The King's Fund

Ideas that change health care

A Consultancy Report by The King's Fund for the Rheumatology Futures Group

January 2009

Supporting evidence

Findings of patient focus groups and professional interviews

1 Introduction

The purpose of this report is to present the findings of Stage 2 of the project to investigate the perceptions of patients and professionals on RA care. It summarises the analysis of information gained through focus groups with patients and interviews with professionals.

Objectives and scope

Stage 2 was designed to collect details on the experiences, perceptions and views of patients and professionals. Personal testimony, insights and specific examples were encouraged. The purpose was to collect evidence at an individual level to complement the broad results provided by large-scale surveys of patients and professionals conducted in Stage 1[1]. Numbers were therefore kept deliberately small and while the intention was to include a range of patients and professionals, it was not designed to be a representative sample.

Approach

A qualitative approach was taken using structured focus groups with patients and telephone interviews with professionals. The content of the questions were directly informed by Stage 1. Issues selected for questioning were identified in the surveys as either important aspects of care or those for which the results were inconclusive (such as marked inconsistencies in responses). Using this approach, the following three 'scenes' were explored, which broadly correspond to elements of the patient pathway:

- initial contact – of a patient who has symptoms that may indicate RA with the NHS, almost always this was with a GP
- specialist care – contact, following referral, of a patient with professionals who specialise in RA, regardless of setting
- ongoing care – the continuing management of a patient's condition, which may involve a range of professionals and care settings. This also includes the specific issue of a flare-up or exacerbation of symptoms.

While a similar overall structure was used for both the focus groups and interviews, the specific questions were drawn up to reflect the differing participants and alternative methods of data collection. Copies of the scripts used for both focus groups and interviews are given in Appendices 1 and 2.

Three focus groups were conducted on non-NHS premises in Birmingham (7 patients), Oxford (4 patients) and York (9 patients). Existing patient support groups and networks, both local and national, were used to invite participation and none were recruited directly through the NHS. Patients varied in terms of age, gender (although most were female as reflects the prevalence of RA), severity and duration of disease and date of initial diagnosis. Patients received a participant information document in advance that explained the purpose of the study and the nature of their involvement. Before the meeting commenced patients signed a form to confirm their willingness to participate. Travel expenses were reimbursed. Two facilitators (the authors of this and the main study report) ran each of the focus groups with one leading and the other recording (noting) the information given. The focus groups lasted up to three hours with approximately 45 minutes spent on each scene.

[1] Supporting evidence Volume 1, York Health Economics Consortium, October 2008

Eighteen telephone interviews were conducted with professionals. Again, while not designed to be representative, participants varied by age, gender, geographic location, care setting and profession (4 consultants; 1 SpR/locum consultant; 4 GPs; 5 specialist nurses, 1 physiotherapist, 1 occupational therapist, 1 podiatrist, 1 nurse manager). A total of 32 people were contacted to recruit the 18. Notes of the interviews were made at the time and were subsequently transcribed. The interviews lasted around 45 minutes to 1 hour.

Confidentiality and limitations

Given the qualitative nature of the study, participants were assured that while the content of their responses would inform the study, no individual comments would be attributed. Quotations cited remain anonymous. For these reasons, the detailed content of each focus group and interview remains confidential.

The remainder of this report summarises the themes and responses to the interviews and focus groups and is structured as follows:

- Section 2 – findings on initial contact
- Section 3 – findings on specialist care
- Section 4 – findings on ongoing care
- Section 5 – additional findings and conclusion

Each section of findings on the three patient scenes is set out using a common format that presents results by theme at a summary level using bullet points rather than narrative. Selected examples given by participants that were cited as good or poor practice are also highlighted. The main findings and implications of this analysis, integrated with the results of the Stage 1 surveys, are presented in the main study report.

As stated in the summary report, it is recognised that the number of participants in this part of the study is small and as they were not selected to be a representative sample there may be some selection bias in participation.

2 Findings on initial contact

The scene

Onset of RA is typically marked by a patient visiting their GP with joint pain, sometimes accompanied by ongoing flu-like symptoms and fatigue. Most patients present with symptoms in the early stages that are difficult to distinguish from other causes. This scene examines early contacts with GPs and is the period before diagnosis and prior to specialist care.

