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health care

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

January 2009

Perceptions of patients and professionals on rheumatoid arthritis care

Contents

Acknowledgements

The authors would like to thank all the professionals and participants who gave their time to be involved in surveys, focus groups and interviews, and all others who have helped in the conduct of this study.

Publication of the findings

This is a consultancy report by The King’s Fund for the Rheumatology Futures Group. Publication of the findings of this research is subject to the advance approval of The King's Fund. Such approval would only be refused on the grounds of inaccuracy or misrepresentation.

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About the authors

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Executive summary

Improving the quality of care for patients with long-term conditions is a priority at national and local levels in the NHS. Rheumatoid arthritis (RA) is a chronic, progressive and disabling autoimmune condition that affects around 420,000 people in the United Kingdom. RA is associated with substantial health, social and economic costs, ranging from direct care such as joint replacement, to the indirect impact of shorter working lives. There is much potential to improve outcomes for people with RA through earlier identification and specialist treatment allied to better support for patient self-management. However, there is a lack of understanding on the quality of RA care and the way in which recent changes in the health service have impacted on both patients and care professionals.

Commissioned by the Rheumatology Futures Group – a consortium of the main patient, professional and pharmaceutical organisations involved in RA care – this report is the result of a study of the perceptions of patients and professionals of the delivery of care. It explores whether care for people with RA has improved in recent years and seeks to determine the key factors influencing perceptions of treatment. The report outlines key priorities for action in how to improve care for people with RA.

The research comprised two main stages.

1. Large-scale surveys of a sample of patients and professionals in England were carried out in April and May 2008. Responses from 912 patients and 501 staff were analysed, representing around half the patients and a quarter of the staff contacted.
2. Informed by the results of the surveys, in-depth patient focus groups (3) and interviews with health care professionals (18) were carried out in September and October 2008.

Results were analysed across three key stages of the 'patient pathway' – initial contact with the NHS (first contact care), specialist intervention and ongoing care. The research found that despite the chronic and debilitating nature of the illness, the availability and take-up of systematic guidance for professionals about the appropriate care pathway for RA patients remains limited. Patients with RA struggle to access care and RA is often perceived as being in the shadow of other more common long-term conditions. In particular, the study revealed reports of significant variation in the nature and quality of RA care leading to the following recommendations for action across the RA 'patient pathway'.

Recommendations

Initial contact with the NHS

- **Improvement is needed in the primary care teams' knowledge** and competence in recognising the early signs and symptoms suggestive of RA so that they identify RA earlier and improve the patient's experience and understanding.

- **Earlier identification and more rapid referral** of patients with RA are important since they can positively influence patient outcomes. These include examination of a patient's symptoms and assessment of whether they indicate a systemic disease.

- **GP education** is required to raise levels of knowledge and awareness of RA and particularly of those indicators that should trigger early referral. GPs also need to be more aware about local services that are available to RA patients.

- **Specialist diagnosis** needs to be available as many patients feel that often their GP is insufficiently aware of the specialist nature of RA and its treatment.

- **Information for patients**, such as access to service summaries and local care pathways explaining what is available and the proposed treatment process, is required.

- **Broader support for patients** beyond assessment of their physical or medical symptoms is needed to empower patients with RA with the confidence and knowledge to manage their symptoms and to give them a better understanding of their care options and choices.

Specialist intervention

- **Variations in the quality and accessibility of specialist RA care** need to be addressed to tackle the current postcode lottery in care. Patients and professionals involved in focus groups and interviews commonly reported stark differences in quality and access to care, suggesting that many patients currently receive sub-optimal care.

- **Input from a coherent and specialist multi-disciplinary team** is needed.

- **Greater integration of knowledge about the patient's treatment** is required, specifically between community care teams and specialist professionals.

- **Enhancing the use of guidelines and pathways** would support service change and improvement.

Ongoing care

- **The quality of ongoing care varies** markedly by geographic location and needs to be improved. The experiences of patients and professionals, reported in focus groups and interviews in particular, ranged from examples of extensive specialist and ongoing care to examples of minimal support.

- **The management of flare-ups** appears to be haphazard. Patients described significant problems including delays in urgent access to specialist advice, lack of knowledge and capacity to intervene among primary care teams (such as with joint injections), and some inappropriate, duplicative routes, such as patients having to return to a GP simply to be told to contact specialist care.

- **Consistent monitoring of RA** and its co-morbidities is poor**.** The management of flare-ups is a particular priority given current levels of dissatisfaction and uncertainty.

- **Ongoing specialist care** is usually located in hospitals. The study found little evidence of consistent progress in care being shifted out of hospital settings or care models that sought to integrate previously fragmented services.

- **Better information, education and support** are extremely important both for recently diagnosed patients and those with a long-standing condition.

Overall, this study showed that opportunities for innovation and improvement in RA services exist and need to be pursued vigorously. These include: improving the accessibility and standard of the initial contact in primary care; ensuring that patients with RA are diagnosed and treated more rapidly; and changing the pattern of care to enable more specialist and ongoing care to be provided out of hospital settings.

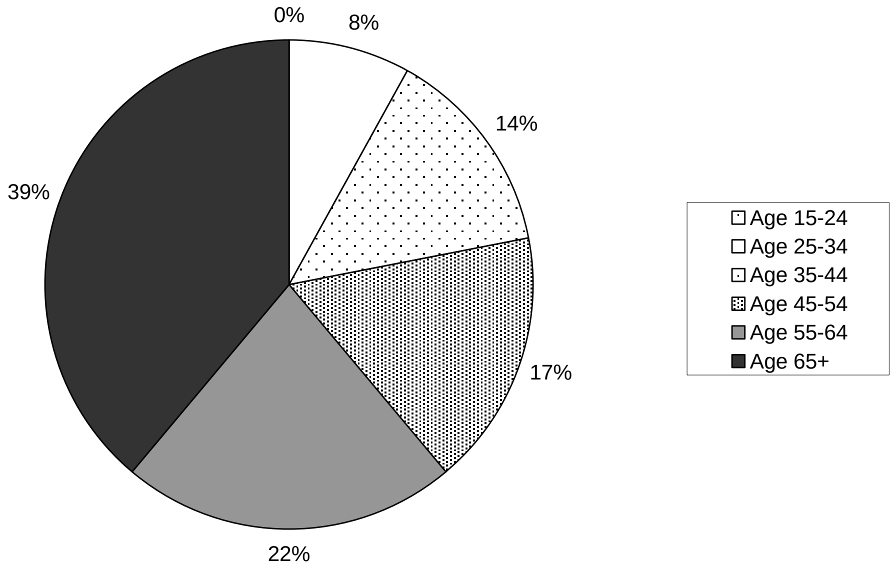
1 Introduction and context

The prevalence of rheumatoid arthritis, its impact and treatment

Inflammatory arthritis is a term used to describe a range of conditions that affect more than 700,000 adults and children in the UK. The most common of these is rheumatoid arthritis (RA), which is a chronic, progressive and disabling autoimmune condition (and is distinct from osteoarthritis). The systemic effects of RA can progress rapidly resulting in co-morbidities and severe disability as a result of long-standing swelling of the joints and damage to cartilage and bone. RA is a painful condition that reduces life expectancy. Age of onset is generally between 40 and 60 years, although it can occur at any age. The prevalence is positively associated with age and is three times greater in women. Although precise values are difficult to determine, estimates in the UK suggest that roughly 420,000 people suffer from RA at a given time.

