a result.

Sick days can also put a dent in people's paychecks and career plans. A US-based study found that workers suffering with chronic pain lost 10.3 working days on average each year compared with 2.8 days for their peers, while a survey of employers' reasons for not promoting employees revealed that 49 percent were less likely to advance those who took too many sick days.

Finally, with many women's menopause symptoms leaving them less able to cope at work, one in four consider leaving, and one in 10 actually do. Research has suggested that the effects of perimenopause and menopause are costing UK businesses 14 million working days per year, the equivalent of £1.88 billion in lost productivity. Meanwhile, the more women that go off sick, the more pressure is piled onto the healthcare system.

Really, what we have discussed here is only the tip of the iceberg: there are many more studies and statistics that demonstrate the damaging effects of continuing with the status quo in women's health.

What's more, investing in women's health is not only a moral imperative; it also makes economic sense. As an article in the *British Medical Journal* states, "Human rights, theory, evidence, and common sense all suggest that greater investment in women's health could be among the 'best buys' for broader economic development and societal well-being." Putting a figure on it, the World Economic Forum's *Insights Report on Closing the Women's Health Gap* has projected that "investments addressing the women's health gap could potentially boost the global economy by $1 trillion annually by 2040."

There's a lot to fix, to put it mildly. But with so many issues at every point of interaction between women and our healthcare systems, where do we start to tackle them?

In addition to experiencing stigma, shame, and judgment, many women feel sidelined, unsupported, and even patronized by the medical profession.

Doubling down on equity

With this in mind, we have outlined the priorities for change and the actions required to begin the process of redesigning healthcare systems with women in mind around six themes.

Shaping the public health agenda

Increase public health advocacy to raise awareness around women's health.

This needs governments to put women's health on—and higher up—the political agenda and target sources of stigma and bias around women's health in the general population. As we have referenced, the UK government has taken steps in this direction. In 2022, it published the Women's Health Strategy for England, outlining its ambitions and actions over a 10-year period to improve the health and well-being of women and girls. Based on input from more than 100,000 individuals and more than 400 organizations and experts in healthcare, it reflects critical issues across each stage of a woman's life course, from disparities in health outcomes to the need for more women-based research, as outlined in this report.

At the same time, patient advisory groups (PAGs) and policymakers should work together to weave compelling communications about novel women's health solutions and how they are improving outcomes for women, not only in terms of their health, but also psychologically and economically. PAGs can play a connecting role across the ecosystem to bring all relevant stakeholders together to share women's experiences of the healthcare system, engage, and feel empowered to collaborate on solutions.

Overhauling medical education

Expand the medical curriculum to cover female and women's health topics adequately and eliminate sources of bias.

This effort must be two-fold:

Educating medical professionals. At the policy level, this means embedding women's health in national school curriculums to build up knowledge and understanding at a young age, and the same must be done in higher education settings—in much more detail—so that the medical profession is armed with scientific and social knowledge relating to female and women's health and knowledge and skills gaps for medical professionals who are already qualified can be bridged. As part of the Women's Health Strategy for England referenced above, specific teaching and assessments on women's health will become mandatory in medical training.

Educating patients. With the right policies in place, female and women patients will benefit from having more useful information at their fingertips about the diseases and conditions that are likely to affect them at all relevant life stages. New technologies and solutions that can offer help to women in a more accessible, less invasive way should also be included on the curriculum. One example is The Femedic, a health platform dedicated to women. Offering education, advice, and information, it is intended to complement professional health advice.

Finally, the importance of listening, an empathetic approach, and training in psychosocial skills cannot be overstated. Healthcare professionals should understand how their own social markers—including class, race, ethnicity, and sexual orientation as well as gender and biological sex—have the potential to influence their interactions with patients and be able to adjust their behaviors accordingly. Dealing with the emotional aspect of the patient relationship sensitively is just as important as the medical aspect (if not more so) and should be included as a core element of medical training.

Raising the stakes on research and development

Increase the volume of clinical and policy research trials on female and women's health conditions, and ensure fair gender representation in all trials.

