



Mann, C., & Goberman-Hill, R. (2011). Health care provision for osteoarthritis: concordance between what patients would like and what health professionals think they should have. *Arthritis Care and Research*, 63(7), 963-972. DOI: 10.1002/acr.20459

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Healthcare provision for osteoarthritis: concordance between what patients would like and what health professionals think they should have.

Cindy Mann and Rachael Goberman-Hill

Healthcare provision for osteoarthritis: concordance between what patients would like and what health professionals think they should have.

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Work supported by a grant from North Bristol NHS Trust small grant scheme

**Wordcount** 3885

## **Objective**

To explore patients' and health professionals' opinions about the provision of healthcare for people with osteoarthritis (OA) and possible service improvements.

## **Methods**

Qualitative methods were used to explore patients' and health professionals' opinions about existing OA care and possible changes in service provision. Sixteen patients, with hip or knee OA, took part in focus groups and twelve health professionals, from primary and secondary care, were interviewed. Focus groups and interviews were audio-recorded, transcribed and anonymised. Transcripts were analysed using Framework method.

## **Results**

Patients' and health professionals' views generally concurred. They felt that OA should receive more attention and better consistency of care. More information and education about the condition, diet, exercise, aids and resources was needed at the time of diagnosis. Patients wanted more time, better continuity, and proactive follow-up from general practitioners, with less variation in accessing joint replacement. Participants suggested access on demand to an 'OA specialist' in primary care and use of a management model comparable to other long-term conditions. Both patients and health professionals wanted better support for self-management to help patients manage their condition more effectively and appropriately.

## **Conclusion**

Patients and health professionals perceived similar problems with OA care. More proactive care and improved information, especially for those with early OA, might achieve better outcomes. Access to a primary care OA specialist might provide better continuity of care, enable patients to meet their needs for information, support and self-management and improve appropriate referral to other resources.

## Significant findings

1. There is a significant degree of agreement between patients and health professionals about healthcare provision for OA.
2. Both patients and health professionals think there should be access to an 'OA specialist' in primary care.
3. Patients and health professionals highlighted the need for better information at, or soon after diagnosis.

Osteoarthritis (OA) is a major cause of persistent pain, causing distress and disability<sup>1-6</sup>. Approximately 95% of people with OA are managed in primary care, with pharmaceutical pain control being the mainstay of treatment. When this approach does not provide enough relief, then joint replacement surgery may be considered as an option. However research suggests significant gaps in care prior to this stage, especially in supporting self-management which is widely accepted as the cornerstone of managing long-term conditions.

Self-management could be enhanced by discussing treatment options with individual patients and tailoring self-management strategies to suit them<sup>7-9</sup>. Recent guidelines concur in recommending advice about activity and exercise, and intervention to help weight loss<sup>9-12</sup> in the context of a 'holistic approach to osteoarthritis assessment and management' centred on 'access to appropriate information'<sup>9</sup>. However, it is not clear how extensively these recommendations have been implemented and there is accumulating evidence of shortcomings in healthcare provision for OA<sup>7, 13</sup>. Support, information and resources to implement self-management strategies such as exercise and weight loss may be lacking<sup>8, 14-16</sup>. Symptoms of OA-related pain, disability and depression may be underestimated and inadequately addressed<sup>14,17</sup> with failings in support and understanding of individuals' plight<sup>17-19</sup>. In addition, there is evidence of patchy access to joint replacement<sup>20</sup>, low safety standards in medication use<sup>21</sup> and a void in care when waiting for joint replacement<sup>19, 22</sup>. Some of these deficiencies may result from patients' and health professionals' low expectations of treatment<sup>20</sup>, the low priority given to a condition seen as a normal part of aging<sup>18</sup>, and the reluctance of

patients to implement treatment recommendations such as regular analgesia<sup>23</sup> or lifestyle changes<sup>14</sup>.

The importance of seeking service users' opinions to inform health care provision is now well recognised. Services can be developed that suit users' needs better and enable providers to focus resources more effectively. This has been widely investigated in mental health and to a lesser extent in other fields<sup>24-27</sup>. Furthermore, concordance between what patients and health professionals think is desirable may increase the likelihood that new services meet patients' needs. However, we do not know whether patients and health professionals perceive the same needs and deficiencies in OA care. This study examined patients' and health professionals' perceptions of current service provision for OA, and their views of the need for improvements.

