



What right to know?

Pharmaceuticals, patients and information

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and

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Informing Patients

About the Speakers

Jorgo Chatzimarkakis (PhD) is a German parliamentarian and one of the three MEPs participating in the High-Level Pharmaceutical Forum. He will discuss how the EU Directive could be amended to allow for quality information within the advertising ban.

Stephen McMahon is Chairman of the Irish Patients Association (IPA), based in Dublin and is a voice for patients in Ireland. The Irish Patients Association listens and learns from the many experiences of patients and their families. The ultimate goal of the Association is a world class, patient centred health care system that is built on trust.

Jorgo Chatzimarkakis

Thank you, Stephen, for this introduction. And thank you all for joining this event, which as you said, touches upon a quite interesting topic – not interesting when it comes to regulation – interesting in understanding how Europe deals with you – with people, with patients, with consumers, and with individuals. And the actual situation is that Europe – especially the member states – does not trust you. They do not trust you to deal with your own body, with your own health.

And that is why direct information, coming from those who take care of your body – at least in most of the cases, the producers of pharmaceuticals – are not allowed to communicate directly with you. And we are not talking about advertising here. We are talking about information. For those who did not know, especially in France, but also in Germany, especially in Belgium, there are different regulations, in the respective Member Countries. But, it is not foreseen that a drug that has to be prescribed by the doctor contains more additional information than the information leaflet, which is in the package. Even on their own website, it is forbidden. So that is the situation right now.

And that is the situation, which has to be changed, which is about to be changed by this Pharmaceutical Forum, a body set up by Commissioners Verheugen and Kyprianou. And we are there, together with Madame Grossetête, from France, Madame Roth-Behrendt, a German colleague, and twenty-seven ministers of health, and ten stakeholders. What are we about to do?

I will try to describe the situation in order to help understanding of what it is about. The current situation is that the Directive 2001 83EC does not allow any form of direct information. Information is only possible via the doctor. Now what would a sixty three year old lady from Oulu, in the northern part of Finland, do when she falls sick of breast cancer? What would she do? She would try to have a meeting with her doctor. Okay. Statistically, in Europe, you see your doctor for a quarter of an hour in a quarter of a year... statistically. And this is getting less and less because our best doctors are leaving Europe. They are going to Dubai, Singapore, and other places of the world. The country I know best, Germany, suffers very much from doctors leaving to go to the United Kingdom, for instance – because they are better paid there – at least on the weekends. So, it is a very difficult situation. This lady would then try to consult everybody on what she should do, in order to live longer, in order to be cured. What should she do?

The young people, here, maybe would consult the internet, and would Google. And maybe she would ask her granddaughter to do so. The granddaughter, then, would come up with one hundred eighty thousand hits, and most of them - ninety percent of them – in the English language. This lady does not speak English. The second problem is that her granddaughter cannot decide which of these hits tell the truth and which are, perhaps, launched by a competitor of a given product. And we do not know – does anybody here know? – how Google prioritizes their information, why they are ranked as they are ranked. It is a million dollar question, please tell me. So, we cannot trust this ranking. And this lady cannot trust this ranking.

That is why she is in a trap. She has no possibility to get good information. It is not allowed, via the law. She has to wait for her doctor. The doctor does not have time. She is not able to cure herself, or to organize herself in the right way. And that is why this situation in Europe is, I would say, a situation that is not bearable anymore. It is not a Europe of free citizens, who are entitled to inform themselves.

Now, other than that, we have, in the United States, a situation, where any form of advertising, of course with some restrictions, is allowed. And, I mean, you refer to my former position at the Centre for the New Europe, and there, you can see that, of course, I am a liberal. I am not an anarcho-liberal, but a very market-oriented liberal. But, I can tell you, as a Member of Parliament, that it would be very, very difficult – I would say impossible – to pass, through this Parliament, and through the Member States, to change this law, in order to have advertising possible. I think you can forget about that. And I say this very clearly, from the very beginning. And that is why I would like to discuss with you possible ways of how to get the patient better informed, without allowing advertising. Because this is no word. It is the red line. And nobody would accept that.

Now, the current situation does not allow broad information. The authorities release only little and limited information. There are differences in Member States. The internet is not a source that you can trust, in any way. That is why we need authorized or certified information. And the body that has the up-to-date information, the body that is researching on diseases is the industry, in many cases.

So, we have to get the industry on board. We have to involve the industry. And this industry must be allowed to give objective information.