Patient perceptions

Awareness and knowledge of RA

- Overall, the awareness of RA in general and knowledge of the treatment options, especially drugs, were seen as in need of improvement.
- Many patients stressed that it would be helpful if GPs were more able to give patients signposts as to where they could access more information and other resources.
- There needs to be more information and education of GPs on the basic symptoms of RA and how it should be treated. Often patients claimed that they had to explain to the GP what drugs they are on and the issues involved (e.g. side effects).
- And several patients said it was with them that the 'penny first dropped', i.e. linking a series of joint-related GP visits to something more systemic.

Speed of access, outcomes and attitudes

- Patients had very mixed experiences of initial GP care – from positive early recognition, good support and rapid referral to specialist care, through to a lack of empathy and delayed or inappropriate referral and initial treatment.
- Many patients had been given the blood test results, although some results were still negative despite having RA. One patient, later diagnosed with RA, had been told by their GP 'at least you haven't got RA' after receiving a negative result.
- An example was given of a patient for whom it took seven years to get a diagnosis. Another stated that the GP had given painkillers only with no other advice or support.
- One patient stated that they had around a dozen visits to the GP with varied joint problems before being diagnosed.
- Several examples were given of inappropriate care, but most were from many years ago. These included excessive and long-term use of steroids, anti-inflammatory drugs and aspirin.
- One patient had received an extremely poor service – from a long delay in diagnosis, to being repeatedly advised by her GP to 'go private' to see a rheumatologist and also a podiatrist.
- Several patients were aware of GPs with a Special Interest (GPwSI) in their local practice but they continued to see their own GP. Another stated that they had to referred by their GP to see the consultant before being referred back to a GPwSI.

Personal insights

- People spoke of how 'frightened' they felt when first diagnosed. And the importance of some physical, tangible support, from leaflets, to telephone help lines and being put in touch with other patients through support groups.
- 'In the first instance, after being diagnosed, I felt terribly, terribly lonely'.
- 'It is a nasty disease, really nasty. The pain is terrible. You cannot describe it.'

- And RA is not taken seriously by the public. People say 'oh, arthritis, I've got a bit of it in my knee', which patients see as insensitive and reflects the low profile of RA.

Professional perceptions

Knowledge and awareness of RA

- The critical issue raised by professionals is the need for GPs to be more aware of the symptoms of RA and to rapidly refer patients to specialist care – because this can have a major impact on outcomes and patient experience. It is not well publicised that a person with suspected RA should be seen very quickly in specialist care so that assessment and treatment can start. Several made the comparison with diabetes – both in terms of needing to start treatment quickly and to consider related co-morbidities.
- The epidemiology of RA and broader inflammatory arthritis makes early identification difficult for GPs. They will not see enough patients to differentiate between types of arthritis. The challenge was to examine the patient and try to understand if a particular symptom on presentation is part of a broader picture. The risk is that GPs refer late and 'are not suspicious enough'.
- Several professionals in specialist care stated that once referred the assessments and quality of referral information from GPs were mostly very good and had improved in recent years.
- Often patients have themselves delayed seeking help, partly reflecting the low awareness of RA in the general population.
- Several professionals referred to problems with the routine blood test (rheumatoid factor antibodies) and other advances, in particular 'anti-CCP' (anti-cyclic citrullinated peptide antibodies).

Education of professionals and patients

- Contrasting examples were given on the level of input given to medical students on RA and rheumatology – from minimal input to a substantial focus.
- Ongoing education for GPs was seen as critical and good examples given of specific sessions run by local consultants.
- ARC and NRAS leaflets and information were seen as very helpful, although may increasingly be replaced by use of the internet and other media (e.g. DVD).

Protocols and guidelines

- An example of best practice is use of a clinical guide to help GPs quickly identify which patients should be referred on to specialist care. It is recognised that to refer patients presenting with joint pain indiscriminately to specialists would swamp the system and be highly inefficient – so the role of the GP as gatekeeper is critical.
- Several examples were given of joint protocols between general and specialist care (usually in primary and secondary settings respectively).
- Choose and Book was highlighted as a protocol itself, although some cited problems with limited choice of where to refer patients and the potential for triage systems to delay contact with specialists.

3 Findings on specialist care

The scene

Referral into specialist care is the second main stage for patients with RA. The complexity of diagnosis, treatment and management of RA means that care is provided by professionals who specialise in the condition. This scene examines treatment by the multidisciplinary team (MDT) and contact with specialists regardless of care setting.

