



## **Eurobarometer Qualitative Study**

# **PATIENT INVOLVEMENT**

## **Aggregate Report** **May 2012**

This study has been requested by the European Commission,  
Directorate-General for health and Consumers

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The interpretations and opinions contained in it are solely those of the authors.

**Qualitative study – TNS Qual+**

**Eurobarometer Qualitative study**

# **Patient involvement**

**Aggregate Report**

Conducted by TNS Qual+ at the request of  
the European Commission,  
Directorate-General for health and Consumers

Survey co-ordinated by the European Commission,  
Directorate-General for Communication  
(DG COMM "Research and Speechwriting" Unit)

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## Country Abbreviations<sup>1</sup>

Austria	AT
Belgium	BE
Czech Republic	CZ
Finland	FI
France	FR
Germany	DE
Greece	EL
Hungary	HU
Italy	IT
Latvia	LV
Poland	PL
Romania	RO
Spain	ES
Slovakia	SK
the United Kingdom	UK

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<sup>1</sup> The listing of Member States in parentheses does not mean that the issue was limited to those countries and is not intended for comparative purposes. Rather it indicates where the issue tended to be more commonly expressed amongst respondents from that particular country.

## 1 KEY CONCLUSIONS

- The term **"Patient involvement"** was not clearly understood by either patients or practitioners and often meant different things to different people. For many patients the term was a nebulous concept revolving around healthy living and being responsible for one's own health. For both practitioners and patients **it was often simply equated with medical compliance and following doctors' orders**. While patient involvement was often seen in terms of patients providing basic information on symptoms to a healthcare professional, it was less widely perceived to include a more interactive dialogue or opportunity for patient feedback.
- While practitioners and patients alike see the benefits of patients being more engaged and taking more responsibility for their health, the more **concrete benefits of involvement in healthcare process are not clearly focused** for either healthcare professionals or patients. For example, the perception of improved cooperation between the healthcare professional and the patient being effective to achieve better health outcomes, was only mentioned by a few respondents.
- **Communication** was central to the idea of patient involvement for many. For patients, this meant practitioners explaining to them the diagnosis and treatment. For practitioners, it meant patients describing symptoms and keeping them updated on the progress of treatment. The **main barrier to effective communication was the time available for doctors to spend with patients**. Both patients and practitioners described how doctors had insufficient time to explain treatment options.
- **Many patients described a "traditional doctor-patient relationship", where the doctor was seen as beyond questioning and patients felt uncomfortable giving feedback**. Where the relationship was seen to be on a more level arrangement, patients found it easier to provide feedback. For this reason, nurses were seen as easier for some patients to communicate effectively with compared with doctors, especially those in hospitals.

- While healthcare professionals tended to be satisfied with the current relationship they have with patients, patients wanted a more balanced relationship and this was often described in terms of information. **While patients did not want to be responsible for decision-making, being able to ask questions and understanding how decisions were made was important.**
- **Choice was also a key aspect of patient involvement for some patients.** Choice encompassed a range of issues including: being able to change doctors and being aware of alternate treatments. Choice was seen as more problematic for practitioners as some felt patients would be confused if given alternatives or would have less faith in the treatment proposed.
- Although related more to the concept of health literacy than patient involvement per se, **the internet was generally felt to be the area where there has been the most significant development** with almost all patients now having greater access to information about their symptoms and healthcare (as well as healthcare options). This was seen as positive by patients but was seen more ambivalently by some practitioners. More regulated information was considered as a useful safeguard against the risk of "internet misdiagnosis" by patients.
- **Practitioners saw the benefits of 'patient involvement' as having more motivated and engaged patients, with increased understanding.** Patients saw the benefits as having more information and options with regard to treatment, and a more open dialogue with practitioners where communication was improved and questions could be asked.
- The two key **risks of "patient involvement"** were perceived to be the resourcing requirements needed (for example, additional time and staffing) and the negative impact it might have on the patient/doctor relationship. More explanation of healthcare and discussion of options means an **increased demand on doctors' time**. More input from the patient – potentially based on inaccurate information gleaned from the internet – could mean **patients disagreeing with the healthcare expert** and refusing the best treatment.
- In addition, there were some general differences that emerged between different types of respondent. **Chronically ill patients tended to have more experience in self-monitoring and other aspects and often had a more tangible understanding of patient involvement.**

- **Younger patients and those with a better education had higher expectations of their own involvement** and tended to be less reluctant to question decisions made about their own healthcare.
- Finally, while there were often similar themes across all of the countries included in the study, **there were differences between certain countries (which for simplicity the report refers to as "east" and "west")**. In general in Eastern countries (the Czech Republic, Hungary, Latvia, Poland, Romania, Slovakia and to a lesser extent Greece) the current state of the healthcare infrastructure was often described as less inadequately funded and there tended to be a less balanced relationship between doctors and patients. In these countries, patients tended to have less understanding of what patient involvement might involve and there was more reluctance to have a more interactive relationship with their healthcare.
- The findings from this qualitative study indicate that patient involvement, in the sense of having patients at the heart of the healthcare process, seems poorly understood by many professionals and patients across the EU, with **only limited concrete ideas and activities which substantiate the concept in real healthcare practices**.

## 2 EXECUTIVE SUMMARY

The aim of this research was to explore views on patient involvement in healthcare across fifteen European Member States. In-depth interviews were carried out with five healthcare practitioners and ten patients, in each country. This research was qualitative in nature and is therefore not intended to be representative of the views of either practitioners or patients in the participating countries. Conclusions reflect the experience and views of those who took part in the study

### 2.1 Overall Opinion of National Healthcare

In order to understand opinions about patient involvement within the wider healthcare context, respondents were asked how they felt about their general perceptions of the healthcare system in their country. It was clear that healthcare experiences varied considerably across the fifteen European countries included in the survey. Respondents in western European countries tended to rate their national healthcare systems more highly than respondents in eastern European countries. The latter described their systems as lacking funding and sometimes basic infrastructure, including hospitals, clinics and equipment.

*"I think it is very unsatisfactory because money that is collected from the population goes first to the national budget and then only a small part goes to the Health Ministry and from here to hospitals so in the end a very small sum of money goes to patients because there are too many intermediaries." [RO, doctor, hospital, cardiologist]*

In general, respondents regarded their healthcare systems positively, both in terms of the access to basic care which is provided to all (at least in principle), and for their highly-qualified and well-trained medical staff. Patients also valued good communications between patients and practitioners, where these were experienced and this **communication was central to many respondents' concept of patient involvement.**

*"I've chatted to the nurse [...] and she was always [...] extremely helpful, she was the one who told me more what my result meant than my GP"(UK, Patient, female, 18-44, PCT, chronic)*



Many respondents complained of the **lack of time** spent by doctors and nurses with individual patients. This was seen as one of the main causes of poor communication and information, and a few practitioners linked this pressure on time to poorer care and treatment outcomes. In eastern European countries, some practitioners reported too few healthcare staff and that existing staff were overworked, both of which limited the time available to spend with patients.

Patients sometimes described inequalities in healthcare provision between rural and urban areas, or regions, within their country. In some eastern European countries, patients spoke of limited access to diagnostic tests, general practitioners and specialists. This was most marked in rural areas. Some also referred to cash, 'gifts' and 'favours' being exchanged for access to doctors. For this reason, some poorer patients could not afford to access healthcare. Healthcare systems were criticised for long waiting lists, especially for appointments with specialists. In some eastern European countries, patients complained of having to wait a long time once in hospital or at doctors' surgeries.

Patients with chronic illnesses and conditions tended to be more critical of their countries' healthcare systems. Some reported that their involvement in healthcare was inhibited by doctors' lack of empathy and consideration, and by insufficient explanation of treatments.

## **2.2 Perceived Responsibility for Healthcare**

Some practitioners (especially doctors and specialists) mostly saw themselves as being responsible for patients' healthcare. When prompted, they conceded that patients held some responsibility too: for preventing ill-health by healthy lifestyles, for providing practitioners with information to assist diagnosis, and for complying with practitioners' instructions.

*"Yes, of course patients have personal responsibility for their own healthcare. They should follow the regimen they are given. There are always some patient groups which phase out in the middle of the treatment." (FI, Nurse, hospital emergency room)*

Other practitioners believed that responsibility for healthcare was shared between practitioner and patient. Patients' responsibility was nevertheless still often perceived in terms of healthy lifestyle, prevention and complying with prescribed treatment. Only a few practitioners expected patients to take a more active role in their healthcare; usually by communicating symptoms.

*'We are a support but their health is up to them. They have to communicate with us about their health' (FR, Nurse, clinic/surgery)*

Some practitioners – especially in eastern European countries - viewed responsibility for healthcare as being shared with national government or national health authority, and the patient. The former funded and controlled the national health system, and so was seen to hold more influence on healthcare than practitioners. These practitioners often reported that they felt limited in their practice by inadequacies in state funding and infrastructure.

In marked contrast to practitioners, many patients saw themselves as holding the main responsibility for their healthcare partly because for many it was difficult to disentangle the idea of healthcare from health. Responsibility was mostly seen to entail being responsible for a healthy lifestyle, by curbing behaviours such as smoking and drinking. Almost all other patients saw themselves as sharing responsibility for their healthcare with practitioners. Few patients saw practitioners as holding sole or main responsibility.

*"One is completely responsible for his or her health. It should be self-evident that people try to control and adjust their way of living, as well as to regularly visit doctors in order to maintain a health check-up!" (AT, Patient, female, 18-44, hospital, chronic)*

Patients with a higher level of education, patients with greater experience of healthcare and patients with chronic conditions were more likely to see themselves as having a more active responsibility for their healthcare. For example, some diabetic patients took responsibility for monitoring their condition, proactively giving feedback to practitioners and being involved in treatment decisions.

*"Yes! As a proof I said I measure my glucose and I write down the figures. I have blood pressure problems so I measure my blood pressure every morning and every night!" [RO, patient, male, 45 years and over, Hospital, chronic]*

### **2.3 Patient Trust and Control**

For patients, trust in practitioners is an essential prerequisite for an effective relationship. Trust was seen to be engendered by good communication and expertise. However, patients in some eastern European countries were discouraged from involvement and a lack of control was often associated with a lack of time spent in consultation with practitioners.

*"No, I don't have a feeling of control. Doctors do everything very quickly. It is difficult to be in control when doctors take you only as a 'check-off' in their book."  
(SK, Patient, Female, 18-44, PCT, Acute)*

A sense of powerlessness was evident in many patients' descriptions of healthcare. This was also linked to insufficient information and discussion about diagnoses and treatments. Patients felt more in control when they could ask questions, were listened to, had enough information, were given choices and were involved in decisions.

*'I have a very good relationship with my general practitioner, he takes me as an equal partner, I can talk to him about everything and he has my full trust, because I know he is an expert.'* (CZ, Patient, male, 45+, both hospital and PCT, acute)

*"My local GP has more time, is more personal, and I feel I am in good hands."* (DE, patient, male, 45+, PCT/HOSPITAL, acute)

Some patients looked for a more **balanced** relationship with doctors than perhaps was typical in the past. For example, they wanted to be given more information and to have a role in decision-making. This was especially true of patients in western Europe, those with a higher level of education, who were young or middle-aged, or had chronic conditions. However, patients were clear that they neither expected nor wanted 'equality': doctors held greater expertise and knowledge than patients. Patients in several eastern European countries seemed more accepting than others of doctors taking a high degree of control over their healthcare. They showed less awareness of opportunities to take control, and less sense of being able to take control.

*"I don't have any options, I must trust this one person. When I have any health problems, I go to him with that and I must trust. I either trust him or don't."* (LV, Patient, female, 18-44, PCT, acute)

## **2.4 Understanding of 'Patient Involvement'**

For respondents, 'patient involvement' was a broad concept. It was most often related to patients taking responsibility for a healthy lifestyle and finding out information about their condition. Examples of involvement in healthcare itself were mostly limited to patients giving doctors simple details about health problems, following doctors'

instructions, complying with treatment and taking medication as prescribed. The potential for patients to be involved in decision-making about their healthcare was rarely mentioned. A more active involvement was mentioned by only a minority of practitioners and by patients with chronic conditions. Their suggestions included patients monitoring the efficacy of treatments and side effects, carrying out blood tests, developing comprehensive knowledge about their condition and how to manage it, and suggesting treatments.

'Patient involvement' was sometimes interpreted as something practitioners did to patients rather than something patients did themselves: according to practitioners, it meant informing patients and explaining diagnoses, conditions and treatment options, as well as educating patients about a healthy lifestyle.

*"This is my opinion: for this reason, I am paternalistic. I am your father and I am going to decide for you. It is acknowledged, deep down it is acknowledged, and there will be doctors, who may not be paternalistic, but deep down the person who will make the decision will be me and whether or not they like the treatment I prescribe, they will let me know. If we are talking about what they know about the treatment, it's one thing; but we are talking about what they don't know, it isn't as if they can say, "Don't tell me to do this because I have already tried it, and still I feel really bad". ". (ES, Doctor, PCT)*

It was reported that patient involvement in healthcare had increased in many countries over the last ten years. Practitioners described patients playing a greater role in prevention, and searching for information about symptoms, conditions and treatments on the Internet.

Being well-informed about health was linked to patients' greater involvement in health care. In all countries, practitioners and patients reported that patients were now better-informed due largely to the development of the Internet. This was accessible to virtually all patients interviewed. Almost all patients had used the Internet to access healthcare information, and a few had found support in online patient forums. Patients rated their ability to be discerning and responsible about information found on the Internet more highly than practitioners did.

Patients' preferred level of involvement in healthcare varied by individual. However, there were some demographic trends: patients with a higher level of education, patients

with chronic conditions, and younger or middle-aged patients wanted (and often expected) more involvement.

*'It is about being active, just visiting the doctor, but not speaking with them, does not put you ahead. Patients have to learn to be pro-active, there is nobody stopping them from asking and nobody is trying not to reply when interviewed.'*  
(CZ, Patient, male, 18-44, both hospital and PCT, acute)

## 2.5 Benefits and Risks of Patient Involvement in Healthcare

Many practitioners, especially in western European countries, believed that patient involvement **improved** the quality of healthcare and posed few risks. The benefits of patient involvement included patients being more motivated, taking better care of themselves, having better understanding of their conditions and treatments, and monitoring their health themselves.

Patients focused more on benefits such as practitioners improving their diagnoses and treatment suggestions, and treatments being more effective, due to increased patient input.

The main risks of patient involvement, mentioned by both patients and practitioners, were increased demands on practitioners' time, and the possibility of patients disagreeing with doctors' opinions. Practitioners worried that some patients might bypass practitioners altogether, and try to diagnosis or treat themselves.

*"Mothers might get the feeling they understand absolutely everything and then become a danger to their children. For example, they might start to think it is suitable to cure laryngitis at home."* (CZ, doctor, both hospital and PCT, paediatrician)

Patients in eastern European countries were most likely to be dissatisfied with their current level of involvement in healthcare and to want to be more involved. However, this response was not universal. More often, it was chronically ill patients that wanted greater involvement in their healthcare.

*'I want to take part in the decision-making about my healthcare. I want to discuss whether that kind of treatment is really necessary or not...I want to be shown different ways of treatment and to make enquiries to find which is best.'*

*But sometimes, doctors seem to have the impression this would lower their status.'* (CZ, patient, female, 18-44, both hospital and PCT, chronic)

Many patients wanted a fuller understanding of the diagnoses and treatments they receive, to be informed about possible outcomes and alternatives, and to be given choices. This would enable patients to participate more in healthcare, and increase healthcare effectiveness. Some patients, especially younger patients and patients with chronic conditions, would like to be more involved in decisions about treatment but they need to know what options are available.

*"I don't know what alternatives there are, to refuse the treatment. I also cannot assess what will happen if I do not accept it."* (DE, patient, male, 45+, PCT/hospital, chronic)

## 2.6 Barriers and improvements

Respondents suggested that the main barriers to patients' involvement in healthcare were patients' attitudes, patients' lack of knowledge and awareness, and practitioners' lack of time and support. Some patients in eastern European countries were inhibited by the lack, or inaccessibility, of basic health services, and a fundamental lack of trust and confidence in their health systems and doctors.

Respondents suggested that patients could become more involved in healthcare if the attitudes of both patients and practitioners changed. Many felt there was a need for **improved communication** between practitioners and their patients, and that more time was required to allow this. Practitioners recognised that this would require considerable funding and extra staffing.

Patients suggested that they be given **more information**, for example about their conditions and alternative treatments. It was felt that written information would be especially useful. This could emphasise the patients' role, and, for example, could be included in written prescriptions and discharge notes. Some practitioners wanted better control of information available online via an authoritative healthcare web site. This could help all types of patients find reliable and comprehensive health information in their own time. Patients could be referred to these approved web sites by practitioners.

It was felt that governments' national health policies should place a greater emphasis on patients' responsibility for healthcare. In eastern European countries, and for patients with chronic conditions, patient support organisations could also play a greater role bridging the gap between patients and healthcare systems.

## 3 OBJECTIVES AND METHODOLOGY

### 3.1 Background and objectives

The relationship between patients and health practitioners is thought to have a direct influence on the quality of healthcare. New insights suggest that a care-management approach which includes patient involvement is more effective than a standard approach which does not. This is especially evident in the management of chronic diseases like diabetes.

However "patient involvement" is not a well-defined concept and is usually referred to within the same context as overlapping terms such as patient participation, patient empowerment, patient centeredness, and patient engagement. The concept of patient involvement refers specifically to the right and the benefits of patients to have a central position in the healthcare process. The benefits of this are expected to be a better outcome for the patient as a result of the improved interaction between the healthcare provider and the patient.

Patient involvement is more than availability of information or health literacy. It is about the interaction between the patient and the healthcare provider and encompasses a wide range of different aspects. Several countries have put patients at the centre of their healthcare policy. The NHS in the UK, for example, has promoted the concept of patient involvement using the slogan, "No decision about me without me."<sup>2</sup> Several definitions are used for the concept: some express the individual responsibility of the patient; for example, the Centre for advancing health in the US defines patient engagement as "actions individuals must take to obtain the greatest benefit from the health care services available to them."<sup>3</sup> The core of the concept is the interaction between the healthcare worker and the patient (or their representing organisations), such as presented in the conceptual model by Longtin et al.<sup>4</sup> In this study, a broad concept was adopted to allow the opportunity for respondents to express spontaneously which elements they saw as comprising patient involvement.

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<sup>2</sup> NHS White Paper, Equity and excellence: Liberating the NHS (July 2010)

<sup>3</sup> A new definition of patient engagement. Center for Advancing Health 2010

<sup>4</sup> MayoClin Proc. 2010;85:53-62

This qualitative study aims to explore the hypothesis that there is limited understanding of the opinions about patient involvement and that the basic principles may not be uniformly understood, through understanding the views and perceptions of both practitioners and patients on the issue.

Aspects of patient involvement have been subject to research in several countries, but no information is available about patients' and health care workers' views in many countries including many EU Member States. Since the topic of patient involvement is related to aspects of the organisation of health care and the attitude of patients and health care workers, there is reason to believe that patient involvement is experienced in different ways in different Member States. To understand patient involvement in this context, this qualitative study examines the ideas and beliefs of healthcare workers and patients across the EU.

At EU level, several initiatives are undertaken in the field of patient safety. More patient involvement is considered an element to support the safety of healthcare. Sharing good practices at EU level for patient involvement needs that we are aware of the variation across EU Member States in opinions, attitudes and practices. . It is intended that the research findings will add valuable information to EU initiatives in this field.

While the overall aim of this research was to explore views on patients' involvement in healthcare, the detailed objectives of the research were to investigate:

- Overall opinions of national healthcare
- Perceptions of responsibility for healthcare
- Patient trust and control
- Understandings of patient involvement
- Benefits and risks of patient involvement
- Satisfaction with patient involvement
- Patients' current involvement in a range of healthcare areas
- Barriers and improvements to patient involvement



### ***3.2 Methodology and sampling***

The method used for this research was a qualitative study comprising in-depth interviews with patients and health practitioners. Fifteen interviews were carried out in each of 15 EU Member States: Austria (AT), Belgium (BE), Czech Republic (CZ), Finland (FI), France (FR), Germany (DE), Greece (EL), Hungary (HU), Italy (IT), Latvia (LV), Poland (PL), Romania (RO), Spain (ES), Slovakia (SK) and the United Kingdom (UK). The countries were selected in order to achieve a geographical spread across the EU. As mentioned earlier, for simplicity and to reflect the broad east/ west geographical distinction in the themes which emerged, the report refers to the difference between "Western" (Austria, Belgium, Finland, France, Germany, Italy, UK) and "Eastern" countries (the Czech Republic, Hungary, Latvia, Poland, Romania, Slovakia and to a lesser extent Greece)

The detailed design is described in the appended technical summary.

## 4 OVERALL CURRENT STATE OF HEALTHCARE EXPERIENCE

This chapter describes respondents' overall opinions about the standard of national healthcare in their country.

### 4.1 Key findings

- Healthcare experiences varied considerably. Respondents in western European countries tended to rate their national healthcare systems more highly than respondents in eastern European countries. The latter described their systems as lacking funding and sometimes basic infrastructure, including hospitals, clinics and equipment.
- Respondents regarded their healthcare systems positively in terms of access to basic healthcare they provided and for their highly-qualified and well-trained medical staff. However healthcare systems were criticised for long waiting lists.
- Central to the idea of patient involvement was a common complaint about **the amount of time spent by doctors and nurses with individual patients**. This was seen as one of the main causes of poor communication and information, and was linked by some respondents to poorer care and treatment outcomes. Patients valued **good communications** between patients and practitioners. These two issues of time and communication were perceived to be the main areas of improvement for patient involvement.
- Chronic patients sometimes expressed the feeling that doctors do not take account of the 'psychological' impact of treatments and their effects in day-to-day life, whether pain or physical changes.
- For some staff increasing patient involvement is seen as a necessity to cope with an already stretched healthcare system.

### 4.2 Overall opinion of national healthcare

Respondents were asked whether, based on their experiences, they considered the healthcare system in their country to be good or bad.

#### 4.2.1 Practitioners

Practitioners in some western European countries tended to consider their national healthcare systems to be excellent or very good, with some (especially those in AT, BE, DE) describing it as one of the best in Europe or even the world.

Practitioners in other countries also tended to describe their healthcare systems positively, generally, to be rather good or quite good.

*"I think the quality of the Spanish healthcare system is quite good. I've seen the results of articles published in other countries such as the US. We are at the same level in terms of management of common diseases that affect the population such as hypertension and diabetes. Their percentages are similar to ours" (ES Doctor, hospital, diabetologist).*

However, in a few countries, including most eastern European countries, practitioners considered their healthcare systems to be of mixed quality or poor.

*"They expect a European-quality service, but the conditions are the same as in the Balkans!" (HU, nurse, hospital, head nurse)*

In those countries where the healthcare system was perceived less positively, some practitioners cited a basic lack of funding as the main obstacle to higher quality healthcare in their country. This funding issue was especially true in Greece and certain eastern European countries.

*"I like to think that the poor provision of care is not to be blamed on the scientific training of the doctors. It has to be blamed on the deficiencies we have at the level of the infrastructure, personnel and resources to process a patient. Hospitals lack diagnostic equipment and machine operators, because there are machines and there are no operators since there is a general freeze of new hiring in the hospitals." (EL, Nurse, hospital, regular clinic)*

*'Regarding the healthcare we give, they (the directors of a private hospital) force us to economise on pharmaceuticals, they keep on saying that we do not have enough profit, etc. It is limiting and stressful.'* (CZ, Doctor, both hospital and PCT, Paediatrician)

In France, a perceived fundamental decline in the quality of healthcare provision was a major concern for some practitioners, and was linked to changes in national economic and social policy. Some practitioners in the UK also reported a general decline in their health service, linked to poor management.

