# Elderly patients' and GPs' views on different methods for patient involvement: an international qualitative interview study

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Geest TA, Wetzels R, Raposo V, Lopes Ferreira P, Baker R, Wensing M and Olesen F on behalf of the Improve Research Group. Elderly patients' and GPs' views on different methods for patient involvement: an international qualitative interview study. *Family Practice* 2005; **22**: 184–191.

**Background.** Elderly patients' interaction with the GP may be improved through patient involvement techniques, and there is a variety of such techniques which improve patients' involvement in their own care, although little is known about their acceptability.

**Objectives.** The aim of this study was to identify barriers and facilitators for using patient information leaflets and patient satisfaction questionnaires as methods for increasing elderly patients' involvement in general practice care by comparing their views with the GPs' views on these two types of methods.

**Methods.** In seven countries (Austria, Denmark, Germany, The Netherlands, Portugal, Slovenia and Switzerland) 146 GPs and 284 patients aged 70 and over were interviewed about the use and the acceptability of these two methods. Interviewers followed a semi-structured interview guide, and all interviews were tape-recorded and transcribed verbatim.

**Results.** The arguments for using patient satisfaction questionnaires were that they would provide the GP with more information, function as a basis for change, increase patients' self-confidence and make them more conscious of what to expect. Barriers for their use were cognitive impairment among patients, fear that they would not answer honestly and opposition to written material. The arguments for patient information leaflets were that they could support patients' memories, educate patients and promote their self-responsibility. The barriers were cognitive impairment among patients and fear that they would give them false impressions of what to expect.

**Conclusion.** Both instruments were generally well accepted by both GPs and patients. Their use seemed to be dependent upon the individual GP's attitude and the patients' cognitive capacities.

Keywords. Elderly, general practice, patient participation, qualitative research.

## Introduction

Involvement in the decision-making and planning of their own care in general practice is actively demanded

## Received 30 August 2004; Accepted 26 November 2004.

<sup>a</sup>Research Unit for General Practice, University of Aarhus, Denmark, <sup>b</sup>Centre for Quality of Care Research, UMC St Radboud, Nijmegen, The Netherlands, <sup>c</sup>Centre for Health Studies and Research, Faculty of Economics, University of Coimbra, Portugal and <sup>d</sup>Clinical Governance Research and Development Unit, Department of Health Sciences, University of Leicester, UK. Correspondence to Tina Aaen Geest, Research Unit for General Practice, University of Aarhus, DK-8000 Aarhus C, Denmark; Email: tag@alm.au.dk by some patients, and it is one of the GP's responsibilities towards his/her patients;<sup>1</sup> it is an ethical principle and, in some countries, even a legal requirement.<sup>2–4</sup> Recognition of the need for patient involvement is rooted in indications that patients often find information from the GPs to be insufficient and inadequate,<sup>5</sup> often do not voice their true agendas in the consultation<sup>6</sup> and seek additional information elsewhere.<sup>5</sup> Lack of patient involvement may also cause some dissatisfaction and lead to poor treatment compliance.

Patient involvement takes many forms and has been variously described in terms like patient empowerment, doctor-patient partnership and shared decision making. These strategies aim to improve the quality and effectiveness of consultations.<sup>7</sup> To overcome the theoretical limitations of these different forms of patient involvement, we use the global term 'patient involvement' which refers to activities aimed at 'enabling patients to take an active role in deciding about and planning their care'.

Procedures involving patients may be implemented on a national, a regional or a practice level and can be applied within an episode of care and in relation to each consultation. Examples of methods involving patients include: (a) Written materials, e.g. information leaflets about clinical conditions or questionnaires seeking patients' views on their care or symptoms; and (b) Interactive communication skills, e.g. those used by the doctor in consultations with patients, or the use of a third person (relative, informal carer, nurse, etc.) to help patients express their preferences. However, the ability of these different methods to actually increase patient involvement remains sparse.

This paper aims to discuss methods for improving involvement in the practice setting and in the single consultation. We will attempt to identify barriers and facilitators for using patient information leaflets and patient satisfaction questionnaires as instruments for increasing elderly patients' involvement in general practice care by comparing their views with the GPs' views on these two types of methods. The study will also explore whether countryspecific differences can be identified.