Patient perceptions

Access to MDTs

- Patients had very variable experiences, especially on the level of access to clinical nurse specialists (CNS) and various therapies. As an example, one patient only heard of the CNS at the local hospital through a support group.
- Patients felt it would be wonderful to have a professional review them in their own home, to see what it is really like, but most thought this unrealistic.
- Most patients spoke highly of their experience of secondary care. Issues of waiting times/waiting lists were little raised and patients spoke of rheumatology comparing well with other experiences in the NHS in terms of the time that staff had available to talk to patients.
- Access to different elements of the MDT varied markedly. The most limited and unavailable part was podiatry. The care focussed primarily (in some cases entirely) on drug therapies. Access to the wider MDT, including specialist nurses, occupational therapists (OTs), physiotherapists and podiatrists was haphazard.
- Other services, especially hydrotherapy had been reduced, despite patient perceptions of this helping to give them a 'feel good' factor.
- Considerable problems had been faced with delayed appointments and Choose and Book was singled out for criticism. For example, some patients could no longer simply book their next appointment as they left the hospital, but rather had to wait to receive a letter by post. If the timing of an appointment had to change, this could lead to a long delay, so for example a follow-up that was meant to be in three months was often in reality closer to six months. Also people had experienced other failings e.g. being told they had not attended an appointment or test that they hadn't been made aware of.
- It was felt that the treatment needed to be highly individual, so, for example, whist input from an OT may help one patient it may not be relevant for another.
- Access was usually steered through the doctor, though this could be haphazard. An example was given of a patient's spouse having asked about OT support that led to a highly beneficial series of inputs. The knowledge, attitude and awareness of medical staff were seen as critical as doctors usually steered access to such MDT support.
- Some patients claimed there was a de facto limit to access to the MDT, i.e. you may have one course of OT or physiotherapy input, but that was it.
- Consideration of the impact of RA beyond the medical symptoms was often limited. Issues regarding continuing to work were highlighted as a neglected area. Several patients reported having to retire (very) early because of their symptoms, especially pain and fatigue.

Information, education and support

- Patients stated that there is a great deal of information available, much of which is of a high standard, e.g. ARC and NRAS leaflets. But access is variable, as is the recognition of its importance among clinicians.

- It was felt that people needed a 'route map' to the resources out there, especially to steer people to reliable sources on the internet.
- It would be really helpful to have a local brief service summary that explains what RA is, what care is available and the wider sources of support. This would be good for both newly diagnosed and established patients – many of the latter have big gaps in their knowledge (and some felt this was a very large pool of people).
- Facilities should be available in hospitals (i.e. at the clinic) for such information to be stored or at least an explanation given of how patients can access further information.
- An excellent example was given of a direct education programme run by OTs that had six two-hour sessions focusing on different topics e.g. pharmaceuticals.
- Improved information and support, with clear signposting, was seen as critical to help patients manage their own disease and adjust to diagnosis in the first place.

Model of care and processes

- The actual care process was extremely individual. Several of the patients in the focus groups had decided to no longer accept any drug therapy, considering the side effects as outweighing the benefits, whereas others saw the drugs, although toxic, as highly beneficial in improving their quality of life. And some were explicit on the potential trade-off between length and quality of life.
- Overall, the care was dominated by specialist intervention – patients need regular (e.g. three monthly) drug testing and close monitoring especially for certain drug therapies. This specialist care was provided mainly in hospital settings – and for some this was seen as more convenient for patients, i.e. all services were accessed in the same, central place.
- The care described followed a very medical model – both in terms of the way care is organised and the perception of a patient as having RA (and failing to look beyond the physical manifestations of disease).
- Access to specialist drugs was seen as problematic. GPs and some specialists were claimed to favour routine (and less expensive) drugs, such as methotrexate. Some patients had anti-TNFs (tumour necrosis factor) but had needed to overcome many hurdles before gaining access. Patients described the need to 'tick all the right boxes' and to come off existing medication (e.g. for up to six months, causing pain and distress), while access to the new drugs in the end was not guaranteed. Several speculated whether these drugs pay for themselves by slowing the disease and helping people stay in work.
- It was claimed that the drugs do work, and have a positive impact on quality of life. But each person reacts so differently, they end up self-managing. And the level of knowledge about the drugs and their side effects was extremely variable.
- Several patients claimed that shorter waiting times for initial treatment (e.g. outpatients) had resulted in a poorer service for existing (follow-up) patients.
- Continuity, i.e. seeing the same specialist doctor or nurse, is extremely important for patients. In overall terms, most stated that the main input they wanted most was from specialists.

