



Chronic pain service redesign

Engagement dates: July - October 2014

Patient feedback report **FINAL**

Nov 2014



Leeds Community Healthcare 
NHS Trust

SpineFit

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more than 12 months?



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Published Nov 2014

Acknowledgements

NHS Leeds West Clinical Commissioning Group would like to thank all the patients, carers and members of the public who took the time to share their thoughts on this proposal.

We would also like to thank Leeds Involving People for their engagement work and staff at the chronic pain services in Leeds for allowing us to spend time in their services.

Executive summary

Everyone suffers from pain now and again, it is a normal sensation that tells us that we might have an injury. Chronic pain is very different. Chronic pain is defined as pain that lasts for more than 12 weeks. It can have a devastating impact on people's physical and mental health. Chronic pain often cannot be cured, but it can be managed effectively.

Evidence tells us that the level and impact of people's pain improves when they are supported to understand and manage their condition. These changes to chronic pain services in Leeds will move to a more evidence based model of supported self-management, where patients are more involved in their own care.

This engagement seeks the views of patients, their carers and the wider public around the proposed changes. This will help us understand what people think of current pain services and help us make sure that the new services meet the needs of patients and their carers. This report outlines the findings of the engagement

A survey was used to gather the thoughts and experiences of patients, carers and the wider public. We also used focus groups to understand the needs of people with chronic pain. We asked about patient satisfaction with the current service and for people's needs and preferences around supported self-management. The survey was shared widely, including with:

- Chronic pain patients in community and hospital settings;
- Carers using local voluntary services;
- CCG patient, public and voluntary sector networks; and
- GP practices in Leeds.

301 patients, carers and members of the public responded to the survey. Patients told us that there are currently a number of different people involved in their care. They receive a variety of different interventions to manage their pain. The majority of patients are prescribed pain medication and few people are referred onto peer support or psychological therapy. Many of the patients not currently involved in their care planning and are unclear about how successful their interventions are.

67% of people were supportive of the redesign and 7% disagreed, however a significant number (26%) did not feel they had enough information to make a decision. People welcomed the opportunity to get more involved in their care and some people thought that GP involvement would provide more convenient and consistent care. Some people were concerned that GPs do not have the skills and knowledge to manage chronic pain patients, while others felt that GPs were ideally positioned to care for these patients.

This report makes a series of recommendations to the project team who will use the findings of the engagement to redesign chronic pain services in Leeds.

A regular briefing will be produced once the project has begun, to show to what extent the engagement recommendations have been implemented. This will be shared with people involved in the engagement and added to the website

The patient feedback will also be used to inform a wider strategy for enhancing communication, access and the quality of services.

This report will be shared with those involved in the engagement and will also be available on the NHS Leeds West CCG website.

Background information

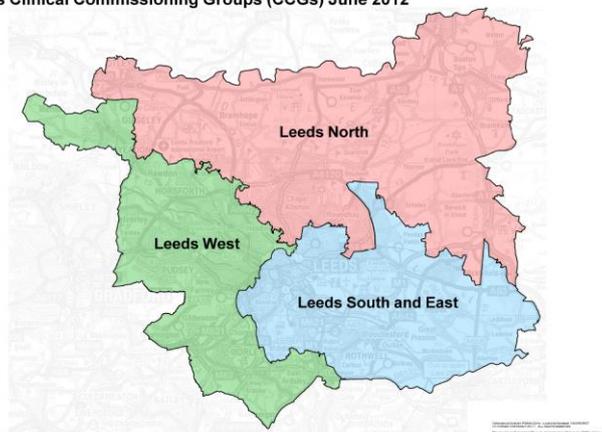
a. Clinical Commissioning Groups in Leeds

There are three clinical commissioning groups (CCGs) in Leeds; NHS Leeds West CCG, NHS Leeds North CCG and NHS Leeds South and East CCG. These organisations are responsible for planning and buying (commissioning) local healthcare services.

The CCG is very different from previous NHS organisations. For the first time, healthcare services will be commissioned by organisations that are led by locally based doctors and nurses, supported by experienced managers.

This means we can have a real, detailed understanding of the health and social care issues there are in our neighbourhoods, and a genuine opportunity to shape health services at a much more local level as well as across the city of Leeds.

Leeds Clinical Commissioning Groups (CCGs) June 2012



The CCGs are made up of 114 GP practices, covering a population of around 800,000 people. Our population extends from some of the most affluent neighbourhoods of Leeds to some of the most deprived. When working on citywide projects, we work together to ensure that we meet the needs of people across the city.

Involving people and the public in developing and evaluating health services is essential if we want to have excellent services that meet local people's needs. It is our responsibility, and one that we take very seriously, to ensure that our local communities have the opportunity to be fully engaged in the decisions we take.

b. Leeds Involving People (LIP)

Leeds Involving People is a voluntary organisation that represents the independent voice of people through the promotion of effective involvement. The organisation involves the community in the development of health and social care services by ensuring their opinions and concerns are at the centre of decision making processes. Due to the scale of the project we commissioned LIP to support this engagement.

c. Chronic pain

Chronic pain is defined as any long term, persistent pain that has lasted for longer than six months. In Leeds over 3500 people with chronic pain are managed by hospital and community services. Many more people are managed by their GP in primary care.

The service in Leeds is aiming to move away from an interventional model into a more appropriate and evidence based model of supported self-management. This is because the nature of chronic pain is that it cannot be successfully cured through interventional treatment. However, by better informing, empowering and supporting patients, they can better determine their own goals, priorities and treatment strategies, and could significantly improve their management of their condition and quality of life.

Cancer is commissioned separately and as such is not included in this service change.

This engagement seeks to understand the views of patients and relatives in regard to the existing and proposed new service.

2. How did we identify and engage with patients?

We developed an Equality Impact Assessment (EIA) to identify the effect, or likely effect the proposal could have on people with protected characteristics. We used the EIA to develop our engagement plan. The EIA is available on request, please use the contact details at the end of this document.

An engagement plan (available on request - please use the contact details at the end of this document) was developed by patients, clinicians and commissioners to ensure that the right people are consulted in the right ways. The plan was taken to the NHS Leeds West Clinical Commissioning Group Patient Assurance Group (PAG). This group is made up of patients and assures the CCG's Governing Body that adequate patient involvement has taken place during consultations and engagement. Patients from the PAGs at the other CCGs were also invited to this meeting. The PAG members at the meeting agreed that the patient groups and engagement methods outlined in the plan were generally appropriate.

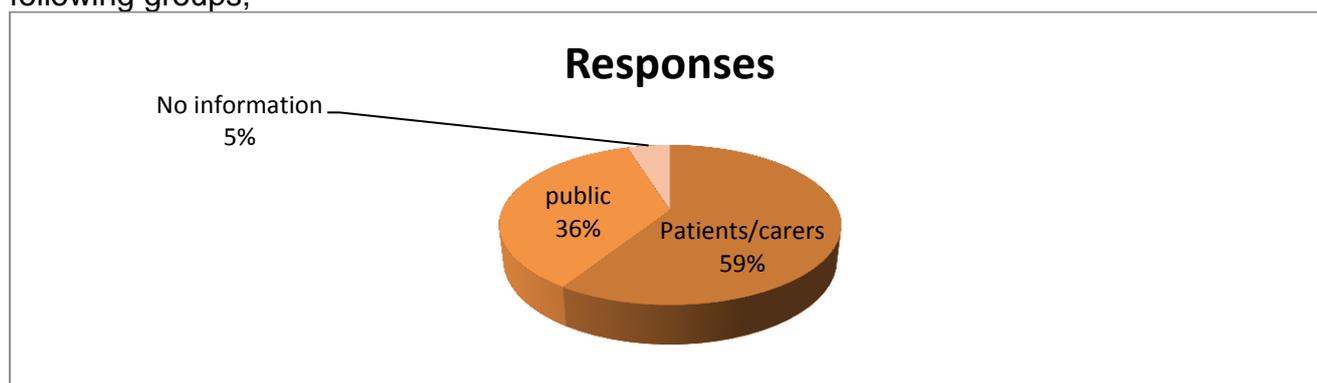
The PAG members at the meeting suggested a number of minor amendments to the survey and engagement plan. They agreed that the patient groups and engagement methods outlined in the plan were appropriate.

Group	Who	How
Chronic pain patients	People who use community chronic pain services	<ul style="list-style-type: none"> Paper copies of survey shared with services LIP attended clinic and filled in survey with patients and carers
	People who use hospital chronic pain services	<ul style="list-style-type: none"> Paper copies of survey shared with services LIP attended clinic and filled in survey with patients and carers
	People who use voluntary organisations for their chronic pain	<ul style="list-style-type: none"> Local VCF sector organisations who work with people with chronic pain we sent links to the survey Links to survey sent to Leeds Beckett Pain Facebook page
	Arthritis Care patients	<ul style="list-style-type: none"> Focus group
Carers of people with chronic pain	Carers, friends and family	Links to engagement were shared with Carers Leeds
		Link to engagement page shared with CCG patient, carer and public networks by email and post
		Link to engagement tweeted to key stakeholders
Public	General public	Shared details of the engagement by social media
		Shared with the NHS Leeds CCG patient, carer and public networks
		Shared with NHS Leeds west CCG voluntary, community and faith sector network
		Paper copies of the survey sent to GP practices across the city
		Poster advertising the engagement sent to GP practices across the city

Group	Who	How
People with protected characteristics as defined by Equality Act 2010	People from Black and minority ethnic (BME) communities	<ul style="list-style-type: none"> • Contacted members of our VCF sector network and informed them of the engagement. • The survey was shared at HealthWatch Leeds event for people who are deaf and hard of hearing. • The survey was shared at a World Mental Health day organised by Volition. • The survey was shared at a Lesbian, Bisexual, Gay and Transgender Challenge event held on 15 July 2014 at Leeds Civic Hall • The survey link was shared on the Doing Good Leeds website
	Carers	
	Children and young people	
	Older people	
	People with disabilities	
	People who use mental health services	
	People who are lesbian, gay, bisexual and transgendered	
	Gypsies and travellers Homeless people	
Partners	Leeds City Council (including public health and adult social care)	Details of the engagement shared through social media.
	Leeds North and Leeds South and East CCGs	<ul style="list-style-type: none"> • Contacted other CCGs with details of the engagement • Engagement added to the CCG websites
Political	Leeds City Council	Contacted LCC with details of the engagement
Providers	<ul style="list-style-type: none"> • Leeds Teaching Hospitals NHS Trust, Leeds Community Healthcare NHS Trust and Leeds & York Partnership NHS Foundation Trust • GP practices • Patient Reference Groups 	<ul style="list-style-type: none"> • Contact all key partners with information for them to disseminate using in-house channels such as newsletters, websites and social media • Copies of the survey were shared at the Leeds Community Healthcare AGM
Media	Local media	Sent out a press release about the engagement. Included media in Twitter and Facebook activity.

3. Who replied?

In total **310** people contributed to the engagement. Feedback was received from the following groups;



4. What did people tell us?

Patients and carers

183 patients and carers shared their thoughts on the chronic pain service redesign proposal. Their feedback came through focus groups and patient surveys. The surveys were distributed across the city and Leeds Involving People also spent time at clinics across Leeds supporting people to fill in the survey. Detail of their feedback can be found in **Appendix B**.

- Feedback about peoples level of pain was shared relatively evenly between, mild, moderate and severe. Slightly more people than we would expect described their pain as severe, although this may be because most of the feedback came from people who were accessing community and hospital pain clinics.
- A third of patients told us that their GP was generally responsible for their pain. A quarter of people were managed by community pain services and over a quarter told us their pain was managed by more than one person/service.
- Most patients (69%) were generally happy with the time it took to get an appointment for their pain.
- Most patients (69%) feel that the right person is supporting them with their pain.
- Over half (55%) of patients felt that they were involved in their care planning. A significant number (24%) were 'not sure'
- Less than half (40%) of patients felt that the interventions they received helped them manage their pain. 18% disagreed that their pain was managed by interventions and 28% were 'not sure'. A number of people commented on the time it took to access physiotherapy. Some people had opted to pay privately for this service due to the waiting time.
- Over half of patients (52%) felt they were in the right place to help them with their pain. 12% disagreed and 25% were 'not sure'.
- Three quarters of patients (124) had been referred to community pain services and just under a third (57) had been referred to hospital pain services. Eight people had been referred to patient groups and two people had been referred to the voluntary sector. Some people reported having to self refer to voluntary sector services because the GP was not aware what existed or did not have time to make the referral.
- Patients reported using a variety of interventions to support them with their pain. Almost a third of people (97) reported using medications. Twelve people reported using psychological interventions such as Cognitive Behavioural Therapy (CBT).
- Most patients who used medications said that it was most effective at reducing their pain. Those people who used psychological interventions said that this improved their mood. People also said that physical therapies helped reduce their pain.
- A variety of interventions help patients feel more confident about self managing their pain. Understanding more about their condition is viewed as important by 18% of patients. Clinicians who understand chronic pain was also seen as important by patients (16%). A number of people expressed frustration at a lack of diagnosis.

'More accurate diagnosis, integrated care'

*'Having access to someone who I can talk to and who understands my condition'
'Get me involved more, get me doing something so I don't have time to think about things'*

- Almost half of patients want to receive information about their condition from a professional. Some people would like to receive information by leaflet, personalised tools and training.
- Patients told us that there are a number of things that would make them feel confident about their GP managing their pain. Seeing the same GP at appointment was seen

as important by 16% of patient. 13% of people said that rapid access to pain services and 12% of people said that training for GPs in chronic pain were important.

- Some people said that they did not want their pain managed by a GP.
'Wouldn't want my GP to do it. Not their specific field'
- Other people reported having a good experience of GP led pain management.
'I feel my GP already does most of these things and he is excellent'
- Patients were asked what might stop them from getting involved in self-management. Motivation (18%), low self-esteem (15%) and lack of information (15%) were seen as significant barriers to self-management. Lack of clinician knowledge (13%) and empathy (11%) were also seen as potential barriers.
- Patient shared lots of ideas about how we might remove these barriers to self-management.

'GP's being more informed'

'Before and after work appointments. More flexibility'

'Give me more information'

'Being listened to'

- A significant number of patients described feeling hopeless about their pain. People also shared their frustrations about clinicians not understanding the impact of their pain.
'No one has been able to help me. Just been told it will heal & it hasn't. Fed up.'
'Nothing they can do, so not bothered anymore.'
'Not changed my health in 12 years - nothing is going to change now'
- Many of the patients value exercise as a way of managing their pain. Exercise took different forms including gardening and swimming. People raised concerns about the costs associated with these activities.
- Some patients valued alternative therapies such as massage and water therapy. People also raised concerns about the cost of accessing these interventions.
- Some patients told us that access to social care services was important in helping them manage their pain and carry out everyday activities

Patients, carers and the public

The second part of the survey outlined the proposals for chronic pain and asked for the views of patients, carers and the wider public. It also asked for people's views on accessing clinics, including location and times. The survey was shared with the public through GP practices, CCG patient networks and at various events across the city. 301 people responded to this part of the survey. Detail of their feedback can be found in **Appendix C**.

- Over two thirds of people (67%) agreed with the proposal to redesign chronic pain services. Only 7% of patients did not agree with the proposal but a significant number of people (26%) were not sure about the plans.
- We received a lot of specific comments on the plan to redesign chronic pain services in Leeds. These comments can be grouped into the following key themes:
 - **Patient involvement** - *'By fully understanding how a person can help themselves they can be more in control of their lives, and will be motivated more to be pro-active'*
 - **GP involvement in chronic pain management** - *'Pain management is complex and specialist and requires more time than a GP is able to give', 'The GP will get to know you and what's happening with your pain'*
 - **Access** - *'This works only if appointments are available outside working hours, not everyone with pain is elderly or out of work'*
 - **Choice** - *'Good to give patients choice when it comes to the treatment they receive'*
- People told us that when choosing the location of clinics we should try to have all the services in one place (27%) and have parking nearby (24%)
- The vast majority of people (168) thought that between 1-5 miles was an acceptable distance to travel.
- Over half of people (55%) told us that they prefer to drive to their appointments
- There was very little difference in the days of the week people would attend appointments. Less people would come to an appointment at the weekend and Sunday was the most unpopular day (although 133 people still said that they would attend appointments on this day)
- People prefer appointments at different times of the day but mornings after 9am (171) and afternoons (155) were the most popular times. We received a number of comments about the importance of being able to access appointments before and after normal working hours.

