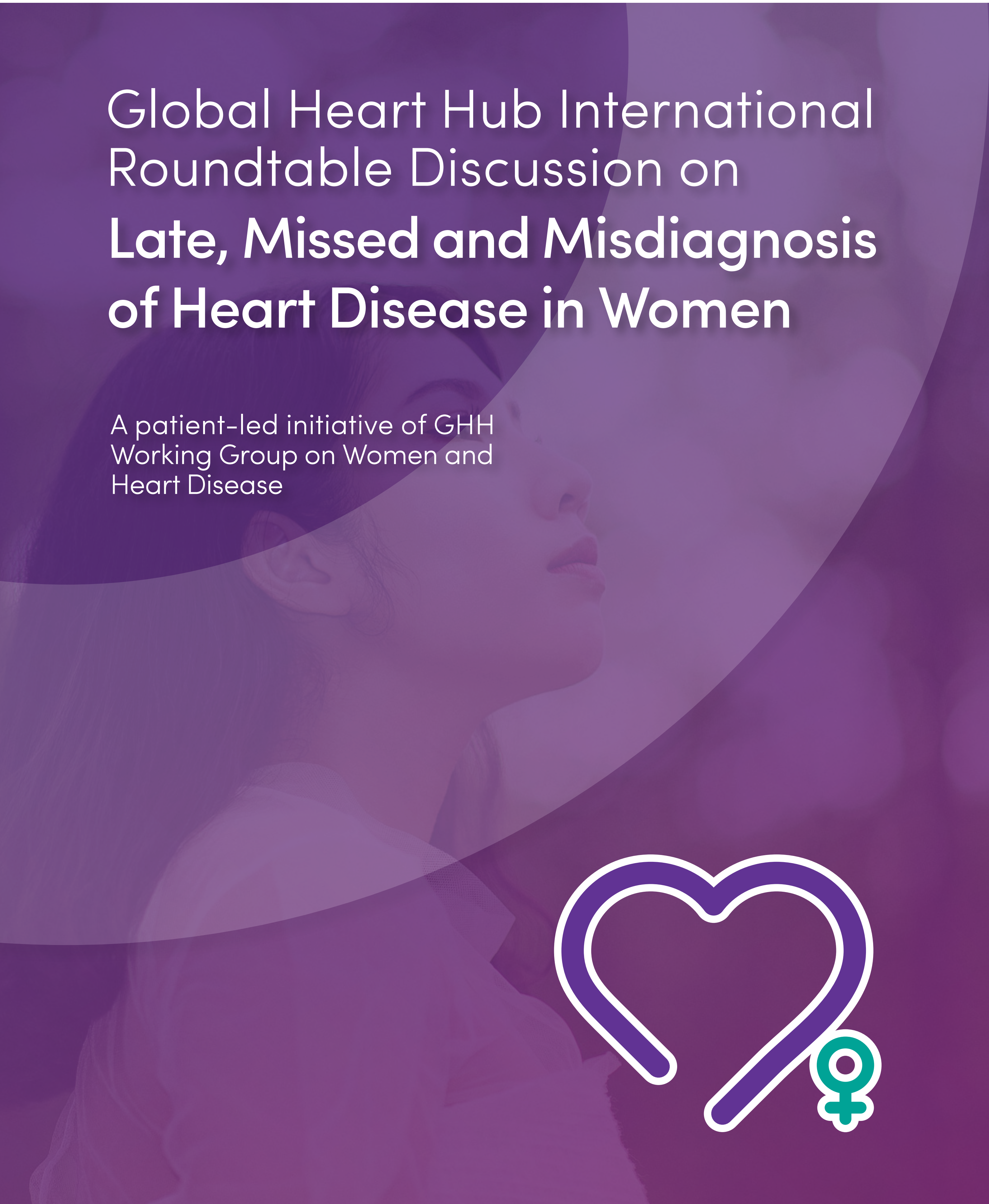
Global Heart Hub

UNIVERSITY OF OXFORD

Centre for Research Equity
through Pharmacy, Communities and Healthcare



Global Heart Hub International Roundtable Discussion on Late, Missed and Misdiagnosis of Heart Disease in Women

A patient-led initiative of GHH Working Group on Women and Heart Disease

The roundtable and resulting report reflect on the environment around diagnosis, treatment and care of cardiovascular disease in women. Addressing women's cardiovascular health recognises the unique challenges and disparities experienced by people who identify as women or otherwise face gender-related barriers in accessing healthcare. Global Heart Hub wishes to underline the importance of equity in healthcare for all, including those from the gender-fluid, nonbinary and transgender communities, as well as those who face additional barriers in relation to factors such as age, socioeconomic status, race, ethnicity and sexual orientation.

