



European Institute of Women's Health, CLG

Annual Report - 1st June 2018 -1st July 2019

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.

The 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 the board which guides EIWH policies and activities.

Board Members

Hildrun Sundseth, President of the EIWH, Germany
 Maeve Cusack, National Cancer Control Programme, Ireland
 Barbara Dowling, University of the Arts London, UK
 Sinead Hewson, TpEBO, Netherlands
 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
 Kristin Semancik, Researcher
 Vanessa Moore, Researcher
 Rebecca Moore, Researcher

Board Activity

Members of the board of the EIWH are located Europe-wide therefore a monthly meeting is hosted by teleconference and annually in person. The Annual face to face meeting took place in Brussels on the 15th of March 2019. 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. At this meeting, the annual report for the financial year 2017-2018 was presented and approved.

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 2017-2018, 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.

Activity Overview 2018-2019

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)

Due to the UK Brexit plans to leave the European Union, the EMA moved their headquarters from London to Amsterdam. The EIWH has been a member of the Patient and Consumer Working Party (PCWP) of the European Medicines Agency for the last 20 years. This 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 is 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)

Monash University

Monash University Research Project - Preconception, Pregnancy and Post-partum Health

In September 2018, EIWH participated in the Monash University Research project on *Health in Preconception, Pregnancy and Postpartum (HiPPP) Global Alliance*. Following the meeting, we contributed to the joint research paper on priorities for the prevention of maternal obesity and related pregnancy and long-term complications. The paper which contains the contribution from various world-wide health experts included the view of EIWH as representative organization from the health user/patient group has now been submitted for publication.

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 EIWH was invited to attend the meeting for the creation of a Coalition for Vaccination on 4 March 2019 in Brussels. The objective of this meeting was to discuss the creation of a Coalition for Vaccination, as requested in the Council Recommendation on strengthened cooperation against vaccine preventable diseases and to reach agreement on the most appropriate structure, scope, governance and general objectives of a Coalition for Vaccination. In order to keep the discussion focused only one participant per organisation can attend.

The EIWH is a member of the Stakeholder group in the Joint Action - Vaccination.

The EIWH attended a meeting on 4th of September 2018. Building on existing initiatives, the EU-JAV is developing common and durable cooperation to build concrete tools useful for EU and non-EU Member States' health authorities. Over a three-year period, the EU-JAV aims to develop tools to strengthen national responses to vaccination challenges in Europe and thereby improve population health. EU-JAV will build on the numerous existing initiatives and projects, first and foremost in Europe, while contributing to sustainability by incorporating its achievements into the health policies of European countries. To contribute to this goal, the EU-JAV will involve a wide range of stakeholders that share a common vision.

The EU-JAV proposes to address important issues, common to many countries by:

- Establishing the sustained cooperation of relevant Member State authorities;
- Defining basic principles for vaccine demand forecasting;
- Developing a concept and prototype for a data warehouse for EU-wide sharing of vaccine supply and demand data among dedicated stakeholders;
- Defining common stages and criteria for priority-setting of vaccine research and development (R&D);
- Developing a concept and prototype for a vaccine R&D priority setting framework;
- Defining structural, technical and legal specifications for data requirements for electronic vaccine registries/databases/Immunisation information systems;
- Providing a framework to cooperate on confidence from research to best practices and implementation.

Health Technology Assessment (HTA)

The EIWH is a member of the EU Commission HTA Stakeholder Pool.

On the 31st of January 2018, the Commission put forward a proposal to boost cooperation amongst EU Member States for assessing health technology. The EIWH welcomes the Commission proposal. Greater transparency will empower patients, by ensuring their access to information on the added clinical value of new technology that could potentially benefit them. The EIWH has prepared a draft position paper on HTA. A Sex & Gender-sensitive approach has not been included in most HTA

assessments and is rarely adopted in the current HTA process. The EIWH argues that S&G considerations must be considered not only to ensure equitable practice, but also to promote effective outcomes for all patients and citizens in Europe. The consistent integration of S&G into each stage of the HTA process will improve the quality of evidence and health outcomes for all in Europe.

The EIWH was invited to a meeting together with six other NGOs with EU Health Commissioner Mr. Andriukaitis to discuss the issues around HTA. In July 2018 the EIWH participated in an EU Commission conference on HTA in Brussels.

On the 16th January 2019 the EIWH attended and contributed to the first meeting of the Stakeholder Pool of the HTA Network. The Chair, **Andrzej Rys**, welcomed participants at the meeting of the HTA Network's Stakeholder Pool and highlighted that this is an important milestone in the ongoing process of the stakeholder involvement. The two new members, EORTC – European Organisation for Research and Treatment of Cancer and ARM - Alliance for Regenerative Medicine, were introduced. Currently the Stakeholder Pool gathers 33 European umbrella organisations, including the EIWH which have been selected through an open call for expression of interest. The member organizations are grouped in four pillars representing: (1) patient/consumers; (2) providers (e.g. health care professionals and academia); (3) payers; (4) industry (both pharmaceutical and medical technologies sectors). The Chair recalled the strategic objectives of the Stakeholder Pool: (1) to contribute to the development related to HTA at EU level; (2) to ensure that the views of different stakeholders are reflected in the policy development in a balanced way; and (3) to create synergies between different stakeholders.

Launch of EIWH Manifesto October 2018

In the run up to the 2019 European Parliament elections, EIWH officially launched its EU Manifesto for Women's Health in the European Parliament on the 10th of October. The event was hosted by Ms. Deirdre Clune. Speakers included Members of European Parliament, representatives from the European Commission, World Health Organization and other key health stakeholders. The event marked the beginning of the EIWH's campaign **Healthy Women—Healthy Europe**, which outlines that Europe **can do more to** prioritise women's health in order thereby improving the health of all.