In their report, *Arthritis: The Big Picture*, the Arthritis Research Campaign (ARC) provides a summary of the results from two studies, one by MORI and one by the ARC Epidemiology Unit. These studies show that the largest sector of the population with RA is among those aged 65 or older, however, RA is a condition that affects a wider range of age groups, as shown in Figure 1.1.

Figure 1.1 Age distribution of people with RA in Great Britain (using MORI data)



A study by Young and colleagues reported that 22% of those diagnosed with RA stopped work after five years because of their RA. The study also found a further group of respondents who stopped work due to a combination of RA and other personal factors, which gave an estimate of 40% of those with RA withdrawing from the workforce because of their condition (Young *et al* 2002).

A survey in 2007 by the National Rheumatoid Arthritis Society (NRAS) showed that people's working lifetimes appear to be significantly curtailed because of RA. Of those surveyed who were not in employment, nearly two-thirds (65%) stated that they were not in employment because they gave up work early as a result of their RA and that this includes people above and below statutory retirement age (NRAS 2002).

Treatment of RA is aimed at suppressing the inflammation to help prevent joint deformity and destruction maintaining optimum function and also to reduce symptoms (such as pain, stiffness and fatigue). Treatment is complex and should be tailored according to the individual's specific disease presentation and progression. It is managed using a variety of methods including drugs, patient education, exercise and therapies to help maintain muscle strength, and surgery to deal with structural change.

The issue of patients with RA struggling to access care is not new and RA is often perceived as being in the shadow of other more common long-term conditions (such as diabetes or cardiovascular disease). This may be exacerbated by a poor understanding of RA in public and professional spheres. The illness can be very difficult to diagnose and appropriate treatment is also complex and varied.

Medications to prevent joint damage fall into three categories: disease modifying anti-rheumatic drugs (DMARDs), steroids and biologic agents. DMARDS (e.g. methotrexate) are used as a first-line treatment option as they slow the progression of RA. Biologics (monoclonal antibody therapies) are commonly used for the treatment of patients with RA whose disease has failed to be controlled by DMARDs. These include drugs that inhibit the mediator tumour necrosis factor alpha, known as 'anti-TNF' or B cell depleters. Steroids may also be used although their long-term use as a disease-modifying agent is controversial as the long-term side effects have to be considered.

Management for people with RA requires a team of specialist professionals, who are most commonly located in hospitals. In addition to medical and specialist nurse input, the multi-disciplinary team should include allied health professionals such as physiotherapists, occupational therapists and podiatrists.

The need for a common framework of care for RA patients has received attention in recent years although the Musculoskeletal Services Framework (Department of Health 2006) was launched under the 18-week initiative and implementation has chiefly focused on targets related to orthopaedics. RA has, in recent years, had a higher profile chiefly in relation to costs of treatment and debates around NICE appraisals of drug therapies.

National policy direction

There have been considerable changes in the external environment over the last year. The national policy context provides an important backdrop to any future service design. For RA, as a long-term condition, the main strategic themes are as follows.

Emphasis on safety, patient experience and outcomes – Lord Darzi's NHS Next Stage Review and particularly *High Quality Care For All*, the final Darzi report (Department of Health 2008) signals the new direction for the NHS. For the first time, a focus on improving the quality and access to care for those with long-term conditions will become a real imperative. Among other issues, it highlights the need to shift the focus from speed of access to the quality of care provided, as measured by patient safety, experience and effectiveness of care (clinical outcomes). Individualised care plans have been recommended by Darzi (2008) as a way of improving access to allied health professionals and other specialists for patients with long-term conditions and supporting a more patient-led model of care. Seeking to address clinical disengagement, it also stresses that improvement must be driven by the decisions and actions of clinicians and informed by the collection, analysis and publication of accurate, credible and comparable clinical data.

Providing care 'closer to home' –Informed by the White Paper *Our Health, Our Care, Our Say: A new direction for community services* (Department of Health 2006), the approach being pursued by primary care trusts (PCTs) is to shift many services, particularly for chronic diseases, outside hospital settings. Rheumatology, which is largely an outpatient based service, is perceived as highly appropriate for this transition. Real integration between primary and secondary care continues to be problematic and new organisational structures will not solve these problems alone.

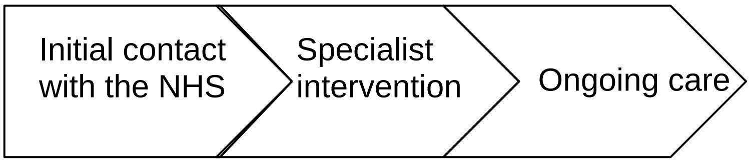
Patient choice – The impact of choice in itself has not been raised greatly during this review. However, the mechanism used for making it happen, Choose and Book, has repeatedly been cited as problematic in two respects. First, professionals highlight examples where the system can result in less choice and flexibility, for example, in the use of RA-specific early intervention pathways. Second, patients have described extensive and repeated administrative problems particularly with appointment systems and communication between those involved in their care.

Finally, the programme of world class commissioning, intended to significantly strengthen the role and influence of PCTs, emphasises the need to improve the health and wellbeing of local populations. Following national direction, PCTs have recently been developing Strategic Commissioning Plans (for the five-year period commencing April 2009). These include explicit local health priorities and respond to the direction to shift the balance of resource allocation away from hospital settings and into primary, community and preventive care. In this context it is crucial that proposed changes to RA services are made relevant to PCTs, such as by emphasising the potential to reduce health inequalities and improve health outcomes.

Rationale for the study and approach

The Rheumatology Futures Group commissioned this study to review patient and professional perceptions of current service delivery and how service transformation (and innovation) is impacting on care delivered to patients. The group wished to identify service changes and clarify the components of care that were most important to patients and professionals with the aim of driving successful innovation. The study investigated the following questions.

- What is the impact of service innovation on patients and staff? In particular, how does it affect the patient experience and the ability of specialist multi-disciplinary teams to provide care?
- How is access to and the provision of specialist care being affected by service innovation (what is working well and what not so well)? How can the NHS support the development of equitable care to ensure that the right patient is seen at the right time?
- What action should be taken to improve RA care and how can decision-makers (commissioners and providers) be best supported in this?
- This report of a study by The King's Fund presents findings based on the analysis of surveys, focus groups and interviews with patients and professionals. The approach has focused on the patient perspective and the results are structured around three main elements or stages along the pathway, which were prioritised as part of the review.



