

# Health Literacy

CONFERENCE REPORT

European Patients' Forum Spring Conference

Brussels, 8-9 April, 2008







# Introductory Remarks



*Anders Olauson*

Dear colleagues and friends,

“Health literate patients, can they really make a difference?” This was one of the key questions raised during the European Patients’ Forum’s Spring Conference on Health Literacy which took place on 8-9 April 2008 in Brussels. After having listened to the presentations and discussions during the conference, I believe this question can be answered with a wholehearted “yes”. Health literacy does make a difference as it is a key dimension of a citizen’s right to health, has major economic consequences and is essential for equity, quality and efficiency of patient-centred healthcare systems.

Health literacy includes being able to access high quality information, but also, and most importantly, skills and the ability “to make sound health decisions” in different settings.

The conference looked at health literacy from different perspectives, first and foremost from a patients’ perspective. In this respect I have to stress how impressed I was with the contributions of the conference participants. Many participants shared their personal experiences - something which is unique and extremely valuable.

Health literacy is a topic close to EPF’s heart. We have been working on health literacy for a number of years now and I am glad to see that progress has been made. The European Commission has recognised the importance of health literacy, can be illustrated for example by the European Health Literacy Survey, a project recently funded through the EU’s Public Health Programme. However, we need to look forward as a lot remains to be done. The concept of health literacy still needs to be promoted and become a health policy priority across Europe.

2009 will be an important year for us: a new European Parliament will be elected and a new European Commission will take office. We therefore need to continue to raise awareness on the need for a patient-centred approach to healthcare and the key role of health literacy in achieving this. Anticipating the important upcoming institutional changes at EU level, EPF will launch a “Patient’s Manifesto - 150 million reasons to act” as an important contribution to improving the quality of healthcare delivered to patients across Europe.

I am delighted to present you with the report of the EPF 2008 Spring Conference report. I hope that it will provide you with useful information and different views on health literacy. The report includes important conclusions and recommendations. We look forward to working with you on these proposed actions, so that by the next EPF Conference we can again look at progress in this area.

I would like to conclude by re-emphasising the words of European Commissioner for Health, Mrs Androulla Vassiliou, who provided the keynote address during our conference and highlighted that access to health information and patient empowerment, key elements of health literacy, can only be achieved through partnerships involving all relevant stakeholders.

With best wishes,

A handwritten signature in blue ink, appearing to read 'A. Olauson', with a stylized flourish at the end.

Anders Olauson,  
President European Patients' Forum

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# Conference Conclusions and Recommendations

## 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 healthcare system, the market place and the political arena”*<sup>1</sup>.
- 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 prioritised.
- Improving health literacy skills of patients, citizens and health professionals should be achieved through strong partnerships involving all of the relevant stakeholders, including the EU 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 organisations have a key advocacy role to play to ensure that health literacy is embedded as policy and programmatic priority in all EU Member States, ensuring “quality” health literacy and “health literacy proofing”.

## 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, recognising that current literature tends to focus only on reading ability and health;
  - patients' challenges in navigating the healthcare system, that will enrich the understanding of health literacy;
  - the cost of health literacy;
  - links and data collection on health literacy and inequality across Europe

and identifies good practice and dissemination strategies.

<sup>1</sup> This is the definition used by Prof. Kickbusch, WHO



### 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 patient organisations 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 criteria<sup>2</sup>.
- A guide should be developed for information providers on how to make information **user-friendly and usable** to the average citizen.
- 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 diseases 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 professional education and productive dialogue

- An EU capacity building programme involving “patient experts” should be set up. This should address education and training for healthcare 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 healthcare providers on “productive dialogue with patients” that you must have studied and passed in order to be able to work across borders.
- Patient organisations 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 most out of their consultations.
- In this regard, the patients' own stories and anecdotes regarding the patients' journey should be recognised 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 marginalised groups.

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<sup>2</sup> A document on quality criteria was agreed in the framework of the Pharmaceutical Forum.

## Conference Conclusions and Recommendations

- Patient organisations 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 organisations across the EU should set up 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 optimises what can be achieved at EU level and what can be achieved at national level.
- The EPF Patient's Manifesto should encapsulate the broad patient perspective on health literacy and engage the support of MEPs and national parliamentarians.
- EU Institutions and Member State governments should institutionalise patient empowerment, and through this commitment 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.



# Summary of Presentations



## KEYNOTE ADDRESS

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Mrs Androulla Vassiliou, European Commissioner for Health

**Main points: Health literacy has a major impact on key health issues such as health status, inequality and costs. Unequal access to information equates to unequal access to healthcare. The patient-centred vision of healthcare today calls for empowerment of patients. Patient representation in healthcare decision-making is an essential element of such empowerment. Patient involvement should become a baseline performance indicator of health systems.**

## SUMMARY OF PRESENTATION

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### Key points with respect to health literacy

The following points need to be addressed in relation to health literacy:

- the link between health and education;
- the importance of the availability of quality health information;
- the central role of partnerships with patients to move forward.

### Health literacy includes different skills

Health literacy can be defined as an individual's capacity to obtain and understand basic health information so as to make appropriate health decisions. Health literacy covers much more than simply the ability to read. It covers reading, listening, analytical and decision-making skills applied to health situations. This will vary according to context, culture and setting, and include language, numerical, reasoning and computer skills.

### Consequences of inadequate health literacy

Inadequate health literacy can have a major impact and result in for example: little or no knowledge of medical care and medical conditions, reduced use of prevention services, poorer self-reported health, poorer compliance rates and health status, increased hospitalisations, higher inequality and increased healthcare costs.

