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Social and psychological barriers for the access to care and for patient empowerment and/or patient's information needs



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This presentation arises from the Joint Action addressing chronic diseases and healthy ageing across the life cycle (JA-CHRODIS) which has received funding from the European Union, under the framework of the Health Programme (2008-2013).

Who is EPF?

- Independent, non-governmental advocacy organisation set up in 2003
- *Members:* EPF represents 64 pan-EU disease-specific organisations and national coalitions
- *Vision:* high quality, patient-centred equitable access to health and social care for all patients in the EU
- *Mission:* a strong and united patients' voice → Putting patients at the centre of EU health policy



**A
STRONG
PATIENTS'
VOICE
TO DRIVE
BETTER HEALTH
IN EUROPE**

Cross-disease issues affecting all patients regardless of condition or background

A working definition of Access

“Accessibility” = Availability + Affordability

- A medicine is accessible when it is functionally available to the patients who need it :
 - When it is possible to prescribe it,
 - it is distributed through reachable channels,
 - and its cost is affordable.
- **If any of these elements is missing, there is a problem!**

(working definition borrowed from DG Enterprise)

Barriers to overcome

- Lack of legislation on patient involvement in contexts that are not clinical or medical and linked to the treatment of individual patients;
- **Poor political culture** and tradition in involving patients' communities in health policy and decision making;
- Meaningful patient involvement requires **access to resources**: financial, human, know-how;
- Access to treatments for **marginalised and vulnerable groups**
- Administrative barriers, lack of mechanism for planning;
- Attitudes and perceptions also play a big role.

Health Inequality

- Health inequalities have not been studied much from the perspective of patients
- Inequalities persist – in terms of access to healthcare and quality of care
- Wide divergences in patients' access to healthcare are unjustifiable and exacerbate health inequalities across the EU
- Access to healthcare, including medicines, is recognised as a main factor behind health inequalities
- Chronic diseases as a factor of health & social inequalities.
- **Patient empowerment and health literacy as key components of the solution**

EMPATHiE working definition of patient empowerment

“

An *empowered patient* has control over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to achieve optimal well-being ”

Social and psychological barriers to PE

Barriers:

- **Attitudes** of healthcare professionals and policy-makers;
- **Differences between EU health systems;**
- Lack of resources and infrastructure;
- Lack of **patient and citizen involvement;**

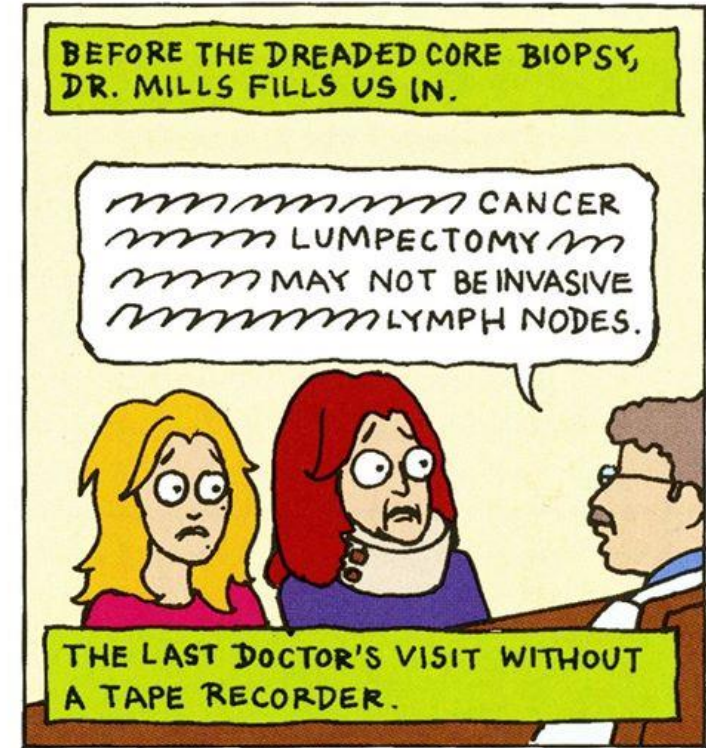
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“You have to learn about thousands of diseases, but I only have to focus on fixing what’s wrong with ME! Now which one of us do you think is the expert?”

Role of Healthcare professionals and information to patients

- Key actor in the management of patients' health conditions
- Barriers?
 - Lack of sufficient dedicated time to face to face meeting;
 - Financial sustainability;
 - Miscommunication and **lack of mutual understanding**;
 - **Lack of trust**
- Patient and healthcare professional: moving from **monologue to dialogue**



Information and Health Literacy

- Further research needed on user-friendly health systems
- A guide on how to make **information user-friendly** and **usable** for the average citizen
- Culture change

Benefits of Health Literacy

1. It enables the individual to understand information about his/her health.
2. It enables a person to make informed decisions and act independently based on his/her knowledge
3. It allows a person to reflect about and explore alternative health-related options
 - A key dimension of patient empowerment
 - Has major economic consequences
 - Essential for equity, quality and efficiency of patient-centred healthcare systems



Access, information and empowerment in the treatment of diabetes

- Disparities in access to care in the 47 countries of the IDF Europe Region
- Cultural and behavioural barriers
- Barriers to appropriate therapy may be generated by GPs
 - Feelings of fear, frustration, lack of control

Self-management is the key!

Access, information and empowerment in the treatment of diabetes

- Access to appropriate treatments for patients with diabetes may depend also on other factors:
 - Lack of accessible (proximity, opening hours) infrastructures
 - Geographical area
 - Vulnerable and/or marginalised population
 - Gender (when associated to health conditions) becomes a double burden of discrimination
 - Ability of HCPs to communicate with patients
- At macro level: mismanagement of health systems

The Joint Action on Chronic Diseases and promoting healthy ageing across the life cycle (JA-CHRODIS)*

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