

Patients' perspectives of healthcare systems in Europe: *A survey of health campaigners*

A Health Consumer Powerhouse Project



PatientView, May 2005

Contact details

Health Consumer Powerhouse

Brussels office
Rue Fossé aux Loups 34, boîte 2, 1000 Bruxelles
Tel: +32-2-218-7393
Fax: +32-2-218-7384
Email: brussels@healthpowerhouse.com

Stockholm office
Högbergsgatan 32, 116 20, Stockholm, Sweden
Tel: +46-8-442-0929
Email: info@healthpowerhouse.com
Mobile phone: +46-70-554-8081

Internet: <http://www.healthpowerhouse.com>

PatientView and *Health and Social Campaigners' News International*

Woodhouse Place
Upper Woodhouse
Knighton, LD7 1NG
Wales
Tel: +44-(0)1547-520-965
Fax: +44-(0)1547-528-501
Email: info@patient-view.com
Internet: <http://www.patient-view.com>

Registered Address for PatientView:
Clements House,
14-18 Gresham Street,
London, EC2V 7NN, UK
Data protection registration number: Z7133076
VAT registration number: GB-760-985-885
Company number: 3944382

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healthcare systems in Europe:
A survey of health campaigners***

May 2005

**A HEALTH CONSUMER POWERHOUSE PROJECT
by PatientView**

May 2005

Contents

Results of survey: highlights	pages 5-15
Appendix 1 (the questionnaire)	pages 16-20
Appendix 2 (named respondents)	pages 21-24
Appendix 3 (respondents' comments)	pages 25-46
Appendix 4 (profile of respondents)	pages 47-51
Appendix 5 (survey results)	pages 52-58

Results of survey: Highlights

In the first two weeks of May 2005, 3,000 health campaigning groups in 12 European countries were sent an email survey containing six simple questions about various aspects of their local healthcare systems. Just over one hundred groups replied. The survey found that respondents considered Switzerland's healthcare system to be the best overall by a significant margin.

The survey

During the first two weeks of May 2005, PatientView (an independent research and publishing organisation) conducted an email survey of approximately 3,000 key health campaigning groups from 12 European countries: Belgium, Estonia, France, Germany, Hungary, Italy, the Netherlands, Poland, Spain, Sweden, Switzerland and the UK (England).

The aim of the survey was to gauge patient/consumer perceptions about the current state of the healthcare systems in the countries in which the groups were headquartered. The survey was commissioned by Health Consumer Powerhouse to complement its other research efforts to estimate the effectiveness of healthcare systems in Europe.

Methodology

The survey was conducted in English. The emails sent to campaigners were introduced by a note of personal invitation from Johan Hjertqvist, head of the Health Consumer Powerhouse. Mr Hjertqvist explained the importance of the survey (the results are due to be released into the public domain at a Brussels-based summit on June 15th 2005). The email also included a questionnaire composed of six short questions. The questions covered a range of topics [see Appendix 1]:

- ▶ Access to a second opinion paid for by the healthcare system.
- ▶ Same-day access to a doctor in a non-emergency situation.
- ▶ Availability of financing for care not reimbursed by the healthcare system.
- ▶ Access to repeat prescriptions.
- ▶ Access to personal medical records.
- ▶ Access to round-the-clock medical advice and information.

Profile of participating groups

The survey attained a total of 102 responses, equating to a response rate of 3.4%—a strikingly good result for a single email shot, given the survey's short two-week time frame, and the fact that the email was only written in a single language (English).

The survey received responses from all of the 12 European countries surveyed (with the exception of Spain, which produced no responses). The highest levels of responses came from England (47) and the Netherlands (18) [Appendix 4].

Respondents were mostly senior executives of well-known patient organisations specialising in disease areas and healthcare interests. Patient groups oriented to arthritis and cancer were particularly well represented among the respondents. Some of the respondent groups acted in a dual capacity, providing care within the healthcare systems analysed. Participants based in the UK included a large number of statutory bodies (11) charged with representing the interests of patients in their local geographic area.

Of the 102 respondents, 38% were local organisations; 62% had a national remit; and 11% worked with international responsibilities. A number of the participating organisations held more than one geographic area of responsibility.

Participants were equally divided among individuals who provided the survey with their personal views, and those who offered the opinions of their organisations. Some respondents commented from both perspectives.

The responses

Access to a second opinion

Ranking of countries according to participants' satisfaction with their access to second opinions [1 ranks highest]			
1=	Belgium / France	7	Germany
3	Switzerland	8	UK (England)
4=	Italy / Netherlands	9=	Hungary / Poland
6	Estonia	11	Sweden
<p>Source: PatientView survey of European healthcare systems, May 2005</p>			

Most European countries stipulate that patients have a right to an alternative medical opinion on their diagnoses and treatment, and that the second opinion should be paid for by the healthcare system. The responses to this survey indicate that such patients' rights exist theoretically, but are rarely applied in practice. Belgium and France are exceptions. All of the respondents in these two countries stated that second opinions were readily available.

The story elsewhere is different. Although the survey's four Swiss participants stated that health insurers in their country pay for second opinions when patients request them, in part because "they help reduce costs", one Swiss respondent qualified that statement. Cheaper Swiss health insurance plans do not cover this patient entitlement, said the other respondent. Italian patients, noted the [Associazione Pugliese Malati Reumatici \(APMAR\)](#) [[Association Pugliese for Patients with Rheumatism](#)], can only get a second opinion for specialist care. The same appears true in Sweden. Polish patients seeking a second opinion must apparently turn to the private sector.

Patient organisations in Estonia, Germany, Poland, Sweden and the UK (England) described various bureaucratic difficulties and geographical inequities facing patients who sought a second opinion. One individual from a UK local statutory group said that English professionals may be insulted by a request for a second opinion, and become difficult and obstructive. Patients in Hungary are too afraid of upsetting their doctor to ask for a second opinion. [Deutsche Leberhilfe e.V.](#) [[German Liver Association](#)] remarked: "It usually requires some negotiations with the healthcare provider. Results are varied, according to patient reports. Sometimes, insurance groups refuse to pay". An arthritis patient organisation from Estonia felt that access to second opinions should be made easier, and ought to be paid for by the Estonian healthcare system.

Other comments mentioned that patients are often uninformed of their right to a second opinion. Meanwhile, [Epilepsie Vereniging Nederland](#) [[Dutch Epilepsy Organisation](#)] noted that a radical reform of the Netherlands healthcare insurance system (scheduled for 2006) will deprive patients of their entitlement to a second medical opinion funded by their state-appointed insurer.

Access to a doctor in a non-emergency situation

Ranking of countries according to participants' satisfaction with access to doctors in non-emergency situations [1 ranks highest]			
1	Belgium	7	Hungary
2	Netherlands	8	Sweden
3=	France / Germany	9	Italy
5	Switzerland	10	Poland
6	UK (England)	11	Estonia
<p>Source: PatientView survey of European healthcare systems, May 2005</p>			

Healthcare systems in many European countries were founded to provide patients with maximum access to medical professionals. But governments seeking to restrain rising healthcare expenditures have since created hurdles to ration demand (such as appointment-only visits, waiting lists, and referral procedures). This is even true in liberal healthcare climates such as Belgium, which scored highest in this survey for access to doctors in non-emergency situations. Belgian respondents said that specialists in their country are not always readily available, and GPs are over-stretched.

For patients in most countries, requesting an appointment to see a specialist on the same day is an impossible hope. [Deutsche Leberhilfe e.V. \[German Liver Association\]](#) noted that the vast majority of German patients with general insurance will have to wait days or weeks to see a specialist. One Hungarian organisation said that doctors in Hungary have so many registered patients that a specialist will take two weeks to see a patient with cancer.

The availability of GPs can be problematic, even in countries such as the Netherlands, which prides itself on the quality of its community care. [Astma Patienten Vereniging \[Asthma Patients' Organisation\]](#) said that nationwide shortages of doctors mean that patients with a chronic condition can find it hard to see a doctor. In Poland, access depends on the vagaries of the doctor. Patients in Belgium, France, Hungary, Italy, the Netherlands, Sweden, Switzerland, and the UK (England) can be allocated another doctor, instead of their own. One local statutory group in England observed: "Practices often have one of their GPs on as a duty doctor, to see people the same day. So, patients don't always see their own or a preferred doctor. People seem happy with that. Problems are more likely when it isn't urgent and the system won't allow pre-booking (even though the system should), because the system is trying to meet 48-hour targets."

Estonian patients usually have to pay out-of-pocket if they want to see a doctor quickly for a non-emergency matter.

Getting funding for care not reimbursed by the state healthcare system

Ranking of countries according to participants' satisfaction with access to private health insurance for care not provided by the state [1 ranks highest]			
1	Belgium	6=	Poland / Sweden
2	Switzerland	8	Estonia
3	Netherlands	9	UK (England)
4	Germany	10	France
5	Italy	11	Hungary

*Source:
PatientView survey of European healthcare systems, May 2005*

Healthcare is provided by the state in all of the countries examined by this survey—bar Switzerland, where care is paid for by private insurance systems. State-run healthcare systems aspire to offer access to the best-possible care. But most, handicapped by finite resources, struggle to do so. Inevitably, limits apply to the availability of state-funded treatments and care. Governments today usually strive to pay for only those medical interventions that can prove their effectiveness. Although many respondents in this survey believed that their healthcare systems paid for all necessary care (but not for cosmetic operations or lifestyle treatments), not all respondents shared that opinion.

This particular question in the survey referred to occasions when patients believe they need a form of care not paid for by the state (or they may simply want to jump a waiting list and get treated more quickly, to avoid pain or a worsening of their condition). One Netherlands cancer patient organisation said that “at least 200 people die each year [in the Netherlands] because they cannot afford expensive medicines”.

Private-sector health insurance is available in all European countries analysed in this survey. But, as one Belgian respondent noted: “Not everyone has a health insurance plan”. A respondent working for an arthritis patient organisation in Estonia said: “Many people still do not have extra health insurance, which would cover some of these costs.”

Specific areas of medicine may be excluded from private insurance cover. According to the [National Rheumatoid Arthritis Society](#) in England, private insurers will not provide coverage for patients with chronic conditions. The same is true for patients who wish to receive weight-loss surgery, said an English obesity patient organisation.

The procedures required to obtain private insurance coverage for exceptional care can be extremely bureaucratic, emphasised one Swiss patient organisation.

If insurance is unavailable, patients typically try to find whatever fees are needed by seeking funding from NGOs, attempting to raise money through charity functions, or—more often—by asking their relatives for a loan, by selling the car, or by borrowing from a bank.

Access to repeat prescriptions

Ranking of countries according to participants' satisfaction with access to repeat prescriptions [1 ranks highest]			
1	Switzerland	7	Hungary
2	Sweden	8=	France / Italy
3	UK (England)	10	Belgium
4=	Estonia / Germany	11	Poland
6	Netherlands		

Source:
PatientView survey of European healthcare systems, May 2005

In almost every European country, obtaining access to medicine is a lengthy and inconvenient process—particularly for patients with a chronic condition. Doctors must first authorise a prescription. The patient then visits the doctor, taking the prescription on to the local pharmacy to be filled. Part of the justification for the red tape is that it allows doctors to keep a watchful eye on their patients. In many instances, though, repeat prescriptions could be given out quite safely without this level of formality. Some healthcare systems have recently been trying to streamline their repeat-prescription procedures.

The majority of survey participants (except those from Poland) said that their healthcare systems have taken steps to improve patient access to repeat prescriptions. In Poland, observed the [Stowarzyszenie Pacjentów Primum Non Nocere \[Polish Patients' Association\]](#), no clear guidelines exist about repeat prescriptions because the healthcare system is undergoing continuous reform. In Germany, the Netherlands, Sweden, and the UK (England), by contrast, groups noted that patients may only need to telephone their clinic to get repeat prescriptions. For asthma patients in the Netherlands, repeat prescriptions can be automatic, said [Astma Patienten Vereniging \[Asthma Patients' Organisation\]](#).

Switzerland appears to have the most efficient system of all. Three patient organisations, specialising in different conditions, stated that once a doctor indicates a repeat prescription for a patient, future medicines can be collected from the pharmacist whenever the patient telephones or emails for a renewed supply.

Some strictures limit the prescribing and dispensing of repeat prescriptions. Survey participants said that repeat-prescription patients are required to obtain regular check-ups from doctors, at intervals varying across conditions and from doctor to doctor. Patients with serious and life-threatening illnesses (or who are on dangerous drugs) are usually obliged to see a doctor before obtaining a prescription. Belgian patients with a mental health problem may only receive a repeat prescription if they can demonstrate that they fully understand the nature of their treatment and illness, said [De Vlaamse Vereniging Voor Manisch Depressieven \[Flemish Organisation for Bipolar and Chronic Depressives\]](#). "This is one of the areas in which we try to educate our members", added the Belgian organisation.

Access to medical records

Ranking of countries according to participants' satisfaction with patients' access to their own medical records [1 ranks highest]			
1	Sweden	6=	Estonia / Poland
2	Hungary	8=	Belgium / Italy
3	Netherlands	10	France
4	Germany	11	UK (England)
5	Switzerland		

Source:
PatientView survey of European healthcare systems, May 2005

The EU Data Protection Act of 2000 required that individuals should be able to access all personal information, including their medical records (except when the information in the records could cause harm to the patient, or when third-party information is contained within the record). Media exposés of medical error and unpleasant side-effects have made patients aware of the fallibility of their treatments and healthcare providers. Some patients have sought access to their medical records, to learn more about the story behind their care.

Only Hungarian and Swedish respondents believed that patients can easily gain access to their medical records. However, one Hungarian respondent pointed out that patient records are frequently written in Latin medical terminology, and are therefore unintelligible to most patients.