Prior to setting out the findings by each of these patient stages, the methods are briefly summarised in the following section.

2 Methods

This report aims to address the questions set out at the end of Section 1. The analysis aimed to establish how patients and professionals perceive RA care. It involved two main components: a large-scale quantitative survey and a subsequent qualitative stage that allowed certain areas to be explored in greater depth. A brief literature review that covered the experiences of patients with RA was also conducted.

Stage 1: Large-scale surveys

In the first stage of the analysis two large-scale surveys of patients and professionals were undertaken during April and May 2008, the detailed results of which are given in Supporting Evidence I – Report on Patient and Health Care Professional Questionnaire Surveys. After data cleaning, 912 patient questionnaires and 501 professional responses were included for analysis. While determining the accurate response rate is complicated by cross-posting, it is estimated that over half the patients and around a quarter of the professionals contacted responded. This element of the project was undertaken by York Health Economics Consortium, part of the University of York. Patients and professionals were recruited using existing networks and directories.

The surveys were designed to gather the views and opinions of patients and professionals on the current and future service provision of RA care. The purpose was to gather new information from a large number of respondents on critical elements of RA care. These were determined by the researchers and informed by a review of the literature, input from key members of the Rheumatology Futures Group and the results from pilot surveys. The final content of the questionnaires are given in the Appendices to the detailed report on the surveys (Supporting evidence I – Report on Surveys). Patients were asked questions on the specifics of their experience of care, ranging from what information they had been given, whether it had become easier or more difficult to make an appointment to see clinicians, through to their views on standards of care. Professionals were asked about their views on the patient pathway, their involvement in and experience of service redesign/improvement and asked for suggestions of how care for people with RA could be improved. The results were analysed and fed back to the RPG at a mid-point.

Stage 2: In-depth interviews and focus groups

The aim of the second stage of the study was to explore the findings from Stage 1 in greater depth. Three patient focus groups (total of 20 patients) were conducted in different geographic locations in order to ensure that a range of different health economies were covered, and 18 face-to-face or telephone interviews with clinicians from a range of professions, including doctors, nurses and allied health professionals were carried out. The aim of this stage was to explore the perceptions of patients and professionals in more detail and collect personal insights and experiences as well as to gather examples of good practice. The research took a patient pathway approach and aimed to identify what patients and professionals would value in their care at three different stages on a patient’s journey: their experiences of early assessment and diagnosis, of specialist and of ongoing care. The participants were assured anonymity and the findings of this stage of the process are not published in detail. A summary of high-level findings is presented in Supporting Evidence II – Findings of Patient Focus Groups and Professional Interviews.

In order to conduct the patient focus groups a semi-structured questionnaire, or script, was used to guide the discussions. The subjects chosen for further deepening in this phase were determined largely by the findings from the questionnaire, for example, it was felt it would be beneficial to understand in more detail from the process and speed of referral by GPs to specialists, the care available to patients during flare-up. The detailed scripts for both elements are given as Appendices to Supporting Evidence II – Findings of Patient Focus Groups and Professional Interviews.

Additionally, to enhance our understanding of the experiences of patients with RA, a range of relevant literature was identified and reviewed. The work was further informed by specific discussions with commissioners to explore their perceptions of RA and to understand how best to present the results. And at the outset of the work a virtual reference group was established to provide an independent, external challenge to the study process and content. This group included clinicians and managers in the NHS, in trusts and PCTs, and researchers who could advise on methodology.

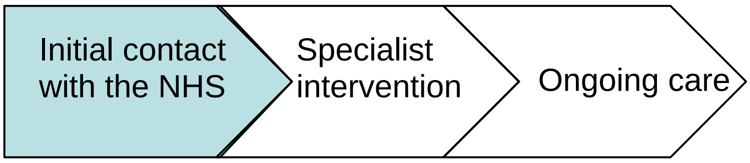
It is recognised that there are limitations to the approach taken, particularly in the potential for recruitment bias towards participants who wish to, and are able to, attend focus groups. The study covers England only. The terms nurse specialist and nurse practitioners are used interchangeably throughout this report. The study was not designed to identify the particular situation of RA patients nor to compare the treatment of people with RA with that of people with other chronic diseases.

The following three sections present the findings of the study by stages along the patient pathway.

3 Initial contact

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. The patient will usually present several times with differing degrees and location of joint pain.

This first stage of the patient pathway invariably is conducted within a GP surgery and is the period of initial investigation and early diagnosis. It is, in many ways, the most important stage for a person with early RA symptoms as the results of this initial consultation will dictate the nature and speed of referral to specialist diagnosis and specialist care.



The evidence

The evidence from this study indicates that what patients want from their initial contact with a GP and wider primary care team is a knowledgeable and supportive environment in which the issue of RA can be identified and discussed. Patients in particular regarded the initial diagnosis of RA to be a critical factor in their access to RA care but felt that knowledge in primary care around the indicators or symptoms that may point to RA – as well as understanding of the next steps along the pathway of care and the most relevant diagnostic investigations to undertake (such as blood tests) – were often lacking. Patients also commonly reported that they would like greater empathy at this initial point of care to manage the pain, distress and uncertainty that comes from repeated visits to the GP with joint pain and other symptoms. In particular, patients would like better support and information on how to deal with their symptoms and their impact on their broader activities of daily living. An ideal characteristic was termed 'supportive initial contact' to include a GP providing more time and interest to investigating whether the presenting symptoms may point to a more serious long-term problem and use available guidelines to trigger appropriate and rapid referrals for specialist diagnosis and care – such rapid referral having a positive impact on managing RA.

GP attitudes

- Before a positive diagnosis of RA is made GP attitudes to patients with joint pain varies. Patients cited some examples of what they perceived to be inappropriate attitudes, including a lack of empathy and support. These perceptions are also supported by a previous mapping project undertaken by NRAS.
- The care described firmly follows a medical model in terms of both the way it is organised and the perception of a patient as having RA. Patients consistently reported that their GP had rarely or never asked how they were coping at work or with the wider activities of daily living. In some cases the patient may be the first to connect symptoms, linking together the isolated joint pain into a broader systemic illness.

GP awareness and knowledge of RA

- GPs play the important role of gatekeeper for access to specialist care. The nature of the symptoms and range of inflammatory conditions mean it is often difficult for

GPs to identify RA, particularly as the number of patients with RA in one practice may be small. However, both patients in focus groups and professionals in interviews claimed that many GPs are not sufficiently aware of the indicators that may suggest RA or of recent evidence that has identified the importance of rapid, aggressive therapy to prevent damage to joints.

