

# **HSCNews INTERNATIONAL**

**THE VIEWS OF HEALTH AND SOCIAL CAMPAIGNERS WORLDWIDE**

Maternity Ward 2  
Maxillofacial G  
Monnow Ward G  
Neurophysiology 2  
Orthopaedic Unit G  
Oxford Suite G  
Pathology G  
Pharmacy 1



## **HEALTH CAMPAIGNERS ON INFORMATION AND COMMUNICATION**

*Plus*

Members' News, Campaigns, Research and Websites on the same theme

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# CONTACT DETAILS

## PATIENTVIEW

HEALTH AND SOCIAL CAMPAIGNERS' NETWORK INTERNATIONAL

*Health and Social Campaigners News International*

### Contact details for PatientView

Woodhouse Place

Upper Woodhouse

Knighton

Powys, LD7 1NG

Wales

Tel: +44-(0)1547-520-965

Fax: +44-(0)1547-528-501

email: [info@patient-view.com](mailto:info@patient-view.com)

Internet: <http://www.patient-view.com>

### COVER ILLUSTRATION

With thanks to Henry Nead, aged 10

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HEALTH AND SOCIAL CAMPAIGNERS'  
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# Information for patients and the public—a global survey of health campaigners

SURVEYS CONDUCTED DURING THE PAST FEW YEARS HAVE CONSISTENTLY SHOWN THAT PATIENTS AND THE PUBLIC BELIEVE THEY DO NOT HAVE ENOUGH HIGH-QUALITY HEALTHCARE INFORMATION (INCLUDING INFORMATION ON PRESCRIPTION MEDICINES). WHAT SUCH RESEARCH HAS BEEN LESS EFFECTIVE AT DEMONSTRATING IS PRECISELY WHICH INFORMATION IS NEEDED, HOW THE INFORMATION SHOULD BEST BE DELIVERED, WHAT DETERMINES WHETHER INFORMATION IS TRUSTWORTHY, OR WHO SHOULD BE PROVIDING THE INFORMATION.

TO EXPLORE HEALTH CAMPAIGNERS' LATEST OPINIONS ON THESE SUBJECTS, *HEALTH AND SOCIAL CAMPAIGNERS' NEWS INTERNATIONAL* CONDUCTED A GLOBAL SURVEY DURING SUMMER 2006. THE RESULTS ARE PUBLISHED IN THIS ISSUE. THE SURVEY ALSO EXAMINED CAMPAIGNERS' FEELINGS ABOUT A SUBJECT OF CONTINUED CONTENTION—PHARMACEUTICAL COMPANIES SUPPLYING HEALTHCARE INFORMATION TO THE PUBLIC. HAVE ATTITUDES HARDENED OVER THE LAST FEW YEARS, RELAXED, OR STAYED ABOUT THE SAME?

THE FINAL PAGES OF *HSCNEWS* ISSUE 31 CONTAIN DETAILS ABOUT WEBSITES, CAMPAIGNS, AND RESEARCH, AND REPORTS FROM HSCNETWORK MEMBERS (ALL ON THE THEME OF HEALTHCARE INFORMATION).

OUR THANKS GO TO THE PATIENT INFORMATION FORUM (PIF) FOR HELPING WITH THE UK ARM OF THIS GLOBAL SURVEY. [[HTTP://WWW.PIFONLINE.ORG.UK](http://www.pifonline.org.uk)]

# Key findings

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## **WHAT THE MAJORITY OF PATIENTS' REPRESENTATIVES THINK ABOUT HEALTHCARE INFORMATION**

~ PATIENTS AND THE PUBLIC REQUIRE MORE AND BETTER HEALTHCARE INFORMATION THAT SUITS THEIR PERSONAL NEEDS. TO BE MADE AVAILABLE THROUGH NUMEROUS CHANNELS. WORKSHOPS FOR THE PUBLIC ARE A PREFERRED NEW COMMUNICATION VEHICLE.

~ THE MOST TRUSTWORTHY HEALTHCARE INFORMATION IS SIMPLE, WELL-SUMMARISED, EASY TO DIGEST, TOTALLY TRANSPARENT (WITH SOURCES AND VESTED INTERESTS MADE KNOWN), AND UNDERPINNED BY EVIDENCE-BASED MEDICINE. DOCTORS ARE THE BEST PEOPLE TO ENDORSE INFORMATION.

~ OUTSIDE THE CLINICAL SETTING, PHARMACISTS ARE HIGHLY FAVOURED BY PATIENTS AND THE PUBLIC AS SOURCES OF HEALTHCARE INFORMATION.

~ PHARMACEUTICAL COMPANIES COMPRISE A LEGITIMATE SOURCE OF HEALTHCARE INFORMATION TO PATIENTS AND THE PUBLIC UNDER CERTAIN CIRCUMSTANCES (FOR INSTANCE, IF THE INFORMATION IS ACCREDITED). BUT CAREFUL MONITORING OF INDUSTRY'S INFORMATIONAL RELATIONSHIPS WITH PATIENTS AND THE PUBLIC (BEYOND PHARMA'S SELF-REGULATORY PROCEDURES) ARE NEEDED.

~ HEALTHCARE INFORMATION SHOULD, ABOVE ALL ELSE, ALLOW PATIENTS AND THE PUBLIC TO MAKE INFORMED DECISIONS ABOUT THEIR HEALTHCARE AND TREATMENT.

# Summary of findings

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This survey found that most health campaigners expect healthcare information for patients or the public to have one overriding aim: to enable individuals to make informed decisions about their healthcare and treatment. Campaigners are enthusiastic about informed decision-making because they believe it will promote public understanding of the limitations of healthcare systems, encourage self-determinism and preventive care, elevate public awareness of care pathways and the choices available within the system, enable patients to contribute to the education of doctors, and convince people of their social responsibilities. The survey discovered that campaigners' other ambitions for healthcare information include increasing patient/public satisfaction with healthcare; enhancing doctor-patient relationships; and encouraging sensible use of products and services. [Question 1, pages 14-15.]

The majority of senior executives of respondent health campaigning organisations, however, indicate that they are dissatisfied with the current standards of, and level of access to, publicly-available healthcare information. Nearly 70% of the 25 mental health groups taking part in this survey, for instance, state as much. Campaigners identify a number of major shortcomings in the present state of healthcare information, including: dissemination not widespread enough; inability to address the needs of minority groups or people with specific needs; some medical conditions not properly covered; the medical profession's unfamiliarity with certain disease areas; and lack of transparency on the vested interests of the source of the information. [Profiling Question, pages 12-13, and Question 1, pages 14-15.]

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#### Footnote:

In all, 192 responses were received from different organisations with varied specialities, including those with interests in alternative medicines. Respondents were based in 28 different countries, though most were located in north America, Europe and Australasia. Though the majority answered in a personal capacity, nearly all were senior executives of campaigning organisations. Half of the participants were attached to nationally-run groups, just over one-third were locally based. The rest had an international remit. [Further details about respondents can be found in the Appendix, pages 37-45—as well as a list of those organisations that wished to be named in this survey, and a copy of the complete questionnaire.]

## WHY DO PATIENTS NEED BETTER INFORMATION?

"When our daughter was diagnosed we were told about the 'risks' that could be associated with her disorder. But the disorder she is suffering from is very complex, and has four different forms. Even if doctors did not know yet which form she was suffering from, they told us about all the associated symptoms for all the different forms, which meant that our daughter could have damage all over her body and inner organs. After announcing that to us, they just let us go back home and wait for further testing (two months later) without any psychological help and support. Now that we know the disorder much better, even if our daughter cannot be exactly classified between autosomal dominant and autosomal recessive type-II forms, we can be sure that there are associated symptoms she will never be suffering from"—Chair, Cutis Laxa Internationale [France].

"Stigma with regard to serious disorders of the brain (such as schizophrenia, bipolar, etc) is so deeply engrained within the general population that we do not even recognise the hurt, nor the harm it does to the patient and his/her family. Specifically, nurses in the inpatient units in all hospitals often completely ignore either family members or patients who approach the main desk. This deliberate, studied insult is designed to make sure that the individual knows that the 'important person' is the nurse. On one occasion, I went to the hospital to visit my son who was extremely ill in a locked ward in the hospital. I rang the bell to get the nurses' attention. He was

sitting at the desk, reading a newspaper. He lowered the paper, looked at me, and went right back to reading the paper. I waited for at least two full minutes while he—I guess—finished what he was reading and then allowed me to enter. As a mother, at this point, I am put in a very difficult situation. I do not dare to question his behaviour, because he has my very sick, very vulnerable son in his grasp. I have to let him get away with this bullying of the worst kind. My question is: if he treats me in that insulting, demeaning manner, what is he doing with my son?"—Programme coordinator, mental health organisation [Canada].

"We have a classic example in Canada of 'learned helplessness'. Government is doing a very poor job of training physicians. So patients get no help, and blame the doctor!"—Help for Headaches [Canada].

"We know that the prostate patients fear to communicate their problems, and need to know by themselves what they must know to make decisions for their treatments, assuming the consequences"—Associação Portugese de Doentes da Próstata [Portuguese Association of Prostate Diseases].

"It is rumoured that many patients fail to complete courses of treatment for lack of knowledge of why this is necessary"—Campaigner, cancer patient group [Scotland].

"From two national UK surveys carried out by the Pulmonary Hypertension Association UK

(2002/2005), it was found that it still takes on average two years for a patient to get a correct diagnosis of pulmonary hypertension. This is due to a lack of awareness and understanding of the condition by both healthcare professionals and the general public"—Pulmonary Hypertension Association UK (PHA-UK).

"My organisation publicly rebutted two very well-known journal reports from high-ranking academic authors, in which two forms of treatment were being touted. Both reports were publicly refuted by my group in the medical journals, and patients were informed as to the lack of evidence, potential bias, and the agenda both sources held"—Endometriosis Research Center [USA].

"Patients / the public require the same information that physicians or anyone else have. We oppose the de facto censorship of information in the medical field. Patients are individuals. They vary greatly as to age, education, interests, abilities, and the degree to which they are willing to allow others to decide matters of healthcare for them"—Association for Medical and Therapeutic Self-determination (MeTZef).

"I am planning to run a project and seek possible EU funding for provision of evidence-based information to patients with the sole purpose of ensuring informed medical decision-taking by patients"—Ivaylo Simeonov, Manager, informed medical decision-making project [Bulgaria].

"The people (and, especially, the women) with erythematic systematic lupus are afraid to confess that they are patients, even to their families"—Cyprus League against Rheumatism.

### **WHICH INFORMATION IS NEEDED?**

Despite an abundance of public-domain healthcare data, most of the survey's participants remain unimpressed and call for more high-quality information. The largest void appears to be in information designed to fulfil the needs of individual patients or members of the public. Over half of the respondents stipulate that more personal information is needed on health services; on disease; on diagnosis and treatments; on alternative therapies; and on prescription medicines. And over half of the participants from the 25 respondent mental health groups argue for more specific information on medicines already being taken by patients. [Question 3, pages 19-20.]

### **HOW SHOULD INFORMATION BEST BE DELIVERED?**

Most publicly-available healthcare information (other than that gained through conversation with healthcare professionals) is currently delivered in print form (as leaflets, or as patient package inserts); through conventional media (as newspapers, radio, and terrestrial and non-terrestrial TV); over the Internet (on websites, in e-forums, or in chat rooms); through email alerts; and via telephone hotlines. Over half of the respondents in this survey declare these mechanisms insufficient to meet the needs of patients or the public. Except 60% of the 26 respondent cancer organisations believe printed leaflets do satisfy their constituency's informational requirements. [Question 4, pages 21-22.]

Some countries (including Australia, Switzerland, and the US) are exploring new ways of making information available to patients, including: direct mail to the home; telemarketing; stand-alone kiosks; mobile phones; in the cinema/on film DVDs; or workshops for patients/the public. Almost three quarters of the respondents approve of patient/public workshops as a vehicle for disseminating more or better healthcare information. Two fifths think that stand-alone kiosks are also a good idea. A similar pattern of thinking is found among respondents from all regions worldwide.

Few respondents like mobile phones or telemarketing as healthcare informational tools, even if these communication methods do personalise information. Campaigners' main objection to mobile phones appears to be the relatively high cost of tariffs for patients/the public. Mobile phone and telemarketing are undesirable because of their unsuitability for socially-sensitive medical conditions (such as HIV/AIDS, herpes, or mental health problems), and their undesirable intrusion into individuals' privacy. These findings have implications for the huge global investments being poured into mobile phone technology for the delivery of personalised healthcare information (notably to promote compliance with prescription medicines). [Question 5, pages 23-24.]

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### **WHAT DETERMINES WHETHER INFORMATION IS TRUSTWORTHY?**

The most trustworthy information, as far as health campaigners are concerned, is simple, well summarised, easy to digest, totally transparent (with sources and vested interests made known), and underpinned by evidence-based medicine. But not all European health advocates are convinced that scientific research can be unbiased, timely, or relevant to patients—only 45% of reckon that information needs to be evidence-based medicine to be trustworthy, against 51% of all survey participants. [Question 6, pages 25-26.]

Over three-quarters of the survey's respondents argue that patients and the public are more likely to trust healthcare information recommended by healthcare professionals (or by their representative bodies), by the medical/scientific press (albeit less so in Europe), by consumer groups, and—unsurprisingly, given that the majority of participants are from patient advocacy groups—by patient organisations.

Participants advise that other issues in addition to trustworthiness need to be considered—not least the public's current inability to discriminate between good and bad information. "The public needs help in evaluating the credibility of sources, understanding any conflicts of interest in sources, and selecting facts that are relevant to their specific conditions", reports the CEO of a US respiratory patient organisation. Respondents point out that the credibility of individual sources, whatever their affiliation, varies widely (so that, for instance, even a doctors' organisation deemed as reputable may contain individuals within it who lack the same degree of credibility). Respondents also observe that even trustworthy sources might not always provide correct information. One respondent insists that the influence of the pharmaceutical industry on all parts of the healthcare system makes any endorsement of pharma-generated information valueless. [Question 7, pages 27-28.]

### **WHO SHOULD BE PROVIDING THE INFORMATION?**

Previous surveys by *HSCNews International*, and by its publisher, PatientView, and others, have consistently shown that patients and the public judge doctors to be the most useful and trustworthy source of healthcare information. Pharmacists usually score poorly (except in a few countries where, like the Netherlands, they are held in especially high regard). Who, then, is best suited to fulfil the needs of patients and the public outside the clinical setting? The results of this survey make clear that patients and the public are most likely to turn for their healthcare information to patient groups and—unexpectedly—pharmacists. "The pharmacist is seen as a good and available resource, relatively unbiased by the desire to sell", states the US-based VHL Family Alliance. The patient organisation element of the finding needs to be treated with caution, given the vested interests of participants. Nonetheless, it does indicate a willingness on the part of patient organisations to participate in the dissemination of information. Consumer organisations receive a high vote from participants in North America, and from groups specialising in mental health issues.

By contrast, only 34% of the participants expect their constituency to turn for information outside the clinic to bodies that represent healthcare professionals. Participants from cancer groups, meanwhile, are reluctant to see the responsibility for supplying cancer information outside the clinical setting passed to any non-medical professionals. [Question 8, pages 29-31.]

