Health Consumer Powerhouse

Response to the open consultation on information to patients

April 2008-04-04

The Health Consumer Powerhouse (HCP) views transparency and open information key for a sustainable development of our future healthcare system. We therefore consider the initiative very important and hope our answers are in some way useful for the Commission.

No-one today disputes the figures showing that the healthcare consumer wants more information. There is a current information gap that needs to be closed.

We would like to start by pointing out that it is often said in the debate around this area that information available to the public on pharmaceuticals would drive costs. We dare question this assumption. One of the countries with the strictest regulations on information is France. Sweden on the other hand has just implemented the directive banning DTC advertising. Sweden further still has a very liberal system when it comes to information on the Internet. Most pharmaceutical companies have fully accessible information about diseases and therapies including their own products. A layman adopted pharmacopoeia (a book with all available drugs listed and explained) is since long sold to the public by the trade association for the pharmaceutical industry. Also, anybody in Sweden can subscribe to for example to the weekly Dagens Medicin with a lot of ads for prescribed medicines.

Still - according to the OECD Health Data – 2005, Sweden spends USD 340 per capita on pharmaceuticals or 12.6 percent of its overall healthcare spending. France on the other hand spends USD 606 per capita or 20.9 percent of its overall healthcare spending.

Information seems rather to decrease costs for pharmaceuticals than increasing it.

More important, we strongly believe that better informed patients have a better therapy outcome. Simply because they are more inclined to follow the therapy recommended. In our modern society not all trust their doctors, as they want to double check what is the best way forward in order to be convinced.

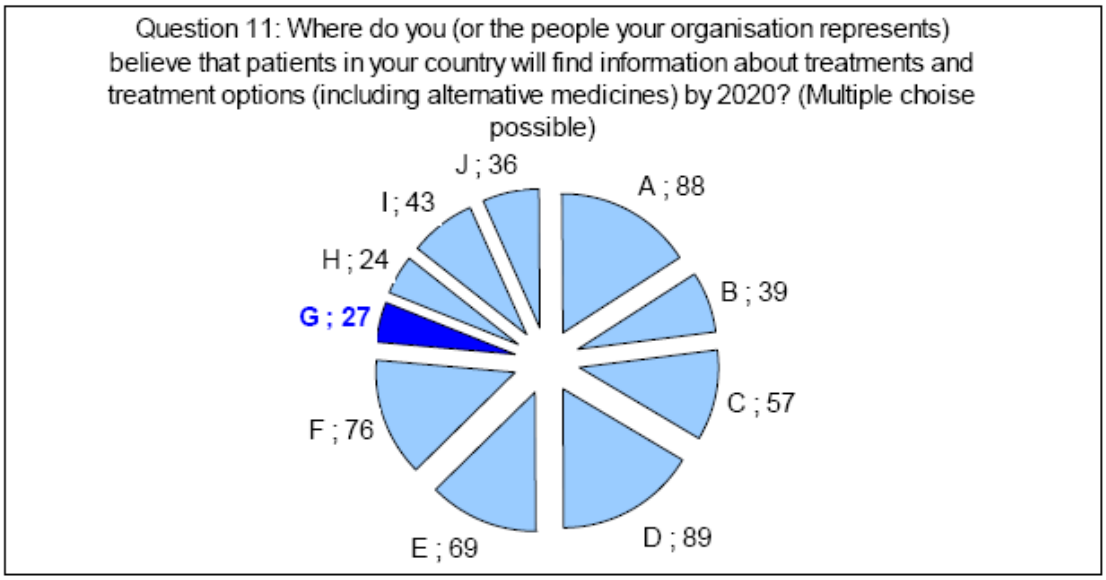
Further those with chronic diseases often know as much or even more about their disease as their doctors. They take the time to learn all there is to learn and follow the development around their specific treatment options. And time is what the healthcare system in so many cases just does not have enough of.

EU Brussels: Rue Fossé aux Loups 34, B - 1000 Brussels, Belgium
Phone: +32-496-23-55-30
info@healthpowerhouse.com www.healthpowerhouse.com

So we cannot see any reason for not opening up "the Pandora's Box" and let the information free.

But there is of course a need for guidelines for what good quality information is. And how should they be monitored?

In our survey with patient organisations across the EU member states we find that:



A.) Official Websites and/or telephone hot lines run by national and/or local government
B.) Official Websites and/or telephone hot lines run by EU bodies
C.) Other, non-official Websites
D.) Trained healthcare professionals (pharmacists, doctors, nurses, etc)
E.) Healthcare providers (including hospitals)
F.) Patient organisations
G.) Pharmaceutical companies

