

# **Moving Stories**



A qualitative study of people's experience of musculoskeletal services in Sheffield

**April 2015** 

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Objective: To discover patients' views of the current musculoskeletal services available in Sheffield, and how well the service they received matched their needs and wants.

#### **Key Findings**

- The majority of people do not feel they have to wait too long to access services.
- While most people we spoke to did receive information on self management and pain control, most of those didn't think there was enough.
- Most people knew where to go and who to speak to in some circumstances, but not all. A worrying 32% of people reported not knowing what to do if they needed urgent help with their condition.
- 72% of people who accessed an MSK service in primary care and 80% who saw a MSK specialist told us they received no information or support on the emotional impact of their condition.
- Patient journeys highlighted specific individual barriers to people feeling better, many of which would have been simple to resolve if identified at the time.

#### **Recommendations**

- People with a diagnosed MSK condition are offered a named person within their practice or a community organisation who they know they can contact about self management.
- To look into whether all people with an MSK condition could be provided with a small, credit card sized card detailing emergency contacts and other sources of information and advice.
- MSK Sheffield to commission the production of an advice leaflet on the emotional aspect of having an MSK condition, including Easy Read and translated versions. This should be freely available at all points where patients use the service, and should include a mixture of information, advice and contacts people can use to speak to someone about their condition.
- MSK Sheffield should work on longer term tracking of outcomes for patients including their emotional wellbeing.
- Further work needs to be done on establishing exactly when and in what format
  patients are most happy to receive information about their condition and potential
  treatment options. Patients' perceived lack of information (whether real or
  unfounded) has an impact on how involved they feel with their treatment and the
  emotional aspect of it.



#### Introduction

#### What is a Musculoskeletal condition?

Musculoskeletal (MSK) conditions affect the muscles, bones, ligaments and tendons. They include common conditions such as back pain, osteoarthritis, shoulder pain and broken bones, and less common ones such as Rheumatoid Arthritis and Polymyalgia Rheumatica. Many people will have a musculoskeletal condition in their lifetime. In 2013/14, 8.3 million working days were lost to a MSK condition in the UK.

"The total population over 45 of Sheffield is 214,064 out of which 23,310 have hip osteoarthritis. There are some significant risk factors in relation to musculoskeletal conditions, the most significant of which are obesity and physical activity. In Sheffield the level of obesity is 24.93% and the national average is 23.11%. 53,366 of people in Sheffield are sedentary [do not do any physical activity]. If more people in your area are less physically active and more likely to be obese, this may be a cause of higher rates of hip osteoarthritis."

Taken from Arthritis Research UK Musculoskeletal Calculator <a href="http://www.arthritisresearchuk.org/arthritis-information/data-and-statistics/musculoskeletal-calculator/map.aspx">http://www.arthritisresearchuk.org/arthritis-information/data-and-statistics/musculoskeletal-calculator/map.aspx</a>

Older people are more likely to have a MSK condition, which can also lead to other issues such as severely restricted mobility which can bring in other factors such as social isolation and depression.

#### What are Musculoskeletal services?

As there are a wide range of conditions in this group, there are a wide range of treatments. People with a MSK condition may manage their own condition, or may only ever see their GP. Others may be referred to an Allied Health Professional (AHP) such as a physiotherapist, or see a specialist hospital team such as rheumatologists or orthopaedics.

The way that people experience care for a MSK condition in Sheffield is changing. Sheffield CCG are commissioning an integrated system, which should mean that everyone treating a person with a MSK condition can work better together, and that from the patient's point of view they should have more information, more options, and generally speaking, a better experience of their care. With this in mind, Healthwatch Sheffield set out to capture people's experiences of MSK treatment before these changes were implemented, so that it would be possible to use this information as a snapshot of the services in April 2015, before changes, and we can then see how things may differ from this in the future.