First, this requires pharmaceutical companies to ensure that all sexes and genders are represented in the development of any new drugs and therapies, for example, by including more women in clinical studies and trials and carrying out more research into female-specific conditions and the impact of other general health conditions on women.

But it doesn't end there. We know that underneath the surface-level problem of not enough women being included in trials, women of color are even more systematically excluded. In the United States, Congress commissioned a report as a means of surfacing and addressing this intersectionality, which includes policies, programs, and projects aimed at increasing the inclusion of these groups in clinical research, and a set of recommendations to boost participation.

Academic institutions can also promote knowledge sharing, dialog, and collaboration on new solutions for women's health by establishing interdisciplinary forums, partnerships, and alliances. One example is the University of Oxford's Research Alliance on Women's Health. This strategic partnership between the university and Bayer HealthCare is focused on researching gynecological therapies and discovering new treatment options for endometriosis and uterine fibroids. Another is the EU's Finding Endometriosis using Machine Learning (FEMaLe) project, part of the Union's funding program for research and innovation. This has brought a coalition of 17 partners from nine European countries together to develop a personalized model for early risk prediction, prevention, and intervention for people with endometriosis.

Building women-centric integrated care pathways

Create care pathways that are accessible and easy for patients to navigate, covering all patient touchpoints.

Enabling policies are the first step here. By building a public health infrastructure that is simple and straightforward for women to access and use—for example, by ensuring sanitary materials, contraception, and sexual and reproductive health services are funded properly and readily available—girls and women will have more control over their own health.

> **"We live in a world where we have the technology already in our hands to eliminate barriers to care access, but we still see unacceptable gaps in health outcomes for women. We need a committed effort to adopt digital health at scale if we want to expand women's participation in clinical research, learn more about their responses to therapy, and deliver personalized care pathways that take their unique experiences into account."**
>
> **Dan Vahdat, CEO and Founder, Huma**

In addition, building convenience into the system through such initiatives assumes even more importance when we consider that women are not only more likely to assume the burden of unpaid work and care than men, they also struggle to put themselves first when it comes to health and well-being. Community pharmacies can provide a first touchpoint for women to discuss their health issues before diagnosis. Virtual clinics, as provided by Tia, a US-based healthcare provider for women, enable users to get help at home, rather than having to attend a doctor's surgery or clinic.

Collaboration across different segments of the medical profession, such as pharmacists and GPs, can also make sure pathways stay intact wherever they are needed and that patients are treated holistically and put at the center of care. For example, Maven is the largest virtual clinic for women's and family health and through a comprehensive platform offers continuous holistic care across fertility, pregnancy, adoption, pediatrics, and menopause. Other new healthcare companies, such as Maeve, have the ambition to build a healthcare system that treats the "whole human" in an integrated way. Maeve is focused on delivering integrated, tech-enabled, and empathetic care whereby dedicated health coaches work alongside an integrated care team (including the likes of GPs, OB-GYNs, physios, therapists, dermatologists, nutritionists, dentists, acupuncturists, personal trainers, and others) to treat women holistically and concurrently.

> **"With the ongoing advances in imaging and generative AI in healthcare, no matter which hospital you are at or who the doctor is, well-trained AI algorithms can automatically detect disease earlier with increasingly high accuracy. I am excited about how AI can democratize healthcare for women by reducing variability in care and increasing access to life-saving treatments."**
>
> **Christopher Mansi, CEO and Co-Founder, Viz.ai**

Getting serious about data

Ensure gender-specific data is collected, regulated, analyzed, and used in a responsible way across the healthcare ecosystem.

There are four main areas to address here.

Empowering women to proactively manage their own health. The rise of wearable technologies and apps such as Clue and Flo, the female health app with more than 300 million users globally, has given women better knowledge, control, and agency over their own health. This not only is in terms of how their body is functioning at a given time, but is also opening up access to related topics and conditions that might affect women in the future and encouraging a more preventive approach to healthcare.