Patients aged 70 years and over were selected because they have many diseases and chronic conditions, the treatment of which requires greater patient involvement. Moreover, the elderly require special attention as they may also find it comparatively more difficult to adequately describe their symptoms<sup>8</sup> and conceptually engage with the GP. Finally, they are often less demanding and more accepting of authorities than younger patients.

Our study was conducted within the framework of the international IMPROVE study<sup>9</sup> set up to investigate barriers and facilitators for increasing the involvement of older patients aged 70 years and over in general practice care. The presented findings are based on data from seven of the eleven participating countries.

## Methods

As part of the international IMPROVE study data were collected from eleven countries, but due to technical problems only data from seven countries were analysed in this study.

### Instruments

We investigated one instrument primarily used for involvement at practice level and one primarily for involvement within an episode of care. As representative of the former, a Patient Satisfaction Questionnaire, the EUROPEP instrument, was chosen. This instrument is fairly new, validated translated versions are available in all the participating countries and it is being widely used in several countries.<sup>10,11</sup> To represent the latter, Patient Information Leaflets were chosen because they are widely used in almost every practice either passively (i.e. they are available in the waiting room) or actively (i.e. the GP hands them out to the patient advising the patient to study the leaflet). No uniform translated version of a patient information leaflet was available and the leaflets used therefore differed from country to country. However, each leaflet was typically a small booklet informing about a specific disease, e.g. diabetes or hypertension.

#### **Participants**

Within the framework of the international IMRPOVE study, a stratified purposeful sample<sup>12,13</sup> of 233 GPs and 360 patients aged 70 and over from 11 countries (Austria, Belgium, Denmark, France, Germany, Israel, The Netherlands, Portugal, Slovenia, Switzerland and the UK) were interviewed about their attitudes towards and experiences with patient involvement and use of the ways of obtaining patient involvement described above.

The GPs were stratified according to sex, age (cut-point: 45 years old) and practice setting (city, urbanised, rural). Patients were stratified according to sex, age (70–79 years and 80+ years) and health status (isolated illness, chronic illness, life threatening illness, non-attenders). A sample of two GPs in each of the 12 stratifying cells and two patients in each of the 16 cells was chosen from each country. We also sought to select patients from the three different settings (city, urbanised, rural).

#### Interviews

Interviews were conducted using a semi-structured interview guide with a combination of pre-structured and open-ended questions<sup>14</sup> developed by the co-ordinating research centre in the UK and adapted in collaboration with the researchers from all 11 participating countries (interview schedules are available on request). The main interview themes were barriers and facilitators for patient involvement in general practice care.

Before the interviews, the GPs received project information detailing, among others, our definition of patient involvement and the two instruments of patient involvement: a national, validated version of the EUROPEP patient satisfaction questionnaire and a patient information leaflet. The patients did not receive these tools before the interviews, but they were presented to them during the interviews. GPs and patients were then asked to describe their experiences with and attitudes towards these types of tools, and what they saw as their advantages and disadvantages.

The interviews were performed either by the researchers themselves or by trained interviewers from August 2000 until April 2001. All interviews were tape-recorded, transcribed verbatim and then entered into the data analysis programmes Atlas.ti or QSR Nudist.

#### Data analysis

All countries conducted the study, but it was not possible for researchers from all countries to access their data files to retrieve the information needed for the joint analysis. The present results are therefore based on data from seven countries: Austria, Denmark, Germany, The Netherlands, Portugal, Slovenia and Switzerland; and they include 146 GPs and 284 patients as illustrated in Tables 1 and 2.

Based on a contents analysis of interviews from four countries (Belgium, Germany, The Netherlands, and Slovenia), a common code list was devised through consensus discussions at a workshop between researchers from six participating countries (Belgium, Denmark, France, Germany, The Netherlands, Slovenia). The GP and patient code-lists paralleled each other, each containing 37 codes categorising GPs' and patients' ideas about patient involvement, like facilitators, barriers, perceptions and opinions of the various methods for patient involvement presented to them. In each participating country, all interviews were then systematically scrutinised for the presence of quotations illustrating these codes. To ensure country-consistent coding, two researchers in each country coded the same five GP interviews and the same five patient interviews independently. At the international level, an interview with a German and a Dutch GP and a German and a Dutch patient were translated into English. Afterwards they were coded independently by a researcher from each country and then compared with the original coding. Finally, a researcher from each country coded an English GP and an English patient interview and then the English co-ordinating team compared the coding results. No important or systematic coding differences were found.

