

Consumer feedback on the current and future management of hip and/or knee osteoarthritis in Victoria

Development of a model of care for Victorians with osteoarthritis
- July 2016 -

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"I don't think I was really listened to initially"

"The combined effort of the physio and GP got me to the right specialist"

"I think there is a blockage in the system with regards to information"

"It's difficult to get a second appointment with the rheumatologist as there are very few of them out here"

"I received up-to-date information, management options and remedies"

"Health professionals should be up-to-date with research and know about services"

"It would be good to have physios and nurses involved in assessments"

"The cost involved is a deterrant"

"Having the right referrals at the right time again contributes to that integrated approach"



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Development of a Model of Care for Victorians with Osteoarthritis

Consumer feedback on the current and future management of hip and/or knee osteoarthritis in Victoria

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Executive Summary

A model of care for osteoarthritis in Victoria is being developed using a comprehensive consultative process, involving clinicians, researchers, policy makers and people diagnosed with osteoarthritis. A model of care is a guide that describes how health services and other resources should be delivered to consumers with a particular health condition. It is informed by the best research evidence for 'what works' and the local Victorian context and it describes *what* care should be provided and *how* it should be delivered. The project has been commissioned by the Victorian Department of Health and Human Services under the auspices of the Musculoskeletal Clinical Leadership Group.

The consumer consultation has been undertaken by *MOVE muscle, bone & joint health* in conjunction with the 'model of care' project team at St Vincent's Hospital, Melbourne.

The consultation involved interviews with 36 people previously diagnosed with hip and/or knee osteoarthritis. The study participants were recruited via various mechanisms employed by *MOVE*, as well as from specialist clinics at St Vincent's Hospital.

A series of questions and information was provided to each of the participants prior to a 20-30 minute phone interview. A thematic analysis of the data was undertaken to identify commonly emerging themes and key issues.

The results of the study indicated that the majority of participants considered the care and management for their osteoarthritis to be less than optimal. The study also showed that participants' satisfaction with their management and care was influenced by the following factors:

- comprehensiveness and timeliness of the assessment and diagnosis
- knowledge and approach of the health professionals with whom they interacted
- coordination of their care
- provision of comprehensive and relevant information
- appropriate pain management
- availability and accessibility of services, especially for physical activity and exercise

Participants were amenable to the consideration of different ways of accessing components of care as a way of reducing waiting times and improving access to health professionals.

This study has identified various issues that require consideration within the broader project, if the needs of Victorians with osteoarthritis are to be comprehensively addressed into the future.

1. Key Recommendations

From the results of the current consultation with people previously diagnosed with hip and/or knee osteoarthritis (OA), a model of care for OA should seek to ensure the:

- comprehensiveness and timeliness of a person's assessment and diagnosis
- knowledge and patient-centred care approach of health professionals
- coordination of a person's care between health professionals and other health service providers
- provision of comprehensive and relevant information in various formats
- appropriate pharmacological and non-pharmacological pain management
- availability and accessibility of services, especially for physical activity and exercise, and specifically in relation to cost and waiting times.

2. Introduction

This document constitutes the report on the consumer consultation component of the project to develop a model of care for Victorians with OA. The consumer consultation has been undertaken by *MOVE muscle, bone & joint health* in conjunction with the 'model of care' project team at St Vincent's Hospital, Melbourne. The project has been commissioned by the Victorian Department of Health and Human Services under the auspices of the Musculoskeletal Clinical Leadership Group.

3. Background

OA is a chronic disease that results in pain, varying degrees of functional limitation and reduced quality of life. About 2.1 million Australians are estimated to have osteoarthritis, making it the most common form of arthritis in Australia. Symptoms are relatively uncommon in people aged under 45, but more than 25 per cent of people 65 or older report some joint symptoms (Australian Commission for Safety and Quality in Healthcare, 2016).

A model of care is a guide that describes how health services and other resources should be delivered to consumers with a particular health condition. It is informed by the best research evidence for 'what works' and the local Victorian context and it describes *what* care should be provided and *how* it should be delivered. A model of care is not an operational plan or a clinical guideline, but a system-level pathway with supporting resources and recommendations for implementation.

The purpose of the project is to develop a model of care for OA in Victoria using a comprehensive consultative process, involving clinicians, researchers, policy makers and people diagnosed with OA. The model of care will describe how health services should be arranged and delivered in Victoria for consumers with hip and/or knee OA, reflecting the best available evidence and best practice. The model of care will consider a consumer's journey from the stage of diagnosis (usually in primary care) through to end stage disease, which may include surgical intervention such as total joint replacement. It is intended that the Victorian model of care reflect and integrate with the existing services and research centres in Victoria and existing Australian state and national models of care, as appropriate.

4. Aim of the consumer consultation

The aim of the consumer consultation was to gain the input of consumers in different geographic settings across Victoria and across the disease spectrum to explore current met and unmet needs related to OA care and resources. The consultation also aimed to gather consumers' views regarding some potential components of a future model of care.

5. Methods

5.1 Study Participants

The study aimed to recruit and interview 40 study participants diagnosed with OA of the hip and/or knee (or a carer for such a person). To gain a range of experiences and views, it was planned to recruit the following:

- Ten participants with recent diagnosis of osteoarthritis (3 months) or a carer for such a person
- Ten participants with early disease management (3-12months) or a carer for such a person
- Ten participants with stable disease management (>12 months) or a carer for such a person
- Ten participants with end stage disease management (severe pain/ready for surgery) or a carer for such a person

It was also intended that the study participants be sought from across regional and rural Victoria and metropolitan areas of Melbourne. Achieving a study group consisting of people of various ages, and of males and females, was also desirable. As the interviews were to be conducted only in English, an ability to read and understand English was a prerequisite.