This roundtable meeting took place in Madrid, Spain on April 22nd 2024 and Global Heart Hub would like to gratefully acknowledge the support of Dr Paula Wray, Centre for Research Equity at the University of Oxford.

This initiative was made possible with support from Bayer, Daiichi Sankyo, Edwards Lifesciences, Medtronic, Novartis and Servier.

PARTICIPANTS IN THIS INTERNATIONAL ROUNDTABLE INCLUDED:

- **International Heart Spasms Alliance**, UK
- **Heart Sistas**, USA
- **WomenHeart**, USA
- **Global Heart Hub**, Ireland
- **Canadian Women's Heart Health Alliance**, Canada
- **HeartLife Foundation**, Canada
- **Heart Valve Voice Canada**, Canada
- **Pacientes Fundación Española del Corazón**, Spain
- **Lithuanian Heart Failure Association**, Lithuania
- **Her Heart**, Australia
- **World Heart Federation**, Switzerland
- **Amsterdam UMC**, Netherlands
- **Ministry of Public Health**, Qatar
- **Institute of Clinical Trials University of Galway**, Ireland
- **Women as One**, USA
- **European Society of Cardiology** (ESC), Ireland
- **HELIS Partners Consulting**, Czech Republic
- **Jagiellonian University Medical College**, 1st Department of Cardiology, Poland
- **Charité - Universitätsmedizin Berlin** and
- **European Institute of Women´s Health** (EIWH), Germany
- **NHS Greater Glasgow & Clyde**, UK
- **Bayer**, Germany
- **Novartis**, Switzerland
- **Daiichi Sankyo**, Germany
- **Medtronic International Trading Sàrl**, Switzerland
- **Edwards Lifesciences**, Switzerland

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Priorities for improving CVD screening, diagnosis and treatment in women

The four areas below are priority action items. They represent a consensus among the participants of this international roundtable discussion on late, missed and misdiagnosis of heart disease in women. These priority areas provide a roadmap for Global Heart Hub (GHH) as it embarks on a journey to engage with relevant stakeholders, with the aim to improve the screening, diagnosis and treatment journey for women with cardiovascular disease (CVD).

HEALTHCARE SYSTEM AND MEDICAL EDUCATION

Embedding women's cardiovascular (CV) health in the Medical Education Curriculum

RESEARCH

Calling for mandatory gender equity and sex-specific data analysis in CVD research

PATIENT AND PUBLIC ENGAGEMENT AND AWARENESS

Launching a global awareness campaign on women's cardiovascular health

POLICY CHANGE AND PUBLIC HEALTH

Prioritise cardiovascular health screenings for women in primary or community care settings

EMBEDDING WOMEN'S CARDIOVASCULAR (CV) HEALTH IN THE MEDICAL EDUCATION CURRICULUM

Current medical education curricula usually do not include or focus on women's CV health. Even when they do, subjects are often optional or do not reflect up-to-date research findings in relation to CVD in women.

Potential short-term strategies for advancing women's CV health in medical education include early health literacy initiatives and continuing medical education (CME) programmes.

In the long-term, advocacy efforts could be led by professional societies' education committees – the stakeholders best placed to amplify women's voices and advocate for policy changes in the medical education curriculum. Collaborative efforts with cross-disciplinary networks and engagement with primary care providers would also be needed.

CALLING FOR MANDATORY GENDER EQUITY AND SEX-SPECIFIC DATA ANALYSIS IN CVD RESEARCH

Today, there is little incentive to prioritise gender equity in research and equitable representation of women is not required by industry standards.