### Communication needs and the role of the individual

Communication needs have become more demanding. Medicine has increasingly become a multidisciplinary team activity and health systems a continuum of services around the patient. As we move towards more patient-centred healthcare systems, individuals are called to take more active roles in healthcare in order to improve quality and reduce costs.

### Role of the EU

Responsibility for healthcare provision lies with the Member States. The European Commission works to ensure a high level of health protection, in full respect of the subsidiarity principle. In this respect, the Commission has funded through the EU Public Health Programme 2007 a project which aims to provide an overview of the situation with respect to health literacy across the EU and to develop a European Health Literacy Survey.

### The importance of information

Objective, reliable and comparative up-to-date information on different treatment options is an important decision-aid to allow patients to make informed decisions on their own care. This is particularly important in self-management of diseases and conditions. In addition, patient adherence to treatment is improved when patients have a better understanding of their illness or condition, the treatments available and how to use them effectively.

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### Unequal access to information, unequal access to healthcare

Although there is a lot of information available, patients do not necessarily have easy access to clear, quality, readable information. As information is essential to exercise rights, unequal access to information equates to unequal access to healthcare. The role of the Commission in this respect is to coordinate action at a European level and to support national, regional and local health information initiatives.

### Relevant EU initiatives

The EU Public Health Portal aims to contribute towards improving information availability and communication with citizens. It provides a single point of entry where citizens, administrations and health specialists can find simple, clear and scientifically sound information from European, national and sub-national levels, empowering them to improve their knowledge on health themes across the range of Community policies. Many Community policies and actions have an impact on health and health systems across Europe. There is a need for coordinated actions involving other policy areas.

### Advertising vs information

Concerns with respect to the distinction between advertising and information is being addressed through the High Level Pharmaceutical Forum and its Working Group on Information to Patients. This Working Group has been mandated to advise the Commission on ways to improve the quality of information on authorised medicines available to European patients.

### Patient empowerment

The patient-centred vision of healthcare today calls for greater empowerment of patients. Patient empowerment is essential in order to achieve improved quality of care and health outcomes, leading to a better quality of life. Patient representation in healthcare decision-making and planning is an essential element of such empowerment. In addition, patient involvement should become a baseline performance indicator of health systems.

### Partnerships

In line with the conclusions of the 2007 EPF Conference, the Commission agrees that health information and patient empowerment should be seen as objectives that can only be achieved through a series of partnerships involving all relevant stakeholders, including the EU Institutions.



## PLENARY SESSION: THE HEALTH LITERATE PATIENT, CAN THEY REALLY MAKE A DIFFERENCE?

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Health literacy: its relevance to citizens and modern societies -  
Prof Ilona Kickbusch, World Health Organisation

**Main points: Health literacy is a key dimension of a citizen's right to health; has major economic consequences for society and healthcare systems and is of high relevance to equity, quality and efficiency of health systems. Health literacy must become a priority for health policy action and investments in health literacy research need to be made. Patients and communities need to be put in the centre.**

### SUMMARY OF PRESENTATION

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#### Active citizenship

Health literacy is active citizenship, a critical empowerment strategy in modern society and a significant dimension of citizens', consumers' and patients' rights.

#### The societal context

Societal structures are changing. In the 21st century, knowledge society and health society are merging, creating added value. Knowledge and health are both crucial to the development of our society. This is why health literacy has become so fundamental.

#### Human capital of knowledge societies

Differences in levels of literacy matter both economically and socially: literacy affects, inter alia, labour quality and flexibility, employment, training opportunities, income from work and wider participation in civic society. The higher the proportion of adults with high literacy skills, the higher the GDP per capita. Furthermore, countries with wider economic inequality also have wider literacy inequality.

#### Access to health information

20-30% of people are illiterate and cannot function in our society. Knowledge and health societies need active and competent citizens. In order to achieve this, it should be recognised that access to health information is a right of citizenship. However, we do not just need knowledge, but also need skills.

#### Definition of health literacy

Health literacy is the capacity to make sound health decisions in the context of every day life - at home, in the community, at the workplace, in the healthcare system, the market place and the political arena. There are different levels of health literacy: critical health literacy, interactive health literacy and functional health literacy. In addition, there are five health literacy domains: home and community, work, market, politics and health system. All domains demand functional, active and critical health literacy.

#### Research

Unfortunately most literature focuses on the ability to read. However, the crucial issue is the capacity to act on the information. Both the concept of health literacy and its role in healthcare use and health outcomes need further evaluation. Taking a patient-centred approach that addresses challenges in navigating the healthcare system and providing self-care may enrich the understanding of health literacy and ultimately how to measure and improve it.

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### Literacy and health inequality

There is a strong relationship between literacy and health. Those with limited literacy skills:

- report poorer overall health;
- are less likely to make use of screening;
- present in later stages of diseases;
- are more likely to be hospitalised;
- have poorer understanding of treatment;
- have lower adherence to medical regimens.

### Tools and good practice examples

There are different tools which aim to provide support in acquiring health literacy skills, such as a health literacy tutorial (<http://healthliteracy.worlded.org>) and discussion groups ([www.nifl.gov](http://www.nifl.gov)). The Health Literacy Portal of the Canadian Public Health Association ([www.cpha.ca](http://www.cpha.ca)) can be seen as a good practice example and promotes “A Vision for a Health Literate Canada”. An additional example of a health literacy project is “Choosing Health” of the UK Department of Health, aiming to make healthy choices easier. Proposals raised by the initiative include: a ban on junk food advertising before 9pm, traffic light coding for supermarket food and access to personal health trainers through the National Health Service.

