



Health Equality  
Europe

**CHALLENGES**  
*FACING THE*  
**HEALTH ADVOCACY COMMUNITY**

**The Views of Policymakers  
and the Media**

To be read alongside accompanying *Main Report*

**APRIL 2006**

*SURVEY AND ANALYSES CONDUCTED BY PATIENTVIEW*

*Health Equality Europe is supported by an educational grant from Novartis*

# CONTACT DETAILS

## HEALTH EQUALITY EUROPE

Enquiries regarding Health Equality Europe should be made to:

Jean Mossman  
jean.mossman@btinternet.com

and

Jo Taylor  
jo.taylor@novartis.com

## PATIENTVIEW

WOODHOUSE PLACE, UPPER WOODHOUSE, KNIGHTON, POWYS, LD7 1NG, WALES

TEL: 0044-(0)1547-520-965 FAX: 0044-(0)1547-528-501

E-MAIL: [INFO@PATIENT-VIEW.COM](mailto:INFO@PATIENT-VIEW.COM)

[HTTP://WWW.PATIENT-VIEW.COM](http://WWW.PATIENT-VIEW.COM)

COPYRIGHT

© 2006 HEALTH EQUALITY EUROPE. ALL RIGHTS RESERVED

# Executive summary

---

During February-March 2006, PatientView conducted a pan-European survey of health campaigners\* on behalf of Health Equality Europe (HEE). The subject of the survey was the challenges facing the health advocacy community (the survey results can be found in this present report's accompanying *Main Report*).

To gauge the viewpoint of the individuals that health campaigners are seeking to impress, PatientView interviewed 16 members of the media and senior policymakers during April 2006. The interviewed stakeholders were asked to express their opinions on the accomplishments and shortcomings of today's European health advocacy movement. The results of the interviews are contained in this present report.

## THE CONTRIBUTION MADE BY HEALTH-ORIENTED NGOS

Members of the media and policymakers believe that health campaigners supply valued services within the healthcare sector at national and European level. These services include the provision of information and support to patients, and helping to educate medical professionals. Behind the accolades, however, are some qualifications:

### STRAYING BEYOND CORE COMPETENCES

Gary Finnegan [Editor, *Irish Medical Times*] argues: "There are limits to it. After all, doctors have a body of knowledge of illness, and they also get feedback from their patients (both of which help to inform)". And Oliver Berlau [Broadcast Journalist, German-Speaking Section, *BBC World Service*] thinks: "I am not at all sure that health professionals would take the advice, as they believe themselves to be the experts."

### VARIABILITY OF PERFORMANCE

"Patient groups vary in competence, professionalism, and age", says Mel Read [former MEP, Labour, UK].

\* "A HEALTH CAMPAIGNING ORGANISATION IS ANY GROUP THAT CLAIMS TO REPRESENT THE INTERESTS OF PATIENTS OR THE PUBLIC IN MATTERS OF HEALTH OR HEALTHCARE."

—A. Wyke, 'Leaders of the revolution: consumer-driven healthcare has arrived', *Scrip Magazine*, April 2006, pages 25-29

---

#### **DISTORTING HEALTHCARE PRACTICE**

Jeremy Laurance [Health Editor, *The Independent*, UK] provides an example of how the focus of healthcare delivery may be unduly influenced by adept campaigning: “A search of my articles showed that when I started on *The Times* in the early 1990s, the stories on heart disease outnumbered the stories on breast cancer by two to one. Now, the proportions are reversed. This is very largely the result of breast cancer lobbying, which has moved the disease way up the medical agenda”.

#### **VESTED INTERESTS GETTING IN THE WAY**

Fabio Turone [Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy] makes the case: “Some grassroots organisations are financed for very specific reasons, and may not know how they are being manipulated”.

#### **PATIENT REPRESENTATION**

The majority of the interviewed policymakers and members of the media generally agree that health campaigning organisations do represent the interests of patients. Only Stephen Pollard [Senior Fellow and Director of health policy programme, Centre for the New Europe, Belgium] and Mr Laurance think that health campaigners do not perform satisfactorily at the task of representing patients. Mr Pollard states: “There is a wide disparity among the groups, some of which may be self-appointed, and little more than talking shops”. Mr Laurance adds: “Lobbying groups are actually capable of distorting things, giving undue attention to certain diseases. For example, look at the attention given to prostate cancer compared with breast cancer—a male cancer that is directly comparable to a female one, but which doesn’t, by any means, have the same representation”.

The interviewees were, however, of the unanimous opinion that health campaigners should represent patients and their constituency. Mr Pollard regards that duty as the health campaigner’s primary role. And Mr Laurance postulates: “I suppose that prompts the question: if they don’t, who is going to?”.

Other important points from the interviewed stakeholders:

#### **GROUPS ARE ONLY GOOD AT REPRESENTING THEIR CONSTITUENCY**

Ms Read emphasises that the representation offered by patient organisations and other health advocates stretches only as far as their constituency, “not the general public”. Lynne Eaton [freelance journalist, *British Medical Journal*, UK] specifies: “And that constituency may be carers, not patients”.

#### **LESS VOCAL PATIENTS MAY HAVE A DIFFERENT VIEWPOINT**

Virginia Bottomley [former Secretary of State for Health, and Director, International Resources Group, UK] is of the opinion: “Health campaigners can be more vociferous and more extreme in their points of view. So it is important to appreciate that the silent majority may have a different emphasis”.

---

#### **AN IMPORTANT ROLE FOR UMBRELLA ORGANISATIONS**

Geert Jan Hamilton [Director of Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport (Ministry of Health, Welfare and Sport), the Netherlands] stresses that large umbrella groups—although they are frequently distant from the grassroots—have an important role to play, because they can take a relatively dispassionate approach to the issues raised.

#### **GOVERNMENT CAN STIFLE THE PATIENT VOICE**

Kathy Sinnott [MEP, Independent, Ireland, and Member of the European Commission's Committee on Employment and Social Affairs] observes: "Unfortunately, the presence of health campaigning groups in government policymaking can be mere tokenism. And only a minority of health campaigners are genuinely able to bring in the patient perspective".

#### **CREDIBILITY OF HEALTH CAMPAIGNING GROUPS**

Health campaigning groups are valued within healthcare systems at national and international levels. But the contributions provided by health advocates vary in quality, say the interviewed media and policymakers. Nonetheless, the prevailing view is that health campaigning organisations can become an effective force within healthcare systems. To do so, groups must address two related topics:

##### **FINANCING**

According to Mr Fabio: "Some grassroots organisations are financed for very specific reasons, and may not know how they are being manipulated".

##### **PROFESSIONALISM**

Ms Eaton advises: "From the point of view of the press, how groups are regarded depends on how good they are at responding to enquiries. Of course, we do understand that the smaller groups just don't have the resources to do this efficiently all of the time. An organisation like Sane is particularly good: it is run by a former journalist, Marjorie Wallace, so she understands how to communicate with us. But I have to say that the Patients' Association is one of the bad ones".

#### **DECIDING ON A CAMPAIGN**

The February-March 2006 HEE survey of 250 health campaigning groups discovered that the majority of respondents manage a delicate balancing act between two sources of information when choosing subjects on which to campaign. Either they respond to large-scale outside events (such as new legislation, or healthcare reforms), or to concerns raised by their constituency / their members. The media and policymakers were asked whether they agree with the finding. Most, but not all of the interviewees concur.

---

Ms Read identifies unnecessary short-termism as a negative consequence of either tactic: “The groups react to immediate events. It is harder to stand back and take the longer view. Umbrella patient groups, such as the European Patients Forum (EPF) and the International Alliance of Patient Organizations (IAPO) make serious efforts, but themselves have limited resources to take a longer view”.

Interviewees are divided as to whether health campaigners should poll the public when deciding on a campaign. Mr Fabio insists: “Yes, of course. This should be the starting point of any advocacy group. The groups should consider what the public knows and wants about a specific health issue, so as to determine what should possibly be the object of a campaign. This is a pivotal role of such groups. Health campaigning groups usually represent a sub-population of patients—expressing the interests of that group. It is then necessary for them to be able to help find a balance between the specific interests of those groups, and the more general interests of the public and the healthcare system.”

But, on the other hand, Arto Koho [Finland’s Permanent Representative to the European Union] is uncertain: “I am not sure. It is something that is very reasonable to ask of these groups. But their time schedules would not always allow this to happen.” And John Bowis [MEP, Conservative, UK] continues: “Not necessarily, as the public may not have an educated view. There might be only a small minority of patients with an understanding of a particular disease or healthcare matter.”

### **EFFECTIVENESS OF HEALTH CAMPAIGNERS**

The media and policymakers were asked whether the activities of patient organisations or other health campaigners have ever changed their perspective on an important healthcare matter. Some say “Yes”, or report that a group has made them more appreciative of the sensitivity and complexity of a topic, or recount that a group has reinforced one of their personal viewpoints.