Location and access

- Patients recognised the differing perspectives on local access – some in rural areas were keen on local clinics, while others based in city centres were pleased to access all services in one place (the hospital).
- Transport and access to facilities could be as important as the actual location. Travelling was often very difficult and painful for RA patients. The clinics themselves should be ideally on the ground floor, with easy access for people with disabilities.

Personal insights

- [Referring to Choose and Book] 'The appointment system puts us into a black hole.'

- 'Taking the drugs is like walking a tightrope. It is difficult but has to be done. Without all the drugs I'd have been a crippled, shrivelled old lady.' [The implication was the importance of information and support to be able to walk this tightrope].
- Many hurdles had to be overcome to get the anti-TNF drugs, but patients cited the need to 'play the game'. The support from 'healthcare at home' was good, i.e. the nurse who came to visit and support home medication

Professional perceptions

Composition of the MDT

- The role of specialist nurses and allied health professionals (AHPs) had expanded rapidly in recent years, bringing many benefits to patients especially relating to information giving and non-medical aspects of the managing their condition.
- Podiatry was in especially short supply, but in recent years there had been pressure to reduce establishments in the wider MDT, especially nurses.
- It was recognised that the evidence base for some of the wider input from the MDT had to be strengthened.
- The overriding message from the professional interviews was the extreme variations in what was available in different settings. Several specialists had moved between hospitals and noted the radical difference in set ups. For example, one consultant was operating as a single-handed clinician with no MDT support. At the other extreme, one described a broad MDT with considerable resources and innovation such as patients being able to self-refer for input from AHPs.
- The most common structure involved a consultant and CNS with some limited access to the wider MDT although often with AHPs having other commitments e.g. orthopaedics.

Access

- Waiting times to see a specialist after referral from a GP had improved greatly and this was being further progressed as a result of the 18-week target. Many described reorganisation (redesign) of services that had resulted in new urgent clinics for new referrals.
- The first appointment was always with a doctor, usually a consultant, which would be followed sometime later (e.g. two weeks) with a visit to the CNS. The latter would help patients learn more about RA and especially the drug treatment. The readiness of patients to receive such information was highly individual and varied.
- The vast majority of specialists were in hospital settings, although some described 'hub and spoke' arrangements and other models including specialist input led in the community and CATS (Clinical Assessment and Treatment Services).
- Few professionals stated that there was too little time in the actual consultations. The main problems with access relate to follow-up patients who have in effect been 'squeezed' out by the focus on new patients.

Protocols and guidelines

- The key guidelines such as British Society for Rheumatology (BSR) guidance and Arthritis and Musculoskeletal Alliance (ARMA) standards of care were cited often. They were seen as useful tools, though implementation had to reflect local circumstances.
- The differing levels of access to drugs were mentioned and particularly the restrictions on the use of anti-TNFs.

4 Findings on ongoing care

The scene

This scene examines the ongoing care of people with established RA that will include a combination of specialist and general professional input. Patients with a chronic disease such as RA also have a central role in monitoring and managing their own condition. Ongoing care includes the issue of how a 'flare-up' or exacerbation of symptoms is managed.

Patient perceptions

Monitoring and managing RA and its co-morbidities

- Most striking of all in terms of ongoing care was the often minimal monitoring of patients beyond the basic requirements – blood test, urine test, weight and blood pressure. Many patients felt that the wider picture was largely ignored in terms of physical condition, e.g. examining other joints, and social/psychological impact, i.e. what effect the disease is having on someone's function.
- An example was given of the need to monitor patients for higher risk of heart disease.
- People felt it important to keep access, however infrequent, to a specialist.
- People would like to be seen in their own home. A good practice example was given of a service ensuring that all patients were seen at least once in their own home. It was claimed that many patients put on a front when visiting the hospital (e.g. looking fine but hiding the fact it took hours to get ready).
- Patients felt they had longer appointments with the nurse specialist and they are worth often long waits on the clinic day.
- It was recognised that usually the drugs and the patient response are closely and carefully monitored.
- There seems to be no consistency in what is tested and how often certain measures are tested. And examples were given of 'the labs not testing for what the doctor or nurse has asked for'.

Location of care and balance between specialist and GP input

- Several patients expressed a fear about transferring more care to GPs unless they are more up to speed and better able to help patients manage their condition.
- It was claimed that GPs needed to be kept more up to date on RA care.
- Some of the communication between specialist care and GPs was seen as poor, such as in managing ongoing treatment and sharing blood results.
- Examples were cited where GPs had felt unable to intervene, e.g. injecting elbows, because the patient has RA and is under the care of a consultant.
- One patient stated that their GP had refused to prescribe methotrexate although this had been advised by the specialist.