5. What are the key themes from the feedback?

A number of themes can be identified through the engagement process:

<p>Patients value involvement in their care Almost 40 patients commented on the benefits of involvement in their care. People felt strongly that taking responsibility for their own care improved outcomes and helped them feel empowered. They told us that in order for this to happen they needed to work in partnership with the clinician and have the right information about their condition.</p>
<p>Some people think GPs <u>are</u> the right people to manage most chronic pain Almost 40 people said that they felt GPs were the right people to manage most chronic pain. People said that this approach would lead to more consistency of care and would be more convenient for patients. People also warned that in order for this to happen successfully, GPs need the right knowledge and skills and should have support from specialist pain services. They also told us that seeing the same GP was important and that empathy skills were essential for pain management.</p>
<p>Most patients think the proposal is a good idea Two thirds of people think the proposal is a good idea and over 30 people specifically commented on the benefits of the proposal. Many of these positive comments were linked to peoples ideas around the benefits of involvement.</p>
<p>Some patients don't know if the proposal is a good idea Over a quarter of people were 'not sure' if the proposal is a good idea. Comments suggest that this uncertainty is because people do not have enough information about the plans. A number of people who think in theory the plans are good are concerned how these will look in practice. Specifically, these concerns centre around the skills, knowledge and capacity of GPs in managing the majority of chronic pain patients.</p>
<p>Some people think GPs <u>are not</u> the right people to manage most chronic pain Almost 30 people said that they felt GPs were not the right people to manage chronic pain. They argued that GPs do not have the time or specialist skills to manage people's chronic pain. They also raised concerns that seeing the same GP can be difficult which would make consistency of care a problem. Feedback suggested that patients need reassurance that their care will be escalated to specialist services when appropriate. We received comments about GPs not referring into voluntary sector services because they didn't have the knowledge or time to make the referral.</p>
<p>Access is important Many people said that rapid and flexible appointments were crucial to the success of the service. Most people want to access appointments at traditional times of the day and days of the week. However, lots of people need access to services in the evenings and at weekends. Some people raised concerns about difficulties getting an appointment at their GP practice. Poor access to physiotherapy was raised by some people. Lengthy waiting times for physiotherapy had led to some people paying privately for this service. People value exercise and alternative therapy as interventions to manage their pain. They raised concerns about how they access these interventions and the associated costs.</p>
<p>Services should be integrated Many of the patients told us how important it is for services to work together. This included communication between primary care (GPs), community care and secondary care (hospitals). People also told us that health and social care need to work together to improve access to occupational therapy and telehealth.</p>
<p>Location is important People want local services that are easy to get to by public transport. Most people want to travel by car to their appointment and so parking is also important.</p>

Understanding self-management and patient involvement

One quarter of patients were 'not sure' if they had been involved in the development of their care plan. This would suggest that a significant number of patients do not fully understand the concepts and potential of self-management and patient involvement. It would also suggest that some clinicians may not be engaging with patient effectively.

Measuring success

Over a quarter of people (28%) were 'not sure' if the interventions they used were appropriate or whether they helped them manage their pain. A quarter of people also told us that they were 'not sure' if they were in the right place to manage their pain. These figures suggest that patients are struggling to measure the success of interventions. These findings could reinforce the need for patients to be involved in their care planning and the setting of goals and targets for their treatment.

Support should be tailored

Patients have individual needs and different levels of motivation. They should be able to make choices about their care, and care planning and self-management should be tailored to reduce barriers to successful treatment. Patients should be able to choose from a menu of intervention options.

Significant numbers of patients feel 'hopeless' about their pain

Some of the patients described a feeling of hopelessness about their condition in the future. They raised concerns that clinicians did not understand their condition and that they had not made progress with their pain levels.

6. Recommendations

Following the engagement the project team are asked to consider ways to:

1. Ensure that clinicians who are responsible for chronic pain patients, have the appropriate skills, knowledge and capacity to support patients effectively.
2. Ensure that clinicians who are responsible for chronic pain patients, have good interpersonal skills such as empathy and understanding.
3. Provide GPs with access to support from pain management specialists.
4. Give chronic pain patients access to the same clinician for their routine appointments where possible. When this is not possible due to illness or annual leave, ensure that the clinician has access to the patient's notes.
5. Provide patients with a choice of appointments, including appointments outside of normal working hours (09:00-17:00).
6. Provide patients with rapid access to urgent support for their chronic pain.
7. Allow patients to measure the success of their chronic pain interventions. This might include scoring pain, involvement in their care planning, the setting of goals and targets and evaluating their care.
8. Provide patients with information about changes to chronic pain services, chronic pain, patient involvement and self-management. This information should be available in different formats such as leaflets and online.
9. Support people to manage their pain in ways that are compatible with their lifestyle. Patients should be able to choose from a menu of options which could include using smartphone apps, online applications, telephone or face-to-face consultations;
10. Provide patients with a choice of interventions so that they can find the right intervention for them at the right time.
11. Improve links with voluntary sector services for people with chronic pain.
12. Consider ways to support patients into exercise and alternative therapy services. Find ways to remove or reduce the cost associated with these services.
13. Provide clarity around the care pathway for chronic pain so that patients understand that care will be escalated to specialist services where appropriate.
14. Improve links between health (including mental health) and social care for people with chronic pain. This should include improving access to services such as occupational therapy and telehealth.

In addition to these, the NHS Leeds West Clinical Commissioning Group Engagement team make the following recommendations:

15. Provide opportunities for patients and carers to routinely share their experiences of using chronic pain services in Leeds.
16. Provide people involved in the engagement with regular project updates (the engagement team will support this work).
17. Recruit patient representatives to the project steering group to ensure that the engagement recommendations are considered by the group.

7. What will we do with the information?

The report will be shared with all the people involved in the project. The report will also be featured in our next newsletter which is sent out to patients, carers, the public and voluntary, community and faith sector services. The report will also be available on the NHS Leeds West CCG website and will be shared with the other CCGs in Leeds.

The chronic pain project team will use the report to redesign chronic pain services in Leeds. We will recruit patient representatives to support the development of the project and ensure that the recommendations made in the report are considered by the project group. Briefings will be produced at regular intervals through the project to show to what extent the recommendations have been implemented. This briefing will be shared with the people and organisations involved in the project.

The patient feedback from this engagement will be added to feedback from other engagements and consultations to help us understand wider healthcare themes. This information will support us to improve communication, access and the quality of services.

Appendix A – Glossary of Terms

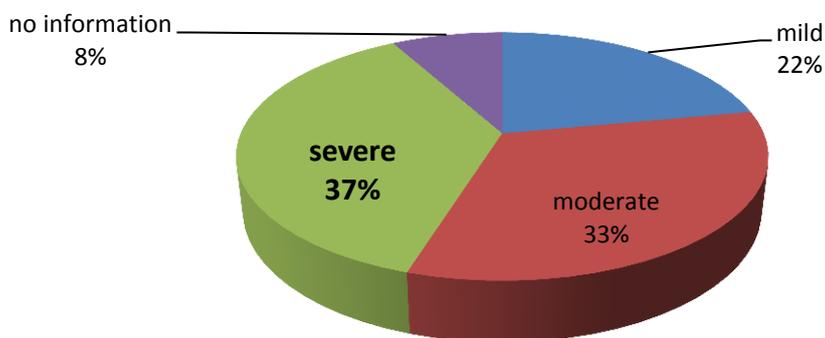
GLOSSARY

Commissioning	Commissioning is the planning and purchasing of services. The Clinical Commissioning Groups are responsible for commissioning most healthcare services.
Procurement	The acquisition of goods or services.
Protected characteristics	<p>The Equality Act 2010 makes it unlawful to discriminate against people with a 'protected characteristic' (previously known as equality strands / grounds). The protected characteristics are as follows:</p> <ul style="list-style-type: none">age;disability;gender reassignment;marriage and civil partnership;pregnancy and maternity;race;religion or belief;sex, andsexual orientation. <p>For more information follow this link: http://www.equalityhumanrights.com/private-and-public-sector-guidance/guidance-all/protected-characteristics</p>
Provider	Providers are the organisations who deliver healthcare services. GP practices and hospitals are providers of healthcare services.

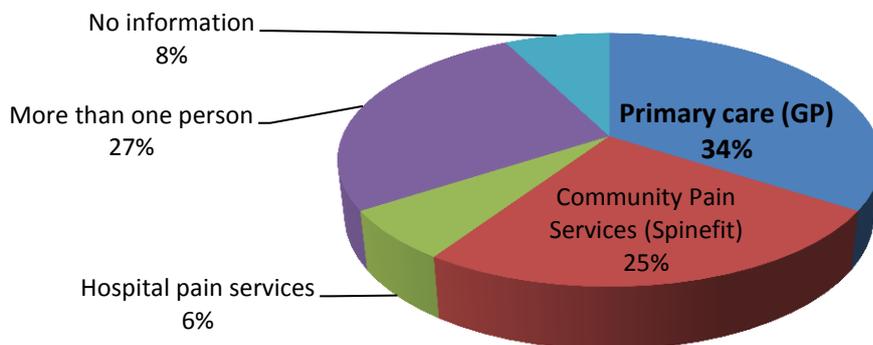
Appendix B – Patient/Carer feedback from the survey

173 Patients responded to the engagement by filling in the survey.

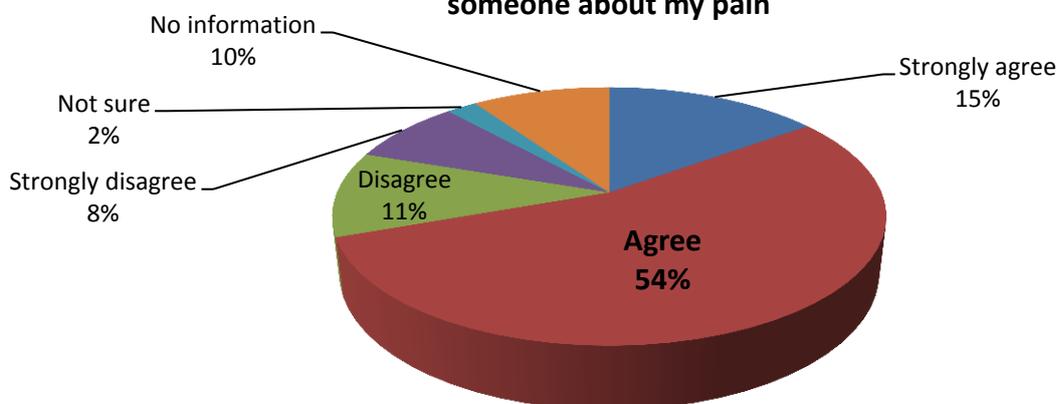
1. How would you describe your chronic pain?



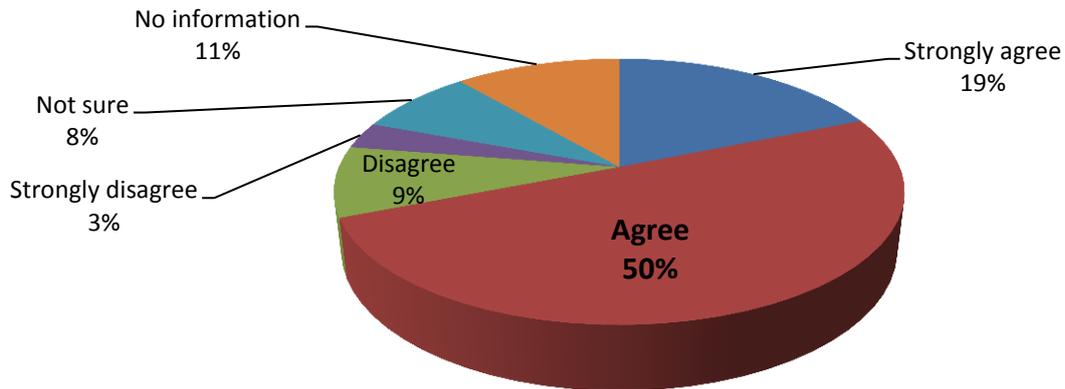
2. Who is generally responsible for supporting the management of your pain?



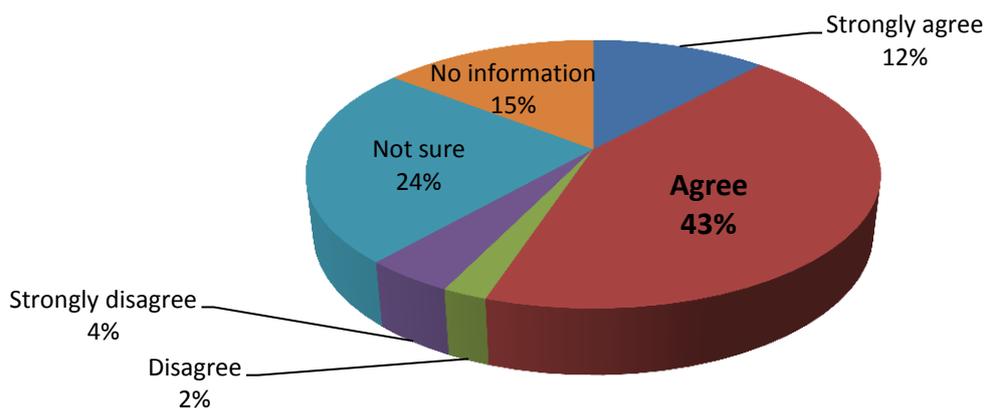
3. Thinking about the service in the last question, to what extent do you agree with the following statement about the management of your pain a. I was happy with the time it took to get an appointment to speak with someone about my pain



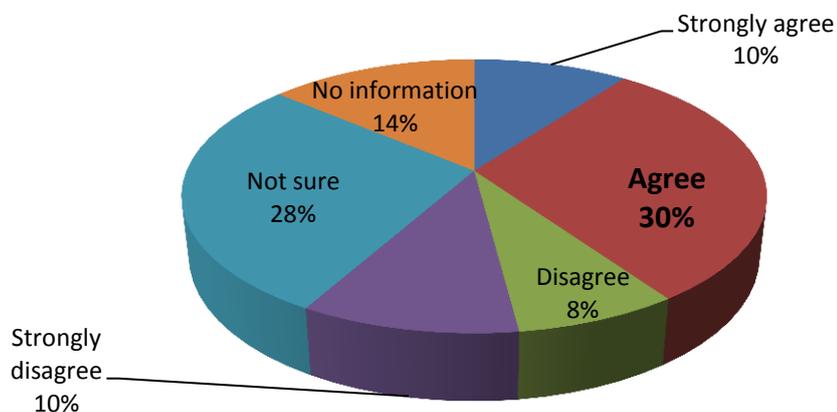
3. Thinking about the service in the last question, to what extent do you agree with the following statement about the management of your pain
b. I feel like the person I spoke to was the right person



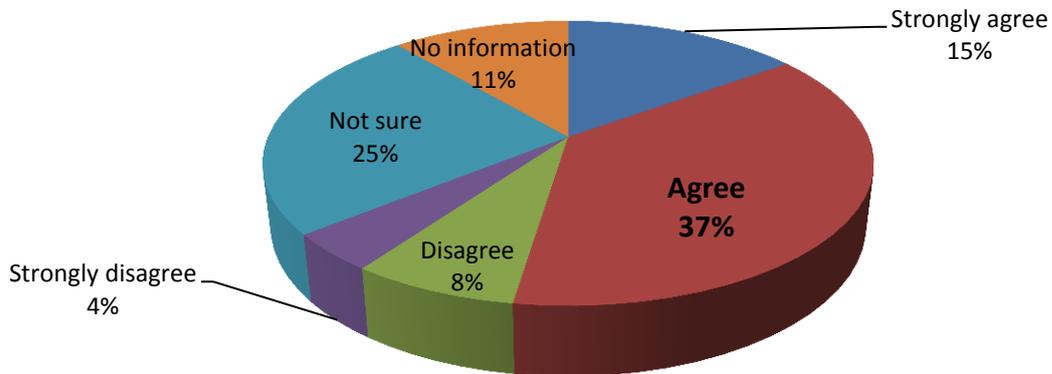
3. Thinking about the service in the last question, to what extent do you agree with the following statement about the management of your pain
c. I was involved in the development of my pain management care plan



