

Women and e-Health

Providing Better Information Resources by Building on Trust

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Celebrating 21 Years of Setting the Agenda in Women's Health

About the EIWH



- The European Institute of Women's Health is a health NGO founded in 1996.
- The EIWH aims to ensure a gender-sensitive approach to health policy, prevention, treatment, care and research in order to reduce health inequalities and improve quality.
- **Organisation:**
 - Extensive multi-national, multi-disciplinary network of patient groups, health NGOs, researchers, gender experts, politicians, and medical professionals
 - Expert Advisory Board

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Chronic Disease Burden



- Chronic disease is responsible for large part of ill health, disability and mortality in the EU in both sexes
 - Leads to increasingly costly health and long-term care if not treated and managed effectively
- Women outlive men by an average of **6 years**, however difference in **healthy** life expectancy is only **18 months**
 - Sex/gender impacts on susceptibility, prevention, diagnosis and treatment of chronic disease
- Research, practice, programming and healthcare systems must better respond to sex and gender-differences

Importance of Health Literacy



- Accessible, easily understood, accurate and appropriately targetted information is a valuable tool to empower patients, caregivers and their families.
- Health literate people have
 - Lower mortality rates
 - Lower useage of healthcare services (shorter stays, fewer visits)
 - Engage in safer use of medicines and manage their chronic conditions betterthan those with low health literacy

EIWH and e-Health



- The EIWH was an early adopter of new technology (1996)
 - Encourage women to use IT
 - Build a diverse audience throughout the EU
 - Reach and support this audiences
 - The EIWH has been involved in various projects to improve health information using new technology to support patients, carers and families in managing their health, adding to health literacy and other information access issues.
- EIWH strived to develop a health information model to:
 - Provide women with information on cancer
 - Provide a working model on what the internet could offer

Information for Women by Women

CanCom and Other Projects



- CanCom was funded by DG SANCO (1996)
 - The Cancom model provides women with high quality information
 - Involved women women groups, oncologists, oncological nurses and other health professionals in development and dissemination.
 - Available in 6 languages since 1997
 - Over 600 "online" packs were distributed to women's groups who held over sixty public health information days
- e-Tearooms
 - EIWH in cooperation with connect.ie in Ireland
 - Led to over 3,200 seniors having their first successful internet experiences (contact families, send pictures) for €5,200
 - Encouraged seniors to be active and mobile

Information for Women by Women

Learning from Feedback



- EIWH over the years has reviewed different models of information provision:
 - How effective are existing models in positively supporting patients to manage their conditions?
 - How can we ensure patients receive the information that they need and how they need it?
 - How information can be personalised?
 - How can information be best provided?
 - How can pilot services be developed to meet patients' information needs?

Information for Women by Women

Health Literacy in the EU



- European Health Literacy Survey (2011) found 12% of people have insufficient and 47% had limited health literacy
 - Large discrepancies persist: rates vary between 29% and 62% nationally
- Certain groups had disproportionately high levels of insufficient or limited health literacy
 - Notably low socioeconomic status
 - Low education
 - Low social status
 - Older age

Healthcare Professionals and Health Literacy



- Patients **trust** the information they receive from their healthcare providers.
- Healthcare professionals could use personally targeted health information to educate and to support their patients and carers, helping them manage their health and avoid potentially adverse outcomes and higher costs.
- Information could act as a reminder, e.g. medication compliance, and support information given during a consultation

MyDiabet.es Development



- Model to initiate the examination and review of current methods, models and tools available
 - Identified existing challenges, gaps and opportunities for improvement with regard to health information
- Basic health literacy information was compiled from the existing knowledge base to assist in writing in accessible language (e.g. national diabetes organisations)
 - Patient focus group established to advise on information content and identify gaps and quality issues.
- Move forward with a dissemination process building on the trust between patients and providers

JA-CHRODIS



- The EU Joint Action on Chronic Diseases and Promoting Healthy Ageing Across the Life-Cycle
 - Reducing the burden of chronic diseases
 - <http://chrodis.eu>
- Work together to identify, validate, exchange and disseminate good practice on chronic diseases across EU Member States
- Focus is health promotion and primary prevention as well as the management of diabetes and multi-morbid chronic conditions.



JA-CHORDIS Pilot Research



Pilot Research Project sought to:

1. Assess the need for health literacy information
2. Obtain preliminary feedback on the information that should be included in an online tool in the future



MyDiabet.es Preliminary Survey



- Healthcare professional survey in February 2017*
 - 44 respondents across various Member States
- The preliminary (draft) results indicate:
 1. A significant perceived need for health literate products
 2. Preliminary predominantly positive feedback on the MyDiabet.es pilot website as a health literate product

**The survey results are not finalised as the report has not yet been approved by the Commission.*

Moving Forward: Next Steps



- Central Findings
 - Positive feedback for MyDiabet.es
 - HCP perceive a need to access a range of health information
 - Need for a reliable online resource that is accessible, accurate, free and available in various languages

Moving Forward: Next Steps



- EIWH action in technology: priority in strategic programme
- Unmet need for HCP to help patients manage information
 - Meet patient needs for information
- Expand the beta and build the system by adding value
- Public-private partnership (currently with SME)
 - Add partners from JA-CHRODIS and others

Thank you. Any questions?



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