### Challenge for the future

Addressing the double inequity (health literacy and skills) will be a major challenge for the future. Interventions are needed in three areas to fight this double inequity: competencies of patients, competencies of healthcare professionals and readability of health systems.

### The role of patient organisations

Patient organisations have a key role to play in advancing health literacy in Europe. They should:

- promote political advocacy (have you voted for your health today?);
- work systematically with political decision-makers and parliamentarians at all levels of governance;
- create new types of public health forums and partnerships at all levels.

An important question in this respect is: how health literate are politicians? Addressing this question may be a new challenge for patient organisations.

### The challenge

There is a strong need to invest in health literacy and to put patients and communities in the centre. Health literacy:

- is a key dimension of a citizen's right to health;
- has major economic consequences for society and healthcare systems;
- is of high relevance for equity, quality and efficiency of health systems;
- must become a priority health policy action area.

### Health literacy research

In addition, investments in health literacy research need to be made, more specifically to:

- improve knowledge on the state of health literacy in Europe;
- stimulate research on health literacy and health outcomes;
- research the costs of health literacy;
- develop a survey of successful policies and programmes;
- support health literacy programmes (interventions, evaluations, etc.);
- build a European alliance on health literacy.



Ms Gabriela Cretu, Member of the European Parliament

**Main points: Awareness needs to be raised on health literacy as a citizen's right. Health literacy is key in addressing inequalities between and within Member States. All stakeholders should be involved in improving health literacy.**

#### SUMMARY OF PRESENTATION

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##### **The EU and cross-border health**

Member States are responsible for health, but what does this mean when people nowadays work, live and travel across borders? In this respect, the role of the EU in health matters has increased.

##### **Citizens' rights**

Health literacy is about citizens' rights. Health illiteracy among EU citizens leads to higher healthcare costs. What can we do to address this? We need to raise awareness on the importance of health literacy and the importance of being involved in decision-making processes. In addition, we should stress the economic,

social and political benefits of representing patients' interests apart from the human rights perspective.

##### **Health literacy and inequalities**

Improving health literacy is not an easy task. All stakeholders need to be involved and a realistic, concrete approach is needed. Considerable inequalities exist between and within Member States. Health and health literacy have an important role to play in reducing these inequalities as they are linked to the economic prosperity of a country.

##### **A society of informed citizens**

It is better to think of a society of informed citizens rather than one of patients.

Ms Aliki Vrienniou, Greek Multiple Sclerosis Society

**Main points: A health literate patient is able to obtain, process and understand basic health information and services needed to make appropriate health decisions. Patient empowerment is key. Knowledge means strength leading to empowerment. Patient organisations, the industry and governments can contribute to this process.**

#### SUMMARY OF PRESENTATION

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##### **The European Multiple Sclerosis Platform**

The European Multiple Sclerosis Platform (EMSP) is a pan-European umbrella organisation representing people with Multiple Sclerosis. EMSP includes 32 member countries. All members are national Multiple Sclerosis societies.

##### **Health literate patient**

A health literate patient is able to obtain, process and understand basic health information and services needed to make appropriate health decisions. Decision-making skills involve comprehension, good knowledge of the issue and rejection of unreliable information.

##### **The example of Multiple Sclerosis**

Multiple Sclerosis is a complex disease which usually affects young adults between fifteen and forty years old. The disease is unpredictable and affects vision, hearing, memory, balance and mobility. Its impact can be felt by family, friends and the community. A newly diagnosed patient is often confused and in need of a lot of information. The patient needs to evaluate this information with respect to its credibility and quality. Finally, the patient needs to decide, based on a risk-benefit analysis.

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### Patient empowerment

Empowering patients in this respect is key. For example, patients can be empowered to describe their symptoms effectively. This will help professionals make the right diagnosis. Patient organisations as well as the industry and governments can contribute to patient empowerment.

### The role of patient organisations

Patient organisations can contribute by developing support programmes to empower patients, such as:

- organising conferences involving highly qualified experts;
- publishing booklets using simple and understandable language;
- raising awareness.

### The role of industry

Industry can contribute by providing high quality information accessible to every individual in a digestible way. This can be achieved by for example including graphics and pictures in leaflets and on websites.

### The role of governments

Governments can contribute by:

- supporting patient organisations;
- creating a legal framework clearly defining the role of the industry as well as the role of healthcare specialists, to the benefit of patients.

### Patients can make a difference

Can patients really make a difference? The answer is yes. Knowledge means strength which in turn means empowerment.

Mr Brian Ager, European Federation of Pharmaceutical Industry Associations

**Main points: Several studies underline the value of health literacy. Better informed patients can lead to more successful health outcomes. Information provided unsolicited to the public should be limited to general health information, not mentioning specific medicines. However, when citizens or patients seek information, companies should be able to provide high quality product information. EFPIA does not support Direct-to-Consumer Advertising in Europe.**

## SUMMARY OF PRESENTATION

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### Dialogue

EFPIA is in regular dialogue with patient groups in order to increase mutual understanding and discuss shared priorities, better understand and address patient needs and concerns on research and medicines and to encourage a representative patient's voice on the EU scene. This dialogue is based on clear rules of engagement, such as a memorandum of understanding and the EFPIA principles for partnership.