Going beyond the individual. Related to the above point, these advances have also started to provide a noticeable uptick in data collection and could be a useful integration point with healthcare systems at each stage of the process—they can even send information such as your heartbeat, respiratory rate, and temperature to a healthcare professional in real time. For example, Ava, a technology company dedicated to women's health, proved the potential benefit of using tech to advance general health when it ran clinical trials to determine whether the fertility data gathered via its tracking bracelets could also be used to detect COVID-19.

Putting a connecting infrastructure in place. Again, policy is the key to making data work for the health-care system and for women. This includes making electronic health record (EHR) systems—supplied by a variety of vendors—fully interconnected and interoperable so that data flows are uninterrupted and any woman's health—including her history, potential flags for certain diseases, and where comorbidities could show up—can be managed holistically. For example, NHS England's Federated Data Platform (FDP), operated by Palantir, will aim to connect data at scale in a safe and secure environment across the health service to deliver more responsive services and more joined up patient care and make it easier for healthcare staff.

Building in security and protection. In addition to ensuring that data is high quality, secure, usable, reliable, and compliant with all required laws and regulations, it's crucial that data is used only to promote women's health and well-being, that its use doesn't place women at risk in any way, and that any fears around trust, identity, privacy, and individual security can be overcome.

> **"Nuffield Health has been campaigning to raise awareness about the long-standing barriers women and girls face when it comes to their health and fitness. Data from our Healthier Nation Index shows that women are more likely to report barriers to exercise than men, which is why we have launched Move Together, an initiative that offers free exercise classes to girls across the UK."**
>
> **Davina Deniszczyc, Medical Director, Nuffield Health**

Accelerating investment

Increase funding across the ecosystem for academic research, product research and development, and consumer health solutions.

Policy input is vital here to make sure funding for research and innovation is directed appropriately and proportionately into female- and women-specific health conditions as well as developing new business models to create affordable solutions. Academic institutions should also consider increasing funding, grants, and special programs to attract more medical and science research into these areas, particularly those that are currently underserved. Pharma companies also have the resources and influence to fund more women-specific clinical research.

Last but not least, private investors and investment funds can make a real difference to women's health. Venture capital funding for women-focused health start-ups was previously sitting at less than $100 million. However, women's health investment has flourished in recent years, experiencing a 314 percent increase compared with a 28 percent increase in overall healthcare investment. One reason could be that more women founders and investors are becoming active in the market. Of women's heath companies, 76 percent have a female founder, which is three times higher than the overall innovation ecosystem. As Jessica Federer, the head of a New York investment company, told the *Financial Times*: "Every human on the planet is the product of women's health. ... Waiting on male investors to invest in [it] clearly hasn't been working."

> **"Investing in research and business in women's health is a mandate that can shift healthcare outcomes, reduce economic burden, promote gender equality, and create economic opportunities. It is a strategic investment and commitment that creates more productive and healthier societies."**
>
> **Carolee Lee, CEO & Founder,**
> **Women's Health Access Matters (WHAM)**

Making it happen: for everyone, by everyone

As with all complex whole-of-society issues, there's no way for any individual or group to solve this on their own. So although various stakeholders can (and must) play their own hand, the real power—and real transformation—will come from deep-rooted, continuous collaboration across all aspects of the health ecosystem. The needs are clear:

Rethinking what equitable healthcare means:

- Understanding what drives worse health outcomes for women, and recognizing the combined impact of all social determinants of health, in addition to biological sex and gender
- Changing the conversation about women's health in schools, at home, at work, and in healthcare settings—and getting society behind this shift
- Increasing the representation of women where it matters

Resyncing all stakeholders around this new mission:

- Establishing more well-funded and highly visible women's health programs and infrastructure that are based on women's experiences, expertise, and insights and joining these together across educational settings, workplaces, and the healthcare system so they become even more dynamic forces for change
- Setting up the communities and groups that provide education, support, encouragement, and safe spaces wherever they are needed
- Supporting, endorsing, and driving action at the most senior leadership levels in government, research, and industry

And ultimately:

Changing the mindset everywhere that matters from "women as the exception to the Reference Man rule" to the rightful "women as 50 percent of the population worth investing in" and therefore **regenerating** healthcare systems so they have true equity at their core.

