



**Physical Health:
Rheumatic & Inflammatory Conditions**

May 2016

Disclaimer

Please note that this report relates to findings from 36 residents. Our report therefore is not a representative portrayal of the experience of all residents, only an account of what was contributed at the time.

Acknowledgements

Healthwatch Blackburn with Darwen would like to thank those who shared their experience and the following organisations for allowing us to engage with residents who use their services or allowed us to hold workshops & engagement events at their venues.

- Derwent Hall
- Fibro Friends
- Trinity United Reformed Church, Blackburn
- Your Support Your Choice

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Introduction

Why Rheumatic & Inflammatory Conditions?

Healthwatch Blackburn with Darwen identified trends appearing in relation to those with Rheumatic & Inflammatory Conditions and their experiences of Health & Social Care provision, especially those living with Arthritis & Fibromyalgia.

Local Statistics

Local statistics specific to Rheumatic & Inflammatory Conditions where difficult to find as where national statistics for Fibromyalgia as further detailed below.

How many existing cases of rheumatoid arthritis are there in the UK?

Age	Males (%)	UK estimate	Females (%)	UK estimate
16-44	0.02*	2,500	0.12	15,100
45-64	0.58	42,900	1.67	126,900
64-74	1.14	27,100	2.56	67,800
75+	2.18	39,100	2.99	85,700
Total adult population	0.44	106,500	1.16	297,600

ME Association, Fibromyalgia Statistics & Department of Health Guidance

How many new cases of rheumatoid arthritis are there in the UK per year?

Age	Males/100,000	UK estimate	Females/100,000	UK estimate
15-24	3.0	120	15.5	610
25-34	5.6	220	29.0	1,150
35-44	12.1	560	50.6	2,370
45-54	31.3	1,210	91.9	3,640
55-64	42.1	1,480	88.1	3,210
65-74	66.6	1,590	94.4	2,500
75+	57.0	1,020	29.8	850

Arthritis Research UK

On 5 September 2014, Minister of State Norman Lamb replied to a Parliamentary Question regarding fibromyalgia:

The Department has made no estimate of the number of fibromyalgia sufferers in the United Kingdom. As the condition is poorly understood and there is not specific diagnostic test, it is difficult to make a reliable estimate.

Although there is no cure for fibromyalgia, some treatments can ease symptoms and support improved quality of life for patients. The treatments offered will depend on the severity of a patient's condition, but may include: pharmacological pain relief; physiotherapy; dietary and exercise advice; counselling or cognitive behavioural therapy; and self-management programmes which aim to give patients the skills and confidence to manage their conditions more effectively. There are also a number of NHS Trusts that offer specialist fibromyalgia clinics, such the Royal National Hospital for Rheumatic Diseases in Bath, which patients can access on referral from the clinician responsible for their care.

In each of the last three years, the Department's National Institute for Health Research has spent 0.1 million pounds on fibromyalgia research.

Variable	Measure	Blackburn with Darwen	North West	England
All Usual Residents (Persons) ¹	Count	147,489	7,052,177	53,012,456
Day-to-Day Activities Limited a Lot (Persons) ¹	Count	15,563	724,045	4,405,394
Day-to-Day Activities Limited a Little (Persons) ¹	Count	14,278	702,760	4,947,192
Day-to-Day Activities Not Limited (Persons) ¹	Count	117,648	5,625,372	43,659,870

Research Methods

Questionnaire

A questionnaire was designed to collect resident's views on their experiences of Health & Social Care Provision, particularly focussing on Diagnosis, Post Diagnosis & Ongoing Support and Treatment & Services. The questionnaire was completed at community access points, lunch clubs and support groups. A number of residents contacted us directly after finding out about the project & wanting to share their own experience.