Participants from other countries reported that doctors do not always comply with the letter of the EU law. Half or more of the respondents in Belgium, Estonia, France, Hungary, Italy, Poland, Switzerland, and the UK (England) believed that procedures to access medical records were overly bureaucratic. [Schildklierstichting Nederland \[Dutch Thyroid Foundation\]](#) stated: "By law, patients are allowed to read their records. However, GPs and hospitals, etc, are unused to patients insisting on this right. Most hospitals have rules (such as: make an appointment, pay for copies) to make the records accessible." According to two of the survey's four Swiss participants, patients can only view their medical records under the supervision of a medical professional. An English patient group said that, in some circumstances, a fee is charged even when the person requesting the information can ill-afford to pay the sum.

Doctors are not always co-operative, and may claim that the appropriate medical records have been lost, argued survey participants from Germany. The [Child Brain Injury Trust](#) in England also referred to difficulties in accessing medical records experienced by parents considering a legal challenge to a medical authority.

A cancer patient organisation from the Netherlands and a UK-based hepatitis group pointed out that older patients may not be aware of their legal rights.







Round-the-clock access to healthcare information and support






Ranking of countries according to participants' satisfaction with patients' access to round-the-clock healthcare information and support [1 ranks highest]			
1	UK (England)	7	Netherlands
2	Sweden	8	Hungary
3=	Switzerland / Germany	9	Estonia
5	Poland	10	Italy
6	Belgium	11	France
Source: <i>PatientView survey of European healthcare systems, May 2005</i>			

Healthcare systems have traditionally care for patients in institutional silos (the doctor's office, hospital, outpatient department, speciality clinic). But patients can fall sick anytime, anywhere. Some need support or information in the middle of night—when healthcare services are restricted. IT now allows patient needs to be serviced 24 hours a day (albeit remotely.)

The English National Health Service (NHS) has spearheaded an initiative to meet the round-the-clock health requirements of patients. Called 'NHS Direct', this telephone facility is staffed by nurses and supported by computer programmes. NHS Direct was uniformly applauded by English survey participants—although they also specified that the service was unavailable in certain locations. In addition, said one participant, NHS Direct was not well briefed on all disease conditions.

Elsewhere, the picture is less rosy. One French participant said that information and support is only available on public-health campaigns, or in an emergency situation (such as HIV/AIDS, or a person contemplating suicide). Patient information in Hungary is very basic, said one organisation specialising in adult cancers. A Netherlands patient organisation dealing in orthopaedics noted that post-operative patients take home a 24-hour telephone number to call if a problem occurs. [Epilepsie Vereniging Nederland \[Dutch Epilepsy Organisation\]](#) stated that several insurers provide telephone information and advice (though few do so around the clock). [Förbundet Blödarsjuka i Sverige \[Swedish Haemophilia Society\]](#) explained that telephone support was only available for specific medical conditions, such as haemophilia. An arthritis organisation in Estonia commented: "I have never heard that we have [a round-the-clock advice service]. It is well hidden, if we have one. The biggest problem is lack of information. People do not know their rights. And even if you have to get some kind of service/treatment/rehabilitation, then you just cannot get it. Patients are not in a good situation. Our legislation is not supporting the patient, and this has to be changed also."

						
	Belgium	England	Estonia	France	Germany	Hungary
Background data <i>Latest available figures</i>						
✳ <i>PPP = Purchasing Power Parity</i> † <i>Statistics are for the UK, not England</i>						
Population in millions	10	60 †	1.3	61	82.4	10
% of population over 65	17	16 †	17	16	19	15.1
Life expectancy at birth	79	78 †	72	83	79	72.4
PPP ✳ per person per year US\$'000	36	30 †	14	29	29	14.9
HIV/AIDS prevalence in adults as a %	0.2	0.2 †	1.1	0.4	0.1	0.1
Diabetes type-2 prevalence among 20-79 year olds	4.2	3.9 †	9.7	6.2	10.2	9.7
Type of healthcare system I = insurance based T = tax based	I	T	I	I	I	I
Patients' perceptions of their healthcare system: Which country's system is the best?						
Points are allocated on the basis of rankings. 1st in the rankings gains a score of 11. Last in the rankings gains a score of 1						
Access to a second opinion	11	4	6	11	5	3
Access to a doctor in a non-emergency situation	11	6	1	9	9	5
Access to funding for care not reimbursed by the state	11	3	4	2	8	1
Access to repeat prescriptions	2	9	8	4	8	5
Access to medical records	4	1	6	2	8	10
Access to round-the-clock medical advice	6	11	3	1	9	4
Total out of a possible 66	45	34	28	29	47	28
<i>... continued on next page</i>						

	 Italy	 Netherlands	 Poland	 Sweden	 Switzerland
Background data <i>Latest available figures</i>					
<i>✖ PPP = Purchasing Power Parity</i>					
Population in millions	58	16.4	39	9	7.5
% of population over 65	19	14	13	17	15
Life expectancy at birth	80	79	70	80	80
PPP ✖ per person per year US\$'000	28	30	12	28	34
HIV/AIDS prevalence in adults as a %	0.5	0.2	0.1	0.1	0.4
Diabetes type-2 prevalence among 20-79 year olds	6.6	3.7	9.0	7.3	9.5
Type of healthcare systems I = insurance based T = tax based	T	I	I	T	I (private)
Patients' perceptions of their healthcare system: Which country's system is the best?					
Points are allocated on the basis of rankings. 1st in the rankings gains a score of 11. Last in the rankings gains a score of 1					
Access to a second opinion	8	8	3	1	9
Access to a doctor in a non-emergency situation	3	10	2	4	7
Access to funding for care not reimbursed by the state	7	9	6	6	11
Access to repeat prescriptions	4	6	1	10	11
Access to medical records	4	9	6	11	7
Access to round-the clock medical advice	2	5	7	10	9
Total out of a possible 66	42	47	38	42	54
Sources: CIA; IDF; Office for National Statistics (UK); Department for Work and Pensions (UK); PatientView survey of European healthcare systems (May 2005)					

Ranking of countries according to participants' satisfaction with access to various healthcare services and facilities [1 ranks highest]	
1	Switzerland
2	Germany
3	Netherlands
4	Belgium
5	Sweden
6	UK (England)
7	France
8	Hungary
9	Italy
10	Estonia
11	Poland
Source: <i>PatientView survey European Healthcare systems, May 2005</i>	

Conclusion

When the rankings of the eleven countries are amalgamated, Switzerland takes the lead as the country with the best healthcare system from the patient perspective. In the survey's six questions, Switzerland scored first, second, third (twice), and fifth (twice).

Switzerland, of course, is the one country among the 11 analysed that has no state-run healthcare system. But Switzerland is exceptional in other ways, too—which may, in part, explain the survey's result. The country has one of the smallest populations among the European countries surveyed (apart from Estonia). And only 15% of the Swiss population are over 65 years of age. In Germany and Italy, by contrast, 19% of the population are aged over 65. Older people place greater demands on healthcare systems.

Nonetheless, this survey suggests that lessons are clearly there to be learned from Swiss healthcare providers and policymakers. The Swiss seem to know more than most countries about improving patient satisfaction by allowing access to healthcare services and facilities.

Appendix 1: Letter of introduction and questionnaire

Dear health campaigner,

I am writing this brief introduction to explain why we would like you to participate in the following very short, six-question e-mail survey by Health Consumer Powerhouse. We are approaching you because of your knowledge of the patient/consumer perspective in your particular area of healthcare expertise.

This short survey hopes to uncover a true picture of how effectively the healthcare systems of 12 European countries work on behalf of patients.

The survey results will form the basis of an article in the June 2005 issue of *HSCNews International*. The survey results will also be fed into a novel **EuroHealth Consumer Index 2005** (due to be unveiled at the 'Health Consumer Summit 2005', hosted by Christoffer Fjellner, MEP, at the Bibliotheque Solvay, Brussels, on June 15th 2005, 3pm-8pm). The *EuroHealth Consumer Index* aims to assist patients and consumers in their campaigns for better healthcare.

To thank you for participating in this short survey, the survey manager, Health and Social Campaigners' Network International, will send you an invitation to attend the 'Health Consumer Summit 2005'. Later in June, you will be sent the June 2005 issue of *HSCNews International* (containing the survey findings), plus a copy of the *EuroHealth Consumer Index 2005*. In addition, you will receive a complimentary one-year membership of Health and Social Campaigners' Network International (entitling you to monthly issues of *HSCNews International*).

I strongly urge you to participate in the survey. The simple questionnaire is below. Hopefully, it should only take about five minutes of your time to complete.

Yours sincerely,

Johan Hjertqvist
 Founder and President
 Health Consumer Powerhouse
Europe's do-tank for better health
<http://www.healthpowerhouse.com>
 Stockholm and Brussels

.....

Note from the survey manager, Health and Social Campaigners' Network International

- + The survey is European. It is being sent to patient and consumer groups.
- + The survey's findings will enter into the *EuroHealth Consumer Index 2005*, and will feature in an article in the June 2005 issue of *HSCNews International* (copies of both due to be sent to respondents in mid-June 2005).

- + You can answer the survey anonymously. Or you can request that your group be attributed in the survey report.
- + No pharmaceutical companies, medical device companies, or health insurance companies are involved in this project.

To fill out the questionnaire, simply hit the reply or forward button to this email, enter your answers in the boxes supplied, and press 'Send'. Your responses will be returned back to Health and Social Campaigners' Network International.

Any further correspondence should be addressed to Health and Social Campaigners' Network International (contact details are at the end of this email).

Patient perspectives on six key healthcare indicators: European survey of patient and consumer groups

SURVEY OBJECTIVE:

"To compare the extent to which the national healthcare systems of Europe are designed to fit the patient and consumer"

The Questionnaire

Question 1/6: Access to a second opinion

If patients (with whom your organisation is familiar) believe that they have been given inadequate diagnosis and treatment, can they readily obtain a second opinion paid for by their country's healthcare system? [You may specify more than one answer if you wish]

- [] Yes—patients can easily obtain a second opinion paid for by the nation's healthcare system.
- [] Yes—but only for specialist (secondary) care.
- [] Yes—but not in all parts of the country.
- [] Yes—but bureaucratic procedures hinder the process.
- [] Sometimes—it depends on the healthcare provider.
- [] No—the system will not pay for a second opinion.
- [] I do not know.

If you would like to add a short comment on the ease, or otherwise, with which patients familiar to your organisation can get a second opinion:

Question 2/6: Access to doctors in non-emergency situations

If patients (with whom your organisation is familiar) wake up feeling unwell, but the ailment does not seem to be life-threatening, can they get an appointment that same day with their own doctor? [You may specify more than one answer if you wish]

- [] Yes.
- [] Yes—but not in all parts of the country.

- Yes—but they may be allocated another doctor instead of their own.
- Sometimes—it depends on the doctor.
- No.
- I do not know.

If you would like to add a short comment on the ease, or otherwise, with which patients familiar to your organisation can get a same-day appointment:

.....

Question 3/6: Seeking funding for care not reimbursed by the state

If patients (with whom your organisation is familiar) want an operation that is not paid for by your country's healthcare system, what do you think may be their best option for funding the considerable cost of the operation? [You may specify more than one answer if you wish]

- Re-mortgaging the house.
- Taking out a bank loan.
- Borrowing from relatives.
- Health insurance plans cover such circumstances.
- No easy options at all, unfortunately.
- I do not know.

Other options that you might like to suggest (or if you would like to add a comment on the ease or otherwise of patients funding operations themselves):

.....

Question 4/6: Access to repeat prescriptions

Can patients (with whom your organisation is familiar) get repeat prescriptions filled without having to make an appointment to see their doctor?

- Yes.
- Yes—but not in all parts of the country.
- Sometimes—it depends.
- No—an appointment with a doctor is necessary first.
- I do not know.

If you would like to add a short comment on the ease, or otherwise, with which patients familiar to your organisation can get a repeat prescription:

.....

Question 5/6: Access to medical records

Are patients (with whom your organisation is familiar) allowed to read their own medical records? [You may specify more than one answer if you wish]

- Yes—no restrictions.

- Yes—but not in all parts of the country.
- Yes—but some bureaucracy applies.
- Yes—but only under the supervision of a medical professional.
- Sometimes—it depends.
- No.
- I do not know.

If you would like to add a short comment on patients' freedom (or otherwise) to read their own medical records:

Question 6/6: Access to healthcare information

Does your country's healthcare system offer patients or consumers a 24-hour, round-the-clock telephone information-and-advice service on healthcare matters?
 [You may specify more than one answer if you wish]

- Yes.
- Yes—but only on general healthcare matters, not on specific medical conditions.
- Yes—but not in all parts of the country.
- Not presently—but plans to.
- No.
- I do not know.

If you would like to add a short comment on this subject:

Lastly, some profiling questions:

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

- Personal.
- My organisation.

b.) What are the geographic areas of interest for your organisation?

- Local.
- National.
- International.

c.) In what country is your organisation based?

.....

d.) In what area of expertise does your organisation specialise?

.....

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

.....

Do you wish your responses to:

Remain anonymous.

Be attributed to your organisation in the report that will be sent to all respondents (please confirm the name of your organisation):

Thank you for your time. That concludes the survey.

