



Annual Report 2024

1. Executive Summary

This report provides an overview of the European Institute for Women's Health, CLG activities, achievements, and financial performance during the year July 2023-June 2024. Our commitment to promoting women's health across Europe continues to guide our efforts.

About the European Institute of Women's Health (EIWH)

The objective of the European Institute of Women's Health (EIWH) is to promote the advancement of education and public awareness of women's and family health issues throughout Europe by conducting research, undertaking surveys, establishing and delivering training programmes, seminars and conferences on all aspects of health care. The EIWH is a registered charity (number 20035167) and is governed by a board of directors. Membership of the EIWH is open to individuals and organisations with an interest in women's and family health. EIWH has a membership base of individuals and organisations that contribute to the ongoing work of the EIWH. http://www.charitiesregulatoryauthority.ie/en/cra/pages/home

2. Mission and Vision

Mission: To improve the health and well-being of women throughout Europe

through evidence-based research, education, and advocacy.

Vision: A world where women have equal access to healthcare resources and receive optimal health services tailored to their needs.

Together with its members, the EIWH works to:

- Promote lifelong health in women and their families.
- Ensure quality and equity in health policy, research, treatment and care for all.
- Draw the attention of policymakers to the obstacles that women who belong to minority and disadvantaged groups face in obtaining a desirable health status.
- Empower individuals to play an active part in their own health management.
- Promote gender-specific biomedical and socioeconomic research that addresses sex and gender-based differences, to ensure equal access to quality prevention, treatment and care for women and their families throughout their lifespan. The EIWH aims to reduce inequalities in health, those due to gender, age and socioeconomic status, by highlighting that sex and gender are important determinants of health. The EIWH works to improve and promote the understanding that vulnerability to, onset and progression of specific diseases vary in men and women.

Key priorities of the EIWH include:

- Prevention of chronic diseases.
- Promotion of health and well-being and combating smoking and obesity in women.
- Promoting active and healthy ageing across the lifespan and increasing healthy life years.
- Ensuring access to high quality treatment and care across an individual's lifespan.
- Ensuring safety of medicines in pregnancy and lactation.
- Highlighting sex and gender in medicines regulation and medical education.

- Promoting vaccination across the lifespan.
- Advocating for healthy pregnancies.
- Advocating for awareness of mental health issues, with a focus on managing depression.
- Advocating for sex and gender sensitive health systems.

The EIWH has an Expert Advisory Group appointed by our Board which guides EIWH policies and activities.

Board Members:

- Maeve Cusack, National Cancer Control Programme, Ireland
- Barbara Dowling, University of the Arts London, UK
- Janusz Janczukowicz, Lodz University, Poland
- Meryam Schouler-Ocak, Charite, Germany
- Heidi Siller, Universität Klagenfurt, Austria
- Rutger Vandr Gaag

Secretariat

- Peggy Maguire, Director General
- Vincent Herity, Financial Manager
- Vanessa Moore, Senior Researcher
- Rebecca Moore, Senior Researcher
- Aoibhinn Collery, Research and Communications Officer

Board Activity

Members of the board of the EIWH are located Europe-wide therefore a bi-monthly meeting is hosted on Zoom. The meetings provide the opportunity to present, review and evaluate the activity undertaken by the EIWH as well as agree an outline of the future activity, direction and priorities for the EIWH.

Financial Overview

One of the main objectives of the board is to ensure the sustainability of the EIWH. The main source of income for the EIWH is through EU project funding. This is supplemented from time to time by industry funding. The EIWH continues to apply for project funding while examining further opportunities to diversify.

Governance

The EIWH initiated the review of its governance code to ensure compliance with the statutory Irish Governance Code for charities. The compliance form has been completed and will be submitted to the charity regulator for review upon acceptance initial review and acceptance from the board.

Activity Overview 2023 - 2024

3. Key Achievements

- Launched the Young Women's Health Group
- Launched the EIWH Manifesto for Women's Health
- Launch of EU Parliament Interest Group for Women's Health aimed at embedding women's Health in the EU Parliament Policy environment.
- Hosted 3 webinars /workshops.
- Collaborated with European Psychiatric Association, Eurocarers and Fertility Europe to enhance different aspects of Women's Health.

3.1 Kick off meeting Young Women's Health Group 20th of September 2023

Young women's health needs are an under-resourced and under-prioritised area of women's health.