Communication, education and information

- Education, information and support are vital to help patients self-manage this long-term condition.
- Patients feel that they need better signposting to the various sources of information and support out there, from help-lines and support groups to leaflets.
- Early on in the disease process, patients felt that they had to closely monitor, and manage their condition.
- A major problem highlighted by patients was communication – between clinicians and clinician to patient. Examples were given of patients being given conflicting advice by consultants at the same hospital (on the management of RA). But more

commonly the problem was a failure to communicate with patients on the likely pattern of disease and especially the options for managing their RA.

- It was felt that the patient often had to be very assertive to get access to services and to have questions answered. Many patients may not be well enough to be so assertive, so could suffer as a result.
- Patients are generally very curious e.g. about the types of medication available, but sometimes a patient may prefer not to know (and might not be ready to receive information).
- It was suggested that an 'RA ready reckoner' would be helpful so that both patients and non-specialist clinicians could see, at a glance, facts on the main issues: what RA is, the support that is available, the progression of disease, the drugs and other treatments that can be used etc.

Management of a flare-up

- When a patient has a flare-up it can be very difficult to get a quick response. Often the GP doesn't have either the specialist knowledge or confidence to take action. By the time the patient sees a specialist the symptoms may have subsided to some extent.
- The approach to managing a flare-up was extremely variable ranging from a patient who had been encouraged just to turn up at any clinic, to others who had been told to go through their GP only to be referred to a specialist.
- Patients on the whole found the management of flare-ups unsatisfactory and stressed that the occurrence of a flare-up was unpredictable, its impact immediate and often significant in terms of pain and loss of function.

Personal insights

- 'I don't think of consulting or involving my GP [in ongoing care]'... 'I have to tell her more of less what to do'.
- RA patients can feel like they are 'the bottom of the pile'... 'we don't tick any boxes, so are ignored'. Problems were seen as shared with some other long-term conditions.
- While we spoke to very aware, active and involved patients, it was felt that the vast majority of patients with RA out there in effect suffer in silence... 'they have little knowledge, low expectations and little access to care'... 'you don't get anything if you don't push for it'.
- 'We dinosaurs [long established patients] should not be forgotten.'
- 'RA makes you feel like you are on an island, all alone.'
- 'Too often the NHS seems to want to make the government feel better, rather than the patient.'

Professional perceptions

Monitoring RA and managing co-morbidities and access

- The monitoring of RA was highly variable. One professional said that 'it is dreadful at the moment', citing a lack of resources and isolation of the service. Others described comprehensive, regular monitoring, such as a wide-ranging annual 'MOT' complemented by patients being able to phone to book an appointment with any member of the MDT. Many used telephone help-lines that were seen as effective in filtering out some appointments, preventing the patient having to come to hospital.
- Similarly, the management of co-morbidities was variable. While some stated that this should occur in primary care, most examples were given in specialist services. Examples of best practice included the use of clear protocols to manage and regularly assess co-morbidities. In many places the CNS had a major role in monitoring co-morbidities.

- The DAS (Disease Activity Score) method of assessment was mentioned by several professionals and seen as a helpful tool to evaluate disease progression and impact.
- The improved access for new patients was regularly claimed to have been detrimental to existing patients.
- Examples of good practice also include the use of telephone clinics and even email systems to reduce the need for follow up appointments.
- The management of a flare-up was recognised as extremely variable and many professionals seemed unclear on what the best approach should be. Some examples were given of GPs doing joint injections and prescribing steroids to help patients manage a flare-up.

Location of services and balance between specialists and GPs

- Several professionals were resistant to the approach of moving services out of hospital settings, usually citing the efficiency and other claimed benefits of co-location.
- Others stated that as patients with RA were not usually in hospital it was a primary care condition and needed to be treated there.
- All recognised the policy message that more care should be provided out of hospital settings and many felt it appropriate that GPs should have a greater role in the management of RA as a chronic, long-term condition. This was almost always qualified by the requirement to raise knowledge and skills to manage RA as a complex condition whose treatment often involved highly toxic drugs.