The aggregated survey results will be sent to you in mid-June 2005

Yours sincerely,

Survey manager,

Dr Alexandra Wyke

CEO

PatientView and Health and Social Campaigners' Network

Woodhouse Place, Upper Woodhouse, Knighton, Powys, LD7 1NG, Wales

Tel: 0044-(0)1547-520-965

Fax: 0044-(0)1547-528-501

Email: info@patient-view.com

For more information on PatientView, Health and Social Campaigners' Network,

or *HSCNews International*: <http://www.patient-view.com/hscnetwork.htm>

Appendix 2: Groups that wanted to be named as respondents to this survey

Weblinks to groups are given when available

Belgium

De Vlaamse Vereniging Voor Manisch Depressieven
[Flemish Organisation for Bipolar (and Chronic) Depressives]
<http://www.vvmd.be>

Fondation contre le Cancer
[Foundation against Cancer]
<http://www.cancer.be>

Psoriasis Stichting Vzw
[Psoriasis Association]
<http://www.psoriasis-vl.be>

Vlaamse Vereniging voor Bechterew-Patiënten vzw
[Flemish Organisation for Rheumatic Patients]
<http://www.vlaamspatientenplatform.be>

Estonia

Eesti Patsientide Esindusühing (EPE)
[Estonian Patients' Advocacy Association]

France

AIDES Ile-de-France
<http://www.aidesidf.com>

Association Pour la Lutte Contre le Psoriasis (APLCP)
[Association for the Fight Against Psoriasis]
<http://www.aplcp.org>

Germany

Deutsche Leberhilfe e.V.
[German Liver Association]
<http://www.leberhilfe.org>

Dagmar Hailer of the **Hepatitis-Selbsthilfe Schleswig-Holstein**
[Hepatitis Self-Help Group, Schleswig-Holstein;
member of Deutsche Leberhilfe e.V., Köln]

Italy

Associazione Pugliese Malati Reumatici (APMAR)
[Association Pugliese for Patients with Rheumatism]
<http://www.alzheimer.it>

Federazione Alzheimer Italia
[Italian Alzheimer's Federation]
<http://www.associazionepugliesemalatioreumatici.it>

Appendix 2: Groups that wanted to be named as respondents to this survey

Italy – continued

Pisa University Hospital

<http://www.diab.it>

Netherlands

Astma Patienten Vereniging

[Asthma Patients' Organisation]

<http://www.astmapatientenvereniging.nl/>

Balans (Groot Den Haag)

<http://www.balansgrootdenhaag.nl>

DEBRA The Netherlands

<http://DebRA.nl>

Epilepsie Vereniging Nederland

[Dutch Epilepsy Organisation]

<http://www.epilepsienukanhetbeter.nl>

Nederlandse Coeliakie Vereniging

[Dutch Coeliac Disease Organisation]

<http://www.coeliakievereniging.nl>

**Nederlandse Vereniging Voor Fibromyalgie-Patiënten
'Eendrachtig Sterk' (F.E.S.)**

[Dutch Association for Patients with Fibromyalgy]

<http://www.fesinfo.nl>

**Netherlands Institute for Health Services Research (NIVEL),
Department of General Practice, University of Nijmegen**

[member of Mental Health Europe]

Schildklierstichting Nederland

[Dutch Thyroid Foundation]

<http://www.schildklier.nl>

Stichting depersonalisatie

<http://www.depersonalisatie.nl>

Stichting Gezond Gewicht

<http://www.gezond-gewicht.nl>

Poland

Polish Association of Young Patients with Arthritis

Stowarzyszenie Pacjentów Primum Non Nocere

[Polish Patients' Association]

<http://www.sppnn.org.pl>

Institute of Psychiatry and Neurology, Warsaw, Poland

[member of Mental Health Europe]

Appendix 2: Groups that wanted to be named as respondents to this survey

Sweden

Astma- och Allergiförbundet
[Swedish Asthma and Allergy Association]
[http:// www.astmaoallergiforbundet.se](http://www.astmaoallergiforbundet.se)

BCF Emelie Bohuslän

Bröstcancerföreningarnas Riksorganisation-BRO
[Swedish Association of Breast Cancer Societies]
<http://www.bro.org.se>

Förbundet Blödarsjuka i Sverige
[Swedish Haemophilia Society]
<http://www.fbis.se>

Migränsföreningen Stockholm
[Migraine Association, Stockholm]

Switzerland

Help C (Deutschschweiz)
www.hepatitis-info.ch

UK (England)

Blackburn and District Blind Society
<http://www.blackburnblind.org.uk>

British Obesity Surgery Patient Association
<http://www.bospa.org>

Child Brain Injury Trust
<http://www.cbituk.org>

Congenital Adrenal Hyperplasia (CAH) Support Group (UK)
<http://www.cah.org.uk>

East Dorset Mencap

Elaine Dowell of the **Encephalitis Society**
<http://www.encephalitis.info>

Epilepsy Network Gravesend

First Steps to Freedom
<http://www.first-steps.org>

The Hepatitis C Project
<http://www.hepatitiscproject.org.uk>

Heplats Brighton

Jo's Trust Fighting Cervical Cancer
<http://www.jotrust.co.uk>

Appendix 2: Groups that wanted to be named as respondents to this survey

UK (England) – continued

Let's Face It

<http://www.letsfaceit.force9.co.uk/>

The ME Association

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

National Association for Patient Participation

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

National Rheumatoid Arthritis Society

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

National M.E. (myalgic encephalomyelitis) Centre

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

Oxfordshire Council of Disabled People (OCDP)

People First Limited

<http://www.peoplefirstltd.com/>

SIRI Counselling

<http://www.siricounselling.com>

Triple X Support Group

<http://www.triple-x.org>

Uveitis Information Group

<http://www.uveitis.net>

Appendix 3: Comments of respondents

Comments are listed in the order of receipt

BELGIUM**Access to a second opinion**

- ▶ **Group dealing with a form of arthritis:** "We are free to go to any doctor or other healthcare provider we want."

Access to a doctor in a non-emergency situation

- ▶ **Group specialising in a form of arthritis.** "Depends if it is a GP or a specialist. Specialists are not always available."
- ▶ **De Vlaamse Vereniging Voor Manisch Depressieven [Flemish Organisation for Bipolar and Chronic Depressives].** "By telephone. Patients have to search till they find the doctor who is always available for them."
- ▶ **Vlaamse Vereniging voor Bechterew-Patiënten vzw [Flemish Organisation for Rheumatic Patients].** "Patients will have to go to the doctor's office. The doctor might not come to the patient's home."

Seeking funding for care not reimbursed by the state

- ▶ **Group specialising in a form of arthritis.** "Not everyone has a health insurance plan."
- ▶ **De Vlaamse Vereniging Voor Manisch Depressieven [Flemish Organisation for Bipolar and Chronic Depressives].** "As our organisation deals with bipolar patients, we are sending a letter to the Minister of Health, or to another Minister, until we find the right solution."
- ▶ **Vlaamse Vereniging voor Bechterew-Patiënten vzw [Flemish Organisation for Rheumatic Patients]:** "People might organise something to raise some money. But, most of the time, that won't bring in enough funds."

Access to repeat prescriptions

- ▶ **Group specialising in a form of arthritis.** "Depends on the doctor."
- ▶ **De Vlaamse Vereniging Voor Manisch Depressieven [Flemish Organisation for Bipolar and Chronic Depressives].** "Patients can get a repeat prescription on condition they know what they want, and—perhaps more importantly—they can tell the specialist what's really happening to them. So they have to know a lot about their own illness. This is one of the areas in which we try to educate our members."

BELGIUM (CONTINUED)**Access to repeat prescriptions (continued)**

- ▶ **Group dealing with a form of arthritis.** “Some doctors write repeat prescriptions, but mostly for people with a chronic disease.”

Access to medical records

- ▶ **Group specialising in a form of arthritis.** “This is a relatively new issue, so the possibilities are not yet very well known.”
- ▶ **De Vlaamse Vereniging Voor Manisch Depressieven [Flemish Organisation for Bipolar and Chronic Depressives].** “If a patient is in a life-threatening situation, than the specialist can decide to refuse to give that patient his or her medical records. However, if the patient gives his/her approval to a second person, then the professional is obliged to provide information from the patient's medical record.”
- ▶ **Vlaamse Vereniging voor Bechterew-Patiënten vzw [Flemish Organisation for Rheumatic Patients].** “If the patient agrees, hospitals will allow the patient's doctor to have immediate access to their medical records.”

**ESTONIA****Access to a second opinion**

- ▶ **Group specialising in a form of arthritis.** “It is difficult to get a second opinion from specialists from other EU countries. It should be more accessible and covered by the healthcare system.”

Access to a doctor in a non-emergency situation

- ▶ **Group specialising in a form of arthritis.** “Many doctors also have a private practise, and you can go there—but you have to pay. This is not covered by the healthcare system.”

Seeking funding for care not reimbursed by the state

- ▶ **Group specialising in a form of arthritis.** “The situation in our country is very bad. People wait for years to get an operation that they need. The worst affected are people from small towns and villages. Many people still do not have extra health insurance to cover some of these costs”.

ESTONIA (CONTINUED)**Access to medical records**

- ▶ **Eesti Patsientide Esindusühing (EPE) [Estonian Patients' Advocacy Association]**. "According to Estonian laws, patients are allowed to get copies of their medical records. But there are cases (usually in psychiatry) when patients are denied access to their records."

**Round-the-clock access
to healthcare information and support**

- ▶ **Group specialising in a form of arthritis**. "I have never heard that we have one. It is well hidden, if we have. The biggest problem is lack of information. People do not know their rights. And, even if you have to get some kind of service/treatment/rehabilitation, then you just cannot get it. Patients are not in a good situation. Our legislation is not supporting the patient, and this has to be changed also."

FRANCE**Access to medical records**

- ▶ **AIDES Ile-de-France**. "Access—but generally some delay, and sometimes expense."

**Round-the-clock access
to healthcare information and support**

- ▶ **AIDES Ile-de-France**. "For some specific public-health issues, such as HIV/AIDS, drugs, suicide, etc."



GERMANY

Access to a second opinion

- ▶ **Deutsche Leberhilfe e.V. [German Liver Association].** “It usually requires some negotiations with the healthcare provider. Results are varied, according to patient reports. Sometimes insurance groups refuse to pay; sometimes they support getting a second opinion. Sometimes they refuse at first, but give in later if patients insist. Insurers then take the necessary bureaucratic steps.”
- ▶ **Dagmar Hailer of the Hepatitis-Selbsthilfe Schleswig-Holstein, Deutsche Leberhilfe e.V., Köln [hepatitis self-help group and member of the German Liver Association, as mentioned above].** “Within four months, you may go to another doctor. But, then you must pay 10 Euros there!!”

Access to a doctor in a non-emergency situation

- ▶ **Deutsche Leberhilfe e.V. [German Liver Association].** “You may turn up at your general practitioner's practice the same day. If patients go to a clinic, they will often have to wait several hours, but still be checked the same day. On the other hand, it is often difficult to get an appointment with a specialist on the same day. There is a two-class system in Germany:
 - **Patients who have general insurance (the vast majority)** usually have to wait longer—which may take a few days or even six-to-eight weeks in some specialist practices/clinics (unless it's an emergency). Also, general insurance patients sometimes have to insist strongly to have some tests conducted, or offer to pay for those tests out of their own pockets.
 - **Patients with private insurance** may quickly get any appointment in a specialist practice/clinic. Medical actions for private patients are partially paid by patients themselves, and well reimbursed by private insurers. While the reimbursement is fixed for general insurance patients, reimbursement for patients in private insurance may be multiple times higher. This may lead to situations where private patients are over-treated, or where unnecessary serological or histological tests are being made for unlikely diseases. Some black sheep may even list fictional additional treatments or tests on the bill to private insurers, or exaggerate the situation, such as ‘in-depth counselling’ (which is legally questionable, of course). On the other hand, a private insurer may refuse to cover the cost of treatments/checks which obviously make no sense to them. Note that the above points DO NOT describe the general situation for German specialist doctors. Some specialists even swim against the stream, and try to give equal and quick care to all patients. These doctors become popular and are soon overrun by patients—which makes it harder for them to give quick appointments. A special situation applies if patients are in the middle of a demanding therapy (for instance, peg-interferon and ribavirin against hepatitis C). In such cases, it

GERMANY (CONTINUED)**Access to a doctor in a non-emergency situation
(continued)**

may be easier to get an appointment with one's specialist, no matter which type of insurance one has. Differences in treatment (and time available) for private insurance patients or general insurance patients are reported in such cases, too."

Seeking funding for care not reimbursed by the state

- ▶ **Patient group specialising in arthritis.** "All necessary operations are paid for by the statutory health insurance."

Access to repeat prescriptions

- ▶ **Dagmar Hailer of the Hepatitis-Selbsthilfe Schleswig-Holstein / Deutsche Leberhilfe e.V., Köln [hepatitis self-help group and member of the German Liver Association as mentioned above].** "Yes, they can ring and order this!!!"

Access to medical records

- ▶ **Patient group dealing with arthritis.** "Patients have a right, but doctors are sometimes not cooperative."
- ▶ **Deutsche Leberhilfe e.V. [German Liver Association].** "Legally speaking, patients may not have their medical records withheld unless seeing their records may put them in danger (as in the case of suicidal patients). Patients may also claim to a photocopy of their report, which is legally theirs. In many cases, this works fine. Some doctors may give their patients' photocopies of their report immediately, or within a few days, even without being asked. Other doctors take longer (up to several weeks), and/or only provide records when patients ask for them. In particular cases, some doctors may try to withhold medical reports, although they are not allowed to. This applies especially if something went wrong, and when a lawsuit is pending. Patients who intend to sue their doctors frequently say that their medical records then went 'lost', or clinics try to insist that patients only get to view their medical records under supervision of a medical professional, without getting the record to take home. In such cases, patients may only get access to their medical records if they take legal action."
- ▶ **Dagmar Hailer of the Hepatitis-Selbsthilfe Schleswig-Holstein / Deutsche Leberhilfe e.V., Köln [hepatitis self-help group and member of the German Liver Association as mentioned above].** "They make a copy to take home!!!"
- ▶ **Group specialising in aspects of heart transplantation.** "[Yes] In certain specific emergency occasions."

GERMANY (CONTINUED)

Access to medical records (continued)

- ▶ **Dagmar Hailer of the Hepatitis-Selbsthilfe Schleswig-Holstein / Deutsche Leberhilfe e.V., Köln [hepatitis self-help group and member of the German Liver Association].** “Yes, there is a day/night and Saturday/Sunday telephone service!”