The European Institute of Women's Health (EIWH) established a Young Women's Health Group to hear the voices of girls and women. The group feeds into the organisation's policy and workplan. Women of all ages deserve a health sector that supports them pro-actively across their lifecourse. Women's health must be supported by culturally appropriate healthcare services in a timely manner with care based on identified needs, and where girls and young women's:

- Voices matter and are represented in decision making,
- Health needs are researched and understood, and no health issue is taboo,
- · Good health is a priority,
- Health services are freely available, accessible and of high quality,
- Concerns about their health are never dismissed.

https://eurohealth.ie/young-womens-health-group/

3.2 Launch of EIWH EU Manifesto for Women's Health

Promoting sex and gender equity has been a long-standing theme in the philosophy and operations of the EU (1) and in line with Articles 160 and 168 of the Treaty on the Functioning of the European Union and the UN Sustainable Development Goals (SDGs).

It has been over 60 years since the Treaty of Rome, where gender equality was enshrined into EU law and yet no country has succeeded in reaching gender equality: this is also reflected in healthcare. The European Institute of Women's Health (EIWH) calls on the EU to commit to the reduction of health inequalities and provide equitable health for all women, through the provision of an EU Strategy for Women's Health.

Leading up to the EU elections in 2024 the EIWH launched its Manifesto for Women's Health

https://eurohealth.ie/2024-womens-health-manifesto/

3.3 Launch of EU Parliament Women's Health Interest Group

The launch of the Women's Health Interest Group, hosted by MEP Tilly Metz (Greens/EFA, LU), took place on 23 October 2023 from 10.00 – 11.00 CET, at the European Parliament (room 5E1) and

online. It was an event filled with empowering and inspiring discussions as we shone a light on women's health inequities, highlighted the important progress made on women's health issues across Member States and discussed the vast work yet to be done. MEPs, women's health champions, patient advocates, NGOs, researchers and many more stakeholders came together to ensure that women's health is prioritised in the EU policy and research agenda.

The European Institute of Women's Health (EIWH) recognises the imperative of prioritising women's health and well-being. The establishment of the Women's Health Interest Group comes at a pivotal time considering the upcoming European elections, with the aim to effectively shape an EU Strategy for Women's Health and advocate for gender equity in health across Europe.

The Women's Health Interest Group aims to embed women's health in the work of the European Parliament by uniting a diverse group of MEPs to promote access to high quality prevention, treatment and healthcare for all women in Europe. We are thrilled to bring together like-minded individuals passionate about women's health.

During the event, speakers raised awareness of the need for gender equity across the healthcare continuum, from design of research protocols and health technology assessment, including open discussion on women's health issues and unmet health needs, to the development of policies and strategies to improve gender equity in healthcare. For more on this https://eurohealth.ie/womens-health-interest-group/

3.4. Meetings and Webinars

The EIWH organised, hosted, chaired, spoke at, attended and participated in a wide variety of meetings and webinars. These included:

- Ppartner with ECDC and EMA European Immunisation week
- Partner with EMA and ECDC in European Antibiotic Awareness Day digital launch event
- Organised Webinar on Maternal Health
- Organised meeting on Gender and Mental Health

4. Advisory Roles

4.1 The EMA

The EIWH has been a member of the Patient and Consumer Working Party (PCWP) of the European Medicines Agency for the last 20 years. The Working Party provides recommendations to EMA human scientific committees on all matters of interest to patients and citizens in relation to the safe and effective use of medicinal products. The European Medicines Agency is the European Union (EU) body responsible for the scientific evaluation and approval of medicines developed by pharmaceutical companies. The EMA centrally reviews and approves innovative medicinal products, based on the clinical trial data supplied by the applicant organisation. This approval process is strictly defined and regulated by EU legislation. Once approved, the medicinal product receives a marketing authorisation for use in the EU and European Economic Area (EEA). The EIWH is a member of EMA Geriatric Expert Group and the EMA working group of Clinical Trials Results for Laypersons.

4.2 European Centre for Disease Control and Prevention (ECDC)

The EIWH is also a member of ECDC Advisory Forum Representing patients, represented by Rebecca Moore. Meetings take place regularly.