3. Thinking about the service in the last question, to what extent do you agree with the following statement about the management of your pain
d. The interventions I get from the service are appropriate and help me manage my pain



**3. Thinking about the service in the last question, to what extent do you agree with the following statement about the management of your pain
e. This feels like the right place to help me with my pain**

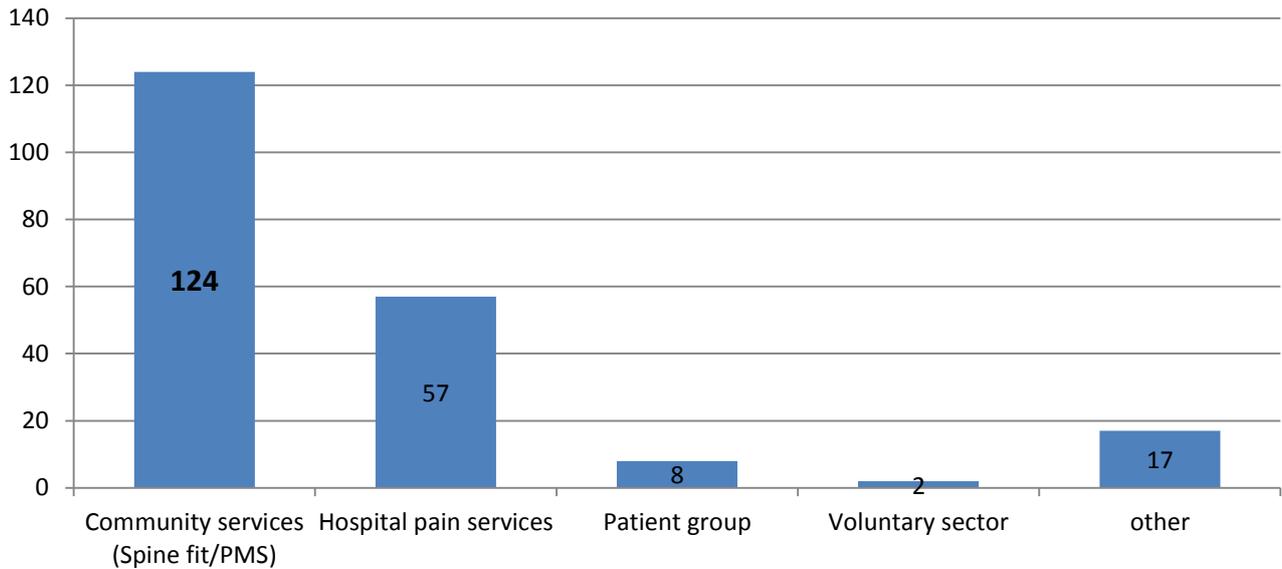


3. Thinking about the service in the last question, to what extent do you agree with the following statement about the management of your pain.

f. Other

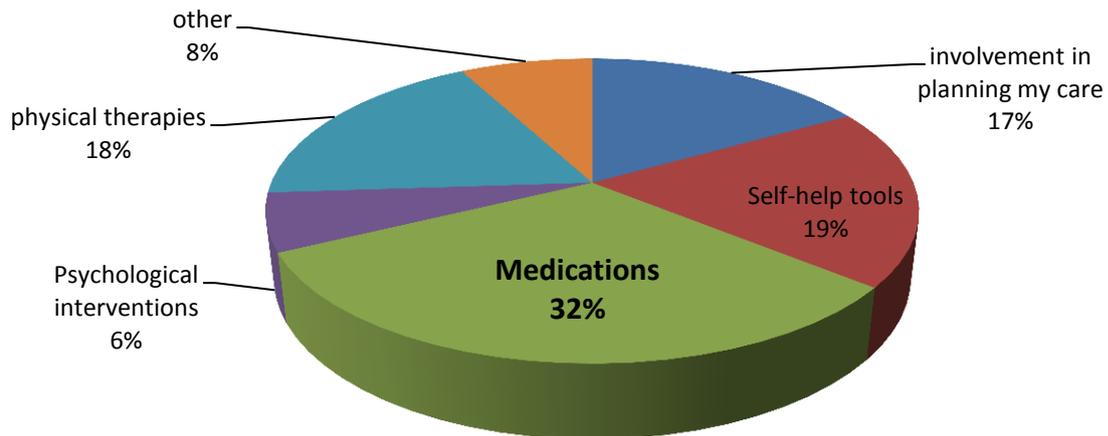
- Health trainer
- Acupuncture, massage & heat therapy have worked. Physio doesn't work.
- Private physio
- Pain Clinic & EPP
- Pain management clinic
- I haven't been referred to any services
- I supplement hospital pain services with regular physio which I have to pay for
- Physio
- MIND mental health memory loss.
- Physio.
- Armley Medical Centre
- Physiotherapy
- MSK physio - awaiting appt as long list
- Physio x 3

4. Which of the following services have you been referred to?

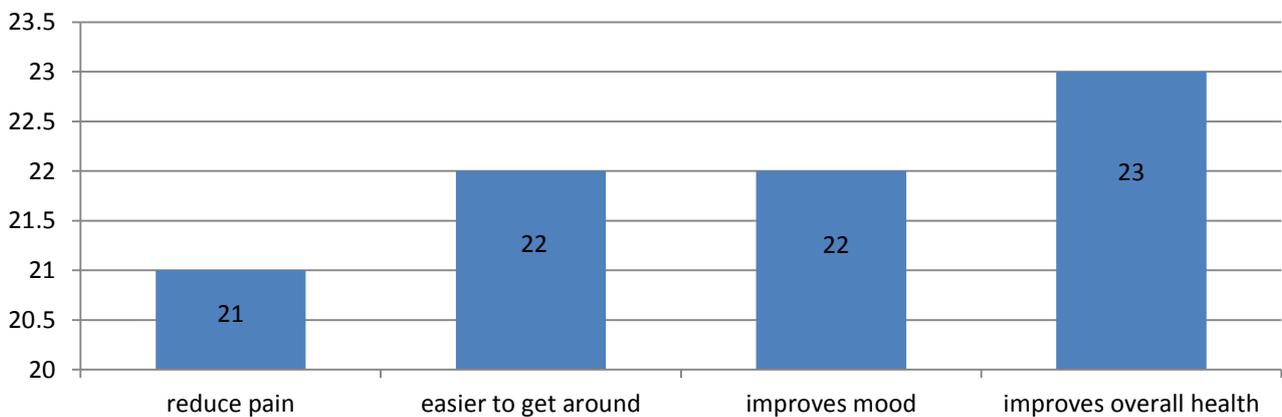


Please note: some of the patients had been referred to more than one service.

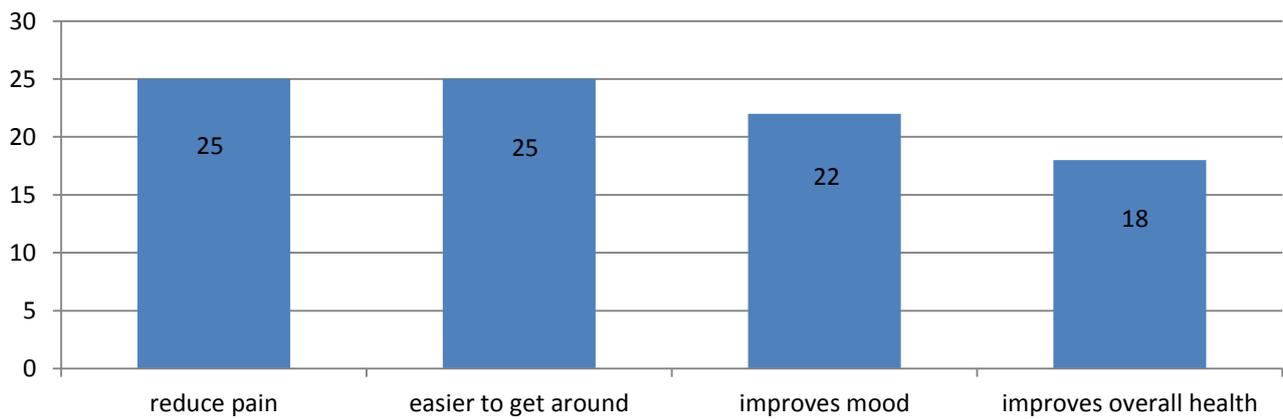
5. Which interventions do you use?



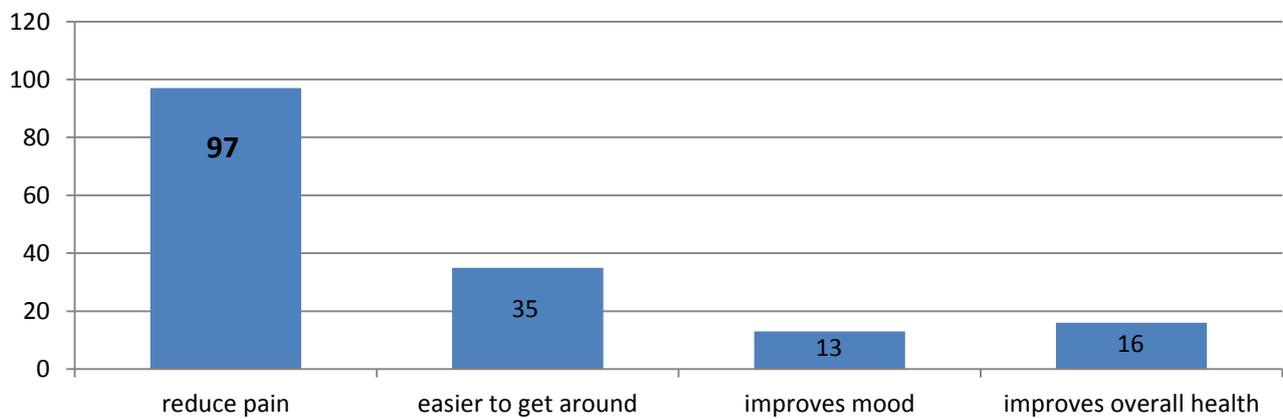
5. Which interventions do you use and how do they help your chronic pain? a. involvement in planning my care



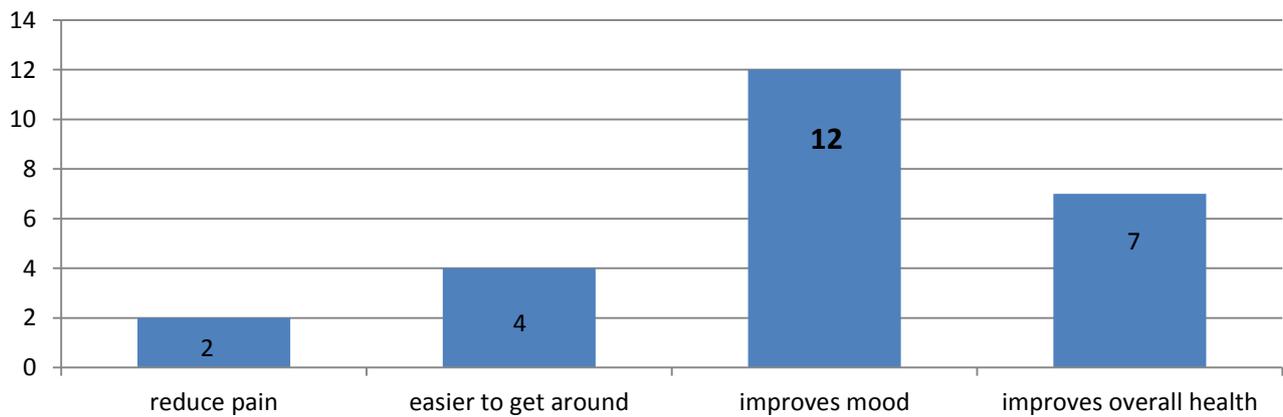
**5. Which interventions do you use and how do they help your chronic pain?
b. self help tools**



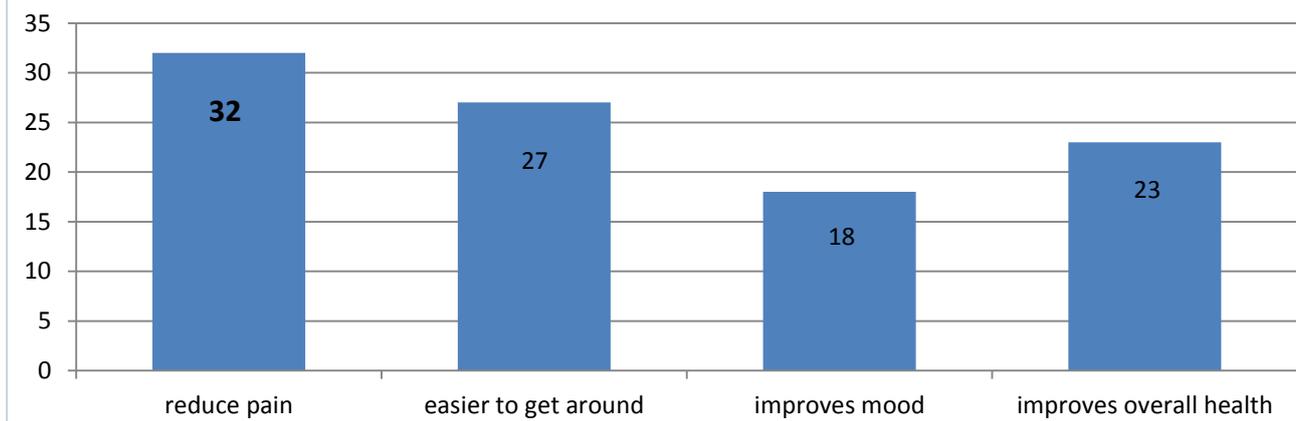
**5. Which interventions do you use and how do they help your chronic pain?
c. medications**



**5. Which interventions do you use and how do they help your chronic pain?
d. psychological interventions**



**5. Which interventions do you use and how do they help your chronic pain?
e. physical therapies**

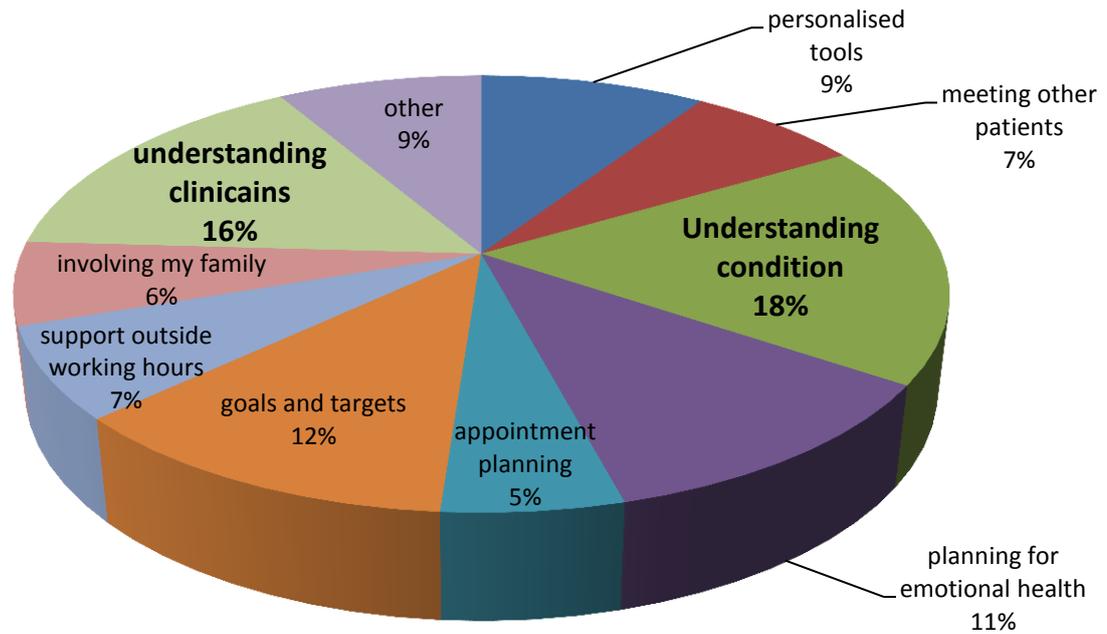


5. Which interventions do you use and how do they help your chronic pain?

f. Other

- Heat pad, tennis machine
- No counselling or involvement
- Meds aren't helping & only been for physio twice. Taking too long for diagnosis, feel passed around
- Nothing helps
- Physio hasn't worked
- This is my first appointment
- This is my first appt
- This is my first physio appt so can't comment
- discharged after massage worked, but now it is back and I've had to be referred back in through GP
- No one has been able to help me. Just been told it will heal & it hasn't. Fed up.
- Physio causing pain for now, but have been told it will do & it will get better.
- Self-help = exercise class
- Studying to be a therapist myself has helped.
- This is my third appt so can't answer most of questions above
- First appt at spine fit so don't answers to above
- This is my 2nd appt. first was a pain management plan book to read. Not had any treatment yet
- Just been to do my care plan. Not had any physical therapy yet but urgently need it
- This is my first appt with spine fit so can't answer
- Injections - back pain
- Meditation type therapy
- private physio helps as does exercise (I go to the gym when I can)
- All None apart from the yes tick
- I have not been involved in planning my care. still waiting for n.p.s
- Acupuncture.
- Walking, floor sleeping
- Am still waiting for an appointment
- Currently trying acupuncture - helps a bit
- Injections

