



**Annual Report 2022**

**The European Institute of Women's Health**

## **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 nominated by members. 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>

### **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 Shouler-Ocak, Charite, Germany
- Heidi Siller, Universität Klagenfurt, Austria

## **Company Secretary**

- Hilary Murphy

## **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 2021 – 2022

### Advisory Roles

#### **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.

#### **European Centre for Disease Control and Prevention (ECDC)**

The EIWH is a member of the Technical Advisory Group on Vaccination. The EIWH attended the technical advisory group for a number of years giving the patient perspective, communicating the efficacy of vaccinations and trying to increase uptake.

The EIWH is also a member of ECDC Advisory Forum Representing patients. During COVID there were meetings every month due to the extent of issues to be discussed.

#### **European Commission DG SANTE**

The EIWH has been a member of Health Technology Assessment Stakeholder Pool for the JA EU-NET-HTA since the beginning of the legislation the commission introduced, in an advisory capacity. 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.

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.

#### **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 [Digital Health Working Group](#) 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 [Universal Access to Healthcare Working Group](#) 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.

The EIWH is a part of the [Label to Enable](#) Advisory Board. This verifies the safety and accuracy of information on patient health and wellness applications. The project focuses on three pillars: trust, use and adoption.

The EIWH is a member of COMPAR-EU. This group focuses on four chronic diseases. In 2022 the EIWH wrote an article for COMPAR-EU titled, [the Gender Perspective and Self-Management Interventions on Chronic Diseases: Diabetes, Obesity, COPD and Heart Failure](#). This was published on their website and disseminated on social media channels.

### **European Public Health Alliance (EPHA)**

The EIWH is a Board Member and a former President of the EPHA.

### **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 liaising 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.

The EIWH contributed to the WHO European Strategy for Women's Health. The EIWH attended meetings, giving content for the strategy.

The EIWH was a contributor to the WHO Eastern Mediterranean Regional Office Report on Gender and Health. This report involved a situational analysis of the gender issues and health of women in this region and focused on areas such as TB, malaria and heart disease. This report will be launched in 2023.

### **Women's Health Taskforce**

The EIWH is a co-chair of the [Women's Health Taskforce](#). 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 project, 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 first Women's Health Action Plan was published as a result of the taskforce. This was launched by the Minister for Health. This plan sets out women's priorities for health as specified by women and women's organisations. The action plan includes a strategic framework for the progress of women's healthcare, identifying gaps in the service, improving women's experiences in the healthcare system and accounting for vulnerable and marginalised groups to improve the standard of care for all. This was accompanied by further public investment in women's health.

The taskforce hosts 'Women's Health Weekly'. This is a forum which brings together experts and advocates to speak on important issues that affect women's health. This sparks debate, discussion and knowledge-sharing.

### **Women in Global Health**

The EIWH sits on the Advisory Board for [Women in Global Health Ireland](#). 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.

### **BRMMI-ERIC**

#### **Research Projects**

##### **CONCEPTION**

[CONCEPTION](#) 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.

##### **IDEAHL**

[IDEAHL](#) 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 person-centred care models.

The EIWH is involved in the gender and inclusion aspects for the co-design, development and implementation of the strategy. Equality and digital accessibility are fundamental for IDEAHL targeted groups, especially those who are at risk of exclusion from the digital world. The EIWH conducted a scoping review of the gender and inclusion aspects in digital health literacy and the relevant policy documents, as well as hosting two workshops on IDEAHL and digital health literacy. Actions will be done based on the EU Digital Principles and the Skills Agenda.

##### **SPIOMET4HEALTH**

[SPIOMET4HEALTH](#) is a clinical trial testing 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.

### **CBIG SCREEN**

The [CBIG-SCREEN](#) 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.

### **Upcoming Research Projects**

#### **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.

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

#### **REWORD**

The EIWH is involved in preparing a project proposal for the European Commission titled REWORD or REsilient health WORKforce Environments Development.

### **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 with regard to women's health and present findings and recommendations aimed at a non-expert audience. They raise awareness on the gender differences in health.

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](#).

## **Research Reports**

### **Midlife and Older Women's Health**

A report on Midlife and Older Women's Health was commissioned and published by the EIWH. This was launched in 2022 at a Roundtable discussion hosted by Sirpa Pietikäinen (MEP). This will be further disseminated in 2023.

### **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.

### **A Lifetime of Caring – Who Cares?**

The 'A Lifetime of Caring – Who Cares?' Report will be 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.

## **EU Consultations**

The EIWH has responded to the following:

- EU Commission Roadmap on Access to Vaccination
- EU Commission Roadmap on Violence against Women
- Consultation EU Beating Cancer Roadmap
- Consultation EU Pharma Strategy
- EU Commission Gender Equality Strategy
- New EMA Regulatory Strategy
- WHO workplan 2021-2027
- EU4Health Programme 2021-2025
- European Public Health Alliance Consultation on EU4Health

## **Meetings and Webinars**

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

- As part of the CBIG Screen project, the EIWH organised and co-hosted a webinar and a roundtable on Cervical Cancer with MEs in the EU Parliament.
- For the Irish Global Health Network Conference, the EIWH with Ailbhe Smyth, an Irish activist co-chaired the Women in Global Health workshop on Leadership.
- Organised a Roundtable in the EU Parliament on the Maternal Health Report. This was co-hosted by Deirdre Clune (MEP).
- Chaired a webinar on digital health literacy as part of the IDEAHL consortium.



- The Midlife and Older Women's Health Report was launched at a Roundtable in the EU Parliament, organised by the EIWH and hosted by Sirpa Pietikäinen (MEP).
- Attended the EFPIA Patient Think Tank contributing to discussions on patient engagement. The EIWH also attended the EU Health Summit: Towards an EU Health Union
- Chaired a meeting on health inequalities for Women Political Leaders
- Partner with ECDC and EMA European Immunisation week
- Speaker for the event titled, 'Addressing Gender related issues and bias in the Prevention and Treatment of Neurological Conditions' in the EU Parliament.
- Partner with EMA and ECDC in European Antibiotic Awareness Day digital launch event
- Speaker at RSV roundtable.
- As a member of the Independent Patient Safety Council, the EIWH attended meetings.

### **EIWH Strategy 2020 – 2025**

- The EIWH promotes an equitable, sex and gender-sensitive approach to health policy, research, treatment and care
- Prioritising women's health in all EU policy, programming and funding mechanism
- Establishing a Women's Health Interest Group in the European Parliament
- Increasing the evidence and advocacy base for women's health issues through publications and social media
- Partnering with EU organisations, efforts and activities
- Capacity-building by expanding EIWH communications and network membership