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Harris, M., Wildgoose, D., Veale, A. & Smith, B., 2009. Providing reviews of evidence to COPD patients: qualitative study of barriers and facilitating factors to patient-mediated practice change. Chronic Respiratory Disease, 7(1), 19-28. © 2009 Sage Publications

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PROVIDING REVIEWS OF EVIDENCE TO COPD PATIENTS: QUALITATIVE STUDY OF BARRIERS AND FACILITATING FACTORS TO PATIENT-MEDIATED PRACTICE CHANGE

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Abstract

Background

Study aimed to identify barriers and facilitating factors to people with COPD performing the following actions:

- (i) reading a manual which contained summaries of evidence on treatments used in chronic obstructive pulmonary disease (COPD)., The manual was developed by using current best practice and designed to facilitate reading and discussion with doctors
- (ii) at a medical consultation, asking questions which were provided in the manual and which were designed to prompt doctors to review current treatments in the light of evidence.

Methods - Design

In-depth interviews with patients who had received the manual.

Methods - Participants and setting

Sixteen of 125 intervention participants from a controlled clinical trial of the manual were interviewed in their homes in and around Adelaide, South Australia.

Results

Plain language writing and a simple layout facilitated reading of the manual by participants. Where the content matched the interests of participants this also facilitated reading. On the other hand, some participants showed limited interest in the evidence summaries. Participant comments indicated that they did not see it as possible or acceptable for patients to master research evidence or initiate discussions of evidence with doctors. These appeared to be the main barriers to effectiveness of the manual.

Conclusions

If evidence summaries for patients are to be used in disease management, they should be understandable and relevant to patients and provide a basis for discussion between patients and doctors. Work is now needed so that we can both present evidence summaries in a way which is relevant to patients, and reduce the barriers to patient-initiated discussions of evidence.

Introduction

Several strategies to reduce the gap between research evidence and clinical practice have been tried, with varied success.¹ However, strategies which provide patients with reviews of evidence have not yet been well studied, even though patients are now expected to participate in clinical decision-making. There is an opportunity to test this kind of strategy in chronic disease, where patients are being given information and education so that they can take a bigger role disease management.²

We conducted a trial of patient reviews of evidence in COPD (chronic obstructive pulmonary disease). The intervention was a novel patient-held manual which was developed using current best practice. It contained summaries of the evidence for treatments used in COPD and suggested questions which could be used to start discussions of evidence with doctors.³ The trial did not find an effect on clinical practice at 12 months [reference to separate paper submitted with this one]. A survey of processes carried out alongside the trial of the COPD manual found that over 90% of participants who received the manual reported reading from it, 42% reported discussing topics with a doctor, but only 10% reported treatment change attributable to the manual [reference to separate paper submitted with this one]. We report here a further component of the process evaluation which used qualitative methods to uncover barriers and facilitating factors influencing the use of the manual by participants and their doctors.

The manual was designed to be used as follows:

- i. The patient reads at least some parts of the manual (using tagged sections to access summaries relevant to a situation they are encountering)
- ii. The patient uses the manual to raise a treatment topic with their doctor (using the boxed question offered as prompts in the manual)
- iii. The doctor understands this as a request to review treatment in the light of the evidence referred to in the manual
- iv. If current treatment is not supported by evidence, the doctor and/or patient decide to change to a treatment supported by evidence.

This study focussed on steps (i) and (ii) as these are required for success of subsequent steps.

Methods

The manual

The manual summarised Cochrane reviews of evidence about COPD treatments and provided additional background topics.³ To encourage discussion of evidence with doctors, a tip or a suggested question that a patient could ask their doctor accompanied each summary of evidence. Questions were suggested as prompts for discussion, rather than overt requests to consider evidence, in keeping with usual patient behaviour in consultations.⁴ Questions were written with health professionals so that they would be the kinds of questions which patients would ask their doctor. The manual used very plain language, lay terminology, small page size and large print, question-and-answer format, and illustrations of people with COPD engaging in activities of daily living as well as in clinical settings. The manual was developed using research-based recommendations on the design of patient information materials. These recommendations include using plain language and the formats which suit patient preferences,⁵ a number of print layout characteristics,⁶⁷ and consultation and repeated testing of drafts with members of the target audience.^{8,9} These recommendations are based on patient satisfaction, because studies are lacking which link characteristics of patient information materials with health outcomes or behaviours.