6. What would make you feel more confident about self management?

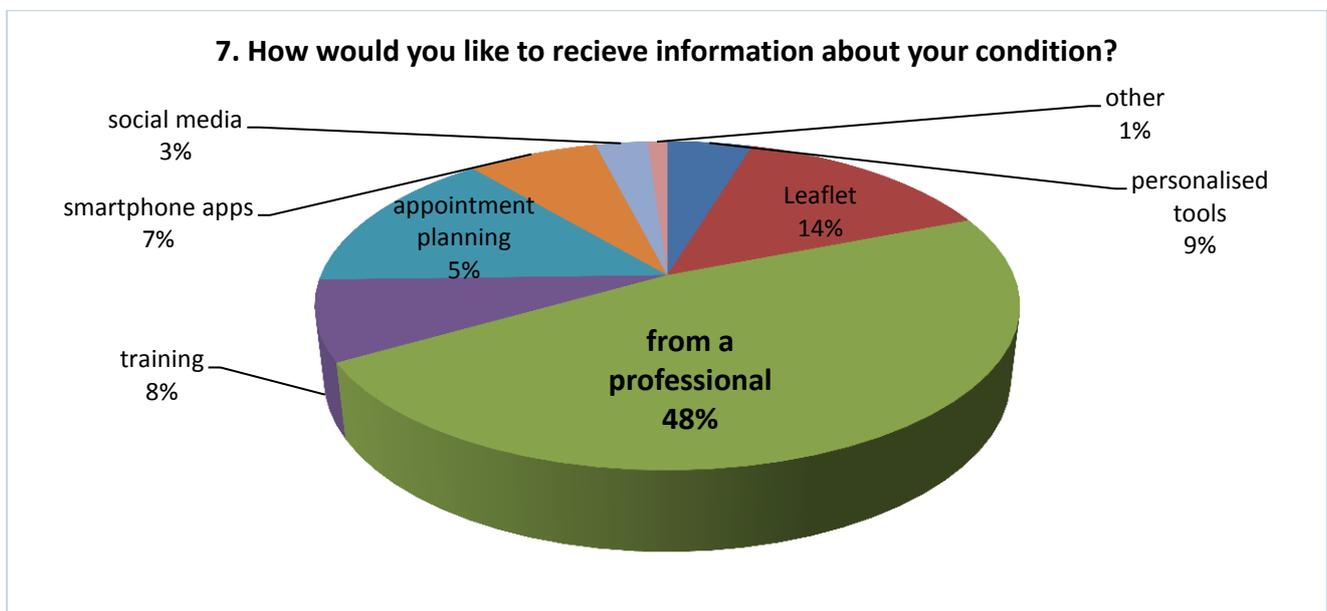


6. What would make you feel more confident about self-management?

Other

- Can cope, just stops me doing the activities that I want to do
- Keen on meeting other patients
- A diagnosis
- An exact diagnosis
- Guidance
- Confident enough
- A slight improvement in my health
- I feel I need another scan to find out what's going on but I've been refused another scan
- Exercise classes maybe. Knowing what's most appropriate exercise to do
- Feel like no one can help me at the moment. If someone suggested something I would do it.
- I'm self-motivated so do my exercised at home.
- Doctors don't seem to know what to do. I got sent to A&E by the doctor and they told me to go back to doctor. Waste of four hours, being sent all over the place.
- Relaxation techniques have helped me, so emotional as well as physical help is important.
- Generally trying to help me improve how I feel. Psychologically.
- Flexibility of medication to cover severe pain spikes
- Get rid of my pain!
- Lots of support
- None of these
- An understanding of why I have this terrible pain
- Already do it
- I already self-manage to the degree I think is possible under the care of expert physicians at Leeds Teaching Hospitals NHS Trust.
- Understanding that sometimes self-management needs to be combined with clinical intervention
- With hypermobile syndrome and osteoarthritis, I find it difficult to control my weight, this deters me from seeking further help as everything seems to revolve around that.
- having access to someone who I can talk to who understands my condition at a time when I need support, or something new happens that I am unsure of.
- Nothing, Everything has been done to help me

- Immediate access to clinicians when you need them.
- More accurate diagnosis, integrated care.
- To listen to me instead of medication.
- Faster help ie 13 hours to have a visit is not acceptable.
- Listen as patients know their own bodies and where their pain is don't fob people off.
- That someone can help when its needed, not having to wait a long time for hospital appointments.
- Get me involved more, get me doing something so I don't have time to think about things.
- Explain my hip problem.
- Diagnosis of cause or pain.
- I wish I knew
- Not having to use taxis as a pensioner when I've paid into the NHS for 38 years.
- I am a new patients so at the very beginning of my care plan. I understand there is a process to go through but waiting for appts or to find a painkiller that helps is very hard. It adds to the stress as I can't keep taking time off work to keep coming back. I know it is h
- More appointments with pain management specialist.
- To see a service that can make a difference.



7. How would you like to receive information about your condition?

Other

- Email
- Nothing they can do, so not bothered anymore.
- I was extremely active - a lot of support is aimed at people who perhaps not as mobile to start with so to talk to others like me would be good. Or get a level of exercises (for example) aimed at someone with my physical ability as opposed to the standard stretches etc.

8. What would make you feel confident about your GP managing your care?

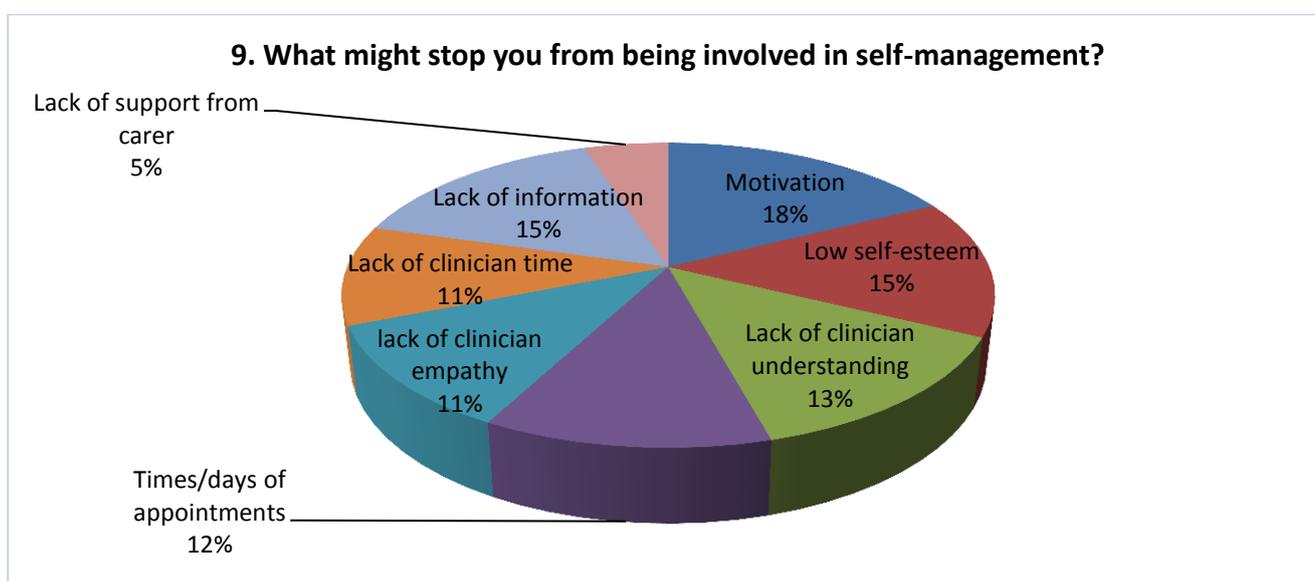


8. What would make you feel confident about your GP managing your care?

Other

- Pain management specialist- GP doesn't understand enough
- Trust in GP
- Wouldn't want my GP managing my care
- New to service, so not done care planning yet.
- Wouldn't want my GP to do it. Not their specific field. GPs can miss thing, as they have too many fields to choose from.
- GP sending me for acupuncture, which will help me
- Don't want to be managed by GP
- Confident enough
- Not happy with GP, they don't listen.
- Nothing, I don't want a GP to manage my care, as my experience has been really bad with them passing the buck.
- Being able to get into the doctors quickly. Personally I would rather go straight to physio.
- If the GP actually did so, etching - lost 2 letters. Had to wait 13 months for an operation, waited another 15 months for a hospital appointment
- Continuity of care is so important in pain management and getting support and guidance at short notice when I am having a flare up
- If the GP actually saw me
- Don't know what question means relating to self care programmes
- No idea who my GP is, I have to book appointments on the day and never see the same person twice.
- not the gp
- I feel my GP already does most of these things and he is excellent. However, he does not have time to discuss pain management with me in sufficient detail, nor is he an expert.
- would have thought that a specialist nurse in a gp practice would also be useful to assist gp. gp would need to be able to give appropriate time for discussion of chronic pain - usual length of appointment would not be sufficient
- GPs being able to spend time with the patient, instead of a rushed one or two slot appointment
- Nothing, My GP is brilliant
- Access to records. Having lead role and responsibility.

- feel my GP is very supportive & helpful with my condition. He admits that although he has studied the condition well, he still does not understand the condition. He always provides for my care as advised by my Consultant and does not change this. I fail to see that my co
- The same answer as at 6 above.
- Make sure that the Care Plan is correct and all medication is down and there are no gaps in treatments.
- Make opening hours longer.
- Nothing. My GP knows me and my paid. The pain team consultant discharged me on the first appointment, telling me that I needed to reduce tramadol and that pain was nothing to do with my multi level stenosis, all without getting out of his chair. I would not want to be seen
- I wish I knew
- As a pensioner, never having to use taxis when I've paid into the NHS for 38 years.
- our GPs are great but again - it would be helpful if they started from the point I was at physically before the pain. I was very fit and very flexible so the standard exams didn't seem appropriate - for example though very painful I can still move my leg much more than perh
- Being able to see the same GP who knows about your condition.



9a. How could we remove these barriers?

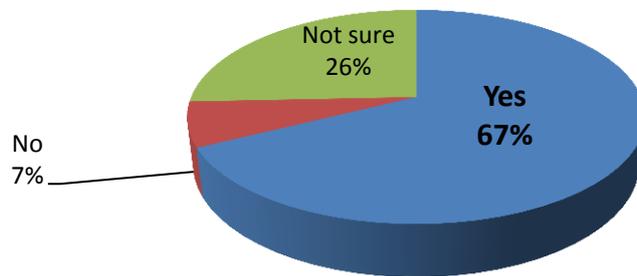
- Going to the same clinician every time
- Motivation isn't an issue at the moment
- Training for staff
- Anti depressant isn't working - another kind maybe. More time to deal with me.
- Finding out what is wrong with me
- GPs being more informed, but this may be hard as back pain is complicated & there are different types.
- Be patient with me
- Flexible appointments
- Needs to be working. Give an accurate diagnosis.
- Been in pain for a long time
- Give more information
- More info
- If the person understands what is wrong with me. Flexible appointments.
- Want paper copies of information alongside seeing a professional.
- GP listening to me
- Before and after work appointments, more flexibility
- More flexible appointments around work
- Flexible appointments

- Slight improvement in my health
- Only me! Coming to Physio more & having targets.
- Trying all they can
- Don't know
- Not sure
- No idea
- Provide more info by gp
- I do not know because it's a state of mind.
- If they talk to the patient and get proper feedback.
- More appointments
- More flexible appointments
- People with more understanding of what you're going through
- Talking to people
- Being listened to.
- Seeing progress in what I'm doing. If I get worse it's obviously not helping. So far there isn't a massive improvement, but small things have helped. Relaxation techniques and some physio.
- Flexible appointment times
- Emotional support to understand my individual experience, not everybody is the same.
- Getting quicker appointments
- Speak to more people about it and see how they feel
- Don't know
- Provide adequate information so I know what to do.
- Having GP more understanding of what's wrong with me. - a proper diagnosis rather than being sent around.'
- Paper trail - need more money government - dvt - doctor sent to hospital - 3 week later and no report on my leg with a circulation issue. Nobody checks to make sure you have a 6 month appointment
- Not really - personal.. Other things are more important - such as young family
- Have appointments readily available at GPs or spine fit to help guide me through managing my pain and everyday life
- More flexible hours and availability
- Personal matter
- It's a personal thing.
- Once the pain recedes
- Give me two new knees
- To show more involvement and understanding of chronic pain
- By taking on board the above
- No idea
- People that are involved to have the best understanding of chronic pain and to care about the patient
- Matters out of your control
- No idea
- Start socialising more - (me)
- More of a personal matter
- I need to do it myself. My mind is willing, but the flesh is weak.
- Flexible appointments. EPP helps self-esteem, but down to the individual.
- Being a bit more gentle with patients, I was told there was nothing that could be done and I had to get on with it.
- Would like practical help. Tools to help me open jars etc.
- Something I would have to overcome myself.
- cannot gps are a complete waste of time
- appropriate training and actually listening to patients/carers about chronic pain
- After several years dealing with joint/ligament pain, and visiting my GP, the arthritis clinic and a physiotherapist, I've never been spoken to about pain management clinics. My weight prevents people seeing my problems. I am over weight but have a difficult life caring for a

- Recognise pain as something that requires regular review. Ask GPs to flag on notes and ask whenever you visit how you are managing.
- Better training for consultants, registrars, other clinicians. Make them understand what pain feels like.
- Better care pathway designed for my condition / issues.
- Remembering that self help is not right for everyone, and not everyone feels comfortable meeting other patients with similar conditions in group situations
- Listen and talk to other specialists have time and fight for your patients/carers and research their conditions don't fob them off. Joined up treatments no gaps or waiting months to see the appropriate specialists.
- Has to be one to one support.
- Stick to appointment times or ring me if you're running late.
- make sure it is a disabled accessible service
- localised clinics to see dr's as well as physiotherapists
- I don't know, but I wish I did know.
- Look at opportunities for interim support either medical. physical or emotional - not sure how but why not get the universities involved - lots of trainee physios, practitioners even sports therapists. We have one of the best teaching hospitals in the county in Leeds - can't

Appendix C – Feedback from patients, carers and the public

10. Do you agree with our proposal to redesign chronic pain services?



10a.

