

Rheumatology Improvement Project

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

Patient focus group 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.

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

This piece of work was being carried out across the Clinical Commissioning Group (CCG) areas that include County Durham, Darlington, Hartlepool, and Stockton and 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 Darling NHS Foundation Trust, South Tees NHS Foundation Trust and NHS North Tees and Hartlepool NHS Foundation Trust.

Approaches taken

Following the targeted patient engagement that took place in August and September 2018 a follow up focus group with patients was arranged.

This focus group invited those patients who had participated in the questionnaire and expressed an interest in being involved in further engagement related to this project, the chance to contribute.

Of the patients who completed the survey (310), 108 had provided some form of contact information for us to be able to follow up with them. These were a combination of emails and phone numbers.



All of these patients were subsequently contacted and offered the opportunity to attend the focus group. At the event, nine patients and one carer were able to attend the event in person. A further 18 patients received the information electronically and were able to share their comments and feedback on the questions posed via email.

Participants were provided with the following in advance of the session;

- The patient engagement summary report
- A summary of the key information from the clinical workshop, outlining the key elements of the proposals for the future

At the event, further background information about the work that is taking place, the triggers and contributing factors and the aspirations for the future of the Rheumatology service were outlined in more detail.

The event also provided the opportunity to explore in more detail the feedback from patients, primary care staff and secondary care staff. The video animation created from the patient interviews that were conducted was also shown to those who attended the session.

Summary feedback

The discussions at the event were structured around the six areas that are shown below. The feedback gathered on the day, as well as that provided electronically from those unable to attend, is recorded under each of those headings.

1. Any potential issues with the pathway from the patient perspective?
2. Would you be willing to receive care and support from a range of qualified professionals as required (pharmacist, physiotherapist)?
3. Your perspectives on localised care for routine appointments and hospital based care for intensive support
4. What support would help you manage conditions day to day
5. Your perspectives on the use of technology (such as Apps/ online) to support care and management
6. Rapid access in times of flare-ups – how best to manage and support this?

1. Any potential issues with the pathway from the patient perspective?

Communication either between patient - GP practice and GP practice – Rheumatology service were highlighted as areas that could be improved to enable the pathway to function efficiently. Specific examples related to the length of time letters take to get to GPs is an issue (as it can delay care) as well as the difficulties some participants highlighted regarding being able to get an appointment with their GP.

Participants felt that enabling the computer systems to link and share information effectively would be a key requirement to support this system to function best for all involved.

There was a lack of awareness regarding the Specialist Nurse role and what they are able to support patients with. Some did not know if they had ever met with a Specialist Nurse, while others acknowledged that they had contact details for one but had not used it as they were unsure what they would be able to provide.

Continuity of clinician was clearly identified as an important factor. This is consistent with the feedback that was gathered through the wider patient questionnaire responses.

2. Would you be willing to receive care and support from a range of qualified professionals as required (pharmacist, physiotherapist)?

Yes - Overall the participants were extremely supportive with the concept of having an integrated team (e.g. MSK, physiotherapist, pain management, Pharmacist) working to support their care.

The participants welcomed the opportunity to see alternative clinicians (e.g. Pharmacist) if they are skilled to see patients with their condition.



Participants recognised that through this approach a Consultant could be freed up to see patients that really need consultant care.

The management of medications and their reviews were a subject that participants recognised was vitally important for patients. This was particularly highlighted in the examples of individuals who have multiple conditions and the role specialist input plays in the careful monitoring of the interactions and side effects that can happen.

There was also a significant amount of discussion regarding how appointments could be better co-ordinated to prevent patients having to make multiple attendances. Participants discussed what opportunities there could be for joint clinics to enable a group of patients to be seen by a range of professionals at one half day session. This could also provide opportunities for peer support, group discussions and information sharing that related to point four, regarding day to day management.

Related to the mixture of experiences that individual staff may have, participants felt that the actual questions staff use in the appointments was pivotal to being able to get to the route of issues. If a patient presented as being 'fine' they felt that they could be quickly moved along and only those who asked questions themselves or pushed for things to happen in their care often received support.

3. Your perspectives on localised care for routine appointments and hospital based care for intensive support

Similar to the discussion regarding point 2 above, participants recognised the value that having more localised opportunities for appointments would provide patients, instead of having to attend at hospital.

