



**Keynote 1:
Patient empowerment through education**

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DISCLOSURES

Conflict of Interest declaration:

I have no actual or potential financial conflicts of interest in relation to this presentation and congress





OVERVIEW

Learning Objectives

Following the presentation the participant should be able:

- to identify the patient as a stakeholder in healthcare
- be aware of the importance of developing health literacy

Three Questions to the Audience

1. How can hospital pharmacists help to educate patients?
2. How can organisations, like EPHA and the EIWH, work with pharmacists to educate patients and reduce health inequalities?
3. What steps should be taken to educate patients and reduce inequalities?



OVERVIEW

Presentation Outline

- Background info
 - EPHA/EIWH
 - Health inequalities and patient empowerment in the EU
- Health literacy & patient empowerment challenges
 - Examples
- Changing healthcare environments: patients as 'case managers'
- Role of hospital pharmacists in educating patients
- Suggestions





WHO ARE WE?

The European Public Health Alliance (EPHA)

- A Brussels-based network representing the public health community throughout Europe
- Comprises +/- 95 member organisations based in EU-28 and EFTA, EU applicant and candidate countries and beyond
- Represents the interests of disease-specific communities, health professionals, vulnerable individuals, academics
- Advocates for more citizen involvement and transparency in political decision-making processes on health policy at EU level



WHO ARE WE?

EPHA

- Mission: to bring together the public health community to provide thought leadership and facilitate change; to improve health and reduce health inequalities
- Vision: a Europe with universal good health and well-being, where all have access to a sustainable and high quality health system: A Europe whose policies and practices contribute to health, within & beyond its borders
- Values: equity, sustainability, diversity, solidarity, universality, good governance



WHO ARE WE?

The European Institute of Women's Health (EIWH)

- The European Institute of Women's Health (EIWH) is a health NGO launched in 1996 based in Dublin, Ireland
- **Vision:** *Health for All*—across lifespan
- **Organisation:**
 - Extensive multi-national, multi-disciplinary network of patient groups, health NGOs, researchers, gender experts, politicians, and medical professionals
 - Expert Advisory Board



Why Women's Health?

Gender Inequities

- Women's health is more than reproductive health— it is health across the life-span.
 - The incidence and prevalence of certain diseases are higher among women. Others affect men and women differently.
- Gender is a key determinant of health closely linked with socio-economic factors.
 - Women in the main are the family health managers.



Health Inequalities

Select EPHA activities

- EPHA's European Charter for Health Equity (2010)
- Impact of austerity policies on healthcare, equity & solidarity in Europe
- Medicines & medical devices
- Health workforce
- Sexual health & reproductive rights, children's & women's health, mental health



Health inequalities

Example: Roma health

- EPHA Position on Roma health in Europe (2012),
- Roma health fellowship programme (2012-14) – building up EU advocacy champions (RO, HU, FYROM)
- Analysing implementation of National Roma Integration Strategies
- Better access to healthcare (traditional health systems & use of ICT) for sedentary & migrant Roma



How to **improve health literacy** of society's most vulnerable?

What differences in reaching out to women, men and children?



Health inequality

EIWH activities

Women in Clinical Trials

- The statistically significant under-representation of women in clinical trials needs to be corrected.
- Women have more ADR.
- The interaction of pregnancy and medications is understudied.
- Revision of the Clinical Trials Regulation.



Health inequalities

Promoting Gender Equity in Health

- **ENGENDER Project** (DG SANCO)
 - Inventory of good practices - promoting gender equity in health
- **EUGenMed Project** (DG Research, FP7)
 - Introduce Sex and Gender aspects into biomedical and health research
 - Innovative Roadmap to implement S&G into medicine



Patient Empowerment



Example:

e-&mHealth: Too much information = confusion?

'For many people in Europe, mHealth constitutes the first concrete manifestation of eHealth (...) smartphones and tablets are bringing the digital world closer into the realm of ordinary people'
(EPHA response to European Commission Green Paper consultation, 2014)



eHealth Stakeholder Group

EPHA-led report on eHealth & Health Inequalities, 2014

Quotes:

'Although the **digital divide** appears to be narrowing slowly but steadily as far as access to technology is concerned.

'The ultimate risk is that the **flaws of the traditional health system will be mirrored and potentially even aggravated online**'



Patient empowerment

individuals & vulnerable groups



- Experience working at the National Maternity Hospital in Dublin, Ireland
 - Developed literature for various ages (such as 17-19, 50-70) groups in conjunction with public the and professionals
 - Materials distributed by hospital then by the local community in Dublin
 - Lessons learned



Patient empowerment

individuals & vulnerable groups

Empowerment goes beyond information – ideally, it entails building up skills, motivation and confidence, and *appropriate action leading to better health outcomes*.

Some challenges:

• Access, affordability

• Importance of expert professional advice: self-diagnosis leading to bad decisions, harm

• Patient safety



Health literacy

Health literacy today is increasingly complex and involves different literacies that require cognitive and behavioural competences applied simultaneously:

- Health skills are also by-products of formal education....
- Kickbusch reported, a 'Health Literacy Workshop' meeting in June 2000 [(Kickbusch, 2001), p. 293]: "...resolved to widen the glossary definition to include the dimensions of community development and health-related skills beyond health promotion, and to understand health literacy not only as personal characteristic, but also a key determinant of population health."