One of the clearest results of the interviews is that mental health groups seem to have had a powerful impact upon the way a number of the policymakers and journalists regard stigma, quality-of-life issues, and the role of medication in treating patients. Joanne Shaw [Vice-Chair, NHS Direct, and Chairman, ‘Ask About Medicines’] provides an example: “Yes, I think they have influenced my views. Groups such as MIND have made me reconsider the role of medication in mental health. More generally, over the past five years, patient organisations have given me a greater appreciation of the importance that patients place on the quality of life, rather than taking a purely medical view. I have gradually realised that the issue for many people is more about quality of life, and less about treatment.”

---

However, both Peter Brosch [Head of E-Government and New Media Unit, Bundesministeriums für Gesundheit und Frauen (Ministry of Health and Women), Austria] and an unnamed representative from DG Sanco argue that it is not the job of policymakers to be unduly influenced by lobbyists from a single camp. The official from DG Sanco explains: “No. [Editor: from a European policymaker’s perspective] patient organisations are just one type of stakeholder. We embrace other healthcare stakeholders, and are not focused especially on one interlocutor.”

### **GOVERNMENT SUPPORT: INFRASTRUCTURE**

Governments can support health campaigners by many other means than simply handing over money. Examples include: the introduction of legal rights for health advocates (which would then underpin campaigning activities, for instance); simplified registration procedures for charities; a national agency to support citizen advocacy; guidelines for ethical funding; and public consultation with health campaigners. The general consensus among the interviewed media and policymakers is that government should provide a modicum of support—and, in some cases, government falls short of this mark.

Dr Brosch estimates that the infrastructural support given to health campaigners may not, at present, go far enough: “I should also say that there are more needs than just infrastructure. It is also a question of how groups manage their PR, marketing, and advertising in the first place that determines whether they get government support. Some don’t manage to get public attention, and, very often, this means they do not get the government support they need”.

Interviewees share qualms about the relationships that health campaigning groups can maintain with government:

#### **GETTING TOO CLOSE TO GOVERNMENT**

Ms Sinnott notices that health campaigning groups which are overly dependent on government may end up having to be “polite to government”.

#### **A NEED TO PROTECT THE PUBLIC**

Ms Eaton remarks: “Regarding a simplified system of allowing health charities to register: no, because the system should be as rigorous as possible”. In other words regulators should not relax policy simply to encourage the health-oriented NGO movement, if there is a possibility it will endanger public safety.

#### **NOT THE ONLY PLAYER AT THE TABLE**

Marcello Justo [Producer, Spanish-Speaking Section, BBC World Service, UK] says: “Regarding independent agencies to support citizen advocacy: I would say ‘Yes’, but

---

it depends on what kind of support. If independent agencies means the regulators, they must give support, but must not get too close.”

### **FUNDING OF HEALTH CAMPAIGNERS**

The interviewed media and policymakers feel that health campaigners that rely too heavily on certain sources of funding (whether it be the European Commission, national government, or the healthcare industry) will inevitably be compromised. These groups should turn to their members or to the public for funds, instead. The picture is, however, confused by a widespread lack of transparency surrounding campaigners' financing. Interviewees make various recommendations:

#### **SEED-CORN FINANCING**

Mr Bowis considers: “Government should provide seed-corn financing, but shouldn't encourage a culture of dependency. They should help patient organisations get going”.

#### **TOTAL TRANSPARENCY ON SOURCES OF FUNDING**

Ms Eaton believes: “If their money does come from pharmaceuticals companies, charities should make it absolutely clear what proportion of the funding comes from which source. This information should be put up on their website—not just in their annual report—so that it's absolutely clear where the money's coming from”. Mr Fabio adds: “In Italy, we don't have a great deal of clarity on the funding of patient groups. The status of not-for-profit, for instance, doesn't ensure that they're not spending money on hidden interests”.

#### **GROUPS NEED TO ENSURE THAT THEY ARE NOT COMMERCIALY DRIVEN**

Mr Laurance reflects: “Money comes from all the sources you have mentioned. But my biggest worry is that an increasing amount is coming from industry, that [the advocacy groups] are commercially driven”.

#### **A CLEAR, BUT LIMITED, ROLE FOR THE EU SAY SOME (BUT NOT ALL)**

Several interviewees feel that the Commission could make a range of limited interventions, such as: promoting patient rights for cross-border care; helping to fund smaller NGOs; and defining acceptable ethical and financial standards for health campaigners. An equal number of interviewees threw out the idea of any EU interference.

#### **ETHICAL FUNDING BY THE HEALTHCARE INDUSTRY**

Ms Read predicts: “There is a suggestion that companies might pay into a pot for distribution to patient organisations. This would have the disadvantage of lessening the direct input of companies into patient advocacy, where non-monetary advice and support can be invaluable”.

---

### **RESTRICTIONS ON FUNDING**

None of the interviewees argue for restrictions on funding (other than those which ensure financial probity and good governance). The official from DG Sanco, in fact, believes that it is up to the health campaigners themselves to define the restrictions: “No—I think it should be the other way round. Patient organisations should provide conditions for their funding.”

### **CHARACTERISTICS OF AN INFLUENTIAL CAMPAIGNING GROUP**

The interviewed media and policymakers outline some of the characteristics that they believe should be possessed by ideal health campaigning groups, these are (in no particular order):

- Clarity on objectives, with specific end-points in mind, and the right mix of activities.
- Evidence- and knowledge-based decision-making. Judgments reached after understanding all points of view.
- Credibility, professionalism, good governance, and financial robustness. An ability to avoid being hijacked by individuals with a particular passion. Getting the work done well.
- Representative and accessible to as broad a range of the constituency as possible—in part, by being client-oriented, by being in touch with people, and by operating with the authority of the constituency.
- Effectiveness in deploying campaigning tools—in particular, by developing a good media profile, by providing support to policymakers, by intervening in a timely fashion, and by understanding how government and politics function.

### **STATUS OR POTENCY OF HEALTH ADVOCACY**

On the whole, health campaigners are valued by the interviewed media and policymakers. But, rightly or wrongly, some groups are perceived by interviewees to be more potent and to be able to command more esteem than others. So Mr Bowis, for instance, notes: “Leprosy gets more money than epilepsy”. And Ms Sinnott declares: “Europe has a golden circle of diseases. Often, these are the more common diseases. But there are forgotten diseases, and advocates are also forgotten.”

# Policymakers and the media —comments

*“ The Netherlands has had a patient movement since the 1970s.  
Today, the movement holds a wide variety of disease-oriented organisations with solid foundations.  
The former Minister of Health, Mrs Els Borst, for instance, chairs an organisation of cancer patients.  
This shows how accepted these groups have become in the Netherlands.”*

—Geert Jan Hamilton, Director of Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport  
[Ministry of Health, Welfare and Sport], the Netherlands.

**QUESTION 1: CONTRIBUTION MADE BY PATIENT ORGANISATIONS AND OTHER HEALTH-ORIENTED NGOS**

Part 1. Do you believe that health campaigning groups supply valuable information to patients or the public in your country [or across Europe]?

POLICYMAKERS

"Yes, undoubtedly. Patients are still mystified by the medical profession, and frequently need to go over information several times before making a decision about their healthcare. Health campaigners co-mediate in the process, and doctors accept this situation."

—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"Yes. The Netherlands has had a patient movement since the 1970s. Today, the movement holds a wide variety of disease-oriented organisations with solid foundations. The former Minister of Health, Mrs Els Borst, for instance, chairs an organisation of cancer patients. This shows how accepted these groups have become in the Netherlands."

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"Yes—especially well targeted."

—Arto Koho, Finland's Permanent Representative to the European Union.

"Yes, but they vary in competence, in professionalism, and in age."

—Mel Read, former MEP, Labour, UK.

"Yes—lots of examples in the UK."

—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, 'Ask About Medicines'.

"Yes. I can answer both from my Irish and European experience. Since becoming an MEP, I have gone to as many mental health seminars as I could, to look for similarities between the situation in Ireland and Europe. I have sat in on survivor group meetings. And, also, I wrote the opinion on the Green Paper for Mental Health on behalf of the Employment and Social Affairs Committee [Editor: draft opinion published February 1st 2006]. My knowledge of health campaigners, however, includes groups that represent people with disabilities, and the chronically ill. In answer to this question, then, I do believe that health campaigners absolutely provide valuable information to patients and the public."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"Yes. A patient perspective is most important overall, and the media are always happy to hear it."

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"Yes. It is quite obvious that health campaigning groups have raised their profile over the past 15-20 years. Before then, only experts and doctors used to be the authorities on an illness."

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

"Yes. However, this is not always the case, as some grassroots organisations are financed for very specific reasons, and may not know how they are being manipulated."

—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

**QUESTION 1: CONTRIBUTION MADE BY PATIENT ORGANISATIONS AND OTHER HEALTH-ORIENTED NGOS**

Part 2. Do you believe that health campaigning groups supply valuable support to patients or the public in your country [or across Europe]?

---

POLICYMAKERS

“Yes. Information, especially.”

—John Bowis, MEP, Conservative, UK.

“Yes, but this varies group by group. Very valuable information is supplied to patients by diabetes support groups, based on information gained from their own experiences—particularly on how people with diabetes can live and manage everyday life.”