#### What did we do?

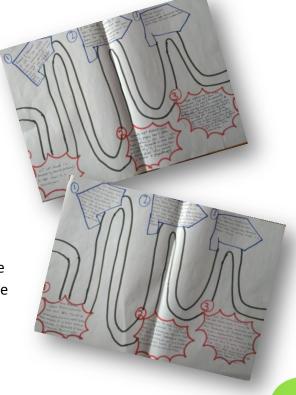
Our work took into account a report into MSK carried out by Sheffield CCG and published in November 2014. (See Appendix A for weblink). Sheffield CCG spoke to over 100 stakeholders at an engagement event, and captured 213 surveys and 23 patient journeys. There were a number of themes that came out of this report, around managing your own condition, being offered appropriate choices, the emotional impact of your condition, receiving the right information and advice and controlling pain. We decided to base the things we asked people on these areas, and focus on getting to the bottom of those issues and what they really meant to people, and what worked for them.



We designed a four page (A3, folded, double sided, see Appendix B) set of questions based on the previous findings of Sheffield CCG. Additionally, we produced an easy read version of the questions with pictures and limited language. (see Appendix C) We distributed these questions through our membership, our Virtual Advisory Network, and through other informal routes citywide. We received a total of 112 responses to the first survey, and one easy read response.

#### Who did we speak to?

We also invited interested people to a MSK discussion forum which was held at South Yorkshire Fire and Rescue, Eyre Street on Wednesday 15<sup>th</sup> April 2015. By the time we held this event we had been able to produce an initial set of findings from the surveys, so we used this event to really understand people's journeys through the system, where their barriers were, and to talk about the areas that would become our key findings. 15 people attended this forum. We asked these 15 people to complete patient journey sheets for us, detailing the barriers to improved health and the ways these could have been overcome.





These people have agreed to let us revisit their journey in six months time to see how things have changed for them.

#### What did people tell us?

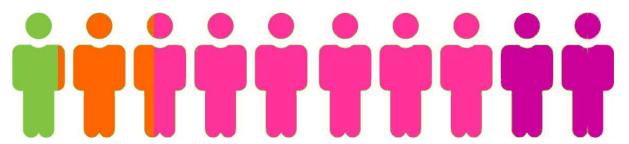
We asked a total of 33 questions in our initial survey. These are reported below by theme.

#### **Waiting Times**

People told us that they generally didn't consult the GP about a MSK condition immediately, and that the majority (76%) had either waited longer than 6 weeks before going to see their GP, or couldn't remember how long it had been before they went.

Once they had received a referral to another service, they were generally seen by the next service promptly, with 60% of people receiving an appointment within 6 weeks.

Responses to Question: How long did you have this problem before you consulted your GP?



Less than 2 weeks

2-6 weeks

More than 6 weeks

I don't recall

#### **Self Management**

Just over half of the people we spoke to (54%) told us that they did get information from their GP on how to manage their condition themselves, but of these, just over half (52%) didn't think it was enough. Many of the people we spoke to told us that they do successfully self manage, though others struggled to control their condition.

"I treat the condition with respect and act accordingly."

"You cannot rely on just medications you also have a responsibility to help yourself. Keeping moving is the best thing you can do for yourself. Positive thinking is vital."



"You need to provide yourself with the tools and information to self care and be able to speak to professionals to ensure the best quality care for you."

People told us that physiotherapy was an excellent way of getting support, but one person commented that they found it harder to follow online exercises, and preferred to be shown what to do. Several people recommended Tai Chi as an alternative to physiotherapy. Others told us that having a single, supportive GP was a great help, and that one of the drawbacks to self management was having to see multiple GPs and having to explain your condition each time.

"Different GPs don't work for me, I find it better to see the same one each time."

"I value my supportive GP. They are clear on what I can and can't do."

#### **RECOMMENDATION**

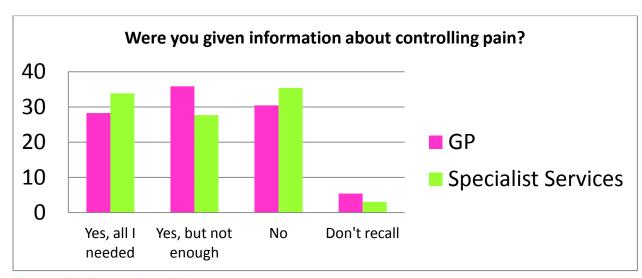
People with a diagnosed MSK condition are offered a named person within their practice or a community organisation who they know they can contact about self management.

