



European Federation of Pharmaceutical
Industries and Associations

The role of industry in the provision of information

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EFPIA representative in HLPF Information to Patients Working
Group

- Representative voice of the research-based pharmaceutical industry operating in Europe

Founded in 1978

- Membership
 - 32 associations (EU + Switzerland + Norway + Iceland + Turkey)
 - 44 companies
- Two specialised groups within EFPIA:
 - EVM - European Vaccine Manufacturers
 - EBE – European Biopharmaceutical Enterprises

“The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health.”

World Health Organization
Preamble to the Constitution



efpia* 21st century - Information age



What is at stake ?

"Patients have a legitimate need for and right to information on medicinal products, including those available on prescriptions"

European Parliament, 2001

"The current situation is unsatisfactory and in my view even unacceptable"

Commissioner Verheugen, 29 September 2006

"Well-informed and empowered patients are a strong asset for European societies. Health-literate citizens can take better care of their own and family members' health.

However, there are differences between the Member States in terms of access and availability of information. It is against this background that the EU has an important role to help ensure that all citizens have equal access to necessary information. No matter where they live, what condition they have or what language they speak."

Commissioner Kyprianou, 29 September 2006

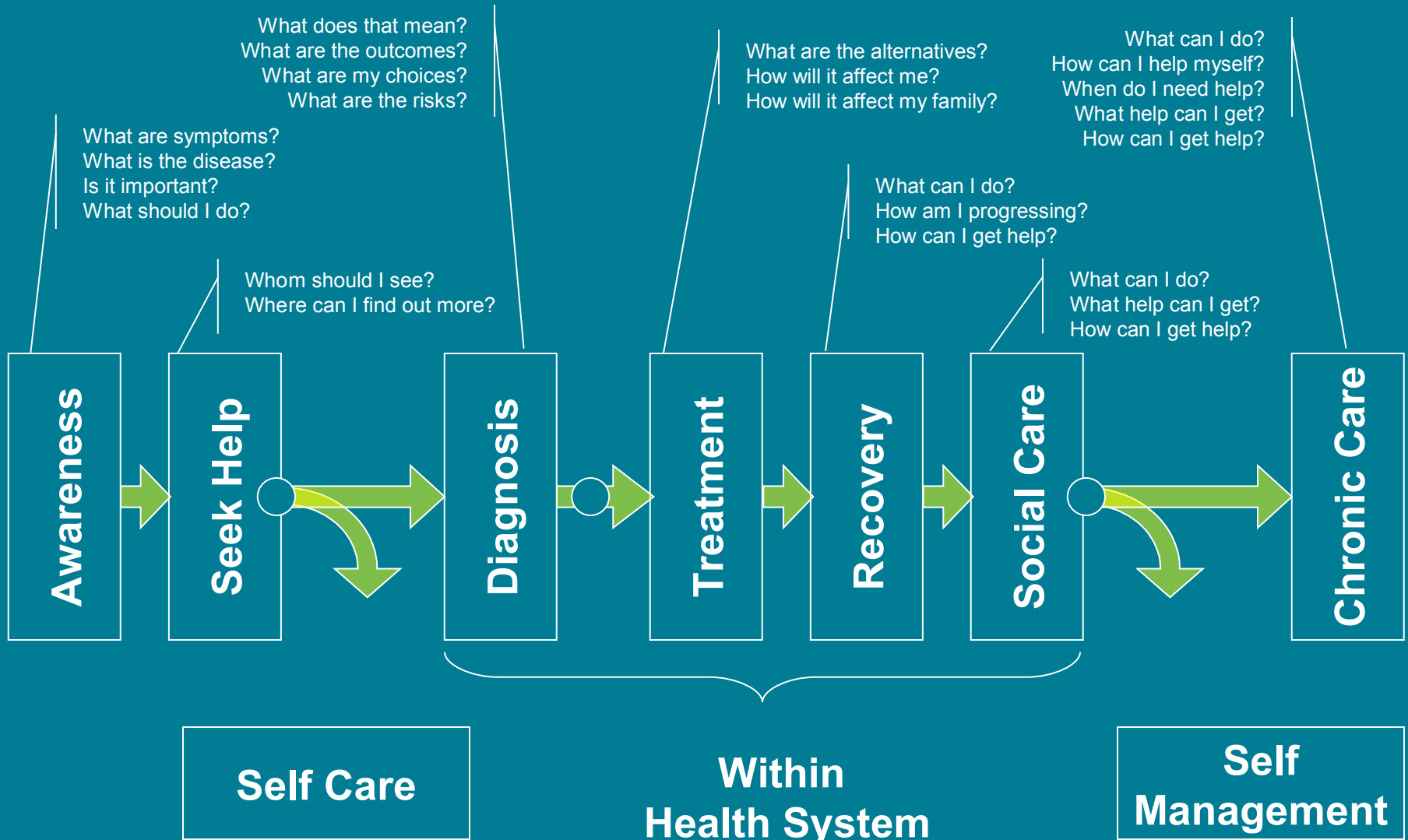
"There is a growing consensus among policy makers and stakeholders that there are health information asymmetries and gaps. (...) We strongly support the right to access quality health information for all those who need it or seek it, including information about medicines, as a pillar for ensuring patient safety and patient outcomes" - **Joint statement by 21 different health stakeholders, September 2007**