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

“Yes. The best do, the worst don't. Lack of funding and a need for greater professionalism are the main hurdles. It is more than just pointing out the dreadfulness of a disease. Health campaigners also need to be more detached, and less emotional about the issues. When it comes to campaigning on behalf of patients, they need to realise they can only have one crack at a politician. They need to come prepared and targeted. And make sure that they are talking to the right people. The task is so difficult that even full-time professional lobbyists can get things wrong.”

—Mel Read, former MEP, Labour, UK.

“Yes. Some groups lobby at top level, some at ground level. Those at the grassroots can provide a lot of support.”

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

“Yes, though as I haven't been ill for years, I don't have direct experience. It's simply that these things should be talked about—people should be made aware.”

—Oliver Berlau, Broadcast Journalist, German-Speaking Section, BBC World Service.

“Yes. By providing information through advice lines, on their websites, and in their magazines. And by being spokespeople to the media generally—for example, on health pages, or giving comments on specific issues as they come up.”

—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

“Yes. Basically, by providing psychological and peer support to patients, and information about the structure of the healthcare system, and where and how patients can find assistance.”

—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

“Yes. By providing a voice for patients—thus helping to keep them at the centre of the debate. It's easy to have a situation whereby you have groups—such as doctors—that dominate.”

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

“Yes. With the Internet, it is now much easier to get access to particular groups and the information they have to offer.”

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

“Yes, on the whole. By providing information; by being a resource; and by putting patients in touch with other patients.”

—Jeremy Laurance, Health Editor, *The Independent*, UK.

“Yes. Those who are suffering from certain illnesses can go to groups for support, and they can be put in touch with other sufferers. Groups help with more practical issues, too.”

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

**QUESTION 1: CONTRIBUTION MADE BY PATIENT ORGANISATIONS AND OTHER HEALTH-ORIENTED NGOS****Part 3. Do you believe that health campaigning groups have the ability to educate health professionals?**POLICYMAKERS

"Groups are already available for health professionals. So, it is not a problem if patient organisations are not involved in the education of health professionals."

—Representative, Health Strategy, DG Sanco.

"Yes. Medical training tries to train health professionals out of any inherent patronising or superior attitudes to patients—though usually fails. Health campaigners can mediate between patients and professionals effectively."

—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"Yes. Because patients have a unique experience of the disorder, they can play a part in deciding with the healthcare professional which care services they should have."

—John Bowis, MEP, Conservative, UK.

"Yes. But, certainly, again this depends on the types of problems. Some patient organisations focused on chronic conditions have assimilated information in a sophisticated way."

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"Yes. The groups are close to patients, and have concrete ideas about them."

—Arto Koho, Finland's Permanent Representative to the European Union.

"Yes, they do. I think there is a need for training and support from patient organisations."

—Mel Read, former MEP, Labour, UK.

"Yes, definitely. And a large number of organisations will have relationships with health professionals. For instance, I believe Diabetes UK has many health professionals as members."

—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, 'Ask About Medicines'.

"Yes. And they are going to get information that is not in the textbooks."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"I am not at all sure that health professionals would take the advice, as they believe themselves to be the experts."

—Oliver Berlau, Broadcast Journalist, German-Speaking Section, BBC World Service.

"Yes. In a way. Health professionals should, of course, have a certain knowledge of various illnesses already. But you can't expect them to be up to the minute on every single condition. Health campaigning groups can educate professionals by informing them of advances made in a particular disease—for example, by explaining how a person with that condition will feel, or what their particular concerns will be."

—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

"Yes, but there are limits to it. After all, doctors have a body of knowledge of illness, and they also get feedback from their patients (both of which help to inform)."

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"Yes. They can make health professionals aware of the psychology of patients, and help

them to understand the importance of steering family and carers through an illness."

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

"Yes. They certainly have the ability. And the evidence is that they change professional behaviour. It's a while ago, I know, but a campaign on the Esther Rantzen TV programme 'That's Life' had a significant effect on the way GPs prescribed Valium to women. Some years later, an editorial in the *British Medical Journal* traced the change directly to this campaign. Also, a search of my articles showed that when I started on *The Times* in the early 1990s, the stories on heart disease outnumbered the stories on breast cancer by two to one. Now, the proportions are reversed. This is very largely the result of breast cancer lobbying, which has moved the disease way up the medical agenda."

—Jeremy Laurance, Health Editor, *The Independent*, UK.

"Yes. They can sometimes move things beyond the textbooks into the real world. And, on occasions, they can help with medical developments, advances in technology, or the introduction of a new drug—that sort of thing."

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

"Yes and no. There is a wide range of different health campaigning groups—some of which are able to educate health professionals, others which are not. So the answer is: yes in theory, but not always in practice. I'd cite the importance of always considering the point of view of the patients as among the most valuable contributions they can offer."

—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

**QUESTION 2: ON PATIENT REPRESENTATION****Part 1. Do you believe that health campaigning groups truly represent patients or the public in policymaking?**POLICYMAKERS

"Partly, but not all patients. At the moment, an umbrella organisation is required to represent the needs of several patient organisations. This is a particular problem for policymakers—no one interlocutor."  
—Representative, Health Strategy, DG Sanco.

"Yes, to a certain extent. Health campaigners can be vociferous and more extreme in their points of view. So it is important to appreciate that the silent majority may have a different emphasis."  
—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"In general, yes. But you need to look at the different groups. Larger federations representing the interests of diverse patients groups—although more distant from patients—are able to develop more abstract thinking and consensus points of view (even if they are not representative of all patients' needs). Federations need to talk about the financing of healthcare and other matters, and filter what the mass of patients are thinking."  
—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"Yes, by raising overall awareness."  
—Arto Koho, Finland's Permanent Representative to the European Union.

"Yes—their constituency, not the public. With some provisos. To ensure proper representation, groups need to find out what patients want. But that can be hard. Most patients just say they want to get better. But you need to scratch beneath the surface, and find out more. Patient organisations thus maintain a delicate balance between leading and being lead. Lack of

money and limited resources make the difference between those that are good at representation, and those that are not very good."  
—Mel Read, former MEP, Labour, UK.

"There are two elements here. First, whether they actively represent their constituency. The answer here would be 'Yes'. The second is whether these organisations represent a fairly balanced view of both patients and the public. Here the answer is 'No', since patients are not the same as the public."  
—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, 'Ask About Medicines'.

"Yes—when they are allowed to. Unfortunately, the presence of health campaigning groups in government policymaking can be mere tokenism. And only a minority of health campaigners are genuinely able to bring in the patient perspective."  
—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"I believe that patients are truly represented. However, I am not sure about the public. If a patient group concentrates on diabetes, for example, they will focus on that percentage of the population that suffers from the illness, and represent them."  
—Oliver Berlau, Broadcast Journalist, German-Speaking Section, BBC World Service.

"Yes and no. It depends on the organisation, and what the membership criteria of the organisation are. For some groups, a large proportion of their members are carers, rather than the patients themselves. This is particularly the case with mental-disability organisations. For example, with an

organisation like Rethink [schizophrenia], often it's the carer, not the patient, who is represented."  
—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

"Yes. But they should continue to invite subscriptions from as wide a range as possible, so that they remain truly representative."  
—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"Yes. But there is always a danger that they follow their own agenda."  
—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

"No. On the basis of what I said earlier, lobbying groups are actually capable of distorting things, giving undue attention to certain diseases. For example, look at the attention given to prostate cancer compared with breast cancer—a male cancer that is directly comparable to a female one, but which doesn't by any means have the same representation."  
—Jeremy Laurance, Health Editor, *The Independent*, UK.

"No. I think they can, but this is not universally the case. There is a wide disparity among the groups, some of which may be self-appointed, and little more than talking shops."  
—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

"Yes. Again, there are some groups which can be considered representative, and some groups which are rather easily manipulated (by those organisations providing them more or less systematically with financing)."  
—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

**QUESTION 2: ON PATIENT REPRESENTATION****Part 2. Do you believe that health campaigning groups should represent patients or the public in policymaking?**POLICYMAKERS

“Yes. They have a valuable contribution to make. Although the role of health campaigners in decision- and policy-making is less clear they may have a partial perspective.”

—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

“Yes, if these groups are claiming to speak on behalf of patients. They should be able to demonstrate they are genuinely representing who they are standing for.”

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

“Yes, health campaigners have a role to play. But, because there are sub-groups within the health campaigning community—like cancer patient organisations—they are not the only important spokesperson. You would not expect a cancer patient organisation to know about the priorities of patients with other diseases.”

—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, ‘Ask About Medicines’.

“Yes. If you are calling yourself an multiple sclerosis group, then you must not falsely act as the advocate of such patients.”

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

“Yes, they should.”

—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

“Yes, absolutely. In Ireland—and probably elsewhere—there’s a lot of talk about patient-centred services, but most of the dialogue is between the government and doctors. Patients should have some stake in this.”

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

“Yes, but they should not be the only representatives. In theory, governments should do this. Health campaigning groups are able to concentrate more on the patient, whereas governments have wider concerns.”

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

“Yes. I suppose that prompts the question: if they don’t, who is going to?”

