



European Institute of Women's Health, CLG

Annual Report 2019 - 2020

European Institute of Women's Health, CLG

Dublin, Ireland

Register Charity Number 20035167

CHY Number 12184

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 bio-medical 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
Karen Ritchie, INSERM, Montpellier, France
Orla Shiels, Trinity College, Dublin, Ireland

Company Secretary, Hilary Murphy

Secretariat

Peggy Maguire, Director General
Vincent Herity, Financial Manager

Board Activity

Members of the board of the EIWH are located Europe-wide therefore a bi-monthly meeting is hosted by teleconference and annually in person. The Annual face to face meeting took place as a webinar April 2020. The meeting provided the opportunity to present, review and evaluate the activity undertaken by the EIWH in the preceding 12 months 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 a small amount of industry funding. EIWH Treasurer Sinead Hewson, having examined the audited accounts, noted an improvement in the finances for financial year 2019-2020, compared to previous years. The board agreed to continue its focus on applying 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 will be completed and submitted to the Charity Regulator in January 2021

Activity Overview 2019-2020

The EIWH takes an active and prominent role in contributing to and shaping European policy on women's health and that of their families. The EIWH is proud of its continuing partnership with and contribution to agencies including the World Health Organization (WHO), the European Medicines Agency, The EU Commission and the EU Parliament. The work of the EIWH has helped to shape health policy that

affects and benefits women Europe-wide. The EIWH is wholly committed to continuing its role in promoting the importance of gender equality in health and social policy, research and care, and to ensure access to quality treatment and care for women across their life-course, regardless of their economic status.

Representation: European Medicines Agency (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).

Why the work of the EMA important to women's health?

Women are some of the heaviest users of medicines, starting early with birth control pills, and across their lifespan as longevity champions. Additionally, due to women's reproductive and their caring role in society, women have a specific interest in, but also knowledge to offer about medicines use for themselves and their families.

For more information about the EMA and the Patient and Consumer Working Party: http://www.ema.europa.eu/ema/index.jsp?curl=pages/contacts/CHMP/people_listing_000017.jsp

New EMA Regulatory Strategy

EIWH contributed to the EMA consultation for the EMA Regulatory Strategy 2025, commenting on the need for EMA to consider certain vulnerable population groups such as pregnant and lactation women in the regulatory strategy, as well as older patient with several different medical conditions.

Raising the issues about Safe use of Medicines during Pregnancy and Lactation with EMA

EIWH President attended several EMA meetings to highlight the EIWH work on the Safe Use of Medicines during Pregnancy and Lactation as outlined in the EIWH Policy Brief. This issue is currently a neglected medical and public health need, as little or no information is available to pregnant and lactating women and their health professionals regarding which medicines are safe to take during this period.

EIWH's efforts to highlight this regulatory and societal gap in public health, has resulted in the Innovative Medicines Initiative (IMI) to set up the Research Consortium called "ConCEPTion". (see below)

European Centre for Disease Control and Prevention (ECDC) - Technical Advisory Group on Vaccination uptake

EIWH continues to interact and support the European Centre for Disease Control and Prevention (ECDC) -Technical Advisory Group on Vaccination and the development of the ECDC Information portal which will be launched in 2020. The portal will provide information on vaccination to health care professionals and the general public.

ECDC Patient group representation: The Commission launched a selection procedure to appoint the representatives of non-governmental organisation representing patients at the Advisory Forum of the European Centre for Disease Prevention and Control (ECDC). The EIWH application was successful and will participate in ECDC meetings four times per year representing patient organisations.

The EU Commission Coalition for Vaccination

The EU Commission Coalition for Vaccination has been established and the EIWH is part of the network. Due to Covid-19 the face to face meeting of the Coalition for Vaccination was not able to take place but keep the network updated by email.

EIWH, Member of the Joint Action Stakeholder group, vaccination.

The EIWH contributed to the Joint Action survey on prioritising research on vaccination and contributed to the survey on vaccination hesitancy. The EIWH will take part in the online annual meeting of the Joint Action in September 2020.

Health Technology Assessment (HTA)

The EIWH is a member of the EU Commission HTA Stakeholder Pool and continued to take part in the online meetings.

European Immunisation Week

The EIWH developed a key vaccination policy brief titled 'Women and Vaccination in the EU'. In support of the European Immunisation Week in April 2020, the EIWH re-issued this vaccination policy brief with a press release to media. The theme was #VaccinesWork for All and the campaign focus was on how vaccines and the people who develop, deliver and receive them are heroes by working to protect the health of everyone, everywhere. A social media campaign saw pertinent vaccination information and messages being shared daily.

Antimicrobial Awareness Day

The EIWH participated in the discussion of the Antimicrobial Awareness Day, held by the European Centre for Disease Control (ECDC) and Prevention November 2019. The growing resistance to many antibiotics is a public health threat that has been steadily increasing in recent decades. As a result, many common infections are becoming difficult or even impossible to treat, sometimes turning a simple infection

into a life threatening condition. Antibiotics are vital in reducing the risk of complications in complex medical intervention such as hip replacements, organ transplants, cancer chemotherapy and the care of premature babies. The EIWH partnered with the ECDC annually to raise awareness of the threat through targeted media relations on Antimicrobial Awareness Day.