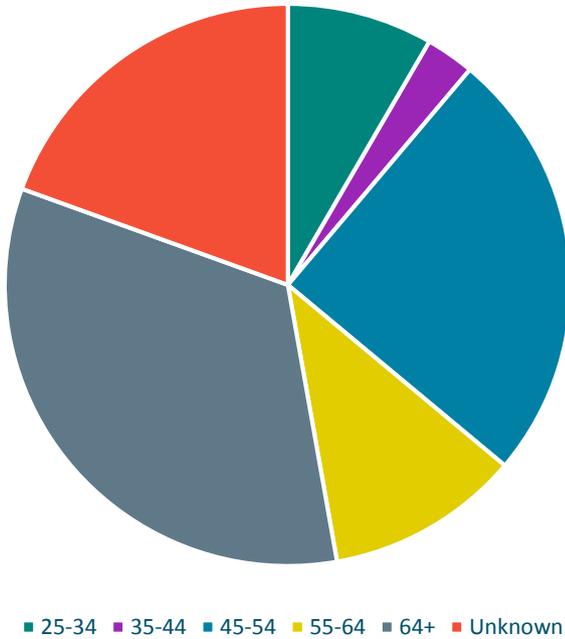
Your View Your Voice

Your View Your Voice is an interactive monthly workshop which allows residents to share their views & experiences, a monthly theme aims to target a particular demographic, health condition or related theme. Ten residents attended a YVYV Workshop on Rheumatic & Inflammatory conditions and had the opportunity to discuss & debate whilst sharing their own personal views & experiences in detail.

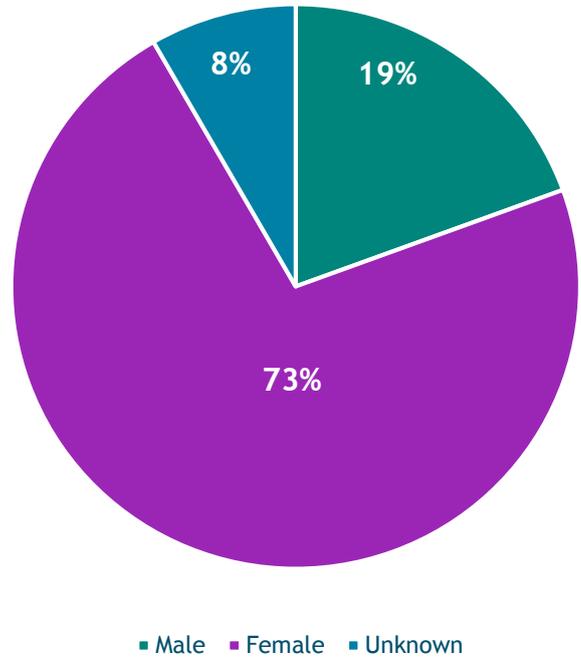
Who we spoke to?

In total we engaged with 36 residents with a Rheumatic or Inflammatory Condition.