Now, how can this happen? Even if we have this situation, that we have a body, or we have a website on the internet, with certified information, we, in the end, have the problem. And I can tell you that my mother has breast cancer. And she is not using the internet. She is reading tabloids and things like that. And if I am going to do something for the European public, to do something that attracts my mother, also, to read that stuff, and to get informed. So, I do not have only the problem of how to make this information available to a specialized public, but I have, also, the problem of how to disseminate this.

And to make this very, very clear, as a Member of Parliament, my position in this Pharmaceutical Forum is very much the position of patient. That is why I am very happy that Stephen [McMahon] is representing the patients here. I am not representing editors in Europe, who have, of course, an interest in this whole game, because the editors have lost the ability to advertise for tobacco. They will lose the possibility to advertise for alcohol. So, they need new sources. And, you can imagine that editors are quite pushy, when it comes to allowing advertising for drugs. So, I am not representing them.

But, I am interested in how to get them involved, because I need their help, and their infrastructure, in order to get disseminated the good and right information, the objective information on drugs. And I am not representing the industry, because the industry has other interests, other than the editors. The industry, at the moment, uses one door to reach the patient. That is the doctor, because that is, at the moment, the situation, how it works. It is the doctor who prescribes. It is the doctor who is the goalkeeper. And, it is the doctor who is almighty in this situation. And you can imagine that the doctors want to keep that position.

My view is that of the patient. And my view is that of the politician, who wants as many Europeans as possible to have the right information, and to be cured, and to be capable of doing what they need to do to live longer, and to be in a situation to survive longer.

Now, how can this work? I can tell you that it is not so easy. I do not know how many representatives of the Commission are here. But, normally, it is like that. The Pharmaceutical Forum is divided into working groups. And the working groups get information, sometimes only eight hours before... although, it is every three months, you get, eight hours before it starts, a sheet of paper, about what we are going to discuss. So, I question this mechanism. But never mind. I think I am the only Member of Parliament who goes to the working groups, and listens to what is happening there, because the Pharmaceutical Forum, itself, just comes together once per year.

What we need, in order to get out of that difficult situation, and in order to have healthier Europeans, is a model of a public private partnership. This model needs

some guidelines. First of all, you have to decide who is part of that. Now, the role of policy, of politicians, is to draw up these guidelines, and to say: *You have to provide for information that is not advertising.* And there, I mean, we have to distinguish between advertising and information, and that is a very difficult deal, because if you were a philosopher, you would distinguish differently from a lawyer.

Now, I can give you some ideas how to do this, because this is the first thing. We have to define what is information, and when does it end? Information is something which is objective, evidence-based, reliable, understandable, accessible, transparent, relevant, and up-to-date, to give you some examples. And, it is very, very important to really define this clear definition, to really have this clear definition of information, to use this as the basis for the guidelines. And the guidelines will then bring together in this public private partnership people from the industry, of course, because they have the up-to-date information. Also, doctors. It is very difficult for me to say that, but I think we cannot avoid to having the sick [insurance] funds, as well, because the sick funds are influencing, at the moment, to a very high extent, their Member States, in order not to have more information to patients, because they want to keep the patient uninformed, or badly informed.

Some doctors would like to have uninformed patients, because it is annoying for a doctor. I can understand that; if a patient comes with something he finds on Google and says: *Why do you prescribe this? I want that.* And he is not well informed. And this, also, makes very urgent a common base, a common, certified base, where you have all this information together. The pharmacists should be part of it, and scientific associations. And I think that it is fair enough that if you have this bunch of people together, in a self-regulation body, *self-regulation*, that, then, you do not need us. We can provide guidelines, but the rest goes with self-regulation. And I think that this is very important. If somebody goes against the rules, ex post, we can sanction. And that we should also foresee, in what we do, as politics.

Now, the source of the information, of course, will be the up-to-date information from industry. There could be foreseen a corporation with an authority. In the case of the European Union Pharmaceuticals Sector, it is the EMEA in London. But, it would be very, very tough for them to provide this information for approximately forty thousand drugs in the European market. So, it is impossible. What they could do is to take care of the approximately three hundred drugs that pass by them, to set up a website that has a common architecture. The EMEA provides it for all Member States. And, those drugs, which have passed the authorization process, in all the respective countries... the respective information can be put into the same architecture, so, you have one big website.

So, this is the mechanism, how it could work. That is why we would call it public private partnership, because this is the public part, the part of EMEA. I visited EMEA. I had a look. I know that the Parliament cut down the funds, the budget for the EMEA. So, we cannot ask them to take care of all forty thousand drugs. But, we can ask them to provide the architecture. And we have to find a way to translate, possibly, the information into as many languages as possible.