#### **THE ROLE OF PHARMACEUTICAL COMPANIES**

Opposition to the supply of publicly-available information by pharma is higher in Europe than elsewhere in the world—over one third of respondents from the region are opposed to pharma involvement. Globally, between 16% to one quarter of the survey's respondents feel that pharmaceutical companies should never supply information to the public—even if the information goes through an accredited third party, or even if patients themselves individually request the information.

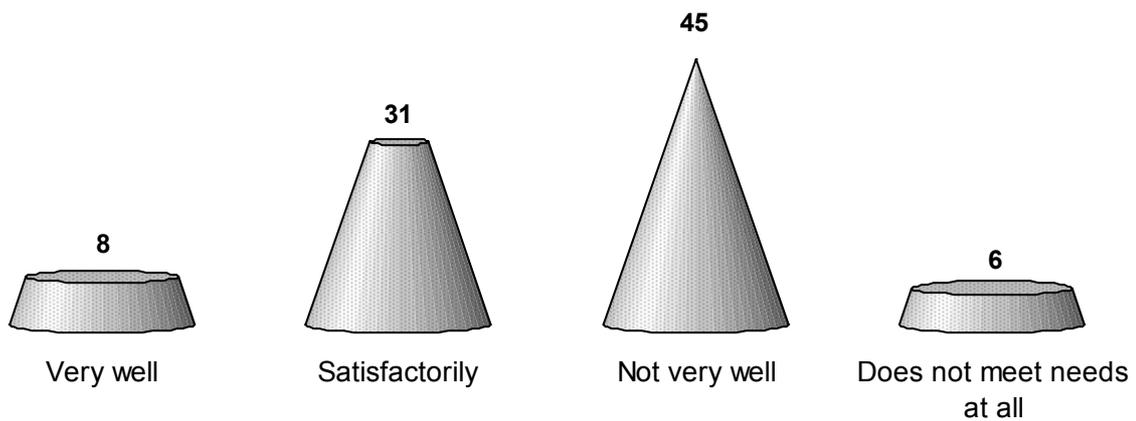
The remaining majority of the survey's respondents, however, perceive pharma as a legitimate supplier of healthcare information to patients and the public. Respondents do specify, however, the circumstances under which they believe such provision should take place. The vast majority of participants, for instance, would not be happy if the industry merely self-regulates its informational interactions with patients/the public. Pharma information also needs accreditation. These qualifications probably explain why participants think the information currently provided by the industry not to be useful or trustworthy. [Question 9, pages 32-33, and Question 10, pages 34-36.]

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## **PROFILING QUESTION**

### **HOW WELL DOES THE HEALTHCARE INFORMATION AVAILABLE IN YOUR COUNTRY MEET THE NEEDS OF THE PEOPLE YOU REPRESENT?**

*% of total responses [total = 192]*



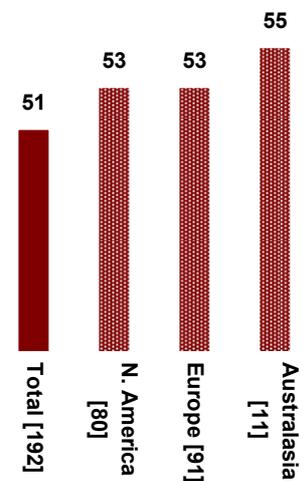
Source: HSCNews International, August 2006

Whether the participants to this survey come from North America, Europe, or Australasia, the majority feel that the provision of healthcare information to patients and the public is less than adequate. For example, 17 of the 25 respondent mental health organisations estimate the present supply of healthcare information to be far from satisfactory.

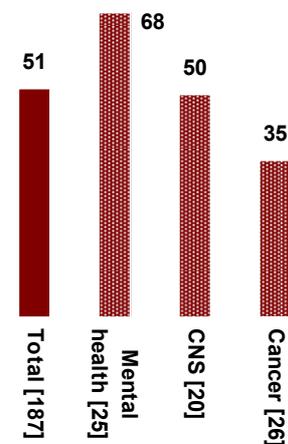
The main shortcomings appear to be:

- **Little information exists on some medical conditions**, notes Canada's Help for Headaches.
- **Information is not widely disseminated**—an issue that is of concern to a UK multiple sclerosis group.
- **Failure to reach people with special needs.**  
 "Adequate information does not exist for all the ethnic groups that we currently see in a large inner-city London hospital", emphasises a UK cancer group. A patient employed by a regional organisation representing the interests of the blind in the US comments: "People who work in hospitals (including nurses and doctors) have no concept of how to work with people who are blind or hard of hearing. I am both. I am also severely diabetic, and do not read Braille. I need talking prescription bottles for capsules and pills which can be identified by touch. Otherwise, I cannot tell the difference by size of pill".
- **Ill-informed physicians.** The leader of a US support group for people with restless leg syndrome (RLS) argues: "Physicians are not well informed yet. The RLS Foundation has done an outstanding job of spreading awareness and information to physicians at medical meetings, and via research reports, and to patients through over 100 support groups. But physicians need more training in recognition and treatment of the condition".

**% OF RESPONDENTS STATING THAT THE SUPPLY OF INFORMATION IS INADEQUATE (BY REGION)**



**% OF RESPONDENTS STATING THAT THE SUPPLY OF INFORMATION IS INADEQUATE (BY SPECIALTY)**



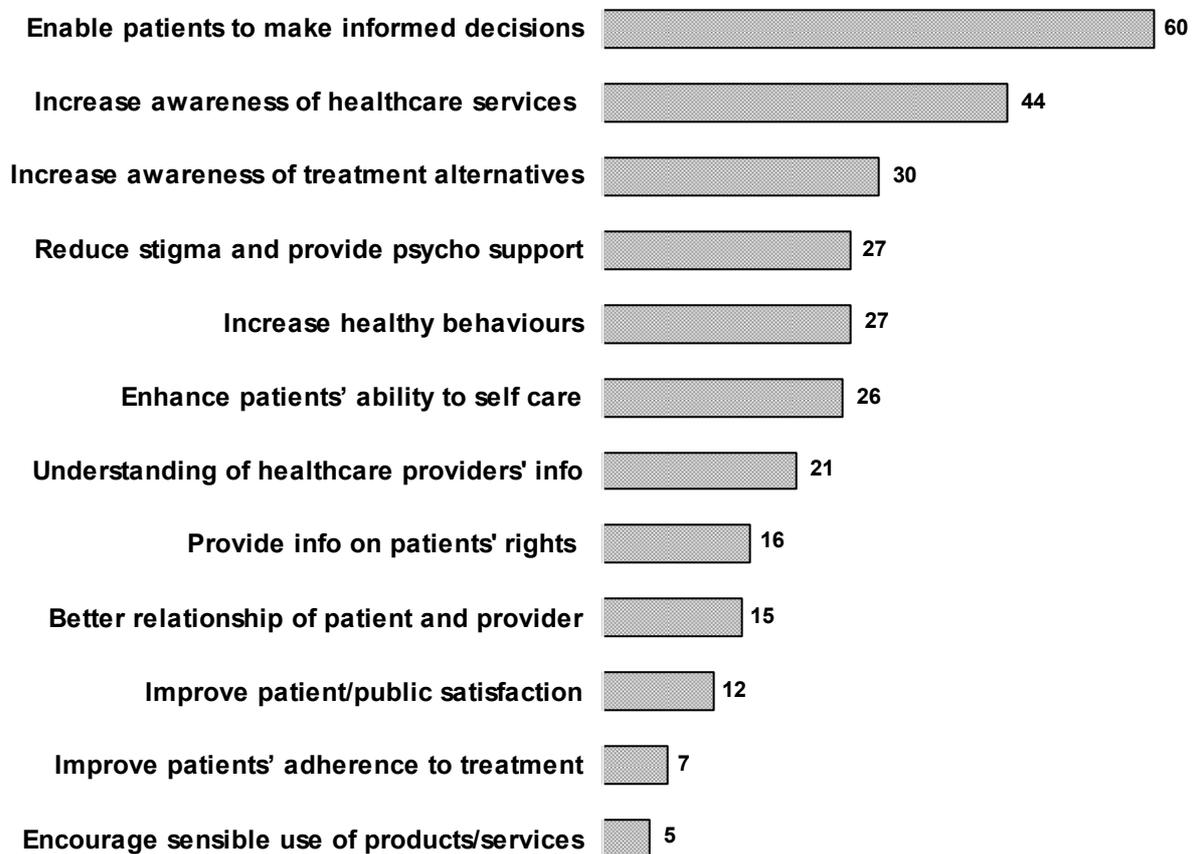
[Figure in brackets = total number of respondents in category.  
 CNS = neurological.]

HSCNEWS, August 2006

**QUESTION 1:**

**WHAT DO YOU THINK SHOULD BE THE TOP  
THREE GOALS OF ANY PUBLICLY-AVAILABLE  
HEALTHCARE INFORMATION SERVICE  
IN YOUR COUNTRY?**

*% of total responses [total = 192]*



Source: HSCNews International, August 2006

As many as 60% of survey participants believe that the top goal of publicly-available healthcare information is enabling individuals to make informed decisions about their own healthcare and treatment.

Ten of the eleven respondent Australasian groups, for instance, share the belief that informed decision-making by patients should be a number-one priority for healthcare information. A second important aim is increasing awareness of healthcare services (44% of respondents). A third target is boosting public knowledge of treatment alternatives (30%). Several participants make the point that family, carers and other partners in treatment and rehabilitation should also be included in the process by which patients become informed. A similar pattern of answers to this question is seen in North America and Europe.

Factors such as patient/public satisfaction, enhancing doctor-patient relationships, or even encouraging sensible use of products and services are considered lower priorities by respondents.

Several reasons are given for the opinions. Participants say that informed decision-making in healthcare leads to:

- **Greater understanding of the limits of healthcare systems.** The American Iatrogenic Association expects information to “explain to consumers that patients' rights are a myth”.
- **Greater self-determinism.** People can learn to use changes in lifestyle to prevent disease or the worsening of long-term condition.
- **Elevation of the understanding of care pathways**—for example, when and what treatment choices and social and community support are on offer. “Improve patients’ ability to understand what the doctor says, and the context of the doctor's thinking”, stresses the US-based VHL Alliance.
- **Patients/public enabled to inform primary-care doctors**, who are unfamiliar with conditions such as brain aneurysms or rarer cancers.
- **People convinced of their social responsibilities**, particularly in public-health efforts to combat communicable diseases.

Participants familiar with people with mental health problems express different priorities. Almost three quarters feel that information should help reduce stigma and provide psychological support.

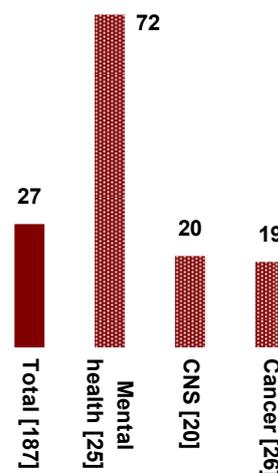
**THE ROLE OF GOVERNMENT**

A few participants fear that the healthcare goals of government can conflict with those of patients/ the public.

“Australian State and Federal governments openly claim that publicly-available healthcare information is to assist in saving government money, and to facilitate choice among patients as a basis to create competitive markets in healthcare eventually”—Australia's Chronic Illness Alliance (CIA).

“We feel that there is no such thing as unbiased information, and that, therefore, the state should not engage in the business of informing the public about healthcare products and services. The role of the state, at most, is to inform the public about the various laws concerning healthcare”—Association for Medical and Therapeutic Self-Determination (MeTZef) [Netherlands].

**% OF RESPONDENTS STATING THAT THE MAIN GOAL OF INFORMATION IS STIGMA REDUCTION**



[Figure in brackets = total number of respondents in category. CNS = neurological.]

HSCNEWS, August 2006

## QUESTION 2:

# CAN YOU SUGGEST CASE STUDIES FROM YOUR COUNTRY THAT FULFIL ANY OF THE GOALS MENTIONED IN QUESTION ONE?

### EUROPE

"Psychosocial accompanying of kidney patients; two-year project"—European Kidney Patients' Federation (CEAPIR).

"In 2005, the suicide-rate in Burgenland, Austria, dropped due to information given by general practitioners"—Campaigner, mental health group [Austria].

"Patients with rheumatic diseases work together with healthcare providers. We have a Reumafonds, where we discuss different studies and projects. And we have the social issues committee, where professionals and the patients work out events, improving relations between patients and providers"—ReumaNet vzw [Belgium].

"Hospitals must describe healthcare activities to patients when sent home"—Executive, osteoporosis group [Denmark].

"The Irish Cancer Society campaigns to increase awareness of prostate cancer and the importance of early diagnosis"—Communications Officer, gastro-intestinal patient group [Ireland].

"The law on patients' rights (Ministry for Social Welfare and Health)"—Campaigner, mental health group [Finland].

"National programme to detect, diagnose, and treat people with familial hypercholesterolemia (via cascade screening), to prevent a

strongly-increased risk for avoidable premature death from a silent but treatable disease"—Bloedlink Foundation [Netherlands].

"The three goals of our own leukaemia organisation are: raising awareness; representation of patients' interests; and contact with fellow patients"—Secretary, leukaemia patient organisation [Netherlands].

"We are the national lead on producing patient information on a wide range of epilepsy issues. We are currently working towards producing information on epilepsy for people with learning difficulties, and on increasing the accessibility of our website"—Epilepsy Scotland.

"All our patient information fulfils the chosen three goals. Reducing stigma is important for us because the subject is incontinence. Awareness of available services is important because there are specialist nurses, and people who don't know about the nurses often go to a GP, who hardly have any of the requisite knowledge. Making information decisions would apply to all disease areas"—Continenence Foundation [UK].

"The programme 'Open the Doors', to reduce stigma among mental health users"—Institute of Psychiatry and Neurology, Warsaw [Poland].

"We launched a Volunteer Support Network in 2003, and

now have 170 trained patients with rheumatoid arthritis who can provide peer-to-peer support on the telephone to others with the disease, and who work with us in many different ways to support each other, improve self help, and help us deliver the aims of our charity"—Campaigner, arthritis group [UK].

"We have developed our own web-based patient information system for our clinicians to use to access good information for their patients. Clinicians will run off leaflets containing excellent information for patients about to have a test or an operation. There is additional information: for newly-diagnosed diabetes patients; for patients with one of the nationally-recognised top-ten conditions; about good websites; about national organisations that offer good support; and about local support groups. We also offer information in various formats: in different languages, in Braille, on audio cassette tapes, and in leaflets that, if played on a computer by a family member/friend, can speak the words on the leaflet for someone with a visual disability"—Patient Advice and Liaison Officer, local Primary Care Trust [UK].

### NORTH AMERICA

"I work with deaf individuals who have traditionally been unable to access information on health services. Public forums are not offered in sign language and

brochures are written at a language level that is too high for those with low English skills. We have been encouraging the development of sign language videos and signed prevention courses (such as first aid, and cardio-pulmonary resuscitation). Recently, a young deaf woman who had taken a signed course saved the life of her mother using her newly-acquired CPR skills"—Deafness Advocacy Association of Nova Scotia [Canada].

"Our website has increased from 400 to 120,000 hits per month in four years. We answer 350 to 450 emails per month. All with just volunteers, and one part-time employee"—Lupus group [Canada].

"Development of a *Consumer Guide*, and sensitising healthcare professionals to open discussion when seeing their patients"—Executive, continence organisation [Canada].