Redesign

- When redesign techniques were cited they mostly referred to new pathways aimed at rapid access of new patients e.g. to urgent clinics. Leadership by clinicians complemented by managerial support were seen as critical to successful service innovation. Although some changes could have unintended consequences, such as greater delays for patients with existing disease and pathways that could be 'faster but less clear'.
- RA and rheumatology in general could be swamped by:
- The focus on an acute model that doesn't apply to a long-term condition.
- The emphasis on orthopaedics within musculoskeletal (MSK).
- A lack of incentives and targets (carrots and sticks) relating to RA.
- Examples of best practice included the use of 'tight control', a technique to 'front load' the management of a patient's RA, including monthly appointments in the first year (alternating between consultant and CNS). Others included the development of specialist care in community settings including specific services for MSK triage and treatment.
- Joint protocols such as to monitor the use of methotrexate were cited. Several claimed that the greater use of local management plans could help improve care for patients and better integrate currently disparate elements of specialist and general care.

5 Additional findings and conclusion

Variation in care

All of the focus groups identified wide variations in the level of care and support available across the pathway and over time, including the following.

- The level of knowledge among GPs and patients.
- Access to a specialist nurse.
- The amount of education and information given to new and existing patients.
- The level of detail given on the potential benefits and side effects of a particular drug.
- Access to a range of services among long-term patients.

Several professionals made the point that variation in service is often not determined by the profile of the patient or their disease, but that of the department.

Commissioning

Specific input on the commissioning perspective on RA was sought using sources such as telephone interviews and discussions with commissioners and via a Virtual Reference Group. The main messages included the following.

- The relatively low profile of RA, as several claimed ‘it is not on the agenda’. An example of this is the low knowledge of the NHS Musculoskeletal Services Framework.
- Commissioning is going through a major transformation, much of which is driven by The World Class Commissioning programme. This results in a greater emphasis on outcomes and the need to critically and transparently assess the use of existing resources.
- PCTs are completing Strategic Commissioning Plans that will be published in early 2009. In disseminating the results of this study it will be important to consider the timing of these plans, the content of which will have been prepared during summer/autumn 2008 (although they will be subject to annual review and updating). The emphasis of such plans are likely to include:
  - shifting resources out of hospital settings.
  - targeting effort and resources on local priorities, while continuing to meet national targets.
  - greater focus on measuring benefits using ‘PROMs and PREMs’ – Patient Reported Outcome/Experience Measures.
  - a shift towards prevention of ill health and health promotion.

Some RA specialists claimed that RA often had good outcome measures and monitoring that could feed into the desire for better data on the impact of treatments, but that it could not tap into the preventative agenda (unlike diabetes).

Conclusion

The findings of the focus groups and interviews are only summarised above, although the full records have been used to inform the main report. Synthesis with the outcome of Stage 1 was carried out through thematic assessment of responses following the three patient ‘scenes’ prioritised during the review process. The implications of the findings of Stage 2 are presented in the main report.

Appendix 1 – Script for Focus Groups with Patients

The following sets out the questioning route developed for the focus groups and informed by the findings of Stage 1, large-scale surveys.

Scene 1: Initial contact and assessment

This covers first contacts with a GP, the period before coming under the care of the specialist and his/her team and may cover the period after the referral to the specialist.

Notes for the group
This scene covers your early treatment and your GP's level of understanding and awareness of RA and the needs of RA patients. We are going to ask questions about events before and during diagnosis and referral to a specialist.

Notes for the facilitator
We are interested in the knowledge and awareness of RA by GPs: how well GPs understand the needs of RA patients, whether GPs are identifying RA early on and what sort of information and support you received before specialist referral and whether RA patients benefitted from seeing a nurse practitioner/specialist early on. We are also interested in what happens when they are referred to a specialist.

1.0 Patient-centred consultations

1.1 When you first visited your health centre were you seen by a GP or a nurse?

1.2 Did you feel they listened to you and took your symptoms seriously?

1.3 What impact was the condition having on your life at that time?

1.4 Did they show an understanding of the effect your illness was having on your day-to-day life (activities of daily living and psychologically)?

1.5 Did they give you a good understanding of what they thought the problem was?

1.6 Looking back on this experience what would have helped you the most?

2.0 Effective symptom control

2.1 When you were first seen did your GP prescribe any drugs to help control your symptoms?

2.2 Did they give you any advice or help on how else you could manage your symptoms or what they thought the next steps in your care would involve?

3.0 Referral to a specialist

3.1 How long did it take before a decision was made to refer you to a specialist?
3.2 Did the GP explain why you needed to be referred and what benefit the referral would give you?