Researchers were subsequently asked to return to the original documents and to identify all the coding results and quotations made on the patient information leaflet and the patient satisfaction questionnaire and subdivide those codes into smaller meaning units presenting arguments for and against these instruments. The new

TABLE 1	Demographic	characteristics	of interviewed	GPs
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Country	A	ge	Gender			Total		
	<45	≥45	Male	Female	City	Urban	Rural	
Austria	7	13	11	9	9	5	6	20
Denmark	6	6	5	7	4	4	4	12
Germany	11	14	15	10	10	6	9	25
The Netherlands	10	10	11	9	7	6	7	20
Portugal	12	11	9	14	10	8	5	23
Slovenia	13	13	12	14	11	7	8	26
Switzerland	6	14	14	6	9	3	8	20
Total	65	81	77	69	60	39	47	146

TABLE 2 Demographic characteristics of interviewed patients

Country	Ag	e	Ge	nder		Region			Healt	h Status		Total
	70-80	80+	Male	Female	City	Urban	Rural	Is <sup>a</sup>	Ch <sup>b</sup>	LTc	NA <sup>d</sup>	
Austria	32	18	16	34	27	6	17	1	44	4	1	50
Denmark	14	10	11	13	10	6	8	5	9	7	3	24
Germany	19	16	14	21	7	17	11	5	20	7	3	35
The Netherlands	15	13	13	15	8	14	6	4	12	6	6	28
Portugal	41	38	38	41	30	20	29	22	19	17	21	79
Slovenia	22	16	19	19	_	_	_	10	11	8	9	38
Switzerland	15	15	10	20	_	_	_	8	9	8	5	30
Total	158	126	121	163	(82)	(63)	(71)	55	124	57	48	284

<sup>a</sup> Isolated illness, <sup>b</sup> Chronic illness, <sup>c</sup> Life threatening illness, <sup>d</sup> Non-attenders.

sub-codes, all illustrated with a typical quotation translated into English, were then sent to the two first authors (TAG and RW) who compared the new codes, traced countryspecific characteristics and then merged the new codes into inclusive categories representing all countries.

## Results

The stratification criteria outlined in the sample for both GPs and patients were met in the total sample. A total of 146 GPs were interviewed: 53% were male, their mean age was 47 years (range: 31–81) with 45% under 45 years of age. 41% came from city practices, 27% from urban practices and 32% from rural practices (Table 1). Among the 284 interviewed patients, 43% were male and their mean age was 79 years (range: 70–96) with 56% between 70 and 80 years of age (Table 2).

#### Patient Satisfaction Questionnaire

An overview of the identified categories and their typical expressions is shown in Table 3 and Box 1. GPs and patients in most countries agreed that the patient satisfaction questionnaires would give the GP additional information and that the questionnaires might serve as a basis for change. In some countries, GPs thought the questionnaires would enhance patients' self-confidence and make them more conscious of what to expect. Patients found that the use of such questionnaires would promote openness, make it easier for them to express their criticisms and improve confidence between patient and GP.

Some GPs and patients thought that the patient satisfaction questionnaire method would mislead the GPs because patients would be reluctant to demonstrate

 TABLE 3
 Advantages of patient satisfaction questionnaires (the numbers refer to the corresponding citations in Box 1)

GPs	Patients
<b>√</b> 1	√2
√3	<b>√</b> 4
√5	√6
<b>√</b> 7	
<b>√</b> 8	
	√9
	<b>√</b> 10
	✓1 ✓3 ✓5 ✓7

A = Austria; DK = Denmark; G = Germany; NL = The Netherlands; P = Portugal; SL = Slovenia; SW = Switzerland. disloyalty and therefore would not always answer the questionnaire truthfully (Table 4 and Box 2). Both GPs and patients also thought that the questionnaire would often be too difficult for elderly people due mainly to cognitive or physical deficits, e.g. lack of education, sight problems, etc. Preference for oral conversation over written material was mentioned both by GPs and patients as another argument against the satisfaction questionnaires as a method for improving patients' involvement. In addition, some GPs were afraid that questionnaires would augment organisational work, be time consuming and give patients unrealistic expectations that the GP would be unable to meet. Apart from the arguments against the use of patient satisfaction questionnaires in general, both GPs and patients had objections concerning the design of the instrument, e.g. its length and readability.