### Ethical code

EFPIA has developed a code on relationships between the pharmaceutical industry and patient organisations. This code aims to achieve ethical and transparent relationships, recognising the independence of patient groups. The code should be implemented across Europe in 31 countries by 1 July 2008. The code focuses on key issues such as non-promotion of prescription medicines, the importance of written agreements, use of logos and proprietary materials, transparency and diversified funding.



### Health information in Europe

According to the European Commission in its Communication on current practice with regard to information provision of December 2007, EU citizens have unequal access to information and a lack of information may result in uninformed choices. In addition, the Communication indicated that a lack of EU quality standards for information increases the risk of wrong, misleading or confusing information creating health risks. Better information can contribute to better health conditions, more efficient use of resources and better adherence. In its Communication, the Commission concluded that the internet plays a central role, but there is a need for non-electronic tools for large parts of the population.

### Role of the industry

Member State authorities are not able to fully address patients' needs in terms of substance of information and access via different means. In turn, the pharmaceutical industry possesses key information on their medicines. However, this information can currently not be made available to patients throughout the EU.

### Industry's views

Contributing to the public consultation launched by the European Commission on a legal proposal on information to patients, EFPIA stated that:

- It welcomes a patient-centred approach and general objectives and calls on policy-makers to develop a modern EU framework for information without further delay.
- Companies have a legitimate role, and responsibility, to provide to patients non-promotional, quality information on their products, among others. The doctor-patient relationship remains crucial.
- It supports the objective to develop a workable distinction between information and advertising. EFPIA does not support Direct-to-Consumer Advertising in Europe.

EFPIA believes that information which is provided unsolicited to the public should be limited to general health information such as prevention and awareness, but not mentioning specific medicines. However, when citizens or patients seek information, companies should be able to provide high-quality product information, for example on company websites, and in the context of compliance programmes.

### Public-private partnerships

Successful public-private partnerships in certain Member States demonstrate the value that the industry can bring to improve citizens' understanding of its products. Examples are the "Medicines Information Partnership" and the "Ask About Medicines" Project in the UK and the Swedish FASS (Swedish Association of the Pharmaceutical Industry) system as the trusted medicines information source, including a website with four million hits per month.

### A European health information challenge

The development of a modern reform of health information in Europe can only be achieved through partnerships with other stakeholders. The patients' voice is key in this.

### Improving the patient-doctor relationship - Dr Michael Wilks, President Standing Committee of European Doctors

**Main points: The patient-doctor relationship has changed with time and has been impacted by changing societal values and expectations. Patients can contribute information and responsibility to the patient-doctor relationship; doctors can bring clinical, professional and communication skills. Tools and other initiatives can be developed to promote health literacy. A more dynamic patient-doctor relationship needs to be developed.**

#### SUMMARY OF PRESENTATION

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##### Health literacy and health outcomes

Many factors influence health outcomes, such as: self-care, public policy, clinical standards, healthcare systems, income inequality, education, patient safety and prevention. The issue of health literacy should therefore be put in the right context. What we all want is to improve health outcomes and to improve the relationship between patients and doctors.

##### Different skills

Patients can contribute information and responsibility to the patient-doctor relationship. Doctors can bring clinical skills, professionalism and communication skills. Clinical skills are influenced by a wide range of issues, such as overspecialisation, working time arrangements, re-licensing and re-specialisation, the role of regulatory bodies and professional mobility.

##### The patient-doctor relationship

Changing societal values and expectations have impacted the patient-doctor relationship. This relationship has changed with time also because of the involvement of more stakeholders such as nurses, therapists and pharmacists. Technological developments also have had an impact, for example through the introduction of electronic patient records.

##### Examples of health literacy initiatives

Tools and other initiatives can be developed to promote health literacy, such as the provision of printed leaflets and health information packages as well as computer based and internet health information. In addition, targeted approaches to tackle low levels of health literacy in disadvantaged groups can be developed together with targeted mass media campaigns. Specific training for clinicians can contribute to improving clinical decision-making. In this respect, decision aids, coaching and question prompts can offer support to patients.

##### Improving self-care and patient safety

In addition, certain interventions can improve self-care and enhance patient safety, such as self-management education, patient access to personal medical information, information to help choose safe providers, self help groups and peer support and patient reporting of adverse drug events.

##### A more dynamic patient-doctor relationship

Health information materials, decision aids, self management action plans, and other “technologies” of patient engagement are most effective when they supplement or augment, rather than replace, the patient-doctor relationship<sup>3</sup>. A more dynamic patient-doctor relationship needs to be developed, based on dialogue, problem solving, trust and a joint plan.





## FROM THEORY TO PRACTICE

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Health literacy in Europe: from theory to practice - Prof Jen Wang, University of Zürich

**Main points: The concept of health literacy is currently virtually unknown in Europe. Given its importance, health literacy should be recognised and addressed by governments across Europe. As an important milestone, the European Commission has supported an EU health literacy project: "HLS EU".**

### SUMMARY OF PRESENTATION

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#### **The active citizen**

An important question is to what extent citizens have the skills to meet the challenge of living and working in today's information-rich and knowledge intensive society. In current times, people need many different skills, such as scientific, financial, technological, IT, media, information and multicultural skills.

#### **Competencies to maintain good health**

Different competencies and resources are needed to acquire and maintain good health. These competencies include knowledge, cognitive skills, practical skills, motivation, attitudes and values. In this respect:

**Health literacy** requires cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.

**Patient empowerment** is an educational process designed to help patients develop the knowledge, skills, attitudes and degree of self-awareness necessary to effectively assume responsibility for their health-related decisions.