"Our agency provides separate weekly and/or monthly peer-support groups for adults and youth with epilepsy, and for siblings of children with any health condition. We also have a monthly dinner and education programme at local restaurants in each of the counties that we serve, as well as educational conferences open to the public, and promoted through the media. These programmes are designed to provide talks by neurologists, disseminate printed information, provide individual and family support, and to reduce the stigma attached to epilepsy"—Epilepsy Foundation South Central Wisconsin [USA].

"We have invested a lot of time in letting people know about alternative treatments, and given lots of advice to patients to help educate their healthcare providers. Our condition is very unique in how it is treated, and not all treatments work the same for every patient"—Organization for

Understanding Cluster Headaches (OUCH) [USA].

"Forums of discussion have been helpful for those who are seeking information about their related medical concern. They are organised by email, through Internet groups whose focus is the health matter at hand, and in live discussions at conferences and in small groups"—Turner Syndrome Society of the United States.

"We are developing a 'Tool Kit' that includes sections on healthcare alternatives, descriptions of the disorder (phenylketonuria), practical advice for managing the treatment, and many other sections for transition to adult care. We stressed positive aspects to reduce anxiety related to the information being presented. The 'Tool Kit' will be patient-specific (contain health information about the patient derived from the paediatric metabolic clinic) that can then be shared with the adult care provider"—International group specialising in metabolic disorders [USA].

"NAMI Southwest Pennsylvania, the umbrella organisation for my area, has a programme called CART (Consumer Action Response Team) that works with consumers and their caregivers to assess their satisfaction with their treatment and the system of care"—Volunteer affiliate leader, National Alliance on Mental Illness (NAMI) [USA].

"The National Cancer Institute, Centers for Disease Control and Prevention, and American Cancer Society worked together with African-American churches to develop a packaged programme that would increase physical activity and fruit and vegetable consumption among African-American populations"—Campaigner, cancer organisation [USA].

## REST OF WORLD

"Carers WA (Western Australia) are working towards improving the relationship between carers, patients, and healthcare providers in the 'Prepare to Care' Carer Inclusion Programme"—Campaigner, patient organisation specialising in a congenital condition [Australia].

"Stroke survivors are not always aware that they have the right to a quota of annual paramedical care, and we advertise this on our site. We also ensure that our volunteers who answer the open telephone line make this information available"—Neeman Association for Stroke Survivors [Israel].

"Healthy Living Lifestyle Campaign, by Ministry of Health"—Executive Director, National Cancer Society Malaysia.

"Twenty-five health NGOs have got together and formed the Patient Health Alliance of NGOs, or PHANGO (pronounced p'ungo). Our aim is to educate the public about their healthcare rights and how to attain them, as well as to lobby in South Africa for numerous improvements in public and private healthcare (including a working complaints mechanism). PHANGO is taken seriously, and is already making input into government policy via various committees"—Arthritis Foundation of South Africa.

"Our organisation increases awareness about treatment alternatives through newsletters to patients, website, etc. We also educate doctors on this subject by means of treatment guidelines that get published in our national *Medical Journal*"—Osteoporosis group [South Africa].

## VALUABLE ONLINE SOURCES OF INFORMATION CITED BY RESPONDENTS

QUOTES PROVIDED ARE FROM RESPONDENTS

<http://www.cancer.fi>—website of the Cancer Society of Finland, which has 12 regional societies and four patient groups.

[http://www.cancer.ca/ccs/internet/standard/0,3182,3225\\_14495\\_\\_langId-en,00.html](http://www.cancer.ca/ccs/internet/standard/0,3182,3225_14495__langId-en,00.html)—information service of the Canadian Cancer Society.

<http://www.carcinoidinfo.info>—US-based website providing listings of tests needed to monitor carcinoid cancer. Several experts provide information about latest treatments.

<http://www.degosdisease.com>—"Set up to inform patients of their options, and to share experiences of treatment and medical attitudes in dealing with an exceptionally rare disease".

<http://www.diabetesgesellschaft.ch>—website of the Swiss Diabetes Association, Schweizerische Diabetes-Gesellschaft.

<http://www.dipex.org>—a resource that aims to show what the experience of illness is really like for patients, their carers, and family.

<http://www.dpp.org.uk>—includes details about the Doctor-Patient Partnership's informational campaigns 'Where to Go when Unwell', 'Better Health at Home and at Work', and 'Ever Smoked?'.

<http://www.hdlighthouse.org>—US-based family-run website on Huntington's disease.

<http://www.maternity.org.nz/news.shtml>—specifically on Vitamin-K deficiency bleeding (VKDB) and need to treat. By the Maternity Services Consumer Council, a New Zealand consumer organisation.

<http://www.mayoclinic.com>—"Very helpful website", stated a Canadian Alzheimer's group.

<http://www.nhsdirect.nhs.uk>—government-funded information and patient support service. "NHS Direct has been very good at informing the general public about this excellent service", said a UK health campaigner involved with primary-immune deficiencies.

<http://partnersagainstpain.org>—website of the American Pain Foundation: "A wonderful resource".

<http://www.pparx.org>—website for Partnership for Prescription Assistance, which brings together America's pharmaceutical companies, doctors, other healthcare providers, patient advocacy organisations, and community groups to help qualifying patients who lack prescription coverage get the medicines they need.

<http://www.reginaldkapp.org>—builds on the work of Professor Reginald Kapp (1886-1966), a believer in holistic medicine. "Information should be available on the paradigms underlying conventional medicine, materialist, reductionist, mechanistic, and complementary alternative therapy (holist)".

<http://www.stanford.edu/group/hopes>—HOPES is a team of faculty and undergraduate students at Stanford University dedicated to making scientific information about Huntington's disease more readily accessible to the public.

<http://www.swisscancer.ch/index.php?id=1>—website of the Swiss cancer organisation, Krebsliga.

<http://www.swissheart.ch>—website of the Foundation of Swiss Cardiology, Schweizerische Herzstiftung.

<http://www.seemescotland.org.uk>—website of the 'See Me' Campaign, an organisation in Scotland reducing stigma in mental ill health.

<http://www.stopbreastcancer.org/nbccf/index.html>—*Guide to Quality Breast Cancer Care* is a website of the US-based National Breast Cancer Coalition (NBCC). The site helps healthcare providers find models to enable informed decision-making in patient care and treatment.

[http://www.sydanliitto.fi/fi\\_FI](http://www.sydanliitto.fi/fi_FI)—website of the Finnish Heart Association, which has 85,000 members and 240 NGOs under its umbrella.

<http://www.vhl.org/handbook/index.html>—provides information about Von Hippel-Lindau disease.

**QUESTION 3:**

**DO YOU BELIEVE THAT YOUR COUNTRY'S  
 PATIENTS/PUBLIC REQUIRE BETTER  
 PUBLICLY-AVAILABLE HEALTHCARE  
 INFORMATION  
 ON ANY OF THE TOPICS LISTED BELOW?**

[Please rank each on a scale of 1 to 5, where  
 1 = "Require much more or better information in this area", and  
 5 = "Do not require more or better information in this area"]  
 % of total responses [total = 192]

- 1 = Require much more/better information
- 2
- 3
- 4
- 5 = Require no more information

General info: disease / diagnosis / treatments	21	17	25	12	11
Personal info: disease / diagnosis / treatments	44	20	13	9	6
General info: available healthcare services	14	23	28	13	7
Specific: healthcare services relevant to person	34	30	12	8	4
General info: policy / law / patients' rights	22	18	28	13	7
Specific: policy relevant to person's local area	25	25	23	7	7
General info: prescription medicines	17	15	28	16	11
Specific: prescription drugs relevant to person	34	19	15	15	7
Specific: medicine(s) patients are already taking	24	15	20	17	9
General info: alternative therapies	26	22	19	17	5
Specific: alternative therapies relevant to person	34	23	14	12	6

*Not all columns add up to 100%, as some respondents did not answer the question.*

Source: HSCNews International, August 2006

Despite the existence of an abundance of publicly-available healthcare data, a significant proportion of survey participants insist that much more high-quality healthcare information ought to be made available.

The largest informational gap appears to be in material that is specific to the needs of individual patients or members of the public. Over half of the respondents stipulate that more personal information is needed on disease, diagnosis, and treatments, health services, alternative therapies, and prescription medicines. Over half of the participants from the 25 respondent mental health groups argue for more specific information about the medicines that patients are already taking. In the case of general information, 70% of the respondent campaigners associated with neurological groups feel that more information should be available about policy, law, and patients' rights. The all-respondent equivalent figure is 40%.

These findings are repeated in North America and Europe, and—with one exception—in Australasia. Just over 80% of the respondent health campaigners from Australasia are sure that their constituencies want more and better information about alternative therapies specific to the needs of the individual person. The all-respondent equivalent figure is 57%.

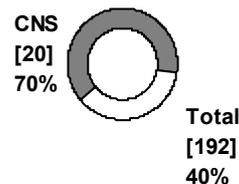
A number of participants identify informational areas in particular need of action, including: patients to be told by their doctors about charitable support associations; help for patients to deal with the current overload of information and guidance about the best sources suitable for the person; information about self-care strategies; details about reimbursement relevant to the person, and how to negotiate the best healthcare package with insurers; more on how to stay healthy and improve wellbeing; information about psychosocial services; and facts about complaints mechanisms.

Respondents' comments spotlight deficiencies in the prevailing system, echoing the findings of the survey's first (profiling) question [pages 12-13]: information has to be in many languages and formats; packaged for people with low literacy levels and people with a range of impairments; validated; evidence-based; comprehensive; and able to make patients more discerning. And it should create a greater awareness among patients of pricing and cost-effectiveness.

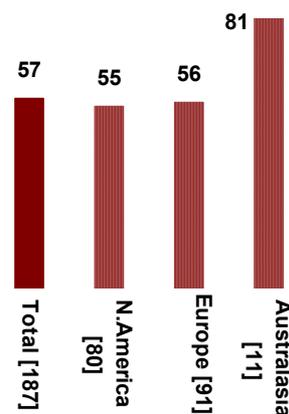
**MENTAL HEALTH GROUPS  
 STATING A NEED  
 FOR MORE INFO ABOUT  
 MEDICINE(S) PATIENTS ARE  
 ALREADY TAKING  
 (VERSUS TOTAL OF GROUPS)**



**NEUROLOGICAL (CNS)  
 GROUPS STATING A NEED  
 FOR MORE INFO ON POLICY,  
 LAW, AND PATIENTS' RIGHTS  
 (VERSUS TOTAL OF GROUPS)**



**% OF RESPONDENTS  
 STATING A NEED FOR  
 BETTER INFO ON  
 ALTERNATIVE THERAPIES  
 RELEVANT TO THE PERSON**



[Figure in brackets = total number of respondents in category]

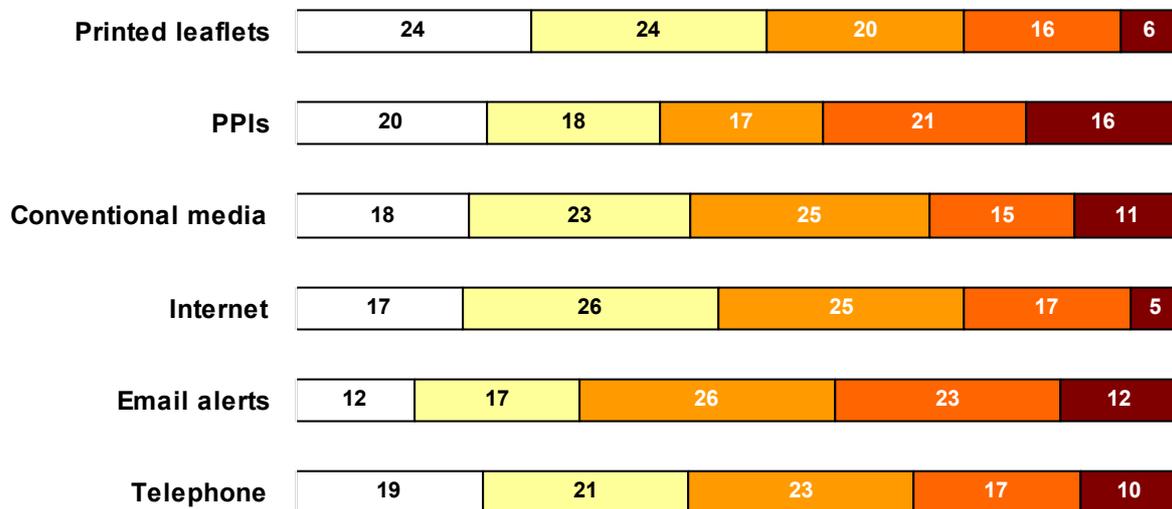
HSCNEWS, August 2006

**QUESTION 4:**

**DO YOU BELIEVE THAT THE CURRENT FORMS  
 BY WHICH PUBLICLY-AVAILABLE  
 INFORMATION ARE TRANSMITTED CAN  
 SATISFY THE NEEDS OF YOUR COUNTRY’S  
 PATIENTS AND PUBLIC?**

[Please rank each on a scale of 1 to 5, where  
 1 = “Likely to do a very good job of satisfying the needs of patients/the public”, and  
 5 = “Not likely to satisfy the needs of patients/the public”]  
 % of total responses [total = 192]

- 1 = Likely to do a very good job satisfying the needs of patients/the public
- 2
- 3
- 4
- 5 = Not likely to satisfy the needs of patients/the public



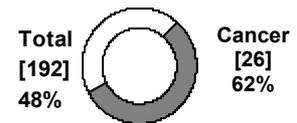
*PPIs = patient package inserts (leaflets inside the packaging of medicines).  
 Not all columns add up to 100%, as some respondents did not answer the question.  
 Source: HSCNews International, August 2006*

Most publicly-available healthcare information (other than that gained through conversation with healthcare professionals) is currently delivered in print form (as leaflets, or as patient package inserts); through conventional media (as newspapers, radio, terrestrial and non-terrestrial TV); over the Internet (on websites, in e-forums, or in chat rooms); through email alerts; and via telephone hotlines. Over half of the survey respondents report that none of these vehicles are sufficient to satisfy the needs of patients or the public. But 62% of health campaigners from respondent cancer organisations expect printed leaflets to satisfy the needs of their constituency [see figure, right], against 48% of all survey participants.

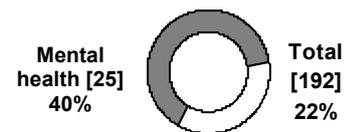
The Australian herpes group, Living Sphere, sums up the sentiments of respondents: "Printed leaflets: these resources are not offered by doctors, many people are unaware that they exist, and don't know where to get them. Patient package inserts in medicines packaging: these are available, but from the amount and type of questions I hear, they don't appear to be read or understood. Conventional media (magazines and newspapers): they usually focus on sensation, and don't do enough 'real-life stories', or stories with a positive focus. The Internet: a huge amount of info and support is available on the internet; unfortunately, some of it is not reputable, accurate, or helpful, and some people are completely unaware that such resources exist. Email alerts: not a service that is greatly used. Telephone hotlines: the existing herpes hotline service does not provide any live help (though you can leave a message)".

Respondents' main criticisms of current methods of information delivery are: inadequate access by all types of patients to the various communication tools; ignorance on the part of patients that a service exists (in part, due to public apathy); lack of professionalism, particularly on telephone hotlines; failure of delivery tools to provide personalised information; not enough personal contact; and unreliable delivery tools.