5.2 Recruitment

Information about the study to encourage the voluntary participation of people was placed in a range of locations and distributed via the following means:

- Listing on *MOVE muscle, bone & joint* website
- Raised during *MOVE* HelpLine calls (with callers identifying as having OA)
- Listing on *MOVE* 'Facebook' page
- Listing in *MOVE* newsletter and e-newsletter
- Information flyers distributed at *MOVE* seminars in regional Victoria
- Emails sent to *MOVE* peer support groups and members
- Information flyers provided to relevant patients attending specialist clinics at St Vincent's Hospital, Melbourne

Potential participants responded voluntarily and either had already received sufficient information about the study or were provided with further information about the study prior to making a decision to participate.

5.3 Data collection

Once verbal consent was obtained, a suitable time was arranged with each participant to conduct the interview by phone. The duration of the phone interview was approximately 30 minutes.

A document containing information and a list of questions was provided via email or post to each participant prior to the interview. The questions aimed to gather participants' views and experiences in the diagnosis and management of their OA, as well as their views regarding some potential components of a future model of care. The questions were informed by the European 'Standards of Care for People with Osteoarthritis' developed by the European Musculoskeletal Conditions Surveillance and Information Network (eumusc.net) (2013).

The document containing the interview questions is included at Appendix One.

Relevant demographic data was obtained from each participant at the commencement of the interview and responses from the interviews were recorded and de-identified.

5.4 Data analysis

As the purpose of the study was to gather participants' experiences of their management and care and gain their views regarding potential components of a future model of care, a 'Grounded Theory' approach was utilised. This involved the identification of commonly emerging themes and key issues arising from the data that would be of relevance to the development of a model of care for OA.

5.5 Ethics approval

Approval for this study was provided by the St Vincent's Human Research Ethics Committee (Approval QA 027/16).

6. Results

6.1 Study participant overview

At the conclusion of the recruitment phase of the study, 56 people had expressed initial interest in participating in the study either directly or via staff at St Vincent's specialist clinics. Despite various attempts, six could not be contacted or did not respond to phone messages and another 11 people indicated that they were no longer interested or available to take part in the study due to time pressures or health reasons. Another three people, who initially expressed interest, did not have sufficient English language skills to participate in the interview. In the end, interviews were conducted with 36 eligible participants. None of those interviewed was a carer of a person with hip and/or knee OA.

As outlined in Table 1, the majority of the 36 participants were female (75%) and 50 per cent of the participants were aged between 61–70 years.

Table 1: Age and sex of study participants

	Number of Participants		
Age (in years)	Male	Female	TOTAL
41–50		1	1
51–60	4	4	8
61–70	3	15	18
71–80	2	6	8
81–90		1	1
TOTAL	9	27	36

Seventy-five per cent of the study participants lived in metropolitan Melbourne, 14 per cent in regional Victoria and 11 per cent in rural Victoria. This is fairly consistent with the spread of the general population. They had received information about the study from either *MOVE muscle, bone & joint health* or St Vincent's Hospital as listed in Table 2.

Table 2: Participant sources of study information

Organisation	
<i>MOVE muscle, bone & joint health</i>	23
St Vincent's Hospital	13
TOTAL	36

The number of study participants who had had a hip and/or knee replacement as compared to those who had no replacements was evenly spread with the likelihood of having a replacement being associated with the time since original diagnosis as outlined in Table 3.

Table 3: Study participants' history of hip and/or knee replacements

Time since diagnosis	Number of Participants			
	Hip and/or knee replaced	No hip and/or knee replacement	Waiting/scheduled for hip and/or knee replacement	Total
Last 12 months	1	4	1	6
2–4 years	1	5	1	7
5–9 years	4	5	1	10
10–15 years	5	3		8
16–20 years	3			3
25+ years	1		1	2
TOTAL	15	17	4	36

The age of the study participants and their history of hip and/or knee replacements are detailed in Table 4. The data are consistent with the prevalence of OA increasing with age (Arthritis and Osteoporosis Victoria, 2013).

Table 4: Age of study participants and their history of hip and/or knee replacements

Age (in years)	Number of Participants			
	Hip and/or knee replaced	No hip and/or knee replacement	Waiting/scheduled for hip and/or knee replacement	Total
41–50		1		1
51–60	4	3	1	8
61–70	7	11		18
71–80	4	2	2	8
81–90			1	1
TOTAL	15	17	4	36

The highest education levels of the participants and their current employment status are detailed in Tables 5 and 6 respectively.

Table 5: Highest education level achieved by the participants

	Number of Participants		
	Male	Female	TOTAL
Didn't complete secondary school	3	7	10
Completed secondary school	1	4	5
Certificate course Diploma Advanced diploma	3	3	6
Bachelor degree	1	6	7
Post-grad/Masters degree	1	6	7
Doctoral degree		1	1
TOTAL	9	27	36

Table 6: Participants' current employment status

	Number of Participants		
	Male	Female	TOTAL
Working part-time		4	
Working full-time	4	4	
Home duties		1	
Not working/retired for health reasons	1	2	
Unemployed		1	
Retired	4	15	
TOTAL	9	27	

6.2 Participant feedback regarding their care and the management of their condition

The first few questions in the interview aimed to gain participants' feedback in relation to the diagnosis and management of their OA and were as follows:

1) Guidelines on what care should be available for people with osteoarthritis are well established in Australia and in many countries worldwide. A summary is provided in the table below. Looking at the table, we will ask you the following questions:

a) Do you feel satisfied with the care you have received to date for your osteoarthritis?

Yes/no? Why?

b) Was there anything that you feel you were not offered, or you were unable to have, that

would have been appropriate for your care?

c) In your opinion, what were the reasons preventing you receiving the care you wanted or needed?

d) Can you comment on what things helped you to get the right care?