**Self-management** includes an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent to living with a chronic condition.

#### **Involvement in health related decisions**

According to a recent health literacy survey<sup>4</sup>, people want to participate in treatment decisions. However, the survey shows that in practice only a minority of people are actually involved by their general practitioner in medical decisions. Health related decisions are complex. People are faced with many choices in the healthcare arena, such as selecting a sick-fund or a general practitioner. The survey shows that almost all respondents want freedom of choice which in their opinion strengthens trust. However, just half believe they have enough information to choose the right sick-fund or the right doctor for themselves.

#### **Understanding health information**

The media play a key role in the search for information: of the five most cited sources of health information, three belong to the media. The Internet has become the third most important source of health information, just after general practitioners. However, it needs to be stressed that the information currently available has not necessarily contributed to greater comprehension: only 26% of respondents to the above mentioned survey said that the information in the media is easy to understand.

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### Need to raise awareness

Given its importance, health literacy should be recognised and addressed by governments across Europe. The concept of health literacy is currently virtually unknown in Europe, except in Switzerland, Ireland and the UK. In order to raise awareness on the issue, health literacy was discussed at the European Health Forum in Bad Gastein between 2004 and 2006. As an important milestone, health literacy was included as a priority in the work plan and call for proposals of the EU Public Health Programme for 2007.

### EU project on health literacy

As a result, the application for an EU health literacy project, "HLS EU", was accepted by the European Commission. The project aims to establish health literacy networks at national and EU level, collect health literacy data in survey countries and disseminate policy-relevant findings at national and European levels.

Health literacy needs under a major uncertainty crisis: the case of cancer -  
Dr Albert Jovell, Spanish Patients Forum

**Main points: The issue of health literacy needs to be addressed both with the healthcare professional and the patient. After diagnosis, many patients find it difficult to cope with information with respect to the condition itself and different treatment and care options. Doctors often feel that they do not have sufficient time to inform patients and their families. Health literacy is essential for patients as it provides hope.**

### SUMMARY OF PRESENTATION

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#### Why health literacy: the cancer journey

Cancer has three important aspects: physical, emotional and social. When diagnosed with cancer, many questions arise. People are overwhelmed and have to deal with fear, uncertainty, ignorance and urgency. Many people find it difficult to cope with information with respect to the condition itself, the use of medical terms and different treatment and care options.

#### Action is needed

Time is an important issue for doctors, who generally feel that they do not have sufficient time to inform patients or their families. This is also felt by patients who often do not feel understood by their doctor: "Doctors provide care, but they are not supportive during the process". The issue of health literacy needs to be addressed both with the healthcare professional and the patient. Examples of tools are: Internet, tv channels, specific topic toolkits and patient specialist courses.



### Five important steps

The cancer journey involves five important steps. Understanding the disease is a first important step. Newly diagnosed cancer patients and their relatives need to know what cancer means and how to access relevant resources and organisations that can help them. Exchange of experiences and information with other patients is also a valuable support to patients. A good practice example in this respect is “The Patient Cancer

Navigation Journey”, a patients’ university coaching programme for cancer patients, volunteers, and carers in Spain. Other steps are: knowing the system, coping with the disease, back to normal life and helping others.

### Hope

Health literacy is essential for patients: it provides hope.

## The health literate patient: from theory to practice - Mr David Pink, Long Term Conditions Alliance

**Main points: The problem is that patients are not provided with the information they need, in a form that is designed to meet their needs, at a time that they need the information. The provision of information is one of the most important functions of patient organisations. Patient groups should lead the discussion on health literacy in Europe and should continue to convince governments to focus on health literacy.**

### Need for patients to be well-informed

Information is vital for health. Modern evidence-based healthcare means that we have a better understanding of major conditions such as heart disease, diabetes, asthma and cancer. However, in most cases the full engagement of the patient is necessary for the improvement of health outcomes. Modern evidence based healthcare therefore does not remove the need for patients to be well-informed.

### Role of patient organisations

Authorities have not been very good in supporting health literacy. That is why patient organisations have worked for many years to supply the information patients need. The provision of health information is one of the most important functions of patient organisations.

### Health literacy and “health marketing”

Patients need enough information to manage their condition. We should be careful in using terms such as health literacy, as it could be taken to imply that the problem lies with the patient. The problem however is that patients are not provided with the information they need, in a form that is designed to meet their needs, at a time that they need the information. This is not an impossible task. Commercial companies are very successful in providing information. Perhaps we should talk about health marketing instead of health literacy?

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### Information prescription

As a result of efforts of the Long Term Conditions Alliance, such as the launch of a Manifesto supported by all three major political parties, UK politicians are now enthusiastic about the idea of health information or health literacy. They have renamed the idea “information prescription”. The idea is that every patient diagnosed with a long-term condition should be provided with an information prescription. This information prescription should provide the ways in which the patient can then access further information whenever he/she is ready and needs more information. More specifically the prescription aims to give the patient an understanding of the disease, knowledge of treatments and services, an understanding of the potential risks and benefits of treatment and sources of further information and support.

### Making it work

Patient groups play a major role in the development of the information prescription. However, there are many difficulties in making the information prescription work. Healthcare professionals are supporting the initiative, but some use it as a way to have patients do as they are told. Health authorities see it as a way for patients to manage their disease at home. Key questions in relation to information provision are: who will decide on quality of information and who will pay for the system?