Now, the question: *Who controls all that? Who controls the self-regulation body?* Of course, if we talk about self-regulation, everybody controls himself... themselves. But, it is the EMEA, and it could be the European Union Commission that comes into the game, when it is about sanctions, or when it is about abusing the rules.

Now, let us come to the dissemination process, because this is the next step. I think the package leaflet is not enough. The package leaflet, everybody knows, contains basic information, but is really not something you would read during your holidays for fun. So, we need something to make it more interesting. And the media could provide this. I think that the implementation of this is, first, the distinction between advertising and information, but second, the possibility to get – and now I use the Swiss example – to get, also, sponsorship for publishing of certified information, because that makes it more transparent.

At the moment, we have a situation, where a lot of newspapers, and a lot of magazines, all over Europe, would report about a disease, and would report, maybe, about a drug – maybe they do not call it by the name – but maybe a drug that can help. And they do not refer to who sponsored the article. In Switzerland, it is possible to sponsor the article, and to sign: *This article has been prepared in cooperation with Glaxo, or Pfizer, or whatever.* So, in Switzerland, it is possible. And, as I think, it makes things much more transparent than they are now, because now you do not know who pays for that, and who does not pay for that. And that is why there are a lot of possible combinations how you can disseminate information. The only thing is that they have to be covered by these guidelines. And they have to be really covered, also, by the system of self-regulation.

We decided, in the Pharmaceutical Forum, to start with one disease. And, this is diabetes. As a pilot, I can inform you that, a couple of years ago, there was a first attempt, by the Commission, to start this with three pilots: also asthma and AIDS. And, there was a big, big majority in the European Parliament against it - I think seventy percent – half of them, because it was too informative, the other half, because it was not informative enough. And now, the Commission cannot understand that, and is a little bit scared about repetition of that failure. And that is why we have to be very smart in our approach.

But, I think if we concentrate on diabetes, which I would say is a modern epidemic. If you see that, in the year 1945, there were fewer amputations of legs and arms in Germany than in 2005. Then, it was because of the war. Now, it is because of diabetes. I think that it makes sense to take this pan-European epidemic, as a pilot, to start this process. But again, the information has to be objective, evidence based, up-to-date, reliable, and should not be the opposite. And, this is something that we have to discuss.

If you are interested, I could read you, then, the change, because it is just a small change in the respective article, that we have to do. It is very simple, but it would change the bad situation that we have, at the moment. I will just read you the

sentence, so that you can understand how we could change the law. It would read, then: "Within three years... following analysis of the above data, 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."

This is something which is a draft. I am not sure whether it will be, in the end, like I read it to you, but I would be happy if it goes in that direction. And, of course, we are bound on the cooperation of all stakeholders, because that is very, very important. And then, if this works, we have other examples, where self-regulation works quite well. I think that this opens the door to less bureaucracy in Europe, and more self-regulation, because the world becomes more and more complex, and it is more and more impossible to cover everything, by law. And so, self-regulation, the Anglo-Saxon example, becomes, more and more, a very important tool for us Europeans to address problems like this.

Thank you very much for your attention.

[Applause.]

Stephen McMahon

It is, indeed, a very important topic that we are addressing, this whole aspect of information to patients. And just about our own association in Ireland, we are really a health care advocacy body. We are there for patients. We deal directly with patients, who have had problems with their encounters with the health care system. And where we can, we try and have the issue resolved. But importantly, to actually learn from those experiences, to bring it back into the system, when people are discussing how to develop new services, or improve it, or whatever. And we are also independent. We are non-political. We do not have any particular political slant. And I suppose that the key area that we are interested in is encouraging patient-centred care.

And, you know, over the years... I have been doing this, now, for nearly five, six years, or thereabouts, maybe longer... patient-centred care, now, is something you sometimes hear about. It is, you know, in the lexicon. But, sometimes, the people are sometimes using it as a buzzword, and not really understanding what that is all about. And it is the subject for another day's piece of work.

But also I am a member of the board of [IAPO](#) [International Alliance of Patients' Organizations], which is a global patients' organization. And, on the board, there are eight members, from literally all around the world: Pakistan, Uganda, Uruguay, the United States, Ireland, the United Kingdom, and the Netherlands... Australia, as well, too. Some of its members, of the organization, represent entire disease groups.

So, it has been calculated that there would be something like three hundred sixty five million patients in its area of responsibility. And, basically, what IAPO is all about, is to actually promote the whole concept of patient-centred care, and to ensure that the patient is at the centre of all decisions.