Positive features of national healthcare mentioned by practitioners, according to their country, centred mostly around accessibility, staffing and infrastructure.

Making basic healthcare available for all, regardless of income was seen as a key strength of the healthcare system for many practitioners. Having access to a full range of procedures regardless of cost, age or medical status of the patient was also seen as a positive aspect

*"It is good that in Finland care providers aim at giving good care to every patient. The problem is that the number of patients has risen so high that all patients are not able to have that care quickly enough. " (FI, Doctor, PCT, health centre physician)*

Having sufficiently resourced and well trained staff was also viewed positively. This enabled prompt, personal care, more patient choice of doctor or specialist and a better patient-practitioner relationship.

*"Healthcare in Finland is good. It is reliable and we nurse patients as long as it is necessary. Nobody is left without treatment. Sometime it feels that we nurse them too long." (FI, Nurse, hospital, urologic)*

Positive views of the infrastructure, including hospitals and equipment were expressed by some practitioners, including not only physical infrastructure but also the supporting procedures and organisational efficiency.

Practitioners in certain western European countries were concerned about how current high standards would continue to be financed (a view expressed especially in AT, DE, UK). The 'excellence' of their systems was linked to patients holding exaggerated expectations of health care, and lacking understanding of the high cost and effort involved.

*"I think people are offered a lot and they're offered a lot free of charge [...] the trouble is, patients are used to a certain level and they don't like change and they can't see that certain changes are actually going to improve the healthcare system." (UK, Nurse, PCT, general)*

*"It should definitely be taken into consideration how long this healthcare system will still continue to work out financially!" (AT, Doctor, hospital, internist)*

Negative features of national healthcare mentioned by practitioners tended to focus on the same issues – accessibility, staffing and infrastructure. The main complaint in terms of access focussed on patients often spending a long time spent on waiting lists but there were other issues to do with resourcing.

*"I am a pathologist in a hospital. Unfortunately the public health care system is not the ideal one as now there is a heavy workload and many incidents that need to be attended in the emergency duty calls. Thus, it is reasonable that a patient unfortunately must wait 2 and 3 and 4 to 5 hours to get treated. The long wait is due to the lack of the principle of distributing the patients according to the level of emergency. A principle dictating that the emergency incident should be preceded by a classification according to the incident. Maybe in the private sector things are better." (EL, Doctor, hospital, pathologist)*

Inequality of access was also a complaint because of the increasing cost of treatment (and a corresponding lack of subsidy or reimbursement for poorer patients).

*"There are those who can afford care and those who can't. The gap is widening. It's harder and harder to provide quality care for everyone." (FR, nurse, clinic/surgery)*

Staff resourcing was an issue for many, resulting in additional pressure especially on nursing staff. The lack of nurses means that less time is available for nurses to spend with patients, in hospitals and that medical staff generally are over-worked. For some staff increasing patient involvement is seen as a necessity to cope with an already stretched healthcare system.

*'There's a shortage of staff. We have to teach people to fend for themselves, to give themselves injections because we don't have time to do it.' (FR, Nurse, clinic/surgery)*

*"...the amount of staff is not always sufficient...I don't want to work less, but the patient's wellbeing is at stake here, because in a hospital when I have less patients under my care, then I can provide them with more attention, the patient is simply better looked after" (PL, Nurse, hospital).*

Infrastructure was an issue in Eastern Europe especially, where many practitioners complained of old and inadequate hospitals and equipment. Lack of well-organised primary care and inefficient, badly organised systems were also mentioned with bureaucracy and form filling also criticised.

Related to infrastructure problems was a perceived lack of funding, in general, especially in eastern European countries. The funding issues covered budget cuts, allocation of funding, low salaries, and limitation imposed by health insurance systems.

*'We asked the European funds for financial help to buy some medical equipment we could not get through state money, but they did help us. We are very limited by a lack of money, then I feel sorry that I can't help someone due only to the fact we do not have the equipment to do so.'* (CZ, Nurse, hospital, surgery)

Financing was also an issue in some western countries with some practitioners who mentioned the closure of hospitals due to changing economic and social policy. There was also concern about inconsistency of care funding across primary care meaning treatments being available often depended on where you live. Unsustainable resourcing in the long term was also an issue.

*"It should definitely be taken into consideration how long this healthcare system will still continue to work out financially!"* (AT, Doctor, hospital, internist)

#### 4.2.2 Patients

In line with the views of practitioners, there were mixed views of the healthcare system expressed by respondents across the different Member States. Some patients who were interviewed considered their healthcare system to be excellent or very good.

*"We live in a country where the social security system is one of the best in the world".* (AT, patient, 18-44, hospital, acute)

In the majority of countries, patients tended to express generally positive but somewhat mixed views. While patients often had a mostly positive perception of their healthcare system they were at the same time critical of some specific and fundamental aspects.

*"It is overwhelmed, it's very good, for a free service [...] I can see the human side of it [...] with the NHS you have to have patience [...] I know that if someone's had horrific news, you can't just give them 15minutes [...]"*

*It doesn't work to a deadline or timetable, it's purely because of the sheer number of people and it's a very emotional subjects you might be dealing with." (UK, Patient, female, 18-44, PCT, acute)*

In Greece and some Eastern European countries, patients tended to be more negative about their healthcare system usually due to resourcing and funding issues.

*"You must be joking. Health Care in Greece is bad. I have gone to a public hospital unexpectedly, not for a planned surgery, and I was waiting from 11.00 pm until 5.00 in the morning and had not yet been examined by no one. I was given a number [waiting list] and a number was going through every 1.5 hours. So, after all these hours I had finally done some tests but the tests were proven to be false and I had to redo them.... and then eventually I got bored and left without treatment... (EL, Patient, female, 18-44, hospital, acute)*

*"When I need a general check-up, I go to a private clinic because I do not have to wait there. I make an appointment for a specific time and I have the comfort of not having to wait in line" (PL, Patient, male, 45-65, hospital, chronic).*

Patients were often complimentary about the individual healthcare practitioners they dealt with, especially general practitioners who were seen as friendly and accessible. Doctors and other practitioners were generally perceived to be highly qualified and well trained, gave patients confidence, were seen as 'skilled and reliable' and dedicated to their profession.

*"My internal medicine practitioner is someone who is very competent and who really listens." (DE, patient, male, 45+, PCT/HOSPITAL, chronic)*

Patients' comments regarding positive features of national healthcare focused less on infrastructure than did practitioners. Patients tended to focus more on the practical accessibility of healthcare services and their interactions with practitioners, especially doctors.

Negative features of national healthcare mentioned by patients centred on the issue of long waiting list times, especially for appointments with specialists.

*"It can take a long time to get an appointment, sometimes you have to make one 6 months in advance" (BE, Patient, male, 18-44, PCT, chronic)*

The cost of healthcare was also a widely mentioned concern, especially in Eastern Europe. Complaints included the high prices of medical services in comparison with patients' average salary and different treatments and quality of healthcare available to the better off.

*"I go to my general practitioner and ask for a prescription. He says: you don't need it. Why isn't he giving me a prescription if I feel that I need it? I can go [to a specialist doctor] and pay my money. Examination costs 40-50 lats. I cannot afford it from my salary." (LV, Patient, female, 45+, hospital, chronic)*

The inequality of healthcare was not limited to patients in Eastern Europe but also in other countries. Inequality was more usually linked to geographical disparities between rural and urban areas, or regional differences which meant that some patients did not receive the same level of healthcare.

*"It depends on where you go. The quality is different in different districts. I nowadays use mainly the services of the private health care." (FI, patient, female, 18-44, hospital/ PCT, acute)*

The view was also expressed that patients with high incomes being offered, or having access to, better treatment. In some eastern European countries, corruption, including bribery and 'favours' paid for access to services were also mentioned.

*"What can I do? [...]. When I go to the doctor, I do as he says. But, overall, we share responsibility. We give the envelopes with the money [in Greece, many times, it is expected to offer, illegally, to the doctor money for the medical service he offers in a public hospital even if the doctor is being paid by the National Health System]. We go to the doctor and ask him to put us ahead of the waiting line and do various tricks to serve ourselves first and we cannot understand that it takes time though the waiting list is unavoidable." (EL, Patient, female, 45+, hospital, acute)*

*"The fact that I had to face a big queue upset me. Ok, maybe there were many sick children, I understood that. But then, some of them were skipping the queue, they knew the doctor. He was calling them in by their names. I said nothing for the first one, the second one, but then, on the third one I couldn't take it anymore. I entered the cabinet, took out the medical file, signed for leaving and went to another doctor." [RO, patient, male, 18-45, PCI, chronic]*



Some patients complained that a **lack of staff** meant that often practitioners had little time to spend with patients or it resulted in poor information and care for patients. This was often linked to a wider issue of a lack of funding which was expressed by patients mostly in eastern European countries.

*"They don't have proper equipment! You go to a hospital and you see what you see in other countries in museums!" [RO, patient, male, 45+, hospital, chronic]*

Communication issues between patient and practitioner were spontaneously mentioned by some patients, with a perception that some doctors and nurses still not being open to discussion, or to improving communications with patients - sometimes seeming arrogant and unsympathetic.

Some patients with chronic illnesses and conditions tended to be more critical of their countries' healthcare systems than those patients treated for acute conditions. For example, chronically ill patients made specific complaints about being judged as unfit to work 'too quickly', unequal access to certain expensive treatments, lack of empathy and consideration of patients' pain, insufficient explanation about treatment, and changes to treatment.

*'In the hospital, you do not get much information if you do not ask. Doctors do not willingly propose any alternatives.'* (HU, Patient, male, 18-44, PCT, both chronic and acute)

*"You cannot have control. In order to have control over what happens to me I should have been very well informed, well in advance, and be more knowledgeable about the medical condition in order to be able to have an opinion and a level of control over what happens to me."* (EL, Patient, male, 45+, hospital, chronic)

*"Doctors are not always sensitive enough and interested in problems of patient."* (LV, Patient, female, 45+, hospital, chronic)

Chronic patients sometimes expressed the feeling that doctors do not take account of the 'psychological' impact of treatments and their effects in day-to-day life, whether pain or physical changes.

*'When I say that it is hard for me to put up with having gained 20 kilos with my treatments, they aren't concerned. The same thing happens when I say that I'm tired because of all the medicines I take. They can't put themselves in the patient's shoes. They only see a disease.'* (FR, Woman, 45+, >18, hospital, chronic)

Younger patients also tended to be more critical of quality and expertise in healthcare than older patients. As with practitioners, some patients with access to 'excellent' healthcare provision were concerned about how such high standards would continue to be funded.

## 5 PERCEPTIONS OF RESPONSIBILITY

Respondents were asked who they considered to be responsible for patient healthcare, and whether the patient should share responsibility. They were also asked what they understood "patient involvement" to mean.

### 5.1 Key findings

- Patients' responsibility was often perceived by practitioners in terms of healthy lifestyle, prevention and complying with prescribed treatment.
- Patients with a higher level of education, patients with greater experience of healthcare and patients with chronic conditions were more likely to see themselves as holding a more active responsibility for their healthcare.
- The term 'patient involvement' was most often related to patients taking responsibility for a healthy lifestyle and finding out information about their condition.
- More active involvement was mentioned by only a minority of practitioners and by patients with chronic conditions. Their suggestions included patients monitoring the efficacy of treatments and side effects, carrying out blood tests, developing comprehensive knowledge about their condition and how to manage it, and suggesting treatments.
- Many patients wanted a fuller understanding of the diagnoses and treatments they receive, to be informed about possible outcomes and alternatives, and to be given choices. This would enable patients to participate more in healthcare, and increase healthcare effectiveness.
- The main risks of patient involvement, mentioned by both patients and practitioners were the increased demands on practitioners' time and patients disagreeing with doctors' opinions.

### 5.2 Views of responsibility

#### 5.2.1 Practitioners' views of responsibility

Practitioners' perceptions of who held responsibility for patient healthcare fell into three broad categories:

- Practitioners hold overall responsibility
- Responsibility is shared between practitioners and patients
- Responsibility is shared between State, national health authority and patient

These categories did not show any particular geographical pattern. Rather they represent the broad schools of thought which were expressed across most of the countries.

### **1 Practitioners Hold Overall Responsibility**

In some countries, practitioners – especially doctors - saw themselves as holding overall responsibility for patients' healthcare because they provided the treatment. These practitioners generally did not spontaneously mention patients as having responsibility, either for patient safety or quality of care.

*"Ultimately it is the doctor who is responsible for the patient safety and for quality of care; a physician in charge at a polyclinic or at some department. If a nurse makes some mistake it is still the physician who takes liability." (FI, Doctor, hospital, haematologist)*

*"An ill patient should get adequate healthcare. His responsibility or involvement should not play any part in it." (SK, hospital, anaesthetist)*

When prompted, most of these practitioners conceded that patients hold some responsibility for their healthcare. Patients' responsibility was seen to lie in prevention (especially healthy lifestyle), assisting diagnosis by providing information about symptoms and following medical instructions. Some general practitioners more readily acknowledged that responsibility was shared by practitioner and patient than those working in hospitals.

*"Of course, they are very responsible. First of all, they shouldn't wait until the situation becomes severe to go to the doctor. Then a relation between the doctor and the patient needs to be created. Patients need to follow prescribed treatments and give up on certain vices that could affect their health. It is extremely important that the patient understands to prevent diseases and treat certain conditions from the moment they appear." [RO, doctor, PCI, general practitioner]*

## 2 Responsibility is Shared between Practitioners and Patients

Other practitioners responded spontaneously that **responsibility for healthcare was shared** between practitioners, especially doctors, and patients.

*"There is no doctor responsibility without patient responsibility." (BE, doctor, own primary healthcare clinic, GP)*

*"We cannot cure anyone if they do not cooperate with us..." (HU, doctor, hospital, paediatrician – immunologist)*

Doctors were often seen as responsible for diagnosis and treatment and, to an extent, for listening to patients and maintaining dialogue, whereas patients' responsibility was generally more related to lifestyle and preventative behaviours – in other words to take care of their day-to-day health.

*'A doctor is responsible for the quality of intervention, but a patient is responsible for the resulting health, on the whole.'* (CZ, Doctor, hospital, Internist)

*"I'll see a patient for 15 minutes, 3 times a year and the rest of the 365 days a year they'll be on their own so it's crucial that they know what to do to make sure they have better health for longer and live longer" (UK, Doctor, hospital, cardiologist)*

Other perceived responsibilities for the patient included notifying practitioners promptly when symptoms or problems arise, or when intervention was required and following the treatment prescribed for them by the doctor. While some talked of a more active involvement, such as taking more interest in their treatment, seeking the best cure for themselves and gathering accurate information about their condition, or taking some responsibility for choosing an appropriate practitioner – generally speaking **responsibility was described in terms of following doctor's orders.**

*"The patient's responsibility lies with letting himself be treated: when he comes into a hospital, the responsibility passes to the medical staff" (IT, nurse, A&E)*

*"Yes, of course patients have personal responsibility for their own healthcare. They should follow the regimen they are given." (FI, Nurse, hospital emergency room)*

It was acknowledged that patients with chronic medical conditions often assume responsibility for their own care. In the case of certain patients, namely elderly and disabled patients, some practitioners commented that patients' families should also take some responsibility in the treatment process. However, some practitioners criticised patients for not taking enough responsibility for their own healthcare and thereby hindering health outcomes.

*"The doctor tells the patient he should not eat fat sausages because of high cholesterol. However, the patient says that it does not matter because he takes pills to reduce high cholesterol." (SK, Nurse, PCT, Urology)*

*"They shouldn't wait until the situation becomes severe to go to the doctor. Then a relation between the doctor and the patient needs to be created. Patients need to follow prescribed treatments and give up on certain vices that could affect their health." [RO, doctor, PCI, general practitioner]*

### **3 Responsibility is Shared Between State, National Health Authority and Patients**

Some practitioners expressed the view that primary responsibility for patient safety and the quality of healthcare was shared between patients and the State, or national health authority rather than simply between patients and practitioners.

Practitioners often felt that the national government, national health authorities, lobbies and other interest groups held greater responsibility for patient safety and quality of care than practitioners, because of their greater influence and control over the health system. In particular, national authorities made overall decisions regarding financing, and were responsible for establishing and maintaining hospital infrastructure including buildings and systems, healthcare frameworks and governing regulations.

In some countries, mostly eastern European, the national health authorities were criticised for faulty systems and for providing insufficient support, funding or facilities. Consequently, some practitioners felt that they could not be held chiefly responsible for the quality of healthcare. The Government or State was seen as being responsible in terms of providing a healthcare system which was adequately resourced with sufficient staffing, and accessible to all. Government was also seen as responsible for maintaining a good level of education and training for doctors and also providing healthcare information and prevention to the general public.

*"Normally, if we think in a broad perspective, the government should allocate more funds towards hospitals and medical personnel. Everything starts from the money. [RO, nurse, hospital, internal diseases]*

*"By one Act they (the ministry) cut some departments and people have to travel 50km to reach another hospital. Then patients do not get the treatment promptly." (SK, Nurse, PCT, Urology)*

*"Ultimately the most responsible body [...] would be the government because they call the shots regarding what services are available and they determine the infrastructure [...] but on an individual basis the clinician has ultimate responsibility." (UK, Doctor, hospital, cardiologist)*

*"(Who is responsible?) First of all the government...through the Health Ministry. They have the obligation to create and finance all these programs that are necessary to patients." (RO, doctor, primary care, general practitioner)*

## 5.2.2 Patients' views of responsibility

Patients in all countries saw themselves as holding some responsibility for their own health care. Perceptions of responsibility varied depending on understanding of 'health care': some patients saw 'health care' as synonymous with 'health'. **For the majority of patients, the extent of responsibility was in two main areas – lifestyle and compliance.** Firstly, patients described taking responsibility for a healthy lifestyle, which could prevent ill health. This was usually described in terms of diet, physical activity, and health-affecting behaviours such as smoking and drinking, to help prevent illness.

*"One is completely responsible for his or her health. It should be self-evident that people try to control and adjust their way of living, as well as to regularly visit doctors in order to maintain a health check-up!" (AT, Patient, female, 18-44, hospital, chronic)*

*"I definitely feel that I have a personal responsibility for my own healthcare. I have a responsibility of taking care of myself. I don't smoke and I eat healthily. In that way I can prevent diseases." (FI, Patient, female, 18-44, hospital/ PCT, acute)*

*"You have to live healthily yourself and avoid getting sick, your own choices affect to that." (FI, Patient, male, 18-44, PCT, acute)*

Secondly, complying with and following the treatment prescribed for them by the doctor was also seen by many as the main responsibility for the patient. Many patients described this in such passive terms that they actually seem to relinquish all responsibility to the healthcare practitioner.

*"I take my meds, I do what the doctor tells me to do, patients can't do much, they are the ones who are sick, there's not much they can do." (ES, Patient, female, 18-44, PCT, acute)*

Patients with chronic conditions, such as diabetes, or patients with more experience of health services, described a greater responsibility for their own healthcare than other patients. This went beyond responsibility for aspects of lifestyle. Over time, they had gained considerable experience of, and familiarity with, their own condition. This meant that sometimes they were best equipped to monitor their condition, provide feedback and make choices in how to deal with their disease.

*'I have a large responsibility. I know my body better than anyone. I know how to take care of myself. Sometimes doctors make mistakes. We are in a better position to know what suits us when dealing with a serious disease. We are the ones who pay attention' (FR, Woman, 45+, >18, hospital, chronic)*

*"I'm sure that I have the greatest responsibility for my own healthcare. Maybe, on the one hand, I'm to blame for being sick. But on the other hand, I have to inform myself about how to avoid falling ill and causing this sickness by bad lifestyle." (AT, patient, female, 18-44, hospital, chronic)*

### **5.3 Understanding of 'patient involvement'**

Respondents were specifically asked about their understanding of 'patient involvement'. For practitioners, the term 'patient involvement' was most often associated with the patients' attitude and awareness. This was frequently described in terms of patients taking more interest in their healthcare, asking questions and making themselves better informed. It also involved being aware of the basics of their health and taking more responsibility in the maintenance of their own health. Compliance was again the main recurring theme. Many practitioners felt that patient involvement was passive, and involved simply following doctors' prescriptions and regimen.

*"The patient should accept what's suggested, he should follow the prescription as best as possible" (Slovakia, Nurse, hospital, gynaecology)*



Involvement for practitioners also meant patients giving all relevant information to their doctor, for example, about symptoms, and previous test results and keeping doctors informed on the progress and efficacy of treatment they receive and of any adverse side effects.

*"Only when the patients give the most accurate possible information about their complaints and the progress of the therapy and give feedback can I be sure that I am treating them safely and in the right way." (Germany, doctor, ophthalmologist, PCT)*

*"This means the active participation of patients to the process of diagnosis and treatment and is highly wanted. It is very important that patients give all information to specialists in the healthcare field and have an essential role, the same with the doctor, to ensure that the dialogue between them is done with trust and confidentiality." [Romania, doctor, PCI, general practitioner]*

Practitioners also acknowledged that they need to take into account patients' personal attributes and circumstances, needs and concerns, giving them enough time to understand and consider information and make decisions and making it a two way consultation. As part of this, doctors need to inform the patients and explain diagnoses, conditions, and treatment options and their advantages and disadvantages to patients so they can make decisions for themselves.

*"Listening to them, getting them actually involved in shaping their care when they come to hospital, if they can, letting them do as much as they can do themselves." (UK, Nurse, hospital, general)*

Many felt that patient involvement was essential for effective healthcare provision, including the successful treatment of patients' illnesses or conditions. It was felt to be so important as it provided feedback on how the healthcare system is working, it helps make better use of limited resources, and was also seen as a factor which speeds up recovery – the higher the level of involvement, the better and faster the recovery. Some practitioners were not satisfied with the current level of patient involvement and wanted more engagement.

*"A lot of the time I would dearly wish that patients would take more of a role...It's frustrating that we're not able to improve their health if they're not being involved." (UK, practitioner, hospital cardiologist)*

For patients, the term 'patient involvement' meant the same as responsibility. General awareness of health was most commonly mentioned. This encompassed patients taking more interest in, and taking care of their own health, being responsible for a healthy lifestyle, with the aim of preventing illness. For some it also involved being more proactive, in learning about their condition.

*"Means that you take care of yourself and your treatments; not to let your shape deteriorate. I am quite well involved with my healthcare. I can consult my doctor anytime I want, I comply with his recommendations and try to get in better shape by losing weight and exercising more frequently." (FI, Patient, female, 45+, hospital, chronic)'*

Compliance was routinely mentioned and 'patient involvement' often meant little beyond patients **giving simple information about their health problems to doctors, being obedient to instructions, cooperating, and accepting the doctor's decision.**

*'It's the doctor who is in charge, after all. Apart from taking the medicines and not over-indulging, we can't do much.'* (FR, Woman, 45+, >18, hospital, chronic)

Open communication between doctor and patient was seen as a critical part of this involvement. This involved the patients' right to have a say and for practitioners paying attention and listening to patients and treating patients as more of an equal partner.