### Leading role for patient groups

Patient groups should lead the discussion on health literacy in Europe. Having been set up by patients, patient organisations understand the patient perspective, are trusted by patients and recognise that healthcare must always be seen within the context of the lives of real people. Patient groups should continue to convince their national governments to focus on health literacy and push for action at a European level.

## DISCUSSION - KEY REMARKS

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### Need to involve other stakeholders

In addition to the patient-doctor relationship, other relations should be highlighted, such as a patient's relation with carers. It is important to include other stakeholders in the discussion, such as families, carers and nurses. EPF is already cooperating with the European Federation of Nurses Associations on for example the development of advocacy training for nurses.

### Different information needs and options

Different people will require different sorts of information. The challenge for the future will be to identify channels to deliver information to the people who need it. On the other hand, there should be options for people on where to get the information and from which source.

### Health literacy and young people

Many patient groups in Europe are working on health literacy with children and adolescents through for example summer camps. Health literacy needs to be promoted in each country among young people by celebrities who can act as “health literacy champions”.

### Role of health insurers

As health literacy is not only related to health (but also to other sectors), health insurers and for example education authorities may need to become involved and support health literacy initiatives. Health insurers are increasingly supporting the empowerment of patients through evidence-based information. Health insurers are currently still focusing on disease management, but should work more in the area of prevention, health literacy and education of children in particular.

# Summary of Workshop Sessions



## WORKSHOP 1: HEALTH LITERACY AND INFORMATION TO PATIENTS

Moderator: Ms Monika Kosinska, European Public Health Alliance

Rapporteur: Mr Mike O'Donovan, European Patients' Forum

**Information to patients is high on the current EU agenda and in this context, health literacy needs to be further explored. Current healthcare sector expectations and demands often exceed patients' literacy skills: most materials are poorly written and badly designed, many patients do not have the literacy skills to read and understand health related print materials and use IT tools. Strong health literacy skills are crucial for chronic disease self-management.**

### KEY POINTS

#### Accessibility

There is a lot of information around, but not always accessible. In order to improve access, distribution of information should be widened. To simulate this, healthcare professionals could become more active information providers. In addition, translation of information should be enhanced. This could be achieved by patient groups using EU core funding. The EU Health Portal should translate “approved” information. Finally, there should be a pan-European right to access personal medical records.

#### Quality

Information needs to be made more “health literate” for the average user. This could be achieved through training and, for example, the development of a “guide” for information providers on how to make information user-friendly and usable to the average citizen. This could be an initiative to be developed by the European Commission and/or EPF. In addition, information should be verified through an EU quality mark initiative, possibly based upon existing practice in the area of food labelling.

#### More effective patient-doctor dialogue

There are different ways of making conversations between patients and healthcare professionals more productive. First of all, patient organisations and other information providers should focus more on “the questions you need to ask”. In addition, professionals should work with patients on how consultations can be made more

productive. The EU should support a pilot project aimed at developing an education module for healthcare professionals on “productive dialogue with patients”, that you must have studied in order to work across borders.

#### Information and skills

In addition to information available, skills are important. People should have the ability to both access and use the information available. In addition, feedback from other patients and sharing experiences is important. Patient organisations have an important role to play in facilitating and stimulating this.

#### EU legislative proposal on information to patients

Everybody has the right to information. In order to improve access to and quality of information to patients, the European Commission is working on a legal proposal which will cover information on medicinal products only. The exact scope of the proposal will depend on an analysis of contributions to a consultation launched by the Commission on key elements of the legal proposal, together with the outcome of the impact assessment conducted by the European Commission. The Working Group on information to patients of the High Level Pharmaceutical Forum is looking at a broader scope and is addressing for example treatment options as well. The question is how to meet the information needs of patients during the “patient journey” and enhance information on diseases and treatment options.

## WORKSHOP 2: HEALTH LITERACY AND EQUITY AND ACCESS FOR ALL TO HEALTHCARE

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Moderator: Mr John Chave, Pharmaceutical Group of the EU

Rapporteur: Ms Annette Dumas, Alzheimer Europe

Health literacy is a key dimension of a citizen's right to health and of relevance for equity and access to healthcare services. Patients with limited literacy skills tend to present in later stages of disease, are more likely to be hospitalised, have poorer understanding of treatments and thus lower adherence to them. Patients belonging to socially vulnerable groups (e.g. undocumented migrants, homeless people, people with mental health problems, victims of trafficking, asylum seekers) may face stigma, discrimination when accessing healthcare services, no continuity of care, lack of knowledge and understanding about treatments, entitlements and financial obstacles.

### KEY POINTS

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#### **Increasing health literacy and reducing inequalities**

There is a strong need to increase health literacy of patients, citizens and health professionals. Health literacy can play an important role in reducing inequalities. Data on health literacy and inequality need to be collected across Europe in order to enable a comparison between countries, to identify best practices and provide recommendations.

#### **EU and national competence**

Health literacy should be part of a horizontal approach while maintaining a dynamic relationship between EU competence and what can be done at national level.

#### **Strategy**

An EPF EU strategy on health literacy and equity of access to healthcare should seek to:

- promote the collection of best practices across Europe;
- explore how patient rights can be explained and disseminated to disadvantaged groups;
- include the broad patient perspective on the issue of access to health and health literacy in the EPF Patient's Manifesto;
- facilitate partnerships to address health literacy and access to healthcare, for example with health professionals and peers;
- encourage responsiveness of healthcare professionals to the issue of e.g. communicating with patients with low levels of health literacy.