Based on our involvement... on the Irish Patients' Association's involvement, in our direct contacts with patients, there are basic needs: the need to be treated with dignity, the need for equity of access and timely access to treatments and care, and what is relevant today... access to information that informs them. They have a need to give informed consent. And we would argue that it is not just informed consent, as to which limb is going to be operated on, but also in the area of medicines. Pharmaceuticals, prescription medicines can be dangerous, and there are side effects, and there are options, and so on, and so forth. Patients need to have that to enable them to make that decision. And I suppose the bottom line is, from the patient's perspective, is to trust the system – that it is reliable, that it is transparent, that it is accountable, and that it has their needs and interests at the centre of the process.

So, I suppose that the key message, in this short discussion, today, is that the patient is the key person. It is not the size of the pharmaceutical company, or the size of the hospital, or the size of the primary care centre, or the health managers that look after it. It really is all about the patient as the key person. And without patients, probably all of us, here today, would not be here, if we did not have that interest in it. And patients do need to have good, reliable, unbiased information to make those informed decisions. And it is informed decisions... most of the time, we think of it from the point of view of their making decisions about their medicines and treatments... but, patients also need to have information about how their health care system is performing, and where the centres of excellence are, and how they can get access to that, and so on. So, they can also be, as consumers, accessing those sorts of services.

So, I suppose when we talk about pharmaceutical companies, they have a number of accountabilities. They have accountabilities to their shareholders. They have accountabilities to regulators. And, indeed, the most important is that they have accountabilities to the patients, for whom they are producing these wonderful medicines that have transformed the world that we all know.

A few years ago, at the Irish Patients Association, we signed on to a charter, a European Charter of Rights, proposed by the Active Citizen Network in Rome. And coming out of that, we asked Dublin City University to do academic research on the twelve elements of rights, in that area, to see where, in Irish law, we needed to change it, you know, either in our constitutions, and so on. And one of the areas, that was of interest, at the time, was that access to information was seen as a social and economic right. And I think we heard Jorgo mention the fact that there was this distrust that the information that patients and that wider society need to know can be cut off. And, therefore, if you do not know about a new medicine, or you do not know about where there is a hospital that has a far better success rate with a particular treatment, well then, there is going to be no cost associated with that.

Now, we would like to see that this charter of rights and responsibilities was linked to the European Charter of Fundamental Rights, which was going to be subsumed into the constitution. And I suppose, in a way, while I had said that we are non-political, we would have liked to have seen that debate, at home, in Ireland, where we would not have been talking about beef mountains, and wine lakes, and cheese marshes, and all sorts of things like that. But, we would actually be looking at something that unites all Europeans, throughout all of our borders, on the fact that we would, actually, have this set of rights for all patients, and hopefully, that this can succeed, and that we can all share in this equity, and so on.

As we mentioned earlier on, information comes in many forms, the product information leaflet... Research we had conducted, two years ago, told us that people had great difficulty in understanding that leaflet. Teenagers and the elderly were least likely to read it, and that there were also comprehension problems, in that. Other areas that were reliable were doctors, nurses, your pharmacist – the local, community pharmacist - was a centre for providing important information, and the other areas, where, sort of, your friends and relatives, as was mentioned earlier, maybe some tabloid comments that you may read, or whatever else. But, the important thing was that people do need to know, to have the information about their medicines.

We have just finished work for this new agency in Ireland. It is the [interim Health Information Quality Authority](#). And, this body is due to come into legal existence, in the next, hopefully, in the next month or two. But, they asked us to do a study on the whole issue of information to patients. And I was hoping that, before, even in the last five minutes, that I would get a tinkle, so that I could share more of the findings of that report. But really, all I would say, is that the area of direct patient advertising has been rejected by the authors of Dublin City University.

It brings a new language of information bearers. Again, research that we had done with family doctors, sixty percent of them said that they had not gotten enough time, in their consultations, to give adequate information about the medicines to their patients. So, we really need to re-think how we convey the information about medicines, and options, and so on, to patients. So, in having information bearers, it is almost like, just possibly, a new function being created. Certainly, in the report, it does say that the pharmaceutical industry has a role to play. But, it is no more important a role than that of all of the other stakeholders, in that process.

And again, there was a reference to regulation, and so on. Regulation serves us well, in so far as it protects vulnerable people from being influenced in a certain direction. And you know my background. I worked for a multi-national oil company for thirty years, and I did have some experience in the marketing area. And really, I suppose, everything communicates for a brand. It is not just simply putting an ad in a newspaper. It can be a whole lot of other things.