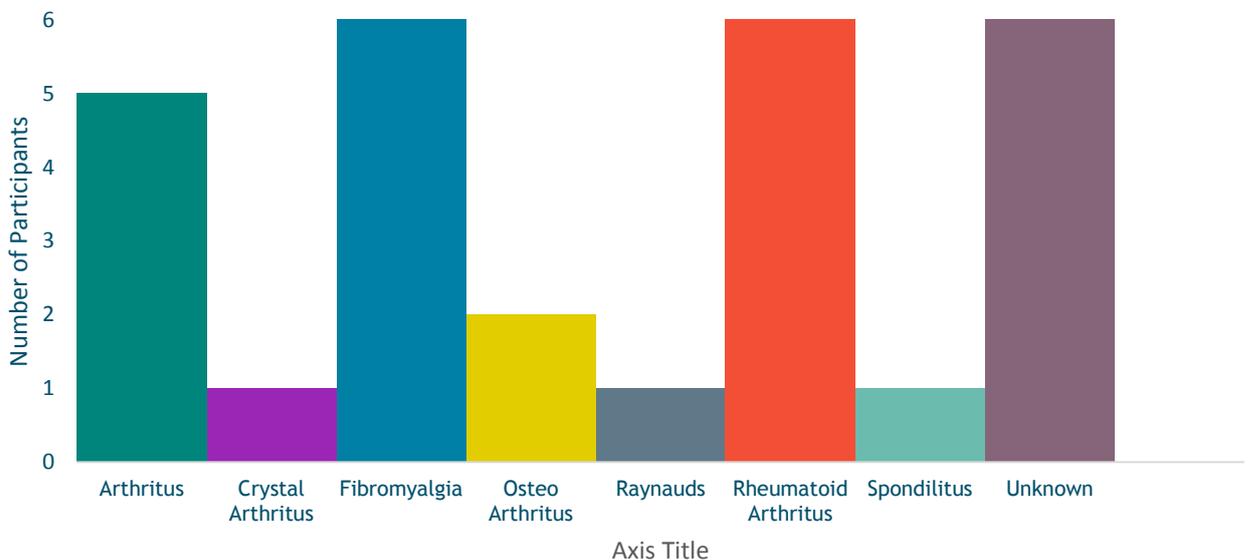
Age of Participants



Gender of Participants



Diagnosis of Participants

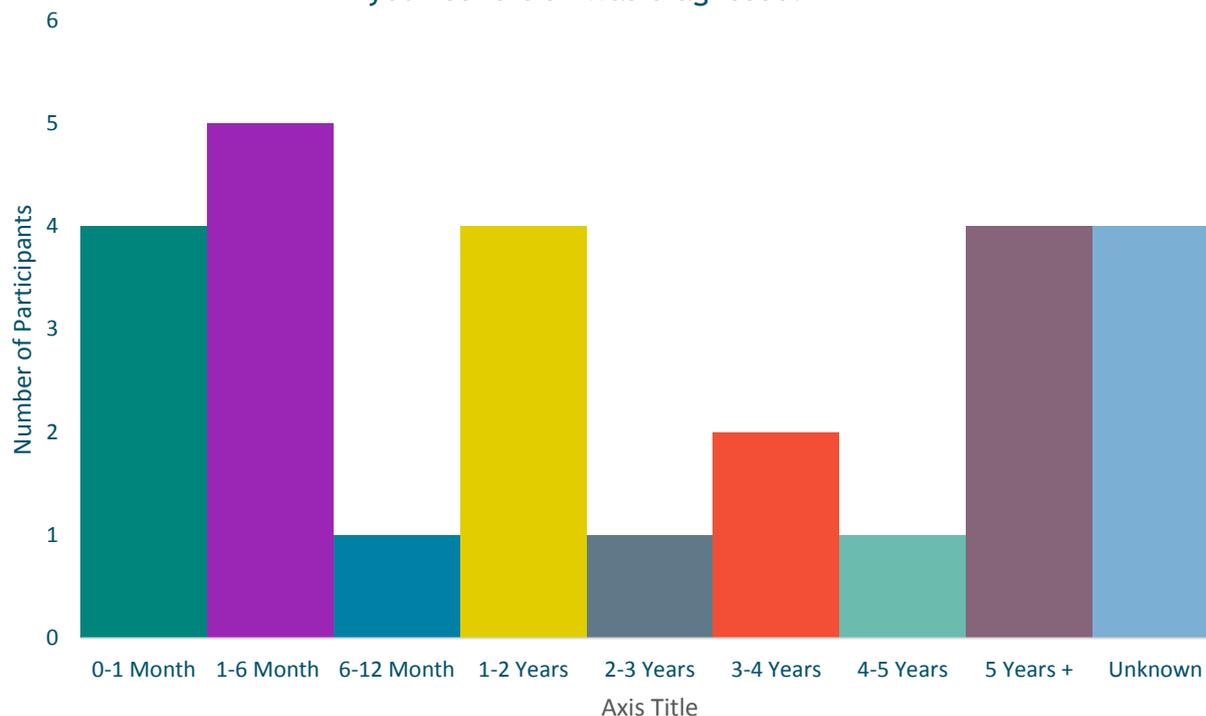


Research Findings & Key Themes

Diagnosis

Time waiting for Diagnosis

Q. If your condition has been diagnosed how long was it from the first time you raised symptoms with a health professional before your condition was diagnosed?



The time people spent waiting for a diagnosis varied widely with diagnosis being almost immediate to in one case 24 years. The vast majority of people found that the time spent waiting for a diagnosis was too long, often a diagnosis was missed with symptoms being blamed on other conditions.

Those with Fibromyalgia had a particularly bad experience, visiting various medical professionals over numerous appointments with differing views. People often felt ignored & let down.

'Fibro was missed due to Crohns Disease, I knew the symptoms weren't just Crohns, I told the GP, he ignored me'

'5+ yrs. At first I thought I had a virus, then joint pain, told to go away and lose weight, and visited GP several times before Fibromyalgia diagnoses'