## WORKSHOP 3: HEALTH LITERACY AND EMPOWERMENT OF PATIENT GROUPS

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Moderator: Mr Tomas Szelagowski, Federation of Polish Patients

Rapporteur: Ms Karen Benn, Europa Donna, The European Breast Cancer Coalition

**Patients need to be supported to build skills in order to understand information about diseases, treatments, measures, procedures; they need to learn how to ask questions to their health professionals with confidence, freedom and dignity. Governments need to take steps forward to institutionalise patients' empowerment. Patient organisations, if adequately supported, can play a key role.**

### KEY POINTS

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#### Definition of health literacy

Referring to the definition provided by Prof Ilona Kickbusch, health literacy can be defined as : “the ability to make sound health decisions in the context of everyday life at home, in the community, at the workplace, the healthcare system, the market place and the political arena”.

#### Objectives

The workshop aimed to explore actions needed from three key stakeholder groups: public authorities, health professionals and patient organisations and individual patients.

#### Public authorities

The political arena is changing because of the growing role of patient organisations: public authorities are influenced by patients and other stakeholders. In order to improve health literacy in Europe, patient organisations should not only focus on Ministries of Health, but also on other relevant Ministries, such as Social Affairs, Education and Finance. A general problem is that Ministries do not always coordinate.

#### Need for systems

Patient organisations should be recognised and supported by public authorities. Public health authorities should involve patients and healthcare professionals to work on health literacy. There should be a system in place to address health literacy, assess quality of information and healthcare services, and to stimulate a dialogue with patient organisations. Some Member States have already established bodies to provide information to patients.

#### Exchange of information and good practice

The exchange of information and good practice among Member States should be stimulated at EU level. EPF can play a key role in this by sharing good practices with the European Commission. In turn, the European Commission should facilitate the exchange of good practices among Member States.

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## Summary of Workshop Sessions

### Healthcare professionals

Healthcare professionals should promote and support membership of patient organisations. Furthermore, patients should be involved in educational systems for healthcare professionals. Continued education for healthcare professionals is essential in order to constantly update knowledge and work on skills. Doctors should learn to use simple, clear language and learn to communicate with patients. Healthcare professionals should not just focus on technical knowledge, but also on “soft skills”, such as communication.

### Patient organisations and individual patients

Patients should be trained to ask the right questions to healthcare professionals. This could also help patients to be more confident. A special “healthcare officer” could be appointed to train patients. Sharing patients' stories and experiences using different media, could contribute considerably to this process. In general, there should be more networking and exchange of information and experience between patient organisations and the EU Institutions on health literacy. EPF could play a key role in facilitating this process.



# Glossary



## **EPF Patients' Manifesto – 150 million reasons to act:**

A Patient's Manifesto in the process of being developed by EPF and to be presented to the European Parliament in advance of the European elections in June 2009.

► [www.eu-patient.eu](http://www.eu-patient.eu)

**EU Health Portal:** The main objective of this official public health portal of the European Union is to provide European citizens with easy access to comprehensive information on Public Health initiatives and programmes at EU level. The portal is intended to help meet EU objectives in the Public Health field, it is an important instrument to positively influence behaviour and promote the steady improvement of public health in the 27 EU Member States.

► [http://ec.europa.eu/health-eu/index\\_en.htm](http://ec.europa.eu/health-eu/index_en.htm)

**EU Structural Funds:** The Structural Funds of the EU fall under the EU's Regional Policy and include four funds allowing the European Union to grant financial assistance to resolve structural economic and social problems: the European Regional Development Funds (ERDF), the European Social Funds (ESF), the European Agricultural Guidance and Guarantee Funds (EAGGF), the Financial Instrument for Fisheries Guidance (FIFG).

► [http://ec.europa.eu/regional\\_policy/funds/prord/sf\\_en.htm](http://ec.europa.eu/regional_policy/funds/prord/sf_en.htm)

**Subsidiarity principle:** This principle aims to ensure that decisions are taken as closely as possible to the citizen and that constant checks are made as to whether action at Community level is justified in the light of the possibilities available at national, regional or local level. Specifically, it is the principle whereby the Union does not take action (except in the areas which fall within its exclusive competence) unless it is more effective than action taken at national, regional or local level. It is closely bound up with the principles of proportionality and necessity, which require that any action by the Union should not go beyond what is necessary to achieve the objectives of the Treaty.

**Health Literacy Survey Europe (HLS EU):** Project funded by the European Commission under the EU Public Health Programme in 2007. It aims to provide an overview of health literacy across Europe and constitutes a European network as the first multi-national expert group on health literacy in Europe.

► [http://ec.europa.eu/phea/documents/Abstracts\\_2007\\_all.pdf](http://ec.europa.eu/phea/documents/Abstracts_2007_all.pdf)

**High Level Pharmaceutical Forum:** The Pharmaceutical Forum was established by the European Commission in 2005 as a high-level platform for discussion. The aim of the Forum is to improve the performance of the pharmaceutical industry in terms of its competitiveness and contribution to social and public health objectives. The Forum brings together Ministers from all European Member States, representatives of the European Parliament, the pharmaceutical industry, healthcare professionals, patients and insurance funds. The Forum is supported by a Steering Committee and three expert Working Groups focusing on three priority issues: information to patients, pricing policies and relative effectiveness assessments.

