

Rheumatology Improvement Project

County Durham, Darlington, Tees and
Hambleton, Richmondshire and Whitby
September 2018

Patient feedback

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Introduction and Context

This improvement project brought together commissioners and providers from a wide geographical area. They were collectively looking at Rheumatology services to be able to consider future options for its safe and effective delivery.

This piece of work was being carried out across the Clinical Commissioning Group (CCG) areas that include County Durham, Darlington, Hartlepool, Stockton, South Tees as well as some of Hambleton, Richmondshire and Whitby.

In doing this it brought together each of the providers in these areas which are; County Durham and Darlington NHS Foundation Trust, South Tees NHS Foundation Trust and North Tees and Hartlepool NHS Foundation Trust.

The engagement activity undertaken was done to support the planned clinical workshops that were taking place as part of this process.

The engagement sought the views from three particular audiences to be able to help build up a picture of the perspectives from;

1. Patients in the services
2. Primary Care staff (contained in separate report)
3. Secondary Care staff (contained in separate report)

Approaches taken

For each of the target audiences that were identified the intention was clear, to understand:

- Their experience of services now – what works and what doesn't
- What areas could be improved for the future implementation of the service

Questionnaires were developed through the steering group membership which included representatives from commissioners and providers involved in the improvement project.

The patient questionnaire was able to be effectively undertaken through the helpful support of staff within each of the providers involved in delivering the current service. In attempts to reach more widely, the information was shared out through each of the CCGs MyNHS contacts lists (database of interested individuals). In addition there were direct approaches made to each of the respective Healthwatch Organisations in the areas involved who were able to assist in utilising their circulation lists to help disseminate further.

As well as this, specific approaches were made to patient support groups for some of the conditions (Rheumatoid Arthritis, Ankylosing Spondylitis and Lupus) that had

branches in the local area. These groups were able help in the distribution of the questionnaire directly to individuals they were connected with.

These groups were also able to help with identifying individuals who were willing to be 'interviewed' about their experience. The audio from these interviews was then used to produce a powerful animation with direct quotes from the patients about their experiences. This was showed as part of the clinical workshop event.

All of the feedback was then able to be collated centrally through an online portal to support the subsequent analysis of the information received.

Summary analysis

The engagement activity took place across four weeks in August and September 2018. Included in the following section is the summary feedback from the patients who attended the clinics during the period of engagement or those who contributed through networks such as the local Healthwatch' and the respective CCG contacts.

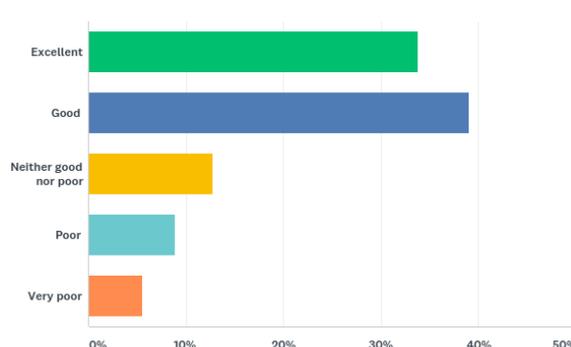
In total there were 310 patient responses to the questionnaire which was circulated. The majority of the questions included were open ended (qualitative) to allow the patients the space to say exactly what they feel is important to them on each of the issues covered.

Patient feedback

Question 1: How well would you say Rheumatology services currently are at supporting you with the health conditions you have?

The first question was intended to gather a snapshot of the perspectives patients have of the current service they are receiving. The summary results can be seen in graph 1 opposite to which 305 individuals provided an answer.

Graph 1: How well would you say Rheumatology services currently are at supporting you with the health conditions you have?



The responses indicate that 34% of patients feel that the current service is 'Excellent', with a further 39% rating it as 'Good'. At the other end of the scale, only 6% of respondents felt that the current service they were receiving was 'Very poor'.

Question2: Considering your overall physical, emotional and social well-being to identify what works well and less well?

Where do services work well?