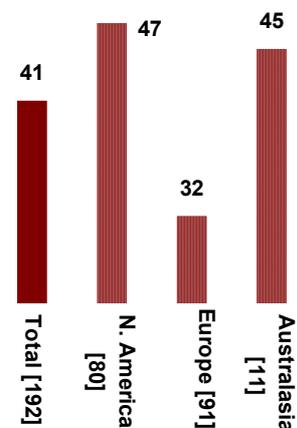
**CANCER GROUPS STATING THAT PRINTED LEAFLETS ARE LIKELY TO SATISFY THEIR CONSTITUENCY (VERSUS TOTAL OF GROUPS)**



**MENTAL HEALTH GROUPS STATING PRINTED LEAFLETS ARE UNLIKELY TO SATISFY THEIR CONSTITUENCY (VERSUS TOTAL OF GROUPS)**



**% OF RESPONDENTS STATING THAT SUPPLYING HEALTHCARE INFORMATION VIA THE MEDIA IS LIKELY TO SATISFY THE NEEDS OF PATIENTS/THE PUBLIC**



[Figure in brackets =total number of respondents in category]

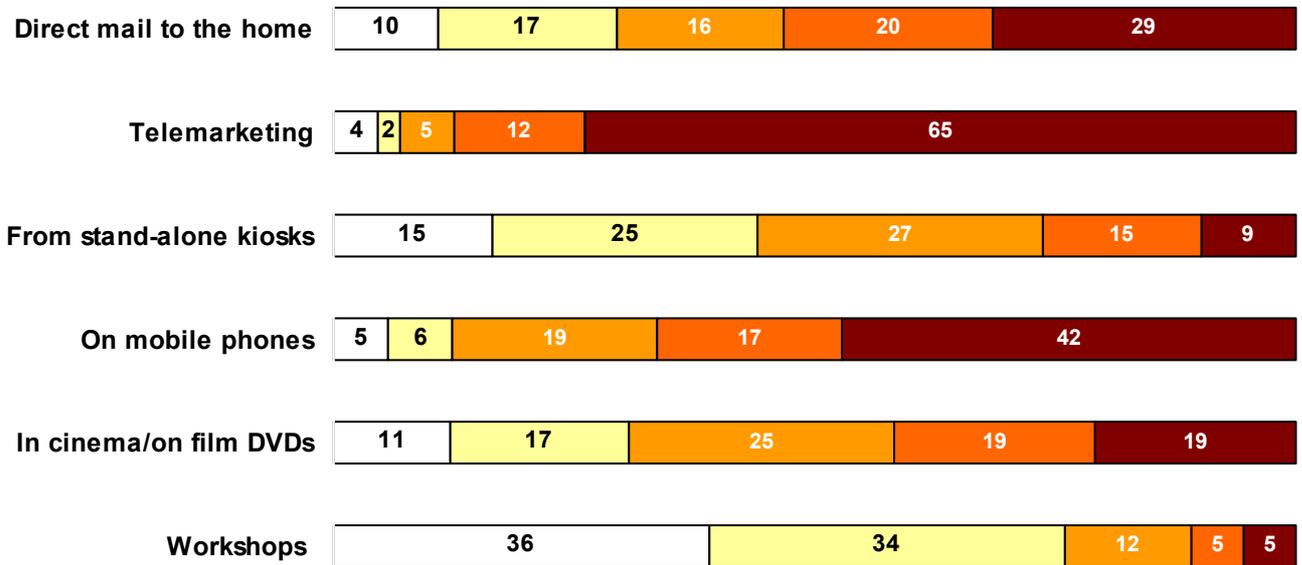
HSCNEWS, August 2006

**QUESTION 5:**

**DO YOU BELIEVE THAT YOUR COUNTRY’S PATIENTS/THE PUBLIC ARE LIKELY TO GET MORE OR BETTER HEALTHCARE INFORMATION IF ANY OF THE FOLLOWING RELATIVELY NEW DELIVERY TOOLS BECOMES WIDELY USED?**

[Please rank each on a scale of 1 to 5, where  
 1 = “Likely to generate much more or better information for patients/the public”, and  
 5 = “Not likely to generate more or better information for patients/the public”]  
 % of responses [total = 192]

- 1 = Likely to generate much more or better information for patients/the public
- 2
- 3
- 4
- 5 = Not likely to generate more or better information for patients/the public



*Not all columns add up to 100%, as some respondents did not answer the question.*

Source: HSCNews International, August 2006

Some countries (such as Australia, Switzerland, and the US) are exploring new ways of getting information to patients, including: direct mail to the home; telemarketing; stand-alone kiosks; mobile phones; in the cinema/on film DVDs; or workshops for patients/the public. Most favoured among these approaches is the last: almost three quarters of the respondents are impressed with the notion of patient/public workshops as a vehicle for disseminating more or better healthcare information. Two fifths of respondents also suspect that stand-alone kiosks are a good idea. A similar pattern of thinking is obtained from respondents throughout the world.

A number of the survey participants insist that new communicational techniques must be practical, convenient, capable of engaging patients/the public (ensuring good uptake), and be managed by reputable individuals/organisations. "Workshops (versus other, more proactive tools for communicating to the public) may only be effective if people were specifically looking for that information—that is, if they were already sick", points out the public affairs officer of a Canadian cancer group. "The success of workshops would depend on who provides them, and how they are publicised", remarks the UK's Continence Foundation.

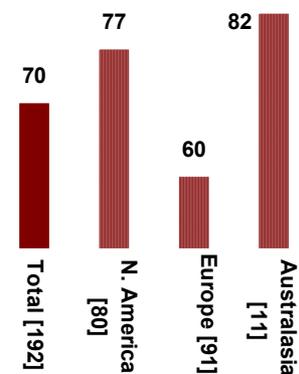
Few respondents approve of mobile phones or telemarketing, even if these communication methods could allow information to be more personalised (a quality called for by health campaigners). The main resistance to mobile phones is the cost of its tariffs.

On both mobile phones and telemarketing, campaigners object to individuals' invasion of privacy. "People do not like their daily lives interrupted by telemarketers or text messaging that does not come from a friend or family member", notes the co-ordinator of a US organisation that concentrates on children with special healthcare needs. "I think that people don't like to feel they are a 'captive audience'. The negative reaction to spam, telemarketing, and junk mail makes these routes counter-productive", observes the US-based VHL Family Alliance. Telemarketing, some groups emphasise, also lacks suitability for socially-sensitive medical conditions (such as HIV/AIDS, herpes, or mental health problems). The finding has implications for the global investments in mobile phone technology for the delivery of personalised healthcare information (notably to promote compliance with prescription medicines).

**MORE EXTENSIVE USE OF THE MEDIA**

"We have a well-developed culture of educational supplements in newspapers and on TV, in terms of children preparing for their final school exams, and so forth. There are daily educational channels on TV, with teachers teaching the syllabus for maths, biology, or whatever. Similar supplements or TV programmes on health issues would be an excellent means of getting the relevant information to the public (not only to the people who have become patients)"—Arthritis Foundation of South Africa.

**% OF RESPONDENTS STATING THAT SUPPLYING HEALTH INFORMATION VIA WORKSHOPS IS LIKELY TO SATISFY THE NEEDS OF PATIENTS/THE PUBLIC**



**MENTAL HEALTH GROUPS STATING THAT DIRECT MAIL IS UNLIKELY TO IMPROVE INFO FOR THEIR CONSTITUENCY (VERSUS TOTAL OF GROUPS)**



[Figure in brackets = total number of respondents in category]

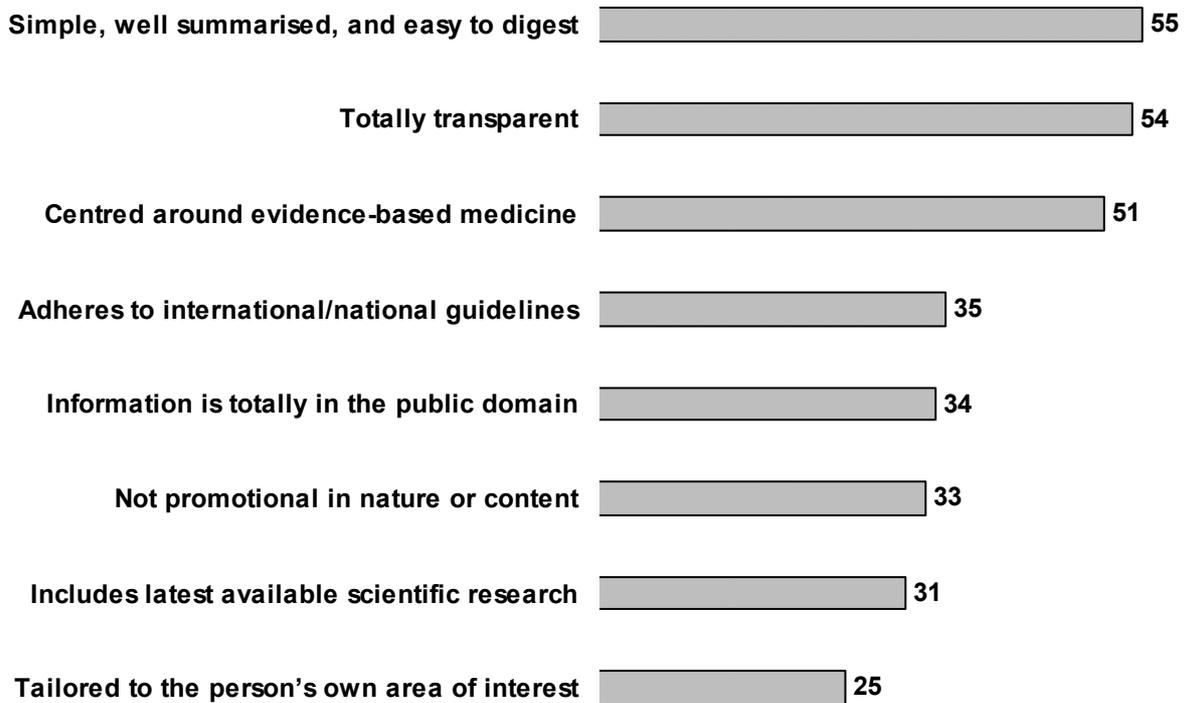
HSCNEWS, August 2006

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**QUESTION 6:**

**DO ANY OF THE FOLLOWING QUALITIES  
HELP MAKE YOUR COUNTRY'S  
PUBLICLY-AVAILABLE HEALTHCARE  
INFORMATION TRUSTWORTHY?**

[Please specify only your top three items]  
% of responses [total = 192]



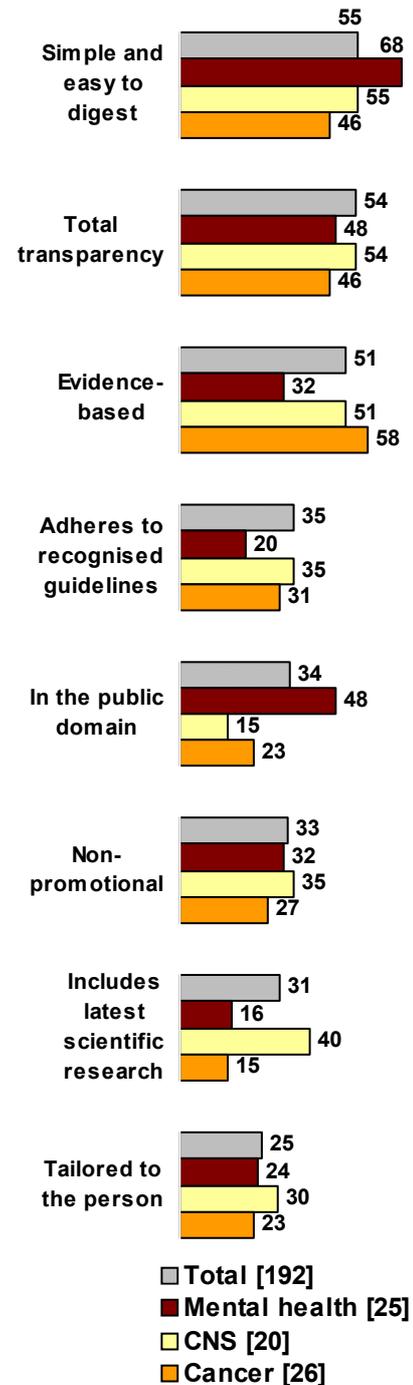
Source: HSCNews International, August 2006

From the perspective of the majority of the respondent health campaigners, the most trustworthy information is that which is simple, well summarised and easy to digest. The information also needs to be totally transparent, with sources and vested interests made obvious. Finally, the information needs to be centred around evidence-based medicine. For mental health groups, simplicity rates above any other characteristic; among cancer groups, scientific assurances count as the lead attribute.

European respondents seem to be somewhat sceptical about whether scientific research can truly be unbiased, timely, and relevant—which is why only 45% of them feel that evidence-based medicine is an essential underpinning to healthcare information. “Some areas of medicine have not received any research funds to allow studies—therefore, little medical information is available”, cautions a campaigner from a UK organisation that specialises in a variety of illnesses. “I haven’t chosen ‘evidence-based’, since medics decide what this means, never patient experience”, advises UK group Battle Against Tranquillisers (BAT). “Evidence-based info is very important, particularly for the needs of academics. For the general public, the most important thing is simple, well-summarised, and easy-to-digest information”, comments a member of English group Bradford Cancer Support.

**QUALITIES THAT HELP MAKE PUBLICLY-AVAILABLE HEALTHCARE INFORMATION MORE TRUSTWORTHY (% OF RESPONDENTS, BY SPECIALITY)**

[Figure in brackets = total number of respondents in category]



Source: HSCNews International, August 2006

**QUESTION 7:**

**WHEN ANY OF THE FOLLOWING RECOMMEND  
 A SOURCE OF HEALTHCARE INFORMATION,  
 WHOSE RECOMMENDATION ARE YOUR  
 COUNTRY'S PATIENTS AND THE PUBLIC MOST  
 LIKELY TO TRUST?**

[Please rank each on a scale of 1 to 5, where  
 1 = "Regarded as very trustworthy by patients/the public", and  
 5 = "Regarded as not trustworthy by patients/the public"]  
 % of total responses [total = 192]

- 1 = Regarded as very trustworthy by patients/the public
- 2
- 3
- 4
- 5 = Regarded as not trustworthy by patients/the public

Healthcare professional	53	24	9	4	2
Healthcare professional/academic body	44	30	10	3	2
Conventional news media	6	21	34	18	8
Medical/scientific press	27	33	21	5	2
Patient organisation	36	37	14	2	3
Consumer organisation	20	30	22	13	2
Healthcare company	3	10	22	30	20
Ministry of Health	17	22	22	17	8
Politician	2	3	10	22	48
Reputable Internet site	9	18	29	17	9
Any Internet site	4	11	20	22	19
Friends and/or family	16	27	31	8	6

*Not all columns add up to 100%, as some respondents did not answer the question.*

Source: HSCNews International, August 2006

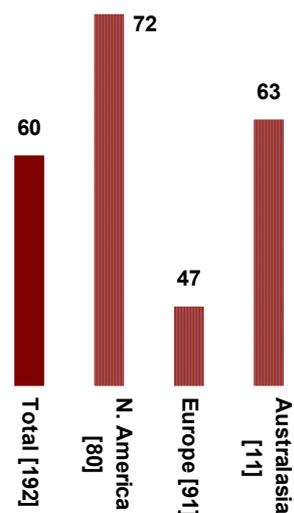
The majority of respondents think that patients and the public are most likely to trust healthcare information recommended by healthcare professionals (or their representative bodies). Significant public trust is placed in guarantees from the medical/scientific press (though less so in Europe). Consumer organisations, too, are considered valid agents to recommend healthcare information as trustworthy. Health campaigners also mention their own patient organisations in this regard. Only a minority of respondents, however, view recommendations from commercial entities or government as valuable. Recommendations from friends or family can have a significant, but not major, effect on whether healthcare information is appreciated as trustworthy.

