



Information to Patients:

Putting Patients First

About EATG

The European AIDS Treatment Group (EATG) was founded in 1992. It is a voluntary organisation made up of 90 members from over 30 different European countries.

Our members are representatives of different communities affected by HIV/AIDS in Europe.

Since its foundation, EATG has been at the forefront of the development of the civil society response to the HIV/AIDS epidemic in Europe.

Our activities focus on treatment literacy and treatment advocacy.

Information is thus one of our key concerns.

EATG's Mission

EATG's mission is to achieve the fastest possible access to state of the art medical products, devices and diagnostic tests that prevent or treat HIV infection or improve the quality of life of people living with HIV, or who are at risk of HIV infection.

In responding to HIV, EATG also considers diseases frequently seen as co-infection in people with HIV, as well as other health issues that increase the risk of HIV.

EATG's primary geographic focus is the member states served by the World Health Organisation (WHO) Regional Office for Europe.

However, EATG does consider opportunities to collaborate with and support similar efforts in other parts of the world.

EATG's Position on Information to Patients

Information to patients is vital, both to save lives and improve quality of life.

Information concerns not merely treatment but how to live with chronic conditions. It should include the perspectives of other patients living with the condition as well as professionals.

Patients need information that is evidence-based, comprehensive, compares the risks and benefits of treatments and no treatment, and is transparent as to source. It should be accessible to patients at different levels of experience and expertise, easy to use, in the patient's mother tongue, and adapted to their culture.

HIV is a disease area which has led the way in the provision of independent information sources. Nearly all of these receive some funding from pharmaceutical companies, but do not depend exclusively on them. There is no reason why patient-led information and the organisations that supply it should be biased as long as:

- They provide evidence-based, comprehensive information.
- They are not dependent (entirely or mainly) on funding from a single industry source.
- They are transparent about their sources of funding.
- They have clear guidelines and contractual arrangements about what the funding is for.
- The funding is provided as unrestricted grants which do not dictate content.

EATG feels that information provided directly to the patient by pharmaceutical companies, or by patient groups predominantly or entirely depending on a single pharmaceutical company for funding, cannot satisfy the requirements for unbiased information. Pharmaceutical companies have a conflict of interest between patients' needs and shareholder interests. They market treatments and are therefore unlikely to have an unbiased opinion about not taking their treatment. They are unlikely and usually unable to provide information about competitor products. And, regrettably, they have a history of concealing or failing to publicise research that reflects negatively on their products.

The EATG supports information provided by 'expert patients' which have educated themselves as intermediaries between the complex world of medicine and patient needs in general. The EATG does not endorse information provided directly to patients by the pharmaceutical industry and the manufacturers of other medical products.

Introduction: Discussion Framework

Information to Patients is a hot topic surrounded by much discussion and debate.

One of the main or most obvious platforms for this discussion at European level is the Pharmaceutical Forum, which was established by the European Commission (Directorates General Enterprise and SANCO) to provide strategic direction to the different work streams of the new post G10 strategy as well as to provide a political mandate for the process.

The Forum is made up of three Working Groups which are addressing 3 priority areas: Information to Patients, Pricing and Relative Effectiveness.

This Forum does bring together all the main European stakeholders (Ministers from all European Member States, Representatives of the European Parliament, the Pharmaceutical Industry, Health Care Professionals, Patients and Insurance Funds).

However, the main 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 discussion is therefore taking place in a pre-defined framework, a set paradigm, in which the pharmaceutical industry is a key player and where its interests are very much in the forefront.

It would appear that a priori, the European Commission, not only foresees but indeed also plans the provision of Information to Patients through a public private partnership, in which the pharmaceutical industry plays a significant role.

Discussion on Information to Patients within the Pharmaceutical Forum is therefore now focused on the nature and implications of such a PPP.

EATG and most other Patient Organisations have strong reservations and concerns about establishing PPPs to provide information to patients.

Indeed, the idea of establishing a PPP to provide information to patients is extremely controversial.

There is a very real concern that this could be the "thin end of the wedge" that would allow direct to consumer advertising, which EATG and other patient organisations strongly oppose.

Concerns about PPPs are further heightened by talk of/suggestions that information to patients could / should be governed by "self regulation". This is definitely not acceptable.

EATG's Involvement in the discussion on Information to Patients within the Pharmaceutical Forum

EATG was invited to participate in Pillar III (Improving Access to Information), within the Information to Patients Working Group of the Pharmaceutical Forum.

We took part in discussions and debates on access to information, commented on documents and reports and co-organised (together with PGEU and CPME) two workshops on Improving Patients' Access to Information in Hospitals and Pharmacies.

The workshops gave us the opportunity to involve and obtain the input of other patient organisations, including the European Cancer Patients Coalition, AGE and HAI to name just a few.

During the workshops organised within the framework of Pillar III there was discussion about what type of information patients want and need and who could/should produce and provide information to patients.

A number of different information needs were identified, including:

- Information about the patient
- Information about the disease
- Information about the medication
- Information about treatment more broadly

This information should take into consideration:

- Cultural / linguistic background of patient
- Age
- Level of education / health literacy
- Other "factors" (mental health, blindness, special needs etc)

A key issue identified was the need for the health professionals to (a) provide coherent information and advice; and (b) to be able to communicate well with the patient.

The professional-patient relationship and the interaction between them need to be based on trust and mutual understanding / respect.