## **Participants and Methods**

### **Study design**

A qualitative design was used to elicit opinions about OA health care and experiences<sup>28</sup>. The study comprised two focus groups with 16 patients living with OA, and one-to-one interviews with 12 health professionals from specialities providing health care for OA. Focus groups with patients were considered preferable to one-to-one interviews because group interaction can generate freer, more broad-ranging expression of ideas and opinions and can facilitate clarification<sup>29</sup>. Individualised information about condition severity and OA-related health care was collected through a brief questionnaire prior to each focus group to inform analysis of



focus group data and to provide additional information about service use (Table 3). One-to-one interviews with professionals were chosen as a means of generating data relating to each of their specialities, in confidence and at times to suit their work commitments.

### **Sample and recruitment**

Patients who were potential participants were identified through the practice database of a large General Practitioner (GP) practice employing 16 GPs. The practice covers a suburban area with less than average England deprivation score but higher than average older population<sup>30</sup>. Eligible patients were those with a diagnosis of lower limb OA and without severe mental illness or a diagnosis of inflammatory arthritis. A total of 38 patients were approached by letter and asked to return a reply slip if they were interested in discussing study participation. When a reply was received, the researcher telephoned each patient to discuss the study and confirm eligibility. Once the first four patients had agreed to attend a focus group, purposive sampling ensured broad variation in the sample with regard to age, illness severity, length of illness, co-morbidity, and a balance of men and women<sup>29</sup>. Sampling continued until 16 patients (9 women and 7 men) agreed to take part, at which point the sample was deemed diverse enough to include sufficient variation in experience<sup>29</sup>. Each focus group comprised 8 patients.

Health professionals working in primary and secondary care were approached. The GPs, nurse practitioner and practice nurses all worked at the same GP practice where the patients were registered but other health professionals were recruited from diverse sources. All were identified using known contacts and 'snowballing'

technique<sup>31</sup> facilitated by the researcher's position as a clinical nurse specialist in rheumatology, and previous work as a practice nurse in the same GP practice. Participants were recruited until we were sure that the main specialities involved in providing care for people with OA were included. 19 health professionals were approached and 12 agreed to take part.

At the start of each focus group or interview, participants provided their written, informed consent to take part and be audio-recorded. Ethical approval was provided by the UK's National Research Ethics Service.

### **Data collection**

**Focus groups:** The patients' focus groups each lasted one-and-a-half hours and were conducted on primary care premises. At the start of each focus group, participants each completed a questionnaire about OA history and related health care. Next, the researcher (CM) used a topic guide to facilitate discussion about patients' experience of care, their perception of gaps in care, and suggestions for improvements (Table 1). A scribe was present to note down the first words of each participant's utterance to ease transcription.

**Interviews:** The interviews with health professionals lasted 15-50 minutes each and were semi-structured with a topic guide (Table 1). Questions focused on current care and professionals' views about possible improvements to OA care. Probes and additional open ended questions were used to achieve depth<sup>31</sup>.

Focus groups and interviews were audio-recorded, transcribed and anonymised. All data were collected in 2009.

## **Analysis**

Framework method was used to code and categorise the focus group and interview data<sup>32, 33</sup>. This method allows for the inclusion of new themes generated by the data, as well as the broad themes of interest contained in the topic guides. Transcriptions were read and re-read, and codes describing content were ascribed to sections and sentences. From this, a list of key concepts and recurrent themes was generated. A second researcher (RG-H) independently coded both focus group transcripts and four interview transcripts. After discussion between the two researchers, the code lists were combined into two lists (one for the focus groups, the other for the interviews) and tabulated into a framework of broader themes. These reflected the questions put to participants and also the dominant themes that emerged from their responses (Table 2). This aided comparison between health professionals' and patients' views. Ongoing analysis ensured that findings from the focus groups and early health professional interviews informed subsequent health professional interviews. A descriptive account was written of each focus group and a brief summary was made of the views of each health professional and returned to the participants who had requested this. No comments were received.

## **Results**

The data presented here reflect the two main areas in which patients and health professionals would like to see improvements in care: information and access to treatment and services. Data about patients' views are presented first.

## **Patients focus groups**

Sixteen patients participated in two focus groups. Characteristics of individual group members and data collected with the brief questionnaire are shown in Table 3.

Quotes are presented in Table 4.