- I've only been here once
- Seems like a good way of doing things, good idea with the patients taking responsibility for themselves
- GPS are so busy and don't have time.
- Improved services. More patient involvement
- Is It just a way of cost cutting self managing pain or is there real evidence it woks
- Plan going well
- Good advice from clinics
- It'll fulfil my needs
- If patients and their GP have more of an understanding about the contains and needs of a patient then the care we receive will be much better.
- Knowing that you have a set date to see specialist
- Will make the GPs think more about MY condition and how MY needs can be met. Everyone is different.
- More options
- David suggests things to me and I decide whether to do it or not
- Want as many options as possible.
- Continuity of patient care with someone who knows me we'll.
- GP will help
- Trust GP, have confidence in GP.
- Know what's going to happen
- GP not really helped me so far
- GP can't deal with everything, so would want referral
- Want medical advice
- On paper yes, but wouldn't want advise from someone who isn't specialist.
- GP needs input as well, as you can't fully decide what works without medical guidance
- Options are good
- Lack of confidence in GP
- People should look after their own health
- Rather take guidance from GP
- My GP doesn't understand spinal injuries, just gives me pain killers. Hospital staff understand. Want to get back to work, so want this treating.
- Rather try alternative therapies to an operation. Worried about effects of the operation.
- GP will get to know you & what's happening.
- Choice. GPs inundated with work, so easier for them to signpost to specialist services.
- Tried lots of different things and not much has worked. Spinefit is my only option, due to medication clashing with other health conditions.
- Won't have to keep seeing your GP

- GP knows more about me than Spinefit
- GP is very good, happy as I am. Good support from community & hospital services.
- Not sure what more they can do
- Knowledge helps
- Depends on GP that's involved with my care
- A good idea
- If it helps the patient it's worthwhile changing
- If it works it can only be a good thing but people. Eyed to be motivated to do it.
- It might help keep costs down for the NHS
- Good to give patients choice when it comes to the treatment they receive
- Physio doesn't work for me, but other treatments have. Would like to choose my treatments.
- Would like choice
- Off GPs back and more professional involvement for longer appointments
- What happened when I first went to my GP. I was given choice of where to go and when to attend. Picked most local service for me.
- Unless you've been before you don't know about your pain, need direction on where to go.
- You get more of a direct & specialist response to your problem
- Not having to go from person to person all the time
- Choice is good
- I've picked where to come, but it's still not helping. Would like x-raying to find out what's causing my pain.
- If they can actually manage it then it would be good. However, my past experience has been poor so I would prefer them to be fully trained about pain services and treatments.
- It's very similar to what's happened already. It would be quicker than waiting for a referral to come through. Better to make referral appointment with GP there and then.
- I know what's wrong with me and I can estimate whether the person that they're referring ,me to is the right one. I don't really want to take pain killers.
- What I've done and it's worked so far
- Yes, but I would like to see the same person each time. Spinefit have really helped me, and the understanding that they have has helped me emotionally as well as physically.
- From personal experience this has worked for me. I wanted to strengthen what I have now, rather than taking Meds.
- From personal experience, I have been bounced backwards and forwards between different services.
- I think you need to see a senior physio to get a diagnosis. GPs aren't trained.
- Waited a long time for appointment - should make process more efficient
- Think it's a good idea
- It's what they should do
- Every thing is fine I am understand
- Think you need to see a specialist like a physio not a gp
- Makes sense. Better method
- Gp practices base their referrals and treatments on what it will cost their individual practice rather than the needs of the patient. Doctors need to approach the patients needs in a wholistic manner with easy access to further support. Doctors need to keep patients up to d
- Saves me having to go over to sea croft to see people I don't know - had this problem 30 years - keeps getting worse - last 4 years been given morphine. Spongilitis and nerve damage. - great deal of pain- increased morphine dose but won't help much more than that
- It's-always good to involve the patient and anything that helps improve the service is always good
- Should listen to us. We are in pain. Not them. GP need more control - too much waiting - going round in circles- it's a nightmare
- GP knows you better - problem ATM- gotta phone up before 8:30 - if work get appointment on evening which is a lie. Doesn't suit me. Don't book it before 8:30 then no appointment - can't ring on way or at work
- Needs quicker appointment, much quicker
- You shouldn't have to

- GP s don't have enough time to spend on you so how can they take this role on too?
- Because I do think it's more convenient for patients to get to their local GP
- I agree cos that's what you need to do
- Everything has worked well for me so not sure it needs changing
- I've had 5 spinal operations. It's best that one person deals with you and it's more consistent and personal as they know your history better
- I need quicker appointments and have had very long waits in the past
- Yes because I've had to wait a long time to get this appointment
- If it's made to work well and benefits the patient
- What's happened to me, it's worked for me so far.
- Here for another treatment. Have little knowledge of pain management to comment
- Can't get my head round it
- Sounds ok
- I'm not sure it's not taking the physiotherapists job away?
- Not sure on my opinion
- Alright as it is
- Has trouble with the service as it is - on appointment day - miss 2 appointments because they gave me 2 on the same day at different locations. Thought I had missed 2 appointments so it took me a while to get an appointment again
- Depends on the patient. Sometimes I don't want to talk about it
- This method works
- When I'm told what to do its good - system at the moment works for me
- Personalised involvement with one leader is good, each patients needs are unique to them and need to be treated individually. A quick referral does alleviate stresses. Having various services under one roof such as spine fit is a good thing
- I'm happy the way it is
- Definitely need advice - can't do everything on your own- some things you can't answer.. More help at spine fit than GP- don't have the time to listen to you
- Gives the patient more control and options
- I don't have enough information.
- Change is good
- Having chronic pain for so long I realise the best help over the years is having more information to understand why my pain is behaving in such a way and that makes me understand how certain interventions work
- Only just started on this service. - not sure which would be better
- Very happy with the service at the moment
- Not changed my health in 12 years - nothing is going to change now
- GP s are so busy; takes a long time to see them
- So,e might be able to handle it but some won't.
- Not really been using the service long
- Have to trust the professionals
- Depends on the patient - how they react to the responsibility
- It's a good idea to involve people
- Got to be involved - more motivated
- Not sure what happens here yet!
- Took a long time to get from physio to spine fit - physio was useless
- Nobody understands the pain unless they have been in it themselves
- The more a patient feels supported and understood the more confidence they have in their ability to get well doctors who listen and understand and provide swift service will be a great help to people who suffer with the chronic pain and the depression of dealing with it on a
- People are more involved - would be more motivated to do it
- Better idea to be more involved
- The Gps are horrendous and don't listen and don't want to treat me with Meds when you come to spine fit. They don't understand
- More motivated this way

- Don't know enough
- No point in having a Gp to be referred around by the Gp.
- More patient involvement makes sense
- Not familiar with this
- It's commonsense
- Not sure because have never used the service
- Better for a quicker referral
- Drs don't understand and should fully understand chronic pain
- Not sure if it's better or not
- I trust the professionals,
- My Gp is closer than the clinic - easier to get to
- It's a good idea
- Definitely
- I'm already involved in controlling my long term pain
- Think that initially patients should be assessed and directed to the right treatment without going through a set process which delays treatment needed in certain areas.
- It gives ownership to patients
- Works the way it is, the proposal sounds good too
- I attend the chronic pain clinic Seacroft and more local clinics would be better forme
- I've been in pain since ten years old. This appears to be a positive way forward
- It should be quicker to get referred
- I agree with the principal of accessing support via Gp practice, however I am concerned about access to specialist healthcare eg physio. I am also unable to comment further as I feel I am being consulted on a general principal without knowing how current services are accesse
- That's what I would want for myself
- Aren't gps busy enough
- Far too many people rely on Gp and don't look after their own health.
- If it means being seen quicker. I'm here to see a physio today after waiting a further 5 weeks since my initial appointment which I feel has been too. Long. My condition to my knee has progressively worsened week by week and I am in great pain. I feel I am in need of a scan
- Hopefully will be better
- Sounds sensible
- Less waiting time
- If it helps and makes it quicker
- It's fine the way it is
- It's easier to get to my GPs surgery
- Sounds good
- It sounds good
- If it has better outcomes then will be beneficial
- Think it's a good idea to speed things up
- Think might be better for patients
- It's a good idea
- Sounds good
- Good to be more involved
- If it's accurate then it should be great
- Important to have a voice!
- Patients need quick referrals to specialists
- Don't know how it works at present
- If these are the goals then it sounds acceptable
- Depends on the Gp - reputation you have with the centre.
- I've been waiting to see a physio since July. It's now October. So appointments need to be much quicker. I've not heard back regarding my proposed scan either.
- Think it's a good idea! Been travelling a long way for physio- why can't she have it here?
- Me and my wife have had wonderful care in the past so I don't see how what we've experienced can be improved upon

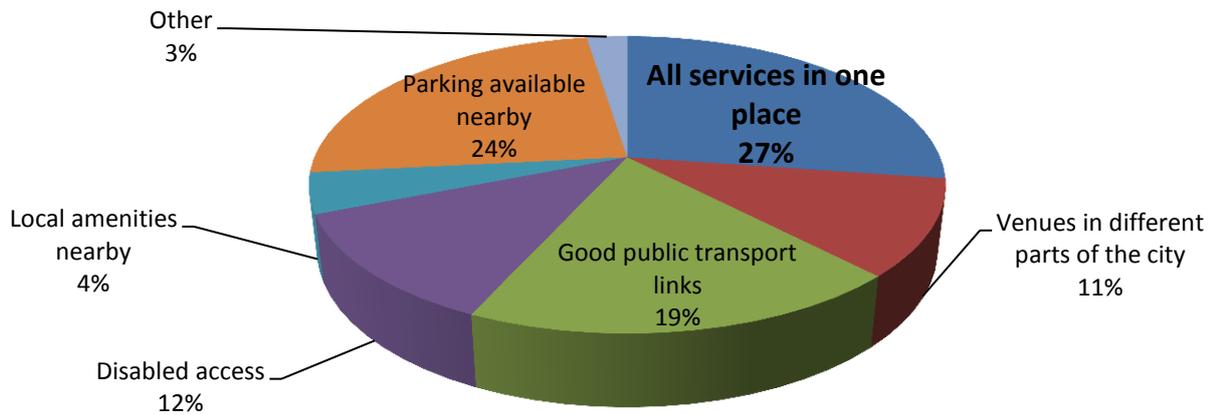
- Will help people get the right help quickly
- When you're in pain you need attention very quickly
- Not sure because this doesn't affect me
- More patient input in their care. Hopefully less jargon to deal with and easier to understand language.
- It's a good idea. I don't use the service but I need it. I've been waiting for one month for results of a shoulder x ray at Wharfedale General. My GP still hasn't got my results and nobody can help me. Meantime I'm in constant pain and nobody is doing anything to help me.
- If they could keep up to it, seem to start things and then not finish them. Consistency of careers - see same people and then get to know them.
- If it's better for all
- It sounds like it will be managed better
- You can talk to your GP, I know mine well.
- More direct, not being sent all over the place, end up back at the GP each time
- Why not! Good idea. Individual involvement in planning.
- You would be getting sent to where you need to go
- Talk with GP more
- I've had a lot of support from my GP, so I'm happy with this.
- I've had to ask for my referral into Spinefit. My GP should have told me about the service. What about patients who don't have the confidence to ask. Concern about the GP not having the time to talk. Health Care Assistants tend to manage referrals based upon what GPs are sayi
- If they understand what I'm going through. Sometimes you don't get support , just pain killers. Would like more support.
- I've had this condition for 40 years, and they've not been able to help. I've just got my Care Plan, so not sure how that'll go.
- Good experience of self-management
- The event : In 1995 the patient suffered a burst disc (a prolapsed sequestered disc at L5 S1 left sided + other bulging disk) This resulted in severe left sided back and leg pain. An operation to clear up the debris (several months after the initial event) was a failure in
- Leeds service is very poor. No care at all really!
- I Have been a long term chronic pain sufferer (11years) I am at the present moment self_managing, because my G.P. does not seam to understand my pain and because I don't fit into a health group they don't know where to send me and because a CONSULTANT caused my disability no
- I have suffered for over 40 years now and have been prodded pushed ignored until I am totally fed up of the whole NH system. Since I have now retired and am near 70 NO ONE is interested in my problems since I can not be forced into work. I am sorry to be so negative but the
- GP's unreliable access. Do not see the same GP. Problems with appointments for reviews and regular attendance
- I would be good to have more detail about the plans. I agree that GPs need to understand chronic pain and related services as I think there is sometimes a focus on finding and curing the cause, which isn't always possible. I would also support fast, appropriate referrals. My
- Getting an appt with my GP - who is totally understanding of my condition - is easier than getting an appt at the Pain Clinic which is totally over stretched and under resourced.
- By fully understaning how a person can help themselves they can be more in control of their lives, and will be motivated more to be pro active.
- By empowering the patients you will be giving a better understanding to better manage their pain.
- As a graduate of the Expert Patient Program I can testify to the benefits of this method.
- Do not agree with using the G.P. for this. Unless the pain is very severe, G.P.s already dish out enough pain medication, but do not have the specialist knowledge, and never will, of my own pain consultant. It may be a cheaper option initially, but if patients are not treat
- I have had 4 hernia operations and I am still in pain

- Extremely. Let down by hospital service, came away feeling worse than before. Very poor consultant experience. No patient skills, talked about his own agenda. I feel positive that changes need to be made.
- GPs don't do their normal job right, so ask them to do this it's a joke leave well alone it is working only very slow
- It is very difficult to speak to hospital doctor and have to wait 18 wks after initial treatment and most times have to ring them if I have not heard in that time.
- Your survey starts from the premise that expert clinicians in secondary care do not involve patients in decisions about their own care and treatment. This is not true. Pain management is complex and specialist, and requires more time than a GP is able to give. I would prefer
- If GPs are responsible - it would be a more personalised service
- Because this is the first time I have been involved in this.
- Not entirely sure I understand how the process will work.
- Chronic pain is generally not understood well perhaps because it is invisible. It's the difference between a headache and a migraine - unless you have experienced a migraine you do not understand the difference - much the same with chronic pain - unless you have experienced it
- All Drs should know about chronic pain, not just what they specialise in.
- Variability in the quality of GP practices / the motivated will accessibility to get a GP appointment some chronic pain is treated by spinal injections which GPs can't do.
- GPs are overloaded as it is. I do not think they have enough time to properly engage with the patient, as a quick 10 min appointment is not going to be sufficient and you would need to see the same GP for follow up appointments which could prove difficult.
- GP not understanding the level of pain I am in on a day to day basis.
- Because I agree that involvement in decisions about your own care is beneficial as long as there are qualified clinicians to support the chronic pain sufferer.
- This works, only if appointments are available outside working hours, not everyone with pain is elderly or out of work. Some of us hold down quite high level jobs, despite our pain, and would like to have access to services including empathetic GPs at times that are more convenient
- I think it makes sense that if patients are more involved in their care this will have a more positive outcome.
- There is no detail in this proposal. The involvement of patients in decisions on their own healthcare is welcomed, but there needs to be more information on what this means in practice
- If GPs are provided with all the information they require, this will help enormously
- Because the Doctor Edwards who is ever so good otherwise request me strong medication as I do have 100grams Tramadol or 50grams of which has effect at about 2 in afternoon
- My impression is that presently patients are referred on for specialist advice from information you have given and I don't believe GPs will be able to provide same expertise in important area.
- Variability in the quantity of GP practices/the motivated with accessibility to get a GP appointment. Some chronic pain is treated by spinal injections which GPs can't do.
- Leeds service sucks, from consultant downwards. No empathy whatsoever. Then the CCG rejects what they might suggest to save money.
- Specialists may be better informed of condition / treatments but GP should be ultimately responsible and oversee.
- I was not confident to say "yes" because the information given about the proposals is limited and I have no experience relevant to the issue.
- Concerned that GPs will not have the time or specialist knowledge to see patients regularly and develop plans with them.
- GP resources are spartan to say the least, GP's needs more regular Doctors and Nurses.
- I am answering as a member of the public but I was a carer for my late husband who suffered with chronic pain. My view is that anything that help individuals feel they have more control should be encouraged.
- I feel that the proposal to change the chronic pain service would be counter productive in managing my condition. As usual it assumes that all patients with a certain condition have the same needs.