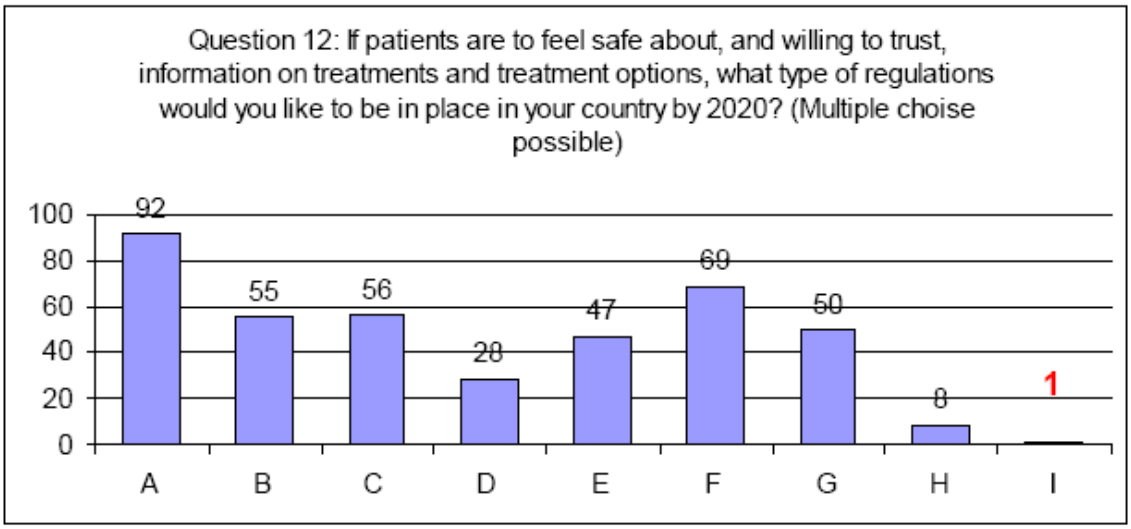
The survey makes it clear that we have very different views on whom to trust or rather whom not to trust. It mainly points to the pharma industry or the government. But everyone also knows how few people actually trust the media. In our survey there are statements ranging from: "Most official sources are funded by drug companies – not trustworthy information" to: "There is a huge mistrust between the consumer and government. And, therefore, due to this, people will seek independent bodies to get their information, or will look for information from people they trust."

And the field is complicated. If those that deliver the information is not to be trusted nor those that safeguards the content, what use will the information be of? Hence the "good legislation" principle is needed more than one could imagine. This is not only about banning and making statements to safeguard patients. As one of the patient organisations explains in the open answers to the survey:

"All governments need to change their attitude to legislation. At the moment, there is so much legislation that the consumers don't know WHAT their rights are. Brussels is too far away; each country needs to have legislation from Brussels on how to win the trust back from their voters. One of the most frustrating

problems with legislation is that if a country doesn't adhere to the rules, there is no follow-up - and this includes not only the governments themselves, but also Brussels."

Yes. As found in our 2020 survey with patient organisations across the EU (performed by the Patient View) this proves exactly to be what is needed. I.e. a base for an ISO certification or a similar arrangement regarding healthcare information. This is the "consume-driven" approach.



A.) Quality labelling, such as environmental ISO certification of hospitals/clinics
B.) EU guidelines
C.) National advertising standards legislation
D.) All information is pre-vetted by national government-appointed regulators
E.) All information is approved by national government-appointed regulators
F.) Policing by patient organizations
G.) Policing by consumer organizations
H.) The current situation is about right
I.) By 2020, patients will be knowledgeable enough not to need safety assurances

Today's situation is not good enough in spite all the regulations. As one patient organization puts it: "A huge mistrust exists between consumer and government. Therefore, due to this, people will seek independent bodies to get their information, or will look for information from people they trust". (Quote from a Netherlands group specializing in rare blood disorders).

We could note that the –presently - very over-regulated proposal is in line with D and E. These are the solutions the least preferred by the patient organization. Except of cause continue with the current situation that basically no one prefers.

To put up a new bureaucracy of this kind cannot be right. When self regulation is the way forward in the food area (similar important if not even more so for the citizens) it seems hard to understand the need for deciding that the government should monitor all information in this case.

So even if we see the proposal as a step forward we also note that for our own home country this is a severe restriction compared to the situation today.

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In short what we would like to see changed is:

- We believe that all information on the internet, except pop-ups and banners on popular non healthcare related sites should be viewed as "searched by citizens".
- We believe that all monitoring should be based on complaints to lower bureaucracy – the key to secure a good content is the penalties used.
- The national tradition should prevail when the country decide what body should monitor. We do not see a need for the EU to decide how that body is organized.
- We think it would be of great benefit for the consumer if comparative selections between medicinal products where available.
- We also think that there should be no demand for using different mechanisms. We fear that this will make information to expensive.
- We do not believe the governments are capable of deciding what is relevant for the patient. Still today most of the governments do not realize how relevant and needed information to patient is. If we look at how different the current directive is implemented in various countries this is very clear. That is why we strongly recommend that these criteria should be abandoned.
- Even though we in principle believe in the direction the evidence-based, objective and unbiased criteria are aiming at we have hesitations. We trust that the final proposal will take into consideration the problems around evidence-based information with regards to for example rare diseases. We think that patient safety could be reached with only the first objective and unbiased criteria if well defined.

A final remark that we would like to make is that the Internet and mailboxes are daily filled with information about diseases and cheap drugs. It seems strange that the stakeholders who produce and legally must take responsibility for the use of their products should be the only ones excluded from information around these very products.

If information is limited there is no way for the consumer to make good choices. Therefore it is unacceptable that certain countries have put up bans on the right of products and care providers to communicate with the consumer via third parties. Nor should the citizens be banned from seeking and digesting certain types of information. Here the legislation on EU level should improve according to the principles of freedom of information, care consumer empowerment and partnership in care.

That is why we think that the EU directive 2001/83/EC should be amended to include diagnostics, treatments and medicines available, not depending on whom is the sender of information, and at the same time allow for direct communication between citizens, care providers and pharmaceutical companies. Any amendments to the Directive must take the freedom of information of all stakeholders into account, and any limitations must be clearly justified and defined.

Thank you again for this opportunity to contribute to a more consumer friendly internal market for healthcare!

Johan Hjertqvist
President

Kajsa Wilhelmsson
VP External Affairs

EU Brussels: Rue Fossé aux Loups 34, B - 1000 Brussels, Belgium
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