A person with osteoarthritis:

- is able to see and receive treatment from experienced health professionals (e.g. this may include doctor, physiotherapist, psychologist and dietician)
- is given accurate and easy-to-understand information about osteoarthritis and advice on how to live with and manage it.
- is given information about a healthy lifestyle and benefits of exercise and how to maximise their physical function.
- receives regular assessment of their osteoarthritis and how they are coping with their everyday life
- receives a plan outlining treatment and what they should expect.
- is given advice on how to control pain associated with their osteoarthritis
- is given information about pain relieving medication, its risk and benefits
- is given an exercise program specifically for their needs
- is able to attend local facilities to exercise safely
- receives information about weight reduction (if overweight)
- receives information and advice on aids and devices to assist their daily living
- is given information about joint replacement surgery, including its risks and benefits
- is able to see a surgeon without delay when/if required

(European Musculoskeletal Conditions Surveillance and Information Network (eumusc.net), 2013)

6.2.1 Satisfaction with care

The responses to the first question varied greatly with some people being satisfied with their care (n=13) and others being very dissatisfied (n=3). The most common response was the words, 'Yes and no' (n=20). As one person stated, 'Overall, I wouldn't say I'm dissatisfied, but it is easy to point out issues I have had.'

Summarising responses according to commonly recurring themes allowed the identification of key issues.

Health professionals

When commenting about the health professionals with whom they had interacted, participants referred to general practitioners, physiotherapists, rheumatologists and orthopaedic surgeons. A small number of participants were very satisfied with their health professionals, with one person commenting that they were 'helpful and knowledgeable' and another stating that she was very happy with her orthopaedic surgeon and rheumatologist as she is 'able to ring either of these specialists whenever I need and I am very happy with that.' Another person commented, '...with all the different people that I've seen, I feel that they have covered all angles that I can think of.'

The positive responses, however, were outnumbered by participants detailing negative experiences with their health professionals. Many participants were critical of the care they received from their general practitioners (GP) citing a lack of information and advice as a key concern. This was evidenced by statements such as the following:

'I wasn't offered anything else except for a referral to a surgeon. My GP could have offered more information but felt that she had done her bit and I was told to take Panadol Osteo.'

'Overall, I am very disappointed with my GP. I feel somewhat neglected and left in the dark. I don't feel that I was given adequate time by my doctor and attention for my condition. I felt rushed by my doctor and wasn't given the opportunity to ask questions, which was very disappointing.'

'On the whole, I think the local GPs aren't overly helpful, they seem to just want to write scripts; they don't take the time to talk to you, to explain things and to hear what you have to say.'

Another participant reported that she had found her contact with a surgeon unhelpful:

'I wasn't very happy with the surgeon I saw. He told me off for being overweight, which he could have said in a nicer and more professional manner; and he told me I had to walk for an hour each day, which I physically couldn't do at the time. He also suggested treatments, which I was unable to do and had previously been ruled out from doing.'

Another participant commented that she wasn't provided with options that she wanted or which suited her needs. Yet another stated that, 'when you see your rheumatologist, you have only 10 minutes to cover so much'. Contrary to this, another participant reported that her doctors asked her questions and listened to her point of view.

Timely diagnosis and management

The dissatisfaction of several participants was based on their missed or late diagnosis, which often resulted in a deterioration of their condition. One participant commented that her pain was not taken seriously enough and it wasn't given much attention and another stated that, during the 15 months that it took to diagnose her OA, 'I deteriorated a lot'.

Another participant cited the issue of a more holistic assessment not being undertaken at the time of her initial diagnosis by a rheumatologist of knee OA, given that she was found to have severe inflammatory OA many years later. This initial incorrect diagnosis had led to years of 'incorrect and inappropriate therapies' and 'wasting time and money on poor treatment'. Yet another participant reported that she couldn't 'get her knee done as they said she was too young' and that she 'ended up waiting for about 10 years'.

Coordination and integration of services

Several participants indicated that they were satisfied with coordination of their care between various health professionals, with one person stating that 'the combined medical effort of the physio and GP got me to the right specialist' and several others commenting that they were quite satisfied with the referrals they had received.

Conversely, another participant commented that, in his experience, there are not good links between hospital-based and community-based clinicians and services. Other participants felt strongly about the lack of coordination in their care:

'Information and communication exchange between the health professionals I saw was poor; they had no interaction and weren't all on the same page, which complicated things and made it difficult to know what to do and which path to take. I insisted that the doctor contact the osteopath because neither of them knew what to do next. The process took a very long time ... there was a lot of back and forth and it was tiring.'

'Having the right referrals at the right time again contributes to that integrated approach. Knowing who to see and being informed of these would be useful ... I've had to find them myself and many times you struggle to find the right person. Many times, it was by luck that I found the right health professional.'

Physical activity and exercise

The majority of participants indicated that they were either undertaking physical activity or exercise or were aware of the importance of exercise in the management of their condition. Many of them had seen a physiotherapist. Comments made by participants regarding their interactions with physiotherapists were positive, not only regarding treatment but also as a source of information.

'I took myself off to the physio and she has been helping me as there is a six-week wait to see the surgeon. All my information has come from the physio...'

Self-efficacy

As evident in the last quotation, one aspect that was a recurring theme in many participants' stories was the important role of self-efficacy in the management of their condition. This was evident in such statements as:

'I'm generally satisfied with the care, but I feel that it's arisen out of sheer determination on my part to get the care that I need and the information that I wanted.'

'When I took initiative and searched for help I received a response from my doctor, but he never took initiative as a health professional to help me.'

All forms of management were based on my own research; I wasn't given any advice on this.'