- One major cause of delays for many patients is the low level of awareness of RA among the wider population, i.e. patients may themselves delay seeking help. This may be partly related to not knowing the difference between RA and osteoarthritis and also to the incorrect assumption that ‘nothing can be done’. Indeed a large proportion (some estimate as much as 25%) of GP consultations are for musculoskeletal joint pain and these patients would benefit from a more structured approach in the assessment and management of pain.
- The level of knowledge and support from GPs could be improved. In the survey, of patients diagnosed in the last three years (313) around 40% either agreed or strongly agreed that their GP was knowledgeable about RA and provided good support. The researchers found no benchmarks or standards from other studies against which to compare this result.
- Medical education could play a role in increasing the awareness of future GPs about RA. Feedback from professionals varied, with some citing education that provided considerable input on RA while others claimed it was given minimal attention and often lost in the focus on orthopaedics. The time spent with rheumatology specialists on clinical placement may be short, such as two weeks.
- A good example was given of an evidence-based clinical guide that GPs can use to inform decision-making on early referrals (Emery *et al* 2002).

Speed of access and outcomes

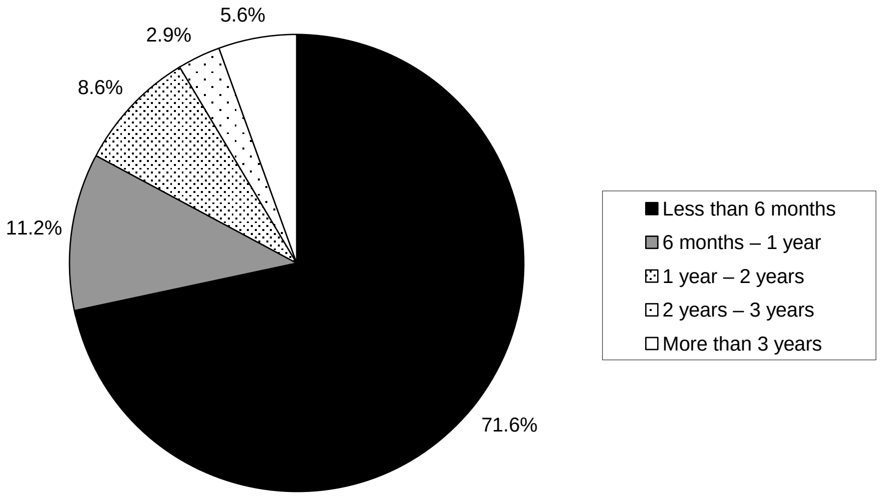
- Many patients are being referred within six months of presentation although there are still examples of patients who have waited for over a year. The survey indicates that of patients diagnosed in the last three years around a third were seen for up to three consultations before being referred on to specialist care and over two-thirds saw a specialist within six months of first seeing their GP. Once referred, new patient waiting times for specialist care were claimed by professionals to have reduced and were often cited as four to six weeks or less.
- Rapid referral to specialist diagnosis and specialist care is important and can strongly influence clinical outcomes and the patient experience; there is a ‘window of opportunity’. Patients and professionals cited examples where ‘if only’ treatment had been initiated sooner joint problems and disabilities could have been avoided. This message was given by most professionals and all the GPs involved in the interviews. Several specialists cited positive examples of GPs sending referrals in sooner, use of pathways and protocols and formal training for GPs to support such improvements.
- Several patients had received an exceptionally poor service ranging from a very long delay in diagnosis (counted in years not months) to being repeatedly advised by a GP to ‘go private’ to see a rheumatologist and podiatrist. While these are isolated examples, they were given in the context of a general need for all professionals whom a patient sees to be knowledgeable about RA, not just the specialist team, and to improve knowledge, awareness and most of all the treatment and support for people with RA.
- Examples of inappropriate long-term management of severe joint pain with long-term use of anti-inflammatory drugs and steroids were also highlighted, such as a patient who had gained a lot of weight following years of being treated with only steroids. Specialist care professionals also stated that in such circumstances the use of these drugs could mask the underlying illness once people are referred on.

GPs and the wider clinical teams in primary care can play a major role in:

- providing support for patients by looking beyond managing the pain and physical symptoms to recognition of the impact it has on other activities of daily living, work, home and how patients are coping
- recognising the social and psychological impact including the loneliness and fear that can occur when diagnosed with a long-term condition such as RA
- signposting patients to the range of health services available to them and helping them to find ways to reach related services
- acting as a conduit to access wider information and support on RA, including that provided by voluntary sector organisations
- recognising the co-morbidity of RA with other health matters and doing regular checks to support monitoring.

Figure 3.1 shows the variation in reported length of time between respondents first seeing their GP about their symptoms and seeing a specialist in a hospital. Almost three-quarters of respondents (71.6%) saw a specialist in a hospital within six months of first seeing their GP about their symptoms.

Figure 3.1: Time between first seeing GP about symptoms and seeing a specialist in a hospital



Some patients were referred to a specialist after three or fewer appointments with their GP while others saw their GP more than 10 times before being referred to a specialist (Table 3.1).

Table 3.1: Number of GP visits prior to being referred to a specialist

GP visits	**Number of responses**	**Percent (%)**
0-3	121	38.7
4-7	74	23.6
8-10	20	6.4
> 10	21	6.7
No response	77	24.6
Total	**313**	**100.0**

Priorities for improvement

- **Better awareness of RA treatment among GPs** is needed as many patients feel that their GP is insufficiently aware of the specialist nature of RA and its treatment. While such tensions are inherent in the balance between generalist and specialist care, it is clear that more could be done to improve the links between these parts.

- **Earlier identification, rapid referral and prompt diagnosis** can improve patient outcomes and experiences. Best practice examples include the use of protocols to highlight which patients should be referred to a specialist, regardless of setting, practitioner triage models and the use of technologies such as ultrasound and magnetic resonance imaging.

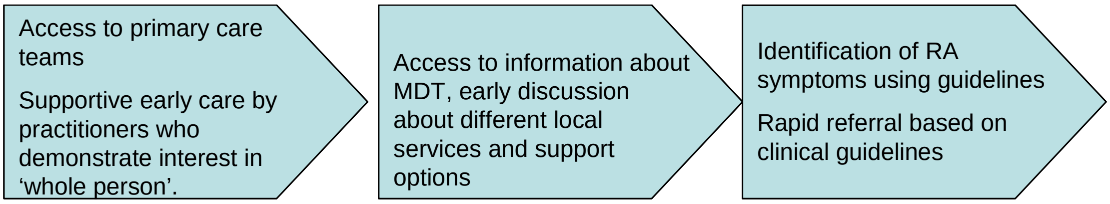
- **Broader support for patients** should go beyond purely physical or medical symptoms.

- **Information for patients**, for example, access to service summaries and local pathways explaining what is available and the proposed treatment process would be helpful.

- **The use of referral criteria, structured local pathways and access to service summaries** would assist GPs and raise awareness about treatment goals, the local services available to RA patients and the preferred process.

After the initial contact, there are opportunities for and some good examples of primary care teams playing a much more proactive role in the ongoing management of RA. In general, however, much of the care remains concentrated in purely specialist services, which themselves are predominantly hospital based. As one clinician said in an interview 'RA is a primary care disease, it should be treated there'.