—Jeremy Laurance, Health Editor, *The Independent*, UK.

“Yes, definitely. That’s what their primary role should be.”

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

“Yes. But only provided they disclose their potential conflicts of interest—first of all, by declaring all their sources of funding.”

—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

**QUESTION 3: THE CREDIBILITY OF HEALTH CAMPAIGNING GROUPS**

Part 1. How well regarded are patient organisations and other health campaigners in your country (or across Europe)?

---

POLICYMAKERS

"Very well—mostly, prominent disease-oriented groups."  
—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"Very well—on the whole."  
—John Bowis, MEP, Conservative, UK.

"Very well in Finland. Not quite so well in Europe."  
—Arto Koho, Finland's Permanent Representative to the European Union.

"In my experience, patient organisations have integrity and mean well, but are not always well regarded in terms of their effectiveness."  
—Mel Read, former MEP, Labour, UK.

"Quite well. Increasingly, health campaigners are invited to have a role in policymaking. But, there are two caveats: are they professional enough?; and do they put forward a balanced view?"  
—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, 'Ask About Medicines'.

"Very well. I believe that patient and other health campaigning groups have gained a place. People now know that they have to be involved in any consultation process and are a vital stakeholder."  
—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"It varies from one group to another. From the point of view of the press, how groups are regarded depends on how good they are at responding to enquiries. Of course, we do understand that the smaller groups just don't have the resources to do this efficiently all of the time. An organisation like Sane is particularly good: it is run by a former journalist, Mary Wallace, so she understands how to communicate with us. But I have to say that the Patients' Association is one of the bad ones."  
—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

"Very well. The better established groups have become very professional in recent years."  
—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"Very well. This is generally my impression: health campaigners are increasingly well regarded as people feel that such groups are more immediately related to their own concerns."  
—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

"Some are much better than others. It is mixed."  
—Jeremy Laurance, Health Editor, *The Independent*, UK.

"Quite well and not very well. There's a spectrum—from being borderline, to not being as well regarded as they should be."  
—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

**QUESTION 3: THE CREDIBILITY OF HEALTH CAMPAIGNING GROUPS**

Part 2. Do you believe that the patient/health advocacy movement could become an effective force within healthcare systems?

---

POLICYMAKERS

"Yes, they should."

—Representative, Health Strategy, DG Sanco.

"Yes. Particularly in planning, the provision of services, and support for patients."

—John Bowis, MEP, Conservative, UK.

"Yes. Certainly, with regard to the latest healthcare reforms that came into force on January 1st 2006 in the Netherlands. The legislation places a strong focus on individual responsibility, and more on market forces. Thus, consumers of healthcare now have a bigger voice, and the role of patient organisations is all the greater."

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"Yes—but that is an optimistic view."

—Arto Koho, Finland's Permanent Representative to the European Union.

"Yes, they could. And it is in the interests of patients that they should become so. Patient organisations can provide valuable feedback to pharma and medical device companies."

—Mel Read, former MEP, Labour, UK.

"Yes. In the UK, they are almost there. I think what still needs to be done is that umbrella organisations such as the Long-term Medical Conditions Alliance (LMCA) need to be better funded. Patient advocates also need to be self-critical. The people they put forward as their representatives need to be effective."

—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, 'Ask About Medicines'.

MEDIA

"A few things would have to change, but, in principle, yes."

—Oliver Berlau, Broadcast Journalist, German-Speaking Section, BBC World Service.

"Yes, but they'll always have to battle for airtime with the likes of doctors, nurses, and political players."

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"Yes, I think it is becoming an active force. There are already links between government policy and different patient groups. It's happening in Argentina (my home country), too."

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

"Yes. It already is."

—Jeremy Laurance, Health Editor, *The Independent*, UK.

"Yes, absolutely. And it will. This is a definite trend."

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

**QUESTION 4: HOW HEALTH CAMPAIGNERS DECIDE WHICH CAUSES TO SUPPORT**

Part 1. The survey found that most health campaigning groups managed a delicate balancing act between two sources of information when they chose the subjects of their campaigns. A.) They responded to large-scale outside events (such as new legislation, or healthcare reforms). B.) They also responded to concerns raised by their constituency / their members. Is that your general impression, as well?

POLICYMAKERS

"Yes, definitely."

—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"No. Whether in Europe or the UK, most patient organisations decide campaigns as a reaction to outside events—especially new legislation." —John Bowis, MEP, Conservative, UK.

"I think that, on the whole, the groups respond to outside events—but I am not sure." —Peter Brosch, Head of E-Government and New Media Unit, Bundesministerium für Gesundheit und Frauen [Ministry of Health and Women], Austria.

"Yes. With regard to the legislation I mentioned in my previous answer, which has effectively transformed the structure and financing of healthcare in the Netherlands, the NPCF [Editor: De Nederlandse Patiënten Consumenten Federatie, or Federation of Patients and Consumer Organisations in the Netherlands] was involved in discussions right from the beginning. The group followed the whole process, step by step, lobbied Parliament, proposed changes to the legislation, but generally supported the reforms." —Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"Yes, but that's only a general impression. I do not have any proper background information about this."

—Arto Koho, Finland's Permanent Representative to the European Union.

"Yes, I think that is accurate. The groups react to immediate events. It is harder to stand back and take the longer view. Umbrella patient groups, such as the European Patients' Forum (EPF) and the International Alliance of Patient Organizations (IAPO) make serious efforts, but themselves have limited resources to take a longer view" —Mel Read, former MEP, Labour, UK.

"I guess the answer is 'Yes'. Groups are both proactive and reactive. An example from the UK of reactive campaigning is a group's response to the activities of the National Institute of Clinical Excellence (NICE). If NICE is looking at their condition, the campaigning group will put its efforts into lobbying NICE."

—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, 'Ask About Medicines'.

"No. I am answering for Ireland here. In Ireland, the NGO health movement grew up largely in response to personal experience. Advocates might know someone who had died of cancer, and discovered that services were not there, or had a child with a disability, or they might have a mental health problem. In most cases, the people behind the NGOs have fought for issues from the grassroots up, rather than responding to large-scale outside events."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"In general, yes."

—Oliver Berlau, Broadcast Journalist, German-Speaking Section, BBC World Service.

"I'm unsure. It's a difficult question. As a journalist, I wouldn't be aware of this. Having said that, health campaigning groups of course have to be aware that the comments they are making, and the issues they are raising, are representative of their members' views."

—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

"Yes. Patient groups are particularly good at tapping into the public mood. But they have a duty to inform patients of what is going on."

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"Yes. This is a fair comment. I would say that the term "outside events" also refers to a situation such as a new drug coming to market. For example, the Seroxat scandal, in which the drug was prescribed to children."

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

"Yes. That must be right. Such groups try to serve the interests of their constituency, but also try to anticipate [certain trends] by watching external events."

—Jeremy Laurance, Health Editor, *The Independent*, UK.

"I guess that's true, yes."

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

"As a general impression, no."

—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

**QUESTION 4: HOW HEALTH CAMPAIGNERS DECIDE WHICH CAUSES TO SUPPORT**

Part 2. Do you believe that health advocacy groups should canvass public views on healthcare issues before deciding on a campaign?

POLICYMAKERS

"Not necessarily. It depends on who they represent. If they represent AIDS patients, then they should talk to them. That is sufficient."

—Representative, Health Strategy, DG Sanco.

"Yes. Ideally the motivation for taking up a campaign should come from canvassing public or patient views on an issue. But, given that the whole energy behind a campaign frequently has emotional beginnings and is backed by people who profoundly believe in the cause, it will not always happen. Responsible campaigners should try to take broader public opinion into account at some stage."

—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"Not necessarily, as the public may not have an educated view. There might be only a small minority of patients with an understanding of a particular disease or healthcare matter."

—John Bowis, MEP, Conservative, UK.

"If indeed the intent is to speak up. They must first show that they have investigated, and listened to people concerned."

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"I am not sure. It is something that is very reasonable to ask of these groups. But their time schedules would not always allow this to happen."

—Arto Koho, Finland's Permanent Representative to the European Union.

"No, they can't do it. It is difficult and costly. But they should canvass the views of their own constituency."

—Mel Read, former MEP, Labour, UK.

"No. "I don't think that that is the nature of campaigning, really. Not the role of an advocacy group. The group advocates for its constituency, and not what the public thinks."

—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, 'Ask About Medicines'.

"Yes. I think it is essential when launching any campaign, if you are going to maximise the effectiveness of that campaign. You need to have a feeling of public prejudices, what they know, and what they don't know. You don't want to spend money on a campaign focusing on issues where people are already on your side. That's only common sense. You need not spend lots of money on expensive surveys, just need to get an idea of public opinion."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"No, Because they should represent the people in their particular group. If advocacy groups don't know where they're going, it won't be much use talking to the public. They should know exactly what their approach is before going to the public. There is so much information in the public sphere already, that the job of such groups should be to clarify: to put the information in clear and simple terms, so that everyone can understand them."

—Oliver Berlau, Broadcast Journalist, German-Speaking Section, BBC World Service.

"No, not necessarily. What's important to a health campaigning group wouldn't necessarily have the same relevance in the public domain."