#### **Pain Control**

For the majority of people with a MSK condition, pain control was one of the most important issues.

"I would love to be taken seriously when I tell a GP that I am in pain."

Similarly to the information received about self management, the majority of people did receive information about pain control (64%) but more than half of these (56%) did not feel that it was enough information.





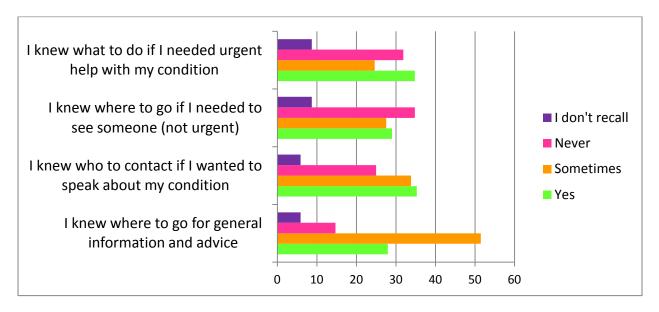
When asked about pain control, most people relied upon self management through exercise and over the counter medication. One person commented that they found conflicting information about pain (i.e. when to rest and when to exercise) confusing.

#### Who do I speak to?

We asked people to tell us if they knew where to go in particular situations. Did they know where to go for general information on their condition? Did they know who they needed to speak to between appointments or in an emergency?

"I find it difficult to get through to the department I need to speak to. On several occasions I have had to leave a letter at reception which in itself causes problems as I have to rely on Care Assistants."

#### Responses to Questions 19 to 22 – I knew where to go when...



Worryingly, just over 30% of respondents reported never knowing where they should go if they needed urgent help with their condition. More than a third of people also reported never knowing what to do if they needed to see someone before their next scheduled appointment (but not urgently). Clearly there was some confusion in the people we spoke to around where to go and who to contact. We propose a simple solution.

#### **RECOMMENDATION**

To look into whether all people with an MSK condition could be provided with a small, credit card sized card detailing emergency contacts and other sources of information and advice.



#### Personal Choice and treatment of the person rather than the condition

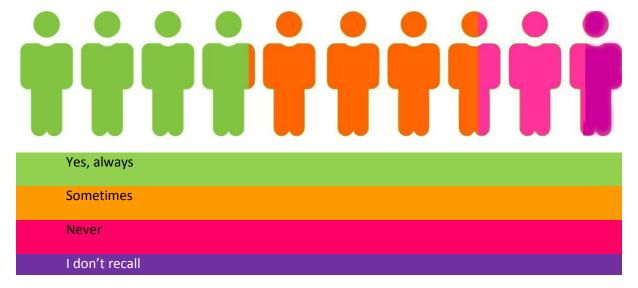
Several people told us that they felt they were not always treated as a person.

"The doc referred me to the physio. But the condition was never really explained."

"Not enough choice or information. I felt exasperated with the rushed 2 x 15 minute slots that I had."

We asked people if they felt that their personal choices had been fully taken into account.

#### Responses to Question 28: My personal choices were fully taken into account



While it is clear that the majority of people (76%) did feel that their choices were always or sometimes taken into account, it is notable that 16% did not ever feel that this was the case.

We also asked if they felt they had been treated as an individual, rather than as a condition.

#### Responses to Question 29: I have been treated as an individual, rather than a condition



Yes, always

Sometimes

Never

I don't recall



More people (81%) felt that they had been treated as an individual rather than that their choices had been respected. This may indicate a lack of explanation or information provided about procedures and why they were appropriate (or indeed, why other avenues may not be). Several people told us they didn't understand why they hadn't been referred for particular types of treatment.

"I have never been referred for further investigation. I would like to know what the cause of my problem really is. If this was the case maybe some specialist treatment targeting the problem would be beneficial instead of just taking drugs and getting on with it."

"I was never given a diagnosis, x-ray or anything. I was told I had some abnormality in your neck and spine which did not warrant further investigation apparently."

#### RECOMMENDATION

Further work needs to be done on establishing exactly when and in what format patients are most happy to receive information about their condition and potential treatment options. Patients' perceived lack of information (whether real or unfounded) has an impact on how involved they feel with their treatment and the emotional aspect of it.