#### Patient Information Leaflet

The identified categories and typical expressions pertaining to the leaflets appear in Table 5 and Box 3. GPs and patients in all countries agreed that patient



- 1 Well, but you do get a lot of good information about it. In that way you may get a chance to influence e.g. the telephone hours. Perhaps the telephone hours are too short—or the telephone hours should be organised differently. They must go to the secretary instead of directly to the GP when they come in. And also some other things. It might be very good to find out from a questionnaire like this what the patients actually think. [DK 13]
- 2 Well, I think it's kind of useful for a patient and for a GP to see the patient's view of the matter, and it's also good for a GP to get feedback. I don't have any negative opinions. [SL 6]
- 3 It is important that patients have them and make their evaluations on how the service works in this way. It is very important they give their opinion. [P 11]
- 4 Because I think that most of the patients don't dare to contradict the GP. If they have a questionnaire, they can write it down, which is easier. [A 43]
- 5 For sure it [the questionnaire] is quite interesting. I would regard it as positive. [G 12]
- 6 Well, if I read it properly, I would probably agree with everything and would only express a positive opinion. Because in my entire lifetime—and I'm 71 years old—I haven't had any troubles with a doctor. And I like it: like him, like me. [SL 2]
- 7 The patient can see that his opinion is important, that he can contribute something and is taken seriously. [SW 1]
- 8 A good thing is that people might get more conscious themselves about what they may expect. [NL]
- 9 It could give you a kind of a line of approach to greater confidence through such things, right? It would give you greater confidence in the GP? Yes, I would think so. [DK 1]
- 10 The questions are posed in a way, which is understandable to everyone.

Table 4	Barriers to using patient satisfaction questionnaires (th	le
n	umbers refer to corresponding citations in Box 2)	

	GPs	Patients
Misleading/not a true picture (patients afraid to show disloyalty) [A,DK,D,NL,P,SL,SW]	<b>√</b> 1	<b>√</b> 2
Too difficult for elderly people (cognitive and/or physical deficits) [A,DK,G,NL,P,SL,SW]	<b>√</b> 3	<b>√</b> 4
Useless – doubtful effect / people are not interested [A,DK,G,NL,SL,SW]	√5	<b>√</b> 6
Prefer oral conversation [A,SL,SW]	√7	<b>√</b> 8
More organisational work/time consuming [A,G,NL,P]	<b>√</b> 9	
Give patients unrealistic expectations [DK,NL]	<b>√</b> 10	
Instrument characteristics (e.g. too long, too difficult) [A,DK,G,NL,P,SL,SW]		<b>√</b> 11

A = Austria; DK = Denmark; G = Germany; NL = The Netherlands; P = Portugal; SL = Slovenia; SW = Switzerland.

Box 2 Citations illustrating the themes in Table 4

- 1 I am afraid that the patient will often be too nice to the GP. And, on the other hand, it is also important for the GP to get personal feedback from the patient. That is, you can say incredibly much that can be misunderstood. [DK 15]
- 2 ... if you imagine that it is someone who must go back to the GP, right? Then it might—some of the answers will perhaps not be well received by the GP. Therefore you might have second thoughts about being quite honest when you answer it. [DK 3]
- 3 I have not seen someone of 75 years complete such a list easily; I think it is very difficult for them. [NL]
- 4 Perhaps it's really too difficult for some people who are less acquainted with all these things. [SL 19]

It is not easy for someone who cannot read or write. Many cannot see well either. You know when your eyes start to get tired, there is nothing you can do, and many cannot see well. [P 1]