—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

"Yes. Patient groups bring the public mood to the forefront of attention, but must be aware of patients' need to be kept informed."

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"Yes. Because the public is part of the whole equation. If you don't have this, there's an underlying assumption that the public doesn't have the knowledge, that they are being treated like children. The public should be represented, because it is actually happening to them. They are a useful source of information, of course, because of their direct experience."

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

**Continued from previous page****QUESTION 4: HOW HEALTH CAMPAIGNERS DECIDE WHICH CAUSES TO SUPPORT**

Part 2. Do you believe that health advocacy groups should canvass public views on healthcare issues before deciding on a campaign?

---

"No. Why do they exist, other than to represent their patients?"

—Jeremy Laurance, Health Editor, *The Independent*, UK.

"No. I think it depends on each individual case. But, in general, their role should be about bringing issues to the attention of the public. For example, if you have a multiple sclerosis group, its aim should be to promote the needs of MS sufferers, rather than screening the general public's reaction to doing it."

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

"Yes, of course. This should be the starting point of any advocacy group. The groups should consider what the public knows and wants about a specific health issue, so as to determine what should possibly be the object of a campaign. This is a pivotal role of such groups. Health campaigning groups usually represent a sub-population of patients—expressing the interests of that group. It is then necessary for them to be able to help find a balance between the specific interests of those groups, and the more general interests of the public and the healthcare system."

—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

**QUESTION 5: EFFECTIVENESS OF HEALTH CAMPAIGNERS**

Have the activities of patient organisations or other health campaigners ever changed your perspective on an important healthcare issue?

POLICYMAKERS

"No. [Editor: from a European policymaker's perspective.] patient organisations are just one type of stakeholder. We embrace other healthcare stakeholders, and are not focused especially on one interlocutor."

—Representative, Health Strategy, DG Sanco.

"Yes, in a number of ways. I have become sensitised to the issues surrounding the care and treatment of people with mental health problems and those with HIV/AIDS. I have been deeply impressed by the parents of children and young adults with mental health problems. Often, families with a member who is mentally ill have been unfairly perceived as being part of the problem. Families who care for people with dementia frequently find themselves tossed between social and healthcare systems. They need to put all the energy they can muster into negotiating the system, at the same time as caring for their loved one."

—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"Yes, frequently. For example, from mental health groups, who have identified gaps in services to patients. Also, patient organisations help explain what sort of information patients need. Patient organisations are quite different from consumer groups. Consumers are frightened about the advertising of prescription products to patients. But patients want information on their disease, what progress has been made within the clinical setting, and information on side-effects. Different attitudes exist between the general public and patients. But, in this instance, I believe patient organisations have the right approach."

—John Bowis, MEP, Conservative, UK.

"Yes, but only in the sense that the views of groups I have come across in the field of prevention (be it health, nutrition, anti-smoking, AIDS, cancer) have tended to support my own views. I am not really a person whose attitudes are likely to change, given my position (which is to organise public health campaigns)."

—Peter Brosch, Head of E-Government and New Media Unit, Bundesministeriums für Gesundheit und Frauen [Ministry of Health and Women], Austria.

"Yes, in some circumstances. One example that I think I have already mentioned is the diabetes self-help groups which have proved to me they are able to have an enormous impact. Instead of offering help from professionals, they have demonstrated their ability to empower patients, enabling patients to help themselves and each other."

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"No. But their activities have confirmed my own opinions, in many cases."

—Arto Koho, Finland's Permanent Representative to the European Union.

"No, but their activities have made me more careful to consider why I take a line. I was involved in the EU Pharmaceutical Review [Editor: concluded 2003], and the discussions about prescription drug information to patients. Parliament was opposed to the supply of such information. But patient organisations argued that they needed to get access. The groups made me see that the issue was more complex than I originally thought."

—Mel Read, former MEP, Labour, UK.

"Yes, I think they have influenced my views. Groups such as MIND have made me reconsider the role of medication in mental health. More generally, over the past five years, patient organisations have given me a greater appreciation of the importance that patients place on the quality of life, rather than taking a purely medical view. I have gradually realised that the issue for many people is more about quality of life, and less about treatment."

—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, 'Ask About Medicines'.

"Yes. As an MEP, I rely on groups like health campaigners to come forward and inform me when I am voting on this or that. I need to know how a policy I am voting on will affect people on the ground. I need to be told."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"Yes. For example, I saw something about taking more exercise to avoid heart trouble, and about certain dietary guidelines as well (like eating olive oil, instead of butter). I took that advice on board."

—Oliver Berlau, Broadcast Journalist, German-Speaking Section, BBC World Service.

"Yes. I wouldn't say that my perspective has been changed, but patient groups have certainly increased my knowledge of particular illnesses. For example, the Herceptin [breast-cancer treatment] case springs to mind. I am now certainly better informed—but that's not to say my opinion has changed."

—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

**Continued from previous page**

**QUESTION 5: EFFECTIVENESS OF HEALTH CAMPAIGNERS**—Have the activities of patient organisations or other health campaigners ever changed your perspective on an important healthcare issue?

---

“Yes. Patient groups consistently remind us of the people behind these stories—that it could be any of us in such situations, at any given point.”

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

“Yes, though I am not sure, because I am not suffering from anything myself. All my information comes from the media, and an article that I have read, say, in the paper has several different sources—which may well include a patient group. However, I reach my own conclusion, and cannot define what is the source of the information—which is, after all, an amalgamation.”

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

“Yes. The example I just gave of now writing twice as many articles on breast cancer as on heart disease supports this. But I am a cog in the wheel. They do influence my editors, and they do influence the whole agenda. Though, as I said, I do think there is a distorting effect that such organisations can have, that is a bit worrying.”

—Jeremy Laurance, Health Editor, *The Independent*, UK.

“No. They’ve informed me, certainly, but that’s not to say they’ve changed my view. My belief is that the patient always comes first. Patient organisations would not be able to change that belief—and they wouldn’t want to, anyway.”

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

“Yes. Patient organisations have been able to express the personal point of view of individuals, thus augmenting my knowledge of a medical problem (which previously has been informed only by the literature). This has sometimes changed my perspective of a condition, yes.”

—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

**QUESTION 6: INFRASTRUCTURE SUPPORT THAT GOVERNMENTS MIGHT GIVE TO HEALTH CAMPAIGNING GROUPS**

Part 1. Respondent healthcare groups across Europe said that governments offered them little or no infrastructure support. (No governments seemed to provide support across all categories reviewed in the survey.) Is that your general impression, as well?

POLICYMAKERS

"Yes—if you mean by that patient and public consultation. That is already in place at European level."  
—Representative, Health Strategy, DG Sanco.

"In the UK, governments give grants to health NGOs. But this in itself creates a dilemma, as the government then wants editorial control over the output. The Community Health Councils (CHCs), which were funded by government, had an important role to play in the UK. They were abolished and nothing adequate has been put in their place."  
—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"At least when I was in the British government, we provided helplines and other support to patient organisations."  
—John Bowis, MEP, Conservative, UK.

"Yes. But I should also say that there are more needs than just infrastructure. It is also a question of how groups manage their PR, marketing, and advertising in the first place that determined whether they get government support. Some don't manage to get public attention, and, very often, this means they do not get the government support they need."  
—Peter Brosch, Head of E-Government and New Media Unit, Bundesministeriums für Gesundheit und Frauen [Ministry of Health and Women], Austria.

"Following the growth of the patient movement in the 1970s and 1980s, and much lobbying of these organisations, the Netherlands introduced a Patients' Bill of Rights. Healthcare institutions (hospitals, rehabilitation centres, and nursing

homes) are, today, legally required to facilitate a 'Council of Clients'. These clients (which may be patients, or someone appointed by them) have a say in the running of the institution. The Netherlands also has a healthcare authority that supervises the medical institutions, to ensure that they behave appropriately, and do not abuse their monopolies. That legislation was recently amended, so that any decision made by the institution can be challenged and even brought to court by a relevant representative patient organisation." [Editor's comment: respondent groups from the Netherlands reported a greater level of government support than respondents from other European countries.]

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"I am not sure. In Finland, they may get support to put up websites for free. However, the groups do not have access to all the informational and infrastructural support provided by the Cabinet and government. Regarding strictly organised help for groups, I am unaware of any. And health campaigners have no infrastructure without money."  
—Arto Koho, Finland's Permanent Representative to the European Union.

"I agree at national level. But the Commission does provide some practical support. It has, however, a tiny budget when compared with the needs involved. No source of funding is disinterested. Groups are compromised whoever they get money from. Groups need to be professional about managing their financing, and keep a distance from their funders, in order to retain their integrity."  
—Mel Read, former MEP, Labour, UK.

"In Ireland, this is very poor, except for big established organisations. Then they may have to be polite to government."  
—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"No, this is not necessarily the case in the UK. The Department of Health does fund very specific areas of work."  
—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

"Yes, with the exception in Ireland of some victim-support groups—such as the organ-retention support group—which are supported and funded by the government."  
—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"I am not able to answer that, as I'm not even aware of the funding mechanisms in place in this country."  
—Jeremy Laurance, Health Editor, *The Independent*, UK.

