

EPF Conference on Health Literacy 8 -9 April 2008

MAIN CONCLUSIONS AND RECOMMENDATIONS

This conference, a unique opportunity to address the theme of health literacy at EU level brought together 130 patient leaders, health policy makers and health stakeholders from throughout the European Union to explore health literacy, its importance and why and how this should be taken forward as a policy priority. A detailed report will be produced and the following brief document summarizes the main conclusions and recommendations emerging from the two days' discussions.

Main Conclusions

- Although there are different definitions of health literacy, common elements include skills, understanding, access, use of, information, knowledge, empowerment, decision-making. One definition that was taken up in the working groups was *'the ability to make sound health decisions in the context of everyday life at home, in the community, at the workplace, the health care system, the market place and the political arena'*¹
- From a patient's perspective, the knowledge and competence gained through health literacy lead to the strength and empowerment needed to manage well a disease/condition and its impacts on quality of life.
- Health literacy is a right, and also a critical strategy to move towards health equity, empowerment and patient-centred healthcare in modern society. There are significant differences across EU Member States on how health literacy is perceived and prioritized.
- Improving health literacy skills of patients, citizens and health professionals should be achieved through strong partnerships involving all of the relevant stakeholders, including the European institutions. We need to 'mobilise actors and fuel momentum'. This echoes very much the spirit of the last EPF Spring Conference "Moving forward together".
- There is increasing recognition across the patient and healthcare community of the need to move from 'monologue' to dialogue between the patient and the healthcare provider, to have the opportunity to share decision making. Health literacy is a key driver for this to happen effectively.
- The dynamics of health literacy highlight the vulnerability of those patients and citizens who are not health literate and who are exposed to double inequities – first in relation to using health promotion information and advice on prevention, second in relation to acquiring the knowledge and the skills set to deal with a disease or illness.
- Patient organizations have a key advocacy role to play to ensure that health literacy is embedded as policy and programmatic priority in all EU member states; and ensuring "quality" health literacy and "health literacy proofing".

¹ This is the definition used by Prof. Kickbusch, WHO

RECOMMENDATIONS

Collectively, all of these recommendations should be used to strengthen the “health literacy” component of the EU Health Strategy – “Together for Health”. The European Patients’ Forum is committed to contributing actively in taking forward these recommendations in partnership with the European Commission and other stakeholders.

- **Further Research**

Further targeted research is required that explores and evaluates

- the concept of health literacy and its role in healthcare and health outcomes, recognizing that current literature tends to focus only on reading ability and health.
- patients’ challenges in navigating the health care system, that will enrich the understanding of health literacy.
- the cost of health illiteracy
- links and data collection on health literacy and inequality across Europe

and identifies good practice and dissemination strategies.

- **A comprehensive EU project leading to an EU Health Literacy Network**

The proposed EU Health Literacy Project currently limited to six countries should be given the political and financial resources to advance and extend its scope across the EU with minimal delay. The project should involve EPF and other patients’ organizations at EU and at national level and have an explicit link with the EU Health Strategy.

One of the key deliverables of the project should be the setting up of an EU Health Literacy Network involving all interested stakeholders to benchmark, stimulate and promote good practice in health literacy.

- **Health Information and Information to Patients**

A wider distribution of “information to patients” is needed that meets core quality criteria²

- A “guide” should be developed for information providers on how to make information user-friendly and usable to the average citizen.

² The document on quality criteria was agreed in the framework of the Pharmaceutical Forum

- An EU “quality mark” initiative should be explored, based upon existing food labelling practices.
- The EU health portal should further be developed in order to provide approved information in all EU languages.
- NGOs should be able to seek funding from the Commission specifically to help them translate information on management of disease into a greater number of languages.
- Patients throughout the EU should have the right to access their medical records in an understandable and transparent format. E-health records should also be “owned” by and accessible to the patient him or herself.

Patient and Professionals Education and Productive Dialogue

An EU capacity building programme involving ‘patient experts’ should be set up. This should address education and training for health care providers on communications and shared decision-making and draw on current good practice in this area.

The European Commission should pilot an education module for health care providers on “productive dialogue with patients” that you must have studied and passed in order to be able to work across borders

- Patients’ organizations should be provided adequate resources to carry out quality health literacy programmes with patients, particularly regarding the key questions to ask their healthcare providers, and getting the most out of their consultations.
- In this regard; the patients’ own stories and anecdotes regarding their patients’ journey should be recognized as a key resource.

Involvement of patients and their representative organisations

- The meaningful involvement of patients should become a baseline performance indicator of health systems and *inter alia* the application of policies and programmes on health literacy.
- Patient groups and their allies should explore how “patients rights” instruments can be used effectively in promoting health literacy, particularly among disadvantaged and marginalized groups.

- Patients organizations alongside other independent stakeholders also have a role in ensuring quality assurance linked to health literacy initiatives and 'health literacy proofing' healthcare and health information developments.
- Patient organizations across the EU should set up of a 'clearing house' to translate and adapt high quality information to patients and not re-invent the wheel

Political Momentum and Resources

- Health literacy should be part of a broader patients and citizens' information strategy that respects and optimizes what can be achieved at EU level and what can be achieved at national level.
- The EPF Patient Manifesto should encapsulate the broad patient perspective on health literacy and engage MEPs' and national parliamentarians' support.
- EU Institutions and Member States governments should 'institutionalize patients' empowerment, and through this commit to supporting and implementing health literacy policies and programmes
- Given the importance of supporting actions at regional level and local level, greater emphasis should be placed within the EU Structural Funds to resource health literacy interventions.