#### The emotional impact of a MSK condition

We received a lot of responses to our survey and at our focus group that led us to believe that MSK conditions caused a significant amount of emotional stress, upset and depression.

"The effect on your personal relationships – it causes guilt on your part because you're dependant."

"I get really depressed."

"I would like acknowledgement of how upset I get about my condition. Sometimes I feel very helpless and despairing."

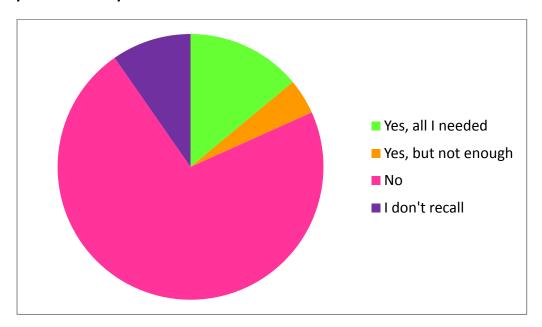
"It's affecting my mental health."

"I feel as if until it's resolved any job opportunities, full social life or companionship aren't possible."

With this in mind, we asked people if they received sufficient information or support on the emotional impact of their condition. We found that on the whole, they didn't.

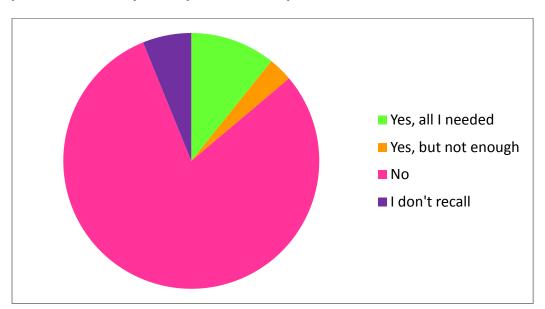


## Were you given information or support by your GP about how your condition may affect you emotionally?



72% of people who answered this question told us they received no information or support on this issue from their GP at all.

## Were you given information or support by the service you were referred on to about how your condition may affect you emotionally?



This figure rose to 80% when people were seen by a specialist within the MSK service.

At our focus groups, people shared their experience of not feeling supported with the emotional side of their condition, speaking often of having to 'keep a stiff upper lip' and 'just get on with it.'



"You sometimes have to try and keep active even though you are in pain, and keep going. The downside is that the GP or hospital think you're ok or fine, when you're not."

It is clear to us that there are two issues that need addressing. Firstly there is a lack of information given on the emotional impact of an MSK condition. Secondly there are people who live with feelings of worthlessness, depression and anxiety and who either do not discuss it with their GP because they don't want to bother them, or 'put a brave face on it' because they don't want to be a burden to others who they feel are doing enough through caring for them. While the first is more straightforward, developing understanding about emotional responses to having an MSK condition and the potential impact on mental health of living with an ongoing MSK condition may take time.

#### RECOMMENDATION

MSK Sheffield to commission the production of an advice leaflet on the emotional aspect of having an MSK condition, including Easy Read and translated versions. This should be freely available at all points where patients use the service, and should include a mixture of information, advice and contacts people can use to speak to someone about their condition.

### Patient Journeys - What people told us

A total of 15 people completed their patient journey. We felt it was worth sharing two of these as they highlight some of the simple ways in which the MSK journey could be made much better for the patient.

#### Patient 1

This person told us that they had been for a CAT scan and X-ray for their condition. When they asked the person treating them if they could see the x-ray they were told that there was no point as it was too complex and they wouldn't understand what they were seeing. The person felt that even if this was the case, which they didn't agree with, being able to see the scan would have helped them to come to terms with their condition sooner, and helped them to adjust to their new diagnosis.

#### Patient 2

This person told us that their GP was limited by the referral pathways available to them, and as a result they were referred to a physiotherapy service which the patient knew would not help as they had already had prolonged physiotherapy. After this was proven to be the case,



the physiotherapist was able to refer to a neurologist. The patient felt that if their GP had been able to do this in the first place, their condition may not have taken so long to resolve.