"Yes, this is probably true—but is not necessarily a bad thing."  
—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

**QUESTION 6: INFRASTRUCTURE SUPPORT THAT GOVERNMENTS MIGHT GIVE TO HEALTH CAMPAIGNING GROUPS**

Part 2. Do you believe that governments should provide patient organisations and health campaigners with any of the following types of infrastructural support?

POLICYMAKERS

*Legislative support (such as patients' rights laws):* "I am unsure. Charters are already in place. I am not sure we should have legislation on patients' rights."

*Public / patient consultation procedures in policymaking:* "We already have this."

*Guidelines for ethical funding:* "Yes, but not regulation on this. We are already reflecting on this, and the thinking is ongoing."

*Independent agencies to support citizen advocacy:* "No."  
—Representative, Health Strategy, DG Sanco.

*"Independent agencies to support citizen advocacy:* "Like the CHCs. The loss of the CHC is a tragedy, an act of vandalism."  
—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

*Legislative support (such as patients' rights laws):* "No. Not necessary to be legislative."  
—John Bowis, MEP, Conservative, UK.

*Legislative support (such as patients' rights laws):* "Already does."  
—Peter Brosch, Head of E-Government and New Media Unit, Bundesministeriums für Gesundheit und Frauen [Ministry of Health and Women], Austria.

"There is no legal requirement or guidance on ethical funding, but this is a matter for discussion within the groups. If links are known to exist between patient organisations and pharmaceutical companies, then credibility problems might occur. There are no laws that dictate how

organisations should be funded. But financing contributions should really begin with members and stakeholders. Also, in the Netherlands, the government lays aside a budget of 30 million Euros a year to finance health campaigning organisations."

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"On legislation and public consultation, there are some efforts taking place, and there is always space to do it better, and move in the right direction. But efforts are not going well here. I am unsure whether there should be government guidelines for ethical funding at national level. Rather, this should be a background discussion at global level."

—Arto Koho, Finland's Permanent Representative to the European Union.

"I would prefer patient groups to be independent, and not have their agenda determined by external bodies. Government measures must facilitate patient advocacy, rather than qualify it. As to guidelines on ethical funding, individual groups such as the ECCA [European Cervical Cancer Association], of which I am president, and a number of patient organisations are unilaterally working on codes of practice and degrees of separateness."

—Mel Read, former MEP, Labour, UK.

*Public / patient consultation procedures in policymaking:* "Yes—within limits."

—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, 'Ask About Medicines'.

*Legislative support (such as patients' rights laws):* "Yes, we are headed that way. It shouldn't be necessary. But there is a need to pin down patient prerogatives in law. Lack of action has made this so. Ireland has provided poor support to persons' national circle of advocacy. There is likely to be legislation in Ireland to get government to support advocacy groups. But once supported, there is a possibility that the groups become suspect. But, at the moment, it is better than nothing."

*Guidelines for ethical funding:* "Yes, strong guidelines."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

*Legislative support (such as patients' rights laws):* "In principle, I say 'Yes'. But I would have to see the exact law. For example, I don't want governments forcing people to buy olive oil, instead of butter!"  
—Oliver Berlau, Broadcast Journalist, German-Speaking Section, BBC World Service.

*A simplified system of allowing health charities to register:* "No, because the system should be as rigorous as possible."  
—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

*Legislative support (such as patients' rights laws):* "Yes, it's happening. There are patients' rights all over the EU."

*Public / patient consultation procedures in policymaking:* "Yes, this is coming up. It's happening in the UK, Spain, and Argentina. It

**Continued from previous page****QUESTION 6: INFRASTRUCTURE SUPPORT THAT GOVERNMENTS MIGHT GIVE TO HEALTH CAMPAIGNING GROUPS**

Part 2. Do you believe that governments should provide patient organisations and health campaigners with any of the following types of infrastructural support?

---

may be not as organic or systematic as it should be, but it's happening."

*A simplified system of allowing health charities to register:* "I'm not sure that the system is all that complex. And there is a danger of over simplification, whereby anyone could get in."

*Independent agencies to support citizen advocacy:* "I would say yes, but it depends on what kind of support. If independent agencies means the regulators, they must give support, but must not get too close."

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

*A simplified system of allowing health charities to register:* "Sounds like a thoroughly good thing, although I am not aware that it is all that complex now."

—Jeremy Laurance, Health Editor, *The Independent*, UK.

*Public / patient consultation procedures in policymaking:* "Yes, they should have some role."

*A simplified system of allowing health charities to register:* "Yes, although I'm not aware that there's a particular problem with this."

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

**QUESTION 7: FUNDING OF HEALTH CAMPAIGNERS****Part 1. Where do you believe patient organisations and health advocacy groups get most of their money? [answers in order of magnitude of funding.]**POLICYMAKERS

"I don't know. It depends on the group. Some are highly funded by government, some by industry (including pharma), others via public donations."

—Representative, Health Strategy, DG Sanco.

"No idea. Probably in the UK: 1.) members and users; 2.) not-for-profit foundations; and 3.) the healthcare industry (including pharma)."

—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"Mostly industry."

—John Bowis, MEP, Conservative, UK.

"I don't know. It depends on the group. Some are 1.) highly funded by government; 2.) some by industry (including pharma); and 3.) others via public donations."

—Peter Brosch, Head of E-Government and New Media Unit, Bundesministeriums für Gesundheit und Frauen [Ministry of Health and Women], Austria.

"I don't know. There are no facts and figures, other than the 30 million Euros provided by the Netherlands government."

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"Four sources of funding (in no particular order): not-for-profit foundations; national governments; the European Commission; and the healthcare industry (including pharma)."

—Arto Koho, Finland's Permanent Representative to the European Union.

"At present, it is mainly pharma. But this needs to be improved, and the basis of funding widened. There is a suggestion that companies might pay into a pot for distribution to patient organisations. This would have the disadvantage of lessening the direct input of companies into patient advocacy, where non-monetary advice and support can be invaluable."

—Mel Read, former MEP, Labour, UK.

"In Ireland, from government and private fundraising."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

*The healthcare industry (including pharma):* "Applies to the small health advocacy groups."

*Trading outlets/conferences:* "Only applies to really big charities, such as MIND."

"In short, depends on the charity. It is my perception that the smaller ones get their funding from the pharmaceuticals industry—something I'm very concerned about. If their money does come from pharmaceuticals companies, charities should make it absolutely clear what proportion of the funding comes from which source. This information should be put up on their website—not just in their annual report—so that it's absolutely clear where the money's coming from."

—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

"1.) The healthcare industry (including pharma); 2.) the public; 3.) members and users; and 4.) the European Commission."

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"Four sources of funding (in no particular order): members and users; the public; not-for-profit foundations; and the healthcare industry (including pharma)."

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

"Money comes from all the sources you have mentioned. But my biggest worry is that an increasing amount is coming from industry, that [the advocacy groups] are commercially driven."

—Jeremy Laurance, Health Editor, *The Independent*, UK.

"1.) Members and users; 2.) the healthcare industry (including pharma); and 3.) the public."

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

"This is a very general question, and there are many differences between patient groups. Some have a huge membership, and must respond to their membership. Some seem to be more the result of the work of a single specialist who looks for more attention towards the illness he specialises in. Still others have sprung up thanks to industry funding. In Italy, we don't have a great deal of clarity on the funding of patient groups. The status of not-for-profit, for instance, doesn't ensure that they're not spending money on hidden interests."

—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

**QUESTION 7: FUNDING OF HEALTH CAMPAIGNERS**

Part 3. Do you believe that national governments should be responsible for funding their own country's health advocacy groups?

---

POLICYMAKERS

"Yes, certainly. The Commission has a role to promote certain activities of patient and consumer organisations. But there is a need to link those activities with those of the EU, versus that of national governments. But I feel there is a case. Cross-border healthcare plays an increasing part of overall healthcare. The EU should maintain an eye on matters such as patients' rights."

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"Yes—to some extent, but not totally."

—Arto Koho, Finland's Permanent Representative to the European Union.

"I'm not totally sure. The Commission should provide some money, but not all."

—Mel Read, former MEP, Labour, UK.

"Yes, the Commission should share in the process. In 2005, I did support an amendment of DG Employment and Social Affairs that smaller NGOs should gain support, rather than just a few NGOs."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"I'm unsure. I don't know enough about it, but some amount would be appropriate. However, the EC should not be the sole financier."

—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

"I'm unsure. I'm not certain it should be a responsibility, per se. However, getting funding from the European Commission is preferable to obtaining it from national governments."

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"I'm unsure. I think this should preferably be the responsibility of national governments."

—Jeremy Laurance, Health Editor, *The Independent*, UK.

"No, absolutely not."

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

"Yes. Of course, this would allow a general growth of the sector within uniform rules and borders."