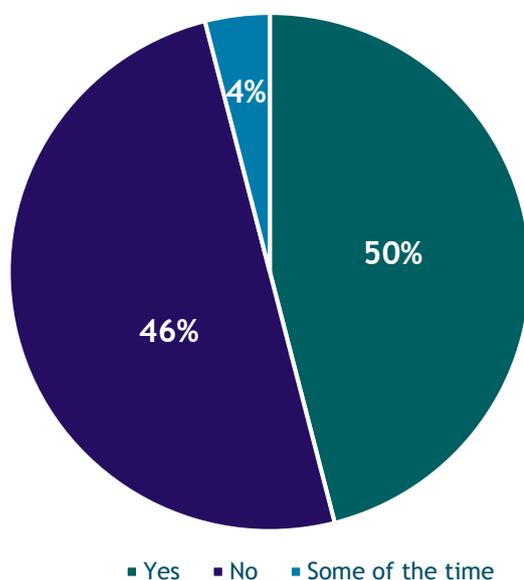
'In 1991 I raised my symptoms, I have only just been diagnosed in May'15. It took 24 years to be diagnosed with Fibro.'

'GP knew there was something wrong, got sent to quite a few places told nothing wrong, all in my head.'

'You have to go through lots of different systems first, whilst waiting your condition gets worse before you see someone.'

Information

Q. Were you offered information about your condition?

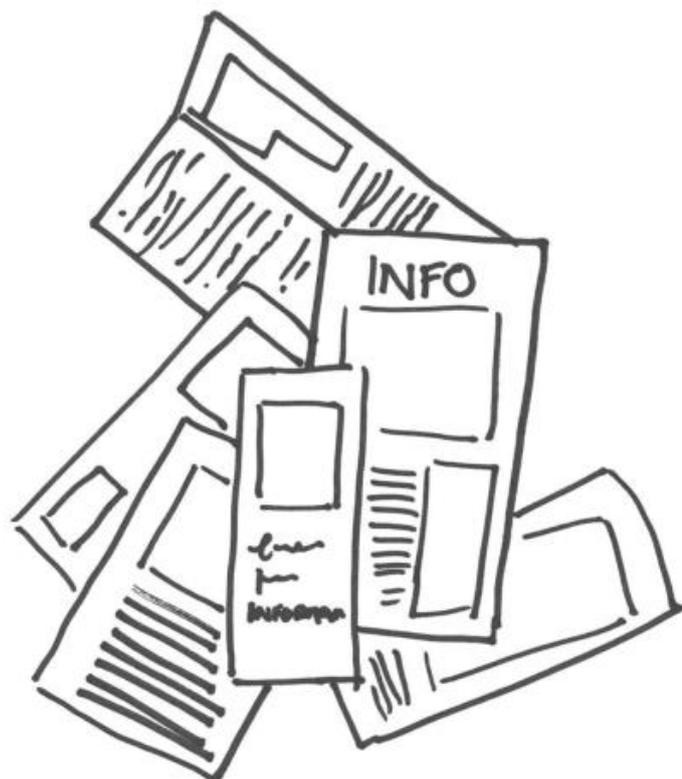


50% of participants weren't offered information about their condition

A number of people we spoke to including a lady with a nursing background said they had to do their own research on their condition and often felt more informed than professionals. These participants were having to inform professionals about their condition having done the research themselves but weren't always taken seriously.

Many of those offered information were given a leaflet, although this was useful for some a number of participants found it impersonal and the information provided was too generic, not correlating to one's personal experience & symptoms.

No information seemed to be provided on what those diagnosed expected in the future, no discussion or information was provided in relation to what happens with work, income & the wider impact.



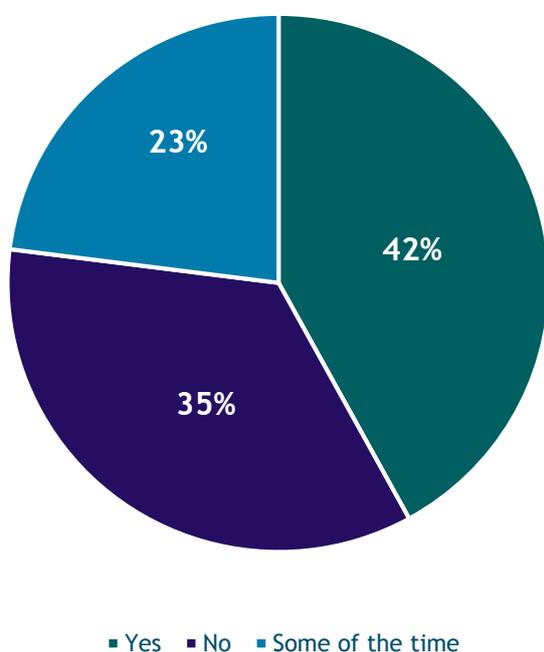
Standard info in a leaflet, told the only way to treat it is anti-depressants and painkillers.'