'Yes, I am satisfied with my care, mainly because I am not "backward in coming forward". I work hard at having a good relationship with my health professionals ... I have lots of questions as I do a lot of reading.'

Information

The above quotations also indicate the vital importance of information and this was another recurring theme arising from the interview data. Some participants were satisfied with the level of information they had received, but others felt they had not been provided with sufficient information. One participant commented that she was 'told what it was, but not

what to do'. Another commented that she felt sorry for people who aren't computer literate, as she wasn't offered anything else except for a referral to a surgeon.

Several people mentioned that they had gained information from Arthritis and Osteoporosis Victoria (now *MOVE muscle, bone & joint health*) with most being satisfied, but with one person making the following comment:

'I'm not entirely satisfied with the information put out by a group like Arthritis Victoria. I think their content is good, but the focus should be more on alternative physical activity methods to manage OA.'

Another person made reference to one of *MOVE's* peer support groups as her main source of information, although she didn't consider this as ideal:

'I have also been to the local OA club and I attend meetings with them to get information. They've been the main information source for me, I think. I would have liked more from the health professional I saw, though.'

Pain management

Several participants were instructed by their doctors to take 'Panadol Osteo' for their OA-associated pain, which some found satisfactory and others not. A couple of participants were prescribed 'Mobic', and one reported that she was given no information about its side-effects and was then diagnosed with stomach ulcers eight years later. Another participant stated that her doctor 'was inclined to fill me up on anti-inflammatories, which I don't like taking.' Several participants also commented that they were not provided with information about other ways of managing their pain, as indicated by the following statement:

'Basically, the only advice/information I have been given was to take more cortisone. I also saw a surgeon and he suggested going to a particular gym, but I couldn't afford it when I'm not working. Cortisone and morphine is my pain plan and that's all. Reading about cortisone and morphine, I'm concerned about becoming a drug addict.'

Availability and accessibility of services

The availability and accessibility of services was another evident issue in the interview data. This was specifically in relation to cost, location, waiting times and access to items such as the GP management plans listed on the Medicare Benefits Schedule.

Regarding the latter, one person had heard about GP management plans from her 'pensioner friends' but stated that 'my GP for some reason hasn't allowed me to have these or provided information about these to me.' Another person commented:

'I tried physiotherapy but you only get four visits from the government. Four isn't enough and it's too expensive.'

Another comment in relation to cost:

'I was also referred to a gym which was very helpful ... even the person at the gym was familiar with my condition. I went for 12 months and it really helped, but it became very expensive. Physio was good too, but that was too expensive after a while too.'

Several people from regional Victoria commented on the availability of services and the necessity to travel to obtain the services they need:

'I have chosen to attend the physio [at a metropolitan hospital] even though it's far, because the one here is very expensive and not as good.'

'I have been to a physio eight months ago and have been doing exercises I was taught from back then, but I had to travel a bit far to attend, so I don't go regularly.'

'It is difficult to get a second appointment with the rheumatologist as there are very few of them out here, so that's a pain ... but I can call them.'

Waiting times, especially for public hospital clinics, was mentioned by several people, with one person reporting that she had to wait for 18 months before she was seen. Another person commented:

'The waiting periods are too long and no-one follows up anything. I've been waiting for so long for things and no-one even lets you know what's going on or what stage you're at in the waiting process. Waiting 14 months whilst you're in agony, trying to get by on pain killers, is torture.'

People who had attended public hospital clinics (not only at St. Vincent's Hospital) were generally satisfied with the care they had received, often because their access to various health practitioners (rheumatologist, orthopaedic surgeon and physiotherapist) and appropriate facilities (hydrotherapy pool) in the one location.

6.2.2 Other care components that would have been appropriate and beneficial

This question aimed to further ascertain whether there were other aspects that people felt they were not offered, or were unable to have, that would have been appropriate for their care.

Participants raised the following issues:

Self-management support

One person from regional Victoria commented that self-management courses and resources are limited. She had previously undertaken a self-management course with Arthritis and Osteoporosis Victoria, but had to travel to Melbourne to attend. She commented that such programs should be offered more widely and frequently across regional areas, maybe through regional health centres.

Treatment plans

Another participant was prompted by the table accompanying the first set of questions and commented that she would have liked to have received a plan outlining treatment and what she should expect, advice on how to control pain associated with her OA, information about pain-relieving medication and an exercise program specifically for her needs.

Information about services

One participant commented that she would like to be given information about relevant services in her area (for example, community health centre programs) and what they offer, rather than having to always use her own initiative to find information.

6.2.3 Factors preventing receipt of the right care

Where participants had expressed dissatisfaction with aspects of their care, this question aimed to have them identify the reasons they perceived as preventing them from receiving the care they wanted or needed.

A couple of people identified their carer responsibilities preventing them from accessing the care they needed, but for other participants, the following issues were strongly expressed:

Location, availability and funding of services

One participant mentioned that many community-based exercise classes are only available during business hours and only cater for retired and elderly people, not working people. Another participant from regional Victoria suggested that location was a major issue and there was a need for 'funding for centres to run programs.'

Management by health professionals

A perceived lack of care by health professionals was cited by several people in response to this question.

'With some health professionals, there is a general lack of interest in OA ... they treat it as an inevitable part of ageing, so it makes it hard to receive the care you need and to get the right information.'

Another commented:

'I don't think I was really listened to initially, and even when I did see the specialist, the MRI didn't depict the pain and disability I was experiencing. The MRI showed what they deemed to be insignificant but I was in a lot of pain and my life was being impacted greatly but I felt they wouldn't listen to me because the MRI didn't support what I was saying. They don't take the time to hear the patient out. If the scans don't support it they rule it out but what the individual feels, and the impact their condition has on them can be so extreme even if the scans don't seem that bad, but they won't acknowledge it.'