The key areas highlighted by patients about what works well for them related to

- How contactable the service is and the support from the phone line
- Managing care and medication
- Staff and individual relationships

For many of the respondents, the reassurance that is provided by knowing that there is a member of staff and support available at the end of the phone line is invaluable. There were a number of comments expressing this such as;

- *“Knowing that they are there at the end of the phone if I’m having a bad day”*
- *“Supporting me if I have a query about anything”*
- *“They are always around whether that be a phone call or in clinic whenever you need them. “*

Other responses clearly highlighted aspects of the care they receive that for them, provided the greatest benefit, which included:

- *“Getting mobile again”*
- *“Help reducing my pain and having steroid injections and fluid drained”*
- *“Medical (prescriptions etc.) help has vastly improved my symptoms”*

There were also a number of comments that highlighted that it was the *“friendly staff”* and the *“good support from nurses”* that was recognised. There were also comments that specifically referenced their local GP, nurse led clinics, rheumatology nurses and nurse specialists as playing an important role in what works well for their care.

Where do services work less well?

There was a very mixed picture about what patients feel currently works ‘less well’ in the rheumatology service.

Waiting times was a particular aspect that came through quite clearly. This was in relation to the fact that it can take a *“long time from referral by GP to seeing consultant”* and also the fact that *“sometimes waiting time high in clinics”*. There were also references to experiences of *“a number of cancelled appointments”* plus when patients did have appointments they felt that there was often a *“lack of continuity with consultants and specialist nurses”*.

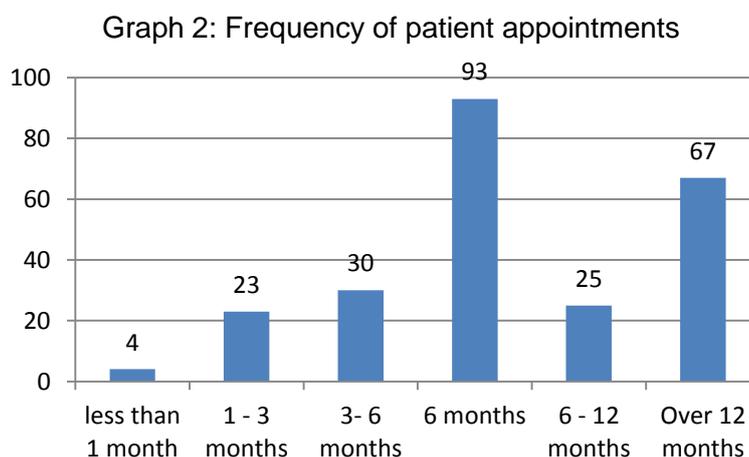
The breadth of support, in particular in relation to the lack of emotional well-being aspects of the support were identified as working less well for some of those who responded.

Other more practical elements of support such as “*side effects from treatment*”, the impact of “*external companies that deliver medication can often lack flexibility regarding deliveries*” as well as feeling there was “*not enough physiotherapy*” were highlighted.

Question 3: How often are your appointments?

There appears to be a very wide range in the frequency of the appointments that individuals are attending for. This question had responses from 277 individuals. Some of this is likely to be accounted for in relation to the levels of support that are required for their individual circumstances and the management of their care.

As shown in graph 2 the main frequency of those who responded was for 6 monthly appointments (93 responses). Second to this were individuals reporting more than 12 months between their appointments (67 responses).

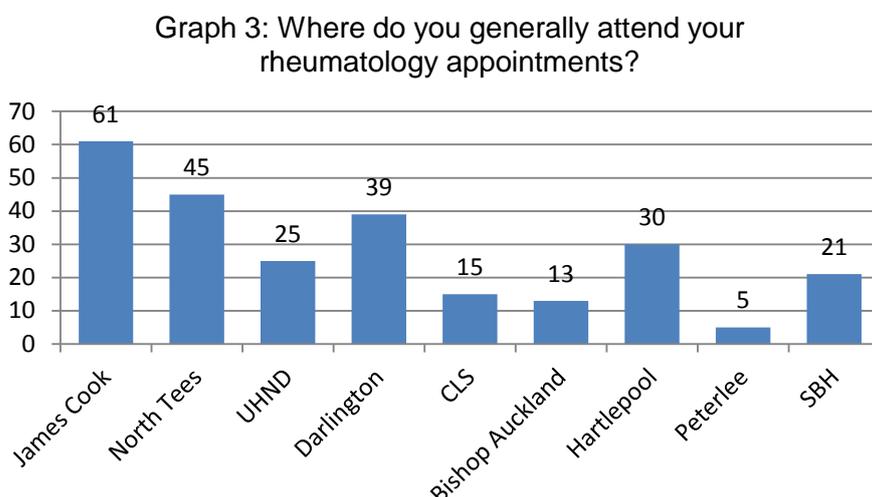


There were comments from 22 individuals about the fact that they do not have any regular frequency in their appointments. Included in these were comments such as; “*Not able to say because of the shortage of Rheumatologists*”, “*Varies, No consistency*” and “*Vary depending on flare ups*”.