Rheumatologist nurse spoke about what things could inflame it. I was in shock, the nurse gave me quite a lot of information, they could explain things to me, cried after first diagnosed, felt listened too'

Post Diagnosis & Ongoing Support

Confidence in Health Professional

Q. Do you have confidence in health professionals ability to manage your condition?



Only 42% of participants had confidence in health professional's ability to manage their condition

People gave mixed feedback regarding their GP's, with some being very helpful & others appearing disinterested, patronising or unable to help. There seemed to be a lack of consistency for many, especially if they saw more than one GP with differing approach and views. This also provided difficulty in regards to having to repeat themselves.

'My friend, who after numerous bad experiences, has lost all confidence in medical professionals. She now avoids the GP or waits too long for an appointment, as a result of this her health is out of control.'

A number of people with Fibromyalgia spoke about how medical professionals would blame other symptoms on the Fibromyalgia diagnosis, the diagnosis then becoming a challenge in itself as they didn't make much effort to investigate other symptoms further. A lack of knowledge on the professional's part was again mentioned here.

A number of people spoke about the attitude and behaviour of GP's receptionists. One resident spoke of how when they call the GP the doctors receptionist tells them to 'just take painkillers'. Many were uncomfortable with how receptionists were asking why they wanted to see the GP, asking about symptoms and taking decisions into their own hands. A number also spoke of confidentiality when visiting the GP and how personal questions were asked around other patients.

Two participants spoke of how they had been offered a prayer when calling/visiting the GP, saying 'God will take care of it', this was found as both inappropriate and offensive.

'I didn't think the consultant I was seeing was passionate about her job, I felt fobbed off.'

'Yes, I do have confidence, they are very good, I go to Burnley Rheumatoid department'

'Tell them I have all this pain and they tell you to take paracetamol every 4 hours.'

'I get cream and oil, don't really have any confidence in health professionals.'

'One GP listens, the other GP is a bit patronising. Don't know if she completely believes it (fibro).'

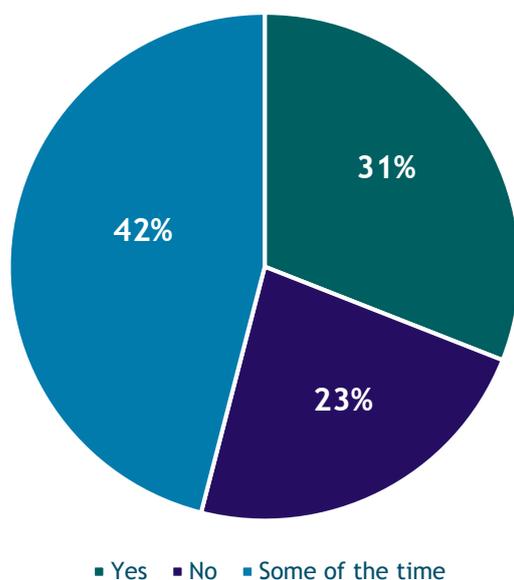
'I have zero confidence... no GPs keep up-to-date with the recent info. I know more about it than any of them.'

'At first health professionals made me feel like it's all in my head'



Understanding and Supporting Individual Situation and Needs

Q. Do you feel health professionals understand and support your individual situation and needs?



Over 60% of participants felt health professionals didn't understand and support their individual situation and needs, or only did so some of the time.

This again seemed to depend very much on an individual GP and their attitude.

Those with Fibromyalgia again felt Health Professionals didn't have enough understanding of the condition to fully understand or support their individual needs.

GP's and specialists received mixed feedback whilst people's experience of Physio or Pain Management was generally a good one.

A number of people spoke about how Health Professionals often think they know best yet often don't take into consideration the individual, rather using a one size fits all approach.

A number spoke of difficulty in getting an appointment, one person spoke of how they had recently had three appointments cancelled.

When attending appointments they were often at the far end of a building or corridor which became a challenge for those struggling to walk distances or in pain.

'My doctor is not bad but he could be better. He listens but he doesn't do much.'