Sampling

Intervention participants from the clinical trial [reference to paper accompanying this one] were asked if they wished to be available for this study also. Fifty-one of the 125 agreed and formed the sampling pool. Rather than reflect the intervention group or wider population numerically, the aim for this component was to explore the range of behaviours, barriers and facilitating factors. Maximum variation purposive sampling ¹⁰ was therefore applied to this sampling pool, for variation in reading and use of the manual and for gender, socioeconomic status, severity of COPD and presence/absence of carer. Sampling was continued until analysis revealed no new information.

Data collection and analysis

Data were transcripts of in-depth interviews and the field notes made after each interview. During interviews participants were shown photographic vignettes to help them to remember their own thoughts and feelings when they were in the depicted situation. The

first vignette showed someone of the same gender as the participant reading a manual in a home setting. The other showed someone of the same gender as the participant holding a manual in consultation room with a doctor of the same gender as the participant's general practitioner.

Analysis of transcripts and field notes, concurrent with data collection was performed using QSR NUD.IST 4 software.

Data were collected and analysed in three phases.

Phase 1

Initially, the participant's views about using the manual as an aid to living with COPD were described using open interviews and grounded data analysis..^{10;11}

Phase 2

Next, a series of opening questions in standardised open-ended interviews¹¹ and the framework¹² used for analysis focussed in detail on the actions of reading and asking the questions offered in the manual.

- Next, a series of opening questions in standardised open-ended interviews were used to explore four factors that may have influenced the participants' reading and responses to the manual. The same factors were used as the framework¹² for analysis and were adapted from theoretical models used in behavioural psychology and health promotion: 13-15 Outcome expectations: Advantages and disadvantages perceived by the participant
- *Social pressures*: Social pressures felt by the participant to perform or not perform the actions
- Capability: Participant perceptions of their own capability to perform the action
- External factors: Participant perception of environmental factors helping or hindering them from performing the action

Phase 3

Analysis from Phase 1 was integrated into the analysis of Phase 2. . Participants were sent a summary of the findings and asked if their views were reflected and if any changes should be made..

Sharing of data collection and analysis:

MH and DW developed theme lists with input from AV, BS and advice from Bruce Johnson. Interviews were conducted by MH and DW and audiotapes were transcribed by an external agency. MH and DW each made individual preliminary analyses of a small number of transcripts then jointly agreed on concept definitions, which they discussed with AE then used for all transcripts.

Sample Characteristics

Eight participants were interviewed for Phase 1 and a further eight for Phase 2. Of the total 16 participants, eight were male and eight female, ages ranged from 45 to 90 years, four reported that they currently smoked and three used oxygen therapy. Participant postcodes covered a range of socioeconomic classifications. Duration of formal education ranged from 7 to 13 years.

Results

Descriptions of behaviours are given, followed by analysis of barriers and facilitating factors. Participant codes are given in brackets after illustrative quotes.

Descriptions of reading

Participant descriptions showed that the manual was read with varying levels of interest.

... I didn't put it down until I'd finished. (M5*)

When I first got it I used it a great deal ... I used it very much as a referral. (D2)

Yeah, I went through it and then I have gone back and thought what was that about and gone back and read a bit more. (M1)

I*. ... So did you read this booklet [manual] when you were first interviewed? P. Well I did but it was ages ago. (D6)

I've read through it yes. (D3)

No, I read it once, it is a bit boring. (M2)

- I. So you read through this booklet [manual]. Did you find anything in it to be of use?
- P. I can't remember now it's been such a long time. I was thinking about it today and I thought I don't know what I did with that book. (D4)

^{*}Participant codes are given in brackets after quotes. Where quotes include words spoken by both interviewer and participant, these are indicated by I and P respectively.

Descriptions of question-asking

While some participants spoke about asking questions at a consultation after reading topics from the manual, no participant said that they asked or intended to ask the questions offered in the manual.

No, I didn't think I needed to talk to him [the doctor] about them all [the questions from the manual]. (M1)

No, I don't suppose. They [the questions I asked] may have been in there, but I just ask him, just ordinary, just how I feel. (M6)

It tells you what to ask your doctor, but me being me, I don't do things. (M7)

Participants raised issues covered in the manual using their own questions. While some appeared to have used questions similar to those suggested in the manual, there was no reference to evidence.