In addition to these responses, a further 9 individuals were attending for their first visit.

Question 4: Where do you generally attend your rheumatology appointments?

The information displayed in graph 3, demonstrates the range of sites attended by



those individuals who contributed to the survey attend.

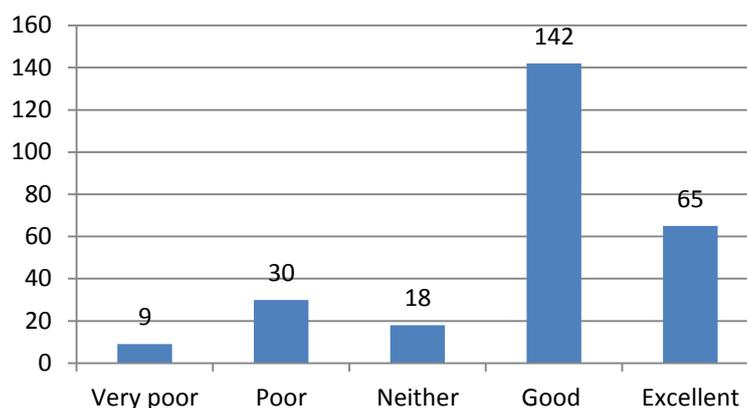
Question 5: How easy is the service to access?

The patients were asked to consider how accessible and easy to access the service is from their perspective.

As can be seen, the overall experience of being able to access the appointments / service is positive.

Those who reported a 'Poor' or 'Very poor' experience included comments that related to car parking (and related car parking charges) as well as the distance that they have to travel on the site in order to attend the appointment in the department.

Graph 4: How easy is the service to access?



Question 6: Have you needed to be seen between routine visits and how easy was this?

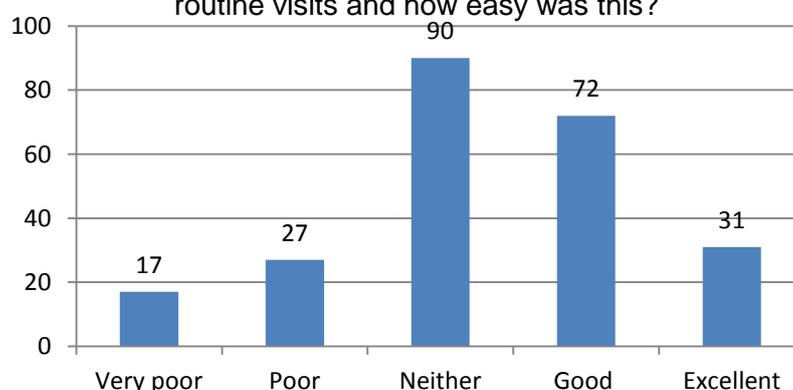
For many of the respondents (90, which related to 38%) this was not something that they had had to try to do in between their routine appointments.

For those who had needed to access support outside of their routine appointments the overall picture was that this was a relatively easy thing to do.

From the responses, 30% of patients felt their experience was 'Good' and a further 13% found it 'Excellent' when they had needed to be seen outside of their routine appointment visits.

The figures from this group of patients record that 7% found it 'Very poor' when they needed to try to access the service outside of their routine appointments.

Graph 5: Have you needed to be seen between routine visits and how easy was this?



Question 7: Thinking about your appointments what works well and less well?

We wanted to explore in more detail the experiences that patients have when attending their appointments. This question allowed patients the opportunity to elaborate on what it is that, for them, worked well or less well when attending the service.

What works well?

The experience of patients in their appointments is recorded as extremely positive. This is particularly due to the approaches taken by staff in how they communicate with the patients in the appointment.

- *“Really easy to talk to, always put at ease”*
- *“Listened to, things explained well”*

There were numerous examples of how valued and included the patients felt by being involved in discussions about their care and the resulting decisions that were taken to support them with their condition.