### **1. Information**

Most patients expressed a strong desire for improved information about OA and its likely progression (Table 4 a-e), particularly at diagnosis and in its early stages, so that they could know what to expect and feel confident in their management of the condition. Information needs included diet and exercise, how to minimise OA symptoms and progression, and practical information about aids and local services.

When these needs were not met, some patients turned to the internet for information, which did not always reflect current scientific evidence (Table 4 b-d).

One patient highlighted a difference between care received early in her OA trajectory and that which she received later (Table 4 e). Only 1 patient felt that she had always been given adequate information and care (Table 4 f).

### **2. Access to treatment and services**

All patients had seen their GP at some time about their arthritis, although 1 patient was not aware that she had osteoarthritis until she received the study invitation letter. Two other patients had experienced difficulty in obtaining a diagnosis (Table 4 g). Five patients had already undergone a hip or knee replacement. Seven patients had not seen a health care professional about their arthritis in the last year. One of these experienced severe daily pain but had no prescribed analgesia (Table 3).

Many patients were not aware of having received advice about exercise or weight

control. Other services were not well accessed with only half the patients having had physiotherapy (Table 3) and no-one aware of any other services, such as occupational therapy. Several patients felt that physiotherapy should be more widely available.

Seven patients described feeling left to cope on their own and that nothing was done once the X-ray had confirmed the diagnosis (Table 4 h). One patient noted that care was reactive rather than proactive (Table 4 i) and others found it difficult to know when they should return to the doctor (Table 4 j). Some felt that regular review and information about the likely course of OA would help them to make a judgement about their own need and felt that this could support self-management (Table 4 k). Continuity of care was also considered important (Table 4 l).

Patients commented that OA appeared to be a low priority in health care. Patients agreed with each other that GPs were generally too busy to spend much time discussing OA and were not specialists in arthritis. Patients expressed a desire to have access to someone with specialist knowledge of arthritis, possibly a practice nurse (Table 4 m), who was 'fully genned up' and easily accessible who 'can tell you exactly ... what's going to happen ... and you can get the advice off of her' [M6]. This would avoid concern that they might be 'bothering' the GP unnecessarily (Table 4 n).

The general view was that the only effective treatment was joint replacement surgery. Access to joint replacement was a concern and patients noted that clinicians' decisions or advice were not always consistent (Table 4 o, p). Some patients also expressed anxiety about identifying the right time to have a

replacement because they felt this was left up to them and they lacked sufficient information to make that judgement (Table 4 q).

### **Health professionals interviews**

The twelve health professionals who took part in interviews comprised 2 GPs, 2 orthopaedic surgeons, 1 rheumatologist, 1 occupational therapist, 2 physiotherapists, 1 nurse practitioner, and 3 practice nurses (Table 5). Quotes are presented in Table 6.

#### **1. Information**

Every health professional identified insufficient information for OA patients. One GP and the nurse practitioner acknowledged they were not providing information leaflets. The need for early education about OA and its likely course was emphasised, as patients' expectations and illness perceptions have an important effect on their acceptance of self-management and treatment options. Health professionals also thought patients should have the opportunity to discuss these options and be provided with more information to aid self-management at, or soon after, diagnosis for maximum effectiveness (Table 6 a-d). However, some expressed doubts about patients' willingness to make behavioural changes (Table 6 e,f). The surgeons identified an information gap prior to referral for surgery as they sometimes saw patients who they felt had unrealistic expectations of the outcome of joint replacement (Table 6 g).

## **2. Access to treatment and services**

The health professionals all thought that OA was not given enough attention, and symptoms were often dismissed or minimised in health care (Table 6 h-j). Some identified the lack of provision for patients who were not candidates for surgery. One practice nurse felt that patients had to carry on too long without help before being considered for surgery (Table 6 k).

It was thought that patients lacked pro-active follow-up to support self-management (Table 6 l). The rheumatologist thought that patients would be better served by a long-term condition model of care providing consistency over time, rather than one that consisted of episodes of care in response to symptom exacerbation. This might also reduce repeated referrals (Table 6 m). Eight health professionals considered the possibility of using a model similar to that used in primary care for patients with diabetes. However 3 health professionals also felt that routine follow-up was not the best use of their time or healthcare resources and that patients should initiate their own follow-up when needed (Table 6 n).