Survey participants suggest that other forces must be contemplated—especially the public’s inability to discriminate between good and bad information. “I don’t think that people ask themselves this question!”, comments the executive officer of a UK respiratory group. “Unfortunately, poorly-educated people tend not to distinguish between different sources when it comes to trustworthiness (ie, if it’s in print, it must be true). I think, in general, that most people take what their friends and families say as more trustworthy than any other source—which may be crazy, but it’s human nature”, estimates the Arthritis Foundation of South Africa.

Other respondents declare that the credibility of individuals and organisations varies. Even the most trustworthy of recommendations, argue some respondents, may not guarantee the correctness of the information. “Unfortunately, some healthcare professionals are better than others—and that goes for patient organisations, too. Friends and family, while considered trustworthy, may give totally wrong information”, judges the chief executive of a UK arthritis group.

One respondent thinks that the influence of the pharmaceutical industry over all parts of the healthcare system nullifies the value of any recommendation: “None of above. All have been known to act in the interests of pharmaceutical manufacturers, or to have been unwittingly manipulated by them”, argues the Chronic Illness Alliance of Australia.

**% OF RESPONDENTS STATING THAT THE MEDICAL/SCIENTIFIC PRESS COULD VALIDATE INFO AS TRUSTWORTHY**



**MENTAL HEALTH GROUPS STATING THAT THE GENERAL MEDIA CAN VALIDATE INFO AS TRUSTWORTHY (VERSUS TOTAL OF GROUPS)**



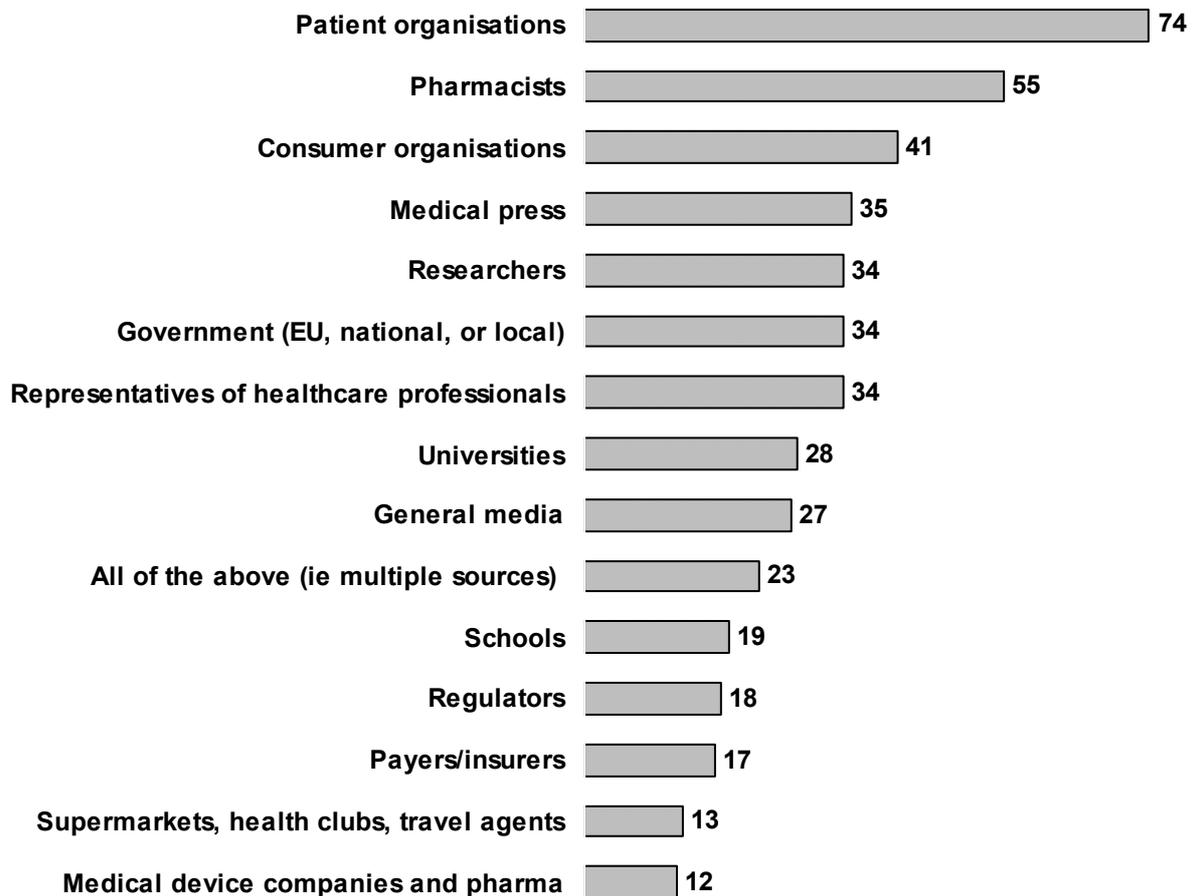
[Figure in brackets = total number of respondents in category]

HSCNEWS, August 2006

**QUESTION 8:**

**WHICH SOURCES OF HEALTHCARE  
INFORMATION DO YOU BELIEVE COULD BEST  
FULFIL THE NEEDS OF YOUR COUNTRY'S  
PATIENTS/THE PUBLIC  
OUTSIDE THE CLINICAL SETTING?**

*% of total responses [total = 192]*

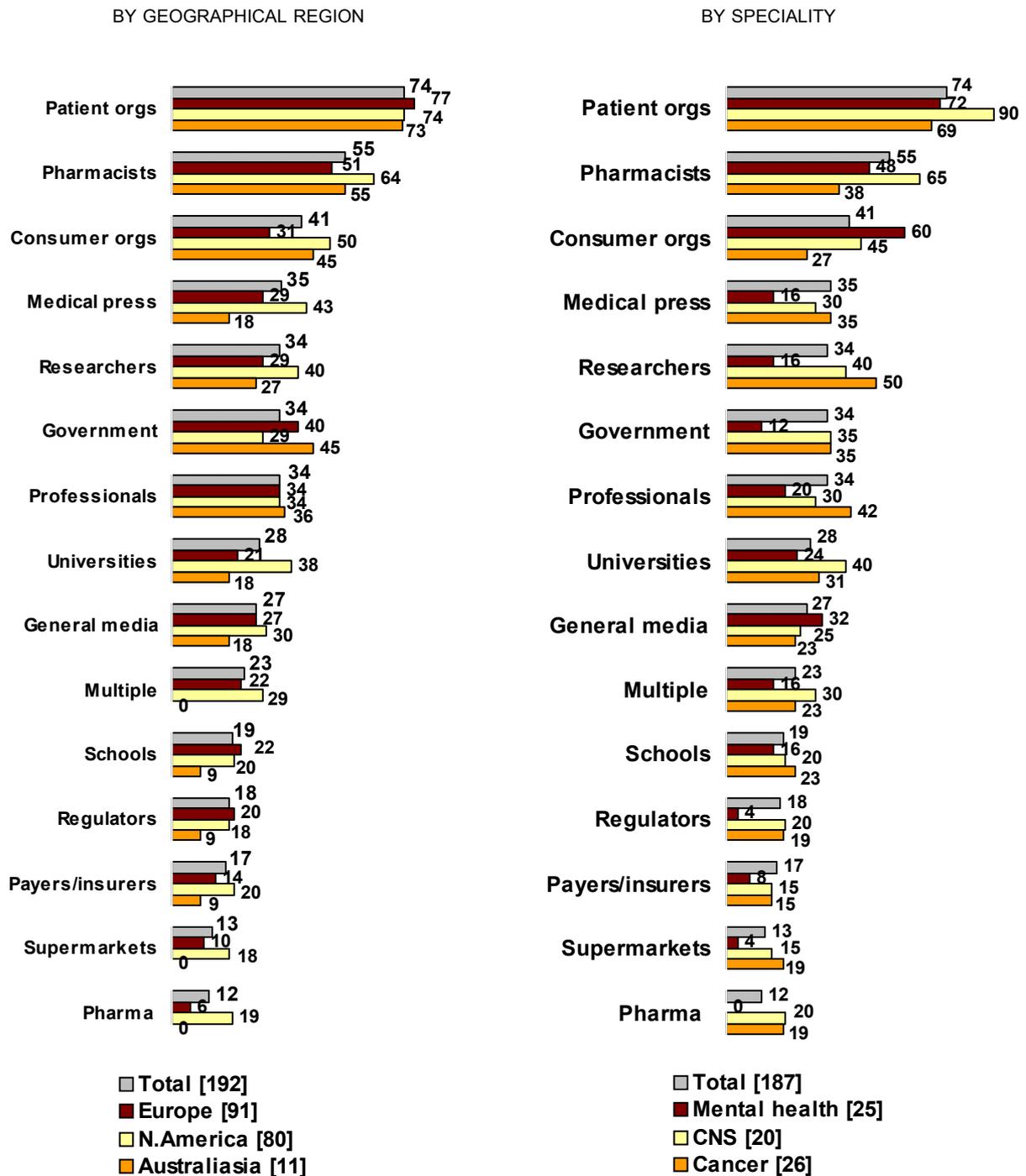


Source: HSCNews International, August 2006

**SOURCES OF HEALTHCARE INFORMATION ABLE TO FULFIL THE NEEDS OF RESPONDENTS' CONSTITUENCIES OUTSIDE THE CLINICAL SETTING**

(% OF RESPONDENTS, BY SPECIALITY, AND BY GEOGRAPHIC REGION)

[Figure in brackets = total number of respondents in category]



Source: HSCNews International, August 2006

Previous surveys by *HSCNews International*, its publisher, PatientView, and others, have consistently shown doctors to be the most useful and trustworthy source of healthcare information for public and patients.

This survey's participants from cancer groups were more reluctant than any other section of respondents to pass responsibility for the supply of information outside the clinical setting to non-medical professionals.

The Netherlands-based Association for Medical and Therapeutic self-determination (MeTZef) insists, though, that doctors should be held more accountable as information providers. "Firstly, the providers of healthcare goods and services are, or should be, responsible for informing their clients honestly and accurately, just as are the providers of any other product or service. When they fail to do so, it should be possible to sue them in court, just as it would be possible in any other market field. Secondly, information itself is a product, with providers and users who should be able to find each other in an open, free, market place. It is precisely the privileged 'priestly' status of medicine that blocks information to the patient."

Who, then, is most likely to fulfil the informational needs of patients and the public outside the clinical setting? This survey's results make clear that patients and public are most likely to turn to two sources of information.

The first is patient organisations—a finding that must inevitably be interpreted with care, given the composition of the survey's participants. And, as the UK-based ITP Support Association indicates, "Patient organisations vary considerably. They need some sort of kite-mark assessment for the clinical accuracy of the information they give out". Nonetheless, the result is important, as it does indicate a willingness on the part of patient organisations to participate in the dissemination of information.

*HSCNews International* surveys on information supply have usually found pharmacists scoring indifferently (except among respondents from countries where pharmacists are held in especially high regard, such as the Netherlands). In this survey, however, pharmacists are singled out as the public's preferred source for information by over half of respondents (the figure is

higher still among North American participants and those that specialise in neurological conditions [see figure on previous page]). "The pharmacist is seen as a good and available resource, relatively unbiased by the desire to sell", explains the US-based VHL Family Alliance.

Consumer organisations also receive a high vote from participants in North America and from groups specialising in mental health issues.

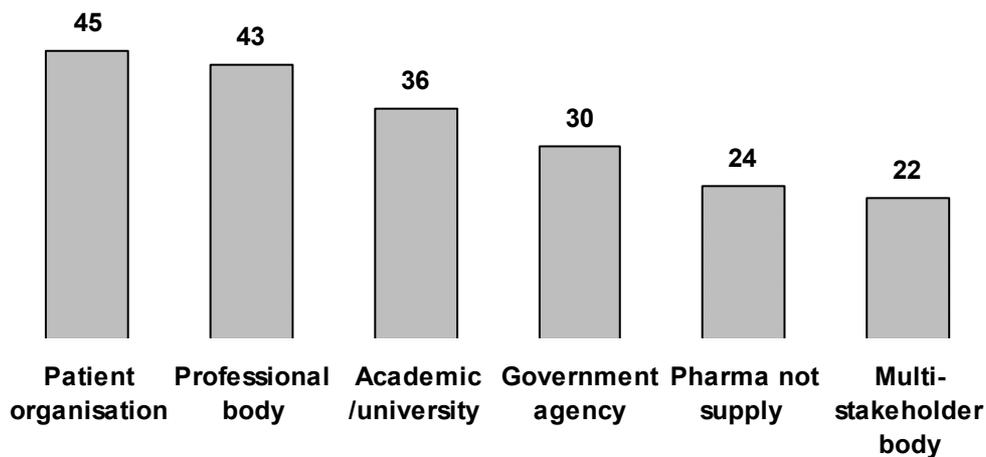
By contrast, only 34% of participants expect their constituency to look for information to the bodies that represent the interests of health professionals.

Respondents find the least useful informational sources to be pharmaceutical companies, medical device companies, retail outlets, insurers, and regulators. Less than two-in-ten respondents expect their constituency to turn to these groups for assistance in fulfilling informational needs. "I would be less likely to trust the payers, the government, regulators, and the general press because they often have hidden agendas", writes the US-based National Chronic Pain Society.

**QUESTION 9:**

**SHOULD PHARMACEUTICAL COMPANIES BE  
ABLE TO SUPPLY PRESCRIPTION MEDICINES  
INFORMATION TO YOUR COUNTRY'S  
PATIENTS/PUBLIC, IF THE INFORMATION  
GOES THROUGH ANY OF THE FOLLOWING AS  
AN ACCREDITED THIRD-PARTY?**

*% of total responses [total = 192]*



Source: HSCNews International, August 2006

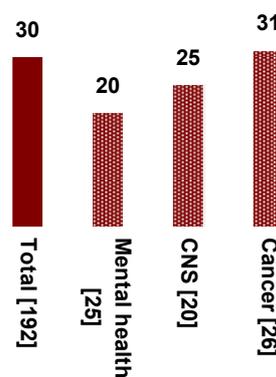
One quarter of the respondents feel that pharmaceutical companies should never supply information to the public/patients on any account—even if the information goes through an accredited third party. The figures from North American, European, and Australasian respondents are 16%; 29%, and 27% respectively. One opponent is the Auckland Women’s Health Council: “We are totally opposed to DTC [direct to consumer]. New Zealand is a terrible example of what happens when DTC is permitted.” The US-based Berkeley Gray Panthers comments: “Pharmaceutical companies should not be advertising directly to the public—it increases the costs of drugs, and is inappropriate”.