Several avenues could be explored towards ensuring equity, including:

- Integrating gender equity and sex-specific research modules into medical and research training programmes to enhance the awareness and skills of future healthcare professionals and researchers on these topics.
- Standardising sex-specific data collection and analysis across regulatory frameworks and industries.
- Fostering awareness around successful examples of inclusive research to inspire broader adoption of best practices and collaboration across sectors.
- Leveraging technological advancements, including artificial intelligence (AI) and big data, to analyse large datasets to uncover gender-specific health insights.

LAUNCHING A GLOBAL AWARENESS CAMPAIGN ON WOMEN'S CV HEALTH

Women often lack a comprehensive and accurate understanding of their CVD risk factors, potential CVD symptoms, and how menstruation, pregnancy, and menopause can impact their CV health.

An awareness campaign could be launched through social media platforms to disseminate information among women globally. This campaign should use messages and visuals to showcase women's personal stories and experiences, providing them with information about their CV risks. In the planning of this campaign, it is important to:

- Gather patient insights to ensure the campaign resonates with women of different backgrounds and age groups.
- Establish collaborations with local patient organisations and community groups to enhance the campaign's cultural relevance and impact.

PRIORITISE CV HEALTH SCREENINGS FOR WOMEN IN PRIMARY OR COMMUNITY CARE SETTINGS

CVD is the number one killer of women globally. Yet, it is not standard practice to offer tailored or even basic CV health screenings to a wider range of women, starting from a younger age.

CV health screening programmes should be implemented starting with common risk factors, such as blood pressure, cholesterol and weight, before expanding to other important tests and interventions. By creating opportunities for women to voice concerns and receive appropriate support from healthcare providers (HCPs) these could significantly shorten the time to diagnosis. Potential for integration with existing screening programmes exists given the interconnectedness of risk factors for CVD, stroke, and diabetes. While the implementation of such programmes at primary care and community settings would be instrumental, opportunities exist to tap into other HCPs who have more frequent touchpoints with patients, including pharmacists and nurses.


Roundtable on Late, Missed and Misdiagnosis of Heart Disease in Women
Madrid, 22 April 2024
#TakeAction
Global Heart Hub


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Why this roundtable needed to happen

CVD: THE LEADING CAUSE OF DEATH IN WOMEN

Cardiovascular disease (CVD) is the leading cause of death in women globally – in 2019 over a third (35%) of all deaths in women were due to CVD. Yet, CVD in women remains understudied, under-recognised, underdiagnosed, and undertreated.[i]

There is generally a limited awareness, including among women and healthcare providers (HCPs), about how the signs and symptoms of CVD present differently in women, how some CVD conditions are more common in women, or how menstruation, pregnancy, and menopause can impact CV health[ii]. In fact, one study reported that only 22% of primary care providers and 42% of cardiologists felt extremely well prepared to assess CVD risk in women.[iii]

As a result, women are more likely to dismiss the signs of CVD and delay seeing an HCP.[iv] When they do seek medical attention, they are more likely to have their symptoms dismissed or attributed to another cause (e.g. stress, anxiety, acid reflux).[v] Even with a diagnosis, undertreatment persists: women have less frequent access to tests and are less likely to receive life-saving therapies or referrals to rehabilitation. This is especially true for women from historically underserved communities (e.g. of colour, economically disadvantaged, from low- and middle-income countries), who face less access to diagnostic tests and treatments.[vi]

Moreover, even though there are important physiological differences and risk factors in women that impact treatment and outcomes,[vii] women are significantly under-represented in research. Enrolment of women in clinical trials rarely exceeds 30%, despite representing almost half the world's population. This can result in less effective or even potentially harmful treatments for women.[viii]

This means that women living with CVD are more likely to have poorer health outcomes and lower quality of life. Rates of disability and heart failure are higher for women, and many women are dying of preventable or treatable CVD.[ix]

URGENT GLOBAL ACTION IS REQUIRED TO ENSURE ALL WOMEN ARE DIAGNOSED AND RECEIVE HIGH QUALITY TREATMENT.

Within this context, GHH recently established a working group on Women and Heart Disease made up of patients and patient advocates from within its Affiliate network. The group's aim is to promote solutions to improve women's CV health outcomes and achieve gender equity in healthcare.