Lack of time to give patients sufficient opportunity to discuss their condition arose in all but 1 of the health professional interviews. Quality of care was also thought to be adversely affected by general lack of expertise and interest in OA in the community (Table 6 o-r). Some health professionals pointed out that variation in the expertise and interest of GPs could lead to inequity in care (Table 6 q), partly because their role as gatekeepers to other services required knowledge of what those services could offer and of new developments in treatments. Without this, there could be inappropriate referral or sub-optimal access to services, which could be exacerbated

by discontinuity in care. One suggestion was to allow patients to use a direct access system after initial referral to a service so that they could decide when they needed further treatment and request it without the need for re-referral (Table 6 r). Some health professionals suggested that care could be improved if every GP practice contained an individual who took a particular interest in OA.

Regardless of who held the role of gatekeeper, access to services such as occupational therapy and physiotherapy and the provision of these services in the community was universally described as inadequate. The physiotherapists both highlighted a lack of facilities to promote continuing exercise in the community. One of them (HP11) lamented the lack of co-ordination between leisure services, social services and health services. The GPs, physiotherapist (HP05), nurse practitioner and 1 practice nurse felt that the wait for physiotherapy was too long and there was insufficient intervention when patients were seen (Table 6 s). Two health professionals (HP18, HP06) thought that physiotherapists did not find it rewarding or interesting to treat OA patients as they could not be cured. The surgeons felt that non-surgical treatment options had not been adequately tried before referral for surgery (Table 6 t). Finally, the occupational therapist observed that there should be OA specialist clinicians from all the relevant allied health professions providing services in the community.

### **Results summary**

Patients and health professionals thought that OA should receive more attention. Both groups singled out lack of sufficient information in the early stages as a primary concern. Patients felt that they needed more information about OA and its likely



progression to empower them to manage their condition more effectively, including information about the right type of diet and exercise, and practical aids. Health professionals felt that lack of good quality specific information in the early stages of OA may have a damaging effect on patients' expectations and self-management strategies, with potentially negative consequences for health resource use. However some health professionals felt that simply giving information was insufficient to achieve behaviour change. Other shared concerns were lack of consistency in the care offered, inadequate continuity of care, and failing to take OA sufficiently seriously. Patients did not feel confident that a GP unknown to them would be able to understand their situation adequately, to the detriment of their care. Some health professionals advocated continuity of care, as provided by a long-term condition model of care, to avoid repeated or unhelpful referrals as well as to enhance overall care.

It was felt that inconsistency in care provision resulted in part from the diversity of health professionals' expertise, some of whom are not interested in treating OA. Patients wanted access to specialist knowledge and advice and regular access to someone known to them who understood the problems caused by OA, with whom they could discuss concerns and who could knowledgeably assess the need for further treatment or modification of management strategies. Health professionals also felt that providing access to someone with a specific interest in OA would improve standards of care for all patients with OA and optimise use of health resources. Patients' concern about lack of ongoing support was reflected in health professionals' opinion that a long-term condition model of care would be more appropriate than an acute episodic model.

## **Discussion**

### **Significance of results**

In this study there was notable similarity between patients' and health professionals' views of improvements needed in OA care. Both groups wanted to enhance patients' ability to self-manage in order to improve symptoms and outcomes and identified better information as a route to achieving this. Patients focused primarily on their need for more information to give them greater control over their condition, and enable them to take responsibility for managing their OA successfully and independently. When patients expressed dissatisfaction, it was often because they felt that health professionals had not provided them with sufficient information to undertake this responsibility adequately. Previous studies have also identified information needs, particularly specific information and advice about their individual situation<sup>14, 16, 18</sup> to help them take appropriate responsibility<sup>34</sup>. Patients' dissatisfaction is significant in the light of several guidelines<sup>7, 9, 10</sup>, which all advocate information provision to support self-management. In this study, health professionals were aware of the shortcomings in provision of information and most felt that they should devote more time to providing information and supporting self-management. However, they considered behaviour change as the primary component of self-management and highlighted the difficulty of helping patients to make lasting changes to their behaviour solely through information provision. This view is supported by the finding that self-management programmes that combine behaviour modification techniques with provision of information are more effective than

information alone<sup>35</sup>. When health professionals advocated more regular follow-up, it was primarily because they felt this would provide more support for self-management. The physiotherapists were particularly aware of the gap in community provision of supervised exercise opportunities.