The following diagram summarises some of the main elements of care that were highlighted as good or ideal in responses from patients and professionals.



Access to primary care teams

Supportive early care by practitioners who demonstrate interest in 'whole person'.

Access to information about MDT, early discussion about different local services and support options

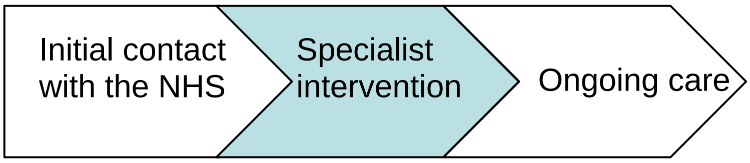
Identification of RA symptoms using guidelines

Rapid referral based on clinical guidelines

4 Specialist care

Once referred for specialist diagnosis and/or to specialist care, most patients are assessed first by a consultant in hospital and this is usually complemented by an appointment to see a specialist nurse, either at the same visit or perhaps two weeks after diagnosis. The patient will be advised on the treatment options, likely to include drug therapy. Much of the detailed information on the disease and particularly the risks and benefits of the drugs are given by the nurse/practitioner. Response to different treatments is highly individual and changes over time. It is common for patients to attend hospital to see the specialist doctor or nurse regularly (say three monthly) over the first year or two until there is evidence of effective disease control. The frequency is reduced with improved disease control. The patient may have access to the wider multi-disciplinary team, particularly allied health professionals, although the extent, availability and timing of this are highly variable.

This scene examines treatment by the multi-disciplinary team and contact with specialists regardless of care setting.



The evidence

The evidence from this study indicates that patients want to be seen quickly by a core of specialist advice, including a doctor and nurse, for rapid assessment and intensive early management of RA. This includes the provision of education and support specific to the patient’s condition and readiness to receive information. The provision of this core service should be available much more consistently across the NHS. Access to the full range of multi-disciplinary team members (e.g. occupational therapist and podiatrist) need to be more open and less dependent on the individual knowledge of the consultant, or assertiveness of the patient (or the relative) and less susceptible to being constrained by clinicians who may be acting as gatekeepers to the local resources.

The input of specialist nurses is valued highly by patients, although there have been repeated claims by professionals in interviews that the number of such nurses is falling. The main benefits relate to nurses performing the following roles:

- managing a telephone helpline service that acts as a main prompt point of contact
- providing specialist telephone advice and preventing requests for additional outpatient appointments, inpatient or emergency admissions
- co-ordinating care between different professionals
- educating and informing patients about RA, drugs and looking beyond the medical and physical elements of disease.

Variation in levels of care and support

- The overriding issue that emerged on specialist care, from the focus groups and interviews in particular, is the extreme range in the level of support available in different parts of the NHS. As one professional put it, ‘people talk about the postcode lottery for prescribing, but the bigger problem is the postcode lottery for care’. While services will always vary to some extent, descriptions of the range from a single-handed consultant with no support to full multi-disciplinary teams providing rapid and even patient-directed access were striking and claimed by some professionals as alarming.

- Professionals cited the importance of local clinical leaders who have led service improvements and are knowledgeable about what different specialists can do for RA.
- The study was not designed to identify the causes of such variation or to look at comparisons between RA and other disease areas. However, discussions on the reasons for differences pointed to historical causes and particularly the lack of clear mandates, incentives or targets on RA (such as in the Musculoskeletal Framework).
- Podiatry was highlighted frequently by patients and professionals as an underused and under-resourced service. The main issue concerned the lack of access and the lost opportunities to help people with RA.
- The survey indicated that for patients who had been diagnosed with RA for three or more years (599) over 80% had been offered an appointment with a nurse specialist, while around half had been offered an appointment with a physiotherapist, occupational therapist and podiatrist.
- Access times – the delay between referral by the GP and first attendance – have, according to professionals interviewed, improved markedly. Much of the work on redesign in the NHS has focused on improving initial access, particularly the development of urgent clinics, which have been given further impetus by the 18-week target. While this is positive, it was claimed by professionals to have some knock-on effects, specifically greater delays in seeing patients with existing disease (follow-up attendances). It was suggested by many interviewees that policy drivers that focus on increasing the ratio between new and follow-up patients can leave those with long-term disease unable to get follow-up appointments.

Assertiveness of patients

- Many patients stressed the need to be assertive to gain access to treatment and to get questions answered. It is recognised that the patients who took part in the surveys or focus groups may be more interested in self-management than the average (selection bias). Participants claimed that there may be a large pool of patients who are not well enough, or sufficiently assertive, to push for the care they require.

Access to drugs

- Many patients recognised that there were stages of drug therapies and that access was often driven by protocols. Patients cited difficulties in accessing different levels and some described having to ‘play the game’ to gain quicker access to some drugs.
- Professionals who responded to questions in the survey about prescribing biologics (444) were split relatively equally between those who do and those who do not feel that there are constraints (such as financial and staffing resources).
- Nearly three-quarters (74.1%) perceived that NICE guidelines constrain prescribing.
- Almost one-third (29.5%) responded that PCT capping numbers was a constraint on prescribing biologics.

Location of specialist care

- Specialist RA care located in hospital settings is usually the norm. Several patients and professionals claimed that locating services in the same central place improved efficiency and convenience, while others stated that the future delivery should be concentrated in primary and community settings.
- For patients a related issue was access, i.e. transport routes, parking fees and the specific location of facilities (e.g. ground floor).
- Examples were given by professionals of new, innovative practice that had resulted in much of the care previously provided in a hospital outpatient clinic shifting into

community settings. Only a few patients gave examples of care provided in their own home, such as through specialist nurse visits, and other initiatives such as telephone-based outpatient consultations supported by monitoring (e.g. blood tests) in primary care.

Continuity

- Continuity, particularly with medical staff, was valued highly by patients and survey results showed that nearly two-thirds of patients diagnosed with RA for three years or longer (599) indicated that they had a preference as to who they saw.
- Most spoke highly of the experience of specialist care. Patients are generally positive about their relationships with consultants.

The period of time between seeing a GP and seeing a specialist ranged from less than six months to more than three years (Table 4.1).