- I. So can you tell me what happened for you when you went to the doctor...? P...... I asked him about some medicine on page 31 and he said that he didn't think it was any good for me. (M2)
- I. Did you yourself ask any of those [questions] in the little boxes?
- P. Not really. There was one about a drug that was in there that I think I asked the specialist about.
- I. Which one was that?
- P. I can't remember. In there [points to the manual]. I asked the specialist about it. I couldn't have it for some reason. It obviously didn't go with something I had, or he didn't want to change my medication. (M5)

Oh he just discussed with me what he thought. ... He said, well, Ventolin. And after a while we discussed it again and he said we will try this. That is all the discussion we have had. (M8)

Barriers and facilitating factors to reading and question-asking

Tables 1 and 2 summarise findings on barriers and facilitating factors to reading the manual and asking the offered questions. Barriers and facilitating factors are grouped according to whether they relate most closely to outcome expectations, social pressures, capability or external factors.

Reading was generally facilitated by the design of the manual, though not for people who seldom read books of any sort, and there was no discouragement by family or doctors. When information was seen as useful in itself, this was also an incentive to read.

Conversely, when information in general or the particular kind of information in the manual was not seen as providing benefits, this was a disincentive to reading.

In most instances, participants felt they could raise issues with their doctors when they wanted to, though they were aware of consultation time limitations. Some participants did ask their doctors whether treatments covered in the manual would be suitable for them in particular. However, participants did not see advantages in asking the questions suggested in the manual. The manual was seen as containing medically oriented information which was the main province of the doctor rather than the patient.

Characteristics of participants who encountered fewest barriers

While they did not use the questions offered in the manual, some participants progressed to asking their doctors their own questions. Participants who asked questions showed similar demographic characteristics to those who did not, but with one exception, question-askers were the participants who spoke about a predisposition for seeking out information relevant to their current concerns. The one participant who talked about himself as an information seeker, but who did not question his doctor after reading the manual, commented that he was happy with his level of knowledge about COPD and was no longer actively seeking information on this subject.

Discussion

This study identified both facilitators and barriers for reading and discussion of evidence with doctors. Plain English writing and the style of the manual facilitated reading, with variation in reading behaviour linked to varying pre-existing interest in the information contained in the manual. Information avoidance or difficulties with print were further barriers to reading.

Reading was a prerequisite for question-asking, therefore barriers to reading were also barriers to question-asking. Participants did not see advantages in raising issues from the manual with a doctor. Participants held the view that doctors and not patients were in a position to master the material included in the manual and initiate reviews of medical treatments. Where reading did lead to questioning a doctor, this took the form of a request for the doctor's opinion about the suitability of the treatment, rather than a suggestion that the doctor consult research evidence.

The study used patient interview data only. Further insights on the use of the manual could have been obtained by use of think-aloud or similar techniques which examine cognitive processes during reading, ¹⁶ observation of consultations, and examination of consultation records. A further viewpoint could have been obtained by interviewing doctors also. However, reading by patients and patient initiated discussions at consultations were fundamental to the effectiveness of the manual, and we selected an approach which directly obtained patients' views on those behaviours.

Patient interest in summaries of evidence

Other recent studies have also shown people with COPD and other chronic illnesses to be focused on the concerns of everyday life, such as practical aspects of managing activities of daily living and dealing with the effects of disability on the individual and the family, rather than on the medical aspects of their condition. ^{17;18}

Patients suggesting treatment reviews

Participants in this study did not see it as their role to suggest treatment reviews to doctors. This is consistent with common findings that older patients and those with greatest socioeconomic disadvantage and disease severity are least likely to participate actively in consultations. Similar findings were also demonstrated in a recent evaluation of an existing published set of evidence summaries for a younger group: women using maternity services. Women trusted health professionals' choices and rarely asked questions or made requests, and health professionals' behaviour supported informed compliance rather than participation. Description of the participation.

Implications for further research

Strategies to meet the reading skills and preferences of the target group contributed to the high rate of readership of the manual and should be employed for other interventions. To increase patient interest, evidence summaries may have to be integrated with patient-identified topics.

Barriers to raising issues with doctors must also be addressed, and these may be different for different patient groups. It also remains to investigate barriers to doctors acting on patient suggestions and ways of preparing doctors to respond to patient mediated interventions. The UK Medical Research Council has suggested a process for identifying and dealing with these kinds of barriers during the development of behavioural interventions.²²

Conclusion

If evidence summaries for patients are to be used in disease management, they should be understandable and relevant to patients and provide a basis for discussion between patients and doctors. Work is now needed so that we can both present evidence summaries in a way which is relevant to patients, and reduce the barriers to patient-initiated discussions of evidence.