Full regeneration is a tough—and essential—ask. But it's possible, especially if done through creativity, community, and collaboration. In the words of Gloria Steinem, one of the original advocates for women's reproductive rights, health, and well-being, "The future can be what it should be, because we are going to make it what it should be."

Come and join us.

About FemTechnology

FemTechnology.org is on a mission to close the gender data health gap via their flagship **Summit** – bringing together corporates, femtech start-ups, researchers, and clinicians for a 360-degree perspective on innovation in order to tackle collective pain points in women's health; **University Series** – scouting groundbreaking researchers and innovators in women's health to help disseminate their work to a broader audience and connect them to funding opportunities; and **Guide** – aggregating women's health solutions to match innovations directly to women in need and build the foundational database for future breakthroughs in women's health.

femtechnology.org

About Kearney

Kearney is a leading global management consulting firm. For nearly 100 years, we have been a trusted advisor to C-suites, government bodies, and nonprofit organizations. Our people make us who we are. Driven to be the difference between a big idea and making it happen, we work alongside our clients to regenerate their businesses to create a future that works for everyone.

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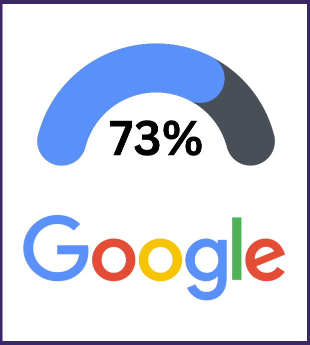
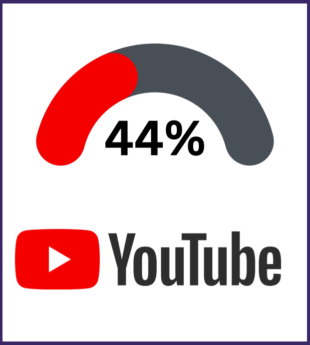
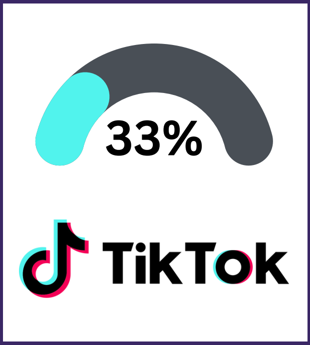
FemTechnology Summit 2023

ROLE OF THE MEDIA IN WOMEN'S HEALTH

GenZers who consult social media for health advice before turning to their doctor:







Question tackled:

More than 84% of women feel that their healthcare professionals were not listening to them. This comes at a moment in time when Social Media is increasingly relied upon as a source of health information.

How can we use media (social, traditional or otherwise) as an effective educational tool? And what can be done to restore public faith in clinicians?

IN COLLABORATION WITH Roche

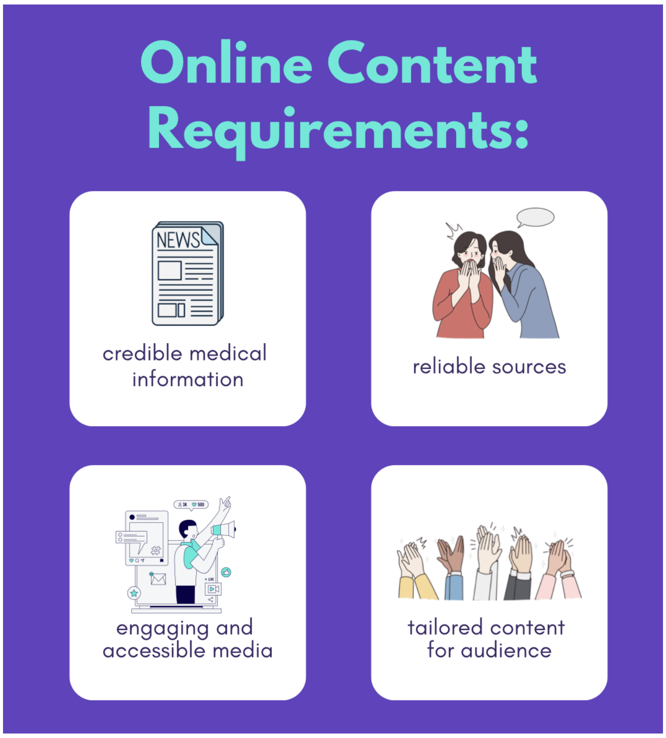
What is The Role of Media in Women's Health?