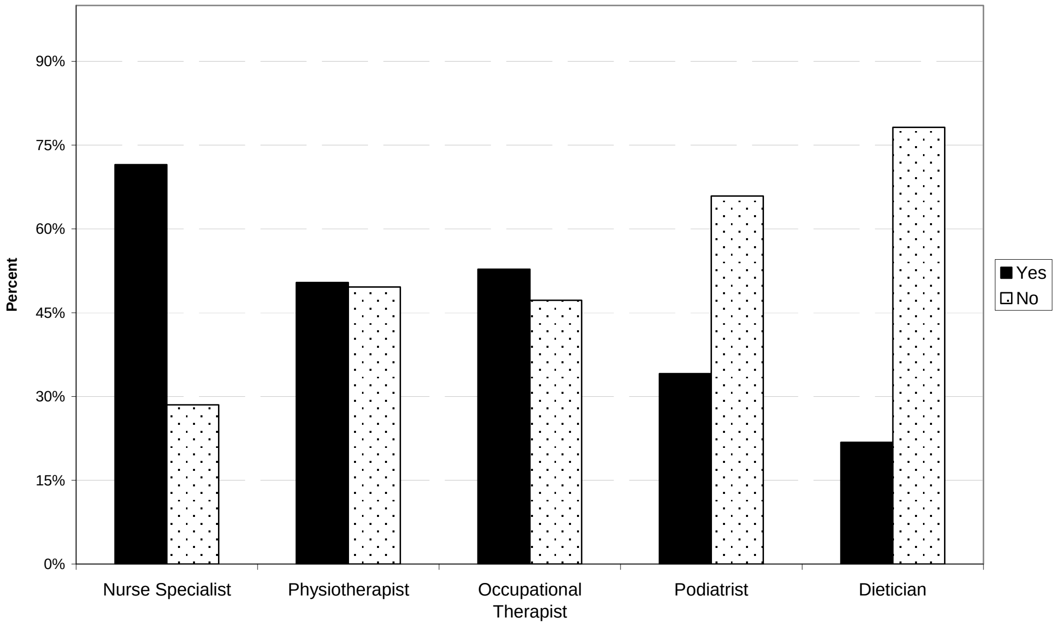
Table 4.1: Time between first seeing GP about symptoms and seeing a specialist in a hospital

Timeframe	**Number of responses**	**Percent (%)**
Less than 6 months	224	71.6
6 months – 1 year	35	11.2
1 year – 2 years	27	8.6
2 years – 3 years	9	2.9
More than 3 years	18	5.6
Total	**313**	**100.0**

Patients were asked if, within six months of diagnosis, they had been offered an appointment with any of the following health care professionals: nurse specialist, physiotherapist, occupational therapist, podiatrist or dietician.

Figure 4.1 shows that 71.5% of patients indicated that they were offered an appointment with a nurse specialist.

Figure 4.1: Patients who had been offered appointments with health care professionals within six months of diagnosis



Priorities for improvement

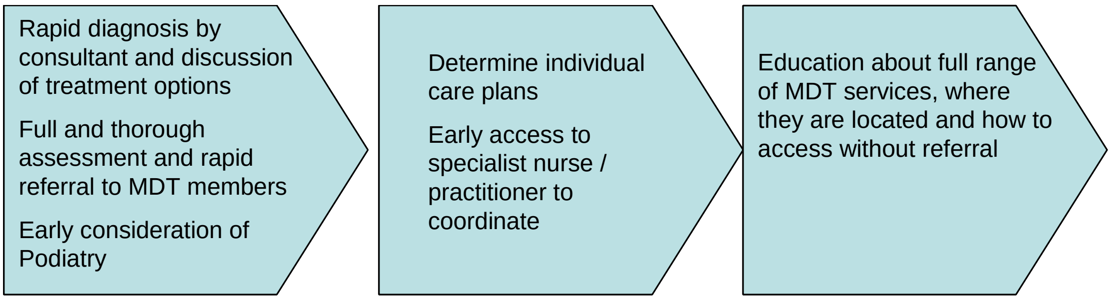
- **More consistent provision of full multi-disciplinary team members** is needed as there are wide inequalities in the range of specialist services that patients can access and in the frequency of contact when it is offered. The variation highlighted by patients and professionals involved in this study was stark and suggests that many patients may currently receive sub-optimal care. Professionals and patients also suggested there were inequalities in the care provided for recently diagnosed patients compared to those with established RA.

- **Learning from best practice examples of self-managed care**, which included patients accessing a range of multi-disciplinary team members directly, without the consultant or GP acting as ‘gatekeeper’.

- **Extending the use of referral criteria, guidelines and pathways** to build on several locally developed, clinically led and reviewed guidelines and pathways that are available and seen as a valuable tool to support service change and improvement. They retain the ability of professionals to tailor care to the individual patient and their condition. The use of pathways allied to service innovation provides an established approach to tackling variation and other issues highlighted above, such as continuity and access to drugs**.** The process to help professionals reassess and redesign how care is provided is critical and requires strong clinical and managerial leadership. The use of guidance may be given further impetus by forthcoming detailed clinical guidelines on the management and treatment of RA in adults that are currently being developed for NICE by the National Collaborating Centre for Chronic Diseases, due for publication in February 2009.

- **Providing more care outside of hospitals** is a stated NHS policy. Patients and professionals indicated that the vast majority of specialist care is currently located in hospital settings. Delivery of more care outside hospitals will require considerable changes in the pattern of service provision. The impact of this could be significant and could affect GPs, the wider primary care team and specialists through significant changes in roles and responsibilities. The study found little evidence of consistent progress in this area although there are positive examples of care being shifted, particularly with the development of new organisational models that seek to integrate previously separate services.

The following diagram summarises some of the main elements of care that were highlighted as good or ideal in responses from patients and professionals.



5 Ongoing care

This stage of the care pathway examines the ongoing care of people with established RA, a process which includes a combination of specialist and generalist professional input. Ongoing care includes the monitoring of the severity of the condition; the issue of how a flare-up or exacerbation of symptoms is managed, and decisions on how drugs are used in ongoing treatment.

The evidence

Patients reported that they had a low awareness of RA at the point of first contact but that during ongoing care they should become experts in the management of their own condition. Hence, patients and professionals often stated that ongoing care should involve more self-directed monitoring and management by patients. As RA is a long-term, chronic condition patients will need additional education and more structured support to enable them to better manage their condition. Patients would like ongoing access to the specialist clinical knowledge and skills that are required for RA, regardless of location. Patients have asserted that they would like services to be closer to their homes but do not want to trade off local access with specialist knowledge and advice – in other words, the continuity of access to specialist advice and care should not be lost in this transition.

Location of services
Different ways in which services have been moved out of the secondary care setting to the community setting included the following examples.

- Shared care arrangements, with GPs taking a more active role in ongoing care, although there was evidence that it was difficult to persuade GPs to take up some additional roles. Real integration of care would require GPs to have a better understanding of the monitoring and management of the patient’s care and drugs regime.
- Appointment of community-based RA specialist nurses were welcomed by patients, who appreciated being seen in their homes, and nurse specialists could play a more active role in supporting GPs.
- ‘Hub and spoke’ models, where consultants from the hospital hold clinics in primary and community settings.
- Use of Clinical Assessment and Treatment Services (CATS) for the initial assessment after referral by a GP.
- Several contrary examples made clear that co-location of services did not necessarily mean real integration of primary and secondary care, such as a GP with special interest (GPwSI) in RA who did not receive referrals from GPs in his practice, but rather saw patients after they had been referred back from the consultant.