But, we have to find ways to ensure, as the report suggests, that a patient is assessed on their ability to understand the information that is going to be there, or to find different ways, such as, maybe, talking tablets, where people might have difficulty in reading, and literacy problems, and so on. So, I think that, really, we are at a stage to ensure that all of this, that what is happening in Europe, is within a framework that is ethical, and that we can all work in a trusting partnership. Because trust, as in all things in our personal lives – it can be difficult enough to restore it. But, among strangers, it can be an even trickier situation.

I just made quick reference, with my IAPO hat on, to a report that was presented, there, in London, a month or two ago. It was conducted by Consensus, which is a market research company in the States. And, there was some funding from Pfizer with IAPO as a partner in this. And really, one of the things that did stand out was the fact that, obviously, there were twelve hundred patients, from twelve European countries. And they included Canada and Nigeria. But, on the European side, ninety six percent of patients surveyed, that were members of patient groups, really saw that the fundamental right of patient-centred care was very important. Where Germany and the Czech Republic gave it one hundred percent, the United Kingdom gave it ninety seven percent. But I think when we look at ninety six percent of any population that is being surveyed, that it is a very significant number.

But, another area, too, that I think is of interest is that the also ninety eight percent said that comprehensive information must be provided in an understandable format. And ninety eight percent agreed with that finding, where France, Czech Republic, and Hungary gave it one hundred percent. And there was an area in it, which I found interesting, which was their willingness to take action, particularly in the area of politics. And thirty nine percent of the patients, surveyed, said that they would support candidates or parties that reflected their particular values, and so on. In the United Kingdom, that was thirty eight percent who felt that way, in Spain, forty seven percent, in Belgium, fifty percent, Italy thirty six percent, Germany thirty nine percent. And I think that the point that I am trying to make, here, is not so much a political point, but that patients, and that patient groups, and patient advocates, I see it as something wonderful, that we are talking to one another. We are sharing ideas, around the world, about what is happening. That it is, now, I suppose, slowly making our way to the tables, where future decisions are going to have an impact, directly on patients, as opposed to a myriad of vested interests. So, really, I suppose the message I am trying to leave with is that, yes, patients need reliable information.

I would just like to make one final point, which is, again, quoting from this report from DCU. Once again, it was Dublin City University. They did this evaluation for us. And there is one area, I think, that just caught my attention, on the plane this morning, was information versus understanding. And I think that this is a value that must be understood, here:

“Just as we found of rights in general, the principle of autonomy is a very noble, ethical tenet, but it is not without its difficulties. Even the right to information and free choice may have some ambiguous

difficulties. At times, it is difficult to determine whether patients really understand the information given to them about their health and the decisions that they face. In education circles, for example, it is generally accepted that intelligence is not a single entity, but a multiplicity of intelligences.”

For instance, Howard Gardner’s theory of [multiplicity of intelligences](#) is based on the demonstration that all people do not learn the same information in the same way. He goes on to describe linguistic intelligence, logical, mathematical intelligence, musical intelligence, and so on. I am not going to go on any further, other than to make the point that when we are actually designing information vehicles for patients, and the public, that we actually must also take this other dimension into account that, as you know, as Jacob was saying there about an elderly person, that is not discriminating against elderly people, assuming that they will have difficulties in this way. But, people from various socio-economic groups, lower socio-economic groups that did not have opportunities to education, and so on, may need that information, in a way that it is easy for them to understand.

I was with the president of one of our leading medical schools in Dublin on Friday. And he was showing me some wonderful new technologies, and devices that are in the pipeline – almost science fiction stuff, in a way. But, one thing that I did realize was that, while the technology was useful for medical students, surgeons, to practice, in a virtual way, the various, tricky operations that they could do, rather than actually practicing on patients, which is a good thing... They were also able to use some of this video work to explain to patients, about some certain complex operations, maybe shunts being installed, and so on. And that is a very useful exercise. So, it is not just information about, as I say, about medicines. It is the whole way that patients are informed.

And with that, thank you very much.

[Applause.]

Q and A

Question 1

If I may, with your indulgence, a very short comment, and a very short question. Á propos of the second speaker's remarks about the constitution, if the choice is either to have the European Constitution, and to have a new statement of patients' rights, or have neither, then I think that I would choose neither, because I am not prepared to trade the independence of my country, not even for a new statement of patients' rights.

My question is about the opening comment, about its being – did I hear you say something about its being illegal to make available information on drugs? And I simply do not understand how that could be done, because presumably, there will be websites in America, where anybody who wants to access information on a drug, at least from an American company, you can get it. How are people prevented from doing that?