*"The Patient should be elucidated about his or her medical treatment, and he should have the right to ask questions and also to contradict any medical procedures!"* (AT Patient, 18-44, female, PCT, acute illness)

For chronically ill patients, 'patient involvement' had a more practical meaning. They often commented that they had 'no choice' but to be actively involved in their healthcare on a daily basis and often considered that they knew their own body and health better than the doctors. For these patients it was a more proactive involvement. Following their treatment regimen was part of it, with the same compliance of other patients. However involvement also meant being alert to side effects and changes in their condition, checking own symptoms, learning more about their condition and how to manage it and staying informed about treatment options.

*'I want to take part in the decision-making about my healthcare. I want to discuss whether that kind of treatment is really necessary or not...I want to be shown different ways of treatment and to make enquiries to find which is best. But sometimes, doctors seem to have the impression this would lower their status.'* (CZ, patient, female, 18-44, both hospital and PCT, chronic)

Generally where patients wanted more involvement, they wanted **more choice (including different treatment options), more time, more information, more participation in the decision-making but with limitations as to the extent of their involvement.**

*"It is good to have information, but there should be a limit to patient involvement. I am not a specialist so I would not go to a doctor and tell him what my diagnosis was and what treatment I wanted. I would rather describe what kind of problem I have and then leave the decision about treatment to him.'* (CZ, patient, female, 18-44, PCT, acute)

## 6 PATIENT TRUST AND CONTROL

Patients were asked about their perceptions of balance within the patient-practitioner relationship, specifically in terms of trust, equality, power, support and control.

### 6.1 Key findings

- For patients, trust in practitioners is an essential prerequisite for an effective relationship and was often seen as being associated with good communication and expertise.
- A sense of powerlessness was evident in many patients' descriptions of healthcare. This was often linked to insufficient information and discussion about diagnoses and treatments. **Patients felt more in control when they could ask questions, were listened to, had enough information, were given choices and were involved in decisions.**
- Some patients looked for a more balanced relationship with doctors than perhaps was typical in the past. For example, they wanted to be given more information and to have a role in decision-making. However, patients were clear that they neither expected nor wanted 'equality': doctors held greater expertise and knowledge than patients

### 6.2 Trust

Patients often thought the relationships they had with doctors were generally good or very good - based on a high level of trust, open communication and a caring approach.

*"[One doctor] is talking to you in a sensible way – did explain why I had cyst in my nose. Another one just went: oh, you have a cyst, you are ill, like you are not suitable for service any more – kind of unpleasant attitude." (LV, Patient, male, 18-44, PCT, acute)*

*"You are sick and concerned about your health; it's not nice to meet with a person who is not amiable and friendly. They need to put themselves in your shoes, we are concerned about our health, they should use psychology as we don't go to the doctor because we like it."*

*(ES, Patient, female, 45+, PCT, acute)*

Where patients described the relationship negatively, this was often characterised by mistrust, partly due to flaws in the overall healthcare system and lack of interest or willingness on the part of doctors and nurses to discuss, or even explain, conditions and treatments in detail. For some patients, their ability to find a doctor they could trust was undermined by a fundamental distrust of their healthcare system overall and its perceived poor organisation.

*"Older doctors are not very welcoming to a patient wanting to ask and co-decide. They take them all for laypersons. This has changed with the younger generation of doctors. They are already more open." (CZ, Patient, female, 45+, both hospital and PCT, acute)*

*"We trusted the doctor. They told us to take my mom home; they prescribed her some medicine. However, when the pain did not go away in two days we took her back to the hospital. The doctor hospitalized her. After this experience, we knew the first doctor could not be trusted." (SK, Patient, Male, 45+, PCT, Acute)*

Patients looked for trust in their practitioner as a prerequisite for a good relationship. Trust was engendered by perceptions of the doctors' level of expertise, skill and knowledge, good communications between practitioners and patients and opportunities to be involved in their healthcare, for example, by participating in decision-making.

*"My son's paediatrician is excellent, I believe what he says, he must be 55 or 60, very experienced." (ES, Patient, female, 18-44, PCT, acute)*

General practitioners were often described as being most open in their communications with patients and most trusted. Practitioners' familiarity with their patients – examples were given of long-standing, family general practitioners – was linked to greater trust, better communications, attentiveness and less inequality between practitioner and patient.

*'I have a very good relationship with my general practitioner, he takes me as an equal partner, I can talk to him about everything and he has my full trust, because I know he is an expert.' (CZ, Patient, male, 45+, both hospital and PCT, acute)*

*"My relationship with my doctor is very good and confidential. He is a wonderful person. It is also an "equal" relationship where he listens to what I have to say and also takes that into account." (FI, Patient, male, 45+, hospital/ PCT, chronic)*

*My local GP has more time, is more personal, and I feel I am in good hands." (DE, patient, male, 45+, PCT/HOSPITAL, acute)*

Nurses were generally viewed more favourably: they are seen to be closer to the patient and the relationship is more likely to be characterised by trust and equality.

*"Everybody thinks nurses are a bit friendlier, a bit more approachable, a little bit 'on the same level' [...] they viewed as people who are compassionate, caring and helpful." (UK, Patient, female, 18-44, PCT, acute)*

*"Patients come looking for nurses, getting more answers from them" (ES, nurse, A&E)*

Many patients felt that **poor communication** had caused, or contributed to, a lack of trust and prevented a good relationship developing.

*"I don't like situations when I don't receive enough information or when they use too many technical terms." (AT, Patient, female, 18-44, hospital, acute illness)*

*"Of course, I understand the diagnosis, yet I haven't heard so far to be alternative treatments for my illness. [...] Because I don't understand something, when he start to talk in Latin terms and want to show me his knowledge I tell him to take it easy with me because I want to understand. For my illness there are teas and some other things like that but I haven't heard about any proof of their efficiency." [RO, patient, male, 18-44 years, PCT/chronic]*

### 6.3 Communication and dialogue

For some patients, it was important that practitioners seemed interested and **took time to listen to patients** in order to get a full picture, and to learn their views and opinions. Otherwise, patients could feel powerless and lacking control. This discouraged, or excluded, them from participating in their own healthcare process. Some patients also reported that poor communication could lead them to distrust the thoroughness of doctors' examinations and diagnosis.

*"The practitioners in the hospital were overloaded, everything was done very briskly. I would have expected a bit more sensitivity." (DE, patient, female, 18-44, PCT/HOSPITAL, acute)*

*"... They only look at the computer, they don't even look at you, very cold. They are too cold and I don't feel like asking questions." (ES, Patient, female, 45+, PCT, acute)*

*'In the hospital, you do not get much information if you do not ask. Doctors do not willingly offer any alternatives.' (CZ, Patient, male, 18-44, PCT, both chronic and acute)*

Patients suggested that poor communications with healthcare practitioners were caused by a lack of time allocated to communications, often due to a lack of staff but also due to a lack of training. Culturally, some patients described a distant or officious attitude, with limited interest shown in what the patient says or might have to say.

*"This is connected to our doctors' education and training. They don't communicate with the patients and they don't have assistants, persons to do things for them. Usually, patients communicate with each other in the waiting room. That's where you find more than you find from the doctor. And this is not good, because everybody has a different experience, a different context, you can be misled. Usually the doctor doesn't take the time to explain you too much." [RO, patient, male, 18-44, PCI, chronic]*

*"Whether they listen to us? It is an interesting question. After the PCs have entered the doctor's room, I feel... yes, the doctor listens to me; however, he still writes. I understand that he is saving time when writing while I talk, but then I miss the eye contact." (SK, Patient, Female, 45+, PCT, Chronic)*

*"If I make the effort to be polite even after waiting several hours, then I do not understand why doctors cannot do the same." (HU, patient, woman, 18-44, PCT, acute)*

*"He doesn't speak reasonably to me at all. I don't have any say either. He is always the one who decides. So he doesn't need to explain anything." (DE, patient, male, 18-44, PCT, acute)*

*"At the gastroscopy the practitioner was very superficial, reeled off the results passionlessly, he didn't even look at me. I was just a number." (DE, patient, female, 45+, PCT/hospital, acute)*

*"You are sick and concerned about your health; it's not nice to meet with a person who is not amiable and friendly. They need to put themselves in your shoes, we are concerned about our health, they should use psychology as we don't go to the doctor because we like it."*  
(ES, Patient, female, 45+, PCT, acute)

In many countries, some patients faced with poor communication from practitioners said they had considered the option of changing doctor. This was often due to a lack of trust, not being taken seriously, dissatisfaction with the diagnosis or prescribed treatment or with the amount of information given to them.

*"I had problems with my doctor and decided to switch, she was not attentive or reasonable so I had to switch doctors." (ES Patient, male, 45+, PCT, chronic)*

For some patients who decided to change to a different doctor, changing doctors was not necessarily straightforward. It could be difficult to find another doctor who was willing to communicate more openly with patients. Some of these patients tended to feel that they had little power or control over their healthcare. They become cautious and suspicious, and turned to friends and relatives for health-related information, instead of practitioners.

*"I had something, a gynaecology problem and I went to the hospital and the doctor there sent me away, too busy she said. I had to go to other people I knew, to some relatives to find out more." [RO, patient, female, 18-44, PCI, acute]*

## **6.4 Equality**

Patients did not expect or look for a fully equal relationship with their practitioner, their reason being that doctors (in particular) had more knowledge and expertise than they did.

'Trust' was desired, rather than full 'equality', 'power' or 'control'. However, a more balanced relationship was often desired. This was particularly true of younger well-educated patients, those with chronic conditions and geographically was more prevalent in western European countries.



**Good, open, unhurried, two-way communication was seen as fundamental to the 'more equal' relationship** which these patients desired. Some patients reported a clear development of the practitioner-patient relationship in their country over the last few years, from 'practitioner control' to 'shared control'.

*'Older doctors are not very welcoming to a patient wanting to ask and co-decide. They take them all for laypersons. This has changed with the younger generation of doctors. They are already more open.'* (CZ, Patient, female, 45+, both hospital and PCT, acute)

By contrast, patients in several eastern European countries tended to be more accepting of practitioners taking a high degree of control over their healthcare. For these patients, 'normal' relationships with practitioners tended to be characterised by doctors giving instructions and patients willingly submitting. Older patients, and those with a lower level of education were also more likely to expect practitioners to maintain control of patients' healthcare, and were more likely to describe the following attitudes and behaviours.

*"The relationship is often not equal. The doctor is a half-god. You do not feel you are on the same level. Doctors should be more focused on communication. Sometimes they just prescribe something for you with no explanation then send you home."* (CZ, patient, female, 45+, PCT, both chronic and acute)

*"In the end the practitioner makes his diagnosis and decides what has to be done. And that is the way it should be."* (DE, patient, male, 45+, PCT/HOSPITAL, chronic)

## 6.5 Control

A general sense of lacking power or control was implied by many patients. Patients described a sense of powerlessness in terms of not being able to control waiting times for hospitals for example.

*"It can take a long time to get an appointment, sometimes you have to make one 6 months in advance"* (BE, Patient, male, 18-44, PCT, chronic)

However it **was more generally related to a lack of information, especially about diagnoses and treatments**. This also included not being offered alternative treatment options and patients feeling rushed during the consultation.

*"You cannot have control. In order to have control over what happens to me I should have been very well informed, well in advance, and be more knowledgeable about the medical condition in order to be able to have an opinion and a level of control over what happens to me." (EL, Patient, male, 45+, hospital, chronic)*

*'It's a bit of a regret for me. I would like to be more involved in the choice of treatments.'* (FR, Woman, 18-44, >18, primary care in surgery, chronic)

*"I do what I am told. If I don't have any other options, I accept what I am given."* (LV, Patient, male, 45+, hospital, chronic)

Some chronically ill patients described a strong sense of powerlessness in their ongoing medical treatment, for example, when being prescribed medicines without information or consultation about side effects or subjected to a 'trial and error' approach with many different tests and medicines. Some doctors took insufficient account of the impact of the chronic condition on their day-to-day life, psychologically and physically, increasing their sense of powerlessness in their life in general, beyond healthcare.

*"The relationship has been very distant since my doctors do not care what I say to them; they listen to me but they do not take that into account. I have continuously felt very powerless and not in control about the situation. Hence I have become much more passive and I currently try to avoid going to the doctor's office." (FI, Patient, male, 45+, hospital, chronic)*

Patients described a sense of control in relation to **choice**. There was a feeling for many that they had a choice of hospital, and doctor and that they could change doctors if dissatisfied. Choice in terms of treatment options was only occasionally mentioned.

*'Today there is more choice between traditional or official care and other options like osteopathy or natural treatments recommended by pharmacists' (FR, Man, 45+, >18, primary care in surgery, acute)*

Certain demographic factors – specifically, educational level, age and experience - were seen as influencing individual patient's sense of being able to take control. Patients of lower educational level tended to be more in awe of healthcare practitioners and so took less control of their healthcare. Elderly patients were also more likely to delegate to

practitioners or relatives were more trusting and less informed and so had less involvement in their healthcare.

*"There are people who get more involved, it's easier to have a better relationship if the patient has a high socio-cultural level, compared to a 70 year old patient with lower educational level who has been raised in a different place. People with less knowledge delegate more compared to the ones who know more."*  
(ES, Nurse, hospital, Emergency Room).

Patients with extensive previous experience of healthcare, either through their own past treatment or that of family members, had more confidence in taking control than less-experienced patients. This was not always viewed positively by practitioners.

*"Patients who have medical training or a higher level of education are the most difficult. They always ask most questions and I have to dedicate more time to them."* (BE, doctor, hospital, assistant neurologist)

In eastern European countries, patients were less likely to have a sense of being able to take control, of their own healthcare (other than through living a healthy lifestyle). Concepts of patients' 'power' or 'control' seemed less relevant or meaningful to them.

*"I have to rely on the doctor, I can't do it on my own. You need to trust them, instead of putting up a negative attitude"* (PL, Patient, male, 18-44, PCT, chronic).

*"The patient cannot be responsible if he is at the mercy of the doctor!"* (HU, patient, man, 45+, PCT, acute)

*"I don't have any options, I must trust this one person. When I have any health problems, I go to him with that and I must trust. I either trust him or don't."* (LV, Patient, female, 18-44, PCT, acute)

Much of their emphasis was on poor healthcare infrastructure, lack of access to healthcare or poor socio-economic conditions. They were skeptical about the possibility of patients sharing in decision-making and mentioned problems with doctors feeling 'superior'.

*"It will never be equal. The doctor sets the rules. We are asking for help."* (SK, Patient, Male, 45+, Hospital, Acute)

## 7 CURRENT INVOLVEMENT IN DIFFERENT AREAS

Respondents were asked about specific aspects of healthcare and the extent to which patients were involved in each.

### 7.1 Key findings

- Both practitioners and patients felt they knew and understood the diagnosis and treatment given to patients, however practitioners believed that few patients **fully** understood the diagnosis. Also, patients were seldom made aware of possible alternative treatments. The issue of time spent in consultations, lack of information and lack of choice emerged again as themes.
- There was little awareness of patient safety and quality standards and patients were generally uninterested. Patients tended to be more focused on their own treatment and were willing to presume standards were met.
- Patient control was something people struggled to understand and was often associated with signing consent forms, refusing treatment. It was also associated with choice, and this is the area where patients wanted more control.
- Questions and feedback were an area where patients were felt to be involved to a limited extent – however the lack of time doctors can spend with patients limited the opportunities for this to happen. Also cultural aspects of the doctor/ patient relationship affected some patients' willingness to ask questions, especially in Eastern Europe. Similarly, while patients can in principle disagree with treatment, in reality it was felt this does not happen.
- Self-care was widely associated with "following doctor's orders", the issue of compliance which is seen throughout the results. Some chronic patients reported more active self-care.
- The internet and access to health information was considered an important development related to patient involvement. While patients see it as empowering, practitioners were often negative and worried of the risks of misinformation and increasing patient anxiety. It was also felt it might undermine the authority of the doctor role.

- Decision-making was an area where patients wanted involvement in the sense of being informed of why a decision was made, rather than being responsible for the decision itself. In some (mostly eastern European) countries, for patients this was about getting more **information**. In other countries, it revolved more around the idea of **choice**.

## 7.2 Diagnosis

Respondents were asked whether patients currently know and understand the diagnosis and treatment they receive and if they are aware of possible alternative treatments. They were also asked if they should be more involved in this area.

Both practitioners and patients in most countries thought that it was generally true that patients knew and understood the diagnosis and treatment they received. However, practitioners doubted that patients always **fully** understand diagnosis and treatment, and the likely impact. This tended to be because **practitioners lacked time to help patients understand fully**, some patients were perceived to be less interested in understanding fully and were happy to trust doctors' judgments.

*"Patients understand, at that moment, which medical procedures need to be carried out. But they often forget about these details as soon as they leave the hospital or doctor's office. There is too much information in too little time." (AT, nurse, hospital, gynaecology)*

According to some practitioners, elderly patients and those with a low level of education were less able to understand, as were some acutely ill patients presenting to Accident and Emergency. Some practitioners also reported that they withheld more complex information because they were concerned about the potential for patients to misunderstand. A few practitioners withheld full diagnoses, for example, of terminal cancer, in case patients 'couldn't cope with it' or the amount and quality of information provided varied by practitioner.

*"There are only 24 hours in the day and it depends on how we divide them up. If the patient is interested and able to understand, we inform them (of alternative treatments). But sometimes explanations are a waste of time." (CZ, doctor, hospital intern)*

A few patients who said they received **insufficient information** at the time of diagnosis described feeling disempowered and anxious as a result. According to a few respondents, general practitioners were expected to explain diagnoses and treatments more thoroughly than specialists and identified more with this task.

Certain practitioners reported that they appreciated patients' active enquiries and interest: cooperation with treatment was easier to achieve with enlightened and informed patients. However, some cautioned that patients will always know less and understand less than doctors: although there is scope for improvement, practitioners – as relative experts - need to keep some control of the information patients receive.

*"There are people who are well-aware. They search the web, sometimes even try to come up with their own initial diagnosis. And there are also people who are completely like 'I have no idea'." (PL, doctor, PCT, GP).*

*"They know their diagnosis and understand precisely the prescribed treatment and when they don't understand I try to help them. It is in their own interest to follow the medical prescriptions because it means improving your life quality and also to increase your life expectancy." [RO doctor, PCI, general practitioner]*

In many countries, practitioners and patients would generally like patients to be more involved in knowing and understanding their diagnosis and treatment. Patients could then participate more in their healthcare even if they are not "experts".

*"As a layman I cannot consider the appropriate treatment; however, by knowing the alternatives, I could choose between more or less financially or time demanding treatment." (SK, Patient, Female, 45+, PCT, Chronic)*

Although it was generally believed that patients were informed about their diagnosis and treatment, there were many practitioners who believe that **patients were often not made aware of possible alternative treatments**. Practitioners explained that of there was not enough time to go over the alternatives, they had decided beforehand which treatment would be best, and proposed this to the patient, without referring to alternatives or it was not seen as necessary – or even helpful - for patients to know the alternatives as a matter of course although they could ask for them. Some doctors did not want to complicate things for patients or did not want to feel less confident about the treatment that had been recommended.

*"You shouldn't always openly present possible alternative treatments. You might give the impression that you are not convinced of the effectiveness of the prescribed treatment." (BE, doctor, hospital, assistant-neurologist)*

Correspondingly, many patients, primarily but not exclusively in eastern European countries reported that they were **not aware of there being any alternative treatments**. No alternatives were presented to them. However, some patients reported that if they specifically asked, practitioners would let them know of alternatives. Chronically ill patients tended to be more aware of alternative treatments. A few patients did not seem to grasp the concept of 'alternative treatments', thinking that there could be only one possible treatment. The term 'alternative' treatments' was sometimes misinterpreted as meaning non-conventional, non-medical or non-clinical treatments, such as homeopathy. Some practitioners were reported to be particularly unwilling to mention or discuss 'alternative treatments', particularly if they were seen as unconventional or expensive ones.

*"They don't say the possible alternatives, they speak of what is easy for them and good economically" (IT, patient, female, 18-44, hospital, chronic)*

By definition, it was hard for patients to be certain whether the full range of alternatives has been presented to them or not, but many felt that they would like it to be.

*"The doctor told me everything; I think that everything was good. I am not competent. Therefore there is a doctor who is competent in this sphere. He tells what would be better for me." (LV, Patient, male, 45+, hospital, chronic)*

Many patients would like more involvement in knowing about alternative treatments. Respondents stressed that **practitioners would need more time with patients to enable improvement in these areas and others worried that it would undermine the perceived efficacy of the prescribed treatment**.

*"The more the person knows, the more anxious, suspicious he becomes, therefore more indecisive, more mistrustful. A big amount of information is not always beneficial. But there is some conditioned minimum which they must understand to be able to take decisions." (LV, Doctor, hospital, urologist)*

### 7.3 Patient safety and quality standards

Respondents were asked whether patients knew about the patient safety and quality standards in place in healthcare institutions, and whether patients should be more involved in this area.

In almost all countries, the majority of practitioners and patients thought it was untrue that patients knew about patient safety and quality standards in healthcare institutions. When patients had knowledge, this was likely to be basic or minimal. Some practitioners thought that this lack of detailed knowledge probably did not matter.

*"It is not worth anything (for a patient) to know that a nurse should change her gloves and the floor should be cleaned with a particular liquid...but there should be access to the normal standards if someone is interested in them...There is no need for patients to know them, or to sign anything saying they do." (CZ, doctor, PCT, gynaecology)*

*"Most of the time, the patient is only interested in what is currently bothering him, what is disturbing him at this particular moment in the treatment process." (AT, doctor, hospital, intern)*

*"They shouldn't need to worry about whether standards are being maintained... they are too ill. They need to focus on getting better." (UK, Doctor, hospital, cardiologist)*

*"I don't think it is necessary for patients to know about the safety and quality standards. Doctors should know the standards and patients should rely on them." (SK, Doctor, Hospital, Anaesthetist)*

Many practitioners and patients considered that most patients were not interested in knowing about standards. Patients were focused on their own healthcare and what happened to them and were willing to presume that standards were met. However, some patients with chronic conditions were more interested to know whether or not practitioners were meeting standards that related to specific aspects of their healthcare.

*"Such things as cleaning surgical instruments, wearing gloves, taking special care with injections..." (DE, patient, female, 18-44, PCT/HOSPITAL, chronic)*



In some countries, basic information about patient safety and quality standards was accessible to patients, for example, through posters hanging on hospital walls.

*'As a rule these are posted in hospitals. You see the charters prominently displayed on the wall.'* (FR, Man, 45+, >18, primary car at surgery, acute)

*"It is hanging on the wall there. They can read it if they like and they can also ask the patient advocate about it, but we do not have the capacity for this kind of work!"* (HU, nurse, hospital, nursing director)

*"I would like to know who will do that. Because nurses unfortunately cannot provide so much information, because there are very many patients in the hospital department, and there are just 2 nurses. It is hard to run around all 40-50 patients and tell it everybody...there could be some person who deal exactly with this question."* (LV, Nurse, hospital, blood-vessel surgery)

However, most patients admitted that they did not read it. In other countries, safety and quality standards were seen as inaccessible to patients – they were not on display or presented to patients in any way, and patients did not know how to find out more about them.

*"I suspect they are not known by my patients since they are not on display anywhere."* (FI, Doctor, PCT, health centre physician)

Standards were sometimes described verbally to patients with regard to specific procedures or treatments.