Furthermore, the information should be independent from commercial interests.

Patients stressed that all information should be:

- Independent

- Objective
- Non-promotional
- Tailor-made

It was agreed that quality rather than quantity of information is what matters and that the underlying concern should be patient safety.

It was unanimously agreed that the pharmaceutical industry should not produce information about medication or diseases for patients.

Some argued that it would be worth considering developing a PPP (involving government, health professionals, patients and industry) to fund, produce and disseminate information. However, many patients were cautious about this.

The following key issues / concerns were identified:

- nature and structure of PPP
- role and mandate of each partner
- concern re: “leverage” of industry, given that “money talks”
- need for an independent body to vet the information before it is disseminated

We have a somewhat ambiguous feeling about our involvement in the Pharmaceutical Forum. On the one hand we welcomed the opportunity to be actively involved in the debate and indeed to put forward the patient perspective, which is in our view crucial. On the other hand, we did feel frustrated by the fact that discussions sometimes appeared to be governed by foregone conclusions. One example being that PPPs should be established to provide information to patients.

Other criticisms leveled at the Pharmaceutical Forum include the approach to the involvement of Civil Society, the lack of resources provided to carry out the work and the lack of transparency.

Looking at Information to Patients outside the Framework

We, EATG, and many other patient groups, would like to separate the discussion on Information to Patients from the Pharmaceutical Forum and to address the question in a more neutral and objective way.

The first and most obvious question we would like to raise, or people to consider, is what does the target audience want and need? In other words what do Patients want and need?

Personal experience of our members, feedback from other patients and patient organisations and research (our own and external research) show that different Patients have different information needs.

Their needs depend on a number of different factors including:

- type of illness, disease or disability
- level (stage) of illness, disease or disability
- whether the illness, disease or disability is heavily stigmatised or not
- age, gender, social and cultural background, level of education, level of treatment literacy of the patient and so forth.

However, underlying all this, there are two crucial things all Patients have in common:

They all seek **accurate** and **unbiased** information about their condition and possible treatments.

In terms of treatment, patients want to be informed about the potential risks as well as expected benefits.

That is to say, patients do not want to be overloaded with information and to receive information for information's sake.

They want to be confident that the information they are receiving is accurate and unbiased.

They want to receive information that will help them make an informed decision about their treatment.

Quality and not quantity of information is key.

From a patient perspective "quality information" is not only about focus (type of information) and language (level of technicality), but also, crucially, about authorship, sponsorship and transparency.

Recent Steps

EATG is co-signatory of a Joint Statement on Information to Patients entitled "The Way Forward to an EU Health Information Strategy", which was drafted by EPHA (the European Public Health Alliance) with the input of all 20 organisations who signed the document.

The statement calls for a debate on Information to Patients which ensures that Patients' needs are adequately met by the future EU Health Information Strategy.

It outlines concrete actions to be taken by EU policy makers to define an accurate and forward looking health information strategy, whilst reaffirming the commitment of several organisations who wish to have an active role in developing such a strategy.

The signatories stress the importance of prioritising the EMEA's (European Medicines Agency) project "EudraPharm" to foster national platforms for health information and to develop health literature for patients and libraries.

The first sentence of the Executive Summary stresses that:

Information to Patients is about Patients and should therefore respond to patient needs, contribute to improving health and ensure providing best care.

The organisations undersigning this statement:

- 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;
- strongly support the empowerment of patients and potential users of health services and acknowledge the important role of patient and consumer organisations towards achieving this goal;
- emphasise the relevance of sustaining and further developing the role of health professionals as the primary reliable source of health information to patients;
- support action towards improving accessibility to different sources of quality information, preferably tailored to the specific needs of the person requiring that information and which have a formal guarantee that they are objective and unbiased;
- support appropriate EU action to promote these objectives.

Conclusion

The issue of information to patients is far from resolved. There is still need for discussion, clarification and consensus building.

More preparatory work / research needs to be carried out on the best ways of providing quality information to patients.

In the joint statement some very practical recommendations were put forward:

- a comprehensive exercise has yet to be done, in order not only to gather and critically analyse important evidence from diverse sources, but also to carry out further research so as to understand and identify the dimensions, extent and specificities of existing asymmetries and gaps (7th FW Programme);
- the recommendation of the European Union Health Policy Forum (EHPF) on Health Information calling for a comprehensive mapping exercise to identify all initiatives and policies addressing the different aspects of health information as part of current EU activities should receive due attention;
- an in depth assessment of existing initiatives and good practices in the provision of information, including public private partnerships (PPP), at country level in and outside the EU, to map and compare current cooperation mechanisms would prove to be not only necessary but beneficial;
- the future EU Health Information Strategy should devise measures to use the EMEA's full potential in dissemination of information on medicinal products, including speeding up the process of developing the EudraPharm database and further expanding the collaboration with Civil Society through the working parties with patients, consumer and healthcare professionals' organisations;
- national platforms, under the coordination of the respective national medicines agency, should be fostered to improve awareness and access to existing sources of high quality, unbiased and independent, evidence-based and patient-centred information. The experience gained with these national platforms could be exchanged at the EMEA level;
- the future strategy should also devise measures to develop patients' health literacy;
- structural funds should be available to ensure that healthcare professionals have equal access to the best information for patient care in order to sustain and further develop their essential role in information to patients.