Jorgo Chatzimarkakis

I would like to describe the fantastic situation between Belgium and the Netherlands. In the Netherlands, the current situation is a little bit more liberal than in Belgium. In Belgium, it is absolutely, totally forbidden to give more than what is written in the package leaflet, on the website of the respective company. And so, what a Dutch speaking person would do, of course, is check the Dutch website. But, if it would be a Belgian website, then there would be a punishment by the Belgian state, by Belgian law. So they do it by punishing, of course, the holders of the website, within their countries, if they discover that it is hosted, and stored, in that respective country.

Of course, you can have access, via the internet, and check American databases. That is what I tried to elaborate on when I quoted the one hundred eighty thousand hits that you get. And most of them are from the United States. But, that is the problem with being able to trust these sources.

So, you are right. It is difficult to imagine, but it happens. And our European Member States are, sometimes, doing the impossible. Yes.

Question 2

I am a practicing lawyer, working a lot in the pharmaceutical field. I had one little, additional comment on this point, here. It is obviously very complicated to make the distinction, now, under the existing legal rules, between what is prohibited, and what is not, in some countries. In Sweden, for instance, if you have a website with

information on medicines; [inaudible] password protection for the prescription only medicines. [inaudible] I think that it is a very important concept, a distinction between push and pull.

If a patient, or a member of the public, wants to access information, I think that he should be, really, free to go anywhere, and find that information. And that should not be considered advertising. There are still countries, of course, which do consider even that accessible information as advertising.

Now, another point, which has not been raised yet, of advertising prescription-only medications, is a financial one. It is a budgetary consideration of the Member States, because they are afraid that it would be in too high demand. How is that being addressed in the working group?

Jorgo Chatzimarkakis

My reflection on the sick funds... I was not very happy to have them on board. I tried to answer this question, during my speech. Of course, it is they, mainly they, who try to block any movement, to any direction, because they fear that the demand would be higher.

The reality shows that if you compare the European drug market with the American, for instance, it is true that medicines, that drugs that have to be prescribed are much, much higher in price, much more expensive. But, the generics are much, much lower in price, much, much cheaper. So, in the long run, every drug will become very generic. In the long run, the United States' system is much more interesting, also for the pharmaceutical industry, but also for the patient, than in the short run. In the short run, of course, our system here, with very regulated prices, is more interesting for the sick funds, and more interesting for Member States.

So, how is this addressed? It is addressed by taking the sick funds on board, but by moving them in a new direction. And I was very happy to see the reactions of the three big Member States, because they are, I mean...you take out Germany, France, and Italy from the European Union, we would not have a problem with the Lisbon strategy, and competitiveness, and so on. I mean, that is the truth. I say that, as a German, and knowing the situation.

And that is why I was so happy that especially Germany, but also France, and Italy, less than the others, in this first Pharmaceutical Forum, moved, showed an interest in a new direction. So, I think that there is a movement. And I think that it has to come by the Member States, the Member States who have to put pressure on the sick funds.

And, of course, I would like to announce that I initiated the European Life Science Circle, where I would like to promote new forums, not only of treatments, but of patenting, and so on, and so forth. I would like to have a comparison of the public

sick funds and modern sick funds, that allow for other drugs, that allow for that. They exist. They are much more successful, in many ways, and I would like to compare these publicly, which is not the case in some Member States, where the public sick funds still have some monopoly, when it comes to the public debate. Unfortunately.

Stephen McMahon

Thank you. I was just sort of thinking of the study, as I said, which has not been published...saying that it does not favour direct-to-consumer advertising, simply because of the experiences in the United States, New Zealand, and the various tables of the amount of money that was spent on marketing, and that the amount of money that was actually spent, as a result of the public being aware of, or patients being aware... the public being aware of particular drugs.

I think one interesting development that I have noticed, in the area of public health, I suppose: most countries' departments of health have budgetary problems. And I have noticed that, certainly in Ireland, there has been an emergence, now, of what you would call "public awareness advertising", which would say, in the area of cholesterol, in the area of colon cancer, and while it is not actually naming the product, because there are a number of products from different pharmaceutical companies, it does have a very valuable contribution to the society, to people that would not normally get tested, actually to go and get tested. And if there is something wrong, then they can actually go and get preventative medicines, which may help them.

In Ireland, I think that we may not have the same difficulty, as in some other countries within Europe, that if there is a new medicine that is proved, and that is tested, and so on, so that that is made available to patients, so that you do not have to go down the road of having huge court claims to get access to new technologies. And, obviously, that is something that we want to defend very strongly, in Ireland, that patients can get access to new medicines, and so on, and so forth.