*"Patients are informed, if they have an intravenous catheter inserted in the hospital, then it can stay there for 72 hours, and then it must be replaced. Patients know it and demand."* (LV, Nurse, hospital, blood-vessel surgery)

*"Patients sign a consent form for beam and chemotherapy that he is informed what therapy he receives, about the safety of this therapy. Likewise these consent forms are about operations...about safety standards - yes, I think, that these our patients are informed...we guarantee confidentiality."* (LV, Doctor, hospital, oncologist-chemotherapist)

Some practitioners also felt unfamiliar with their institutions' patient safety and quality standards or felt unclear on their responsibilities on informing patients about them.

*"Even we don't read the hospital documents" (IT, GP)*

*"Not true since we ourselves are not familiar with all of them." (FI, Nurse, hospital emergency room)*

*"Should I inform them [patients] personally? Should I tell that we disinfect instruments, for instance? Or that I have a certificate? I don't know." (LV, Doctor, hospital, urologist)*

Sometimes, patients showed only limited understanding of safety and quality standards. Patient safety and quality standards were thought of only in terms of hygiene and quality standards for equipment, or the appearance of the hospital environment. Some patients struggled to imagine what patient safety and quality standards might be.

*'I suppose standards are defined in the insurance framework, but in reality, I do not know what it covers.'* (CZ, Patient, male, 18-44, PCT, both chronic and acute)

Most respondents thought that it was not important that patient involvement in knowing about patient safety and quality standards improved. Typical responses were that patients were happy to trust practitioners, or to use common sense and hearsay to deduce the standards of healthcare institutions.

*"I'm not so interested to find out more since I have a certain basic confidence that basics are in order." (FI, Patient, male, 18-44, PCT, acute)*

*'We're not well informed, but we don't care.'* (FR, Woman, 45+, >18, hospital, chronic)

*"It is hard to tell about those standards... I have not faced. I have not taken interest. I know that it aches here, I need to eliminate that. I have not taken interest about those standards." (LV, Patient, male, 18-44, PCT, acute)*

However, some practitioners and patients would like to see improvement in this area. Patients would have a benchmark for comparing the quality of healthcare received, which would develop expectations of healthcare institutions and government provision. The

functioning of healthcare institutions would improve. Patients would respect health procedures more and the functioning of healthcare institutions would improve. They were curious about patient safety and quality standards and would feel more secure and better informed if they knew more about them.

*'It would be good to have a ranking of clinics. I think this may already exist, but it's not clear. (FR, Woman, 18-44, <18, hospital, chronic)*

*"I had my hand X-rayed, and if I did not ask for a protection vest, I would not get one." (SK, Patient, Male, 18-44, Hospital, Acute)*

## 7.4 Control

Respondents were asked about the extent that patients felt in control about what happened with their healthcare. There were mixed opinions on whether patients were in control of their healthcare, to some extent.

Patients tended to be more likely to feel they were in control than practitioners but the meaning of 'control' used by respondents in their responses varied widely. A fairly basic understanding was implicit in responses from eastern European patients. For instance, some patients saw 'control' as referring simply to receiving information about diagnosis and condition for example, complying with treatment, signing consent forms, self-monitoring and being able to refuse treatment or see a different doctor

*"Yes by following exactly the medication and the indications which the doctor prescribe them." [RO, doctor, PCI, general practitioner]*

Respondents in most countries – especially practitioners – did not want more patient involvement in the control of healthcare. The control patients already had was felt to be sufficient. Some practitioners thought giving patients more than very limited control was undesirable. It was enough that patients could ask questions and receive answers, or choose whether to accept medication or not. Control was also seen in that patients could go somewhere else if they're not satisfied.

*'Patients primarily control their healthcare by deciding where to go and where to not go.' (CZ, Doctor, PCT, Gynaecology)*

*"People are becoming like consumers. Rather than going to the doctor for advice, they are consuming the doctor [...] It's much like going to the shop or hairdressers and they complain if they don't get what they want." (UK, Doctor, hospital, general)*

Some practitioners described the scope of patients' control as necessarily limited or even 'illusory'. Patient control is not always possible or desirable, otherwise all kinds of complications might arise. Patients cannot control waiting times or access to specialists, and practitioners. There would be a risk of patients obstructing treatment.

*"There are also the people who don't read. So they have control because it's them who sign, but in the same time they don't know what they're signing" (PL doctor, hospital, pulmonologist).*

*"There is one example when patient involvement might make the quality of care worse: Doctor's time is wasted if the patient suggests countless alternative treatments." (FI, Nurse, hospital emergency room)*

Few practitioners wanted more patient involvement in the control of healthcare. In Austria and Latvia the view was expressed that they would like more patients to take a responsible attitude throughout the healthcare process, and to be more engaged. There was the perception that such control would benefit patients' health.

Some patients would also like more involvement in the control of their healthcare. Specifically, they mentioned that they would like more control in terms of **choice of treatment and involvement in decisions, more opportunities to give feedback and have dialogue**. Waiting times were the main areas where patients feel that they lack control. Younger patients, in particular, would like more control of what happens in their healthcare, including more information and to play a more active role in decision making. Older patients, on the other hand, were often satisfied with their current situation, thought they had enough say and looked for less 'control'. Patients with a higher level of education also sometimes felt more 'in control'. Those with a lower level of education, those in hospital or undergoing an operation, those with severe conditions, and those with less familiarity with their illness, or the healthcare system, and those with less information tended to feel less 'in control'.

Several respondents suggested that patients with chronic illness, such as diabetes, both wanted and developed a higher level of control as they constantly monitored and managed their own health and healthcare.

*"I can choose my doctor for myself. If I ever had the feeling that I was losing control about what was happening to me, I would immediately look for another doctor." (Patient, female, 45+, PCT, chronic)*

## 7.5 Questions and feedback

Respondents were asked about the extent that patients can ask questions and give feedback on the healthcare they receive.

Practitioners and patients in most countries reported that patients felt that they could ask questions and give feedback about the healthcare they received. Many commented that 'naturally' or 'of course' patients could ask questions. However, in certain countries, the view was sometimes expressed that it was more difficult for patients to give feedback.

In practice, there were many reasons why patients' involvement in asking questions and giving feedback was limited. Limitations were described in all countries, although fundamental, cultural barriers were most often mentioned in relation to eastern European countries. Practitioners, primarily in these countries, sometimes mentioned that it was often 'irrelevant' what patients thought or said about treatment and patients were often felt to be limited in their ability to understand.

*"Patient involvement' is about common sense; one cannot be forced to it." (SK, Doctor, Hospital, Anaesthetists)*

*"Patients want to have clear opinions. Many of them want to be given guidance and then they focus their efforts on implementing my advice." (DE, doctor, ophthalmologist, PCT)*

*"I can suggest, but they don't take it on, they're like 'no, no, no, we're going to do it this way." (UK, Patient, male, 18-44, PCT, acute)*

Both practitioners and patients spoke of a **key limitation that practitioners allowed little or no time for patients' questions and feedback.**

*"Every time you go to a doctor they are very busy, or at least my doctor is very busy. Then you have to be brief because there are another ten patients waiting to see that doctor. Because of this you don't feel you are listened to." (RO, patient, male, 18-44, primary care/hospital, acute)*

*"There are only 24 hours in a day and it depends on how we divide them. If the patient is interested and is able to understand it, we inform them, but sometimes explanations are a waste of time." (CZ, Doctor, hospital, Internist)*

Patients often talked about practitioner attitudes limiting the opportunity to ask questions – often specialists in secondary care often seemed distant and closed to discussing questions. In some eastern European countries, patients feared being penalised for giving 'negative' feedback - the practitioner might somehow withhold good service or treatment from them. Patients were not used to 'complaining' or asking questions and found it hard to pluck up courage – especially for in-patients in hospital, difficult to find the right person to ask. Some patients doubted that their feedback would be taken in to account.

*"To teach a doctor, to say to him you should do like this, would that doctor send me home and say why are spending my time when you're so smart..." [RO, patient, male, 18-44 years, PCT/chronic]*

*"A person who opposes a lot will have a hard time of it. The practitioner will say, well, if you know better about it all, we may as well forget it." (DE, patient, female, 45+, PCT/HOSPITAL, chronic)*

It was often felt that patients got an inconsistent response if they tried to ask questions and that opportunities often varied by type of practitioner or care setting. **General practitioners were generally perceived to be more open to being asked questions and receiving feedback than doctors working in secondary care and hospitals.** In the hospital environment, nurses were seen to be more open to patients' questions than doctors, but often had too little time to engage in dialogue.

*"They ask us (GPs) lots of questions but there is more deference to specialists." (IT, GP, primary care)*

The same recurring demographic differences by type of patient were seen. Chronically ill patients were more motivated and more involved in asking questions and giving feedback than acutely ill patients. Patients with a higher level of education also found it easier to ask questions and give feedback than those with a lower level of education.

*"The more patients are independent and with a higher level of education, the more they want information and put up barriers... the older they are and physically limited, the less say they have in the care given" (IT, nurse, hospital ward, general medicine)*

Only a few practitioners or patients expressed a desire for greater patient involvement in asking questions and giving feedback. Of these, some practitioners explained that they would like their patients to ask more questions because this would help patients better understand their treatment and improve health services. Some patients said that they would like to see their feedback taken into consideration.

## 7.6 Self-care

Respondents were asked about the role of patients in 'self-care' in either treatment or recuperation. There was near-unanimous agreement across all countries, amongst both practitioners and patients, that it is self evident that patients have a role in 'self care'.

Self-care was presented to respondents as follows: "You are given a role in "self-care" in the treatment or in the recuperation period (for example: doing exercises, taking medication)" and respondents usually described it in terms of medical compliance - patients were often described as being involved in self-care in terms of keeping healthcare appointments, taking medication or carrying out exercises prescribed by physiotherapists. In other countries, self-care was described in terms of following a healthy diet and lifestyle.

*"Yes. Because they play the key role in adopting a healthy life style by quitting eating salt and fat and also by respecting the medication the doctor prescribe them." [RO doctor, PCI, general practitioner]*

According to both practitioners and patients, the self-care role was particularly evident and important for chronically ill patients, for instance, diabetics. They were more active in their self-care and linked this directly to their ability to become more independent, for example, by monitoring their own blood sugar levels at home.

It was considered important that chronically ill patients were helped to be as involved in their self-care as they wanted. Some chronically ill patients thought that it would be beneficial if they could have more treatments at home, to reduce their time as in hospital.

*"Yes, I do help the doctor because I live with my medical condition and I am experienced. I have had it for years. I know my problem, I know myself and I know my body, so I would report anything new or different that would help the doctor." (EL, patient, female, 45+, hospital, chronic)*

*"I read medical literature myself, and as much as I can, as much as I wish, I also do it. Actually I have always done morning exercises at home more or less when I have the mood." (LV, Patient, male, 45+, hospital, chronic)*

*"For me as a person, them giving me physio and me making a commitment to do it was wonderful [...] I felt it was more of a two way thing [...] I felt I was making a big contribution to my recovery [...] I felt empowered." (UK, Patient, male, 45+, PCT, hospital, acute/chronic)*

Practitioners and patients in eastern European countries were most likely to see the self-care role simply as one of living a healthier lifestyle, and complying with practitioners' instructions, for instance, taking medication as instructed. In these countries, few mentioned the possibility of patients carrying out more active self-care and only under strict guidance.

*"Yes, we give recommendations taking into account that these after effects are rather many after the treatment, but these recommendations are more related to medications which they should take, and what should be done if specific symptoms appear after the received treatment." (LV, Doctor, hospital, oncologist-chemotherapist)*

All patients reported that they saw it as natural to assume responsibility for self-care. However, some practitioners criticised some patients for lacking commitment or ability, being unreliable, lacking discipline or willpower and not carrying out tasks themselves. Ability and commitment to self-care varied by individual patient with some who felt that some patients seemed de-motivated by old age or from living alone without a close family or relatives).



*"The more patients can be independent, then the quicker their recovery will be. And if we can't get them to have a role in their recuperation, then we might involve a family member to help them because they may feel in more control to what's happening to them."*(Nurse, PCT, general)

*"If the patient does not take care of himself, he cannot expect the healthcare system to take care of him."* (SK, doctor, hospital, anaesthetist)

Practitioners in some countries, notably eastern European countries, would like to see greater patient involvement in self-care. eastern European practitioners explained that this would improve the general state of health, aid recovery and improve treatment outcomes, particularly through patients improving their lifestyle.

Other practitioners wanted more patients to measure blood pressure at home, and patients on blood thinning drugs to record their blood values. However it was expressed that patients do not have the resources or equipment to do this.

*"Many patients with high blood pressure do not have a measuring device of their own. They go to the practitioner from time to time and push the responsibility onto him."* (DE, doctor, diabetes/internal medicine specialist, hospital)

Patients tended to be satisfied with the current extent of their role in self-care, although this is largely due to the association of self-care with following or "obeying" the medical instructions rather than a more active responsibility.

*"Yes, I have been given a role in self-care and I always have had my own responsibilities in obeying them."* (FI, Patient, female, 18-44, PCT, acute)

## **7.7 Use of the internet**

All practitioners and patients reported that patients are using the Internet to find out healthcare information. Usage varied by type of patient with a general feeling that younger patients and those with chronic conditions referred to the Internet most. A few older patients asked relatives and friends to help them.

Practitioners were generally negative about patients' use of the Internet. They were concerned mostly about the **risk of misinformation** and the impact this could have.

There was a widely expressed concern that patients often receive 'wrong' or incomplete information, often as a result of internet forums which provided non-expert and unauthorized advice and support. Regardless of the accuracy of the information, another concern was the effect the availability of information on the internet has on patients – some **practitioners were concerned that self-diagnosis encouraged hypochondria**, and made patients more anxious and the other concern was that patients were overloaded and confused by information.

*"There are no portals which can be totally trusted...To choose what is right you have to have at least basic information...The Internet is only useful for those who are clever and it is dangerous for those who are silly. It can blind them and then they come up with all sorts of crazy opinions." (CZ, doctor, hospital, intern)*

As well as the impact on patients, the unregulated information available to patients on the internet is also perceived by practitioners to affect their own relationship with patients. With self-diagnosis, it can be difficult and time consuming for practitioners to persuade patients to change their minds, or correct them. Patients can become less trusting of their doctor or develop unrealistic expectations of health services, especially if treatments or specific brands of medication which exist (and are promoted online) are not available or are too costly.

*"On the one hand, it is good that they come well informed. On the other hand, it puts an additional load on us when we have to tell them that yes, it is written so, but ... Each case with the patient practically is individual even having the same illness. We have to find this personal approach to this patient, where all the therapy is heading in oncology – this personalized medicine, to this individualized medicine.... We cannot work according to one scheme as a standard, there is one situation... This therapy tactics is searched for each patient individually." (LV, Doctor, hospital, oncologist-chemotherapist)*

However, some practitioners conceded that the Internet could be useful for patients, especially in terms of community support for chronically ill patients, post-diagnosis information seeking and encouraging preventative behaviours.

*"The Internet makes patients more active and responsible. They visit their doctor more often, do self check-ups and so on." (CZ, nurse, PCT, general practice)*

*"I guess the Internet has changed things a lot. When patients are confronted with a diagnosis, they often start to look for information on the Internet. This causes both good and bad consequences." (AT, doctor, hospital, intern)*

*"It happens that the patient finds something on the Internet and comes to me and suggests the diagnosis and treatment. The patient sometimes has a fixed opinion and does not want to change it; and I don't want to fight with him." (SK, Doctor, PCT, General practitioner)*

Some practitioners said that they hoped patients would visit official and reliable websites, containing correct information about their illnesses and treatments. These sites could be selected and recommended by practitioners. Some practitioners suggested that an authoritative website, providing comprehensive answers to patients' questions, be established.

**Patients tended to be highly positive about their use of the internet.** Patients described the Internet as very useful as a quick, easy way to gather information and opinions about any medical condition and also about medications and treatments proposed by practitioners. Some patients in eastern Europe used the Internet to find information they could not elicit from their practitioners for instance, due to practitioners' lack of time. Many simply said that they used the Internet to get 'additional' information.

Patients generally felt they were able to use the Internet in a responsible and constructive way whereas practitioners were much more skeptical. However some patients also recognised that the information to be found online was not always reliable. Some patients were aware that they had to exercise some discernment when it came to trust in the source of information - for instance, scientific texts and articles were seen as more reliable than information posted on online message boards. The exacerbation of hypochondria and anxiety were also seen as risks. Some patients said that they would never rely solely on the Internet as an independent source and would always consult their doctor about health information found on the Internet. However a minority of patients did admit that information found on the Internet might convince them there was no need to see a doctor about their symptoms at all.

*"The Internet may harm the quality of care, unless you use an official site. You can't always trust the advice given on the Internet, you can't be sure of the source" (BE, Patient, male, 18-44, PCT, chronic)*

## 7.8 Decision-making

Respondents were asked whether patients are getting more involved in decision-making.

There was a mixed picture in perceptions of the level of patient inclusion in decision-making about treatments. The majority of both practitioners and patients considered that patients were included in decision making about treatment. However, some reported that patients were generally not included. Patients in eastern European countries in particular seemed to have less active involvement in decision-making and in these countries were also more likely than practitioners to report that patients were not included, suggesting a divergence between practitioners' and patients' perceptions of patients' experiences in these countries.

*"If the doctor proposes something to me, I can hardly disagree: I am involved in my treatment by agreement already. I am a lay person, the doctor is the specialist." (CZ, patient, male, 45+, both hospital and PCT, chronic).*

Respondents gave a wide range of examples of what patient inclusion in decision-making meant to them. It tended to focus on **being provided with information rather than being responsible for the decision itself**.

There were also differences in the interpretation of decision-making between eastern and western Member States. **In some eastern European countries, patients and practitioners suggested that 'patient involvement in decision making' comprised a basic information and understanding** - knowing and understanding their diagnosis and treatment, being informed about treatment, procedures or medication and being able to agree or disagree with the treatment suggested.

*'I follow what the doctor says. Everyone is good at something different and I am not a health specialist. I know it is modern to have something to say about everything, even something I am not good at, but this is not my case.'* (CZ, Patient, male, 45+, both hospital and PCT, acute)

*"No! I leave myself on doctor' hands because for this he go six years to school!"*  
[RO, patient, male, 45 years and over, Hospital, chronic]

In other countries, **involvement was associated more with choice**: being kept up to date about new, alternative treatments, being offered a choice of treatment options, engaging in dialogue and providing information about their condition to help identify the most appropriate treatment.

*'Let's say that it doesn't go very far. Maybe on the dosage or on how to take the medicine, but that's all.'* (FR, Man, 45+, >18, primary care at surgery, acute)

Some practitioners and patients commented that patients can only have a limited role in decision making. Patients lack expertise or are not well enough informed and so decision making is largely the role of practitioners who 'know best'.

*"I think they know better, no point at all [for her to be part of the decision-making process] if they know what's best for me."* (UK, Patient, female, 18-44, PCT, acute)

Some practitioners commented that elderly patients with dementia, psychiatric and psychologically-ill patients, and children, generally lacked the awareness required to play a role in decision-making about treatment.

The extent to which patients wished to be involved in decision-making varied. Many elderly patients were happy to be relatively passive whereas younger patients were often more proactive and willing to take the initiative by asking questions about proposed treatments. Chronically ill patients saw themselves as better informed than other patients, and more willing to involve themselves in decision-making. However, chronically ill patients sometimes reported that practitioners were not always open to their attempts to be involved in decision-making.

*"There are people who put up with things and there are people who are pro-active. It's an individual thing."* (BE, nurse, hospital, diabetics)

*'The doctor should provide more information about alternative treatments and discuss at greater length the side effects we are willing to accept'* (FR, Woman, 18-44, >18, primary care at surgery, chronic)

Certain types of patient wanted more involvement in decision-making about treatment. Younger patients also tended to be less satisfied with their current level of involvement in decision-making, and to want more.

*'It is about being active, just visiting the doctor, but not speaking with them, does not put you ahead. Patients have to learn to be pro-active, there is nobody stopping them from asking and nobody is trying not to reply when interviewed.'*  
(CZ, Patient, male, 18-44, both hospital and PCT, acute)

## 7.9 Disagreeing with treatment

Respondents were asked whether patients felt able to disagree with the treatment they receive. Practitioners and patients in the majority of countries believed that patients were entitled to disagree with proposed treatments. Practitioners and patients in only a few countries said that this was generally not the case. However further clarification from both practitioners and patients revealed that, **although in principle, patients could disagree with proposed treatment in practice, direct disagreement does not often happen.**

Respondents described several reasons for patients rarely disagreeing with proposed treatments. **Patients usually had no reason to disagree and often felt they were unlikely to be offered an alternative.**

*"The doctor is a specialist and when I see that he cares, I don't have a reason to disagree with the treatment."* (SK, patient, female, 18-44, PCT, acute)

*"I don't know what alternatives there are, to refuse the treatment. I also cannot assess what will happen if I do not accept it."* (DE, patient, male, 45+, PCT/hospital, chronic)

There was widespread belief amongst patients that they did not have the medical expertise to disagree. This was often associated with a lack of confidence, or inhibition to challenge the doctor, especially in eastern European countries. In these countries especially, patients felt that practitioners would not tolerate disagreement or that they may be viewed negatively by practitioners as a result. If a patient wanted to disagree with a treatment, many felt they could only do so indirectly, by changing doctors.

*"Patients often do not directly disagree. Instead, they complain, make themselves angry, leave and change doctors."* (CZ, nurse, PCT, general practice)

## 8 OTHER ASPECTS OF INVOLVEMENT

Respondents were asked about other aspects of healthcare and the role patients play, in more detail.

### 8.1 Key findings

- Patient monitoring (in terms of communicating complications, self measurement, compliance to treatment) was seen as beneficial both in terms of treatment effectiveness and management of resources. Patients were less clear on what such responsibility would involve and were sometimes concerned that they would not receive enough support. Chronically ill patients had a clearer idea of what monitoring involved and were used to doing this already.
- Patient feedback about the healthcare treatment they receive was seen positively but there was some concern expressed by practitioners about how this feedback could be used and there were fears of increased litigation. The cultural deference to the doctor expressed by many patients also was mentioned here, with some patients reluctant to complain.
- Patients assumed they had access to their medical records but few had tried to access them. Practitioners were ambivalent about full access, as they expressed concern about the psychological impact on patients.
- While there was some awareness of patient organizations, this was limited mostly to some nurses and some chronically ill patients. There was less awareness in eastern European countries and few respondents had personal dealings with these.

### 8.2 Monitoring

Respondents were asked about whether the patient should have responsibility for monitoring the efficacy of any ongoing treatment they may be receiving. Generally, practitioners thought that it was important that patients take part in the monitoring process. Patients also saw it as their personal duty to control or help manage their healthcare, and thought they were often best-placed to monitor their own response to treatment. Practitioners, in particular, linked patients' active self-monitoring to greater compliance and cooperation, as well as the increased effectiveness of treatment.

*"It is advisable so that the doctor and the nursing staff are able to get more information and give better treatment." (FI, Patient, female, 18-44, PCT, acute)*

The main benefit of self-monitoring mentioned by both practitioners and patients was that it is necessary for **ensuring effectiveness** – a more active role was linked to better improvement in condition and treatment outcomes, as it can help find optimal treatment whilst minimising side effects. There were also practical benefits for patients and practitioners. Patients did not have to go to the hospital so often, and some of the burden of practitioners was delegated which saved time and resources.