4.3 European Commission DG SANTE

The EIWH has been a member of Health Technology Assessment Stakeholder Network the EIWH highlights the gender perspective and communicates this to the group. The EIWH also produced a position paper on gender and health technology assessment. Rebecca Morre made a presentation to the Network on Gender and HTA.

As a member of the DG SANTE Joint Action on Vaccination Stakeholder Network, the EIWH gives the patient and the gender perspective on vaccination and the issues around research, education and communication.

4.4 European Patients Forum (EPF)

The EIWH is a member of two working groups: the Digital Health Working Group and the Universal Access to Healthcare Working Group.

The <u>Digital Health Working Group</u> will contribute to developing EPF's overall strategy in digital health, including work towards the gathering of patients' views on various topics related to digital health, including the protection and sharing of data from patients' electronic health records.

In its work it will take into account EPF's ongoing work on health data, including the work within the IMI project, the European Health Data Network (EHDEN); issues emerging from the IMI ADAPT SMART project on real-world evidence; and the implementation of the EU Data protection Regulation (GDPR) from the health governance perspective. The group will also inform EPF membership on technical topics through briefings.

The group will take a lead on specific activities as defined by its members in an annual work plan or as requested by the EPF Board or Secretariat. Position documents developed by the group will be subject to a consultation of the full membership before their formal adoption.

The <u>Universal Access to Healthcare Working Group</u> is working towards developing a vision of what constitutes a high-quality, safe, equitable and sustainable healthcare system from the patient perspective. The working group informs, guides and supports EPF's work on Universal Health Coverage and Access to healthcare from both a strategic and content perspective, in order to support EPF's broader membership, Board and the Secretariat in this work. The working group will work towards the implementation of the EPF Roadmap to achieving universal health coverage for all by 2030, using it as a guide and reference. The group will take a lead on specific activities as defined by its members in an annual work plan.

4.5 The World Health Organisation

The EIWH has been working with the WHO as an external consultant since 2000, with a focus on gender mainstreaming.

In partnership with the WHO Academy Quality Committee Board, the EIWH is leading the Patients and Community of Interest Group, creating action plans, organising meetings and consulting with stakeholders in each of the WHO regions. The Patient and Communities of Interest Working Group will support the WHO Academy Quality Committee by advising, supporting and co-creating learning modules for healthcare workers across the WHO Regions as defined in the WHO Charter. In

November 2023, a meeting was held with the eLearning design team in the Academy and outlined the added value of the patient input into the eLearning education modules.

4.6 Women's Health Taskforce

The EIWH is a co-chair of the <u>Women's Health Taskforce</u>. The EIWH supported the establishment of a Women's Health Task Force in the Department of Health in Ireland. This is made up of members of the Department of Health as well as from other government departments, the Health Service Executive, the National Women's Council of Ireland, the Institute of Public Health, healthcare professionals and many others. The taskforce was developed to improve women's health outcomes and the experiences of women in the healthcare setting, and to create new initiatives in coherence with existing policies to progress women's health nationally. The inclusion of women's voices across the life course was central to this initiate, including both positive and negative experiences of the healthcare system. The social determinants of health were also considered to ensure marginalised and minority women were included and considered. The taskforce performs radical listening exercises, listening to and engaging with women and women's organisations across Ireland. This is an example of open policymaking.

Ireland's second Women's Health Action Plan is currently being developed and will be launched in 2024. https://www.gov.ie/en/campaigns/-womens-health/

4.7 Women in Global Health

The EIWH sits on the Advisory Board for <u>Women in Global Health Ireland</u>. This is a group of individuals who represent academia, private sector and non-governmental organisations coming together to support gender equality in global health leadership. The EIWH took part in a panel on Women in Leadership organised by Women in Global Health

5. Research Projects

5.1 CONCEPTION

<u>CONCEPTION</u> is a project aiming to generate and disseminate reliable evidence-based information regarding effects of medications used during pregnancy and breastfeeding to women. The overall role of the EIWH is to bring the voice of women as (future) mothers, patients and family carers to the research project. The EIWH participates in the dissemination and education process for healthcare professionals, pregnant and breastfeeding women and the general public; cross-stakeholder engagement; information and data governance; and scientific coordination, project management & sustainability.

5.2 IDEAHL

<u>IDEAHL</u> stands for Improving Digital Empowerment for Active Healthy Living. The ultimate purpose of the project is to empower EU citizens in using digital tools to have a more active role in the management of their own health and well-being, as well as supporting social innovations for personcentred care models.