'I have paid privately for a chiropractor. If I went to the NHS I would only get painkillers'

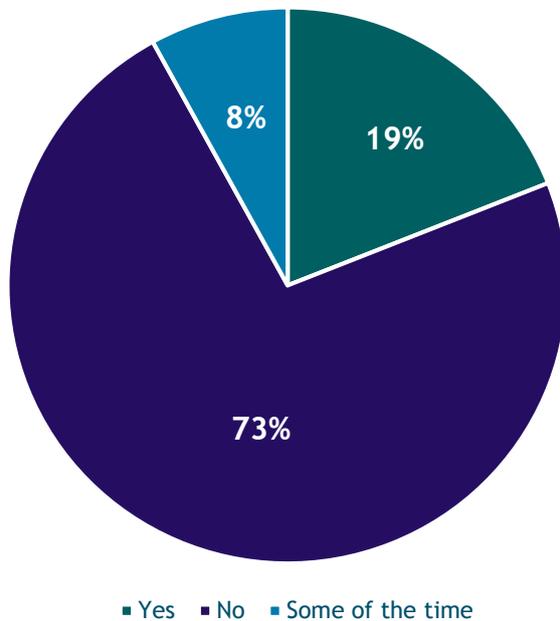
'Some do, majority don't. Might be because of lack of information but some are just in it for the money.'

'No, they have been trained to look at a situation but if they haven't been through it how do they know. They should treat the individual not the condition.'

'I was looking at alternative things I could do with myself. They signed me off because I was looking at other treatment.'

Choice & Involvement

Do you feel you were given a choice and involved in your support and treatment?



73% of participants felt they weren't given a choice or involved in their support and treatment

Many people felt there was a lack of choice, with medication and treatments given without discussing different options available. One resident spoke about how they felt like they were being 'told off' for asking questions.

Many spoke about how there only ever seemed to be one choice and this was made by the medical professional, in many cases this didn't suit the individual in question.

When residents suggested alternative treatment and therapies they were discouraged or ignored.

'Not happy, not enough to handle the pain nor does it address the medical condition, anti-depressants don't help, they just make things worse'

'No one has ever asked me what I would like to do. Listened to them and gone along with it.'

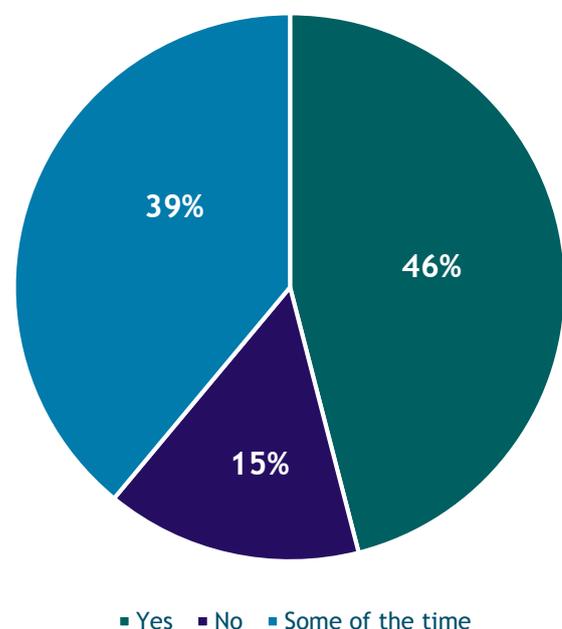
'I am informing them because I have researched it.'

'There's only ever one option to take...'

Treatment, Services & Local Provision

Managing Pain

Q. Are you happy with the treatment you get for your pain?



Only 46% of participants were happy with the treatment they received for their pain

Many residents spoke of medication being changed regularly to find one that properly manages the pain, in some cases ending up on the original medication, 'it's a round and round thing', after long periods of experimentation. One resident spoke of how they started off with the cheaper medications and it took many years to get the 'really good stuff' which properly managed the pain, they would have liked this process to have happened more quickly or not at all.

Differing views of nurses & consultants was picked up on by a number of residents, this resulted in confusion or delay in treatment.

Many were in constant pain, medication changed regularly to try and manage this but often with little or short term success.

One resident with Fibromyalgia talked of how they attended Royal Blackburn Hospital with severe pain but the consultant said 'it was in my mind, people with fibro have pain differently, he said it wasn't real.'

A number of people spoke about how they preferred managing their condition themselves through the use of alternative therapies, complimentary medicine, swimming and apple cider vinegar.