- 5 I haven't seen anything useful with this questionnaire. I don't see what benefit the patients can get from it. It is only worth something for the person carrying out the research. The patients don't get any benefit from it. [SL 5]
- 6 It isn't bad, is it? But most patients aren't interested. They are satisfied to get their pills and leave. [G 24]
- 7 I would prefer to talk to them because that is more useful. [A 14]
- 8 I still believe that a conversation is better than filling out a questionnaire [A 8]
- 9 The organisational expenses are simply too big. [G 8]

The questionnaire takes lots of time and work. [P 22]

- 10 The problem is that you get some expectations that are higher than the GP can meet. [DK 10]
- 11 This [type size] is too small, and it needs a line otherwise it will not work. If you would like to focus on older people, then, yes, a lot bigger. [NL]

information leaflets were excellent means of supporting patients' memories, of educating patients and thus of supporting and promoting their self-responsibility. GPs also mentioned that use of information leaflets saves time, increases compliance, promotes patient involvement and paves the way for involving a third person such as a carer or a relative. Patients further mentioned having written materials could save them a visit to the GP and reduce their worries because they would know more about their condition.

Arguments voiced against the leaflet (Table 6 and Box 4) were that it was too difficult to use for older people because of their cognitive and/or physical deficits, e.g. poor evesight, and that it could make patients more anxious and represent a possible source of misunderstanding, e.g. if the patient did not understand the contents of the leaflet or if the contents was at variance with the GP's opinion or recommendations. Other arguments against the leaflet from both GPs and patients were that it was too general and not focused on the individual patient. One GP added that it could also serve as an excuse to the GPs who would just hand out the leaflet to the patient without giving him/her adequate information. Some GPs and patients found the leaflets to be unhelpful either because they thought they would not be accepted by the patients or the GPs or because they preferred oral conversation. Again extra work was mentioned by some GPs as a barrier and, finally, both GPs and patients acknowledged that the design of the leaflet, including its layout and sponsorship, could prevent it from being an easy and honest source of information and patient involvement.

#### *Country-specific themes*

Not all themes were found in all participating countries, but no systematic differences between countries could be identified.

## Discussion

The results of this qualitative study pointed to both some positive and some negative aspects of patient information leaflets and patient satisfaction questionnaires which may have implications for their use in daily clinical practice.

The patient information leaflets were widely accepted and used among GPs as well as patients. Positive aspects were that patient information leaflets can support patients' memories; educate patients and support their self-responsibility; promote involvement; increase compliance and save time, which is consistent with what has been found elsewhere.<sup>5</sup> Further, it has been shown that patient information leaflets increase patient satisfaction and perception of communication.<sup>15</sup> Despite discussions on whether the purpose of patient information leaflets is to *educate* or to *empower* patients,<sup>16</sup> it seems beyond questioning that use of patient information leaflets is a

Table 5	Advantages of using patient information leaflets (the	
numl	bers refer to the corresponding citations in Box 3)	

	GPs	Patients
Support memory [A,DK,G,NL,P,SL,SW]	<b>√</b> 1	√2
Educate patients and support self-responsibility [A,DK,G,NL,P,SL]	√3	<b>√</b> 4
Promote involvement/involve third parties or relatives [DK,NL,P,SL]	√5	<b>√</b> 6
Instrument characteristics [A,DK,G,NL,P,SL,SW]	<b>√</b> 7	<b>√</b> 8
Save time [A,G,SL,SW]	√9	
Increase compliance [P,SL]	<b>√</b> 10	
Save a visit to the GP [DK,G,SL]		<b>√</b> 11
Reduce worries [DK]		<b>√</b> 12

A = Austria; DK = Denmark; G = Germany; NL = The Netherlands; P = Portugal; SL = Slovenia; SW = Switzerland.

good idea and a helpful tool to patients as well as to GPs when used with care. One of the major barriers to using patient information leaflets may be the difficulty in finding non-commercial leaflets of high quality tailored to the individual patient.

Our study findings show that leaflets should always be accompanied by careful oral instruction and/or information to the patients about the content and use of the leaflets. This may influence the timesaving aspect in the short run, but in the long run the leaflet may still save the patient one or more visits to the GP providing it is a good leaflet with relevant, easy to understand information and instructions.