But, I think that there are other opportunities there that perhaps can be explored, that can meet, more importantly, the needs of patients, to know about what is happening, what is new. I think that there is, now, some European website that now produces all of the trial results of...I cannot think of the name. Maybe someone might remember it. But, that is there.

But, there is one final thing about the internet – I would like to make a point. And that is, it is great if you can go to a site that you know is reliable, and has its certificate and all the rest of it. The real concern, I suppose, that we have is that people, who are using the internet, may then start to self-prescribe, and that opens up a whole hornet's nest of, you know, the traceability of the product, at the moment. Like, at the moment, if you buy a medicine in your pharmacy – certainly, I would say, in Ireland, you can trace it pretty far back – but it is to be sure that the medicine

that you are actually using is the medicine that will do the job, that it is not counterfeit, or that it is not just being sold to you, to make a quick buck, by somebody.

Question 3

I am here, representing the Czech Republic. I would like to support fully, *I would like to support fully* the ideas presented by my colleague, Jorgo, about health, about prevention, and also about drugs, and medical technologies. So, I can agree fully with my colleague that now, unfortunately, now, it is not possible to pass through this European Parliament, through today's national parliaments, the free advertisements for drugs. But, I believe, in general, that advertisements are the natural way to disseminate information to the clients. I think that we should not resign this activity. We should not resign to try and to speak about free advertisement of drugs, as a normal way to push information, to disseminate information to the patients, to the clients.

[Applause.]

Jorgo Chatzimarkakis

Well, that gives me hope to have a group of friends that supports the idea of, at least, having information. But, we should be very careful which catch words we use. I can give you one example, and then, unfortunately, I have to leave.

I was referred to in the most serious – I do not think it is the most serious newspaper in Germany, but it is supposed to be the most serious – Frankfurter Allgemeine Zeitung, where, after the first meeting of the Pharmaceutical Forum, where I said exactly what I said today - that I am not in favour of advertising, but I am in favour of information – the headline was: *Member of European Parliament In Favour of Advertising Drugs To Be Prescribed Only*. Thank you very much!

So, my other colleagues, especially Mrs Roth-Behrendt – those of you who know her know that she is very, very direct – said to me, when we were together in the elevator, "I knew that you are a new liberal bugger."

"Thank you," I said. "Did you read the article?"

And she said, "Not needed."

Because, in the article, everything was right, but the headline was very bad. So, it is very, very important to take care of the catch-words and the headlines. I have, unfortunately, to leave. But, thank you very much for the attention. And I would like to have your support, at least, for those Members of Parliament who really want

a freer Europe of citizens, Europe of patients, and sometimes of nation states. Okay, if it helps, it is okay.

Thank you very much.

[Applause.]

Stephen Pollard

Jorgo has to leave. Thank you very much, Jorgo. But, we do not have to. We can take another question, or two, or comment, if people have any. And Stephen is able to stay afterwards, and answer questions. Johan, did you have something that you wanted to say?

Question 4: Johan Hjertqvist

Thank you. You, in that case, help [Health Consumer Powerhouse](#). We rank, you might say, the healthcare systems, from the consumer's point of view. And, of course, access to information, access to medication is a key quality, of course, to help consumers. One reflection, from listening to this discussion, is that it looks like it is a pity that Jorgo had to leave. But, it looks like the idea of the European Union is to build one single system. I mean, this private public partnership, self-governed, information system will be the sole one to serve the people with information. To me...

[break in tape]

...In a sophisticated society of today, you usually can rely on different information sources. To me, it sounds a bit obsolete. I think just one system that will provide people with information about pharmaceuticals. Of course, the natural question to Stephen and others is: Does that sound very attractive, or interesting, to have just one... well, you might just say, just to be provocative... one monopoly information system about pharmaceuticals?

Stephen McMahon

I suppose, in an ideal world, if you could have that one system, where there is full cooperation amongst all of the pharmaceuticals, to be able to share all of that information, then, that would be useful. But, I think, really, we will have different ways of delivering information to patients, other than simply this one, big, gigantic database. On the other hand, you know, if you have a large, reliable database, within, say, Europe, all of the innovations for both medicines, and devices, and all of that are all there, and that, then, you have other, smarter systems that can deliver that information to patients, where they can actually understand that information.

Again, if you think of it, patients are not doctors, nurses, microbiologists, or health administrators, or managers. You know, you come across somebody... you know the way we often hear that you have to change your job, and re-skill yourself, and up-skill yourself, just in, you know, in modern day industry. So, when somebody gets sick, they have to re-educate themselves to get knowledge about their particular illness, about the tools that they can use to get better, and so on. And so, that education process... not everybody is at third level university, or even high school, or junior school. It has to be tailored for their ability to take that on board.