As Reported by Danielle Perro, Postdoctoral Researcher: epidemiology to study period pain in adolescence and understand both its causes and impact on chronic pain later in life.

Context:

In an increasingly digitised society, most people stay up to date with the world around them through social media. It is therefore no surprise that people do the same to find out about their world within. Now more than ever, as health care systems continue to stretch beyond their capacity, women need answers about their bodies, and they need them quicker than existing health care infrastructures can provide.

At this year's FemTechnology Summit in Basel (June 6th & 7th 2023), stakeholders working at FemTech Startups, Academia, Clinicians and social media influencers, joined forces to consider current challenges in the way the media is used to supplement women's health information, and how moving forward, these could be addressed.



Facilitated by Dr. Mitzi Krockover, key pain points and questions to be answered were identified.

Social media offers a rich hub of women's health information and support, yet medical misinformation is rife on these platforms. As someone who has personally used social media to engage and translate my PhD research to different audiences, (especially Twitter during its less turbulent times), extra thought is required to ensure that the content is in the first instance accurate, but importantly, designed with your audience in mind. With such a plethora of information available online, it can be challenging for consumers to access robust health information, especially if possibly less credible health information is presented in a more engaging way.

How bad is this problem, and what does this mean for women?

According to a recent study done by Flo Health on menstrual and reproductive misinformation, 22% of women aged 18-24 are receiving their sex and reproductive health information from social media–however–10% of these women don't fact check through a second source, to ensure that what they're seeing is trustworthy and reliable. If you've ever done a deep dive into your own reproductive health questions on the internet, you may have noticed that it's not hard to find a convincing post on social media spreading inaccurate information. If this information comes from someone with a large following, or a professional accreditation, it is more challenging to discern fact from fiction.

As a group, we acknowledged that in our fast-paced world, many women play multiple roles in society and the household, which may reduce capacity to seek a second source, while proposing that this process could be streamlined, and the burden, taken away from the woman. Could the future of women's health information dissemination online look like, as we saw with the COVID-19 pandemic, articles or social media posts flagging an article as containing misinformation or information from an untrustworthy source? I think this is crucial.

A further challenge we encountered was how we better bridge the divide between knowledge producers and users.

How do we incentivise the production of accurate information online by knowledge generators?

As mentioned above, women's health infrastructures within existing health systems are struggling. As a result of the pandemic, wait times for gynaecological procedures were in some cases, years, (though wait times have improved, they are still too long) and health care provider (HCP) burnout is on the rise. So, how do we incentivise the creation of engaging medical communications from leading HCP or researchers in the field? As of now, for many, it is done in their own time and without additional financial compensation. From personal experience as a women's health researcher, science communication and public engagement still aren't seen as integral parts of the science life cycle, rather a tick box exercise now required by some funders. Is it a researchers' duty (aside from funding body requirements) to engage the public with their research? I would argue yes, but this remains to be discussed by the research community.

Structurally, there still exists a disconnect between research and health care provision priorities and science communication or co-production. With Flo's report, and mounting evidence from researchers in the digital health space, it's clear that women are turning to social media for health information. When done correctly, disseminating information, and engaging with the public on social media can be mutually beneficial for the user and HCP alike. Women get access to evidence based information, and HCP/researchers increase the awareness and impact of their work. The ultimate question though, is how do we fund this type of work, and how does it become prioritised in the women's health landscape?

What does the future of women's health and the media look like?

