The Gender Data Health Gap:

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

FemTechnology | Women At The Table
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WOMEN AT THE TABLE

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]

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.

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 i**ndirect 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](#)