It appears that both GPs and patients see some advantages and benefits of using patient satisfaction questionnaires. Studies that have used patient satisfaction questionnaires one way or another practically all report response rates of 70% or higher<sup>17-21</sup> which indicates that a majority of patients are willing to spend time using the instrument. However it has been shown that acceptance and responses to patient satisfaction questionnaires are associated with variations in patient characteristics, i.e. increased age and increased proportion of male patients are associated with lower satisfaction scores.<sup>21</sup> Concerning the acceptability among GPs, a randomized study showed that GPs who had used a patient satisfaction questionnaire saw more barriers and found it less relevant to their practice than a group of control GPs, who had not used the tool.<sup>22</sup>

The barriers found in our study clearly address some points that should be taken into consideration when designing and using patient information leaflets as well as patient satisfaction questionnaires with elderly patients. It is important that these tools are written in large type, easy to understand yet not too simple and, perhaps most important, that the handing over to the patient is Box 3 Citations illustrating the themes in Table 5

- 1 That they take it again and again and maybe sometimes it would be successful... or when forgotten they can look it up themselves. [A 18]
- 2 It informs clearly and concisely about a subject and you read it again whenever you have forgotten something. [NL]
- 3 ... as I say, it is a chronic disease, they get diagnosed and that means it is something they have to live with for the rest of their lives. And it is something they have to get involved in and take responsibility for. Otherwise you cannot have diabetes. That's why I think it can be good to give them a bit of material to bring home, and then come back so they have a little more knowledge about it the next time we are going to talk about it. Then they get a little more information that way. [DK 3]
- 4 It is useful because you can read it yourself and see, for instance, what high blood pressure means to your health, you read about organ damages and so on. Then you can take measures yourself or change your way of life. You live a healthier life. You eat healthier food, you move more and so on. [SL 12]
- 5 I also give a leaflet to relatives. If there is something a patient doesn't notice, the relatives can notice it. And then the relatives participate. They can help. They do it together. [SL]
- 6 So that we get in touch with the GP and tell her that we need this or that. [P 21]
- 7 When the leaflets have drawings—and some of them have—they are good and we use them. [P 31]
- 8 If there are no foreign words in it, everything is told in German, it is all right. It could be expanded. [G 23]
- 9 If it is an information leaflet, then it actually helps saving time. [G 22]
- 10 Let's say with a certain disease, when a disease gets worse. If you give a patient a leaflet about it, for instance proper blood pressure regulation, then this advice will bear more fruit. [SL 1]
- 11 I think it might be good. You could see what—and perhaps save a visit to the GP as well. If you could find out by yourself. Now I haven't read it, so I really don't know what it contains. [DK 17]
- 12 Yes, it might be good. You might feel more safe by getting to know a little about what it is about. [DK 7]

followed by clear and understandable oral information on its purpose and its use.

Comparisons of GPs' and patients' views on patient information leaflets and the EUROPEP revealed no conflicting findings. The within-group variation seemed to exceed the between-group variation, but it should be noted that in another part of the IMPROVE study we found that GPs and patients did seem to differ in their global conceptions of patient involvement. GPs' perception of patient involvement tended to be very much in line with our definition, i.e. as a question of assigning a more active role to the patients,<sup>23</sup> while patients were more likely to perceive patient involvement as a 'caring relationship' (Bastiaens H, Van Royen P, Pavlic DR *et al.* unpublished work).

	GPs	Patients
Too difficult for elderly people (cognitive and/or physical deficits) [A,DK,G,NL,P,SL,SW]	<b>√</b> 1	<b>√</b> 2
Make patients more anxious/basis for misunderstanding [A,DK,G,NL,P,SL,SW]	√3	<b>√</b> 4
Too general/too simple/not focused on the individual patient [A,NL,P,SL,SW]	√5	<b>√</b> 6
Useless/not accepted by patients or GPs [A,DK,G,NL,SW]	√7	<b>√</b> 8
Instrument characteristics [A,DK,G,P,SW]	√9	<b>√</b> 10
Pretext to the GPs [DK]	<b>√</b> 11	
More organisational work [A,G,NL,SW]	<b>√</b> 12	
Too many different leaflets [NL]		<b>√</b> 13

A = Austria; DK = Denmark; G = Germany; NL = The Netherlands; P = Portugal; SL = Slovenia; SW = Switzerland.