Lack of good quality information

One participant cited reluctance by health professionals to discuss management issues in which she was interested:

'I think there is a blockage in the system with regards to information. For example, I am interested in information about stem cell treatments and I am finding it very hard to find a medical professional willing to take the time to give me this information and explain it all to me.'

Another commented that some of the information she had sourced was contradictory ('The book I read stated that no dairy should be eaten, but others told me I should eat dairy').

6.2.4 Factors assisting receipt of the right care

This question provided participants with the opportunity to identify the things that helped them to get the right care. The key issues that were identified in response to this question were:

Good health professionals

Many participants mentioned their GP and seeing a physiotherapist as key factors in response to this question. One participant identified the assistance from an occupational therapist as being highly important in helping them to get the right care.

Personal factors

Many participants cited their personal determination and initiative and using an insistent and assertive approach with health professionals as being the main factor in them getting the right care. Having a relevant professional background, doing lots of reading and having an increasing level of personal awareness and knowledge were also mentioned.

Good quality information

Having good quality information was cited by many participants as a key factor in helping them to get the right care. *MOVE muscle, bone & joint health* was mentioned by several participants as a source of good quality information.

Physical activity and exercise

In addition to many participants acknowledging the role of a physiotherapist in getting the right care, several participants specifically mentioned physical activity and exercise as being important in being able to reduce their use of pain medication.

Referrals to health professionals

Several participants mentioned that they were happy with the referrals they had received and cited this as a factor in them getting the right care.

Support from others

Talking with other people and having support from family and friends were also identified as assisting participants to obtain the right care.

6.3 What health professionals need to ensure people receive the right care

The second question addressed to participants was as follows:

The table below lists what health professionals need in order for you to receive the right care for your osteoarthritis.

Thinking about your interaction with your health professional/s, do you have any comments on the list of items below?

Health professionals should:

- Use questionnaires to help diagnose osteoarthritis and measure its impact on your life
- Have resources available to help refer you to the right health professionals at the right time
- Have information resources to give to you, available in different formats (e.g. pamphlets, online material) and in different languages
- Be educated about the latest research evidence for the management of osteoarthritis
- Have information about local health services and other health professionals who can help in the management of your osteoarthritis

All participants agreed that the components listed in the table accompanying question 2 were important with one person stating, 'You can put a circle around the whole lot!' and another stating, 'I would have thought this was the default.' Others commented that their care had included the components, such as the following:

'I found I've had all of the things in the table given to me, it's always been very good. I received up-to-date information, management options and remedies, and medicines. I've always been well informed I think. I also participated in a questionnaire for a university, which was quite extensive and I completed it yearly for a while. It covered all aspects of my condition, the physical, social and mental side.'

While some participants indicated that they had completed questionnaires in the course of their management, other participants suggested that the use of questionnaires would be good as 'it would make for a more integrated approach and would provide more of an accurate insight into the condition from the patient's perspective.' Another participant, however, commented that 'everyone is an individual and may not fit the questionnaire. Everyone experiences pain and other symptoms differently.' This was supported by another participant's comment that 'questionnaires are only aids and it still needs to be about the person holistically.' Yet another participant commented that a questionnaire 'asked if you experienced pain when walking upstairs' but she said that 'most people completing that question couldn't even walk upstairs and there was no room on the questionnaire to state this.'

The role of doctors, and specifically GPs, was considered to be vital by many participants. As one participant stated, 'it's important for them to be able to teach their patients what to do and they need to be the link to what is available out there.' Another participant suggested:

'Doctors and specialist are all very busy. For people with more than one major health challenge, they need a link person or a case worker to link the various doctors to the right person. There are groups, but if you're not well, you can't attend these, so there needs to be a "middle man" you can contact to get the help you need.'

A variation on this issue was provided with the comment, '...if we had one specialised GP in OA who we can go to, to access the right information, especially in rural areas, that would make our life a lot easier.'

All participants indicated the importance of referrals to other relevant health professionals and the coordination of care among them:

'I think the coordination of health professionals needs to be improved. It would be good for health professionals to share information; for example, if you're not referred to a physio by your doctor, then they won't receive a report from the physio. I think this is important.'

'Health professionals should be up-to-date with research and know about services, resources and other doctors or whatever, because if they can't help you, they should know someone who can.'

Another participant commented that 'doctors need to acknowledge that physios have a role to play' and that they needed 'a lot more education on conservative management.'

The availability of up-to-date information resources was a major issue cited by a large number of participants, with a strong emphasis placed on the importance of information about the availability of local services:

'There haven't been enough information resources available, at least not at the GP. The only information I've gotten is from Arthritis and Osteoporosis Victoria really, and in fact I lent those resources to my GP. Information needs to be more easily accessible, or at least we need to be guided to the right places to find it.'

'One thing I have found is that there is not one source like a directory to look to find information on resources such as all the hydrotherapy classes in the area. Maybe the local council could put out a one-stop directory of resources for people to be able to locate services near them.'

It was also suggested that an information resource with questions for a patient to ask their doctor would be helpful. Information in different languages was also considered important – as one participant said, 'I have 30 relatives who are aged and none of them speak English'.

Online information was also suggested with one participant stating, 'I've never been provided with online information which, in today's technology age, would be quite popular, I imagine.' Another participant commented that a person is unlikely to pick up a hardcopy information pamphlet if they are 'screen-focused'. Online or hardcopy information about how to do exercises correctly was raised by several participants as 'often you don't know what to do, how to do it, how often and the extent.'

6.4 Recommendations for government and local community resources

The third question in the interview was as follows:

The table below lists recommendations for government and indicates what local community resources should be in place for people with OA to receive the right care. Do you have any comments?