EIWH meeting in EU Parliament “Healthy Women Healthy Europe

On the 6th of November 2019, the European Institute of Women’s Health (EIWH) and Sirpa Pietikäinen, Member of the European Parliament (MEP) from Finland, hosted a Women’s Health Information Day in the European Parliament EP): ‘Economy of Well being: Healthy Women – Healthy Europe’. Speakers included MEPs, representatives from the European Commission, World Health Organisation, National Governments and other key health stakeholders.. This event took place under the EIWH’s campaign **Healthy Women - Healthy Europe**, which profiles that Europe could and should do more to prioritise women’s health.

E.U. Projects

MOPEAD IM1 H2020 project: Models of Patient Engagement for Alzheimer Disease (AD)

The .MOPEAD project was successfully completed in December 2019

<https://www.mopead.eu/>

EIWH was a task leader in WP Dissemination and participated in Partner Meetings, contributed to the Project Newsletter and to the article on Alzheimer disease. The EIWH also completed a policy brief on Gender and Alzheimer Disease.

<https://www.imi.europa.eu/content/mopead>.

MyHealth Project

The EIWH is a partner in the project MyHealth which is funded by DG Sante. The EIWH is leading the Communication and Dissemination Work package. The main aim of MyHealth is to improve the healthcare access of vulnerable immigrants and refugees newly arrived in Europe, by developing and implementing models based on know-how of a European multidisciplinary network.

During the monthly teleconferences and AGMs, EIWH ensures that communication and dissemination is considered throughout the project, including during the development of tools, reports and other activities. The EIWH works to make the public documents accessible and user friendly to encourage dissemination. The EIWH and partners have been adjusting the communication strategy throughout the project to improve dissemination moving forward.

The EIWH conducted the legal and organizational mapping of partner countries on access to health services. The results are being used as part of the basis for an interactive map. This map was shared with the MigHealthCare project for use as

their template as well. The map was designed to be user friendly throughout the application.

The EIWH disseminates project results and reports as well as publicises project events. The EIWH advises partners when queried on communication and dissemination issues, such as how to increase the response rate of the mapping surveys. The EIWH is working with partners to identify and engage key stakeholders in order to involve diverse actors in the project and disseminate project results. The EIWH has worked with partners to identify strengths and weaknesses of communication to improve the efforts moving forward.
<http://www.healthonthemove.net/>

GO NANO project - Governing nanotechnologies through societal engagement.

The EIWH is a partner in Go Nano project. The project enables co-creation between citizens, civil society organisations, industry, researchers and policy makers across Europe to align future nanotechnologies with societal needs and concerns. GoNano aims to demonstrate how researchers can work with public and professional stakeholders to create novel suggestions for future nanotechnology products. The goal is to co-create concrete product suggestions within the areas of **food, health and energy**, illustrate new opportunities for innovation and develop policy recommendations. The EIWH completed a literature review on nanotechnology gender and culture. The EIWH has completed a white paper on Gender and Nano technology and contributed to several other papers relating to Nano technology.
<http://gonano-project.eu/>

ConcePTION – use of medication during pregnancy and lactation

ConcePTION is a large 5 year landmark Innovative Medicines (IMI-2) research project funded in part by the European Community budget and contributions from pharmaceutical companies. Its aim is to build ***a pan European ecosystem for generating, monitoring and providing robust information on medication safety in pregnancy and breast feeding.***

The project unites an unprecedented 88 organizations from 22 countries, including the European Medicines Agency, drug manufacturers, academia, public health organizations, researchers and teratology networks to innovate new solutions to a long neglected public health issue.

With a shared vision that there is a societal obligation to radically and rapidly reduce uncertainty about the safety of medication use in pregnancy and breastfeeding, the **ConcePTION** team will work to create sustainable solutions to the current information gap.. Through better use of existing health data from routine, daily practice together with enhanced methods to collect patient-reported data, and with new research capabilities to predict and measure maternal medication in breast milk, the team hopes to close the current information gap.

The EIWH is involved in several Work Packages and has a seat on the Management

Board of ConcePTION.

For more information, please visit www.imi-conception.eu/

Proposals submitted:

Revised proposal on Cervical Cancer prevention which has been renamed CCBIG SCREEN, the proposal got through the first stage evaluation and the second stage proposal will be submitted in July 2020. EIWH will co-lead the Communication Work package with Inserm.

CCBIG SCREEN aims to create a projection model to evaluate targeted population based interventions accounting for country-specific contextual factors such as costs, and estimate impact according to improving coverage and participation in screening among women who are hard to reach and are at increased risk for Cervical Cancer. .