European patients do not get the health and medicines information they need

- **Unequal access**: Patchwork of different regulations and different interpretations of the same EU Directive; Citizens who speak English and have internet access are advantaged
- **"Empowered" patients** want to take part in decisions concerning their health and demand more and better high-quality information from **multiple sources in their language**
- Information **overload** on the Internet, but need for non-electronic tools for parts of population (e.g. the elderly)
- Many Member States prevent companies - legally liable for their products - from communicating even basic and legally authorised information about medicines to the public, but ironically anyone else can do so (e.g. Internet)

Evidence suggests value of health literate patients

- Starting point: ‘The patient’ does not exist – need individual approach
- Better prevention, early diagnosis, treatment and adherence
- Better informed patients support understanding between doctor and patient: primary information source for patients, but no single source can provide all the information
- Better informed patients will lead to more successful health outcomes, a more efficient use of healthcare resources (e.g. less need for expensive hospital stays and long-term care) and ultimately to healthier societies
- **Partnerships** between various health stakeholders are needed to reduce the information gap



- Pharmaceutical companies have unique disease and product expertise – R&D process takes 10-12 years on average
- They are thus important contributors to health information, together with other providers such as healthcare professionals, patients, regulatory agencies
- Any efforts to improve patient information in Europe should aim at improving the crucial doctor/patient interaction

- “Acceptability” of health information should depend on its **QUALITY** rather than on the source providing it
 - e.g. EFPIA Internet Guidelines 2001; EFPIA principles and guidance notes for high quality information 2005
- Companies expect to be held to the highest standard of behaviour in providing non-promotional, high-quality disease and treatment information to EU citizens
- EFPIA has repeatedly stated that it is not seeking US-style Direct to Consumer advertising in Europe

1. European citizens expect and deserve a modern and comprehensive EU information strategy that will truly benefit them and help to improve public health.
2. Access for all EU citizens and patients to non-promotional health and medicines information in their language must be improved.
3. Access to high quality medicines information from multiple sources is needed, including from the pharmaceutical industry, respecting the highest quality standards. Information should be judged by its actual quality, not the source providing it.
4. Availability of, and access to high-quality medicines information via the Internet must be enhanced, while recognising the need for non-electronic tools for parts of the population and for improving access to such tools.

1. Public Private Partnerships, involving a range of healthcare stakeholders, could be one part of a comprehensive strategy.
2. Legislative reform at EU level is needed with the primary goal of giving the same opportunities to all EU citizens, taking into account positive experiences gained at individual Member State level.
3. Self-regulatory schemes with efficient governance and enforcement procedures would be the most practical and beneficial way forward, provided that an adequate legal system is put in place allowing the provision of high quality information from multiple sources.

Microsoft Internet Explorer

Address: http://www.efpia.eu/efpia/efpia.html?ID=1204

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Information to patient
Health Information for Europe's citizens.

Europeans have a fundamental right to information about diseases and medicines. However, differences in EU Member States currently prevent people from having full access to high quality information in their own language, thus limiting their ability to make fully informed decisions about their own health.

- Information can contribute to prevention, early diagnosis, better treatment of disease as well as improved adherence. Enhanced access for all citizens to high quality health information and greater participation of well-informed patients in decisions affecting their lives will therefore lead to healthier societies around Europe.
- Together with other interested parties, the pharmaceutical industry can play an essential role in the provision of high quality health information.

EFPIA's general principles concerning the provision of non-promotional information on prescription medicines

- Enhanced access to health and medicines information is needed for all patients and citizens in Europe
- Quality medicines information from multiple sources should be promoted
- Openness for medical needs in medicines information world is essential
- Regulatory requirements should build on current best practices in Europe
- A comprehensive information strategy that will truly benefit patients and citizens in

IFPMA Clinical Trials Portal

Health portal

Direct to Consumer Advertising in Europe - White Paper by Françoise Agel (The Lancet, 1 May 2007)

*If you currently struggle to understand you are in my view even unscripted - you can speak English and use a computer, you already have access to a lot of information on

Thank you for your attention.