HUNGARY

Access to a second opinion

- ▶ **Group specialising in cancers in adults.** “Patients do not ask for a second opinion very often, although there is no legal or financial reason for that. They are reluctant to ask for a second opinion because they are afraid that their doctor would get to know about it, and would not treat them the same way as before. Also, doctors are not willing to ‘rewrite’ the diagnoses of their colleagues. So, often, they would agree to the first opinion (except if there is a personal conflict between the two doctors). So, in the end, the patient can get into a very inconvenient situation.”
- ▶ **Group specialising in a form of arthritis.** “If the family doctor agrees.”

Access to a doctor in a non-emergency situation

- ▶ **Group specialising in cancers in adults.** “It is normal to be able to fix an appointment in one or two weeks’ time. This is not because of the doctors’ wrong attitude in most cases, but because of the system. The doctors have so many patients that the waiting time may be very long.”

Seeking funding for care not reimbursed by the state

- ▶ **Group specialising in cancers in adults.** “Ask for help from civil organisations or foundations. If no one can help, sell the house, the car—anything.”

Access to repeat prescriptions

- ▶ **Group specialising in cancers in adults.** “In cancer therapies, the appointment with the doctor is a must. Otherwise, people can have a prescription for a chronic disease, etc, without an appointment.”

HUNGARY (CONTINUED)

Access to repeat prescriptions (continued)

- ▶ **Group specialising in a form of arthritis.** "Except for life-threatening conditions."

Access to medical records

- ▶ **Group specialising in cancers in adults.** "Medical records are in Latin, so the question is whether they are explained or not. Very often, people even with a chronic disease, or cancer, do not know what their disease is! They cannot name it, which often causes misunderstandings."

Round-the-clock access to healthcare information and support

- ▶ **Group specialising in cancers in adults.** "Very basic information on hospitals and GPs. No doctors or specialists are available."



ITALY

Access to a second opinion

- ▶ **Associazione Pugliese Malati Reumatici (APMAR) [Association Pugliese for Patients with Rheumatism].** "[Yes, but only for specialist secondary care]. However, the patient is compelled to pay a tax."

Seeking funding for care not reimbursed by the state

- ▶ **Associazione Pugliese Malati Reumatici (APMAR) [Association Pugliese for Patients with Rheumatism].** "Organising charity funding events."



NETHERLANDS

Access to a second opinion

- ▶ **Group specialising in a form of adult cancer.** “Sometimes, older patients are not aware of this right.”
- ▶ **Group specialising in rare inherited disorders.** “Only if the general practitioner agrees with the indication. In cases of private insurance coverage, it depends on the individual conditions of the insurance policy.”
- ▶ **Schildklierstichting Nederland [Dutch Thyroid Foundation].** “A second opinion is not just useful to check an inadequate diagnosis and treatment—it can also make sure a bad message is true.”
- ▶ **Epilepsie Vereniging Nederland [Dutch Epilepsy Organisation].** “In 2006, our healthcare insurance will be dramatically changed. One of the patients’ rights set to disappear is the right for a second opinion.”
- ▶ **Balans (Groot Den Haag).** “We are in the field of children’s psychiatric disorders. Apparently, it is not done to ask for a second opinion in children’s mental healthcare matters, whereas this is common in physical healthcare matters. I detect a slight change in attitude these days, but it’s not convincing.”
- ▶ **Nederlandse Coeliakie Vereniging [Dutch Coeliac Disease Organisation].** “Depends a bit on the healthcare provider.”
- ▶ **Astma Patienten Vereniging [Asthma Patients’ Organisation].** “Even if the doctor is disapproving, he must provide a second opinion when a patient wants this.”
- ▶ **Netherlands Institute for Health Services Research (NIVEL), Department of General Practice, University of Nijmegen, and member of Mental Health Europe.** “This answer means that it is not easy, especially because it takes experts within the forensic psychiatric system, and government permission. But there are possibilities.”
- ▶ **Nederlandse Vereniging Voor Fibromyalgie-Patiënten "Eendrachtig Sterk" (F.E.S). [Dutch Association for patients with Fibromyalgy].** “There are several organisations (local and national) which will/can help patients in that process.”

Access to a doctor in a non-emergency situation

- ▶ **Group specialising in a form of adult cancer.** “Allocation of another doctor may occur in group practices.”
- ▶ **Group specialising in orthopaedics.** “When the doctor is an orthopaedic surgeon, it is not possible to get access on the same day for a non-emergency situation.”
- ▶ **Schildklierstichting Nederland [Dutch Thyroid Foundation].** “Most GPs work in a team, to make sure there is everyday care (even at weekends).”

NETHERLANDS (CONTINUED)**Access to a doctor in a non-emergency situation
(continued)**

- ▶ **Stichting Gezond Gewicht [group specialising in obesity problems].** "It depends on how full the doctor's agenda is. But you can certainly speak to him/her by telephone."
- ▶ **Epilepsie Vereniging Nederland [Dutch Epilepsy Organisation].** "For GPs, it is possible, but depends on the part of the country (we have a shortage of GPs in some areas), and also on the kind of illness. For a specialist, it is hardly possible."
- ▶ **Astma Patienten Vereniging [Asthma Patients' Organisation].** "With asthmatics, the treatment is mostly regulated by the patient. Without breath, however, there is no patient left. So, it is vital to treat a breathless patient as soon as possible. Even so, it is sometimes hard to see a doctor (especially those who qualified a long time ago)."
- ▶ **Netherlands Institute for Health Services Research (NIVEL), Department of General Practice, University of Nijmegen, and member of Mental Health Europe.** "First, they have to ask the medical unit. But, mostly, the wish is fulfilled."
- ▶ **Nederlandse Vereniging Voor Fibromyalgie-Patiënten "Eendrachtig Sterk" (F.E.S) [Dutch Association for Patients with Fibromyalgy].** "Normally, the healthcare system includes a visit to the GP. There are two possibilities: one is arranging an appointment. The second is that there are general hours when patients can come to see the GP. In weekends, there is the possibility of seeing a team in a general central place."

Seeking funding for care not reimbursed by the state

- ▶ **Group specialising in a form of adult cancer.** "Private health insurance sometimes covers the costs. I do not know, for I cannot look into other people's financial situation. But, many people do not own houses. Today, approximately at least 200 people die each year because they cannot afford expensive medicines. Operations, too, must be very hard to finance if the country's healthcare system does not pay."
- ▶ **Group specialising in rare inherited disorders.** "The national health system excludes only a few operations."
- ▶ **Schildklierstichting Nederland [Dutch Thyroid Foundation].** "Necessary operations are paid for by the insurance/healthcare system."
- ▶ **Epilepsie Vereniging Nederland [Dutch Epilepsy Organisation].** "I do not know exactly what you mean. In our country, some cosmetic operations and circumcisions were recently not paid for. All other operations are reimbursed. I personally think that it is very difficult to exclude these kind of operations. But, should society pay for every cosmetic operation? Perhaps clearer criteria are necessary?"

NETHERLANDS (CONTINUED)**Seeking funding for care not reimbursed by the state
(continued)**

- ▶ **Nederlandse Vereniging Voor Fibromyalgie-Patiënten "Eendrachtig Sterk" (F.E.S).** [Dutch Association for patients with Fibromyalgy]. "The patients with whom we are familiar are not the patients who need operations. But, sometimes, they want to find alternative forms of care. Some are (partly) covered by a health insurance company. Others are not."

Access to repeat prescriptions

- ▶ **Group specialising in a form of adult cancer.** "It depends. Prescriptions from the family doctor cause no problems, but with specialists a visit is necessary."
- ▶ **Schildklierstichting Nederland [Dutch Thyroid Foundation].** "It is necessary to get a prescription every three months. In practice, it is sufficient to ask by telephone for this from an assistant at the doctor's office. Officially, there must be at least a telephone appointment with the GP. Repeat prescriptions for unlimited use are no longer permitted (although this would be logical for most thyroid patients)."
- ▶ **Epilepsie Vereniging Nederland [Dutch Epilepsy Organisation].** "It depends on the kind of medicine. More dangerous medicines cannot be obtained for long periods of time. But, you can get prescriptions by telephone. And, recently, repeat prescriptions can be delivered to the home, by emailing the doctor."
- ▶ **Astma Patienten Vereniging [Asthma Patients' Organisation].** "Asthmatics who are 'fine tuned' to their medicines will automatically get a repeat prescription. Once in a while, they will be called in for a checkup to gauge the effect of their medicine."
- ▶ **Nederlandse Vereniging Voor Fibromyalgie-Patiënten "Eendrachtig Sterk" (F.E.S).** [Dutch Association for patients with Fibromyalgy]. "If the patients are regularly seen by the GP, then the repeat prescription is no problem. If, however, the prescription needs surveillance, than there is a need to see the GP before getting a prescription."

Access to medical records

- ▶ **Group specialising in a form of adult cancer.** "There are no legal restrictions for normal adults. But, again, not all older patients are aware of their rights."
- ▶ **Schildklierstichting Nederland [Dutch Thyroid Foundation].** "By law, patients are allowed to read their records. However, GPs, hospitals, etc, are unused to patients insisting on this right. Most hospitals have rules (such as make an appointment, pay for copies) to make the records accessible."

NETHERLANDS (CONTINUED)**Access to medical records (continued)**

- ▶ **Epilepsie Vereniging Nederland [Dutch Epilepsy Organisation].** "This is a patient right. You have to make an appointment, and you pay for copy cost if you want access to your medical records."
- ▶ **Astma Patienten Vereniging [Asthma Patients' Organisation].** "I myself can."
- ▶ **Nederlandse Vereniging Voor Fibromyalgie-Patiënten "Eendrachtig Sterk" (F.E.S). [Dutch Association for patients with Fibromyalgy].** "In principle, patients are allowed to see any of their medical files. Sometimes, patients have to make an official request. Other times, they simply have to ask to see the file. In some cases, another (medical) person may see the records, if the safety of the patient is at stake."

**Round-the-clock access
to healthcare information and support**

- ▶ **Group specialising in a form of adult cancer.** "I do not know for sure, but I am almost certain the answer should be No."
- ▶ **Group specialising in orthopaedics.** "Post-surgery patients receive a special, local, 24-hour phone number from their hospital/clinic for 'contact' if necessary (for instance, when problems occur)."
- ▶ **Schildklierstichting Nederland [Dutch Thyroid Foundation].** "Several insurers have telephone information-and-advice facilities—some during office hours and some round the clock. Several hospitals also provide telephone information, and, of course, the patient organisations provide telephone information and advice (but only during limited periods)."
- ▶ **Epilepsie Vereniging Nederland [Dutch Epilepsy Organisation].** "Not 24 hours. Some insurers do provide such information and support, but only from 8am to 10pm. Our organisation provides this help from 9am to 5pm. And there is a lot on the Internet."
- ▶ **Balans (Groot Den Haag) [organisation specialising in children's psychiatric disorders].** "If they do, they've kept it well hidden."
- ▶ **Nederlandse Vereniging Voor Fibromyalgie-Patiënten "Eendrachtig Sterk" (F.E.S). [Dutch Association for patients with Fibromyalgy].** "I'm not sure whether it is a general rule, but there are some healthcare insurance organisations who provide 24 hour access to healthcare information and support—either by phone or via the Internet. There are also several general Internet sites which provide such options."



POLAND

Access to a second opinion

- ▶ **Polish Association of Young Patients with Arthritis.** “The easiest way to get a second opinion is to visit a private medical practice—but then you have to pay.”

Access to a doctor in a non-emergency situation

- ▶ **Polish Association of Young Patients with Arthritis.** “If it is the primary-care physician, you can get an appointment the same day. If it is the specialist (a rheumatologist, for instance), that depends on the doctor.”

Seeking funding for care not reimbursed by the state

- ▶ **Stowarzyszenie Pacjentów Primum Non Nocere [Polish Patients' Association].** “Unsure whether it is possible to obtain health insurance.”
- ▶ **Polish Association of Young Patients with Arthritis.** “Most of the operations are paid for by the Polish healthcare system. Only for plastic surgery (aesthetic operations), or for some very rare operations (which are not performed in Poland) are patients supposed to pay themselves.”

Access to repeat prescriptions

- ▶ **Stowarzyszenie Pacjentów Primum Non Nocere [Polish Patients' Association].** “The situation and the law in Poland changes every day because of reform in the healthcare system.”



SWEDEN

Access to a second opinion

- ▶ **Bröstcancerföreningarnas Riksorganisation-BRO [The Swedish Association of Breast cancer Societies].** “As a breast cancer patient, you are entitled to a second opinion.”
- ▶ **Astma- och Allergiförbundet [Swedish Asthma and Allergy Association].** “You will have to pay the small fee.”

SWEDEN(CONTINUED)**Seeking funding for care not reimbursed by the state**

- ▶ **Astma- och Allergiförbundet [Swedish Asthma and Allergy Association].** “It rarely happens to our patients, as they have no need for operations.”

Access to repeat prescriptions

- ▶ **Förbundet Blödarsjuka i Sverige [Swedish Haemophilia Society].** “Haemophilia is a chronic disease from which you cannot be cured.”
- ▶ **Astma- och Allergiförbundet [Swedish Asthma and Allergy Association].** “Yes, in principle.”

**Round-the-clock access
to healthcare information and support**

- ▶ **Förbundet Blödarsjuka i Sverige [Swedish Haemophilia Society].** “Yes, but only on a specific medical condition—haemophilia.”

SWITZERLAND**Access to a second opinion**

- ▶ **Group specialising in a neurological muscular disorder.** “There are certain health insurance plans at reduced price in which the freedom of choice is restricted.”
- ▶ **Group (separate from above) specialising in a neurological muscular disorder.** “There is no Swiss national healthcare (like, for instance, the NHS in the UK). But insurance companies generally welcome second opinions, since these may also help reduce costs.”