EIWH National Focal Points

The EIWH is working to continue linking as well as strengthening its European and national activities and has been distributing the EIWH Manifesto to national health attachés and other Member State representatives in order to increase awareness of major health and social issues that affect women in Europe

The Institute of Public Health, Austria and **Charité, Germany** are the first EIWH focal points and set an example of how further national focal points can be developed. The EIWH has identified further potential **focal points** and developed a terms of reference document for use in all Member States.

Consultations

- Responded EU Commission Roadmap: Vaccination
https://ec.europa.eu/health/sites/health/files/vaccination/docs/2020_confidence_rep_en.pdf
- Responded EU Commission Roadmap on Violence against Women
https://ec.europa.eu/smartregulation/roadmaps/docs/2015_just_010_istanbul_convention_en.pdf
- Responded to consultation EU Beating Cancer Roadmap.
https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12154-Europe-s-Beating-Cancer-Plan/feedback?p_id=6335574&page=34
- Responded to consultation EU Pharma Strategy
https://ec.europa.eu/health/human-use/strategy_en
- Responded to consultation EU Commission Gender Equality Strategy

https://ec.europa.eu/info/policies/justice-and-fundamental-rights/gender-equality/gender-equality-strategy_

- Responded to consultation WHO workplan 2021-2027
<https://www.euro.who.int/en/health-topics/health-policy/european-programme-of-work>
- Responded to EU Commission consultation EU4Health Programme 2021-2025 https://ec.europa.eu/health/funding/eu4health_en
- Responded to European Public Health Alliance consultation on EU4Health <https://epha.org/eu4health>
- Prepared amendments to strengthen the health aspect in the Gender Equality Strategy and tabled by selected MEPs who were at our November EP meeting.
- Prepared amendments to strengthen the gender aspect in EU4Health programme, to establish a reference network on risk in pregnancy and tabled by selected MEP who was at our November EP meeting.

Communications

The EIWH engages with media and the public to promote key initiatives and partnerships and to raise general awareness around major issues and conditions affecting women and their families. Outlined below is a sample of news releases issued by the EIWH in 2019 and 2020.

Social Media

The EIWH has increased its social media presence by regular tweeting. For example: Tweeted in September, which was World Alzheimer month, Go Nano Tweets, meetings attended.

Publications - Policy Briefs

The European Institute of Women's Health generates policy briefs on many issues and makes recommendations for policy action. In keeping with the objective of the EIWH, policy briefings are developed following consultation with the Institute's network and are pertinent to women's health. Policy statements are distributed widely to stakeholders, policymakers and citizens and are available to view online at www.eurohealth.ie

The following policy briefs were completed during this period.

Gender and Health Technology Assessment (HTA)

Gender PB for MOPEAD, 2019:

<https://17215c60-696c-4eb6-9adb-50cde843a50f.filesusr.com/ugd/>

[e8882a_08fb25c1523345ed90dd6b3e32cede6b.pdf](https://www.ncbi.nlm.nih.gov/pubmed/31076376)

Gender and Nutrition

Impact of Covid 19 on Women and their families

Request for Briefing by Evelyn Regner -Chair of European Parliament (EP) Committee on Gender Equality (FEMM) Evelyn Regner approached us to complete a briefing on the impact of COVID-19 on women. We prepared the brief and sent to her office and also the office of the chair of the EP Environment and Public health Committee and other MEP

Policy Briefs / position paper(s) currently in preparation:

Maternal Health Report

Midlife and Older Women's Health

Women as Carers across the life course

Published articles

Alzheimer's disease 1 , 2019:

<https://www.ncbi.nlm.nih.gov/pubmed/31076376>

Alzheimer's disease , 2018:

[https://alzheimersanddementiajournal.com/article/S1552-5260\(18\)31837-5/pdf](https://alzheimersanddementiajournal.com/article/S1552-5260(18)31837-5/pdf)

Gender PB for MOPEAD, 2019:

https://17215c60-696c-4eb6-9adb-50cde843a50f.filesusr.com/ugd/e8882a_08fb25c1523345ed90dd6b3e32cede6b.pdf

EIWH membership/ Advisory Roles

The EIWH will continue in its role as advisor to the following:

- European Medicines Agency (EMA): Member of Patient and Consumer Working party
- European Commission, DG SANTE: HTA Stakeholder pool
- DG SANTE: Member of the Joint Action -Vaccination Stakeholder platform
- European Centre for Disease Control and Prevention (ECDC): Formal Advisory Group Representing-Patients (Observer)
- European Centre for Disease Control and Prevention (ECDC) Technical Advisory Group on Vaccination Uptake
- European Public Health Alliance (EPHA): Board Member and former Presidency,
- European Patients Forum: Member of the Digital Advisory Group
- Member of Patient/Industry Think Tank of the European Federation of Pharmaceutical Industries and Associations (EFPIA).
- WHO: Expert Advisor to and Member of the Expert Group on gender mainstreaming and WHO Women's Strategic Plan

- Member of BBRMI Eric, a European research infrastructure for biobanking
- Fundamental Rights Agency: Member of the Stakeholder Platform
- Co-Chair of the Department of Health (Ireland), Women's Health Task Force
- Member, Department of Health (Ireland), Independent Patient Safety Council.