The majority of respondents from all regions of the world, however, see pharma as a legitimate supplier of information to patients and the public—particularly if third-party accreditation is present. This finding occurred despite the fact that many respondents do not currently rate pharma as a useful informational resource [see Question 8, pages 29-31]. Respondents’ remarks on the subject include:

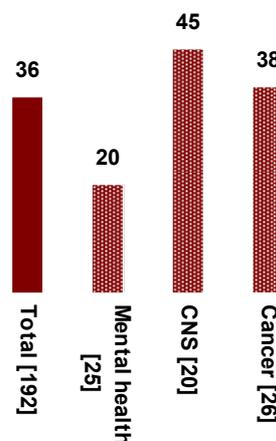
- “As long as the information is accurate, and is not only there to promote the prescription, then the above choices are fine. Information about the drugs is critical, no matter where it comes from”, comments a campaigner from a Canadian group specialising in cerebral aneurysm.
  - “The information that pharma supplies is generally very accurate, and mentions all possible side-effects (to cover themselves in case of insurance claims). However, it does come with more credibility if it is attested to by a university, and supported by a patient organisation”, emphasises the Arthritis Foundation of South Africa.

Respondents not unnaturally consider patient groups to be a good choice of organisation to accredit the information. Next comes professional bodies, academics/universities [though only 26% of European participants voted for this latter option], government agencies, and, finally, multi-stakeholder bodies.

**% OF RESPONDENTS STATING THAT PHARMA COULD PROVIDE PRESCRIPTION MEDICINES INFO TO PUBLIC, IF ACCREDITED BY A GOVERNMENT AGENCY**



**% OF RESPONDENTS STATING THAT PHARMA COULD PROVIDE PRESCRIPTION MEDICINES INFO TO PUBLIC/PATIENTS, IF ACCREDITED BY AN ACADEMIC OR UNIVERSITY**



Figures in brackets = total number of respondents

CNS = neurological

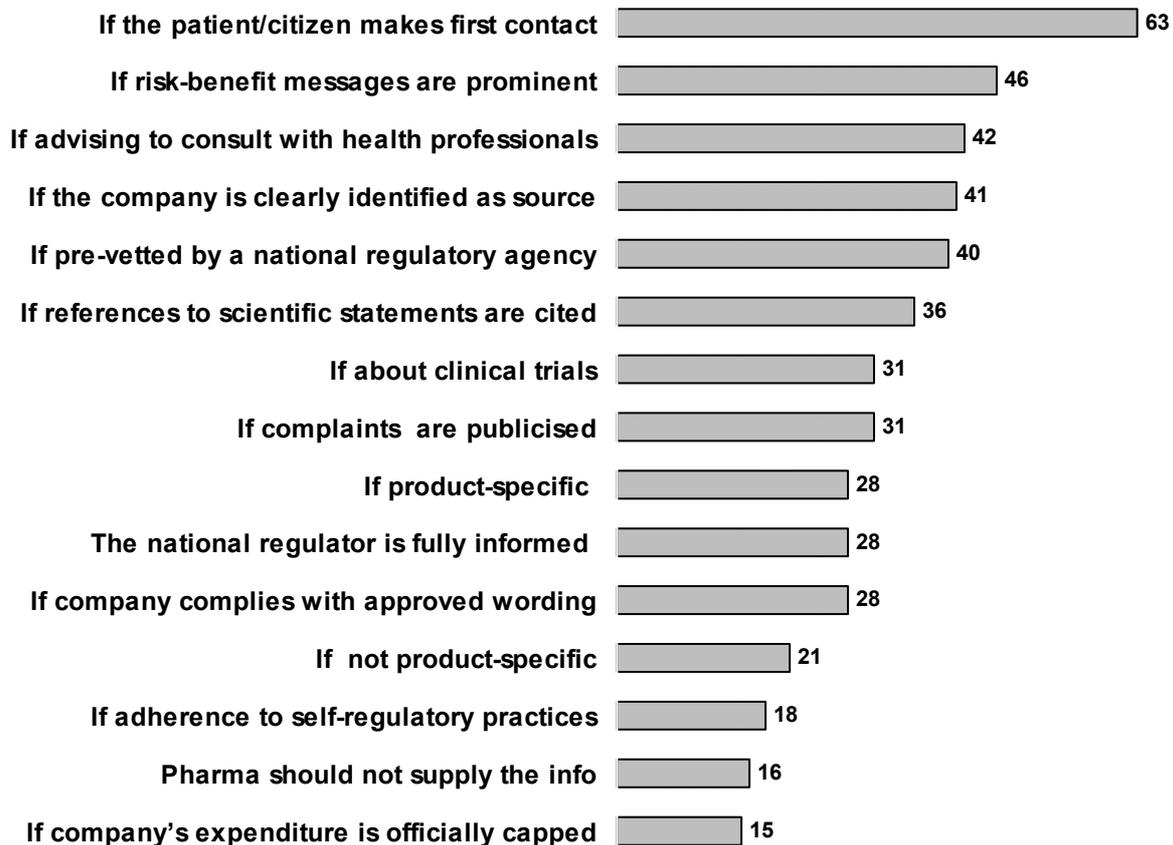
HSCNEWS, August 2006

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**QUESTION 10:**

**DO ANY OF THE FOLLOWING  
CIRCUMSTANCES OFFER A VALID REASON  
FOR PHARMA TO SUPPLY INFORMATION ON  
PRESCRIPTION MEDICINES  
TO YOUR COUNTRY'S PATIENTS/PUBLIC?**

[You may specify more than one item if you wish]  
% of total responses [total = 192]



*Not all columns add up to 100%, as some respondents did not answer the question.*

*Source: HSCNews International, August 2006*

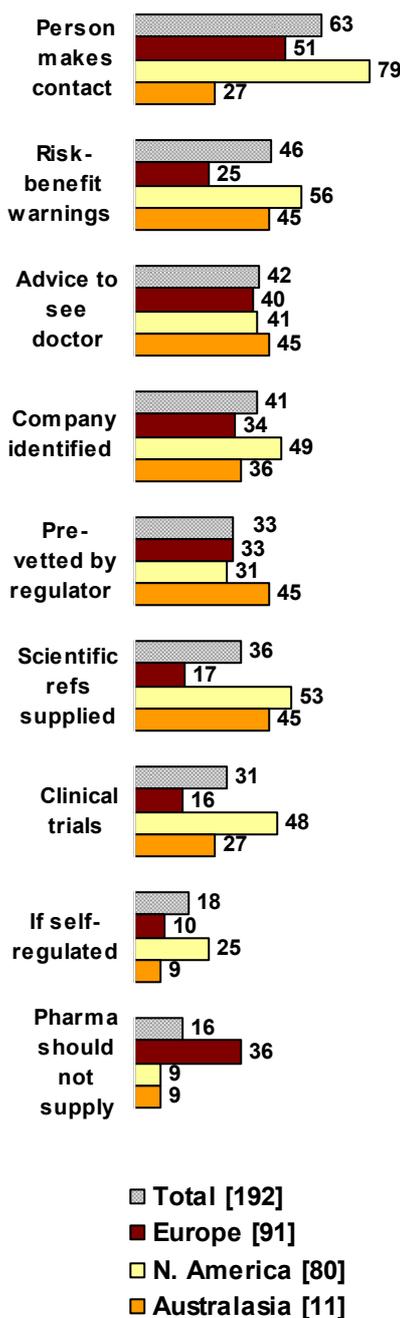
Opposition to pharmaceutical companies supplying the public with healthcare information is stronger in Europe than elsewhere in the world. Over one third of the survey's European respondents disapprove of pharma involvement, versus 16% of the total respondent body. One UK respondent writes: "Information from companies will always be designed to sell their medicines. They are used to getting round constraints". And although only three participants from the 26 respondent cancer groups are against direct contact between pharma and patients/the public, not many of the other cancer respondents wish to highlight circumstances that might justify such a relationship. For instance, no more than 35% of the cancer respondents support the idea of pharma passing information to patients or citizens who initiate the first contact.

But, as with Question 9, the remaining and vast majority of respondents (including two thirds of those from Europe) feel that drug companies should—in theory, at least—be allowed to provide information under certain circumstances. "In my opinion, the patients in both the UK and Europe that I work with want to be informed about medications and therapies available now, and in the future (ie, trials). The majority also wish to have the right to address questions, not only to their healthcare professional, but also to the pharmaceutical industry", reports an executive committee member from the Pulmonary Hypertension Association Europe (PHAE).

Respondents specify a number of the qualifications that they would like to see operational before informational connections between pharma and the public could become a fact. For example, two thirds of all respondents (and over 80% of those from the US) believe that pharma companies are an acceptable source of information if the patient or member of the public is the one who makes the initial approach to the company (rather than vice versa).

Although such contact is permissible in the UK (provided that pharma sticks to certain guidelines), it is not allowed in some other countries (including Italy and the Czech Republic).

**% OF RESPONDENTS SAYING THAT PHARMA IS AN ACCEPTABLE SOURCE OF PRESCRIPTION DRUG INFORMATION IN THE FOLLOWING CIRCUMSTANCES**



Source: HSCNEWS, August 2006

North American and Australasian respondents take a more liberal stand on the range of informational relationships that they estimate should be possible between pharma and patients/the public. For instance, roughly half of North American and Australasian participants (but only one quarter of Europeans) argue that industry/public informational communications are legitimate if risk-benefit warnings are clearly highlighted during the exchange.

Comments from the survey's participants show that health advocacy groups would, in addition, expect careful observation of any informational engagement between pharma and patients and the public. "Because of the conflict of interest, information supplied to the general public by pharmaceutical companies needs to be very carefully monitored", proposes a programme director from a Canadian mental health group.

The bulk of respondents also caution against pharma self-regulating its informational interactions with patients/the public. "Self-regulatory practices? Recent media reports in Australia show that the Medicines Australia members regularly disregard their own Code of Practice", asserts Australia's Chronic Illness Alliance. "Our organisation has had to report a drug company to the ABPI [Association of British Pharmaceutical Industry] because of inaccurate info about recommended treatment options on their website. Thus we are very wary about drug company info, and self regulatory practices", stresses the UK ITP Support Association.

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## APPENDIX: THE SURVEY'S QUESTIONNAIRE

### WHAT ARE THE GOALS OF PUBLICLY-AVAILABLE HEALTHCARE INFORMATION?

**Question 1:** What do you think should be the top three goals of any publicly-available healthcare information in your country?

[Please specify only your top three items]

- Increase awareness of available healthcare services (and the quality of those services)
- Enhance patients' ability to engage in self-care [ie, to care for themselves]
- Enable patients to make informed decisions about their own healthcare and treatment
- Increase awareness of treatment alternatives, based on the latest science
- Facilitate better understanding of information from healthcare providers
- Encourage appropriate use of healthcare products and services
- Improve patients' adherence to treatment regimes
- Produce greater patient/public satisfaction with their healthcare and treatment
- Improve relationships between patients and healthcare providers
- Reduce stigmas attached to certain diseases, and provide psychological support
- Increase healthy behaviours, to help prevent (or slow) progression of disease
- Provide information on patients' rights

*Would you like to mention other goals of importance to you? .....*

**Question 2:** Can you suggest an example/case study from your country that fulfils at least one of the above goals?

[The example may, or may not, be from own organisation]

### WHICH INFORMATION IS NEEDED?

**Question 3:** Do you believe that patients/the public in your country require more or better publicly-available healthcare information on any of the topics listed below?

[Please rank each on a scale of 1 to 5, where  
1 = "Require much more or better information in this area", and  
5 = "Do not require more or better information in this area"]

- General information about disease, diagnosis and treatment options
- Specific information about disease, diagnosis and treatment options relevant to the person's own medical condition
- General information about available healthcare services
- Specific information about available healthcare services relevant to the person's own medical condition
- General information about healthcare policy, legislation and patients' rights
- Specific information about healthcare policy relevant to the person's own local area
- General information about available prescription medications
- Specific information about available prescription medications relevant to the person's own medical condition
- Specific information about a medicine(s) they are already taking
- General information about alternative therapies
- Specific information about alternative therapies for the person's own medical condition

*Can you suggest any other types of publicly-available healthcare information that might be in demand? .....*

**HOW CAN THE INFORMATION BEST BE DELIVERED?**

**Question 4:** Most publicly-available healthcare information (other than that gained through conversation with healthcare professionals) is currently delivered in print form (for instance, as leaflets, or as patient package inserts); through conventional media (such as newspapers, radio, terrestrial and non-terrestrial TV); over the Internet (for instance, on websites, e-forums, or in chat rooms); through email alerts; and via telephone hotlines. Do you believe that these forms of information transmission are likely to satisfy the needs of patients and the public in your country?

[Please rank each on a scale of 1 to 5, where  
1 = "Likely to do a very good job of satisfying the needs of patients/the public", and  
5 = "Not likely to satisfy the needs of patients/the public"]

- Printed leaflets
- Patient package inserts in medicines packaging
- Conventional media
- Internet
- Email alerts
- Telephone hotlines

Comments? .....

**Question 5:** Do you believe that patients/the public in your country are likely to get more or better healthcare information if any of the following relatively new delivery tools becomes widely used? [Note that this question refers only to the effectiveness of the mechanism of delivery, not to who is providing the information—a subject mentioned in Question 8]

[Please rank each on a scale of 1 to 5, where  
1 = Likely to generate much more or better information for patients/the public", and  
5 = Not likely to generate more or better information for patients/the public"]

- Direct marketing to the home [in the form of leaflets through the mail box]
- Telemarketing [unsolicited telephone calls to the home]
- From stand-alone kiosks [in shopping centres, doctors' offices, pharmacists, etc]
- On mobile phones [SMS texting]
- In the cinema, or as features on film DVDs
- Workshops for patients and the public

Comments? .....

**WHAT DETERMINES WHETHER INFORMATION IS TRUSTWORTHY?**

**Question 6:** Do any of the following qualities help to make publicly-available healthcare information in your country trustworthy? [Note that this question refers only to the reliability or trustworthiness of information, not to who is providing the information—a subject mentioned in question 8]

[Please specify only your top three items]

- Accessible to all—the information is totally in the public domain
- Tailored to the person's own area of interest
- Simple, well summarised, and easy to digest
- Centred around evidence-based medicine, and references all sources of information, to validate scientific statements
- Includes the latest available scientific research

- Totally transparent about who is providing the information (including declarations of any vested interests)
- Not promotional in nature or content.
- Adheres to a set of widely-accepted international or national guidelines

Comments? .....

**Question 7: When any of the following recommend a source of healthcare information to patients/the public, whose recommendation are your country's patients and the public most likely to trust?** [Note that this question refers only to the reliability or trustworthiness of the recommender of the information, not to who is providing the information—a subject mentioned in Question 8]

[Please rank each on a scale of 1 to 5, where  
1 = "Regarded as very trustworthy by patients/the public", and  
5 = "Regarded as not trustworthy by patients/the public"]

- Healthcare professional
- Healthcare professional body / academic body
- Conventional news media (TV, newspaper, radio)
- Medical / scientific press
- Patient organisation
- Consumer organisation
- Company within the healthcare industry
- Recommendation / accreditation by the Ministry of Health
- Politician
- An Internet site run by one of the above categories
- An Internet site run by none of the above categories
- Friends and/or family

Comments? .....