Acknowledgements

We thank the patients, carers and health workers who contributed to development of the manual and assisted with vignettes, the health workers who assisted with recruitment, and the patients and carers who provided interviews for this study. Dr Jill Francis provided very helpful pointers after reading an earlier version of this paper. Funding for the manual was provided to the Australian Cochrane Airways Group by the Australian Department of Health and Ageing. MH was supported by a TQEH Research Foundation Postgraduate Research Scholarship while conducting this study.

Ethics considerations

Ethics approval was received from committees of the following agencies: The Queen Elizabeth Hospital and Health Service, Flinders Medical Centre, Repatriation General Hospital and the Australian Commonwealth Department of Veteran Affairs.

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Table 1. Barriers and facilitating factors for reading the manual

Type of barrier or facilitating factor	Barriers and Facilitating factors	Illustrative comments
Outcome expectations as barriers	Information in general not seen as providing advantages Some absent outcome expectations were linked to participants' feelings that their current level of knowledge was sufficient for their purposes.	I. And you found some useful information in [manual]? P. No. No only because I suppose I'm inclined to ask questions and I know what's going on. I've got a doctor who explains everything and he always explains things at the hospital so in that sense no. (D3) I don't take notice, I can be a funny person I suppose, but I sort of take my life as it rolls along. (M6)
	Particular information in manual not seen as providing beneficial outcomes, or information wanted by participant was not provided in manual	The book just covers the medical side of it, the physical changes happening to your body and the medical things you can do for it but it doesn't explain to you how to cope with the day to day living, as a person.(M4) I don't see any point in it. It doesn't, well, I suppose it doesn't answer the questions that I've asked about this business. (D3)
	Possible negative outcome that information may cause worry Thought the manual was commonly seen as not confronting, some participants who were coping by avoiding particular kinds of information about COPD experienced some worry when reading parts of the manual.	I what was going through your head while you were [reading the manual]? P. Well I was a little bit worried actually, because when you read about something that you've got well it is only natural that, you know, is that me? (M3)

Type of barrier or facilitating factor	Barriers and Facilitating factors	Illustrative comments
	Not reading because reading can encourage hypochondria	I'm not one of those who goes into reading. You know when you get a book and you read everything. I think no I don't want to know about that. You get everything that's in the book. (D4)
	Reading some kinds of medical information was thought to encourage lay self-diagnosis. However, it appears that this outcome expectation did not apply to the experimental manual.	Well I would say the only disadvantage is the same as reading any medical conditions that people have a tendency to think that they have got them symptoms. (M8)
Outcome	Information advantageous in itself	at certain points it jumps out at you and you think oh my God I was wondering about that (D5)
expectations as facilitating factors	Information was valued by some if specific to participants current concerns, or in general, especially for participants who self-identified as information seekers.	I mean you can pick it, you know if there's something not right. I mean I could go and pick the book up and probably find it in there because it is related to the chest. (M5)
		I think the booklet, for someone who wasn't informed, it was very good. (D8)
		Yes, yes, we [participant and wife] are big readers and right oh if I'm in the library and some funny little thing has come up I will look it up in their books. Mind you I've got fair references myself but by the same token I will go and look these things up and read about them. I feel that information is what you need all the time, it really is. (D2) if I get something like that and I've got diabetes, I usually go and research into it myself anyway and then find out what my body needs and what I should do and all that. But you know there are things in there [manual] too that were a bit different that helped. (D7)

Type of barrier or facilitating factor	Barriers and Facilitating factors	Illustrative comments
	Information as potentially helpful for self management of COPD Positive outcome expectations were occasionally expressed towards information which might help in self-management of COPD but these positive outcome expectations were not clearly linked to the experimental manual.	Oh its good to find out like if you've got anything and what you do about it and you know if you need to sort of – like I go to the respiratory doctor regularly at the hospital but this is what I mean you know – reading – that it sort of tells me that you've got to look after yourself. (D7)
	Information in manual did not cause distress. Many participants were not worried by the content of the manual.	I don't see any disadvantages at all. If someone is someone who wants to ignore the information available to them about their illness then that is their business, but personally myself I think you need to have more information available, I think people should know what they are dealing with. (D8)
Social pressures as facilitating factors	Supportive or neutral family and close contacts	I showed it to my sister because she's got emphysema - she's younger than me - and she had a quick read (M5) you can show your friends, family and loved ones what you are having to deal with, which I have done with this book so yeah I think a hard copy is quite useful. (D8)
	Supportive doctors The social acceptability of the manual was demonstrated by the many participants who informed their GP and/or specialist about it.	I took it to my doctor like a while ago, just after I'd got it and he said oh, that's good and he'd heard about it yes. (D7) And I told him I'd got this book and he said that's interesting and he said did you read it and I said 'course I read it (M5)