One participant's husband massaged the area affected by arthritis for her every night to ease the pain. Sometimes the pain was so severe she felt like she wanted to 'scream and cry'. Massages were found to be a benefit for a number of participants but they aren't something professionals often suggest & individuals

have to pay themselves as it isn't provided on the NHS. Those without a family member able to provide massages are at an immediate disadvantage unless they can afford to pay themselves.



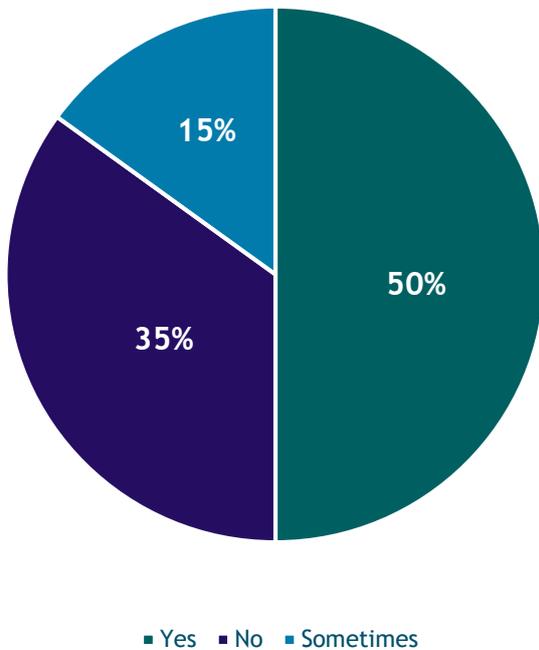
'Have to go to Burnley for injections - 6 hr round trip - if I was under a consultant based in Blackburn I'd be able to go there.'

'Not really no but I don't want to complain about it.'

'...manage my condition myself, medical professionals don't walk in my shoes'

Challenges

Are there any parts of the services you have received you are unhappy with or have found particularly challenging?



85% of participants were unhappy with parts of the services they had received or had found them challenging at least some of the time

Age

Rheumatic & Inflammatory Conditions were seen to be something that professionals related to Old Age. This resulted in those younger people with a diagnosis being ignored or having lack of suitable provision, whilst older residents also felt ignored, as if having the diagnosis was just part of old age.

'I don't think they take arthritis seriously, they just think it's one of those things you get when you're older, they just think it's an old persons disease.'

'Unhappy with first and second consultant. I feel like they have too many patients on their books to be able to care properly.'

'I gave up and did my own thing.'

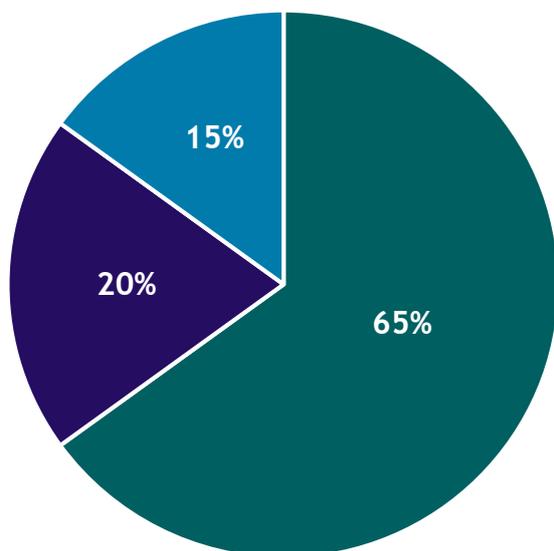
'A challenge to get them to acknowledge there was anything wrong with me in the first place.'

'You have to find out info yourself, it's not offered to you'

'I have to get a taxi or bus to hospital appointments, it costs too much money'

What participants would like to see locally?

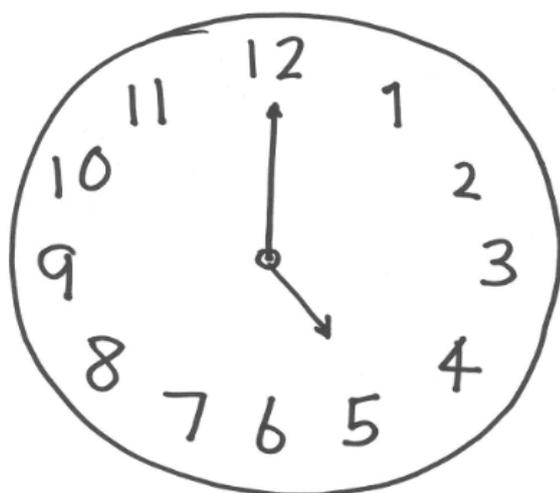
Q. Are there any services you would like access to locally but don't currently?