The finding that both patients and health professionals think that OA receives insufficient attention underlines the relevance of recent drives to improve care<sup>7, 13</sup>. While previous studies have indicated the existence of gaps in care, our study shows that health professionals are well aware of these. Health professionals from all included specialities clearly empathised with the situation of OA patients. They were perhaps more aware of shortcomings in care than the patients themselves who had not experienced alternative models of care with which to compare their experience. However there was some disagreement when it came to regular follow-up. Some patients indicated that they would value the reassurance and support provided by regular follow-up even if their situation had not deteriorated, whereas at least one health professional felt that this would not be good use of their time. Patients' desire to have regular follow-up bears out the NICE<sup>9</sup> recommendation that this should be provided. The existence of a specialist in each GP practice could meet patients' desire both for continuity of care and specialist knowledge and go some way towards achieving greater consistency of care.

The finding that patients and health professionals share similar concerns over health care for OA has significance for the development of better services. When users are consulted about service development this is likely to result in services that are better at meeting patients' needs<sup>24, 25, 36</sup> and user involvement in service planning is now

strongly advocated for this reason<sup>37</sup>. However, to our knowledge, the additional impact of concordance between patients and providers about healthcare delivery has not been specifically investigated. If new OA services are based on ideas that patients and health professionals agree upon, then patients might be more satisfied with their care. This issue warrants further research.

### **Limitations**

In the focus groups, the sample of 16 patients was drawn from one GP practice which may have affected the transferability of the results. However the sample comprised men and women and was selected to ensure a good range of ages, OA duration and severity. It also included four participants with co-morbidities. Although we cannot be sure that saturation was reached in the focus groups<sup>38</sup>, the data collected was rich and wide-ranging.

In the interviews, the sample size of 12 health professionals was relatively small and only included between 1 and 3 representatives from each profession. Also the primary care professionals all worked in the same large GP practice from which the patients were recruited. However, all the health professionals provided candid reflections on service gaps and contributed diverse perspectives. This indicates that including professionals from the same practice as patients did not constrain professionals' responses and that the sampling strategy was appropriate for the research aims. The inclusion of a variety of health professionals from both primary and secondary care was a strength, contributing compelling evidence of need from those practising in different sectors. In spite of the small sample size, saturation was achieved in identifying the principal limitations in OA care. In-depth responses were

obtained in both individual interviews and focus groups, while the group interaction in the focus groups generated additional data<sup>29</sup>.

The research was conducted in one location which might have different service organisation than other areas. However, the system of GP care is universal in the UK and most of the findings related to this. The study's approach is consistent with 'rapid appraisal'<sup>31</sup> of health care need, which does not aim to achieve generalisability, but is the first step in the development of new services. Further investigation would be required to quantify and apply the findings more widely.

### **Rigour**

Double coding and provision of descriptive accounts to participants enhanced rigour in data analysis<sup>39</sup>. Reflexivity is also important to ensure rigour<sup>40</sup>. The researcher was a clinical nurse specialist in rheumatology, which presented benefits in the recruitment of professionals, many of whom were known to the researcher. Her detailed knowledge of OA and services assisted in the development of interview questions. However, participants' knowledge of the nurse's professional status might have affected their responses and health professionals may have felt under examination<sup>41</sup>. To mitigate this, she openly acknowledged her clinical background while also taking care to distance herself from her own pre-conceptions about current service provision<sup>40, 42</sup>.

### **Conclusions**

The concerns and need for improvements in care for OA identified by both patients and health professionals in this study are consistent with those found elsewhere.

However, this study is the first to show congruence between patients' and health professionals' overall concerns, albeit some motivations for improvement may differ. Importantly, patients and health professionals emphasised the desirability of patient-initiated follow-up with a primary care-based health professional specialising in OA. This is a new finding. Having access in primary care to a health professional with a specialist interest in OA could potentially address all the identified concerns. Future research could address the feasibility and effectiveness of such a system, which potentially could also address the current imperative of providing high quality health care with increased cost-effectiveness.

### **Acknowledgements**

The authors' current positions are funded within a programme of independent research commissioned by the UK's National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0407-10070). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

We are very grateful to the patients and health professionals who took part.