- There should be general public health information about osteoarthritis. This should include advice about prevention and management.
- There should be local health facilities (e.g. gyms, pools) available for the public
- Funding should be available so a person with osteoarthritis can see more than one health professional a number of times, if necessary, for the appropriate management of your condition

As one participant stated in response to this question, ‘...in an ideal world, I’d love all of the points in table three to happen, and there’s no reason why they shouldn’t.’ The two major issues about which many participants made specific comment, however, were increased funding and access to low cost, appropriate exercise.

One participant commented that ‘waiting is the big problem’ and that further funding may assist in addressing waiting times. Another commented that ‘it would be good to have more funds going to conservative management of OA.’ Several participants specifically mentioned the GP management plans and how it would be beneficial to extend the services and number of visits covered by these plans:

‘I know chronic health management only provides five visits in a year, which is often not quite enough. If you had five visits and you have to see a range of health professionals, for example, a podiatrist and a physio, you may use up three visits at the podiatrist and then you are only able to see the physio twice.’

‘There are care plans but that only includes five visits a year, which isn’t really enough so some financial support would be great. If the government could make it more of a priority and put more funding towards it, it would be better for all of us; it would even cut their costs down if they are able to get help to patients sooner and prevent them from getting worse.’

Another participant suggested that, with further funding, initial assessments and consultations could be more thorough:

‘There should be provisions in place to make sure that doctors have the time to listen to a patient, because now I get charged extra for a longer appointment. Patients should be able to sit down and have a thorough chat with their doctor about their issue, at least for this first appointment anyway ... maybe an introductory session system to discuss the issue in detail and then proceed with shorter consultations from then on. It would save money, and taking more time to talk to patients means that they will receive better

information which may mean better management, and therefore less need for hip replacements, or at least postponing these for longer.

Having access to pools, facilities and staff for exercise at a reasonable cost was mentioned by several participants:

'There are services available, such as gymnasiums, and they are marvellous, but the cost involved is a deterrent. Making it more affordable or having sessions where people can go for a couple weeks and learn how to do exercises so they can then continue this at home would be great and save money. I think funding would be great because, if you don't have the funds, you are unable to access the right care and then things get worse and it goes downhill from there.'

Access to appropriate exercise was also mentioned as, according to one participant, 'there is no point in sending you to someone who just wants to get you fit.' Several participants suggested appropriately tailored exercise classes involving:

'...health professional leaders, who are actually qualified to train people with specific conditions and are capable of tailoring the activity to them ... because now, none of the trainers really know what someone with a hip replacement, for example, can do, or should or shouldn't do.'

Another person was concerned about doctors being aware of people's progress with their exercise programs:

'There are local health facilities available, I attend a pool and gym and that's good. The only thing I can think of regarding this is that doctors may know about pools and gyms but they don't know how a patient is progressing when using these. Maybe some input or assessment from a GP or relevant health professional to measure progress would be good.'

In relation to general public health information about OA, several participants thought that this was important, especially for younger people and for people engaged in sport and physical occupations, which may potentially make them more prone to OA in the future. One participant commented that people should be made aware that obesity is a risk factor for OA and, as another participant stated, '...if we're informing people earlier on about prevention methods, then maybe it wouldn't progress to such a big issue later on.'

Another participant was sceptical about the notion of public health information, however, as 'general public health information is a bit bombarding. I think the information should be more targeted to relevant persons. If there's too much around in the community about health, people tend to switch off.' Instead this participant suggested that, for people with OA, 'there should be coordination of all the services available and information about it should be kept up-to-date, maybe as an online site where people can go to access information on services and on what's available.'

Finally, the location of services was identified as important with transport being mentioned by several participants. As one person from regional Victoria stated, ‘to travel to Melbourne often becomes expensive and we have a poor train service, which further adds to the issue.’

Another person suggested that:

‘There should be some sort of transport for people, and maybe a service to link people to practical transport, so people can get to appointments and get the right care. I know from my own experience that travel by train can be very difficult and not practical, especially if you’re travelling alone and have no one to help you.’

6.5 Improving the workings of the Victorian health system

The last question addressed to participants was as follows:

The table below lists some ideas to improve the workings of the Victorian health system. Do you have any comments?

- Re-thinking the roles of different health professionals. For example, initial tests and assessments for osteoarthritis might be undertaken by physiotherapists and nurses instead of a medical doctor.
- Supporting the use of new and different ways of delivering health services, e.g. via telephone or Internet services such as Skype.

While a couple of participants preferred to remain with the *status quo*, the majority of participants were generally very positive about the examples of delivering health services in different ways. Their enthusiasm was motivated by the possibility of improved access to health services, reducing waiting times and the pressure on GPs, as well as potentially receiving improved care:

‘I find sometimes, instead of having to clog up a doctor’s surgery for something that the nurses and physios can deal with, that would be an excellent idea.’

‘Too much is put on the doctor and they don’t necessarily do a good job of everything because there’s so much to do.’

‘It would be good to have physios and nurses involved in assessments and initial tests to share the workload and have more options for people to not be limited to just seeing a GP.’

Some participants preferred nurses and others physiotherapists, but all stated that nurses or physiotherapists should be suitably trained so that they are ‘specialised to deal with the conditions’ and so ‘they know their stuff.’

Again for reasons of improving access, the majority of participants were positive about the use of the phone or internet in connecting with health professionals and in receiving care. All

participants, however, did not see the use of these means as completely replacing face-to-face contact.

As one person stated:

'I think the use of all of that technology is possible where an examination is not required, so it should be a way to deliver treatment in the future, but not for examinations. I believe it is already being done to an extent. I guess it's dependent on the doctor, but yes, definitely more of that would be good.'

