

Von: "From PatientView " <info@patient-view.com>

Datum: 16. Februar 2006 16:25:56 MEZ

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Betreff: Health Equality Europe and Sir Ken Collins invite you to participate in a study

Dear health campaigner,

Health Equality Europe, a newly-launched alliance of prominent healthcare stakeholders [see

To thank you for participating in this study, PatientView, the survey manager, will send you a PDF of the headline findings in May 2006, and a complimentary one-year membership of Health and Social Campaigners' Network International (allowing you to receive monthly issues of HSCNews International).

I strongly urge you to participate in the study, which should take only about ten minutes of your time to complete. The closing date is Wednesday, March 15th 2006.

How you can reply to this survey:

u Hitting the forward key in your email messaging, putting a cross in the appropriate boxes throughout the questionnaire, and clicking on your email's 'Send'.

u Posting your completed survey to the survey manager: 'Health Equality Europe Survey', PatientView, Woodhouse Place, Upper Woodhouse, Knighton, Powys, LD7 1NG, Wales.

u Or by faxing your completed survey to the survey manager: 00-44-(0)1547-528-501.

Yours faithfully,

Sir Ken Collins
Chair
Health Equality Europe

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Health Equality Europe is a new alliance of prominent healthcare stakeholders. Its mission is to promote greater health equality. As of February 2006, the following individuals had joined the alliance in a personal capacity:
Sir George Alberti, National Director for Emergency Access, UK National Health Service (NH
New Europe; Simona Sapier, Active Citizenship Network; Mike Sobanja, NHS Alliance;
Erica Terpstra, President, the Netherlands National Olympic Committee; Yvonne
Wengström, European Oncology Nurses' Society (EONS).

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

Health advocacy in 2006 and beyond

SURVEY OBJECTIVE:

“To identify the challenges faced by the patient and health advocacy movement today, and assess what interventions must take place to maximise the movement’s influence.”

The Questionnaire

ACTIVITIES AND SERVICES

Question 1/12: In which of the following activities and/or services does your group make a significant and noticeable contribution in your country? [Please specify no more than three answers]

- Providing high-quality information to patients/the public.
- Supplying patients/the public with the facility to network with each other.
- Providing patient/public support (counselling, advice, etc).
- Managing patients’ complaints and concerns about the healthcare system.
- Promoting social inclusion and/or campaigning against discrimination.
- Campaigning for the rights of patients within healthcare systems.
- Raising awareness of important healthcare issues.
- Representing the views of patients/the public to set the national healthcare agenda.
- Educating health professionals about patients’ perspectives.
- Monitoring the quality of healthcare providers.
- Improving access to healthcare and/or treatment.
- Providing healthcare (primary, secondary and/or community care).
- Contributing to clinical guidelines.
- Raising funds for research, or conducting research (clinical or other).

Please supply case examples, if you wish:

...

Question 2/12: If your group possessed the appropriate financial and staffing resources, would it like to get involved in any new activities and/or services? [You may specify more than one answer if you wish]

- Providing high-quality information to patients/the public.
- Supplying patients/the public with the facility to network with each other.
- Providing patient/public support (counselling, advice, etc).
- Managing patients’ complaints and concerns about the healthcare system.
- Promoting social inclusion and/or campaigning against discrimination.
- Campaigning for the rights of patients within healthcare systems.
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- Contributing to clinical guidelines.
- Raising funds for research, or conducting research (clinical or other).

None of the above.

Other/comments?:.....

IMAGE AND STANDING

Question 3/12: Which of the following categories of people values your group, and takes its views seriously? [You may specify more than one answer if you wish]

- The people who know about are members or users of your group.
- Your country's politicians.
- Your country's media.
- Healthcare professionals.
- The general public.

Other/comments?:.....

YOUR METHODOLOGIES

Question 4/12: How does your organisation decide which policies and campaign strategies to adopt? [You may specify more than one answer if you wish]

- From concerns raised by users.
- Following the canvassing of grassroots opinion.
- When our members call for a policy.
- By identifying patient/public need from medical, media and other literature.
- When we are approached by other healthcare stakeholders.
- When there is a need to respond to proposed legislation or other external events.

Other/comments?:.....