Examples regarding bloods which could or should be done in a GP practice (in advance of the planned follow up appointments at hospitals) as they can be arranged much more conveniently for patients. One example highlighted a query regarding why one set of blood tests were done in Hospital and one by GP and if there could be a way of co-ordinating this better for all concerned.

One slight hesitation from participants related to the (comparative) lack of detail about the conditions that staff in general practice have. Some patients highlighted occasions when they would be the ones informing the staff in their GP practice about their condition and care, rather than the other way around.

4. What support would help you manage conditions day to day



There was a general consensus that patients didn't get the required information at diagnosis on their condition and self-help tips. Patients highlighted that they were unaware of the importance of a physiotherapist, for example.

The importance of access to therapy services was identified as crucial to enabling this to happen. Participants highlighted the need for support from physiotherapists to show patients the exercises to ensure they are done appropriately.

Examples were shared of self-referring into physiotherapist. This case resulted in an experience of just advice rather than any practical 'teaching' how to perform exercises when at home. There were suggestion of the benefit education sessions for a group of patients could have enabling them to learn exercises over a few weeks.

Access to hydro therapy, or lack of it, was also a common experience for patients in the focus group. Participants highlighted that there had been short courses of this but then it stops and for some this was a highlight of their treatment.

Other stated that they have found the information and support provided through websites, national charities for their condition and even some social media groups the better places to obtain support about day to day management from.

There were a range of experiences on advice provided by staff in their GP practice. In the conversations participants felt that clearer guidelines could enable them to provide consistent advice to patients, which would be advantageous. However, this was not the experience of all patients. Some have very experienced a consistent service from their GP / Practice no matter who they see.

There was experience of peer support groups and the value that individuals were able to take from those. These were highlighted as key places to obtain information from peers, information from staff and self-help advice that could be taken back into day to day management.

5. Your perspectives on the use of technology (such as Apps/ online) to support care and management

Overall the offer of alternative methods for information, advice and support was welcomed. There was some hesitancy in recognising that this is not always going to be appropriate for the patients that are being seen. Participants felt that in some of these cases this could still be an option if there was training available. Alternatively if there were peer support systems in place that enabled other patients or volunteers to assist those who were at a disadvantage in terms of using technology e.g. some elderly patients.

Skype consultations for those patients who are still working were well received. This flexibility was extremely valuable for those who work and find it difficult to continually attend appointments in office hours.

Where telephone advice might be available, this would be ok if the patients were able to hear / have someone to help directly on the end of the phone. There had been experiences of messages being left with secretaries but sometimes they don't get a call back. Telephone consultations were felt to be able to work well with a range of professionals (GP, Consultant, specialist nurse) where contact can be restricted.

6. Rapid access in times of flare-ups – how best to manage and support this

Patients want to be able to address any flare ups as soon as they occur to avoid admission. For them to feel able to do this, fast access when the warning signs appear is required. There was a query regarding whether this would be co-ordinated through the Single Point of Access that had been previously identified in the discussions.

Where a circumstance was identified as urgent, participants looked for this to be able to be escalated to the Consultant as a priority case. Participants were realistic about open access only when absolutely needed and the variations between individuals in levels of 'flare-up' and therefore managing demand to make sure the service is not abused. Participants recognised that to help prevent any 'overuse' that there needs to be a gatekeeper in some format.

Linking to the previous discussion about localised access and wider teams involved, participants looked at the possibility of accessing GP practices for prescriptions for items such as rescue pads or steroids.

Alternatively participants queried if there could be access to a specialist rheumatology nurse who can prescribe to enable interventions to be provided more readily for patients in time of need. If this were available it could potentially reduce the number of contacts that patients would need to have in order to resolve their immediate circumstances.

Underlying all of this the patients stated there needs to be confidence in who they see. The implementation of shared care records was also recognised as central to enabling this to work effectively and potentially reduce flare ups (or their significance) through earlier interventions.

Uses of feedback and next steps

The information from this focus group has been collated as shown in this report to highlight the key themes from the discussions.

This information is to be included as part of the discussions planned for late November with the clinicians from the providers and CCGs involved in this project at their next workshop.

The views and information gathered from the patients involved have helped to shape and refine the proposals that are being developed throughout this project. The offer of participants being able to join in the sessions with clinicians was made to enable them to directly contribute to those discussions in the future.

Information is going to be shared back to those patients who provided contact details as this work develops to continue the 'feedback loop' of information between the patient and clinical discussions.