Other participants commented that the use of other technology would be best as a means of patients accessing advice, information and reassurance. As one participant stated, '...once you are discharged from rehab, you are really in the wind.' Other comments reinforced the benefit of being able to 'check in' when needed, without having to travel:

'As much as I'd like to resist, I think eventually it will happen ... there will be more demand for Skype and video-conferencing, which would be appropriate for certain health conditions ... maybe not for diagnosis, but for advice. I think for advice it would be good to just be able to phone the doctor and ask a question.'

'Someone on the end of a phone that you can ring when it is really out of control is really important.'

Some participants were concerned about modalities such as Skype and phone not being suitable for older people. As one participant, aged 73, stated:

'I work with a lot of elderly people and half of them wouldn't even know what Skype is or own a computer, so that's not appropriate. They need to go see their doctor. As for phone, I think that's better for younger people, older people might like that too; but from personal experience, older people like things demonstrated in front of them. So I think seeing a doctor in person is still the best option. So technology isn't the best option for older people.'

Providing another perspective on this issue, a participant in her eighties, stated, 'I'm a face-to-face person but I use my computer a lot. We have to get on board with technology, but it's important to talk with someone.'

Another participant also raised the issue of potential isolation without discounting the concept of doing things differently:

'There are risks associated with new and different ways, because people can be more isolated when they don't have to go out and physically see someone. I think it carries risks that need to be monitored carefully, but it does have a lot of potential for distributing information. However, it should not be used for everything ... maybe only as an information source.'

7. Discussion

The majority of participants in this study considered there was room for improvement in the care and management for their OA. Being diagnosed and living with an often painful, chronic health condition can be difficult enough, without also experiencing challenges from the system that should be helping them.

The frustration of many participants was obvious when asked the question about whether they were satisfied with their care. There was no discernible difference in the responses to this question based on gender or stage of disease, however, the 'tyranny of distance' and the location of services meant people from regional Victoria experienced more frustration than those in Melbourne.

Almost half the participants had not had a hip/knee replacement, but all participants had contact with a GP at the time of diagnosis. It appeared that this first point of contact was vital in influencing the quality of people's subsequent experiences.

The factors involved in determining whether this initial contact in the primary health setting was positive or not included the comprehensiveness and timeliness of the assessment and diagnosis, the knowledge and approach of the GP and the provision of information to enable an understanding of the condition and the approach to be taken to manage it.

Placing these results in a broader context, the European 'Standards of Care for People with Osteoarthritis' provide a useful benchmark. A recent systematic scoping review funded by *MOVE muscle, bone & joint health* examining the needs of consumers with musculoskeletal conditions, is also valuable.

The latter publication states that 'consumers desired high quality, accurate information with simple explanations of their condition, delivered in a supportive and non-judgemental fashion' (Wluka et al, 2016). The 'standards of care' document details various components of tailored information that should be provided, covering issues such as the importance of ideal body weight, support groups and patient organisations and aids and devices for environmental adaptations (European Musculoskeletal Conditions Surveillance and Information Network (eumusc.net), 2013).

While 13 participants in the current study were very satisfied with their overall care, the majority of participants did not receive consistent, comprehensive and high quality information from their health professionals. That one participant lent her information resources to her GP potentially indicates that, even where information resources exist, health professionals may not be aware of them. Ensuring that good quality consumer information is widely available will be an important aspect of an improved model of care.

It is also concerning that many participants had to rely on their own initiative and determination to find the information they required, given that many people may not have the necessary personal skills and resources to undertake this course of action. It was acknowledged by several participants, however, that workload pressures on GPs were an issue.

A key mechanism to ensure consumers are well informed about their diagnosis and treatment is a treatment plan. It was noteworthy that few study participants mentioned the words 'treatment plan' or 'plan'. This is not to say that some study participants may not have had treatment plans in place, although one participant did specifically state that it would have been helpful to have a treatment plan and another commented that she was told what her condition was, 'but not what to do.'

As identified in the systematic scoping review, many consumers 'felt that their general practitioner's lack of knowledge about their condition was a barrier to their information needs being met' (Wluka et al, 2016). This lack of knowledge has implications for another desirable standard of care regarding comprehensive assessment and diagnosis and 'people with symptoms of OA having access to a health professional competent in making a differential diagnosis' (eumusc.net, 2013).

While some participants in this study were satisfied with the process around their diagnosis, others reported dissatisfaction due to an incorrect or late diagnosis.

No participants indicated that the diagnostic and assessment process involved consideration of their function and ability to do their daily tasks and/or work. The importance of such a comprehensive diagnostic assessment covering these and other aspects is highlighted by three study participants indicating they were no longer working or had retired for health reasons.

The systematic scoping review by Wluka et al. examining the needs of consumers with musculoskeletal conditions found:

'Consumers perceived the main barriers to healthcare services to be cost, followed by access issues, related to waiting times for appointments and referrals, and the convenience of the healthcare provider's location. Compliance with allied health programs was identified as problematic due to lack of time, transport, cost and a variety of other factors.'

This finding was supported by the evidence arising from the current study with cost and waiting times, especially for surgery, clearly identified as barriers to seeking and obtaining care. The positive response of the majority of participants to the idea of using phones and the internet to have improved access to health professionals was principally seen as a means of reducing waiting times and gaining support, advice and further information at the time that it was needed.

The study also identified that general practice did not acknowledge the important role of allied health support in the management of some participants' OA, or at least could have been arranged and communicated better. It was also concerning that only one participant mentioned contact with an occupational therapist, given the impact of OA on people's activities of daily living.