- *“Being treated like an individual, full participation in my care”*
- *“Staff are always considerate of how we as patients are, always involving me in decisions that have been made about my treatment checking how I am between treatments”*

This was reinforced by many references to the fact that patients are given time to talk things through with staff and did not feel rushed out of the door.

- *“Appointments never feel rushed, usually see the same doctor, giving good continuity of care as well as nursing support”.*
- *“Plenty of time to ask questions... involved in decisions and treatment as an individual”*

There were also a couple of comments about the communication and connections between departments including staff working in GP practices to be able to *“provide me with the treatment I need for my condition”*.

What works less well?

There were less than half as many responses to the question of what works less well in terms of the current rheumatology service. Included in these responses were key themes relating to;

Information not always being provided to the patients which may have been in relation to medication, upon diagnosis (*“just handed leaflets”*) and the fact that for one person at least *“self-care is pretty much left to me or pain clinic”*.

There were a couple of comments regarding “*miscommunication with other services*” which did specifically include patients GP practices. For some this has led to them thinking that “*care doesn’t always feel joined up*”.

The main area highlighted in the responses was that patients felt they needed more time with a consultant or at least these to be available more frequently than they currently are.

Question 8: Are you aware of any local community / voluntary sector support that can help you manage your condition and if so how have they helped you?

This broader support appears to be an area which is not actively included in the care and treatment of patients currently. From the responses provided, 77% of the patients identified that they had not received any information about other types of support that was or could be available to them.

For those who have accessed support from other types of services these have typically been for a local support group (or even just the website) that relates to their particular condition.

Question 9: Considering all services that support you, are there any current gaps or poor co-ordination between services that make it difficult to manage your condition?

The main issues patients have reported in relation to gaps from their perspective were in relation to communication.

This was regarding communication between different aspects of their care and treatment as well as communication with a patients GP practice.

- “*Communication between different departments needs improving*”
- “*As I have to see oral and eye specialist alongside rheumatologists, they don’t seem to communicate with each other*”
- “*Very little co-ordination. I needed a range of appointments and had to communicate to each department separately what the others did*”
- “*No link between GP and consultant without going through physiotherapy*”
- “*Poor communication and support between physiotherapists, occupational therapists*”

In addition, and similarly to the responses to previous questions, patients have reflected that for them a current gap is in relation to the “*lack of consultants*” and there being a need for “*continuity with consultants*”.

In addition, the subject of emotional support was raised as an area in which there is an on-going need for individuals after diagnosis as “*it is a daily struggle living with the pain and very draining*”.

Question 10: What is most important to you in your care that you would hope would be taken into account for the planning of future services?

Continuity of both staff and the location of care were highlighted in a number of the responses patients provided.

For many the lack of Consultant staff and the need for regular access to specialist nurses and doctors were key issues for the future planning of services. The fact that many individuals know and have established relationships with the staff that they see is important to them. This familiarity and consistency was recognised as being valuable to the levels of care and treatment that they receive.

A prevalent theme in the responses was that patients wanted to be able to receive care delivered locally to where they are. Included in the responses were specific requests for services to be retained in the local sites that they currently use and that they would not want to have to travel beyond these facilities to access their care.

Communication both with the patient and any decisions about their care as well as more widely with other teams / GP practices were also highlighted. Patients recognised that they are treated like individuals which really mattered to them in the management of their care.

Pain management was another common comment regarding which patient felt there needs to be consistency and at times of ‘flare-ups’ easy access into the service.

In addition there were a number of comments that specifically stated that for them, the current service is working really well and that they felt this did not need to change to best support them and their needs.

Question 11: Do you have any specific suggestions in how services across health, social care and the voluntary sector might better support yours, your carers or family needs in the future?

For many, having access to peer support opportunities with other patients with similar conditions would be welcome to provide that network outside of the medical settings. There was also reference for the role that (family) Carers support services have in enabling family members to be able to help while also looking after themselves.

Practicalities such as reminders the week before appointments, weekend appointments and the wider support regarding benefits and allowances were also referenced.

For many there was a clear issue regarding the sharing of information across departments but also more widely between different parts of the health and social care services, which included the comment *“digital co-operation”*.

- *“Need a ‘joined-up’ service where there is communication between all concerned”*.
- *Continued liaisons between health and care professionals to provide person centred care”*

In addition there were suggestions regarding the ability to train up and support staff in Primary Care to be able to assist patients more readily when at home rather than having to access hospital appointments – *“one GP in every practice has a greater knowledge of Rheumatoid Arthritis”*.