While capturing patient journeys we noted a number of themes which had arisen as barriers for the people present. These were; inappropriate referrals, not being able to self-refer, being given the wrong tests, not being given the right information, and waiting times both to see a specialist or for tests. As all of these people are actively receiving treatment for their conditions, this offers us the opportunity to revisit them in six or twelve months and check what has changed following the start of the new service.

#### **RECOMMENDATION**

MSK Sheffield should work on longer term tracking of outcomes for patients including their emotional wellbeing.

#### **Thanks**

We would like to thank Sheffield CCG for asking us to take a snapshot of people's experience of MSK services. Thanks are also due to our volunteers Pam Enderby, Tony Whiting and Maggie Campbell who have worked on the early stages of this project.

Most importantly, thanks to the people of Sheffield who responded to our survey, came to our focus group and told us about their experiences. Your views matter, and we hope we have represented them fairly.



#### Appendix A

#### Sheffield CCG Moving Together Report:

http://www.sheffieldccq.nhs.uk/Downloads/MSK/MSK%20Services%20Engagement%20Report%20and%20Appendices%20A-F.pdf

Appendix B



Musculoskeletal Survey 2015

Do you have a **Musculoskeletal Disorder?** Have you received the right help to get better or manage your condition?

A Musculoskeletal Disorder is a problem affecting the human body's movement (or musculoskeletal) system (i.e. muscles, tendons, ligaments, nerves, discs etc). It is most commonly experienced as pain, stiffness and/or difficulty with movement or completing everyday tasks.

Please answer this questionnaire if you currently have a Musculoskeletal Disorder, or have had one in the last 6 months so we can help to change services for the better.

Please answer all the questions that are relevant to you, by circling one choice.

Thinking about the time before you consulted your GP...

Q1 How long did you have this problem before you consulted your GP?

Less than 2 weeks 2-6 weeks More than 6 weeks

Don't recall

Thinking about when you consulted your GP...



Q2 How many times did you consult your GP before being referred to another service? Once 2-3 times 4 or more times Don't recall Q3 Were you given information by your GP about recommended treatment? Yes, all I needed Yes, but not enough Don't recall No Q4 Were you given information by your GP about managing your condition yourself? Don't recall Yes, all I needed Yes, but not enough No Q5 Were you given information by your GP about controlling pain? Yes. all I needed *Yes, but not enough* Don't recall No Q6 Were you given information or support by your GP about how your condition may affect you emotionally? Don't recall Yes, all I needed Yes, but not enough No Q7 Were you given information by your GP about how your follow on appointment would be arranged? Yes, all I needed Yes, but not enough No Don't recall Q8 Were you given information by your GP about who you would see at your follow on appointment? Don't recall Yes, all I needed *Yes, but not enough* No

Thinking about after your GP had referred you on to the Musculoskeletal (MSK) service...

Q9 How long did you wait between being referred to the MSK service and being contacted by them?

Less than 2 weeks 2-6 weeks more than 6 weeks Don't recall

Q10How long was the wait between your GP's referral and your first MSK appointment?

Less than 2 weeks 2-6 weeks more than 6 weeks Don't recall

Thinking about when you attended the MSK service...



Q11 Were you given information about the recommended treatment?

Yes, all I needed Yes, but not enough No Don't recall

Q12 Were you given information about managing your condition yourself?

Yes, all I needed Yes, but not enough No Don't recall

Q13 Were you given information about controlling pain?

Yes, all I needed Yes, but not enough No Don't recall

Q14 Were you given information about how your condition may affect you emotionally?

Yes, all I needed Yes, but not enough No Don't recall

Q15 Were you given information how your next appointment would be arranged?

Yes, all I needed Yes, but not enough No Don't recall

Q16 Were you given information about who you would see at your next appointment?

Yes, all I needed Yes, but not enough No Don't recall

Q17a Thinking about questions <u>11 to 16</u> – do you think you were given the right amount of choice?

Yes, all I needed Yes, but not enough No Don't recall

Q17b Do you have anything to add about information and choice?