3.3 Were you happy with the time it took for your GP to refer you?

Prompt: If felt the wait was too long, do you know why you weren't referred straight away?

3.4 How did the experience of waiting for a diagnosis make you feel?

3.5 When you were referred was it to a consultant or a nurse specialist?

3.6 Prompt: If they were referred to a consultant – were they then referred to a nurse specialist?

4.0 Information and other services

4.1 Did your GP or the hospital team arrange for you to see an Occupational Therapist or Physiotherapist?

4.2 Did your GP or consultant/hospital team talk to you about contacting a support group or any specialist clinics or other services available locally?

4.3 Did your GP or consultant/hospital team give you any written information or refer you to any other sources of information?

4.4 What did your GP or consultant/hospital team do well that made a difference to you at this time?

4.5 What could have been better? What worked well?

Scene 2: Appropriate specialist interventions

– covers contact with clinicians who specialise in the care of people with RA (regardless of setting).

Notes for the group
This scene explores how patients feel about the treatment from the MDT.

Notes for the facilitator
We are interested in whether patients feel that MDT specialists are listening appropriately to them, are making appropriate diagnoses and offering appropriate interventions. Q1 is a repeat from Scene 1 as a lead in (but may be excluded).

1.0 Key points of access

1.1 On average, how long did you have to wait to be referred to a specialist?

1.2 Which specialist did you first see? (consultant, registrar, specialist nurse)

1.3 Did you feel the person you were referred to listened to you and took your symptoms seriously?

1.4 Were you offered tests and treatment for the problems you were experiencing?

1.5 How do you feel about how quickly RA was identified?

1.6 How do you feel about the treatment/intervention that you have received?

1.7 Are there any treatments that you have asked for but have been told they are unavailable? (If yes, what was the reason given)

1.8 What worked well in your initial contact with specialist care?

1.9 What could have worked better?

Scene 3: Ongoing care and flare-up

This covers the ongoing management of RA and response of the NHS when a patient has a flare-up.

Notes for the group

In this scene we are interested in the long-term care you receive (how you cope with your condition in the time after you are diagnosed and get started on treatment) and its effectiveness and quality. We want to know how your care could be improved, for example does your overall care appear to work and flow well between your GP care and the specialists (nurses and doctors) who oversee your RA treatment.

Notes for the facilitator

This is a large scene (like Scene 1) and we want to know about how long-term care works well and what can be improved, whether patients know how to get the right support when needed and how to access better treatment for your RA but also how other risks related to your health are taken care (for example heart problems). We are also interested to know how you managed when you experienced a flare-ups and how this affected your quality of life.

1.0 Key points of access to MDT – specialist RA care services

1.1 On average are you happy with the time between appointments?

1.2 How do you feel about continuity of care, i.e. do you see the same person?

1.3 Do you know what specialist team support can be provided to RA patients?

1.4 Do you understand what OTs do and when you need to see them?

1.5 Do you understand what Physiotherapists do and when you need to see them?

1.6 What is your experience of care from a nurse specialist?

1.7 Have you been given access to all the people who can help you? (Prompt: if no, why?)

1.8 Has it become easier or harder to gain access to any of these professionals over the last two to three years in your area?

2.0 Monitoring

2.1 Do you feel you know enough about how progress of your disease is assessed?

2.2 Do you think the progress of your disease and the effectiveness of the drugs are monitored often enough?

2.3 Has anyone explained to you what the next steps in your care will be if your current treatment doesn't control your RA enough?

2.4 Do you have enough opportunities to discuss your treatment?

2.5 How do you find out how safe are the drugs you are on?

2.6 Do you feel your overall general health risks are monitored closely enough? For example do you have your blood pressure checked or are you asked about other aspects of health – such as cholesterol? (note: knowledge of co-morbidities may vary)

2.7 What other checks are offered by your RA specialist? (in brief)

2.8 Do you know who is checking your regular blood tests – is it your GP or the specialist team?

2.9 Do you know who you should get in touch with initially when you have a problem?

2.10 Does this first point of contact work well for you?

2.11 Does your GP understand your ongoing RA treatment?

3.0 Information and other services

3.1 Would you like to know more about RA and what services are available locally? For example do you know about support groups or other local support?