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**Table 1: Questions used in patients' focus groups and health professionals' interviews**

**Patients' focus groups**

**Health professionals' interviews**

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General questions:

- |                                                        |                                     |
|--------------------------------------------------------|-------------------------------------|
| 1. Could more be done to help you with your arthritis? | 1. What do you think of OA care?    |
| 2. If so, what would that be?                          | 2. Could it be improved?            |
| 3. How important would those extra things be to you?   | 3. If so, how could it be improved? |

Prompt questions:

- |                                                                         |                                                                                                         |
|-------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------|
| 1. How does having arthritis affect you in what you think, feel and do? | 1. What is your perception of the health care of people with OA?                                        |
| 2. Who or what can help you with your arthritis?                        | 2. Which of the recommended treatments for OA do you think your patients are able to access adequately? |
| 3. What treatments/services are there?                                  | 3. How could the health care of people with OA be improved?                                             |
| 4. Which would you like to be able to use?                              | 4. Which improvements could be made at primary care level?                                              |
| 5. Which have you been offered or been able to use?                     | 5. What would be the most important improvements in your opinion?                                       |
| 6. What gaps, if any, do you think there are in the care that you       | 6. What do you think are the most                                                                       |

- receive for your arthritis?
7. How do you think the care could be improved?
  8. What improvements to your care would be the most important?
- important improvements to people with OA?
7. What would help you in the care of people with OA?
  8. Who should be involved in the care of people with OA at primary care level?
  9. Who should deliver the NICE core treatments?

**Table 2: example of coding framework applied to patient data**

Theme of interest to researcher	Questions used to explore theme	Examples of initial codes	Broad themes	Final themes
Gaps in care	<p>What gaps, if any, are there in the care that you receive for your arthritis?</p> <p>What more could be done to help you with your</p>	<p>Not enough information about OA and what to expect, just told it's 'wear and tear', not enough information about services, and things that will help/make it worse, care reactive, 'come back when it's worse', 'nothing proactive coming from the doctor', 'can't always see same doctor', GP too busy to explain, not enough access to physio, delayed diagnosis, variations in advice, joint replacement difficult to get, difficulty in knowing 'right time' to ask for joint replacement, wait until unbearable, need specialist advice, 'someone who knows you', someone 'who is OK</p>	<p>Not enough information</p> <p>Not enough follow-up</p> <p>Variation in provision of services</p> <p>Specialist advice</p> <p>Need for continuity</p> <p>Negative messages</p>	<p>Access to services</p> <p>Information</p>



	arthritis?	with what you're talking about', empathy, need easy access to advice for more minor concerns, don't want to bother doctor, resist labelling of old age, told nothing can be done		
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**Table 3: Focus group participants' details collected from questionnaire**

Code	Age	Years with OA	Seen a physio	HP visits in 1 year	Daily pain and severity	Analgesia prescribed	Joint replaced
<u>Focus group 1</u>							
F1	62	>5	Y	0	Y Mild	N	N
F2	72	12	N	0	Y Severe	N	N
F3	72	20	Y	0	N Mild	Y	Y
F4	80	10	N	0	N Mild	N	N
F5	79	25-30	N	1-3	Y Moderate	Y	N
M1	65	19	Y	0	Y Moderate	N	N
M2	58	-	Y	0	N None	N	Y
M3	65	-	N	1-3	Y Moderate	N	N
<u>Focus group 2</u>							
F6	59	3	Y	1-3	N Moderate	Y	N
F7	81	2	N	1-3	N Moderate	N	N
F8	64	-	N	0	N None	N	Y
F9	77	10	Y	4-6	Y Severe	Y	Y
M4	63	-	N	1-3	- Mild	N	N
M5	61	7	N	1-3	N Mild	N	N
M6	77	6-7	Y	4-6	Y Moderate	Y	Y
M7	56	2	Y	1-3	Y Moderate	N	N
Total			8		8	5	5

*Key: F1 – F9 female participants; M1 – M7 male participants; HP health professional*

## **Table 4: Patients quotes**

### **Information**

- a. 'Well, it's a pity they can't tell you how it progresses and if it progresses in everyone' [F7]
- b. 'I got a phone call to say, "I've got some bad news, you've got arthritis in both hips", ... he didn't say," Come and see me and we'll talk about it" it was "Goodbye". ... I think he said "You've got marked arthritis in both hips", and I didn't really understand what that meant. So I had to go on the internet and have a look and see what it was all about.' [M7]
- c. 'When you are diagnosed with it, you are not given enough information, now I have never been told at all about anything to do with certain foods not to eat. But I have found out since there are certain foods that you shouldn't touch, ... that was picked up on the internet by my son, but I mean I have never been told by a doctor to cut out anything that would aggravate arthritis.' [F4]
- d. 'I think there's certain gadgets that people don't know about that I know if you go to a mobility shop, you can pick up a catalogue and they have got valuable things there.' [F4]
- e. 'I don't think you ever get told what it is, or why you've got it, except that well it's just wear and tear, and that's as far as you go. In the beginning I'm talking about. I do get very good treatment now.' [F9]
- f. 'Because I just can't understand this where you're all saying you don't get any advice. Anything I've ever come for it's been explained to me.' [F7]