So, I have gone on a little bit there, Johan. I agree with you. In the ideal world, you would have this wonderful, big, master database. But, I honestly cannot see that as the answer.

Question 5

I would also hope that our patients' organizations will be looking at, what I call, almost information overload, what we already get with our prescriptions, at the moment.

And I am sort of curious, or cantankerous, by nature. And I will always read the leaflets, or question a doctor, if he gives me a prescription. And I will, also, to be honest, say: *Is there the same equivalent generic, which will cost one fifth of the cost of some brand name you might prescribe me?*

But, if you actually read the leaflet you already get, and look at the contraindications, I think most people, with an average education, would be afraid of their lives to take anything – even aspirin, today, with the contraindications, or paracetamol, with the contraindications, you know.

So, in a sense, information... Yes. I am all for more information. I am not quite clear how you will separate that from advertising, or to put it another way, how you would convince Member States' health budgets that you can separate information from advertising. Because we might be, sort of, a little bit cynical about saying the political opposition, particularly at the council level, because they would be afraid that it would drive the drugs budgets up in every country, which advertising, as such, would.

You get fashionable drugs. Then you sort of have a survival of the fittest, in terms of the marketing prowess of different pharmaceutical companies, with the fashionable drug of choice. Often, when there is an equally good, or absolutely similar generic, which would cost the taxpayers of your country one tenth to treat you with the generic version, rather than the sort of sexy one, in terms of the marketing prowess.

So, I do not think it is quite as simple as presented. Nor do I think we should knock the health authorities in each country for being genuinely afraid, in this area. But, there must be a way where patients, particularly inquisitive, contrary patients like

myself, and most patients, I would like to think, can actually get more straightforward information on any particular drug that we have been prescribed.

I think that you have diagnosed the problem. But, I do not think we have any solutions, as far as I can see, as to what we can do, in this particular area.

But, you know, let's be honest. I was not sure what Jorgo meant when he talked about sick funds. Was that health insurance monies? Or was it public health funding?

Several People

Insurance.

Question 5, continued

Insurance? We have to be positive. We call it health insurance, rather than sick insurance. You know, health insurance. Yeah, okay. So, that clarifies that. Thank you.

Stephen McMahon

Thanks. You are right. I mean, there is more to information than simply the printed leaflet that you would read, or the printout from your internet, and all the rest of it. There are other, very important elements in this that I think that the regulators, or the health departments, in different countries, could look at. And it centres around the importance of... certainly a value we hold dear is the importance of the doctor/patient relationship – that trusting relationship between you and your doctor, and that the medicines that are being prescribed for you are the appropriate ones, and that doctors, as has just been announced, in the last two or three days, in Ireland, will now undergo regular competence assurance, and three hundred sixty degree assessments, which includes patients in their practices, so that their knowledge of the medicines that are appropriate for their patients are the right ones.

Now, on the other side of that, you are right. You have, you know, the person that is assertive (and I know quite a few of them), that will actually question: *What are the side effects of this drug? By the way, I am taking three or four other medications, here.* And we know that medication errors are a big problem. You know, I think that up to ten percent of hospital admissions, some studies suggest, people go into hospital, as a result of that.

So, if we can deal with those sorts of real challenges in the area of preventing adverse incidents, that releases a huge amount of resource for new medicines, and so on, and so forth, rather than actually saving that money, and passing it back to the.... We

like... the Irish Patients' Association... if the minister of the day gives a certain amount of money, we want to see it there next year, but to get better... to squeeze better value out of that, you know.

Stephen Pollard

Thank you very much for that, Stephen. In conclusion, if I could just maybe abuse my own position as Chairman, and say what I think, which is that the fundamental problem, I think, is, as most of us at the Centre for the New Europe believe, is the same fundamental problem as with most problems with healthcare, which is, as some people here have hinted at, but maybe do not take it in quite the same way as I mean it, that the real problem is that the state is in control of most healthcare budgets, rather than patients, themselves. And that if the state got out of the way and let patients run things, that this, amongst other problems, would be a lot easier.

But, to take a rosier view, I think, rather than undermining this entire debate, I do think that this is an almost irrelevant debate. At least, it will be, if we look back in ten years' time. As one of the speakers said, asking what about the internet, the idea that a government can legislate to ban information, I think, in ten years' time, will be such a preposterous notion, that there will be almost no control of information, because information will be there on the internet, anyway. No government, whether it is Europe-wide or nation state, can ban the free flow of information.

Anyway, that is me, abusing my position.

Thank you.

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