Seeking funding for care not reimbursed by the state

- ▶ **Group specialising in a neurological muscular disorder.** “Patients may put a request into their health insurance company about the necessity of an operation. Insurers will judge the merit of such operations on a case-by-case basis, and with regard to the respective politics of the health company involved. If the insurer gives its approval, the operation is paid for. This does mean, of course, a lot of writing and waiting.”

SWITZERLAND (CONTINUED)

Access to repeat prescriptions

- ▶ **Help C (Deutschschweiz).** "If the drugstore has a former prescription, or if the doctor has marked the new prescription 'R' for a repeat prescription."
- ▶ **Group specialising in heart disease.** "For a first prescription, an appointment with the doctor is necessary. Then, a prescription can be obtained by phone or by email."
- ▶ **Group specialising in a neurological muscular disorder.** "You have to make an appointment from time to time, depending on the illness and the doctor. For some drugs, you cannot get a repeat prescription at all."
- ▶ **Group (separate from above) specialising in a neurological muscular disorder.** "It depends on the politics of the doctor. In fact, though, doctors are strongly advised to see their patients before repeating the prescription."

Access to medical records

- ▶ **Help C (Deutschschweiz).** "Some restrictions exist for psychiatric illness."
- ▶ **Group specialising in a neurological muscular disorder.** "In principle, there are no restrictions. Yet there may be bureaucracy, or a professional may supervise the process in special cases (for example, when a patient with psychiatric illness accesses his/her medical records)."
- ▶ **Group (separate from above) specialising in a neurological muscular disorder.** "It does actually make sense to have a professional help the patient understand his or her record, since the medical language and its abbreviations make the records themselves quite illegible."

Round-the-clock access to healthcare information and support

- ▶ **Help C (Deutschschweiz).** "Yes, but for emergency situations."
- ▶ **Group specialising in a neurological muscular disorder.** "It should be noted that in Switzerland, we do not have a national healthcare system. It is, however, compulsory to get basic insurance cover with one of the many private health insurance companies. The latter may offer a service like the one mentioned here. There also exists private information-and-advice services on health matters."



UK-ENGLAND

Access to a second opinion

- ▶ **National Rheumatoid Arthritis Society.** "If patients are in a geographic area where there is no other specialist near enough, second opinions can be difficult. Some consultants get quite upset if their patients ask for a second opinion."
- ▶ **National M.E. (myalgic encephalomyelitis) Centre.** "Unfortunately, ME/CFS is a condition that still causes much controversy within the medical fraternity as to whether it is physical or psychological. The truth is that it is probably a bit of both, but it is unusual to get one consultant who will look at all aspects."
- ▶ **Local statutory group.** "[Yes,] except when the professional concerned takes it personally, and becomes 'difficult' or obstructive. Patients do not have a legal right to second opinions, but, in practice, can get them if they are prepared to wait for an appointment with 'the second opinion'."
- ▶ **Uveitis Information Group.** "Varies considerably from region to region."
- ▶ **British Obesity Surgery Patient Association.** "A second opinion (specialist care) is never offered. But, if requested by the patient, then it is usually with another doctor in the same hospital. Rarely are patients referred to renowned experts in the field, just to local services (which are sometimes sub-optimal)."
- ▶ **Local statutory group.** "In my experience, it is difficult to persuade healthcare professionals within the National Health Service (NHS) to agree to a second opinion. Frequently, if the patient is dissatisfied with the diagnosis given, they have no other recourse but to seek a second opinion privately and self-funded."
- ▶ **Local statutory group.** "Patients are entitled to a second opinion should they ask for it. In our acute hospital trust, either a consultant or the patient's GP would ask for that second opinion."
- ▶ **The Hepatitis C Project.** "It takes some time."
- ▶ **Local statutory group.** "They might have to wait longer for an NHS opinion than they would for a private referral."
- ▶ **Hepatitis organisation.** "Most patients are totally unaware of the procedure, and are often reluctant to seek a second opinion because they believe that doctors often stick together."
- ▶ **First Steps to Freedom.** "This organisation helps and support those people who are suffering any and all forms of anxiety. Our answers ["Yes, patients can easily obtain a second opinion"] are purely based on information we receive from service users."
- ▶ **Congenital Adrenal Hyperplasia (CAH) Support Group (UK).** "Although entitled to a second opinion, it can take a considerable amount of time before your request is dealt with."
- ▶ **Heplats Brighton.** "There is dislike and ignorance of alternative practitioners by the system."

UK-ENGLAND (CONTINUED)**Access to a second opinion (continued)**

- ▶ **National Association for Patient Participation.** “They may be unwilling to do so, for fear of souring their relationship with the doctor.”
- ▶ **Child Brain Injury Trust.** “This is not a common issue for callers to our helpline. But I know that it can be difficult for some people.”
- ▶ **Group specialising in substance abuse.** “Within drug services, most patients have to actively seek advocates to fight decisions they disagree with specifically, and do not have this offered routinely.”

Access to a doctor in a non-emergency situation

- ▶ **National Rheumatoid Arthritis Society.** “GPs usually have an emergency appointment system, which operates at the end of the day. But you have to see whichever doctor is on duty.”
- ▶ **Local statutory group.** “Certainly within 48 hours—usually, same day. But practices often have one of their GPs on as duty doctor, to see people the same day. So, patients don't always see their own or a preferred doctor. People seem happy with that. Problems are more likely when it isn't urgent, and the system won't allow pre-booking (even though the system should), because the system is trying to meet 48-hour targets.”
- ▶ **Organisation dedicated to tackling obesity.** “Five days is more likely. It won't be more than 14 days, because practice diaries do not look forward further than 14 days (so that government targets can be concentrated upon).”
- ▶ **British Obesity Surgery Patient Association.** “The NHS system only makes it possible to ring up on the day to make an appointment. But appointments are often not available, so the patient has to ring day after day. However, if they are an emergency, or if the patient is sick, they will be seen by someone else, or by the GP practice located at the nearest hospital accident department. Sadly, people rarely benefit from having a personal doctor anymore, and so the history and relationship is lost.”
- ▶ **Local statutory group.** “GPs are notoriously overworked in my area, and same-day appointments are very difficult to come by. Some GPs have a time set aside for emergency appointments only. But these are ‘first-come, first-served’, and get used up very quickly. The norm seems to be a minimum of four working days before an appointment can be given—but often longer than that. It is much easier to get an appointment to see your vet with a sick pet, than your doctor with a sick child!”
- ▶ **Local statutory group.** “Within 48 hours at most.”
- ▶ **Local statutory group.** “This does not seem to apply to acute trusts, and is probably intended for primary care. However, if a same-day appointment slot was available in this acute trust, it is unlikely that the patient would be seen by their named consultant.”

UK-ENGLAND (CONTINUED)**Access to a doctor in a non-emergency situation
(continued)**

- ▶ **Hepatitis organisation.** “It is extremely unlikely that anybody can get an appointment to see a doctor the same day, although I have heard of it happening on very rare occasions.”
- ▶ **Organisation specialising in chronic fatigue.** “[Yes,] if you phone for an appointment before nine o'clock in the morning.”
- ▶ **First Steps to Freedom.** “Again, our answer [“Yes, but not in all parts of the country”] is purely based on information we receive from service users.”
- ▶ **Congenital Adrenal Hyperplasia (CAH) Support Group (UK).** “To get a same-day appointment you have to call as soon as appointment lines are open. If you do not have a serious illness, you may only be able to get an appointment with a nurse practitioner, who can prescribe for minor illnesses.”
- ▶ **Heplats Brighton.** “Possible for patients with a well-known history of serious difficulties.”
- ▶ **National Association for Patient Participation.** “The national target is to be able to see a nurse within 24 hours, or a doctor within 48 hours. Patients are no longer registered with an individual doctor, but with the GP practice.”
- ▶ **Group specialising in substance abuse.** “Sometimes, clients such as ours cannot get an appointment for a couple of weeks with a GP. If they are with a specific homeless health centre, they can queue up and use the ‘first-come, first-served’ scheme.”

Seeking funding for care not reimbursed by the state

- ▶ **National Rheumatoid Arthritis Society.** “With chronic diseases like RA, health insurers will usually not cover.”
- ▶ **Local statutory group.** “Often difficult to explain to patients that the reason some operations are not available is because there have not been full clinical trials, or the effectiveness is not fully understood. Our healthcare service doesn't give information on what is not available—which can be very confusing for patients.”
- ▶ **Elaine Dowell of the Encephalitis Society.** “The only types of operations not funded by the NHS would be cosmetic.”
- ▶ **Organisation dedicated to tackling obesity.** “Those in the UK who wish to receive weight-loss surgery on the NHS are on a two-year-plus waiting list. Insurers look at this as elective surgery, and therefore don't fund. So, raising private cash is the only answer.”
- ▶ **British Obesity Surgery Patient Association.** “This is an area I am very closely involved in with obesity surgery. As there are no contracts between primary-care trusts and hospitals for this treatment, we have to make funding applications on a case-by-case basis—which is an onerous bureaucratic process. But ‘exceptional’ funding is available if the government (via the UK

UK-ENGLAND (CONTINUED)**Seeking funding for care not reimbursed by the state
(continued)**

National Institute for Clinical Excellence, NICE) have recommended a treatment. In some cases, patients have to put pressure on the primary-care trusts by getting their MPs involved, which seems to get things happening faster. As long as a treatment is recommended by NICE, there should be no need for the patient to have to pay for it.”

- ▶ **Local statutory group.** “In my experience, taking a bank loan or using credit cards seems to be the most common way of raising funds. Some private hospitals now offer finance arrangements—which is a step forward.”
- ▶ **Local statutory group.** “Most surgery will be paid for by the healthcare system. But some cosmetic procedures may have to be paid for by the patient. Some patients opt for private medical care, and some will have health insurance. Some will find a way to pay, so that they do not have to wait on a waiting list for NHS treatment. Often, they will borrow money, or use their savings to do this.”
- ▶ **The Hepatitis C Project.** “Some insurance policies cover some operations.”
- ▶ **Local statutory group.** “The NHS covers all medical-related operations, and some lifestyle procedures (such as IVF). No further operations should be needed.”
- ▶ **Local statutory group.** “This would not happen, as the NHS provides universal care based on clinical need.”
- ▶ **Local statutory group.** “Possibly pay out of savings or capital.”
- ▶ **First Steps to Freedom.** “In my role as a representative of First Steps to Freedom, I am not at liberty to give my opinion.”
- ▶ **Local statutory group.** “The answer really depends on the cost of the operation. A loan from relatives for an inexpensive operation (such as laser eye surgery) could be a possibility. But, for other non-essential cosmetic surgery—which could be very expensive—then re-mortgaging, or a bank loan, would probably be the only routes.”
- ▶ **Congenital Adrenal Hyperplasia (CAH) Support Group (UK).** “All the above options are possible. But, if a patient has paid into the healthcare system and needs an operation for a medical complaint, I do not feel they should have to pay. Cosmetic operations (solely to improve looks, and which are not necessitated by underlying disease) are another matter, and the patient should pay for these procedures. Thankfully, all operations needed for patients are available on the NHS (although a wait is often necessary).”
- ▶ **Heplats Brighton.** “Insurance plans specifically exclude the most vulnerable individuals, such as poor people, or those with re-occurring conditions.”

UK—ENGLAND (CONTINUED)**Seeking funding for care not reimbursed by the state
(continued)**

- ▶ **National Association for Patient Participation.** “It will vary.”
- ▶ **Epilepsy Network Gravesend.** “Most operations would be covered by the NHS.”
- ▶ **Local statutory group (Acute Trust).** “Depends on their personal circumstances.”
- ▶ **Child Brain Injury Trust.** “Some of our clients are injured in road traffic accidents. Where there is a legal claim, costs can sometimes be met by this. This is a more difficult issue for those whose injuries are the result of an illness, or a 'no fault' accident.”
- ▶ **Group specialising in substance abuse.** “Our type of patients do not have access to cash to go to private healthcare. They have to go without, or wait for NHS treatment.”

Access to repeat prescriptions

- ▶ **Local statutory group.** “Patients have to have medication reviewed by doctors regularly, and are not given repeat prescriptions for longer than a month without contact with the doctor. This is good clinical practice, but I am sure some patients find it inconvenient.”
- ▶ **Organisation dedicated to tackling obesity.** “This is done in my area by a pro-forma slip sent to the doctor, who sends back the prescription by post. Very Effective! Not sure how common this is.”
- ▶ **British Obesity Surgery Patient Association.** “My awareness is that millions of repeat prescriptions are never filled. This means that either we have the potential to waste an awful lot of money if they were to be (doctors would be over-prescribing), or patient compliance with medication is very poor.”
- ▶ **Local statutory group.** “Repeat prescriptions are normally easy to obtain, providing the GP has indicated that the patient can apply for a repeat. In the case of certain drug therapies (such as HRT or expensive drugs), an appointment to see the GP or practice nurse is required.”
- ▶ **Local statutory group.** “In an acute hospital trust, the patient would not receive repeat prescriptions, but may get this from their GP.”
- ▶ **Children's cancer organisation.** “Sometimes, the doctor needs to see the patient for review.”
- ▶ **Blackburn and District Blind Society.** “The system in the UK allows for telephone repeat prescription and home delivery, if required.”
- ▶ **Hepatitis organisation.** “Most people can get repeat prescriptions without much difficulty.”