—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

**QUESTION 7: FUNDING OF HEALTH CAMPAIGNERS**

**Part 2. Do you believe that the funding of European groups should be one of the responsibilities of the European Commission?**

---

POLICYMAKERS

"Yes, up to a point. Government should provide seed-corn financing, but shouldn't encourage a culture of dependency. They should help patient organisations get going."  
—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"Yes. Austria already has a scheme known as the 'Fund for Healthy Austria', with a budget of 7.5 million Euros. The money largely goes toward health promotion, and prevention activities undertaken by health-oriented NGOs (large and small) throughout the country."  
—Peter Brosch, Head of E-Government and New Media Unit, Bundesministeriums für Gesundheit und Frauen [Ministry of Health and Women], Austria.

"Yes, to some extent."  
—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"As with the last question—yes, to some extent, but not totally."  
—Arto Koho, Finland's Permanent Representative to the European Union.

"Again, I'm not totally sure. National government should provide some money, but not all."  
—Mel Read, former MEP, Labour, UK.

"Yes, when they relate to national issues, such as diabetes groups delivering treatment, or maybe even prevention. But the EU has a role in intergovernmental issues: cross-border research, database, and developing minimum standards of best practice."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"Not entirely, no, as this would be quite a dangerous model."  
—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

"No, because patients need to be able to criticise government and governmental services without any fear of doing so."  
—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"I am unsure. There is a risk here of budgetary problems (as well as bureaucratic ones), and I wouldn't want to add another layer of problems for governments or the EC. Also, they shouldn't be wholly responsible. There is always a limited amount of money, which is why I'm dubious."  
—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

"Yes, Because they reflect local needs and issues [in a way that the EC does not]."

—Jeremy Laurance, Health Editor, *The Independent*, UK.

"No, absolutely not."  
—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

"Yes. There should be clear rules concerning the way they shape their policies, both from an ethical and financial point of view."  
—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

**QUESTION 7: FUNDING OF HEALTH CAMPAIGNERS**

**Part 4. Do you believe that the healthcare industry (including pharmaceutical companies) should be responsible for funding health advocacy groups?**

---

POLICYMAKERS

"No—should not be the main responsibility of the healthcare industry."

—Representative, Health Strategy, DG Sanco.

"Pharma can contribute. But this should be done in an ethical way."

—John Bowis, MEP, Conservative, UK.

"I am unsure. This is a personal view. I know pharma does fund patient organisations. But, sometimes, I am not sure what interests are at stake, or whether they are purely marketing activities of the companies concerned. If groups can find money elsewhere, it would be better."

—Peter Brosch, Head of E-Government and New Media Unit, Bundesministeriums für Gesundheit und Frauen [Ministry of Health and Women], Austria.

"I am unsure. This is a delicate matter. If it happens, then the transactions need to be fully open and transparent. It is important that patient organisations are not rewarded by industry for taking certain positions, as these groups make themselves vulnerable if they accept funds on this basis. In addition, patient organisations should not permit pharma to interfere with an accurate portrayal of any research or facts which has been funded by industry and then obtained by patient organisations."

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"Again—yes, to some extent, but not totally."

—Arto Koho, Finland's Permanent Representative to the European Union.

"Similarly, the healthcare industry should also provide some money, but not all."

—Mel Read, former MEP, Labour, UK.

"Interesting, but no—I do not think it is the health industry's responsibility."

—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, 'Ask About Medicines'.

"I am unsure. When groups get pharma funding, it can be hard to retain independence."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

world, and I realise that this is not ideal for the patient groups."

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

"Yes. If it wasn't for their funding, patient groups wouldn't be able to operate. But this is part of the concern about the distorting effect of such groups."

—Jeremy Laurance, Health Editor, *The Independent*, UK.

"No. They should not be responsible as such—but there is no problem with them doing it."

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

MEDIA

"No. Again, they shouldn't be held responsible—although, having said that, they should be funding health advocacy groups off their own bat."

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"No. This is a bit risky. The involvement of pharmaceutical companies would be unhealthy, encouraging the self-promotion of pharmaceutical products. There should be a flow of information between patient groups and the healthcare industry, rather than a flow of money. However, it is important to add that this is an ideal

**QUESTION 8: CONDITIONS THAT SOME FUNDERS PLACE ON THEIR DONATIONS**

When funds are provided to patient organisations or other health advocates, do you think that payments should carry any conditions or restrictions?

POLICYMAKERS

"No—I think it should be the other way round. Patient organisations should provide conditions for their funding."

—Representative, Health Strategy, DG Sanco.

"No. No conditions other than governance and probity. If it is pharma or government, it is unacceptable that the sponsor should have editorial control over how the money is used."

—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"Yes. Groups should be accountable. But the money should not have strings attached. Nor should groups be obliged to endorse government, a company—or, worse—a product."

—John Bowis, MEP, Conservative, UK.

"Yes. If groups are in receipt of public money, they need to document what they have done. And they need to prove that the money was used for the purpose intended."

—Peter Brosch, Head of E-Government and New Media Unit, Bundesministerium für Gesundheit und Frauen [Ministry of Health and Women], Austria.

"Yes. Certainly there should be restrictions. There are regarding government funding of groups in the Netherlands, which have been imposed during the last few years. Before, the government would subsidise a group simply because they existed. Now, the government invests in the group's activities. There should be financial accountability, and the money

received should be spent on the purpose for which it was intended."

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"Yes. In most cases the condition should be a pre-requisite for funding in the first place. Today, the Finnish Ministry of Social Affairs and Health cannot give money away if the recipient does not meet certain legal and technical pre-requisites."

—Arto Koho, Finland's Permanent Representative to the European Union.

"Yes, though it depends on what these restrictions are. Nobody will just hand over money. The nature of the relationship should be negotiated at the outset. Funders should make clear what the money is for. Often, funders prefer the money to go to projects. But organisations need core funding to gain stability and coherence."

—Mel Read, former MEP, Labour, UK.

"Depends. There should be a mix of unrestricted funds for financing core activities, and restricted funds for projects in which there are shared interests."

—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, 'Ask About Medicines'.

"No. The groups should not be financed at all if they are not above board. The groups should be screened before money is given."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"Yes. There should, of course, be a certain accountability—such as a group being able to show exactly what it intends to spend the money on, and showing that this has been achieved."

—Oliver Berlau, Broadcast Journalist, German-Speaking Section, BBC World Service.

"No. But I'm sure they do! The big pharmaceuticals companies, that is. There are, on the whole, too many restrictions."

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"Yes. The main condition that springs to mind is that the money is allocated to the thing it was given for."

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

"No. Ideally not, though I can see it would be difficult—people always want to get something back. Just look at loans for peerages, after all."

—Jeremy Laurance, Health Editor, *The Independent*, UK.

"No. Unequivocally, they shouldn't."

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

**QUESTION 9: CHARACTERISTICS OF AN INFLUENTIAL CAMPAIGNING GROUP**

What do you believe are the three main characteristics of an influential patient organisation/ health advocacy group?

POLICYMAKERS

"1.) Above all, the group should be credible (that means transparent and clear about its financing, etc); 2.) the group should represent as many countries as possible across Europe; and 3.) it should lobby (for example, talk to people, arrange events, etc)."  
—Representative, Health Strategy, DG Sanco.

"1.) The group should have evidence-based decision making; 2.) governance should be such that the group cannot be hijacked by individuals with a particular passion; and 3.) it should be accessible to a broad section of patients who suffer from the condition in which the group is interested."  
—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"1.) The group should be clear on its objectives; 2.) the group should be close to policymakers in a supportive way; and 3.) it should be honest about other points of view, so that it finds it easier to make a judgment on what others are saying."  
—John Bowis, MEP, Conservative, UK.

"1.) The group should be able to raise public awareness; 2.) the group should act in a professional manner; and 3.) it should have the right mix of activities."  
—Peter Brosch, Head of E-Government and New Media Unit, Bundesministerium für Gesundheit und Frauen [Ministry of Health and Women], Austria.

"1.) The group should be knowledge-based (they should know what they are speaking about); 2.) the group should be representative; and 3.) it should have clarity of views."  
—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"1.) The group should have well-ordered aims and objectives; 2.) the group should be client oriented; and 3.) the group should be effective—it can be a small or large organisation, but it must get its work done well."  
—Arto Koho, Finland's Permanent Representative to the European Union.

"1.) The group should have professionalism; 2.) the group should be capable of timely intervention; and 3.) the group should be effective and timely in its consultation—in other words, it should have the authority of its constituency."  
—Mel Read, former MEP, Labour, UK.

"1.) The group should be an effective organisation, and be professional; 2.) the group should have passion; and 3.) it should also have political savvy."  
—Joanne Shaw, Vice-Chair, NHS Direct, and Chairman, 'Ask About Medicines'.

"1.) The group should be in touch with the people; 2.) the group should stay on the message (remain

focused); and 3.) it should be completely independent—that is, if research is undertaken, the approach should be devoted to getting the truth, and not be influenced by whoever produces the funds."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"1.) The group should possess knowledge and experience in its speciality area; 2.) the group should be sure that its mission is broadly in line with the needs of its constituency; and 3.) it should be good at getting end results (for instance, attaining goals, and changing healthcare systems)."  
—Oliver Berlau, Broadcast Journalist, German-Speaking Section, BBC World Service.