#### **WHO SHOULD SUPPLY HEALTHCARE INFORMATION TO THE PUBLIC?**

**Question 8: Which sources of healthcare information do you believe could best fulfil the needs of your country's patients/the public OUTSIDE THE CLINICAL SETTING?**

[You may specify more than one item if you wish]

- Pharmacists
- Payers / insurers [the bodies, organisations or companies that pay medical bills]
- Researchers
- Manufacturers (including medical device companies and pharmaceutical companies)
- Government (EU, national or local)
- Regulators
- Patient organisations
- Consumer organisations
- Organisations representing healthcare professionals
- Universities
- Schools
- General media
- Medical press

- Consumer service companies, such as supermarkets, health clubs, and/or travel agents
- All of the above, since patients/the public prefer to get their healthcare information from multiple sources

Comments? .....

**Question 9: Campaigners' latest views on DTC: do you think that pharmaceutical companies should be able to supply information on prescription medicines to your country's patients/the public if the information goes through any of the following as an accredited third party?**

[You may specify more than one item if you wish]

- An academic or a university
- A government agency
- A body that represents healthcare professionals
- A multi-stakeholder body
- A patient organisation
- Pharmaceutical companies should not be allowed to supply the public with information about prescription medicines under these or other circumstances

Comments? .....

**Question 10: Campaigners' latest views on DTC: do any of the following circumstances offer a valid reason for pharmaceutical companies to supply information on prescription medicines to your country's patients/the public?**

[You may specify more than one item if you wish]

- If the patient/citizen contacts the company and asks for the information
  - If the company clearly identifies itself as the source of the information
  - If the company makes safety and risk-benefit messages prominent in the information
  - If the company includes references and citations to validate scientific statements
  - If the company's information is not product-specific
  - If the company's information is product-specific, but also contains details about disease and diagnosis
  - If the company's information is about clinical trials
  - If the company strongly advises that patients consult a health professional
  - If the information is pre-vetted by the national regulatory agency
  - If the company uses wording that is consistent with that approved by the national regulatory agency
  - If the company fully informs the national regulator of its activities in providing the public with prescription medicines information
  - If the company makes public any complaints made about its information
  - If the company's expenditure on this form of activity is officially capped, to ensure a 'level playing field' for all pharmaceutical company information providers
  - If the company adheres to self-regulatory practices, as set by its national trade association
- Pharmaceutical companies should not be allowed to supply the public with information about prescription medicines under these or other circumstances

Comments? .....

## APPENDIX: RESPONDENT GROUPS THAT WISH TO BE NAMED

Some respondents from the groups listed below answered in a personal, rather than an organisational, capacity. The country in brackets holds each respondent's geographic headquarters.

Advocacy France  
 American Iatrogenic Association  
 Antipsychiatry Coalition [USA]  
 Arthritis Foundation of South Africa, The  
 Asociación de lucha contra la Enfermedad Fibroquística del Páncreas  
 [Argentine Cystic Fibrosis Association, Buenos Aires]  
 Asperger's Syndrome Support Group [USA]  
 Associação Portuguesa de Doentes da Próstata  
 [Portuguese Association of Prostate Diseases]  
 Association "Women Without Osteoporosis" [Bulgaria]  
 Association for Medical and Therapeutic Self-Determination (MeTZef) [Netherlands]  
 Auckland Women's Health Council [New Zealand]

Battle Against Tranquillisers (BAT) [UK]  
 Berkeley-East Bay Gray Panthers [USA]  
 Bloodlink Foundation [Netherlands]  
 Bradford Cancer Support [UK]

Canadian Paraplegic Association, Ontario  
 Cancer Association of South Africa  
 Carcinoid Cancer [USA]  
 Chronic Illness Alliance [Australia]  
 Continence Foundation [UK]  
 Cutis Laxa Internationale [France]  
 Cyprus League against Rheumatism

Deafness Advocacy Association of Nova Scotia [Canada]  
 Degos Disease Support Network [UK]  
 Developing Patient Partnerships [UK]  
 District 69 Society of Organised Support Groups [Canada]  
 Dystonia Association of Kentucky [USA]

Endometriosis Research Center  
 Epilepsy Foundation South Central Wisconsin [USA]  
 Epilepsy Scotland  
 European Federation of Patients Associations for Anthroposophic Medicine (EFPAM)  
 European Kidney Patients' Federation (CEAPIR)

Fonds des Affections Respiratoires (FARES asbl) [Belgium]  
 Foundation for the Support of Bone Marrow Transplantation [Switzerland]  
 Frauenselbsthilfe nach Krebs, Vorarlberg [Women's post-cancer self-help group] [Austria]

GENTEST sro [Czech Republic]

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HEART EU [pan-European]  
 Help for Headaches [Canada]  
 Hepatitis C Project, The [UK]  
 Herpes Viruses Association [UK]  
 HIV/AIDS Network of Southeastern Alberta Association [Canada]  
 Institute of Psychiatry and Neurology, Warsaw [Poland]  
 International Painful Bladder Foundation [Netherlands]  
 Idiopathic Thrombocytopenic Purpura (ITP) Support Association [UK]

Kentro Prostatias Katanaloton (KEPKA) [Consumers' Protection Center] [Greece]  
 Klinefelter Organisation [UK]

Let's Face It [UK]  
 Living Sphere [Australia]

National Alliance for the Mentally Ill (NAMI), Connecticut [USA]  
 National Alliance for the Mentally Ill (NAMI), Dallas [USA]  
 National Alliance for the Mentally Ill (NAMI), Wilmington [USA]  
 National Cancer Society Malaysia  
 National Chronic Pain Society [USA]  
 Nationale Vereniging voor Fibromyalgie-Patiënten "Eendrachtig Sterk" (FES)  
 [National Association for Patients with Fibromyalgia, "Strength in Unity"] [Netherlands]

Neeman Association for Stroke Survivors [Israel]

Organization for Understanding Cluster Headaches, The (OUCH) [USA]

Parents of Autistic Spectrum Disorder Adults (PASDA) [UK]  
 Patient Information Forum [UK]  
 Patients' Rights Advocacy Waikato Incorporated [New Zealand]  
 Planet Janet [UK]  
 Pulmonary Hypertension Association UK (PHA-UK)  
 Pulmonary Hypertension Association Europe (PHAE) [UK]

ReumaNet vzw [Belgium]

Simeonov, Ivaylo (personal), Informed Medical Decision-Making Project [Bulgaria]  
 Sydney Group, The [Australia]

Tourette Spectrum Disorder Association, Inc, The [USA]  
 Tourette Syndrome Association, Inc, Southern California Chapter [USA]  
 Touchstone [UK]  
 Turner Syndrome Society of the United States

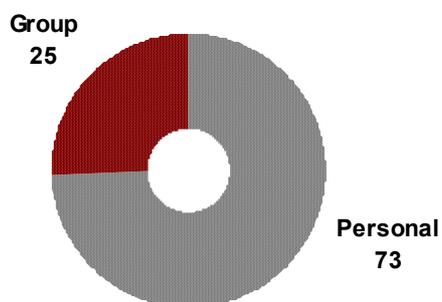
Von Hippel-Lindau (VHL) Family Alliance [USA]

Wegener's and Neuropathy Support Group [Canada]

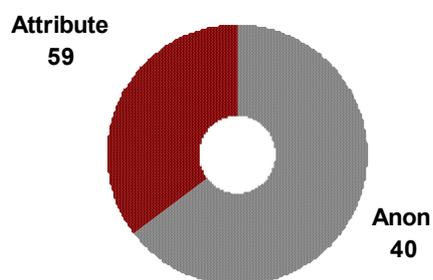
## APPENDIX: PROFILE OF RESPONDENTS

*% OF RESPONDENTS [TOTAL = 192]*

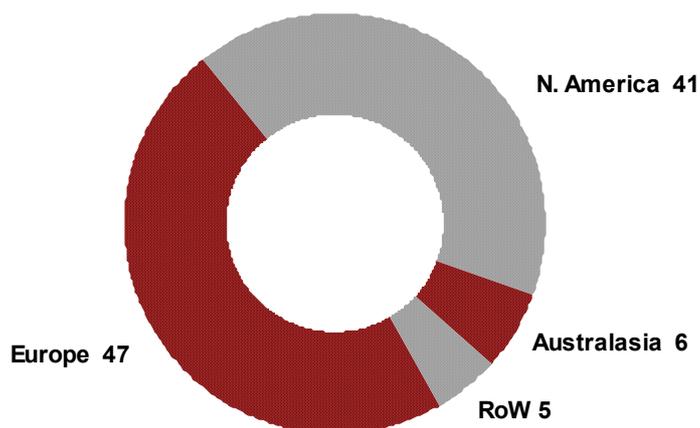
PERCENTAGE OF RESPONDENTS WHO REPLIED ON BEHALF OF THEIR ORGANISATION / PERSONALLY



PERCENTAGE OF RESPONDENT GROUPS THAT WISHED TO BE ATTRIBUTED / ANONYMOUS



GEOGRAPHIC BASE OF GROUPS (%)



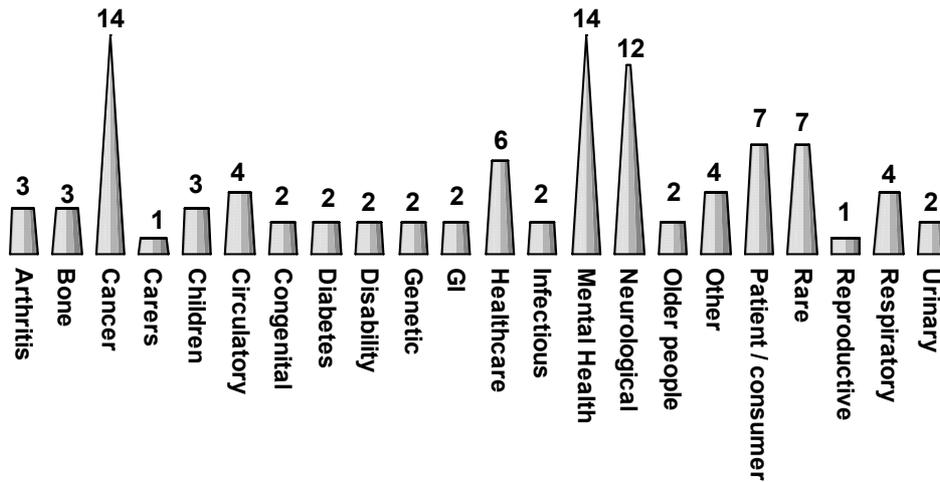
*Not all columns add up to 100%, as some respondents did not answer the question.*

UK represents 52% of European respondents; USA represents 65% of N. American respondents

Source: HSCNews International, August 2006

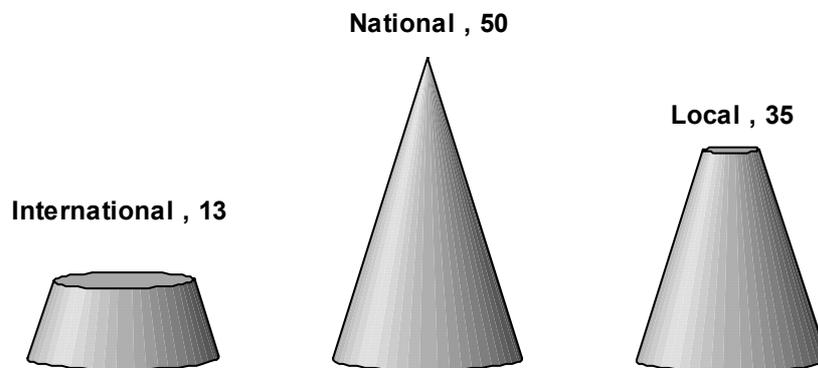
### PROFILE OF RESPONDENTS BY SPECIALITY

% OF RESPONDENTS [TOTAL = 192]



### GEOGRAPHIC REMIT OF RESPONDENTS

% OF RESPONDENTS [TOTAL = 192]



Footnote: Not all columns add up to 100%, as some respondents did not answer the question  
All figures are rounded

Source: HSCNews International, August 2006

# Members' News

—**PATIENT INFORMATION FORUM [UK]**

The Forum acts as UK partner in the *HSCNews* summer 2006 survey on campaigning groups' attitudes to patient information

—**SATELLIFE [US]**

Merger of two American groups

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## A MAJOR RESOURCE TO IMPROVE PATIENT INFORMATION

### THE GROUP BEHIND THE NEWS

The Manchester, England-headquartered Patient Information Forum (PiF) was founded in 1997 as an independent membership body of organisations and individuals united by a desire to see high-quality information developed and disseminated to patients, carers and families.

<http://www.pifonline.org.uk>

Partnering (as a UK 'arm') the *HSCNews* Summer 2006 survey on patient information was the UK umbrella group, Patient Information Forum (PiF).

Operating under the banner "Better communication, better health", the PiF functions as an independent forum for the sharing of best practice on high-quality patient information. The organisation encourages people from any category of healthcare stakeholder (whether patients, patient groups, providers, professionals, academics, regulators, policymakers, or industry) to become members. These members provide the PiF with unrivalled 'hands-on' experience in the creation and distribution of patient information.

The PiF website contains a great deal of useful and highly-practical advice for anyone wishing to become involved in the subject of patient information. Topics examined on site include: "Accessibility and usability"; "Design of health information"; "Establishing and running health information services"; "Evaluating the quality of health information"; "Health literacy"; "Sourcing health information"; "Medicines information"; and "Using electronic media".

The organisation runs numerous conferences, workshops, and seminars on how to ensure that accurate and timely information reaches patients through the appropriate means. PiF plans to expand its services in the future, undertaking formal training on the development and delivery of patient information, and offering an appraisal service for producers of patient information.

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### PiF EVENTS DURING LATE 2006 AND EARLY 2007

Forthcoming networking events managed wholly or jointly by the PiF include the following:

▶ PiF workshop: 'Harnessing Patient Access to Medical Records'.  
Monday, October 2nd 2006, London.  
A half-day workshop that will allow participants to share and learn from the experiences of people working in this field.

▶ 'Scottish Patient Information Conference'.  
Tuesday, November 14th 2006, Glasgow.  
A conference that will concentrate on three aspects of information provision: quality, access, and sharing.

▶ 'Delivering Effective Patient Information: Sharing the Welsh Experience'.  
Tuesday, November 21st 2006, Cardiff.

▶ 'PiF Annual Conference'.  
Wednesday, February 28th 2007, London.

## SATELLIFE MERGES WITH ANOTHER GROUP

### THE GROUP BEHIND THE NEWS

Founded in 1989, the Watertown, Massachusetts-based **SATELLIFE** is an organisation that specialises in creating solutions to the informational needs of healthcare professionals working in resource-poor countries.

SATELLIFE achieves change through three approaches:

1. Disseminating information.
2. Forming communities (global, regional, or local) that share information and conduct mutual support.
3. Supplying information technologies and training local healthcare personnel in their use.

SATELLIFE's online news publication, *HealthNet News*, also appears in three specialist subdivisions—*HIV/AIDS*, *Community Health*, and *Nursing*.

<http://www.healthnet.org>

As of July 1st 2006, SATELLIFE was absorbed by another NGO, the Washington DC-based Academy for Educational Development (AED) [<http://www.aed.org>]. Satellife's activities, structure, staff, location, contact details, and website will all remain relatively unaltered, but its name will change to the **AED SATELLIFE Center for Health Information Technology**.