Another of the European standards states that 'people with OA should achieve optimal pain control using pharmacological and non-pharmacological means.' however, this was not borne out by the evidence gathered in the current study. The skills and knowledge of

medical practitioners in best practice pharmacological and non-pharmacological management of persistent pain has been previously identified as an issue requiring attention in Victoria (Arthritis and Osteoporosis Victoria, 2014) and the experiences of the participants in this study confirm that pain management remains an issue of concern for people living with OA.

8. Limitations of the study

The scope, scale and timeframe of the study did not allow recruitment from a broader range of sources (for example, GP clinics or hospitals in regional/rural settings). The data gathered during the study provides a most useful snapshot of the key issues for people diagnosed with hip and/or knee OA, but would be further enhanced by a larger number of participants from a more diverse range of sources.

It would have also been preferable if more men had engaged with the study but the ratio of female-to-male participants (75% and 25% respectively) closely aligned to the prevalence figure of two-thirds of people with OA being female.

The interviews being only conducted in English restricted representation from culturally diverse groups. The involvement of such people may have identified another range of issues not represented by the current participant group.

Finally, the study would have benefited from the involvement of more people who were currently working (only 33%) to provide greater identification of the issues faced by this group when managing OA.

9. Conclusion

The rapid increase in osteoarthritis across the community requires a response. Prevention campaigns, addressing environmental factors and improved community knowledge may help curtail the growth in the prevalence of osteoarthritis. However, improved prevention will only slow the growth. Demographic and lifestyle factors indicate that more and more Victorians will be living with osteoarthritis into the future.

Currently, osteoarthritis cannot be cured, it can only be managed symptomatically. A best-practice osteoarthritis model of care will ensure that pain and disability, and economic and social costs, will be minimised.

The voice of people living with various stages of osteoarthritis is vital to ensure that the revised model of care is realistic, meets the needs of patients, their families and carers, and importantly, allows people living with osteoarthritis to get on with their lives.

This study shows that there is clearly room for improvement. Thus the project to revise the model of care is necessary and timely. Patients are ready for change.

10. References

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Development of a Model of Care for Victorians with Osteoarthritis

Introduction

A project is being undertaken in Victoria in 2016 to develop a Model of Care (MoC) for osteoarthritis. The project has been commissioned by the Victorian Government (Department of Health and Human Services). This information sheet provides a summary of the project and questions for consumers.

What is a Model of Care (MoC)?

A MoC is a guide that describes how health services and other resources should be delivered to consumers with a particular health condition. It describes *what* care should be provided and *how* it should be delivered, informed by the best research evidence for 'what works' and the local Victorian context.

What is the purpose of this project?

The purpose of this project is to develop a MoC for osteoarthritis in Victoria, with input from health professionals, people who live with osteoarthritis and their carers and the best research evidence. The MoC will describe how health services should be arranged and delivered in Victoria for consumers with hip and/or knee osteoarthritis. The MoC will consider a consumer's journey from the stage of diagnosis of osteoarthritis through to advanced stages of the condition, which may include surgery such as total joint replacement.

As a person with osteoarthritis, your experience and opinions related to your care are important in the development of the MoC. We will ask you to respond to the following information and questions when we arrange a time to speak to you over the phone.

1) Guidelines on what care should be available for people with osteoarthritis are well established in Australia and in many countries worldwide. A summary is provided in the table below. Looking at the table, we will ask you the following questions:

a) Do you feel satisfied with the care you have received to date for your osteoarthritis?

Yes/no? Why?

b) Was there anything that you feel you were not offered, or you were unable to have, that would have been appropriate for your care?

c) In your opinion, what were the reasons preventing you receiving the care you wanted or needed?

d) Can you comment on what things helped you to get the right care?

A person with osteoarthritis:

- is able to see and receive treatment from experienced health professionals (e.g. this may include doctor, physiotherapist, psychologist and dietician)
- is given accurate and easy-to-understand information about osteoarthritis and advice on how to live with and manage it.
- is given information about a healthy lifestyle and benefits of exercise and how to maximize their physical function.
- receives regular assessment of their osteoarthritis and how they are coping with their everyday life
- receives a plan outlining treatment and what they should expect.
- is given advice on how to control pain associated with their osteoarthritis
- is given information about pain relieving medication, its risk and benefits
- is given an exercise program specifically for their needs
- is able to attend local facilities to exercise safely
- receives information about weight reduction (if overweight)
- receives information and advice on aids and devices to assist their daily living
- is given information about joint replacement surgery, including its risks and benefits
- is able to see a surgeon without delay when/if required

2) The table below lists what health professionals need in order for you to receive the right care for your osteoarthritis.

Thinking about your interaction with your health professional/s, do you have any comments on the list of items below?

Health professionals should:

- Use questionnaires to help diagnose osteoarthritis and measure its impact on your life
- Have resources available to help refer you to the right health professionals at the right time
- Have information resources to give to you, available in different formats (e.g. pamphlets, online material) and in different languages
- Be educated about the latest research evidence for the management of osteoarthritis
- Have information about local health services and other health professionals who can help in the management of your osteoarthritis

3) The table below lists recommendations for government and indicates what local community resources should be in place for people with OA to receive the right care. Do you have any comments?

- There should be general public health information about osteoarthritis. This should include advice about prevention and management.
- There should be local health facilities (e.g. gyms, pools) available for the public
- Funding should be available so a person with osteoarthritis can see more than one health professional a number of times, if necessary, for the appropriate management of your condition

4) The table below lists some ideas to improve the workings of the Victorian health system. Do you have any comments?

- Re-thinking the roles of different health professionals. For example, initial tests and assessments for osteoarthritis might be undertaken by physiotherapists and nurses instead of a medical doctor.
- Supporting the use of new and different ways of delivering health services, e.g. via telephone or Internet services such as Skype.