Finally, there were calls from some of the respondents to ensure that there are sufficient staffing levels to ensure the level of care provided does not deteriorate, which would support the continuity of care previously mentioned.

Patient information

A series of questions were also asked of the patients in order to understand the range of individuals who were responding to the survey.

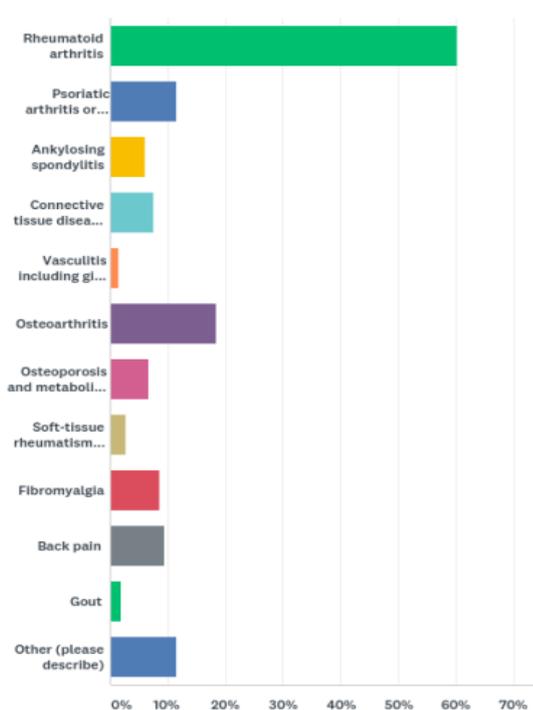
Graph 6 outlines the range of conditions that patients identify as being the main condition that they attend the rheumatology clinics for.

Rheumatoid Arthritis was clearly identified as the main diagnosis that was recorded. This was followed by Osteoarthritis and then Psoriatic Arthritis or other inflammatory arthritis.

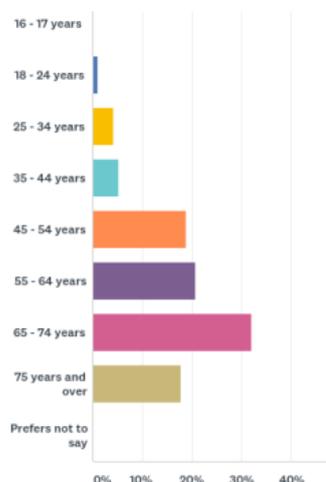
We also asked for a range of information, some of which is displayed below to give an outline of the nature of respondents.

Graph 7 shows the spread of ages of the individuals who responded to the survey, showing that the main age range for respondents was between 65 – 74 years of age.

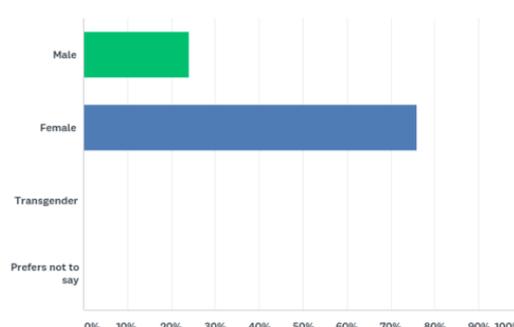
Graph 6: What is the main condition you attend the rheumatology clinic for?



Graph 7: What is your age?



Graph 8: What is your gender?



Graph 8 shows the breakdown of gender from the respondents with 75% of those who contributed to the survey stating that they are female.

We also asked participants to provide the first part of their postcode in order to get a sense from where the responses were provided. Included below is a graphical representation of the spread of responses, the larger the size of the font, the more

TS5 TS17 TS23 TS20 DL5 DH1 DH9 TS26 DL1 TS25
 DH8 TS6 DL14 SR8 TS19 TS24 DH2 DH6 DL3 TS16

frequently that postcode was provided as a response to the question.

Uses of feedback and next steps

All of the information from these survey questions will be reviewed alongside the feedback that was received as part of the staff questionnaires.

This information was then presented to the clinicians involved in the review as part of their planned workshops. This enabled the views of patients to be directly incorporated into the conversations that were taking place as this work progresses.

Future patient engagement opportunities are also planned to help continue to involve patients in this process to comment on the proposals clinicians are considering.