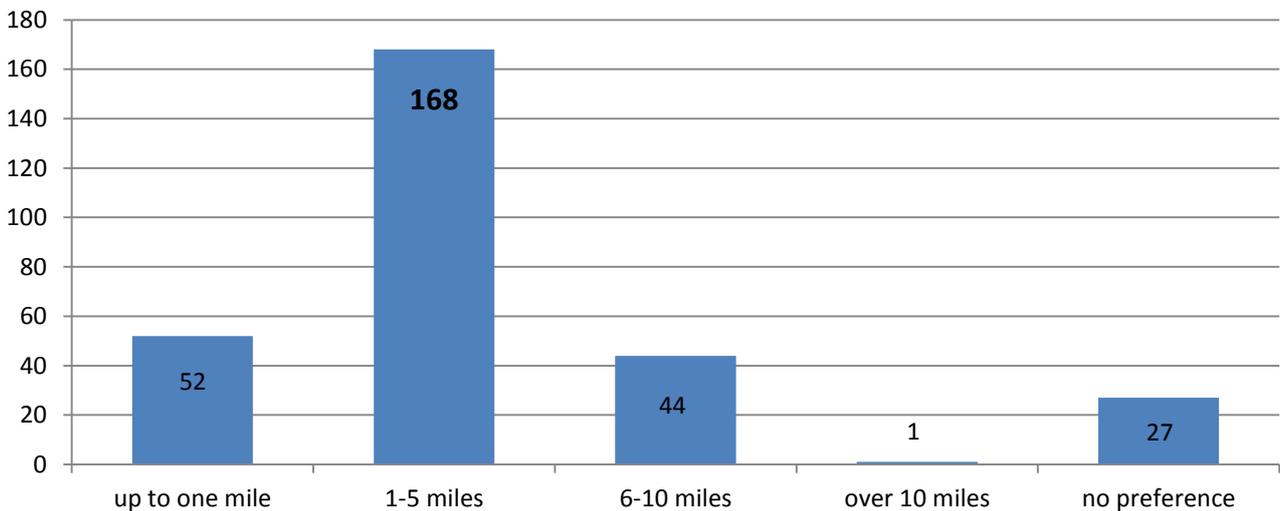
- Having been involved with my wife's Chronic pain problem for the past 20 years my direct experience is that GP's are not trained sufficiently to deal with the nuances and specialised needs that are more routinely observed and acted upon by those with the specialised training
- GPs are usually too busy and often not easily available. There is also the question of not considering non-medical treatments which can be very helpful.
- Waiting for hours for help, may be there would be a better outcome.
- Making patients more involved in their own care means less frustration at the chronic delays in setting specialist opinion when GP refers the patient (or it should).
- 11 years of pain constant waiting no joined up care. And the lack of information. If there is a treatment cost should not play apart in the decision it should be what is best for the patients.
- Will there be a key worker to manage and review my care and stop me getting lost in the system? I don't want to keep seeing different people. I want consistency of care.
- We need to do everything we can to keep people away from hospitals. As the evidence shows self-managed care improves outcomes and costs less.
- Patients should be given all the choices available to them of whats on offer to help them with pain relief and getting a quick appointment so you are not left waiting stuck at home not knowing what to do next with no help. Is no use going to physio when they only give y
- GPs understanding needs raising and a clear pathway without a lot of fuss would be good and clearly understood.
- I'm happy with most of the services but you're not prepared to tolerate prejudice of patients. I feel you get used to one care professional who you develop rehabilitation with.
- My hip problem is recent. Had a scan and X-ray. The X-ray revealed the problem. As I understand there is not a cure. I was taking cocodamol GP thinks they constipated me and changed them to paracetamol.
- You do not have enough specialists to see all patients with chronic pain.
- I am not sure how to answer, my pain is everywhere and I feel a durden on the doctors.
- many gp's don't have the time and generally the knowledge. often dismissing pain for months by which time your told you'll have to live with it as its to chronic to treat. early diagnosis of underlying condition or conditions and the correct treatment. prevention where possi
- Appts too far apart. I have had to ring up on various occasions. GP intervned last time and brought my appt forward by 8 weeks.
- I have been taking different pain killers for many years, but now I feel I am not benefitting from them
- The patient understands how they feel better than anyone, therefore they should have involvement in the plan to treat themselves.
- They show you think about and re-assess how you are doing and how quickly you could improve.
- GP is the person that you usually have a more regular contact with.
- I would always prefer to attend at my GP, sometimes feel that better understanding of conditions such as chronic pain would make sufferers life easier.
- Empower the patient, relationship building with your own GP and Community Healthcare provider. Closer to home. Ease of just popping in for a chat or ask important questions. Local.
- I have never been in this position before so - like a typical patient - I didn't even think about it until it affected me. I really believe people should be involved, everyone in the process (doctors, staff, carers, family, etc). I think the challenge for overworked profess
- My own experience over the past year is that I cannot get to see my GP when I need to, often its more than a week unless I get an urgent appointment. This proposal will make the situation worse for all.
- Because the hospital system is overloaded and its impossible to get regular or urgent appointments.
- If you could see the same GP every time who understands your pain, it would save time and money getting to the hospital and leave appointments for more serious complaints.
- Pain is a very specialist area. Many Gp's may not be interested in this.

- I am a little cynical about spine fit, I attended 3 appointments, first one was just to fill forms in, second was just given exercises for 5 weeks. I had physio previously on 3 occasions and exercises, nothing worked so was unhappy that I was only given exercises from spine
- Chronic pain has a severe impact on the person's life and everything possible with all working together needs to be done.
- This moves towards person centered care and allows patients to have more input and responsibility of their own care management.
- Some GPs cannot give information about condition due to shortage of time and all not fully aware of appropriate action, too much red tape.

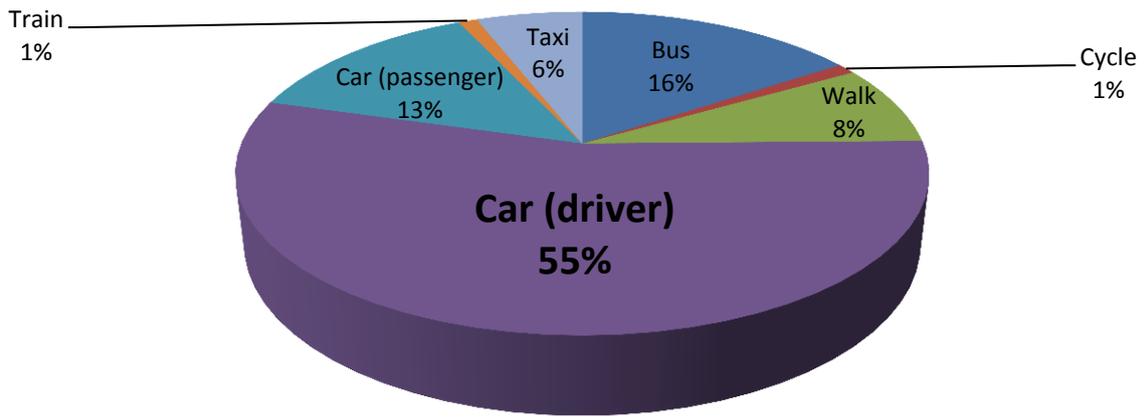
11a. What THREE factors are most important when choosing the location of a pain clinic?



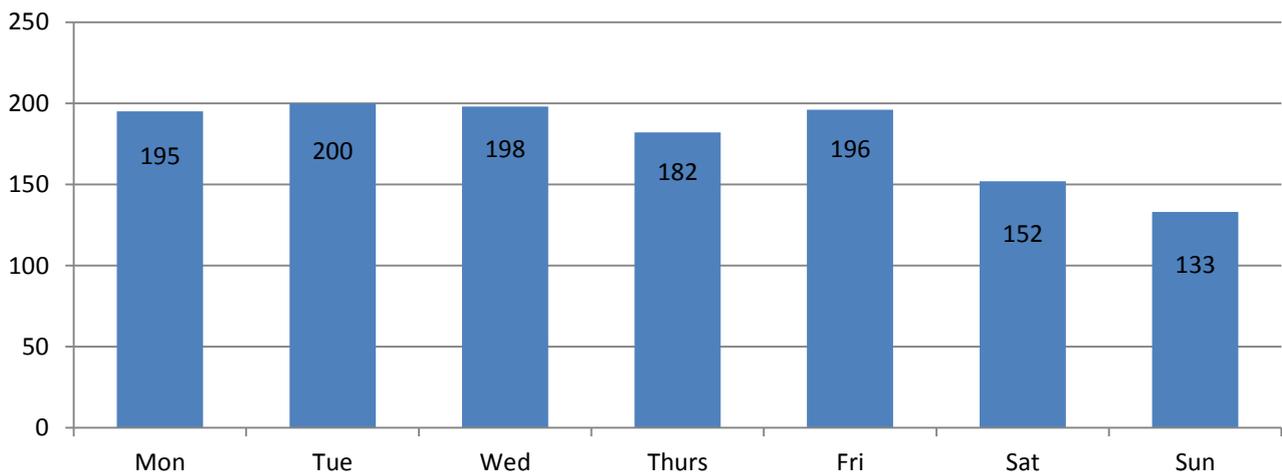
11b. What do you think is an acceptable distance to travel to a clinic?



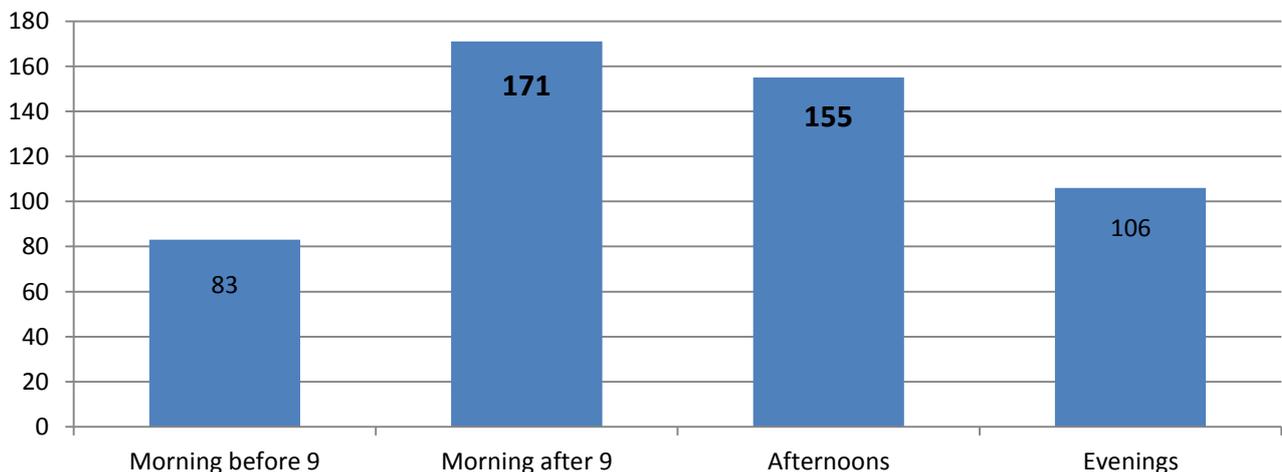
11c. How would you prefer to travel to your appointment?



11d. What days of the week would be most convenient for you to attend an appointment?



11e. What times of the day would be most convenient for you to attend an appointment?



Appendix D – Arthritis Care focus group 1 feedback

Chronic Pain Focus Group with Arthritis Care - Tuesday 30th September

Six participants attended the focus group. They were all recruited through Arthritis Care. They were all female, and none of them identified themselves as being a different gender than they were born as. None of the participants said that they were pregnant, or had given birth in the last 26 weeks. Three of the participants were aged 66-75, three 76-85. Four of the participants said that they were heterosexual, two of them didn't answer the question. Three of the participants identified themselves as Christian, one of them said that they had no religion and two of them didn't answer the question. Five of the participants identified themselves as White British, one didn't answer the question. Two of the participants identified themselves as having Long Standing Conditions, two of them identified themselves as having Physical Disabilities. Only one of the participants identified themselves as a carer. Five of the participants lived in the North Leeds Clinical Commissioning Group, one in the West.

1. What was it like when you first asked for support with you chronic pain?
 - Four of the participants said that they went to their GP Surgery when they first noticed their pain. They were all referred onto other services, and felt that their GPs listened to them. None of them were given any information about how to manage their pain in the interim. Although, one of them was given pain killers to take.
 - One of the participants said that she went to speak to a Rheumatoid Arthritis Specialist at the Hospital that she used to work in.
 - One participant said that she was diagnosed with Rheumatoid Arthritis by accident. She was at a health research event, and mentioned that her wrist has been causing her pain. She had a scan and was diagnosed there and then.
 - All of the participant's initial experiences were three to 30 years ago. The most recent experience being that of the participant who had her wrist scanned at the health research event.
 - All the participants said that if they have any new pains, or if the severity of their pain increases, they go and speak to their GP. All, but one participant said that they see the same GP each time they go to their GP Surgery. The participant who said that she doesn't see the same GP each time, said that she feels that no one will help her with her pain, and she is just told to live with it. The other five participants said that they only want to speak to their usual GP about their pain, as they don't want to speak to GPs who don't know them and may not be able to understand them.

2. Tell us what interventions help you manage your chronic pain?
 - One of the participants said that she has very good medication, but the Chemist seems reluctant to give it to her, as it's an expensive one. She said that if she didn't take this medication, she wouldn't be able to stand up.
 - Two of the participants said that they can't have anything more than Paracetamol, due to the tablets they are taking for their high blood pressure. They both said that they feel like there is nothing that can help them with their pain, so they just live with it.
 - One of the participants said that she has had injections, and these have taken the pain away for up to eight weeks. However, how many of these she can have is limited. She just asks her GP for them if she knows she is going on holiday, as they take the edge off the pain.
 - One of the participants said that she used to go to Chapel Allerton Hospital for massage and water therapy. Both of these interventions helped her a great deal, but are no longer available.
 - There was a discussion about medications, and the side-effects of some of them. None of the participants said this about themselves, but they all knew people who didn't want to take medications.
 - One of the participants said that she had a number of tests done at Chapel Allerton Hospital. They found that she needed a hip replacement, and she was booked in a week later. She said that her friends who have recently had hip replacements weren't booked in as quickly, and weren't given a choice as to when they could have the operation.

- One of the participants said that she had accessed the Expert Patient Programme about Pain Management. She found out about this herself, and referred herself into the service. She said that it was alright, but a lot of it was common sense. However, she said that she found it useful to be around people who are also living with pain.
 - The other participants echoed this, saying that they like attending the Arthritis Care Group. They find it helpful to hear the experiences of other people who are living with the condition.
3. Tell us about your understanding of self-management?
- All of the participants said that they manage their own pain in various ways.
 - One participant said that she reads to distract herself.
 - Two of the participants said that they go out together a lot, and help get each other out of the house if one of them isn't feeling motivated enough to go out.
 - The participant who said that she accessed the Expert Patient Programme said that she sets herself daily manageable goals to achieve.
 - Four of the participants said that they garden to help distract themselves, and they love spending time in their gardens. They help each other and share advice about how to make their gardens accessible for their needs.
 - One of the participants said that when she has tasks to do, she writes a list and takes a couple of Paracetamol, so she can get them done. Another participant said that she does this as well, and she feels pleased when she has achieved what she needs to get done.
 - All of the participants said that they do exercises at home to help their pain. The group agreed that the exercises make their pain easier to live with. They all agreed that the worst thing that they can do is sit around and do nothing, they said that they need to get on with their lives.
 - Two of the participants said that they go to the gym to have massages, as they help ease the pain. They are expensive, so they don't go often.
 - Two of the participants responded to this saying that they go to the College for massages and facials. They said that it is important to look after themselves, as if they get tense, their pain is worse.
4. What do people think of the proposal?
- All the participants said that they agreed with the proposal.
 - They shared concerns that their GP may not have the time to listen to them, as appointments only last ten minutes.
 - However, they said that they would want to be triaged into another service that can actually help them.
 - They also said that they would appreciate more choice in the services that they can access.
 - All the participants agreed that they want to speak to someone who actually understands their needs and has the time to properly listen to them.
5. How can we make chronic pain services easier to access?
- The participants were all keen to speak to the same GP each time they have an appointment.
 - None of the participants shared concerns about where they travel to for their appointments.