Type of barrier or facilitating factor	Barriers and Facilitating factors	Illustrative comments
Capability barriers	Perceptions of low reading ability One participant saw the manual as containing much medical terminology and some did not read books of any sort.	Well right through I had to refer a couple of times to the dictionary and everything Plus I have got a daughter that is connected with medical position, so she helped me a few times. (M8) but as to pick a book up and read it no ways, I can't. I've only ever read one book in my life. (M1)

Capability - facilitating factors	Facilitating factor: Perceptions of ability in reading Most participants said they found the manual easy to read and understand	Oh aye good, and I'm not the most educated person but yes it was very easy to understand. (D5) Yeah I didn't find it [reading and understanding the manual] a problem, I think it was easy to reference, it was easy text, the information was pretty straightforward, the headings were pretty straightforward. (D8)
External factors as barriers or facilitating factors	No external factors identified as barriers or facilitating factors for reading	

Table 2. Barriers and facilitating factors for question-asking from the manual

Type of barrier or facilitating factor	Barriers and Facilitating factors	Illustrative comments
Outcome expectations as barriers	No outcomes from asking questions in manual apparent to participants Even when probed, participants had very little to say about any possible outcomes of asking the particular questions from the manual.	No, I didn't think I needed to talk to him [the doctor] about them all [the questions in the manual]. (M1) I. Did you take the booklet to your doctor - your GP or your specialist? P. No I didn't actually because, no. I don't know why I didn't. My GP is an - actually an asthma specialist and is actually very, really up in this sort of stuff. I don't actually know why I didn't take it to him. (D8) I. Is there anything that you wanted to ask your doctor out of this booklet? P. No I don't think so. I. Can you see any advantages in asking your doctor any of the questions that are in this book P. No. I think that if I was more advanced than what I am and got a little bit, well. I could easily do that. (M6)
	No beneficial outcomes apparent from asking questions in general Though participants had not taken note of the questions suggested in the manual, they spoke about their own questions. A common remark was that the participant's questions had already been asked earlier in the course of their COPD.	P. But I feel such an old stager at this, I think to myself, well what else is there you know what I mean about my condition. And that's what we're talking about, not everything else. I. So was there anything that you thought you needed to do in relation to it. P. No, not at all I don't mean to sound blasé but I mean that you have a condition and you just live with it. (D6) No, I was pretty well informed about the drugs I was pretty well informed by my GP and also by myself, because I have got a very good GP. He is very straightforward and very informative cause he does specialise in COPD and asthma and stuff like that. (D8)
	No beneficial outcomes apparent from application of evidence Even for participants who recognised that questions were to promote evidence, this evidence was not seen as providing advantages.	P. Yes, yes, you can see that that's only research. You are looking for clues to try to get something to help people. But you are not there yet. I. No, what do you think about people getting that information when it is in that stage? P. Unless something is found it doesn't help a lot No, I read it once, it is bit boring. (M2)