SATELLIFE and AED are already accustomed to cooperation. Each have worked together before on at least two projects, including:

1. The introduction of 50 hand-held computers into rural Nepalese healthcare centres between 2003-2005 (project funded by US-AID).
2. ProNUTRITION, a website [<http://www.pronutrition.org>] that acts as an informational tool for healthcare workers interested in issues of nutrition. The site contains an electronic discussion group, ProNUT-HIV, through which information on nutrition can be shared.

The merger between the two organisations delivers extra strength and resources to both. AED is an older and much larger group, with almost 2,000 staff and a 2005 budget of US\$286 million [Euros 224 million]. AED runs over 250 aid programmes in the US and numerous developing countries, and concentrates on improving the education,

healthcare, and economic potential of disadvantaged people. AED's financial weight will give SATELLIFE security and the ability to map out its long-term future. In turn, SATELLIFE's expertise will enhance AED's ability to drill down information, medical knowledge, and technological equipment, skill, and training to even the poorest and most remote of localities.

# Campaigns

## —AUSTRALIAN CONSUMERS' ASSOCIATION

The Association draws attention to the ending of funding for the country's Adverse Medication Events Telephone Line

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## A PUSH FOR RENEWED FUNDING FOR AN ADVERSE EVENTS LINE

### THE GROUP BEHIND THE NEWS

Founded in 1959, the Marrickville, New South Wales-based **Australian Consumers' Association (ACA)** is the largest consumer organisation in the country. The Association studies subjects "that really matter to consumers", and is self-financing through the sale of its publications (notably CHOICE magazine).

<http://www.choice.com.au>

The most recent health campaign by the Australian Consumers' Association is an attempt to publicise the cessation of funding on June 30th 2006 for Australia's national Adverse Medicine Events (AME) Line [<http://www.mater.org.au/ame>].

Run on behalf of the Australian Commission on Safety and Quality in Health Care by pharmacists attached to Mater Misericordiae Hospitals (a chain of public and private hospitals in Queensland), the two-year-old toll-free national telephone hotline allows members of the public to report adverse reactions, medication errors, or 'near misses', whether these are in prescription, over-the-counter, or complementary medicines.

An abstract written by two of the pharmacists staffing the AME Line, and presented on June 9th 2006 at Australia's National Medicines Symposium 2006, Canberra, testified to the apparent value of the service [<http://www.icms.com.au/nms2006/abstract/132.htm>]. The abstract noted that the Line was contacted 3,400 times by consumers by its two-year point. The majority of the telephone calls (43%) were triggered by stories in the media, but calls from consumers who were prompted to use the service by health professionals or consumer representatives also figured prominently, at 32%. The abstract authors stated that about 20% of calls generated a report from the AME Line to the Adverse Drug Reactions Committee (ADRAC), which advises on pharmaceutical safety to the Australian government's medicines regulatory agency, the Therapeutic Goods Administration (TGA). Some 5% of calls

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### CLOSING DOWN

The Adverse Medicines Line reported or provided advice on adverse drug reactions or errors associated with medicines use. It was available Australia-wide for the cost of a local call. According to the service's still-operational website, the Adverse Medicine Events (AME) Line:

- Provides consumers with a mechanism to report adverse experiences with medicines.
- Provides an opportunity for consumers to consult with a pharmacist about medicine safety.
- Ensures that consumers' concerns about medicine safety are taken seriously and reported to the relevant authority.

The AME Line was an initiative of the Australian Commission on Safety and Quality in Health Care, and was operated by Mater Misericordiae Health Services Brisbane Limited.

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apparently resulted in an error or quality report. The authors argued that the statistic “compares favourably with signal-to-noise ratio in health professional reporting”.

The abstract's two author's praised the effects of the AME Line, including:

- The identification of over 100 serious reactions and medicine-induced hospitalisations not reported by health professionals.
- The reporting of adverse drug reactions, 20% of which involved symptoms not mentioned in the medicine's prescribing data.

The authors concluded that the service “provides a unique, first-hand perspective on adverse events, different from the health professional perspective”, and that “consumers make a valuable contribution to pharmacovigilance, which is different from, but complementary to, that made by health professionals”.

The Australian Consumers' Association (ACA) agrees that Australian consumers form a valuable resource for information on drug safety. The organisation deplores the ending of funding for, and imminent closure of, the Adverse Medicine Events Line. The country's consumers, says the ACA, should continue to be able to report adverse medicines events directly, without having to return to a system of reporting in which GPs act as intermediaries.

The ACA has identified three potential sources of continued funding for the AME Line:

- The Therapeutic Goods Administration (TGA).
- The AME Line's founding body, the Australian Commission on Safety and Quality in Healthcare.
- The country's National Prescribing Service (NPS).

Unfortunately, the ACA points out that “at this stage, neither the Commission, the NPS, nor the TGA have committed to funding an adverse medicine events line for consumers”.

# Research

—**NATIONAL CANCER INSTITUTE [US]**

2003 and 2005 surveys on the American public's methods of seeking and using information about cancer

—**PICKER INSTITUTE EUROPE [UK]**

A study that seeks to determine whether doctors are trained in patient partnership

## “HOW AMERICANS FIND AND USE CANCER INFORMATION”

The US National Cancer Institute (NCI) [<http://www.cancer.gov>, part of the US National Institutes of Health (NIH)], runs a two-yearly telephone survey of the American public. The survey, entitled Health Information National Trends Survey (HINTS), collects what the NCI believes are “nationally-representative” data about the American public’s use of information on cancer.

The first HINTS was conducted 2002-2003, and took data from 6,369 members of the American public. The second, in 2005, sampled the views of 5,586 respondents. As an ongoing programme, HINTS is well placed to monitor changes in the quickly-evolving subject of healthcare communication.

Some of the questions answered by participating members of the public include:

### ► RESPONDENT’S RELATIONSHIP WITH HEALTH COMMUNICATION

#### Cancer communication

Respondent’s cancer experience/history; their information-seeking habits; their experiences of seeking cancer information; the efficacy of the information; and the sources of the information.

#### Healthcare communication

The respondent’s level of exposure to the media; their exposure to healthcare information; their trust in the information sources; their Internet usage.

### ► RESPONDENT’S SCREENING ACTIVITIES AND KNOWLEDGE OF CANCER

Respondent’s perceived risk of developing various types of cancer; their screening behaviour; their knowledge about the subject; their levels of concern.

### ► RESPONDENT’S CHARACTERISTICS

#### Demographics

Their employment, marital status, income, race/ethnicity, etc.

#### Health Status

Their perception of their own health (including mental health); their healthcare coverage, etc.

Researchers study the data generated by HINTS to:

- Learn how adults exploit the various available informational resources (such as the Internet) to gain important healthcare information for themselves, and their friends and family.

- Check theories of health communication in the information age.
- Build communication strategies capable of surmounting the obstacles that presently prevent the public from accessing health information (thereby improving society's chances of lowering the incidence of cancer in the population).

HINTS data are freely available on the HINTS website [<http://cancercontrol.cancer.gov/hints/about.jsp>] to any visitor who is willing to register.

### **AN INTRODUCTION TO HINTS RESULTS**

An excellent introduction to some of the findings from the HINTS can be found in B. Hesse, R. Moser, L. Rutten, and G. Kreps, 'The health information national trends survey: research from the baseline', *Journal of Health Communication*, 11, vii-xvi, 2006, Supplement.

The authors mention many of the most significant published studies of the HINTS database. The article looks at three types of findings made by HINTS researchers: the public's knowledge of cancer; its cancer cognition and risk

perception; and its efforts at seeking information on cancer.

An example of the sort of study noted by the authors is 'Cancer scanning and seeking is associated with knowledge, by lifestyle choices, and screening behaviour', by M. Shim, B. Kelly, and R. Hornik. The Shim research emphasises the difference between 'information seeking' and 'information scanning': "Seeking can be considered a relatively active process of looking for cancer information when a specific information need arises. Scanning, on the other hand, can be seen as a

more passive state of vigilance to the health information environment."

Using the HINTS baseline data, the Shim study "partitions respondents into groups of seeking versus non-seeking, and high versus low scanning. Both seeking and scanning were found to be significantly related to increased knowledge about cancer, to engagement in preventive health behaviours, and to colorectal and prostate cancer screening. Only scanning was related to reports of recent mammography, suggesting a less-engaged degree of vigilance for this particular type of screening test".

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## ALL QUIET ON THE EDUCATION FRONT

Written by the Picker Institute Europe, *Education for Partnership* scrutinises the degree to which doctors are being trained to function in partnership with patients. The June 2006 report, which draws information from a literature search and through interviews with key medical professionals, investigates the UK situation only (though the authors suspect that their findings might bear relevance to other countries).

*Education for Partnership* introduces its subject by emphasising the importance of a particular element of patient-centred care known as ‘patient partnership’. “Healthcare delivery”, insists the study, “is still characterised by paternalistic attitudes in which the patient’s role in protecting and promoting their own health is not properly recognised and supported”. The document argues that “instead of the clinician being the primary decision-maker and care organiser, clinicians must learn to treat patients as important participants in the process of managing disease”—in fact, as partners.

*Education for Partnership* examines a number of related variables, including:

- What is the concept of patient partnership?
- Does patient partnership appear in medical education?
- Can education make a difference?
- If so, what needs to be done?

The report is certain that “medical education has a key task to play in shaping the attitudes and practice of future doctors. Fostering a culture of partnership between doctors and patients requires doctors to develop a specific set of skills and attributes. In order to engage patients more fully in their own care, they must learn about the theory and practice of developing health literacy, enabling shared decision-making, and supporting self-care—all of which demand excellent communication skills”.

Unfortunately, the report indicates that “there is still a tendency to encourage medical trainees to focus on the disease, rather than the person, downplaying the complexity of both the doctor-patient encounter, and the importance of patients’ values, preferences, and self-knowledge”.

The authors of *Education for Partnership* believe that “if the situation is to improve, students and trainees will need to be taught how to engage with patients as healthcare partners. Patient partnerships should be reinforced at all levels of education—undergraduate, postgraduate, and continuing professional education—if a more balanced relationship is to be achieved between doctors and patients”.

Hasman, A. Coulter, J. Askham, *Education for Partnership: Developments in Medical Education*, June 2006, Picker Institute Europe, PDF, 36 pages.

[http://www.pickereurope.org/Filestore/RapidResponse/E4P\\_report\\_19-5-06\\_with\\_cover.pdf](http://www.pickereurope.org/Filestore/RapidResponse/E4P_report_19-5-06_with_cover.pdf)

# Websites

—SEVEN WEBSITES DEDICATED TO PROVIDING  
HEALTH INFORMATION, OR WHICH ARE  
CAMPAIGNING FOR ITS PROVISION

<http://ec.europa.eu/health-eu> [pan European]

<http://www.eldis.org> [UK]

<http://equipmentdirect.org.uk> [UK]

<http://www.hypertensionfoundation.org/home.cfm> [US]

<http://www.nationalhealthfreedom.org> [US]

<http://www.orpha.net> [France]

<http://psnet.ahrq.gov> [US]

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## **PUBLICLY-AVAILABLE WEBSITES DEDICATED TO PROVIDING HEALTHCARE INFORMATION**

### **<http://ec.europa.eu/health-eu> [pan-European]**

Health EU is the official public health portal of the EU. The site covers all EU 25 Member States, and provides information and data on public health relative to EU policy. For this reason, only medical conditions that interest EU policymakers are mentioned on the site, including: asthma and other respiratory conditions; cancer; cardiovascular disease; dementia; diabetes; HIV/AIDS; influenza and some other communicable diseases; mental health; osteoporosis and other musculoskeletal conditions; and rare diseases.

### **<http://www.eldis.org> [UK]**

Based at the Institute of Development Studies at the University of Sussex, England, and financed by a number of government development agencies, Eldis seeks to be an information gateway that shares the best information about development, policy, research, and practice for southern-hemisphere countries. The site contains 18,000 text documents, newsletters, RSS newsfeeds, country profiles, events, and jobs. Healthcare is only one of many categories of information carried onsite.

### **<http://equipmentdirect.org.uk> [UK]**

Equipmentdirect.org.uk was launched in June 2006. The site is run by the Hampshire Coalition of Disabled People, an English user-led charity that, for the last two years, has been building nationally-oriented, fully-accessible website facilities designed to allow disabled and older people to find equipment and information that can help them live their lives independently. Sponsored by England's Department of Health, the site was awarded over £1 million [US\$1.9 million; Euros 1.5 million] in 2003 by the Treasury to develop a "one-stop shop", in line with the Government's e-policy, to provide a national solution to the statutory service's requirement for self-referral/self assessment. Equipmentdirect.org.uk is the largest free-to-access database of equipment suppliers in the UK. Its features include:

- Online assessment of equipment that could help users. How to get this equipment. Ability to self-refer directly to local social services.
- Browse-able national directory listing suitable equipment and suppliers.
- Useful information on rights and entitlements (in government benefits, healthcare, jobs, education, etc).
- Links to other websites of interest.
- Latest disability news.
- A members' forum.

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**<http://www.hypertensionfoundation.org/home.cfm> [US]**

A website managed by the New York-based Hypertension Education Foundation (HEF), which was founded in 1997 to promote research and education in the field of hypertension. The president of HEF is Dr Marvin Moser, Clinical Professor of Medicine at Yale University School of Medicine. The website contains advice for people who believe they may be hypertensive, and has recommendations on how to manage the condition. Two downloadable patient-education leaflets are available online. The site also holds a number of publications primarily aimed at the medical profession, and which have been published in the *Journal of Clinical Hypertension*.

**<http://www.nationalhealthfreedom.org> [US]**

The website is run by the St Paul, Minnesota-based National Health Freedom Coalition (NHFC), which was founded by lawyers and other professionals to promote access to all healthcare information, as well as services, treatments, and products. As the website points out, the Coalition also wishes to promote an understanding of the laws and factors that have an effect upon the health of Americans. This interactive website is a cornerstone of NHFC's campaigning efforts.

**<http://www.orpha.net> [France]**

Paris, France-based ORPHANET is a database dedicated to information on rare diseases and so-called 'orphan' drugs. The database, which is free of charge to access, aims to improve management and treatment of genetic, auto-immune or infectious rare diseases, rare cancers, or not-yet-classified rare diseases. ORPHANET offers services adapted to the needs of patients and their families, health professionals and researchers, support groups, and industry. The site has links to a number of relevant patient organisations.

**<http://psnet.ahrq.gov> [US]**

This US web resource features the latest news and essential resources on patient safety. The site offers weekly updates of patient-safety literature, and gives details about tools and meetings ("What's New"), plus a vast set of carefully-annotated links to important research and other information on patient safety ("the Collection"). The site is managed by the Agency for Healthcare Research and Quality (AHRQ) of the US government Department of Health and Human Services.



## **HEALTH and SOCIAL CAMPAIGNERS' NEWS INTERNATIONAL**

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PATIENTVIEW  
WOODHOUSE PLACE  
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KNIGHTON  
POWYS, LD7 1NG  
WALES

TEL: 0044-(0)1547-520-965  
FAX: 0044-(0)1547-528-501  
EMAIL: [INFO@PATIENT-VIEW.COM](mailto:INFO@PATIENT-VIEW.COM)

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

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Registered Address for PatientView:  
Millennium Bridge House, 2 Lambeth Hill, London, EC4 4AJ, UK