Appendix E – Arthritis Care focus group 2 feedback

Chronic Pain Focus Group with Arthritis Care – Wednesday 1st October

Three participants attended the focus group. They were all recruited through Arthritis Care. They were all female, and none of them identified themselves as being a different gender than they were born as. None of the participants said that they were pregnant, or had given birth in the last 26 weeks. One of the participants was aged 56-65, one 66-75 and one 76-85. All of the participants said that they were heterosexual. Two of the participants identified themselves as Christian, one of them said that they had no religion. All three participants identified themselves as White British. Two of the participants identified themselves as having Long Standing Conditions, two of them identified themselves as having Physical Disabilities. None of the participants identified themselves as a carer. All three participants lived in the North Leeds Clinical Commissioning Group.

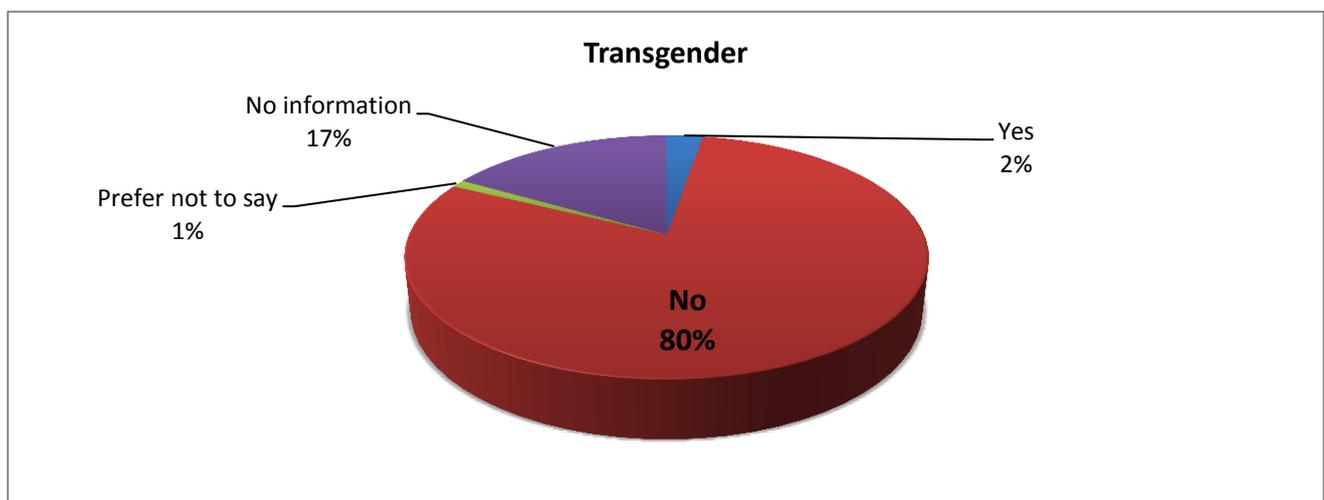
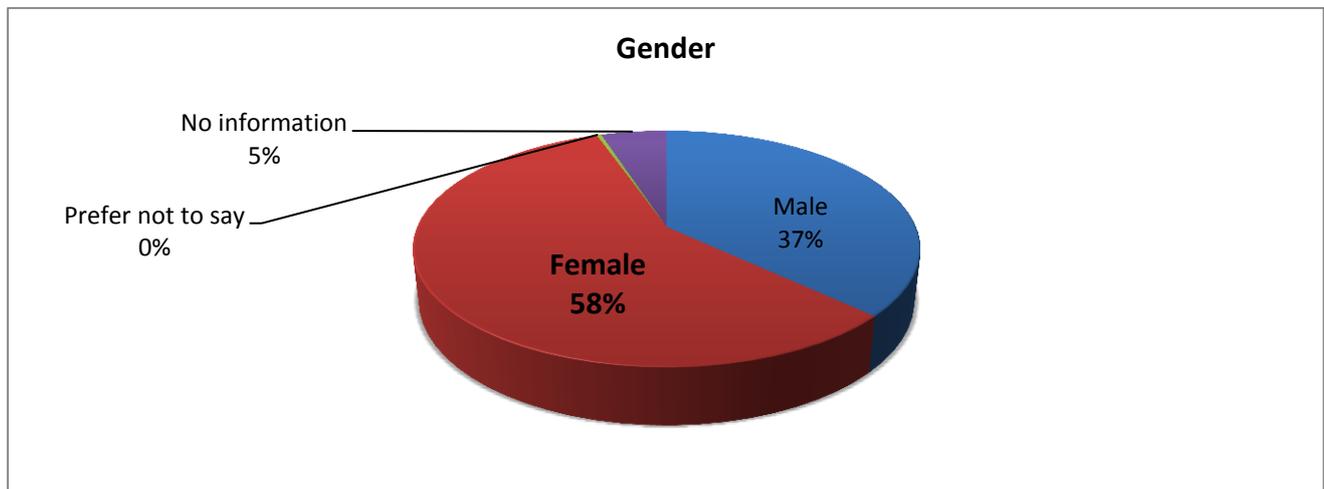
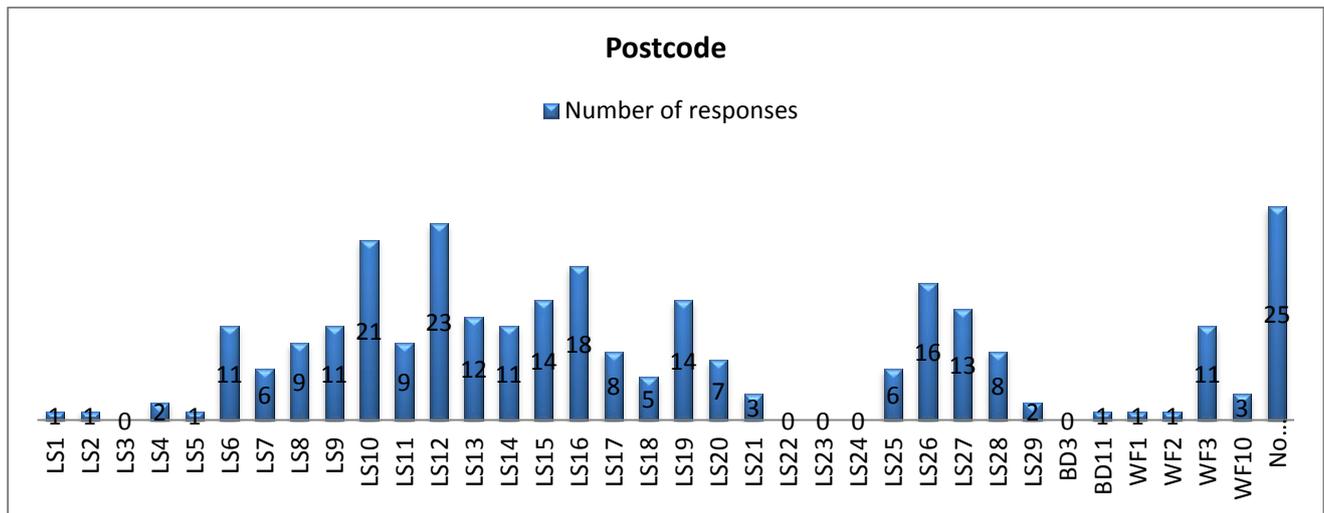
1. What was it like when you first asked for support with you chronic pain?
 - One of the participants said that she spoke to her GP, and asked for pain killers. Her GP said that he wouldn't give her pain killers, and referred her along to the Expert Patient Programme for Pain Management. She said that she feels like no one understands her pain, and she shouldn't have been left to self-manage without having any initial support.
 - The second participant said that her pain comes from a fall that she had 15 years ago. For a long time her GP said that it was Sciatica, and just gave her medication. She used to go swimming, but the leisure centre won't let her in anymore due to her using a frame. She referred herself into the Expert Patient Programme for Pain Management. She said that she feels like no one ever asks about your mental health when you are living with pain. She admitted that she has found her pain very difficult to live with, and at one point she couldn't even get out of bed. She would have appreciated more mental health support. She also said that Doctors are very quick to blame her weight for her problems, her GP told her that she has to lose weight first and then they will look at her pain. She said that when she pushes her GP, she tends to get what she wants from her. She has been referred into Bariatric Services, they gave her a walking frame, which she uses, but nothing else. She showed her referral letter, and said that it was full of medical terminology that she couldn't understand. She also had to independently travel over to Wetherby for her appointment.
 - The third participant said that she always has aches and pains, particularly in her neck. She said that her feet are very painful. She has spoken to her GP about this, but he won't make a referral for her to have a fitting for orthopaedic shoes.
 - The first participant said that she has had orthopaedic shoes made. She said that she asked for them, and that she depends on her bold personality a lot to get what she wants from health care services.
2. Tell us what interventions help you manage your chronic pain?
 - One of the participants said that she has raised furniture in her house. She said that it is important for her to focus on her posture. She learnt this when she was using a shopping trolley, and found the extra support and change to her posture made her more mobile. She said that she isn't able to get in and out of her bath anymore, so she goes to the swimming pool instead, as she finds the showers there easier to use instead.
 - Two of the participants said that they do Tai Chi, which helps them. They both do this because they can't do aerobics. They said that you adapt to what you can do, so you can actually exercise.
 - One of the participants said that she was involved in a research programme arranged by Leeds Metropolitan University and Chapel Allerton Hospital. She felt that the research programme made a difference to everyone involved. She said that she also does her own research on new drugs using the internet and Facebook.
 - One of the participants said that she hasn't been as well supported since her GP left the Practice. She now sees someone who is a Rheumatoid Arthritis Specialist, but she is unsure of his ability. She wants someone who understands her pain and needs.

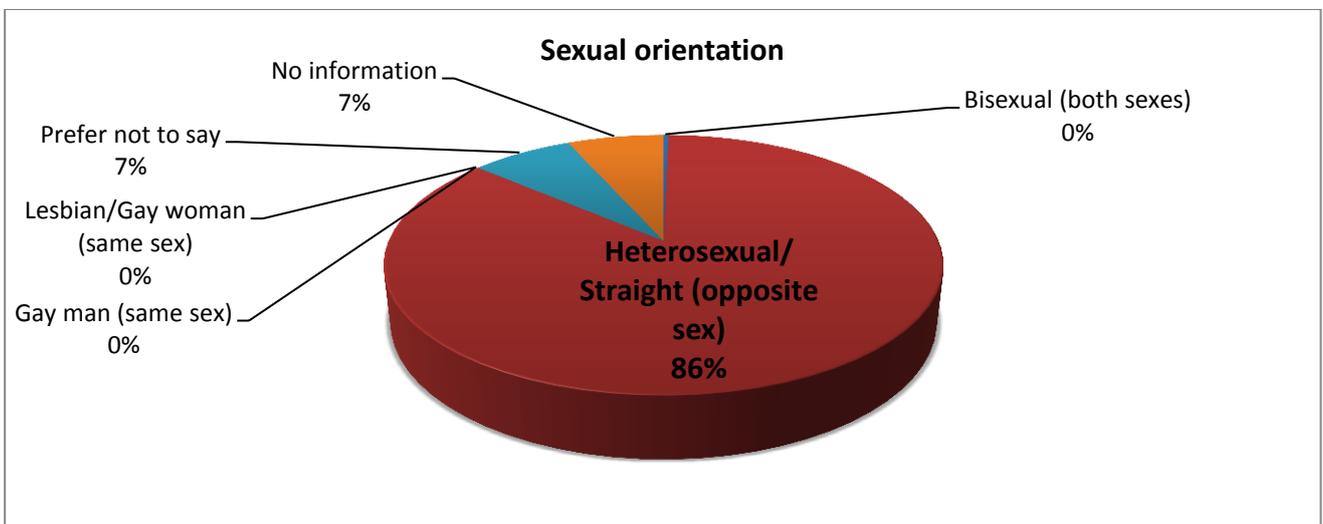
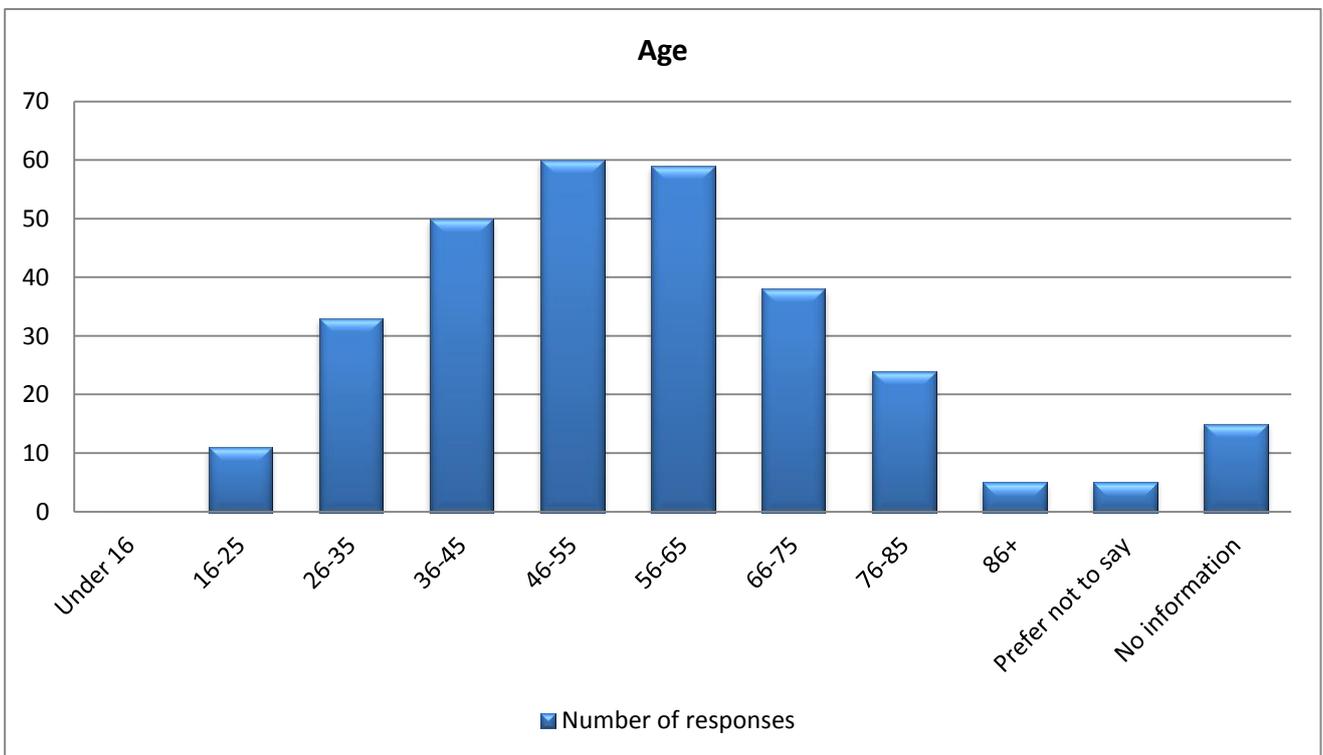
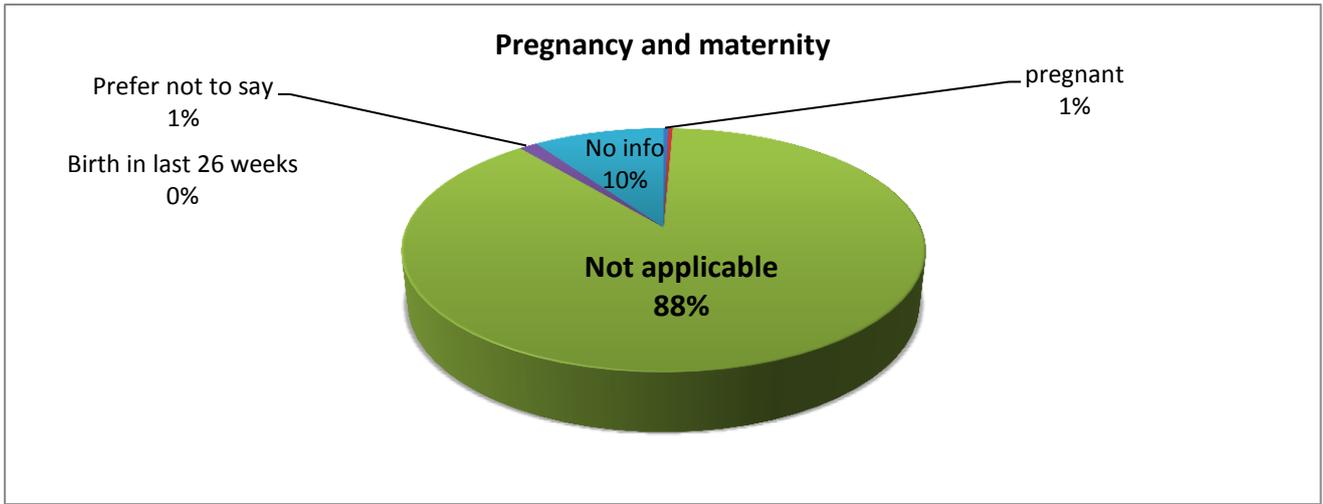
- There was a discussion about the cost of exercise classes, as one participant said that she goes swimming three times a week and this really helps ease the pain. She also attends a seated exercise class. Neither of these are particularly expensive, as the swimming pool is a Council one and the exercise class is run through Feel Good Factor, which is a charity. There was some agreement that not everyone could even afford this though. Another participant said that she attends a seated exercise class, and it helps her to mix with other people who are living with pain.
 - One of the participants said that she has paid for acupuncture and counselling. One of the respondents said that she has considered paying for acupuncture, but was worried about it making her condition worse.
3. Tell us about your understanding of self-management?
- All three of the participants self-manage their pain, as there isn't really another option for them when they are living with Arthritis.
4. What do people think of the proposal?
- One of the participants said that she liked the idea of the proposal. She needed an operation on her shoulder, and her GP gave her a choice of which hospital she could go to. Spire was the nearest hospital, and the closest one to her home. She said that she felt bad about going to Spire, as she knew it cost a lot more for the NHS, but she needed an operation, and travelling was difficult for her.
 - The participants said that they would want the option to access services to help them live with their pain through the voluntary sector, as it'll be a cheaper and more accessible option for them.
 - When discussing Adult Social Care, none of the participants said that they receive help. They said that if they had Care Plans and were treated as patients rather than conditions, they would be supported better and referred into the services that they need to be accessing to help them live with their pain.
5. How can we make chronic pain services easier to access?
- Two of the participants said that they have difficulties traveling at times, as cars and buses can be bumpy and jar their joints, making them more painful. For this reason they would services as close to their homes as possible.

