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Presentation
www.informationtopatients.org

by

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June 2005

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Current EU Guidelines

- Directive 92/28/EEC (art. 88.1) states that pharmaceuticals cannot disseminate information directly to patients.
- An exception was made in COM (2001) 404 final for AIDS, Diabetes, Asthma & chronic bronco pulmonary disorders.

Problem with the Guidelines

- Anyone other than pharmaceuticals can provide information on therapies
- With the growth of the internet and broadband there is a lot of information out there – problem: sources are not always reputable and there is no regulation on the information put there.

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Problem facing the Patient

- With constant research and development of treatments, it is impossible for GPs to know everything about every single treatment for every disease area
- With the growth of broadband more patients are looking for information online → the result is information overload
- Patient has to discern between “good” and “bad” information but often may lack the skills to do so due to complexity

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Patient Empowerment (Model)

Diagnosis

This is the first piece of information the patient receives having seen a doctor/specialist and undergone tests. The patient will now have a name for their condition.

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Patient Empowerment (Model)

Disease

Next the patient obtains facts about the disease such as:

- What the disease is?
- What does it mean?
- What are the effects?
- Is it contagious?

This information is generally obtained from: doctors, specialists, patient groups, information leaflets, online, etc.

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Patient Empowerment (Model)

Stages

Further information the patient will obtain is on the progression (stages) of the disease:

- What stage of the disease they are at
- What it means to them

Again this information is generally obtained from: doctors, specialists, patient groups, information leaflets, online, etc.

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Patient Empowerment (Model)

Lifestyle

This is information that the patient has.

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Patient Empowerment (Model)

- What is needed to directly involve the patient in their treatment?
- How can the patient make an informed decision?
- What information is still missing?

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Patient Empowerment (Model)

- Available treatment
- Contra-indications
- Dosages
- Side-effects
- Drug interactions
- Latest up-to-date research
- Clinical trials

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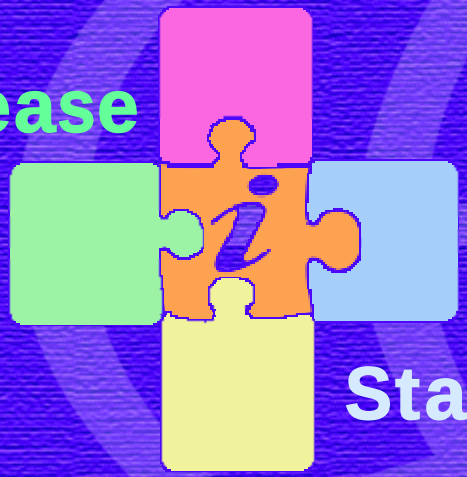
Patient Empowerment (Model)

Diagnosis

Disease



Stages

Lifestyle

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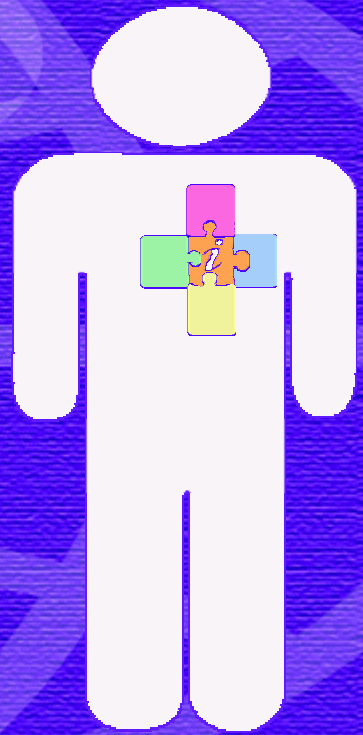

information *to* patients

empowered patient

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Aims of the Site

The aims of the site are two-fold which is reflected in its structure:

- To encourage the health information debate
- To provide and prove it is possible to provide high quality, unbiased information

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Why ECPP?

- ECPP is a patient organisation with years of expertise
- With HIV/AIDS it has been proven that direct communication between manufacturers and consumers works – patients in this field have had to become “experts”

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Debate Section

The purpose of this section is to encourage participation in the debate by:

- Giving background information – chronology, issues, stakeholders etc.
- Discussion forum with moderated events from time to time
- Patient survey – data to be presented to EU Commission
- Newsletter

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Therapy Section

Provide high quality, unbiased information by:

- Giving links to reputable sites regarding information on the disease, prevention etc.
- Abiding by HON Code (Health on the Net: www.hon.ch)
- Putting information in layman's terms, so it can be understood by everyone
- Giving up-to-date information on research and putting it into context

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Access to Information for everyone on the EU

- Initially site rolls out in English
- Over time it will roll out in main European languages so as to ensure the maximum number of people will be able to access the information