This roundtable was the first ever patient-led initiative bringing together a diverse group of international stakeholders with expertise in key areas such as women's health, cardiology, diabetes, psychiatry, nursing, medical education and public health policy. The roundtable was focused on solutions and innovative ideas to drive change, with the ultimate goal of laying the groundwork for impactful advocacy recommendations and actions that could enhance health outcomes for women globally. Being driven by patients, this initiative ensured that these recommendations are patient centred and targeted towards addressing women's specific needs and concerns.

How we reached consensus on priority actions

This one-day international roundtable discussion, an initiative of Global Heart Hub with support from the University of Oxford Centre for Research Equity, took place in Madrid on 22 April 2024. It brought together stakeholders such as international clinical experts, researchers, patient representatives, patients, industry representatives and policy advisors to focus on the issues of:

LATE, MISSED AND MISDIAGNOSIS OF HEART DISEASE IN WOMEN

UNDER-REPRESENTATION OF WOMEN IN CLINICAL TRIALS

UNDER-RESEARCH OF FEMALE-SPECIFIC HEART CONDITIONS AND RISK FACTORS

In the morning, following a short plenary, participants split in smaller breakout sessions which were organised around four key discussion areas previously prioritised by the GHH working group as critical pillars in understanding and addressing the complexities of the aforementioned issues. Those four discussion areas were:

HEALTHCARE SYSTEM AND MEDICAL EDUCATION

RESEARCH

PATIENT AND PUBLIC ENGAGEMENT AND AWARENESS

POLICY CHANGE AND PUBLIC HEALTH

Each breakout group had mixed stakeholder representation. During these discussions, participants discussed key challenges and potential solutions for each of these pillars and, for each breakout session, a list of potential priority actions was identified and brought forward to the afternoon agenda. A summary of the outcomes of each breakout session can be found in the 'Deep dive on the challenges and solutions identified' chapter of this report.

In the afternoon, the entire group reconvened to discuss the most pressing challenges and promising solutions identified in the morning session and reached a consensus on the concrete actions that could effectively address the challenges in women's CV health. These can be found in the 'Priorities for improving CVD screening, diagnosis and treatment in women' chapter of this report.

This report summarises the outcomes of the roundtable discussions, laying the foundations for future advocacy work to be led by GHH.

Deep dive on the challenges and solutions identified

The following pages summarise the outcomes of the discussions held within each of the breakout rooms, whereby participants discussed key challenges and potential solutions for each of the pillars outlined below:

OVERARCHING CHALLENGES

HEALTHCARE SYSTEM AND MEDICAL EDUCATION

RESEARCH

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POLICY CHANGE AND PUBLIC HEALTH

OVERARCHING CHALLENGES

Across the different breakout discussions, several themes emerged which highlighted deep-rooted and cross-connected challenges that, if addressed, could foster a more inclusive healthcare environment that prioritises women's CV health, enhances accountability, improves health literacy, and mobilises greater healthcare investment and policy change.

TOPICS:	CHALLENGES DISCUSSED:
Inherent bias in healthcare practice	• Current practices in healthcare, education, research, public health policy and health messaging are influenced by inherent bias or neglect of women's CV health. • A lack of consideration and underrepresentation of the needs of women is a historical reality.
Lack of incentives to encourage change	• Due to the absence of concrete accountability measures, stakeholders have little to no incentive to implement changes, from greater adherence to clinical guidelines and best practices, to increased female representation in clinical trials, to updating public health messaging on women's heart health.
Health literacy	• There is a need to increase awareness among women about their CV health and their specific CVD risk factors so that they are better able to advocate for themselves. This includes conveying their symptoms to their HCPs as well engaging more in research and advocacy efforts. • However, an assessment needs to be made on how to best frame this information and how to communicate it in the context of health literacy challenges.
Lack of investment and urgency among stakeholders	• Limited awareness and urgency, including among policy- and decision-makers, of CVD in women is evidenced by insufficient investment and disparities in healthcare accessibility. Advocacy efforts are urgently required to highlight the importance of this issue and, more importantly, the cost of inaction.