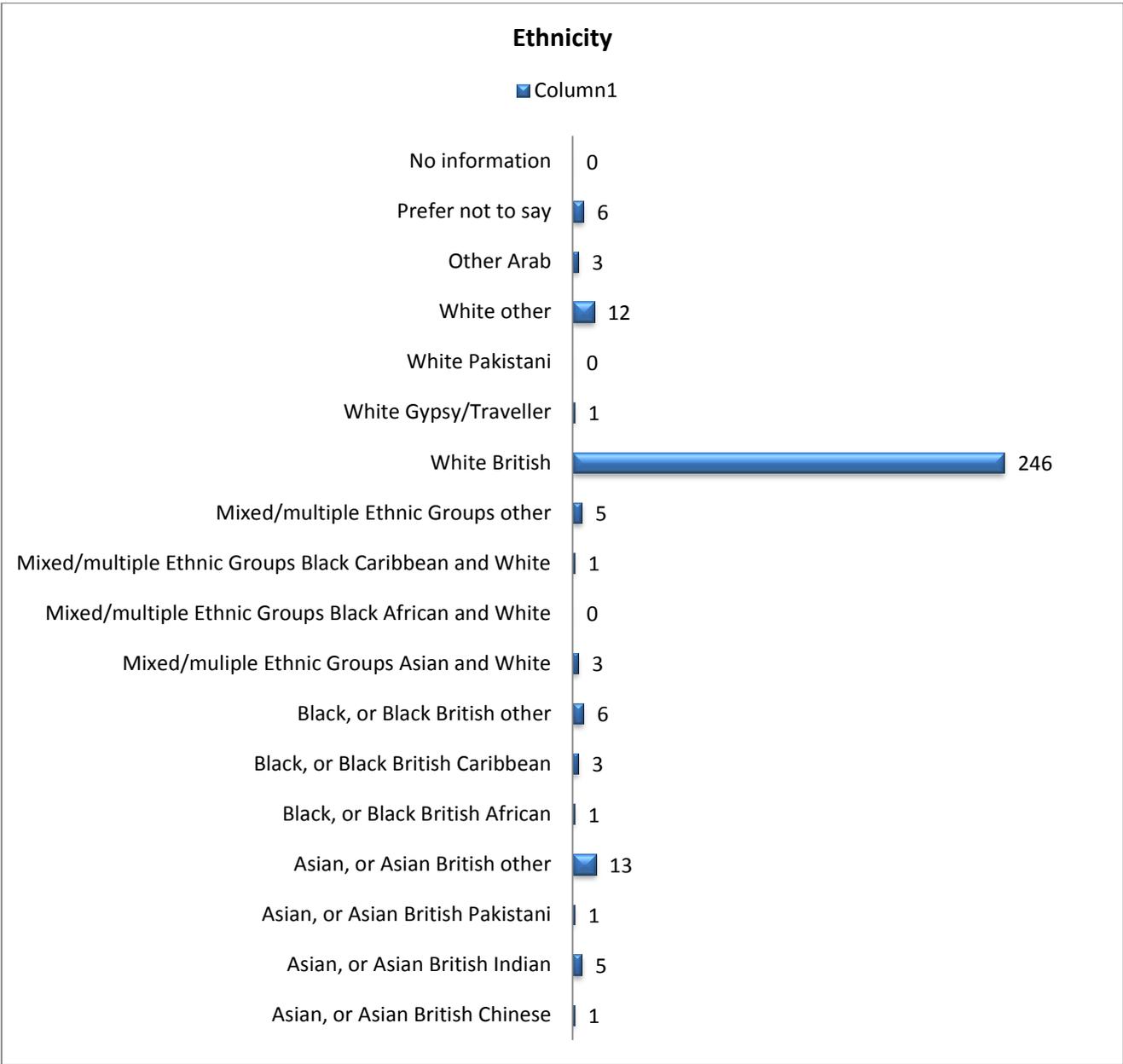
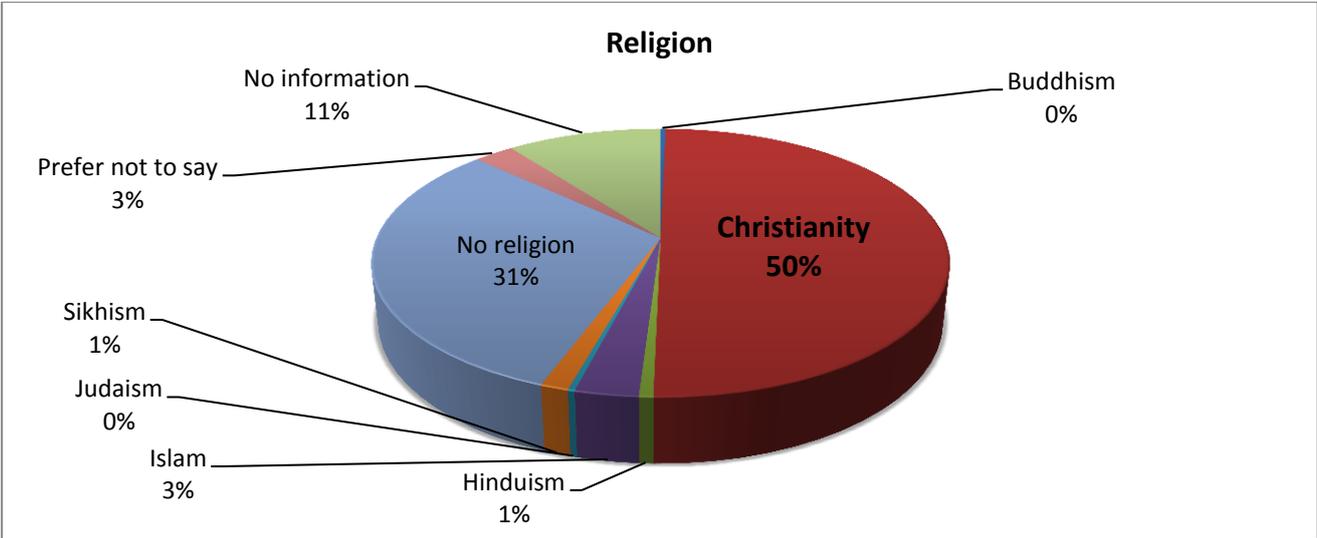
Appendix F - Detail about the people who were involved

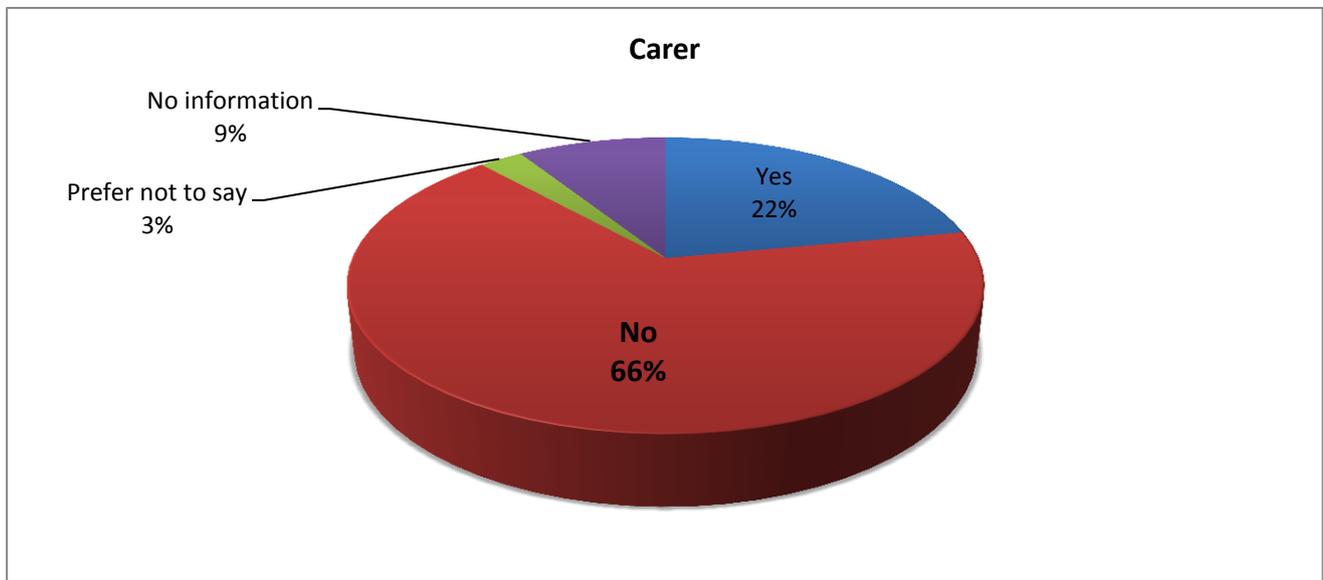
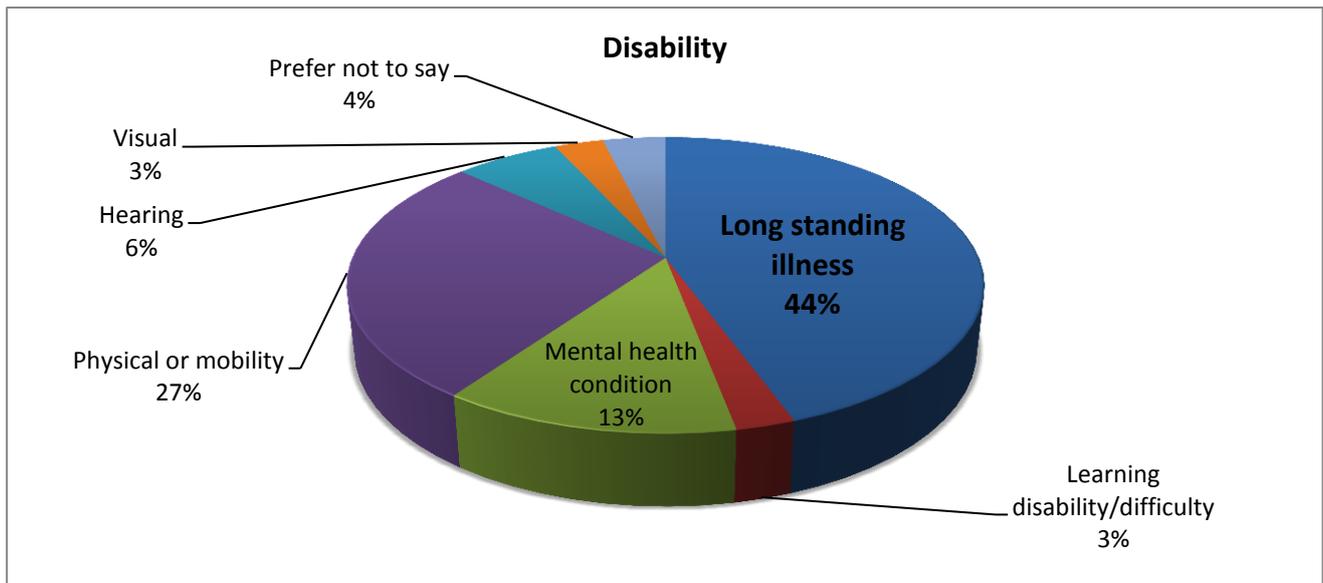
We want our events to be attended by a representative section of our population. When we ask people to get involved we also ask people to give us some information about themselves so that we have a better understanding of which groups are not represented. Using this information we will work hard at future events to invite people from under-represented communities. Patients are able to opt out of giving personal information.

Postcodes map









Who was under-represented at this event?

Equality monitoring was not carried out with people who attended the focus groups. In addition, a number of people chose not to complete the equality monitoring section of the survey used by NHS Leeds West CCG and therefore it is difficult to ascertain which population groups in Leeds were under-represented. However, the data suggests that the following groups were underrepresented:

- Some areas of Leeds
- The LGBT community
- Various ethnicities
- Various faiths

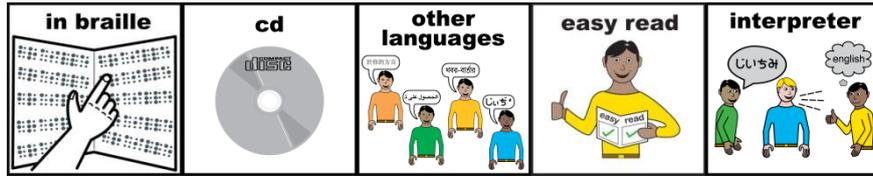
Alternative formats

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If you need this information in another language or format please contact us by telephone: **0113 84 35470** or by email: commsleedswestccg@nhs.net

'Jeśli w celu zrozumienia tych informacji potrzebuje Pan(i) pomocy w innym języku lub innej formie, prosimy o kontakt pod numerem tel.: **0113 84 35470** lub poprzez email na adres: commsleedswestccg@nhs.net

اگر آپ کو ان معلومات کو سمجھنے کے لیے یہ کسی اور زبان یا صورت میں درکار ہوں تو برائے مہربانی سے اس نمبر پر فون کر کے رابطہ کریں: 0113 8435470 یا اس پتہ پر ای میل لکھیں: commsleedswestccg@nhs.net



Further information

If you would like any more information about this project or NHS Leeds West Clinical Commissioning Group, or have any questions or comments, please write to:

Chris Bridle

Engagement lead

NHS Leeds West Clinical Commissioning Group

Suites 2-4

Wira House

West Park Ring Road

Leeds, LS16 6EB

Main switchboard: 0113 84 35470

Email: commsleedswestccg@nhs.net

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