Women and health literacy

EIWH is committed to health literacy:

- Provision of factsheets to stakeholders (e.g. chronic disease)
- Working with citizens to design effective information solutions(focus groups on women's cancers) disseminating results in multiple languages.
 - Women's role as carer—importance of health literacy for themselves and their families.



Minority Women's Project

- Target demographic
 - Women different socioeconomic backgrounds and countries
- Discussion documents
- Heart disease, depression, osteoporosis, cervical cancer
- Focus groups
 - Showing different information (not just EIWH)
 - Based on comments, drafted a document reviewed again by group



Example: Cancom

- **Cancom**, a cancer communication & information initiative for women & families funded by DG SANCO
- Cancom was a solution to encourage women to use the web
- Cancom gave women high quality information.



Example: Cancom

- Gave local groups editorial control -with guidelines.
- Involved a number of discrete groups of women:
Women at work | Women at Home | Younger women
- The project is 20 years old - in 5 languages



Example: eTearoom

- To improve health information dissemination .
- Early 2000's - elderly not seen as a technological audience.
- Over 3 years the project taught 3,200 seniors.
- Project rated as the best, most cost effective way of meeting the needs of seniors by an EU research programme.



Patients as case managers

New powers of patients

- Better informed due to ubiquitousness of ICT (Internet, broadband etc.)
- Questioning medical authority & status as 'passive subjects'
- Involvement of patient group representatives at policy level (e.g. European Medicines Agency's Patients' and Consumers' Working Party & PRAC Committee): providing expert advice on patient leaflets & how to communicate medicines to patients



Patients as case managers

New responsibilities:

- More complex personal & medical histories
- Providing feedback on medicines and treatments, recording information & experiences
- Feedback about areas where patient knowledge / support is lacking



Patient safety concerns

Non-adherence to medicines

Many **reasons for non-adherence to medicines:**

- Lack of ability to navigate health system
- Patient leaflets / patient information too complex unclear & not concise enough
- Unaware/ underestimate consequences of not using medicines
- Different messages from different HCPs, other patients, carers



Hospital pharmacists

Role in patient empowerment / education

Challenges-Who,What,When,How and Why

- Inform patients about hospital pharmacist function – creating 'visibility'
- Experts using ICT for 'bedside support' in communicating treatments, medicines
- Educating patients about efficacy and potential risks, e.g. ADRs, drug interactions
- Building up relationships of trust within short time frames



Hospital pharmacists

Role in patient empowerment / education

Advantages

- As experts, pharmacists are well placed to advise & educate patients
- Face-to-face contact contributes to improved understanding -resulting in better treatment compliance
- Subtleties -context-specific information can be brought to light and discussed



Hospital pharmacists

Role in patient empowerment / education

European Statements of Hospital Pharmacy

Agreed at EAHP Summit, May 2014– relevant examples of **Clinical Pharmacy Services**

- 4.1 'They (...) should play a full part in decision making including advising, implementing & monitoring medication changes in full partnership with patients, carers and other HCPs'
- 4.5 'They should promote seamless care by contributing to the transfer of information about medicines whenever patients move between and within healthcare settings'
- 4.6 'As an integral part of all patient care teams, they should ensure that patients and carers are offered information about their clinical management options, and especially about the use of their medicines, in terms they can understand'
- 4.7 'They should inform, educate and advise patients, carers and other health care professionals when medicines are used outside of their marketing authorisation'
- 4.8. 'Clinical pharmacy services should continuously evolve to optimise patient outcomes'



Hospital pharmacists

Role in patient empowerment / education

European Statements of Hospital Pharmacy

Agreed at EAHP Summit, May 2014– relevant examples of **Patient Safety**

- 5.1 'The 'seven rights' (the right patient, right medicine, right dose, right route, right time, right information, right documentation) should be fulfilled in all medicines-related activities in the hospital'
- 5.4 'They should ensure the reporting of ADRs and medication errors to regional or national pharmacovigilance programmes or patient safety programmes'
- 5.8 'They should ensure accurate recording of all allergy and other relevant medicine-related information in the patient's health record'
- 5.9 'They should ensure that the information needed for safe medicines use, including both preparation and administration, is accessible at the point of care'
- 5.11 'They should support and implement systems that allow traceability of all medicines dispensed by the pharmacy'



Suggestions

Improving patient empowerment

- Need to better **INFORM** the public about hospital pharmacist roles
 - Make use of ICT & social media to reach young patients in particular
- Gather & track as much information about patients' past and present medicines use as possible
- Work in collaboration with entire healthcare team to ensure best possible medicines reconciliation & continuity of care
- Engage in Continuous Professional Development to keep up with patient education trends and meet the needs of diverse/vulnerable patients
- Ensure patients become interested in/enthusiastic about taking part in co-producing their health!



Patient empowerment

individuals & vulnerable groups



Thank you for your attention.

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