No obvious or systematic differences were observed between countries in terms of opinions about patient information leaflets and patient satisfaction questionnaires, but this lack of data is not tantamount to claiming that such differences do not exist. The qualitative design of this study was not optimal for documenting significant differences between countries, which may be better explored by means of quantitative methods.

A large, international qualitative study like the present has several weaknesses which should be considered. The most important are probably the language barrier, the distance between researchers and the difficulties in using uniform procedures for gathering, processing and analysing data. As described in the method section, care was taken to ensure consistency in sampling, interviewing and data analysis. This and the large number of GPs and patients from different countries participating in the study strengthen the reliability of the findings. We therefore have reason to believe that this study reflects GPs' and elderly patients' views on the selected methods for patient involvement. However it should be stressed that a qualitative study like this ought to be followed by a larger quantitative study to assess the general feasibility; acceptability and effect of the patient involvement approach on patient outcome and provider and patient satisfaction.

#### Conclusion

The diversity of opinions about and preferences for the studied patient involvement methods draws a rather nuanced and complex picture of patient involvement and also reflects and underscores the point that patient involvement achieved by these methods may not be within the reach of all patients and perhaps not all GPs. Some patients are not capable of being involved and Box 4 Citations illustrating the themes in Table 6

- 1 I think it is quite complicated for older people. Most of my patients won't be able to handle it. [G 6]
- 2 ... there are many who don't read it properly. That—eh about reading—and understanding the meaning, that is probably a problem for many older people. [DK 18]

Older people cannot understand even if they can read. [P 8]

3 Disadvantages may be that sometimes a patient reads a certain thing and misunderstands it. If he doesn't have a possibility of talking with somebody, he can understand it in a wrong way and interpret a certain sentence in a wrong way. [SL 2]

There are only few patient leaflets that don't arouse fear. [SW 14]

- 4 If you know too much, it's even worse. If I read something now, if something is written about a disease, I might think: I have exactly this [disease]. You see, and I would torment myself, I would feel anxious again. [SL 3]
- 5 Sometimes the story that's in there does not fit the patient at all. It is a good global leaflet, but it is not focused on the individual patient. [NL]
- 6 It isn't individual. It is general but every patient has his/her own nature. [A 1]
- 7 There are many patients who are not interested in getting a leaflet every time. [G 22]
- 8 Interviewer: Do you think it might be useful to get such a thing to take home with you, e.g. if you got diabetes II or some other disease? Interviewee: I don't know. Because I get—then we get told by the GP. I count on. Because when we get tablets and things like that—start at something, they inform us all right. [DK 9]
- 9 Also, very often they don't have complete information as we wish, or else they have too much information and it is discouraging for the patient to be forced to read. [P 11]
- 10 It isn't individual, it is general, but every patient has his/her own nature. [A 1]
- 11 ... to the GP it can become a pretext. You think you have given them something to bring home, but they have just brought it home and they haven't read it. Then you think you have informed them about something. [DK 3]
- 12 Maybe it's a disadvantage that there are too many papers. I have a lot of information leaflets; my tables are full of them. [A 8]
- 13 There are shelves full of leaflets. Then you think what on earth should I take with me? A bit too many. [NL]

others do not want to be involved, and likewise some GPs were much in favour of using these methods, while others had various reservations. The main barriers to using these types of instruments may be the lack of instruments tailored to meet the needs of the elderly and the individual GP's attitude. This should be considered in dealing with GP education. This study confirms that a conscious and goal-oriented use of these approaches on selected patients and perhaps selected conditions may be one way of improving involvement in European general practice, but we need further studies to assess the general feasibility and effect of this approach to raise patient involvement.

## Acknowledgements

We wish to thank the researchers in the IMPROVE group and all the participating GPs and patients.

## Declaration

Funding: the IMPROVE project was funded by the European Union Funding Programme (Quality of Life and Management of Living Resources (1998–2002), The ageing population and disabilities, QLRT-1999–02035). Ethical approval: was obtained in Slovenia, but was not necessary in six other participating countries. Conflicts of interest: None.