3.2 Do you know about the NHS expert patient program?

3.3 Do you know about any programs for patients/peers to support one another?

3.4 Looking back over your care - What other information, education or support would you have liked to have available?

4.0 Flare-ups and chronic conditions

4.1 Has access to support when you have a flare up changed over the last few years?

4.2 When you have a flare-up, who do you want to see?

4.3 How quickly can you get an appointment with that person?

4.4 How do you feel about the length of time it takes to get that appointment?

4.5 Are there other support services (nurses or doctors or other healthcare professionals) that you can access in your area if you have a flare-up?

4.6 Are there opportunities for more of your ongoing care, including flare-ups, to be managed differently?

4.7 What would be a good example of support for flare up?

Prompt: e.g. outside hospitals, by different professions.

Final check – any other comments or questions that people want to ask before the end of the focus group.

Appendix 2 – Script for Interviews with Professionals September 2008

The following sets out the questioning route for telephone interviews with professionals.

Scene 1: Initial contact and assessment

This covers first contacts with a GP, the period before and up to the first coming under the care of the specialist and his/her team and may cover the period after the referral to the specialist.

Notes for the interviewer

We are interested in your perception of how primary care teams understand and manage the needs of RA patients: how aware they are of the support and information that would benefit patients, whether GPs are identifying RA early on and whether RA patients benefitted from seeing a nurse practitioner/specialist early on. We are also interested in what happens when the patient is referred to a specialist. Note may need to rephrase questions for different professionals.

	Questions and prompts - initial contact and assessment
1	What is your view of the initial contact of patients with the NHS, when they present with symptoms that may indicate RA? • Do patients see the right professional at the right time? • How good is the initial assessment process? • What is the level of understanding of RA among GPs?
1B	What is your view of the initial contact by patients with the NHS when they present with symptoms that may indicate RA? • Who, in your view, is the right professional to see them? • Are patients able to see the right professional? • Does this work well for the patient? • How does the initial assessment process work? • [If appropriate] What would you like to be able to do differently? • What is the level of understanding of RA among most primary care teams, e.g. GPs?
2	What are your perceptions on the referral to a specialist? • Who is the patient referred to and how quickly? • Quality of referral • Experience when in specialist care • Have you ever had patients seek to go private to reduce waiting times? • Are there joint protocols agreed between primary and specialist care for suspected inflammatory arthritis?
3	• What is your assessment of the level of information, education and support available to patients once diagnosed with RA? • Written documents (which ones, availability) • Expert patients (Local groups and national programmes) • Support group and formal education • Is there anything unique in your area that is provided to help patients self-manage their RA? • Is there anything missing in the education and support available?
4	What could be done to improve initial assessment of patients?

Scene 2: Appropriate specialist interventions

This covers contact with clinicians who specialise in the care of people with RA (regardless of setting).

Notes for the interviewer

We are interested in your views on the specialist care and how easily patients can access the right professional, whether they are being encouraged to have an active role in their management decisions, and whether specialists are making appropriate diagnoses and offering appropriate interventions.

	Questions and prompts – specialist intervention
1	What is your view of access to specialist care? • Who patients see (which profession) • Access (referral time and duration of appointment) • Setting (where patients are seen) • Balance between specialist and general health care
2	What are your perceptions on the assessments and treatments that are available to patients? • Access to particular professions (members of the MDT, e.g. podiatry) • Tests (what is available) • Treatments (e.g. drug therapies, are NICE approved drugs funded) • Is the timescale to access these services reasonable?
3	How could specialist care be improved? • Is there an issue with people going privately to reduce the time to access specialist care? • Do specialists have enough time with patients? • To what extent are relevant clinical guidelines used?

Scene 3: Ongoing care and flare-up

This covers the ongoing management of RA and response of the NHS when a patient has a flare.

Notes for the interviewer

We want to know about how long-term care works well and what can be improved, whether patients know how to get the right support when needed and how to access better treatment for their RA but also how other risks related to RA are managed (for example heart problems). We are also interested to know how the regular flare-ups are managed.

	Questions and prompts – ongoing care and flare-up
1	How well do you feel patients' RA is monitored? • Availability of information • Frequency and availability of tests • How well co-morbidities are managed, e.g. do they carry out an annual review including cardiovascular risk • Time between reviews • Do patients have access to a nurse-led help line
2	How well are flare-ups managed? • Who do patients access and how long do they have to wait • What services are readily available • What is not available but should be
3	What are your views on service redesign (in general) and its impact on the experiences of patients and professionals
4	What could be done to improve ongoing care?

	Any other comments/questions Final check – any other comments or questions that you would like to ask before the end of the interview?

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