"1.) The group should possess knowledge and experience in its speciality area; 2.) the group should be effective at deploying campaign tools (such as lobbying, marketing, networking, public relations, approaching the media, etc); and 3.) it should be good at getting end results (for instance, attaining goals, and changing healthcare systems) —this latter may sound obvious, but they don't always manage it. Being financially robust is not so important, as most groups limp from one financial crisis to another, but still survive."  
—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

**Continued from previous page**

**QUESTION 9: CHARACTERISTICS OF AN INFLUENTIAL CAMPAIGNING GROUP**—What do you believe are the three main characteristics of an influential patient organisation/ health advocacy group?

---

“1.) The group must always be in touch with the public mood; 2.) the group must be an authority in its subject area, and up to speed with the latest statistics; and 3.) it must have a good knowledge of how the government and politics work.”

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

“All the following points are the main characteristics: the group should possess knowledge and experience in its speciality area; the group should be effective at deploying campaign tools; the group should be good at getting end results; and the group should be financially robust.”

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

“All the characteristics that you list are important. But a group’s media profile—how much politicians know about them, that sort of thing—is most important (as an initial measure, anyway).”

—Jeremy Laurance, Health Editor, *The Independent*, UK.

“That the group is good at getting end results is the most important characteristic of all.”

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

“1.) The group should possess knowledge and experience in its speciality area; 2.) the group should be sure that its mission is broadly in line with the needs of its constituency; and 3.) it should be good at getting end results (for instance, attaining goals, and changing healthcare systems).”

—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

**QUESTION 10: THE STATUS OR POTENCY OF HEALTH ADVOCACY—HOW WEAK OR STRONG**

Almost half of the respondent groups from **western Europe** said that the status or potency of health advocacy depends upon the group's particular disease area. Is that your general impression, as well?

POLICYMAKERS

"Yes—when it comes to financing and money. Rare disease groups have more difficulty getting money. It depends on what you want. If policymakers are going to discuss nutrition, you do not go to AIDS patient organisations."

—Representative, Health Strategy, DG Sanco.

"Yes. Cancer groups are particularly prominent; incontinence groups, less so."

—Baroness Virginia Bottomley, former Secretary of State for Health, and Director, IRG, UK.

"Yes. That's why leprosy gets far more public donations than epilepsy."

—John Bowis, MEP, Conservative, UK.

"Yes, that is true. Although the NPCF [Editor: De Nederlandse Patiënten Consumenten Federatie, or Federation of Patients and Consumer Organisations in the Netherlands] has high status and potency, but deals at higher levels of abstraction, in more politically-sensitive areas, and can talk about any subject, no matter what disease—whether the topic is "informed consent", "data protection" or "patients' rights". The federation has been going for 30 years. At the beginning, the NPCF had a lot to deal with. There was also a lot of complaining. But the NPCF has entered into a period of maturity, and knows its own political strength. It is trying to make contributions, and is appreciated for that."

—Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport [Ministry of Health, Welfare and Sport], the Netherlands.

"Yes, maybe. But that is not the total picture. More general organisations cover many areas, and can get involved in policymaking. The EFA [European Federation of Allergy and Airway Diseases Patients Organisation] is one such organisation."

—Arto Koho, Finland's Permanent Representative to the European Union.

"It's a little more complex. Several factors determine status and potency: 1.) The group should have a long tradition; 2.) the group should be well-funded and staffed by professionals; and 3.) it should have a clear agenda."

—Mel Read, former MEP, Labour, UK.

"Yes. Europe has a golden circle of diseases. Often, these are the more common diseases. But there are forgotten diseases, and advocates are also forgotten."

—Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs, European Commission.

MEDIA

"Unfortunately, yes, because some health problems get more publicity than others—often unfairly so. This occurs either due to the media, the government, a particular campaign focus, or a special case that catches the eye of the public—to the detriment of other health-campaigning groups."

—Oliver Berlau, Broadcast Journalist, German-Speaking Section, BBC World Service.

"Yes. It is true to say that it doesn't necessarily depend on how widespread a disease is. For

example, a small specific group like that for testicular cancer is very effective, whereas so many people suffer from heart disease, but campaigning has not been effective."

—Lynne Eaton, freelance journalist, *British Medical Journal*, UK.

"Yes. For two reasons. Firstly, volume. It is obviously easier to advocate for cancer than psoriasis, say. The sheer numbers of sufferers affect the efficacy of a group. Secondly, openness. There is an advantage to having a greater degree of openness in discussion of a particular disease. For example, openness is harder to achieve with a problem such as mental illness."

—Gary Finnegan, Editor, *Irish Medical Times*, Ireland.

"Yes. There are certain illnesses that affect many more people than others. And because governments are highly concerned about the costs entailed in treating a prevalent disease, patient groups get a much more immediate response from the press, and so on. There is, of course, more competition among the groups supporting such illnesses. The groups campaigning for the minority illnesses must get overlooked in the process."

—Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service.

"Yes, it's undoubtedly true. However, it's now just the lobbying groups that contribute: the breast cancer response, for example, was also partly due to a national obsession with women's breasts."

—Jeremy Laurance, Health Editor, *The Independent*, UK.

"Yes. Because their effectiveness depends either on how widespread a disease is, or how heart-tugging it

**Continued from previous page****QUESTION 10: THE STATUS OR POTENCY OF HEALTH ADVOCACY—HOW WEAK OR STRONG**

Almost half of the respondent groups from *western Europe* said that the status or potency of health advocacy depends upon the group's particular disease area. Is that your general impression, as well?

---

is. That is not to say that the prevalence of an illness guarantees the efficacy of a campaign. So a pressure group for the common cold won't get far, but one for the mothers of two-year-olds with cancer certainly will."

—Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe.

"Yes. A lot depends on the prevalence of the disease. It is easier to raise money when you have a large number of people with a certain condition, and for chronic illnesses (such as diabetes and cardiovascular disease). Where there are commercial interests, there is big funding. And that funding has a great role in giving potency to the patient groups in getting spending on a particular area."

—Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico Pediatria*, Italy.

## LIST OF INDIVIDUALS interviewed for this report

[Includes each individual's own assessment of their approximate familiarity with the topic of health campaigning groups]

### POLICYMAKERS

Representative, Health Strategy, DG Sanco [Belgium]  
[Good knowledge of health campaigning groups]

Virginia Bottomley, former Secretary of State for Health, and Director, IRG [UK]  
[Very good knowledge of health campaigning groups]

John Bowis, MEP, Conservative [UK]  
[Very good knowledge of health campaigning groups]

Peter Brosch, Head of E-Government and New Media Unit, Bundesministeriums für Gesundheit und Frauen  
[Ministry of Health and Women] [Austria]  
[Very good knowledge of health campaigning groups]

Geert Jan Hamilton, Director, Legislation and Legal Affairs, Ministerie van Volksgezondheid, Welzijn en Sport  
[Ministry of Health, Welfare and Sport] [the Netherlands]  
[Good knowledge of health campaigning groups]

Arto Koho, Finland's Permanent Representative to the European Union  
[Good knowledge of health campaigning groups]

Mel Read, former MEP, Labour [UK]  
[Very good knowledge of health campaigning groups]

Joanne Shaw, Vice-Chair, NHS Direct and Chairman, 'Ask About Medicines' [UK]  
[Good knowledge of health campaigning groups]

Kathy Sinnott, MEP, Independent, Ireland, and Member, Committee on Employment and Social Affairs,  
European Commission  
[Very good knowledge of health campaigning groups]

### MEDIA REPRESENTATIVES

Oliver Berlau, Broadcast Journalist, German-Speaking Section, BBC World Service  
[Good knowledge of health campaigning groups]

Lynne Eaton, freelance journalist, *British Medical Journal* [UK]  
[Good knowledge of health campaigning groups]

Gary Finnegan, Editor, *Irish Medical Times* [Ireland]  
[Very good knowledge of health campaigning groups]

Marcello Justo, Producer, Spanish-Speaking Section, BBC World Service  
[Very good knowledge of health campaigning groups]

Jeremy Laurance, Health Editor, *The Independent* [UK]  
[Very good knowledge of health campaigning groups]

Stephen Pollard, Senior Fellow and Director, health policy programme, Centre for the New Europe [Belgium]  
[Very good knowledge of health campaigning groups]

Fabio Turone, Medical Journalist, Agenzia Zoe di Informazione Medica e Scientifica, and Editor-in-Chief, *Occhio Clinico  
Pediatrica* [Italy]  
[Not a very good knowledge of health campaigning groups]

# **HEALTH EQUALITY EUROPE**

HEALTH EQUALITY EUROPE  
IS A NEW ALLIANCE OF PROMINENT  
HEALTHCARE STAKEHOLDERS.  
ITS MISSION IS TO PROMOTE  
GREATER HEALTH EQUALITY

INDIVIDUALS JOINING THE ALLIANCE  
ACT IN A PERSONAL CAPACITY.  
A FULL LIST OF ALLIANCE MEMBERS IS TO BE  
FOUND IN THE APPENDIX TO THIS REPORT

*Health Equality Europe is supported by  
an educational grant from Novartis*

*April 2006*