Avoid misinformation by…

1. Credible information and source standard

2. Technology filter for newly generated and shared data

3. Increase health literacy

For online communications to be as beneficial a supplement to health care as possible, this work must be accessible, patient-centred, and crucially, accurate. Particularly as we see a stark move towards digital health platforms and FemTech solutions, these factors are even more important. From this workshop, Dr Krockover was 'energised by the depth of discussion and breadth of participant backgrounds' at the table to envisage this new future together. By canvassing the current situation, as well as identifying the need for health literacy, a solid foundation for considering next steps was laid. To action these, Mitzi outlined some necessary advancements:

1. A consensus on what is classified as credible information and sources, and from there;
2. Technology to cull through the overwhelming amount of new data generated daily, considering the consumer's educational background.
3. Increased health literacy, and possible guidelines for women to help them become aware of the credibility of information and the motivations of those providing it.

It's clear that a movement is needed, and perhaps it's one that we're already a part of, with ***all*** stakeholders at the table. If tech will be playing such a massive part of our health knowledge, literacy and care, infrastructure needs to be put in place to ensure that women are able to access and understand high quality health information on social media. On the other hand, and importantly, we must consider where our health information is coming from online. With the momentum from the Summit, the impact of these conversations has only just begun.

Leveraging this with the diverse experiences, resources, and dedication from attendees, it will be promising to see how in a year's time, we've been able to further its impact.

Additional perspectives:

<u>**Daphne Petrich - Senior Business Development Manager @HelloBetter**</u>

FEMTECHNOLOGY SUMMIT

June 6 + 7 @Basel, Switzerland

Daphne Petrich

US Business Development Lead

HelloGina

World's first evidence-based digital therapy for overcoming painful intimacy

We discussed the topic of ad censorship, which is a timely topic given the CIJ's recent legal complaint ([Sign the petition here)]()

We discussed how women are taking charge of their health due to systematic misdiagnoses and disregarded pain. Trust is at an all-time low, especially for vaginal discomfort (BV, vaginismus etc.) and autoimmune diseases. We highlighted the power of social media in democratizing access to science. Women can make sense of their symptoms and turn to the best specialists to 'optimize' their health outcomes. At the same time, consuming health information in a bite-size format is limiting and potentially dangerous. We discussed how different stakeholders could protect us from misinformation.

Lily Pemberton - Women's Health Physician

I think one of the recurrent themes of our workshop was that women often don't feel heard in the medical system. Women often put themselves last when it comes to their health needs, and when they do make it to the healthcare system, their symptoms are often ignored or dismissed. This is multifactorial and has to do with a lack of physician education and awareness, a historical lack of information regarding women's specific health issues and natural history of disease in women, and stereotypes and gender biases that lead physicians to ignore or try to "normalize" women's symptoms as part of "just being a woman". My personal solution as a physician is to keep myself informed about emerging evidence in women's health, as well as practicing empathy and "believing" my patients when they feel like something is wrong. I think a large part of the solution in addressing women's health is to first teach student physicians and other healthcare workers about these historical biases in medicine against women, and to build on the growing emerging knowledge regarding women's differences in physiology. I think the "male mode;" as normal has existed for far too long, and the teaching as well as the practice of medicine need to be adjusted.

Kathryn King - Founder @Bloody Honest

It certainly shocked me to learn just how poor education is on Women's Health when I first started having these discussions. Some of the most common questions I get on TikTok is "Where is the vagina?" and "How many holes do I have?". It's hard to tell how old some of these young people are but I would guess around 11-14.

I think while there are so many amazing people doing amazing work in the area, it's so easy for people who have knowledge and expertise not to realise just how low the bar is for health literacy.

I don't have an academic or clinical background so some people might wonder what gives me the right to talk about it. In reality, it's because I'm not a clinician or an academic that helps me communicate with the young people who so desperately need the discussions.

I am incredibly conscious of the damage misinformation can cause, and make every effort to be as responsible with my platform as possible. I tend to stick to personal experience or what's considered 'common knowledge' as far as possible; or ensure I cite anything further and will often discuss topics as theory vs fact. It can feel impossible, even for people who have some knowledge on the subject, to know where and how to access credible, reliable information.

It's imperative for the advancement of women's health literacy that there is constructive collaboration between media and experts, built on mutual respect and core understanding of the needs of the public.

Written by Danielle Perro, BMSc, PhD
Illustrations by Kryza Talavera
Edited by Oriana Kraft and Emma Ricci-De Lucca

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