### **Access to treatment and services**

- g. 'It just flared up, just became swollen and extremely sore. I had no idea what

- had caused it, went to the doctor, they had no idea for about seven months. Then I went for an arthroscopy and that's when it was diagnosed.' [F6]
- h. 'I had the X Ray, look it's getting worse but at the moment it's livable, so you go on until it causes sheer misery.' [F3]
- i. 'Well I think I was told that, "At some stage you will need a hip replacement," but ... "you are a bit too young, you know, to have that done." And my doctor said, "If it gets any worse come back," which I did, and then he said, "If it gets any worse come back."... There is nothing proactive coming from the doctor to manage that condition.' [M7]
- j. 'But that leaves it up to you then, doesn't it? You think how much I can bear before I have to go back again and say this has got so bad now I can't do anything.' [F1]
- 'And then to be told' [F5]
- 'Yeah. If you'd come earlier and you shouldn't have let it go on as long as this.' [F3]
- k. 'A review might help because it's not got worse, rather than it has got worse ... so it may be useful to have a review to see what I'm doing right that has stopped it getting worse' [M7]
- l. 'And very often if you're written up to see a special – your own special doctor, then you can't get in. They say well any doctor will do, but any doctor won't do because they haven't got time to stop and read all the way through your notes, they don't know you well enough.' [F9]
- m. 'Someone that specialises purely in general arthritis, then at least when you went in there to speak, to see them you'd know that they're OK with what you're talking about.' [M3]

- n. 'I always think there's room for someone ... who you could go see and say "look I'm getting this, I'm getting that" and they could tell you what to do and that is good advice, would be excellent I think. You don't want to keep on with your GP.' [M1]
- o. 'I am a bit disappointed with certain medical advice because I thought I was going to be operated on but people didn't seem to want to do it.' [M1]
- p. 'Sometimes it depends on the GP and that. Some send you straight to a consultant, some say "oh, it's old age" and leave you to it. They vary' [F9]
- q. 'You need consultation ... from the onset and how to cope as it gets worse ... You need it otherwise you are scared that it will deteriorate to a degree that is almost impossible to repair. ... You need good advice, someone [who] knows when is the opportune time to have it done.' [M3]

**Table 5: health professionals' position and experience**

Health professional	Code	Position and experience
GP 1	HP18	Partner in GP practice of 14,000 patients for over 5 years.
GP 2	HP12	Salaried GP for less than 5 years in GP practice of 14,000 patients. Previous experience in rheumatology
Orthopaedic surgeon 1	HP09	Consultant specialising in hip arthroplasty for over 5 years. Has professional interest in OA research
Orthopaedic surgeon 2	HP16	Consultant specialising in hip arthroplasty for over 5 years
Occupational therapist	HP15	Senior secondary care occupational therapist for over 5 years. Extensive rheumatology experience. Research experience
Physiotherapist 1	HP05	Academic physiotherapist for over 5 years who has investigated provision of services for people with OA
Physiotherapist 2	HP11	Practising in rheumatology department for over 5

years. Research active

Rheumatologist	HP06	Consultant for over 5 years. Experience working with community rheumatology services
Nurse in GP practice	HP03	Less than 5 years experience in GP practice and of running chronic disease clinics.
Nurse in GP practice	HP07	Over 5 years experience in GP practice and running chronic disease clinics. Less than 5 years seeing patients in surgery as quasi GP
Nurse in GP practice	HP14	Over 5 years experience in GP practice and running chronic disease clinics. Close relative with severe OA
Nurse in GP practice	HP19	Over 5 years experience in GP practice and running chronic disease clinics. Suffers from OA