HEALTHCARE SYSTEM & MEDICAL EDUCATION

TOPICS:	CHALLENGES DISCUSSED:	SOLUTIONS DISCUSSED:
Medical Education on women's CV health	• Current medical education curricula do not include or focus on women's CV health and do not appear to reflect up-to-date research findings in relation to CVD in women. • Women's CV health is often covered only as a stand-alone, optional module, which many HCPs choose not to attend. • An inadequate representation of women in the development of medical education curricula contributes to under-informed content on women's health. • This extends to other HCPs, such as paramedics and nurses, who often receive insufficient education on women's health.	• Specialist study modules on improving detection and diagnosis of CVD in women could be developed for general practitioners, allied healthcare professionals and cardiologists as a key component rather than an optional one. • Women with lived experience could be engaged in the design of the medical education curricula.
Focus on women in CVD clinical guidelines	• Clinical guidelines fail to adequately address the specificities of CVD in women, including women-specific risk factors. • Clinicians may fail to adhere to guidelines, particularly with female patients. • Knowledge gaps or biases can interfere with a clinician's ability to accurately diagnose their patient. • From a patient perspective, there is little to no recourse when a clinician does not adhere to care recommended by guidelines.	• Involving women with lived experience in the development of CVD clinical guidelines. • Developing a patient-friendly version of the CVD clinical guidelines which highlights sex differences, as appropriate. • Having guideline recommended care linked to electronic health records or tools employed by healthcare systems.

HEALTHCARE SYSTEM & MEDICAL EDUCATION

Communication between clinicians and women	• Communications between female patients and doctors are frequently suboptimal. • Misunderstandings can arise due to differences in communication styles (particularly between male doctors and female patients), cultural backgrounds and the complexity of medical information. • Pervasive bias within healthcare systems regarding gender (e.g. women's symptoms) easily become barriers to open dialogue. • Frequently, there is a lack of interest or initiative from HCPs to engage and empathise with women's health concerns, coupled with a failure to acknowledge the urgency of addressing gender disparities in healthcare. This often leads to defensiveness and denial of biases, contributing to a situation where women may be unfairly blamed for their health issues.	• A communications guide co-created by clinicians and women. This guide could illuminate pathways to early detection and diagnosis, for example by providing language that encourages the use of open-ended questions and suggests terms to accurately convey the type and urgency of symptoms experienced. • Implementing training programmes to raise awareness of gender biases, fostering a culture of sensitivity to women's health issues. • Build cross-sectoral partnerships within the health system to enhance communication across the different specialties, to avoid the siloing of women's health.
Women's specific challenges in navigating the healthcare system	• Women must navigate healthcare systems that are under strain, while at the same time, juggling family responsibilities and/or being challenged by health literacy and other social barriers. There is a great need to improve the accessibility and efficiency of healthcare systems to support them to engage as informed and proactive patients. • A women's healthcare journey through the silos of distinct medical specialties may result in missed diagnostic opportunities.	• Implementing training programmes to raise awareness of gender biases, fostering a culture of sensitivity to women's health issues. • Promoting cross-disciplinary training of HCPs and integrated care to cater for the diverse care needs of women (e.g. connections between reproductive health and CVD).

RESEARCH

TOPICS:	CHALLENGES IDENTIFIED:	SOLUTIONS DISCUSSED:
Women's participation in clinical trials	• Underrepresentation of women in clinical trials (participation rates sometimes as low as 30%). • Clinical trials often overlook the constraints placed on women and researchers fail to make the adjustments necessary for their participation. • Recruitment and communication activities around clinical trials often fail to appeal to women. • Clinicians tend to under-refer women to trials.	• Meaningful engagement of women and relevant patient organisations at all stages of clinical trial design, promotion, implementation, and follow-up to ensure trials are relevant and effective for women. • Flexible trial designs that accommodate women's schedules (e.g. evening and weekend appointments) and needs (e.g. childcare support, remote participation). • Working with patient organisations to develop sensitive and patient-friendly language. • Collaborating with patient community networks in raising awareness about clinical trial opportunities and encouraging diverse populations to participate.
Incentives to Sex Equity in Research	• There is little incentive within the research community to prioritise gender equity. • Industry standards often do not mandate equitable representation of women. • There is a common perception among researchers that engaging with women is time-consuming and resource intensive. Many do not allocate the necessary time and resources towards ensuring equity.	• Academic journals and funding sources to mandate sex-equitable representation in clinical trials and require sex-specific data analysis for research publication and funding, respectively. • Institutions and funding bodies to establish awards and funding initiatives specifically designed to celebrate and support researchers who demonstrate excellence in this area.
Women's representation in research community	• Women continue to be significantly under-represented in the research community, particularly in leadership roles. This disparity undoubtedly contributes to the insufficient attention given to conditions that predominantly impact women.	• Research and academic institutions could encourage greater gender diversity in research leadership, including through mentorship programmes, funding initiatives, and advocacy for equitable career advancement opportunities.