The EIWH held consultation workshops online with the Young Women's Health Group, policy makers from the DOH and midlife women to get their input on health information and gaps that need to be addressed. is involved in the gender and inclusion aspects for the co-design, development and implementation of the strategy. Vanessa Moore organised the Worksop and wrote a report for the project deliverables.

5.3 SPIOMET4HEALTH

<u>SPIOMET4HEALTH</u> is a clinical trial assessing a novel treatment for adolescent girls and young adult women with Polycystic Ovary Syndrome (PCOS) that tackles the root of the problem rather than masking symptoms.

The EIWH's role in the project is to develop the tools and materials for project communication and dissemination activities and in patient engagement. The EIWH also contributed to creating awareness among key stakeholders of the need to address PCOS in broader health promotion and disease prevention programmes due to the high prevalence and under-diagnosis of the condition. The EIWH created a series of blogs in partnership with Make Mothers Matter as well as the clinical trial information for potential participants.

5.4 CBIG SCREEN

The <u>CBIG-SCREEN</u> project aims to reduce inequality by improving access to cervical cancer screening for vulnerable and underserved groups.

EIWH is the lead on communications and social media. The EIWH has co-hosted a webinar with Sirpa Pietikäinen (MEP) in the EU Parliament; produced content including interviews with various stakeholders including policymakers; hosted a Roundtable in the EU Parliament with Tilly Metz (MEP); created the newsletter and numerous podcasts.

5.5 REAL4REG

Regulatory and health technology assessment (HTA) agencies, academic institutions and patient organisations from six EU countries will improve the use of real-world data (RWD) in regulatory decision-making under a new project funded by the Horizon Europe Programme.

The Real4Reg project stands for development, optimisation and implementation of artificial intelligence methods for RWD analyses in regulatory decision-making and HTA along the product lifecycle. Rebecca will look at preparing a paper on Gener and real-world Data.

The EIWH engages in the gender perspective in all the work packages and the communication and dissemination strategy.

Publications

6. Policy Briefs

The EIWH has a series of policy briefs. These are short but comprehensive documents on specific health or disease related topics. They provide an overview of the current state of play about women's health and present findings and recommendations aimed at a non-expert audience. They raise awareness on the gender differences in health. Recent policy brief includes, Women and Menstruation, Women and Menopause, Endometriosis Policy Brief.

The full list of policy briefs, which were updated in 2022, are available on the EIWH website and are regularly promoted on the organisation's Twitter account. They are available in English, and one policy brief thus far, on women and vaccination, is available in 7 European languages. Policy briefs include Women and AIDS/HIV; Women and Breast Cancer in the EU – A Life Course Approach; and Women and Diabetes in the EU, among many more. There are 29 policy briefs in total and the full list can be found on our website.

7. Research Reports

7.1 Maternal Health

A EIWH report titled, 'Maternal Health in the EU' was launched at a Roundtable in 2022 hosted by Deirdre Clune (MEP). A panel of experts at the event included the EU Commission, the WHO, the EU Midwives Association and the EIWH Advisory Board on Maternal Health. This report will be promoted through the EIWH online platforms and at the EIWH events.

7.2 A Lifetime of Caring – Who Cares?

The 'A Lifetime of Caring – Who Cares?' Report was launched in 2023. The report highlights the central issues surrounding women's caring roles across the life course from rearing children to caring for young, elderly, disabled or sick family members. Lack of resources, decision-making power and unfair work divisions have large repercussions and opportunity costs for women and girls. In support of the EU Caring Strategy (2022), the EIWH will use the recommendations to develop an EIWH Advisory Group, which will include Age Platform, EUROCARERS and Alzheimer's Europe Age Platform on older women's health. Again, this report will be distributed to the European Commission, the European Parliament and other key stakeholders, whilst also promoting it widely on the EIWH media outlets and at the upcoming conference on Women's Health.

8. Publications

- Maternal Health in the EU launched in 2023 with a successful webinar.
- A lifetime of caring: who cares? In partnership with EUROCARERS
- Women Seeking International Protection in the European Union
- Scoping Review of Young Women's Health published.
- Mapping of Models of Good Practice in EU completed 9. 10. Acknowledgments

Thank you to our staff, board members, volunteers, and donors for their continued support and dedication.