The **EU Manifesto for Women's Health** highlights some central issues in women's health and calls on the Europe to do more now. European stakeholders must work together to enact, enforce, support, protect, partner, share and research. Only through concerted, concrete and swift action can women's and their families' health be improved across the EU. The EIWH calls on the European Parliament and other stakeholders to implement the Manifesto and include women's health in the questioning of Commissioners in the new government.

The EIWH's EU **Manifesto for Women's Health and** supporting documents are available online:

<https://eurohealth.ie/manifesto2018/>

World Congress in Paris on Women's Mental Health

In April 2019 EIWH, WHO and the Austrian Institute for Health jointly organised a successful workshop at the World Congress in Paris. The EIWH presentation topic was "Depression in Pregnancy". Writing a Policy Brief on Women and Depression is now one of the priorities for EIWH.

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 on 18th November 2018. 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 partners with the ECDC annually to raise awareness of the threat through targeted media relations on Antimicrobial Awareness Day.

European Immunisation Week

The EIWH developed a key vaccination policy brief titled 'Women and Vaccination in the EU'. In support of European Immunisation Week in April 2019, the EIWH re-issued this vaccination policy brief with a press release to media. A social media campaign saw pertinent vaccination information and messages being shared daily. The aim of the campaign was to increase awareness of the importance of vaccination in preventing the spread of infectious disease which is particularly relevant at a time when vaccination participation is decreasing.

EIWH Women and Alzheimer Advisory Council and Dementia Report

The EIWH European Advisory Council on Women's and Alzheimer's Disease was formally launched on the 22nd of January 2019 with the publication of the EIWH Position paper Women and Dementia in the EU. At this meeting in the European Parliament in Brussels, EIWH also officially launched its Position Paper "*Women and Dementia in Europe: Addressing the disproportionate burden of dementia on women*". <https://eurohealth.ie/2019/01/>

The event was hosted by Sirpa Pietikäinen, Finnish Member of the European Parliament (MEP) and longstanding advocate of women's health issues and dementia at European and national level. Speakers included representatives from the EIWH, European Commission, European Brain Council, Eurocarers, Age Platform EU, national Alzheimer's associations and Fundació ACE. This event took place under the EIWH's campaign **Healthy Women—Healthy Europe**, which profiles that Europe can do more to prioritize women's health

The Alzheimer's conference report highlights the disproportionate burden of Dementia on Women, both in terms of being affected by the disease themselves but also as carers of Alzheimer's family members. Members of the Alzheimer's Council spoke at the launch giving their perspective on this devastating disease. <https://eurohealth.ie/women-and-dementia-paper-launch/>

Women's Brain Project International Conference

The EIWH was invited to make the keynote speech at the Women's Brain Project International Conference in Zurich ,on the 9th June 2019. The Presentation included information on the biological and social determinants of women's health and outlined the EIWH Manifesto "Europe Can Do More"

EU- Projects

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

Objective of the project was to establish multiple key regional project sites across Europe to identify and test models of efficient earlier identification of mild AD patients, awareness of AD, memory complaints, and cognitive decline risks.MOPEAD will establish regional hubs across five EU countries (ES, DE, NL, SE, and SL). <https://www.mopead.eu/>

EIWH is task leader in WP Dissemination and participated in Partner Meetings, contributed to the Project Newsletter and to the article on Alzheimer disease.

The EIWH will complete a policy brief on Gender and Alzheimer Disease with the research starting

at the beginning of 2019. The EIWH takes part in a bi-monthly TC to discuss communication issues and activities with the other partners. The EIWH provides input into infographics, including quotes and English revision, and newsletters.
<https://www.imi.europa.eu/content/mopead>.

MyHealth Project

The EIWH is a partner in the project MY Health 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 base for the 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 through the application.

The EIWH disseminates project results and reports as well as publicizes 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 TALENTED on Cervical Cancer prevention

The old proposal has been revised and is now called TALENTED has been successful in getting through the first stage. EIWH are leading the Communication Work package and are currently completing the WP outline for the co-ordinator at the French research Institute (Inserm).

TALENTED aims to create the 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 re hard to reach and are at increased risk for Cervical Cancer.

Proposal: ARTEMIS-Understanding causative mechanisms in co- and multi morbidities combining mental and non-mental disorders. Unfortunately, this proposal was not successful.

Proposal: Gender aspect in transport and social inclusion.

EIWH was approached by a partner in the Go Nano project, to consider taking part in a Horizon 2020 proposal on transport. The co-ordinator of the project is the Center for Innovation in Transport (CENIT) is a research group of the International Center for Numerical Methods in Engineering (CIMNE). Unfortunately, this proposal was not successful

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: European-Partnership-for-innovative-health :https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/11906-European-Partnership-for-innovative-health/feedback?p_id=5722422-
- Responded to ECDC public consultation on draft guidance for introduction of HPV vaccines in EU countries: focus on 9-valent HPV vaccine and vaccination of boys and people living with HIV
<https://www.ecdc.europa.eu/sites/portal/files/documents/hpv-public-consultation-1-April-2019.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

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 2018 and 2019.

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 have been 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

Policy Briefs/position paper currently being written

Maternal Health Report

Midlife and Older Women's Health

Gender and Digital Health

Women as Carers across the life course

Gender and Nutrition

Published articles

Chronic Inequities Health Management (Politico), 2018:

<https://healthmanagement.org/c/healthmanagement/issuearticle/chronic-inequities-the-top-killer-of-women-in-europe>

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

[50cde843a50f.filesusr.com/ugd/e8882a_08fb25c1523345ed90dd6b3e32cede6b.pdf](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 of the Department of Health (Ireland), Independent Patient Safety Council