UK—ENGLAND (CONTINUED)**Access to repeat prescriptions (continued)**

- ▶ **Local organisation specialising in Alzheimer's disease.** "Too easily—patients could receive a repeat prescription for a considerable amount of time without seeing a doctor."
- ▶ **Local statutory group.** "They can at their GP practice (dependent upon the medication), but not within a hospital setting."
- ▶ **First Steps to Freedom.** "Again, this answer ["Yes, but not in all parts of the country"] is based on information received from our service users."
- ▶ **Jo's Trust Fighting Cervical Cancer.** "In our health region, certain drugs require an appointment for repeat prescriptions."
- ▶ **Local statutory group.** "There is a system in place whereby patients on long-term, regular medication can have up to three repeat prescriptions without seeing the doctor (once the doctor has been satisfied that the medication is being taken responsibly, and is not causing unforeseen side effects). Patients just apply to the practice for a repeat form, which is sent by the practice to the pharmacy. A couple of days later, the patient can call in and pick up the medicine. It depends on the regime. Some drugs have to be monitored very closely, so the doctor may have to see the patient each time before writing a repeat prescription. There are also facilities in place for patients to self-test their blood at home every 7-14 days, to ensure their blood levels are within normal bounds. If outside normal range, then the patient has been trained to know how much more or less tablets to take to bring the blood readings within acceptable levels. This is more convenient for the patient, and means fewer people attending hospital/doctors' clinics for simple blood screening."
- ▶ **Congenital Adrenal Hyperplasia (CAH) Support Group (UK).** "Prescriptions are put on the patients' records for repeat if the doctor feels the medication may be required again for one year's duration. After this time, the patient has to see the doctor again for a review. Only one month's medication is generally allowed at a time—which, for a lifelong condition, is not long, and means a patient has to continually fill in a form every four weeks for a repeat."
- ▶ **Epilepsy Network Gravesend.** "Most GPs in this area review all medications annually."
- ▶ **Group specialising in substance abuse.** "Not prescriptions for substitute medication for substance mis-users—only prescriptions for general ailments. Patients can access these through email at some practices."

UK—ENGLAND (CONTINUED)**Access to medical records**

- ▶ **National Rheumatoid Arthritis Society.** “I believe we are now allowed to see our medical records in the UK. But I have never asked, so I don't actually know.”
- ▶ **Local statutory group.** “All patients are allowed to access copies via the Medical Records Act. For reading and viewing records, a consultant's approval is usually sought first.”
- ▶ **Local statutory group.** “With a few restrictions—for instance, unless records make reference to third parties, or if seeing records may cause harm to patients (if, for example, they have a mental health problem). Patients do have a right to see their records, as long as these exceptions do not apply.”
- ▶ **Local statutory group.** “To comply with the Data Protection Act and the Access to Health-Service Records Act, patients have to complete a form. Permission from the clinicians who have written in the notes has to be sought. There is a 40 working-day time scale.”
- ▶ **Organisation dedicated to tackling obesity.** “See link for the legal structure http://www.hms.o.gov.uk/acts/acts1988/Ukpga_19880028_en_1.htm.”
- ▶ **British Obesity Surgery Patient Association.** “I am not quite sure. I understand that, with the new Freedom of Information Act, they can see them. But I am not sure if there are rules attached to that.”
- ▶ **Local statutory group.** “Patients may apply for access to their health records. But this has to be approved by the consultant caring for them first. Access is rarely denied, and will only be denied if it would cause the patient harm, or if there is third-party information within the record.”
- ▶ **Local statutory group.** “The answer would only be ‘no’ if the medical records contain information about a third party, or if the record holder can show that disclosing the information would be damaging to the patient.”
- ▶ **Local statutory group.** “The health organisations in the UK reserve the right to charge a one-off fee for a patient's medical records. All notes are available.”
- ▶ **Hepatitis organisation.** “Most people are reluctant to ask to see their medical records, or do not know that it is their right.”
- ▶ **Local statutory group.** “Patients are entitled to access copies of their records under the Data Protection Act, and there is a process in place for this. However, a clause allows doctors to withhold some or all of the records if they feel that seeing them would be detrimental to a patient's wellbeing. If a patient only wishes to read their notes, then this takes a little more organising, as somebody with clinical knowledge has to be available to help with the task. Again, this request will be accommodated.”

UK—ENGLAND (CONTINUED)**Access to medical records (continued)**

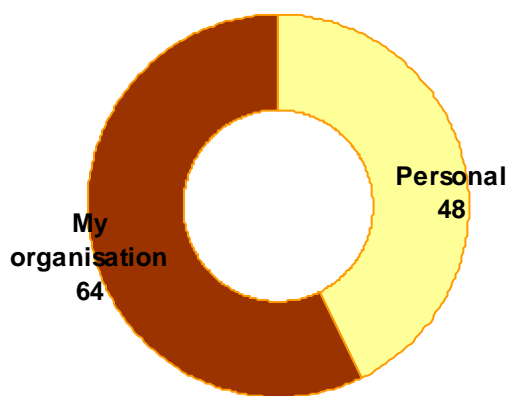
- ▶ **Congenital Adrenal Hyperplasia (CAH) Support Group (UK)**. “In general, this is allowed, but records can only be seen after a certain date, and doctors can withhold certain records if they feel it is not in the patient’s best interest to learn the content.”
- ▶ **Heplats Brighton**. “Our local hospital charges money, even to sick people on benefit.”
- ▶ **Child Brain Injury Trust**. “I think so. But this issue has only been raised with us when trying to get children’s records (sometimes from years ago) when parents are considering challenging the medical authority on treatment given.”

**Round-the-clock access
to healthcare information and support**

- ▶ **National Rheumatoid Arthritis Society**. “I believe that NHS Direct is 24/7. But I am not sure that you would always get an answer to everything you want to know.”
- ▶ **Local statutory group**. “NHS Direct: 0845-4647 (including access to interpreters).”
- ▶ **British Obesity Surgery Patient Association**. “Yes, NHS Direct is actually a very good service. Response times are fast, and information pretty accurate.”
- ▶ **Local statutory group**. “This is a very limited service, and not particularly satisfactory.”
- ▶ **Blackburn and District Blind Society**. “We have NHS Direct, which would also arrange a doctor if required.”
- ▶ **Local statutory group**. “NHS Direct is available in some parts of the country.”
- ▶ **Local statutory group**. “I have often used the NHS Direct phone line, and found it to be extremely helpful. I have given the number to several people who were unaware that it existed.”
- ▶ **Congenital Adrenal Hyperplasia (CAH) Support Group (UK)**. “Yes, it is called NHS Direct. It can often prevent people from going to hospital unnecessarily, or ensure that people who should be going to an Accident and Emergency department are encouraged to do so.”
- ▶ **Heplats Brighton**. “Poor knowledge of hepatitis C.”
- ▶ **Local statutory group (Acute Trust)**. “Not 24 hour across the board. But information is available in certain circumstances.”



Appendix 4
Survey results:
Profile of respondents

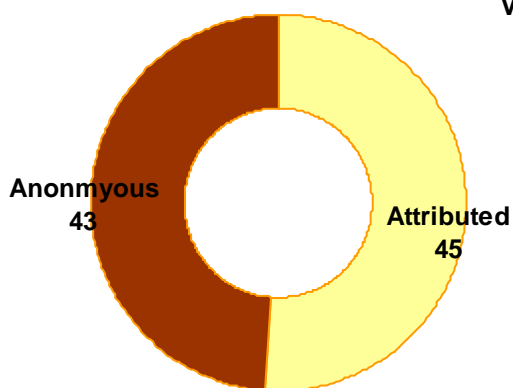


Whose views are you expressing in this survey?

% of respondents
number = 104

Some respondents expressed both personal views and the views of their organisations

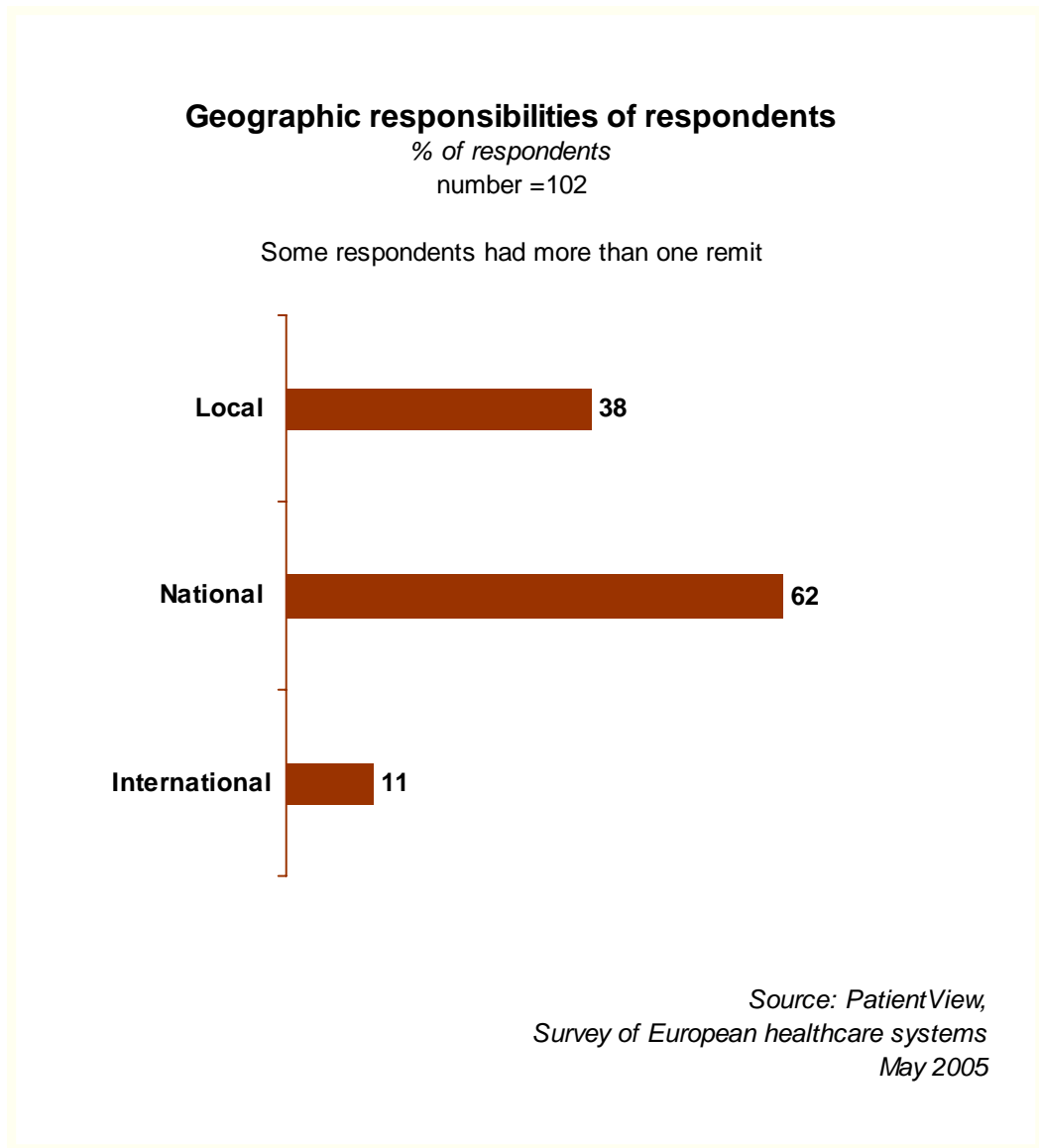
Source: PatientView, Survey of European healthcare systems May 2005