► [http://ec.europa.eu/enterprise/phabiocom/comp\\_pf\\_en.htm](http://ec.europa.eu/enterprise/phabiocom/comp_pf_en.htm)

**Working Group on Information to Patients:** The aim of the Forum's Working Group on Information to Patients is to advise the Commission on ways to improve the quality of, and access to, information on authorised medicines and related health areas to European patients. The Working Group is aiming to make progress in three areas: access to and dissemination of information in healthcare settings (such as pharmacies and hospitals), quality and the practical implementation of partnership for an information package at the national level.

► [http://ec.europa.eu/health/ph\\_overview/other\\_policies/pharmaceutical/working\\_group\\_en.htm#1](http://ec.europa.eu/health/ph_overview/other_policies/pharmaceutical/working_group_en.htm#1)

**EU Health Strategy:** The European Commission adopted a new Health Strategy “Together for Health: A Strategic Approach for the EU 2008-2013” in October 2007. This Strategy aims to provide, for the first time, an overarching strategic framework spanning core issues in health as well as health in all policies and global health issues. The Strategy aims to set clear objectives to guide future work on health at the European level, and to put in place implementation mechanisms to achieve those objectives, working in partnership with Member States.

- ▶ [http://ec.europa.eu/health/ph\\_overview/strategy/health\\_strategy\\_en.htm](http://ec.europa.eu/health/ph_overview/strategy/health_strategy_en.htm)

**EU Public Health Programme:** a new Programme for “Community Action in the field of Health” has come into effect in 2008 and will set the framework for the Commission's funding of projects relating to health between 2007-2013. The Programme will be part of a strategy bringing together the broad range of Community health action to define goals and priorities to help improve the health of European citizens. The Programme has three broad objectives: improve citizens' health security; promote health for prosperity and solidarity; generate and disseminate health knowledge. For each year covered by the Programme, the Commission adopts an annual work plan outlining more specific objectives and priorities.

- ▶ [http://ec.europa.eu/health/ph\\_overview/pgm2007\\_2013\\_en.htm](http://ec.europa.eu/health/ph_overview/pgm2007_2013_en.htm)

**European Commission report on current information practices on medicinal products:** According to Directive 2001/83/EC, article 88, the European Commission has an obligation to present a report to the European Parliament and the Council in 2007 on “current practice with regard to information provision - particularly on the Internet - and its risks and benefits for patients”. The same article also provides that “the Commission shall, if appropriate, put forward proposals setting out an information strategy to ensure good quality, objective, reliable and non promotional information on medicinal products and other treatments and shall address the question of the information source's liability”. Based on this piece of legislation, a “Communication from the Commission concerning the Report on current practices with regard to the provision of information to patients on medicinal products” was adopted by the Commission in December 2007.

- ▶ [http://ec.europa.eu/enterprise/pharmaceuticals/patients/patients\\_key.htm](http://ec.europa.eu/enterprise/pharmaceuticals/patients/patients_key.htm)

**Public consultation on key ideas of a legal proposal on information to patients:** The “Report on current practices with regard to the provision of information to patients on medicinal products” (see above), revealed the need to harmonise the way in which information on medicinal products is made available in the EU in order to ensure that all patients have equal access to information on medicinal products. With this in mind, the European Commission invited stakeholders to contribute to a public consultation on key ideas of a legal proposal aiming at ensuring that all EU citizens have access to good-quality, objective, reliable and non promotional information on prescription-only medicinal products. Results of this consultation were published on the Commission's website in May 2008.

- ▶ [http://ec.europa.eu/enterprise/pharmaceuticals/patients/patients\\_key.htm](http://ec.europa.eu/enterprise/pharmaceuticals/patients/patients_key.htm)

# About the European Patients' Forum

## The European Patients' Forum:

- Was set up in 2003 to become the strong and united collective patients' voice at European level and to put patients at the centre of EU healthcare policy and programmes.
- Adopts a holistic interpretation of healthcare, to include prevention, and the social, economic, environmental, cultural and psychological aspects of health.
- Has both a proactive and reactive role by acting as a catalyst and consultative partner for positive change in EU healthcare systems and as a “watchdog”, closely monitoring EU policy and legislative initiatives.
- Is a credible and professional partner for cooperation, dialogue and negotiation with a broad range of EU level health stakeholders.
- Facilitates exchange of good practice and challenging of bad practice on patients' rights, equitable access to treatment and care, and health-related quality of life between patient organisations at European level and at Member State level.
- Offers a resource for member organisations on EU healthcare intelligence, information dissemination, baseline patient-rights policy responses to the EU Institutions to enable them to focus on disease specific responses.
- Is open to European patient organisations and national umbrella organisations that fulfil criteria relating to legitimacy, representation, democracy, accountability and transparency. EPF has currently 27 member organisations.

**Our vision** is to establish patient-centred, equitable healthcare throughout the European Union. In order to achieve this, EPF demonstrates the solidarity, power and unity needed for an effective EU patients' movement.

**Our core values** emphasise a patient centred approach to healthcare, inclusiveness, non-discrimination, patient empowerment, consultation and independency and transparency.

**Our key goals** for 2007-2012 focus on:

- Equal access for EU patients to best quality information and healthcare.
- Meaningful patient involvement in EU health-related policy-making, programmes and projects.
- The inclusion of a patients' perspective in developments at EU level on health economics and health efficacy, stressing health related quality of life.
- Sustainability of patient organisations, to foster inclusive, effective and sustainable representative patient organisations.
- Patient solidarity and unity across the EU's patient movement.

For more information on the European Patients' Forum:  
[www.eu-patient.eu](http://www.eu-patient.eu)





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