Question 5/12: Having decided on a campaign, what tools does your organisation typically use to promote the campaign? [You may specify more than one answer if you wish]

- Running high-profile events to highlight the cause.
- Launching a website/s about the campaign.
- Engaging the public through leafleting, petitions and other means.
- Forming coalitions with like-minded organisations.
- Getting stories in the media.
- Lobbying politicians.
- Lobbying other healthcare stakeholders.
- Arranging non-violent protests.
- Marketing and advertising.
- Conducting extensive research investigations to back up the case.
- Taking the issue to court.
- I don't know.

Other/comments?:.....

GOVERNMENT SUPPORT

Question 6/12: Does your national government provide any of the following types of infrastructural support to groups like your own? [You may specify more than one answer if you wish]

- A legal system that views advocacy as a basic constitutional right (including the right to campaign at a political level).
- User-friendly procedures for gaining legal status as a health charity.
- A national independent agency to support citizen advocacy.
- Consultation mechanisms to enable patient/public input into government policymaking.
- Established guidelines to ensure independence and probity in fund-raising.

FUNDING

Question 7/12: Do any of the following form the major sources of your group's funding? [You may specify more than one answer if you wish]

- The European Commission.
- National government (including tax incentives).
- Healthcare companies.

Other/comments?:.....

Question 8/12: As part of its financial relationship with your group, does your main funder (if relevant) expect any of the following? [You may specify more than one answer if you wish]

- Transparency about the financial relationship.
- That your group possesses a conflict-of-interest statement.
- That the results of any project financed are placed in the public domain.
- Restrictions on how the money is spent.
- Regular financial statements detailing how the money is spent.
- That your group attains certain milestones before more money is released.
- Involvement more widely in your group's activities.
- Involvement in only that activity which was funded with their money.
- Your organisation's endorsement of the funder and/or its products.
- The right to use your organisation's name in its own marketing activities.
- None of the above—the money from our group's main funder carries no restrictions.

Comments?:.....

BARRIERS TO SUCCESS

Question 9/12: What do you think are the three biggest challenges facing your group? [Please specify only three answers]

- Developing sustainable income.
- Recruiting and keeping able salaried staff.
- Recruiting and keeping able volunteers.
- Capacity building.
- Lack of time.
- Instituting good governance.
- Overcoming public apathy.
- Keeping members motivated.
- Building up good business skills.
- Circumventing infighting among peer advocacy groups.
- Raising the group's profile.
- Educating health professionals about the group's objectives.
- Being recognised by other healthcare stakeholder communities.

Other/comments?:.....

Question 10/12: If the resources were available, which of the following would be your group's priorities for investment? [You may specify more than one answer if you wish]

- Human resources.
- Information technology.
- Fundraising.
- Public relations.
- Marketing and advertising.
- Financial management.
- Time management.
- Business planning.
- Capacity building.
- Writing applications for grants.
- How to get on government policymaking agendas.
- Lobbying.
- Networking with other healthcare stakeholders.

Other/comments?:.....

CHARACTERISTICS OF SUCCESS IN PATIENT ADVOCACY

Question 11/12: What do you think are the three main characteristics of influential health campaigning groups (whether local, national or pan-European)? [Please specify only three answers]

1.
2.
3.

Question 12/12: How would you describe the status of health campaigning groups in your country? [Please specify no more than one category]

- Infancy.

- Growing.
- Mature, though not very effective.
- Mature and effective.
- It varies according to disease area.

Other/comments?:.....

LASTLY, SOME PROFILING QUESTIONS

a.) Whose views are you expressing in this survey?

- Personal.
- My organisation.

b.) What is your own position in the organisation?

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c.) What are the geographic areas of interest for your group?

- Local.
- National.
- International.

d.) What area of expertise does your group specialise in?

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e.) Which of the following broad categories does your group's annual income fall into?

- Below 50,000 Euros.
- Between 50,000 and 499,000 Euros.
- Between 500,000 and 1 million Euros.
- Above 1 million Euros.

Would you be happy if Health Equality Europe or PatientView ask for your involvement again in any follow-up studies on the subject of the future of health advocacy?

- Yes.
- No (except to be sent the results of this study).

Do you wish your responses to ...

- Remain anonymous.
- Or be attributed to your organisation in the report (which will be sent to all respondents and will be available in the public domain).

[Please confirm the name of your organisation]:

Thank you for your time. That concludes the survey.

You will be sent the aggregated results of this study
(due to be published in the form of a short report around May 2006)

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