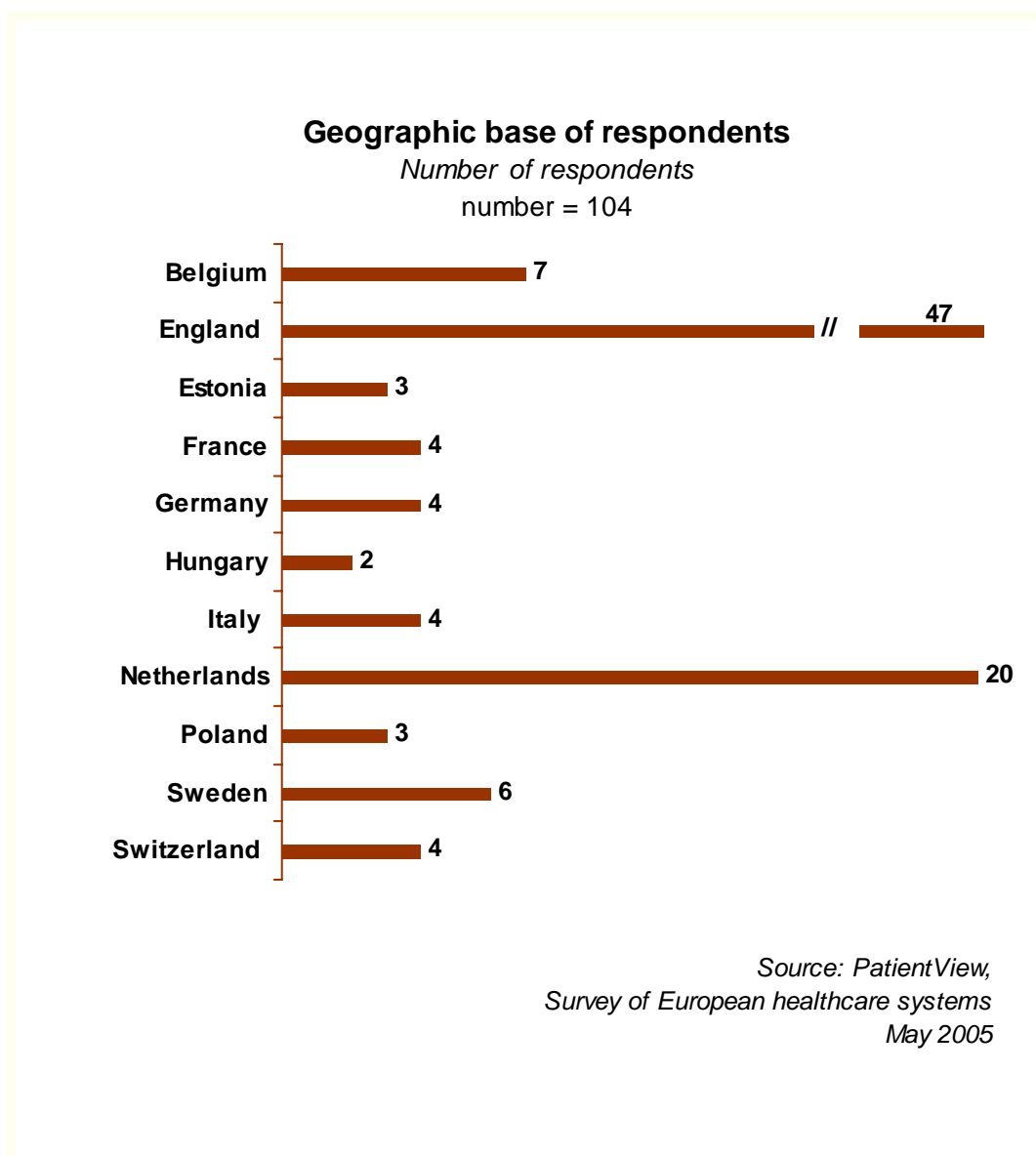


Views for attribution versus anonymity

% of respondents
number = 102

Source: PatientView, Survey of European healthcare systems May 2005





Speciality remit of respondents Total number = 104	
CATEGORY SUB-CATEGORY	NUMBER
Advocacy	1
Allergy —Food	1
Arthritis —Ankylosing spondilitis —Rheumatology	11
Asthma —Allergy —Chronic Obstructive Pulmonary Disease —Eczema —Hypersensitivity	2
Blindness	1
Blood —Haemophilia	1
Brain injury —Children	1
Cancer —Breast —Cervical —Facial —Leukaemia in adults —Prostate	10
Dementia —Alzheimer's Disease	2
Diabetes	1
Disability	1
Dystonia	2
Emergency and elective healthcare	1
Encephalitis	1
Endocrine —Thyroid	3
Epilepsy	3
Eye conditions	1
Fatigue —Chronic fatigue —Fibromyalgia	4
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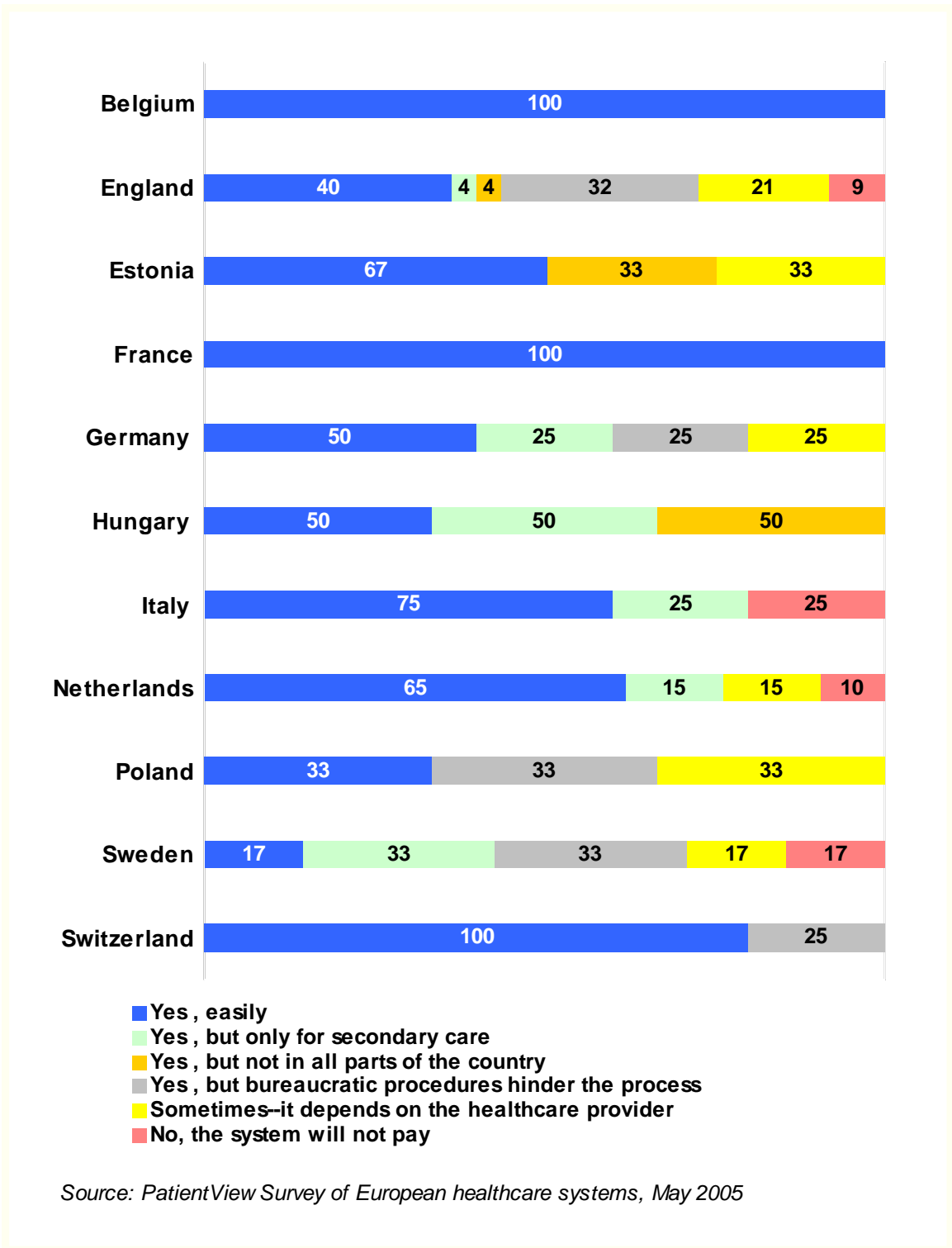
CATEGORY SUB-CATEGORY	% OF TOTAL
Gastrointestinal —Coeliac disease —Irritable Bowel Syndrome	2
Haematology	1
Heart disease —Medical implants	2
Hospital care	1
Immune deficiencies	1
Infectious —Hepatitis —HIV/AIDS —Post-polio	7
Liver disease	1
Medical malpractice	1
Mental health —Anxiety —Bipolar disease —Children's development disorders —Chronic depression —Learning disabilities —Panic	14
Metabolic diseases	1
Migraine/headache	1
Mucopolysaccharidoses	1
Obesity —Surgery —Weight loss	4
Orthopaedics	2
Parkinson's disease	1
Patients rights	1
Rare disease —Triple-X syndrome —Epidermolysis bullosa (EB)	2
Skin —Psoriasis	1
Statutory	12
Substance misuse	1
<i>Source: PatientView, Survey of European healthcare systems, 2005</i>	

Access to a second opinion

If patients (with whom your organisation is familiar) believe that they have been given inadequate diagnosis and treatment, can they readily obtain a second opinion paid for by their country's healthcare system?

% of participants from each country

[Respondents were permitted to select more than one option]

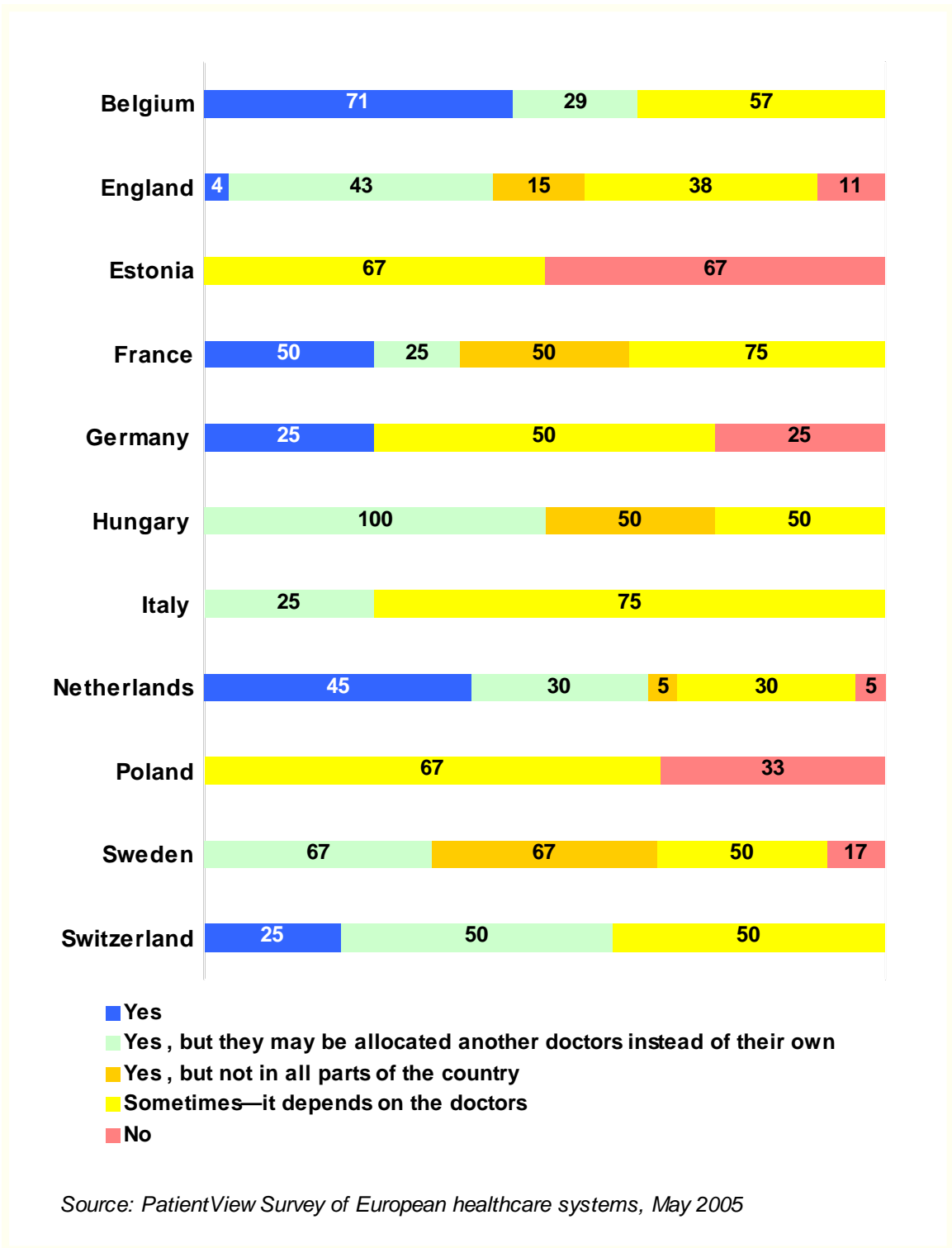


Access to a doctor in a non-emergency situation

If patients (with whom your organisation is familiar) wake up feeling unwell, but the ailment does not seem to be life-threatening, can they get an appointment that same day with their own doctor?

% of participants from each country

[Respondents were permitted to select more than one option]

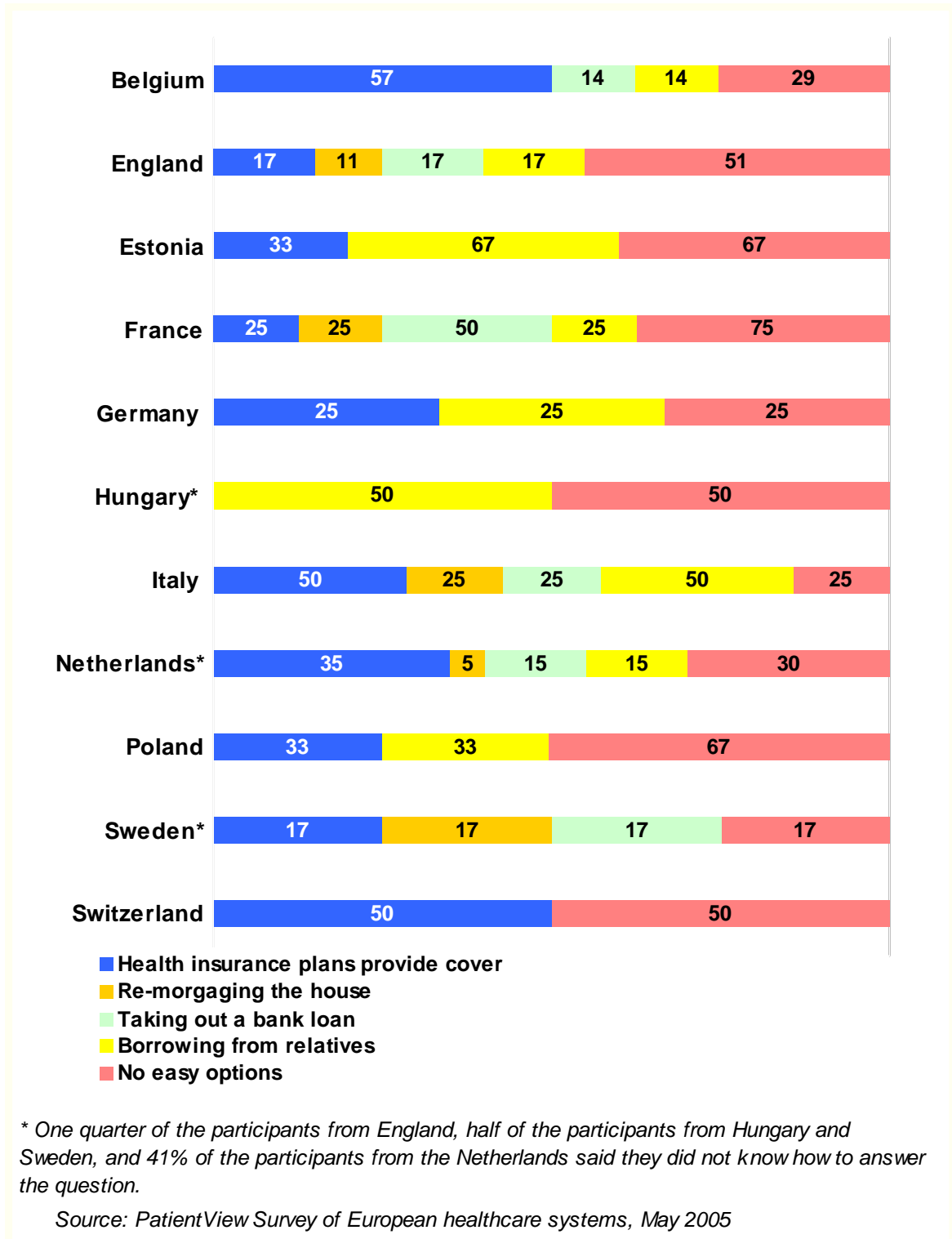


Seeking funding for care not reimbursed by the state

If patients (with whom your organisation is familiar) want an operation that is not paid for by your country's healthcare system, what do you think may be their best option for funding the considerable cost of the operation?