However some concerns were mentioned. Patients need to demonstrate responsibility in order to commit to monitoring their own treatment or condition and it was expressed that self-monitoring should not be allowed to replace the doctors' or nurses' involvement.

*'As long as it doesn't lead to uncontrolled prescriptions it's positive. But they mustn't step out of their role as patients and try to play family doctor' (FR, doctor, hospital, general practitioner)*

*When patients, or also pharmacists or opticians measure values, this can lead to illusory interpretations of findings. A highly precise numerical measurement is often too confusing for patients." (DE, doctor, ophthalmologist, PCT)*

It was important that patients remained under the doctors' care and did not feel abandoned. It was also felt that some types of patients were more suited to self-monitoring than others – especially chronically ill patients and also patients with a higher level of education more engaged and more conscientious of their monitoring role.

*Yes. I do help the doctor because I live with my medical condition and I am experienced, I have it for years. I know my problem, I know myself, and I know my body so I would say anything new or different that would help the doctor." (EL, Patient, female, 45+, hospital, chronic)*

Conversely, although some felt that self-monitoring should include all types of patients, the more widely held view was that for certain patients (e.g. children, those with psychological and psychiatric conditions) self-monitoring was clearly inappropriate.



*"With married patients it is easier than with patients, who are on their own. It is important that somebody at home takes care of the patient. With elderly patients it might also become a bit more complicated."* (FI, Doctor, hospital, cardiologist)

Many patients were vague as to what healthcare tasks might be involved in self-monitoring. However, practitioners offered many concrete examples, tending to centre around regular record-keeping and feedback on symptoms and treatment- for example; reporting changes, side-effects, rehabilitation progress; keeping records, measuring blood pressure or sugar at home, adjusting medication according to guidance.

*'The current medicine tries to be customer-oriented, with mobile medical aids, for instance, where a patient can measure their EKG on their own. Some measuring devices are so sophisticated and easy to handle, they offer precise algorithms showing the measured status.'* (CZ, Doctor, hospital, Internist)

Overall, practitioners and patients were not keen on the idea of using the Internet as a medium for receiving patients' monitoring feedback. This was for two main reasons. Firstly, the personal, face-to-face meeting of practitioners and patients was seen as vitally important, and sometimes irreplaceable by any other medium. Secondly, practitioners were worried that providing an on line communication channel to their patients might increase, rather than decrease, their work load.

*'It's too complicated. It requires psychology. A real contact is necessary.'* (FR, Doctor, clinic/surgery, dermatologist)

### **8.3 Feedback**

Respondents were asked about the importance of patient feedback. Many - especially patients - interpreted 'patient feedback' as complaints made by patients. Many practitioners saw patient feedback as being of vital importance or value, and said they actively encouraged feedback.

According to these respondents, patient feedback showed how well care processes are working and where improvements can be made to increase the quality of service offered to patients.

*"If you sweep dissatisfaction under the carpet, it doesn't help anyone. I would like to know whenever something goes wrong. Only in that way can I eliminate my mistakes."* (BE, doctor, surgeon/transplant specialist, hospital)

However, a few practitioners considered that patient feedback had no place, due to the imbalance in the practitioner-patient relationship: doctors were the experts and patients' role was to agree. Others reported a health system suffering from considerable financial and resourcing problems and were unable to deal with patients' feedback or use the information provided to make changes or improvements. There were fears of a growing litigious culture putting pressure on practitioners.

*'I am not really in favour. Doctors are human beings and mistakes are possible, excluding cases such as a surgeon who is drunk, obviously. But complaints against obstetricians because the baby has Down's syndrome are ridiculous' (FR, Nurse, clinic/surgery)*

In some eastern European countries, practitioners reported that, culturally, their patients were not used to giving feedback and some comments supported the idea that patients' complaints might not be taken seriously with complaints sometimes described as 'not legitimate' or 'very irritating'.

*"I'm not sure whether patients are willing to complain. It is difficult to say a complaint. Patients don't want to harm doctors, and they respect them. The relationship would get worse." (SK, patient, Male, 45+, PCT, Acute)*

Patients in eastern European countries also concurred that they would not give negative feedback about their healthcare. However, they did give positive feedback to practitioners when they were satisfied with their healthcare, for instance, in the form of 'thank you' notes for doctors. When these patients were not satisfied, they tended not to complain and sometimes said they would prefer to simply change doctors than express dissatisfaction.

*"I have never tried to disagree with a doctor. Doctors do not perceive of you as an equal partner. It is useless to dispute with them: they just tell you that you do not understand and have no right to say anything about it." (CZ, patient, female, 45+, PCT, both chronic and acute)*

Practitioners in some western European countries spoke of having formal healthcare complaint systems place which were easy to use. However even here patients were not always confident that their complaints would be taken seriously or they predicted that formal complaints would take a very long time to be dealt with.

Rather than use a formal complaint system, some patients would chose to speak about their complaints with a friend or relative instead.

However, some patients – usually in western European countries - found it quite easy to give feedback more informally, including 'negative' feedback, to their doctors or nurses during the course of their consultation. Some practitioners claimed they actively asked patients for feedback as part of their usual consultations.

*"Each negative or positive reaction is good for the improvement of service quality." (RO, nurse, PCI, gynaecology)*

Some practitioners argued that, to be effective, any formal procedure for dealing with patients' feedback must manage to sort and prioritise patients' comments, in a time-efficient manner. Selected feedback could then be dealt with as part of regular staff meetings, for example, and used to make changes and improvements to future healthcare delivery. However part of this requires a cultural shift to move away from the perception that it is always about complaints or litigation and can be used to improve processes.

*"You have to learn that this is feedback and not only criticism." (AT, Doctor, hospital, internist)*

## **8.4 Medical records**

Respondents were asked about patient access to medical records. Most practitioners agreed that patients should have access to their medical records. For many patients, they were not fully aware if they currently had access to their medical records but they assumed they did. Very few patients had chosen to access their own medical file however generally it was assumed the freedom to access their medical files was a democratic right.

*"It's their health. It's their file. They have the right to consult their own file." (BE, patient, female, 18-44, hospital, acute)*

None of the patients interviewed described any experience of being denied access, although it was evident from the lack of awareness around the issue that access was not actively encouraged.

*"I requested to have a look at my medical record. You will not receive it automatically and nobody seems to be very pleased about your request." (AT, Patient, 18-44, female, hospital, chronic)*

Although most practitioners thought that it was right that patients should be able to access their records, many practitioners – and some patients – were nevertheless ambivalent or uncertain about the benefits of patients doing so.

*"Many diagnoses are often considered to be incurable. A patient, reading about this diagnosis in the medical record will definitely get scared and confused! The patient probably won't know how to deal with this diagnosis!" (AT, General Practitioner, PCT)*

The two main benefits of patients' access to medical records tended to focus on the right of accessibility and the broader issue of keeping patients informed– the information is about the patient therefore they should have the right to see it. If patients – through accessing their medical records can become better informed about their condition then this can be useful especially for chronically ill patients. They will have a better understanding of their condition but also the rationale for the treatment prescribed for them.

*"They should have access to their medical record since it could be useful for patients to understand their conditions better." (FI, doctor, PCT, health centre physician)*

The main risks associated with access to medical records were to do with confusing patients who might not understand properly, or that patients may become anxious or upset – not only at the diagnosis aspect but also any other records which may relate to their perceived emotional or mental state. Another concern for some practitioners was that it would take up time having to explain medical records to patients.

*"Many diagnoses are often considered to be incurable. A patient, reading about this diagnosis in the medical record will definitely get scared and confused. The patient probably won't know how to deal with this diagnosis." (AT, general practitioner, PCT)*

It was common for practitioners to argue that access should be limited and that not all aspects of disease should be stated in the medical records, to reduce the risk of frightening patients. For the same reason, some practitioners would exclude patients with serious diagnoses from accessing their medical files. Certain practitioners argued that there were other types of patient who should not be given access to their records: namely those with some form of dementia or psychological illness.

## 8.5 Patient organisations

Respondents were asked about their views and experience of dealing with patient organisations. Generally, practitioners and patients thought that patient organisations could be very useful or useful, and endorsed them. Practitioners and patients in some western European countries had more awareness of, and opportunities to be involved with, patients' organizations. However even here the level of awareness varied – nurses tended to be seen more as likely to have contact compared with doctors and were more likely to be aware. Similarly, chronically ill patients were more likely to know of such organizations

*'I am not familiar with these associations. It never enters my mind to put my patients in contact with them.'* (FR, Doctor, clinic/surgery, dermatologist)

*"They (nurses) are very good at managing patient problems and dealing with more social and emotional side of things as opposed to the medical side."* (UK Doctor, hospital, cardiologist)

Practitioners and patients (especially in eastern European countries) were often vague or unaware of the existence of patient organisations. Some said that none existed in their country. These respondents tended to imagine their role as being to collect money for charity, or support or advise patients about legal issues.

*"There is nothing like that in Latvia, I haven't come across anything like it, which could be defined so [as a patient organisation]."* (LV, Doctor, PCT, general practitioner)

Despite this general lack of awareness and experience, respondents suggested several positive features of patient organizations mostly related to providing additional information and support, about both illnesses and treatments available. They were also felt to represent patient interests and provide peer support by putting people in touch with others with the same condition.

*"They give lectures, some of which are open to the general public. They are really useful." (FI, patients, female, 45+, hospital, chronic)*

*"This support group published folder with telephone numbers in our station. There also exists a hospital psychologist. Patient organizations are very constructive. We have special centres, where you get information about the departments and supervision ... which doctors are operating and which nurses have a special qualification. " (AT, Nurse, hospital, gynaecology)*

Only a few practitioners recognized that patient organisations might support practitioners as well as patients, through updating them with specialist information and organising lectures, or by reducing the burden on practitioners by providing information and pastoral care to patients. It seemed that sometimes nurses tended to have more contact with patient organisations than doctors, and were more likely to mention such organisations to patients.

*"I always advise new diabetes patients to contact chronic illness associations. I am not diabetic and so I don't know their daily suffering." (BE, nurse, hospital, diabetics)*

*"This support group published a folder with telephone numbers...Patient organisations are very constructive. We have special centres where you get information about departments and supervision...which doctors are operating and which nurses have specialist qualifications." (AT, nurse, hospital, gynaecology)*

*"I know that there is such organisation and that they come here and sometimes check something. They sometimes walk around the departments and ask patients to fill in questionnaires regarding patient's care." (LV, Nurse, hospital, blood-vessel surgery)*

*"They are OK, sometimes they give us quite useful brochures. I have also participated in some of their lectures." (FI, Nurse, hospital emergency room)*

Very few practitioners or patients described any personal contact with patient organisations themselves – those with a chronic condition were the most likely to have had direct contact and many patients imagined that they might be in contact with a patient organisation if they had a serious or chronic illness or condition or needed legal helps.

*"Personally, I would consider contacting a patient organisation in case of a chronic disease, where I would have to reorganize my life, in order to know, how living with this disease could be facilitated." (AT, Patient, 18-44, male, hospital, acute illness)*

*"These organizations are useful to support the patients directly and maybe to establish a confidence base, to deal with problems, to exchange experiences and to render assistance, in the best way possible." (AT, Patient, female, 45+, PCT, chronic)*

## 9 BARRIERS AND IMPROVEMENTS TO PATIENT INVOLVEMENT

Respondents were asked what opportunities there were for improving and increasing patient involvement.

### 9.1 Key findings

- Respondents suggested that the main barriers to patients' involvement in healthcare were patients' attitudes, patients' lack of knowledge and awareness, and practitioners' **lack of time and support**. Some patients in eastern European countries were inhibited by the lack, or inaccessibility, of basic health services, and a fundamental lack of trust and confidence in their health systems and doctors.
- Many felt there was a **need for improved communication between practitioners and their patients**, and that **more time** was required in consultations to allow this. Practitioners recognised that this would require considerable funding and extra staffing.
- Patients suggested that they be given **more information**, for example about their conditions and alternative treatments.

### 9.2 Barriers

Initial discussion focused on barriers which may prevent patients from being involved in their own healthcare. The key barriers to patients being involved in their own healthcare, according to both practitioners and patients in almost all countries, were mostly related to **patient attitudes and a lack of willingness to get involved**.

*'Patients should be aware of the diagnosis and what it means ...but if a person is not interested in their own health, nothing can help.'* (CZ, Nurse, hospital, surgery)

This is often associated with a general lack of knowledge and awareness amongst patients in relation to their own healthcare and to their own involvement in that overall process. This was often described by practitioners in terms of a lack of motivation or commitment, lack of interest and passivity denial of illness and lack of commitment to a healthy lifestyle.



By contrast, patients spoke of their attitudes limiting involvement more in terms of **lack of confidence**, anxiety or embarrassment, shame about poor home conditions and certain diseases, including some cancers and HIV, insecurity and a tendency to feel overwhelmed.

It was widely recognised amongst both practitioners and patients that there is a natural tendency to be in denial about health problems.

*"Some people don't go for preventive examinations because they are afraid that a severe illness could be diagnosed. Without such examination patients are happy that they do not suffer any illness." (SK, Nurse, Hospital, Plastic surgery)*

*"There can be the ostrich attitude, the fear of facing the illness" (IT, patient, female, 45+, hospital, acute)*

It was also described as a broader shyness or reticence amongst patients about discussing such personal matters – especially elderly and poor patients.

*"I don't like to talk about my personal matters for anyone, that's a barrier." (FI, Patient, female, 45+, hospital, chronic)*

This was exacerbated by the cultural situation in certain – mostly but not exclusively eastern European countries – where the doctor role has an elevated status and many **patients felt too deferential to have any more involvement**. This common perception of practitioners as authorities beyond questioning was seen by many patients a barrier to their involvement. They felt unconfident due to a lack of knowledge with both healthcare, generally, and with medical terminology. Patients with lower levels of education tended to feel they lacked the skills for engaging in dialogue with doctors or with their own research. In combination, their lack of knowledge and skills inhibited them from being able to make informed choices. Some practitioners reported that patients were often unaware of the opportunities for their further involvement. Patients in eastern European countries in particular explained that their lack of trust or confidence in doctors, or in their health systems overall, prevented their involvement in healthcare.

*"There is a reticence when they tell us all about their sufferings. Many times we find out an anaemia is caused by food deficit and very seldom a patient admits that." [RO, doctor, hospital, internist]*

Practitioners frequently referred to a **lack of time** for engaging patients in their healthcare, in terms of either their own lack of time, or a lack of staff or 'resources'.

*"Organisation of this state medical system is very important. If patients will become more demanding and will be pushing this state organisation, the more they [officials] will have to think. Because these people, they are not requesting... But there have to be funds, this accessibility. State should take care for its people. Because number of medical professionals is as high as it is. These things are mutually dependent, all are suffering from that." (CZ, Doctor, hospital, oncologist-chemotherapist)*

*"To encourage obese patients to take more exercise requires a great deal of effort. It is cheaper to write a prescription." (DE, doctor, diabetes/internal medicine specialist, hospital)*

*'If the patient does not accept what we propose, when we are sure that we have the right information, it's complicated to insist. Information can lead to a loss of trust.' (FR Nurse, clinic/surgery)*

*"I think that patients are under-informed, there is no time to sit down with the patient and (...) explain. Then the patient, once more aware of the illness or better informed on the preventive measures, takes more responsibility. Once the patients are more aware – they can assume more responsibility" (PL, doctor, hospital, cardiologist).*

Sometimes, lack of practitioner support for increasing patient involvement in healthcare was linked to practitioners not having the time to spend with patients, not giving enough information, a lack of training to make practitioners more empathetic to the needs of the patient, and a cultural view of the patient as a case rather than a participant.

*'Doctors would understand this as a lowering of their position, because now they perceive of patients like a bricklayer perceives of a brick.' (CZ, Patient, female, 18-44, both hospital and PCT, acute)*

*"Part of our medical training now is very much this attitude that patients must be involved. You must tell them as much as you can, which is a government strategy" (UK, doctor, Hospital, cardiology)*

*"This is connected to our doctors' education and training. They don't communicate with the patients and they don't have assistants, persons to do so for them. Usually, patients communicate with each other in the waiting room. That's where you find more than you find from the doctor. And this is not good, because everybody has a different experience, a different context, you can be misled. Usually the doctor doesn't take the time to explain you too much." [RO, patient, male, 18-44, PCI, chronic]*

*"I don't want to be given the impression that I am just a number, if that happens, the motivation on my part falls very low." (DE, patient, male, 45+, PCT/hospital, chronic)*

Support was also described in terms of **maintaining a relationship with the patient**. Some patients feared that "patient involvement" would mean they would not receive the same medical attention that they currently receive, or that they would be given more responsibility than they felt comfortable with.

*'Patients should be involved more, but that mustn't mean that we're left on our own' (FR, Man, 45+, >18, primary care at surgery, acute)*

### 9.3 Improvements

Respondents were then asked what improvements could be made to facilitate patient involvement. Many practitioners suggested that if patients' attitudes changed, their involvement in their own healthcare would increase. Specifically mentioned were patients consciously taking over more of the responsibility for their healthcare and for a healthier lifestyle.

Educating patients to be **more health conscious** was also mentioned along with encouragement. Financial incentives could be offered, for smoking cessation or weight loss, for example, or treatments withheld until patients make such changes. This was part of a wider emphasis on patients **taking a preventative approach to healthcare**, both in terms of lifestyle and also with more regular checkups and health screening, including a reminder system.

*"Many patients could be more involved in medical check-ups, healthy nutrition and doing sports. This relates to patient involvement very much." (AT, doctor, hospital, intern)*

*'Depressing messages on packs of cigarettes are useless. Classes are needed at primary school to make an impression on very young children. We have a very poor record on prevention in France. We're good at curing but not at preventing. School medicine and occupational medicine have an important role to play.'*  
(Doctor, hospital, general practitioner)

Patients, by contrast, emphasised that practitioners' attitudes should change, if patients were to be involved more in healthcare. They needed to be more willing to let patients get involved, listen more closely to patients and allow more questioning. They also needed to be more open and informative with patients, to allow them to more fully understand both the diagnosis and treatment options available.

There was a strong emphasis (especially amongst patients) for a **need for improved communications** between practitioners and their patients, both in terms of tailoring information to individual patient needs (e.g. in terms of the terminology and language used) and also in terms of it being a more two way dialogue, with increased opportunities for patient questions and feedback.

*'We're only informed about treatment. Care instructions, for example, could include a section that explains the diagnosis.'* (FR, Man, 45+, >18, primary care at surgery, acute)

There was a widespread feeling that **if patients were to be more involved in their healthcare, more time would need to be allocated to this**. This would require considerable funding especially for extra staffing in both primary and secondary care environments.

*"The time, which is allocated at a conversation with the doctor, should be longer and more intense. Everything should be discussable with the doctor; the doctor should become acquainted with the patient and should be on a familiar ground with weaknesses and strengths of the patient"* (AT, Patient, female, 45+, PCT, chronic)

*"In my opinion, the government does not say the truth about the healthcare system. There is not enough money and we cannot be pushed to work only because of the Hippocratic oath."* (SK, Nurse, PCT, Urology)

Some practitioners were concerned that **too much time was being taken up in consultations with patients**, with involvement from patients leading to possible arguments and time-wasting, and patients disagreeing with doctors' diagnoses and treatment proposals.

Many patients and practitioners suggested that patients should be given more, clearer information in order to facilitate patient involvement. While patients requested more information, it was not just the content but the way that the information was presented and patients wanted clearer information about their conditions and about alternative treatments options. Practitioners also felt that this information needed to be available

*"It should be advertised that if you have this cancer, it doesn't mean that you have to go and straight away kill yourself, but that there are treatment methods which can help to fight it successfully." (LV, Doctor, hospital, oncologist-chemotherapist)*

*"Part of our medical training now is very much this attitude that patients must be involved. You must tell them as much as you can, which is a government strategy" (UK Doctor, Hospital, cardiology)*

Some mentioned that governmental or authoritative healthcare web sites should be established and promoted to safeguard against the risks of patients using the Internet to search for healthcare information. These 'approved' sites could be recommended to patients by their practitioners. Respondents also suggested that national health policies should emphasise patients' responsibility for their own healthcare more. Policy makers could allocate more responsibilities to patients, to make them better understand the importance of healthy lifestyle, the importance of compliance with treatment, the costs of treatment and the impact of a lack of patient involvement or commitment. Advice could also be given regarding expected standards of healthcare services, so patients are better equipped to make informed judgments about the quality of care received.

*"Considering that so many Romanians have access to the Internet, there should be web-sites of information that should be supervised by professional organizations of doctors. So you can be sure that the information you get is verified by them." [RO, patient, male, 18-44, PCI, chronic]*

At a more basic level, some respondents in eastern European countries suggested that their governments should develop and implement healthcare strategy and quality standards, with patient input. In these countries, basic healthcare structures were often lacking, preventing patient involvement in healthcare in the most fundamental way.

It was felt by some that patient support organisations could play a greater role in facilitating patient involvement in healthcare, especially for patients with chronic conditions. They could support patients, provide information to patients and act as a 'connecting bridge' between patients and practitioners. Support organisations could further develop the information they currently provide, in leaflets and on web sites, and aim for a greater media presence.

## 10 APPENDIX 1 – METHODOLOGY

The method used for this research was **in-depth interviews** with patients and health practitioners.

Fifteen interviews were carried out in each of 15 EU Member States: Austria (AT), Belgium (BE), Czech Republic (CZ), Finland (FI), France (FR), Germany (DE), Greece (EL), Hungary (HU), Italy (IT), Latvia (LV), Poland (PL), Romania (RO), Spain (ES), Slovakia (SK) and the United Kingdom (UK).

Interviews were conducted using discussion guides developed in close collaboration with the project team from DG for Health and Consumers and DG Communication and with reference to the existing literature on patient involvement<sup>5</sup>.

The overall design is described below.

Number of interviews per Member State	Quota details
10	<p><b>Patients</b></p> <p>Length of interview: 60 minutes</p> <p>Respondents had either been to hospital in the last 5 years or had any experience of healthcare system in last 12 months</p> <p>5 x Men</p> <p>5 x Women</p> <p>5 x 18-44</p> <p>5 x 45 and over</p> <p>Mix of hospital/ primary health care</p> <p>Mix of chronic/ acute illness</p>
5	<p><b>Practitioners</b></p> <p>Length of interview: 45 minutes</p> <p>Doctors or nurses at hospitals/ clinics/ surgeries/ any healthcare institutions</p>

The interviews were conducted between 14 April and 12 May 2011.

<sup>5</sup> Discussion guides can be found in Appendix 3

All interviews were conducted face to face at the respondent's home or place of work. The respondents were recruited by the local institutes using standard qualitative recruitment procedures. The specifications were relatively straightforward and no major difficulties were encountered in the recruitment of respondents.

All of the institutes are covered by ISO 9001 (or an equivalent professional standard) or are actively working to update their standards in line with the new ISO 20252 standard. The quality procedure for Eurobarometer Qualitative Surveys consists of a set of uniform checking procedures, which allow for standardised survey production and ensure the results are comparable. Below are the various controls undertaken for Eurobarometer Qualitative Surveys.

### **Recruitment**

Signed attendance and individual information sheets verify that the people selected to participate match the profiles in the recruitment sheet drafted by the Coordination Centre. Eligibility of participants is checked at recruitment and confirmed immediately before the group or interview.