Service transformation

- From the survey responses around three-quarters of professionals indicated that some service change and redesign had taken place over the last three years, mostly related to Choose and Book and the 18-week pathway. However, most did not report that they had experienced significant service change as a result of

redesign initiatives and nearly two-thirds said they had not been involved in the development of such plans.
- Most patients also indicated that they did not perceive that major changes had taken place over recent years, including the area that is usually the focus of redesign – access to services.

Monitoring of RA and its co-morbidities

- The monitoring of patients is vital but remains hugely variable. Some patients described being 'left on the sidelines' for years with little assessment or support, whereas others had full annual 'MOTs' that included not only physical examination, but also the wider consideration of health, personal and psychological issues. Several also cited a discrepancy in that there was a relatively good system for recently diagnosed patients, contrasting with that available for the large pool of existing patients, some of whom may assume 'nothing can be done'.
- The variation occurred in both specialist and general care. For example, patients cited differences in the frequency and extent of joint checks when seeing the specialist and variation in who conducted the regular blood monitoring required for much RA drug therapy. The level of expertise of GPs and their capability and capacity to support ongoing care ranged widely.
- An issue closely related to ongoing monitoring is the additional need to assess co-morbidities. Again this varied from good, comprehensive, regular and evidence-based assessment for the main health conditions associated with RA, through to virtually no active consideration of co-morbidities. Again, a further uncertainty arose concerning who was in the best position to monitor co-morbidities. The main examples of best practice cited were located in specialist care, often provided by nurse specialists, though others claimed such monitoring and ongoing management should be conducted by primary care teams. A major constraint appears to be the often limited knowledge among such teams of the specifics of RA and particularly the treatment regimens.
- Examples of good practice included reference to 'tight control', an approach involving high-intensity monitoring and treatment after initial diagnosis (e.g. monthly appointments for the first year, alternating between consultant and specialist nurse), which evidence has highlighted as having a major positive impact on outcomes and patient experience.

Managing a flare-up

- In the survey almost 90% of patients diagnosed for three years or longer had experienced a sudden flare-up or exacerbation of symptoms.
- The management of flare-ups appears to be haphazard. Descriptions by patients and professionals on the most appropriate approach to managing a flare-up were often unclear. Significant problems were described with the current situation, including delays in urgent access to specialists, lack of knowledge and capacity to intervene among GPs (such as with joint injections) and some inappropriate, duplicative routes, such as patients having to return to their GP simply to be told to contact specialist care. The overall impression was one of an underlying uncertainty on how a flare-up should be managed. As one GP stated 'this is becoming a thorny issue in general practice'.
- When facing problems managing their condition many patients see the nurse specialist as a key 'bridge' to access specialist care. Some patients reported visiting the clinic and being seen on the day of presentation with a flare-up, while others had to book an appointment through their GP and waited several weeks for access to specialist advice by which time their flare-up has resolved. The patient who has frequent flare-ups as a result of poorly controlled disease may have to contend with time off work, potential risks to employment, disability and incur further joint damage before treatment plans are reviewed.

Access to services

- Patients referred to diminishing access to a range of other services such as hydrotherapy and wax treatments. While not thought to be effective in managing disease progression, patients perceived such services as helpful in symptom control and promoting wellbeing.

Support and education

- A common theme in ongoing care concerned patients' desire to be supported and educated, so that they are better able to self-monitor and manage their condition. For such a painful and potentially disabling disease patients could not overemphasise the need for continuing education, information and structured support. One patient described taking their decisions on managing RA as 'walking a tightrope', referring to the beneficial effects but toxic nature of the drugs.
- While some patients choose not to explore further the information available, most involved in this study have stated that education and support is a critical need that is sometimes poorly met. Examples of good practice included the use of Arthritis Research Campaign (ARC) and National Rheumatoid Arthritis Society (NRAS) leaflets, which are well regarded, regular contact with specialist nurses who focus on information-giving and structured programmes of education and support involving the multi-disciplinary team. Best practice also included regular audits of patient views and even an annual patient conference. However, the availability of such services and even the basic leaflets, contact details and links to readily available resources were patchy, indicating that education and support varies markedly between locations.
- Some patients reported fear and loneliness when they were first diagnosed with RA and stated the need for information and support early on in the process. While around 80% of patients diagnosed in the last three years said they had been offered written information and 70% a helpline number, feedback from surveys and focus groups suggest that they are keen for broader and more formal support. Of patients diagnosed more than three years ago, around two-thirds had been offered or given written information and a helpline number. This may suggest an improvement in the provision of education although there is also the potential for recall bias.

Patients received a range of information as part of their ongoing RA care. In some instances, more than three-quarters of patients were not provided with particular sources of information (Table 5.1).

Table 5.1: Number of respondents offered or given different forms of information during the past three years

	Yes	**No**
Teaching/education sessions about your disease and treatments	132 (24.4%)	408 (75.6%)
Written information about your disease and treatments	349 (62.2%)	212 (37.8%)
Details of organisations to contact for further information and support	203 (37.1%)	344 (62.9%)
Details on how to contact the NHS Expert Patient Programme	73 (13.5%)	467 (86.5%)
Information about continuing employment/education or returning to work	84 (24.6%)	258 (75.4%)
Information about social security benefits	96 (20.7%)	367 (79.3%)
Information about continuing your interests and leisure activities	111 (21.3%)	408 (78.7%)
A helpline number in case you need help, advice or support between outpatient visits	391 (68.2%)	182 (31.8%)

Patients experienced considerable variation in their care after having experienced a flare-up. Some patients were able to access care within 24 hours, while others took more than a few weeks (Table 5.2).

Table 5.2: Care after a sudden 'flare-up'

	Within 24 hours	**Within one week**	**Within a few weeks**	**Longer**	**Did not respond**
An appointment with a GP (your own or another from your practice)	214 (35.7%)	198 (33.1%)	18 (3.0%)	5 (0.8%)	164 (27.4%)
Help from a hospital team	100 (16.7%)	138 (23.0%)	125 (20.9%)	67 (11.2%)	169 (28.2%)
Access to services in the community	6 (1.0%)	20 (3.3%)	32 (5.3%)	70 (11.7%)	471 (78.6%)
Guidance from NHS Direct	61 (10.2%)	13 (2.2%)	2 (0.3%)	33 (5.5%)	490 (81.8%)
Other source of telephone guidance	72 (12.0%)	32 (5.3%)	6 (1.0%)	27 (4.5%)	462 (77.1%)

Priorities for improvement

- **Care needs to be provided more consistently;** the experiences of patients and professionals ranged from examples of extensive specialist and ongoing care to alarming examples of minimal support – a situation that one professional characterised as a 'postcode lottery of care'.