Type of barrier or facilitating factor	Barriers and Facilitating factors	Illustrative comments
	Disadvantageous outcome is that doctor's answer to a question may cause worry	I. Do you ever ask the doctor any questions? P. No, I was given a book with what to ask your doctor but I suppose it's a sort of denial thing. If he thinks I'm bad, he'll tell me. Otherwise, I don't want to know, you know? (M4)
	There was sometimes a reluctance to ask questions to avoid answers which may cause worry. Participants spoke about worry in terms of their own questions, so this barrier may not be applicable to the questions given in the manual.	Or a couple of times you want to ask something but you don't really want to know the answer. It is a vicious circle, in one way you want to know but if it is not going to be good you don't want to know. It is hard. (D1)
Social pressures as barriers	Doctors, rather than patients, make decisions about treatments Treatment selection and initiating change seemed to be see as solely or mainly the doctor's concern. Participants did not see themselves suggesting treatment reviews. When participants spoke about making suggestions about treatments, this was limited to asking about adjusting timing or delivery of medications.	Well you see he is basically a professional. You're supposed to trust him. He is the doctor, not you, although you know your body. And if he advises you against a particular medicine like the one on page 31, who are you to dispute that, thinking that, OK, well maybe the reason is because it might counteract something else. And that's why, you know, you basically don't question him. Especially if you trust your doctor, which you are supposed to trust him. (Carer of M2) I. Did you feel that you needed to do anything in relation to your lung condition after you had read the book? P. No, only under my doctors supervision. (M8) I. Would [the doctor] be open to [changing the dose of a medication]? P. I don't know. I am going to ask when I go. (D1)
	The patient's role is as recipient of medical instruction Though participants reported asking questions when visiting the doctor, these questions were invariably described in terms of requests for information from someone with greater knowledge. Participants never spoke of using questions as a way of making suggestions.	My doctor would give me an answer, you know, depending if I wanted to know, and he would be only too happy to put me right. (M6) Here is [vignette of patient with manual consulting doctor]. Can you remember any of the things that you did ask your doctor? P. Well, just general things like why am I so short of breath, and what is the COPD doing to me, and what should I be doing about it. (M7)

Type of barrier or facilitating factor	Barriers and Facilitating factors	Illustrative comments
	The patients focus is on non-medical issues Though not asked about them, participants often spoke about life issues which were affected by their COPD. They appeared to see these, not treatment issues, as those the patient should manage.	I am looking for a unit I thought I would try and find something a little bit newer that doesn't need a lot of work and perhaps a strata title, just a small block. And that will give me a few dollars for a trip to England and that will give me a big boost.(D1) Oh, I hate a desolate place I am very pleased to be able to keep going. It is a delight to grow our own bits and pieces and I have a pride in it and when someone stops and says Wow! [laughter](D2) The campervan yes, that's a project we got that last year and we were going away you know, up the Riverland. Oh, I am all right driving that's terrific if I take my time . (D5)
Capability barriers	Perceived inability to ask questions of some doctors. Difficulties with asking or persisting with questions were sometimes experienced only with particular doctors.	I Did you try and talk to the GP? P. Yes I tried to but he didn't seem to, he seemed to think that I knew what it was all about, you know. And didn't enlighten me much (M3) I. And what about in the hospital, did you find them pretty easy to talk to - the doctors there? P. No, very hard. Perhaps because they are busy, with so many patients and they are always looking to squeeze something in, so I thought it was a bit hard. I. And have you ever had a GP like that? P. Well, not really. No, because with the GP you, you keep them, like. (M8)
	Perceived inability to ask questions due to perception of relative ignorance	I don't really understand much. I'm not a very good educated person so you know so I thought oh well they're going to tell me if something's really bad I suppose. (M3)
	Perceived inability to ask questions due to memory problems	I must write down all those things I've got to remember - I usually forget something. (D4)

Type of barrier or facilitating factor	Barriers and Facilitating factors	Illustrative comments
Capability - facilitating factors	Participant ability to ask questions Most participants were not conscious of any personal skill deficiencies to asking questions of their GP, in particular, though they appeared to see this in terms of requesting information rather than making suggestions. They sometimes ascribed this ability to the skills of the doctor rather than the patient.	No, it doesn't worry me, I just ask anything. (D7) Quite easy [to talk] as far as I am concerned because as I say, if you can't talk to your doctor [GP] you are wasting your time to go and see the doctor. (M8) It is just the sort of person I am. I've got an inquiring mind. If I had anything to ask, I'd ask it. (D5) I just thought, ask the doctor. Because I have got a really good doctor, Dr [M]. and he is a very understanding man and I just have a talk to him about things and he gives me a truthful answer to what I want. (M6)
External factors as barriers	Awareness of doctors' lack of time Several participants spoke about doctors' time limitations. However, most saw this as a surmountable barrier when they had an important question to ask.	some people get some doctors and they are feeling that they can't wait to get to the next game of golf (D5) I. Would the busyness ever make you think you would ask the question another day, or would you ask it anyway? P. Six of one and half a dozen of the other. If it was an important question yes I would ask him but if it was just something I wanted to know I would leave it till next time. (M7)