#### Thinking about the times between MSK appointments would you say...

Q18 I knew where to go for general information or advice

Yes, always Sometimes Never Don't recall

Q19 I knew who to contact if I wanted to speak to someone about my condition

Yes, always Sometimes Never Don't recall

Q20 I knew what to do if I needed to see someone before my next appointment (but not urgently)



Yes, always	Sometimes	Never	Don't recall		
Q21 I knew what to do if I needed urgent help with my condition					
Yes, always	Sometimes	Never	Don't recall		

### Thinking about the past 6 months please tell us about how you have felt...

F1	It has been easy to balance my day to day life and my condition				
	Yes, always	Sometimes	Never	Don't recall	
F2	F2 I have had to change my day to day life because of my condition				
	Yes, always	Sometimes	Never	Don't recall	
F3	F3 I have had to change my day to day life because of <u>treatment</u> for my condition				
	Yes, always	Sometimes	Never	Don't recall	
F4	F4 My treatment needs were considered				
	Yes, always	Sometimes	Never	Don't recall	
F5	F5 My treatment choices were respected				
	Yes, always	Sometimes	Never	Don't recall	
F6	F6 My personal choices were fully taken into account				
	Yes, always	Sometimes	Never	Don't recall	
F7	7 I have been treated as an individual, rather than as a condition				
	Yes, always	Sometimes	Never	Don't recall	

### Thinking about the people who have helped you over the past 6 months...

Who has helped to make a difference to your condition? (please circle as many as you like)			
Me	A friend or relative	My GP	A specialist at the hospital
Someone who treats me in the community		A g	roup I attend
Other: (please write)			



Please put an 'x' next to the one that has made the MOST difference to your condition.

Thinking generally about your condition...

How has having this condition impacted on your life and how has any treatment affected this?			

Is there anything else you would like to tell us about your condition, its treatment or you?

Thank you for your time. If you would like any further information or would like to tell us anything else, please call 0114 2536688 or email info@healthwatchsheffield.co.uk

Appendix C



Musculoskeletal Survey 2015

THESE QUESTIONS ARE ABOUT YOUR DOCTOR, AND IF YOU HAVE BEEN TO SEE THEM ABOUT YOUR BONES, MUSCLES OR JOINTS.
PLEASE PUT A CIRCLE ROUND THE RIGHT ANSWER.



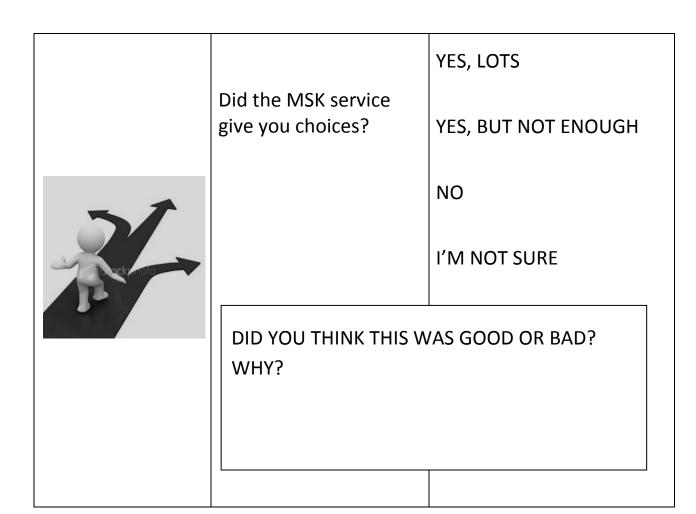
	·	
	Have you seen your doctor about your bones, muscles or joints in the last 6 months?	YES NO  IF YOU SAID 'NO', YOU DON'T NEED TO ANSWER ANY MORE QUESTIONS.
	How many times did you go to your doctor before they sent you to see someone else?	1 2 3 4 MORE THAN 4 I NEVER WENT TO SEE ANYONE ELSE
	Did your doctor give you enough information about how your condition might make you feel?	YES, LOTS YES, BUT NOT ENOUGH NO I'M NOT SURE
0000000	Did your doctor give you enough information about where you would go and who you would see next?	YES, LOTS YES, BUT NOT ENOUGH NO I'M NOT SURE