% of participants from each country

[Respondents were permitted to select more than one option]

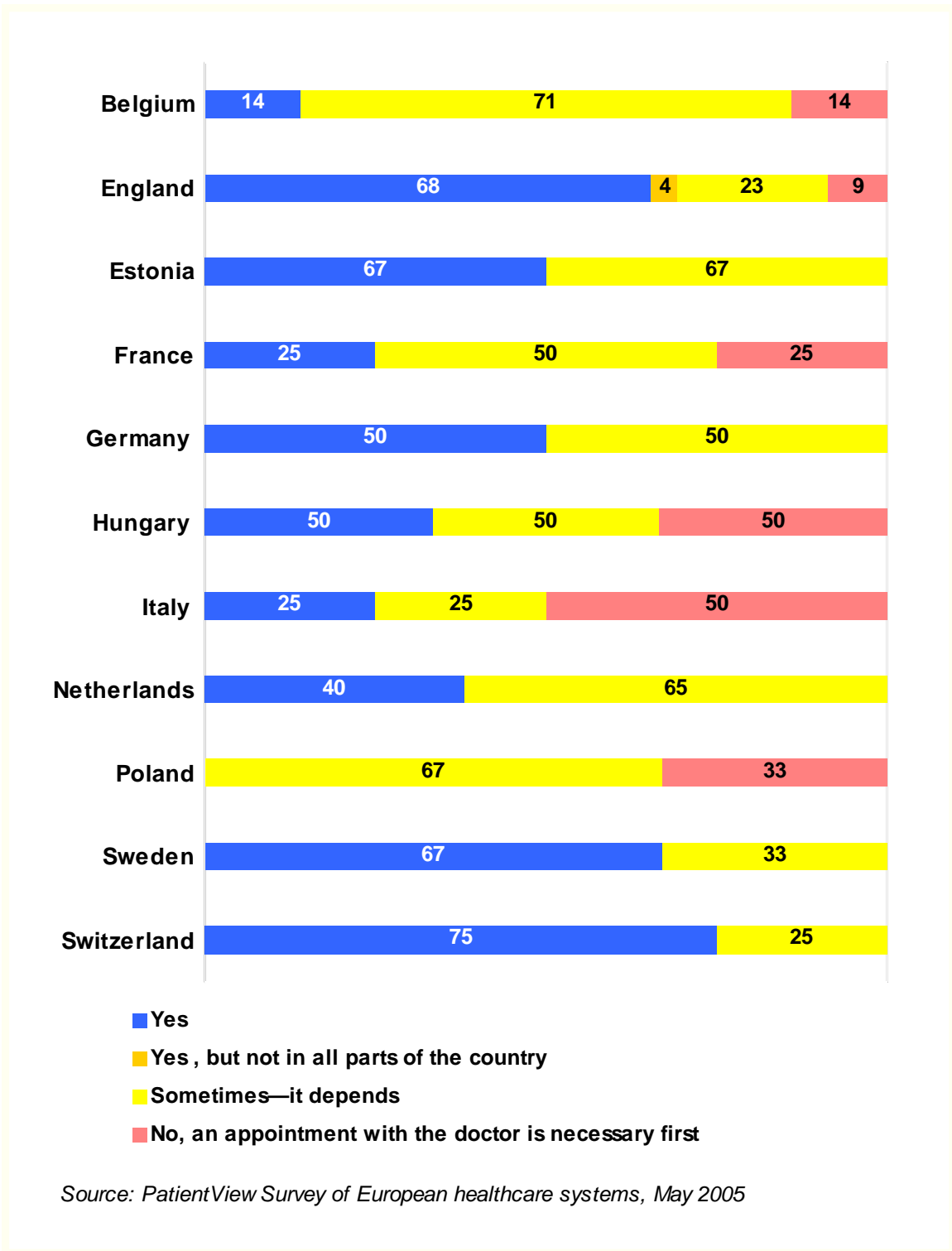


Access to repeat prescriptions

If patients (with whom your organisation is familiar) believe that they have been given inadequate diagnosis and treatment, can they readily obtain a second opinion paid for by their country's healthcare system?

% of participants from each country

[Respondents were permitted to select more than one option]

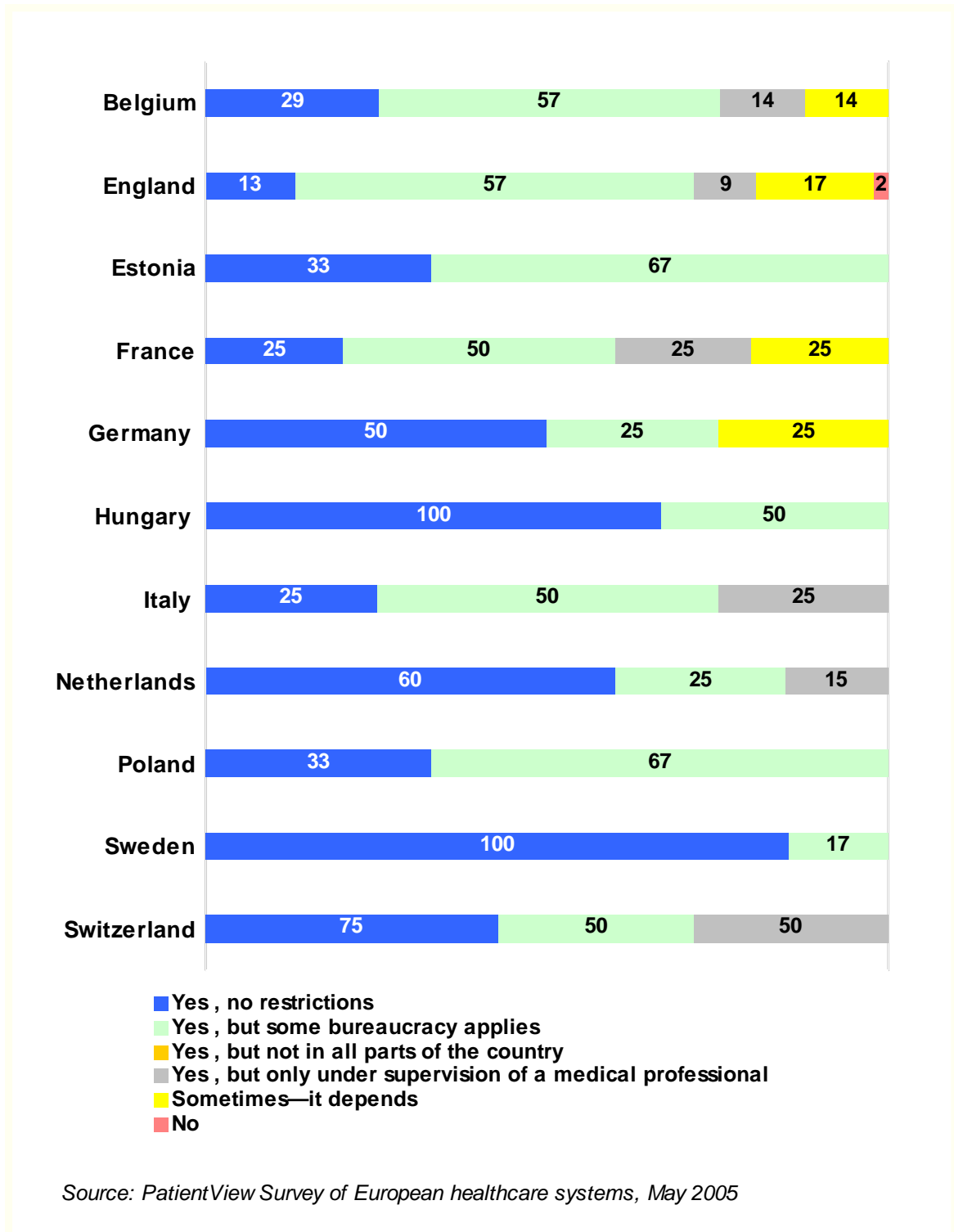


Access to medical records

Are patients (with whom your organisation is familiar) allowed to read their own medical records?

% of participants from each country

[Respondents were permitted to select more than one option]

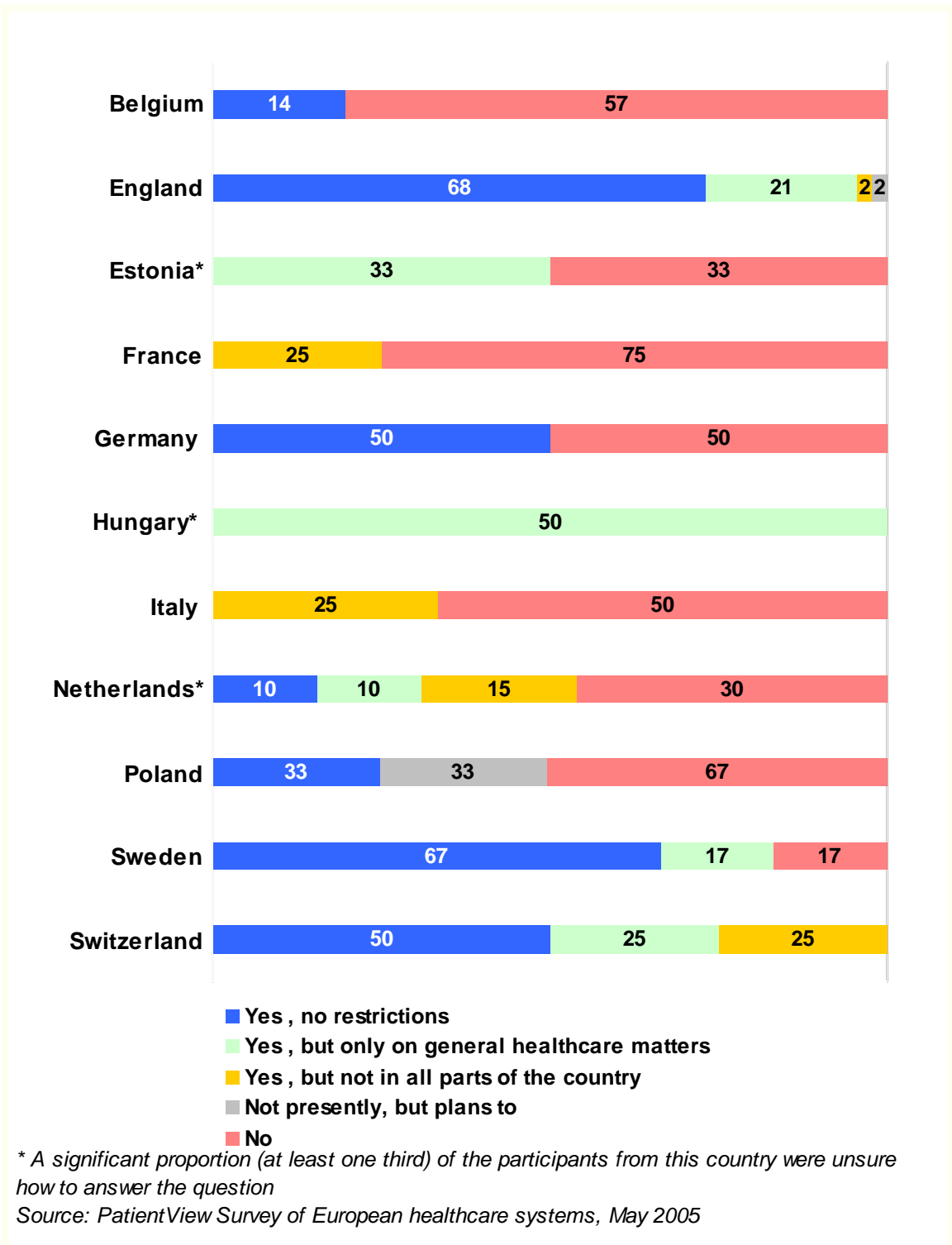


Round-the-clock access to healthcare information and support

Does your country's healthcare system offer patients or consumers a 24-hour, round-the-clock telephone information-and-advice service on healthcare matters?

% of participants from each country

[Respondents were permitted to select more than one option]



Health Consumer Powerhouse

Brussels office
Rue Fossé aux Loups 34, boîte 2,
1000 Bruxelles
Tel: +32-2-218-7393
Fax: +32-2-218-7384
Email: brussels@healthpowerhouse.com

Stockholm office
Högbergsgatan 32,
116 20, Stockholm,
Sweden
Tel: +46-8-442-0929
Email: info@healthpowerhouse.com
Mobile phone: +46-70-554-8081
Internet: <http://www.healthpowerhouse.com>

PatientView and *Health and Social Campaigners' News International*

Woodhouse Place
Upper Woodhouse
Knighton, LD7 1NG
Wales
Tel: +44-(0)1547-520-965
Fax: +44-(0)1547-528-501
Email: info@patient-view.com
Internet: <http://www.patient-view.com>

Registered Address for PatientView:
Clements House,
14-18 Gresham Street,
London, EC2V 7NN, UK
Data protection registration number: Z7133076
VAT registration number: GB-760-985-885
Company number: 3944382

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