### **The translation of documents**

The translation of all documents for Eurobarometer Qualitative Studies follows the standard quality procedures detailed in the Eurobarometer Contract. Double translation is conducted by experienced translators speaking fluent French and/or English followed by a back-translation of the final draft by the Coordination Centre's network of translators.

### **Organisation**

The moderators responsible for Eurobarometer Qualitative Surveys are briefed directly by the Coordination Centre via TNS 6dTV® and by the survey director locally. A recording of TNS 6dTV® session is available.

All interviews are recorded and saved on audio or video CD.

As practitioners are generally really busy, the telephone option was sometimes used – instead of the face-to-face one – to conduct a few interviews with practitioners.

### **Analysis**

Analysis is conducted at local level using thematic analysis methods which use a combination of notes and transcripts. Findings are synthesised into a national report which is first verified centrally and the main findings combined in an aggregated report.



## **11 APPENDIX 2 – RESPONDENT PROFILE**

The tables below provide full profiles of the respondents who participated in interviews, on a country by country basis:

### ***11.1 Practitioners***

Austria	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
Key details of the interview	Date of interview	Tuesday, April 19	Tuesday, April 26	Wednesday, May 4	Friday, May 6	Thursday, May 5
	Time of interview	14:00	12:00	15:00	12:00	10:00
	Duration of interview	50 minutes	1 hour	45 minutes	1 hour	45 minutes
	Type of interview					
	Phone					
	Face-to-face	X	X	X	X	X
	If face-to-face					
	Type of venue	Gallup Institute	Vienna General Hospital	medical practice	Gallup Institute	Vienna General Hospital
	Location of venue	Vienna	Vienna	Vienna	Vienna	Vienna
	Q2 Type of institution					
	Primary health care			X	X	
	Hospital	X	X			X
	Q3 Occupation					
	Doctor		X	X		X
	Nurse	X			X	
Key responsibilities						
Healthcare specialism - types of illness (OPEN)	head nurse, gynecology	internist	general practitioner	midwife	cardiologist	
Types of patients deal with (OPEN)		cardiac diseases				
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit
Any technical issues regarding the conduct of the interview	Your overall comments	No issues	No issues	No issues	No issues	No issues

Belgium	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
Key details of the interview	Date of interview	Wednesday 4th of May	Wednesday 4th of May	Thursday 12th of May	Tuesday 3rd of May	Tuesday 3rd of May
	Time of interview	15:00	17:30	19:15	17:15	10:00
	Duration of interview	45 min	45 min	45 min	45 min	45 min
	Type of interview					
	Phone					
	Face-to-face	X	X	X	X	X
	If face-to-face					
	Type of venue	Central Location	In-Office	In-Office	Central Location	In-office
	Location of venue	Antwerp	Antwerp	Antwerp	Namur	Namur
	Q2 Type of institution					
	Primary health care	X	X			
	Hospital			X	X	X
	Q3 Occupation					
	Doctor		X	X		X
Nurse	X			X		
Key responsibilities						
Healthcare specialism - types of illness (OPEN)	Independent home nurse	Family Doctor	Neurologist	Nurse specialised in diabetology	Lung specialist	
Types of patients deal with (OPEN)	All kind of patients	All kind of patients	Neurosis	Diabetes	Lung problems	
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...
Any technical issues regarding the conduct of the interview	Your overall comments	No issues....	No issues....	No issues....	No issues....	No issues....

Czech Republic	Parameters	Nurse 1	Nurse 2	Practitioner 3	Practitioner 4	Practitioner 5
Key details of the interview	Date of interview	Monday 18th April	Tuesday 19th April	Tuesday 19th April	Tuesday 19th April	Thursday 21th April
	Time of interview	14:00	15:00	16:45	18:00	9:00
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview					
	Phone					
	Face-to-face	X	X	X	X	X
	If face-to-face					
	Type of venue	In the studio	In the studio	In the studio	In the studio	In the studio
	Location of venue	Prague	Prague	Prague	Prague	Prague
	Q2 Type of institution					
	Primary health care		X	X	X	
	Hospital	X			X	X
	Q3 Occupation					
	Doctor		X		X	X
	Nurse	X		X		
	Key responsibilities					
Healthcare specialism - types of illness (OPEN)	Surgery	Gynaecology	General Practitioner	Paediatrician	Internist	
Types of patients deal with (OPEN)	adults 18+	women 15+	adults 18+	children 0-19	older patients, chronic and heart diseases	
<b>Brief comment on recruitment process</b>	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit
<b>Any technical issues regarding the conduct of the interview</b>	Your overall comments	No issues	No issues	No issues	No issues	No issues

Finland	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
Key details of the interview	Date of interview	Tuesday 26th April	Tuesday 26th April	Wednesday 27th April	Monday 2nd May	Tuesday 3rd May
	Time of interview	13:00	14:30	19:00	15:45	16:00
	Duration of interview	45 minutes	45 minutes	45 minutes	45 minutes	45 minutes
	Type of interview					
	Phone					
	Face-to-face	X	X	X	X	X
	If face-to-face					
	Type of venue	TNS Gallup Premises	TNS Gallup Premises	TNS Gallup Premises	Health care center	Health Care Center
	Location of venue	Espoo	Espoo	Espoo	Espoo	Helsinki
	Q2 Type of institution					
	Primary health care				X	X
	Hospital	X	X	X		
	Q3 Occupation					
	Doctor		X		X	X
	Nurse	X		X		
Key responsibilities						
Healthcare specialism - types of illness (OPEN)	Internal medicine, surgery	haemorrhagic diseases	urology	internal medicine	general Medicine	
Types of patients deal with (OPEN)	Internal medicine	haemorrhagic patients	adults	mainly adults, all kinds of patients	all kinds of patients	
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit
Any technical issues regarding the conduct of the interview	Your overall comments	No issues....				

France	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
<b>Key details of the interview</b>	Date of interview	Friday 29th April	Tuesday 26th April	Thursday 22th April	Thursday 21st april	Thursday 21st april
	Time of interview	16:00	14:00	15:00	15:15	9:30
	Duration of interview	45 minutes	45 minutes	45 minutes	45 minutes	45 minutes
	Type of interview					
	Phone	X	X	X	X	X
	Face-to-face					
	If face-to-face					
	Type of venue					
	Location of venue					
	Q2 Type of institution					
	Primary health care	X	X		X	X
	Hospital	X		X		
	Q3 Occupation					
	Doctor	X	X	X		
	Nurse				X	X
Key responsibilities						
Healthcare specialism - types of illness (OPEN)	Pediatrist	Dermatologist	General practitioner	General public		
Types of patients deal with (OPEN)					Elderly persons	
<b>Brief comment on recruitment process</b>	Easy, difficult, why and how solved... etc	Difficult to find time to do the interview as very busy. Wanted to do the interview by phone.	Difficult to find time to do the interview as very busy. Wanted to do the interview by phone.	Difficult to find time to do the interview as very busy. Wanted to do the interview by phone.	Difficult to find time to do the interview as very busy. Wanted to do the interview by phone.	Difficult to find time to do the interview as very busy. Wanted to do the interview by phone.
<b>Any technical issues regarding the conduct of the interview</b>	Your overall comments	No issues....	No issues....	No issues....	No issues....	No issues....

Germany	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
<b>Key details of the interview</b>	Date of interview	Wednesday 11th May	Monday 2nd may	Friday 6th May	Friday 6th May	Tuesday 10th May
	Time of interview	17:00	19:00	15:30	17:30	18:30
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview					
	Phone					
	Face-to-face	X	X	X	X	X
	If face-to-face					
	Type of venue	at home	Eyes ambulance	in studio	in studio	in studio
	Location of venue	Munich	Munich	Munich	Munich	Leipzig
	Q2 Type of institution					
	Primary health care	X	X			X
	Hospital	X		X	X	
	Q3 Occupation					
	Doctor	Physical therapist	X	X	X	X
	Nurse					
Key responsibilities						
Healthcare specialism - types of illness (OPEN)	surgeries, orthopedics	Ophthalmologist	Internist	Surgeon	Internist practitioner	
Types of patients deal with (OPEN)			Diabetic	renal transplantation	lifestyle diseases	
<b>Brief comment on recruitment process</b>	Easy, difficult, why and how solved... etc	Easy to recruit...	easy to recruit	easy to recruit	easy to recruit	easy to recruit
<b>Any technical issues regarding the conduct of the interview</b>	Your overall comments	No issues....	no issues	No issues....	No issues....	No issues....

Greece	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
Key details of the interview	Date of interview	Monday 2nd May	Tuesday 3rd May	Tuesday 3rd May	Wednesday 4rd May	Friday 6th May
	Time of interview	14:00	17:00	19:00	18:00	17:00
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview					
	Phone					
	Face-to-face	X	X	X	X	X
	If face-to-face					
	Type of venue	office	Euaggelismos hospital	office	Erithros stauros hospital	KAT hospital
	Location of venue	doctor's office	Athens	doctor's office	athens	athens
	Q2 Type of institution					
	Primary health care	X		X		
	Hospital		X		X	X
	Q3 Occupation					
	Doctor	X	X	X		
	Nurse				X	X
Key responsibilities						
Healthcare specialism - types of illness (OPEN)	Pathologist	Pathologist	Pathologist	Working on the cardiological department	Working on the neurological department	
Types of patients deal with (OPEN)	all illnesses	all illnesses	all illnesses	deals with cardiological problems	deals with neurological problems	
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit
Any technical issues regarding the conduct of the interview	Your overall comments	No issues	No issues	No issues	No issues	No issues



Hungary	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
Key details of the interview	Date of interview	Tuesday, 19th April	Tuesday, 26th April	Thursday, 28th April	Thursday, 28th April	Wednesday 4th May
	Time of interview	9:00	15.30	12:30	14:00	12:00
	Duration of interview	94mins	64mins	53mins	88mins	63mins
	Type of interview					
	Phone					
	Face-to-face	x	x	x	x	X
	If face-to-face					
	Type of venue	TNS Hoffmann	TNS Hoffmann	Private med. center	Hospital Szt.Laszlo	doctor's office
	Location of venue	Budapest	Budapest	Budapest	Budapest	village
	Q2 Type of institution					
	Primary health care			x		x
	Hospital	x	x	x	x	
	Q3 Occupation					
	Doctor			x	x	X
	Nurse	x	x			
Key responsibilities						
Healthcare specialism - types of illness (OPEN)	director of nursing at a hospital	matron at a hospital	paediatrician at a hospital	internist	family doctor	
Types of patients deal with (OPEN)	no patients	adult / pulmonology dep.	children / immunology dep.	adult / contagion dep.	all type of local patients	
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	We could achieve her via a common friend	One respondent recommended her, and helped us to recruit	She was recruited via our operators.	We could achieve her via a common friend	She was recruited via our operators
Any technical issues regarding the conduct of the interview	Your overall comments	She was thinking seriously about the advantage of Patiente Involvement	She thinks about only prevention regarding to our topic	Her top of mind thought is the prevention regarding to our topic	He was very reflexive and informative	She was very helpfull and informative

Italy	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
Key details of the interview	Date of interview	Monday 2nd May	Tuesday 3rd May	Thursday 5 May	Friday 6th May	Wednesday 11 May
	Time of interview	15:00	15:00	12:00	10:00	17:00
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview					
	Phone					
	Face-to-face	X	X	X	X	X
	If face-to-face					
	Type of venue	TNS	TNS	Consulting room	TNS	Consulting room
	Location of venue	Milan	Milan	Milan	Milan	Milan
	Q2 Type of institution					
	Primary health care		X	X		
	Hospital	X			X	X
	Q3 Occupation					
	Doctor		X	X		X
	Nurse	X			X	
Key responsibilities						
Healthcare specialism - types of illness (OPEN)	A & E	GP (specialist: haematology & nephrology)	GP (specialist in food science)	General ward	Neurology	
Types of patients deal with (OPEN)	Emergency	General population	General population	diabetics, cardiovascular	Neurological diseases in an orthopaedic hospital	
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...
Any technical issues regarding the conduct of the interview	Your overall comments	traditional up/down approach	traditional up/down approach	sympathetic approach	patient-oriented approach	patient-oriented approach

Latvia	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
<b>Key details of the interview</b>	Date of interview	Friday 22nd April	Monday 2nd May	Monday 2nd May	Thursday 28th April	Tuesday 10th May
	Time of interview	15:00	17:00	14:00	10:00	14:00
	Duration of interview	1 hour 6 min	50 min	1 hour 15 min	50 min	1 hour 50 min
	Type of interview					
	Phone					
	Face-to-face	X	X	X	X	X
	If face-to-face					
	Type of venue	At TNS Latvia office	Hospital Gailezers	Hospital Stadini	At TNS Latvia office	At TNS Latvia office
	Location of venue	Riga	Riga	Riga	Riga	Riga
	Q2 Type of institution					
	Primary health care	X				X
	Hospital		X	X	X	
	Q3 Occupation					
	Doctor	X	X	X		
	Nurse				X	X
Key responsibilities						
Healthcare specialism - types of illness (OPEN)	General practitioner	Urologist	Oncologist-chemotherapist	Nurse in blood-vessel surgery unit	Nurse in primary healthcare	
Types of patients deal with (OPEN)	Adults and children	Mostly men	Mostly women	Adults, elderly people	Adults and children	
<b>Brief comment on recruitment process</b>	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit
<b>Any technical issues regarding the conduct of the interview</b>	Your overall comments	No issues	No issues	No issues	No issues	No issues

Poland	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
Key details of the interview	Date of interview	Wednesday April 20	Wednesday April 20	Thursday April 14	Thursday April 14	Monday April 18
	Time of interview	9:00	10:45	13:00	15:30	11:00
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview					
	Phone					
	Face-to-face	X	X	X	X	X
	If face-to-face					
	Type of venue	At work	At work	Central location	Central location	Central location
	Location of venue	Lubartow	Lubartow	Warsaw	Warsaw	Warsaw
	Q2 Type of institution					
	Primary health care	X			X	
	Hospital		X	X		X
	Q3 Occupation					
	Doctor		X	X	X	
	Nurse	X				X
Key responsibilities						
Healthcare specialism - types of illness (OPEN)	without socialization	Pulmonology	Cardiology	Physician	without socialization	
Types of patients deal with (OPEN)						
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit
Any technical issues regarding the conduct of the interview	Your overall comments	No issues.	No issues.	No issues.	No issues.	No issues.

Romania	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
<b>Key details of the interview</b>	Date of interview	Wednesday April 27th	Thursday, May 5th	Monday May 2nd	Friday, April 29th	Thursday, April 28th
	Time of interview	10:00	9:00	17:00	12:00	10:00
	Duration of interview	0:40 hour	0:35 hour	0:45 hour	0:40 hour	0:40 hour
	Type of interview					
	Phone					
	Face-to-face	x	x	x	x	x
	If face-to-face					
	Type of venue	Clinical Hospital Coltea Bucharest	GP practice	County Emergency Hospital of Ploiesti	County Emergency Hospital of Ploiesti	PLUS MEDICA Clinic
	Location of venue	Bucharest	Craiova	Ploiesti	Ploiesti	Craiova
	Q2 Type of institution					
	Primary health care		x			x
	Hospital	x		x	x	
	Q3 Occupation					
	Doctor	x	x	x		
	Nurse				x	x
	Key responsibilities					
Healthcare specialism - types of illness (OPEN)	Cardiologist	General practitioner	Internist	Primary nurse	Gynaecology nurse	
Types of patients deal with (OPEN)	patients with both acute and chronic cardiac illnesses	all kind of patients with different diseases	patients with both acute and chronic internal illnesses	patients with all kind of acute and chronic illnesses	patient women of different ages	
<b>Brief comment on recruitment process</b>	Easy, difficult, why and how solved... etc	Relatively easy to recruit.	Relatively easy to recruit.	Relatively easy to recruit.	Relatively easy to recruit.	Relatively easy to recruit.
<b>Any technical issues regarding the conduct of the interview</b>	Your overall comments	No issues.	No issues.	No issues.	No issues.	No issues.

Slovakia	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
Key details of the interview	Date of interview	Monday 2nd May	Monday 2nd May	Tuesday 3rd May	Tuesday 3rd May	Thursday 5th May
	Time of interview	13:00	15:00	15:30	9:00	14:00
	Duration of interview	1:30 hour	1:00 hour	45 min	45 min	45 min
	Type of interview					
	Phone					
	Face-to-face	x	x	x	x	x
	If face-to-face					
	Type of venue	Departmental Hospital with Polyclinic 'Milosrdny bratia'	Departmental Hospital with Polyclinic of St. Cyril and Metod	Kysuce' Departmental Hospital with Polyclinic in Cadca	Policlinic 'ZILPO'	Departmental Hospital with Polyclinic of F.D. Roosevelt
	Location of venue	Bratislava	Bratislava	Zilina	Zilina	Banska Bystrica
	Q2 Type of institution					
	Primary health care	x			x	
	Hospital		x	x		x
	Q3 Occupation					
	Doctor	x	x	x		
	Nurse				x	x
	Key responsibilities					
Healthcare specialism - types of illness (OPEN)	General practitioner	Haematology, Carcinology	Anaesthetist	Urology	Plastic surgery	
Types of patients deal with (OPEN)	general patient, adult, with general health problems	70% of the patients suffer from leukaemia, the rest of the patients suffer from other cancer types	patients undertaking surgery, patients in coma	adult men with urological problems	patients with injuries, burns, scars, birthmarks	
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Overall, the practitioners were easy to recruit. Some practitioners were not willing to take part because they were overloaded and did not want to spend their free time by participating in our research.				
Any technical issues regarding the conduct of the interview	Your overall comments	no issues				

Spain	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
<b>Key details of the interview</b>	Date of interview	Tuesday 26th April	Thursday 29th April	Thursday 29th April	Tuesday 3 May	wednesday 4th May
	Time of interview	17:00	17:00	11:00	12:30	10:00h
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview					
	Phone					
	Face-to-face	X	X	X	X	X
	If face-to-face					
	Type of venue	At home address	Primary health centre	TNS Spain Central Location	Fundación Jiménez Díaz Hospital	Centro de salud Montesa (specialities centre)
	Location of venue	Madrid	Madrid	Madrid	Madrid	Madrid
	Q2 Type of institution					
	Primary health care	X	X			X
	Hospital			X	X	
	Q3 Occupation					
	Doctor	X	X		X	X
	Nurse			X		
	Key responsibilities					
Healthcare specialism - types of illness (OPEN)	Geriatric care	family doctor	Medical Emergencies.	Urologist	Diabetologist	
Types of patients deal with (OPEN)	Elderly people	Broad spectrum of patients	Any kind of patient in a amergency	Adult men (prostate disfunction, etc.)	Patients with diabetes, obesity, etc.	
<b>Brief comment on recruitment process</b>	Easy, difficult, why and how solved... etc	Easy to recruit.	Easy to recruit.	Easy to recruit.	Easy to recruit	This respondant works in a speciality centre (where patients receive attention of any specialized doctor, such as dermatologist, psychiatrist, neurologist,etc). We agreed with TNSopinion that specialities centres would be considered primary health care, as they are not hospitals.
<b>Any technical issues regarding the conduct of the interview</b>	Your overall comments	No issues.	No issues.	No issues.	No issues.	Easy to recruit.

United Kingdom	Parameters	Practitioner 1	Practitioner 2	Practitioner 3	Practitioner 4	Practitioner 5
Key details of the interview	Date of interview	Tuesday 26th April	Tuesday 26th April	Thursday 28th April	Wednesday 4th May	Thursday 5th May
	Time of interview	12noon	7.30pm	3pm	4.30pm	7pm
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview					
	Phone					
	Face-to-face	x	x	x	x	x
	If face-to-face					
	Type of venue	Home	Home	Hospital	Office	Office
	Location of venue	London	London	Kings College (London)	London (MLP)	London (MLP)
	Q2 Type of institution					
	Primary health care					x
	Hospital	x	x	x	x	
	Q3 Occupation					
	Doctor	x	x	x		
	Nurse				x	x
Key responsibilities						
Healthcare specialism - types of illness (OPEN)	Cardiology	Dr in A&E (training to be GP)	Dr in A&E	??	All	
Types of patients deal with (OPEN)	All	All	All	??	All	
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Fairly difficult to recruit	Fairly difficult to recruit	Fairly difficult to recruit	More difficult than normal to recruit but not as hard as Dr's	More difficult than normal to recruit but not as hard as Dr's
Any technical issues regarding the conduct of the interview	Your overall comments	Was difficult to get Dr's to fit in within their busy schedule's	Was difficult to get Dr's to fit in within their busy schedule's	Was difficult to get Dr's to fit in within their busy schedule's		



## 11.2 Patients

Austria	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10
Key details of the interview	Date of interview	Wednesday, April 27	Friday, April 29	Monday, April 18	Thursday, April 28	Monday, April 18	Tuesday, April 19	Wednesday, April 27	Wednesday, April 27	Tuesday, April 26	Monday, May 2
	Time of interview	10:00	12:00	11:00	10:00	13:00	12:00	11:00	15:00	14:00	13:00
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview										
	Phone										
	Face-to-face	X	X	X	X	X	X	X	X	X	X
	If face-to-face										
	Type of venue	Gallup Institute	Gallup Institute	Gallup Institute	Gallup Institute	Gallup Institute	Gallup Institute	Gallup Institute	Gallup Institute	Gallup Institute	Gallup Institute
	Location of venue	Vienna	Vienna	Vienna	Vienna	Vienna	Vienna	Vienna	Vienna	Vienna	Vienna
	Q3 Gender										
	Female						X	X	X	X	X
	Male	X	X	X	X	X					
	Q4 Age	61	23	51	54	18	54	29	49	28	24
	Q5/6 Recent contact with health service										
	Primary health care in the last 12 months	X		X	X				X		X
	Hospital within the last five years		X				X	X	X		X
	Type of illness (OPEN)	hypertension	hand fracture	pneumonia	eye disease	ligament rupture	arm injury	breast reduction	thyroid dysfunction	endometriosis	dental operation
	Chronic	X						X	X	X	
	Acute		X	X	X	X	X				X
	Procedure / type of care received (OPEN)		surgery	medical treatment	medical treatment	surgery	surgery	surgery	medical treatment	surgery	surgery
	Duration of care	regularly	4 days	1 weeks	3 days	1 week		2 weeks	regularly	1 week	3 days
	Q7 Age of education										
	16 or under		X	X				X		X	
Over 16	X			X	X			X		X	
Q8 Currently work											
Yes - SPECIFY OCCUPATION (OPEN)			technician	office clerk		cleaning lady	office employee		office employee		
No - unemployed / retired	X							X			
No - student		X				X			X		
No - other											
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit
Any technical issues regarding the conduct of the interview	Your overall comments	No issues	No issues	No issues	No issues	No issues	No issues	No issues	No issues	No issues	No issues

Belgium	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10
Key details of the interview	Date of interview	Tuesday 3rd of May 2011	Tuesday 3rd of May 2011	Wednesday 4th of May	Wednesday 4th of May	Tuesday 10th of May 2011	Wednesday 4th of May	Wednesday 4th of May	Monday the 9th of May 2011	Monday the 9th of May 2011	Monday the 9th of May 2011
	Time of interview	18:30	19h45	17h15	19h45	14h	14h	16h	14h	15h	16h
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview										
	Phone										
	Face-to-face	X	X	X	X	X	X	X	X	X	X
	If face-to-face										
	Type of venue	Central Location	Central Location	Central Location	Central Location	Central Location	Central location	Central location	Central location	Central location	Central location
	Location of venue	Namur	Namur	Namur	Namur	Namur	Antwerp	Antwerp	Antwerp	Antwerp	Antwerp
	Q3 Gender										
	Female			X	X	X		X		X	X
	Male	X	X				X		X		
	Q4 Age	57	19	32	45	36	32	53	62	58	41
	Q5/6 Recent contact with health service										
	Primary health care in the last 12 months	X	X	X	X	X	X	X	X	X	X
	Hospital within the last five years	X	X	X	X	X	X	X		X	X
	Type of illness (OPEN)	Osteoarthritis	Diabetes	Discal hernia	Polyarthritis	Acute	Hernia	Multiple	Diabetes	Intestine	Taking a cyst
	Chronic		X	X	X			X	X		
	Acute	X				X	X			X	X
	Procedure / type of care received (OPEN)	Surgery & Hospital	Surgery & Hospital	Surgery & Hospital	Surgery & Hospital	Surgery & Hospital	Surgery & Hospital	Surgery & Hospital	Surgery & Hospital	Surgery & Hospital	Surgery & Hospital
	Duration of care	2 years	3 years	2 years	8 years	1 year	3 months	1 week	1 week	5 days	1 day operation
	Q7 Age of education										
	20 or under			X		X	X	X			
	Over 20	X	X		X				X	X	X
	Q8 Currently work										
	Yes - SPECIFY OCCUPATION (OPEN)			Employee	Employee	Employee	Employee				Employee
	No - unemployed / retired	X						X	X	X	
No - student		X									
No - other											
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...
Any technical issues regarding the conduct of the interview	Your overall comments	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....