PATIENT AND PUBLIC ENGAGEMENT AND AWARENESS

TOPICS:	CHALLENGES IDENTIFIED:	SOLUTIONS DISCUSSED:
Addressing women's health literacy and awareness	• Women often lack a comprehensive and accurate understanding of CVD risk factors, symptoms and the special considerations for women across their lifespan. • This CVD awareness has been declining among women. • Existing CV risk assessments are often made with information based on men and therefore might not be suited for women.	• Launching a global awareness campaign, co-created with women affected by CVD, that delivers clear, consistent and patient-friendly messaging on women's heart health. • Developing and/or promoting a comprehensive CV risk assessment tool specifically for women, which can empower them to self-assess their risks and facilitate information discussions with HCPs to improve early detection. • Co-creation and dissemination, between patient groups and clinical societies, of educational resources on CVD in women. • Dissemination of such resources at various healthcare touchpoints, including visits to specialists such as gynecologists, general practitioners, and nurses.
Overcoming cultural and societal barriers	• There are important cultural and societal differences that impact how women can access diagnosis and treatment (e.g. women are often responsible for family care). • HCPs often misinterpret women's health concerns – attributing them to reproductive or mental health issues – which may delay diagnosis and treatment. • Lack of empowerment of women's voices in healthcare settings, worsened by communication barriers between them and clinicians.	• Collaborating with patient organisations in advocating for stronger representation of women's voices in healthcare policies and practices, to ensure they are informed by the lived experiences and needs of women affected by CVD. • Improving flexibility and accessibility of healthcare services for women who may struggle to engage based on the current design (e.g. telehealth, weekend or evening appointments) • Co-creation and dissemination, between patient groups and clinical societies, of patient-friendly discussion guides that can facilitate the communication between women and their HCPs. • Implementing in community health settings CV health programmes designed to screen for risk factors and raise awareness of CVD, to lower engagement barriers.

PUBLIC HEALTH AND POLICY CHANGE

TOPICS:	CHALLENGES IDENTIFIED:	SOLUTIONS DISCUSSED:
Health policy	• Lack of awareness and associated urgency among policy-makers about the unique challenges of CVD in women. • CVD in women is not adequately prioritised on public health agendas and doesn't receive the necessary funding to drive change. • Stark absence of data for evaluating existing health service provision for women and resulting gaps in understanding prevalence, risk factors management, and health outcomes.	• Campaign targeted at policy-makers to highlight the burden of CVD in women and the economic benefits of investing in the early screening and diagnosis. This should foster a favourable environment for policy changes and resource allocation. • Policies that mandate adherence to guidelines for prevention, detection, and treatment of CVD in women across different healthcare delivery settings. These should align with evidence-based practices and standards of care. • Development, by public health agencies, of comprehensive data collection mechanisms for CVD that collect health outcomes in women and guide evidence-based decision-making processes.
Public health programmes	• CVD is the number one killer of women globally – there is a pressing need for publicly funded health programmes specifically tailored to women's CV health. • It is not standard practice to offer basic CV health screenings (e.g. blood pressure screenings, stethoscope checks, cardiac risk assessment) to a wider range of women, particularly younger ones.	• Establishing public health programmes focusing on CVD prevention and detection as standard practice for women in primary or community care settings to put women on the path to timely diagnosis and care.

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