■ Yes ■ No ■ Unsure

All Age, all hours

A number of residents, especially those of working age or with children spoke of how services appeared to be aimed at older people and services/support sessions didn't happen outside of working hours.



Exercise

Aqua Mobility & Gentle Exercise were mentioned on numerous occasions, again at times which suit all individuals and not just those who can attend during the day.

Support

Having someone to talk to or a local support group was seen as something that would have a positive impact on those living with a Rheumatic or Inflammatory Condition.

'Maybe somewhere where you can go for a discussion about arthritis.'

Alternative Treatment

On numerous occasions throughout the project participants spoke of Alternative Treatments which they felt would help their condition but were never looked into or supported by medical professionals.

A number of residents had used alternative therapies themselves and had seen some benefit.

Yoga was also mentioned by a small number of participants and was something GP's hadn't suggested.



'Tried to access chiropractor but NHS won't fund it. Would have to pay £90 which I can't afford.'

Conclusion

1. Those living with Rheumatic & Inflammatory Conditions on the whole had a negative experience in regards to Health & Social Care.
2. Those with Fibromyalgia had a particularly bad experience and participants felt there was much improvement in terms of knowledge, experience and understanding needed.
3. Participants felt diagnosis was often lengthy and a frustrating experience, especially for those with Fibromyalgia.
4. Once individuals had received a diagnosis this then became a challenge in its self, as medical professionals associated other symptoms on the diagnosed condition. This resulted in new conditions being missed.
5. 50% of participants felt they did not receive information about their condition and to help manage symptoms.
6. 42% of participants had confidence in their health professional to manage their condition.
7. 60% of participants felt health professionals didn't understand or support their individual needs.
8. 73% of participants did not feel fully involved in their support or their treatment.
9. Many individuals struggled to get suitable treatment and felt local provision lacked in diversity and suitability.
10. Some participants felt medical professionals were disinterested in alternative treatments. This resulted in many individuals treating themselves. This was a financial difficulty for some as desired treatments weren't available on NHS.
11. Those who couldn't access services or support during the day were unfairly disadvantaged. Professionals didn't seem to acknowledge younger people who had Rheumatic & Inflammatory Conditions. Participants felt this stigmatised people as it was almost seen as part of getting old.
12. As the conditions aren't visual participants felt there was a certain level of stigma and lack of compassion or understanding from health professionals.

Recommendations

- Participants highlighted issues with lengthy diagnosis and felt they did not receive enough information about their condition and managing it. It is recommended that services improve the information given to patients about managing their care. This is in line with NICE Clinical Guidance 138; 1.5.11.
- 73% of patients did not feel as involved in their treatment as they'd like to be. It is recommended that services improve the involvement of the patients, and professionals need to know & treat each patient as an individual. This is in line with NICE Clinical Guidance 138; 1.1.1, 1.1.3, 1.1.7.
- 60% of participants did not feel professionals understood or support their individual needs. It is recommended that services ensure professionals understand and support patients individual needs, and tailor care accordingly. This is in line with NICE Clinical Guidance 138; CG138; 1.3.1.
- Participants felt they were unable to access services due as they were not available outside of working hours. It is recommended that services review their opening hours to best meet the needs of all residents.
- Participants felt there was a stigma in relation to some Rheumatic & Inflammatory Conditions from health professionals. It is recommended that this stigma is challenged through raised awareness & education.

NICE Guidelines CG138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services:

- 1.1.1 Develop an understanding of the patient as an individual, including how the condition affects the person, and how the person's circumstances and experiences affect their condition & treatment.
- 1.1.3 Ask the patient about and take into account any factors, such as their domestic, social and work situation and their previous experience of healthcare
- 1.1.7 If appropriate, discuss with the patient their need for psychological, social, spiritual and/or financial support. Offer support and information to the patient and/or direct them to sources of support and information. Review their circumstances and need for support regularly.
- 1.3.1 Adopt an individualised approach to healthcare services that is tailored to the patients needs and circumstances, taking into account their ability to access
- 1.5.11 Give the patient information, and support they need to make use of the information, in order to promote their active participation in care and self-management

Contact us

If you would like more information about Healthwatch Blackburn with Darwen, a hard copy of this report or to find out how you can get involved in future projects please get in touch:

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