Czech Republic	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10
Key details of the interview	Date of interview	Monday 18th April	Monday 18th April	Tuesday 19th April	Tuesday 19th April	Wednesday 20th April	Wednesday 20th April	Wednesday 20th April	Thursday 21st April	Thursday 21st April	Thursday 21st April
	Time of interview	15:15	16:45	14:00	15:15	14:00	15:15	16:45	14:00	15:15	16:45
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview										
	Phone										
	Face-to-face	X	X	X	X	X	X	X	X	X	X
	If face-to-face										
	Type of venue	In the studio	In the studio	In the studio	In the studio	In the studio	In the studio	In the studio	In the studio	In the studio	In the studio
	Location of venue	Prague	Prague	Prague	Prague	Prague	Prague	Prague	Prague	Prague	Prague
	Q3 Gender										
	Female		X		X	X	X			X	
	Male	X		X				X	X		X
	Q4 Age	31	47	44	33	68	35	54	31	65	57
	Q5/6 Recent contact with health service										
	Primary health care in the last 12 months	X	X	X	X	X	X	X	X	X	X
	Hospital within the last five years			X	X	X		X	X	X	X
	Type of illness (OPEN)	allergy	eczema/ovarit	disc herniation	psoriasis/disc	Carpal tunnel	dental caries	thrombosis	pneumothorax	insomnia/mood	thrombosis
	Chronic	X	X			X		X			
	Acute	X	X	X	X		X		X	X	X
	Procedure / type of care received (OPEN)	diagnose, vaccination,	ointment/antibiotics	computed tomography	diagnose and physiotherapy	surgery	dental mouthpiece and	surgery, physiotherapy	conservative treatment	ultrasound	diagnose and monitoring
	Duration of care	continual	1 year/2 months	3 months	1 month / 2	2 days	6 months	6 months	10 days	6 months	8 days
	Q7 Age of education 16 or under										
	Over 16	X	X	X	X	X	X	X	X	X	X
	Q8 Currently work										
Yes - SPECIFY OCCUPATION (OPEN)	financial controller	accountant	head of operations - digitizing	maternity leave	retired	IT project manager	facility manager	IT development	operator - tele-communications	civil servant	
No - unemployed / retired											
No - student											
No - other											
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	
Any technical issues regarding the conduct of the interview	Your overall comments	No issues	No issues	No issues	No issues	No issues	No issues	No issues	No issues	No issues	

Finland	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10
Key details of the interview	Date of interview	Tuesday 26th April	Tuesday 26th April	Wednesday 27th April	Wednesday 27th April	Thursday 28th April	Thursday 28th April	Monday 2nd May	Wednesday 4th May	Thursday 5th May	Thursday 5th May
	Time of interview	11:00	16:30	14:00	15:30	15:00	17:00	18:00	12:30	12:00	13:30
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview										
	Phone										
	Face-to-face	X	X	X	X	X	X	X	X	X	X
	If face-to-face										
	Type of venue	TNS Gallup	TNS Gallup	TNS Gallup	TNS Gallup	TNS Gallup	TNS Gallup	TNS Gallup	TNS Gallup	TNS Gallup	TNS Gallup
	Location of venue	Espoo	Espoo	Espoo	Espoo	Espoo	Espoo	Espoo	Espoo	Espoo	Espoo
	Q3 Gender										
	Female		X	X	X		X			X	
	Male	X				X		X	X		X
	Q4 Age	63	39	74	26	59	25	43	34	61	62
	Q5/6 Recent contact with health service										
	Primary health care in the last 12 months	X	X		X	X	X	X	X		X
	Hospital within the last five years			X	X		X			X	X
	Type of illness (OPEN)	Depression	acute inflammation	heart arrhythmia	acute flu, chronic	chronic diabetes, bad	leg operation	acute flu	acute flu	breast cancer	mild heart defect
	Chronic	X		X	X	X	X				X
	Acute		X		X		X	X	X	X	
	Procedure / type of care received (OPEN)	Medical care, continuous	antibiotics	anesthesia, electric shock /	medical care for flu / continuous	Medical care, continuous	Operation, Physiotherapy,	antibiotics and allergy tests	nothing	Operation, cytostatic	Check up
	Duration of care	continuous	1 week	15 hours	1 week / continuous	continuous / awaiting knee	1 year	1 week	sick leave	4 months / continuous	1 hour
	Q7 Age of education										
	16 or under										
	Over 16	X	X	X	X	X	X	X	X	X	X
Q8 Currently work											
Yes - SPECIFY OCCUPATION (OPEN)		Teacher				Sales consultant	Computer	peace officer	nursemaid, cook		
No - unemployed / retired	X		X		X					X	
No - student				X							
No - other											
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	
Any technical issues regarding the conduct of the interview											

France	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10
Key details of the interview	Date of interview	Thursday 21st april	Tuesday 26th april	Friday 22nd april	Wednesday 20th april	Friday 29th april	Friday 22nd april	Tuesday 26th april	Wednesday 20th april	Thursday 21th april	Friday 29th april
	Time of interview	11:00	12:15	13:30	14:00	10:00	11:30	18:00	15:30	12:30	11:30
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview										
	Phone										
	Face-to-face	X	X	X	X	X	X	X	X	X	X
	If face-to-face										
	Type of venue	At home	At a café	At home	At home	At home	At home	At a café	At home	At a café	At a café
	Location of venue	Paris	Pavillon sous	Paris	Nancy	Lyon	Paris	Asnières sur	Nancy	Paris	Lyon
	Q3 Gender										
	Female	X		X	X	X	X				
	Male		X					X	X	X	X
	Q4 Age	44	47	50	52	22	67	34	46	39	24
	Q5/6 Recent contact with health service										
	Primary health care in the last 12 months		X	X		X	X	X	X		X
	Hospital within the last five years	X			X	X				X	
	Type of illness (OPEN)	Gastric band / asthma	Persistent coughing and	Diabetes	Sarcoidosis and cardiac	Endocrinian issue	Diabetes and hyper-tension	Bronchitis and twisted ankle	General checking	Appendicitis and knee surgery	flu symptoms, feet and pelvis
	Chronic	X		X	X	X	X				X
	Acute		X				X	X	X	X	X
	Procedure / type of care received (OPEN)	Surgery	No surgery	Regular treatment							
	Duration of care	1 week	single day	Regular	Regular	1 week	Regular	Occasional	1 consultation	1 week	regular
	Q7 Age of education										
	18 or under	X		X	X					X	
	Over 18		X			X	X	X	X		X
Q8 Currently work											
Yes - SPECIFY OCCUPATION (OPEN)	cafeteria	accountant		Administration			Engineer	magistrate	Electrical		
No - unemployed / retired			X		X						
No - student					X					X	
No - other											
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	
Any technical issues regarding the conduct of the interview	Your overall comments	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	

Germany	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10	
Key details of the interview	Date of interview	Monday 2nd May	Thursday 5th may	Friday 6th may	Friday 6th may	Friday 6th may	Friday 6th may	Tuesday 10th may	Tuesday 10th may	Tuesday 10th may	Thursday 12th my	
	Time of interview	8:00	20:00	9:30	11:00	16:30	18:30					
	Duration of interview	1 hour	1 hour	1 hour	75 minutes	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	
	Type of interview											
	Phone											
	Face-to-face	X	X	X	X	X	X	X	X	X	X	
	If face-to-face											
	Type of venue	at home	at home	in studio	in studio	in studio	in studio	in studio	in studio	in studio	in studio	at home
	Location of venue	Munich	Munich	Munich	Munich	Munich	Munich	Munich	Leipzig	Leipzig	Leipzig	Munich
	Q3 Gender											
	Female				X	X	X		X			X
	Male	X	X	X					X		X	
	Q4 Age	38	52	60	58	30	26	45	71	32	56	
	Q5/6 Recent contact with health service											
	Primary health care in the last 12 months	X	X	X	X	X	X	X	X	X	X	X
	Hospital within the last five years		X	X	X	X	X	X	X	X	X	X
	Type of illness (OPEN)	injury of the hip	arthritis shoulder und foot	diabetic, venous insufficiency	diabetic, arthritis, high	ankle fracture	chronic headache,	allergies	neurolocig patient	thyroid dysfunktion	gallbladder stones,	
	Chronic			X	X		X	X	X	X		
	Acute	X	X			X					X	
	Procedure / type of care received (OPEN)	diagnosis, physiotherapie	surgery .physiotherapy	insulin therapie, lymphatic		surgery, physiotherapie	pain manegement				surgery, medical therapie	surgery
	Duration of care	3 months	2 months	9 years	15 years	6 months	2 years	since years	6 years	2 years	4 months	
	Q7 Age of education											
	16 or under			X	X			X		X		
	Over 16	X	X			X	X		X		X	
Q8 Currently work	X	X	X		X	X	X	X	X	X		
Yes - SPECIFY OCCUPATION (OPEN)	engineering		electricians		independent	someliere	photovoltaic			cook	bank officer	
No - unemployed / retired				X				X			X	
No - student												
No - other												
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	
Any technical issues regarding the conduct of the interview	Your overall comments	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	No issues....	

Greece	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10
Key details of the interview	Date of interview	Monday 18th of April	Monday 18th of April	Monday 25th of April	Tuesday 26th of April	Tuesday 26th of April	Tuesday 26th of April	Friday 29th of April	Friday 29th of April	Friday 29th of April	Monday 2nd of May
	Time of interview	14:00	15:00	17:00	17:00	15:00	15:00	14:00	19:00	18:00	15:00
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview										
	Phone										
	Face-to-face	X	X	X	X	X	X	X	X	X	
	If face-to-face										
	Type of venue	offices	offices	offices	offices	offices	offices	offices	offices	offices	offices
	Location of venue	TNS premises	TNS premises	TNS premises	TNS premises	TNS premises	TNS premises	TNS premises	TNS premises	TNS premises	TNS premises
	Q3 Gender										
	Female		X	X		X	X				X
	Male	X			X			X	X	X	
	Q4 Age	42	33	21	46	36	57	21	50	46	45
	Q5/6 Recent contact with health service										
	Primary health care in the last 12 months				X		X		X		X
	Hospital within the last five years	X	X	X		X		X		X	
	Type of illness (OPEN)	Broken leg	gynecological	Dermatological	problems with	gynecological	cardiological	diaphragm	slipped disk	hernia	gynecological
	Chronic		X				X		X		
	Acute			X	X	X					X
	Procedure / type of care received (OPEN)	Surgery						Surgery		Surgery	
	Duration of care	2 weeks	5 days	1 week	4 days	2 weeks	1 month	3 days	2 weeks	1 week	2 days
	Q7 Age of education										
	16 or under		X								
	Over 16	X	housewife	X	X	X	X	X	X	X	X
	Q8 Currently work										
	Yes - SPECIFY OCCUPATION (OPEN)	civil servant			free lance	teacher			working in	civil servant	civil servant
	No - unemployed / retired										
No - student			student				student				
No - other		housewife				housewife					
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	
Any technical issues regarding the conduct of the interview	Your overall comments	No issues	No issues	No issues	No issues	No issues	No issues	No issues	No issues	No issues	

Hungary	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10
Key details of the interview	Date of interview	Wednesday, 20th May	Wednesday, 20th May	Tuesday, 26th April	Monday, 2th May	Thursday, 28th April	Friday, 29th April	Friday, 29th April	Friday, 29th April	Wednesday, 4th May	Wednesday, 4th May
	Time of interview	10:00	15:30	17:00	17:00	17:00	9:30	15:00	17:00	14:00	15:30
	Duration of interview	78mins	59mins	55mins	64mins	61mins	58mins	15+31mins	45mins.	48 mins.	69 mins.
	Type of interview										
	Phone										
	Face-to-face	x	x	x	x	x	x	X	x	X	X
	If face-to-face										
	Type of venue	TNS Hoffmann	TNS Hoffmann	TNS Hoffmann	at home	TNS Hoffmann	at home	at home	TNS Hoffmann	at workplace	at home
	Location of venue	Budapest	Budapest	Budapest	Budapest	Budapest	Budapest	Budapest	Budapest	village	village
	Q3 Gender										
	Female	x	x	x			x	X			
	Male				X	x			X	x	x
	Q4 Age	68	21	47	55	40	37	33	31	47	68
	Q5/6 Recent contact with health service										
	Primary health care in the last 12 months	x	x	x	X	x		X	x	x	X
	Hospital within the last five years	x		x	X	x	X	X	x		X
	Type of illness (OPEN)	accident, diabetes	tonsillitis	colds, cancer	neurological problems,	broken arms, reflux	heart attack, hypertonia	childbirth, haemorrhoids	flu, broken finger	Flu	heart disease, cancer
	Chronic	x		x	X	x	X				X
	Acute	x	x	x	X	x	x	X	x	X	X
	Procedure / type of care received (OPEN)	surgery, blood-sugar controll,	medication	family doctor, surgery	medication, insuline	surgery, medicine	surgery, medicine	surgery, PCT, gynecologist	family doctor, surgery	family doctor	surgery, oncology,
	Duration of care										
	Q7 Age of education										
	16 or under										
Over 16	x	x	x	X	x	X	x	x	x	X	
Q8 Currently work											
Yes - SPECIFY OCCUPATION (OPEN)			hotel -		policeman			logistics	school director		
No - unemployed / retired	x retired									X	
No - student		x									
No - other				x	x	x	x	x maternity leave			
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	We found her via our operators	We found her via our operators	We found her via our operators	We found him via our operators	We found him via our operators	We found her via our operators	We found her via our operators	We found him via our operators	We found him via our operators	We found him via our operators
Any technical issues regarding the conduct of the interview	Your overall comments	She was opened, and had positive thinking	She was opened	She was reticent, uncommunicative	He took it very seriously	He was opened	She was very kind and helpful	There were some difficulties because of her crying baby	He was very kind and helpful	He was opened	He was kind and opened



Italy	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10
Key details of the interview	Date of interview	Tuesday 3rd May	Wednesday 4th May	Wednesday 4th May	Wednesday 4th May	Thursday 5th May	Friday 6th May	Friday 6th May	Thursday 12th May	Thursday 12th May	Thursday 12th May
	Time of interview	10:00	16:00	18:00	19:00	14:00	14:00	15:00	14:00	15:00	18:00
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview										
	Phone										
	Face-to-face	X	X	X	X	X	X	X	X	X	X
	If face-to-face										
	Type of venue	TNS	TNS	TNS	TNS	TNS	TNS	TNS	TNS	TNS	TNS
	Location of venue	Milan	Milan	Milan	Milan	Milan	Milan	Milan	Milan	Milan	Milan
	Q3 Gender										
	Female	X	X			X				X	X
	Male			X	X		X	X	X		
	Q4 Age	63	58	36	27	66	57	49	69	38	41
	Q5/6 Recent contact with health service										
	Primary health care in the last 12 months			X					X	X	
	Hospital within the last five years	X	X	X	X	X	X	X	X	X	X
	Type of illness (OPEN)	Vertiginous syndrome	Ovarian cyst	Allergy	Torn meniscus in knee	Malleolus fracture (ankle)	Prostate cancer	Radiculopathy	Inguinal hernia	Allergy	Torn ligament in thumb and wrist
	Chronic	X		X				X		X	
	Acute		X		X	X	X		X		X
	Procedure / type of care received (OPEN)	Admitted for tests and pharmaceutical treatment	Admitted for an operation	Pharmaceuticals	Admitted for surgery + physiotherapy	Plaster + physiotherapy	Admitted for surgery	Physiotherapy	planning tests and surgery	tests and pharmaceuticals	plaster + surgery
	Duration of care	5 days	2 days	2-4 months	3 days + 6	3 months + 5	7 days	2 weeks	1 month	each season	6 months
	Q7 Age of education										
	16 or under	X			X	X		X	X		
Over 16		X	X			X				X	
Q8 Currently work											
Yes - SPECIFY OCCUPATION (OPEN)	secretary		Bank clerk			ballet teacher	employee		insurance	employee	
No - unemployed / retired		X			X			X			
No - student				X							
No - other											
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	Easy to recruit...	
Any technical issues regarding the conduct of the interview	Your overall comments	Anxious woman	No issues ...	No issues..	No issues ...	No issues ...	No issues ...	No issues ...	No issues ...	No issues ...	incorrect indications about the treatment have made the problem chronic and made movement difficult for the respondent

Latvia	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10	
Key details of the interview	Date of interview	Monday 18th April	Tuesday 19th April	Wednesday 20th April	Wednesday 20th April	Wednesday 27th April	Friday 6th May	Thursday 12th May	Friday 13th May	Friday 13th May	Tuesday 10th May	
	Time of interview	17:00	12:00	18:00	19:30	13:00	14:00	18:00	14:30	16:00	11:00	
	Duration of interview	1 hour 5 min	1 hour	1 hour	1 hour	55 min	1 hour 20 min	1 hour 7 min	55 min	1 hour	1 hour 10 min	
	Type of interview											
	Phone											
	Face-to-face	X	X	X	X	X	X	X	X	X	X	
	If face-to-face											
	Type of venue	At TNS Latvia	At TNS Latvia	At TNS Latvia	At TNS Latvia	At TNS Latvia	At TNS Latvia	At TNS Latvia	At TNS Latvia	At TNS Latvia	At TNS Latvia	At hospital
	Location of venue	Riga	Riga	Riga	Riga	Riga	Riga	Riga	Riga	Riga	Riga	Riga
	Q3 Gender											
	Female		X		X	X	X		X			
	Male	X		X					X		X	
	Q4 Age	23	47	73	39	41	47	26	20	62	71	
	Q5/6 Recent contact with health service											
	Primary health care in the last 12 months	X	X	X	X	X	X	X	X	X	X	
	Hospital within the last five years		X	X	X		X				X	
	Type of illness (OPEN)	Toothache, a metal shaving in	Mastopathy, acute problem	Heart arrhythmia	Erysipelas, lymph stasis,	Acute respiratory	Diabetes mellitus, heart	Stomach problems, heavy	Chronic, allergic rhinitis	Chronic back problems,	Oncologic diagnosis	
	Chronic			X	X		X		X	X	X	
	Acute	X	X			X		X				
	Procedure / type of care received (OPEN)	Therapy, removing the	Therapy	Therapy	Therapy	Therapy	Therapy, surgery	Therapy	Therapy	Therapy	Chemotherapy	
	Duration of care	At the dentist's - regular visits in 2 month time, in case of the	4 days at hospital	Several days in hospital, regular visits at the general	4 days in hospital (in relation to pregnancy),	In each case one/ several visits	Regular check up at the general practitioner (5 years), several	2 months	Regular exacerbations 3-4 times a year	Sustained therapy for 22 years	Therapy in the form of a course - second course	
	Q7 Age of education											
	16 or under							X			X	
Over 16	X	X	X	X	X		X	X		X		
Q8 Currently work												
Yes - SPECIFY OCCUPATION (OPEN)	National Armed Forces Guard of Honour – Vice Commander of			art model	bank branch manager	cleaner	IT specialist	clerk in the kindergarten		Member of Board at garage co-operative		
No - unemployed / retired		X	X						X			
No - student								X				
No - other												
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit		
Any technical issues regarding the conduct of the interview	Your overall comments	No issues	No issues	No issues	No issues	No issues	No issues	No issues	No issues	No issues		

Poland	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10
Key details of the interview	Date of interview	Wednesday April 20	Wednesday April 20	Thursday April 14	Thursday April 14	Monday April 18	Monday April 18	Friday April 15	Friday April 15	Friday April 15	Friday April 15
	Time of interview	10:45	9:00	10:00	11:30	9:00	15:00	14:30	16:00	12:00	11:00
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview										
	Phone										
	Face-to-face	X	X	X	X	X	X	X	X	X	X
	If face-to-face										
	Type of venue	At home	At home	Central location	Central location	Central location	Central location	Central location	Central location	Central location	Central location
	Location of venue	Lubartów	Lubartów	Warsaw	Warsaw	Warsaw	Warsaw	Warsaw	Warsaw	Warsaw	Warsaw
	Q3 Gender										
	Female		X	X			X		X		X
	Male	X			X	X		X		X	
	Q4 Age	76	38	55	42	48	40	33	23	21	31
	Q5/6 Recent contact with health service										
	Primary health care in the last 12 months	X	X	X	X	X	X	X	X	X	X
	Hospital within the last five years	X		X	X	X	X	X			
	Type of illness (OPEN)	Problems with prostate, loungs, blood pressure	Tonsillitis	Bunion	Diverticulosis	High blood pressure, problems with spinal cord	Emphysema	Bicycle accident, bruises	Laryngitis	Tonsillitis	Cold
	Chronic	X		X		X	X				
	Acute		X		X			X	X	X	X
	Procedure / type of care received (OPEN)	Antibiotics	Antibiotics, injections	Surgery	Surgery	tests	Surgery	first aid help	Antibiotics	Antibiotics	Antibiotics
	Duration of care	1 week	1 week	1 week	1 hour	2 weeks in	6 days	2 hours	15 min	1 week	
	Q7 Age of education										
	16 or under	X	X	X	X	X	X	X		X	
Over 16								X		X	
Q8 Currently work											
Yes - SPECIFY OCCUPATION (OPEN)		Saleswoman on leave	part-time Librarian	Taxidriver	Salesman	Office worker	TV production		Cook	Economist	
No - unemployed / retired	X										
No - student								x			
No - other											
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit
Any technical issues regarding the conduct of the interview	Your overall comments	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.