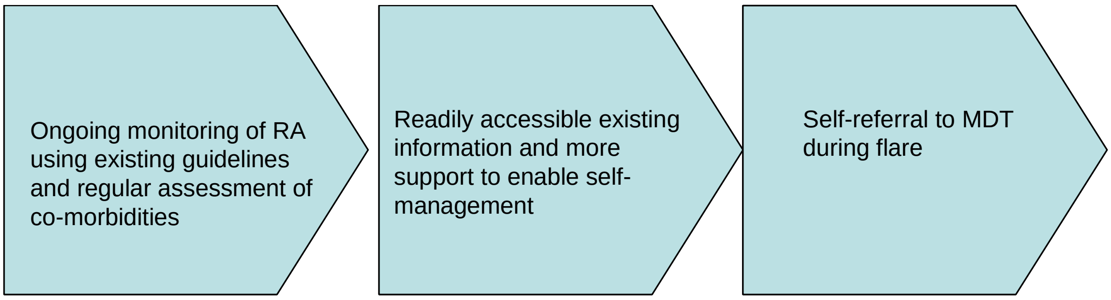
- **Better information, education and support** is extremely important both for recently diagnosed patients and those with a long-standing condition. Patients stated that access to information and support can help tackle feelings of loneliness, fear and despair and positively help them in managing their RA. Excellent resources are already available, such as from Arthritis Research Campaign (ARC), National Rheumatoid Arthritis Society (NRAS) and Arthritis Care (AC), and they should be more consistently provided to patients. Several patients suggested a simple pack or an RA 'ready-reckoner' that would concisely explain the nature of RA, the likely treatment and signpost other support, particularly from patient groups and networks would be valuable.

- **Consistent monitoring of RA and its co-morbidities** is required to improve RA care and seek to manage related health risks. The use of pathways and guidance can support this work and help clarify the balance between specialist and general care. The management of flare-ups is a particular priority given current levels of dissatisfaction and uncertainty.

- **Providing specialist care** outside of hospital settings is required. Patients and professionals indicated that the vast majority of specialist care is currently located in hospital settings. The study found little evidence of consistent progress in care being shifted out of hospital settings although some examples were identified, such as the development of new organisational models that seek to integrate previously fragmented services.

- **Opportunities for innovation and improvement** exist and need to be pursued vigorously. These range from improving the initial contact in primary care to ensure that RA patients are diagnosed and treated more rapidly, to changing the whole pattern of care if more specialist and ongoing care is to be provided out of hospital settings.

The following diagram summarises some of the main elements of care that were highlighted as good or ideal in responses from patients and professionals.



6 Conclusion

People with a long-term condition such as RA make up a significant proportion of those receiving NHS care.

Although the specific data for RA are limited, in 2000 there were 1.9 million GP consultations and around 46,000 hospital admissions for the broader classification of inflammatory arthritis (of which RA is the largest element). This is a painful and distressing condition that affects all age groups and has a major impact on economically active patients, a significant proportion of whom are forced to give up work temporarily or permanently.

The review involved extensive investigation of patient and professional perceptions and highlights aspects of care delivery that have long been seen as problematic. The findings establish that care for RA patients is dominated by specialist services that are predominantly hospital based. A specific finding of this study is that during a flare-up, which the vast majority of patients experience, the support and treatment received by patients are haphazard and the current role of the primary care teams in ongoing care is limited.

In summary, three overriding messages emerged. First, ongoing, long-term specialist follow-up care to support patients in managing their own condition is lacking. Patients need more information and easier access to specialist functions to manage their own condition. Second, patients and professionals perceive an unacceptably wide variation in the level and quality of care currently available. Third, the role of primary care clinicians could be enhanced across the pathway, from ensuring more rapid referral for specialist assessment to supporting the ongoing management and treatment of people with RA.

Individualised care plans have been recommended by Darzi (2008) as a way of improving access to allied health professionals and other specialists for patients with long-term conditions and supporting a more patient-led model of care. This study suggests that RA patients might, as a patient group, benefit from this initiative. Furthermore, the current pattern of ongoing care, with its domination by hospital-based specialists and wide variations in levels of access and quality of care, is inadequate to meet new health policy objectives.

The inequalities of access to care and support in different parts of the NHS identified in this study suggests that commissioners could be more demanding of their providers to reduce unnecessary variation and ensure people with RA receive more consistent access to high-quality and evidence-based care. The impetus for this improvement is given by the Darzi approach (specifically on patient experience, outcomes, clinical leadership and a focus on long-term conditions) combined with existing direction to provide more care closer to home and improve commissioning through meeting world class commissioning competencies. This momentum will be enhanced further by the publication of NICE clinical guidelines on the treatment of RA anticipated in early 2009, which will provide further evidence on how care should be provided.

A wide range of resources are already available to support action to tackle these problems a selection of which is given below. This report represents the culmination of the first element of work commissioned by the Rheumatology Futures Group. While the dissemination and use of the results will rest with the Rheumatology Futures Group, one anticipated follow-up is the development of a commissioning pathway to help both raise the profile of RA and provide a simple mechanism to assess and improve local services to match the best that is already available.

Selected resources

Issue	**Resources**
Patient information	Arthritis Research Campaign www.arc.org.uk www.arc.org.uk/arthinfo/default.asp National Rheumatoid Arthritis Society www.rheumatoid.org.uk www.rheumatoid.org.uk/index.php?page_id=30 Arthritis Care www.arthritiscare.org.uk www.arthritiscare.org.uk/PublicationsandResources
Guidelines, standards and frameworks	British Society for Rheumatology www.rheumatology.org.uk/guidelines/clinicalguidelines Arthritis and Musculoskeletal Alliance Standards of Care www.arma.uk.net/care.html Musculoskeletal Framework (Department of Health) www.18weeks.nhs.uk/Asset.ashx?path=/Publications/15445_Final.pdf Note: forthcoming NICE clinical guidelines on RA (due February 2009)
Joint working	'Teams without Walls' – joint report from three Royal Colleges: www.rcgp.org.uk/pdf/Teams%20without%20Walls%20web%20navigable.pdf

Two volumes of supporting information on the detailed findings are available at www.rheumatoid.org.uk

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Young A, Dixey J, Kulinskaya E, Cox N, Davies P, Devlin J, Emery P, Gough A, James D, Prouse P, Williams P, Winfield J (2002). 'Which patients stop working because of rheumatoid arthritis? Results of five years' follow up in 732 patients from the Early RA Study (ERAS)'. *Annals of the Rheumatic Diseases*, vol 61, pp 335-40.

The following organisations comprise the membership of the Rheumatology Futures Group

Patient groups

- Arthritis Care
- Arthritis and Musculoskeletal Alliance
- National Rheumatoid Arthritis Society
- National Ankylosing Spondylitis Society

NHS

- St Albans PCT

Professional organisations

- British Health Professionals in Rheumatology
- British Society for Rheumatology
- Primary Care Rheumatology Society
- Royal College of Nursing
- Royal College of Physicians

Pharmaceutical companies

- Abbott Laboratories
- Bristol Myers-Squibb
- Roche
- Schering-Plough
- UCB Pharma
- Wyeth Laboratories

  (Representatives from the above companies are from Government and Public Affairs departments)

Communications and public affairs

- Helen Johnson Consulting Ltd

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