## **Table 6: Health professionals' quotes**

### **Information**

- a. 'But quite often I only give them a very basic explanation of what osteoarthritis is, ... [a] rudimentary sort of wear and tear, degenerative explanation, which of course is only part of the story. ... I'm trying to think if I use any patient information leaflets, and I don't regularly do that for osteoarthritis actually. ... there is a lack of information I'd say.' [HP18]
- b. 'I think it's really good to be targeting the people that are newly diagnosed, and hopefully reassuring them about the pathology of osteoarthritis as well, so that they don't think it's a wear and tear disease, and don't think that they're going to wear their knee out by using it more, and realise that actually exercise is going to help to keep their joint healthy.' [HP05]
- c. 'That initial education phase is actually really important and, you know, helping them to understand ... what arthritis means, what they can do to help themselves and ... what other things are available down the line, I think is really important.' [HP12]
- d. 'I think just better education around everything, around the nature of the disease, what it involves, about what the treatments are, and about not just sort of tending to think, "Oh well I need a knee replacement and ... that's it. And I'm not going to get any better until I get one," ' [HP07]
- e. 'We probably ... give them the advice and think, "Well I know that they're not going to do it". Because the patients very rarely do the advice that you give them, ... lose weight or try and do the exercise' [HP07]
- f. 'I've learned through experience ... if you just say, "Well, we've talked a bit about



arthritis, so here's a booklet to take away and read", the chances are they won't even open it' [HP15]

- g. 'The one that isn't addressed so much [is] "What is a broad likely quality of life and outcome from [surgical intervention]?" I think if just a very simple couple of phrases like that were used in primary care, so the patient was coming with appropriate expectations, that would be good.' [HP16]

### **Access to services**

- h. '...chronic musculoskeletal pain is almost like the poor partner and isn't being managed effectively.' [HP11]
- i. 'Because it's a condition that's associated with ageing, ... both the patients and the health care professionals will tend to say, "Oh it's just a part of getting old," so that they will tend to minimise it. ... And health care professionals, I think, just tend to leave them to get on with it. ... you are often told, "Oh my GP just says well, you know, it's just something you have to learn to live with."' [HP15]
- j. 'If somebody came and saw me with ... knee pain, I'd probably tell them to take some paracetamol and go away. And if they came back and saw me again ... and said it was still painful, then I might send them for an x-ray. And then if that came back and said osteoarthritis I would ... say, "Well yes it's osteoarthritis, but there isn't very much we can do about it at the moment.'" [HP07]
- k. 'I think it's the amount of time people have to actually wait before anybody does anything. You have to get to a certain level with your arthritis before anybody is actually going to listen to you. Just aches and pains and a small amount shown on an x-ray of arthritis, is probably just thought nothing of. You have to wait until it gets to that really crippling stage almost before anybody does listen to you.' [HP14]

- l. 'Because it's not seen or managed in the same way as other common diseases seem to be ... with regular follow up and regular sort of monitoring and regular management.' [HP18]
- m. ' ... often what we're asked to do is make sure it's not rheumatoid. So having done that, it would be very nice to be able to ... pass the person on to somewhere where they would be supported in their self-management, and safe, and able to be reassessed without being referred back to hospital. ... you feel you're ... discharging them back to the community ... to sort of sink or swim and just get on with it themselves.' [HP06]
- n. 'I think to just get somebody up on a routine basis, and if they come up go, "Oh no well actually everything's absolutely fine," I don't think that that's a good use of a patient's time or our time. So I think it probably would be better for it to be at the patient's request.' [HP12]
- o. 'If somebody had time and could concentrate on that person and educate them more about it then perhaps that person could self-manage their arthritis better.' [HP06]
- p. 'I don't think the GP's have got time if they have the knowledge to actually go through everything with them ... for them not to be fearful about it, and actually look at strategies at how best they can manage it. And some knowledge about the treatment, and ... what the benefits of the treatment are.' [HP03]
- q. 'I think there are GP's that may have a greater interest, and a better understanding of the disease, and there's others that may not have quite that same knowledge base or experience and I think that's why it does often prove inconsistent in the GP's approach to the treatment and care of these patients.' [HP03]

- r. 'What you need is someone who's sympathetic who's competent, who could enable things and who knows what is available and ... my idea would not even have that person be the gatekeeper to the next level. Let the patient be the gatekeeper' [HP09]
- s. 'I think the provision of physio definitely. And I think that's very poor. They have to wait, if we did refer them to physio, they have to wait a long time to get a physio appointment. And they're probably just given a set of exercises and then the physios probably don't want to see them again unless there's a problem.'  
[HP07]
- t. '... before they see us a lot of the patients are not on optimal treatments to deal with their pain and they're not on optimal social supports to help them with their day to day functioning and participation in society ... . If you can optimise that it would increase the interval from when they get their arthritic symptoms to when they have their operation.' [HP09]