Romania	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10
Key details of the interview	Date of interview	Wednesday April 27th	Thursday, April 28th	Friday, April 29th	Sunday May 1st	Saturday April 30th	Saturday April 30th	Wednesday May 4th	Monday 2nd May	Monday 2nd May	Monday 2nd May
	Time of interview	11:00	13:30	15:00	12:00	16:00	14:00	15:00	13:30	14:30	16:00
	Duration of interview	1:19 hour	1:04 hour	1 hour	0:50 hour	0:46 hour	0:47 hour	1:04 hour	0:50 hour	0:49 hour	0:46 hour
	Type of interview										
	Phone										
	Face-to-face	x	x	x	x	x	x	x	x	x	x
	If face-to-face										
	Type of venue	CURS HQ	CURS HQ	CURS HQ	At home	At home	At home	CURS HQ	At home	At home	County Emergency
	Location of venue	Bucharest	Bucharest	Bucharest	Craiova	Craiova	Craiova	Bucharest	Bucov village, Prahova county	Brazi village, Prahova county	Ploiesti
	Q3 Gender										
	Female				x	x	x			x	x
	Male	x	x	x				x	x		
	Q4 Age	36	44	69	42	43	58	27	76	44	55
	Q5/6 Recent contact with health service										
	Primary health care in the last 12 months	x	x	x	x	x	x	x		x	x
	Hospital within the last five years	x	x	x		x		x	x		x
	Type of illness (OPEN)	Sinusitis and high blood	Hepatitis type B+D	Diabetes and heart attack	Flu	Fluctuating blood pressure	Respiratory infection	Virus infection ("lime")	Adenoma prostate	Diabetes	Diabetes, hepatitis type C
	Chronic	x	x	x						x	x
	Acute				x	x	x	x	x		x
	Procedure / type of care received (OPEN)	Surgery and examination	Examination, treatment	Examinations and medical consultation	Examinations and prescription	ECG and supervised treatment	Medical consultation and prescription	Examinations, consultation, prescriptions.	Surgery	Examination, prescription	Examination, prescription
	Duration of care	1 week hospitalized and continuous treatment	3 weeks hospitalized for examination and continuous treatment	Continuous treatment	2 weeks	3 months	2 weeks	4 months and will continue for another 2 months	1 week	Continuous treatment	Continuous treatment
	Q7 Age of education										
	16 or under					x			x	x	x
	Over 16	x	x	x	x		x	x			
Q8 Currently work											
Yes - SPECIFY OCCUPATION (OPEN)	Accountant	University professor	Retiree	Water operator	Governess	Retiree	Self-employed	Retiree	Retiree	Retiree	
No - unemployed / retired											
No - student											
No - other											
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	Easy to recruit	
Any technical issues regarding the conduct of the interview	Your overall comments	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.	

Slovakia	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10
Key details of the interview	Date of interview	Friday 29th April	Friday 29th April	Monday 2nd May	Monday 2nd May	Tuesday 3rd May	Tuesday 3rd May	Tuesday 3rd May	Thursday 5th May	Thursday 5th May	Thursday 5th May
	Time of interview	10:00	13:00	10:00	11:30	10:15	11:30	13:00	8:50	11:30	13:00
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview										
	Phone										
	Face-to-face	x	x	x	x	x	x	x	x	x	x
	If face-to-face										
	Type of venue	TNS office	TNS office	TNS office	TNS office	Hotel	Hotel	Hotel	TNS office	TNS office	TNS office
	Location of venue	Bratislava	Bratislava	Bratislava	Bratislava	Zilina	Zilina	Zilina	Banska Bystrica	Banska Bystrica	Banska Bystrica
	Q3 Gender										
	Female	x			x		x	x	x	x	
	Male		x	x		x					x
	Q4 Age	21	53	37	30	45	65	61	34	45	22
	Q5/6 Recent contact with health service										
	Primary health care in the last 12 months		x		x		x			x	
	Hospital within the last five years	x		x		x		x	x		x
	Type of illness (OPEN)	problems with thyroid	acute tooth ache	edema on intervertebral disc; pins and needles in extremities	beginning problems with thyroid	urological problems	pain in backbone	seizure apoplectic	broken arm	intervertebral disc problems	broken arm
	Chronic	x		x			x			x	
	Acute		x		x	x		x	x		x
	Procedure / type of care received (OPEN)	hospitalization; medicine treatment	cleaning, pain-killing shot, treatment, filling	hospitalization; medicine treatment	examination, setting medicine treatment	hospitalization; medicine treatment	examinations and setting treatment to lessen the pain in the backbone, patient refuses 3rd backbone surgery	hospitalization; medicine treatment	2 surgeries within half a year	medicine treatment and rehabilitation	2 surgeries within half a year
	Duration of care	14 days	30 min	7 days	30 min; plus repeated check-	5 days	30 min; plus repeated check-	9 days	5 days	30 min; plus repeated check-	2 weeks
	Q7 Age of education										
	16 or under										
Over 16	x	x	x	x	x	x	x	x	x	x	
Q8 Currently work											
Yes - SPECIFY OCCUPATION (OPEN)		zoo-technician	self-employee	public servant	sales manager			teacher	teacher		
No - unemployed / retired						x	x				
No - student	x									x	
No - other											
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Overall, the patients were easy to recruit.									
Any technical issues regarding the conduct of the interview	Your overall comments	There were 3 out of the 10 recruited respondents who had to cancel their participation at the last minute (the evening before, or the morning before the ID) due to illness, work obligations. In order to keep the timing and conduct the IDs in the set locations we recruited substitute respondents and, thus, were not able to have 10 different types of illnesses.									

Spain	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10	
Key details of the interview	Date of interview	Friday 29th April	Friday 29th April	Friday 29th April	Friday 29th April	Friday 29th April	Tuesday 3 May	Tuesday 3 May	Wednesday 4th May	Wednesday 4th May	Wednesday 4th May	
	Time of interview	10:00	11:00	12:00	13:00	14:00	10:00	11:00	16:00	17:00	19:00	
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	
	Type of interview											
	Phone											
	Face-to-face	X	X	X	X	X	X	X	X	X	X	
	If face-to-face											
	Type of venue	TNS Spain Central Location	TNS Spain Central Location	TNS Spain Central Location	TNS Spain Central Location	TNS Spain Central Location	TNS Spain Central Location	TNS Spain Central Location	TNS Spain Central Location	TNS Spain Central Location	TNS Spain Central Location	TNS Spain Central Location
	Location of venue	Madrid	Madrid	Madrid	Madrid	Madrid	Madrid	Madrid	Madrid	Madrid	Madrid	
	Q3 Gender											
	Female	X	X						X		X	
	Male			X	X	X	X	X		X		
	Q4 Age	19	39	45	51	63	34	34	26	47	57	
	Q5/6 Recent contact with health service											
	Primary health care in the last 12 months	X	X	X					X		X	
	Hospital within the last five years				X	X	X		X		X	
	Type of illness (OPEN)	asthma	Pustules in the throat	hepatitis	Hernia	Angina pectoris	Viral infection	Flu	Asthma	Depression	hysterectomy	
	Chronic	X		X		X			X	X		
	Acute		X		X		X	X			X	
	Procedure / type of care received (OPEN)	Outpatient clinic	Primary care: visit to the doctor	Family doctor firts, then hepatologist.	Surgery	Surgery	Hospital	Family doctor visit/chest x-ray	Hospital care and medication	1 day Hospital admission	Surgery	
	Duration of care	Continuous	30 min	Continuous	1 day	15 days of hospital admission/ continuous	2 days	2 weeks	1 day of hospital admission	continous	1 week	
	Q7 Age of education											
	16 or under			X						X		
Over 16	X	X		X	X	X	X	X		X		
Q8 Currently work												
Yes - SPECIFY OCCUPATION (OPEN)		Administrative assistant	Air conditioning salesman	Administrative assistant	Police civil servant	Graphic artists	Accountant	Civil servant		Housewife		
No - unemployed / retired												
No - student	X											
No - other									X			
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Easy to recruit.	Easy to recruit.	Easy to recruit.	Easy to recruit.	Easy to recruit.	Easy to recruit.	Easy to recruit.	Easy to recruit.	Easy to recruit.		
Any technical issues regarding the conduct of the interview	Your overall comments	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.	No issues.		

United Kingdom	Parameters	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10
Key details of the interview	Date of interview	Tuesday 3rd May	Wednesday 4th May	Wednesday 4th May	Wednesday 4th May	Wednesday 4th May	Thursday 5th May	Tuesday 10th May	Tuesday 10th May	Wednesday 11th May	Thursday 12th May
	Time of interview	1:00pm	1:00pm	3.30pm	5.45pm	7pm	5.30pm	10.45am	12noon	4.30pm	5.15pm
	Duration of interview	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour	1 hour
	Type of interview										
	Phone										
	Face-to-face	x	x	x	x	x	x	x	x	x	x
	If face-to-face										
	Type of venue	Office (MLP)	Office (MLP)	Office (MLP)	Office (MLP)	Office (MLP)	Office (MLP)	Office (MLP)	Office (MLP)	Office (MLP)	Office (MLP)
	Location of venue	London	London	London	London	London	London	London	London	London	London
	Q3 Gender										
	Female	x	x		x		x				x
	Male			x		x		x	x		x
	Q4 Age	36	30	64	46	62	40	38	47	53	24
	Q5/6 Recent contact with health service										
	Primary health care in the last 12 months	x	x	x			x	x		x	x
	Hospital within the last five years				x	x			x		
	Type of illness (OPEN)	Sleep Apnia & cemcal problem	Abnormal smear test	Type 2 Diabetes/ Bursitis	Shoulder Arthroscopy/ subacromial de-compression	Knee replacement & wrist fracture	Ovarian Cysts (Previously had cancer)	Latent TB	Testicular Cancer (Currently checking for bowel cancer)	Brain hemorrhage	Asthma
	Chronic	x		x		x		x	x		x
	Acute		x	x	x		x			x	
	Procedure / type of care received (OPEN)	Surgery	Laser treatment	Key-hole surgery	Key-hole surgery	Surgery & Physio	Surgery		Surgery	Surgery	Additional breathing equipment given (Asthma pump)
	Duration of care	1 week	on-going	on-going	1 week	On -going	On - going	On - going	On-going	6 monthly check ups	On-going
	Q7 Age of education										
	16 or under					x			x	x	
Over 16	x	x	x	x		x				x	
Q8 Currently work											
Yes - SPECIFY OCCUPATION (OPEN)	x	x	x	x	x	x		x	x	x	
No - unemployed / retired							x				
No - student											
No - other											
Brief comment on recruitment process	Easy, difficult, why and how solved... etc	Average	Average	Average	Average	Average	Average	Average	Average	Average	
Any technical issues regarding the conduct of the interview	Your overall comments	No issues	No issues	No issues	No issues	No issues	No issues	No issues	No issues	No issues	

## 12 APPENDIX 3 - INTERVIEW GUIDES

The discussion guides were developed in close collaboration with the project team from DG for Health and Consumers and DG Communication and with reference to the existing literature on patient involvement.

The final discussion guides in English are included in below. They were translated into the relevant local languages by TNS opinion and then final reviews were undertaken by the local institutes.

The conduct of the interviews was relatively straightforward with no particular problems encountered.



## 12.1 Practitioners

### **PATIENT INVOLVEMENT QUALITATIVE EUROBAROMETER DISCUSSION GUIDE – HEALTHCARE PRACTITIONERS – FINAL**

*In 2011 a Joint Action under the Health Programme is planned focusing on Patient Safety and Quality of healthcare. The aim of the Joint Action is, among other things, that Member States have good practices and learn from each other in their approach. Potential partners have expressed their preference for including patient involvement as one of the major themes of the Joint Action.*

*The objective for this research is to explore patients' and healthcare practitioners' ideas and attitudes, expectations and wishes on patient involvement in the care process. This discussion guide has been developed for healthcare practitioners.*

*As with all qualitative discussion guides this document is not intended to be an exhaustive questionnaire but, rather, an indication to the moderator of the topics to be covered, the approximate time to be apportioned to each area of discussion and to provide some suggestions around possible areas of investigation. The discussion guide will be accompanied by an in-depth briefing of the moderators, to provide them with a full understanding of the programme and its objectives.*

#### **1) INTRODUCTIONS (5 minutes)**

*In this section the moderator establishes the rules of the depth interview, and begins to develop the essential rapport with respondents, putting them at their ease and beginning to get to know them.*

##### Moderator

- Introduce self
- TNS Qual+ / local institute
- Independent

##### Process

- Audio recording
- No right / wrong answers
- Confidentiality
- Personal views and views in general of colleagues

### Subject

- Understanding the views and expectations of healthcare practitioners on patient involvement
- Exploring the area of patient involvement across the healthcare process
- Understanding the benefits and challenges for healthcare practitioners
- Similar interviews with healthcare practitioners and patients taking place in other EU Member States

### Respondents

- Name
- Role (doctor/nurse; primary healthcare/hospital)
- Key responsibilities (healthcare speciality / types of patients)

## 2) Overall current state of healthcare experience (10 minutes)

Based on your experience would you say the healthcare in [COUNTRY] is good or bad? Why do you say that?

Who do you think is mainly responsible for patient safety and for quality of care in [COUNTRY]?

PROBE: Government, hospital, medical staff, anyone else?

Do you feel that patients have any personal responsibility for the healthcare they receive? Why do you say that?

## 3) CURRENT ATTITUDES TO PATIENT INVOLVEMENT (15 minutes)

*In this section we explore **healthcare practitioners' views about the importance and benefits of increased patient involvement.***

What do you think "patient involvement" means in relation to healthcare?

In general how important do you think it is that patients are involved in their own healthcare? Why do you say this?

Has patient involvement changed over the last 10 years? In what ways?

How willing are your patients to be involved in healthcare? Are there any particular types of patient (e.g. different ages, socio-economic backgrounds etc) are more or less willing to be involved?  
How satisfied are you with the current level of involvement that patients have with their own healthcare? Why do you say that?

To what extent are patients currently involved? Which aspects?

PROBE FOR EACH OF THE FOLLOWING LISTED BELOW, ASKING TWO QUESTIONS:

*1. In general, is this something which you feel is currently true for your patients? Why? Why not?*

*2. Would you like patients to get (more) involved in these situations?*

1. Patients know and understand the diagnosis and treatment they receive, and are aware of possible alternative treatments.
2. Patients know about the safety and quality standards in place in health care institutes.
3. Patients are in control about what happens with their healthcare
4. Patients feel they can ask questions to doctors and nurses, and give feedback about the healthcare they receive.
5. Patients are given a role in "self-care" in the treatment or in the recuperation period (for example: doing exercises, taking medication)
6. Patients use the internet to find out more about their healthcare
- 7. Patients are included in decision-making about their treatment
- 8. Patients can disagree with a proposed treatment

Do you consider that patients can help to improve the safety and quality of healthcare?

- In what way?
- **PROBE:** Can you provide any examples from your own practice?

How do you inform your patients about their treatment and the care they receive from you? Do you have a standard procedure for this?

What do you consider are the main risks, if any of patients being more fully involved in their healthcare in the healthcare process?

Do you personally have any experience of dealing with patient organisations?

- Which ones?
- In what ways do you deal with them?

What do you perceive the role of patient organisations is?

Do you include such organisations in the healthcare process?  
In what way?

How useful are patient organisations? How could their role be improved?

#### **4) SPECIFIC ASPECTS OF PATIENT INVOLVEMENT (15 minutes)**

*In this section we explore **healthcare practitioners' attitudes to involving patient in specific aspects of healthcare.***

##### **MONITORING**

If a patient requires ongoing treatment, how should this be monitored in terms of whether the treatment and the care process is satisfactory and effective

To what extent should the patient have a responsibility for this (think of: communicating complications, self measurement, compliance to treatment, etc) ? Why do you say that?

- Is it beneficial for patients?
- Is it beneficial for practitioners?
- Should it be for all patients? Should any patients be excluded?

Do you see an added value in using technology/e-health solutions (such as remote communication using internet)?

##### **FEEDBACK**

Do you think that receiving and using patients' feedback should be a criterion of good quality healthcare?

Are patients encouraged to give feedback about the treatment/care received and about the process of care delivery? Is this information used to make changes/improvements?

Do you think it is good that patients should be able to make a complaint about doctors and other healthcare providers?

Why? Under what circumstances?

Can you see any reasons why it might not be a good idea for patients to be able to complain?

Is there a system in place at your hospital/ practice for addressing medical errors and complaints?

IF YES: What are the benefits

IF NO: Why not

## **MEDICAL RECORDS**

Do you think patients should have access to their medical records?

- Is it beneficial for patients? In what way?
- Is it beneficial for practitioners? In what way?
- Should it be for all patients? Should any patients be excluded?
- Should it be to all aspects of their medical records? Or should access be limited?

Do patients have access to their medical records at your hospital/ practice? Do they have the right to make a copy of their medical records?

Do you think there is a role for patients (organisations) in the training and education of healthcare practitioners? Why do you say that?

## **5) IMPROVEMENTS TO PATIENT INVOLVEMENT (10 minutes)**

*In this section we explore **whether healthcare practitioners' views consider there are opportunities for greater patient involvement.***

Do you consider that patients are involved enough in their own healthcare, or should they be more involved? Why do you say this? In which areas?

What do you consider are the main barriers to patients being more involved in healthcare?

What could be done to improve patient involvement?

In which areas do you see a role for greater patient participation / involvement?

Are there any areas in which you consider increased patient involvement presents a challenge for healthcare practitioners?

- What are the challenges for healthcare practitioners?

- Are there ways in which these challenges can be tackled / overcome?

If there was one thing that the policy makers in [COUNTRY] and the EU could do to improve patient involvement in health care what would it be?

Thank participants for their time and close the session

## 12.2 Patients

### PATIENT INVOLVEMENT SURVEY PATIENT TOPIC GUIDE – FINAL

*In 2011 a Joint Action under the Health Programme is planned focusing on Patient Safety and Quality of healthcare. The aim of the Joint Action is, among other things, that Member States have good practices and learn from each other in their approach. Potential partners have expressed their preference for including patient involvement as one of the major themes of the Joint Action.*

*The objective for this research is to explore patients' and healthcare practitioners' ideas and attitudes, expectations and wishes on patient involvement in the care process. This discussion guide has been developed for patients.*

*As with all qualitative discussion guides this document is not intended to be an exhaustive questionnaire but, rather, an indication to the moderator of the topics to be covered, the approximate time to be apportioned to each area of discussion and to provide some suggestions around possible areas of investigation. The discussion guide will be accompanied by an in-depth briefing of the moderators, to provide them with a full understanding of the programme and its objectives.*

#### **1) Introduction (5minutes)**

*In this section the moderator establishes the rules of the depth interview, and begins to develop the essential rapport with respondents, putting them at their ease and beginning to get to know them.*

##### Moderator

- Self
- TNS
- Independent

##### Process

- Confidential
- No right or wrong answers
- All views equally important
- Views on own health care received, and also more general views

##### Topic

- Health care and patient involvement

Respondent [this information will be collected at the recruitment stage]

- Name, age, occupation, level of education, brief summary of recent contact with health service, type of illness, procedure received, type of care received, duration of care.

## 2) Overall current state of healthcare experience (10 minutes)

*General attitudes to relationship with healthcare providers and improvement to patient experience*

Based on your experience, would you describe the healthcare in [COUNTRY] as good or bad? Why do you say that?

Are you satisfied with the healthcare you have recently received?

How would you describe the relationship you have with your doctor or other medical professionals you have dealt with?

Why do you say that?

PROBE FOR: How much trust do you have? Is it an "equal" relationship? Do they listen to what you say?

Have there ever been any situations in your own healthcare where you have felt powerless or that you did not have sufficient information/ support/ control?

IF YES: PROBE FOR EXAMPLES - What did you do?

IF NO: RECORD IN WHAT WAYS THEY FEEL THEY HAVE POWER/ CONTROL ETC

Do you feel that you have any personal responsibility for your own healthcare? Why do you say that?

### **PATIENT ORGANISATIONS**

Are you aware of any patient organisations?

PROBE FOR SPECIFIC EXAMPLES

What do these organisations do?

Have you had any contact with any?

IF YES PROBE FOR DETAILS – IF NO ASK WHY NOT

How useful was this contact?



PROBE: Support, advice

What were the benefits/ drawbacks of the contact?

**3) Current attitudes and behaviours around involvement** (15 minutes)

*Overall attitude to involving patient in healthcare decisions*

What do you think "patient involvement" means in relation to your healthcare?

To what extent would you say you are currently involved with your own healthcare? Has this changed in the last 10 years?

How satisfied are you with the current level of involvement you have with your own healthcare?

Why do you say that

PROBE FOR EACH OF THE FOLLOWING LISTED BELOW, ASKING TWO QUESTIONS:

- 1. Is this something which you feel is currently true for you? Why? Why not?*
- 2. Would you like to be (more) involved in these situations?*
9. You know and understand the diagnosis and treatment you receive, and are aware of possible alternative treatments.
10. You know about patient safety and quality standards in place in health care institute.
11. You feel in control about what is happening with your healthcare and are involved in decision-making
12. You feel you can ask questions to doctors and nurses, and give feedback about the healthcare you receive.
13. You are given a role in "self-care" in the treatment or in the recuperation period (for example: doing exercises, taking medication)
14. You use the internet to find out more about yours or someone else's health
  -
15. You are included in decision-making about your treatment
  -
16. You feel able to disagree with treatment proposed for you

Do you think patient involvement might benefit the quality of care? In what ways?

In what ways do you think patient involvement might make the quality of care worse?

#### **4) Attitudes to specific aspects of involvement (15 minutes)**

*Overall attitude to being involved in specific aspects of healthcare*

##### **MONITORING**

When you have required/ a patient requires ongoing treatment, should you/the patient monitor that the treatment and the care process is satisfactory and effective and communicate this to the doctor/ nurse?

To what extent should the patient be responsible for this? Why do you say that?

Would you be willing to monitor your own health and keep in touch with the doctor if there were any changes?

Why/ why not?

Would you be happy to do this via the internet, e-mail, telephone, etc. ?  
Why/ Why not?

##### **FEEDBACK**

Have you ever given feedback (positive or negative) on treatment or healthcare you have received?

IF YES: How easy was it to do? Did they listen to your comments?

IF NO: Why not?

Have you ever felt at risk of being harmed or having an adverse experience by healthcare?

In what way? Why?  
What did you do about it?

Have you ever made a complaint about treatment you have received from a doctor or other healthcare provider?

If yes – what was the reason for the complaint? What made you feel that you had the right to complain? How easy was it to make the complaint? Did they pay attention?

If no – why not?

Do you think it is good that patients should be able to make a complaint about doctors and other healthcare providers?

Why? Under what circumstances?

Can you see any reasons why it might not be a good idea for patients to be able to complain?

If you were making a complaint about a doctor or healthcare provider, would you know what to do? Who would you go to?

Have you ever not believed what you have been told by a doctor or thought that they were wrong in their diagnosis/ treatment? What did you do?

Would you ever seek a second opinion? PROBE FOR DETAILS ON HOW AND UNDER WHAT CIRCUMSTANCES

### **MEDICAL RECORDS**

Do you know if you have access to your own medical records? And if you have the right to have a copy of your medical record?

Do you think you should have access?

What would be the benefits for you of being able to see your own medical records?

### **5) Future improvements and barriers for involvement (5 minutes)**

*What might prevent patient from getting involved*

What could be done to improve patient involvement?

In what aspects would you like to be more involved?

How would you like to be more involved?

What would stop you from wanting to be involved in your own healthcare?

PROBE: Lack of confidence/ ability

Rather leave it to experts/ might make mistakes

What things would encourage you to play more of a role in your future healthcare? (For example: support from healthcare professionals, more encouragement by health care professionals, clearer information, support from patient organisations.)

If there was one thing that the policy makers in [COUNTRY] and the EU could do to improve the way you have involvement in your health care what would it be?

**Thank and close**