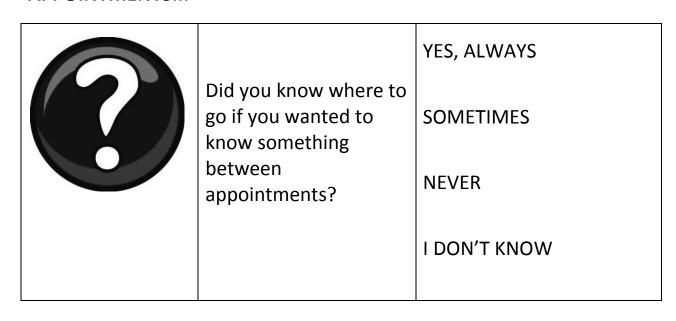
# THESE QUESTIONS ARE ABOUT THE MSK SERVICE. THIS STANDS FOR MUSCULOSKELETAL SERVICE, AND THIS IS THE SERVICE YOUR DOCTOR SENT YOU TO SEE...

Description	How long was the wait between seeing your doctor and seeing the MSK service?	LESS THAN 2 WEEKS  2 TO 6 WEEKS  MORE THAN 6 WEEKS  I'M NOT SURE
	Did the MSK service give you information?	YES, LOTS  YES, BUT NOT ENOUGH  NO  I'M NOT SURE
	DID YOU THINK THIS WAS GOOD OR BAD? WHY?	





# THESE QUESTIONS ARE ABOUT THE TIMES BETWEEN APPOINTMENTS...







Did you know where to go if you needed help in a hurry because it was urgent? YES, ALWAYS

**SOMETIMES** 

**NEVER** 

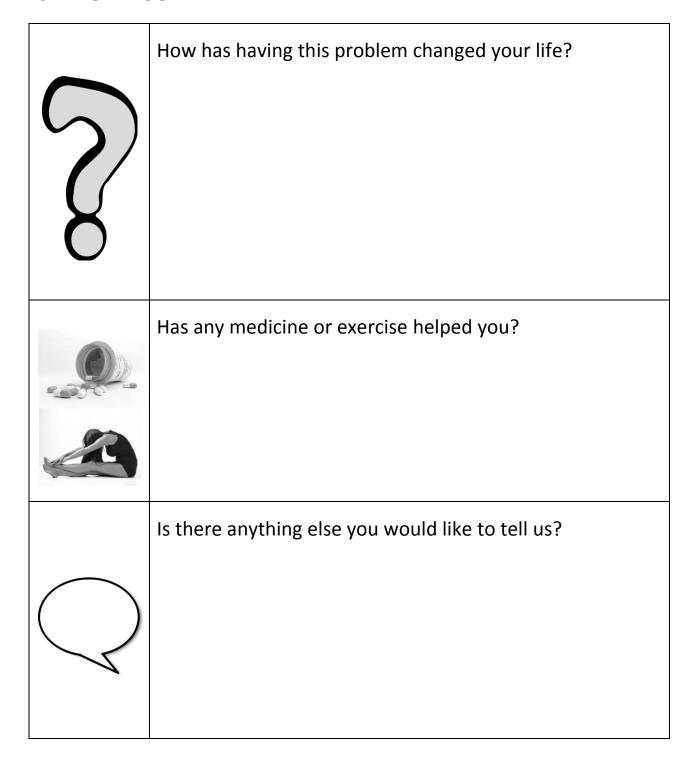
I DON'T KNOW

# THESE QUESTIONS ARE ABOUT THE PEOPLE WHO HAVE HELPED YOU...

		ME
	Who has helped you with your illness? (you can circle as many as	MY FRIEND
	you like)	MY FAMILY
allo		MY DOCTOR
		THE HOSPITAL
		A GROUP I GO TO
		SOMEONE ELSE
Ter	Please write in the next box which one has helped you the most.	



# THESE QUESTIONS ARE ABOUT YOUR ILLNESS AND HOW IT HAS CHANGED YOUR LIFE...





Thank you for your time.

#### Please post your survey to:

HEALTHWATCH SHEFFIELD, THE CIRCLE, 33 ROCKINGHAM LANE, SHEFFIELD, S4 1FW

If you would like to know anything else about Healthwatch, or you have something to tell us, please telephone us (0114) 2536688 or email us info@healthwatchsheffield.co.uk