## References

- <sup>1</sup> Buetow S. The scope for the involvement of patients in their consultations with health professionals: rights, responsibilities and preferences of patients. *J Med Ethics* 1998; **24:** 243–247.
- <sup>2</sup> Coulter A, Elwyn G. What do patients want from high-quality general practice and how do we involve them in improvement? *Br J Gen Pract* 2002; **52(Suppl):** S22–S26.
- <sup>3</sup> Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. *Br J Gen Pract* 1999; **49:** 477–482.
- <sup>4</sup> Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N *et al.* Systematic review of involving patients in the planning and development of health care. *Br Med J* 2002; **325:** 1263.
- <sup>5</sup> Coulter A, Entwistle V, Gilbert D. Informing Patients. An assessment of the quality of patient information materials. London: King's Fund; 1998.
- <sup>6</sup> Barry CA, Bradley CP, Britten N, Stevenson FA, Barber N. Patients' unvoiced agendas in general practice consultations: qualitative study. *Br Med J* 2000; **320**: 1246–1250.

- <sup>7</sup> Wensing M, Baker R. Patient involvement in general practice care: a pragmatic framework. *Euro J Gen Pract* 2003; 9: 62–65.
- <sup>8</sup> Morgan R, Pendleton N, Clague JE, Horan MA. Older people's perceptions about symptoms. *Br J Gen Pract* 1997; **47:** 427–430.
- <sup>9</sup> IMPROVE study. http://oase.uci.kun.nl/~improve/
- <sup>10</sup> Grol R, Wensing M. Patients evaluate general/family practice: the EUROPEP instrument. Nijmegen: Centre for Quality of Care Research, 2000.
- <sup>11</sup> EUROPEP instrument. http://www.equip.ch/groups/europep.html
- <sup>12</sup> Miles MB, Huberman AM. Qualitative data analysis—An expanded sourcebook. Thousand Oaks: SAGE Publications; 1994.
- <sup>13</sup> Sandelowski M. Sample size in qualitative research. *Res Nurs Health* 1995; **18**: 179–183.
- <sup>14</sup> Britten N. Qualitative Research: Qualitative interviews in medical research. Br Med J 1995; **311**: 251–253.
- <sup>15</sup> Little P, Dorward M, Warner G, Moore M, Stephens K, Senior J *et al.* Randomised controlled trial of effect of leaflets to empower patients in consultations in primary care. *Br Med J* 2004; **328:** 441.
- <sup>16</sup> Dixon-Woods M. Writing wrongs? An analysis of published discourses about the use of patient information leaflets. *Soc Sci Med* 2001; **52**: 1417–1432.
- <sup>17</sup> Zebiene E, Razgauskas E, Basys V, Baubiniene A, Gurevicius R, Padaiga Z et al. Meeting patient's expectations in primary care consultations in Lithuania. *Int J Qual Health Care* 2004; **16**: 83–89.
- <sup>18</sup> Wensing M, Vedsted P, Kersnik J, Peersman W, Klingenberg A, Hearnshaw H *et al.* Patient satisfaction with availability of general practice: an international comparison. *Int J Qual Health Care* 2002; **14:** 111–118.
- <sup>19</sup> Meakin R, Weinman J. The 'Medical Interview Satisfaction Scale' (MISS-21) adapted for British general practice. *Fam Pract* 2002; **19:** 257–263.
- <sup>20</sup> Kersnik J, Svab I, Vegnuti M. Frequent attenders in general practice: quality of life, patient satisfaction, use of medical services and GP characteristics. *Scand J Prim Health Care* 2001; **19:** 174–177.
- <sup>21</sup> Baker R. Characteristics of practices, general practitioners and patients related to levels of patients' satisfaction with consultations. *Br J Gen Pract* 1996; **46:** 601–605.
- <sup>22</sup> Wensing M, Vingerhoets E, Grol R. Feedback based on patient evaluations: a tool for quality improvement? *Patient Educ Couns* 2003; **51**: 149–153.
- <sup>23</sup> Wetzels R, Geest T, Wensing M, Ferreira P, Grol R, Baker R. GPs' views on involvement of older patients: A European Qualitative study. *Patient Educ Couns* 2004; **53**: 183–188.